



20 facts on Living with lupus in 2020

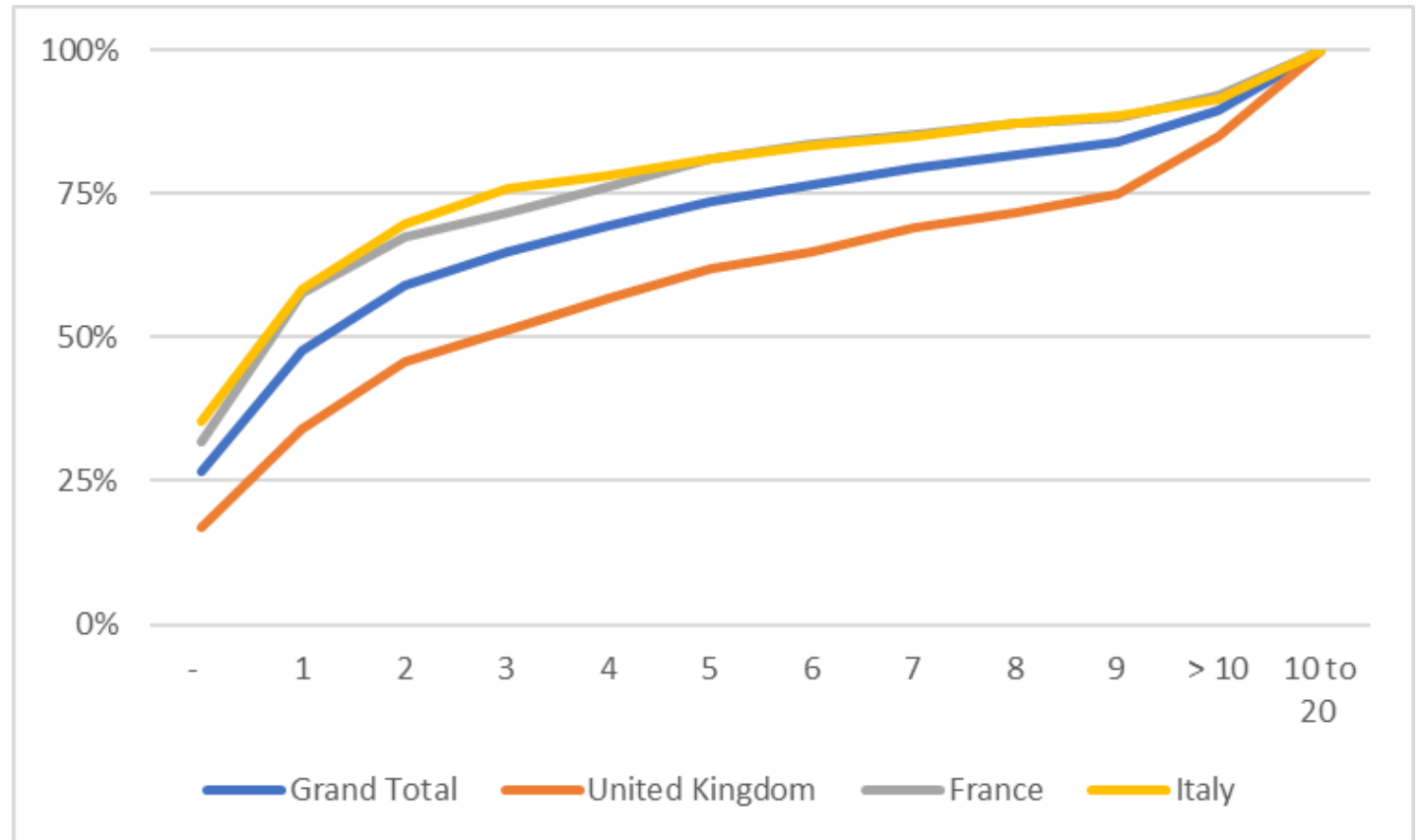
Some key findings – not all of which are in our Lupus Science and medicine publication

<http://dx.doi.org/10.1136/lupus-2020-000469>



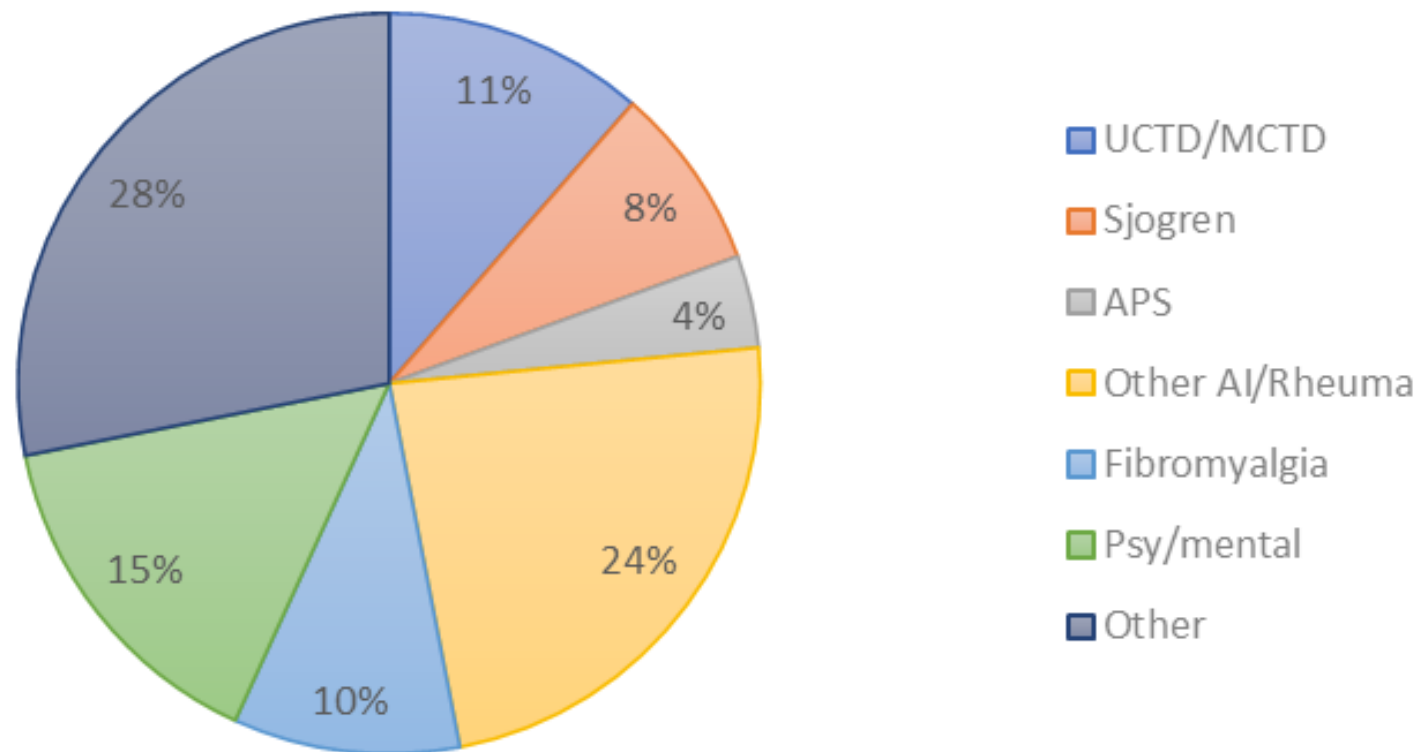
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Median time
to diagnosis
is 2 years
(IQR25-75 : 0-6)



When prior diagnosis of fibromyalgia, median time to diagnosis increases to 7 years
When kidney involvement, median time to diagnosis drops to 1 year

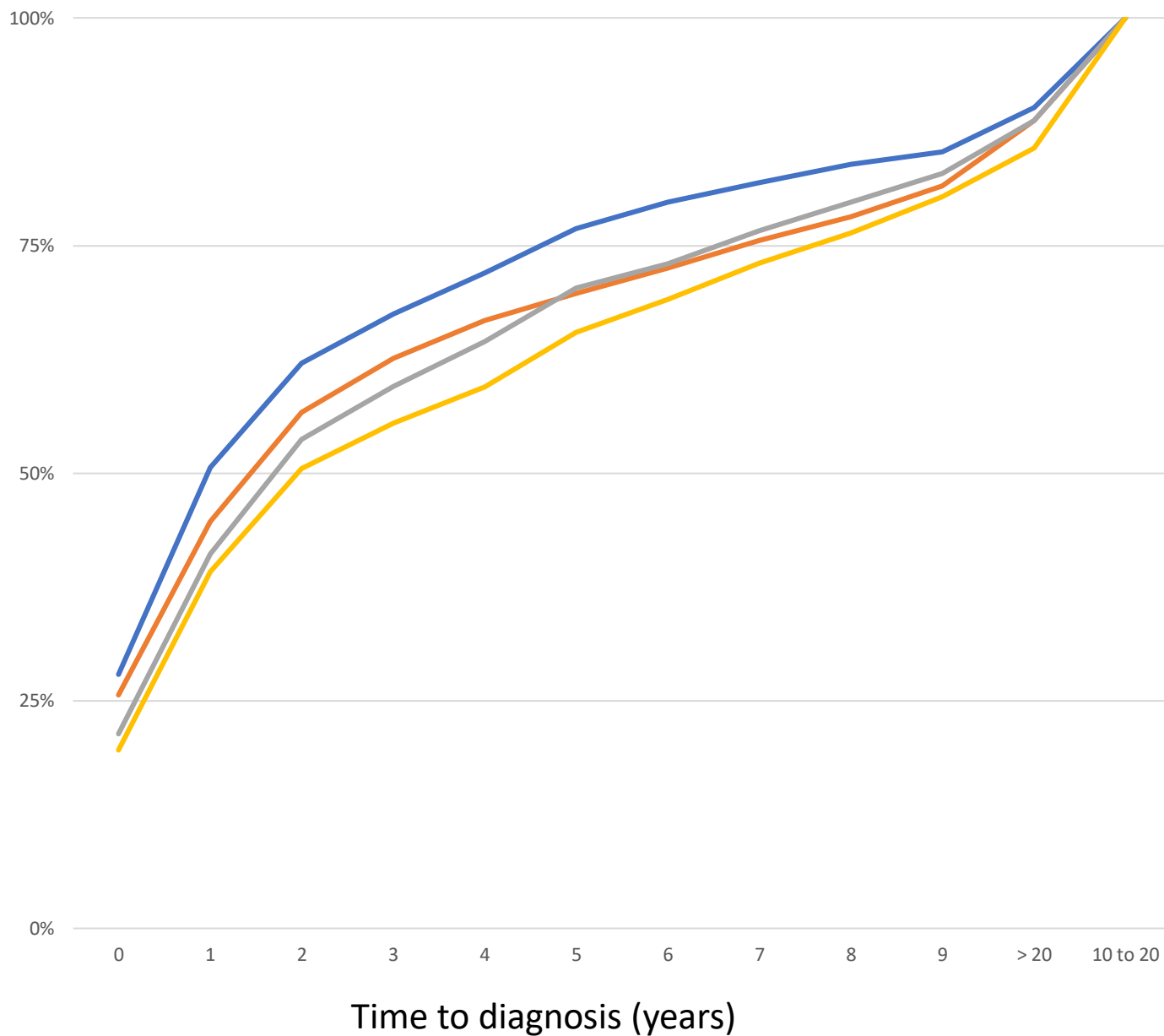
45% of SLE patients have first received another diagnosis



Prior diagnosis received by 1925 out of 4275 SLE patients

Time to diagnosis is significantly influenced by economic status

- A. no difficulties paying all bills.
- B. occasional difficulties paying all bills.
- C. often difficulties paying all bills
- D. Always difficulty paying all bills



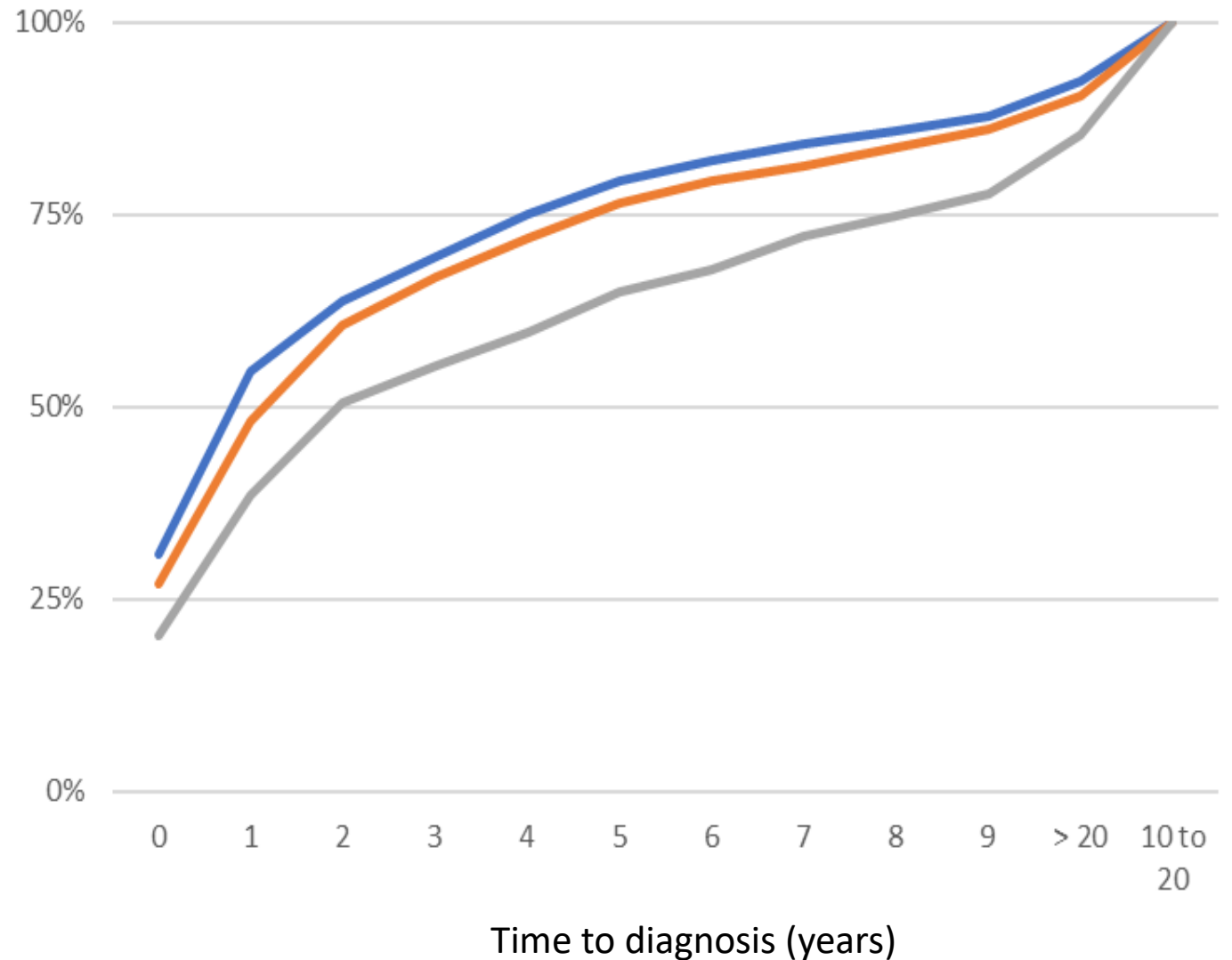


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Time to diagnosis is significantly reduced by access to an experienced lupus doctor

Do you have access to an experienced lupus doctor?

- A. Strongly agree
- B. Agree
- C. Neutral/Negative



Lupus impacts studies: 48.2% of patients below 25 and 68.1% of childhood onset lupus patients said it affected their studies

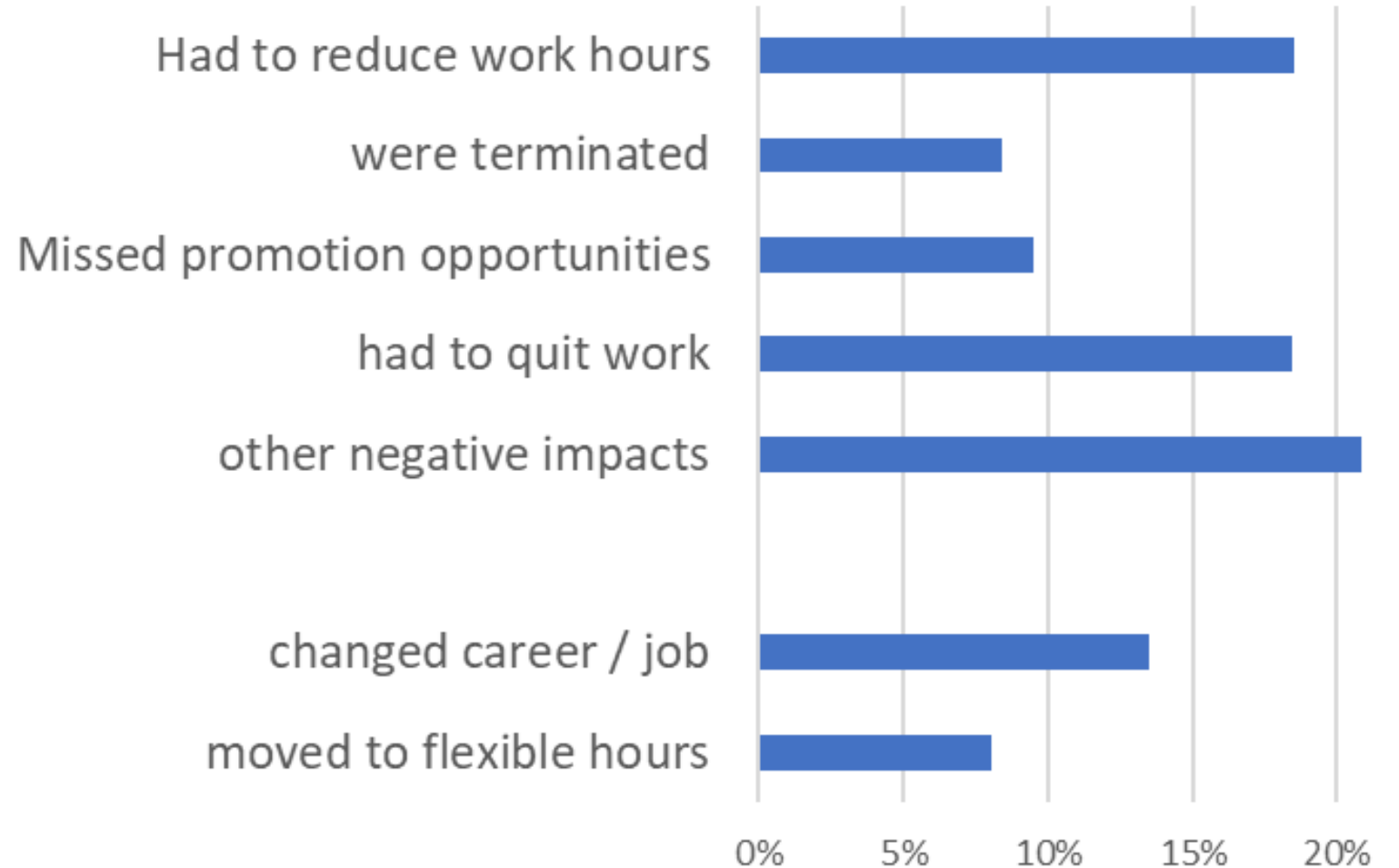
	Patients < 25 years (n=1492)	Childhood onset (n=244)
Could not study what they wanted	18.8%	29.1%
Needed special arrangements	13.7%	22.9%
Other negative effect(s)	22.5%	29.1%
Positive effect	2.5%	2.9%
Chose a more relevant study field	6.0%	11.9%





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Lupus impacts careers: 57.9% identified impact as negative, 1.8% as positive



N=4024 – excludes “students”

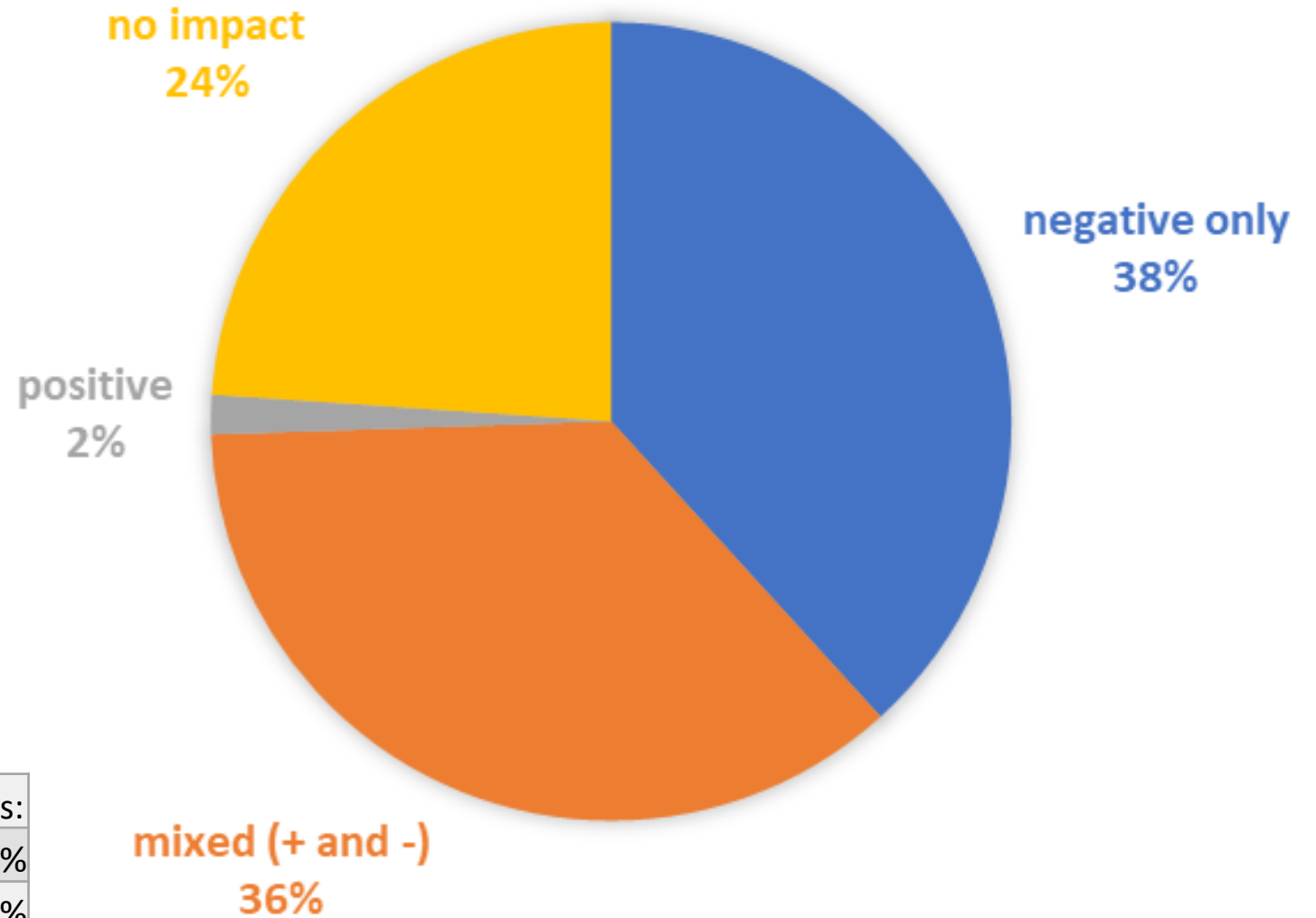


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Lupus
impacts
couple life
for 3 out of 4

Amongst 2875 respondents identifying negative impacts:

difficult for me	68.4%
difficult for my partner	26.7%
creates tensions in the couple	33.2%
concerned for my couple	12.2%
relationship ended	16.6%



Lupus flares worsen impact on couple lives

Lupus under control past 3 months	Total answers	Negative impact (n)	Negative impact %
No	1181	579	49.0%
Yes	3018	1027	34.0%

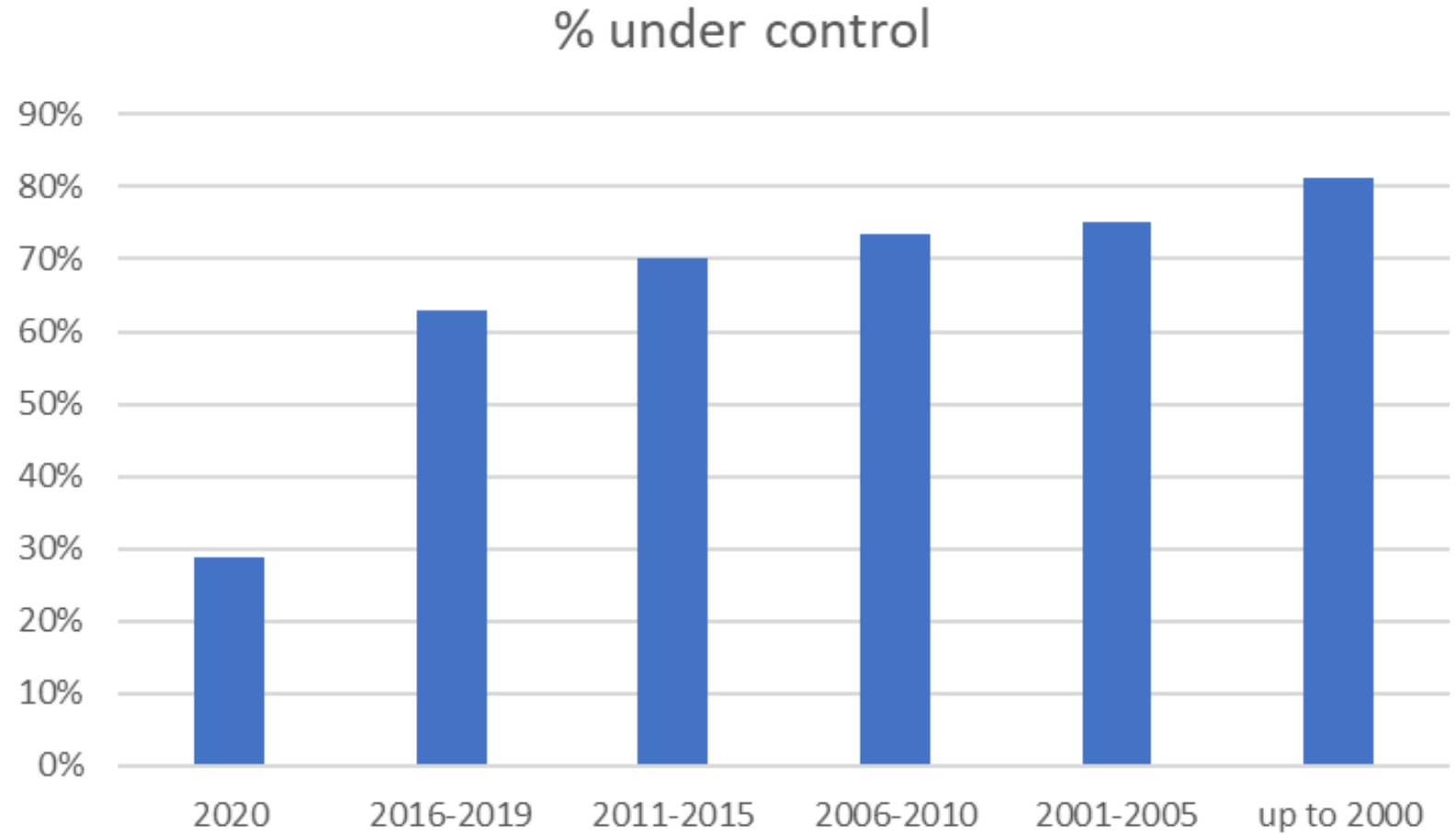
Patients whose lupus has not been under control over past 3 months report substantially more negative impact on their emotional or sexual life





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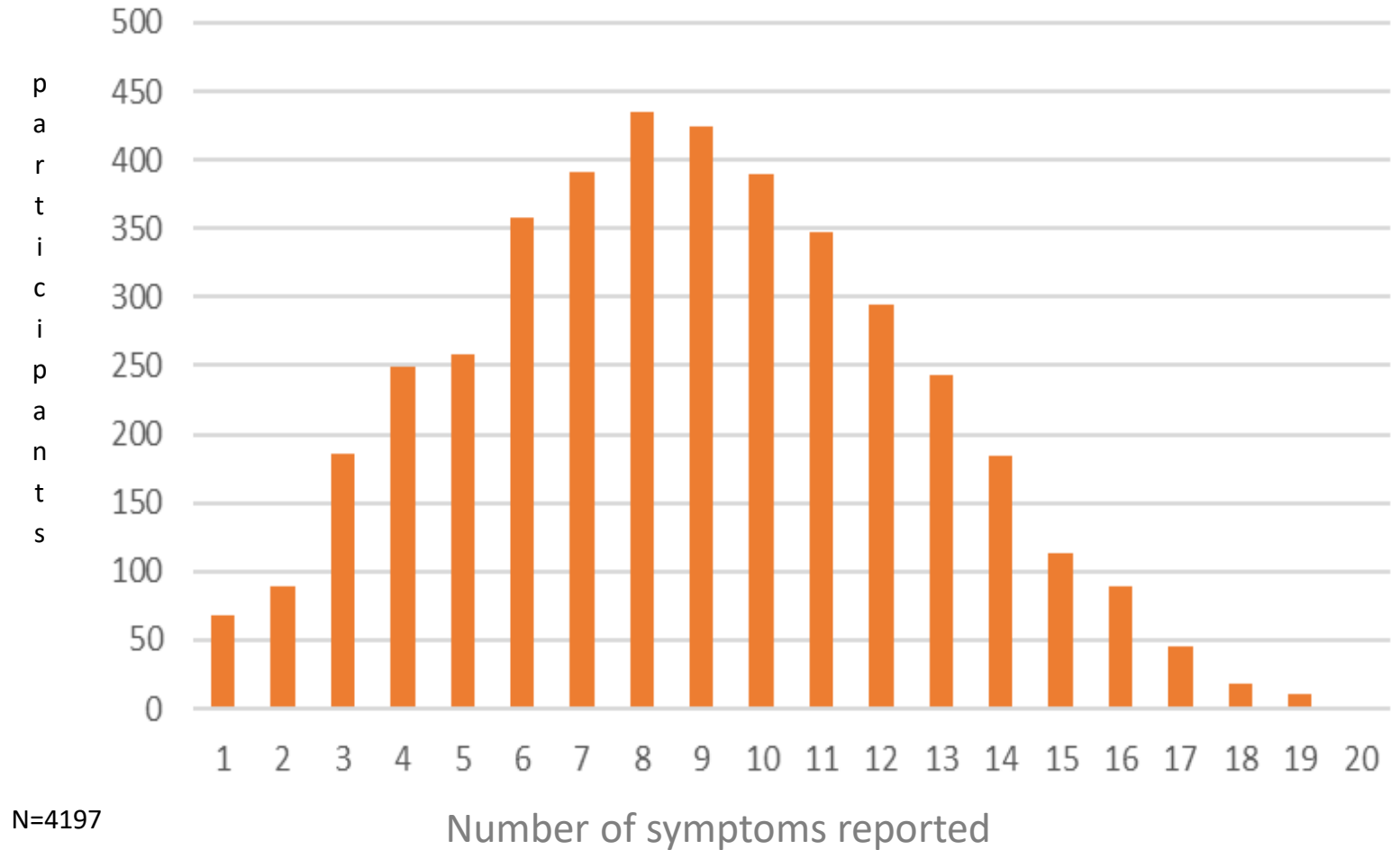
71.7% say their lupus has been under control over the past 3 months



Diagnosis year

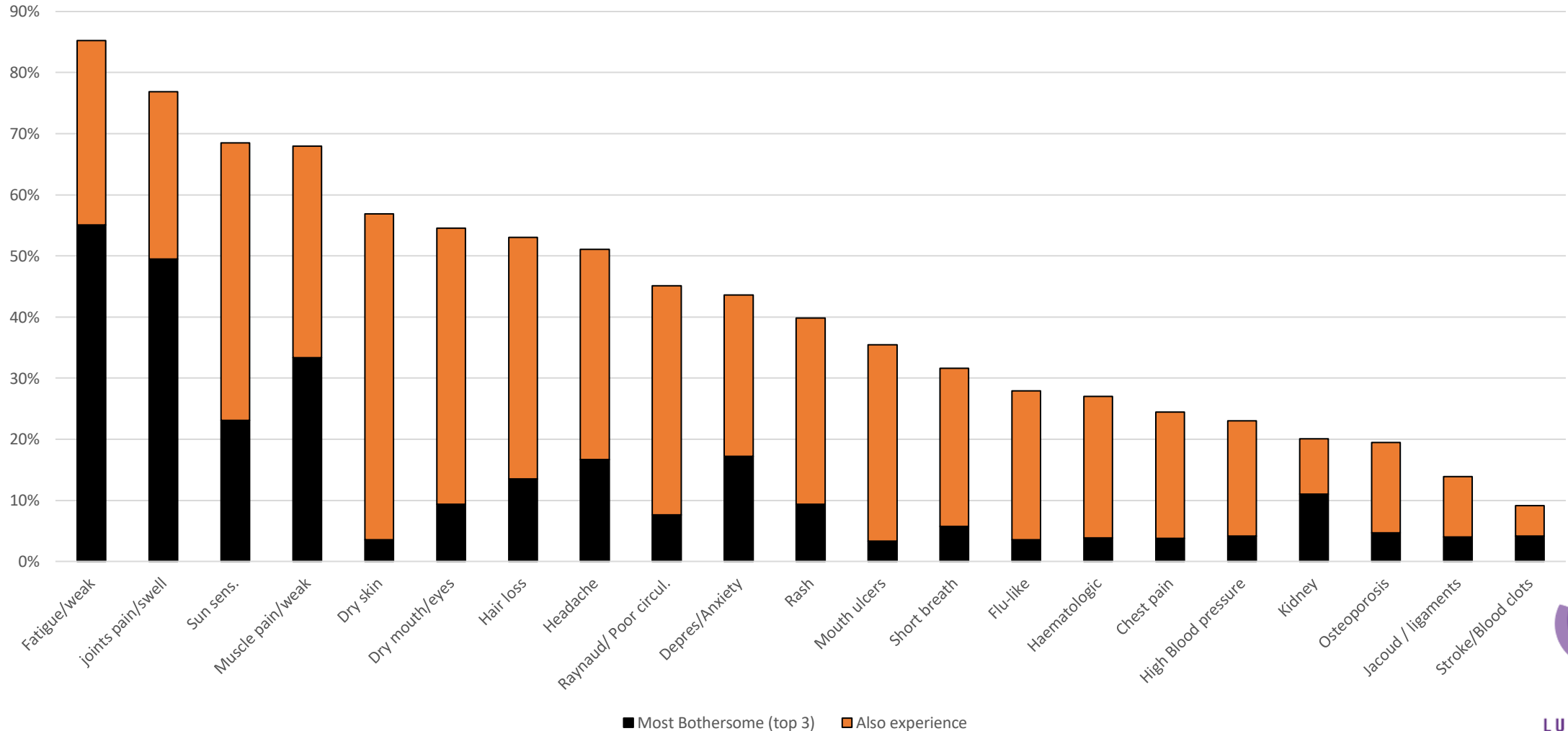
(N=4228)

Median number of symptoms regularly experienced is 9 from a list of 21 possible features



Heterogeneity : 4197 respondents => 3313 different combination of symptoms!

Fatigue, joint pain and sun sensitivity are the most experienced symptoms. Fatigue, joint pain and muscle pain/weakness, the most bothersome.

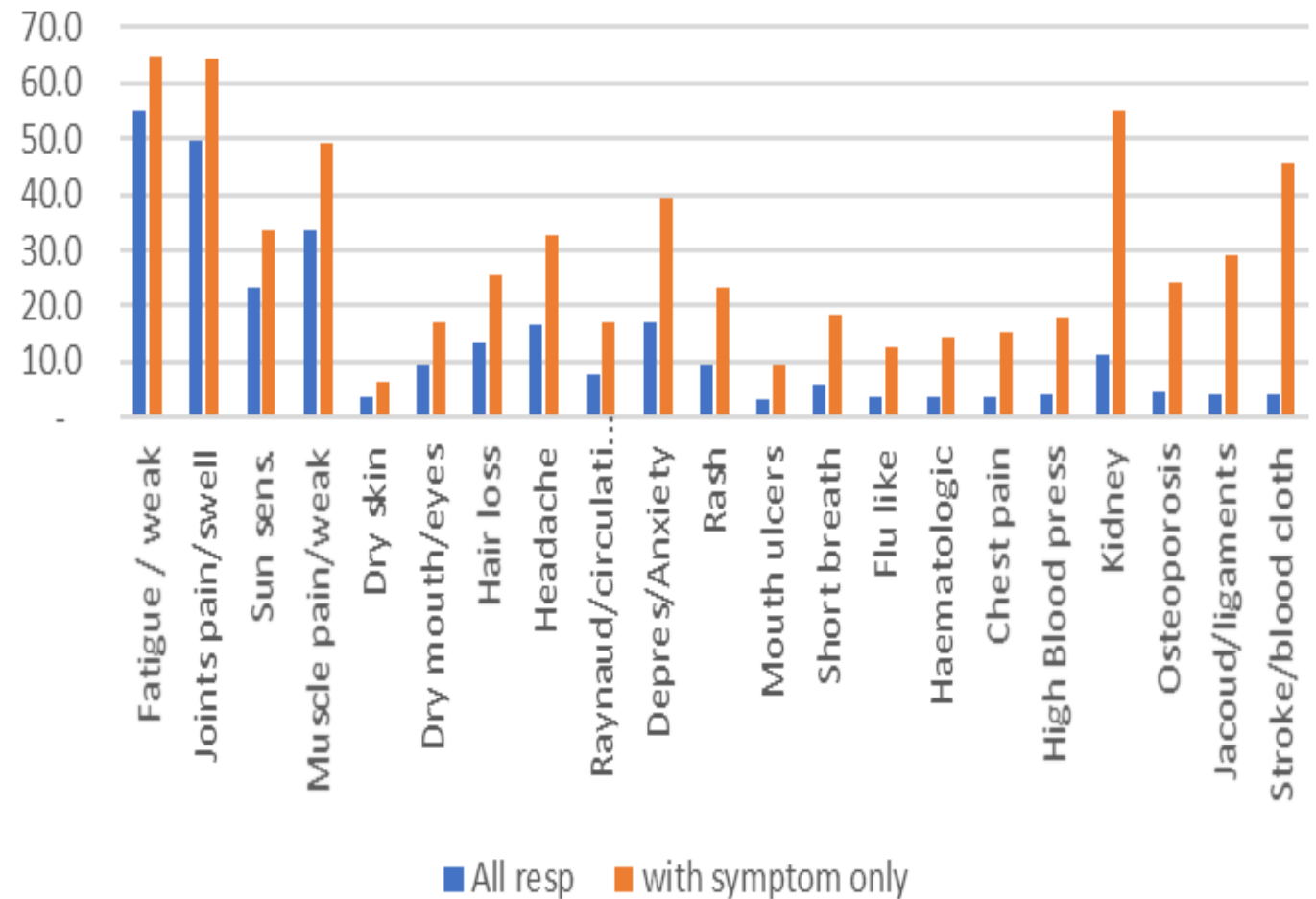




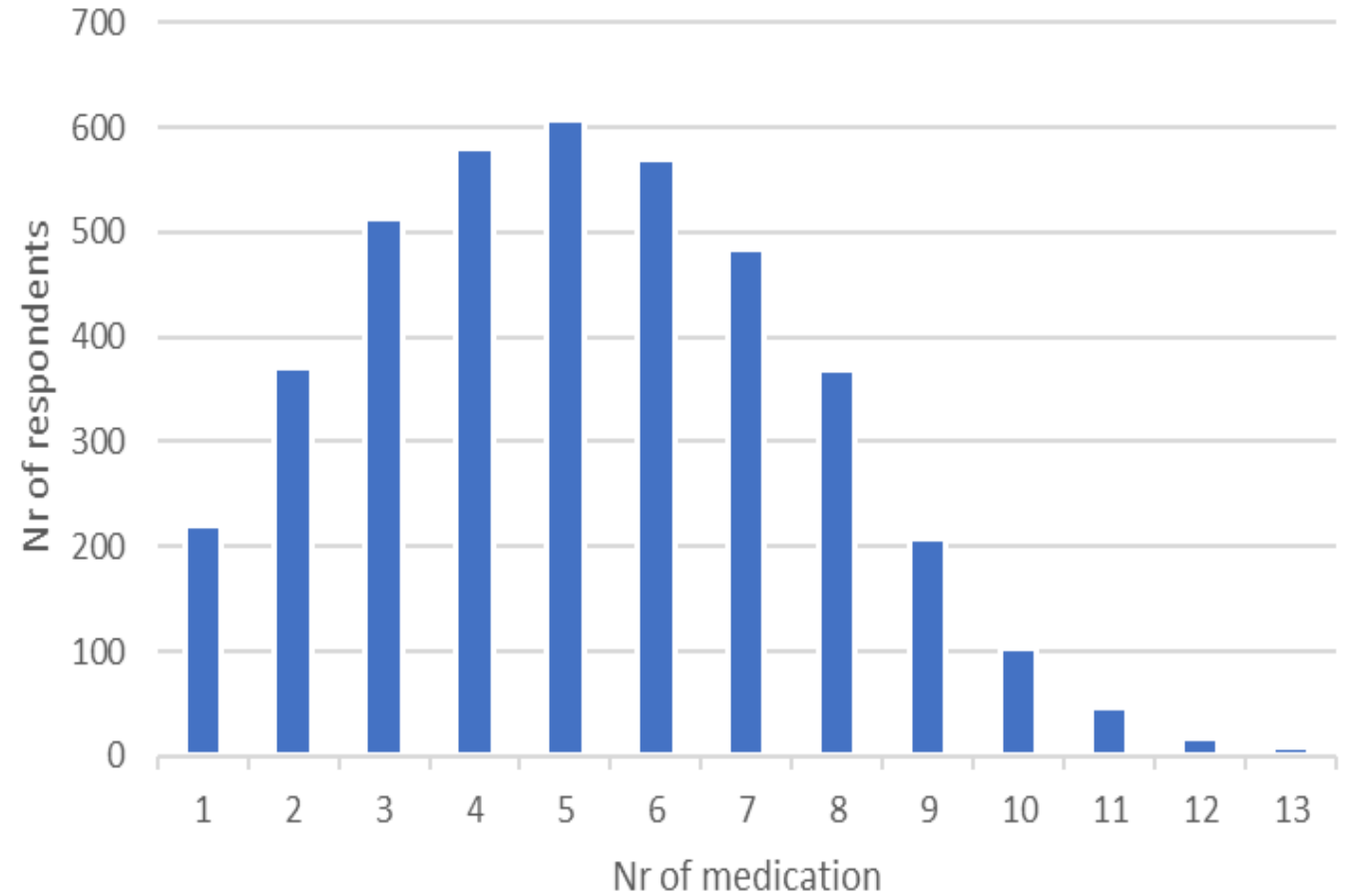
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For those affected, kidney issue, stroke/blood cloth or depression are very significant issues

% reporting symptom as Top 3 most bothersome



People living with lupus take on average 5 different medications for their lupus





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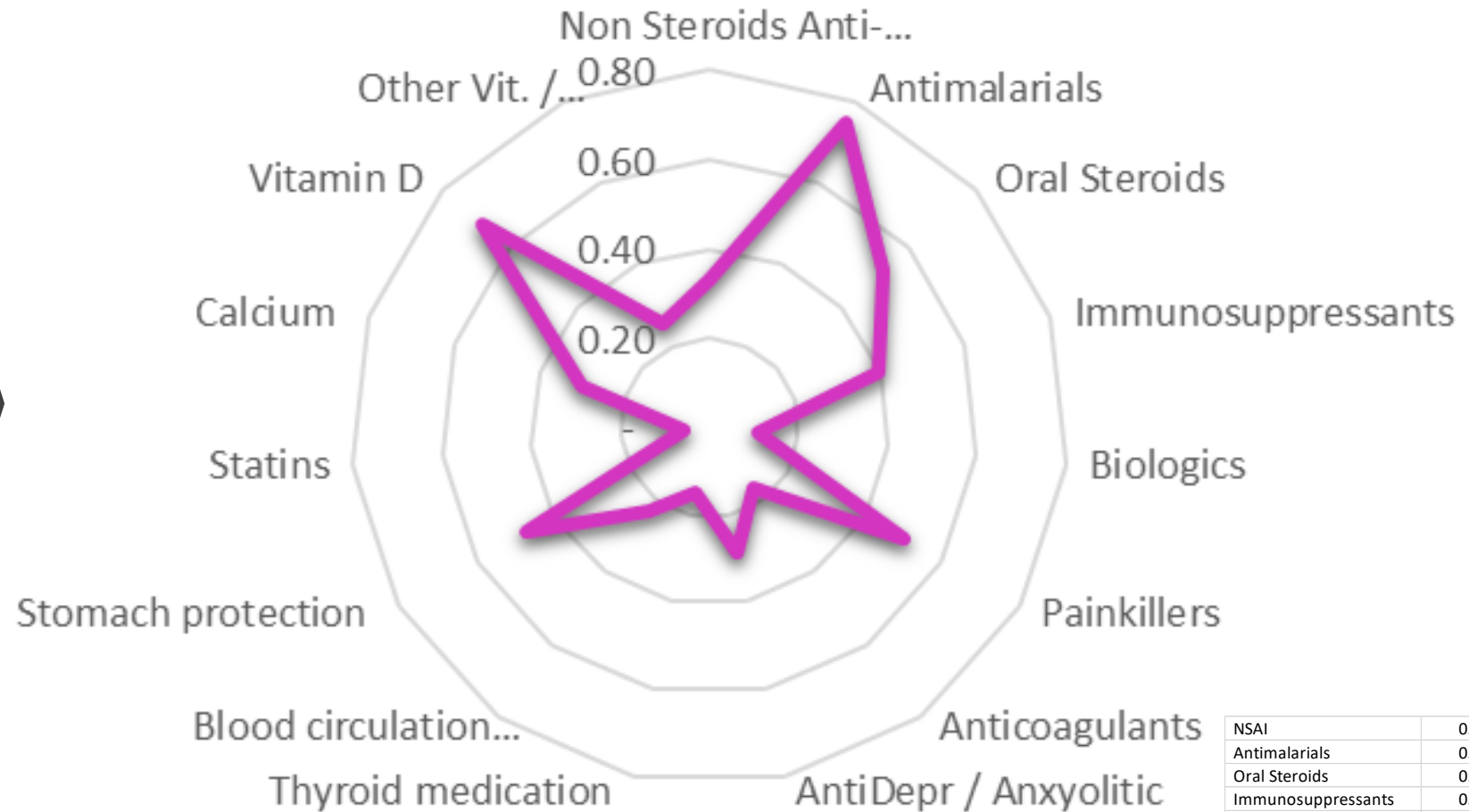
Even when
lupus is “under
control”
Patients take 5+
medications

	Lupus “under control”	Lupus “NOT under control”
Average number of medications	5.06	5.59 (p<0.0001)
Take corticosteroids	47.6%	53.7%
Take immunosuppressants	35.7%	41.9%
Note: Fibromyalgia diagnosis	4.15%	10.5%



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Reported medication regularly taken (n=4099)



NSAID	0.33
Antimalarials	0.75
Oral Steroids	0.52
Immunosuppressants	0.40
Biologics	0.11
Painkillers	0.50
Anticoagulants	0.17
AntiDepr / Anxyolitic	0.29
Thyroid medication	0.15
Blood circulation and hea	0.23
Stomach protection	0.47
Statins	0.06
Calcium	0.30
Vitamin D	0.68
Other Vit. / complements	0.25

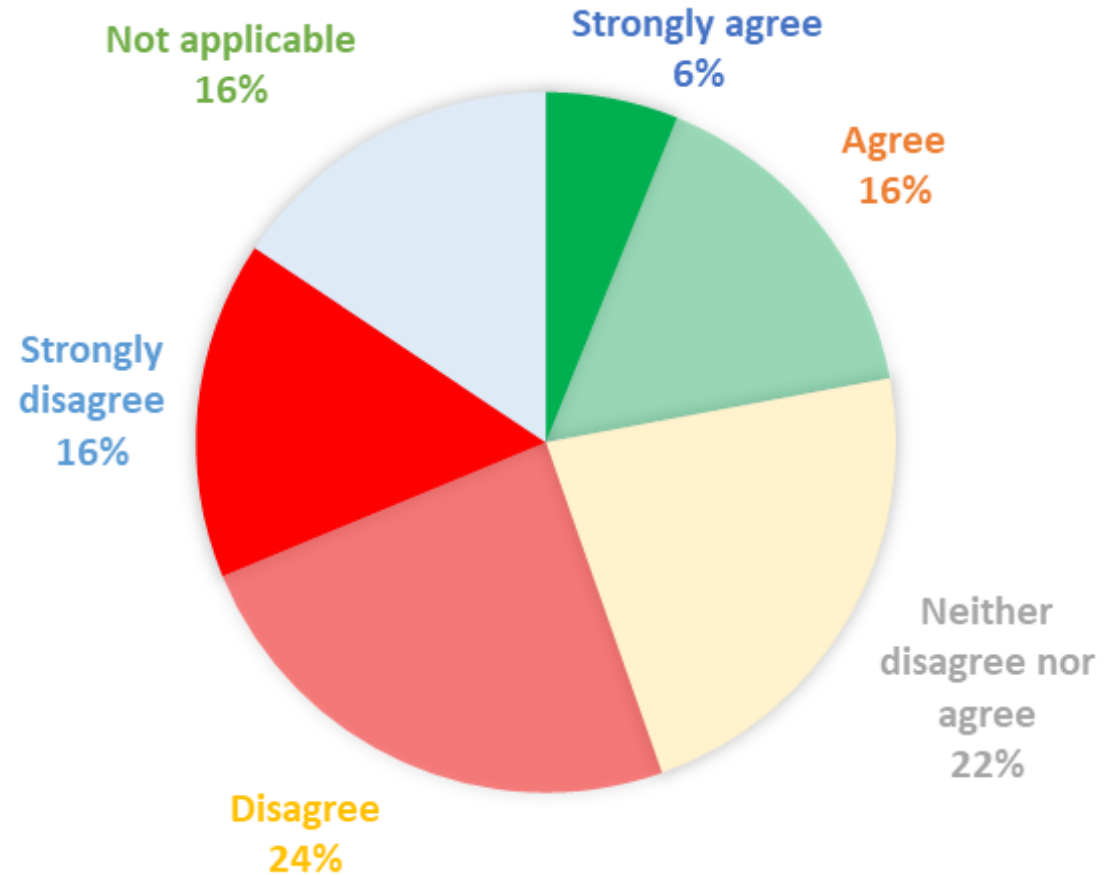
One out of 2
lupus patients
faces depression
or anxiety, but it
is under treated
(1)

Face depression / anxiety vs. take medication for it:

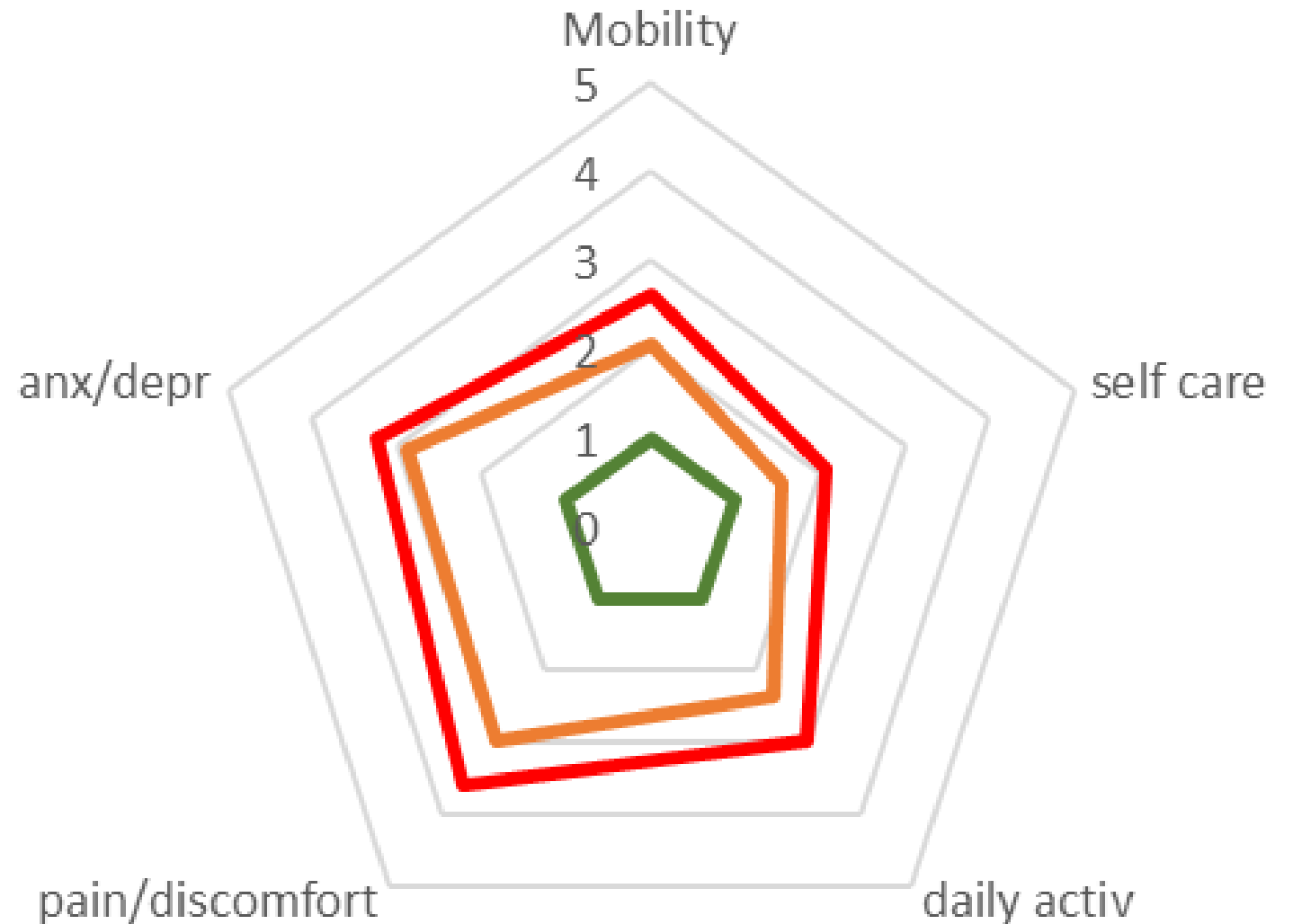
Depression /Anxiety is:	total (n)	medicated	% medicated
1st most bothersome symptom	166	77	46%
2nd most bothersome	254	120	47%
3rd most bothersome	263	118	45%
Also faced regularly	1148	414	36%
Not a regular symptom	2366	228	10%
TOTAL	4197	957	23%

One out of 2
lupus patients
faces depression
or anxiety, but it
is under treated
(2)

I have appropriate access to professional
psychologic support:



Lupus significantly affects quality of life



Reference: fully healthy person, no HRQoL (EQ5D) limitations at all

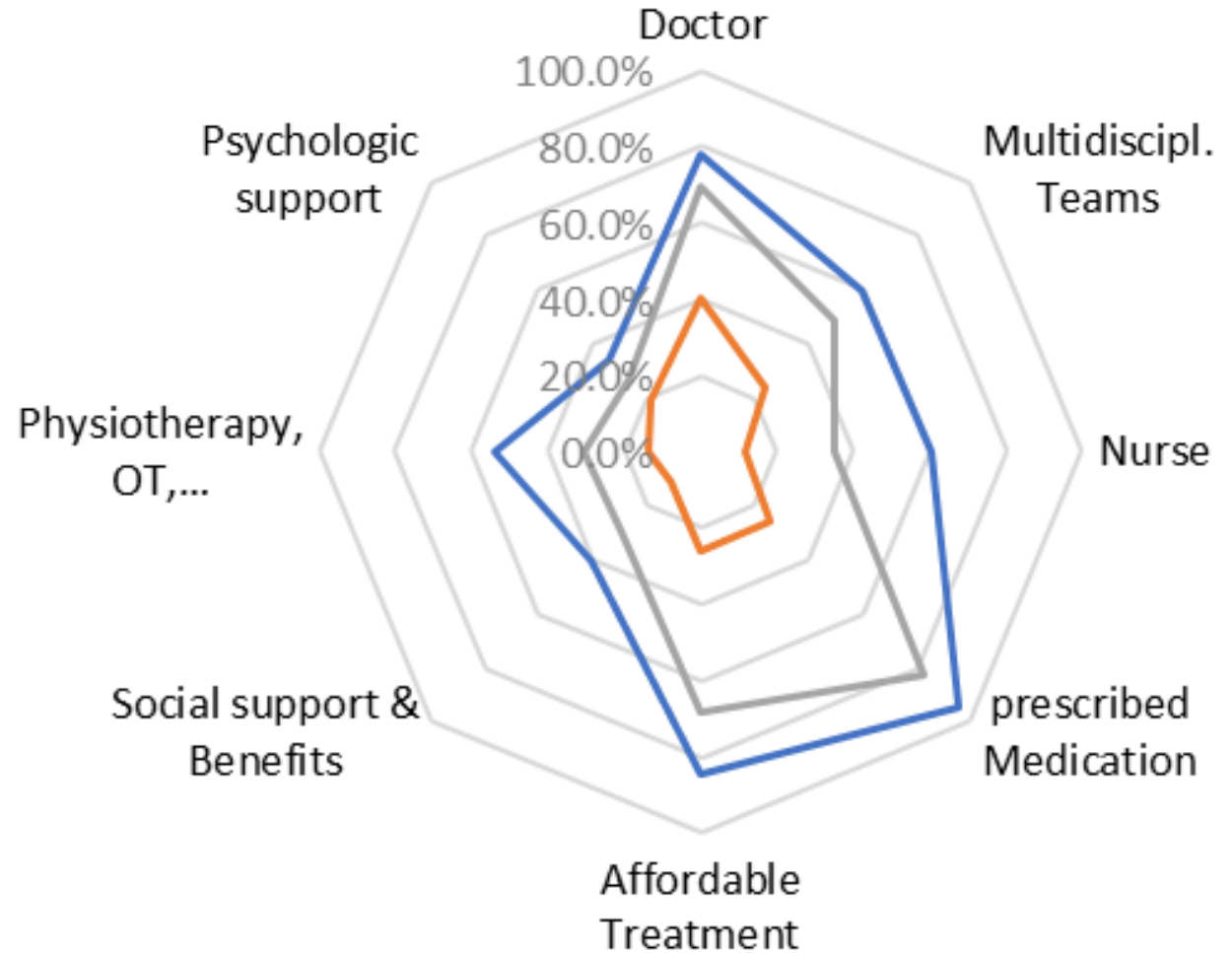
Average – lupus under control (n=2980)

Average – lupus NOT under control (n=1166)



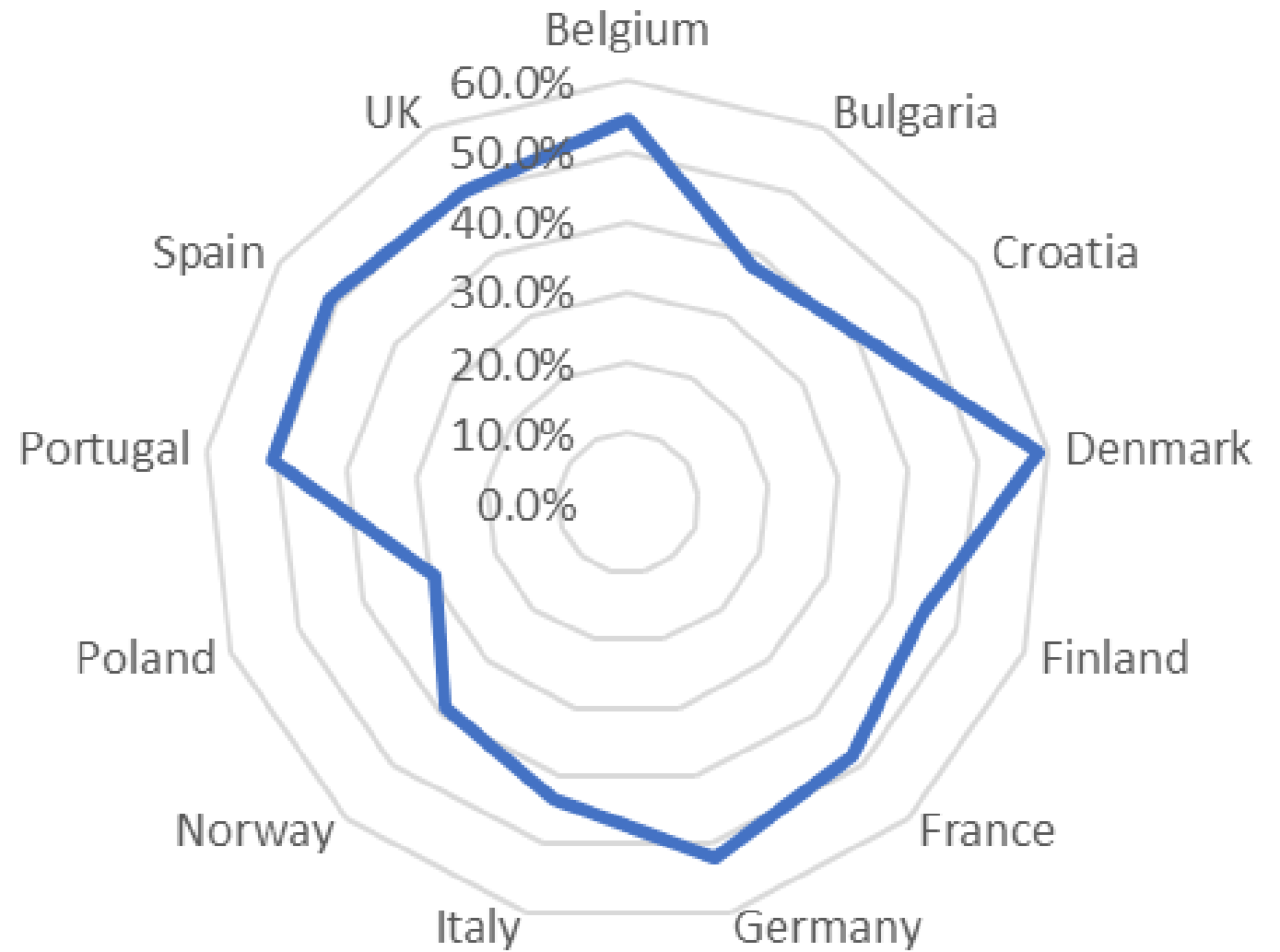
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Access is substantially lagging in 5 out of 8 domains



Worst, average and best countries by access domain

Access
inequalities
are big in
Europe



Average access across 8 domains, by country