Caregiver Proxy Health Status Form

This health status form should be completed with caregivers who have a child under the age of 18, enrolled in a PHACS study, or to caregivers who provide assistance to a PHACS study participant. The form is designed to check-in on the participant's general health and well-being and to specifically inquire about significant respiratory illnesses that they have experienced since January 1, 2020 that may be COVID-19-related.

If a caregiver has more than one child enrolled in a PHACS study, under the age of 18, a separate form should be completed for each child enrolled.

Please enter the participant's PID, the date you made contact with this participant's caregiver, and your PHACS site number.

Participant Number (PID): ☐☐☐☐☐☐☐

Date of contact with participant's caregiver (mm/dd/yyyy): ☐☐ ☐☐ ☐☐☐☐

PHACS Site Number: ☐☐

Contact Information

1. Were you able to make contact with the participant's caregiver? (1-Yes, 2-No) ☐
   If No, complete 1a and STOP.
   If Yes, continue.

   a. Specify why no contact was made: _____

2. How did you make contact with the caregiver? ☐
   If 1-4, go to question 3.
   If 5, STOP.
   If 9, complete 'a' and continue.

   1-Telephone
   2-In Clinic
   3-FaceTime or Video conference
   4-Telehealth
   5-Contact made but did not speak to the caregiver (e.g. text, email)
   9-Other

   a. If Other, please specify: _____

Health Status

READ: Now I would like to ask you some more questions about the health of your child/the person you care for. I will be asking you a series of questions about respiratory illnesses and symptoms they may have had.

General Health

3. I'd like to start off by checking in on their health status over the last two weeks. In general, how would you say their health has been over the last two weeks? ☐
   If 6, STOP.
   If 7 or 9, go to question 5.

   1-Excellent
   2-Very good
   3-Good
   4-Fair
   5-Poor
   6-Caregiver unable to respond (no time or privacy)
   7-Caregiver declined to answer
   9-Unknown

4. Is this better, worse, or the same, than before the pandemic started? ☐
   (1-Better, 2-Worse, 3-Same, 4-Unknown)

READ: The next few questions ask about a respiratory illness that has been affecting people, called coronavirus. You may have also heard coronavirus called COVID-19 or SARS-CoV-2. We want to understand how this pandemic has affected your child/the person you care for.

5. I would like to talk with you more about how your child/the person you care for is doing and ask you some questions about COVID-19 and other respiratory illnesses that may have affected them. Do you have 15-20 minutes and a private place to talk further? (1-Yes, 2-No) ☐

   If No, ask the caregiver if you can contact them at a later time, then go to question 35. Document in question 35 if the caregiver will allow you to contact them at a later time.
   If Yes, continue.

COVID-Related

NOTE TO INTERVIEWER: In this next question, please provide examples of what would classify as "worse than the common cold." Examples of a common cold include a runny nose, sneezing, sometimes a sore throat, and no fever.

6. Since January 1, 2020, has your child/the person you care for had any respiratory illnesses that were worse than the common cold? (1-Yes, 2-No) ☐
   If No, go to Section B and complete.
   If Yes, complete 6a, then go to Section A, and complete.

   a. How many respiratory illnesses did they have since January 1, 2020 that were worse than the common cold? (Indicate number) ☐☐

<u>SECTION A:</u> The following questions (7-24) will be asked for each respiratory illness individually. Illume will allow for data entry for each illness (if > 1).

7. When did the respiratory illness begin? Please use your best guess.

   Month (mm): ☐☐ Year (yyyy): ☐☐☐☐

8. Did the illness begin at the beginning of the month, the middle of the month or the end of the month? ☐
   (1-Beginning, 2-Middle, 3-End, 4-Unknown)

READ: I am going to ask you questions about the illness that occurred in (specify month/year).

9. Do you know the number of days that this respiratory illness lasted? (1-Yes, 2-No) ☐
   If Yes complete 'a' and go to question 10.
   If No, complete 'b' and go to question 10.

   a. How long did this respiratory illness last? (Number of days) ☐☐

   b. Please estimate the length of your respiratory illness using these time periods? ☐
      1- Less than 1 week
      2- Between 1-2 weeks
      3- More than 2 weeks
      4- Don't know

10. Overall, did you feel that this respiratory illness was mild, moderate or severe? ☐
    (1-Mild, 2-Moderate, 3-Severe)

11. Did your child/the person you care for have any of the following symptoms during this respiratory illness?

NOTE TO INTERVIEWER: If the caregiver says "Yes" to having any of the symptoms below, please ask the caregiver to rank the severity as, Mild, Moderate or Severe.

Symptom	Please answer Yes or No to each (1-Yes, 2-No).	**If Yes,** please indicate Mild, Moderate or Severe for each.		
		Mild	Moderate	Severe
Fever. If yes, record the highest temperature (°F) _____	☐	☐	☐	☐
Headache	☐	☐	☐	☐
Cough with sputum (mucus) production	☐	☐	☐	☐
Dry cough without sputum (mucus) production	☐	☐	☐	☐
Shortness of breath	☐	☐	☐	☐
Sore throat	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐
Body aches	☐	☐	☐	☐
Chills	☐	☐	☐	☐
Night sweats	☐	☐	☐	☐
Tightness in chest	☐	☐	☐	☐
Vomiting	☐	☐	☐	☐
Diarrhea	☐	☐	☐	☐
Abdominal pain	☐	☐	☐	☐
Loss of taste	☐	☐	☐	☐
Loss of smell	☐	☐	☐	☐
Red eyes or conjunctivitis	☐	☐	☐	☐
Other. Please specify the other symptom_____	☐	☐	☐	☐

12. Did you or your child/the person you care for discuss the respiratory illness with any healthcare provider by phone, text, email, Telehealth, a COVID-19 hotline staffed by healthcare personnel, etc?
If 1, 3, or 4 complete 'a' and continue.
If 2, go to question 13.

☐

1-Yes
2-No
3-Attempted to contact the healthcare facility/provider but was unable to make contact with anyone
4-Contacted the healthcare facility/provider but no health care professional was available

a. Please list the name of the healthcare provider/facility that you contacted or attempted to contact.

Healthcare provider/facility name: _____

13. Did your child/the person you care for go to a healthcare facility for this respiratory illness? Please check all that apply.
If No, go to question 14.
If Yes, complete 'a' and continue.

☐ No, did not go to a healthcare facility

☐ Yes; Doctor's office (Primary care clinic or office, HIV Care Clinic, OB Clinic)

☐ Yes; Urgent Care

☐ Yes, Minute Clinic

☐ Yes; Hospital or Emergency Department

☐ Yes; Telehealth visit

☐ Yes; Drive-through testing

☐ Yes; Other. Please specify:_____

a. Please list the name(s) of the healthcare facility(ies)/provider(s):

Healthcare facility/provider name(s):
1.
2.
3.
4.
5.

14. Was your child/the person you care for hospitalized for this respiratory illness? (1-Yes, 2-No) ☐
    If No, go to question 15.
    If Yes, continue.

    a. For how many days were they hospitalized? (Number of days) ☐☐

15. Was your child/the person you care for tested for **COVID-19** during this illness? ☐
    (1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown)
    If 1, complete 'a' then go to question 16.
    If 3, complete 'b' then go to questions 16.
    If 2 or 4, go to question 16.

    a. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐☐☐☐☐☐☐	☐
2. Test 2:	☐☐☐☐☐☐☐☐	☐
3. Test 3:	☐☐☐☐☐☐☐☐	☐

    b. Please explain why they couldn't get tested: _____

16. Was your child/the person you care for tested for the **flu** during this illness? ☐
    (1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown)
    If 1, complete 'a' then go to question 17.
    If 3, complete 'b' then go to question 17.
    If 2 or 4, go to question 17.

    a. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐☐☐☐☐☐☐	☐
2. Test 2:	☐☐☐☐☐☐☐☐	☐
3. Test 3:	☐☐☐☐☐☐☐☐	☐

    b. Please explain why they couldn't get tested: _____

17. Was your child/the person you care for tested for any **other virus** during this illness? ☐
(1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown)
If 1, complete 'a' and 'b' then go to question 18.
If 3, complete 'c' then go to question 18.
If 2 or 4, go to question 18.

a. Please specify the other virus they were tested for: _____

b. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐ ☐☐ ☐☐☐☐	☐
2. Test 2:	☐☐ ☐☐ ☐☐☐☐	☐
3. Test 3:	☐☐ ☐☐ ☐☐☐☐	☐

c. Please explain why they couldn't get tested: _____

18. In the 2 weeks before their (your child/the person you care for) symptoms started for this respiratory illness, did anyone in their household get tested for any of the following viruses?

Virus	Tested? (1-Yes, 2-No, 3-Unknown)	If Tested, indicate result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
a. The coronavirus that causes COVID-19 (SARS-CoV-2)	☐	☐
b. Flu	☐	☐
c. Other virus, specify if known _____	☐	☐

19. In the 2 weeks before their (your child/the person you care for) symptoms started for this respiratory illness, did they have any close contact with a confirmed case of COVID-19 or with someone with an illness they thought might be COVID-19? (1-Yes, 2-No, 3-Unknown) ☐
If Yes, continue.
If No or Unknown, go to question 20.

a. Was that contact feeling sick? (1-Yes, 2-No, 3-Unknown) ☐

20. Did a healthcare provider give your child/the person you care for any of the following medications to treat COVID-19? Please respond with Yes, No, or Unknown for each.

Medication	1-Yes, 2-No, 3-Unknown
Lopinavir/Ritonavir (Kaletra)	☐
Hydroxychloroquine (Plaquenil)	☐
Hydroxychloroquine (Plaquenil) with Azithromycin (Zithromax, Z-Pak)	☐
Chloroquine	☐
Ribavirin (Moderiba or Rebetol)	☐
Remdesivir	☐
Azithromycin (Zithromax, Z-Pak)	☐
Atorvastatin (Lipitor)	☐
Pravastatin (Pravachol)	☐
Sarilumab (Kevzara)	☐
Tocilizumab (Actemra)	☐
Other. Please specify _____	☐

21. Is your child/the person you care for enrolled in a treatment trial for COVID-19? (1-Yes, 2-No) ☐
    If No, go to question 22.
    If Yes, complete 'a' and continue.

    a. What is the name of the trial? _____

22. In the 2 weeks before their symptoms started for this respiratory illness, did your child/the person you care for travel anywhere outside the area of their normal activities?
    If No, go to question 23. (1-Yes, 2-No)
    If Yes, continue. ☐

Where did they travel? (Country, State, City, Different neighborhood)
a.
b.
c.
d.

23. You said your child/the person you care for had at least one respiratory illness that was worse than the common cold. In addition to the illnesses that we just discussed, we want to know about any other symptoms they may have had that were not connected to the illnesses we just discussed.

    NOTE TO INTERVIEWER: If the caregiver says "Yes" to having any of the symptoms below, please ask the caregiver to rank the severity as, Mild, Moderate, or Severe.

Symptom	Please answer Yes or No to each (1-Yes, 2-No).	**If Yes,** please indicate Mild, Moderate or Severe for each.		
		Mild	Moderate	Severe
Fever. If yes, record the highest temperature (°F) _____	☐	☐	☐	☐
Headache	☐	☐	☐	☐
Cough with sputum (mucus) production	☐	☐	☐	☐
Dry cough without sputum (mucus) production	☐	☐	☐	☐
Shortness of breath	☐	☐	☐	☐
Sore throat	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐
Body aches	☐	☐	☐	☐
Chills	☐	☐	☐	☐
Night sweats	☐	☐	☐	☐
Tightness in chest	☐	☐	☐	☐
Vomiting	☐	☐	☐	☐
Diarrhea	☐	☐	☐	☐
Abdominal pain	☐	☐	☐	☐
Loss of taste	☐	☐	☐	☐
Loss of smell	☐	☐	☐	☐
Red eyes or conjunctivitis	☐	☐	☐	☐
Other. Please specify the other symptom_____	☐	☐	☐	☐

24. I previously asked you if your child/the person you care for was tested for COVID-19 during their respiratory illness(es). Were they tested for **COVID-19** at any other time? (1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown) ☐
    If 1, complete 'a' then go to Section C and complete.
    If 3, complete 'b' then go to Section C and complete.
    If 2 or 4, go to Section C and complete.

    a. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐☐☐☐☐☐☐	☐
2. Test 2:	☐☐☐☐☐☐☐☐	☐
3. Test 3:	☐☐☐☐☐☐☐☐	☐

    b. Please explain why they couldn't get tested: _____

Go to SECTION C

SECTION B:

25. You said your child/the person you care for **did not** have any respiratory illnesses that were worse than the common cold. Now I want to ask if they had any of these symptoms since January 1, 2020.

NOTE TO INTERVIEWER: If the caregiver says "Yes" to having any of the symptoms below, please ask the caregiver to rank the severity as, Mild, Moderate or Severe.

Symptom	Please answer Yes or No to each (1-Yes, 2-No).	**If Yes,** please indicate Mild, Moderate or Severe for each.		
		Mild	Moderate	Severe
Fever. If yes, record the highest temperature (°F) _____	☐	☐	☐	☐
Headache	☐	☐	☐	☐
Cough with sputum (mucus) production	☐	☐	☐	☐
Dry cough without sputum (mucus) production	☐	☐	☐	☐
Shortness of breath	☐	☐	☐	☐
Sore throat	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐
Body aches	☐	☐	☐	☐
Chills	☐	☐	☐	☐
Night sweats	☐	☐	☐	☐
Tightness in chest	☐	☐	☐	☐
Vomiting	☐	☐	☐	☐
Diarrhea	☐	☐	☐	☐
Abdominal pain	☐	☐	☐	☐
Loss of taste	☐	☐	☐	☐
Loss of smell	☐	☐	☐	☐
Red eyes or conjunctivitis	☐	☐	☐	☐
Other. Please specify the other symptom_____	☐	☐	☐	☐

26. Was your child/the person you care for tested for **COVID-19**? ☐
(1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown)
If 1, complete 'a' then go to question 27.
If 3, complete 'b' then go to questions 27.
If 2 or 4, go to question 27.

a. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐ ☐☐ ☐☐☐☐	☐
2. Test 2:	☐☐ ☐☐ ☐☐☐☐	☐
3. Test 3:	☐☐ ☐☐ ☐☐☐☐	☐

b. Please explain why they couldn't get tested: _____

27. Was your child/the person you care for tested for the **flu**? ☐
(1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown)
If 1, complete 'a' then go to question 28.
If 3, complete 'b' then go to question 28.
If 2 or 4, go to question 28.

a. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐ ☐☐ ☐☐☐☐	☐
2. Test 2:	☐☐ ☐☐ ☐☐☐☐	☐
3. Test 3:	☐☐ ☐☐ ☐☐☐☐	☐

b. Please explain why they couldn't get tested: _____

28. Was your child/the person you care for tested for any **other virus**? ☐
(1-Yes, 2-No, 3-Tried but couldn't get tested, 4-Unknown)
If 1, complete 'a' and 'b' then go to question 29.
If 3, complete 'c' then go to question 29.
If 2 or 4, go to question 29.

a. Please specify the other virus they were tested for: _____

b. Please provide the date(s) they were tested and the result(s) of the test:

	Date of Test (mm/dd/yyyy)	Result (1-Positive, 2-Negative, 3-Pending, 4-Unknown)
1. Test 1:	☐☐ ☐☐ ☐☐☐☐	☐
2. Test 2:	☐☐ ☐☐ ☐☐☐☐	☐
3. Test 3:	☐☐ ☐☐ ☐☐☐☐	☐

c. Please explain why they couldn't get tested: _____

SECTION C:

READ: Now I have some questions about how coronavirus may be affecting the daily life of your child/the person you care for.
I will be asking how it impacts your child/the person you care for, their household, their adherence to their medications, and their access to medical care.

29. Has their (your child/the person you care for) health care been affected by the pandemic? ☐

    1- No, they have kept all appointments (Including those moved to telehealth)
    2- Yes, their doctor office(s) has cancelled or rescheduled one or more of their appointments
    3- Yes, they have cancelled one or more scheduled doctor appointments or have not gone to the doctor when they felt they needed to

30. Have they had a hard time taking their medications during this pandemic? ☐
    (1-Yes, 2-No, 3-Not taking any medications)
    If No or Not taking any medications, go to question 31.
    If Yes, complete 'a' and continue.

    a. Please explain why they had a hard time taking their medications:
    _____

31. Were they hospitalized for any other illnesses since January 1, 2020? (1-Yes, 2-No) ☐
    If No, go to question 32.
    If Yes, continue.

    a. For how many days were they hospitalized? ☐☐

32. In the past two weeks did they feel:
    (Please choose 1-Not at all, 2-Very little, 3-Somewhat, or 4-Very Much for each.)

    ☐ Calm
    ☐ Happy
    ☐ Resilient/Strong
    ☐ Hopeful
    ☐ Optimistic
    ☐ Organized
    ☐ Sad
    ☐ Angry
    ☐ Frustrated
    ☐ Depressed
    ☐ Overwhelmed
    ☐ Anxious/Worried
    ☐ Scared /Afraid
    ☐ Helpless
    ☐ Grief
    ☐ Hopeless

33. Please rate the level of stress your child/the person you care for has felt in the past two weeks about the following issues. Please choose Not at all, Very little, Somewhat, Very Much, or Not applicable for each.

(1-Not at all, 2-Very little, 3-Somewhat, 4-Very much, 5-Not applicable)

- ☐ a. Being infected with COVID-19
- ☐ b. The possibility of becoming infected with COVID-19
- ☐ c. Having a family member(s) or a person they are close with who tested positive for COVID-19
- ☐ d. The possibility of a family member or a person close to them becoming infected with COVID-19
- ☐ e. Lack of in-person contact with family members and/or friends
- ☐ f. Having to restrict family members from in-person social contact
- ☐ g. Lack of activities or interactions in the community (church, shopping, gym, etc)
- ☐ h. Parenting children who are out of school during this period of sheltering-in-place
- ☐ i. Managing the household during this period of sheltering-in-place
- ☐ j. Financial challenges due to COVID-19
- ☐ k. Difficulties being able to receive needed medications
- ☐ l. Difficulties being able to access healthcare due to the system being overloaded with COVID-19
- ☐ m. Managing feelings of anxiety, depression, fear, and/or loneliness
- ☐ n. Helping their friends navigate through the COVID-19 pandemic
- ☐ o. Managing other health conditions during this pandemic

34. Would you like to discuss any other issues your child/the person you care for has had with coping during this time? (1-Yes, 2-No) ☐
If Yes, complete ‘a’ and continue.
If No, go to question 35.

a. Comments:

_____

_____

_____

_____

_____

_____

_____

READ: Thank you for taking the time to answer these questions for us. They will be very helpful to better understand the COVID-19 pandemic and allow us to give continued support to our PHACS participants.

For the Interviewer:

35. Does the interviewer have comments to share regarding their discussion with the caregiver? ☐
(1-Yes, 2-No)
If No, STOP.
If Yes, continue.

COMMENTS: