

What Is Long COVID and What Can We Do to Address the Problem?

Series | COVID-19 & response strategy

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[This document is a one of a series of discussion notes addressing fundamental questions about the COVID-19 crisis and response strategies. These documents are based on the best scientific information available and may be updated as new information comes to light.]

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The findings of a number of studies suggest that **between 10% and 15% of all patients** who develop COVID-19 present **persistent symptoms** weeks or even months after the original infection. In Catalonia alone, this would represent a considerable burden of disease, amounting to an estimated 90,000 people affected. This estimate would rise to 400,000 for Spain as a whole and **22 million people worldwide**.

Persistent COVID symptoms can have a serious impact on the patients’ ability to return to work, with significant psychological, social and economic consequences for them, their families and society as a whole.

In light of this, it is now vital to **clearly define the problem, understand it and develop appropriate strategies** to deal with this additional disease burden attributable to COVID-19 and to minimise its impact¹ ●

*Multidisciplinary Collaborative Group for the Scientific Monitoring of COVID-19 (GCMSC). Lledó, G., Sellares J., Brotons C., Sans M., Díez, J., Blanco J, Bassat Q., Sarukhan A., Campins M., Guerri R., Miró JM., de Sanjosé, S. *Post-Acute COVID Syndrome (PACS): Definition, Impact and Management*. June 2021.

¹ Rajan S, Khunti K, Alwan N, et al. *In the wake of the pandemic: Preparing for Long COVID* [Internet]. Copenhagen (Denmark): European Observatory on Health Systems and Policies; 2021. (Policy Brief, No. 39.)

1. What Is Long COVID?

“While many different terms have been proposed (long COVID, persistent COVID-19 symptoms, post-COVID syndrome, and chronic COVID syndrome, among others), we support the term post-acute COVID syndrome (PACS).”

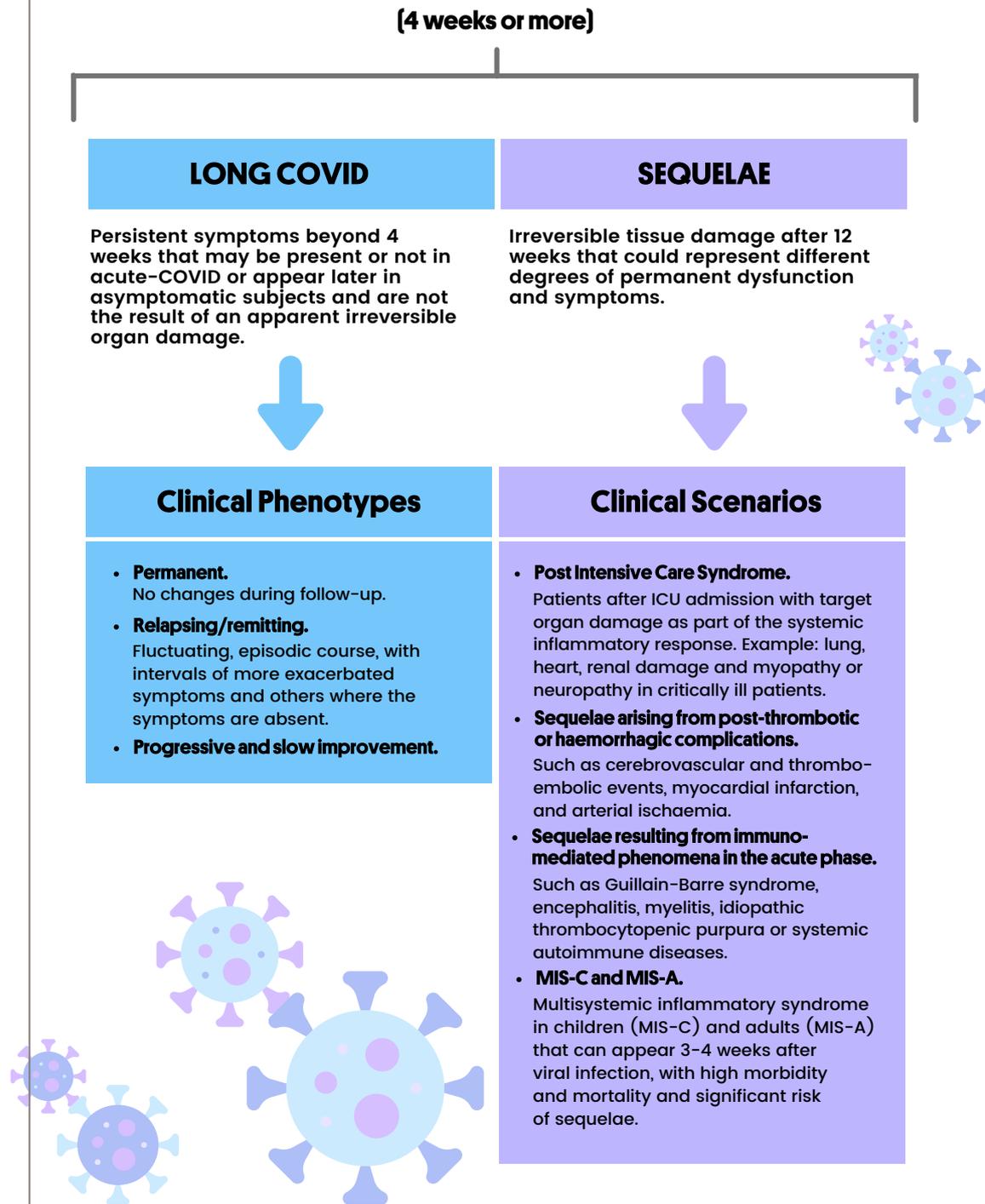
Information is now emerging about the persistent symptoms and sequelae of COVID-19, of which some of the most frequently reported are **fatigue, respiratory impairment** and **neurological manifestations**, such as “brain fog” (poor concentration and inability to focus). The mechanisms underlying these multisystem manifestations are, as yet, poorly understood, but they are probably the result of immune dysregulation, cell damage affecting various tissues and inflammatory organ damage caused by the SARS-CoV-2 infection. In addition, patients with COVID-19 who required prolonged intensive care also experience the inevitable sequelae associated with critical care. While scant information is available on how long persistent symptoms last, several prospective studies have shown some improvement in most cases. Fatigue is one of the most long-lasting symptoms.

Many different terms have been proposed to describe this entity (long COVID, persistent COVID-19 symptoms, post-COVID syndrome and chronic COVID syndrome, among others) and we support the term **post-acute COVID syndrome (PACS)** proposed by Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases of the US National Institutes of Health (NIH).

PACS encompasses two scenarios, which are not mutually exclusive:

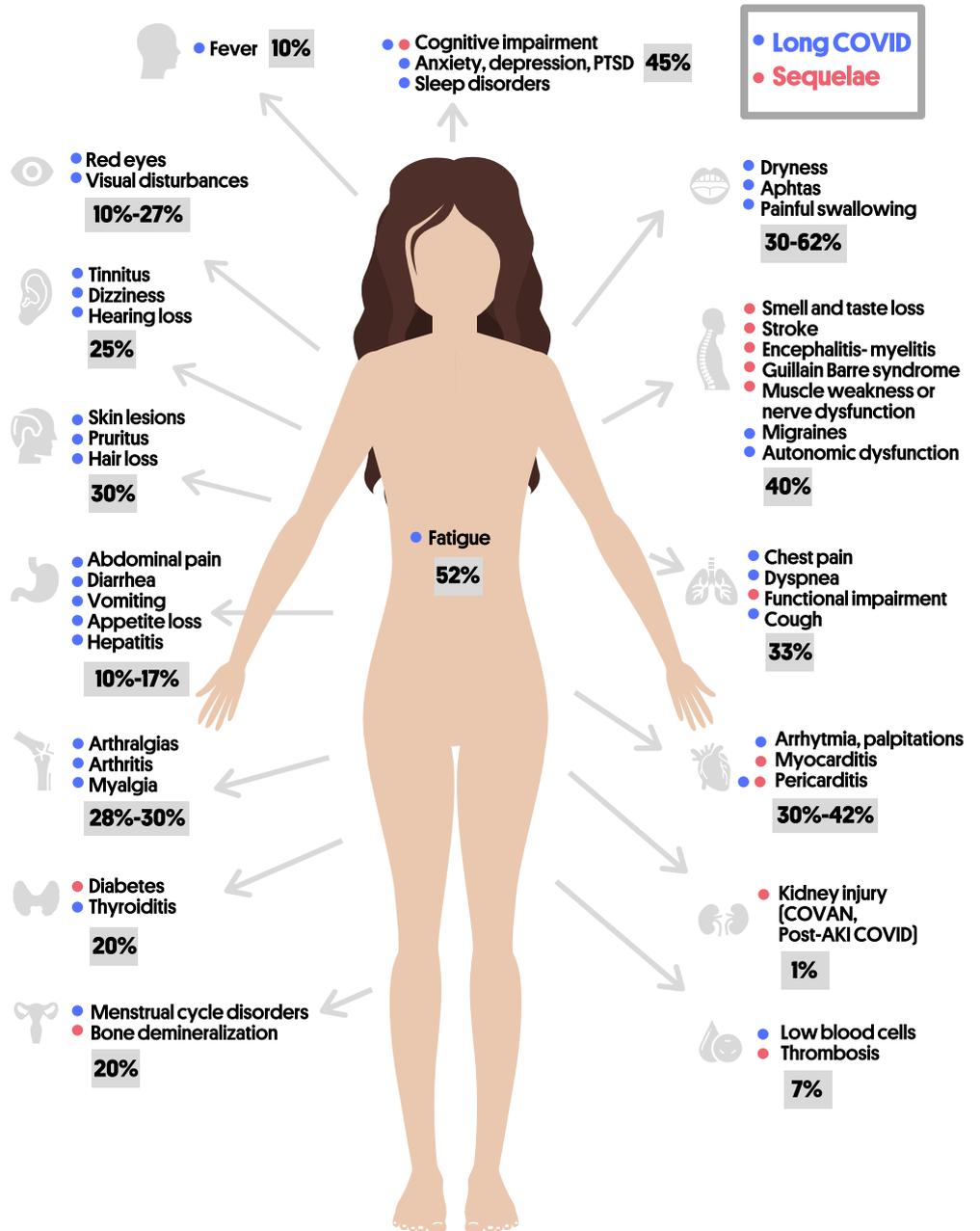
- **Long COVID:** persistent symptoms beyond 4 weeks that may be present or not in acute-COVID or appear later in asymptomatic subjects and are not the result of an apparent irreversible organ damage.
 - **Sequelae:** irreversible tissue damage after 12 weeks that could represent varying degrees of permanent dysfunction and symptoms ●
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Figure 1. Post-Acute COVID Syndrome.



Source: Multidisciplinary Collaborative Group for the Scientific Monitoring of COVID-19 (GCMSC). Lledó, G., Sellares J., Brotons C., Sans M., Díez, J., Blanco J, Bassat Q., Sarukhan A., Campins M., Guerri R., Miró JM., de Sanjosé, S. Post-Acute COVID Syndrome (PACS): Definition, Impact and Management. June 2021.

Figure 2. Post-Acute COVID: Clinical Manifestations.



Source: Multidisciplinary Collaborative Group for the Scientific Monitoring of COVID-19 (GCMSC). Lledó, G., Sellares J., Brotons C., Sans M., Diez, J., Blanco J, Bassat Q., Sarukhan A., Campins M., Guerri R., Miró JM., de Sanjosé, S. Post-Acute COVID Syndrome (PACS): Definition, Impact and Management. June 2021.

2. Magnitude and Impact of Post-Acute COVID Syndrome

“Since it is likely, that a large number of people will continue to have persistent symptoms for at least some years, the health authorities must be prepared to address the problem on a system-wide scale.”

PACS affects many different groups of patients: those hospitalised with more or less severe COVID-19, but also symptomatic and even asymptomatic patients who were not hospitalised due to the infection.

The report *Post-Acute COVID Syndrome (PACS): Definition, Impact and Management* (June 2021) reviews all the **studies** that provide data on the prevalence of persistent symptoms or long COVID among hospitalised and non-hospitalised patients. It is estimated that between 10% and 15% of COVID-19 patients develop PACS, although the prevalence of persistent symptoms is difficult to estimate because of differences between the populations studied and the methodologies used. Some studies mix data from hospitalised patients (a population in which the percentage of patients with persistent symptoms is clearly higher) with data from patients who did not require hospital care. The prevalence of PACS in children is not known. The most frequently reported **symptoms** are fatigue (52%), cardio-respiratory impairment (30%-42%) and neurological (40%) manifestations.

PACS is still poorly understood and **very little is known** about the natural history of long COVID, particularly in relation to its probable duration in those affected. However, since it is likely that a large number of people will continue to have persistent symptoms for at least some years, it is important that health authorities be prepared to address the problem on a system-wide scale ●

3. Considerations Relating to Patients, Medical Professionals and the Health System

“It is now essential to establish a clear and suitable definition of this syndrome and to set up the necessary patient registries and monitoring systems.”

As mentioned above, multiple definitions and terms are currently used to describe the condition known colloquially as long COVID. It is now essential to establish a **clear and suitable definition** of this syndrome and to set up the necessary patient registries and monitoring systems. A **specific ICD code** for this syndrome and its sub-entities is needed to facilitate diagnosis and comparisons, and to better evaluate the worldwide impact of the syndrome. In addition to data on initial symptoms and the course of the disease, registries should also collect **patient data**, including variables providing information on social inequalities in health, occupation, financial situation and employment status, as well as on psychological and social factors, such as quality of life and mental and emotional health.

When symptoms last more than 4 weeks after infection – or 12 weeks in the case of sequelae – several medical tests are required to rule out other complications or serious diseases that could explain the symptoms and confirm that the patient has PACS.

Several **clinical guidelines** on the syndrome already exist, (for example, those published in the UK by the National Institute for Health and Clinical Excellence² and in Spain by the Sociedad Española de Medicina de Familia y Comunitaria³, the Sociedad Española de Médicos Generales y de Familia, and CatSalut). However, what is currently needed is consensus on a minimum set of actions and clinical tests and on the appropriate referral pathways between the primary setting and hospital care. Ideally, these should be defined at the international level and in parallel with the definition of PACS.

Moreover, since the symptoms of long COVID are highly varied and can affect multiple systems in the body, it will be essential to establish **long COVID clinics** that bring together different medical specialists⁴. These clinics must be user-friendly and use a person-centred approach to ensure comprehensive patient assessment and management as well as appropriate evaluation, treatment and, especially, rehabilitation.

Box 1. United Kingdom Launches Long COVID Clinics.

In Autumn 2020, the British National Health Service (NHS) announced the launch of **40 long COVID specialist clinics**. These clinics use standardised functional assessment tools and screening questionnaires and refer patients for specialist care when sequelae are suspected.

The services offered are focused on the individual's **physical and mental health** and include the possibility of taking part in self-care groups and community therapy, when appropriate.

They also refer patients to Your COVID Recovery, a **digital platform** created by the NHS to provide support for patients recovering from the disease. This online platform includes self-management tips for tackling daily activities, returning to work and seeking help.

All patients hospitalised with acute COVID-19 are followed up remotely or face-to-face at six weeks to monitor symptoms.

² National Institute for Health and Clinical Excellence. [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#). London: NICE; 2020.

³ semFyC. [Manifestaciones persistentes de la COVID-19. Guía práctica clínica - semFyC](#) [Internet]. 2021 [cited 2021 May 20].

⁴ The specialties involved in the post-COVID clinics include the following: neurology, cardiology, pulmonary medicine, psychiatry, gastroenterology, internal medicine, otorhinolaryngology, rheumatology, physical rehabilitation, physiotherapy, occupational therapy, sports therapy, psychology, speech therapy, and social work.

Patient groups and networks have emerged in several countries. These organisations and platforms facilitate the exchange of information, provide mutual support through social networks and helped patients with self-care, especially when the health system was saturated or very focused on the care of critical patients. On occasion, it has fallen to these patient groups to call attention to the problem of

long COVID and demand recognition for the condition. In some countries, these groups have even carried out research and created patient registers. Involving patient associations and support groups will be key to dealing with PACS. The testimonies of these patients will help to inform the design of some of the interventions outlined in this report, including group and community therapy.

Table 1. Examples of Long COVID Patient Support Groups and Patient Networks.

Group/Network	Country	Description and Link
LongCovidSOS (Body Politic)	United Kingdom	Political advocacy organisation: https://www.longcovidsos.org/ Audiovisual material: https://www.longcovidsos.org/film
Noi che il Covid lo abbiamo sconfitto	Italy	Facebook group: https://www.facebook.com/groups/3044276745637072
Long Covid Kids	United Kingdom	https://www.longcovidkids.org/
Post-COVID HUB	United Kingdom	Platform set up by the Asthma UK and British Lung Foundation Partnership https://www.post-covid.org.uk
#AprèsJ20- Association Covid Long France	France	https://www.apresj20.fr/qui-sommes-nous
Colectivos autonómicos de afectados de COVID-19 persistente (Long Covid ACTS)	Spain	Twitter profile: LongCovid ACTS (Autonomous Communities Together Spain) @longcovidspain Facebook group: https://www.facebook.com/groups/256612158996233/ Collaboration with Scientific Societies on the development of clinical guidelines and population surveys: https://www.semg.es/index.php/noticias/item/594-noticia-20200929
Covid Survivor Indonesia	Indonesia	https://www.instagram.com/covidsurvivor.id/?hl=es

Another important task is to produce **informative materials about** long COVID, including sections on topics such as self-care, well-being and mental health. These materials should be designed particularly for the patient groups and for healthcare workers (a population particularly affected by COVID-19 and its long-term effects).

Finally, there is considerable scope for **clinical and epidemiological research** on this topic. Ideally, studies should include large cohorts of patients infected with SARS-CoV-2 representative of different clinical stages and geographic regions (including low- and middle-income countries). As the evidence accumulates and

more is known, different therapeutic approaches must be assessed, ideally through clinical trials. Research would benefit from multicentre studies, as well as from more international cooperation, including novel research funding mechanisms.

In light of the impact of PACS, health authorities must allocate **sufficient resources to address this problem** and to optimise research and health care outcomes ●

4 Social and Work Considerations

“PACS has serious repercussions on the patients’ ability to return to work, and significant psychological, social and economic consequences for the patients, their families and society. It should be a priority for social protection systems and in the sphere of occupational health as a whole.”

Persistent COVID symptoms can have serious repercussions on the individual’s ability to return to work and significant psychological, social and economic consequences for the patients, their families and society.

According to data from the Spanish National Institute of Social Security (INSS 2021), the average duration of **sick leave in Spain** is short (around 21 days), and 90% of cases are resolved within 60 days. In around 10% of cases, sick leave lasted more than two months, sometimes up to one year⁵.

It is important to further investigate the long-term impact of COVID-19 on the **work capacity** of people affected by PACS. In Spain, sick leave and leave granted due to temporary disability are official recognition that the individual is unable to perform his or her usual work activity due to a medical problem. This recognition generally entitles the patient to financial compensation. The medical personnel who assess these patients use tables drawn up by the INSS, which cover the conditions that can result in occupational disabilities and specify the standard duration of medical leave for each condition. However, since no **specific protocols** existed for persistent symptoms following COVID-19, return to work among patients with PACS has been based on the type and intensity of symptoms and the type of work activity involved. This has given rise to greater variability over time in the measures taken with PACS patients. Ultimately, these patients are monitored by their **primary health care team**, who are also responsible for extending the sick leave and the decision to reassess the individual’s status in relation to employment: asymptomatic, requiring adaptation of work activity within the company, or a gradual return to work.

It is clear that PACS has **serious repercussions**⁶ on the patients’ ability to return to work and psychological, social and economic consequences for patients, their families and society. In the case of women, it increases the occupational precariousness of a group already facing greater challenges in the labour market. PACS should be a **priority** for social protection systems and occupational health as a whole ●

⁵ José Manuel Vicente Pardo, Araceli López-Guillén García. [El Síndrome Post COVID, Incapacidad Temporal Laboral y Prevención](#). [Internet]. Prevenir. 15 Abril 2021.

⁶ Pernicious effects of long COVID in health care workers: GPs stricken by long Covid ‘shocked and betrayed’ at being forced from jobs. The Guardian. 23 May 2021

5. PACS: Recommendations for a Comprehensive Approach

“Although some aspects of PACS are not yet fully understood, health policy makers should take the necessary steps to develop a comprehensive approach to this problem, taking into account everything from diagnosis to treatment as well as occupational issues.”

In summary, although some aspects of PACS are not yet fully understood, the health authorities should take the necessary steps to develop a comprehensive approach to this problem, taking into account everything from diagnosis to treatment as well as occupational issues.

1. The first essential step is to **create appropriate registries and surveillance systems** to ensure long-term follow-up of what could become a chronic post-COVID syndrome.

2. **Clinical care and best practice guidelines** are needed, in addition to **multidisciplinary teams and clinics** capable of ensuring appropriate patient assessment and management.

3. It is vital that **patients and patient groups** be involved in the process to ensure a response that is Long Covid effective and focused on quality of life.

4. The broader repercussions of PACS on the patient’s return to work must also be addressed, including **labour rights**, policies relating to the disease and access to social protection measures.

5. A specific package in health budgets **should be assigned to dealing with the problems associated with post-COVID recovery** ●

FOR MORE INFORMATION

- Multidisciplinary Collaborative Group for the Scientific Monitoring of COVID-19 (GCMSC). Lledó, G., Sellares J., Brotons C., Sans M., Díez, J., Blanco J, Bassat Q., Sarukhan A., Campins M., Guerri R., Miró JM., de Sanjosé, S. Post-Acute COVID Syndrome (PACS): Definition, Impact and Management. June 2021.
- Recording of the webinar in Catalan *“Presentation of the Report: Post-Acute COVID Syndrome Definition, Impact and Management”* which took place on Tuesday 22 June 2021 organised by the Barcelona Medical Association (CoMB) and ISGlobal.

Return to Work (international data and good practice):

- NHS. Your COVID Recovery. Returning To Work. 2021.
- Leanne Godfrey. Yorkshire Care Equipment. Tips for returning to work after Long COVID. April 12, 2021.
- Acas Working for everyone. Long COVID-advice for employers and employees. Last reviewed 30 April 2021.
- Nic Paton. Occupational health & wellbeing. Could ‘long Covid’ become the biggest return-to-work challenge yet for OH? 6 November 2020.

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<https://www.isglobal.org/en/-/que-es-la-covid-prolongada-y-que-podemos-hacer-frente-a-ella->

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