



Appendix 1

1 (22)

Priority setting of future research into long-term symptoms of Covid-19 infection (post-acute sequelae of Covid-19 or Long Covid)

Appendix 1 Results of questionnaires 1 and 2

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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
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%

ID	Question	In total		Relative		Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)					
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%
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%	-

ID	Question	In total		Relative		Other	Researcher		Patient	Clinicians		Clinicians (or researcher) as well as patient (or relative)			
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%	-
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	3%	-	0%	-	6%	-	0%	-	3%	-	0%	-	6%	-

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	betablockers on people with long-term symptoms of Covid-19?														
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%	-
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	5%	-	17%	-	13%	-	0%	-	5%	-	0%	-	6%	-

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	exacerbated by use of certain medication intended for other conditions?														
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%	-

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	2%	-	0%	-	0%	-	5%	-	1%	-	18%	-	0%	-

ID	Question	In total		Relative		Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)					
	offer people with long-term symptoms of Covid-19?														
31	What is the effect of cognitive training on people with long-term symptoms of Covid-19?	4%	-	0%	-	6%	-	5%	-	4%	-	9%	-	0%	-
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	11%	-	17%	-	6%	-	0%	-	13%	-	0%	-	9%	-

ID	Question	In total		Relative		Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)					
	long-term symptoms of Covid-19?														
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%	-
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	19%	27%	6%	29%	25%	27%	20%	29%	20%	27%	18%	35%	13%	22%

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	impaired breathing function/ oxygen uptake or problems with respiratory arrest, associated with Covid-19?														
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%
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%

ID	Question	In total		Relative		Other		Researcher		Patient		Clinicians		Clinicians (or researcher) as well as patient (or relative)	
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%	-
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	6%	-	0%	-	13%	-	10%	-	5%	-	9%	-	6%	-

ID	Question	In total		Relative		Other	Researcher		Patient	Clinicians		Clinicians (or researcher) as well as patient (or relative)			
	children and adults and the underlying causes?														
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%
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	23%	22%	44%	35%	13%	9%	15%	21%	23%	22%	27%	18%	22%	25%

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	have had a positive PCR test during the acute phase, or if they have demonstrable antibodies?														
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%
63	Should other examinations or investigations be carried out, depending on how long the person has	3%	-	0%	-	6%	-	0%	-	4%	-	9%	-	0%	-

ID	Question	In total		Relative		Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)					
	experienced symptoms of Covid-19?														
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%	-
69	What is the effect (benefit or risk) of vaccination against Covid-19 for	26%	32%	11%	41%	6%	9%	25%	8%	29%	37%	9%	0%	25%	25%

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	people with long-term symptoms of Covid-19 and does this differ depending on the type of vaccine administered?														
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	5%	-	6%	-	0%	-	0%	-	6%	-	0%	-	0%	-

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	are in contact with patients?														
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%

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
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%
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	1%	-	6%	-	0%	-	0%	-	1%	-	9%	-	0%	-

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)							
	suffering long-term symptoms of Covid-19?														
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%
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	2%	-	0%	-	13%	-	10%	-	1%	-	9%	-	3%	-

ID	Question	In total		Relative		Other	Researcher		Patient		Clinicians		Clinicians (or researcher) as well as patient (or relative)		
	long-term symptoms of Covid-19?														
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%	-
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	1%	-	6%	-	0%	-	0%	-	1%	-	0%	-	0%	-

ID	Question	In total		Relative		Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)					
	healthcare system, the Swedish Social Insurance Agency, and employers?														
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%
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	-	2%	-	0%	-	0%	-	17%	-	1%	-	6%	-	0%

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)
	intensive care for reasons other than Covid-19?							
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%
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)	- 11%	- 12%	- 18%	- 29%	- 9%	- 6%	- 16%

ID	Question	In total	Relative	Other	Researcher	Patient	Clinicians	Clinicians (or researcher) as well as patient (or relative)
	which can be used in the acute phase to predict which patients will develop long-term symptoms of Covid-19?							
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%