

Survey questionnaire: Health impacts and information needs in “long-COVID”

--- NOTE – at the bottom of this page you can choose between seeing the survey customised to computer (standard) or mobile interface.

--- It is important that you carefully read through all information below before you answer the survey!

What is the purpose of this survey?

The purpose of this survey is to collect, directly from people that experience long-term illness after a COVID-19 infection, data on perceived symptoms, health impacts and treatments, as well as perceptions of personal information needs and activities to meet this need.

To whom is the survey directed?

The target group for this survey is people who have gone through a confirmed or suspected COVID-19 infection and experience persistent health impacts for more than three months after becoming ill.

The survey is made available through an open invitation to people in the target group via the Swedish COVID Association, through postings in Swedish Facebook groups for so-called long-COVID sufferers, and through the research project's website.

In its current layout, the survey can only be read and answered in Swedish, but it is allowed to let a representative / proxy answer the survey on behalf of a person who finds it difficult to answer by her-/himself.

What happens with the survey answers?

The compiled and analysed results of the survey will be published as statistics, data visualisations, and one or several reports and publications in scientific journals.

The results will also, to the largest extent possible, be published as freely available dataset (open access) through the website of the research project, the digital archives of partner universities, and the Swedish COVID Association's website.

The response data from this survey will, after the finished research project, be made available through an open research archive. This means that the data can also be used in other research projects. Nowhere in this data will it be possible to discern the identities of those who participated in the study. Your participation is anonymous from start to finish (see below).

Who is behind the study?

The University of Borås is responsible for this study.

The survey is performed as part of the research project Crowdsourcing Long-COVID – Sweden (CiLC-S). Information about the project and its researchers is found at: <https://www.hb.se/en/research/research-portal/projects/cilc-s---crowdsourcing-long-covid-sweden/>

The project is carried out as a research project involving researchers in information science (University of Borås), statistics (Linköping University), medicine (Karolinska Institutet), and cognitive neuroscience (University of Skövde).

Who can respond to the survey?

For the results to become as reliable as possible, it is important that you who answer the survey match the selection criteria. These are:

1. You or the person that you answer on behalf of must have gone through a confirmed or suspected COVID-19 infection.
2. You or the person that you answer on behalf of must have experienced health impacts lasting more than 3 months after the start of the infection.
3. You or the person that you answer on behalf of must be 18 years old or more.

What does the survey look like?

The survey is divided into 9 parts.

Most of the questions in the first 6 parts are obligatory and must be answered in order for you to be able to submit the survey. These questions are mostly of multiple choice type.

The questions in the final parts (parts 7-9) are voluntary (it is possible to hand in your response to this survey without responding to these questions). These questions are a mixture of closed and open types.

The survey is arranged as follows:

1. General background questions about your person
2. Background questions concerning your COVID-19 infection
3. Symptoms during the first three months
4. Symptoms from month four onwards
5. Possible treatments and effects
6. Possible sick leave, diagnosis and experiences from healthcare encounters
7. Information needs and information practices as long term ill (*voluntary questions*)
8. Assessment of selected symptoms according to validated scales (*voluntary questions*)
9. Closing question concerning the survey and possibility to add additional remarks (*voluntary question*)

How is the survey to be answered?

The survey can be answered both via mobile (smartphone) and computer. The default setting from start is customised to computer, and using a computer to answer the survey is recommended because the list of symptoms is long. There are also some optional free text questions where you may want to write longer answers. However, if you prefer to answer with a mobile phone, you can choose to adapt the survey to mobile format by changing the setting at the bottom of this page.

Calculated time to respond to the survey is 40 - 60 minutes (depending on how many questions you receive and how much detail you choose to add in your answers).

Certain questions concern events in time so if you have recorded details about the course of your disease it will be good to have these available (for example: at what time you think that you fell ill, how long you have been ill, or approximately when in the course of the disease that you experienced different symptoms). If you do not have such notes, a calendar / almanac can still be good to have available as a memory aid.

ATTENTION! During the time that you are logged into the survey, it is possible to go back and check or change answers to previous questions, but it is **NOT POSSIBLE TO SAVE RESPONSES** from one session and come back at a later time. All responses must, in other words, be given at one and the same occasion without logging out in between.

The survey is open until August 1, 2021.

The survey can only be answered one time per person.

Is it safe to answer the survey?

Yes. We do not use or collect any sort of personal identifying data in this study. You who answer the survey are completely anonymous. This means that no one can connect your responses to you as a person.

Your anonymity is secured in three ways:

1. the survey is openly shared (it is not sent out to specific, identified recipients),
2. the survey tool that is used (Sunet survey) does not save any information about the computer or mobile used to answer the survey, and
3. the survey is designed so that no questions concern information that can identify an individual.

The survey and the research project have been reviewed by the Swedish Ethical Review Board, no: 2021-02490.

Participation is voluntary

Your participation is voluntary and you are free to stop your participation at any time. If you choose not to participate or wish to cancel your participation, you do not need to state a reason why.

Responsible for the study

Contact person for the study is:

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Your participation is important

Thank you for your time and participation!

Control questions

Please confirm by selecting the answer options that describe you that you meet the criteria for participating in this survey.

As a last control before you start the survey we ask you to generate a unique 6-figure code by selecting one letter or number from each of the drop-down menus, finally inputting the entire 6-figure code in the text box below.

We also ask you to write down and save this code for yourself for use in any future follow-up surveys. We ask everyone who answers the survey to create a unique code in this way, in case we get the opportunity to follow long-term patients over time in several studies. For this to work, we need to be able to follow responses from one and the same individual over time, even though you who participate are anonymous the whole the time in this study and all that may follow. This code that you will generate and save for yourselves makes it possible for us to connect answers from different surveys to the same individual, without us knowing who this individual is.

You will also be able to save your code together with your responses to the survey as a whole if you choose to print your response as a pdf file when you are done with the survey and click "Submit", in which case you will also have permanent access to your own unique code in that pdf file. To be sure, we recommend that you **both write down your code somewhere right now, and save your answers as a pdf on your computer when you submit your answers.**

We thank you in advance for your help with this!

1. I confirm that I have read the information about the study and the terms of my participation on the previous page. By checking "yes" I agree to participation in the study on these terms.

- Yes
- No

2. I confirm that I experience / have experienced health impact lasting more than 3 months after a suspected or confirmed COVID-19 infection.

- Yes
- No

3. I confirm that I am 18 years old or more

- Yes
- No

Generate your unique 6-figure code by selecting one letter or number from each of the drop-down menus below. Try to make your code unique by selecting random symbols from all over the lists (i.e. do not select the first option "A" and "0" in every box, but select with variation.

4. Choose your first sign from the list below.

[Drop-down menu with signs A-Z inserted here]

5. Choose your second sign from the list below.

[Drop-down menu with signs 0-9 inserted here]

6. Choose your third sign from the list below.

[Drop-down menu with signs A-Z inserted here]

7. Choose your fourth sign from the list below.

[Drop-down menu with signs 0-9 inserted here]

8. Choose your fifth sign from the list below.

[Drop-down menu with signs A-Z inserted here]

9. Choose your sixth sign from the list below.

[Drop-down menu with signs 0-9 inserted here]

10. Write your entire self-generated code in the text box below. Note: the code must be the exact 6 signs chosen above, and in the exact chosen order. Do not forget to note your code for yourself somewhere in a safe place!

Part 1: General questions concerning your person

This first part of the survey contains a number of questions concerning your background.

11. On whose behalf are you answering this survey?

- On behalf of myself
- On behalf of another person who is too ill to respond by her-/himself
- On behalf of another person who is experiencing technical difficulties answering
- On behalf of another person who has linguistic difficulties answering
- Do not wish to answer / Do not know

NOTE

To you who are answering the survey on behalf of someone else, please note that the pronouns "I", "Me", "My", "You" and "Your" always refer to the long-term ill person.

12. Which county do you belong to? (Voluntary question).

This can be the county that you are registered in, or the county that you live in if you do not have Swedish citizenship.

[Drop-down menu with the counties of Sweden inserted here]

13. How old are you? (Voluntary question).

[Drop-down menu with options '18' – '99 or above' inserted here]

14. What is your biological sex?

- Female
- Male
- Do not wish to answer / Do not know

15. What is your blood type?

- A
- B
- AB
- 0
- Do not wish to answer / Do not know

16. Before you became ill with COVID-19, how much time did you spend in an average week doing physical exercise that made you short of breath, such as running, gymnastics or ball sports?

Add up all times extending over at least 10 minutes per time. Choose the alternative that is the closest.

- No time
- About 30 minutes
- About 1 hour
- About 2 hours
- About 3 hours
- About 4 hours
- About 5 hours
- About 6 hours
- 7 hours or more
- Do not wish to answer / Do not know

17. Before you became ill in COVID-19, how much time did you spend in an average week doing everyday exercise, for example walking, cycling or gardening?

Add up all times extending over at least 10 minutes per time. Choose the alternative that is the closest.

- No time
- About 30 minutes
- About 1 hour
- About 2 hours
- About 3 hours
- About 4 hours
- About 5 hours
- About 6 hours
- 7 hours or more
- Do not wish to answer / Do not know

18. How tall were you at the time for becoming ill with COVID-19? (Voluntary question).

Respond in cm rounded off to nearest whole number. If for example you were 173.6 cm you answer: 174.

19. Approximately how much did you weigh at the time for becoming ill with COVID-19? (Voluntary question).

Respond in kg rounded off to the nearest whole number. If for example you weighed 68.8 kg you answer: 69.

20. Were you using tobacco on a daily basis at the time of becoming ill with your confirmed or suspected COVID-19 infection?

Multiple answers possible.

- Yes, snuff
- Yes, smoking tobacco (cigarettes, pipe or similar)
- No
- Do not wish to answer / Do not know

21. What is your highest completed level of education?

- Primary school education (or equivalent)
- Secondary education (or equivalent)
- Post-secondary education (not College/University)
- College/University education
- Other
- Do not wish to answer / Do not know

22. What was your main employment at the time of becoming ill with COVID- 19?

The question refers to which of the following occupations that you spent at least 50 % of your working time on.

Multiple answers possible.

- Gainfully employed full time (80 % - 100 %)
- Gainfully employed part-time (50% - 79%)
- Job seeking (unemployed)
- Student
- Pensioner
- Sick leave
- Other
- Do not wish to answer / Do not know

23. How would you describe your main type of work or employment before you became ill with COVID-19?

- Not applicable to me (retired, job seeking, on sick leave or similar)
- Mostly physical work
- Mostly sedentary work (including studies/being a student)
- Both physical and sedentary work
- Do not wish to answer / Do not know

24. Do you have any of the following diseases / risk factors from earlier (before the COVID-19 infection)?

Multiple answers possible.

- I had no diseases from earlier (before COVID-19 infection)
- Asthma
- Allergy

- Chronic obstructive pulmonary disease (COPD)
- Pulmonary arterial hypertension (PAH)
- Pulmonary embolism
- Blood clot (DVT, deep vein thrombosis)
- High blood pressure
- Atrial fibrillation (arrhythmia)
- Heart failure
- Inflammatory intestinal disease (ulcerous colitis, Crohn's disease)
- Irritable bowel syndrome (IBS)
- Gluten intolerance
- Diabetes type 1
- Diabetes type 2
- Kidney disease affecting kidney function
- Liver disease affecting liver function
- Previous (not currently ongoing) cancer
- Hypothyroidism (underactive thyroid gland)
- Hyperthyroidism (overactive thyroid gland)
- Rheumatoid arthritis
- Other rheumatic disease (not rheumatoid arthritis)
- Ehler Danlos disease (EDS)
- SLE (lupus)
- Psoriasis
- Fibromyalgia
- Multiple sclerosis (MS)
- Alopecia (hair loss)
- Burnout syndrome
- Overweight (BMI over 25)
- Depression
- Anxiety
- ME/CFS (myalgic encephalomyelitis / chronic fatigue syndrome)
- POTS (postural orthostatic tachycardia syndrome)
- Ongoing treatment with cortisone (tablet treatment)
- Other
- Do not wish to respond / Do not know

If "Other", please state which one(s) with your own words (voluntary). (Remember not to write personal identifiable information in your answer).

25. Are you a member of the Swedish COVID Association?

- Yes
- No
- Do not wish to answer / Do not know

26. Are you a member of any Facebook group for long COVID / post-COVID sufferers?

- Yes
- No
- Do not wish to answer / Do not know

27. How did you hear about this survey?

Multiple answers possible.

- Posting in a Facebook group
- Information from the Swedish COVID Association
- Research project website
- Radio / TV / newspapers
- Other
- Do not wish to answer / Do not know

If "Other", please state what (voluntary). Remember not to write personally identifiable information in your answer.

Part 2: Background questions concerning your COVID-19 infection

This part contains a number of background questions concerning your confirmed or suspected infection with COVID-19.

28. **When did you fall ill you with the confirmed or suspected COVID-19 infection that caused your long term symptoms? (Voluntary).**

If you do not know exactly then estimate what is likely.

 

29. **Converted to number of months, how long has it been since you became ill with the confirmed or suspected COVID-19 infection that caused your long-term symptoms? (Voluntary question).**

[Drop-down menu with options '4-6 months', '7-9 months', '10-12 months', 'More than 12 months', 'Do not know / Do not wish to answer' inserted here]

30. **What is the status of your illness at the time of participation in this survey? (The question refers to symptoms that you associate with your contraction of the COVID-19 infection).**

- I am symptom-free since more than 6 months
- I have been symptom-free for 3-6 months
- I am periodically symptom-free, but new or old symptoms have always returned / kept appearing up to this time
- I am almost never symptom-free
- I experience symptoms all the time
- Do not wish to answer / Do not know

31. **Did you notice a difference between the first "acute" infection phase and a following period with so-called "long-term symptoms" / "long-term COVID" / "post-COVID"?**

- No, I have not experienced a difference
- Yes, I have experienced a difference
- Do not wish to answer / Do not know

32. **If you have noticed a difference between the first acute infection phase and the subsequent phase with long-term symptoms, did you experience a break in time between the two phases?**

- I did not notice a difference between the first acute infection phase and the following phase with long-term symptoms
- I noticed a difference but the long-term symptoms followed immediately upon the acute infection phase (there was no time in between when I felt completely or almost completely well)
- I noticed a difference and the break in time lasted a shorter time period (1-4 weeks, i.e. up to 1 month) between the two phases, when I felt completely or almost completely well
- I noticed a difference and the break in time lasted a longer time (5-12 weeks, i.e. 2-3 months) between the two phases, when I felt completely or almost completely well
- I noticed a difference and the break in time lasted a long time (13 weeks or more, i.e. more than 3 months) between the two phases, when I felt completely or almost completely well
- Do not wish to answer / Do not know

33. Were you tested for your suspected or confirmed COVID-19 infection?

Check the boxes of answers that apply to you.

Multiple answers possible.

- Yes, I have done one or several tests for ongoing COVID-19 infection (PCR test and / or antigen test)
- Yes, I have done one or more "regular" tests for antibodies (antibody test)
- Yes, I have done one or several "special tests" for immunity (T-cell test)
- No, I have not tested for anything
- Do not wish to answer / Do not know

34. If you have done tests for your confirmed or suspected COVID-19 infection, mark the statements that apply to you.

Multiple answers possible.

///Question only visible at positive response on question 33///

- I have tested positive for ongoing COVID-19 infection (PCR test and / or antigen test)
- I have tested positive in a "regular" test for antibodies (antibody test)
- I have tested positive for immunity with special test (T-cell test)
- I have only tested negative
- Do not wish to answer / Do not know

35. Have some of your test answers mentioned above been contradictory to each other?

Multiple answers possible.

///Question only visible at positive response to question 33///

- Yes, I tested positive for ongoing infection (PCR test and / or antigen test) but negative on "regular" antibody test (i.e. not T-cell test)
- Yes, I tested positive for ongoing infection (PCR test and / or antigen test) but negative on subsequent "special test" for immunity (T-cell test)
- Yes, I tested positive for antibodies and / or on "special test" for immunity (antibody test and / or T-cell test) but negative on previous tests for ongoing infection (PCR test and/or antigen test)
- Yes, I tested positive for antibodies ("plain" antibody test) but negative on T-cell test for immunity
- Yes, I tested positive on T-cell test for immunity but negative on "regular" antibody test
- No, the test answers have been consistent
- Do not wish to answer / Do not know

If there have been contradictions between your test answers, please state how long time that passed in between those tests). (Remember not to write any personal identifiable information in your answer).

36. Do you know, or suspect, that you have been infected with COVID-19 more than once?

- Yes, both times confirmed with positive test answers for ongoing infection (PCR test and / or antigen test)
- Yes, but only the first the time confirmed with positive test answer for ongoing infection (PCR test and / or antigen test)
- Yes, but only the second time confirmed with positive test answers for ongoing infection (PCR test and / or antigen test)
- Yes, but not confirmed with positive test answers for ongoing infection (PCR test and / or antigen test) for either time
- No
- Do not wish to answer / Do not know

37. Have you been admitted to a hospital care unit for treatment of your COVID-19 infection during the first three months after the illness?

Multiple answers possible.

- Yes, to an intensive care unit, with respiratory care
- Yes, to an intensive care unit, without respiratory care
- Yes, to a regular care department
- No
- Do not wish to answer / Do not know

38. Have you been admitted to a hospital care unit for treatment of your COVID-19 infection four months or more after becoming ill (after the initial infection)?

Multiple answers possible.

- Yes, to an intensive care unit, with respiratory care
- Yes, to an intensive care unit, without respiratory care
- Yes, to a regular care unit
- No
- Do not wish to answer / Do not know

39. Have some members of your nearest family also been affected by suspected long-COVID / post-COVID?

Multiple answers possible.

- Yes, one or several parents
- Yes, one or more children
- Yes, one or several siblings
- No
- Do not wish to answer / Do not know

40. How much time in your current situation do you devote in an average week to physical exercise that usually - that is, before your onset of the COVID-19 infection - would have caused you to become short of breath, for example running, gymnastics or ball sports?

Add all episodes over 10 minutes per time. Choose the alternative that is closest.

- No time
- About 30 minutes
- About 1 hour
- About 2 hours
- About 3 hours
- About 4 hours
- About 5 hours
- About 6 hours
- 7 hours or more
- Do not wish to answer / Do not know

41. How much time in your current situation do you devote in an average week to everyday exercise, for example walking, cycling or gardening?

Add all episodes over 10 minutes per time. Choose the alternative that is closest.

- No time
- About 30 minutes
- About 1 hour
- About 2 hours
- About 3 hours
- About 4 hours
- About 5 hours
- About 6 hours
- 7 hours or more
- Do not wish to answer / Do not know

Part 3: Symptoms during the first three months

*This part contains questions concerning what symptoms that you experienced during the **first three months** after your suspected or confirmed COVID-19 infection. The questions concern symptoms that you associate with your illness from COVID infection and these can be symptoms that are completely new to you or symptoms that you have had before but that have significantly increased or changed as a result of the COVID infection.*

(On the next page you will get the same questions but for long term symptoms, which we here count as symptoms occurring from four months onwards in the course of the illness).

Respond by checking, or leaving blank, the box next to each symptom.

To make it easier to answer, the list of symptoms is divided into smaller groups based on where in the body they mainly manifest. This division of symptoms is therefore based on practical concerns, and have no correspondence to theories of relationships between underlying factors.

42. Which of the following symptoms in the category "Nervous System" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Dizziness
- Problems with balance
- Extremely tired / exhausted (fatigue)
- Headache
- Anxiety
- Low mood
- Depression
- Confusion
- Difficulty concentrating
- "Brain fog"
- Slurred speech
- Difficulties finding the right words
- Personality change
- Impaired short-term memory
- Impaired long-term memory
- Difficulty sleeping (unable to relax, "speeded")
- Nightmares (when sleeping)
- Daydreams / visual hallucinations (when awake)
- Clumsiness / fumbling
- Numbness (in arms, legs, hands, feet)
- Numbness (of the skin)
- Prickling sensation (of the skin)
- Tremor (shaking hands and / or body)
- Fever (38.0 degrees or higher)
- Subfebrile (37.5-37.9 degrees)
- Feeling sick without fever (<37.5 degrees)
- Chills with fever
- Chills / feeling cold without fever (difficult to become warm)
- Increased sensitivity to heat
- Increased sensitivity to cold
- Cold extremities (hands, feet and similar)
- Night sweats
- Sweating during day time (without connection to physical exertion)

43. Which of the following symptoms in the category "Ears / nose / throat" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Sensitivity to sound
- Tinnitus
- Deteriorated hearing
- Rhinitis (chronic sneezing or runny nose)
- Congestion of the nose
- Dryness in the nose
- Icy feeling in the nose
- Itching in the nose
- "Carbonated" feeling in the nose
- Pain / increased pressure in the sinuses
- Loss of taste (ageusia)
- Altered sense of taste (dysgeusia)
- Phantom taste ("taste hallucination")
- Loss of smell (anosmia)
- Altered sense of smell (parosmia)
- Phantom smell (phantosmia, "olfactory hallucinations")
- Dry throat
- Dry mouth
- Soreness in mouth
- Sore throat
- Itching in mouth / palate
- Difficulty swallowing
- "Lump in the throat" sensation
- Pressure sensation in throat (from outside or from within)
- Hoarseness
- Changed voice

44. Which of the following symptoms in the category "Airways" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Burning sensation in the airways when inhaling and exhaling
- Icy sensation in the airways when inhaling and exhaling
- Dry cough
- Phlegm cough
- Shortness of breath (tachypnea) when resting
- Shortness of breath (dyspnea, "air hunger") when resting
- Shortness of breath (dyspnea, "air hunger") when lying down
- Shortness of breath (dyspnea, "air hunger") during physical exertion
- Shortness of breath (dyspnea, "air hunger") when speaking
- Noise from the lungs

45. Which of the following symptoms in the category "Heart / veins" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Chest pains
- Tachycardia (heart beat over 100 beats per minute)
- Heart palpitations (fast-beating, fluttering or pounding heart) when resting
- Heart palpitations when changing position
- Irregular heartbeat

- High blood pressure
- Low blood pressure
- Bulging blood vessels / veins

46. Which of the following symptoms in the category "Stomach / intestines" did you experience during the first three months after your confirmed or suspected covid-19 infection?

- Nausea
- Vomiting
- Constipation
- Diarrhea
- Increased thirst
- Increased hunger
- Loss of appetite
- Acid reflux / heartburn
- Burning sensation / pain in the stomach tract
- Other abdominal pain (around the navel and in the lower part of abdomen)
- Bloating stomach
- Increased gas formation in the stomach
- Changed smell / color / consistency of stool

47. Which of the following symptoms in the category "Urinary tract" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Pain / burning sensation when urinating
- Urgent urination (pressing need to urinate often)
- Urinary tract infection
- Increased urine volume
- Decreased urine volume
- Changed smell / color / character of urine

48. Which of the following symptoms in the category "Skin / mucous membranes" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Skin rash
- Skin blisters
- Burning sensation of the skin in the face
- Burning sensation of the skin on the body (not face)
- Hot flushes in the face and neck
- Hot flushes in the rest of the body
- Blisters in the mouth
- Bleeding gums
- Swollen gums
- Deteriorated dental health
- Color changes of the toes ("COVID toes")
- Dry skin
- Flaky skin
- Itching of the skin
- Dry scalp
- Dandruff of the scalp
- Hair loss

- Nail changes and / or dropped nails
- Bruises

49. Which of the following symptoms in the category "Joints / muscles" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Swelling of the joints
- Joint pain
- Stiff joints
- Muscle cramps
- Muscle pain
- Muscle weakness
- Involuntary muscle twitching
- Neck pain
- Stiff neck
- Jaw pain
- Pain / ache in the lower part of the back
- Pain / ache in the upper part of the back
- Pain / ache in the hips
- Lactic acid sensation in muscles during exertion

50. Which of the following symptoms in the category "Eyes" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Stye in the eye
- Eye infection
- Dry eyes (gravel-like feeling)
- Pain in eye / eyes (stinging, sharp pain)
- Watery eyes
- Sensitivity to light
- Deteriorated vision
- Foggy sight / difficult to focus
- Flashes / dots in the field of vision

51. Which of the following symptoms in the category "Other" did you experience during the first three months after your confirmed or suspected COVID-19 infection?

- Edema (accumulation of fluid in tissues)
- Deterioration with increased symptoms after physical exertion
- Deterioration with increased symptoms after mental effort
- Deteriorated feeling after meals (general)
- Deteriorated feeling after consuming a diet rich in sugar
- Deteriorated feeling after consuming a diet high in carbohydrates (other than sugar)
- Deteriorated feeling after consuming alcohol
- Deteriorated feeling after consumption of (other) histamine-rich food/diet
- Deterioration with increased symptoms in connection with ovulation and / or menstruation
- Menstrual disorder
- Weight gain
- Weight loss
- Pain in the testicles
- Erectile dysfunction
- Decreased sex drive
- Tender / painful and/or swollen lymph nodes

- 52. If there are one or several symptoms from your first three months that was missing in the lists above you are welcome to add them here. (Voluntary). (Remember not to write any personal identifying information in your answer).**

Part 4: Symptoms in the following long-term COVID phase (from month four and forward)

In this part you are asked which symptoms that you have experienced **starting from month four** after your confirmed or suspected COVID-19 infection. The questions concern symptoms that you associate with your illness from the COVID infection and these can be symptoms that are completely new to you or symptoms that you have had before but that have significantly increased or changed as a result of the COVID infection.

Respond by checking, or leaving blank, the box next to each symptom.

If you have not been ill as long as 6-9 months or 10-12 months, leave each of these boxes blank (do not check).

To make it easier to answer, the list of symptoms is divided into smaller groups based on where in the body they mainly manifest. This division of symptoms is therefore of a practical character and have no connection to theories concerning relationships of underlying factors.

53. Which of the following symptoms in the category "Nervous System" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Dizziness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems with balance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extremely tired / exhausted (fatigue)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Headache	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Confusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
"Brain fog"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Slurred speech	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty finding the correct word	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personality change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated short-term memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated long-term memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty sleeping (unable to relax, "speeded")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nightmares (when sleeping)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daydreams / visual hallucinations (when awake)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clumsiness / fumbling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Numbness (in arms, legs, hands, feet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Numbness (in the skin)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prickling sensation in the skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tremor (shaking in hands and / or body)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fever (38.0 degrees or higher)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Subfebrile (37.5-37.9 degrees)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Feeling sick without fever (<37.5 degrees)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chills with fever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chills without fever (difficult to become warm)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased sensitivity to heat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased sensitivity to cold	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cold extremities (hands, feet and similar)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Night sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sweating in day time (without connection to physical exertion)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

54. Which of the following symptoms in the category "Ears / nose / throat" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Sensitivity to sound	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tinnitus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rhinitis (chronic sneezing or runny nose)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nasal congestion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dryness in nose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Icy feeling in the nose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching in the nose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carbonated feeling in the nose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain / increased print from sinuses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of taste (ageusia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed sense of taste (dysgeusia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phantom taste ("taste hallucination")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of smell (anosmia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed sense of smell (parosmia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phantom smell (phantosmia, "olfactory hallucinations")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dry throat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tenderness in the mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dry mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sore throat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching in mouth / palate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties to swallow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
"Lump in the throat" sensation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pressure sensation of the throat (from outside or inside)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hoarseness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

55. Which of the following symptoms in the category "Airways" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Burning sensation in the airways when inhaling and exhaling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Icy sensation in the airways when inhaling and exhaling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dry cough	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phlegm cough	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rapid and shallow breathing (tachypnea) when resting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath (dyspnea, "air hunger") when resting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath (dyspnea, "air hunger") when lying down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath (dyspnea, "air hunger") during physical exertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath (dyspnea, "air hunger") when speaking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Noise from the lungs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

56. Which of the following symptoms in the category "Heart / veins" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Chest pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tachycardia (heart beat over 100 beats per minute)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart palpitations (fast-beating, fluttering or pounding heart) when resting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart palpitations when changing position	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irregular heartbeat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bulging blood vessels / veins	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

57. Which of the following symptoms in the category "Abdomen / intestines" did you experience from month four after your confirmed or suspected infection with COVID-19?

	Month 4-6	Month 7-9	From month 10
Nausea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased thirst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased hunger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acid reflux / heartburn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Burning sensation / pain in the abdominal tract	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other abdominal pains (around the navel and in the lower part of the abdomen)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bloated stomach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased gas formation in stomach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed smell / color / consistency of stool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

58. Which of the following symptoms in the category "Urinary tract" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Pain / burning sensation when urinating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urgent urination (frequent need to pee)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urinary tract infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased urine volume	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Decreased urine volume	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed smell / colour / character of urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

59. Which of the following symptoms in the category "Skin / mucous membranes" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Skin rash	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin blisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Burning sensation of skin in the face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Burning sensation of skin on the body (not face)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hot flashes in face and neck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hot flashes in the rest of the body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blisters in the mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bleeding gums	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swollen gums	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated dental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Color changes of toes ("COVID toes")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dry skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Flaking skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dry scalp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dandruff of the scalp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hair loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nail changes and / or lost nails	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bruises	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

60. Which of the following symptoms in the category "Joints / muscles" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Swelling of joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joint pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stiff joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muscle cramps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muscle pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muscle weakness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involuntary muscle twitching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neck pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stiff neck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jaw pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain / ache in lower back	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain / ache in upper back	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain / ache in the hips	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lactic acid feeling in muscles during exertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

61. Which of the following symptoms in the category "Eyes" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Stye in the eye	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Infection of the eye	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dry eyes (gravel-like feel)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain in eye / eyes (piercing, sharp pain)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watery eyes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sensitivity to light	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blurred vision / difficult to focus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Flashes / dots in the field of vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

62. Which of the following symptoms in the category "Other" did you experience from month four after your confirmed or suspected COVID-19 infection?

	Month 4-6	Month 7-9	From month 10
Edema (accumulation of fluid in tissues)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deterioration with increasing symptoms after physical exertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deterioration with increasing symptoms after mental exertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated feeling after meals (in general)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated feeling after consuming a diet rich in sugar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated feeling after consuming a diet rich in carbohydrates (other than sugar)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated feeling after consuming alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorated feeling after consuming (other) histamine-rich food/diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deterioration with increased symptoms in connection with ovulation and / or menstruation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Menstrual disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weight gain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain in the testicles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Erectile dysfunction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduced sex drive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tender / painful and / or swollen lymph nodes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 63. If there are one or more of your symptoms from month four onwards that were missing from the lists above, please add them here. State also during which of the above specified time periods that these symptoms occurred. (Voluntary). (Remember not to write any personal identifiable information in your answer).**

Part 5: Treatment and effects

This part contains questions concerning potential treatment of your long-term symptoms and what potential effects that you may have experienced in connection with this.

64. Have your long-term symptoms been treated in some way as the result of referral, prescription or other advice from a doctor or equivalent medical professional?

Multiple answers possible.

- No
- Yes, physiotherapy / rehab training
- Yes, medication
- Yes, counselling therapy / cognitive behavioral therapy (CBT) or similar
- Yes, other
- Do not wish to answer / Do not know

If "yes" describe, if you wish, in the box below which treatments this concerned more specifically and whether you experienced positive effects on your symptoms or not (*voluntary*). (Remember not to write any personal identifiable information in your answer).

65. Have you on your own initiative treated your long-term symptoms with alternative treatments and / or methods?

Multiple answers possible.

- No
- Yes, through physiotherapy / rehab training on my own initiative
- Yes, through self-medication with non-prescription drugs
- Yes, through intake of dietary supplements (vitamins, minerals, other health supplements)
- Yes, through a changed / adapted diet
- Yes, through self-initiated counselling therapy / CBT (cognitive behavioural therapy) or similar
- Other
- Do not wish to answer / Do not know

If "yes" describe, if you wish, in the box below which treatments this concerns and whether you have experienced any positive effects on your symptoms or not (*voluntary*). (Remember not to write any personal identifiable information in your answer).

66. Have you been vaccinated against COVID-19 and if so, how has this affected your long term COVID symptoms? *N.B. the question refers to at least two shots, not merely a singular / first shot.*

- No, I have not been vaccinated
- Yes, I have been vaccinated but it is **too early to assess** (vaccinated less than 4 weeks ago)
- Yes, I have been vaccinated more than 4 weeks ago and it did **not affect my long term COVID** to either the better or worse
- Yes, I have been vaccinated more than 4 weeks ago and it **affected my long term COVID for the worse**
- Yes, I have been vaccinated more than 4 weeks ago and it **affected my long term COVID for the better**
- Do not wish to answer / Do not know

Possible commentary (voluntary). (Remember not to write any personal identifiable information in your answer).

Part 6: Sick leave, diagnoses and treatment

This part contains questions concerning your potential contacts with health care and social services concerning your long-term illness, and how you have been treated in connection with these; potential diagnoses; as well as your potential need for sick leave during the period of long-term illness.

67. Have you met with a physician concerning your long-term problems after the suspected or confirmed COVID-19 infection (from month four onwards after the infection)?

- No
- Yes, about 1-5 times
- Yes, about 6-10 times
- Yes, about 11-20 times
- Yes, more than 20 times
- Do not wish to answer / Do not know

68. How do you experience the physician's attitude towards you regarding your long-term health impacts after the COVID-19 infection (from month four onwards after the infection)?

- I have not met with a physician for these symptoms / this illness
- Mostly very good
- Mostly good
- Mostly bad
- Mostly very bad
- Do not wish to answer / Do not know

If you wish, you can describe in the box below more about your experience of physicians' attitudes towards you (*voluntary*). (*Remember not to write any personal identifiable information in your answer*).

69. Have you received any diagnoses from a physician concerning your long-term health impacts after the confirmed or suspected COVID-19 infection? (*Voluntary*).

Multiple answers possible.

- U07.1 COVID-19, virus identified
- U09.9 Post-infectious condition after COVID-19, unspecified
- Anxiety
- Depression
- Fatigue
- POTS (postural orthostatic tachycardia syndrome)
- ME or ME/CFS (myalgic encephalomyelitis / chronic fatigue syndrome)
- MCAS (mast cell activation syndrome)
- Inflammation of the meninges (encephalitis)
- Pneumonia
- Myocarditis (inflammation of the heart muscle)
- Pericarditis (inflammation of the pericardium / 'heart sac')
- High blood pressure
- Low blood pressure
- Heart attack
- Cardiac arrhythmia
- Pulmonary embolism

- Blood clot (deep vein thrombosis)
- Low oxygenation / desaturation when resting
- Low oxygenation / desaturation following exertion
- Pulmonary fibrosis
- COPD (chronic obstructive pulmonary disease)
- Asthma
- Allergy
- Sinusitis
- Urinary tract infection
- Protein in urine
- Blood in urine
- Renal pelvic inflammation
- Rose fever (erysipelas)
- Inflammation in blood vessel (vasculitis)
- High blood sugar
- Diabetes
- High blood fats
- IBS (irritable bowel syndrome)
- Fungal infection in the underbelly or someone elsewhere on the body
- Shingles
- Dementia
- PTSD (post-traumatic stress disorder)
- Premature menopause
- Underactive thyroid gland (hypothyroidism)
- Overactive thyroid gland (hyperthyroidism)
- Costochondritis / Tietzes syndrome (inflammation of the ribs and cartilage on sternum)
- Other
- Do not wish to answer / Do not know

If "Other" you may describe this, if you wish, in the box below (voluntary). (Remember not to write any personal identifiable information in your answer).

70. Were you completely or partly on sick leave during the first three months after your confirmed or suspected COVID-19 infection?

- Not applicable to me (retired, already on sick leave, or similar)
- No
- Yes, less than 1 week
- Yes, 1-2 weeks
- Yes, 3-4 weeks
- Yes, 5-8 weeks
- Yes, 9-12 weeks
- Do not wish to answer / Do not know

71. Have you been completely or partially on sick leave from month four after your confirmed or suspected COVID-19 infection?

- Not applicable to me (retired, already on sick leave, or similar)
- No
- Yes, less than 1 month
- Yes, 1-2 months
- Yes, 3-4 months
- Yes, 5-6 months
- Yes, 7 months or more
- Do not wish to answer / Do not know

72. Have you had the possibility to be on sick leave to the extent that you have needed as a consequence of your suspected or confirmed COVID-19 infection and following long-term illness?

- Not applicable to me (retired, already on sick leave, or similar)
- I have not needed to be on sick leave
- Yes, I have been able to be on sick leave to the extent that I have needed
- No, physician and / or the Social Insurance Agency (Försäkringskassan) have not granted me sick leave to the extent that I have needed
- No, I have self-selected to not be on sick leave to the extent that I would have needed as my work / other situation does not allow me to do that
- Other
- Do not wish to answer / Do not know

If "Other", specify if you wish in the box below (voluntary). (Remember not to write any personal identifiable data in your answer).

73. How do you experience the attitude from the Swedish Social Insurance Agency (Försäkringskassan) regarding you and your potential need for extended sick leave as a consequence of long-term health impacts after your suspected or confirmed COVID-19 infection?

- I have not been in contact with the Social Insurance Agency concerning this
- Mostly very good
- Mostly good
- Mostly bad
- Mostly very bad
- Do not wish to answer / Do not know

If you wish, you can describe in the box below how you have experienced your encounters with the Swedish Social Insurance Agency regarding this (voluntary). (Remember not to write any personal identifiable information in your answer).

74. Have you applied for reimbursement from your private insurance regarding your long-term health impacts after your suspected or confirmed COVID-19 infection, and if so, how do you experience being treated in connection with this?

- No, I have not had contact with my insurance company regarding this
- Yes, and the treatment was very good
- Yes, and the treatment was quite good
- Yes, and the treatment was quite bad
- Yes, and the treatment was very bad
- Do not wish to answer / Do not know

If you wish, you can describe in the box below how you have experienced your encounters with your private insurance company (*voluntary*). (Remember not to write any personal identifiable information in your answer).

75. Have you reported your long-term health impacts after your suspected or confirmed COVID-19 infection as a work injury, and if so how do you experience your treatment in connection with this?

- No, not applicable to me (I do not work, alternatively have no reason to believe having been infected while doing my job)
- No, I was probably infected at work but have not reported it as a work injury
- Yes, I have reported it as a work injury and it was treated very well
- Yes, I have reported it as a work injury and it was treated quite well
- Yes, I have reported it as a work injury and it was treated quite badly
- Yes, I have reported it as a work injury and it was treated very badly
- Do not wish to answer / Do not know

If you wish, you can describe in the box below how you have experienced the treatment from your employer in connection with such a report or why you did not report it as a work injury even if you suspect that you were infected at work (*voluntary*). (Remember not to write any personal identifiable information in your answer).

Part 7: Information needs and information strategies as long-term ill

This part contains questions concerning your experienced information needs as long-term ill, how you go about handling them, and how you think the Swedish authorities have handled the information collection about and dissemination to the group of long-term ill in society.

Note that these questions are voluntary, it is possible to submit the survey without answering them. We are grateful if you still want and can take the time to answer these questions.

State, for each type of information below, how interested you, in your capacity of long term ill, are in getting / having access to it, i.e. your information needs regarding each type of information.

Note that you should state your needs of and interest for each information type without considering whether you have actually been able to obtain this information or not (the extent to which each type of information has actually been available to you, will be asked in the next question).

You are to answer on a scale from 0 - 5, where 0 = "No need at all" (no interest) and 5 = "Very large need" (very high interest).

76. What is your information need (interest) regarding information about long-term ill in an international perspective? (e.g. number of ill, data / statistics on symptoms and consequences)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

77. What is your information need (interest) regarding information about long-term ill in a national perspective? (e.g. number of ill, data / statistics on symptoms and consequences)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

78. What is your information need (interest) regarding research on long-COVID / post-COVID? (e.g. research results and scientific articles with studies on causes, symptoms, trial treatments)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

79. What is your information need (interest) regarding information about secondary (specialised) healthcare services for long-term ill? (e.g. what options there are and how to contact them)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

80. What is your information need (interest) regarding information about self-referrals within the healthcare system? (e.g. how to go about writing such a referral)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

81. What is your information need (interest) regarding information about antibody testing? (i.e. what testing options for antibodies that exist – "ordinary" antibody tests)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

82. What is your information need (interest) regarding information about other antibody testing? (i.e. T-cell test options)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

83. What is your information need (interest) regarding information about other testing for the long-term ill? (e.g. relevant medical test suggestions for investigation of symptoms and causes)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

84. What is your information need (interest) regarding information about your own test answers? (e.g. what they mean, how they should be interpreted)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

85. What is your information need (interest) regarding information about medical treatment of long-COVID / post-COVID? (e.g. what possible alternatives that exist and are recommended by authoritative agents)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

86. What is your information need (interest) regarding information about physical rehabilitation for the long-term ill? (e.g. what possible alternatives that exist and how to contact them)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

87. What is your information need (interest) regarding information about vaccine for the long-term ill? (e.g. where there is / will be availability; what effects that have been observed / can be expected; recommendations on vaccine for the long-term ill)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

88. What is your information need (interest) regarding information about personal advice? (e.g. opportunities of help and support for handling your personal health situation)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

89. What is your information need (interest) regarding information about standardised diagnostic codes concerning long-COVID / post-COVID? (e.g. what codes that are available; benefits and disadvantages with getting a diagnosis)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

90. What is your information need (interest) regarding information about rules and regulations in healthcare? (i.e. your rights and obligations as patient)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

91. What is your information need (interest) regarding information about labour law? (i.e. your rights and obligations as employed with long-term illness)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

92. What is your information need (interest) regarding information about the Swedish Social Security Agency's (Försäkringskassans) rules and regulations? (i.e. concerning your social security as long-term ill)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

93. What is your information need (interest) regarding information about student finance (grants and loans) through the Swedish Board of Student Finance (CSN)? (i.e. your related rights and obligations as long-term ill)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

94. What is your information need (interest) regarding information concerning how to exert political influence on behalf of the long-term ill / post-COVID sufferers? (e.g. how to act to affect the situation for you and other long-term ill in society)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

95. What is your information need (interest) regarding information about other long-COVID / post-COVID sufferers? (e.g. personal contact and communication possibilities)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

96. What is your information need (interest) regarding information about self-care? (e.g. alternatives and options for personal treatment of long-term symptoms outside of public healthcare)

- 0 - No need at all
- 1 - Very small need
- 2 - Quite small need
- 3 - Neither large nor small need
- 4 - Quite large need
- 5 - Very large need

**Possible additional comment to the questions concerning information needs (interest) above (*voluntary*).
(Remember not to write any personal identifiable information in your answer).**

State in the same way for each information type below how satisfied (content) you are with your ability to obtain (get hold of) and understand this information - "your access" to this information.

You are to answer on a scale from 0 - 5 where 0 = "Not used / No perception" and 5 = "Very satisfied" (completely content).

97. What do you think about your ability to access information about the long-term ill in an international perspective? (e.g. number of ill, data / statistics on symptoms and consequences)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

98. **What do you think about your ability to access information about the long-term ill in a national perspective? (e.g. number of ill, data / statistics on symptoms and consequences)**

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

99. **What do you think about your ability to access information about research on long-COVID / post-COVID? (e.g. research results and scientific articles with studies on causes, symptoms, trial treatments)**

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

100. **What do you think about your ability to access information about secondary (specialised) healthcare services for the long-term ill? (e.g. what options there are and how to contact them)**

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

101. **What do you think about your ability to access information about self-referrals within the healthcare system? (e.g. how to go about writing such a referral)**

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

102. What do you think about your ability to access information about ordinary antibody testing? (i.e. what testing options for antibodies that exist – "ordinary" antibody tests)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

103. What do you think about your ability to access information about other antibody testing? (i.e. T-cell test options)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

104. What do you think about your ability to access information about other testing for the long-term ill? (e.g. relevant medical test suggestions for investigation of symptoms and causes)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

105. What do you think about your ability to access information about your own test answers? (e.g. what they mean, how they should be interpreted)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

106. What do you think about your ability to access information about medical treatment of long-COVID / post-COVID? (e.g. what possible alternatives that exist and are recommended by authoritative agents)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

107. What do you think about your ability to access information about physical rehabilitation for the long-term ill? (e.g. what possible alternatives that exist and how to contact them)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

108. What do you think about your ability to access information about vaccine for the long-term ill? (e.g. where there is / will be availability; what effects that have been observed / can be expected; recommendations on vaccine for the long-term ill)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

109. What do you think about your ability to access information about personal advice? (e.g. opportunities of help and support for handling your personal health situation)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

110. What do you think about your ability to access information about standardised diagnostic codes concerning long-COVID / post-COVID? (e.g. what codes that are available; benefits and disadvantages with getting a diagnosis)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

111. What do you think about your ability to access information about rules and regulations in healthcare? (i.e. your rights and obligations as patient)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

112. What do you think about your ability to access information about labour law? (i.e. your rights and obligations as employed with long-term illness)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

113. What do you think about your ability to access information about the Swedish Social Security Agency's (Försäkringskassans) rules and regulations? (i.e. concerning your social security as long-term ill)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

114. What do you think about your ability to access information about student finance (grants and loans) through the Swedish Board of Student Finance (CSN)? (i.e. your related rights and obligations as long-term ill)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

115. What do you think about your ability to access information about how to exert political influence on behalf of the long-term ill (post-COVID sufferers)? (e.g. how to act to affect the situation for you and other long-term ill in society)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

116. What do you think about your ability to access information about other long-COVID / post-COVID sufferers? (e.g. personal contact and communication possibilities)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

117. What do you think about your ability to access information about self-care? (e.g. alternatives and options for personal treatment of long-term symptoms outside of public healthcare)

- 0 - Not used / no perception
- 1 - Very dissatisfied
- 2 - Quite dissatisfied
- 3 - Neither dissatisfied nor satisfied
- 4 - Quite satisfied
- 5 - Very satisfied

**Possible additional comment to the questions concerning information access above (*voluntary*).
(Remember not to write any personal identifiable information in your answer).**

118. Do you think that the long-term ill (post-COVID sufferers) in Sweden require more help than is currently available concerning possibilities to get hold of and interpret any or some of the types of information mentioned in the question above?

- Yes
- No
- Do not wish to answer respond / Do not know

If "Yes", you can explain in the box below which types of information that you mainly think about and how you would like such help to be offered (*voluntary*). (Remember not to write any personal identifiable information in your answer).

Significance and usability of information sources

In similar ways as above, we ask here below which of the following information sources that you have accessed or used during your time as long-term ill and how you value their significance and usability for you concerning your information needs as long-term ill (post-COVID sufferer).

You are to answer on a scale from 0-5 where 0 = "Not used / No perception" and 5 = "Very significant".

119. How significant and useful has a general (medical) practitioner been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

120. How significant and useful has an expert (specialist) doctor (not at specific / secondary post-COVID healthcare centre) been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

121. How significant and useful has an expert (specialist) doctor at a specific / secondary post-COVID healthcare centre been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

122. How significant and useful has public healthcare advice over the phone (1177, the Swedish Healthcare Guide) been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

123. How significant and useful has public healthcare advice online as written information (text) and 'chatbot' (1177.se, the Swedish Healthcare Guide online) been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

124. How significant and useful has the Swedish COVID Association been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

125. How significant and useful has research that you have sought and found on your own been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

126. How significant and useful has information on the internet (not research) that you have sought and found on your own been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

127. How significant and useful have Facebook groups for the long-term ill been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

128. How significant and useful have other social media groups for the long-term ill (not Facebook) been as information source to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

129. How significant and useful have private contacts (family, friends, and acquaintances) been as information sources to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

130. How significant and useful has other sources been as information sources to you?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

131. If "Other", you can explain in the box below which other sources of information that have been significant and useful as information sources to you (voluntary). (Remember not to write any personal identifiable information in your answer).

Valuation of information from public authorities

In the same way as above you will here receive a number of questions of how you value a few central public authorities concerning how significant and useful information that you as a long-term ill / post-COVID sufferer have been able to get from them.

You are to answer on a scale from 0-5 where 0 = "Not used / No perception" and 5 = "Very significant".

132. How significant and useful information have you as long-term ill (post-COVID sufferer) been able to get from the Swedish Public Health Agency (Folkhälsomyndigheten)?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

133. How significant and useful information have you as long-term ill (post-COVID sufferer) been able to get from the Swedish National Board of Health and Welfare (Socialstyrelsen)?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

134. How significant and useful information have you as long-term ill (post-COVID sufferer) been able to get from the Swedish Social Insurance Agency (Försäkringskassan)?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

135. How significant and useful information have you as long-term ill (post-COVID sufferer) been able to get from the Swedish Social Contingencies Agency (Myndigheten för samhällsskydd och beredskap)?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

136. How significant and useful information have you as long-term ill (post-COVID sufferer) been able to get from the Swedish Work Environment Authority (Arbetsmiljöverket)?

- 0 - Not used / no perception
- 1 - Very insignificant
- 2 - Quite insignificant
- 3 - Neither insignificant nor significant
- 4 - Quite significant
- 5 - Very significant

137. If you wish, you can explain in the box below more about your experience of the significance and usefulness of information from the Swedish public authorities to you as long-term ill (*voluntary*). (Remember not to write any personal identifiable information in your answer).

138. Do you think that the Swedish state and public authorities have done enough to produce knowledge about the long-term ill / post-COVID sufferers (e.g. by collecting data, information, experiences and points of view from the group of long-COVID sufferers themselves)?

- Yes, completely
- Yes, partly
- No
- Do not wish to answer / Do not know

139. Do you think that the Swedish state and public authorities have done enough to try to reach, communicate, and share information with the long-term ill (post-COVID) sufferers (e.g. concerning healthcare options, post-COVID research and knowledge, national and local plans and recommendations for care, treatment, and similar)?

- Yes, completely
- Yes, partly
- No
- Do not wish to answer / Do not know

140. Do you have any suggestions on how the Swedish state's and public authorities' information management concerning the long-term ill (post-COVID sufferers) could be improved? Write in your own words (voluntary). (Remember not to write any personal identifying information in your answer).

Clarification: "information management" is used here to denote all forms of collection of information, data and views from the group of long-term ill, as well as communication / sharing of relevant information and knowledge back to this group.

141. Have you, during your time of suffering from long COVID, answered questions concerning your health / your wellbeing in so called "polls" or "mini polls" on Facebook?

- Yes
- No
- Do not wish to answer / Do not know

142. Have you, during your time as long-term ill (post-COVID sufferer), answered questions about your health / your wellbeing in other surveys on the internet (besides questions on Facebook) that have not been part of ethically reviewed and approved research projects?

Clarification: if a questionnaire / survey is part of an ethics-reviewed research study, then all participants will be provided with clear information that the study has been reviewed and approved by an ethics review board in connection with the participation. The participants will then also be informed of whether participation in the study will involve the collection and processing of personal data and if so, how such data will be processed, and who is responsible for the study (as you were informed about such issues at the start of this survey).

- Yes
- No
- Do not wish to answer / Do not know

143. If you have answered "yes" to either of the two questions above (that is: if you have responded to non-ethically reviewed questions concerning your health in Facebook polls or in any other form on the internet), are you worried about what might happen to your personal data in connection with this?

- I have not answered such questions
- I have answered such questions but it does not worry me
- I have answered such questions and it worries me a little or a lot
- Do not wish to answer / Do not know

If you have responded to such questions, and worry "a little or a lot" about your personal privacy in connection with this, you may describe here below why you nevertheless decided to respond to these questions / surveys (voluntary). (Remember not to write any personal identifiable information in your answer).

144. If it would have been possible, would you be interested in participating in a research-led social forum (platform) on the internet where long-term ill (post-COVID sufferers) in Sweden could share and discuss healthcare administered test results, personally collected measurements (such as heart rate, sleep data and the like), experiences of symptoms and suggestions on interesting research questions with each other and with researchers?

- Yes
- No
- Do not wish to answer / Do not know

Possible comment (voluntary). (Remember not to write any personal identifying data in your response).

Part 8: Assessment of selected symptoms according to validated scales

In this second to last part of the survey, you get to respond more specifically concerning your experienced **character or degree of a few selected symptoms**. Please note that these questions are also optional (it is possible to submit the survey without answering them).

We are grateful if you still can take you time to respond to these questions.

If you have not had one or several of the symptoms below, do not mark any response on these questions (leave them blank).

145. Assessment for respiration according to the Chronic Obstructive Pulmonary Disease Assessment Test (CAT)

Below follows a few claims and answering options related to your respiration. The question that applies to all answer options is: How do you experience your respiration (breathing)?

Choose one alternative (0-5) for each question that best describes how you presently feel. Calculate a balanced representation of your experience over the nearest time period, i.e. during the last month. Choose only one answer per question.

- 0 = I never cough
 - 1
 - 2
 - 3
 - 4
 - 5 = I cough all the time
-
- 0 = I have no phlegm (mucus) on my chest at all
 - 1
 - 2
 - 3
 - 4
 - 5 = My chest is full of phlegm (mucus)
-
- 0 = My chest does not feel tight at all
 - 1
 - 2
 - 3
 - 4
 - 5 = My chest feels very tight
-
- 0 = When I walk up a hill or a flight of stairs I am not out of breath
 - 1
 - 2
 - 3
 - 4
 - 5 = When I walk up a hill or a flight of stairs I am completely out of breath

- 0 = I am not limited to doing any activities at home
 - 1
 - 2
 - 3
 - 4
 - 5 = I am completely limited to doing all activities at home
-
- 0 = I am confident leaving my home despite my lung condition
 - 1
 - 2
 - 3
 - 4
 - 5 = I am not confident leaving my home at all because of my lung condition
-
- 0 = I sleep soundly
 - 1
 - 2
 - 3
 - 4
 - 5 = I do not sleep soundly because of my lung condition
-
- 0 = I have lots of energy
 - 1
 - 2
 - 3
 - 4
 - 5 = I have no energy at all

146. Assessment for dyspnoea (respiratory distress) following the Modified Medical Research Council (mMRC) Dyspnea Scale

This rating scale is intended to measure your experience of dyspnoea (respiratory distress, or "air hunger"). Calculate a representative balance of your experiences in the nearest time period, i.e. during the last month.

Mark the alternative that best corresponds with your situation.

- I only get breathless with strenuous exercise
- I get short of breath when hurrying on level ground or walking up a slight hill
- I walk slower than people of the same age because of breathlessness, or I have to stop for breath when walking at my own pace on level ground
- I stop for breath after walking about 100 yards or after a few minutes on level ground
- I am too breathless to leave the house, or I am breathless when dressing or undressing

147. Assessment according to the mental fatigue scale (MFS)

In the questions that now follow we are interested in your current state, i.e. how you have been over the last month. When you are to compare with how it was before, you shall compare with how you were feeling before you became ill (in the suspected or confirmed COVID-19 infection). For each question there are four statements describing None (0), Mild (1), Moderate (2) and Severe (3).

We want you to mark the number that stands beside the statement that best describes your situation. Should you find that your problem falls between two statements, there are also figures to indicate this.

Fatigue

Have you felt fatigued during the past month? It does not matter if the fatigue is physical (muscular) or mental. If you recently experienced something unusual (for example an accident or short illness) you should try to disregard it when assessing your fatigue.

- 0 = I do not feel fatigued at all. (No abnormal fatigue, do not need to rest more than usual).
- 0.5
- 1 = I feel fatigued several times every day but I feel more alert after a rest.
- 1.5
- 2 = I feel fatigued for most of the day and taking a rest has little or no effect.
- 2.5
- 3 = I feel fatigued all the time and taking a rest makes no difference.

Lack of initiative

Do you find it difficult to start things? Do you experience resistance or a lack of initiative when you have to start something, no matter whether it is a new task or part of your everyday activities?

- 0 = I have no difficulty starting with things
- 0.5
- 1 = I find it more difficult starting things than I used to. I'd rather do it some other time.
- 1.5
- 2 = It takes a great effort to start things. This applies to everyday activities such as getting out of bed, washing myself and eating.
- 2.5
- 3 = I can't do the simplest of everyday tasks (eating, getting dressed). I need help with everything.

Mental fatigue

Does your brain become fatigued quickly when you have to think hard? Do you become mentally fatigued from things such as reading, watching TV or taking part in a conversation with several people? Do you have to take breaks or change to another activity?

- 0 = I can manage in the same way as usual. My ability for sustained mental effort is not reduced.
- 0.5
- 1 = I become fatigued quickly but am still able to make the same mental effort as before.
- 1.5
- 2 = I become fatigued quickly and have to take a break or do something else more often than before.
- 2.5
- 3 = I become fatigued so quickly that I can do nothing or have to abandon everything after a short period (approx. five minutes).

Mental recovery

How long do you need to recover after you have worked "until you drop" or are no longer able to concentrate on what you are doing?

- 0 = I need to rest for less than an hour before continuing whatever I am doing.
- 0.5
- 1 = I need to rest for more than an hour but do not require a night's sleep.
- 1.5
- 2 = I need a night's sleep before I can continue whatever I am doing
- 2.5
- 3 = I need several days rest in order to recover.

Concentration difficulties

Do you find it difficult to gather your thoughts and concentrate?

- 0 = I can concentrate as usual.
- 0.5
- 1 = I sometimes lose concentration, for example when reading or watching TV.
- 1.5
- 2 = I find it so difficult to concentrate that I have problems, for example reading a newspaper or taking part in a conversation with a group of people.
- 2.5
- 3 = I always have such difficulty concentrating that it is almost impossible to do anything.

Memory problems

Do you forget things more often than before, do you need to make notes or do you have to search for things at home or at work?

- 0 = I have no memory problems
- 0.5
- 1 = I forget things slightly more often than I should, but I am able to manage by making notes
- 1.5
- 2 = My poor memory causes frequent problems (for example forgetting important meetings or turning off the cooker).
- 2.5
- 3 = I can hardly remember anything at all.

Slowness of thinking

Do you feel slow or sluggish when you think about something? Do you feel that it takes an unusually long time to conclude a train of thought or solve a task that requires mental effort?

- 0 = My thoughts are neither slow nor sluggish when it comes to work involving mental effort.
- 0.5
- 1 = My thoughts are a bit slow one or a few times each day when I have to do something that requires serious mental effort.
- 1.5
- 2 = My thoughts often feel slow and sluggish, even when carrying out everyday activities, for example a conversation with a person or when reading the newspaper.
- 2.5
- 3 = My thoughts always feel very slow and sluggish.

Sensitivity to stress

Do you find it difficult to cope with stress that is, doing several things at the same time while under time pressure?

- 0 = I am able to cope with stress, in the same way as usual.
- 0.5
- 1 = I become more easily stressed, but only in demanding situations that I was previously able to manage.
- 1.5
- 2 = I become stressed more easily than before. I feel stressed in situations that previously did not bother me.
- 2.5
- 3 = I become stressed very easily. I feel stressed in unfamiliar or trying situations.

Increased tendency to become emotional

Do you find that you cry more easily than previously? Do you often burst into tears when, for example, you watch a sad film or talk with your family members? If you recently experienced something unusual (e.g. an accident or short illness) you should try to disregard it in your assessment.

- 0 = I am not more emotional than I used to be.
- 0.5
- 1 = I am more emotional than other people but it is something that is natural for me. I start to cry or my eyes fill with tears easily, but only in relation to things that affect me deeply.
- 1.5
- 2 = My emotions are problematic or embarrassing. I sometimes even start to cry about things that mean nothing to me. I try to avoid certain situations because of this.
- 2.5
- 3 = My emotions cause me great problems. They disturb my day-to-day relationship with members of my immediate family and make it difficult for me to cope outside the home.

Irritability or "a short fuse"

Are you unusually short-tempered or irritable about things that previously did not bother you?

- 0 = I am not more short-tempered or irritable than I used to be.
- 0.5
- 1 = I become more easily irritated, but it does not last very long.
- 1.5
- 2 = I become irritated very quickly about small things or things that do not bother other people.
- 2.5
- 3 = I react with extreme anger or rage, which I find very difficult to control.

Sensitivity to light

Are you sensitive to strong light?

- 0 = I have no increased sensitivity to light.
- 0.5
- 1 = I sometimes experience problems with strong light such as sunlight reflected by snow, water or glass, or strong lights at home, but I am able to cope with it, for example by wearing sunglasses.
- 1.5
- 2 = I am so sensitive to light that I prefer to carry out my daily activities in dim light. I find it difficult to leave the house without sunglasses.
- 2.5
- 3 = My sensitivity to light is so strong that I am unable to leave the house without sunglasses. I keep the blinds (or equivalent) drawn at all times.

Sensitivity to noise

Are you sensitive to noise?

- 0 = I do not suffer from increased sensitivity to noise.
- 0.5
- 1 = I sometimes have difficulty with loud noise (for example music, noise from the TV or radio or sudden, unexpected sounds), but I can deal with it easily by turning down the volume. My sensitivity to noise does not disturb my everyday life.
- 1.5
- 2 = I have a marked over-sensitivity to noise. I have to avoid loud noise or reduce it (for example by means of ear plugs) in order to cope with everyday life.
- 2.5
- 3 = My sensitivity to noise is so great that I find it difficult to manage at home despite sound insulation.

Decreased sleep at night

Do you sleep badly at night? If you are sleeping more than before at night, please check the "0". If you are taking sleeping tablets and sleep normally, please check "0".

- 0 = I do not sleep less than before.
- 0.5
- 1 = I have slight problems falling asleep or my sleep is shorter, lighter or more restless than before.
- 1.5
- 2 = I sleep at least two hours less than before and wake up frequently during the night without anything disturbing me
- 2.5
- 3 = I sleep less than two to three hours per night.

Increased sleep

Do you sleep longer and/or more deeply than before? If you are sleeping less than before, please check the "0". N.B. Please take account of time spent sleeping during the day.

- 0 = I do not sleep more than usual.
- 0.5
- 1 = I sleep longer or deeper, but less than two hours more than usual, including naps during the day.
- 1.5
- 2 = I sleep longer or deeper. At least two hours more than usual, including naps
- 2.5
- 3 = I sleep longer or deeper. At least four hours more than usual, and in addition I need to take a nap during the day.

24-hour variations

Do you find that at certain times of the day or night the problems we asked about (for example tiredness, lack of concentration) are better or worse? In the statements below, "regularly" means at least 3 to 4 days of the week

- 0 = I have not noticed that my problems are regularly better or worse at certain times, or I do not have any specific problems.
- 1 = There is a clear difference between certain times of the day. I can predict that I will feel better at certain times and worse at other times
- 2 = I feel unwell at all times of the day and night.

148. Assessment of reflux according to the RESQ-7 scale (Rydén, Denison, Karlsson & Vakil, 2013).

This section contains a number of questions that you are to answer according to your experience of reflux, heartburn.

For each question, choose the most suitable answer for you. Mark only one response per question / row.

Thinking about your symptoms over the past 7 days, how often have you had the following?

	Have not had	1 day	2 days	3-4 days	5-6 days	Daily
A burning feeling behind your breastbone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain behind your breastbone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A burning feeling in the centre of the upper stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain in the centre of the upper stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An acid taste in your mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unpleasant movement of material upwards from the stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Burping (gas coming from the stomach through the mouth)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Hoarseness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coughing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty swallowing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A bitter taste in your mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stomach contents (liquid or food) moving upwards to your throat or mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heartburn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thinking about your symptoms over the past 7 days, how would you rate the intensity of the following?

	Did not have	Very mild	Mild	Moderate	Moderately severe	Severe
A burning feeling behind your breastbone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain behind your breastbone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A burning feeling in the centre of the upper stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain in the centre of the upper stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An acid taste in your mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unpleasant movement of material upwards from the stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Burping (gas coming from the stomach through the mouth)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoarseness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coughing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty swallowing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A bitter taste in your mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stomach contents (liquid or food) moving upwards to your throat or mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heartburn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Part 9: Final question

Voluntary addition / remarks on the survey

149. In this last question of the survey, you can, if you wish, tell us about your experience of the survey or add things that you think that we should have asked about (*voluntary*). (*Remember not to write any personal identifying information in your answer*).

Thank you for your participation and important reminder!

Thank you for your participation in the survey! We wish to remind you to note and save your unique code for possible follow-up studies.

You may also print and save your submitted answers as a pdf file on your computer when you click submit to hand in your answers.

Do not forget to complete the survey by clicking "Submit response" below.