

KVČB v Sloveniji – prvi podatki po več kot dekadi

Izr. prof. dr. David Drobne, dr. med



79. srečanje SZGH

Redno spomladansko srečanje SZGH
Anin dvor, Rogaška Slatina • 21. in 22. maj 2026



UR-CARE



GASTROENTEROLOGY
HEPATOLOGY

Posredno obvestilo

Naj 19. letni skupni Slovenski zbirni štatski dan 10.6.2019, je bila splošno izjavljena izbira za Slovenski IBD. Za prvega predsednika raziskovalne skupine za raziskovanje IBD (SAGH) je bil izvoljen Dr. Milan Stefanović.

Martino, 16. 8. 2019

SLOVENSKO ZDRUŽENJE
ZA GASTROENTEROLOGIJO
IN HEPATOLOGIJO

Update of SING (Slovenian IBD National study Group) steering committee

At the regular member meeting of Slovenian association of Gastroenterology and Hepatology (SAGH) on January 31st 2024 the update of the steering committee of SING was elected. David Drobne steps down from the position of president. The elected period of the next steering committee is for 2 years, from March 1st 2024 until March 1st 2026:

1. Dr. Gregor Novak – President
2. Dr. Andreja Očepek – President-Elect
3. Dr. David Drobne – Past-President
4. Dr. Sara Nikolić – Secretary

Dr. Milan Stefanović – SAGH President

Date: February 27th 2024

Action plan for UR CARE in Slovenia from 2019

- to form Slovenian IBD study group → SING
- to identify IBD centres in Slovenia
- to disseminate idea of IBD registry among Slovenian gastroenterologists
- to do the paperwork: EC, GDPR
- to communicate with ECCO
- To help with contracts between individual IBD centre and ECCO/UR CARE
- To stimulate IBD centres to start UR CARE
- To maintain UR CARE on the long term
- To report on the epidemiology of IBD in Slovenia annually
- To enable pan-Slovenian research „Slovenian IBD cohort“



IBD, inflammatory bowel disease

ECCO, the European Crohn's and Colitis Organisation

EC, ethics committees

GDPR, General Data Protection Regulation

UR-CARE, the United Registries for Clinical Assessment and Research

Identified 14 IBD centres in Slovenia

- UMC Ljubljana – Division of Internal Medicine, Dept. Gastroenterology
- UMC Ljubljana – Division of Surgery, Dept. Abdominal surgery
- UMC Ljubljana – Division of Paediatrics, Dept. Gastroenterology, Hepatology and Nutrition
- UMC Maribor – Division of Internal Medicine, Dept. Gastroenterology
- UMC Maribor – Division of Surgery, Dept. Abdominal surgery
- GH Celje
- GH Izola
- GH Jesenice
- GH Novo mesto
- GH “Dr. Franc Derganec” Nova Gorica
- GH Trbovlje
- GH Slovenj Gradec
- Diagnostic Centre Bled
- Abakus Medico
- GH Rakičan, Murska Sobota
- Iatros Medical centre
- GH Brežice

Asist. dr. David Drobné, dr. med., specialist
gastroenterologije in hepatologije
Klinični center za gastroenterologijo
UKC Ljubljana
Japljeva ulica 2
1000 Ljubljana
david.drobne@gmail.com

Številka: 0120-5762019/7
Datum: 10. februar 2020

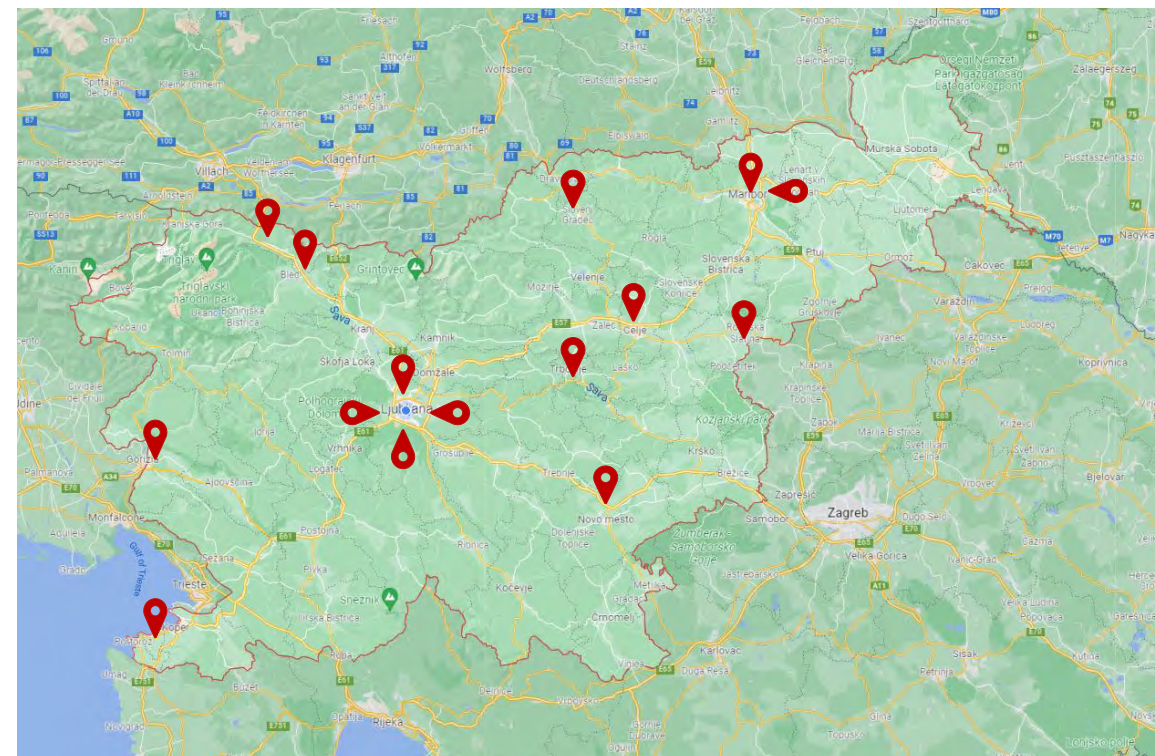
Zadeva: Ocena etičnosti predložene raziskave

Sploševani:

Komiteja Republike Slovenije za medicinsko etiko (KME) je dne 29. 11. 2019 (sklepano z datumi 6. 10. 2019) od vas prejel vlogo za oceno etičnosti raziskave z naslovom "SINGS (Slovenian IBD National study Group) - vps bolnikov s KVČE v Evropski register UR-CARE"



Način in oblika: <https://www.dobrosos.com/medicinska-etika>
Sloga: soglasje s strani medicinske komisije in s strani komisije za medicinsko etiko
URL: <https://www.dobrosos.com/medicinska-etika>
Nacionalni študij: <https://www.dobrosos.com/medicinska-etika>



Source of picture: Google maps

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596 KB

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Dušan Baraga



David Drobne

How can the hospital benefit from the UR-CARE Registry?

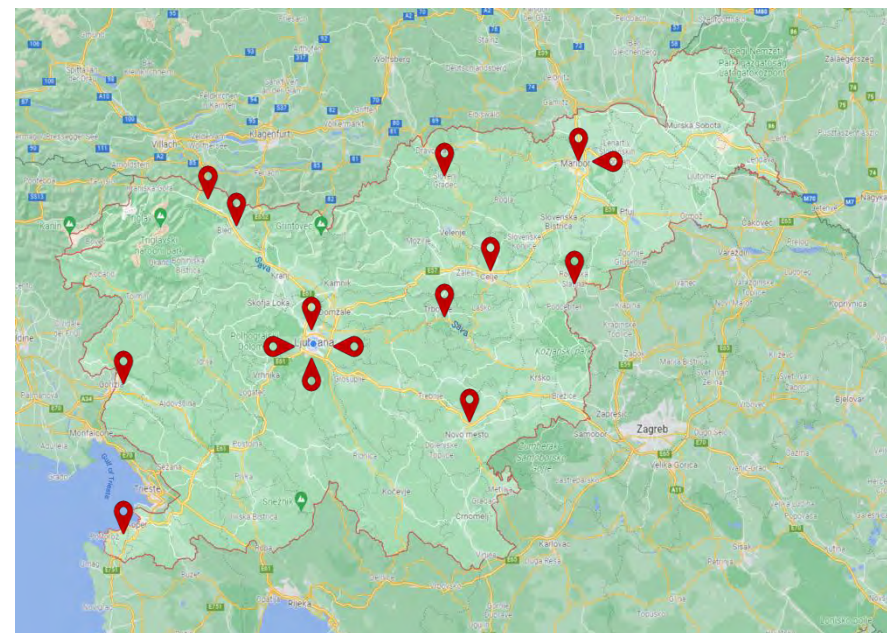
DB ver 3

Stockholm 2024

8 active UR CARE centres in Slovenia / February 2025

YEAR	2023	2024	Feb-26		
IBD centre/	Included patients (N) - total			NEW last year	
University Medical Centre of Ljubljana	2458	2774	3037	263	9,5 %
University Medical Center Maribor	552	639	740	101	15,8 %
Celje General Hospital	288	354	472	118	33,3 %
Izola General Hospital	283	293	337	44	15,0 %
General Hospital Jesenice	110	137	152	15	10,9 %
Splosna bolnisnica Slovenj Gradec	140	190	235	45	23,7 %
Diagnosticni Center Bled	93	127	169	42	33,1 %
Splosna bolnisnica Dr Franca Derganca Nova Gorica	57	74	91	17	23,0 %
Total included in Slovenia	3759	4588	5233		

Feb 2026:
5233 patients



Source of picture: Google maps. Personal archive of the author.

GH - General hospital; UMC - University medical centre.

Slovenia:
University Medical Centre of Ljubljana
David Drobne – Gregor Novak
Hospital - IBD clinic

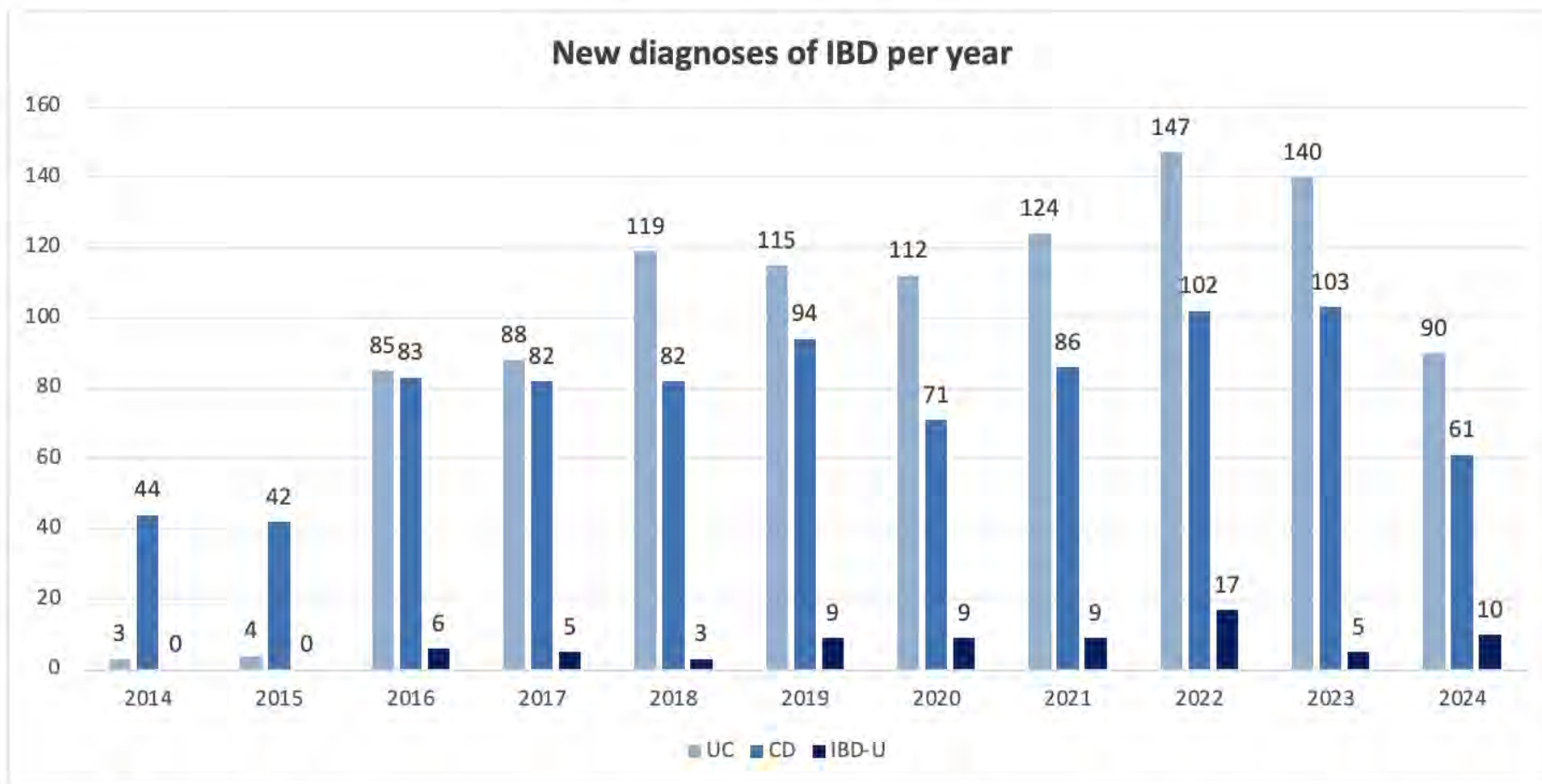
Greece:
Patrelon Athinon, Polykliniki
Nikolaos Vlazis
rology Department

Imelda Hospital
Lieven Posillon - Peter Bossuyt
University H
Dav

Egypt:
Mansoura University - Specialized Medical H
Maha Maher – Nabil Alaa
GHA Evaggelismos-Ophthalmiatr

Greece:
Alexandra General Hospital – Gastroenterolo
Evanthia Zambeli – Spyridon Michopoulos





]

1 **Figure 2:** Number of newly diagnosed patients with inflammatory bowel disease (IBD) in the last 10 years collected from all Slovenian
 2 IBD centres. IBD – inflammatory bowel disease, UC – ulcerative colitis, CD – Crohn's disease, IBD-U – inflammatory bowel disease,
 3 unclassified

Table 2: Calculated incidence rate for new IBD cases in Slovenia during the period 2016-2024

Year	Total New Cases	Estimated Incidence IBD (/100,000)	Estimated Incidence CD (/100,000)	Estimated Incidence UC (/100,000)	Estimated Incidence IBD-U (/100,000)
2016	174 (UC 85 + CD 83 + IBD-U 6)	8.3	3.9	4.0	0.3
2017	175 (88 + 82 + 5)	8.3	3.9	4.2	0.2
2018	206 (119 + 82 + 5)	9.8	3.9	5.6	0.1
2019	218 (115 + 94 + 9)	10.4	4.5	5.4	0.4
2020	192 (112 + 71 + 9)	9.1	3.4	5.3	0.4
2021	219 (124 + 86 + 9)	10.4	4,1	5.9	0.4
2022	266 (147 + 102 + 17)	12.7	4.8	7.0	0.8
2023	248 (140 + 103 + 5)	11.8	4.9	6.6	0.2
2024	161 (90 + 61 + 10)	7.7 (likely incomplete)	2.9	4.3	0.5

* *Based on estimated population of 2.1 million in Slovenia; IBD – inflammatory bowel disease, UC – ulcerative colitis, CD – Crohn’s disease, IBD-U – inflammatory bowel disease, unclassified*

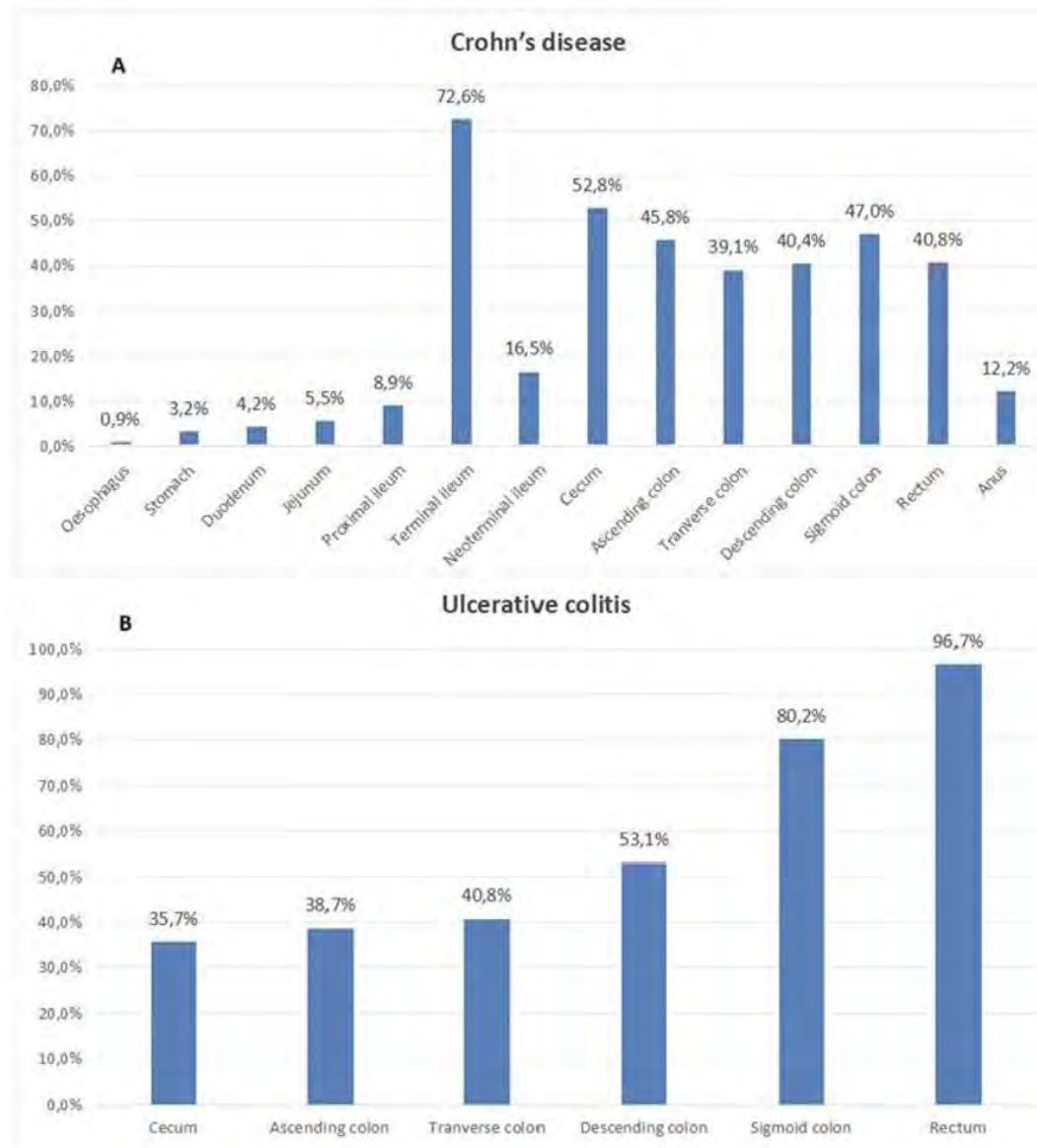


Figure 3: Disease extension in patients with (A) Crohn's disease and (B) ulcerative colitis in all Slovenian Inflammatory bowel disease centres.

Some lessons learnt from the UR CARE Registry - Slovenia





Lesson 1:

Drug access improves outcome

DRUG SURVIVAL IMPROVED AFTER REALEASE OF LIMITATIONS FOR 1ST LINE BIOLOGICAL

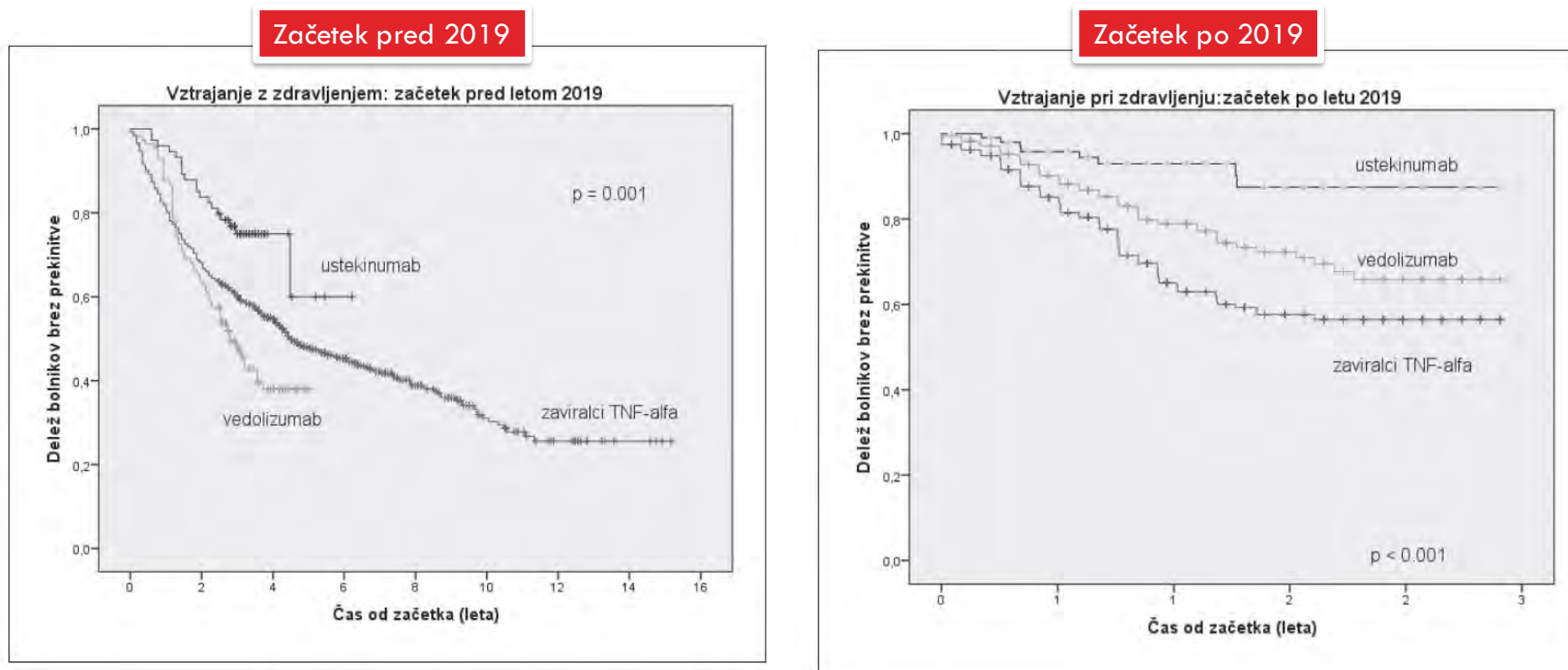


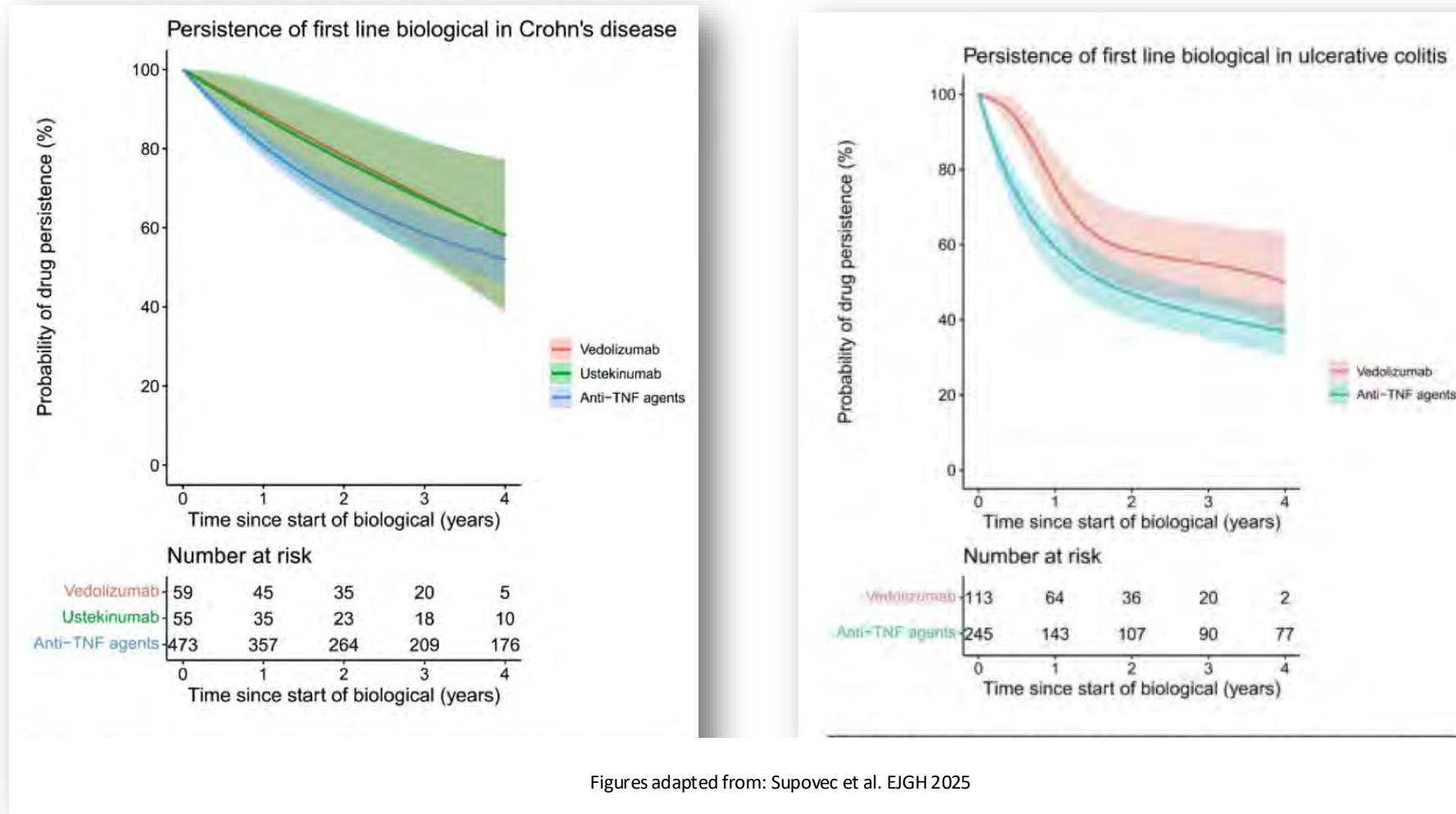
Tabela 3. Vztrajanje z zdravljenjem glede na leto začetka biološkega zdravila prvega reda po 2,5 leta

	Pred letom 2019	Po letu 2019
zaviralci TNF-alfa	66 %	59 %
vedolizumab	57 %	71 %
ustekinumab	69 %	86 %

First-line anti-TNF agents, ustekinumab and vedolizumab perform similarly in Crohn's disease, but not in ulcerative colitis

Eva Supovec^a, Jurij Hanžel^{a,b}, Gregor Novak^{a,b}, Damjan Manevski^c, Borut Štabuc^{a,b} and David Drobne^{a,b}

Physicians had no limitation on choice of 1st line biological



Figures adapted from: Supovec et al. EJGH 2025

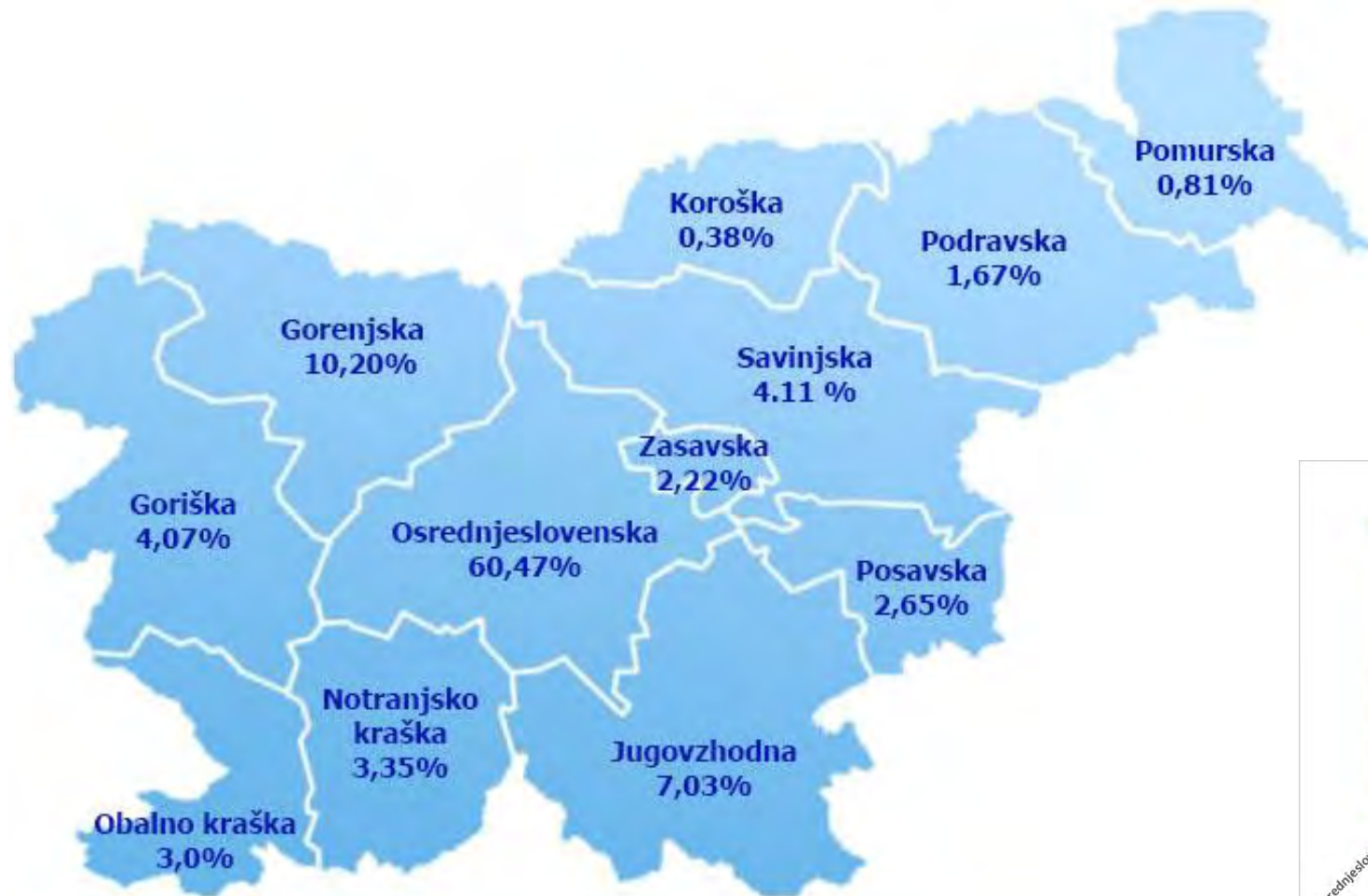
Lesson 2:

No need for centralization of biologicals treatments

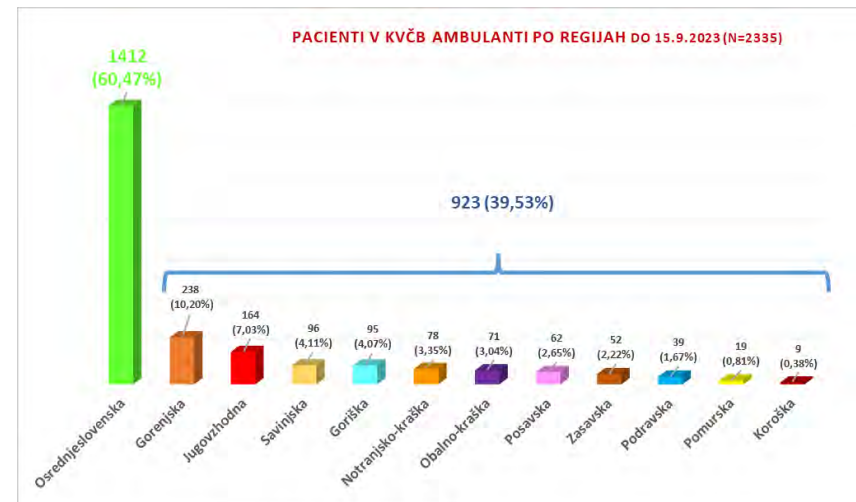
Biological treatment approach to inflammatory bowel disease is similar in academic and nonacademic centres – prime time for decentralisation of inflammatory bowel disease care?

Katja Tepeš^a, Jurij Hanžel^{b,c}, David Štublar^d, Karin Strmšek^e, Luka Erjavec^f, Eva Supovec^g, Zala Jagodic^h, Mirjam Končanⁱ, Jan Grosek^{j,k}, Jurij Aleš Košir^l, Aleš Tomažič^{m,n}, Urška Kogovšek^o, Gregor Norčič^{p,q}, Renata Šibič^r, Marija Žnidaršič^s, Tadeja Pačnik Vižintin^t, Barbara Sodin^u, Janez Breznik^v, Vanesa Anderle Hribar^w, Andreja Očepek^x, Cvetka Pernat Drobež^y, Nejc Bukovnik^z, Andrej Zafošnik^{aa}, Tamara Marušič^{ab}, Nataša Juređič Brglez^{ac}, Maja Denkovski^{ad}, Nataša Smrekar^{ae}, Gregor Novak^{af}, Matic Koželj^{ag}, Tina Kurent^{ah}, Jože Simonič^{ai}, Špela Pintar^{aj}, Borut Štabuc^{ak} and David Drobne^{al}

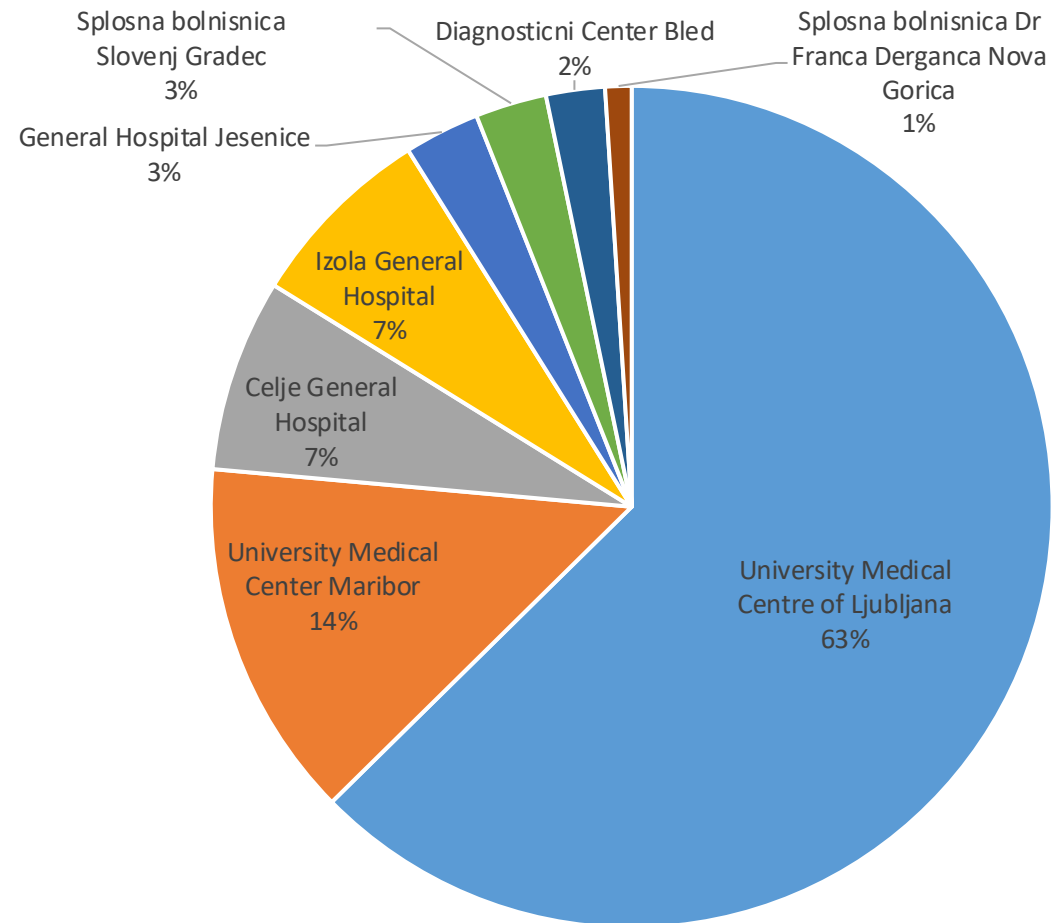
Residency of IBD patients treated at UMC Ljubljana



≈ 40% of pts from another region in Slovenia



Patient disposition across IBD centres in Slovenia



2/3 pts (still) treated
at academic medical centres

Effect of travel distance to quality of life?

For patients with stone-related symptoms, they experience an estimated

3% reduction in quality of life for every 100 km traveled.



Image generated by ChatGPT

related

es in WISQOL score for subjects
 mptoms based on demographic
 e factors, and distance

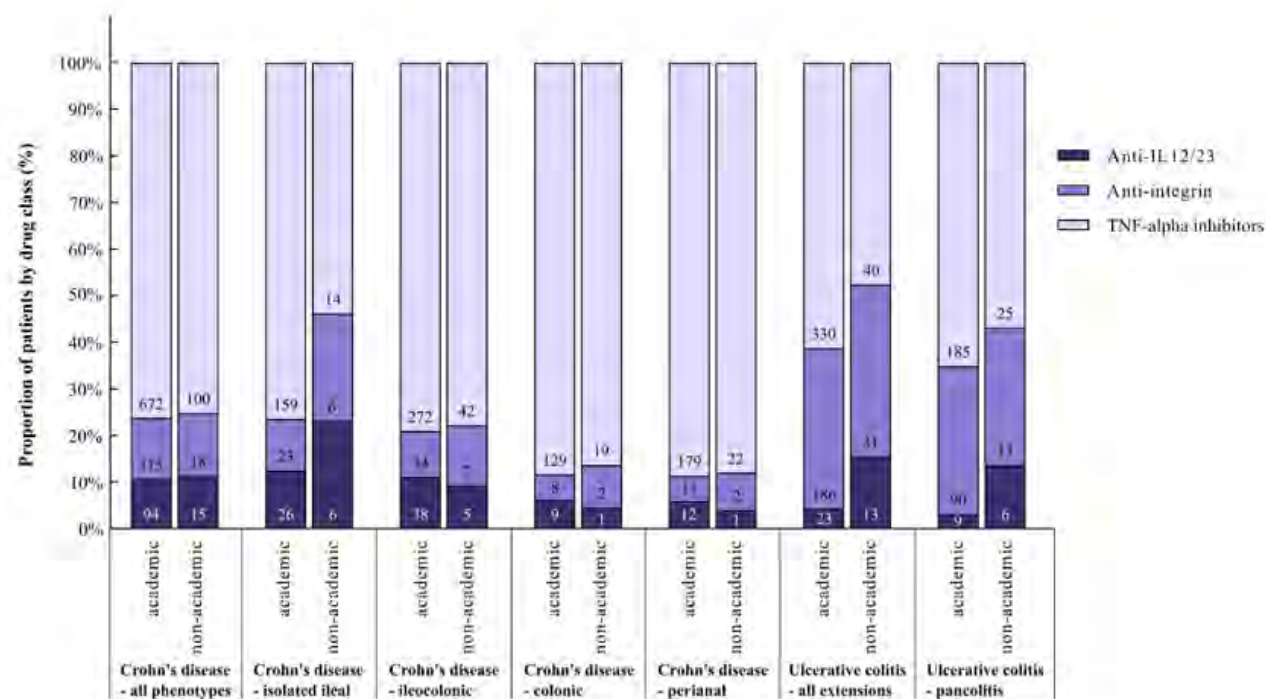
	Estimate	p
	98.560	
	0.362	<0.0001
		<0.0001
		0.0249
Underweight	-2.235	
Normal	ref	
Overweight	0.619	
Obese class I	1.174	
Obese class II	-1.772	
Obese class III	-11.026	
		0.0571
Asian	8.051	
Black/African American	-6.091	
White - Latino	-5.760	
White - non-Latino	ref	
Other	-16.035	
	-0.126	0.0322
	-2.817	0.0002
	-17.327	<0.0001
	-0.047	0.0001

0 km. BMI: body mass index; WISQOL: Wisconsin

Biological treatment patterns of IBD: academic vs. nonacademic centres

	Overall	Academic centres	Nonacademic centres	p value
Total number of patients with IBD*	2748	2319 (84.4%)	429 (15.6%)	0.656
CD** - N (%)	1405 (51.1%)	1191 (51.4%)	214 (49.9%)	
UC*** - N (%)	1237 (45.0%)	1040 (44.8%)	197 (45.9%)	
IBD-U**** - N (%)	95 (3.5%)	83 (3.6%)	12 (2.8%)	
Crohn's with isolated ileum disease - N (% of all CD)	326 (23.2%)	286 (24.0%)	40 (18.7%)	0.090
Crohn's with ileocolonic disease - N (% of all CD)	518 (36.9%)	431 (36.2%)	87 (40.7%)	0.212
Crohn's perianal - N (% of all CD)	264 (18.8%)	229 (19.2%)	35 (16.4%)	0.322
Age at diagnosis CD - years (mean± standard deviation)	33.1±16.9	32.3±16.8	37.5±17.4	<0.001
Age at diagnosis UC - years (mean± standard deviation)	36.6±16.8	36.4±17.0	37.7±15.9	0.292
Disease duration until biologic initiation (start of biological treatment from 2020-2022 (mean± standard deviation) [months])	4.68±4.44	4.92±4.68	3.72±2.88	0.265
Disease duration until biologic initiation [months]	11.16±10.08	11.28±10.08	10.44±10.08	0.236
Extraintestinal manifestations - N (% of all IBD patients)	338 (12.3%)	279 (12.0%)	59 (17.9%)	0.277

Figure 1: Choice of first-line biological treatment in academic vs. nonacademic centres for specific phenotypes of inflammatory bowel disease



IBD – Inflammatory bowel disease.

Figures adapted from: EJGH 2024. Tepeš et al.



Lesson 3:

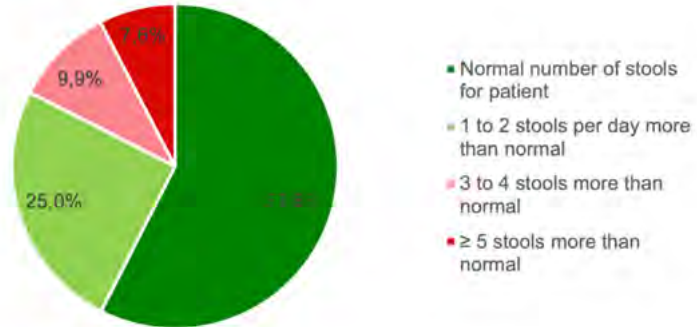
Many patients still fail to reach complete disease control

Clinical symptoms in **Ulcerative Colitis**

- cross section of SLO IBD data from UR-CARE registry

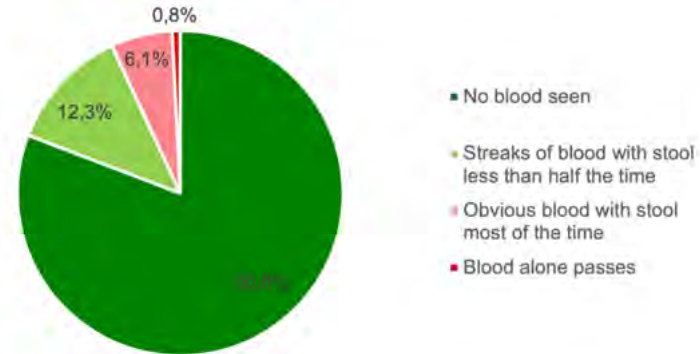
A

Stool frequency



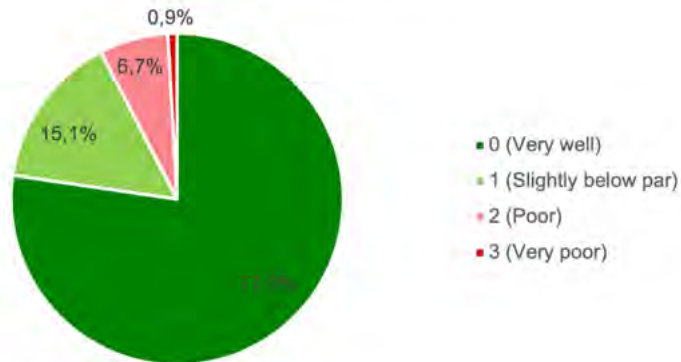
B

Rectal bleeding



C

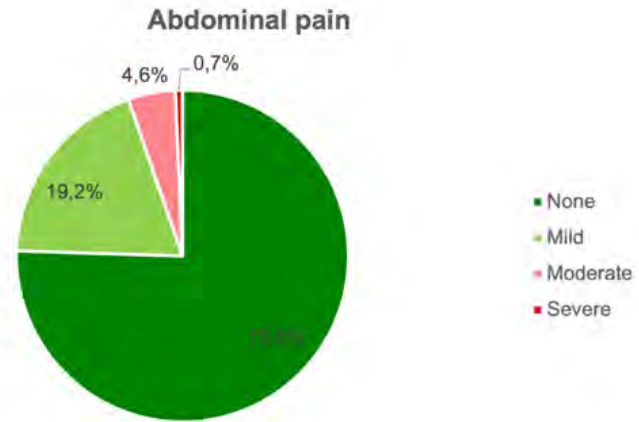
Physician global assessment



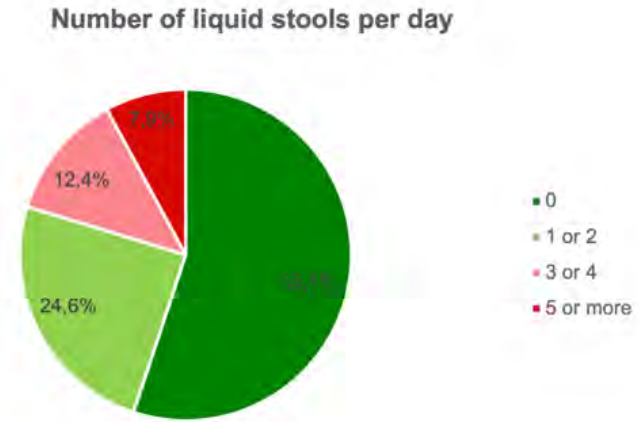
Clinical symptoms in Crohn's disease

- cross section of SLO IBD data from UR-CARE registry

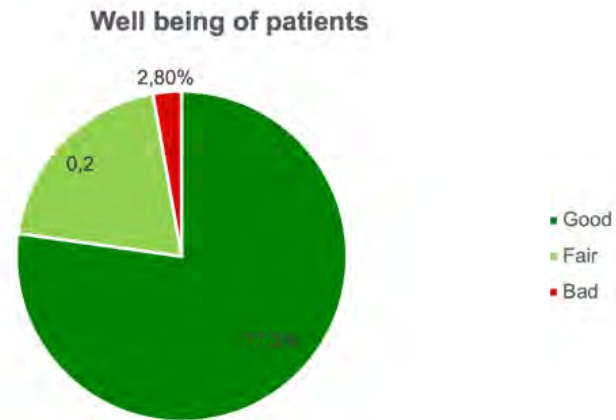
A



B



C



Printed forms to facilitate data entry



624

PREDIZPOLNJEN VPRASALNIK ZA PLANIRANO INFUZIJO BIOLOŠKEGA ZDRAVILA



DATUM:

Tel. višina: Tel. Teža:

ALI IMA KDO V DRUŽINI Ulcerozni kolitis / Crohnovo bolezen? NE DA:

KAJENJE: DA NIKOLI KADIL/A BIVŠI KADILEC/KA:(vpišite kdaj ste prenehali)

ALI STE BILI NA POTOVANJU IZVEN EU? NE DA KJE?:

STE BILI V STIKU Z OSEBO S TUBERKULOZO? NE DA KDAJ?:

Redna terapija za UC / CB na dan infuzije (obkrožite): Medrol, Hidrokortizon, Budezonid, Budenofalk, Sulfasalazin, Pentasa, Salofalk, Imuran, Azafalk, Puri-Nethol, Metotrexat, Xeljanz, Jyseleca

- | | | |
|--|----|----|
| 1. Imate vročino oz. ste jo imeli v zadnjih 14 dneh? | DA | NE |
| 2. Ste prejemali antibiotik v zadnjih 14 dneh? | DA | NE |
| 3. Imate herpes? | DA | NE |
| 4. Ste bili cepljeni v zadnjih 14 dneh? | DA | NE |
| 5. Obstaja možnost, da ste noseči? | DA | NE |
| 6. Imate novonastale spremembe na koži? | DA | NE |
| 7. Imate predviden kirurški poseg? | DA | NE |

Vprašalnik za **ULCEROZNI KOLITIS** - delni Mayo točkovnik

1. Dnevna pogostost odvajanja blata ali sluzi

a) tolikokrat kot preden sem zbolel/a za ulkolutis	0t
b) 1-2 odvajanja več kot običajno	1t
c) 3-4 odvajanja več kot običajno	2t
d) 5 ali več odvajanj več kot običajno	3t

2. Kri na blatu

a) v blatu ni krvi	0t
b) srage krvi ob manj kot polovici odvajanj	1t
c) primesi krvi ob večini odvajanj	2t
d) odvajanje samo krvi brez blata	3t

Splošna ocena stanja (IZPOLNI ZDRAVNIK)

a) normalno	0t
b) blaga bolezen	1t
c) zmerno huda bolezen	2t
d) huda bolezen	3t

Skupno št. Točk []

a) remisija	do 1t
b) blago aktivna	2 - 4 t
c) srednje aktivna	5 - 7 t
d) močno aktivna	8 in več t

Vprašalnik za **CROHNOVO BOLEZEN** - HBI točkovnik

1. Kolikokrat ste včeraj odvajali tekoče, zelo mehko blato ali sluz?
(vsaka stolica = 1t) []

2. Ocenite splošno počutje na dan pred pregledom

a) dobro	0t
b) srednje	2t
c) slabo	4t

3. Ocenite bolečino v trebuhu na dan pred pregledom

a) brez	0t
b) blaga	1t
c) zmerna	2t
d) huda	3t

IZPOLNI ZDRAVNIK!

Tipna rezistenca v trebuhu

a) ne	0t
b) morda	1t
c) zagotovo	2t
d) zagotovo; boleča	3t

Zapleti (vsak zaplet = 1t) []

artralgija; uveitis; absces; nodozni eritem; afte v ustih; pioderma g.; analna fisura; novonastala fistula

Skupno št. točk: []

a) remisija	0 - 4 t
b) blago aktivna	5 - 7 t
c) srednje aktivna	8 - 16 t
d) močno aktivna	17 in več t

Podpis pacienta:

KZ izpolnjena obrazca 624

Večja verzija je dostopna v sistemu EDS.

1/2

OB 5270 v2



624

OCENA ENDOSKOPSKE AKTIVNOSTI CROHNOVE BOLEZNI



SES - CD TOČKOVNIK ZA OCENO ENDOSKOPSKE AKTIVNOSTI CROHNOVE BOLEZNI - PROSIM IZPOLNITI IN PRILOŽITI IZVIDU KOLONOSKOPIJE

IME in PRIIMEK BOLNIKA: DATUM ROJSTVA: DATUM KOLONOSKOPIJE:

KOLONOSKOPSKI SEGMENTI	REKTUM	LEVI KOLON	TRANSVERZUM	DESNI KOLON	ILEUM
Velikost ulkusov - A					
0 točk	Ni ulkusov				
1 točka	Ahtozni ulkus (Ø 0,1-0,5 cm)				
2 točki	Velik ulkus (Ø 0,5-2 cm)				
3 točke	Zelo veliki ulkusi (Ø > 2 cm)				
k	kirurško resekciran segment ali nepregle	točk	točk	točk	točk
Delež prizadete sluznice, zajete z ulkusi - B					
0 točk	Nič				
1 točka	< 10 %				
2 točki	10-30 %				
3 točke	> 30 %				
k	kirurško resekciran segment ali nepregle	točk	točk	točk	točk
Delež prizadete sluznice z boleznijo - C					
0 točk	Naprizadet segment				
1 točka	< 50 %				
2 točki	50-70 %				
3 točke	> 70 %				
k	kirurško resekciran segment ali nepregle	točk	točk	točk	točk
Prisotnost stenoz - D					
0 točk	Ni stenoz				
1 točka	Ena prehodna stenoz				
2 točki	Več kot ena stenoz, vse prehodne				
3 točke	Naprehodne stenoz				
k	kirurško resekciran segment ali nepregle	točk	točk	točk	točk
Segmenti SES - CD (vsota A+B+C+D) _____ točk _____ točk _____ točk _____ točk _____ točk					
SES CD skupni (vsota točk vseh segmentov) _____ točk					

IZPOLNI ENDOSKOPIST

IZPOLNI KVČB AMBULANTA

Endoskopska ocena bolezn (obkroži!)

a) endoskopsko aktivna bolezen (SES-CD 4 (N vsej en aftozni ulkus v vsej enem segmentu))

b) endoskopska remisija

Displazija v histologiji

a) ne

b) da



624

OCENA ENDOSKOPSKE AKTIVNOSTI ULCEROZNEGA KOLITISA



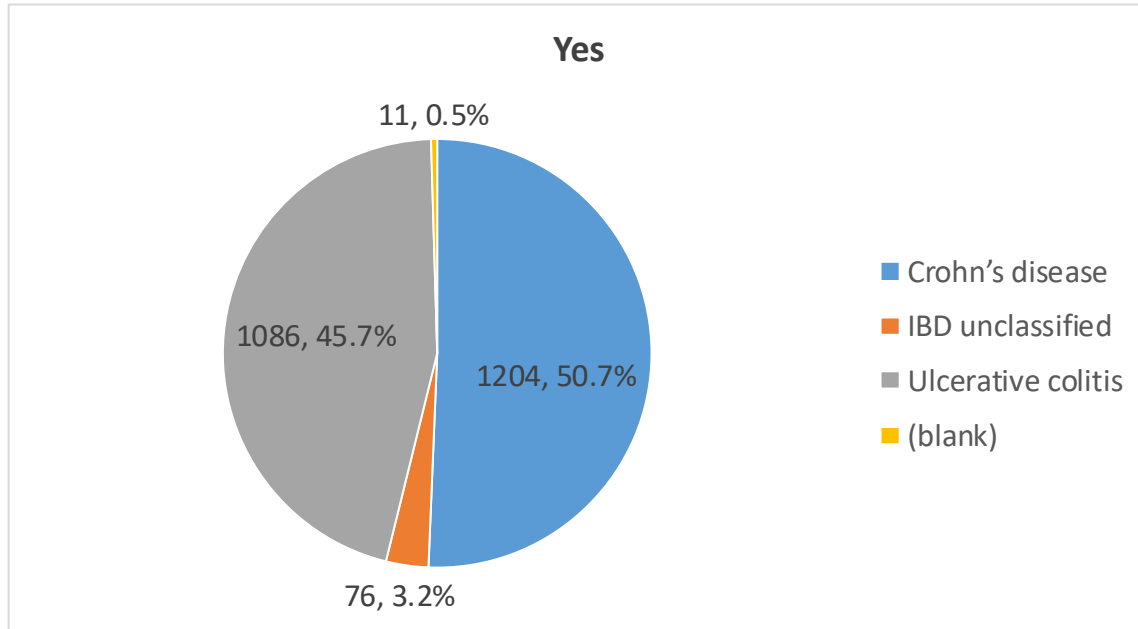
IZPOLNI ENDOSKOPIST

OCENA ENDOSKOPSKO AKTIVNOSTI ULCEROZNEGA KOLITISA

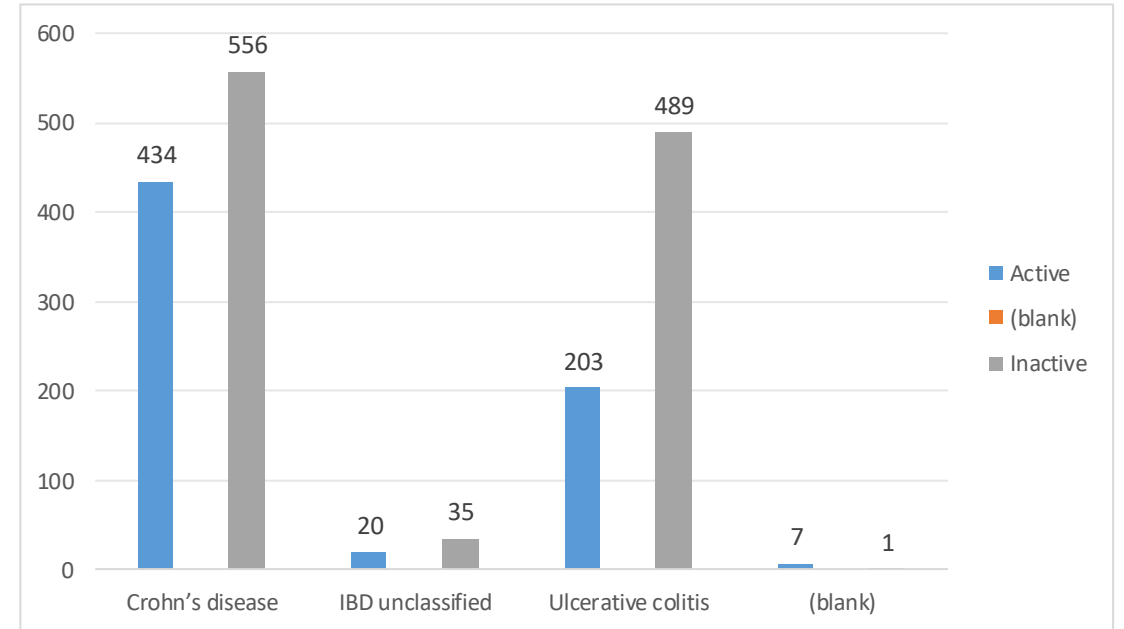
IZPOLNI KVČB AMBULANTA

Endoscopic activity

Ileocolonoscopy performed



Ileocolonoscopy activity



Hospital	Date of examination II												Grand Total
	before 2015	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025	
Celje General Hospital	36 (69,2%)	9 (64,3%)	6 (40,0%)	17 (37,8%)	21 (30,0%)	23 (19,5%)	30 (14,1%)	27 (12,4%)	52 (27,8%)	52 (14,9%)	67 (10,1%)	16 (3,7%)	356 (15,0%)
Diagnosticni Center Bled	2 (3,8%)		2 (13,3%)	2 (4,4%)	4 (5,7%)	6 (5,1%)	12 (5,6%)	18 (8,3%)	40 (21,4%)	31 (8,9%)	38 (5,7%)	17 (3,9%)	172 (7,2%)
General Hospital Jesenice Splosna bolnisnica Dr Franca Derganca Nova Gorica	1 (1,9%)			2 (4,4%)	3 (4,3%)		5 (2,3%)	4 (1,8%)	5 (2,7%)	1 (0,3%)	1 (0,2%)		16 (0,7%)
Splosna bolnisnica Slovenj Gradec	3 (5,8%)		2 (13,3%)	1 (2,2%)	3 (4,4%)	7 (5,9%)	12 (5,6%)	18 (8,3%)	36 (19,2%)	50 (14,3%)	24 (3,6%)	14 (3,2%)	170 (7,2%)
University Medical Center Maribor University Medical Centre of Ljubljana	8 (15,4%)	4 (28,6%)		4 (8,9%)	4 (5,7%)	12 (10,2%)	10 (4,7%)	25 (11,5%)	35 (18,7%)	85 (24,3%)	117 (17,6%)	54 (12,5%)	358 (15,1%)
	2 (3,8%)	1 (7,1%)	5 (33,3%)	19 (42,2%)	35 (50,0%)	70 (59,3%)	143 (67,1%)	117 (53,9%)	14 (7,5%)	127 (36,3%)	417 (62,7%)	330 (76,6%)	1280 (53,8%)
Grand Total	52	14	15	45	70	118	213	217	187	350	665	431	2377

Endoscopic endpoints in **Crohn's disease**

- cross section of SLO IBD data from UR-CARE registry

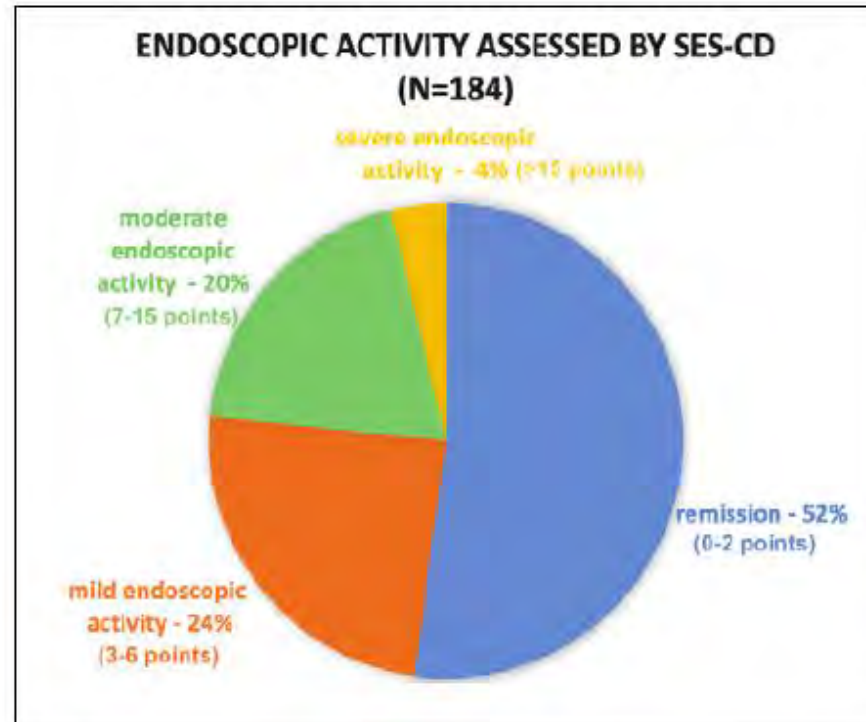


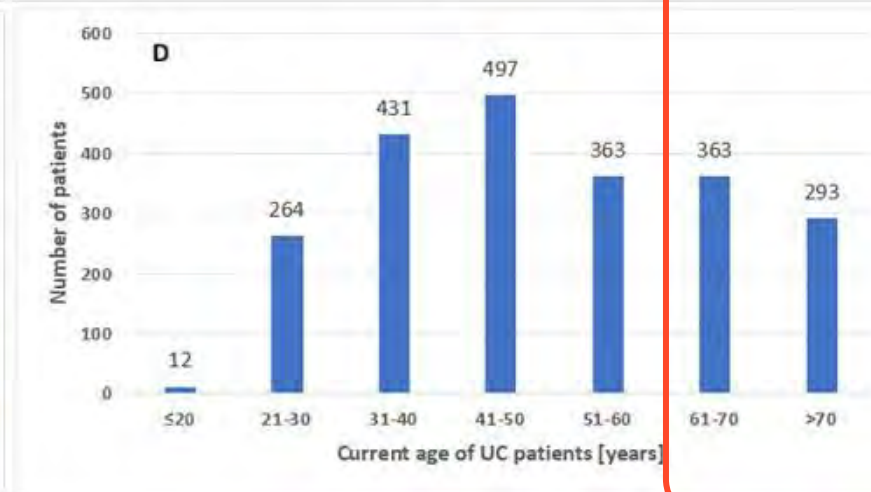
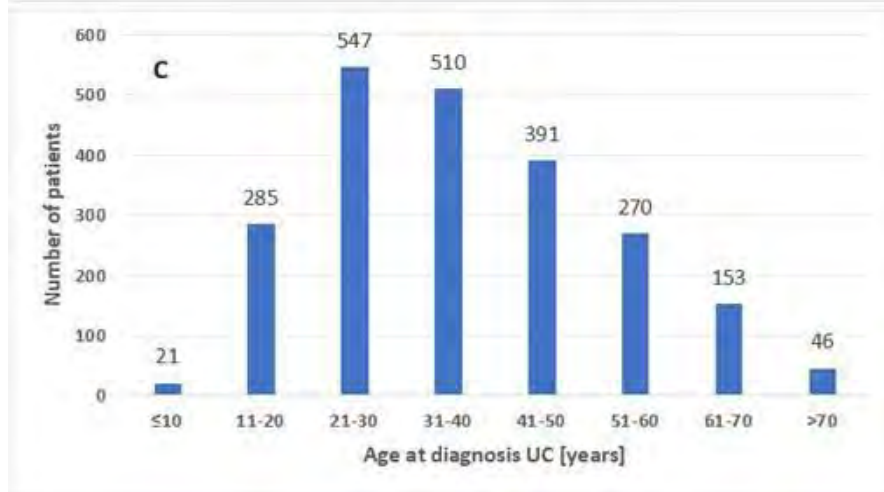
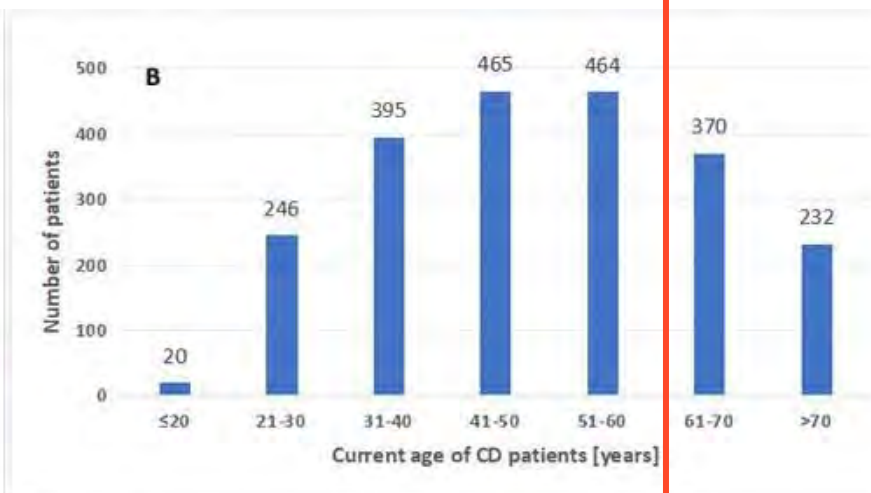
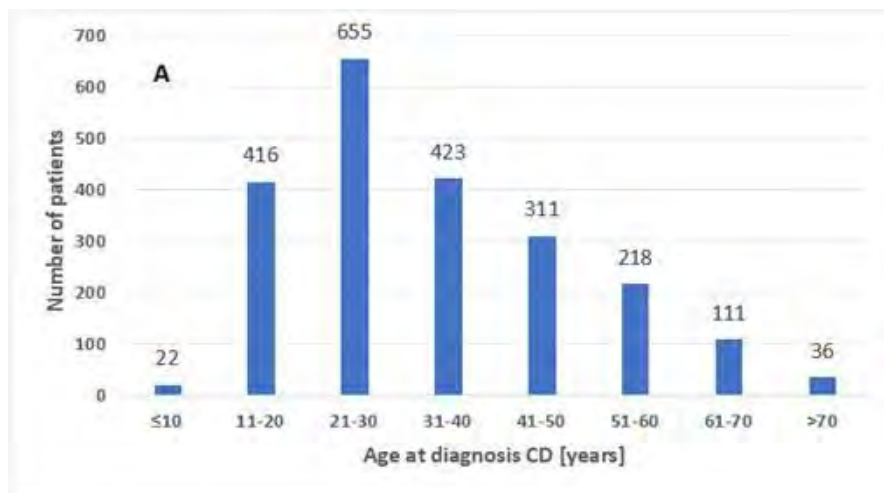
Figure 8



Lesson 4:

Patient demographics is changing

IBD population in Slovenia getting older



Age at diagnosis:
35.7 years \pm 15.5

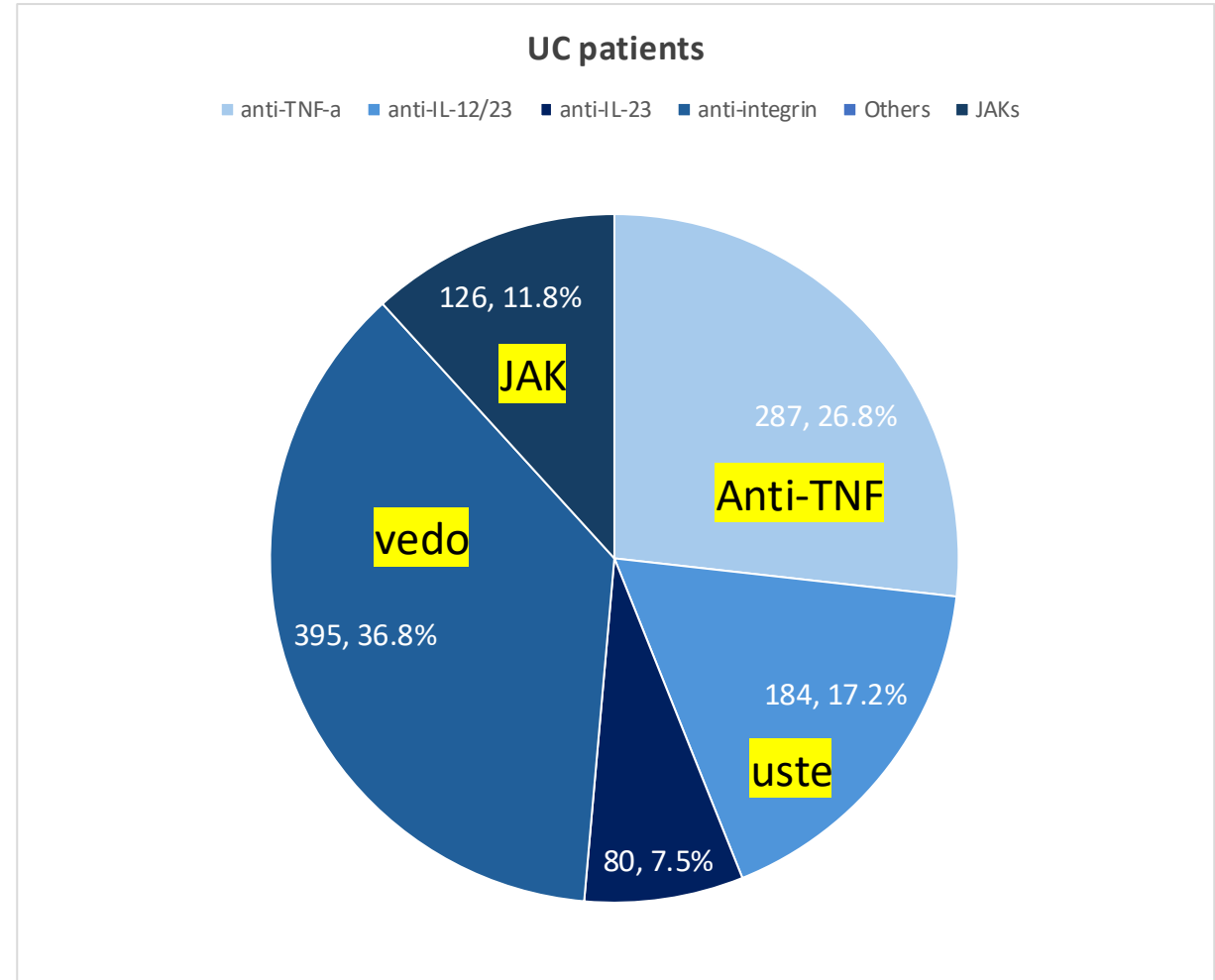
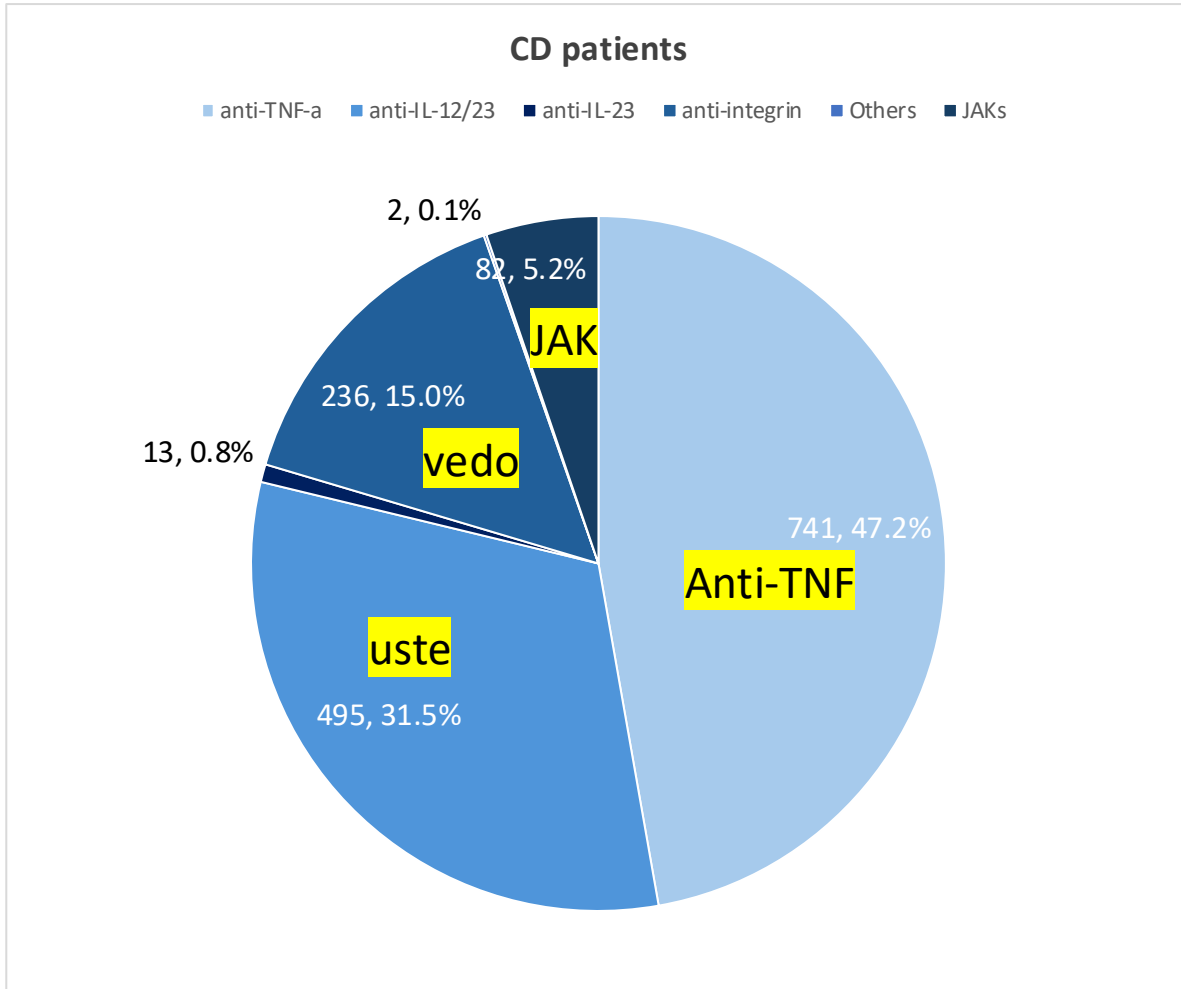
Current age:
50.0 years \pm 16.0

Data on file from UR-CARE Slovenia (data export Dec 31st 2024)

Figures adapted from: UR-CARE - the United Registries for Clinical Assessment and Research

SLO, Slovene; IBD, Inflammatory bowel disease, CD, Crohn's disease; UC, Ulcerative Colitis

Number of patients receiving advanced treatment with different classes of therapy for CD and UC at the end of 2025





Ne pride daleč, kdor gre kar naravnost.

The Little Prince



ANTOINE DE SAINT-EXUPÉRY

