Post-acute COVID Questionnaire

Thank you for participating in our study to better understand long term outcomes in children and families affected by COVID-19. Please answer each question on behalf of your child. Once you 'Submit' a form you cannot return to it.

This section is required	
Progress: 0%	
Study ID	
Child's current age?	○ 1-12 months
	○ 13-24 months○ 2-4 years
	5-7 years
	○ 8-12 years
	○ 13-18 years



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Consent

Please complete the survey below.

Thank you!

Do you consent? 3)

○ Yes○ No(Just testing consent conditional)



Symptoms

This section is required Progress: 15%

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For each of the symptoms listed below, please answer whether your child had any new or continuing symptoms after the hospitalization that included a COVID-19 or MIS-C diagnosis. You can type in other symptoms at the bottom of this section.

	Yes, new symptom that started after hospital discharge	Yes, symptom occurred in the hospital and continued after discharge	No	Unsure
Headache	\bigcirc	\circ	\circ	0
Loss of smell	\circ	\circ	\circ	\circ
Loss of taste	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Vision problems	\circ	\bigcirc	\bigcirc	\bigcirc
Lightheadedness or fainting	\circ	\bigcirc	\bigcirc	\bigcirc
Seizures	\circ	\bigcirc	\bigcirc	\bigcirc
Numbness	\circ	\bigcirc	\bigcirc	\bigcirc
Weakness	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Shooting or burning pain	\circ	\bigcirc	\bigcirc	\bigcirc
Tingling sensations	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Muscle aches or pain	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Dizziness (room is spinning)	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Balance problems	\bigcirc	\bigcirc	\bigcirc	0
Delirium or confusion	\bigcirc	\bigcirc	\bigcirc	\circ
Trouble with remembering	\bigcirc	\bigcirc	\circ	\circ
things Thinking or concentration problem	0	0	\bigcirc	0
Sad or depressed	\bigcirc	\circ	\bigcirc	\bigcirc
Anxious	\bigcirc	\circ	\circ	\circ
Fever	\bigcirc	\bigcirc	\circ	\circ
Cough	\bigcirc	\circ	\circ	\circ
Fatigue or tiredness	\circ	\circ	\circ	\circ
Loss of appetite	\bigcirc	\bigcirc	\circ	\circ
Diarrhea	\circ	\circ	\circ	\circ
Throat Pain	\bigcirc	\circ	\circ	\circ
Abdominal Pain	\bigcirc	\bigcirc	\bigcirc	\bigcirc



Swollen glands	\circ	\circ	\bigcirc	\circ
Vomiting or nausea	\bigcirc	\circ	\bigcirc	\bigcirc
Joint pain	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Sleep problems	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Palpitations (rapid heartbeat, skipping heartbeats)	0	0	\bigcirc	0
Trouble breathing	\bigcirc	\bigcirc	\bigcirc	\circ
Speaking or communicating problem	0	0	0	0
Swallowing or chewing problem	0	0	0	0
Other symptom #1, please describe	2			
New or Continuing symptom #1?		○ New○ Continuir	ng	
Other symptom #2, please describe	2			
New or Continuing symptom #2?		○ New○ Continuir	ng	
Other symptom #3, please describe	2			_
New or Continuing symptom #3?		○ New○ Continuir	ng	

Please check which symptom, if any, has had the most negative impact on your child's health and functioning after hospital discharge	 ☐ Headache ☐ Loss of smell ☐ Loss of taste ☐ Vision problems ☐ Lightheadedness or fainting ☐ Seizures ☐ Numbness ☐ Weakness ☐ Shooting or burning pain ☐ Tingling sensations ☐ Muscle aches or pain ☐ Dizziness (room is spinning) ☐ Balance problems ☐ Delirium or confusion ☐ Trouble with remembering things ☐ Thinking or concentration problems ☐ Sad or depressed ☐ Anxious ☐ Fever ☐ Cough ☐ Fatigue or tiredness ☐ Loss of appetite ☐ Diarrhea ☐ Throat Pain ☐ Abdominal Pain ☐ Swollen glands ☐ Vomiting or nausea ☐ Joint pain ☐ Sleep problems ☐ Palpitations (rapid heartbeat, skipping heartbeats) ☐ Trouble breathing ☐ Speaking or communicating problem ☐ Swallowing or chewing problem ☐ Swallowing or chewing problem ☐ Swallowing or chewing problem ☐ Other symptom #1
	 Speaking or communicating problem

Healthcare Utilization

The questions below relate to the rapies and emergency and hospital readmissions your child experienced since the hospitalization that included COVID-19/MIS-C diagnosis.

This section is required	
Progress: 35%	
Since your child's recent hospitalization that included a COVID-19/MIS-C diagnosis, has your child been evaluated in an emergency department?	○ Yes ○ No
How many total emergency visits did your child have since that hospitalization?	
Approximately how many weeks or months after hospital discharge did the first emergency department visit occur?	○ 0-2 weeks○ 2-4 weeks○ 1-3months○ 3-6months○ >6 months
What was the reason he or she needed to be evaluated in the first emergency department visit after discharge from the hospital?	
What was your child diagnosed with in the emergency department the first time he or she visited?	
What was your child's disposition during this emergency department the first time he or she visited?	○ Home with you○ Hospital intensive care unit○ Hospital ward○ Long term care facility○ Other
Other	
Approximately how many weeks or months after hospital discharge did the most recent emergency department visit occur?	0-2 weeks2-4 weeks1-3months3-6months>6 months
What was the reason he or she needed to be evaluated in the emergency department the most recent time he or she visited?	
What was your child diagnosed with in the emergency department the most recent time he or she visited?	



What was your child's disposition during this emergency department the most recent time he or she visited?	○ Home with you○ Hospital intensive care unit○ Hospital ward○ Long term care facility○ Other
Other	
Since your child's recent hospitalization that included a COVID-19/MIS-C diagnosis, has your child stayed overnight in a hospital?	○ Yes ○ No
How many total hospital re-admissions did your child have?	
Approximately how many weeks or months after hospital discharge did the first hospital readmission occur?	○ 0-2 weeks○ 2-4 weeks○ 1-3months○ 3-6months○ >6 months
What was your child diagnosed with during this hospitalization?	
Was your child ever admitted to an intensive care unit during this visit?	○ Yes ○ No
What was your child's disposition during this hospital admission?	○ Home with you○ Inpatient rehabilitation○ Long term care facility○ Other
Other	
Approximately how many weeks or months after hospital discharge did the most recent hospital readmission occur?	○ 0-2 weeks○ 2-4 weeks○ 1-3months○ 3-6months○ >6 months
What was your child diagnosed with during this hospitalization?	
Was your child ever admitted to an intensive care unit during this visit?	○ Yes ○ No
What was your child's disposition during this hospital admission?	 ○ Home with you ○ Hospital intensive care unit ○ Hospital ward ○ Long term care facility ○ Other

hild was posi	itive for COVID-19 or MIS-C, did
ig health exp	erts and/or clinics:
○ Yes	○ No
	yes Y



Medications

	This section is optional Progress: 40%	
82)	Is your child taking any new medications after discharge from the hospitalization from COVID-19 for any of the following treatment reasons (by category)?	☐ Seizures ☐ Pain ☐ Anxiety ☐ Depression ☐ Drug withdrawal ☐ Heart problems ☐ Lung problems ☐ Antibiotics ☐ Steroids ☐ Other psychiatric medications (e.g., mood stabilizers, antipsychotics) ☐ Postural orthostatic tachycardia syndrome (POTS)
83)	Other medications	



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Participation

Progress: 45%	
Do you feel your child has fully recovered from his or her COVID-19 or MIS-C related illness?	YesNoUnsure
Has your child returned to school since being discharged from the hospital in which he or she had COVID-19 or MIS-C related illness?	 Yes in person Yes from home Yes mixed Not in school prior to COVID No Not enrolled in school
If yes (returned to school), is your child receiving any special education services or accommodations? This means any added services that help your child learn and are provided by the school.	○ Yes ○ No
Was your child receiving special educational services or resources (for example a 504 plan or Individualized Education Plan) when attending school prior to developing COVID-19 or MIS-C?	○ Yes ○ No
Does your child have any new problems since the hospital admission that are not being treated or managed?	○ Yes ○ No
If yes, please describe the problem(s) and the reason(s) your child's new problem is not being addressed.	
Please tell us about any other ways your child's hospitalization for COVID-19 or MISC-C has impacted your life.	

Functional Status Scale measure

Please answer the questions below about your child's function in 6 domains.

This section is required Progress: 55%	
Please choose the answer that best describes your child's mental status or alertness at baseline.	 Normal sleep/wake periods; appropriate responsiveness. Sleepy but arousable to noise/touch/movement and/or periods of social nonresponsiveness. Lethargic and/or irritable. Minimal arousal to stimuli (stupor). Unresponsive, coma, and/or vegetative state.
Please choose the answer that best describes your child's sensory functioning status (e.g., hearing, vision, response to touch).	 Intact hearing and vision and responsive to touch. Suspected hearing or vision loss. Not reactive to auditory stimuli 'or' to visual stimuli. Not reactive to auditory stimuli 'and' to visual stimuli Abnormal responses to pain or touch.
Please choose the answer that best describes your child's communication status.	 Appropriate noncrying vocalization, interactive facial expressiveness, or gestures. Diminished vocalization, facial expression, and/or social responsiveness. Absence of attention getting behavior. No demonstration of discomfort. Absence of communication.
Please choose the answer that best describes your child's physical functioning status.	 Coordinated body movements, normal muscle control and awareness of action and reason. One limb functionally impaired. Two limbs functionally impaired. Poor head control. Diffuse spasticity, paralysis, or decerebrate/decorticate posturing.
Please choose the answer that best describes your child's feeding status.	 All food taken by mouth with age-appropriate help. Nothing by mouth or need for age-appropriate help with feeding. Oral and tube feedings. Parenteral nutrition with oral or tube feedings. All parenteral nutrition.
Please choose the answer that best describes your child's respiratory (breathing) status.	 Room air and no artificial support or aids. Oxygen/treatment and/or suctioning. Tracheostomy. Continuous positive airway pressure treatment for all or part of the day and/ or mechanical ventilator support for part of the day. Mechanical ventilator support for all of the day and night.
Functional Status Scale (FSS) Total	



Pediatric Quality of Life Inventory™ (PedsQL™) Parent Report 1-12 Months

_						
	This section is required Progress: 70%					
Ī	DIRECTIONS					
	On the following page is a Please tell us how much of month by choosing:	_		-		he past ONE
	0 if it is never a problem 1 if it is almost never a pro 2 if it is sometimes a probl					
	3 if it is often a problem 4 if it is almost always a pr					
	There are no right or wron	g answers.				
	In the past ONE month, how muc	h of a problem	has your child had v	vith		
	PHYSICAL FUNCTIONING (p		=			
`	1	Never0	Almost Never1	Sometimes2	Often3	Almost Always
)	 Low energy level Difficulty participating in active play 	0	0	0	0	0
0)	3. Having hurts or aches	\circ	\circ	\circ	\circ	\circ
	4. Feeling tired	\circ	\circ	\circ	\circ	\circ

₹EDCap°

102) 5. Being lethargic103) 6. Resting a lot

104) Scaled Score

PHYSICAL SYMPTOMS (proble	ems with)			
-	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
105) 1. Having gas	\circ	\circ	\circ	0	\circ
106) 2. Spitting up after eating	\circ	\circ	\circ	\circ	\circ
107) 3. Difficulty breathing	\bigcirc	\circ	\circ	\circ	\circ
108) 4. Being sick to his/her stomach	\bigcirc	\circ	\circ	\circ	\circ
109) 5. Difficulty swallowing	\bigcirc	\circ	\circ	\circ	\circ
110) 6. Being constipated	\bigcirc	\circ	\circ	\circ	\circ
111) 7. Having a rash	\bigcirc	\circ	\bigcirc	\circ	\bigcirc
112) 8. Having diarrhea	\bigcirc	\bigcirc	\circ	\circ	\bigcirc
113) 9. Wheezing	\bigcirc	\bigcirc	\bigcirc	\circ	\circ
114) 10. Vomiting	\circ	\circ	0	0	0
115) Scaled Score		_			-
EMOTIONAL FUNCTIONING (p					
116) 1 Fooling afraid or scared	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
116) 1. Feeling afraid or scared		0	0	0	0
117) 2. Feeling angry	\circ			0	0
118) 3. Crying or fussing when left alone	O	O	O	O	0
119) 4. Difficulty soothing himself/herself when upset	0	0	0	0	0
120) 5. Difficulty falling asleep	\bigcirc	\bigcirc	\circ	\bigcirc	\bigcirc
121) 6. Crying or fussing while being cuddled	0	\circ	0	0	0
122) 7. Feeling sad	\circ	\circ	\circ	\circ	\bigcirc
123) 8. Difficulty being soothed when picked up or held	0	0	0	0	0
124) 9. Difficulty sleeping mostly through the night	0	0	0	0	0
125) 10. Crying a lot	\circ	\circ	\circ	\circ	0
126) 11. Feeling cranky	\bigcirc	\circ	\circ	\bigcirc	\circ
127) 12. Difficulty taking naps during the day	0	0	0	0	0
128) Scaled Score					

Social Functioning (problems	with)				
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
129) 1. Not smiling at others	\circ	\circ	\circ	\circ	\circ
130) 2. Not laughing when tickled	\bigcirc	\circ	\circ	\circ	\circ
131) 3. Not making eye contact with a caregiver	0	0	0	0	0
132) 4. Not laughing when cuddled	0	0	0	\circ	0
133) Scaled Score		_			
COGNITIVE FUNCTIONING (pr					
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
134) 1. Not imitating caregivers' actions	0	0	O	0	0
135) 2. Not imitating caregivers' facial expressions	0	0	0	0	0
136) 3. Not imitating caregivers' sounds	0	0	0	0	0
137) 4. Not able to fix his/her attention on objects	0	0	0	0	0
138) Scaled Score		_			
139) Physical Health					
140) Psychosocial		_			
141) Total Scale					

Pediatric Quality of Life Inventory™ (PedsQL™) Parent Report 13-24 Months

This section is required Progress: 70%					
DIRECTIONS					
On the following page is a Please tell us how much of month by choosing: 0 if it is never a problem 1 if it is almost never a pro 2 if it is sometimes a probl 3 if it is often a problem 4 if it is almost always a problem	a problem e oblem em		•		he past ONE
There are no right or wron	n answers.				
In the past ONE month, how muc	h of a problem		with		
PHYSICAL FUNCTIONING (p	Never0	h) Almost Never1	Sometimes2	Often3	Almost Always4
2) 1. Low energy level	Nevero	Aimost Never1	O	Oiteiis	Almost Always4
B) 2. Difficulty participating in active play	0	0	0	0	0
1) 3. Having hurts or aches	\circ	\circ	\circ	\circ	\bigcirc
5) 4. Feeling tired			\circ		
5) 5. Being lethargic	\bigcirc	\bigcirc	0	\bigcirc	\bigcirc

PRISICAL STMPTOMS (proble	ems with				PHYSICAL SYMPTOMS (problems with)							
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4							
152) 1. Having gas	\circ	\circ	\circ	\circ	\circ							
153) 2. Spitting up after eating	\circ	\circ	\circ	\circ	\circ							
154) 3. Difficulty breathing	\bigcirc	\circ	\circ	\circ	\bigcirc							
155) 4. Being sick to his/her stomach	\bigcirc	\circ	\circ	\circ	\circ							
156) 5. Difficulty swallowing	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc							
157) 6. Being constipated	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc							
158) 7. Having a rash	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\circ							
159) 8. Having diarrhea	\bigcirc	\circ	\circ	\bigcirc	\circ							
160) 9. Wheezing	\bigcirc	\circ	\circ	\circ	\bigcirc							
161) 10. Vomiting	\circ	\circ	0	\circ	0							
162) Scaled Score		_			-							
EMOTIONAL FUNCTIONING (p												
163) 1. Feeling afraid or scared	Never0	Almost Never1	Sometimes2	Often3	Almost Always4							
	\circ	0	0	0	0							
164) 2. Feeling angry	\circ		0	0								
165) 3. Crying or fussing when left alone				O								
166) 4. Difficulty soothing himself/herself when upset	\circ	0	0	0	0							
167) 5. Difficulty falling asleep	\circ	0	\cap	\cap	\cap							
		_	\circ	\circ	\cup							
168) 6. Crying or fussing while being cuddled	0	0	0	0	0							
cuddled	0	0	0	0	0							
cuddled 169) 7. Feeling sad	0	0	0	0	0							
cuddled 169) 7. Feeling sad 170) 8. Difficulty being soothed when picked up or held	0 0 0	0 0	0 0	0 0	0 0 0							
cuddled 169) 7. Feeling sad 170) 8. Difficulty being soothed when picked up or held 171) 9. Difficulty sleeping mostly through the night	0 0 0	0 0 0	0 0 0									
169) 7. Feeling sad170) 8. Difficulty being soothed when picked up or held171) 9. Difficulty sleeping mostly	0 0 0 0 0	0 0 0										

SOCIAL FUNCTIONING (proble	ems with)			
-	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
176) 1. Not smiling at others	\circ	\circ	\circ	\circ	\circ
177) 2. Not laughing when tickled	\bigcirc	\circ	\circ	\bigcirc	\circ
178) 3. Not making eye contact with a caregiver	0	\circ	0	0	0
179) 4. Not laughing when cuddled	\circ	\circ	\circ	\bigcirc	\circ
180) 5. Being uncomfortable around other children	0	0	0	0	0
181) Scaled Score		_			
COGNITIVE FUNCTIONING (pr					
182) 1. Not imitating caregivers' actions	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
183) 2. Not imitating caregivers' facial expressions	0	0	0	0	0
184) 3. Not imitating caregivers' sounds	0	0	0	0	0
185) 4. Not able to fix his/her attention on objects	0	0	0	0	0
186) 5. Not imitating caregivers' speech	\circ	0	0	0	0
187) 6. Difficulty pointing to his/her body parts when asked	0	0	0	0	0
188) 7. Difficulty naming familiar objects	0	0	0	0	0
189) 8. Difficulty repeating words	\circ	\circ	\circ	\bigcirc	\circ
190) 9. Difficulty keeping his/her attention on things	0	0	0	0	0
191) Scaled Score		_			
192) Physical Health		_			
193) Psychosocial		_			
194) Total Scale					

Pediatric Quality of Life Inventory™ (PedsQL™) Parent Report 2-4 years

On this page, there is a list of	of things th	at might be a p	roblem for you	r child. Ple	ase tell us hov
much of a problem each one	has been f	or your child du	ring the past (ONE month	by checking:
0 if it is never a problem					
1 if it is almost never a prob	lem				
2 if it is sometimes a proble	m				
3 if it is often a problem					
4 if it is almost always a pro	blem				
There are no right or wrong	answers.				
There are no right or wrong If you do not understand a q		ease ask for hel	p		
	uestion, pl		-		
If you do not understand a q	uestion, pl		-		
If you do not understand a q	juestion, pl oof a problem h		-		
If you do not understand a quality in the past one month, how much of the past one month of the past of the past of the past of the past one month of the past of	problem here with) Never0	as your child had w	Sometimes2	Often3	Almost Always
If you do not understand a quantum in the past one month, how much of the past one month of the past of the past of the past of the past one month of the past of	problem h	as your child had w	rith	Often3	Almost Always
If you do not understand a quality on the past one month, how much on the past one month of the past of the past one month of the past	problem here with) Never0	as your child had w	Sometimes2	_	
If you do not understand a quantum In the past one month, how much of the Physical Functioning (problems) 1. Walking	problem h	Almost Never1	Sometimes2	0	0
If you do not understand a quantum In the past one month, how much of the Physical Functioning (problem 195) 1. Walking 196) 2. Running 197) 3. Participating in active play or	pf a problem h	Almost Never1	Sometimes2	0	0
If you do not understand a quantum line the past one month, how much of the past one month of the past of the past of the past one month of the past one month of the past of the past of the past of th	pf a problem h	Almost Never1	Sometimes2	0	0
If you do not understand a quantum In the past one month, how much of the Physical Functioning (problems). Physical Functioning (problems). 1. Walking 2. Running 3. Participating in active play or exercise 3. 4. Lifting something heavy 9. 5. Bathing	problem h	Almost Never1	Sometimes2	0	0
If you do not understand a quantum line the past one month, how much of the past one month of the past of the past one month of the past	problem h	Almost Never1	Sometimes2	0	0

Emotional Functioning (prob	lems with?)					
	Never0	Almost Never		es2	Often3	Almost Always4
204) 1. Feeling afraid or scared	\circ	\circ	\circ		\circ	\circ
205) 2. Feeling sad or blue	\bigcirc	\circ	\circ		\circ	\circ
206) 3. Feeling angry	\bigcirc	\circ	\circ		\bigcirc	\circ
207) 4. Trouble sleeping	\bigcirc	\circ	\bigcirc		\bigcirc	\bigcirc
208) 5. Worrying	0	0	0		0	\circ
209) Scaled Score						
Social Functioning (problem						
210) 1 Planting with athen shilders	Never0	Almost Never		es2	Often3	Almost Always4
210) 1. Playing with other children	0	0	0		0	0
211) 2. Other kids not wanting to play with him or her	O	O	O		O	O
212) 3. Getting teased by other children	0	\circ	0		0	0
213) 4. Not able to do things that other children his or her age can do	0	0	0		0	0
214) 5. Keeping up when playing with other children	0	0	0		0	0
215) Scaled Score						
School Functioning (problem	ns with)					
	Never0	Almost ! Never1	Sometimes2	Often3	Almost Always4	
216) 1. Doing the same school activities as peers	0	0	0	0	0	0
217) 2. Missing school/daycare because of not feeling well	0	0	0	0	0	0
218) 3. Missing school/daycare to go to the doctor or hospital	0	0	0	0	0	0
219) Scaled Score						

Cognitive Fatigue					
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
220) Difficulty keeping his/her attention on things	0	0	0	0	0
221) Difficulty remembering what people tell him/her	0	0	0	0	0
222) Difficulty remembering what he/she just heard	0	0	0	0	0
223) Difficulty thinking quickly	\circ	\circ	\circ	\circ	\circ
224) Trouble remembering what he/she was just thinking	0	\circ	0	0	0
225) Trouble remembering more than one thing at a time	0	0	0	0	0
226) Scaled Score		_			
227) Psychosocial					
228) Total Scale					

Pediatric Quality of Life Inventory™ (PedsQL™) Parent Report 5-7 years

This section is required Progress: 70%	

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by choosing:

0 if it is never a problem

- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past one month, how much of a problem has your child had with...

Physical Functioning (problems with)							
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4		
229) 1. Walking more than one block	\circ	\circ	\circ	\bigcirc	\bigcirc		
230) 2. Running	\bigcirc	\bigcirc	\circ	\circ	\circ		
231) 3. Participating in sports activity or exercise	0	0	\circ	0	\circ		
232) 4. Lifting something heavy	\circ	\circ	\bigcirc	\bigcirc	\bigcirc		
233) 5. Taking a bath or shower by him or herself	0	0	0	0	0		
234) 6. Doing chores, like picking up his or her toys	0	0	0	0	0		
235) 7. Having hurts or aches	\bigcirc	\circ	\circ	\bigcirc	\circ		
236) 8. Low energy level	\circ	0	0	0	0		
237) Scaled Score		_					

Emotional Functioning (prob	lems with)				
	Never0	Almost Nev		nes2	Often3	Almost Always4
238) 1. Feeling afraid or scared	0	\circ	\circ		\circ	\circ
239) 2. Feeling sad or blue	\circ	\circ	\circ		\circ	\circ
240) 3. Feeling angry	\bigcirc	\circ	\circ		\circ	\circ
241) 4. Trouble sleeping	\circ	\circ	\circ		\circ	\circ
242) 5. Worrying about what will happen to him or her	0	0	0		0	0
243) Scaled Score						
Social Functioning (problem						
240.1.6.11	Never0	Almost Nev		nes2	Often3	Almost Always4
244) 1. Getting along with other children	0	0	0		0	O
245) 2. Other kids not wanting to be his or her friend	0	0	0		0	0
246) 3. Getting teased by other children	0	0	0		\circ	0
247) 4. Not able to do things that other children his or her age can do	0	0	0		0	0
248) 5. Keeping up when playing with other children	0	0	0		0	0
249) Scaled Score						
School Functioning (problem	ns with)					
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4	
250) 1. Paying attention in class	\circ	\circ	\circ	\circ	0	0
251) 2. Forgetting things	\circ	\circ	\circ	\circ	\circ	\circ
252) 3. Keeping up with school activities	0	0	0	0	0	0
253) 4. Missing school because of not feeling well	0	0	0	0	0	0
254) 5. Missing school to go to the doctor or hospital	0	0	0	0	0	0
255) Scaled Score						

Cognitive Fatigue (Problems with)								
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4			
256) Difficulty keeping his/her attention on things	0	0	0	0	0			
257) Difficulty remembering what people tell him/her	0	0	0	0	0			
258) Difficulty remembering what he/she just heard	0	0	0	0	0			
259) Difficulty thinking quickly	\circ	\circ	\circ	\bigcirc	\circ			
260) Trouble remembering what he/she was just thinking	0	0	0	0	0			
261) Trouble remembering more than one thing at a time	0	0	0	0	0			
262) Scaled Score		_						
263) Psychosocial								
264) Total Scale								



Pediatric Quality of Life Inventory™ (PedsQL™) Parent Report 8-12 years

This section is required Progress: 70%	

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by choosing:

0 if it is never a problem

- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past ONE month, how much of a problem has your child had with ...

PHYSICAL FUNCTIONING (pro	blems with	1)			
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
265) 1. Walking more than one block	\bigcirc	\circ	\circ	\circ	\circ
266) 2. Running	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
267) 3. Participating in sports activity or exercise	0	\circ	0	0	\circ
268) 4. Lifting something heavy	\bigcirc	\circ	\circ	\bigcirc	\circ
269) 5. Taking a bath or shower by him or herself	0	\circ	0	0	0
270) 6. Doing chores around the	\circ	\circ	\circ	\circ	\circ
271) house 271) 7. Having hurts or aches	\bigcirc	\circ	\circ	\bigcirc	\circ
272) 8. Low energy level	\circ	0	0	0	0
273) Scaled Score					

EMOTIONAL FUNCTIONING (p	roblems w	ith)			
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
274) 1. Feeling afraid or scared	0	\circ	\circ	\circ	\circ
275) 2. Feeling sad or blue	\circ	\circ	\circ	\circ	\circ
276) 3. Feeling angry	\circ	\bigcirc	\bigcirc	\bigcirc	\bigcirc
277) 4. Trouble sleeping	\bigcirc	\bigcirc	\bigcirc	\circ	\circ
278) 5. Worrying about what will happen to him or her	0	0	0	0	0
279) Scaled Score		_			-
SOCIAL FUNCTIONING (probl) Almost Never1	Comptings	Often	Almost Always 4
280) 1. Getting along with other children	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
281) 2. Other kids not wanting to be his or her friend	0	0	0	0	0
282) 3. Getting teased by other children	\circ	0	0	0	0
283) 4. Not able to do things that other children his or her age can do	0	0	0	0	0
284) 5. Keeping up when playing with other children	0	0	0	0	0
285) Scaled Score		_			
SCHOOL FUNCTIONING (prob			Comptions 2	Officer	Almost Alusass 4
286) 1. Paying attention in class	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
287) 2. Forgetting things	\bigcirc	\bigcirc	0	\bigcirc	0
288) 3. Keeping up with schoolwork	\bigcirc	\bigcirc	\bigcirc	\bigcirc	0
, - ,	\bigcirc		\bigcirc	\bigcirc	0
289) 4. Missing school because of not feeling well		\bigcup			
290) 5. Missing school to go to the doctor or hospital	0	0	0	0	0
291) Scaled Score					

Cognitive Fatigue (problems	with)				
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
292) Difficulty keeping his/her attention on things	0	0	0	0	0
293) Difficulty remembering what people tell him/her	0	0	0	0	0
294) Difficulty remembering what he/she just heard	0	0	0	0	0
295) Difficulty thinking quickly	\circ	\circ	\circ	\circ	\circ
296) Trouble remembering what he/she was just thinking	0	0	0	0	0
297) Trouble remembering more than one thing at a time	0	0	0	0	0
298) Scaled Score		_			
299) Psychosocial		_			
300) Total Scale					

Pediatric Quality of Life Inventory™ (PedsQL™) Parent Report 13-18 years

This section is required Progress: 70%	

DIRECTIONS

On this page, there is a list of things that might be a problem for your teen. Please tell us how much of a problem each one has been for your teen during the past ONE month by checking:

0 if it is never a problem

1 if it is almost never a problem

2 if it is sometimes a problem

3 if it is often a problem

4 if it is almost always a problem

There are no right or wrong answers.

In the past one month, how much of a problem has your teen had with...

Physical Functioning (proble	ms with)				
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
301) 1. Walking more than one block	\circ	\circ	\circ	\circ	\circ
302) 2. Running	\bigcirc	\bigcirc	\bigcirc	\circ	\bigcirc
303) 3. Participating in sports activity or exercise	0	0	0	0	0
304) 4. Lifting something heavy	\circ	\circ	\circ	\bigcirc	\circ
305) 5. Taking a bath or shower by him or herself	0	0	0	0	0
306) 6. Doing chores around the	\bigcirc	\circ	\circ	\circ	\circ
307) 7. Having hurts or aches	\bigcirc	\circ	\circ	\bigcirc	\circ
308) 8. Low energy level	\circ	0	0	\circ	0
309) Scaled Score					

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Emotional Functioning (prob	lems with)				
-	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
310) 1. Feeling afraid or scared	\circ	\circ	\circ	\circ	\bigcirc
311) 2. Feeling sad or blue	\bigcirc	\circ	\bigcirc	\bigcirc	\circ
312) 3. Feeling angry	\bigcirc	\bigcirc	\bigcirc	\circ	\bigcirc
313) 4. Trouble sleeping	\bigcirc	\circ	\bigcirc	\circ	\bigcirc
314) 5. Worrying about what will happen to him or her	0	0	0	0	0
315) Scaled Score		_			-
Social Functioning (problems	with)				
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
316) 1. Getting along with other teens	0	0	O	0	O
317) 2. Other teens do not want to be his or her friend	O	O	O	O	O
318) 3. Getting teased by other teens	\bigcirc	\bigcirc	\circ	\circ	\circ
319) 4. Not able to do things that other teens his or her age can do	0	0	0	0	0
320) 5. Keeping up with other teens	0	0	0	0	0
321) Scaled Score					-
School Functioning (problem	s with)				
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
322) 1. Paying attention in class	\circ	0	\circ	0	0
323) 2. Forgetting things	\circ	\circ	\circ	\bigcirc	0
324) 3. Keeping up with schoolwork	\bigcirc	\circ	\circ	\circ	\circ
325) 4. Missing school because of not feeling well	0	0	0	0	0
326) 5. Missing school to go to the doctor or hospital	0	0	0	0	0

327) Scaled Score

Cognitive Fatigue (Problems	with)				
	Never0	Almost Never1	Sometimes2	Often3	Almost Always4
328) Difficulty keeping his/her attention on things	0	0	0	0	0
329) Difficulty remembering what people tell him/her	0	0	0	0	0
330) Difficulty remembering what he/she just heard	0	0	0	0	0
331) Difficulty thinking quickly	\bigcirc	\circ	\circ	\circ	\bigcirc
332) Trouble remembering what he/she was just thinking	0	0	0	0	0
333) Trouble remembering more than one thing at a time	0	0	0	0	0
334) Scaled Score		_			
335) Psychosocial					
336) Total Scale					

PROMIS Global Health 7 + 2 Survey, Parent/Proxy

	Please complete the survey below.					
	Thank you!					
-	This section is required Progress: 75%					
Ī	Please respond to each ques	stion or stat	ement by mark	ing one box pe	er row.	
		Excellent	Very Good	Good	Fair	Poor
337)	In general, would you say your child's health is:	0	0	0	0	0
338)	In general, would you say your child's quality of life is:	0	0	0	0	0
339)	In general, how would you rate your child's physical health?	0	0	0	0	0
	In general, how would you rate your child's mental health, including mood and ability to think?	0	0	0	0	0
-		Never	Rarely	Sometimes	Often	Always
341)	In general, would you say your child's health is:	0	O	0	0	Õ
=		Always	Often	Sometimes	Rarely	Never
	How often does your child have fun with friends?	0	0	0	0	0
343)	How often does your child feel that you listen to his or her ideas?	0	0	0	0	0
	In the past 7 days					
		Never	Almost Never	Sometimes	Often	Almost Always
-	My child got tired easily	O	0	O	0	O
345)	My child had trouble sleeping when he/she had pain	0	O	0	O	0
346)	Total (global 7 questions)		_			
347)	PROMIS Total:		_			



Promis Young Child

This section is required Progress: 75%

.

Please respond to each que	stion or state	ement by marki	ing one box p	er row.		
	Excellent	Very Good	Good	Fair	Poor	
348) In general, would you say your child's health is:	0	0	0	0	0	
349) In general, would you say your child's quality of life is:	0	0	0	\circ	0	
350) In general, how would you rate your child's physical health?	0	0	0	0	0	
351) In general, how would you rate your child's mental health?	0	0	0	0	0	
352) How would you rate your child's mood?	0	0	0	0	0	
353) How would you rate your child's social skills?	0	0	0	0	0	
354) How would you rate your child's ability to think?	0	0	0	0	0	
355) How well is your child meeting developmental milestones?	\circ	\circ	0	\circ	0	



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Pediatric Cerebral Performance Category (PCPC) Scale

This section is optional Progress: 78%

Please choose the category that best fits your child's functional status today.

- At age-appropriate level; if school-age child attending regular school classroom
- Conscious, alert, and able to interact at age-appropriate level; if school-age child attending regular school classroom, but grade perhaps not appropriate for age
- Conscious; sufficient cerebral function for age-appropriate independent activities of daily life; if schoolage child attending special education classroom and/or learning deficit present
- Oconscious; dependent on others for daily support because of impaired brain function
- O Any degree of coma, no interaction with environment



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PedsQL™ Family Impact Module Version 2.0 survey

This section is required Progress: 90%					
Families of children sometimes hav things that might be a problem for past ONE month.					
Physical					
253 5 111 11 11 11	Never	Almost Never	Sometimes	Often	Almost Always
357) Feel tired during the day	0	0	0	0	0
358) Feel tired when I wake up in the morning	O	O	O	O	O
359) Feel too tired to do the things I like to do	0	0	0	0	0
360) Get headaches	\bigcirc	\circ	\circ	\circ	\circ
361) Feel physically weak	\bigcirc	\circ	\circ	\circ	\circ
362) Feel sick to my stomach	\circ	0	0	\circ	0
363) Physical Score					
		_			
Emotional					
364) Feel anxious	Never	Almost Never	Sometimes	Often	Almost Always
365) Feel sad	0		0	0	0
366) Feel angry	\bigcirc		0	0	0
367) Feel frustrated	0				0
368) Feel helpless or hopeless	\bigcirc			\circ	
300/1 eer Helpiess of Hopeless	O	0	0	O	0
369) Emotional Score					
					•
Social					
370) Feel isolated from others	Never	Almost Never	Sometimes	Often	Almost Always
371) Have trouble getting support from others	0	0	0	0	0
372) Hard to find time for social activities	0	0	0	0	0
373)					

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[s	Do not have enough energy for social activities	0	0	0	0	0
374) S	Social Score		_			-
(Cognitive					,
	t is hard for me to keep my attention on things	Never	Almost Never	Sometimes	Often	Almost Always
	t is hard for me to remember what people tell me	0	0	0	0	0
	t is hard for me to remember what I just heard	0	0	0	0	0
378) I	t is hard for me to think quickly	\bigcirc	\bigcirc	\bigcirc	\circ	\bigcirc
	have trouble remembering what I was just thinking	0	0	0	0	0
_	Cognitive Score		_			-
(Communication					
		Maria	Alasa al Massa	C L'	00-	Alasa a at Alasa a
_ 381)	feel that others do not understand my family's situation	Never	Almost Never	Sometimes	Often	Almost Always
381) I u 382) I				_		_
381) I 382) Ii 383) Ii	understand my family's situation t is hard for me to talk about my	0		_		
381) II to 382) III co	understand my family's situation t is hard for me to talk about my child's health with others t is hard for me to tell doctors	0		_		
381) II C 382) III C 383) III a 384) C	understand my family's situation t is hard for me to talk about my child's health with others t is hard for me to tell doctors and nurses how I feel	0 0	0	0	0	
381) II C 382) III C 383) III C 384) C 385) II	understand my family's situation t is hard for me to talk about my child's health with others t is hard for me to tell doctors and nurses how I feel Communication Score	0		_		
381) I C C S 383) II C C S 384) C S 385) I C C S S 386) I C C S S S S S S S S S S S S S S S S S	understand my family's situation t is hard for me to talk about my child's health with others t is hard for me to tell doctors and nurses how I feel Communication Score Worry worry about whether or not my child's medical treatments are	Never	Almost Never	Sometimes	Often	Almost Always
381) I C C S 383) II C C S 384) C C S 385) I C C S S 386) I C C S S 387) I C C S S S S S S S S S S S S S S S S S	t is hard for me to talk about my child's health with others t is hard for me to tell doctors and nurses how I feel Communication Score Worry worry about whether or not my child's medical treatments are working worry about the side effects of my child's medications/medical	Never	Almost Never	Sometimes	Often	Almost Always

	I worry about how my child's illness is affecting other family members	0	0	0	0	0
389)	I worry about my child's future	0	0	\circ	0	0
390)	Worry Score		_			
	Daily Activities					
		Never	Almost Never	Sometimes	Often	Almost Always
391)	Family activities taking more time and effort	0	O	0	O	O
392)	Difficulty finding time to finish household tasks	0	0	0	0	0
393)	Feeling too tired to finish household tasks	0	0	0	0	0
394)	Daily Activities Score					
,	Facilia Dalatiana kina					
	Family Relationships					
	Family Relationships	Never	Almost Never	Sometimes	Often	Almost Always
395)	Lack of communication between family members	Never	Almost Never	Sometimes	Often	Almost Always
	Lack of communication between	_		_	_	_
396)	Lack of communication between family members Conflicts between family	_		0	_	0
396) 397)	Lack of communication between family members Conflicts between family members Difficulty making decisions	_		0	_	0
396) 397) 398)	Lack of communication between family members Conflicts between family members Difficulty making decisions together as a family Difficulty solving family	_		0	_	0
396) 397) 398) 399)	Lack of communication between family members Conflicts between family members Difficulty making decisions together as a family Difficulty solving family problems together Stress or tension between family	_		0	_	0
396) 397) 398) 399) 400)	Lack of communication between family members Conflicts between family members Difficulty making decisions together as a family Difficulty solving family problems together Stress or tension between family members	_		0	_	0
396) 397) 398) 399) 400)	Lack of communication between family members Conflicts between family members Difficulty making decisions together as a family Difficulty solving family problems together Stress or tension between family members Family Relationships Score	0 0 0		0	_	0



Coronavirus Impact Scale

This section is optional Progress: 95%	
Rate how much the Coronavirus pandemic has changed your life in each of the following ways: Routines	 No change. Mild. Change in only one area (e.g. work, education, social life, hobbies, religious activities). Moderate. Change in two areas (e.g. work, education, social life, hobbies, religious activities). Severe. Change in three or more areas (e.g. work, education, social life, hobbies, religious activities).
Family Income/employment	 No change. Mild. Small change; able to meet all needs and pay bills. Moderate. Having to make cuts but able to meet basic needs and pay bills. Severe. Unable to meet basic needs and/or pay bills.
Food access	 No change. Mild. Enough food but difficulty getting to stores and/or finding needed items. Moderate. Occasionally without enough food and/or good quality (e.g., healthy) foods. Severe. Frequently without enough food and/or good quality (e.g., healthy) foods.
Medical health care access	 No change. Mild. Appointments moved to telehealth. Moderate. Delays or cancellations in appointments and/or delays in getting prescriptions; changes have minimal impact on health. Severe. Unable to access needed care resulting in moderate to severe impact on health.
Mental health care access	 No change. Mild. Appointments moved to telehealth. Moderate. Delays or cancellations in appointments and/or delays in getting prescriptions; changes have minimal impact Severe. Unable to access needed care resulting in severe risk and/or significant impact
Access to extended family and on-family social supports	 No change. Mild. Continued visits with social distancing and/or regular phone calls and/or televideo or social media contacts. Moderate. Loss of in person and remote contact with a few people, but not all supports. Severe. Loss of in person and remote contact with all supports.



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Experiences of stress related to coronavirus pandemic	 None. Mild. Occasional worries and/or minor stress-related symptoms (e.g., feel a little anxious, sad, and/or angry; mild/rare trouble sleeping). Moderate. Frequent worries and/or moderate stress-related symptoms (e.g., feel moderately anxious, sad, and/or angry; moderate/occasional trouble sleeping). Severe. Persistent worries and/or severe stress-related symptoms (e.g., feel extremely anxious, sad, and/or angry; severe/frequent trouble sleeping).
Stress and discord in the family	 None. Mild. Family members occasionally short-tempered with one another; no physical violence. Moderate. Family members frequently short-tempered with one another; and/or children in the home getting in physical fights with one another. Severe. Family members frequently short-tempered with one another and adults in the home throwing things at one another, and/or knocking over furniture, and/or hitting and/or harming one another.
Personal diagnosis of coronavirus	 None. Mild. Symptoms effectively managed at home. Moderate. Symptoms severe and required brief hospitalization. Severe. Symptoms severe and required ventilation.
Number of immediate family members diagnosed with coronavirus:	
Rate the symptoms of the person who was most sick:	 Mild. Symptoms effectively managed at home. Moderate. Symptoms severe and required brief hospitalization. Severe. Symptoms severe and required ventilation. Immediate family member died from coronavirus
Number of extended family member(s) and/or close friends diagnosed with coronavirus:	
Rate the symptoms of the person who was most sick:	 Mild. Symptoms effectively managed at home. Moderate. Symptoms severe and required brief hospitalization. Severe. Symptoms severe and required ventilation. Extended family member and/or close friend died of coronavirus.
Please tell us about any other ways the coronavirus pandemic has impacted your life:	



Vaccination

Progress: 95%	
•	
Was your child vaccinated against COVID-19?	○ Yes ○ No
Do you plan to have your child vaccinated against COVID-19?	○ Yes○ No○ Unsure
Did your child participate in a randomized trial to test COVID-19 vaccines?	○ Yes ○ No
If yes, and you are aware, did your child receive the vaccine or placebo (sugar)?	○ Vaccine○ Placebo○ Unsure

THANK YOU

Thank you very much for completing the study. Please see the list below of resources for families with children affected by COVID and MIS-C.

- 1. Center for Disease Control (US-based)
 Children, Teens, and Young Adults: Sections on school, coping and support, health and well-being in the pandemic. https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/caring-for-children.html
- 2. Local, national, and international post-COVID clinics. Your primary care provider, local or regional hospital, or Children's hospital may have resources for children affected by COVID/MIS-C.

One example is the Kennedy Krieger Institute has a Pediatric Post COVID-19 Rehabilitation Clinic: https://www.kennedykrieger.org/patient-care/centers-and-programs/pediatric-post-covid-19-rehabilitation-clinic



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