

# THE LANCET

## Rheumatology

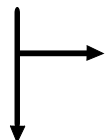
### Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed. We post it as supplied by the authors.

Supplement to: Putman M, Kennedy K, Sirolich E, et al. COVID-19 vaccine perceptions and uptake: results from the COVID-19 Global Rheumatology Alliance Vaccine Survey. *Lancet Rheumatol* 2022; published online Feb 8. [https://doi.org/10.1016/S2665-9913\(22\)00001-7](https://doi.org/10.1016/S2665-9913(22)00001-7).

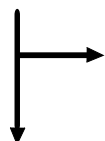
**Appendix for COVID-19 vaccine perceptions and uptake in people with rheumatic disease:  
Results from the COVID-19 Global Rheumatology Alliance Vaccine Survey**

10511 responses from  
April 2, 2021 to July 5th, 2021



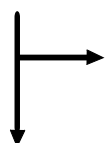
710 did not  
consent

9801 respondents  
provided consent



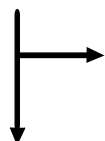
284 excluded for age  
<18 and survey ended

9517 adult respondents



850 excluded for reporting only  
non-inflammatory rheumatic conditions  
(e.g. osteoarthritis, fibromyalgia)

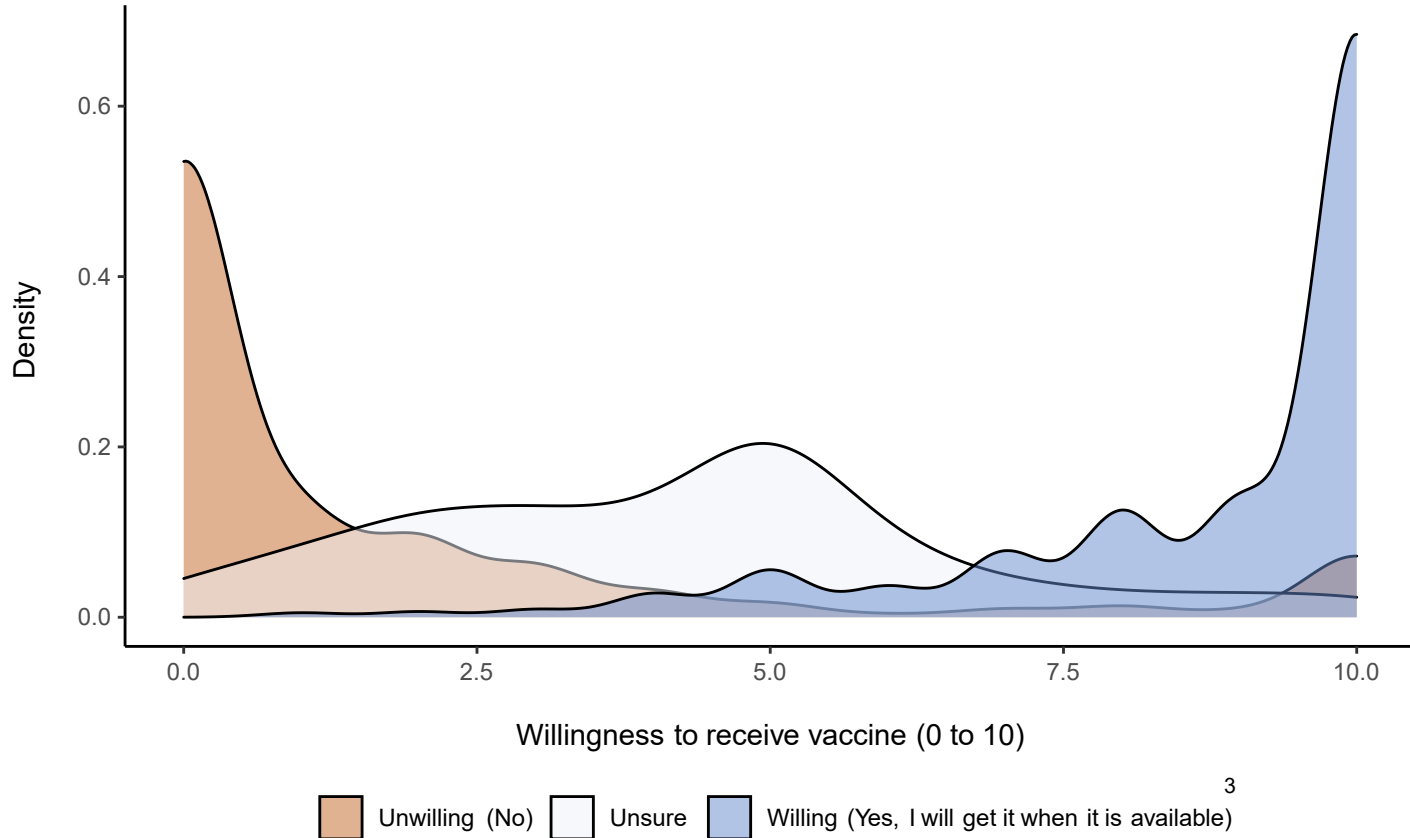
8224 respondents with  
inflammatory rheumatic  
condition.



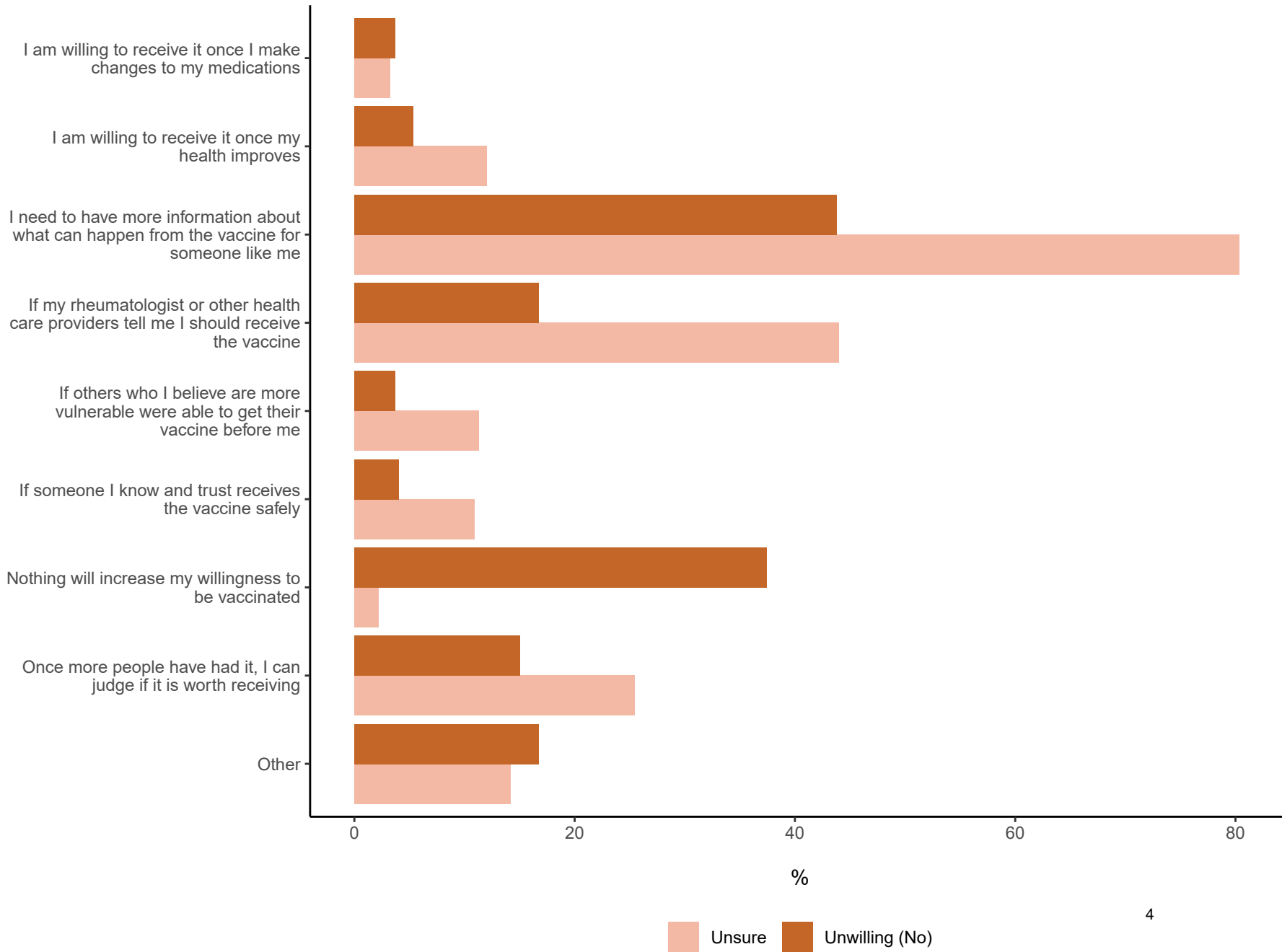
1219 excluded for failing  
to complete survey

7005 respondents  
included for analysis

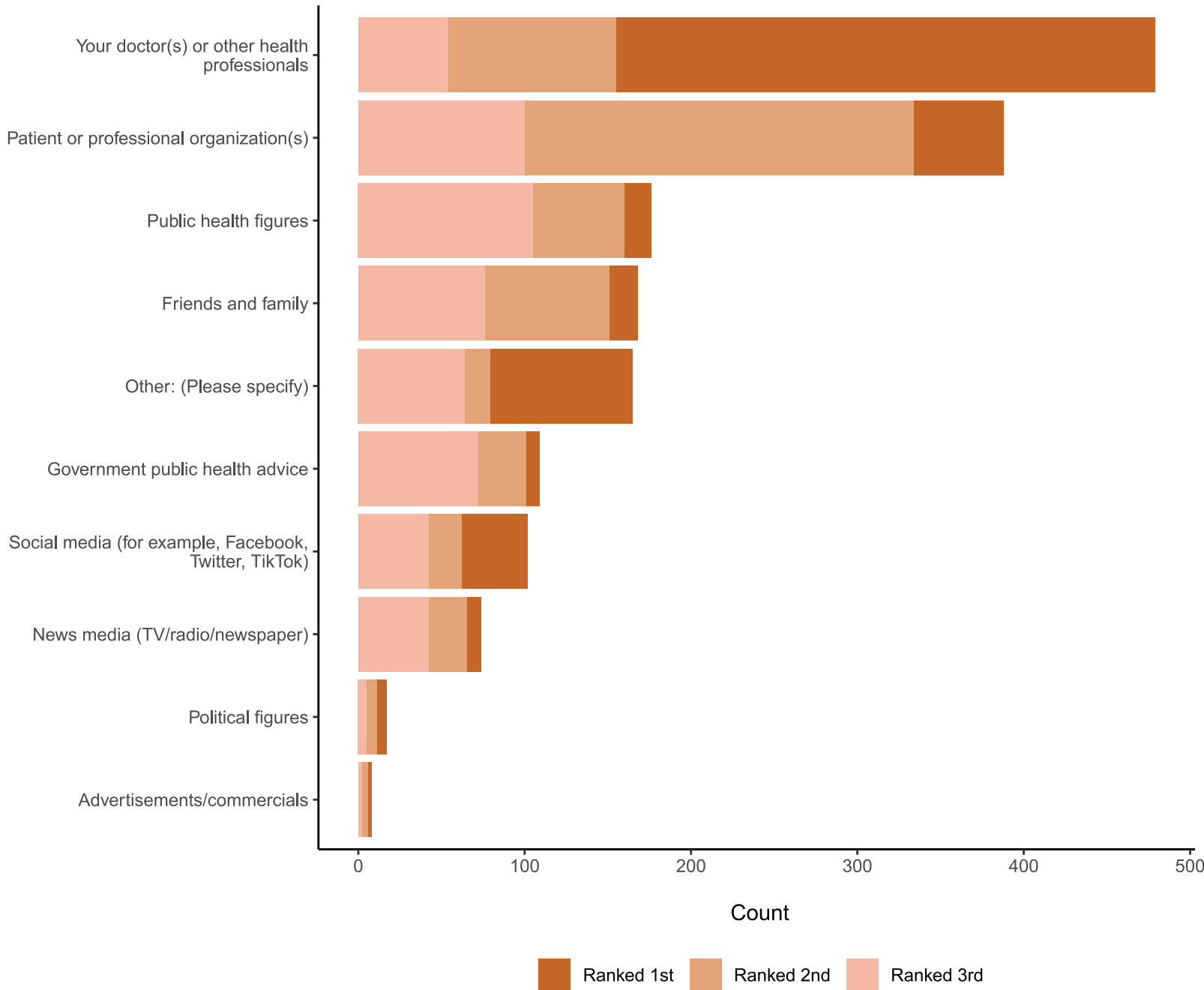
Figure 1. Degree of willingness to be vaccinated among patients who self report to be unsure, unwilling or have not yet received a COVID-19 vaccine. (n = 1457)



**Figure 2.** Factors most likely to increase willingness to be vaccinated for those who are undecided or against receiving the COVID-19 vaccine. (n = 574)



*Figure 3.* Sources of information most likely to influence decision to receive COVID-19 Vaccine for those who are undecided or against receiving the COVID-19 vaccine. (n = 562)



**Supplemental Table 1: Vaccination perceptions among respondents who were unwilling to be vaccinated, n = 299**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Not applicable
The COVID-19 vaccines were developed too quickly	18	13	30	44	189	5
I'm concerned about side effects to the COVID-19 vaccine	7	7	11	33	240	1
I think the COVID-19 vaccine is unsafe	23	16	66	71	121	2
I am afraid of needles/injections	203	8	30	5	10	43
I am worried about being able to pay for the COVID-19 vaccine	179	3	19	3	5	90
I am worried that travel will be too difficult to obtain the COVID-19 vaccine	180	9	28	9	8	65
I am worried it will be too complicated to get an appointment to receive the COVID-19 vaccine	185	12	23	13	7	59
I will have a milder course of COVID-19 if I am vaccinated	81	23	108	32	25	30
I consider myself as being 'pro-vaccine'	49	22	74	56	80	18
I never get very ill with infections so the COVID-19 vaccine is not needed for me	90	37	92	34	17	29
I am worried the vaccine could cause COVID-19 infection	108	28	66	38	43	16
The COVID-19 vaccine will not work as well for me	40	18	125	38	47	31
I would rather wait for a specific type of COVID-19 vaccine	68	22	86	42	41	40
I don't think the vaccine is helpful because it will not protect me against new variants of COVID-19.	38	25	74	75	76	11

**Supplemental Table 2: Vaccination perceptions among respondents who were unsure of vaccination, n = 275**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Not applicable
The COVID-19 vaccines were developed too quickly	12	18	49	87	106	3
I'm concerned about side effects to the COVID-19 vaccine	1	4	7	74	189	0
I think the COVID-19 vaccine is unsafe	16	35	94	87	39	4
I am afraid of needles/injections	167	19	24	14	12	39
I am worried about being able to pay for the COVID-19 vaccine	123	7	31	15	12	87
I am worried that travel will be too difficult to obtain the COVID-19 vaccine	122	12	50	26	10	55
I am worried it will be too complicated to get an appointment to receive the COVID-19 vaccine	109	25	42	40	17	42
I will have a milder course of COVID-19 if I am vaccinated	35	17	99	76	36	12
I consider myself as being 'pro-vaccine'	30	22	82	69	51	21
I never get very ill with infections so the COVID-19 vaccine is not needed for me	112	62	60	17	3	21
I am worried the vaccine could cause COVID-19 infection	83	37	54	56	31	14
The COVID-19 vaccine will not work as well for me	37	29	106	60	22	21
I would rather wait for a specific type of COVID-19 vaccine	17	16	79	74	70	19
I don't think the vaccine is helpful because it will not protect me against new variants of COVID-19.	34	35	90	76	34	6



**Supplemental Table 3. Demographics and clinical characteristics of 7,005 GRA Vax Survey respondents, presented as N(%) unless otherwise specified**

	Vaccinated or Willing to be Vaccinated (n=6431)	Unvaccinated and Unsure of Vaccination (n=275)	Unvaccinated and Unwilling to be Vaccinated (n=299)
Age (years), mean (SD)	53.6 (14.2)	47.7 (12.4)	51.2 (13.5)
Age (years) categories			
18-29	343 (5.3)	23 (8.4)	18 (6)
30-49	2222 (34.6)	131 (47.6)	121 (40.5)
50-69	3006 (46.7)	111 (40.4)	127 (42.5)
70+	860 (13.4)	10 (3.6)	33 (11)
Sex at birth			
Female	5533 (86)	240 (87.3)	250 (83.6)
Male	878 (13.7)	31 (11.3)	45 (15.1)
Other/prefer not to say	20 (0.3)	4 (1.5)	4 (1.3)
Race/Ethnicity			
Asian (South, East Asian)	179 (2.8)	23 (8.4)	10 (3.3)
Black	80 (1.2)	8 (2.9)	5 (1.7)
Hispanic or Latin American	477 (7.4)	25 (9.1)	9 (3)
Middle Eastern or North African	100 (1.6)	8 (2.9)	16 (5.4)
American Indian/ Alaska Natve/Aboriginal/ Indigenous/ 1st Nations	18 (0.3)	0 (0)	0 (0)
White	4997 (77.7)	157 (57.1)	213 (71.2)
Other <sup>†</sup>	580 (9)	54 (19.6)	46 (15.4)
WHO Region			
Region of the Americas	3330 (51.8)	107 (38.9)	182 (60.9)
European Region	2749 (42.7)	105 (38.2)	88 (29.4)
Western Pacific Region	24 (0.4)	3 (1.1)	2 (0.7)
African Region	34 (0.5)	4 (1.5)	2 (0.7)
South-East Asian Region	225 (3.5)	48 (17.5)	16 (5.4)
Eastern Mediterranean Region	68 (1.1)	6 (2.2)	9 (3.0)
Educational level			
High school (secondary level)/GED or less	840 (13.1)	56 (20.4)	50 (16.7)

Some college	1273 (19.8)	37 (13.5)	64 (21.4)
Bachelor degree (graduated college)	1693 (26.3)	84 (30.5)	93 (31.1)
Graduate or professional degree	2625 (40.8)	98 (35.6)	92 (30.8)
Rheumatic Disease Diagnosis*			
Rheumatoid arthritis	2558 (39.8)	91 (33.1)	91 (30.4)
Myositis	1001 (15.6)	38 (13.8)	73 (24.4)
Systemic lupus erythematosus	957 (14.9)	48 (17.5)	48 (16.1)
Sjogren's syndrome	901 (14)	40 (14.5)	48 (16.1)
Spondyloarthritis, other than psoriatic disease	720 (11.2)	45 (16.4)	30 (10)
Psoriatic arthritis	507 (7.9)	26 (9.5)	17 (5.7)
Vasculitis	381 (5.9)	22 (8)	20 (6.7)
Systemic sclerosis	234 (3.6)	7 (2.5)	11 (3.7)
Antiphospholipid syndrome	181 (2.8)	15 (5.5)	14 (4.7)
Autoinflammatory disease	74 (1.2)	6 (2.2)	5 (1.7)
Sarcoidosis	50 (0.8)	0 (0)	0 (0)
Other connective tissue disease <sup>††</sup>	374 (5.8)	15 (5.5)	21 (7)
Systemic glucocorticoids	1803 (28)	82 (29.8)	73 (24.4)
NSAIDS	1672 (26)	81 (29.5)	74 (24.7)
Antirheumatic medications			
Methotrexate	1870 (29.1)	62 (22.5)	64 (21.4)
Antimalarials	1662 (25.8)	83 (30.2)	85 (28.4)
csDMARDs other than methotrexate**	1159 (18)	39 (14.2)	46 (15.4)
TNF inhibitors	1099 (17.1)	37 (13.5)	27 (9)
Mycophenolate	524 (8.1)	16 (5.8)	24 (8)
Rituximab	352 (5.5)	18 (6.5)	28 (9.4)
JAK inhibitors	247 (3.8)	9 (3.3)	2 (0.7)
IVIG	199 (3.1)	9 (3.3)	9 (3)
Abatacept	142 (2.2)	4 (1.5)	4 (1.3)
Other antimetabolites***	66 (1)	5 (1.8)	1 (0.3)

Other biologics****	438 (6.8)	14 (5.1)	14 (4.7)
None	1232 (19.2)	74 (26.9)	95 (31.8)
Number of DMARDs			
0	1232 (19.2)	74 (26.9)	95 (31.8)
1	2882 (44.8)	116 (42.2)	121 (40.5)
2 or more	2317 (36)	85 (30.9)	83 (27.8)
Patient Global Assessment (0-10)			
Mean (SD)	4.4 (2.4)	5.4 (2.6)	5.1 (2.6)
Comorbidities			
Hypertension	1970 (30.6)	70 (25.5)	74 (24.7)
Lung disease	1498 (23.3)	53 (19.3)	72 (24.1)
Obesity	1413 (22)	62 (22.5)	61 (20.4)
Diabetes	382 (5.9)	18 (6.5)	23 (7.7)
Cardiovascular disease	384 (6)	26 (9.5)	13 (4.3)
Osteoarthritis	1042 (16.2)	38 (13.8)	42 (14.0)
Fibromyalgia	929 (14.4)	57 (20.7)	64 (21.4)
None	1970 (30.6)	78 (28.4)	98 (32.8)
History of adverse vaccine reaction			
Yes	449 (7)	52 (18.9)	79 (26.4)
No	5767 (89.7)	190 (69.1)	182 (60.9)
Unsure	215 (3.3)	33 (12)	38 (12.7)
Regularly receive influenza vaccination			
Yes	5083 (79)	101 (36.7)	111 (37.1)
No	1270 (19.7)	166 (60.4)	179 (59.9)
Unsure	56 (0.9)	6 (2.2)	3 (1)
Prefer not to say	22 (0.3)	2 (0.7)	6 (2)
Ever previously declined to receive a recommended vaccine?			
Yes	689 (10.7)	60 (21.8)	116 (38.8)
No	5645 (87.8)	203 (73.8)	170 (56.9)
Not sure	97 (1.5)	12 (4.4)	13 (4.3)

\*Participants may indicate more than one rheumatic disease and more than one anti-rheumatic medication.  
Patient Global assessment captured from a visual analogue scale was adapted to capture disease activity.

NSAIDS = non-steroidal anti-inflammatory drugs; csDMARDs = conventional synthetic disease modifying anti-rheumatic drugs; JAK = janus kinase inhibitors; TNF = tumor necrosis factor; IVIG = intravenous immunoglobulin.

\*\* Includes apremilast, azathioprine, 6-mercaptopurine, leflunomide, sulfasalazine.

\*\*\* Includes calcineurin inhibitors (cyclosporine, tacrolimus), cyclophosphamide, thalidomide, and lenalidomide.

\*\*\*\*Includes belimumab, IL-1 inhibitors (anakinra, canakinumab, rilonacept), IL-6 inhibitors (tocilizumab, sarilumab, siltuximab), IL-12/23 inhibitors (ustekinumab, guselkumab), IL-17 inhibitors (secukinumab, ixekizumab), eculizumab, mepolizumab and vedolizumab.

\*\*\*\*\*Includes Novavax, Sinovac/Sinopharm, Sputnik V, CanSino, “not sure,” and “other”.

Other participants include Pacific Islander, other, prefer not to say and don't know/unsure.

Other connective tissue disease include mixed connective tissue disease and undifferentiated connective tissue disease.

**Supplemental Table 4. Demographics and clinical characteristics of 7,005 GRA Vax Survey respondents, presented as N(%) unless otherwise specified**

	All Respondents n = (7005)	Vaccinated n = (5548)	Willing to be Vaccinated n = (883)	Unvaccinated and Unsure of Vaccination n = (275)	Unvaccinated and Unwilling to be Vaccinated n = (299)
Age (years), mean (SD)	53.2 (14.2)	54.7 (14.1)	46.4 (12.8)	47.7 (12.4)	51.2 (13.5)
Age (years) categories					
18-29	384 (5.5)	253 (4.6)	90 (10.2)	23 (8.4)	18 (6)
30-49	2474 (35.3)	1772 (31.9)	450 (51)	131 (47.6)	121 (40.5)
50-69	3244 (46.3)	2694 (48.6)	312 (35.3)	111 (40.4)	127 (42.5)
70+	903 (12.9)	829 (14.9)	31 (3.5)	10 (3.6)	33 (11)
Sex at birth					
Female	6023 (86)	4751 (85.6)	782 (88.6)	240 (87.3)	250 (83.6)
Male	954 (13.6)	784 (14.1)	94 (10.6)	31 (11.3)	45 (15.1)
Other/prefer not to say	28 (0.4)	13 (0.2)	7 (0.8)	4 (1.5)	4 (1.3)
Race/Ethnicity					
Asian (South, East Asian)	212 (3)	101 (1.8)	78 (8.8)	23 (8.4)	10 (3.3)
Black	93 (1.3)	72 (1.3)	8 (0.9)	8 (2.9)	5 (1.7)
Hispanic or Latin American	511 (7.3)	345 (6.2)	132 (14.9)	25 (9.1)	9 (3)
Middle Eastern or North African	124 (1.8)	86 (1.6)	14 (1.6)	8 (2.9)	16 (5.4)
American Indian/ Alaska Native/Aboriginal/ Indigenous/ 1st Nations	18 (0.3)	15 (0.3)	3 (0.3)	0 (0)	0 (0)
White	5367 (76.6)	4476 (80.7)	521 (59)	157 (57.1)	213 (71.2)
Other <sup>†</sup>	680 (9.7)	453 (8.2)	127 (14.4)	54 (19.6)	46 (15.4)
WHO Region					
Region of the Americas	3619 (51.7)	2925 (52.7)	405 (45.9)	107 (38.9)	182 (60.9)
European Region	2942 (42)	2427 (43.7)	322 (36.5)	105 (38.2)	88 (29.4)
Western Pacific Region	<b>289 (4.1)</b>	<b>109 (2)</b>	<b>116 (13.1)</b>	<b>48 (17.5)</b>	<b>16 (5.4)</b>
African Region	29 (0.4)	12 (0.2)	12 (1.4)	3 (1.1)	2 (0.7)
South-East Asian Region	40 (0.6)	17 (0.3)	17 (1.9)	4 (1.5)	2 (0.7)

Eastern Mediterranean Region	83 (1.2)	57 (1)	11 (1.2)	6 (2.2)	9 (3)
Educational level					
High school (secondary level)/GED or less	946 (13.5)	703 (12.7)	137 (15.5)	56 (20.4)	50 (16.7)
Some college	1374 (19.6)	1093 (19.7)	180 (20.4)	37 (13.5)	64 (21.4)
Bachelor degree (graduated college)	1870 (26.7)	1437 (25.9)	256 (29)	84 (30.5)	93 (31.1)
Graduate or professional degree	2815 (40.2)	2315 (41.7)	310 (35.1)	98 (35.6)	92 (30.8)
Rheumatic Disease Diagnosis*					
Rheumatoid arthritis	2740 (39.1)	2239 (40.4)	319 (36.1)	91 (33.1)	91 (30.4)
Myositis	1112 (15.9)	940 (16.9)	61 (6.9)	38 (13.8)	73 (24.4)
Systemic lupus erythematosus	1053 (15)	763 (13.8)	194 (22)	48 (17.5)	48 (16.1)
Sjogren's syndrome	989 (14.1)	787 (14.2)	114 (12.9)	40 (14.5)	48 (16.1)
Spondyloarthritis, other than psoriatic disease	795 (11.3)	595 (10.7)	125 (14.2)	45 (16.4)	30 (10)
Psoriatic arthritis	550 (7.9)	435 (7.8)	72 (8.2)	26 (9.5)	17 (5.7)
Vasculitis	423 (6)	336 (6.1)	45 (5.1)	22 (8)	20 (6.7)
Systemic sclerosis	252 (3.6)	179 (3.2)	55 (6.2)	7 (2.5)	11 (3.7)
Antiphospholipid syndrome	210 (3)	141 (2.5)	40 (4.5)	15 (5.5)	14 (4.7)
Autoinflammatory disease	85 (1.2)	66 (1.2)	8 (0.9)	6 (2.2)	5 (1.7)
Sarcoidosis	50 (0.7)	43 (0.8)	7 (0.8)	0 (0)	0 (0)
Other connective tissue disease <sup>[7][7]</sup>	410 (5.9)	333 (6)	41 (4.6)	15 (5.5)	21 (7)
Systemic glucocorticoids	1958 (28)	1528 (27.5)	275 (31.1)	82 (29.8)	73 (24.4)
NSAIDs	1827 (26.1)	1405 (25.3)	267 (30.2)	81 (29.5)	74 (24.7)
Antirheumatic medications					
Methotrexate	1996 (28.5)	1634 (29.5)	236 (26.7)	62 (22.5)	64 (21.4)
Antimalarials	1830 (26.1)	1389 (25)	273 (30.9)	83 (30.2)	85 (28.4)
csDMARDs other than methotrexate**	1244 (17.8)	978 (17.6)	181 (20.5)	39 (14.2)	46 (15.4)
TNF inhibitors	1163 (16.6)	967 (17.4)	132 (14.9)	37 (13.5)	27 (9)

Mycophenolate	564 (8.1)	439 (7.9)	85 (9.6)	16 (5.8)	24 (8)
Rituximab	398 (5.7)	303 (5.5)	49 (5.5)	18 (6.5)	28 (9.4)
JAK inhibitors	258 (3.7)	223 (4)	24 (2.7)	9 (3.3)	2 (0.7)
IVIg	217 (3.1)	187 (3.4)	12 (1.4)	9 (3.3)	9 (3)
Abatacept	150 (2.1)	134 (2.4)	8 (0.9)	4 (1.5)	4 (1.3)
Other antimetabolites***	72 (1)	48 (0.9)	18 (2)	5 (1.8)	1 (0.3)
Other biologics****	466 (6.7)	381 (6.9)	57 (6.5)	14 (5.1)	14 (4.7)
None	1401 (20)	1053 (19)	179 (20.3)	74 (26.9)	95 (31.8)
Number of DMARDs					
0	1401 (20)	1053 (19)	179 (20.3)	74 (26.9)	95 (31.8)
1	3119 (44.5)	2497 (45)	385 (43.6)	116 (42.2)	121 (40.5)
2 or more	2485 (35.5)	1998 (36)	319 (36.1)	85 (30.9)	83 (27.8)
Patient Global Assessment (0-10)					
Mean (SD)	4.4 (2.5)	4.3 (2.4)	4.5 (2.4)	5.4 (2.6)	5.1 (2.6)
Comorbidities					
Hypertension	2114 (30.2)	1781 (32.1)	189 (21.4)	70 (25.5)	74 (24.7)
Lung disease	1623 (23.2)	1336 (24.1)	162 (18.3)	53 (19.3)	72 (24.1)
Obesity	1536 (21.9)	1262 (22.7)	151 (17.1)	62 (22.5)	61 (20.4)
Diabetes	423 (6)	342 (6.2)	40 (4.5)	18 (6.5)	23 (7.7)
Cardiovascular disease	423 (6)	341 (6.1)	43 (4.9)	26 (9.5)	13 (4.3)
None	2146 (30.6)	1642 (29.6)	328 (37.1)	78 (28.4)	98 (32.8)
History of adverse vaccine reaction					
Yes	580 (8.3)	381 (6.9)	68 (7.7)	52 (18.9)	79 (26.4)
No	6139 (87.6)	5031 (90.7)	736 (83.4)	190 (69.1)	182 (60.9)
Unsure	286 (4.1)	136 (2.5)	79 (8.9)	33 (12)	38 (12.7)
Regularly receive influenza vaccination					
Yes	5295 (75.6)	4578 (82.5)	505 (57.2)	101 (36.7)	111 (37.1)
No	1615 (23.1)	918 (16.5)	352 (39.9)	166 (60.4)	179 (59.9)
Unsure	65 (0.9)	33 (0.6)	23 (2.6)	6 (2.2)	3 (1)
Prefer not to say	30 (0.4)	19 (0.3)	3 (0.3)	2 (0.7)	6 (2)

Ever previously declined to receive a recommended vaccine?					
Yes	865 (12.3)	615 (11.1)	74 (8.4)	60 (21.8)	116 (38.8)
No	6018 (85.9)	4860 (87.6)	785 (88.9)	203 (73.8)	170 (56.9)
Not sure	122 (1.7)	73 (1.3)	24 (2.7)	12 (4.4)	13 (4.3)

\*Participants may indicate more than one rheumatic disease and more than one anti-rheumatic medication.

Patient Global assessment captured from a visual analogue scale was adapted to capture disease activity.

NSAIDS = non-steroidal anti-inflammatory drugs; csDMARDs = conventional synthetic disease modifying anti-rheumatic drugs; JAK = janus kinase inhibitors; TNF = tumor necrosis factor; IVIG = intravenous immunoglobulin.

\*\* Includes apremilast, azathioprine, 6-mercaptopurine, leflunomide, sulfasalazine.

\*\*\* Includes calcineurin inhibitors (cyclosporine, tacrolimus), cyclophosphamide, thalidomide, and lenalidomide.

\*\*\*\*Includes belimumab, IL-1 inhibitors (anakinra, canakinumab, rilonacept), IL-6 inhibitors (tocilizumab, sarilumab, siltuximab), IL-12/23 inhibitors (ustekinumab, guselkumab), IL-17 inhibitors (secukinumab, ixekizumab), eculizumab, mepolizumab and vedolizumab.

\*\*\*\*\*Includes Novavax, Sinovac/Sinopharm, Sputnik V, CanSino, "not sure," and "other".

☐ Other participants include Pacific Islander, other, prefer not to say and don't know/unsure.

☐☐ Other connective tissue disease include mixed connective tissue disease and undifferentiated connective tissue disease.



# Vaccine survey

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Start of Block: Block 1

Q1

The COVID-19 Global Rheumatology Alliance (GRA) is studying how COVID-19 affects people with rheumatic diseases throughout the world. The GRA is seeking to learn about perspectives and experience from adults with rheumatic diseases related to the COVID-19 vaccine.

Eligibility for the COVID-19 vaccine survey:                      -You have a diagnosis of a rheumatic disease                      -You are 18 years or older

You are eligible to complete the survey regardless of whether or not you have received the COVID-19 vaccine.

All of the information we collect is anonymous. Everyone is welcome and asked to complete this survey, even those who may have taken other surveys from the GRA. Have questions? Visit our website at [rheum-covid.org](http://rheum-covid.org) or email us at [rheum.covid@gmail.com](mailto:rheum.covid@gmail.com).

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Q2 By participating, I confirm to be at least 18 years of age and provide consent for the information I provide to be used in analysis conducted by the COVID-19 Global Rheumatology Alliance. I understand that my data are anonymous and that I will not be able to be personally identified from my responses today.

- Confirm (1)
- Exit Survey (2)

*Skip To: End of Survey If By participating, I confirm to be at least 18 years of age and provide consent for the informatio... = Exit Survey*

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Q3 What year were you born?

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*Skip To: End of Survey If Condition: What year were you born? Is Greater Than or Equal to 2004. Skip To: End of Survey.*

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Page Break

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Q4 Has a doctor ever told you that you had any of the following rheumatologic diseases?  
(Check all that apply)

- ANCA-associated vasculitis (e.g. granulomatosis with polyangiitis [GPA] - microscopic polyangiitis [MPA] - eosinophilic GPA - Wegener's - Churg-Strauss) (1)
- Ankylosing spondylitis or axial spondyloarthritis (2)
- Antiphospholipid antibody syndrome (3)
- Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or others) (4)
- Behcet's syndrome (5)
- Chronic recurrent multifocal osteomyelitis (CRMO) or SAPHO (6)
- Dermatomyositis - polymyositis - inclusion body myositis - or other inflammatory muscle diseases (7)
- Eye inflammation (scleritis - uveitis - etc.) (8)
- Fibromyalgia (9)
- Giant cell arteritis (temporal arteritis) (10)
- Gout (11)
- IgG4-related disease (12)
- Juvenile idiopathic arthritis (JIA) - not including the systemic subtype (13)
- Systemic juvenile idiopathic arthritis (SJIA) / adult-onset Still's Disease (14)
- Kawasaki disease (15)
- Lupus (systemic lupus erythematosus/SLE) (16)

- Mixed connective tissue disease (MCTD) (17)
- Relapsing Polychondritis (18)
- Polymyalgia rheumatica (PMR) (19)
- Psoriatic arthritis (PsA) (20)
- Rheumatoid arthritis (RA) (21)
- Kikuchi syndrome (22)
- Osteoarthritis (23)
- Raynaud's (24)
- Sarcoidosis (25)
- Sjogren's syndrome (26)
- Systemic sclerosis (scleroderma) (27)
- Undifferentiated connective tissue disease (28)
- Other crystalline arthritis (including pseudogout) (29)
- Other inflammatory arthritis (30)
- Other spondyloarthritis (including reactive arthritis) (31)
- Other systemic vasculitis (polyarteritis nodosa - Henoch-Schonlein purpura - cryoglobulinemia) (32)
- I do not have a rheumatologic diagnosis (33)

Other (please specify): (34)

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*Skip To: End of Survey If Has a doctor ever told you that you had any of the following rheumatologic diseases? (Check all t... = I do not have a rheumatologic diagnosis*

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Page Break

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Display This Question:

If Has a doctor ever told you that you had any of the following rheumatologic diseases? (Check all t...  
= Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or others)



Q5 What autoinflammatory disease do you have?

- TRAPS (1)
- CAPS (2)
- FMF (3)
- HIDS (4)
- PFAPA (5)
- Other (Please Specify): (6) \_\_\_\_\_

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Page Break



Carry Forward Selected Choices from "Has a doctor ever told you that you had any of the following rheumatologic diseases? (Check all that apply)"



Q6 What approximate year were you diagnosed with this rheumatic condition? (If unknown, enter 9999)

	Year of Diagnosis (1)
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<p>ANCA-associated vasculitis (e.g. granulomatosis with polyangiitis [GPA] - microscopic polyangiitis [MPA] - eosinophilic GPA - Wegener's - Churg-Strauss) (x1)</p>	
<p>Ankylosing spondylitis or axial spondyloarthritis (x5)</p>	
<p>Antiphospholipid antibody syndrome (x3)</p>	
<p>Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or others) (x4)</p>	
<p>Behcet's syndrome (x7)</p>	
<p>Chronic recurrent multifocal osteomyelitis (CRMO) or SAPHO (x8)</p>	
<p>Dermatomyositis - polymyositis - inclusion body myositis - or other inflammatory muscle diseases (x11)</p>	
<p>Eye inflammation (scleritis - uveitis - etc.) (x15)</p>	
<p>Fibromyalgia (x33)</p>	

Giant cell arteritis (temporal arteritis) (x9)	
Gout (x28)	
IgG4-related disease (x10)	
Juvenile idiopathic arthritis (JIA) - not including the systemic subtype (x13)	
Systemic juvenile idiopathic arthritis (SJIA) / adult-onset Still's Disease (x12)	
Kawasaki disease (x2)	
Lupus (systemic lupus erythematosus/SLE) (x23)	
Mixed connective tissue disease (MCTD) (x14)	
Relapsing Polychondritis (x31)	
Polymyalgia rheumatica (PMR) (x16)	

Psoriatic arthritis (PsA) (x17)	
Rheumatoid arthritis (RA) (x18)	
Kikuchi syndrome (x32)	
Osteoarthritis (x29)	
Raynaud's (x30)	
Sarcoidosis (x20)	
Sjogren's syndrome (x22)	
Systemic sclerosis (scleroderma) (x24)	
Undifferentiated connective tissue disease (x25)	
Other crystalline arthritis (including pseudogout) (x34)	

Other inflammatory arthritis (x19)	
Other spondyloarthritis (including reactive arthritis) (x6)	
Other systemic vasculitis (polyarteritis nodosa - Henoch-Schonlein purpura - cryoglobulinemia) (x35)	
<input checked="" type="checkbox"/> I do not have a rheumatologic diagnosis (x26)	
Other (please specify): (x27)	

Page Break



Q7 Which of the following rheumatology medications are you currently taking? (Check all that apply).

- Abatacept (Orencia) (1)
- Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (2)
- Apremilast (Otezla) (3)
- Azathioprine / 6-MP (Imuran, mercaptopurine) (4)
- Belimumab (Benlysta) (5)
- Bisphosphonates (pamidronate, alendronate, risedronate, zoledronic acid) (6)
- Calcineurin inhibitors (cyclosporine, tacrolimus) (7)
- Cyclophosphamide (Cytoxan) (8)
- Colchicine (Mitigare, Colcrys) (9)
- Denosumab (Prolia) (10)
- IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) (11)
- IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (12)
- IL-12/23 inhibitors (including ustekinumab/Stelara, guselkumab/Tremfya) (13)
- IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (14)
- Intravenous immunoglobulin (IVIG) (15)
- JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq) (16)

- Leflunomide (Arava) (17)
  - Methotrexate (Trexall) (18)
  - Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (19)
  - NSAIDs (non-steroidal anti-inflammatory drugs including ibuprofen/Advil/Motrin, naproxen/Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others) (20)
  - Rituximab (Rituxan and biosimilar version) (21)
  - Sclerostin inhibitor (Romosozumab) (22)
  - Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, prednisolone, dexathemason, Decadron, glucocorticoids, corticosteroids, cortisol, and others) (23)
  - Sulfasalazine (Asulfidine, salazine) (24)
  - Teriparatide (Forteo) (25)
  - Thalidomide / lenalidomide (Thalomid, Revlimid) (26)
  - TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (27)
  - None (28)
  - I don't know the type or name of my medication (29)
  - Other (please specify): (30)
-



X→

Q8 Has a doctor ever told you that you had any of the following medical conditions? Check all that apply

- High blood pressure (1)
- Immunodeficiency (2)
- Lung disease such as: asthma - emphysema - chronic bronchitis - COPD (3)
- High blood pressure in the lungs (pulmonary hypertension) (4)
- Interstitial lung disease (ILD) / idiopathic pulmonary fibrosis (IPF) (5)
- Other lung disease (6)
- Obesity (body mass index  $\geq 30$ ) (7)
- Severe obesity (body mass index  $\geq 40$ ) (8)
- Diabetes (9)
- Cancer (10)
- Heart disease (myocardial infarction/heart attack, heart failure, valvular disease, pericarditis) (11)
- HIV/AIDS (12)
- Chronic viral hepatitis (B, C, D or E) (13)
- Chronic kidney disease (14)
- Inflammatory bowel disease (Crohn's disease or Ulcerative colitis) (15)
- Organ transplant recipient (16)
- Liver disease (17)

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (18)
- Psoriasis (19)
- Stroke (20)
- Chronic neurological or neuromuscular disease (multiple sclerosis, ALS, etc.) (21)
- None (22)
- Don't know (23)

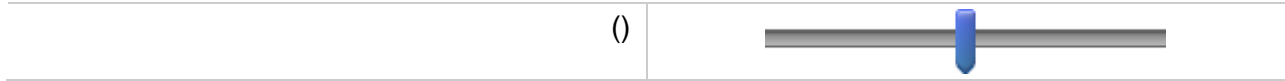
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Q9 Considering all the ways your rheumatic disease affects you, rate your overall rheumatic disease activity TODAY on a scale from 0 (very low disease activity) to 10 (very high/active disease activity)?

**0 = very low**  
(doing extremely well)      **10 = very high**  
(doing extremely poorly)

0 1 2 3 4 5 6 7 8 9 10



Page Break



Q10 If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated?

- Yes, I have already received at least one dose (1)
- Yes, I will get it when it is available (2)
- No (3)
- Unsure (4)

*Display This Question:*

*If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated? = Yes, I will get it when it is available*

*Or If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated? = No*

*Or If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated? = Unsure*

Q11 How willing are you to receive the COVID-19 vaccine? If you already received the COVID-19 vaccine, please answer what your willingness was prior to the vaccine.

**0 = not willing at all      10 = very willing**

0 1 2 3 4 5 6 7 8 9 10

Willingness to receive COVID-19 Vaccine ( )



*Display This Question:*

*If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated? = No*

*Or If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated? = Unsure*



Q12 What would increase your willingness to be vaccinated with a COVID-19 vaccine? (Check all that apply)

- If someone I know and trust receives the vaccine safely (1)
- I need to have more information about what can happen from the vaccine for someone like me (2)
- Once more people have had it, I can judge if it is worth receiving (3)
- If others who I believe are more vulnerable were able to get their vaccine before me (4)
- If my rheumatologist or other health care providers tell me I should receive the vaccine (5)
- I am willing to receive it once my health improves (6)
- I am willing to receive it once I make changes to my medications (7)
- Nothing will increase my willingness to be vaccinated (8)
- Other (9) \_\_\_\_\_

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Page Break



Q13 Please rate the following statements related to the COVID-19 vaccine from strongly agree to strongly disagree.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)	Not applicable (6)
The COVID-19 vaccines were developed too quickly (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm concerned about side effects to the COVID-19 vaccine (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think the COVID-19 vaccine is unsafe (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am afraid of needles/injections (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about being able to pay for the COVID-19 vaccine (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried that travel will be too difficult to obtain the COVID-19 vaccine (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried it will be too complicated to get an appointment to receive the COVID-19 vaccine (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I will have a milder course of COVID-19 if I am vaccinated (25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



I consider myself as being “pro-vaccine” (26)

I never get very ill with infections so the COVID-19 vaccine is not needed for me (27)

I am worried the vaccine could cause COVID-19 infection (28)

The COVID-19 vaccine will not work as well for me (3)

I would rather wait for a specific type of COVID-19 vaccine (29)

I don't think the vaccine is helpful because it will not protect me against new variants of COVID-19. (30)

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Page Break



Q14 Please rank at least TOP THREE sources of information most likely to influence your decision whether or not to receive a COVID-19 vaccine by entering 1, 2, 3 in each box.

\_\_\_\_\_ Social media (for example, Facebook, Twitter, TikTok) (1)

\_\_\_\_\_ Your doctor(s) or other health professionals (2)

\_\_\_\_\_ Patient or professional organization(s) (3)

\_\_\_\_\_ Political figures (4)

\_\_\_\_\_ Public health figures (5)

\_\_\_\_\_ Advertisements/commercials (6)

\_\_\_\_\_ Friends and family (7)

\_\_\_\_\_ Government public health advice (8)

\_\_\_\_\_ News media (TV/radio/newspaper) (9)

\_\_\_\_\_ Other: (Please specify) (10)



Q15 Please rate the following statements from strongly agree to strongly disagree.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Letting the infection run through the population is the best way to deal with the pandemic (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 is not dangerous for my health (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The vaccine will help us return to how life was before COVID-19 (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being vaccinated will alleviate the fears and worries I have about the pandemic (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I want to protect myself and my family from COVID-19 (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe in natural or traditional remedies (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not get vaccinations for religious reasons (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The vaccine will lessen the financial hardships of the pandemic (8)

I generally trust information and instructions from the government (9)

Wearing masks and social distancing are important ways to control COVID-19 (10)

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Page Break

Display This Question:

If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you get it? If Yes, I have already received at least one dose



Q16 If you got the COVID-19 vaccine, how likely do you think it is that you would experience serious side effects?

- Very likely (1)
- Somewhat likely (2)
- Unsure (3)
- Not so likely (4)
- Not at all likely (5)



Q17 Please rate the following statements from strongly agree to strongly disagree.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I would be willing to stop my regular rheumatic condition medication(s) for a short time so I could take the vaccine (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried that taking the vaccine will cause a flare of my rheumatic condition (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about being exposed to COVID-19 at the facility to get a vaccine (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break



Q18 Have you ever previously declined to receive a vaccine (NOT for COVID-19) that was recommended to you by your doctor or health professional?

- Yes (1)
- No (2)
- Not sure (3)

---

*Display This Question:*

*If Have you ever previously declined to receive a vaccine (NOT for COVID-19) that was recommended t... = Yes*



Q19 What were the reason(s) you declined to receive a vaccine (NOT for COVID-19) that was recommended to you by your doctor or health professional in the past? (Check all that apply)

- I never take vaccines (1)
- I was worried it was not safe (2)
- I was worried about possible side effects (3)
- I thought it was not needed (4)
- I doubted it would work for me (5)
- I did not think I was susceptible to the disease/infection (6)
- I did not think the infection was very serious (7)
- I was concerned I would get that disease/infection from the vaccine (8)
- I never get sick so it was not needed (9)
- Other health issues were active (10)
- I previously had a bad reaction to a vaccine (11)
- I did not trust pharmaceutical companies (12)
- I did not trust my health care professional (13)
- I had a previous allergy to a vaccine (14)
- I did not think I should take it due to my underlying conditions or medications (15)
- I do not remember (16)



Other reasons: (Please Specify) (17)

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Q20 Do you regularly get the influenza immunization (flu shot)?

- Yes (1)
  - No (2)
  - Not sure (3)
  - Prefer not to say (4)
- 



Q21 Have you ever had a serious reaction to a vaccine NOT for COVID-19 (that you experienced within two months of the vaccination)?

- Yes (1)
  - No (2)
  - Not sure (3)
- 

*Display This Question:*

*If srs\_react\_nonCOVID\_vacc = Yes*



Q22 Which vaccine(s) did you have a serious reaction(s) to? (Check all that apply)

- Tetanus (1)
  - Hepatitis B (2)
  - Zoster/Shingles (3)
  - Pneumococcal (pneumonia shot) (4)
  - Influenza (flu shot) (5)
  - I do not remember (6)
  - Other (Please Specify): (7)
- 

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Page Break

Display This Question:

If which\_vax\_srs = Tetanus

X→

Q23 What were the serious side effect(s) you experienced to Tetanus vaccine? (Check all that apply)

- Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (1)
  - Other allergic reaction (2)
  - Rash (3)
  - Fever or chills (4)
  - Widespread muscle/joint pain (5)
  - Fatigue or sleepiness (6)
  - Headache (7)
  - Nausea (8)
  - Vomiting (9)
  - Poor appetite (10)
  - Flare of my existing rheumatic disease (11)
  - New rheumatic or other autoimmune disease (12)
  - Chest pain - palpitations (13)
  - Other: (please specify) (14)
-

---

*Display This Question:*

*If tetanus\_react = Flare of my existing rheumatic disease*



Q24 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

*Display This Question:*

*If which\_vax\_srs = Tetanus*

*And tetanus\_react = New rheumatic or other autoimmune disease*

Q25 What new rheumatic or other autoimmune disease developed due to a Tetanus vaccine?

\_\_\_\_\_

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Page Break

Display This Question:

If which\_vax\_srs = Hepatitis B



Q26 What were the serious side effect(s) you experienced to Hepatitis B vaccine? (Check all that apply)

- Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (1)
  - Other allergic reaction (2)
  - Rash (3)
  - Fever or chills (4)
  - Widespread muscle/joint pain (5)
  - Fatigue or sleepiness (6)
  - Headache (7)
  - Nausea (8)
  - Vomiting (9)
  - Poor appetite (10)
  - Flare of my existing rheumatic disease (11)
  - New rheumatic or other autoimmune disease (12)
  - Chest pain - palpitations (13)
  - Other: (please specify) (14)
-

---

*Display This Question:*

*If hebB\_react = Flare of my existing rheumatic disease*



Q27 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

*Display This Question:*

*If hebB\_react = New rheumatic or other autoimmune disease*

Q28 What new rheumatic or other autoimmune disease developed due to Hepatitis B vaccine?

\_\_\_\_\_

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Page Break

Display This Question:

If which\_vax\_srs = Zoster/Shingles



Q29 What were the serious side effect(s) you experienced to Zoster/Shingles vaccine? (Check all that apply)

- Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (1)
  - Other allergic reaction (2)
  - Rash (3)
  - Fever or chills (4)
  - Widespread muscle/joint pain (5)
  - Fatigue or sleepiness (6)
  - Headache (7)
  - Nausea (8)
  - Vomiting (9)
  - Poor appetite (10)
  - Flare of my existing rheumatic disease (11)
  - New rheumatic or other autoimmune disease (12)
  - Chest pain - palpitations (13)
  - Other: (please specify) (14)
-



---

*Display This Question:*

*If zoster\_react = Flare of my existing rheumatic disease*



Q30 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

*Display This Question:*

*If zoster\_react = New rheumatic or other autoimmune disease*

Q31 What new rheumatic or other autoimmune disease developed due to Zoster/Shingles vaccine?

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Page Break

Display This Question:

If which\_vax\_srs = Pneumococcal (pneumonia shot)



Q32 What were the serious side effect(s) you experienced to Pneumococcal (pneumonia shot) vaccine? (Check all that apply)

- Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (1)
  - Other allergic reaction (2)
  - Rash (3)
  - Fever or chills (4)
  - Widespread muscle/joint pain (5)
  - Fatigue or sleepiness (6)
  - Headache (7)
  - Nausea (8)
  - Vomiting (9)
  - Poor appetite (10)
  - Flare of my existing rheumatic disease (11)
  - New rheumatic or other autoimmune disease (12)
  - Chest pain - palpitations (13)
  - Other: (please specify) (14)
-

---

*Display This Question:*

*If pneum\_react = New rheumatic or other autoimmune disease*

Q33 What new rheumatic or other autoimmune disease developed due to Pneumococcal (pneumonia shot) vaccine?

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*Display This Question:*

*If pneum\_react = Flare of my existing rheumatic disease*



Q34 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

Page Break

Display This Question:

If which\_vax\_srs = Influenza (flu shot)

X→

Q35 What were the serious side effect(s) you experienced to Influenza (flu shot) vaccine?  
(Check all that apply)

- Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (1)
  - Other allergic reaction (2)
  - Rash (3)
  - Fever or chills (4)
  - Widespread muscle/joint pain (5)
  - Fatigue or sleepiness (6)
  - Headache (7)
  - Nausea (8)
  - Vomiting (9)
  - Poor appetite (10)
  - Flare of my existing rheumatic disease (11)
  - New rheumatic or other autoimmune disease (12)
  - Chest pain - palpitations (13)
  - Other: (please specify) (14)
-

---

*Display This Question:*

*If influenza\_react = New rheumatic or other autoimmune disease*

Q36 What new rheumatic or other autoimmune disease developed due to Influenza (flu shot) vaccine?

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*Display This Question:*

*If influenza\_react = Flare of my existing rheumatic disease*



Q37 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

Page Break

Display This Question:

If which\_vax\_srs = Other (Please Specify):



Q38 What were the serious side effect(s) you experienced to a non-COVID-19 vaccine `other` vaccine? (Check all that apply)

- Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (1)
  - Other allergic reaction (2)
  - Rash (3)
  - Fever or chills (4)
  - Widespread muscle/joint pain (5)
  - Fatigue or sleepiness (6)
  - Headache (7)
  - Nausea (8)
  - Vomiting (9)
  - Poor appetite (10)
  - Flare of my existing rheumatic disease (11)
  - New rheumatic or other autoimmune disease (12)
  - Chest pain - palpitations (13)
  - Other: (please specify) (14)
-

---

*Display This Question:*

*If other\_react = New rheumatic or other autoimmune disease*

Q39 What new rheumatic or other autoimmune disease developed due to a non-COVID-19 'other' vaccine?

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*Display This Question:*

*If other\_react = Flare of my existing rheumatic disease*



Q40 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

Page Break



Q41 Please indicate how you have communicated (contacted by phone, email, or some other method of communication) with your healthcare provider about whether to receive a COVID-19 vaccine.

	Yes (1)	No (2)	Not sure (3)	Not applicable (4)
Have you reached out to your physician or other health care provider about whether to receive the vaccine? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has your care provider reached out to you about the vaccine? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you discuss the vaccine with your provider during a visit (in-person or telehealth)? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If you communicated with multiple providers about the vaccine, was there agreement between them? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*Display This Question:*

*If Please indicate how you have communicated (contacted by phone, email, or some other method of com... = Yes*





Q42 What advice did you receive from your healthcare provider about whether to receive a COVID-19 vaccine?

- My healthcare provider strongly endorsed it (1)
- My healthcare provider suggested it (2)
- My healthcare provider was unsure (3)
- My healthcare provider advised against it (4)
- My healthcare provider strongly discouraged it (5)
- Unsure (6)

---

*Display This Question:*

*If Please indicate how you have communicated (contacted by phone, email, or some other method of com... = Yes*



Q43 How satisfied were you with this conversation with your healthcare provider?

- Very satisfied (1)
- Satisfied (2)
- Neither satisfied nor dissatisfied (3)
- Dissatisfied (4)
- Very dissatisfied (5)

---

*Display This Question:*

*If If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, wo... != Yes, I have already received at least one dose*



Q44 Have you been told you are currently eligible to receive a COVID-19 vaccine?

Yes (1)

No (2)

Not sure (3)

---

Page Break

*Display This Question:*

*If If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, wo... = Yes, I have already received at least one dose*



Q45 Which vaccine did you receive?

- Pfizer-BioNTech (mRNA) (1)
- Moderna (mRNA) (2)
- Janssen/Johnson & Johnson (J&J) (3)
- Oxford-AstraZeneca (4)
- Novavax (5)
- Sinovac/Sinopharm (Chinese) (6)
- Sputnik V (Russian) (7)
- Cansino (8)
- Not sure (9)
- Other (please specify) (10) \_\_\_\_\_

*Display This Question:*

*If If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, wo... = Yes, I have already received at least one dose*

*And Which of the following rheumatology medications are you currently taking? (Check all that apply). != None*



Q46 Did you stop (either temporarily or permanently) any of your rheumatic medications before or after receiving the COVID-19 vaccine?

- Yes (1)
- No (2)
- Not sure (3)

---

*Display This Question:*

*If Did you stop (either temporarily or permanently) any of your rheumatic medications before or afte...  
= Yes*



Q47 Did you discuss these changes to your rheumatic medication(s) with your rheumatologist (or other health care provider that manages your rheumatic condition)?

- Yes (1)
- No (2)
- Not sure (3)

---

Page Break

*Display This Question:*

*If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you get it? = Yes, I have already received at least one dose*



Q48 Did you have a serious reaction to the COVID-19 vaccine (except for anaphylaxis, lasting more than 2 days and within two months of the vaccination)? (Check all that apply)

- No (1)
  - Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, nausea, vomiting, difficulty breathing, and throat tightening needing emergency medical response such as an EpiPen) (2)
  - Other allergic reaction (3)
  - Rash (4)
  - Fever or chills (5)
  - Widespread muscle/joint pain (6)
  - Fatigue or sleepiness (7)
  - Headache (8)
  - Nausea (9)
  - Vomiting (10)
  - Poor appetite (11)
  - Flare of my existing rheumatic disease (12)
  - New rheumatic or other autoimmune disease (13)
  - Chest pain - palpitations (14)
  - Other (15) \_\_\_\_\_
-

Display This Question:

*If Did you have a serious reaction to the COVID-19 vaccine (except for anaphylaxis, lasting more than... = New rheumatic or other autoimmune disease*

Q49 What new rheumatic or other autoimmune disease developed due to the COVID-19 vaccine?

---

Display This Question:

*If Did you have a serious reaction to the COVID-19 vaccine (except for anaphylaxis, lasting more than... = Flare of my existing rheumatic disease*



Q50 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?

- Yes (1)
- No (2)
- Not sure (3)

---

Page Break

*Display This Question:*

*If Which of the following rheumatology medications are you currently taking? (Check all that apply).  
!= None*

*Carry Forward Selected Choices from "Which of the following rheumatology medications are you currently taking? (Check all that apply)."*





Q51 If you were asked by your physician or other health professional, would you be willing to temporarily stop your medication(s) listed below if it would improve the effectiveness of a COVID-19 vaccine?

	Yes, I would stop my medication (1)	No, I would NOT stop my medication (2)	Not sure (3)
Abatacept (Orencia) (x2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (x3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Apremilast (Otezla) (x4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Azathioprine / 6-MP (Imuran, mercaptopurine) (x5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belimumab (Benlysta) (x6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bisphosphonates (pamidronate, alendronate, risedronate, zoledronic acid) (x28)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Calcineurin inhibitors (cyclosporine, tacrolimus) (x29)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclophosphamide (Cytoxan) (x7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colchicine (Mitigare, Colcrys) (x27)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Denosumab (Prolia) (x9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) (x10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (x11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

IL-12/23 inhibitors (including ustekinumab/Stelara, guselkumab/Tremfya) (x12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (x13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intravenous immunoglobulin (IVIG) (x14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq) (x15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leflunomide (Arava) (x16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methotrexate (Trexall) (x17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (x18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NSAIDs (non-steroidal anti-inflammatory drugs including ibuprofen/Advil/Motrin, naproxen/Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others) (x8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rituximab (Rituxan and biosimilar version) (x19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sclerostin inhibitor (Romosozumab) (x30)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, prednisolone, dexathemason, Decadron, glucocorticoids, corticosteroids, cortisol, and others) (x20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sulfasalazine (Asulfidine, salazine) (x21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Teriparatide (Forteo) (x31)

Thalidomide / lenalidomide  
(Thalomid, Revlimid) (x23)

TNF-inhibitors  
(infliximab/Remicade,  
etanercept/Enbrel,  
adalimumab/Humira,  
golimumab/Simponi,  
certolizumab/Cimzia, and  
biosimilar versions) (x24)

None (x1)

I don't know the type or  
name of my medication (x25)

Other (please specify): (x26)

---

*Carry Forward Selected Choices from "If you were asked by your physician or other health professional, would you be willing to temporarily stop your medication(s) listed below if it would improve the effectiveness of a COVID-19 vaccine?"*

X→

Q52 What is your greatest concern about temporarily stopping your rheumatic medication?

	Disease Flare (1)	Withdrawal effects (2)	Side effects when previously stopped (3)	I tried to temporarily stop before and it didn't work (4)	Rheumatic medication may no longer work as well (5)	No concerns (6)
Abatacept (Orencia) (xx2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (xx3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Apremilast (Otezla) (xx4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Azathioprine / 6-MP (Imuran, mercaptopurine) (xx5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belimumab (Benlysta) (xx6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bisphosphonates (pamidronate, alendronate, risedronate, zoledronic acid) (xx28)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Calcineurin inhibitors (cyclosporine, tacrolimus) (xx29)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclophosphamide (Cytoxan) (xx7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colchicine (Mitigare, Colcrys) (xx27)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Denosumab (Prolia) (xx9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) (xx10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (xx11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

IL-12/23 inhibitors (including ustekinumab/Stelara, guselkumab/Tremfya) (xx12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (xx13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intravenous immunoglobulin (IVIG) (xx14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq) (xx15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leflunomide (Arava) (xx16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methotrexate (Trexall) (xx17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (xx18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NSAIDs (non-steroidal anti-inflammatory drugs including ibuprofen/Advil/Motrin, naproxen/Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others) (xx8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rituximab (Rituxan and biosimilar version) (xx19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sclerostin inhibitor (Romosozumab) (xx30)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, prednisolone, dexathemason, Decadron, glucocorticoids, corticosteroids, cortisol, and others) (xx20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sulfasalazine (Asulfidine, salazine) (xx21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Teriparatide (Forteo) (xx31)

Thalidomide / lenalidomide  
(Thalomid, Revlimid) (xx23)

TNF-inhibitors  
(infliximab/Remicade,  
etanercept/Enbrel,  
adalimumab/Humira,  
golimumab/Simponi,  
certolizumab/Cimzia, and  
biosimilar versions) (xx24)

None (xx1)

I don't know the type or  
name of my medication  
(xx25)

Other (please specify): (xx26)

---

Page Break

X→

Q53 Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection?

- Yes (1)
- No (2)
- Not sure (3)

*Skip To: Q60 If Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection? = Not sure*

*Skip To: Q60 If Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection? = No*

X→

Q54 In which approximate month was the diagnosis of COVID-19 made?

▼ December 2019 (1) ... November 2021 (24)

X→

Q55 How was COVID-19 diagnosed?

- I diagnosed myself based on symptoms (1)
- My doctor diagnosed me based only on symptoms (2)
- I was diagnosed based on positive test results for COVID-19 or SARS-CoV-2 (such as PCR or antibodies) (3)
- Not sure (4)
- Other (please specify): (5) \_\_\_\_\_

Page Break



Q56 Has your COVID-19 infection resolved at the time of this survey (meaning you no longer have symptoms related to COVID-19)?

- Yes (1)
- No (2)
- Not sure (3)

---

*Display This Question:*

*If Has your COVID-19 infection resolved at the time of this survey (meaning you no longer have sympt... = Yes*



Q57 How many days did your symptoms last, from the first day you became ill until symptoms resolved?

---

---

*Display This Question:*

*If Has your COVID-19 infection resolved at the time of this survey (meaning you no longer have sympt... = No*

*Or Has your COVID-19 infection resolved at the time of this survey (meaning you no longer have sympt... = Not sure*



Q58 For how many days have you been ill, counting from the first day you became ill until today?

---





Q59 What happened during the course of your COVID-19 infection?

I was not hospitalized and had no difficulties performing my daily activities (bathing, eating, dressing, etc.) (1)

I was not hospitalized but did have some difficulties performing my daily activities (bathing, eating, dressing, etc.) (2)

I was hospitalized (3)

I was hospitalized and required ICU care such as a breathing machine (ventilator) (4)

---

Page Break



Q60 What is your present gender identity?

- Female (1)
  - Male (2)
  - Transgender Female/ Trans woman (3)
  - Transgender Male/ Trans man (4)
  - Genderqueer/ Gender non-conforming (5)
  - Different identity (please specify): (6)  
\_\_\_\_\_
  - Prefer not to answer (7)
- 



Q61 What sex were you assigned at birth, meaning on your original birth certificate?

- Male (1)
  - Female (2)
  - Prefer not to say (3)
- 

Page Break

---

*Display This Question:*

*If What sex were you assigned at birth, meaning on your original birth certificate? = Female*



Q62 Are you currently pregnant, or have you been pregnant in the last 6 weeks?

- I am not pregnant (1)
- I am currently pregnant (2)
- I was pregnant in the last 6 weeks (3)
- Not applicable (4)
- Not sure (5)
- Prefer not to answer (6)

*Display This Question:*

*If What sex were you assigned at birth, meaning on your original birth certificate? = Female*



Q63 Are you currently breastfeeding or lactating and feeding pumped milk to your baby?

- Yes (1)
- No (2)
- Not sure (3)
- Not applicable (4)

Page Break



Q64 Do you currently, or have you ever smoked tobacco?

- Yes, I am a current tobacco smoker (1)
- Yes, I am a former tobacco smoker (2)
- No, I never smoked (3)

---

Page Break



Q65 What is your highest level of education obtained?

- Less than high school (secondary level) (1)
- High school (secondary level) / GED (2)
- Some college (3)
- Bachelor degree (graduated college) (4)
- Graduate or professional degree (5)

---

Page Break



Q66 Which single option best describes your current employment or student status?

- Employed full time (1)
- Employed part-time (2)
- Not employed, looking for work (3)
- Not employed, NOT looking for work (4)
- Retired (5)
- Not able to work due to disability (6)
- Part-time student (7)
- Full-time student (8)

---

Page Break



Q67 What is your ancestry, race, or ethnic background? (Check all that apply)

- Middle Eastern or North African (1)
  - Black (2)
  - East Asian (3)
  - Hispanic, Latinx, or Latin American (4)
  - South Asian (5)
  - Pacific Islander (6)
  - White (7)
  - American Indian / Alaska Native / Aboriginal / Indigenous / 1st Nations (8)
  - Don't know (9)
  - Prefer not to answer (10)
  - Other (please specify): (11)
- 

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Page Break



Q68 In what country do you live?

▼ Afghanistan (1) ... Zimbabwe (201)

---

*Display This Question:*

*If In what country do you live? = Canada*



Q69 In what province/territory do you live?

▼ Ontario (1) ... Saskatchewan (13)

---

*Display This Question:*

*If In what country do you live? = United States of America (USA)*



Q70 In what state do you live?

▼ Alabama (1) ... Wyoming (51)

---

Page Break





Q71 Do you belong to any of the following patient support organizations? Check all that apply

- American Behcet's Disease Foundation (ABDA) (1)
- Arthritis Consumer Experts (2)
- Arthritis Foundation (3)
- Arthritis Life (4)
- Association of Rheumatology Concerns (5)
- Autoinflammatory Alliance (6)
- Canadian Arthritis Patient Alliance (7)
- CARRA (8)
- CreakyJoints (9)
- CureJM (10)
- Deutsche Rheuma-Liga (11)
- Disability Federation of Ireland (12)
- EULAR PARE (13)
- Foundation for Sarcoidosis Research (14)
- Hospital Clinic, Barcelona, Spain (15)
- Hospital Especialidades Centro Médico Nacional IMSS (16)
- Instituto de Investigación Hospital 12 de Octubre (RIER, Red de Investigación en Inflamación y Enfermedades Reumáticas) (17)

- International Foundation for Autoimmune & Autoinflammatory Arthritis (18)
- Iran University of Medical Sciences (19)
- JIA Matters (20)
- Juvenile Arthritis Research (JAR) (21)
- Klinik für Kinder- und Jugendmedizin I des UKSH, Campus Kiel (22)
- Lupus Foundation of America (23)
- Mayo Clinic Health System (24)
- Medical University of Lodz, Department of Rheumatology, (25)
- Mifrakim Tz'eirim (26)
- National Axial Spondyloarthritis Society (NASS) (27)
- Norwegian Rheumatism Association (28)
- Ontario Rheumatology Association (29)
- Piedmont Healthcare - Piedmont Atlanta Rheumatology (30)
- Psoriasis and Psoriatic Arthritis Alliance (PAPAA) (31)
- RA chicks (32)
- RareConnect (33)
- Rheumatology Specialists of Connecticut, Inc. (34)
- Rheumatology UKE Hamburg (35)

- Rhumatologie Hopital Maisonneuve-Rosemont (36)
- Scleroderma Clinical Trials Consortium (37)
- Sociedad Chilena de Reumatología (SOCHIRE) (38)
- Spanish Society of Rheumatology (39)
- St James's Hospital (40)
- Stowarzyszenie "3majmy się razem" (41)
- Spondylitis Association of America (42)
- Systemic JIA Foundation (43)
- The Myositis Association (44)
- The Polyclinic (45)
- UK National Rheumatoid Arthritis Society (NRAS) (46)
- Universita Politecnica Delle Marche (47)
- University of Michigan (48)
- Vasculitis Foundation (49)
- Vasculitis UK (50)
- Versus Arthritis (51)
- Women with Rheumatoid Disease (52)
- None (53)

Other (please specify with the full name of the organization): (54)

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Page Break

Q72 Do you have any other questions, comments, or concerns? We would love to hear your feedback!

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End of Block: Block 1

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