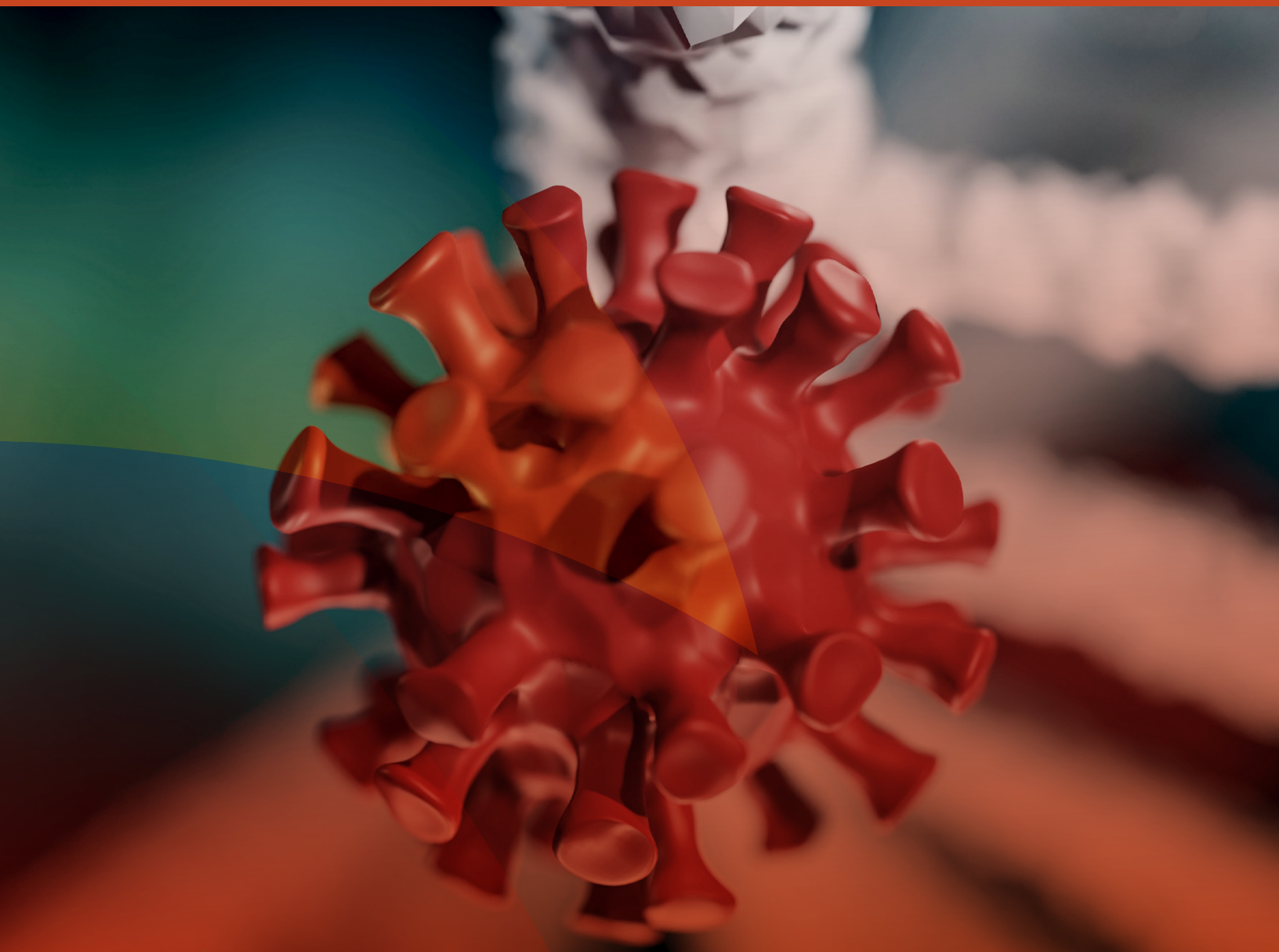


ENDVOC

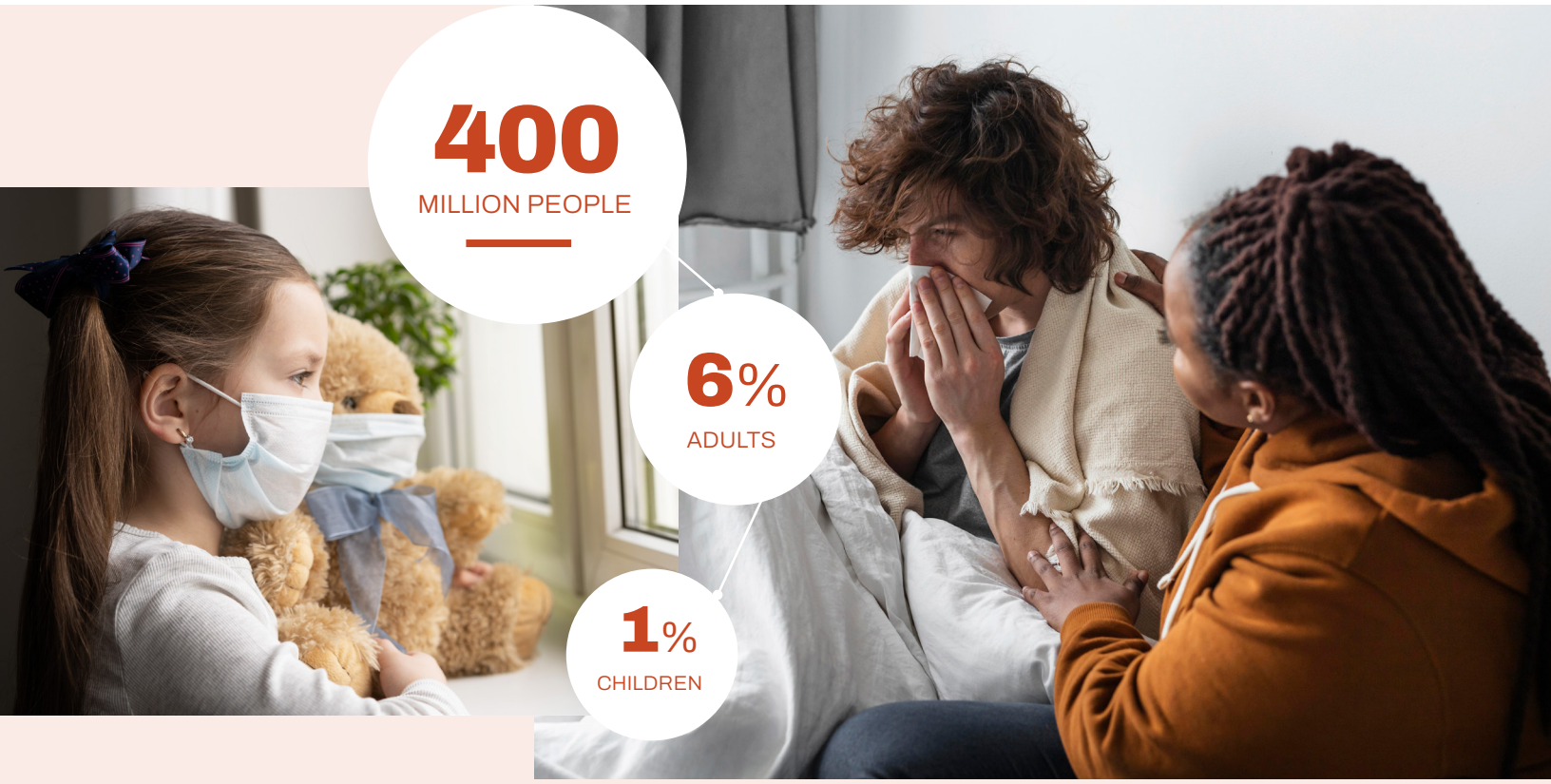
POLICY BRIEF

Long COVID and Post-Acute Infection Syndromes

Evidence, Impact, and Policy Directions

Funded by the European Union under grant agreement N.101046314. Views and opinions are those of the author(s) only and do not necessarily reflect those of the European Union.

Content



Executive summary

More than five years after the onset of the COVID-19 pandemic, Long COVID —a chronic condition following SARS-CoV-2 infection— remains a significant global health and policy challenge.

By 2023, an estimated 400 million people worldwide had experienced Long COVID, representing 6% of adults and 1% of children. The economic toll is immense, with global costs estimated at $3.7 trillion in 2022 alone. Yet, policy and research responses have lagged.

Long COVID encompasses a wide range of symptoms affecting multiple organ systems and can occur even after asymptomatic or mild SARS-CoV-2 infections.

Risk factors include female sex, socioeconomic deprivation, air pollution, and infection with earlier virus variants. Other social determinants such as poverty and migration status also increase vulnerability, highlighting stark inequities.

Long COVID and other post-acute infection syndromes (PAIS) lack standardised definitions, diagnostic tools, and treatments. These conditions are under-recognised and poorly supported in most health systems, despite their severe impact on patients' daily lives.

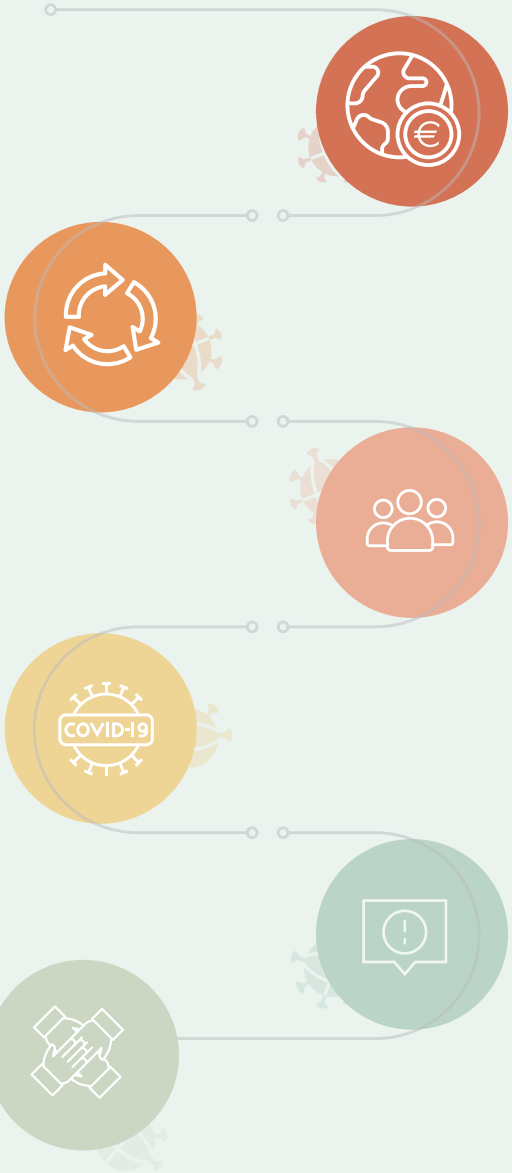
-

To address these gaps, this policy brief calls for:

Research:
Establishment of representative, longitudinal cohorts, with standardised and integrated data collection.

Advocacy:
Recognition of Long Covid as a disability, with inclusion in international legal frameworks.

Preparedness:
Integration of PAIS into pandemic preparedness planning.



Funding:
Increased funding and international coordination for Long COVID and PAIS research.

Health systems:
Training of healthcare professionals and resource allocation for the delivery of comprehensive care.

Communication:
Improved communication and collaboration with patient groups to inform care and policy.

1. Introduction

MORE THAN FIVE YEARS AFTER THE BEGINNING OF THE COVID-19 PANDEMIC, THE WORLD IS STILL STRUGGLING TO OVERCOME THE CONSEQUENCES OF THIS CRISIS.

Millions of people lost their lives or loved ones; national economies still battle the remnants of inflation caused in part by COVID relief policies; many global health metrics have yet to return to pre-pandemic levels; and workers are pushing back against corporate pressure to abandon remote work —which became the new norm during the pandemic.

However, a portion of the population is still battling the consequences of COVID quite literally.

LC is not universally recognised as a disability, including in many parts of Europe.

By 2023, an estimated 400 million people in the world had suffered from Long COVID (LC), a chronic condition that occurs after a SARS-CoV-2 infection[1]. That is equivalent to about 6% of all adults and 1% of all children on the planet. One study estimated that all costs stemming from LC amounted to $3.7 trillion worldwide in 2022[2].

Despite the high incidence of LC and its substantial economic burden, the condition has received relatively little attention from policymakers. Greater investment in LC research is essential to advance our understanding of its causes, diagnosis, prognosis, long-term consequences, drive meaningful improvements, and identify and design treatments.

Patients with LC require more comprehensive policies to support them in managing their condition.

For example, while LC is recognised as a disability in some countries, such as the USA[3] , it does not fall within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). As a result, it is not universally recognised as a disability, including in many parts of Europe.This policy brief has the **objective of describing the current evidence on the epidemiology and burden of LC and proposing policy recommendations** to improve research, patient care management and societal awareness on the condition.

1/ Al-Aly Z, Davis H, McCorkell L, Soares L, Wulf-Hanson S, Iwasaki A, et al. Long COVID science, research and policy. *Nat Med* 30, 2148–2164 (2024). doi: 10.1038/s41591-024-03173-6.

2/ Cutler, D. The Economic Cost of Long COVID: An Update. *Harvard Kennedy School* (2022).

3/ Cohen J, Rodgers YVM. Long COVID Prevalence, Disability, and Accommodations: Analysis Across Demographic Groups - PMC. *Journal of occupational rehabilitation* 34(2), 335–349 (2024). doi: 10.1007/s10926-024-10173-3.

2. *What is Long COVID?*

THERE IS NO SINGLE, CONSENSUS DEFINITION OF LONG COVID, AS IT COMPRISES A NUMBER OF AFFLICTIONS, ALSO KNOWN AS POST-COVID CONDITIONS.

The WHO defines LC as a condition that "occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually three months from the onset of COVID-19 with symptoms that last for at least two months and cannot be explained by an alternative diagnosis". [4]

According to the 2024 NASEM definition, LC is "an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least three months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems".[5]

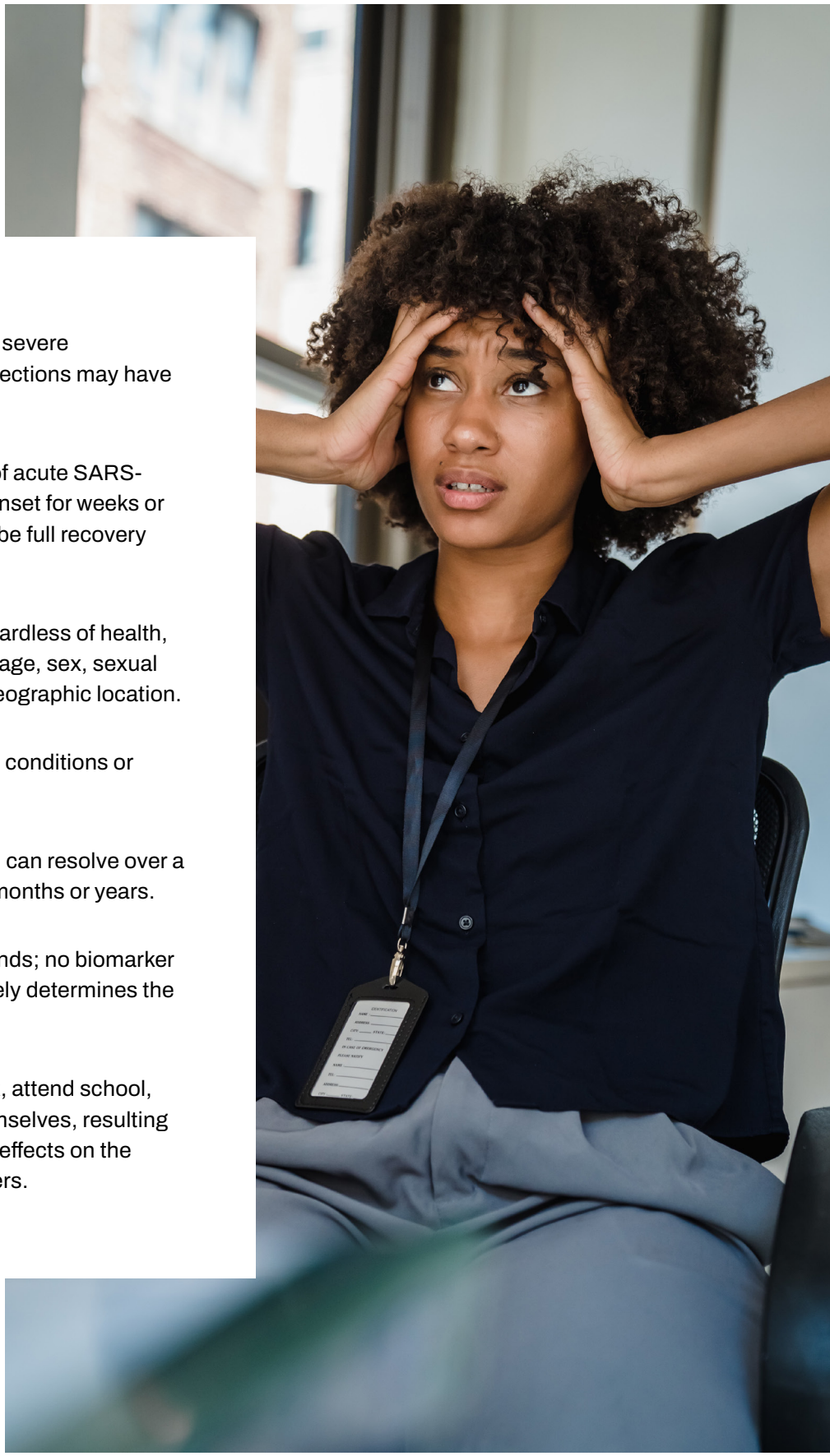
Something that complicates the elaboration of a comprehensive definition is that there are many possible signs, symptoms, and diagnosable conditions of LC.

Any organ or system can be affected, with patients presenting with a wide range of disorders, from memory changes to shortness of breath, from blood clots to joint pain.

4/ World Health Organization. A clinical case definition of post COVID-19 condition by a Delphi consensus. Geneva: *WHO*; 2021.

5/ Ely EW, Brown LM, Fineberg HV. Long Covid Defined. *N Engl J Med* 391, 1746-1753 (2024).

The NASEM definition outlines some relevant features of LC:



- It can follow asymptomatic, mild, or severe SARS-CoV-2 infection. Previous infections may have been recognised or unrecognised.
- It can be continuous from the time of acute SARS-CoV-2 infection or have a delayed onset for weeks or months after what had appeared to be full recovery from acute infection.
- It can affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, sexual orientation, race, ethnic group, or geographic location.
- It can exacerbate preexisting health conditions or present as new conditions.
- It can range from mild to severe and can resolve over a period of months or can persist for months or years.
- It can be diagnosed on clinical grounds; no biomarker that is currently available conclusively determines the presence of this condition.
- It can impair patients' ability to work, attend school, take care of family, and care for themselves, resulting in profound emotional and physical effects on the patients, their families, and caregivers.

3. Who is at higher risk?

A 2021 SYSTEMATIC REVIEW FOUND THAT FEMALE SEX, HAVING MORE THAN FIVE EARLY SYMPTOMS, EARLY DYSPNOEA, PRIOR PSYCHIATRIC DISORDERS, AND SPECIFIC BIOMARKERS SEEMED TO BE RISK FACTORS ASSOCIATED WITH LC. [6]

Other studies support these conclusions, especially the association between female sex and respiratory symptoms, and LC.[7-8-9]

Evidence shows that infections with early variants of the virus (up to Omicron BA.1) were associated with a higher probability of developing LC, compared to infections caused by more recent Omicron sub-variants.[10]

A 2023 meta-analysis showed that COVID-19 vaccination before SARS-CoV-2 infection was associated with a lower risk of LC.[11] However, most of the patients with ongoing LC did not experience any changes in their condition following vaccination.[12]

6/ Yong SJ. Long COVID or post-COVID-19 syndrome: putative pathophysiology, risk factors, and treatments - PubMed. *Infect Dis* (Lond) 53(10), 737-754 (2021). doi: 10.1080/23744235.2021.1924397.

7/ Asadi-Pooya AA, Akbari A, Emami A, Lotfi M, Rostamihosseinkhani M, Nemati H, et al. Risk Factors Associated with Long COVID Syndrome: A Retrospective Study. *Iran J Med Sci.* 46(6), 428-436 (2021). doi: 10.30476/ijms.2021.92080.2326

8/ Thompson EJ, Williams DM, Walker AJ et al. Long COVID burden and risk factors in 10 UK longitudinal studies and electronic health records. *Nat Commun* 13, 3528 (2022). doi: 10.1038/s41467-022-30836-0.

9/ Kogevinas M, Karachaliou M, Espinosa A et al. Risk, determinants, and persistence of long-COVID in a population-based cohort study in Catalonia. *BMC Med* 23, 140 (2025). doi: 10.1186/s12916-025-03974-7.

10/ Beale S, Yavlinsky A, Fong WLE, et al. Long-term outcomes of SARS-CoV-2 variants and other respiratory infections: evidence from the Virus Watch prospective cohort in England. Epidemiology and Infection 152, e77 (2024). doi: 10.1017/S0950268824000748.

Several studies point to **social determinants of health** as an influential factor. Socioeconomic deprivation in particular appears to increase the likelihood of LC.[13]

A study by the END-VOC consortium with data from over 8,000 participants, found that deprivation, especially among women before the Omicron wave, was linked to a higher LC risk. Migrants and ethnic minorities also had higher LC rates, with more pronounced disparities among men. These differences lessened during the Omicron period.

The findings suggest that both increased exposure and post-infection factors contribute to higher LC rates, underscoring the need for targeted public health measures, equitable healthcare access, and further research on the social drivers of LC.[14]

Environmental factors, such as exposure to particulate matter ($PM_{2.5}$ and PM_{10}) due to air pollution, were also linked to a longer duration of LC symptoms.[15]

Despite the growing body of evidence on LC, many uncertainties remain. For example, **more research is needed to identify biomarkers that can be used for LC diagnosis and prognosis.**

The prognosis is still unclear: some people recover in months, but others have lived with the condition for years now, without improvement.

There is no single, effective cure, and any treatment is symptomatic.

11/ European Centre for Disease Prevention and Control. Does COVID-19 vaccination reduce the risk and duration of post COVID-19 condition? *Stockholm: ECDC* (2025).

12/ Watanabe A, Iwagami M, Yasuhara J, Takagi H, Kuno T. Protective effect of COVID-19 vaccination against long COVID syndrome: A systematic review and meta-analysis. *Vaccine* 41(11), 1783-1790 (2023). doi: 10.1016/j.vaccine.2023.02.008.

13/ Shabnam S, Razieh C, Dambha-Miller H, Yates T, Gillies C, Chudasama YV, et al. Socioeconomic inequalities of Long COVID: a retrospective population-based cohort study in the United Kingdom. *Journal of the Royal Society of Medicine* 116(8), 263–273 (2023). doi: 10.1177/01410768231168377.

14/ Fong WLE, Beale S, Nguyen VG et al. Estimating the risk of post-COVID condition (PCC) in deprived communities, migrants and ethnic minorities in England: Findings from Virus Watch. *medRxiv* (2024). doi: 10.1101/2024.11.26.24317965.

15/ Saucy A, Espinosa A, Iraola-Guzmán S, Castaño-Vinyals G, Harding BN, Karachaliou M, et al. Environmental Exposures and Long COVID in a Prospective Population-Based Study in Catalonia (COVICAT Study) | Environmental Health Perspectives. *Environmental Health Perspectives* 132, 11 (2024). doi: 10.1289/EHP15377.

Box 1
Main research highlights arising from END-VOC cohorts' data

- The COVICAT study using the GCAT-CONTENT cohort found an association between exposure to atmospheric contaminants with a higher prevalence of LC.[9] **Risk factors** included being female, under the age of 50, low-income status, having had severe COVID-19, high pre-vaccination IgG levels, obesity, and chronic conditions (especially asthma, COPD, and mental health disorders). In 2021, 56% of LC cases had symptoms lasting over two years, and between 2021–2023, 23% of those infected with SARS-CoV-2 developed LC. Protective factors included vaccination prior to infection, infection during the Omicron era, regular physical activity, and getting 6–8 hours of sleep.

- Another study with the COVICAT cohort found that LC, particularly in individuals with neuropsychiatric symptoms, was associated with **higher IgG levels against certain latent viruses** such as Epstein-Barr virus and varicella Zoster virus.[16]

- The Virus Watch cohort study in England and Wales examined LC risk across SARS-CoV-2 variants and its link to immune response. After adjusting for key factors, it found **LC was more common following infection with early variants** compared to later Omicron sub-variants (11–14%).

- Persistent symptoms also occurred after non-COVID respiratory infections (8–23%), while people with no infection had the lowest rates (1–3%). These findings highlight the **broader risk of persistent symptoms following respiratory infections** and underscore the need for further research.

- Another Virus Watch study examined antibody responses over time in individuals with mild-to-moderate SARS-CoV-2 infections, comparing those who developed LC to those who fully recovered. Those who developed LC showed persistently higher post-infection anti-nucleocapsid antibody levels, while vaccine-induced anti-spike antibody responses were similar in both groups.[17] The findings suggest that **people with LC may have a stronger and more prolonged immune response to infection**, which points towards a potential role of the immune system in developing the condition.

16/ Karachaliou M, Ranzani O, Espinosa A, Iraola- Guzmán S, Castaño- Vinyals G, Vidal M, et al. Antibody responses to common viruses according to COVID- 19 severity and postacute sequelae of COVID- 19 - Karachaliou - 2024 - Journal of Medical Virology - Wiley Online Library. *J Med Virol* 96, e29862 (2024). doi: 10.1002/jmv.29862.

17/ Beale S, Yavlinsky A, Moncunill G, Fong WLE, Nguyen VG, Kovar J, et al. Anti-nucleocapsid and anti-spike antibody trajectories in people with post-covid condition versus acute-only infections: a nested longitudinal case-control study within the Virus Watch prospective cohort | Nature Communications. *Nat Commun* 16, 3686 (2025). doi: 10.1038/s41467-025-58766-7.

4. *Why does it matter for policy-makers?*

WHILE THE ACUTE IMPACT OF COVID-19 HAS DECLINED OVER TIME, LC CONTINUES TO POSE A SIGNIFICANT HEALTH AND ECONOMIC BURDEN.

Millions still experience persistent symptoms that affect daily functioning, productivity, and healthcare systems.

Continued research is essential to answer unresolved questions about LC's real burden, as well as its causes, risks, and long-term effects.

At the same time, **targeted policies are needed to reduce its health and economic impact and support affected individuals.**

a. Health burden

The Global Burden of Disease Study (GBD) is the most comprehensive international research study on the health impact of different conditions, including LC.

Using data from 183 studies from different countries around the world (155 published studies and 28 collaborating cohorts providing individual-level data), **the GBD team has produced updated estimates of the global burden of three key LC symptom clusters** (persistent fatigue with bodily pain or mood swings; cognitive problems; and respiratory problems) up to the end of 2023.[18]

END-VOC researchers worked together with the GBD team to provide cohort data for inclusion in modelling, including analysis of the impact of different virus variants.

The updated GBD estimates have provided important insights into the burden of LC as COVID-19 shifts from an acute pandemic to an endemic infection. Notably, the results show a clear decline in the risk of developing a new case of LC across time, likely reflecting the impact of changing SARS-CoV-2 variants and immunity from vaccination and prior infections.

An estimated 130 million new LC cases meeting one of the three symptom cluster definitions occurred globally in 2020 and 67 million in 2021.

In 2023, only 6.1 million new cases meeting the symptom cluster definitions were estimated to have occurred, and around 1.3 million were predicted for 2024. However, despite lower numbers of new cases, the findings highlighted the importance of understanding and finding solutions for LC for people who are still suffering.

Notably, the duration that people suffer symptoms is considerable, with symptoms lasting an estimated average of 14.2 months across clusters following infection in the community.

The average estimated level of disability (i.e. 'disability weights') caused by LC is also high, with estimates similar to those for conditions known to substantially affect people's lives such as inflammatory bowel disease and severe neck pain.

While there is a lower —but still considerable— number of new cases over time, people living with the condition are substantially impacted and solutions and policy recognition is important.

Cohort-based research from the END-VOC project found LC incidence rates ranging from 6% to 59% across different countries and cohorts. These variations likely reflect differences in the populations studied, follow-up durations, and LC definitions used (see Table 1). The findings highlight the importance of studying diverse populations and the need to clearly define cohort characteristics and use consistent, harmonised case definitions in LC research.

18/ Institute for Health Metrics and Evaluation (IHME). Global Burden of Disease study: Long COVID analysis. Seattle, WA: IHME, University of Washington, 2025.

Table 1.

Characteristics of the cohorts contributing to Long-COVID research in the END-VOC consortium

Country	Population tracked	Enrollment and follow-up dates	Number of participants
Mozambique	Acute COVID-19 Patients	Feb. 2020 - Feb. 2021	100
	General Population	Jan - Jun 2022	4,814
Brazil	General Population with comorbidities	Mar. 2020 - Nov. 2021	4,401
Palestine	General Population	Jan. - Dec. 2023	5,662
Spain	General Population	Jun. - Oct. 2020; May. Jul. 2021, Feb. - Jun. 2023	9,548
	Long COVID Patients only	Nov. 2021 - May. 2022	435
United Kingdom	General Population	Jun. 2020 - Mar. 2022	12,000

b. Economic impact

A 2022 estimate of LC costs found that **USD $2.2 trillion was lost in quality of life, $1 trillion in lost earnings, and $528 billion in increased medical spending, totaling $3.7 trillion globally** —which, to contextualise, is more than twice the annual GDP of Spain.

LC can often result in disability, but estimates of its specific impact on employment outcomes vary. A 2022 study estimated that one in ten people who develop LC stopped working [19] equivalent to 110,000 workers being off sick in the UK. Another study estimated 27 000 working-age adults in the UK were economically inactive because of LC as of July 2022.[20] A 2023 analysis estimated that LC was associated with 44% higher odds of not working and 27% lower odds of working full-time.[21]

A recent study estimated that lost earnings due to LC among working-age adults in the U.S. totaled $211 billion in 2022 and $218 billion in 2023.

Approximately **24 million working-age adults** are estimated to have experienced, or may still be at risk of, adverse socioeconomic and mental health outcomes related to LC.[22]

Long COVID is not the only **post-infection chronic syndrome**. Other acute infections have long been linked to chronic disability in some patients.

LC is classified as a post-acute infection syndrome (PAIS), a group of conditions that remain largely unexplained and understudied.

Hopefully, emerging evidence on Long Covid will help elucidate their causes and guide effective treatments.

19/ Waters T, Wernham T. Long COVID and the labour market. *IFS* (2022). doi: 10.1920/BN.IFS.2022.BN0346.

20/ Ayoubkhani D, Zaccardi F, Pouwels KB et al. Employment outcomes of people with Long Covid symptoms: community-based cohort study. *European Journal of Public Health* 34(3), 489–496 (2024). doi: 10.1093/eurpub/ckae034.

21/ Perlis RH, Trujillo KL, Safarpour A, Santillana M, Ognyanova K, Druckman J, et al. Association of Post-COVID-19 Condition Symptoms and Employment Status. *JAMA network open* 6(2), e2256152 (2023). doi: 10.1001/jamanetworkopen.2022.56152.

22/ Kim, D. A nationwide study of risk factors for long COVID and its economic and mental health consequences in the United States | Communications Medicine. *Commun Med* 5, 104 (2025). doi: 10.1038/s43856-025-00759-0.

5. What are Post-Acute Infection Syndromes (PAIS)?

POST-ACUTE INFECTION SYNDROMES (PAIS) ARE CHRONIC CONDITIONS THAT DEVELOP IN A SUBSET OF INDIVIDUALS FOLLOWING AN ACUTE INFECTION, CHARACTERISED BY PERSISTENT, UNEXPLAINED SYMPTOMS DESPITE RECOVERY FROM THE INITIAL ILLNESS. [23]

These conditions are often marked by neurological, cognitive, and fatigue-related symptoms, without clear diagnostic markers or detectable pathogens. While long overlooked, the emergence of Long COVID, with its particularly heavy burden of neurological and cognitive symptoms [24] , has drawn renewed attention to PAIS.

Importantly, an END-VOC study found that individuals with any viral infection —whether COVID-19 or another virus— had a significantly higher risk of developing PAIS compared to uninfected individuals. This finding supports **infection itself, rather than pandemic-related stress, as the primary driver of these syndromes**.[10]

Any type of infectious agent can be associated with PAIS, including bacteria, virus and parasites. Table 2 shows an overview of unexplained PAIS associated with documented infections.

At the same time, targeted policies are needed to reduce its health and economic impact and support affected individuals.

23/ Choutka J, Jansari V, Hornig M, Iwasaki A. Unexplained post-acute infection syndromes. *Nat Med* 28(5), 911–923 (2022). doi: 10.1038/s41591-022-01810-6. Erratum in: Nat Med 28(8), 1723 (2022). doi: 10.1038/s41591-022-01952-7.

24/ Gao Y, Wang Y, Chen L, Xie J, Prieto-Alhambra D. Hospitalization for COVID-19, Other Respiratory Infections, and Postacute Patient-Reported Symptoms. *JAMA network open* 7(10), e2441615 (2024). doi: 10.1001/jamanetworkopen.

Table 2
Overview of unexplained PAISs associated with documented infections.

Pathogen	Name of PAIS
VIRAL PATHOGENS	
SARS-CoV-2	Post-acute sequelae of SARS-CoV-2 infection (PASC) Post-acute COVID-19 syndrome (PACS) Long COVID
Ebola	Post-Ebola syndrome (PES) Post-Ebola virus disease syndrome (PEVDS)
Dengue	Post-dengue fatigue syndrome (PDFS)
Polio	Post-polio syndrome (PPS)
SARS	Post-SARS syndrome (PSS)
Chikungunya	Post-chikungunya chronic inflammatory rheumatism (pCHIK-CIR) Post-chikungunya disease
EBV	No name
West Nile virus	No name
Ross River virus	No name
Coxsackie B	No name
H1N1/09 influenza	No name
VZV	No name
NON-VIRAL PATHOGENS	
Coxiella burnetii	Q fever fatigue syndrome (QFS)
Borrelia	Post-treatment Lyme disease syndrome (PTLDS)
Giardia lamblia	No name
Tuberculosis	No name
Plasmodium	Post-malaria neurological syndrome

23 / Adapted from: Choutka J et al23.

The causes, prevalence and prognosis of PAIS remain unclear, and more data and research are needed to improve our understanding of this syndrome.

Box 2
Potential causes of PAIS

Similarities suggest common underlying mechanisms which could include:

- Small traces of the pathogen remain hidden even after the initial infection is gone, triggering chronic inflammation and lingering symptoms. This has been observed in some Ebola and COVID-19 survivors.

- An overactive immune response that results in the attack of the body's own tissues. This can happen if the virus or bacteria has components that look similar to human proteins, triggering the production of self-reactive cells and antibodies. Scientists have found autoantibodies in people with LC, suggesting a similar process might be at play. There is also evidence that infections can weaken important barriers such as the one protecting the brain, making it more vulnerable to attacks by the immune system.

- Changes in the body's microbiome, the collection of bacteria and viruses that normally live inside us. Some infections can disturb this balance, allowing the reactivation of dormant viruses or causing inflammation.

- Other explanations include:

  - Irreparable organ damage sustained during infection, leading to long-term health effects, such as lung dysfunction following severe COVID-19.

  - Microclots, capillary dysfunction, and reduced oxygen delivery as a result of infection and immune responses. Elevated markers of coagulation and vascular injury have been observed in individuals with LC.

  - Mitochondrial dysfunction, with altered cellular energy metabolism, may be linked to post-exertional malaise symptoms often experienced by LC patients.

These explanations are not mutually exclusive, and PAIS may result from a combination of these factors.

This likely contributes to the wide range of symptoms observed. In the case of LC, the strength and nature of the immune response seems to play an important role, but more research is needed.

Box 3
Incorporating PAIS data collection to preparedness frameworks

During the COVID-19 pandemic we were largely unprepared for the emergence of LC.

Health policies did not anticipate a PAIS following SARS-CoV-2 infection, and no standardized data collection protocol was implemented either in hospitals or in research studies.

This lack of preparedness hindered the diagnosis and care of LC patients, leading to significant health and economic consequences.[25]

It is crucial to integrate PAIS to pandemic preparedness frameworks.

The next pandemic will likely be caused by another respiratory virus, and **healthcare workers and policy makers must be aware of the possibility of another PAIS.**

We need to collect data in a standardized way from the beginning, including adequate control groups, to better understand mechanisms, risk factors and possible biomarkers.

Furthermore, these data should be shared among countries, so researchers can compare their work and learn from each other.

PAIS research should not be limited to outbreak periods. Longitudinal studies conducted during inter-pandemic periods are essential to understand the nature of these conditions.

The END-VOC project exemplifies this approach by continuing to collect longitudinal data as COVID-19 transitions from a pandemic to an endemic disease.
END-VOC also contributes valuable insights by including populations in the global South that are underrepresented in LC research.

25/ Górska A, Canziani LM, Rinaldi E, Pana ZD, Beale S, Bai F, et al. Learning from post-COVID-19 condition for epidemic preparedness: a variable catalogue for future post-acute infection syndromes. *Clin Microbiol Infect* 31(3), 380–388 (2025). doi: 10.1016/j.cmi.2024.12.001.

6. Recommendations

LONG COVID AND OTHER PAIS AFFECT MILLIONS OF PEOPLE WORLDWIDE, RESULTING IN REDUCED QUALITY OF LIFE, DISABILITY, AND ECONOMIC LOSS.

Despite their significant impact, these conditions have received relatively little attention and funding for research and patient care. In the context of pandemic planning, PAIS are a risk to quality of life, livelihoods, and health systems that must be addressed proactively.

We propose the following policy recommendations to advance the understanding and management of Long COVID and PAIS:

Funding.

Increase specific international and national funding for research on LC and PAIS, including mechanisms, diagnostic markers and epidemiological studies.

The vast economic consequences of LC and the potential impact of a new PAIS in the next pandemic justify the increased investment.

Research.

Establish fully representative cohorts for epidemiological studies, with well-documented infectious triggers. These cohorts should allow:

i. **Standardised data collection**, during peacetime and during future pandemics. The Cohort Coordination Board (CCB), a knowledge exchange forum for EU-funded COVID-19 observational cohort projects, proposes the use of an experience-based PAIS data catalogue to facilitate data collection.

ii. **Integrated data collection and research** in the European Union, fostering the sharing and comparison of research protocols and results. END-VOC members are working on a standardised and adaptable protocol for early phases of infectious diseases outbreaks that could allow rapid data collection and sharing to support generation of real-time evidence for clinical guidance.

iii. **Longitudinal, multicentric studies** that collect data on individuals before, during, and after infection. When designing these studies, it is crucial to also understand if the controls are healthy people or people with other respiratory infections, because they give fundamentally different information.

iv. **Correct measure of the unequal impact** of PAIS, addressing the social determinants of health that influence the condition.

Health systems.

Provide training and resources to health systems to strengthen comprehensive patient care.

Priorities should include increasing awareness in primary care and improving access to specialized multidisciplinary clinics offering integrated support.

Advocacy.

Increase awareness among policymakers about the impact of LC and PAIS on quality of life and their economic burden.

Advocate for the **universal recognition of disability status** for LC and PAIS patients across Europe and support the inclusion of LC and PAIS within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).[26] Advocate for the recognition of the role of inequalities in PAIS.

Communication.

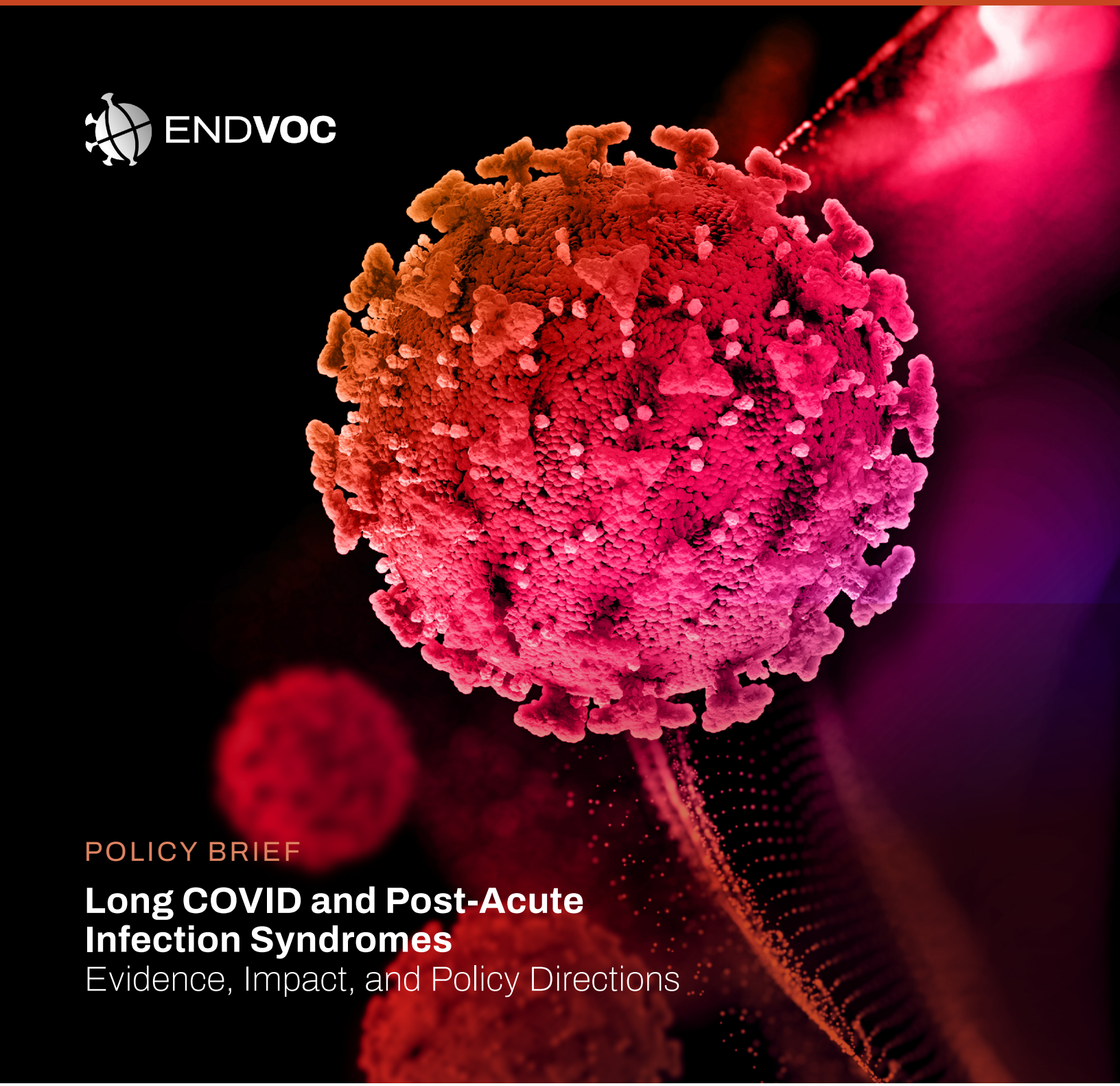
Raise awareness of LC among healthcare professionals and the wider public to help reduce stigma. Actively c**ollaborate with LC patient groups** and advocacy organizations to share research findings and develop joint campaigns to raise broader awareness.

Preparedness.

Embed PAIS directly within pandemic planning. Potential workforce impacts need to be considered proactively. Infrastructure designed to detect and respond to PAIS needs to be scalable and adaptable to large-scale pandemic demands.

TO KNOW MORE ABOUT PAIS: Choutka J, Jansari V, Hornig M, Iwasaki A. Unexplained post-acute infection syndromes. Nature Medicine. 2022 May 1;28(5):911–23. Available from: www.nature.com/articles/s41591-022-01810-6

26/ Council of Europe. "Long Covid" and access to the right to health. *Strasbourg: Council of Europe* (2023).



POLICY BRIEF

Long COVID and Post-Acute Infection Syndromes

Evidence, Impact, and Policy Directions

Authors

Clara Marin[1], Sarah Beale[2], Robert Aldridge[2], Elizabet Diago[1], Erica Fong[2], Claudia Garcia-Vaz[1], Gemma Moncunill[1], Adelaida Sarukhan[1], Fernando Val[3], Sarah Wulf-Hanson[4]

ON BEHALF OF THE END-VOC CONSORTIUM.

1/ Barcelona Institute for Global Health, Spain
2/ University College London, UK
3/ Fundação de Medicina Tropical Doutor Heitor Vieira Dourado, Brazil
4/ Institute for Health Metrics and Evaluation, USA

Funded by the European Union under grant agreement N.101046314. Views and opinions are those of the author(s) only and do not necessarily reflect those of the European Union.