

COVID-19 Global Rheumatology Alliance Patient Experience Survey

Start of Block: Default Question Block

Q1 The COVID-19 Global Rheumatology Alliance is conducting a study to understand how COVID-19 (novel Coronavirus disease, also called SARS-CoV-2) affects adults and children with rheumatic diseases throughout the world. Adults (aged 18 and over) and parents of children with rheumatic disease are invited to participate (whether or not you or your child have been diagnosed with COVID-19). All the information we collect is anonymous. Our aim is to help improve the care of patients with rheumatic diseases during this pandemic. Have questions? Visit our website at rheum-covid.org or email us at rheum.covid.patient.registry@gmail.com.



Q2 Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease?

- For myself (adult aged 18 and over) (1)
 - For my child (2)
-

Display This Question:

If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? = For my child

Q3 As a parent or caregiver of a child with a rheumatic disease, please answer all questions on behalf of your child. Remember, when questions ask about "YOU," we're really asking about YOUR CHILD. Thanks for helping us out!



Q4 What is your rheumatologic disease diagnosis (check all that apply)?

- ANCA-associated vasculitis (e.g., granulomatosis with polyangiitis (GPA), microscopic polyangiitis (MPA), EGPA) (1)
- Ankylosing spondylitis (2)
- Anti-phospholipid antibody syndrome (3)
- Autoinflammatory disease (including TRAPS, CAPS, FMF) (4)
- Behcet's syndrome (5)
- Chronic recurrent multifocal osteomyelitis (CRMO) (6)
- Dermatomyositis, polymyositis, or other inflammatory muscle diseases (7)
- Eye inflammation (scleritis, uveitis, etc.) (8)
- Giant cell arteritis (temporal arteritis) (9)
- Gout (10)
- IgG4-related disease (11)
- Juvenile idiopathic arthritis (JIA), not systemic (12)
- Systemic juvenile idiopathic arthritis (SJIA) / Still's Disease (13)
- Kawasaki disease (14)
- Lupus (15)
- Mixed connective tissue disease (16)

- Polymyalgia rheumatica (PMR) (17)
 - Psoriatic arthritis (18)
 - Rheumatoid arthritis (RA) (19)
 - Other inflammatory arthritis (20)
 - Other spondyloarthritis (including reactive arthritis) (21)
 - Sarcoidosis (22)
 - Sjogren's syndrome (23)
 - Systemic sclerosis (scleroderma) (24)
 - Undifferentiated connective tissue disease (25)
 - I do not have a rheumatologic diagnosis (26)
 - Other (please specify): (27)
-

Skip To: End of Survey If What is your rheumatologic disease diagnosis (check all that apply)? = I do not have a rheumatologic diagnosis

Display This Question:

If What is your rheumatologic disease diagnosis (check all that apply)? = Other inflammatory arthritis

Q5 Please specify which type of inflammatory arthritis you have:

Display This Question:

If What is your rheumatologic disease diagnosis (check all that apply)? = Autoinflammatory disease (including TRAPS, CAPS, FMF)

Q6 Please specify which autoinflammatory disease you have:

Display This Question:

If What is your rheumatologic disease diagnosis (check all that apply)? = Autoinflammatory disease (including TRAPS, CAPS, FMF)

Or What is your rheumatologic disease diagnosis (check all that apply)? = Systemic juvenile idiopathic arthritis (SJIA) / Still's Disease

Or What is your rheumatologic disease diagnosis (check all that apply)? = Lupus



Q7 Have you ever had macrophage activation syndrome (MAS)?

Yes (1)

No (2)

Don't know (3)



Q8 In the past 3 months, which of the following rheumatology medications have you taken?
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)
- Cyclophosphamide (Cytoxan) (6)
- Cyclosporine (Neoral/Sandimmune) (7)
- Denosumab (Prolia) (8)
- IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) (9)
- IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (10)
- IL-12/23 inhibitors (including ustekinumab/Stelara, guselkumab/Tremfya) (11)
- IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (12)
- Intravenous immunoglobulin (IVIG) (13)
- JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq) (14)
- Leflunomide (Arava) (15)
- Methotrexate (Trexall) (16)

- Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (17)
 - Rituximab (Rituxan) (18)
 - Steroids (prednisone, methylprednisolone, Medrol, etc.) (19)
 - Sulfasalazine (Asulfidine) (20)
 - Tacrolimus (Prograf) (21)
 - Thalidomide / lenalidomide (Thalomid, Revlimid) (22)
 - TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (23)
 - None (24)
 - I don't know (25)
 - Other (please specify): (26)
-



Q9 In the past 3 months, have you taken any of the following other medications? Check all that apply.

- ACE inhibitor (lisinopril, captopril, ramipril, enalapril, etc) (1)
- Angiotensin receptor blocker (valsartan, losartan, candesartan, telmisartan, etc.) (2)
- Nonsteroidal anti-inflammatory drugs (NSAIDs such as ibuprofen/Motrin, naproxen/Aleve, etc, but NOT including acetaminophen/Tylenol or paracetamol) (3)
- Celecoxib / Celebrex (7)
- PD5 inhibitors (Sildenafil, Viagra, Revatio, Cialis, Levitra) (4)
- Colchicine/Colcrys/Mitigare (5)
- None (6)



Q10 Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection?

- Yes (1)
- No (2)
- Don't know (3)

Skip To: Q26 If Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection? = No

Skip To: Q26 If Have you been diagnosed with, or thought you had, COVID-19 (Coronavirus) infection? = Don't know



Q11 What symptoms did you have associated with COVID-19 infection? Check all that apply.

- Fever (1)
 - Malaise/fatigue (2)
 - Irritability/confusion (3)
 - Headache (4)
 - Sore throat (5)
 - Runny nose (6)
 - Cough (7)
 - Shortness of breath (8)
 - Chest pain (9)
 - Joint pain (10)
 - Muscle aches (11)
 - Belly pain (12)
 - Diarrhea, vomiting or nausea (13)
 - Loss of smell (anosmia) (14)
 - Altered sense of taste (dysgeusia) (15)
 - Other (please specify): (16)
-



Q12 In which month was the diagnosis of COVID-19 made?

▼ December 2019 (1) ... Prefer not to answer (13)



Q13 Where was the diagnosis of COVID-19 made?

- Home or standalone testing (e.g. drive-through testing site) (1)
 - Nursing home or assisted living facility (2)
 - Outpatient clinic (3)
 - Emergency Department (4)
 - Hospital / inpatient unit (5)
 - Telehealth/telemedicine (6)
 - Other (please specify): (7) _____
-



Q14 How was COVID-19 diagnosed?

- I diagnosed myself based on symptoms (1)
 - My doctor diagnosed me based only on symptoms (2)
 - My doctor diagnosed me based on positive test results (3)
 - Don't know (4)
 - Other (please specify): (5) _____
-

Display This Question:

If How was COVID-19 diagnosed? = I diagnosed myself based on symptoms

Or How was COVID-19 diagnosed? = My doctor diagnosed me based only on symptoms



Q15 Why did you not obtain testing for COVID-19?

- Testing was not available in my area (1)
- Testing was not recommended by my physician (2)
- Other (please specify): (3) _____



Q16 Have you received any of the following medications to treat COVID-19 infection? Check all that apply.

- Anti-virals (e.g. lopinavir-ritonavir/Kaletra, remdesivir, oseltamivir/Tamiflu, favipiravir/Avigan) (1)
- Anti-malarials (e.g. chloroquine, hydroxychloroquine/Plaquenil) (2)
- Azithromycin (14)
- Bevacizumab/Avastin (3)
- Ciclesonide (Alvesco/Zetonna) (4)
- Colchicine (16)
- IL-1 inhibitors (anakinra/Kineret, canakinumab/Ilaris) (15)
- IL-6 inhibitors (e.g. Tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (5)
- IVIG (6)
- JAK Kinase inhibitors ((including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq, ruxolitinib/Jakafi)) (7)
- Plasma from recovered patients (8)
- Serpin inhibitors (9)
- Steroids (prednisone, methylprednisone) (10)
- Don't know (11)
- I did not receive any treatment (12)

Other (please specify): (13)



Q17 Has your COVID-19 infection resolved at the time of this survey?

- Yes (1)
- No (2)
- Don't know (3)

Display This Question:

If Has your COVID-19 infection resolved at the time of this survey? = Yes



Q18 How many days did your symptoms last, from the first day you became ill until symptoms resolved?

▼ 1 (1) ... 20+ (20)

Display This Question:

If Has your COVID-19 infection resolved at the time of this survey? = No



Q19 For how many days have you been ill, counting from the first day you became ill until today?

▼ 1 (1) ... 20+ (20)



Q20 What happened during the course of your illness?

- 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 but did not require oxygen (3)
- I was hospitalized and required oxygen (4)
- I was hospitalized and required non-invasive ventilation (CPAP) or high-flow oxygen devices (5)
- I was hospitalized and required a breathing machine/ventilator (6)



Q21 Did you have any of the following exposures during the 14 days before you became ill?
Check all that apply.

- Travel to an area with many cases of COVID-19 infection (1)
- Close contact with a confirmed or probable case of COVID-19 infection (2)
- Presence in a healthcare facility where COVID-19 infections have been managed (3)
- Don't know (4)
- None (5)
- Other (please specify): (6) _____

Q22 How was your rheumatic disease controlled at the time that you were diagnosed with COVID-19 infection?

0 = very well

10 = very poor

0 1 2 3 4 5 6 7 8 9 10

Rheumatic disease control ()



Display This Question:

If In the past 3 months, which of the following rheumatology medications have you taken? Check all that apply. != None

And In the past 3 months, which of the following rheumatology medications have you taken? Check all that apply. != I don't know

Carry Forward Selected Choices from "In the past 3 months, which of the following rheumatology medications have you taken? Check all that apply."



Q23 At the time you were diagnosed with COVID-19, had you been taking the following medications as prescribed? If so, were the medications continued or stopped after the diagnosis?

	Yes, I was taking this medication and it was CONTINUED after diagnosis (1)	Yes, I was taking this medication, but it was STOPPED after diagnosis (2)	No, I was not taking this medication (3)	Other (4)
Abatacept (Orencia) (x2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (x3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Apremilast (Otezla) (x4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Azathioprine / 6-MP (Imuran, mercaptopurine) (x5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belimumab (Benlysta) (x6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclophosphamide (Cytoxan) (x7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclosporine (Neoral/Sandimmune) (x8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Denosumab (Prolia) (x9)	<input type="radio"/>	<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"/>	<input type="radio"/>
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (x11)	<input type="radio"/>	<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"/>	<input type="radio"/>

IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (x13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intravenous immunoglobulin (IVIG) (x14)	<input type="radio"/>	<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"/>	<input type="radio"/>
Leflunomide (Arava) (x16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methotrexate (Trexall) (x17)	<input type="radio"/>	<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"/>	<input type="radio"/>
Rituximab (Rituxan) (x19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Steroids (prednisone, methylprednisolone, Medrol, etc.) (x20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sulfasalazine (Asulfidine) (x21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tacrolimus (Prograf) (x22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thalidomide / lenalidomide (Thalomid, Revlimid) (x23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (x24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> None (x1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> I don't know (x25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify): (x26)



Skip To: Q24 If Condition: 1 Is Selected 1. Skip To: How much steroids were you taking eve...

Display This Question:

If At the time you were diagnosed with COVID-19, had you been taking the following medications as pr... Steroids (prednisone, methylprednisolone, Medrol, etc.) - Yes, I was taking this medication and it was CONTINUED after diagnosis Is Selected

Or Or At the time you were diagnosed with COVID-19, had you been taking the following medications as pr... Steroids (prednisone, methylprednisolone, Medrol, etc.) - Yes, I was taking this medication, but it was STOPPED after diagnosis Is Selected



Q24 At the time you were diagnosed with COVID-19, how much steroids were you taking every day, in milligrams (mg)? If you were taking IV steroids, please enter 99.

Display This Question:

If In the past 3 months, have you taken any of the following other medications? Check all that apply. != None

Carry Forward Selected Choices from "In the past 3 months, have you taken any of the following other medications? Check all that apply."



Q25 At the time you were diagnosed with COVID-19, were you taking the following drugs? If so, were they continued after diagnosis?

	Yes, and this medication was CONTINUED (1)	Yes, and this medication was STOPPED at diagnosis (2)	No, I was not taking this medication (3)	Don't know (4)
ACE inhibitor (lisinopril, captopril, ramipril, enalapril, etc) (x1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Angiotensin receptor blocker (valsartan, losartan, candesartan, telmisartan, etc.) (x2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nonsteroidal anti-inflammatory drugs (NSAIDs such as ibuprofen/Motrin, naproxen/Aleve, etc, but NOT including acetaminophen/Tylenol or paracetamol) (x3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Celecoxib / Celebrex (x7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PD5 inhibitors (Sildenafil, Viagra, Revatio, Cialis, Levitra) (x4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colchicine/Colcrys/Mitigare (x5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> None (x6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break



Q26 Over the past 30 days, what methods have you been using to protect yourself from COVID-19?

- Social distancing (avoiding crowds and large groups of people) (1)
- Quarantine (staying home and avoiding others as much as possible) (2)
- Using gloves and/or masks during social interactions (3)
- None (4)
- Other (please specify): (5) _____

Display This Question:

If Over the past 30 days, what methods have you been using to protect yourself from COVID-19? = Quarantine (staying home and avoiding others as much as possible)



Q27 Who made the decision for quarantine?

- Myself (1)
- Imposed by my city/state/province/country (2)
- Don't know (3)



Q28 In the last 30 days, have you participated in any of the following activities? Check all that apply

- Travel to an area with many cases of COVID-19 infection (2)
- Close contact with a confirmed or probable case of COVID-19 infection (3)
- Presence in a healthcare facility where COVID-19 infections have been managed (4)
- None (1)
- Don't know (5)
- Other (please specify): (6) _____

Display This Question:

If In the past 3 months, which of the following rheumatology medications have you taken? Check all that apply. != None

And In the past 3 months, which of the following rheumatology medications have you taken? Check all that apply. != I don't know

Carry Forward Selected Choices from "In the past 3 months, which of the following rheumatology medications have you taken? Check all that apply."



Q29 Do you continue to take the following medications as prescribed? If not, why not?

	Yes, I continue to take this drug (1)	No, pharmacy did not have supply (2)	No, it was not effective (3)	No, I want to avoid immunosuppression (4)
Abatacept (Orencia) (x2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (x3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Apremilast (Otezla) (x4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Azathioprine / 6-MP (Imuran, mercaptopurine) (x5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belimumab (Benlysta) (x6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclophosphamide (Cytoxan) (x7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclosporine (Neoral/Sandimmune) (x8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Denosumab (Prolia) (x9)	<input type="radio"/>	<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"/>	<input type="radio"/>
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (x11)	<input type="radio"/>	<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"/>	<input type="radio"/>
IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (x13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intravenous immunoglobulin (IVIG) (x14)	<input type="radio"/>	<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"/>	<input type="radio"/>
Leflunomide (Arava) (x16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methotrexate (Trexall) (x17)	<input type="radio"/>	<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"/>	<input type="radio"/>
Rituximab (Rituxan) (x19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Steroids (prednisone, methylprednisolone, Medrol, etc.) (x20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sulfasalazine (Asulfidine) (x21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tacrolimus (Prograf) (x22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thalidomide / lenalidomide (Thalomid, Revlimid) (x23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (x24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> None (x1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> I don't know (x25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify): (x26)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Do you continue to take the following medications as prescribed? If not, why not? = No, I want to avoid immunosuppression

Or Or Do you continue to take the following medications as prescribed? If not, why not? Abatacept (Orencia) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Apremilast (Otezla) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Azathioprine / 6-MP (Imuran, mercaptopurine) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Belimumab (Benlysta) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Cyclophosphamide (Cytoxan) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Cyclosporine (Neoral/Sandimmune) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Denosumab (Prolia) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? IL-12/23 inhibitors (including ustekinumab/Stelara, guselkumab/Tremfya) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Intravenous immunoglobulin (IVIG) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Leflunomide (Arava) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Methotrexate (Trexall) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Rituximab (Rituxan) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Steroids (prednisone, methylprednisolone, Medrol, etc.) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Sulfasalazine (Asulfidine) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Tacrolimus (Prograf) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? Thalidomide / lenalidomide (Thalomid, Revlimid) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) - No, I want to avoid immunosuppression Is Selected

Or Or Do you continue to take the following medications as prescribed? If not, why not? TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) - No, I want to avoid immunosuppression Is Selected

Carry Forward Selected Choices from "Do you continue to take the following medications as prescribed? If not, why not?"



Q30 Who decided to decrease or stop the following immunosuppressive drugs?

	My rheumatologist recommended it (1)	I decided to change my medication and told my rheumatologist about it (2)	I decided to change my medication and DID NOT tell my rheumatologist about it (3)
Abatacept (Orencia) (xx2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (xx3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Apremilast (Otezla) (xx4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Azathioprine / 6-MP (Imuran, mercaptopurine) (xx5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belimumab (Benlysta) (xx6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclophosphamide (Cytoxan) (xx7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cyclosporine (Neoral/Sandimmune) (xx8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Denosumab (Prolia) (xx9)	<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"/>
IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (xx11)	<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"/>
IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (xx13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Intravenous immunoglobulin (IVIG) (xx14)	<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"/>
Leflunomide (Arava) (xx16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methotrexate (Trexall) (xx17)	<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"/>
Rituximab (Rituxan) (xx19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Steroids (prednisone, methylprednisolone, Medrol, etc.) (xx20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sulfasalazine (Asulfidine) (xx21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tacrolimus (Prograf) (xx22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thalidomide / lenalidomide (Thalomid, Revlimid) (xx23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (xx24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> None (xx1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> I don't know (xx25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify): (xx26)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q31 In the past 30 days, how have you communicated with your rheumatologist? Check all that apply.

- I have not needed to communicate with my rheumatologist (1)
- Phone call (2)
- Email / patient portal (3)
- Telemedicine / Videoconference (4)
- Office visit (5)
- I have not been able to communicate with my rheumatologist through any methods (6)
- Other (please specify): (7) _____

Q32 Considering all the ways your rheumatic disease affects you, rate how well you are doing TODAY on the following scale:

0 = very well

10 = very poor

0 1 2 3 4 5 6 7 8 9 10

Rheumatic disease control ()



Display This Question:

If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? = For my child

Q33 Remember, even though we're asking questions about "YOU," please enter the following information about YOUR CHILD.



Q34 How old are you?



Q35 What is your gender?

- Male (1)
- Female (2)
- Prefer not to answer (3)
- Other (please specify): (4) _____

Display This Question:

If How old are you? Text Response Is Greater Than 12

And How old are you? Text Response Is Less Than 50



Q36 Are you, or have you been pregnant in the last 6 weeks?

- Not applicable (1)
- I am currently pregnant (2)
- I was pregnant less than 6 weeks ago (3)
- I'm not pregnant (4)
- Don't know (5)
- Prefer not to answer (6)

Display This Question:

If If How old are you? Text Response Is Greater Than 12

And And How old are you? Text Response Is Less Than 50

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



Q37 At the time you were diagnosed with COVID-19, were you pregnant or within 6 weeks of pregnancy?

- Not applicable (1)
- I was pregnant (2)
- I was within 6 weeks of my pregnancy (3)
- I was not pregnant (4)
- Don't know (5)
- Prefer not to answer (6)



Q38 In what country do you live?

▼ Afghanistan (1) ... Zimbabwe (199)

Display This Question:

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



Q39 In what state do you live?

▼ Alabama (1) ... Wyoming (51)

Display This Question:

If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? = For my child

Q71 Remember, even though we're asking questions about "YOU," please enter the following information about YOUR CHILD.



Q40 What is your race or ethnic origin (Check all that apply)

- Arab (1)
 - Black (2)
 - East Asian (3)
 - South Asian (4)
 - West Asian (5)
 - Pacific Islander (6)
 - Latin American (7)
 - White (8)
 - Native American / Aboriginal / 1st Nations (9)
 - Don't know (10)
 - Prefer not to answer (11)
 - Other (please specify): (12)
-



Q41 Do you, or have you smoked tobacco?

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



Q42 Do you, or have you used vaping products or e-cigarettes?

- Yes, I am a current user (1)
 - Yes, I am a former user (2)
 - No, I never used those products (3)
-



Q43 Do you have any of the following medical conditions? Check all that apply

- Asthma, emphysema, or COPD (1)
- Cancer (2)
- Chronic kidney disease (3)
- Chronic neurological or neuromuscular disease (multiple sclerosis, ALS, etc.) (4)
- Diabetes (5)
- Fibromyalgia / amplified musculoskeletal pain syndrome (AMPS) (6)
- Heart disease (heart attack, congestive heart failure, etc.) (7)
- High blood pressure (8)
- High blood pressure in the lungs (pulmonary hypertension) (9)
- Immunodeficiency (10)
- Inflammatory bowel disease (Crohn's disease or Ulcerative colitis) (11)
- Interstitial lung disease (e.g. nonspecific interstitial pneumonia, idiopathic pulmonary fibrosis, etc.) (12)
- Liver disease (13)
- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (14)
- Other lung disease (15)
- Obesity (Body mass index ≥ 30) (25)

- Severe obesity (Body mass index ≥ 40) (18)
 - Organ transplant recipient (16)
 - Psoriasis (24)
 - Psychiatric condition (schizophrenia, bipolar, etc.) (17)
 - Stroke (23)
 - Trisomy 21 (19)
 - None (20)
 - Don't know (21)
 - Other (please specify): (22)
-



Q44 On January 1, 2020, what was your 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)
- Disabled, not able to work (6)
- Full-time student (7)

Display This Question:

If On January 1, 2020, what was your employment or student status? != Full-time student



Q45 Has your employment or student status changed as a result of the COVID-19 pandemic?

- Yes (1)
- No (2)
- Don't know (3)

Display This Question:

If On January 1, 2020, what was your employment or student status? = Full-time student



Q46 How are you now participating in classes?

- I attend classes in the classroom (1)
- I attend classes virtually in the computer (2)
- Classes were cancelled (3)
- Other (please specify): (4) _____

Display This Question:

If Has your employment or student status changed as a result of the COVID-19 pandemic? = Yes



Q47 What is 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)
- Disabled, not able to work (6)
- Full-time student (7)

Display This Question:

*If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? =
For myself (adult aged 18 and over)*

X→

Q48 Please respond to each question or statement by checking one box per row

	Excellent (1)	Very good (2)	Good (3)	Fair (4)	Poor (5)
In general, how would you rate your mental health, including your mood and your ability to think? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate your satisfaction with your social activities and relationships? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate your physical health? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? = For myself (adult aged 18 and over)



Q49 Please respond to each question or statement by checking one box per row

	Completely (1)	Mostly (2)	Moderately (3)	A little (4)	Not at all (5)
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? = For my child



Q50 Please respond to each question or statement by checking one box per row

	Excellent (1)	Very good (2)	Good (3)	Fair (4)	Poor (5)
In general, would you say your child's health is... (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, would you say your child's quality of life is... (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate your child's physical health? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate your child's mental health, including mood and ability to think? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Will you be completing the survey for yourself, or on behalf of your child with rheumatic disease? = For my child



Q51 Please respond to each question or statement by checking one box per row

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)
How often does your child feel really sad? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often does your child have fun with friends? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often does your child feel that you listen to his or her ideas? (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q52 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)
- CARRA (7)
- CreakyJoints (8)
- CureJM (9)
- Deutsche Rheuma-Liga (10)
- Disability Federation of Ireland (11)
- EULAR PARE (50)
- Foundation for Sarcoidosis Research (12)
- Hospital Clinic, Barcelona, Spain (13)
- Hospital Especialidades Centro Médico Nacional IMSS (14)
- Instituto de Investigación Hospital 12 de Octubre (RIER, Red de Investigación en Inflamación y Enfermedades Reumáticas) (15)

- International Foundation for Autoimmune & Autoinflammatory Arthritis (49)
- Iran University of Medical Sciences (16)
- JIA Matters (17)
- Juvenile Arthritis Research (JAR) (48)
- Klinik für Kinder- und Jugendmedizin I des UKSH, Campus Kiel (18)
- Lupus Foundation of America (19)
- Mayo Clinic Health System (20)
- Medical University of Lodz, Department of Rheumatology, (21)
- Mifrakim Tz'eirim (22)
- National Axial Spondyloarthritis Society (NASS) (51)
- Norwegian Rheumatism Association (23)
- Ontario Rheumatology Association (24)
- Piedmont Healthcare - Piedmont Atlanta Rheumatology (25)
- Psoriasis and Psoriatic Arthritis Alliance (PAPAA) (26)
- RA chicks (27)
- RareConnect (28)
- Rheumatology Specialists of Connecticut, Inc. (29)

- Rheumatology UKE Hamburg (30)
- Rhumatologie Hopital Maisonneuve-Rosemont (31)
- Scleroderma Clinical Trials Consortium (32)
- Sociedad Chilena de Reumatología (SOCHIRE) (33)
- Spanish Society of Rheumatology (34)
- St James's Hospital (35)
- Stowarzyszenie "3majmy się razem" (36)
- Spondylitis Association of America (37)
- Systemic JIA Foundation (38)
- The Myositis Association (52)
- The Polyclinic (39)
- UK National Rheumatoid Arthritis Society (NRAS) (40)
- Universita Politecnica Delle Marche (41)
- University of Michigan (42)
- Vasculitis UK (43)
- Versus Arthritis (44)
- Women with Rheumatoid Disease (45)

None (46)

Other (please specify): (47)

Q53 Do you have any other questions, comments, or concerns? We'd love to hear your feedback!

End of Block: Default Question Block
