



Priority setting of future research into long-term symptoms of Covid-19 infection

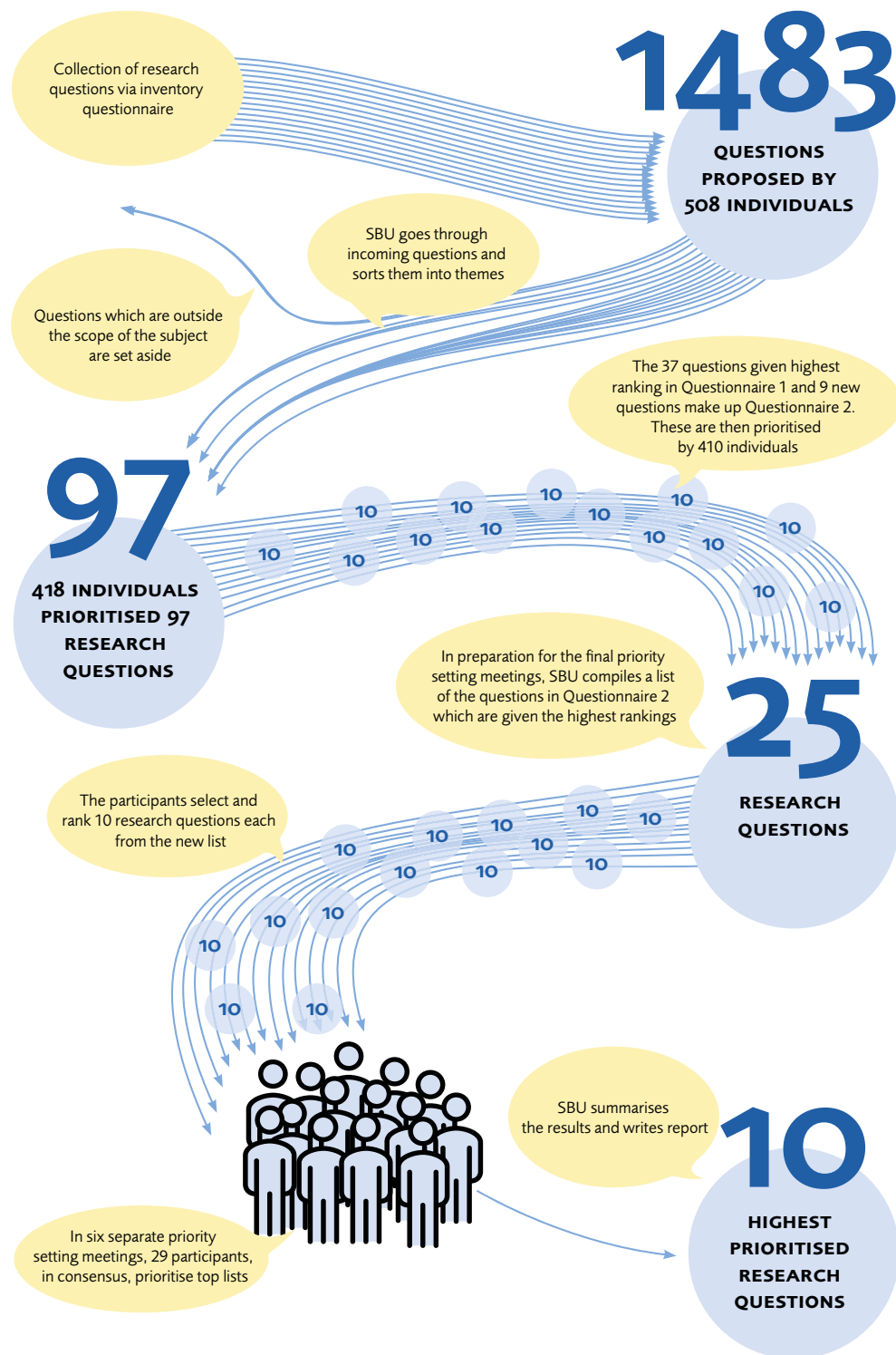
Post-acute sequelae of Covid-19 or Long Covid

Prioritering baserat på James Lind Alliance metod

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Figure 4.1 Flow chart of the project process.



that including other participants in the group could have yielded a different result. The strengths of the compilation of the working groups are that the participants came from different regions of the country, were of varying age and gender, and different professions, and represent both afflicted people with persistent symptoms, people who have recovered over time, those who were cared for in hospital or at home, and representatives of various professions, such as registered nurses, medical doctors with different specialties, enrolled nurses, speech therapists, physiotherapists and occupational therapists and psychotherapists.

A methodological difference between the present project and projects usually conducted by The James Lind Alliance is that throughout the process we have included researchers as one perspective. This perspective is not usually included in the final stages of the priority setting process because active researchers can be considered to have conflicts of interest. We chose to make an exception to this, because Covid-19 is a novel disease and research into the long-term symptoms is at an initial phase. Another reason for inclusion of researchers is that many people who are researching these topics are also those who have had most contact with these patients in the hospital setting. Moreover, we considered it important because the framework of the project did not allow a thorough search of all the available research: thus the researchers who were participating in the project could provide information in cases where further knowledge was required about the research questions being given priority. To reduce possible dominance of opinion, the project group ascertained that the researchers who participated in the priority setting meetings represented different disciplines and that discussion about their own fields of interest did not dominate during the meetings. It is also possible that nursing personnel, patients and relatives have conflicts of interest, and therefore every potential participant in the priority setting meetings was required to declare possible conflicts of interest before being included.

The frequency of responses to both questionnaires was relatively high, 76 and 74 per cent respectively. There is, however, a risk that the volume of information to be read and understood can have been overwhelming for certain people who are still suffering from severely impaired function. We have however, seen no difference in attrition among representatives for the various perspectives. To counteract this, we have tried to keep the information brief and easy to read and suggested that participants are welcome to seek help of a relative or the like when completing the questionnaire. In sending out the second questionnaire, we also decided to include all who initially notified their interest in participating, even if they had not responded to Questionnaire 1. Our hope was that those who may have had problems prioritising among the initial 97 questions, might be able to participate by prioritising from the shorter list in the second questionnaire.

Usually, projects of this kind are concluded with a physical full day meeting, of about 12 to 18 participants. Because of the restrictions at the time for a meeting of this size, the meeting was held digitally instead of in person. Other modifications made for the final priority setting meeting were to hold several shorter meetings instead of one longer meeting. Other modifications were also

made to the meeting structure to ease participation, as even a digital meeting of less than three hours can be difficult for participants, especially for those with cognitive issues, but also for clinicians with heavy workloads. Partakers were offered the opportunity to participate for a limited time or the opportunity to present their priority list early in the meeting. The advantages of this plan are: people who suffer, for example, from fatigue and cognitive dysfunction have a greater opportunity to participate; we could offer a larger group the opportunity to participate and so include more perspectives; and participants were given a choice of several meeting dates, which improved the potential for people to participate. The project group decided that a concluding discussion with all participants was not feasible, not only for practical reasons (like finding a time when everyone could attend) but also because of the limitations of the digital format (difficult to hold group discussions with a larger number of participants). We have therefore based the final results on a combination of the top lists compiled at each of the six priority setting meetings. However, to consolidate the results, the top list was sent out to all participants for perusal and comments. The disadvantage of this procedure is that we had no final mutual concluding discussion involving all the participants. Such a discussion could have resulted in a change in ranking of some of the questions, or inclusion of a question which was just outside the list, and in turn, removal of one of the existing questions. However, it is the opinion of the project team, based on the feedback we received, that the majority of participants are satisfied with this top list.

It may be stated that in general, there were similar discussions in all six priority setting meetings. All emphasised the importance of multifaceted research, covering the pattern of symptoms, cause, diagnosis, and treatment. It was acknowledged that as a basis for future research into treatment, it was important to establish the cause and the pattern of symptoms and to research the immune response, but it was also emphasised that initiation of treatment studies is important for those who currently have long-term symptoms. The groups pointed out that the types of treatment given this population vary, and that at present they are given inconsistent information about what rehabilitation etc. they should consider. Therefore, there was emphasis on the importance of a structured approach, through clinical research, to determine the effects of various forms of treatment. In this context the importance of study design was also discussed. Unfortunately, SBU's experience from previous systematic reviews is that in a large proportion of studies, the study design yields result that cannot be implemented. For example, uncontrolled studies, small studies, or studies in which the population and/or the intervention are inadequately described to allow replication of the study, or inclusion of the results in a systematic review and clinical application.

Covid-19 is a novel disease, and it may be debatable whether at this early stage it is an advantage or a disadvantage to compile a priority list of research questions. With high research activity, information on prioritised questions might enhance the potential for research to provide answers to those questions nominated as important by patients and health workers. At the same time the knowledge base is rapidly changing because of the intensive research activity and this could influence the results of the priority setting, and its useful life.

With respect to the research questions listed as priorities, a thorough audit of the state of research has not been undertaken. In December 2020, SBU published a report on research about the incidence of symptoms and treatment for people with long-term symptoms of Covid-19. However, this field of research is so dynamic that there may already be several new studies which influence the state of knowledge in the field. This implies that there are probably both published and ongoing studies in several of the prioritised research fields. It is therefore important that before initiating a new study, researchers update their assessment of the current state of knowledge. It is also important that in future, studies, after publication, are collated and evaluated in systematic reviews.

6 Project group

6.1 Experts

JUDITH BRUCHFELD
Senior medical officer,
Karolinska University Hospital

EMMA MÅRTENSSON
Patient advocate

6.2 Secretariat

MARIE ÖSTERBERG
Project Manager

IRINI ÅBERG
Project Administrator

CHRISTEL HELLBERG
Project Manager

SOFIA TRANÆUS
Head of department

6.3 Working group for priority setting meetings

Table 6.1 Working group for priority setting meetings

| Name | Perspective | Occupation/ other additional perspective | Participated in priority setting meetings |
|-------------------|---|--|---|
| Maria Rydberg | Personal experience of long-term symptoms of Covid-19 | | 1 |
| Anonymous | Relative | | 1 |
| Mia Marttinens | personal experience of long-term symptoms of Covid 19/relative | Midwife | 1 |
| David Gyll | Clinician (General medicine practitioner) | | 1 |
| Marta Santander | Personal experience of long-term symptoms of Covid-19 | | 2 |
| Lars Nord | Personal experience of long-term symptoms of Covid 19 | | 2 |
| Maziar Mohaddes | Other (Scientific secretary of Swedish Orthopaedic Association) | Orthopaedic surgeon, Researcher (Associate professor, Orthopaedics), Chief Medical Officer | 2 |
| Sture Eriksson | Researcher (Associate Professor, Psychogeriatric medicine) | ME relative. | 2 |
| Stefan Berg | Personal experience of long-term symptoms of Covid 19 | | 3 |
| Mathilda Sundvall | Personal experience of long-term symptoms of Covid-19 | Representative of Swedish Covid Association | 3 |
| Gisela Rosenkvist | Relative | Registered nurse | 3 |
| Lotti Orwelius | Researcher (Intensive care) | Intensive care nurse | 3 |
| Cia Skog | Personal experience of long-term symptoms of Covid 19 | Psychotherapist | 3 |
| Catarina Trägert | Personal experience of long-term symptoms of Covid- 19 | Paediatrician, Representative of Swedish Covid Association | 3 |
| Inger Nordlander | Relative | | 4 |
| Lasse Hagman | Personal experience of long-term symptoms of Covid-19 | | 4 |
| Hanna C Persson | Researcher (Rehabilitation medicine) | Senior physiotherapist | 4 |

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Table 6.1 continued

| Name | Perspective | Occupation/ other additional perspective | Participated in priority setting meetings |
|-------------------------|--|---|---|
| Lisbeth Friman | Personal experience of long-term symptoms of Covid -19 | Registered nurse, Political expert, Greater Stockholm region | 4 |
| Ted Eriksson | Relative | | 5 |
| Malin Sylveston | Personal experience of long-term symptoms of Covid -19 | | 5 |
| Artur Fedorowski | Clinician (cardiology) | Researcher (Associate professor, Cardiovascular Research), Senior Medical Officer | 5 |
| Annica Lifbom Johansson | Clinician (Registered physiotherapist) | | 5 |
| Eva Höglund | Personal experience of long-term symptoms of Covid-19/relative | Specialist registered nurse | 5 |
| Liisa Pettersson | Relative | Physiotherapist | 6 |
| Sara Johansson | Personal experience of long-term symptoms of Covid-19 | | 6 |
| Kristina Franzon | Personal experience of long-term symptoms of Covid-19 | Speech therapist | 6 |
| Kristian Borg | Researcher (Professor, Rehabilitation medicine) | Chief Medical Officer | 6 |
| Pia Nyberg | Personal experience of long-term symptoms of Covid-19 | Enrolled Nurse | 6 |
| Katarina Niward | Researcher (Inflammation and infection) | Chief Medical Officer infectious disease | 6 |

6.4 External reviewers

LARS-MAGNUS ANDERSSON

MD, PhD, Chairman Infectious diseases Clinic, Chief Medical Officer, Associate Professor Sahlgrenska University Hospital/East, Chairman of the Swedish Association of Specialists in Infectious Diseases.

MATS ULFENDAHL

Director of Research, Region Östergötland.

SBU appoints external scrutineers to evaluate its reports. They have contributed valuable comments which have improved the report. SBU has however, not always been able to accommodate their proposals for change and the external scrutineers do not necessarily support all the conclusions and texts in the report.

6.5 Conflicts of interest

In accordance with SBU's requirements, the experts, external reviewers participating and all participants in the priority setting meetings in this project have submitted statements about conflicts of interest. These documents are available at SBU's secretariat. SBU has determined that the conditions described in the submissions are compatible with SBU's requirements for objectivity and impartiality

6.6 SBU's scientific advisory board

SVANTE TWETMAN

Chair (dental), Professor emeritus,
University of Coopenhagen

CHRISTEL BAHTSEVANI

Malmö University, vice chair
(care science)

ANNA EHRENBORG, FALUN

Dalarna University (care science)

ANNA SARKADI

Uppsala University (social medicine)

ATA GHADERI, UPPSALA

Karolinska Institute (psychology)

BRITT-MARIE STÅLNACKE

Umeå University (medicine)

CHRISTINA NEHLIN-GORDH

Uppsala University (social care)

JAN HOLST

Malmö and Lund University
(medicine)

KATARINA STEEN CARLSSON

Lund University (health economy)

LARS SANDMAN

Linköping University (ethics)

LENA DAHLBERG

Falun, Dalarna University (social care)

MAGNUS SVARTENGREN

Uppsala University (working
environment)

MAGNUS TIDEMAN

Halmstad University (disability
research)

MARTIN BERGSTRÖM

Lund University (social care)

MARTIN HENRIKSSON

Linköping University (health
economy)

MUSSIE MSGHINA

Örebro University (medicine)

PERNILLA ÅSENLÖF

Uppsala University (physiotherapy)

STEN-ÅKE STENBERG

Stockholm University (social care)

SVERKER SVENSJÖ

Falun and Uppsala University
(medicine)

ULRIK KIHLMAN

Uppsala University (ethics)

7 Tables of questions received

| ID nr | Category | Research question | Question prioritised |
|-------|----------|---|--|
| 1 | Symptom | Are there differences in the course of the disease and types of persistent symptoms of Covid-19 between: men and women, people from different age groups, or people of different socioeconomic status (education, income, non-European origin)? | Carried forward to Questionnaire 2, then to priority setting meeting |
| 2 | Symptom | How do long-term symptoms of Covid-19 affect the body in people with other underlying health conditions? | |
| 3 | Symptom | How long can various symptoms of Covid-19 persist and do the different symptoms follow a specific course? | Carried forward to Questionnaire 2, then further to priority setting meeting |
| 4 | Symptom | How do the type and duration of long-term symptoms of Covid-19 and functional incapacity differ between those who needed intensive care and those who managed with self-care at home? | Carried forward to Questionnaire 2 |
| 5 | Symptom | What different kinds of long-term symptoms of Covid-19 occur and what proportion of patients are afflicted by the various symptoms? | Carried forward to Questionnaire 2, then further to priority setting meeting |
| 6 | Symptom | Is there a risk that certain long-term symptoms/ complications of Covid-19 can become chronic? | Carried forward to Questionnaire 2 and then on to priority setting meeting |

Tabell 7.1 Tables of questions received. Questions added after the first questionnaire are listed as ID number 100 to 108.

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|--|--|--|
| 7 | Symptom | What clinical manifestations occur in persons affected by long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 and then on to priority setting meeting. Included in final top list |
| 8 | Symptom | Which psychological symptoms occur in persons with long-term symptoms of Covid-19? | |
| 9 | Symptom | Which of the long-term symptoms of Covid-19 are potentially serious and which can confidently be allowed to heal themselves? | Carried forward to Questionnaire 2 and then on to priority setting meeting |
| 10 | Symptom | Which long-term symptoms of Covid-19 have the greatest effect on the daily life of patients? | Carried forward to Questionnaire 2 |
| 11 | Treatment/ complementary and alternative medicine | What are the positive and negative effects of complementary and alternative treatment methods for people with long-term symptoms of Covid-19? | |
| 12 | Treatment/ pharmaceuticals | What are the positive and negative effects of using immunosuppressive drugs in patients with long-term symptoms of covid-19? | |
| 13 | Treatment/ pharmaceuticals | What are the effects of treatment with antiallergenic drugs for people with long-term symptoms of Covid-19? | |
| 14 | Treatment/ pharmaceuticals | What are the positive and negative effects of betablockers on people with long-term symptoms of Covid-19? | |
| 15 | Treatment/ pharmaceuticals | What are the positive and negative effects of steroids/cortisone and other anti-inflammatory or analgesic drugs on people with long-term symptoms of covid-19? | Carried forward to Questionnaire 2 and then on to priority setting meeting |
| 16 | Treatment/ pharmaceuticals | What effects do antibiotics have on people with long-term symptoms of Covid-19? | |
| 17 | Treatment/ pharmaceuticals | What are the effects of antiviral treatment on people with long-term symptoms of covid-19? | |
| 18 | Treatment/ pharmaceuticals | What effects do immunomodulatory drugs have on people with long-term symptoms of Covid-19? | |
| 19 | Treatment/ pharmaceuticals | What effects do bronchodilators have on people with long-term symptoms of Covid-19? | |
| 20 | Treatment/ pharmaceuticals | Can the long-term symptoms of Covid-19 be exacerbated by use of certain medication intended for other conditions? | |
| 21 | Treatment/ pharmaceuticals | What is the effect of anticoagulants on people with long-term symptoms of Covid-19? | |
| 22 | Treatment/ pharmaceuticals | What are the effects of ataractic (anti-anxiety) and antidepressant medicine on people with long-term symptoms of covid-19? | |

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|--|---|--|
| 23 | Treatment/ pharmaceuticals | What effects are there, on the course of Covid-19 and on the body, from long-term treatment with analgesics? | |
| 24 | Treatment/ psychological treatment/ support | What effect does psychological/ psychiatric treatment have on people with long-term symptoms of Covid-19? | |
| 25 | Treatment/ psychological treatment/ support | What is the effect of various forms of support for relatives of people with long-term symptoms of Covid-19? | |
| 26 | Treatment/ psychological treatment/ support | What type of support can people with long-term symptoms of Covid-19 need and can this hasten recovery? | Carried forward to Questionnaire 2 |
| 27 | Treatment/ rehabilitation | Do people with long-term symptoms of Covid-19, who have not required hospitalisation, need the same type of rehabilitation as people who have been hospitalised? | Carried forward to Questionnaire 2 |
| 28 | Treatment/ rehabilitation | How can rehabilitation efforts after long-term symptoms of Covid-19 be optimised and what measures should be included (occupational therapy, physiotherapy, psychology, social worker, speech therapist, dietitian etc.)? | Carried forward to questionnaire 2, then to priority setting meeting, then on to the top priority list |
| 29 | Treatment/ rehabilitation | What physiotherapy treatment has the best effect on people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 |
| 30 | Treatment/ rehabilitation | What interventions should occupational therapists offer people with long-term symptoms of Covid-19? | |
| 31 | Treatment/ rehabilitation | What is the effect of cognitive training on people with long-term symptoms of Covid-19? | |
| 32 | Treatment/ rehabilitation | What rehabilitation/measures are optimal to facilitate return to work for people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2, then further to priority setting meeting |
| 33 | Treatment / rehabilitation | What is the effect of graded exercise training on people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 |
| 34 | Treatment / rehabilitation | Does pacing work for people with long-term symptoms of Covid-19? | |
| 35 | Treatment/ symptoms | What is effective treatment for people with long-term symptoms of Covid-19 experiencing disturbed sleep? | |
| 36 | Treatment/ symptoms | How can the cyclical course of symptoms best be reduced in cases of long-term symptoms of Covid-19? | |
| 37 | Treatment/ symptoms | What treatment is effective against long-term loss of sense of taste and smell associated with Covid-19? | Carried forward to Questionnaire 2 |

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|------------------------|---|---|
| 38 | Treatment/ symptoms | What treatment is most effective against persistent fever with Covid-19? | |
| 39 | Treatment/ symptoms | What treatment is effective against persistent neurological symptoms and cognitive disturbances (such as brain fog, memory loss, difficulty concentrating, fatigue, numbness, tremor, headache) associated with Covid-19? | Carried forward to Questionnaire 2 Then to priority setting meeting, Included in final top list |
| 40 | Treatment/ symptom | What treatment is effective for persistent hearing problems associated with Covid-19? | |
| 41 | Treatment/ symptom | What is the most effective treatment for persistent gastrointestinal symptoms associated with Covid-19? | |
| 42 | Treatment/ symptom | What is the most effective treatment for long-term impaired breathing function/ oxygen uptake or problems with respiratory arrest, associated with Covid-19? | Carried forward to questionnaire 2, then to priority setting meeting and to final top list |
| 43 | Treatment/ symptom | What is the most effective treatment for persistent cardiovascular symptoms associated with Covid-19 (including the risk of blood clots)? | Carried forward to Questionnaire 2 then further to priority setting meeting |
| 44 | Treatment/ symptom | What is the optimal treatment for persistent cramps and swelling in the diaphragm associated with Covid-19? | |
| 45 | Treatment/ symptom | What sort of treatment may be available to relieve coughing and phlegm in the lungs which are symptoms of long-term problems of Covid-19? | |
| 46 | Treatment/ selfcare | What are the positive and negative effects of physical training on people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 |
| 47 | Treatment/ selfcare | What selfcare advice helps people with long-term symptoms of Covid-19? | |
| 48 | Treatment/ selfcare | What is the effect of different diets/nutritive treatments on long-term symptoms of Covid-19? | |
| 49 | Treatment/ selfcare | What is the effect of treatment with vitamins, minerals or antioxidants on people with long-term symptoms of Covid-19? | |
| 50 | Treatment | Does treatment need to differ for women, men and possibly children with long-term symptoms of Covid-19? | |
| 51 | Children/ treatment | What form of treatment/rehabilitation is most effective for children with long-term symptoms of Covid-19? | |
| 52 | Children/ treatment | What complications are children at risk for after they develop long-term symptoms of Covid-19? | |

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|---------------------------|--|---|
| 53 | Children/ treatment | Is there any difference between the long-term symptoms of Covid-19 in children and adults and the underlying causes? | |
| 54 | Children/ treatment | What are the symptoms or clinical manifestations of long-term Covid-19 in children | |
| 55 | Attitudes/ experiences | How do people with long-term symptoms of Covid-19 describe the attitude of healthcare professionals? | |
| 56 | Attitudes/ experiences | How should clinicians' approach and best support people with long-term symptoms of Covid-19? | |
| 57 | Attitudes/ experiences | How do people with long-term symptoms of Covid-19 and their relatives perceive their illness (physical and mental function) and its impact on quality of life? | Carried forward to Questionnaire 2 |
| 58 | Attitudes/ experiences | What effect does the attitude of clinicians have on the course of Covid-19? | |
| 59 | Diagnosis/ follow-up | How can an objective diagnosis be made of people with long-term symptoms of covid-19, regardless of whether they have had a positive PCR test during the acute phase, or if they have demonstrable antibodies? | Carried forward to questionnaire 2, further to priority setting meeting, Included in final top list |
| 60 | Diagnosis/ follow-up | Can various types of assessment scales aid in determining subjective symptoms in patients with long-term problems after infection with Covid-19? | |
| 61 | Diagnosis/ Follow-up | Can expanded diagnosis, to investigate which organs are involved, result in better treatment and eventually prevent future complications in people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2, then to priority setting meeting, Included in final top list |
| 62 | Diagnosis/ Follow-up | What is a reasonable diagnostic procedure to follow for people with long-term symptoms of Covid-19 and what differential diagnoses should be excluded? | Carried forward to Questionnaire 2 and then to priority setting meeting |
| 63 | Diagnosis/ follow-up | Should other examinations or investigations be carried out, depending on how long the person has experienced symptoms of Covid-19? | |
| 64 | Diagnosis/ follow-up | What effect does being diagnosed with Covid-19 have on the likelihood of receiving treatment for long-term symptoms? | |
| 65 | Diagnosis/ follow-up | What follow-up and controls are optimal for people with long-term symptoms of Covid-19? | |
| 66 | Complications | Is there a heightened risk of people with long-term symptoms of Covid-19 contracting illnesses (both while the disease is active or after recovery)? | Carried forward to Questionnaire 2 and then to priority setting meeting |
| 67 | Sequelae | How many patients are afflicted with secondary complications after suffering long-term symptoms of Covid-19? | |

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|--------------------------|---|---|
| 68 | Sequelae | How do people with long-term symptoms of Covid-19 respond to other infections? | |
| 69 | Immunity and vaccination | What is the effect (benefit or risk) of vaccination against Covid-19 for people with long-term symptoms of Covid-19 and does this differ depending on the type of vaccine administered? | Carried forward to Questionnaire 2 and then to priority setting meeting |
| 70 | Immunity and vaccination | Is the immune response (e.g. T-cell response, antibodies to Covid-19, development of autoimmunity) different in people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 and then to priority setting meeting, Included in final top list |
| 71 | Immunity and vaccination | Is it possible to be reinfected even while currently suffering long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 |
| 72 | Organisation | What facilities do clinicians need to support a return to health and rehabilitation of people with long-term symptoms of covid-19? | |
| 73 | Organisation | What is the best means of disseminating information about long-term symptoms of Covid-19 to clinicians and administrative staff who are in contact with patients? | |
| 74 | Organisation | What is the best way of organizing care for people with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 and then to priority setting meeting |
| 75 | Organisation | What is the effect of supportive central postcovid-19 teams /specialist clinics for people with long-term symptoms of Covid-19? | |
| 76 | Organisation | What is the effect of multidisciplinary teams for people with long-term symptoms of Covid-19? | |
| 77 | Organisation | Can adopting procedures from other countries/ international co-operation result in more effective treatment for people with long-term symptoms of Covid-19? | |
| 78 | Cause | To what extent is it the virus or the person's own immune response which gives rise to symptoms in those with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 and then to priority setting meeting |
| 79 | Cause | What is the underlying cause of the various patterns of symptoms in people with long-term symptoms of covid-19? | Carried forward to Questionnaire 2, then to priority setting meeting, Included in final top list |
| 80 | Cause | Why do the symptoms occur intermittently in people with long-term symptoms of Covid-19? | |

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|----------------------------------|--|---|
| 81 | Cause | Can the virus remain in the body of a person with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 then to priority setting meeting |
| 82 | Cause | Are the long-term symptoms of Covid-19 caused by the same disease mechanism or should they be regarded as several different courses of events? | |
| 83 | Prevention of long-term symptoms | What treatment can be given during the acute phase to prevent the development of long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 then to priority setting meeting, included in final top list |
| 84 | Association/risk | What is the significance of environmental factors for people in need of rehabilitation after suffering long-term symptoms of Covid-19? | |
| 85 | Association/risk | Why do certain people develop long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 then to priority setting meeting, included in final top list |
| 86 | Association/risk | Is there a link between previous illness/conditions and long-term symptoms of covid-19? | Carried forward to Questionnaire 2 |
| 87 | Association/risk | Is there an association between how sick the person was during the acute phase and the occurrence of long-term symptoms of Covid-19? | |
| 88 | Other | What risks are associated with premature/rapid return to work for people with long-term symptoms of Covid-19? | |
| 89 | Other | Are there similarities between other diseases and long-term symptoms of Covid-19? | |
| 90 | Other | What is the cost-benefit of all the research, interventions and treatment strategies for long-term symptoms of Covid-19? | |
| 91 | Other | How long is a person with long-term symptoms of Covid-19 infectious? | |
| 92 | Other | How can research conducted on hospitalised patients be applied to the group of long-term patients with Covid-19 who were not treated in hospital? | |
| 93 | Other | How do the Swedish Social Insurance Agency's regulations and decisions affect recovery and rehabilitation of patients with long-term symptoms of Covid-19? | Carried forward to Questionnaire 2, then to priority setting meeting |
| 94 | Other | How are relationships, parenthood and partnerships influenced by long-term Covid-19 symptoms? | |
| 95 | Other | How does the language used to describe long-term symptoms after Covid-19 influence how this condition is handled by healthcare system, the Swedish Social Insurance Agency, and employers? | |

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Table 7.1 continued

| ID nr | Category | Research question | Question prioritised |
|-------|----------|--|------------------------------------|
| 96 | Other | What will be the economic consequences, for patients and society, of long-term symptoms of Covid-19? | Carried forward to Questionnaire 2 |
| 97 | Other | What is the need for sick leave among people with long-term symptoms of Covid-19? | |
| 100 | New | What is the best way of differentiating people with psychosomatic symptoms who seek treatment for long-term symptoms of Covid-19? | |
| 101 | New | What are the differences in persistent symptoms, severity of functional incapacity, duration of symptoms, and how many are afflicted, with Post Intensive Care Syndrome (PICS) between those who were infected with Covid-19 and needed intensive care, compared with those who needed intensive care for reasons other than Covid-19? | |
| 102 | New | What is the relationship between Postural Orthostatic Tachycardia syndrome (POTS) and long-term symptoms of Covid-19? | |
| 103 | New | What is the relationship between hormones and long-term symptoms of Covid-19? For example, related to menopause, menstruation and metabolism. | |
| 104 | New | What are the positive and negative effects of treatment based on pressure changes, so-called hyperbaric oxygen treatment? | |
| 105 | New | How many people in Sweden have long-term symptoms of Covid-19 and what is the best way of applying the existing diagnostic codes? | |
| 106 | New | Is there any method (test, estimate, biomarker) which can be used in the acute phase to predict which patients will develop long-term symptoms of Covid-19? | |
| 107 | New | How are people with long-term symptoms of Covid-19 affected by a possible reinfection? | |
| 108 | New | How can society progress/ learn from the way the health sector has managed the disease, the treatment decisions, documentation and research with reference to long-term symptoms of Covid-19? | |

8 Glossary and Abbreviations

| | |
|-----------------------------------|---|
| Delphi Method | A panel of people who, independently of one another, anonymously answer a questionnaire multiple times. The repetition gives the participants the opportunity to re-evaluate their answers. The questionnaires are compiled and form the basis of a consensus decision |
| Evidence | Research results which are systematically searched, assessed for relevance and quality and summarized. |
| Implementation | A procedure used to introduce new methods or knowledge into everyday routines. Implementation also includes discarding, i.e., less effective methods are abandoned or used less when other methods which have been shown to be more effective are introduced. |
| Intervention | A measure which is tested, usually treatment for a disease (pharmaceutical, surgical procedure. etc.) or a preventive method. |
| Consensus | Agreement which is reached by a group of people. Also includes the ethical conditions and the means used to arrive at this agreement. |
| Practice-oriented research | Research undertaken into procedures applied in the practice of health and medicine, social services and LSS-activity (or new measures which might be introduced). Often two or more measures are compared, to determine their positive and negative effects (e.g. randomised trials and observational studies), but it can also include qualitative studies of experiences. |
| Primary study | A study in which data are collected on individuals. The term is used to differentiate these studies from secondary studies which involve analysis of data collected from previous studies (for example in a systematic review). |
| RCT | Randomised controlled trial. An investigation which is both randomised and comparative (controlled). |
| Systematic overview | Summary of the results of studies on a specifically formulated question, which have been identified by systematic and explicit methods, then selected and critically appraised |
| Risk of bias | The risk of an error arising in results in the research process, which has occurred in the study design, conduct, assessment of effect, publication or other handling of the results and which is not due to co-incidence |
| Outcome | In an intervention study, it is the outcome which is ultimately measured. |

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Appendix 1

Results of questionnaires

Table xx Results of questionnaires 1 and 2

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|-----|----------|-----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| | | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 |
| | Questionnaire | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 |
| 1 | Are there differences in the course of the disease and types of persistent symptoms of Covid-19 between: men and women, people from different age groups, or people of different socioeconomic status (education, income, non-European origin)? | 7% | 7% | 0% | 0% | 19% | 27% | 25% | 42% | 4% | 3% | 36% | 18% | 9% | 6% |
| 2 | How do long-term symptoms of Covid-19 affect the body in people with other underlying health conditions? | 6% | – | 0% | – | 0% | – | 0% | – | 7% | – | 0% | – | 6% | – |
| 3 | How long can various symptoms of Covid-19 persist and do the different symptoms follow a specific course? | 26% | 27% | 22% | 12% | 6% | 18% | 20% | 17% | 26% | 29% | 27% | 24% | 41% | 22% |
| 4 | How do the type and duration of long-term symptoms of Covid-19 and functional incapacity differ between those who needed intensive care and those who managed with self-care at home? | 7% | 6% | 6% | 0% | 6% | 18% | 30% | 25% | 5% | 4% | 27% | 6% | 9% | 9% |
| 5 | What different kinds of long-term symptoms of Covid-19 occur and what proportion of patients are afflicted by the various symptoms? | 25% | 26% | 33% | 35% | 38% | 55% | 40% | 42% | 21% | 23% | 45% | 24% | 44% | 34% |

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Table xx continued

| ID | Question | In total | | Relative | | Other | Researcher | | Patient | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | | | |
|----|---|----------|-----|----------|-----|-------|------------|-----|---------|------------|-----|---|-----|-----|-----|
| 6 | Is there a risk that certain long-term symptoms/ complications of Covid-19 can become chronic? | 49% | 53% | 39% | 53% | 0% | 9% | 20% | 21% | 56% | 60% | 18% | 12% | 38% | 44% |
| 7 | What clinical manifestations occur in persons affected by long-term symptoms of Covid-19? | 26% | 31% | 22% | 29% | 25% | 55% | 40% | 25% | 24% | 30% | 9% | 24% | 44% | 47% |
| 8 | Which psychological symptoms occur in persons with long-term symptoms of Covid-19? | 5% | – | 0% | – | 13% | – | 10% | – | 5% | – | 9% | – | 0% | – |
| 9 | Which of the long-term symptoms of Covid-19 are potentially serious and which can confidently be allowed to heal themselves? | 28% | 33% | 39% | 47% | 19% | 27% | 10% | 13% | 31% | 37% | 0% | 12% | 19% | 16% |
| 10 | Which long-term symptoms of Covid-19 have the greatest effect on the daily life of patients? | 8% | 11% | 11% | 6% | 19% | 18% | 10% | 25% | 7% | 10% | 18% | 12% | 9% | 9% |
| 11 | What are the positive and negative effects of complementary and alternative treatment methods for people with long-term symptoms of Covid-19? | 10% | – | 17% | – | 0% | – | 5% | – | 11% | – | 0% | – | 9% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|-----|----------|-----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| 12 | What are the positive and negative effects of using immunosuppressive drugs in patients with long-term symptoms of covid-19? | 13% | – | 11% | – | 6% | – | 10% | – | 14% | – | 9% | – | 9% | – |
| 13 | What are the effects of treatment with antiallergenic drugs for people with long-term symptoms of Covid-19? | 6% | – | 0% | – | 0% | – | 0% | – | 8% | – | 0% | – | 3% | – |
| 14 | What are the positive and negative effects of betablockers on people with long-term symptoms of Covid-19? | 3% | – | 0% | – | 6% | – | 0% | – | 3% | – | 0% | – | 6% | – |
| 15 | What are the positive and negative effects of steroids/ cortisone and other anti-inflammatory or analgesic drugs on people with long-term symptoms of covid-19? | 19% | 28% | 22% | 24% | 13% | 36% | 25% | 29% | 20% | 28% | 9% | 12% | 13% | 31% |
| 16 | What effects do antibiotics have on people with long-term symptoms of Covid-19? | 2% | – | 0% | – | 0% | – | 0% | – | 2% | – | 0% | – | 6% | – |
| 17 | What are the effects of antiviral treatment on people with long-term symptoms of covid-19? | 12% | – | 6% | – | 6% | – | 5% | – | 13% | – | 0% | – | 13% | – |
| 18 | What effects do immunomodulatory drugs have on people with long-term symptoms of Covid-19? | 9% | – | 11% | – | 13% | – | 10% | – | 7% | – | 9% | – | 16% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|---|----------|---|-------|---|------------|---|---------|---|------------|---|---|---|
| 19 | What effects do bronchodilators have on people with long-term symptoms of Covid-19? | 5% | – | 6% | – | 0% | – | 0% | – | 5% | – | 9% | – | 9% | – |
| 20 | Can the long-term symptoms of Covid-19 be exacerbated by use of certain medication intended for other conditions? | 5% | – | 17% | – | 13% | – | 0% | – | 5% | – | 0% | – | 6% | – |
| 21 | What is the effect of anticoagulants on people with long-term symptoms of Covid-19? | 3% | – | 0% | – | 6% | – | 5% | – | 2% | – | 0% | – | 3% | – |
| 22 | What are the effects of ataractic (anti-anxiety) and antidepressant medicine on people with long-term symptoms of covid-19? | 1% | – | 0% | – | 0% | – | 0% | – | 1% | – | 18% | – | 0% | – |
| 23 | What effects are there, on the course of Covid-19 and on the body, from long-term treatment with analgesics? | 2% | – | 0% | – | 0% | – | 0% | – | 2% | – | 0% | – | 6% | – |
| 24 | What effect does psychological/ psychiatric treatment have on people with long-term symptoms of Covid-19? | 2% | – | 6% | – | 6% | – | 10% | – | 1% | – | 18% | – | 0% | – |
| 25 | What is the effect of various forms of support for relatives of people with long-term symptoms of Covid-19? | 0% | – | 0% | – | 0% | – | 0% | – | 0% | – | 0% | – | 0% | – |

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Table xx continued

| ID | Question | In total | Relative | Other | Researcher | Patient | Clinicians | Clinicians (or researcher) as well as patient (or relative) | | | | | | | |
|----|---|----------|----------|-------|------------|---------|------------|---|-----|-----|-----|-----|-----|-----|-----|
| 26 | What type of support can people with long-term symptoms of Covid-19 need and can this hasten recovery? | 8% | 15% | 22% | 18% | 19% | 27% | 10% | 13% | 8% | 16% | 9% | 6% | 0% | 16% |
| 27 | Do people with long-term symptoms of Covid-19, who have not required hospitalisation, need the same type of rehabilitation as people who have been hospitalised? | 9% | 10% | 0% | 6% | 6% | 0% | 15% | 21% | 8% | 9% | 36% | 18% | 9% | 13% |
| 28 | How can rehabilitation efforts after long-term symptoms of Covid-19 be optimised and what measures should be included (occupational therapy, physiotherapy, psychology, social worker, speech therapist, dietitian etc.)? | 33% | 42% | 50% | 41% | 25% | 55% | 55% | 33% | 29% | 42% | 64% | 53% | 41% | 34% |
| 29 | What physiotherapy treatment has the best effect on people with long-term symptoms of Covid-19? | 10% | 11% | 6% | 12% | 6% | 36% | 5% | 8% | 9% | 11% | 36% | 12% | 19% | 13% |
| 30 | What interventions should occupational therapists offer people with long-term symptoms of Covid-19? | 2% | – | 0% | – | 0% | – | 5% | – | 1% | – | 18% | – | 0% | – |
| 31 | What is the effect of cognitive training on people with long-term symptoms of Covid-19? | 4% | – | 0% | – | 6% | – | 5% | – | 4% | – | 9% | – | 0% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|-----|----------|----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| 32 | What rehabilitation/measures are optimal to facilitate return to work for people with long-term symptoms of Covid-19? | 11% | 13% | 6% | 0% | 13% | 0% | 10% | 29% | 10% | 13% | 36% | 29% | 9% | 13% |
| 33 | What is the effect of graded exercise training on people with long-term symptoms of Covid-19? | 3% | 3% | 0% | 6% | 0% | 9% | 5% | 0% | 2% | 4% | 27% | 0% | 3% | 0% |
| 34 | Does pacing work for people with long-term symptoms of Covid-19? | 4% | – | 11% | – | 6% | – | 0% | – | 3% | – | 0% | – | 13% | – |
| 35 | What is effective treatment for people with long-term symptoms of Covid-19 experiencing disturbed sleep? | 5% | – | 6% | – | 0% | – | 0% | – | 6% | – | 0% | – | 6% | – |
| 36 | How can the cyclical course of symptoms best be reduced in cases of long-term symptoms of Covid-19? | 11% | – | 17% | – | 6% | – | 0% | – | 13% | – | 0% | – | 9% | – |
| 37 | What treatment is effective against long-term loss of sense of taste and smell associated with Covid-19? | 8% | 9% | 0% | 0% | 19% | 18% | 0% | 8% | 7% | 8% | 18% | 18% | 9% | 13% |
| 38 | What treatment is most effective against persistent fever with Covid-19? | 8% | – | 17% | – | 0% | – | 0% | – | 8% | – | 0% | – | 16% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|--|----------|-----|----------|-----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| 39 | What treatment is effective against persistent neurological symptoms and cognitive disturbances (such as brain fog, memory loss, difficulty concentrating, fatigue, numbness, tremor, headache) with Covid-19? | 38% | 53% | 61% | 82% | 38% | 45% | 30% | 54% | 39% | 54% | 18% | 47% | 25% | 41% |
| 40 | What treatment is effective for persistent hearing problems associated with Covid-19? | 3% | – | 0% | – | 0% | – | 0% | – | 3% | – | 0% | – | 3% | – |
| 41 | What is the most effective treatment for persistent gastrointestinal symptoms associated with Covid-19? | 5% | – | 11% | – | 0% | – | 0% | – | 6% | – | 0% | – | 6% | – |
| 42 | What is the most effective treatment for long-term impaired breathing function/ oxygen uptake or problems with respiratory arrest, associated with Covid-19? | 19% | 27% | 6% | 29% | 25% | 27% | 20% | 29% | 20% | 27% | 18% | 35% | 13% | 22% |
| 43 | What is the most effective treatment for persistent cardiovascular symptoms associated with Covid-19 (including the risk of blood clots)? | 16% | 22% | 17% | 29% | 19% | 18% | 15% | 13% | 17% | 24% | 18% | 6% | 9% | 19% |

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| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|-----|----------|----|-------|----|------------|-----|---------|-----|------------|-----|---|-----|
| 44 | What is the optimal treatment for persistent cramps and swelling in the diaphragm associated with Covid-19? | 2% | – | 0% | – | 0% | – | 0% | – | 3% | – | 0% | – | 3% | – |
| 45 | What sort of treatment may be available to relieve coughing and phlegm in the lungs which are symptoms of long-term problems of Covid-19? | 5% | – | 6% | – | 0% | – | 5% | – | 5% | – | 0% | – | 0% | – |
| 46 | What are the positive and negative effects of physical training on people with long-term symptoms of Covid-19? | 17% | 14% | 22% | 6% | 19% | 9% | 30% | 13% | 16% | 15% | 0% | 12% | 22% | 16% |
| 47 | What selfcare advice helps people with long-term symptoms of Covid-19? | 10% | – | 11% | – | 13% | – | 5% | – | 10% | – | 9% | – | 9% | – |
| 48 | What is the effect of different diets/nutritive treatments on long-term symptoms of Covid-19? | 5% | – | 6% | – | 0% | – | 0% | – | 6% | – | 0% | – | 3% | – |
| 49 | What is the effect of treatment with vitamins, minerals or antioxidants on people with long-term symptoms of Covid-19? | 8% | – | 11% | – | 0% | – | 0% | – | 8% | – | 0% | – | 16% | – |
| 50 | Does treatment need to differ for women, men and possibly children with long-term symptoms of Covid-19? | 5% | – | 11% | – | 0% | – | 15% | – | 4% | – | 9% | – | 0% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|--|----------|-----|----------|-----|-------|----|------------|-----|---------|-----|------------|-----|---|-----|
| 51 | What form of treatment/ rehabilitation is most effective for children with long-term symptoms of Covid-19? | 6% | – | 6% | – | 6% | – | 5% | – | 7% | – | 9% | – | 0% | – |
| 52 | What complications are children at risk for after they develop long-term symptoms of Covid-19? | 6% | – | 0% | – | 13% | – | 0% | – | 6% | – | 9% | – | 0% | – |
| 53 | Is there any difference between the long-term symptoms of Covid-19 in children and adults and the underlying causes? | 6% | – | 0% | – | 13% | – | 10% | – | 5% | – | 9% | – | 6% | – |
| 54 | What are the symptoms or clinical manifestations of long-term Covid-19 in children | 3% | – | 0% | – | 0% | – | 0% | – | 3% | – | 9% | – | 3% | – |
| 55 | How do people with long-term symptoms of Covid-19 describe the attitude of healthcare professionals? | 7% | – | 11% | – | 6% | – | 15% | – | 6% | – | 0% | – | 13% | – |
| 56 | How should clinicians' approach and best support people with long-term symptoms of Covid-19? | 14% | – | 6% | – | 6% | – | 5% | – | 16% | – | 0% | – | 13% | – |
| 57 | How do people with long-term symptoms of Covid-19 and their relatives perceive their illness (physical and mental function) and its impact on quality of life? | 4% | 12% | 0% | 24% | 19% | 9% | 15% | 25% | 2% | 10% | 0% | 12% | 6% | 16% |

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| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|--|----------|-----|----------|-----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| 58 | What effect does the attitude of clinicians have on the course of Covid-19? | 4% | – | 0% | – | 13% | – | 5% | – | 4% | – | 0% | – | 3% | – |
| 59 | How can an objective diagnosis be made of people with long-term symptoms of covid-19, regardless of whether they have had a positive PCR test during the acute phase, or if they have demonstrable antibodies? | 23% | 22% | 44% | 35% | 13% | 9% | 15% | 21% | 23% | 22% | 27% | 18% | 22% | 25% |
| 60 | Can various types of assessment scales aid in determining subjective symptoms in patients with long-term problems after infection with Covid-19? | 3% | – | 0% | – | 0% | – | 15% | – | 2% | – | 18% | – | 0% | – |
| 61 | Can expanded diagnosis, to investigate which organs are involved, result in better treatment and eventually prevent future complications in people with long-term symptoms of Covid-19? | 20% | 26% | 28% | 47% | 6% | 27% | 10% | 17% | 22% | 28% | 9% | 12% | 19% | 13% |
| 62 | What is a reasonable diagnostic procedure to follow for people with long-term symptoms of Covid-19 and what differential diagnoses should be excluded? | 16% | 19% | 33% | 24% | 31% | 36% | 5% | 17% | 13% | 18% | 36% | 29% | 25% | 13% |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|--|----------|-----|----------|-----|-------|-----|------------|----|---------|-----|------------|-----|---|-----|
| 63 | Should other examinations or investigations be carried out, depending on how long the person has experienced symptoms of Covid-19? | 3% | – | 0% | – | 6% | – | 0% | – | 4% | – | 9% | – | 0% | – |
| 64 | What effect does being diagnosed with Covid-19 have on the likelihood of receiving treatment for long-term symptoms? | 1% | – | 0% | – | 0% | – | 0% | – | 2% | – | 0% | – | 0% | – |
| 65 | What follow-up and controls are optimal for people with long-term symptoms of Covid-19? | 11% | – | 11% | – | 6% | – | 5% | – | 11% | – | 9% | – | 9% | – |
| 66 | Is there a heightened risk of people with long-term symptoms of Covid-19 contracting illnesses (both while the disease is active or after recovery)? | 18% | 30% | 6% | 12% | 31% | 18% | 10% | 8% | 19% | 32% | 0% | 29% | 19% | 41% |
| 67 | How many patients are afflicted with secondary complications after suffering long-term symptoms of Covid-19? | 6% | – | 0% | – | 6% | – | 10% | – | 6% | – | 9% | – | 16% | – |
| 68 | How do people with long-term symptoms of Covid-19 respond to other infections? | 7% | – | 0% | – | 0% | – | 0% | – | 8% | – | 0% | – | 6% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|-----|----------|-----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| 69 | What is the effect (benefit or risk) of vaccination against Covid-19 for people with long-term symptoms of Covid-19 and does this differ depending on the type of vaccine administered? | 26% | 32% | 11% | 41% | 6% | 9% | 25% | 8% | 29% | 37% | 9% | 0% | 25% | 25% |
| 70 | Is the immune response (e.g. T-cell response, antibodies to Covid-19, development of autoimmunity) different in people with long-term symptoms of Covid-19? | 14% | 30% | 0% | 0% | 19% | 27% | 10% | 21% | 16% | 33% | 9% | 24% | 13% | 19% |
| 71 | Is it possible to be reinfected even while currently suffering long-term symptoms of Covid-19? | 7% | 8% | 0% | 29% | 19% | 0% | 0% | 13% | 7% | 7% | 9% | 0% | 3% | 9% |
| 72 | What facilities do clinicians need to support a return to health and rehabilitation of people with long-term symptoms of covid-19? | 4% | – | 6% | – | 13% | – | 0% | – | 3% | – | 9% | – | 6% | – |
| 73 | What is the best means of disseminating information about long-term symptoms of Covid-19 to clinicians and administrative staff who are in contact with patients? | 5% | – | 6% | – | 0% | – | 0% | – | 6% | – | 0% | – | 0% | – |

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Table xx continued

| ID | Question | In total | | Relative | | Other | Researcher | | Patient | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | | | |
|----|---|----------|-----|----------|-----|-------|------------|-----|---------|------------|-----|---|-----|-----|-----|
| 74 | What is the best way of organizing care for people with long-term symptoms of Covid-19? | 17% | 26% | 22% | 29% | 6% | 18% | 20% | 29% | 16% | 26% | 9% | 29% | 28% | 25% |
| 75 | What is the effect of supportive central postcovid-19 teams /specialist clinics for people with long-term symptoms of Covid-19? | 3% | – | 0% | – | 6% | – | 5% | – | 2% | – | 9% | – | 3% | – |
| 76 | What is the effect of multidisciplinary teams for people with long-term symptoms of Covid-19? | 5% | – | 6% | – | 13% | – | 15% | – | 3% | – | 18% | – | 6% | – |
| 77 | Can adopting procedures from other countries/ international co-operation result in more effective treatment for people with long-term symptoms of Covid-19? | 6% | – | 0% | – | 13% | – | 0% | – | 7% | – | 0% | – | 0% | – |
| 78 | To what extent is it the virus or the person's own immune response which gives rise to symptoms in those with long-term symptoms of Covid-19? | 19% | 27% | 6% | 29% | 13% | 18% | 20% | 21% | 22% | 28% | 0% | 12% | 6% | 22% |
| 79 | What is the underlying cause of the various patterns of symptoms in people with long-term symptoms of covid-19? | 12% | 22% | 17% | 18% | 25% | 0% | 15% | 17% | 10% | 21% | 9% | 41% | 22% | 34% |

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| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|--|----------|-----|----------|-----|-------|-----|------------|-----|---------|-----|------------|-----|---|-----|
| 80 | Why do the symptoms occur intermittently in people with long-term symptoms of Covid-19? | 16% | – | 0% | – | 13% | – | 5% | – | 18% | – | 9% | – | 6% | – |
| 81 | Can the virus remain in the body of a person with long-term symptoms of Covid-19? | 18% | 23% | 6% | 12% | 0% | 9% | 10% | 4% | 22% | 27% | 0% | 12% | 6% | 22% |
| 82 | Are the long-term symptoms of Covid-19 caused by the same disease mechanism or should they be regarded as several different courses of events? | 5% | – | 6% | – | 6% | – | 5% | – | 4% | – | 18% | – | 9% | – |
| 83 | What treatment can be given during the acute phase to prevent the development of long-term symptoms of Covid-19? | 17% | 21% | 28% | 29% | 25% | 36% | 30% | 33% | 15% | 19% | 18% | 18% | 19% | 22% |
| 84 | What is the significance of environmental factors for people in need of rehabilitation after suffering long-term symptoms of Covid-19? | 1% | – | 6% | – | 0% | – | 0% | – | 1% | – | 9% | – | 0% | – |
| 85 | Why do certain people develop long-term symptoms of Covid-19? | 24% | 31% | 17% | 29% | 6% | 45% | 50% | 46% | 22% | 28% | 18% | 29% | 41% | 47% |
| 86 | Is there a link between previous illness/conditions and long-term symptoms of covid-19? | 5% | 9% | 0% | 0% | 13% | 9% | 5% | 8% | 4% | 9% | 27% | 18% | 9% | 9% |

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| ID | Question | In total | | Relative | | Other | | Researcher | | Patient | | Clinicians | | Clinicians (or researcher) as well as patient (or relative) | |
|----|---|----------|---|----------|---|-------|---|------------|---|---------|---|------------|---|---|---|
| 87 | Is there an association between how sick the person was during the acute phase and the occurrence of long-term symptoms of Covid-19? | 2% | – | 0% | – | 6% | – | 5% | – | 1% | – | 0% | – | 6% | – |
| 88 | What risks are associated with premature/rapid return to work for people with long-term symptoms of Covid-19? | 6% | – | 0% | – | 6% | – | 5% | – | 7% | – | 0% | – | 0% | – |
| 89 | Are there similarities between other diseases and long-term symptoms of Covid-19? | 3% | – | 0% | – | 13% | – | 10% | – | 2% | – | 0% | – | 9% | – |
| 90 | What is the cost-benefit of all the research, interventions and treatment strategies for long-term symptoms of Covid-19? | 2% | – | 0% | – | 13% | – | 10% | – | 1% | – | 9% | – | 3% | – |
| 91 | How long is a person with long-term symptoms of Covid-19 infectious? | 5% | – | 0% | – | 6% | – | 10% | – | 5% | – | 18% | – | 6% | – |
| 92 | How can research conducted on hospitalised patients be applied to the group of long-term patients with Covid-19 who were not treated in hospital? | 2% | – | 0% | – | 0% | – | 0% | – | 2% | – | 0% | – | 6% | – |

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|-----|--|----------|-----|----------|-----|-------|------------|-----|---------|------------|-----|---|-----|----|-----|
| 93 | How do the Swedish Social Insurance Agency's regulations and decisions affect recovery and rehabilitation of patients with long-term symptoms of Covid-19? | 13% | 13% | 28% | 41% | 19% | 9% | 20% | 13% | 12% | 12% | 9% | 12% | 6% | 9% |
| 94 | How are relationships, parenthood and partnerships influenced by long-term Covid-19 symptoms? | 2% | – | 0% | – | 0% | – | 0% | – | 3% | – | 9% | – | 0% | – |
| 95 | How does the language used to describe long-term symptoms after Covid-19 influence how this condition is handled by healthcare system, the Swedish Social Insurance Agency, and employers? | 1% | – | 6% | – | 0% | – | 0% | – | 1% | – | 0% | – | 0% | – |
| 96 | What will be the economic consequences, for patients and society, of long-term symptoms of Covid-19? | 6% | 7% | 28% | 6% | 6% | 9% | 5% | 13% | 5% | 7% | 9% | 12% | 3% | 3% |
| 97 | What is the need for sick leave among people with long-term symptoms of Covid-19? | 10% | – | 11% | – | 6% | – | 20% | – | 10% | – | 9% | – | 6% | – |
| 100 | What is the best way of differentiating people with psychosomatic symptoms who seek treatment for long-term symptoms of Covid-19? | – | 6% | – | 0% | – | 18% | – | 13% | – | 3% | – | 24% | – | 13% |

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|-----|---|----------|----------|-------|------------|---------|------------|---|-----|---|-----|---|-----|---|-----|
| 101 | What are the differences in persistent symptoms, severity of functional incapacity, duration of symptoms, as well as how many are afflicted, with Post Intensive Care Syndrome (PICS) between those who were infected with Covid-19 and needed intensive care, compared with those who needed intensive care for reasons other than Covid-19? | – | 2% | – | 0% | – | 0% | – | 17% | – | 1% | – | 6% | – | 0% |
| 102 | What is the relationship between Postural Orthostatic Tachycardia syndrome (POTS) and long-term symptoms of Covid-19? | – | 16% | – | 24% | – | 18% | – | 13% | – | 15% | – | 24% | – | 19% |
| 103 | What is the relationship between hormones and long-term symptoms of Covid-19? For example, related to menopause, menstruation and metabolism. | – | 17% | – | 6% | – | 0% | – | 8% | – | 19% | – | 0% | – | 28% |
| 104 | What are the positive and negative effects of treatment based on pressure changes, so-called hyperbaric oxygen treatment? | – | 5% | – | 0% | – | 0% | – | 13% | – | 5% | – | 12% | – | 0% |

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|-----|--|----------|----------|-------|------------|---------|------------|---|-----|---|-----|---|-----|---|-----|
| 105 | How many people in Sweden have long-term symptoms of Covid-19 and what is the best way of applying the existing diagnostic codes? | – | 14% | – | 24% | – | 9% | – | 4% | – | 15% | – | 6% | – | 13% |
| 106 | Is there any method (test, estimate, biomarker) which can be used in the acute phase to predict which patients will develop long-term symptoms of Covid-19? | – | 11% | – | 12% | – | 18% | – | 29% | – | 9% | – | 6% | – | 16% |
| 107 | How are people with long-term symptoms of Covid-19 affected by a possible reinfection? | – | 14% | – | 12% | – | 9% | – | 4% | – | 15% | – | 6% | – | 16% |
| 108 | How can society progress/learn from the way the health sector has managed the disease, the treatment decisions, documentation and research with reference to long-term symptoms of Covid-19? | – | 16% | – | 12% | – | 27% | – | 8% | – | 17% | – | 12% | – | 13% |