Post Acute Sequelae of SARS-CoV-2 Infection (PASC)

Formally Long COVID

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Terminology

- **Acute COVID-19**
  - Signs and symptoms of COVID-19 for up to 4 weeks from symptom onset
- **Ongoing symptomatic COVID-19**
  - Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.
- **Post-COVID-19 syndrome**
  - Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.
  - It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.
- **Long COVID**
  - In addition to the clinical case definitions, the term 'Long COVID' is commonly used to describe 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).
- **Post-Acute Sequelae of SARS-CoV-2 infection (PASC)**
  - Persistence of signs and symptoms associated COVID-19 beyond 4 weeks of acute illness not better explained by another disease process.

(National Institute for Health and Care Excellence (NICE), UK)

Background

- “Long Haulers”– First Articles as early as February 2020
  - Stories of patients reporting persistence of symptoms months after their initial diagnosis shared on Blogs, Facebook Groups and other social media platforms
  - Concerned whether these were as a result of ongoing infection
  - Whether they could infect other people
- Initial Medical Response was poor – Focused on those who were acutely ill

COVID-19 SUPPORT GROUP

When members of our team fell ill in March, we relied on each other for emotional support. In creating the COVID-19 support group, we wanted to provide others with that same opportunity to feel connected and supported through infection, symptoms, and

LONG COVID SUPPORT

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1000s of people with #LongCovid need:

Rehab - Research - Recognition

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The Problem of 'Long Haul' COVID

More and more patients are dealing with major symptoms that linger for months

By Carolyn Barber on December 29, 2020

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12 hours ago — Luke Taylor and Nature magazine

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13 hours ago — Ann Crawford-Roberts, Sonya Shadravan, Jennifer Tsai, Nicolás E. Barceló, Allie Gips, Michael Mensah,

facebook

Long Covid Support Group

Private group · 37.9K members

About Discussion

About this group

This is a private group for people with Lo long haul Covid, post-Covid syndrome) o someone ... See more

COVID-19 Arts + Culture Business + Economy Education Environment + Energy Health + Medicine Politics Science + Technology

I'm a COVID-19 long-hauler and an epidemiologist – here's how it feels when symptoms last for months

Waking up to PASC

- Current Literature on PubMed:
  - Long Haulers: 22 results
  - Long COVID: 133 results
  - Post Acute COVID: 1 214 results
  - COVID-19/complications: 3,326 results
  - COVID-19: 113 657 results

Causes of PASC

- May be as result of the inflammation and injury that occurs during the acute infectious period
- Injuries can occur in a variety of organ systems including the brain, heart and of course the lungs
  - Ultimately the injury may be widespread throughout all organ systems in the body
- No ongoing SARS-COV-2 infection – Non-Communicable per se

Presentation of PASC

- **Most Common Symptoms**
  - Severe fatigue
  - Shortness of breath/breathlessness
  - Persistent cough
  - Chest pain or heaviness
  - Joint pain or swelling

The syndrome is often accompanied by anxiety and depression, associated with the protracted and unpredictable course of the symptoms.

- **Other Symptoms**
  - Cognitive impairment – “brain fog”
  - Muscle pain
  - Headache
  - Intermittent fever
  - Palpitations
  - Anosmia and/or ageusia
  - Reduced exercise capacity
  - Vertigo and tinnitus
  - Peripheral neuropathy
  - Metallic or bitter taste
  - Skin rash

Prevalence of Persistent Symptoms

- Amongst 9 studies, the prevalence of ≥1 persistent symptoms ranges from 29-93% (Follow up ranged from 1-7 months)

Most Commonly reported Symptoms amongst 14 Studies with ±9 000 patients

Symptoms	Range	Studies
Fatigue	9-84%	13
Cognitive Impairment/Brain Fog	2-82%	3
Anosmia	9-74%	9
Dyspnoea	11-66%	14
Headache	2-64%	8
Ageusia	10-64%	3
Muscle Pain	2-60%	5
Sore Throat	10-60%	2
Anxiety	15-58%	4
Memory Impairment	51%	1
Depression	47%	1
PTSD	24-47%	2

Symptoms	Range	Studies
Sleeping Disorder	8-44%	6
Palpitations	9-40%	3
Menstrual Disturbances	36%	1
Sexual Dysfunction: Male	15-33%	2
Fever	0-31%	5
Chest Pain	5-28%	8
Joint Pain	7-27%	5
Cough	2-21%	8
Diarrhoea	1-21%	6
Sexual Dysfunction: Non-Binary	16%	1
Lack of Appetite	10-14%	2
Sexual Dysfunction: Female	8%	1

Diagnosis of PASC

- No laboratory test verified
  - Antibody testing is not reliable or translatable
- Diagnosis is primarily clinical and based on exclusion
  - Confirmed acute COVID with persistent symptoms >4 weeks
  - COVID-like illness without confirmation but persistence of symptoms >4 weeks

Risk Factors for PASC

- 10% of patients who suffered from COVID-19 may be at risk
- Severity of acute COVID-19 infection not shown to be a factor associated with the development of PASC
- Early data on at-risk groups:
  - Pre-existing depression is associated with severe post-COVID fatigue
  - Male sex (twice as common than in woman)
    - Data is conflicting (Need to consider health seeking behavior between sexes)
  - High BMI

Impact of Activities of Daily Living and Occupation

- Haeverall, et al., 2021
  - 8% reported long-term symptoms moderately to markedly disrupted their work life
  - 15% reported long-term symptoms moderately to markedly disrupted their social life
  - 12% reported long-term symptoms moderately to markedly disrupted their home life
- Garrigues, et al., 2020
  - 56 (47%) were active workers; amongst them, 38 (69%) had gone back to work.
  - 39 patients who had performed regular sports activity before their hospitalization for COVID-19, 28 (72%) have been able to resume physical activity, but at a lower level for 18 (46%).
  - Reduced proportion of patients returning to work amongst ICU patients (47% versus 78%, P = 0.061).
- Carvalho-Schneider et al. 2021
  - 20% of patients were on sick leave at the 1 month follow up
  - 11% of patients were on sick leave at the 2 month follow up

NICD (DATCOV) LONG COVID/PASC STUDY

Study Overview

- Study Design:
  - *Quantitative Longitudinal Cohort*
  - *ISARIC - International collaboration with 10 countries*
- Purpose:
  - *Establish the presence of long-term complications in COVID-19 survivors and guide their rehabilitation.*
- Objectives:
  - *Characterize physical and psychosocial consequences in patients post-COVID-19 infection.*
  - *Estimating the risk of and risk factors for post-COVID-19 medical sequelae, psychosocial consequences and post COVID-19 mortality.*
- Ethics:
  - *Wits HREC Approval Number M201150*
- Funding*:*
  - *Bill and Melinda Gates Foundation*

- Sampling:
  - *Currently only patients discharged post-hospitalisation are included*
- Methodology:
  - Utilize DATCOV Hospital Surveillance database to extract potential participants based on Outcome Dates
  - Research Assistants and Surveillance Officers trained to conduct 15-20 min telephonic interview
  - 1, 3, 6 and 12 month follow up
  - ~120 questions CRF
    - Presenting Symptoms
    - On going symptoms
    - Quality of Life Validated tools
    - Changes in employment status/activities of daily living

Participants enrolled

Total Calls	4 462	100%
Total Unreachable	3 083	69%
Total Refusals	315	7%
Total Surveys Completed	1 061	24%

*Unreachable are predominately due to incorrect contact numbers extracted from the DATCOV Database and the Master Linelist.

Time from discharge to survey date:

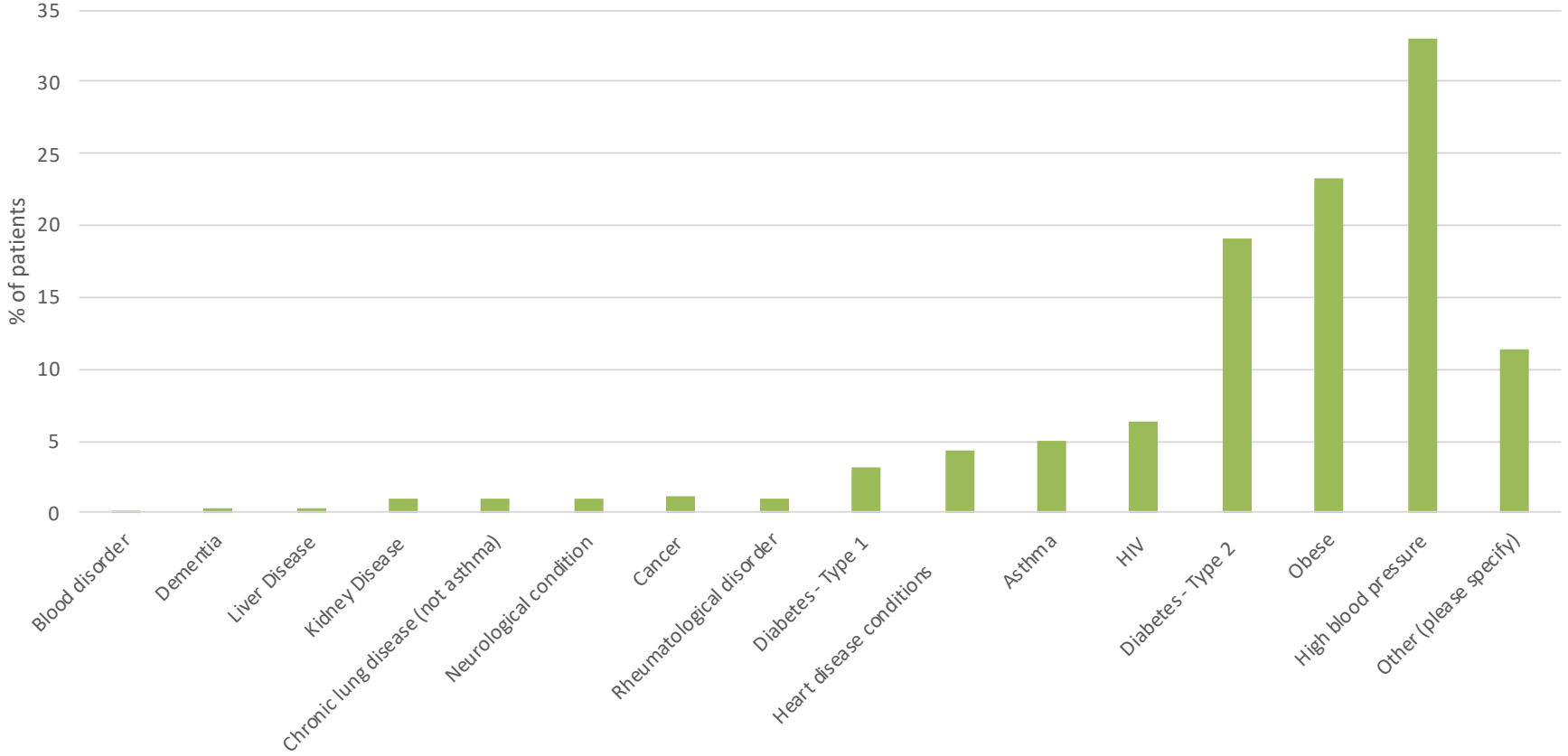
Median: 28 days

IQR [28 - 29]

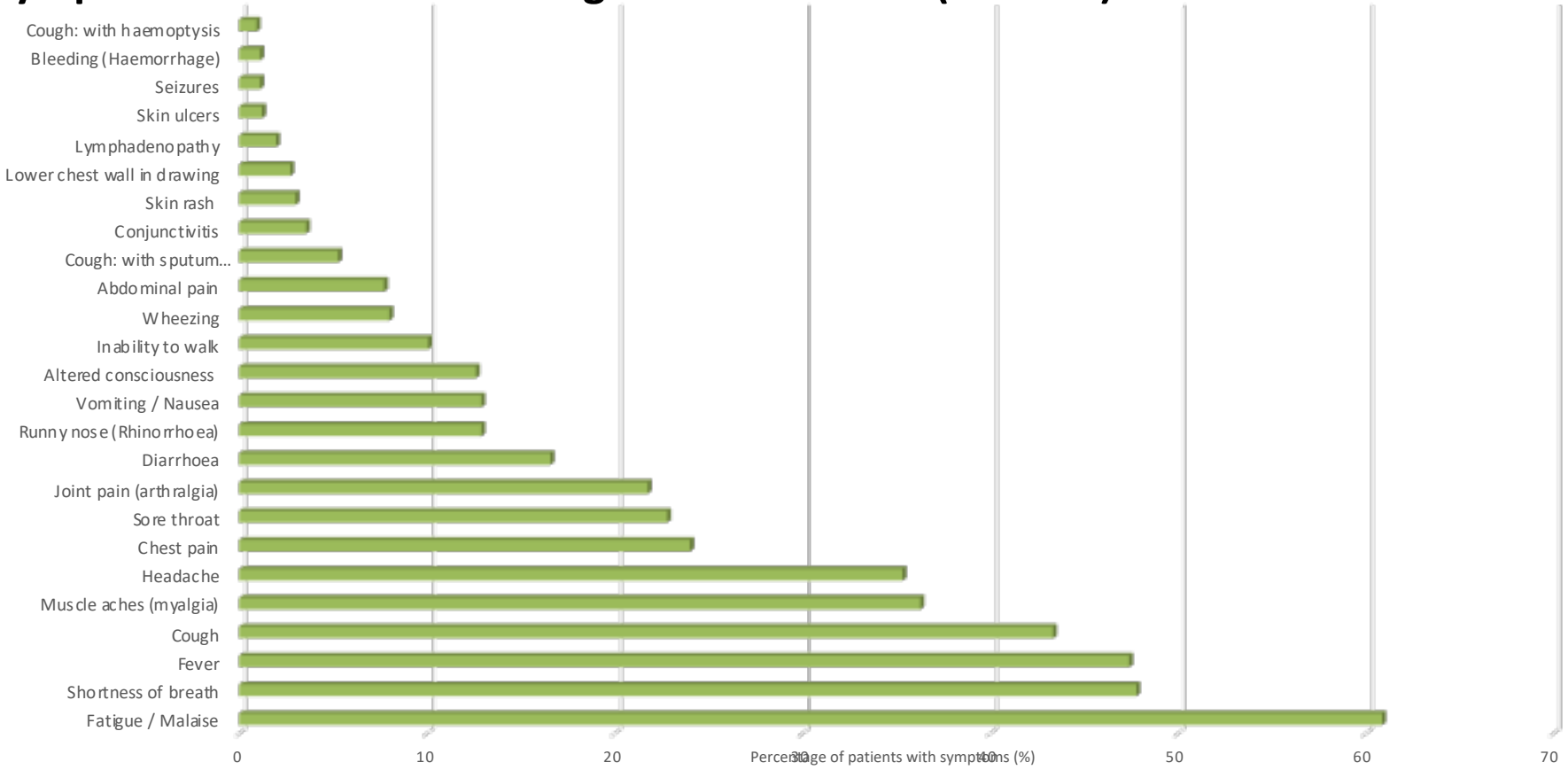
Demographic characteristics

Characteristic	Female	Male	Total
	Female 548 (51.7%)	Male 513 (48.4%)	N=1 061
Median age (IQR)	50 [38-60]	53 [44-62]	52 [40 - 61]
Age group			
<40 years	155 (28.3)	93 (18.2)	248 (23.4)
40-64 years	305 (55.7)	319 (62.3)	624 (58.9)
≥65 years	87 (15.9)	100 (19.5)	187 (17.6)
Unknown	1 (0.2)		1 (0.1)
Race			
White	62 (11.3)	84 (16.4)	146 (13.8)
Africans	280 (51.1)	211 (41.1)	491 (46.3)
Coloured	37 (6.8)	36 (7.0)	73 (6.9)
Indian	34 (6.2)	33 (6.4)	67 (6.3)
Other	2 (0.4)	1(0.2)	3 (0.3)
Unknown	133 (24.3)	148 (28.9)	281 (26.5)

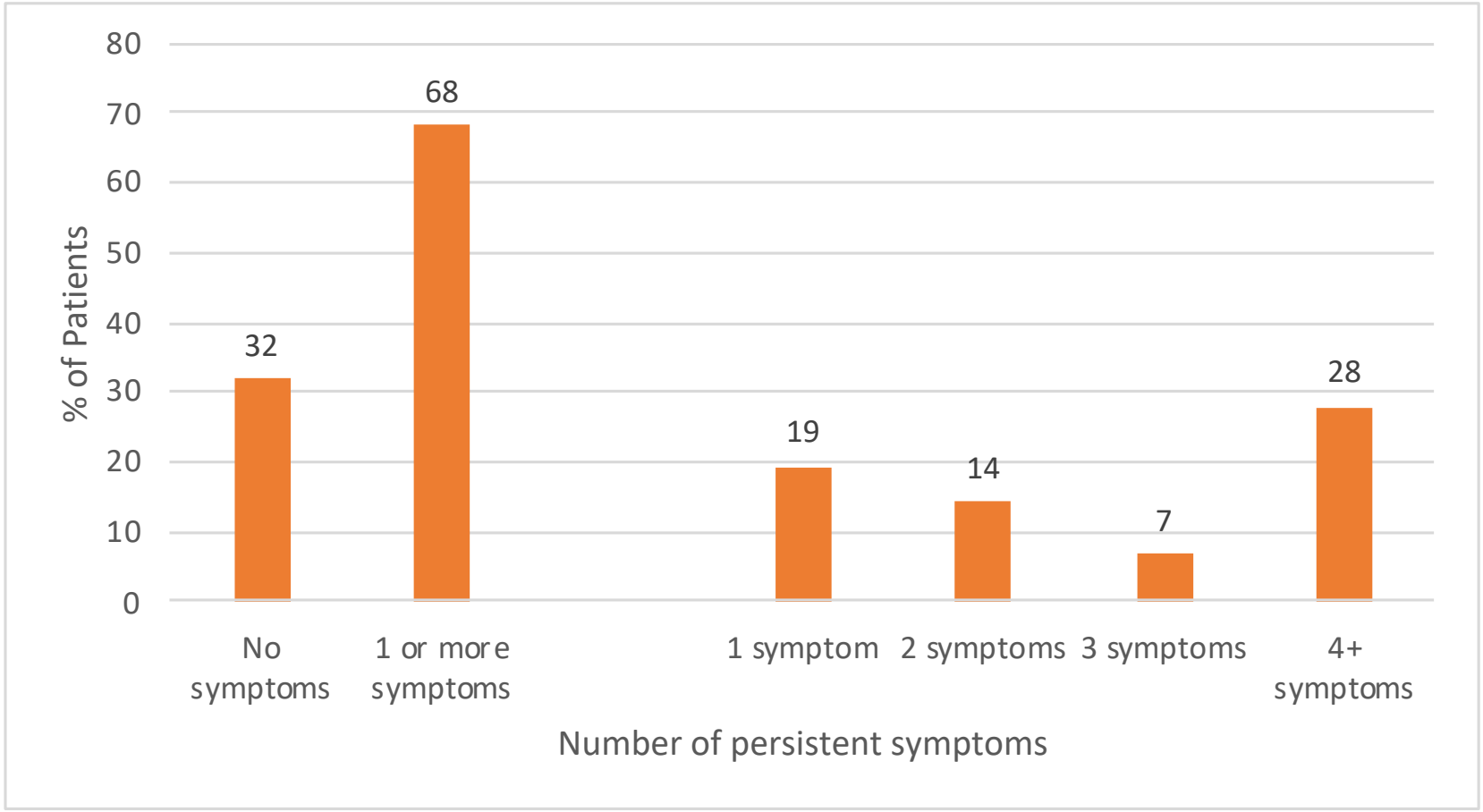
Prevalence of comorbidities (N=1061)



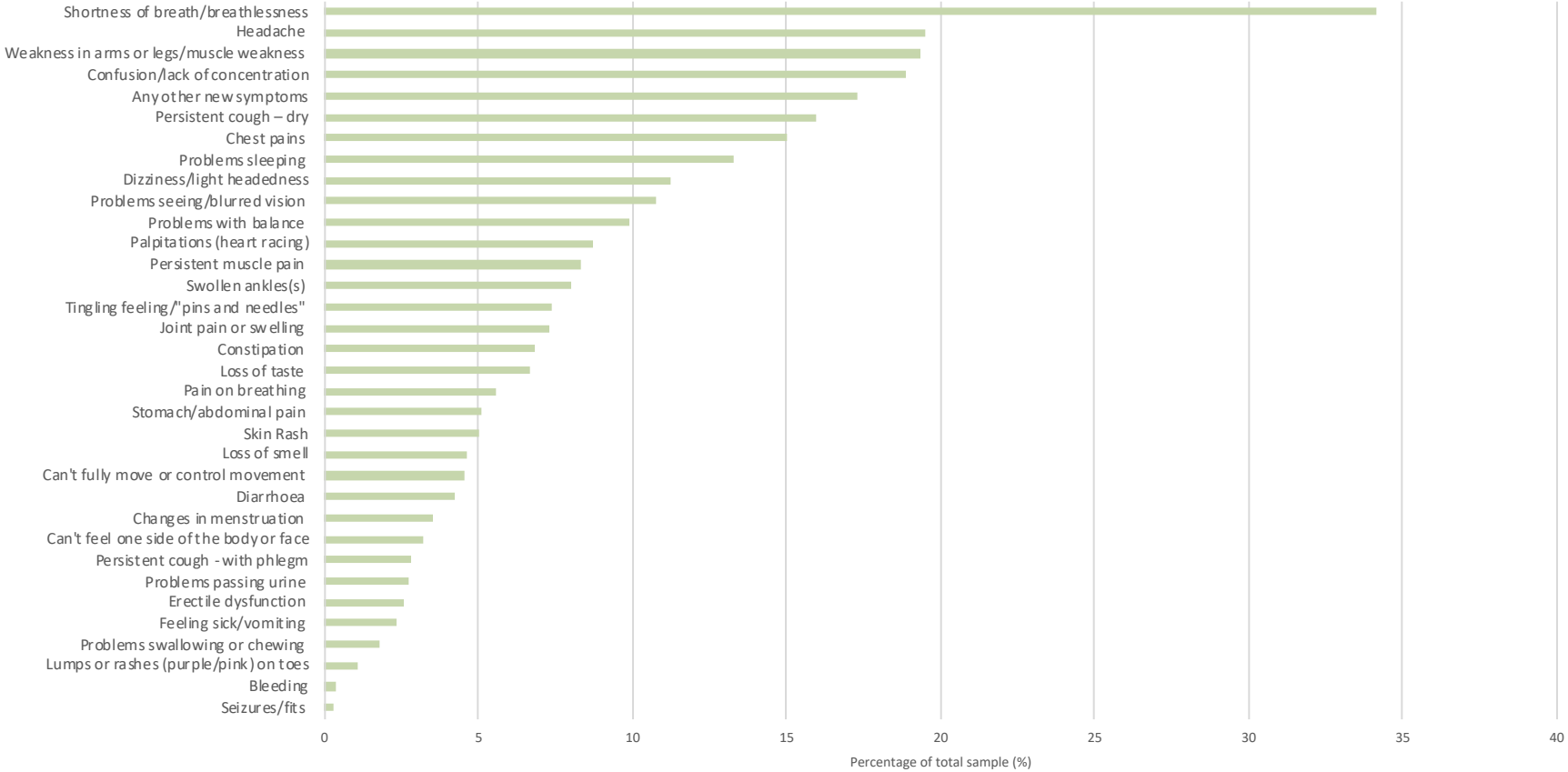
Symptoms on admission during acute COVID-19 (N=1061)



Number of Persistent Symptoms (N=1061)



Symptoms at 1 month (N=1061)



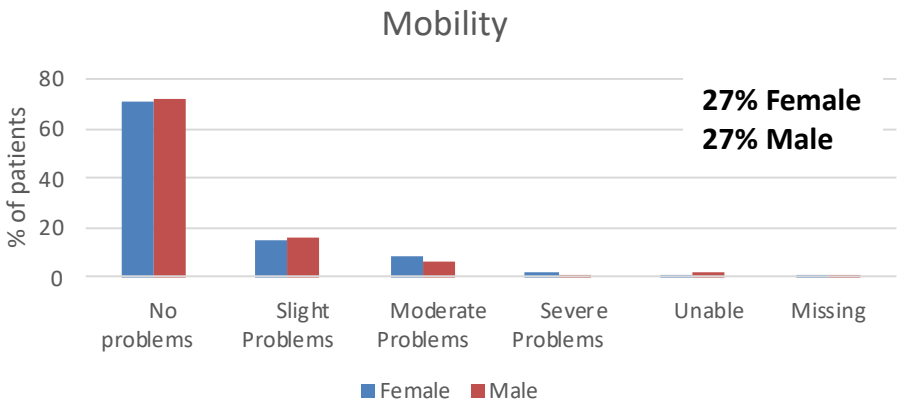
Symptoms at 1 month by Sex (N=1061)

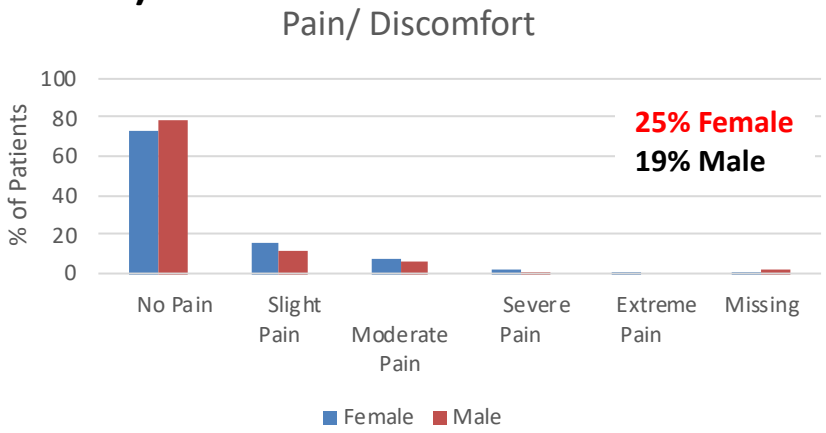
Characteristic	Symptoms in the past seven days		
	Female (%)	Male (%)	Total (%)
Shortness of breath/breathlessness	33.9	34.3	34.1
Headache	22.5	16.4	19.5
Weakness in arms or legs/muscle weakness	18.1	20.7	19.3
Confusion/lack of concentration	21.4	16.2	18.9
Persistent cough – dry	15.0	17.0	15.9
Chest pains	17.7	12.1	15.0
Problems sleeping	12.8	13.8	13.3
Dizziness/light headedness	13.7	8.6	11.2
Problems seeing/blurred vision	12.6	8.8	10.7

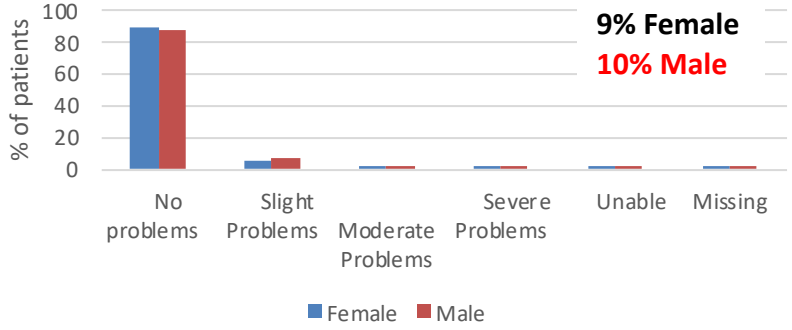
Severe complications by Sex (N=1061)

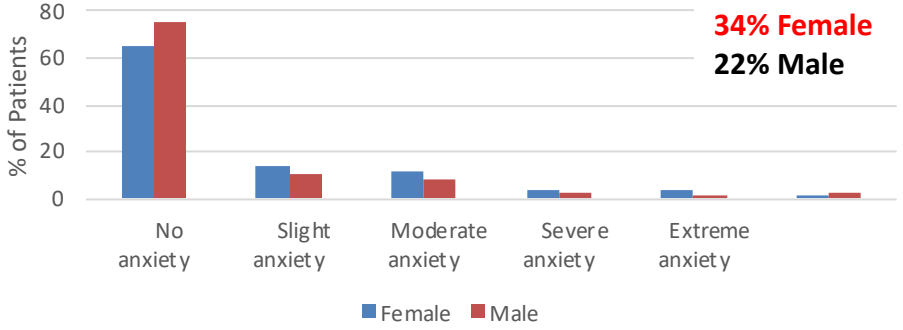
Disease	Diagnosis after COVID Diagnosis		
	Female n=548(%)	Male n=513 (%)	Total N= 1 061
Heart Attack			
Yes	5 (0.9)	2 (0.4)	7 (0.7)
No	536 (97.8)	501 (97.7)	1037 (97.7)
Not sure	3 (0.6)	1 (0.2)	4 (0.4)
Deep vein thrombosis (DVT)			
Yes	2(0.4)	0	2 (0.2)
No	538 (98.2)	501 (97.7)	1 039 (97.9)
Not sure	3 (0.6)	3 (0.6)	6 (0.6)
Stroke or mini stroke/TIA			
Yes	3 (0.6)	1 (0.2)	4 (0.4)
No	537 (98.2)	501 (97.7)	1 038 (97.8)
Not sure	3 (0.6)	2 (0.4)	5 (0.5)
Pulmonary embolism (PE)			
Yes	7 (1.3)	7 (1.4)	14 (1.3)
No	532 (96.9)	491 (95.7)	958 (96.3)
Not sure	4 (0.7)	4 (0.8)	8 (0.8)
Kidney problems			
Yes	10 (1.8)	16 (3.1)	26 (2.5)
No	527 (96.2)	484 (94.4)	1 011 (95.3)
Not sure	5 (0.9)	2(0.4)	7 (0.7)

Difficulties with Activities of Daily Living by Sex (N=1061)

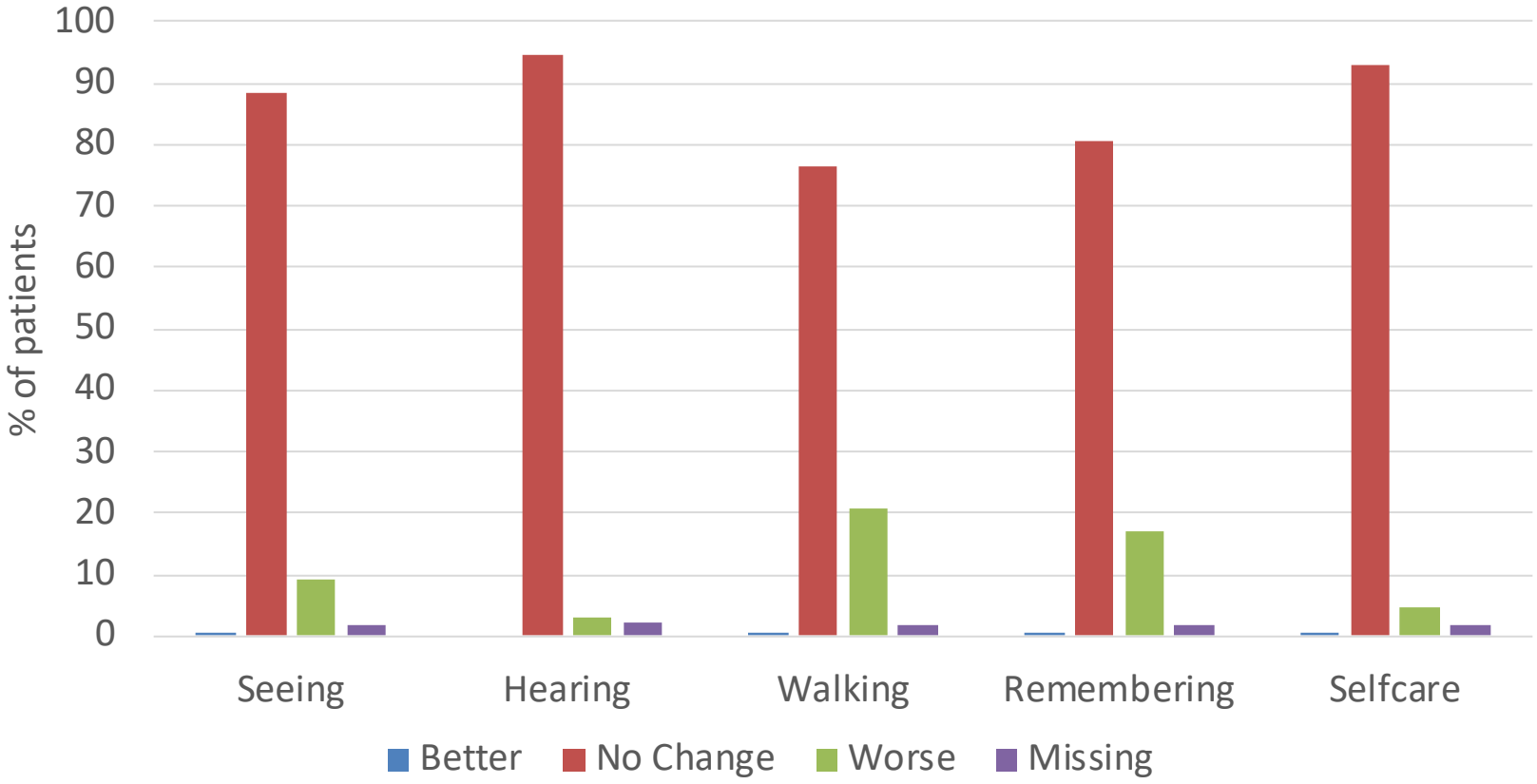




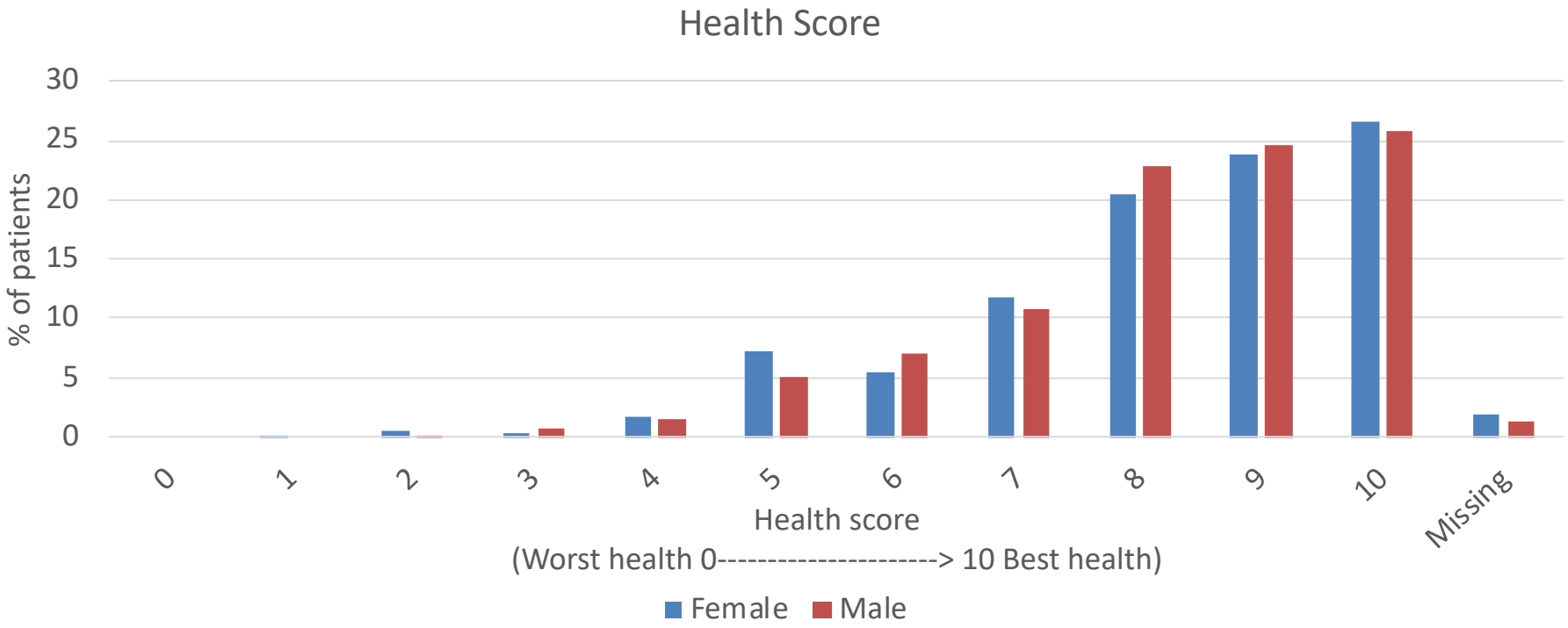




Changes in Activities of Daily Living (N=1041)

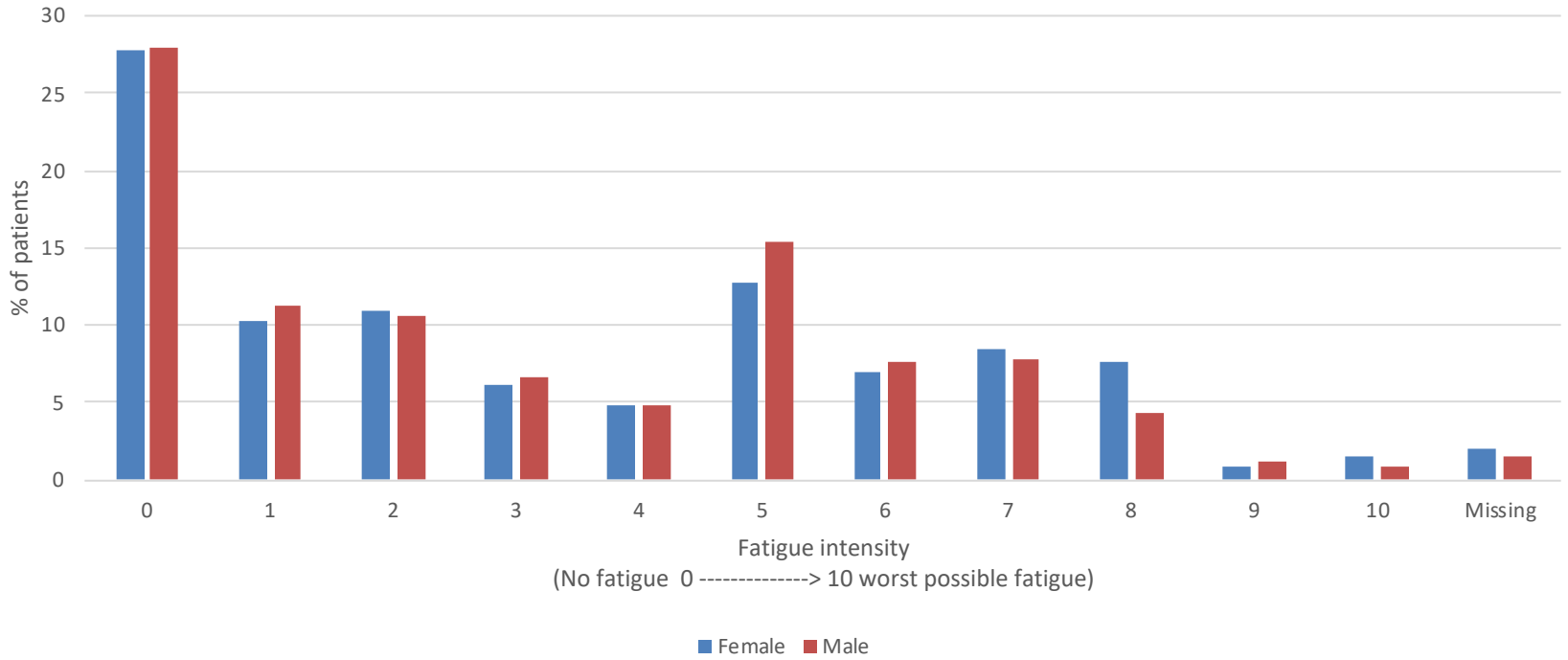


Self Perceived Health Score (N=1061)



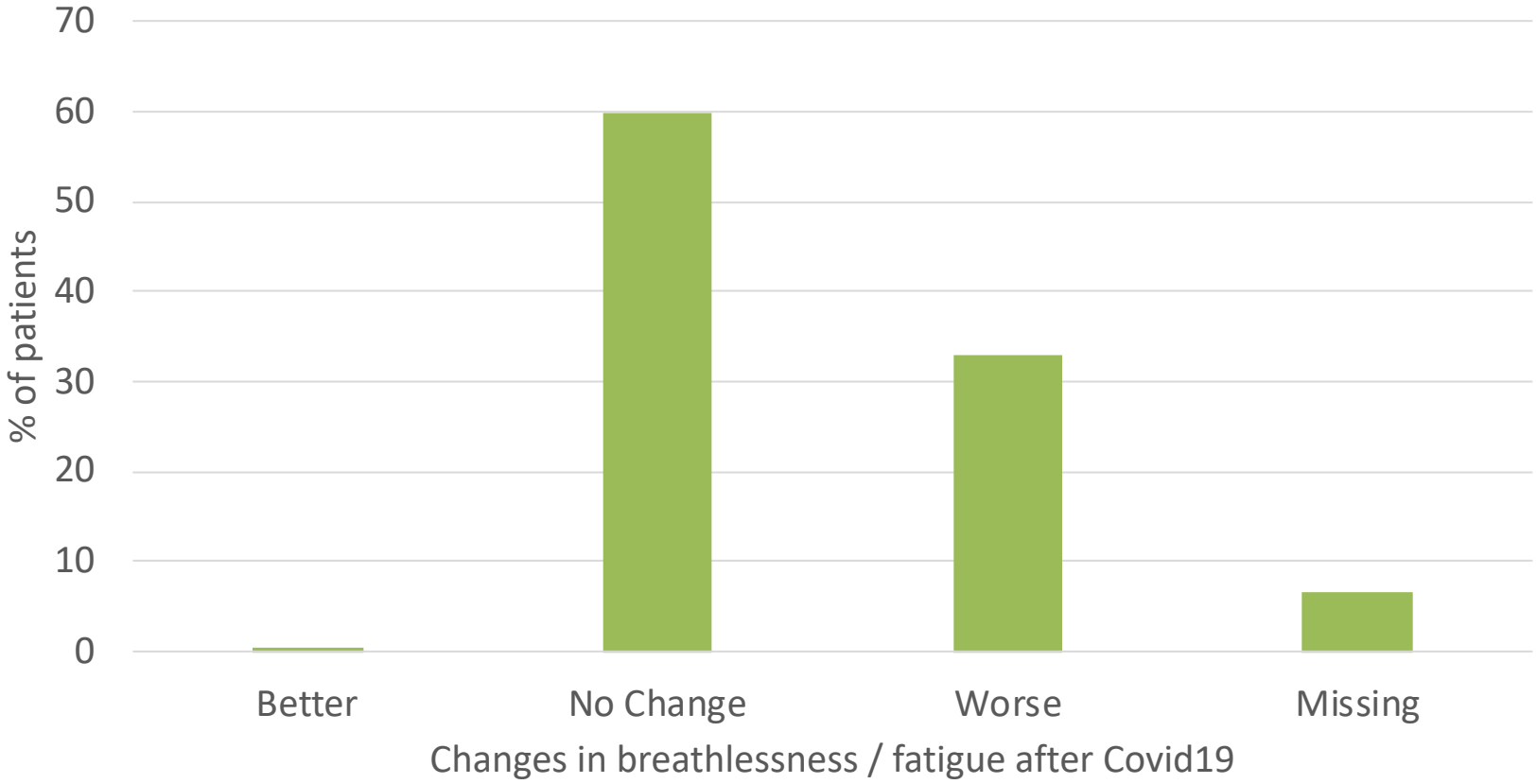
16% Females and 15% Male Reporting Health Score ≤6

Fatigue Intensity among patients reporting Fatigue (n=1061)

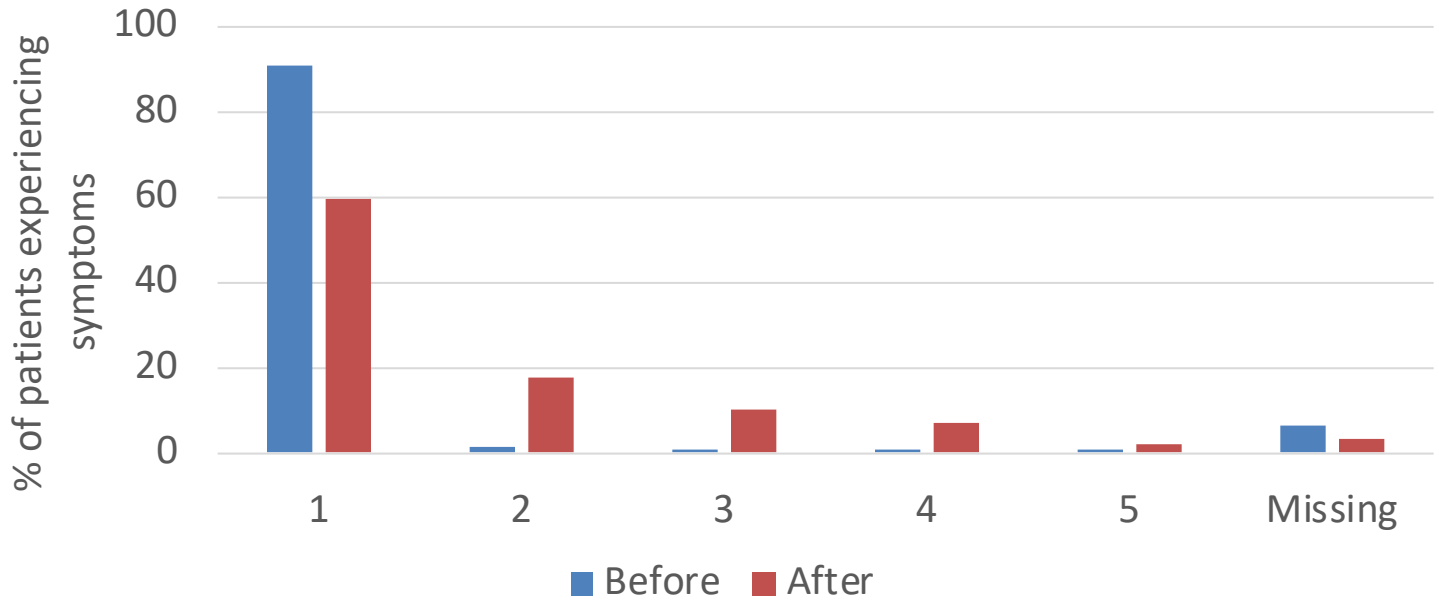


38% Females and 37% Male Reporting Fatigue Intensity ≥5

Change in breathlessness/ fatigue (N=1061)



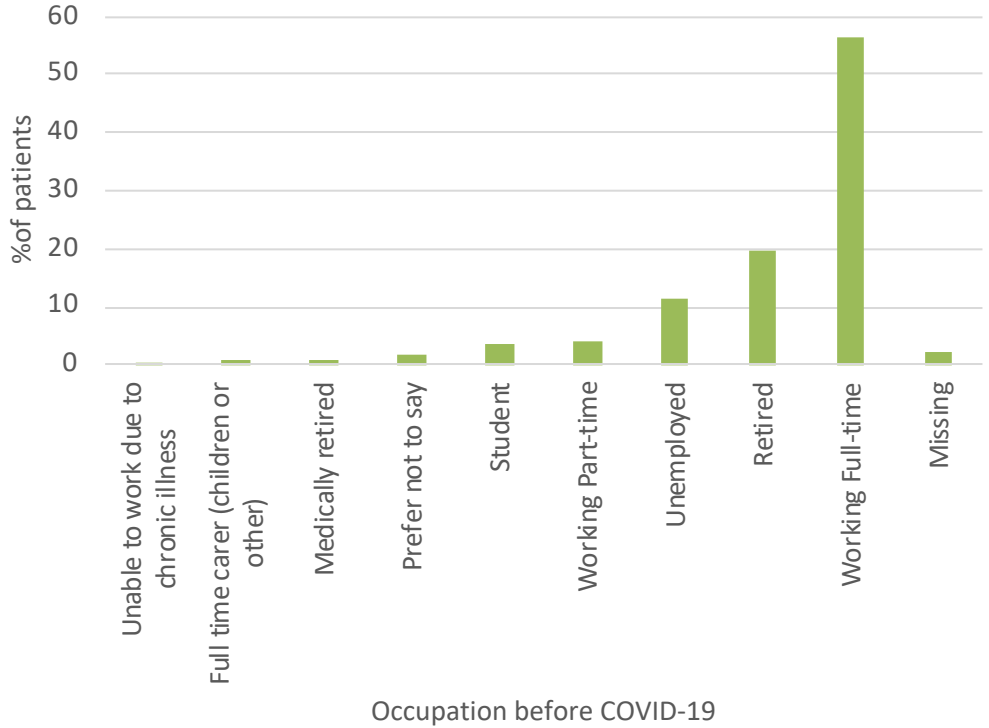
Shortness of Breath (N=1061)

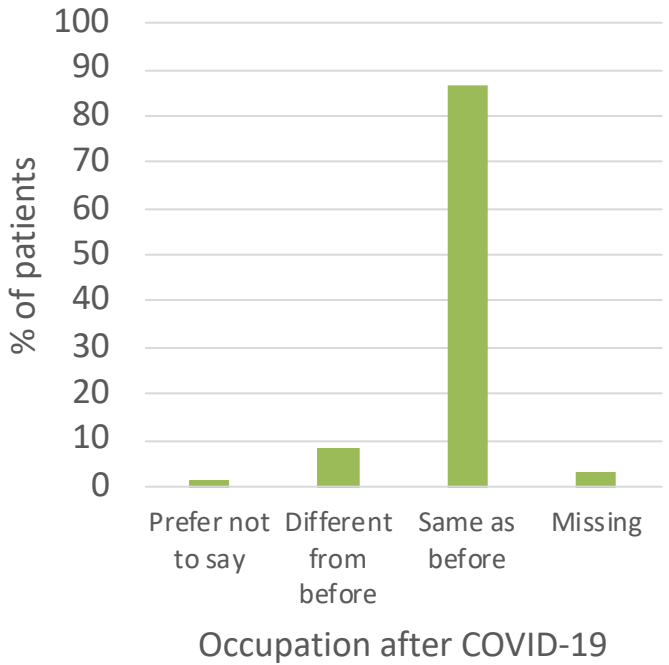


Key

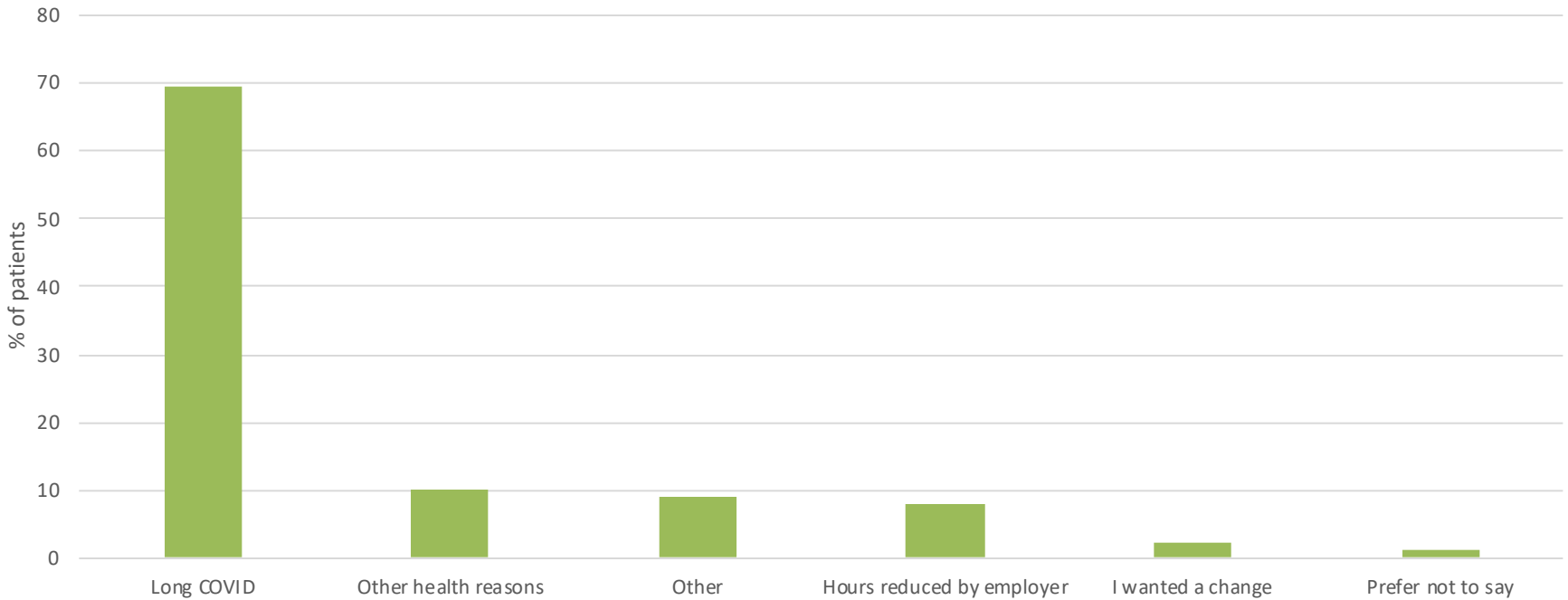
1 - Not troubled by breathlessness except on strenuous exercise
2 - Short of breath when hurrying or when walking up a slight hill
3 - Walked slower than most people of my age because of breathlessness, or had to stop for breath when walking at own pace
4 - Stopped for breath after walking 100 yards/ 90-100 meters, or after a few minutes on level ground
5 - Too breathless to leave the house, or breathless when dressing/undressing

Occupation before and after COVID-19 (N=1061)





Reasons for Changed Occupation (N=88)



70% of patients who changed occupation following Acute COVID illness reported that the reason for the change was due to Long COVID

Lifestyle changes (N=995)

Disease	Life style changes			
	Smoking	Drinking alcohol	Eating healthy food	Physical activity
I do this more often	0.6	0.5	49.7	21.4
I do this less often	3.1	20.5	4.0	30.5
No difference	22.7	30.8	44.2	45.2
I did not do this before COVID-19	71.9	46.2	-	-

WHAT NEXT

What next…

- Guidelines and training for health providers
- Collaboration with NDoH, media, advocacy organizations
  - Health messaging on PASC
    - YourCOVIDRecovery website
  - Inform members of the public, improve enrollment
  - Plan for health services needs for people with PASC
  - Virtual consultation with health services
- Project Expansion
  - Conduct survey among non-hospitalized patients

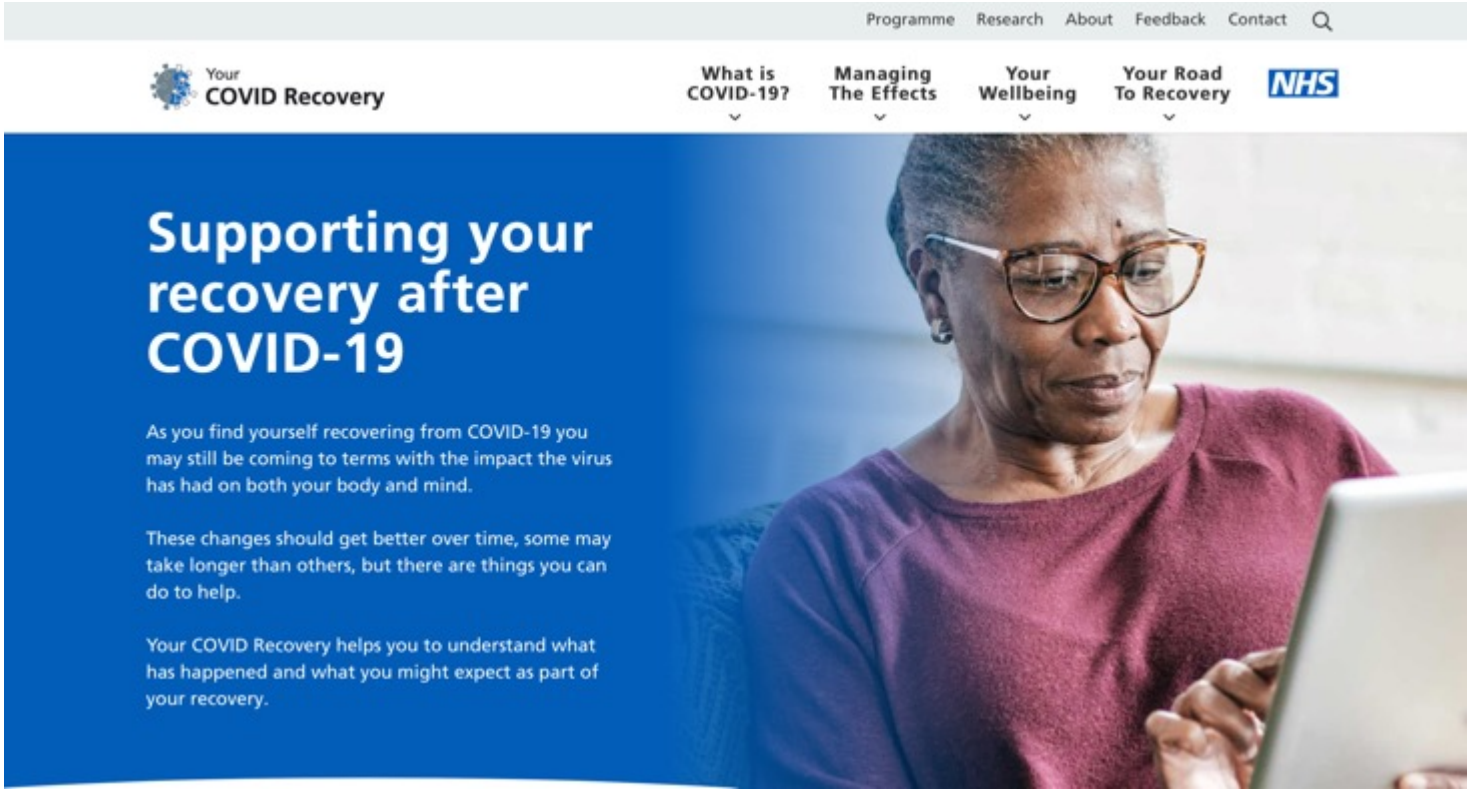
Occupational Health Recommendations

- Formulation and Dissemination of Guidelines
- Training of Health Care Professionals
  - Rule out other potential diagnoses
- Patient Messaging and Engagement
  - What to expect
  - Self management techniques
  - When to seek help
- Establish PASC Clinics
  - Provide support to patients
  - Outpatient and/or Virtual Consultations
- Provisions for support services
  - Psychology & Counselling services
  - Social Support Services
  - Rehabilitation
    - Occupational and Physiotherapy
    - Home Oxygen

YourCOVIDRecovery UK

https://www.yourcovidrecovery.nhs.uk

- Public platform to address acute COVID and PASC
- NDOH and NIOH involvement



YourCOVIDRecovery UK

https://www.yourcovidrecovery.nhs.uk

Learning about your recovery

What is COVID-19?

Understanding COVID, your symptoms and experience of this illness.

- Background About COVID
- How Can COVID Affect You?
- After a Stay On An Intensive Care Unit

Your Wellbeing

Supporting your wellbeing during your recovery.

- Eating Well
- Sleeping Well
- Getting Moving Again
- Family, Friends and Carers
- Grief and Bereavement

Your Road to Recovery

Information for your life beyond COVID.

- Coming Home From Hospital
- Managing Daily Activities
- Returning To Work
- When Do I Need To Seek Help?
- What Next?

Testimonial Clip

- Please find a link for a video testimonial from two PASC patients in the USA

  https://www.washingtonpost.com/technology/2020/10/01/long-haulers-covid-facebook-support-group/

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