# **Background**

An April 2024 Economist Impact report titled <u>An incomplete picture: understanding the burden of long Covid</u> highlights the critical need to address global challenges related to long Covid, including:

- Finding a common framework for the description and study of long Covid;
- Developing a coherent policy framework;
- · Prioritising better collection and collation of data; and
- Supporting and prioritising the needs of individuals with long Covid.

With these findings in mind, Economist Impact established an Advisory Council composed of 15 experts with diverse insights and perspectives and representing four regions—North America, Latin America, Europe and Asia—to reach a consensus on how long Covid should be defined, understood and addressed globally. Economist Impact held two virtual sessions with Advisory Council members in July 2024.



Advisory Council members ratified the consensus statement below on 3 September 2024.

This consensus statement outlines key opportunities to mitigate the consequences of long Covid by bridging gaps in understanding and promoting comprehensive public health strategies, support systems and patient advocacy.

### Statement of purpose

Recognising long Covid as an ongoing health crisis with long-term implications, we:

- Endorse a systematic, multifaceted and comprehensive approach to addressing this condition.
- Advocate for improved coordination amongst various stakeholders to develop a common framework and definition for long Covid, enhance research efforts and treatment development, promote better diagnosis and symptom management, and implement best practice policies.
- Urge decision-makers to actively engage key stakeholders, including patients, families, carers and healthcare providers, in the development and implementation of strategies, concepts and policies.

## Introduction

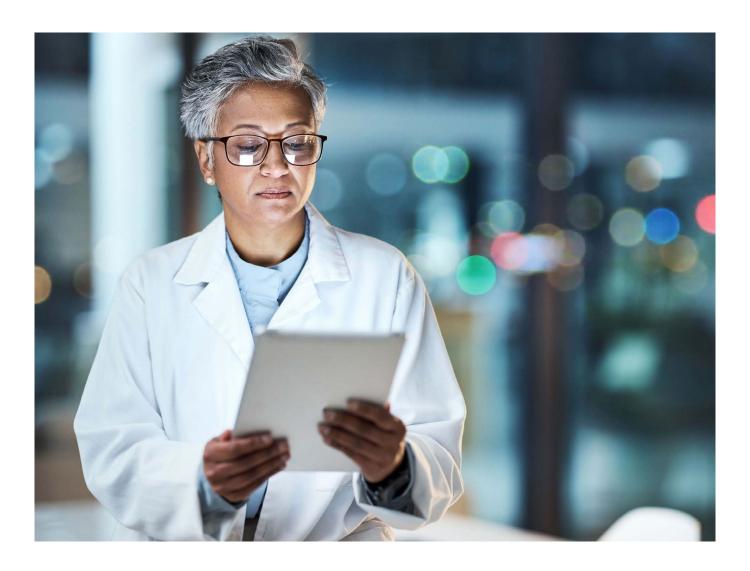
Long Covid is a significant and enduring challenge resulting from the Covid-19 pandemic. According to the World Health Organization (WHO), approximately 10–20% of individuals infected with SARS-CoV-2 may experience symptoms that qualify as long Covid.¹ These include exertion intolerance, brain fog, cognitive dysfunction and fatigue, which significantly impact daily life and overall well-being.<sup>2,3</sup>

Despite international research efforts, a universally accepted definition of long Covid remains elusive among academics, policymakers and healthcare professionals: different organisations and experts propose varied conceptualisations of the condition.

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The WHO defines long Covid or post-Covid-19 condition as "the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation." Other health organisations and researchers use varying time frames and symptoms, complicating clinical interventions and policy responses. More than 40 definitions of long Covid are in use according to an Economist Impact tally in July 2024.

Without a concerted effort to develop a standardised framework for long Covid, the global community's ability to understand and address this condition will remain limited, posing ongoing challenges for individuals, healthcare systems and society. Drawing on expert insights, we have identified five critical points of consensus on how to tackle some of these challenges.



## **Nomenclature**

There is an established need for consistent, global messaging regarding long Covid, including how the condition is described and conceptualised. The Advisory Council recommends:



## Aligning on the name of the condition

The condition involving long-term symptoms resulting from Covid-19 has been referred to by several names, including post-Covid-19 condition(s), post-acute sequelae of SARS-CoV-2 (often abbreviated as PASC) and long-haul Covid. To reach a global consensus, agreeing on a single name is crucial. Our experts suggest using "long Covid" due to its frequency of use, simplicity and accessibility to the public.



Many patients report one or more of the over 200 possible symptoms of long Covid (ie, sequelae), with varying severity. Other patients develop new or worsening chronic conditions, such as diabetes, cardiovascular, or neurodegenerative diseases, after SARS-CoV-2 infection, which may be directly or indirectly related to the viral infection. While all of these symptom presentations are considered long Covid, it can be helpful to differentiate between the different manifestations (ie, subphenotypes)-particularly for patients with new or worsening chronic conditions. Our experts recommend classifying chronic conditions secondary to Covid-19 as "post-Covid" chronic conditions (eg, 'post-Covid diabetes') to establish that this

group of patients tend to have different symptoms and needs than patients with typical long Covid symptoms. This distinction emphasises the need to utilise tailored care pathways and support for individuals with long Covid based on their specific symptoms and disease manifestations.



### **Establishing a clear timeframe**

Alignment on a definitive timeframe for long Covid is necessary for diagnosing patients and determining the condition's prevalence. The WHO considers long Covid to begin at least 12 weeks after a SARS-CoV-2 infection, while other organisations, such as the US Centers for Disease Control and Prevention (CDC) and the UK's National Institute for Health and Care Excellence (NICE), specify at least four weeks as the starting point. 6,7,8 Experts have agreed that individuals can be diagnosed with long Covid when there is a "continuation or development of new symptoms three months after the initial infection." They also suggest that, for patients with persistent symptoms, the time between when acute Covid-19 ends (generally two weeks post-infection) and long Covid begins should be called suspecting long Covid. Assigning a name to the period before long Covid can be diagnosed will provide clarity for individuals with long-lasting symptoms and allow them to begin managing symptoms with their healthcare providers.



## **Definition**

A universally accepted definition of long Covid would ensure clarity among stakeholders and consistency in clinical practice, research and policymaking. However, the current state of knowledge poses significant challenges. As evidence continues to accumulate and our understanding of the condition evolves, defining it with a single, one-size-fits-all approach may be premature and counterproductive in addressing the diverse needs of patients. Given the complex and varied nature of long Covid, its different subtypes and the ongoing research, experts suggest the following:



### **Employing a general,** inclusive definition

The definition should be inclusive to allow people living with different manifestations of long Covid to see themselves reflected in it, ensuring no one is left behind. Moreover, the absence of a definitive Covid-19 diagnosis—largely due to the lack of testing—should not be a barrier to a long Covid diagnosis.

Listing specific symptoms is useful, but doing so may limit the definition's applicability to individuals affected by long Covid. Experts suggest incorporating the phrase "impacts daily functioning" in the definition to better capture the wide variety of symptoms and their severity.

The definition should also use plain, non-technical language that can easily be understood by individuals from all stakeholder groups, including patients.



### Using a tailored definition for different stakeholders

Experts believe it is beneficial to first establish a general, overarching definition of long Covid and then systematically define the condition based on the specific needs of various sectors and stakeholders. Different groups, such as clinicians and researchers, could benefit from having a tailored definition of long Covid, with components specific to their work. For example, the clinical definition might include a more comprehensive list of symptoms to aid diagnosis. These specific components of the definition can be combined with the overarching definition (mentioned above) to provide a more comprehensive and practical description of long Covid.

This approach would appear as follows:

Overarching long Covid definition that includes "bothersome symptoms that may reduce quality of life or impact daily functioning" Clinical-Policy-Researchoriented oriented oriented This definition This definition This definition should include should consider should include clinical the economic subgroups of characteristics and impact of the patients for condition and possible symptoms. tailored clinical and categorise prioritise equity. trials and support symptoms as mild, a counterfactual moderate, severe approach. Confirmed or very severe to prioritise treatment Covid-19 for those who diagnoses may be required for need greater care. Diagnosis should not accurate data require a confirmed collection case of Covid-19.



#### **Promoting periodic reviews**

Considering ongoing research, the definition of long Covid should be periodically updated as new evidence emerges. While alignment on a flexible, global definition is crucial for coordination, it is important to incorporate new research findings, such as diagnostic advancements, as they become available.

# **Policy**

Comprehensive policy on long Covid is vital to ensure better support for patients, provide adequate investment in research, and mitigate the societal and economic consequences of long Covid. Experts agree that political commitment is critical to achieving these goals. Advisory Council members have identified the following policy priorities:



### Advocating for global coordination

Policies should encourage global coordination between key stakeholders such as international organisations, private period,



#### **Focusing on prevention**

sector, researchers, civil society and patient advocacy

groups, to promote shared strategies and resources.

Policymakers must prioritise sustainable strategies for preventing long Covid and advocate for the widespread availability of preventive measures. Prevention programmes should include measures to prevent the spread of Covid-19, such as improved air filtration, ventilation and masking in high-risk settings. Prevention programmes should also include measures with potential to reduce the risk of severe Covid-19 illness and long Covid, such as ongoing vaccination programmes and early intervention during acute illness.<sup>8,9,10,11</sup>



#### **Increasing funding**

Following the end of the global Covid-19 emergency period, funding and political support for Covid and long Covid programmes has significantly waned. Long-term funding is essential for implementing effective long Covid policies and solutions.



### **Improving awareness**

Public education and awareness campaigns can better equip individuals to identify the symptoms of long Covid and improve knowledge about available resources. Training programmes for healthcare providers should be implemented to improve their understanding and clinical management of long Covid. This will help reduce care inequities, address the "medical gaslighting" many individuals with long Covid experience and promote better outcomes.







## Ensuring access, quality and equity in care

Equitable access to Covid-19 vaccines, multidisciplinary care and multisectoral support which encompasses physical, cognitive, occupational and social aspects for people with long covid, is crucial for care improvement. Policies should more effectively address the needs and challenges of marginalised groups including uninsured individuals, residents of underserved communities and workers in less-adaptable employment situations as well as those living in economically vulnerable countries and regions globally. Addressing specific populations' needs will help prevent disparities in diagnosis, access to resources and outcomes.



### Closing the gender gap

Long Covid tends to affect women more frequently and has a greater impact on their financial stability. Missing work due to long Covid symptoms contributes to higher rates of job loss among women. Despite this, women's specific experiences with long Covid are under-researched, under-diagnosed and under-treated. Greater focus and investment are needed to bridge these gaps, reduce disparities and mitigate the impact of long Covid on women's livelihoods.



### **Strengthening support systems**

Providing adequate support for individuals with long Covid requires a robust policy framework that includes disability benefits, comprehensive social support and assistance with medical expenses. Effective frameworks will ensure that patients receive the necessary resources and services to manage their condition, enhance and improve their quality of life and achieve financial stability.



#### **Enabling economic participation**

People living with long Covid face a higher risk of job loss and challenges in re-entering the labour market. To support them, government and private sector policies must offer accommodations that enable workers and students to maintain their economic activity now and in the future. These accommodations could include facilitating educational attainment, flexible or reduced work hours, remote work options, retraining for suitable roles and assistance in finding employment.<sup>12</sup>

## Research

Continued investment in long Covid research is needed to increase understanding of the condition, particularly in pathogenesis, clinical diagnosis, risk factors, treatment and prevention. Experts suggest the following opportunities for continued study:



# Continuing the search for diagnostics

A reliable biomarker or set of biomarkers for diagnosing long Covid has yet to be identified, leading to challenges like misdiagnosis and inadequate patient care.

Developing better diagnostic tools, including imaging techniques, blood and tissue tests, and biosensors, is crucial for accurate diagnosis and monitoring of disease progression. However, the complexity of biological mechanisms and the current lack of funding are major barriers to progress in this essential area of research.



#### **Creating a measurement tool**

To date, no standardised measurement tools for long Covid exist. Our experts propose adopting a Disability Rating Scale (DRS) that measures functional and cognitive impairment due to long Covid symptoms, along with symptom frequency. DRSs can help clinicians diagnose long Covid and guide treatment by standardising clinical assessments of severity and tracking disease progression. A DRS would enable clinicians to measure the severity of long Covid, distinguishing between mild, moderate, severe and very severe cases. Advisory Council members suggested that a DRS that includes an evaluation of a patient's ability to work could assist in social assistance provision and workforce allocation.



### Promoting studies on long-term risk

Research is needed to understand the long-term risk of long Covid and how the condition may evolve over time. For example, brain fog may increase the risk of neurodegenerative diseases like Alzheimer's, while conditions like tachycardia might raise the risk of heart failure.

Given the high numbers of reinfections and the continual emergence of new variants, research must also focus on the long-term risk of developing long Covid after a SARS-CoV-2 infection. This research will provide valuable insight into which variants are most likely to result in severe cases of long Covid and how repeated SARS-CoV-2 infections

may impact patients' overall health. Historical evidence from other infections, such as polio, indicates that health risks can emerge decades later. Whether Covid-19 will have similar long-term effects remains unclear. Long-term studies are needed to evaluate these potential risks over five, ten and twenty years. Additional areas of interest include the development of comorbidities linked to Covid-19 and the impact of vaccination. Altogether, these research priorities will help assess the increased risk for general and vulnerable populations developing the condition.



### **Identifying effective interventions**

Research on drug repurposing and other interventions holds great potential to improve patients' quality of life. By using existing medications, drug repurposing can save time and resources. However, realising the full potential of these interventions requires greater investment in clinical trials (eg, adaptive platform trials) and coordinated efforts by governments and the private sector. Longterm investment is crucial for discovering safe, effective treatments and ensuring that new interventions make a meaningful and lasting impact. Support from drug regulators such as the US Food and Drug Administration (FDA) and the European Union's European Medicines Agency (EMA) is essential for making progress in this area.



### Investigating the disease burden

More research is needed to understand the burden of disease and disability due to long Covid, including years of healthy life lost due to disability (YLDs) and quality-adjusted life years (QALYs). These metrics are necessary for accurately assessing the true burden of this new condition, relative to other well-characterised conditions, such as cancer and heart disease, and understanding its impact on health systems and the economy. Burden metrics can also help to guide health policy and the effective allocation of resources. Moreover, research focusing on long Covid manifestations in children and adolescents is key to understanding the overall burden of this condition.



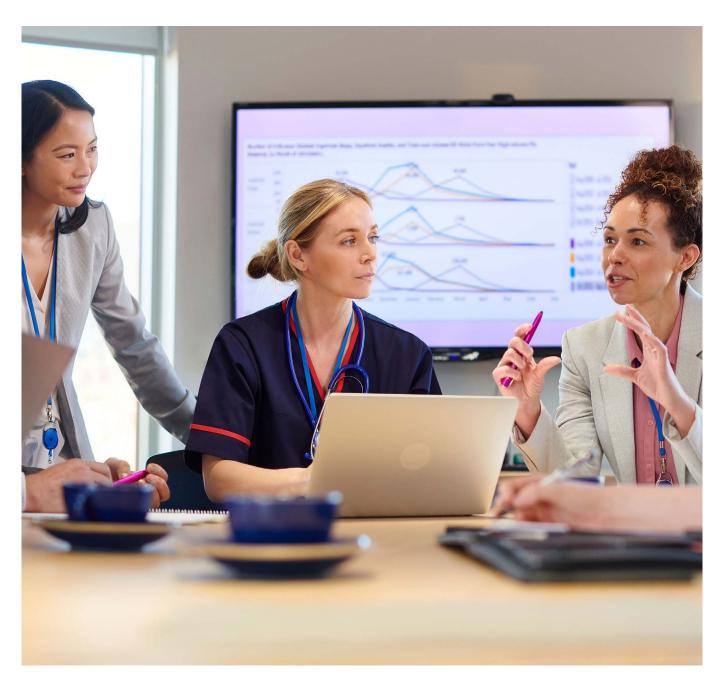
### **Constructing a data repository**

By creating a comprehensive long Covid database with information on symptoms, severity, progression, treatment responses and other health data, such as primary series vaccinations and booster shots, researchers can identify patterns in how long Covid manifests, enabling informed decision-making and better disease management. Our experts also recommend collecting demographic and workforce-related data to better understand the condition's economic impact.



## Understanding the global economic impact of the condition

A significant gap remains in understanding the economic impact of long Covid—particularly in low-income countries. The broader research community, including economists and social scientists, should actively evaluate the economic cost at both national and global levels as new prevalence data becomes available. By providing more accurate estimates of productivity loss and healthcare costs, researchers can produce a clearer picture of the overall economic burden on individuals and society.



# Symptom management

Advisory Council members noted the importance of addressing the care needs of people with long Covid. Timely identification of people with long Covid and effective symptom management will help to improve outcomes and enhance the quality of life for individuals with long Covid. Opportunities for improving symptom management include:



# Promoting sustainable and multidisciplinary care models

Developing sustainable care models based on equity, prevention and social support is essential. Competence centres\* for post-acute infectious syndromes and care models should ensure equitable access to quality care for all people with long Covid and promote multidisciplinary treatment approaches, with support from clinicians, including neurologists, cardiologists, physical medicine and rehabilitation specialists.<sup>10</sup>



Long Covid results in a wide array of clinical, physiological and metabolic issues that can prevent individuals from participating in everyday activities. Rehabilitation may be an essential component of symptom management and key to improving outcomes when designed to address the specific challenges of this condition. Rehabilitation programmes can help some patients regain independence and return to daily activities, reducing the long-term burden of long Covid. Prioritising safe, tailored rehabilitation programmes can help to manage the multifaceted impacts of long Covid, while reducing the risk of adverse events from poorly adapted rehabilitation practices.

Our experts recommend focussing on multidisciplinary rehabilitation treatments that are tailored to the patient's basic metabolism, current health issues and existing chronic conditions. The process should be easy for patients to understand, cost-effective and suitable for their health needs.



Some existing medications have shown potential for reducing long Covid symptoms but many physicians remain unaware of their therapeutic value or remain hesitant to prescribe them. And insurance providers often deny coverage for non-approved use of medications. To address these challenges, organisations like the Federal Institute for Drugs and Medical Devices (BfArM) in Germany are currently compiling a list of these drugs. Our experts recommend creating a formal, global registry of existing medications with early evidence of success in treating long Covid symptoms that incorporate data on treatment responses. This registry could improve treatment accessibility and provide additional therapeutic options.



## Learning from existing conditions with similar presentations

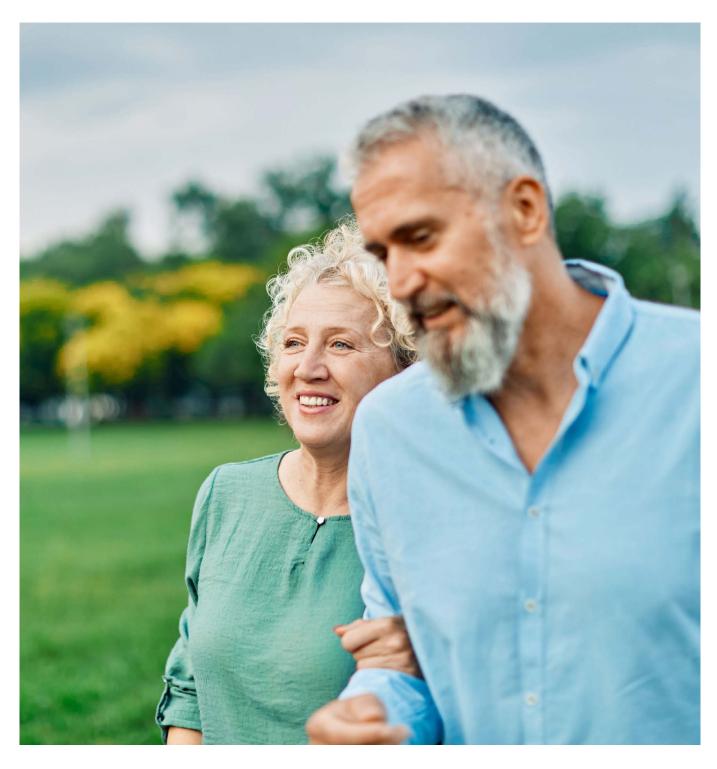
Our experts suggest that healthcare practitioners should draw on existing knowledge of similar conditions, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), to improve symptom management for long Covid. Symptoms such as debilitating fatigue, cognitive dysfunction and dysautonomia, commonly seen in other post-viral diseases, are commonly reported by people with long Covid.<sup>13</sup> Practitioners should consider what is already known about the causes and management of these conditions when treating long Covid symptoms.

<sup>\*</sup> Competence centres for post-acute infectious syndromes, such as long Covid, are specialised healthcare facilities designed to provide comprehensive, multidisciplinary care for patients suffering from prolonged symptoms following an acute infection.

## **Conclusion**

Addressing the multifaceted impacts and challenges of long Covid is essential for mitigating its consequences and improving patient outcomes. Establishing a broad and universal definition of long Covid is key to ensuring clarity, accurate diagnosis and effective disease management across diverse populations. Policymakers should prioritise equity in diagnostics, care and resources while ensuring adequate funding and ongoing support for people with long Covid.

Increased funding for research from governments and the private sector is necessary to advance understanding and develop solutions for long Covid. Symptom management strategies must follow best practices and incorporate emerging treatment options as they become available. Together, these actions will encourage better coordination within the global health community and enhance care and support for individuals with long Covid.



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