

NEW Pediatric vaccine survey v2022-10

Start of Block: Consent

Q1.1 GRA COVID-19 Pediatric Survey: Welcome + Consent

Q1.2

The COVID-19 Global Rheumatology Alliance (GRA) studies how COVID-19 affects people with rheumatic diseases throughout the world. For this survey, the GRA wants to learn about the experiences of children with rheumatic diseases regarding COVID-19 infection, long-term effects, and decisions regarding COVID-19 vaccines.

You are eligible to complete this COVID-19 survey if: 1. You are 18 years of age or older
AND

2. You are the caregiver of a child less than 18 years of age with a diagnosis of a pediatric rheumatic disease You are eligible to complete the survey on behalf of your child regardless of whether or not your child has had COVID-19 infection or received the COVID-19 vaccine.

We will not collect your name, email address, IP address, or other data that will make you easily identifiable. Everyone is welcomed to complete this survey, even those who may have taken other surveys from the GRA in the past.

Have questions? Visit our website at rheum-covid.org or email us at rheum.covid@gmail.com.

Q1.3 Click to write the question text

Browser (1)

Version (2)

Operating System (3)

Screen Resolution (4)

Flash Version (5)

Java Support (6)

User Agent (7)

Q1.4 By participating, I confirm to be at least 18 years of age and the caregiver of a child with a rheumatic disease. I give my consent to use my data that describes me and my child for analyses by the COVID-19 Global Rheumatology Alliance.

Confirm (1)

Exit Survey (2)

Skip To: End of Survey If By participating, I confirm to be at least 18 years of age and the caregiver of a child with a rh... != Confirm

Q1.5

End of Block: Consent

Start of Block: Parent

Q2.1 Parent / Caregiver Questions

Q2.2 All of the questions in this section are about YOU, the caregiver. Please answer the questions about yourself and your experiences.



Q2.3 In what year were you born?

▼ 2007 (2007) ... 1930 (1930)



Q2.4 What is YOUR gender identity?

- Female (1)
 - Male (2)
 - Transgender Female / Trans female (3)
 - Transgender Male / Trans male (4)
 - Genderqueer / Gender non-conforming (5)
 - Non-binary (6)
 - Different identity (please specify): (7)
-
- Prefer not to answer (-7777)



Q2.5 What sex were you assigned at birth, meaning on your original birth certificate?

- Male (1)
- Female (0)
- Prefer not to say (-8888)



Q2.5 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 (13)
 - South Asian (4)
 - Pacific Islander (6)
 - American Indian / Alaska Native / Aboriginal / Indigenous / 1st Nations (9)
 - Mixed (15)
 - White (8)
 - Other (please specify): (10)
-
- Don't know (11)
 - Prefer not to answer (12)



Q2.6 In what country do you live?

▼ Afghanistan (1) ... Zimbabwe (199)

Display This Question:

If In what country do you live? = Canada

Q2.7 In what province/territory do you live?

▼ Ontario (1) ... Saskatchewan (24)

Display This Question:

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

Q2.8 In what state do you live?

▼ Alabama (1) ... Wyoming (51)

Page Break

Q2.9 To what extent do you agree or disagree with the following statements?

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)	Not sure (6)
The COVID-19 vaccines were developed too quickly (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receiving a COVID-19 vaccine is important to protect the health of others (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 vaccines are unsafe (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 vaccines will not protect against new variants of COVID-19 (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Natural or traditional remedies are more effective than a COVID-19 vaccine (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My religion does not allow for vaccinations (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 vaccines should be	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

required for
children
attending
school (22)



Q2.10 Overall, how hesitant about regular childhood vaccines (not including COVID-19 vaccine) would you consider yourself to be?

	Not at all hesitant (1)	Not too hesitant (2)	Not sure (3)	Somewhat hesitant (4)	Very hesitant (5)
1 (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q2.11 Have you (the caregiver) received at least one dose of the COVID-19 vaccine?

- Yes (1)
- No (0)



Q2.12 How many children under the age of 18 do you have under your care?

▼ 0 (0) ... 7 (7)



Q2.13 How many children under the age of 18 in your household have rheumatic disease(s)?

▼ 0 (0) ... 6 (6)

End of Block: Parent

Start of Block: Child Block

Q3.1 Child Questions for $\{Im://Field/1\}\{Im://Field/2\}$ Child with Rheumatic Disease

Q3.2

You will be asked to answer a few questions about each child who is under the age of 18 and has a rheumatic disease. It may be helpful to think of the birth order for each child who is under 18 and has rheumatic disease. If you are responsible for multiple children with rheumatic disease, you will be asked to fill out this section of the survey for EACH CHILD WITH A RHEUMATIC DISEASE. The next questions pertain to **your $\{Im://Field/1\}\{Im://Field/2\}$ child** under 18 with rheumatic disease.

(This is child number: $\{Im://CurrentLoopNumber\}$ of $\{Im://TotalLoops\}$ about whom we will inquire).

Q3.3

How are you related to this child?

- Parent (5)
 - Grandparent (4)
 - Legal guardian (1)
 - Other (3) _____
-



Q3.4 What **YEAR** was this child **BORN**?

▼ 2005 (2005) ... 2023 (2023)

X→

Q3.5 Has a doctor or other healthcare provider diagnosed your child with any of the following rheumatic diseases? Check all that apply.

- ANCA-associated vasculitis (e.g. granulomatosis with polyangiitis [GPA] - microscopic polyangiitis [MPA] - eosinophilic GPA - Wegener's - Churg-Strauss) (1)
- Henoch-Schonlein purpura (HSP), IgA vasculitis, or other systemic vasculitis (e.g. polyarteritis nodosa) (35)
- Antiphospholipid antibody syndrome (3)
- Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or others) (4)
- Behcet's syndrome (7)
- Chronic recurrent multifocal osteomyelitis (CRMO) or SAPHO syndrome (8)
- Dermatomyositis - polymyositis - or other inflammatory muscle disease (11)
- Eye inflammation (scleritis - uveitis - etc.) (15)
- Fibromyalgia, pain amplification syndrome, or complex regional pain syndrome (33)
- IgG4-related disease (10)
- Juvenile idiopathic arthritis (JIA) - not including the systemic subtype (oligoarthritis, polyarthritis, enthesitis-related arthritis, psoriatic arthritis, undifferentiated arthritis) (13)
- Systemic juvenile idiopathic arthritis (SJIA) (12)
- Kawasaki disease (2)
- Lupus (systemic lupus erythematosus/SLE) (23)

Mixed connective tissue disease (MCTD) (14)

Raynaud's (30)

Sarcoidosis (20)

Sjogren's syndrome (22)

Systemic sclerosis (scleroderma) (24)

Undifferentiated connective tissue disease (25)

Other inflammatory arthritis (19)

Other (please specify): (27)

None, my child does not have a rheumatologic diagnosis (26)

Skip To: End of Block If Has a doctor or other healthcare provider diagnosed your child with any of the following rheumati... = None, my child does not have a rheumatologic diagnosis

Page Break

Carry Forward Selected Choices - Entered Text from "Has a doctor or other healthcare provider diagnosed your child with any of the following rheumatic diseases? Check all that apply."



Q3.6 Please indicate the year in which your child was diagnosed with the specific rheumatic disease.

ANCA-associated vasculitis (e.g. granulomatosis with polyangiitis [GPA] - microscopic polyangiitis [MPA] - eosinophilic GPA - Wegener's - Churg-Strauss) (x1)	▼ 2004 (1) ... I don't know (23)
Henoch-Schonlein purpura (HSP), IgA vasculitis, or other systemic vasculitis (e.g. polyarteritis nodosa) (x35)	▼ 2004 (1) ... I don't know (23)
Antiphospholipid antibody syndrome (x3)	▼ 2004 (1) ... I don't know (23)
Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or others) (x4)	▼ 2004 (1) ... I don't know (23)
Behcet's syndrome (x7)	▼ 2004 (1) ... I don't know (23)
Chronic recurrent multifocal osteomyelitis (CRMO) or SAPHO syndrome (x8)	▼ 2004 (1) ... I don't know (23)
Dermatomyositis - polymyositis - or other inflammatory muscle disease (x11)	▼ 2004 (1) ... I don't know (23)
Eye inflammation (scleritis - uveitis - etc.) (x15)	▼ 2004 (1) ... I don't know (23)
Fibromyalgia, pain amplification syndrome, or complex regional pain syndrome (x33)	▼ 2004 (1) ... I don't know (23)
IgG4-related disease (x10)	▼ 2004 (1) ... I don't know (23)
Juvenile idiopathic arthritis (JIA) - not including the systemic subtype (oligoarthritis, polyarthritis, enthesitis-related arthritis, psoriatic arthritis, undifferentiated arthritis) (x13)	▼ 2004 (1) ... I don't know (23)
Systemic juvenile idiopathic arthritis (SJIA) (x12)	▼ 2004 (1) ... I don't know (23)
Kawasaki disease (x2)	▼ 2004 (1) ... I don't know (23)
Lupus (systemic lupus erythematosus/SLE) (x23)	▼ 2004 (1) ... I don't know (23)
Mixed connective tissue disease (MCTD) (x14)	▼ 2004 (1) ... I don't know (23)
Raynaud's (x30)	▼ 2004 (1) ... I don't know (23)
Sarcoidosis (x20)	▼ 2004 (1) ... I don't know (23)

Sjogren's syndrome (x22)
Systemic sclerosis (scleroderma) (x24)
Undifferentiated connective tissue disease
(x25)
Other inflammatory arthritis (x19)
Other (please specify): (x27)
 **None, my child does not have a
rheumatologic diagnosis** (x26)

▼ 2004 (1) ... I don't know (23)
▼ 2004 (1) ... I don't know (23)
▼ 2004 (1) ... I don't know (23)
▼ 2004 (1) ... I don't know (23)
▼ 2004 (1) ... I don't know (23)
▼ 2004 (1) ... I don't know (23)

Page Break

Display This Question:

If Loop current: Has a doctor or other healthcare provider diagnosed your child with any of the following rheumati... = Autoinflammatory disease (including TRAPS - CAPS - FMF - HIDS - PFAPA - or others)

Q3.7 Which autoinflammatory disease does the child have?

- TNF-Receptor Associated Periodic Syndrome (TRAPS) (1)
 - Cryopyrin Associated Periodic Syndrome (CAPS, NLRP3- AID: FCAS, Muckle-Wells, NOMID/CINCA) (2)
 - Familial Mediterranean Fever (FMF) (3)
 - Hyper-IgD Syndrome (HIDS) / Mevalonate Kinase Deficiency (MKD) (4)
 - Periodic fevers, aphthous stomatitis, pharyngitis, and adenitis (PFAPA) (5)
 - Chronic Recurrent Multifocal Osteomyelitis (CRMO) (7)
 - Deficiency of Adenosine Deaminase 2 (DADA2) (8)
 - Blau Syndrome (9)
 - Unclassified Autoinflammatory Syndrome (uSAID) (10)
 - NLRP12 Associated Autoinflammatory Disorders (NLRP-12 AID, FCAS2) (13)
 - Other (Please Specify): (6)
-

Q3.8 Has a doctor or other healthcare provider diagnosed your child with any of the following diseases? Select all that apply.

- Anxiety (35)
- Asthma (7)
- Attention-deficit/hyperactivity disorder (ADHD) or ADD (31)
- Autism spectrum disorder (30)
- Cancer (11)
- Cerebral palsy (15)
- Chronic kidney disease (10)
- Cystic fibrosis (29)
- Depression (39)
- Developmental disabilities (32)
- Diabetes (2)
- Down Syndrome (36)
- Ehler's-Danlos, Marfans Syndrome, or other hereditary disease of connective tissue (38)
- Epilepsy (seizures) (33)
- High blood pressure (28)

- High blood pressure in the lungs (pulmonary hypertension) (6)
- Immunodeficiency (not due to medications) (13)
- Inflammatory bowel disease (Crohn's disease or Ulcerative colitis) (16)
- Interstitial lung disease (ILD) / idiopathic pulmonary fibrosis (IPF) (8)
- Irritable bowel syndrome (37)
- Liver disease (14)
- Obesity or overweight (25)
- Psoriasis (24)
- Stroke (23)
- Other (34) _____
- I don't know** (19)
- None of these** (1)

Page Break



Q3.9 At present, which of the following rheumatic disease medications is your child **currently** taking? Check all that apply.

- Abatacept (Orencia) (2)
- Antimalarials (including hydroxychloroquine/Plaquenil, chloroquine) (3)
- Apremilast (Otezla) (4)
- Azathioprine / 6-MP (Imuran, mercaptopurine) (5)
- Belimumab (Benlysta) (6)
- Calcineurin inhibitors (cyclosporine, tacrolimus) (29)
- Cyclophosphamide (Cytoxan) (7)
- Colchicine (Mitigare, Colcrys) (27)
- IL-1 inhibitors (including anakinra/Kineret, canakinumab/Ilaris, rilonacept/Arcalyst) (10)
- IL-6 inhibitors (including tocilizumab/Actemra, sarilumab/Kevzara, siltuximab/Sylvant) (11)
- IL-12/23 inhibitors (including ustekinumab/Stelara, guselkumab/Tremfya) (12)
- IL-17 inhibitors (including secukinumab/Cosentyx, ixekizumab/Taltz) (13)
- Intravenous immunoglobulin (IVIG) (14)
- JAK inhibitors (including tofacitinib/Xeljanz, baricitinib/Olumiant, upadacitinib/Rinvoq) (15)
- Leflunomide (Arava) (16)

- Methotrexate (Trexall) (17)
 - Mycophenolate mofetil / mycophenolic acid (Cellcept, Myfortic) (18)
 - NSAIDs (non-steroidal anti-inflammatory drugs including ibuprofen/Advil/Motrin, naproxen/Naprosyn, celecoxib/Celebrex, indomethacin, diclofenac, meloxicam, and others) (8)
 - Rituximab (Rituxan and biosimilar version) (19)
 - Steroids (including prednisone, prednisolone, methylprednisolone, Medrol, dexamethasone, Decadron, glucocorticoids, corticosteroids, cortisol, and others) (20)
 - Sulfasalazine (Asulfidine, salazine) (21)
 - Thalidomide / lenalidomide (Thalomid, Revlimid) (23)
 - TNF-inhibitors (infliximab/Remicade, etanercept/Enbrel, adalimumab/Humira, golimumab/Simponi, certolizumab/Cimzia, and biosimilar versions) (24)
 - Other (please specify): (26)
-
- I don't know the type or name of my child's medication (25)
 - None of these medications (1)

Page Break



Q3.10 Has your child received at least one dose of the COVID-19 vaccine?

- Yes (1)
 - No (0)
 - I don't know (-6666)
-

Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = No



Q3.11 Is your child currently eligible to receive the COVID-19 vaccine?

- Yes (1)
 - No (0)
 - Don't know (-6666)
-

Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = No

Q3.12 To what extent do you agree or disagree with the following statements.

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
The COVID-19 vaccine will cause long term side effects in my child (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 infection is not dangerous to my child's health (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child already had COVID-19 and does not need to be vaccinated (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A COVID-19 vaccine will cause a flare of my child's rheumatic condition (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is afraid of needles/injections (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is insufficient information about the safety of the vaccine for children with my child's health condition (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am willing to provide the vaccine to my child once their health improves (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am unwilling to have my child vaccinated because of the medications they are currently taking (20)

My child will receive a COVID-19 vaccine if it is required by their school (11)

Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = No

Q3.13 How willing are you to give your child a COVID-19 vaccine?

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

0 1 2 3 4 5 6 7 8 9 10

Willingness to give COVID-19 vaccine to your child ()



Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = Yes

Q3.14 How many doses of the COVID-19 vaccine has your child received? Please enter month/year for each dose received (these dates can be found on your child's vaccination card). If your child has not received a dose, indicate "Not received."

First dose (7)	▼ Not received (38) ... I really don't know (48)
Second dose (8)	▼ Not received (38) ... I really don't know (48)
Third dose (9)	▼ Not received (38) ... I really don't know (48)
Fourth dose (10)	▼ Not received (38) ... I really don't know (48)
Fifth dose (11)	▼ Not received (38) ... I really don't know (48)

Page Break

Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = Yes

Q3.15 Which COVID-19 vaccines has your child received? Select all that apply.

- Original Pfizer-BioNTech (mRNA) (1)
 - Updated Pfizer-BioNTech Bivalent Booster (mRNA) (14)
 - Original Moderna (mRNA) (3)
 - Updated Moderna Bivalent Booster (mRNA) (16)
 - Janssen/Johnson & Johnson (J&J) (5)
 - Oxford-AstraZeneca (9)
 - Novavax (10)
 - Sinovac/Sinopharm (11)
 - Sputnik V (12)
 - Cansino (13)
 - Other (please specify) (7)
-
- Not sure** (6)

Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = Yes

Q3.16 Did your child stop or delay any of their rheumatic disease medications at around the time of vaccination?

Yes (1)

No (2)

Not sure (3)

Page Break

Display This Question:

If Loop current: Has your child received at least one dose of the COVID-19 vaccine? = Yes

Q3.17 Did your child have a serious reaction to the COVID-19 vaccine (such as anaphylaxis or other reactions lasting more than 2 days), experienced within two months of the vaccination)?

- Yes (12)
 - No (1)
 - Don't know (21)
-

Display This Question:

If Loop current: Did your child have a serious reaction to the COVID-19 vaccine (such as anaphylaxis or other reac... = Yes

Q3.18 Which of the following serious reactions to the COVID-19 vaccine did your child experience? Check all that apply.

- Anaphylaxis (severe, potentially life-threatening allergic reaction with rash, nausea, vomiting, difficulty breathing, or throat tightening) (1)
- Other allergic reaction (2)
- Rash (4)
- Fever or chills (5)
- Widespread muscle/joint pain (6)
- Fatigue or sleepiness (7)
- Headache (8)
- Nausea (11)
- Vomiting (10)
- Poor appetite (18)
- Flare of their existing rheumatic disease (13)
- Development of new rheumatic, autoimmune, or inflammatory disease (9)
- Chest pain or palpitations (14)
- Pericarditis (inflammation around the heart) (19)
- Multisystem inflammatory syndrome in children (MIS-C) (20)

Other (15) _____

None (12)

Display This Question:

If Loop current: Which of the following serious reactions to the COVID-19 vaccine did your child experience? Check... = Development of new rheumatic, autoimmune, or inflammatory disease

Q3.19 What new rheumatic, autoimmune, or inflammatory disease did your child develop within 2 months of receiving the COVID-19 vaccine?

Display This Question:

If Loop current: Which of the following serious reactions to the COVID-19 vaccine did your child experience? Check... = Flare of their existing rheumatic disease

X→

Q3.20 Did this flare of their rheumatic disease require a change in treatment (such as increasing medication dosages or adding new medications)?

Yes (1)

No (0)

Not sure (-6666)

Page Break _____

Q3.21 Has your child ever had a serious reaction to another vaccine (NOT including COVID-19 vaccine)

Yes (3)

No (1)

Not sure (2)

Page Break _____



Q3.22 Please respond to each question or statement by checking one box per row.

	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (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"/>



Q3.23 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"/>

Page Break

Q3.24 What is your child's gender identity?

- Female (5)
 - Male (6)
 - Transgender Female/ Trans female (15)
 - Transgender Male/ Trans male (16)
 - Genderqueer/ Gender non-conforming (17)
 - Non-binary (20)
 - Different identity (please specify): (18)
-

Prefer not to answer (19)



Q3.25 What sex was your child assigned at birth, meaning on their original birth certificate?

- Male (1)
- Female (0)
- Prefer not to say (-8888)



Q3.26 What is your child's 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 (13)
 - South Asian (4)
 - Pacific Islander (6)
 - White (8)
 - American Indian / Alaska Native / Aboriginal / Indigenous / 1st Nations (9)
 - Mixed (15)
 - Other (please specify): (10)
-
- Don't know (11)
 - Prefer not to answer (12)
-

Q3.27 Has your child been diagnosed with, or did you think your child ever had a COVID-19 infection?

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

Skip To: End of Block If Has your child been diagnosed with, or did you think your child ever had a COVID-19 infection? != Yes

Q3.28 How many times has your child been infected with COVID-19?

▼ 1 (21) ... 5 or more (25)



Q3.29 In the previous school year (July 2021 - June 2022), how many days of school did your child miss because of COVID-19 (either related to acute infection or prolonged symptoms afterwards)?

Q3.30 Has your child been diagnosed with chronic COVID, long COVID, or post-acute sequelae of COVID-19 infection (PASC) by a healthcare provider?

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

Q3.31 Did your child ever develop multisystem inflammatory syndrome in children (MIS-C), also called pediatric inflammatory multisystem syndrome (PIMS)?

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

Display This Question:

If Loop current: Did your child ever develop multisystem inflammatory syndrome in children (MIS-C), also called pe... = Yes

Q3.32 What symptoms of (multisystem inflammatory syndrome) MIS-C did your child experience? Please select all that apply.

- Fever lasting longer than 24 hours (1)
- Diarrhea (2)
- Vomiting (3)
- Stomach pain (4)
- Cough (5)
- Difficulty breathing (6)
- Fatigue (7)
- Skin rash (8)
- Conjunctivitis (red or bloodshot eyes) (9)
- Dizziness or lightheadedness (10)
- Redness or swelling of the lips and tongue (11)
- Redness or swelling of the hands or feet (12)
- Headache (13)
- Confusion (14)

- Heart abnormalities (abnormal EKG, echocardiogram, or elevated troponin or BNP) (16)
- Neurologic abnormalities (Guillain-Barre, weakness, seizures, meningitis) (17)
- Macrophage activation syndrome (MAS) / hemophagocytic lymphohistiocytosis (HLH) (18)
- Other (15) _____
- None of these symptoms** (19)

Display This Question:

If Loop current: Did your child ever develop multisystem inflammatory syndrome in children (MIS-C), also called pe... = Yes

Q3.33 What type of treatment did your child require for their MIS-C? Select all that apply.

- Admission to the hospital (5)
 - Supplemental oxygen (face mask, nasal cannula) (1)
 - Mechanical ventilation (ventilator) (2)
 - Medications to help maintain their blood pressure (epinephrine, dopamine, norepinephrine, etc.) (3)
 - Admission to intensive care unit (ICU) (4)
 - Intravenous immunoglobulin (IVIG) (6)
 - Steroids (prednisone, methylprednisolone, cortisone) (7)
 - Biologics (8)
 - Other (specify) (9)
-
- None of these** (10)

Display This Question:

If Loop current: Did your child ever develop multisystem inflammatory syndrome in children (MIS-C), also called pe... = Yes

Q3.34 What was the outcome of your child's MIS-C?

- They recovered completely (1)
- My child continues to have symptoms related to MIS-C (2)
- My child died (3)

Page Break

Display This Question:

If If How many times has your child been infected with COVID-19? Text Response Is Greater Than or Equal to 1

Q4.1 COVID-19 questions in $\{\text{Im://Field/1}\}\{\text{Im://Field/2}\}$ Child with Rheumatic Disease

For the following questions, please describe the $\{\text{Im://Field/1}\}\{\text{Im://Field/2}\}$ child's **most severe** episode of COVID-19. This means the episode that either had the most severe acute symptoms or the one that caused symptoms to last the longest.

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Q4.2 In which month and year was THIS diagnosis of COVID-19 made? All of the following questions pertain to THIS diagnosis.

▼ December 2019 (1) ... December 2023 (49)

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Q4.3 How was COVID-19 diagnosed?

- I diagnosed my child based on their symptoms (1)
 - My doctor diagnosed my child based only on symptoms (2)
 - My child was diagnosed based on positive test results for COVID-19 (such as a nasal swab test or at-home COVID test) (3)
 - Not sure (4)
 - Other (please specify): (99)
-

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Q4.4 What happened during the course of your child's COVID-19 infection?

- My child was NOT hospitalized and had NO difficulties performing any of their daily activities (bathing, eating, dressing, etc.) (1)
- My child was NOT hospitalized but did have some difficulties performing their daily activities (bathing, eating, dressing, etc.) (2)
- My child was hospitalized but did not require intensive care (ICU) or mechanical ventilation (ventilator) (3)
- My child was hospitalized and required intensive care (ICU) and/or a breathing machine (ventilator) (4)
- My child died (5)

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QQ4.5 Have your child's COVID-19 symptoms resolved at the time of this survey (meaning they no longer have any symptoms related to this infection)?

- Yes (1)
- No (0)
- Don't know (6789)

Display This Question:

If Loop current: Have your child's COVID-19 symptoms resolved at the time of this survey (meaning they no longer h... = Yes



QQ4.6 How many days did your child's symptoms last, from the first day they became ill until symptoms resolved?

Display This Question:

If Loop current: Have your child's COVID-19 symptoms resolved at the time of this survey (meaning they no longer h... = Don't know



QQ4.8 For approximately how many days has your child been ill, counting from the first day they became ill until today?

Display This Question:

If If How many times has your child been infected with COVID-19? Text Response Is Greater Than or Equal to 1

Q4.9 Which of the following symptoms did your child develop during this COVID-19 infection?
Check all that apply.

- Tiredness or fatigue (2)
- Symptoms that get worse after physical or mental activities (post-exertional malaise) (3)
- Fever (14)
- Flare of their rheumatic disease (31)
- Difficulty breathing or shortness of breath (1)
- Cough (5)
- Congested or runny nose (29)
- Sore throat (32)
- Headache (8)
- Joint or muscle pain (10)
- Chest pain (6)
- Stomach pain (7)
- Difficulty thinking or concentrating ("brain fog") (4)
- Insomnia or sleep problems (13)
- Mood changes (including anxiety or depression) (17)

- Loss/change in smell or taste (18)
 - Dizziness or vertigo (22)
 - Blurry vision (28)
 - Diarrhea (12)
 - Fast-beating or pounding heart (palpitations) (9)
 - Dizziness on standing (lightheadedness, POTS) (15)
 - Low blood pressure (30)
 - Pins-and-needles feeling (11)
 - Burning sensations (on skin or internally) (25)
 - Rash (16)
 - Inflammation / swelling / redness that is **not** associated with pre-existing autoimmune/autoinflammatory disease (e.g. red/swollen "COVID toes") (26)
 - Hair loss (27)
 - Changes in menstrual period cycles (19)
 - Other (20) _____
 - None, no symptoms** (24)
-

Display This Question:

If If How many times has your child been infected with COVID-19? Text Response Is Greater Than or Equal to 1

And If

If Which of the following symptoms did your child develop during this COVID-19 infection? Check all... q://QID479/SelectedChoicesCount Is Greater Than 0

And Loop current: Which of the following symptoms did your child develop during this COVID-19 infection? Check all... != None, no symptoms

Carry Forward Selected Choices - Entered Text from "Which of the following symptoms did your child develop during this COVID-19 infection? Check all that apply."



Q4.10 Of the various symptoms that your child developed during this COVID-19 infection, please indicate which symptoms have resolved, and which symptoms are still present today.

	Symptom resolved (1)	Symptom is still present today (2)	Don't know (3)
Tiredness or fatigue (x2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Symptoms that get worse after physical or mental activities (post-exertional malaise) (x3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fever (x14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Flare of their rheumatic disease (x31)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty breathing or shortness of breath (x1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cough (x5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Congested or runny nose (x29)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sore throat (x32)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache (x8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Joint or muscle pain (x10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chest pain (x6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stomach pain (x7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty thinking or concentrating ("brain fog") (x4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insomnia or sleep problems (x13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Mood changes (including anxiety or depression) (x17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss/change in smell or taste (x18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dizziness or vertigo (x22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blurry vision (x28)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diarrhea (x12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fast-beating or pounding heart (palpitations) (x9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dizziness on standing (lightheadedness, POTS) (x15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low blood pressure (x30)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pins-and-needles feeling (x11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Burning sensations (on skin or internally) (x25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rash (x16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inflammation / swelling / redness that is not associated with pre-existing autoimmune/autoinflammatory disease (e.g. red/swollen "COVID toes") (x26)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hair loss (x27)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in menstrual period cycles (x19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (x20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

None, no symptoms
(x24)



Display This Question:

If If How many times has your child been infected with COVID-19? Text Response Is Greater Than or Equal to 1

And Loop current: Of the various symptoms that your child developed during this COVID-19 infection, please indicate... = Symptom resolved

Carry Forward Selected Choices from "Of the various symptoms that your child developed during this COVID-19 infection, please indicate which symptoms have resolved, and which symptoms are still present today. "



Q4.11 How many days did each symptom last, from its beginning until they recovered completely?

	1-27 days (1)	28-89 days (2)	90+ days (3)
Tiredness or fatigue (xx2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Symptoms that get worse after physical or mental activities (post-exertional malaise) (xx3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fever (xx14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Flare of their rheumatic disease (xx31)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty breathing or shortness of breath (xx1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cough (xx5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Congested or runny nose (xx29)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sore throat (xx32)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache (xx8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Joint or muscle pain (xx10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chest pain (xx6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stomach pain (xx7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty thinking or concentrating ("brain fog") (xx4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insomnia or sleep problems (xx13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Mood changes (including anxiety or depression) (xx17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss/change in smell or taste (xx18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dizziness or vertigo (xx22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blurry vision (xx28)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diarrhea (xx12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fast-beating or pounding heart (palpitations) (xx9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dizziness on standing (lightheadedness, POTS) (xx15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low blood pressure (xx30)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pins-and-needles feeling (xx11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Burning sensations (on skin or internally) (xx25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rash (xx16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inflammation / swelling / redness that is not associated with pre-existing autoimmune/autoinflammatory disease (e.g. red/swollen "COVID toes") (xx26)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hair loss (xx27)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in menstrual period cycles (xx19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (xx20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

None, no symptoms
(xx24)



Page Break

Q9.1 This Concludes the Questions for the [\\${Im://Field/1}\\${Im://Field/2}](#) Child with Rheumatic Disease

End of Block: Child Block

Start of Block: Final Questions

Q10.1 Thank you for completing the Global Rheumatology Alliance COVID-19 Pediatric Vaccine Survey!

Please let us know if you have any questions, comments, or concerns about this survey. We would love to hear your feedback!

End of Block: Final Questions

Start of Block: Block 4
