



## SELF-SCORED IMPAIRMENTS IN FUNCTIONING AND DISABILITY IN POST-COVID SYNDROME FOLLOWING MILD COVID-19 INFECTION

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**Objectives:** To investigate functioning, activity and disability in people with post-COVID syndrome.

**Design:** Cross-sectional.

**Subjects/patients:** Participants were recruited online via Facebook and a stakeholders' organization for post-COVID syndrome in Sweden.

**Methods:** Sociodemographic data and International Classification of Functioning, Disability and Health (ICF)-based questionnaire were collected via an online platform and analysed.

**Results:** A total of 100 participants were included (mean age 44.5 years, 82% women, 61% with higher education, and 56% working full- or part-time). For the ICF component Body Functions, the most impaired functions were: fatigability and energy drive (98–99%); higher cognitive functions (74–94%); sleep functions (98%); muscle functions (93%); respiratory functions (92%); heart functions (82%); emotional functions (80%); sexual functions (77%); pain problems (56–90%); and thermoregulatory functions (68%). For the component Activity, the most frequent limitations were: handling stressful situations (98%); remunerative employment (95%); recreation and leisure (94%); climbing the stairs (94%); doing housework (84%); and informal socializing (64%). The most frequent degrees of impairment/limitations were light and moderate, except for severe-complete for fatigue, higher cognitive functions, multitasking, handling stressful situations; and recreation and leisure activities.

**Conclusion:** Post-COVID syndrome following a mild COVID-19 infection can result in impaired body functions and activities. These results support the importance of a multidisciplinary rehabilitation approach for these patients.

**Key words:** post-COVID syndrome; International Classification of Functioning, Disability and Health; fatigue; functioning; activity; quality of life.

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Since the start of the COVID-19 pandemic in December 2019, several hundred million people have been infected, resulting in several million deaths worldwide and overloaded healthcare systems in many countries.

### LAY ABSTRACT

The SARS-CoV-2 (COVID-19) pandemic has infected several hundred million people worldwide to date. A proportion of people with COVID-19 who develop a mild initial illness, mainly staying at home or requesting few days of hospitalization, do not subsequently recover fully. Some of them develop new persistent symptoms and an increased level of disability, affecting their functioning. This study describes functioning and disability in people with post-COVID syndrome after a mild initial infection, using a self-scored questionnaire based on the International Classification of Functioning and Disability. A total of 100 participants were included in the study. Participants were relatively young and healthy prior to the infection. The majority were female, with a high level of education, and mostly working full- or part-time. Many disabling symptoms were found to persist, indicating the need for further research into post-COVID syndrome, and supporting the use of a multidisciplinary rehabilitation approach for these patients.

The SARS-CoV-2 virus is known to affect the host in different ways: from asymptomatic infection to lethal course, probably depending on the host's immune response (1). A neurological impact of the SARS-CoV-2 virus has been speculated, both in the pathways of respiratory failure (2) and in other neurological symptoms (3). The acute symptomatology of COVID-19 is now well-characterized, as acute respiratory failure, thrombosis, kidney failure, etc. (4, 5), and long-term symptoms are now affecting patients during the subacute (3–6 months after infection) and chronic periods (longer than 6 months after infection). Long-COVID or post-COVID syndrome appears in both hospitalized (6) and un-hospitalized patients (7). Follow-up of patients hospitalized during the acute period has identified ongoing symptoms, such as fatigue, breathing difficulties, cognitive symptoms, persistent musculoskeletal pain, sleeping difficulties, etc. (8, 9). Regardless of the severity of the initial infection, persistent fatigue appears to be the most bothersome symptom in patients with post-COVID syndrome (10). The World Health Organization (WHO) appealed to healthcare providers regarding post-COVID syndrome and estimates that approximately 10% of all infected people may develop post-COVID syndrome (11). However, knowledge about post-COVID syndrome is scarce, and future levels of healthcare needs for these patients might be extremely

high. There is an urgent need for scientific data about post-COVID syndrome, and the role of rehabilitation interventions to prevent disability in these patients.

Although the clinical picture of post-COVID syndrome is broad, one way to analyse it is to assess functioning, activity and disability according to the International Classification of Functioning, Disability and Health (ICF). The ICF is a classification of health and health-related domains describing functioning, activity and disability, which was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21) (12). ICF is the WHO's framework in categorizing health and disability at both individual and population levels and is recommended for use in clinical and research practise. The ICF Core Sets were developed for several (chronic) health conditions (13–18), but, until now, not for post-COVID syndrome.

The aim of the current study was therefore to assess functioning, activity, and disability, using an adapted list of ICF categories for patients with post-COVID syndrome.

## METHODS

Participants were recruited via Facebook sites and stakeholders' organization for post-COVID syndrome in Sweden (*Svenska covidföreningen*). An online announcement briefly describing the study, with inclusion and exclusion criteria, was published, and a link provided to more detailed information. Thereafter, participants could sign into the online platform BASS at the eHealth Core Facility at Karolinska Institutet, using a 2-step identification factor. The online platform BASS also allows an electronically signed agreement to participate and questionnaires to be collected.

Inclusion criteria were: (i) COVID-19 infection supported by anamnesis and/or positive tests for COVID-19 virus (PCR) and/or positive immunoglobulin response; (ii) age 18–70 years; (iii) significantly reduced level (at least 50%) of functioning and activity/participation in daily life compared with before infection; (iv) persistent symptom duration at least 12 weeks after acute infection; (v) medically assessed participants, in case of co-morbidities, those should be satisfactory managed; (vi) participants are able to use the internet, complete internet-based questionnaires and participate in a rehabilitation programme delivered via the internet for a group of maximum 25 participants during an 8-week period.

Exclusion criteria were: (i) unclear onset of symptoms in relation to COVID-19 (e.g. stress factors, post-traumatic stress disorder, other types of psychological and somatic trauma in combination with COVID-19 infection or before it); (ii) abuse of alcohol or psychotropic substances; (iii) presence of diagnosis of a psychological or somatic condition that might require, or requires, appropriate treatment (e.g. hypothyreosis, lung, heart, kidney diseases, psychosis, suicidality, etc.); (iv) ongoing psychological and medical treatments that may interfere with the rehabilitation (e.g. other psychotherapies, ongoing introduction and adjustment of pharmacological drugs).

In brief, participants fulfil sociodemographic data and questionnaires regarding persistent symptoms after COVID-19 infection. The study was registered at ClinicalTrials.gov (identifier: NCT04961333) and approved by the Swedish Ethical

Authorities (*Etikprövningsmyndigheten*), Dnr. 2020-07216.

This study presents the sociodemographic data and the Functional Compass COVID-19 questionnaire, although part of the data before rehabilitation, collected via BASS.

The Functional Compass COVID-19 is a self-assessment questionnaire developed from the Functional Barometer and adapted to the ICF regarding patients' disability, activity, limitations and participation (12). The Functional Barometer is a validated and quality assured self-assessment instrument for patients with chronic pain and is, to date, the only questionnaire in Swedish using ICF variables based on pain (19).

The Functional Compass COVID-19 questionnaire consists of 47 questions; "Do you, after your COVID-19 infection, experience long-standing problems, such as...?" Twenty-three specified variables cover body function and activities/participation according to the ICF and 1 additional optional item variable is included. Questions are formulated to self-assess functions regarding impairments in body functions, such as respiratory, cardiovascular, thermoregulatory, olfactory, gustatory, tactile perceptions, muscular and joint functions. Variables concerning quality of life (QoL) (but also overlapping body functions) are included: sleep, cognitive functions, fatigue/fatigability, exhaustion, handling stress and psychological demands, social relationships, as well as work-, house- and leisure-related activities. Eight questions regarding the pain situation were asked. In addition, all items were assessed on a verbal descriptive problem scale, the same as the ICF qualifier, with 5 categories graded 0–4. The categories were defined as 0: no problems; 1: light; 2: moderate; 3: severe; and 4: total problems (19). Another 10 questions regarding work and daily activities are included in the questionnaire. In addition, there is 1 optional item variable for the participant regarding "What would you like to do if you felt a little better?" (not presented in this study). The questionnaire will provide the respondent and the evaluator with a common picture of the subject's daily life situation, helping to establish which measures and treatments are needed and what the respondent can manage despite the post-COVID symptoms.

The current study analyses and presents 42 categories based on the ICF. A total of 4 activity- and participation-related questions based on the same ICF category, b280, "Sensation of pain", and the optional item variable "What would you like to do if you felt a little better?" were excluded from analysis.

### Statistical analysis

Descriptive statistics for nominal data (genus, origin, education, sick leave, etc.) are presented as the number of participants per group. Body mass index (BMI) is presented as mean, standard deviation and range. Descriptive statistics were used for ICF qualifiers ranging from 0 to 4 (12). The current study presents only those ICF categories in which at least 25% of participants reported impairments. Statistical package SPSS, version 27, IBM (International Business Machines Corporation), US, 2020, was used for analyses.

## RESULTS

### Characterization of study population

Data from 107 consecutive participants were included in the analysis. One participant was excluded based on the exclusion criteria (ongoing rehabilitation due to previous comorbidities) and 6 participants were excluded due to

**Table I.** Background data for 100 participants (equal to 100%).

Characteristics	Number of persons
Age, years, mean (SD) [range]	44.5 (10.6) [20–66]
Sex	
Female	82
Male	18
Place of birth	
Sweden	88
Outside Sweden	12
Marital status	
Married	49
Having partner	24
Single	27
Having children	
Yes	73
No	27
Living circumstances	
Condominium	17
Own house	53
Rental house	22
Inherent	1
Other	7
Education	
Primary (<9 years)	1
Secondary (10–12 years)	31
Higher (>12 years)	61
Other education	7

SD: standard deviation.

missing data for ICF variables. Table I summarizes the sociodemographic characteristics of the participants. Among 100 participants, the mean age was 44 years, 82% were female, 88% born in Sweden, 49% married, 73% had children, 53% lived in their own houses, and 61% had completed higher education. A total of 92 participants provided data on the duration of symptoms, with a mean duration of 47 weeks (standard deviation 20 weeks, range 12–83 weeks). Eighty-six percent indicated that they had had a laboratory PCR test for SARS-CoV-2, and 46% reported a positive result. Those who reported a negative PCR test (40%) or did not give an answer (14%) were all infected during the first pandemic wave, except for 2 participants. Eighty-one percent

**Table II.** Sick-leave and work ability data of 100 participants (equal to 100%).

Parameters	Number of persons
Working right now	56
Employed	81
Jobseekers	7
Studying	6
Not gainful employment	6
Financial security, %	
Sick-leave 25	3
Sick-leave 50	7
Sick-leave 75	2
Sick-leave 100	26
Disability pension 50	3
Disability pension 100	10
Unemployment benefits 100	3
Student aid 100	1
Social security contribution	4
Other	2

reported that they had been tested with an antibody test for SARS-CoV-2. Only 3 participants reported either negative or absent PCR tests and absent antibody tests. Among them, 1 reported being denied a primary healthcare appointment during the first pandemic wave and 1 reported being diagnosed with post-COVID syndrome based on clinical symptoms.

Table II summarizes the financial security of the participants, showing that 56% of participants were working full- or part-time, 81% were employed, and 13% were seeking work, studying or had other economic support during recruitment to the study. Regarding social security benefits, 38% were on full- or part-time sick-leave, 13% had disability pensions, 3% had unemployment benefits, and only 4% had social security benefits.

Table III presents comorbidities before COVID-19 infection. Sixty-seven percent of participants reported being completely healthy prior to COVID-19 infection, with no contact with the healthcare system. The population has a slight tendency to overweight, with a mean BMI of 26.5 kg/m<sup>2</sup>.

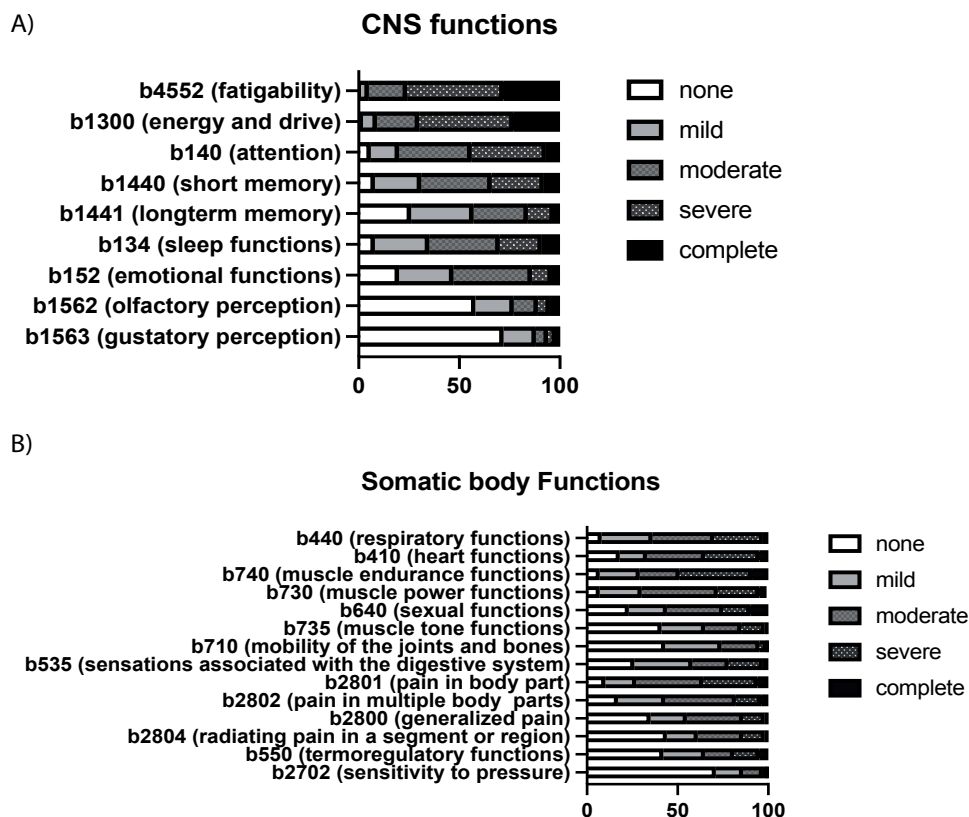
#### *Impairments in functioning and activity/participation according to ICF-based questionnaire*

The original ICF-based questionnaire contained 47 questions on function and activity/participation. The

**Table III.** Comorbidities among 100 participants (equal to 100%).

Disorders before COVID-19 infection	Number of persons
Total number of persons with disorders before infection	33
Hypertension and other heart disorders	7
Metabolic diseases	6
Hypothyreosis	4
Overweight	1
PCOS	1
ME/CFS	2
Lung disorders	11
Asthma	10
Chronic obstructive lung disease	1
Allergies	2
Psychiatric disorders	11
Stress-related exhaustion syndrome	1
Anxiety/depression	6
Bipolar disorder	1
ADHD	2
PTSD	1
Sleep disorders	
Sleep apnoea syndrome	1
Inflammatory disorders	9
Endometriosis	2
Crohn's disease	2
Arthritis/polyarthritis	2
Chronic pain	3
Vitamin deficiency	2
Anaemia	1
Herpesvirus	1
BMI, kg/m <sup>2</sup> , mean (SD) [range]	26.5, (5.9) [17–58]

PCOS: polycystic ovarian syndrome; ME/CFS: myalgic encephalomyelitis/chronic fatigue syndrome; ADHD: attention-deficit/hyperactivity disorder; PTSD: post-traumatic stress disorder; BMI: body mass index; SD: standard deviation.



**Fig. 1.** (A) Impairments in higher central nervous (CNS) functions in at least 75% of participants according to the International Classification of Functioning and Disability (ICF). *n* = 100 participants (equal to 100%). (B) Impairments in body functions in at least 75% of participants according to the ICF.

optional item describing “What would you like to do if you felt a little better?” is not included in the analyses. The 4 final questions were on temporal and quantitative features of pain (b280) and are also not presented. Fig. 1 presents 23 body functions according to ICF categories with degrees of impairments. Fig. 1A presents 9 body functions related to central nervous system (CNS) functions, and Fig. 1B presents 14 body functions related to somatic body functions. The most impaired function was fatigability (b4552) found in 99% participants, in 28% scored as totally and in 48% as severely impaired. Energy and drive function (b130) was impaired in 98% of participants. Of these, 23% scored it as totally and 47% as severely impaired. Attention (b140) and short memory (b1440) functions were impaired in 94% and 92% of participants, respectively. Sleep functions (b134) were impaired in 92% and emotional functions (b152) in 80% of participants. Olfactory functions (b1562) were impaired in 42% and gustatory (b1563) in 28% of participants (Fig. 1A). Regarding somatic body functions, impairments in respiratory (b440) and heart functions (b410) occurred in 92% and 82% of participants, respectively. The impairments were scored as severe in 27% and 30%,

for respiratory and heart functions, respectively; or moderate in 34% and 16%, for respiratory and heart functions, respectively. Among muscle functions, 93% of participants reported impaired muscle power (b730) and endurance (b740) with impairments of moderate and severe degrees (22–42%) (Fig. 1B). Pain in 1 part of the body (b2801) was reported in 90% of participants; mostly as severe (30%) or moderate (37%). Pain in multiple body parts (b2802) in 83%, mostly as moderate (39%) or light (26%). Generalized pain (b2800) was scored in 65% of participants, in 31% as moderate (Fig 1B). Thermoregulatory functions were impaired in 58% of participants, mostly at mild (23%) degree. The following body functions were impaired in less than 25% of participants: dressing (d540) was impaired in 22%; tactile perception (b1564) in 7%; sensitivity to vibration (b2701) in 10%; and sensitivity to temperature (b2700) in 18% of participants and, therefore, are not presented.

Fifteen d-categories are shown in Fig. 2. The most impaired activity was handling stress and other psychological demands (d240) scored by 98% of participants, with total impairment in 19% and severe in 33%. Remunerative employment (d850) was impaired

## Activity and participation



**Fig. 2.** Impairments in body functions in at least 75% of participants according to the International Classification of Functioning and Disability (ICF).  $n=100$  participants (equal to 100%), except for d850 ( $n=91$ ) and d4751 ( $n=81$ ).

in 96%, with total degree in 23% and severe degree in 24%, of participants. The cognitive activity completing multiple tasks (d2201) was impaired in 95%, with total degree in 13% and severe degree in 34% of participants. The category recreation and leisure (d920) was impaired in 94% of participants, with total degree 14% and severe degree 32% (Fig. 2). Among physically demanding activities, the most impaired activity was climbing stairs (d4551), impaired in 96% of participants, in 24% as severe and in 42% as moderate grade. Lifting and carrying objects (d430) was impaired in 92% of participants, mostly as moderate (34%) and mild (31%). Doing housework (d640) was impaired in 84%, mostly as moderate (33%) or mild (28%). Informal social relationships (d750) were impaired in 81%, mostly scored as moderate (43%) and mild (23%) (Fig. 2).

## DISCUSSION

This is the first study to evaluate ICF-based impairments in post-COVID syndrome, and one of the first reports describing post-COVID syndrome in participants who have had a mild initial infection with few participants being hospitalized. None of the participants were hospitalized in an intensive care unit. A major proportion of participants comprised early middle-age, highly educated women, who were healthy before the infection. Despite post-COVID symptoms, a major part of participants was working still full- or part-time. The cohort consisted mainly of participants from the both the “first” (winter–spring 2020) and “second” (autumn 2020–winter 2021) waves of the pandemic. Despite the known difficulties in getting tested during the first pandemic wave (winter–spring 2020) in Sweden, due to the absence of testing possibilities, most of the study population (97% of participants) had undergone either antigen or antibody testing for SARS-CoV-2. This

indicates that participants did perceive the presence of COVID-19 infection. Another fact that supports new developed symptoms is that participants were relatively healthy before COVID-19 infection, and were still in active employment.

In the present study, 27 body functions were chosen, among those, 8 were from the second level. Twenty-three ICF b-categories were found to be impaired in at least 75% of participants. The degree of impairments varied between total-moderate, indicating pronounced disability due to several important body functions to be highly affected in post-COVID syndrome.

A total of 15 body activities/participations were chosen, among those, 3 from the second level. All 15 ICF d-categories were restricted among at least 75% of the participants, indicating difficulties in activities and participation. The degree of impairments among activities and participations requiring cognitive and energy functions (stress handling, employment, multitasking) varied between total and severe. The degree of impairments among activities demanding more physical effort (e.g. climbing, lifting, carrying objects) varied between moderate and mild.

It appears that COVID-19 infection results in at least 2 clinically different post-COVID syndromes. One of these is post-COVID syndrome in hospitalized patients (6), and another in those who have had mild–moderate infection and did not need hospitalization (7). Hospitalization during the acute period allowed patients to be followed up and evaluated for ongoing symptoms, such as fatigue, breathing difficulties, cognitive symptoms, persistent musculoskeletal pain, sleeping difficulties, etc. (8, 9). Regardless of the severity of the initial infection, persistent fatigue seems to be the most bothersome symptom of post-COVID syndrome (10). This is also supported by research by the Swedish National Health Board, in studying the sick-leave patterns after the first wave of the pandemic,

in 2020. According to the report, 582 males were on sick-leave for longer than 12 weeks; 66% of them after hospitalization and 34% without hospitalization. For 685 females the corresponding proportions were 34% and 65% (20). Kedor et al. recently reported that 19 of 42 patients (the majority of patients were female) with initially mild–moderate COVID-19 infection fulfilled the criteria for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), which is a disabling chronic condition (21). Moreover, data regarding the long-term effects of similar coronavirus infections (SARS and MERS) show that approximately 30% of those who were hospitalized developed cognitive symptoms and fatigue, and approximately 20% had not returned to work 1 year after the infection (22). Therefore, it should be a priority to further investigate this group and the rehabilitation needed for restoration of functioning and activity levels, including work ability. It is also important to prevent the establishment of disabling conditions, such as ME/CFS, fibromyalgia, etc. The WHO estimates that 10% of all infected people might develop post-COVID syndrome; however, it is unknown how many of them will develop it after an initially mild infection. Therefore, further research is crucial in order to identify this population, and to understand (future) disability in people with post-COVID syndrome.

The ICF-based questionnaire (The Functional Compass COVID-19) includes 5 of 7 ICF categories, which are considered to be a minimal generic set of functioning and health (b130 Energy and drive functions, b152 Emotional functions, b280 Sensation of pain, d450 Walking and d850 Remunerative employment) as suggested by the WHO (12). Therefore, categories Carrying out daily routine (d230) and Moving around (d455) were not included. The Functional Compass COVID-19 is a further development of The Functional Barometer for long-lasting non-malignant pain, another ICF-based self-cored questionnaire (19). Therefore, 42 ICF categories in b- body functions and d- activities and participation were chosen based on our previous studies on ICF-based impairments among patients with long-lasting non-malignant pain, at the same time, adapting to the broad picture of post-COVID syndrome (19, 23, 24).

There is a lack of studies in which ICF coding is included and, particularly, there is a lack of post-COVID studies using the ICF. It is of interest to use the ICF-based questionnaires, for example, Functional Compass COVID-19, in investigation, assessment, making diagnosis, assignments, interventions, and follow-up evaluation, in order to provide the optimal rehabilitation measures for patients with late symptoms after COVID-19. The use of ICF-based assessment will

also enable comparison of disability in these patients with that in other chronic conditions, such as chronic ischaemic heart disease, widespread pain, multiple sclerosis and myalgic encephalomyelitis/chronic fatigue syndrome (15, 25–27). The Functional Compass COVID-19 is, to our knowledge, and to date, the only questionnaire using ICF variables for late symptoms after COVID-19 infection. Knowledge about defined body functions or activities being impaired according to the ICF or Functional Compass COVID-19 can be used to create rehabilitation guidelines for specific functions; for example, impaired lung and heart functions, pain and sleep problems, etc.

### *Study limitations*

This study is internet-based. Therefore, it does not allow to control clinical data collected via internet platform, even though all participants signed in with their personal online bank certificate (bank-id). Initially, the current study includes an 8-week internet-delivered rehabilitation programme. Hence, a major proportion of participants will have almost weekly online appointments with a member of a multimodal team, including a specialist in rehabilitation medicine, to confirm the appropriateness of participation in the study according to inclusion and exclusion criteria, post-COVID syndrome diagnosis, rehabilitation plan, and functional impairments. Fifty out of 100 participants have participated or are participating in the rehabilitation programme and are controlled for inclusion and exclusion criteria. The online collection of data might affect the study population, since women and highly educated early middle-aged participants predominated. On the other hand, it cannot be excluded that non-hospitalized woman are more likely to be affected by post-COVID syndrome after a milder form of infection (20). Further research into correlations with age, sex and sociodemographic factors, as well as comorbidities, is priority in order to understand the pathophysiology of post-COVID syndrome.

Motivational bias to participate in the multimodal rehabilitation programme, while answering the questionnaires is not excluded. At the same time, functional impairments have been discussed individually during individual appointments confirming disability at the individual level. Therefore, self-scoring of impairments in functions and activities/participations is another limitation and should be avoided when applying ICF assessments (27). Our previous study on another ICF-based self-scored questionnaire, The Functional Barometer for long-lasting pain, showed disagreement ranging from 18% to 51% in the degree of impairments scored by the multimodal rehabilitation team compared

with those scored by the patients with chronic pain themselves (19). However, in the current study, due to the pandemic, the researchers decided that all assessments should be performed at home by participants and submitted through the online platform BASS at Karolinska Institutet. A further development could be integration of online appointments with team members with participant's completed ICF questionnaire, in order to reevaluate the self-scored impairments. However, this was not a primary purpose of the current study.

Although the region of Sweden in which patients live was not included in the questionnaire, individual appointments revealed that approximately 30% of 50 participants lived in the Stockholm area. A major proportion of participants joined the study from places where access to healthcare structures at a specialized rehabilitation clinic for COVID-19 was absent or limited. Preliminary results from online appointments in the present study point out that a part of participants had already participated in tailored rehabilitation in the primary healthcare system; however, not feeling that they got better. It is possible, that including participants from the whole of Sweden, independent of where they live, creates a generalizability of the study results. Environmental factors were not included in the Functional Compass COVID-19. The next step in improving this multidimensional ICF-based assessment is to include the environmental milieu as facilitator or barrier, which is particularly important during the pandemic situation due to social isolation and less access to different authorities and healthcare givers.

In conclusion, this is the first time that an ICF-based questionnaire, The Functional Compass COVID-19, has been used to assess functioning from the participant's perspective with post-Covid syndrome. The use of standardized ICF assessments with the same scales (ICF Qualifiers) provides additional information regarding the participants' functioning, activity, and participation in comparison with other chronic conditions. It also provides an opportunity to describe possible differences in estimation and perception between participants and professionals. The results describe a population with post-COVID syndrome who initially had a mild infection, but developed pronounced impairments in functioning and disability. These results support the need for specialized multidisciplinary rehabilitation structures for people with post-COVID syndrome.

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*The authors have no conflicts of interest to declare.*

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