

# National Database of the German Collaborative Arthritis Centres – Trends in Health Care Provision 2024



Kerndokumentation



Regionale Kooperative  
Rheumazentren

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German Rheumatism Research Centre Berlin

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**DRFZ**  **BERLIN**

Deutsches Rheuma-Forschungszentrum  
Ein Institut der Leibniz-Gemeinschaft

# Imprint



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# Participating rheumatology centres



We would like to thank all facilities, their employees and their patients who contributed data for the German National Database in 2022.

## Rheumatology Centres

Medizinische Klinik mit Schwerpunkt Rheumatologie und Klinische Immunologie, Charité Universitätsmedizin Berlin

Medizinische Klinik und Poliklinik III, Rheumatologie, Universitätsklinikum Carl-Gustav-Carus, Dresden

Klinik für Rheumatologie, Medizinische Fakultät, Universitätsklinik Düsseldorf, Heinrich-Heine Universität Düsseldorf  
Hiller Forschungszentrum Rheumatologie, Medizinische Fakultät, Universitätsklinikum Düsseldorf, Heinrich-Heine-Universität Düsseldorf

Universitätsklinikum der Ruhr-Universität Bochum, Rheumazentrum Ruhrgebiet, Herne

Klinik für Innere Medizin III – Rheumatologie/Osteologie, Universitätsklinikum Jena

Zentrum für Interdisziplinäre Rheumatologie, klinische Immunologie und Autoimmunerkrankungen (INDIRA), Department für Innere Medizin II;  
Universitätsklinik Tübingen

Immanuel-Krankenhaus Berlin, Rheumatologie, klinische Immunologie und Osteologie

Rheumazentrum Ratingen, Rheumatologische Gemeinschaftspraxis, Ratingen

Internistisch-rheumatologische Gemeinschaftspraxis, Bayreuth

Praxis für Rheumatologie und Innere Medizin, Berlin

Rheumapraxis Dilltal, Ehringshausen, Burbach

Rheumapraxis München-Pasing

Rheumapraxis Stadthagen

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German Society for Rheumatology, Status 01/2024:



via a joint contribution to the  
Rheumatological Training Academy.

# Abbreviations



Diagnoses		Therapy		Instruments	
AAV	ANCA-associated Vasculitides	Aza	Azathioprine	BASDAI	Bath Ankylosing Spondylitis Disease Activity Index
AOSD	Adult Onset Still Syndrome	bDMARD	biologic DMARD	BASFI	Bath Ankylosing Spondylitis Functional Index
AxSpA	Axial Spondyloarthritis	csDMARD	conventional synthetic DMARD		
BD	Behçet Disease	DMARD	disease-modifying anti-rheumatic drug	CDAI	Clinical Disease Activity Index
CPPD	Chondrocalcinosis	GC	Glucocorticoids	DAS28	Disease Activity Score with 28 joints
IIM	Idiopathic Inflammatory Myopathies	HCQ	Hydroxychloroquine	ECLAM	European Consensus Lupus Activity Measurement Index
MCTD	Mixed Connective Tissue Diseases	IL-1/6/17i	Interleukin inhibitor	FFbH	Functional questionnaire Hanover
PMR	Polymyalgia Rheumatica	JAKi	Januskinase inhibitor	SDAI	Simple Disease Activity Index
PsA	Psoriatic Arthritis	Lef	Leflunomide	SJC	Number of swollen joints
RA	Rheumatoid Arthritis	MMF	Mycophenolate	TJC	Number of painful joints
GCA	Giant Cell Arteritis	MTX	Methotrexate	WHO-5	Questionnaire on well-being
SLE	Systemic Lupus Erythematosus	NSAIDS	non-steroidal anti-inflammatory drugs		
SjS	Sjögren's Syndrome	PDE4i	Phosphodiesterase inhibitor		
SSc	Systemic Sclerosis	RTX	Rituximab		
TA	Takayashu Arteritis	SSZ	Sulfasalazine		
		TNFi	Tumournecrosis factor inhibitor		
		tsDMARD	targeted-synthetic DMARD		

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# Characteristics

Case numbers  
Distance to the rheumatological facility  
Diagnostic spectrum  
Frequency of diagnoses  
Age distribution, age of onset  
Duration of symptoms at first presentation

# Case numbers



	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
Total	16,940	17,667	16,286	16,418	16,841	17,632	13,243	12,820	12,030	11,006	10,927	12,675	13,887
<i>Care provider</i>													
University Hospital	5,932	6,495	5,333	5,151	5,554	5,742	5,349	4,689	4,651	4,705	4,776	7,338	7,953
Hospital	1,404	1,313	614	620	566	610	903	1,050	505	281	493	592	584
Rheumatology practice	9,604	9,859	10,339	10,647	10,721	11,280	6,991	7,081	6,874	6,020	5,658	4,745	5,350



# Case numbers 2010 - 2022



	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
RA	8,362	8,594	7,967	8,101	8,304	8,721	6,364	6,241	5,745	5,077	5,019	5,425	5,998
axSpA	1,448	1,502	1,359	1,339	1,334	1,402	1,037	994	883	824	827	1,341	1,449
PsA	1,720	1,813	1,712	1,736	1,709	1,925	1,421	1,431	1,347	1,250	1,292	1,528	1,795
SLE	1,075	1,057	1,056	1,001	1,007	1,044	846	768	781	787	829	893	946

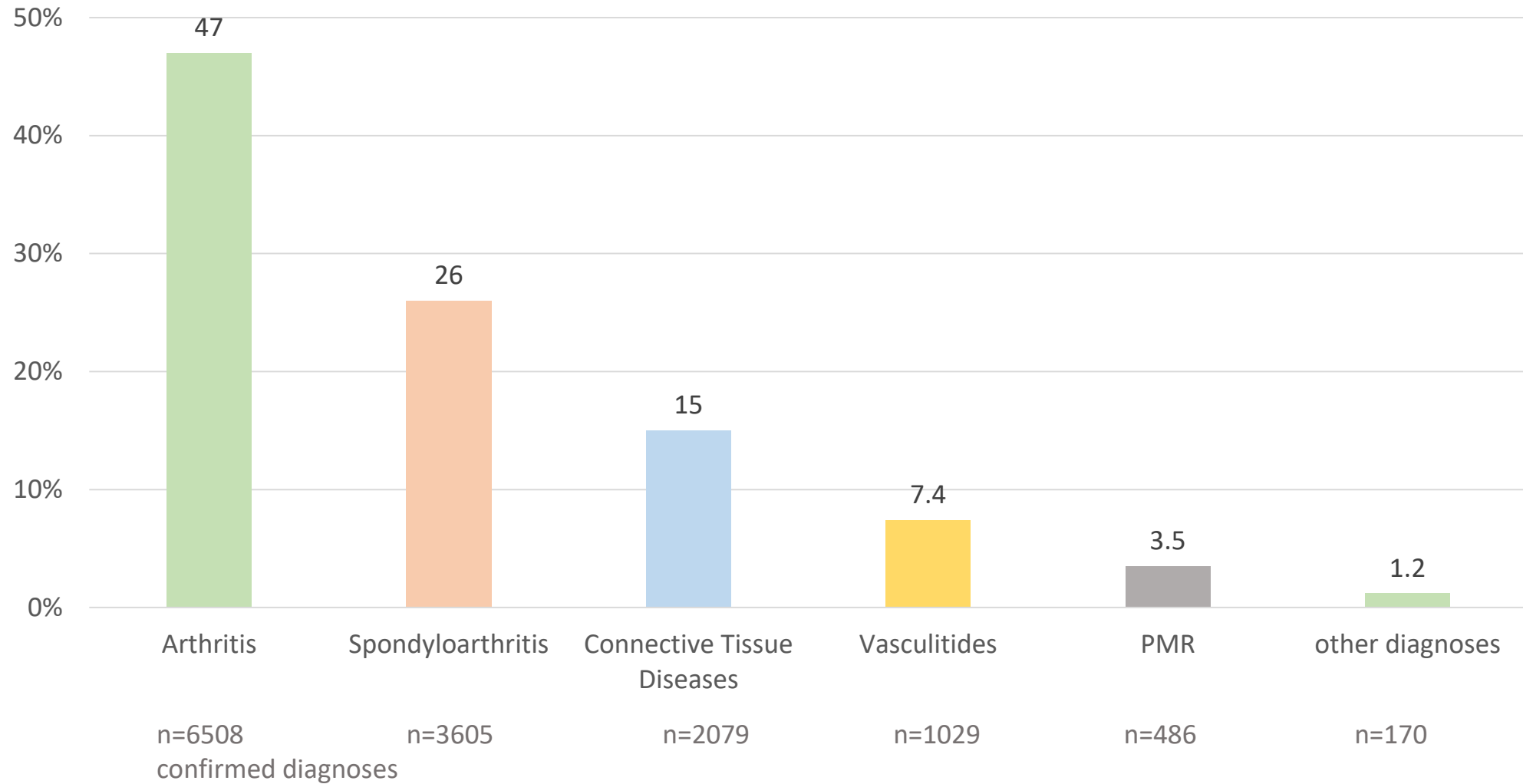
# Diagnostic spectrum



	Main diagnosis	ICD-10	Number of cases
Arthritis	seropositive rheumatoid arthritis (+RA)	M05	3,930
	seronegative rheumatoid arthritis (-RA)	M06.0x	2,036
	RA without specification RF	M06.8,M06.9	32
	Adult Onset Still's disease (AOSD)	M06.1	84
	Other arthritis		426
Spondyloarthritis	Axial spondyloarthritis (axSpA)	M45, M08.1xx	1,449
	Psoriatic arthritis (PsA)	M07.0-3, L40.5; M09.00-09	1,795
	Enteropathy-associated arthritis	M07.4-6; M09.20-29	37
	Reactive arthritis	M02, M03, I01.1	27
	other spondylopathies	M46	297
Collagenoses	Systemic Lupus Erythematosus (SLE)	M32.1, M32.8-9	946
	Sjögren's Syndrome (SjS)	M35.0	253
	Systemic Sclerosis (SSc)	M34	367
	Idiopathic inflammatory myopathies (IIM)	M33	106
	Mixed connective tissue disease (MCTD)	M35.1	144
	Other connective tissue diseases		263
Vasculitis	Polymyalgia rheumatica (PMR)	M35.3	486
	Giant cell arteritis (GCA)	M31.5, M31.6	355
	Takayasu arteritis (TA)	M31.4	44
	ANCA-associated vasculitis (AAV)	M30.1, M31.3, M31.7	332
	Behçet disease (BD)	M35.2	192
	Panarteritis, GBM, IgA, Cryoglobulinaemia	D69.0, D89.1, M30.0, M31.0,M30.8	37
	Other vasculitides		69
Other diagnoses	Gout, CPPD	M10, M11	15
	Sarcoidosis	D86, M63.3	45
	Recurrent polychondritis	M94.1	15
	Osteomyelitis	M86	22
	Other		73

The number of cases includes suspected and confirmed diagnoses. Only cases with a confirmed diagnosis are included in the analyses.

# Frequency of diagnoses

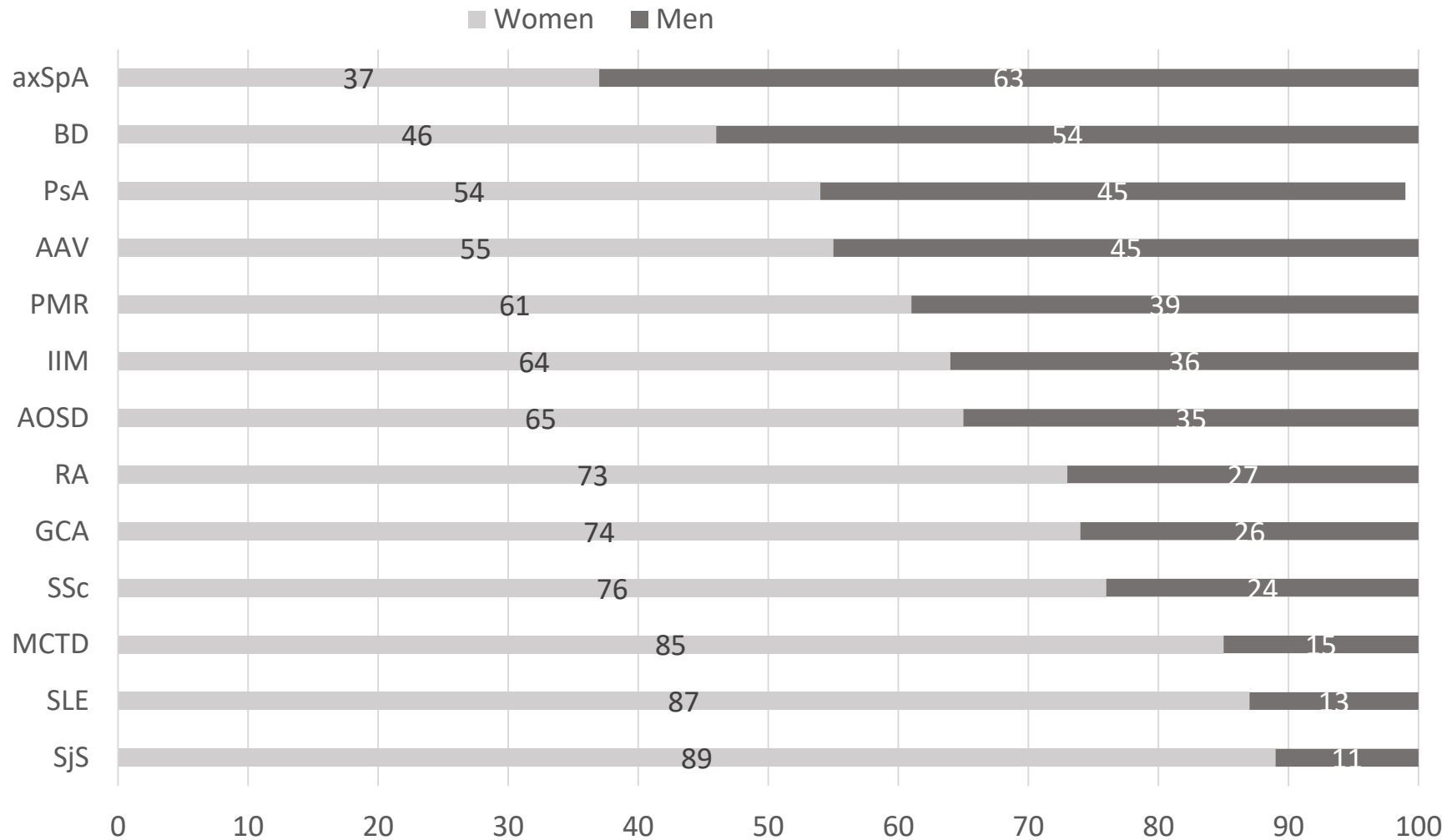


# Characteristics

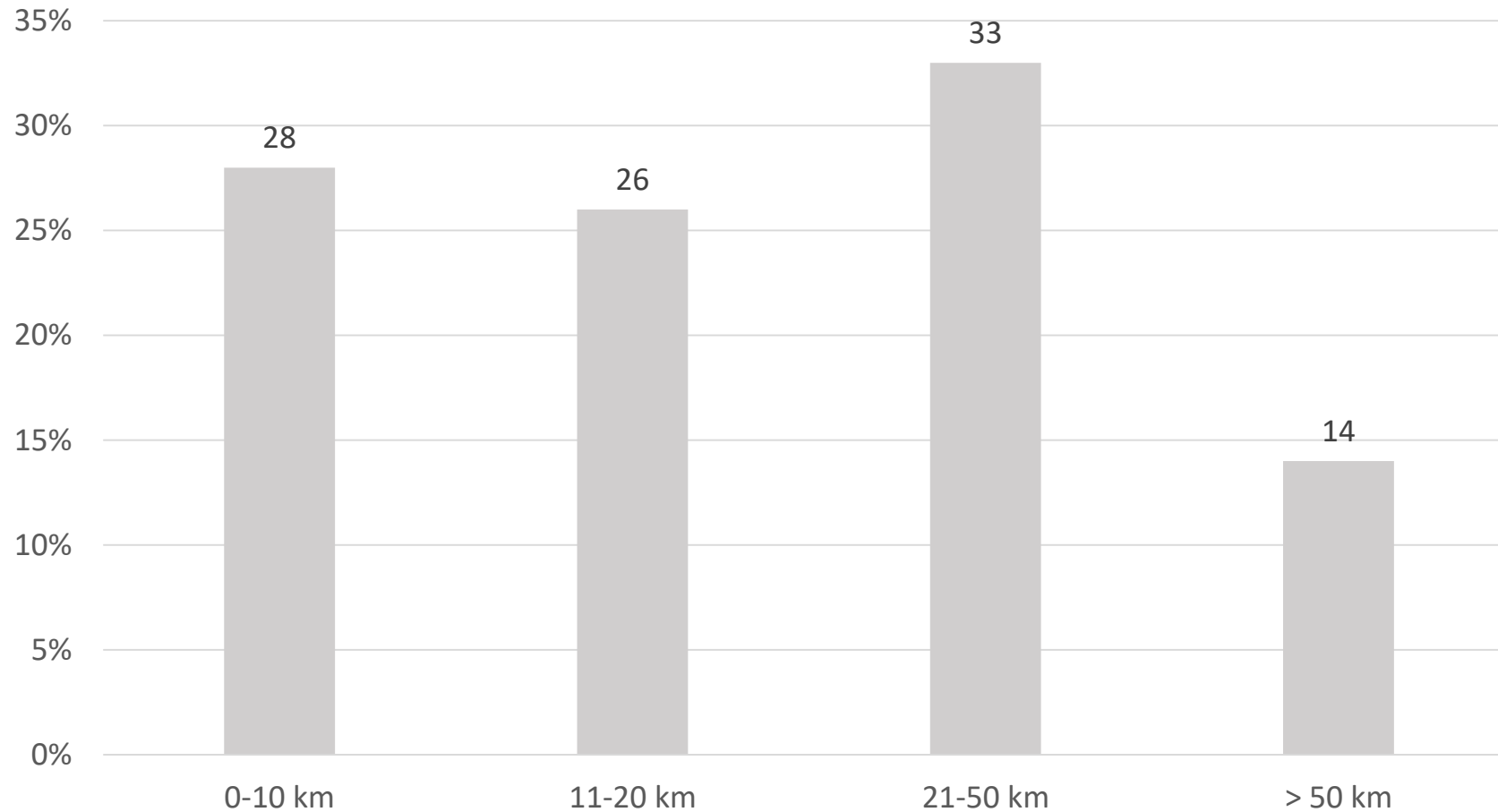


	Female (%)	Mean age	Mean age of onset	disease duration			
				Mean	<2 years (%)	2-5 years (%)	>5 years (%)
RA	73	63	49	14	9	16	75
AOSD	65	49	37	12	8	23	69
axSpA	37	49	30	19	5	10	85
PsA	54	56	43	14	9	16	75
SLE	87	49	32	18	5	9	86
SjS	89	56	43	12	8	16	77
SSc	76	58	45	12	8	17	75
IIM	64	56	46	10	16	17	67
MCTD	85	52	37	15	9	8	83
PMR	61	72	67	5	38	27	36
GCA	73	73	67	6	23	31	47
AAV	55	60	49	11	12	20	69
BD	45	45	28	16	1	13	86

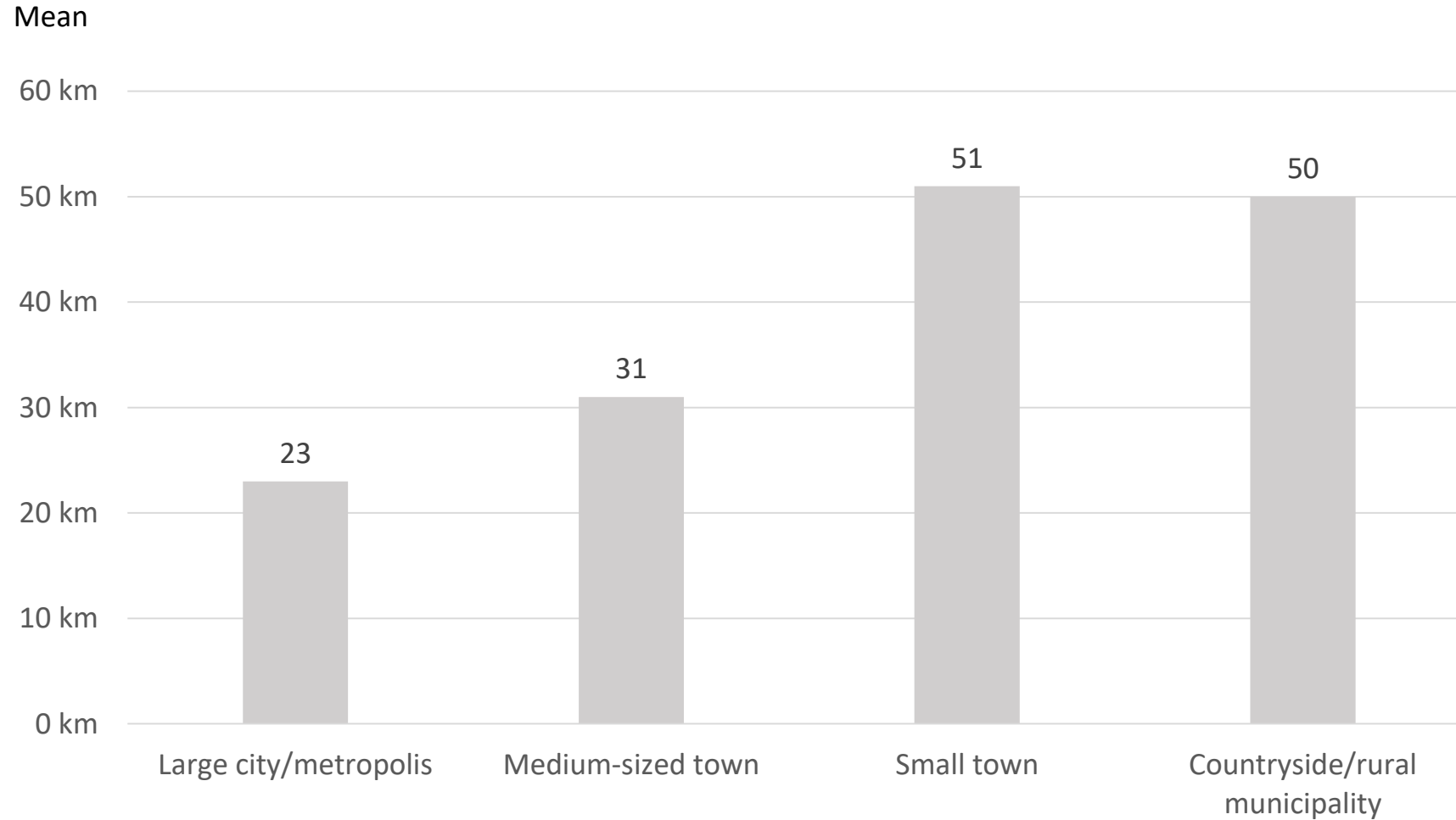
# Proportion of women and men



# Distance between place of residence and rheumatological facility



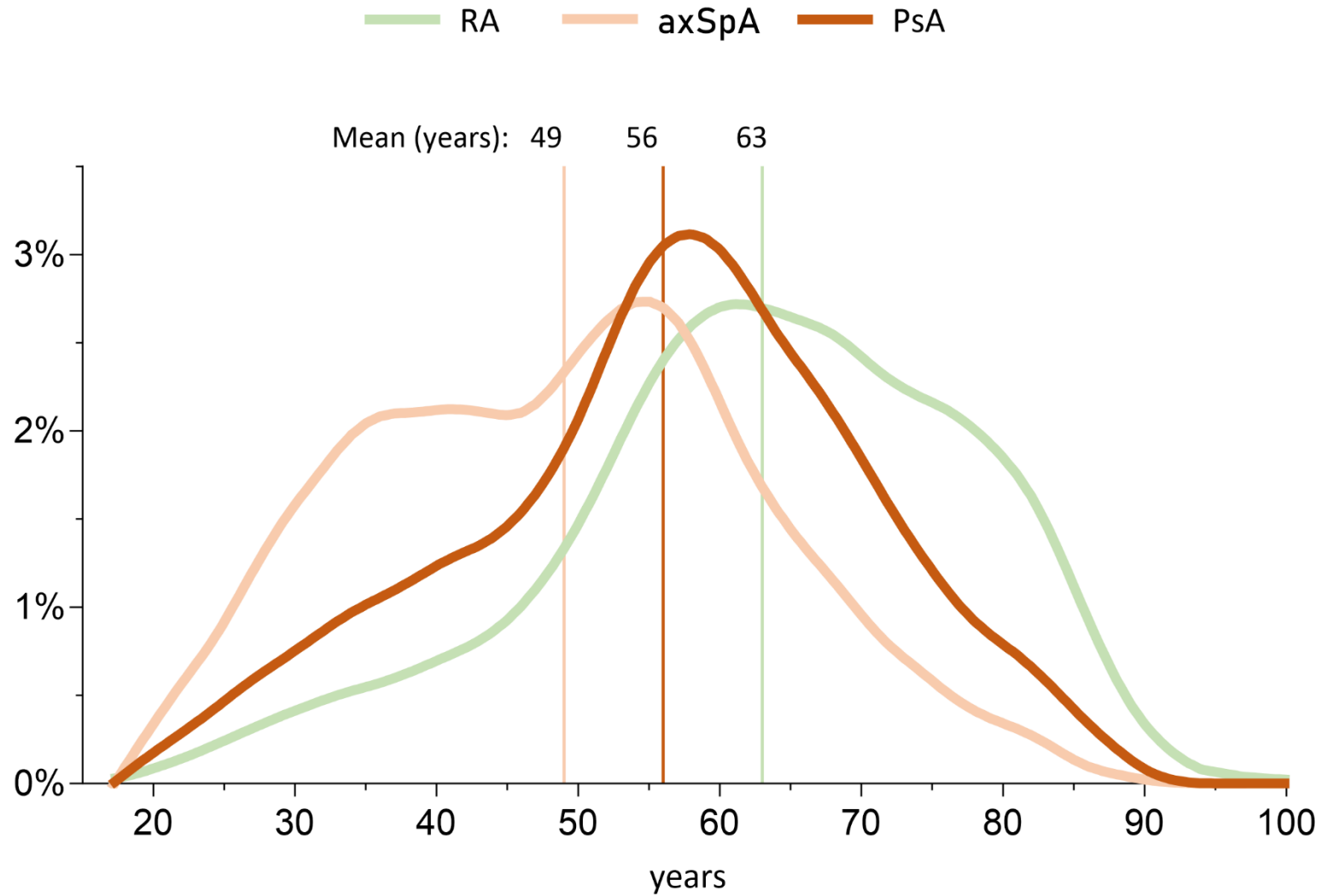
# Distance to rheumatological facility by type of city and municipality



# Age distribution

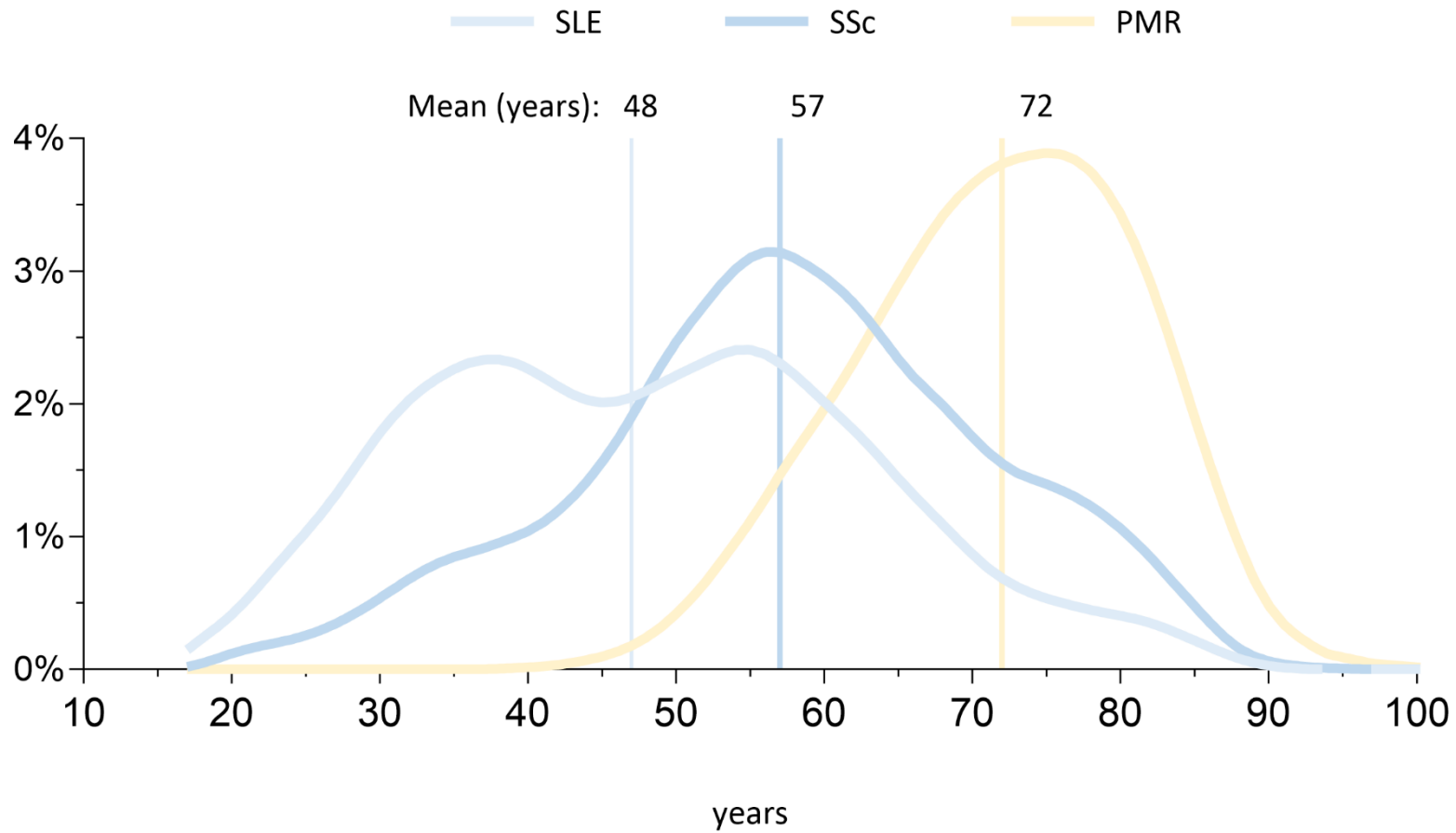


Example: 2.5% of RA patients are around 63 years old.

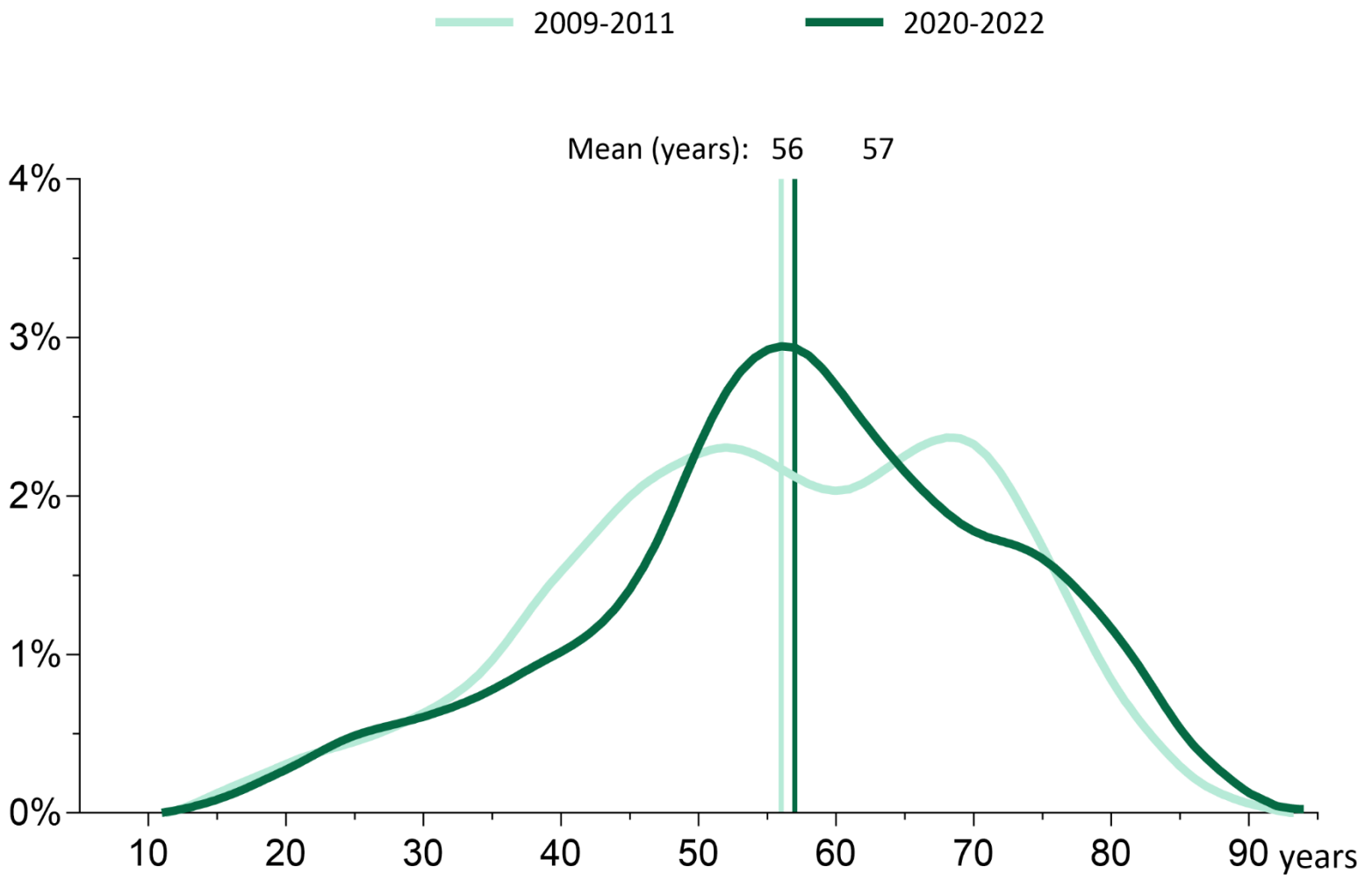


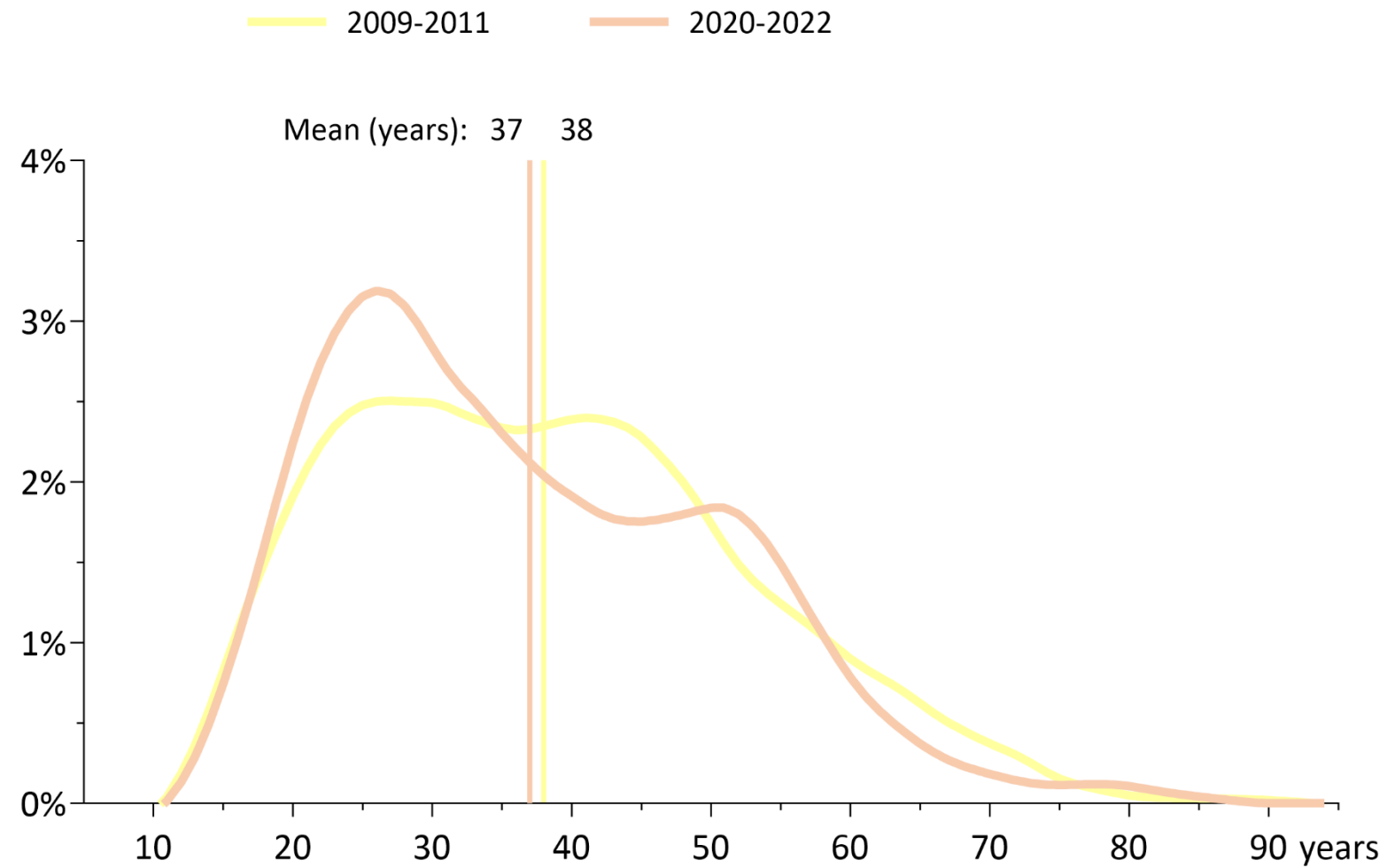


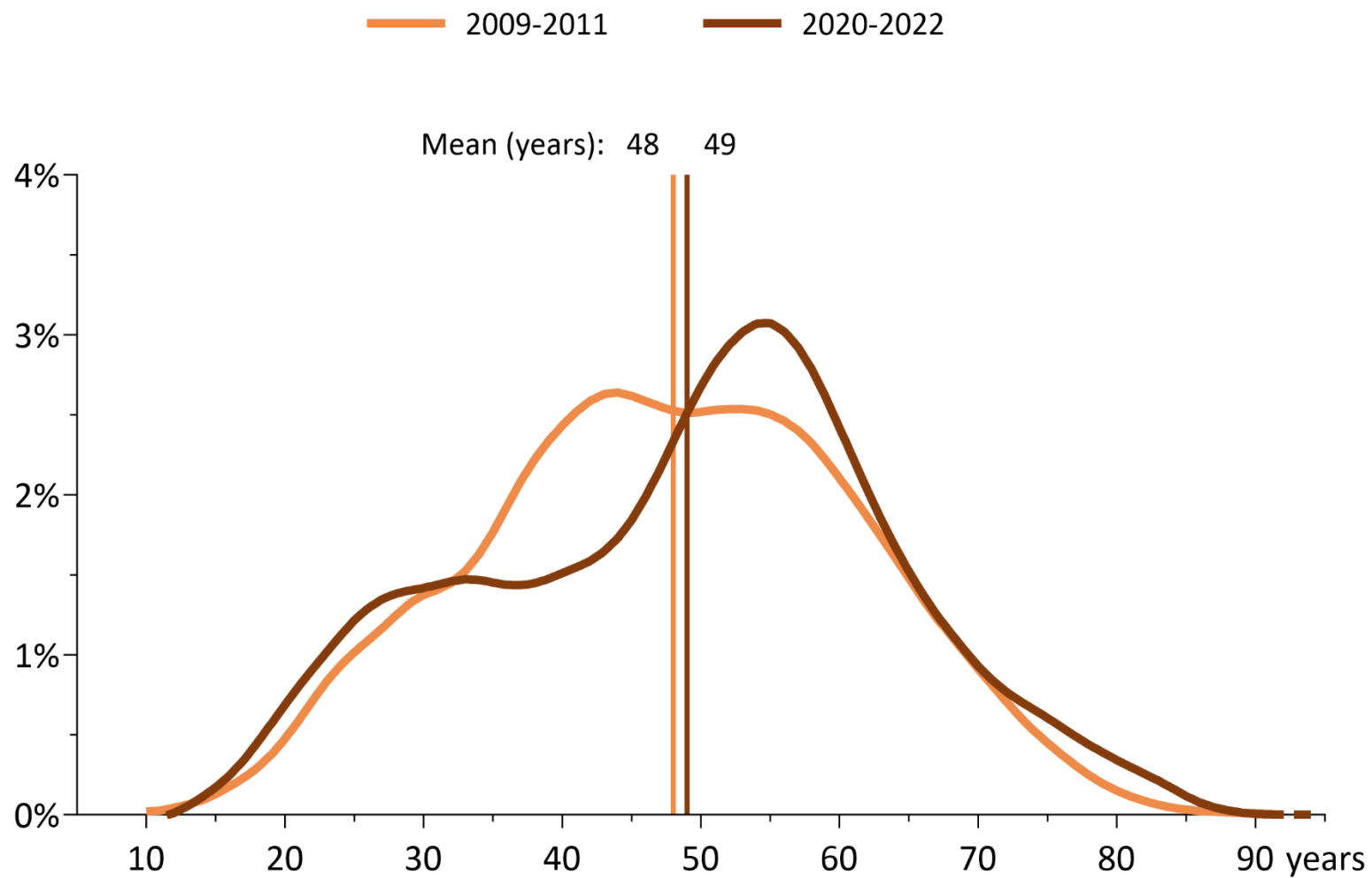
# Age distribution

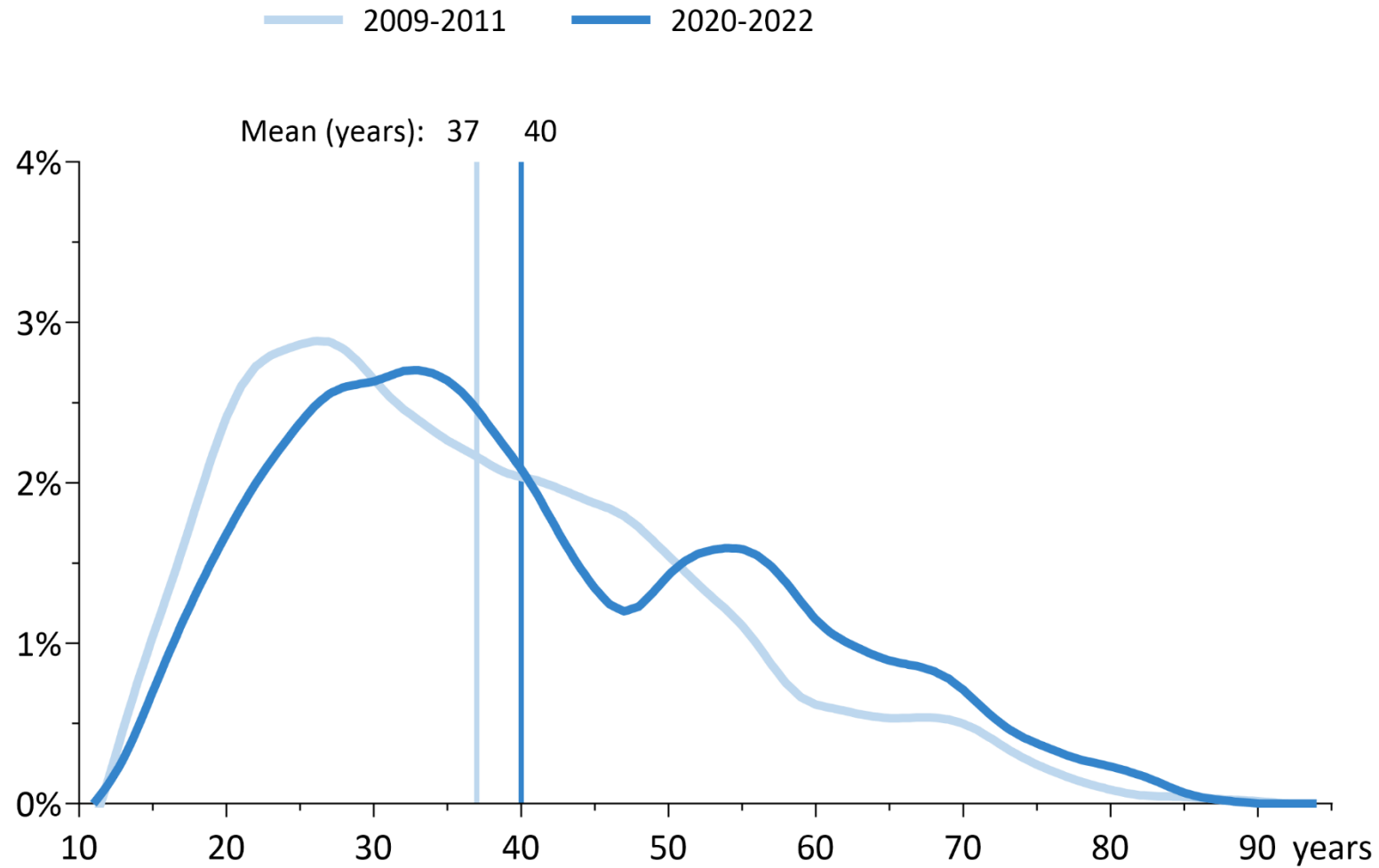


# RA Age of onset

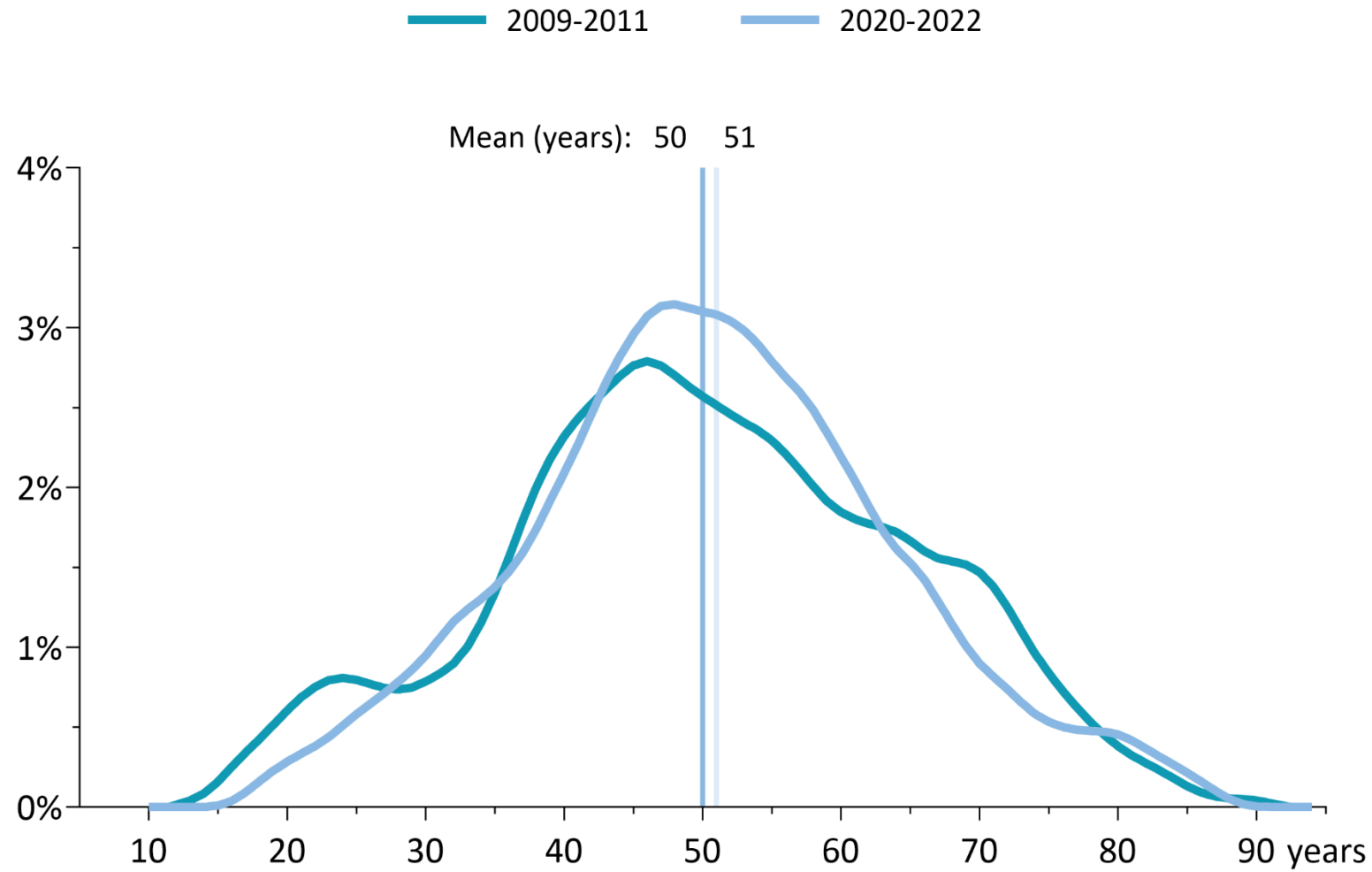






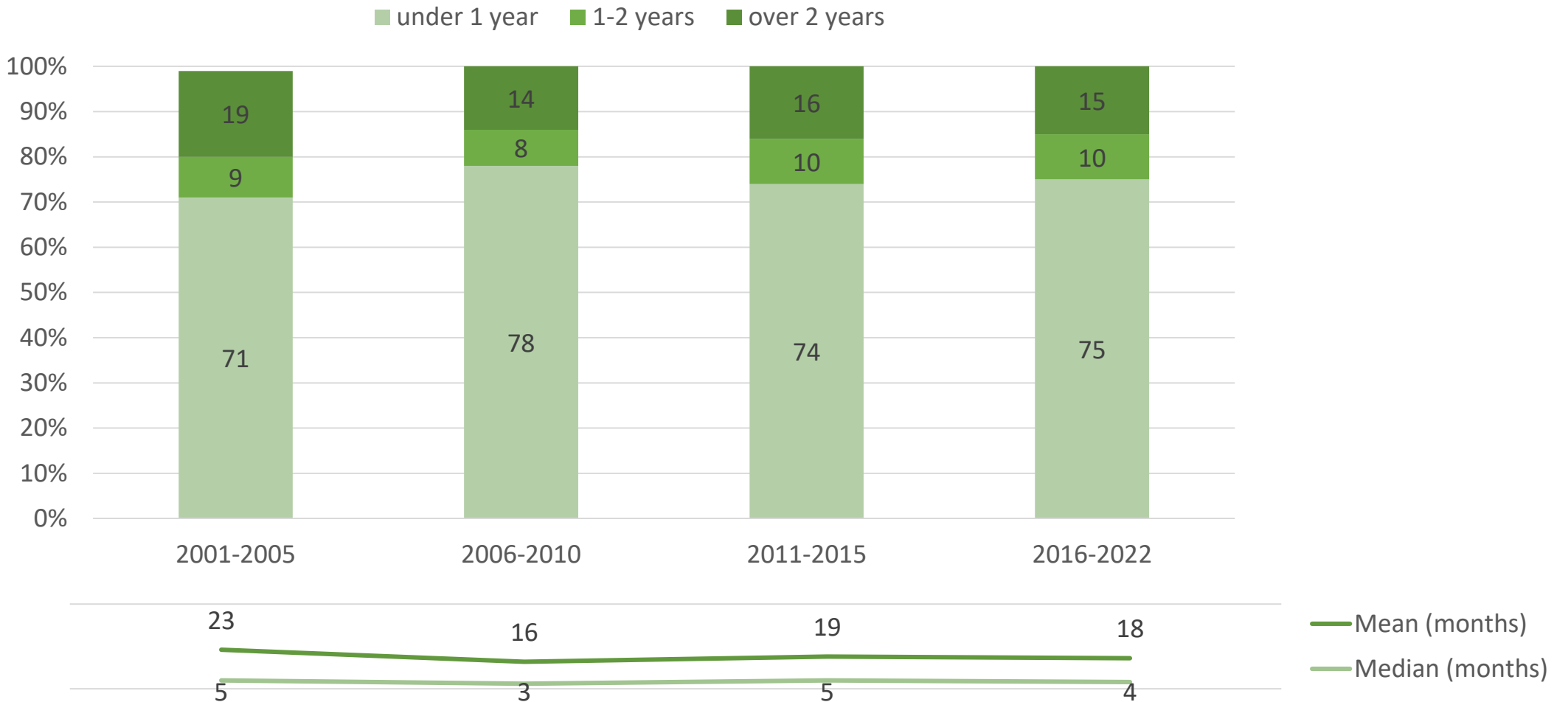


# SSc Age of onset



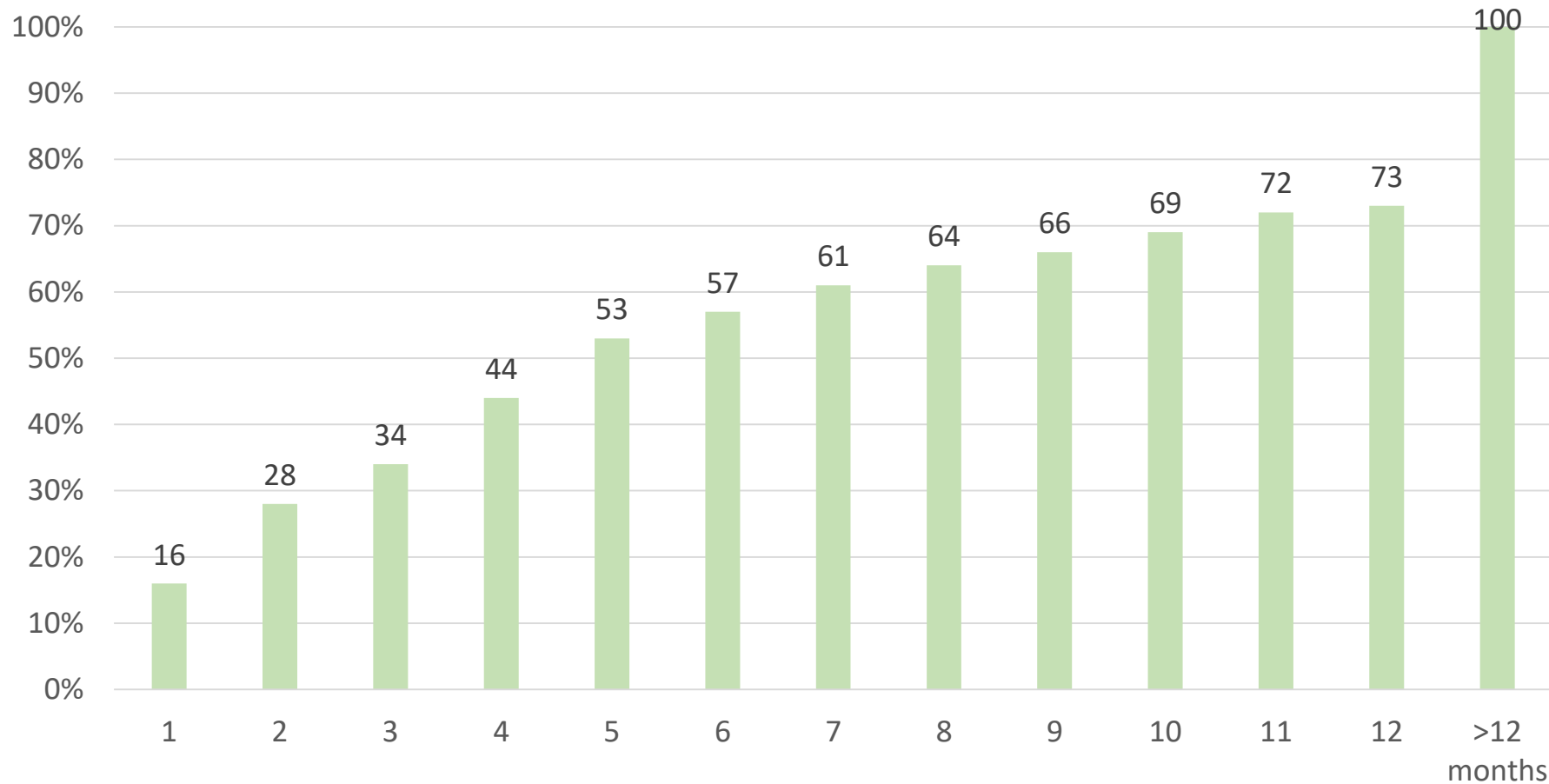


Proportion of patients (%) with symptom duration in years



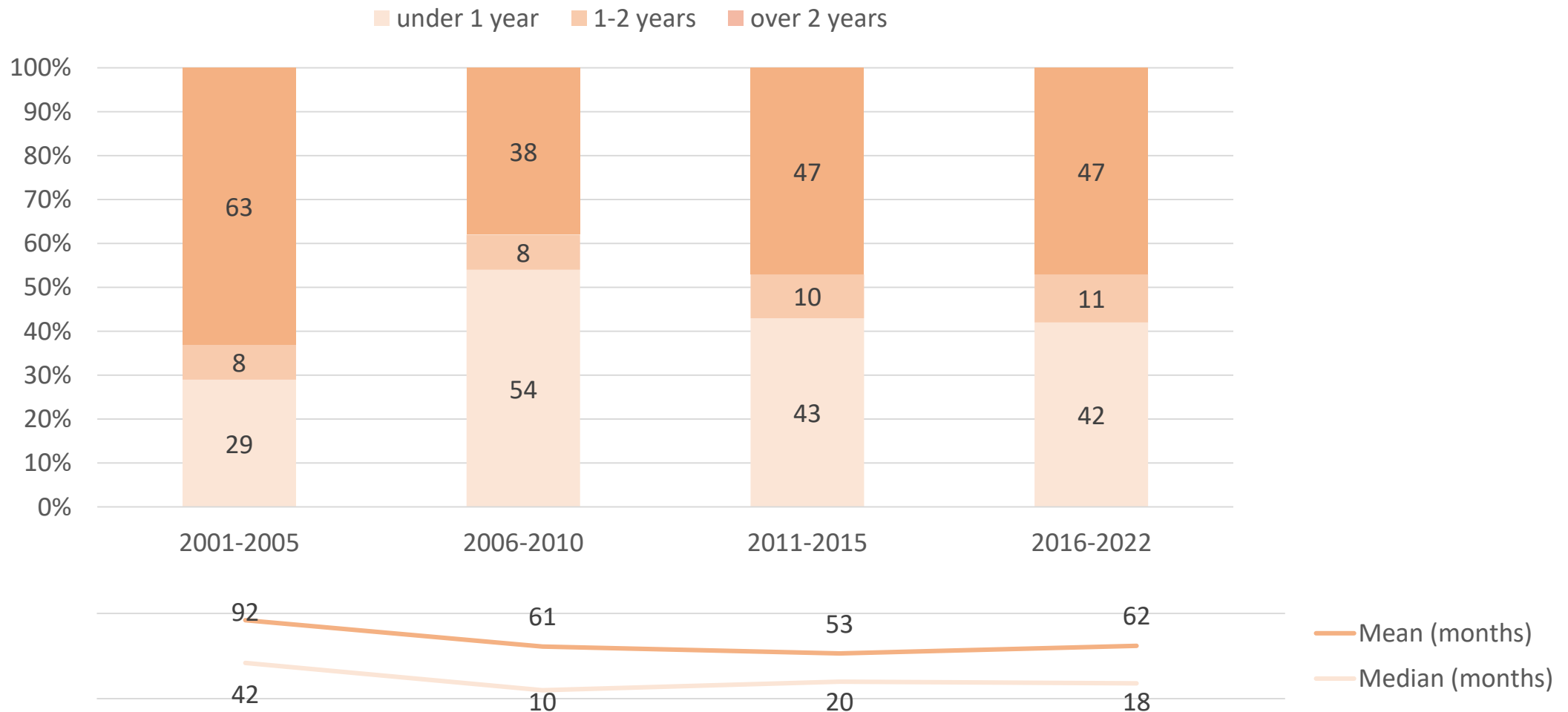


Proportion of patients (cumulative in %) with presentation to a rheumatologist within ... months





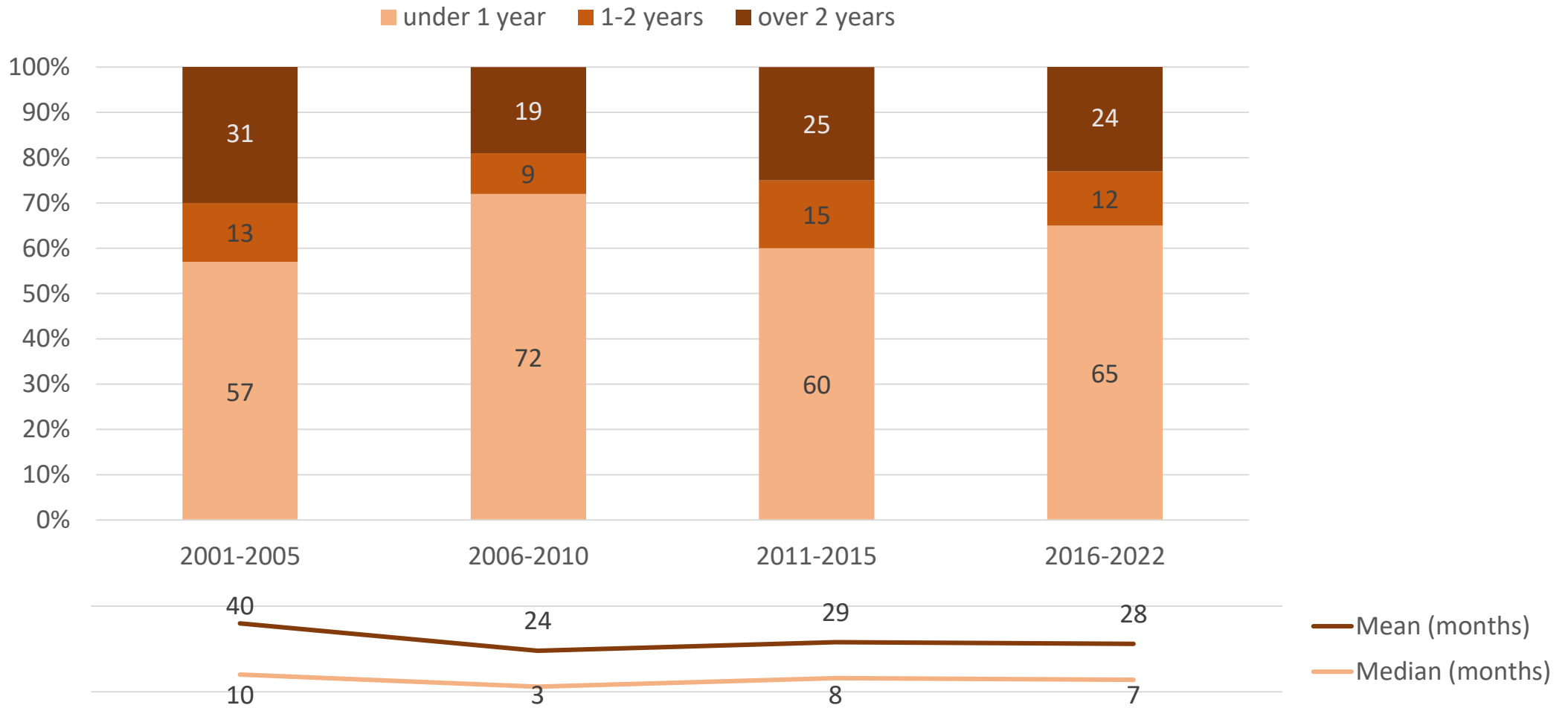
Proportion of patients (%) with symptom duration in years



n=215 axSpA patients with first presentation in 2016-2022



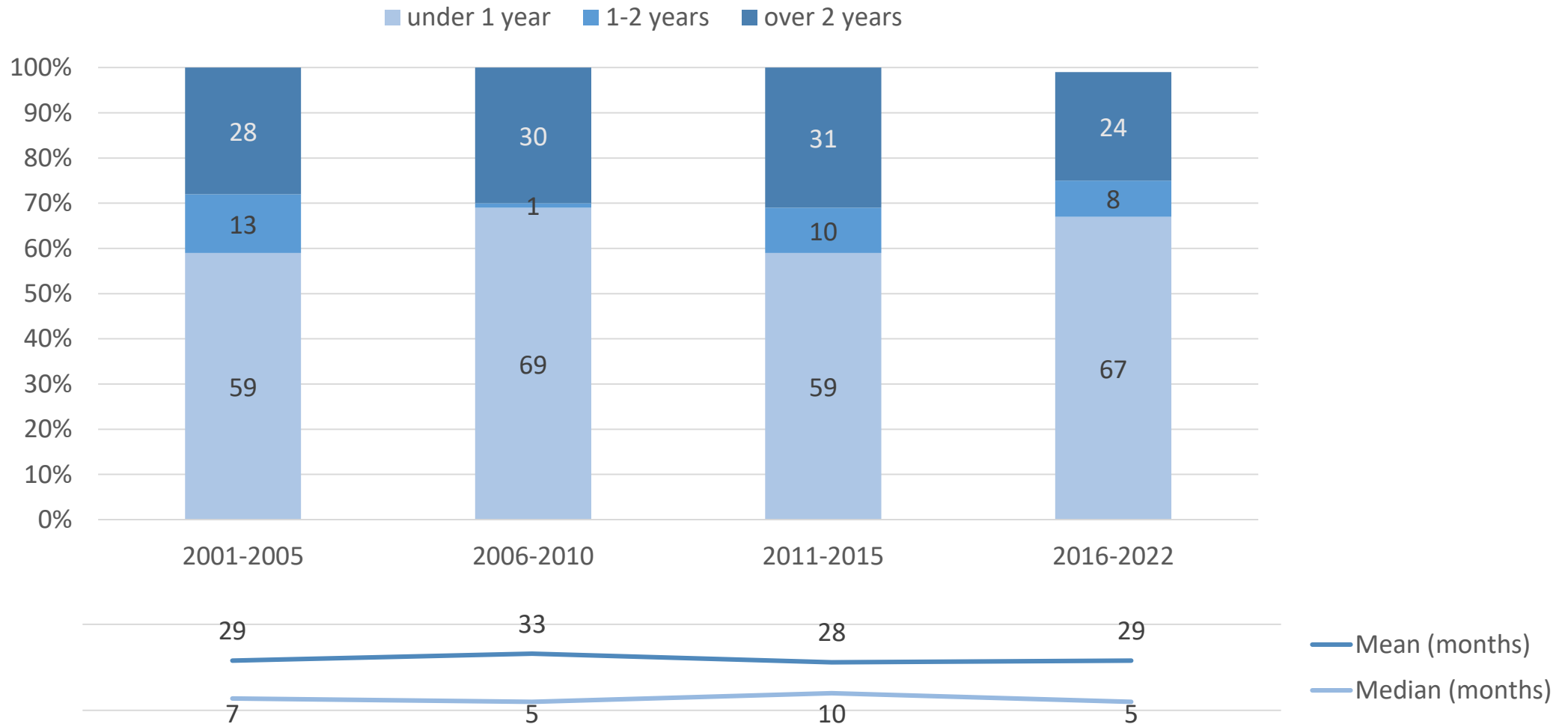
Proportion of patients (%) with symptom duration in years



n=232 PsA patients with first presentation in 2016-2022



Proportion of patients (%) with symptom duration in years



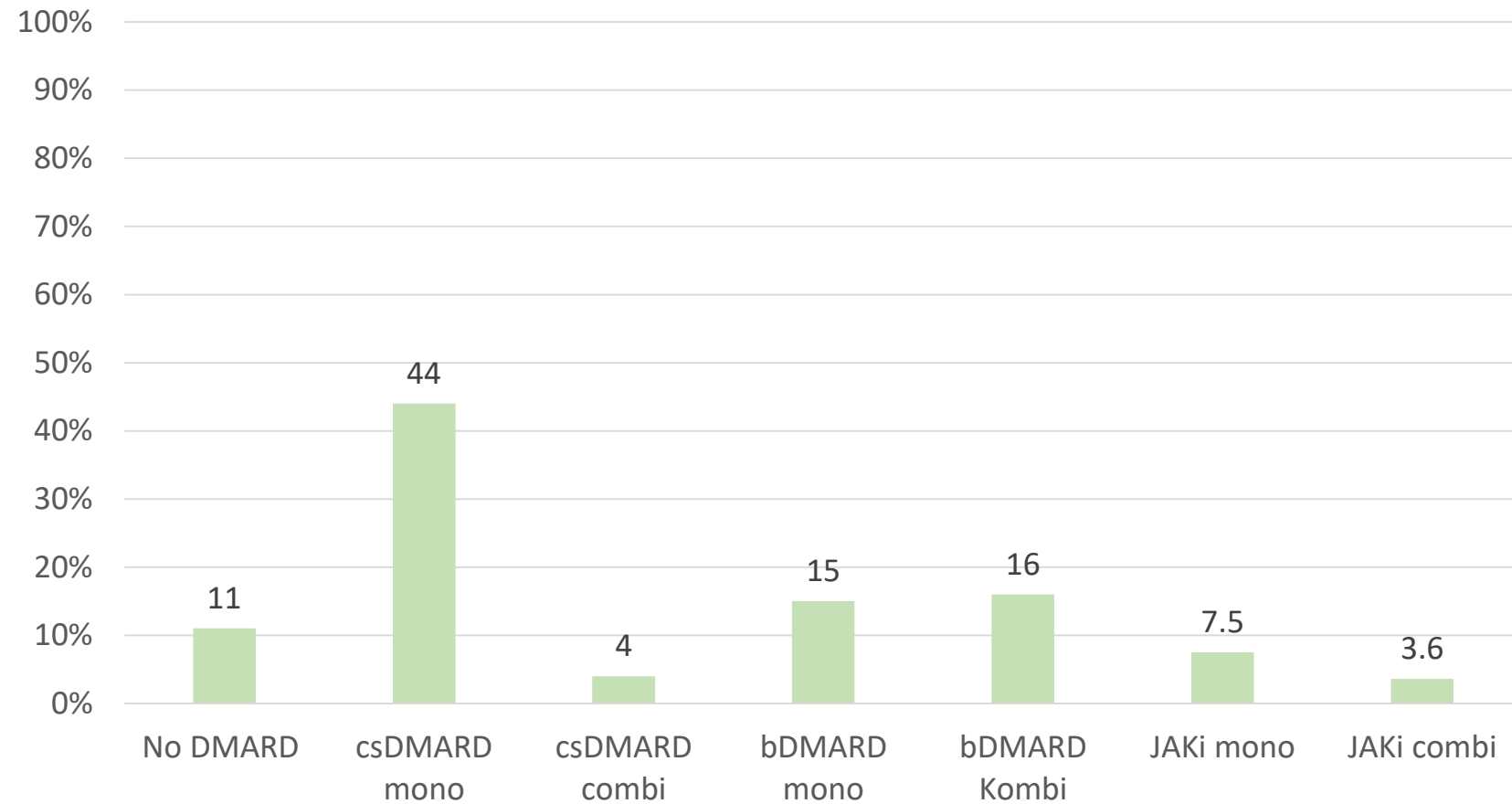
n=86 SLE patients with first presentation in 2016-2022



# Medication

Overview  
Therapy strategy  
DMARDs  
Monotherapy/combination therapy  
Glucocorticoids  
Biosimilars  
Development 2010 - 2022

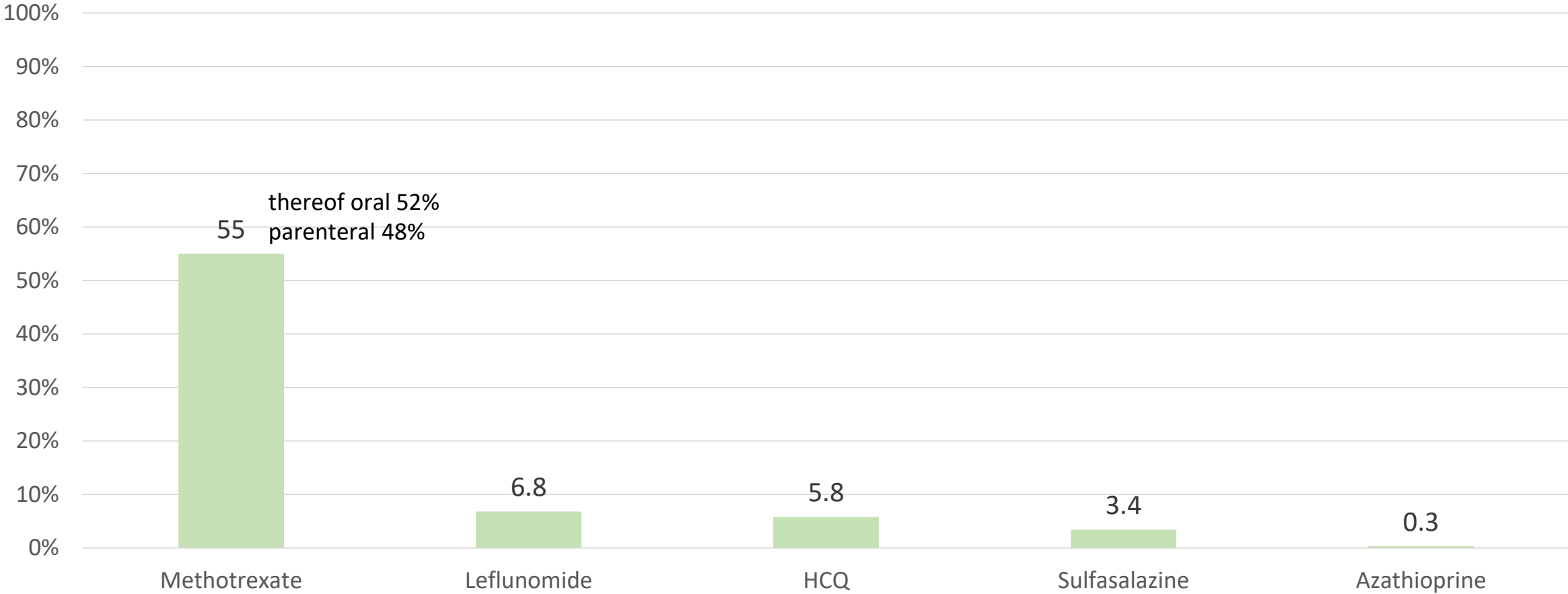
# RA DMARD therapy



# RA csDMARDs



Proportion of patients (%) with csDMARD



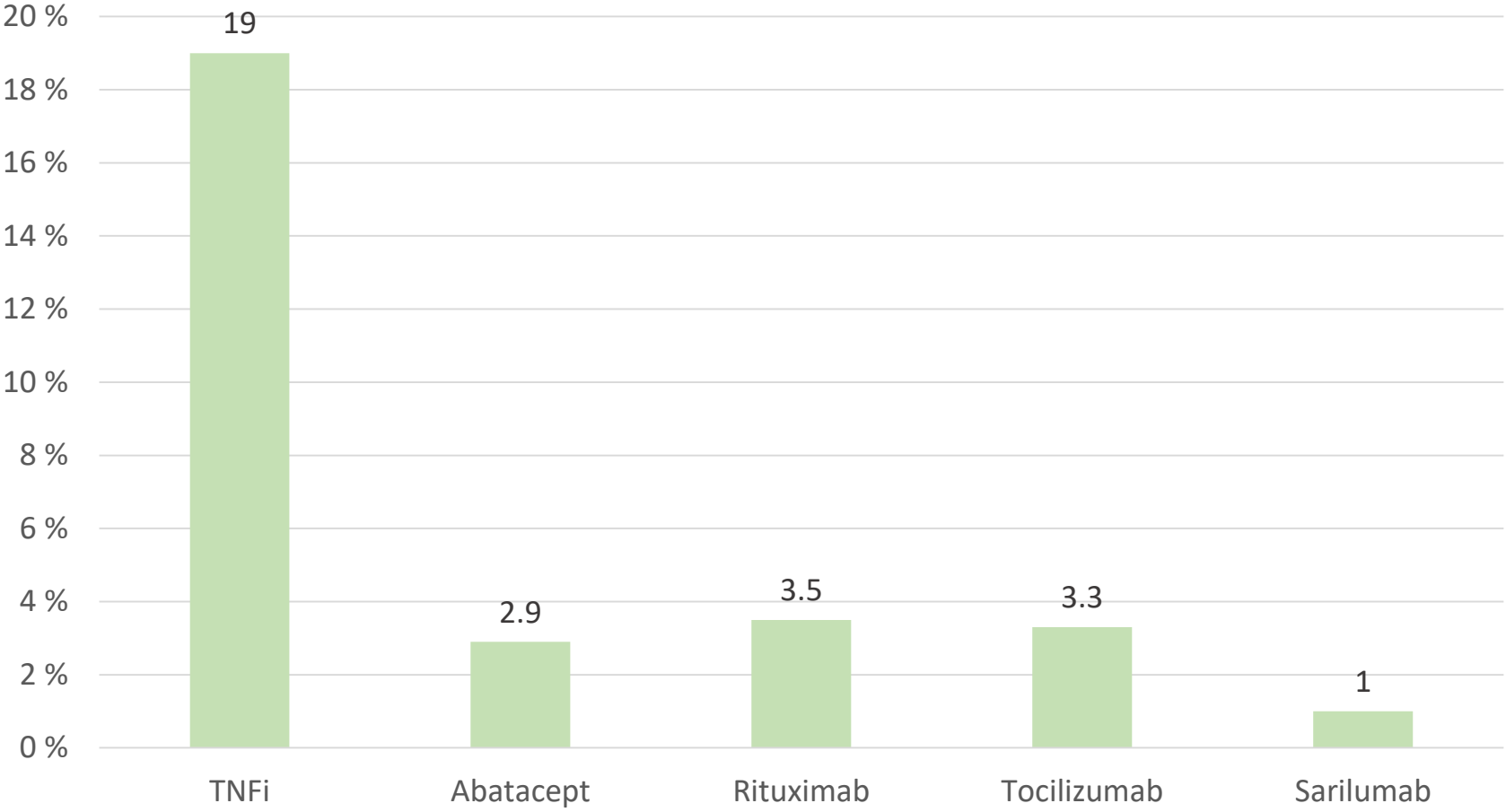
Source: German National Database, data collected in 2022

n=5,787 RA patients with information on therapy

# RA bDMARDs



Proportion of patients (%) with bDMARD therapy



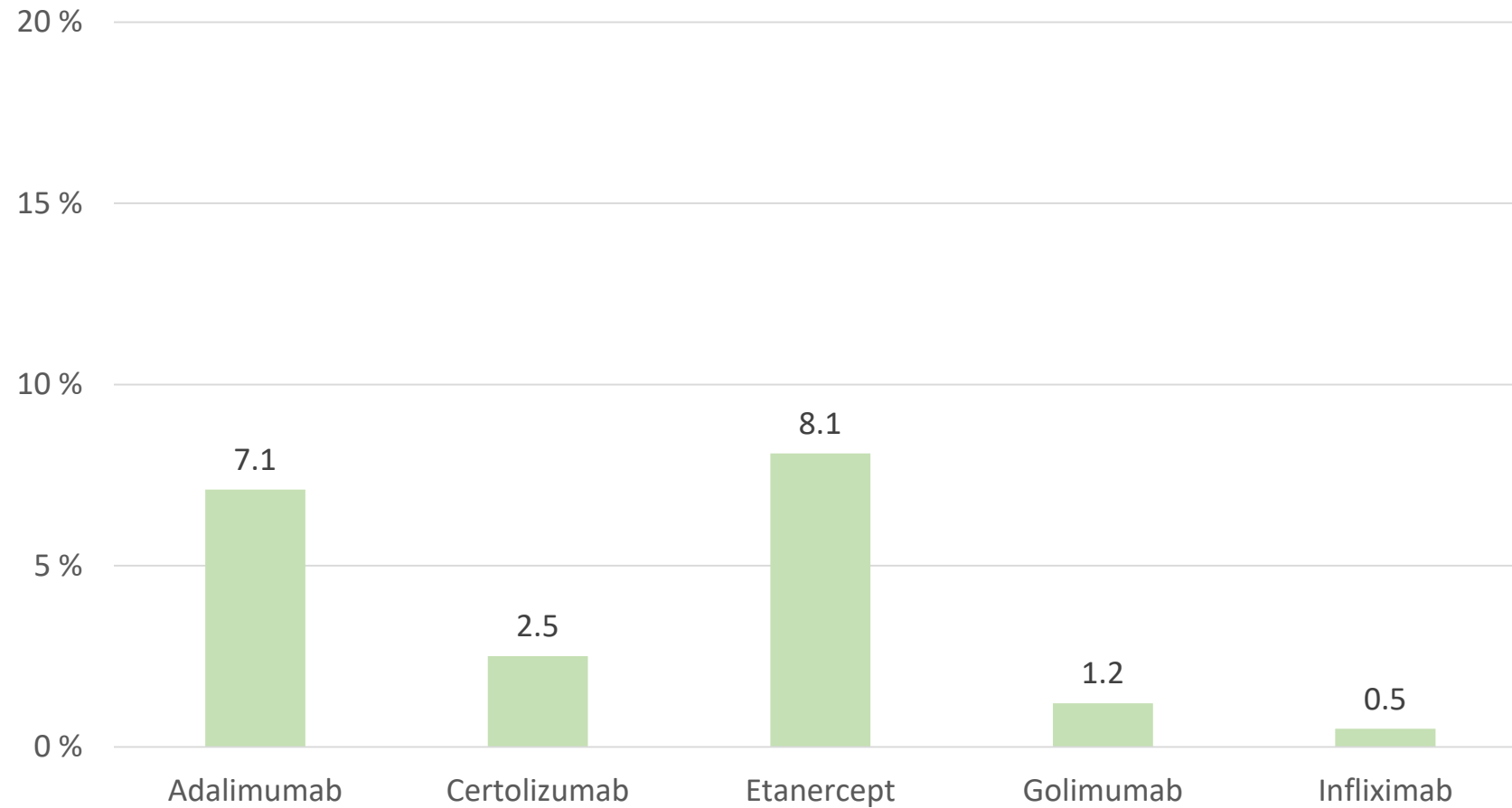
Source: German National Database, data collected in 2022

n=5,787 RA patients with information on therapy

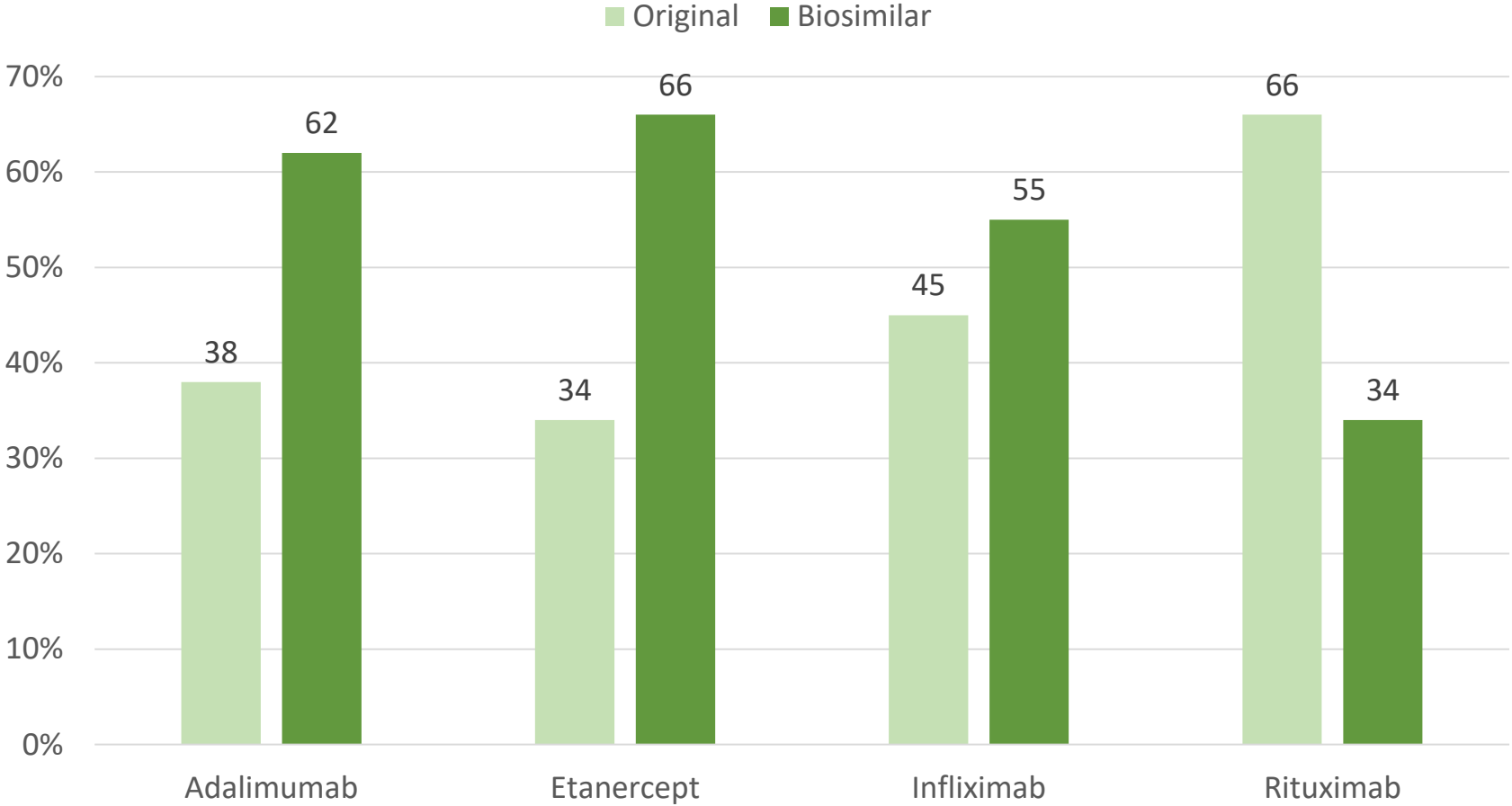
# RA TNF-inhibitors



Proportion of patients (%) with TNF-inhibitors of all RA patients

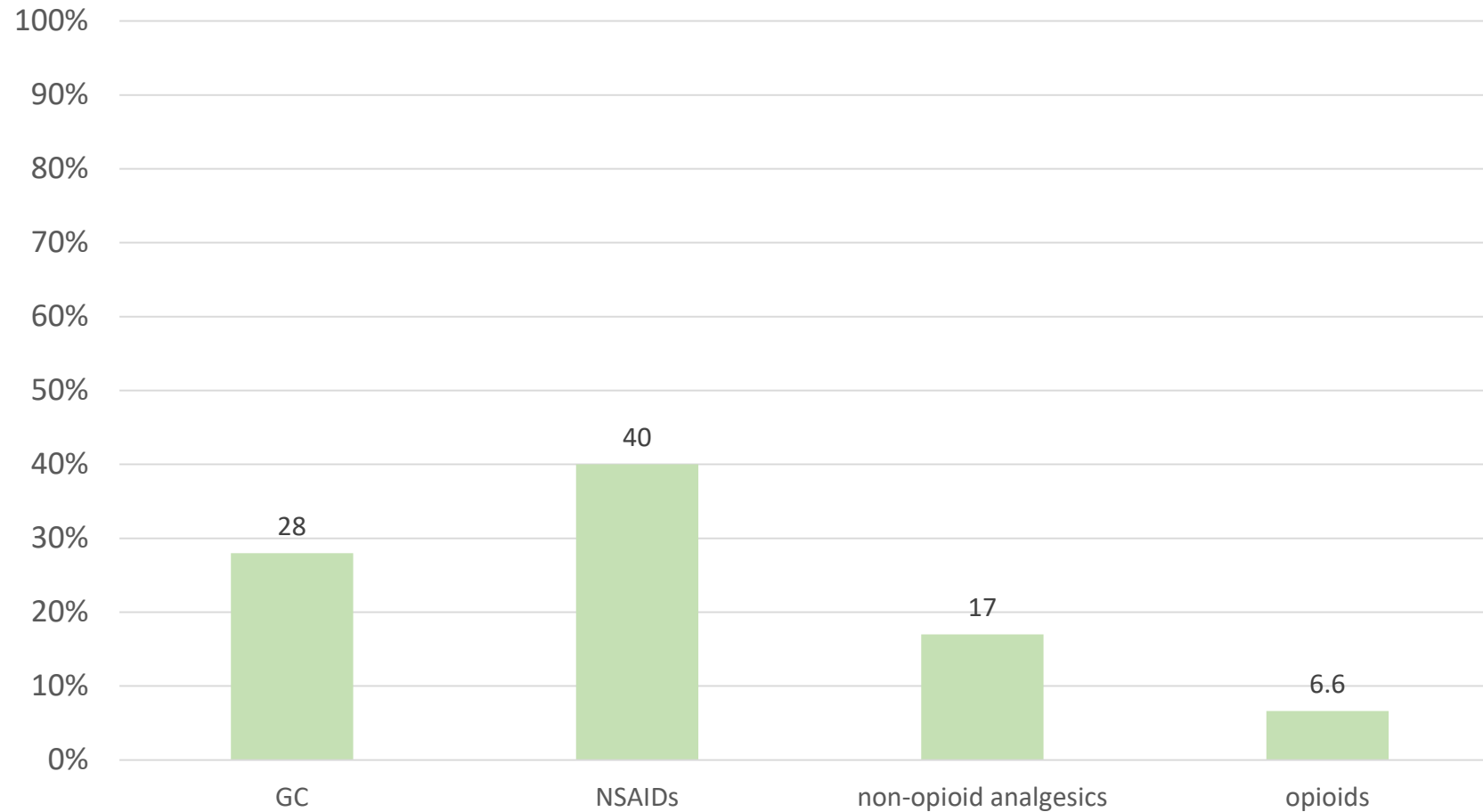






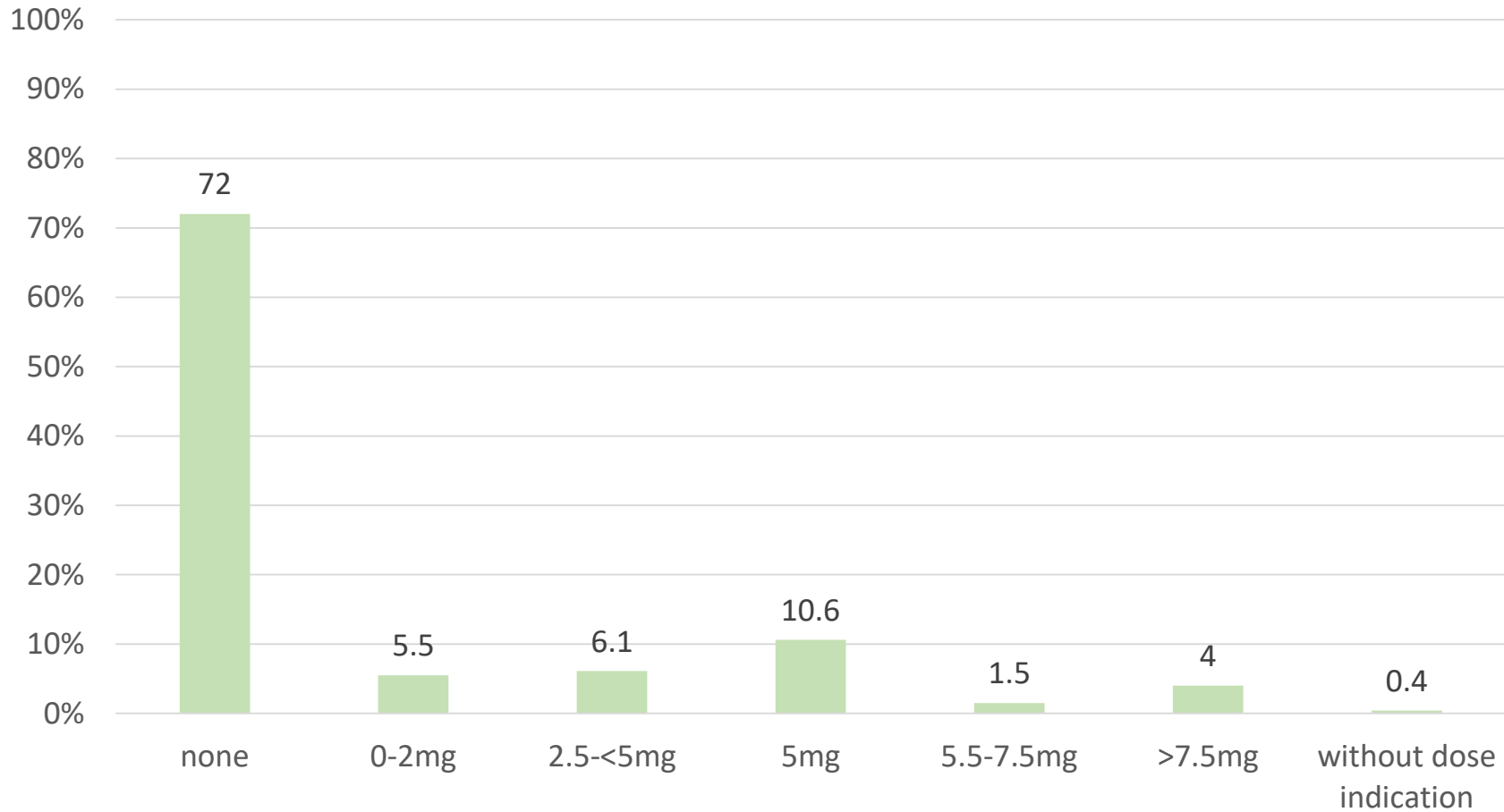
Source: German National Database, data collected in 2022

n=1,243 RA patients with TNFi/rituximab therapy

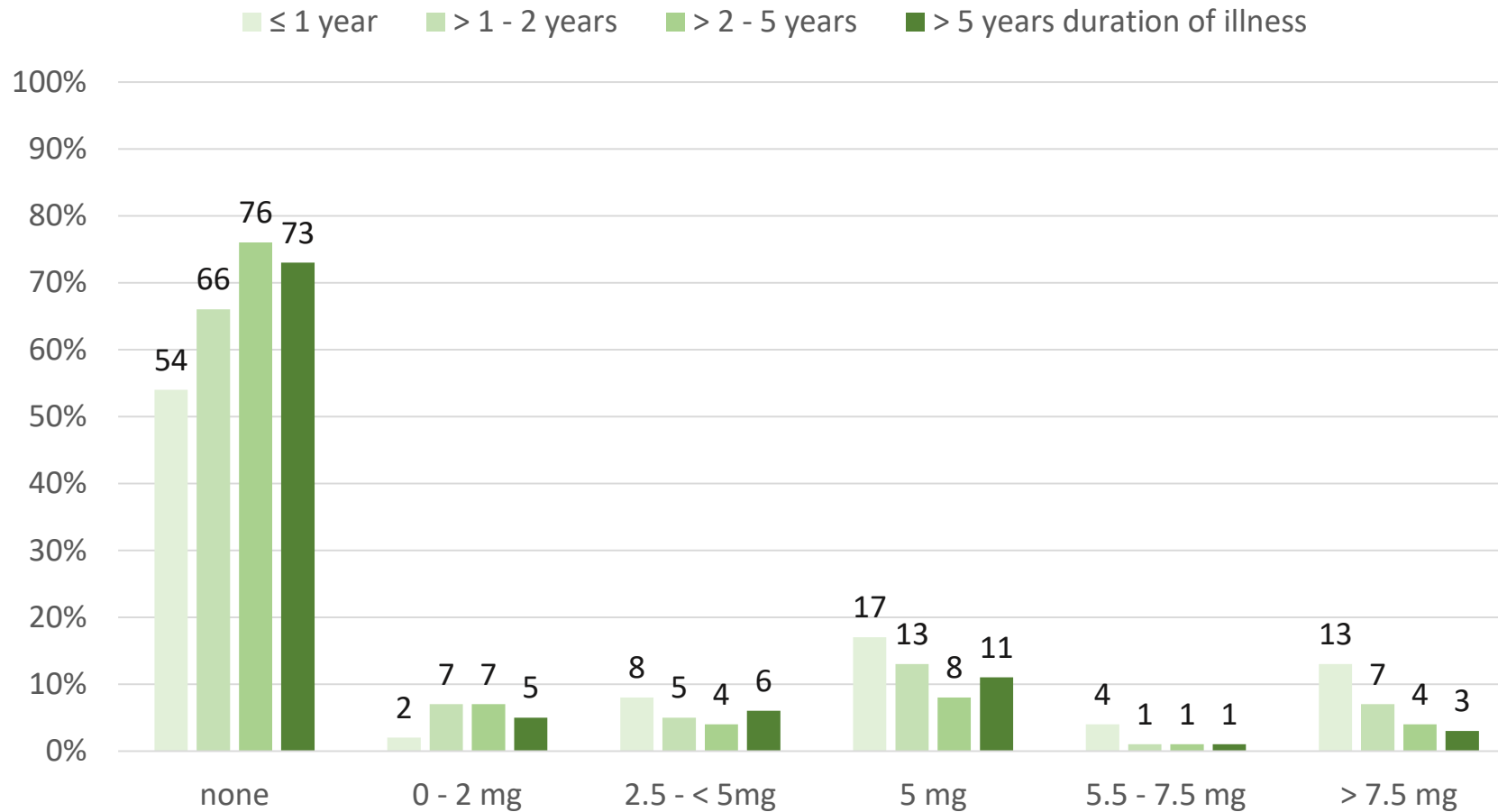


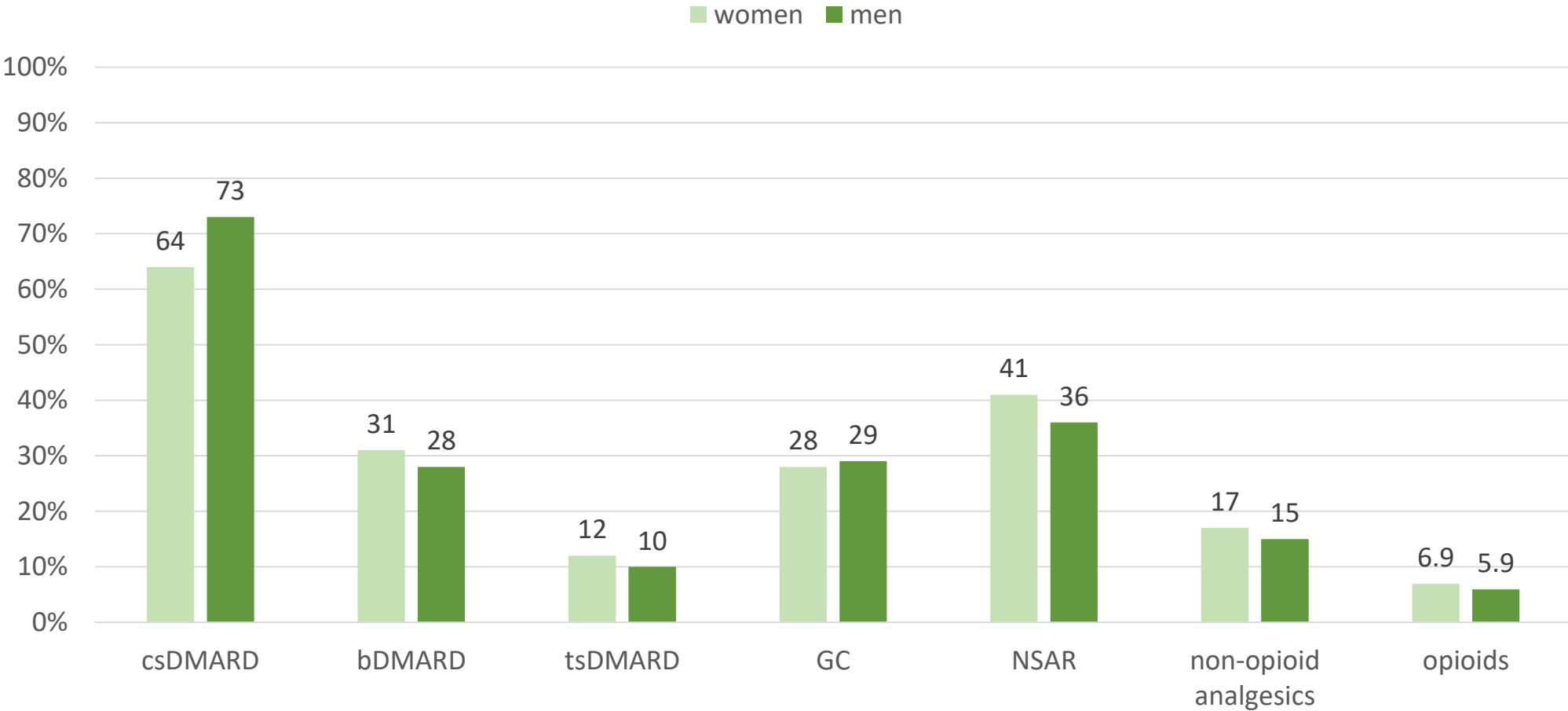


Proportion of patients (%) with current GC dose (prednisolone equivalent per day)



Proportion of patients (%) with current GC dose (prednisolone equivalent per day)

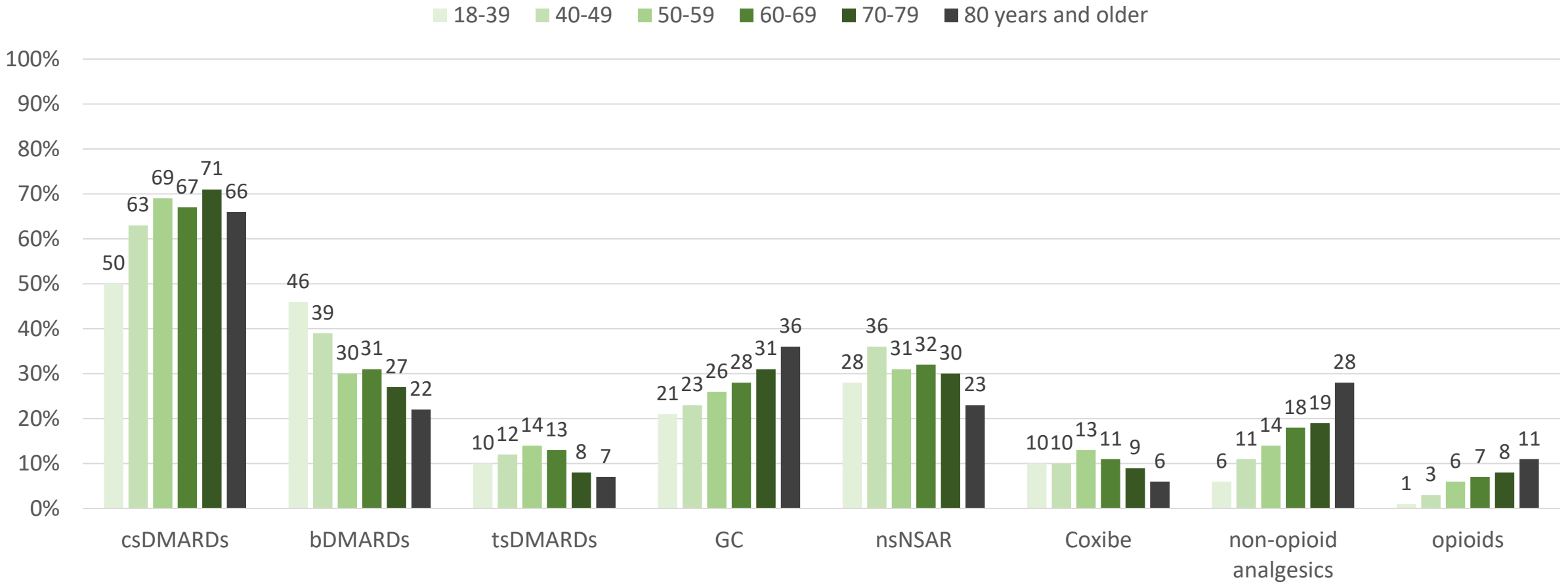




Source: German National Database, data collected in 2022

n=5,787 patients with RA and treatment indication

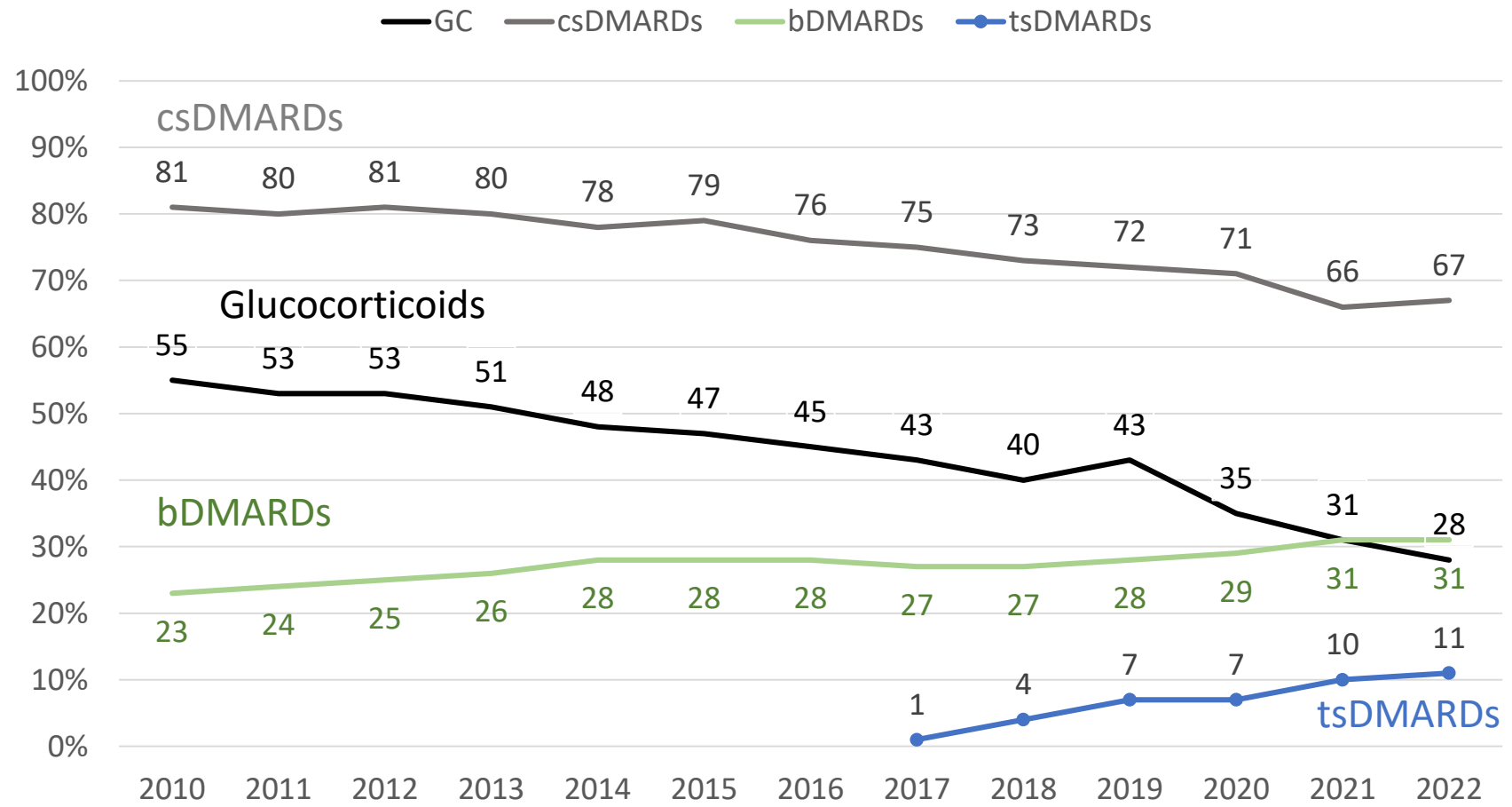
# RA Therapy according to age



Source: German National Database, data collected in 2022

n=5,787 patients with RA and treatment indication

# RA Therapy 2010-2022

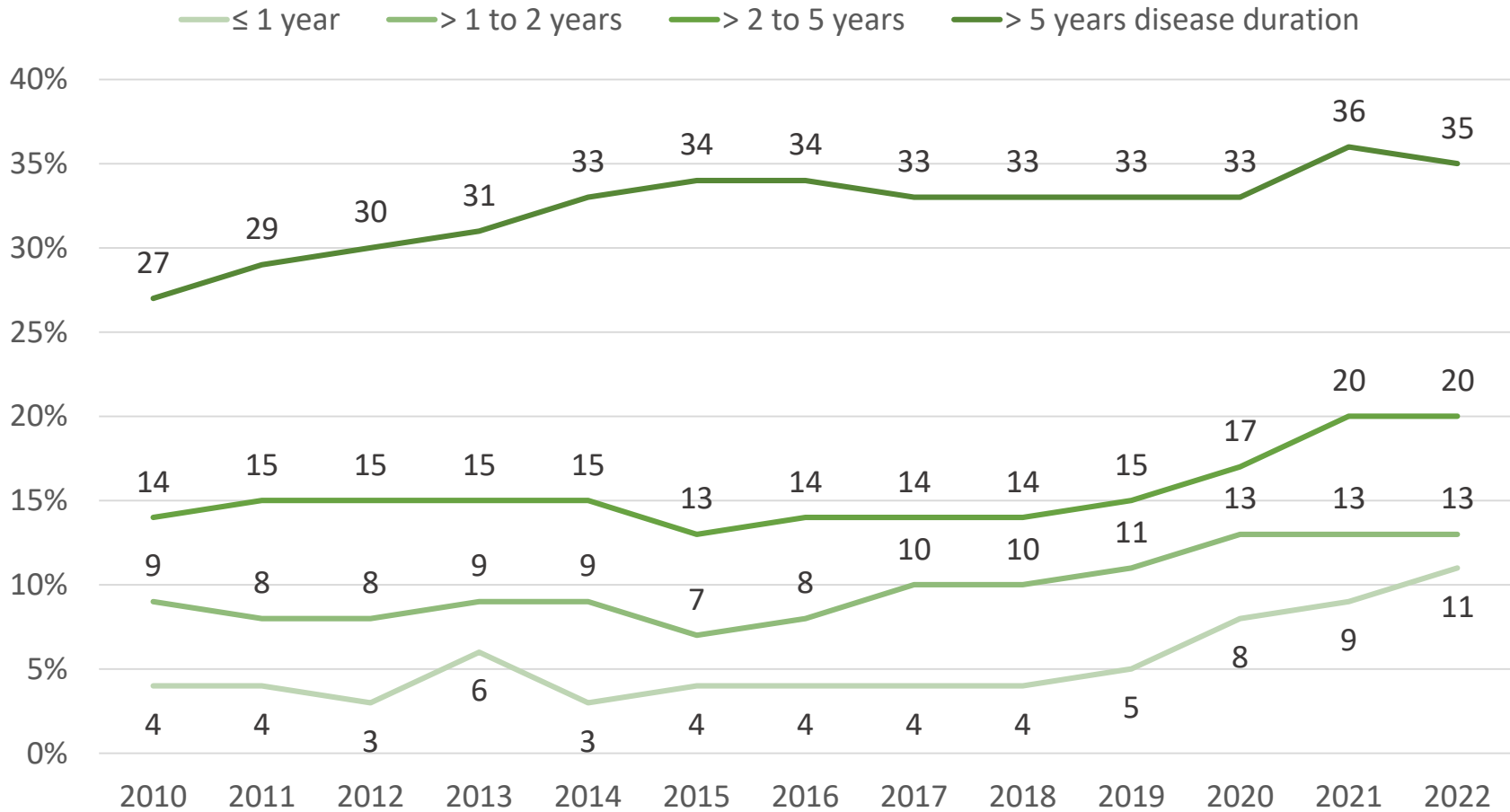


Source: German National Database, data collected in 2022 n=5,715 (2010) - 5,787 (2022) RA patients with treatment indication

# bDMARDs by disease duration

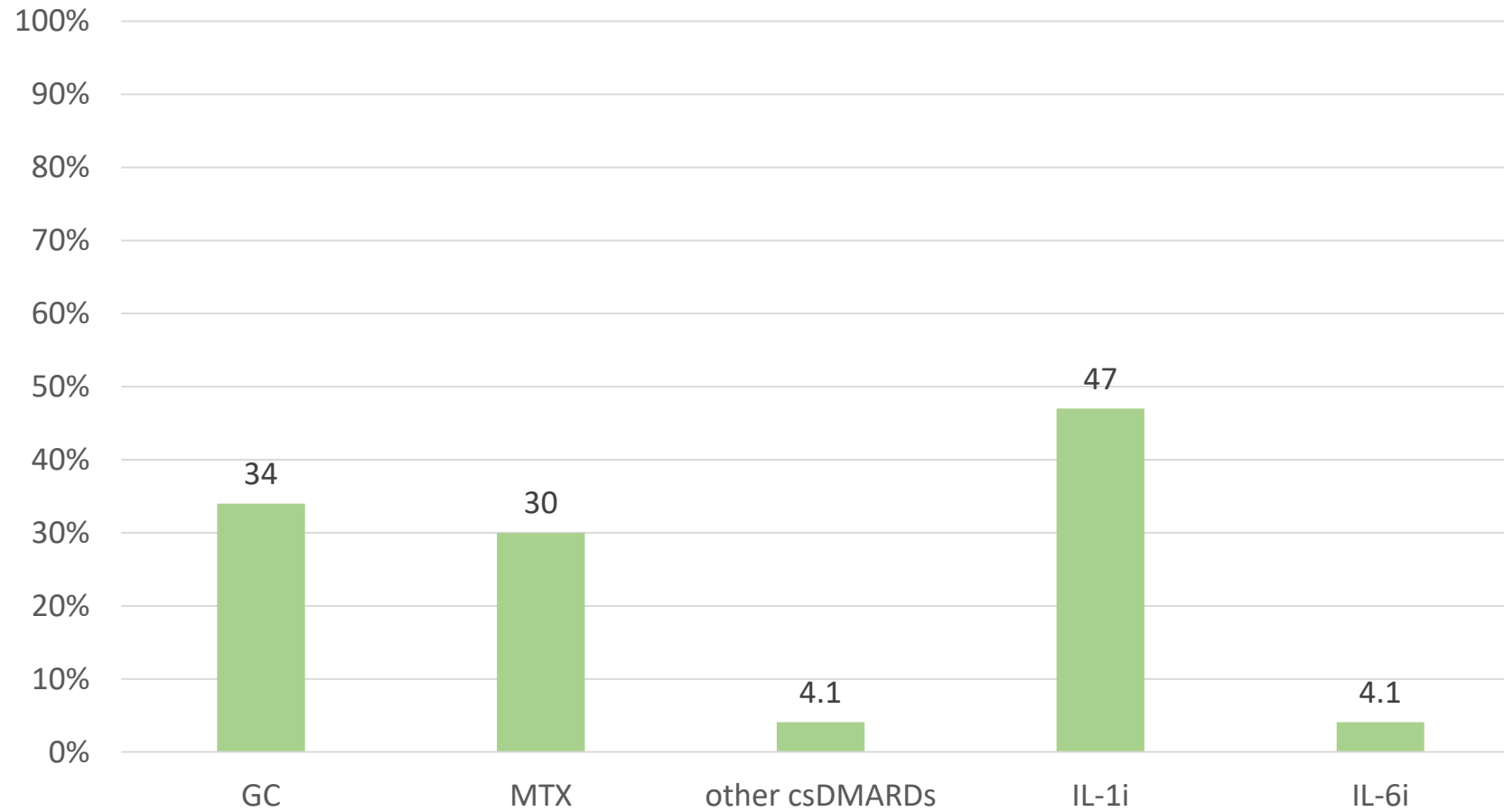


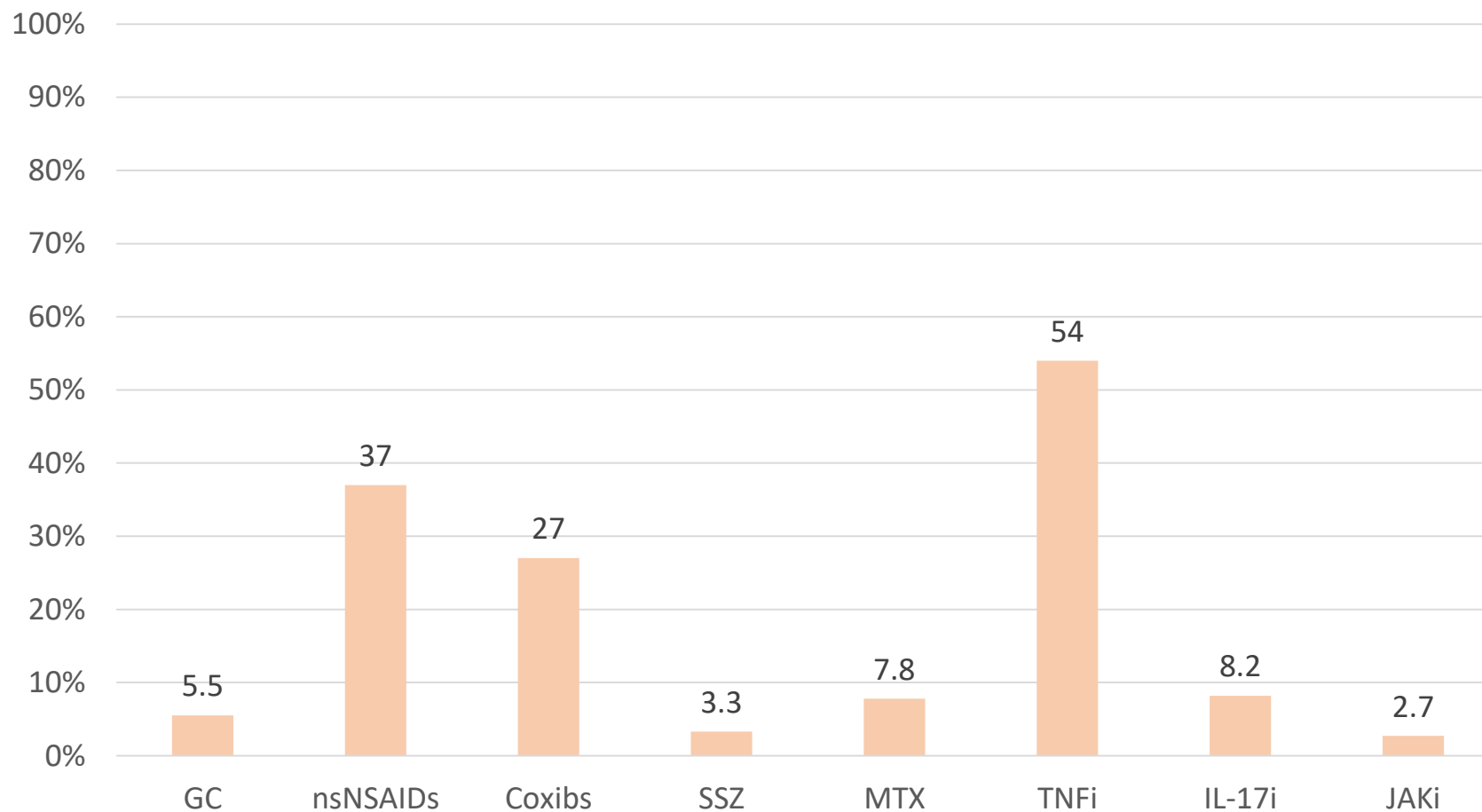
Proportion of patients with bDMARD therapy in the respective disease duration group

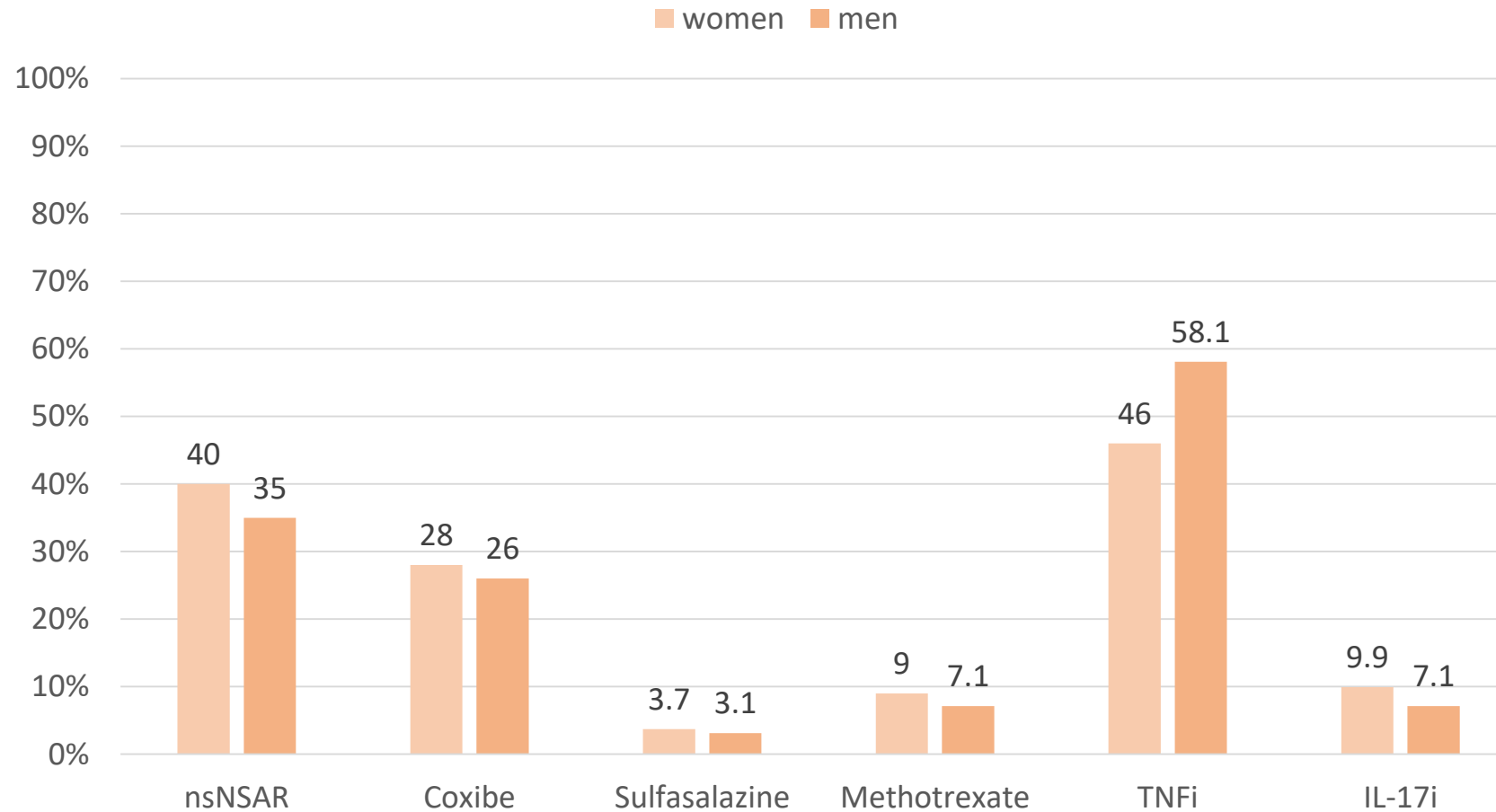


Source: German National Database, data collected in 2022 n=5,715 (2010) - 5,787 (2022) RA patients with treatment indication

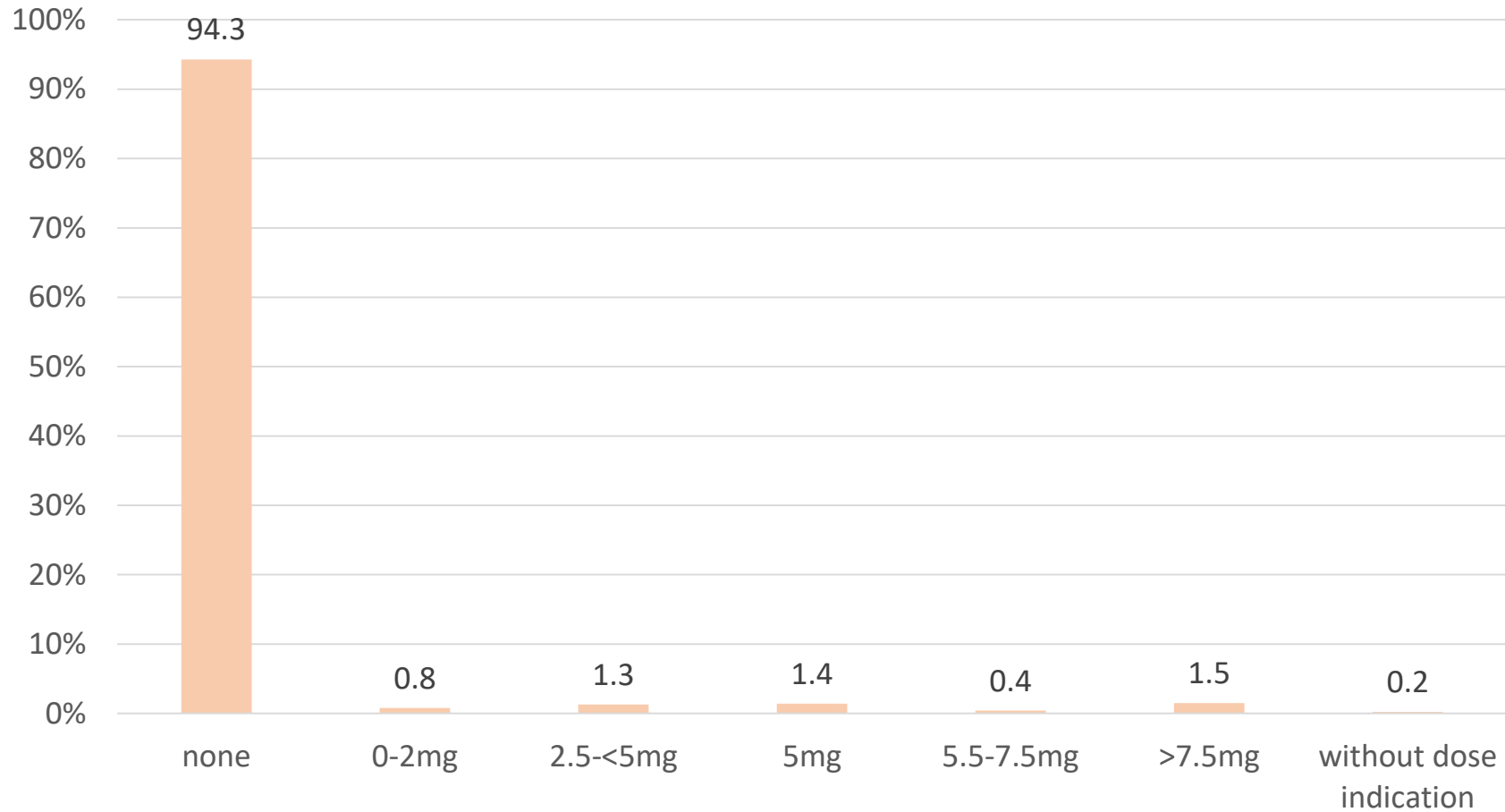




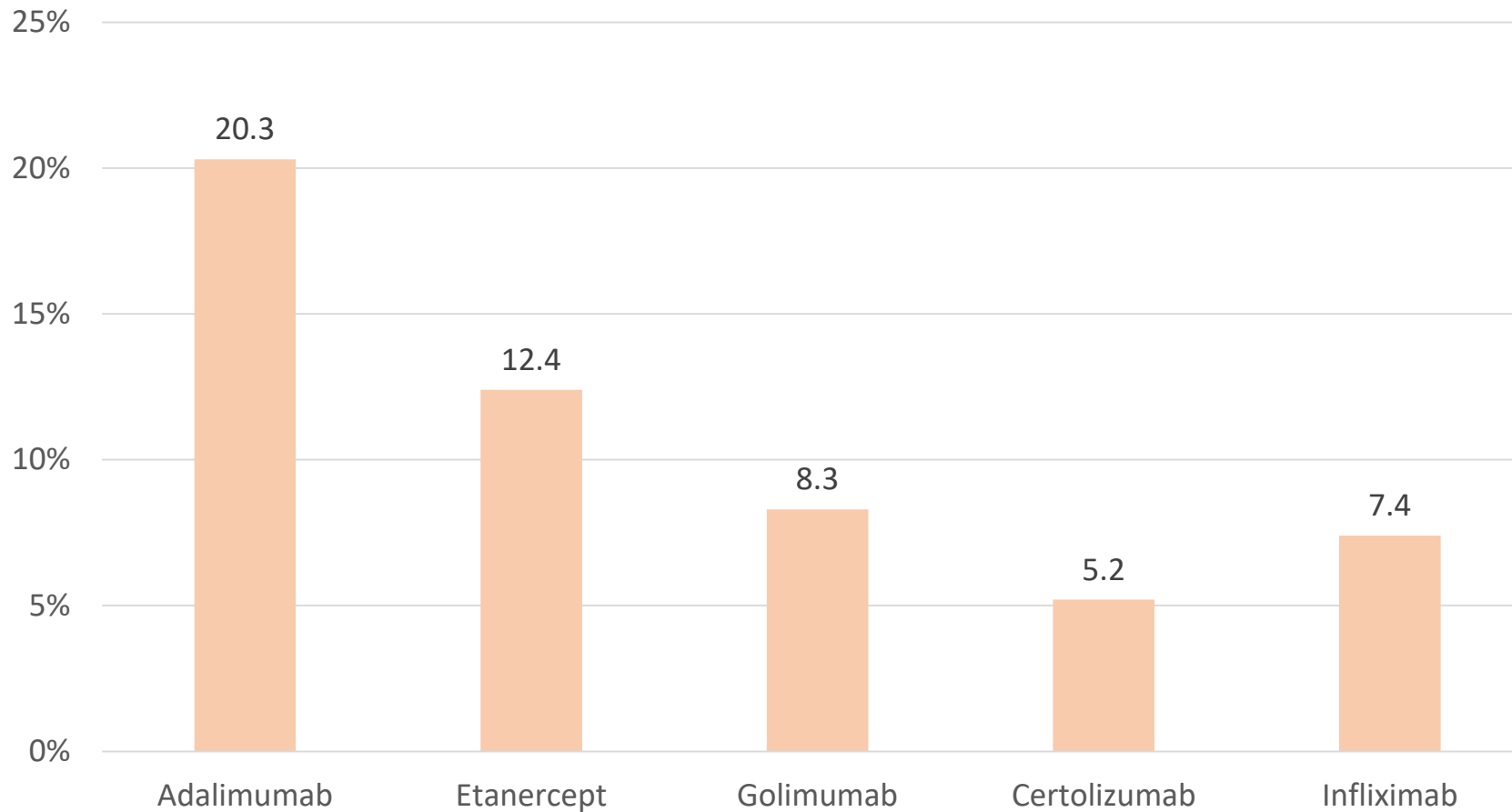




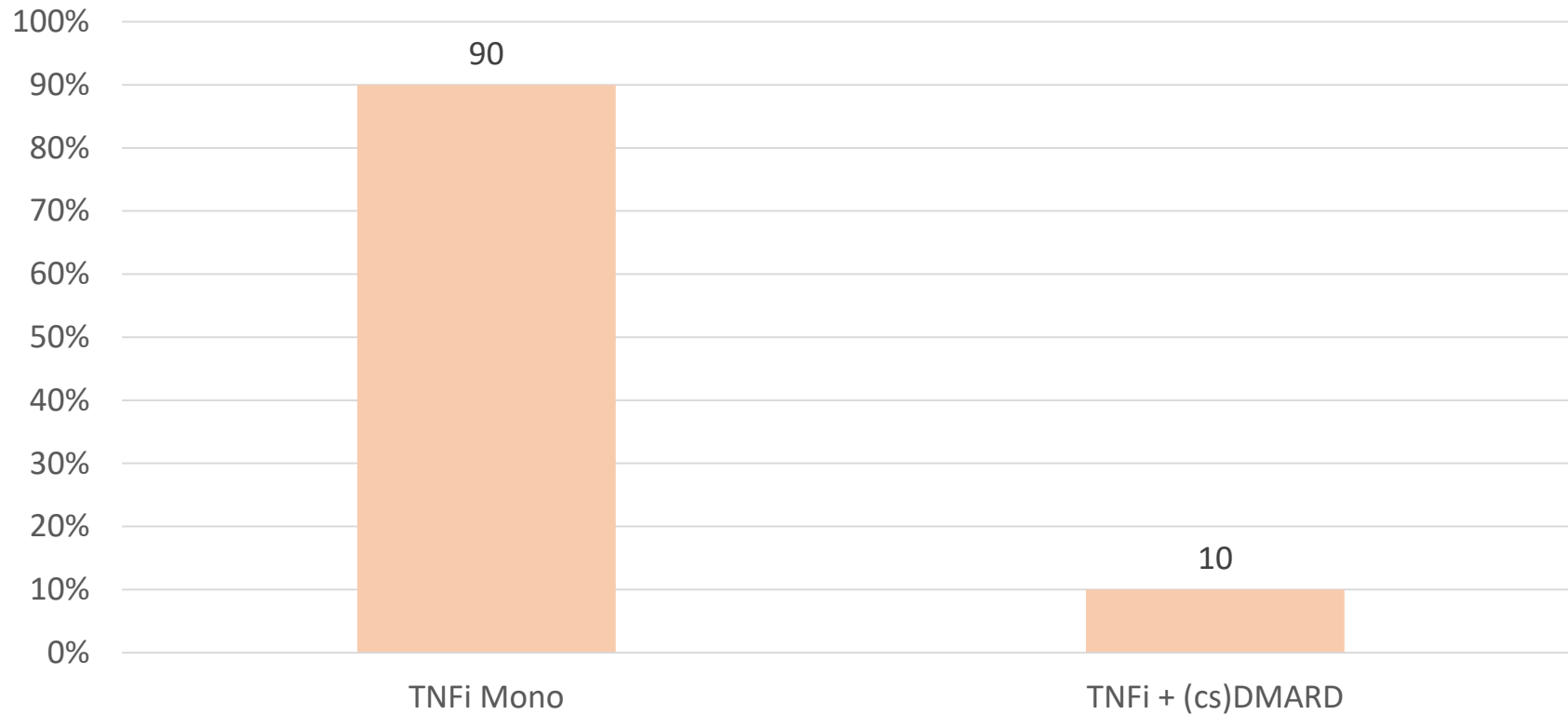
Proportion of patients (%) with current GC dose (prednisolone equivalent per day)



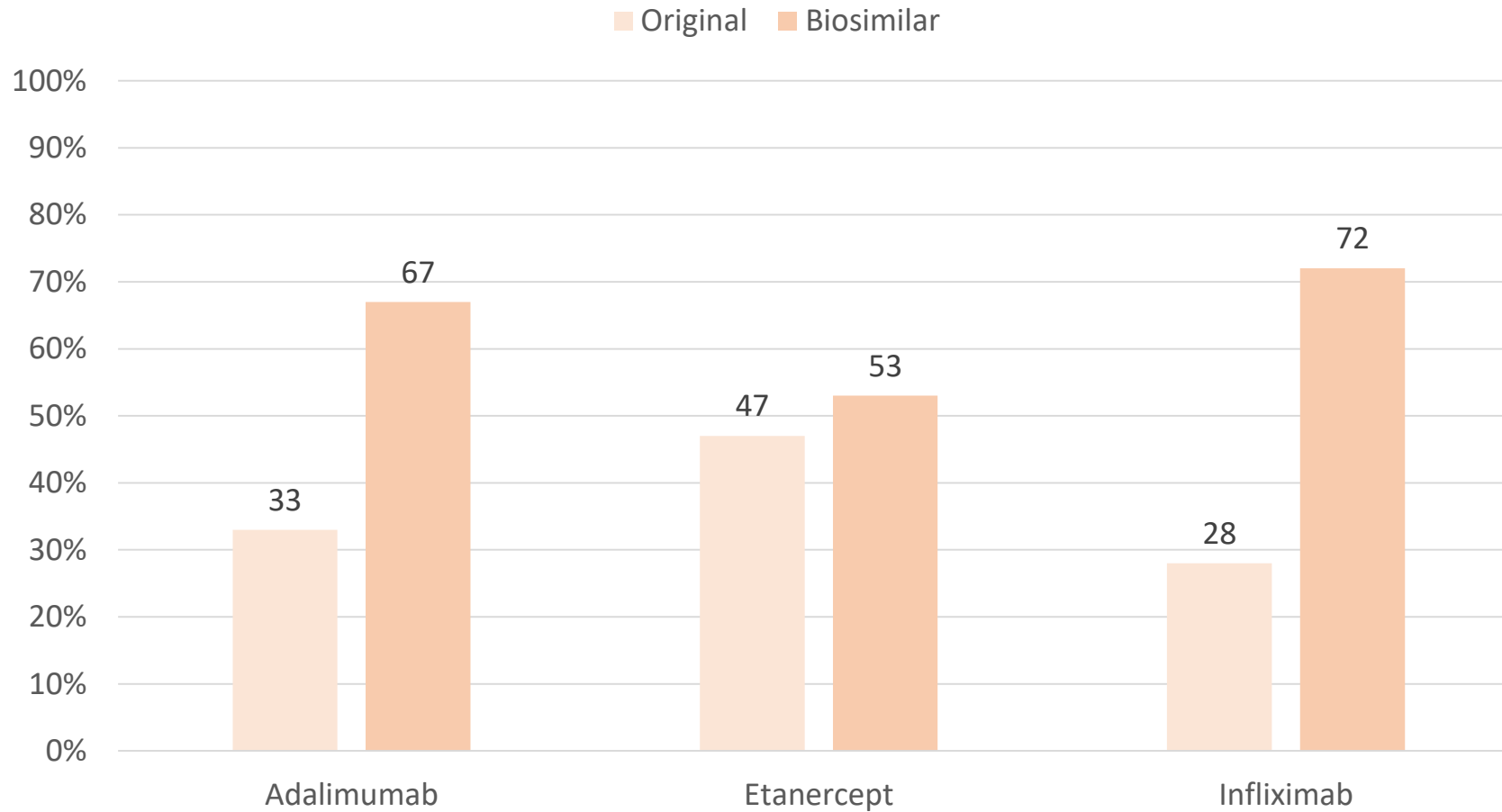
Proportion of patients (%) with TNF-inhibitors

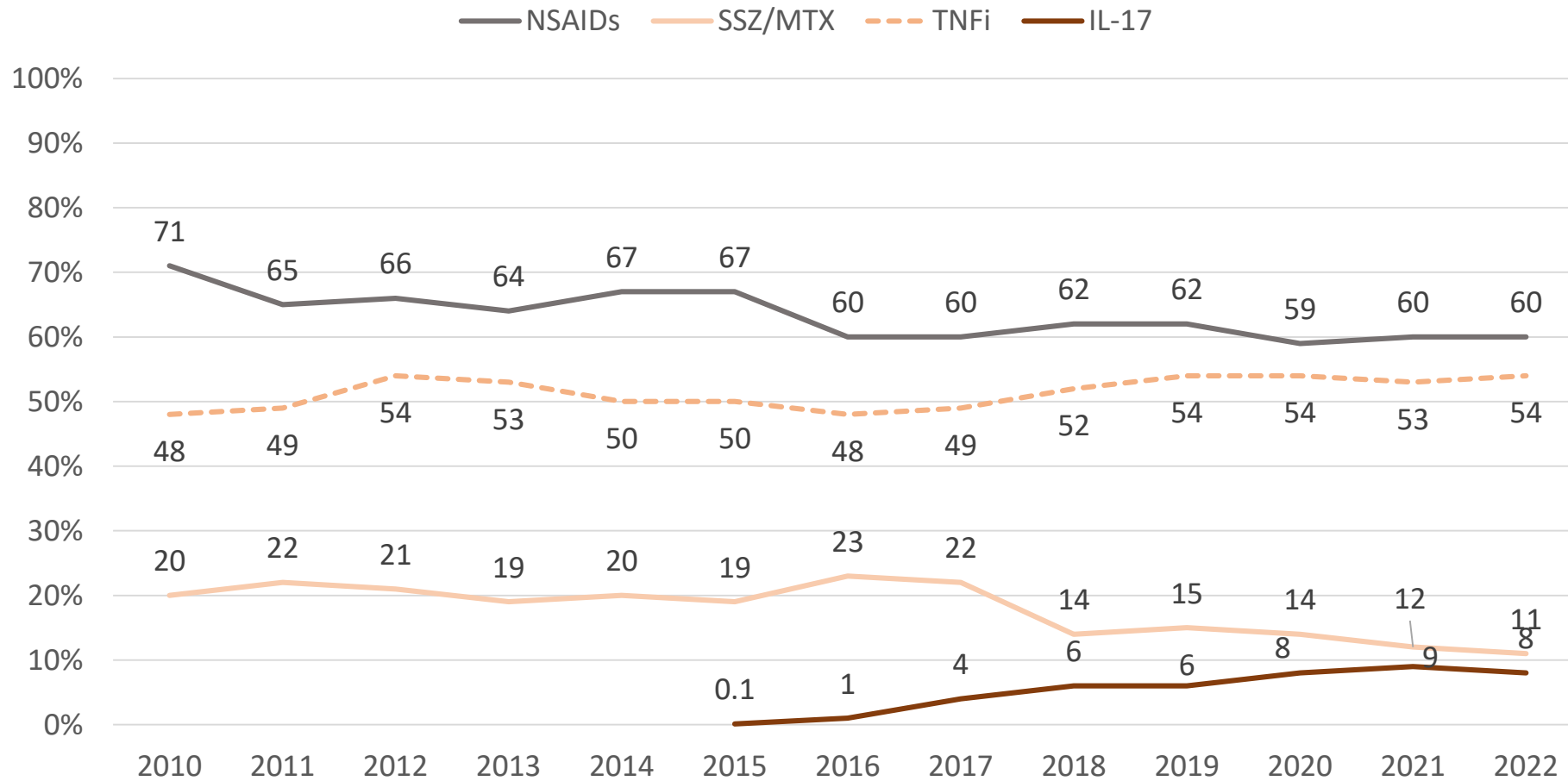


Proportion of monotherapy/combination therapy of all patients with TNFi therapy (100%)

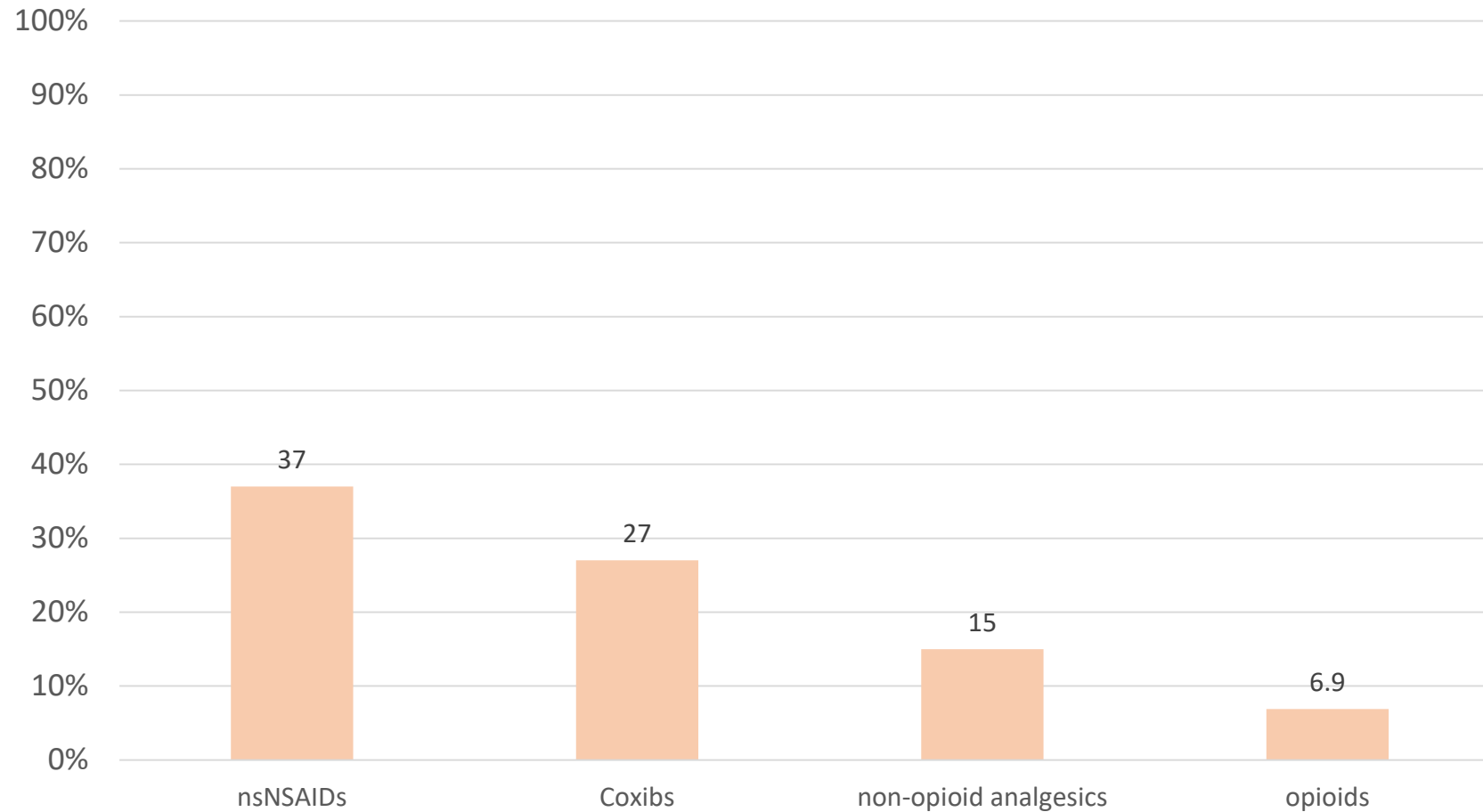


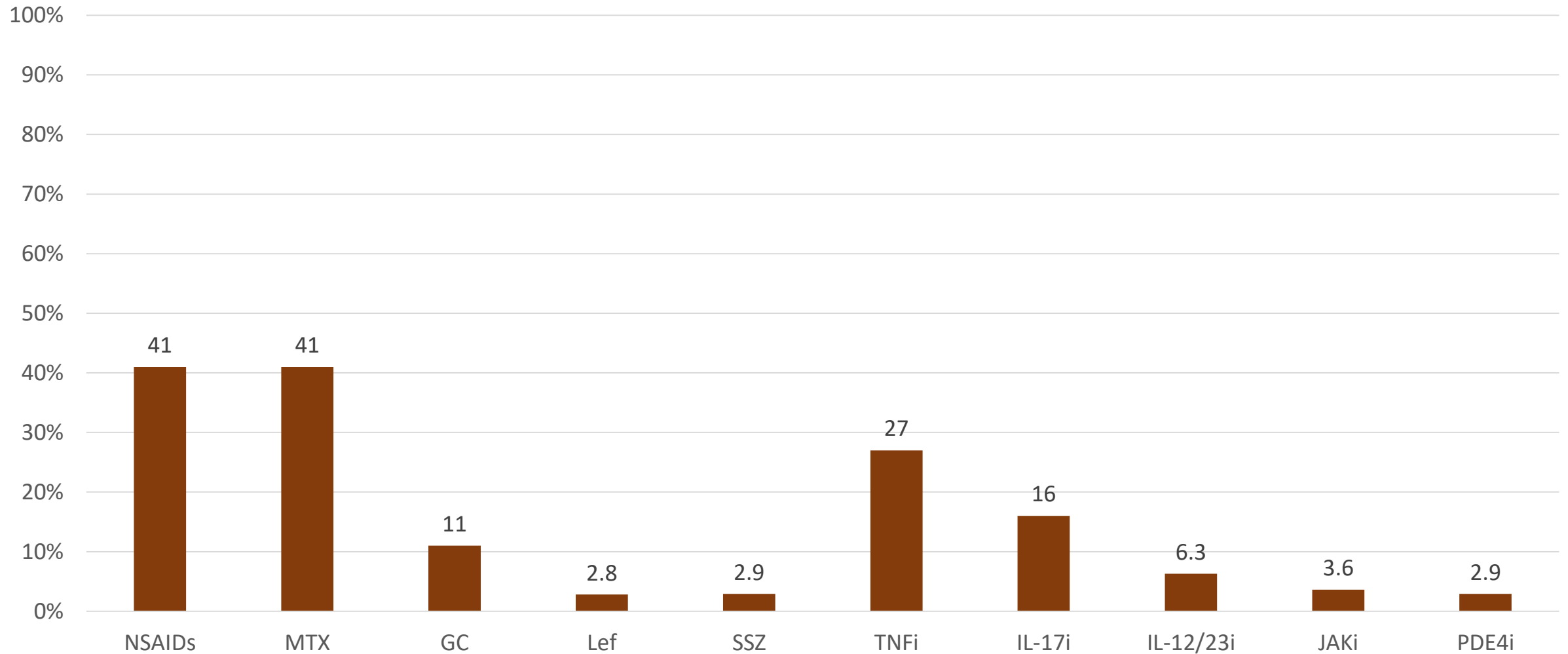
Proportion of biosimilar/original product (%)

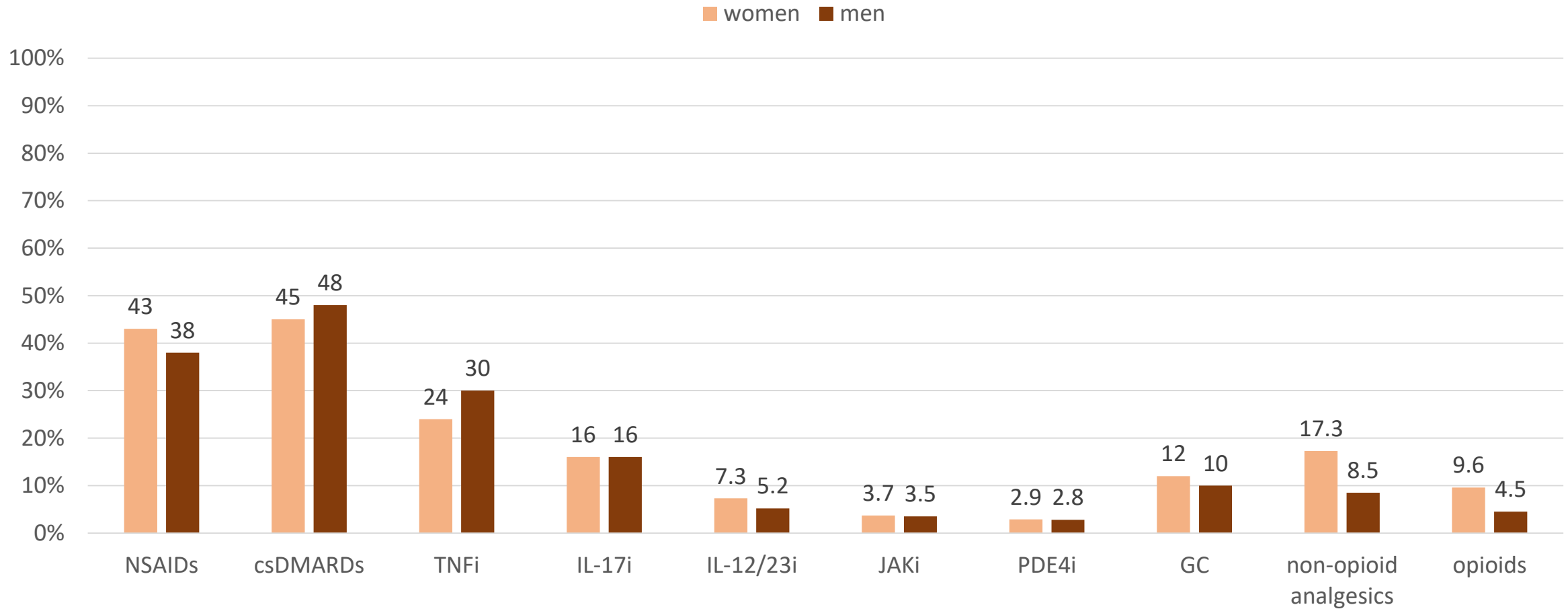




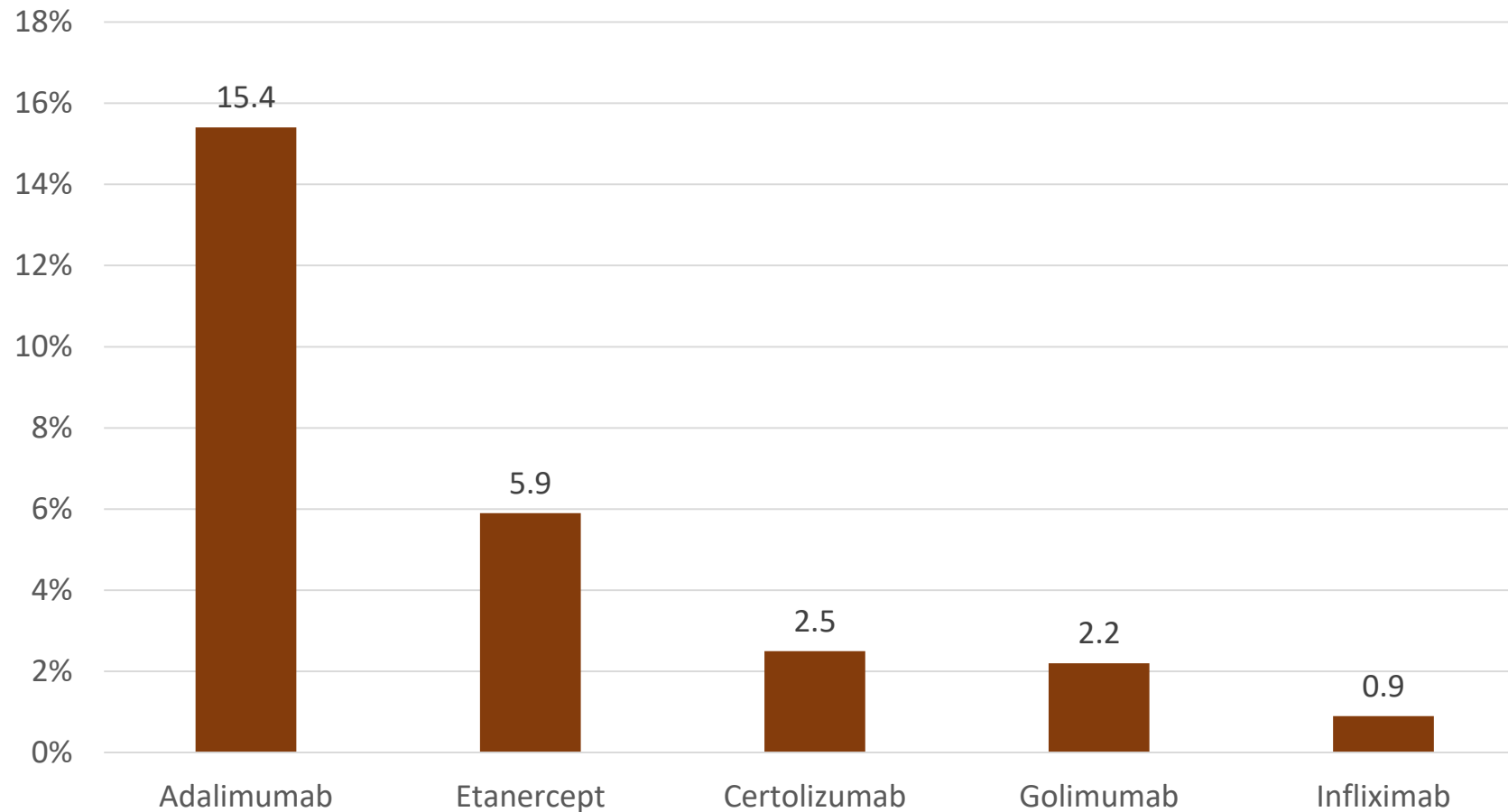




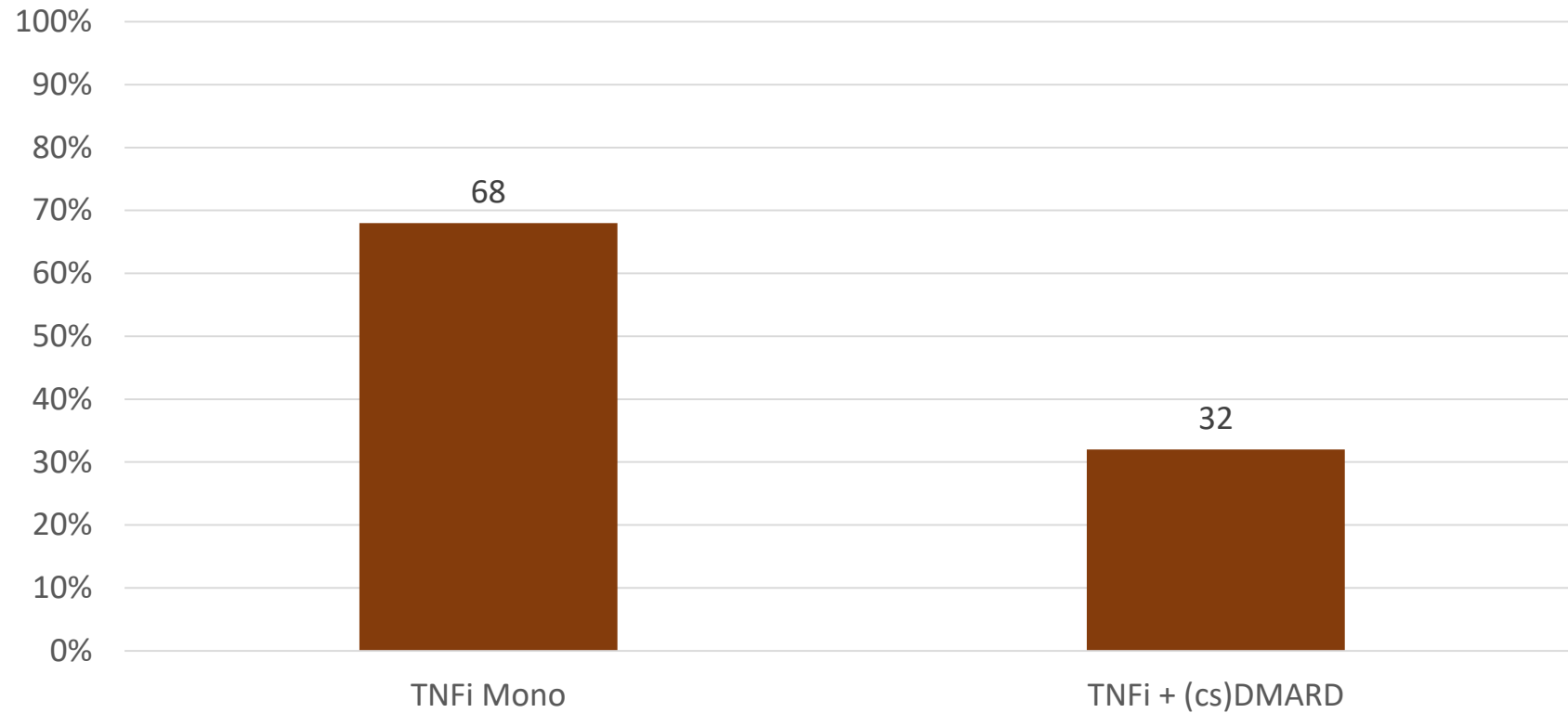




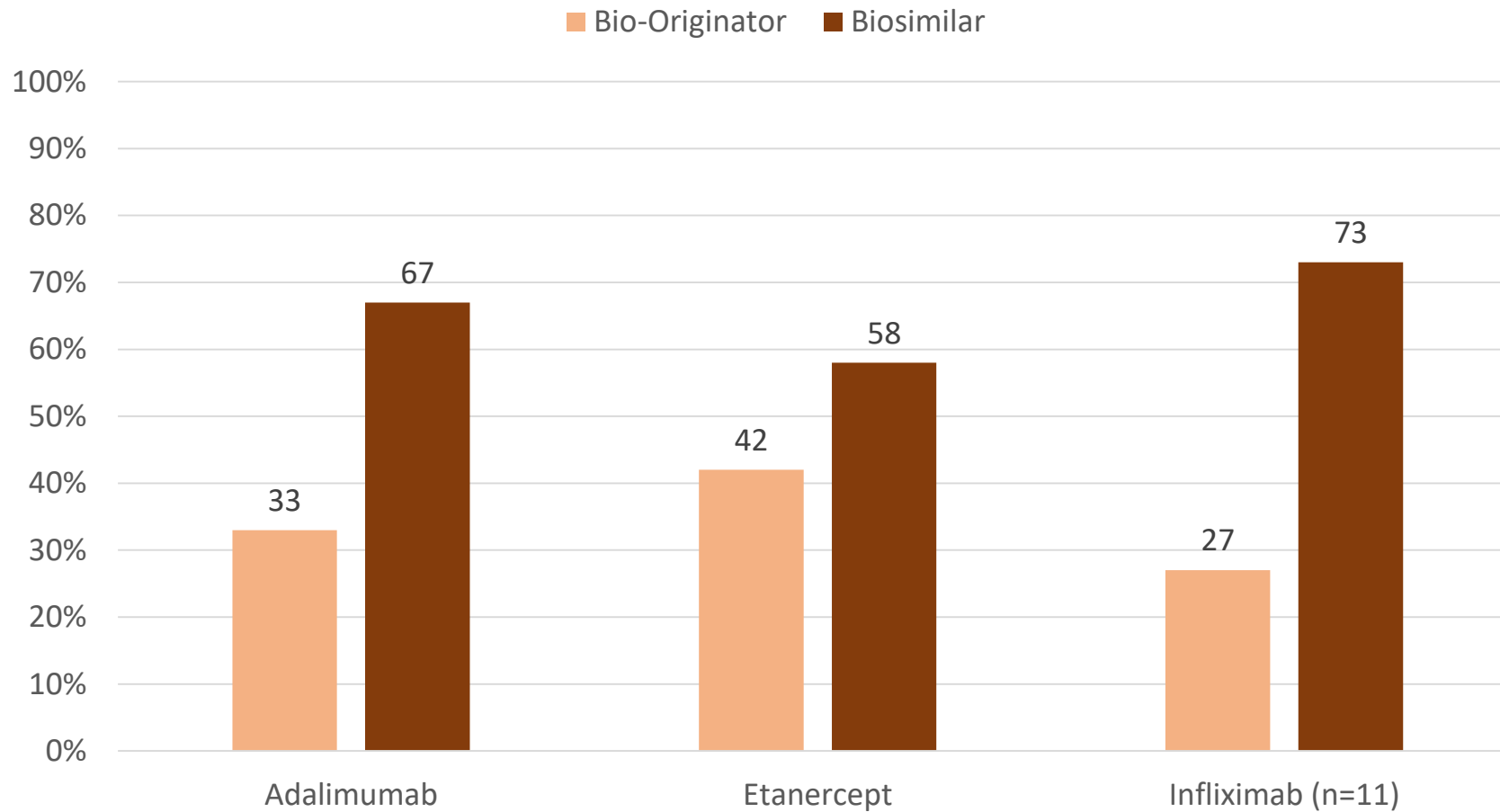
Proportion of substances (%) of the 25% with TNFi therapy



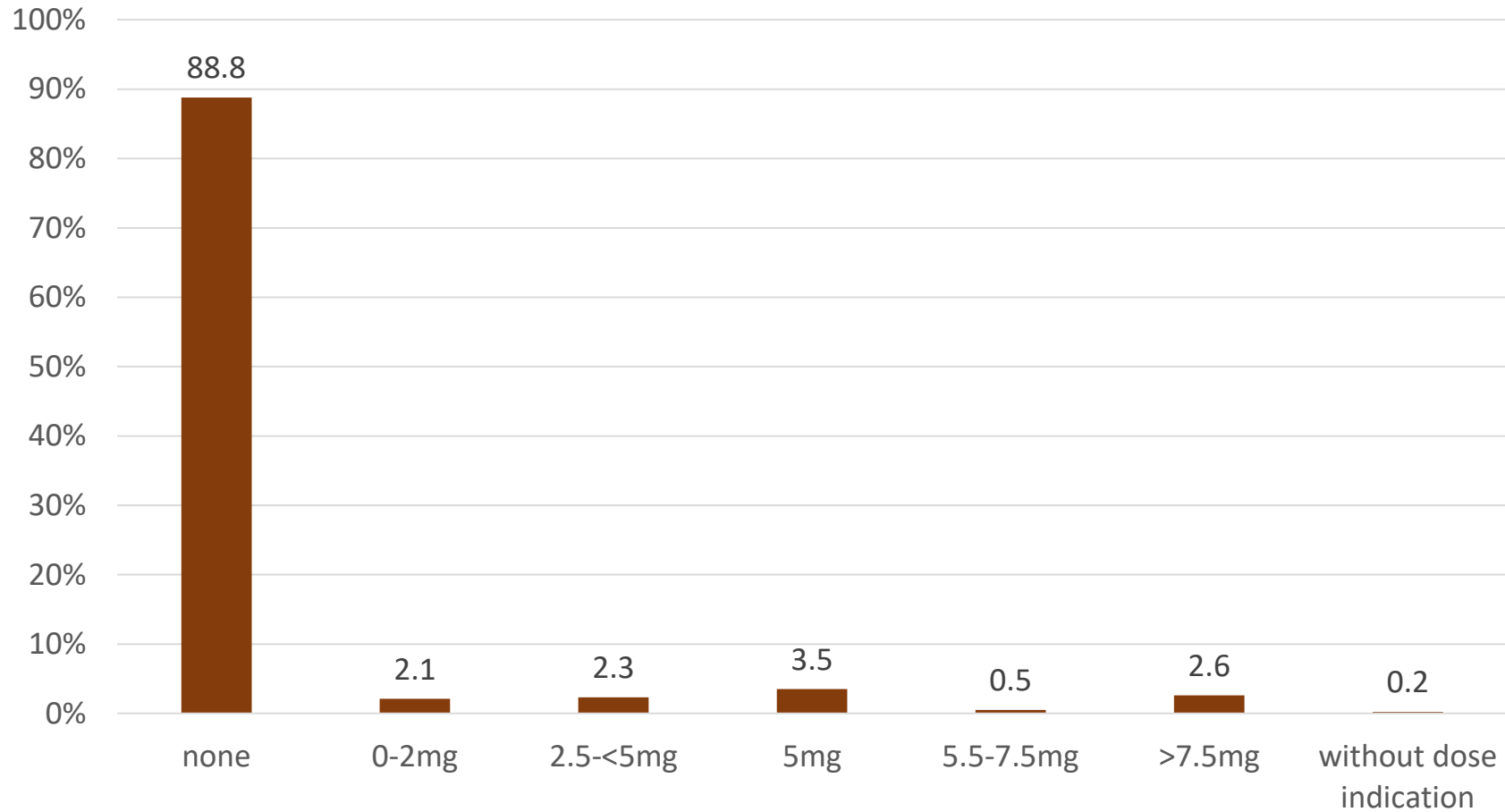
Proportion of monotherapy/combotherapy of all patients with TNFi therapy (100%)

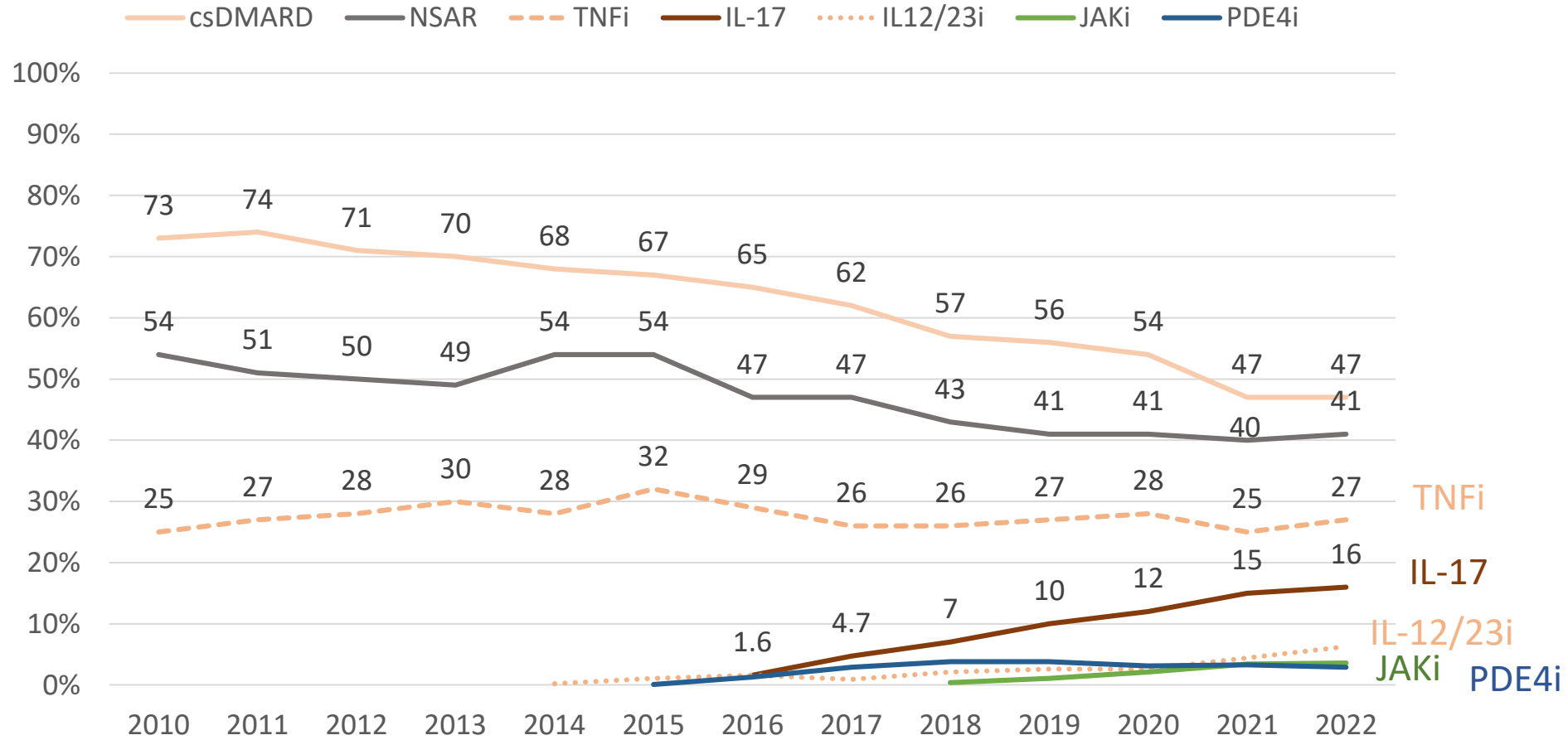


Proportion of biosimilar/original product



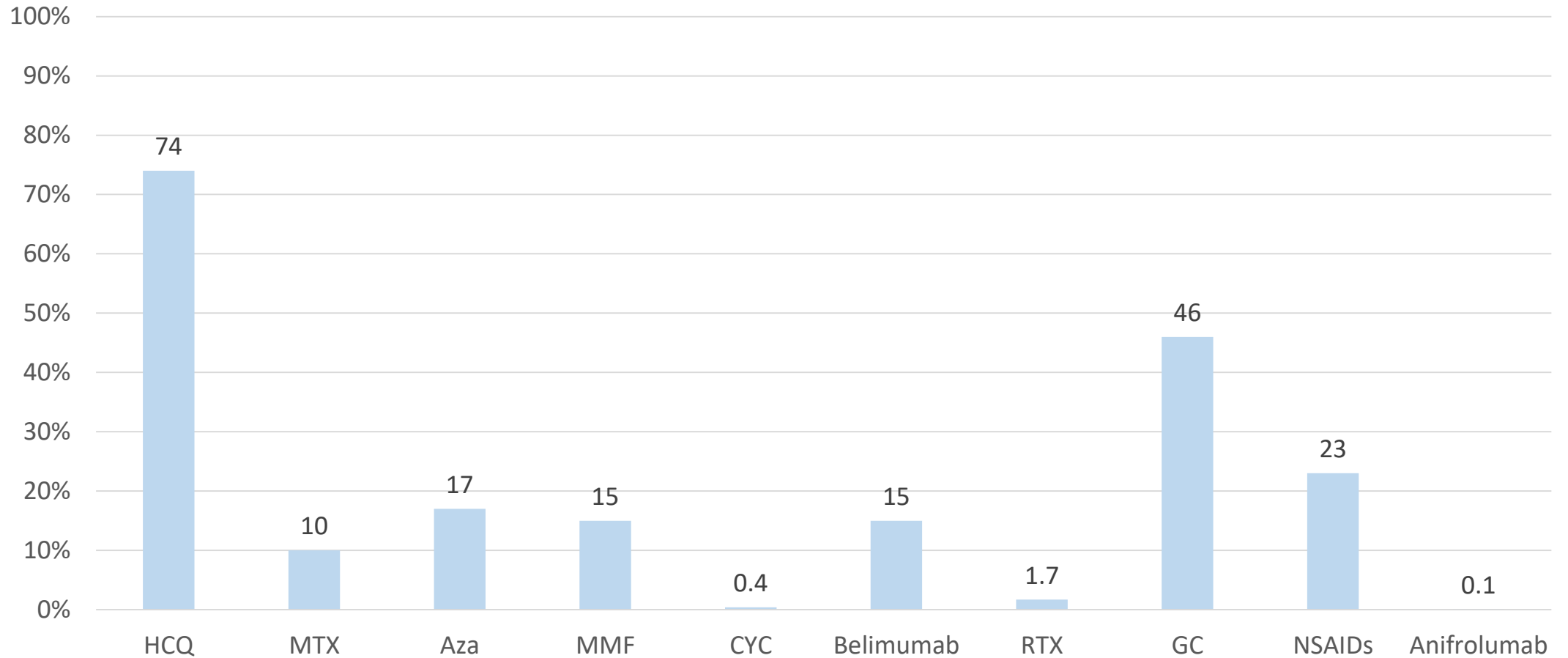
Proportion of patients (%) with current GC dose (prednisolone equivalent per day)



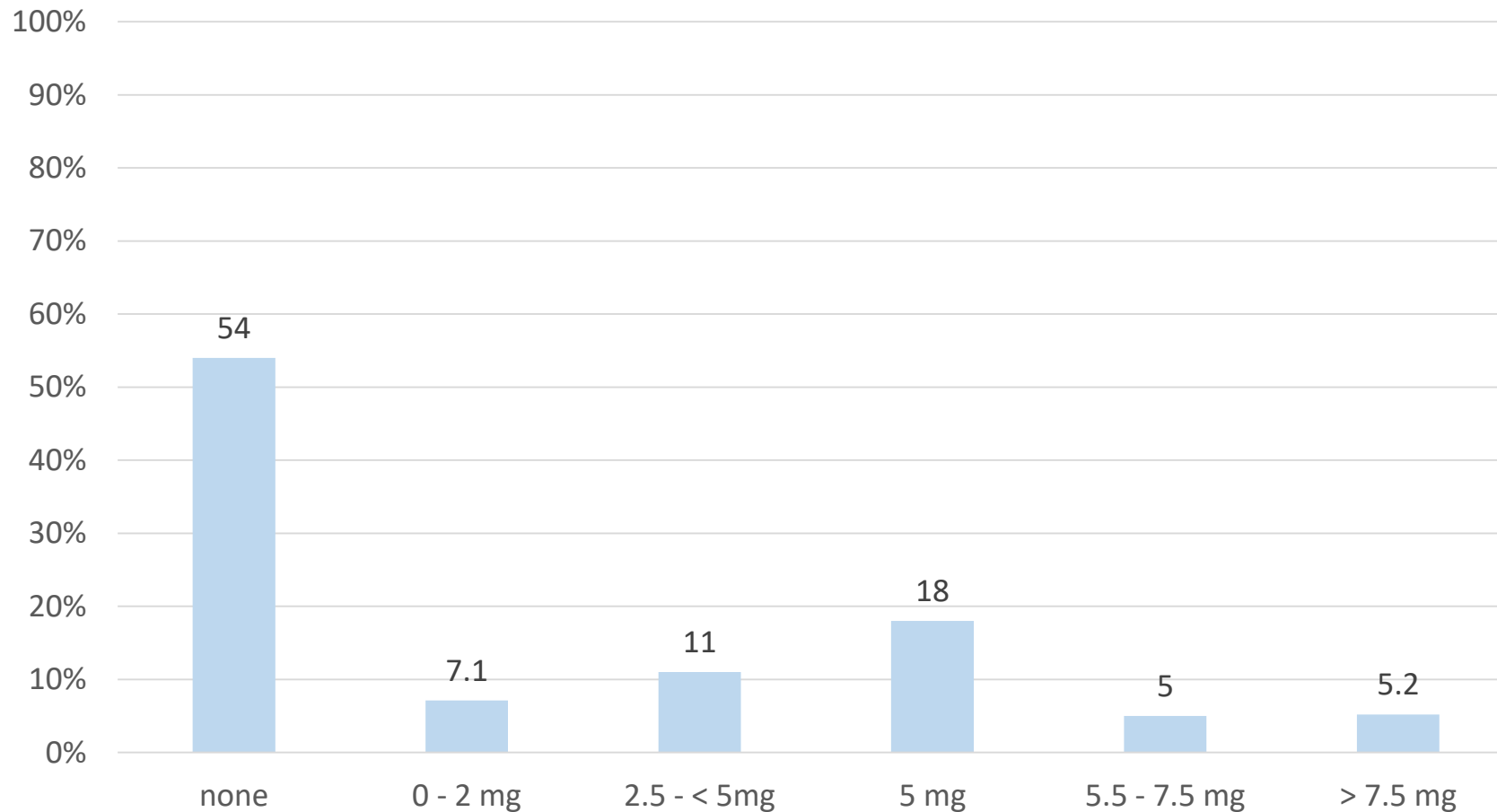


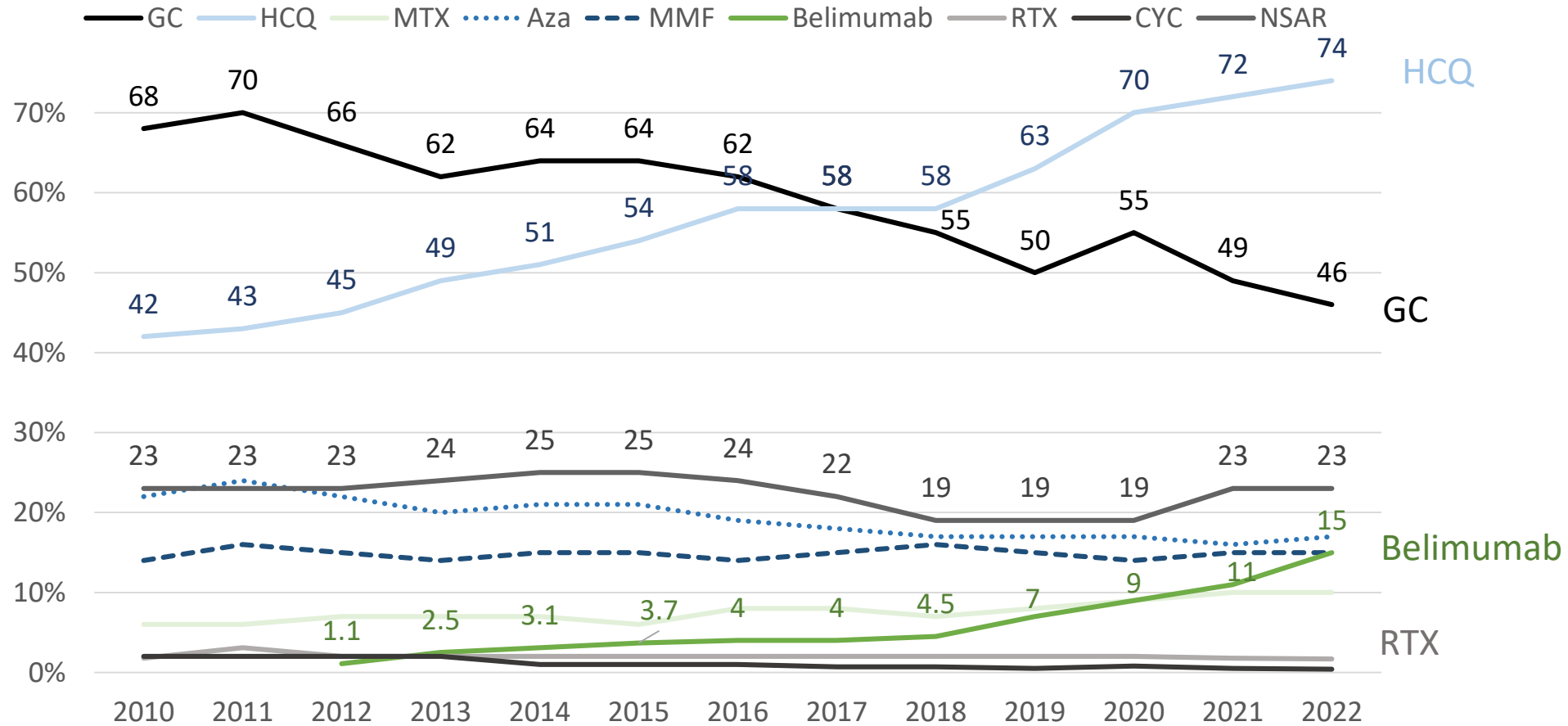


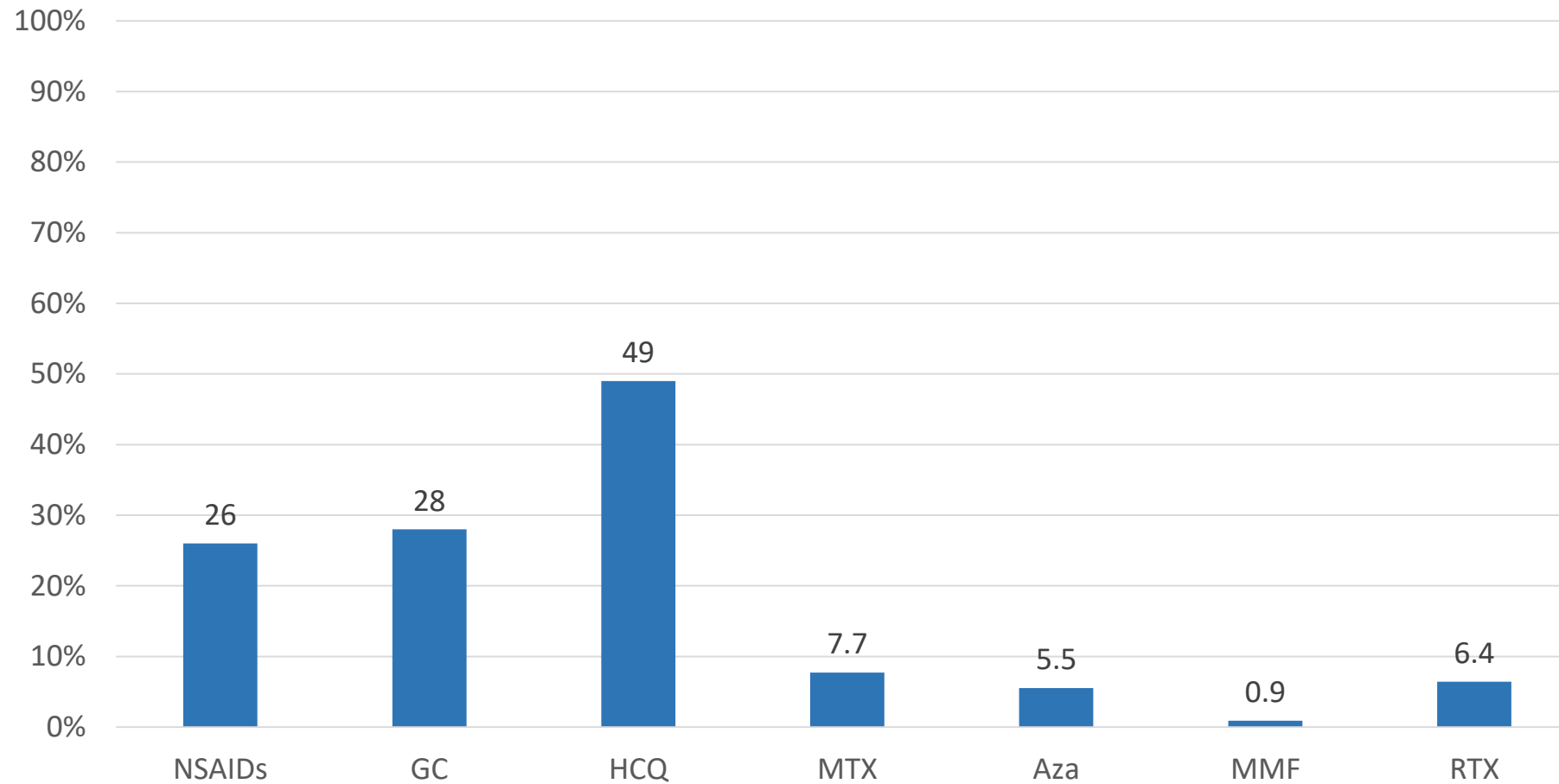
# SLE Therapy

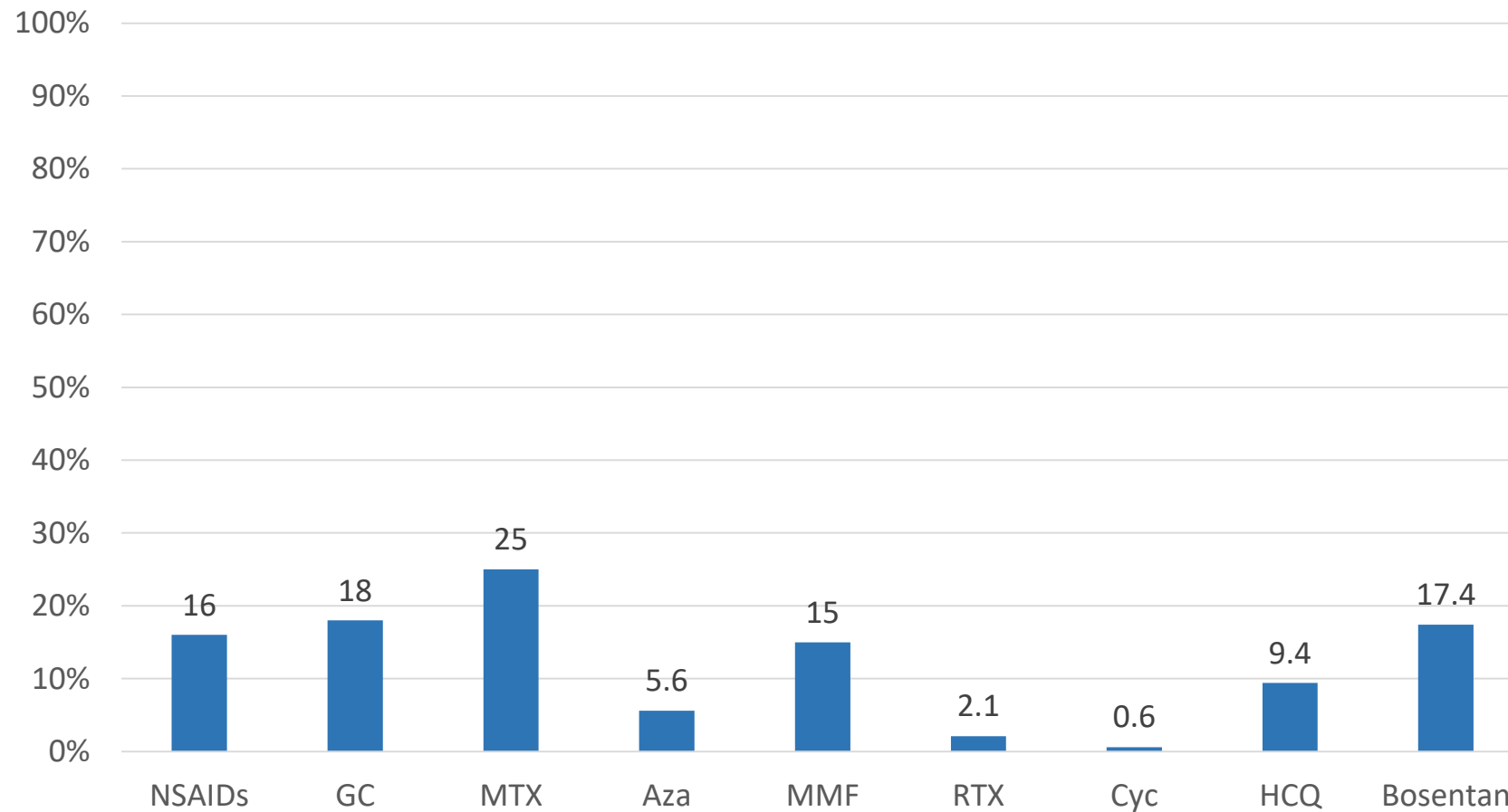


Proportion of patients (%) with current GC dose (prednisolone equivalent per day)

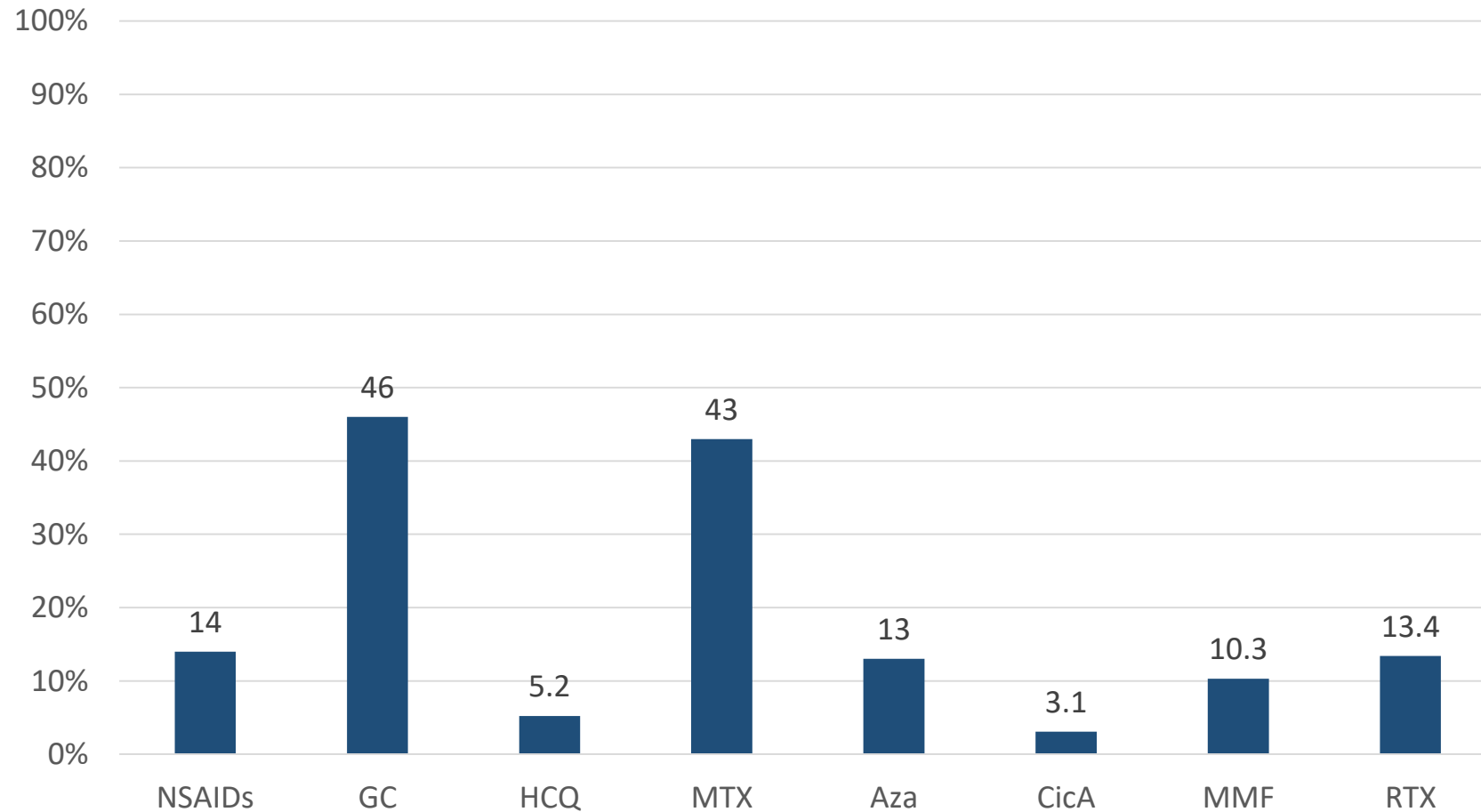


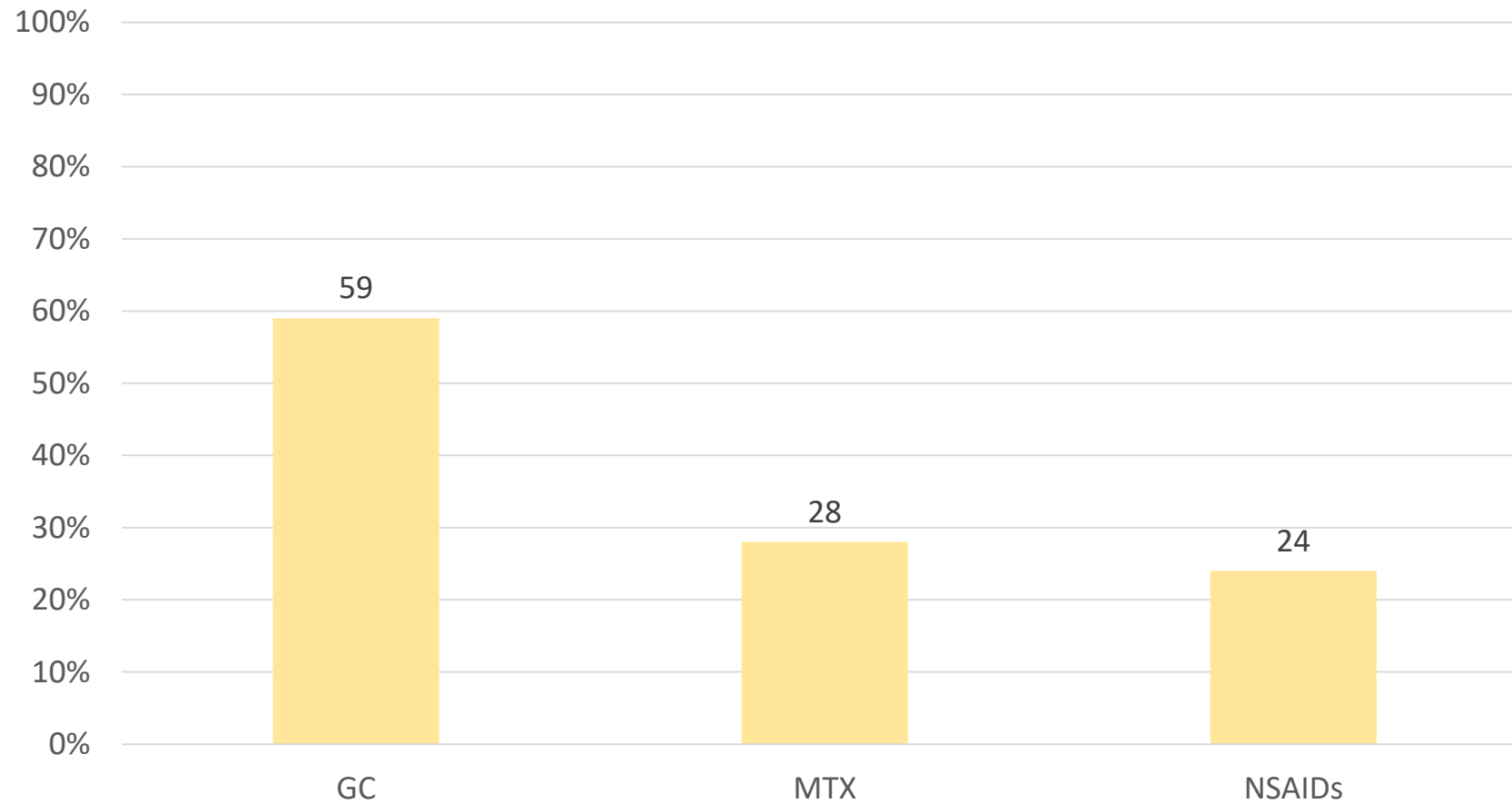






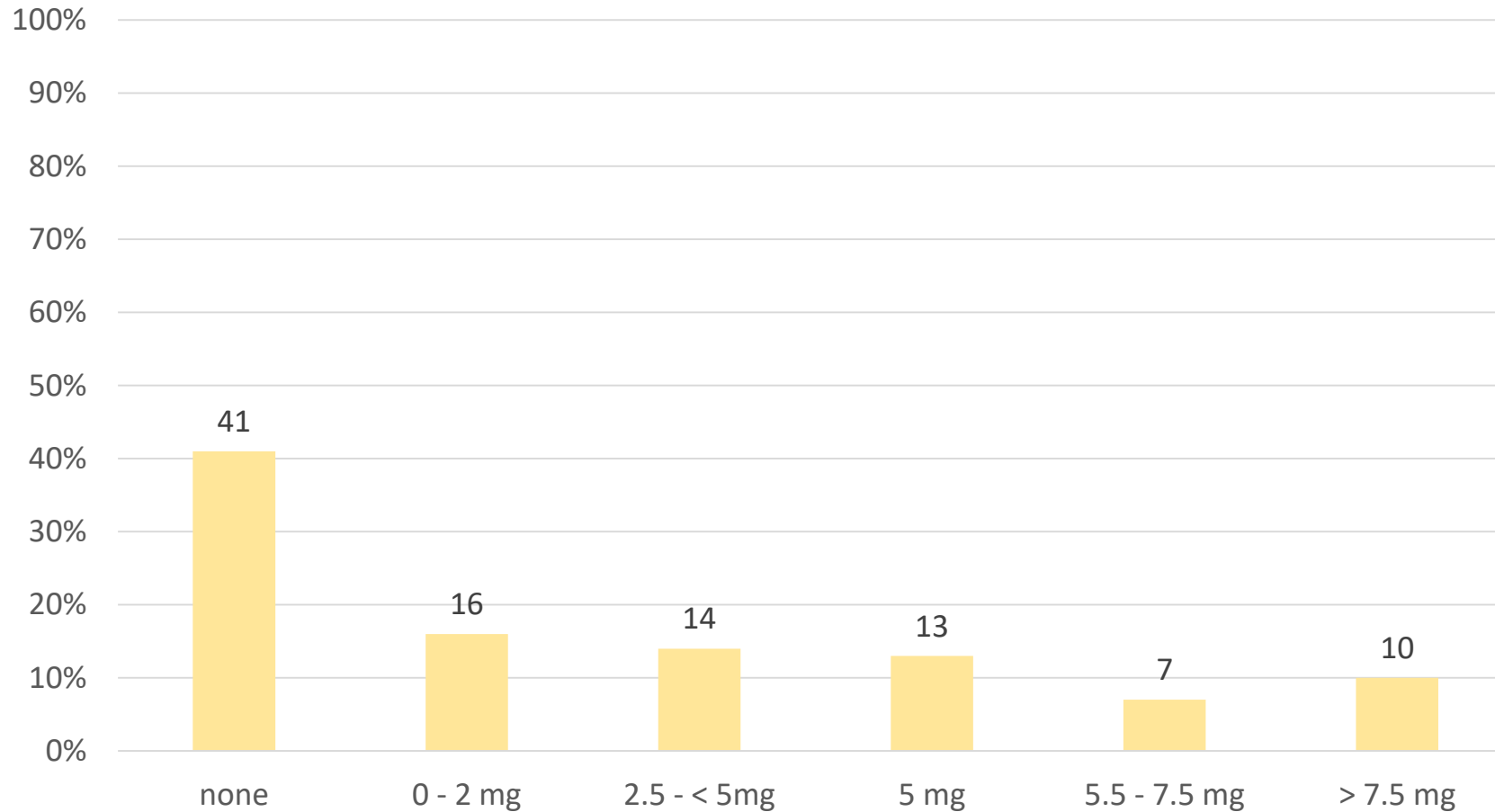
Bosentan is not recorded in all facilities.





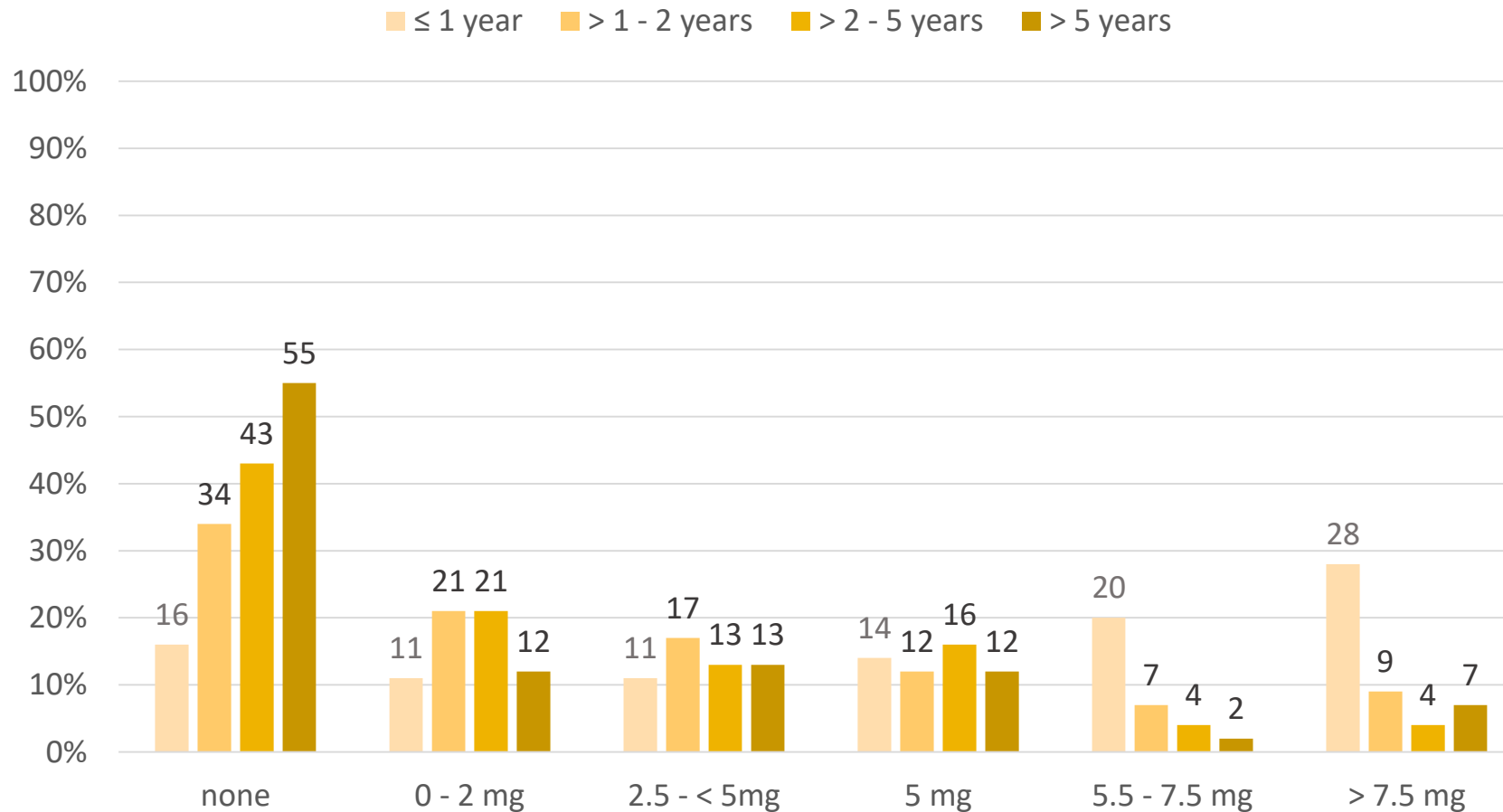


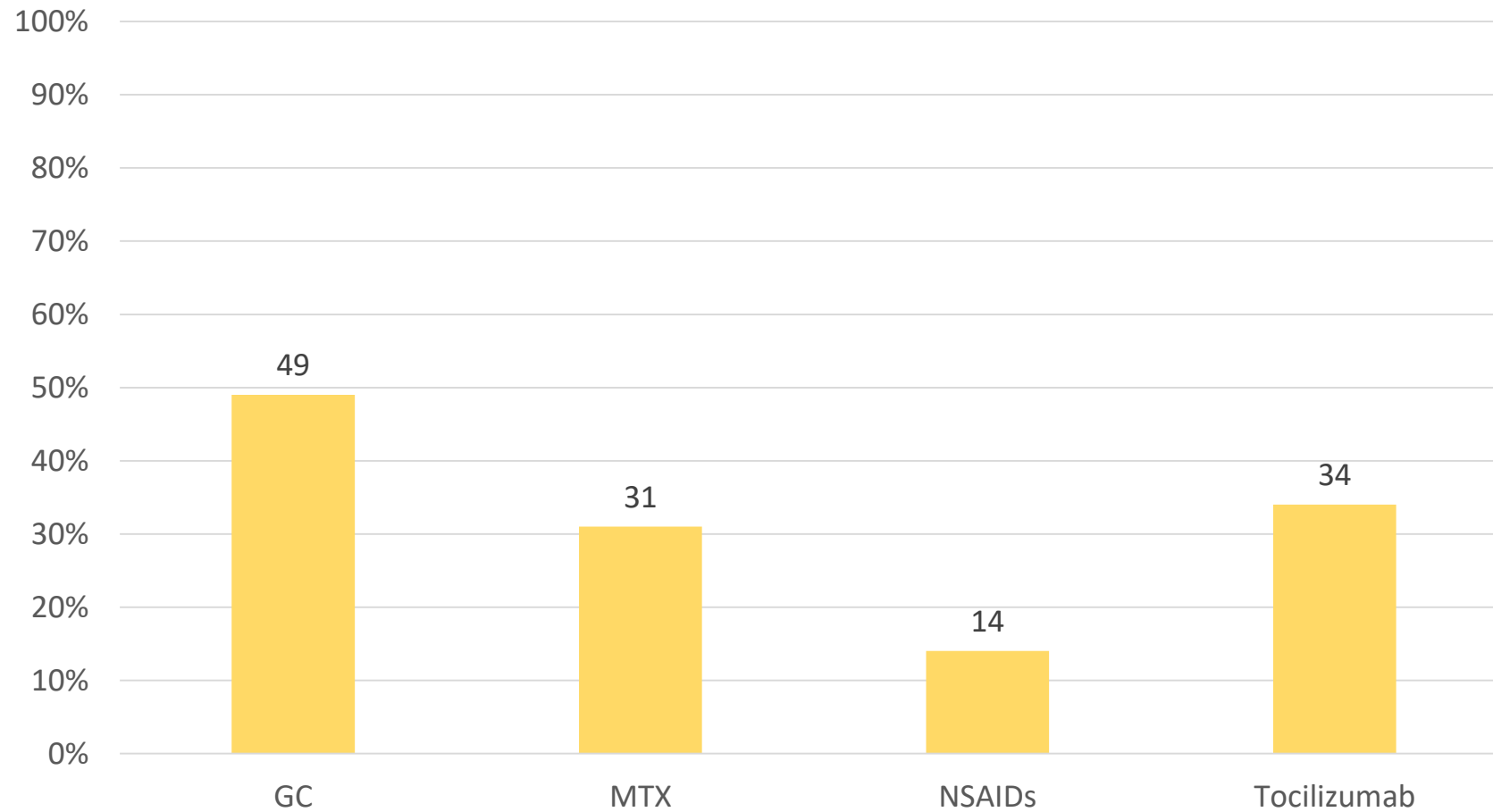
Proportion of patients (%) with current GC dose (prednisolone equivalent per day)



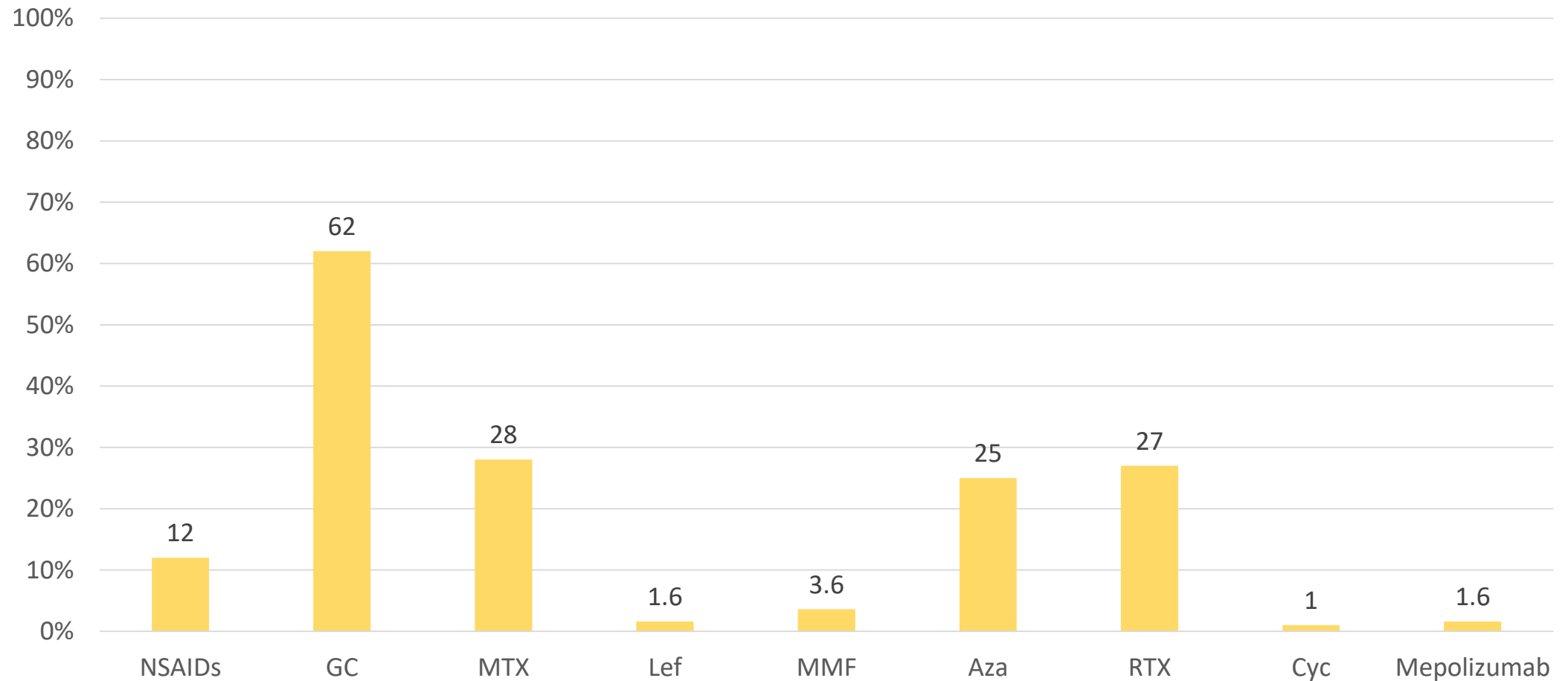


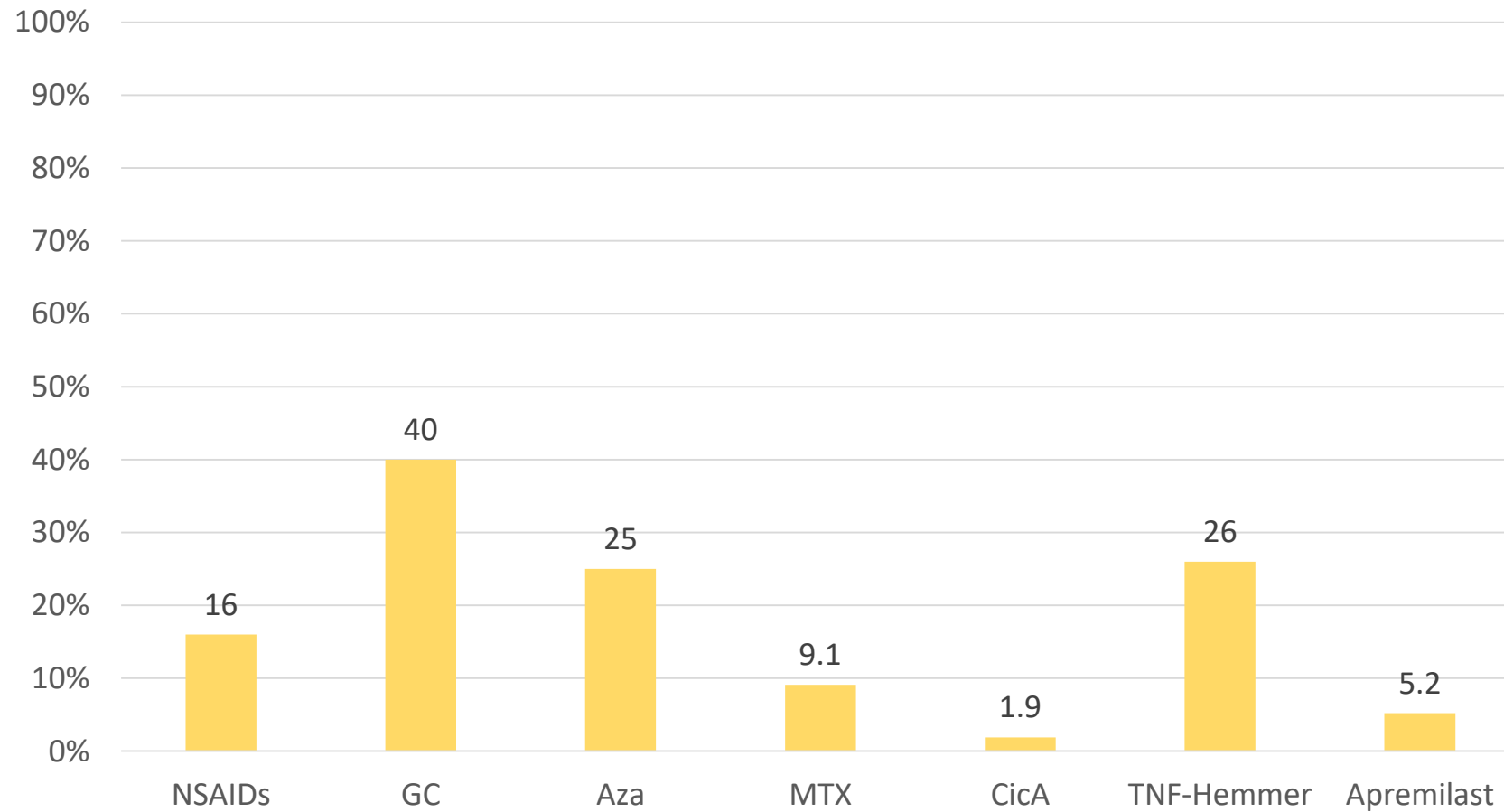
Proportion of patients (%) with current GC dose (prednisolone equivalent per day)





The variance in the institutions is high for tocilizumab







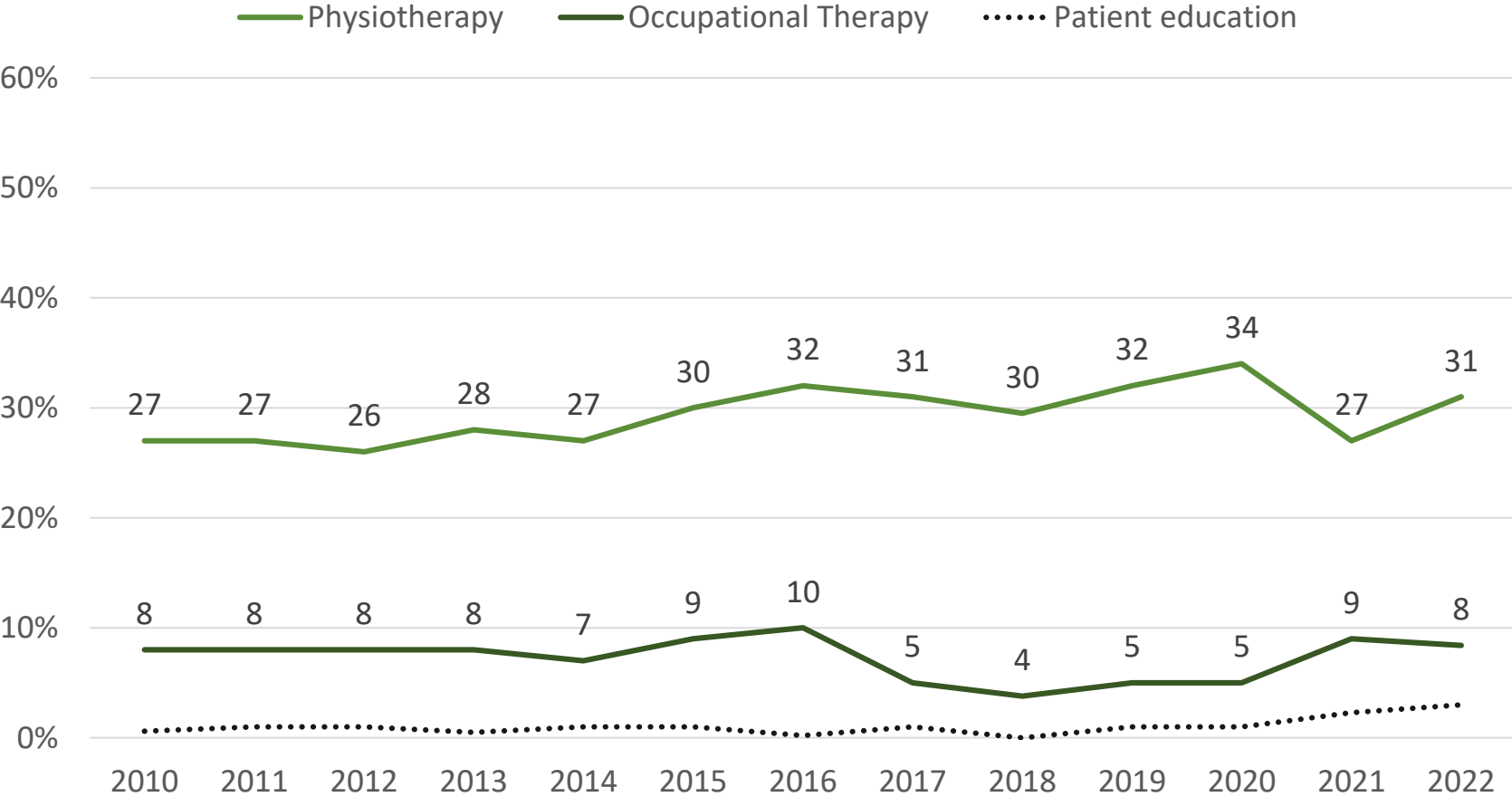
# Non-drug therapy

Physiotherapy  
Occupational therapy  
Patient education

# Non-drug therapy 2010 - 2022

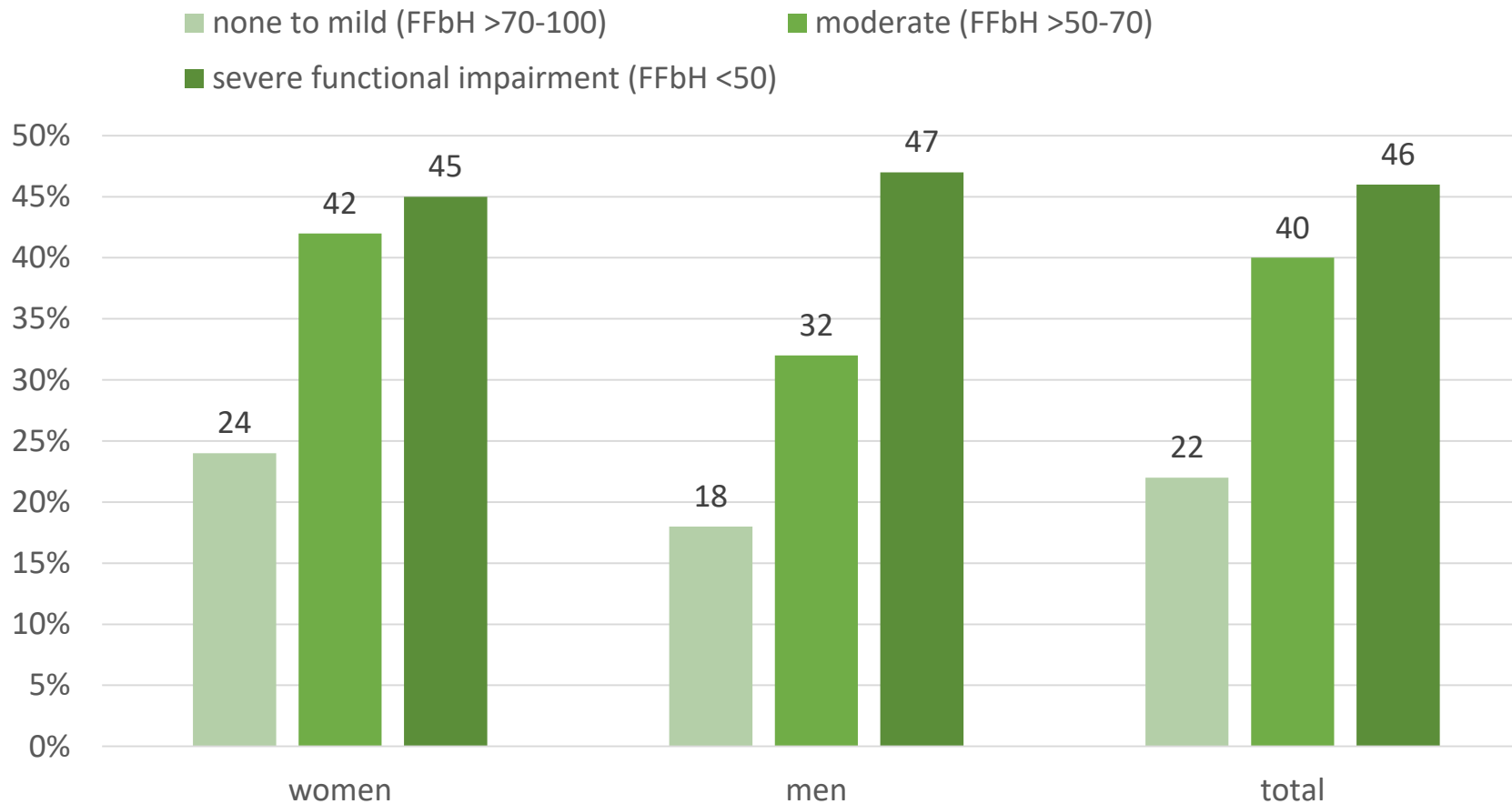


Proportion of patients (%) with outpatient therapy in the last 12 months

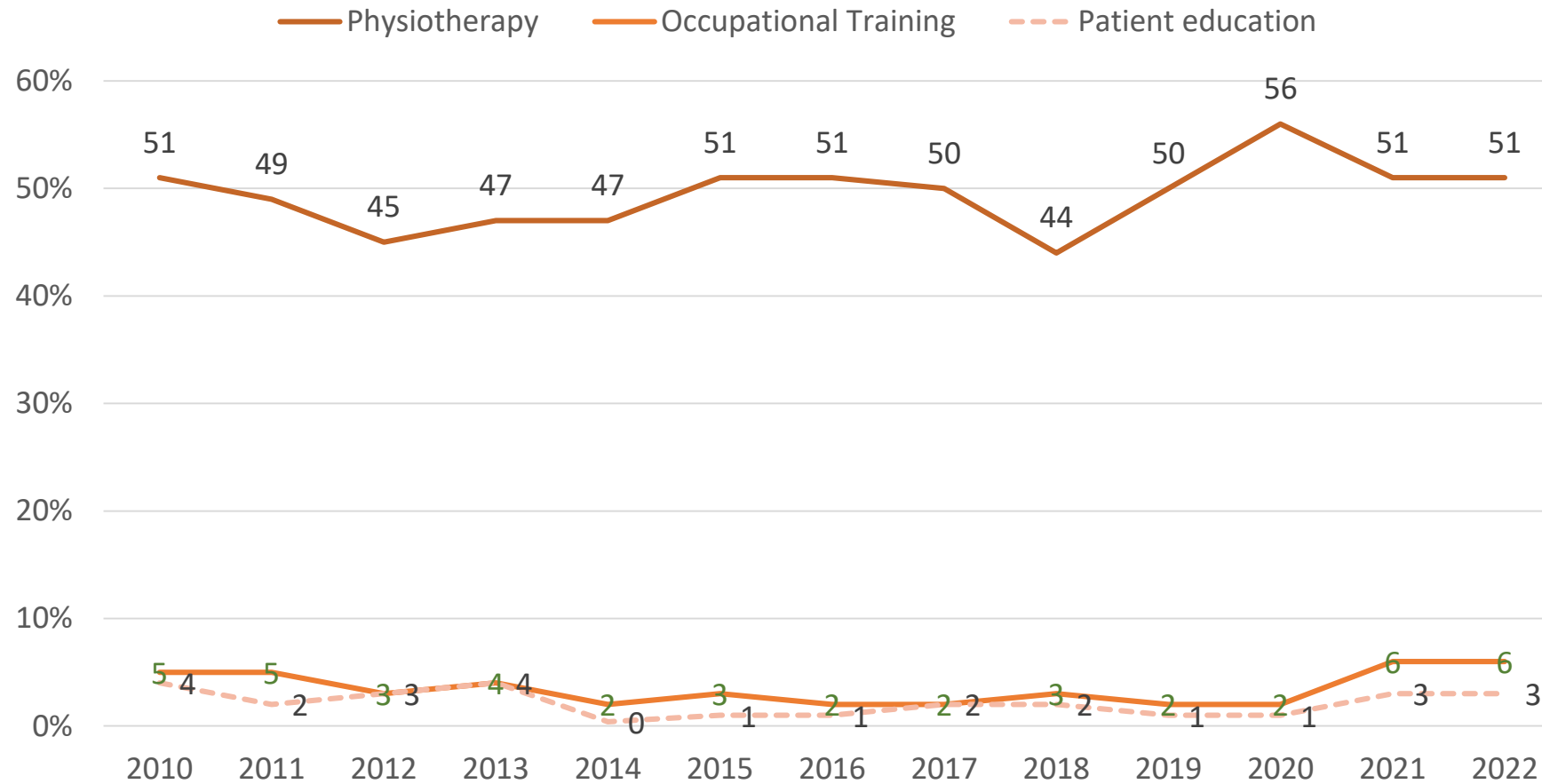


Source: German National Database, data collected in 2022

Proportion of patients (%) with outpatient physiotherapy in the last 12 months

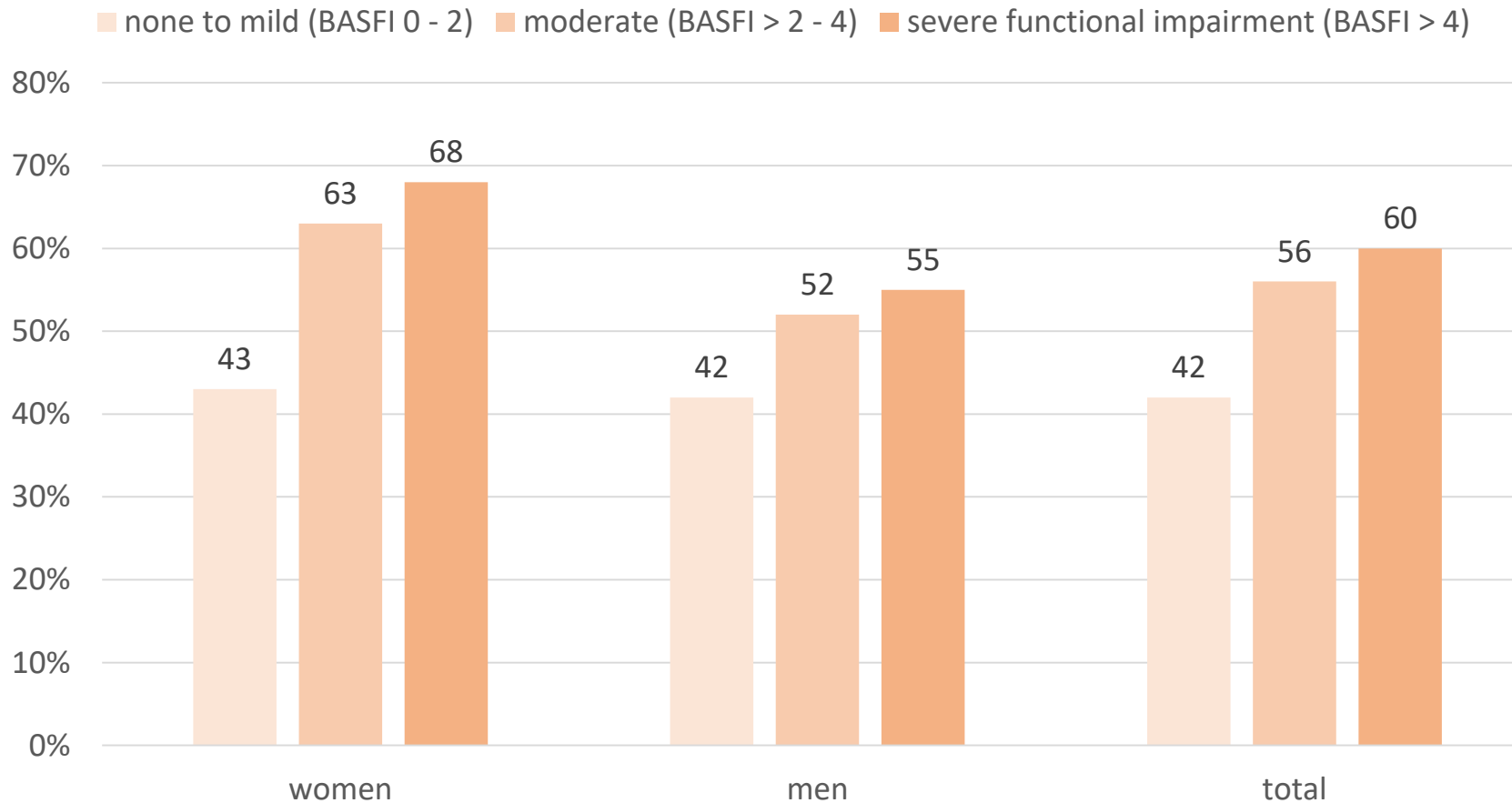


Proportion of patients (%) with outpatient therapy in the last 12 months

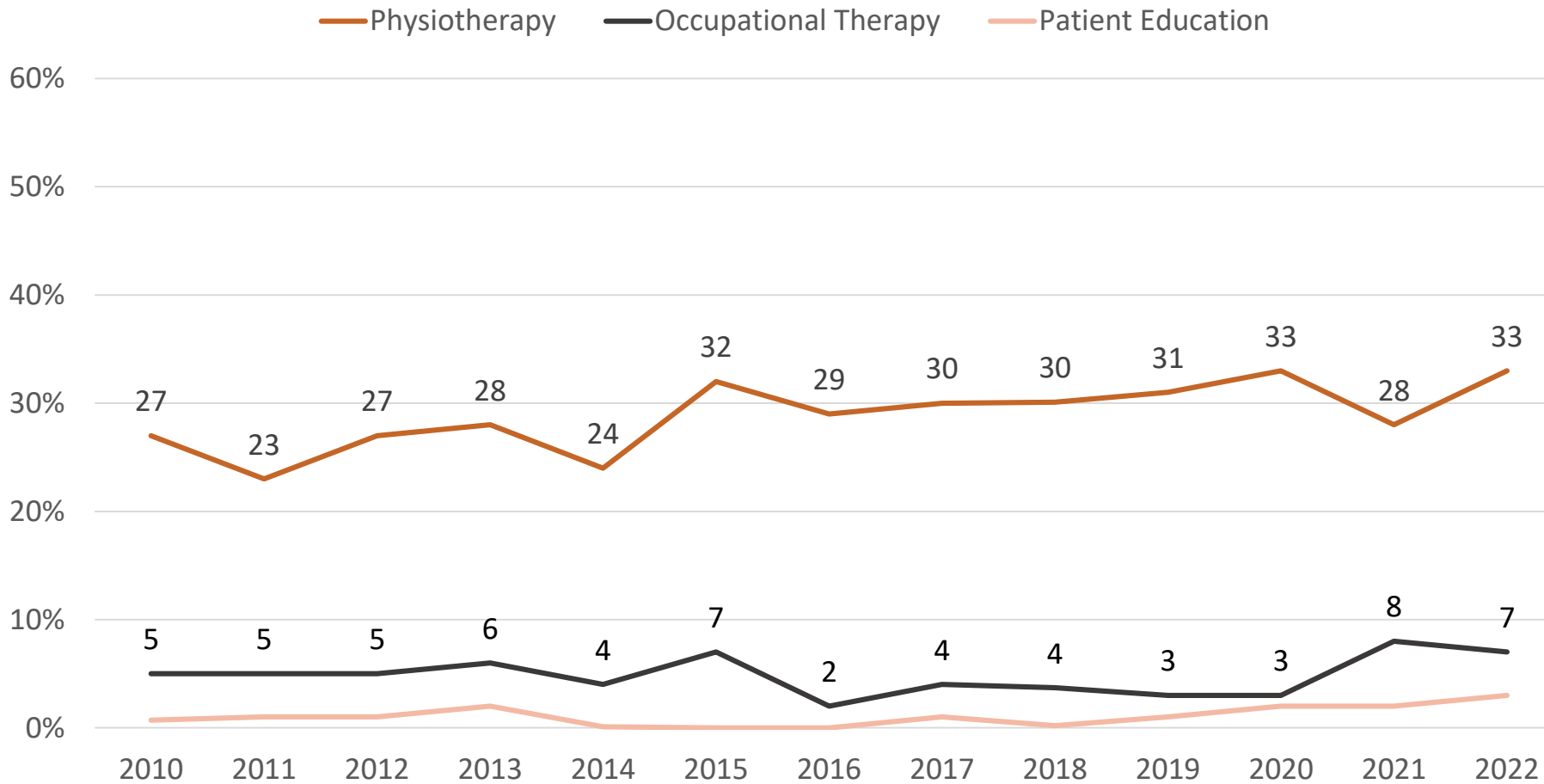




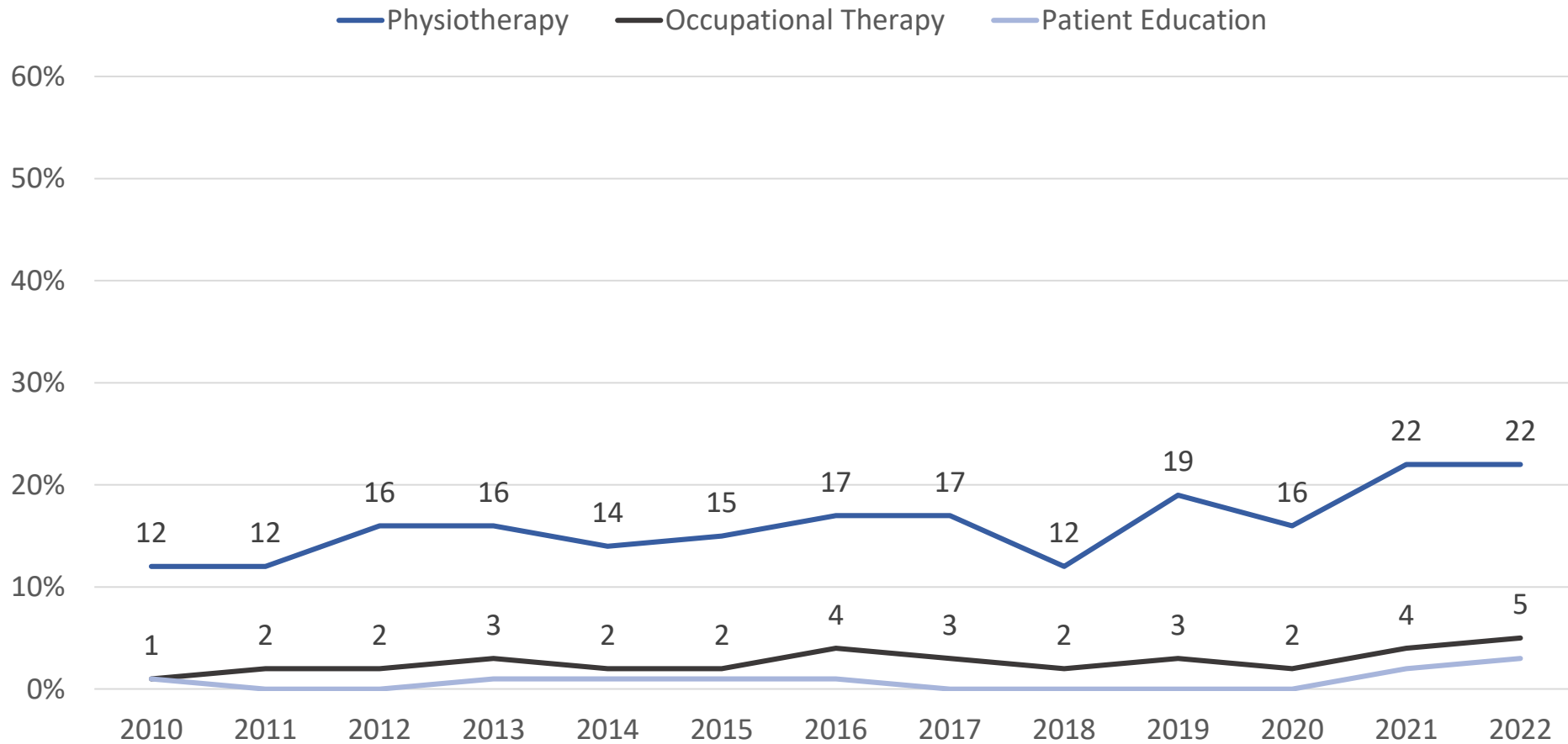
Proportion of patients (%) with outpatient physiotherapy in the last 12 months



Proportion of patients (%) with outpatient therapy in the last 12 months



Proportion of patients (%) with outpatient therapy in the last 12 months



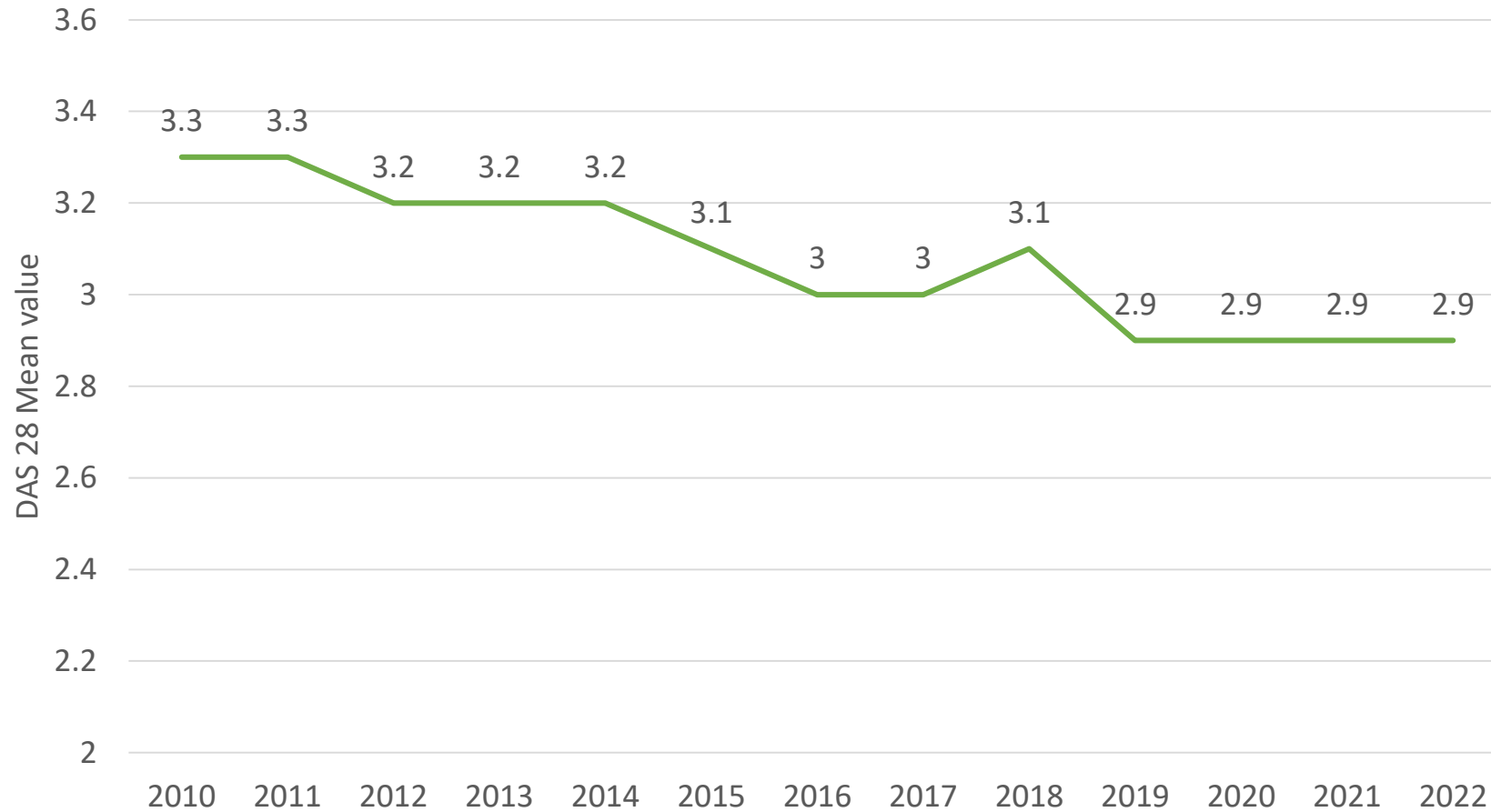


# Disease activity

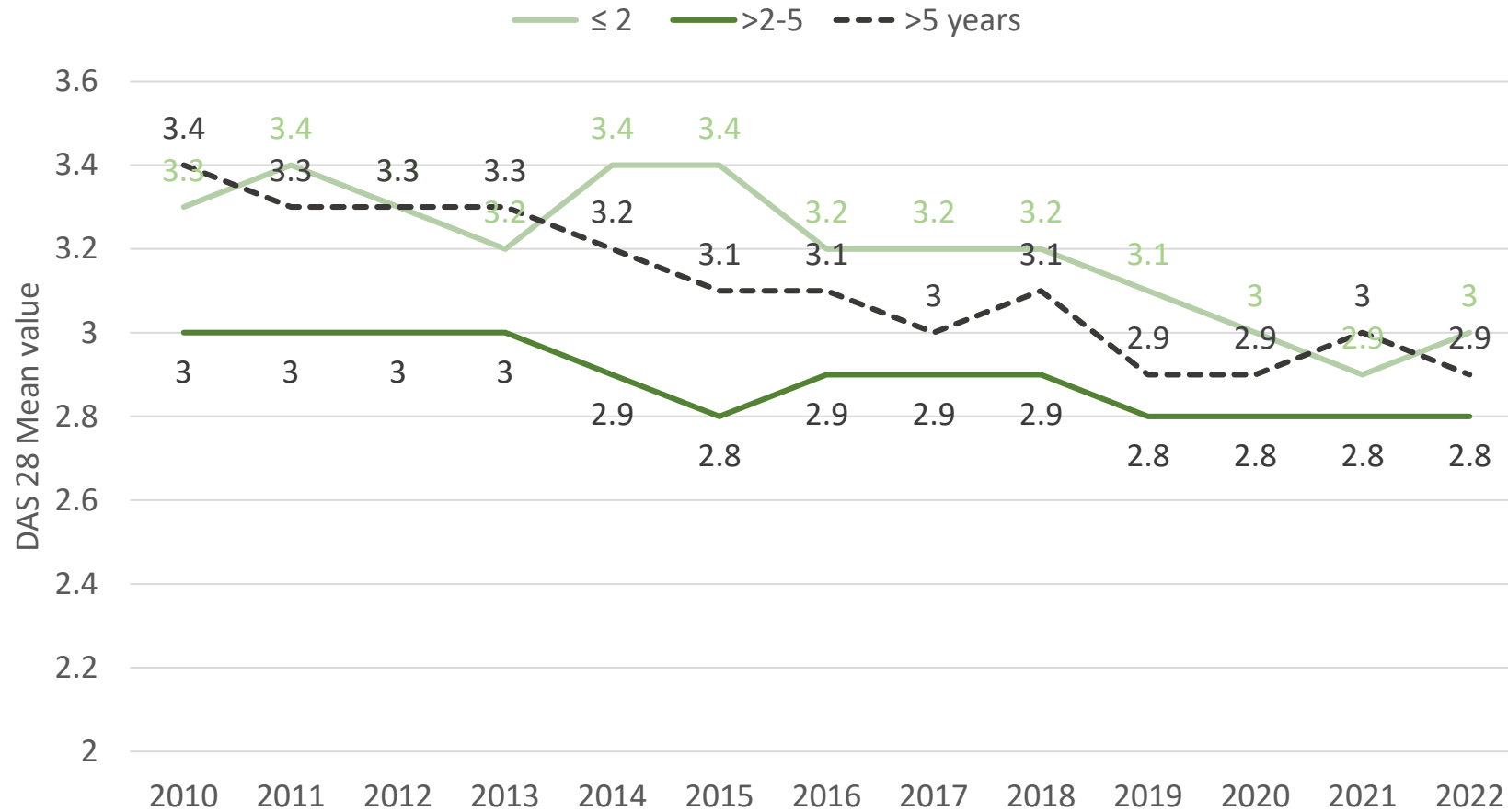
DAS28  
Remission  
CDAI  
Physician assessment (NRS 0-10)  
BASDAI  
ECLAM



Average DAS28 from 2010 - 2021



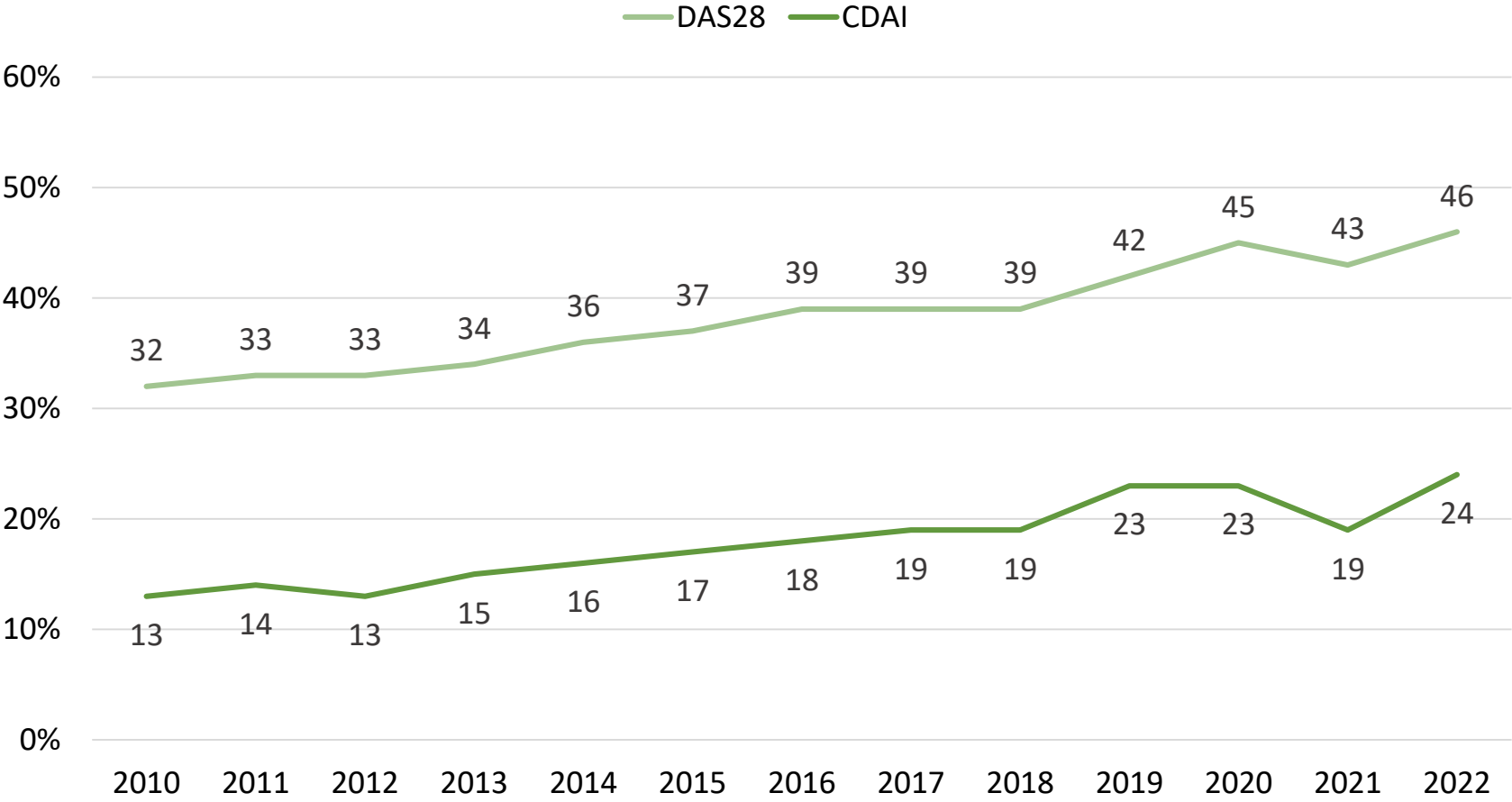
Average DAS28 by disease duration from 2010 - 2021



# RA Remission



Proportion of patients (%) in DAS28 or CDAI remission

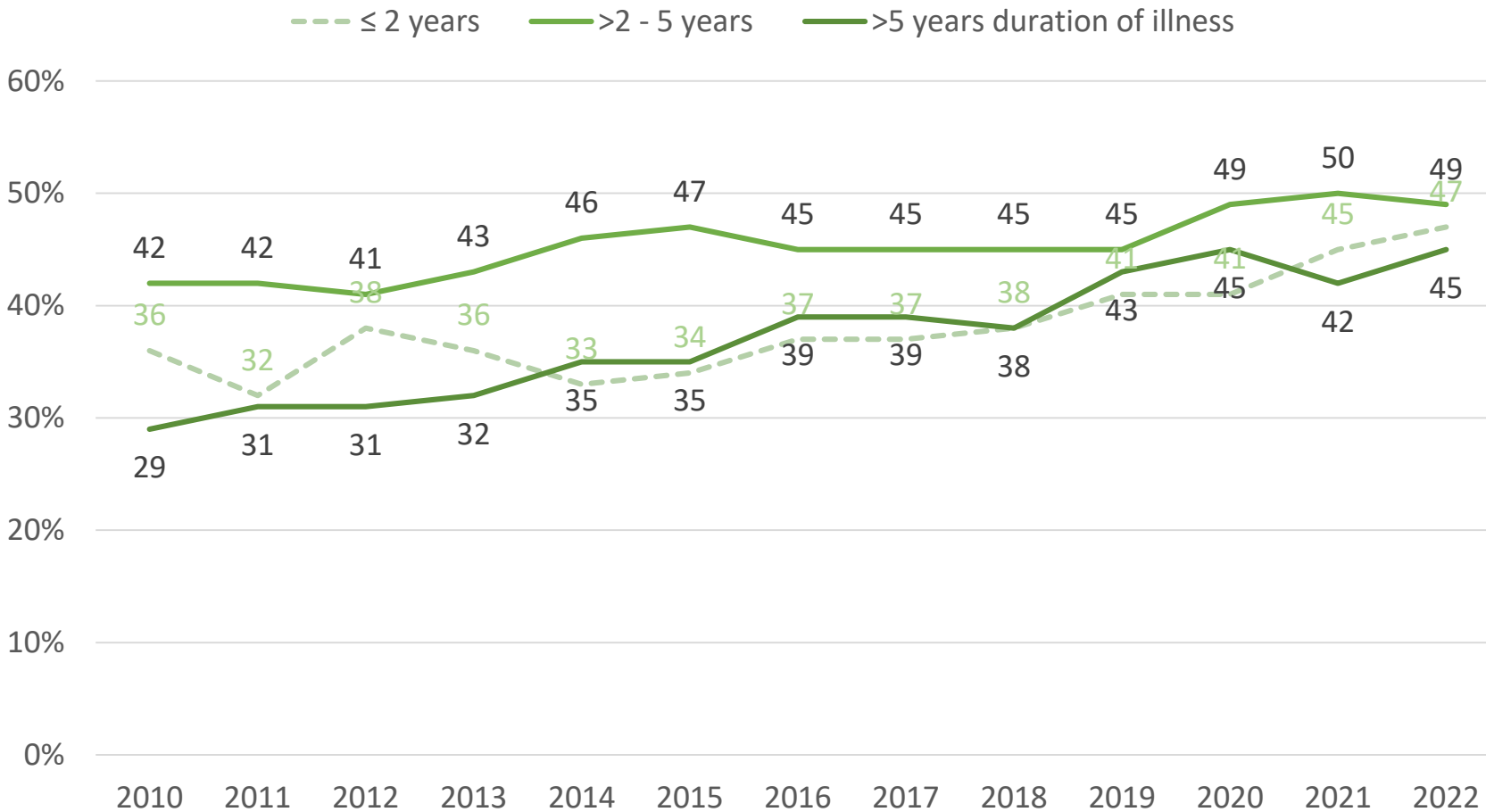


Source: German National Database, data collected in 2022

n=4,697 (2010) to 4,607 (2022) RA patients with DAS28



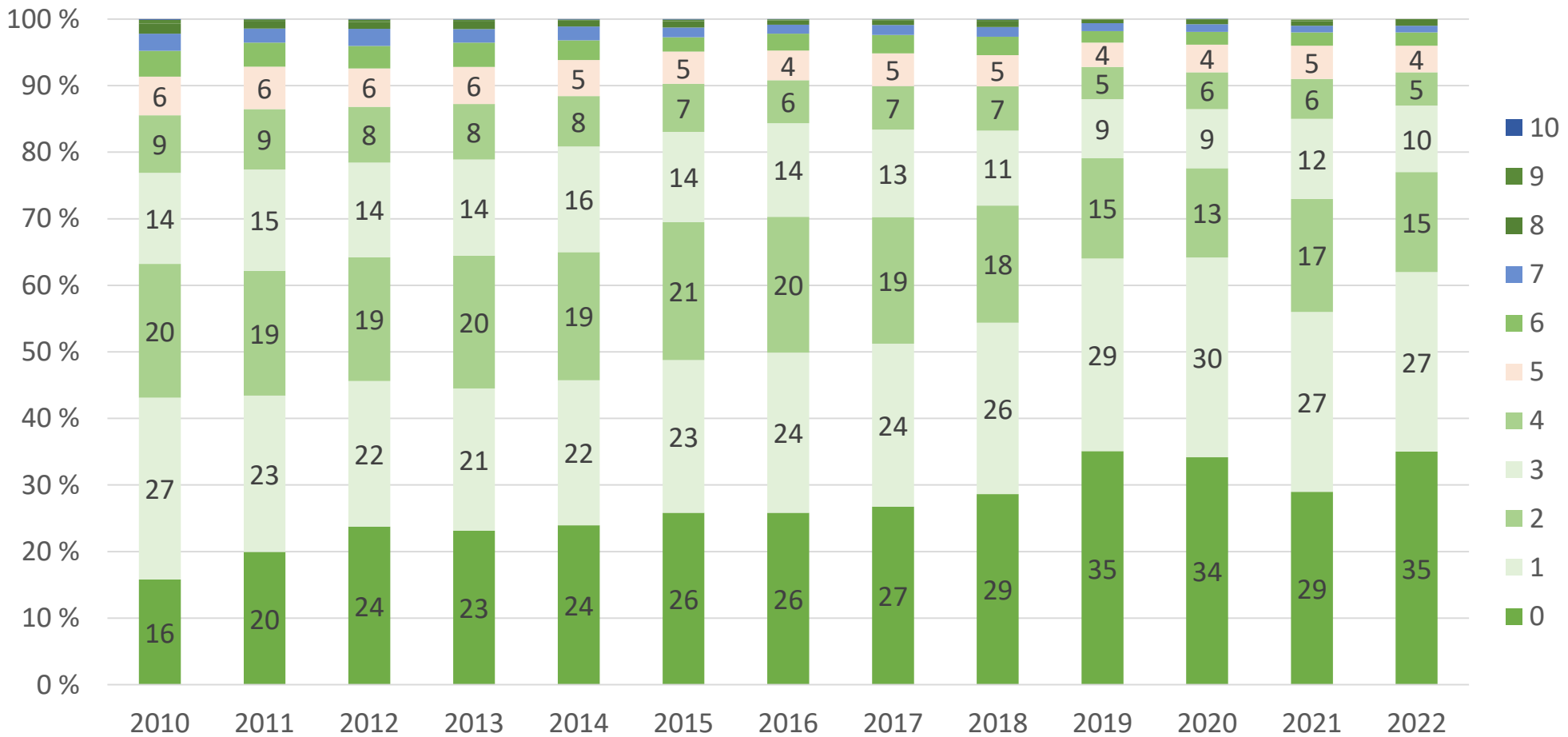
Proportion of patients (%) in DAS28 remission (<2.6)





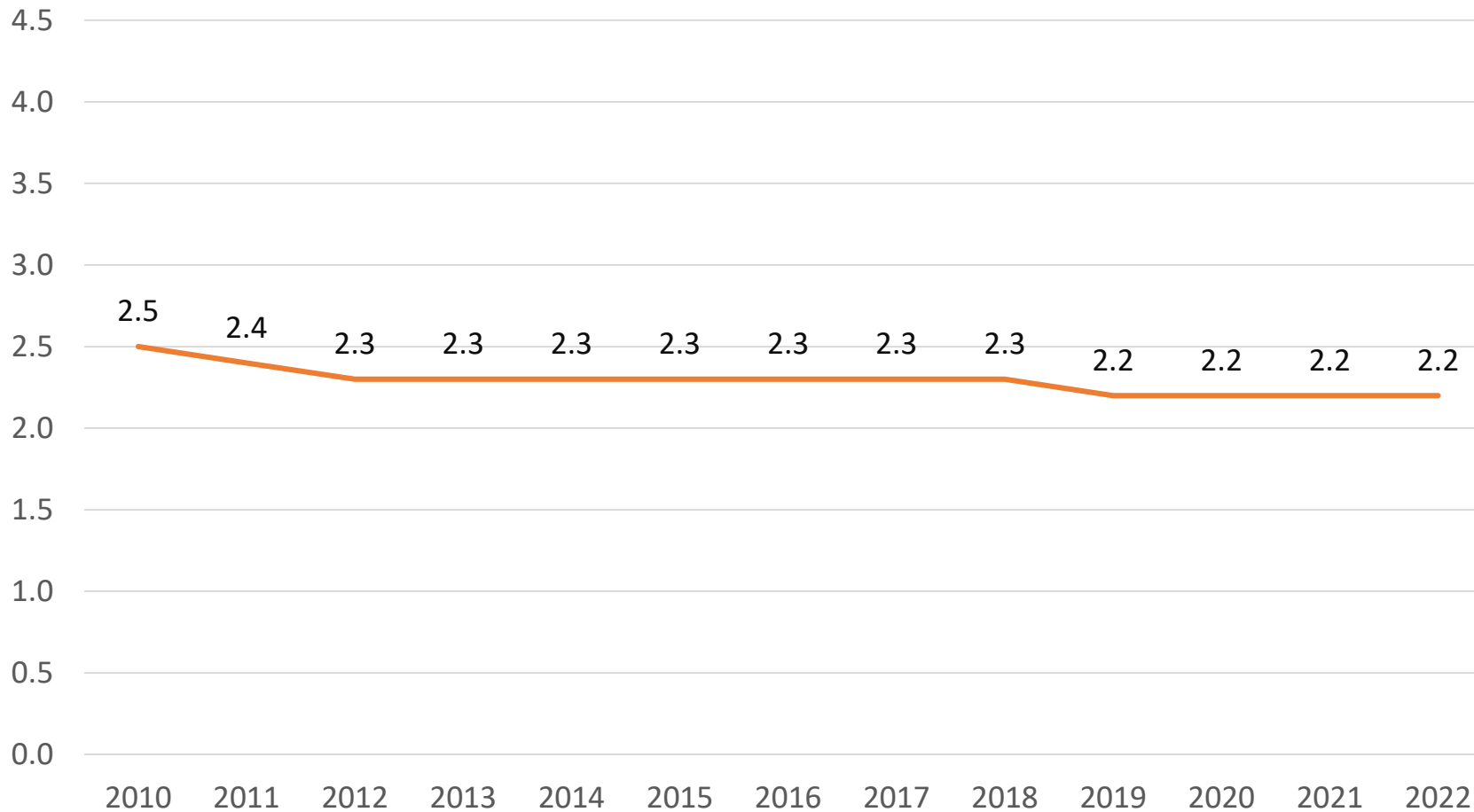


Proportion of patients (%) without (0), with low (1) to high (10) disease activity according to physician's assessment (NRS 0-10)

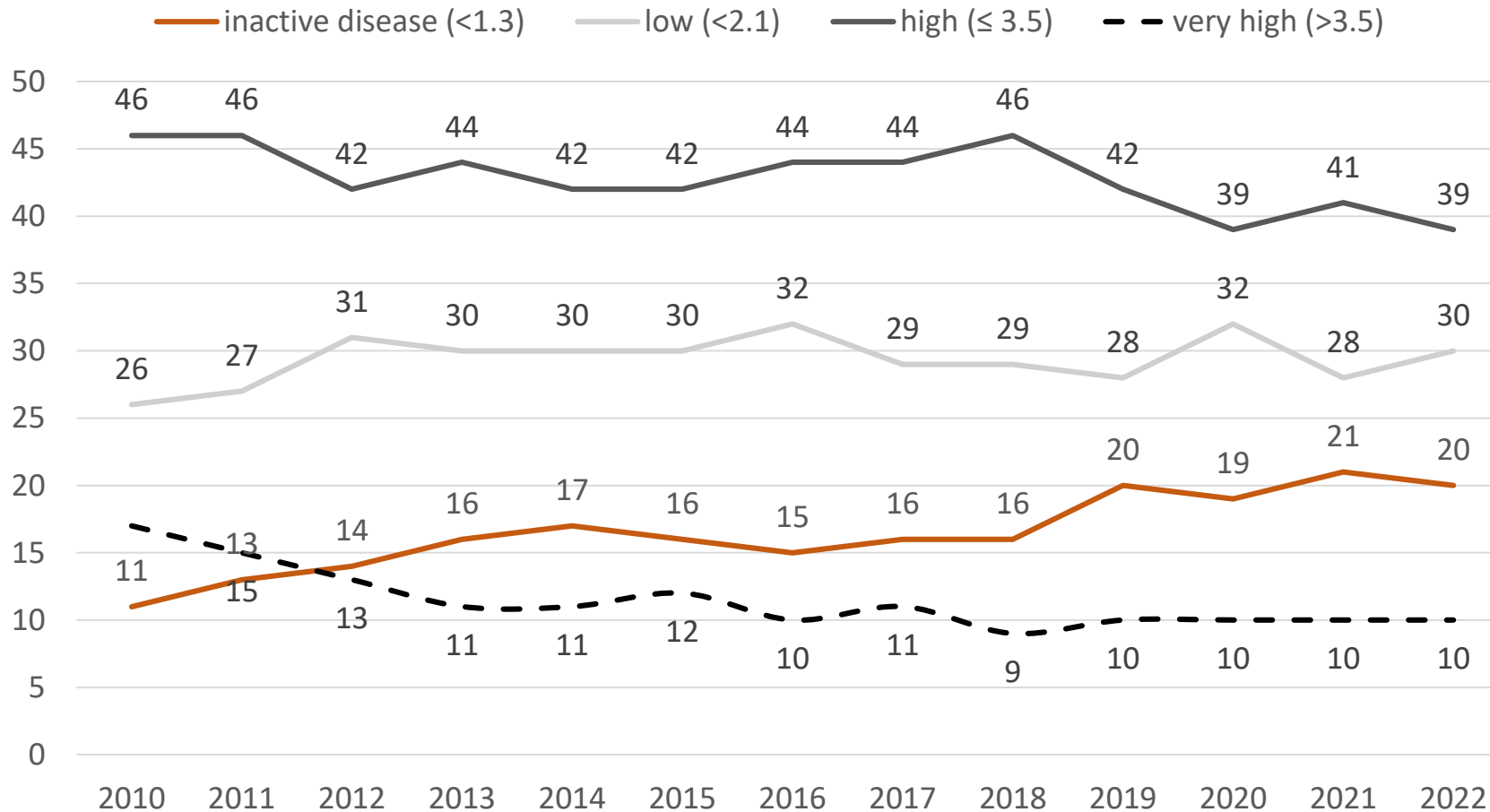




ASDAS-CRP annual mean values from 2010 - 2022

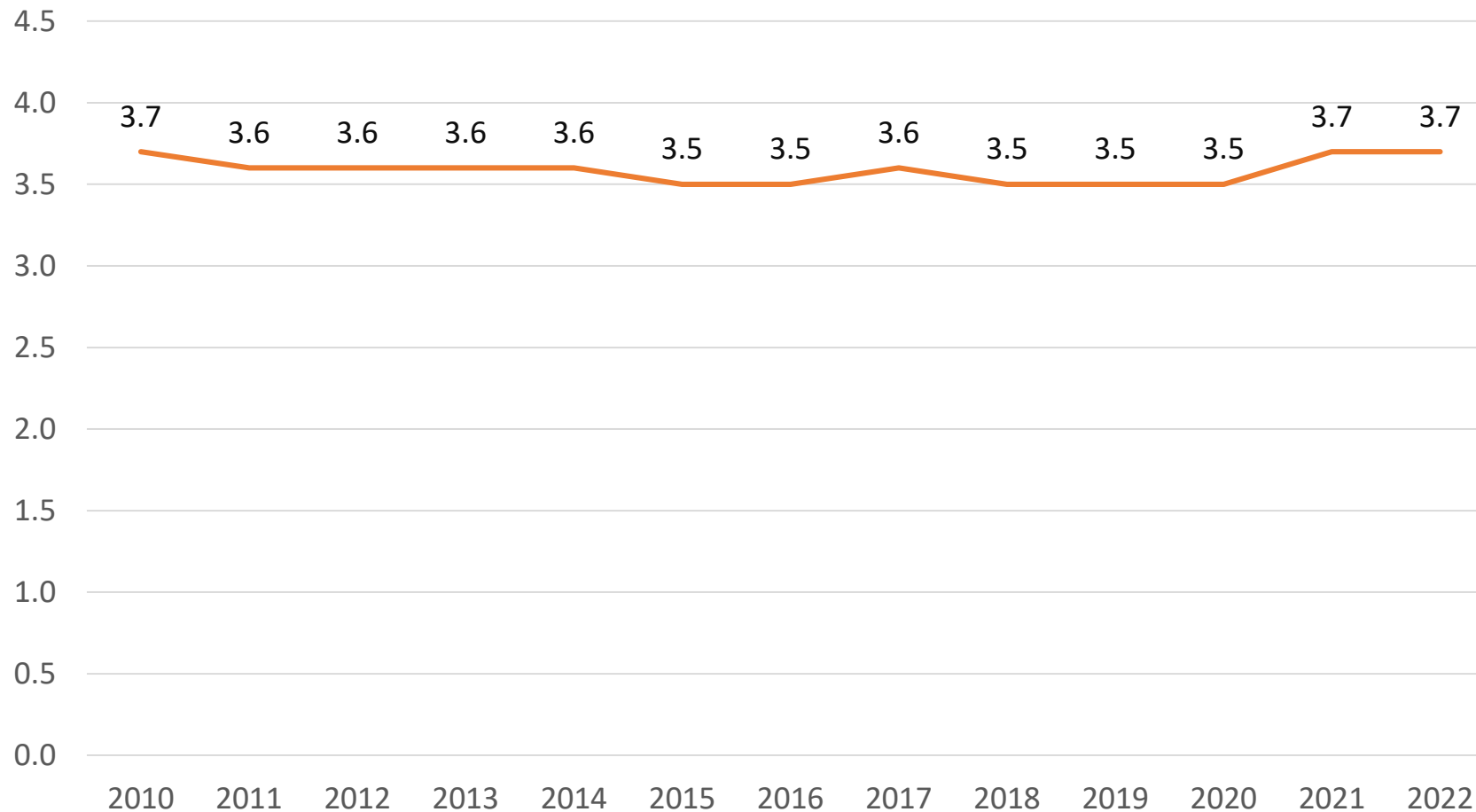


Proportion of patients with inactive disease / low or high disease activity from 2010 - 2022

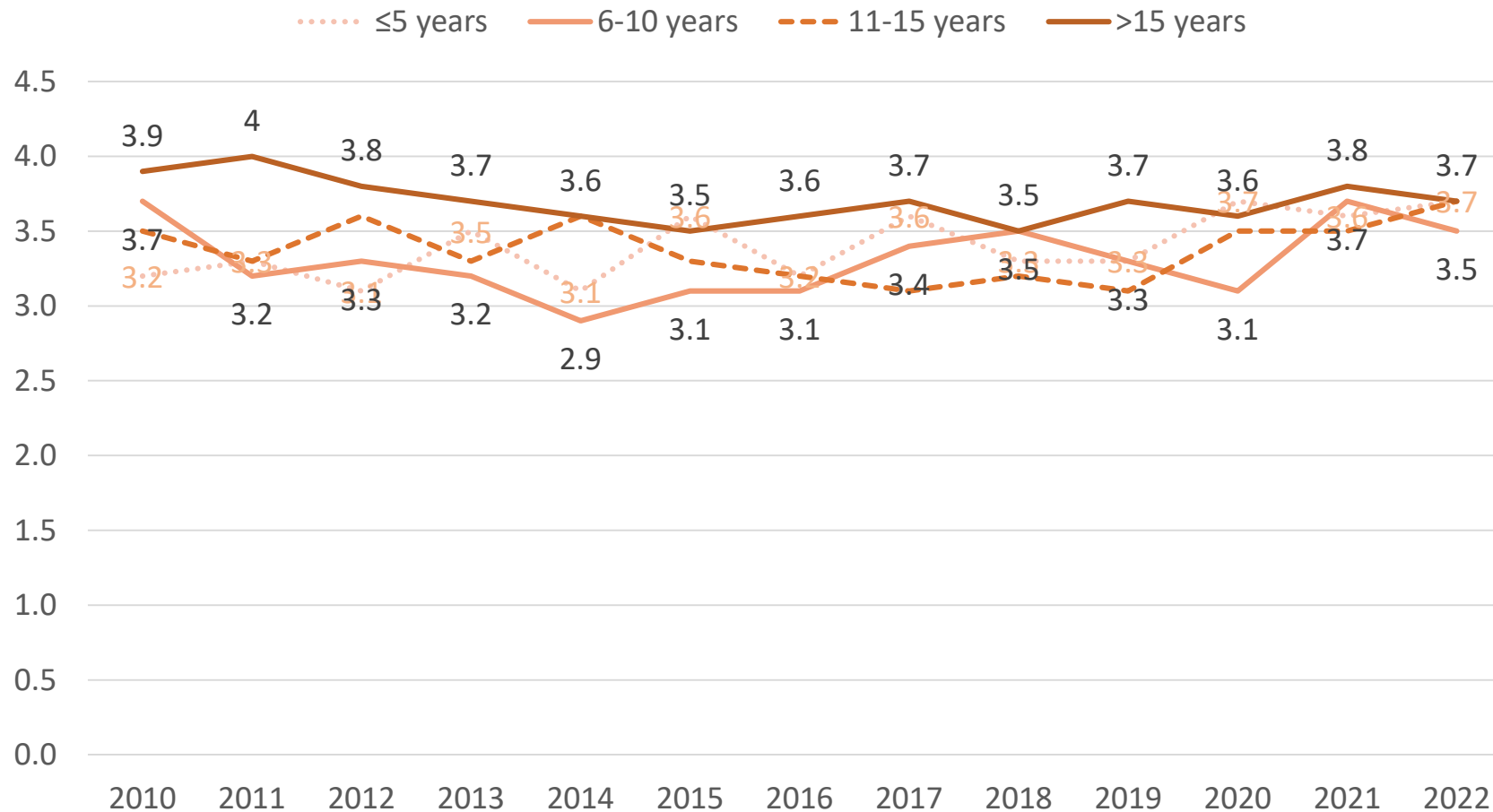




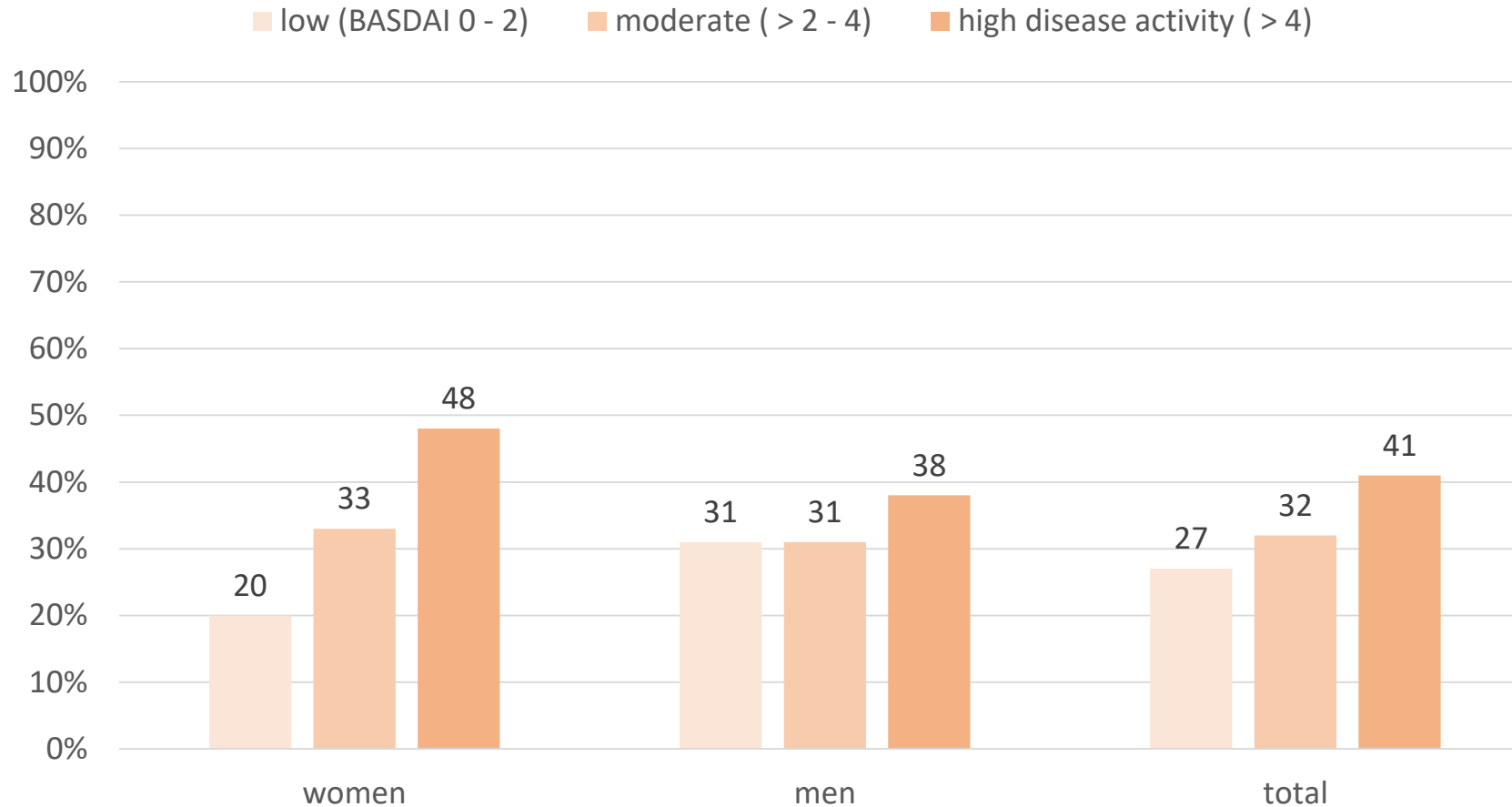
BASDAI annual averages from 2010 - 2022



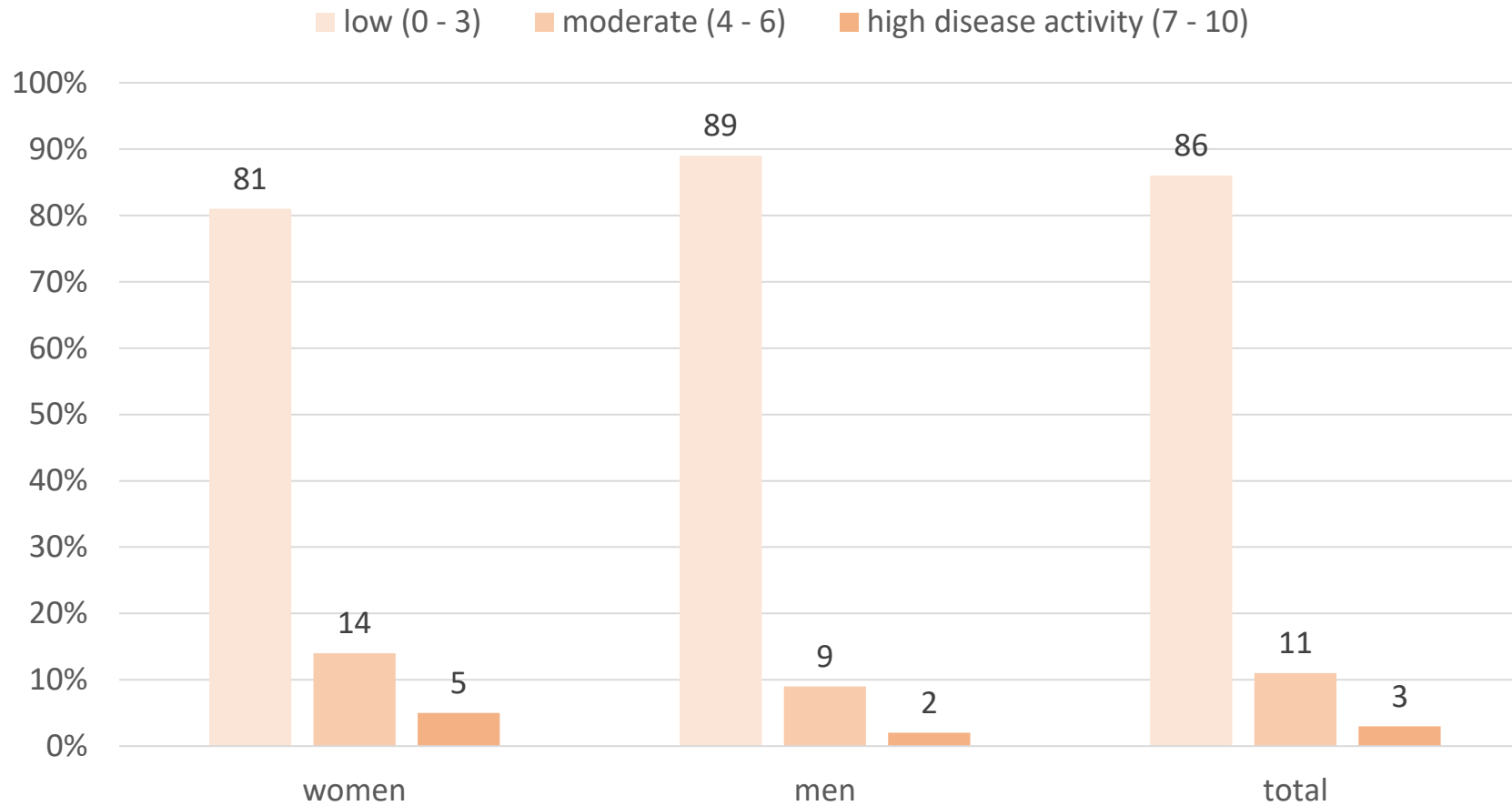
BASDAI annual mean values by disease duration from 2010 - 2022



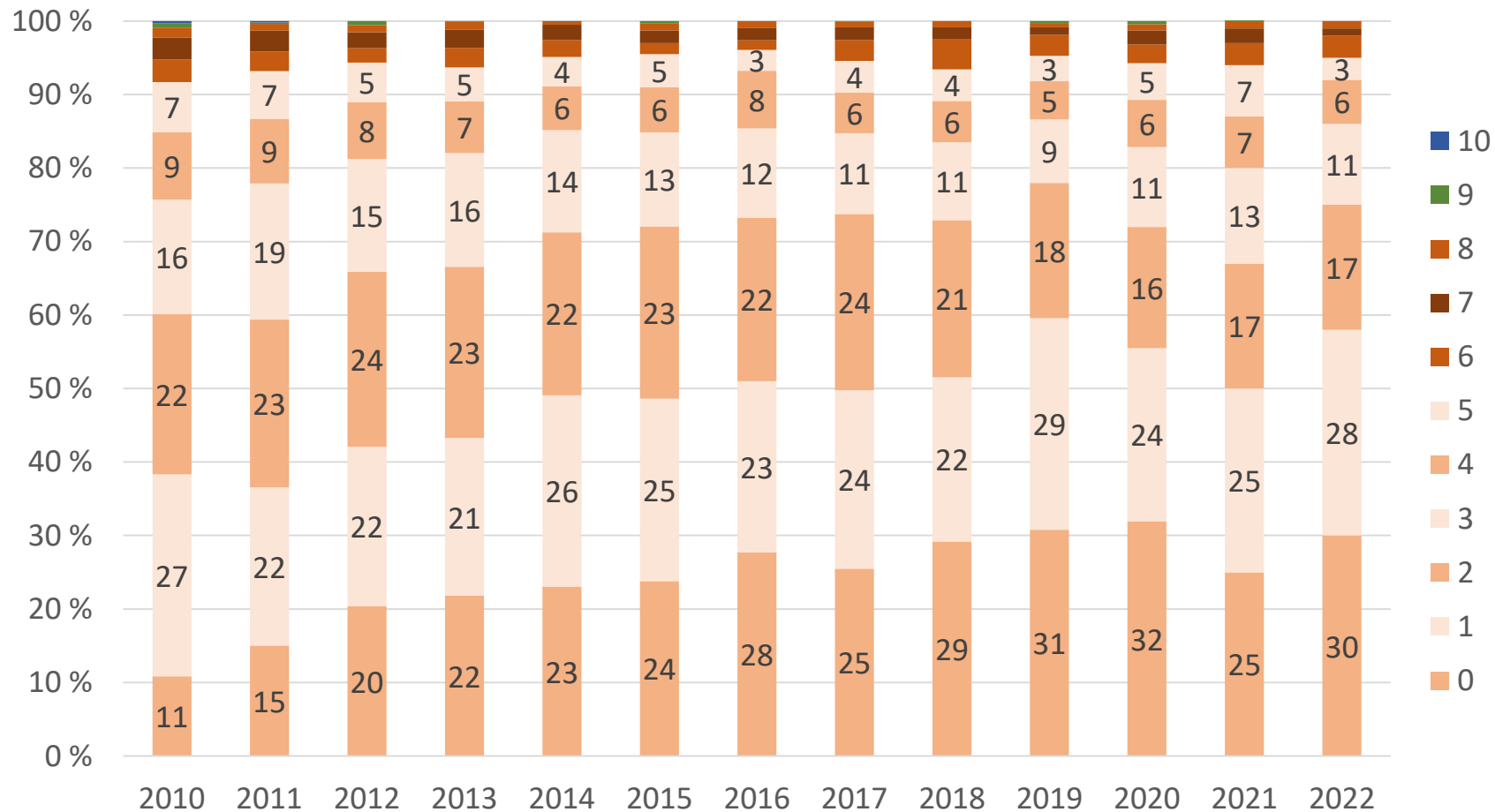
Proportion of patients (%) with low, medium or high disease activity according to the BASDAI



Proportion of patients (%) with low (0-3) to high (7-10) disease activity according to physician's assessment (NRS 0-10)



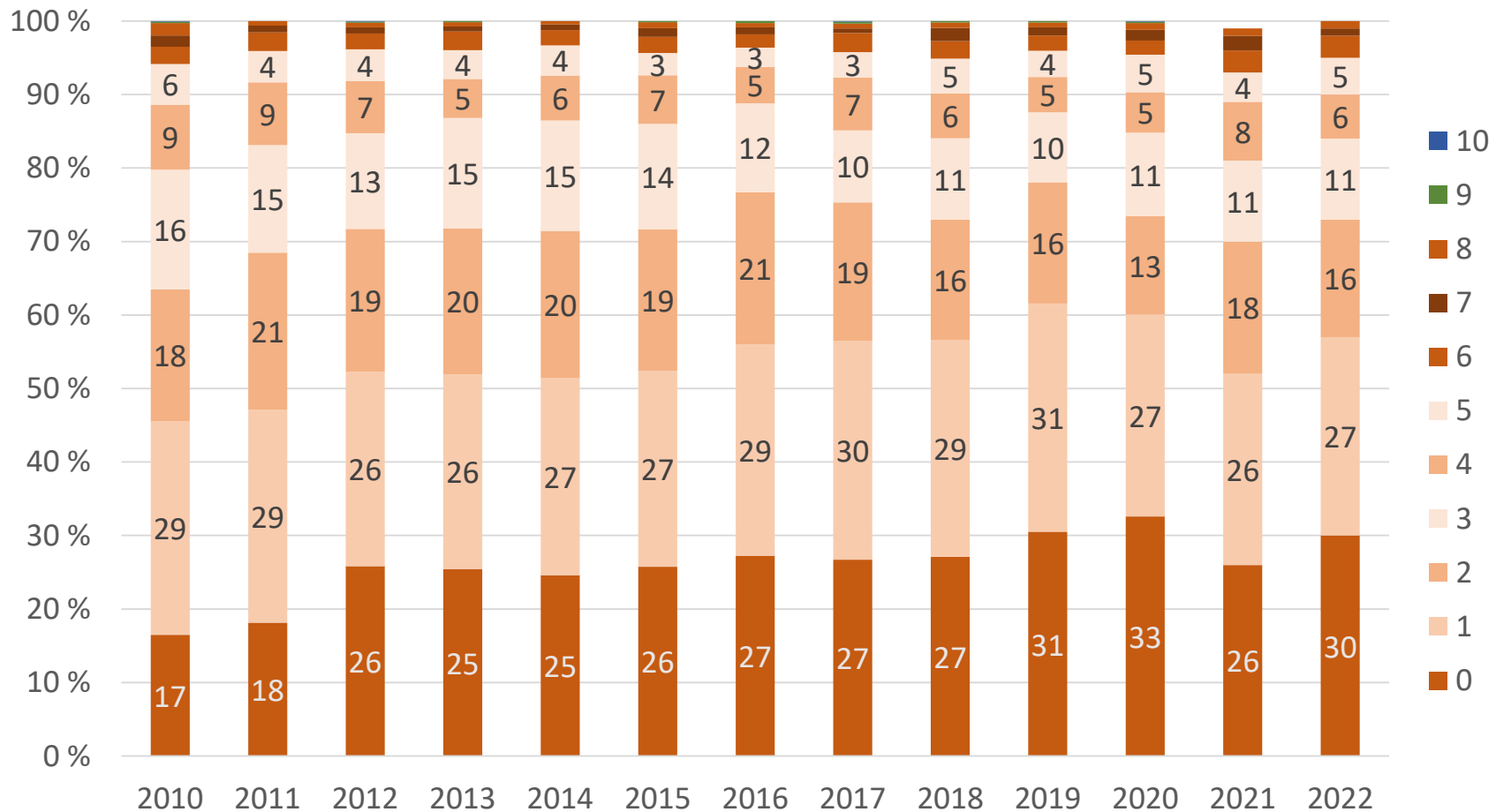
Proportion of patients (%) without (0), with low (1) to high (10) disease activity according to physician's assessment (NRS 0-10)





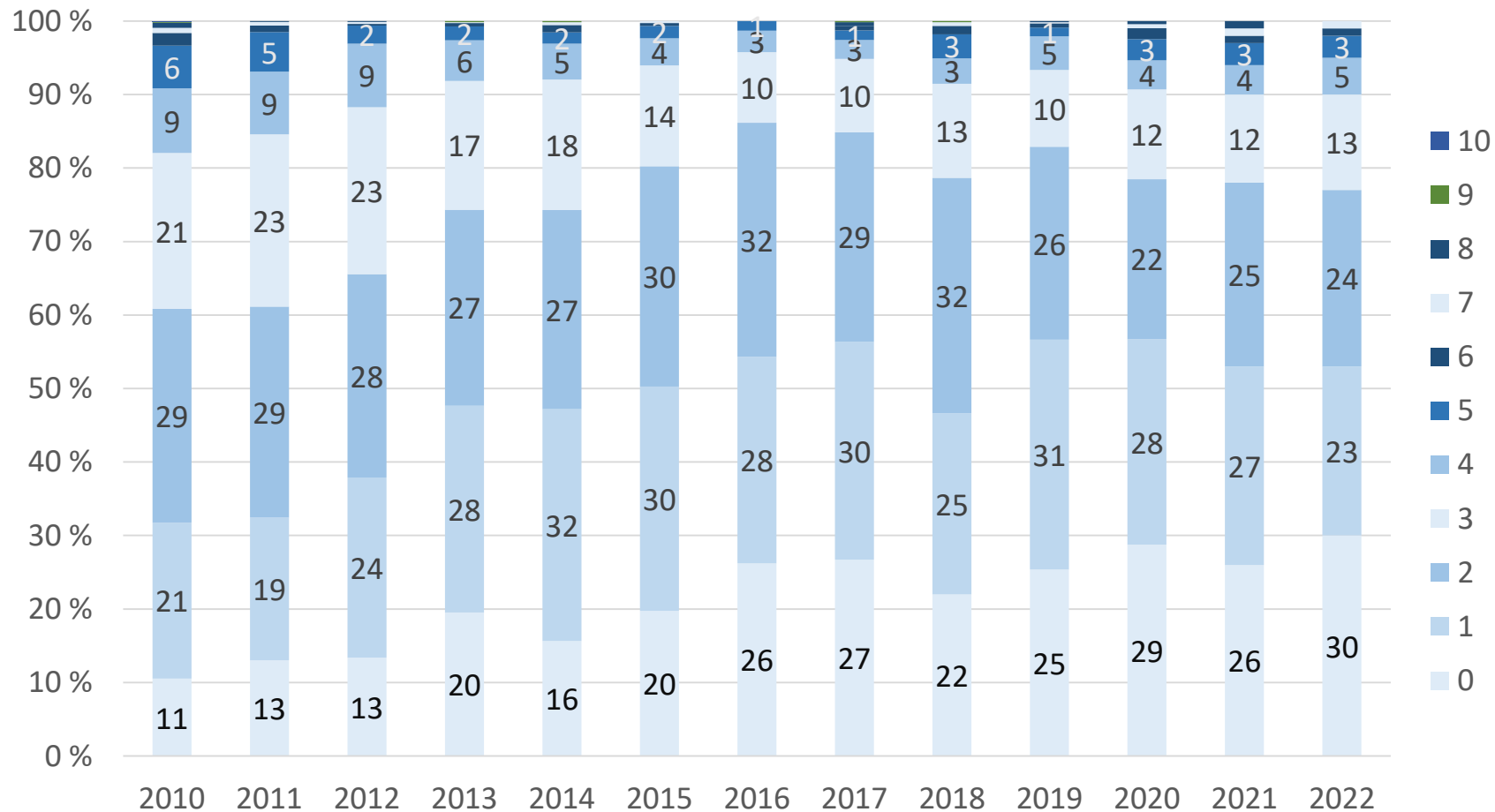


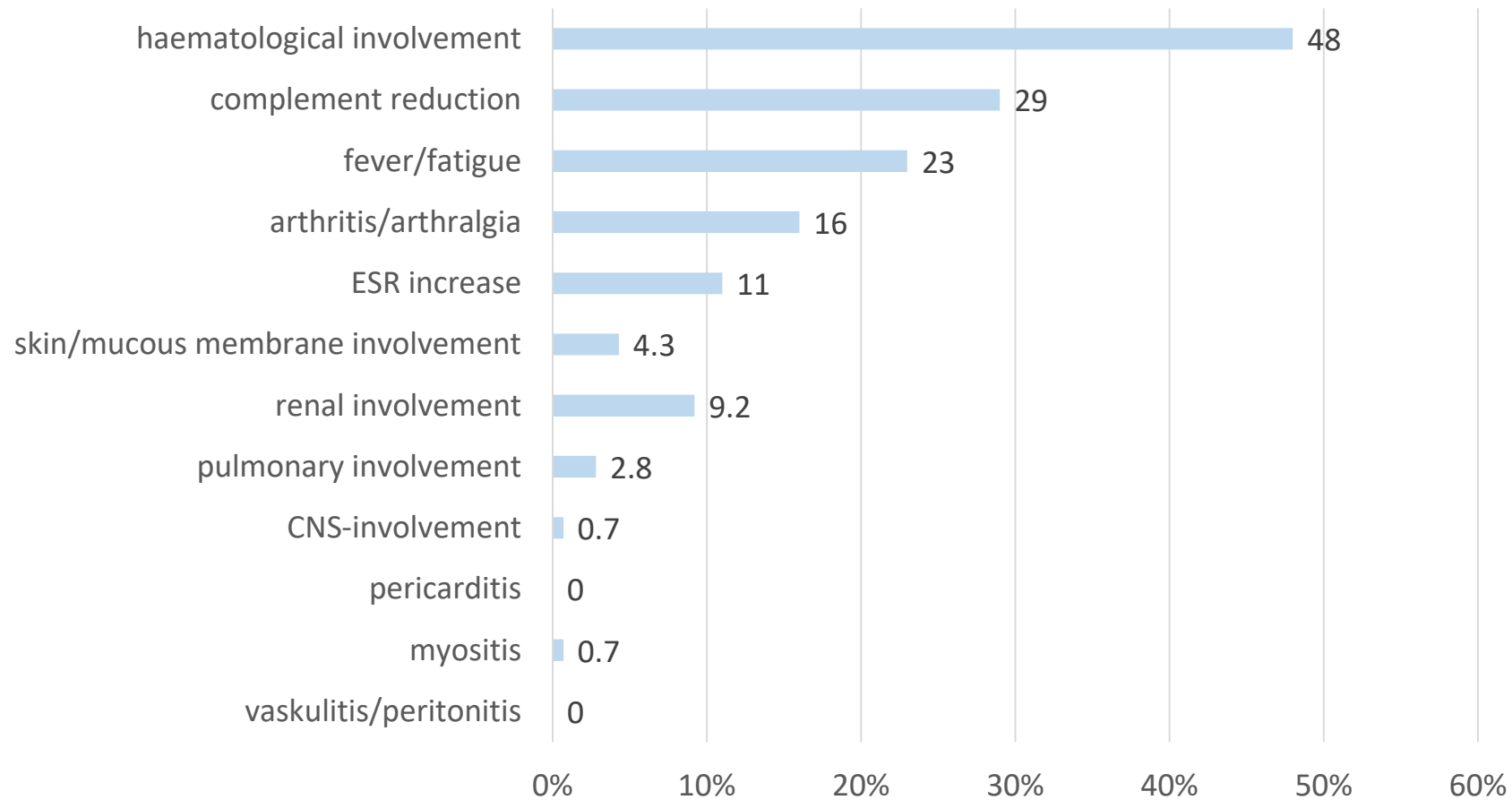
Proportion of patients (%) without (0), with low (1) to high (10) disease activity according to physician's assessment (NRS 0-10)

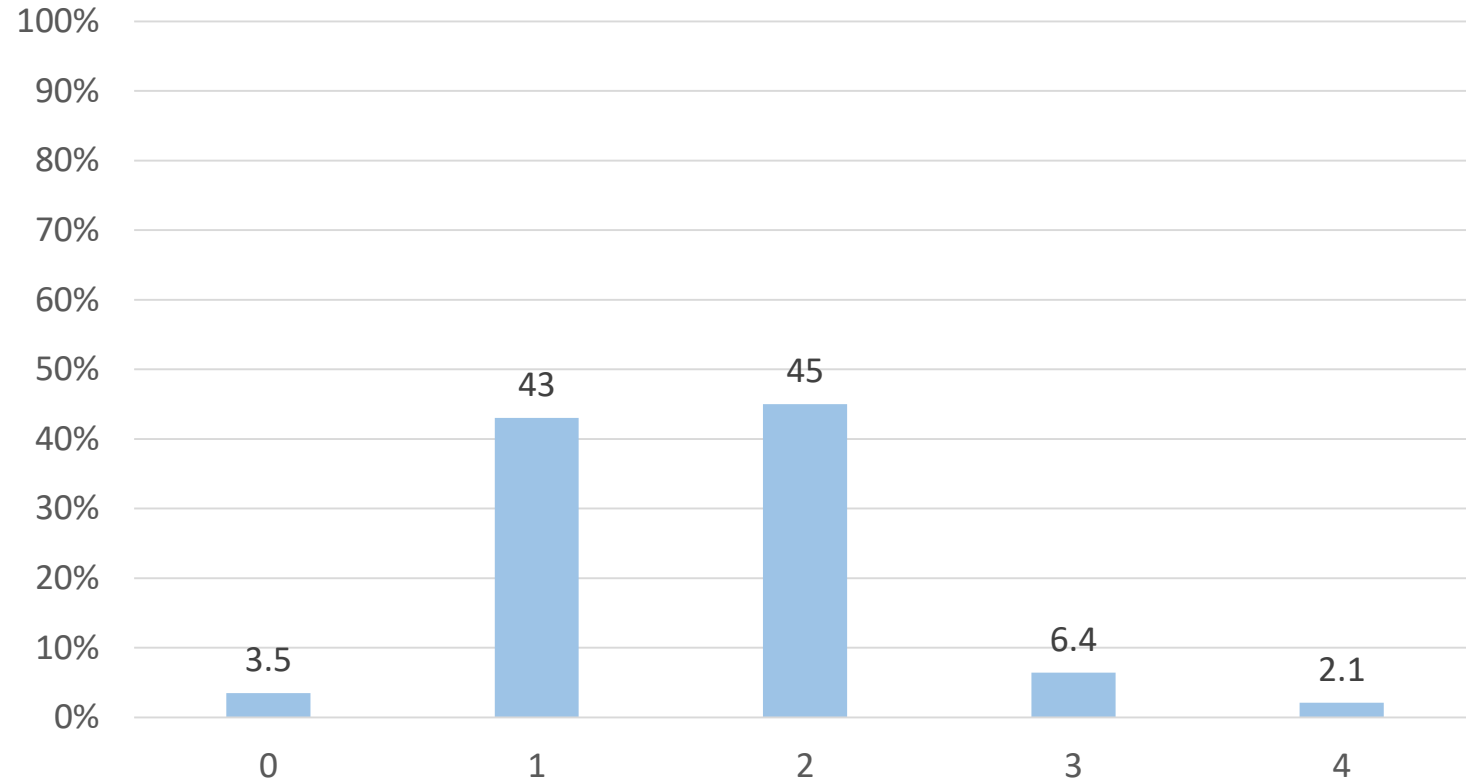




Proportion of patients (%) without (0), with low (1) to high (10) disease activity according to physician's assessment (NRS 0-10)



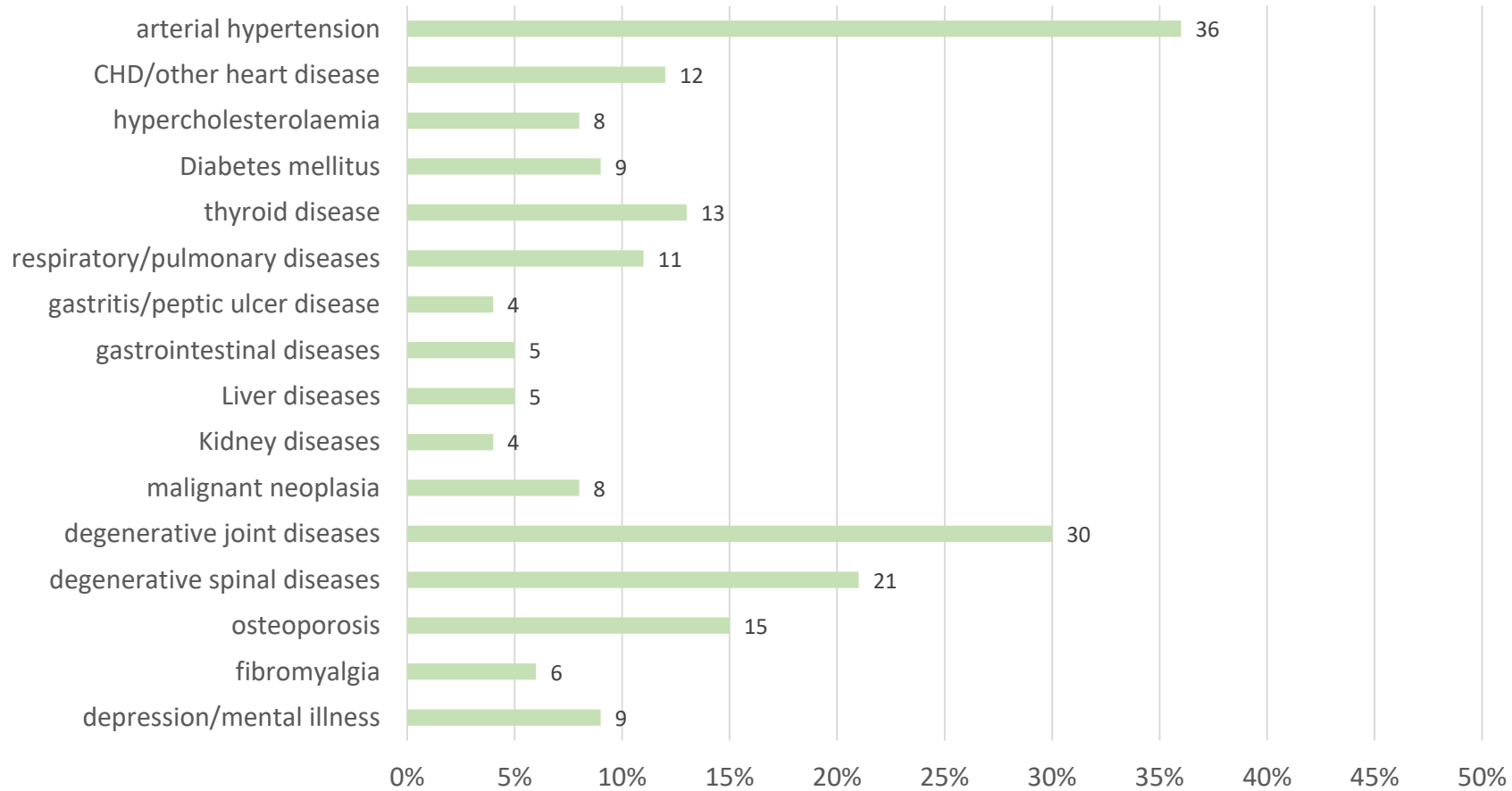


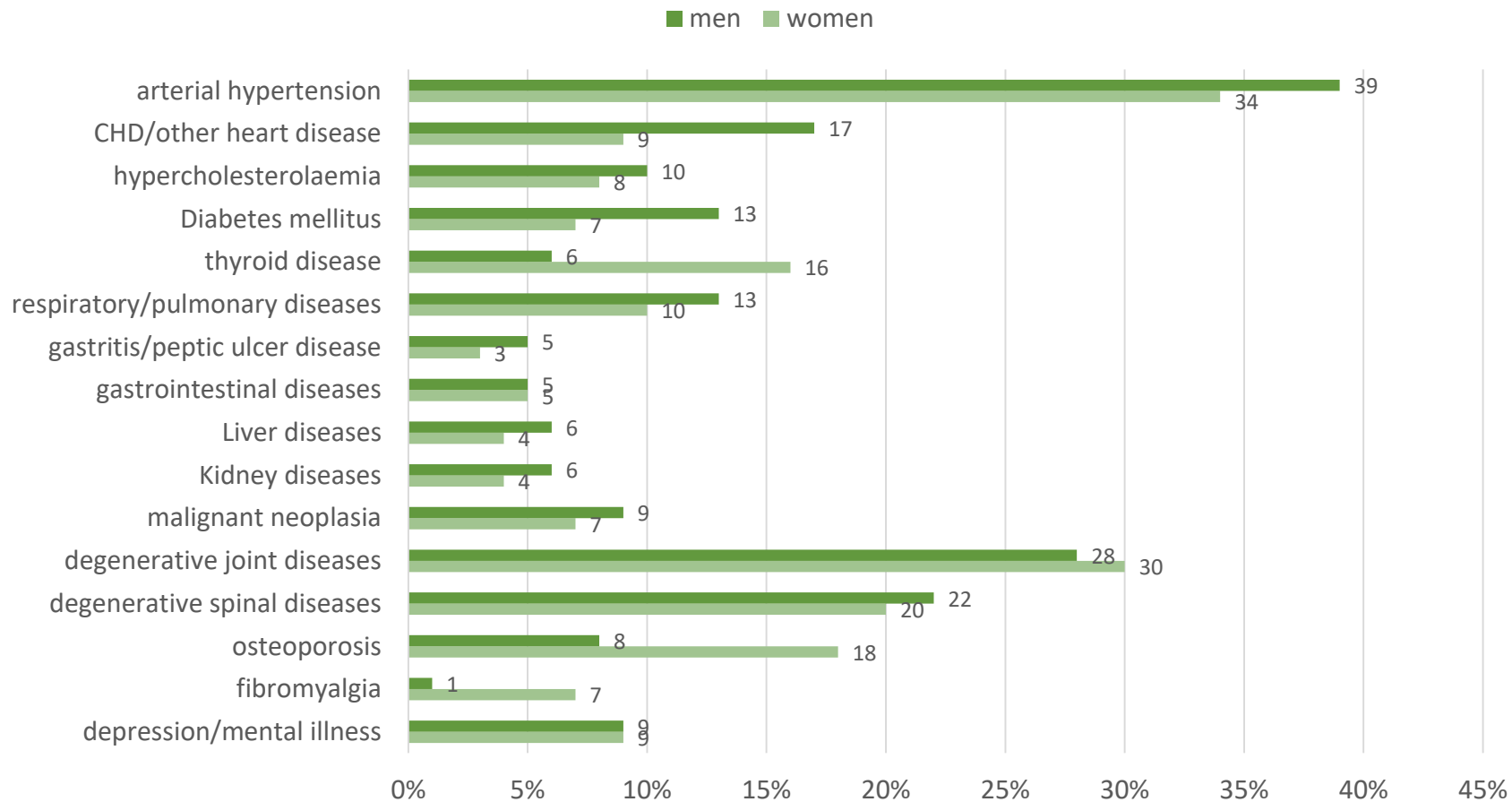


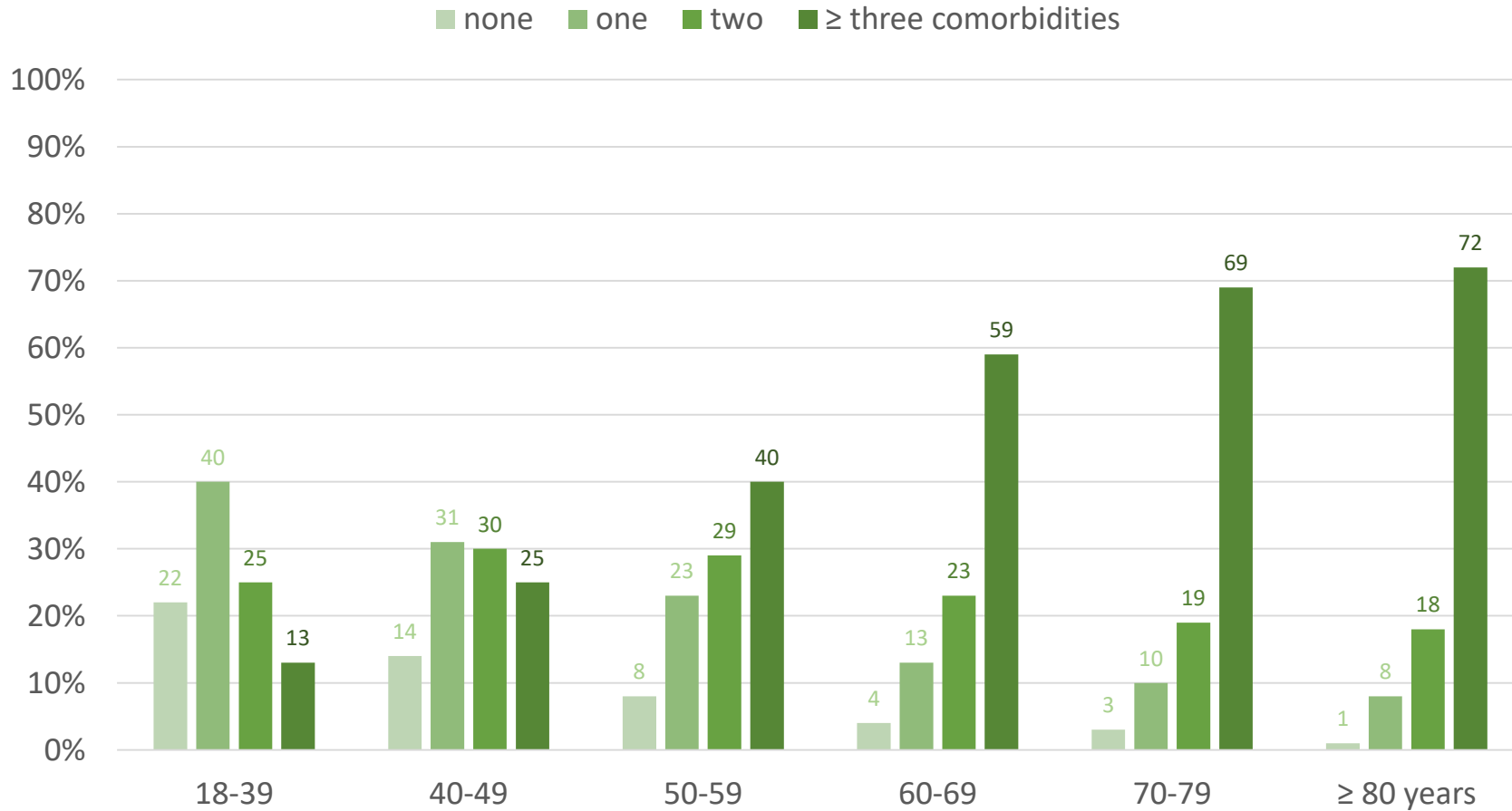
ECLAM Score 0-10:  
0 = inactive, 10 highest disease activity



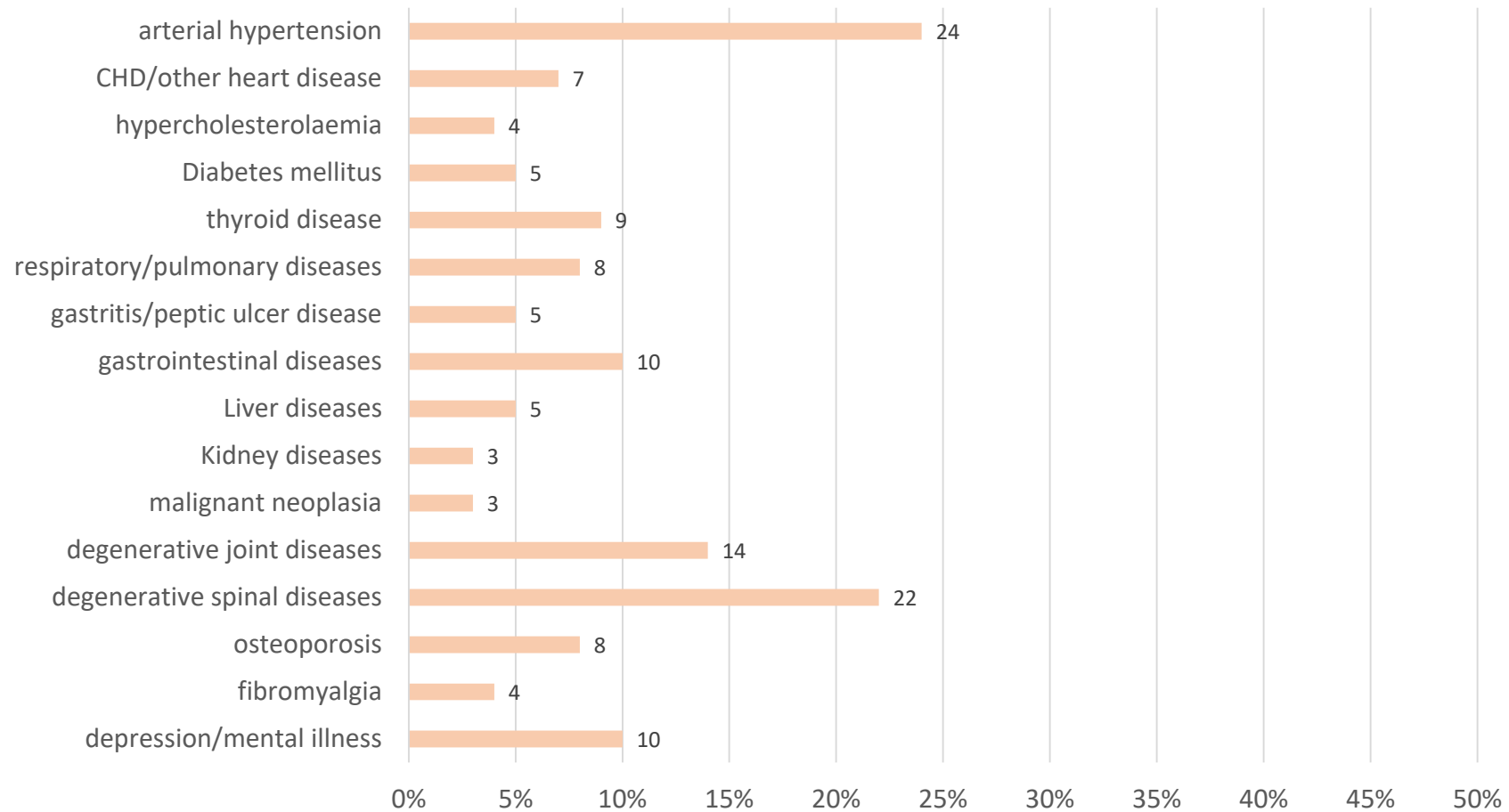
# Comorbidities

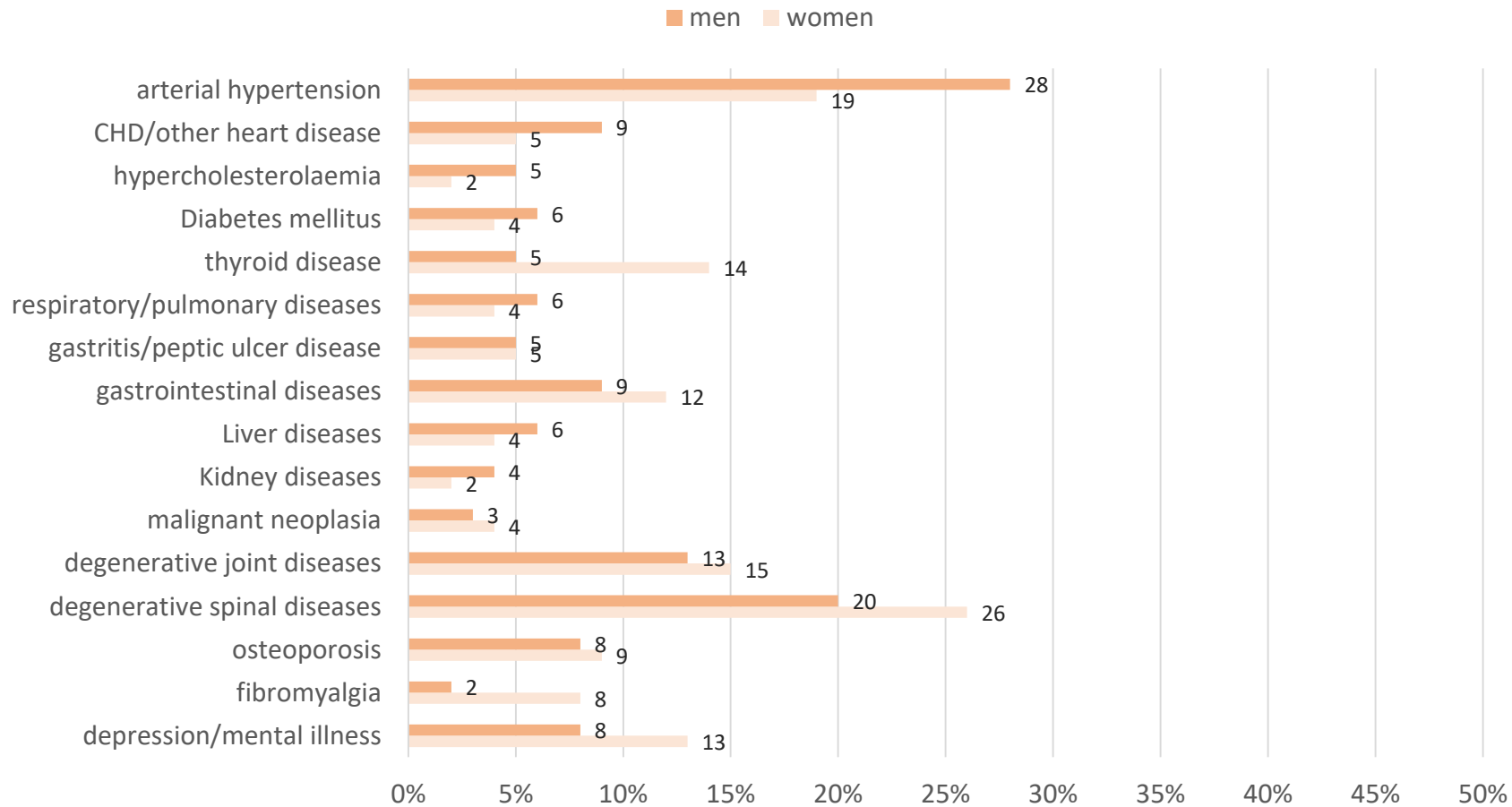


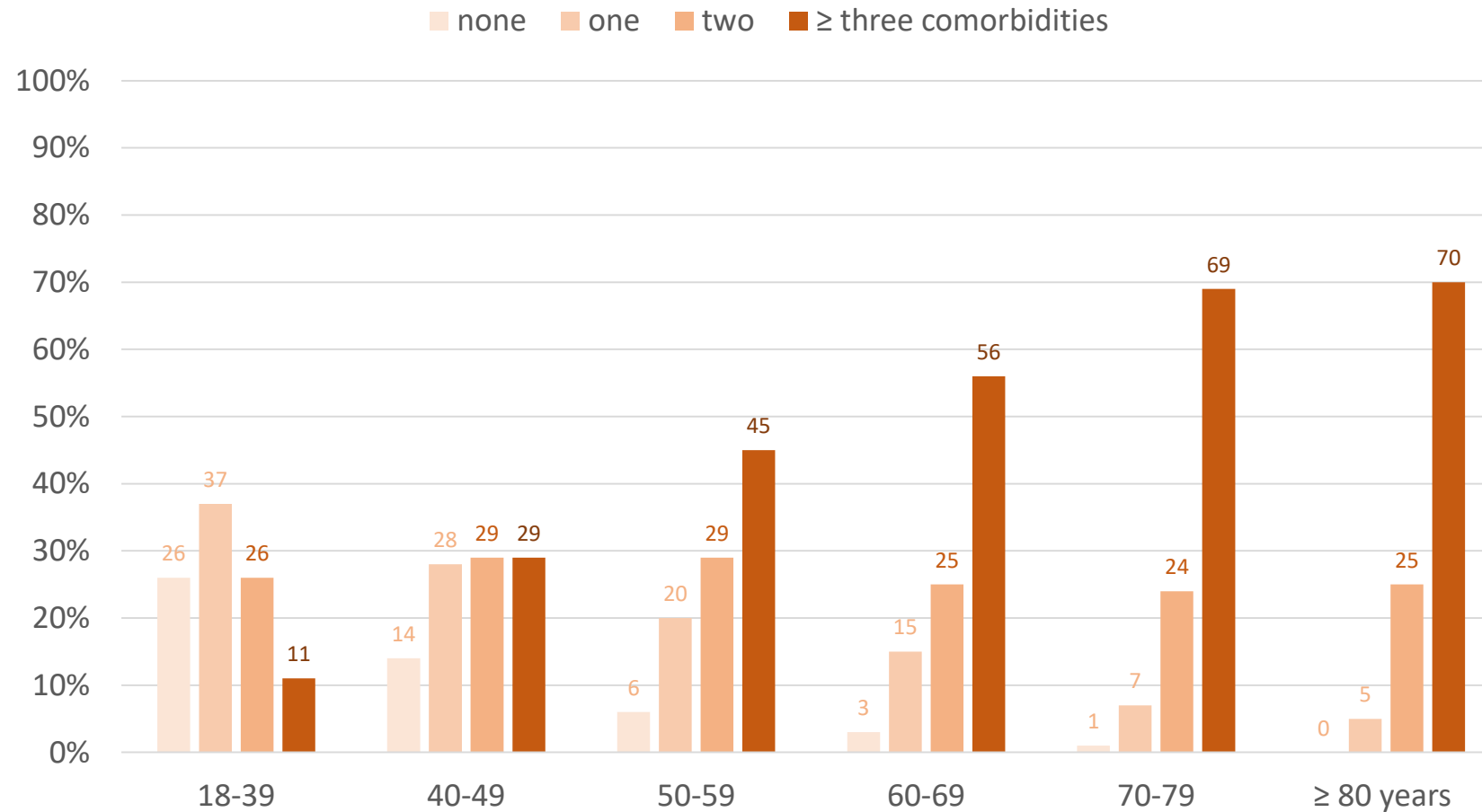


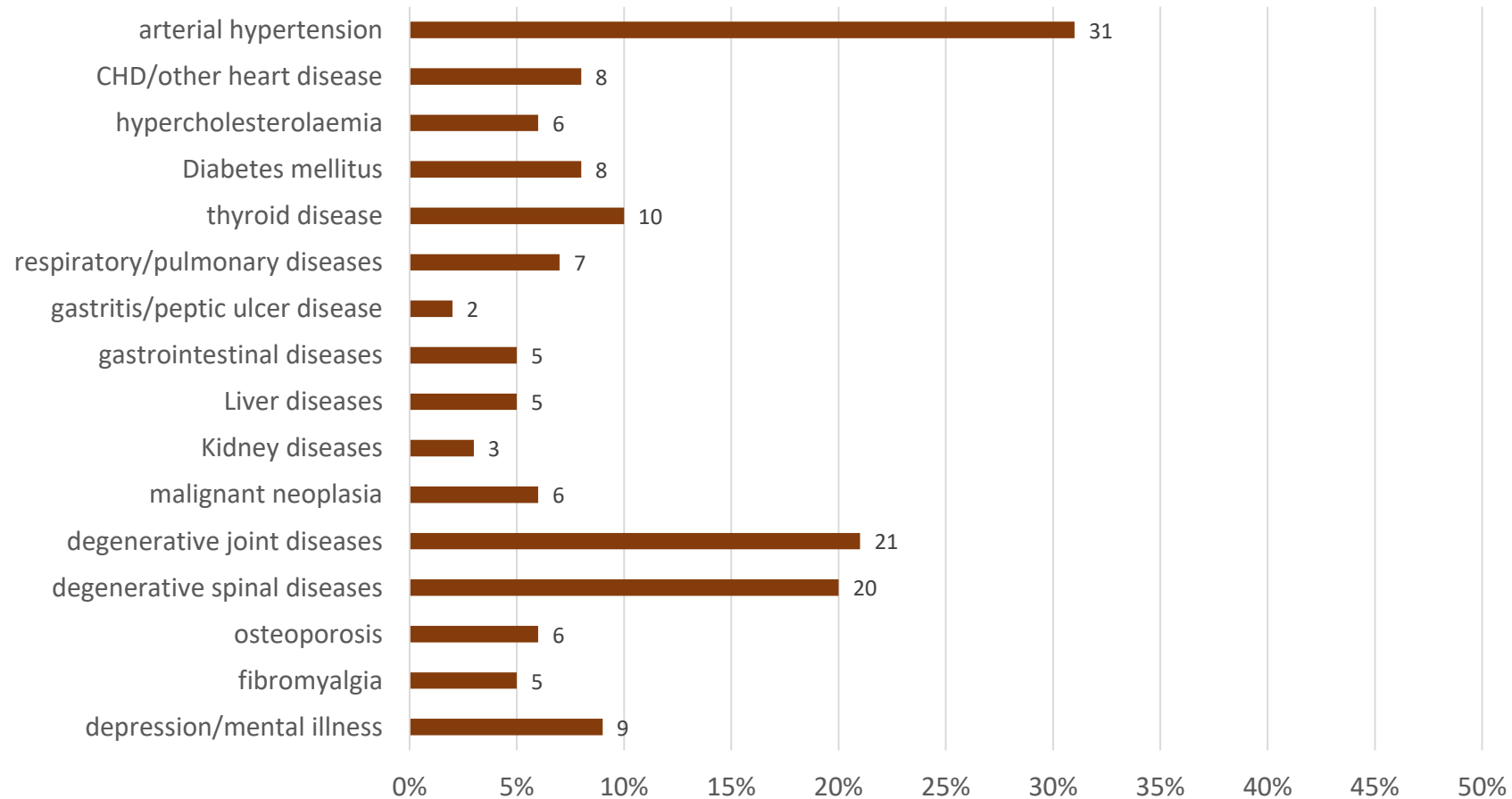


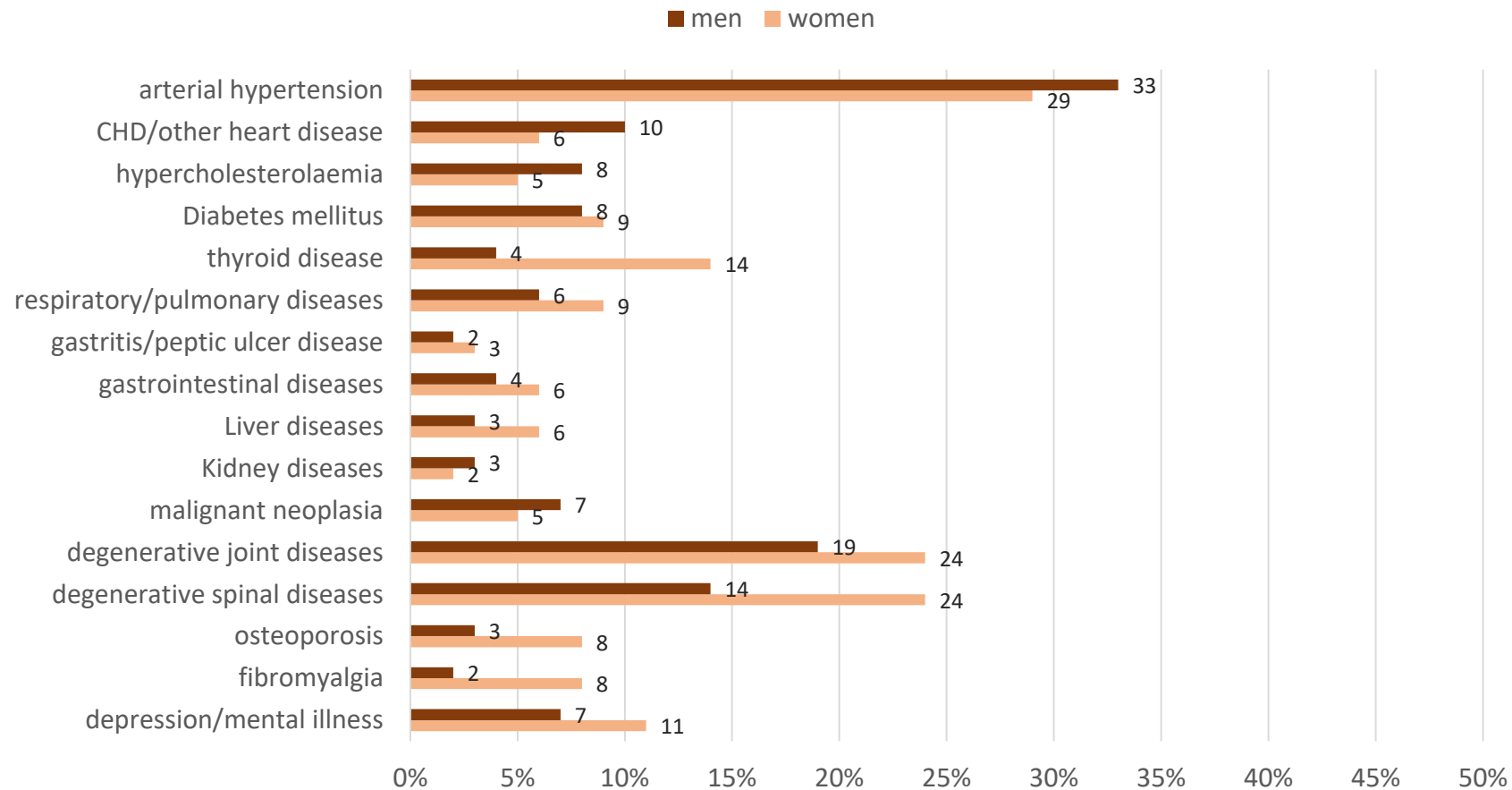


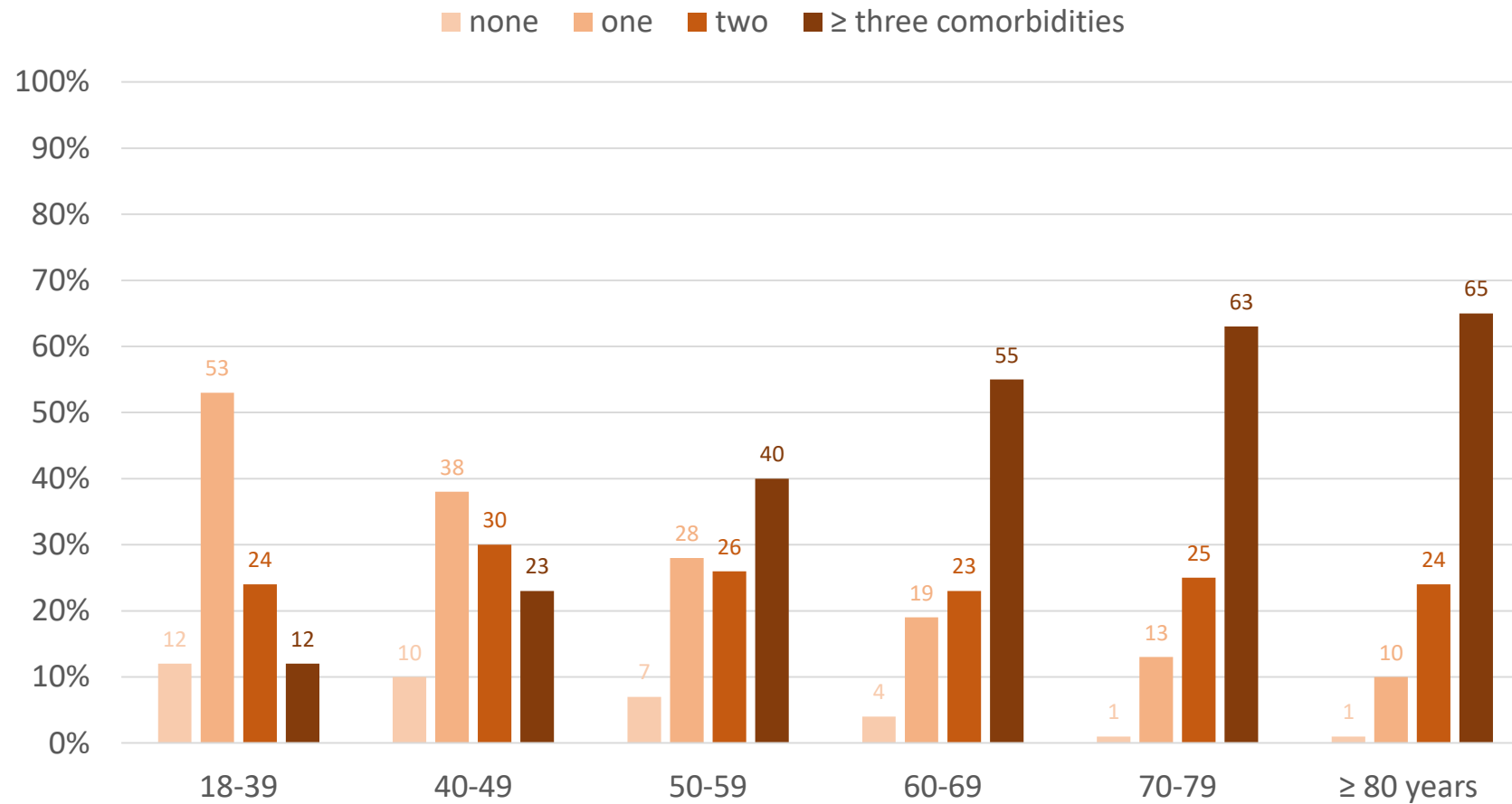


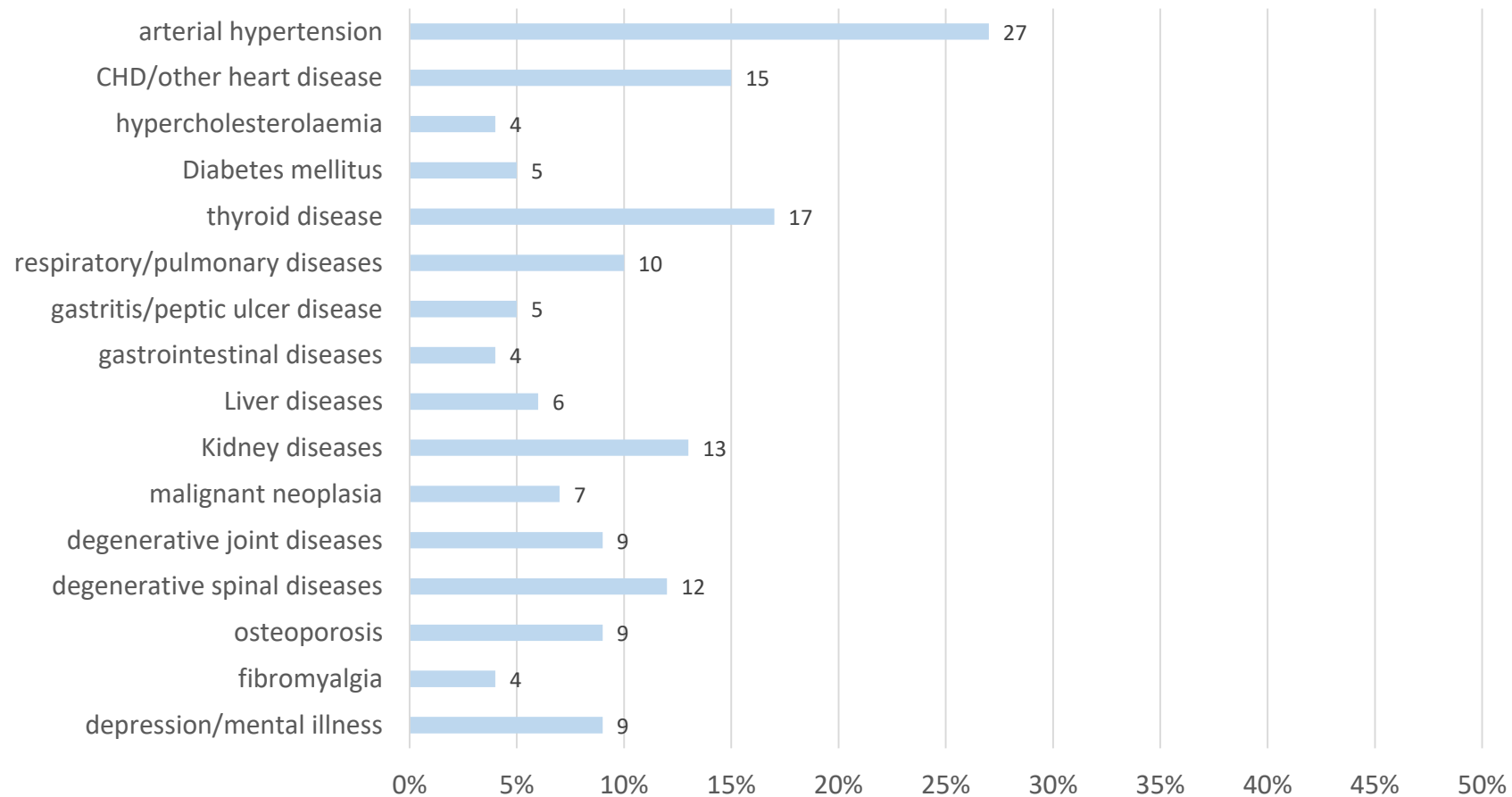


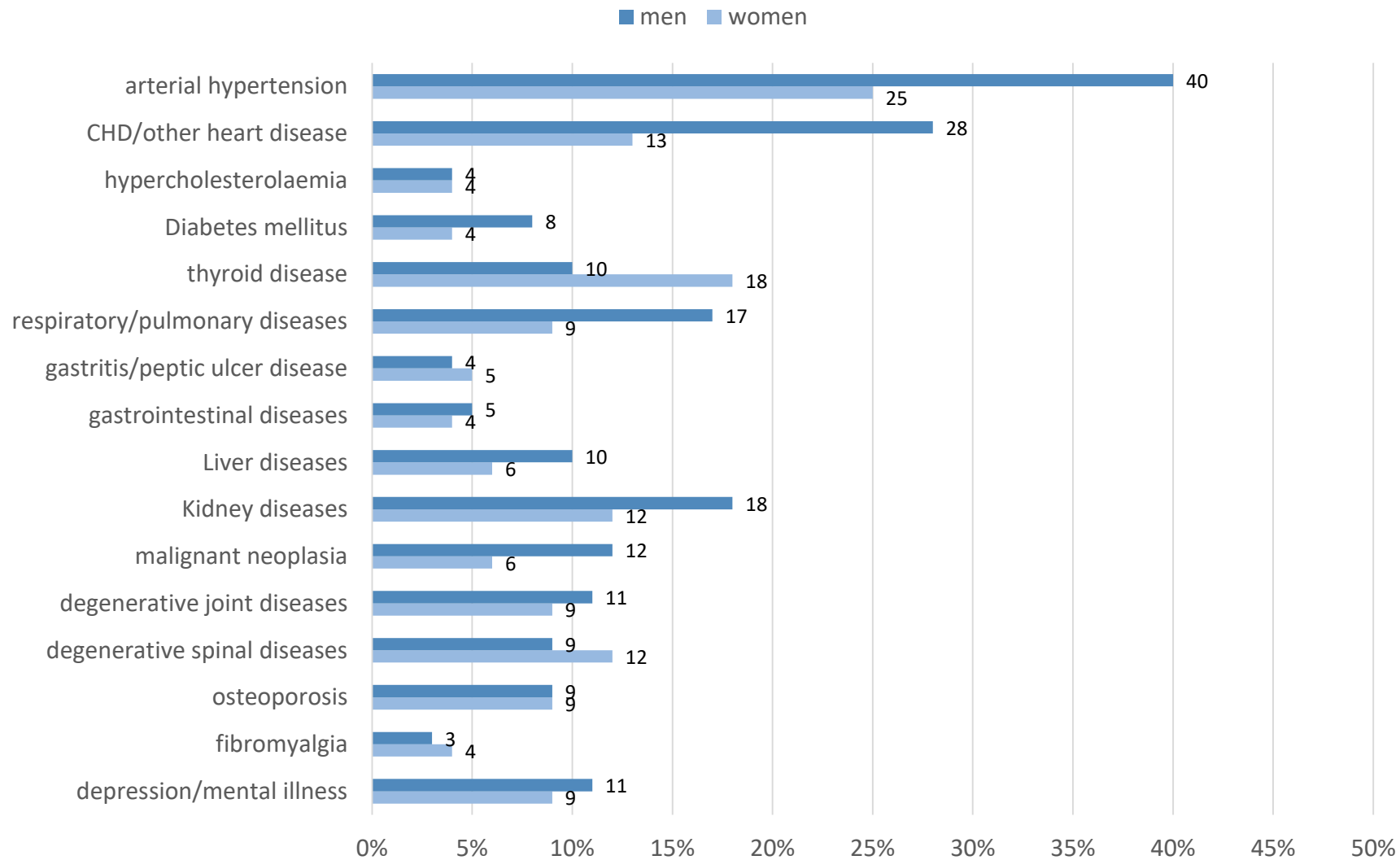




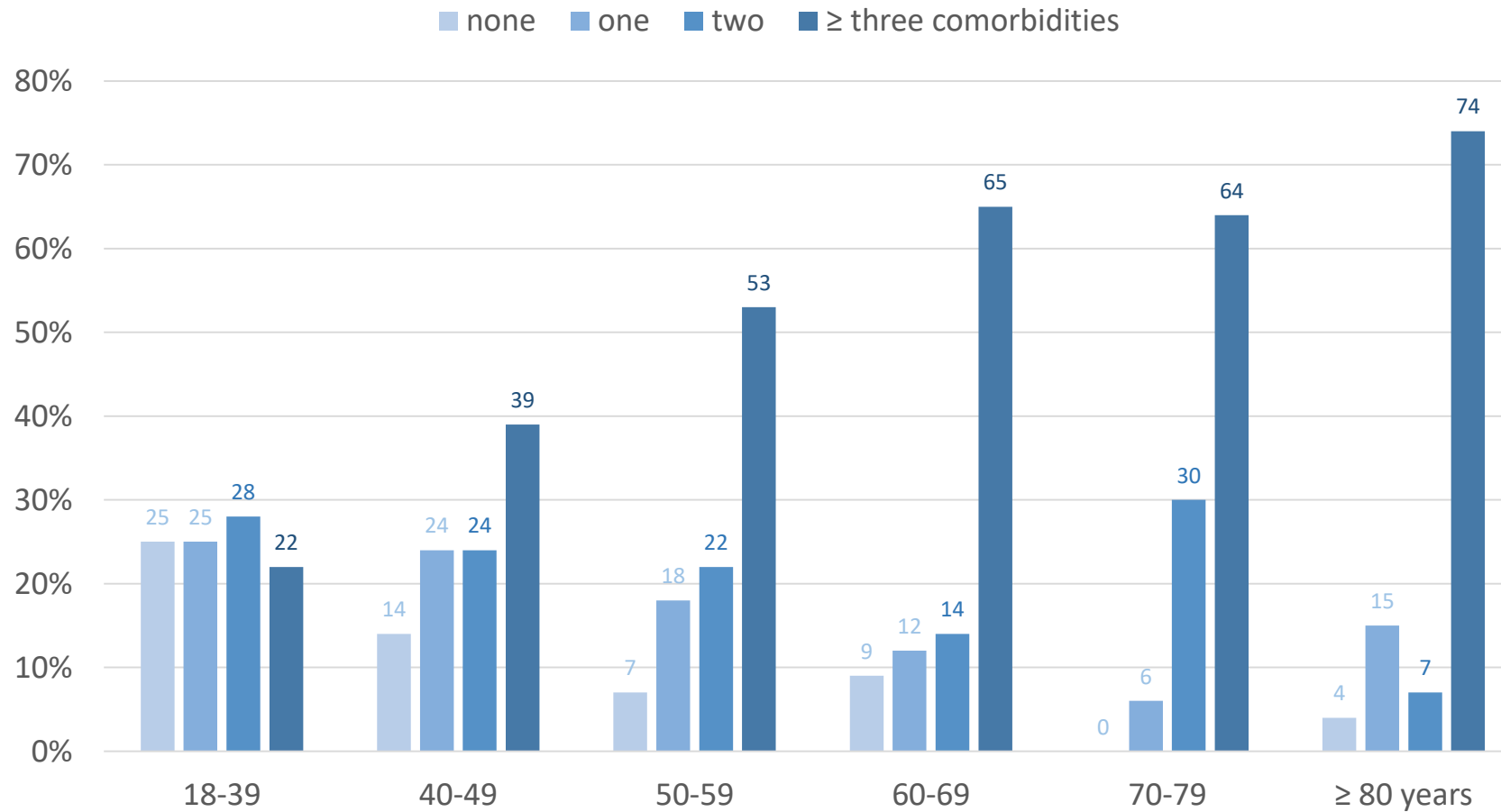


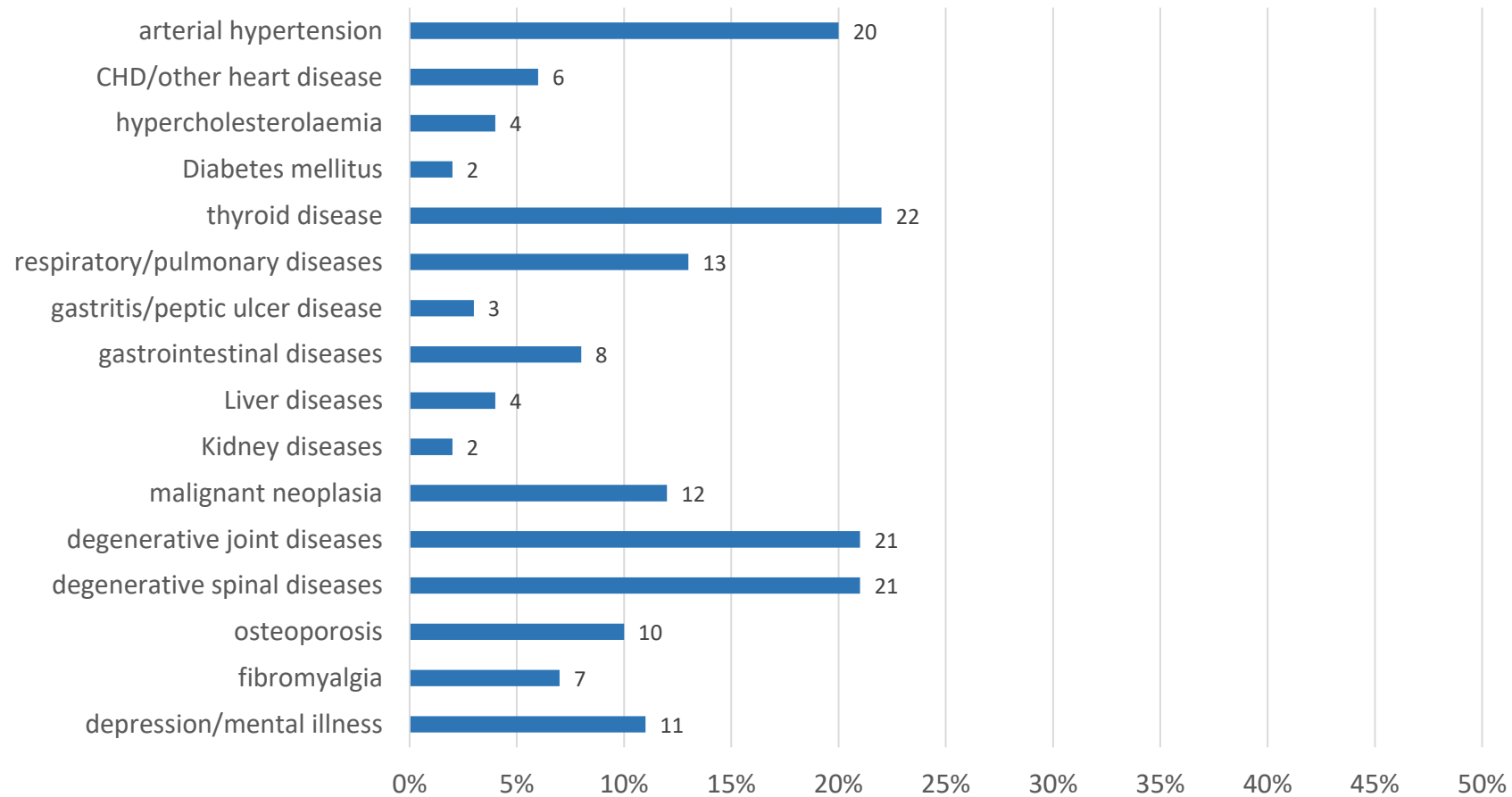


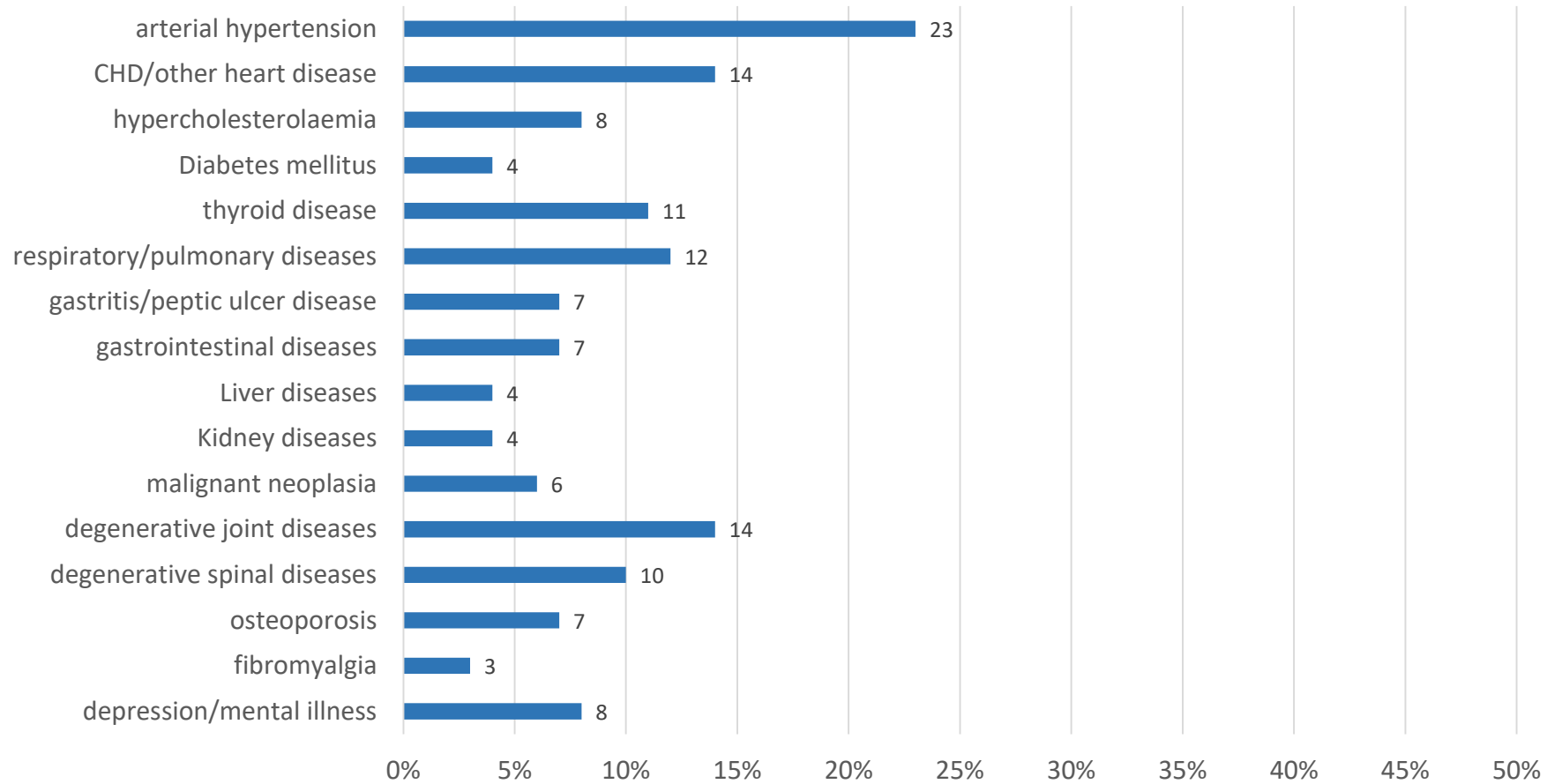


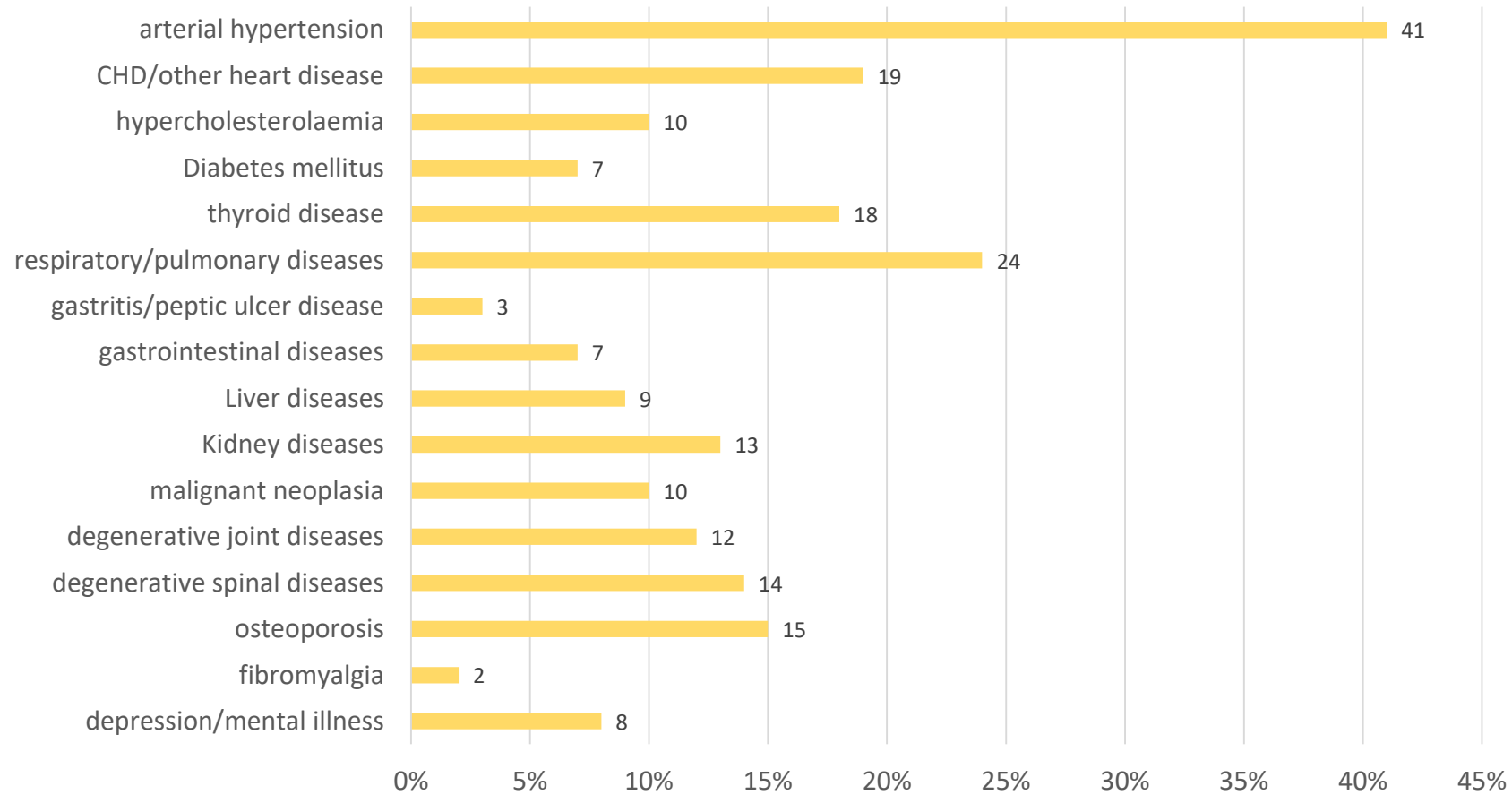


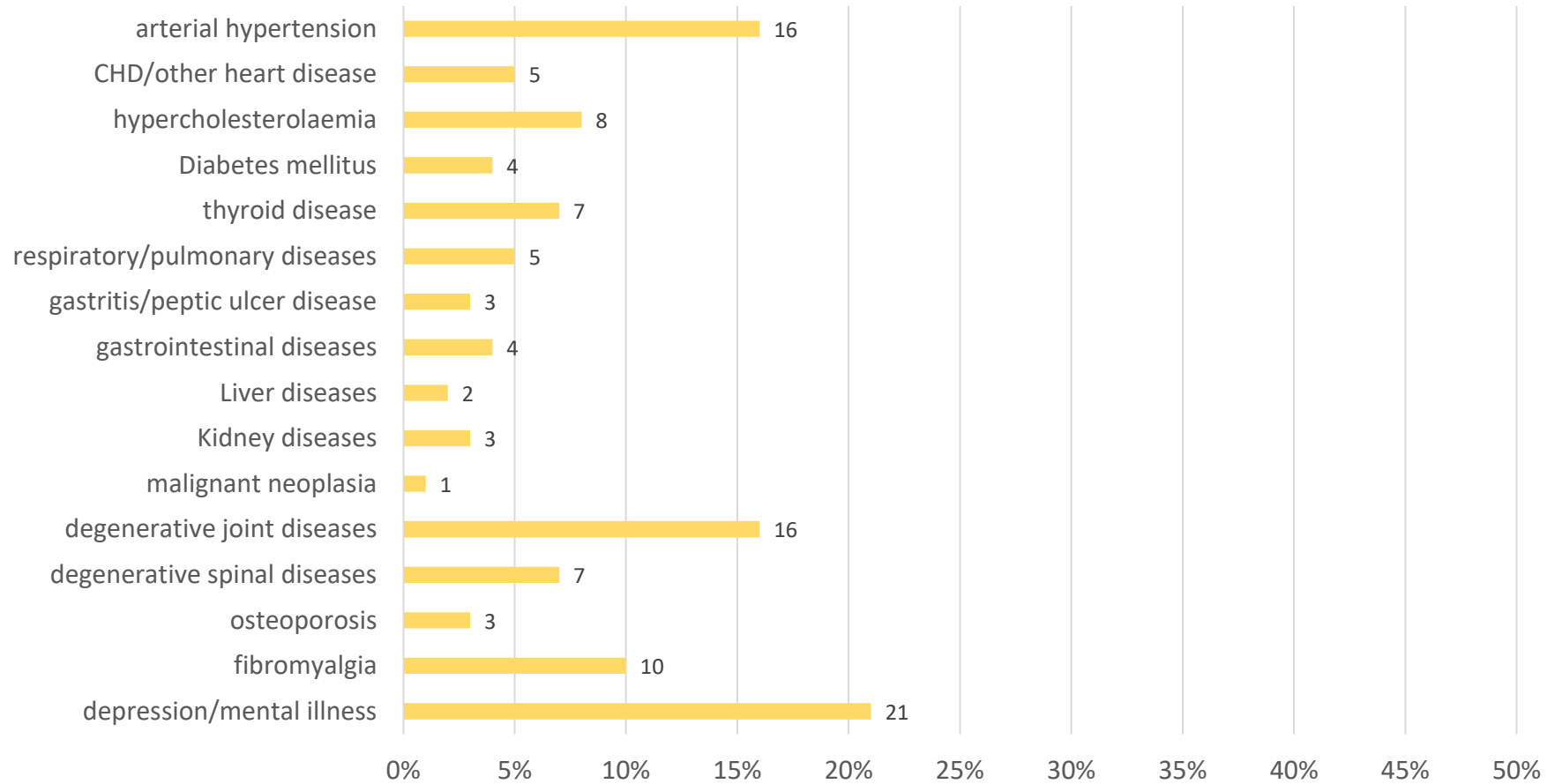






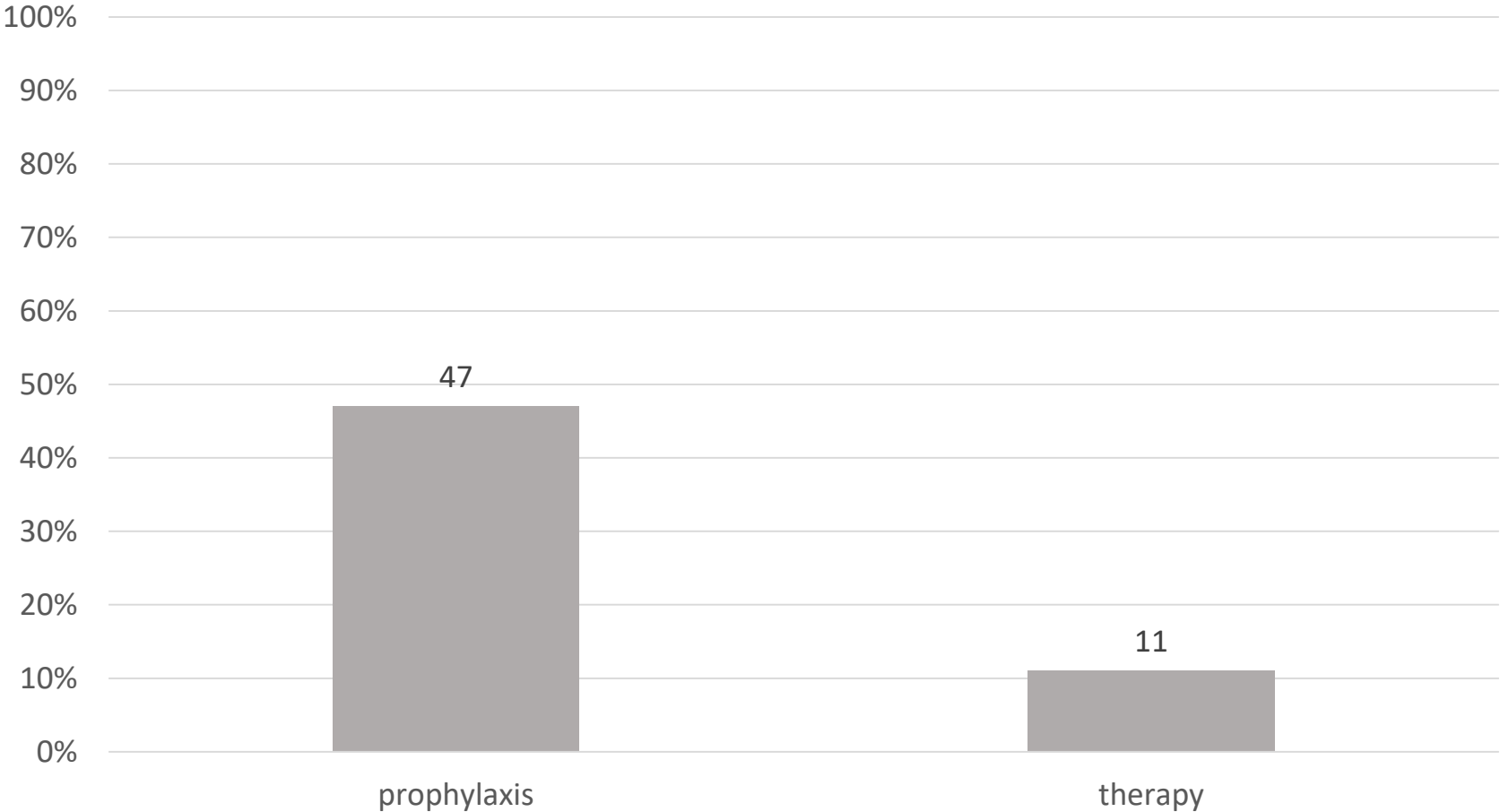








Proportion of all RA patients (%) with osteoporosis prophylaxis or therapy

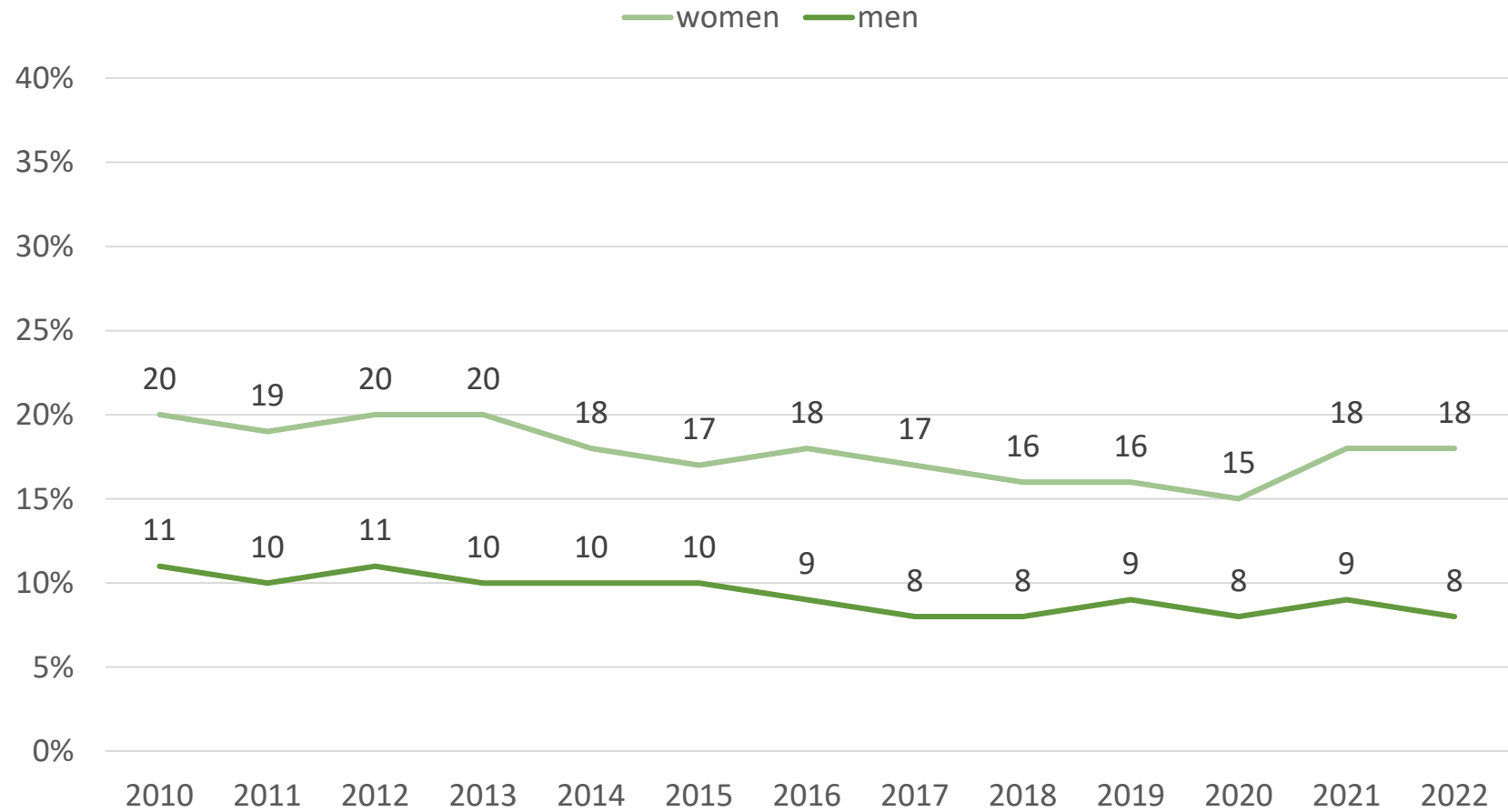


Source: German National Database, data collected in 2022

n=5,761 RA patients with information on therapy

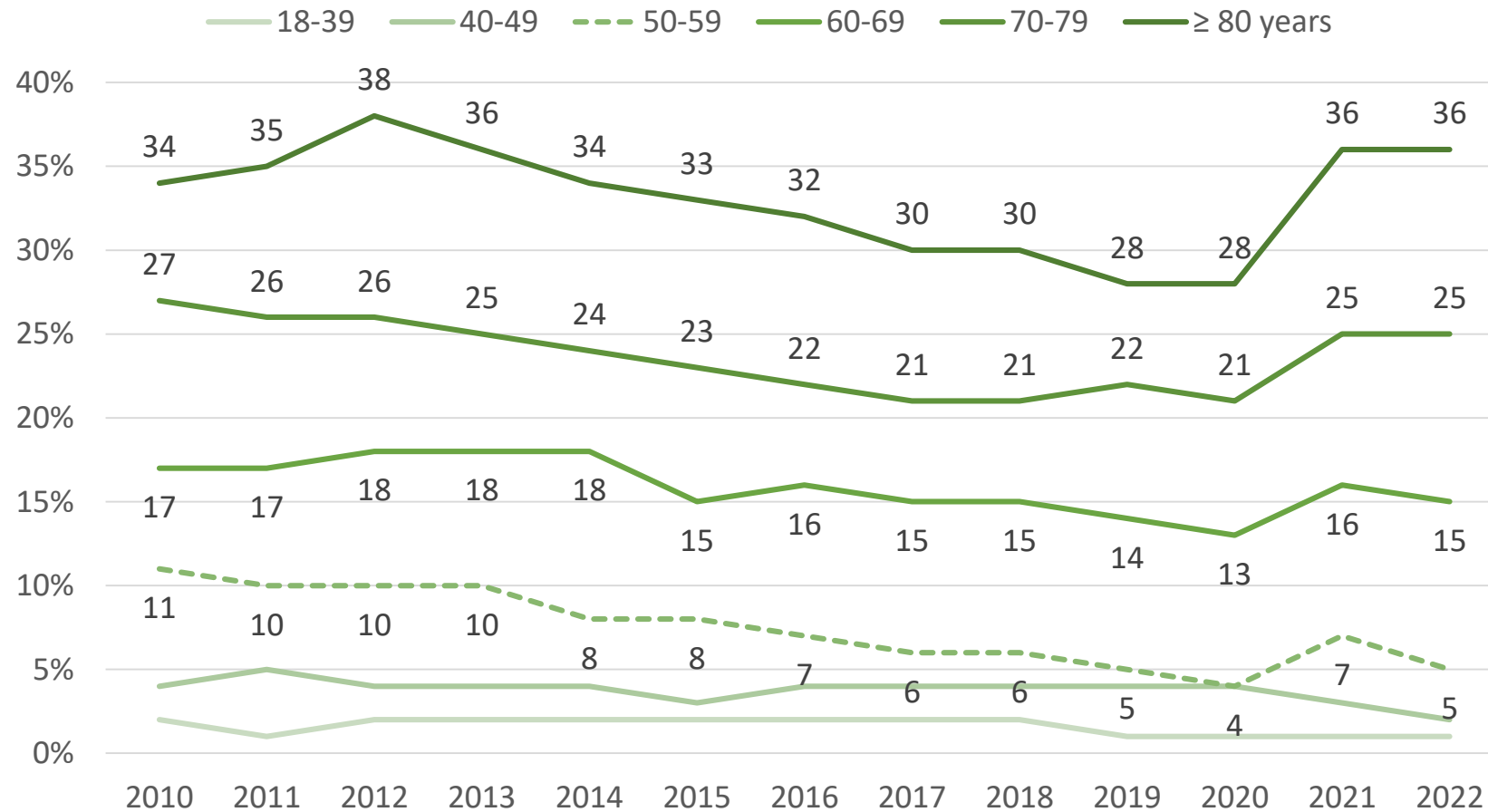


Proportion of patients (%) with osteoporosis





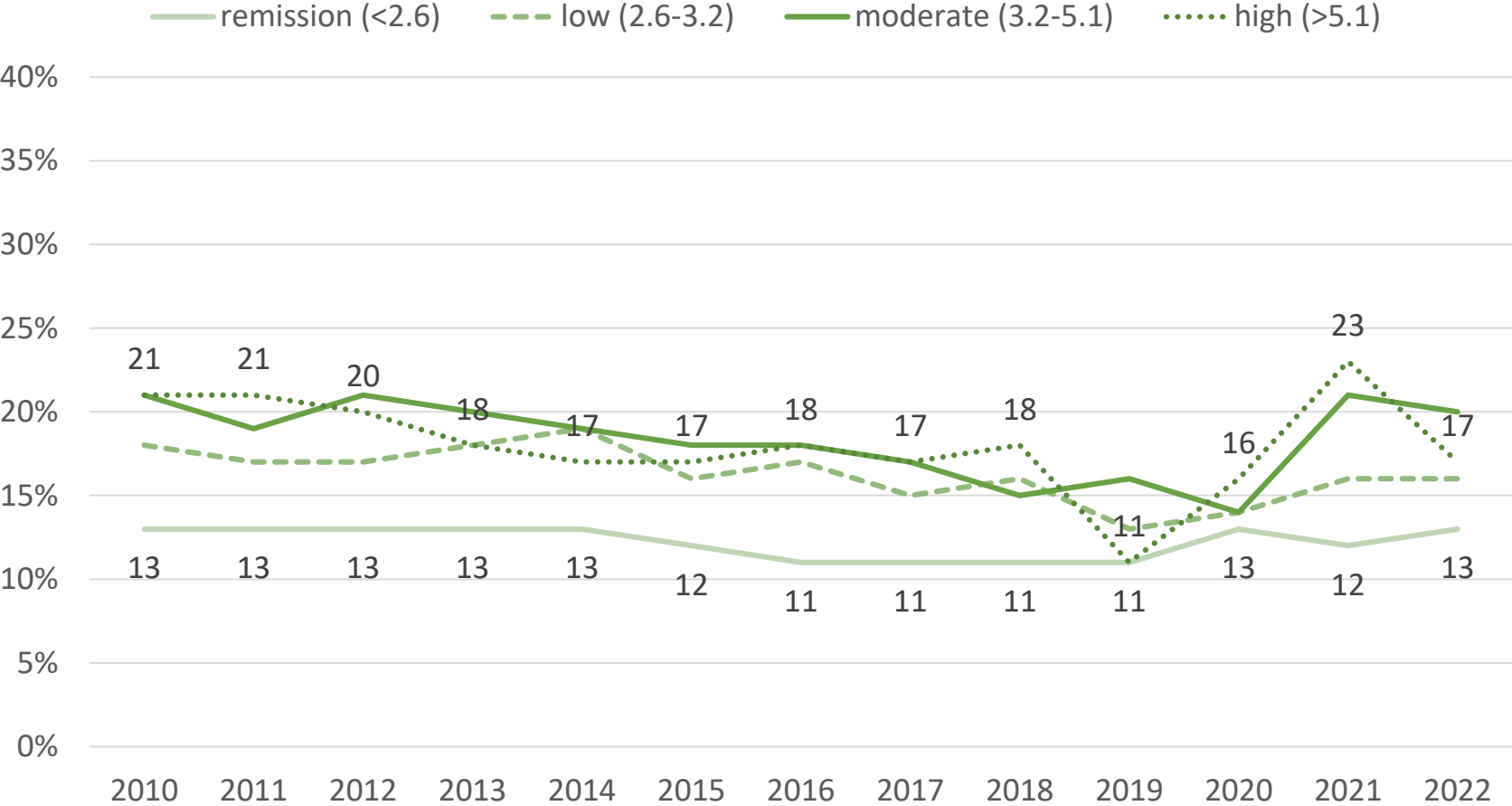
Proportion of patients (%) with osteoporosis







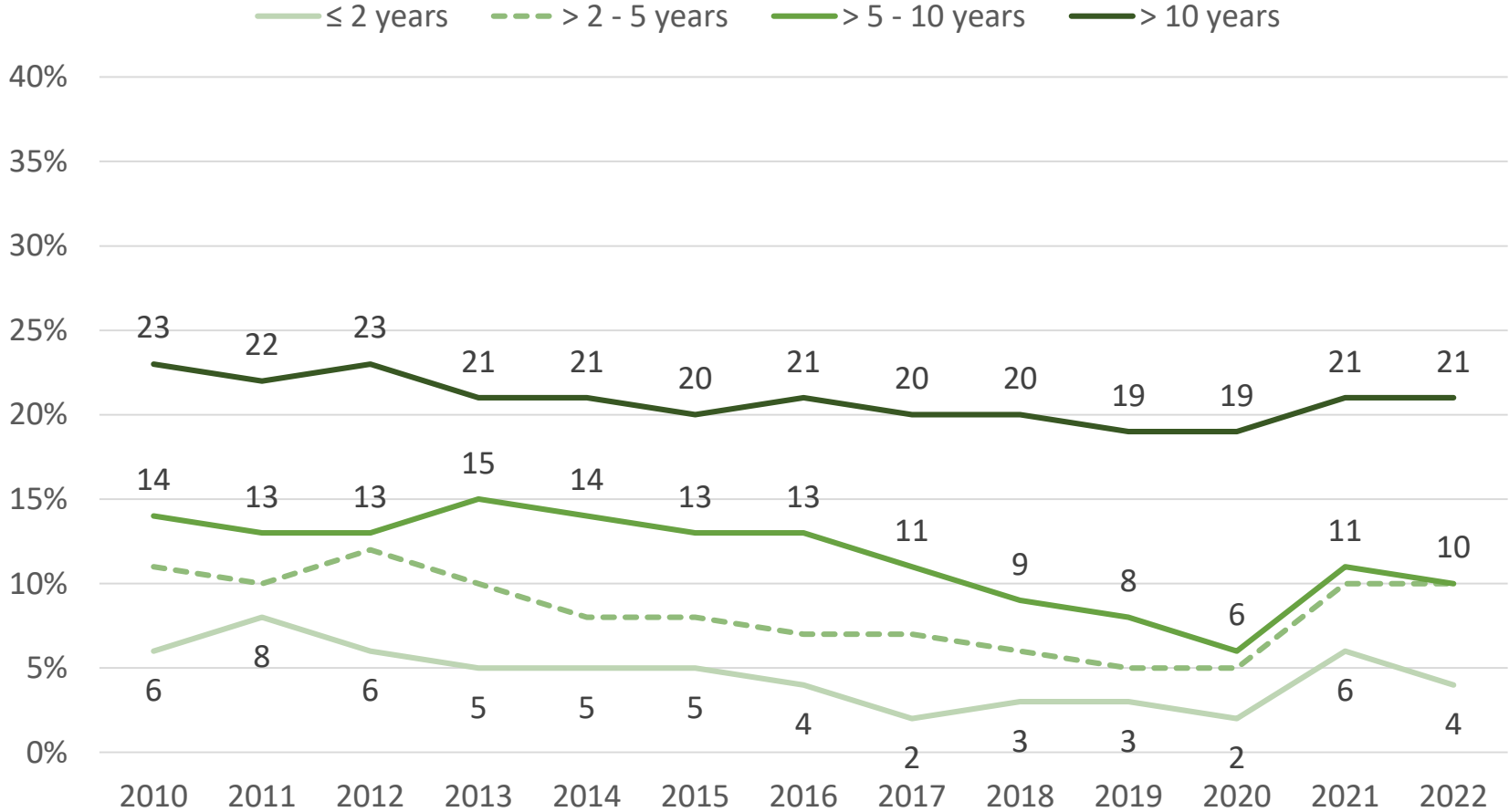
Proportion of patients (%) with osteoporosis by disease activity, measured by DAS28



# Osteoporosis by disease duration



Proportion of patients (%) with osteoporosis



Source: German National Database, data collected in 2022

n=4,776 patients with RA and indication of osteoporosis

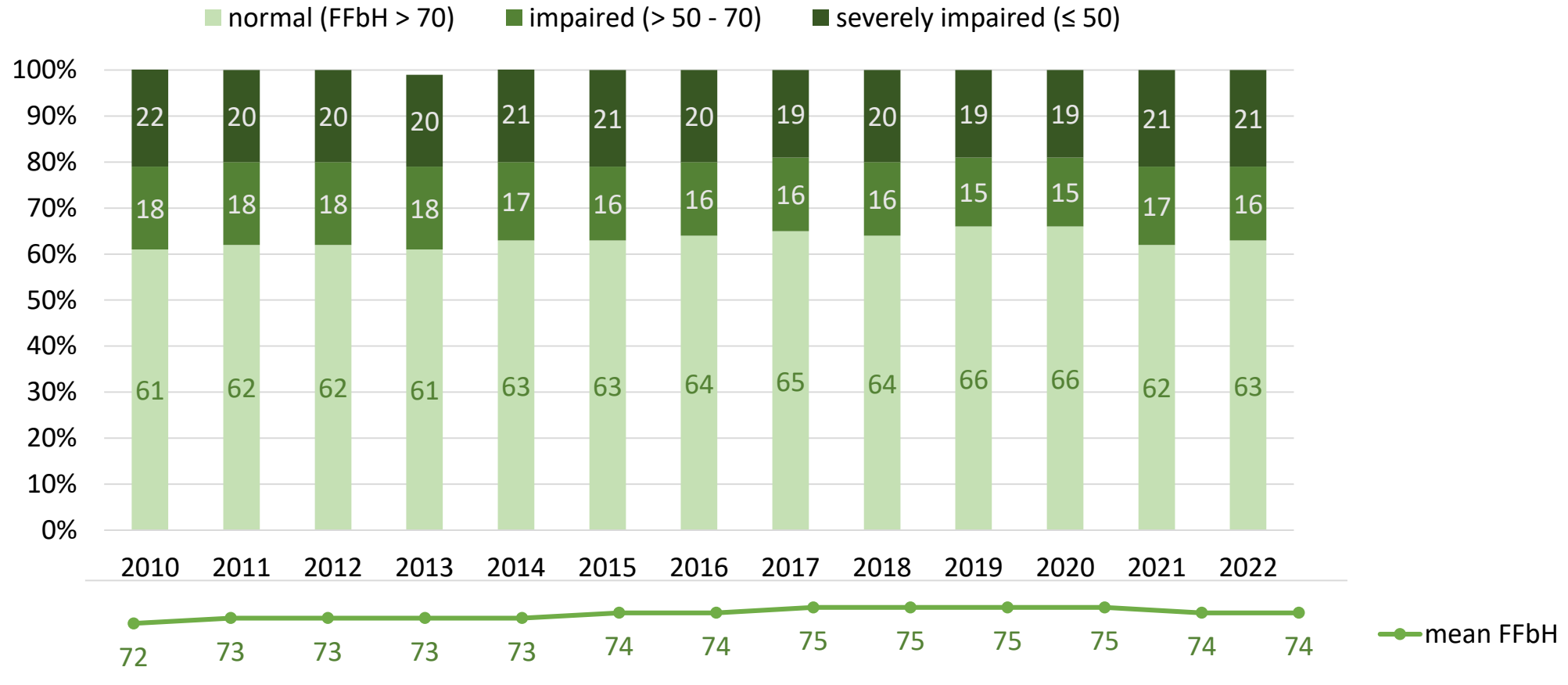


# Patient reported Outcomes

FFbH  
BASFI  
RAID (pain, fatigue, sleep disorders)  
WHO-5 (well-being)  
Therapy satisfaction



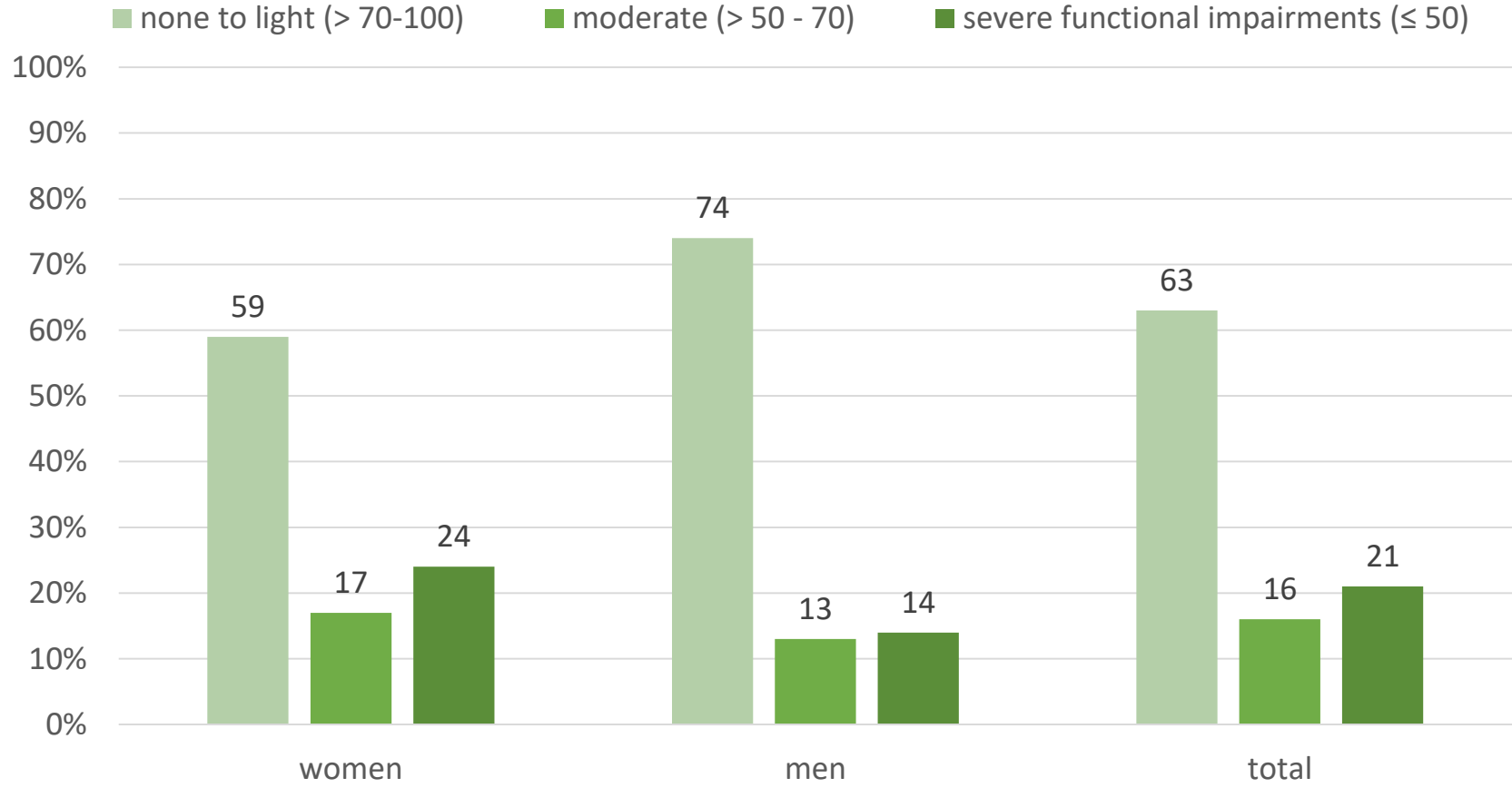
Proportion of patients (%) with normal, impaired and severely impaired functional capacity



# RA FFbH by gender



Proportion of patients (%) with functional impairments according to the FFbH



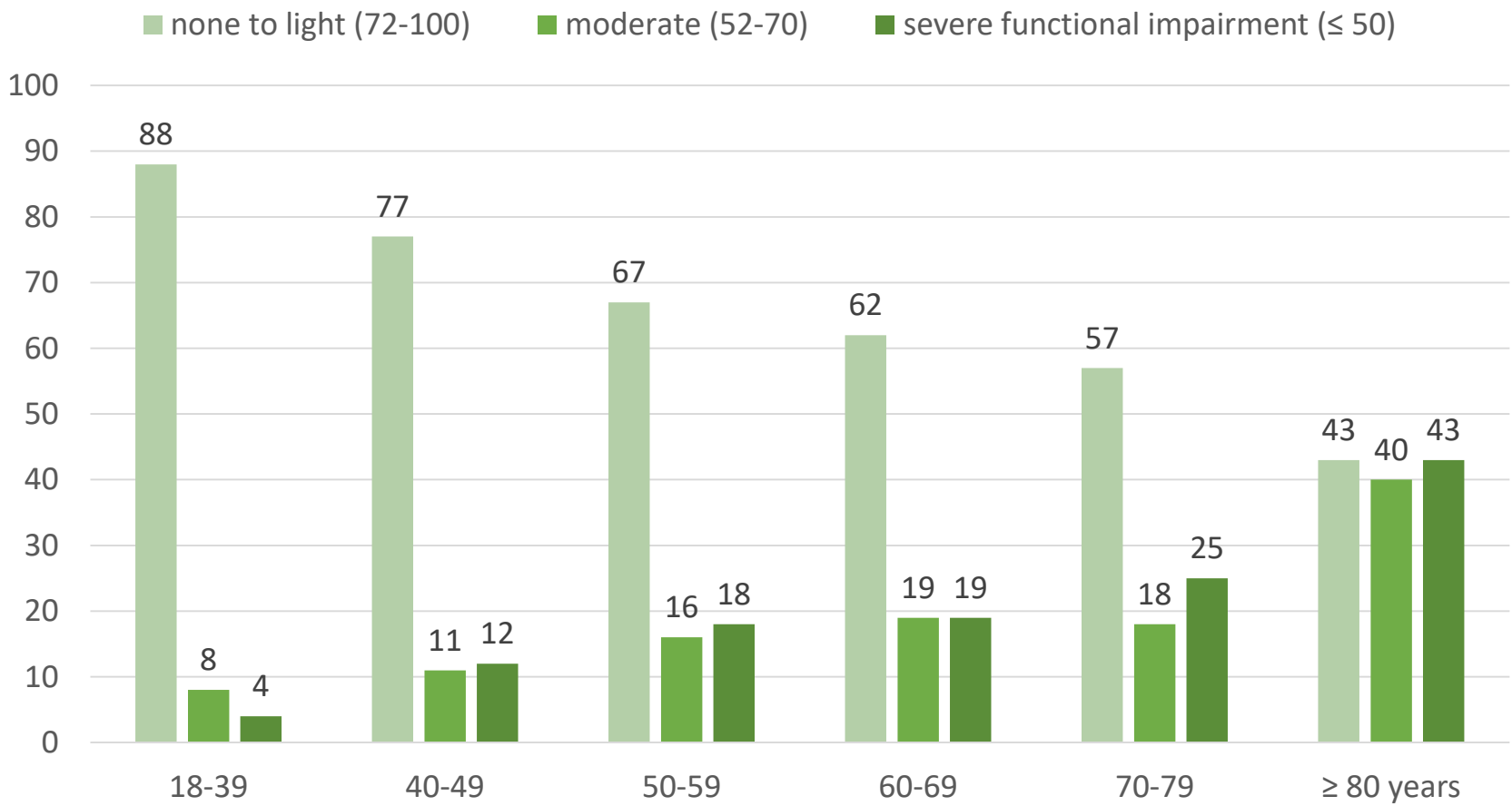
Source: German National Database, data collected in 2022

n=5,229 (2022) RA patients with FFbH

# RA FFbH by age



Proportion of patients (%) with functional impairments according to the FFbH



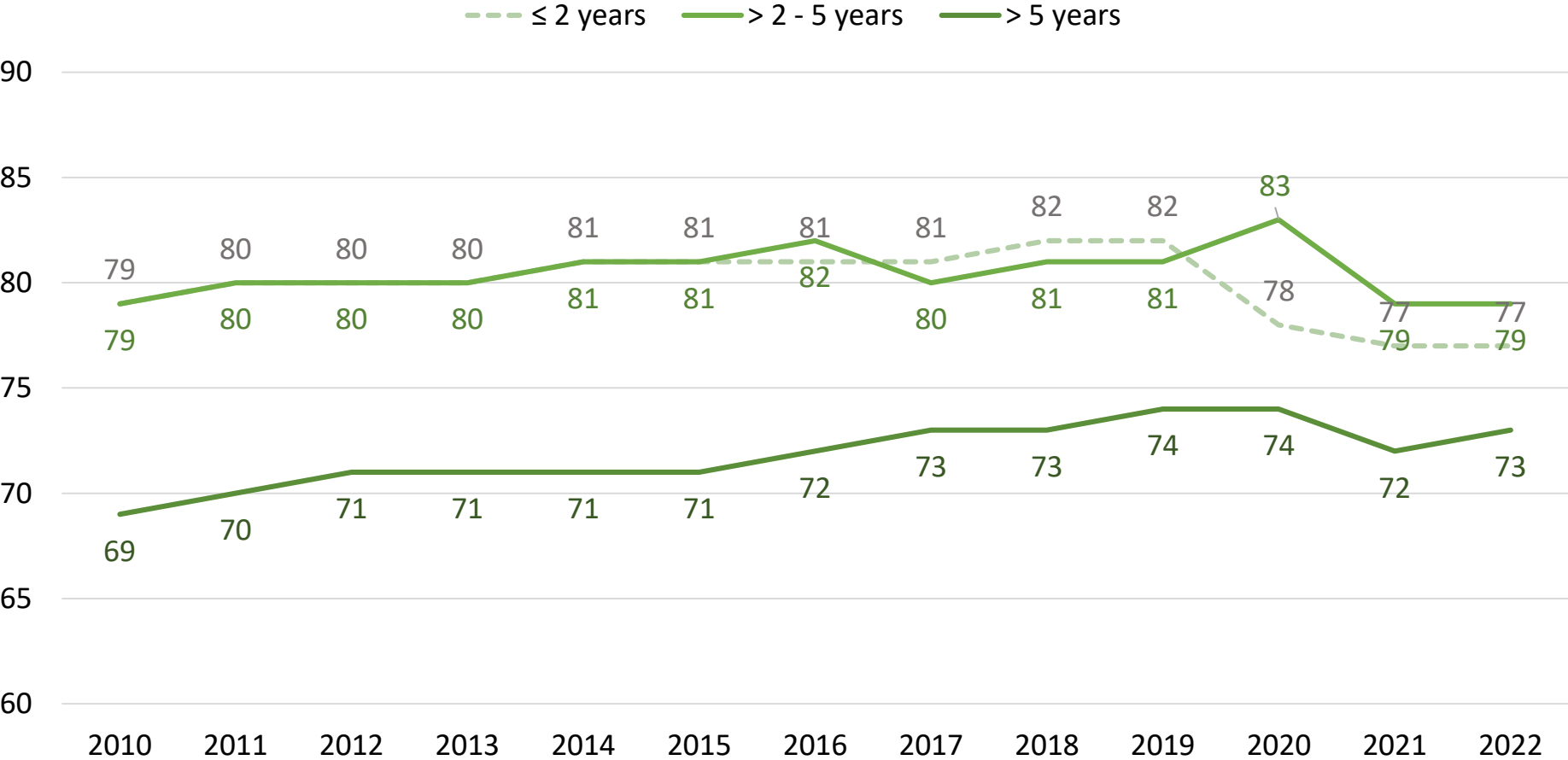
Source: German National Database, data collected in 2022

n=5,229 (2022) RA patients with FFbH

# Mean FFbH by disease duration



FFbH (0-100, 100 corresponds to full function) Annual mean values 2010-2020



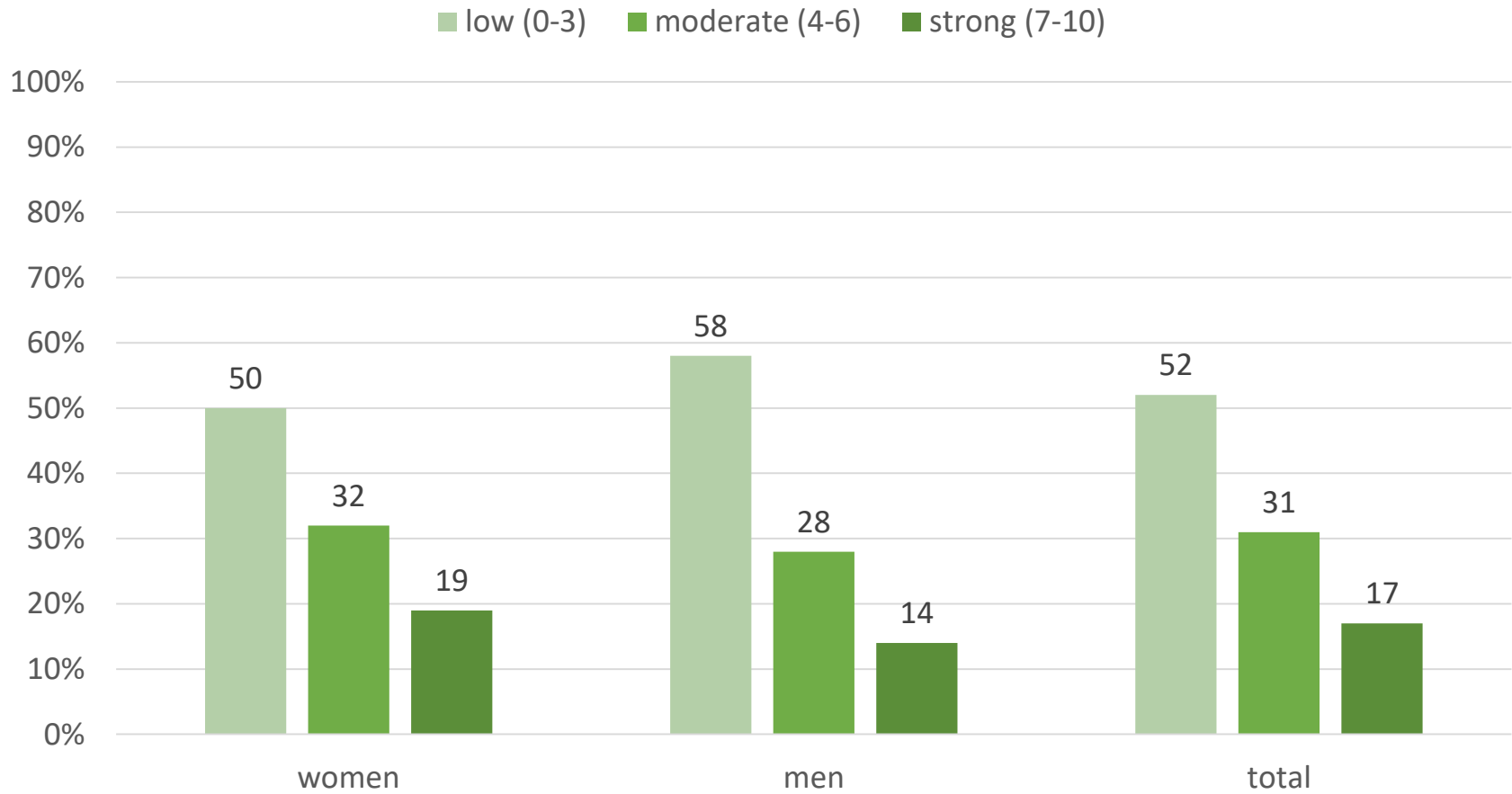
Source: German National Database, data collected in 2022

n=6,524 (2010) to 5,095 (2022) RA patients with FFbH and information on disease duration

# RA Pain by gender

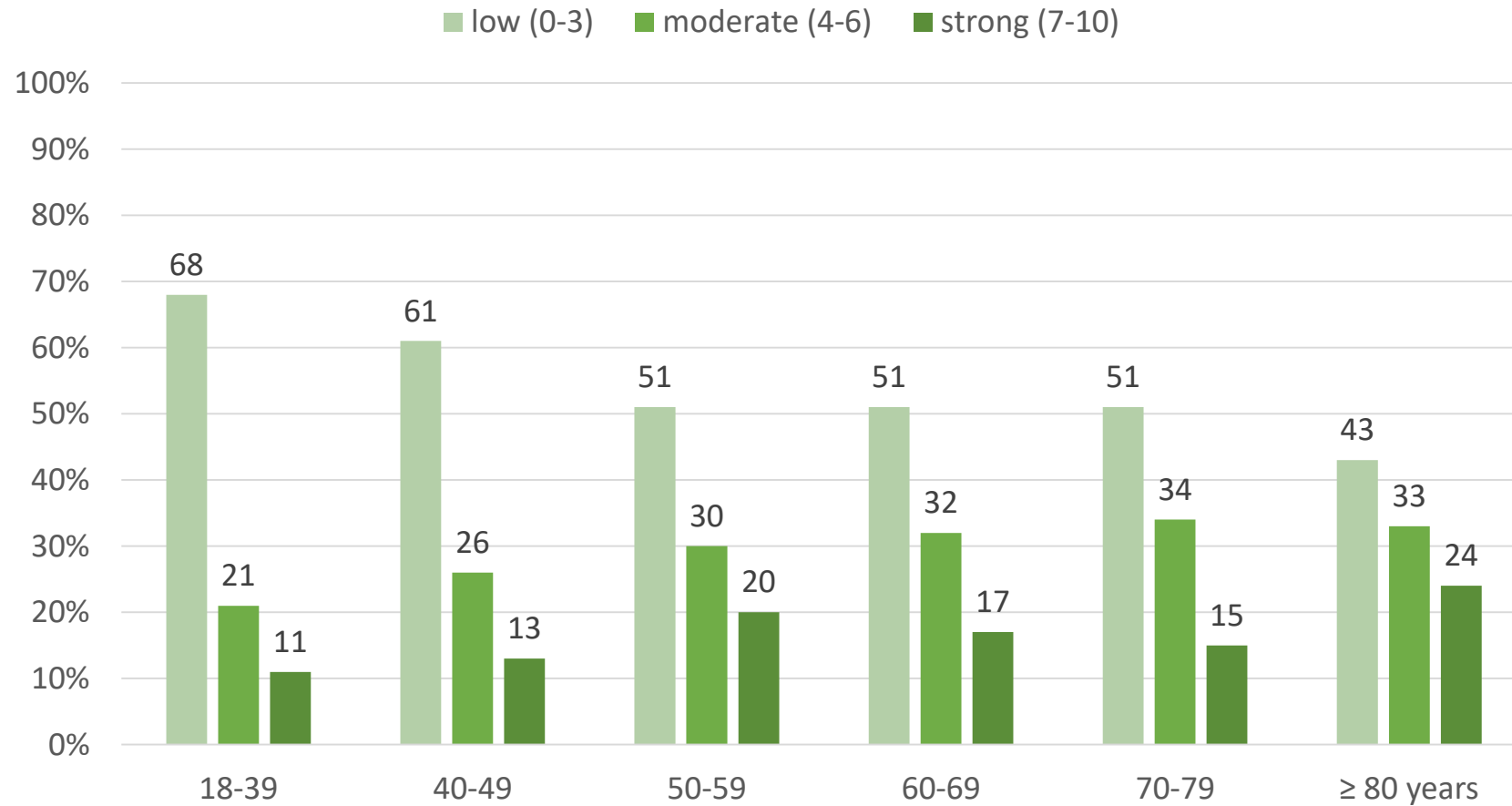


"How would you rate the intensity of your pain in the last 7 days?"

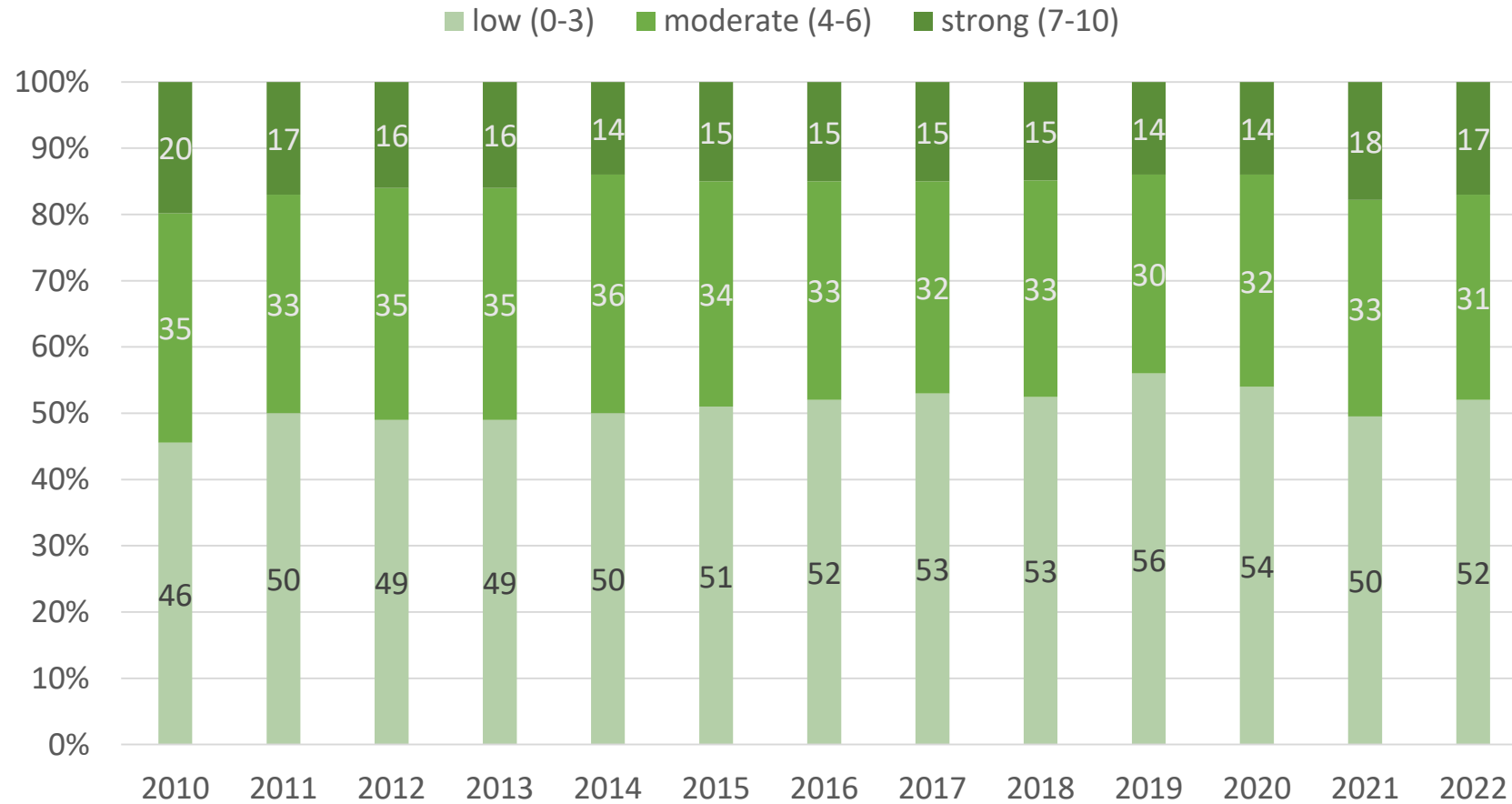


NRS 0-10  
0 = no pain  
10 = unbearable pain





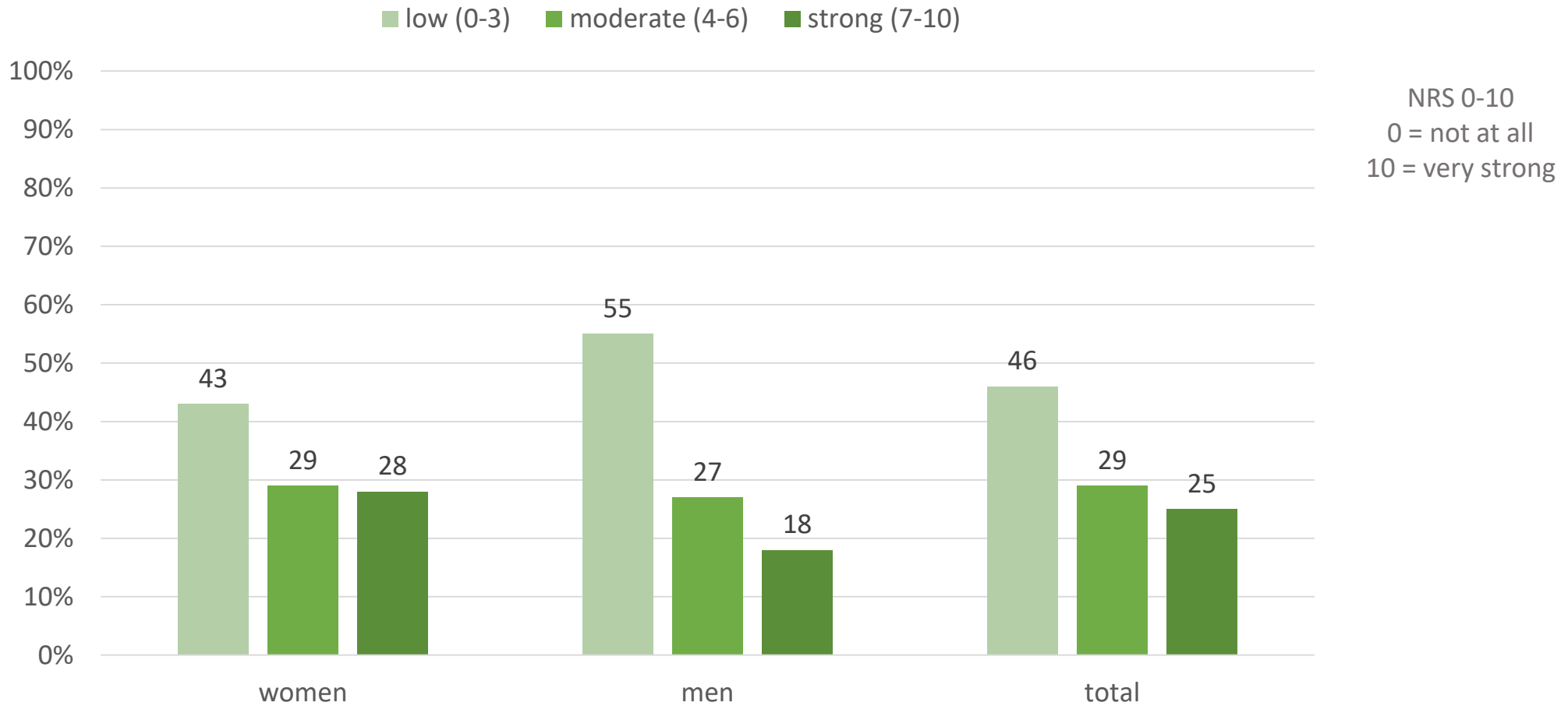
NRS 0-10  
0 = no pain  
10 = unbearable pain



NRS 0-10  
0 = no pain  
10 = unbearable pain

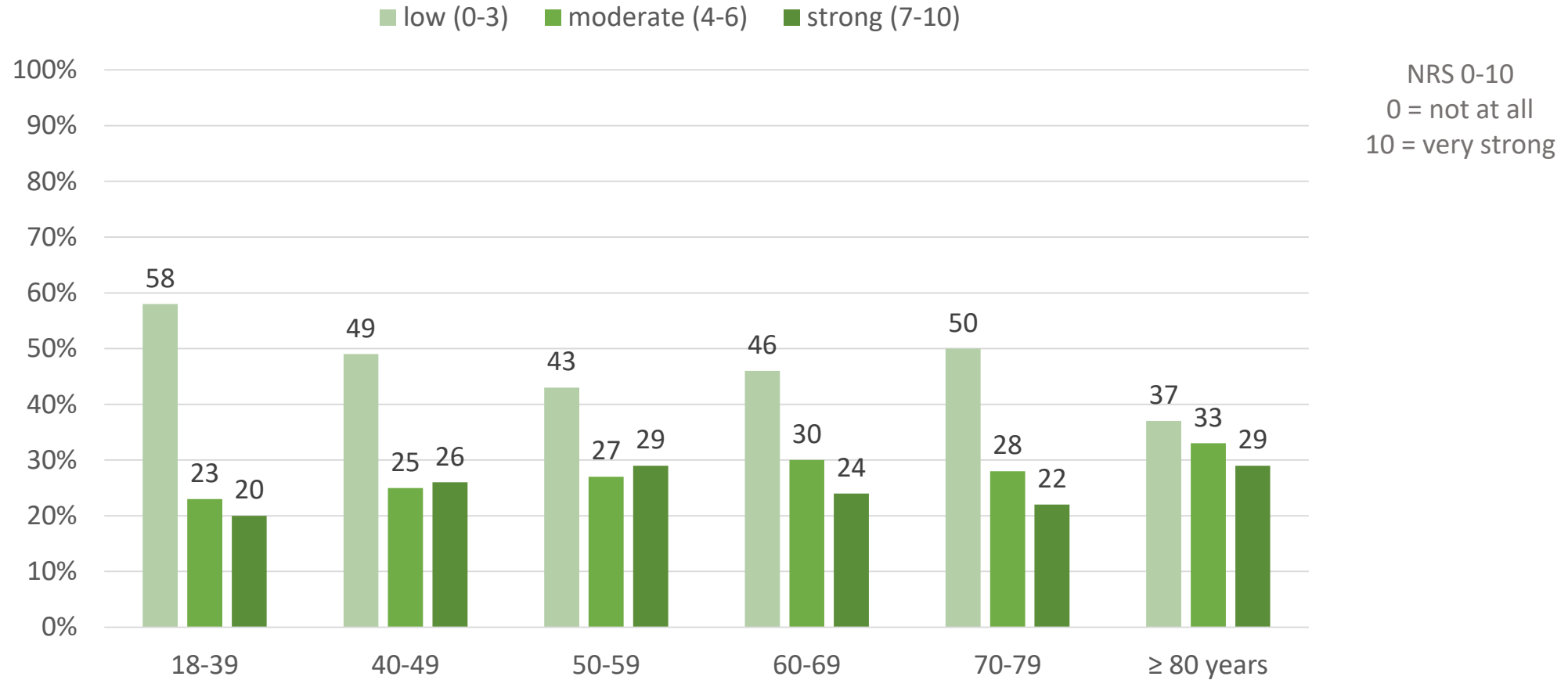


"How much have you suffered from unusual exhaustion and tiredness in the last 7 days?"



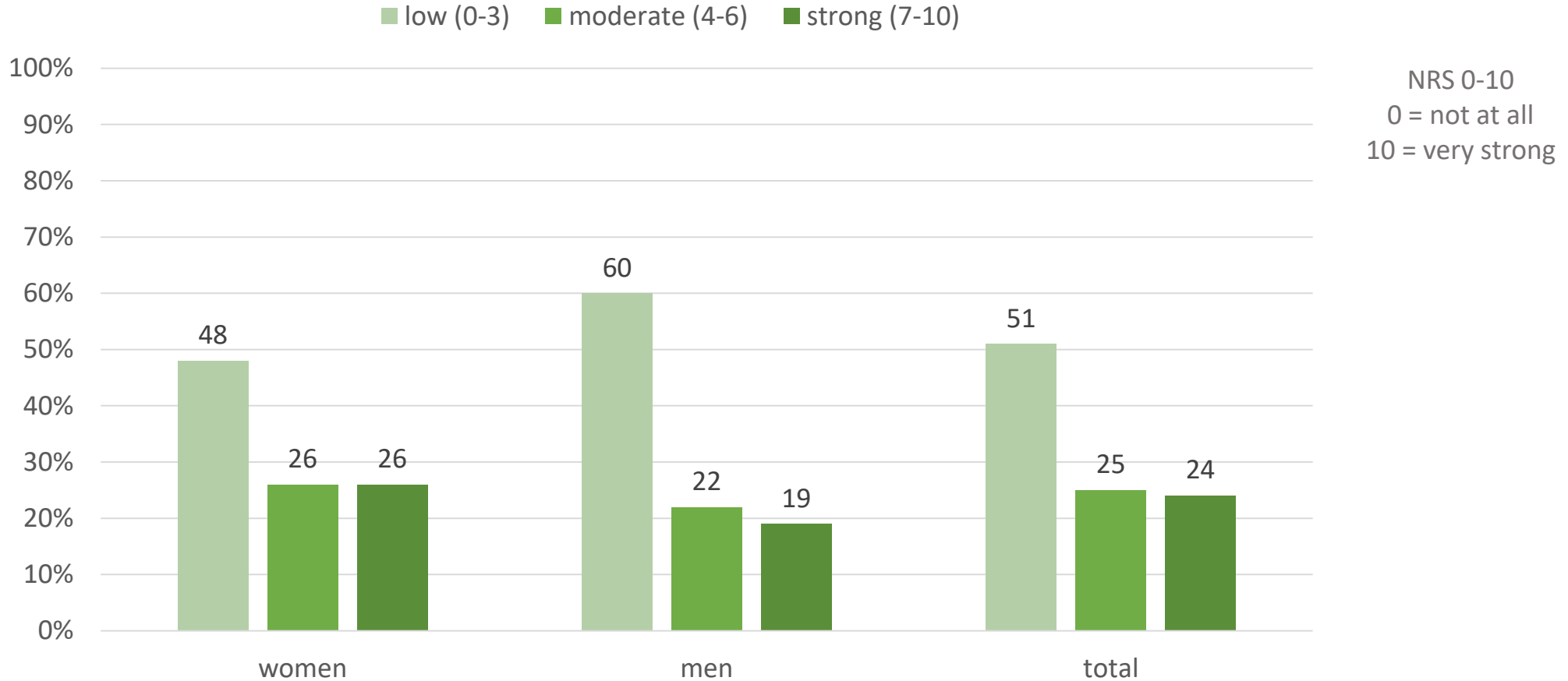


"How much have you suffered from unusual exhaustion and tiredness in the last 7 days?"



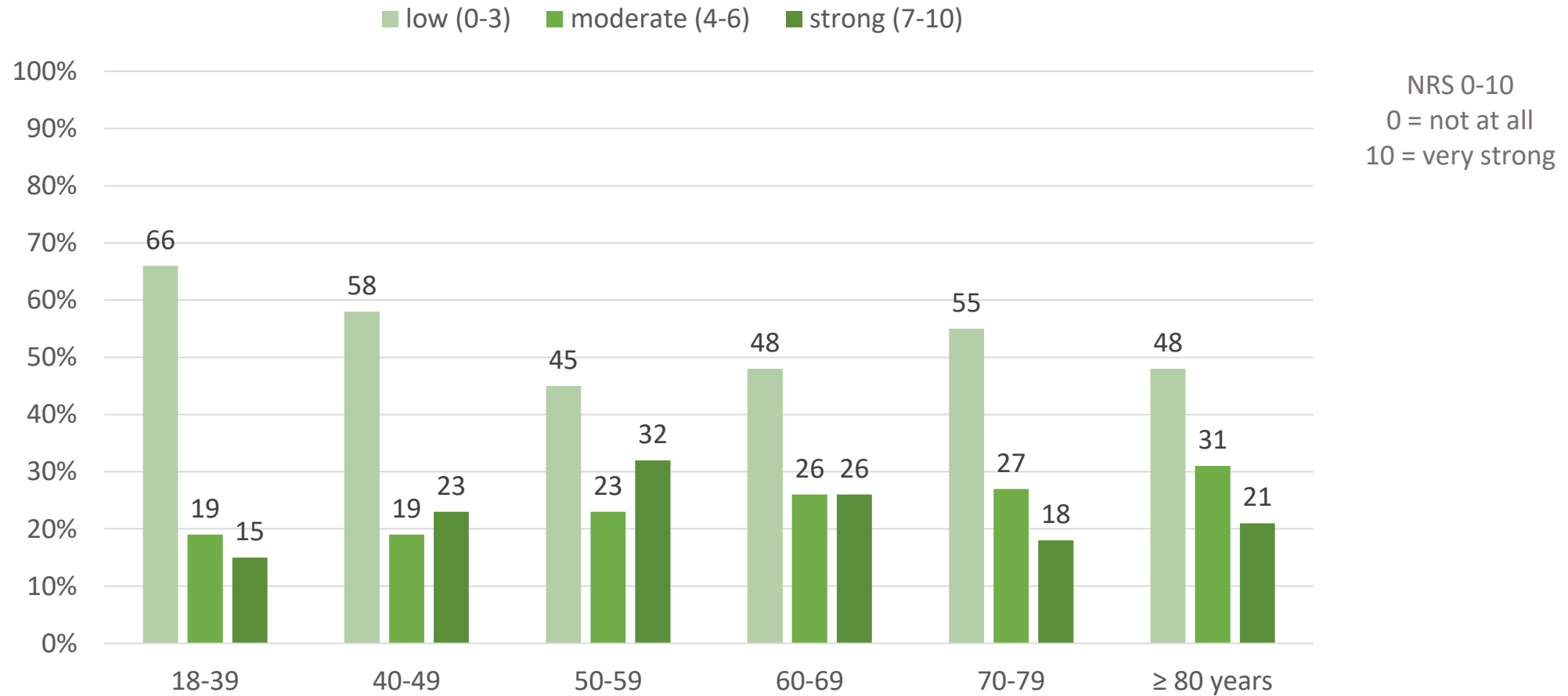


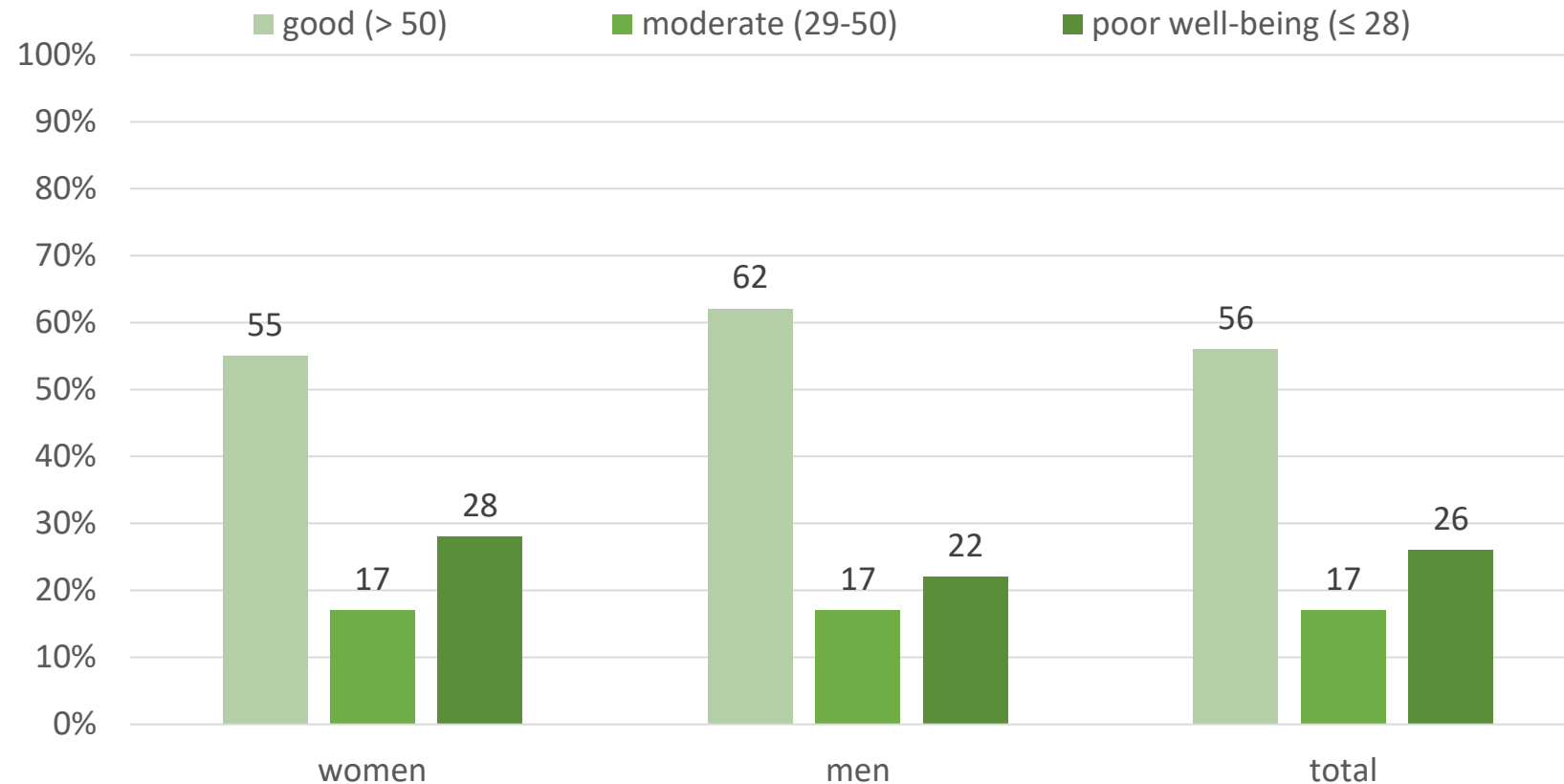
"Have you suffered from sleep disorders in the last 7 days? (Problems falling asleep or staying asleep)?"

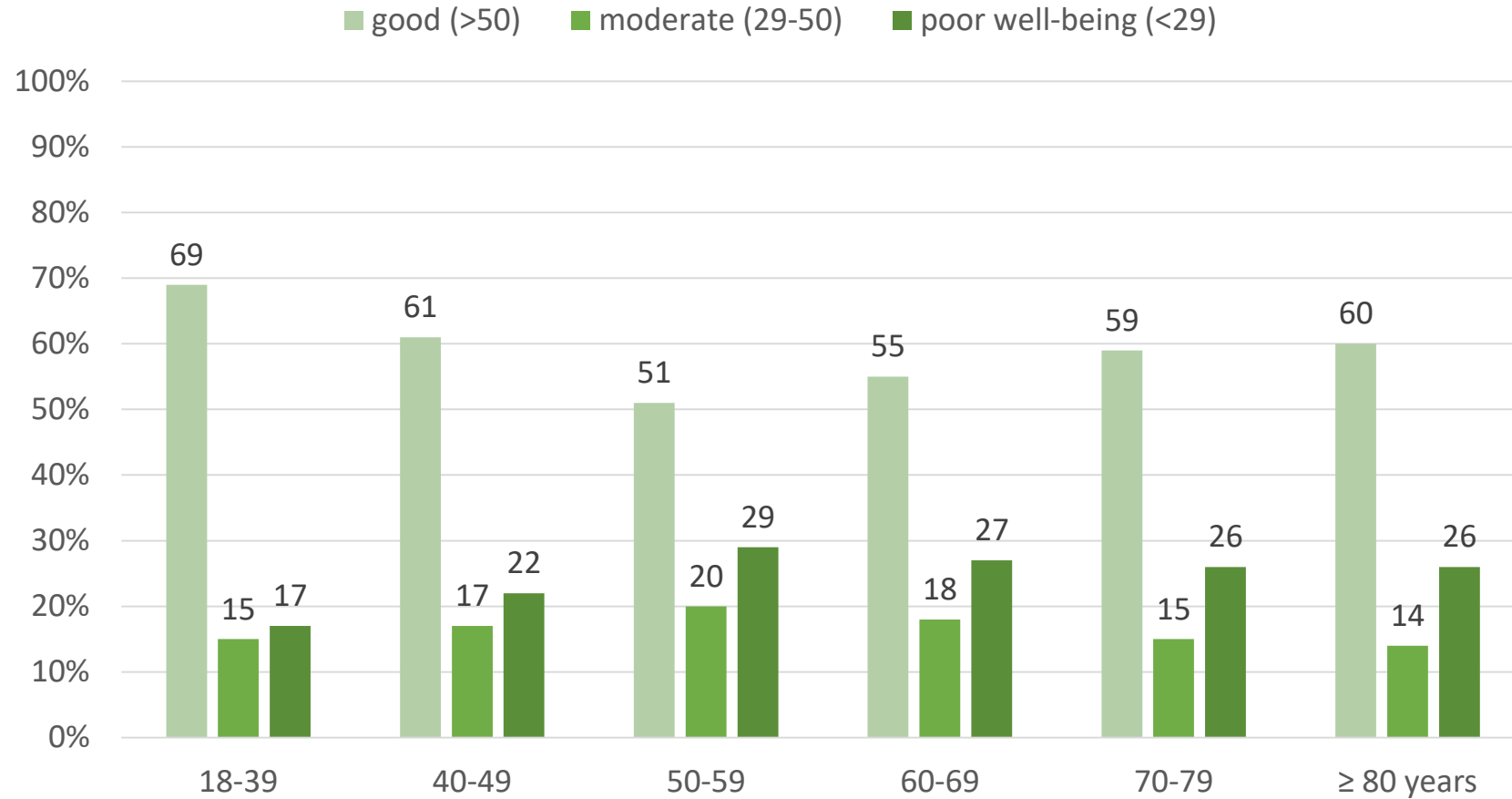




"Have you suffered from sleep disorders in the last 7 days? (Problems falling asleep or staying asleep)?"



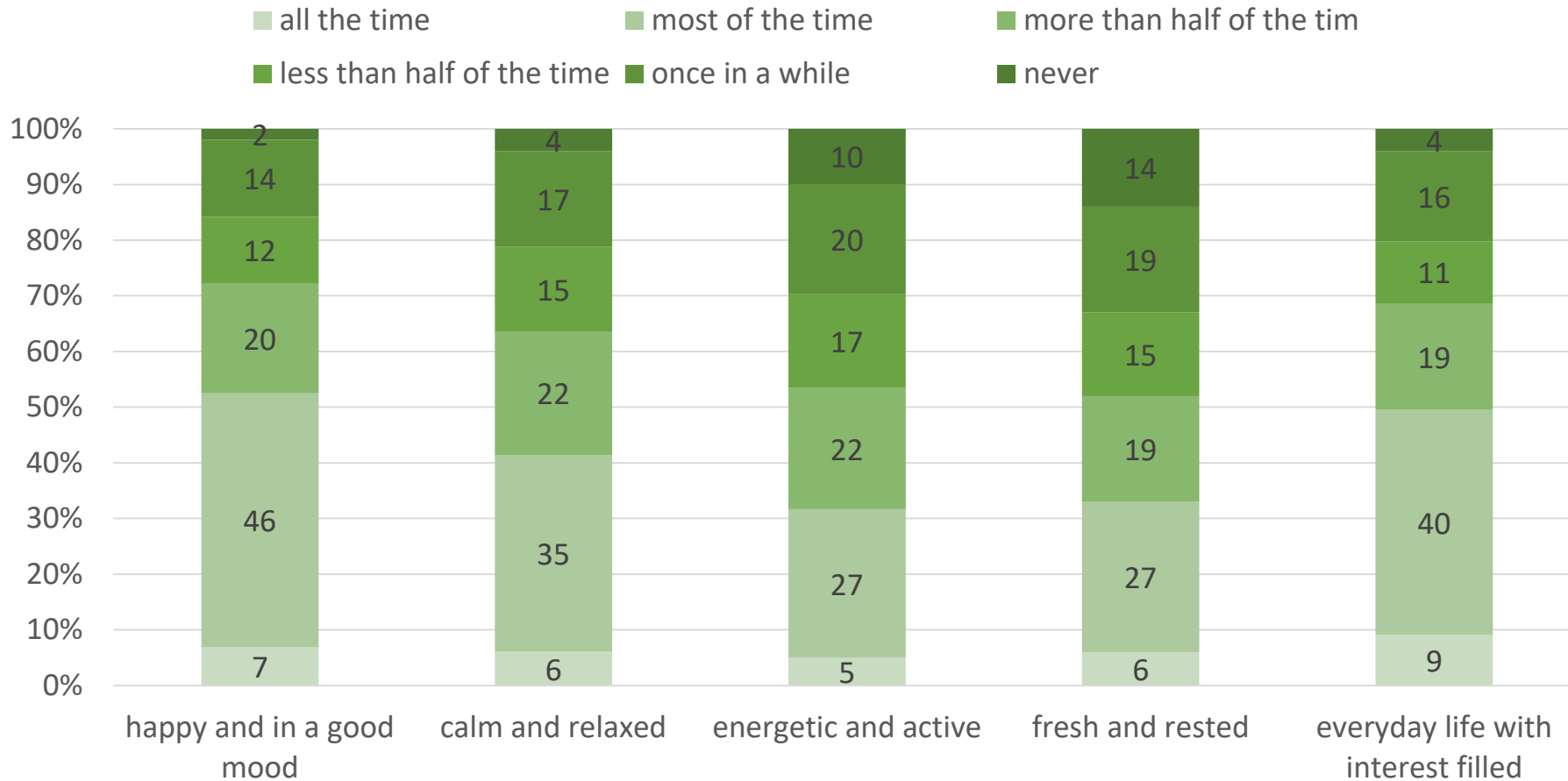






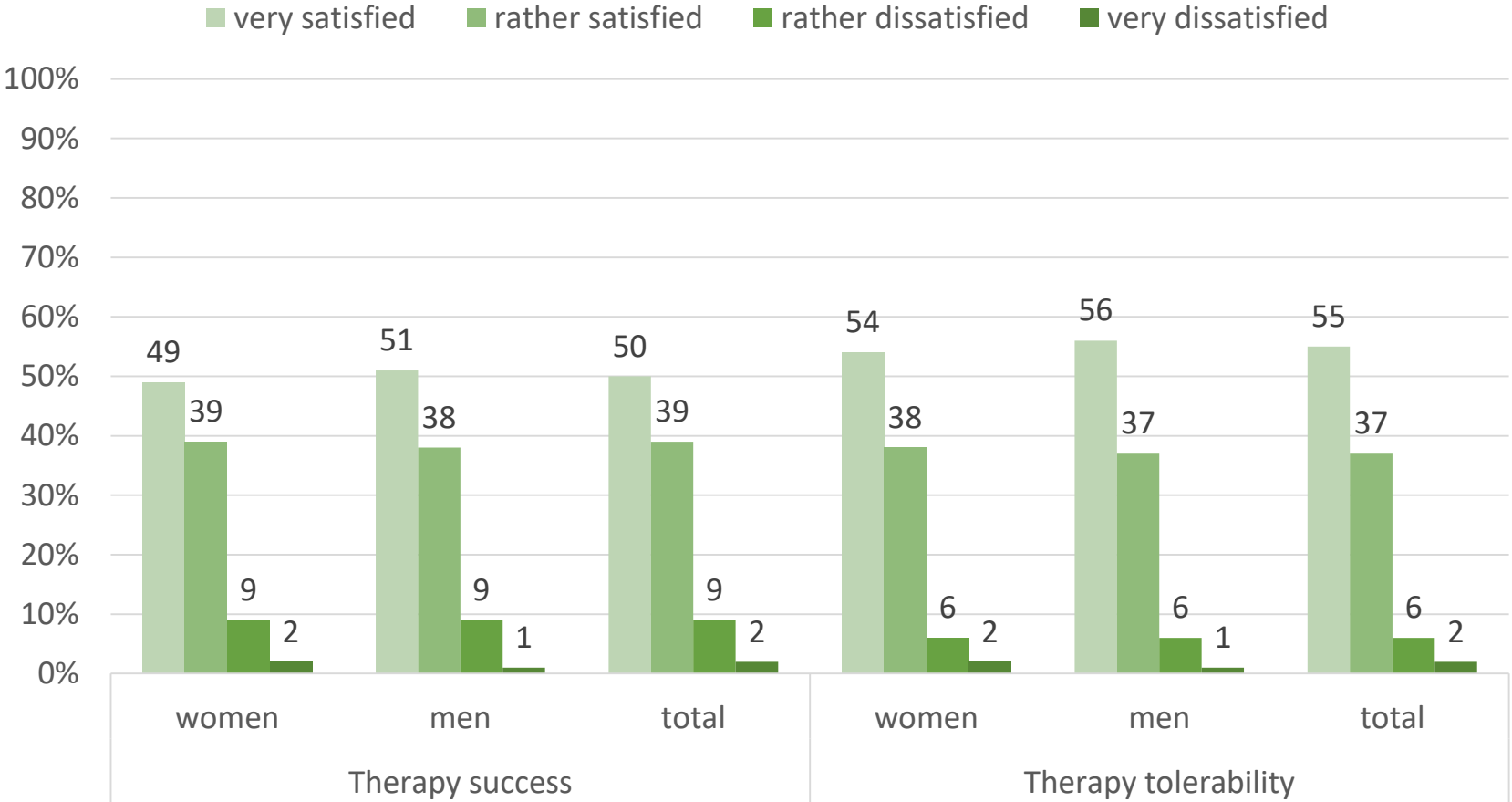


"In the last two weeks I've been..."

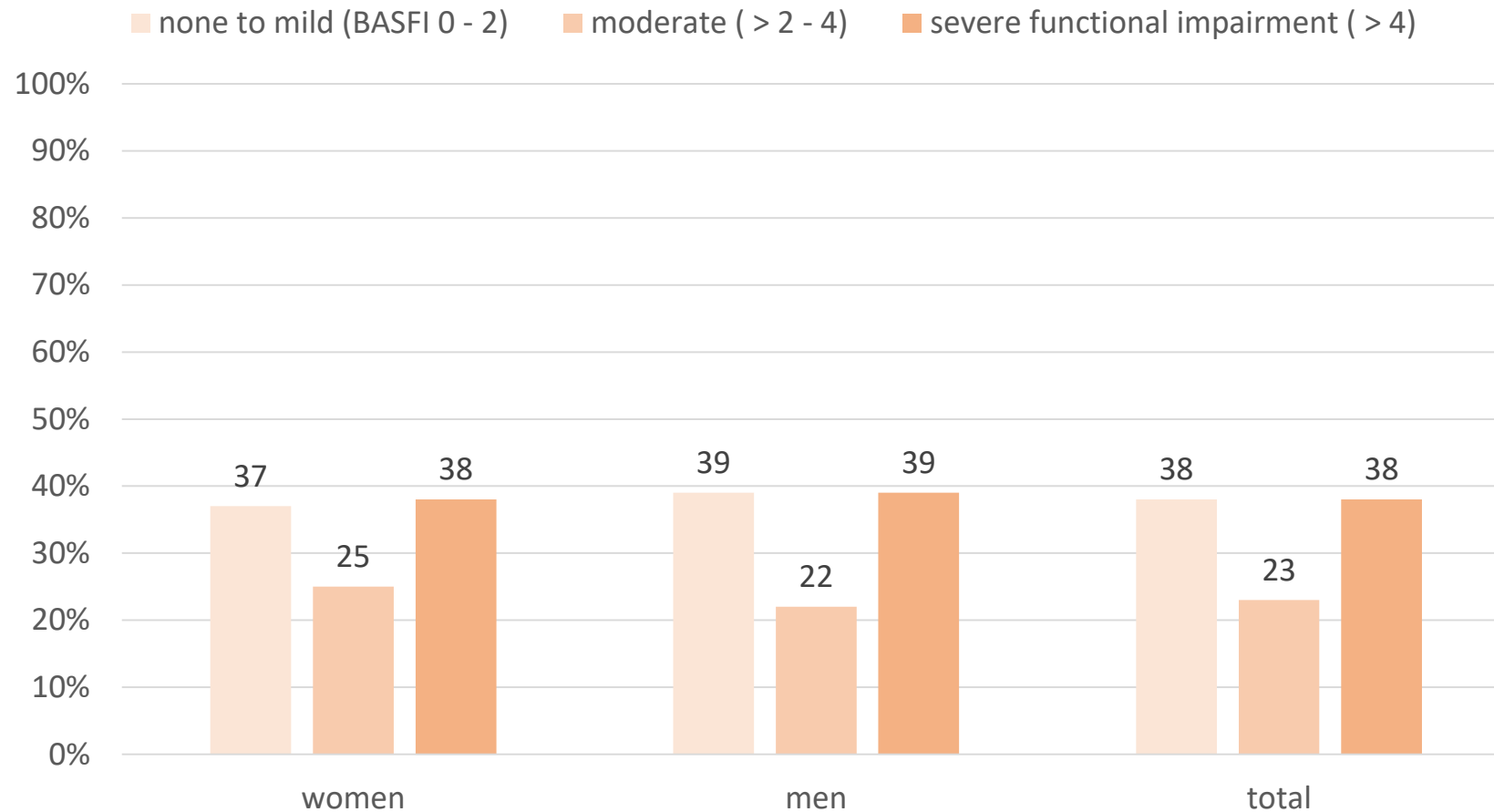




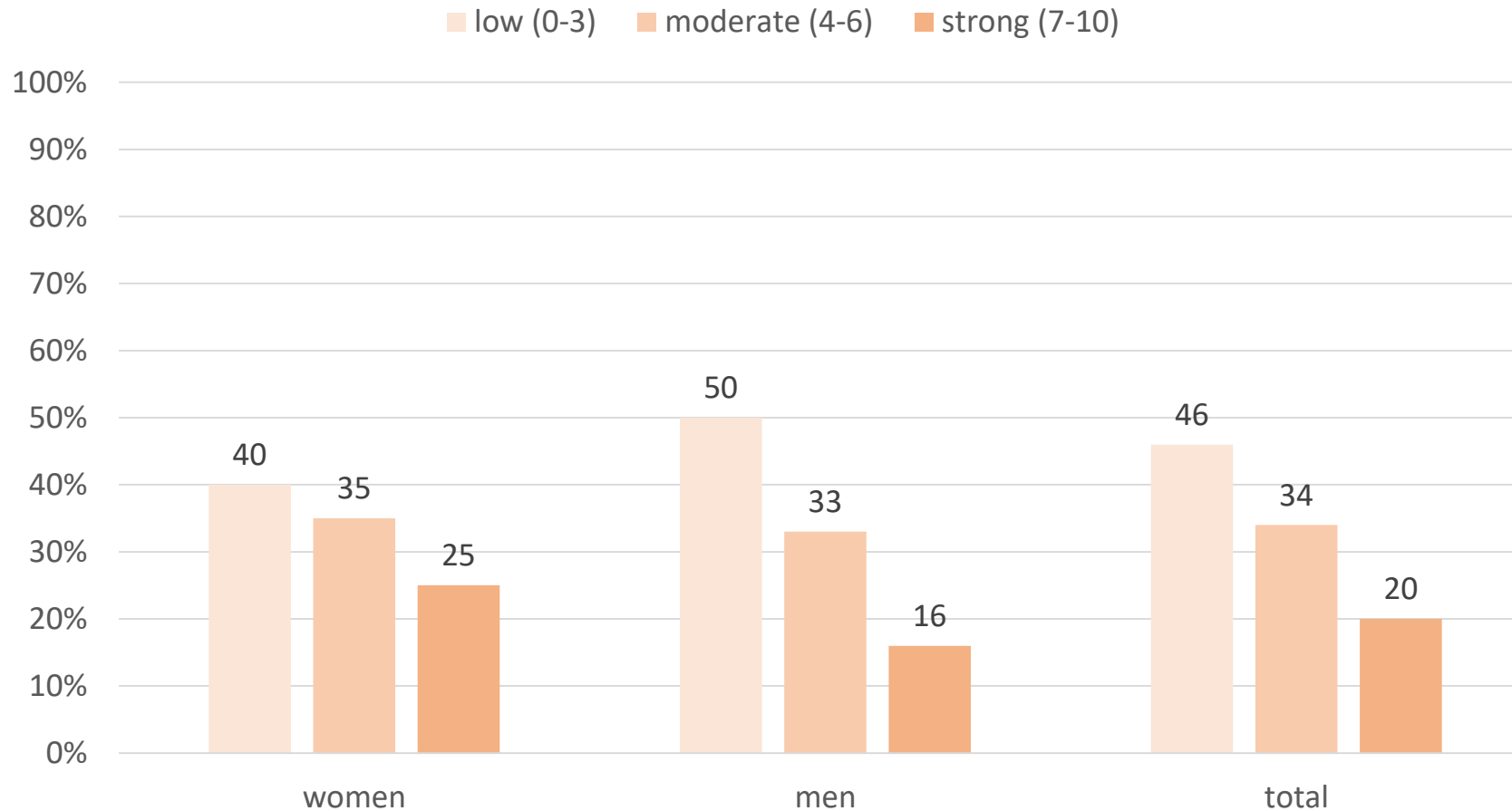
"How satisfied are you with the success / tolerability of your current rheumatism therapy?"



Proportion of patients (%) with functional impairments according to the BASFI

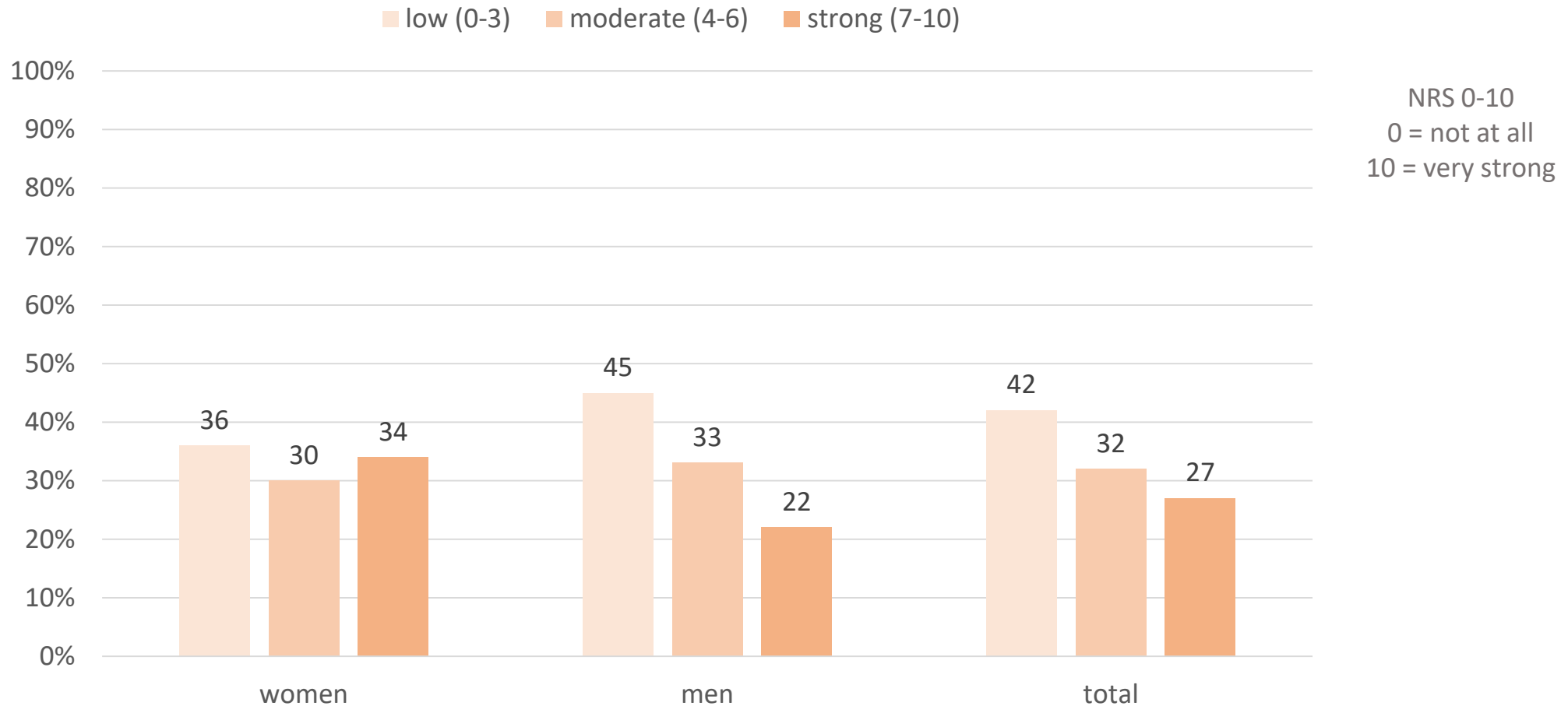


"How would you rate the intensity of your pain in the last 7 days?"

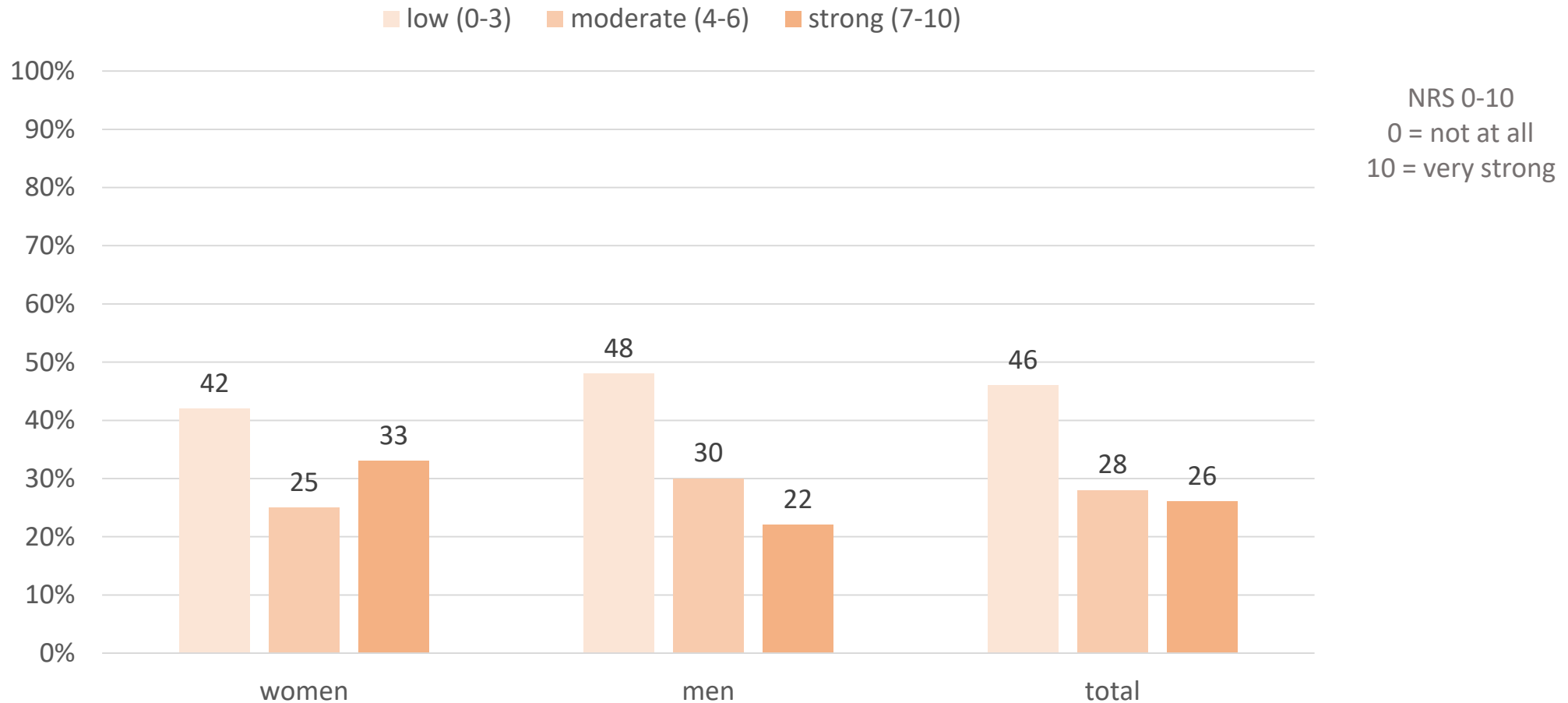


NRS 0-10  
0 = no pain  
10 = unbearable pain

"How much have you suffered from unusual exhaustion and tiredness in the last 7 days?"

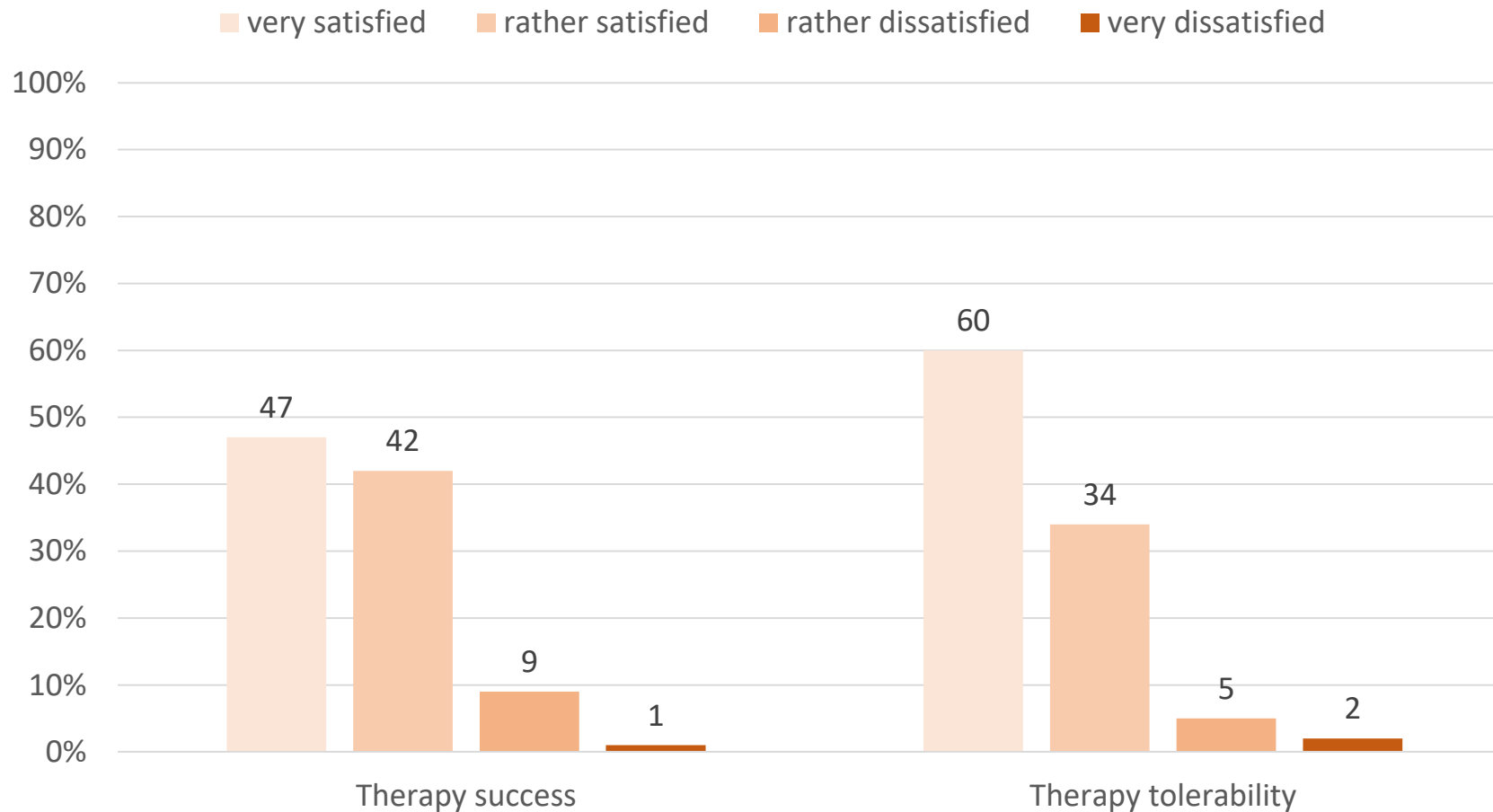


"Have you suffered from sleep disorders in the last 7 days? (Problems falling asleep or staying asleep)?"



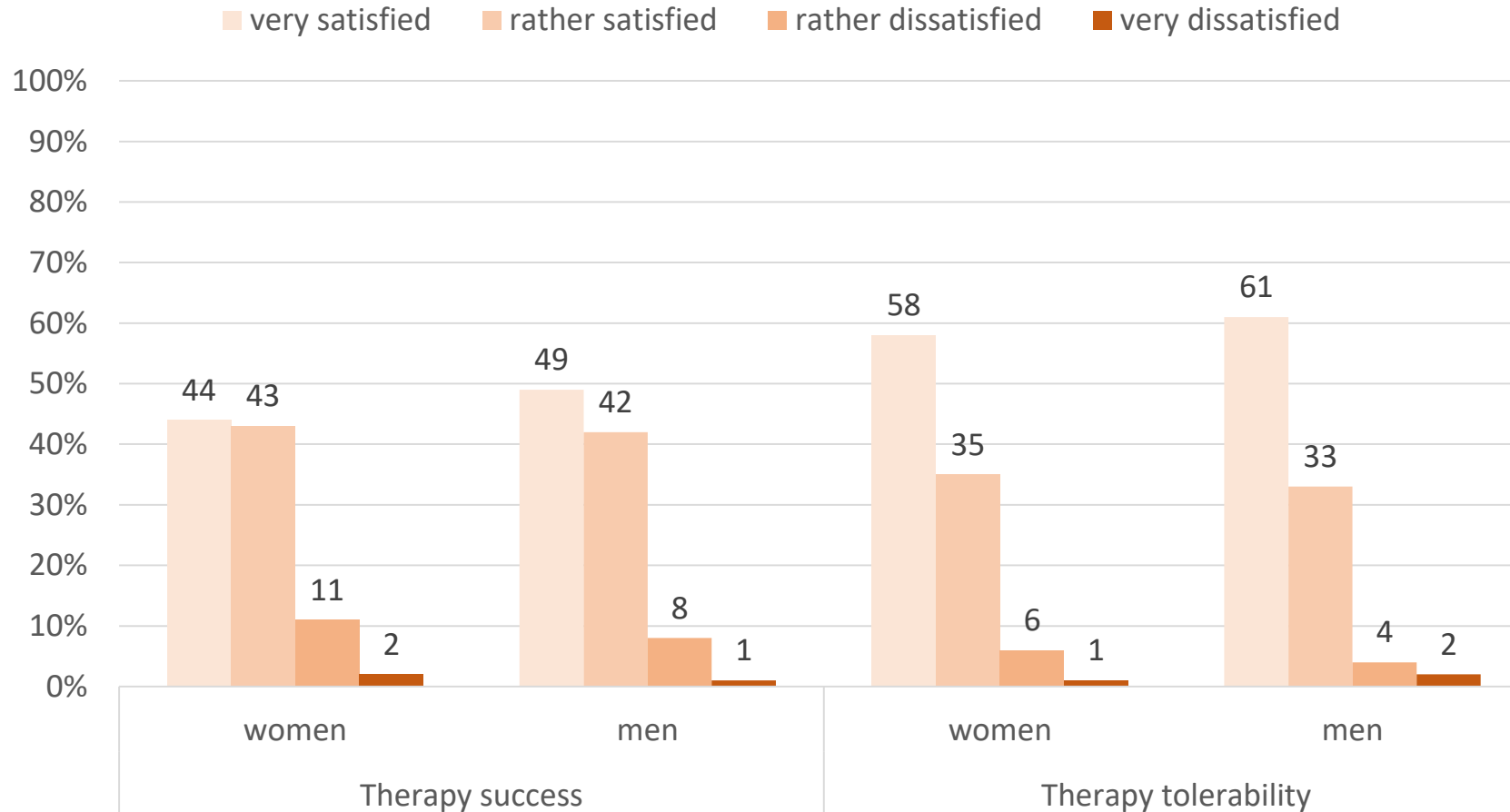


"How satisfied are you with the success/tolerability of your current rheumatism therapy?"

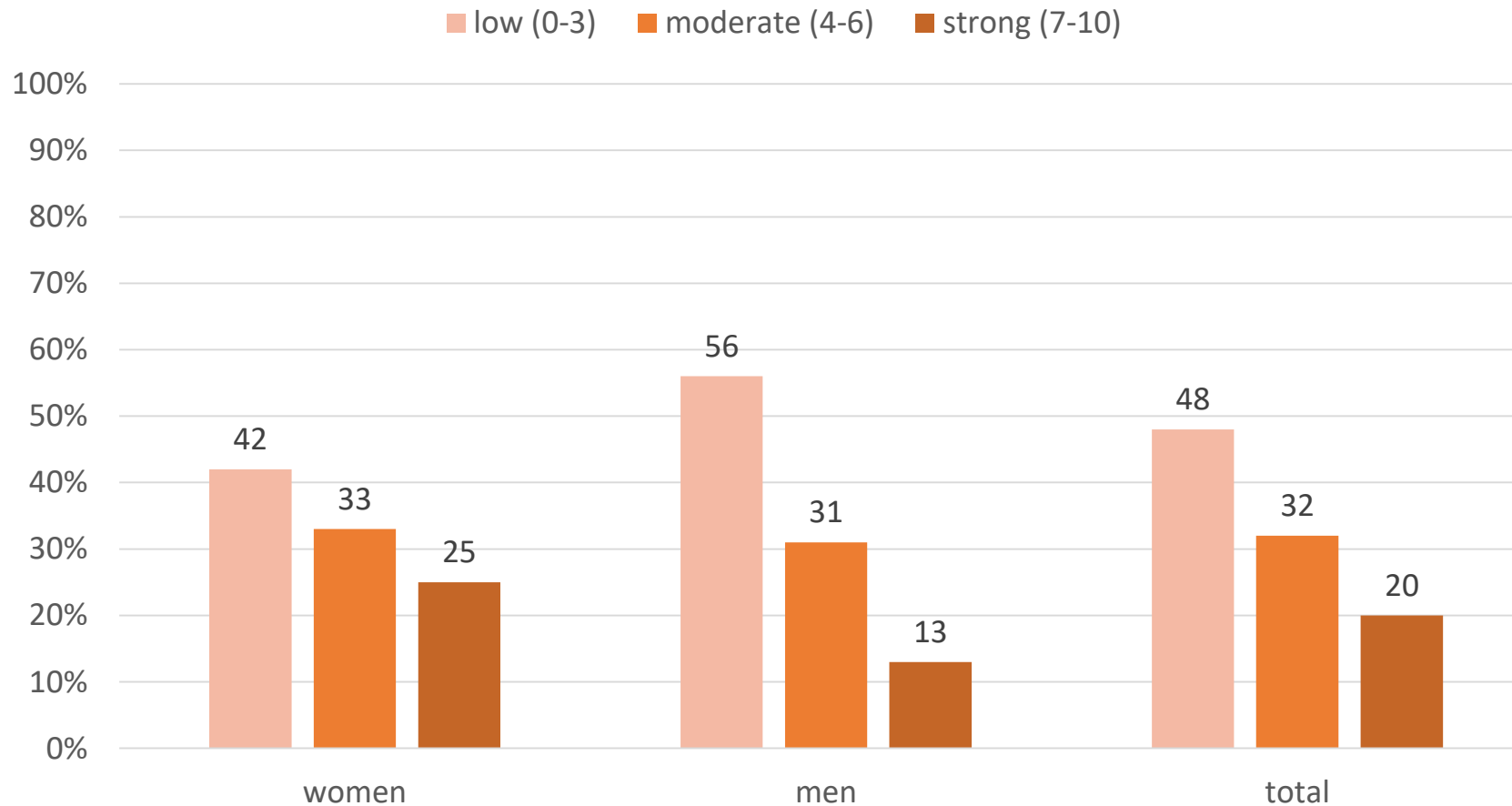




"How satisfied are you with the success / tolerability of your current rheumatism therapy?"

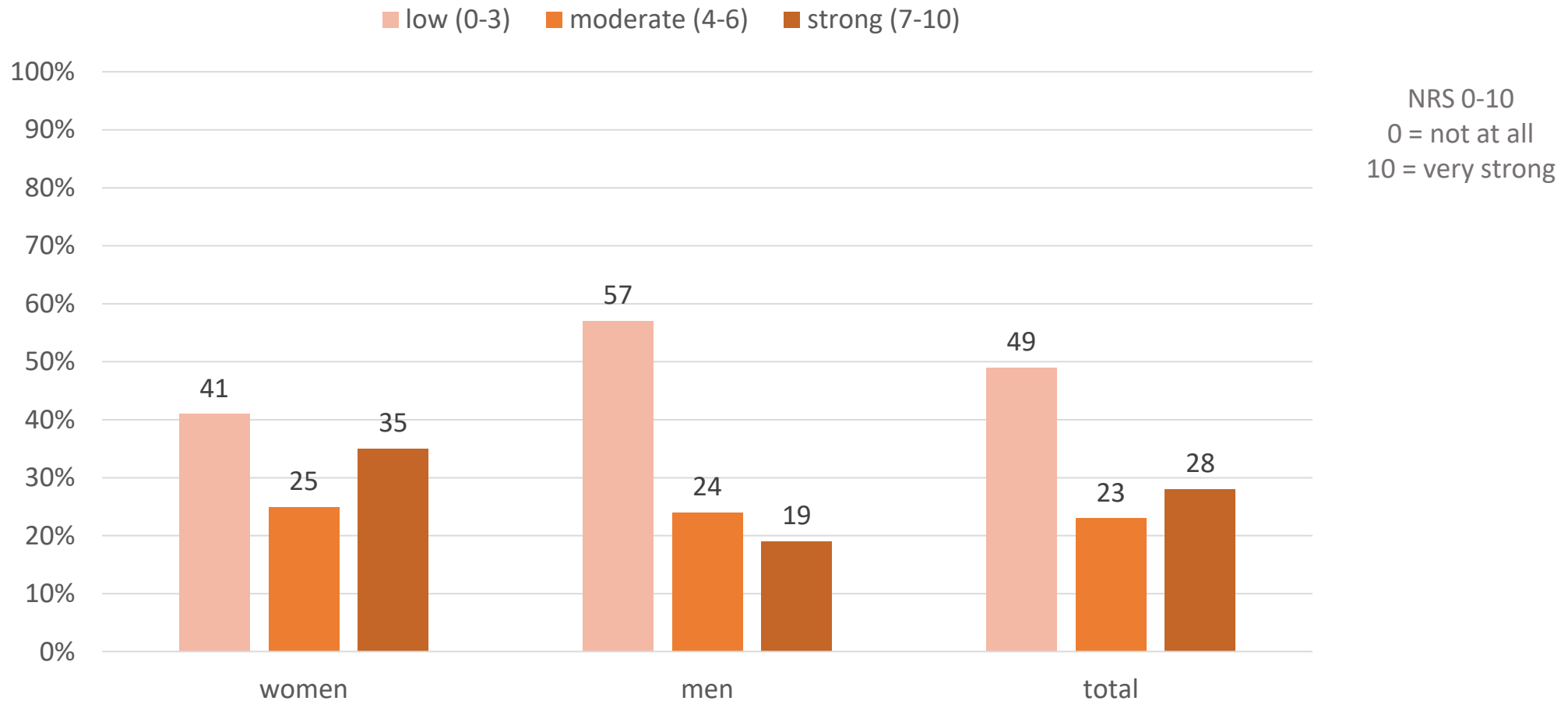


"How would you rate the intensity of your pain in the last 7 days?"

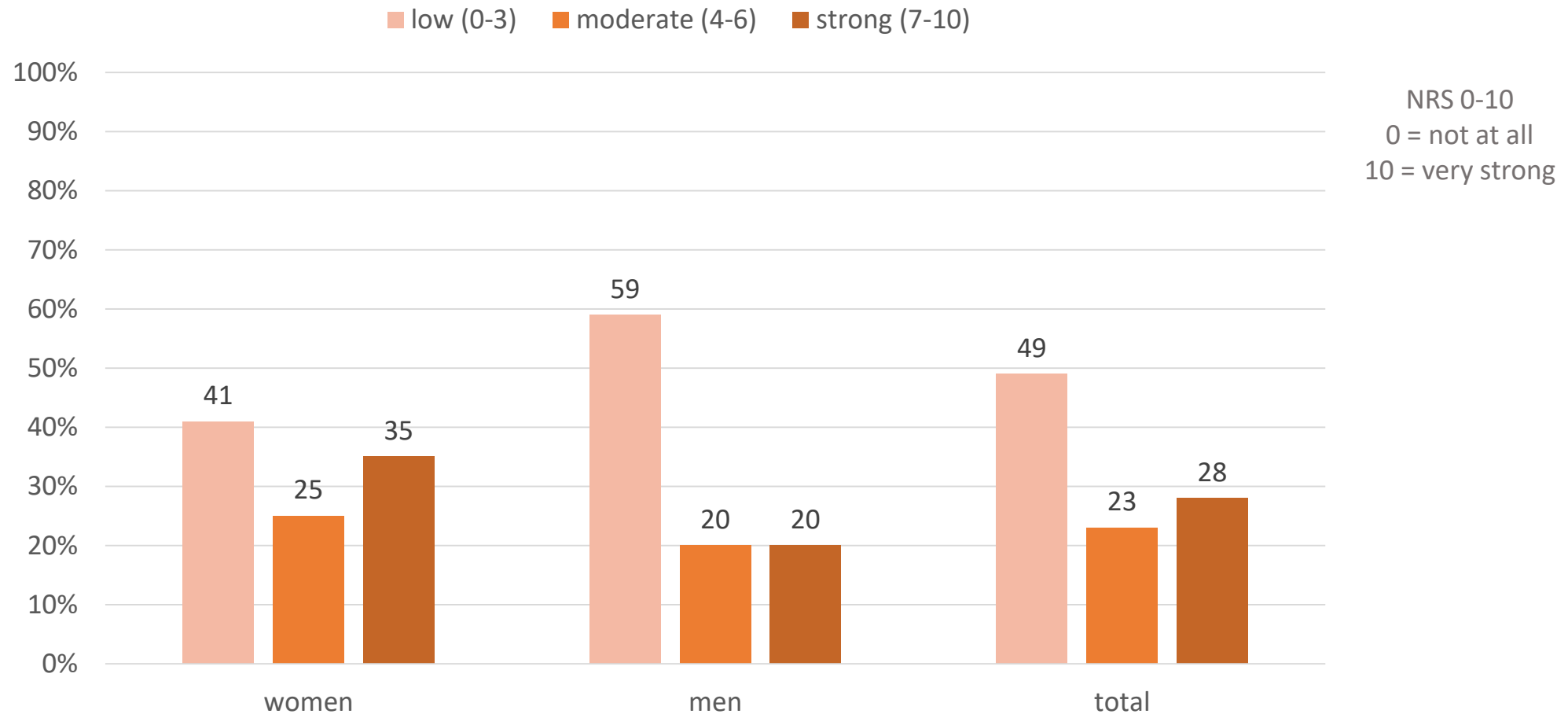


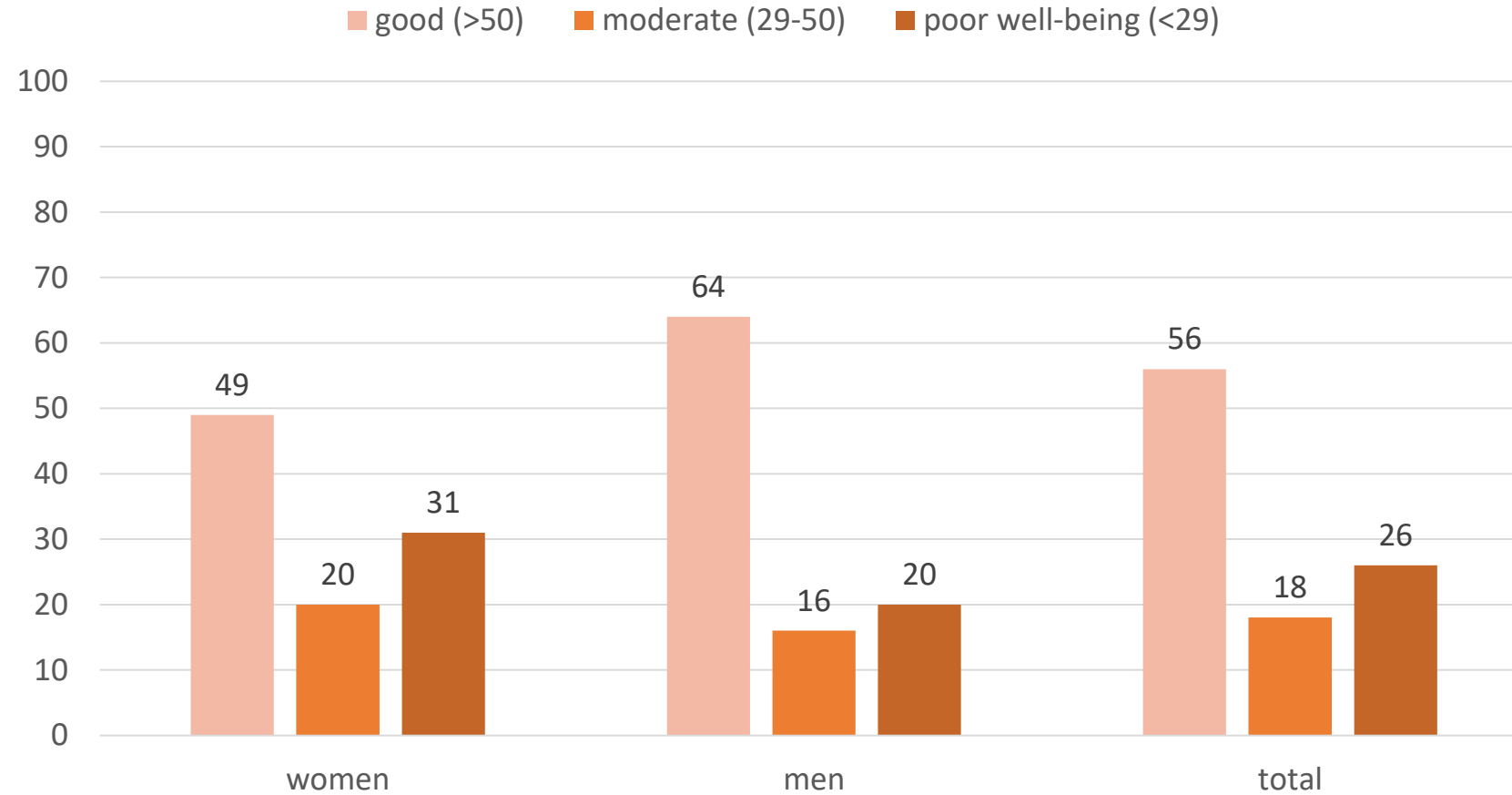
NRS 0-10  
0 = no pain  
10 = unbearable pain

"How much have you suffered from unusual exhaustion and tiredness in the last 7 days?"

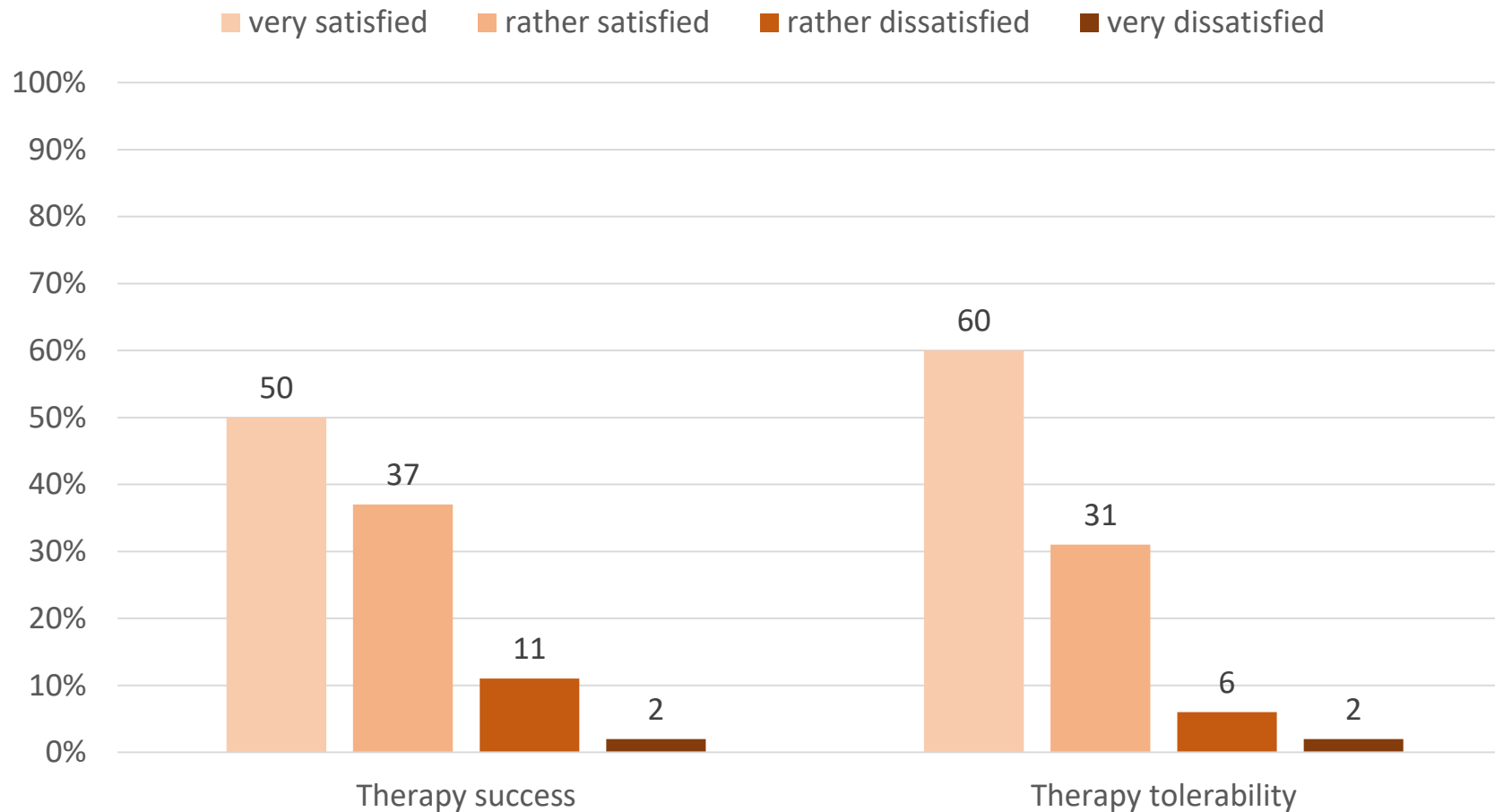


"Have you suffered from sleep disorders in the last 7 days? (Problems falling asleep or staying asleep)?"

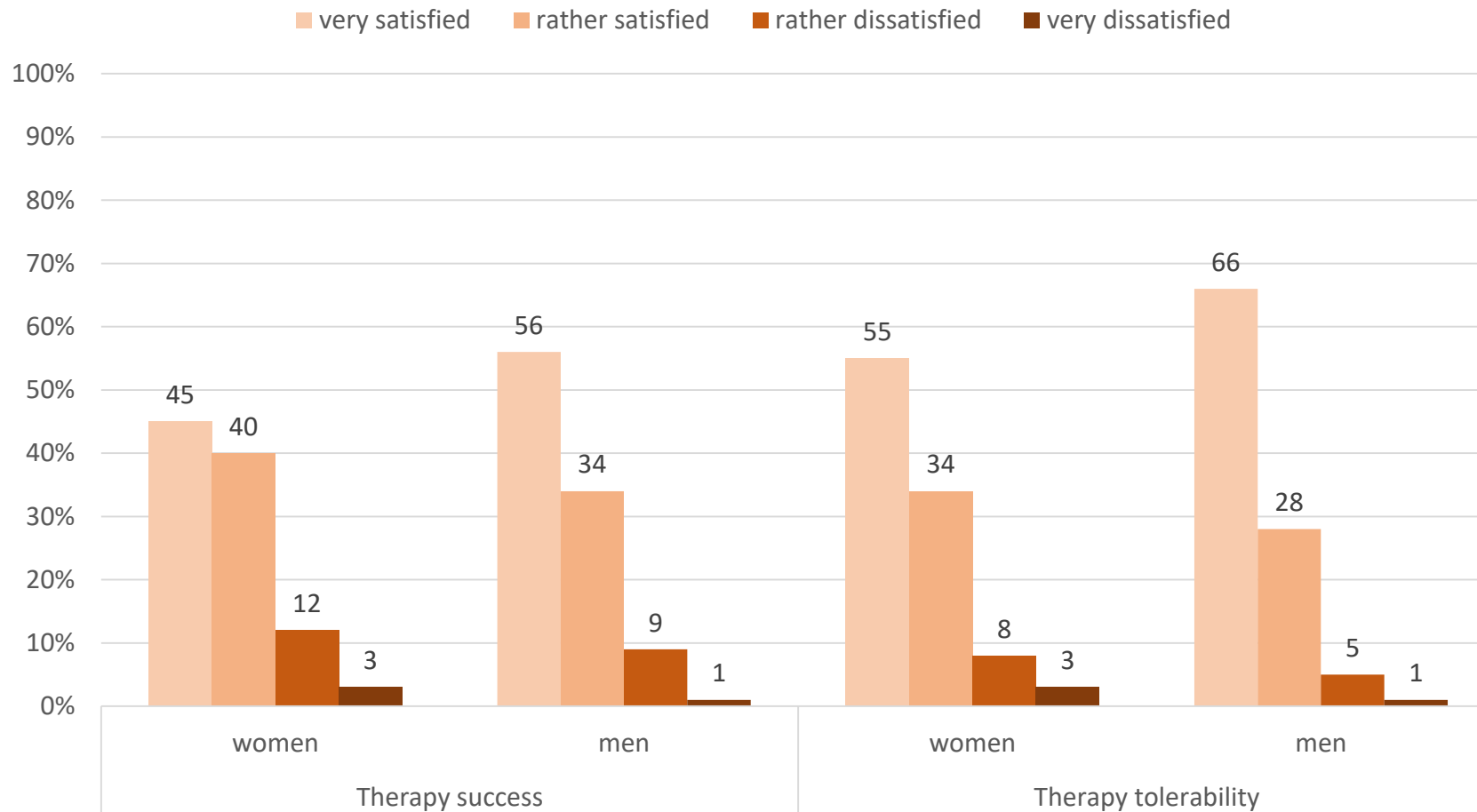




"How satisfied are you with the success/tolerability of your current rheumatism therapy?"

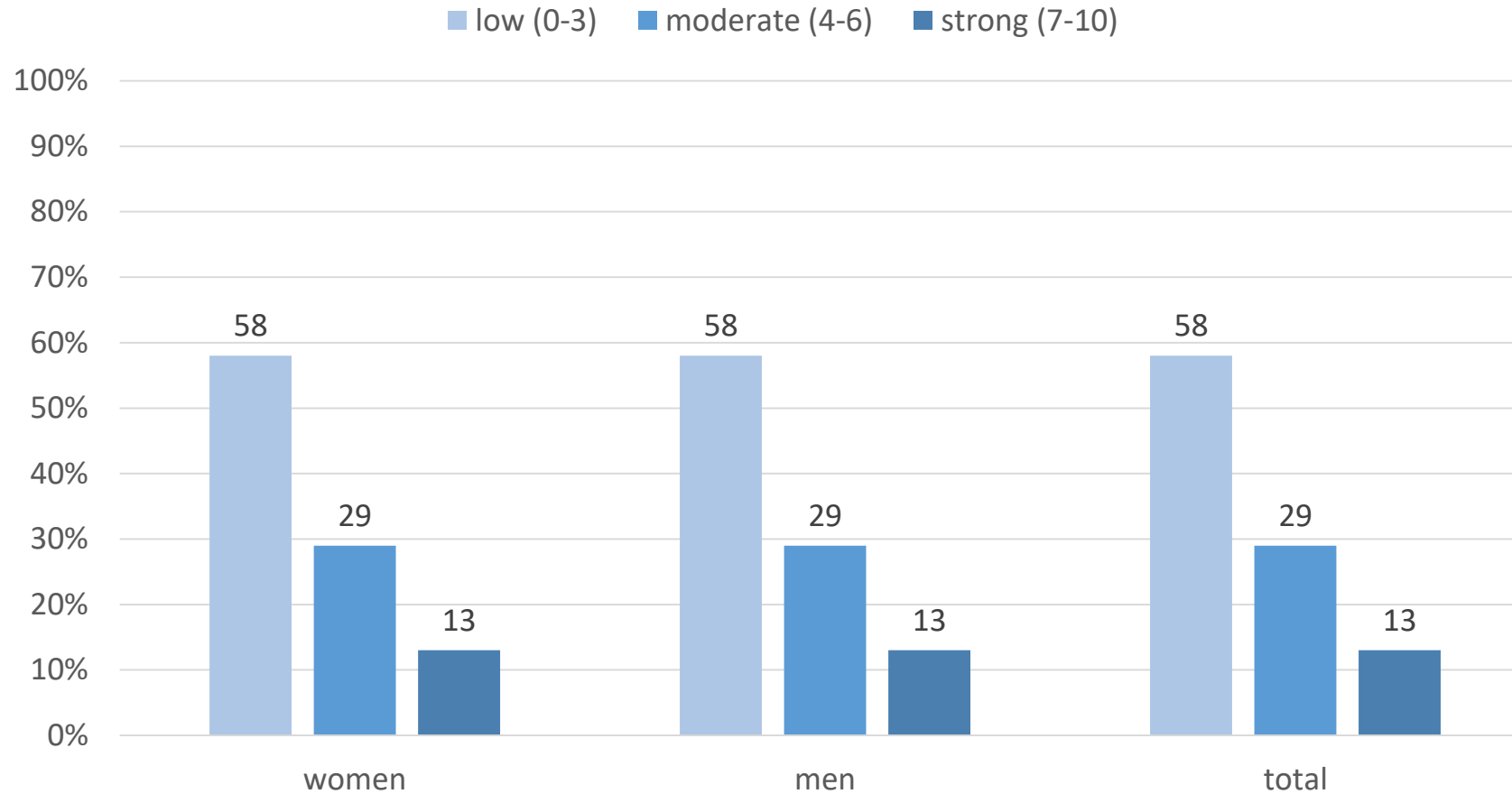


"How satisfied are you with the success/tolerability of your current rheumatism therapy?"





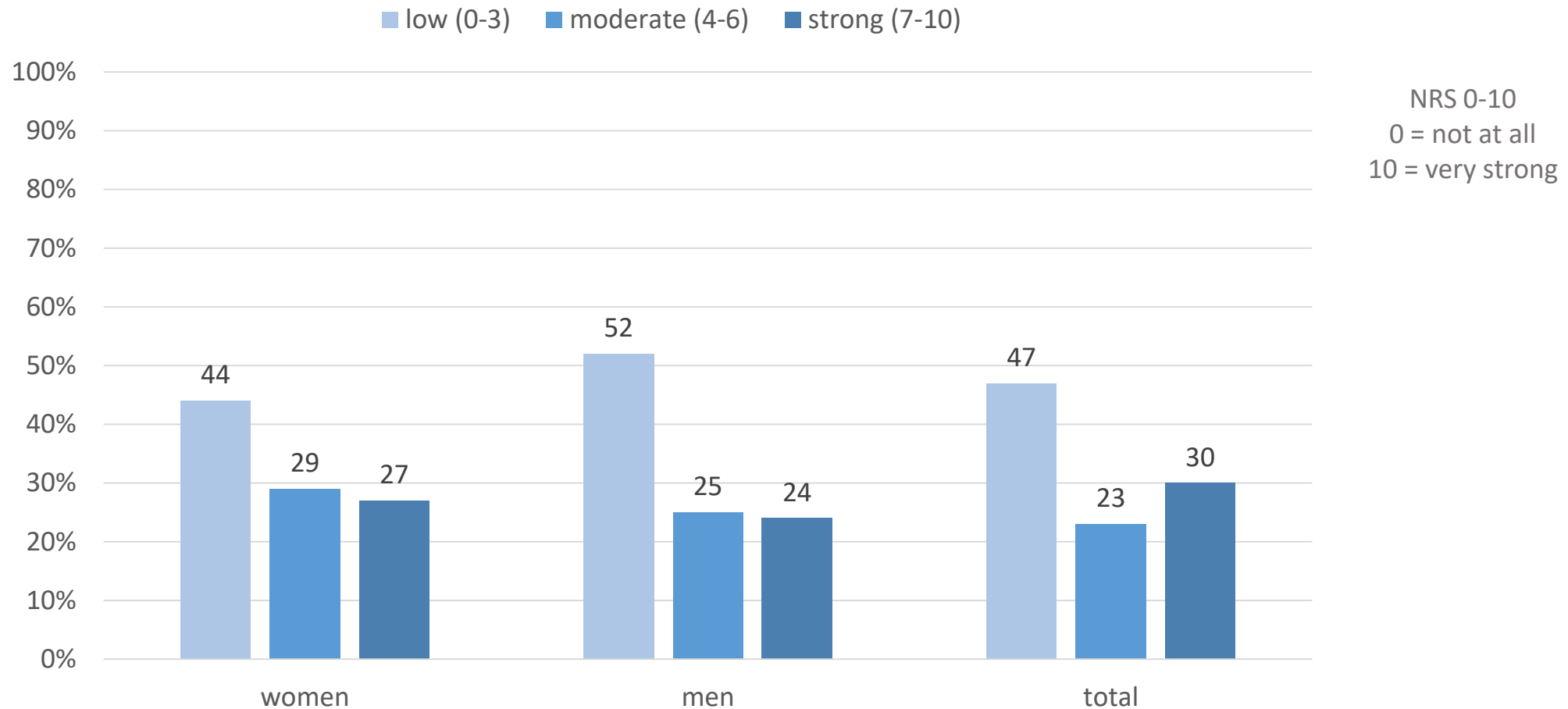
"How would you rate the intensity of your pain in the last 7 days?"



NRS 0-10  
0 = no pain  
10 = unbearable pain

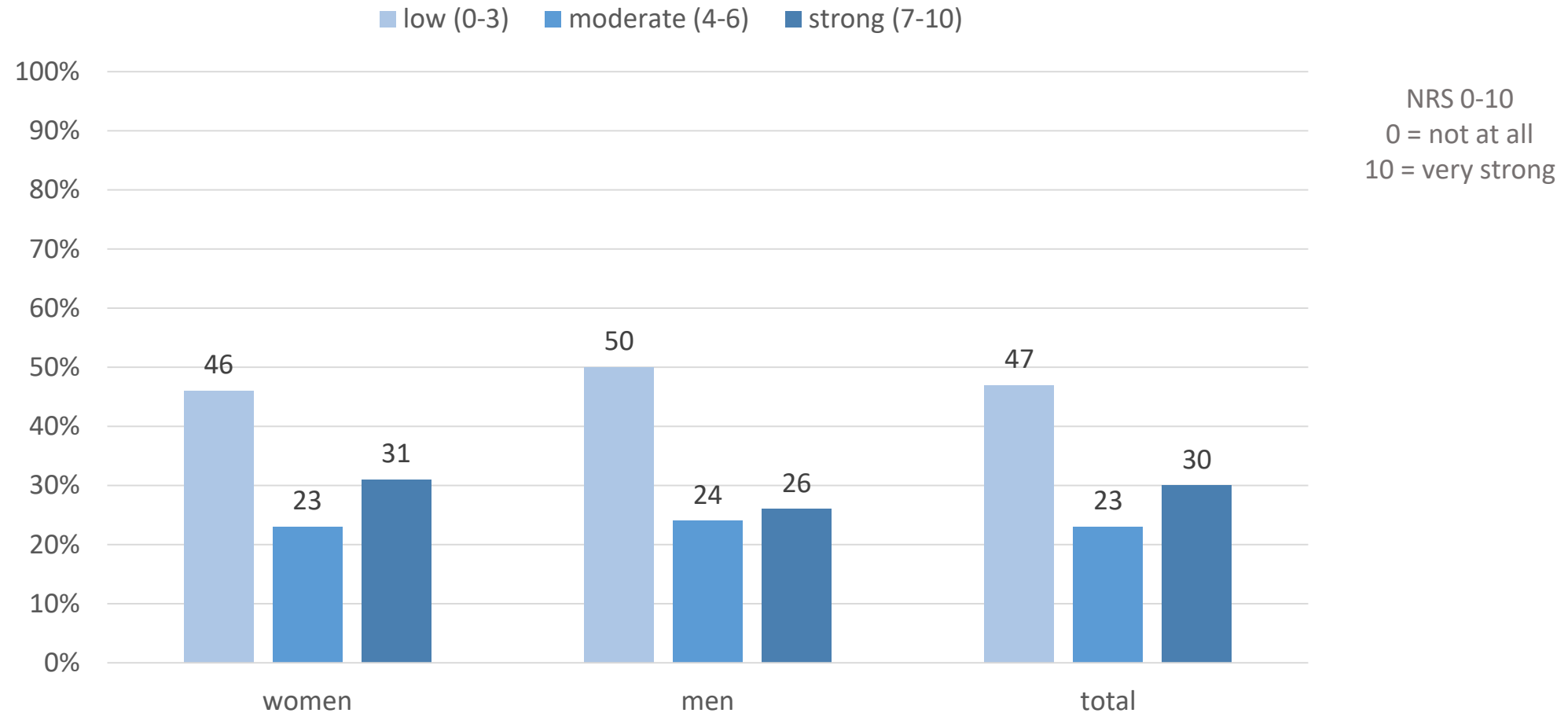


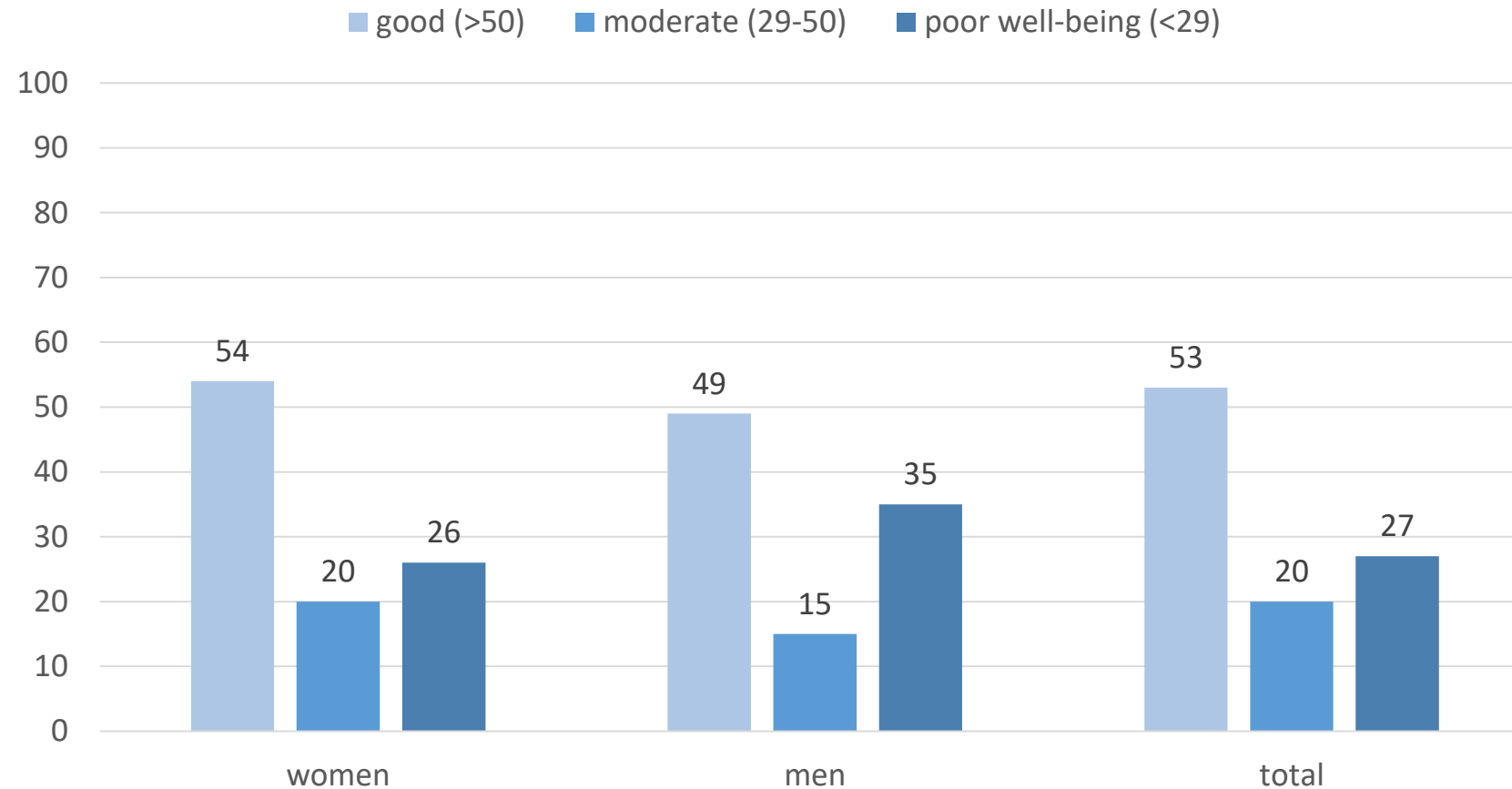
"How much have you suffered from unusual exhaustion and tiredness in the last 7 days?"



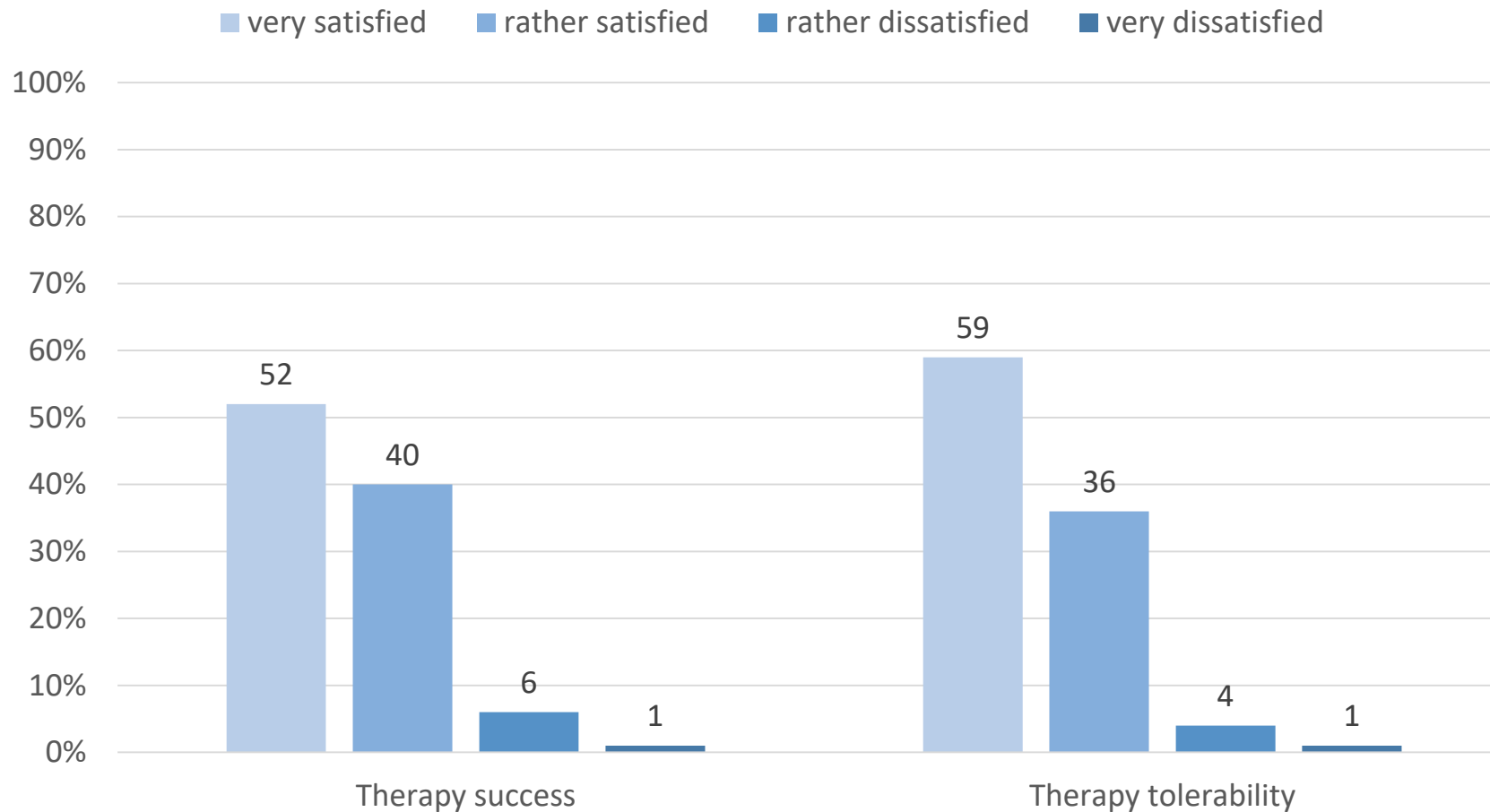


"Have you suffered from sleep disorders in the last 7 days? (Problems falling asleep or staying asleep)?"





"How satisfied are you with the success/tolerability of your current rheumatism therapy?"





# Employment Hospitalisation

Professional situation  
Employment  
Retirement, disability pension  
Sick leave  
Hospitalisation  
Medical rehabilitation



# RA Retirement



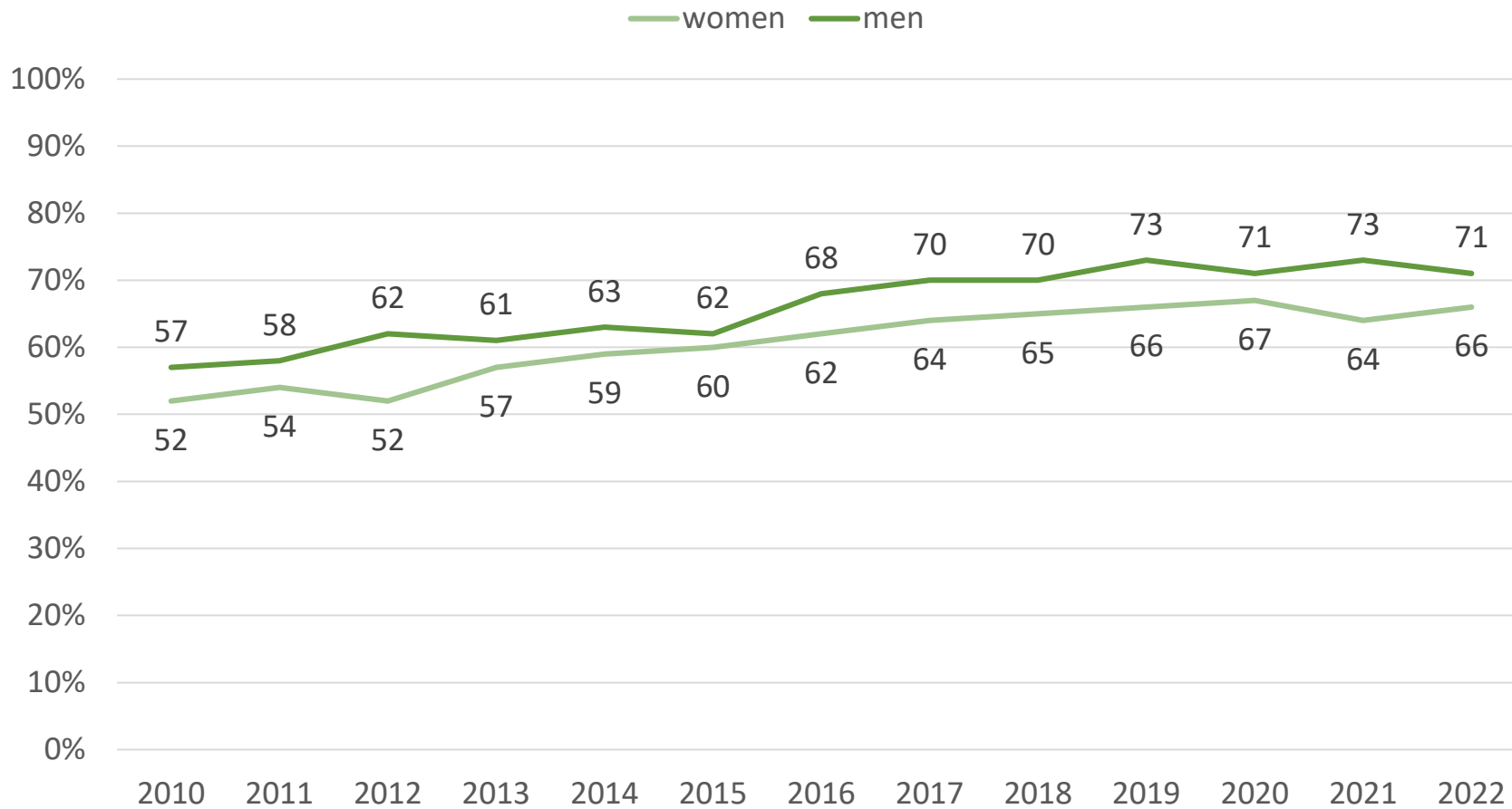
Reason for retirement (%) for pension statement < 65 years (18%)



Source: German National Database, data collected in 2022 n=2,627 RA patients <65 years with information on their professional situation



Proportion of employed persons < 65 years in full-time or part-time employment (%)



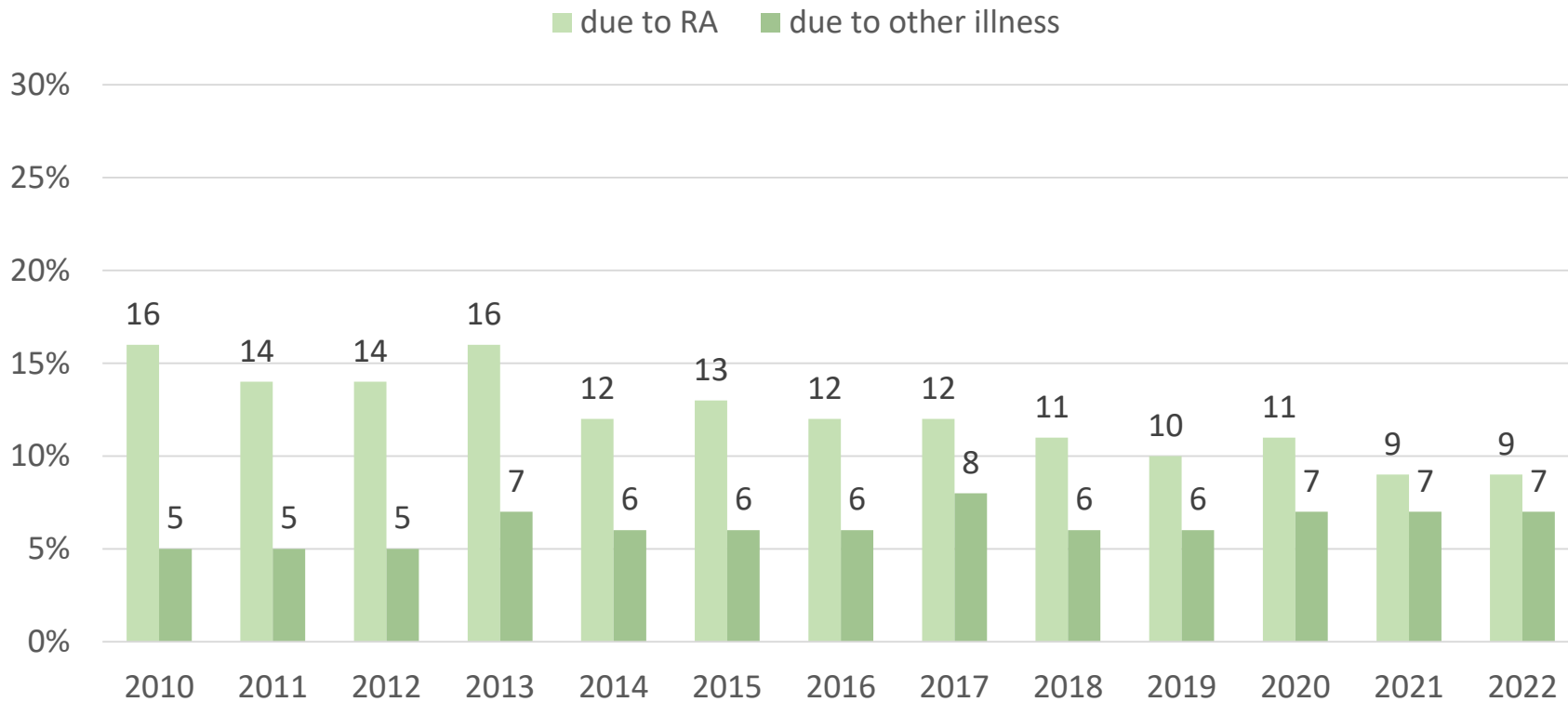
Source: German National Database, data collected in 2022

N=2,236 (2010) to n=2,627 (2022) RA patients <65 years with information on their professional situation



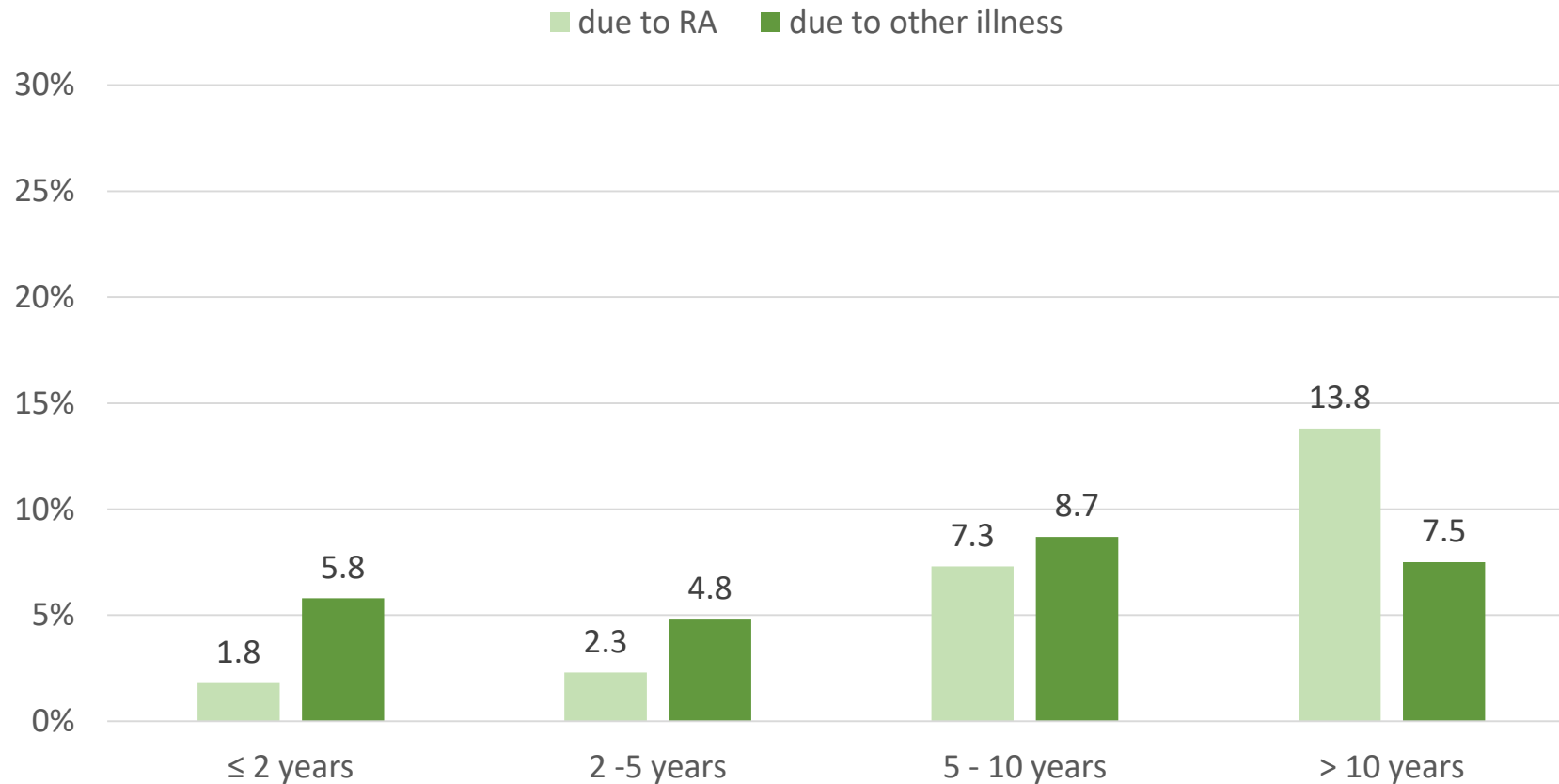


Proportion of people aged < 65 (%) with disability pension 2010-2021





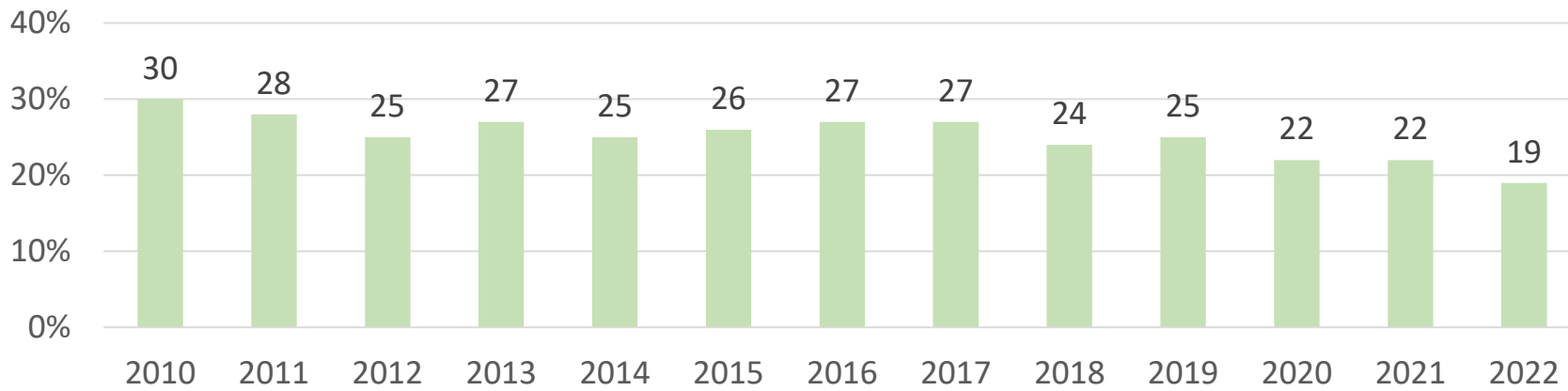
Proportion of people (%) <65 years with disability pension by disease duration



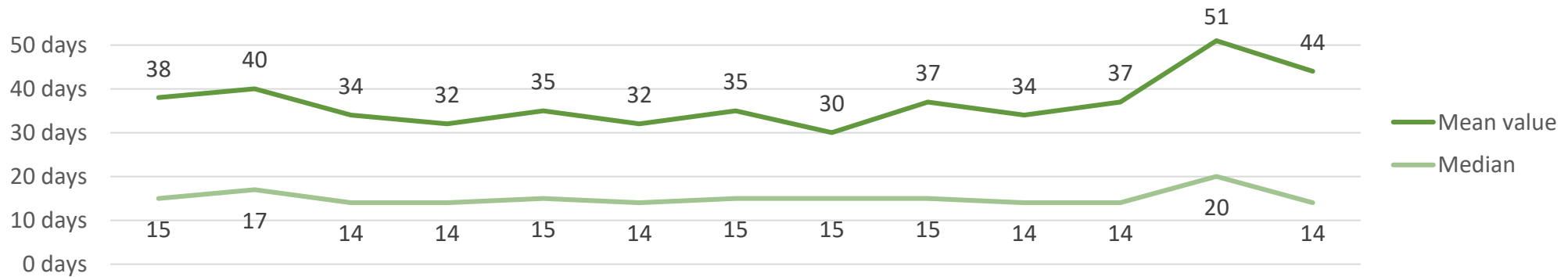
Source: German National Database, data collected in 2022

n=2,585 RA patients <65 years with information on pension and disease duration

Proportion of employed persons with sick leave in the last 12 months due to rheumatic disease



Average sick leave duration in days



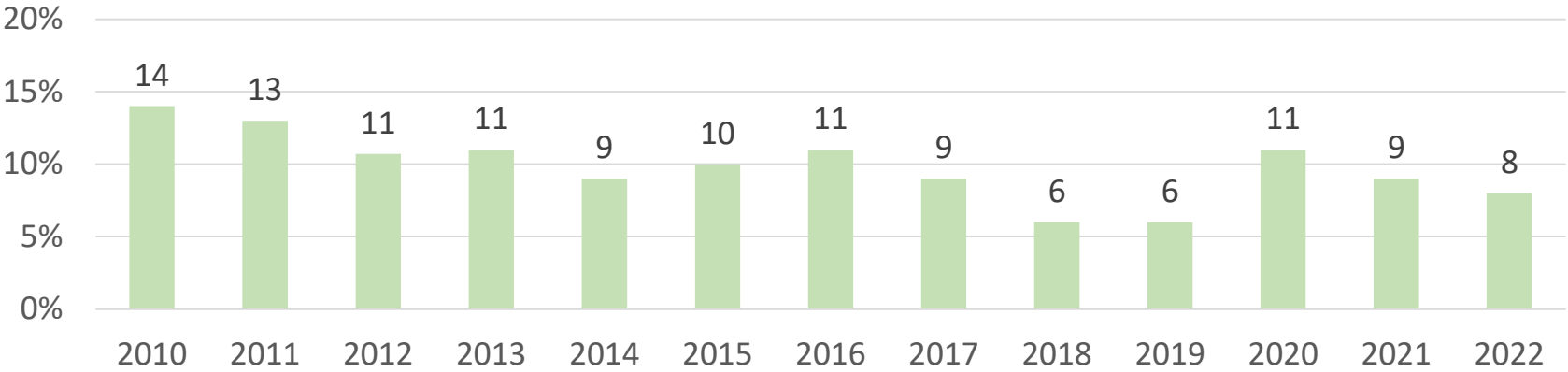
Source: German National Database, data collected in 2022

n=1,131 (2010) to n= 1,737 (2022) employed RA patients with information on sick leave

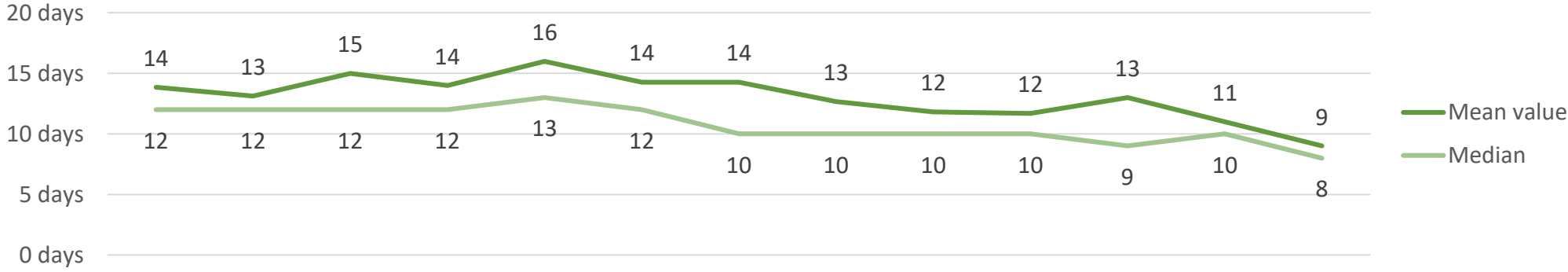
# RA Hospitalisation



Proportion of people hospitalised in the last 12 months due to rheumatic disease



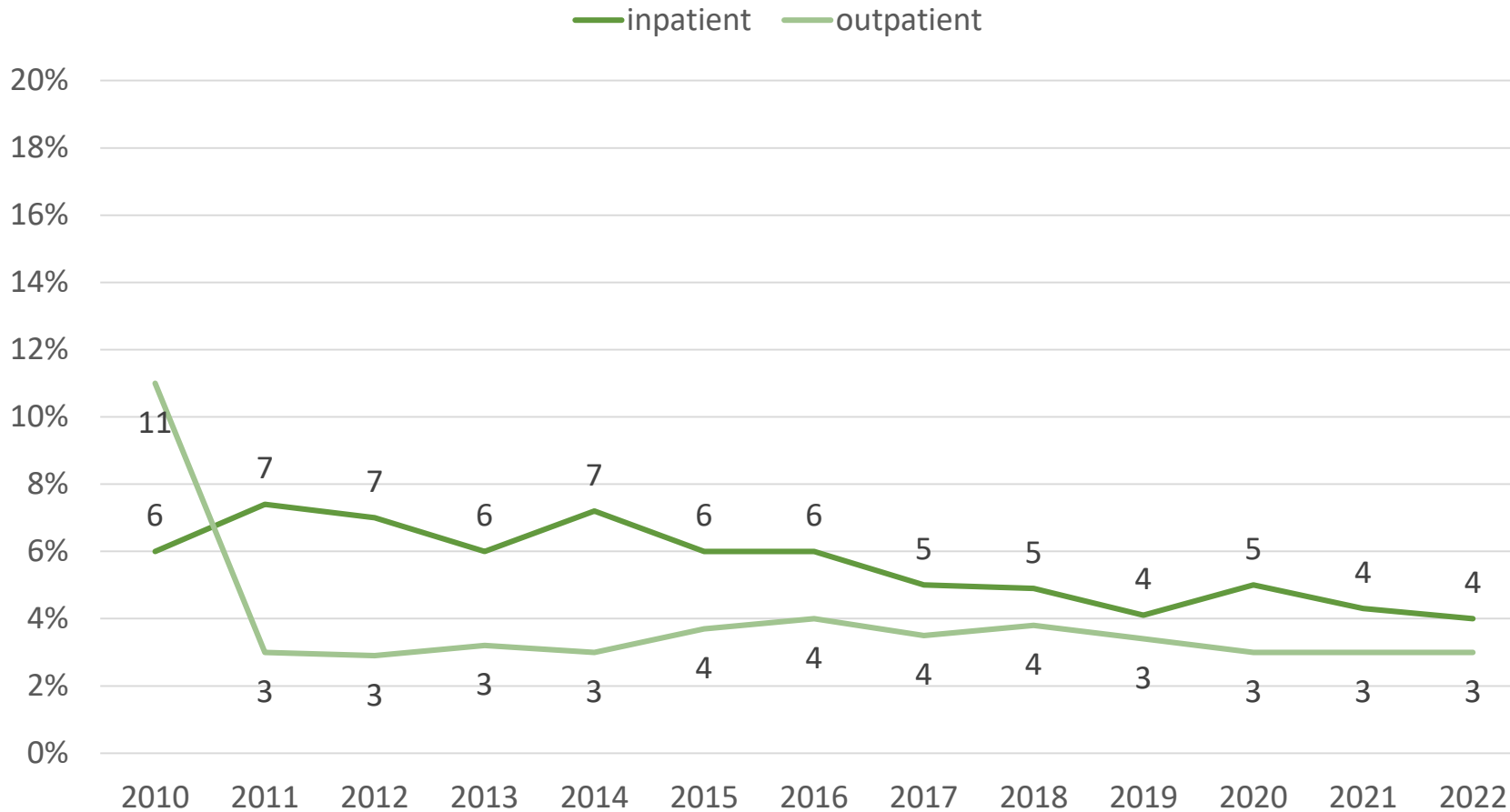
Average length of stay in days



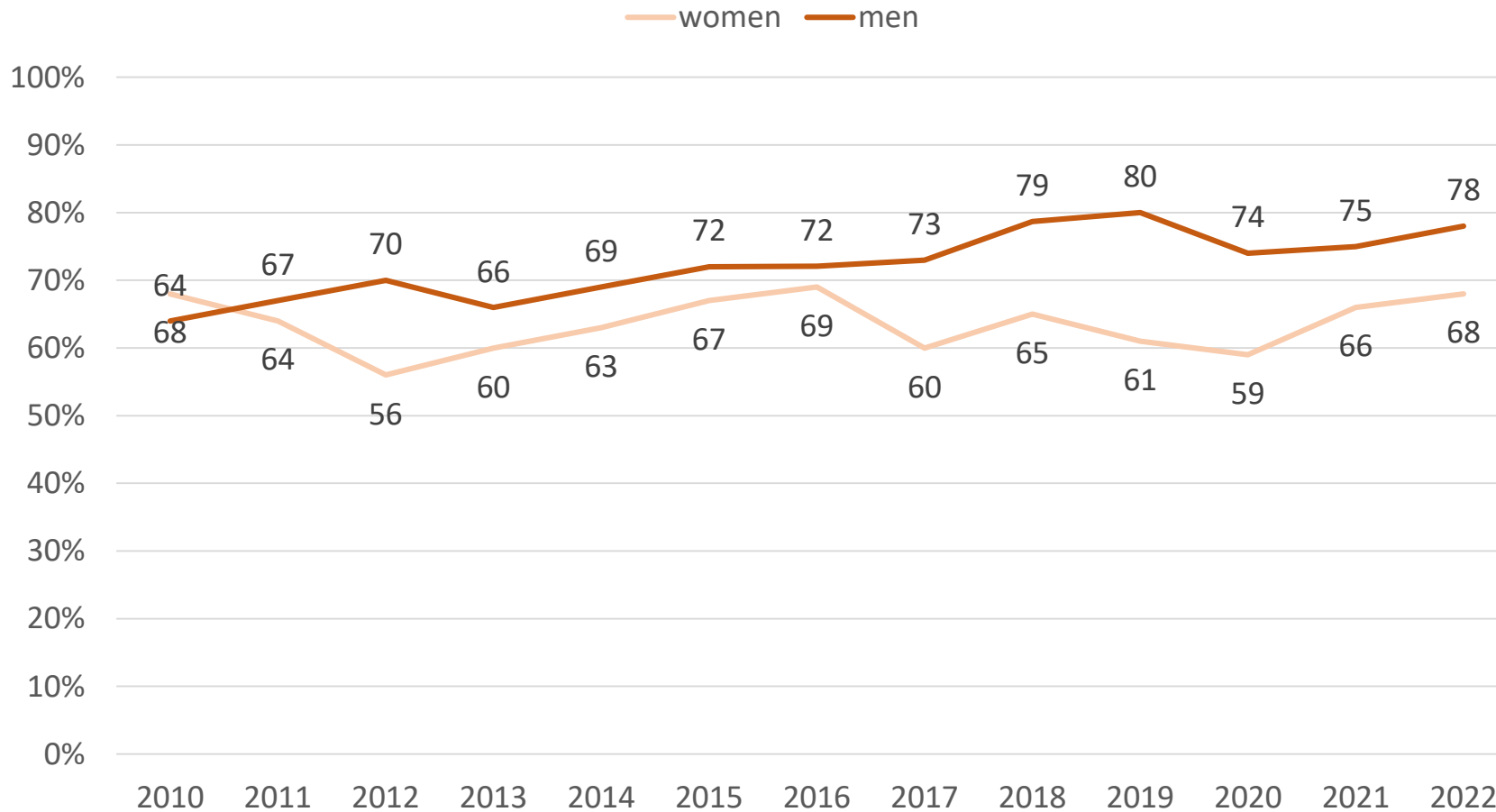
Source: German National Database, data collected in 2022

n=4,318 (2010) to n=5004 (2022) RA patients with information on inpatient stays

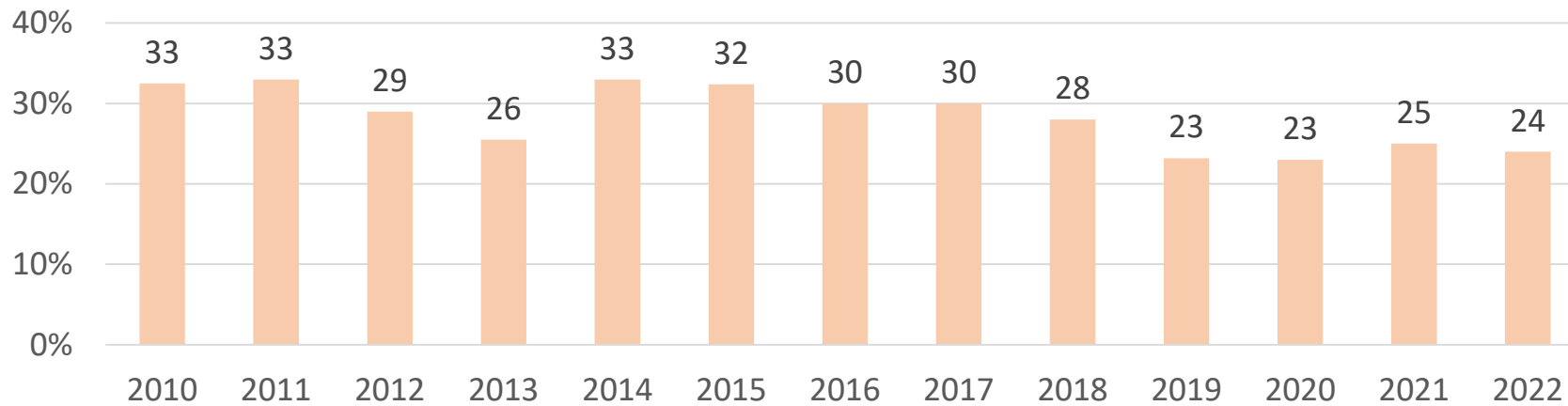
Proportion of patients with medical rehabilitation in the last 12 months



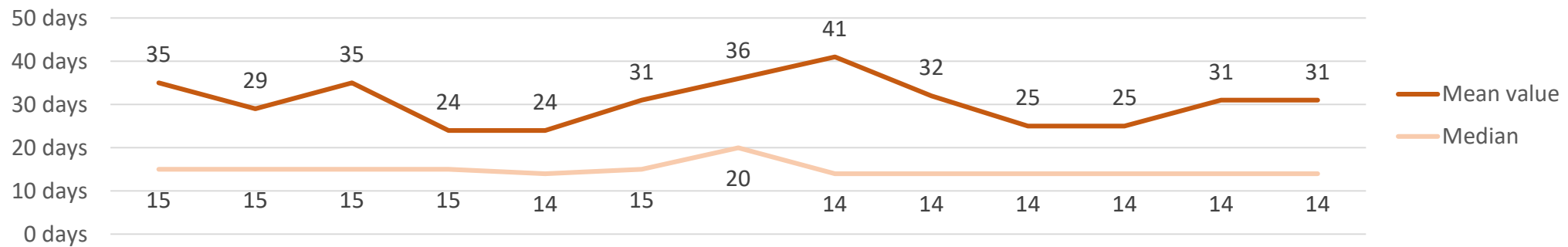
Proportion of employed persons < 65 years in full-time or part-time employment (%)



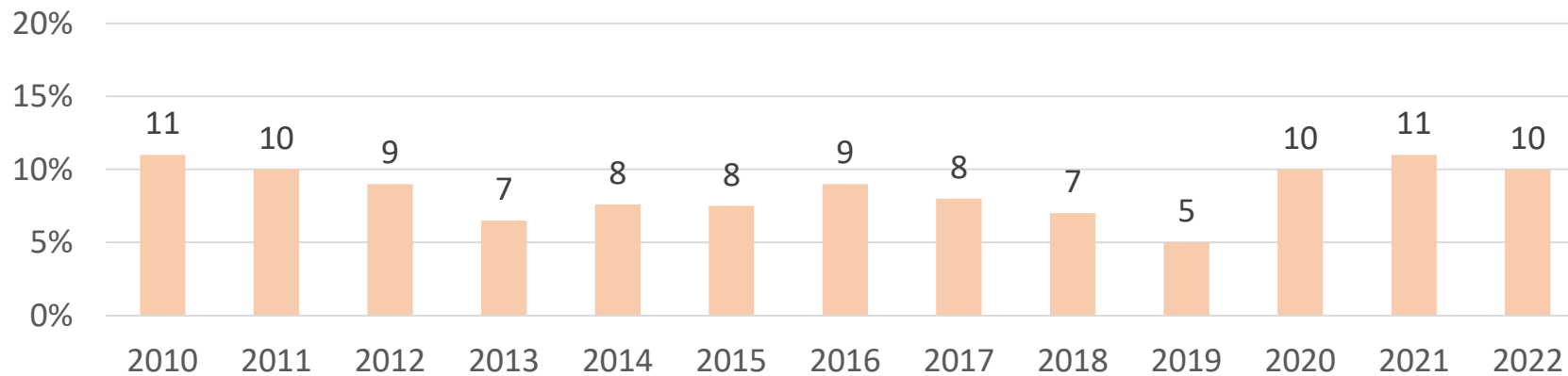
Proportion of employed persons with sick leave in the last 12 months due to rheumatic disease



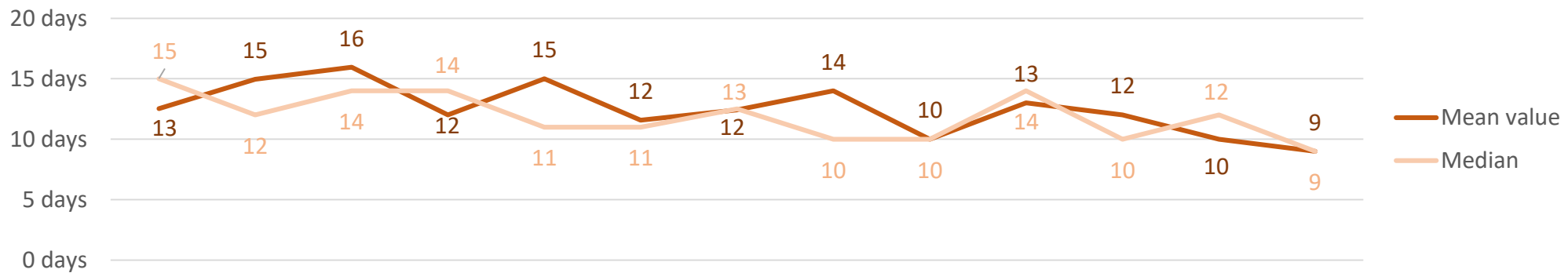
Average sick leave duration in days



Proportion of people hospitalised in the last 12 months due to rheumatic disease

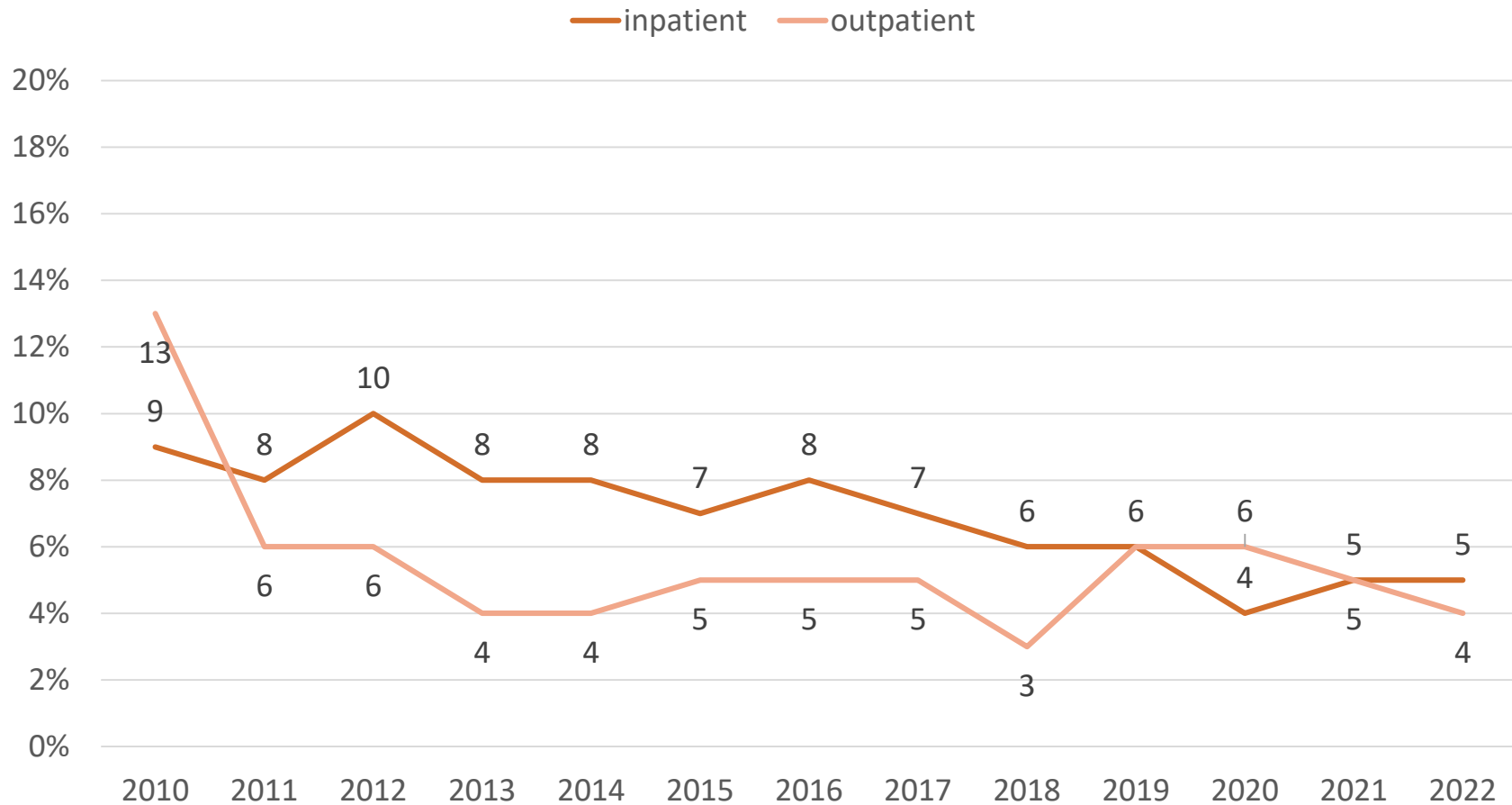


Average length of stay in days

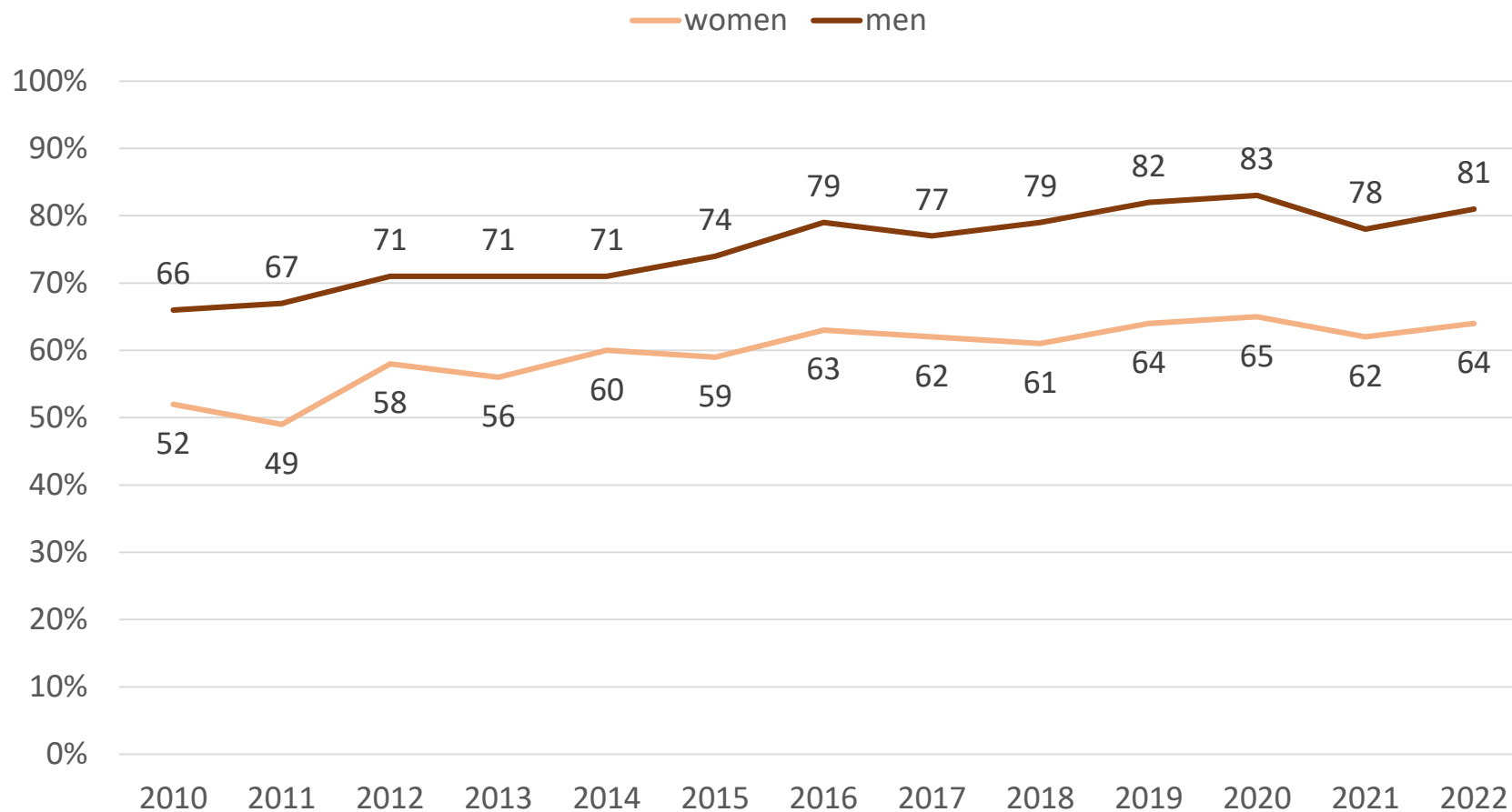




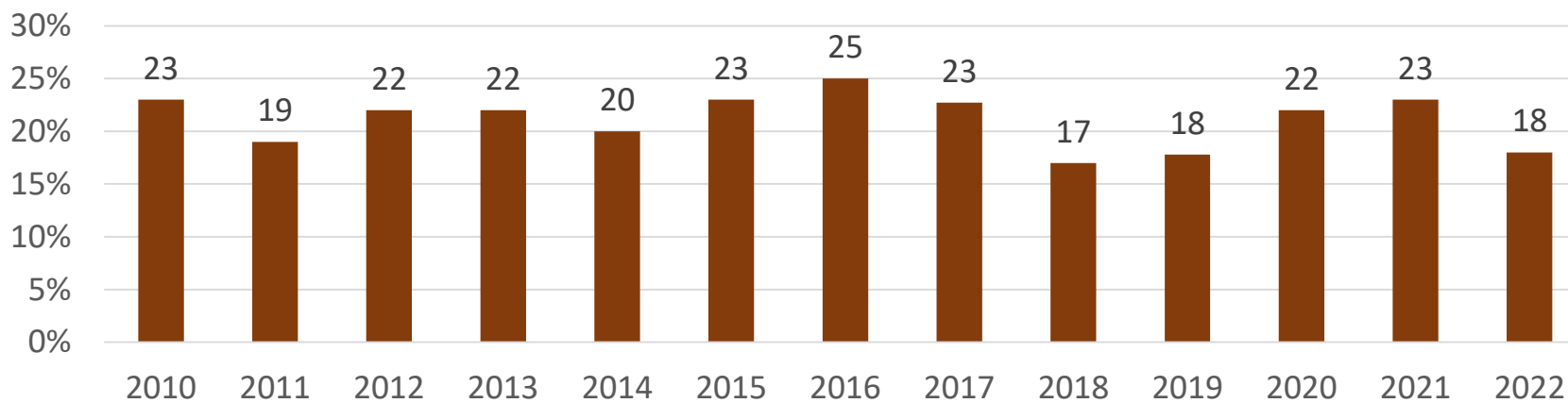
Proportion of patients with medical rehabilitation in the last 12 months



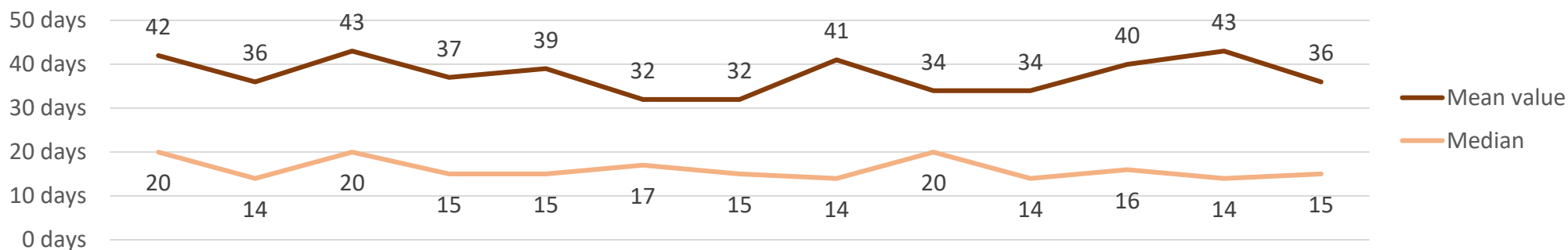
Proportion of employed persons < 65 years in full-time or part-time employment (%)



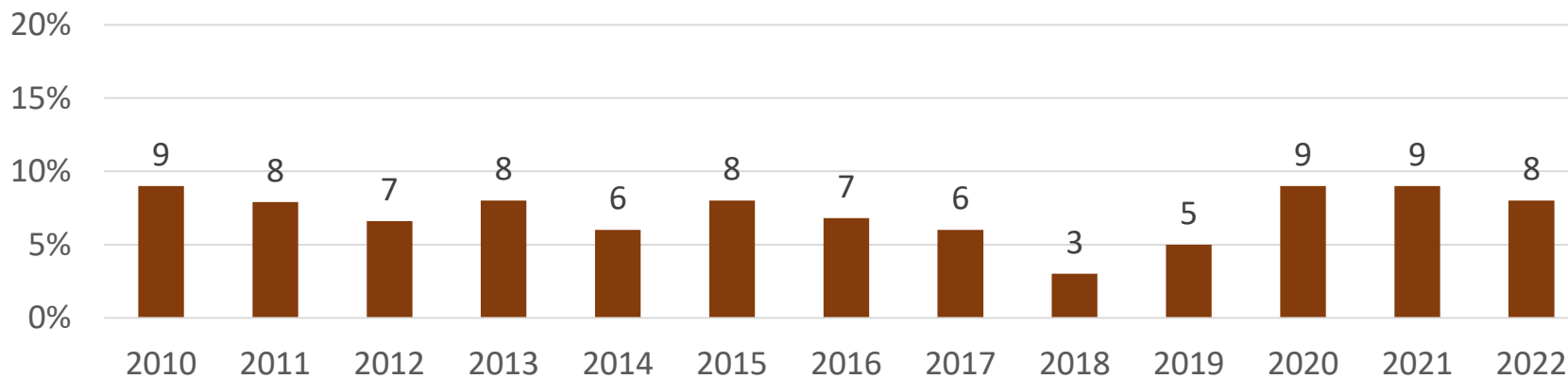
Proportion of employed persons with sick leave in the last 12 months due to rheumatic disease



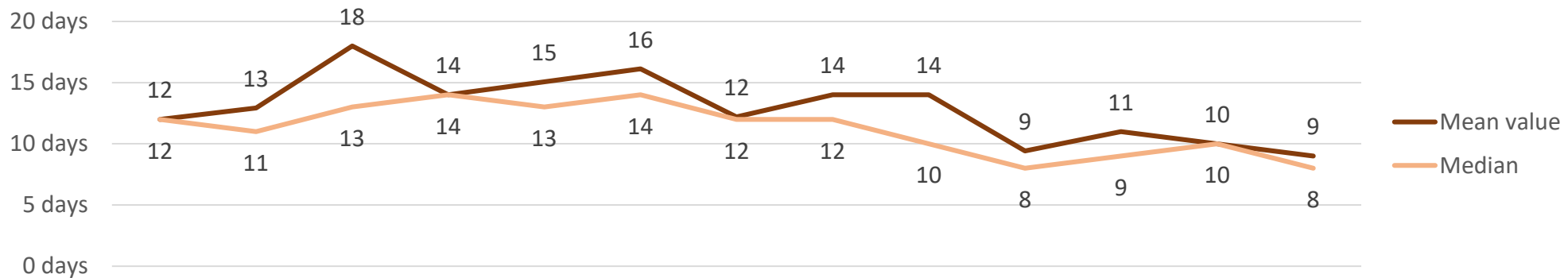
Average sick leave duration in days



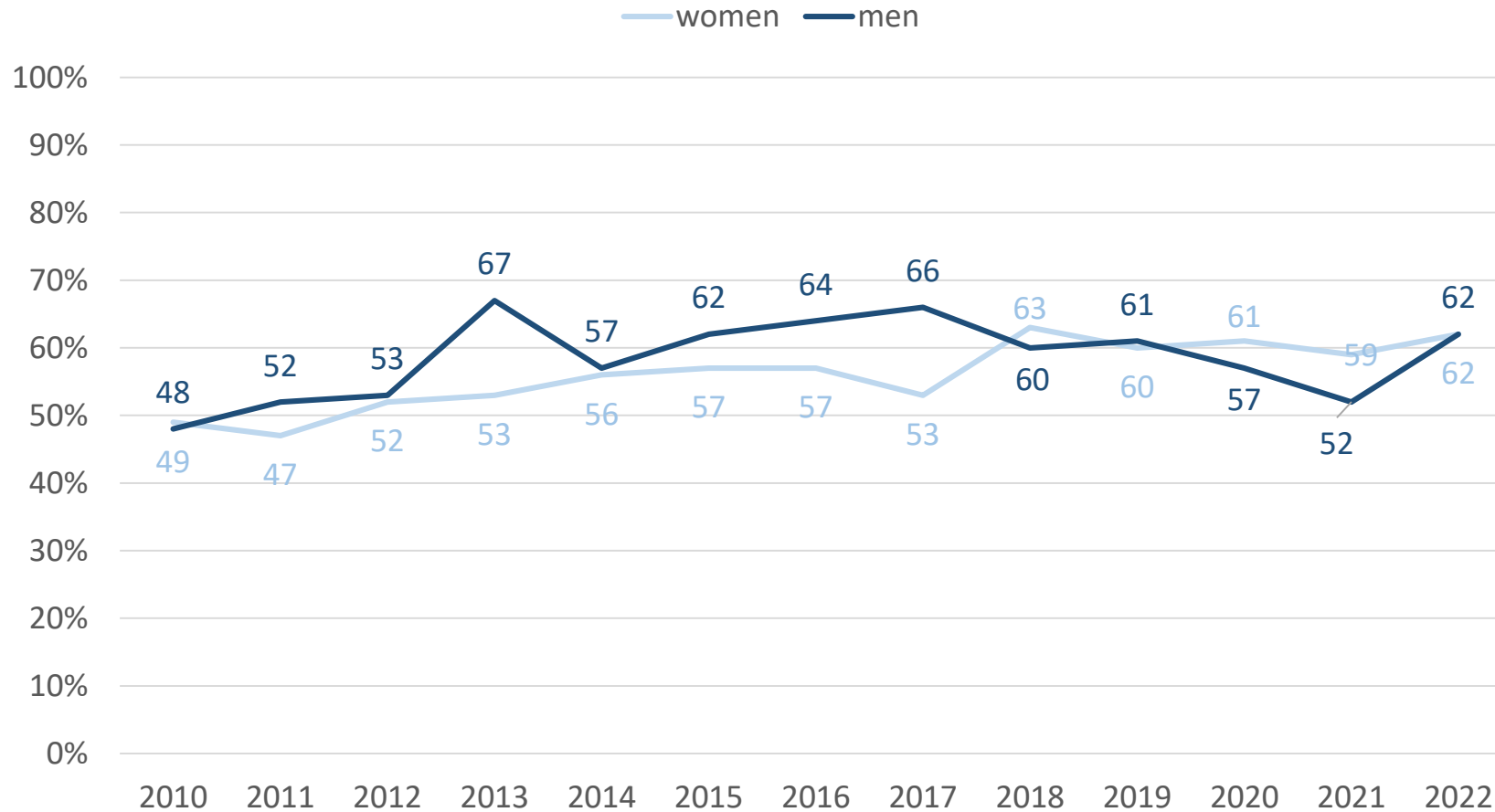
Proportion of people hospitalised in the last 12 months due to rheumatic disease



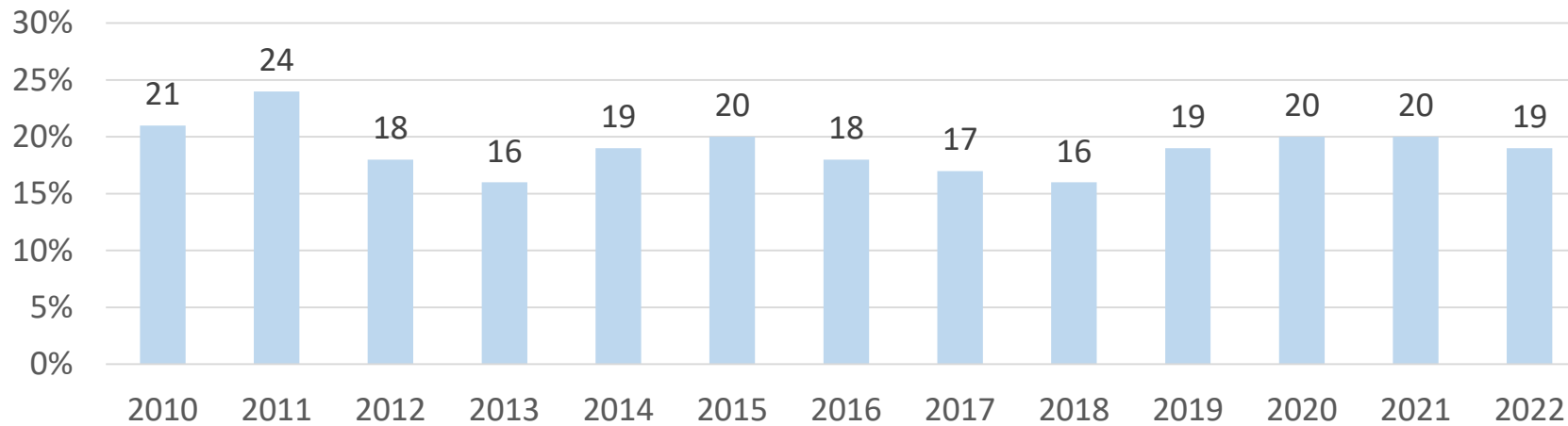
Average length of stay in days



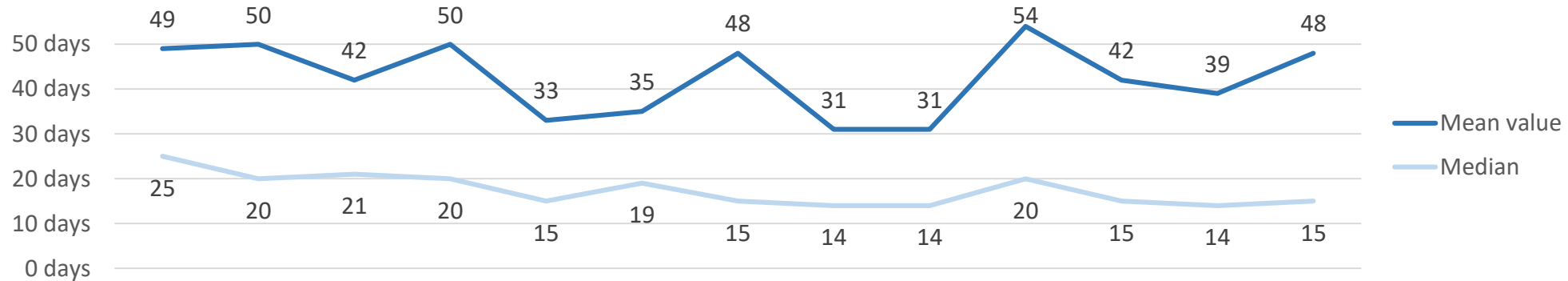
Proportion of employed persons < 65 years in full-time or part-time employment (%)



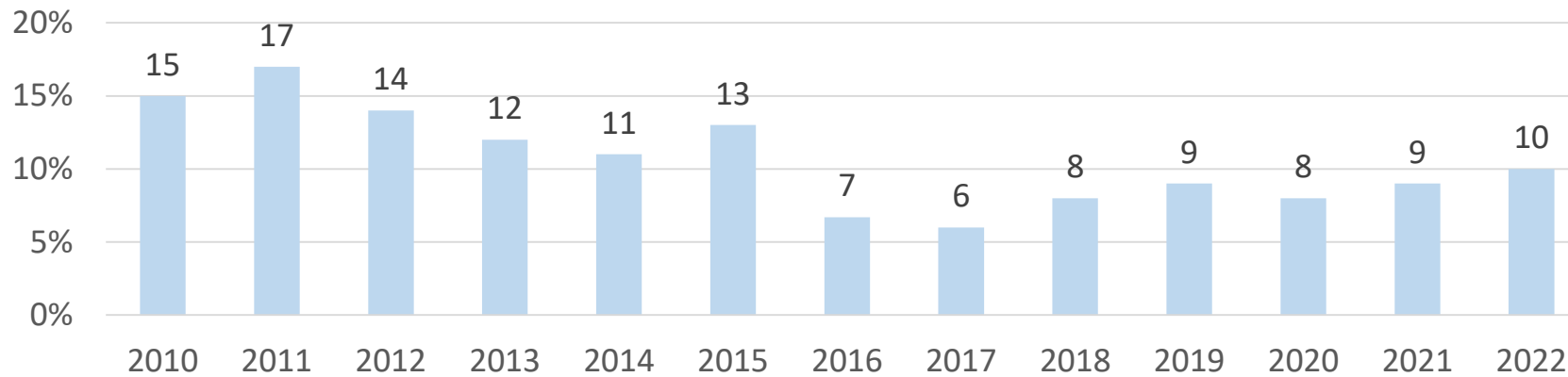
Proportion of employed persons with sick leave in the last 12 months due to rheumatic disease



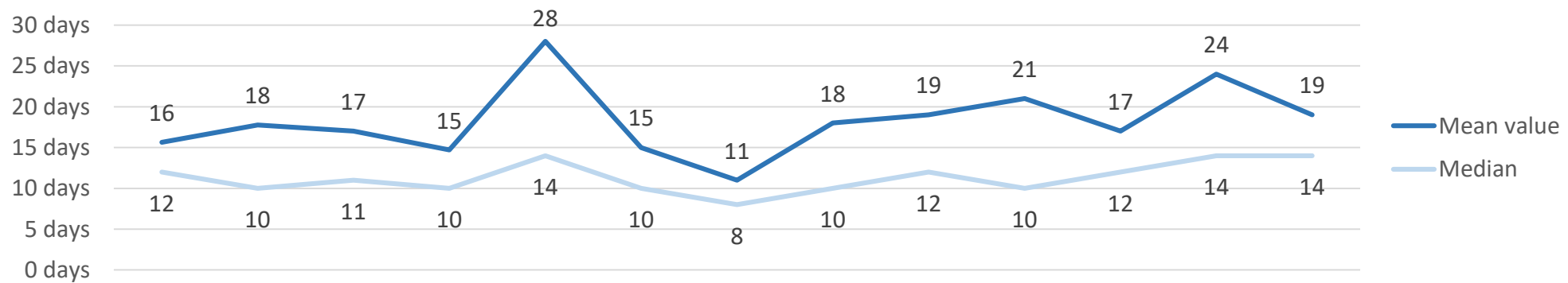
Average sick leave duration in days



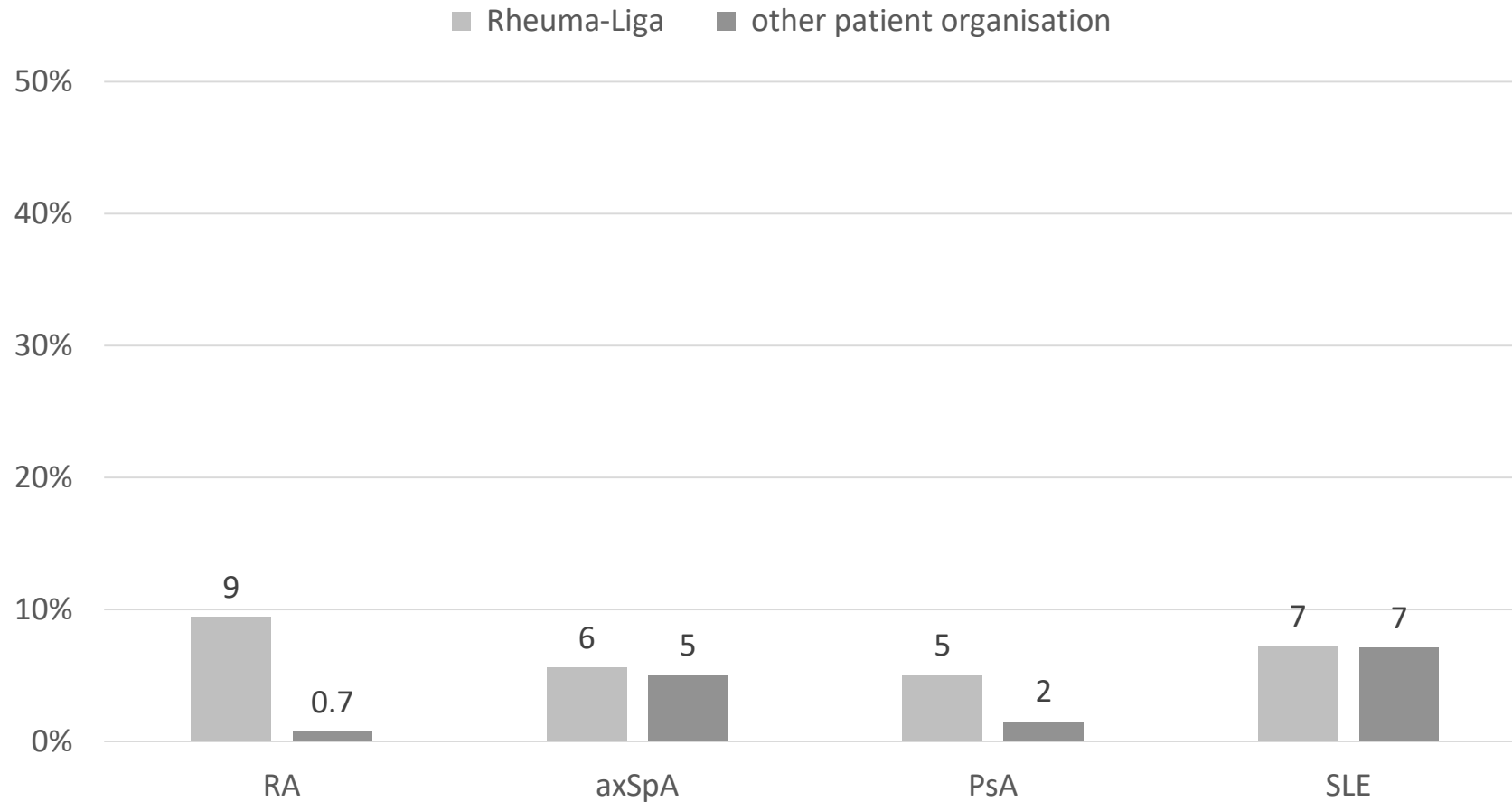
Proportion of people hospitalised in the last 12 months due to rheumatic disease



Average length of stay in days

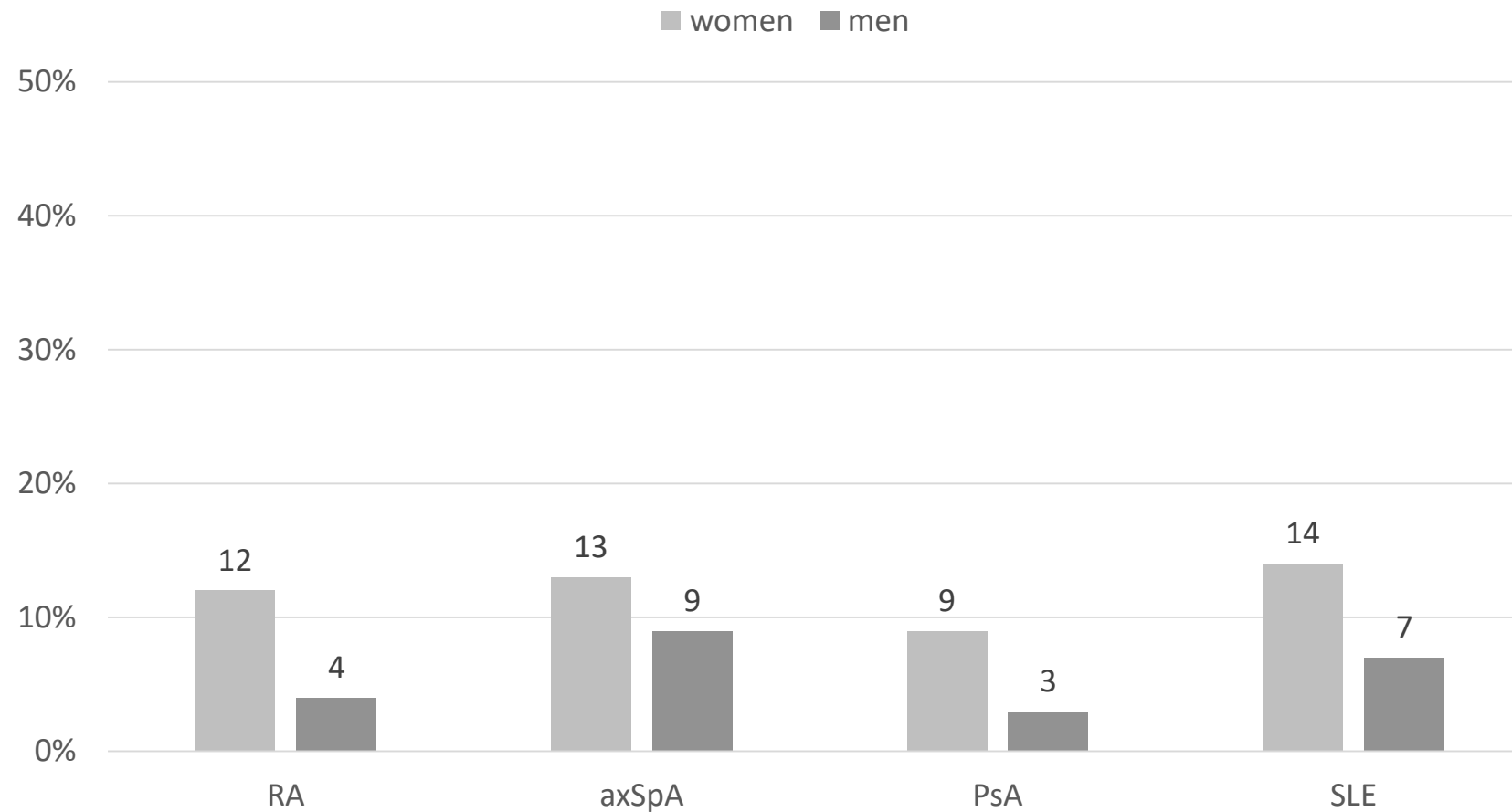


# Membership of a patient organisation

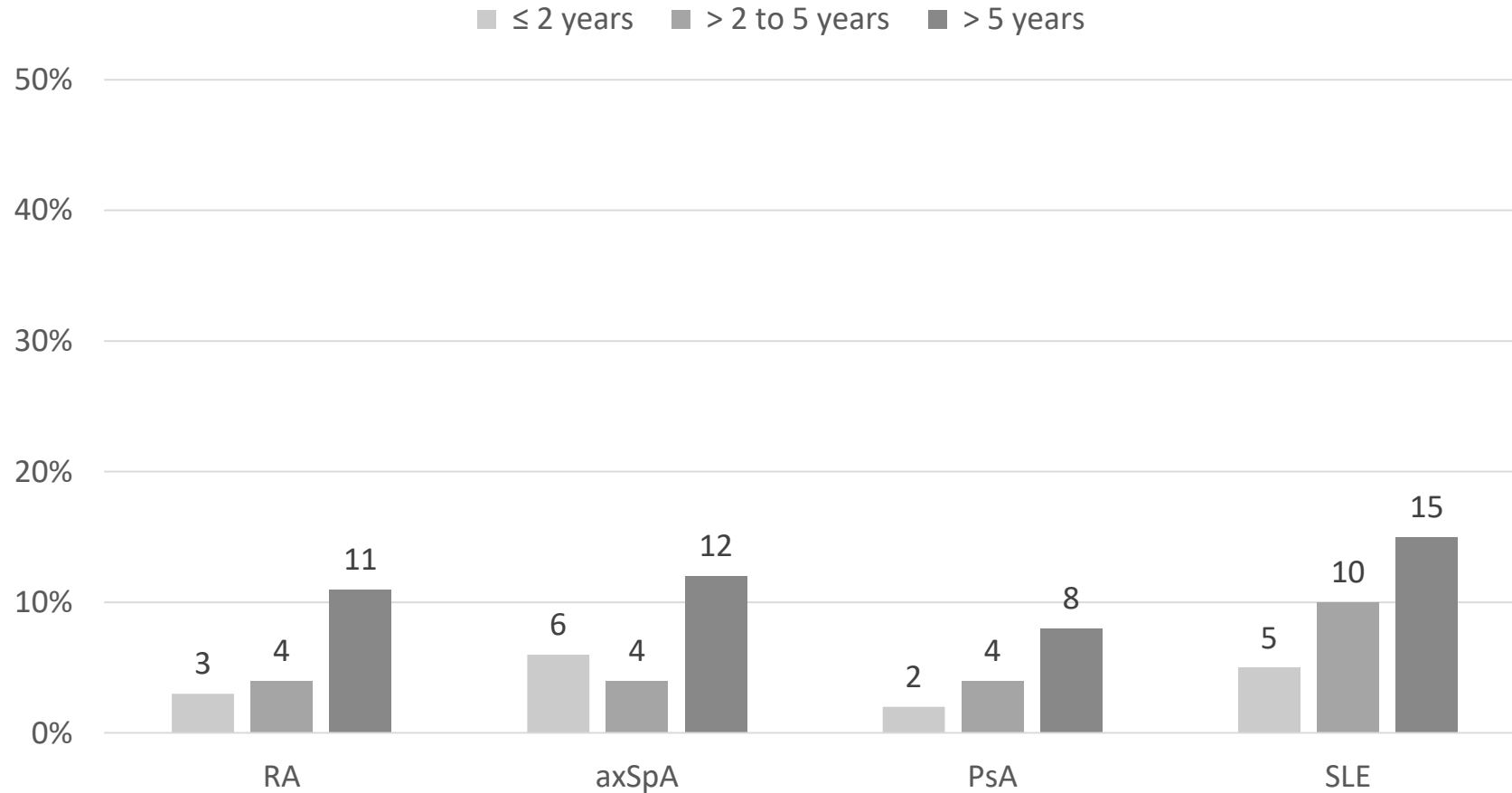




# Membership of a patient organisation by gender



# Membership of a patient organisation by disease duration





# Instruments reference

FFbH  
BASDAI  
BASFI  
RAID  
WHO-5

# FFbH Functional Questionnaire Hanover



*In den folgenden Fragen geht es um Tätigkeiten aus dem täglichen Leben. Bitte beantworten Sie jede Frage so, wie es für Sie im Moment (in Bezug auf die letzten 7 Tage) zutrifft und kreuzen Sie die entsprechende Zahl an.*

*Sie haben drei Antwortmöglichkeiten:*

**1 Ja**  
Sie können die Tätigkeit ohne Schwierigkeiten ausführen.

**2 Ja, aber mit Mühe**  
Sie haben dabei Schwierigkeiten, z.B. Schmerzen, es dauert länger als früher oder Sie müssen sich dabei abstützen.

**3 Nein oder nur mit fremder Hilfe**  
Sie können es gar nicht oder nur, wenn eine andere Person Ihnen dabei hilft.

		Ja	Ja, aber mit Mühe	Nein oder nur mit fremder Hilfe
1.	Können Sie Brot streichen?	1	2	3
2.	Können Sie aus einem normal hohen Bett aufstehen?	1	2	3
3.	Können Sie mit der Hand schreiben (mindestens eine Postkarte)?	1	2	3
4.	Können Sie Wasserhähne auf- und zudrehen?	1	2	3
5.	Können Sie sich strecken, um z.B. ein Buch von einem hohen Regal oder Schrank zu holen?	1	2	3
6.	Können Sie einen mindestens 10 kg schweren Gegenstand (z.B. einen vollen Wassereimer oder Koffer) hochheben und 10 Meter weit tragen?	1	2	3
7.	Können Sie sich von Kopf bis Fuß waschen und abtrocknen?	1	2	3
8.	Können Sie sich bücken und einen leichten Gegenstand (z.B. ein Geldstück oder zerknülltes Papier) vom Fußboden aufheben?	1	2	3
9.	Können Sie sich über einem Waschbecken die Haare waschen?	1	2	3
10.	Können Sie 1 Stunde auf einem ungepolsterten Stuhl sitzen?	1	2	3
11.	Können Sie 30 Minuten ohne Unterbrechung stehen (z.B. in einer Warteschlange)?	1	2	3
12.	Können Sie sich im Bett aus der Rückenlage aufsetzen?	1	2	3
13.	Können Sie Strümpfe an- und ausziehen?	1	2	3
14.	Können Sie im Sitzen einen kleinen heruntergefallenen Gegenstand (z.B. eine Münze) neben Ihrem Stuhl aufheben?	1	2	3
15.	Können Sie einen schweren Gegenstand (z.B. einen gefüllten Kasten Mineralwasser) vom Boden auf den Tisch stellen?	1	2	3
16.	Können Sie sich einen Wintermantel an- und ausziehen?	1	2	3
17.	Können Sie ca. 100 Meter schnell laufen (nicht gehen), etwa um einen Bus zu erreichen?	1	2	3
18.	Können Sie öffentliche Verkehrsmittel (Bus, Bahn usw.) benutzen?	1	2	3

Bitte hier nichts eintragen! © FFbH

Anzahl '1'  Anzahl '2'  Anzahl '3'

**Vielen Dank für Ihre Mitarbeit.**

© DRFZ 2022

The FFbH contains 18 questions on everyday activities.

The evaluation is carried out in a range of 0-100, with 100 corresponding to full functionality.

The score is calculated as follows:

"Yes" → 2 points "Yes, but with difficulty" → 1 point "No or only with outside help" → 0 points

$$FFbH = (\text{sum of all points}) * 100 / 36$$

Categories:

100-72 none to light

52-70 moderate

0-50 severe functional impairments

Reference:

Lautenschläger J, Mau W, Kohlmann T, Raspe HH, Struve F, Brückle W, Zeidler H. Comparative evaluation of a German version of the Health Assessment Questionnaire (HAQ) and the Functional Questionnaire Hannover (FFbH). *Z Rheumatol.* 1997 May-Jun;56(3):144-55. doi: 10.1007/s003930050030.

# BASDAI Bath Ankylosing Spondylitis Disease Activity Index



Bitte Patienten ID eintragen: \_\_\_\_\_

**BASDAI**

Erhebungsdatum: [ ][ ][ ][ ][ ][ ][ ][ ]

**Wie ist es Ihnen in den letzten 7 Tagen ergangen?**  
Bitte kreuzen Sie auf den nachfolgenden Skalen jeweils eine Zahl an. Auch wenn die Beschwerden (Schmerzen, Müdigkeit) geschwankt haben, entscheiden Sie sich bitte für eine Zahl als Angabe für die durchschnittliche Stärke der Beschwerden.

1. Wie würden Sie Ihre allgemeine Müdigkeit und Erschöpfung beschreiben?  
keine Müdigkeit Erschöpfung [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] sehr starke Müdig./Ersch.

2. Wie stark waren Ihre Schmerzen in Nacken, Rücken oder Hüfte?  
keine Schmerzen [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] sehr starke Schmerzen

3. Wie stark waren Ihre Schmerzen oder Schwellungen in anderen Gelenken?  
keine Schmerzen [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] sehr starke Schmerzen

4. Wie unangenehm waren für Sie besonders berührungs- oder druckempfindliche Körperstellen?  
gar nicht [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] sehr stark

5. Wie ausgeprägt war Ihre Morgensteifigkeit nach dem Aufwachen?  
gar nicht [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] sehr stark

6. Wie lange dauert diese Morgensteifigkeit im Allgemeinen?  
in Stunden [0] [¼] [½] [¾] [1] [1¼] [1½] [1¾] [≥2]  
hatte keine

© 1997 2002

The BASDAI contains five questions to record disease activity with numerical rating scales from 0-10 and one question on morning stiffness

The score is calculated as follows (Q1=Question 1 etc.)

$$\text{BASDAI} = \frac{Q1 + Q2 + Q3 + Q4 + \left(\frac{Q5 + Q6}{2}\right)}{5}$$

Categories:

0-2 none to light

3-4 moderate

>4 high disease activity

Reference:

Garret S, Jenkinson T, Kennedy LG, Whitelock H, Gaisford P, Calin A. A new approach to defining disease status in ankylosing spondylitis: the Bath Ankylosing Spondylitis Disease Activity Index. *J Rheumatol* 1994 Dec;21(12):2286-91.

# BASFI Bath Ankylosing Spondylitis Functional Index



Bitte Patienten-ID eintragen: \_ \_ \_ \_ \_

**Kerndokumentation**

**BASFI**

Erhebungsdatum: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

*Kreuzen Sie bitte an, wie gut Sie während den letzten 7 Tagen die jeweiligen Tätigkeiten allein, also ohne fremde Hilfe oder Hilfsmittel ausführen konnten. Entscheiden Sie sich bitte für eine Zahl als Angabe für die durchschnittliche Schwierigkeit, die Sie mit der Tätigkeit hatten.*

1. Ohne Hilfe und Hilfsmittel (z.B. Strumpfanzieher) Socken oder Strümpfe anziehen  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
2. Ohne Hilfe von der Hüfte aus nach vorn beugen, um einen Kugelschreiber vom Boden aufzuheben  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
3. Ohne Hilfe (z.B. Greifzange) etwas von einem hohen Regal herunternehmen  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
4. Von einem Stuhl ohne Armlehne aufstehen, ohne dabei die Hände oder andere Hilfe zu benutzen  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
5. Ohne Hilfe vom Boden aufstehen, wenn Sie auf dem Rücken liegen  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
6. Ohne Beschwerden 10 Minuten stehen, ohne sich anzulehnen  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
7. 12-15 Treppenstufen steigen ohne Benutzung des Geländers oder von Gehhilfen. 1 Schritt pro Stufe!  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
8. Über die Schulter sehen, ohne den Oberkörper zu drehen  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
9. Körperlich anstrengende Tätigkeiten verrichten (z.B. krankengymnastische Übungen, Gartenarbeit oder Sport)  
[0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich
10. Zu Hause oder bei der Arbeit den ganzen Tag aktiv sein  
einfach [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] unmöglich

© BASFI

The BASFI contains nine numerical rating scales from 0-10 for everyday activities.

Categories:

0-2 none to light

3-4 moderate

>4 severe functional impairments

The score is calculated as the average of all entries

Reference:

Calin A, Garrett S, Whitelock H, Kennedy LG, O'Hea J, Mallorie P, Jenkinson T. A new approach to defining functional ability in ankylosing spondylitis: the development of the Bath Ankylosing Spondylitis Functional Index. *J Rheumatol.* 1994 Dec;21(12):2281-5.

# RAID Rheumatoid Arthritis Impact of Disease Questionnaire



**Wie würden Sie die Stärke Ihrer Schmerzen in den letzten 7 Tagen einschätzen?**  
keine Schmerzen 0 1 2 3 4 5 6 7 8 9 10 unerträgliche Schmerzen

**Wie schwierig war es in den letzten 7 Tagen für Sie, alltäglichen körperlichen Tätigkeiten nachzugehen?**  
nicht schwierig 0 1 2 3 4 5 6 7 8 9 10 sehr schwierig

**Wie sehr haben Sie in den letzten 7 Tagen unter ungewöhnlicher Erschöpfung und Müdigkeit gelitten?**  
gar nicht 0 1 2 3 4 5 6 7 8 9 10 sehr stark

**Litten Sie in den letzten 7 Tagen unter Schlafstörungen? (Probleme beim Ein- oder Durchschlafen)**  
gar nicht 0 1 2 3 4 5 6 7 8 9 10 sehr stark

**Wie war Ihr körperliches Wohlbefinden in den letzten 7 Tagen?**  
sehr gut 0 1 2 3 4 5 6 7 8 9 10 sehr schlecht

**Wie war Ihr psychisches Wohlbefinden in den letzten 7 Tagen?**  
sehr gut 0 1 2 3 4 5 6 7 8 9 10 sehr schlecht

**Wie schwierig war es in den letzten 7 Tagen für Sie, mit Ihrer rheumatischen Erkrankung zurechtzukommen?**  
nicht schwierig 0 1 2 3 4 5 6 7 8 9 10 sehr schwierig

Seven numerical rating scales  
(NRS 0-10)

Calculation of the score as a weighted average:

$$\text{RAID} = 0.21 * \text{Pain}$$

$$+ 0.16 * \text{physical activities}$$

$$+ 0.15 * \text{fatigue}$$

$$+ 0.12 * \text{sleep}$$

$$+ 0.12 * \text{physical well-being}$$

$$+ 0.12 * \text{mental well-being}$$

$$+ 0.12 * \text{coming to terms with the disease}$$

Categories for individual items:

0-3 none/mild

4-6 moderate

7-10 strong/bad

## Reference:

Gossec L, Paternotte S, Aanerud GJ, et al. Finalisation and validation of the rheumatoid arthritis impact of disease score, a patient-derived composite measure of impact of rheumatoid arthritis: a EULAR initiative. *Ann Rheum Dis.* 2011 Jun;70(6):935-42. doi: 10.1136/ard.2010.142901.

# WHO-5 questionnaire on well-being



**Die folgenden Aussagen betreffen Ihr Wohlbefinden in den letzten zwei Wochen.**

Bitte markieren Sie bei jeder Aussage die Rubrik, die Ihrer Meinung nach am besten beschreibt, wie Sie sich in den letzten zwei Wochen gefühlt haben.

In den letzten zwei Wochen ...	die ganze Zeit	meistens	etwas mehr als die Hälfte der Zeit	etwas weniger als die Hälfte der Zeit	ab und zu	zu keinem Zeitpunkt
... war ich froh und guter Laune.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... habe ich mich ruhig und entspannt gefühlt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... habe ich mich energisch und aktiv gefühlt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... habe ich mich beim Aufwachen frisch und ausgeruht gefühlt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... war mein Alltag voller Dinge, die mich interessieren.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Five 6-point Likert scales  
Total 0-25 x4 results in  
Range from 0-100

Categories:

>50 good well-being

29-50 moderate well-being,  
indication of mild depressive  
symptoms

<29 Poor well-being, indication  
of moderate to severe  
depressive symptoms

Reference:

Topp CW, Østergaard SD, Søndergaard S, Bech P. The WHO-5 Well-Being Index: a systematic review of the literature. *Psychother Psychosom* 2015;84(3):167-76. doi: 10.1159/000376585. Epub 2015 Mar 28.



# ECLAM European Consensus Lupus Activity Measurement Index



European Consensus Lupus Activity Measurement (ECLAM)	
<b>1. Allgemeinsymptome</b> <small>Score 0,5</small> Fieber <input type="checkbox"/> Müdigkeit <input type="checkbox"/>	<b>8. ZNS-Beteiligung *</b> <small>Score 0,5</small> nur bei neu oder schlechter Kopfschmerzen, Migräne <input type="checkbox"/> Krampfanfälle <input type="checkbox"/> Schlaganfall <input type="checkbox"/> Himorganisches Psychosyndrom <input type="checkbox"/> Psychose <input type="checkbox"/>
<b>2. Gelenksbeschwerden</b> <small>Score 0,5</small> Arthritis <input type="checkbox"/> neue Arthralgien <input type="checkbox"/>	<b>9. Nierenbeteiligung *</b> <small>Score 0,5</small> Pat. mit terminaler NI werden nicht gewertet neu oder verschlechtert: +2,0 <input type="checkbox"/> Proteinurie (>= 500 mg/d) <input type="checkbox"/> Pathol. Sediment <input type="checkbox"/> Hämaturie <input type="checkbox"/> Funktionseinschränkung <input type="checkbox"/>
<b>3. Haut-Schleimhaut Beteiligung</b> <small>Score 0,5</small> neu oder verschlechtert: +1,0 <input type="checkbox"/> Schmetterlingserythem <input type="checkbox"/> generalisiertes Erythem <input type="checkbox"/> diskoides Erythem <input type="checkbox"/> Vaskulitis der Haut <input type="checkbox"/> orale Ulzera <input type="checkbox"/>	<b>10. Hämatologische Beteiligung</b> <small>Score 0,5</small> nicht-hämolytische Anämie <input type="checkbox"/> hämolytische Anämie * <input type="checkbox"/> Leuko- oder Lymphopenie <input type="checkbox"/> Thrombopenie <input type="checkbox"/>
<b>4. Myositis *</b> <small>Score 0,5</small> <input type="checkbox"/>	<b>11. BSG (&gt;25 mm/h)</b> <small>Score 0,5</small> <input type="checkbox"/>
<b>5. Perikarditis</b> <small>Score 0,5</small> <input type="checkbox"/>	<b>12. Komplementerniedrigung</b> <small>Score 0,5</small> verschlechtert: +1,0 <input type="checkbox"/> C3 <input type="checkbox"/> CH50 <input type="checkbox"/>
<b>6. Intestinale Beteiligung</b> <small>Score 0,5</small> Vaskulitis <input type="checkbox"/> sterile Peritonitis <input type="checkbox"/>	<b>Summe</b> <input type="checkbox"/>
<b>7. Pulmonale Beteiligung</b> <small>Score 0,5</small> Pleuritis <input type="checkbox"/> Pneumonitis <input type="checkbox"/> zunehmende Dyspnoe <input type="checkbox"/>	
*sollte dies die einzige SLE-Manifestation sein, werden 2 Punkte zusätzlich addiert. Sollte die errechnete Summe keine ganze Zahl ergeben, wird bei Werten <6 ab- und bei Werten >6 aufgerundet. Scores über 10 werden auf 10 abgerundet.	
errechneter ECLAM-Score [0 bis 10]: <input type="text"/>	erfasst von: <input type="text"/> am: <input type="text"/>

34 items are recorded in 12 domains.

In the evaluation for the standard presentation, participation is reported on the basis of the 12 domains (slide 86)

The ECLAM score is calculated (not the sum of all data) and has a range of 0-10

**Reference:**

Mosca M, Bencivelli W, Vitali C, Carrai P, Neri R, Bombardieri S. The validity of the ECLAM index for the retrospective evaluation of disease activity in systemic lupus erythematosus. *Lupus*. 2000;9(6):445-50. doi: 10.1191/096120300678828640.