

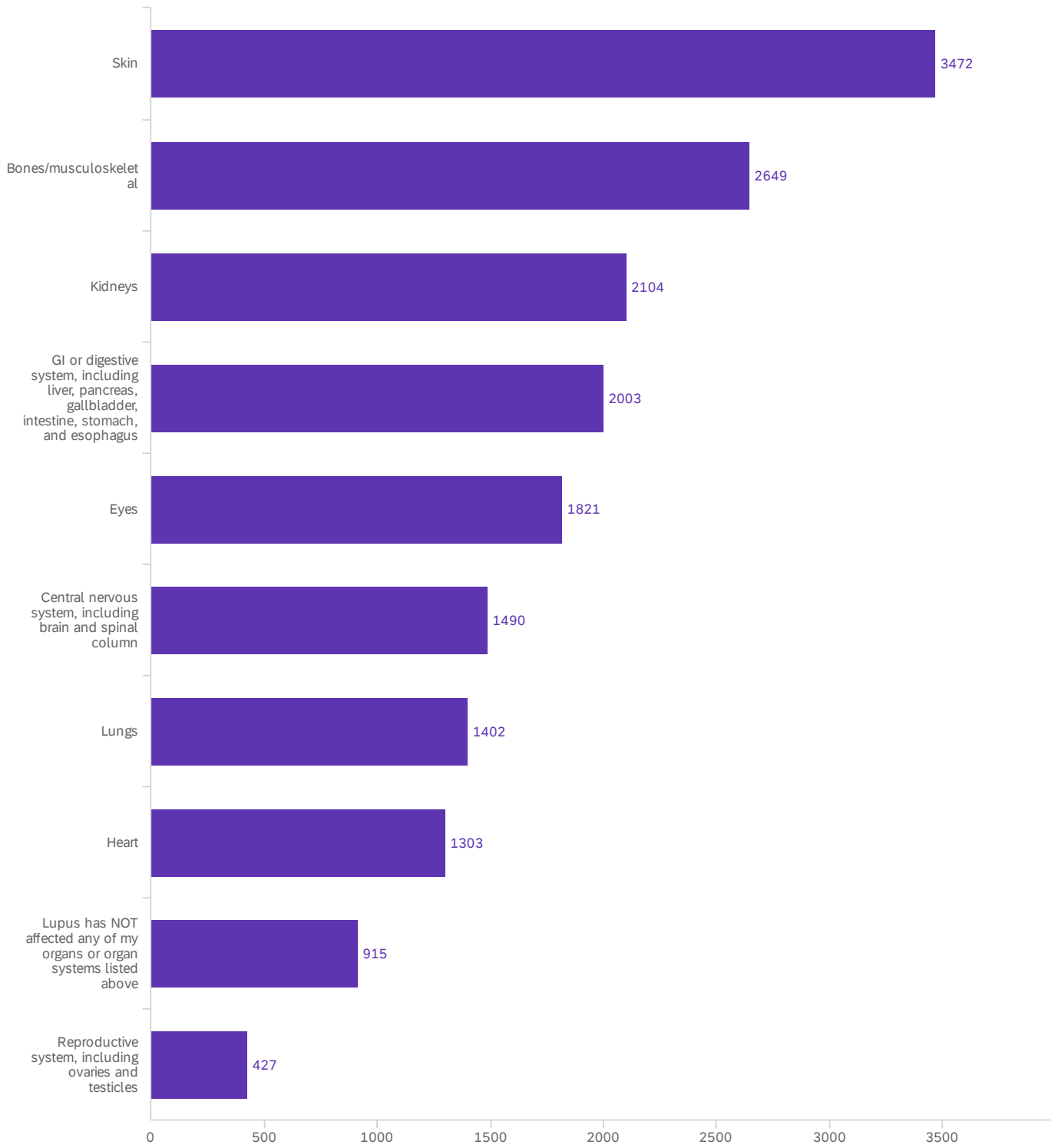
# World Lupus Federation Impact of Lupus on Organ Systems

*World Lupus Federation 2022: The Impact of Lupus on Organs*

May 6, 2022 7:50 PM EDT

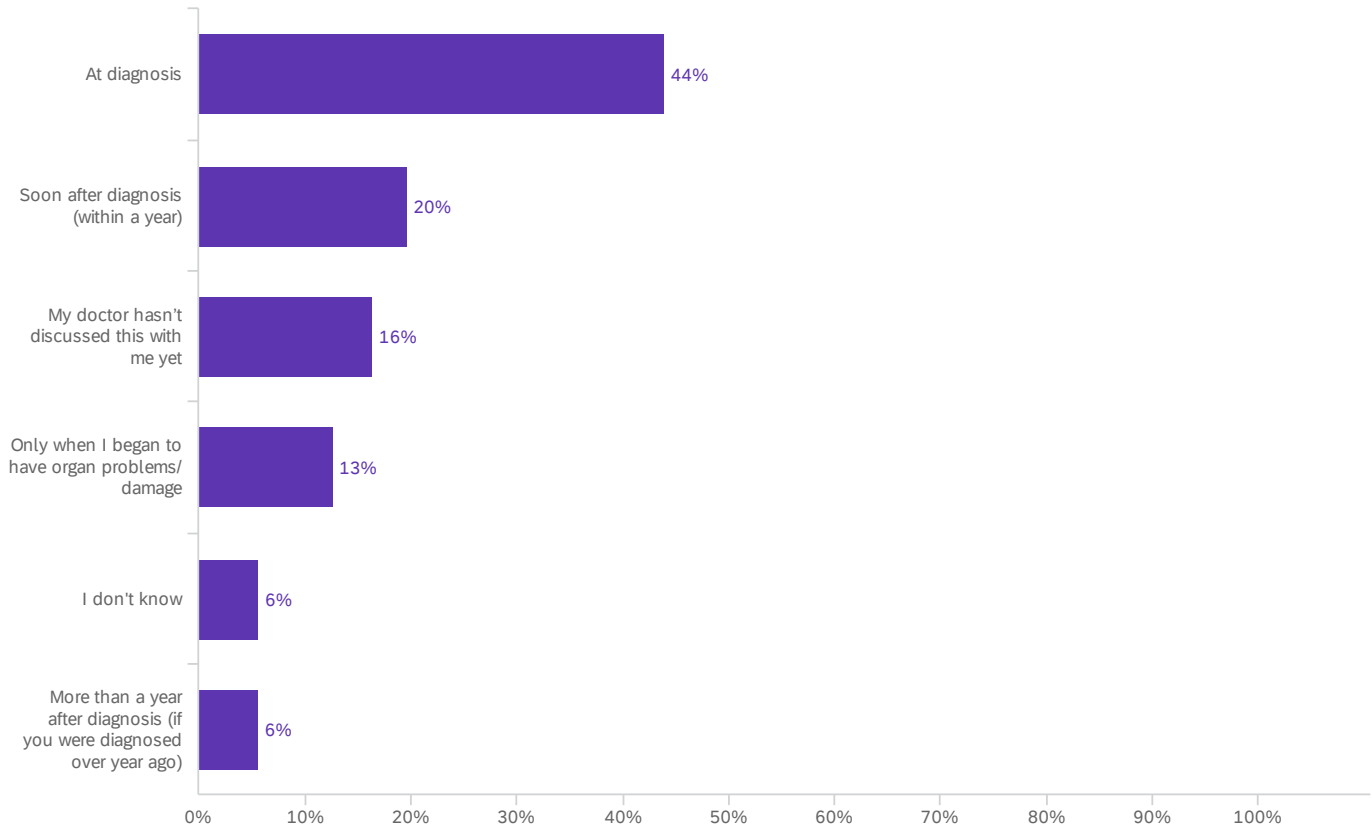
Has lupus affected any of your following organs or organ systems? (Please check all that ap...

**Number of Respondents**



# When did your doctor first discuss the possibility that lupus could seriously impact or cause i...

Percent of respondents (Respondents could choose more than one.)

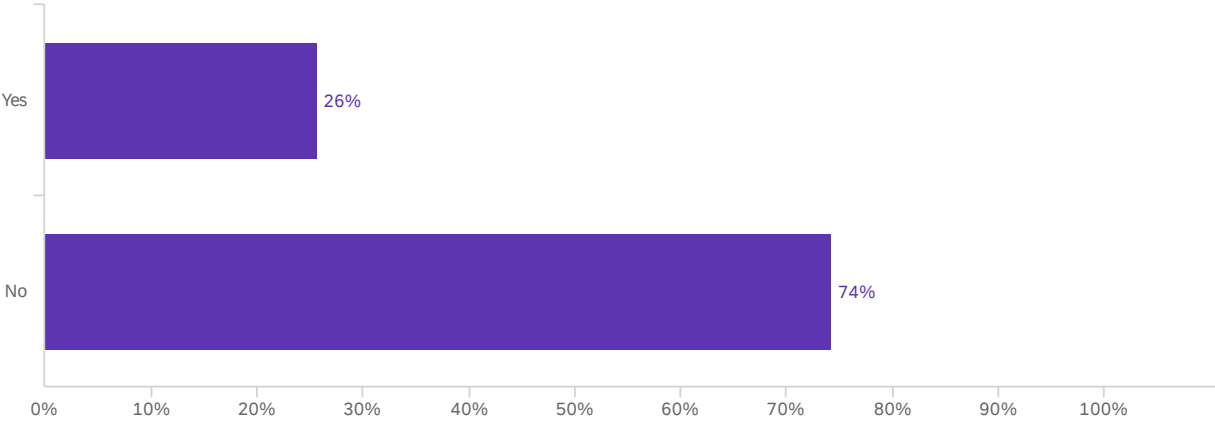


Field	Choice Count
Soon after diagnosis (within a year)	20% 1136
Only when I began to have organ problems/ damage	13% 731
My doctor hasn't discussed this with me yet	16% 948
More than a year after diagnosis (if you were diagnosed over year ago)	6% 326
I don't know	6% 327
At diagnosis	44% 2539

5774

Have you ever been told by a doctor that any of your current or previous lupus treatments dir...

Percent of Respondents

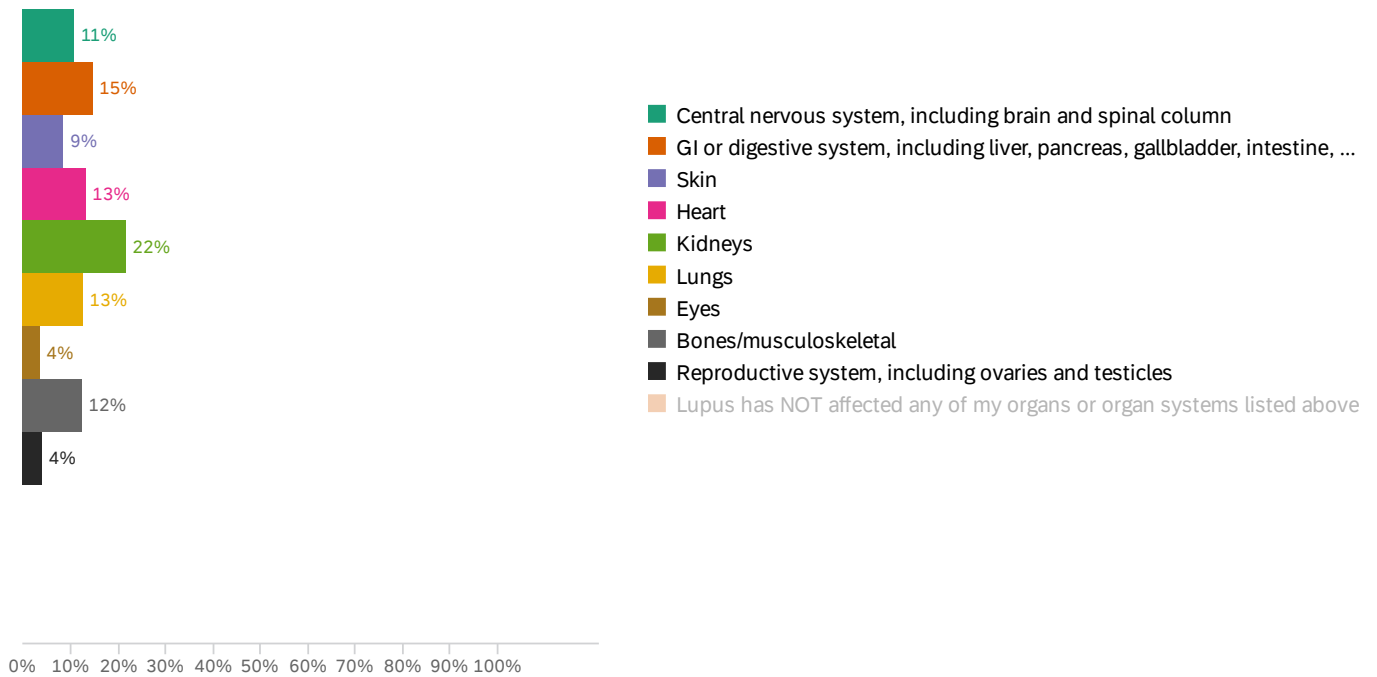


Field	Choice	Count
No	74.28%	4024
Yes	25.72%	1393
		5417

Showing rows 1 - 3 of 3

Have you ever been hospitalized because of organ damage to the following organs because...

**Percent of Respondents Hospitalized (Lupus-Related Organ Damage)**

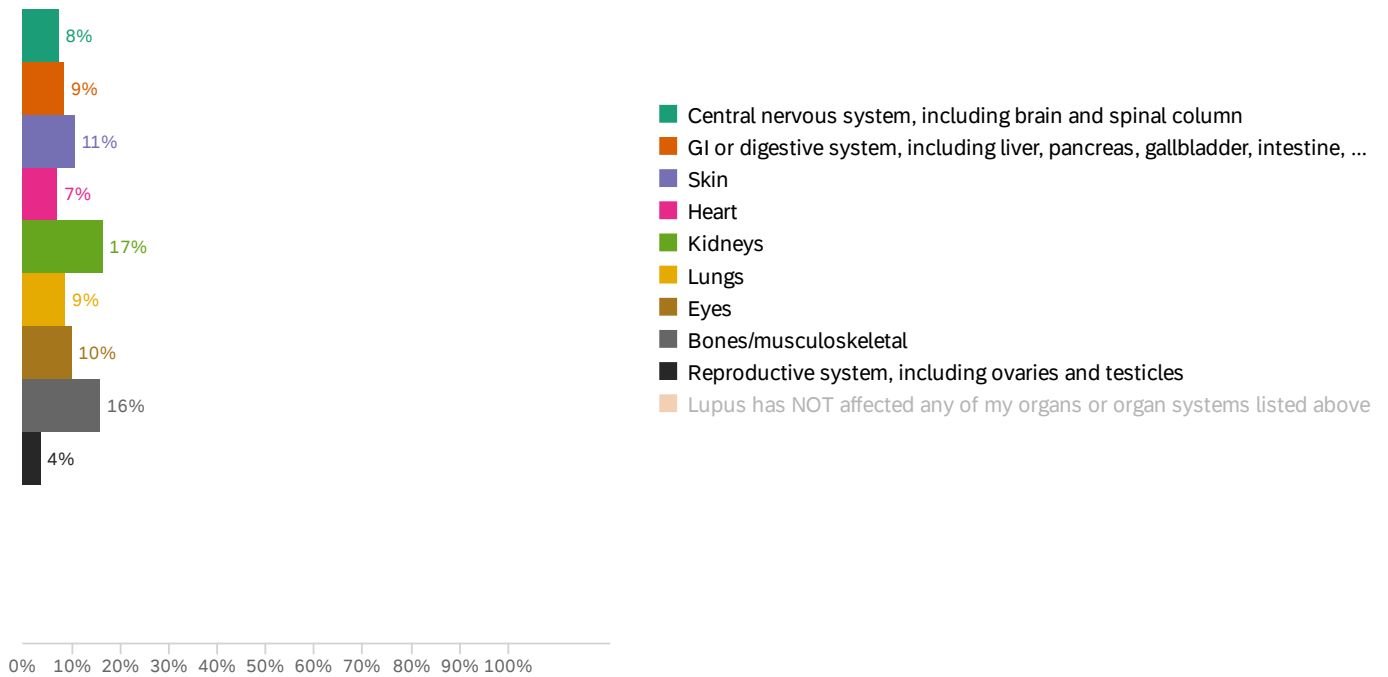


Field	Yes	No	Total
Skin	14% 499	86% 2943	3442
Bones/musculoskeletal	27% 723	73% 1914	2637
Kidneys	60% 1262	40% 841	2103
GI or digestive system, including liver, pancreas, gallbladder, intestine, stomach, and esophagus	43% 856	57% 1142	1998
Eyes	12% 210	88% 1603	1813
Central nervous system, including brain and spinal column	43% 632	57% 853	1485
Lungs	53% 736	47% 665	1401
Heart	59% 770	41% 531	1301
Reproductive system, including ovaries and testicles	56% 240	44% 185	425



# Have you ever been told by a doctor you have irreversible organ damage because of lupus?

## Percent of Respondents Told Irreversible Organ Damage



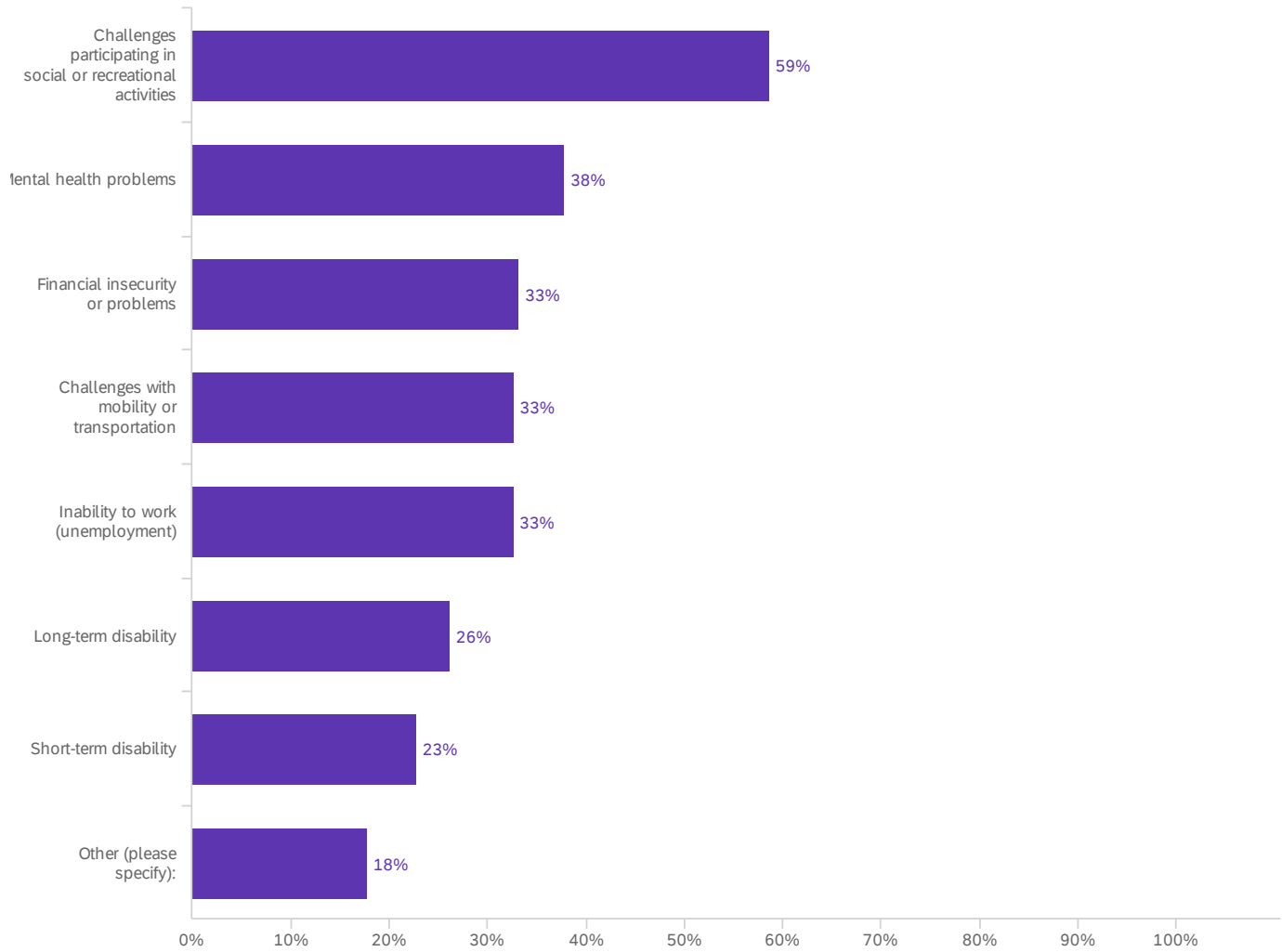
Field	Yes	No	Total
Skin	19% 599	81% 2591	3190
Bones/musculoskeletal	38% 892	62% 1478	2370
Kidneys	48% 919	52% 1003	1922
GI or digestive system, including liver, pancreas, gallbladder, intestine, stomach, and esophagus	27% 478	73% 1322	1800
Eyes	35% 563	65% 1057	1620
Central nervous system, including brain and spinal column	31% 417	69% 914	1331
Lungs	39% 491	61% 759	1250
Heart	35% 401	65% 736	1137
Reproductive system, including ovaries and testicles	56% 208	44% 165	373





Has your lupus-related organ damage led to any of the following? (Please check all that apply.)

**Percent of Respondents**



Field	Choice Count
Short-term disability	23% 1321
Long-term disability	26% 1519
Inability to work (unemployment)	33% 1892
Financial insecurity or problems	33% 1924
Mental health problems	38% 2192
Challenges participating in social or recreational activities	59% 3399
Challenges with mobility or transportation	33% 1893

Field

Choice  
Count

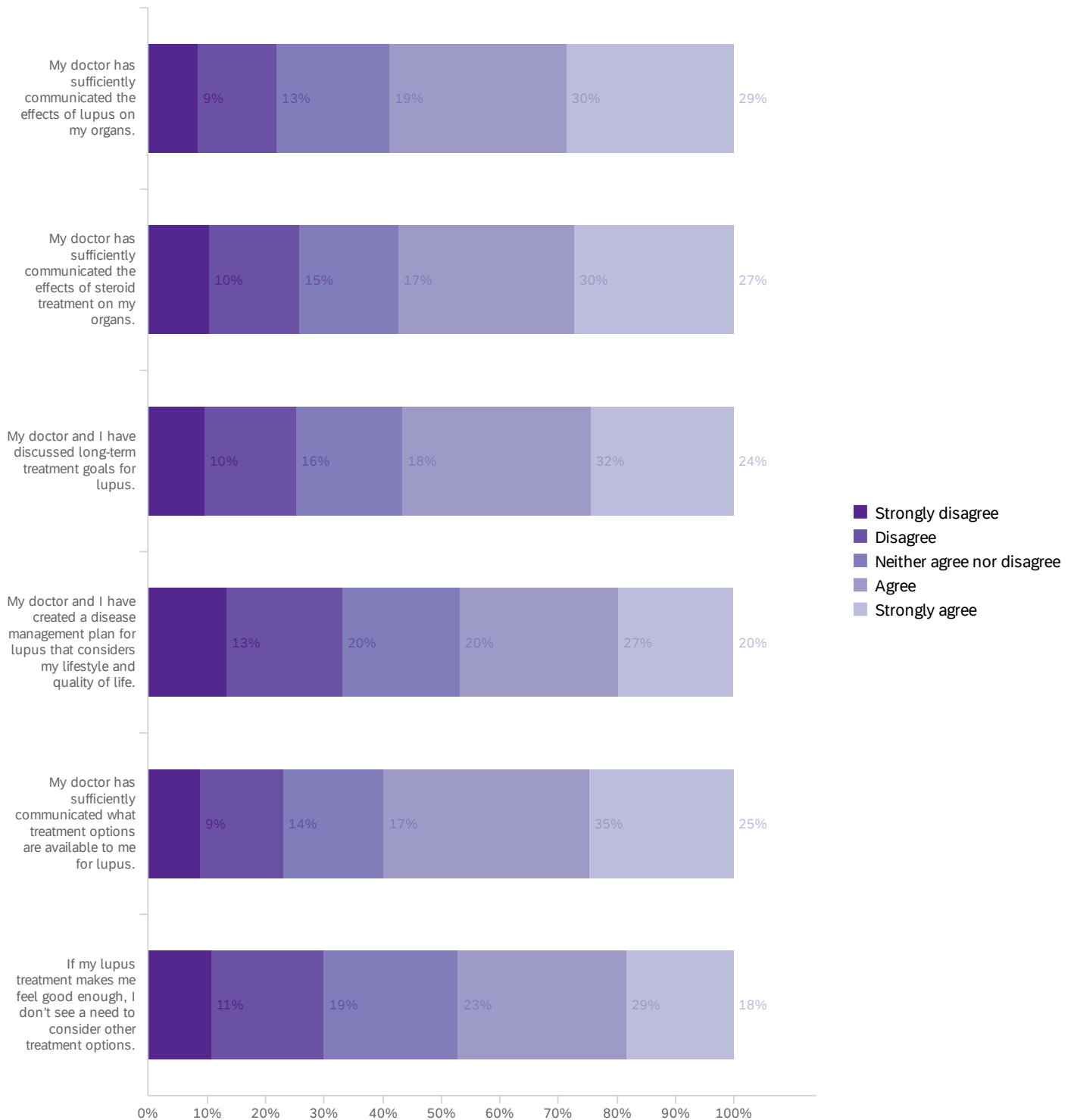
Other (please specify):

18% 1032

5789

Showing rows 1 - 9 of 9

Please indicate your level of agreement or disagreement with the following statements.

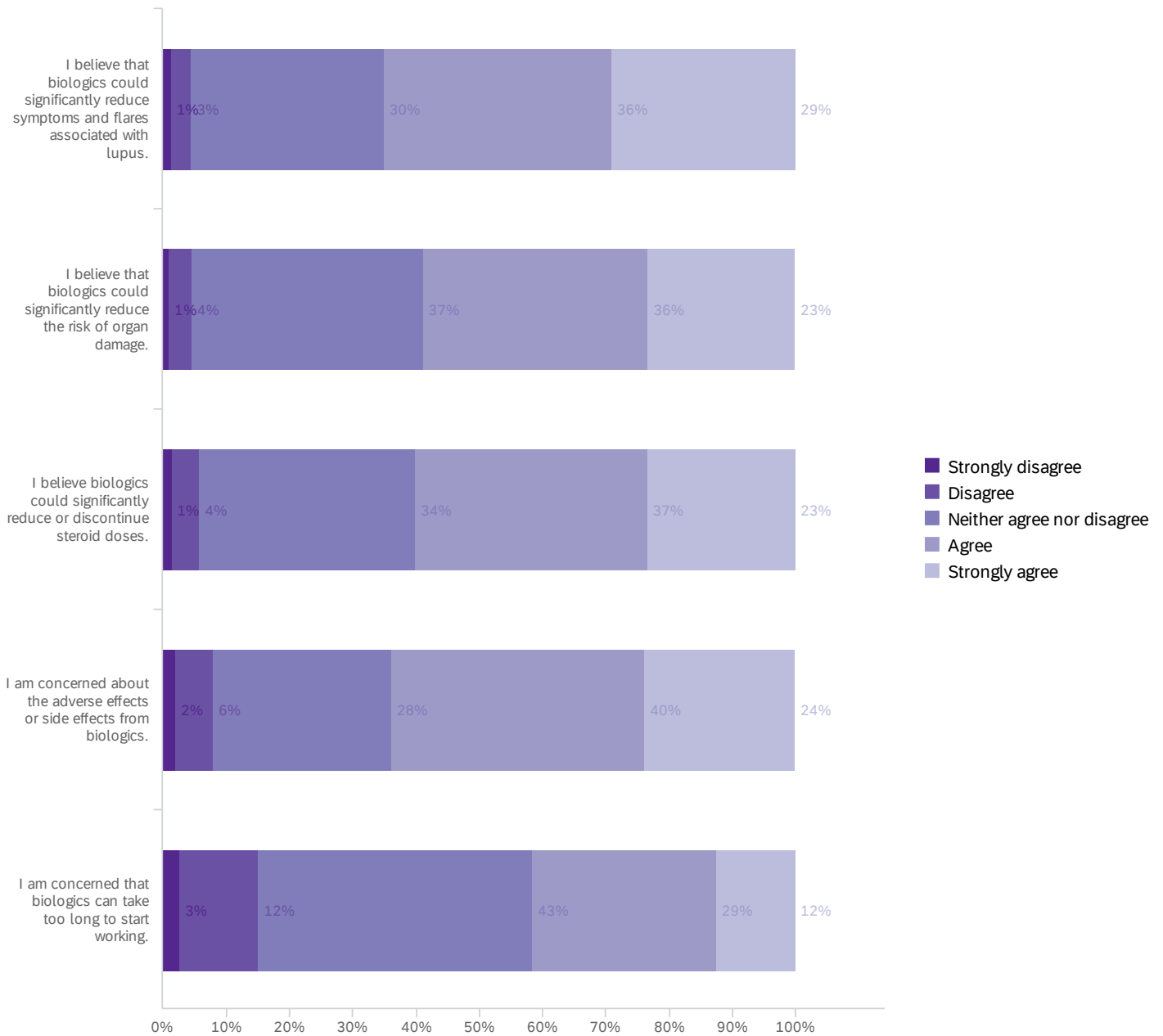


Field	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
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Field	Strongly disagree		Disagree		Neither agree nor disagree		Agree		Strongly agree		Total
My doctor has sufficiently communicated the effects of lupus on my organs.	9%	482	13%	756	19%	1088	30%	1699	29%	1606	5631
My doctor has sufficiently communicated the effects of steroid treatment on my organs.	10%	563	15%	827	17%	908	30%	1609	27%	1458	5365
My doctor and I have discussed long-term treatment goals for lupus.	10%	541	16%	875	18%	1018	32%	1794	24%	1363	5591
My doctor and I have created a disease management plan for lupus that considers my lifestyle and quality of life.	13%	744	20%	1092	20%	1107	27%	1496	20%	1085	5524
My doctor has sufficiently communicated what treatment options are available to me for lupus.	9%	502	14%	800	17%	966	35%	1974	25%	1385	5627
If my lupus treatment makes me feel good enough, I don't see a need to consider other treatment options.	11%	605	19%	1073	23%	1277	29%	1602	18%	1020	5577

Showing rows 1 - 6 of 6

Please indicate your level of agreement or disagreement with the following statements relating to biologics.



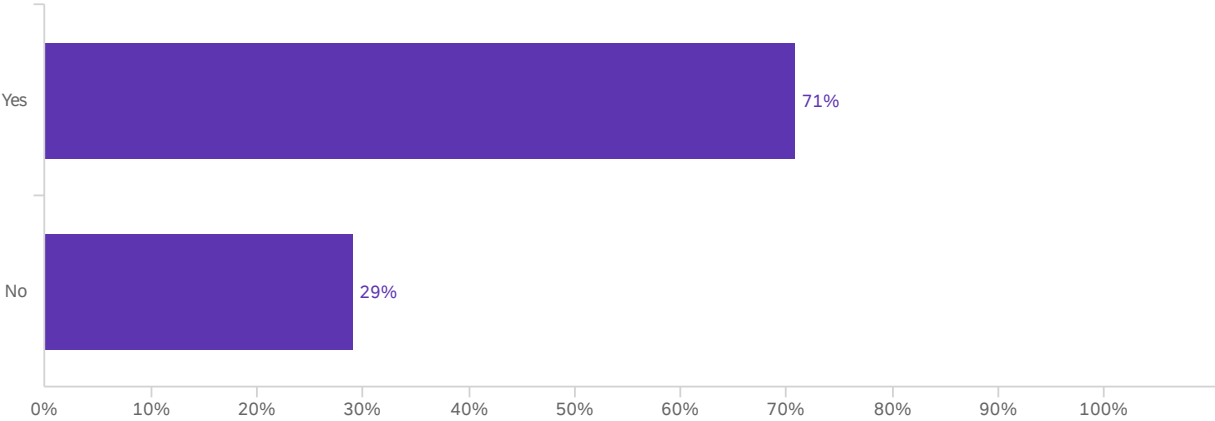
Field	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
I believe that biologics could significantly reduce symptoms and flares associated with lupus.	1% 51	3% 117	30% 1120	36% 1322	29% 1067	3677
I believe that biologics could significantly reduce the risk of organ damage.	1% 38	4% 127	37% 1311	36% 1273	23% 833	3582

Field	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
I believe biologics could significantly reduce or discontinue steroid doses.	1% 52	4% 156	34% 1212	37% 1303	23% 830	3553
I am concerned about the adverse effects or side effects from biologics.	2% 83	6% 237	28% 1120	40% 1593	24% 946	3979
I am concerned that biologics can take too long to start working.	3% 99	12% 455	43% 1578	29% 1060	12% 455	3647

Showing rows 1 - 5 of 5

# Have you taken any medications specifically to treat lupus-related organ problems?

Percent of Respondents

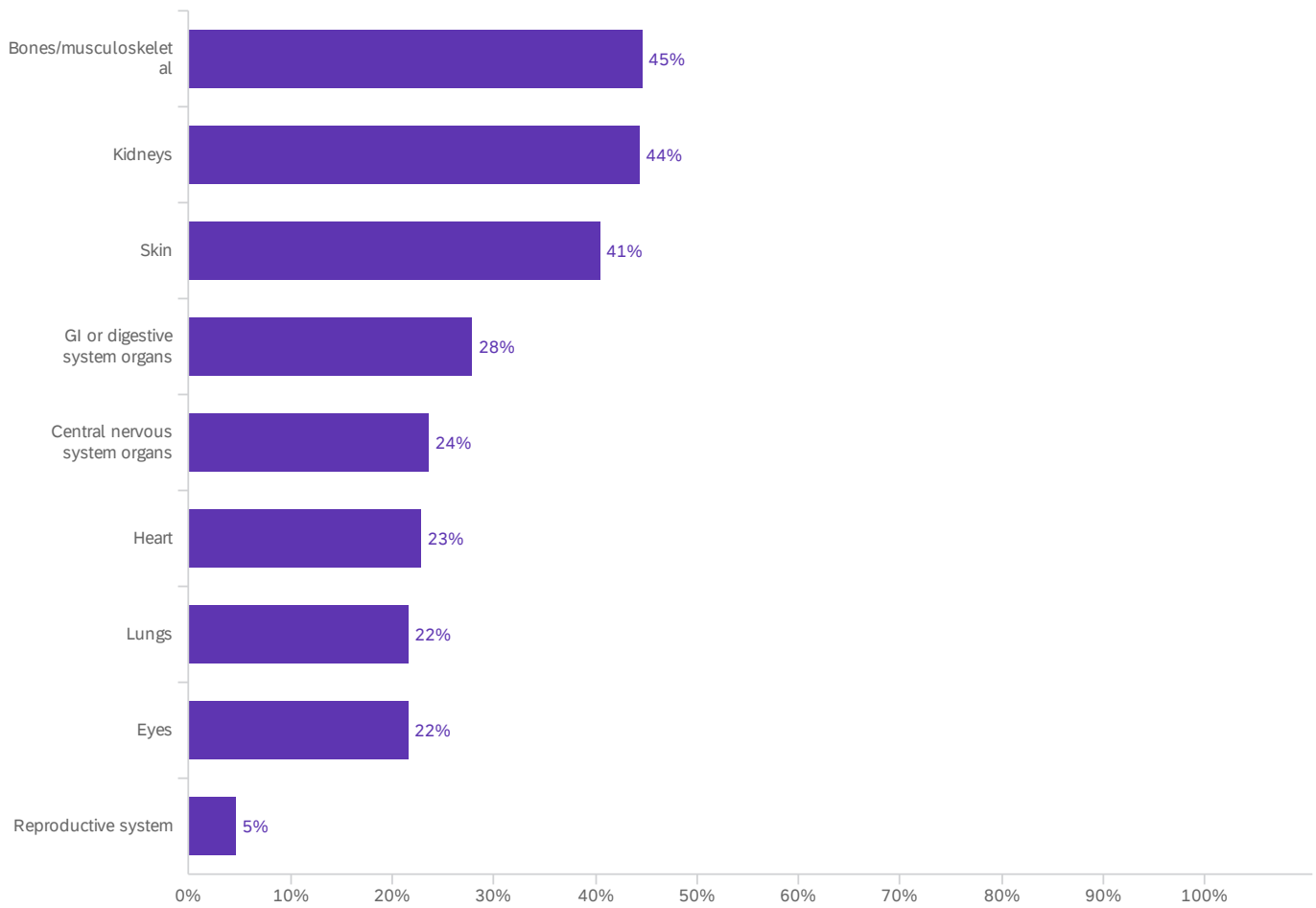


Field	Choice	Count
Yes	71%	3446
No	29%	1416
		4862

Showing rows 1 - 3 of 3

Which organs affected by lupus have you taken medication to treat? (Please check all that a...

Percent of Respondents



Field	Choice Count
Central nervous system organs	24% 795
GI or digestive system organs	28% 938
Skin	41% 1360
Heart	23% 769
Kidneys	44% 1491
Lungs	22% 727
Eyes	22% 726
Bones/musculoskeletal	45% 1500



Field

Choice  
Count

Reproductive system

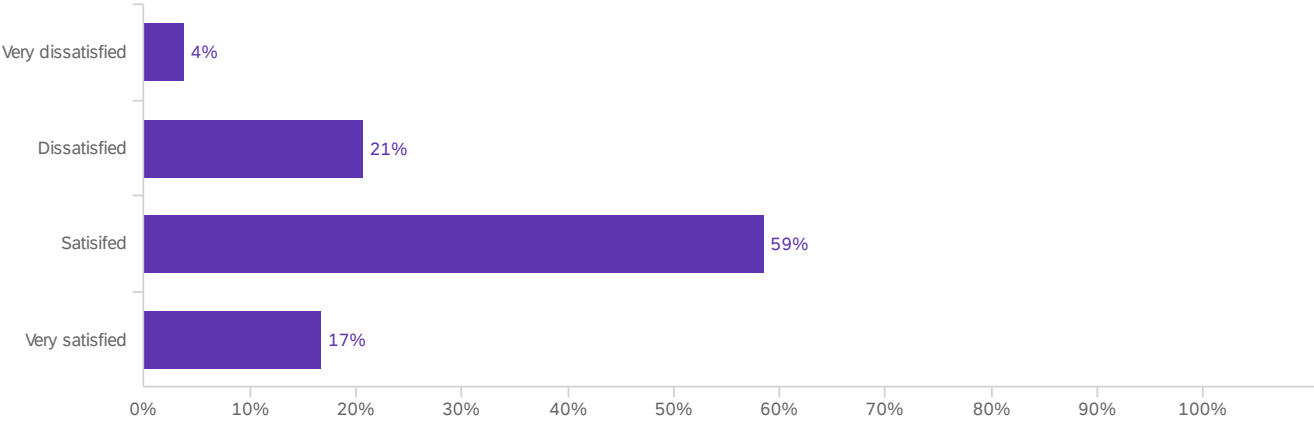
5% 158

3357

Showing rows 1 - 10 of 10

How satisfied or dissatisfied are you with the treatments you outlined in the question above?

Percent of Respondents



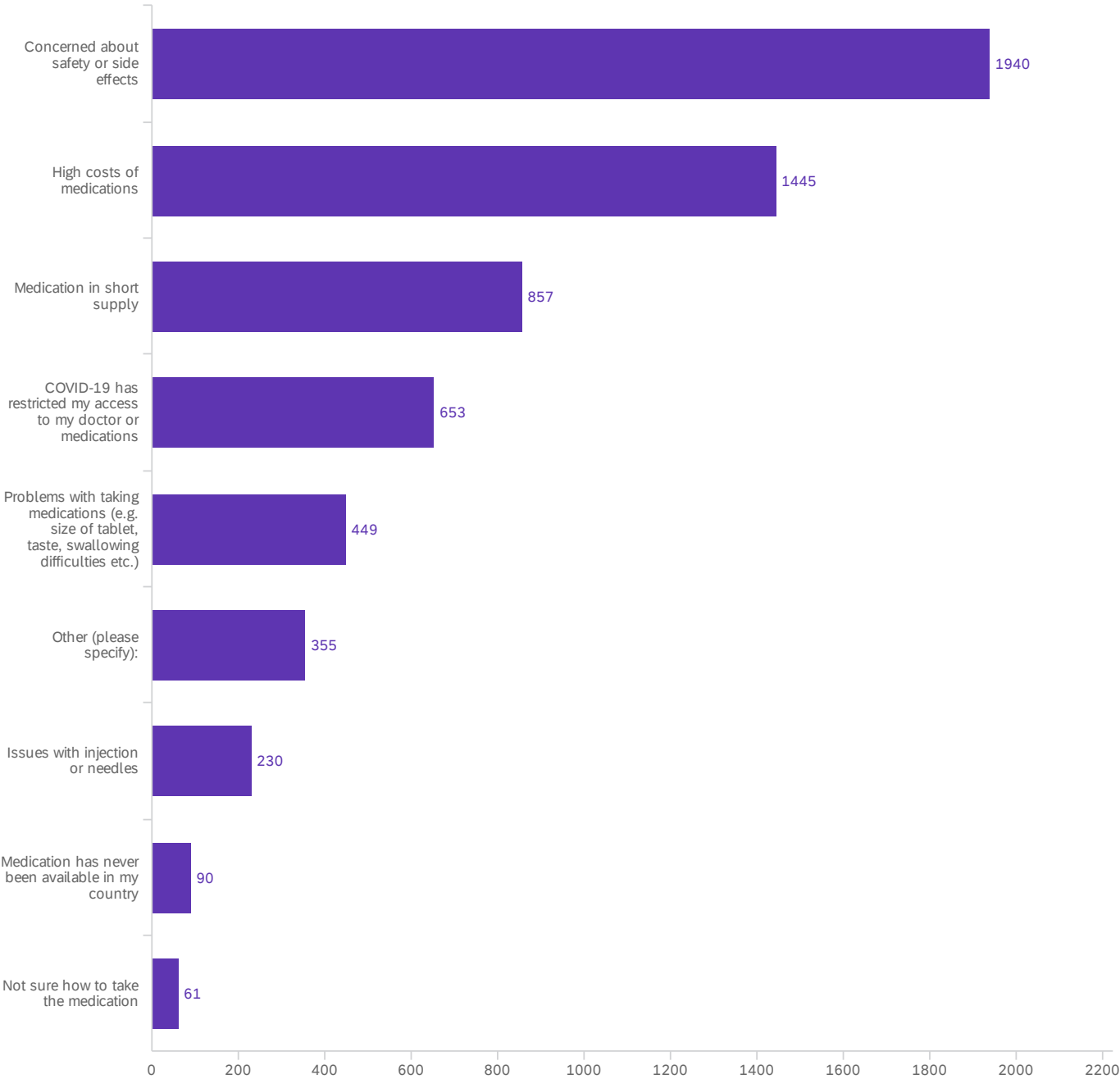
Field	Choice Count
Satisfied	58.60% 1810
Dissatisfied	20.75% 641
Very satisfied	16.80% 519
Very dissatisfied	3.85% 119

3089

Showing rows 1 - 5 of 5

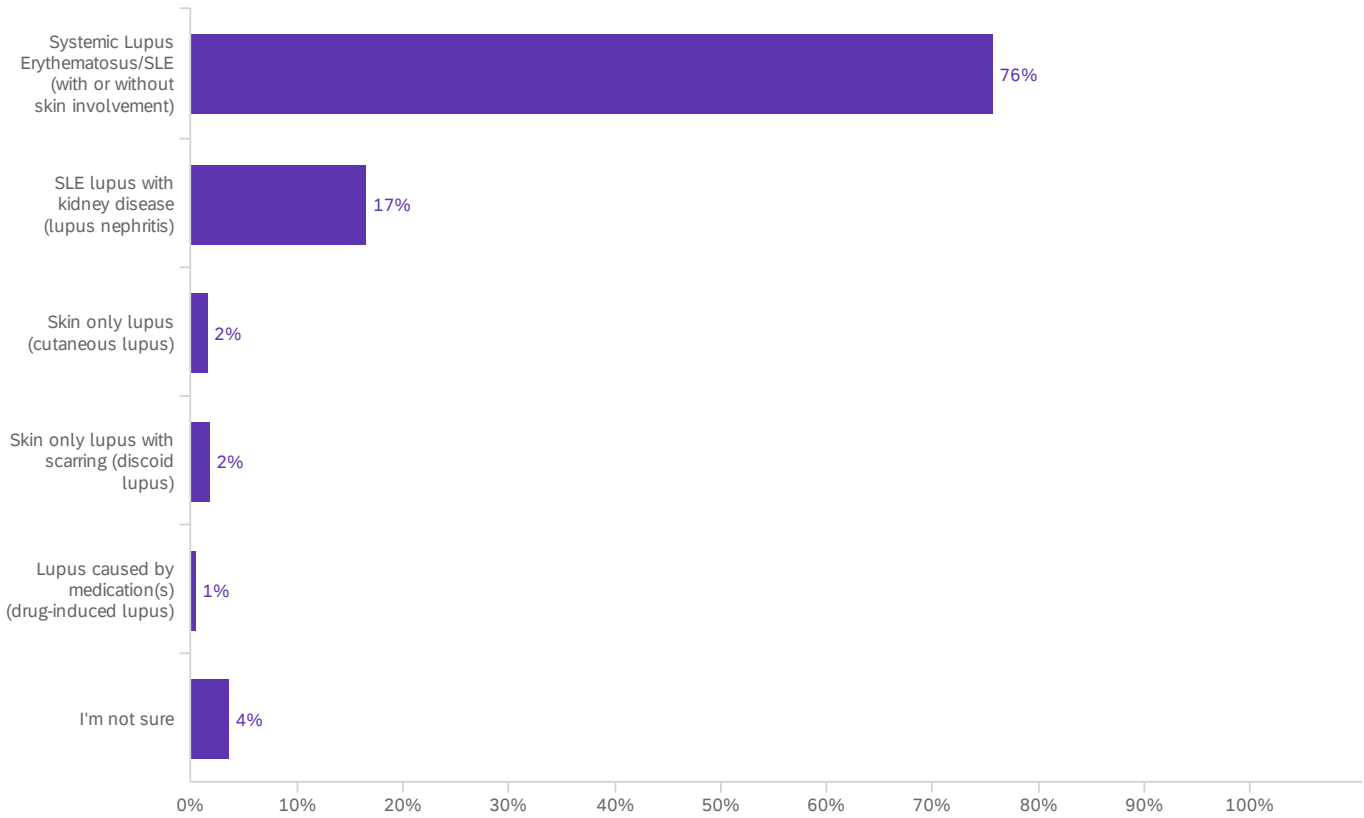
# Have you experienced any of the following challenges when trying to obtain or take medicati...

## Number of Respondents



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

## Type of Lupus and Percent of Respondents



Field	Choice Count
Systemic Lupus Erythematosus/SLE (with or without skin involvement)	75.78% 5080
SLE lupus with kidney disease (lupus nephritis)	16.62% 1114
Skin only lupus (cutaneous lupus)	1.63% 109
Skin only lupus with scarring (discoid lupus)	1.82% 122
Lupus caused by medication(s) (drug-induced lupus)	0.51% 34
I'm not sure	3.65% 245

6704

Showing rows 1 - 7 of 7

## List of Respondent Countries

Field ▼	Choice Count
Afghanistan	0% 0
Albania	0% 1
Algeria	0% 0
Andorra	0% 1
Angola	0% 0
Antigua and Barbuda	0% 0
Argentina	3% 150
Armenia	0% 1
Australia	1% 45
Austria	0% 3
Azerbaijan	0% 0
Bahamas	0% 1
Bahrain	0% 1
Bangladesh	1% 29
Barbados	0% 1
Belarus	0% 0
Belgium	0% 16
Belize	0% 1
Benin	0% 0
Bhutan	0% 0

Field ▼	Choice Count
Bolivia	0% 1
Bosnia and Herzegovina	0% 0
Botswana	0% 1
Brazil	0% 26
Brunei Darussalam	0% 0
Bulgaria	0% 0
Burkina Faso	0% 0
Burundi	0% 0
Cambodia	0% 0
Cameroon	1% 30
Canada	2% 128
Cape Verde	0% 0
Central African Republic	0% 0
Chad	0% 0
Chile	0% 12
China	0% 2
Colombia	1% 44
Comoros	0% 0
Congo, Republic of the...	0% 1
Costa Rica	0% 15
Croatia	0% 0

Field ▼	Choice Count
Côte d'Ivoire	0% 2
Cuba	0% 0
Cyprus	0% 13
Czech Republic	0% 1
Democratic People's Republic of Korea	0% 0
Democratic Republic of the Congo	0% 0
Denmark	1% 42
Djibouti	0% 0
Dominica	0% 0
Dominican Republic	0% 5
Ecuador	0% 19
Egypt	0% 2
El Salvador	0% 16
Equatorial Guinea	0% 0
Eritrea	0% 0
Estonia	0% 2
Ethiopia	0% 1
Fiji	0% 0
Finland	0% 4
France	1% 64
Gabon	0% 0

Field ▼	Choice Count
Gambia	0% 0
Georgia	0% 5
Germany	0% 14
Ghana	0% 3
Greece	2% 108
Grenada	0% 4
Guatemala	0% 10
Guinea	0% 0
Guinea-Bissau	0% 0
Guyana	0% 1
Haiti	0% 0
Honduras	0% 2
Hong Kong (S.A.R.)	0% 2
Hungary	0% 2
Iceland	0% 26
India	0% 16
Indonesia	1% 50
Iran, Islamic Republic of...	0% 0
Iraq	0% 0
Ireland	0% 12
Israel	0% 0



Field ▼	Choice Count
Italy	2% 109
Jamaica	0% 19
Japan	0% 2
Jordan	0% 0
Kazakhstan	0% 0
Kenya	0% 0
Kiribati	0% 0
Kuwait	0% 1
Kyrgyzstan	0% 0
Lao People's Democratic Republic	0% 0
Latvia	0% 0
Lebanon	0% 1
Lesotho	0% 0
Liberia	0% 0
Libyan Arab Jamahiriya	0% 0
Liechtenstein	0% 0
Lithuania	0% 1
Luxembourg	0% 1
Madagascar	0% 0
Malawi	0% 0
Malaysia	0% 14

Field ▼	Choice Count
Maldives	0% 0
Mali	0% 1
Malta	0% 0
Marshall Islands	0% 0
Mauritania	0% 0
Mauritius	0% 3
Mexico	5% 260
Micronesia, Federated States of...	0% 0
Monaco	0% 0
Mongolia	0% 0
Montenegro	0% 0
Morocco	0% 3
Mozambique	0% 0
Myanmar	0% 1
Namibia	0% 1
Nauru	0% 0
Nepal	0% 3
Netherlands	1% 44
New Zealand	0% 9
Nicaragua	0% 11
Niger	0% 0

Field ▼	Choice Count
Nigeria	0% 10
North Korea	0% 0
Norway	0% 3
Oman	0% 0
Other	1% 54
Pakistan	0% 3
Palau	0% 0
Panama	0% 4
Papua New Guinea	0% 0
Paraguay	0% 2
Peru	1% 39
Philippines	0% 18
Poland	0% 2
Portugal	3% 162
Qatar	0% 1
Republic of Korea	0% 0
Republic of Moldova	0% 0
Romania	0% 2
Russian Federation	0% 1
Rwanda	0% 0
Saint Kitts and Nevis	0% 0

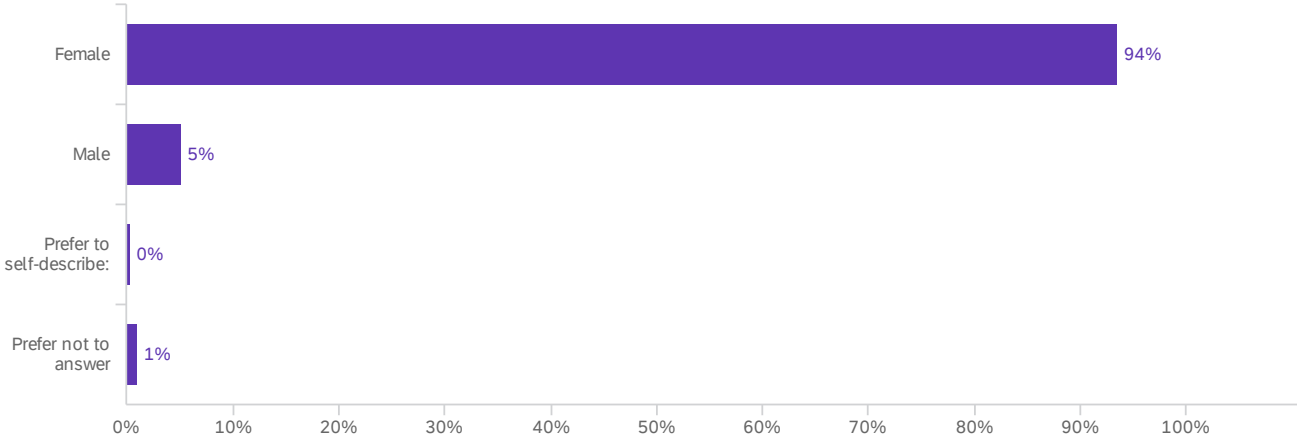
Field ▼	Choice Count
Saint Lucia	0% 4
Saint Vincent and the Grenadines	0% 0
Samoa	0% 0
San Marino	0% 0
Sao Tome and Principe	0% 0
Saudi Arabia	0% 1
Senegal	0% 2
Serbia	0% 3
Seychelles	0% 0
Sierra Leone	0% 0
Singapore	0% 2
Slovakia	0% 23
Slovenia	0% 0
Solomon Islands	0% 0
Somalia	0% 0
South Africa	2% 118
South Korea	0% 0
Spain	5% 268
Sri Lanka	0% 1
Sudan	0% 0
Suriname	0% 0

Field ▼	Choice Count
Swaziland	0% 1
Sweden	0% 3
Switzerland	0% 10
Syrian Arab Republic	0% 0
Taiwan	0% 25
Tajikistan	0% 0
Thailand	0% 0
The former Yugoslav Republic of Macedonia	0% 0
Timor-Leste	0% 0
Togo	0% 0
Tonga	0% 0
Trinidad and Tobago	0% 3
Tunisia	0% 0
Turkey	0% 3
Turkmenistan	0% 0
Tuvalu	0% 0
Uganda	0% 0
Ukraine	0% 2
United Arab Emirates	0% 2
United Kingdom of Great Britain and Northern Ireland	6% 324
United Republic of Tanzania	0% 1

Field ▼	Choice Count
United States of America	53% 2878
Uruguay	0% 10
Uzbekistan	0% 1
Vanuatu	0% 0
Venezuela, Bolivarian Republic of...	0% 13
Viet Nam	0% 2
Yemen	0% 0
Zambia	0% 0
Zimbabwe	0% 3
	5424

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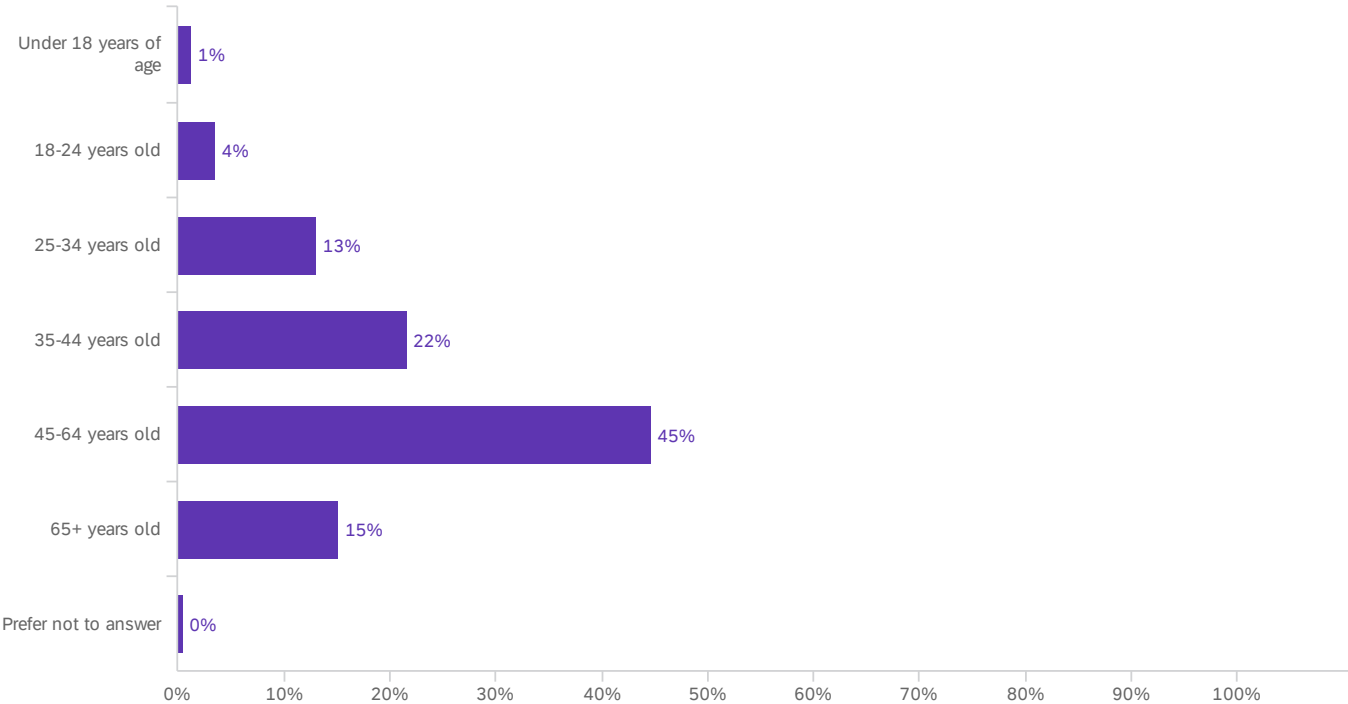
# Respondent Gender Reported



Field	Choice Count
Female	94% 5072
Male	5% 278
Prefer to self-describe:	0% 17
Prefer not to answer	1% 55
	5422

Showing rows 1 - 5 of 5

# Age Category of Respondent



Field	Percentage
45-64 years old	45%
35-44 years old	22%
25-34 years old	13%
18-24 years old	4%
65+ years old	15%
Under 18 years of age	1%
Prefer not to answer	0%
	5423

Showing rows 1 - 8 of 8

**End of Report**



