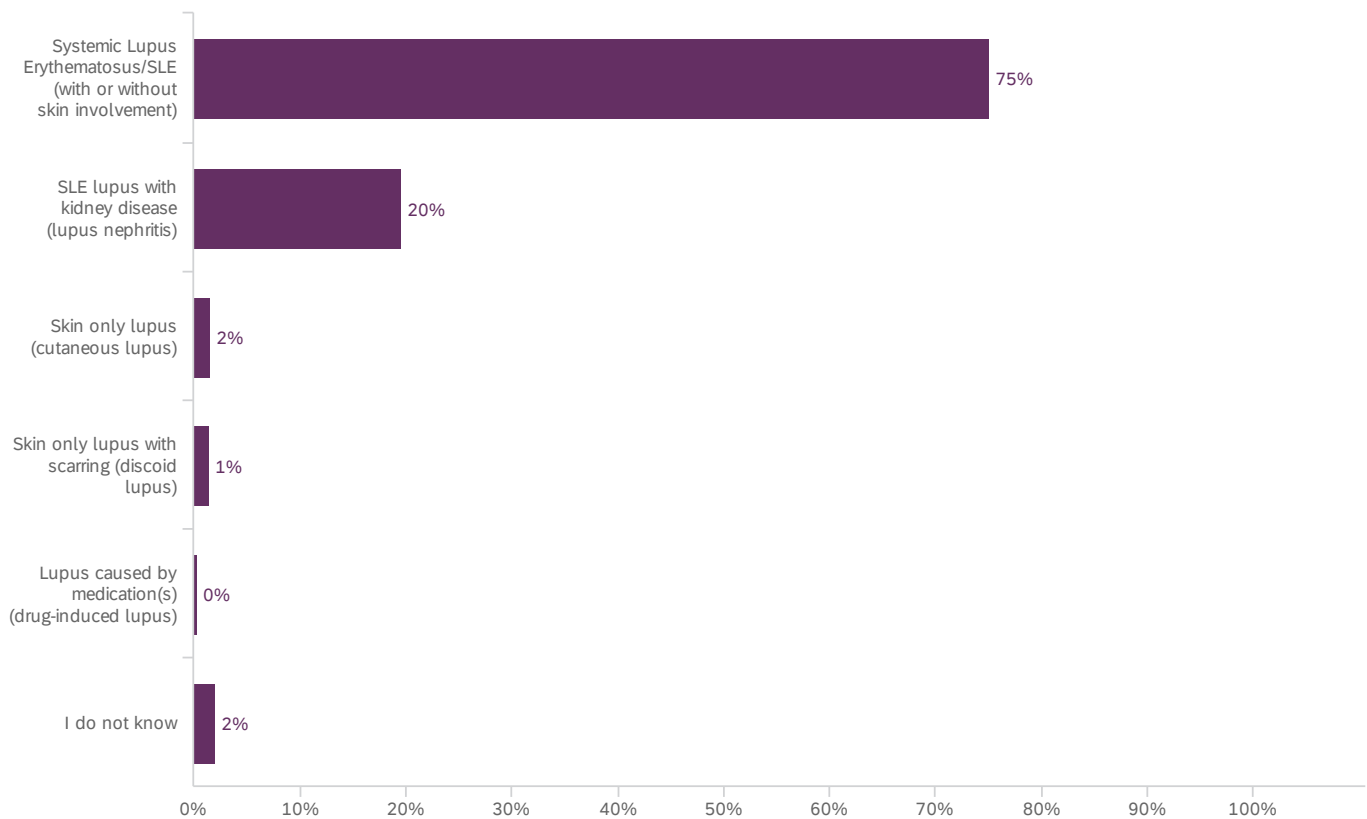


# WLF 2024 Survey: Steroid Use for Lupus Care (External)

World Lupus Federation 2024: Steroid Use for Lupus Care

May 13, 2024 7:56 PM EDT

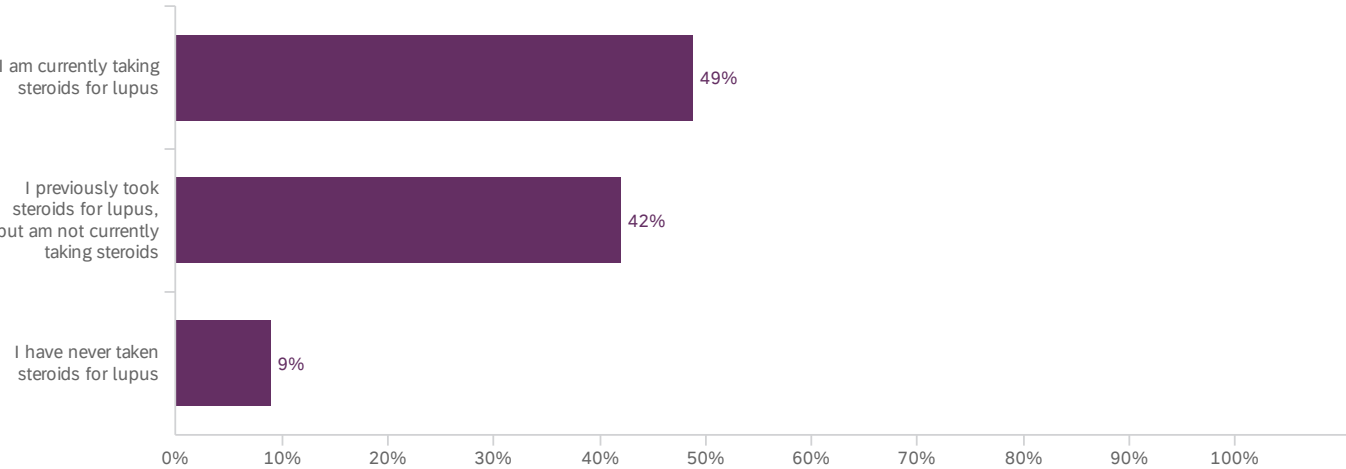
What type of lupus do you (or the person you care for) have?



Field	Choice Count
Systemic Lupus Erythematosus/SLE (with or without skin involvement)	75% 5814
SLE lupus with kidney disease (lupus nephritis)	20% 1516
Skin only lupus (cutaneous lupus)	2% 120
Skin only lupus with scarring (discoid lupus)	1% 111
Lupus caused by medication(s) (drug-induced lupus)	0% 23
I do not know	2% 157

Showing rows 1 - 7 of 7

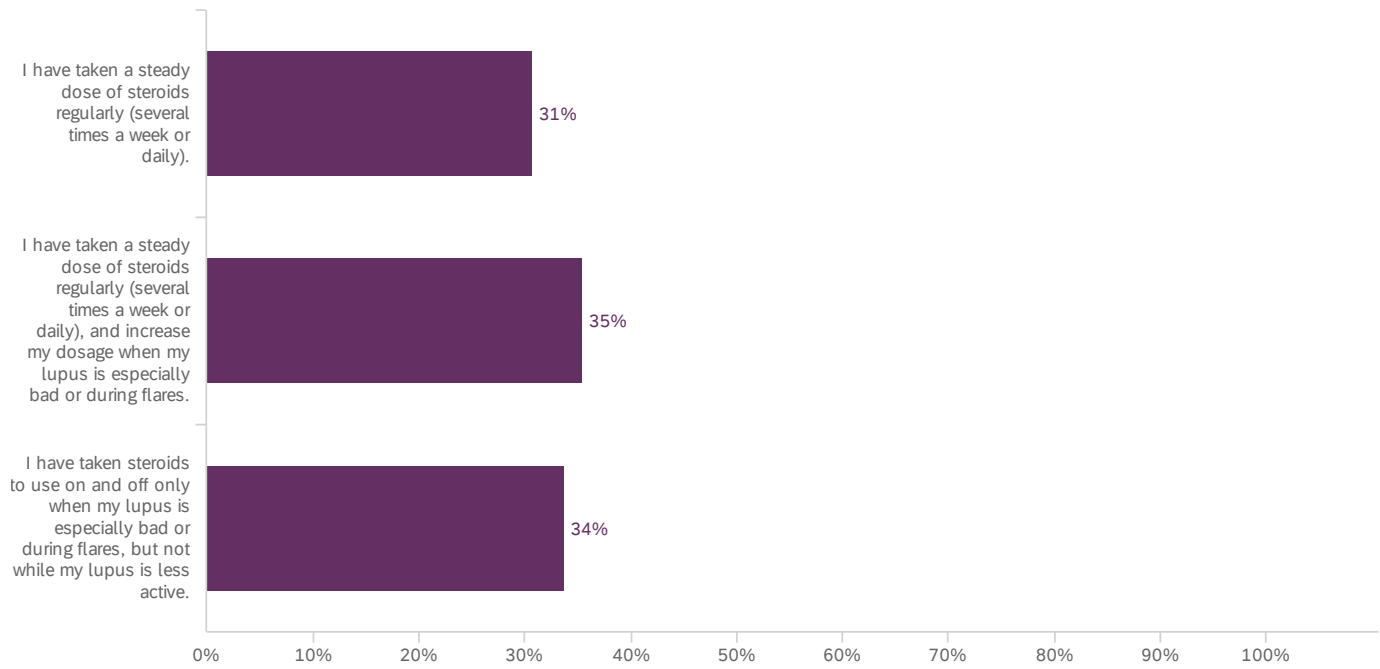
Are you currently or have you previously taken oral corticosteroids or steroids, such as pred...



Field	Choice Count
I am currently taking steroids for lupus	49% 3785
I previously took steroids for lupus, but am not currently taking steroids	42% 3258
I have never taken steroids for lupus	9% 698
	7741

Showing rows 1 - 4 of 4

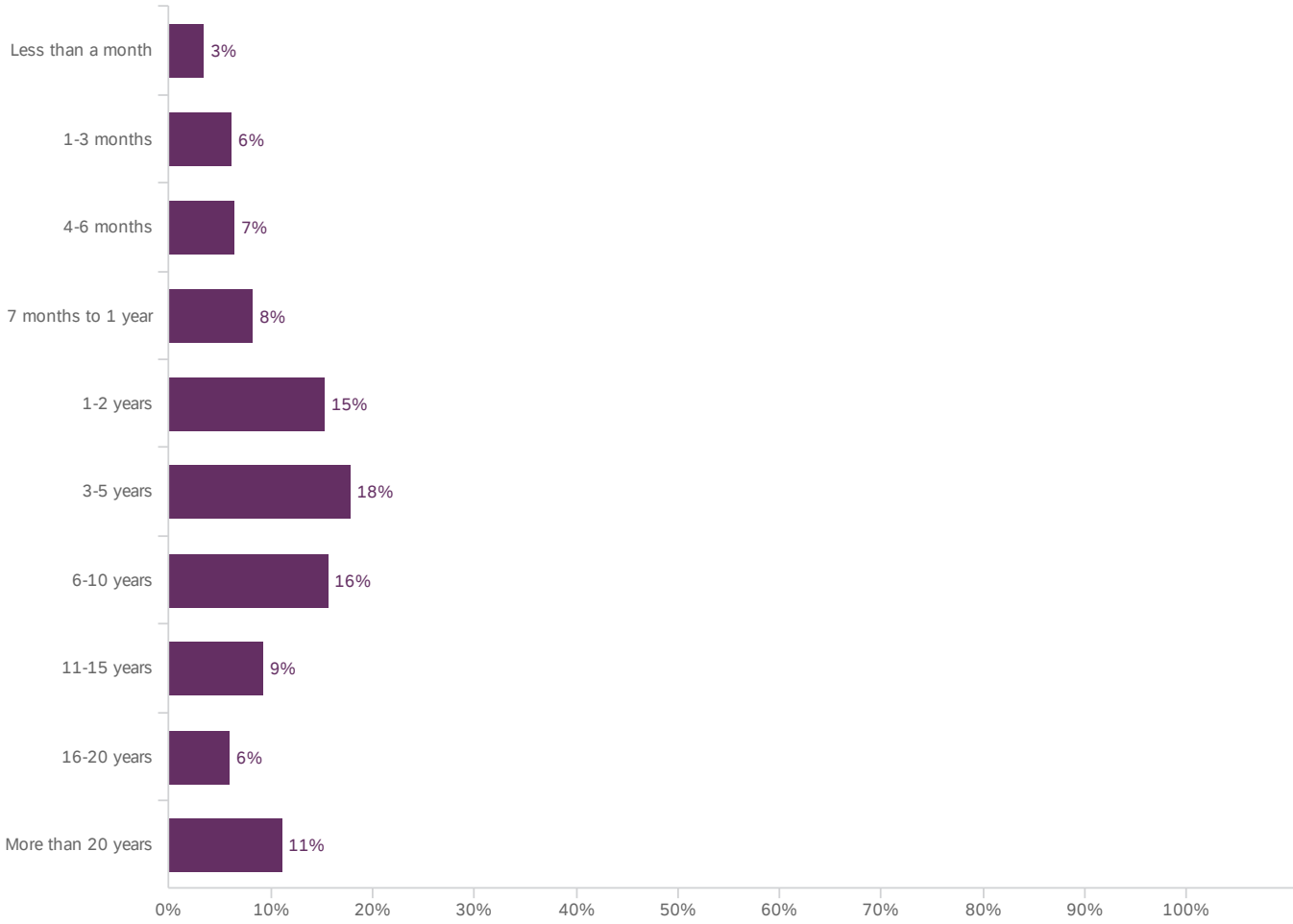
Which statement best describes how you have mostly used steroids (past and/or present) fo...



Field	Choice Count
I have taken steroids to use on and off only when my lupus is especially bad or during flares, but not while my lupus is less active.	34% 2376
I have taken a steady dose of steroids regularly (several times a week or daily), and increase my dosage when my lupus is especially bad or during flares.	35% 2500
I have taken a steady dose of steroids regularly (several times a week or daily).	31% 2167
	7043

Showing rows 1 - 4 of 4

Approximately how long in TOTAL have you been taking (or did you take) steroids for lupus?



Field	Choice Count
16-20 years	6% 420
11-15 years	9% 649
6-10 years	16% 1092
3-5 years	18% 1245
1-2 years	15% 1069
7 months to 1 year	8% 578
4-6 months	7% 453
1-3 months	6% 433

▲  
Field

Choice  
Count

More than 20 years

11% 776

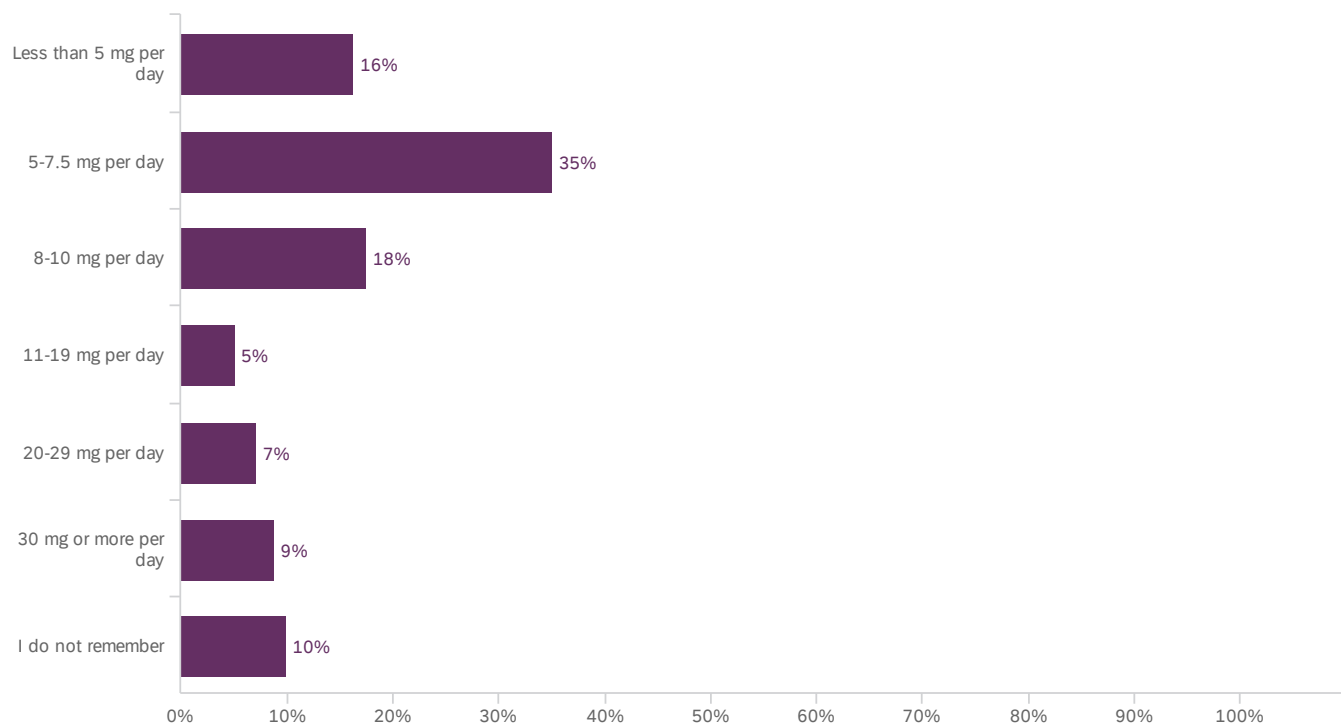
Less than a month

3% 243

6958

Showing rows 1 - 11 of 11

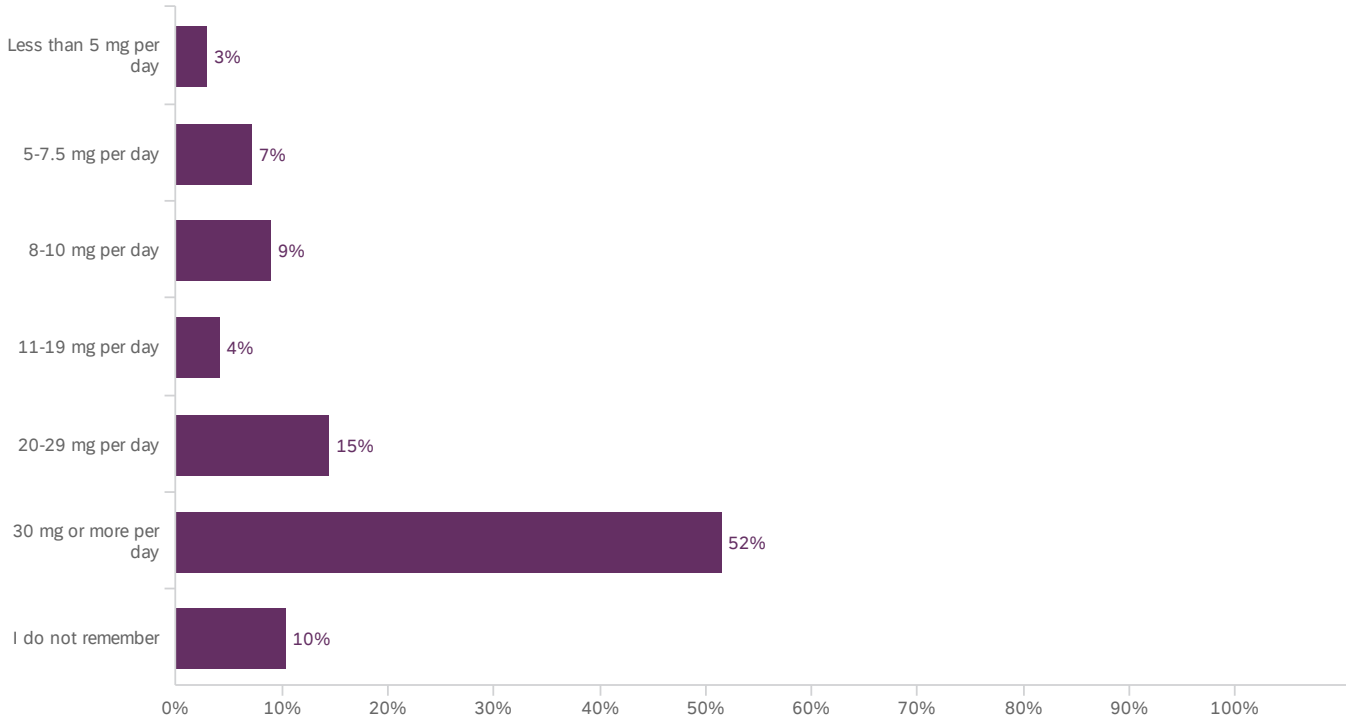
## What has been your typical everyday prescribed steroid dosage?



Field	Choice Count
Less than 5 mg per day	16% 1150
5-7.5 mg per day	35% 2472
8-10 mg per day	18% 1236
11-19 mg per day	5% 360
20-29 mg per day	7% 503
30 mg or more per day	9% 622
I do not remember	10% 700
	7043

Showing rows 1 - 8 of 8

# What was the maximum steroid dosage you have ever been prescribed by a doctor?

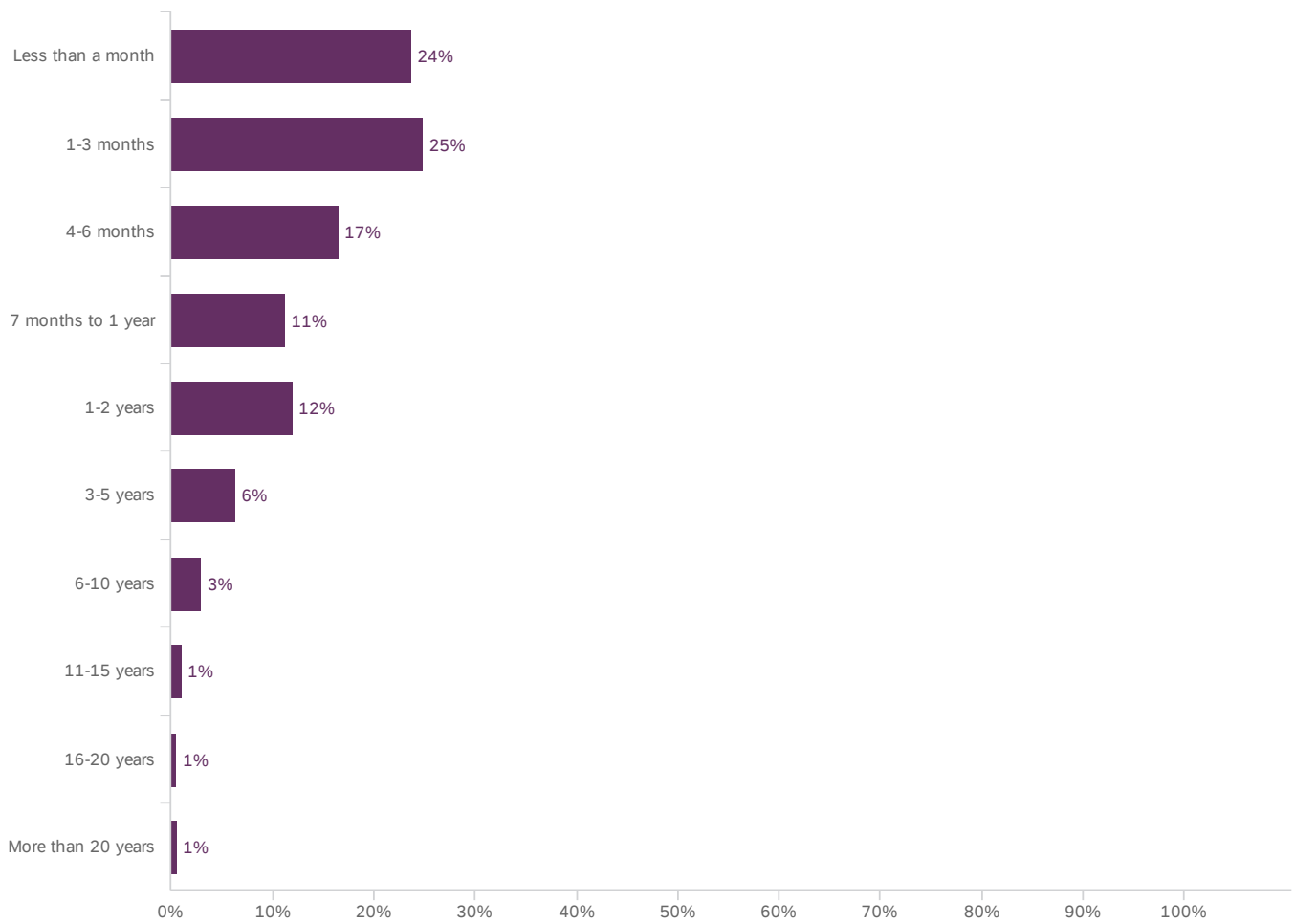


Field	Choice Count
Less than 5 mg per day	3% 210
5-7.5 mg per day	7% 510
8-10 mg per day	9% 637
11-19 mg per day	4% 295
20-29 mg per day	15% 1024
30 mg or more per day	52% 3632
I do not remember	10% 735
	7043

Showing rows 1 - 8 of 8



[For those with a maximum dose] How long were you on the maximum steroid dosage report...



Field

Choice  
Count

16-20 years	1%	34
11-15 years	1%	64
6-10 years	3%	181
3-5 years	6%	386
1-2 years	12%	729
7 months to 1 year	11%	684
4-6 months	17%	1004
1-3 months	25%	1512

▲  
Field

Choice  
Count

More than 20 years

1% 35

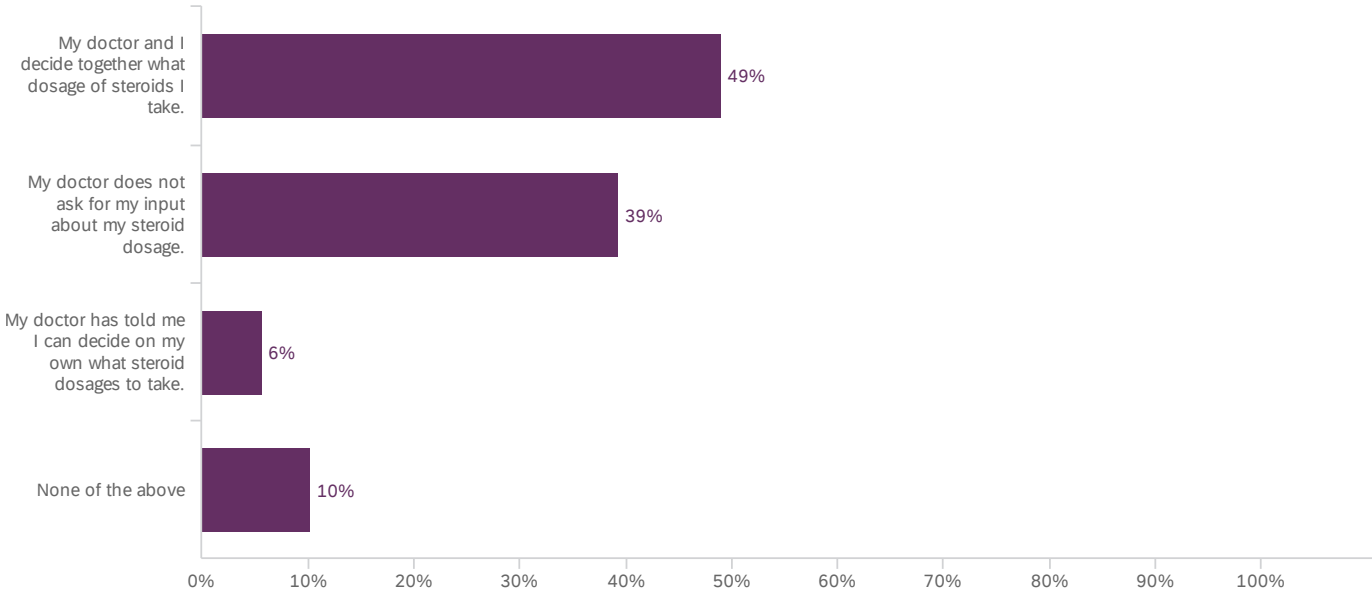
Less than a month

24% 1440

6069

Showing rows 1 - 11 of 11

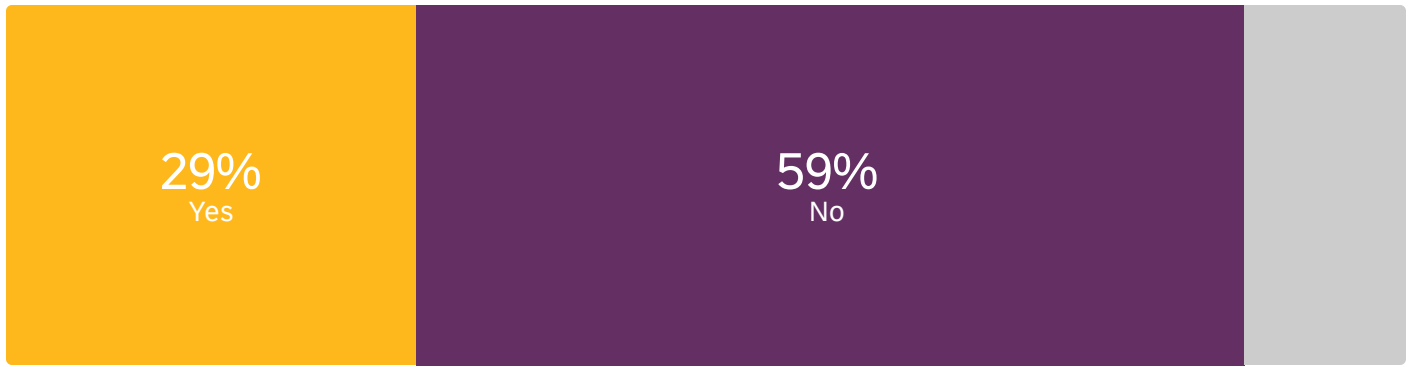
Please indicate which statements apply to you, if any. (Please check all that apply.)



Field	Choice Count
My doctor and I decide together what dosage of steroids I take.	47% 3449
My doctor does not ask for my input about my steroid dosage.	38% 2768
My doctor has told me I can decide on my own what steroid dosages to take.	5% 399
None of the above	10% 722
	7338

Showing rows 1 - 5 of 5

Does your doctor want you to continue taking steroids even when your lupus is un...



Yes No I do not know

Field	Choice	Count
I do not know	12%	817
No	59%	4168
Yes	29%	2058
		7043

Showing rows 1 - 4 of 4

# Has your doctor warned you about the negative effects of long-term steroid usage?

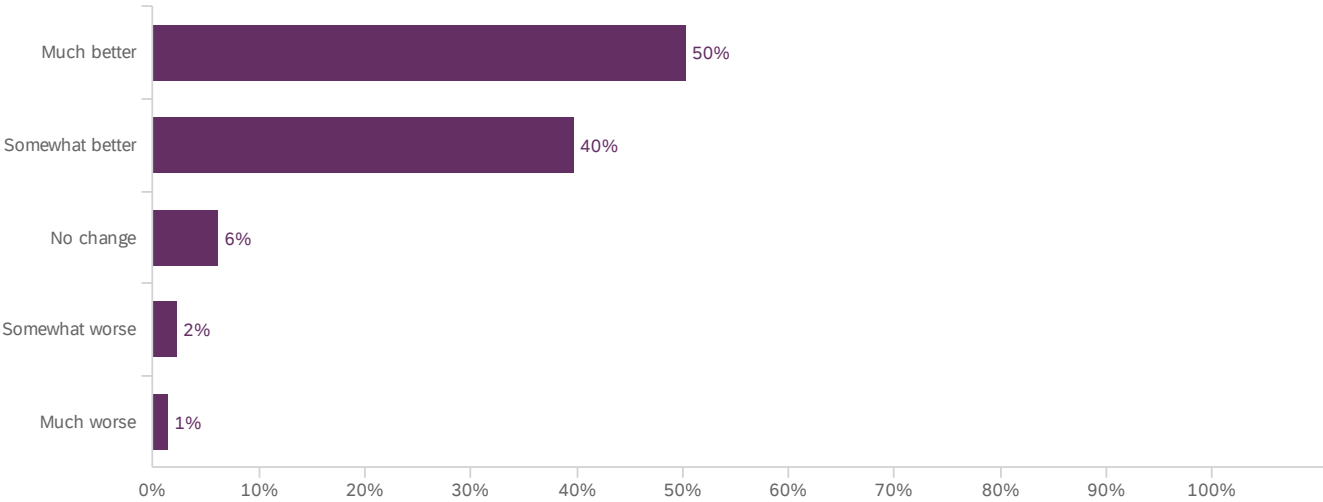


■ Yes   ■ No   ■ I do not know

Field	Choice	Count
I do not know	4%	257
No	23%	1627
Yes	73%	5159
		7043

Showing rows 1 - 4 of 4

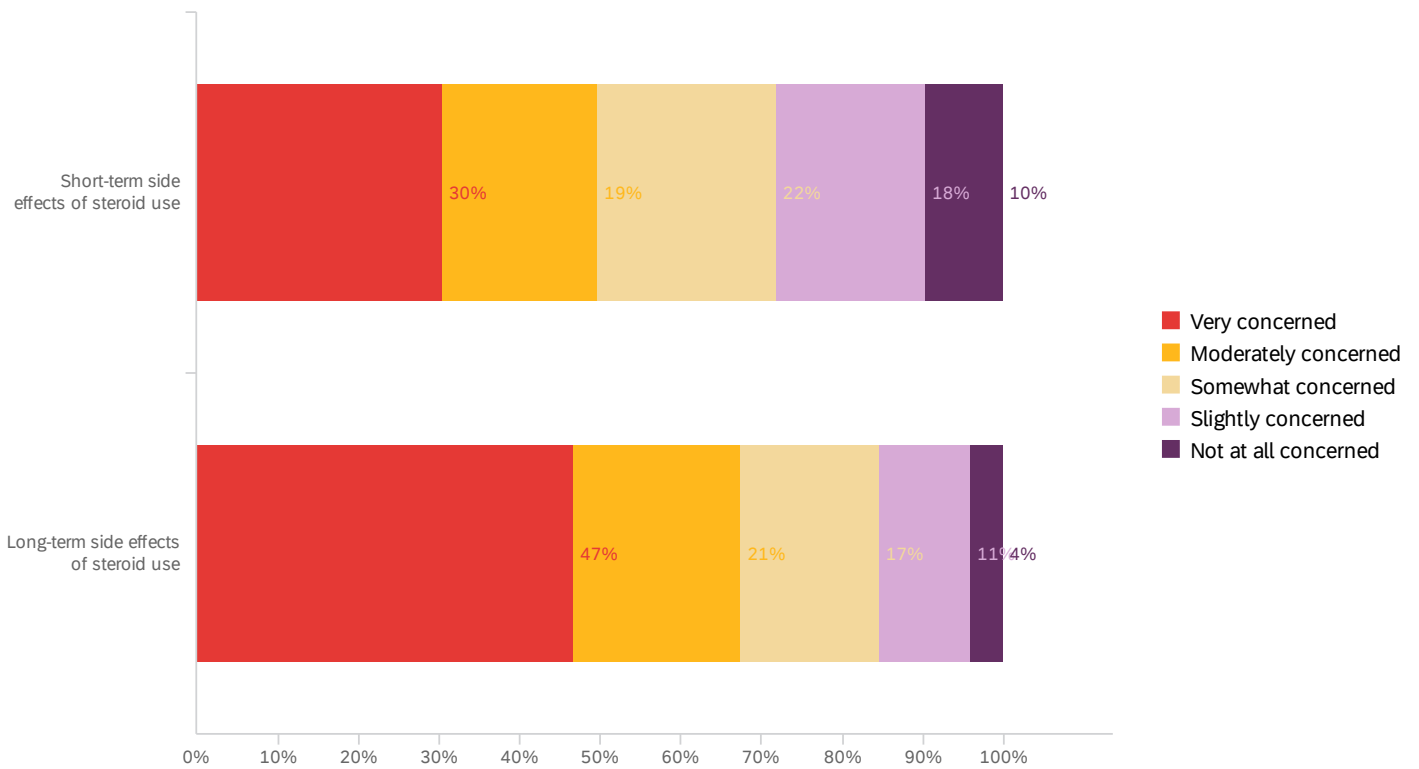
In general, how do you feel steroid use has made your lupus symptoms?



Field	Choice Count
Much better	50% 3545
Somewhat better	40% 2801
No change	6% 434
Somewhat worse	2% 161
Much worse	1% 102
	7043

Showing rows 1 - 6 of 6

## How concerned are you about the short-term and long-term side effects of steroid use?

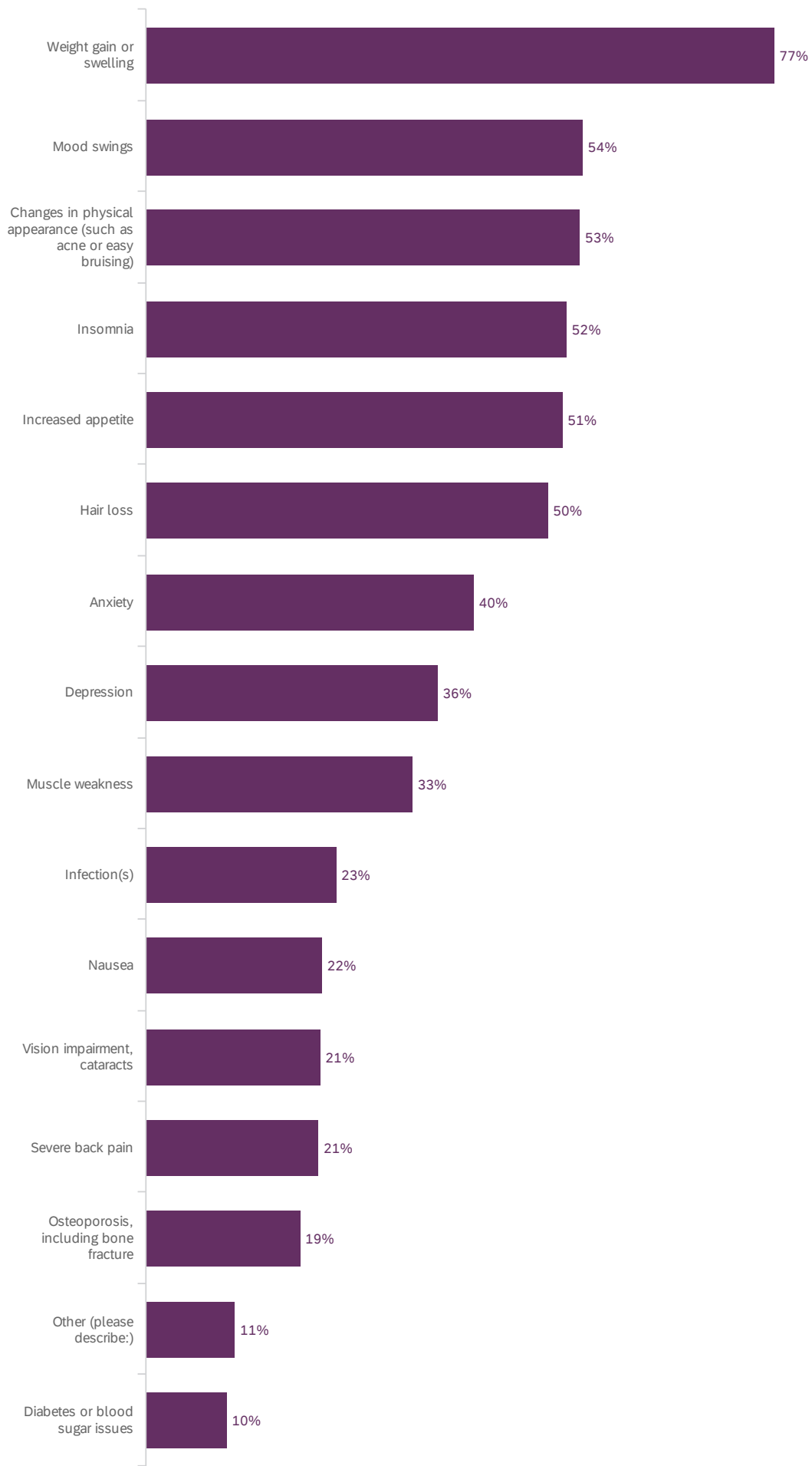


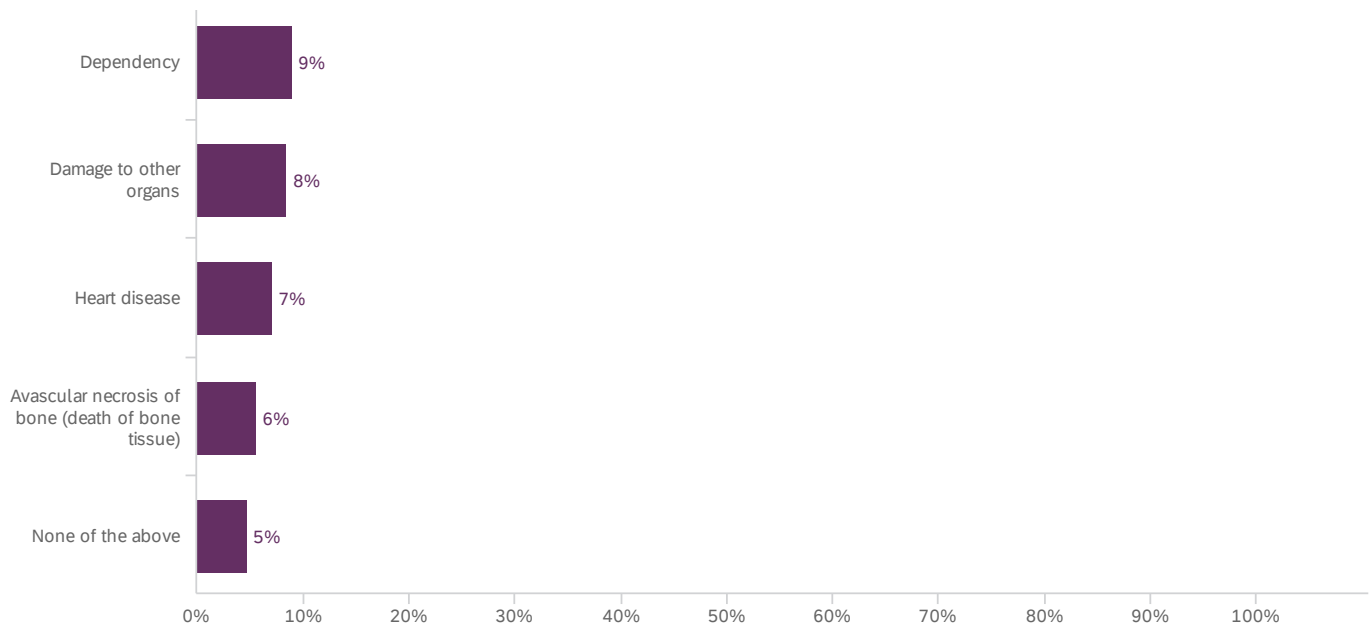
Field	Not at all concerned	Slightly concerned	Somewhat concerned	Moderately concerned	Very concerned	Total
Short-term side effects of steroid use	10% 677	18% 1302	22% 1560	19% 1357	30% 2147	7043
Long-term side effects of steroid use	4% 282	11% 798	17% 1208	21% 1462	47% 3293	7043

Showing rows 1 - 2 of 2

Because of steroid use, have you experienced any of the following side effects? (Please che...





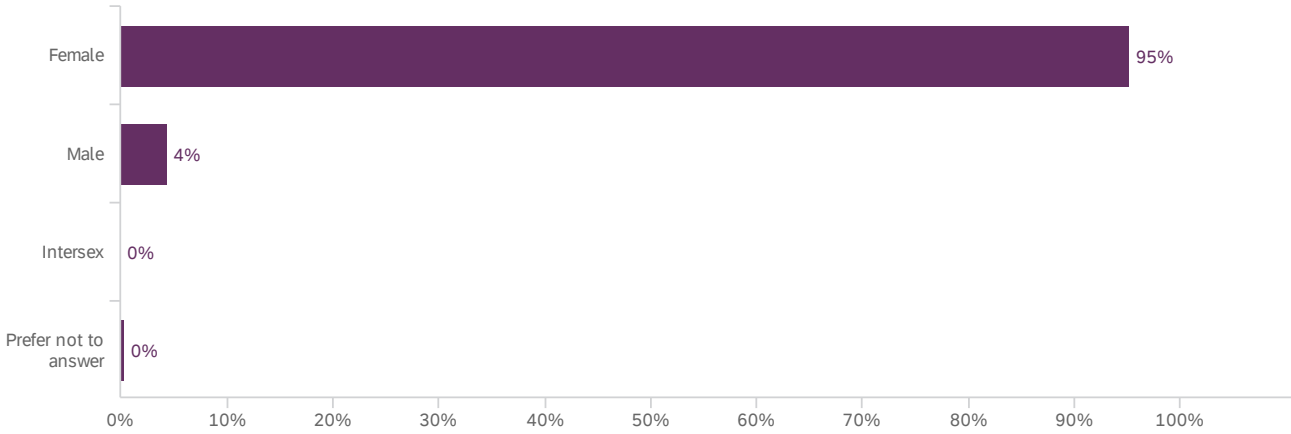


Field	Choice Count
Weight gain or swelling	77% 5449
Mood swings	54% 3790
Changes in physical appearance (such as acne or easy bruising)	53% 3764
Insomnia	52% 3650
Increased appetite	51% 3614
Hair loss	50% 3487
Anxiety	40% 2844
Depression	36% 2529
Muscle weakness	33% 2313
Infection(s)	23% 1650
Nausea	22% 1528
Severe back pain	21% 1496
Vision impairment, cataracts	21% 1513
Osteoporosis, including bone fracture	19% 1337

Field	Choice Count
Other (please describe:)	11% 771
Diabetes or blood sugar issues	10% 700
Dependency	9% 632
Damage to other organs	8% 598
Heart disease	7% 502
Avascular necrosis of bone (death of bone tissue)	6% 395
None of the above	5% 334
	7043

Showing rows 1 - 22 of 22

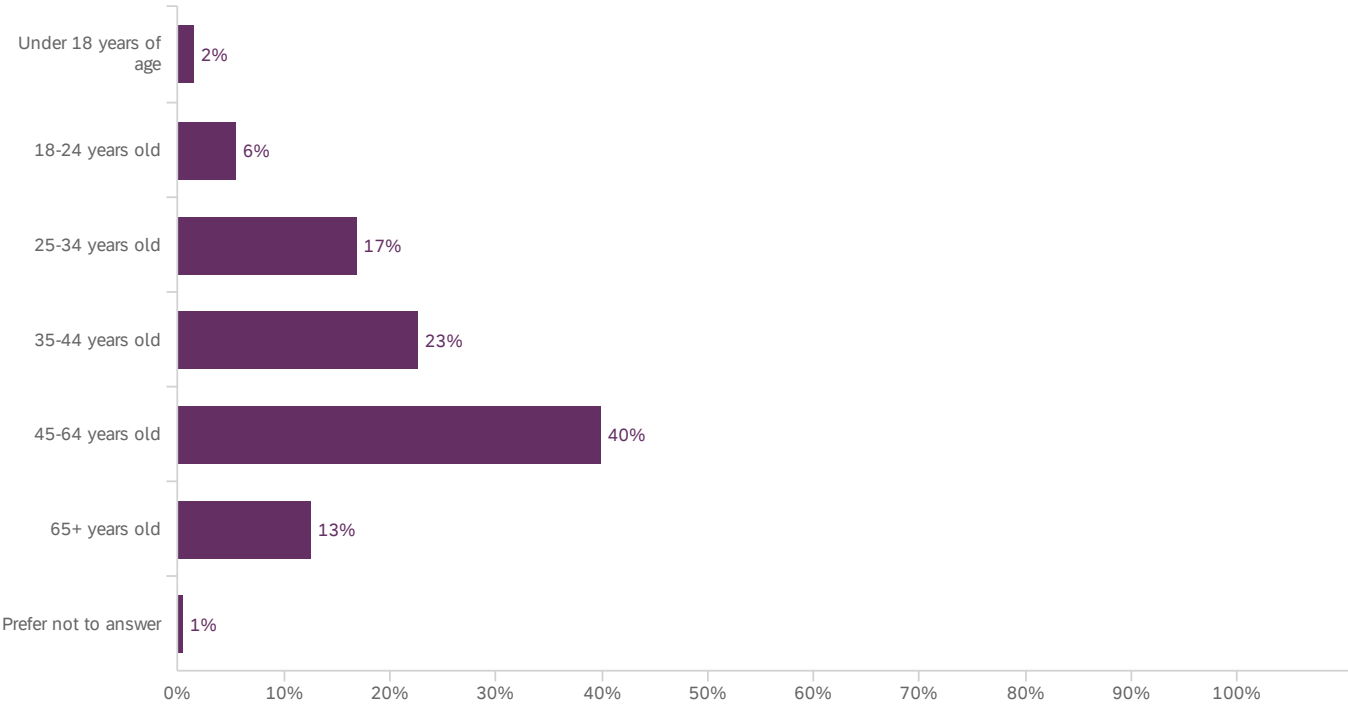
# What was your biological sex assigned at birth?



Field	Choice Count
Female	95% 7259
Male	4% 334
Intersex	0% 1
Prefer not to answer	0% 27
	7621

Showing rows 1 - 5 of 5

# What is your age?



Field	Choice Count
Prefer not to answer	1% 42
Under 18 years of age	2% 121
18-24 years old	6% 422
25-34 years old	17% 1292
35-44 years old	23% 1733
45-64 years old	40% 3049
65+ years old	13% 962
	7621

Showing rows 1 - 8 of 8

## Respondent Countries

Field	Choice Count
Afghanistan	0% 3
Albania	0% 1
Algeria	0% 2
Andorra	0% 1
Angola	0% 0
Antigua and Barbuda	0% 0
Armenia	0% 2
Austria	0% 14
Azerbaijan	0% 1
Bahamas	0% 11
Bahrain	0% 0
Barbados	0% 2
Belarus	0% 1
Belgium	0% 14
Belize	0% 1
Benin	0% 0
Bhutan	0% 0
Bolivia	0% 12
Bosnia and Herzegovina	0% 1

Field	Choice Count
Botswana	0% 0
Brazil	0% 11
Brunei Darussalam	0% 0
Bulgaria	0% 2
Burkina Faso	0% 0
Burundi	0% 0
Cambodia	0% 0
Cameroon	0% 0
Cape Verde	0% 0
Central African Republic	0% 0
Chad	0% 0
China	0% 0
Comoros	0% 0
Congo, Republic of the...	0% 0
Costa Rica	0% 37
Côte d'Ivoire	0% 0
Croatia	0% 3
Cuba	0% 1
Cyprus	0% 1
Czech Republic	0% 5
Democratic People's Republic of Korea	0% 0

Field	Choice Count
Democratic Republic of the Congo	0% 0
Denmark	0% 3
Djibouti	0% 0
Dominica	0% 6
Dominican Republic	0% 21
Egypt	0% 2
El Salvador	0% 6
Equatorial Guinea	0% 1
Eritrea	0% 0
Estonia	0% 2
Ethiopia	0% 0
Fiji	0% 1
Finland	0% 2
France	0% 8
Gabon	0% 0
Gambia	0% 0
Georgia	0% 5
Ghana	0% 4
Grenada	0% 2
Guatemala	0% 23
Guinea	0% 0



Field	Choice Count
Guinea-Bissau	0% 0
Guyana	0% 5
Haiti	0% 0
Honduras	0% 23
Hong Kong (S.A.R.)	0% 2
Hungary	0% 1
Iceland	0% 3
Iran, Islamic Republic of...	0% 4
Iraq	0% 0
Ireland	0% 27
Israel	0% 0
Japan	0% 13
Jordan	0% 0
Kazakhstan	0% 0
Kiribati	0% 0
Kuwait	0% 0
Kyrgyzstan	0% 0
Lao People's Democratic Republic	0% 0
Latvia	0% 0
Lebanon	0% 0
Lesotho	0% 0

Field	Choice Count
Liberia	0% 0
Libyan Arab Jamahiriya	0% 0
Liechtenstein	0% 0
Lithuania	0% 1
Luxembourg	0% 0
Madagascar	0% 0
Malawi	0% 1
Maldives	0% 1
Mali	0% 0
Malta	0% 0
Marshall Islands	0% 0
Mauritania	0% 0
Mauritius	0% 3
Micronesia, Federated States of...	0% 0
Monaco	0% 0
Mongolia	0% 1
Montenegro	0% 1
Morocco	0% 0
Mozambique	0% 0
Myanmar	0% 2
Namibia	0% 1

Field	Choice Count
Nauru	0% 0
Nepal	0% 2
New Zealand	0% 9
Nicaragua	0% 11
Niger	0% 0
Nigeria	0% 24
North Korea	0% 0
Oman	0% 0
Pakistan	0% 6
Palau	0% 0
Panama	0% 8
Papua New Guinea	0% 0
Paraguay	0% 30
Peru	0% 34
Poland	0% 2
Qatar	0% 0
Republic of Korea	0% 1
Republic of Moldova	0% 0
Romania	0% 1
Russian Federation	0% 0
Rwanda	0% 0

Field	Choice Count
Saint Kitts and Nevis	0% 0
Saint Lucia	0% 4
Saint Vincent and the Grenadines	0% 1
Samoa	0% 0
San Marino	0% 0
Sao Tome and Principe	0% 0
Saudi Arabia	0% 0
Senegal	0% 0
Serbia	0% 5
Seychelles	0% 0
Sierra Leone	0% 0
Singapore	0% 6
Slovakia	0% 24
Slovenia	0% 2
Solomon Islands	0% 0
Somalia	0% 0
South Korea	0% 0
Sri Lanka	0% 1
Sudan	0% 0
Suriname	0% 0
Swaziland	0% 1

Field	Choice Count
Sweden	0% 13
Switzerland	0% 9
Syrian Arab Republic	0% 0
Taiwan	0% 13
Tajikistan	0% 0
Thailand	0% 2
The former Yugoslav Republic of Macedonia	0% 0
Timor-Leste	0% 0
Togo	0% 0
Tonga	0% 0
Tunisia	0% 0
Turkey	0% 5
Turkmenistan	0% 0
Tuvalu	0% 0
Uganda	0% 3
Ukraine	0% 0
United Arab Emirates	0% 5
United Republic of Tanzania	0% 1
Uruguay	0% 12
Uzbekistan	0% 1
Vanuatu	0% 0

Field	Choice Count
Viet Nam	0% 0
Yemen	0% 0
Zambia	0% 2
Zimbabwe	0% 0
Australia	1% 55
Bangladesh	1% 72
Colombia	1% 77
Greece	1% 73
India	1% 43
Indonesia	1% 60
Italy	1% 46
Jamaica	1% 40
Kenya	1% 44
Norway	1% 45
Philippines	1% 49
Portugal	1% 53
Trinidad and Tobago	1% 60
Venezuela, Bolivarian Republic of...	1% 39
Other	1% 74
Canada	2% 162
Ecuador	2% 120

Field	Choice Count
Germany	2% 117
Malaysia	2% 186
Chile	3% 222
Netherlands	3% 217
South Africa	3% 225
Argentina	4% 319
United Kingdom of Great Britain and Northern Ireland	5% 396
Mexico	6% 428
Spain	6% 478
United States of America	44% 3382
	7621

Showing rows 1 - 198 of 198

**End of Report**