Policy paper

The prevalence and impact of Long COVID in the primary care population

Findings from the OECD PaRIS survey

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Abstract

Long COVID is a condition developing after initial COVID-19 that results in a range of persistent symptoms, impacting physical and mental health, causing disability and reducing productivity. The OECD Patient-Reported Indicator Surveys (PaRIS) collected data from 2023 to 2024 from 107 011 primary care patients aged 45 years and older in 19 countries, and included questions related to Long COVID. According to PaRIS data, approximately 7% of primary care patients aged 45 years and older reported ever having Long COVID, while an estimated 5% reported living with persisting Long COVID symptoms at the time of survey. Patients living with Long COVID reported lower self-rated physical and mental health and poorer healthcare experiences compared to those without. Implementation of standard care pathways for the diagnosis, management and co-ordination of Long COVID care is needed to improve patient healthcare experiences. The long-term health and social impact of Long COVID remains uncertain, requiring continued surveillance and research to estimate the socio-economic costs of the disease burden, in order to better inform health policy.

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Austria, Australia, Belgium, Czechia, Colombia, Finland, France, Germany, Iceland, Japan, Latvia, Luxembourg, Norway, Sweden, Slovenia and Switzerland participated in the snapshot survey of countries in November and December 2024.

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Table of contents

FIGURES

TABLES

Acronyms and abbreviations

PaRIS	Patient-Reported Indicator Surveys
NASEM	National Academies of Sciences, Engineering and Medicine
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
WHO	World Health Organization

Executive summary

Long COVID presents considerable challenges for patients, healthcare providers and policy makers, with millions of people still suffering from this condition five years after the pandemic began. Patients with Long COVID experience a wide range of persistent symptoms that impact their physical and mental health, ability to work and engage in daily activities. Many also encounter frustration and inadequate care co-ordination within the healthcare system, leading to difficulties in recognising and diagnosing Long COVID.

Health system planning for Long COVID management requires **reliable estimates of prevalence, health impact, and costs to patients, health systems and economies.** This is difficult due to epidemiological uncertainties on Long COVID, including unknown duration, long-term effects and future incidence. **Robust data collection and economic analysis are essential to inform effective policies**, yet most countries lack routine surveillance for estimating country-level prevalence of Long COVID. OECD countries typically rely on coding of hospitalised patients or research studies, not representative of the primary care or general population. **Primary care-based surveys may provide more representative estimates of the impact of Long COVID on populations.** The patient perspective of living with Long COVID is important to capture in order to inform more effective and people-centred heath policy and care pathways.

To estimate the disease burden of Long COVID in OECD populations, **we used the PaRIS dataset to provide estimates of prevalence, as well as its health and social impact**. The OECD Patient-Reported Indicator Surveys (PaRIS) is a cross-sectional survey of 107 011 primary care patients aged 45 years and older across 16 OECD countries, who had a primary care contact within the previous six months. Surveyed primary care patient reported sociodemographic status, chronic conditions, health outcomes, healthcare experiences and Long COVID symptoms.

According to the PaRIS survey data collected in 2023, **7.2% of the primary care population aged 45 years and older across 16 OECD countries are estimated to have ever had Long COVID, ranging from 3.9% in Greece to 10.8% in Norway**. An estimated 5.1% of the primary care population aged 45 years and older were estimated to be living with Long COVID in 2023. Among primary care patients, the reported Long COVID prevalence was significantly higher among **females, those aged 45-54 years, and with a higher educational level.** Long COVID prevalence increased with the number of other chronic conditions, **but 6% of patients without any other chronic condition still reported ever having Long COVID.**

People living with Long COVID reported poorer physical and mental health. Three in four people with Long COVID self-rated their mental health as good, compared to over four in five people without Long COVID. Only six in ten people with Long COVID self-rated their physical health as good, compared to seven in ten people without Long COVID. **One in five patients with Long COVID reported severe fatigue, compared to one in ten patients without Long COVID.** Patients living with Long COVID reported higher rates of severe fatigue than those without, even when their number of chronic conditions was accounted for. **One in eight patients with Long COVID were unemployed or on sick leave. Patients with Long COVID reported higher prevalence of musculoskeletal, respiratory, neurological and mental health disorders**, which represent the main recognised clinical subtypes of Long COVID.

Patient-reported healthcare experiences were worse in patients who reported having Long COVID. **One in three patients with Long COVID reported having to repeat information that should already be in their medical records**, compared to one in four patients without Long COVID. In addition, a **lower proportion of people with Long COVID reported trust in the healthcare system (58%),** compared to people without Long COVID (64%)**.** Having to repeat information is likely linked to lack of co-ordinated healthcare for Long COVID, leading to lower trust.

Co-ordinated and standardised care pathways can help to detect, diagnose and manage patients living with Long COVID. The PaRIS survey revealed considerable country variation in reported Long COVID prevalence across OECD countries surveyed, as well as the different symptom presentations of Long COVID. Health policy makers may consider i) developing training for healthcare professionals to improve recognition of symptoms and prompt diagnosis of Long COVID for patients; ii) prioritising establishment of integrated and standardised care pathways for diagnosis and management of Long COVID, to improve the co-ordination and experience of healthcare for patients.

1 Long COVID has emerged as a serious long-term consequences of the pandemic

Long COVID (Post COVID-19 condition) presents considerable challenges for patients, healthcare providers and policy makers, with millions of people still suffering from this condition five years after the pandemic began (Espinosa Gonzalez and Suzuki, 2024[1]). Patients with Long COVID experience a wide range of persistent symptoms that impact their physical and mental health, ability to work, care for their families, and engage in daily activities (Ely, Brown and Fineberg, 2024[2]). Many also encounter frustration and inadequate care pathways within the healthcare system, complicated by a lack of effective diagnostic tools or biomarkers leading to difficulties in clinically recognising and diagnosing Long COVID. The lack of a standardised case definition for Long COVID also negatively impacts recognition and diagnosis for patients and physicians. Although there has been increasing consensus on the case definition, implementing this in clinical practice across health systems may prove challenging (see Box 1).

This lack of recognition of Long COVID and organised care models exacerbates the already significant challenges patients face in managing their complex and disabling conditions. Planning for the management and long-term impacts of Long COVID requires reliable estimates of the prevalence of the condition, its persistence over time, costs to patients, health systems, and economies. However, this is challenging due to the epidemiological uncertainties, such as the still-unknown duration, long-term effects of, and future incidence of the condition. While some patients seem to recover over months, others suffer relapses or endure persistent symptoms for months or even years (Cai et al., 2024[3]).

Given these uncertainties, early findings paint a concerning picture. If Long COVID symptoms persist long-term as a chronic condition, its societal impact will be immense. It also presents clear equity challenges, disproportionately affecting women, essential workers, and individuals in more socio-economically deprived areas (Subramanian et al., 2022[4]). Shedding light on the clinical, epidemiological, and economic implications of Long COVID through robust data collection and economic analysis is essential to inform effective policy responses.

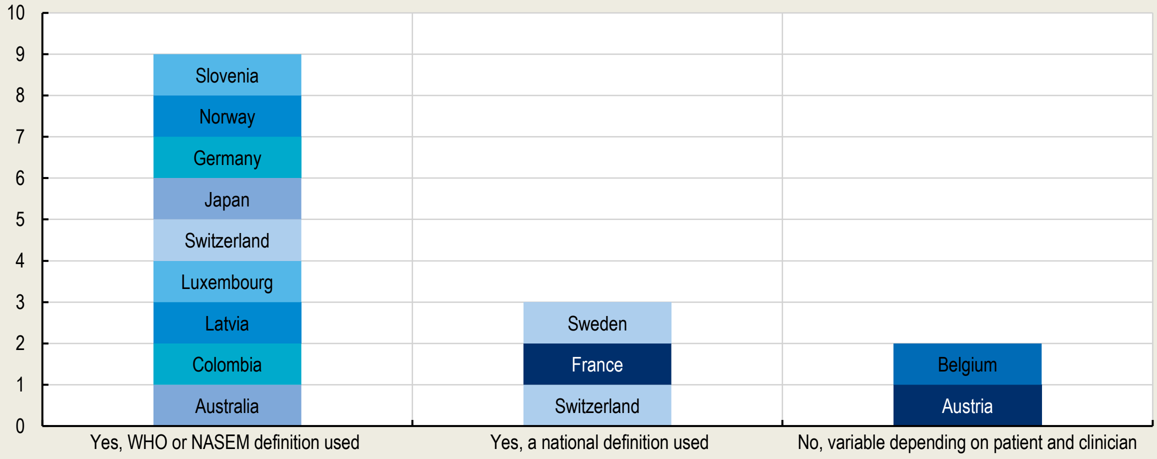
Up-to-date, population-level estimates of Long COVID prevalence are required for OECD countries to budget and plan the allocation of healthcare resources. However, most countries currently lack routine surveillance for estimating country-level prevalence of Long COVID. Currently, most OECD countries are reliant on clinical coding of hospitalised patients or COVID-19 research studies to inform estimates, which may not be generalisable to the primary care or general population.

Primary care-based surveys such as PaRIS (see Box 2) may provide more representative estimates of the impact of Long COVID on populations. The patient perspective of living with Long COVID is important to capture. Patient-reported health outcome (PROMs) and healthcare experience measures (PREMs) can be used to inform more effective and people-centred heath policy and care pathways. An understanding of the health and social impact on patients in terms of their reported well-being and functioning, and their experience of navigating the healthcare system, can help inform the organisation of care pathways and optimise the detection, diagnosis and management of patients living with Long COVID.

Box 1. Recognising, diagnosing and managing Long COVID in OECD countries in 2024

OECD countries are adopting consensus around a common case definition for Long COVID. A majority (64%) of OECD countries surveyed in November 2024 reported use of either the World Health Organization (WHO) or National Academies of Sciences, Engineering and Medicine (NASEM) case definition (see Figure 1). These two definitions have emerged as the consensus to define and detect Long COVID – which applies to patients presenting with new or persistent symptoms for at least two to three months, after an initial SARS-CoV-2 infection (COVID-19). They provide a basis for detecting and referring suspected cases in a standardised way for healthcare systems, however the relative recency of their development (WHO in 2022 and NASEM in 2024), and gradual adoption by healthcare systems, limited the recognition of earlier cases of Long COVID prior to this, likely leading to an underestimation of Long COVID burden. Five surveyed OECD countries reported either use of a national case definition or lacking a standardised case definition depending on patient and healthcare provider.

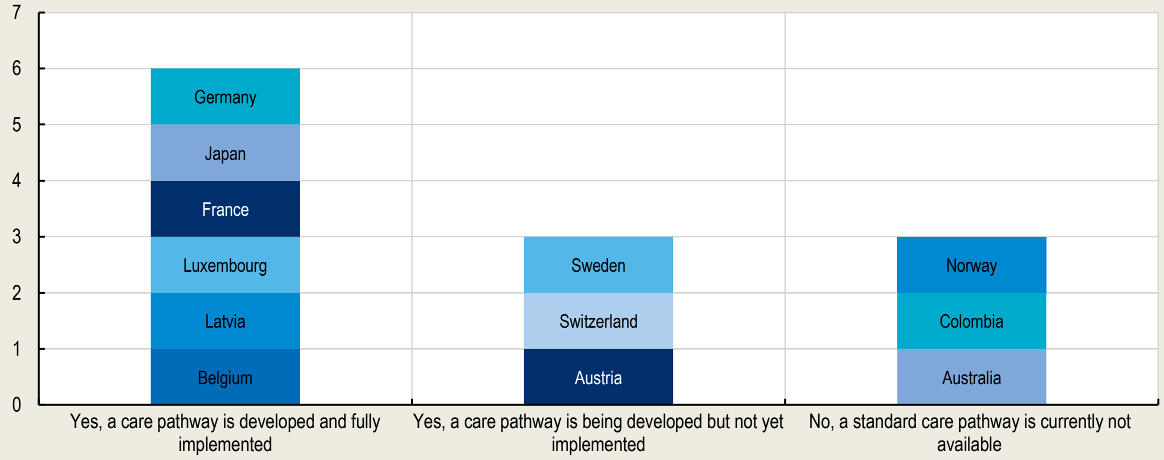
Figure 1. Use of a standardised case definition to diagnose Long COVID



Source: OECD Survey on the Assessment of the Adoption of Systems and Interventions to Improve Diagnostic Safety, 2024.

Among OECD countries surveyed in November 2024, six (Belgium, France, Germany, Japan, Latvia and Luxembourg) reported having a national standard care pathway for referral and management of patients with suspected Long COVID (see Figure 2). Pathways typically involve organisation of care for patients to either specialist or primary care for standardised assessment to confirm or exclude Long COVID diagnosis and offer multidisciplinary management. Three countries surveyed reported a national care pathway being developed, but not yet implemented in practice. Lack of implementation of a standard care model is a barrier to timely detection and management of Long COVID and represents a challenge for patients and healthcare providers in OECD countries. For many, implementation of a care model is still in progress as of 2024 with organisation of care pathways and drafting of clinical guidelines.

Figure 2. Standard care pathways for referral and management of patients with Long COVID



Source: OECD Survey on the Assessment of the Adoption of Systems and Interventions to Improve Diagnostic Safety, 2024.

Box 2. Using the PaRIS results to shed light on Long COVID

PaRIS and recruitment of participants from primary care

The OECD Patient-Reported Indicator Surveys (PaRIS) initiative conducted a cross-sectional survey of 107 011 primary care patients aged 45 years and older, who had a primary care contact within the 6 months preceding the sampling (de Boer et al., 2022[5]; Valderas et al., 2024[6]). The PaRIS study design, sampling method of primary care practices and patients, and participant characteristics are detailed in Chapter 7, "PaRIS data and methods" in *Does Healthcare Deliver?: Results from the Patient-Reported Indicator Surveys (PaRIS)* (OECD, 2025[7]). Data were collected from May 2023 to January 2024. PaRIS surveyed COVID-19 related outcomes in patients from 16 OECD countries: Australia, Belgium, Canada, Czechia, France, Greece, Iceland, Italy, Luxembourg, the Netherlands, Norway, Portugal, Slovenia, Spain, Switzerland and Wales (United Kingdom), and two non-OECD countries: Romania and Saudi Arabia. PaRIS patients from the United States were aged 65 years and older and were not asked the questions related to Long COVID. Patients were recruited from 1 816 primary care practices. This period corresponds to the fourth year of the COVID-19 pandemic, by which time a substantial proportion of the population had contracted COVID-19. PaRIS surveyed primary care patient reported sociodemographic status, chronic conditions, healthcare experiences, health outcomes and Long COVID symptoms. To estimate the disease burden of Long COVID in OECD populations, we used the PaRIS dataset to provide estimates of its prevalence, as well as its health and social impact.

Defining and measuring Long COVID using PaRIS

For analysis purposes, Long COVID was defined as persistence or onset of new symptoms for more than three months after initial COVID-19, aligning with the WHO (2022)[1] and NASEM (2024)[2] case definitions. Of note, the outcome was measured as patient-reported persistence of symptoms, without confirmation based on medical records or diagnosis. We defined Long COVID prevalence as the percentage of participants in the total primary care population of PaRIS who reported ever having Long COVID according to the case definition. The COVID-related questions were based on those of the US Pulse household survey.[3] The PaRIS patient questionnaire is available on the OECD PaRIS website.[4]

Firstly, crude estimates of COVID-19 and Long COVID prevalence were calculated for the overall PaRIS survey population. Prevalence of Long COVID was calculated as the number of patients who fulfilled the case definition divided by the total primary care population of PaRIS. A multilevel model provided adjusted country-specific estimates of Long COVID prevalence and an overall prevalence estimate, with comparative intervals (CI).[5] The multilevel model accounts for variation arising from different countries and primary care providers, which could influence the characteristics of the patients included in the survey from each location.

Estimates of Long COVID prevalence were calculated for the following sociodemographic variables: sex, age, income level, educational level, employment status, and presence of chronic conditions, and analysed for any statistical difference in prevalence for each variable. These prevalence estimates were standardised by age and sex using the country reference populations and included comparative intervals. Given the impact of pre-existing chronic conditions on the risk developing of Long COVID, the crude analysis of prevalence was stratified by the number of patient chronic conditions. Participants with missing data for variables of interest were excluded from the sub-analysis.

Measuring patient reported outcomes and experiences using the PaRIS survey

Adjusted estimates of patient-reported health and social outcomes (severe fatigue, being on sick leave or unemployed, self-rated physical health and self-rated mental health) and patient-reported healthcare experience (having to repeat information on medical record and having trust in the healthcare system), according to Long COVID status (presence or absence of Long COVID), were produced using a different multilevel model. Finally, crude estimates of the prevalence of chronic conditions by Long COVID status were provided to examine for clustering of certain chronic conditions, and to profile the chronic disease pattern of patients with Long COVID.

1. World Health Organization (2022), *Post COVID-19 condition (Long COVID)*, https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition.

2. National Academies of Sciences Engineering and Medicine (2024), *A Long COVID definition: A chronic, systemic disease state with profound consequences*, https://nap.nationalacademies.org/read/27768/chapter/3#28.

3. United States Census Bureau (2023), *Phase 3.7 Household Pulse Survey*, https://www2.census.gov/programs-surveys/demo/technical-documentation/hhp/Phase_3-7_Household_Pulse_Survey_ENGLISH.pdf.

4. www.oecd.org/health/PaRIS.

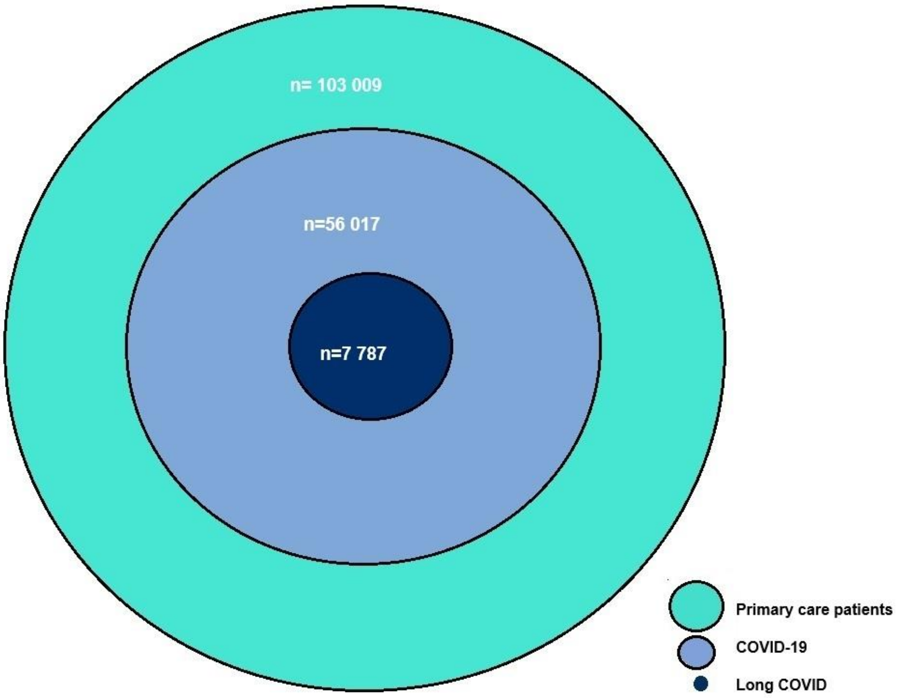
5. The resulting comparative interval is equivalent to 84% confidence interval, which widens the intervals slightly beyond traditional 95% confidence limits to account for multiple comparisons, so their overlap effectively implies no statistically significant difference at the 5% error level (Goldstein and Healy, 1995[8]).

2

The prevalence of Long COVID across OECD countries as measured by PaRIS

In 2023, approximately six out of ten primary care patients reported ever having COVID-19. In total, 107 011 primary care patients participated in the PaRIS survey in 2023, for which complete data were available for 103 000. Approximately 56 000 reported ever testing positive for or being diagnosed with COVID-19. Among these, approximately 7 800 reported having symptoms persisting beyond three months, consistent with a Long COVID diagnosis (see Figure 3). Those who did not report being diagnosed with COVID-19 were classified as not having Long COVID.

Figure 3. Primary care users surveyed by COVID-19 and Long COVID status



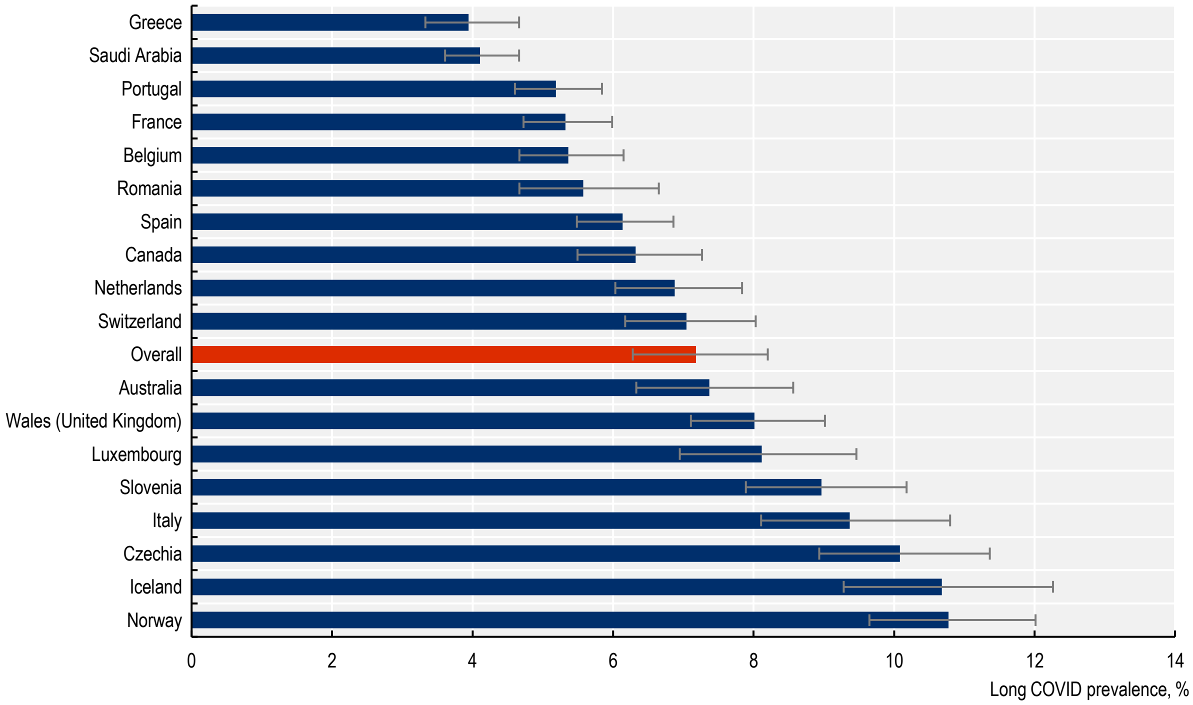
Note: Long COVID status refers to having ever had Long COVID.
Source: OECD PaRIS 2024 Database.

Approximately 7% of primary care patients surveyed in 2023 reported ever having Long COVID. Overall, among all the primary care patients surveyed, 54.4% reported having tested positive for or being diagnosed with COVID-19. Among those who had experienced COVID-19, 13.9% reported persistence of symptoms of Long COVID beyond 3 months (adjusted[1] estimate 13.9%, (CI 12.3-15.7)), and 6.5% reported persistent symptoms beyond 12 months. The overall Long COVID prevalence reported among primary care patients in the PaRIS survey was 7.6% (adjusted estimate 7.2% (CI 6.3-8.2)). Overall, in 2023, 5.6% (adjusted estimate 5.1% (CI 4.5-5.9)) reported persisting Long COVID symptoms, and 3.5% (adjusted estimate 3.2% (CI 2.8-3.8)) of primary care patients reported persistence of Long COVID beyond 12 months.

2.1. Long COVID prevalence in primary care varies from 4% to 11% across surveyed countries

The proportion of primary care patients reporting ever having COVID-19 ranged from 32.6% in Romania to 77.7% in Iceland. The proportion of COVID-19 infected patients who reported developing Long COVID ranged from 8.0% (CI 6.8-9.4) in Greece to 22.9% (CI 20.3-25.8) in Italy. Long COVID prevalence estimates among primary care patients ranged from 3.9% (CI 3.3-4.7) in Greece to 10.8% (CI 9.7-12.0) in Norway (see Figure 4). Patients who reported persistence of Long COVID symptoms beyond 12 months ranged from 1.7% (CI 1.3-2.1) in Greece to 4.5% (CI 3.7-5.3) in Iceland.

Figure 4. Estimated Long COVID prevalence in primary care patients in 2023



Note: Adjusted estimates using the multilevel model, with comparative intervals for the estimates indicated by the span of the bars in grey. No estimate was available for the United States as American PaRIS participants were not asked the questions related to Long COVID.
Source: OECD PaRIS 2024 Database.

2.2. The prevalence of Long COVID in primary care has long-term implications for population health and disease burden

In PaRIS, Long COVID is a frequent complication reported by on average 14% of patients with prior COVID-19 across OECD countries. This is a similar proportion to that reported in a cohort study of COVID-19 patients in the Netherlands (13%) in 2021 (Ballering et al., 2022[9]), in the United States in 2021/22 (14.6%) (Perlis et al., 2023[10]), and higher than in a UK cohort study in 2021 (5.4%) (Subramanian et al., 2022[4]).

The estimated prevalence of ever having had Long COVID of 7.2% in the primary care population represents a considerable disease burden, and is highly consistent with the 6.9% estimate from a the United States survey in 2023 (Fang, Ahrnsbrak and Rekito, 2024[11]; Adjaye-Gbewonyo et al., 2023[12]). Earlier studies from 2022 in France (4.0%) (Coste et al., 2023[13]), Germany (5.4%) (Diexer et al., 2024[14]), Scotland (6.6%) (Hastie et al., 2023[15]) and the United Kingdom (5.8%) (Whitaker et al., 2022[16]) reported estimates similar to the 5.6% with persisting Long COVID symptoms in the PaRIS survey.

2.3. Cross-country variation in reported Long COVID prevalence is likely related to awareness and recognition of the condition

The patient-reported prevalence of Long COVID among OECD countries varies by a 7 percentage point difference. This likely reflects variation in the epidemiology of COVID-19 incidence, different SARS-CoV-2 (the virus that causes COVID-19) variants across waves of the pandemic, and variation in COVID-19 vaccination uptake between countries. For example, the risk of Long COVID declined with subsequent waves of wild-type, alpha, delta and omicron variants of SARS-CoV-2 infections during the pandemic (Xie, Choi and Al-Aly, 2024[17]). Re-infection with SARS-CoV-2 and not being vaccinated against COVID-19 are associated with increased risk of Long COVID (Wang et al., 2025[18]).

Additionally, information bias linked to increased recognition and self-reporting of Long COVID symptoms likely also accounts for differences in reported prevalence between countries. Countries where patients are more aware of and healthcare professionals better at recognising Long COVID are more likely to self-report higher prevalence. Reporting a prior diagnosis of COVID-19 is a necessary component of the case definition of Long COVID, therefore international differences in testing for and awareness of COVID-19 also explain reported differences in Long COVID prevalence between countries (see Figure A.1 for correlation). The multilevel model overall prevalence estimate (7.2%) differed slightly from the crude overall prevalence estimate (7.6%). This difference may be attributed to the country level effect, the primary care provider effect, and the effect of age and sex standardisation. The observed variation in country-specific prevalences may account for most of this difference. A possible explanation is that the probability of self-reporting Long COVID symptoms is influenced by differences in the education level and awareness of Long COVID among primary care patients between different countries (see Table 1).

The persistence of symptoms beyond 12 months reported by 3.5% of primary care patients constitutes the potential long-term disease burden of the COVID-19 pandemic, supported by estimates that only 7-10% of Long COVID patients recover after two years of follow-up (Al-Aly et al., 2024[19]).

3 Sociodemographic differences in the prevalence of Long COVID

3.1. Long COVID is more common among younger (aged 45-54) and female patients, with a higher educational level and living with a chronic condition

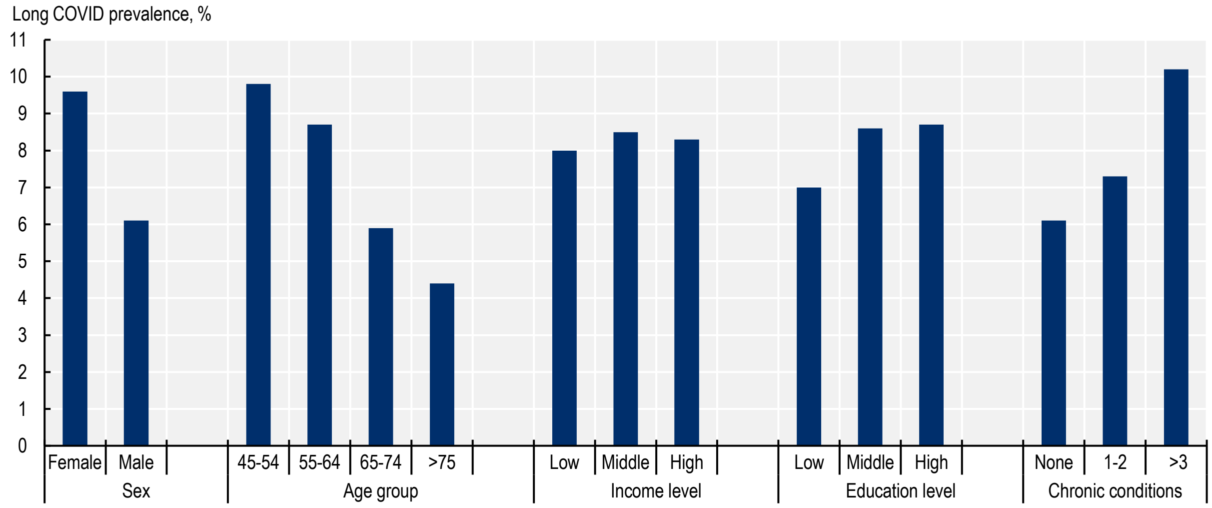
Long COVID prevalence was higher among females (10%), younger age groups (45-54 years) (10%), those with higher education (9%), and those having another chronic condition (8%) (see Figure 5). This is consistent with the published literature, where Long COVID is consistently more prevalent among females and younger patients (Diexer et al., 2024[14]; Subramanian et al., 2022[4]). The likely explanation for higher prevalence among younger patients aged 45-54 years is the increased risk of contracting COVID-19 in younger patients, who were more likely to survive COVID-19 and subsequently become at risk of developing Long COVID, compared to older patients who were likely to survive COVID-19 (survival bias).

In addition, older patients are more likely to have chronic conditions, and may attribute the relatively non-specific symptoms of fatigue, memory impairment and reduced concentration due to Long COVID to a pre-existing chronic condition, thus resulting in lower self-reported prevalence among older patients. Even in the absence of a chronic condition, 6% of primary care patients still report ever having Long COVID symptoms, underlining its high disease burden in the primary care population.

3.2. Patients with more chronic conditions report higher rates of Long COVID

Primary care patients without a chronic condition reported lowest prevalence of Long COVID (6%), which increased significantly with number of chronic conditions reported (see Figure 5). Long COVID prevalence also differed slightly according to education level. Patients with higher educational level were more likely to report testing positive for or being diagnosed with COVID-19 (64% versus 51%) compared to those with lower educational level, and thus more likely to fulfil the case definition for Long COVID.

Figure 5. A higher prevalence of Long COVID is reported among younger patients aged 45-54, those who are female, and living with more chronic conditions



Note: The differences in prevalence were statistically significant for sex, age group, education level, and number of chronic conditions (*p*<0.001).
Source: PaRIS 2024 Database.

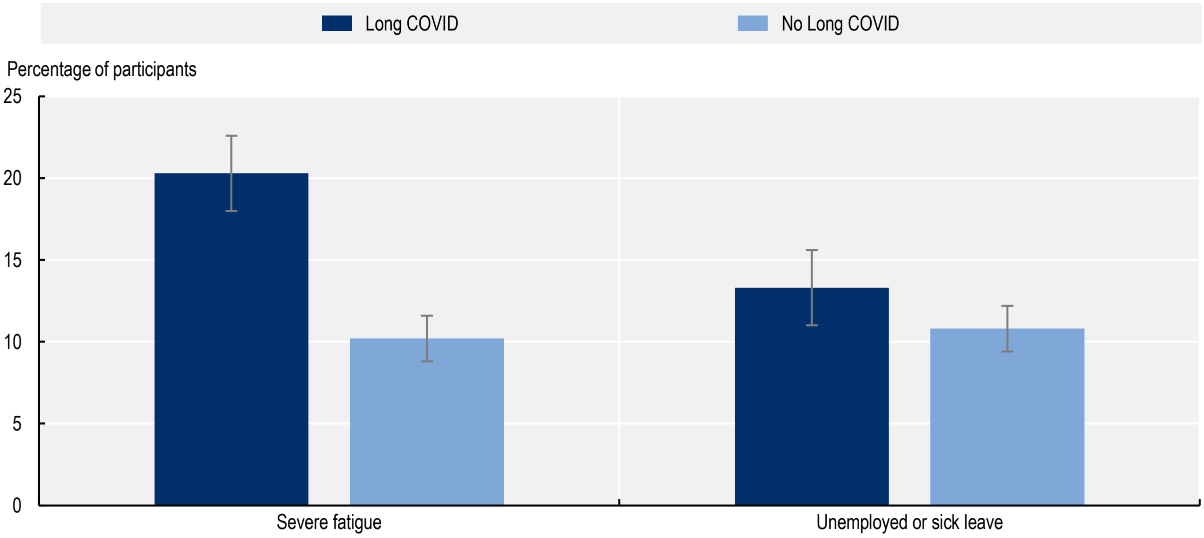
4 Patient reported health outcomes of Long COVID

4.1. Health and social outcomes are worse among patients with Long COVID

Compared to patients without Long COVID, those with Long COVID reported higher rates of severe fatigue (20% versus 10%). Those with Long COVID also reported higher rates of being on sick leave or unemployed and not looking for work (13% versus 11%), although the difference was not significant (see Figure 6).

Patients with Long COVID without another chronic condition reported lower rates of sick leave (3%) than those with 1-2 chronic conditions (9%) or more than 2 chronic conditions (26%) (see Table A.2). However, among patients who had the same number of chronic conditions, there was no difference in rates of sick leave between patients with Long COVID and those without Long COVID (see Table A.2). This may indicate that patients are more likely to be unemployed and not looking for work or on sick leave due to already living with chronic conditions, rather than because of Long COVID.

Figure 6. Patients with Long COVID report significantly higher rates of severe fatigue

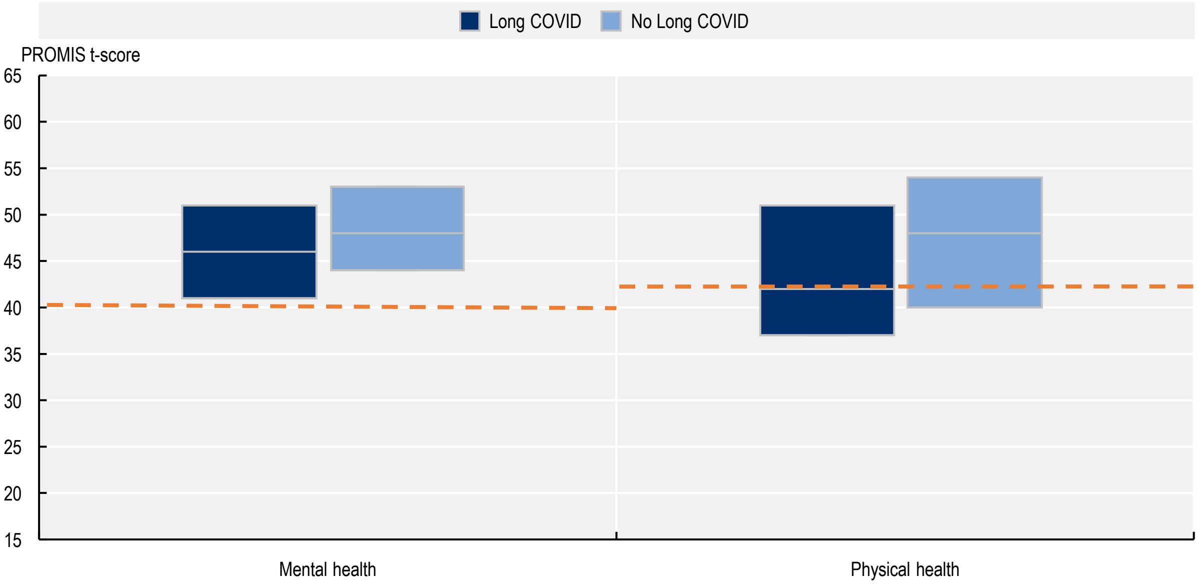


Source: OECD PaRIS 2024 Database.

Patients with Long COVID had significantly lower average (42 versus 48) self-rated physical health T-scores and a slightly lower average (46 versus 48) self-rated mental health T-scores, compared to patients without Long COVID (see Figure 7). The range and cut-off for T-scores are defined and explained in the notes of Figure 7.

A significantly lower percentage of patients with Long COVID (75%) self-rated their mental health as “good” compared to those without Long COVID (81%). The average physical health T-score for patients with Long COVID is classified as borderline “fair”, as opposed to “good” for those without Long COVID. A significantly lower percentage of patients with Long COVID (60%) self-rated their physical health as “good” compared to those without Long COVID (70%).

Figure 7. Distribution of self-rated physical and mental health T-scores by Long COVID status



Notes: PROMIS® Scale v1.2 – Global Health component for mental health is a T-score metric with a range of 21-68, and a good-fair cutoff of 40 (orange dashed line), higher values represent better mental health. For physical health the T-score metric has a range of 16-68, and a good-fair cutoff of 42 (orange dashed line). The boxplot displays the median, and upper and lower quartiles for the T-score.
Source: OECD PaRIS 2024 Database.

4.2. Severe fatigue is a major symptom of Long COVID, although this does not appear to affect workforce participation

Compared to those without Long COVID, patients with Long COVID reported significantly higher rates of severe fatigue and worse physical and mental health, regardless of the number of chronic conditions they have. A household survey of American participants in 2021/22 reported higher unemployment in patients living with Long COVID (12.3%) compared to those without (8.7%), and those living with Long COVID were 29% less likely to be working fulltime (Perlis et al., 2023[10]). However, analysis of PaRIS data shows that Long COVID does not result in significantly higher rates of reported unemployment or sick leave among primary care patients in the working age group, once number of chronic conditions are accounted for (see Table A.2). This suggests that while the impact of Long COVID on patients’ self-reported health is considerable, their participation in the workforce may be less impacted. This analysis was restricted to participants of working age, who did not report already being retired, and does not account for potential increases in presenteeism (where an employee attends work despite a medical illness that will prevent them from fully functioning) or reduced productivity or ability to work fulltime (Widera, Chang and Chen, 2010[20]), as a result of Long COVID in OECD economies.

5

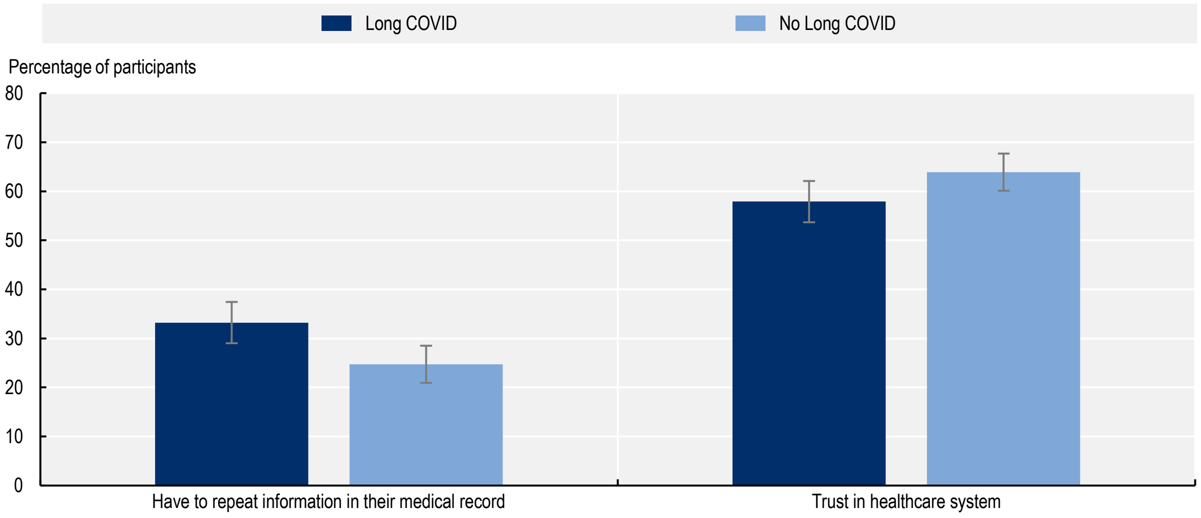
Patient reported experiences of Long COVID

5.1. Patients with Long COVID report worse experiences of healthcare and lower trust in the healthcare system

Good care co-ordination is an essential component of high-quality care, and the lack of co-ordination undermines trust in healthcare and healthcare professionals. Needing to repeat healthcare information that should be in a person's care record during a visit, for example, indicates poor care integration, inadequate data infrastructure, poor data capture processes, and poor capacity to facilitate care transitions. This is associated with lower levels of trust in the healthcare system (OECD, 2025[7]).

Patients with Long COVID report challenges navigating healthcare, in their interactions with healthcare providers and accessing specialist services (Baz et al., 2023[21]). They are also referred to a higher number of different specialists owing to the multisystemic impact of Long COVID, requiring multiple consultations (Turk et al., 2023[22]). Compared to patients without Long COVID, significantly more patients with Long COVID reported having to repeat information that should be in their medical records (33% versus 25%). A lower proportion of patients with Long COVID reported having trust in the healthcare system (58% versus 64%) compared to those without Long COVID (see Figure 8).

Figure 8. Patients with Long COVID report worse experiences of the healthcare system



Source: OECD PaRIS 2024 Database.

5.2. Poorer experiences of and lower trust in the healthcare system likely reflect challenges in diagnosis of and co-ordination of care for patients with Long COVID

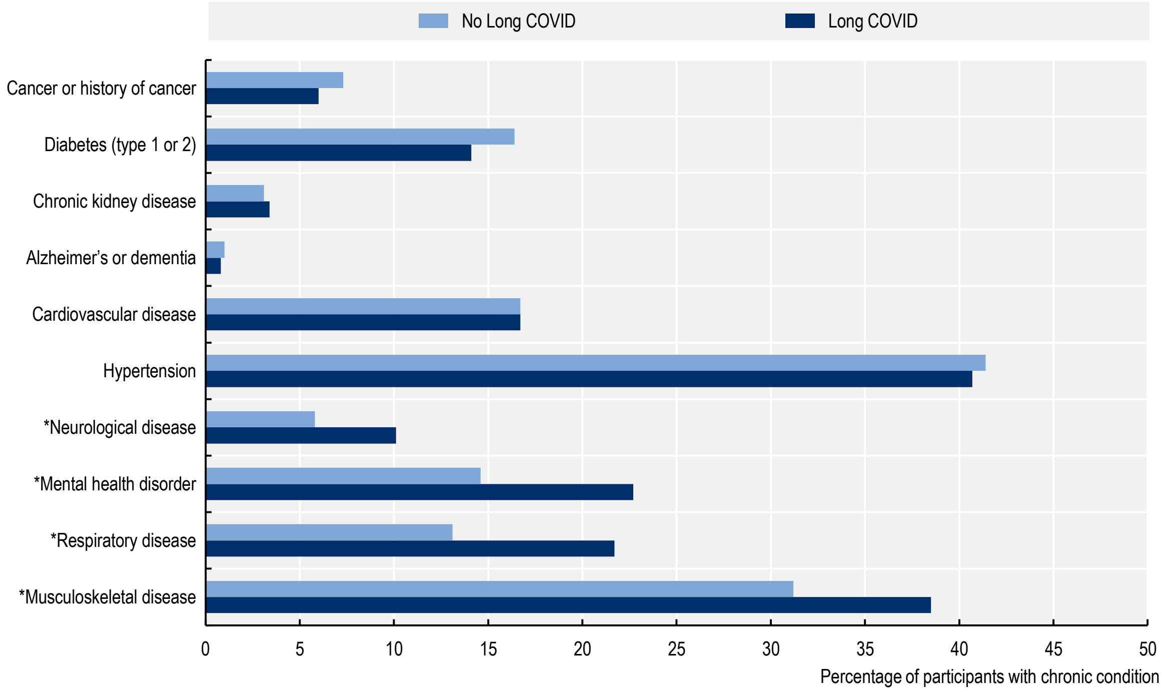
The reported lower levels of trust in the healthcare system, and the more frequent need to repeat information may reflect dissatisfaction with the healthcare provided for Long COVID. As a novel and evolving disease entity, standard definitions and care pathways for Long COVID care are still being developed and rolled out by countries. The majority of patients with Long COVID will present to primary care in their first consultation. However, the diagnosis may only be available or confirmed in specialised outpatient clinics, resulting in diagnostic delays. The symptoms are also highly variable, involving different systems and thus the need to consult different medical specialties (e.g. musculoskeletal, respiratory and neurological) for management. A lack of co-ordinated and integrated primary and secondary care for Long COVID likely explains the need to repeat information and lower trust in healthcare reported by patients. Better training and education on Long COVID for healthcare professionals in primary and specialist care could help improve recognition of symptoms of Long COVID, and deliver a timely diagnosis to patients.

6 Chronic disease profile of patients with Long COVID

6.1. Clustering of chronic conditions identifies the main clinical subtypes of Long COVID

Four chronic conditions are more common in patients with Long COVID. Patients with Long COVID reported significantly higher rates of musculoskeletal, respiratory, neurological, and mental health conditions specifically, compared to those without Long COVID (see Figure 9). The rates of respiratory (22% versus 13%) and neurological (10% versus 6%) disease in patients with Long COVID are almost double those reported by those without Long COVID. Conversely, patients with Long COVID had significantly lower rates of diabetes and cancer. There was no significant difference in rates of hypertension, cardiovascular disease, dementia or kidney disease, according to Long COVID status. When analysed separately by gender, higher rates of the same chronic conditions were reported by both genders.

Figure 9. Long COVID patients have higher prevalence of musculoskeletal, respiratory, neurological and mental health disorders



Note: * indicates chronic conditions with a statistically significant higher prevalence among Long COVID patients.
Source: OECD PaRIS 2024 Database.

People may be more susceptible to certain subtypes of Long COVID if they have pre-existing chronic conditions (Wang et al., 2025[18]). The higher prevalence of musculoskeletal, respiratory and neurological disease among Long COVID patients is consistent with findings reported in the medical literature (Canas et al., 2023[23]; Subramanian et al., 2022[4]). These chronic conditions over-represented in patients with Long COVID likely reflect symptom clustering into the three main subtypes of Long COVID: cardiorespiratory syndrome, neurocognitive syndrome, and musculoskeletal inflammatory syndrome (Kenny et al., 2022[24]; Deer et al., 2021[25]; Wang et al., 2025[18]). Clustering likely represents pre-existing chronic conditions that increase the risk of developing Long COVID subtypes, as well as the multiple manifestations of Long COVID affecting different organ systems.

Box 3. Contributions and limitations of PaRIS to the evidence on Long COVID

The PaRIS survey recruited only participants who had a primary care consultation in the previous six months. This may exclude certain subpopulations who lack access to, who consult very infrequently, or who bypass primary care for other healthcare providers. Thus, reported Long COVID prevalence and outcomes are not representative of the general population, but rather of the typical primary care population. Depending on the OECD country, this representativity is likely to vary with coverage and utilisation of primary care. The survey population excludes patients aged under 45 and so does not assess Long COVID in the younger population. If prevalence changes with younger age, then the overall prevalence in the primary care population surveyed may be an under or overestimate. Long COVID status is based on patient-reported symptoms, without confirmation from medical records, and may be subject to information biases.

Due to the cross-sectional study design, it is not possible to estimate risk of Long COVID, but instead the prevalence of those who have ever had, or currently have, persisting symptoms in 2023 among people who visited primary care services. On the contrary, the assessment of other symptoms and health outcomes, such as severe fatigue, self-rated physical and mental health, and trust in healthcare are assessed at the time of survey completion. As a result, any associations with health outcomes and experiences such as these may not necessarily overlap with the time in which a person had Long COVID. Thus, causality from Long COVID cannot be established, merely association.

The findings reported by PaRIS are coherent with the findings in the published medical literature on Long COVID prevalence and risk factors. The large study population of 103 000 patients provides statistically robust international estimates, and the multicentre study design and multilevel model limit the effect of selection bias due to the effect of the country and primary care providers sampled. The multi-country survey provides updated international Long COVID prevalence estimates in the primary care population in 2023, accounting for new SARS-CoV-2 infections and thus new Long COVID cases, across 16 OECD countries worldwide. The findings highlight the considerable disease burden due to Long COVID consistently reported across OECD countries, allowing for international comparison.

7

Considerations for health policy

Long COVID constitutes a considerable disease burden for patients, which affects approximately 7% of the primary care population in the PaRIS survey. Its negative health impacts of severe fatigue and poorer physical and mental health are significant for patients living with Long COVID. While its impact on social functioning does not appear associated with reduced workforce participation as measured by the survey, this may mask short-term impacts on employment and sick leave and long-term impact on productivity. The persistence of Long COVID symptoms beyond 12 months affects approximately 3% of primary care patients, which represents a long-term disease burden.

Patients with Long COVID report worse healthcare experiences, likely resulting from a lack of co-ordinated care for Long COVID and having to consult repeatedly or consult multiple specialties. Investing in training and education on Long COVID for healthcare professionals should improve recognition of Long COVID symptoms and timeliness of diagnosis for patients. Not having a single healthcare provider to consult for most of healthcare problems is associated with 10 percentage points lower trust in the healthcare system in the PaRIS survey (OECD, 2025[7]). This underlines the urgent need for integrated and standardised care pathways to detect, diagnose and manage patients living with Long COVID in order to reduce their medico-administrative burden, improve the co-ordination and quality of care delivered, and address the health impacts of this prevalent condition (Al-Aly et al., 2023[26]).

The long-term socio-economic costs of Long COVID are difficult to estimate owing to uncertainties on the impact on workforce participation and the duration of symptoms. Continued surveillance and follow-up of this patient cohort is required to monitor trends in prevalence and recovery from Long COVID, to better plan for the associated disease burden for patients and healthcare systems in OECD countries.

Annex A. Supplementary figure and tables

Table A.1. Prevalence of Long COVID by sociodemographic profile, stratified by number of chronic conditions

	None			1-2			≥ 3		
	No Long COVID N = 18 675	Long COVID N = 1 233	p-value	No Long COVID N = 53 722	Long COVID N = 4 304	p-value	No Long COVID N = 24 703	Long COVID N = 2 855	p-value*
Sex			<0.001			<0.001			<0.001
Female	10 519 (92%)	867 (7.6%)		27 542 (91%)	2 778 (9.2%)		13 051 (87%)	1 897 (13%)	
Male	7 238 (95%)	347 (4.6%)		23 736 (94%)	1 476 (5.9%)		10 643 (92%)	922 (8.0%)	
Age group			<0.001			<0.001			<0.001
45-54	8 065 (92%)	673 (7.7%)		14 357 (90%)	1 638 (10%)		4 300 (85%)	764 (15%)	
55-64	5 719 (94%)	383 (6.3%)		16 092 (92%)	1 474 (8.4%)		6 861 (88%)	978 (12%)	
65-74	3 388 (96%)	133 (3.8%)		14 427 (95%)	831 (5.4%)		7 192 (91%)	703 (8.9%)	
≥75	1 429 (97%)	42 (2.9%)		8 579 (96%)	351 (3.9%)		6 226 (94%)	400 (6.0%)	

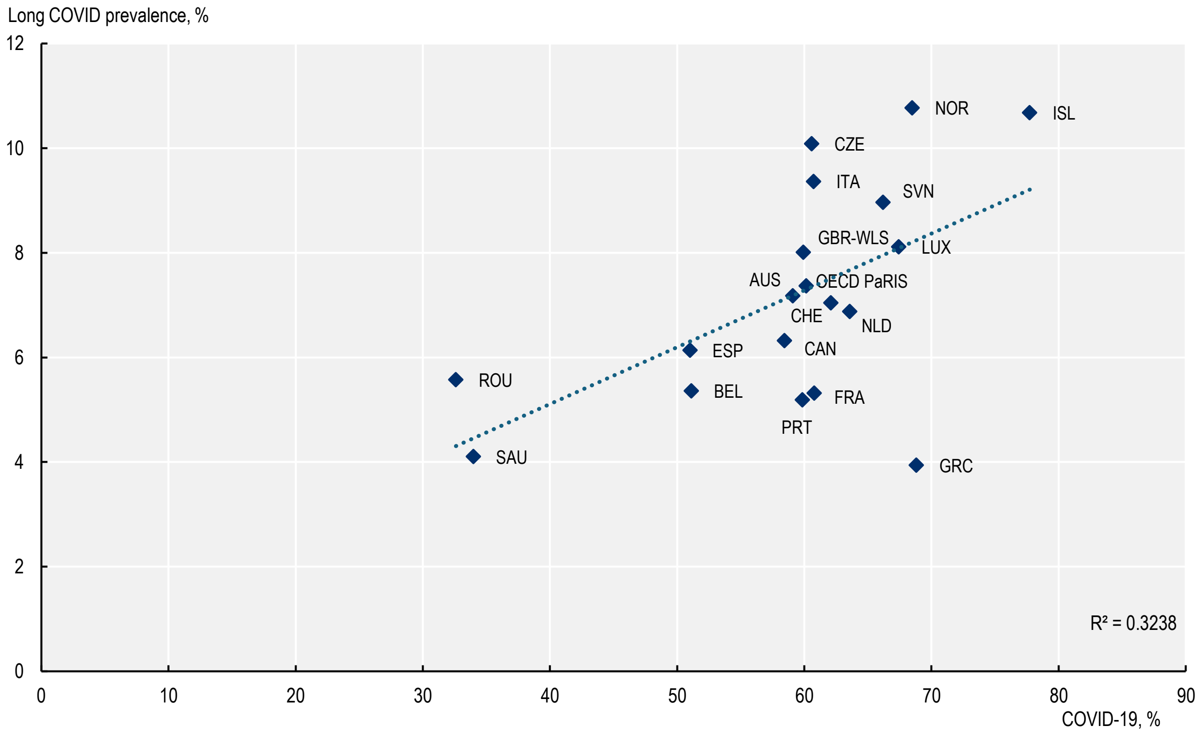
Source: OECD PaRIS 2024 Database.

Table A.2. Health and social outcomes according to Long COVID status, stratified by number of chronic conditions

	No Chronic condition					1-2 Chronic conditions					≥ 3 Chronic conditions				
	No Long COVID N = 18 675		Long COVID N = 1 233		p-value	No Long COVID N = 53 722		Long COVID N = 4 304		p-value	No Long COVID N = 24 703		Long COVID N = 2 855		p-value*
Unemployed or on sick leave	n	%	n	%	0.6	n	%	n	%	0.7	n	%	n	%	0.2
No	12 160	97%	968	97%		24 895	91%	2 676	91%		7 745	75%	1 236	74%	
Yes	317	2.5%	28	2.8%		2 418	8.9%	253	8.6%		2 542	25%	441	26%	
Severe fatigue					<0.001					<0.001					<0.001
No	17 652	95%	1 094	89%		48 652	91%	3 556	83%		19 115	78%	1 795	63%	
Yes	939	5.1%	139	11%		4 938	9.2%	736	17%		5 504	22%	1 056	37%	
Trust system					<0.001					<0.001					<0.001
No	5 930	33%	492	41%		16 900	33%	1 694	40%		7 992	34%	1 206	43%	
Yes	11 853	67%	722	59%		34 551	67%	2 552	60%		15 739	66%	1 612	57%	
Having to repeat information					<0.001					<0.001					<0.001
No	13 113	80%	818	74%		35 800	75%	2 642	67%		14 489	66%	1 491	57%	
Yes	3 205	20%	290	26%		12 117	25%	1 316	33%		7 522	34%	1 115	43%	

Source: OECD PaRIS 2024 Database.

Figure A.1. The correlation between reporting ever having COVID-19 and the prevalence of Long COVID is likely linked to testing and diagnosis of COVID-19 and awareness of Long COVID in different OECD PaRIS countries



Source: OECD PaRIS 2024 Database.

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Notes

[1] Estimates adjusted by age, gender and country variation using the multilevel model.