

SLOVENSKI REGISTER ZA CEREBRALNO PARALIZO (CP) IN POMEN ZA OBRAVNAVO OTROK S CP

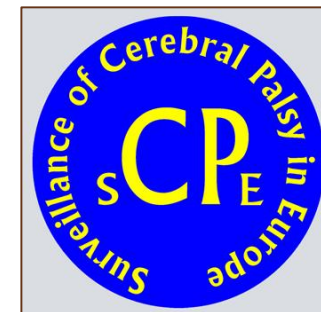
Anja Troha Gergeli, spec. ped.

Klinični oddelek za otroško, mladostniško in
razvojno nevrologijo

Srečanje CIRIUS Kamnik, 19.11.2021

ZGODOVINA SLOVENSKEGA REGISTRA ZA CEREBRALNO PARALIZO (SRCP)

- L.1998 formirana Evropska baza podatkov za nadzor otrok s CP (ang. *Surveillance of Cerebral Palsy in Europe, SCPE*)
- SCPE – podatki iz 20 EU držav, 31 medicinskih centrov o otrocih s CP
- L.2010 ustanovitev SRCP na Pediatrični kliniki
- L.2011 vzpostavitev elektronske baze SRCP
- SRCP je del SCPEja
- L.2016 SCPE postane del EU Platforme za Registracijo Redkih Bolezni (Platform for Rare Diseases Registration, Joint Research Centre (JRC))



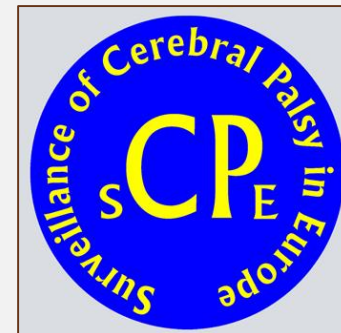
SCPE



[https://eu-rd-
platform.jrc.ec.europa.eu/scpe](https://eu-rd-platform.jrc.ec.europa.eu/scpe)

SURVEILLANCE OF CEREBRAL PALSY IN EUROPE (SCPE)

- Zajema več kot 20.000 otrok s CP (roj l. 1975 – 2012)
- Združevanje podatkov iz različnih evropskih centrov:
 - poenotena definicija CP
 - poenotenje klasifikacijskih lestvic
 - longitudinalno epidemiološko spremljanje CP
 - možnost zanesljivih analiz (epidemiologija CP pri različnih populacijah, opis klinične slike pri redkejših oblikah CP)
 - skupna baza za ev. intervencijske študije
 - vir podatkov za oblikovanje evropskih političnih strategij o zdravstvenem varstvu, izobraževanju in socialnih storitvah



SLOVENSKI REGISTER ZA CEREBRALNO PARALIZO (SRCP)

- Vpis otrok rojenih od l.1998 do l. 2011
- V SRCP je skupno vpisanih pribl 660 otrok
- Vir podatkov:
 - razvojne ambulante: izpolnjeni vprašalniki za vpis v SRCP s strani razvojnih pediatrij
 - dokumentacija Pediatrice klinike
 - rehabilitacijski, izobraževalni centri: CIRIUS Kamnik, URI Soča

SCPE DEFINICIJA CP

CP označuje trajne motnje gibanja in položaja telesa, ki so posledica nenapredujoče okvare v razvijajočih se možganih.

Med CP **ne spadajo**:

- Progresivne nevrološke bolezni
- Bolezni hrbtenjače
- Bolezni z izolirano hipotonijo.

Diagnoza temelji na **klinični sliki in anamnezi** in zajema bolezni z različno etiologijo!

SODELOVANJE PRI DELOVNI SKUPINI ZA POSTNEONATALNO CP PRI SCPE

- Poenotenje definicije **postneonatalne CP**: dogodek, ki je vzročen za CP se zgodi v obdobje med 29. dnem po rojstvu in 2. letom.
- Predlagana nova
klasifikacija postneonatalne CP

New Classification proposed
A Infections
A1 Encephalitis (all origins, except autoimmune origin)
A2 Meningitis (bacterial, viral, fungal, etc.)
A3 Respiratory infections (whatever the mechanism later resulting in CP)
A4 Severe sepsis, septicemia and septic chock
A5 Other infections and consequences, Reye's syndrome, gastroenteritis with severe dehydration, flu, varicella etc. ...
B Head Injury
B1 Road traffic accident
B2 Other accidental injury
B3 Non accidental injury
B4 Unspecified
C Post-operative brain damage (surgery or another invasive medical act)
C1 Cerebrovascular accident post-heart surgery or post-other surgery or post-invasive medical act
C2 Anoxic brain damage after surgery (heart or other surgery or post-invasive medical act)
C3 Post-operative (heart or other surgery or post-invasive medical act) brain damage without precision
C4. Sequelae of brain surgery for brain tumor or other brain surgery
D Cerebrovascular accident (if no identifiable cause described in A, B or C)
D1 Ischemic spontaneous
D2 Hemorrhagic spontaneous
D3 Unspecified
E Anoxic brain damage (if no identifiable cause described in A, B or C)
E1 Near-miss sudden infant death syndrome
E2 Near-Drowning
E3 Respiratory distress syndrome of non-infection origin (traumatic or related to foreign body in respiratory tract etc. ...)
E4 Cardiac arrest and heart infarction
E5 Anoxic of other origin (hypoglycemic coma, electrocution etc. ...)
E6 Anoxic brain damage without precision
F Other-Miscellaneous
F1 Status epilepticus, convulsions
F2 Others including Acute disseminated encephalitis

SRCP VPRAŠALNIK

- Vsebuje vse potrebne postavke za vpis v SCPE + prilagoditve, ki upoštevajo slovensko zdravstveno organizacijo
- Definicije, klasifikacije so poenotene s SCPEjem
- Vsebinsko zajema:
 - demografske podatke
 - podatke o nosečnosti, rojstvu in perinatalnem dogajanju
 - podatke o CP
 - podatke o slikovnih nevroloških preiskavah
 - podatke o epilepsiji in pridruženih motnjah
 - oblike zdravljenja
 - socialno-ekonomske značilnosti

OBRAZEC SRCP

Slovenski register cerebralne paralize (SRCP)

Otrokovo ime Ime Priimek M / Ž Identifikacijska št.
 Datum rojstva

CEREBRALNA PARALIZA:

DEFINICIJA: Cerebralna paraliza je izraz za skupino motenj, ki prizuženejo hojo, gibanje in /ali dlo. Je trajna, vendar ne nespremenljiva. Je posledica nenapredujoče okvare, nastale v razvijajočih se, nezrelih možganih. Otroci, pri katerih se razvije do petega leta starosti, so vključeni v slovensko bazo podatkov SRCP (Slovenski register cerebralne paralize) in evropsko SCPE (Surveillance of Cerebral Palsy in Europe). SCPE skupine je oblikovale tudi smernice za lažjo opredelitev cerebralne paralize in njenih značilnosti. (dosagljivo na: SCPE - Reference and Training Manual: <http://www.scpennetwork.eu>)

Ta vprašalnik je namenjen otrokom nad 4. letom starosti s postavljeno diagnozo oziroma sumom na cerebralno paralizo.

Trenutna diagnoza (vpisati tudi kodo MKS):

Starost ob postavitvi diagnoze: ☐ po 2. letu ☐ po 4. letu ☐ Ni znano ☐

A. PODATKI O NOSEČNOSTI, ROJSTVU IN ZGOONJEM POPORODNEM POTEKU

A1. Število predhodnih živorojenih ali mrtvrojenih otrok (izključeni spontani in terapevtski splavi):

☐ nič ☐ Eden ☐ Dva ☐ Več kot dva ☐ Ni znano ☐

A2. Ali so bili v nosečnost prisotni dejavnik tveganja?

☐ da ☐ ne ☐ Ni znano ☐

A3. Ostali dejavnik tveganja (možnih več odgovorov):

☐ Pozitivna družinska anamneza (za nevrološko / genetsko bolezen)	☐ Nenormalni nevrološki znaki
☐ Nedoraslost / prenaslednost (gestacijska starost <37 ali >42 tednov)	☐ Hiperbilrubinemija
☐ Hipoksija (nehemija ob porodu; drugi Apgar < 7)	☐ Hude okužbe novorojenčka
☐ Prehodna presnovna motnja	☐ Zavrtja intrauterina res
☐ Težave pri sesanju / požiranju	☐ Ogroženost v nosečnosti (npr. TORCH)
☐ KIS / epileptični napadi	☐ Nenormalen izvid pri oceni spontanega celostnega gibanja
☐ Cianozični / apnoični napadi	
☐ Drugi dejavnik tveganja (prosimo navedite spodaj):	

A3. Leto rojstva matere in starost ob rojstvu otroka: Leto rojstva: Starost: let ☐ Ni znano ☐

A4. Leto rojstva očeta in starost ob rojstvu otroka: Leto rojstva: Starost: let ☐ Ni znano ☐

A5. Stalno prebivališče matere v času rojstva otroka: ☐ V Sloveniji ☐ Izven Slovenije ☐ Ni znano ☐

A6. Mesto rojstva:

☐ Doma / na pol / v ustanovi, ki ni porodnišnica
☐ Porodnišnica:
☐ Porodnišnica z 1 – 499 rojstvi / leto ☐ Porodnišnica z 1500 – 1999 rojstvi / leto
☐ Porodnišnica z 500 – 999 rojstvi / leto ☐ Porodnišnica z 2000 – 3999 rojstvi / leto
☐ Porodnišnica z 1000 – 1499 rojstvi / leto ☐ Porodnišnica z več kot 4000 rojstvi / leto ☐ Ni znano ☐

A7. Porodna teža: gramov ☐ Ni znano ☐

A8. Gestacijska starost (zaključeni tedni): tednov ☐ Ni znano ☐

A9. Način poroda: ☐ Vaginalni ☐ Električni caski rez / CR pred pričetkom poroda ☐ Urgentni caski rez / CR med porodom ☐ Ni znano ☐

A10. Število istočasno rojenih otrok: ☐ Eden ☐ Dva ☐ Več kot dva ☐ Ni znano ☐

A11. Kateri po vrsti je otrok rojen, če je bila nosečnost večplodna? ☐ Prvi ☐ Drugi ☐ Tretji ali več ☐ Ni znano ☐

A12. Apgar po 5. min (vrednost od 0-10): ☐ Ni znano ☐

A13. Ali je bil otrok sprejet v neonatalno enoto ali EIT? ☐ da ☐ ne ☐ Ni znano ☐

A14. Ali je bil predihan z respiratorjem ali CPAP 24 ur ali več? (izključeno naplovanje preko maske ali kratkotrajna intubacija – npr. za transport) ☐ da ☐ ne ☐ Ni znano ☐

A15. Ali je bila izvajana terapevtska hipotermija? ☐ da ☐ ne ☐ Ni znano ☐

A16. Pojav epileptičnih krčev v prvih 72. urah? ☐ da ☐ ne ☐ Ni znano ☐

A17. Ali so bili prisotni zapleti v 1. mesecu življenja?

☐ da ☐ Kateri? ☐ ne ☐ Ni znano ☐

B. SLIKOVNE NEVROLOŠKE PREISKAVE

B1. Ali so bile slikovne preiskave opravljene ☐ da ☐ ne ☐ Ni znano ☐

B2. Slikovne preiskave v NEONATALNEM OBDOBJU:

B2.1. Katere? ☐ UZ ☐ MRI ☐ CT

B2.2. Neonatalni MR opravljen? ☐ da ☐ ne ☐ V kronološki starosti: dni ☐ Ni znano ☐

B2.3. Ultrazvok možganov opravljen? ☐ da ☐ ne ☐ Kronološka starost ob zdrženju UZ: tednov (00= neznan, 99= ni bil opravljen) ☐ Ni znano ☐

PRIVOLITEV ZA VPIS V REGISTER

ZADEVA: prošnja za privolitev vpisa otroka v Slovenski Register Cerebralne Paralize

Spoštovani,

kot starša otroka s cerebralno paralizo vas prosimo za privolitev za vpis otrokovih kliničnih podatkov v Slovenski Register Cerebralne Paralize.

Slovenski Register Cerebralne Paralize je elektronski dokument, voden na Kliničnem oddelku za otroško, mladostniško in razvojno nevrologijo na Pediatrični kliniki v Ljubljani, pri njegovem sestavljanju pa sodelujejo tudi vsi slovenski razvojni pediatri in nekateri zdravniki iz Univerzitetnega rehabilitacijskega inštituta Republike Slovenije - Soča.

Namen registra je združevanje in primerjanje kliničnih podatkov otrok s cerebralno paralizo, na podlagi katerih dobijo specializirani strokovnjaki dragoceno znanje o tej bolezni in lahko zgradijo predloge za izboljšanje obravnave otrok, tako z vidika novih možnosti ugotavljanja vzrokov, kot tudi boljšega zdravljenja. Vsi podatki so obravnavani strogo zaupno, dostop do njih pa imajo le zdravniki, ki jim to odobri Komisija Republike Slovenije za medicinsko etiko.

Vodenje podobnih registrov je v svetu uveljavljeno kot standardni postopek pri obravnavi bolnikov s kroničnimi boleznimi.

Zahvaljujemo se vam za pomoč pri izboljšanju obravnave otrok s cerebralno paralizo in vas lepo pozdravljamo,

Vodja registra:

prof. dr. David Neubauer, dr. med., višji svetnik, predstojnik Kliničnega oddelka za otroško, mladostniško in razvojno nevrologijo, UKC Ljubljana

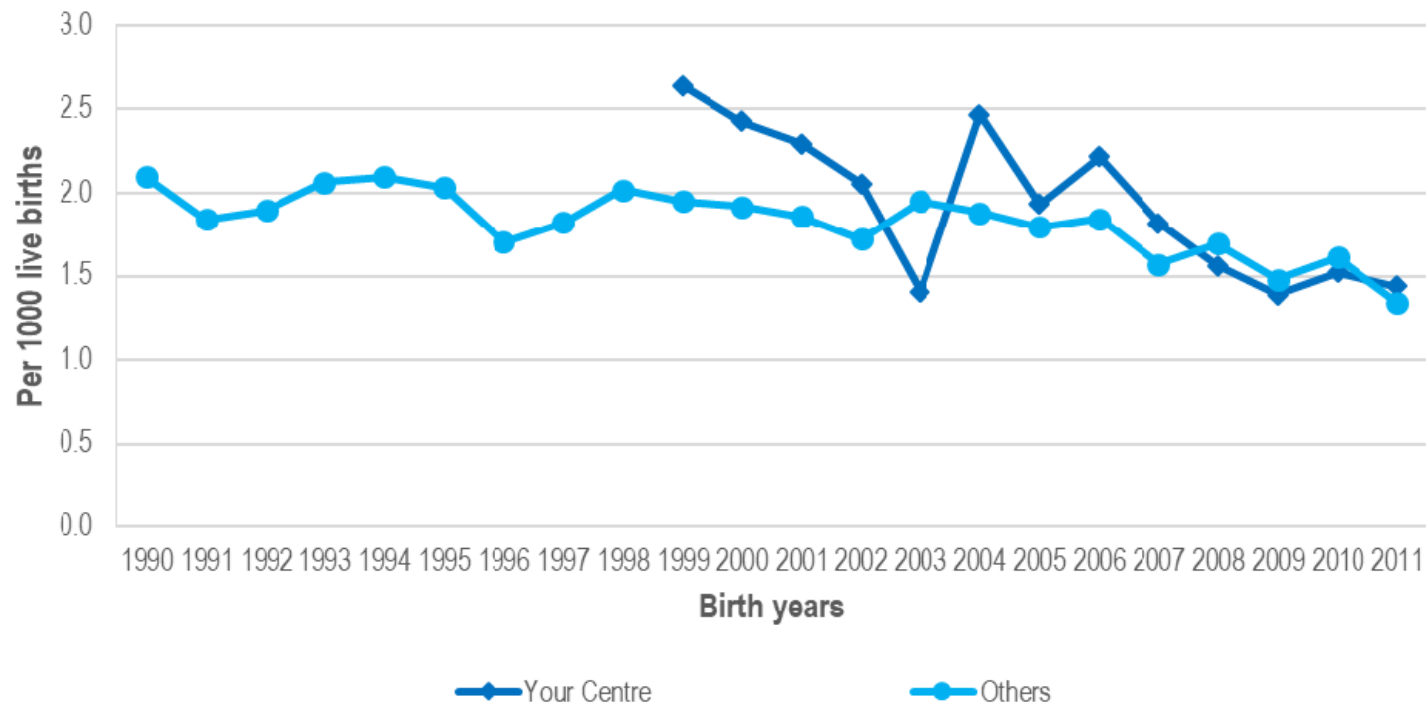
Spodaj podpisani starš otroka _____ (IME IN PRIIMEK OTROKA) _____,
_____ (IME IN PRIIMEK STARŠA) _____,
dosegljiv na: _____ (TEL, ST, ali E-MAIL) _____,
soglašam z vpisom otroka v Slovenski Register Cerebralne Paralize.

Kraj in datum: _____ Podpis: _____

V primeru, da se starši/skrbniki z vpisom v register CP ne strinjajo, otroka anonimno vpišemo v SRCP

SRCP/SCPE PREVALENCA CP

Figure1. Prevalence rates in your centre and the 14 other considered centres since 1990



CP RAZPOREDITEV GLEDE NA GESTACIJSKO STAROST (SRCP)

Distribution by gestational age categories in your centre over the period 2007 - 2011

Gestational age categories	Birth year					Total
	2007	2008	2009	2010	2011	
uk-nc	0	2	2	0	1	5
	0.00	5.56	4.88	0.00	3.23	2.78
very low gestational age	13	9	13	14	11	60
	32.50	25.00	31.71	43.75	35.48	33.33
middle low gestational age	8	5	5	5	6	29
	20.00	13.89	12.20	15.63	19.35	16.11
above 37 weeks	19	20	21	13	13	86
	47.50	55.56	51.22	40.63	41.94	47.78
Total	40	36	41	32	31	180
	100.00	100.00	100.00	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

Skoraj polovica otrok s CP je donošenih.

Variable GA_CAT - Gestational age categories

Distribution by gestational age categories

Gestational age categories	Registry		
	Your centre	Others	Total
very low gestational age	11	205	216
	36.67	31.35	31.58
middle low gestational age	6	113	119
	20.00	17.28	17.40
above 37 weeks	13	336	349
	43.33	51.38	51.02
Total	30	654	684
	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

PODVRSTA CP

Distribution by CP categories in your centre over the period 2007 - 2011

CP classification	Birth year					Total
	2007	2008	2009	2010	2011	
unknown	0	0	0	1	0	1
	0.00	0.00	0.00	3.13	0.00	0.56
spastic	35	33	35	28	28	159
	87.50	91.67	85.37	87.50	90.32	88.33
dyskinetic	3	3	5	2	3	16
	7.50	8.33	12.20	6.25	9.68	8.89
ataxic	2	0	1	1	0	4
	5.00	0.00	2.44	3.13	0.00	2.22
Total	40	36	41	32	31	180
	100.00	100.00	100.00	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

85-90% spastična CP,
9% diskinetična CP,
2-3% ataktična CP

Distribution by CP categories

CP classification	Registry		Total
	Your centre	Others	
spastic	28	578	606
	90.32	86.14	86.32
dyskinetic	3	59	62
	9.68	8.79	8.83
ataxic	0	34	34
	0.00	5.07	4.84
Total	31	671	702
	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

- https://eu-rd-platform.jrc.ec.europa.eu/scpe/reference-and-training-manual_en

Reference and Training Manual

The aim of the SCPE Reference and Training manual is to promote a shared understanding of the words and phrases used to describe the clinical, functional and neurological features of CP. Text and video material are used to illustrate these features and discuss pitfalls in diagnosis and classification.

The RTM is designed for health professionals who are compiling CP registers and those wishing to enter data onto the SCPE database. It can be also used for training purposes for health professionals interested in children with cerebral palsy.

The RTM is divided into 6 sections.

1. CP and CP subtypes
2. Functional grading
3. Neuroimaging in the child with CP
4. Cases
5. References and Abbreviations
6. Neonatal imaging

RAZPOREDITEV GLEDE NA STOPNJO GROBOMOTORIČNE PRIZADETOSTI (GMFCS KLASIFIKACIJA)

Distribution by GMFCS levels

Gross Motor Function Classification System	Registry		
	Your centre	Others	Total
level I	12 38.71	229 33.83	241 34.04
level II	6 19.35	161 23.78	167 23.59
level III	1 3.23	77 11.37	78 11.02
level IV	7 22.58	102 15.07	109 15.40
level V	5 16.13	108 15.95	113 15.96
Total	31 100.00	677 100.00	708 100.00

First row has *frequencies* and second row has *column percentages*

POMEN NEVROFIZIOTERAPEVTOV

	GMFCS Level I Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.
	GMFCS Level II Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.
	GMFCS Level III Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.
	GMFCS Level IV Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.
	GMFCS Level V Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors copyright: © Palisano et al. (1997) Dev Med Child Neurol 39:214-22
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Illustrations copyright: © Neil Graham, Bill Reid and Adrienne Hanley
The Royal Children's Hospital, Melbourne

RAZPOREDITEV GLEDE NA STOPNJO FINOMOTORIČNE PRIZADETOSTI (BFMF KLASIFIKACIJA)

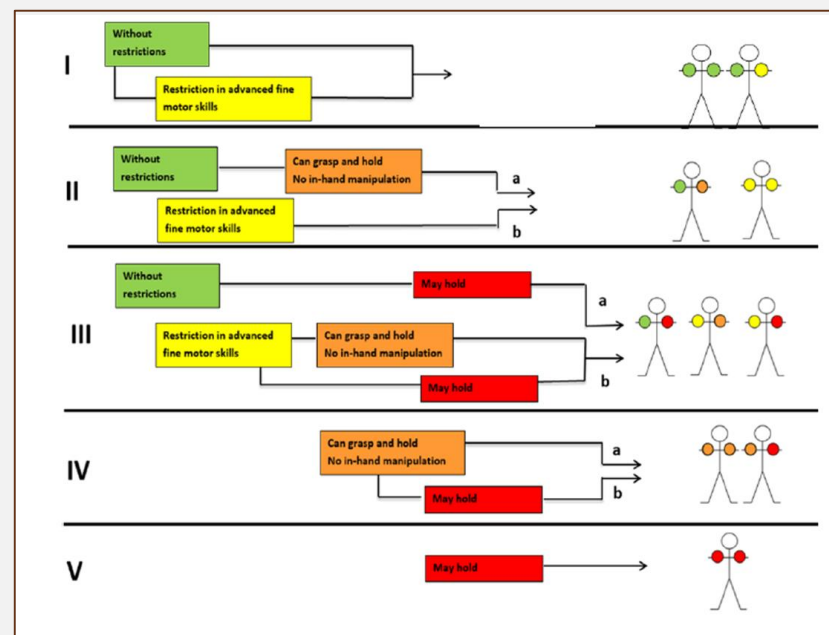
Variable BFMF - Bimanual Fine Motor Function Classification

Distribution by BFMF levels

Bimanual Fine Motor Function Classification	Registry		
	Your centre	Others	Total
level 1	11	163	174
	37.93	31.77	32.10
level 2	6	137	143
	20.69	26.71	26.38
level 3	5	77	82
	17.24	15.01	15.13
level 4	3	57	60
	10.34	11.11	11.07
level 5	4	79	83
	13.79	15.40	15.31
Total	29	513	542
	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

POMEN DELOVNIH TERAPEVTOV



GOVORNO-JEZIKOVNA MOTNJA (VIKING KLASIFIKACIJA)

Distribution by VIKING levels

Viking speech scale	Registry		
	Your centre	Others	Total
level I	10	214	224
	35.71	36.52	36.48
level II	7	159	166
	25.00	27.13	27.04
level III	4	58	62
	14.29	9.90	10.10
level IV	7	155	162
	25.00	26.45	26.38
Total	28	586	614
	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

POMEN LOGOPEDOV



Viking Speech Scale, 2010

Read the descriptions of children's speech overleaf. Circle the level that best describes the child's speech.

- I. Speech is not affected by motor disorder.
- II. Speech is imprecise but usually understandable to unfamiliar listeners.
- III. Speech is unclear and not usually understandable to unfamiliar listeners out of context.
- IV. No understandable speech.

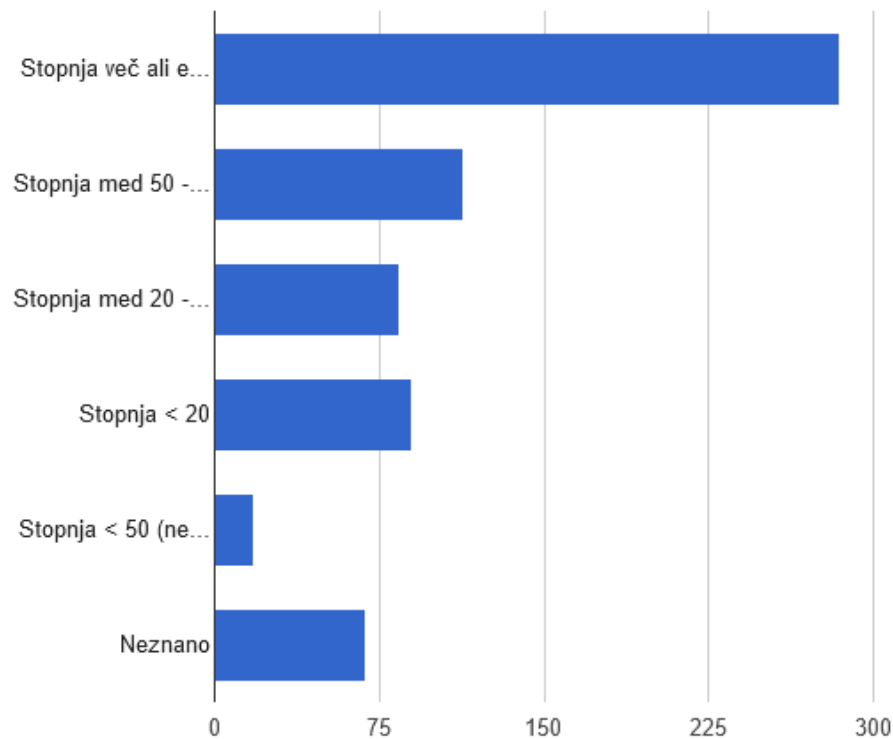
KOGNITIVNA OKVARA

Stopnja kognitivne okvare (*intel_imp*)

[Refresh Plot](#)[View as Bar Chart](#) ▾

Total Count (N)	Missing	Unique
659	2 (0,3%)	6

Counts/frequency: Stopnja več ali enako 70 (285, 43,2%), Stopnja med 50 - 69 (113, 17,1%), Stopnja med 20 - 49 (84, 12,7%), Stopnja < 20 (90, 13,7%), Stopnja < 50 (neopredeljena prizadetost) (18, 2,7%), Neznano (69, 10,5%)

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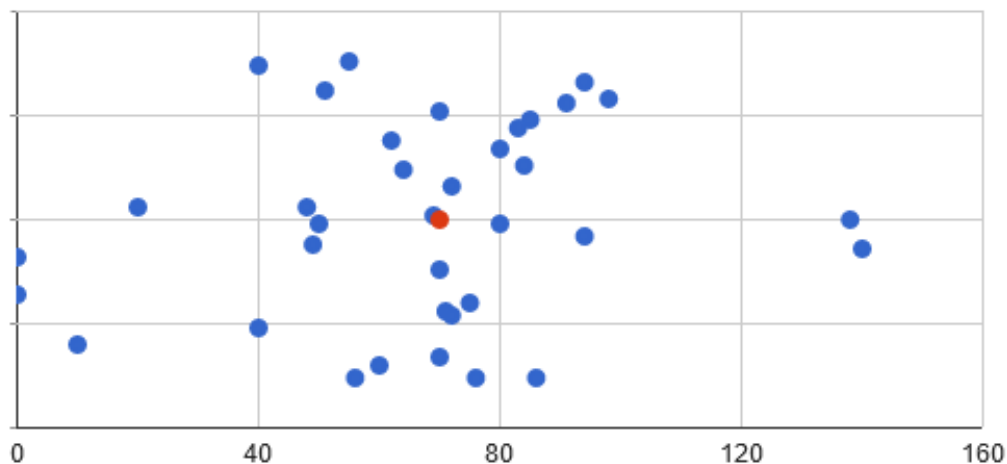
IQ VREDNOSTI

Vrednost IQ testiranja *(si_iq_vrednost)* [Refresh Plot](#)

Total Count (N)	Missing	Unique	Min	Max	Mean	StDev	Sum	Percentile						
								0,05	0,10	0,25	0,50 Median	0,75	0,90	0,95
36	625 (94,6%)	29	0,00	140,00	66,75	30,54	2.403,00	7,50	30,00	50,75	70,00	83,25	94,00	108,00

Lowest values: 0, 0, 10, 20, 40

Highest values: 94, 94, 98, 138, 140



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HUDA INTELIGENČNA MANJZMOŽNOST (IQ LESTVICA)

Variable **SEV_INTEL_IMP** - Severe intellectual impairment*

Distribution by intellectual impairment severity

Severe intellectual impairment	Registry		
	Your centre	Others	Total
yes	10 43.48	186 31.63	196 32.08
no	13 56.52	402 68.37	415 67.92
Total	23 100.00	588 100.00	611 100.00

First row has *frequencies* and second row has *column percentages*

Pearson chi2 = 1.4255 Pr = 0.233

Note: 25.8% unknown/not collected values for your registry and 14.9% for the 14 other registries

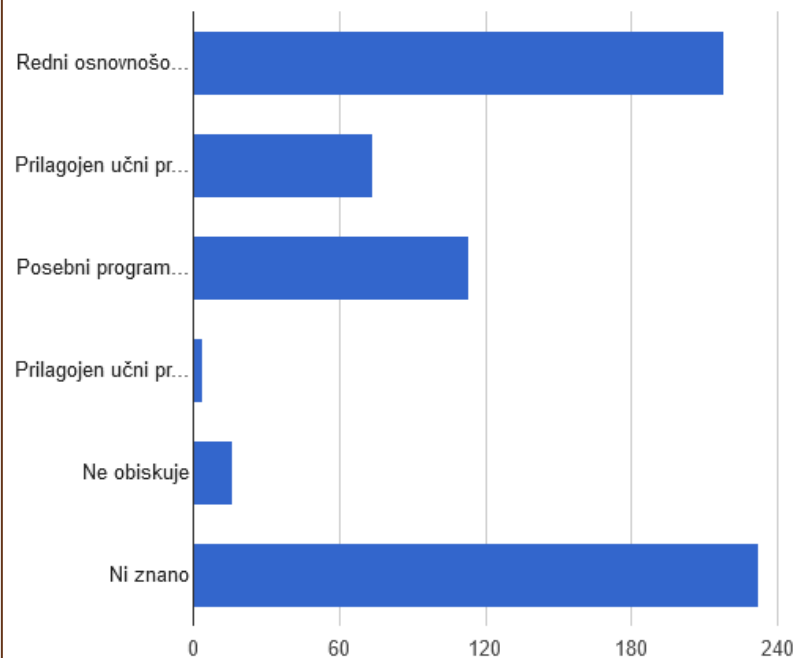
IQ < 20

POMEN SPECIALNIH PEDAGOGOVI,
PSIHOLOGOV, PEDOPSIHIATROV

IZOBRAŽEVANJE OTROK S CP

Total Count (N)	Missing	Unique
657	3 (0,5%)	6

Counts/frequency: Redni osnovnošolski program (218, 33,2%), Prilagojen učni program z nižjim izobrazbenim standardom (74, 11,3%), Posebni program vzgoje in izobraževanja (OVI) (113, 17,2%), Prilagojen učni program na domu (4, 0,6%), Ne obiskuje (16, 2,4%), Ni znano (232, 35,3%)



Download image

MOTNJA VIDNE FUNKCIJE

Distribution by visual impairment severity

	Registry		
	Your centre	Others	Total
Severe visual impairment			
yes	2	72	74
	7.14	11.46	11.28
no	14	201	215
	50.00	32.01	32.77
uk-nc	1	29	30
	3.57	4.62	4.57
no visual impairment	11	326	337
	39.29	51.91	51.37
Total	28	628	656
	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

Pearson chi2 = 3.9877 Pr = 0.263

Note: 9.7% unknown/not collected values for your registry and 9.1% for the 14 other registries

Huda okvara vida:
vidna ostrina < 0.1

POMEN TIFLOPEDAGOGOVI,
OKULISTOV

MOTNJA SLUŠNE FUNKCIJE

Distribution by hearing impairment severity

	Registry		
	Your centre	Others	Total
Severe hearing impairment			
yes	1 3.45	20 3.31	21 3.31
no	1 3.45	18 2.98	19 3.00
uk-nc	1 3.45	6 0.99	7 1.10
no hearing impairment	26 89.66	561 92.73	587 92.59
Total	29 100.00	605 100.00	634 100.00

First row has *frequencies* and second row has *column percentages*

Pearson chi2 = 1.5631 Pr = 0.668

Note: 6.5% unknown/not collected values for your registry and 12.4% for the 14 other registries

Raven izgube sluha
>70db na obeh ušesih

PRIDRUŽENA EPILEPSIJA (AKTIVNA OBLIKA)

Distribution by epilepsy activity

Activity of epilepsy	Registry		
	Your centre	Others	Total
no epilepsy	12	398	410
	40.00	62.28	61.29
activ epilepsy	17	192	209
	56.67	30.05	31.24
inactiv epilepsy	1	35	36
	3.33	5.48	5.38
activity uk-nc	0	14	14
	0.00	2.19	2.09
Total	30	639	669
	100.00	100.00	100.00

L.2011

Slaba tretjina otrok ima aktivno obliko epilepsije

First row has *frequencies* and second row has *column percentages*

Pearson chi2 = 9.7236 Pr = 0.021

Note: 3.2% unknown/not collected values for your registry and 7.5% for the 14 other registries

Distribution by epilepsy activity in your centre over the period 2007 - 2011

Activity of epilepsy	Birth year					Total
	2007	2008	2009	2010	2011	
epilepsy uk-nc	0	1	1	1	1	4
	0.00	2.78	2.44	3.13	3.23	2.22
no epilepsy	28	25	25	20	12	110
	70.00	69.44	60.98	62.50	38.71	61.11
activ epilepsy	6	8	10	8	17	49
	15.00	22.22	24.39	25.00	54.84	27.22
inactiv epilepsy	4	2	5	3	1	15
	10.00	5.56	12.20	9.38	3.23	8.33
activity uk-nc	2	0	0	0	0	2
	5.00	0.00	0.00	0.00	0.00	1.11
Total	40	36	41	32	31	180
	100.00	100.00	100.00	100.00	100.00	100.00

First row has *frequencies* and second row has *column percentages*

SLIKOVNA DIAGNOSTIKA

Variable IMAGE - Has imaging been performed?

Distribution by image

Has imaging been performed?	Registry		
	Your centre	Others	Total
Yes	29 93.55	647 97.44	676 97.27
No	2 6.45	17 2.56	19 2.73
Total	31 100.00	664 100.00	695 100.00

First row has *frequencies* and second row has *column percentages*

Pearson chi2 = 1.6866 Pr = 0.194

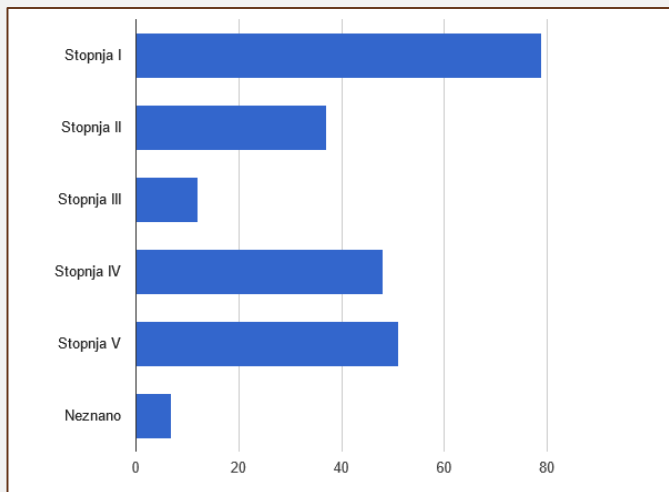
Note: 0.0% unknown/not collected values for your registry and 3.9% for the 14 other registries

Distribution by image in your centre over the period 2007 - 2011

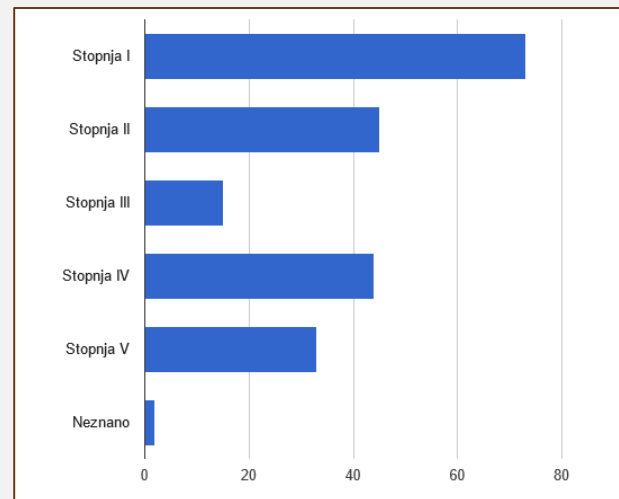
Has imaging been performed?	Birth year					Total
	2007	2008	2009	2010	2011	
uk-nc	1 2.50	1 2.78	0 0.00	0 0.00	0 0.00	2 1.11
Yes	38 95.00	31 86.11	38 92.68	31 96.88	29 93.55	167 92.78
No	1 2.50	4 11.11	3 7.32	1 3.13	2 6.45	11 6.11
Total	40 100.00	36 100.00	41 100.00	32 100.00	31 100.00	180 100.00

Prbl 6% otrok ni imelo nikoli slikovne dg (UZ/CT/MR)

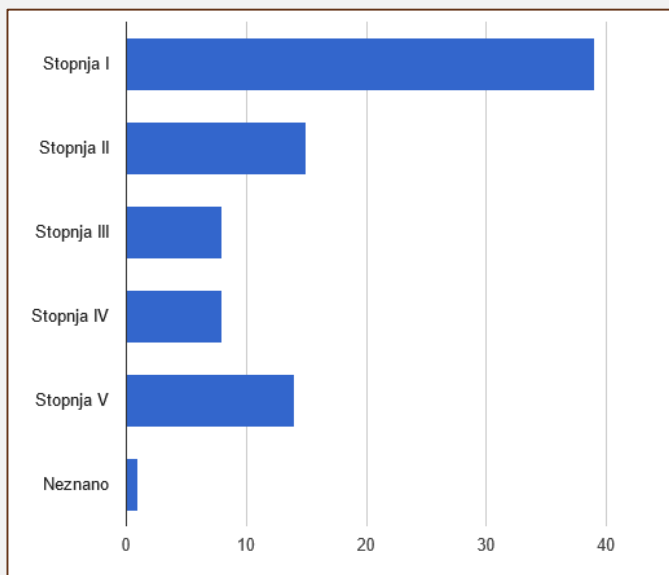
POVEZANOST MED KLINIČNIM IZHODOM IN OBSEGOM TERAPIJ, PODPORNO OBRAVNAVO?



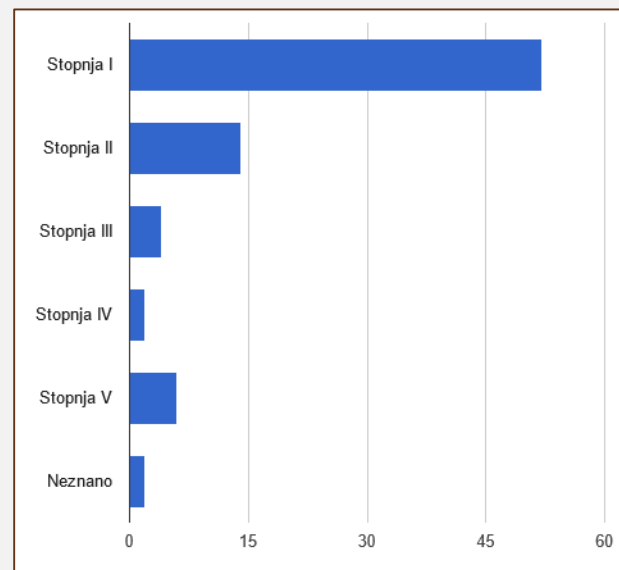
Vključenost
v RA med
1.-3. mes
in stopnja
prizadetosti
po GMFCS



Vključenost
v RA med
3.-6. mes
in stopnja
prizadetosti
po GMFCS



Vključenost
v RA med
6.- 12. mes
in stopnja
prizadetosti
po GMFCS



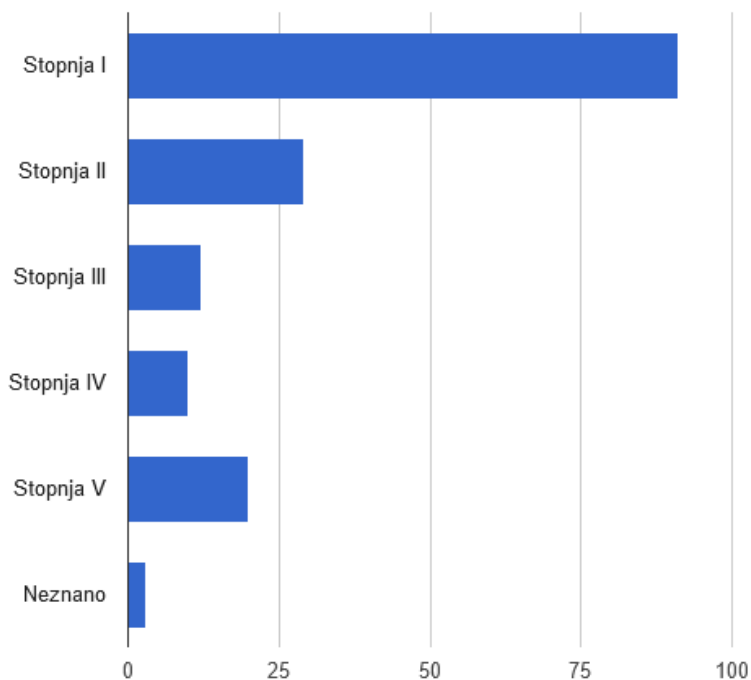
Vključenost
v RA med
3.-6. mes
in stopnja
prizadetosti
po GMFCS

OTROCI VKLJUČENI V RA PO 6. MESECU STAROSTI

Razvrstitev glede na grobe motorične funkcije Gross Motor Function Classification / GMFCS (gmfcs) [Refresh Plot](#) | [View as Bar Chart](#) ▼

Total Count (N)	Missing	Unique
165	0 (0,0%)	6

Counts/frequency: Stopnja I (91, 55,2%), Stopnja II (29, 17,6%), Stopnja III (12, 7,3%), Stopnja IV (10, 6,1%), Stopnja V (20, 12,1%), Neznano (3, 1,8%)



Download image

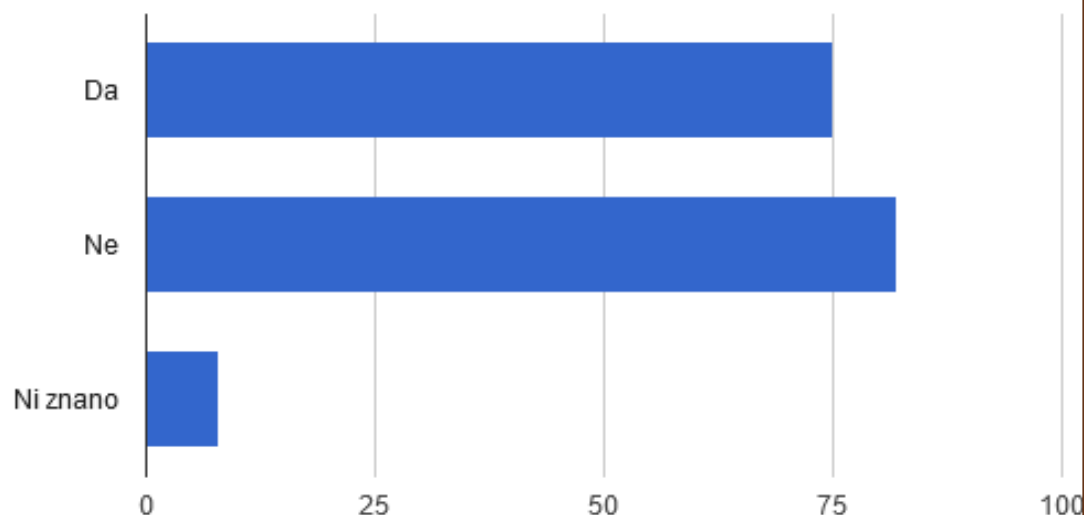
PRISOTNOST RIZIČNIH DEJAVNIKOV V NOSEČNOSTI/ ZGODNJEM PERINATALNEM OBDOBJU PRI OTROCIH VKLJUČENIH V RA NAD 6. MESECEM STAROSTI

Ali so bili v nosečnosti prisotni dejavniki tveganja? *(si_deja)*

View as Bar Chart ▾

Total Count (N)	Missing	Unique
165	0 (0,0%)	3

Counts/frequency: Da (75, 45,5%), Ne (82, 49,7%), Ni znano (8, 4,8%)



45% otrok, ki je imelo prisotne rizične dejavnike, je bilo vključenih v RA po 6 mesecu starosti

POVEZAVA NACIONALNEGA PERINATALNEGA REGISTRA S SRCP

310 Original Article

Apgar Score and Risk of Cerebral Palsy in Preterm Infants: A Population-Based Cohort Study

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Neuropediatrics 2021;52:310–315.

Abstract

A low Apgar score is associated with increased risk of cerebral palsy (CP) in term infants, while such association remains controversial in preterm neonates. The objective of this study was to assess association between 5-minute Apgar scores and CP in different subcategories of preterm birth based on gestational age. The Slovenian National Perinatal Information System was used to identify singleton children without congenital malformations live-born at 22 to 37 weeks of gestation between 2002 and 2010. Data were linked to the Slovenian Registry of Cerebral Palsy in children born between 2002 and 2010. CP was diagnosed at a minimum of 5 years of age. Of 11,924 children included, 241 (2.0%) died before discharge and 153 (1.3%) were diagnosed with CP. Five-minute Apgar scores <7 were significantly associated with higher risk of death or CP (compared with scores >9) at all preterm gestations. CP alone was associated with Apgar scores <7 only at moderately or late preterm gestation (32–36 weeks) (adjusted relative risk [aRR]: 8.27; 95% confidence interval [CI]: 1.87–36.64 for scores 0–4 and aRR: 4.96; 95% CI 1.89–13.06 for scores 5–6). In conclusion, a low 5-minute Apgar score was associated with combined outcome of neonatal death or CP in all preterm births, while in surviving preterm infants at >32 weeks a low 5-minute Apgar score was associated with CP.

Keywords

- Apgar score
- cerebral palsy
- preterm birth

KAKOVOST ŽIVLJENJA PRI OTROCIH S CP



10.1515/sjph-2017-0001

Zdr Varst 2017; 56(1): 1-10

Radseel A, Osredkar D, Neubauer D. Health-related quality of life in children and adolescents with cerebral palsy. Zdr Varst 2017; 56(1): 1-10

HEALTH-RELATED QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH CEREBRAL PALSY Z ZDRAVJEM POVEZANA KAKOVOST ŽIVLJENJA OTROK IN NAJSTNIKOV S CEREBRALNO PARALIZO

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Uvod. V luči vse večjega trenda k celostnemu pristopu obravnave otrok s cerebralno paralizo se poleg dobrega poznavanja in vrednotenja otrokove oviranosti med glavna orodja, ki so v pomoč pri načrtovanju obravnav, uvrščajo vprašalniki za oceno z zdravjem povezane kakovosti življenja. Cilja raziskave sta bila pridobiti vpogled v z zdravjem povezano kakovost življenja pri skupini slovenskih otrok s cerebralno paralizo in najti morebitne povezave z njihovimi demografskimi in kliničnimi podatki.

Metode. V okviru presečne kohortne raziskave je bilo iz Slovenskega registra otrok s cerebralno paralizo naključno izbranih 122 družin. Skrbniki otrok so bili pozvani k sodelovanju z izpolnitvijo proxy različice vprašalnika o z zdravjem povezani kakovosti življenja. Otroci brez kognitivne okvare so bili naprošeni, naj izpolnijo različico vprašalnika, namenjeno samoocenjevanju.

Rezultati. Pri oceni z zdravjem povezane kakovosti življenja je sodelovalo 91 družin. Skrbniki 43 otrok in 48 najstnikov so izpolnili svoje različice vprašalnikov (proxy različica). Oseminštirideset otrok in najstnikov brez kognitivne okvare je samih izpolnilo vprašalnik (self različica). Ocenjena z zdravjem povezana kakovost življenja je bila dobra. Otroci so jo ocenili bolje kot najstniki (povprečno 80,8, SD 10,0 proti povprečno 69,4, SD 19,4; $p=0,01$). Preiskovanci so jo ocenili bolje kot njihovi skrbniki (povprečno 75,6, SD 15,9 proti povprečno 72,3, SD 17,9; $p=0,048$). Višja starost ($p<0,001$), prisotnost bolečine ($p<0,001$) in motnje spanja ($p=0,002$) so bili močni napovedni dejavniki za slabšo z zdravjem povezano kakovost življenja. Socialna vključenost in samostojnost sta bili najslabše ocenjeni domeni. Vprašalnik DISABKIDS se je izkazal za dobro orodje za oceno z zdravjem povezane kakovosti življenja otrok s cerebralno paralizo.

Sklep. Slovenski otroci s cerebralno paralizo ocenjujejo svojo z zdravjem povezano kakovost življenja kot dobro. Otroci jo ocenjujejo bolje kot najstniki ali njihovi skrbniki. Bolečina je najmočnejši napovedni dejavnik slabše z zdravjem povezane kakovosti življenja.

KAKOVOST ŽIVLJENJA PRI OTROCIH S CP



SPARCLE

A Study of Participation and Quality of Life of
Children with Cerebral Palsy Living in Europe

Denmark, France, Germany, Ireland, Italy, Sweden,
England and Northern Ireland

The key findings were:

- Children and young people with cerebral palsy experience **much pain**, more than their peers in the general population and more than had been appreciated before the study
- Children and young people with cerebral palsy are more likely to have **psychological problems** than their peers in the general population
- Parents of children with cerebral palsy are more likely to experience **significant stress** than parents of children in the general population
- Children and young people with cerebral palsy who can self-report have **similar Quality of Life** to other children of their age – both at age 8-12 years and at 13-17 years, except that at 13-17 years, the young people experienced lower Quality of Life concerning 'social support and relationships with peers'
- For children and young people with **severe learning difficulties**, we rely on parents to report what they think is their child's Quality of Life. In general Quality of Life was reported to be good unless the child had much pain or psychological problems or the parents were very stressed
- Children and young people with cerebral palsy take part in **fewer activities** than their peers; and the activities they do take part in are usually engaged in less often
- Quality of Life and Participation of young people with cerebral palsy **are predicted** by their Quality of Life and Participation when they were 8-12 years old; but they are also predicted by pain, psychological difficulties and parenting stress when the young people had been 8-12 years old.
- **Some European countries** provide environments which enable children and young people with cerebral palsy to participate much more in life than children in other countries

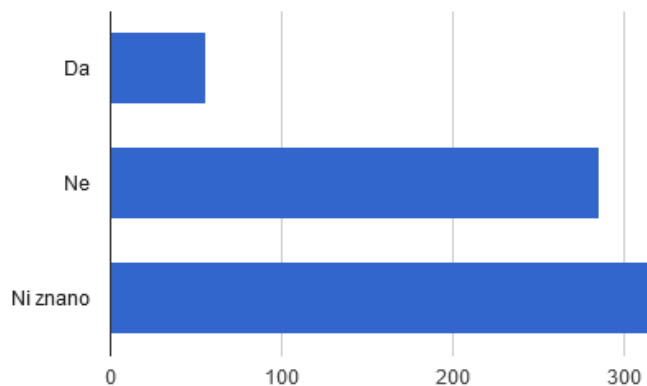
More information on the study and its published research papers are on the
SPARCLE website: <http://research.ncl.ac.uk/sparcle>

MOTNJE SPANJA PRI OTROCIH S CP

Ima otrok težave s spanjem? (*si_spanec*) [Refresh Plot](#) | [View as Bar Chart](#)

Total Count (N)	Missing	Unique
659	2 (0,3%)	3

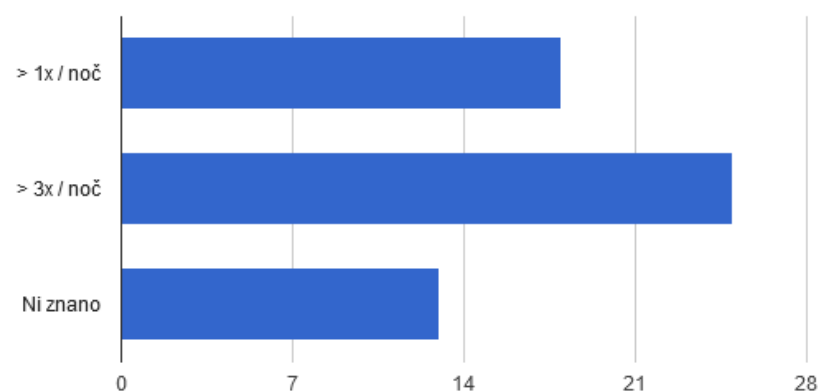
Counts/frequency: Da (56, 8,5%), Ne (286, 43,4%), Ni znano (317, 48,1%)



Kako pogosto se zbuja? (*si_zbujanje*) [Refresh Plot](#) | [View as Bar Chart](#)

Total Count (N)	Missing	Unique
56	605 (91,5%)	3

Counts/frequency: > 1x / noč (18, 32,1%), > 3x / noč (25, 44,6%), Ni znano (13, 23,2%)

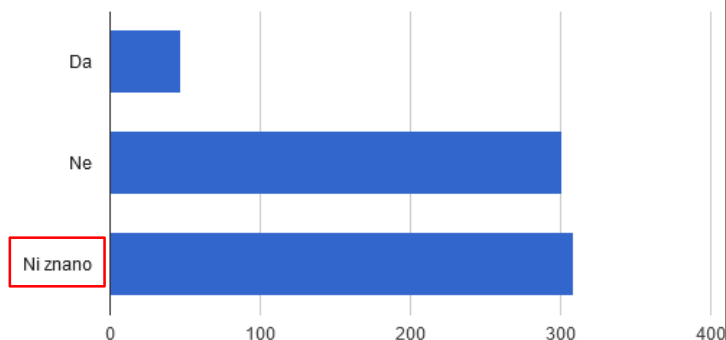


BOLEČINA PRI OTROCIH S CP

Ali otrok / starši poročajo o bolečinah? (*si_bol*) [Refresh Plot](#) | [View as Bar Chart](#)

Total Count (N)	Missing	Unique
657	3 (0,5%)	3

Counts/frequency: Da (47, 7,2%), Ne (301, 45,8%), Ni znano (309, 47,0%)

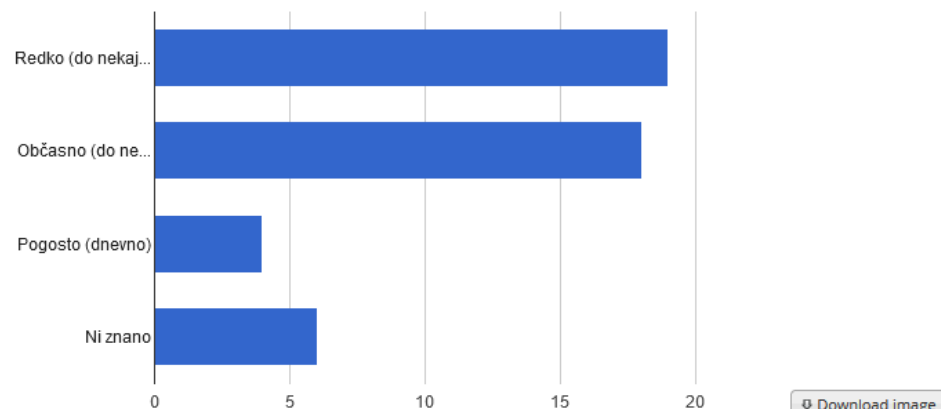


Pozornost na bolečino, ki pomembno vpliva na kvaliteto življenja otrok s CP.

Kako pogosto? (*si_bol_pog*) [Refresh Plot](#) | [View as Bar Chart](#)

Total Count (N)	Missing	Unique
47	613 (92,9%)	4

Counts/frequency: Redko (do nekajkrat v mesecu) (19, 40,4%), Občasno (do nekajkrat v tednu) (18, 38,3%), Pogosto (dnevno) (4, 8,5%), Ni znano (6, 12,8%)



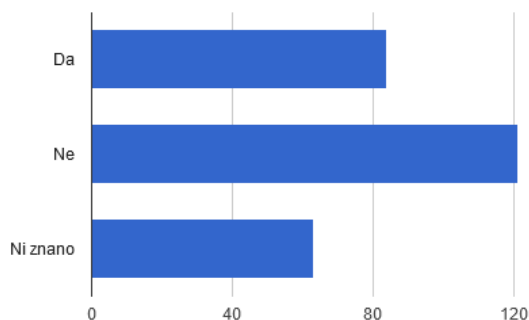
[Download image](#)

SPREMLJANJE KOSTNEGA ZDRAVJA PRI OTROCIH S CP III.-V. STOPNJE PO GMFCS

Kostna gostota izmerjena? (*si_kostna_gostota*) [Refresh Plot](#)

Total Count (N)	Missing	Unique
268	0 (0,0%)	3

Counts/frequency: Da (84, 31,3%), Ne (121, 45,1%), Ni znano (63, 23,5%)

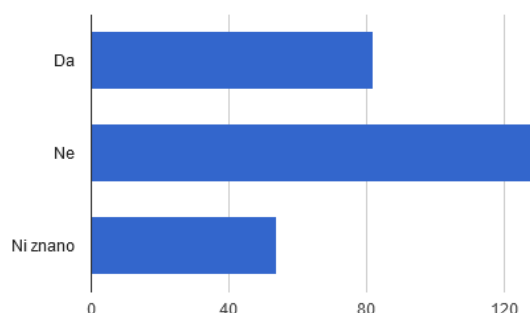


Je bil otrok zdravljen zaradi osteoporoze / osteopenije?

View as Bar Chart

Total Count (N)	Missing	Unique
268	0 (0,0%)	3

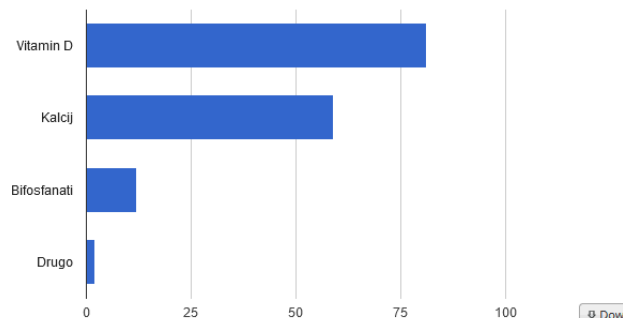
Counts/frequency: Da (82, 30,6%), Ne (132, 49,3%), Ni znano (54, 20,1%)



Vrsta terapije osteoporoze / osteopenije? (*si_kostna_gostota_th_kaj*) [Refresh Plot](#)

Total Count (N)	Missing	Unique
83	185 (69,0%)	4

Counts/frequency: Vitamin D (81, 97,6%), Kalcij (59, 71,1%), Bifosfanati (12, 14,5%), Drugo (2, 2,4%)

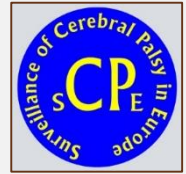


	GMFCS Level I Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.
	GMFCS Level II Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.
	GMFCS Level III Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.
	GMFCS Level IV Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.
	GMFCS Level V Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GENETSKO PRESEJANJE BOLNIKOV NA KO OMRN, PEK

- Genetsko presejanje bolnikov s cerebralno paralizo na Pediatrični kliniki v Ljubljani
- **KDAJ?** Pričetek maja 2021-->
- **KDO?** Bolniki s cerebralno paralizo (CP), ki so vključeni v Slovenski register za cerebralno paralizo. Zaenkrat vključenih prbl 120 otrok otrok.
- **KAJ?** Odvzem krvi za genetsko testiranje – NGS panel več kot 100 genov, ki so vzročni za bolezni, ki spominjajo na cerebralno paralizo „CP-mimicking disease“, **vključno z DDC genom**.
- **ZAKAJ?** 20-40% bolnikov z dg CP ima v
- **osnovi genetsko obolenje, ki spominja na CP.** Jin SC et al. Mutations disrupting neuritogenesis genes confer risk for cerebral palsy. Nat Genet. 2020 Oct;52(10):1046-1056. doi: 10.1038/s41588-020-0695-1
- **ZAKAJ?** Možnost specifičnega zdravljenja pri določenih genetskih boleznih, napovedovanje poteka bolezni, genetsko svetovanje.

ZAKLJUČEK



- SRCP je del evropskega registra. <https://eu-rdplatform.jrc.ec.europa.eu/scpe>
- Pomen registra: usklajenost in oblikovanje skupnih definicij, klasifikacijskih lestvic.
- Spremljanje epidemioloških trendov, ovrednotenje oviranosti na različnih področjih pri otrocih s CP → sooblikovanje smernic obravnave in političnih strategij na področju zdravstvenega varstva, izobraževanja in socialnih storitvah.
- Analiza podatkov iz registra – osvetlitev močnih področjih/pomanjkljivosti pri obravnavi otrok s CP v našem prostoru in primerjava z drugimi eu centri
- Povezovanje strokovnjakov s področja CP → izmenjava novih spoznanj, možnost konzultacij
- Raziskovalno delo – nova spoznanja na področju CP – pomen za razvijanje stroke
- Baza podatkov, ki omogoča vključevanje otrok v intervencijske študije (tarčna, podporna zdravljenja)

ZAHVALA

- Staršem in otrokom s CP
- Razvojnim ambulantam, rehabilitacijskim in izobraževalnim ustanovam za sodelovanje pri vpisu v SRCP
- VAM ZA POZORNOST!



VPRAŠANJA?

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