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Early View

Original article

# Recovery from COVID-19: a sprint or marathon? 6 months follow-up data of online long COVID-19 support group members

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## Recovery from COVID-19: a sprint or marathon?

## 6 months follow-up data of online long COVID-19 support group members

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## Take-home message

Patients who are members of online long COVID-19 peer support groups may still experience persistent symptoms about 6 months after the onset of symptoms, which can affect work productivity, functional status and quality of life.

#### Abstract

**Background** It remains unknown whether and to what extent members of online long COVID-19 peer support groups remain symptomatic and limited over time. Therefore, we aimed to evaluate symptoms in members of online long COVID-19 peer support groups up to 6 months after the onset of COVID-19-related symptoms.

**Methods** Demographics, symptoms, health status, work productivity, functional status and health-related quality of life were assessed about 3 and 6 months after the onset of COVID-19-related symptoms in members of online long COVID-19 peer support groups.

**Results** Data of 239 patients with a confirmed COVID-19 diagnosis (83% women; median (IQR) age: 50 (39-56) years) were analysed. During the infection, a median (IQR) of 15 (11-18) symptoms was reported, which was significantly lower 3 and 6 months later: 6 (4-9) and 6 (3-8), respectively (p<0.05). From 3 to 6 months follow-up, the proportion of patients without symptoms increased from 1.3% to only 5.4% (p<0.001). Patients also reported a significantly improved work productivity (work absenteeism and presenteeism: 73% versus 52% and 66% versus 60%), self-reported good health (9.2% versus 16.7%), functional status (Post COVID-19 Functional Status scale: 2.4 (0.9) versus 2.2 (0.8)) and health-related quality of life (all p<0.05).

**Conclusion** Although patients with confirmed COVID-19, who were all members of online long COVID-19 peer support groups, reported significant improvements in work productivity, functional status and quality of life between 3 and 6 months follow up, these data clearly highlight the long-term impact of COVID-19, as approximately 6 months after the onset of COVID-19-related symptoms a large proportion still experienced persistent symptoms, a moderate-to-poor health, moderate to severe functional limitations, considerable loss in work productivity, and/or an impaired quality of life. Action is needed to improve the management and healthcare of these patients.

#### Background

Recovery from COVID-19 can take weeks up to months in previously hospitalized and nonhospitalized adult patients. Even though a large proportion recover fully, case reports and several cohort studies have shown that part of the patients have persistent symptoms (for more than 12 weeks after the COVID-19 related infection), such as fatigue, dyspnoea, chest tightness, headache and muscle pain[1-9]Moreover, an impaired functional status, post-traumatic stress disorder and poor quality of life have been reported in previously hospitalized and non-hospitalized adults recovering from COVID-19[4, 5, 7, 10, 11]. These data suggest the presence of a post-COVID-19 syndrome (i.e. long COVID or long-haul COVID, as called by several patient groups which refer to the long-lasting COVID-19 symptoms), which is defined by clusters of symptoms lasting for more than 12 weeks and may arise from any system in the body[1, 9, 12, 13]. The National Institute for Health Care Excellence (NICE) guideline for managing the long term effects of COVID-19 defined the term 'long COVID' for patients having signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more) [13].

It has been estimated that approximately 5-10% of the people experience prolonged symptoms after COVID-19[3, 6, 14]. A growing number of these patients have gathered on online forums and social media, as they mostly feel unheard, perceive insufficient support from clinicians, and lack clearly defined healthcare pathways, especially when they were not admitted to the hospital[1, 15, 16]. These so-called long COVID-19 peer support groups serve as source of support through shared experiences, knowledge and expertise, have taken the lead in generating evidence on COVID-19 with persisting symptoms and campaigning for better and more consistent healthcare[15, 16].

Our data from a first survey among members of online long COVID-19 peer support groups about 3 months after the onset of COVID-related symptoms already highlighted the major impact of multiple persistent symptoms on patients' daily lives[1, 10]. To date, it remains unknown whether and to what extent these patients with the so-called post-COVID-19 syndrome remain symptomatic and limited in daily functioning over time. Therefore, we aimed to evaluate symptoms in these COVID-19 patients up to 6 months after the onset of COVID-19 related symptoms. We hypothesized that patients still suffer from multiple symptoms and report limitations in work productivity, functional status, and quality of life after 6 months of follow up, but to a lesser extent compared to 3 months after the onset of symptoms.

#### Methods

#### Study design, setting and participants

Between June 4 and June 11 2020, 1939 members of two long COVID Facebook groups or an online COVID-19 panel (*www.coronalongplein.nl*) completed the first survey (T1) [1]. 1556 of these respondents consented to be approached for future research, and were invited to complete a second survey between August 31 and September 8 2020 (T2). See Supplementary Figure 1 for all details.

The medical ethics committee of Maastricht University stated that the Medical Research Involving Human Subjects Act (WMO) did not apply for this study and that an official approval of this study by the committee was not required (METC2020-1978 and METC2020-2554). The medical ethics committee of Hasselt University formally judged and also approved the study (MEC2020/041). All adult respondents (age 18 years or older) gave digital informed consent at the start of the second survey. Without the informed consent, the survey could not be continued. The study was registered before its start (trialregister.nl; NL8705).

#### Measures

The survey contained questions regarding demographics, pre-existing comorbidities, COVID-19 diagnosis (based on reverse transcription polymerase chain reaction (RT-PCR) and/or computed tomography (CT) scan of the thorax; symptom-based medical diagnosis; no test/medical diagnosis), intensive care unit (ICU) or hospital admission, current self-reported health status (good/moderate/poor) and received care (help with personal care/physiotherapy/rehabilitation; yes/no, frequency). In addition, respondents were asked about the presence (yes/no) of a list of symptoms during the acute infection (To, retrospectively) and at time of completing the questionnaires (T1 and T2; 'symptoms at this moment'). Scientists, methodologists, healthcare professionals and COVID-19 patients from the Facebook groups of The Netherlands and Flanders were closely involved in putting together the list of 29 symptoms that were studied: increased body temperature (37.0-37.9 °C), fever (body temperature ≥38.0 °C), cough, mucus, nose cold, sneezing, dyspnoea, sore throat, fatigue, muscle pain, joint pain, anosmia, ageusia, headache, dizziness, diarrhoea, nausea, vomiting, red spots on toes/feet, pain/burning feeling in the lungs, ear pain, chest tightness, pain between shoulder blades, heart palpitations, increased resting heart rate, eye problems, sudden loss of body weight, burning feeling in the trachea, and heat flushes. Moreover, there was the option of an open text field to add other symptoms. These data contained many different symptoms, including loss of concentration and cognitive function, hair loss, chills, rashes, and sleeping problems. However, these 'other' symptoms were not analysed in detail due the large heterogeneity.

In addition, participants were asked to complete the following validated questionnaires:

1) the Work Productivity and Activity Impairment (WPAI) questionnaire to assess COVID-19-related absenteeism, presenteeism, overall work impairment (absenteeism and presenteeism combined), and impairment of regular activities during the preceding seven days[17]. Scores are presented as percentages and higher percentages indicate greater impairment and compromised productivity, as described before[18];

2) the Post COVID-19 Functional Status (PCFS) Scale to assess the impact on self-reported functional status at time of completing the questionnaire[19, 20]. The PCFS scale stratification is composed of five scale grades: grade o (No functional limitations); grade 1 (Negligible functional limitations); grade 2 (Slight functional limitations); grade 3 (Moderate functional limitations) and grade 4 (Severe functional limitations). A final scale grade 5 'death' that is required to be able to use the scale as outcome measure in clinical trials, was left out for this self-administered questionnaire;

3) the 5-level EuroQol-5 Dimensions version (EQ-5D-5L) to assess generic quality of life, providing an index score which ranges from -0.329 (worst quality of life) to 1 (best quality of life)[21]. The EQ-5D-5L includes a vertical visual analogue scale (VAS) ranging from 0 ('the worst health you can imagine') to 100 points ('the best health you can imagine')[22]. The reference values of Grochtdreis and colleagues[23] were used to calculate the proportion of patients with an EQ-5D index below the 5<sup>th</sup> percentile (1.64 x standard deviation (SD)) of the mean age/gender-based reference values.

#### Statistical methods

Continuous data are presented as mean and standard deviation (SD), median and interquartile range (IQR), as appropriate. Categorical data are presented as absolute and relative frequencies. The proportion of patients selecting 'yes' per symptom was calculated, including 'other' if selected. Sensitivity analyses were performed to identify potential differences between specific subgroups (hospitalized/non hospitalized, responders/non-responders), using Chi square tests or Mann-Whitney U Tests. Differences between 3 and 6 months follow-up were evaluated with the McNemar Test or Wilcoxon Signed Rank test. Initial analyses were performed in patients with a RT-PCR or CT confirmed diagnosis and a sensitivity analyses were performed to confirm the results for patients with no formal COVID-19 diagnosis. An exploratory analyses was performed to

identify predicting variables of having persistent symptoms about 6 months after the onset of COVID-19 related symptoms, using the following predicting variables in a stepwise logistic regression analysis: age, sex, education level, marital status, body mass index, number of comorbidities, self-reported health status before the onset of COVID-19 related symptoms and number of symptoms during the infection. Statistics were performed using SPSS version 25.0. A *priori*, the level of significance was set at p<0.05.

## Results

Of the initial 1556 patients who completed the first survey about 3 months after the onset of COVID-related symptoms (T1) and consented to be approached for future research, 1005 patients (65%) completed the second survey about 6 months after onset of the COVID-related symptoms (T2). Generally, the results from the first survey were comparable between the patients who did and did not complete the second survey (Supplementary Table 1).

Two hundred and thirty-nine patients (24%) had a RT-PCR and/or computed tomography scan confirmed diagnosis. Patients were mostly middle-aged women with a slightly overweight body mass index (BMI) (Table 1). Sixty-two patients(26%) were hospitalized (without admission to the ICU) and 177 (74%) were not hospitalized at the time of the infection. Generally, results were comparable between hospitalized and non-hospitalized patients (please see Supplementary Table 2) The remaining 766 patients who also completed both surveys were suspected to have had COVID-19. They did not have a formal COVID-19 testing at the time of the suspected infection.

	All patients (n=239)
Women, n (%)	198 (82.8)
Age, years (median, interquartile range)	50.0 (39.0-56.0)
BMI, kg/m²(median, interquartile range)	26.0 (23.4-30.5)
Married/living with partner, n (%)	173 (72.4)
Pre-existing comorbidities, n (%)	
None	142 (59.4)
1	62 (25.9)
≥2	35 (14.6)
Health status before infection, n (%)	
Good	208 (87.0)
Moderate	28 (11.7)
Poor	3 (1.3)

Table 1. Characteristics and outcomes of 239 patients with confirmed COVID-19 diagnosis

(SD))	
First questionnaire (T1) Second questionnaire (T2)	10.4 (2.4) 22.6 (2.4)
Number of symptoms, n (median, interquartile range)	22.0 (2.7)
То	15 (11-18)
Τ1	6 (4-9)*
T2	6 (3-8)*#
Nork Productivity and Activity Index	
Percentage of work time missed due to ill health (absenteeism) (mean (SD))	
(dbscheelshi) (mean (55)) Ti	72.9 (35.2)
T2	52.4 (38.4)#
Percentage of impairment while working (presenteeism) (mean (SD))	
T1	66.1 (25.8)
	59.7 (24.0)#
Overall work impairment due to health (work productivity), % (mean (SD))	
(30)) T1	89.3 (19.4)
T2	78.6 (26.0)#
Activity impairment, % (mean (SD))	
T1	71.4 (21.7)
T2	59.7 (22.8)#
Self-reported poor health, %	12
То	1.3 25.5*
T1 T2	25.5** 10.5*#
Post-COVID-19 Functional Status Scale	, "
Grade (mean (SD))	
T1	2.4 (0.9)
T2	2.2 (1.0)#
Quality of life	
EQ-5D index (mean (SD))	0.645 (0.181)
T1 T2	0.645 (0.161 <i>)</i> 0.694 (0.165)#
EQ-5D index < P5 reference values [23], %	0.094 (0.00)
T1	36.8
T2	26.8#
Today's health status (VAS 0-100), points	
T1 T2	49 (19)
T2 Received care	56 (18)#
Received care Physiotherapy, %	
Between To and Ti	31.8
Between T1 and T2	61.9 #
Rehabilitation, %	
Between To and Ti	4.2
Between T1 and T2	11.7#
Need for help with personal care From partner, %	
Before	5.0
Between To and T1	46.0*
Between T1 and T2	21.3*#
From family, %	
Before	1.7 17.2*
Between To and T1	

Between T1 and T2	7.1*#	

\*p<0.05 vs. before; #p<0.05 vs. T1; P5=percentile five; VAS=visual analogue scale

## Number of Symptoms

During the COVID-related infection a median of 15 (11-18) symptoms was reported, which was significantly about 3 and 6 months later: 6 (4-9) and 6 (3-8), respectively (p<0.001) (Table 1, Figure 1). At all three time points, fatigue was the most prevalent symptom (Figure 2).

The proportion of patients with zero symptoms increased between 3 and 6 months follow-up, from 1.3 % to 5.4% (p<0.001). After about 6 months, 98 patients (41.0%) reported 1 to 5 symptoms, 69 patients (40%) reported 6 to 10 symptoms, and 32 patients (13%) reported more than 10 symptoms (Supplementary Figure 2). In a stepwise logistic regression model, having persistent symptoms after about 6 months was significantly associated with female sex (odds ratio (OR); 95% confidence interval (CI): 4.596; 1.405-15.038; p=0.012) and number of symptoms during the infection (OR; 95%CI: 1.168; 1.022-1.334; p=0.022). To correct for the unequal sex distribution, analyses were repeated in female patients, showing that only the number of symptoms during the infection was associated with having persistent symptoms (OR; 95%CI: 1.186; 1.005-1.400; p=0.043).

## Work productivity

The majority of patients (87.9%) reported to have a job before the infection. The mean proportion of work time missed in the previous week due to ill health (absenteeism) and impairment while working (presenteeism) reduced from 73% to 52% and from 66% to 60%, respectively (both p<0.001; Table 1). In addition, average work productivity loss reduced from 89% to 79%, resulting in an overall working impairment of 71% and 60% after about 3 and 6 months follow-up, respectively (both p<0.001; Table 1).

Self-reported health, functional status, and quality of life

Pre-infection, 87.0% of the patients had a good self-reported health-status. After 3 months followup, only 9.2% of the patients rated their health as 'good', which significantly increased up to 16.7% after about 6 months follow-up (p<0.001, Figure 3a). Consequently, 83.3% of the patients still reported a moderate-to-poor self-reported health after 6 months.

Compared to 3 months follow-up, patients had a significantly lower grading (= better self-reported functional status) on the PCFS scale (2.4 (0.9) versus 2.2 (0.8); p<0.001; Table 1). Functional status improved in 26.8% of the patients, and deteriorated in 15.5% of the patients. The proportion of patients reporting to have currently no limitations in everyday life without infection-related symptoms increased significantly from 1.9 to 6.5% (p<0.001; Figure 3b).

On the EQ-5D-5L questionnaire, the proportion of patients who had problems with mobility, selfcare, and/or daily activities, who had pain or discomfort, or felt anxious or depressed reduced significantly between 3 and 6 months of follow-up (Figure 3c). Still, 62% of the patients had moderate to extreme problems with daily activities at 6 months, and 49% of the patients experienced moderate to severe pain or discomfort (Figure 3c). The mean EQ-5D index (from 0.645 (0.181) to 0.694 (0.165)) and the EQ-VAS (from 49 (19) to 56 (18)) improved significantly (p<0.001; Table 1). Compared to age/gender-matched reference values[23], also the percentage of patients who had an EQ-5D index that was below the fifth percentile significantly reduced from 36.8 to 26.8% (p<0.001; Table 1).

## Received care

The proportion of patients receiving physiotherapy or rehabilitation between 3 and 6 months of follow up was significantly higher compared to the period from the infection to 3 months of follow-up (61.9% versus 31.8%; and 11.7% versus 4.2%, respectively, p<0.05; Table 1), and median (IQR) number of sessions increased significantly from 7 (4-10) to 12 (8-24) (p<0.001). The dependency on partner or family for personal care significantly decreased from 3 to 6 months follow-up (from 46.0% to 21.3% and from 17.2% to 7.1%, respectively, p<0.05), though the proportion of patients needing help from their partner or family was still significantly higher compared to before the infection (21.3% versus 5.0% and 7.1% versus 1.7%, respectively; p<0.05). A subgroup analyses comparing patients who did and did not receive physiotherapy or rehabilitation is included in the Supplementary Material (Supplementary Table 3). In brief, 3 and 6 months after the onset of COVID-19 related symptoms, patient receiving physiotherapy reported more symptoms and a worse self-reported health, work productivity, functional status and quality of life compared to patients who did not receive physiotherapy or rehabilitation. Between 3 and 6

months of follow-up, significant improvements were found in both patients who did and did not receive physiotherapy or rehabilitation.

### Patients with suspected COVID-19 diagnosis

The results of the 766 patients with suspected COVID-19 show similarities to those of the patients with confirmed COVID-19 diagnosis (Supplementary Material).

### Discussion

This is the first study to demonstrate that about 6 months after the onset of COVID-19-related symptoms, patients who are member of online long COVID support groups still suffer from a median of six symptoms. Although significant improvements in health status, work productivity and functional status were found between 3 and 6 months of follow-up, these data clearly highlight the long-term impact of COVID-19 and support the existence of a post-COVID-19 syndrome in a subset of patients[1, 7, 12, 13]. Indeed, the vast majority of patients (94.6%) still experienced one or more symptoms 6 months after being infected. Moreover, 83% of the patients still reported a moderate-to-poor self-reported health, and about half of the patients (49%) reported moderate to severe functional limitations. Furthermore, there was a considerable loss in work productivity, and about a quarter of the patients had an impaired quality of life.

Data from the COVID-19 Symptom Study suggest that most people recover from COVID-19 within two weeks[6], though it is increasingly recognized that a subgroup of patients with COVID-19 may develop long-term symptoms. Our findings clearly demonstrate that a subset of patients with persistent symptoms 3 months after the onset of the infection still suffer from a median of six symptoms 6 months after being infected, including non-respiratory related symptoms like fatigue, pain at different body locations and a loss of smell and/or taste. Remarkably, these patients are generally middle aged, with no or few other underlying chronic conditions before the infection and a good self-reported health. These symptoms seriously limit patients' daily life, as patients experience functional limitations and impaired work productivity, or are even unable to return to work. Fallout from work can not only result in a high financial burden for these patients, but can even have global consequences for the economy and society in the long run. Indeed, this middleaged population is considered the back-bone of most modern economies as they have high shares of labour participation, tax payment and contribute significantly to countries' gross domestic product. Therefore, the involvement of occupational medicine or even interdisciplinary rehabilitation in the patients' return to work seems a necessity to minimize the post-COVID-19 societal impact. Importantly, the impact of COVID-19 in general on work productivity is likely underestimated in this study, as many patients with persistent symptoms may have no test-confirmed COVID-19 diagnosis, since symptoms were not severe enough to require hospitalization, and/or they were not tested because of test scarcity or had false negative test results[24]. Intriguingly, our analyses including patients with a suspected COVID-19 diagnoses yielded similar worrying results. As indicated by the NICE guideline for managing the long term effects of COVID-19, having a positive RT-PCR test or hospitalization is not a prerequisite for COVID-19 diagnosis and healthcare should also focus on these patients with suspected COVID-19 [13]. Furthermore, ICU survivors were not included in the present study, whilst a recent meta-analysis showed that one-third of the previously employed ICU survivors (non-COVID-19 related critical illness) are unemployed and 77% incurred lost earnings five years after hospital discharge[25].

Our findings show that a proportion of patients with persistent symptoms generally have significant improvements in functional and health-related outcomes between 3 and 6 months of follow-up. Then again, only 5% of the patients had zero symptoms after 6 months follow-up and a majority of patients showed no improvement in symptoms and/or self-reported health (17% and 63%, respectively), or even experienced a worsening (34% and 5%, respectively) (Figure 1 and 3b). Interestingly, the current data also show that there are patients with persistent symptoms about 3 and 6 months after the infection who do not experience substantial limitations in their daily lives. To date, it remains unclear why these patients report less/no impact of the persistent symptoms on their daily activities.

The current findings show the major impact of COVID-19 on individual patients and justify a close follow up by healthcare professionals of hospitalized and non-hospitalized COVID-19 patients. To date, there is no consistent approach for the diagnosis, management and follow-up of these patients with the so-called long COVID or post-COVID-19 syndrome. Through online long COVID-19 peer support groups, patients aim to create broader awareness for their unmet care needs[1, 15, 16]. Indeed, an accurate diagnosis and treatment of the possible underlying causes of the persistent symptoms seems very important to restore patients' health and quality of life. Identification of physical, emotional, cognitive and social treatable traits may play an important role to go towards interim guidance for pharmacological and/or non-pharmacological treatment options. Currently, many COVID-19 patients experience that they do not have access to appropriate healthcare and/or continuity of care is often lacking[15]. Although more than half of the patients in this study received physiotherapy, many of them still experienced multiple symptoms 6 months after being infected, and the number of symptoms was even higher compared to patients not receiving physiotherapy. It can be argued that the patients receiving physiotherapy are probable the more impaired patients with more symptoms and poorer health status, yet our findings indicate that physiotherapy alone may not be sufficient for a full recovery. Indeed, it has already been recognized that COVID-19 is not limited to the respiratory system, but is considered as a systemic disease, including cardiovascular, neurological, haematological, gastrointestinal, renal and skin manifestations[26, 27]. Therefore, a multidisciplinary approach will most probably be needed for providing optimal care of these patients. Healthcare professionals, employers, insurers and society need to take action to improve the management and healthcare of these patients.

The following methodological limitations need to be considered. Some questions may have been affected by recall bias. Additionally, we cannot rule out that the patients who completed the baseline and follow-up questionnaires are the ones who experienced the most symptoms. Then again, the median number of reported symptoms 3 months after the onset of symptoms was comparable between patients who completed the survey twice (June and September) and patients who only completed the survey only in June (Supplementary Table 1). The majority of respondents were female, though, this is consistent with the gender distribution of previous studies [6, 15, 16, 28, 29], and can at least partly be explained by the higher number of women in online long COVID-19 support groups[15, 16]. Moreover, it has been suggested that persistent symptoms after COVID-19 are more common in women than men[6]. Obviously, long-term followup data from COVID-19 patients are lacking, and therefore, little is known about different recovery trajectories in these patients. More insight in COVID-19 is needed to identify patients at risk for post-COVID-19 syndrome and to develop targeted treatment plans. Similar to our findings, previous studies indicated that experiencing more than five symptoms during the first week of infection is associated with long-term health complaints [6, 8]. From influenza A (H7N9) and acute respiratory distress syndrome survivors is already known that impaired health-related quality of life, functional disability and psychological problems that persisted up to 2 years of follow-up[30-32]. Finally, this study aimed to evaluate the natural course of symptoms among members of online long COVID-19 peer support groups. Therefore, our findings cannot be generalized to all COVID-19 patients.

To conclude, patients who are all members of online long COVID-19 peer support groups may still experience persistent symptoms 6 months after the onset of symptoms, which can affect work productivity, functional status and quality of life. These findings support the existence of a post COVID-19 syndrome. More research is needed to better understand the long-term consequences of COVID-19 and to improve guidance and care of these patients.

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## **Contributor statement**

AWV, YMJG, MVH, FVCM, RM, JD, SHW were responsible for the data collection. MAS is the principal investigator of this trial. AWV, MAS drafted the manuscript. All authors critically reviewed and revised the manuscript.

## **Competing interests**

All authors have completed the ICMJE uniform disclosure form and declare: FMEF reports grants and personal fees from AstraZeneca, personal fees from Boehringer Ingelheim, personal fees from Chiesi, personal fees from GlaxoSmithKline, grants and personal fees from Novartis, personal fees from TEVA, outside the submitted work (FMEF); personal fees from Novartis, personal fees from Boehringer Ingelheim, personal fees from AstraZeneca, outside the submitted work (DAJ); grants from Bayer, grants from Bristol Meyer Squibb, grants from Boehringer-Ingelheim, grants from MSD, grants from Daiichi-Sankyo, grants from Actelion, grants from the Dutch thrombosis association, grants from the Dutch Heart foundation, grants from the Netherlands Organisation for Health Research and Development, outside the submitted work (FAK); other from CIRO, outside the submitted work (DM); and grants from Lung Foundation Netherlands, grants from Stichting Astma Bestrijding, grants and personal fees from Boeheringer Ingelheim, and grants and personal fees from AstraZeneca, outside the submitted work (MAS).

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## **Figure legends**

## Figure 1 Prevalence and change in the total number of symptoms during the infection and after 3 months and 6 months of follow-up.

The width of lines is proportional to the flow rate.

- No symptoms; 1-5 symptoms; 6-10 symptoms; >10 symptoms
- 0.4% of the patients:  $1-5 \rightarrow 1-5 \rightarrow 0$ ; 2.1% of the patients:  $1-5 \rightarrow 1-5 \rightarrow 1-5$ ;
- 0.4% of the patients:  $1-5 \rightarrow 1-5 \rightarrow 6-10$ ; 0.4% of the patients:  $1-5 \rightarrow 6-10 \rightarrow 1-5$ ;
- $\blacksquare$  0.4% of the patients: 1-5  $\rightarrow$  6-10  $\rightarrow$  6-10;  $\blacksquare$  0.4% of the patients: 1-5  $\rightarrow$  6-10  $\rightarrow$  >10;
- 0.8% of the patients: 6-10  $\rightarrow$  0  $\rightarrow$  0; 0.4% of the patients: 6-10  $\rightarrow$  0  $\rightarrow$  1-5;
- 1.7% of the patients: 6-10  $\rightarrow$  1-5  $\rightarrow$  0; 10.0% of the patients: 6-10  $\rightarrow$  1-5  $\rightarrow$  1-5;
- 2.1% of the patients: 6-10  $\rightarrow$  1-5  $\rightarrow$  6-10; 0.4% of the patients: 6-10  $\rightarrow$  6-10  $\rightarrow$  0;
- 1.3% of the patients: 6-10  $\rightarrow$  6-10  $\rightarrow$  6-10; 0.4% of the patients: 6-10  $\rightarrow$  6-10  $\rightarrow$
- >10;  $\blacksquare$  0.8% of the patients: >10  $\rightarrow$  1-5  $\rightarrow$  0;  $\blacksquare$  15.5% of the patients: >10  $\rightarrow$  1-5  $\rightarrow$  1-5;
- 8.8% of the patients: >10  $\rightarrow$  1-5  $\rightarrow$  6-10; 0.8% of the patients: >10  $\rightarrow$  6-10  $\rightarrow$  0;
- 11.3% of the patients: >10  $\rightarrow$  6-10  $\rightarrow$  1-5; 23.0% of the patients: >10  $\rightarrow$  6-10  $\rightarrow$  6-
- 10;  $\blacksquare$  3.8% of the patients: >10  $\rightarrow$  6-10  $\rightarrow$  >10;  $\blacksquare$  0.4% of the patients: >10  $\rightarrow$  >10  $\rightarrow$
- o;  $\blacksquare$  1.3% of the patients: >10  $\rightarrow$  >10  $\rightarrow$  1-5;  $\blacksquare$  4.2% of the patients: >10  $\rightarrow$  >10  $\rightarrow$  6-
- 10;  $\blacksquare$  8.8% of the patients: >10  $\rightarrow$  >10  $\rightarrow$  >10
- Figure 2 Prevalence of symptoms during the infection and after 3 months and 6 months of follow-up.

Abbreviations: temp.=temperature; BW=body weight; HR=heart rate.

■ During infection; ■ 3 months after start symptoms; ■ 6 months after start symptoms

## Figure 3 Self-reported health, Functional Status, and Quality of life

 Self-reported health status before the infection and after 3 months and 6 months of follow-up

The width of lines is proportional to the flow rate.

- Good; Moderate; Poor
- 6.3% of the patients: good  $\rightarrow$  good  $\rightarrow$  good; 2.1% of the patients: good  $\rightarrow$
- good  $\rightarrow$  moderate;  $\blacksquare$  8.8% of the patients: good  $\rightarrow$  moderate  $\rightarrow$  good;  $\blacksquare$  49.8%

of the patients: good  $\rightarrow$  moderate  $\rightarrow$  moderate;  $\blacksquare$  1.3% of the patients: good  $\rightarrow$  moderate  $\rightarrow$  poor;  $\blacksquare$  0.8% of the patients: good  $\rightarrow$  poor  $\rightarrow$  good;  $\blacksquare$  12.1% of the patients: good  $\rightarrow$  poor  $\rightarrow$  moderate;  $\blacksquare$  5.9% of the patients: good  $\rightarrow$  poor  $\rightarrow$  poor;  $\blacksquare$  0.8% of the patients: moderate  $\rightarrow$  good  $\rightarrow$  moderate;  $\blacksquare$  0.4% of the patients: moderate  $\rightarrow$  moderate  $\rightarrow$  good;  $\blacksquare$  4.2% of the patients: moderate  $\rightarrow$ moderate  $\rightarrow$  moderate;  $\blacksquare$  0.4% of the patients: moderate  $\rightarrow$  moderate  $\rightarrow$ poor;  $\blacksquare$  0.4% of the patients: moderate  $\rightarrow$  good;  $\blacksquare$  2.5% of the patients: moderate  $\rightarrow$  poor  $\rightarrow$  moderate;  $\blacksquare$  2.9% of the patients: moderate  $\rightarrow$ poor;  $\blacksquare$  0.4% of the patients: poor  $\rightarrow$  moderate;  $\blacksquare$  0.8% of the patients: poor  $\rightarrow$  poor

b. Post-COVID-19 Functional Status Scale after 3 months and 6 months of followup

The width of lines is proportional to the flow rate.

Grade o: I have no limitations in my everyday life and no symptoms, pain, depression or anxiety related to the infection.

Grade 1: I have negligible limitations in my everyday life as I can perform all usual duties/activities, although I still have persistent symptoms, pain, depression or anxiety.

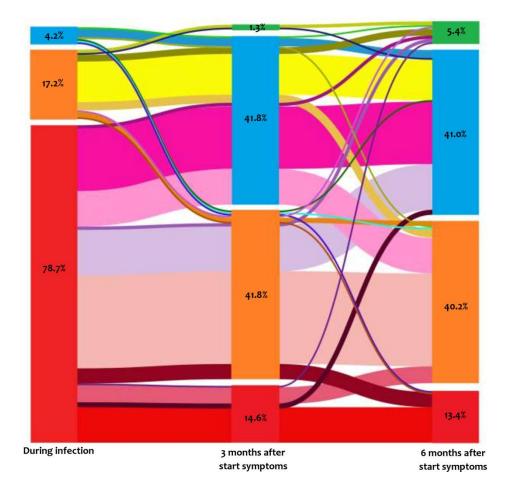
Grade 2: I suffer from limitations in my everyday life as I occasionally need to avoid or reduce usual duties/activities or need to spread these over time due to symptoms, pain, depression or anxiety. I am, however, able to perform all activities without any assistance.

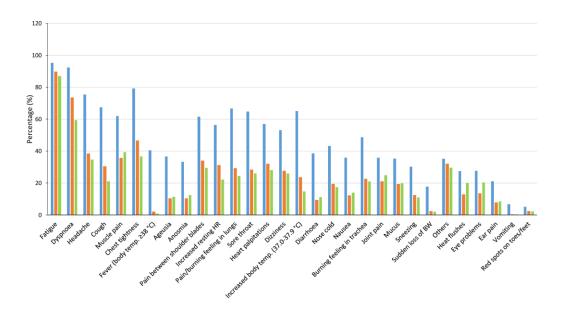
Grade 3: I suffer from limitations in my everyday life as I am not able to perform all usual duties/activities due to symptoms, pain depression or anxiety. I am, however, able to take care of myself without any assistance. Grade 4: I suffer from severe limitations in my everyday life: I am not able to take care of myself and therefore I am dependent on nursing care and/or assistance from another person due to symptoms, pain, depression or anxiety.

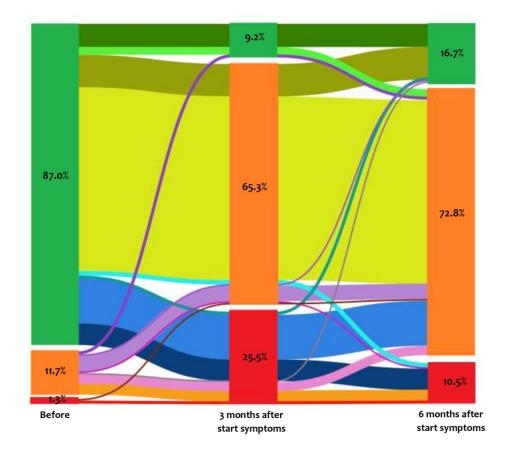
■ Grade 0; ■ Grade 1; ■ Grade 2; ■ Grade 3; ■ Grade 4

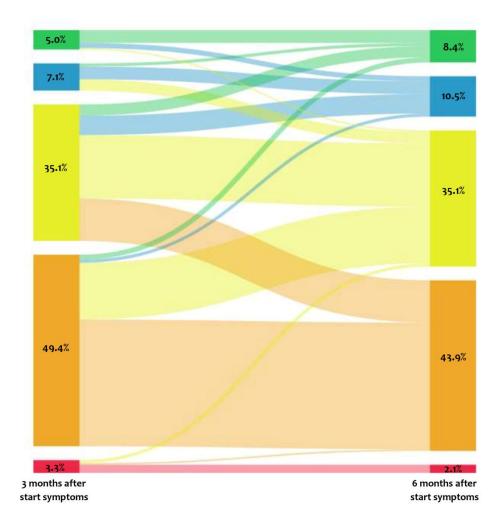
3.3% of the patients: Grade  $0 \rightarrow$  Grade 0; 1.3% of the patients: Grade  $0 \rightarrow$  Grade 1; 0.4% of the patients: Grade  $0 \rightarrow$  Grade 2; 0.8% of the patients: Grade  $1 \rightarrow$ Grade 0; 3.3% of the patients: Grade  $1 \rightarrow$  Grade 1; 2.9% of the patients: Grade  $1 \rightarrow$  $\rightarrow$  Grade 2; 2.9% of the patients: Grade  $2 \rightarrow$  Grade 0; 5.0% of the patients: Grade  $2 \rightarrow$  Grade 1; 16.3% of the patients: Grade  $2 \rightarrow$  Grade 2; 10.9% of the patients: Grade  $2 \rightarrow$  Grade 3; 1.3% of the patients: Grade  $3 \rightarrow$  Grade 0; 0.8% of the patients: Grade 3  $\rightarrow$  Grade 1; 14.6% of the patients: Grade 3  $\rightarrow$  Grade 2; 32.6% of the patients: Grade 3  $\rightarrow$  Grade 3; 0.8% of the patients: Grade 4  $\rightarrow$  Grade 2; 0.4% of the patients: Grade 4  $\rightarrow$  Grade 3; 2.1% of the patients: Grade 4  $\rightarrow$  Grade 4

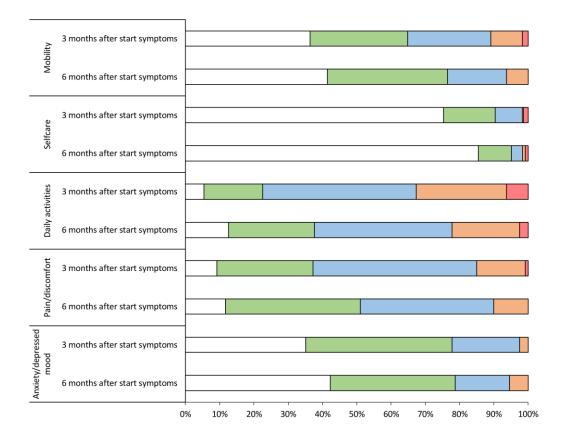
c. Problems on EQ-5D-5L domains after 3 months and 6 months of follow-up
 □ No problems; ■ Slight; ■ Moderate; ■ Severe; ■ Extreme/unable











## Supplementary Material

## Recovery from COVID-19: a sprint or marathon?

## 6 month follow-up of long COVID-19 support group members

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## Results

## Patients with suspected COVID-19 diagnosis

Seven hundred and sixty-six patients who completed both surveys were presumed to have had COVID-19. They did not have a formal COVID-19 testing at the time of the presumed infection. Patients were mostly middle-aged women with a normal body mass index. The vast majority of the patients reported a moderate to good health status before infection (99.2%) (Supplementary Table 4).

## Number of Symptoms

During the COVID-related infection a median of 14 (11-18) symptoms was reported, which was significantly lower 3 and 6 months later: 7 (4-9) and 6 (3-9), respectively (p<0.001, Supplementary Table 3). At all three time points, fatigue was the most prevalent symptom (Supplementary Figure 3).

The proportion of non-symptomatic patients increased between 3 and 6 months follow-up, from 0.5 % to 4.0% (p<0.001). After 6 months, 305 patients (40%) reported 1 to 5 symptoms, 314 patients (41%) reported 6 to 10 symptoms, and 116 patients (15%) reported more than 10 symptoms (Supplementary Figure 4).

#### Work productivity

The majority of patients (83.1%) reported to have a job before the infection. The mean proportion of work time missed in the previous week due to ill health (absenteeism) and impairment while working (presenteeism) reduced from 61% to 48% and from 65% to 57%, respectively (both p<0.001; Supplementary Table 4). In addition, average work productivity loss reduced from 82% to 74%, resulting in an overall working impairment of 73% and 62% after 3 and 6 months, respectively (both p<0.001; Supplementary Table 4).

Self-reported health, functional status, and quality of life

Pre-infection, 85.2% of the patients had a good self-reported health-status. After 3 months followup, only 4.3% of the patients rated their health as 'good', which significantly increased up to 17.0% after 6 months follow-up (p<0.001). Consequently, 83.0% of the patients still reported a moderateto-poor self-reported health after 6 months (Supplementary Figure 5a).

Self-reported functional status did not improve from 3 to 6 months follow-up, however, the proportion of patients reporting to have currently no limitations in everyday life without infection-related symptoms significantly increased from 0.9 to 5.9% (p<0.001; Supplementary Table 4, Supplementary Figure 5c).

The mean EQ-5D index and the EQ-VAS improved significantly from 0.621 (0.184) to 0.689 (0.171) and 46 (19) to 54 (19) points, respectively (p<0.001; Supplementary Table 4). Compared to age/gender-matched reference values (1), also the proportion of patients who had an EQ-5D index that was below the fifth percentile significantly reduced from 39.4 to 28.2% (p<0.001; Supplementary Table 4). Still, 64% of the patients had moderate to extreme problems with daily activities after 6 months, and 54% of the patients experienced moderate to extreme pain or discomfort (Supplementary Figure 5d).

#### Received care

The proportion of patients receiving physiotherapy or rehabilitation between 3 to 6 months of follow up was significantly higher compared to the period from the infection to 3 months of follow-up (57.2% versus 24.3% and 4.4 versus 1.3%, respectively, p<0.05; Supplementary Table 4). The dependency on partner or family for personal care significantly decreased from 3 to 6 months follow-up (from 37.7% to 18.4% and from 12.1% to 4.2%, respectively, p<0.05) , though the proportion of patients needing help from their partner of family was still significantly higher compared to before the infection (18.4% versus 4.8% and 4.2% versus 1.2%, respectively; p<0.05).

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**Supplementary Table 1** Patient characteristics of responders and non-responders to the second survey

	Responders 2 <sup>nd</sup> survey	Non-responders 2 <sup>nd</sup> survey
	(n=1005)	(n=551)
Women, n (%)	850 (84.6)	473 (85.8)
Age, years (median, interquartile range)	48.0 (40.0-54.5)	44.0 (37.0 – 52.0)*
BMI, kg/m <sup>2</sup> (median, interquartile range)	25.1 (22.5-28.7)	25.1 (22.5 – 28.7)
Married/living with partner, n (%)	716 (71.2)	394 (71.5)
Pre-existing comorbidities, n (%)		
None	617 (61.4)	341 (61.9)
1	258 (25.7)	142(25.8)
≥2	130 (12.9)	68 (12.3)
Place of COVID-19 diagnosis and treatment, n (%)		*
Hospitalized, test-based diagnosis	62 (6.2)	18 (3.3)
Non-hospitalized, test-based diagnosis	177 (17.6)	86 (15.6)
Suspected COVID-19	766 (76.2)	447 (81.1)
Time between symptom onset (To) and completion first	11.3 (2.2)	11.4 (2.4)
questionnaire (T1), weeks (mean (SD))		
Health status before infection, n (%)		
Good	861 (85.7)	470 (85.3)
Moderate	135 (13.4)	80 (14.5)
Poor	9 (0.9)	1 (0.2)
Self-reported poor health, %		
Before	0.9	0.2
T1	32.3†	29.8†
Number of symptoms, n (median, interquartile range)		
То	14 (11-18)	14 (10-18)
T1	7 (4-9)†	6 (4-10)†

\*p<0.05 vs. responders 2<sup>nd</sup> round; †p>0.05 vs To

	Hospitalized	Non-hospitalized
	patients (n=62)	patients (n=177)
Women, n (%)	39 (62.9)	159 (89.8)†
Age, years (median, interquartile range)	53.0 (47.8-60.0)	48.0 (37.5-54.5)†
BMI, kg/m²(median, interquartile range)	28.2 (24.8-32.6)	25.6 (23.0-29.4)†
Married/living with partner, n (%)	43 (69.4)	130 (73.4)
Pre-existing comorbidities, n (%)		+
None	28 (45.2)	114 (64.4)
1	23 (37.1)	39 (22.0)
≥2	11 (17.7)	24 (13.6)
Health status before infection, n (%)		
Good	49 (79.0)	159 (89.8)
Moderate	12 (19.4)	16 (9.0)
Poor	1 (1.6)	2 (1.1)
Time between symptom onset (To) and completion questionnaire, weeks (mean (SD))		
First questionnaire (T1)		
Second questionnaire (T2)	11.1 (2.0)	10.1 (2.4)
	23.4 (2.0)	22.4 (2.4)
Number of symptoms, n (median, interquartile range)		
Το	14 (10-17)	15 (12-18)
T1	6 (4-8)*	6 (4-9)*
T2	6 (2-8)*	6 (3-8)*#
Work Productivity and Activity Index	. ,	· · · /
Percentage of work time missed due to ill health (absenteeism) (mean (SD))		
T1	81.5 (29.0)	70.4 (36.5)
Τ2	60.0 (36.9)#	50.0 (38.6)#
Percentage of impairment while working (presenteeism) (mean (SD))		,
τη Τ1	67.8 (29.0)	65.8 (25.2)
T2	59.7 (23.3)#	59.7 (24.3)#
Overall work impairment due to health (work productivity), % (mean (SD))		
T1	93.0 (16.5)	88.2 (20.1)
T2	82.9 (26.2)#	77.3 (25.9)#
Activity impairment, % (mean (SD))		
T1	71.8 (22.9)	71.3 (21.3)
T2	57.3 (24.6)#	60.5 (22.1)#
Self-reported poor health, %	. •	
То	1.6	1.1
T1	25.8*	25.4*
T2	8.1*#	11.3*#
Post-COVID-19 Functional Status Scale, Grade (mean (SD))		
Τ1	2.3 (1.1)	2.4 (0.8)
T2	2.2(1.1)	2.2 (0.9)#
Quality of life		
EQ-5D index (mean (SD))		
T1	0.643 (0.202)	0.646 (0.173)
T2	0.710 (0.180)#	0.688 (0.159)#
EQ-5D index < P5 reference values [23], %		,,
T1	35.5	37.3
Τ2	24.2#	27.7#
Today's health status (VAS 0-100), points	•	
Τ1	49 (21)	49 (18)
T2	57 (20)#	56 (18)#

# **Supplementary Table 2** Patient characteristics of hospitalized and non-hospitalized patients with confirmed COVID-19 diagnosis

Received care			
	Physiotherapy, %		
	Between To and T1	48.4	26.0†
	Between T1 and T2	61.3#	62.1#
	Rehabilitation, %		
	Between To and T1	9.7	2.3†
	Between T1 and T2	12.9	11.3#
Need for help with personal care			
	From partner, %		
	Before	6.5	4.5
	Between To and T1	56.5*	42.4*
	Between T1 and T2	22.6#	20.9*#
	From family, %		
	Before	1.6	1.7
	Between To and T1	22.6*	15.3*
	Between T1 and T2	9.7*#	6.2*#

†p<0.05 vs. hospitalized patients; \*p<0.05 vs. before; #p<0.05 vs. T1; P5=percentile five; VAS=visual analogue scale

and patients not receiving physiotherapy/rehabi		
	Patients receiving physiotherapy/rehabilitation (n=155, 64.9%)	Patients not receiving physiotherapy/rehabilitation (n=84, 35.1%)
Women, n (%)	133 (85.8)	65 (77.4)
Age, years (median, interquartile range)	50.0 (40.0-56.0)	49.0 (39.0 - 57.8)*
BMI, kg/m <sup>2</sup> (median, interquartile range)	26.2 (23.7-30.7)	25.6 (23.1 – 29.3)
Married/living with partner, n (%)	113 (72.9)	60 (71.4)
Pre-existing comorbidities, n (%)		
None	93 (60.0)	49 (58.3)
1	38 (24.5)	24 (28.6)
≥2	24 (15.5)	11 (13.1)
Place of COVID-19 diagnosis and treatment, n (%)		*
Hospitalized, test-based diagnosis	41 (26.5)	21 (25.0)
Non-hospitalized, test-based diagnosis	114 (73.5)	63 (75.0)
Health status before infection, n (%)		
Good	131 (84.5)	77 (91.7)
Moderate	21 (13.5)	7 (8.3)
Poor	3 (1.9)	0 (0.0)
Number of symptoms, n (median, interquartile range)		
То	15 (12-18)	14 (10-17)
Τ1	7 (5-9)†	5 (3-8)*†
T2	6 (4-9)	4 (2-7)*
Self-reported poor health, %		
Before	1.9	0.0
T1	32.3†	13.1*†
T2 Work Productivity and Activity Index Percentage of work time missed due to ill health (absenteeism) (mean (SD))	13.5†	4.8*†
T1	82.0 (28.3)	56.2 (40.4)*
T2 Percentage of impairment while working (presenteeism) (mean (SD)) –	64.8 (34.3)†	28.5 (34.4)*†
T1	75.0 (22.7)	55.2 (25.4)*
T2 Overall work impairment due to health (work productivity), % (mean (SD))	66.1 (20.4) <del>†</del>	49.5 (26.0)*
T1	93.5 (14.7)	80.8 (24.5)*
T2	86.6 (18.9)†	62.2 (30.6)*†
Activity impairment, % (mean (SD))		
Τ1	77.0 (17.5)	61.2 (24.9)*
Τ2	64.8 (19.7)†	50.1 (25.0)*†
Post-COVID-19 Functional Status Scale		
Grade (mean (SD))		
T1	2.6 (0.7)	2.0 (0.7)*
Τ2	2.5 (0.8)	1.8 (1.0)*
Quality of life		
EQ-5D index (mean (SD))		
T1	0.613 (0.173)	0.706 (0.179)*
T2	0.663 (0.155)†	0.751 (0.168)†*
EQ-5D index < P5 reference values [20], %	44.5	28.6
T1 T2	41.3	
	30.3†	20.2
Today's health status (VAS 0-100), points		

**Supplementary Table 3** Patient characteristics of patients receiving physiotherapy/rehabilitation and patients not receiving physiotherapy/rehabilitation

T1 T2	45 (18) 52 (18)†	57 (17)* 65 (17)†*
Need for help with personal care		
From partner, %		
Before	5.2	4.8
Between To and T1	50.3†	38.1†
Between T1 and T2	24.5†#	15.5†#
From family, %		
Before	1.9	1.2
Between To and T1	21.3†	9.5†*
Between T1 and T2	7.7†#	6.0

\*p<0.05 vs. patients receiving physiotherapy/rehabilitation; p>0.05 vs before/during infection; p<0.05 vs. T1

	N=766
Women, n (%)	652 (85.1)
Age, years (median, interquartile range)	48.0 (40.0-54.0)
BMI, kg/m² (median, interquartile range)	24.7 (22.2-28.1)
Married/living with partner, n (%)	543 (70.9)
Pre-existing comorbidities, n (%)	
None	475 (62.0)
1	196 (25.6)
٤2	95 (12.4)
Health status before infection, n (%)	
Good	653 (85.2)
Moderate	107 (14.0)
Poor	6 (0.8)
between symptom onset (To) and completion questionnaire, weeks (mean (SD))	
First questionnaire (T1)	11.5 (2.1)
Second questionnaire (T2)	23.8 (2.1)
Number of symptoms, n (median, interquartile range)	
To	14 (11-18)
T1 T2	7 (4-9)* 6 (2-0)*t
12 Work Productivity and Activity Index	6 (3-9)*†
Percentage of work time missed due to ill health	
(absenteeism) (mean SD))	
T1	61.4 (38.0)
$T_2$	47.5 (39.8)*
Percentage of impairment while working (presenteeism) (mean (SD))	(1, 2, 2)
T1 T2	64.9 (25.3) 57.3 (26.5)*
Overall work impairment due to health (work productivity), %	57.3 (20.5)*
(mean (SD))	
T1	82.2 (24.8)
T2	74.0 (28.8)*
Activity impairment, % (mean (SD))	
T1	72.9 (20.9)
Т2	61.8 (24.0)*
Self-reported poor health, %	
Before	0.8
T1	34.5*
T2	15.1*†
Post-COVID-19 Functional Status Scale	
Grade (mean (SD))	
T1 T2	2.6 (0.7)
Quality of life	2.6 (0.9)
EQ-5D index (mean (SD))	
	0.621 (0.184)
T2	0.689 (0.171)*
EQ-5D index < P5 reference values (1), %	51009 (01171)
T1	39.4
Τ2	28.2*
Today's health status (VAS 0-100), points	
T1	46 (19)
T2	54 (19)*

## Supplementary Table 4 Characteristics of patients with suspected COVID-19

Received care		
	Physiotherapy, %	
	Between To and T1	24.3
	Between T1 and T2	57.2*
	Rehabilitation, %	
	Between To and T1	1.3
	Between T1 and T2	4.4*
Need for help with personal care		
	From partner, %	
	Before	4.8
	Between To and T1	37.7*
	Between T1 and T2	18.4*†
	From family, %	
	Before	1.2
	Between To and T1	12.1*
	Between T1 and T2	4.2*†

\*p<0.05 vs. before; †p<0.05 vs. T1

Supplementary Figure Legends

Supplementary Figure 1	Study flow chart
Supplementary Figure 2	Number of symptoms during the infection and after 3 months and 6 months of follow-up patients with confirmed COVID-19 diagnosis (n=239) During infection; 3 months after start symptoms; 6 months after start symptoms
Supplementary Figure 3	<pre>Prevalence of symptoms during the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766) Abbreviations: temp.=temperature; BW=body weight; HR=heart rate. During infection; 3 months after start symptoms; 6 months after start symptoms</pre>
Supplementary Figure 4	<ul> <li>Number of symptoms during the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)</li> <li>During infection; = 3 months after start symptoms; = 6 months after start symptoms</li> </ul>
Supplementary Figure 5	<ul> <li>Self-reported health, Functional Status, and Quality of life in patients with suspected COVID-19 (n=766)</li> <li>a. Self-reported health status before the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)</li> <li>The width of lines is proportional to the flow rate.</li> <li>Good; Moderate; Poor</li> <li>b. Post-COVID-19 Functional Status Scale after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)</li> </ul>

The width of lines is proportional to the flow rate. Grade o: I have no limitations in my everyday life and no pain, depression or anxiety related to the infection. Grade 1: I have negligible limitations in my everyday life as I can perform all usual duties/activities, although I still have persistent symptoms, pain, depression or anxiety. Grade 2: I suffer from limitations in my everyday life as I occasionally need to avoid or reduce usual duties/activities or need to spread these over time due to symptoms, pain, depression or anxiety. I am, however, able to perform all activities without any assistance.

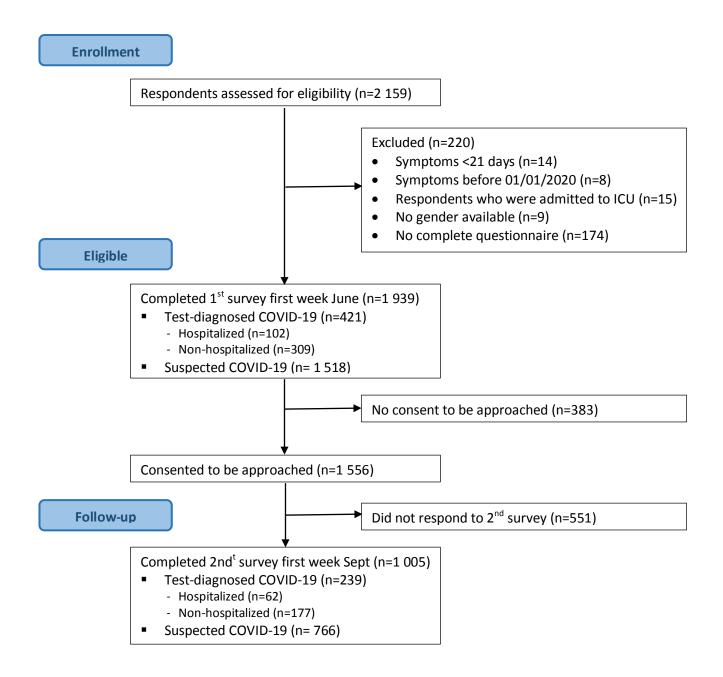
Grade 3: I suffer from limitations in my everyday life as I am not able to perform all usual duties/activities due to symptoms, pain depression or anxiety. I am, however, able to take care of myself without any assistance.

Grade 4: I suffer from severe limitations in my everyday life: I am not able to take care of myself and therefore I am dependent on nursing care and/or assistance from another person due to symptoms, pain, depression or anxiety.

- Grade 0; Grade 1; Grade 2; Grade 3; Grade 4
- c. Problems on EQ-5D-5L domains after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

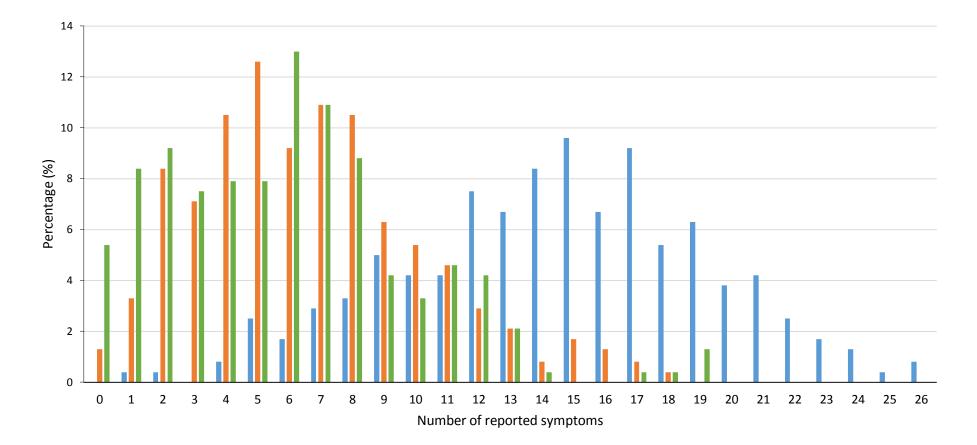
No problems; Slight; Moderate; Severe;
 Extreme/unable

## Supplementary Figure 1 Study flow chart



## Supplementary Figure 2 Number of symptoms during the infection and after 3 months and 6 months of follow-up in patients with confirmed COVID-19 diagnosis (n=239)

During infection; = 3 months after start symptoms; = 6 months after start symptoms

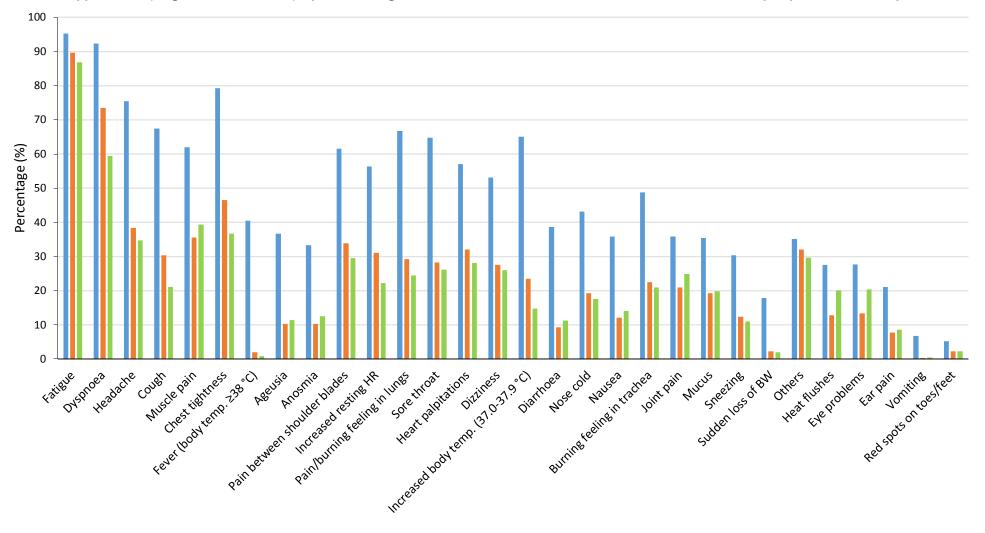


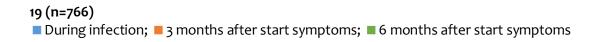
# Supplementary Figure 3 Prevalence of symptoms during the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

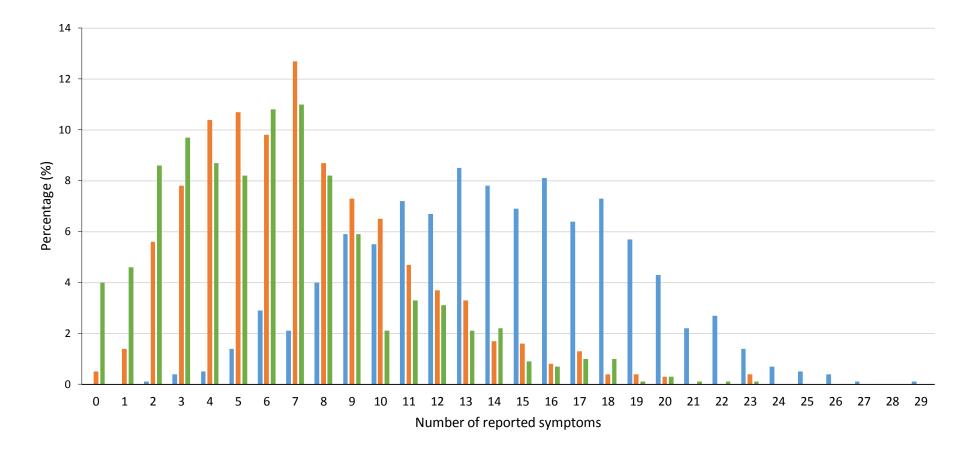
Abbreviations: temp.=temperature; BW=body weight; HR=heart rate.

During infection; 3 months after start symptoms; 6 months after start symptoms

Supplementary Figure 4 Number of symptoms during the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-







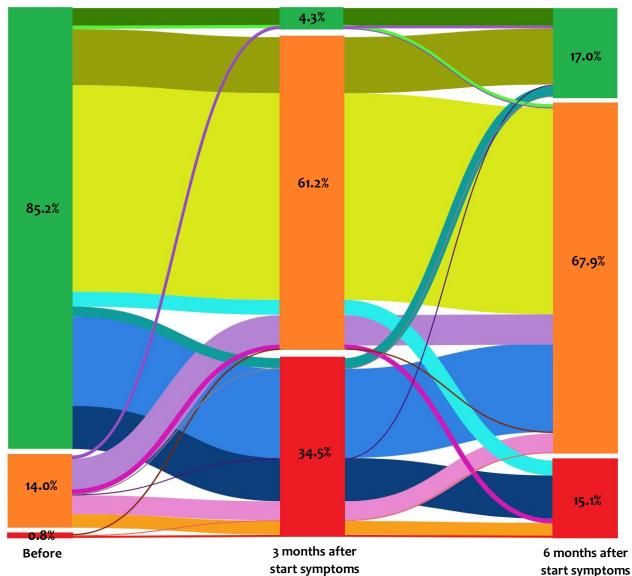
Supplementary Figure 5 Self-reported health, Functional Status, and Quality of life in patients with suspected COVID-19 (n=766)

a. Self-reported health status before and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

The width of lines is proportional to the flow rate.

■ Good; ■ Moderate; ■ Poor

■ 3.4% of the patients: good → good → good; ■ 0.7% of the patients: good → good → moderate; ■ 10.8% of the patients: good → moderate → good; ■ 39.9% of the patients: good → moderate → moderate; ■ 2.9% of the patients: good → moderate → poor; ■ 2.0% of the patients: good → poor → good; ■ 17.2% of the patients: good → poor → moderate; ■ 8.4% of the patients: good → poor → poor; ■ 0.1% of the patients: moderate → good → good; ■ 0.1% of the patients: moderate → good → moderate; ■ 0.5% of the patients: moderate → moderate → good; ■ 5.9% of the patients: moderate → moderate; ■ 0.9% of the patients: moderate → moderate → poor; ■ 0.1% of the patients: moderate → good; ■ 3.7% of the patients: moderate → poor → moderate; ■ 2.6% of the patients: moderate → poor → poor; ■ 0.3% of the patients: poor → moderate; ■ 0.1% of the patients: poor → poor; ■ 0.4% of the patients: poor → poor → poor

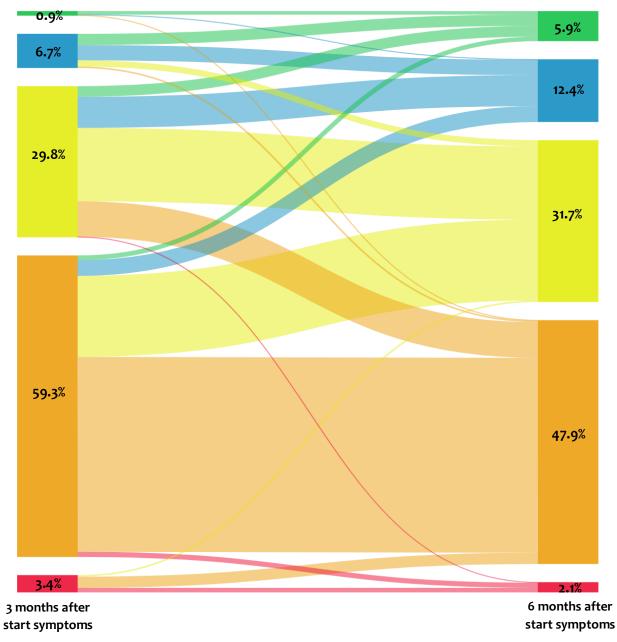


# b. Post-COVID-19 Functional Status Scale after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

The width of lines is proportional to the flow rate.

Grade 0 Grade 1 Grade 2 Grade 3 Grade 4

6.5% of the patients: Grade  $0 \rightarrow$  Grade 0; 0.1% of the patients: Grade  $0 \rightarrow$  Grade 1; 0.3% of the patients: Grade  $0 \rightarrow$  Grade 3; 2.2% of the patients: Grade  $1 \rightarrow$  Grade 0; 3.0% of the patients: Grade  $1 \rightarrow$  Grade 1; 1.2% of the patients: Grade  $1 \rightarrow$  Grade 2; 0.3% of the patients: Grade  $1 \rightarrow$  Grade 3; 2.1% of the patients: Grade  $2 \rightarrow$  Grade 0; 6.1% of the patients: Grade  $2 \rightarrow$  Grade 1; 14.4% of the patients: Grade  $2 \rightarrow$  Grade 2; 7.0% of the patients: Grade  $2 \rightarrow$  Grade 3; 0.1% of the patients: Grade  $2 \rightarrow$  Grade 4; 0.9% of the patients: Grade  $2 \rightarrow$  Grade 0; 3.1% of the patients: Grade  $3 \rightarrow$  Grade 1; 15.9% of the patients: Grade  $3 \rightarrow$  Grade 2; 38.3% of the patients: Grade  $3 \rightarrow$  Grade 2; 2.2% of the patients: Grade  $3 \rightarrow$  Grade  $4 \rightarrow$  Grade 2; 2.2% of the patients: Grade  $3 \rightarrow$  Grade  $4 \rightarrow$  Grade 2; 2.2% of the patients: Grade  $3 \rightarrow$  Grade 3; 0.9% of the patients: Grade  $4 \rightarrow$  Grade 2; 2.2%



# c. Problems on EQ-5D-5L domains after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766) No problems; Slight; Moderate; Severe; Extreme/unable

Mobility	3 months after start symptoms											
Mo	6 months after start symptoms											
Selfcare	3 months after start symptoms											
Self	6 months after start symptoms											
Daily activities	3 months after start symptoms											
Daily ac	6 months after start symptoms											
comfort	3 months after start symptoms											
Pain/discomfort	6 months after start symptoms											
epressed od	3 months after start symptoms											
Anxiety/depressed mood	6 months after start symptoms											
	0	1%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%