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The impacts of long COVID across OECD countries

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Abstract

Even as countries have long emerged from the dramatic restrictions imposed on populations during the height of the COVID-19 pandemic, an important subset of people infected with COVID-19 continue to struggle with symptoms, in some cases debilitating, that persist for weeks or even months after their initial infection. The analysis in this paper looks at the burden of long COVID across OECD countries. It examines its implications for the health of individuals and how long COVID may impact productivity and the labour force, as well as what countries are doing to address the condition. It further identifies priorities for improving care for people living with long COVID.

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Key findings

1. While a precise estimate of long COVID prevalence is still emerging, current research suggests that up to **10-30% of people who contracted COVID-19 exhibit symptoms** corresponding to long COVID in the weeks and months following acute infection. Across OECD countries at a minimum, this would represent upwards of **39 million people** who had or are currently living with long COVID. Sustainable investment in long COVID research is crucial to inform health and social care resource allocation. As the evidence base grows, **developing standardised measures of symptoms and functional impact** to support **a more precise definition** that enables the disaggregation of levels of long COVID severity could be useful to better understand the condition, assess its impact, and to tailor care and support.
2. **Standardised definition and surveillance systems remain critical challenges** in better understanding long COVID: Four countries responding to the 2022 OECD Long COVID Health Systems Survey reported that they had national estimates of long COVID prevalence in their country. While most countries had adopted definitions of long COVID that were broadly in line with WHO and NICE guidelines, important differences still emerged in how countries interpreted the condition. A more systematic and consistent definition and uptake of long COVID coding, aligned to evidence-based standardised measures reflecting symptom severity and duration, is needed to support the development of standardised surveillance infrastructure and facilitate the comparative epidemiological assessment of long COVID across OECD countries.
3. **Long COVID can severely limit people's ability to undertake basic activities of daily life** and can dramatically hamper quality of life. **More than 7 million quality-adjusted life years** may be lost annually across OECD countries due to the condition. Studies from across a range of OECD countries suggest that **one sixth to more than one-third** of people may have persistent cognitive symptoms, often lasting more than 12 weeks, after a COVID-19 infection.
4. Even conservative estimates of long COVID prevalence would indicate that long COVID may be **reducing the workforce by nearly 3 million workers** across OECD countries, amounting to an **economic cost of at least \$141 billion USD** from lost wages alone. Moreover, even among those who were able to return to the labour force, a significant proportion reported needing to reduce the number of hours they worked, compared to before their infection.
5. **The economic and social welfare costs of long COVID are dramatic:** Even excluding the direct costs of health care, long COVID is **likely costing OECD countries as much as \$864 billion - \$1.04 trillion USD per year due to reductions in quality of life and labour force participation**. The limitations in activities experienced by long COVID patients, including dropping out or reducing their participation in the labour force, as well as direct medical care costs, can have dramatic implications on their financial well-being. Costs to health and social protection systems may also be high over time.
6. **Long COVID could further exacerbate inequalities:** The COVID-19 pandemic brought attention to longstanding socioeconomic and demographic inequalities in health. Evidence from some countries suggests that certain groups – including populations with lower education attainment, and those living in more deprived areas – may be at risk of developing long COVID, and of experiencing more severe symptoms.

7. **Patients have played a critical role in bringing attention and action to long COVID:** Throughout the pandemic, countries deprioritized many key aspects of person-centred care in exchange for rapidly implementing policies intended to contain the virus. While the need for rapid action was clear, the lack of patient voice in the process was notable. In contrast, patients and patient groups have been at the forefront of advocating for both a recognition of long COVID as a legitimate condition, in articulating their care and support needs, and in spearheading research into the condition. In many cases, countries have responded by actively working together with patient groups to disseminate information and develop patient-centred support services.
8. In many countries **primary care has played a key role in the care pathway for people living with long COVID.** Many people with long COVID can be supported in primary care, though specialist services and dedicated long COVID clinics have been necessary to care for people living with more debilitating symptoms or complex needs. **At least 22 OECD countries have set up dedicated long COVID clinics.** Nevertheless, demand for long COVID services such as multidisciplinary clinics appears to exceed available supply, with long waiting times reported in some countries.
9. Long COVID is not the first chronic condition faced by countries, and the care and support for people living with long COVID should **draw on lessons learned** in developing approaches to care for other chronic conditions and post-viral syndromes, such as myalgic encephalomyelitis (also known as chronic fatigue syndrome (ME/CFS)). Similarly, policymakers should actively consider how and what lessons might be drawn from their experience scaling up the response to long COVID to allocate resources and implement sustainable care pathways for such conditions.
10. Countries must adopt a **multi-sectoral response** to long COVID, taking into account its implications not only for health but also for broader well-being and labour force participation. Policies that help to cushion the financial impact of long COVID are critical, including to prevent the condition from further exacerbating inequalities.

1 Towards a common understanding of long COVID

There is no single consensus definition of long COVID, though most countries broadly adhere to international guidance

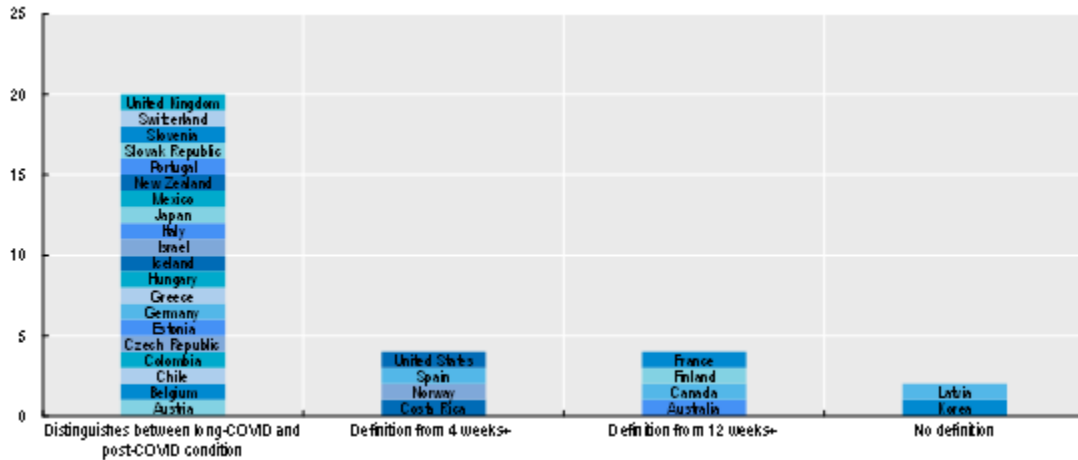
11. Over four years into the pandemic, long COVID remains poorly understood, with a lack of consensus around its specific definition and aetiology often posing a barrier to effective diagnosis, treatment and care for those living with the condition. Even though definitions will evolve as more evidence on long COVID becomes available, consensus on an evidence-based definition is necessary to inform development of clinical pathways, surveillance systems (including coding) and comparable research.

12. A clinical case definition of long COVID, also known as post-COVID condition, was published by WHO in October 2021 – two years after COVID-19 first emerged – following a Delphi consensus (WHO, 2021^[11]). Reflecting the complexity of long COVID, even this definition acknowledges a wide variation on the time frame of symptom occurrence, the wide array of signs and symptoms presented by patients and the possibility for symptoms to fluctuate over the course of the condition (Soriano et al., 2022^[2]). More recently, a separate definition of long COVID has been developed to apply to children and adolescents, reflecting the different needs of this population. (World Health Organization, 2023^[3]).

13. The WHO defines long COVID as “a set of signs and symptoms that usually present within three months following SARS-CoV-2 infection and last for at least two months, in the absence of an alternative diagnosis” (Soriano et al., 2022^[2]; WHO, 2021^[11]). This definition has received some criticism from researchers who felt that the list of signs and symptoms for diagnosis was too vague, the time frame too strict, and the lack of a laboratory confirmation of SARS-CoV-2 for diagnosis problematic (Villar et al., 2022^[4]). Nonetheless, most countries have adopted definitions that are broadly in line with the description of symptoms and time frame identified by the World Health Organization.

14. In the United Kingdom, the National Institute for Health Care and Excellence developed a definition for COVID-19 that classifies the virus into four categories. Ongoing symptomatic COVID-19 is identified when symptoms last from four weeks to 12 weeks; post-COVID-19 syndrome when signs and symptoms last longer than 12 weeks; and long COVID when symptoms persist for more than four weeks, including both ongoing symptomatic COVID-19 and post-COVID-19 syndrome (National Institute for Health and Care Excellence (NICE), 2022^[5]).

Figure 1.1. Most countries have defined long COVID, but time frames differ



Note: Some countries may have updated their definitions since the time of this survey. In the chart above, 'long COVID' refers to symptoms that persist more than 4 weeks after initial infection, and post-COVID condition refers to symptoms persisting more than 12 weeks after initial infection. Some countries use different terminology. Iceland's definition categorizes post-COVID infections from 3 weeks after acute infection, instead of 4, and chronic COVID from 12 weeks. For further details on how countries define long COVID, please see Annex I.

Source: 2022 OECD Long COVID Health Systems Survey; national sources (OECD, 2022^[6]).

15. Across OECD countries, at least 33 countries have developed a definition characterising long COVID. The majority of countries have either adopted WHO or NICE definitions or are broadly in line with them. Most countries distinguish between acute, ongoing, and longer-term phase of COVID-19 based on the time since infection, with infections frequently broken into phases: the initial acute infection, symptoms continuing or developing more than four weeks after an infection, symptoms that develop or continue between four and 12 weeks after infection, and symptoms that emerge or persist three months (12 weeks) after an initial infection.

Box 1.1. The use of the term 'long COVID' in this working paper

For the purposes of this paper, the term 'long COVID' is used to refer to the collection of symptoms that develop or persist for over four weeks following the onset of a COVID-19 infection. This paper does not take one definition of long COVID, but rather uses the term to as an umbrella that encompasses the differences across how countries currently define post-acute COVID-19 syndrome in order to be as inclusive as possible and avoid excluding country experiences and policies due to definitional differences.

The use of this term is not intended to comport with the precise definitions of the condition adopted by individual countries, or developed through international efforts. It instead reflects the evolving understanding of the condition and the reality that not all countries have adopted the same definition. Moreover, the use of the term 'long COVID' has been widely adopted among patients, the general public, and even the academic literature to refer to the spectrum of conditions encompassing ongoing symptoms following an initial acute COVID-19 infection (Davis et al., 2023^[7]).

Long COVID likely already impacts tens of millions of people in OECD countries

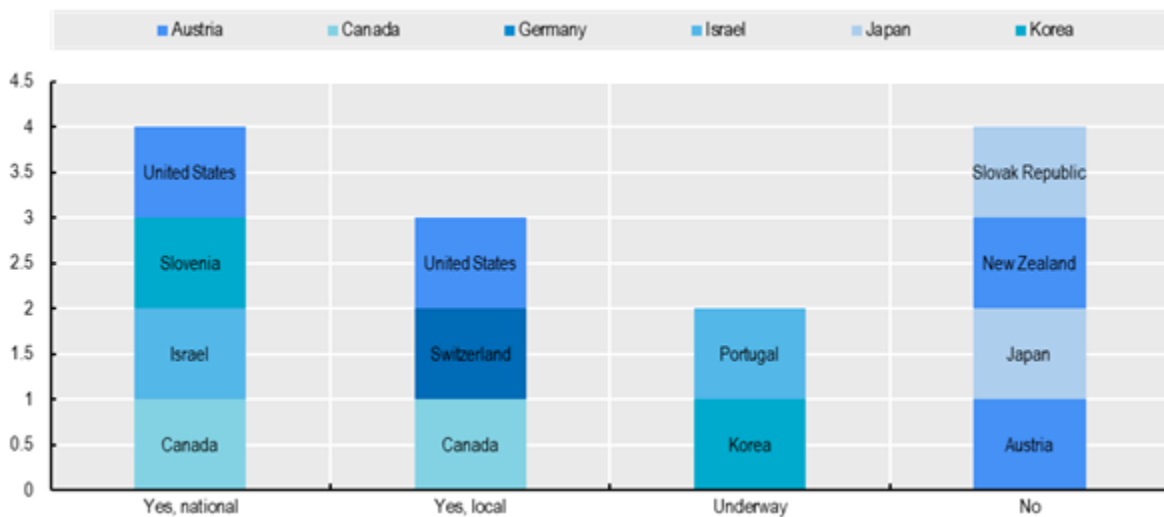
16. Since the first SARS-Cov-2 infection cases were identified in the Wuhan province in China in November 2019, COVID-19 has caused more than around 500 million infections and over 6 million deaths worldwide (WHO, 2022^[8]). As the pandemic progressed and countries put in place policies and mechanisms to cope with the unprecedented crisis, accounts from patients and healthcare practitioners that some people may have lingering symptoms lasting for weeks or months following the acute infection gave rise to concerns that COVID-19 may have even longer-lasting effects than was initially understood.

17. A lack of agreement on the definition of long COVID, a lack of national estimates and the use of differing research approaches in studying long COVID has meant that the prevalence of long COVID has been difficult to establish precisely. Many studies focus on subsets of COVID-19 patients, such as using data from hospitalised patients, or patients who were in intensive care (Ledford, 2022^[9]; Ziauddeen et al., 2022^[10]). Patients who were hospitalised or otherwise suffered severe cases of COVID-19 may differ from the general population in their propensity to develop COVID-19, limiting the generalizability of findings from these studies. Prevalence estimates from published literature vary widely, with estimates of long COVID prevalence for non-hospitalised patients ranging from 7% to 42%, and for hospitalised patients from 3% to well over half of patients, depending on how long COVID is defined (Taquet et al., 2021^[11]; Wolf and Erdös, 2021^[12]; Nittas et al., 2022^[13]; Ziauddeen et al., 2022^[10]).

18. Responses from the 2022 OECD Long COVID Health Systems Survey demonstrated that very few countries have undertaken national surveillance or surveys to estimate the prevalence of long COVID on the national level (Figure 1.2).

Figure 1.2. Few countries are able to estimate long COVID prevalence at the national level

Countries responding the availability of national and local prevalence estimates for long COVID



Source: 2022 OECD Long COVID Health Systems Survey (OECD, 2022^[6]).

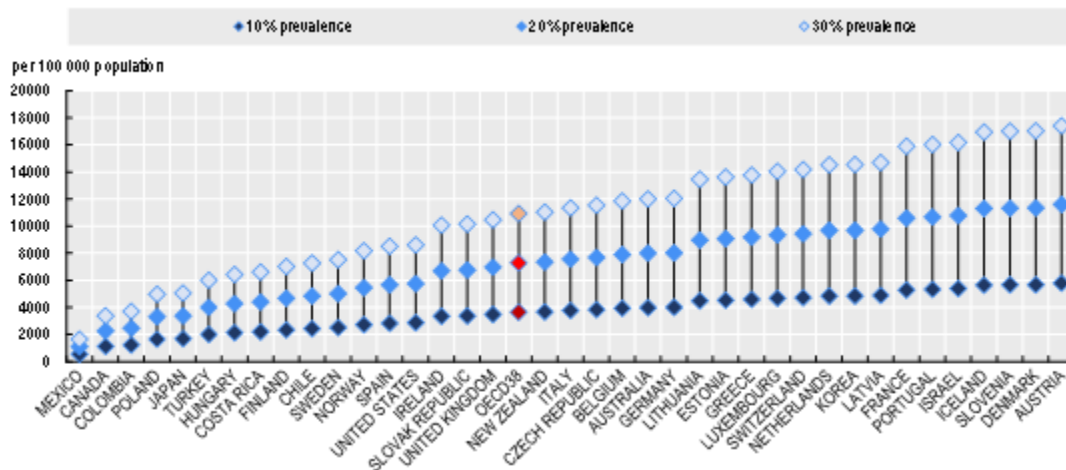
19. Four of sixteen responding countries (Canada, Israel, Slovenia and the United States) reported having national estimates of long COVID prevalence. In the United States, three in ten adults (29.6%) who reported that they had been infected with COVID-19 had experienced symptoms of long COVID at some point following their infection, including 15% who reported that they were experiencing symptoms of long

COVID at the time they were surveyed in October 2022 (U.S. Census Bureau, 2023^[14]). In Canada, 14.8% of adults who had tested positive for COVID-19 or had a suspected case of COVID-19 reported experiencing symptoms for at least three months (Public Health Agency of Canada, 2022^[15]). Of these, nearly half (47.3%) reported that their symptoms persisted for at least a year (Public Health Agency of Canada, 2022^[15]). In Slovenia, consecutive panel surveys indicated that between 44.2% and 51.5% of adults who had been infected with COVID-19 exhibited symptoms of long COVID at least three months after their infection (OECD, 2022^[6]). In Israel, more than half (53.6%) of adults aged 21 or over who had been infected with COVID-19 had at least one symptom of long COVID three to six months after their acute infection, compared to three in ten (29.3%) among the control group who had not been infected (OECD, 2022^[6]) and in Poland, 70.7% of patients from the STOP COVID registry had at least one symptom three months after acute infection (Chudzik et al., 2022^[16]).

20. While establishing a precise prevalence estimate is difficult, a number of researchers have suggested that, based on available evidence, roughly 10-30% of COVID-19 patients could be expected to demonstrate prolonged symptoms 12 weeks after the onset of their infection (Greenhalgh et al., 2020^[17]; Castanares, Hanquet and van den Heede, 2021^[18]; Davis et al., 2021^[19]; Logue et al., 2021^[20]; Pavli, Theodoridou and Maltezou, 2021^[21]; University of Oxford, 2021^[22]; Phetsouphanh et al., 2022^[23]). These estimates align with recent data from WHO Europe and IHME, which estimated that 10-20% of people develop symptoms of long COVID following an infection (WHO/IHME, 2022^[24]).

21. Using 10% and 30% as an estimate of the possible range of long COVID prevalence and data from WHO on confirmed COVID-19 cases by country, an estimated 39 to 117 million people across OECD countries may have experienced or are currently living with long COVID.

Figure 1.3. Long COVID prevalence is likely high across most OECD countries



Source: Author’s calculations, modelled using data on cumulative number of COVID-19 cases per 100,000 population from World Health Organization Coronavirus Monitoring Dashboard (2022) and OECD Health Statistics (2022) (WHO, 2022^[18]; OECD, 2022^[25]).

Box 1.2. What are the symptoms of long COVID, and why does it occur?

In general, the most frequent signs and symptoms as reported in the literature can be classified according to the organ or systems affected, including:

- Neurological: Cognitive and memory impairment, e.g., brain fog; poor concentration, confusion, light-headedness; sleep disorders; ageusia; anosmia; headache; autonomic nervous system dysfunction, e.g., numbness in fingers, heat or cold intolerance, increased sensitivity to sound and light;
- Gastrointestinal: Diarrhoea, constipation, vomiting, abdominal pain;
- Cardiovascular: Chest pain, palpitations, postural tachycardia, orthostatic hypotension;
- Respiratory and ENT: Dyspnoea, cough, sputum production, rhinitis, sore throat, wheeze, hoarse voice;
- Musculoskeletal: Arthralgia, myalgia, post exertional malaise, muscle weakness;
- Other signs and symptoms: Fever, functional impairment, distress, fatigue or exhaustion, anorexia, dizziness, anxiety and depression.
- Source: (Cabrera Martimbianco et al., 2021^[26]; Fernández-de-las-Peñas et al., 2021^[27]; Michelen et al., 2021^[28]; Nurek et al., 2021^[29]; Salamanna et al., 2021^[30]; Sundar Shrestha and Love, 2021^[31]; Soriano et al., 2022^[2]; Ballering et al., 2022^[32])

Understanding the mechanisms underlying long COVID is currently a subject of active research. Several hypotheses have been proposed. For example, it is suggested that during acute infection SARS-CoV-2 enters the cells through ACE2-receptors, triggering a coagulation cascade and the formation of microthrombi, which are believed to cause some of the symptoms observed (Nalbandian et al., 2021^[33]; Vallée, 2021^[34]; Galea, Agius and Vassallo, 2022^[35]). Another prominent hypothesis, based on the observation of persistent inflammation in long COVID patients, is that long COVID symptoms may result from viral reservoirs that persist in certain sites in the body for long periods after the initial infection (Peluso et al., 2024^[36]). Moreover, the deconditioning due to prolonged bed rest, hypoxia and hypovolemia caused by the infection; the oxidative stress and cytokines storm caused by persistent inflammation, autoimmunity and latent reactivation of other pathogens are potential mechanisms that could contribute to COVID-19 long-term complications (Komaroff and Lipkin, 2021^[37]; Larsen, Stiles and Miglis, 2021^[38]; Silva-Hernández et al., 2021^[39]; Ståhlberg et al., 2021^[40]; Buoite Stella et al., 2021^[41]; Dotan et al., 2022^[42]; Davis et al., 2023^[7]; Mantovani et al., 2022^[43]).

There is also active research to attempt to classify long COVID patients according to clusters of symptoms that may have common underlying pathophysiology, which may point towards a more individualised treatment pathway for each cluster of patients (The Consortium for Characterization of COVID-19 by EHR (4CE), 2021^[44]; Liu et al., 2021^[45]; Azzolini et al., 2022^[46]; Ziauddeen et al., 2022^[10]).

22. Researchers are still working to identify what may increase the likelihood of a COVID-19 patient developing long COVID. Current research suggests that certain demographic, socioeconomic, health status and lifestyle factors may influence the risk of long COVID, including female sex, middle age, lower socioeconomic status, smoking, high body-mass index and the presence of comorbidities (Ledford, 2022^[9]; Cabrera Martimbianco et al., 2021^[26]; Liu et al., 2021^[45]; Michelen et al., 2021^[28]; Ziauddeen et al., 2022^[10]; Azzolini et al., 2022^[46]; Antonelli et al., 2022^[47]; Al-Aly, Bowe and Xie, 2022^[48]; Subramanian et al., 2022^[49]; U.S. Census Bureau, 2023^[14]) (Whitaker et al., 2022^[50]).

23. The risk of developing long COVID has also been associated with actions and outcomes related to COVID itself, including a lower risk of long COVID following COVID-19 vaccination and a higher risk of long COVID with certain virus variants and after a severe initial infection, including cases where patients

were hospitalised or required supplemental oxygen (Cabrera Martimbianco et al., 2021^[26]; Liu et al., 2021^[45]; Michelen et al., 2021^[28]; Skyrud, Telle and Magnusson, 2021^[51]; Al-Aly, Bowe and Xie, 2022^[48]; Antonelli et al., 2022^[47]; Subramanian et al., 2022^[49]; Ayoubkhani et al., 2022^[52]; Azzolini et al., 2022^[46]; Ledford, 2022^[9]). Recent evidence also points out the role of genetic polymorphism, such as the expression of APOE4, in the development of long COVID (Ballouz et al., 2023^[53]).

Coding standards for long COVID have been adopted, but implementation varies

24. The assessment of the health, social and economic burden caused by long COVID in OECD countries remains hampered by a lack of comparable data. Better data on the burden of long COVID requires the development, dissemination and use of clinical guidelines on disease diagnosis and management, as well as an adequate reporting infrastructure that systematically employs standardised diagnostic codes to track the condition (Iqbal et al., 2021^[54]; Expert Panel on effective ways of investing in health (EXPH), 2022^[55]; Kluge et al., 2022^[56]).

25. To improve data on the condition, an International Classification of Diseases (ICD) code for long COVID was published in October 2021. The code (U09.9) is intended to capture “post-COVID 19 condition, unspecified,” as a means to connect persisting or emerging symptoms with a previous COVID-19 infection. Countries including **Austria, Canada, Germany, Israel, Japan, the Netherlands, Poland, Slovak Republic**, and the **United States** report using the long COVID ICD code (OECD, 2022^[6]). Other ICD codes used to capture long COVID include U08.9 (Personal history of COVID-19, unspecified) and U10.9 (Multisystem inflammatory syndrome associated with COVID-19, unspecified) (Rajan et al., 2021^[57]).

26. Despite the development of an ICD code to capture long COVID, its use is not systematic. In Austria, for example, coding for long COVID is done systematically in hospitals, but not in most outpatient settings. Moreover, differing definitions of long COVID may complicate the comparability of data. A study conducted in the United States, for example, found the median number of days between an acute COVID-19 infection and the use of the long COVID code to be 56 days – past the 4 week definition of ‘long COVID’ in the United States, but well under the 12-week threshold used by many countries to define post COVID condition (McGrath et al., 2022^[58]). In a study that included nearly 27 000 patients with documented cases of long COVID using data from the VA’s electronic health records system in the United States, very few patients – less than 4% - had the ICD post COVID condition code U09.9 included in their records (Ioannou et al., 2022^[59]).

2 Long COVID has been associated with substantial impacts on well-being

Many people living with long COVID will have physical and mental health consequences that persist well beyond twelve weeks and leads to increased health care demands

27. As seen, a growing body of evidence suggests that for many people, the impacts of a COVID-19 infection will persist long beyond the initial infection or even the minimum threshold for being considered to have long COVID. Recent analyses have suggested that even relatively mild COVID-19 infections can have long-term, damaging consequences for health, including cardiovascular, respiratory and neurological complications. For example, studies using data from the US Veterans Affairs health system found that people with a COVID-19 infection were at increased risk of a range of cardiovascular events and conditions one year on, including stroke and heart failure, as well as at higher risk of developing diabetes (Xie et al., 2022^[60]; Xie and Al-Aly, 2022^[61]). In the United Kingdom, research found that more than 10% of patients included in a study of COVID patients following hospital discharge had lung abnormalities visible in a CT scan even after they were discharged from hospital (Stewart et al., 2023^[62]).

28. People living with long COVID have reported persistent and long-lasting fatigue as a key symptom of the condition and an important disrupter of returning to their previous levels of activity. Researchers have found evidence of persistent cognitive symptoms, including 'brain fog', memory problems, difficulty concentrating, and sleeping difficulties, in a significant proportion of people following a COVID-19 infection.

- In **Austria**, researchers found that 18% of patients with background of COVID-19 infection had persistent neurocognitive symptoms 12 weeks after onset (Hüfner et al., 2022^[63]). nearly three-quarters (72.1%) of respondents with long COVID to reported experiencing (Government of Canada, 2023^[64])
- In **Belgium**, results of the COVIMPACT cohort study show that half of survey respondents reported fatigue or exhaustion 3 and 6 months following COVID-19 infection (Smith et al., 2022^[65]).
- A study in **Denmark** found that 33% and 28% of patients had mental exhaustion and concentration difficulties respectively, while 27% had memory issues (Sørensen et al., 2022^[66]).
- In **France**, a study of patients after hospital discharge found that about three in ten had concentration (28%) and sleeping (31%) disorders nearly four months after being discharged (Garrigues et al., 2020^[67]).
- In **Israel**, cognitive impairment or memory disorders was reported in 6% to 17% of patients three months following the onset of symptoms (Klein et al., 2021^[68]; Ceban et al., 2022^[69]).

- More than one-fifth (23%) of a sample of non-hospitalised COVID-19 patients in **Italy** had persistent neurocognitive symptoms such as cognitive impairment 12 weeks after onset of COVID-19 symptoms, while deficits in memory and attention, as well as sleep disorders, were found in three in ten patients after discharge from hospital (Hüfner et al., 2022^[63]; Pilotto et al., 2021^[70]).
- In the **Netherlands**, 36% of a group of patients reported cognitive impairment or mental health problems six weeks post-discharge (van den Borst et al., 2020^[71]).
- Patients surveyed 12 months following hospital discharge in **Spain** reported increased incidence of confusion and memory loss (risk ratio 3.50) as memory loss was reported by 16% of the sample (Rivera-Izquierdo et al., 2022^[72]).
- In **Switzerland**, 90 COVID-19 patients were followed up for one year after discharge and 31% had concentration difficulties and 26% memory loss (Becker, 2021^[73]). In a long-term follow-up study of patients with COVID-19, researchers found that among patients who had not been vaccinated against COVID-19, a quarter of respondents had not fully recovered at six months, with 17% still living with symptoms one year after infection, and 15% not fully recovered even after 18 months (Ballouz et al., 2022^[74]).

29. Long COVID symptoms such as fatigue, brain fog, cardiovascular or neurological problems, as well as the psychological distress of living with a prolonged and unclear health condition, has also affected the mental health of patients (Matsumoto et al., 2022^[75]; Tabacof et al., 2022^[76]). In Canada, the British Columbia health authority issued guidelines for the management of mental health problems in patients with long COVID (Provincial Health Services Authority, 2022^[77]) as a study found that 39% of long COVID patients reported mental health problems (Tilo, 2022^[78]). Data gathered by the Belgium Health Care Knowledge Centre showed that 33% of long COVID patients were affected by associated anxiety and depression (Galvani et al., 2022^[79]).

30. Similar findings have been reported in other OECD countries. In Austria, 22% of a sample of long COVID patients said their mental health was poor at 12 weeks after onset of COVID-19 symptoms (Hüfner et al., 2022^[63]). In Japan and Sweden, researchers found that, among the patients that reported symptoms of long COVID in an online survey, 39.3% had depression and 24.4% generalized anxiety patients reported depression, and 31% anxiety (Matsumoto et al., 2022^[75]). In Canada, 24.2% of adults with long COVID reported stress and or anxiety, and 18.8% reported sadness, pessimism, hopelessness or depression according to CCAHS (Government of Canada, 2023^[64]). In New Zealand, 30% of respondents to an online survey for people living with long COVID reported anxiety or depression and around 25-28% of respondents reported persistent pain (Morton, 2022^[80]), and, in Türkiye, 35% of patients with long COVID reported post-traumatic stress disorder, anxiety and/or depression at least 12 weeks after the onset of their acute infection; post-traumatic stress disorder was the condition most frequently reported (25%) (Poyraz et al., 2021^[81]).

31. The increased risks of worse health outcomes over the longer term associated with long COVID also appear to be borne out by higher healthcare utilisation in the months following an infection. Patients who had been hospitalised for an initial COVID-19 infection have been found to have a higher risk of readmission to hospital in the months following discharge, while people who tested positive for COVID-19 have also been found to be more likely to use a range of health care services, including not only hospital care (inpatient and emergency services), but also telemedical services, surgeries and cardiology services (Koumpias, Schwartzman and Fleming, 2022^[82]; Mannucci et al., 2022^[83]). In the United States, for example, people with a COVID-19 diagnosis were found to have an average of 1.2 monthly healthcare visits in the six months following their positive test, compared to 0.5 visits prior to their diagnosis (Koumpias, Schwartzman and Fleming, 2022^[79]).

Long COVID may be leading to an annual reduction of more than seven million quality-adjusted life years across OECD countries

32. Long COVID can have long-lasting symptoms affecting individuals ability to return to daily activities and affecting their quality of life. Evidence from across OECD countries drive home the impact that long COVID has had on the daily lives and activities of people living with the condition. Recent survey data collected by the Office for National Statistics in the United Kingdom, where 2.9% of the population was estimated to live in households with someone experiencing long COVID as of March 2023, suggests that long COVID patients may suffer from limitations in their daily activities and functioning that persist for 12 weeks or more (Office for National Statistics (ONS), 2023^[84]). According to this source, the number of people with self-reported long COVID that stated having their daily activities limited “a lot” 12 months after the acute infection was to 3.9% (72 individuals out of 1879 that answered the survey), while 12.5% (i.e., 236/1879) reported still having their daily activities limited “a little” a year after COVID-19 infection (Office for National Statistics (ONS), 2023^[84]). In Canada, where data shows that, a year after the infection, 47% of the people present at least one long COVID symptom (Public Health Agency of Canada, 2022^[15]), the Canadian COVID-19 Antibody and Health Service (CCAHS) reported that 1 out of 5 adults with long term COVID-19 symptoms often to always have their daily activities limited by symptoms (Government of Canada, 2023^[64]). In the United States, four-fifths (81%) of adults reporting living with long COVID in March 2023 stated that the condition led to activity limitations, including over a quarter (26%) who reported that long COVID had imposed significant daily activity limitations (U.S. Census Bureau, 2023^[14]). Moreover, in Belgium, nearly a quarter (23%) of respondents to the COVIMPACT survey reported limitations of functionality, including 4% who experienced severe limitations, with close to 3 in 10 (27%) reporting they were doing less physical activity at 6 months following the infection (Smith et al., 2022^[65]).

33. Recent studies have shown health-related quality of life scores to be affected among long COVID patients, with physical limitations and pain, reductions in normal activities, increases in anxiety and impacts on mental health, and reduced energy all associated with reductions in quality of life due to long COVID (Poudel et al., 2021^[85]; van der Sar - van der Brugge et al., 2021^[86]; Willi et al., 2021^[87]; Tabacof et al., 2022^[76]; Tsuzuki et al., 2022^[88]; Och et al., 2021^[89]; Malinowska et al., 2021^[90]; Poyraz et al., 2021^[81]; Raman et al., 2021^[91]).

- In **Austria** and **Italy**, researchers found that 20.3% and 25.9% of COVID-19 patients respectively thought their quality of life was still poor 12 weeks after onset of COVID-19 symptoms (Hüfner et al., 2022^[63]).
- In **Japan**, the health-related quality of life scores in a Japanese cohort of patients that had had long COVID and identified a decreased quality of life compared with COVID-19 patients that did not have symptoms four weeks after acute infection (EQ-5D-3L 0.81 vs 1.00, respectively) (Tsuzuki et al., 2022^[88]). Similarly, in the **Netherlands**, a study found that health related quality of life at six weeks following acute infection was affected, mainly due to physical limitations and functioning and vitality (van der Sar - van der Brugge et al., 2021^[86]).
- In **Norway**, health-related quality of life was decreased one to six months following acute infection, particularly in regards to the development of their usual activities (Garratt et al., 2021^[92]). Similarly in **Poland**, quality of life was also found to have decreased in all domains in a cohort of COVID-19 patients followed up after three and six months after discharge, particularly due to pain and anxiety (Och et al., 2021^[89]).
- In **Türkiye** and the **United Kingdom**, the quality of life was assessed using EQ-5D-5L scale and areas of mobility, usual activities, emotional dimension and pain were more affected in participants that reported more long COVID symptoms, in cases involving a marked role limitation (Poyraz et al., 2021^[81]; Raman et al., 2021^[91]). In the United Kingdom, there was a clinically significant drop in EQ-5D in 45.6%-68.8% of ward and ICU-discharged participants four to eight weeks after discharge (Halpin et al., 2020^[93]).

- In the **United States**, nearly one-third (31%) of patients reported worse health-related quality of life compared with baseline, at six months following acute disease (Logue et al., 2021^[20]). Another study assessing the negative outcomes of COVID-19 in functionality and quality of life in a sample of patients nearly a year after acute infection found that EQ-5D-5L self-care and usual activities areas were impaired (EQ-5D-5L visual scale was 64) (Tabacof et al., 2022^[76]).

34. Using the approach developed by Cutler (2022) to calculate the impact of long COVID on quality-adjusted life years and assuming 10% of population with COVID-19 will develop long COVID, we find that across OECD countries, more than 7.2 million QALYs may be lost per year due to the reductions in quality of life associated with long COVID (Cutler, 2022^[94])¹. Adopting Cutler's assumption of a value of good health equalling \$100,000, this would imply a cost of nearly \$723 billion USD per year across OECD countries attributable to the long COVID-associated loss in QALYs alone.

The effects of long COVID have impacted productivity across OECD countries

A significant proportion of people with long COVID may not have returned to work, or have returned at a reduced schedule

35. Long COVID symptoms such as fatigue, cognitive impairment (brain fog) and depression or anxiety can affect the ability to work and have led to reduced working hours, reduced performance, prolonged sick leave and job absenteeism and made patients susceptible to loss of employment, with its attendant implications for both individual and population health and well-being (Lorenz-Dant and Comas-Herrera, 2021^[95]; The British Academy, 2021^[96]).

36. There is growing evidence that a non-negligible proportion of people who contract COVID-19 are unable to return to work after experiencing sustained symptoms of long COVID. In a survey collecting data from 3,762 long COVID patients from 56 countries one to seven months following the onset of symptoms, more than one-fifth (22%) were not working due to illness when they were surveyed (Davis et al., 2021^[19]). A recent systematic review showed that, among COVID-19 patients that had been hospitalised, 9%–40% were still off work two to three months after discharge (Nittas et al., 2022^[13]).

- In **Belgium**, 60% of long COVID patients who responded to the Belgian Health Care Knowledge Centre survey reported that they continued to experience symptoms that limited their ability to work, including 37% who had not returned to work at 6 months following COVID-19 infection (Belgian Health Care Knowledge Centre, 2021^[97]).
- In **Canada**, nearly three-quarters (74.1%) of respondents to the Canadian COVID-19 Antibody and Health Survey (Cycle 2) who had symptoms of long COVID reported that they had missed at least one day of work or school because of their symptoms, with an average time off work or school of 20 days (Public Health Agency of Canada, 2022^[15]).
- In **Chile**, analysis of sick leave patterns among state-funded patients (FONASA beneficiaries) from March 2020 to February 2021 found that 18% of COVID-19 patients had been on sick leave for over 30 days, and 4.7% had been absent from work for over 90 days (Universidad de Chile, 2022^[98]).
- In **Denmark**, people who tested positive for COVID-19 were 56% more likely to take sick leave between 4 weeks and 6-12 months after their positive test, compared with people who did not have COVID-19 (Sørensen et al., 2022^[66]).

¹ See Annex for methodological details.

- In **Germany**, data from the German Social Accident Insurance found that among people on sick leave for COVID-19-related illness, some 6% remained on sick leave for at least 4 weeks following their symptom onset (Jacob et al., 2021^[99]).
- In **Spain**, about 10% of case of sick leave due to COVID-19 infection lasted for more than three months, while some 2% extended to over six months (Asociacion Española de Especialistas en Medicina del Trabajo, 2021^[100]).
- In the **United States**, analysis from the Brookings Institution estimates that up to 2% of the labour force – between 2-4 million workers – could have dropped out of the labour force because of long COVID (Bach, 2022^[101]). A recent analysis further suggests that among workers who missed at least one week of work due to an initial COVID-19 infection, the likelihood of remaining in the labour force a year later was 7 percentage points lower than people who had not missed work (Shah Goda and Soltas, 2022^[102]). In a recent working paper, economists from the Federal Reserve Bank of Minneapolis found that more than one-quarter (25.9%) of people with long COVID symptoms had their working lives affected by the condition, with 43% out of the labour force and 57% experiencing a reduction in hours of an average of 10 fewer hours per week (Ham, 2022^[103]).

37. Research also indicates that even when people are able to resume working, long COVID affects the ability of people to return full time, and to participate fully when they are there. In the survey of over 3700 long COVID across 56 countries, nearly half of respondents (45%) required a reduced work schedule, beyond those who were unable to return at all (Davis et al., 2021^[104]). A systematic review found that three to seven months after an acute COVID infection, 12-23% of patients who had not been hospitalised had still not returned to their regular work schedule (Nittas et al., 2022^[13]). Beyond the nearly two-fifths of survey respondents in **Belgium** who were unable to return to work, a further 26% reported that they were working on a reduced schedule (Belgian Health Care Knowledge Centre, 2021^[97]). In **Canada**, 13% of surveyed workers living with long COVID reported a reduction in their working hours (Tilo, 2022^[78]).

38. Patients who were previously hospitalised during their COVID-19 infection appear to be particularly affected by long-term long COVID symptoms that hinder their ability to return to work, or to return to work full-time. In a study in **Denmark** using registry data to identify all adults of working age (18-64) who had a positive PCR test result between January and May 2020, people who were hospitalised for COVID-19 were significantly less likely to have returned to work within one month or six months, with patients who had been hospitalised in intensive care the least likely to have returned to work after six months (Jacobsen et al., 2022^[105]). In France, a study of previously hospitalised patients found that after an average of 110 days following hospital discharge, more than one-fifth (21%) who had been working full time prior to infection had not returned to work (Garrigues et al., 2020^[67]). In Finland, a study using data from 101 hospitalised COVID-19 patients found that 11% of those that were working full time had not returned to their jobs six months following hospital discharge (Lindahl et al., 2021^[106]).

The costs of long COVID could be as high as \$864 billion - \$1.04 trillion USD across OECD countries

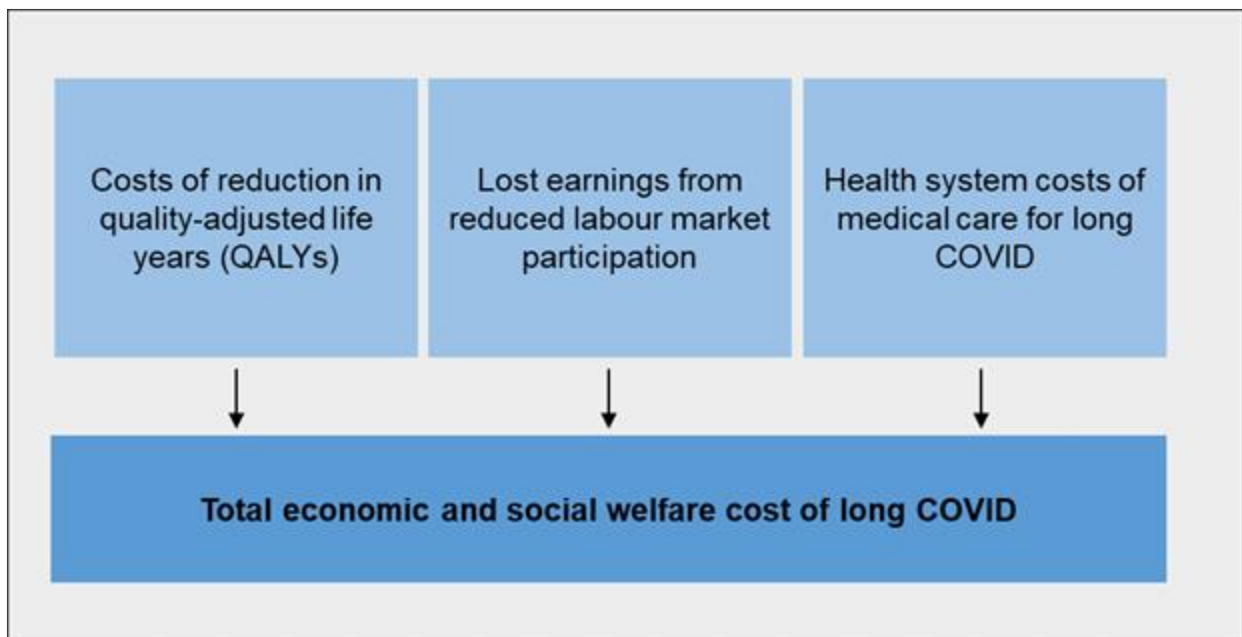
39. The disability or limitations in function that long COVID patients may experience can have devastating financial impacts. Dropping out of the workforce or being forced to return at a reduced schedule do to persistent symptoms from long COVID can lead both to financial strain and broader well-being and poor mental health (Garrigues et al., 2020^[67]; Townsend et al., 2020^[107]; Townsend et al., 2021^[108]; Chopra et al., 2021^[109]; Davis et al., 2021^[19]; Halpin et al., 2020^[93]; Havervall et al., 2021^[110]; Jacobson et al., 2021^[111]; Poyraz et al., 2021^[81]; van der Sar - van der Brugge et al., 2021^[86]). In Japan, researchers identified that the productivity loss due to COVID-19 and long COVID was equivalent to \$1,424 per patient compared to \$606 due to other influenza-like illness (Tsuzuki, Ohmagari and Beutels, 2021^[112]). Researchers using survey data in the United Kingdom and other countries found that 37% of respondents

(80% of whom were from the United Kingdom) reported having lost income due to their symptoms (Ziauddeen et al., 2022^[10]).

40. The direct costs of care themselves can also create financial strain on people living with long COVID. In a recent study using survey data from Greece found that 47.6% of the sample had spent 50 euros in their treatment while 31.3% had spent more than 500 euros (Katsarou et al., 2022^[113]). In Belgium, 37% of surveyed individuals with self-reported long COVID stated that they had financial problems due to increased medical expenses or decreased earnings (Belgian Health Care Knowledge Centre, 2021^[97]) and 3% in the COVIMPACT study sample reported having had a financial loss due to COVID-19 that was putting them in great difficulty at 6 months after COVID-19 infection (Smith et al., 2022^[65]).

41. The long-term economic and social welfare implications of long COVID are still emerging but are likely to be significant. In an analysis of the cost of long COVID to the United States economy in 2020, researchers identified three separate pathways by which long COVID would have economic costs for the country: (1) the impacts of long COVID on well-being and quality of life imply a serious disease burden and attendant impact on quality-adjusted life years; (2) the impact of long COVID on labour force participation; and (3) costs of care for the health system (Cutler and Summers, 2020^[114]). At that time, authors estimated that the long-term consequences of COVID-19 pandemic effects could cost the US up to \$2.6 trillion, which was still looking plausible in an updated viewpoint published in 2022 (Cutler, 2022^[115]; Cutler, 2022^[94]).

Figure 2.1. Estimating the economic and social welfare costs of long COVID



Source: Author's illustration based on methodology from *The Economic Cost of Long COVID: An Update (2022)* (Cutler, 2022^[94]).

42. Adopting the models developed by the Brookings Institution and Cutler (2022) offers an indication of the possible magnitude of the cost of long COVID across OECD countries, both in terms of quality-adjusted life years and their value, and in terms of labour market implications (Bach, 2022^[101]; Cutler, 2022^[94]). Using the approach adopted by Bach (2022) at the Brookings Institution and an assumption that 10% of people who contract COVID-19 go on to develop symptoms of long COVID, we find that there could be a reduction of up to 0.5% to 1.2% in labour force participation on average across OECD countries, equivalent to between 2.7 million and 6.1 million full-time equivalent workers. This range is based on varying estimates of the impact of long COVID on workforce participation (Ham, 2022^[103]; Davis et al.,

2021^[19]). The economic costs of this reduction in labour force participation in terms of wage loss would amount to some \$141 - \$317 billion USD per year across OECD countries in total².

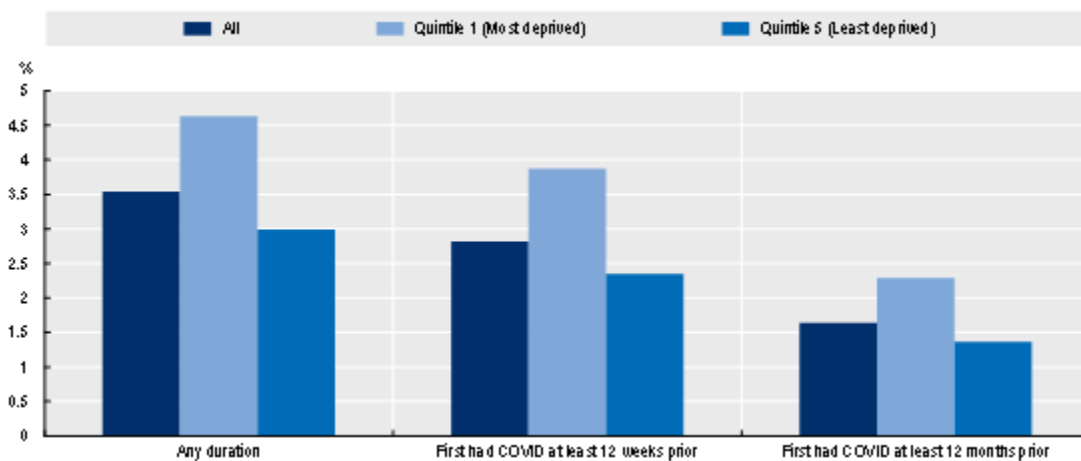
Long COVID threatens to exacerbate inequalities laid bare by the pandemic

43. The impact of the COVID-19 on pre-existing socioeconomic and demographic inequalities is well documented. Previous OECD work found the risk of mortality from COVID-19 to be 80% higher for people living in the most deprived areas compared to those living in the least deprived areas on average across 13 OECD countries (DELSA/HEA(2021)21). Certain ethnic minorities were also found to have a mortality risk from COVID-19 that was at least twice as high as the white population in a number of countries (DELSA/HEA(2021)21). Other health outcomes, including poor mental health, were worse for poorer populations than wealthier populations, while delays and interruptions in health care due to the pandemic also hit disadvantaged populations hard (DELSA/HEA(2021)21).

44. Data from the United Kingdom suggests that more deprived populations may be disproportionately experiencing the impact of long COVID. Estimates from the Office for National Statistics (ONS) indicate that the relative risk of living in a household where someone was experiencing long COVID was at least 55% higher among people living in the most geographically deprived quintile, compared to the least (Office for National Statistics (ONS), 2023^[84]). The relative risk of long COVID rose for people in the most deprived quintile as the duration of long COVID progressed. People in the most deprived quintile were 68% more likely to live in a household with someone who had suffered from long COVID symptoms for more than a year after the initial COVID-19 infection, compared with people in the least deprived quintile (2.3% vs 1.4%) (Office for National Statistics (ONS), 2023^[84]).

Figure 2.2. People in deprived areas are more likely to report long COVID

Percentage of people living in households with self-reported long COVID, by long COVID duration



Note: Data refers to the four-week period ending September 3, 2022.

Source: (Office for National Statistics (UK), 2022^[116])

² Excludes Chile, Colombia and Costa Rica, for which average annual wage data was unavailable.

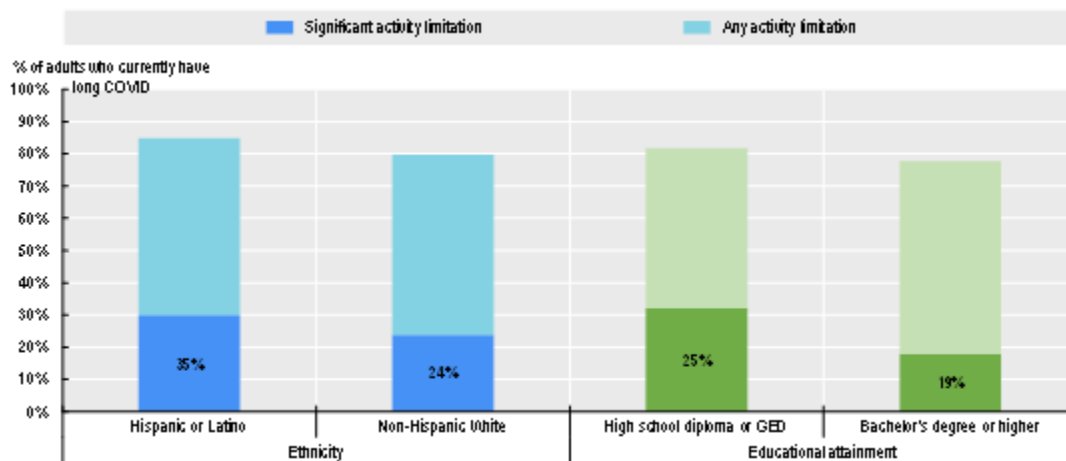
45. The same socioeconomic and demographic characteristics that put minority and disadvantaged populations at a higher risk of comparatively poorer outcomes for a range of pandemic-associated challenges may also point to a high likelihood that they will be disproportionately impacted by long COVID (Whitaker et al., 2022^[50]). Throughout the pandemic, lower-income individuals were less likely to be able to work remotely; similar dynamics may make it more difficult for them to reduce their hours or otherwise receive workplace accommodations that could help them should they require occupational adaptations following long COVID. Similarly, the impact of working reduced hours or dropping out of the labour force may be more devastating for lower-income and lower-skilled individuals, particularly those who do not have access to adequate social protection following the loss of a job.

46. Data from the United States suggests that certain minority groups may be more likely to develop long COVID following a COVID-19 infection. A study of nearly 200 000 people who had COVID-19 among users of the US Veteran’s Affairs health system found that Black Americans had significantly higher odds of having received care for long COVID than white Americans, while people with Hispanic or Latino ethnicity also had significantly higher odds of receiving care for long COVID than those who were not Hispanic or Latino (Ioannou et al., 2022^[59]).

47. Beyond differences in the prevalence of long COVID among people who were previously infected with COVID-19, same survey data suggested that there may be further inequalities in the severity of long COVID, with implications for both the health and economic well-being of individuals living with long COVID. In the United States, adults of Hispanic or Latino and non-Hispanic White ethnicity were nearly equally likely to report at least some activity limitations due to long COVID, but adults of Hispanic or Latino ethnicity were much more likely to report significant activity limitations. Adults with at least a bachelor’s degree were also less likely to report significant activity limitations, compared with adults with a high school diploma or GED.

Figure 2.3. Inequalities may exist in the prevalence of significant activity limitation due to long COVID, including by ethnicity and education

% of adults currently living with long COVID who report any or significant activity limitations due to long COVID, United States (March 2023)



Source: U.S. Census Bureau, Household Pulse Survey (Phase 3.8), 2023 (U.S. Census Bureau, 2023^[14]). (note: data are not age-standardised)

3 Policies and actions taken to address long COVID

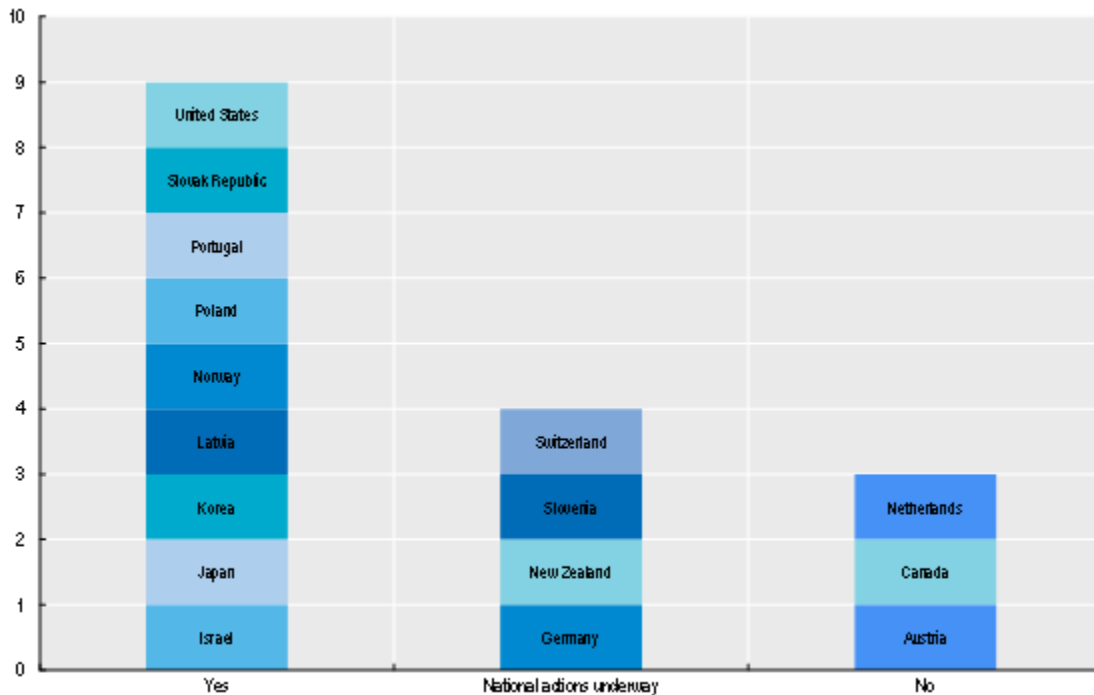
Primary care represents the main point of contact for treating patients with long COVID in many countries

48. While long COVID can have debilitating effects on the daily lives of those living with the condition, many of its most common symptoms do not necessarily require specialist or in-patient treatment and can often be managed at the primary care level (Expert Panel on effective ways of investing in health (EXPH), 2022^[55]; Décarry et al., 2022^[117]).

49. A number of countries report that primary care serves as the first and main point of contact for patients in the community living with long COVID. In many countries that have developed clinical pathways for long COVID, including **Austria, Germany, Japan and Norway**, for example, treatment pathways designed for long COVID identify general practitioners and primary care doctors as the first point of entry for assessment, with an interdisciplinary, specialist assessment and rehabilitation following where needed (OECD, 2022^[6]). In **Portugal**, a partnership including the Directorate General of Health developed an interactive clinical pathway to help physicians in their decision-making around care for people presenting with long COVID symptoms, including recommendations for further evaluation, laboratory tests and rehabilitative care (UpHill Health, 2022^[118]). In **Italy**, general practitioners help with care co-ordination and use telemonitoring and community nurses to help oversee care for people living with long COVID in the community (Rajan et al., 2021^[57]). Guidelines to help inform clinical decision-making for physicians were similarly reported in **Austria, Canada** (interim guidelines at the provincial/territorial level), **Czech Republic, Germany, Japan, Israel, Latvia, Netherlands, New Zealand** (in process), **Norway, Poland, Portugal**, the **Slovak Republic, Spain** and the **United States** (OECD, 2022^[6]; C-Support, 2023^[119]; Rajan et al., 2021^[57]).

50. The majority of OECD countries responding to the 2022 OECD Long COVID Health Systems Survey report that they have developed national plans to address long COVID or are in the process of developing a national response (Figure 3.1).

Figure 3.1. Most countries report having developed national plans for long COVID



Note: N=16

Source: 2022 OECD Long COVID Health Systems Survey (OECD, 2022^[6])

51. The very recent onset of COVID-19 and long COVID mean that the evidence base around long COVID and the understanding around how best to treat those living with long COVID symptoms is constantly evolving. In reflection of this, many countries have set up mechanisms to rapidly disseminate new information about managing long COVID to practitioners on the ground. Countries including **Canada**, the **Slovak Republic**, **Switzerland**, and the **United States**, report offering ongoing trainings or webinars for practitioners to quickly communicate best practices around the care of people living with long COVID (OECD, 2022^[6]).

52. In the **Netherlands**, people who tested positive for COVID-19 or are suspected to have been infected and are suffering from extended symptoms are eligible for an additional paramedical recovery package, on top of basic care (Zorginstituut Nederland, 2022^[120]). Patients must be referred (by their general practitioner or a specialist) to the paramedical recovery package within six months of their acute infection, and are then entitled to a range of supportive treatments to aid their recovery, including occupational therapy, physiotherapy, and speech therapy. Reflecting the rapidly developing state of research into long COVID, patients must agree to participate in research being undertaken on the recovery treatments, in exchange for inclusion in the scheme (Zorginstituut Nederland, 2022^[120]).

The majority of countries have set up long COVID clinics to help treat patients with multiple or complex symptoms

53. Where patients cannot be sufficiently cared for by their primary care physician, specialised long COVID clinics have been developed in many countries to provide patients the specialised, often

interdisciplinary care they need to treat the complex array of symptoms associated with long COVID (Décary et al., 2022^[117]).

54. At least 22 OECD countries, including **Australia, Austria, Belgium, Canada, Colombia, Czech Republic, France, Germany, Ireland, Israel, Italy, Japan, Korea, Latvia, Luxembourg, Norway, Poland, Spain, Sweden, Switzerland**, the **United Kingdom**, and the **United States**, have developed at least some specialised clinics to care for people with long COVID.

55. While the structure and organisation of long COVID clinics differs between countries, many share certain characteristics. Clinics are often multidisciplinary and can help to organise and co-ordinate the many different tests, diagnoses, treatments and rehabilitation efforts that are needed – a complex task for a condition with many manifestations.

56. In **Belgium**, for example, long COVID care is covered for patients who have been diagnosed with post-COVID-19 by a general practitioner. Available pathways for care include both care organised around the general practitioner but including additional first-line services from a psychologist, speech therapist, or physiotherapist, or multidisciplinary first-line care including services from physiotherapists, speech therapy, occupational therapy, dieticians, psychologists and neuropsychologists. Each patient is appointed a care coordinator, who receives a set fee (120 EUR) for their coordination services, and the multidisciplinary team includes the patient, coordinator, general practitioner, and all other providers (primary or specialist) included in their care (OECD, 2022^[6]).

57. In France, the care pathway for long COVID patients is oriented around general practitioners. Together with the TousPartenairesCovid association, the national health insurance system has supported a long COVID care pathway structured around three levels: **general practitioners** at the centre of the system, **specialist doctors** in town or hospital, for complex diagnoses and the management of functional explorations (respiratory, cardiological, neurological, ENT) and so-called functional disorders, and follow-up care and rehabilitation services for the most complex patients. In addition, it includes **coordination units** aimed at supporting, informing, guiding professionals and patients, and coordinating interventions for the most complex patients (OECD, 2022^[6]).

58. Some countries have outlined clear care pathways for patients experiencing symptoms of long COVID. In **Luxembourg**, for example, patients are first seen by general practitioners (or in some cases specialists) before being assigned a case manager, who provides support via teleconsultation to signpost patients to the correct care. Where patients have isolated symptoms, they are referred via the case manager to appropriate specialists. Where patients have multiple symptoms, follow-up analyses are undertaken, following which a multidisciplinary care team decides jointly on the best course of action, which may include specialist treatment, telemonitoring, or care in specialist rehabilitation and multidisciplinary units (Government of Luxembourg, 2021^[121]).

59. In the **United Kingdom**, a unique integration rehabilitation pathway was developed in Leeds aligned to the NHS Five-Point plan to deal with post-covid syndrome assessment across England. The model included three tiers to which the patient can access following triage at community level by community matron and/or general practitioner in primary care. Self-management using online resources (level 3) is recommended for patients that have 1-2 months of symptoms. Following this, if additional support is necessary, and the patient level of complexity is low or moderate (for example, the patient does not require input from different specialists), an occupational therapist and physiotherapist can be provided at community level (level 2). Level 3 is provided by a specialised MDT service consisting of rehabilitation medicine, respiratory medicine and cardiology consultants and supported by respiratory nurse, respiratory physiotherapist, dietitians and neurological occupational therapist. There is a single point of urgent referral triage system to which GPs or nurses can refer patients. Community matron and GP assess the patient to rule out risk flags of urgent respiratory or cardiovascular cause of symptoms before referral to COVID rehabilitation service. Level 3 can also seek input from speech and language therapist or ENT language

therapy. A mixture of virtual and face to face consultations are provided and standardised assessment is carried out.

60. In the **United States**, the Johns Hopkins Post-Acute Team (PACT) implemented a care pathway to which patients requiring post-discharge rehabilitation, those with ongoing or pre-existing respiratory need for treatment and those had on-going symptoms 4-6 weeks could access. The service accepted referrals from hospital and ambulatory services through centralised e-mail monitored by referral coordinator and supported by nurses and physicians to identify severity and carry out triage through standardised questionnaires, which can be completed by the patient before attending the clinic to individualise the care pathway. The service consists of an MDT with specialities including respiratory, cardiologist and rehabilitation providers coordinated by primary care team and provides a mixture of virtual and face to face consultation with the support of nursing and homecare teams. Patient monitoring is carried out by Johns Hopkins Homecare Group Remote Patient Monitoring team, which provides pulse oximeters. The assessment follows standardised guidelines and scales to facilitate the recording of comparable and traceable patient data.

61. Given the higher propensity of patients who experienced more severe cases of initial COVID-19 to experience long-lasting symptoms, in some countries care pathways have been developed that target patients who were hospitalised with COVID-19. In the **Netherlands, United Kingdom, and the United States**, for example, patients who were hospitalised during their acute COVID-19 infection are recommended to organise a specialist follow-up visit in the weeks after hospital discharge (Wolf, Zechmeister-Koss and Erdös, 2022^[122]).

Box 3.1. Long COVID care pathways

In response to the increased health care demands due to the proportion of COVID-19 patients presenting long-term COVID-19 complications requiring lengthy rehabilitation programmes, policy makers have deployed intelligence and resources to reorganise health services to be able to address the complex needs of this population. This has also prompted an active involvement by international organisations, such as the WHO, as well as the academic community to design suitable and sustainable models of care for these patients.

A recent scoping review on local and national long COVID care pathways identified the following common components (Wolf, Zechmeister-Koss and Erdös, 2022^[122]). Care should be:

- based at and coordinated by community care providers (involvement of family medicine physicians/nurse), with a community-based triage system that identifies patient's severity and symptoms;
- patient-centred and flexible, adapting care to specific needs and changing symptoms of the patient;
- multidisciplinary: including respiratory, cardiologist, rehabilitation and neurologist team, supported by occupational therapist, physiotherapist, psychologist, speech and language therapist and mental health coordinated by a community care team;
- a mixture of face to face and virtual consultations to increase access and digital monitoring (via pulse oximeters, for example)
- sufficiently resourced to encourage self-management and patients' support groups;
- financially stable and sustainable
- evidence-based.

Demand for long COVID services may exceed supply, with long waiting times reported in some countries

62. While not all people living with long COVID will require special care services and data remains scarce, demand appears to exceed the available supply for specialised care in some cases, with reports of long waiting times to access services such as long COVID clinics reported in a number of countries. At the main rehabilitation centre in **Latvia**, for example, the waiting list for patients is nearly as long as the number who have received treatment, while in **Australia**, waiting times at respiratory and rehabilitation clinics have been reported to be as long as four to five months (Latvia Public Broadcasting, 2021^[123]; Martin, 2022^[124]).

Patients have been integral to recognizing long COVID as a legitimate condition, and to informing clinical treatment

63. The emergence and recognition of long COVID as a legitimate and concerning health condition underscores the indispensable role of patient voice in informing health care and policy. Patients living with long COVID were the first to sound the alarm that COVID-19 infections could create ongoing health problems. As countries implemented policies and coping strategies to respond to the increased health and social demands caused by the initial waves, patients' and healthcare practitioners' accounts of their disease evolution suggested that some people may have lingering symptoms lasting for weeks or months following the acute infection. Yet patients frequently reported feeling ignored and having their symptoms neglected, with impacts on their well-being and professional lives. This prompted widespread campaigns by national and international patient-led support groups such as the *Body Politic* group in the United States, *Long COVID SOS* in the UK, *#AprèsJ20 - Association COVID long* in France, and *Noi che il COVID l'abbiamo sconfitto* in Italy to make the case to health policy makers that the condition should be recognised and adequate resources for its management be provided.

64. Research led by patient advocates has contributed significantly to the global body of evidence and understanding about the condition. Beyond traditional patient advocacy and an active online presence, patient groups have organised online surveys of people living with long COVID that have contributed to the body of research around key characteristics and symptoms of the disease, and have been published in academic journals (Davis et al., 2021^[19]; Iqbal et al., 2021^[54]).

Some countries have actively included patients in developing their policy response to long COVID

65. Many countries reported active participation by patients and patient advocacy groups in designing the health systems response to long COVID (OECD, 2022^[6]). Some of the biggest resources for people living with long COVID have emerged from patient-led initiatives, or have actively cooperated with patient-led support groups. Patients have also been included in the development of research and reviews of evidence that have been undertaken to help identify how work should be focused in a patient-centric manner.

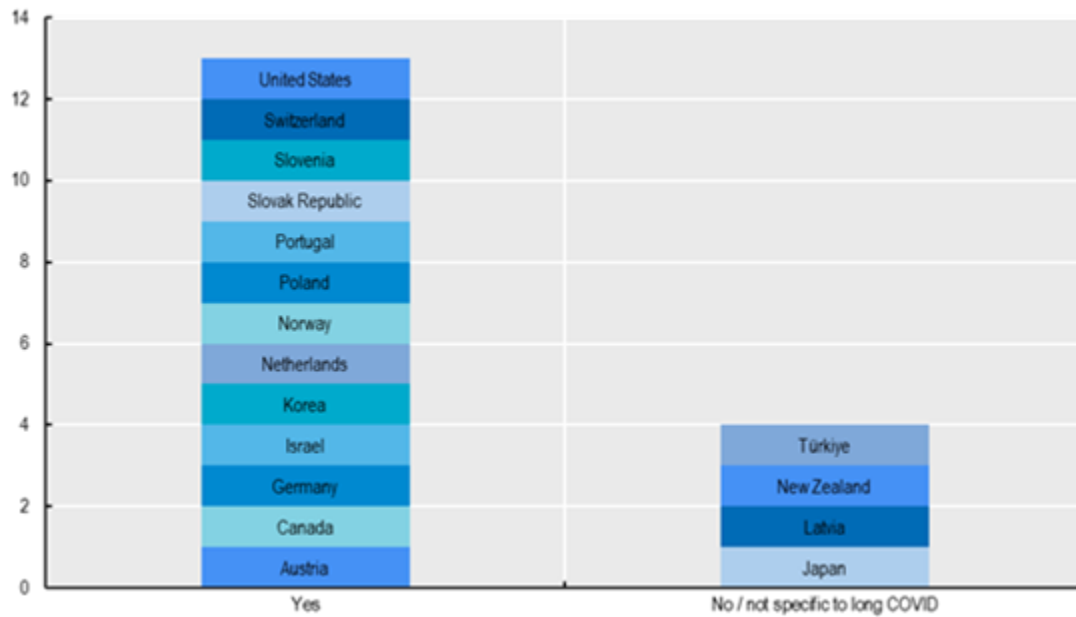
- In **Austria**, patients were included in professional workshops organized to assess long COVID care in the country (OECD, 2022^[6]). Patients reported that in some cases, finding good care felt like an “odyssey”, with difficulties and stress resulting from care that was not adequately co-ordinated around their needs. Recommendations emerging from the review pointed to the need for more specialist outpatient clinics (depending on disease burden), as well as an expansion of care pathways available in certain regions (Tyrol) to other parts of the country (Winkler et al., 2022^[125]).

Patients were also included in the design of a website and guidelines for long COVID, as well as updates to the Austrian Health Portal (OECD, 2022^[6]).

- In **Canada**, patients have been involved from the beginning of the pandemic in helping to shape the federal response to COVID-19 and long COVID. Patient and community involvement around long COVID has focused on priority setting, understanding the preferences and values of patients, and improving communication around long COVID to patients and the broader community (OECD, 2022^[6]). Patients with long COVID were also invited by the Public Health Agency of Canada to help to inform systematic reviews on the evidence around long COVID, including helping to generate research questions, highlight gaps in research, and improve the communication of new information to patients, healthcare workers, and the broader community (OECD, 2022^[6]).
- In **Germany**, patients and patient associations have been involved in health education and research, such as in research conducted by the Robert Koch Institute (Robert Koch Institute, 2022^[126]). One major support initiative for people living with long COVID, Long COVID Deutschland, originates from a self-help Facebook group formed by people living with the condition and offers their own information and resources, in addition to cooperating with the Federal Centre for Health Education (Bundeszentrale für Gesundheitliche Aufklärung, BzG-A) to help disseminate information about long COVID and signposting support and care (OECD, 2022^[6]).
- In **Israel**, support groups for people living with long COVID have been developed by the country's leading HMO, Clalit Health Services (OECD, 2022^[6]).
- In **Korea**, patients living with long COVID have been included in a large-scale study run by the Korea Disease Control and Prevention Agency (KCDA) to understand long COVID trends (OECD, 2022^[6]).
- **New Zealand** has launched a national survey of people's experiences with COVID-19, which is intended to inform the Ministry of Health in its COVID-19 response and improve services going forward. One of the four key areas covered by the survey concerns long COVID (OECD, 2022^[6]).
- In **Norway**, the response to long COVID has been shaped by co-operation with patient associations, as well as with municipalities and hospitals, to ensure an adequate understanding of patient needs (OECD, 2022^[6]).
- In the **United States**, the government developed the National Research Action Plan on Long COVID with input from Long COVID patients and caregivers, long COVID advocacy groups, patients with disabilities and chronic illness and their caregivers as well as disability and chronic illness advocacy groups (Department of Health and Human Services, 2022^[127]). Similarly, persons affected by the longer-term impacts of COVID-19 were among the stakeholders consulted in the development of a report outlining the services and mechanisms of support across government agencies that assist the American public in addressing the longer-term effects of COVID-19, including mental health, substance use, bereavement, long COVID and related conditions (Department of Health and Human Services, 2022^[127]). Three-quarters (12 / 16) of countries responding to the 2022 OECD Long COVID Health Systems Survey report having developed recommendations or guidelines for patients on self-management of long COVID (Figure 3.2). Most countries reported having developed or supported online resources for patients needing information about living with or seeking care for symptoms of long COVID, including in **Austria, Canada** (provincial/territorial level), **Germany, Korea, Norway, Portugal, the Slovak Republic, Slovenia, Switzerland** and the **United States** (OECD, 2022^[6]).

Figure 3.2. Most countries have developed guidelines for patient’s self-management of long COVID

Countries reporting recommendations and guidelines on patient’s self-management



Note: n=16. Categorization based on responses to the question: “Has your country issued recommendations and guidelines on patient’s self-management (such as exercising at home, stress reduction or participation in long COVID online programmes for example)?”
 Source: 2022 OECD Long COVID Health Systems Survey, C-Support (OECD, 2022^[6]; C-Support, 2023^[119]).

4

Priorities for improving care for people living with long COVID

Improved long COVID monitoring infrastructure is needed in almost all countries to develop a better understanding of long COVID impact

66. While the development of a long COVID ICD code has been helpful to recognising the condition and drawing the attention of clinicians, its use is not widespread or systematic. Better and more consistent uptake of coding for long COVID in inpatient and outpatient settings could help to clarify understanding around both who has long COVID and the course of the condition. No countries reported that long COVID ICD codes are regularly used across different parts of the health system, with uptake most likely in hospital settings and less often in primary care, where many cases of long COVID in the community are treated.

67. Moreover, few OECD countries have undertaken regular surveys or other methods to quantify the estimated proportion of the population living with long COVID. An important exception is the **United Kingdom's** ongoing Coronavirus (COVID-19) Infection Survey, which includes questions on the proportion of individuals with and living in households with long COVID, by duration from the initial acute infection. In the **United States**, several federally sponsored national health surveys now include questions on long COVID, including the U.S. Census Bureau's Household Pulse Survey (see ref 8), the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the Behavioural Risk Factor Surveillance System (results not yet available).

A clearer and more disaggregated definition of long COVID could help to improve clinical management and better target policies

68. The breadth of symptoms and time frames that currently fall under the broad definition of long COVID have been helpful to recognising the wide range of symptoms that patients can experience, as well as the potential scope of the challenge faced by so many people following a COVID-19 infection. At the same time, there is likely an important proportion of people who are covered by the current, expansive definition of long COVID who may not require such long-term care and support or additional healthcare resources, and who are able to resume previous activities – including returning to work – relatively quickly. Better disaggregating between these and others who face long-term, life limiting symptoms from long COVID (i.e., by developing standardised measures to identify long COVID phenotypes and severity) would help countries to better understand the level of resources – such as the development of long COVID clinics – to direct, as well as better anticipate the potential broader societal and economic costs of long COVID going forward,

Policies to tackle long COVID should be informed by other chronic conditions – and help to inform responses to other chronic diseases in turn

69. Long COVID is a new condition, but it is not the first chronic condition to hit health systems, and many lessons can be taken from how health and social protection schemes care for people living with other conditions and support them in their working lives. In particular, patients living with conditions such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) have been identified as demonstrating similar characteristics and symptoms as people exhibiting symptoms of long COVID. In the **United States**, methods and data collection instruments developed for research on ME/CFS are being applied to long COVID research. Many countries, such as Austria and the United Kingdom, have already developed care pathways for the treatment and support of people living with ME/CFS, while well-developed care pathways for other chronic conditions also exist across OECD countries that could be potentially adapted to be used by long COVID patients (Gesundheit Österreich, 2022^[128]; National Institute for Health and Care Excellence, 2021^[129]). As support mechanisms for long COVID are developed or scaled up, and research into the condition leads to a better understanding of the most effective ways to treat people living with long COVID, lessons learned from the development of care systems for other chronic conditions should play a key role in informing the long COVID care, while policymakers should also consider whether lessons from their experience supporting people with long COVID can also be applied to other chronic conditions.

Patient involvement is critical in designing policies for long COVID patients and ensuring care is well integrated

70. Throughout the pandemic, ensuring care was person-centred took a back seat as countries focused on putting in place containment measures that often ran counter to key principles of person-centred care. In scaling up policies to support people with long COVID, it is critical that countries ensure people living with the condition have a seat at the table and a real voice to help shape the development of the actions and policies that will affect them. Patient groups have already played a key role in drawing attention to the phenomenon of long COVID and having policymakers – as well as healthcare professionals – take it seriously. Involving patient groups in the design and implementation of policies, as well as in ongoing research into long COVID, offers an opportunity for countries to actively practice what they preach in orienting their health systems around the patient. In addition to policy design, health systems should actively involve patients and patient groups in disseminating information around long COVID and support services for the condition (Iqbal et al., 2021^[54]; Kluge et al., 2022^[56]).

Sustainable investment in long COVID research and development are needed

73. To support the undertaking of prioritised areas mentioned above requires a sustainable commitment to facilitate appropriate research funds and capacity to continue increasing the understanding of the condition and its impact. This can be achieved in part by supporting state and private universities, policy think-tanks, research institutions and industries involved in research.

A multi-sectoral policy response is needed to address inequalities and prevent long COVID from exacerbating them further

71. As the health system response to long COVID is further developed, policymakers must pay close attention to trends in inequalities related to the condition, including differences in prevalence and severity between different groups. Policies that strengthen the role of primary care (such as ensure adequate

training of primary care providers and longer consultation times to address complex needs of long COVID patients) and facilitate outreach can help to address some inequalities, as can ensuring information about long COVID and opportunities for care and support are clearly and widely disseminated (DELSA/HEA(2021)21). At the same time, other social systems have an important role to play in ensuring long COVID does not further widen existing social inequalities. The growing evidence base pointing to the impacts of long COVID on reductions in labour market participation mean social protection systems must be equipped to supporting those who cannot return to work, or are forced to reduce their working hours. This includes ensuring long COVID is recognised as a valid reason for taking sick leave – by both health care professionals and employers. In some countries, such as the United States, long COVID has been recognised as a disability, with rights to disability programs and benefits open to certain people with long COVID symptoms (U.S. Department of Health & Human Services, 2023^[130]).

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