# **Vaccine survey**

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 or email us at rheum.covid@gmail.com.



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.
Oconfirm (1)
O 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

Page Break ———



## Q3 What year were you born?

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



(Check all tha	it apply)
microscop	ANCA-associated vasculitis (e.g. granulomatosis with polyangiitis [GPA] - oic polyangiitis [MPA] - eosinophilic GPA - Wegener's - Churg-Strauss) (1)
	Ankylosing spondylitis or axial spondyloarthritis (2)
	Antiphospholipid antibody syndrome (3)
others) (4	Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or
	Behcet's syndrome (5)
	Chronic recurrent multifocal osteomyelitis (CRMO) or SAPHO (6)
muscle dis	Dermatomyositis - polymyositis - inclusion body myositis - or other inflammatory seases (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)
cryoglubul	Other systemic vasculitis (polyarteritis nodosa - Henoch-Schonlein purpura - inemia) (32)
	⊗I do not have a rheumatologic diagnosis (33)

	Other (please specify): (34)	
	of Survey If Has a doctor ever told you that you had any of the following rheumatologic leck all t = I do not have a rheumatologic diagnosis	
Page Break		

### 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 autoinflamatory disease do you have?
O TRAPS (1)
O CAPS (2)
○ FMF (3)
O HIDS (4)
O PFAPA (5)
Other (Please Specify): (6)
Page Break -

rheumatologic diseases? (Check all that apply)"	
$X \rightarrow X \rightarrow$	
Q6 What approximate year were you diagnosed enter 9999)	with this rheumatic condition? (If unknown,
	Year of Diagnosis (1)

Carry Forward Selected Choices from "Has a doctor ever told you that you had any of the following

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

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 - cryoglubulinemia) (x35)	
Other (please specify): (x27)	
Page Break	



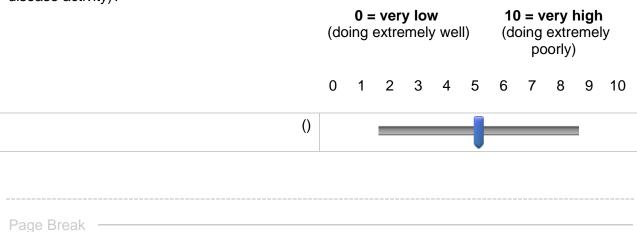
Q7 Which of the apply).	ne following rheumatology medications are you currently taking? (Check all that
	Abatacept (Orencia) (1)
	Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (2)
	Apremilast (Otezla) (3)
	Azathioprine / 6-MP (Imuran, mercaptopurine) (4)
	Belimumab (Benlysta) (5)
	Bisphosphonates (pamidronate, alendronate, risedronate, zoledronic acid) (6)
	Calcineurin inhibitors (cyclosporine, tacrolimus) (7)
	Cyclophosphamide (Cytoxan) (8)
	Colchicine (Mitagare, Colcrys) (9)
	Denosumab (Prolia) (10)
rilonacept/	IL-1 inhibitors (including anakinra/Kineret, canakinumab/llaris, 'Arcalyst) (11)
siltuximab/	IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, /Sylvant) (12)
	IL-12/23 inhibitors (including ustekinemab/Stelara, guselkumab/Tremfya) (13)
	IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (14)
	Intravenous immunoglobulin (IVIG) (15)
upadicitinil	JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, b/Rinvoq) (16)

	Leflunomide (Arava) (17)
	Methotrexate (Trexall) (18)
	Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (19)
naproxen/ (20)	NSAIDs (non-steroidal anti-inflammatory drugs including ibuprofren/Advil/Motrin, Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others)
	Rituximab (Rituxan and biosimilar version) (21)
	Sclerostin inhibitor (Romosozumab) (22)
prednisolo others) (2	Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, one, dexathemasone, Decadron, glucocorticoids, corticosteroids, cortisol, and (3)
	Sulfasalazine (Asulfidine, salazine) (24)
	Teriparatide (Forteo) (25)
	Thalidomide / Ienalidomide (Thalomid, Revlimid) (26)
golimumal	TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, b/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)
Page Break	

Q8 Has a doct that apply	for ever told you that you had any of the following medical conditions? Check all
	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 ≥ 30) (7)
	Severe obesity (body mass index ≥ 40) (8)
	Diabetes (9)
	Cancer (10)
pericarditis	Heart disease (myocardial infarction/heart attack, heart failure, valvular disease, s) (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)
(21)	Chronic neurological or neuromuscular disease (multiple sclerosis, ALS, etc.)
	None (22)
	Don't know (23)
Page Break	

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)?





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,	have alread	v received	at least	one dose	(1)	)
		,			٠.,	,

Yes, I will get it when it is available (2)

O No (3)

O Unsure (4)

#### 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 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, wo... = No

Or If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, wo... = 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 ()



If If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, wo... = No

Or If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, wo... = Unsure

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all that apply)	build increase your willingness to be vaccinated with a COVID-19 vaccine? (Check
	If someone I know and trust receives the vaccine safely (1)
someone	I need to have more information about what can happen from the vaccine for like me (2)
	Once more people have had it, I can judge if it is worth receiving (3)
me (4)	If others who I believe are more vulnerable were able to get their vaccine before
vaccine (	If my rheumatologist or other health care providers tell me I should receive the (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)
 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)	0	0	0	0	0	0
I'm concerned about side effects to the COVID-19 vaccine (1)	0	0	0	$\circ$	0	0
I think the COVID-19 vaccine is unsafe (2)	0	0	0	0	0	0
I am afraid of needles/injections (21)	0	$\circ$	$\circ$	$\circ$	0	$\circ$
I am worried about being able to pay for the COVID-19 vaccine (22)	0	0	0	0	0	0
I am worried that travel will be too difficult to obtain the COVID-19 vaccine (23)	0	0	0	0	0	0
I am worried it will be too complicated to get an appointment to receive the COVID-19 vaccine (24)	0	0	0	0	0	0
I will have a milder course of COVID-19 if I am vaccinated (25)	0	0	0	0	0	0

I consider myself as being "pro- vaccine" (26)	0	$\circ$	$\circ$	$\circ$	$\circ$	0
I never get very ill with infections so the COVID-19 vaccine is not needed for me (27)	0	0	0	0	0	0
I am worried the vaccine could cause COVID-19 infection (28)	0	0	0	0	0	0
The COVID-19 vaccine will not work as well for me (3)	0	0	0	0	0	$\circ$
I would rather wait for a specific type of COVID-19 vaccine (29)	0	$\circ$	$\circ$	$\circ$	$\circ$	0
I don't think the vaccine is helpful because it will not protect me against new variants of COVID-19. (30)	0	0	0	0	0	0
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)
$\chi_{\Rightarrow}$

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)	0	0	0	0	0
COVID-19 is not dangerous for my health (2)	0	0	0	$\circ$	$\circ$
The vaccine will help us return to how life was before COVID-19 (3)	0	0	0	0	0
Being vaccinated will alleviate the fears and worries I have about the pandemic (4)	0	0	0	0	0
I want to protect myself and my family from COVID- 19 (5)	0	0	0	0	0
I believe in natural or traditional remedies (6)	0	0	0	0	0
I do not get vaccinations for religious reasons (7)	0	0	0	0	0

The vaccine will lessen the financial hardships of the pandemic (8)	0	0	0	0	0
I generally trust information and instructions from the government (9)	0	0		0	0
Wearing masks and social distancing are important ways to control COVID-19 (10)	0				
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



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

O Very likely (1)
O Somewhat likely (2)
O Unsure (3)
O Not so likely (4)
O 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)	0	0	0	0	0
I am worried that taking the vaccine will cause a flare of my rheumatic condition (2)	0	0	0	0	0
I am worried about being exposed to COVID-19 at the facility to get a vaccine (3)	0	0	0		0
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?

O Yes (1)

O No (2)

O 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



	re the reason(s) you declined to receive a vaccine (NOT for COVID-19) that was I 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)
(15)	I did not think I should take it due to my underlying conditions or medications
	I do not remember (16)

	Other reasons: (Please Specify) (17)
Page Break	



Q20 Do you regularly get the influenza immunization (flu shot)?
○ Yes (1)
O No (2)
O Not sure (3)
O Prefer not to say (4)
X→
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)
O No (2)
O Not sure (3)
Display This Question:
If srs_react_nonCOVID_vacc = Yes
$X \rightarrow$

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)
Page Break	



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, omiting, difficulty breathing, and throat tightening needing emergency medical 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
$\chi_{\Rightarrow}$
Q24 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
O Yes (1)
O No (2)
O 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?
Page Break ————————————————————————————————————



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
X÷
Q27 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
○ Yes (1)
O No (2)
O 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?
Page Break ————————————————————————————————————



X→		
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, omiting, difficulty breathing, and throat tightening needing emergency medical 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
X
Q30 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
○ Yes (1)
○ No (2)
O Not sure (3)
Disales This Oscarian
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?
Page Break ————————————————————————————————————



X→		
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, omiting, difficulty breathing, and throat tightening needing emergency medical 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?
Display This Question:
If pneum_react = Flare of my existing rheumatic disease
$X \rightarrow$
Q34 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
○ Yes (1)
O No (2)
O Not sure (3)
Page Break ————————————————————————————————————

Display This Q	uestion:
If which_v	ax_srs = Influenza (flu shot)
X→	
Q35 What we (Check all tha	ere the serious side effect(s) you experienced to Influenza (flu shot) vaccine?
	Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, omiting, difficulty breathing, and throat tightening needing emergency medical 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?
Display This Question:  If influenza_react = Flare of my existing rheumatic disease
X+
Q37 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
○ Yes (1)
O No (2)
O Not sure (3)
Page Break

Display This Q	
X→	ax_srs = Other (Please Specify):
000 14/1	
	ere the serious side effect(s) you experienced to a non-COVID-19 vaccine `other` eck all that apply)
	Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, omiting, difficulty breathing, and throat tightening needing emergency medical 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?
Display This Question:
If other_react = Flare of my existing rheumatic disease  X+
Q40 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
○ Yes (1)
O No (2)
O 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)	0	0	0	0
Has your care provider reached out to you about the vaccine? (4)	0	0	0	0
Did you discuss the vaccine with your provider during a visit (in- person or telehealth)? (5)	0	0		0
If you communicated with multiple providers about the vaccine, was there agreement between them?	0	0		0

## 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)
Ounsure (6)
Display This Question:
If Please indicate how you have communicated (contacted by phone, email, or some other method of com = Yes
X
Q43 How satisfied were you with this conversation with your healthcare provider?
O Very satisfied (1)
O Satisfied (2)
O Neither satisfied nor dissatisfied (3)
Obissatisfied (4)
O 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

244 Have you been told you are currently eligible to receive a COVID-19 vaccine:
○ Yes (1)
O No (2)
O 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 V	Vhich vaccine did you receive?
C	Pfizer-BioNTech (mRNA) (1)
C	Moderna (mRNA) (2)
C	Janssen/Johnson & Johnson (J&J) (3)
C	Oxford-AstraZeneca (4)
C	Novavax (5)
C	Sinovac/Sinopharm (Chinese) (6)
C	Sputnik V (Russian) (7)
C	Cansino (8)
C	Not sure (9)
C	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



or after receiving the COVID-19 vaccine?
○ Yes (1)
O No (2)
O Not sure (3)
Display This Question:
If Did you stop (either temporarily or permanently) any of your rheumatic medications before or afte = Yes
$X \rightarrow$
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)
O No (2)
O 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



 nave a serious reaction to the COVID-19 vaccine (except for anaphylaxis, lasting ays and within two months of the vaccination)? (Check all that apply)
No (1)
Anaphylaxis (severe, potentially life-threatening allergic reaction often with rash, omiting, difficulty breathing, and throat tightening needing emergency medical 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)

tha = 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 tha = Flare of my existing rheumatic disease
$X \rightarrow$
Q50 Did this flare or worsening require change in treatment (increasing dosages, adding new medications) for your rheumatic disease?
○ Yes (1)
O No (2)
O Not sure (3)
Page Break ————————————————————————————————————

If Did you have a serious reaction to the COVID-19 vaccine (except for anaphylaxis, lasting more

Display This Question:

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)	0	0	$\circ$
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (x3)	0	$\circ$	0
Apremilast (Otezla) (x4)	0	$\circ$	$\circ$
Azathioprine / 6-MP (Imuran, mercaptopurine) (x5)	0	$\circ$	0
Belimumab (Benlysta) (x6)	0	$\circ$	$\circ$
Bisphosphonates (pamidronate, alendronate, risedronate, zoledronic acid) (x28)	0	0	0
Calcineurin inhibitors (cyclosporine, tacrolimus) (x29)	0	0	0
Cyclophosphamide (Cytoxan) (x7)	0	0	$\circ$
Colchicine (Mitagare, Colcrys) (x27)	0	$\circ$	0
Denosumab (Prolia) (x9)	0	$\circ$	$\circ$
IL-1 inhibitors (including anakinra/Kineret, canakinumab/llaris, rilonacept/Arcalyst) (x10)	0	$\circ$	0
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (x11)	0	$\circ$	0

IL-12/23 inhibitors (including ustekinemab/Stelara, guselkumab/Tremfya) (x12)	0	0	0
IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (x13)	0	0	0
Intravenous immunoglobulin (IVIG) (x14)	0	0	0
JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadicitinib/Rinvoq) (x15)	0	0	0
Leflunomide (Arava) (x16)	0	0	0
Methotrexate (Trexall) (x17)	0	$\bigcirc$	0
Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (x18)	0	0	0
NSAIDs (non-steroidal anti- inflammatory drugs including ibuprofren/Advil/Motrin, naproxen/Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others) (x8)	0	0	0
Rituximab (Rituxan and biosimilar version) (x19)	0	0	$\circ$
Sclerostin inhibitor (Romosozumab) (x30)	0	0	$\circ$
Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, prednisolone, dexathemasone, Decadron, glucocorticoids, corticosteroids, cortisol, and others) (x20)	0		0
Sulfasalazine (Asulfidine, salazine) (x21)		$\circ$	$\bigcirc$

$\circ$	$\circ$	$\circ$
0	$\circ$	$\circ$
0		
$\circ$	$\circ$	$\circ$
0	0	0
0	$\circ$	0

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?"



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)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (xx3)	0	0	$\circ$	0	0	$\circ$
Apremilast (Otezla) (xx4)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Azathioprine / 6-MP (Imuran, mercaptopurine) (xx5)	0	0	$\circ$	0	$\circ$	0
Belimumab (Benlysta) (xx6)	0	$\circ$	$\bigcirc$	$\circ$	$\circ$	$\circ$
Bisphosphonates (pamidronate, alendronate, risedronate, zoledronic acid) (xx28)	0	0	0	0	0	0
Calcineurin inhibitors (cyclosporine, tacrolimus) (xx29)	0	$\circ$	0	$\circ$	0	$\circ$
Cyclophosphamide (Cytoxan) (xx7)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Colchicine (Mitagare, Colcrys) (xx27)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Denosumab (Prolia) (xx9)	0	$\circ$	$\bigcirc$	$\circ$	$\circ$	$\circ$
IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) (xx10)	0	0	0	0	0	$\circ$
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (xx11)	0	0	0	0	0	0

IL-12/23 inhibitors (including ustekinemab/Stelara, guselkumab/Tremfya) (xx12)	0	$\circ$	$\circ$	$\circ$	$\circ$	0
IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (xx13)	0	0	$\circ$	$\circ$	$\circ$	$\circ$
Intravenous immunoglobulin (IVIG) (xx14)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadicitinib/Rinvoq) (xx15)	0	0	0	0	0	0
Leflunomide (Arava) (xx16)	0	0	$\circ$	$\circ$	$\circ$	$\circ$
Methotrexate (Trexall) (xx17)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (xx18)	0	$\circ$	$\circ$	$\circ$	$\circ$	0
NSAIDs (non-steroidal anti- inflammatory drugs including ibuprofren/Advil/Motrin, naproxen/Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others) (xx8)	0	0	0	0	0	0
Rituximab (Rituxan and biosimilar version) (xx19)	0	$\circ$	$\circ$	$\circ$	$\bigcirc$	$\circ$
Sclerostin inhibitor (Romosozumab) (xx30)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, prednisolone, dexathemasone, Decadron, glucocorticoids, corticosteroids, cortisol, and others) (xx20)	0	0	0	0	0	0
Sulfasalazine (Asulfidine, salazine) (xx21)	0	0	0	$\circ$	$\circ$	0

Teriparatide (Forteo) (xx31)	0	$\bigcirc$	$\circ$	$\circ$	$\bigcirc$	$\circ$
Thalidomide / lenalidomide (Thalomid, Revlimid) (xx23)	0	$\circ$	$\circ$	$\circ$	$\bigcirc$	$\circ$
TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (xx24)	0	0	0	0	0	0
None (xx1)	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I don't know the type or name of my medication (xx25)	0	0	0	0	0	0
Other (please specify): (xx26)	0	$\bigcirc$	$\circ$	$\circ$	$\bigcirc$	$\circ$
						_

Page Break ———

$X \rightarrow$
Q53 Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection?
○ Yes (1)
O No (2)
O 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
$\chi_{\Rightarrow}$
Q54 In which approximate month was the diagnosis of COVID-19 made?
▼ December 2019 (1) November 2021 (24)
$X \rightarrow$
Q55 How was COVID-19 diagnosed?
I diagnosed myself based on symptoms (1)
My doctor diagnosed me based only on symptoms (2)
<ul> <li>I was diagnosed based on positive test results for COVID-19 or SARS-CoV-2 (such as PCR or antibodies) (3)</li> </ul>
O 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)		
O No (2)		
O 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?		
X		

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)
<ul> <li>I was not hospitalized but did have some difficulties performing my daily activities (bathing, eating, dressing, etc.) (2)</li> </ul>
O I was hospitalized (3)
O I was hospitalized and required ICU care such as a breathing machine (ventilator) (4)
Page Break ————————————————————————————————————



Q60 What is your present gender identity?
O Female (1)
O Male (2)
Transgender Female/ Trans woman (3)
Transgender Male/ Trans man (4)
O Genderqueer/ Gender non-conforming (5)
Oifferent identity (please specify): (6)
O Prefer not to answer (7)
$\chi_{\Rightarrow}$
Q61 What sex were you assigned at birth, meaning on your original birth certificate?
○ Male (1)
O Female (2)
O 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	
$X \rightarrow$	
Q62 Are you currently pregnant, or have you been pregnant in the last 6 weeks?	
O I am not pregnant (1)	
I am currently pregnant (2)	
Tam currently program (2)	
O I was pregnant in the last 6 weeks (3)	
O Not applicable (4)	
O Not sure (5)	
O Prefer not to answer (6)	
Display This Question:	
If What sex were you assigned at birth, meaning on your original birth certificate? = Female	
$X \rightarrow$	
Q63 Are you currently breastfeeding or lactating and feeding pumped milk to your baby?	

$\circ$	Yes (1)
$\circ$	No (2)
$\circ$	Not sure (3)
0	Not applicable (4)
Page I	 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)
O No, I never smoked (3)
Page Break



Q65 What is your highest level of education obtained?
O Less than high school (secondary level) (1)
O High school (secondary level) / GED (2)
○ Some college (3)
O 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)
C Employed part-time (2)
O Not employed, looking for work (3)
O Not employed, NOT looking for work (4)
Retired (5)
O Not able to work due to disability (6)
O 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)	
Page Break		

X+
Q68 In what country do you live?
▼ Afghanistan (1) Zimbabwe (201)
Display This Question:
If In what country do you live? = Canada
X÷
Q69 In what province/territory do you live?
Q09 III 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)
X÷
Q70 In what state do you live?
▼ Alabama (1) Wyoming (51)
Page Break

ا Do you b	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)
Inflamació	Instituto de Investigación Hospital 12 de Octubre (RIER, Red de Investigación er ón 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)	
Page Break		

Q72 Do you have any other questions, comments, or concerns? We would love to hear your feedback!	
End of Block: Block 1	