EXECUTIVE SUMMARY

# LONG COVID
## HEALTHCARE
needs, barriers,
and opportunities in
Rio de Janeiro City

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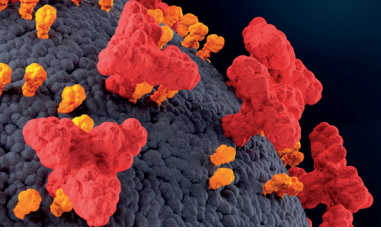




## BACKGROUND

Post-COVID condition, sometimes called Long COVID or post-COVID syndrome (term adopted in this document), is an infection-associated chronic condition (IACC) that can develop after a SARS-CoV-2 infection and last at least three months to years[1]. IACCs are a group of chronic health conditions triggered by infections that share common symptoms such as fatigue, muscle and joint pain, cognitive dysfunction, and sleep problems[2]. Post-COVID syndrome is estimated to affect millions of Brazilians, with disproportional impact on marginalized populations already facing challenges accessing quality healthcare[3]. Post-COVID syndrome may involve one to several symptoms in multiple body systems, which can fluctuate over time; patients with post-COVID syndrome may also experience organ damage.

Public healthcare for post-COVID syndrome is essential to combatting socioeconomic and health inequities: without appropriate care, patients' health will worsen, they may be unable to continue working to support themselves or their families, which in turn may increase difficulty getting the necessary care. However, post-COVID syndrome diagnosis and care coordination within the Unified Health System (Sistema Único de Saúde, SUS) is challenging due to limited healthcare provider literacy about post-COVID syndrome and IACCs and low public awareness about post-COVID syndrome more broadly.

More than four years into the COVID-19 pandemic, most people with post-COVID syndrome worldwide struggle to access adequate care. In a survey of 806 U.S. physicians, only 7% and 4% reported being "very confident" about diagnosing and treating post-COVID syndrome, respectively[4]. Post-COVID syndrome patients often report difficulty receiving a diagnosis[5], and dismissal or disbelief from healthcare providers[6]. Despite a Global prevalence of many millions of people affected[7], research on models of care for post-COVID syndrome is sparse, especially in low-resource settings and low and middle-income countries. Based on the national household sample survey in 2023, the Brazilian Institute of Geography and Statistics estimated that one in four Brazilian adults who had had COVID-19 developed post-COVID syndrome, keeping or not the condition at the interview[8]. Yet there is a dearth of research on healthcare provision, and patient needs to support and inform the response of the SUS.

Multiple disease-causing mechanisms for post-COVID syndrome have been described to date, including microclots, autoimmunity and immune dysregulation, neuroinflammation, microbiome disruption, and SARS-CoV-2 persistence[7]. Post-COVID syndrome shares some underlying disease-causing mechanisms with other IACCs like myalgic encephalomyelitis/ chronic fatigue syndrome and dysautonomia[2]. Other IACCs of epidemiological relevance in Brazil include post-chikungunya and post-dengue syndromes. Our review of literature on healthcare for post-COVID syndrome and IACCs in Brazil suggested the provision of effective and equitable care for IACCs in Brazil is hampered by three high-level challenges: (i) limited evidence-based understanding of IACCs; (ii) competing healthcare priorities in the context of limited resources; and (iii) social inequalities in the burden of illness.

## RESEARCH OBJECTIVES

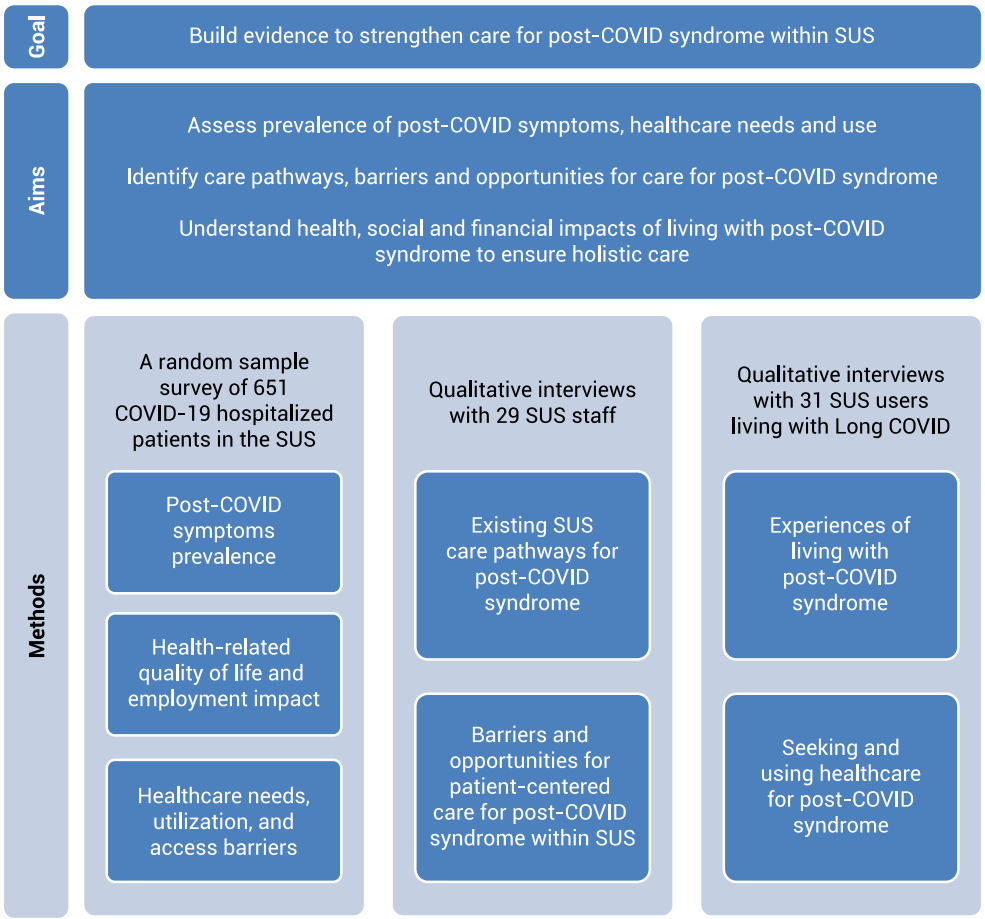
Focusing on Rio de Janeiro city, we aimed to estimate post-COVID syndrome prevalence, impacts, and healthcare needs, use, and access barriers, and to evaluate patient and SUS staff perceptions of post-COVID syndrome care. Our goal was, to build the evidence base to inform equity-centered healthcare policy for post-COVID syndrome within SUS.

## STUDY DESIGN

Our interdisciplinary, patient-engaged study had three strands: survey, qualitative interviews with SUS staff, and with SUS users living with post-COVID syndrome (Figure 1). Data was collected between November 2022 and April 2024.

FIGURE 1

Long COVID Healthcare study's goal, aims, and methods. Rio de Janeiro City, 2024.



Participants in the study included adults previously hospitalized for COVID-19; SUS professionals involved with post-COVID syndrome care planning, monitoring, and provision, from senior administrators to multidisciplinary frontline teams; and SUS users living with post-COVID syndrome, including those who had not been hospitalized.

Making sure we had a diverse sample that included those worst affected by COVID-19 and post-COVID syndrome was central to how we conducted the research. In our survey study, for instance, many of our participants identified as Black or mixed-race and had lower education and income, contrasting with post-COVID syndrome literature largely built upon white, highly-educated samples.

**For more on the collaborative development of the survey, see Caldas *et al*. (2024). Promoting Equity, Diversity, and Inclusion in Surveys: Insights from a Patient-engaged Study to Assess Long COVID Healthcare Needs in Brazil. *J Clin Epidemiology*. Available at: https://www.sciencedirect.com/science/article/pii/S0895435624001781.**

## KEY FINDINGS

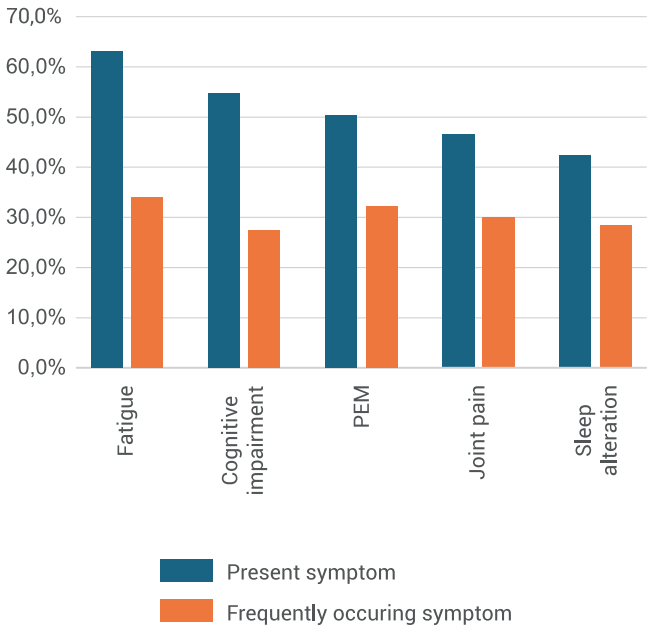
**High prevalence of post-COVID symptoms.** 91.1% reported at least one post-COVID symptom, and 71.3% reported at least one frequently occurring post-COVID symptom.

39.3% of participants self-reported having post-COVID syndrome, yet only 8.3% had a post-COVID syndrome diagnosis from a healthcare professional.

The five **most common post-COVID symptoms** were: fatigue, post-exertional malaise (i.e., worsening or emergence of symptoms between 24 and 72 hours after physical or cognitive exertion), joint pain, sleep alterations, and cognitive impairment (Figure 2).

FIGURE 2

Most common post-COVID symptoms. Study among COVID-19 patients hospitalized in SUS hospitals between Dec 2020 and Nov 2022. Rio de Janeiro City, 2024.




Other symptoms with high prevalence (i.e., occurring in more than 25% of the population) included numbness, feeling anxious, and feeling down. Importantly, our qualitative data suggest that the difficulties people experienced getting care for or understanding about their post-COVID symptoms from friends, employers and family contributed to feelings of anxiety and depression.

There was a high prevalence of comorbidities prior to hospitalization for COVID-19, especially high blood pressure, affecting a little over half of them, in addition to obesity, diabetes, and heart disease.

Symptom occurrence was neither associated with Intensive Care Unit (ICU) utilization nor ventilatory invasive support. Among hospitalized individuals, our data do not show that more critical patients were more prone to post-COVID syndrome.

There was a high mortality rate (12.4%) after the COVID-19 hospitalization discharge assessed in our study.

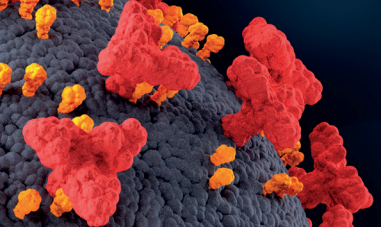
Almost **50% of participants reported needing healthcare services** for conditions that appeared or worsened after COVID-19 in the previous six months. The general need for some healthcare service was significantly associated with age groups between 30 and 59 years, use of ICU during COVID hospitalization, number of post-COVID symptoms, and post-COVID new diagnoses of cardiovascular disease (reported by 15.3% of the participants), endocrine disorders (10.5%), musculoskeletal disorders (7.8%) and kidney disease (6.3%).

Specialist medical care, pharmacy, outpatient primary care, and laboratory services were the most needed services among the participants who reported needing healthcare (Table 1). Specifically, the need for specialist medical care and inpatient/emergency care were associated with post-COVID syndrome self-report.

TABLE 1

Services needed among those who reported needing healthcare for conditions that appeared or worsened after COVID-19 in the previous six months. Study among COVID-19 patients hospitalized in SUS hospitals between Dec 2020 and Nov 2022. Rio de Janeiro City, 2024.

| Service needed | % |
|---|---|
| Other specialist/specialty medical care | 76.5 |
| Pharmacy | 76.5 |
| Outpatient primary healthcare unit | 72.6 |
| Laboratory/specimen collection | 73.3 |
| Scans or imaging | 61.6 |
| Hospital / Emergency care | 33.4 |
| Mental health care | 22.8 |
| Post-COVID Syndrome reference center /rehabilitation service | 17.4 |
| Home healthcare/aid | 15.6 |
| Alternative medicine (herbalist, acupuncturist, etc.) | 12.2 |





Regarding specific healthcare services, there was a high level of usage among those who reported needing primary healthcare (PHC) (89.2%) and hospital emergency care (95.8%), most of the time via the SUS (95%). Although specialist medical care was used by 81.7% of participants who reported needing it, more than half (55.3%) used private specialist providers.[a]

Almost half of the people who reported needing a post-COVID clinic or rehabilitation service did not access it (47.7%), with many unaware of any post-COVID clinics in Rio de Janeiro City.

Similarly, a high percentage of those who reported needing mental healthcare were not able to use it (43.1%). Access to mental healthcare was mainly through private providers (70.9%).

Many **factors obstructed access** to primary and specialized healthcare for post-COVID syndrome (e.g., medical specialists, rehabilitation, post-COVID clinic). Some of these related to (and illustrated) the high-level challenges anticipated in the literature review, like:

- The impacts on SUS of context characterized by increasing social inequality, unemployment; overburdened health system; and a desire amongst health professionals, heavily impacted by the demands of the pandemic, to move from COVID
- Inadequate data collection and surveillance which resulted in limited understanding or awareness of the extent of 'need' or demand for post-COVID syndrome care. Neither senior administrators nor frontline professionals were using the specific post-COVID syndrome code from the International Classification of Diseases (i.e., U09.9 Post COVID-19 condition, unspecified), which would have improved data capture/surveillance.
- Lack of provider knowledge of post-COVID syndrome, evidenced by limited understanding and misconceptions of the condition; and lack of clear protocol for diagnosis and referral, with different views on how and where patients should be treated.

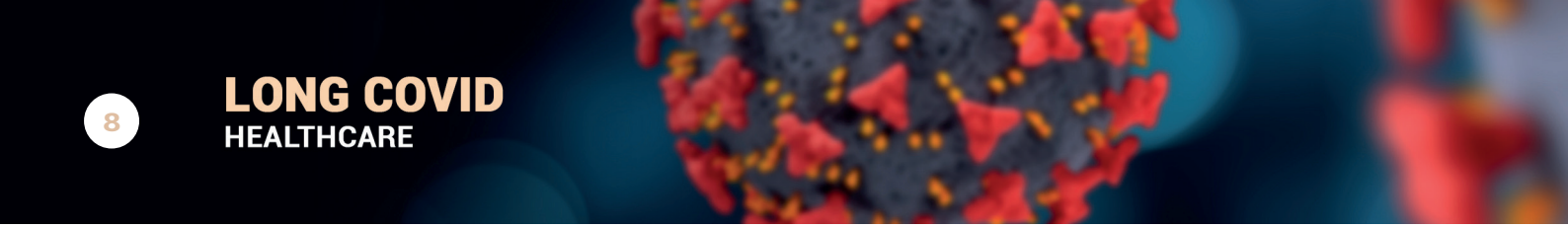
Other factors relate to SUS system features, like:

- General challenges/failures of referral system (common to the management of other chronic conditions), including long waiting time to get an appointment, lack of communication between services, the possibility of referring patients by symptoms or by condition, co-existence of two referral systems (i.e., SISREG, under municipal management, and SER, under state management).

Post-COVID clinics established by a teaching hospital and the Municipal Health Department were a positive innovation with the potential to provide specialized multidisciplinary healthcare. However, despite the high burden of need our study demonstrates, they were underused (consistent reports of vacancy in many appointment slots).

Some of these **factors also prevented the provision of post-COVID syndrome care** for patients successfully accessing primary and/or specialized healthcare. With no clear protocol for post-COVID syndrome treatment and management or training, clinicians were ill-equipped to provide effective care. For

[a] We cannot attribute all healthcare needs and use for conditions that worsened or appeared after COVID-19 as related to post-COVID syndrome, but it is plausible to think that part of them is.



patients followed by specialized care, problems with communication between services made coordination of care by the PHC team nearly impossible. Additionally, neither senior administrators nor frontline professionals were aware of the technical notes issued by the Ministry of Health since late 2021. The lack of prioritization of post-COVID syndrome was reflected, for instance, in the absence of post-COVID syndrome in the health plan document and lack of training.

All of these factors fed into a vicious cycle, perpetuating the challenges that patients and healthcare professionals faced in getting or providing good care for post-COVID syndrome. At the same time, failures in surveillance/data capture, failures to diagnose the condition and to facilitate access to care served to erase from public view the suffering and needs of people with post-COVID syndrome.

**In participants' own words…**

**"[Patients with post-COVID symptoms] are not a priority. We just address their pain, prescribe, and goodbye. [..] I think [if] the person has improved [from COVID], didn't die, let's move on to the next, you know? The next person who needs more." (PHC professional)**

**"I can't get anything through SUS. [..] If I had the money, I wouldn't waste my time there [SUS]. [..] Every time people go to the clinic, they get a "no" answer: "there's no doctor, you can't do it, you have to wait" and stuff like that. Then people sit at home and don't go." (Woman living with post-COVID syndrome since 2022)**

**"I don't know if there is a protocol for these [post-COVID] syndromes; what happens depends on the professional who's assisting the patient." (Administrator)**

**"Why would we identify something if we don't know what we're going to do with it?" (PHC professional)**

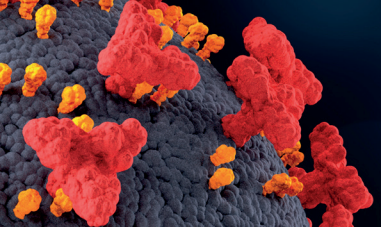
**"They all said 'no. It was a long time ago. You had it in 2021. It's something else.' And that was the end of the matter. [..] It seems to me that professionals are not informed or trained on long COVID, so that was really frustrating. [..] They don't even consider long COVID in their diagnoses. It's like it's not a reality for them" (Woman living with post-COVID syndrome since 2021)**

**"The planning occurs based on demand, and if there are underdiagnoses and underreporting, we have a problem. I believe that we still have underdiagnosis of Long COVID." (Administrator)**

## IMPACT OF LIVING WITH POST-COVID SYNDROME / LONG COVID

**Post-COVID syndrome caused a radical change in people's lives** with significant negative impacts, such as:

- Not being able to work or having to reduce hours of work, but rarely being able to access formal benefits/medical leave.





- Being unable to do activities of daily living like housework, taking children to school.
- Not being able to access care they needed through SUS; spending often reduced income on private services and medications.

**In participants' own words…**

**"After I went back to work, I had a lot of sequalae, I couldn't work shifts anymore, so I had to quit" (Woman living with post-COVID syndrome since 2020)**

**"So, due to all these health problems, unfortunately I need my [teenager] daughter's help a lot. Sometimes even to unbutton my shorts or go to the bathroom." (Woman living with post-COVID syndrome since 2022)**

**"My financial life changed, because before I worked a lot, earned a lot. I'm a salesman, I work on commission, I earn what I sell, I don't have a salary. So, being stopped for this long, and things started going downhill, downhill, downhill, it all went downhill. And now I'm trying to pick up everything again." (Man living with post-COVID syndrome since 2021)**

**"I used to have a routine. I managed to keep everything organized. I had an organized life. Nowadays I only clean my house once a month. I can't do any more than that. You know? Everything of mine is a mess. I had a life before." (Woman living with post-COVID syndrome since 2022)**

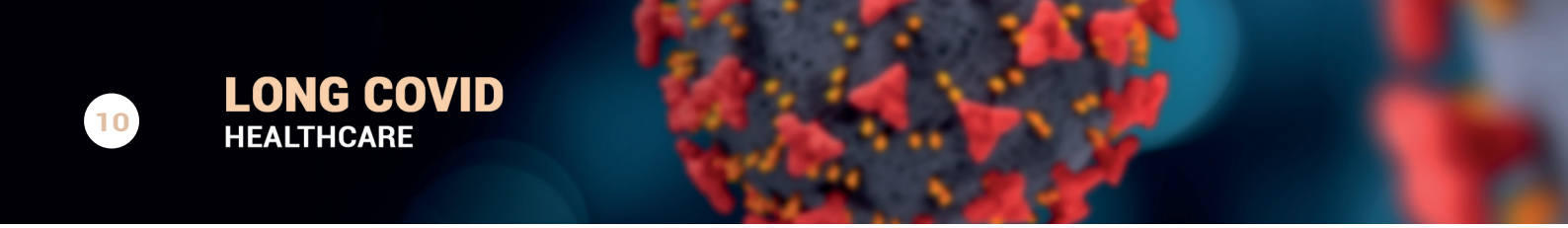
**"I have a very different life today than I did before. I used to have two jobs, I did consultancy work, I took care of my children, the house, everything, and today I can't do that. I can't go to the market, for example. [..] my children suffer from it today." (Woman living with post-COVID syndrome since 2020)**

**"I keep thinking to myself, Damn, why did I spend all my time working, with a formal contract and stuff, dedicating myself [..] running to work, so and so? I went with COVID, sick. Now you need a benefit, help, and you can't find anyone- a hospital so you can be seen, a health center, an appointment, medication I still have to pay for, because I can't get it through SUS." (Woman living with post-COVID syndrome since 2022)**

**To know more on experiences of people living with post-COVID syndrome check these videos at ENSP's website: https://informe.ensp.fiocruz.br/secoes/noticia/45094/55520**

## RECOMMENDATIONS FOR STRENGTHENING SUS CARE FOR POST-COVID SYNDROME

There is a very high burden of post-COVID syndrome, but very low awareness and understanding of post-COVID syndrome. Patients are not able to get the care they need, and professionals are currently not equipped to care for them. A huge cost to individuals, their families, and the health care system.



Preparedness of the healthcare system to identify and care for post-COVID syndrome patients would bring wider benefits for other 'neglected' IACCs. Based on our findings, we make the following recommendations:

For managers:

- Provide education of healthcare professionals to improve diagnosis and appropriate offers of care. Topics such as:
  - Post-COVID syndrome and IACC awareness and epidemiology;
  - Post-COVID syndrome causing mechanisms, symptoms, disease presentations and associated diagnoses (e.g. post-exertional malaise, myalgic encephalomyelitis/chronic fatigue syndrome, dysautonomias);
  - Available care pathways involving specialist care (including technical guidance on referral processes)
- Improvements in health surveillance to detect post-COVID syndrome demand, for instance, promoting consistent and appropriate use of relevant ICD code.
- Capitalize on existing efforts and strengths of the system regarding multidisciplinary care. For instance, in PHC, invest in coordination of multidisciplinary integrated ancillary health services; and build on specialist post-COVID clinics, using them to identify lessons and ways to improve.

For frontline professionals:

- Listen to patients, validate people's experience and post-COVID syndrome impacts, and partner with them to figure out best avenues to pursue for care and social support according to each patient context (i.e., post-COVID syndrome presentation, family and employment status).
- Involve patients in efforts to improve service.
- Support peer support groups.

For people living with post-COVID syndrome:

- Know your rights:
  - Post-COVID syndrome is a medical diagnosis with International Classification of Diseases code U09.9; talk to your PHC physician about getting a post-COVID syndrome diagnosis.
  - There are post-COVID clinics that can provide specialized care; talk to your PHC physician about a referral.

## ACKNOWLEDGEMENTS

We would like to thank all study's participants, the Rio de Janeiro Municipal Health Department and our funders, Programa de Fomento ao Desenvolvimento Científico e Tecnológico, ENSP/Fiocruz, and Harvard University Lemann Brazil Research Fund.

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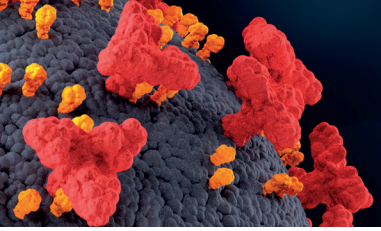



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## FURTHER READING

*Resources for clinicians*

World Health Organization information on post-COVID syndrome

https://www.who.int/teams/health-care-readiness/post-covid-19-condition

A guide on post-exertional malaise and strategies for its prevention and/or mitigation, such as pacing, which is useful in helping to diagnose and manage this symptom commonly reported in Long COVID patients.

https://patientresearchcovid19.com/storage/2024/03/Brazilian-Portuguese-Updated-Pacing-Guide-PLRC-MeAction.pdf

*Resources for patients*

Infographic with general information about Long COVID and its most common symptoms, useful for helping family and friends understand Long COVID

https://world.physio/sites/default/files/2021-07/WPTD2021-InfoSheet1-WhatisLongCOVID-Final-A4-brazilian-portuguese.pdf

Infographic explaining fatigue and post-exertional exacerbation in the context of Long COVID, and how to use the Pacing technique, or activity grading, used to manage these symptoms in order to reduce them

https://world.physio/sites/default/files/2021-07/WPTD2021-InfoSheet3-Fatigue-and-PESE-brazilian-portuguese.pdf

Collection of resources on Long COVID in Portuguese, including information on post-exertional symptom exacerbation and symptom management techniques such as Pacing

https://pt-br.longcovid.physio/resources

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