*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

The Journey to Diagnosis for People Living with Rare Diseases

A Rare Barometer Survey

Target population:

- Patients living with a rare disease
- People not yet diagnosed but living with a disease considered to be rare
- Their family member (parents or close relatives)

March 17 - June 15, 2022

13300 respondents worldwide and

10486 in Europe

27 languages

107 countries

1900+ diseases represented

Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

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 journey to diagnosis for people living with a rare disease.

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 27 languages of the survey.

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
- or visit the Rare Barometer website at eurordis.org/rare-barometer

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Chapter 2: Average diagnosis journey

Chapter 3: Age at first symptoms

Chapter 4: Family members were previously diagnosed

Chapter 5: Symptom characteristics: body parts

Chapter 6: Symptom characteristics: types of symptoms

Chapter 7: Prevention (prenatal and at birth)

Chapter 8: Number of healthcare professionals consulted

Chapter 9: Referred to a Centre of Expertise

Chapter 10: Misdiagnosis

Chapter 11: Diagnostic tests conducted (declarative)

Chapter 12: Cross-border healthcare

Chapter 13: Support

Chapter 14: In touch with other people living with rare diseases

Chapter 15: Consequences of diagnosis

Chapter 16: Questions for undiagnosed / unsolved cases

Chapter 1.

Sample description

Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

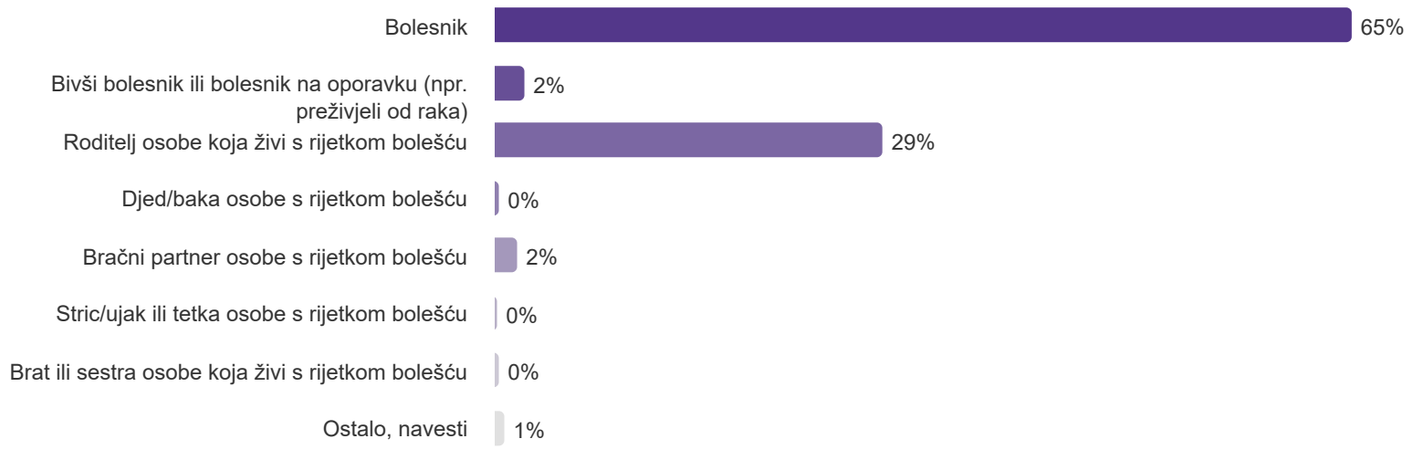
Number of respondents

10.486

Jeste li...

	N
Bolesnik	6.772
Bivši bolesnik ili bolesnik na oporavku (npr. preživjeli od raka)	247
Roditelj osobe koja živi s rijetkom bolešću	3.078
Djed/baka osobe s rijetkom bolešću	40
Bračni partner osobe s rijetkom bolešću	186
Stric/ujak ili tetka osobe s rijetkom bolešću	23
Brat ili sestra osobe koja živi s rijetkom bolešću	48
Ostalo, navesti	92
TOTAL	**10.486**

Jeste li...



Respondents can be:

- **the person directly affected** by the rare disease

- **or family members of the person affected** (parents, grand-parents, spouses, uncles/aunts, siblings or other family member).

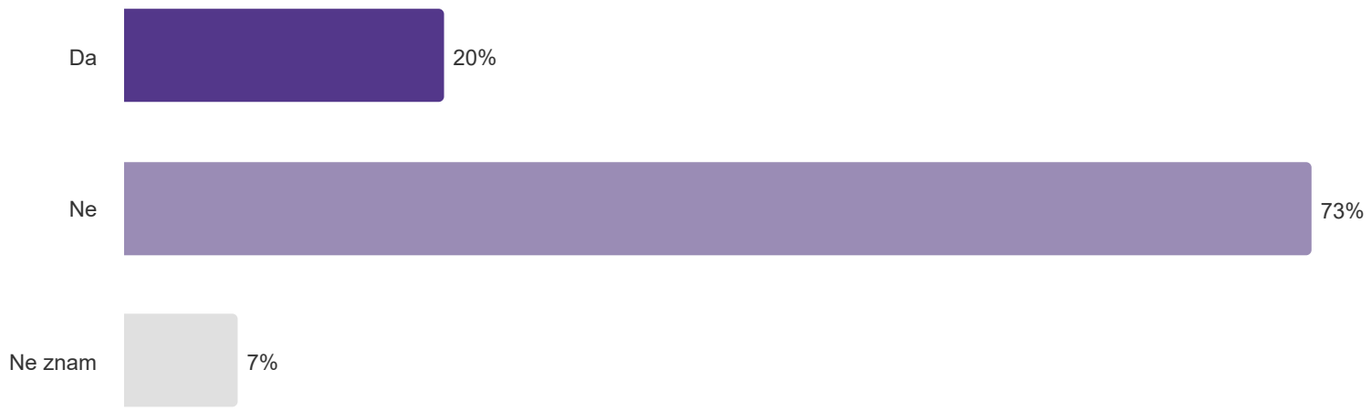
Jeste li...



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

	N
Da	2.073
Ne	7.666
Ne znam	747
TOTAL	**10.486**

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



Age of the respondent when the questionnaire was filled in

Calculated based on:

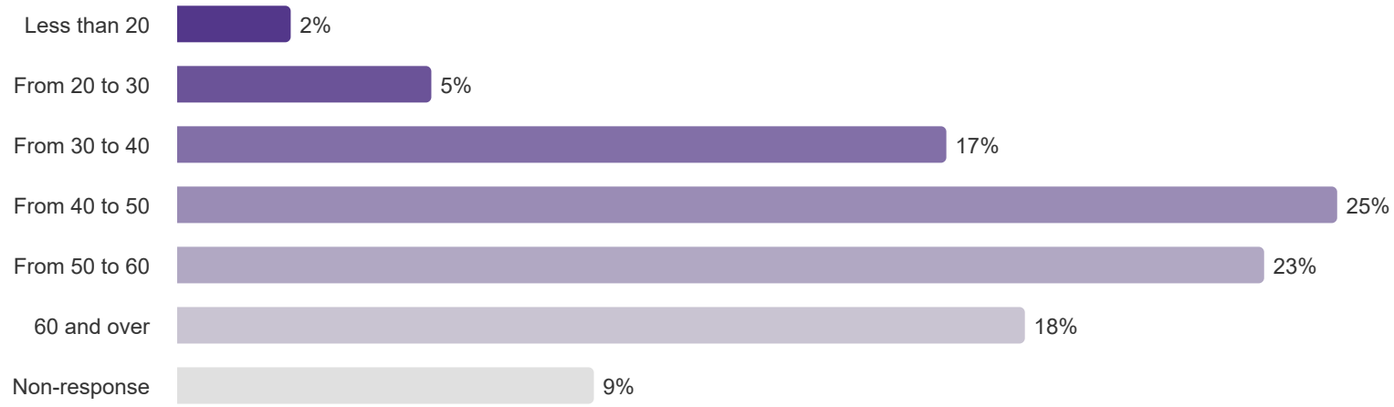
- the date of birth of the respondent: "What is your month and year of birth?"

- the date when questionnaire was filled (automatically saved by the software)

Age of the respondent when filling the questionnaire

	N
Less than 20	259
From 20 to 30	575
From 30 to 40	1.734
From 40 to 50	2.614
From 50 to 60	2.451
60 and over	1.913
Non-response	940
TOTAL	**10.486**

Age of the respondent when filling the questionnaire



Age of the person affected by the rare disease when the first symptoms were noticed

Calculated based on:

- date of birth of the respondents who are patients themselves: "What is your month and year of birth?"

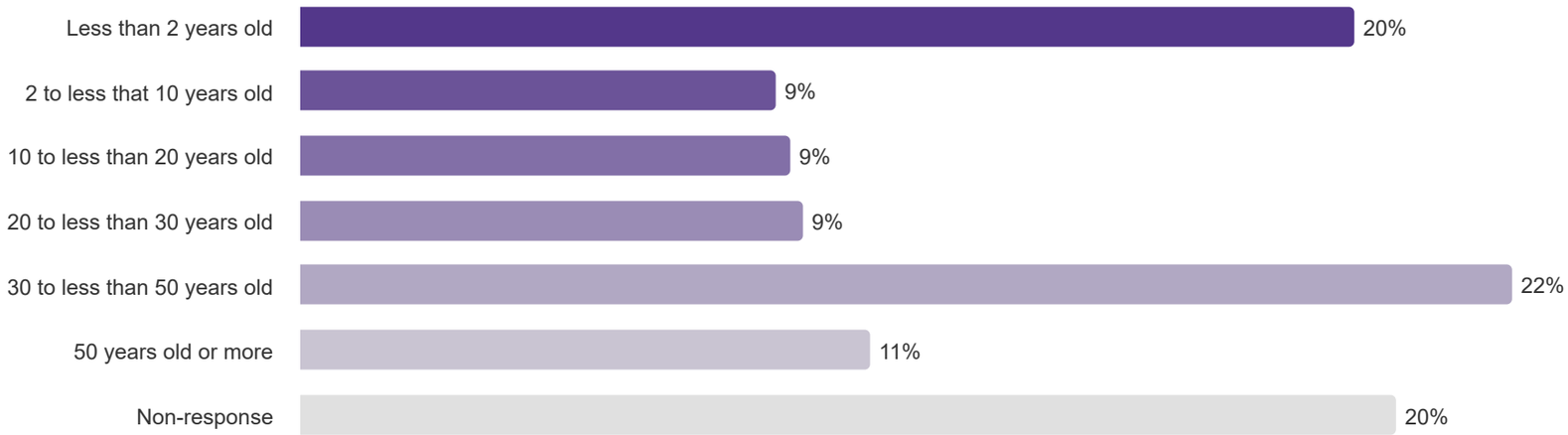
- date of birth of the patient when respondents are family members of the person affected by the rare disease: "What is the month and year of birth of the person affected by the rare disease?"

- date when first symptoms were noticed: "As far as you remember, when did you or a healthcare professional first notice the symptoms of the rare disease or think that something was wrong?"

Age of the person affected by the rare disease when first symptoms were noticed

	N
Less than 2 years old	2.045
2 to less that 10 years old	925
10 to less than 20 years old	952
20 to less than 30 years old	978
30 to less than 50 years old	2.353
50 years old or more	1.107
Non-response	2.126
TOTAL	**10.486**

Age of the person affected by the rare disease when first symptoms were noticed

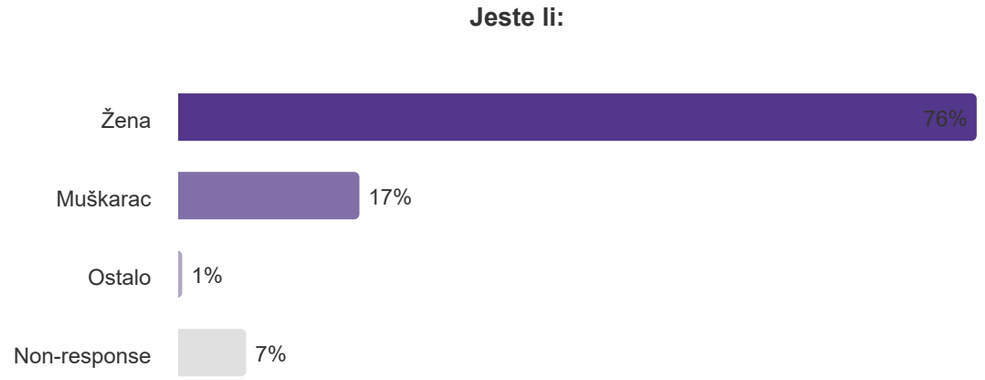


*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Gender of the respondent

Jeste li:

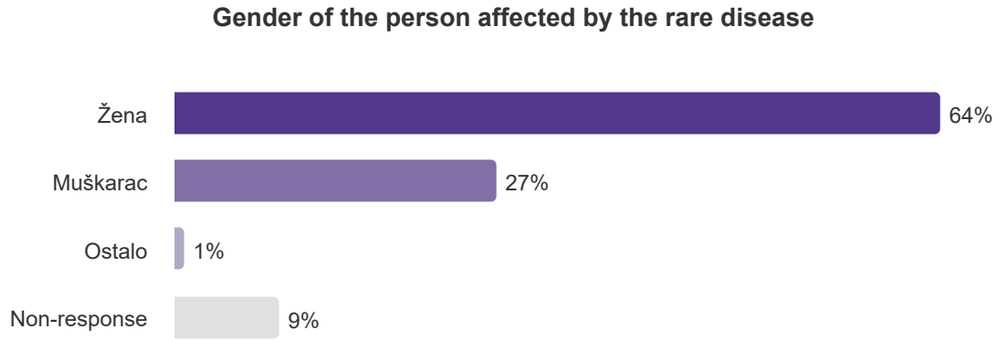
	N
Žena	7.930
Muškarac	1.807
Ostalo	56
Non-response	693
TOTAL	**10.486**



Gender of the person affected by the rare disease

Gender of the person affected by the rare disease

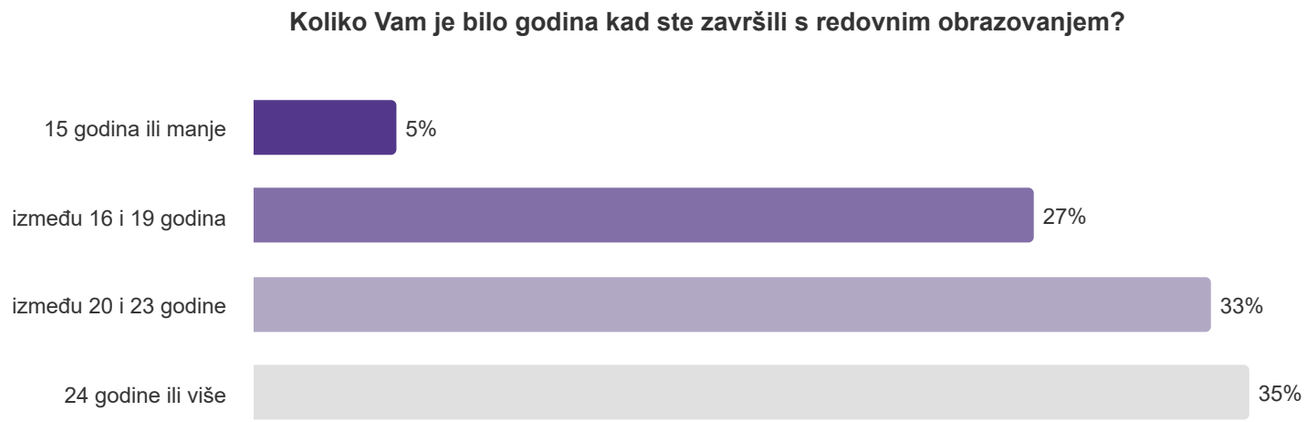
	N
Žena	6.659
Muškarac	2.810
Ostalo	101
Non-response	916
TOTAL	**10.486**



Education of the respondent

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

	N
15 godina ili manje	455
između 16 i 19 godina	2.464
između 20 i 23 godine	3.022
24 godine ili više	3.145
TOTAL	**9.086**

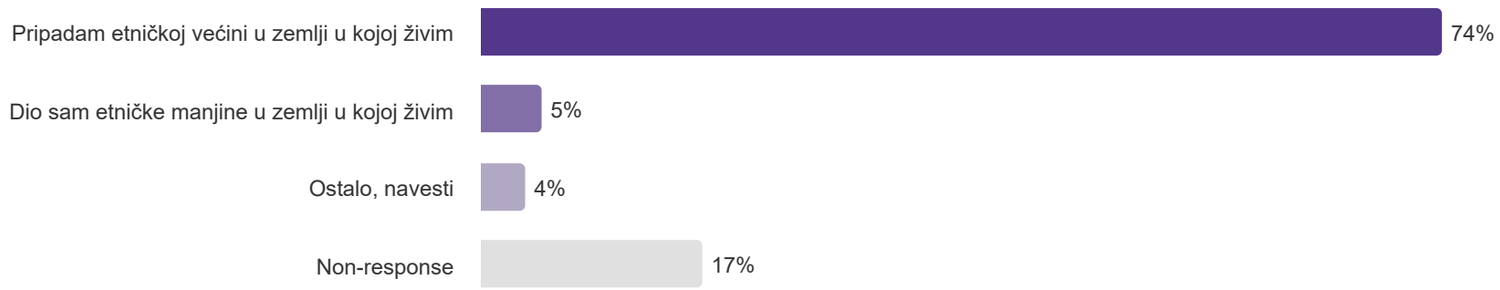


*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Kako biste najbolje opisali sebe?

	N
Pripadam etničkoj većini u zemlji u kojoj živim	7.125
Dio sam etničke manjine u zemlji u kojoj živim	465
Ostalo, navesti	337
Non-response	1.653
TOTAL	**9.580**

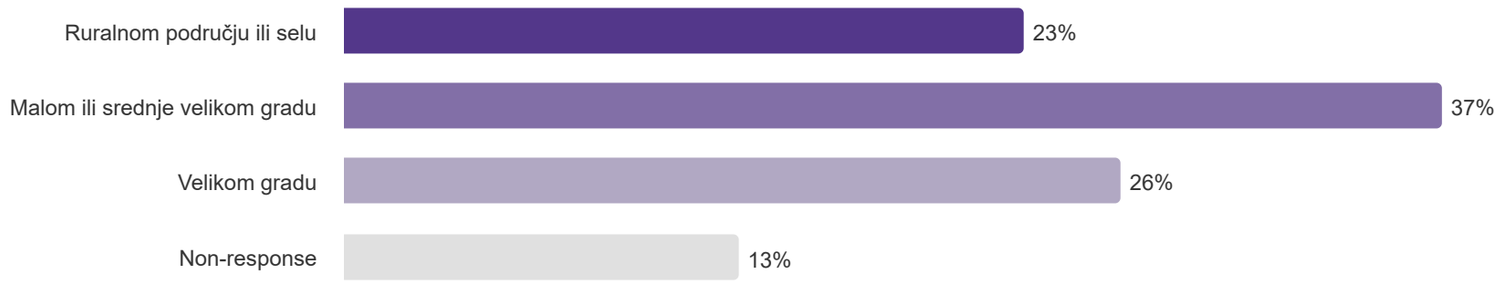
Kako biste najbolje opisali sebe?



Biste li rekli da Vi ili osoba o kojoj skrbite živite u:

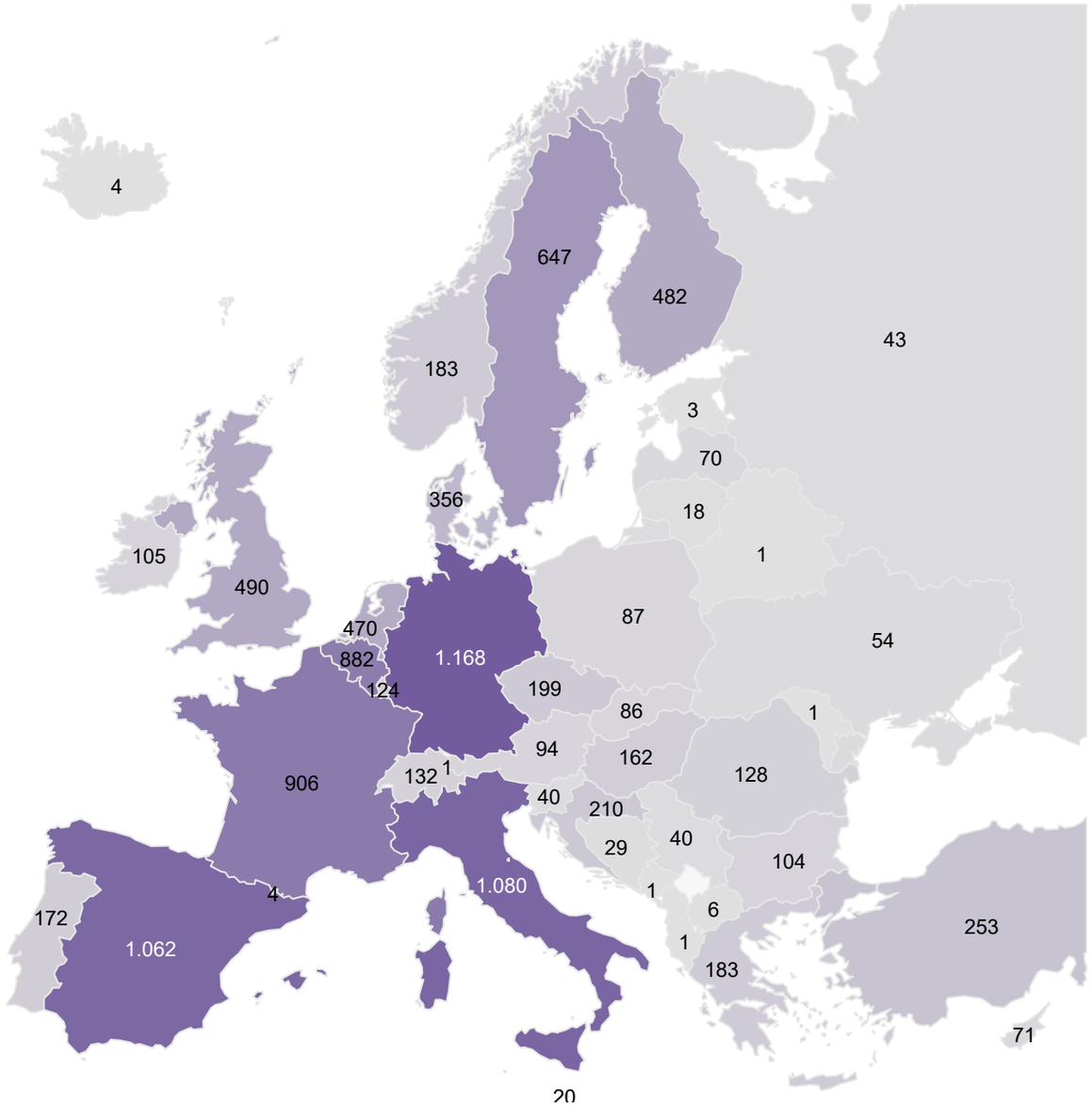
	N
Ruralnom području ili selu	2.416
Malom ili srednje velikom gradu	3.901
Velikom gradu	2.760
Non-response	1.409
TOTAL	**10.486**

Biste li rekli da Vi ili osoba o kojoj skrbite živite u:

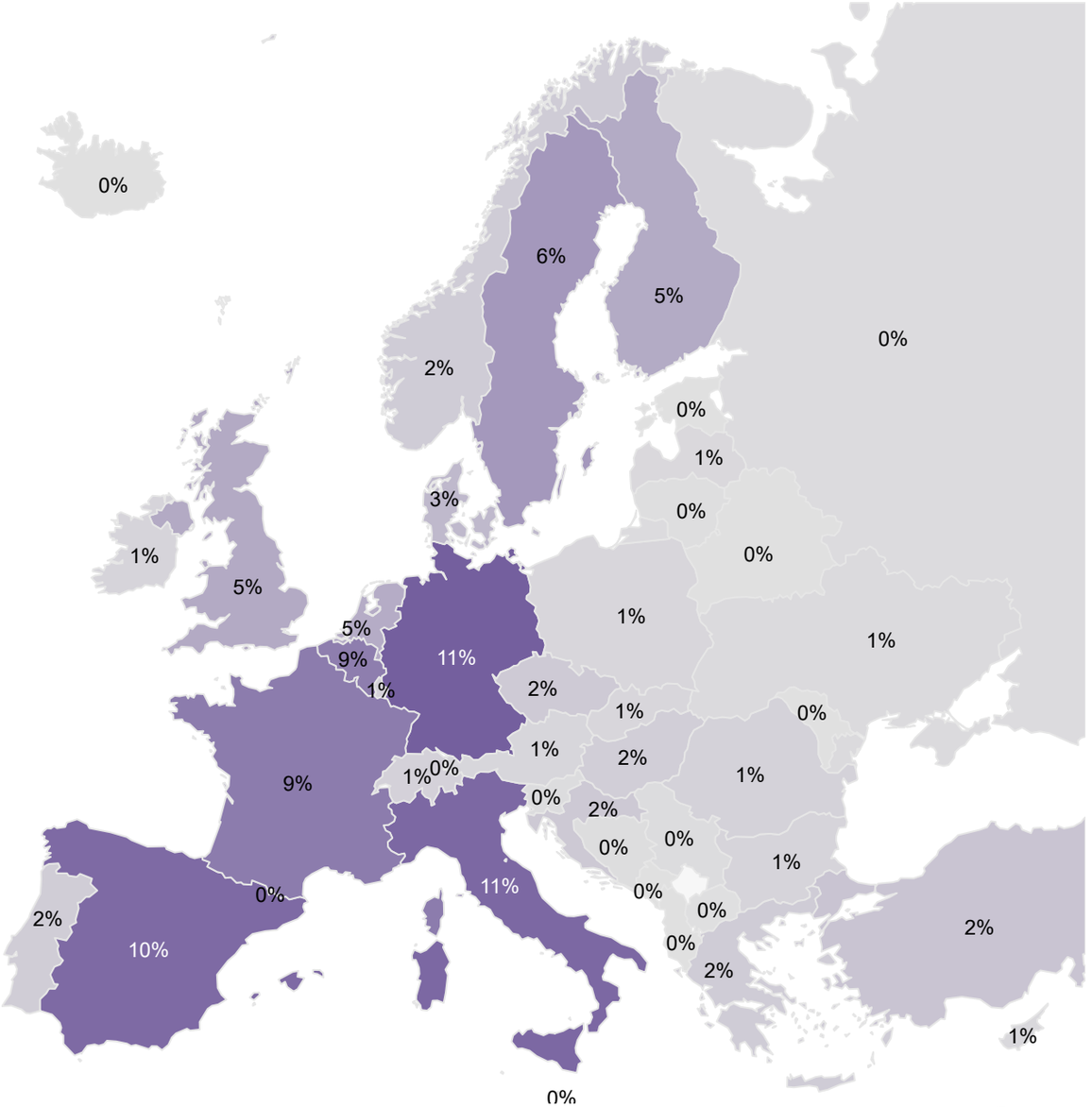


*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

U kojoj državi živite?



U kojoj državi živite?



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions as they appear in the questionnaire:

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)	9.048	86%
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	760	7%
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	306	3%
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	348	3%
Ostalo, navesti	24	0%
TOTAL	**10.486**	**100%**

Simplified items corresponding to the questions above:

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

	N
Confirmed diagnosis	9.048
Initial diagnosis	760
Partial diagnosis	306
Unsolved case	372
TOTAL	**10.486**

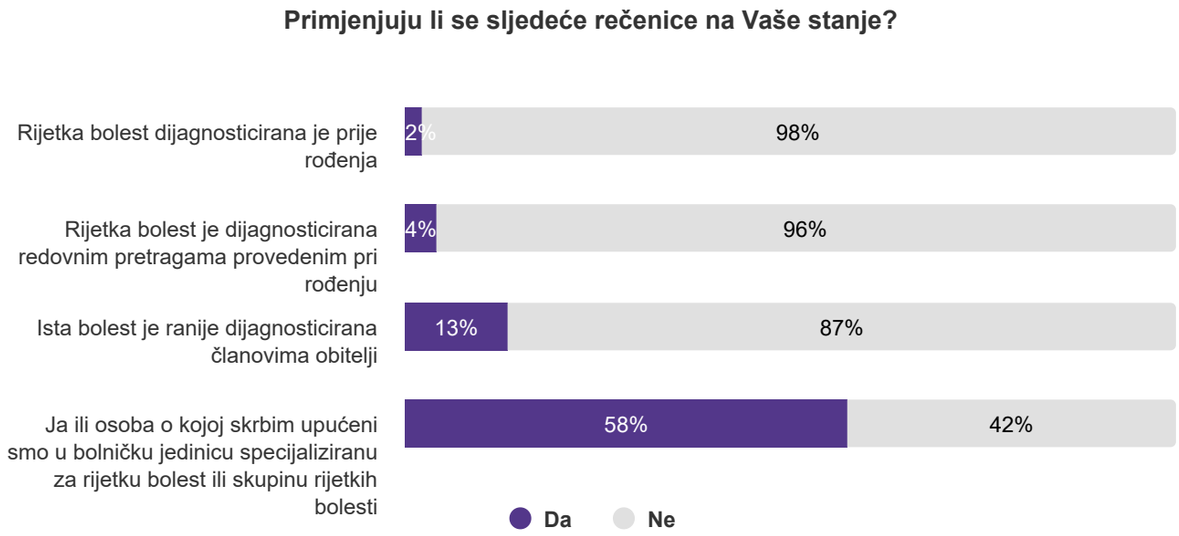
Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete:



Sample information : ***IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Primjenjuju li se sljedeće rečenice na Vaše stanje?

	DA	NE	TOTAL
Rijetka bolest dijagnosticirana je prije rođenja	222	9.513	**9.735**
Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju	396	9.139	**9.535**
Ista bolest je ranije dijagnosticirana članovima obitelji	1.309	8.426	**9.735**
Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti	5.998	4.415	**10.413**
TOTAL	**7.925**	**31.493**	**39.418**



Newborn screening

Respondents living with a disease that is being screened as part of a compulsory newborn screening programme in their country AND who answered "yes" to the question "The rare disease was diagnosed through standard tests carried out at birth" (see previous page).

Source: ISNS list of diseases screened per country.

https://membership.isns-neoscreening.org/public/screening-panels?export=0&name=&disorder=®ion=2&country=&province=&pp=200

Respondent living with a rare disease that is currently part of the NBS programme of the country they live in Source: ISNS

64

*Sample information : **NBS_recod among "Da"***

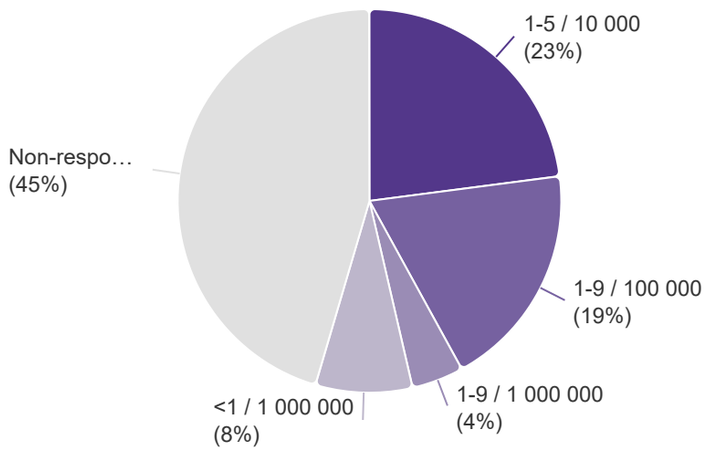
Variables calculated based on the name of respondents' disease and Orphanet data

orphadata.org

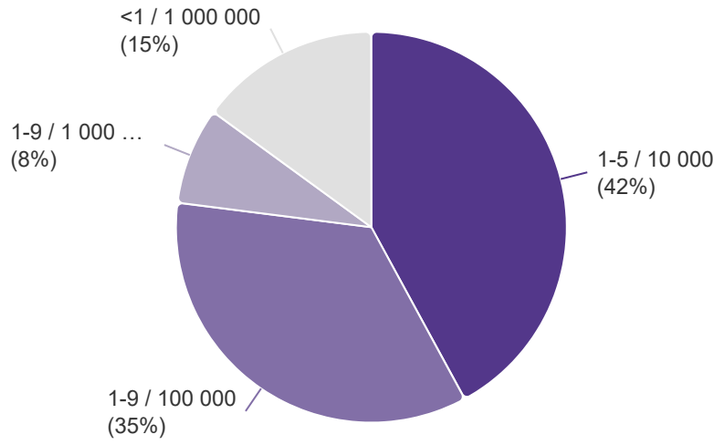
Calculation of point prevalence 2 modalities

	N	%
1-5 / 10 000	2.407	23%
1-9 / 100 000	1.999	19%
1-9 / 1 000 000	459	4%
<1 / 1 000 000	856	8%
Non-response	4.765	45%
TOTAL	**10.486**	**100%**

Calculation point prevalence



Calculation point prevalence



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

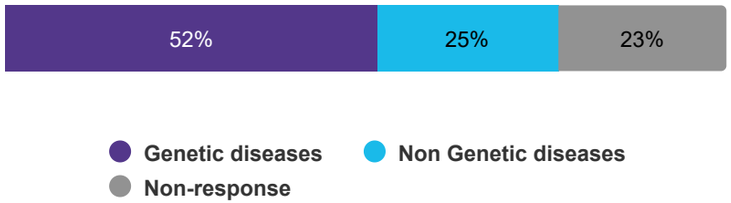
Variables calculated based on the name of respondents' disease and Orphanet data

orphadata.org

Genetic diseases

	N
Genetic diseases	5.447
Non Genetic diseases	2.627
Non-response	2.412
TOTAL	**10.486**

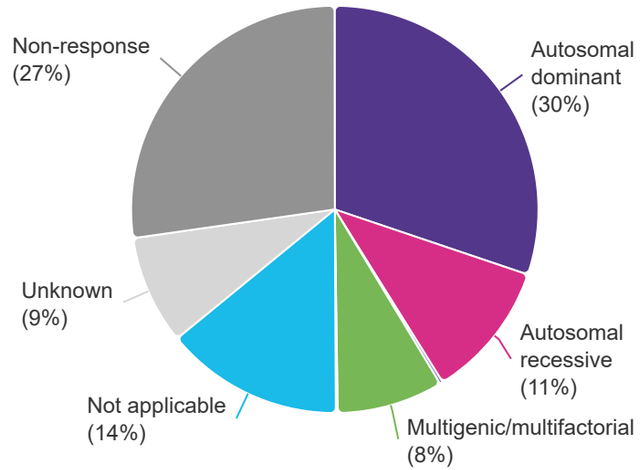
Genetic diseases



Transmission mode of the disease

	N
Autosomal dominant	3.165
Autosomal recessive	1.147
Mitochondrial inheritance	25
Multigenic/multifactorial	882
No data available	15
Not applicable	1.486
Unknown	907
X-linked dominant	0
X-linked recessive	0
Non-response	2.858
TOTAL	**10.485**

Transmission mode of the disease



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Sample size 10486 responses

orphacode

1.679

Orphacode associated nomenclature (english)

	N	%
Hereditary hemorrhagic telangiectasia	458	5%
Hypermobile Ehlers-Danlos syndrome	317	4%
Sarcoidosis	170	2%
Classical Ehlers-Danlos syndrome	137	2%
Williams syndrome	136	2%
Cystic fibrosis	128	2%
Myasthenia gravis	120	1%
Systemic sclerosis	107	1%
Tuberous sclerosis complex	98	1%
Neurofibromatosis type 1	92	1%
Interstitial cystitis	74	1%
Addison disease	73	1%
22q11.2 deletion syndrome	68	1%
Chronic inflammatory demyelinating polyneuropathy	65	1%
Perineural cyst	63	1%
Acute inflammatory demyelinating polyradiculoneuropathy	62	1%
Rett syndrome	60	1%
Marfan syndrome	52	1%
Fragile X syndrome	49	1%
BehÃ§et disease	47	1%
Primary sclerosing cholangitis	46	1%
Primary lymphedema	43	1%
Granulomatosis with polyangiitis	42	0%

EURORDIS European Federations

	N
HHT Europe	458
Federation of European Scleroderma Associations	200
Sarcoidosis	178
Lupus Europe	150
European Myasthenia Gravis Association	139
European Federation of Williams Syndrome	136
CF Europe	128
NF Patients United	125
European Tuberous Sclerosis Complex Association	98
PHA Europe (Pulmonary Arterial Hypertension)	86
22Q11 Europe	80
Multinational Interstitial Cystitis Association	74
Marfan Europe Network	72
Rett Syndrome Europe	65
Perineural cyst	63
European Federation for Hereditary Spastic Paraplegia	52

EURORDIS European Federations

	N
European Fragile X Network	49
Sclerosing Cholangitis	46
European Society for Phenylketonuria	45
OIFE - Osteogenesis Imperfecta Federation Europe	43
Albi France	41
Duchenne Muscular Dystrophy	41
European Federation of Associations of Patients with Haemochromatosis	41
SMA Europe	35
MPS Europe	34
European Idiopathic Pulmonary Fibrosis & Related Disorders Federation	32

Variables calculated based on the name of respondents' disease and Orphanet data

orphadata.org

Orphanet_classification

	N	%
Abdominal surgical diseases	239	3%
Allergic diseases	3	0%
Bone diseases	799	9%
Cardiac diseases	660	8%
Cardiac malformations	295	3%
Circulatory system diseases	1.351	16%
Developmental anomalies during embryogenesis	3.347	40%
Diseases due to toxic effects	3	0%
Endocrine diseases	995	12%
Gastroenterological diseases	305	4%
Genetic diseases	5.447	65%
Gynecologic/obstetric diseases	284	3%
Hematological diseases	412	5%
Hepatic diseases	891	11%
Immunological diseases	286	3%
Inborn errors of metabolism	774	9%
Infectious diseases	17	0%
Infertility	410	5%
Neoplastic diseases	870	10%
Neurological diseases	4.169	49%
Odontological diseases	222	3%
Ophthalmic diseases	1.784	21%
Ophthalmic disorders	7	0%



Chapter 2.

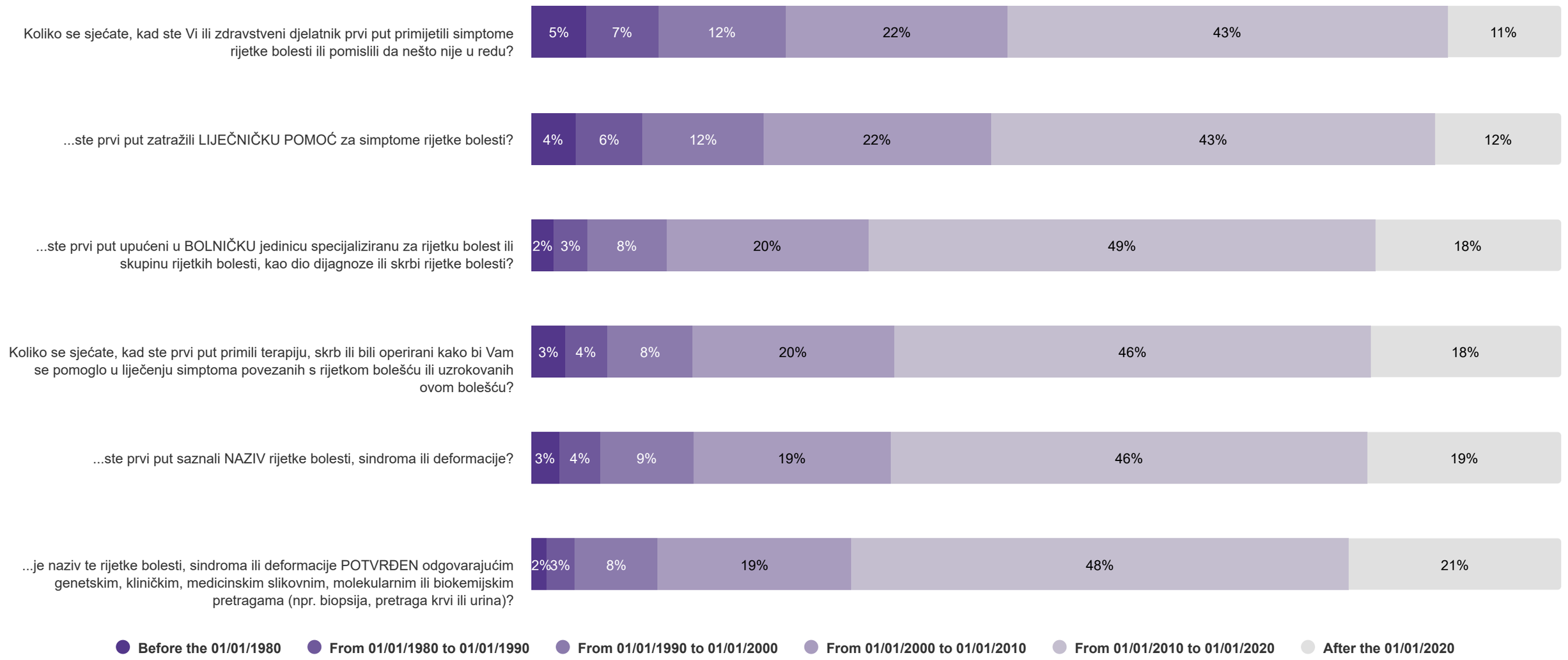
Diagnosis journey

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RARE DISEASES EUROPE

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Sample size 10486 responses

Combined analysis



Average diagnosis journey

If number of years is negative, it means that on average the step of the diagnosis journey happened before first symptoms were noticed

	MEAN	LOWER QUARTILE	MEDIAN	UPPER QUARTILE	MINIMUM	MAXIMUM	FREQUENCY
Time between first symptoms and first medical contact, in years	0,5	0,0	0,0	0,3	−58,9	78,1	7.820
Time between first symptom and first symptomatic treatment, in years	3,5	0,0	0,5	3,6	−56,9	62,7	7.322
Time between first symptoms and first referral to a Centre of Expertise, in years	3,9	0,0	0,4	3,4	−51,9	70,0	4.335
Time between first symptoms and initial diagnosis (first hearing the name of the disease), in years	3,6	0,0	0,4	3,8	−54,6	70,0	7.843
Time between first symptoms and confirmed diagnosis, in years	4,7	0,1	0,8	5,0	−54,6	71,2	6.507
Time from first symptom to when the questionnaire was filled, for undiagnosed respondents (unsolved cases and "other"), in years	13,8	4,2	9,5	20,6	0,0	63,6	378

First symptoms = when they, or a healthcare professional, first noticed the symptoms of the rare disease or thought that something was wrong.

First medical contact = when they first seeked medical help regarding the symptoms of the rare disease

First symptomatic treatment = when they first receive treatments, surgery or care to help them manage the symptoms associated with the rare disease or caused by this disease.

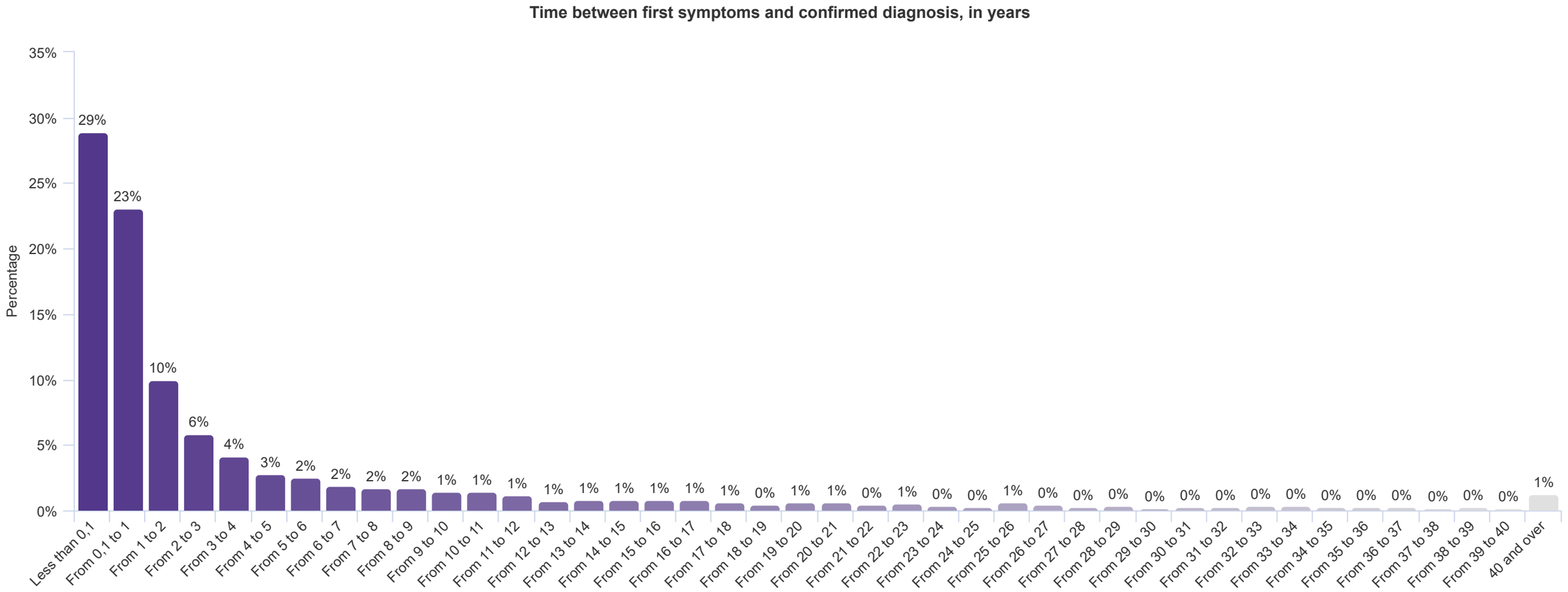
The initial diagnosis = the first time they heard the name of the rare disease, syndrome or malformation.

The first referral to a centre of expertise (CoE) = when they were first referred to a hospital unit specialised in the rare disease or group of rare diseases, as part of the diagnosis or care of the rare disease (only for respondents who said they were referred to a centre of expertise).

Confirmed diagnosis = when 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).

Average number of years	Number of years it took for **25%** of the sample to get to this step of their diagnosis journey	Number of years it took for **50%** of the sample to get to this step of their diagnosis journey	Number of years it took for **75%** of the sample to get to this step of their diagnosis journey	Lowest number of years	Highest number of years	Number of respondents for which we have the number of years to this step of the diagnosis journey

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Gender of the person affected by the rare disease	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Žena	0,6	5.053	4,1	4.750	4,6	2.787	4,2	5.050	5,4	4.193
Muškarac	0,3	2.113	2,5	1.976	2,4	1.198	2,5	2.186	3,7	1.839

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Fisher= 2,4.
Inter variance= 107,9. Intra variance= 45,4.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Multiple Cross

Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
15 godina ili manje	0,6	292	3,7	298	4,1	170	3,9	312	4,9	253
između 16 i 19 godina	0,6	1.807	3,6	1.677	3,9	951	3,4	1.835	4,9	1.495
između 20 i 23 godine	0,5	2.340	3,5	2.163	3,9	1.323	3,6	2.345	4,7	1.987
24 godine ili više	0,4	2.435	3,5	2.303	3,8	1.372	3,7	2.454	4,7	2.067

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,8 ; Fisher= 0,3.
Inter variance= 13,5. Intra variance= 45,2.

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Kako biste najbolje opisali sebe?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Pripadam etničkoj većini u zemlji u kojoj živim	0,3	5.468	3,5	5.124	3,7	2.962	3,5	5.494	4,7	4.605
Dio sam etničke manjine u zemlji u kojoj živim	0,8	324	3,3	305	3,9	156	3,6	323	4,2	268
Ostalo, navesti	0,7	243	3,3	222	4,0	103	4,6	233	5,1	196

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Fisher= 1,2.
Inter variance= 51,2. Intra variance= 44,3.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Multiple Cross

Biste li rekli da Vi ili osoba o kojoj skrbite živite u:	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Ruralnom području ili selu	0,4	1.841	3,5	1.732	4,1	1.019	3,7	1.847	4,8	1.520
Malom ili srednje velikom gradu	0,4	2.974	3,7	2.749	3,8	1.656	3,5	2.981	4,8	2.500
Velikom gradu	0,6	2.051	3,4	1.955	3,8	1.138	3,5	2.111	4,8	1.776

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Fisher= 0,8.
Inter variance= 36,5. Intra variance= 45,1.

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete:	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	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)	0,5	6.818	3,4	6.506	3,6	3.876	3,3	7.135	4,7	6.501
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	0,8	566	5,2	475	6,1	228	6,6	539	−6,0	3
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	−0,2	190	3,1	167	6,5	95	6,2	167	−0,7	2
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	0,7	241	2,7	168	4,7	134	2,5	2	0,1	1
Ostalo, navesti	0,9	5	9,7	6	11,0	2		0		0

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,5 ; Fisher= 0,9.
Inter variance= 40,1. Intra variance= 46,0.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,5	4.422	3,3	4.272	3,9	4.334	3,0	4.491	4,3	3.875
Ne	0,5	3.345	3,8	2.999	33,0	1	4,4	3.299	5,4	2.594

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,7 ; Fisher= 0,1.
Inter variance= 5,6. Intra variance= 46,2.

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Ista bolest je ranije dijagnosticirana članovima obitelji	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	1,9	785	5,7	757	5,9	527	1,3	834	7,1	707
Ne	0,3	6.552	3,2	6.175	3,4	3.543	3,8	6.840	4,4	5.797

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 40,1.
Inter variance= 1.832,5. Intra variance= 45,7.

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Point prevalence of the rare disease	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
1-5 / 10 000	0,8	1.802	4,4	1.753	4,9	1.087	3,4	1.925	5,7	1.674
1-9 / 100 000	0,3	1.544	3,2	1.486	3,1	929	3,1	1.640	4,0	1.417
1-9 / 1 000 000	0,1	352	3,8	330	3,7	188	4,1	379	5,0	335
<1 / 1 000 000	0,3	638	3,4	567	3,8	326	4,9	654	5,5	528

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Fisher= 2,1.
Inter variance= 98,0. Intra variance= 46,3.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Disease prevalence:

- **very rare diseases**: less than 1 case for 100,000 people
- **less rare diseases**: from 2 cases for 5,000 people to 1 case for 100,000 people.
- **Non-response**: unsolved cases (undiagnosed respondents) or disease prevalence unknown.

Source: orpha.data

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Genetic diseases	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Genetic diseases	0,6	4.017	4,1	3.700	4,6	2.368	4,2	4.276	5,9	3.632
Non Genetic diseases	0,1	2.154	2,4	2.161	2,3	1.142	2,2	2.247	2,6	1.888

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 8,5.
Inter variance= 352,6. Intra variance= 41,6.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Chapter 3.

Age of the person affected when first symptoms were noticed

Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Less than 2 years old	1,1	1.699	3,2	1.576	3,4	989	4,4	1.762	5,0	1.529
2 to less that 10 years old	1,8	758	6,5	705	7,7	417	7,0	789	8,8	666
10 to less than 20 years old	3,1	819	8,3	767	9,7	438	8,0	815	10,4	629
20 to less than 30 years old	0,6	841	4,2	773	4,3	451	3,8	841	5,5	691
30 to less than 50 years old	−0,7	2.062	2,3	1.904	2,2	1.120	1,6	2.005	2,7	1.671
50 years old or more	−1,5	941	0,3	943	0,6	549	0,0	972	0,6	807

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 64,8.
Inter variance= 2.821,1. Intra variance= 43,5.

If number of years is negative, it means that on average the step of the diagnosis journey happened before first symptoms were noticed

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Žena	1.069	18%	550	10%	750	13%	800	14%	1.882	33%	735	13%	5.786	100%
Muškarac	939	38%	360	14%	188	8%	174	7%	461	19%	369	15%	2.491	100%
Ostalo	37	45%	15	18%	14	17%	4	5%	10	12%	3	4%	83	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 580,2 ; dof= 10.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	114	29%	64	17%	51	13%	31	8%	81	21%	46	12%	387	100%
između 16 i 19 godina	434	20%	230	11%	236	11%	243	11%	659	31%	353	16%	2.155	100%
između 20 i 23 godine	668	25%	315	12%	285	10%	323	12%	771	28%	357	13%	2.719	100%
24 godine ili više	807	29%	293	10%	329	12%	335	12%	755	27%	310	11%	2.829	100%
TOTAL	**2.023**	**25%**	**902**	**11%**	**901**	**11%**	**932**	**12%**	**2.266**	**28%**	**1.066**	**13%**	**8.090**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 100,0 ; dof= 15.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Ruralnom području ili selu	536	25%	215	10%	234	11%	221	10%	642	30%	305	14%	**2.153**	**100%**
Malom ili srednje velikom gradu	828	24%	396	11%	392	11%	425	12%	971	28%	450	13%	**3.462**	**100%**
Velikom gradu	655	27%	291	12%	273	11%	286	12%	651	26%	310	13%	**2.466**	**100%**
TOTAL	**2.019**	**25%**	**902**	**11%**	**899**	**11%**	**932**	**12%**	**2.264**	**28%**	**1.065**	**13%**	**8.081**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 19,9 ; dof= 10.

Cross: Typology of countries based on size and welfare / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	454	35%	213	16%	145	11%	142	11%	272	21%	67	5%	**1.293**	**100%**
Group B ('Western Europe')	986	23%	445	10%	486	11%	543	13%	1.253	29%	593	14%	**4.306**	**100%**
Group C ('Northern Europe')	601	22%	264	10%	315	12%	288	11%	817	30%	442	16%	**2.727**	**100%**
TOTAL	**2.041**	**25%**	**922**	**11%**	**946**	**11%**	**973**	**12%**	**2.342**	**28%**	**1.102**	**13%**	**8.326**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 228,7 ; dof= 10.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.612	25%	705	11%	716	11%	723	11%	1.778	28%	836	13%	6.370	100%
Dio sam etničke manjine u zemlji u kojoj živim	107	27%	57	14%	36	9%	61	15%	113	28%	26	7%	400	100%
Ostalo, navesti	73	25%	28	10%	20	7%	27	9%	92	32%	49	17%	289	100%
TOTAL	**1.792**	**25%**	**790**	**11%**	**772**	**11%**	**811**	**11%**	**1.983**	**28%**	**911**	**13%**	**7.059**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 34,8 ; dof= 10.

Cross: Genetic diseases / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)															
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		NON-RESPONSE		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	1.656	30%	675	12%	554	10%	465	9%	886	16%	324	6%	887	16%	5.447	100%
Non Genetic diseases	119	5%	123	5%	199	8%	320	12%	988	38%	594	23%	284	11%	2.627	100%
TOTAL	**1.775**	**22%**	**798**	**10%**	**753**	**9%**	**785**	**10%**	**1.874**	**23%**	**918**	**11%**	**1.171**	**15%**	**8.074**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.500,5 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete:

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:									
	CONFIRMED DIAGNOSIS		INITIAL DIAGNOSIS		PARTIAL DIAGNOSIS		UNSOLVED CASE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	1.838	90%	95	5%	48	2%	64	3%	**2.045**	**100%**
2 to less that 10 years old	814	88%	54	6%	27	3%	30	3%	**925**	**100%**
10 to less than 20 years old	789	83%	98	10%	27	3%	38	4%	**952**	**100%**
20 to less than 30 years old	850	87%	79	8%	21	2%	28	3%	**978**	**100%**
30 to less than 50 years old	2.009	85%	188	8%	69	3%	87	4%	**2.353**	**100%**
50 years old or more	973	88%	79	7%	21	2%	34	3%	**1.107**	**100%**
TOTAL	**7.273**	**87%**	**593**	**7%**	**213**	**3%**	**281**	**3%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 50,0 ; dof= 15.

Cross: Calculation of point prevalence 2 modalities / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

CALCULATION OF POINT PREVALENCE 2 MODALITIES	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Respondents with less rare diseases	772	20%	418	11%	481	13%	473	12%	1.127	29%	572	15%	**3.843**	**100%**
Respondents with very rare diseases	365	33%	170	16%	102	9%	107	10%	239	22%	111	10%	**1.094**	**100%**
TOTAL	**1.137**	**23%**	**588**	**12%**	**583**	**12%**	**580**	**12%**	**1.366**	**28%**	**683**	**14%**	**4.937**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 123,7 ; dof= 5.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	1.120	23%	527	11%	532	11%	570	12%	1.350	28%	737	15%	4.836	100%
4-7 body parts	677	27%	269	11%	274	11%	269	11%	701	28%	279	11%	2.469	100%
8-11 body parts	181	24%	87	11%	98	13%	105	14%	214	28%	78	10%	763	100%
12-15 body parts	54	23%	28	12%	37	16%	27	11%	76	32%	13	6%	235	100%
16 body parts or more	13	23%	14	25%	11	19%	7	12%	12	21%	0	0%	57	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,5 ; dof= 20.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	726	31%	342	15%	274	12%	219	9%	539	23%	214	9%	2.314	100%
Ne	1.243	22%	557	10%	644	11%	717	13%	1.705	30%	851	15%	5.717	100%
Ne znam	76	23%	26	8%	34	10%	42	13%	109	33%	42	13%	329	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 185,7 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	900	38%	314	13%	190	8%	210	9%	563	24%	189	8%	2.366	100%
Ne	1.099	19%	586	10%	744	13%	733	13%	1.723	30%	874	15%	5.759	100%
Ne znam	46	20%	25	11%	18	8%	35	15%	67	29%	44	19%	235	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 418,1 ; dof= 10.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	963	20%	506	10%	600	12%	651	14%	1.488	31%	612	13%	4.820	100%
Ne	908	30%	359	12%	295	10%	282	9%	723	24%	413	14%	2.980	100%
Ne znam	174	31%	60	11%	57	10%	45	8%	142	25%	82	15%	560	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 174,5 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	821	14%	555	10%	752	13%	795	14%	1.939	34%	804	14%	5.666	100%
Ne	966	42%	307	14%	176	8%	170	7%	379	17%	276	12%	2.274	100%
Ne znam	258	61%	63	15%	24	6%	13	3%	35	8%	27	6%	420	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.196,8 ; dof= 10.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	891	24%	397	11%	435	12%	491	13%	1.072	29%	458	12%	3.744	100%
Ne	1.040	25%	479	11%	476	11%	440	11%	1.150	28%	594	14%	4.179	100%
Ne znam	114	26%	49	11%	41	9%	47	11%	131	30%	55	13%	437	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 23,6 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	134	14%	89	9%	144	15%	164	17%	297	31%	119	13%	**947**	**100%**
Ne	1.795	26%	775	11%	737	11%	758	11%	1.873	27%	926	13%	**6.864**	**100%**
TOTAL	**1.929**	**25%**	**864**	**11%**	**881**	**11%**	**922**	**12%**	**2.170**	**28%**	**1.045**	**13%**	**7.811**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 99,2 ; dof= 5.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Less than 2 years old	1.219	60%	817	40%	**2.036**	**100%**
2 to less that 10 years old	540	59%	380	41%	**920**	**100%**
10 to less than 20 years old	537	57%	413	43%	**950**	**100%**
20 to less than 30 years old	535	55%	441	45%	**976**	**100%**
30 to less than 50 years old	1.312	56%	1.028	44%	**2.340**	**100%**
50 years old or more	644	58%	460	42%	**1.104**	**100%**
TOTAL	**4.787**	**57%**	**3.539**	**43%**	**8.326**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 10,7 ; dof= 5.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	46	2%	270	13%	848	41%	379	19%	138	7%	364	18%	2.045	100%
2 to less that 10 years old	11	1%	70	8%	381	41%	194	21%	74	8%	195	21%	925	100%
10 to less than 20 years old	9	1%	70	7%	346	36%	182	19%	86	9%	259	27%	952	100%
20 to less than 30 years old	6	1%	93	10%	424	43%	185	19%	79	8%	191	20%	978	100%
30 to less than 50 years old	17	1%	217	9%	1.062	45%	530	23%	197	8%	330	14%	2.353	100%
50 years old or more	12	1%	138	12%	605	55%	193	17%	68	6%	91	8%	1.107	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 271,1 ; dof= 25.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	338	17%	679	33%	1.028	50%	2.045	100%
2 to less that 10 years old	176	19%	377	41%	372	40%	925	100%
10 to less than 20 years old	176	18%	489	51%	287	30%	952	100%
20 to less than 30 years old	185	19%	507	52%	286	29%	978	100%
30 to less than 50 years old	479	20%	1.183	50%	691	29%	2.353	100%
50 years old or more	242	22%	420	38%	445	40%	1.107	100%
TOTAL	**1.596**	**19%**	**3.655**	**44%**	**3.109**	**37%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 293,4 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	206	10%	717	35%	1.122	55%	2.045	100%
2 to less that 10 years old	91	10%	458	50%	376	41%	925	100%
10 to less than 20 years old	96	10%	597	63%	259	27%	952	100%
20 to less than 30 years old	115	12%	561	57%	302	31%	978	100%
30 to less than 50 years old	334	14%	1.249	53%	770	33%	2.353	100%
50 years old or more	139	13%	420	38%	548	50%	1.107	100%
TOTAL	**981**	**12%**	**4.002**	**48%**	**3.377**	**40%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 417,5 ; dof= 10.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	525	26%	748	37%	772	38%	2.045	100%
2 to less that 10 years old	282	30%	414	45%	229	25%	925	100%
10 to less than 20 years old	252	26%	534	56%	166	17%	952	100%
20 to less than 30 years old	260	27%	545	56%	173	18%	978	100%
30 to less than 50 years old	591	25%	1.312	56%	450	19%	2.353	100%
50 years old or more	278	25%	488	44%	341	31%	1.107	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 341,2 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	1.648	81%	332	16%	65	3%	2.045	100%
2 to less that 10 years old	657	71%	218	24%	50	5%	925	100%
10 to less than 20 years old	484	51%	388	41%	80	8%	952	100%
20 to less than 30 years old	425	43%	461	47%	92	9%	978	100%
30 to less than 50 years old	863	37%	1.304	55%	186	8%	2.353	100%
50 years old or more	300	27%	681	62%	126	11%	1.107	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.344,8 ; dof= 10.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	1.788	87%	190	9%	67	3%	2.045	100%
2 to less that 10 years old	830	90%	73	8%	22	2%	925	100%
10 to less than 20 years old	894	94%	37	4%	21	2%	952	100%
20 to less than 30 years old	919	94%	49	5%	10	1%	978	100%
30 to less than 50 years old	2.192	93%	123	5%	38	2%	2.353	100%
50 years old or more	1.038	94%	49	4%	20	2%	1.107	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,7 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …je niste mogli priuštiti?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	Have you ever needed a genetic test but could not access it because... …JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	199	10%	1.565	77%	281	14%	2.045	100%
2 to less that 10 years old	111	12%	679	73%	135	15%	925	100%
10 to less than 20 years old	110	12%	639	67%	203	21%	952	100%
20 to less than 30 years old	112	11%	638	65%	228	23%	978	100%
30 to less than 50 years old	249	11%	1.509	64%	595	25%	2.353	100%
50 years old or more	56	5%	681	62%	370	33%	1.107	100%
TOTAL	**837**	**10%**	**5.711**	**68%**	**1.812**	**22%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 241,5 ; dof= 10.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …nije bila dostupna u Vašoj zemlji?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	Have you ever needed a genetic test but could not access it because... …NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	279	14%	1.482	72%	284	14%	2.045	100%
2 to less that 10 years old	124	13%	667	72%	134	14%	925	100%
10 to less than 20 years old	131	14%	597	63%	224	24%	952	100%
20 to less than 30 years old	98	10%	626	64%	254	26%	978	100%
30 to less than 50 years old	213	9%	1.467	62%	673	29%	2.353	100%
50 years old or more	74	7%	628	57%	405	37%	1.107	100%
TOTAL	**919**	**11%**	**5.467**	**65%**	**1.974**	**24%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 312,2 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

Have you ever needed a genetic test but could not access it because...

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	543	27%	1.254	61%	248	12%	2.045	100%
2 to less that 10 years old	272	29%	535	58%	118	13%	925	100%
10 to less than 20 years old	321	34%	453	48%	178	19%	952	100%
20 to less than 30 years old	295	30%	478	49%	205	21%	978	100%
30 to less than 50 years old	608	26%	1.141	48%	604	26%	2.353	100%
50 years old or more	183	17%	556	50%	368	33%	1.107	100%
TOTAL	**2.222**	**27%**	**4.417**	**53%**	**1.721**	**21%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 334,3 ; dof= 10.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	456	28%	532	32%	341	21%	269	16%	17	1%	41	2%	369	22%	1.648	
2 to less that 10 years old	161	25%	216	33%	119	18%	77	12%	14	2%	12	2%	175	27%	657	
10 to less than 20 years old	113	23%	170	35%	48	10%	33	7%	13	3%	8	2%	154	32%	484	
20 to less than 30 years old	122	29%	144	34%	54	13%	22	5%	16	4%	12	3%	118	28%	425	
30 to less than 50 years old	233	27%	277	32%	98	11%	56	6%	43	5%	15	2%	260	30%	863	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 227,3 ; dof= 30.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	177	11%	84	5%	1.387	84%	**1.648**	**100%**
2 to less that 10 years old	**83**	**13%**	35	5%	**539**	**82%**	**657**	**100%**
10 to less than 20 years old	54	11%	18	4%	412	85%	**484**	**100%**
20 to less than 30 years old	38	9%	17	4%	370	87%	**425**	**100%**
30 to less than 50 years old	86	10%	44	5%	733	85%	**863**	**100%**
50 years old or more	**20**	**7%**	12	4%	**268**	**89%**	**300**	**100%**

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 13,2 ; dof= 10.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NEZ…		NEZADOVOLJAN/NEZ…		NITI ZADOVOLJAN/ZADOV… NITI NEZADOVOLJAN/NEZ…		ZADOVOLJAN/ZADOV…		VRLO ZADOVOLJAN/ZADOV…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	**197**	**12%**	200	12%	343	21%	572	35%	267	16%	**69**	**4%**	**1.648**	**100%**
2 to less that 10 years old	63	10%	**95**	**14%**	138	21%	221	34%	116	18%	24	4%	**657**	**100%**
10 to less than 20 years old	44	9%	**72**	**15%**	109	23%	148	31%	85	18%	26	5%	**484**	**100%**
20 to less than 30 years old	47	11%	58	14%	87	20%	142	33%	70	16%	21	5%	**425**	**100%**
30 to less than 50 years old	83	10%	**77**	**9%**	200	23%	295	34%	149	17%	**59**	**7%**	**863**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 60,5 ; dof= 25.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	793	48%	322	20%	413	25%	120	7%	**1.648**	**100%**
2 to less that 10 years old	252	38%	140	21%	222	34%	43	7%	**657**	**100%**
10 to less than 20 years old	157	32%	108	22%	176	36%	43	9%	**484**	**100%**
20 to less than 30 years old	134	32%	89	21%	179	42%	23	5%	**425**	**100%**
30 to less than 50 years old	272	32%	210	24%	318	37%	63	7%	**863**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 122,3 ; dof= 15.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Genetska(-e) pretraga(-e)

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	296	18%	1.314	80%	38	2%	**1.648**	**100%**
2 to less that 10 years old	130	20%	511	78%	15	2%	**656**	**100%**
10 to less than 20 years old	62	13%	405	84%	17	4%	**484**	**100%**
20 to less than 30 years old	55	13%	360	85%	10	2%	**425**	**100%**
30 to less than 50 years old	103	12%	739	86%	21	2%	**863**	**100%**
50 years old or more	26	9%	271	90%	3	1%	**300**	**100%**
TOTAL	**672**	**15%**	**3.600**	**82%**	**104**	**2%**	**4.376**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 46,6 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	280	16%	1.470	82%	37	2%	1.787	100%
2 to less that 10 years old	143	17%	677	82%	10	1%	830	100%
10 to less than 20 years old	127	14%	754	84%	13	1%	894	100%
20 to less than 30 years old	144	16%	758	82%	17	2%	919	100%
30 to less than 50 years old	294	13%	1.861	85%	37	2%	2.192	100%
50 years old or more	133	13%	896	86%	9	1%	1.038	100%

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 20,1 ; dof= 10.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Less than 2 years old	515	25%	1.485	73%	45	2%	2.045	100%
2 to less that 10 years old	230	25%	676	73%	19	2%	925	100%
10 to less than 20 years old	183	19%	753	79%	16	2%	952	100%
20 to less than 30 years old	185	19%	777	79%	16	2%	978	100%
30 to less than 50 years old	414	18%	1.908	81%	31	1%	2.353	100%
50 years old or more	145	13%	956	86%	6	1%	1.107	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 110,7 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …psihološka podrška

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	200	10%	180	9%	211	10%	489	24%	965	47%	2.045	100%
2 to less that 10 years old	72	8%	93	10%	88	10%	236	26%	436	47%	925	100%
10 to less than 20 years old	73	8%	87	9%	113	12%	254	27%	425	45%	952	100%
20 to less than 30 years old	67	7%	76	8%	85	9%	297	30%	453	46%	978	100%
30 to less than 50 years old	213	9%	213	9%	212	9%	739	31%	976	41%	2.353	100%
50 years old or more	106	10%	105	9%	64	6%	477	43%	355	32%	1.107	100%
TOTAL	**731**	**9%**	**754**	**9%**	**773**	**9%**	**2.492**	**30%**	**3.610**	**43%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 184,8 ; dof= 20.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	471	23%	66	3%	341	17%	216	11%	951	47%	2.045	100%
2 to less that 10 years old	199	22%	36	4%	141	15%	99	11%	450	49%	925	100%
10 to less than 20 years old	146	15%	26	3%	123	13%	135	14%	522	55%	952	100%
20 to less than 30 years old	153	16%	27	3%	124	13%	159	16%	515	53%	978	100%
30 to less than 50 years old	422	18%	78	3%	313	13%	397	17%	1.143	49%	2.353	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 168,0 ; dof= 20.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	391	19%	45	2%	334	16%	464	23%	802	39%	**2.036**	**100%**
2 to less that 10 years old	144	16%	30	3%	125	14%	238	26%	383	42%	**920**	**100%**
10 to less than 20 years old	85	9%	21	2%	110	12%	340	36%	394	41%	**950**	**100%**
20 to less than 30 years old	90	9%	17	2%	100	10%	354	36%	415	43%	**976**	**100%**
30 to less than 50 years old	256	11%	34	1%	226	10%	917	39%	907	39%	**2.340**	**100%**
50 years old or more	137	12%	31	3%	76	7%	589	53%	271	25%	**1.104**	**100%**
TOTAL	**1.103**	**13%**	**178**	**2%**	**971**	**12%**	**2.902**	**35%**	**3.172**	**38%**	**8.326**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 474,3 ; dof= 20.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	1.135	56%	998	49%	113	6%	41	2%	235	11%	65	3%	84	4%	2.045	
2 to less that 10 years old	478	52%	419	45%	45	5%	30	3%	121	13%	45	5%	50	5%	925	
10 to less than 20 years old	477	50%	515	54%	52	5%	11	1%	104	11%	49	5%	48	5%	952	
20 to less than 30 years old	471	48%	505	52%	36	4%	7	1%	116	12%	66	7%	48	5%	978	
30 to less than 50 years old	1.228	52%	1.167	50%	76	3%	30	1%	270	11%	101	4%	115	5%	2.353	
50 years old or more	547	49%	487	44%	31	3%	15	1%	149	13%	66	6%	68	6%	1.107	
TOTAL	**4.336**	**52%**	**4.091**	**49%**	**353**	**4%**	**134**	**2%**	**995**	**12%**	**392**	**5%**	**413**	**5%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 109,4 ; dof= 30.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	134	7%	908	47%	717	37%	96	5%	72	4%	**1.927**	**100%**
2 to less that 10 years old	91	11%	432	50%	281	33%	30	3%	28	3%	**862**	**100%**
10 to less than 20 years old	97	11%	420	48%	303	35%	32	4%	24	3%	**876**	**100%**
20 to less than 30 years old	88	10%	407	44%	353	38%	40	4%	29	3%	**917**	**100%**
30 to less than 50 years old	223	10%	963	45%	808	37%	99	5%	70	3%	**2.163**	**100%**
50 years old or more	115	11%	410	39%	403	39%	65	6%	50	5%	**1.043**	**100%**
TOTAL	**748**	**10%**	**3.540**	**45%**	**2.865**	**37%**	**362**	**5%**	**273**	**4%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 61,5 ; dof= 20.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Razumijevanje toga kako će bolest napredovati...

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	114	6%	1.156	60%	506	26%	97	5%	54	3%	**1.927**	**100%**
2 to less that 10 years old	64	7%	523	61%	216	25%	46	5%	13	2%	**862**	**100%**
10 to less than 20 years old	78	9%	516	59%	237	27%	31	4%	14	2%	**876**	**100%**
20 to less than 30 years old	72	8%	510	56%	290	32%	39	4%	6	1%	**917**	**100%**
30 to less than 50 years old	172	8%	1.161	54%	676	31%	129	6%	25	1%	**2.163**	**100%**
50 years old or more	84	8%	533	51%	353	34%	55	5%	18	2%	**1.043**	**100%**
TOTAL	**584**	**7%**	**4.399**	**56%**	**2.278**	**29%**	**397**	**5%**	**130**	**2%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,9 ; dof= 20.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	58	16%	78	21%	144	39%	30	8%	59	16%	**369**	**100%**
2 to less that 10 years old	53	16%	66	20%	144	44%	25	8%	40	12%	**328**	**100%**
10 to less than 20 years old	120	17%	145	21%	278	40%	55	8%	100	14%	**698**	**100%**
20 to less than 30 years old	126	15%	164	19%	334	39%	72	9%	151	18%	**847**	**100%**
30 to less than 50 years old	340	17%	353	17%	803	39%	194	9%	361	18%	**2.051**	**100%**
50 years old or more	98	10%	119	13%	365	39%	86	9%	268	29%	**936**	**100%**
TOTAL	**795**	**15%**	**925**	**18%**	**2.068**	**40%**	**462**	**9%**	**979**	**19%**	**5.229**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 111,9 ; dof= 20.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Mogućnost uključivanja u školski sustav…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	184	10%	425	22%	720	37%	128	7%	470	24%	**1.927**	**100%**
2 to less that 10 years old	139	16%	192	22%	313	36%	42	5%	176	20%	**862**	**100%**
10 to less than 20 years old	123	14%	91	10%	244	28%	53	6%	365	42%	**876**	**100%**
20 to less than 30 years old	69	8%	37	4%	158	17%	69	8%	584	64%	**917**	**100%**
30 to less than 50 years old	97	4%	56	3%	244	11%	158	7%	1.608	74%	**2.163**	**100%**
50 years old or more	34	3%	12	1%	54	5%	47	5%	896	86%	**1.043**	**100%**
TOTAL	**646**	**8%**	**813**	**10%**	**1.733**	**22%**	**497**	**6%**	**4.099**	**53%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 2.268,3 ; dof= 20.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Mogućnost obavljanja radne djelatnosti…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	387	20%	183	9%	671	35%	151	8%	535	28%	1.927	100%
2 to less that 10 years old	192	22%	90	10%	294	34%	61	7%	225	26%	862	100%
10 to less than 20 years old	247	28%	98	11%	287	33%	43	5%	201	23%	876	100%
20 to less than 30 years old	290	32%	112	12%	265	29%	45	5%	205	22%	917	100%
30 to less than 50 years old	765	35%	191	9%	591	27%	86	4%	530	25%	2.163	100%
50 years old or more	236	23%	53	5%	167	16%	36	3%	551	53%	1.043	100%
TOTAL	**2.117**	**27%**	**727**	**9%**	**2.275**	**29%**	**422**	**5%**	**2.247**	**29%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 532,3 ; dof= 20.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	230	12%	345	18%	726	38%	221	11%	405	21%	1.927	100%
2 to less that 10 years old	100	12%	137	16%	345	40%	86	10%	194	23%	862	100%
10 to less than 20 years old	114	13%	89	10%	301	34%	105	12%	267	30%	876	100%
20 to less than 30 years old	121	13%	76	8%	279	30%	106	12%	335	37%	917	100%
30 to less than 50 years old	280	13%	183	8%	648	30%	265	12%	787	36%	2.163	100%
50 years old or more	111	11%	71	7%	241	23%	99	9%	521	50%	1.043	100%
TOTAL	**956**	**12%**	**901**	**12%**	**2.540**	**33%**	**882**	**11%**	**2.509**	**32%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 425,7 ; dof= 20.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Pristup kliničkim ispitivanjima…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	104	5%	548	28%	698	36%	307	16%	270	14%	1.927	100%
2 to less that 10 years old	59	7%	259	30%	329	38%	117	14%	98	11%	862	100%
10 to less than 20 years old	59	7%	234	27%	318	36%	127	14%	138	16%	876	100%
20 to less than 30 years old	68	7%	234	26%	292	32%	174	19%	149	16%	917	100%
30 to less than 50 years old	175	8%	462	21%	779	36%	394	18%	353	16%	2.163	100%
50 years old or more	70	7%	188	18%	365	35%	198	19%	222	21%	1.043	100%
TOTAL	**535**	**7%**	**1.925**	**25%**	**2.781**	**36%**	**1.317**	**17%**	**1.230**	**16%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 120,0 ; dof= 20.

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	264	14%	86	4%	601	31%	384	20%	592	31%	1.927	100%
2 to less that 10 years old	168	19%	31	4%	250	29%	173	20%	240	28%	862	100%
10 to less than 20 years old	212	24%	14	2%	253	29%	152	17%	245	28%	876	100%
20 to less than 30 years old	244	27%	9	1%	231	25%	155	17%	278	30%	917	100%
30 to less than 50 years old	490	23%	13	1%	566	26%	369	17%	725	34%	2.163	100%
50 years old or more	114	11%	21	2%	161	15%	157	15%	590	57%	1.043	100%
TOTAL	**1.492**	**19%**	**174**	**2%**	**2.062**	**26%**	**1.390**	**18%**	**2.670**	**34%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 468,1 ; dof= 20.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Vaš društveni život…

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	791	41%	175	9%	765	40%	57	3%	139	7%	1.927	100%
2 to less that 10 years old	384	45%	78	9%	334	39%	14	2%	52	6%	862	100%
10 to less than 20 years old	413	47%	93	11%	325	37%	14	2%	31	4%	876	100%
20 to less than 30 years old	482	53%	91	10%	300	33%	9	1%	35	4%	917	100%
30 to less than 50 years old	1.289	60%	128	6%	627	29%	37	2%	82	4%	2.163	100%
50 years old or more	621	60%	48	5%	306	29%	11	1%	57	5%	1.043	100%
TOTAL	**3.980**	**51%**	**613**	**8%**	**2.657**	**34%**	**142**	**2%**	**396**	**5%**	**7.788**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 240,3 ; dof= 20.

Chapter 4.

Family members were already diagnosed with the same rare disease

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Ista bolest je ranije dijagnosticirana članovima obitelji	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	1,9	785	5,7	757	5,9	527	1,3	834	7,1	707
Ne	0,3	6.552	3,2	6.175	3,4	3.543	3,8	6.840	4,4	5.797

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 40,1.
Inter variance= 1.832,5. Intra variance= 45,7.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Jeste li predstavnik bolesnika, tj. uključeni u aktivnosti politike za podršku pitanja rijetkih bolesti?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	JESTE LI PREDSTAVNIK BOLESNIKA, TJ. UKLJUČENI U AKTIVNOSTI POLITIKE ZA PODRŠKU PITANJA RIJETKIH BOLESTI?							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	257	20%	964	74%	88	7%	**1.309**	**100%**
Ne	1.701	20%	6.137	73%	584	7%	**8.422**	**100%**
TOTAL	**1.958**	**20%**	**7.101**	**73%**	**672**	**7%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,8 ; Chi2= 0,3 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	134	14%	89	9%	144	15%	164	17%	297	31%	119	13%	**947**	**100%**
Ne	1.795	26%	775	11%	737	11%	758	11%	1.873	27%	926	13%	**6.864**	**100%**
TOTAL	**1.929**	**25%**	**864**	**11%**	**881**	**11%**	**922**	**12%**	**2.170**	**28%**	**1.045**	**13%**	**7.811**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 99,2 ; dof= 5.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Gender of the person affected by the rare disease / Ista bolest je ranije dijagnosticirana članovima obitelji

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Žena	848	14%	5.320	86%	**6.168**	**100%**
Muškarac	348	13%	2.305	87%	**2.653**	**100%**
Ostalo	6	7%	76	93%	**82**	**100%**
TOTAL	**1.202**	**14%**	**7.701**	**86%**	**8.903**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 3,3 ; dof= 2.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Ista bolest je ranije dijagnosticirana članovima obitelji

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
15 godina ili manje	55	13%	358	87%	**413**	**100%**
između 16 i 19 godina	360	16%	1.931	84%	**2.291**	**100%**
između 20 i 23 godine	371	13%	2.460	87%	**2.831**	**100%**
24 godine ili više	359	12%	2.558	88%	**2.917**	**100%**
TOTAL	**1.145**	**14%**	**7.307**	**86%**	**8.452**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 13,5 ; dof= 3.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Kako biste najbolje opisali sebe? / Ista bolest je ranije dijagnosticirana članovima obitelji

KAKO BISTE NAJBOLJE OPISALI SEBE?	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	866	13%	5.779	87%	6.645	100%
Dio sam etničke manjine u zemlji u kojoj živim	78	19%	343	81%	421	100%
Ostalo, navesti	37	13%	259	88%	296	100%
TOTAL	**981**	**13%**	**6.381**	**87%**	**7.362**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 10,5 ; dof= 2.

Cross: Typology of countries based on size and welfare / Ista bolest je ranije dijagnosticirana članovima obitelji

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Group A ('Eastern Europe')	140	9%	1.472	91%	1.612	100%
Group B ('Western Europe')	660	14%	4.157	86%	4.817	100%
Group C ('Northern Europe')	456	15%	2.556	85%	3.012	100%
TOTAL	**1.256**	**13%**	**8.185**	**87%**	**9.441**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,3 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Ista bolest je ranije dijagnosticirana članovima obitelji

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Ruralnom području ili selu	314	14%	1.931	86%	**2.245**	**100%**
Malom ili srednje velikom gradu	503	14%	3.135	86%	**3.638**	**100%**
Velikom gradu	328	13%	2.233	87%	**2.561**	**100%**
TOTAL	**1.145**	**14%**	**7.299**	**86%**	**8.444**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 1,8 ; dof= 2.

Cross: Point prevalence of the rare disease / Ista bolest je ranije dijagnosticirana članovima obitelji

POINT PREVALENCE OF THE RARE DISEASE	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
1-5 / 10 000	494	21%	1.887	79%	**2.381**	**100%**
1-9 / 100 000	222	11%	1.744	89%	**1.966**	**100%**
1-9 / 1 000 000	57	13%	397	87%	**454**	**100%**
<1 / 1 000 000	95	12%	727	88%	**822**	**100%**
TOTAL	**868**	**15%**	**4.755**	**85%**	**5.623**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 89,7 ; dof= 3.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Orphacode associated nomenclature (english) / Ista bolest je ranije dijagnosticirana članovima obitelji

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	294	65%	160	35%	454	100%
Hypermobile Ehlers-Danlos syndrome	43	14%	268	86%	311	100%
Sarcoidosis	7	4%	163	96%	170	100%
Classical Ehlers-Danlos syndrome	13	10%	122	90%	135	100%
Williams syndrome	0	0%	134	100%	134	100%
Cystic fibrosis	14	11%	113	89%	127	100%
Myasthenia gravis	3	3%	115	97%	118	100%
Systemic sclerosis	5	5%	100	95%	105	100%
Tuberous sclerosis complex	8	8%	90	92%	98	100%
Neurofibromatosis type 1	19	21%	73	79%	92	100%
Interstitial cystitis	2	3%	72	97%	74	100%
Addison disease	5	7%	68	93%	73	100%
22q11.2 deletion syndrome	3	4%	65	96%	68	100%
Chronic inflammatory demyelinating polyneuropathy	1	2%	62	98%	63	100%
Perineural cyst	3	5%	58	95%	61	100%
Acute inflammatory demyelinating polyradiculoneuropathy	1	2%	61	98%	62	100%
Rett syndrome	1	2%	59	98%	60	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 3.382,7 ; dof= 1.629.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / Ista bolest je ranije dijagnosticirana članovima obitelji

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Abdominal surgical diseases	14	6%	221	94%	235	100%
Allergic diseases	0	0%	3	100%	3	100%
Bone diseases	88	11%	695	89%	783	100%
Cardiac diseases	77	12%	577	88%	654	100%
Cardiac malformations	6	2%	285	98%	291	100%
Circulatory system diseases	389	29%	941	71%	1.330	100%
Clinical sign	0	0%	0	0%	0	100%
Developmental anomalies during embryogenesis	600	18%	2.678	82%	3.278	100%
Diseases due to toxic effects	0	0%	3	100%	3	100%
Endocrine diseases	69	7%	913	93%	982	100%
Gastroenterological diseases	37	12%	262	88%	299	100%
Genetic diseases	952	18%	4.362	82%	5.314	100%
Gynecologic/obstetric diseases	24	9%	257	91%	281	100%
Hematological diseases	41	10%	354	90%	395	100%
Hepatic diseases	345	39%	540	61%	885	100%
Immunological diseases	25	9%	249	91%	274	100%
Inborn errors of metabolism	90	12%	667	88%	757	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 2.168,5 ; dof= 34.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	34	3%	275	21%	604	46%	184	14%	63	5%	149	11%	1.309	100%
Ne	112	1%	815	10%	3.730	44%	1.701	20%	665	8%	1.399	17%	8.422	100%
TOTAL	**146**	**2%**	**1.090**	**11%**	**4.334**	**45%**	**1.885**	**19%**	**728**	**7%**	**1.548**	**16%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 198,8 ; dof= 5.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	858	66%	442	34%	1.300	100%
Ne	4.717	56%	3.647	44%	8.364	100%
TOTAL	**5.575**	**58%**	**4.089**	**42%**	**9.664**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 42,5 ; dof= 1.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Da	906	69%	332	25%	71	5%	1.309	100%
Ne	4.206	50%	3.544	42%	672	8%	8.422	100%
TOTAL	**5.112**	**53%**	**3.876**	**40%**	**743**	**8%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 169,3 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.123	86%	143	11%	43	3%	1.309	100%
Ne	7.691	91%	530	6%	201	2%	8.422	100%
TOTAL	**8.814**	**91%**	**673**	**7%**	**244**	**3%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 42,6 ; dof= 2.

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...
…JE NISTE MOGLI PRIUŠTITI?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	119	9%	1.000	76%	190	15%	1.309	100%
Ne	826	10%	5.693	68%	1.903	23%	8.422	100%
TOTAL	**945**	**10%**	**6.693**	**69%**	**2.093**	**22%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 47,7 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …nije bila dostupna u Vašoj zemlji?

Have you ever needed a genetic test but could not access it because...
…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	131	10%	956	73%	222	17%	1.309	100%
Ne	924	11%	5.448	65%	2.050	24%	8.422	100%
TOTAL	**1.055**	**11%**	**6.404**	**66%**	**2.272**	**23%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,4 ; dof= 2.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	337	26%	795	61%	177	14%	1.309	100%
Ne	2.121	25%	4.485	53%	1.816	22%	8.422	100%
TOTAL	**2.458**	**25%**	**5.280**	**54%**	**1.993**	**20%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 47,6 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	311	34%	242	27%	106	12%	45	5%	15	2%	14	2%	260	29%	906	
Ne	1.079	26%	1.354	32%	685	16%	441	10%	107	3%	92	2%	1.148	27%	4.206	
TOTAL	**1.390**	**27%**	**1.596**	**31%**	**791**	**15%**	**486**	**10%**	**122**	**2%**	**106**	**2%**	**1.408**	**28%**	**5.112**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 66,3 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Da	67	7%	25	3%	814	90%	906	100%
Ne	471	11%	213	5%	3.522	84%	4.206	100%
TOTAL	**538**	**11%**	**238**	**5%**	**4.336**	**85%**	**5.112**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,0 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NEZA…		NEZADOVOLJAN/NEZA…		NITI ZADOVOLJAN/ZADOVO… NITI NEZADOVOLJAN/NEZA…		ZADOVOLJAN/ZADOVO…		VRLO ZADOVOLJAN/ZADOVO…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	86	9%	68	8%	174	19%	332	37%	203	22%	43	5%	906	100%
Ne	439	10%	481	11%	879	21%	1.518	36%	699	17%	190	5%	4.206	100%
TOTAL	**525**	**10%**	**549**	**11%**	**1.053**	**21%**	**1.850**	**36%**	**902**	**18%**	**233**	**5%**	**5.112**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 26,7 ; dof= 5.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Da	403	44%	218	24%	222	25%	63	7%	**906**	**100%**
Ne	1.626	39%	922	22%	1.363	32%	295	7%	**4.206**	**100%**
TOTAL	**2.029**	**40%**	**1.140**	**22%**	**1.585**	**31%**	**358**	**7%**	**5.112**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,9 ; dof= 3.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Genetska(-e) pretraga(-e)

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	90	10%	792	87%	24	3%	**906**	**100%**
Ne	668	16%	3.430	82%	107	3%	**4.205**	**100%**
TOTAL	**758**	**15%**	**4.222**	**83%**	**131**	**3%**	**5.111**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 20,9 ; dof= 2.

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	147	13%	955	85%	21	2%	**1.123**	**100%**
Ne	1.122	15%	6.437	84%	131	2%	**7.690**	**100%**
TOTAL	**1.269**	**14%**	**7.392**	**84%**	**152**	**2%**	**8.813**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 1,9 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	219	17%	1.057	81%	33	3%	**1.309**	**100%**
Ne	1.700	20%	6.575	78%	147	2%	**8.422**	**100%**
TOTAL	**1.919**	**20%**	**7.632**	**78%**	**180**	**2%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 11,6 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …psihološka podrška

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	97	7%	116	9%	94	7%	557	43%	445	34%	1.309	100%
Ne	746	9%	778	9%	758	9%	2.439	29%	3.701	44%	8.422	100%
TOTAL	**843**	**9%**	**894**	**9%**	**852**	**9%**	**2.996**	**31%**	**4.146**	**43%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 101,5 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	306	23%	56	4%	150	11%	285	22%	512	39%	1.309	100%
Ne	1.680	20%	309	4%	1.196	14%	1.246	15%	3.991	47%	8.422	100%
TOTAL	**1.986**	**20%**	**365**	**4%**	**1.346**	**14%**	**1.531**	**16%**	**4.503**	**46%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 65,6 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	155	12%	37	3%	104	8%	547	42%	457	35%	1.300	100%
Ne	1.162	14%	186	2%	991	12%	2.824	34%	3.201	38%	8.364	100%
TOTAL	**1.317**	**14%**	**223**	**2%**	**1.095**	**11%**	**3.371**	**35%**	**3.658**	**38%**	**9.664**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 45,0 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	751	57%	576	44%	64	5%	14	1%	112	9%	71	5%	117	9%	1.309	
Ne	4.333	51%	4.142	49%	348	4%	143	2%	963	11%	429	5%	354	4%	8.422	
TOTAL	**5.084**	**52%**	**4.718**	**48%**	**412**	**4%**	**157**	**2%**	**1.075**	**11%**	**500**	**5%**	**471**	**5%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 79,4 ; dof= 6.

Chapter 4.

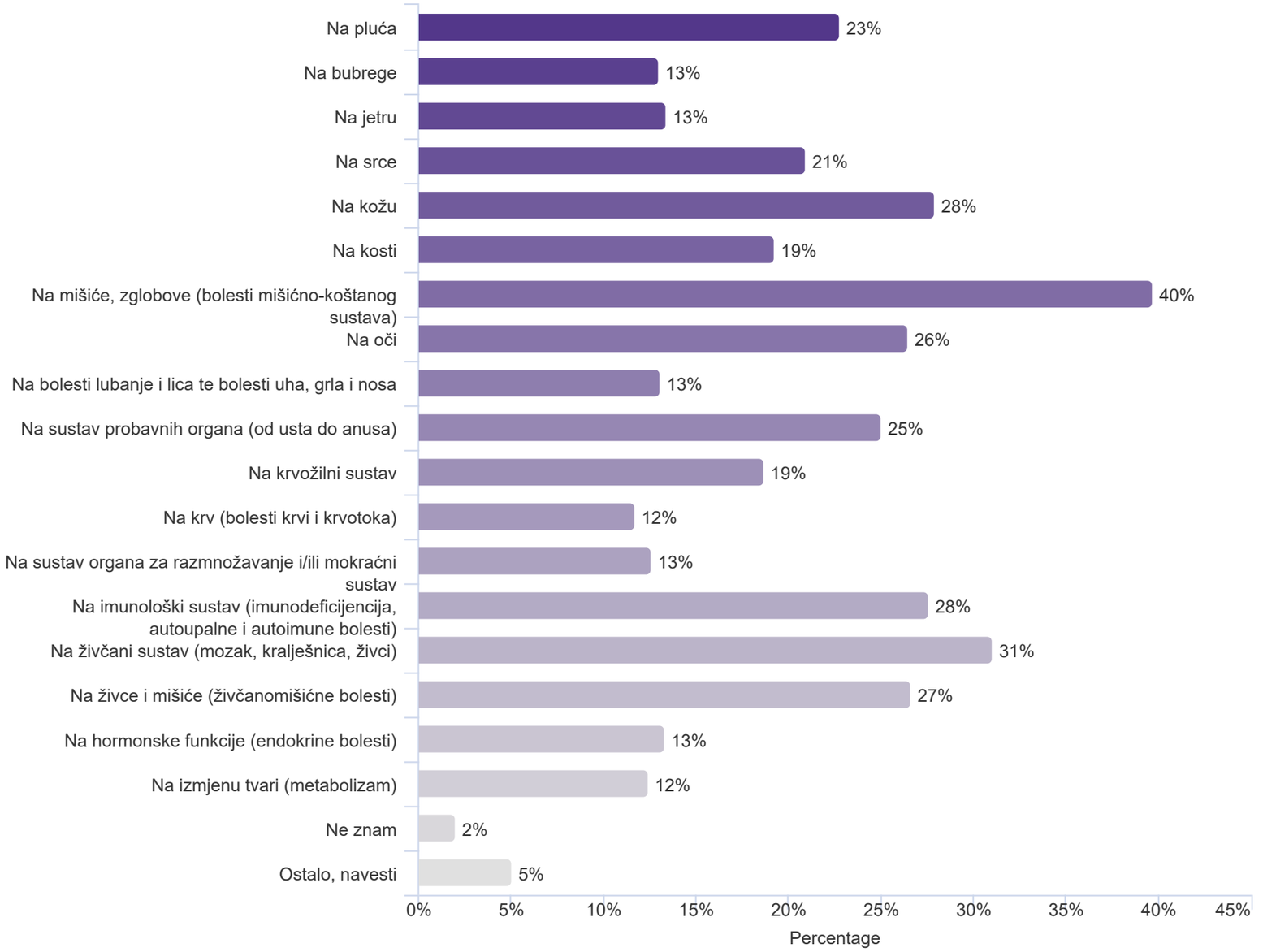
Family members were already diagnosed with the

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Na koje dijelove tijela utječe rijetka bolest?

	N
Na pluća	2.386
Na bubrege	1.365
Na jetru	1.405
Na srce	2.198
Na kožu	2.929
Na kosti	2.016
Na mišiće, zglobove (bolesti mišićno-koštanog sustava)	4.164
Na oči	2.777
Na bolesti lubanje i lica te bolesti uha, grla i nosa	1.371
Na sustav probavnih organa (od usta do anusa)	2.624
Na krvožilni sustav	1.957
Na krv (bolesti krvi i krvotoka)	1.232
Na sustav organa za razmnožavanje i/ili mokraćni sustav	1.324
Na imunološki sustav (imunodeficijencija, autoupalne i autoimune bolesti)	2.892
Na živčani sustav (mozak, kralješnica, živci)	3.254
Na živce i mišiće (živčanomišićne bolesti)	2.795
Na hormonske funkcije (endokrine bolesti)	1.393
Na izmjenu tvari (metabolizam)	1.301
Ne znam	208
Ostalo, navesti	529
TOTAL	**10.486**

Na koje dijelove tijela utječe rijetka bolest?

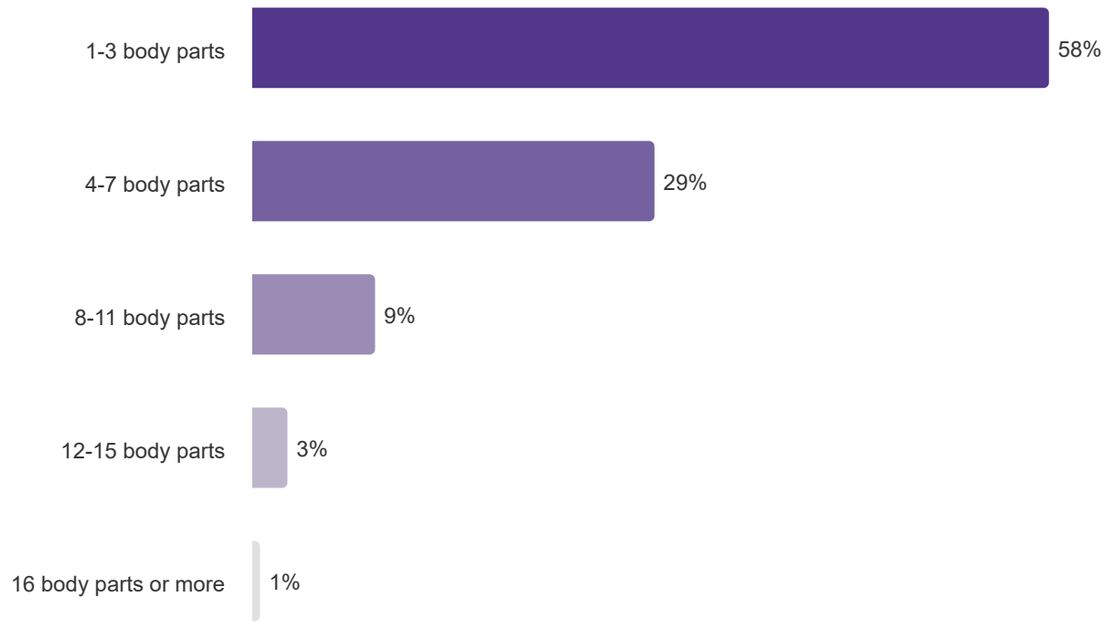


Complexity of the rare disease: number of body parts impacted by the rare disease

Disease complexity classified into five groups, based on the number of affected body parts.

	N
1-3 body parts	6.103
4-7 body parts	3.081
8-11 body parts	951
12-15 body parts	286
16 body parts or more	65
TOTAL	**10.486**

Disease complexity classified into five groups, based on the number of affected body parts.



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Disease complexity classified into five groups, based on the number of affected body parts.	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
1-3 body parts	0,5	4.500	3,0	4.202	2,9	2.526	2,7	4.536	3,9	3.796
4-7 body parts	0,6	2.312	3,7	2.227	4,4	1.286	3,9	2.321	5,1	1.937
8-11 body parts	0,1	729	5,0	649	6,3	383	5,9	722	7,2	563
12-15 body parts	0,0	228	5,3	201	8,1	109	8,3	217	9,2	172
16 body parts or more	3,5	51	10,3	43	14,0	31	12,2	47	12,2	39

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 3,6.
Inter variance= 167,4. Intra variance= 45,9.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Jeste li predstavnik bolesnika, tj. uključeni u aktivnosti politike za podršku pitanja rijetkih bolesti?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	JESTE LI PREDSTAVNIK BOLESNIKA, TJ. UKLJUČENI U AKTIVNOSTI POLITIKE ZA PODRŠKU PITANJA RIJETKIH BOLESTI?							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	1.149	19%	4.525	74%	429	7%	6.103	100%
4-7 body parts	629	20%	2.237	73%	215	7%	3.081	100%
8-11 body parts	207	22%	674	71%	70	7%	951	100%
12-15 body parts	72	25%	188	66%	26	9%	286	100%
16 body parts or more	16	25%	42	65%	7	11%	65	100%
TOTAL	**2.073**	**20%**	**7.666**	**73%**	**747**	**7%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 17,7 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable)

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)													
	LESS THAN 2 YEARS OLD		2 TO LESS THAT 10 YEARS OLD		10 TO LESS THAN 20 YEARS OLD		20 TO LESS THAN 30 YEARS OLD		30 TO LESS THAN 50 YEARS OLD		50 YEARS OLD OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	1.120	23%	527	11%	532	11%	570	12%	1.350	28%	737	15%	4.836	100%
4-7 body parts	677	27%	269	11%	274	11%	269	11%	701	28%	279	11%	2.469	100%
8-11 body parts	181	24%	87	11%	98	13%	105	14%	214	28%	78	10%	763	100%
12-15 body parts	54	23%	28	12%	37	16%	27	11%	76	32%	13	6%	235	100%
16 body parts or more	13	23%	14	25%	11	19%	7	12%	12	21%	0	0%	57	100%
TOTAL	**2.045**	**24%**	**925**	**11%**	**952**	**11%**	**978**	**12%**	**2.353**	**28%**	**1.107**	**13%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,5 ; dof= 20.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Disease complexity classified into five groups, based on the number of affected body parts.

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.											
	1-3 BODY PARTS		4-7 BODY PARTS		8-11 BODY PARTS		12-15 BODY PARTS		16 BODY PARTS OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	3.647	55%	2.033	31%	707	11%	216	3%	56	1%	6.659	100%
Muškarac	1.837	65%	758	27%	162	6%	48	2%	5	0%	2.810	100%
Ostalo	62	61%	26	26%	9	9%	2	2%	2	2%	101	100%
TOTAL	**5.546**	**58%**	**2.817**	**29%**	**878**	**9%**	**266**	**3%**	**63**	**1%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 131,1 ; dof= 8.

Cross: Typology of countries based on size and welfare / Disease complexity classified into five groups, based on the number of affected body parts.

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.											
	1-3 BODY PARTS		4-7 BODY PARTS		8-11 BODY PARTS		12-15 BODY PARTS		16 BODY PARTS OR MORE		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	1.005	56%	546	30%	184	10%	52	3%	7	0%	1.794	100%
Group B ('Western Europe')	3.138	61%	1.450	28%	381	7%	111	2%	25	0%	5.105	100%
Group C ('Northern Europe')	1.764	54%	998	30%	362	11%	116	4%	33	1%	3.273	100%
TOTAL	**5.907**	**58%**	**2.994**	**29%**	**927**	**9%**	**279**	**3%**	**65**	**1%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 80,7 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Disease complexity classified into five groups, based on the number of affected body parts.

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.					
	1-3 BODY PARTS	4-7 BODY PARTS	8-11 BODY PARTS	12-15 BODY PARTS	16 BODY PARTS OR MORE	TOTAL
Ruralnom području ili selu	59%	29%	9%	3%	1%	**100%**
Malom ili srednje velikom gradu	59%	29%	9%	3%	1%	**100%**
Velikom gradu	57%	30%	9%	3%	1%	**100%**
TOTAL	**58%**	**29%**	**9%**	**3%**	**1%**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,6 ; Chi2= 6,2 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete:

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:											
	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)		ZNAM NAZIV RIJETKE BOLESTI, SINDROMA ILI DEFORMACIJE, ŠTO JOŠ NIJE POTVRĐENO ODGOVARAJUĆIM GENETSKIM, KLINIČKIM, MEDICINSKIM SLIKOVNIM, MOLEKULARNIM ILI BIOKEMIJSKIM TESTOVIMA		IMAM SAMO DJELOMIČNE INFORMACIJE O NAZIVU RIJETKE BOLESTI ILI S TIME POVEZANOM GENU ILI VRSTI BOLESTI		ZNAM DA JE TA BOLEST RIJETKA, NO NJEZIN NAZIV ILI UZROK NISU PRONAĐENI		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	5.333	87%	388	6%	169	3%	197	3%	16	0%	**6.103**	**100%**
4-7 body parts	2.652	86%	225	7%	90	3%	109	4%	5	0%	**3.081**	**100%**
8-11 body parts	781	82%	111	12%	27	3%	30	3%	2	0%	**951**	**100%**
12-15 body parts	230	80%	29	10%	17	6%	9	3%	1	0%	**286**	**100%**
16 body parts or more	52	80%	7	11%	3	5%	3	5%	0	0%	**65**	**100%**
TOTAL	**9.048**	**86%**	**760**	**7%**	**306**	**3%**	**348**	**3%**	**24**	**0%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 53,4 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Genetic diseases

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	GENETIC DISEASES					
	GENETIC DISEASES		NON GENETIC DISEASES		TOTAL	
	N	%	N	%	N	%
1-3 body parts	2.995	64%	1.665	36%	4.660	100%
4-7 body parts	1.726	72%	670	28%	2.396	100%
8-11 body parts	527	70%	223	30%	750	100%
12-15 body parts	158	72%	60	28%	218	100%
16 body parts or more	41	82%	9	18%	50	100%
TOTAL	**5.447**	**67%**	**2.627**	**33%**	**8.074**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 54,5 ; dof= 4.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Calculation of point prevalence 2 modalities

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	CALCULATION OF POINT PREVALENCE 2 MODALITIES					
	RESPONDENTS WITH LESS RARE DISEASES		RESPONDENTS WITH VERY RARE DISEASES		TOTAL	
	N	%	N	%	N	%
1-3 body parts	2.431	77%	745	23%	3.176	100%
4-7 body parts	1.357	77%	412	23%	1.769	100%
8-11 body parts	449	79%	118	21%	567	100%
12-15 body parts	135	80%	33	20%	168	100%
16 body parts or more	34	83%	7	17%	41	100%
TOTAL	**4.406**	**77%**	**1.315**	**23%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 3,9 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Rijetka bolest dijagnosticirana je prije rođenja

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA					
	DA		NE		TOTAL	
	N	%	N	%	N	%
1-3 body parts	147	3%	5.539	97%	5.686	100%
4-7 body parts	54	2%	2.799	98%	2.853	100%
8-11 body parts	15	2%	867	98%	882	100%
12-15 body parts	3	1%	251	99%	254	100%
16 body parts or more	3	5%	53	95%	56	100%
TOTAL	**222**	**2%**	**9.509**	**98%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 9,4 ; dof= 4.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU					
	DA		NE		TOTAL	
	N	%	N	%	N	%
1-3 body parts	256	5%	5.307	95%	5.563	100%
4-7 body parts	111	4%	2.678	96%	2.789	100%
8-11 body parts	24	3%	851	97%	875	100%
12-15 body parts	2	1%	250	99%	252	100%
16 body parts or more	3	5%	53	95%	56	100%
TOTAL	**396**	**4%**	**9.139**	**96%**	**9.535**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 14,7 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	88	1%	775	13%	3.067	50%	1.113	18%	406	7%	654	11%	6.103	100%
4-7 body parts	41	1%	304	10%	1.171	38%	700	23%	258	8%	607	20%	3.081	100%
8-11 body parts	21	2%	62	7%	269	28%	174	18%	93	10%	332	35%	951	100%
12-15 body parts	5	2%	7	2%	54	19%	38	13%	27	9%	155	54%	286	100%
16 body parts or more	0	0%	2	3%	8	12%	8	12%	7	11%	40	62%	65	100%
TOTAL	**155**	**1%**	**1.150**	**11%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 943,4 ; dof= 20.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
1-3 body parts	3.515	58%	2.544	42%	6.059	100%
4-7 body parts	1.784	58%	1.275	42%	3.059	100%
8-11 body parts	514	54%	432	46%	946	100%
12-15 body parts	144	51%	141	49%	285	100%
16 body parts or more	41	64%	23	36%	64	100%
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 12,1 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	1.230	20%	2.152	35%	2.721	45%	6.103	100%
4-7 body parts	552	18%	1.513	49%	1.016	33%	3.081	100%
8-11 body parts	135	14%	587	62%	229	24%	951	100%
12-15 body parts	30	10%	213	74%	43	15%	286	100%
16 body parts or more	3	5%	55	85%	7	11%	65	100%
TOTAL	**1.950**	**19%**	**4.520**	**43%**	**4.016**	**38%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 505,4 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	759	12%	2.405	39%	2.939	48%	6.103	100%
4-7 body parts	385	12%	1.592	52%	1.104	36%	3.081	100%
8-11 body parts	79	8%	652	69%	220	23%	951	100%
12-15 body parts	17	6%	231	81%	38	13%	286	100%
16 body parts or more	6	9%	54	83%	5	8%	65	100%
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 533,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	1.656	27%	2.467	40%	1.980	32%	6.103	100%
4-7 body parts	774	25%	1.661	54%	646	21%	3.081	100%
8-11 body parts	203	21%	614	65%	134	14%	951	100%
12-15 body parts	46	16%	219	77%	21	7%	286	100%
16 body parts or more	4	6%	57	88%	4	6%	65	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 474,2 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	3.054	50%	2.561	42%	488	8%	6.103	100%
4-7 body parts	1.741	57%	1.098	36%	242	8%	3.081	100%
8-11 body parts	506	53%	372	39%	73	8%	951	100%
12-15 body parts	151	53%	115	40%	20	7%	286	100%
16 body parts or more	38	58%	25	38%	2	3%	65	100%
TOTAL	**5.490**	**52%**	**4.171**	**40%**	**825**	**8%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	5.458	89%	459	8%	186	3%	6.103	100%
4-7 body parts	2.832	92%	191	6%	58	2%	3.081	100%
8-11 body parts	870	91%	62	7%	19	2%	951	100%
12-15 body parts	263	92%	17	6%	6	2%	286	100%
16 body parts or more	59	91%	4	6%	2	3%	65	100%
TOTAL	**9.482**	**90%**	**733**	**7%**	**271**	**3%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 20,2 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	492	8%	4.261	70%	1.350	22%	6.103	100%
4-7 body parts	347	11%	2.115	69%	619	20%	3.081	100%
8-11 body parts	172	18%	574	60%	205	22%	951	100%
12-15 body parts	84	29%	133	47%	69	24%	286	100%
16 body parts or more	22	34%	33	51%	10	15%	65	100%
TOTAL	**1.117**	**11%**	**7.116**	**68%**	**2.253**	**21%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 255,4 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …nije bila dostupna u Vašoj zemlji?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI? Have you ever needed a genetic test but could not access it because...							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	569	9%	4.056	66%	1.478	24%	6.103	100%
4-7 body parts	362	12%	2.025	66%	694	23%	3.081	100%
8-11 body parts	177	19%	569	60%	205	22%	951	100%
12-15 body parts	74	26%	142	50%	70	24%	286	100%
16 body parts or more	15	23%	36	55%	14	22%	65	100%
TOTAL	**1.197**	**11%**	**6.828**	**65%**	**2.461**	**23%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 148,7 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI? Have you ever needed a genetic test but could not access it because...							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	1.310	21%	3.458	57%	1.335	22%	6.103	100%
4-7 body parts	900	29%	1.600	52%	581	19%	3.081	100%
8-11 body parts	388	41%	405	43%	158	17%	951	100%
12-15 body parts	165	58%	77	27%	44	15%	286	100%
16 body parts or more	42	65%	16	25%	7	11%	65	100%
TOTAL	**2.805**	**27%**	**5.556**	**53%**	**2.125**	**20%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 383,6 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	820	27%	903	30%	475	16%	299	10%	87	3%	56	2%	857	28%	**3.054**	
4-7 body parts	449	26%	572	33%	307	18%	195	11%	29	2%	39	2%	474	27%	**1.741**	
8-11 body parts	140	28%	191	38%	68	13%	51	10%	11	2%	7	1%	127	25%	**506**	
12-15 body parts	41	27%	53	35%	24	16%	15	10%	5	3%	13	9%	40	26%	**151**	
16 body parts or more	10	26%	12	32%	6	16%	7	18%	3	8%	2	5%	13	34%	**38**	
TOTAL	**1.460**	**27%**	**1.731**	**32%**	**880**	**16%**	**567**	**10%**	**135**	**2%**	**117**	**2%**	**1.511**	**28%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 70,0 ; dof= 24.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	311	10%	127	4%	2.616	86%	**3.054**	**100%**
4-7 body parts	192	11%	83	5%	1.466	84%	**1.741**	**100%**
8-11 body parts	66	13%	28	6%	412	81%	**506**	**100%**
12-15 body parts	18	12%	20	13%	113	75%	**151**	**100%**
16 body parts or more	3	8%	8	21%	27	71%	**38**	**100%**
TOTAL	**590**	**11%**	**266**	**5%**	**4.634**	**84%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 53,6 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NE…		NEZADOVOLJAN/NE…		NITI ZADOVOLJAN/ZADO… NITI NEZADOVOLJAN/NE…		ZADOVOLJAN/ZADO…		VRLO ZADOVOLJAN/ZADO…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	296	10%	303	10%	607	20%	1.138	37%	548	18%	162	5%	**3.054**	**100%**
4-7 body parts	183	11%	206	12%	402	23%	586	34%	280	16%	84	5%	**1.741**	**100%**
8-11 body parts	54	11%	84	17%	102	20%	166	33%	69	14%	31	6%	**506**	**100%**
12-15 body parts	27	18%	26	17%	39	26%	32	21%	23	15%	4	3%	**151**	**100%**
16 body parts or more	12	32%	4	11%	9	24%	8	21%	3	8%	2	5%	**38**	**100%**
TOTAL	**572**	**10%**	**623**	**11%**	**1.159**	**21%**	**1.930**	**35%**	**923**	**17%**	**283**	**5%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,6 ; dof= 20.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
1-3 body parts	1.214	40%	695	23%	900	29%	245	8%	**3.054**	**100%**
4-7 body parts	693	40%	374	21%	555	32%	119	7%	**1.741**	**100%**
8-11 body parts	175	35%	80	16%	220	43%	31	6%	**506**	**100%**
12-15 body parts	48	32%	27	18%	68	45%	8	5%	**151**	**100%**
16 body parts or more	7	18%	3	8%	27	71%	1	3%	**38**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 81,6 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Genetska(-e) pretraga(-e)

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	465	15%	2.505	82%	83	3%	**3.053**	**100%**
4-7 body parts	262	15%	1.439	83%	40	2%	**1.741**	**100%**
8-11 body parts	74	15%	416	82%	16	3%	**506**	**100%**
12-15 body parts	24	16%	123	81%	4	3%	**151**	**100%**
16 body parts or more	6	16%	32	84%	0	0%	**38**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 1,0 ; Chi2= 2,6 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	767	14%	4.580	84%	111	2%	**5.458**	**100%**
4-7 body parts	426	15%	2.361	83%	44	2%	**2.831**	**100%**
8-11 body parts	142	16%	716	82%	12	1%	**870**	**100%**
12-15 body parts	55	21%	206	78%	2	1%	**263**	**100%**
16 body parts or more	13	22%	45	76%	1	2%	**59**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 18,8 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	1.109	18%	4.858	80%	136	2%	6.103	100%
4-7 body parts	652	21%	2.382	77%	47	2%	3.081	100%
8-11 body parts	223	23%	707	74%	21	2%	951	100%
12-15 body parts	84	29%	197	69%	5	2%	286	100%
16 body parts or more	15	23%	50	77%	0	0%	65	100%
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 44,4 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …psihološka podrška

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	544	9%	599	10%	458	8%	2.009	33%	2.493	41%	6.103	100%
4-7 body parts	281	9%	242	8%	317	10%	864	28%	1.377	45%	3.081	100%
8-11 body parts	66	7%	80	8%	129	14%	226	24%	450	47%	951	100%
12-15 body parts	24	8%	26	9%	38	13%	56	20%	142	50%	286	100%
16 body parts or more	7	11%	8	12%	10	15%	10	15%	30	46%	65	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 129,6 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	1.316	22%	266	4%	764	13%	1.113	18%	2.644	43%	6.103	100%
4-7 body parts	597	19%	97	3%	486	16%	387	13%	1.514	49%	3.081	100%
8-11 body parts	136	14%	20	2%	156	16%	115	12%	524	55%	951	100%
12-15 body parts	30	10%	4	1%	41	14%	12	4%	199	70%	286	100%
16 body parts or more	4	6%	4	6%	16	25%	0	0%	41	63%	65	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 245,7 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	855	14%	169	3%	630	10%	2.368	39%	2.037	34%	6.059	100%
4-7 body parts	428	14%	55	2%	408	13%	931	30%	1.237	40%	3.059	100%
8-11 body parts	98	10%	16	2%	140	15%	201	21%	491	52%	946	100%
12-15 body parts	23	8%	1	0%	40	14%	40	14%	181	64%	285	100%
16 body parts or more	1	2%	2	3%	14	22%	4	6%	43	67%	64	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

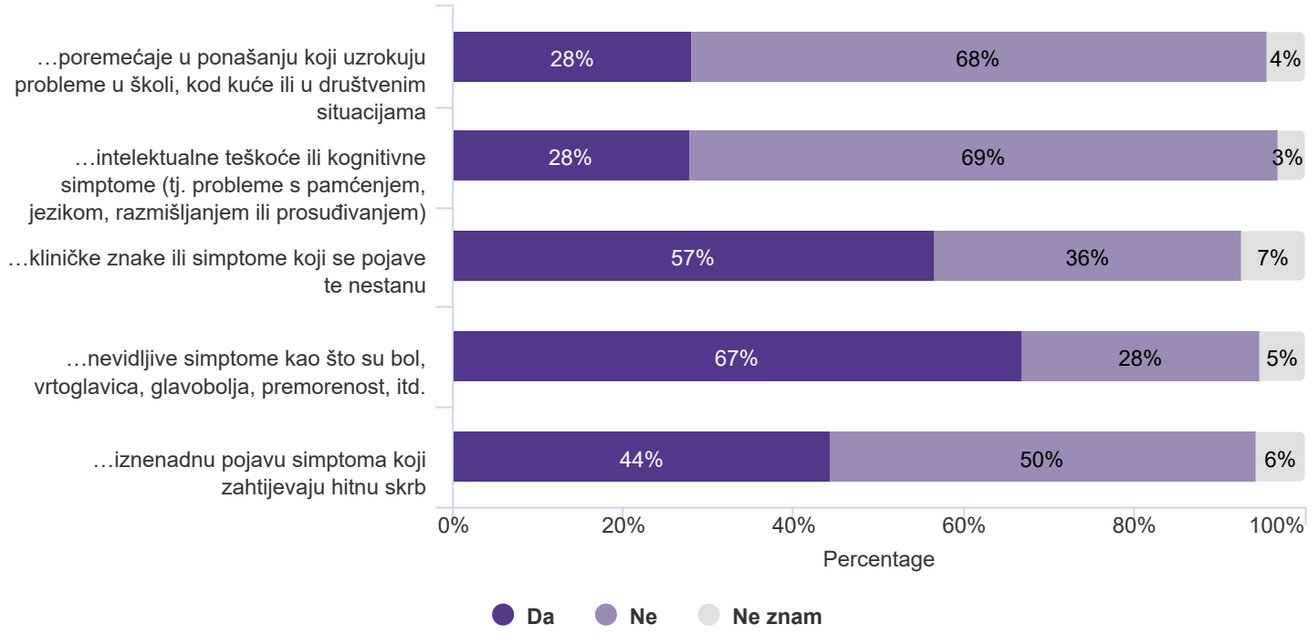
The relationship is very significant. p-value= < 0,01 ; Chi2= 363,7 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Jesu li prvi znaci bolesti uključivali…

	DA	NE	NE ZNAM	TOTAL
…poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama	2.957	7.085	444	**10.486**
…intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem)	2.936	7.236	314	**10.486**
…kliničke znake ili simptome koji se pojave te nestanu	5.940	3.788	758	**10.486**
…nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd.	7.020	2.916	550	**10.486**
…iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb	4.648	5.251	587	**10.486**

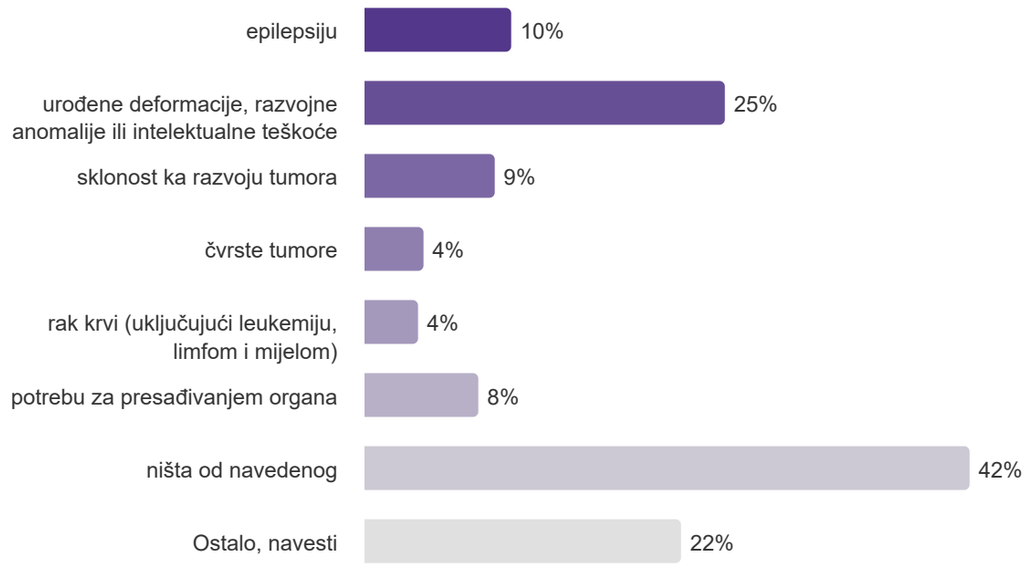
Jesu li prvi znaci bolesti uključivali…



A ta rijetka bolest uzrokuje:

	N
epilepsiju	997
urođene deformacije, razvojne anomalije ili intelektualne teškoće	2.424
sklonost ka razvoju tumora	877
čvrste tumore	409
rak krvi (uključujući leukemiju, limfom i mijelom)	365
potrebu za presađivanjem organa	766
ništa od navedenog	4.064
Ostalo, navesti	2.133
TOTAL	**9.693**

A ta rijetka bolest uzrokuje:



Chapter 4.

Family members were already diagnosed with the

Rare Barometer
A EURORDIS INITIATIVE

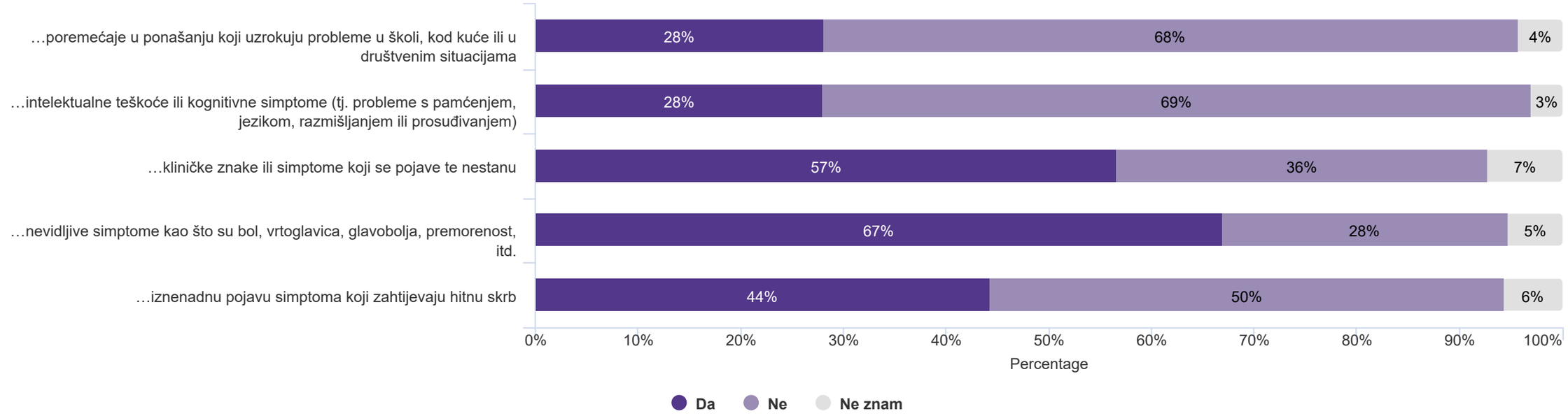
EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Jesu li prvi znaci bolesti uključivali…

	DA	NE	NE ZNAM	TOTAL
…poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama	2.957	7.085	444	**10.486**
…intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem)	2.936	7.236	314	**10.486**
…kliničke znake ili simptome koji se pojave te nestanu	5.940	3.788	758	**10.486**
…nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd.	7.020	2.916	550	**10.486**
…iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb	4.648	5.251	587	**10.486**
TOTAL	**23.501**	**26.276**	**2.653**	**52.430**

Jesu li prvi znaci bolesti uključivali…



Did the first symptoms include...

Multiple Cross

…poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,8	2.226	3,6	2.003	3,8	1.172	3,9	2.190	5,0	1.783
Ne	0,4	5.320	3,5	5.071	3,8	3.032	3,5	5.370	4,6	4.501
Ne znam	−0,4	274	2,9	248	4,8	131	3,8	283	5,2	223

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 5,0.
Inter variance= 230,0. Intra variance= 46,0.

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Did the first symptoms include...

Multiple Cross

…intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem)	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,3	2.254	3,0	1.967	3,4	1.147	3,8	2.220	4,5	1.830
Ne	0,6	5.358	3,7	5.172	4,0	3.075	3,5	5.431	4,8	4.517
Ne znam	−0,2	208	2,4	183	4,8	113	3,4	192	4,9	160

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Fisher= 3,3.
Inter variance= 150,6. Intra variance= 46,0.

Mean = average time, in number of years

N = number of respondents for which we have the average time

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Did the first symptoms include...

Multiple Cross

...kliničke znake ili simptome koji se pojave te nestanu	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,4	4.586	4,0	4.324	4,4	2.467	4,1	4.488	5,4	3.680
Ne	0,6	2.744	2,8	2.547	3,0	1.600	2,8	2.858	3,8	2.417
Ne znam	0,3	490	2,7	451	3,7	268	3,4	497	4,1	410

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,6 ; Fisher= 0,6.
Inter variance= 26,9. Intra variance= 46,0.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Did the first symptoms include...

Multiple Cross

...nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd.	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,4	5.372	3,9	5.099	4,5	2.939	4,2	5.271	5,1	4.309
Ne	0,6	2.071	2,6	1.902	2,6	1.197	2,4	2.191	3,9	1.877
Ne znam	0,5	377	1,8	321	2,6	199	2,7	381	3,8	321

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,7 ; Fisher= 0,4.
Inter variance= 18,8. Intra variance= 46,0.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Did the first symptoms include...

Multiple Cross

...iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,2	3.601	3,1	3.462	3,8	1.947	3,5	3.547	4,8	2.940
Ne	0,7	3.836	3,8	3.526	3,7	2.180	3,6	3.917	4,6	3.280
Ne znam	0,7	383	4,3	334	5,4	208	4,5	379	5,1	287

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Fisher= 4,1.
Inter variance= 190,5. Intra variance= 46,0.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOI U DRUŠTVENIM SITUACIJAMA						
	DA		NE		NE ZNAM		TO
	N	%	N	%	N	%	N
Žena	1.702	26%	4.661	70%	296	4%	6.659
Muškarac	912	32%	1.795	64%	103	4%	2.810
Ostalo	35	35%	57	56%	9	9%	101
TOTAL	**2.649**	**28%**	**6.513**	**68%**	**408**	**4%**	**9.570**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 56,6 ; dof= 4.

Cross: Gender of the person affected by the rare disease / …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem)

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLE PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)						
	DA		NE		NE ZNAM		TO
	N	%	N	%	N	%	N
Žena	1.735	26%	4.721	71%	203	3%	6.659
Muškarac	873	31%	1.858	66%	79	3%	2.810
Ostalo	37	37%	58	57%	6	6%	101
TOTAL	**2.645**	**28%**	**6.637**	**69%**	**288**	**3%**	**9.570**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,8 ; dof= 4.

Cross: Gender of the person affected by the rare disease / …kliničke znake ili simptome koji se pojave te nestanu

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU						
	DA		NE		NE ZNAM		TO
	N	%	N	%	N	%	N
Žena	4.062	61%	2.137	32%	460	7%	6.659
Muškarac	1.363	49%	1.239	44%	208	7%	2.810
Ostalo	50	50%	41	41%	10	10%	101
TOTAL	**5.475**	**57%**	**3.417**	**36%**	**678**	**7%**	**9.570**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 137,2 ; dof= 4.

Cross: Gender of the person affected by the rare disease / …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd.

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBC PREMORENOST, ITD.						
	DA		NE		NE ZNAM		TO
	N	%	N	%	N	%	N
Žena	4.869	73%	1.506	23%	284	4%	6.659
Muškarac	1.542	55%	1.067	38%	201	7%	2.810
Ostalo	57	56%	34	34%	10	10%	101
TOTAL	**6.468**	**68%**	**2.607**	**27%**	**495**	**5%**	**9.570**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 308,1 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Žena	3.016	45%	3.242	49%	401	6%	6.659	100%
Muškarac	1.202	43%	1.479	53%	129	5%	2.810	100%
Ostalo	41	41%	50	50%	10	10%	101	100%
TOTAL	**4.259**	**45%**	**4.771**	**50%**	**540**	**6%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 19,8 ; dof= 4.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	176	39%	252	55%	27	6%	455	100%
između 16 i 19 godina	737	30%	1.585	64%	142	6%	2.464	100%
između 20 i 23 godine	814	27%	2.090	69%	118	4%	3.022	100%
24 godine ili više	809	26%	2.234	71%	102	3%	3.145	100%
TOTAL	**2.536**	**28%**	**6.161**	**68%**	**389**	**4%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 73,7 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem)

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	149	33%	282	62%	24	5%	455	100%
između 16 i 19 godina	719	29%	1.662	67%	83	3%	2.464	100%
između 20 i 23 godine	814	27%	2.124	70%	84	3%	3.022	100%
24 godine ili više	868	28%	2.197	70%	80	3%	3.145	100%
TOTAL	**2.550**	**28%**	**6.265**	**69%**	**271**	**3%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 23,1 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …kliničke znake ili simptome koji se pojave te nestanu

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	249	55%	160	35%	46	10%	**455**	**100%**
između 16 i 19 godina	1.377	56%	889	36%	198	8%	**2.464**	**100%**
između 20 i 23 godine	1.740	58%	1.079	36%	203	7%	**3.022**	**100%**
24 godine ili više	1.810	58%	1.136	36%	199	6%	**3.145**	**100%**
TOTAL	**5.176**	**57%**	**3.264**	**36%**	**646**	**7%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 13,6 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd.

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	289	64%	135	30%	31	7%	**455**	**100%**
između 16 i 19 godina	1.705	69%	639	26%	120	5%	**2.464**	**100%**
između 20 i 23 godine	2.033	67%	816	27%	173	6%	**3.022**	**100%**
24 godine ili više	2.040	65%	940	30%	165	5%	**3.145**	**100%**
TOTAL	**6.067**	**67%**	**2.530**	**28%**	**489**	**5%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 17,7 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	224	49%	204	45%	27	6%	455	100%
između 16 i 19 godina	1.165	47%	1.141	46%	158	6%	2.464	100%
između 20 i 23 godine	1.303	43%	1.542	51%	177	6%	3.022	100%
24 godine ili više	1.337	43%	1.659	53%	149	5%	3.145	100%
TOTAL	**4.029**	**44%**	**4.546**	**50%**	**511**	**6%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,7 ; dof= 6.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	45	2%	248	8%	1.161	39%	642	22%	253	9%	608	21%	2.957	100%
Ne	96	1%	852	12%	3.218	45%	1.314	19%	507	7%	1.098	15%	7.085	100%
Ne znam	14	3%	50	11%	190	43%	77	17%	31	7%	82	18%	444	100%
TOTAL	**155**	**1%**	**1.150**	**11%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 101,9 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	47	2%	242	8%	1.104	38%	634	22%	274	9%	635	22%	2.936	100%
Ne	102	1%	880	12%	3.335	46%	1.334	18%	494	7%	1.091	15%	7.236	100%
Ne znam	6	2%	28	9%	130	41%	65	21%	23	7%	62	20%	314	100%
TOTAL	**155**	**1%**	**1.150**	**11%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 148,7 ; dof= 10.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	66	1%	503	8%	2.378	40%	1.230	21%	533	9%	1.230	21%	5.940	100%
Ne	69	2%	555	15%	1.834	48%	666	18%	214	6%	450	12%	3.788	100%
Ne znam	20	3%	92	12%	357	47%	137	18%	44	6%	108	14%	758	100%
TOTAL	**155**	**1%**	**1.150**	**11%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 295,6 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	65	1%	619	9%	2.878	41%	1.432	20%	608	9%	1.418	20%	7.020	100%
Ne	77	3%	468	16%	1.454	50%	478	16%	148	5%	291	10%	2.916	100%
Ne znam	13	2%	63	11%	237	43%	123	22%	35	6%	79	14%	550	100%
TOTAL	**155**	**1%**	**1.150**	**11%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 364,2 ; dof= 10.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	65	1%	419	9%	1.857	40%	957	21%	398	9%	952	20%	4.648	100%
Ne	77	1%	674	13%	2.469	47%	949	18%	353	7%	729	14%	5.251	100%
Ne znam	13	2%	57	10%	243	41%	127	22%	40	7%	107	18%	587	100%
TOTAL	**155**	**1%**	**1.150**	**11%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 149,7 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	1.669	57%	1.259	43%	**2.928**	**100%**
Ne	4.110	58%	2.933	42%	**7.043**	**100%**
Ne znam	219	50%	223	50%	**442**	**100%**
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 13,8 ; dof= 2.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	1.564	54%	1.349	46%	**2.913**	**100%**
Ne	4.260	59%	2.927	41%	**7.187**	**100%**
Ne znam	174	56%	139	44%	**313**	**100%**
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 27,0 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	3.342	57%	2.555	43%	5.897	100%
Ne	2.218	59%	1.542	41%	3.760	100%
Ne znam	438	58%	318	42%	756	100%
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 5,1 ; dof= 2.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	3.972	57%	2.993	43%	6.965	100%
Ne	1.721	59%	1.177	41%	2.898	100%
Ne znam	305	55%	245	45%	550	100%
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 5,8 ; dof= 2.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	2.674	58%	1.932	42%	**4.606**	**100%**
Ne	3.005	58%	2.216	42%	**5.221**	**100%**
Ne znam	319	54%	267	46%	**586**	**100%**
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 2,8 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	527	18%	1.382	47%	1.048	35%	2.957	100%
Ne	1.351	19%	2.935	41%	2.799	40%	7.085	100%
Ne znam	72	16%	203	46%	169	38%	444	100%
TOTAL	**1.950**	**19%**	**4.520**	**43%**	**4.016**	**38%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 26,5 ; dof= 4.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	338	11%	1.624	55%	995	34%	2.957	100%
Ne	863	12%	3.076	43%	3.146	44%	7.085	100%
Ne znam	45	10%	234	53%	165	37%	444	100%
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 124,5 ; dof= 4.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	776	26%	1.525	52%	656	22%	2.957	100%
Ne	1.797	25%	3.271	46%	2.017	28%	7.085	100%
Ne znam	110	25%	222	50%	112	25%	444	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 45,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

…INTELEKTU… TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJA… ILI PROSUĐIVA…	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	514	18%	1.368	47%	1.054	36%	2.936	100%
Ne	1.383	19%	3.010	42%	2.843	39%	7.236	100%
Ne znam	53	17%	142	45%	119	38%	314	100%
TOTAL	**1.950**	**19%**	**4.520**	**43%**	**4.016**	**38%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,1 ; dof= 4.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

…INTELEKTUAL… TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJ… ILI PROSUĐIVAN…	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	327	11%	1.602	55%	1.007	34%	2.936	100%
Ne	876	12%	3.161	44%	3.199	44%	7.236	100%
Ne znam	43	14%	171	54%	100	32%	314	100%
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 115,5 ; dof= 4.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	787	27%	1.493	51%	656	22%	2.936	100%
Ne	1.817	25%	3.366	47%	2.053	28%	7.236	100%
Ne znam	79	25%	159	51%	76	24%	314	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.062	18%	3.070	52%	1.808	30%	5.940	100%
Ne	745	20%	1.171	31%	1.872	49%	3.788	100%
Ne znam	143	19%	279	37%	336	44%	758	100%
TOTAL	**1.950**	**19%**	**4.520**	**43%**	**4.016**	**38%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 468,4 ; dof= 4.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	703	12%	3.352	56%	1.885	32%	5.940	100%
Ne	447	12%	1.264	33%	2.077	55%	3.788	100%
Ne znam	96	13%	318	42%	344	45%	758	100%
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 570,6 ; dof= 4.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.485	25%	3.340	56%	1.115	19%	5.940	100%
Ne	987	26%	1.364	36%	1.437	38%	3.788	100%
Ne znam	211	28%	314	41%	233	31%	758	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 532,5 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVI… GLAVOBOL… PREMOREN… ITD.	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.330	19%	3.580	51%	2.110	30%	7.020	100%
Ne	533	18%	775	27%	1.608	55%	2.916	100%
Ne znam	87	16%	165	30%	298	54%	550	100%
TOTAL	**1.950**	**19%**	**4.520**	**43%**	**4.016**	**38%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 687,8 ; dof= 4.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / … zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	850	12%	3.966	56%	2.204	31%	7.020	100%
Ne	332	11%	780	27%	1.804	62%	2.916	100%
Ne znam	64	12%	188	34%	298	54%	550	100%
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 898,9 ; dof= 4.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.793	26%	3.932	56%	1.295	18%	7.020	100%
Ne	743	25%	899	31%	1.274	44%	2.916	100%
Ne znam	147	27%	187	34%	216	39%	550	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 826,2 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	852	18%	2.315	50%	1.481	32%	4.648	100%
Ne	1.001	19%	1.925	37%	2.325	44%	5.251	100%
Ne znam	97	17%	280	48%	210	36%	587	100%
TOTAL	**1.950**	**19%**	**4.520**	**43%**	**4.016**	**38%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 204,3 ; dof= 4.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	517	11%	2.443	53%	1.688	36%	4.648	100%
Ne	651	12%	2.180	42%	2.420	46%	5.251	100%
Ne znam	78	13%	311	53%	198	34%	587	100%
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 138,4 ; dof= 4.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.118	24%	2.531	54%	999	21%	4.648	100%
Ne	1.406	27%	2.187	42%	1.658	32%	5.251	100%
Ne znam	159	27%	300	51%	128	22%	587	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 193,2 ; dof= 4.

Chapter 4.

Prevention

Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

Only respondents living with a diagnosed rare disease

Cross: Typology of countries based on size and welfare / Rijetka bolest dijagnosticirana je prije rođenja

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Group A ('Eastern Europe')	23	1%	1.589	99%	1.612	100%
Group B ('Western Europe')	153	3%	4.664	97%	4.817	100%
Group C ('Northern Europe')	39	1%	2.973	99%	3.012	100%
TOTAL	**215**	**2%**	**9.226**	**98%**	**9.441**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 35,8 ; dof= 2.

Cross: Typology of countries based on size and welfare / Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Group A ('Eastern Europe')	155	10%	1.457	90%	1.612	100%
Group B ('Western Europe')	336	7%	4.481	93%	4.817	100%
Group C ('Northern Europe')	93	3%	2.919	97%	3.012	100%
TOTAL	**584**	**6%**	**8.857**	**94%**	**9.441**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 87,7 ; dof= 2.

Only respondents living with a diagnosed rare disease

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Rijetka bolest dijagnosticirana je prije rođenja

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	39	3%	1.270	97%	**1.309**	**100%**
Ne	183	2%	8.239	98%	**8.422**	**100%**
TOTAL	**222**	**2%**	**9.509**	**98%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 3,3 ; dof= 1.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	38	3%	1.249	97%	**1.287**	**100%**
Ne	358	4%	7.887	96%	**8.245**	**100%**
TOTAL	**396**	**4%**	**9.136**	**96%**	**9.532**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 5,4 ; dof= 1.

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	5	2%	34	15%	112	50%	39	18%	11	5%	21	9%	222	100%
Ne	141	1%	1.056	11%	4.222	44%	1.846	19%	717	8%	1.527	16%	9.509	100%
TOTAL	**146**	**2%**	**1.090**	**11%**	**4.334**	**45%**	**1.885**	**19%**	**728**	**7%**	**1.548**	**16%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 14,3 ; dof= 5.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?													
	0		1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	22	6%	91	23%	191	48%	47	12%	10	3%	35	9%	396	100%
Ne	116	1%	964	11%	4.050	44%	1.808	20%	712	8%	1.489	16%	9.139	100%
TOTAL	**138**	**1%**	**1.055**	**11%**	**4.241**	**44%**	**1.855**	**19%**	**722**	**8%**	**1.524**	**16%**	**9.535**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 141,8 ; dof= 5.

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	146	66%	75	34%	221	100%
Ne	5.429	57%	4.014	43%	9.443	100%
TOTAL	**5.575**	**58%**	**4.089**	**42%**	**9.664**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 6,5 ; dof= 1.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Da	271	69%	120	31%	391	100%
Ne	5.185	57%	3.893	43%	9.078	100%
TOTAL	**5.456**	**58%**	**4.013**	**42%**	**9.469**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,8 ; dof= 1.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / …psihološka podrška

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	27	12%	21	9%	31	14%	47	21%	96	43%	**222**	**100%**
Ne	816	9%	873	9%	821	9%	2.949	31%	4.050	43%	**9.509**	**100%**
TOTAL	**843**	**9%**	**894**	**9%**	**852**	**9%**	**2.996**	**31%**	**4.146**	**43%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 17,1 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / …psihološka podrška

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	54	14%	51	13%	44	11%	90	23%	157	40%	**396**	**100%**
Ne	762	8%	829	9%	783	9%	2.869	31%	3.896	43%	**9.139**	**100%**
TOTAL	**816**	**9%**	**880**	**9%**	**827**	**9%**	**2.959**	**31%**	**4.053**	**43%**	**9.535**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 31,2 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	59	27%	11	5%	37	17%	29	13%	86	39%	222	100%
Ne	1.927	20%	354	4%	1.309	14%	1.502	16%	4.417	46%	9.509	100%
TOTAL	**1.986**	**20%**	**365**	**4%**	**1.346**	**14%**	**1.531**	**16%**	**4.503**	**46%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 10,2 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	129	33%	19	5%	61	15%	48	12%	139	35%	396	100%
Ne	1.805	20%	333	4%	1.250	14%	1.458	16%	4.293	47%	9.139	100%
TOTAL	**1.934**	**20%**	**352**	**4%**	**1.311**	**14%**	**1.506**	**16%**	**4.432**	**46%**	**9.535**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 48,0 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	39	18%	7	3%	37	17%	61	28%	77	35%	**221**	**100%**
Ne	1.278	14%	216	2%	1.058	11%	3.310	35%	3.581	38%	**9.443**	**100%**
TOTAL	**1.317**	**14%**	**223**	**2%**	**1.095**	**11%**	**3.371**	**35%**	**3.658**	**38%**	**9.664**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 13,2 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	88	23%	21	5%	54	14%	93	24%	135	35%	**391**	**100%**
Ne	1.202	13%	193	2%	1.016	11%	3.237	36%	3.430	38%	**9.078**	**100%**
TOTAL	**1.290**	**14%**	**214**	**2%**	**1.070**	**11%**	**3.330**	**35%**	**3.565**	**38%**	**9.469**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 59,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	131	59%	95	43%	6	3%	2	1%	23	10%	15	7%	7	3%	**222**	
Ne	4.953	52%	4.623	49%	406	4%	155	2%	1.052	11%	485	5%	464	5%	**9.509**	
TOTAL	**5.084**	**52%**	**4.718**	**48%**	**412**	**4%**	**157**	**2%**	**1.075**	**11%**	**500**	**5%**	**471**	**5%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 8,1 ; dof= 6.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	243	61%	166	42%	18	5%	5	1%	33	8%	19	5%	16	4%	**396**	
Ne	4.736	52%	4.473	49%	383	4%	148	2%	1.013	11%	469	5%	445	5%	**9.139**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 14,1 ; dof= 6.

Chapter 4.

Prevention

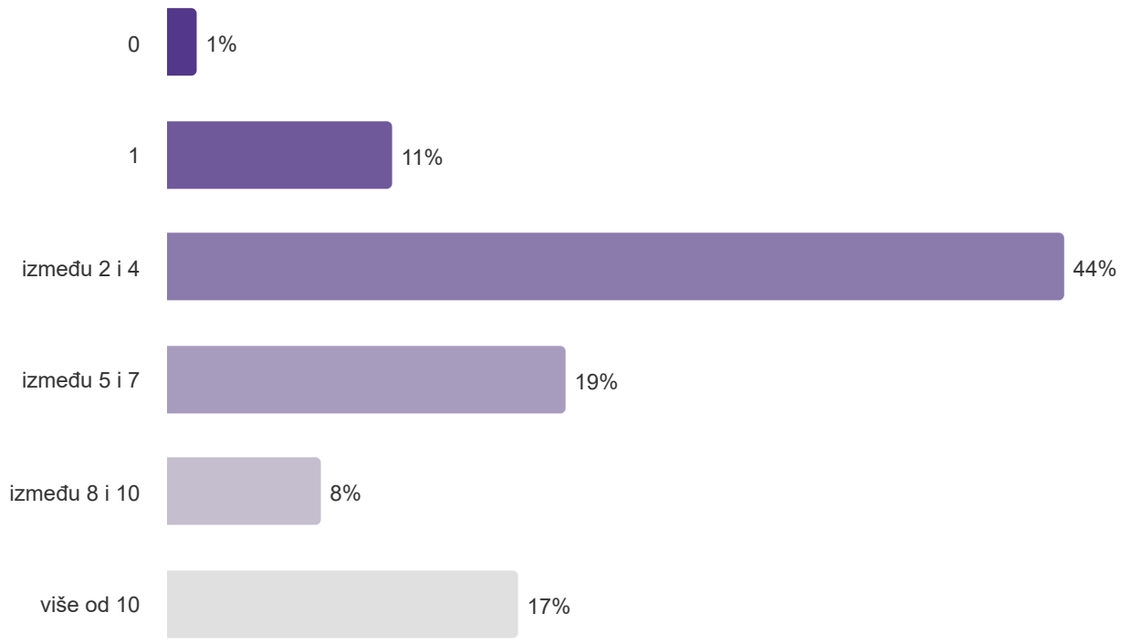
Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

	N
0	155
1	1.150
između 2 i 4	4.569
između 5 i 7	2.033
između 8 i 10	791
više od 10	1.788
TOTAL	**10.486**

Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
0-1	1,3	846	2,4	815	3,1	532	1,0	924	2,5	824
između 2 i 4	0,7	3.394	2,5	3.213	2,5	2.042	1,8	3.478	3,1	2.956
između 5 i 7	0,3	1.600	3,1	1.501	3,7	806	3,3	1.563	4,4	1.276
između 8 i 10	0,4	597	4,4	575	4,8	304	5,5	592	6,9	455
više od 10	−0,3	1.383	6,9	1.218	8,6	651	9,7	1.286	10,9	996

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 7,9.
Inter variance= 362,7. Intra variance= 45,8.

Mean = average time, in number of years

N = number of respondents for which we have the average time

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	747	11%	2.821	42%	1.315	20%	532	8%	1.244	19%	6.659	100%
Muškarac	393	14%	1.324	47%	538	19%	189	7%	366	13%	2.810	100%
Ostalo	16	16%	45	45%	15	15%	6	6%	19	19%	101	100%
TOTAL	**1.156**	**12%**	**4.190**	**44%**	**1.868**	**20%**	**727**	**8%**	**1.629**	**17%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 67,3 ; dof= 8.

Cross: Point prevalence of the rare disease / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

POINT PREVALENCE OF THE RARE DISEASE	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	338	14%	1.102	46%	409	17%	178	7%	380	16%	2.407	100%
1-9 / 100 000	271	14%	934	47%	399	20%	117	6%	278	14%	1.999	100%
1-9 / 1 000 000	54	12%	191	42%	103	22%	43	9%	68	15%	459	100%
<1 / 1 000 000	89	10%	334	39%	170	20%	76	9%	187	22%	856	100%
TOTAL	**752**	**13%**	**2.561**	**45%**	**1.081**	**19%**	**414**	**7%**	**913**	**16%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 61,9 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	316	15%	848	41%	379	19%	138	7%	364	18%	2.045	100%
2 to less that 10 years old	81	9%	381	41%	194	21%	74	8%	195	21%	925	100%
10 to less than 20 years old	79	8%	346	36%	182	19%	86	9%	259	27%	952	100%
20 to less than 30 years old	99	10%	424	43%	185	19%	79	8%	191	20%	978	100%
30 to less than 50 years old	234	10%	1.062	45%	530	23%	197	8%	330	14%	2.353	100%
50 years old or more	150	14%	605	55%	193	17%	68	6%	91	8%	1.107	100%
TOTAL	**959**	**11%**	**3.666**	**44%**	**1.663**	**20%**	**642**	**8%**	**1.430**	**17%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 257,8 ; dof= 20.

Cross: Genetic diseases / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

GENETIC DISEASES	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	775	14%	2.278	42%	1.003	18%	399	7%	992	18%	5.447	100%
Non Genetic diseases	244	9%	1.315	50%	560	21%	210	8%	298	11%	2.627	100%
TOTAL	**1.019**	**13%**	**3.593**	**45%**	**1.563**	**19%**	**609**	**8%**	**1.290**	**16%**	**8.074**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 122,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	802	13%	2.812	47%	1.085	18%	408	7%	891	15%	5.998	100%
Ne	497	11%	1.731	39%	933	21%	372	8%	882	20%	4.415	100%
Non-response	6	8%	26	36%	15	21%	11	15%	15	21%	73	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 111,9 ; dof= 8.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	309	24%	604	46%	184	14%	63	5%	149	11%	1.309	100%
Ne	927	11%	3.730	44%	1.701	20%	665	8%	1.399	17%	8.422	100%
Non-response	11	14%	24	31%	18	23%	2	3%	22	29%	77	100%
TOTAL	**1.247**	**13%**	**4.358**	**44%**	**1.903**	**19%**	**730**	**7%**	**1.570**	**16%**	**9.808**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 212,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	181	9%	1.092	56%	398	20%	134	7%	145	7%	1.950	100%
DA, nekoliko puta	186	4%	1.386	31%	1.084	24%	504	11%	1.360	30%	4.520	100%
NE	938	23%	2.091	52%	551	14%	153	4%	283	7%	4.016	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 2.022,5 ; dof= 8.

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	116	9%	660	53%	276	22%	83	7%	111	9%	1.246	100%
DA, nekoliko puta	277	6%	1.600	32%	1.142	23%	551	11%	1.364	28%	4.934	100%
NE	912	21%	2.309	54%	615	14%	157	4%	313	7%	4.306	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.612,0 ; dof= 8.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	304	11%	1.402	52%	529	20%	186	7%	262	10%	2.683	100%
DA, nekoliko puta	229	5%	1.683	34%	1.184	24%	529	11%	1.393	28%	5.018	100%
NE	772	28%	1.484	53%	320	11%	76	3%	133	5%	2.785	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.947,3 ; dof= 8.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	50	11%	214	47%	77	17%	33	7%	81	18%	455	100%
između 16 i 19 godina	312	13%	1.135	46%	449	18%	181	7%	387	16%	2.464	100%
između 20 i 23 godine	362	12%	1.337	44%	627	21%	227	8%	469	16%	3.022	100%
24 godine ili više	374	12%	1.303	41%	622	20%	246	8%	600	19%	3.145	100%
TOTAL	**1.098**	**12%**	**3.989**	**44%**	**1.775**	**20%**	**687**	**8%**	**1.537**	**17%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 30,5 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	835	12%	3.062	43%	1.419	20%	550	8%	1.259	18%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	57	12%	207	45%	82	18%	31	7%	88	19%	**465**	**100%**
Ostalo, navesti	43	13%	143	42%	68	20%	25	7%	58	17%	**337**	**100%**
TOTAL	**935**	**12%**	**3.412**	**43%**	**1.569**	**20%**	**606**	**8%**	**1.405**	**18%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,9 ; Chi2= 2,9 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	863	14%	3.067	50%	1.113	18%	406	7%	654	11%	**6.103**	**100%**
4-7 body parts	345	11%	1.171	38%	700	23%	258	8%	607	20%	**3.081**	**100%**
8-11 body parts	83	9%	269	28%	174	18%	93	10%	332	35%	**951**	**100%**
12-15 body parts	12	4%	54	19%	38	13%	27	9%	155	54%	**286**	**100%**
16 body parts or more	2	3%	8	12%	8	12%	7	11%	40	62%	**65**	**100%**
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 927,2 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	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)	1.182	13%	4.122	46%	1.731	19%	645	7%	1.368	15%	9.048	100%
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	65	9%	236	31%	172	23%	85	11%	202	27%	760	100%
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	25	8%	94	31%	61	20%	28	9%	98	32%	306	100%
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	27	8%	109	31%	68	20%	30	9%	114	33%	348	100%
Ostalo, navesti	6	25%	8	33%	1	4%	3	13%	6	25%	24	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 262,3 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	118	26%	230	50%	53	12%	22	5%	35	8%	458	100%
Hypermobile Ehlers-Danlos syndrome	7	2%	44	14%	55	17%	39	12%	172	54%	317	100%
Sarcoidosis	20	12%	86	51%	37	22%	10	6%	17	10%	170	100%
Classical Ehlers-Danlos syndrome	5	4%	33	24%	25	18%	11	8%	63	46%	137	100%
Williams syndrome	35	26%	57	42%	27	20%	5	4%	12	9%	136	100%
Cystic fibrosis	34	27%	62	48%	22	17%	3	2%	7	5%	128	100%
Myasthenia gravis	10	8%	67	56%	20	17%	8	7%	15	13%	120	100%
Systemic sclerosis	13	12%	66	62%	17	16%	6	6%	5	5%	107	100%
Tuberous sclerosis complex	19	19%	50	51%	19	19%	4	4%	6	6%	98	100%
Neurofibromatosis type 1	15	16%	49	53%	15	16%	6	7%	7	8%	92	100%
Interstitial cystitis	3	4%	22	30%	25	34%	12	16%	12	16%	74	100%
Addison disease	6	8%	35	48%	18	25%	5	7%	9	12%	73	100%
22q11.2 deletion syndrome	17	25%	26	38%	13	19%	6	9%	6	9%	68	100%
Chronic inflammatory demyelinating polyneuropathy	9	14%	34	52%	11	17%	3	5%	8	12%	65	100%
Perineural cyst	5	8%	22	35%	18	29%	6	10%	12	19%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	2	3%	36	58%	14	23%	4	6%	6	10%	62	100%
Rett syndrome	4	7%	26	43%	12	20%	5	8%	13	22%	60	100%
Marfan syndrome	8	15%	16	31%	10	19%	7	13%	11	21%	52	100%
Fragile X syndrome	4	8%	23	47%	12	24%	6	12%	4	8%	49	100%
BehÃ§et disease	1	2%	14	30%	15	32%	5	11%	12	26%	47	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 8.482,9 ; dof= 6.700.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Abdominal surgical diseases	27	11%	77	32%	39	16%	19	8%	77	32%	239	100%
Allergic diseases	0	0%	1	33%	2	67%	0	0%	0	0%	3	100%
Bone diseases	140	18%	310	39%	145	18%	59	7%	145	18%	799	100%
Cardiac diseases	88	13%	348	53%	119	18%	34	5%	71	11%	660	100%
Cardiac malformations	63	21%	128	43%	49	17%	18	6%	37	13%	295	100%
Circulatory system diseases	230	17%	616	46%	239	18%	102	8%	164	12%	1.351	100%
Clinical sign	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%
Developmental anomalies during embryogenesis	479	14%	1.310	39%	602	18%	265	8%	691	21%	3.347	100%
Diseases due to toxic effects	0	0%	1	33%	1	33%	0	0%	1	33%	3	100%
Endocrine diseases	124	12%	455	46%	217	22%	75	8%	124	12%	995	100%
Gastroenterological diseases	57	19%	147	48%	50	16%	20	7%	31	10%	305	100%
Genetic diseases	775	14%	2.278	42%	1.003	18%	399	7%	992	18%	5.447	100%
Gynecologic/obstetric diseases	49	17%	112	39%	55	19%	24	8%	44	15%	284	100%
Hematological diseases	70	17%	190	46%	77	19%	31	8%	44	11%	412	100%
Hepatic diseases	207	23%	446	50%	124	14%	39	4%	75	8%	891	100%
Immunological diseases	33	12%	106	37%	51	18%	25	9%	71	25%	286	100%
Inborn errors of metabolism	110	14%	338	44%	150	19%	53	7%	123	16%	774	100%
Infectious diseases	3	18%	5	29%	4	24%	1	6%	4	24%	17	100%
Infertility	76	19%	183	45%	76	19%	25	6%	50	12%	410	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.122,8 ; dof= 136.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	293	10%	1.161	39%	642	22%	253	9%	608	21%	2.957	100%
Ne	948	13%	3.218	45%	1.314	19%	507	7%	1.098	15%	7.085	100%
Ne znam	64	14%	190	43%	77	17%	31	7%	82	18%	444	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 89,2 ; dof= 8.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	289	10%	1.104	38%	634	22%	274	9%	635	22%	2.936	100%
Ne	982	14%	3.335	46%	1.334	18%	494	7%	1.091	15%	7.236	100%
Ne znam	34	11%	130	41%	65	21%	23	7%	62	20%	314	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 141,2 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	569	10%	2.378	40%	1.230	21%	533	9%	1.230	21%	5.940	100%
Ne	624	16%	1.834	48%	666	18%	214	6%	450	12%	3.788	100%
Ne znam	112	15%	357	47%	137	18%	44	6%	108	14%	758	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 290,5 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	684	10%	2.878	41%	1.432	20%	608	9%	1.418	20%	7.020	100%
Ne	545	19%	1.454	50%	478	16%	148	5%	291	10%	2.916	100%
Ne znam	76	14%	237	43%	123	22%	35	6%	79	14%	550	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 355,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	484	10%	1.857	40%	957	21%	398	9%	952	20%	4.648	100%
Ne	751	14%	2.469	47%	949	18%	353	7%	729	14%	5.251	100%
Ne znam	70	12%	243	41%	127	22%	40	7%	107	18%	587	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 143,7 ; dof= 8.

Cross: …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani? / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	155	6%	853	30%	611	22%	287	10%	899	32%	2.805	100%
Ne	896	16%	2.702	49%	1.012	18%	338	6%	608	11%	5.556	100%
Nije bitno	254	12%	1.014	48%	410	19%	166	8%	281	13%	2.125	100%
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 886,3 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	712	13%	2.342	44%	1.024	19%	397	7%	851	16%	**5.326**	**100%**
DA, preko internetskih zajednica	551	11%	2.011	40%	1.010	20%	419	8%	1.001	20%	**4.992**	**100%**
DA, putem lokalnih mreža (npr. škole)	47	11%	180	41%	78	18%	39	9%	92	21%	**436**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	21	11%	77	41%	35	18%	15	8%	42	22%	**190**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	141	11%	558	43%	274	21%	90	7%	247	19%	**1.310**	**100%**
NE, jer ne želim	89	16%	284	52%	72	13%	38	7%	64	12%	**547**	**100%**
Ostalo, navesti	81	16%	225	44%	93	18%	40	8%	75	15%	**514**	**100%**
TOTAL	**1.305**	**12%**	**4.569**	**44%**	**2.033**	**19%**	**791**	**8%**	**1.788**	**17%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 122,4 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Ruralnom području ili selu	287	12%	1.102	46%	476	20%	179	7%	372	15%	2.416	100%
Malom ili srednje velikom gradu	458	12%	1.730	44%	770	20%	288	7%	655	17%	3.901	100%
Velikom gradu	353	13%	1.151	42%	528	19%	219	8%	509	18%	2.760	100%
TOTAL	**1.098**	**12%**	**3.983**	**44%**	**1.774**	**20%**	**686**	**8%**	**1.536**	**17%**	**9.077**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 14,7 ; dof= 8.

Cross: Typology of countries based on size and welfare / Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?											
	0-1		IZMEĐU 2 I 4		IZMEĐU 5 I 7		IZMEĐU 8 I 10		VIŠE OD 10		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	184	10%	813	45%	356	20%	134	7%	307	17%	1.794	100%
Group B ('Western Europe')	682	13%	2.323	46%	988	19%	377	7%	735	14%	5.105	100%
Group C ('Northern Europe')	394	12%	1.297	40%	631	19%	253	8%	698	21%	3.273	100%
TOTAL	**1.260**	**12%**	**4.433**	**44%**	**1.975**	**19%**	**764**	**8%**	**1.740**	**17%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 84,6 ; dof= 8.

Chapter 4.

Prevention

Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

Cross: Gender of the person affected by the rare disease / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Žena	3.729	56%	2.904	44%	6.633	100%
Muškarac	1.674	60%	1.124	40%	2.798	100%
Ostalo	59	58%	42	42%	101	100%
TOTAL	**5.462**	**57%**	**4.070**	**43%**	**9.532**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 10,5 ; dof= 2.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
15 godina ili manje	283	63%	168	37%	451	100%
između 16 i 19 godina	1.368	56%	1.092	44%	2.460	100%
između 20 i 23 godine	1.756	58%	1.248	42%	3.004	100%
24 godine ili više	1.771	57%	1.363	43%	3.134	100%
TOTAL	**5.178**	**57%**	**3.871**	**43%**	**9.049**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 10,8 ; dof= 3.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	3.966	56%	3.123	44%	**7.089**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	263	57%	201	43%	**464**	**100%**
Ostalo, navesti	179	53%	158	47%	**337**	**100%**
TOTAL	**4.408**	**56%**	**3.482**	**44%**	**7.890**	

Under-represented elements *Over-represented elements*

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

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	N	%	N	%	N	%
Ruralnom području ili selu	1.378	57%	1.031	43%	**2.409**	**100%**
Malom ili srednje velikom gradu	2.253	58%	1.628	42%	**3.881**	**100%**
Velikom gradu	1.543	56%	1.207	44%	**2.750**	**100%**
TOTAL	**5.174**	**57%**	**3.866**	**43%**	**9.040**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 2,5 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Group A ('Eastern Europe')	960	54%	833	46%	1.793	100%
Group B ('Western Europe')	2.863	56%	2.207	44%	5.070	100%
Group C ('Northern Europe')	2.003	61%	1.269	39%	3.272	100%
TOTAL	**5.826**	**57%**	**4.309**	**43%**	**10.135**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,2 ; dof= 2.

Cross: Point prevalence of the rare disease / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

POINT PREVALENCE OF THE RARE DISEASE	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
1-5 / 10 000	1.464	61%	934	39%	2.398	100%
1-9 / 100 000	1.220	61%	772	39%	1.992	100%
1-9 / 1 000 000	253	56%	200	44%	453	100%
<1 / 1 000 000	437	51%	414	49%	851	100%
TOTAL	**3.374**	**59%**	**2.320**	**41%**	**5.694**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 30,7 ; dof= 3.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	369	81%	86	19%	455	100%
Hypermobile Ehlers-Danlos syndrome	146	46%	170	54%	316	100%
Sarcoidosis	79	47%	90	53%	169	100%
Classical Ehlers-Danlos syndrome	67	50%	68	50%	135	100%
Williams syndrome	79	58%	57	42%	136	100%
Cystic fibrosis	111	87%	17	13%	128	100%
Myasthenia gravis	70	58%	50	42%	120	100%
Systemic sclerosis	65	61%	42	39%	107	100%
Tuberous sclerosis complex	62	64%	35	36%	97	100%
Neurofibromatosis type 1	68	74%	24	26%	92	100%
Interstitial cystitis	36	49%	38	51%	74	100%
Addison disease	35	48%	38	52%	73	100%
22q11.2 deletion syndrome	38	56%	30	44%	68	100%
Chronic inflammatory demyelinating polyneuropathy	35	54%	30	46%	65	100%
Perineural cyst	7	11%	56	89%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	29	47%	33	53%	62	100%
Rett syndrome	37	62%	23	38%	60	100%
Marfan syndrome	24	50%	24	50%	48	100%
Fragile X syndrome	26	53%	23	47%	49	100%
BehÃ§et disease	30	64%	17	36%	47	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 2.217,6 ; dof= 1.672.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Abdominal surgical diseases	135	57%	102	43%	**237**	**100%**
Allergic diseases	1	33%	2	67%	**3**	**100%**
Bone diseases	441	56%	351	44%	**792**	**100%**
Cardiac diseases	399	61%	260	39%	**659**	**100%**
Cardiac malformations	181	61%	114	39%	**295**	**100%**
Circulatory system diseases	904	67%	436	33%	**1.340**	**100%**
Clinical sign	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	1.931	58%	1.395	42%	**3.326**	**100%**
Diseases due to toxic effects	2	67%	1	33%	**3**	**100%**
Endocrine diseases	551	56%	435	44%	**986**	**100%**
Gastroenterological diseases	201	66%	104	34%	**305**	**100%**
Genetic diseases	3.237	60%	2.181	40%	**5.418**	**100%**
Gynecologic/obstetric diseases	161	58%	118	42%	**279**	**100%**
Hematological diseases	259	63%	151	37%	**410**	**100%**
Hepatic diseases	645	73%	243	27%	**888**	**100%**
Immunological diseases	173	62%	108	38%	**281**	**100%**
Inborn errors of metabolism	477	62%	295	38%	**772**	**100%**
Infectious diseases	5	29%	12	71%	**17**	**100%**
Infertility	292	72%	116	28%	**408**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 437,3 ; dof= 34.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	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)	5.298	59%	3.692	41%	8.990	100%
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	322	43%	429	57%	751	100%
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	159	52%	146	48%	305	100%
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	206	60%	139	40%	345	100%
Ostalo, navesti	13	59%	9	41%	22	100%
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 77,6 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Genetic diseases / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

GENETIC DISEASES	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
Genetic diseases	3.237	60%	2.181	40%	5.418	100%
Non Genetic diseases	1.465	56%	1.148	44%	2.613	100%
TOTAL	**4.702**	**59%**	**3.329**	**41%**	**8.031**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 9,8 ; dof= 1.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI					
	DA		NE		TOTAL	
	N	%	N	%	N	%
1-3 body parts	3.515	58%	2.544	42%	6.059	100%
4-7 body parts	1.784	58%	1.275	42%	3.059	100%
8-11 body parts	514	54%	432	46%	946	100%
12-15 body parts	144	51%	141	49%	285	100%
16 body parts or more	41	64%	23	36%	64	100%
TOTAL	**5.998**	**58%**	**4.415**	**42%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 12,1 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Da	3.458	58%	2.038	34%	502	8%	5.998	100%
Ne	1.998	45%	2.097	47%	320	7%	4.415	100%
TOTAL	5.456	52%	4.135	40%	822	8%	10.413	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 195,7 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Da	5.513	92%	348	6%	137	2%	5.998	100%
Ne	3.906	88%	381	9%	128	3%	4.415	100%
TOTAL	9.419	90%	729	7%	265	3%	10.413	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 36,2 ; dof= 2.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...
…JE NISTE MOGLI PRIUŠTITI?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	507	8%	4.292	72%	1.199	20%	5.998	100%
Ne	587	13%	2.780	63%	1.048	24%	4.415	100%
TOTAL	**1.094**	**11%**	**7.072**	**68%**	**2.247**	**22%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 100,9 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …nije bila dostupna u Vašoj zemlji?

Have you ever needed a genetic test but could not access it because...
…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	607	10%	4.045	67%	1.346	22%	5.998	100%
Ne	578	13%	2.738	62%	1.099	25%	4.415	100%
TOTAL	**1.185**	**11%**	**6.783**	**65%**	**2.445**	**23%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,7 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI? Have you ever needed a genetic test but could not access it because…							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.372	23%	3.451	58%	1.175	20%	5.998	100%
Ne	1.408	32%	2.064	47%	943	21%	4.415	100%
TOTAL	**2.780**	**27%**	**5.515**	**53%**	**2.118**	**20%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 137,2 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	945	27%	1.079	31%	562	16%	330	10%	84	2%	70	2%	960	28%	3.458	
Ne	498	25%	648	32%	315	16%	231	12%	51	3%	47	2%	540	27%	1.998	
TOTAL	**1.443**	**26%**	**1.727**	**32%**	**877**	**16%**	**561**	**10%**	**135**	**2%**	**117**	**2%**	**1.500**	**27%**	**5.456**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 9,5 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Da	325	9%	143	4%	2.990	86%	3.458	100%
Ne	258	13%	119	6%	1.621	81%	1.998	100%
TOTAL	**583**	**11%**	**262**	**5%**	**4.611**	**85%**	**5.456**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 27,6 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/N…		NEZADOVOLJAN/N…		NITI ZADOVOLJAN/ZAD… NITI NEZADOVOLJAN/N…		ZADOVOLJAN/ZAD…		VRLO ZADOVOLJAN/ZAD…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	351	10%	353	10%	690	20%	1.232	36%	656	19%	176	5%	3.458	100%
Ne	216	11%	269	13%	459	23%	685	34%	264	13%	105	5%	1.998	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 43,4 ; dof= 5.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Da	1.398	40%	827	24%	972	28%	261	8%	**3.458**	**100%**
Ne	733	37%	340	17%	785	39%	140	7%	**1.998**	**100%**
TOTAL	**2.131**	**39%**	**1.167**	**21%**	**1.757**	**32%**	**401**	**7%**	**5.456**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 82,4 ; dof= 3.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Genetska(-e) pretraga(-e)

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	490	14%	2.871	83%	96	3%	**3.457**	**100%**
Ne	337	17%	1.615	81%	46	2%	**1.998**	**100%**
TOTAL	**827**	**15%**	**4.486**	**82%**	**142**	**3%**	**5.455**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 7,9 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	754	14%	4.652	84%	107	2%	**5.513**	**100%**
Ne	644	16%	3.199	82%	62	2%	**3.905**	**100%**
TOTAL	**1.398**	**15%**	**7.851**	**83%**	**169**	**2%**	**9.418**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 15,5 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.150	19%	4.720	79%	128	2%	**5.998**	**100%**
Ne	920	21%	3.417	77%	78	2%	**4.415**	**100%**
TOTAL	**2.070**	**20%**	**8.137**	**78%**	**206**	**2%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 5,8 ; dof= 2.

Chapter 10.

Misdiagnosis

Rare Barometer
A EURORDIS INITIATIVE

EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

…pogrešno pripisani barem još jednoj tjelesnoj bolesti?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, jednom	0,3	1.542	2,6	1.448	2,4	838	2,7	1.506	3,5	1.274
DA, nekoliko puta	0,4	3.471	4,8	3.203	5,7	1.753	5,9	3.389	6,9	2.720
NE	0,7	2.807	2,4	2.671	2,8	1.744	1,4	2.948	3,0	2.513

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Fisher= 2,3.
Inter variance= 105,6. Intra variance= 46,0.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

…zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, jednom	0,3	958	2,4	899	2,3	521	2,4	951	3,0	805
DA, nekoliko puta	0,5	3.785	5,1	3.486	6,0	1.867	5,7	3.691	6,9	2.927
NE	0,5	3.077	2,0	2.937	2,2	1.947	1,5	3.201	3,0	2.775

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,6 ; Fisher= 0,5.
Inter variance= 23,0. Intra variance= 46,0.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, jednom	0,5	2.058	3,2	1.917	3,4	1.095	3,0	2.055	4,2	1.704
DA, nekoliko puta	0,4	3.867	4,6	3.570	5,3	1.972	5,6	3.764	6,5	3.052
NE	0,7	1.895	1,8	1.835	2,1	1.268	0,6	2.024	2,2	1.751

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Fisher= 1,2.
Inter variance= 53,4. Intra variance= 46,0.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Žena	2.291	34%	1.215	18%	3.153	47%	6.659	100%
Muškarac	1.275	45%	555	20%	980	35%	2.810	100%
Ostalo	45	45%	14	14%	42	42%	101	100%
TOTAL	**3.611**	**38%**	**1.784**	**19%**	**4.175**	**44%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 138,5 ; dof= 4.

Cross: Gender of the person affected by the rare disease / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Žena	2.382	36%	765	11%	3.512	53%	6.659	100%
Muškarac	1.444	51%	348	12%	1.018	36%	2.810	100%
Ostalo	45	45%	12	12%	44	44%	101	100%
TOTAL	**3.871**	**40%**	**1.125**	**12%**	**4.574**	**48%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 234,0 ; dof= 4.

Cross: Gender of the person affected by the rare disease / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Žena	1.706	26%	3.453	52%	1.500	23%	6.659	100%
Muškarac	747	27%	1.119	40%	944	34%	2.810	100%
Ostalo	21	21%	45	45%	35	35%	101	100%
TOTAL	**2.474**	**26%**	**4.617**	**48%**	**2.479**	**26%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 157,8 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	190	42%	99	22%	166	36%	**455**	**100%**
između 16 i 19 godina	924	38%	447	18%	1.093	44%	**2.464**	**100%**
između 20 i 23 godine	1.212	40%	532	18%	1.278	42%	**3.022**	**100%**
24 godine ili više	1.144	36%	594	19%	1.407	45%	**3.145**	**100%**
TOTAL	**3.470**	**38%**	**1.672**	**18%**	**3.944**	**43%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 19,5 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	189	42%	56	12%	210	46%	**455**	**100%**
između 16 i 19 godina	991	40%	298	12%	1.175	48%	**2.464**	**100%**
između 20 i 23 godine	1.247	41%	363	12%	1.412	47%	**3.022**	**100%**
24 godine ili više	1.267	40%	346	11%	1.532	49%	**3.145**	**100%**
TOTAL	**3.694**	**41%**	**1.063**	**12%**	**4.329**	**48%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,7 ; Chi2= 4,1 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	146	32%	188	41%	121	27%	**455**	**100%**
između 16 i 19 godina	582	24%	1.220	50%	662	27%	**2.464**	**100%**
između 20 i 23 godine	798	26%	1.408	47%	816	27%	**3.022**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,3 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

KAKO BISTE NAJBOLJE OPISALI SEBE?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	2.637	37%	1.287	18%	3.201	45%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	184	40%	93	20%	188	40%	**465**	**100%**
Ostalo, navesti	127	38%	74	22%	136	40%	**337**	**100%**
TOTAL	**2.948**	**37%**	**1.454**	**18%**	**3.525**	**44%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 7,5 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

KAKO BISTE NAJBOLJE OPISALI SEBE?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	2.858	40%	837	12%	3.430	48%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	188	40%	57	12%	220	47%	**465**	**100%**
Ostalo, navesti	138	41%	42	12%	157	47%	**337**	**100%**
TOTAL	**3.184**	**40%**	**936**	**12%**	**3.807**	**48%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 1,0 ; Chi2= 0,5 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

KAKO BISTE NAJBOLJE OPISALI SEBE?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.775	25%	3.530	50%	1.820	26%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	126	27%	217	47%	122	26%	**465**	**100%**
Ostalo, navesti	84	25%	158	47%	95	28%	**337**	**100%**
TOTAL	**1.985**	**25%**	**3.905**	**49%**	**2.037**	**26%**	**7.927**	

Under-represented elements *Over-represented elements*

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	675	38%	363	20%	756	42%	**1.794**	**100%**
Group B ('Western Europe')	1.887	37%	1.025	20%	2.193	43%	**5.105**	**100%**
Group C ('Northern Europe')	1.325	40%	503	15%	1.445	44%	**3.273**	**100%**
TOTAL	**3.887**	**38%**	**1.891**	**19%**	**4.394**	**43%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 34,8 ; dof= 4.

Cross: Typology of countries based on size and welfare / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	806	45%	250	14%	738	41%	**1.794**	**100%**
Group B ('Western Europe')	2.031	40%	636	12%	2.438	48%	**5.105**	**100%**
Group C ('Northern Europe')	1.344	41%	316	10%	1.613	49%	**3.273**	**100%**
TOTAL	**4.181**	**41%**	**1.202**	**12%**	**4.789**	**47%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 47,4 ; dof= 4.

Cross: Typology of countries based on size and welfare / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	431	24%	861	48%	502	28%	**1.794**	**100%**
Group B ('Western Europe')	1.399	27%	2.442	48%	1.264	25%	**5.105**	**100%**
Group C ('Northern Europe')	784	24%	1.567	48%	922	28%	**3.273**	**100%**
TOTAL	**2.614**	**26%**	**4.870**	**48%**	**2.688**	**26%**	**10.172**	

Under-represented elements *Over-represented elements*

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	265	58%	61	13%	132	29%	458	100%
Hypermobile Ehlers-Danlos syndrome	35	11%	31	10%	251	79%	317	100%
Sarcoidosis	36	21%	51	30%	83	49%	170	100%
Classical Ehlers-Danlos syndrome	18	13%	16	12%	103	75%	137	100%
Williams syndrome	76	56%	24	18%	36	26%	136	100%
Cystic fibrosis	67	52%	19	15%	42	33%	128	100%
Myasthenia gravis	38	32%	37	31%	45	38%	120	100%
Systemic sclerosis	44	41%	25	23%	38	36%	107	100%
Tuberous sclerosis complex	63	64%	16	16%	19	19%	98	100%
Neurofibromatosis type 1	58	63%	14	15%	20	22%	92	100%
Interstitial cystitis	9	12%	16	22%	49	66%	74	100%
Addison disease	25	34%	17	23%	31	42%	73	100%
22q11.2 deletion syndrome	37	54%	11	16%	20	29%	68	100%
Chronic inflammatory demyelinating polyneuropathy	24	37%	18	28%	23	35%	65	100%
Perineural cyst	9	14%	7	11%	47	75%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	23	37%	22	35%	17	27%	62	100%
Rett syndrome	25	42%	10	17%	25	42%	60	100%
Marfan syndrome	26	50%	6	12%	20	38%	52	100%
Fragile X syndrome	29	59%	10	20%	10	20%	49	100%
BehÃ§et disease	3	6%	10	21%	34	72%	47	100%
Primary sclerosing cholangitis	25	54%	10	22%	11	24%	46	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 4.655,5 ; dof= 3.350.

Cross: Orphacode associated nomenclature (english) / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?			
	DA, JEDNOM	DA, NEKOLIKO PUTA	NE	TOTAL
Hereditary hemorrhagic telangiectasia	7%	39%	53%	100%
Hypermobile Ehlers-Danlos syndrome	5%	89%	6%	100%
Sarcoidosis	14%	49%	37%	100%
Classical Ehlers-Danlos syndrome	5%	85%	10%	100%
Williams syndrome	13%	32%	56%	100%
Cystic fibrosis	12%	27%	62%	100%
Myasthenia gravis	19%	43%	38%	100%
Systemic sclerosis	14%	35%	51%	100%
Tuberous sclerosis complex	12%	28%	60%	100%
Neurofibromatosis type 1	17%	37%	46%	100%
Interstitial cystitis	5%	82%	12%	100%
Addison disease	14%	64%	22%	100%
22q11.2 deletion syndrome	4%	41%	54%	100%
Chronic inflammatory demyelinating polyneuropathy	23%	28%	49%	100%
Perineural cyst	10%	83%	8%	100%
Acute inflammatory demyelinating polyradiculoneuropathy	27%	27%	45%	100%
Rett syndrome	10%	50%	40%	100%
Marfan syndrome	15%	46%	38%	100%
Fragile X syndrome	12%	53%	35%	100%
RobÃ§at disease	13%	77%	11%	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 4.664,6 ; dof= 3.350.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	124	27%	149	33%	185	40%	458	100%
Hypermobile Ehlers-Danlos syndrome	55	17%	253	80%	9	3%	317	100%
Sarcoidosis	47	28%	97	57%	26	15%	170	100%
Classical Ehlers-Danlos syndrome	24	18%	105	77%	8	6%	137	100%
Williams syndrome	35	26%	43	32%	58	43%	136	100%
Cystic fibrosis	20	16%	48	38%	60	47%	128	100%
Myasthenia gravis	29	24%	60	50%	31	26%	120	100%
Systemic sclerosis	29	27%	42	39%	36	34%	107	100%
Tuberous sclerosis complex	30	31%	22	22%	46	47%	98	100%
Neurofibromatosis type 1	32	35%	24	26%	36	39%	92	100%
Interstitial cystitis	20	27%	52	70%	2	3%	74	100%
Addison disease	28	38%	36	49%	9	12%	73	100%
22q11.2 deletion syndrome	18	26%	21	31%	29	43%	68	100%
Chronic inflammatory demyelinating polyneuropathy	15	23%	31	48%	19	29%	65	100%
Perineural cyst	13	21%	48	76%	2	3%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	21	34%	26	42%	15	24%	62	100%
Rett syndrome	19	32%	27	45%	14	23%	60	100%
Marfan syndrome	14	27%	22	42%	16	31%	52	100%
Fragile X syndrome	23	47%	13	27%	13	27%	49	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 4.559,4 ; dof= 3.350.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Genetic diseases / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

GENETIC DISEASES	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Genetic diseases	2.311	42%	909	17%	2.227	41%	5.447	100%
Non Genetic diseases	855	33%	602	23%	1.170	45%	2.627	100%
TOTAL	3.166	39%	1.511	19%	3.397	42%	8.074	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 86,5 ; dof= 2.

Cross: Genetic diseases / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

GENETIC DISEASES	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Genetic diseases	579	11%	2.463	45%	2.405	44%	5.447	100%
Non Genetic diseases	386	15%	1.234	47%	1.007	38%	2.627	100%
TOTAL	965	12%	3.697	46%	3.412	42%	8.074	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,9 ; dof= 2.

Cross: Genetic diseases / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

GENETIC DISEASES	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Genetic diseases	1.390	26%	2.434	45%	1.623	30%	5.447	100%
Non Genetic diseases	690	26%	1.340	51%	597	23%	2.627	100%
TOTAL	2.080	26%	3.774	47%	2.220	27%	8.074	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 47,8 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Point prevalence of the rare disease / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

POINT PREVALENCE OF THE RARE DISEASE	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	1.008	42%	418	17%	981	41%	**2.407**	**100%**
1-9 / 100 000	778	39%	409	20%	812	41%	**1.999**	**100%**
1-9 / 1 000 000	166	36%	95	21%	198	43%	**459**	**100%**
<1 / 1 000 000	335	39%	124	14%	397	46%	**856**	**100%**
TOTAL	**2.287**	**40%**	**1.046**	**18%**	**2.388**	**42%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 24,8 ; dof= 6.

Cross: Point prevalence of the rare disease / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

POINT PREVALENCE OF THE RARE DISEASE	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	256	11%	1.184	49%	967	40%	**2.407**	**100%**
1-9 / 100 000	260	13%	845	42%	894	45%	**1.999**	**100%**
1-9 / 1 000 000	47	10%	215	47%	197	43%	**459**	**100%**
<1 / 1 000 000	111	13%	403	47%	342	40%	**856**	**100%**
TOTAL	**674**	**12%**	**2.647**	**46%**	**2.400**	**42%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 25,1 ; dof= 6.

Cross: Calculation point prevalence / The variable computes the number of times respondents were misdiagnosed an classifies them accordingly.

POINT PREVALENCE OF THE RARE DISEASE	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	640	27%	1.089	45%	678	28%	**2.407**	**100%**
1-9 / 100 000	503	25%	925	46%	571	29%	**1.999**	**100%**
1-9 / 1 000 000	127	28%	220	48%	112	24%	**459**	**100%**
<1 / 1 000 000	203	24%	431	50%	222	26%	**856**	**100%**
TOTAL	**1.473**	**26%**	**2.665**	**47%**	**1.583**	**28%**	**5.721**	

Under-represented elements *Over-represented elements*

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	2.721	45%	1.230	20%	2.152	35%	6.103	10
4-7 body parts	1.016	33%	552	18%	1.513	49%	3.081	10
8-11 body parts	229	24%	135	14%	587	62%	951	10
12-15 body parts	43	15%	30	10%	213	74%	286	10
16 body parts or more	7	11%	3	5%	55	85%	65	10
TOTAL	**4.016**	**38%**	**1.950**	**19%**	**4.520**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 505,4 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	759	12%	2.405	39%	2.939	48%	6.103	10
4-7 body parts	385	12%	1.592	52%	1.104	36%	3.081	10
8-11 body parts	79	8%	652	69%	220	23%	951	10
12-15 body parts	17	6%	231	81%	38	13%	286	10
16 body parts or more	6	9%	54	83%	5	8%	65	10
TOTAL	**1.246**	**12%**	**4.934**	**47%**	**4.306**	**41%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 533,1 ; dof= 8.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
1-3 body parts	1.656	27%	2.467	40%	1.980	32%	6.103	100%
4-7 body parts	774	25%	1.661	54%	646	21%	3.081	100%
8-11 body parts	203	21%	614	65%	134	14%	951	100%
12-15 body parts	46	16%	219	77%	21	7%	286	100%
16 body parts or more	4	6%	57	88%	4	6%	65	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 474,2 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	697	53%	166	13%	446	34%	1.309	100%
Ne	3.104	37%	1.639	19%	3.679	44%	8.422	100%
TOTAL	**3.801**	**39%**	**1.805**	**19%**	**4.125**	**42%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 130,7 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

ISTA BOLEST JE RANIJE DIJAGNOSTICIR… ČLANOVIMA OBITELJI	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	125	10%	534	41%	650	50%	1.309	100%
Ne	1.027	12%	3.986	47%	3.409	40%	8.422	100%
TOTAL	**1.152**	**12%**	**4.520**	**46%**	**4.059**	**42%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,0 ; dof= 2.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	323	25%	486	37%	500	38%	1.309	100%
Ne	2.190	26%	4.093	49%	2.139	25%	8.422	100%
TOTAL	**2.513**	**26%**	**4.579**	**47%**	**2.639**	**27%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 100,9 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
0-1	938	72%	181	14%	186	14%	1.305	100%
između 2 i 4	2.091	46%	1.092	24%	1.386	30%	4.569	100%
između 5 i 7	551	27%	398	20%	1.084	53%	2.033	100%
između 8 i 10	153	19%	134	17%	504	64%	791	100%
više od 10	283	16%	145	8%	1.360	76%	1.788	100%
TOTAL	**4.016**	**38%**	**1.950**	**19%**	**4.520**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 2.022,5 ; dof= 8.

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
0-1	912	70%	116	9%	277	21%	1.305	100%
između 2 i 4	2.309	51%	660	14%	1.600	35%	4.569	100%
između 5 i 7	615	30%	276	14%	1.142	56%	2.033	100%
između 8 i 10	157	20%	83	10%	551	70%	791	100%
više od 10	313	18%	111	6%	1.364	76%	1.788	100%
TOTAL	**4.306**	**41%**	**1.246**	**12%**	**4.934**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.612,0 ; dof= 8.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
DA, jednom	791	29%	337	13%	1.555	58%	2.683	100%
DA, nekoliko puta	730	15%	909	18%	3.379	67%	5.018	100%
NE	2.785	100%	0	0%	0	0%	2.785	100%
TOTAL	**4.306**	**41%**	**1.246**	**12%**	**4.934**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 5.615,6 ; dof= 4.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	2.555	43%	1.119	19%	2.324	39%	5.998	100%
Ne	1.445	33%	813	18%	2.157	49%	4.415	100%
TOTAL	**4.000**	**38%**	**1.932**	**19%**	**4.481**	**43%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 125,0 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	2.772	46%	705	12%	2.521	42%	5.998	100%
Ne	1.509	34%	527	12%	2.379	54%	4.415	100%
TOTAL	**4.281**	**41%**	**1.232**	**12%**	**4.900**	**47%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 165,6 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.512	25%	2.613	44%	1.873	31%	5.998	100%
Ne	1.157	26%	2.359	53%	899	20%	4.415	100%
TOTAL	**2.669**	**26%**	**4.972**	**48%**	**2.772**	**27%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 165,6 ; dof= 2.

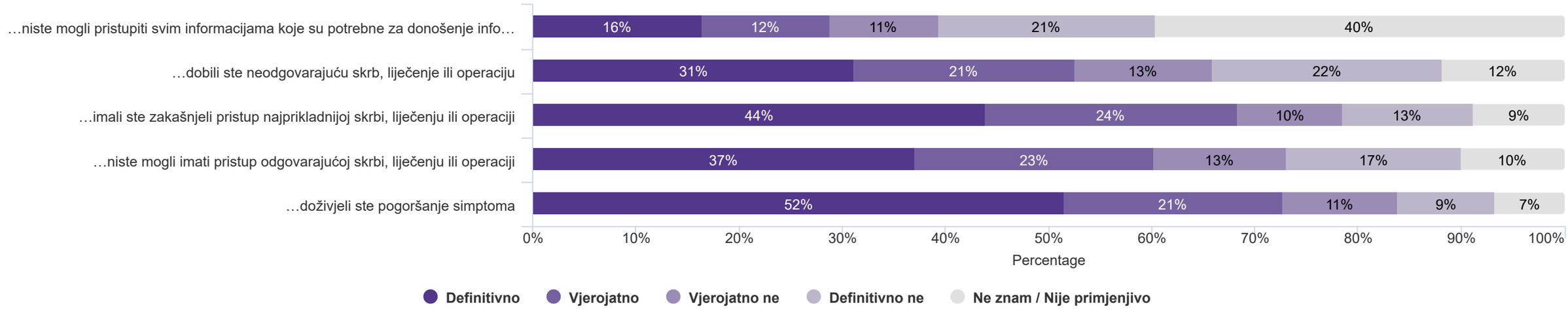
*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Kao posljedica pogrešne dijagnoze, recite nam ako Vi ili osoba o kojoj skrbite…

	DEFINITIVNO	VJEROJATNO	VJEROJATNO NE	DEFINITIVNO NE	NE ZNAM / NIJE PRIMJENJIVO	TOTAL
…niste mogli pristupiti svim informacijama koje su potrebne za donošenje informiranih reproduktivnih odluka kao što su planiranje hoćete li imati djece ili ne ili odlučivanje hoćete li provesti prenatalne pretrage ili ne	1.264	956	810	1.621	3.050	**7.701**
…dobili ste neodgovarajuću skrb, liječenje ili operaciju	2.400	1.647	1.033	1.709	912	**7.701**
…imali ste zakašnjeli pristup najprikladnijoj skrbi, liječenju ili operaciji	3.380	1.883	787	973	678	**7.701**
…niste mogli imati pristup odgovarajućoj skrbi, liječenju ili operaciji	2.858	1.786	991	1.297	769	**7.701**
…doživjeli ste pogoršanje simptoma	3.967	1.634	856	724	520	**7.701**
TOTAL	**13.869**	**7.906**	**4.477**	**6.324**	**5.929**	**38.505**

Kao posljedica pogrešne dijagnoze, recite nam ako Vi ili osoba o kojoj skrbite…



Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …niste mogli pristupiti svim informacijama koje su potrebne za donošenje informiranih reproduktivnih odluka kao što su planiranje hoćete li imati djece ili ne ili odlučivanje hoćete li provesti prenatalne pretrage ili ne

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…NISTE MOGLI PRISTUPITI SVIM INFORMACIJAMA KOJE SU POTREBNE ZA DONOŠENJE INFORMIRANIH REPRODUKTIVNIH ODLUKA KAO ŠTO SU PLANIRANJE HOĆETE LI IMATI DJECE ILI NE ILI ODLUČIVANJE HOĆETE LI PROVESTI PRENATALNE PRETRAGE ILI NE											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	232	12%	227	12%	231	12%	497	25%	763	39%	1.950	100%
DA, nekoliko puta	885	20%	605	13%	455	10%	824	18%	1.751	39%	4.520	100%
NE	147	12%	124	10%	124	10%	300	24%	536	44%	1.231	100%
TOTAL	**1.264**	**16%**	**956**	**12%**	**810**	**11%**	**1.621**	**21%**	**3.050**	**40%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 128,6 ; dof= 8.

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …dobili ste neodgovarajuću skrb, liječenje ili operaciju

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…DOBILI STE NEODGOVARAJUĆU SKRB, LIJEČENJE ILI OPERACIJU											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	397	20%	377	19%	288	15%	637	33%	251	13%	1.950	100%
DA, nekoliko puta	1.756	39%	1.074	24%	556	12%	707	16%	427	9%	4.520	100%
NE	247	20%	196	16%	189	15%	365	30%	234	19%	1.231	100%
TOTAL	**2.400**	**31%**	**1.647**	**21%**	**1.033**	**13%**	**1.709**	**22%**	**912**	**12%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 542,3 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …imali ste zakašnjeli pristup najprikladnijoj skrbi, liječenju ili operaciji

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…IMALI STE ZAKAŠNJELI PRISTUP NAJPRIKLADNIJOJ SKRBI, LIJEČENJU ILI OPERACIJI											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	592	30%	498	26%	273	14%	394	20%	193	10%	1.950	100%
DA, nekoliko puta	2.381	53%	1.103	24%	364	8%	369	8%	303	7%	4.520	100%
NE	407	33%	282	23%	150	12%	210	17%	182	15%	1.231	100%
TOTAL	**3.380**	**44%**	**1.883**	**24%**	**787**	**10%**	**973**	**13%**	**678**	**9%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 502,9 ; dof= 8.

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …dobili ste neodgovarajuću skrb, liječenje ili operaciju

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…DOBILI STE NEODGOVARAJUĆU SKRB, LIJEČENJE ILI OPERACIJU											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	397	20%	377	19%	288	15%	637	33%	251	13%	1.950	100%
DA, nekoliko puta	1.756	39%	1.074	24%	556	12%	707	16%	427	9%	4.520	100%
NE	247	20%	196	16%	189	15%	365	30%	234	19%	1.231	100%
TOTAL	**2.400**	**31%**	**1.647**	**21%**	**1.033**	**13%**	**1.709**	**22%**	**912**	**12%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 542,3 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …doživjeli ste pogoršanje simptoma

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…DOŽIVJELI STE POGORŠANJE SIMPTOMA											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	747	38%	449	23%	294	15%	314	16%	146	7%	1.950	100%
DA, nekoliko puta	2.730	60%	946	21%	390	9%	238	5%	216	5%	4.520	100%
NE	490	40%	239	19%	172	14%	172	14%	158	13%	1.231	100%
TOTAL	**3.967**	**52%**	**1.634**	**21%**	**856**	**11%**	**724**	**9%**	**520**	**7%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 532,7 ; dof= 8.

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …niste mogli pristupiti svim informacijama koje su potrebne za donošenje informiranih reproduktivnih odluka kao što su planiranje hoćete li imati djece ili ne ili odlučivanje hoćete li provesti prenatalne pretrage ili ne

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…NISTE MOGLI PRISTUPITI SVIM INFORMACIJAMA KOJE SU POTREBNE ZA DONOŠENJE INFORMIRANIH REPRODUKTIVNIH ODLUKA KAO ŠTO SU PLANIRANJE HOĆETE LI IMATI DJECE ILI NE ILI ODLUČIVANJE HOĆETE LI PROVESTI PRENATALNE PRETRAGE ILI NE											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	133	11%	133	11%	141	11%	313	25%	526	42%	1.246	100%
DA, nekoliko puta	1.005	20%	665	13%	490	10%	870	18%	1.904	39%	4.934	100%
NE	126	8%	158	10%	179	12%	438	29%	620	41%	1.521	100%
TOTAL	**1.264**	**16%**	**956**	**12%**	**810**	**11%**	**1.621**	**21%**	**3.050**	**40%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 235,0 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …dobili ste neodgovarajuću skrb, liječenje ili operaciju

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…DOBILI STE NEODGOVARAJUĆU SKRB, LIJEČENJE ILI OPERACIJU											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	301	24%	237	19%	181	15%	364	29%	163	13%	1.246	100%
DA, nekoliko puta	1.868	38%	1.157	23%	573	12%	800	16%	536	11%	4.934	100%
NE	231	15%	253	17%	279	18%	545	36%	213	14%	1.521	100%
TOTAL	**2.400**	**31%**	**1.647**	**21%**	**1.033**	**13%**	**1.709**	**22%**	**912**	**12%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 531,2 ; dof= 8.

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …imali ste zakašnjeli pristup najprikladnijoj skrbi, liječenju ili operaciji

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…IMALI STE ZAKAŠNJELI PRISTUP NAJPRIKLADNIJOJ SKRBI, LIJEČENJU ILI OPERACIJI											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	421	34%	344	28%	152	12%	203	16%	126	10%	1.246	100%
DA, nekoliko puta	2.600	53%	1.143	23%	387	8%	400	8%	404	8%	4.934	100%
NE	359	24%	396	26%	248	16%	370	24%	148	10%	1.521	100%
TOTAL	**3.380**	**44%**	**1.883**	**24%**	**787**	**10%**	**973**	**13%**	**678**	**9%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 619,7 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …niste mogli imati pristup odgovarajućoj skrbi, liječenju ili operaciji

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…NISTE MOGLI IMATI PRISTUP ODGOVARAJUĆOJ SKRBI, LIJEČENJU ILI OPERACIJI											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	319	26%	301	24%	170	14%	300	24%	156	13%	1.246	100%
DA, nekoliko puta	2.280	46%	1.193	24%	523	11%	519	11%	419	8%	4.934	100%
NE	259	17%	292	19%	298	20%	478	31%	194	13%	1.521	100%
TOTAL	**2.858**	**37%**	**1.786**	**23%**	**991**	**13%**	**1.297**	**17%**	**769**	**10%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 785,3 ; dof= 8.

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …doživjeli ste pogoršanje simptoma

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…DOŽIVJELI STE POGORŠANJE SIMPTOMA											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	547	44%	266	21%	188	15%	157	13%	88	7%	1.246	100%
DA, nekoliko puta	2.945	60%	1.010	20%	414	8%	272	6%	293	6%	4.934	100%
NE	475	31%	358	24%	254	17%	295	19%	139	9%	1.521	100%
TOTAL	**3.967**	**52%**	**1.634**	**21%**	**856**	**11%**	**724**	**9%**	**520**	**7%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 570,3 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … niste mogli pristupiti svim informacijama koje su potrebne za donošenje informiranih reproduktivnih odluka kao što su planiranje hoćete li imati djece ili ne ili odlučivanje hoćete li provesti prenatalne pretrage ili ne

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…NISTE MOGLI PRISTUPITI SVIM INFORMACIJAMA KOJE SU POTREBNE ZA DONOŠENJE INFORMIRANIH REPRODUKTIVNIH ODLUKA KAO ŠTO SU PLANIRANJE HOĆETE LI IMATI DJECE ILI NE ILI ODLUČIVANJE HOĆETE LI PROVESTI PRENATALNE PRETRAGE ILI NE											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	311	12%	300	11%	294	11%	675	25%	1.103	41%	2.683	100%
DA, nekoliko puta	953	19%	656	13%	516	10%	946	19%	1.947	39%	5.018	100%
NE	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%
TOTAL	**1.264**	**16%**	**956**	**12%**	**810**	**11%**	**1.621**	**21%**	**3.050**	**40%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 99,5 ; dof= 4.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … dobili ste neodgovarajuću skrb, liječenje ili operaciju

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…DOBILI STE NEODGOVARAJUĆU SKRB, LIJEČENJE ILI OPERACIJU											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	515	19%	475	18%	405	15%	864	32%	424	16%	2.683	100%
DA, nekoliko puta	1.885	38%	1.172	23%	628	13%	845	17%	488	10%	5.018	100%
NE	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%
TOTAL	**2.400**	**31%**	**1.647**	**21%**	**1.033**	**13%**	**1.709**	**22%**	**912**	**12%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 464,6 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … imali ste zakašnjeli pristup najprikladnijoj skrbi, liječenju ili operaciji

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…IMALI STE ZAKAŠNJELI PRISTUP NAJPRIKLADNIJOJ SKRBI, LIJEČENJU ILI OPERACIJI											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	821	31%	655	24%	357	13%	517	19%	333	12%	2.683	100%
DA, nekoliko puta	2.559	51%	1.228	24%	430	9%	456	9%	345	7%	5.018	100%
NE	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%
TOTAL	**3.380**	**44%**	**1.883**	**24%**	**787**	**10%**	**973**	**13%**	**678**	**9%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 408,4 ; dof= 4.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … niste mogli imati pristup odgovarajućoj skrbi, liječenju ili operaciji

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…NISTE MOGLI IMATI PRISTUP ODGOVARAJUĆOJ SKRBI, LIJEČENJU ILI OPERACIJI											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	674	25%	540	20%	422	16%	671	25%	376	14%	2.683	100%
DA, nekoliko puta	2.184	44%	1.246	25%	569	11%	626	12%	393	8%	5.018	100%
NE	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%
TOTAL	**2.858**	**37%**	**1.786**	**23%**	**991**	**13%**	**1.297**	**17%**	**769**	**10%**	**7.701**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 432,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents who said that the rare disease has already been misdiagnosed

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … doživjeli ste pogoršanje simptoma

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…DOŽIVJELI STE POGORŠANJE SIMPTOMA											
	DEFINITIVNO		VJEROJATNO		VJEROJATNO NE		DEFINITIVNO NE		NE ZNAM / NIJE PRIMJENJIVO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	1.022	38%	583	22%	370	14%	426	16%	282	11%	2.683	100%
DA, nekoliko puta	2.945	59%	1.051	21%	486	10%	298	6%	238	5%	5.018	100%
NE	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%
TOTAL	**3.967**	**52%**	**1.634**	**21%**	**856**	**11%**	**724**	**9%**	**520**	**7%**	**7.701**	

Under-represented elements *Over-represented elements*

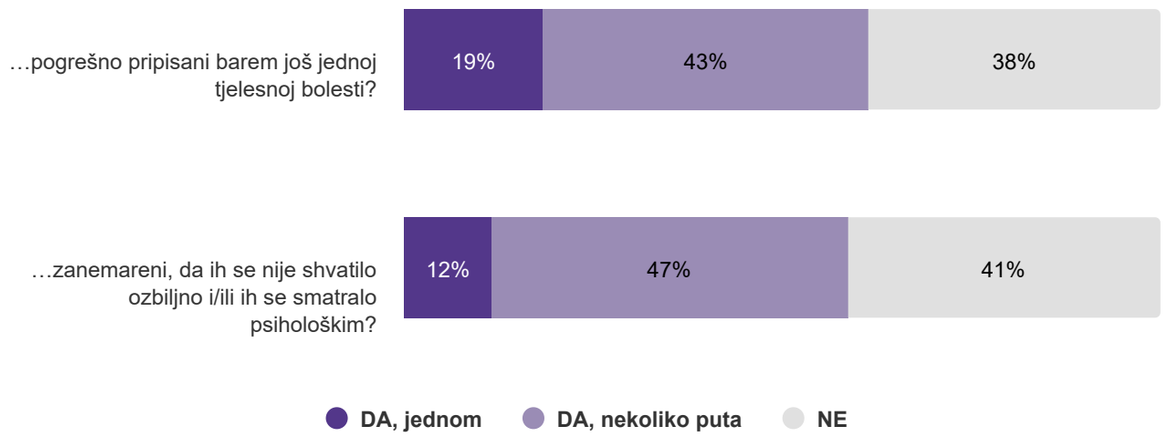
The relationship is very significant. p-value= < 0,01 ; Chi2= 440,8 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Je li se ikada dogodilo da su simptomi rijetke bolesti bili…

	DA, JEDNOM	DA, NEKOLIKO PUTA	NE	TOTAL
…pogrešno pripisani barem još jednoj tjelesnoj bolesti?	1.950	4.520	4.016	**10.486**
…zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?	1.246	4.934	4.306	**10.486**
TOTAL	**3.196**	**9.454**	**8.322**	**20.972**

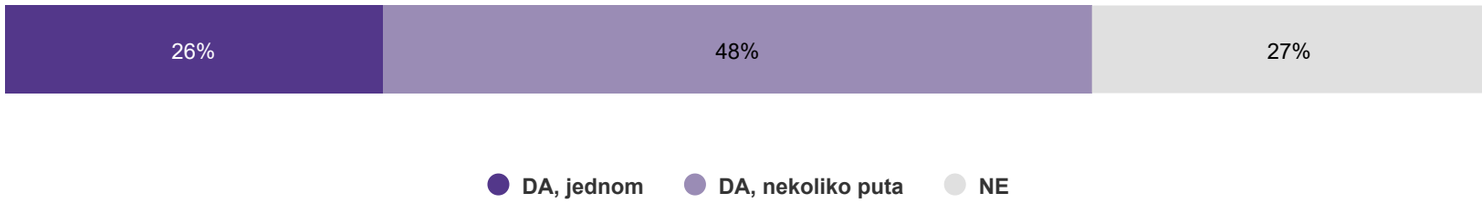
Je li se ikada dogodilo da su simptomi rijetke bolesti bili…



Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

	N
DA, jednom	2.683
DA, nekoliko puta	5.018
NE	2.785
TOTAL	**10.486**

Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.



Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante) / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	2.330	42%	969	18%	2.191	40%	5.490	100%
Ne	1.369	33%	812	19%	1.990	48%	4.171	100%
Ne znam / Ne sjećam se	317	38%	169	20%	339	41%	825	100%
TOTAL	4.016	38%	1.950	19%	4.520	43%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 97,5 ; dof= 4.

Cross: Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante) / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	2.503	46%	606	11%	2.381	43%	5.490	100%
Ne	1.453	35%	529	13%	2.189	52%	4.171	100%
Ne znam / Ne sjećam se	350	42%	111	13%	364	44%	825	100%
TOTAL	4.306	41%	1.246	12%	4.934	47%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 117,9 ; dof= 4.

Cross: Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante) / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.428	26%	2.419	44%	1.643	30%	5.490	100%
Ne	1.045	25%	2.208	53%	918	22%	4.171	100%
Ne znam / Ne sjećam se	210	25%	391	47%	224	27%	825	100%
TOTAL	2.683	26%	5.018	48%	2.785	27%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 96,0 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd. / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	3.539	37%	1.771	19%	4.172	44%	9.482	100%
Ne	345	47%	136	19%	252	34%	733	100%
Ne znam / Ne sjećam se	132	49%	43	16%	96	35%	271	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 44,3 ; dof= 4.

Cross: Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd. / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	3.848	41%	1.139	12%	4.495	47%	9.482	100%
Ne	329	45%	83	11%	321	44%	733	100%
Ne znam / Ne sjećam se	129	48%	24	9%	118	44%	271	100%
TOTAL	4.306	41%	1.246	12%	4.934	47%	10.486	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 11,0 ; dof= 4.

Cross: Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd. / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	2.421	26%	4.619	49%	2.442	26%	9.482	100%
Ne	196	27%	290	40%	247	34%	733	100%
Ne znam / Ne sjećam se	66	24%	109	40%	96	35%	271	100%
TOTAL	2.683	26%	5.018	48%	2.785	27%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,2 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …je niste mogli priuštiti? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

Have you ever needed a genetic test but could not access it because...

…JE NISTE MOGLI PRIUŠTITI?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	228	20%	174	16%	715	64%	1.117	100%
Ne	2.997	42%	1.355	19%	2.764	39%	7.116	100%
Nije bitno	791	35%	421	19%	1.041	46%	2.253	100%
TOTAL	4.016	38%	1.950	19%	4.520	43%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 280,9 ; dof= 4.

Cross: …je niste mogli priuštiti? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

Have you ever needed a genetic test but could not access it because...

…JE NISTE MOGLI PRIUŠTITI?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	228	20%	113	10%	776	69%	1.117	100%
Ne	3.266	46%	830	12%	3.020	42%	7.116	100%
Nije bitno	812	36%	303	13%	1.138	51%	2.253	100%
TOTAL	4.306	41%	1.246	12%	4.934	47%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 335,4 ; dof= 4.

Cross: …je niste mogli priuštiti? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

Have you ever needed a genetic test but could not access it because...

…JE NISTE MOGLI PRIUŠTITI?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	233	21%	760	68%	124	11%	1.117	100%
Ne	1.846	26%	3.109	44%	2.161	30%	7.116	100%
Nije bitno	604	27%	1.149	51%	500	22%	2.253	100%
TOTAL	2.683	26%	5.018	48%	2.785	27%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 292,5 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nije bila dostupna u Vašoj zemlji? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

Have you ever needed a genetic test but could not access it because... …NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI? NE N	NE %	DA, JEDNOM N	DA, JEDNOM %	DA, NEKOLIKO PUTA N	DA, NEKOLIKO PUTA %	TOTAL N	TOTAL %
Da	305	25%	195	16%	697	58%	1.197	100%
Ne	2.848	42%	1.284	19%	2.696	39%	6.828	100%
Nije bitno	863	35%	471	19%	1.127	46%	2.461	100%
TOTAL	**4.016**	**38%**	**1.950**	**19%**	**4.520**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 171,2 ; dof= 4.

Cross: …nije bila dostupna u Vašoj zemlji? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

Have you ever needed a genetic test but could not access it because... NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM? NE N	NE %	DA, JEDNOM N	DA, JEDNOM %	DA, NEKOLIKO PUTA N	DA, NEKOLIKO PUTA %	TOTAL N	TOTAL %
Da	348	29%	135	11%	714	60%	1.197	100%
Ne	3.053	45%	788	12%	2.987	44%	6.828	100%
Nije bitno	905	37%	323	13%	1.233	50%	2.461	100%
TOTAL	**4.306**	**41%**	**1.246**	**12%**	**4.934**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 140,4 ; dof= 4.

Cross: …nije bila dostupna u Vašoj zemlji? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

Have you ever needed a genetic test but could not access it because... …NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED. DA, JEDNOM N	DA, JEDNOM %	DA, NEKOLIKO PUTA N	DA, NEKOLIKO PUTA %	NE N	NE %	TOTAL N	TOTAL %
Da	252	21%	756	63%	189	16%	1.197	100%
Ne	1.769	26%	3.016	44%	2.043	30%	6.828	100%
Nije bitno	662	27%	1.246	51%	553	22%	2.461	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 190,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	594	21%	463	17%	1.748	62%	2.805	100%
Ne	2.641	48%	1.069	19%	1.846	33%	5.556	100%
Nije bitno	781	37%	418	20%	926	44%	2.125	100%
TOTAL	4.016	38%	1.950	19%	4.520	43%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 715,0 ; dof= 4.

Cross: …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Da	552	20%	329	12%	1.924	69%	2.805	100%
Ne	2.913	52%	656	12%	1.987	36%	5.556	100%
Nije bitno	841	40%	261	12%	1.023	48%	2.125	100%
TOTAL	4.306	41%	1.246	12%	4.934	47%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 916,3 ; dof= 4.

Cross: …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	645	23%	1.873	67%	287	10%	2.805	100%
Ne	1.453	26%	2.115	38%	1.988	36%	5.556	100%
Nije bitno	585	28%	1.030	48%	510	24%	2.125	100%
TOTAL	2.683	26%	5.018	48%	2.785	27%	10.486	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 797,1 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za… / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Samo jednim genom	632	43%	269	18%	559	38%	1.460	100%
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	641	37%	307	18%	783	45%	1.731	100%
Cijelom DNK (sekvenciranje cijelog genoma)	398	45%	157	18%	325	37%	880	100%
Svim genima (sekvenciranje cijelog egzoma)	221	39%	97	17%	249	44%	567	100%
Tumorom (genetsko profiliranje tumora)	48	36%	32	24%	55	41%	135	100%
Drugim (epigenom, RNK, itd.)	47	40%	17	15%	53	45%	117	100%
Ne znam	667	44%	235	16%	609	40%	1.511	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 44,3 ; dof= 12.

Cross: Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za… / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	NE		DA, JEDNOM		DA, NEKOLIKO PUTA		TOTAL	
	N	%	N	%	N	%	N	%
Samo jednim genom	670	46%	153	10%	637	44%	1.460	100%
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	735	42%	177	10%	819	47%	1.731	100%
Cijelom DNK (sekvenciranje cijelog genoma)	441	50%	110	13%	329	37%	880	100%
Svim genima (sekvenciranje cijelog egzoma)	271	48%	68	12%	228	40%	567	100%
Tumorom (genetsko profiliranje tumora)	52	39%	21	16%	62	46%	135	100%
Drugim (epigenom, RNK, itd.)	43	37%	20	17%	54	46%	117	100%
Ne znam	696	46%	169	11%	646	43%	1.511	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,2 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za… / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Samo jednim genom	389	27%	624	43%	447	31%	**1.460**	**100%**
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	449	26%	844	49%	438	25%	**1.731**	**100%**
Cijelom DNK (sekvenciranje cijelog genoma)	225	26%	363	41%	292	33%	**880**	**100%**
Svim genima (sekvenciranje cijelog egzoma)	141	25%	269	47%	157	28%	**567**	**100%**
Tumorom (genetsko profiliranje tumora)	31	23%	67	50%	37	27%	**135**	**100%**
Drugim (epigenom, RNK, itd.)	32	27%	58	50%	27	23%	**117**	**100%**
Ne znam	363	24%	672	44%	476	32%	**1.511**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,6 ; dof= 12.

Cross: Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti? / …pogrešno pripisani barem još jednoj tjelesnoj bolesti?

JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?	…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
DA, jednom	121	21%	260	44%	209	35%	**590**	**100%**
DA, nekoliko puta	40	15%	152	57%	74	28%	**266**	**100%**
NE, nikad	808	17%	1.779	38%	2.047	44%	**4.634**	**100%**
TOTAL	**969**	**18%**	**2.191**	**40%**	**2.330**	**42%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 52,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti? / …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim?

JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?	…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
DA, jednom	75	13%	277	47%	238	40%	590	100%
DA, nekoliko puta	32	12%	144	54%	90	34%	266	100%
NE, nikad	499	11%	1.960	42%	2.175	47%	4.634	100%
TOTAL	**606**	**11%**	**2.381**	**43%**	**2.503**	**46%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 25,6 ; dof= 4.

Cross: Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
DA, jednom	151	26%	297	50%	142	24%	590	100%
DA, nekoliko puta	49	18%	166	62%	51	19%	266	100%
NE, nikad	1.228	26%	1.956	42%	1.450	31%	4.634	100%
TOTAL	**1.428**	**26%**	**2.419**	**44%**	**1.643**	**30%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 55,5 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Vrlo nezadovoljan/nezadovoljna	155	27%	283	49%	134	23%	572	100%
Nezadovoljan/nezadovoljna	159	26%	335	54%	129	21%	623	100%
Niti zadovoljan/zadovoljna niti nezadovoljan/nezadovoljna	306	26%	572	49%	281	24%	1.159	100%
Zadovoljan/zadovoljna	518	27%	773	40%	639	33%	1.930	100%
Vrlo zadovoljan/zadovoljna	222	24%	323	35%	378	41%	923	100%
Ne znam	68	24%	133	47%	82	29%	283	100%
TOTAL	**1.428**	**26%**	**2.419**	**44%**	**1.643**	**30%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 134,4 ; dof= 10.

Cross: Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
DA, kod genetskog savjetnika ili kliničkog genetičara	565	26%	813	38%	759	36%	2.137	100%
DA, kod zdravstvenog djelatnika	313	27%	496	42%	370	31%	1.179	100%
NE, nije mi ponuđeno genetsko savjetovanje	452	26%	946	53%	372	21%	1.770	100%
Nisam siguran/sigurna / Ne sjećam se	98	24%	164	41%	142	35%	404	100%
TOTAL	**1.428**	**26%**	**2.419**	**44%**	**1.643**	**30%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 129,8 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Genetska(-e) pretraga(-e) / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
GENETSKA(-E) PRETRAGA(-E)	N	%	N	%	N	%	N	%
Da	219	26%	397	48%	215	26%	831	100%
Ne	1.171	26%	1.967	44%	1.377	30%	4.515	100%
Ne znam	37	26%	55	38%	51	36%	143	100%
TOTAL	**1.427**	**26%**	**2.419**	**44%**	**1.643**	**30%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 10,5 ; dof= 4.

Cross: Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd. / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.	N	%	N	%	N	%	N	%
Da	337	24%	768	55%	298	21%	1.403	100%
Ne	2.036	26%	3.780	48%	2.092	26%	7.908	100%
Ne znam	48	28%	71	42%	51	30%	170	100%
TOTAL	**2.421**	**26%**	**4.619**	**49%**	**2.441**	**26%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 29,2 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno) / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
Da	529	25%	1.086	52%	468	22%	2.083	100%
Ne	2.095	26%	3.856	47%	2.243	27%	8.194	100%
Ne znam	59	28%	76	36%	74	35%	209	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 36,8 ; dof= 4.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … psihološka podrška

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	232	9%	237	9%	205	8%	802	30%	1.207	45%	2.683	100%
DA, nekoliko puta	358	7%	376	7%	586	12%	1.271	25%	2.427	48%	5.018	100%
NE	332	12%	342	12%	161	6%	1.092	39%	858	31%	2.785	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 416,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	525	25%	682	33%	876	42%	2.083	100%
DA, ali nije potrebno / nije bilo potrebno	106	27%	127	32%	158	40%	391	100%
DA, ali NE dovoljno da zadovolji moje potrebe	395	27%	744	51%	324	22%	1.463	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	423	26%	556	34%	648	40%	1.627	100%
NE, ali je potrebno / je bilo potrebno	1.234	25%	2.909	59%	779	16%	4.922	100%
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 866,1 ; dof= 8.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … financijska potpora, uključujući pogodnosti socijalnog osiguranja

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	339	13%	61	2%	306	11%	958	36%	1.005	38%	2.669	100%
DA, nekoliko puta	526	11%	79	2%	633	13%	1.443	29%	2.291	46%	4.972	100%
NE	540	19%	103	4%	293	11%	1.143	41%	693	25%	2.772	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 436,6 ; dof= 8.

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed.

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE		TOTAL	
	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	1.389	26%	2.465	46%	1.472	28%	**5.326**	**100%**
DA, preko internetskih zajednica	1.264	25%	2.602	52%	1.126	23%	**4.992**	**100%**
DA, putem lokalnih mreža (npr. škole)	103	24%	224	51%	109	25%	**436**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	42	22%	100	53%	48	25%	**190**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	325	25%	634	48%	351	27%	**1.310**	**100%**
NE, jer ne želim	142	26%	215	39%	190	35%	**547**	**100%**
Ostalo, navesti	128	25%	233	45%	153	30%	**514**	**100%**
TOTAL	**2.683**	**26%**	**5.018**	**48%**	**2.785**	**27%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 84,3 ; dof= 12.

Chapter 11.

Misdiagnosis

Rare Barometer
A EURORDIS INITIATIVE

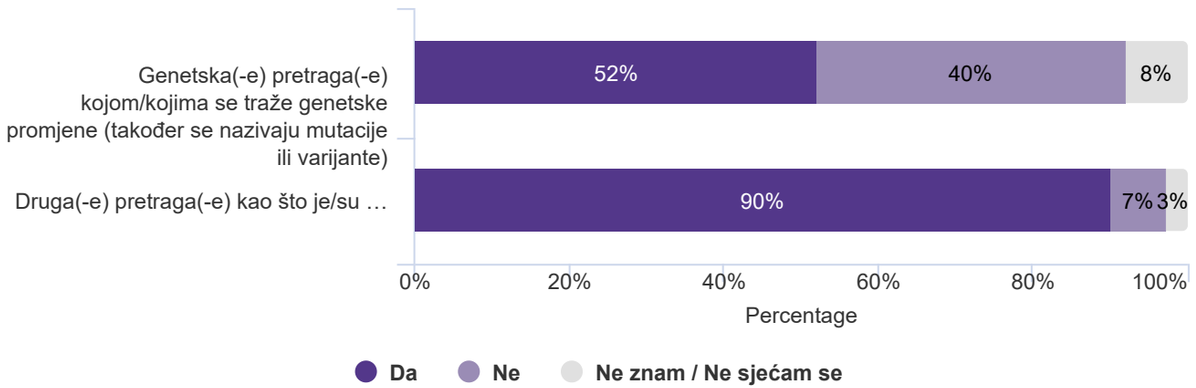
EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Koje su pretrage provedene u sklopu dijagnoze rijetke bolesti?

	DA	NE	NE ZNAM / NE SJEĆAM SE	TOTAL
Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)	5.490	4.171	825	**10.486**
Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.	9.482	733	271	**10.486**

Koje su pretrage provedene u sklopu dijagnoze rijetke bolesti?



Cross: Genetic diseases / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
GENETIC DISEASES	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Genetic diseases	3.862	71%	1.338	25%	247	5%	**5.447**	**100%**
Non Genetic diseases	540	21%	1.760	67%	327	12%	**2.627**	**100%**
TOTAL	**4.402**	**55%**	**3.098**	**38%**	**574**	**7%**	**8.074**	

Under-represented elements *Over-represented elements*

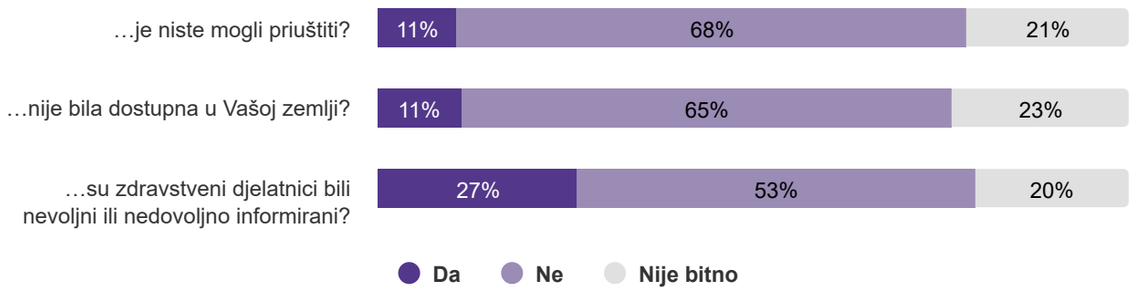
The relationship is very significant. p-value= < 0,01 ; Chi2= 1.811,7 ; dof= 2.

Only respondents who had genetic tests

Jeste li ikada trebali kakvu genetsku pretragu, no niste joj mogli pristupiti jer…

	DA	NE	NIJE BITNO	TOTAL
…je niste mogli priuštiti?	1.117	7.116	2.253	**10.486**
…nije bila dostupna u Vašoj zemlji?	1.197	6.828	2.461	**10.486**
…su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?	2.805	5.556	2.125	**10.486**

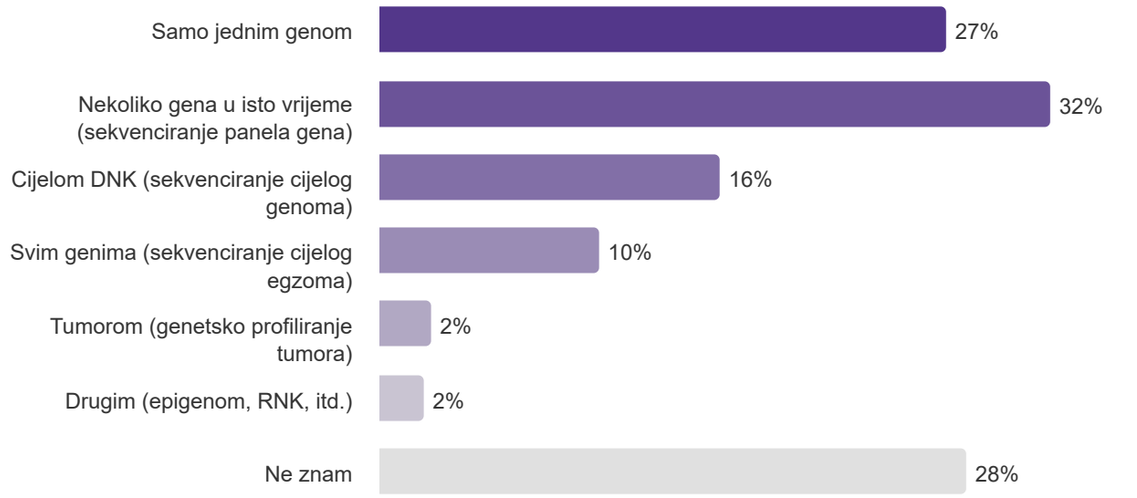
Jeste li ikada trebali kakvu genetsku pretragu, no niste joj mogli pristupiti jer…



Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

	N
Samo jednim genom	1.460
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	1.731
Cijelom DNK (sekvenciranje cijelog genoma)	880
Svim genima (sekvenciranje cijelog egzoma)	567
Tumorom (genetsko profiliranje tumora)	135
Drugim (epigenom, RNK, itd.)	117
Ne znam	1.511
TOTAL	**5.490**

Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents who had genetic tests

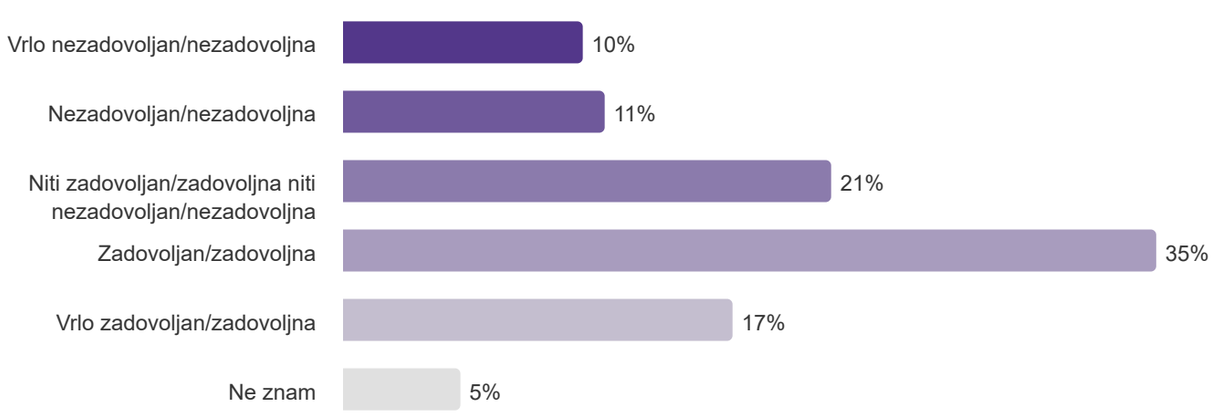
Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

	N
DA, jednom	590
DA, nekoliko puta	266
NE, nikad	4.634
TOTAL	**5.490**



Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

	N
Vrlo nezadovoljan/nezadovoljna	572
Nezadovoljan/nezadovoljna	623
Niti zadovoljan/zadovoljna niti nezadovoljan/nezadovoljna	1.159
Zadovoljan/zadovoljna	1.930
Vrlo zadovoljan/zadovoljna	923
Ne znam	283
TOTAL	**5.490**



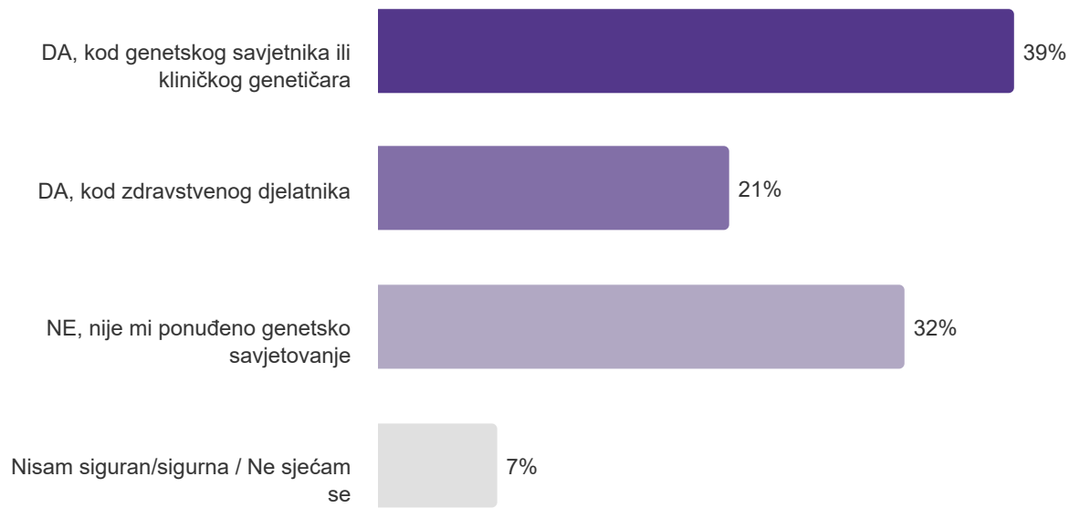
*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents who had genetic tests

Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

	N
DA, kod genetskog savjetnika ili kliničkog genetičara	2.137
DA, kod zdravstvenog djelatnika	1.179
NE, nije mi ponuđeno genetsko savjetovanje	1.770
Nisam siguran/sigurna / Ne sjećam se	404
TOTAL	**5.490**

Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?



Only respondents who had genetic tests

Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,7	4.023	3,7	3.655	4,2	2.451	3,8	4.096	5,6	3.565
Ne	0,2	3.263	3,4	3.138	3,7	1.564	3,6	3.216	3,9	2.506
Ne znam / Ne sjećam se	0,5	534	2,1	529	2,2	320	2,5	531	2,9	436

Under-represented elements *Over-represented elements*

Have you ever needed a genetic test but could not access it because...

…je niste mogli priuštiti?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,4	812	5,3	705	6,1	334	5,6	742	7,0	513
Ne	0,6	5.349	3,4	5.028	3,7	3.148	3,3	5.442	4,7	4.639
Nije bitno	0,3	1.659	3,1	1.589	3,6	853	3,6	1.659	4,1	1.355

Under-represented elements *Over-represented elements*

Have you ever needed a genetic test but could not access it because...

...nije bila dostupna u Vašoj zemlji?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,7	866	4,4	765	5,0	409	5,1	830	6,8	624
Ne	0,5	5.170	3,5	4.830	3,8	2.972	3,4	5.212	4,6	4.405
Nije bitno	0,4	1.784	3,2	1.727	3,7	954	3,5	1.801	4,1	1.478

Under-represented elements *Over-represented elements*

Have you ever needed a genetic test but could not access it because...

...su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,6	2.081	5,1	1.874	6,0	984	6,1	2.014	7,7	1.493
Ne	0,6	4.167	2,9	3.930	3,2	2.513	2,6	4.247	3,9	3.664
Nije bitno	0,2	1.572	3,0	1.518	3,2	838	3,2	1.582	3,8	1.350

Under-represented elements *Over-represented elements*

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Samo jednim genom	0,7	1.078	4,1	973	4,3	682	3,3	1.097	5,4	995
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	0,8	1.328	4,1	1.202	5,3	800	4,5	1.318	6,5	1.130
Cijelom DNK (sekvenciranje cijelog genoma)	0,6	653	3,1	588	3,3	413	3,6	674	4,9	576
Svim genima (sekvenciranje cijelog egzoma)	0,5	429	2,9	377	3,1	236	4,7	408	5,3	353
Tumorom (genetsko profiliranje tumora)	0,2	99	3,4	109	3,5	55	2,7	95	3,1	83
Drugim (epigenom, RNK, itd.)	0,7	85	5,1	73	5,2	48	5,9	86	6,3	67
Ne znam	0,8	1.065	3,7	986	4,0	636	3,8	1.101	5,4	931

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 1,0 ; Fisher= 0,3.
Inter variance= 11,4. Intra variance= 43,7.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, jednom	0,7	437	3,6	372	4,0	215	3,9	434	4,9	373
DA, nekoliko puta	0,2	196	3,9	170	4,3	91	3,2	189	4,7	162
NE, nikad	0,7	3.390	3,8	3.113	4,2	2.145	3,8	3.473	5,7	3.030

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,6 ; Fisher= 0,6.
Inter variance= 26,0. Intra variance= 46,9.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Vrlo nezadovoljan/nezadovoljna	0,4	434	3,2	385	4,5	249	3,9	428	5,6	362
Nezadovoljan/nezadovoljna	0,8	475	4,3	430	5,1	258	4,8	470	6,1	373
Niti zadovoljan/zadovoljna niti nezadovoljan/nezadovoljna	0,7	845	4,4	734	4,3	480	4,1	831	5,5	686
Zadovoljan/zadovoljna	0,8	1.405	3,3	1.297	3,8	879	3,5	1.473	5,4	1.339
Vrlo zadovoljan/zadovoljna	0,7	666	3,9	646	4,5	479	3,2	716	5,9	679
Ne znam	0,3	198	3,5	163	3,3	106	3,8	178	4,0	126

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,9 ; Fisher= 0,3.
Inter variance= 14,9. Intra variance= 46,9.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, kod genetskog savjetnika ili kliničkog genetičara	0,7	1.594	3,3	1.428	4,0	1.025	3,3	1.629	5,6	1.477
DA, kod zdravstvenog djelatnika	0,7	859	4,0	813	3,9	601	3,6	915	5,2	817
NE, nije mi ponuđeno genetsko savjetovanje	0,7	1.312	4,2	1.176	5,2	674	4,4	1.286	5,9	1.064
Nisam siguran/sigurna / Ne sjećam se	0,4	258	3,5	238	2,9	151	4,0	266	4,6	207

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,9 ; Fisher= 0,2.
Inter variance= 9,0. Intra variance= 46,9.

Cross: Gender of the person affected by the rare disease / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Žena	3.113	47%	3.004	45%	542	8%	6.659	100%
Muškarac	1.801	64%	820	29%	189	7%	2.810	100%
Ostalo	62	61%	31	31%	8	8%	101	100%
TOTAL	**4.976**	**52%**	**3.855**	**40%**	**739**	**8%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 248,0 ; dof= 4.

Cross: Gender of the person affected by the rare disease / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Žena	6.095	92%	406	6%	158	2%	6.659	100%
Muškarac	2.506	89%	229	8%	75	3%	2.810	100%
Ostalo	89	88%	6	6%	6	6%	101	100%
TOTAL	**8.690**	**91%**	**641**	**7%**	**239**	**2%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 19,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Have you ever needed a genetic test but could not access it because...

Cross: Gender of the person affected by the rare disease / …je niste mogli priuštiti?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Žena	721	11%	4.376	66%	1.562	23%	6.659	100%
Muškarac	242	9%	2.053	73%	515	18%	2.810	100%
Ostalo	21	21%	54	53%	26	26%	101	100%
TOTAL	**984**	**10%**	**6.483**	**68%**	**2.103**	**22%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 63,5 ; dof= 4.

Cross: Gender of the person affected by the rare disease / …nije bila dostupna u Vašoj zemlji?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Žena	726	11%	4.225	63%	1.708	26%	6.659	100%
Muškarac	320	11%	1.922	68%	568	20%	2.810	100%
Ostalo	13	13%	61	60%	27	27%	101	100%
TOTAL	**1.059**	**11%**	**6.208**	**65%**	**2.303**	**24%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 33,1 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Have you ever needed a genetic test but could not access it because...

Cross: Gender of the person affected by the rare disease / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Žena	1.884	28%	3.318	50%	1.457	22%	6.659	100%
Muškarac	645	23%	1.657	59%	508	18%	2.810	100%
Ostalo	27	27%	50	50%	24	24%	101	100%
TOTAL	**2.556**	**27%**	**5.025**	**53%**	**1.989**	**21%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 66,9 ; dof= 4.

Cross: Gender of the person affected by the rare disease / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Žena	820	26%	991	32%	458	15%	279	9%	86	3%	73	2%	899	29%	3.113	
Muškarac	504	28%	575	32%	314	17%	227	13%	38	2%	30	2%	434	24%	1.801	
Ostalo	12	19%	20	32%	7	11%	10	16%	2	3%	0	0%	20	32%	62	
TOTAL	**1.336**	**27%**	**1.586**	**32%**	**779**	**16%**	**516**	**10%**	**126**	**3%**	**103**	**2%**	**1.353**	**27%**	**4.976**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 41,3 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Žena	322	10%	141	5%	2.650	85%	**3.113**	**100%**
Muškarac	191	11%	93	5%	1.517	84%	**1.801**	**100%**
Ostalo	8	13%	5	8%	49	79%	**62**	**100%**
TOTAL	**521**	**10%**	**239**	**5%**	**4.216**	**85%**	**4.976**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,5 ; Chi2= 3,1 ; dof= 4.

Cross: Gender of the person affected by the rare disease / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NEZA…		NEZADOVOLJAN/NEZA…		NITI ZADOVOLJAN/ZADOVO… NITI NEZADOVOLJAN/NEZA…		ZADOVOLJAN/ZADOVO…		VRLO ZADOVOLJAN/ZADOVO…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Žena	329	11%	380	12%	656	21%	1.056	34%	509	16%	183	6%	**3.113**	**100%**
Muškarac	182	10%	189	10%	375	21%	658	37%	333	18%	64	4%	**1.801**	**100%**
Ostalo	6	10%	7	11%	18	29%	16	26%	8	13%	7	11%	**62**	**100%**
TOTAL	**517**	**10%**	**576**	**12%**	**1.049**	**21%**	**1.730**	**35%**	**850**	**17%**	**254**	**5%**	**4.976**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 29,3 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Žena	1.168	38%	623	20%	1.071	34%	251	8%	3.113	100%
Muškarac	734	41%	443	25%	515	29%	109	6%	1.801	100%
Ostalo	26	42%	8	13%	19	31%	9	15%	62	100%
TOTAL	**1.928**	**39%**	**1.074**	**22%**	**1.605**	**32%**	**369**	**7%**	**4.976**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,0 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	259	57%	143	31%	53	12%	455	100%
između 16 i 19 godina	1.217	49%	1.003	41%	244	10%	2.464	100%
između 20 i 23 godine	1.584	52%	1.212	40%	226	7%	3.022	100%
24 godine ili više	1.720	55%	1.256	40%	169	5%	3.145	100%
TOTAL	**4.780**	**53%**	**3.614**	**40%**	**692**	**8%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 65,1 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	406	89%	30	7%	19	4%	455	100%
između 16 i 19 godina	2.240	91%	155	6%	69	3%	2.464	100%
između 20 i 23 godine	2.749	91%	199	7%	74	2%	3.022	100%
24 godine ili više	2.858	91%	224	7%	63	2%	3.145	100%
TOTAL	**8.253**	**91%**	**608**	**7%**	**225**	**2%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 10,9 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	61	13%	297	65%	97	21%	455	100%
između 16 i 19 godina	283	11%	1.641	67%	540	22%	2.464	100%
između 20 i 23 godine	295	10%	2.054	68%	673	22%	3.022	100%
24 godine ili više	287	9%	2.171	69%	687	22%	3.145	100%
TOTAL	**926**	**10%**	**6.163**	**68%**	**1.997**	**22%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 14,6 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …nije bila dostupna u Vašoj zemlji?

Have you ever needed a genetic test but could not access it because...

…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	60	13%	287	63%	108	24%	**455**	**100%**
između 16 i 19 godina	260	11%	1.593	65%	611	25%	**2.464**	**100%**
između 20 i 23 godine	334	11%	1.953	65%	735	24%	**3.022**	**100%**
24 godine ili više	355	11%	2.069	66%	721	23%	**3.145**	**100%**
TOTAL	**1.009**	**11%**	**5.902**	**65%**	**2.175**	**24%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,5 ; Chi2= 5,5 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	130	29%	241	53%	84	18%	**455**	**100%**
između 16 i 19 godina	654	27%	1.287	52%	523	21%	**2.464**	**100%**
između 20 i 23 godine	**762**	**25%**	1.610	53%	650	22%	**3.022**	**100%**
24 godine ili više	863	27%	1.648	52%	634	20%	**3.145**	**100%**
TOTAL	**2.409**	**27%**	**4.786**	**53%**	**1.891**	**21%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 6,8 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	63	24%	71	27%	40	15%	32	12%	8	3%	6	2%	75	29%	**259**	
između 16 i 19 godina	303	25%	347	29%	213	18%	101	8%	35	3%	20	2%	378	31%	**1.217**	
između 20 i 23 godine	410	26%	517	33%	245	15%	162	10%	39	2%	36	2%	431	27%	**1.584**	
24 godine ili više	508	30%	596	35%	259	15%	208	12%	41	2%	39	2%	398	23%	**1.720**	
TOTAL	**1.284**	**27%**	**1.531**	**32%**	**757**	**16%**	**503**	**11%**	**123**	**3%**	**101**	**2%**	**1.282**	**27%**	**4.780**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 51,6 ; dof= 18.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	26	10%	18	7%	215	83%	**259**	**100%**
između 16 i 19 godina	137	11%	45	4%	1.035	85%	**1.217**	**100%**
između 20 i 23 godine	160	10%	77	5%	1.347	85%	**1.584**	**100%**
24 godine ili više	176	10%	89	5%	1.455	85%	**1.720**	**100%**
TOTAL	**499**	**10%**	**229**	**5%**	**4.052**	**85%**	**4.780**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 7,3 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NEZ…		NEZADOVOLJAN/NEZ…		NITI ZADOVOLJAN/ZADOV… NITI NEZADOVOLJAN/NEZ…		ZADOVOLJAN/ZADOV…		VRLO ZADOVOLJAN/ZADOV…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	41	16%	29	11%	54	21%	89	34%	36	14%	10	4%	**259**	**100%**
između 16 i 19 godina	143	12%	124	10%	259	21%	412	34%	208	17%	71	6%	**1.217**	**100%**
između 20 i 23 godine	151	10%	185	12%	333	21%	576	36%	261	16%	78	5%	**1.584**	**100%**
24 godine ili više	167	10%	221	13%	357	21%	579	34%	312	18%	84	5%	**1.720**	**100%**
TOTAL	**502**	**11%**	**559**	**12%**	**1.003**	**21%**	**1.656**	**35%**	**817**	**17%**	**243**	**5%**	**4.780**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 23,1 ; dof= 15.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	87	34%	71	27%	78	30%	23	9%	**259**	**100%**
između 16 i 19 godina	459	38%	246	20%	413	34%	99	8%	**1.217**	**100%**
između 20 i 23 godine	606	38%	368	23%	496	31%	114	7%	**1.584**	**100%**
24 godine ili više	711	41%	348	20%	550	32%	111	6%	**1.720**	**100%**
TOTAL	**1.863**	**39%**	**1.033**	**22%**	**1.537**	**32%**	**347**	**7%**	**4.780**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 19,3 ; dof= 9.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	3.701	52%	2.899	41%	525	7%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	269	58%	147	32%	49	11%	**465**	**100%**
Ostalo, navesti	169	50%	131	39%	37	11%	**337**	**100%**
TOTAL	**4.139**	**52%**	**3.177**	**40%**	**611**	**8%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,9 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	6.483	91%	472	7%	170	2%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	417	90%	35	8%	13	3%	**465**	**100%**
Ostalo, navesti	299	89%	23	7%	15	4%	**337**	**100%**
TOTAL	**7.199**	**91%**	**530**	**7%**	**198**	**2%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 6,5 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...

KAKO BISTE NAJBOLJE OPISALI SEBE?	…JE NISTE MOGLI PRIUŠTITI? DA N	DA %	NE N	NE %	NIJE BITNO N	NIJE BITNO %	TOTAL N	TOTAL %
Pripadam etničkoj većini u zemlji u kojoj živim	736	10%	4.880	68%	1.509	21%	7.125	100%
Dio sam etničke manjine u zemlji u kojoj živim	76	16%	309	66%	80	17%	465	100%
Ostalo, navesti	45	13%	202	60%	90	27%	337	100%
TOTAL	**857**	**11%**	**5.391**	**68%**	**1.679**	**21%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 28,7 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / …nije bila dostupna u Vašoj zemlji?

Have you ever needed a genetic test but could not access it because...

KAKO BISTE NAJBOLJE OPISALI SEBE?	…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI? DA N	DA %	NE N	NE %	NIJE BITNO N	NIJE BITNO %	TOTAL N	TOTAL %
Pripadam etničkoj većini u zemlji u kojoj živim	809	11%	4.691	66%	1.625	23%	7.125	100%
Dio sam etničke manjine u zemlji u kojoj živim	67	14%	300	65%	98	21%	465	100%
Ostalo, navesti	48	14%	191	57%	98	29%	337	100%
TOTAL	**924**	**12%**	**5.182**	**65%**	**1.821**	**23%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 16,0 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?

KAKO BISTE NAJBOLJE OPISALI SEBE?	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.913	27%	3.778	53%	1.434	20%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	150	32%	236	51%	79	17%	**465**	**100%**
Ostalo, navesti	101	30%	156	46%	80	24%	**337**	**100%**
TOTAL	**2.164**	**27%**	**4.170**	**53%**	**1.593**	**20%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 13,2 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…

KAKO BISTE NAJBOLJE OPISALI SEBE?	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	975	26%	1.225	33%	584	16%	408	11%	94	3%	83	2%	965	26%	**3.701**	
Dio sam etničke manjine u zemlji u kojoj živim	64	24%	86	32%	53	20%	29	11%	7	3%	6	2%	83	31%	**269**	
Ostalo, navesti	54	32%	35	21%	32	19%	15	9%	7	4%	4	2%	59	35%	**169**	
TOTAL	**1.093**	**26%**	**1.346**	**33%**	**669**	**16%**	**452**	**11%**	**108**	**3%**	**93**	**2%**	**1.107**	**27%**	**4.139**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 22,4 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

KAKO BISTE NAJBOLJE OPISALI SEBE?	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	401	11%	185	5%	3.115	84%	3.701	100%
Dio sam etničke manjine u zemlji u kojoj živim	43	16%	14	5%	212	79%	269	100%
Ostalo, navesti	20	12%	12	7%	137	81%	169	100%
TOTAL	**464**	**11%**	**211**	**5%**	**3.464**	**84%**	**4.139**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 8,4 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

KAKO BISTE NAJBOLJE OPISALI SEBE?	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/N…		NEZADOVOLJAN/N…		NITI ZADOVOLJAN/ZAD… NITI NEZADOVOLJAN/N…		ZADOVOLJAN/ZAD…		VRLO ZADOVOLJAN/ZAD…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	374	10%	431	12%	776	21%	1.295	35%	657	18%	168	5%	3.701	100%
Dio sam etničke manjine u zemlji u kojoj živim	33	12%	29	11%	65	24%	92	34%	32	12%	18	7%	269	100%
Ostalo, navesti	25	15%	22	13%	37	22%	51	30%	22	13%	12	7%	169	100%
TOTAL	**432**	**10%**	**482**	**12%**	**878**	**21%**	**1.438**	**35%**	**711**	**17%**	**198**	**5%**	**4.139**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 18,3 ; dof= 10.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.445	39%	823	22%	1.184	32%	249	7%	3.701	100%
Dio sam etničke manjine u zemlji u kojoj živim	88	33%	53	20%	102	38%	26	10%	269	100%
Ostalo, navesti	58	34%	20	12%	71	42%	20	12%	169	100%
TOTAL	**1.591**	**38%**	**896**	**22%**	**1.357**	**33%**	**295**	**7%**	**4.139**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 27,7 ; dof= 6.

Cross: Typology of countries based on size and welfare / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	1.158	65%	485	27%	151	8%	1.794	100%
Group B ('Western Europe')	2.702	53%	2.090	41%	313	6%	5.105	100%
Group C ('Northern Europe')	1.470	45%	1.476	45%	327	10%	3.273	100%
TOTAL	**5.330**	**52%**	**4.051**	**40%**	**791**	**8%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 223,3 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	1.632	91%	108	6%	54	3%	**1.794**	**100%**
Group B ('Western Europe')	4.614	90%	365	7%	126	2%	**5.105**	**100%**
Group C ('Northern Europe')	2.951	90%	239	7%	83	3%	**3.273**	**100%**
TOTAL	**9.197**	**90%**	**712**	**7%**	**263**	**3%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 4,7 ; dof= 4.

Cross: Typology of countries based on size and welfare / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	…JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	389	22%	1.174	65%	231	13%	**1.794**	**100%**
Group B ('Western Europe')	473	9%	3.507	69%	1.125	22%	**5.105**	**100%**
Group C ('Northern Europe')	216	7%	2.220	68%	837	26%	**3.273**	**100%**
TOTAL	**1.078**	**11%**	**6.901**	**68%**	**2.193**	**22%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 355,8 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / …nije bila dostupna u Vašoj zemlji?

Have you ever needed a genetic test but could not access it because...

…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	492	27%	1.056	59%	246	14%	1.794	100%
Group B ('Western Europe')	400	8%	3.493	68%	1.212	24%	5.105	100%
Group C ('Northern Europe')	277	8%	2.060	63%	936	29%	3.273	100%
TOTAL	**1.169**	**11%**	**6.609**	**65%**	**2.394**	**24%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 612,8 ; dof= 4.

Cross: Typology of countries based on size and welfare / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	614	34%	948	53%	232	13%	1.794	100%
Group B ('Western Europe')	1.273	25%	2.779	54%	1.053	21%	5.105	100%
Group C ('Northern Europe')	834	25%	1.652	50%	787	24%	3.273	100%
TOTAL	**2.721**	**27%**	**5.379**	**53%**	**2.072**	**20%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 122,2 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	284	25%	368	32%	193	17%	148	13%	38	3%	34	3%	319	28%	1.158	
Group B ('Western Europe')	761	28%	904	33%	387	14%	258	10%	49	2%	49	2%	695	26%	2.702	
Group C ('Northern Europe')	370	25%	416	28%	282	19%	149	10%	46	3%	31	2%	442	30%	1.470	
TOTAL	**1.415**	**27%**	**1.688**	**32%**	**862**	**16%**	**555**	**10%**	**133**	**2%**	**114**	**2%**	**1.456**	**27%**	**5.330**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 57,6 ; dof= 12.

Cross: Typology of countries based on size and welfare / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	261	23%	139	12%	758	65%	1.158	100%
Group B ('Western Europe')	235	9%	89	3%	2.378	88%	2.702	100%
Group C ('Northern Europe')	79	5%	33	2%	1.358	92%	1.470	100%
TOTAL	**575**	**11%**	**261**	**5%**	**4.494**	**84%**	**5.330**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 418,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NEZ…		NEZADOVOLJAN/NEZ…		NITI ZADOVOLJAN/ZADOV… NITI NEZADOVOLJAN/NEZ…		ZADOVOLJAN/ZADOV…		VRLO ZADOVOLJAN/ZADOV…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	109	9%	124	11%	279	24%	432	37%	161	14%	53	5%	1.158	100%
Group B ('Western Europe')	330	12%	332	12%	577	21%	917	34%	416	15%	130	5%	2.702	100%
Group C ('Northern Europe')	118	8%	149	10%	270	18%	526	36%	320	22%	87	6%	1.470	100%
TOTAL	557	10%	605	11%	1.126	21%	1.875	35%	897	17%	270	5%	5.330	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 68,4 ; dof= 10.

Cross: Typology of countries based on size and welfare / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	410	35%	229	20%	447	39%	72	6%	1.158	100%
Group B ('Western Europe')	1.049	39%	629	23%	817	30%	207	8%	2.702	100%
Group C ('Northern Europe')	617	42%	283	19%	458	31%	112	8%	1.470	100%
TOTAL	2.076	39%	1.141	21%	1.722	32%	391	7%	5.330	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,2 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Ruralnom području ili selu	1.245	52%	968	40%	203	8%	**2.416**	**100%**
Malom ili srednje velikom gradu	2.065	53%	1.546	40%	290	7%	**3.901**	**100%**
Velikom gradu	1.468	53%	1.094	40%	198	7%	**2.760**	**100%**
TOTAL	**4.778**	**53%**	**3.608**	**40%**	**691**	**8%**	**9.077**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 3,7 ; dof= 4.

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Ruralnom području ili selu	2.212	92%	147	6%	57	2%	**2.416**	**100%**
Malom ili srednje velikom gradu	3.520	90%	273	7%	108	3%	**3.901**	**100%**
Velikom gradu	2.515	91%	185	7%	60	2%	**2.760**	**100%**
TOTAL	**8.247**	**91%**	**605**	**7%**	**225**	**2%**	**9.077**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 4,7 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Have you ever needed a genetic test but could not access it because...

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / ...je niste mogli priuštiti?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	...JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Ruralnom području ili selu	201	8%	1.646	68%	569	24%	2.416	100%
Malom ili srednje velikom gradu	400	10%	2.665	68%	836	21%	3.901	100%
Velikom gradu	323	12%	1.847	67%	590	21%	2.760	100%
TOTAL	**924**	**10%**	**6.158**	**68%**	**1.995**	**22%**	**9.077**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 18,7 ; dof= 4.

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / ...nije bila dostupna u Vašoj zemlji?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	...NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Ruralnom području ili selu	230	10%	1.578	65%	608	25%	2.416	100%
Malom ili srednje velikom gradu	401	10%	2.584	66%	916	23%	3.901	100%
Velikom gradu	376	14%	1.736	63%	648	23%	2.760	100%
TOTAL	**1.007**	**11%**	**5.898**	**65%**	**2.172**	**24%**	**9.077**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 28,6 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Have you ever needed a genetic test but could not access it because...

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Ruralnom području ili selu	589	24%	1.301	54%	526	22%	**2.416**	**100%**
Malom ili srednje velikom gradu	1.052	27%	2.053	53%	796	20%	**3.901**	**100%**
Velikom gradu	765	28%	1.428	52%	567	21%	**2.760**	**100%**
TOTAL	**2.406**	**27%**	**4.782**	**53%**	**1.889**	**21%**	**9.077**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 8,5 ; dof= 4.

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Ruralnom području ili selu	329	26%	366	29%	200	16%	133	11%	34	3%	24	2%	368	30%	**1.245**	
Malom ili srednje velikom gradu	565	27%	678	33%	341	17%	193	9%	47	2%	40	2%	538	26%	**2.065**	
Velikom gradu	390	27%	485	33%	216	15%	177	12%	42	3%	37	3%	376	26%	**1.468**	
TOTAL	**1.284**	**27%**	**1.529**	**32%**	**757**	**16%**	**503**	**11%**	**123**	**3%**	**101**	**2%**	**1.282**	**27%**	**4.778**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 19,4 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Ruralnom području ili selu	108	9%	38	3%	1.099	88%	1.245	100%
Malom ili srednje velikom gradu	195	9%	83	4%	1.787	87%	2.065	100%
Velikom gradu	196	13%	108	7%	1.164	79%	1.468	100%
TOTAL	**499**	**10%**	**229**	**5%**	**4.050**	**85%**	**4.778**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 55,9 ; dof= 4.

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NEZ…		NEZADOVOLJAN/NEZ…		NITI ZADOVOLJAN/ZADOV… NITI NEZADOVOLJAN/NEZ…		ZADOVOLJAN/ZADOV…		VRLO ZADOVOLJAN/ZADOV…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Ruralnom području ili selu	126	10%	137	11%	269	22%	440	35%	211	17%	62	5%	1.245	100%
Malom ili srednje velikom gradu	230	11%	239	12%	406	20%	747	36%	329	16%	114	6%	2.065	100%
Velikom gradu	146	10%	183	12%	328	22%	469	32%	275	19%	67	5%	1.468	100%
TOTAL	**502**	**11%**	**559**	**12%**	**1.003**	**21%**	**1.656**	**35%**	**815**	**17%**	**243**	**5%**	**4.778**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 16,1 ; dof= 10.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Biste li rekli da Vi ili osoba o kojoj skrbite živite u: / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

BISTE LI REKLI DA VI ILI OSOBA O KOJOJ SKRBITE ŽIVITE U:	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Ruralnom području ili selu	466	37%	280	22%	401	32%	98	8%	**1.245**	**100%**
Malom ili srednje velikom gradu	**839**	**41%**	458	22%	**619**	**30%**	149	7%	**2.065**	**100%**
Velikom gradu	557	38%	295	20%	**516**	**35%**	100	7%	**1.468**	**100%**
TOTAL	**1.862**	**39%**	**1.033**	**22%**	**1.536**	**32%**	**347**	**7%**	**4.778**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 13,1 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	115	31%	131	36%	45	12%	7	2%	2	1%	1	0%	92	25%	369	
Hypermobile Ehlers-Danlos syndrome	15	16%	51	54%	8	8%	9	9%	0	0%	3	3%	22	23%	95	
Sarcoidosis	2	20%	2	20%	0	0%	1	10%	0	0%	0	0%	5	50%	10	
Classical Ehlers-Danlos syndrome	6	9%	36	56%	7	11%	3	5%	1	2%	2	3%	16	25%	64	
Williams syndrome	49	37%	39	30%	17	13%	5	4%	1	1%	0	0%	30	23%	131	
Cystic fibrosis	47	39%	42	35%	13	11%	6	5%	0	0%	0	0%	22	18%	121	
Myasthenia gravis	1	6%	8	47%	2	12%	0	0%	2	12%	3	18%	5	29%	17	
Systemic sclerosis	0	0%	0	0%	1	25%	0	0%	0	0%	0	0%	3	75%	4	
Tuberous sclerosis complex	17	19%	33	37%	12	13%	3	3%	1	1%	4	4%	26	29%	89	
Neurofibromatosis type 1	20	32%	14	22%	12	19%	1	2%	6	10%	2	3%	20	32%	63	
Interstitial cystitis	0	0%	0	0%	1	25%	0	0%	1	25%	1	25%	2	50%	4	
Addison disease	2	25%	2	25%	0	0%	0	0%	0	0%	0	0%	4	50%	8	
22q11.2 deletion syndrome	20	32%	15	24%	10	16%	6	10%	0	0%	1	2%	16	25%	63	
Chronic inflammatory demyelinating polyneuropathy	4	25%	3	19%	1	6%	0	0%	0	0%	1	6%	8	50%	16	
Perineural cyst	1	17%	4	67%	2	33%	0	0%	1	17%	0	0%	2	33%	6	
Acute inflammatory demyelinating polyradiculoneuropathy	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	3	100%	3	
Rett syndrome	27	48%	19	34%	10	18%	10	18%	0	0%	0	0%	11	20%	56	
Marfan syndrome	13	31%	13	31%	3	7%	1	2%	0	0%	0	0%	14	33%	42	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 9.611,8 ; dof= 7.314.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

MOLIMO ODABERITE REĆENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	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)	1.346	27%	1.510	31%	765	16%	458	9%	121	2%	97	2%	1.345	27%	**4.901**	
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	49	21%	93	39%	31	13%	30	13%	5	2%	10	4%	75	31%	**239**	
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	30	18%	53	32%	36	22%	31	19%	6	4%	4	2%	48	29%	**164**	
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	33	18%	73	40%	47	26%	46	25%	3	2%	5	3%	41	23%	**181**	
Ostalo, navesti	2	40%	2	40%	1	20%	2	40%	0	0%	1	20%	2	40%	**5**	
TOTAL	**1.460**	**27%**	**1.731**	**32%**	**880**	**16%**	**567**	**10%**	**135**	**2%**	**117**	**2%**	**1.511**	**28%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 120,1 ; dof= 24.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

POINT PREVALENCE OF THE RARE DISEASE	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	1.195	50%	1.026	43%	186	8%	**2.407**	**100%**
1-9 / 100 000	1.111	56%	751	38%	137	7%	**1.999**	**100%**
1-9 / 1 000 000	300	65%	132	29%	27	6%	**459**	**100%**
<1 / 1 000 000	547	64%	258	30%	51	6%	**856**	**100%**
TOTAL	**3.153**	**55%**	**2.167**	**38%**	**401**	**7%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 75,9 ; dof= 6.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante)

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Da	3.458	58%	2.038	34%	502	8%	**5.998**	**100%**
Ne	1.998	45%	2.097	47%	320	7%	**4.415**	**100%**
TOTAL	**5.456**	**52%**	**4.135**	**40%**	**822**	**8%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 195,7 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Druga(-e) pretraga(-e) kao što je/su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DRUGA(-E) PRETRAGA(-E) KAO ŠTO JE/SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%
Da	5.513	92%	348	6%	137	2%	5.998	100%
Ne	3.906	88%	381	9%	128	3%	4.415	100%
TOTAL	**9.419**	**90%**	**729**	**7%**	**265**	**3%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 36,2 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …je niste mogli priuštiti?

Have you ever needed a genetic test but could not access it because...

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…JE NISTE MOGLI PRIUŠTITI?							
	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	507	8%	4.292	72%	1.199	20%	5.998	100%
Ne	587	13%	2.780	63%	1.048	24%	4.415	100%
TOTAL	**1.094**	**11%**	**7.072**	**68%**	**2.247**	**22%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 100,9 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …nije bila dostupna u Vašoj zemlji?

Have you ever needed a genetic test but could not access it because...
…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	607	10%	4.045	67%	1.346	22%	5.998	100%
Ne	578	13%	2.738	62%	1.099	25%	4.415	100%
TOTAL	**1.185**	**11%**	**6.783**	**65%**	**2.445**	**23%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,7 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani?

Have you ever needed a genetic test but could not access it because...
…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DA		NE		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.372	23%	3.451	58%	1.175	20%	5.998	100%
Ne	1.408	32%	2.064	47%	943	21%	4.415	100%
TOTAL	**2.780**	**27%**	**5.515**	**53%**	**2.118**	**20%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 137,2 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za…

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…															
	SAMO JEDNIM GENOM		NEKOLIKO GENA U ISTO VRIJEME (SEKVENCIRANJE PANELA GENA)		CIJELOM DNK (SEKVENCIRANJE CIJELOG GENOMA)		SVIM GENIMA (SEKVENCIRANJE CIJELOG EGZOMA)		TUMOROM (GENETSKO PROFILIRANJE TUMORA)		DRUGIM (EPIGENOM, RNK, ITD.)		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	945	27%	1.079	31%	562	16%	330	10%	84	2%	70	2%	960	28%	**3.458**	
Ne	498	25%	648	32%	315	16%	231	12%	51	3%	47	2%	540	27%	**1.998**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 9,5 ; dof= 6.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Da	325	9%	143	4%	2.990	86%	**3.458**	**100%**
Ne	258	13%	119	6%	1.621	81%	**1.998**	**100%**
TOTAL	**583**	**11%**	**262**	**5%**	**4.611**	**85%**	**5.456**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 27,6 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/NE…		NEZADOVOLJAN/NE…		NITI ZADOVOLJAN/ZADO… NITI NEZADOVOLJAN/NE…		ZADOVOLJAN/ZADO…		VRLO ZADOVOLJAN/ZADO…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	351	10%	353	10%	690	20%	1.232	36%	656	19%	176	5%	**3.458**	**100%**
Ne	216	11%	269	13%	459	23%	685	34%	264	13%	105	5%	**1.998**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 43,4 ; dof= 5.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Da	1.398	40%	827	24%	972	28%	261	8%	**3.458**	**100%**
Ne	733	37%	340	17%	785	39%	140	7%	**1.998**	**100%**
TOTAL	**2.131**	**39%**	**1.167**	**21%**	**1.757**	**32%**	**401**	**7%**	**5.456**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 82,4 ; dof= 3.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …je niste mogli priuštiti? / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

Have you ever needed a genetic test but could not access it because...

	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
…JE NISTE MOGLI PRIUŠTITI?	N	%	N	%	N	%	N	%
Da	136	24%	83	15%	353	62%	572	100%
Ne	398	9%	164	4%	3.750	87%	4.312	100%
Nije bitno	56	9%	19	3%	531	88%	606	100%
TOTAL	**590**	**11%**	**266**	**5%**	**4.634**	**84%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 263,5 ; dof= 4.

Cross: …nije bila dostupna u Vašoj zemlji? / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

Have you ever needed a genetic test but could not access it because...

	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
…NIJE BILA DOSTUPNA U VAŠOJ ZEMLJI?	N	%	N	%	N	%	N	%
Da	174	24%	95	13%	470	64%	739	100%
Ne	370	9%	153	4%	3.632	87%	4.155	100%
Nije bitno	46	8%	18	3%	532	89%	596	100%
TOTAL	**590**	**11%**	**266**	**5%**	**4.634**	**84%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 288,4 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani? / Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?	JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?							
	DA, JEDNOM		DA, NEKOLIKO PUTA		NE, NIKAD		TOTAL	
	N	%	N	%	N	%	N	%
Da	264	17%	150	10%	1.106	73%	1.520	100%
Ne	287	8%	101	3%	3.104	89%	3.492	100%
Nije bitno	39	8%	15	3%	424	89%	478	100%
TOTAL	**590**	**11%**	**266**	**5%**	**4.634**	**84%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 229,0 ; dof= 4.

Cross: Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za… / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Samo jednim genom	590	40%	324	22%	471	32%	75	5%	1.460	100%
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	775	45%	359	21%	514	30%	83	5%	1.731	100%
Cijelom DNK (sekvenciranje cijelog genoma)	440	50%	173	20%	214	24%	53	6%	880	100%
Svim genima (sekvenciranje cijelog egzoma)	283	50%	99	17%	163	29%	22	4%	567	100%
Tumorom (genetsko profiliranje tumora)	38	28%	25	19%	60	44%	12	9%	135	100%
Drugim (epigenom, RNK, itd.)	37	32%	26	22%	42	36%	12	10%	117	100%
Ne znam	394	26%	352	23%	568	38%	197	13%	1.511	100%
TOTAL	**2.137**	**39%**	**1.179**	**21%**	**1.770**	**32%**	**404**	**7%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 288,0 ; dof= 18.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti? / Općenito, koliko ste zadovoljni time kako su Vam dani rezultati GENETSKIH PRETRAGA?

JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?	OPĆENITO, KOLIKO STE ZADOVOLJNI TIME KAKO SU VAM DANI REZULTATI GENETSKIH PRETRAGA?													
	VRLO NEZADOVOLJAN/N…		NEZADOVOLJAN/N…		NITI ZADOVOLJAN/ZAD… NITI NEZADOVOLJAN/N…		ZADOVOLJAN/ZAD…		VRLO ZADOVOLJAN/ZAD…		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	63	11%	80	14%	149	25%	193	33%	85	14%	20	3%	590	100%
DA, nekoliko puta	44	17%	40	15%	68	26%	74	28%	32	12%	8	3%	266	100%
NE, nikad	465	10%	503	11%	942	20%	1.663	36%	806	17%	255	6%	4.634	100%
TOTAL	**572**	**10%**	**623**	**11%**	**1.159**	**21%**	**1.930**	**35%**	**923**	**17%**	**283**	**5%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 45,0 ; dof= 10.

Cross: Jeste li ikad zatražili od privatne tvrtke ili laboratorija provođenje genetske pretrage za dijagnosticiranje bolesti? / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

JESTE LI IKAD ZATRAŽILI OD PRIVATNE TVRTKE ILI LABORATORIJA PROVOĐENJE GENETSKE PRETRAGE ZA DIJAGNOSTICIRANJE BOLESTI?	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
DA, jednom	211	36%	125	21%	224	38%	30	5%	590	100%
DA, nekoliko puta	85	32%	55	21%	114	43%	12	5%	266	100%
NE, nikad	1.841	40%	999	22%	1.432	31%	362	8%	4.634	100%
TOTAL	**2.137**	**39%**	**1.179**	**21%**	**1.770**	**32%**	**404**	**7%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,0 ; dof= 6.

Chapter 12.

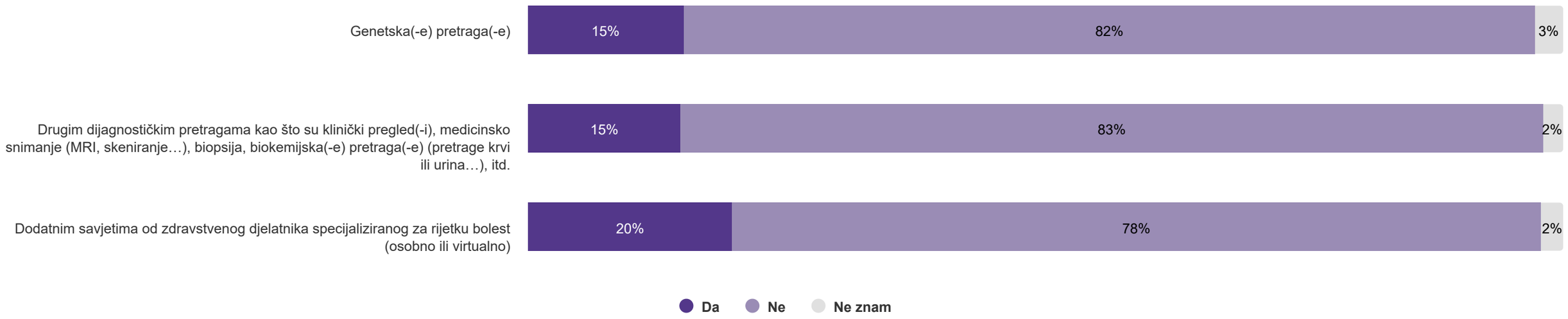
Cross-border healthcare

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Jeste li pristupili nekoj od sljedećih usluga u nekoj drugoj zemlji?

	DA	NE	NE ZNAM	TOTAL
Genetska(-e) pretraga(-e)	831	4.515	143	**5.489**
Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.	1.403	7.908	170	**9.481**
Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)	2.083	8.194	209	**10.486**
TOTAL	**4.317**	**20.617**	**522**	**25.456**

Jeste li pristupili nekoj od sljedećih usluga u nekoj drugoj zemlji?



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Genetska(-e) pretraga(-e)	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,0	624	3,1	548	3,5	344	3,8	612	5,0	543
Ne	0,8	3.307	3,9	3.019	4,4	2.049	3,8	3.388	5,7	2.952
Ne znam	1,2	91	3,5	87	3,7	57	2,6	95	4,6	69

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Fisher= 3,5.
Inter variance= 161,7. Intra variance= 46,8.

Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,2	1.067	3,8	992	3,6	513	4,3	1.028	5,4	861
Ne	0,5	6.037	3,5	5.700	3,9	3.449	3,5	6.062	4,6	5.105
Ne znam	0,6	101	2,6	103	2,8	65	1,5	106	2,5	88

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Fisher= 1,2.
Inter variance= 52,0. Intra variance= 43,6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
Da	0,1	1.591	3,3	1.484	3,7	787	4,0	1.558	4,9	1.291
Ne	0,6	6.113	3,6	5.723	3,9	3.475	3,5	6.165	4,7	5.119
Ne znam	2,1	116	3,4	115	3,2	73	3,4	120	3,5	97

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 6,1.
Inter variance= 279,8. Intra variance= 45,9.

Cross: Gender of the person affected by the rare disease / Genetska(-e) pretraga(-e)

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Žena	396	13%	2.628	84%	88	3%	3.112	100%
Muškarac	320	18%	1.450	81%	31	2%	1.801	100%
Ostalo	20	32%	37	60%	5	8%	62	100%
TOTAL	**736**	**15%**	**4.115**	**83%**	**124**	**2%**	**4.975**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 52,1 ; dof= 4.

Cross: Gender of the person affected by the rare disease / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Žena	853	14%	5.131	84%	111	2%	6.095	100%
Muškarac	394	16%	2.074	83%	37	1%	2.505	100%
Ostalo	20	22%	65	73%	4	4%	89	100%
TOTAL	**1.267**	**15%**	**7.270**	**84%**	**152**	**2%**	**8.689**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 14,2 ; dof= 4.

Cross: Gender of the person affected by the rare disease / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Žena	1.228	18%	5.298	80%	133	2%	6.659	100%
Muškarac	643	23%	2.130	76%	37	1%	2.810	100%
Ostalo	25	25%	70	69%	6	6%	101	100%
TOTAL	**1.896**	**20%**	**7.498**	**78%**	**176**	**2%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,9 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Genetska(-e) pretraga(-e)

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	52	20%	197	76%	10	4%	259	100%
između 16 i 19 godina	161	13%	1.021	84%	35	3%	1.217	100%
između 20 i 23 godine	218	14%	1.332	84%	34	2%	1.584	100%
24 godine ili više	286	17%	1.396	81%	37	2%	1.719	100%
TOTAL	**717**	**15%**	**3.946**	**83%**	**116**	**2%**	**4.779**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 18,4 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	65	16%	328	81%	13	3%	406	100%
između 16 i 19 godina	269	12%	1.931	86%	40	2%	2.240	100%
između 20 i 23 godine	415	15%	2.291	83%	43	2%	2.749	100%
24 godine ili više	451	16%	2.358	83%	48	2%	2.857	100%
TOTAL	**1.200**	**15%**	**6.908**	**84%**	**144**	**2%**	**8.252**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,2 ; dof= 6.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
15 godina ili manje	103	23%	338	74%	14	3%	455	100%
između 16 i 19 godina	430	17%	1.979	80%	55	2%	2.464	100%
između 20 i 23 godine	601	20%	2.376	79%	45	1%	3.022	100%
24 godine ili više	659	21%	2.436	77%	50	2%	3.145	100%
TOTAL	**1.793**	**20%**	**7.129**	**78%**	**164**	**2%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,4 ; dof= 6.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Genetska(-e) pretraga(-e)

KAKO BISTE NAJBOLJE OPISALI SEBE?	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	561	15%	3.055	83%	84	2%	3.700	100%
Dio sam etničke manjine u zemlji u kojoj živim	65	24%	201	75%	3	1%	269	100%
Ostalo, navesti	36	21%	129	76%	4	2%	169	100%
TOTAL	662	16%	3.385	82%	91	2%	4.138	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 19,9 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

KAKO BISTE NAJBOLJE OPISALI SEBE?	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLE MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.						
	DA		NE		NE ZNAM		TOTA
	N	%	N	%	N	%	N
Pripadam etničkoj većini u zemlji u kojoj živim	909	14%	5.471	84%	102	2%	6.482
Dio sam etničke manjine u zemlji u kojoj živim	120	29%	295	71%	2	0%	417
Ostalo, navesti	56	19%	231	77%	12	4%	299
TOTAL	1.085	15%	5.997	83%	116	2%	7.198

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,6 ; dof= 4.

Cross: Kako biste najbolje opisali sebe? / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

KAKO BISTE NAJBOLJE OPISALI SEBE?	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.417	20%	5.598	79%	110	2%	7.125	100%
Dio sam etničke manjine u zemlji u kojoj živim	132	28%	323	69%	10	2%	465	100%
Ostalo, navesti	69	20%	252	75%	16	5%	337	100%
TOTAL	1.618	20%	6.173	78%	136	2%	7.927	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Genetska(-e) pretraga(-e)

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	341	29%	776	67%	41	4%	1.158	100%
Group B ('Western Europe')	234	9%	2.419	90%	49	2%	2.702	100%
Group C ('Northern Europe')	230	16%	1.190	81%	49	3%	1.469	100%
TOTAL	**805**	**15%**	**4.385**	**82%**	**139**	**3%**	**5.329**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 296,0 ; dof= 4.

Cross: Typology of countries based on size and welfare / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	387	24%	1.184	73%	60	4%	1.631	100%
Group B ('Western Europe')	516	11%	4.042	88%	56	1%	4.614	100%
Group C ('Northern Europe')	453	15%	2.449	83%	49	2%	2.951	100%
TOTAL	**1.356**	**15%**	**7.675**	**83%**	**165**	**2%**	**9.196**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 203,6 ; dof= 4.

Cross: Typology of countries based on size and welfare / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	576	32%	1.150	64%	68	4%	1.794	100%
Group B ('Western Europe')	848	17%	4.190	82%	67	1%	5.105	100%
Group C ('Northern Europe')	606	19%	2.602	79%	65	2%	3.273	100%
TOTAL	**2.030**	**20%**	**7.942**	**78%**	**200**	**2%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 262,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Genetska(-e) pretraga(-e)

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	22	6%	339	92%	8	2%	369	100%
Hypermobile Ehlers-Danlos syndrome	6	6%	88	93%	1	1%	95	100%
Sarcoidosis	1	10%	8	80%	1	10%	10	100%
Classical Ehlers-Danlos syndrome	4	6%	58	91%	2	3%	64	100%
Williams syndrome	6	5%	121	92%	4	3%	131	100%
Cystic fibrosis	14	12%	101	83%	6	5%	121	100%
Myasthenia gravis	3	18%	14	82%	0	0%	17	100%
Systemic sclerosis	0	0%	4	100%	0	0%	4	100%
Tuberous sclerosis complex	16	18%	73	82%	0	0%	89	100%
Neurofibromatosis type 1	6	10%	54	86%	3	5%	63	100%
Interstitial cystitis	0	0%	4	100%	0	0%	4	100%
Addison disease	3	38%	5	63%	0	0%	8	100%
22q11.2 deletion syndrome	4	6%	55	87%	4	6%	63	100%
Chronic inflammatory demyelinating polyneuropathy	3	19%	13	81%	0	0%	16	100%
Perineural cyst	0	0%	6	100%	0	0%	6	100%
Acute inflammatory demyelinating polyradiculoneuropathy	0	0%	2	67%	1	33%	3	100%
Rett syndrome	8	14%	46	82%	2	4%	56	100%
Marfan syndrome	5	12%	37	88%	0	0%	42	100%

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 2.456,3 ; dof= 2.438.

Cross: Orphacode associated nomenclature (english) / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	32	8%	368	90%	8	2%	**408**	**100%**
Hypermobile Ehlers-Danlos syndrome	46	16%	235	83%	2	1%	**283**	**100%**
Sarcoidosis	14	8%	154	91%	1	1%	**169**	**100%**
Classical Ehlers-Danlos syndrome	14	11%	110	89%	0	0%	**124**	**100%**
Williams syndrome	5	6%	72	90%	3	4%	**80**	**100%**
Cystic fibrosis	19	17%	89	77%	7	6%	**115**	**100%**
Myasthenia gravis	33	28%	83	70%	2	2%	**118**	**100%**
Systemic sclerosis	6	6%	100	94%	0	0%	**106**	**100%**
Tuberous sclerosis complex	5	5%	91	95%	0	0%	**96**	**100%**
Neurofibromatosis type 1	14	16%	70	81%	2	2%	**86**	**100%**
Interstitial cystitis	7	10%	65	90%	0	0%	**72**	**100%**
Addison disease	9	13%	60	83%	3	4%	**72**	**100%**
22q11.2 deletion syndrome	4	8%	46	88%	2	4%	**52**	**100%**
Chronic inflammatory demyelinating polyneuropathy	12	19%	52	81%	0	0%	**64**	**100%**
Perineural cyst	12	20%	48	79%	1	2%	**61**	**100%**
Acute inflammatory demyelinating polyradiculoneuropathy	5	8%	55	90%	1	2%	**61**	**100%**
Rett syndrome	6	12%	41	84%	2	4%	**49**	**100%**
Marfan syndrome	4	9%	39	91%	0	0%	**43**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 3.368,8 ; dof= 3.164.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	59	13%	389	85%	10	2%	458	100%
Hypermobile Ehlers-Danlos syndrome	59	19%	255	80%	3	1%	317	100%
Sarcoidosis	14	8%	155	91%	1	1%	170	100%
Classical Ehlers-Danlos syndrome	17	12%	119	87%	1	1%	137	100%
Williams syndrome	18	13%	116	85%	2	1%	136	100%
Cystic fibrosis	26	20%	92	72%	10	8%	128	100%
Myasthenia gravis	26	22%	93	78%	1	1%	120	100%
Systemic sclerosis	8	7%	99	93%	0	0%	107	100%
Tuberous sclerosis complex	23	23%	75	77%	0	0%	98	100%
Neurofibromatosis type 1	15	16%	75	82%	2	2%	92	100%
Interstitial cystitis	13	18%	61	82%	0	0%	74	100%
Addison disease	12	16%	57	78%	4	5%	73	100%
22q11.2 deletion syndrome	11	16%	56	82%	1	1%	68	100%
Chronic inflammatory demyelinating polyneuropathy	13	20%	51	78%	1	2%	65	100%
Perineural cyst	22	35%	40	63%	1	2%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	7	11%	53	85%	2	3%	62	100%
Rett syndrome	10	17%	48	80%	2	3%	60	100%
Marfan syndrome	10	19%	41	79%	1	2%	52	100%
Fragile X syndrome	6	12%	40	82%	3	6%	49	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 3.696,6 ; dof= 3.350.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / Genetska(-e) pretraga(-e)

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Abdominal surgical diseases	7	7%	93	89%	5	5%	**105**	**100%**
Allergic diseases	0	0%	1	100%	0	0%	**1**	**100%**
Bone diseases	78	14%	482	84%	16	3%	**576**	**100%**
Cardiac diseases	46	15%	247	83%	5	2%	**298**	**100%**
Cardiac malformations	19	7%	223	88%	12	5%	**254**	**100%**
Circulatory system diseases	82	9%	823	89%	20	2%	**925**	**100%**
Clinical sign	0	0%	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	272	12%	1.942	86%	49	2%	**2.263**	**100%**
Diseases due to toxic effects	0	0%	2	100%	0	0%	**2**	**100%**
Endocrine diseases	70	14%	409	83%	15	3%	**494**	**100%**
Gastroenterological diseases	30	13%	187	83%	9	4%	**226**	**100%**
Genetic diseases	584	15%	3.190	83%	88	2%	**3.862**	**100%**
Gynecologic/obstetric diseases	31	18%	139	79%	6	3%	**176**	**100%**
Hematological diseases	32	15%	181	84%	3	1%	**216**	**100%**
Hepatic diseases	66	10%	585	87%	21	3%	**672**	**100%**
Immunological diseases	42	21%	158	77%	4	2%	**204**	**100%**
Inborn errors of metabolism	139	22%	469	75%	18	3%	**626**	**100%**
Infectious diseases	0	0%	1	100%	0	0%	**1**	**100%**
Infertility	41	13%	250	82%	13	4%	**304**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 201,0 ; dof= 68.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Abdominal surgical diseases	26	12%	191	87%	3	1%	**220**	**100%**
Allergic diseases	0	0%	3	100%	0	0%	**3**	**100%**
Bone diseases	90	13%	579	86%	7	1%	**676**	**100%**
Cardiac diseases	65	10%	549	89%	6	1%	**620**	**100%**
Cardiac malformations	20	10%	178	86%	9	4%	**207**	**100%**
Circulatory system diseases	128	11%	1.038	87%	21	2%	**1.187**	**100%**
Clinical sign	0	0%	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	373	13%	2.488	86%	37	1%	**2.898**	**100%**
Diseases due to toxic effects	0	0%	3	100%	0	0%	**3**	**100%**
Endocrine diseases	115	13%	778	86%	14	2%	**907**	**100%**
Gastroenterological diseases	37	13%	230	83%	11	4%	**278**	**100%**
Genetic diseases	684	14%	4.025	84%	81	2%	**4.790**	**100%**
Gynecologic/obstetric diseases	39	15%	210	83%	3	1%	**252**	**100%**
Hematological diseases	64	16%	319	81%	10	3%	**393**	**100%**
Hepatic diseases	95	12%	697	86%	19	2%	**811**	**100%**
Immunological diseases	41	16%	207	81%	8	3%	**256**	**100%**
Inborn errors of metabolism	136	19%	563	78%	19	3%	**718**	**100%**
Infectious diseases	3	18%	14	82%	0	0%	**17**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 122,9 ; dof= 68.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Abdominal surgical diseases	43	18%	193	81%	3	1%	**239**	**100%**
Allergic diseases	1	33%	2	67%	0	0%	**3**	**100%**
Bone diseases	179	22%	606	76%	14	2%	**799**	**100%**
Cardiac diseases	111	17%	542	82%	7	1%	**660**	**100%**
Cardiac malformations	48	16%	238	81%	9	3%	**295**	**100%**
Circulatory system diseases	226	17%	1.104	82%	21	2%	**1.351**	**100%**
Clinical sign	0	0%	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	664	20%	2.626	78%	57	2%	**3.347**	**100%**
Diseases due to toxic effects	1	33%	2	67%	0	0%	**3**	**100%**
Endocrine diseases	197	20%	775	78%	23	2%	**995**	**100%**
Gastroenterological diseases	55	18%	234	77%	16	5%	**305**	**100%**
Genetic diseases	1.135	21%	4.205	77%	107	2%	**5.447**	**100%**
Gynecologic/obstetric diseases	65	23%	212	75%	7	2%	**284**	**100%**
Hematological diseases	85	21%	317	77%	10	2%	**412**	**100%**
Hepatic diseases	133	15%	730	82%	28	3%	**891**	**100%**
Immunological diseases	58	20%	221	77%	7	2%	**286**	**100%**
Inborn errors of metabolism	188	24%	560	72%	26	3%	**774**	**100%**
Infectious diseases	3	18%	14	82%	0	0%	**17**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 173,2 ; dof= 68.

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Genetska(-e) pretraga(-e)

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	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)	726	15%	4.053	83%	122	2%	**4.901**	**100%**
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	37	16%	191	80%	10	4%	**238**	**100%**
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	29	18%	130	79%	5	3%	**164**	**100%**
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	37	20%	138	76%	6	3%	**181**	**100%**
Ostalo, navesti	2	40%	3	60%	0	0%	**5**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 11,2 ; dof= 8.

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	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)	1.183	14%	6.942	84%	146	2%	**8.271**	**100%**
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	96	16%	502	83%	9	1%	**607**	**100%**
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	62	23%	206	76%	4	1%	**272**	**100%**
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	54	17%	250	80%	8	3%	**312**	**100%**
Ostalo, navesti	8	42%	8	42%	3	16%	**19**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 53,3 ; dof= 8.

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	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)	1.795	20%	7.079	78%	174	2%	**9.048**	**100%**
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	141	19%	609	80%	10	1%	**760**	**100%**
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	73	24%	221	72%	12	4%	**306**	**100%**
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	68	20%	271	78%	9	3%	**348**	**100%**
Ostalo, navesti	6	25%	14	58%	4	17%	**24**	**100%**
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,7 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Genetska(-e) pretraga(-e)

POINT PREVALENCE OF THE RARE DISEASE	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	123	10%	1.039	87%	33	3%	1.195	100%
1-9 / 100 000	160	14%	924	83%	26	2%	1.110	100%
1-9 / 1 000 000	65	22%	227	76%	8	3%	300	100%
<1 / 1 000 000	98	18%	439	80%	10	2%	547	100%
TOTAL	446	14%	2.629	83%	77	2%	3.152	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 36,1 ; dof= 6.

Cross: Point prevalence of the rare disease / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

POINT PREVALENCE OF THE RARE DISEASE	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	243	11%	1.925	87%	34	2%	2.202	100%
1-9 / 100 000	263	14%	1.532	84%	37	2%	1.832	100%
1-9 / 1 000 000	74	18%	343	81%	5	1%	422	100%
<1 / 1 000 000	114	15%	625	83%	13	2%	752	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,6 ; dof= 6.

Cross: Point prevalence of the rare disease / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

POINT PREVALENCE OF THE RARE DISEASE	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
1-5 / 10 000	375	16%	1.989	83%	43	2%	2.407	100%
1-9 / 100 000	392	20%	1.565	78%	42	2%	1.999	100%
1-9 / 1 000 000	104	23%	342	75%	13	3%	459	100%
<1 / 1 000 000	196	23%	645	75%	15	2%	856	100%
TOTAL	1.067	19%	4.541	79%	113	2%	5.721	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 34,5 ; dof= 6.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Genetska(-e) pretraga(-e)

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	263	15%	1.453	82%	54	3%	**1.770**	**100%**
Ne	538	15%	2.892	82%	80	2%	**3.510**	**100%**
Ne znam	30	14%	170	81%	9	4%	**209**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 5,4 ; dof= 4.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	424	16%	2.122	82%	51	2%	**2.597**	**100%**
Ne	915	14%	5.480	84%	107	2%	**6.502**	**100%**
Ne znam	64	17%	306	80%	12	3%	**382**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 14,5 ; dof= 4.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	712	24%	2.185	74%	60	2%	**2.957**	**100%**
Ne	1.304	18%	5.647	80%	134	2%	**7.085**	**100%**
Ne znam	67	15%	362	82%	15	3%	**444**	**100%**
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 53,5 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Genetska(-e) pretraga(-e)

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	309	16%	1.528	81%	51	3%	**1.888**	**100%**
Ne	502	14%	2.875	83%	88	3%	**3.465**	**100%**
Ne znam	20	15%	112	82%	4	3%	**136**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,5 ; Chi2= 3,7 ; dof= 4.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	424	16%	2.116	82%	47	2%	**2.587**	**100%**
Ne	932	14%	5.577	84%	114	2%	**6.623**	**100%**
Ne znam	47	17%	215	79%	9	3%	**271**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 13,6 ; dof= 4.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	706	24%	2.175	74%	55	2%	**2.936**	**100%**
Ne	1.328	18%	5.769	80%	139	2%	**7.236**	**100%**
Ne znam	49	16%	250	80%	15	5%	**314**	**100%**
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 58,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Genetska(-e) pretraga(-e)

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	421	15%	2.350	83%	67	2%	**2.838**	**100%**
Ne	362	16%	1.827	81%	61	3%	**2.250**	**100%**
Ne znam	48	12%	338	84%	15	4%	**401**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 7,5 ; dof= 4.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	844	15%	4.557	83%	86	2%	**5.487**	**100%**
Ne	484	14%	2.805	84%	55	2%	**3.344**	**100%**
Ne znam	75	12%	546	84%	29	4%	**650**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 34,2 ; dof= 4.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.205	20%	4.635	78%	100	2%	**5.940**	**100%**
Ne	757	20%	2.955	78%	76	2%	**3.788**	**100%**
Ne znam	121	16%	604	80%	33	4%	**758**	**100%**
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 30,7 ; dof= 4.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Genetska(-e) pretraga(-e)

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	461	15%	2.587	82%	92	3%	**3.140**	**100%**
Ne	313	16%	1.592	82%	40	2%	**1.945**	**100%**
Ne znam	57	14%	336	83%	11	3%	**404**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 5,5 ; dof= 4.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	994	15%	5.412	83%	114	2%	**6.520**	**100%**
Ne	344	14%	2.110	84%	45	2%	**2.499**	**100%**
Ne znam	65	14%	386	84%	11	2%	**462**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 4,3 ; dof= 4.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.380	20%	5.505	78%	135	2%	**7.020**	**100%**
Ne	593	20%	2.266	78%	57	2%	**2.916**	**100%**
Ne znam	110	20%	423	77%	17	3%	**550**	**100%**
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

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

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Genetska(-e) pretraga(-e)

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	418	17%	1.907	80%	72	3%	2.397	100%
Ne	387	14%	2.372	84%	57	2%	2.816	100%
Ne znam	26	9%	236	86%	14	5%	276	100%
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 33,3 ; dof= 4.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	732	17%	3.508	81%	73	2%	4.313	100%
Ne	610	13%	3.981	85%	77	2%	4.668	100%
Ne znam	61	12%	419	84%	20	4%	500	100%
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 44,1 ; dof= 4.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.052	23%	3.514	76%	82	2%	4.648	100%
Ne	932	18%	4.221	80%	98	2%	5.251	100%
Ne znam	99	17%	459	78%	29	5%	587	100%
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 66,9 ; dof= 4.

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / Genetska(-e) pretraga(-e)

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
0-1	70	9%	664	88%	22	3%	**756**	**100%**
između 2 i 4	303	13%	1.935	84%	56	2%	**2.294**	**100%**
između 5 i 7	158	15%	870	82%	31	3%	**1.059**	**100%**
između 8 i 10	76	19%	312	79%	9	2%	**397**	**100%**
više od 10	224	23%	734	75%	25	3%	**983**	**100%**
TOTAL	**831**	**15%**	**4.515**	**82%**	**143**	**3%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 77,9 ; dof= 8.

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
0-1	121	11%	939	86%	27	2%	**1.087**	**100%**
između 2 i 4	526	13%	3.535	86%	65	2%	**4.126**	**100%**
između 5 i 7	257	14%	1.582	84%	39	2%	**1.878**	**100%**
između 8 i 10	140	19%	579	79%	18	2%	**737**	**100%**
više od 10	359	22%	1.273	77%	21	1%	**1.653**	**100%**
TOTAL	**1.403**	**15%**	**7.908**	**83%**	**170**	**2%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 108,5 ; dof= 8.

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
0-1	185	14%	1.083	83%	37	3%	1.305	100%
između 2 i 4	765	17%	3.728	82%	76	2%	4.569	100%
između 5 i 7	430	21%	1.560	77%	43	2%	2.033	100%
između 8 i 10	210	27%	563	71%	18	2%	791	100%
više od 10	493	28%	1.260	70%	35	2%	1.788	100%
TOTAL	**2.083**	**20%**	**8.194**	**78%**	**209**	**2%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 154,0 ; dof= 8.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Genetska(-e) pretraga(-e)

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	GENETSKA(-E) PRETRAGA(-E)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	490	14%	2.871	83%	96	3%	3.457	100%
Ne	337	17%	1.615	81%	46	2%	1.998	100%
TOTAL	**827**	**15%**	**4.486**	**82%**	**142**	**3%**	**5.455**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 7,9 ; dof= 2.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd.

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	754	14%	4.652	84%	107	2%	**5.513**	**100%**
Ne	644	16%	3.199	82%	62	2%	**3.905**	**100%**
TOTAL	**1.398**	**15%**	**7.851**	**83%**	**169**	**2%**	**9.418**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 15,5 ; dof= 2.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno)

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)							
	DA		NE		NE ZNAM		TOTAL	
	N	%	N	%	N	%	N	%
Da	1.150	19%	4.720	79%	128	2%	**5.998**	**100%**
Ne	920	21%	3.417	77%	78	2%	**4.415**	**100%**
TOTAL	**2.070**	**20%**	**8.137**	**78%**	**206**	**2%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 5,8 ; dof= 2.

Cross: Genetska(-e) pretraga(-e) / Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)?

GENETSKA(-E) PRETRAGA(-E)	JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?									
	DA, KOD GENETSKOG SAVJETNIKA ILI KLINIČKOG GENETIČARA		DA, KOD ZDRAVSTVENOG DJELATNIKA		NE, NIJE MI PONUĐENO GENETSKO SAVJETOVANJE		NISAM SIGURAN/SIGURNA / NE SJEĆAM SE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Da	338	41%	181	22%	268	32%	44	5%	**831**	**100%**
Ne	1.753	39%	974	22%	1.455	32%	333	7%	**4.515**	**100%**
Ne znam	46	32%	23	16%	47	33%	27	19%	**143**	**100%**
TOTAL	**2.137**	**39%**	**1.178**	**21%**	**1.770**	**32%**	**404**	**7%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 35,0 ; dof= 6.

Chapter 13.

Support

Rare Barometer
A EURORDIS INITIATIVE
EURORDIS
RARE DISEASES EUROPE

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

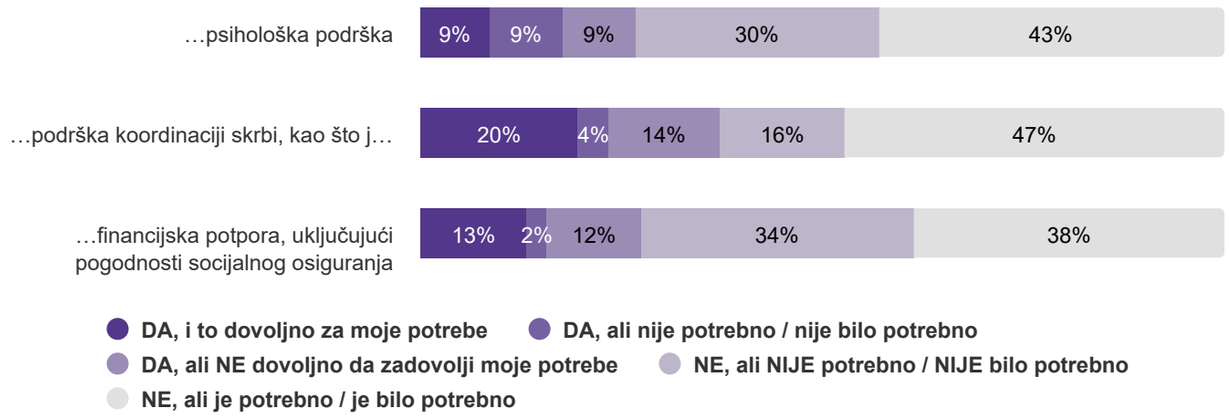
Je li Vam tijekom traganja za dijagnozom bila ponuđena…

	DA, I TO DOVOL… ZA MOJE POTREBE	DA, ALI NIJE POTRE… / NIJE BILO POTRE…	DA, ALI NE DOVOL… DA ZADOV… MOJE POTREBE	NE, ALI NIJE POTRE… / NIJE BILO POTRE…	NE, ALI JE POTR… / JE BILO POTR…	TOTAL
…psihološka podrška	922	955	952	3.165	4.492	**10.486**
…podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.	2.083	391	1.463	1.627	4.922	**10.486**
…financijska potpora, uključujući pogodnosti socijalnog osiguranja	1.405	243	1.232	3.544	3.989	**10.413**

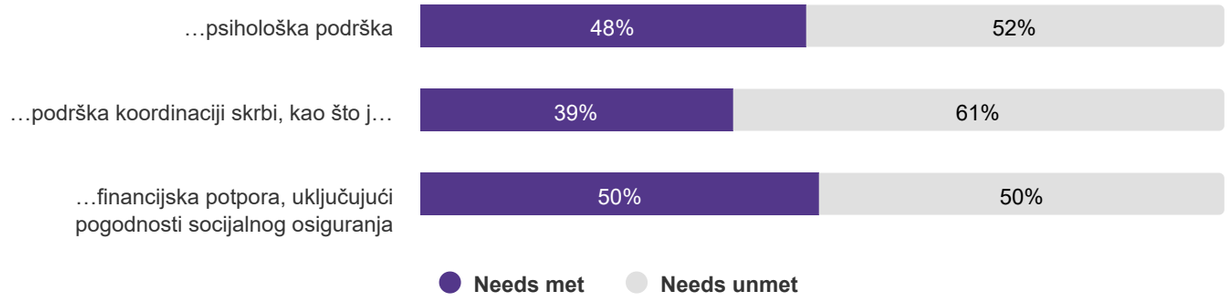
Needs met: YES and enough to meet my needs + YES but it is/was not needed + NO but it is/was NOT needed.

Needs unmet: YES but NOT enough to meet my needs + NO but it is/was needed

Je li Vam tijekom traganja za dijagnozom bila ponuđena…



Je li Vam tijekom traganja za dijagnozom bila ponuđena…



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Multiple Cross

…psihološka podrška	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, i to dovoljno za moje potrebe	−0,3	685	2,1	670	2,0	471	2,0	695	2,5	584
DA, ali nije potrebno / nije bilo potrebno	0,3	688	3,1	664	3,6	461	3,4	717	4,0	615
DA, ali NE dovoljno da zadovolji moje potrebe	0,5	739	3,5	674	4,4	425	4,5	724	5,1	555
NE, ali NIJE potrebno / NIJE bilo potrebno	0,8	2.255	3,9	2.166	3,9	1.280	3,1	2.330	4,9	1.965
NE, ali je potrebno / je bilo potrebno	0,5	3.453	3,6	3.148	4,3	1.698	4,1	3.377	5,2	2.788

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 3,5.
Inter variance= 159,1. Intra variance= 45,9.

Multiple Cross

…podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, i to dovoljno za moje potrebe	0,4	1.551	2,3	1.535	2,4	1.117	1,7	1.619	2,8	1.425
DA, ali nije potrebno / nije bilo potrebno	0,5	258	2,2	248	2,0	167	2,2	268	3,2	235
DA, ali NE dovoljno da zadovolji moje potrebe	0,5	1.109	3,4	1.028	3,6	678	3,7	1.100	4,7	921
NE, ali NIJE potrebno / NIJE bilo potrebno	0,5	1.109	3,5	1.068	3,7	646	2,7	1.149	4,4	978
NE, ali je potrebno / je bilo potrebno	0,5	3.793	4,2	3.443	5,2	1.727	4,8	3.707	5,9	2.948

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 1,0 ; Fisher= 0,1.
Inter variance= 3,4. Intra variance= 46,0.

Multiple Cross

…financijska potpora, uključujući pogodnosti socijalnog osiguranja	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, i to dovoljno za moje potrebe	0,4	1.050	2,6	1.012	2,7	701	2,6	1.084	3,2	932
DA, ali nije potrebno / nije bilo potrebno	0,7	162	2,2	171	3,0	113	1,8	166	2,9	152
DA, ali NE dovoljno da zadovolji moje potrebe	0,3	903	3,2	815	3,8	505	3,9	869	4,6	717
NE, ali NIJE potrebno / NIJE bilo potrebno	0,3	2.686	3,6	2.589	3,5	1.576	2,9	2.756	4,5	2.375
NE, ali je potrebno / je bilo potrebno	0,7	2.966	4,0	2.684	4,9	1.440	4,7	2.915	5,8	2.293

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Fisher= 1,5.
Inter variance= 67,9. Intra variance= 46,2.

Cross: Gender of the person affected by the rare disease / …psihološka podrška

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	536	8%	546	8%	639	10%	1.973	30%	2.965	45%	6.659	100%
Muškarac	280	10%	301	11%	226	8%	921	33%	1.082	39%	2.810	100%
Ostalo	7	7%	15	15%	9	9%	19	19%	51	50%	101	100%
TOTAL	**823**	**9%**	**862**	**9%**	**874**	**9%**	**2.913**	**30%**	**4.098**	**43%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 60,8 ; dof= 8.

Cross: Gender of the person affected by the rare disease / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	1.165	17%	201	3%	902	14%	1.040	16%	3.351	50%	6.659	100%
Muškarac	689	25%	127	5%	424	15%	427	15%	1.143	41%	2.810	100%
Ostalo	19	19%	4	4%	10	10%	14	14%	54	53%	101	100%
TOTAL	**1.873**	**20%**	**332**	**3%**	**1.336**	**14%**	**1.481**	**15%**	**4.548**	**48%**	**9.570**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 107,2 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	818	12%	120	2%	728	11%	2.302	35%	2.665	40%	6.633	100%
Muškarac	421	15%	89	3%	368	13%	985	35%	935	33%	2.798	100%
Ostalo	13	13%	5	5%	17	17%	18	18%	48	48%	101	100%
TOTAL	**1.252**	**13%**	**214**	**2%**	**1.113**	**12%**	**3.305**	**35%**	**3.648**	**38%**	**9.532**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 75,5 ; dof= 8.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …psihološka podrška

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	45	10%	46	10%	44	10%	130	29%	190	42%	455	100%
između 16 i 19 godina	228	9%	225	9%	202	8%	761	31%	1.048	43%	2.464	100%
između 20 i 23 godine	263	9%	275	9%	257	9%	977	32%	1.250	41%	3.022	100%
24 godine ili više	247	8%	273	9%	325	10%	900	29%	1.400	45%	3.145	100%
TOTAL	**783**	**9%**	**819**	**9%**	**828**	**9%**	**2.768**	**30%**	**3.888**	**43%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 25,4 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	91	20%	20	4%	89	20%	57	13%	198	44%	**455**	**100%**
između 16 i 19 godina	498	20%	96	4%	333	14%	357	14%	1.180	48%	**2.464**	**100%**
između 20 i 23 godine	620	21%	96	3%	409	14%	497	16%	1.400	46%	**3.022**	**100%**
24 godine ili više	574	18%	104	3%	442	14%	474	15%	1.551	49%	**3.145**	**100%**
TOTAL	**1.783**	**20%**	**316**	**3%**	**1.273**	**14%**	**1.385**	**15%**	**4.329**	**48%**	**9.086**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 29,7 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	63	14%	11	2%	81	18%	118	26%	178	39%	**451**	**100%**
između 16 i 19 godina	299	12%	43	2%	284	12%	831	34%	1.003	41%	**2.460**	**100%**
između 20 i 23 godine	398	13%	75	2%	349	12%	1.103	37%	1.079	36%	**3.004**	**100%**
24 godine ili više	429	14%	76	2%	360	11%	1.077	34%	1.192	38%	**3.134**	**100%**
TOTAL	**1.189**	**13%**	**205**	**2%**	**1.074**	**12%**	**3.129**	**35%**	**3.452**	**38%**	**9.049**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 44,0 ; dof= 12.

Cross: Kako biste najbolje opisali sebe? / …psihološka podrška

	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	587	8%	617	9%	658	9%	2.185	31%	3.078	43%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	47	10%	55	12%	54	12%	123	26%	186	40%	**465**	**100%**
Ostalo, navesti	42	12%	27	8%	27	8%	90	27%	151	45%	**337**	**100%**
TOTAL	**676**	**9%**	**699**	**9%**	**739**	**9%**	**2.398**	**30%**	**3.415**	**43%**	7.927	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,0 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.378	19%	239	3%	1.015	14%	1.049	15%	3.444	48%	**7.125**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	96	21%	18	4%	68	15%	62	13%	221	48%	**465**	**100%**
Ostalo, navesti	65	19%	14	4%	49	15%	47	14%	162	48%	**337**	**100%**
TOTAL	**1.539**	**19%**	**271**	**3%**	**1.132**	**14%**	**1.158**	**15%**	**3.827**	**48%**	7.927	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 1,0 ; Chi2= 2,1 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	898	13%	155	2%	857	12%	2.494	35%	2.685	38%	7.089	100%
Dio sam etničke manjine u zemlji u kojoj živim	60	13%	14	3%	68	15%	118	25%	204	44%	464	100%
Ostalo, navesti	45	13%	8	2%	42	12%	96	28%	146	43%	337	100%
TOTAL	**1.003**	**13%**	**177**	**2%**	**967**	**12%**	**2.708**	**34%**	**3.035**	**38%**	**7.890**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 25,8 ; dof= 8.

Cross: Typology of countries based on size and welfare / …psihološka podrška

	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	170	9%	180	10%	144	8%	481	27%	819	46%	1.794	100%
Group B ('Western Europe')	399	8%	426	8%	429	8%	1.501	29%	2.350	46%	5.105	100%
Group C ('Northern Europe')	313	10%	306	9%	352	11%	1.097	34%	1.205	37%	3.273	100%
TOTAL	**882**	**9%**	**912**	**9%**	**925**	**9%**	**3.079**	**30%**	**4.374**	**43%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 91,2 ; dof= 8.

Cross: Typology of countries based on size and welfare / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	352	20%	88	5%	277	15%	234	13%	843	47%	**1.794**	**100%**
Group B ('Western Europe')	1.026	20%	160	3%	740	14%	763	15%	2.416	47%	**5.105**	**100%**
Group C ('Northern Europe')	633	19%	119	4%	416	13%	573	18%	1.532	47%	**3.273**	**100%**
TOTAL	**2.011**	**20%**	**367**	**4%**	**1.433**	**14%**	**1.570**	**15%**	**4.791**	**47%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 36,2 ; dof= 8.

Cross: Typology of countries based on size and welfare / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	237	13%	47	3%	326	18%	336	19%	847	47%	**1.793**	**100%**
Group B ('Western Europe')	627	12%	107	2%	526	10%	1.873	37%	1.937	38%	**5.070**	**100%**
Group C ('Northern Europe')	496	15%	81	2%	361	11%	1.228	38%	1.106	34%	**3.272**	**100%**
TOTAL	**1.360**	**13%**	**235**	**2%**	**1.213**	**12%**	**3.437**	**34%**	**3.890**	**38%**	**10.135**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 287,3 ; dof= 8.

Cross: Orphacode associated nomenclature (english) / …psihološka podrška

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	…PSIHOLOŠKA PODRŠKA										TOTAL	
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO			
	N	%	N	%	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	20	4%	28	6%	20	4%	250	55%	140	31%	458	100%
Hypermobile Ehlers-Danlos syndrome	28	9%	40	13%	52	16%	69	22%	128	40%	317	100%
Sarcoidosis	11	6%	10	6%	5	3%	71	42%	73	43%	170	100%
Classical Ehlers-Danlos syndrome	7	5%	16	12%	21	15%	36	26%	57	42%	137	100%
Williams syndrome	15	11%	7	5%	13	10%	28	21%	73	54%	136	100%
Cystic fibrosis	16	13%	21	16%	14	11%	25	20%	52	41%	128	100%
Myasthenia gravis	10	8%	3	3%	6	5%	40	33%	61	51%	120	100%
Systemic sclerosis	6	6%	8	7%	7	7%	43	40%	43	40%	107	100%
Tuberous sclerosis complex	13	13%	9	9%	7	7%	26	27%	43	44%	98	100%
Neurofibromatosis type 1	9	10%	8	9%	9	10%	30	33%	36	39%	92	100%
Interstitial cystitis	6	8%	6	8%	2	3%	15	20%	45	61%	74	100%
Addison disease	3	4%	11	15%	1	1%	25	34%	33	45%	73	100%
22q11.2 deletion syndrome	8	12%	3	4%	7	10%	14	21%	36	53%	68	100%
Chronic inflammatory demyelinating polyneuropathy	8	12%	8	12%	10	15%	21	32%	18	28%	65	100%
Perineural cyst	7	11%	9	14%	5	8%	16	25%	26	41%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	6	10%	11	18%	6	10%	17	27%	22	35%	62	100%
Rett syndrome	4	7%	6	10%	4	7%	14	23%	32	53%	60	100%
Marfan syndrome	2	4%	4	8%	7	13%	16	31%	23	44%	52	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 7.481,1 ; dof= 6.700.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	133	29%	10	2%	53	12%	117	26%	145	32%	458	100%
Hypermobile Ehlers-Danlos syndrome	18	6%	3	1%	27	9%	32	10%	237	75%	317	100%
Sarcoidosis	39	23%	9	5%	15	9%	30	18%	77	45%	170	100%
Classical Ehlers-Danlos syndrome	8	6%	4	3%	15	11%	22	16%	88	64%	137	100%
Williams syndrome	36	26%	5	4%	22	16%	13	10%	60	44%	136	100%
Cystic fibrosis	50	39%	8	6%	17	13%	15	12%	38	30%	128	100%
Myasthenia gravis	18	15%	4	3%	20	17%	19	16%	59	49%	120	100%
Systemic sclerosis	33	31%	9	8%	20	19%	8	7%	37	35%	107	100%
Tuberous sclerosis complex	30	31%	5	5%	18	18%	16	16%	29	30%	98	100%
Neurofibromatosis type 1	25	27%	6	7%	10	11%	18	20%	33	36%	92	100%
Interstitial cystitis	18	24%	2	3%	10	14%	8	11%	36	49%	74	100%
Addison disease	15	21%	3	4%	11	15%	8	11%	36	49%	73	100%
22q11.2 deletion syndrome	13	19%	3	4%	18	26%	9	13%	25	37%	68	100%
Chronic inflammatory demyelinating polyneuropathy	16	25%	1	2%	7	11%	13	20%	28	43%	65	100%
Perineural cyst	4	6%	4	6%	4	6%	5	8%	46	73%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	21	34%	0	0%	13	21%	12	19%	16	26%	62	100%
Rett syndrome	10	17%	2	3%	9	15%	8	13%	31	52%	60	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 7.163,3 ; dof= 6.700.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	69	15%	9	2%	19	4%	235	52%	123	27%	455	100%
Hypermobile Ehlers-Danlos syndrome	23	7%	2	1%	42	13%	73	23%	176	56%	316	100%
Sarcoidosis	11	7%	1	1%	7	4%	97	57%	53	31%	169	100%
Classical Ehlers-Danlos syndrome	8	6%	1	1%	20	15%	33	24%	73	54%	135	100%
Williams syndrome	28	21%	0	0%	17	13%	39	29%	52	38%	136	100%
Cystic fibrosis	38	30%	3	2%	26	20%	20	16%	41	32%	128	100%
Myasthenia gravis	12	10%	1	1%	20	17%	34	28%	53	44%	120	100%
Systemic sclerosis	13	12%	8	7%	7	7%	54	50%	25	23%	107	100%
Tuberous sclerosis complex	12	12%	3	3%	14	14%	38	39%	30	31%	97	100%
Neurofibromatosis type 1	12	13%	1	1%	9	10%	37	40%	33	36%	92	100%
Interstitial cystitis	6	8%	0	0%	6	8%	18	24%	44	59%	74	100%
Addison disease	4	5%	0	0%	8	11%	39	53%	22	30%	73	100%
22q11.2 deletion syndrome	14	21%	3	4%	14	21%	12	18%	25	37%	68	100%
Chronic inflammatory demyelinating polyneuropathy	9	14%	1	2%	5	8%	26	40%	24	37%	65	100%
Perineural cyst	6	10%	1	2%	9	14%	16	25%	31	49%	63	100%
Acute inflammatory demyelinating polyradiculoneuropathy	7	11%	3	5%	6	10%	28	45%	18	29%	62	100%
Rett syndrome	9	15%	0	0%	13	22%	11	18%	27	45%	60	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 7.793,7 ; dof= 6.688.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / …psihološka podrška

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	…PSIHOLOŠKA PODRŠKA										TOTAL	
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO			
	N	%	N	%	N	%	N	%	N	%	N	%
Abdominal surgical diseases	25	10%	27	11%	35	15%	55	23%	97	41%	**239**	**100%**
Allergic diseases	0	0%	0	0%	0	0%	1	33%	2	67%	**3**	**100%**
Bone diseases	62	8%	66	8%	76	10%	231	29%	364	46%	**799**	**100%**
Cardiac diseases	49	7%	57	9%	55	8%	229	35%	270	41%	**660**	**100%**
Cardiac malformations	36	12%	17	6%	32	11%	64	22%	146	49%	**295**	**100%**
Circulatory system diseases	87	6%	89	7%	92	7%	533	39%	550	41%	**1.351**	**100%**
Clinical sign	0	0%	0	0%	0	0%	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	250	7%	269	8%	318	10%	1.041	31%	1.469	44%	**3.347**	**100%**
Diseases due to toxic effects	0	0%	0	0%	0	0%	1	33%	2	67%	**3**	**100%**
Endocrine diseases	75	8%	89	9%	82	8%	303	30%	446	45%	**995**	**100%**
Gastroenterological diseases	32	10%	44	14%	34	11%	67	22%	128	42%	**305**	**100%**
Genetic diseases	450	8%	498	9%	497	9%	1.637	30%	2.365	43%	**5.447**	**100%**
Gynecologic/obstetric diseases	22	8%	33	12%	22	8%	70	25%	137	48%	**284**	**100%**
Hematological diseases	40	10%	36	9%	48	12%	110	27%	178	43%	**412**	**100%**
Hepatic diseases	58	7%	78	9%	53	6%	408	46%	294	33%	**891**	**100%**
Immunological diseases	28	10%	21	7%	27	9%	77	27%	133	47%	**286**	**100%**
Inborn errors of metabolism	79	10%	71	9%	69	9%	224	29%	331	43%	**774**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 478,4 ; dof= 136.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Abdominal surgical diseases	43	18%	8	3%	30	13%	35	15%	123	51%	**239**	**100%**
Allergic diseases	0	0%	0	0%	1	33%	2	67%	0	0%	**3**	**100%**
Bone diseases	165	21%	30	4%	127	16%	114	14%	363	45%	**799**	**100%**
Cardiac diseases	168	25%	31	5%	94	14%	103	16%	264	40%	**660**	**100%**
Cardiac malformations	71	24%	11	4%	51	17%	37	13%	125	42%	**295**	**100%**
Circulatory system diseases	315	23%	44	3%	194	14%	256	19%	542	40%	**1.351**	**100%**
Clinical sign	0	0%	0	0%	0	0%	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	642	19%	93	3%	461	14%	495	15%	1.656	49%	**3.347**	**100%**
Diseases due to toxic effects	0	0%	1	33%	0	0%	1	33%	1	33%	**3**	**100%**
Endocrine diseases	204	21%	36	4%	147	15%	150	15%	458	46%	**995**	**100%**
Gastroenterological diseases	95	31%	14	5%	44	14%	37	12%	115	38%	**305**	**100%**
Genetic diseases	1.100	20%	192	4%	773	14%	811	15%	2.571	47%	**5.447**	**100%**
Gynecologic/obstetric diseases	67	24%	11	4%	32	11%	39	14%	135	48%	**284**	**100%**
Hematological diseases	93	23%	21	5%	51	12%	64	16%	183	44%	**412**	**100%**
Hepatic diseases	256	29%	33	4%	100	11%	204	23%	298	33%	**891**	**100%**
Immunological diseases	55	19%	10	3%	57	20%	43	15%	121	42%	**286**	**100%**
Inborn errors of metabolism	197	25%	38	5%	110	14%	108	14%	321	41%	**774**	**100%**
Infectious diseases	3	18%	0	0%	3	18%	2	12%	9	53%	**17**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 611,4 ; dof= 136.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphanet classification of rare diseases (one disease can be classified in several categories) / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

ORPHANET CLASSIFICATION OF RARE DISEASES (ONE DISEASE CAN BE CLASSIFIED IN SEVERAL CATEGORIES)	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Abdominal surgical diseases	31	13%	6	3%	30	13%	68	29%	102	43%	**237**	**100%**
Allergic diseases	1	33%	0	0%	0	0%	2	67%	0	0%	**3**	**100%**
Bone diseases	128	16%	11	1%	104	13%	236	30%	313	40%	**792**	**100%**
Cardiac diseases	89	14%	18	3%	50	8%	280	42%	222	34%	**659**	**100%**
Cardiac malformations	64	22%	7	2%	41	14%	67	23%	116	39%	**295**	**100%**
Circulatory system diseases	179	13%	27	2%	113	8%	547	41%	474	35%	**1.340**	**100%**
Clinical sign	0	0%	0	0%	0	0%	0	0%	0	0%	**0**	**100%**
Developmental anomalies during embryogenesis	459	14%	64	2%	410	12%	1.027	31%	1.366	41%	**3.326**	**100%**
Diseases due to toxic effects	0	0%	0	0%	0	0%	1	33%	2	67%	**3**	**100%**
Endocrine diseases	128	13%	19	2%	113	11%	395	40%	331	34%	**986**	**100%**
Gastroenterological diseases	59	19%	8	3%	52	17%	79	26%	107	35%	**305**	**100%**
Genetic diseases	771	14%	115	2%	688	13%	1.751	32%	2.093	39%	**5.418**	**100%**
Gynecologic/obstetric diseases	47	17%	12	4%	32	11%	94	34%	94	34%	**279**	**100%**
Hematological diseases	62	15%	9	2%	51	12%	140	34%	148	36%	**410**	**100%**
Hepatic diseases	153	17%	20	2%	73	8%	417	47%	225	25%	**888**	**100%**
Immunological diseases	42	15%	7	2%	50	18%	68	24%	114	41%	**281**	**100%**
Inborn errors of metabolism	123	16%	25	3%	100	13%	250	32%	274	35%	**772**	**100%**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 578,9 ; dof= 136.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / …psihološka podrška

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	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)	790	9%	835	9%	773	9%	2.827	31%	3.823	42%	**9.048**	**100%**
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	61	8%	66	9%	89	12%	185	24%	359	47%	**760**	**100%**
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	25	8%	22	7%	54	18%	69	23%	136	44%	**306**	**100%**
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	44	13%	28	8%	35	10%	80	23%	161	46%	**348**	**100%**
Ostalo, navesti	2	8%	4	17%	1	4%	4	17%	13	54%	**24**	**100%**
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 75,7 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.										
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	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)	1.935	21%	348	4%	1.262	14%	1.439	16%	4.064	45%	9.048	100%
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	62	8%	19	3%	97	13%	102	13%	480	63%	760	100%
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	35	11%	15	5%	45	15%	31	10%	180	59%	306	100%
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	49	14%	8	2%	56	16%	48	14%	187	54%	348	100%
Ostalo, navesti	2	8%	1	4%	3	13%	7	29%	11	46%	24	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 165,3 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	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)	1.257	14%	210	2%	1.032	11%	3.180	35%	3.311	37%	8.990	100%
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	67	9%	14	2%	75	10%	207	28%	388	52%	751	100%
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	31	10%	9	3%	51	17%	66	22%	148	49%	305	100%
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	47	14%	9	3%	66	19%	86	25%	137	40%	345	100%
Ostalo, navesti	3	14%	1	5%	8	36%	5	23%	5	23%	22	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 140,5 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Point prevalence of the rare disease / …psihološka podrška

POINT PREVALENCE OF THE RARE DISEASE	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	194	8%	199	8%	192	8%	823	34%	999	42%	**2.407**	**100%**
1-9 / 100 000	157	8%	215	11%	174	9%	609	30%	844	42%	**1.999**	**100%**
1-9 / 1 000 000	38	8%	51	11%	36	8%	132	29%	202	44%	**459**	**100%**
<1 / 1 000 000	81	9%	62	7%	96	11%	256	30%	361	42%	**856**	**100%**
TOTAL	**470**	**8%**	**527**	**9%**	**498**	**9%**	**1.820**	**32%**	**2.406**	**42%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 31,3 ; dof= 12.

Cross: Point prevalence of the rare disease / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

POINT PREVALENCE OF THE RARE DISEASE	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	525	22%	85	4%	328	14%	379	16%	1.090	45%	**2.407**	**100%**
1-9 / 100 000	422	21%	82	4%	276	14%	325	16%	894	45%	**1.999**	**100%**
1-9 / 1 000 000	98	21%	14	3%	67	15%	66	14%	214	47%	**459**	**100%**
<1 / 1 000 000	170	20%	32	4%	126	15%	129	15%	399	47%	**856**	**100%**

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 1,0 ; Chi2= 5,2 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Point prevalence of the rare disease / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

POINT PREVALENCE OF THE RARE DISEASE	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	295	12%	56	2%	249	10%	940	39%	858	36%	**2.398**	**100%**
1-9 / 100 000	273	14%	47	2%	218	11%	694	35%	760	38%	**1.992**	**100%**
1-9 / 1 000 000	77	17%	13	3%	49	11%	142	31%	172	38%	**453**	**100%**
<1 / 1 000 000	117	14%	12	1%	121	14%	282	33%	319	37%	**851**	**100%**
TOTAL	**762**	**13%**	**128**	**2%**	**637**	**11%**	**2.058**	**36%**	**2.109**	**37%**	**5.694**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,9 ; dof= 12.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …psihološka podrška

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	544	9%	599	10%	458	8%	2.009	33%	2.493	41%	**6.103**	**100%**
4-7 body parts	281	9%	242	8%	317	10%	864	28%	1.377	45%	**3.081**	**100%**
8-11 body parts	66	7%	80	8%	129	14%	226	24%	450	47%	**951**	**100%**
12-15 body parts	24	8%	26	9%	38	13%	56	20%	142	50%	**286**	**100%**
16 body parts or more	7	11%	8	12%	10	15%	10	15%	30	46%	**65**	**100%**
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 129,6 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	1.316	22%	266	4%	764	13%	1.113	18%	2.644	43%	6.103	100%
4-7 body parts	597	19%	97	3%	486	16%	387	13%	1.514	49%	3.081	100%
8-11 body parts	136	14%	20	2%	156	16%	115	12%	524	55%	951	100%
12-15 body parts	30	10%	4	1%	41	14%	12	4%	199	70%	286	100%
16 body parts or more	4	6%	4	6%	16	25%	0	0%	41	63%	65	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 245,7 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	855	14%	169	3%	630	10%	2.368	39%	2.037	34%	6.059	100%
4-7 body parts	428	14%	55	2%	408	13%	931	30%	1.237	40%	3.059	100%
8-11 body parts	98	10%	16	2%	140	15%	201	21%	491	52%	946	100%
12-15 body parts	23	8%	1	0%	40	14%	40	14%	181	64%	285	100%
16 body parts or more	1	2%	2	3%	14	22%	4	6%	43	67%	64	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 363,7 ; dof= 16.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / …psihološka podrška

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	293	10%	226	8%	386	13%	608	21%	1.444	49%	2.957	100%
Ne	597	8%	689	10%	523	7%	2.425	34%	2.851	40%	7.085	100%
Ne znam	32	7%	40	9%	43	10%	132	30%	197	44%	444	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 255,9 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	551	19%	92	3%	488	17%	321	11%	1.505	51%	2.957	100%
Ne	1.464	21%	280	4%	913	13%	1.236	17%	3.192	45%	7.085	100%
Ne znam	68	15%	19	4%	62	14%	70	16%	225	51%	444	100%

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 108,0 ; dof= 8.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	412	14%	53	2%	470	16%	696	24%	1.297	44%	2.928	100%
Ne	958	14%	182	3%	708	10%	2.719	39%	2.476	35%	7.043	100%
Ne znam	35	8%	8	2%	54	12%	129	29%	216	49%	442	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 275,3 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / …psihološka podrška

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	292	10%	231	8%	375	13%	626	21%	1.412	48%	2.936	100%
Ne	604	8%	696	10%	548	8%	2.446	34%	2.942	41%	7.236	100%
Ne znam	26	8%	28	9%	29	9%	93	30%	138	44%	314	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 210,3 ; dof= 8.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	502	17%	84	3%	501	17%	281	10%	1.568	53%	2.936	100%
Ne	1.517	21%	297	4%	918	13%	1.301	18%	3.203	44%	7.236	100%
Ne znam	64	20%	10	3%	44	14%	45	14%	151	48%	314	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 186,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	430	15%	50	2%	503	17%	626	21%	1.304	45%	2.913	100%
Ne	943	13%	182	3%	681	9%	2.822	39%	2.559	36%	7.187	100%
Ne znam	32	10%	11	4%	48	15%	96	31%	126	40%	313	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 363,5 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / …psihološka podrška

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	494	8%	501	8%	588	10%	1.661	28%	2.696	45%	5.940	100%
Ne	372	10%	391	10%	293	8%	1.265	33%	1.467	39%	3.788	100%
Ne znam	56	7%	63	8%	71	9%	239	32%	329	43%	758	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 76,5 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.048	18%	184	3%	862	15%	812	14%	3.034	51%	5.940	100%
Ne	864	23%	174	5%	487	13%	718	19%	1.545	41%	3.788	100%
Ne znam	171	23%	33	4%	114	15%	97	13%	343	45%	758	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 152,2 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	705	12%	111	2%	721	12%	1.941	33%	2.419	41%	5.897	100%
Ne	584	16%	107	3%	408	11%	1.363	36%	1.298	35%	3.760	100%
Ne znam	116	15%	25	3%	103	14%	240	32%	272	36%	756	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 77,4 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / …psihološka podrška

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	625	9%	622	9%	710	10%	1.968	28%	3.095	44%	7.020	100%
Ne	245	8%	284	10%	191	7%	1.043	36%	1.153	40%	2.916	100%
Ne znam	52	9%	49	9%	51	9%	154	28%	244	44%	550	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 83,5 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.257	18%	234	3%	982	14%	1.009	14%	3.538	50%	7.020	100%
Ne	702	24%	135	5%	396	14%	541	19%	1.142	39%	2.916	100%
Ne znam	124	23%	22	4%	85	15%	77	14%	242	44%	550	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 132,7 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	838	12%	146	2%	794	11%	2.295	33%	2.892	42%	6.965	100%
Ne	466	16%	80	3%	340	12%	1.106	38%	906	31%	2.898	100%
Ne znam	101	18%	17	3%	98	18%	143	26%	191	35%	550	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 143,7 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / …psihološka podrška

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	451	10%	403	9%	487	10%	1.202	26%	2.105	45%	4.648	100%
Ne	422	8%	507	10%	390	7%	1.786	34%	2.146	41%	5.251	100%
Ne znam	49	8%	45	8%	75	13%	177	30%	241	41%	587	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 112,6 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	907	20%	148	3%	691	15%	592	13%	2.310	50%	4.648	100%
Ne	1.067	20%	218	4%	673	13%	956	18%	2.337	45%	5.251	100%
Ne znam	109	19%	25	4%	99	17%	79	13%	275	47%	587	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 82,6 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	567	12%	95	2%	605	13%	1.386	30%	1.953	42%	4.606	100%
Ne	760	15%	134	3%	533	10%	1.992	38%	1.802	35%	5.221	100%
Ne znam	78	13%	14	2%	94	16%	166	28%	234	40%	586	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 131,7 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / …psihološka podrška

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
0-1	125	10%	146	11%	66	5%	538	41%	430	33%	1.305	100%
između 2 i 4	429	9%	413	9%	319	7%	1.572	34%	1.836	40%	4.569	100%
između 5 i 7	173	9%	184	9%	220	11%	532	26%	924	45%	2.033	100%
između 8 i 10	59	7%	62	8%	84	11%	182	23%	404	51%	791	100%
više od 10	136	8%	150	8%	263	15%	341	19%	898	50%	1.788	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 385,8 ; dof= 16.

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
0-1	355	27%	67	5%	144	11%	318	24%	421	32%	1.305	100%
između 2 i 4	1.114	24%	213	5%	604	13%	839	18%	1.799	39%	4.569	100%
između 5 i 7	354	17%	65	3%	329	16%	242	12%	1.043	51%	2.033	100%
između 8 i 10	109	14%	14	2%	123	16%	85	11%	460	58%	791	100%
više od 10	151	8%	32	2%	263	15%	143	8%	1.199	67%	1.788	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 767,9 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko ste različitih zdravstvenih djelatnika konzultirali (osobno ili virtualno) dok ste tragali za dijagnozom? / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

KOLIKO STE RAZLIČITIH ZDRAVSTVENIH DJELATNIKA KONZULTIRALI (OSOBNO ILI VIRTUALNO) DOK STE TRAGALI ZA DIJAGNOZOM?	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
0-1	219	17%	47	4%	96	7%	553	43%	384	30%	1.299	100%
između 2 i 4	691	15%	127	3%	458	10%	1.815	40%	1.452	32%	4.543	100%
između 5 i 7	243	12%	44	2%	281	14%	626	31%	824	41%	2.018	100%
između 8 i 10	89	11%	12	2%	93	12%	213	27%	373	48%	780	100%
više od 10	163	9%	13	1%	304	17%	337	19%	956	54%	1.773	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 585,4 ; dof= 16.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …psihološka podrška

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	643	11%	653	11%	567	9%	1.812	30%	2.323	39%	5.998	100%
Ne	276	6%	300	7%	376	9%	1.338	30%	2.125	48%	4.415	100%
TOTAL	**919**	**9%**	**953**	**9%**	**943**	**9%**	**3.150**	**30%**	**4.448**	**43%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 159,2 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.519	25%	268	4%	902	15%	951	16%	2.358	39%	5.998	100%
Ne	550	12%	120	3%	547	12%	668	15%	2.530	57%	4.415	100%
TOTAL	**2.069**	**20%**	**388**	**4%**	**1.449**	**14%**	**1.619**	**16%**	**4.888**	**47%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 421,9 ; dof= 4.

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	974	16%	168	3%	727	12%	2.067	34%	2.062	34%	5.998	100%
Ne	431	10%	75	2%	505	11%	1.477	33%	1.927	44%	4.415	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 151,1 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …psihološka podrška

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	168	9%	183	9%	157	8%	601	31%	841	43%	**1.950**	**100%**
DA, nekoliko puta	321	7%	329	7%	533	12%	1.117	25%	2.220	49%	**4.520**	**100%**
NE	433	11%	443	11%	262	7%	1.447	36%	1.431	36%	**4.016**	**100%**
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 314,6 ; dof= 8.

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	446	23%	90	5%	296	15%	289	15%	829	43%	**1.950**	**100%**
DA, nekoliko puta	559	12%	104	2%	667	15%	478	11%	2.712	60%	**4.520**	**100%**
NE	1.078	27%	197	5%	500	12%	860	21%	1.381	34%	**4.016**	**100%**
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 758,6 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	269	14%	48	2%	220	11%	699	36%	696	36%	1.932	100%
DA, nekoliko puta	448	10%	63	1%	582	13%	1.259	28%	2.129	48%	4.481	100%
NE	688	17%	132	3%	430	11%	1.586	40%	1.164	29%	4.000	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 400,0 ; dof= 8.

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …psihološka podrška

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	113	9%	114	9%	128	10%	384	31%	507	41%	1.246	100%
DA, nekoliko puta	338	7%	356	7%	565	11%	1.135	23%	2.540	51%	4.934	100%
NE	471	11%	485	11%	259	6%	1.646	38%	1.445	34%	4.306	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 512,9 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	253	20%	48	4%	203	16%	212	17%	530	43%	1.246	100%
DA, nekoliko puta	567	11%	108	2%	693	14%	503	10%	3.063	62%	4.934	100%
NE	1.263	29%	235	5%	567	13%	912	21%	1.329	31%	4.306	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.105,3 ; dof= 8.

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / …financijska potpora, uključujući pogodnosti socijalnog osiguranja

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	175	14%	32	3%	141	11%	444	36%	440	36%	1.232	100%
DA, nekoliko puta	433	9%	67	1%	618	13%	1.381	28%	2.401	49%	4.900	100%
NE	797	19%	144	3%	473	11%	1.719	40%	1.148	27%	4.281	100%
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 600,7 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … psihološka podrška

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…PSIHOLOŠKA PODRŠKA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	232	9%	237	9%	205	8%	802	30%	1.207	45%	2.683	100%
DA, nekoliko puta	358	7%	376	7%	586	12%	1.271	25%	2.427	48%	5.018	100%
NE	332	12%	342	12%	161	6%	1.092	39%	858	31%	2.785	100%
TOTAL	**922**	**9%**	**955**	**9%**	**952**	**9%**	**3.165**	**30%**	**4.492**	**43%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 416,1 ; dof= 8.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd.

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	525	20%	106	4%	395	15%	423	16%	1.234	46%	2.683	100%
DA, nekoliko puta	682	14%	127	3%	744	15%	556	11%	2.909	58%	5.018	100%
NE	876	31%	158	6%	324	12%	648	23%	779	28%	2.785	100%
TOTAL	**2.083**	**20%**	**391**	**4%**	**1.463**	**14%**	**1.627**	**16%**	**4.922**	**47%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 866,1 ; dof= 8.

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / … financijska potpora, uključujući pogodnosti socijalnog osiguranja

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA											
	DA, I TO DOVOLJNO ZA MOJE POTREBE		DA, ALI NIJE POTREBNO / NIJE BILO POTREBNO		DA, ALI NE DOVOLJNO DA ZADOVOLJI MOJE POTREBE		NE, ALI NIJE POTREBNO / NIJE BILO POTREBNO		NE, ALI JE POTREBNO / JE BILO POTREBNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	339	13%	61	2%	306	11%	958	36%	1.005	38%	**2.669**	**100%**
DA, nekoliko puta	526	11%	79	2%	633	13%	1.443	29%	2.291	46%	**4.972**	**100%**
NE	540	19%	103	4%	293	11%	1.143	41%	693	25%	**2.772**	**100%**
TOTAL	**1.405**	**13%**	**243**	**2%**	**1.232**	**12%**	**3.544**	**34%**	**3.989**	**38%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 436,6 ; dof= 8.

Chapter 13.

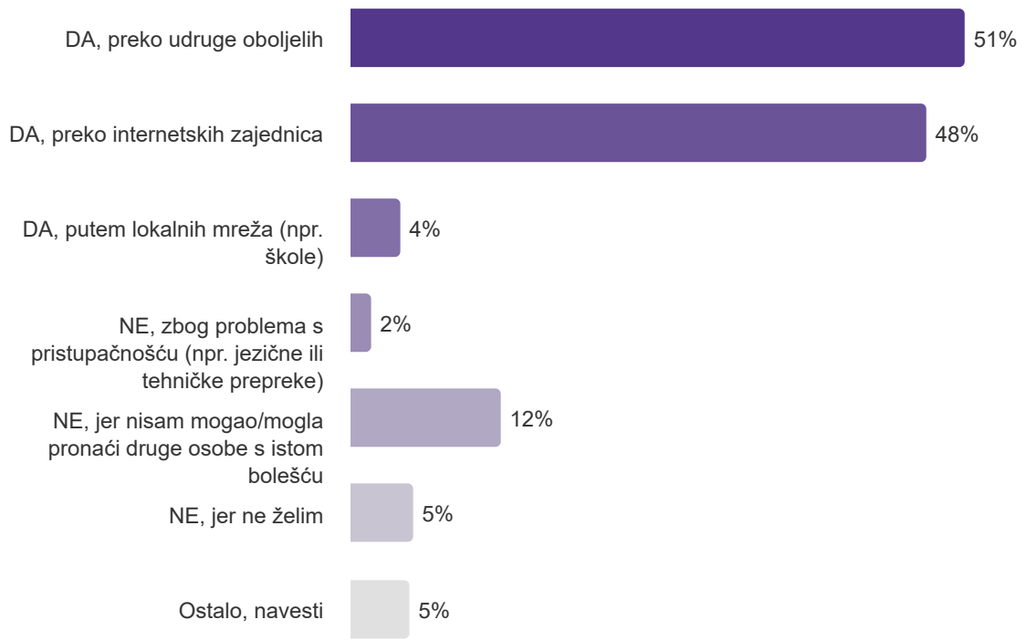
Support

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	N
DA, preko udruge oboljelih	5.326
DA, preko internetskih zajednica	4.992
DA, putem lokalnih mreža (npr. škole)	436
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	190
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	1.310
NE, jer ne želim	547
Ostalo, navesti	514
TOTAL	**10.486**

Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?



Respondents could choose several items

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
DA, preko udruge oboljelih	0,5	4.097	3,7	3.923	4,1	2.416	3,6	4.165	5,0	3.558
DA, preko internetskih zajednica	0,3	3.852	3,9	3.657	4,0	2.100	4,0	3.887	4,9	3.213
DA, putem lokalnih mreža (npr. škole)	0,1	321	4,4	298	4,8	175	4,7	334	5,3	274
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	0,3	126	3,0	114	5,5	72	5,7	124	7,6	96
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	0,6	923	2,6	811	3,1	468	3,9	848	4,4	664
NE, jer ne želim	1,0	368	2,9	339	2,9	222	2,4	361	3,9	299
Ostalo, navesti	0,5	372	3,8	340	4,8	210	3,3	371	5,3	328

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,6 ; Fisher= 0,8.
Inter variance= 38,6. Intra variance= 48,2.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li... / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
JESTE LI...	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Bolesnik	3.481	51%	3.358	50%	240	4%	96	1%	791	12%	356	5%	338	5%	**6.772**	
Bivši bolesnik ili bolesnik na oporavku (npr. preživjeli od raka)	108	44%	94	38%	13	5%	5	2%	39	16%	35	14%	11	4%	**247**	
Roditelj osobe koja živi s rijetkom bolešću	1.560	51%	1.416	46%	160	5%	74	2%	410	13%	121	4%	136	4%	**3.078**	
Djed/baka osobe s rijetkom bolešću	22	55%	18	45%	5	13%	1	3%	5	13%	3	8%	0	0%	**40**	
Bračni partner osobe s rijetkom bolešću	81	44%	56	30%	9	5%	8	4%	37	20%	16	9%	11	6%	**186**	
Stric/ujak ili tetka osobe s rijetkom bolešću	15	65%	7	30%	3	13%	0	0%	3	13%	1	4%	0	0%	**23**	
Brat ili sestra osobe koja živi s rijetkom bolešću	25	52%	16	33%	1	2%	2	4%	2	4%	6	13%	5	10%	**48**	
Ostalo, navesti	34	37%	27	29%	5	5%	4	4%	23	25%	9	10%	13	14%	**92**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 208,5 ; dof= 42.

Respondents can be:

- **patients themselves** (directly affected by the rare disease, or recovering from the rare disease).

- **or family members of patients** (parents, grand-parents, spouses, uncles/aunts, siblings or other family member).

Cross: Age of the person affected by the rare disease when the first symptoms were noticed (calculated variable) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

AGE OF THE PERSON AFFECTED BY THE RARE DISEASE WHEN THE FIRST SYMPTOMS WERE NOTICED (CALCULATED VARIABLE)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Less than 2 years old	1.135	56%	998	49%	113	6%	41	2%	235	11%	65	3%	84	4%	**2.045**	
2 to less that 10 years old	478	52%	419	45%	45	5%	30	3%	121	13%	45	5%	50	5%	**925**	
10 to less than 20 years old	477	50%	515	54%	52	5%	11	1%	104	11%	49	5%	48	5%	**952**	
20 to less than 30 years old	471	48%	505	52%	36	4%	7	1%	116	12%	66	7%	48	5%	**978**	
30 to less than 50 years old	1.228	52%	1.167	50%	76	3%	30	1%	270	11%	101	4%	115	5%	**2.353**	
50 years old or more	547	49%	487	44%	31	3%	15	1%	149	13%	66	6%	68	6%	**1.107**	
TOTAL	**4.336**	**52%**	**4.091**	**49%**	**353**	**4%**	**134**	**2%**	**995**	**12%**	**392**	**5%**	**413**	**5%**	**8.360**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 109,4 ; dof= 30.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	185	47%	166	42%	17	4%	12	3%	58	15%	19	5%	21	5%	**391**	
između 16 i 19 godina	1.139	47%	1.128	47%	100	4%	46	2%	322	13%	121	5%	129	5%	**2.420**	
između 20 i 23 godine	1.588	54%	1.367	46%	121	4%	51	2%	364	12%	144	5%	138	5%	**2.955**	
24 godine ili više	1.547	55%	1.429	51%	121	4%	36	1%	311	11%	127	4%	153	5%	**2.827**	
još uvijek na studiju	220	45%	252	51%	29	6%	13	3%	65	13%	39	8%	24	5%	**494**	
TOTAL	**4.679**	**51%**	**4.342**	**48%**	**388**	**4%**	**158**	**2%**	**1.120**	**12%**	**450**	**5%**	**465**	**5%**	**9.087**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 67,3 ; dof= 24.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Jeste li: / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
JESTE LI:	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Žena	3.891	49%	3.952	50%	317	4%	137	2%	985	12%	381	5%	390	5%	**7.930**	
Muškarac	1.111	61%	725	40%	92	5%	33	2%	207	11%	112	6%	86	5%	**1.807**	
Ostalo	28	50%	29	52%	2	4%	1	2%	6	11%	3	5%	5	9%	**56**	
TOTAL	**5.030**	**51%**	**4.706**	**48%**	**411**	**4%**	**171**	**2%**	**1.198**	**12%**	**496**	**5%**	**481**	**5%**	**9.793**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 86,4 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	211	46%	201	44%	19	4%	14	3%	63	14%	25	5%	26	6%	**455**	
između 16 i 19 godina	1.154	47%	1.144	46%	102	4%	47	2%	333	14%	127	5%	130	5%	**2.464**	
između 20 i 23 godine	1.614	53%	1.399	46%	125	4%	54	2%	373	12%	153	5%	141	5%	**3.022**	
24 godine ili više	1.700	54%	1.598	51%	142	5%	43	1%	350	11%	145	5%	168	5%	**3.145**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 47,4 ; dof= 18.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

KAKO BISTE NAJBOLJE OPISALI SEBE?	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	3.714	52%	3.533	50%	307	4%	111	2%	825	12%	316	4%	352	5%	**7.125**	
Dio sam etničke manjine u zemlji u kojoj živim	179	38%	214	46%	23	5%	16	3%	87	19%	26	6%	22	5%	**465**	
Ostalo, navesti	139	41%	140	42%	12	4%	8	2%	58	17%	24	7%	30	9%	**337**	
TOTAL	**4.032**	**51%**	**3.887**	**49%**	**342**	**4%**	**135**	**2%**	**970**	**12%**	**366**	**5%**	**404**	**5%**	**7.927**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 79,7 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: U kojoj državi živite? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
U KOJOJ DRŽAVI ŽIVITE?	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Austrija	52	55%	53	56%	5	5%	2	2%	10	11%	3	3%	3	3%	**94**	
Belgija	431	49%	334	38%	32	4%	20	2%	157	18%	53	6%	63	7%	**882**	
Bosna i Hercegovina	8	28%	13	45%	3	10%	2	7%	10	34%	0	0%	0	0%	**29**	
Bugarska	61	59%	63	61%	2	2%	1	1%	10	10%	1	1%	4	4%	**104**	
Hrvatska	64	30%	113	54%	7	3%	5	2%	46	22%	2	1%	4	2%	**210**	
Kipar	25	35%	31	44%	2	3%	4	6%	23	32%	5	7%	1	1%	**71**	
Češka Republika	64	32%	103	52%	4	2%	11	6%	38	19%	11	6%	7	4%	**199**	
Danska	189	53%	189	53%	20	6%	3	1%	43	12%	17	5%	24	7%	**356**	
Finska	235	49%	326	68%	13	3%	7	1%	49	10%	14	3%	23	5%	**482**	
Francuska	544	60%	331	37%	33	4%	15	2%	113	12%	63	7%	51	6%	**906**	
Njemačka	702	60%	569	49%	66	6%	15	1%	94	8%	51	4%	57	5%	**1.168**	
Grčka	83	45%	96	52%	5	3%	9	5%	24	13%	6	3%	8	4%	**183**	
Mađarska	75	46%	94	58%	3	2%	3	2%	10	6%	8	5%	3	2%	**162**	
Irska	32	30%	75	71%	2	2%	1	1%	13	12%	5	5%	1	1%	**105**	
Italija	570	53%	460	43%	21	2%	9	1%	121	11%	53	5%	52	5%	**1.080**	
Letonija	13	19%	25	36%	4	6%	7	10%	26	37%	4	6%	6	9%	**70**	
Luksemburg	45	36%	48	39%	6	5%	1	1%	36	29%	8	6%	5	4%	**124**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.071,6 ; dof= 192.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	698	39%	947	53%	63	4%	64	4%	292	16%	92	5%	53	3%	**1.794**	
Group B ('Western Europe')	2.857	56%	2.217	43%	230	5%	70	1%	550	11%	253	5%	235	5%	**5.105**	
Group C ('Northern Europe')	1.632	50%	1.704	52%	130	4%	50	2%	422	13%	177	5%	206	6%	**3.273**	
TOTAL	**5.187**	**51%**	**4.868**	**48%**	**423**	**4%**	**184**	**2%**	**1.264**	**12%**	**522**	**5%**	**494**	**5%**	**10.172**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 222,1 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Orphacode associated nomenclature (english) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

ORPHACODE ASSOCIATED NOMENCLATURE (ENGLISH)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Hereditary hemorrhagic telangiectasia	278	61%	174	38%	10	2%	1	0%	32	7%	30	7%	50	11%	**458**	
Hypermobile Ehlers-Danlos syndrome	169	53%	233	74%	23	7%	7	2%	6	2%	16	5%	17	5%	**317**	
Sarcoidosis	72	42%	78	46%	6	4%	2	1%	24	14%	13	8%	8	5%	**170**	
Classical Ehlers-Danlos syndrome	62	45%	88	64%	9	7%	2	1%	8	6%	10	7%	7	5%	**137**	
Williams syndrome	93	68%	63	46%	9	7%	1	1%	3	2%	2	1%	4	3%	**136**	
Cystic fibrosis	80	63%	78	61%	10	8%	1	1%	2	2%	10	8%	4	3%	**128**	
Myasthenia gravis	63	53%	79	66%	2	2%	2	2%	8	7%	1	1%	3	3%	**120**	
Systemic sclerosis	60	56%	68	64%	3	3%	1	1%	8	7%	5	5%	5	5%	**107**	
Tuberous sclerosis complex	50	51%	37	38%	3	3%	2	2%	12	12%	7	7%	3	3%	**98**	
Neurofibromatosis type 1	46	50%	49	53%	7	8%	0	0%	8	9%	8	9%	6	7%	**92**	
Interstitial cystitis	48	65%	22	30%	2	3%	1	1%	8	11%	3	4%	6	8%	**74**	
Addison disease	35	48%	43	59%	2	3%	2	3%	6	8%	3	4%	4	5%	**73**	
22q11.2 deletion syndrome	47	69%	26	38%	2	3%	3	4%	5	7%	1	1%	3	4%	**68**	
Chronic inflammatory demyelinating polyneuropathy	33	51%	31	48%	4	6%	0	0%	8	12%	6	9%	4	6%	**65**	
Perineural cyst	41	65%	41	65%	1	2%	0	0%	5	8%	0	0%	1	2%	**63**	
Acute inflammatory demyelinating	19	31%	28	45%	2	3%	0	0%	8	13%	13	21%	3	5%	**62**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.385,7 ; dof= 888.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete: / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

MOLIMO ODABERITE REČENICU KOJA NAJBOLJE OPISUJE VAŠU SITUACIJU ILI SITUACIJU OSOBE O KOJOJ SE BRINETE:	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJ BOLEŠĆU?														
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOT
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	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)	4.770	53%	4.356	48%	383	4%	144	2%	991	11%	470	5%	441	5%	**9.048**
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	356	47%	399	53%	31	4%	17	2%	93	12%	33	4%	37	5%	**760**
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	96	31%	118	39%	10	3%	16	5%	89	29%	21	7%	15	5%	**306**
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	98	28%	111	32%	11	3%	12	3%	133	38%	20	6%	16	5%	**348**
Ostalo, navesti	6	25%	8	33%	1	4%	1	4%	4	17%	3	13%	5	21%	**24**
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 416,1 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetic diseases / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
GENETIC DISEASES	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Genetic diseases	2.991	55%	2.660	49%	261	5%	98	2%	545	10%	244	4%	301	6%	5.447	
Non Genetic diseases	1.290	49%	1.274	48%	81	3%	40	2%	327	12%	158	6%	105	4%	2.627	
TOTAL	**4.281**	**53%**	**3.934**	**49%**	**342**	**4%**	**138**	**2%**	**872**	**11%**	**402**	**5%**	**406**	**5%**	**8.074**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 50,7 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

POINT PREVALENCE OF THE RARE DISEASE	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	1.376	57%	1.196	50%	108	4%	27	1%	186	8%	124	5%	150	6%	2.407	
1-9 / 100 000	1.081	54%	1.029	51%	91	5%	29	1%	181	9%	100	5%	98	5%	1.999	
1-9 / 1 000 000	246	54%	228	50%	17	4%	11	2%	51	11%	20	4%	23	5%	459	
<1 / 1 000 000	397	46%	395	46%	33	4%	21	2%	136	16%	39	5%	40	5%	856	
TOTAL	**3.100**	**54%**	**2.848**	**50%**	**249**	**4%**	**88**	**2%**	**554**	**10%**	**283**	**5%**	**311**	**5%**	**5.721**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 79,0 ; dof= 18.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	3.045	50%	2.656	44%	225	4%	94	2%	836	14%	375	6%	306	5%	**6.103**	
4-7 body parts	1.639	53%	1.517	49%	142	5%	66	2%	349	11%	128	4%	141	5%	**3.081**	
8-11 body parts	476	50%	581	61%	45	5%	23	2%	97	10%	30	3%	43	5%	**951**	
12-15 body parts	135	47%	194	68%	18	6%	5	2%	22	8%	9	3%	20	7%	**286**	
16 body parts or more	31	48%	44	68%	6	9%	2	3%	6	9%	5	8%	4	6%	**65**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 166,3 ; dof= 24.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.546	52%	1.329	45%	156	5%	81	3%	350	12%	124	4%	160	5%	**2.957**	
Ne	3.588	51%	3.436	48%	262	4%	96	1%	889	13%	399	6%	323	5%	**7.085**	
Ne znam	192	43%	227	51%	18	4%	13	3%	71	16%	24	5%	31	7%	**444**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 71,7 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.489	51%	1.418	48%	149	5%	82	3%	379	13%	108	4%	141	5%	**2.936**	
Ne	3.694	51%	3.431	47%	277	4%	93	1%	874	12%	428	6%	358	5%	**7.236**	
Ne znam	143	46%	143	46%	10	3%	15	5%	57	18%	11	4%	15	5%	**314**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 84,3 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	3.063	52%	3.046	51%	255	4%	115	2%	667	11%	270	5%	272	5%	**5.940**	
Ne	1.919	51%	1.620	43%	154	4%	62	2%	524	14%	240	6%	193	5%	**3.788**	
Ne znam	344	45%	326	43%	27	4%	13	2%	119	16%	37	5%	49	6%	**758**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 85,1 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	3.518	50%	3.489	50%	286	4%	124	2%	869	12%	355	5%	338	5%	**7.020**	
Ne	1.558	53%	1.238	42%	119	4%	46	2%	353	12%	167	6%	148	5%	**2.916**	
Ne znam	250	45%	265	48%	31	6%	20	4%	88	16%	25	5%	28	5%	**550**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 53,0 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	2.391	51%	2.272	49%	199	4%	77	2%	600	13%	207	4%	207	4%	**4.648**	
Ne	2.673	51%	2.442	47%	210	4%	95	2%	617	12%	313	6%	278	5%	**5.251**	
Ne znam	262	45%	278	47%	27	5%	18	3%	93	16%	27	5%	29	5%	**587**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,2 ; dof= 12.

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	131	59%	95	43%	6	3%	2	1%	23	10%	15	7%	7	3%	**222**	
Ne	4.953	52%	4.623	49%	406	4%	155	2%	1.052	11%	485	5%	464	5%	**9.509**	
TOTAL	**5.084**	**52%**	**4.718**	**48%**	**412**	**4%**	**157**	**2%**	**1.075**	**11%**	**500**	**5%**	**471**	**5%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 8,1 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	243	61%	166	42%	18	5%	5	1%	33	8%	19	5%	16	4%	**396**	
Ne	4.736	52%	4.473	49%	383	4%	148	2%	1.013	11%	469	5%	445	5%	**9.139**	
TOTAL	**4.979**	**52%**	**4.639**	**49%**	**401**	**4%**	**153**	**2%**	**1.046**	**11%**	**488**	**5%**	**461**	**5%**	**9.535**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 14,1 ; dof= 6.

Only respondents living with a diagnosed rare disease

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	751	57%	576	44%	64	5%	14	1%	112	9%	71	5%	117	9%	1.309	
Ne	4.333	51%	4.142	49%	348	4%	143	2%	963	11%	429	5%	354	4%	8.422	
TOTAL	**5.084**	**52%**	**4.718**	**48%**	**412**	**4%**	**157**	**2%**	**1.075**	**11%**	**500**	**5%**	**471**	**5%**	**9.731**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 79,4 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Ja ili osoba o kojoj skrbim upućeni smo u bolničku jedinicu specijaliziranu za rijetku bolest ili skupinu rijetkih bolesti / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

JA ILI OSOBA O KOJOJ SKRBIM UPUĆENI SMO U BOLNIČKU JEDINICU SPECIJALIZIRANU ZA RIJETKU BOLEST ILI SKUPINU RIJETKIH BOLESTI	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	3.221	54%	2.810	47%	261	4%	103	2%	689	11%	348	6%	296	5%	**5.998**	
Ne	2.071	47%	2.150	49%	170	4%	86	2%	615	14%	197	4%	215	5%	**4.415**	
TOTAL	**5.292**	**51%**	**4.960**	**48%**	**431**	**4%**	**189**	**2%**	**1.304**	**13%**	**545**	**5%**	**511**	**5%**	**10.413**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 48,1 ; dof= 6.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …pogrešno pripisani barem još jednoj tjelesnoj bolesti? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…POGREŠNO PRIPISANI BAREM JOŠ JEDNOJ TJELESNOJ BOLESTI?	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	1.019	52%	885	45%	74	4%	27	1%	248	13%	97	5%	80	4%	**1.950**	
DA, nekoliko puta	2.209	49%	2.385	53%	201	4%	96	2%	567	13%	184	4%	209	5%	**4.520**	
NE	2.098	52%	1.722	43%	161	4%	67	2%	495	12%	266	7%	225	6%	**4.016**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 92,8 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …zanemareni, da ih se nije shvatilo ozbiljno i/ili ih se smatralo psihološkim? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…ZANEMARENI, DA IH SE NIJE SHVATILO OZBILJNO I/ILI IH SE SMATRALO PSIHOLOŠKIM?	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	635	51%	582	47%	54	4%	18	1%	166	13%	69	6%	59	5%	**1.246**	
DA, nekoliko puta	2.419	49%	2.608	53%	223	5%	100	2%	599	12%	202	4%	230	5%	**4.934**	
NE	2.272	53%	1.802	42%	159	4%	72	2%	545	13%	276	6%	225	5%	**4.306**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 98,4 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Has the person affected by the rare disease already been misdiagnosed? Calculated variable that computes the number of times the person affected by the rare disease was misdiagnosed. / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

HAS THE PERSON AFFECTED BY THE RARE DISEASE ALREADY BEEN MISDIAGNOSED? CALCULATED VARIABLE THAT COMPUTES THE NUMBER OF TIMES THE PERSON AFFECTED BY THE RARE DISEASE WAS MISDIAGNOSED.	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, jednom	1.389	52%	1.264	47%	103	4%	42	2%	325	12%	142	5%	128	5%	**2.683**	
DA, nekoliko puta	2.465	49%	2.602	52%	224	4%	100	2%	634	13%	215	4%	233	5%	**5.018**	
NE	1.472	53%	1.126	40%	109	4%	48	2%	351	13%	190	7%	153	5%	**2.785**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 84,3 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetska(-e) pretraga(-e) kojom/kojima se traže genetske promjene (također se nazivaju mutacije ili varijante) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

GENETSKA(-E) PRETRAGA(-E) KOJOM/KOJIMA SE TRAŽE GENETSKE PROMJENE (TAKOĐER SE NAZIVAJU MUTACIJE ILI VARIJANTE)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	2.898	53%	2.576	47%	254	5%	122	2%	704	13%	235	4%	278	5%	**5.490**	
Ne	2.063	49%	2.076	50%	155	4%	54	1%	475	11%	250	6%	187	4%	**4.171**	
Ne znam / Ne sjećam se	365	44%	340	41%	27	3%	14	2%	131	16%	62	8%	49	6%	**825**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 80,3 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …su zdravstveni djelatnici bili nevoljni ili nedovoljno informirani? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

Have you ever needed a genetic test but could not access it because...

…SU ZDRAVSTVENI DJELATNICI BILI NEVOLJNI ILI NEDOVOLJNO INFORMIRANI?	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.325	47%	1.494	53%	132	5%	70	2%	399	14%	87	3%	119	4%	**2.805**	
Ne	2.930	53%	2.502	45%	237	4%	81	1%	661	12%	322	6%	274	5%	**5.556**	
Nije bitno	1.071	50%	996	47%	67	3%	39	2%	250	12%	138	6%	121	6%	**2.125**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 105,1 ; dof= 12.

Have you ever needed a genetic test but could not access it because...

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Prema Vašim saznanjima, genetskom(-im) pretragom(-ama) koja(-)e je/su provedena(-e) tragalo se za… / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

PREMA VAŠIM SAZNANJIMA, GENETSKOM(-IM) PRETRAGOM(-AMA) KOJA(-)E JE/SU PROVEDENA(-E) TRAGALO SE ZA…	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Samo jednim genom	860	59%	681	47%	67	5%	20	1%	154	11%	55	4%	75	5%	**1.460**	
Nekoliko gena u isto vrijeme (sekvenciranje panela gena)	942	54%	858	50%	91	5%	39	2%	235	14%	44	3%	82	5%	**1.731**	
Cijelom DNK (sekvenciranje cijelog genoma)	418	48%	411	47%	47	5%	20	2%	159	18%	30	3%	35	4%	**880**	
Svim genima (sekvenciranje cijelog egzoma)	247	44%	293	52%	27	5%	12	2%	111	20%	16	3%	24	4%	**567**	
Tumorom (genetsko profiliranje tumora)	67	50%	63	47%	5	4%	4	3%	20	15%	8	6%	10	7%	**135**	
Drugim (epigenom, RNK, itd.)	59	50%	61	52%	8	7%	4	3%	22	19%	6	5%	3	3%	**117**	
Ne znam	730	48%	670	44%	56	4%	47	3%	184	12%	103	7%	96	6%	**1.511**	
TOTAL	**2.898**	**53%**	**2.576**	**47%**	**254**	**5%**	**122**	**2%**	**704**	**13%**	**235**	**4%**	**278**	**5%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 159,5 ; dof= 36.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Je li Vam ponuđeno genetsko savjetovanje nakon provedenih pretraga (npr. informacije o tome kako bi Vaše genetsko stanje moglo utjecati na Vas i Vašu obitelj)? / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

JE LI VAM PONUĐENO GENETSKO SAVJETOVANJE NAKON PROVEDENIH PRETRAGA (NPR. INFORMACIJE O TOME KAKO BI VAŠE GENETSKO STANJE MOGLO UTJECATI NA VAS I VAŠU OBITELJ)?	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, kod genetskog savjetnika ili kliničkog genetičara	1.161	54%	1.014	47%	100	5%	44	2%	271	13%	89	4%	109	5%	**2.137**	
DA, kod zdravstvenog djelatnika	697	59%	490	42%	61	5%	23	2%	116	10%	57	5%	52	4%	**1.179**	
NE, nije mi ponuđeno genetsko savjetovanje	836	47%	891	50%	78	4%	48	3%	265	15%	60	3%	89	5%	**1.770**	
Nisam siguran/sigurna / Ne sjećam se	204	50%	181	45%	15	4%	7	2%	52	13%	29	7%	28	7%	**404**	
TOTAL	**2.898**	**53%**	**2.576**	**47%**	**254**	**5%**	**122**	**2%**	**704**	**13%**	**235**	**4%**	**278**	**5%**	**5.490**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 68,0 ; dof= 18.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetska(-e) pretraga(-e) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

GENETSKA(-E) PRETRAGA(-E)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	399	48%	414	50%	48	6%	27	3%	125	15%	32	4%	33	4%	**831**	
Ne	2.434	54%	2.094	46%	202	4%	93	2%	555	12%	195	4%	240	5%	**4.515**	
Ne znam	65	45%	68	48%	4	3%	2	1%	24	17%	8	6%	4	3%	**143**	
TOTAL	**2.898**	**53%**	**2.576**	**47%**	**254**	**5%**	**122**	**2%**	**704**	**13%**	**235**	**4%**	**277**	**5%**	**5.489**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 27,3 ; dof= 12.

Cross: Drugim dijagnostičkim pretragama kao što su klinički pregled(-i), medicinsko snimanje (MRI, skeniranje…), biopsija, biokemijska(-e) pretraga(-e) (pretrage krvi ili urina…), itd. / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

DRUGIM DIJAGNOSTIČKIM PRETRAGAMA KAO ŠTO SU KLINIČKI PREGLED(-I), MEDICINSKO SNIMANJE (MRI, SKENIRANJE…), BIOPSIJA, BIOKEMIJSKA(-E) PRETRAGA(-E) (PRETRAGE KRVI ILI URINA…), ITD.	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	698	50%	696	50%	80	6%	32	2%	215	15%	63	4%	62	4%	**1.403**	
Ne	4.029	51%	3.789	48%	320	4%	127	2%	962	12%	414	5%	390	5%	**7.908**	
Ne znam	77	45%	77	45%	2	1%	5	3%	23	14%	13	8%	5	3%	**170**	
TOTAL	**4.804**	**51%**	**4.562**	**48%**	**402**	**4%**	**164**	**2%**	**1.200**	**13%**	**490**	**5%**	**457**	**5%**	**9.481**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 33,2 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Dodatnim savjetima od zdravstvenog djelatnika specijaliziranog za rijetku bolest (osobno ili virtualno) / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

DODATNIM SAVJETIMA OD ZDRAVSTVENOG DJELATNIKA SPECIJALIZIRANOG ZA RIJETKU BOLEST (OSOBNO ILI VIRTUALNO)	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.136	55%	1.099	53%	105	5%	51	2%	245	12%	76	4%	76	4%	**2.083**	
Ne	4.096	50%	3.799	46%	326	4%	130	2%	1.029	13%	453	6%	428	5%	**8.194**	
Ne znam	94	45%	94	45%	5	2%	9	4%	36	17%	18	9%	10	5%	**209**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 72,0 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …psihološka podrška / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	512	56%	435	47%	49	5%	15	2%	104	11%	47	5%	52	6%	**922**	
DA, ali nije potrebno / nije bilo potrebno	511	54%	428	45%	45	5%	14	1%	108	11%	65	7%	48	5%	**955**	
DA, ali NE dovoljno da zadovolji moje potrebe	471	49%	471	49%	41	4%	25	3%	123	13%	40	4%	45	5%	**952**	
NE, ali NIJE potrebno / NIJE bilo potrebno	1.625	51%	1.427	45%	109	3%	49	2%	377	12%	218	7%	165	5%	**3.165**	
NE, ali je potrebno / je bilo potrebno	2.207	49%	2.231	50%	192	4%	87	2%	598	13%	177	4%	204	5%	**4.492**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 78,6 ; dof= 24.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?															
	DA, PREKO UDRUGE OBOLJELIH		DA, PREKO INTERNETSKIH ZAJEDNICA		DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)		NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)		NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU		NE, JER NE ŽELIM		OSTALO, NAVESTI		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	1.215	58%	870	42%	99	5%	29	1%	216	10%	135	6%	97	5%	**2.083**	
DA, ali nije potrebno / nije bilo potrebno	200	51%	171	44%	16	4%	5	1%	45	12%	32	8%	16	4%	**391**	
DA, ali NE dovoljno da zadovolji moje potrebe	788	54%	680	46%	63	4%	32	2%	183	13%	62	4%	73	5%	**1.463**	
NE, ali NIJE potrebno / NIJE bilo potrebno	770	47%	714	44%	51	3%	18	1%	204	13%	148	9%	100	6%	**1.627**	
NE, ali je potrebno / je bilo potrebno	2.353	48%	2.557	52%	207	4%	106	2%	662	13%	170	3%	228	5%	**4.922**	
TOTAL	**5.326**	**51%**	**4.992**	**48%**	**436**	**4%**	**190**	**2%**	**1.310**	**12%**	**547**	**5%**	**514**	**5%**	**10.486**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 206,7 ; dof= 24.

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću?

	JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?							
…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	**DA, PREKO UDRUGE OBOLJELIH**	**DA, PREKO INTERNETSKIH ZAJEDNICA**	**DA, PUTEM LOKALNIH MREŽA (NPR. ŠKOLE)**	**NE, ZBOG PROBLEMA S PRISTUPAČNOŠĆU (NPR. JEZIČNE ILI TEHNIČKE PREPREKE)**	**NE, JER NISAM MOGAO/MOGLA PRONAĆI DRUGE OSOBE S ISTOM BOLEŠĆU**	**NE, JER NE ŽELIM**	**OSTALO, NAVESTI**	**TOTAL**
DA, i to dovoljno za moje potrebe	56%	44%	4%	2%	13%	6%	4%	
DA, ali nije potrebno / nije bilo potrebno	58%	40%	5%	1%	12%	7%	5%	
DA, ali NE dovoljno da zadovolji moje potrebe	49%	48%	5%	4%	14%	4%	5%	
NE, ali NIJE potrebno / NIJE bilo potrebno	53%	45%	3%	1%	11%	6%	5%	
NE, ali je potrebno / je bilo potrebno	47%	51%	5%	2%	13%	4%	5%	
TOTAL	**51%**	**48%**	**4%**	**2%**	**13%**	**5%**	**5%**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 148,2 ; dof= 24.

Chapter 15.

Consequence of being diagnosed

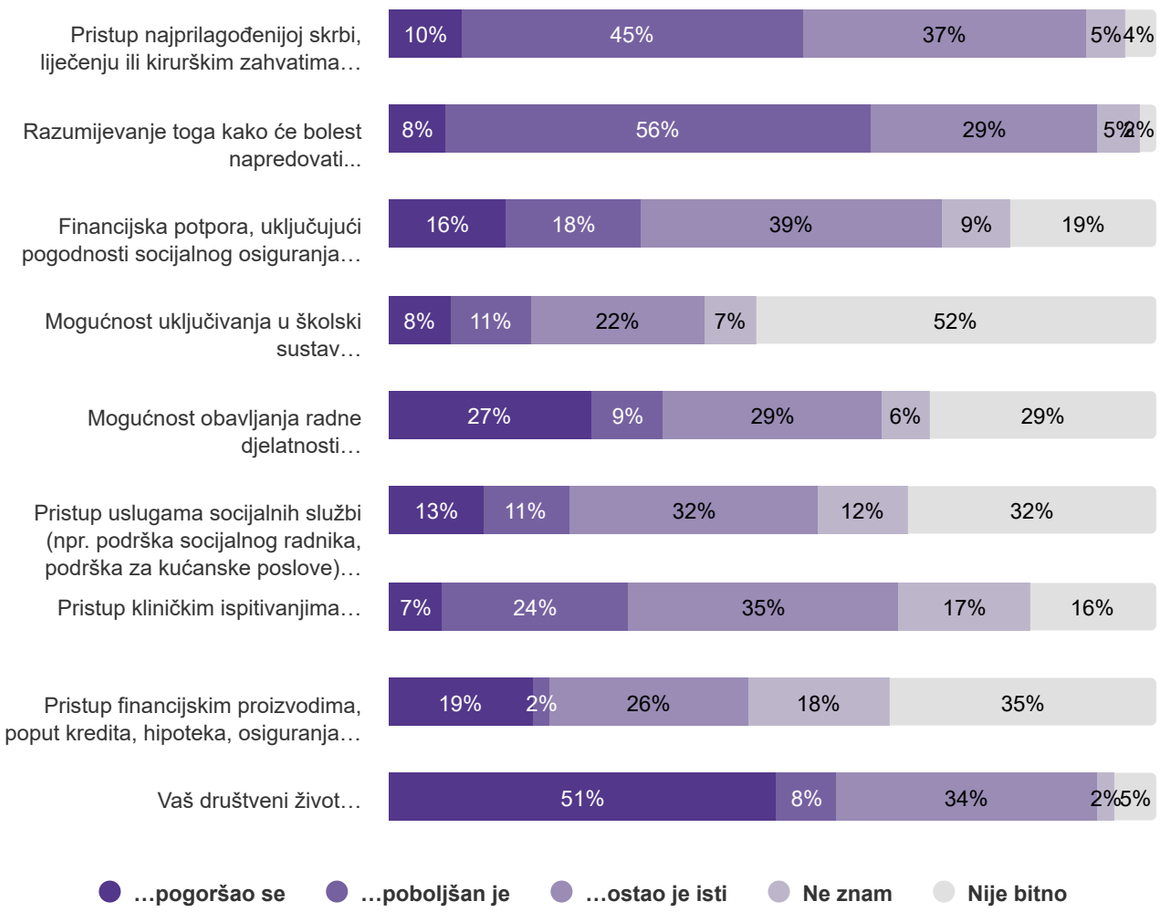
9. Consequences of diagnosis

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

	…POGOR…SE	…POBOLJ…JE	…OSTAO JE ISTI	NE ZNAM	NIJE BITNO	TOTAL
Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…	889	4.020	3.316	457	342	**9.024**
Razumijevanje toga kako će bolest napredovati...	694	4.999	2.644	494	175	**9.006**
Financijska potpora, uključujući pogodnosti socijalnog osiguranja…	928	1.056	2.345	532	1.126	**5.987**
Mogućnost uključivanja u školski sustav…	746	960	2.030	613	4.675	**9.024**
Mogućnost obavljanja radne djelatnosti…	2.411	818	2.587	551	2.638	**9.005**
Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…	1.134	1.011	2.906	1.066	2.887	**9.004**
Pristup kliničkim ispitivanjima…	637	2.197	3.173	1.564	1.452	**9.023**
Pristup financijskim proizvodima, poput kredita,	1.715	200	2.345	1.648	3.114	**9.022**

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?



*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…	**MEAN**	**N**	**MEAN**	**N**	**MEAN**	**N**	**MEAN**	**N**	**MEAN**	**N**
…pogoršao se	0,4	647	3,8	569	3,3	328	3,6	679	4,8	535
…poboljšan je	0,4	3.169	3,9	3.210	4,3	1.897	3,8	3.347	5,2	2.918
…ostao je isti	0,5	2.526	3,1	2.293	3,4	1.353	3,3	2.659	4,4	2.285
Ne znam	1,2	299	2,4	257	2,3	143	2,7	315	3,0	244
Nije bitno	0,3	239	2,6	184	2,5	110	2,8	251	4,4	195

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Fisher= 0,9.
Inter variance= 41,0. Intra variance= 44,2.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Razumijevanje toga kako će bolest napredovati...	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,3	494	3,0	447	3,0	238	3,0	533	4,2	415
…poboljšan je	0,4	3.948	3,7	3.847	4,0	2.305	3,7	4.177	4,9	3.616
…ostao je isti	0,7	1.979	3,4	1.825	3,6	1.063	3,3	2.052	4,8	1.764
Ne znam	0,6	331	3,4	286	3,0	158	3,5	356	4,6	283
Nije bitno	−0,1	118	1,0	97	1,7	61	2,8	121	2,8	91

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Fisher= 1,0.
Inter variance= 44,6. Intra variance= 44,3.

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Financijska potpora, uključujući pogodnosti socijalnog osiguranja…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,4	683	4,2	644	5,2	347	4,6	707	5,8	551
…poboljšan je	0,8	845	5,2	827	5,6	488	5,2	862	6,8	761
…ostao je isti	0,7	1.817	4,6	1.731	5,1	999	4,7	1.886	6,3	1.610
Ne znam	0,7	381	3,8	364	4,3	215	3,1	398	4,4	310
Nije bitno	0,4	816	3,7	800	3,9	448	3,2	878	4,8	746

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,8 ; Fisher= 0,4.
Inter variance= 27,2. Intra variance= 60,8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Mogućnost uključivanja u školski sustav…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,1	579	2,8	534	3,1	302	2,8	602	3,9	508
…poboljšan je	0,1	728	2,8	702	2,6	418	2,8	795	3,7	671
…ostao je isti	0,5	1.558	3,1	1.421	3,1	871	3,5	1.624	4,8	1.410
Ne znam	0,8	428	2,7	394	2,6	247	2,0	460	3,4	376
Nije bitno	0,5	3.587	4,0	3.462	4,5	1.993	4,1	3.770	5,2	3.212

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Fisher= 1,3.
Inter variance= 57,0. Intra variance= 44,2.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Mogućnost obavljanja radne djelatnosti…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,2	1.901	3,5	1.793	3,6	1.004	3,4	1.989	4,5	1.642
…poboljšan je	0,5	663	3,9	639	4,2	370	4,5	683	5,5	593
…ostao je isti	0,6	2.006	3,5	1.858	3,4	1.122	3,6	2.091	4,9	1.840
Ne znam	0,5	355	2,7	338	3,2	204	2,1	398	3,4	323
Nije bitno	0,5	1.945	3,5	1.874	4,3	1.125	3,6	2.078	4,7	1.771

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,5 ; Fisher= 0,9.
Inter variance= 37,7. Intra variance= 44,3.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,2	846	3,1	772	3,7	426	3,5	867	4,5	716
…poboljšan je	0,1	795	3,7	781	3,6	483	3,7	856	4,6	755
…ostao je isti	0,6	2.281	3,6	2.105	3,9	1.211	4,2	2.392	5,4	2.051
Ne znam	0,6	785	3,4	743	4,1	444	2,7	828	4,2	667
Nije bitno	0,5	2.162	3,6	2.100	3,6	1.261	3,1	2.295	4,4	1.979

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Fisher= 1,4.
Inter variance= 61,4. Intra variance= 44,3.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Pristup kliničkim ispitivanjima…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,0	456	3,3	398	2,9	212	2,9	487	4,7	384
…poboljšan je	0,1	1.727	4,0	1.692	4,2	1.047	3,8	1.834	5,6	1.599
…ostao je isti	0,6	2.474	3,5	2.327	3,7	1.315	3,7	2.577	4,7	2.234
Ne znam	0,4	1.157	3,2	1.077	3,2	619	3,4	1.214	4,0	1.007
Nije bitno	1,1	1.065	3,1	1.018	3,9	638	3,3	1.138	4,3	952

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Fisher= 4,4.
Inter variance= 193,2. Intra variance= 44,1.

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,4	1.317	4,0	1.261	4,7	725	4,1	1.377	5,7	1.179
…poboljšan je	0,1	157	2,3	150	3,6	89	2,7	161	3,6	144
…ostao je isti	0,6	1.844	3,7	1.701	4,1	967	4,0	1.910	5,3	1.625
Ne znam	0,5	1.239	3,2	1.152	3,2	723	3,0	1.316	4,0	1.102
Nije bitno	0,4	2.322	3,3	2.248	3,3	1.327	3,3	2.486	4,2	2.126

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,8 ; Fisher= 0,4.
Inter variance= 15,9. Intra variance= 44,3.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Questions asked only to respondents who are diagnosed

Od dobivanja dijagnoze za rijetku bolest, kako su se kod Vas promijenili sljedeći aspekti?

Vaš društveni život…	TIME BETWEEN FIRST SYMPTOMS AND FIRST MEDICAL CONTACT, IN YEARS		TIME BETWEEN FIRST SYMPTOM AND FIRST SYMPTOMATIC TREATMENT, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND FIRST REFERRAL TO A CENTRE OF EXPERTISE, IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND INITIAL DIAGNOSIS (FIRST HEARING THE NAME OF THE DISEASE), IN YEARS		TIME BETWEEN FIRST SYMPTOMS AND CONFIRMED DIAGNOSIS, IN YEARS	
	MEAN	N	MEAN	N	MEAN	N	MEAN	N	MEAN	N
…pogoršao se	0,4	3.556	3,4	3.342	3,4	1.898	3,2	3.728	4,1	3.126
…poboljšan je	0,2	555	4,7	543	5,2	325	5,0	575	6,6	490
…ostao je isti	0,7	2.320	3,7	2.209	4,2	1.350	4,0	2.454	5,5	2.156
Ne znam	0,7	117	2,1	110	3,8	66	3,2	127	4,0	108
Nije bitno	−0,4	321	1,7	297	1,9	186	1,9	354	3,0	288

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Fisher= 2,3.
Inter variance= 101,9. Intra variance= 44,3.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	603	10%	2.638	44%	2.267	38%	299	5%	216	4%	**6.023**	**100%**
Muškarac	250	10%	1.220	46%	917	35%	130	5%	107	4%	**2.624**	**100%**
Ostalo	11	13%	29	35%	30	37%	6	7%	6	7%	**82**	**100%**
TOTAL	**864**	**10%**	**3.887**	**45%**	**3.214**	**37%**	**435**	**5%**	**329**	**4%**	**8.729**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 14,5 ; dof= 8.

Cross: Gender of the person affected by the rare disease / Razumijevanje toga kako će bolest napredovati...

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	474	8%	3.250	54%	1.850	31%	346	6%	103	2%	**6.023**	**100%**
Muškarac	189	7%	1.572	60%	682	26%	124	5%	57	2%	**2.624**	**100%**
Ostalo	7	9%	35	43%	32	39%	4	5%	4	5%	**82**	**100%**
TOTAL	**670**	**8%**	**4.857**	**56%**	**2.564**	**29%**	**474**	**5%**	**164**	**2%**	**8.729**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 41,4 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	748	16%	828	18%	1.846	39%	438	9%	839	18%	4.699	100%
Muškarac	165	14%	213	18%	461	38%	85	7%	275	23%	1.199	100%
Ostalo	7	21%	4	12%	13	38%	4	12%	6	18%	34	100%
TOTAL	**920**	**16%**	**1.045**	**18%**	**2.320**	**39%**	**527**	**9%**	**1.120**	**19%**	**5.932**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 23,1 ; dof= 8.

Cross: Gender of the person affected by the rare disease / Mogućnost uključivanja u školski sustav…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	475	8%	497	8%	1.241	21%	416	7%	3.394	56%	6.023	100%
Muškarac	229	9%	387	15%	677	26%	159	6%	1.172	45%	2.624	100%
Ostalo	14	17%	13	16%	24	29%	6	7%	25	30%	82	100%
TOTAL	**718**	**8%**	**897**	**10%**	**1.942**	**22%**	**581**	**7%**	**4.591**	**53%**	**8.729**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 168,2 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Mogućnost obavljanja radne djelatnosti…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	1.711	28%	552	9%	1.691	28%	332	6%	1.737	29%	6.023	100%
Muškarac	611	23%	239	9%	804	31%	170	6%	799	30%	2.623	100%
Ostalo	20	24%	4	5%	20	24%	12	15%	26	32%	82	100%
TOTAL	**2.342**	**27%**	**795**	**9%**	**2.515**	**29%**	**514**	**6%**	**2.562**	**29%**	**8.728**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,9 ; dof= 8.

Cross: Gender of the person affected by the rare disease / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	777	13%	619	10%	1.946	32%	749	12%	1.932	32%	6.023	100%
Muškarac	299	11%	350	13%	837	32%	260	10%	877	33%	2.623	100%
Ostalo	15	18%	8	10%	29	35%	10	12%	20	24%	82	100%
TOTAL	**1.091**	**13%**	**977**	**11%**	**2.812**	**32%**	**1.019**	**12%**	**2.829**	**32%**	**8.728**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 34,0 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Pristup kliničkim ispitivanjima…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	449	7%	1.397	23%	2.106	35%	1.108	18%	963	16%	**6.023**	**100%**
Muškarac	167	6%	707	27%	930	35%	389	15%	431	16%	**2.624**	**100%**
Ostalo	4	5%	18	22%	30	37%	17	21%	13	16%	**82**	**100%**
TOTAL	**620**	**7%**	**2.122**	**24%**	**3.066**	**35%**	**1.514**	**17%**	**1.407**	**16%**	**8.729**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 28,8 ; dof= 8.

Cross: Gender of the person affected by the rare disease / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	1.207	20%	108	2%	1.541	26%	1.113	18%	2.054	34%	**6.023**	**100%**
Muškarac	438	17%	81	3%	722	28%	435	17%	947	36%	**2.623**	**100%**
Ostalo	22	27%	0	0%	12	15%	27	33%	21	26%	**82**	**100%**
TOTAL	**1.667**	**19%**	**189**	**2%**	**2.275**	**26%**	**1.575**	**18%**	**3.022**	**35%**	**8.728**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 53,9 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Gender of the person affected by the rare disease / Vaš društveni život…

GENDER OF THE PERSON AFFECTED BY THE RARE DISEASE	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Žena	3.194	53%	444	7%	2.004	33%	110	2%	271	4%	6.023	100%
Muškarac	1.200	46%	238	9%	942	36%	59	2%	184	7%	2.623	100%
Ostalo	43	52%	3	4%	24	29%	3	4%	9	11%	82	100%
TOTAL	**4.437**	**51%**	**685**	**8%**	**2.970**	**34%**	**172**	**2%**	**464**	**5%**	**8.728**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 61,6 ; dof= 8.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	59	14%	183	44%	130	31%	25	6%	16	4%	413	100%
između 16 i 19 godina	260	11%	961	42%	840	37%	147	6%	75	3%	2.283	100%
između 20 i 23 godine	257	9%	1.271	45%	1.070	38%	109	4%	117	4%	2.824	100%
24 godine ili više	261	9%	1.314	45%	1.072	37%	140	5%	116	4%	2.903	100%
TOTAL	**837**	**10%**	**3.729**	**44%**	**3.112**	**37%**	**421**	**5%**	**324**	**4%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 45,4 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Razumijevanje toga kako će bolest napredovati...

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	40	10%	205	50%	130	31%	24	6%	14	3%	**413**	**100%**
između 16 i 19 godina	216	9%	1.179	52%	710	31%	140	6%	38	2%	**2.283**	**100%**
između 20 i 23 godine	203	7%	1.570	56%	844	30%	152	5%	55	2%	**2.824**	**100%**
24 godine ili više	189	7%	1.731	60%	780	27%	149	5%	54	2%	**2.903**	**100%**
TOTAL	**648**	**8%**	**4.685**	**56%**	**2.464**	**29%**	**465**	**6%**	**161**	**2%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 52,6 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	44	20%	31	14%	87	40%	22	10%	35	16%	**219**	**100%**
između 16 i 19 godina	275	17%	269	16%	600	37%	170	10%	321	20%	**1.635**	**100%**
između 20 i 23 godine	274	15%	326	17%	762	40%	158	8%	367	19%	**1.887**	**100%**
24 godine ili više	278	15%	364	19%	743	39%	155	8%	349	18%	**1.889**	**100%**
TOTAL	**871**	**15%**	**990**	**18%**	**2.192**	**39%**	**505**	**9%**	**1.072**	**19%**	**5.630**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 23,6 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Mogućnost uključivanja u školski sustav…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	54	13%	62	15%	91	22%	40	10%	166	40%	413	100%
između 16 i 19 godina	174	8%	200	9%	435	19%	197	9%	1.277	56%	2.283	100%
između 20 i 23 godine	226	8%	283	10%	628	22%	161	6%	1.526	54%	2.824	100%
24 godine ili više	250	9%	339	12%	735	25%	159	5%	1.420	49%	2.903	100%
TOTAL	**704**	**8%**	**884**	**10%**	**1.889**	**22%**	**557**	**7%**	**4.389**	**52%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 109,2 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Mogućnost obavljanja radne djelatnosti…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	117	28%	22	5%	98	24%	37	9%	139	34%	413	100%
između 16 i 19 godina	673	29%	185	8%	598	26%	153	7%	674	30%	2.283	100%
između 20 i 23 godine	696	25%	262	9%	833	29%	141	5%	892	32%	2.824	100%
24 godine ili više	763	26%	300	10%	905	31%	169	6%	766	26%	2.903	100%
TOTAL	**2.249**	**27%**	**769**	**9%**	**2.434**	**29%**	**500**	**6%**	**2.471**	**29%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 69,7 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	65	16%	53	13%	133	32%	46	11%	116	28%	413	100%
između 16 i 19 godina	341	15%	221	10%	690	30%	315	14%	716	31%	2.283	100%
između 20 i 23 godine	316	11%	299	11%	929	33%	289	10%	991	35%	2.824	100%
24 godine ili više	331	11%	370	13%	967	33%	331	11%	904	31%	2.903	100%
TOTAL	**1.053**	**13%**	**943**	**11%**	**2.719**	**32%**	**981**	**12%**	**2.727**	**32%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 63,1 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Pristup kliničkim ispitivanjima…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	32	8%	112	27%	132	32%	73	18%	64	15%	413	100%
između 16 i 19 godina	196	9%	520	23%	768	34%	449	20%	350	15%	2.283	100%
između 20 i 23 godine	158	6%	653	23%	1.029	36%	454	16%	530	19%	2.824	100%
24 godine ili više	210	7%	759	26%	1.023	35%	495	17%	416	14%	2.903	100%
TOTAL	**596**	**7%**	**2.044**	**24%**	**2.952**	**35%**	**1.471**	**17%**	**1.360**	**16%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 58,4 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	79	19%	11	3%	104	25%	80	19%	139	34%	**413**	**100%**
između 16 i 19 godina	411	18%	41	2%	549	24%	472	21%	810	35%	**2.283**	**100%**
između 20 i 23 godine	556	20%	56	2%	742	26%	454	16%	1.016	36%	**2.824**	**100%**
24 godine ili više	554	19%	73	3%	807	28%	517	18%	952	33%	**2.903**	**100%**
TOTAL	**1.600**	**19%**	**181**	**2%**	**2.202**	**26%**	**1.523**	**18%**	**2.917**	**35%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 33,1 ; dof= 12.

Cross: Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem? / Vaš društveni život…

KOLIKO VAM JE BILO GODINA KAD STE ZAVRŠILI S REDOVNIM OBRAZOVANJEM?	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
15 godina ili manje	228	55%	29	7%	122	30%	7	2%	27	7%	**413**	**100%**
između 16 i 19 godina	1.235	54%	164	7%	736	32%	46	2%	102	4%	**2.283**	**100%**
između 20 i 23 godine	1.369	48%	210	7%	1.024	36%	44	2%	177	6%	**2.824**	**100%**
24 godine ili više	1.431	49%	254	9%	995	34%	72	2%	151	5%	**2.903**	**100%**
TOTAL	**4.263**	**51%**	**657**	**8%**	**2.877**	**34%**	**169**	**2%**	**457**	**5%**	**8.423**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,8 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	649	10%	2.955	45%	2.456	37%	325	5%	249	4%	**6.634**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	56	13%	154	37%	159	38%	28	7%	23	5%	**420**	**100%**
Ostalo, navesti	40	14%	121	41%	93	32%	22	7%	19	6%	**295**	**100%**
TOTAL	**745**	**10%**	**3.230**	**44%**	**2.708**	**37%**	**375**	**5%**	**291**	**4%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 30,6 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / Razumijevanje toga kako će bolest napredovati...

	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	482	7%	3.757	57%	1.921	29%	352	5%	122	2%	**6.634**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	52	12%	200	48%	123	29%	34	8%	11	3%	**420**	**100%**
Ostalo, navesti	40	14%	142	48%	76	26%	31	11%	6	2%	**295**	**100%**
TOTAL	**574**	**8%**	**4.099**	**56%**	**2.120**	**29%**	**417**	**6%**	**139**	**2%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 55,6 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	664	15%	775	18%	1.718	39%	392	9%	839	19%	4.388	100%
Dio sam etničke manjine u zemlji u kojoj živim	68	25%	45	16%	89	32%	31	11%	44	16%	277	100%
Ostalo, navesti	36	17%	24	11%	77	36%	30	14%	47	22%	214	100%
TOTAL	**768**	**16%**	**844**	**17%**	**1.884**	**39%**	**453**	**9%**	**930**	**19%**	**4.879**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,9 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / Mogućnost uključivanja u školski sustav…

	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	548	8%	701	11%	1.543	23%	436	7%	3.406	51%	6.634	100%
Dio sam etničke manjine u zemlji u kojoj živim	57	14%	54	13%	89	21%	45	11%	175	42%	420	100%
Ostalo, navesti	23	8%	29	10%	47	16%	30	10%	166	56%	295	100%
TOTAL	**628**	**9%**	**784**	**11%**	**1.679**	**23%**	**511**	**7%**	**3.747**	**51%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 45,8 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Mogućnost obavljanja radne djelatnosti…

	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.749	26%	630	9%	1.963	30%	395	6%	1.897	29%	**6.634**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	124	30%	33	8%	113	27%	35	8%	115	27%	**420**	**100%**
Ostalo, navesti	95	32%	25	8%	53	18%	27	9%	95	32%	**295**	**100%**
TOTAL	**1.968**	**27%**	**688**	**9%**	**2.129**	**29%**	**457**	**6%**	**2.107**	**29%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 29,5 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	819	12%	758	11%	2.225	34%	773	12%	2.059	31%	**6.634**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	72	17%	52	12%	136	32%	55	13%	105	25%	**420**	**100%**
Ostalo, navesti	47	16%	34	12%	78	26%	40	14%	96	33%	**295**	**100%**
TOTAL	**938**	**13%**	**844**	**11%**	**2.439**	**33%**	**868**	**12%**	**2.260**	**31%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 20,7 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Kako biste najbolje opisali sebe? / Pristup kliničkim ispitivanjima…

	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	482	7%	1.727	26%	2.437	37%	1.154	17%	834	13%	6.634	100%
Dio sam etničke manjine u zemlji u kojoj živim	43	10%	85	20%	144	34%	83	20%	65	15%	420	100%
Ostalo, navesti	19	6%	59	20%	81	27%	70	24%	66	22%	295	100%
TOTAL	**544**	**7%**	**1.871**	**25%**	**2.662**	**36%**	**1.307**	**18%**	**965**	**13%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 51,0 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
KAKO BISTE NAJBOLJE OPISALI SEBE?	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	1.195	18%	152	2%	1.838	28%	1.237	19%	2.212	33%	6.634	100%
Dio sam etničke manjine u zemlji u kojoj živim	100	24%	13	3%	115	27%	76	18%	116	28%	420	100%
Ostalo, navesti	52	18%	1	0%	56	19%	68	23%	118	40%	295	100%
TOTAL	**1.347**	**18%**	**166**	**2%**	**2.009**	**27%**	**1.381**	**19%**	**2.446**	**33%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,4 ; dof= 8.

Cross: Kako biste najbolje opisali sebe? / Vaš društveni život…

KAKO BISTE NAJBOLJE OPISALI SEBE?	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Pripadam etničkoj većini u zemlji u kojoj živim	3.337	50%	528	8%	2.278	34%	134	2%	357	5%	**6.634**	**100%**
Dio sam etničke manjine u zemlji u kojoj živim	250	60%	28	7%	115	27%	11	3%	16	4%	**420**	**100%**
Ostalo, navesti	163	55%	17	6%	86	29%	6	2%	23	8%	**295**	**100%**
TOTAL	**3.750**	**51%**	**573**	**8%**	**2.479**	**34%**	**151**	**2%**	**396**	**5%**	**7.349**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 23,5 ; dof= 8.

Cross: Typology of countries based on size and welfare / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	173	12%	618	42%	547	37%	79	5%	51	3%	**1.468**	**100%**
Group B ('Western Europe')	454	10%	2.100	46%	1.701	37%	195	4%	165	4%	**4.615**	**100%**
Group C ('Northern Europe')	259	9%	1.247	44%	1.044	37%	179	6%	123	4%	**2.852**	**100%**
TOTAL	**886**	**10%**	**3.965**	**44%**	**3.292**	**37%**	**453**	**5%**	**339**	**4%**	**8.935**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 28,6 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Razumijevanje toga kako će bolest napredovati...

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	207	14%	666	46%	435	30%	120	8%	34	2%	1.462	100%
Group B ('Western Europe')	302	7%	2.732	59%	1.307	28%	206	4%	66	1%	4.613	100%
Group C ('Northern Europe')	179	6%	1.557	55%	879	31%	163	6%	71	2%	2.849	100%
TOTAL	**688**	**8%**	**4.955**	**56%**	**2.621**	**29%**	**489**	**5%**	**171**	**2%**	**8.924**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 177,0 ; dof= 8.

Cross: Typology of countries based on size and welfare / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	146	22%	110	16%	307	46%	49	7%	62	9%	674	100%
Group B ('Western Europe')	464	15%	611	19%	1.227	39%	254	8%	617	19%	3.173	100%
Group C ('Northern Europe')	314	15%	322	15%	783	38%	227	11%	439	21%	2.085	100%
TOTAL	**924**	**16%**	**1.043**	**18%**	**2.317**	**39%**	**530**	**9%**	**1.118**	**19%**	**5.932**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 91,3 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Mogućnost uključivanja u školski sustav…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	175	12%	224	15%	422	29%	137	9%	510	35%	1.468	100%
Group B ('Western Europe')	389	8%	470	10%	1.072	23%	279	6%	2.405	52%	4.615	100%
Group C ('Northern Europe')	176	6%	254	9%	522	18%	190	7%	1.710	60%	2.852	100%
TOTAL	**740**	**8%**	**948**	**11%**	**2.016**	**23%**	**606**	**7%**	**4.625**	**52%**	**8.935**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 263,3 ; dof= 8.

Cross: Typology of countries based on size and welfare / Mogućnost obavljanja radne djelatnosti…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	433	30%	118	8%	456	31%	151	10%	304	21%	1.462	100%
Group B ('Western Europe')	1.386	30%	440	10%	1.423	31%	216	5%	1.148	25%	4.613	100%
Group C ('Northern Europe')	569	20%	256	9%	690	24%	180	6%	1.153	40%	2.848	100%
TOTAL	**2.388**	**27%**	**814**	**9%**	**2.569**	**29%**	**547**	**6%**	**2.605**	**29%**	**8.923**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 352,0 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	243	17%	145	10%	590	40%	175	12%	308	21%	1.461	100%
Group B ('Western Europe')	566	12%	505	11%	1.509	33%	519	11%	1.514	33%	4.613	100%
Group C ('Northern Europe')	315	11%	349	12%	777	27%	367	13%	1.040	37%	2.848	100%
TOTAL	**1.124**	**13%**	**999**	**11%**	**2.876**	**32%**	**1.061**	**12%**	**2.862**	**32%**	**8.922**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 159,2 ; dof= 8.

Cross: Typology of countries based on size and welfare / Pristup kliničkim ispitivanjima…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	146	10%	315	21%	643	44%	206	14%	157	11%	1.467	100%
Group B ('Western Europe')	299	6%	1.165	25%	1.511	33%	775	17%	865	19%	4.615	100%
Group C ('Northern Europe')	187	7%	701	25%	988	35%	571	20%	405	14%	2.852	100%
TOTAL	**632**	**7%**	**2.181**	**24%**	**3.142**	**35%**	**1.552**	**17%**	**1.427**	**16%**	**8.934**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 141,4 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Typology of countries based on size and welfare / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	295	20%	46	3%	521	36%	271	18%	334	23%	1.467	100%
Group B ('Western Europe')	816	18%	92	2%	1.221	26%	835	18%	1.651	36%	4.615	100%
Group C ('Northern Europe')	576	20%	58	2%	587	21%	531	19%	1.099	39%	2.851	100%
TOTAL	**1.687**	**19%**	**196**	**2%**	**2.329**	**26%**	**1.637**	**18%**	**3.084**	**35%**	**8.933**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 172,2 ; dof= 8.

Cross: Typology of countries based on size and welfare / Vaš društveni život…

TYPOLOGY OF COUNTRIES BASED ON SIZE AND WELFARE	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Group A ('Eastern Europe')	796	54%	109	7%	464	32%	28	2%	64	4%	1.461	100%
Group B ('Western Europe')	2.309	50%	394	9%	1.615	35%	82	2%	213	5%	4.613	100%
Group C ('Northern Europe')	1.420	50%	197	7%	961	34%	72	3%	198	7%	2.848	100%
TOTAL	**4.525**	**51%**	**700**	**8%**	**3.040**	**34%**	**182**	**2%**	**475**	**5%**	**8.922**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 40,7 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetic diseases / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	517	10%	2.337	45%	1.918	37%	250	5%	210	4%	**5.232**	**100%**
Non Genetic diseases	232	9%	1.188	47%	901	36%	126	5%	87	3%	**2.534**	**100%**
TOTAL	**749**	**10%**	**3.525**	**45%**	**2.819**	**36%**	**376**	**5%**	**297**	**4%**	**7.766**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 5,0 ; dof= 4.

Cross: Genetic diseases / Razumijevanje toga kako će bolest napredovati...

	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	387	7%	3.015	58%	1.453	28%	248	5%	116	2%	**5.219**	**100%**
Non Genetic diseases	193	8%	1.374	54%	783	31%	145	6%	37	1%	**2.532**	**100%**
TOTAL	**580**	**7%**	**4.389**	**57%**	**2.236**	**29%**	**393**	**5%**	**153**	**2%**	**7.751**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 17,6 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetic diseases / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	458	16%	560	19%	1.139	39%	243	8%	501	17%	2.901	100%
Non Genetic diseases	315	15%	351	16%	823	38%	202	9%	469	22%	2.160	100%
TOTAL	**773**	**15%**	**911**	**18%**	**1.962**	**39%**	**445**	**9%**	**970**	**19%**	**5.061**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 22,1 ; dof= 4.

Cross: Genetic diseases / Mogućnost uključivanja u školski sustav…

	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	474	9%	722	14%	1.434	27%	342	7%	2.260	43%	5.232	100%
Non Genetic diseases	175	7%	127	5%	327	13%	156	6%	1.749	69%	2.534	100%
TOTAL	**649**	**8%**	**849**	**11%**	**1.761**	**23%**	**498**	**6%**	**4.009**	**52%**	**7.766**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 509,4 ; dof= 4.

Cross: Genetic diseases / Mogućnost obavljanja radne djelatnosti…

	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	1.282	25%	484	9%	1.606	31%	328	6%	1.518	29%	5.218	100%
Non Genetic diseases	788	31%	225	9%	619	24%	127	5%	773	31%	2.532	100%
TOTAL	**2.070**	**27%**	**709**	**9%**	**2.225**	**29%**	**455**	**6%**	**2.291**	**30%**	**7.750**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 57,4 ; dof= 4.

Cross: Genetic diseases / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	628	12%	691	13%	1.795	34%	577	11%	1.527	29%	5.218	100%
Non Genetic diseases	334	13%	190	8%	705	28%	318	13%	984	39%	2.531	100%
TOTAL	**962**	**12%**	**881**	**11%**	**2.500**	**32%**	**895**	**12%**	**2.511**	**32%**	**7.749**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 125,8 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetic diseases / Pristup kliničkim ispitivanjima…

	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	360	7%	1.367	26%	1.863	36%	853	16%	789	15%	5.232	100%
Non Genetic diseases	173	7%	576	23%	889	35%	453	18%	442	17%	2.533	100%
TOTAL	**533**	**7%**	**1.943**	**25%**	**2.752**	**35%**	**1.306**	**17%**	**1.231**	**16%**	**7.765**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 16,5 ; dof= 4.

Cross: Genetic diseases / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	989	19%	138	3%	1.486	28%	942	18%	1.676	32%	5.231	100%
Non Genetic diseases	485	19%	38	2%	538	21%	442	17%	1.030	41%	2.533	100%
TOTAL	**1.474**	**19%**	**176**	**2%**	**2.024**	**26%**	**1.384**	**18%**	**2.706**	**35%**	**7.764**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 80,1 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Genetic diseases / Vaš društveni život…

	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
GENETIC DISEASES	N	%	N	%	N	%	N	%	N	%	N	%
Genetic diseases	2.429	47%	452	9%	1.915	37%	109	2%	313	6%	**5.218**	**100%**
Non Genetic diseases	1.481	59%	159	6%	747	30%	46	2%	98	4%	**2.531**	**100%**
TOTAL	**3.910**	**50%**	**611**	**8%**	**2.662**	**34%**	**155**	**2%**	**411**	**5%**	**7.749**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 101,4 ; dof= 4.

Cross: Point prevalence of the rare disease / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	228	10%	1.125	48%	801	34%	124	5%	75	3%	**2.353**	**100%**
1-9 / 100 000	196	10%	825	42%	757	39%	86	4%	86	4%	**1.950**	**100%**
1-9 / 1 000 000	50	11%	207	46%	156	35%	17	4%	19	4%	**449**	**100%**
<1 / 1 000 000	85	11%	311	39%	328	41%	34	4%	39	5%	**797**	**100%**
TOTAL	**559**	**10%**	**2.468**	**44%**	**2.042**	**37%**	**261**	**5%**	**219**	**4%**	**5.549**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 35,8 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Razumijevanje toga kako će bolest napredovati...

	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	154	7%	1.400	60%	645	27%	115	5%	36	2%	**2.350**	**100%**
1-9 / 100 000	147	8%	1.081	55%	570	29%	102	5%	49	3%	**1.949**	**100%**
1-9 / 1 000 000	30	7%	247	55%	140	31%	23	5%	9	2%	**449**	**100%**
<1 / 1 000 000	80	10%	395	50%	256	32%	43	5%	21	3%	**795**	**100%**
TOTAL	**411**	**7%**	**3.123**	**56%**	**1.611**	**29%**	**283**	**5%**	**115**	**2%**	**5.543**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 33,6 ; dof= 12.

Cross: Point prevalence of the rare disease / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	244	14%	323	18%	680	39%	169	10%	332	19%	**1.748**	**100%**
1-9 / 100 000	205	16%	245	19%	496	38%	110	8%	250	19%	**1.306**	**100%**
1-9 / 1 000 000	47	18%	48	19%	95	37%	25	10%	42	16%	**257**	**100%**
<1 / 1 000 000	76	16%	83	18%	185	40%	32	7%	86	19%	**462**	**100%**
TOTAL	**572**	**15%**	**699**	**19%**	**1.456**	**39%**	**336**	**9%**	**710**	**19%**	**3.773**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,7 ; Chi2= 9,5 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Mogućnost uključivanja u školski sustav…

	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	190	8%	227	10%	472	20%	166	7%	1.298	55%	2.353	100%
1-9 / 100 000	141	7%	184	9%	443	23%	112	6%	1.070	55%	1.950	100%
1-9 / 1 000 000	47	10%	65	14%	106	24%	26	6%	205	46%	449	100%
<1 / 1 000 000	68	9%	89	11%	218	27%	51	6%	371	47%	797	100%
TOTAL	**446**	**8%**	**565**	**10%**	**1.239**	**22%**	**355**	**6%**	**2.944**	**53%**	**5.549**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 48,0 ; dof= 12.

Cross: Point prevalence of the rare disease / Mogućnost obavljanja radne djelatnosti…

	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	602	26%	216	9%	685	29%	135	6%	712	30%	2.350	100%
1-9 / 100 000	503	26%	178	9%	559	29%	118	6%	590	30%	1.948	100%
1-9 / 1 000 000	114	25%	42	9%	139	31%	29	6%	125	28%	449	100%
<1 / 1 000 000	204	26%	58	7%	211	27%	42	5%	280	35%	795	100%
TOTAL	**1.423**	**26%**	**494**	**9%**	**1.594**	**29%**	**324**	**6%**	**1.707**	**31%**	**5.542**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,4 ; Chi2= 12,6 ; dof= 12.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	260	11%	214	9%	709	30%	302	13%	865	37%	**2.350**	**100%**
1-9 / 100 000	269	14%	235	12%	625	32%	198	10%	621	32%	**1.948**	**100%**
1-9 / 1 000 000	49	11%	63	14%	132	29%	48	11%	157	35%	**449**	**100%**
<1 / 1 000 000	108	14%	99	12%	269	34%	90	11%	229	29%	**795**	**100%**
TOTAL	**686**	**12%**	**611**	**11%**	**1.735**	**31%**	**638**	**12%**	**1.872**	**34%**	**5.542**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 48,1 ; dof= 12.

Cross: Point prevalence of the rare disease / Pristup kliničkim ispitivanjima…

	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	142	6%	596	25%	822	35%	425	18%	368	16%	**2.353**	**100%**
1-9 / 100 000	141	7%	466	24%	716	37%	318	16%	309	16%	**1.950**	**100%**
1-9 / 1 000 000	29	6%	128	29%	148	33%	81	18%	63	14%	**449**	**100%**
<1 / 1 000 000	59	7%	195	24%	298	37%	116	15%	129	16%	**797**	**100%**
TOTAL	**371**	**7%**	**1.385**	**25%**	**1.984**	**36%**	**940**	**17%**	**869**	**16%**	**5.549**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,2 ; Chi2= 15,0 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Point prevalence of the rare disease / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	437	19%	39	2%	608	26%	441	19%	828	35%	**2.353**	**100%**
1-9 / 100 000	398	20%	35	2%	510	26%	313	16%	693	36%	**1.949**	**100%**
1-9 / 1 000 000	86	19%	15	3%	110	24%	86	19%	152	34%	**449**	**100%**
<1 / 1 000 000	139	17%	25	3%	225	28%	133	17%	275	35%	**797**	**100%**
TOTAL	**1.060**	**19%**	**114**	**2%**	**1.453**	**26%**	**973**	**18%**	**1.948**	**35%**	**5.548**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 21,5 ; dof= 12.

Cross: Point prevalence of the rare disease / Vaš društveni život…

	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
POINT PREVALENCE OF THE RARE DISEASE	N	%	N	%	N	%	N	%	N	%	N	%
1-5 / 10 000	1.142	49%	206	9%	839	36%	50	2%	113	5%	**2.350**	**100%**
1-9 / 100 000	1.017	52%	140	7%	653	34%	35	2%	103	5%	**1.948**	**100%**
1-9 / 1 000 000	228	51%	38	8%	136	30%	13	3%	34	8%	**449**	**100%**
<1 / 1 000 000	392	49%	60	8%	281	35%	20	3%	42	5%	**795**	**100%**
TOTAL	**2.779**	**50%**	**444**	**8%**	**1.909**	**34%**	**118**	**2%**	**292**	**5%**	**5.542**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 18,8 ; dof= 12.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	433	8%	2.340	44%	1.962	37%	291	6%	234	4%	**5.260**	**100%**
4-7 body parts	269	10%	1.199	45%	990	37%	115	4%	82	3%	**2.655**	**100%**
8-11 body parts	113	14%	376	46%	269	33%	40	5%	21	3%	**819**	**100%**
12-15 body parts	53	23%	90	38%	80	34%	7	3%	5	2%	**235**	**100%**
16 body parts or more	21	38%	15	27%	15	27%	4	7%	0	0%	**55**	**100%**
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 146,8 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Razumijevanje toga kako će bolest napredovati...

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	359	7%	2.899	55%	1.575	30%	310	6%	106	2%	**5.249**	**100%**
4-7 body parts	213	8%	1.503	57%	752	28%	129	5%	52	2%	**2.649**	**100%**
8-11 body parts	87	11%	450	55%	235	29%	36	4%	11	1%	**819**	**100%**
12-15 body parts	24	10%	122	52%	68	29%	16	7%	5	2%	**235**	**100%**
16 body parts or more	11	20%	25	46%	14	26%	3	6%	1	2%	**54**	**100%**
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,6 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	438	13%	583	17%	1.353	39%	314	9%	785	23%	3.473	100%
4-7 body parts	284	17%	305	18%	681	40%	157	9%	270	16%	1.697	100%
8-11 body parts	142	24%	121	20%	224	38%	52	9%	58	10%	597	100%
12-15 body parts	51	28%	39	22%	69	39%	9	5%	11	6%	179	100%
16 body parts or more	13	32%	8	20%	18	44%	0	0%	2	5%	41	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 167,0 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Mogućnost uključivanja u školski sustav…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	379	7%	549	10%	1.188	23%	352	7%	2.792	53%	5.260	100%
4-7 body parts	243	9%	293	11%	618	23%	186	7%	1.315	50%	2.655	100%
8-11 body parts	83	10%	88	11%	171	21%	59	7%	418	51%	819	100%
12-15 body parts	30	13%	25	11%	42	18%	14	6%	124	53%	235	100%
16 body parts or more	11	20%	5	9%	11	20%	2	4%	26	47%	55	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 39,0 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Mogućnost obavljanja radne djelatnosti…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	1.224	23%	466	9%	1.612	31%	346	7%	1.600	30%	5.248	100%
4-7 body parts	795	30%	254	10%	710	27%	151	6%	739	28%	2.649	100%
8-11 body parts	269	33%	82	10%	209	26%	41	5%	218	27%	819	100%
12-15 body parts	101	43%	10	4%	48	20%	10	4%	66	28%	235	100%
16 body parts or more	22	41%	6	11%	8	15%	3	6%	15	28%	54	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 115,0 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	572	11%	503	10%	1.614	31%	638	12%	1.920	37%	5.247	100%
4-7 body parts	342	13%	347	13%	909	34%	307	12%	744	28%	2.649	100%
8-11 body parts	154	19%	109	13%	276	34%	96	12%	184	22%	819	100%
12-15 body parts	52	22%	40	17%	90	38%	20	9%	33	14%	235	100%
16 body parts or more	14	26%	12	22%	17	31%	5	9%	6	11%	54	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 213,4 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Pristup kliničkim ispitivanjima…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	310	6%	1.266	24%	1.815	35%	921	18%	947	18%	5.259	100%
4-7 body parts	181	7%	660	25%	977	37%	436	16%	401	15%	2.655	100%
8-11 body parts	96	12%	213	26%	284	35%	147	18%	79	10%	819	100%
12-15 body parts	41	17%	47	20%	84	36%	45	19%	18	8%	235	100%
16 body parts or more	9	16%	11	20%	13	24%	15	27%	7	13%	55	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 137,3 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	863	16%	116	2%	1.337	25%	938	18%	2.004	38%	5.258	100%
4-7 body parts	528	20%	54	2%	749	28%	499	19%	825	31%	2.655	100%
8-11 body parts	214	26%	21	3%	193	24%	162	20%	229	28%	819	100%
12-15 body parts	86	37%	6	3%	56	24%	39	17%	48	20%	235	100%
16 body parts or more	24	44%	3	5%	10	18%	10	18%	8	15%	55	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 171,4 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Vaš društveni život…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	2.396	46%	432	8%	2.003	38%	112	2%	304	6%	5.247	100%
4-7 body parts	1.479	56%	185	7%	791	30%	53	2%	141	5%	2.649	100%
8-11 body parts	504	62%	61	7%	211	26%	14	2%	29	4%	819	100%
12-15 body parts	155	66%	26	11%	47	20%	4	2%	3	1%	235	100%
16 body parts or more	37	69%	4	7%	12	22%	0	0%	1	2%	54	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 169,6 ; dof= 16.

Cross: Disease complexity classified into five groups, based on the number of affected body parts. / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

DISEASE COMPLEXITY CLASSIFIED INTO FIVE GROUPS, BASED ON THE NUMBER OF AFFECTED BODY PARTS.	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
1-3 body parts	863	16%	116	2%	1.337	25%	938	18%	2.004	38%	5.258	100%
4-7 body parts	528	20%	54	2%	749	28%	499	19%	825	31%	2.655	100%
8-11 body parts	214	26%	21	3%	193	24%	162	20%	229	28%	819	100%
12-15 body parts	86	37%	6	3%	56	24%	39	17%	48	20%	235	100%
16 body parts or more	24	44%	3	5%	10	18%	10	18%	8	15%	55	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 171,4 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	317	13%	1.163	46%	854	34%	127	5%	73	3%	2.534	100%
Ne	516	8%	2.733	45%	2.333	38%	286	5%	249	4%	6.117	100%
Ne znam	56	15%	124	33%	129	35%	44	12%	20	5%	373	100%
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 107,0 ; dof= 8.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Razumijevanje toga kako će bolest napredovati...

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	259	10%	1.386	55%	690	27%	153	6%	40	2%	2.528	100%
Ne	398	7%	3.447	56%	1.832	30%	303	5%	127	2%	6.107	100%
Ne znam	37	10%	166	45%	122	33%	38	10%	8	2%	371	100%
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 72,0 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	305	23%	249	19%	496	38%	96	7%	166	13%	1.312	100%
Ne	565	13%	766	17%	1.741	40%	401	9%	921	21%	4.394	100%
Ne znam	58	21%	41	15%	108	38%	35	12%	39	14%	281	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 128,0 ; dof= 8.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Mogućnost uključivanja u školski sustav…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	327	13%	422	17%	653	26%	183	7%	949	37%	2.534	100%
Ne	389	6%	514	8%	1.309	21%	384	6%	3.521	58%	6.117	100%
Ne znam	30	8%	24	6%	68	18%	46	12%	205	55%	373	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 392,9 ; dof= 8.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Mogućnost obavljanja radne djelatnosti…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	788	31%	244	10%	721	29%	171	7%	604	24%	2.528	100%
Ne	1.515	25%	545	9%	1.774	29%	341	6%	1.931	32%	6.106	100%
Ne znam	108	29%	29	8%	92	25%	39	11%	103	28%	371	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 84,8 ; dof= 8.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	431	17%	364	14%	924	37%	268	11%	541	21%	2.528	100%
Ne	644	11%	611	10%	1.866	31%	738	12%	2.246	37%	6.105	100%
Ne znam	59	16%	36	10%	116	31%	60	16%	100	27%	371	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 259,5 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Pristup kliničkim ispitivanjima…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	230	9%	623	25%	919	36%	413	16%	349	14%	2.534	100%
Ne	375	6%	1.509	25%	2.138	35%	1.054	17%	1.040	17%	6.116	100%
Ne znam	32	9%	65	17%	116	31%	97	26%	63	17%	373	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 63,2 ; dof= 8.

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	514	20%	74	3%	731	29%	507	20%	708	28%	2.534	100%
Ne	1.126	18%	125	2%	1.531	25%	1.044	17%	2.289	37%	6.115	100%
Ne znam	75	20%	1	0%	83	22%	97	26%	117	31%	373	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 97,6 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …poremećaje u ponašanju koji uzrokuju probleme u školi, kod kuće ili u društvenim situacijama / Vaš društveni život…

…POREMEĆAJE U PONAŠANJU KOJI UZROKUJU PROBLEME U ŠKOLI, KOD KUĆE ILI U DRUŠTVENIM SITUACIJAMA	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.448	57%	241	10%	702	28%	50	2%	87	3%	**2.528**	**100%**
Ne	2.915	48%	454	7%	2.256	37%	110	2%	370	6%	**6.105**	**100%**
Ne znam	208	56%	13	4%	106	29%	23	6%	21	6%	**371**	**100%**
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 157,7 ; dof= 8.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	323	13%	1.053	42%	935	37%	120	5%	87	3%	**2.518**	**100%**
Ne	535	9%	2.879	46%	2.289	37%	312	5%	243	4%	**6.258**	**100%**
Ne znam	31	13%	88	35%	92	37%	25	10%	12	5%	**248**	**100%**
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 61,6 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Razumijevanje toga kako će bolest napredovati...

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	235	9%	1.368	55%	714	28%	151	6%	41	2%	**2.509**	**100%**
Ne	427	7%	3.530	56%	1.851	30%	312	5%	130	2%	**6.250**	**100%**
Ne znam	32	13%	101	41%	79	32%	31	13%	4	2%	**247**	**100%**
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 64,9 ; dof= 8.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	281	25%	217	19%	430	38%	83	7%	130	11%	**1.141**	**100%**
Ne	604	13%	814	17%	1.848	40%	425	9%	965	21%	**4.656**	**100%**
Ne znam	43	23%	25	13%	67	35%	24	13%	31	16%	**190**	**100%**
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 141,6 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	707	14%	553	11%	1.653	32%	601	12%	1.579	31%	5.093	100%
Ne	348	11%	391	12%	1.041	32%	367	11%	1.137	35%	3.284	100%
Ne znam	79	13%	67	11%	212	34%	98	16%	171	27%	627	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 41,9 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup kliničkim ispitivanjima…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	404	8%	1.314	26%	1.818	36%	865	17%	697	14%	5.098	100%
Ne	188	6%	753	23%	1.136	34%	541	16%	675	20%	3.293	100%
Ne znam	45	7%	130	21%	219	35%	158	25%	80	13%	632	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 112,0 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.080	21%	98	2%	1.345	26%	902	18%	1.673	33%	5.098	100%
Ne	529	16%	87	3%	854	26%	573	17%	1.249	38%	3.292	100%
Ne znam	106	17%	15	2%	146	23%	173	27%	192	30%	632	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 85,9 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Vaš društveni život…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	2.794	55%	392	8%	1.633	32%	85	2%	189	4%	5.093	100%
Ne	1.468	45%	269	8%	1.229	37%	69	2%	249	8%	3.284	100%
Ne znam	309	49%	47	7%	202	32%	29	5%	40	6%	627	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 141,1 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	527	21%	84	3%	687	27%	494	20%	726	29%	2.518	100%
Ne	1.138	18%	114	2%	1.601	26%	1.089	17%	2.314	37%	6.256	100%
Ne znam	50	20%	2	1%	57	23%	65	26%	74	30%	248	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 80,8 ; dof= 8.

Cross: …intelektualne teškoće ili kognitivne simptome (tj. probleme s pamćenjem, jezikom, razmišljanjem ili prosuđivanjem) / Vaš društveni život…

…INTELEKTUALNE TEŠKOĆE ILI KOGNITIVNE SIMPTOME (TJ. PROBLEME S PAMĆENJEM, JEZIKOM, RAZMIŠLJANJEM ILI PROSUĐIVANJEM)	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.506	60%	190	8%	676	27%	49	2%	88	4%	2.509	100%
Ne	2.914	47%	506	8%	2.333	37%	121	2%	374	6%	6.248	100%
Ne znam	151	61%	12	5%	55	22%	13	5%	16	6%	247	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 173,7 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	528	10%	2.365	46%	1.830	36%	219	4%	157	3%	5.099	100%
Ne	302	9%	1.411	43%	1.265	38%	166	5%	149	5%	3.293	100%
Ne znam	59	9%	244	39%	221	35%	72	11%	36	6%	632	100%
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 91,6 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Razumijevanje toga kako će bolest napredovati...

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	427	8%	2.871	56%	1.474	29%	248	5%	74	1%	5.094	100%
Ne	217	7%	1.810	55%	992	30%	175	5%	91	3%	3.285	100%
Ne znam	50	8%	318	51%	178	28%	71	11%	10	2%	627	100%
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 73,8 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	619	17%	655	18%	1.461	40%	307	8%	627	17%	3.669	100%
Ne	248	13%	352	18%	733	38%	159	8%	435	23%	1.927	100%
Ne znam	61	16%	49	13%	151	39%	66	17%	64	16%	391	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 72,1 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Mogućnost uključivanja u školski sustav…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	470	9%	521	10%	1.036	20%	308	6%	2.764	54%	5.099	100%
Ne	220	7%	380	12%	839	25%	221	7%	1.633	50%	3.293	100%
Ne znam	56	9%	59	9%	155	25%	84	13%	278	44%	632	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 105,0 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Mogućnost obavljanja radne djelatnosti…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.513	30%	506	10%	1.415	28%	259	5%	1.401	28%	5.094	100%
Ne	750	23%	271	8%	985	30%	218	7%	1.060	32%	3.284	100%
Ne znam	148	24%	41	7%	187	30%	74	12%	177	28%	627	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 111,6 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	707	14%	553	11%	1.653	32%	601	12%	1.579	31%	5.093	100%
Ne	348	11%	391	12%	1.041	32%	367	11%	1.137	35%	3.284	100%
Ne znam	79	13%	67	11%	212	34%	98	16%	171	27%	627	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 41,9 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup kliničkim ispitivanjima…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	404	8%	1.314	26%	1.818	36%	865	17%	697	14%	5.098	100%
Ne	188	6%	753	23%	1.136	34%	541	16%	675	20%	3.293	100%
Ne znam	45	7%	130	21%	219	35%	158	25%	80	13%	632	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 112,0 ; dof= 8.

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.080	21%	98	2%	1.345	26%	902	18%	1.673	33%	5.098	100%
Ne	529	16%	87	3%	854	26%	573	17%	1.249	38%	3.292	100%
Ne znam	106	17%	15	2%	146	23%	173	27%	192	30%	632	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 85,9 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …kliničke znake ili simptome koji se pojave te nestanu / Vaš društveni život…

…KLINIČKE ZNAKE ILI SIMPTOME KOJI SE POJAVE TE NESTANU	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	2.794	55%	392	8%	1.633	32%	85	2%	189	4%	5.093	100%
Ne	1.468	45%	269	8%	1.229	37%	69	2%	249	8%	3.284	100%
Ne znam	309	49%	47	7%	202	32%	29	5%	40	6%	627	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 141,1 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	648	11%	2.719	45%	2.144	36%	277	5%	193	3%	5.981	100%
Ne	205	8%	1.111	43%	993	39%	137	5%	125	5%	2.571	100%
Ne znam	36	8%	190	40%	179	38%	43	9%	24	5%	472	100%
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 58,2 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Razumijevanje toga kako će bolest napredovati...

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	515	9%	3.265	55%	1.793	30%	315	5%	85	1%	5.973	100%
Ne	142	6%	1.481	58%	727	28%	136	5%	77	3%	2.563	100%
Ne znam	37	8%	253	54%	124	26%	43	9%	13	3%	470	100%
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 65,6 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	788	17%	823	18%	1.830	40%	400	9%	780	17%	4.621	100%
Ne	121	10%	219	18%	470	38%	107	9%	311	25%	1.228	100%
Ne znam	19	14%	14	10%	45	33%	25	18%	35	25%	138	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 92,8 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Mogućnost uključivanja u školski sustav…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	514	9%	520	9%	1.146	19%	395	7%	3.406	57%	5.981	100%
Ne	191	7%	366	14%	755	29%	174	7%	1.085	42%	2.571	100%
Ne znam	41	9%	74	16%	129	27%	44	9%	184	39%	472	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 251,3 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Mogućnost obavljanja radne djelatnosti…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.841	31%	556	9%	1.607	27%	302	5%	1.667	28%	5.973	100%
Ne	485	19%	219	9%	851	33%	197	8%	810	32%	2.562	100%
Ne znam	85	18%	43	9%	129	27%	52	11%	161	34%	470	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 187,7 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	846	14%	614	10%	1.873	31%	718	12%	1.922	32%	5.973	100%
Ne	235	9%	333	13%	859	34%	286	11%	848	33%	2.561	100%
Ne znam	53	11%	64	14%	174	37%	62	13%	117	25%	470	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 66,9 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Pristup kliničkim ispitivanjima…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	475	8%	1.408	24%	2.105	35%	1.046	17%	947	16%	5.981	100%
Ne	142	6%	687	27%	895	35%	405	16%	441	17%	2.570	100%
Ne znam	20	4%	102	22%	173	37%	113	24%	64	14%	472	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 49,5 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.316	22%	114	2%	1.468	25%	1.079	18%	2.004	34%	5.981	100%
Ne	341	13%	74	3%	744	29%	461	18%	949	37%	2.569	100%
Ne znam	58	12%	12	3%	133	28%	108	23%	161	34%	472	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 118,2 ; dof= 8.

Cross: …nevidljive simptome kao što su bol, vrtoglavica, glavobolja, premorenost, itd. / Vaš društveni život…

…NEVIDLJIVE SIMPTOME KAO ŠTO SU BOL, VRTOGLAVICA, GLAVOBOLJA, PREMORENOST, ITD.	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	3.337	56%	468	8%	1.835	31%	105	2%	228	4%	5.973	100%
Ne	1.007	39%	219	9%	1.065	42%	57	2%	213	8%	2.561	100%
Ne znam	227	48%	21	4%	164	35%	21	4%	37	8%	470	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 258,9 ; dof= 8.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	438	11%	1.930	48%	1.369	34%	169	4%	120	3%	4.026	100%
Ne	395	9%	1.915	42%	1.769	39%	233	5%	202	4%	4.514	100%
Ne znam	56	12%	175	36%	178	37%	55	11%	20	4%	484	100%
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 106,2 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Razumijevanje toga kako će bolest napredovati...

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	359	9%	2.268	56%	1.133	28%	197	5%	61	2%	4.018	100%
Ne	284	6%	2.512	56%	1.363	30%	243	5%	104	2%	4.506	100%
Ne znam	51	11%	219	45%	148	31%	54	11%	10	2%	482	100%
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 75,6 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	524	19%	488	18%	1.042	39%	204	8%	435	16%	2.693	100%
Ne	351	12%	523	18%	1.173	40%	281	9%	630	21%	2.958	100%
Ne znam	53	16%	45	13%	130	39%	47	14%	61	18%	336	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 92,8 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Mogućnost uključivanja u školski sustav…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	391	10%	433	11%	879	22%	275	7%	2.048	51%	4.026	100%
Ne	311	7%	482	11%	1.043	23%	282	6%	2.396	53%	4.514	100%
Ne znam	44	9%	45	9%	108	22%	56	12%	231	48%	484	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 45,2 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Mogućnost obavljanja radne djelatnosti…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	1.282	32%	379	9%	1.056	26%	228	6%	1.073	27%	4.018	100%
Ne	990	22%	397	9%	1.394	31%	280	6%	1.444	32%	4.505	100%
Ne znam	139	29%	42	9%	137	28%	43	9%	121	25%	482	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 127,4 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	621	15%	467	12%	1.322	33%	486	12%	1.121	28%	4.017	100%
Ne	431	10%	499	11%	1.429	32%	501	11%	1.645	37%	4.505	100%
Ne znam	82	17%	45	9%	155	32%	79	16%	121	25%	482	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 137,0 ; dof= 8.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Pristup kliničkim ispitivanjima…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	328	8%	1.085	27%	1.390	35%	627	16%	595	15%	4.025	100%
Ne	261	6%	1.015	22%	1.623	36%	813	18%	802	18%	4.514	100%
Ne znam	48	10%	97	20%	160	33%	124	26%	55	11%	484	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 92,4 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	937	23%	86	2%	1.003	25%	709	18%	1.290	32%	4.025	100%
Ne	690	15%	109	2%	1.226	27%	810	18%	1.678	37%	4.513	100%
Ne znam	88	18%	5	1%	116	24%	129	27%	146	30%	484	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 119,4 ; dof= 8.

Cross: …iznenadnu pojavu simptoma koji zahtijevaju hitnu skrb / Vaš društveni život…

…IZNENADNU POJAVU SIMPTOMA KOJI ZAHTIJEVAJU HITNU SKRB	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	2.240	56%	343	9%	1.194	30%	69	2%	171	4%	4.017	100%
Ne	2.074	46%	344	8%	1.715	38%	91	2%	281	6%	4.505	100%
Ne znam	257	53%	21	4%	155	32%	23	5%	26	5%	482	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 129,8 ; dof= 8.

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	22	11%	84	41%	75	36%	9	4%	16	8%	206	100%
Ne	865	10%	3.933	45%	3.241	37%	447	5%	326	4%	8.812	100%
TOTAL	**887**	**10%**	**4.017**	**45%**	**3.316**	**37%**	**456**	**5%**	**342**	**4%**	**9.018**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 9,8 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Razumijevanje toga kako će bolest napredovati...

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	18	9%	100	49%	57	28%	20	10%	9	4%	**204**	**100%**
Ne	676	8%	4.896	56%	2.586	29%	472	5%	166	2%	**8.796**	**100%**
TOTAL	**694**	**8%**	**4.996**	**56%**	**2.643**	**29%**	**492**	**5%**	**175**	**2%**	**9.000**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 15,8 ; dof= 4.

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	27	25%	17	16%	44	41%	5	5%	14	13%	**107**	**100%**
Ne	899	15%	1.038	18%	2.299	39%	527	9%	1.112	19%	**5.875**	**100%**
TOTAL	**926**	**15%**	**1.055**	**18%**	**2.343**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.982**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 11,1 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Mogućnost uključivanja u školski sustav…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	16	8%	26	13%	68	33%	16	8%	80	39%	**206**	**100%**
Ne	730	8%	933	11%	1.961	22%	597	7%	4.591	52%	**8.812**	**100%**
TOTAL	**746**	**8%**	**959**	**11%**	**2.029**	**22%**	**613**	**7%**	**4.671**	**52%**	**9.018**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 18,3 ; dof= 4.

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Mogućnost obavljanja radne djelatnosti…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	42	21%	22	11%	71	35%	17	8%	52	25%	**204**	**100%**
Ne	2.367	27%	796	9%	2.515	29%	534	6%	2.583	29%	**8.795**	**100%**
TOTAL	**2.409**	**27%**	**818**	**9%**	**2.586**	**29%**	**551**	**6%**	**2.635**	**29%**	**8.999**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 9,0 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	32	16%	24	12%	66	32%	26	13%	56	27%	**204**	**100%**
Ne	1.101	13%	987	11%	2.838	32%	1.040	12%	2.828	32%	**8.794**	**100%**
TOTAL	**1.133**	**13%**	**1.011**	**11%**	**2.904**	**32%**	**1.066**	**12%**	**2.884**	**32%**	**8.998**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,5 ; Chi2= 3,2 ; dof= 4.

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Pristup kliničkim ispitivanjima…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	21	10%	50	24%	66	32%	31	15%	38	18%	**206**	**100%**
Ne	614	7%	2.146	24%	3.105	35%	1.532	17%	1.414	16%	**8.811**	**100%**
TOTAL	**635**	**7%**	**2.196**	**24%**	**3.171**	**35%**	**1.563**	**17%**	**1.452**	**16%**	**9.017**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 4,9 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	37	18%	2	1%	65	32%	35	17%	67	33%	**206**	**100%**
Ne	1.677	19%	198	2%	2.279	26%	1.611	18%	3.045	35%	**8.810**	**100%**
TOTAL	**1.714**	**19%**	**200**	**2%**	**2.344**	**26%**	**1.646**	**18%**	**3.112**	**35%**	**9.016**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,3 ; Chi2= 4,5 ; dof= 4.

Cross: Rijetka bolest dijagnosticirana je prije rođenja / Vaš društveni život…

RIJETKA BOLEST DIJAGNOSTICIRANA JE PRIJE ROĐENJA	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	80	39%	20	10%	84	41%	5	2%	15	7%	**204**	**100%**
Ne	4.487	51%	688	8%	2.979	34%	178	2%	462	5%	**8.794**	**100%**
TOTAL	**4.567**	**51%**	**708**	**8%**	**3.063**	**34%**	**183**	**2%**	**477**	**5%**	**8.998**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 11,4 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	55	10%	231	42%	194	35%	36	7%	34	6%	**550**	**100%**
Ne	832	10%	3.786	45%	3.122	37%	420	5%	308	4%	**8.468**	**100%**
TOTAL	**887**	**10%**	**4.017**	**45%**	**3.316**	**37%**	**456**	**5%**	**342**	**4%**	**9.018**	

Under-represented elements *Over-represented elements*

The relationship is significant. p-value= 0,0 ; Chi2= 12,6 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Razumijevanje toga kako će bolest napredovati...

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	24	7%	202	56%	95	26%	22	6%	19	5%	**362**	**100%**
Ne	653	8%	4.708	56%	2.483	29%	457	5%	152	2%	**8.453**	**100%**
TOTAL	**677**	**8%**	**4.910**	**56%**	**2.578**	**29%**	**479**	**5%**	**171**	**2%**	**8.815**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 23,3 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	42	24%	28	16%	55	31%	21	12%	31	18%	**177**	**100%**
Ne	884	15%	1.027	18%	2.288	39%	511	9%	1.095	19%	**5.805**	**100%**
TOTAL	**926**	**15%**	**1.055**	**18%**	**2.343**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.982**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 13,4 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Mogućnost uključivanja u školski sustav…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	33	9%	70	19%	127	35%	43	12%	90	25%	**363**	**100%**
Ne	696	8%	860	10%	1.837	22%	552	7%	4.525	53%	**8.470**	**100%**
TOTAL	**729**	**8%**	**930**	**11%**	**1.964**	**22%**	**595**	**7%**	**4.615**	**52%**	**8.833**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 124,8 ; dof= 4.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Mogućnost obavljanja radne djelatnosti…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	109	20%	66	12%	165	30%	68	12%	141	26%	549	100%
Ne	2.300	27%	752	9%	2.421	29%	483	6%	2.494	30%	8.450	100%
TOTAL	**2.409**	**27%**	**818**	**9%**	**2.586**	**29%**	**551**	**6%**	**2.635**	**29%**	**8.999**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 56,4 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	54	15%	61	17%	106	29%	56	16%	84	23%	361	100%
Ne	1.051	12%	921	11%	2.740	32%	977	12%	2.763	33%	8.452	100%
TOTAL	**1.105**	**13%**	**982**	**11%**	**2.846**	**32%**	**1.033**	**12%**	**2.847**	**32%**	**8.813**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 28,1 ; dof= 4.

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Pristup kliničkim ispitivanjima…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	37	7%	135	25%	188	34%	105	19%	84	15%	**549**	**100%**
Ne	598	7%	2.061	24%	2.983	35%	1.458	17%	1.368	16%	**8.468**	**100%**
TOTAL	**635**	**7%**	**2.196**	**24%**	**3.171**	**35%**	**1.563**	**17%**	**1.452**	**16%**	**9.017**	

Under-represented elements *Over-represented elements*

The relationship is not significant. p-value= 0,8 ; Chi2= 1,5 ; dof= 4.

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	37	10%	14	4%	88	24%	106	29%	117	32%	**362**	**100%**
Ne	1.643	19%	179	2%	2.201	26%	1.503	18%	2.943	35%	**8.469**	**100%**
TOTAL	**1.680**	**19%**	**193**	**2%**	**2.289**	**26%**	**1.609**	**18%**	**3.060**	**35%**	**8.831**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 46,6 ; dof= 4.

Only respondents living with a diagnosed rare disease

Cross: Rijetka bolest je dijagnosticirana redovnim pretragama provedenim pri rođenju / Vaš društveni život…

RIJETKA BOLEST JE DIJAGNOSTICIRANA REDOVNIM PRETRAGAMA PROVEDENIM PRI ROĐENJU	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	141	39%	54	15%	124	34%	16	4%	26	7%	**361**	**100%**
Ne	4.352	51%	634	8%	2.864	34%	162	2%	440	5%	**8.452**	**100%**
TOTAL	**4.493**	**51%**	**688**	**8%**	**2.988**	**34%**	**178**	**2%**	**466**	**5%**	**8.813**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 48,6 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	131	11%	520	43%	420	35%	74	6%	52	4%	**1.197**	**100%**
Ne	756	10%	3.497	45%	2.896	37%	382	5%	290	4%	**7.821**	**100%**
TOTAL	**887**	**10%**	**4.017**	**45%**	**3.316**	**37%**	**456**	**5%**	**342**	**4%**	**9.018**	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 7,7 ; dof= 4.

Only respondents living with a diagnosed rare disease

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Razumijevanje toga kako će bolest napredovati...

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	101	8%	654	55%	384	32%	39	3%	17	1%	**1.195**	**100%**
Ne	593	8%	4.342	56%	2.259	29%	453	6%	158	2%	**7.805**	**100%**
TOTAL	**694**	**8%**	**4.996**	**56%**	**2.643**	**29%**	**492**	**5%**	**175**	**2%**	**9.000**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 18,9 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	127	13%	141	14%	400	41%	109	11%	200	20%	**977**	**100%**
Ne	799	16%	914	18%	1.943	39%	423	8%	926	19%	**5.005**	**100%**
TOTAL	**926**	**15%**	**1.055**	**18%**	**2.343**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.982**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 20,8 ; dof= 4.

Only respondents living with a diagnosed rare disease

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Mogućnost uključivanja u školski sustav…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	68	6%	81	7%	291	24%	87	7%	670	56%	1.197	100%
Ne	678	9%	878	11%	1.738	22%	526	7%	4.001	51%	7.821	100%
TOTAL	**746**	**8%**	**959**	**11%**	**2.029**	**22%**	**613**	**7%**	**4.671**	**52%**	**9.018**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 37,7 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Mogućnost obavljanja radne djelatnosti…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	277	23%	95	8%	369	31%	86	7%	368	31%	1.195	100%
Ne	2.132	27%	723	9%	2.217	28%	465	6%	2.267	29%	7.804	100%
TOTAL	**2.409**	**27%**	**818**	**9%**	**2.586**	**29%**	**551**	**6%**	**2.635**	**29%**	**8.999**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 14,5 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	134	11%	113	9%	340	28%	147	12%	461	39%	1.195	100%
Ne	999	13%	898	12%	2.564	33%	919	12%	2.423	31%	7.803	100%
TOTAL	**1.133**	**13%**	**1.011**	**11%**	**2.904**	**32%**	**1.066**	**12%**	**2.884**	**32%**	**8.998**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 30,8 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Pristup kliničkim ispitivanjima…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	85	7%	345	29%	393	33%	192	16%	182	15%	1.197	100%
Ne	550	7%	1.851	24%	2.778	36%	1.371	18%	1.270	16%	7.820	100%
TOTAL	**635**	**7%**	**2.196**	**24%**	**3.171**	**35%**	**1.563**	**17%**	**1.452**	**16%**	**9.017**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 15,5 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Only respondents living with a diagnosed rare disease

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	262	22%	26	2%	306	26%	213	18%	390	33%	1.197	100%
Ne	1.452	19%	174	2%	2.038	26%	1.433	18%	2.722	35%	7.819	100%
TOTAL	1.714	19%	200	2%	2.344	26%	1.646	18%	3.112	35%	9.016	

Under-represented elements *Over-represented elements*

The relationship is weakly significant. p-value= 0,1 ; Chi2= 7,8 ; dof= 4.

Cross: Ista bolest je ranije dijagnosticirana članovima obitelji / Vaš društveni život…

ISTA BOLEST JE RANIJE DIJAGNOSTICIRANA ČLANOVIMA OBITELJI	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
Da	521	44%	95	8%	465	39%	31	3%	83	7%	1.195	100%
Ne	4.046	52%	613	8%	2.598	33%	152	2%	394	5%	7.803	100%
TOTAL	4.567	51%	708	8%	3.063	34%	183	2%	477	5%	8.998	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 32,7 ; dof= 4.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …psihološka podrška / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	66	9%	384	50%	261	34%	41	5%	20	3%	772	100%
DA, ali nije potrebno / nije bilo potrebno	62	8%	381	46%	306	37%	30	4%	43	5%	822	100%
DA, ali NE dovoljno da zadovolji moje potrebe	104	13%	348	44%	278	35%	44	6%	23	3%	797	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	217	8%	1.232	45%	1.035	37%	142	5%	136	5%	2.762	100%
NE, ali je potrebno / je bilo potrebno	440	11%	1.675	43%	1.436	37%	200	5%	120	3%	3.871	100%
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 71,4 ; dof= 16.

Cross: …psihološka podrška / Razumijevanje toga kako će bolest napredovati...

	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	63	8%	466	61%	204	26%	24	3%	13	2%	770	100%
DA, ali nije potrebno / nije bilo potrebno	48	6%	466	57%	247	30%	42	5%	17	2%	820	100%
DA, ali NE dovoljno da zadovolji moje potrebe	75	9%	409	51%	241	30%	52	7%	19	2%	796	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	146	5%	1.545	56%	850	31%	147	5%	71	3%	2.759	100%
NE, ali je potrebno / je bilo potrebno	362	9%	2.113	55%	1.102	29%	229	6%	55	1%	3.861	100%
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 77,2 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …psihološka podrška / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	63	14%	95	22%	176	40%	22	5%	84	19%	**440**	**100%**
DA, ali nije potrebno / nije bilo potrebno	72	13%	99	18%	218	40%	51	9%	107	20%	**547**	**100%**
DA, ali NE dovoljno da zadovolji moje potrebe	113	25%	78	17%	185	40%	26	6%	57	12%	**459**	**100%**
NE, ali NIJE potrebno / NIJE bilo potrebno	215	10%	325	16%	795	38%	217	10%	539	26%	**2.091**	**100%**
NE, ali je potrebno / je bilo potrebno	465	19%	459	19%	971	40%	216	9%	339	14%	**2.450**	**100%**
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 209,4 ; dof= 16.

Cross: …psihološka podrška / Mogućnost uključivanja u školski sustav…

	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	51	7%	130	17%	156	20%	45	6%	390	51%	**772**	**100%**
DA, ali nije potrebno / nije bilo potrebno	52	6%	85	10%	171	21%	56	7%	458	56%	**822**	**100%**
DA, ali NE dovoljno da zadovolji moje potrebe	110	14%	106	13%	161	20%	51	6%	369	46%	**797**	**100%**
NE, ali NIJE potrebno / NIJE bilo potrebno	133	5%	216	8%	614	22%	200	7%	1.599	58%	**2.762**	**100%**
NE, ali je potrebno / je bilo potrebno	400	10%	423	11%	928	24%	261	7%	1.859	48%	**3.871**	**100%**
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 198,3 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …psihološka podrška / Mogućnost obavljanja radne djelatnosti…

	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	199	26%	80	10%	207	27%	33	4%	251	33%	770	100%
DA, ali nije potrebno / nije bilo potrebno	190	23%	89	11%	223	27%	49	6%	269	33%	820	100%
DA, ali NE dovoljno da zadovolji moje potrebe	257	32%	81	10%	178	22%	56	7%	224	28%	796	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	538	20%	223	8%	845	31%	181	7%	971	35%	2.758	100%
NE, ali je potrebno / je bilo potrebno	1.227	32%	345	9%	1.134	29%	232	6%	923	24%	3.861	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 213,3 ; dof= 16.

Cross: …psihološka podrška / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	78	10%	160	21%	236	31%	76	10%	220	29%	770	100%
DA, ali nije potrebno / nije bilo potrebno	59	7%	115	14%	260	32%	95	12%	291	35%	820	100%
DA, ali NE dovoljno da zadovolji moje potrebe	149	19%	124	16%	264	33%	91	11%	168	21%	796	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	203	7%	228	8%	752	27%	327	12%	1.247	45%	2.757	100%
NE, ali je potrebno / je bilo potrebno	645	17%	384	10%	1.394	36%	477	12%	961	25%	3.861	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 557,1 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …psihološka podrška / Pristup kliničkim ispitivanjima…

	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	38	5%	228	30%	243	31%	131	17%	132	17%	772	100%
DA, ali nije potrebno / nije bilo potrebno	40	5%	200	24%	301	37%	126	15%	155	19%	822	100%
DA, ali NE dovoljno da zadovolji moje potrebe	88	11%	187	23%	269	34%	140	18%	113	14%	797	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	140	5%	693	25%	945	34%	467	17%	516	19%	2.761	100%
NE, ali je potrebno / je bilo potrebno	331	9%	889	23%	1.415	37%	700	18%	536	14%	3.871	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 108,8 ; dof= 16.

Cross: …psihološka podrška / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	140	18%	24	3%	182	24%	132	17%	294	38%	772	100%
DA, ali nije potrebno / nije bilo potrebno	160	19%	23	3%	200	24%	142	17%	297	36%	822	100%
DA, ali NE dovoljno da zadovolji moje potrebe	195	24%	23	3%	197	25%	155	19%	227	28%	797	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	361	13%	47	2%	699	25%	474	17%	1.179	43%	2.760	100%
NE, ali je potrebno / je bilo potrebno	859	22%	83	2%	1.067	28%	745	19%	1.117	29%	3.871	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 207,9 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …psihološka podrška / Vaš društveni život…

	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PSIHOLOŠKA PODRŠKA	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	364	47%	83	11%	269	35%	17	2%	37	5%	770	100%
DA, ali nije potrebno / nije bilo potrebno	369	45%	71	9%	312	38%	12	1%	56	7%	820	100%
DA, ali NE dovoljno da zadovolji moje potrebe	523	66%	71	9%	172	22%	11	1%	19	2%	796	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	1.041	38%	188	7%	1.226	44%	63	2%	239	9%	2.757	100%
NE, ali je potrebno / je bilo potrebno	2.274	59%	295	8%	1.085	28%	80	2%	127	3%	3.861	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 475,9 ; dof= 16.

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	101	6%	960	53%	622	34%	73	4%	61	3%	1.817	100%
DA, ali nije potrebno / nije bilo potrebno	26	8%	147	46%	121	38%	12	4%	12	4%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	135	11%	558	44%	451	36%	67	5%	46	4%	1.257	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	98	7%	596	43%	541	39%	84	6%	81	6%	1.400	100%
NE, ali je potrebno / je bilo potrebno	529	13%	1.759	42%	1.581	37%	221	5%	142	3%	4.232	100%
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 146,4 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Razumijevanje toga kako će bolest napredovati...

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	87	5%	1.145	63%	478	26%	68	4%	35	2%	1.813	100%
DA, ali nije potrebno / nije bilo potrebno	19	6%	171	54%	106	33%	18	6%	4	1%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	107	9%	685	55%	360	29%	76	6%	26	2%	1.254	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	73	5%	759	54%	449	32%	76	5%	41	3%	1.398	100%
NE, ali je potrebno / je bilo potrebno	408	10%	2.239	53%	1.251	30%	256	6%	69	2%	4.223	100%
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 113,4 ; dof= 16.

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	111	10%	210	19%	441	40%	104	9%	243	22%	1.109	100%
DA, ali nije potrebno / nije bilo potrebno	23	11%	40	19%	70	33%	24	11%	53	25%	210	100%
DA, ali NE dovoljno da zadovolji moje potrebe	150	21%	135	19%	276	38%	56	8%	107	15%	724	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	91	8%	158	15%	418	39%	106	10%	309	29%	1.082	100%
NE, ali je potrebno / je bilo potrebno	553	19%	513	18%	1.140	40%	242	8%	414	14%	2.862	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 213,6 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Mogućnost uključivanja u školski sustav…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	107	6%	266	15%	402	22%	124	7%	918	51%	1.817	100%
DA, ali nije potrebno / nije bilo potrebno	20	6%	25	8%	70	22%	34	11%	169	53%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	111	9%	171	14%	317	25%	90	7%	568	45%	1.257	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	65	5%	104	7%	297	21%	89	6%	845	60%	1.400	100%
NE, ali je potrebno / je bilo potrebno	443	10%	394	9%	944	22%	276	7%	2.175	51%	4.232	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 166,9 ; dof= 16.

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Mogućnost obavljanja radne djelatnosti…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	365	20%	213	12%	526	29%	102	6%	607	33%	1.813	100%
DA, ali nije potrebno / nije bilo potrebno	71	22%	18	6%	95	30%	34	11%	100	31%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	384	31%	95	8%	355	28%	91	7%	329	26%	1.254	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	256	18%	118	8%	427	31%	92	7%	504	36%	1.397	100%
NE, ali je potrebno / je bilo potrebno	1.335	32%	374	9%	1.184	28%	232	5%	1.098	26%	4.223	100%
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 208,6 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	144	8%	294	16%	506	28%	191	11%	677	37%	1.812	100%
DA, ali nije potrebno / nije bilo potrebno	25	8%	31	10%	107	34%	42	13%	113	36%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	190	15%	155	12%	423	34%	169	13%	317	25%	1.254	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	100	7%	100	7%	367	26%	162	12%	668	48%	1.397	100%
NE, ali je potrebno / je bilo potrebno	675	16%	431	10%	1.503	36%	502	12%	1.112	26%	4.223	100%
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 415,5 ; dof= 16.

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Pristup kliničkim ispitivanjima…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	61	3%	604	33%	577	32%	267	15%	307	17%	1.816	100%
DA, ali nije potrebno / nije bilo potrebno	20	6%	77	24%	123	39%	47	15%	51	16%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	99	8%	302	24%	463	37%	238	19%	155	12%	1.257	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	56	4%	340	24%	442	32%	230	16%	332	24%	1.400	100%
NE, ali je potrebno / je bilo potrebno	401	9%	874	21%	1.568	37%	782	18%	607	14%	4.232	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 275,3 ; dof= 16.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	260	14%	68	4%	449	25%	306	17%	733	40%	1.816	100%
DA, ali nije potrebno / nije bilo potrebno	49	15%	12	4%	84	26%	56	18%	117	37%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	239	19%	24	2%	349	28%	285	23%	360	29%	1.257	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	207	15%	17	1%	337	24%	234	17%	604	43%	1.399	100%
NE, ali je potrebno / je bilo potrebno	960	23%	79	2%	1.126	27%	767	18%	1.300	31%	4.232	100%
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 199,8 ; dof= 16.

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Vaš društveni život…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	747	41%	175	10%	725	40%	35	2%	130	7%	1.812	100%
DA, ali nije potrebno / nije bilo potrebno	135	42%	21	7%	134	42%	9	3%	19	6%	318	100%
DA, ali NE dovoljno da zadovolji moje potrebe	683	54%	104	8%	397	32%	26	2%	44	4%	1.254	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	538	39%	95	7%	615	44%	26	2%	123	9%	1.397	100%
NE, ali je potrebno / je bilo potrebno	2.468	58%	313	7%	1.193	28%	87	2%	162	4%	4.223	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 322,2 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	83	7%	626	52%	406	34%	44	4%	43	4%	1.202	100%
DA, ali nije potrebno / nije bilo potrebno	15	7%	106	52%	71	35%	4	2%	8	4%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	117	11%	448	44%	373	36%	61	6%	27	3%	1.026	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	195	6%	1.455	46%	1.167	37%	156	5%	165	5%	3.138	100%
NE, ali je potrebno / je bilo potrebno	475	14%	1.364	40%	1.283	38%	190	6%	98	3%	3.410	100%
TOTAL	**885**	**10%**	**3.999**	**45%**	**3.300**	**37%**	**455**	**5%**	**341**	**4%**	**8.980**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 195,3 ; dof= 16.

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Razumijevanje toga kako će bolest napredovati...

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	75	6%	741	62%	297	25%	56	5%	29	2%	1.198	100%
DA, ali nije potrebno / nije bilo potrebno	14	7%	116	57%	61	30%	8	4%	5	2%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	113	11%	551	54%	285	28%	58	6%	15	1%	1.022	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	132	4%	1.825	58%	968	31%	140	4%	72	2%	3.137	100%
NE, ali je potrebno / je bilo potrebno	358	11%	1.741	51%	1.023	30%	228	7%	52	2%	3.402	100%
TOTAL	**692**	**8%**	**4.974**	**55%**	**2.634**	**29%**	**490**	**5%**	**173**	**2%**	**8.963**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 165,5 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	56	9%	234	36%	300	46%	29	4%	29	4%	648	100%
DA, ali nije potrebno / nije bilo potrebno	9	8%	15	13%	64	53%	7	6%	25	21%	120	100%
DA, ali NE dovoljno da zadovolji moje potrebe	127	24%	127	24%	220	42%	22	4%	27	5%	523	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	137	6%	296	12%	854	35%	281	12%	859	35%	2.427	100%
NE, ali je potrebno / je bilo potrebno	599	26%	384	17%	907	40%	193	9%	186	8%	2.269	100%
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.246,3 ; dof= 16.

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Mogućnost uključivanja u školski sustav…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	67	6%	197	16%	288	24%	80	7%	570	47%	1.202	100%
DA, ali nije potrebno / nije bilo potrebno	11	5%	26	13%	58	28%	15	7%	94	46%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	121	12%	144	14%	258	25%	75	7%	428	42%	1.026	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	154	5%	225	7%	632	20%	182	6%	1.945	62%	3.138	100%
NE, ali je potrebno / je bilo potrebno	390	11%	361	11%	783	23%	257	8%	1.619	47%	3.410	100%
TOTAL	**743**	**8%**	**953**	**11%**	**2.019**	**22%**	**609**	**7%**	**4.656**	**52%**	**8.980**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 321,6 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Mogućnost obavljanja radne djelatnosti…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	215	18%	140	12%	322	27%	75	6%	446	37%	1.198	100%
DA, ali nije potrebno / nije bilo potrebno	29	14%	24	12%	71	35%	19	9%	61	30%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	308	30%	77	8%	285	28%	76	7%	276	27%	1.022	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	664	21%	259	8%	991	32%	161	5%	1.062	34%	3.137	100%
NE, ali je potrebno / je bilo potrebno	1.185	35%	314	9%	903	27%	218	6%	781	23%	3.401	100%
TOTAL	**2.401**	**27%**	**814**	**9%**	**2.572**	**29%**	**549**	**6%**	**2.626**	**29%**	**8.962**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 313,4 ; dof= 16.

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	90	8%	245	20%	381	32%	111	9%	371	31%	1.198	100%
DA, ali nije potrebno / nije bilo potrebno	11	5%	29	14%	73	36%	24	12%	67	33%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	187	18%	137	13%	402	39%	122	12%	174	17%	1.022	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	146	5%	236	8%	823	26%	384	12%	1.548	49%	3.137	100%
NE, ali je potrebno / je bilo potrebno	693	20%	358	11%	1.209	36%	421	12%	719	21%	3.400	100%
TOTAL	**1.127**	**13%**	**1.005**	**11%**	**2.888**	**32%**	**1.062**	**12%**	**2.879**	**32%**	**8.961**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 1.079,0 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Pristup kliničkim ispitivanjima…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	45	4%	374	31%	379	32%	202	17%	202	17%	1.202	100%
DA, ali nije potrebno / nije bilo potrebno	8	4%	61	30%	74	36%	37	18%	24	12%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	105	10%	235	23%	380	37%	159	15%	147	14%	1.026	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	109	3%	826	26%	1.054	34%	546	17%	603	19%	3.138	100%
NE, ali je potrebno / je bilo potrebno	367	11%	693	20%	1.265	37%	614	18%	470	14%	3.409	100%
TOTAL	**634**	**7%**	**2.189**	**24%**	**3.152**	**35%**	**1.558**	**17%**	**1.446**	**16%**	**8.979**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 263,0 ; dof= 16.

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	147	12%	60	5%	314	26%	215	18%	466	39%	1.202	100%
DA, ali nije potrebno / nije bilo potrebno	25	12%	6	3%	58	28%	40	20%	75	37%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	275	27%	26	3%	278	27%	193	19%	254	25%	1.026	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	384	12%	41	1%	722	23%	545	17%	1.446	46%	3.138	100%
NE, ali je potrebno / je bilo potrebno	874	26%	66	2%	956	28%	645	19%	867	25%	3.408	100%
TOTAL	**1.705**	**19%**	**199**	**2%**	**2.328**	**26%**	**1.638**	**18%**	**3.108**	**35%**	**8.978**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 534,3 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …financijska potpora, uključujući pogodnosti socijalnog osiguranja / Vaš društveni život…

…FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	516	43%	117	10%	463	39%	21	2%	81	7%	1.198	100%
DA, ali nije potrebno / nije bilo potrebno	75	37%	15	7%	98	48%	5	2%	11	5%	204	100%
DA, ali NE dovoljno da zadovolji moje potrebe	610	60%	81	8%	282	28%	25	2%	24	2%	1.022	100%
NE, ali NIJE potrebno / NIJE bilo potrebno	1.289	41%	248	8%	1.303	42%	62	2%	235	7%	3.137	100%
NE, ali je potrebno / je bilo potrebno	2.058	61%	242	7%	908	27%	68	2%	124	4%	3.400	100%
TOTAL	**4.548**	**51%**	**703**	**8%**	**3.054**	**34%**	**181**	**2%**	**475**	**5%**	**8.961**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 373,8 ; dof= 16.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	435	9%	2.407	51%	1.596	34%	160	3%	148	3%	**4.746**	**100%**
DA, preko internetskih zajednica	439	10%	1.937	44%	1.690	38%	221	5%	139	3%	**4.426**	**100%**
DA, putem lokalnih mreža (npr. škole)	34	9%	201	52%	124	32%	10	3%	15	4%	**384**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	16	11%	38	27%	67	48%	15	11%	5	4%	**141**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	115	12%	332	34%	404	41%	80	8%	45	5%	**976**	**100%**
NE, jer ne želim	41	9%	172	38%	163	36%	37	8%	35	8%	**448**	**100%**
Ostalo, navesti	40	9%	194	44%	146	33%	30	7%	30	7%	**440**	**100%**
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 233,2 ; dof= 24.

Sample information : IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Razumijevanje toga kako će bolest napredovati...

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	RAZUMIJEVANJE TOGA KAKO ĆE BOLEST NAPREDOVATI...											
	...POGORŠAO SE		...POBOLJŠAN JE		...OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	273	6%	3.033	64%	1.206	25%	147	3%	80	2%	**4.739**	**100%**
DA, preko internetskih zajednica	333	8%	2.508	57%	1.273	29%	227	5%	71	2%	**4.412**	**100%**
DA, putem lokalnih mreža (npr. škole)	30	8%	235	61%	102	27%	12	3%	5	1%	**384**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	24	17%	45	32%	49	35%	21	15%	2	1%	**141**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	127	13%	341	35%	369	38%	116	12%	22	2%	**975**	**100%**
NE, jer ne želim	28	6%	206	46%	166	37%	36	8%	12	3%	**448**	**100%**
Ostalo, navesti	39	9%	238	54%	124	28%	19	4%	19	4%	**439**	**100%**
TOTAL	**694**	**8%**	**4.999**	**56%**	**2.644**	**29%**	**494**	**5%**	**175**	**2%**	**9.006**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 474,5 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Financijska potpora, uključujući pogodnosti socijalnog osiguranja…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	FINANCIJSKA POTPORA, UKLJUČUJUĆI POGODNOSTI SOCIJALNOG OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	442	14%	618	20%	1.262	40%	249	8%	571	18%	**3.142**	**100%**
DA, preko internetskih zajednica	514	17%	545	18%	1.184	39%	264	9%	521	17%	**3.028**	**100%**
DA, putem lokalnih mreža (npr. škole)	34	16%	42	19%	84	38%	22	10%	37	17%	**219**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	19	27%	8	11%	27	39%	8	11%	8	11%	**70**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	111	18%	74	12%	261	41%	64	10%	121	19%	**631**	**100%**
NE, jer ne želim	46	14%	56	18%	109	34%	26	8%	83	26%	**320**	**100%**
Ostalo, navesti	42	14%	57	19%	104	34%	30	10%	70	23%	**303**	**100%**
TOTAL	**928**	**16%**	**1.056**	**18%**	**2.345**	**39%**	**532**	**9%**	**1.126**	**19%**	**5.987**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 69,6 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Mogućnost uključivanja u školski sustav…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	MOGUĆNOST UKLJUČIVANJA U ŠKOLSKI SUSTAV…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	373	8%	594	13%	1.084	23%	303	6%	2.392	50%	4.746	100%
DA, preko internetskih zajednica	368	8%	437	10%	955	22%	305	7%	2.361	53%	4.426	100%
DA, putem lokalnih mreža (npr. škole)	38	10%	82	21%	90	23%	18	5%	156	41%	384	100%
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	23	16%	16	11%	39	28%	7	5%	56	40%	141	100%
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	92	9%	70	7%	242	25%	63	6%	509	52%	976	100%
NE, jer ne želim	30	7%	36	8%	93	21%	36	8%	253	56%	448	100%
Ostalo, navesti	36	8%	42	10%	82	19%	27	6%	253	58%	440	100%
TOTAL	**746**	**8%**	**960**	**11%**	**2.030**	**22%**	**613**	**7%**	**4.675**	**52%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 127,4 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Mogućnost obavljanja radne djelatnosti…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	MOGUĆNOST OBAVLJANJA RADNE DJELATNOSTI…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	1.245	26%	489	10%	1.405	30%	253	5%	1.347	28%	**4.739**	**100%**
DA, preko internetskih zajednica	1.261	29%	406	9%	1.205	27%	267	6%	1.273	29%	**4.412**	**100%**
DA, putem lokalnih mreža (npr. škole)	105	27%	39	10%	120	31%	21	5%	99	26%	**384**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	45	32%	9	6%	42	30%	5	4%	40	28%	**141**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	259	27%	56	6%	286	29%	66	7%	307	32%	**974**	**100%**
NE, jer ne želim	90	20%	44	10%	132	29%	36	8%	146	33%	**448**	**100%**
Ostalo, navesti	99	23%	32	7%	114	26%	29	7%	165	38%	**439**	**100%**
TOTAL	**2.411**	**27%**	**818**	**9%**	**2.587**	**29%**	**551**	**6%**	**2.638**	**29%**	**9.005**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 74,7 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Pristup uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove)…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	PRISTUP USLUGAMA SOCIJALNIH SLUŽBI (NPR. PODRŠKA SOCIJALNOG RADNIKA, PODRŠKA ZA KUĆANSKE POSLOVE)…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	556	12%	622	13%	1.559	33%	515	11%	1.486	31%	**4.738**	**100%**
DA, preko internetskih zajednica	566	13%	521	12%	1.443	33%	534	12%	1.348	31%	**4.412**	**100%**
DA, putem lokalnih mreža (npr. škole)	53	14%	68	18%	133	35%	43	11%	87	23%	**384**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	28	20%	8	6%	58	41%	14	10%	33	23%	**141**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	145	15%	79	8%	306	31%	123	13%	321	33%	**974**	**100%**
NE, jer ne želim	47	10%	41	9%	116	26%	59	13%	185	41%	**448**	**100%**
Ostalo, navesti	59	13%	58	13%	113	26%	47	11%	162	37%	**439**	**100%**
TOTAL	**1.134**	**13%**	**1.011**	**11%**	**2.906**	**32%**	**1.066**	**12%**	**2.887**	**32%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 117,7 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Pristup kliničkim ispitivanjima…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	PRISTUP KLINIČKIM ISPITIVANJIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	287	6%	1.458	31%	1.621	34%	689	15%	690	15%	4.745	100%
DA, preko internetskih zajednica	342	8%	1.057	24%	1.598	36%	800	18%	629	14%	4.426	100%
DA, putem lokalnih mreža (npr. škole)	19	5%	119	31%	133	35%	59	15%	54	14%	384	100%
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	23	16%	19	13%	48	34%	32	23%	19	13%	141	100%
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	89	9%	151	15%	353	36%	200	20%	183	19%	976	100%
NE, jer ne želim	24	5%	78	17%	144	32%	105	23%	97	22%	448	100%
Ostalo, navesti	31	7%	107	24%	133	30%	68	15%	101	23%	440	100%
TOTAL	**637**	**7%**	**2.197**	**24%**	**3.173**	**35%**	**1.564**	**17%**	**1.452**	**16%**	**9.023**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 264,4 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Pristup financijskim proizvodima, poput kredita, hipoteka, osiguranja…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	PRISTUP FINANCIJSKIM PROIZVODIMA, POPUT KREDITA, HIPOTEKA, OSIGURANJA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	892	19%	119	3%	1.276	27%	825	17%	1.633	34%	**4.745**	**100%**
DA, preko internetskih zajednica	915	21%	86	2%	1.123	25%	831	19%	1.471	33%	**4.426**	**100%**
DA, putem lokalnih mreža (npr. škole)	74	19%	12	3%	107	28%	63	16%	128	33%	**384**	**100%**
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	37	26%	3	2%	40	28%	22	16%	39	28%	**141**	**100%**
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	175	18%	21	2%	246	25%	183	19%	350	36%	**975**	**100%**
NE, jer ne želim	71	16%	9	2%	98	22%	88	20%	182	41%	**448**	**100%**
Ostalo, navesti	94	21%	10	2%	93	21%	78	18%	165	38%	**440**	**100%**
TOTAL	**1.715**	**19%**	**200**	**2%**	**2.345**	**26%**	**1.648**	**18%**	**3.114**	**35%**	**9.022**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 44,9 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: Jeste li Vi ili osoba o kojoj skrbite u kontaktu s drugim osobama koje žive s istom rijetkom bolešću ili s kakvom nedijagnosticiranom rijetkom bolešću? / Vaš društveni život…

JESTE LI VI ILI OSOBA O KOJOJ SKRBITE U KONTAKTU S DRUGIM OSOBAMA KOJE ŽIVE S ISTOM RIJETKOM BOLEŠĆU ILI S KAKVOM NEDIJAGNOSTICIRANOM RIJETKOM BOLEŠĆU?	VAŠ DRUŠTVENI ŽIVOT…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, preko udruge oboljelih	2.290	48%	452	10%	1.694	36%	79	2%	223	5%	4.738	100%
DA, preko internetskih zajednica	2.375	54%	342	8%	1.407	32%	83	2%	205	5%	4.412	100%
DA, putem lokalnih mreža (npr. škole)	189	49%	39	10%	138	36%	2	1%	16	4%	384	100%
NE, zbog problema s pristupačnošću (npr. jezične ili tehničke prepreke)	75	53%	9	6%	50	35%	0	0%	7	5%	141	100%
NE, jer nisam mogao/mogla pronaći druge osobe s istom bolešću	486	50%	55	6%	338	35%	31	3%	64	7%	974	100%
NE, jer ne želim	206	46%	24	5%	170	38%	12	3%	36	8%	448	100%
Ostalo, navesti	199	45%	33	8%	156	36%	11	3%	40	9%	439	100%
TOTAL	**4.571**	**51%**	**708**	**8%**	**3.064**	**34%**	**183**	**2%**	**478**	**5%**	**9.004**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 109,0 ; dof= 24.

*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Cross: …podrška koordinaciji skrbi, kao što je pomoć u pronalaženju neophodnih informacija o bolesti i odgovarajućim stručnjacima, dogovaranje termina kod različitih zdravstvenih djelatnika, itd. / Pristup najprilagođenijoj skrbi, liječenju ili kirurškim zahvatima…

…PODRŠKA KOORDINACIJI SKRBI, KAO ŠTO JE POMOĆ U PRONALAŽENJU NEOPHODNIH INFORMACIJA O BOLESTI I ODGOVARAJUĆIM STRUČNJACIMA, DOGOVARANJE TERMINA KOD RAZLIČITIH ZDRAVSTVENIH DJELATNIKA, ITD.	PRISTUP NAJPRILAGOĐENIJOJ SKRBI, LIJEČENJU ILI KIRURŠKIM ZAHVATIMA…											
	…POGORŠAO SE		…POBOLJŠAN JE		…OSTAO JE ISTI		NE ZNAM		NIJE BITNO		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
DA, i to dovoljno za moje potrebe	101	6%	960	53%	622	34%	73	4%	61	3%	**1.817**	**100%**
DA, ali nije potrebno / nije bilo potrebno	26	8%	147	46%	121	38%	12	4%	12	4%	**318**	**100%**
DA, ali NE dovoljno da zadovolji moje potrebe	135	11%	558	44%	451	36%	67	5%	46	4%	**1.257**	**100%**
NE, ali NIJE potrebno / NIJE bilo potrebno	98	7%	596	43%	541	39%	84	6%	81	6%	**1.400**	**100%**
NE, ali je potrebno / je bilo potrebno	529	13%	1.759	42%	1.581	37%	221	5%	142	3%	**4.232**	**100%**
TOTAL	**889**	**10%**	**4.020**	**45%**	**3.316**	**37%**	**457**	**5%**	**342**	**4%**	**9.024**	

Under-represented elements *Over-represented elements*

The relationship is very significant. p-value= < 0,01 ; Chi2= 146,4 ; dof= 16.



Chapter 16.

Questions for undiagnosed respondents

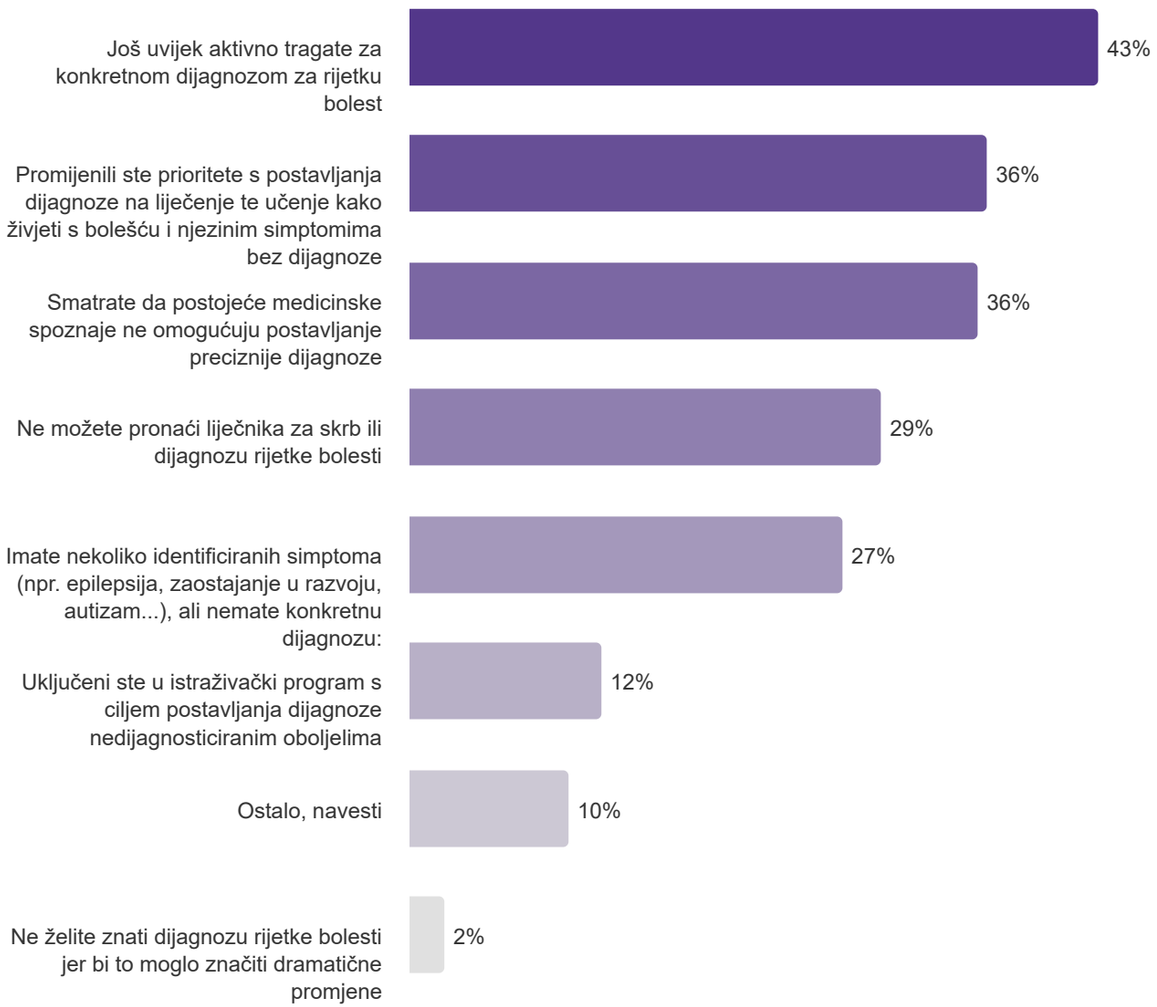
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*Sample information : **IN_TOUCH is not among "Non-response" And CONSENT is not among "Ne" And EUROPE_VS_WORLD among "Europe"***
Sample size 10486 responses

Question asked only to respondents who are undiagnosed (partial diagnosis or unsolved cases)

Odaberite sve izjave koje opisuju Vašu situaciju. Vi ili osoba o kojoj skrbite:



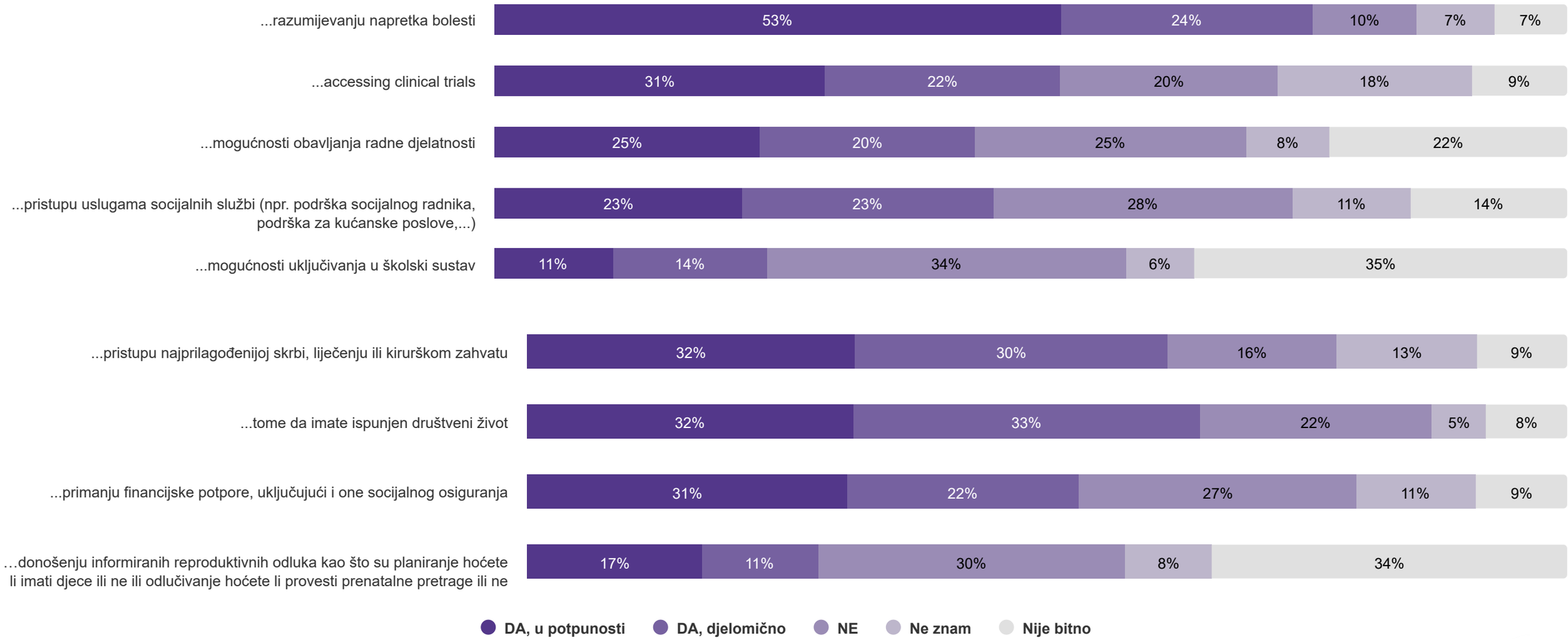
Odaberite sve izjave koje opisuju Vašu situaciju. Vi ili osoba o kojoj skrbite:

	N
Još uvijek aktivno tragate za konkretnom dijagnozom za rijetku bolest	278
Promijenili ste prioritete s postavljanja dijagnoze na liječenje te učenje kako živjeti s bolešću i njezinim simptomima bez dijagnoze	233
Smatrate da postojeće medicinske spoznaje ne omogućuju postavljanje preciznije dijagnoze	229
Ne možete pronaći liječnika za skrb ili dijagnozu rijetke bolesti	190
Imate nekoliko identificiranih simptoma (npr. epilepsija, zaostajanje u razvoju, autizam...), ali nemate konkretnu dijagnozu:	175
Uključeni ste u istraživački program s ciljem postavljanja dijagnoze nedijagnosticiranim oboljelima	78
Ostalo, navesti	65
Ne želite znati dijagnozu rijetke bolesti jer bi to moglo značiti dramatične promjene	15
TOTAL	**645**

10. Consequences of being undiagnosed

Question asked only to respondents who are undiagnosed (partial diagnosis or unsolved cases)

Sprečava li Vas nedostatak precizne dijagnoze rijetke bolesti u...



Question asked only to respondents who are undiagnosed (partial diagnosis or unsolved cases)

Sprečava li Vas nedostatak precizne dijagnoze rijetke bolesti u...

	DA, U POTPUNOSTI	DA, DJELOMIČNO	NE	NE ZNAM	NIJE BITNO	TOTAL
...accessing clinical trials	218	154	143	127	62	**704**
...razumijevanju napretka bolesti	369	164	67	51	46	**697**
...mogućnosti uključivanja u školski sustav	79	101	236	44	244	**704**
...mogućnosti obavljanja radne djelatnosti	173	140	177	53	154	**697**
...pristupu uslugama socijalnih službi (npr. podrška socijalnog radnika, podrška za kućanske poslove,...)	162	163	195	76	101	**697**

	DA, DJELOMIČNO	DA, U POTPUNOSTI	NE	NE ZNAM	NIJE BITNO	TOTAL
...pristupu najprilagođenijoj skrbi, liječenju ili kirurškom zahvatu	212	223	115	95	60	**705**
…donošenju informiranih reproduktivnih odluka kao što su planiranje hoćete li imati djece ili ne ili odlučivanje hoćete li provesti prenatalne pretrage ili ne	78	118	206	58	237	**697**
...primanju financijske potpore, uključujući i one socijalnog osiguranja	155	214	185	79	60	**693**
...tome da imate ispunjen društveni život	232	220	155	36	54	**697**

THANK YOU!

Thank you to all the people living with rare diseases who participated in the survey, and to the Rare Barometer partners and corporate donors in 2021.

A special thank you to our National Alliances and European Federations who helped us spread the word about the survey and contributed to the great number of respondents.

Together we can make the voice of the rare disease community stronger.



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