



Mapping Long COVID across the EU: definitions, guidelines and surveillance systems in EU Member States

Final Report

Specific Contract No SC 2021 P2 03 in the context of the Single Framework Contract
Chafea/2018/Health/03

EUROPEAN COMMISSION

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Executive Summary

Background

A health crisis has arisen as an estimated 36 million people in the WHO European region suffer after a COVID-19 infection from persistent symptoms, termed "Long COVID" or "post-COVID conditions." Achieving a unified and effective response to Long COVID within the EU is challenging due to the diverse symptoms related to Long COVID and a lack of a generally accepted definition and diagnosis. The European Commission underscores the need for a harmonised approach, which has led to the establishment of the Network of Expertise on Long COVID (NELC) in 2023 to facilitate EU-wide collaboration. In order to support the work of the NELC, the EUHealthSupport Consortium was tasked to conduct a rapid mapping study. This mapping study aims to provide insight into the current state of affairs regarding: 1) Long COVID definitions, 2) guidelines and intelligence on diagnosis and treatment, and 3) surveillance systems, as used/implemented EU Member States and beyond.

Methods

A search was conducted to map existing Long COVID and post-COVID definitions, guidelines, and intelligence on diagnosis, treatment, and surveillance systems in 34 selected countries. Documents were collected from EU Member States, Iceland, Norway, the United States, Canada, New Zealand, and Australia. The search encompassed online publications, reports, and guidelines from sources such as PubMed, national public health institutes, Long COVID primary care and medical specialist associations, patient associations, and global entities like WHO and OECD. Key search terms such as 'Long COVID,' 'Long COVID definition,' 'Long COVID treatment,' and others were employed, with translations into national languages.

Definitions of Long COVID

Long COVID definitions were identified in 33 out of 34 selected countries, with Lithuania being an exception. Commonly, these definitions align with WHO or National Institute for Health and Care Excellence (NICE) criteria, distinguishing between duration-based and non-duration-based definitions. Key elements include time criteria, persistent symptoms, ruling out alternative diagnoses, and including a broad range of symptoms. Variations exist in considering impact on daily life, organ system involvement, severity of the initial acute COVID-19 infection, and naming conventions. Insights from the ORCHESTRA study suggested to define several types of Long COVID, based on symptom combinations and their impact on physical and mental well-being.

Long COVID guidelines for diagnosis and treatment

The mapping study's second focus was on Long COVID guidelines for diagnosis and treatment. These were found across 21 out of 34 selected countries. Common elements include advocating a multidisciplinary approach, a central role for primary care, and the focus on rehabilitation. Some guidelines include recommendations for referral to specialised care and follow-up procedures. Guidelines differ in their target audience, addressing healthcare providers in general, secondary (specialised) care, decision makers, and interdisciplinary support involving municipalities. Guidelines also differ to some extent in addressing specific symptoms or organ systems that are affected by Long COVID. A quick literature search indicates that additional guidelines are still under development for various specific medical specialties and possible ways of treatment.

Long COVID surveillance

The third focus of the study was the mapping of Long COVID surveillance systems, initially using the search term 'surveillance system', with no result, and later 'registry.' Seven Long COVID registries were found in Australia, Germany, Spain, Sweden, the Netherlands, New Zealand, and the United States. In addition two additional registries, one from Germany and one from Czechia, were added after a review round among the NELC Members. Five of the mentioned Long COVID registries are based on self-registration. The Spanish registry involves primary care professionals in recruitment and the Swedish registry is based on registration data. The Australian registry uniquely allows carers to register as well. Data linkage to other sources is specified only in the New Zealand registry. Notably, except for the Swedish and one of the German registries, none of the registry websites provide insights gained or expected timelines for results. As limited information is available for most registries, a detailed understanding of their structures and goals in comparison to others is hindered.

Some countries, including Bulgaria, Italy, Germany, and Ireland, have implemented clinical centers for Long COVID patients from which data can be collected that may serve as an alternative source of information on the Long COVID population. Similarly, several countries have implemented or are implementing cohort studies for Long COVID patients.

Reflections and conclusion

This rapid mapping study underlines the interconnectedness of Long COVID definitions, the development of guidelines, and surveillance systems. A clear definition is crucial for developing effective guidelines and surveillance, but defining Long COVID is still challenging due to the broad range of symptoms involved. The ORCHESTRA project's multi-type definition may enhance refined guidelines and surveillance. It can be concluded that in most EU Member States guidelines for the diagnosis and treatment of Long COVID need to be developed or need to be made publicly available. Member States in which guidelines are available could serve as an example.

Given the variability in definitions and the voluntary entry of patients into the existing registries, there are no good estimates yet of the total numbers of patients and the severity of their disease in EU Member States. Linking information from cohort studies and clinical trials may be necessary to provide the full picture of the burden of disease of Long COVID.

1. Background

After the coronavirus pandemic, countries are facing what has been called the next public health crisis (Yang et al., 2023)¹: a large number of people, estimated around 36 million in the WHO European region², developed persistent symptoms of COVID-19, also referred to as "long COVID" or "post-COVID conditions" (Yang et al., 2022)³. One study estimated that almost half the people who caught the coronavirus had unresolved symptoms after about four months (O'Mahoney et al., 2023)⁴. Another study estimated that one in ten persons who caught the coronavirus is suffering from Long COVID (Davis et al., 2023)⁵.

Countries have been responding to long COVID in various ways. Some EU countries initiated a more extensive response to Long COVID than others, including the creation of multidisciplinary Long COVID clinics (Rajan et al., 2021⁶; Health Library Ireland, 2022⁷). However, a coordinated and uniform response to Long COVID is complicated since the identification of people with Long COVID is challenging due to the large variation in mostly non-specific Long COVID symptoms that are often similar to symptoms of other diseases and therefore hamper specific characterisation of a patient.

The European Commission underlines the importance of a harmonised approach when it comes to countries' response to Long COVID and attempts to support EU Member States in this. The European Commission therefore established the Network of Expertise on Long COVID (NELC), soliciting input on current priorities from countries and searching for actions that can promote harmonisation of approaches across countries. Insights from ongoing projects and collaborations, such as [ORCHESTRA](#) and the Long COVID Working Group (led by WHO), are considered in this process. Additionally, other countries, including the United States are examined.

To support the work of the NELC, the EUHealthSupport Consortium was tasked by the European Commission to conduct a mapping study on three aspects of Long COVID: a) definitions of Long COVID; b) guidelines and intelligence on Long COVID diagnosis and treatment; c) surveillance systems that are currently in place to monitor Long COVID patients. These topics were selected as they were prioritised in the EUSurvey on Long COVID priority setting that was distributed among NELC members and members of the Public Health Expert Group (PHEG). The survey comprised prioritising a broad range of public health issues, including issues related to Long COVID.

It is important to note that Long COVID is referred to by a wide range of terms, including: Post-COVID conditions, Post-acute COVID-19, Long-term effects of COVID, Post-acute COVID syndrome, Chronic COVID, Long-haul COVID, and Late sequelae of COVID.⁸ In this mapping study, we specifically searched for definitions of Long COVID.

¹ Yang C, Tebbutt SJ. Long COVID: the next public health crisis is already on its way. *Lancet Reg Health Eur.* 2023 May;28:100612.

² World Health Organization; 2023. [Statement of the Regional Director – 27 June 2023](#)

³ Yang C, Zhao H, Shannon CP, Tebbutt SJ. Omicron variants of SARS-CoV-2 and long COVID. *Front Immunol.* 2022 Dec 9;13:1061686.

⁴ O'Mahoney LL, Routen A, Gillies C, Ekezie W, Welford A, Zhang A, (...), Khunti K. The prevalence and long-term health effects of Long Covid among hospitalised and non-hospitalised populations: A systematic review and meta-analysis. *EClinicalMedicine.* 2022 Dec 1;55:101762.

⁵ Davis HE, McCorkell L, Vogel JM, Topol EJ. Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol.* 2023 Mar;21(3):133-146.

⁶ Rajan S, Khunti K, Alwan N, Steves C, MacDermott N, Morsella A, (...), McKee M. In the wake of the pandemic: Preparing for Long COVID. Copenhagen (Denmark): European Observatory on Health Systems and Policies; 2021.

⁷ Health Library Ireland; 2022. [What models of care are available for patients recovering from COVID-19 with persisting symptoms? What models of care are available for long COVID, or post-acute sequelae of COVID-19?](#)

⁸ National Institute for Health; 2021. [When COVID-19 Symptoms Linger.](#)

2. Methods

To map existing Long COVID definitions, guidelines, and intelligence on Long COVID diagnosis and treatment as well as surveillance systems, a search was conducted for online publications, reports, and guidelines on these topics.

The searches were conducted in PubMed, on national websites of public health institutes, and on websites of Long COVID patient associations, primary care and medical specialist associations, and European Union and international websites, including those of the WHO and OECD. Relevant documents were included from 34 countries, including all EU Member States, plus Iceland, Norway, and Switzerland as well as Australia, Canada, New Zealand and the United States.

Key terms for the search included: 'Long COVID', 'Long COVID definition', 'Long COVID treatment', 'Long COVID guidelines', 'Long COVID surveillance', and 'Long COVID registry'. These search terms were translated into national languages using machine-translation. Documents and websites containing synonyms for Long COVID, such as long-term COVID, post COVID or PASC (post-acute COVID-19) were also reviewed. The documents and websites that were found, were translated into English if needed, through machine-translation. All materials were read and summarised in tables.

In December 2023 NELC members were given the opportunity to review the draft version of this report and to add any missing information. Additional input was provided by: Cyprus, Czechia, France, Germany, Ireland and Slovenia.

In this report the findings are described per topic in chapter 3, highlighting the input that was provided by NELC members.

3. Results

In this chapter, we present the main findings per topic: definitions of Long COVID, guidelines for diagnosis and treatment, and surveillance systems.

3.1. Definitions of Long COVID

The first topic that was addressed in this mapping study, concerns the definitions of Long COVID that are used in EU Member States. We initially searched for definitions that were published on governmental websites or websites of national health institutes or healthcare associations. We next searched for definitions that are used in scientific publications. For the latter definitions it is assumed that these are commonly used in academia but it remains unsure to what extent these are also used by governments or public health institutes.

Findings

For the countries that were part of our search, 34 in total, we were able to find definitions for 33 countries, mostly via governmental websites or the websites of national health institutes. Only for Lithuania we were unable to find a definition.

Annex 1 provides an overview of all the definitions that were found. The definitions that are commonly used within countries are often in line with the WHO definition of Long COVID: *“The continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.”* or with the definition of Long COVID as proposed by the National Institute for Health and Care Excellence (NICE): *“(1) Ongoing symptomatic COVID-19 for people who still have symptoms between 4 and 12 weeks after the start of acute symptoms; and (2) post-COVID-19 syndrome for people who still have symptoms for more than 12 weeks after the start of acute symptoms.”*

Common elements

When evaluating all the definitions that are used, we could group them into **1) Duration based definitions** and **2) Non-duration based definitions**. Definitions that are used in the following countries belong to the first group: Austria, Bulgaria, Canada, Czechia, Denmark, Estonia, Germany, Greece, Finland, Hungary, Ireland, Latvia, Luxembourg, Netherlands, New Zealand, Norway,

Poland, Portugal, Romania, Slovakia, Sweden, the United Kingdom, and the United States. The definitions that were found from these countries distinguish between symptoms lasting more or less than a certain number of weeks (i.e., 4 weeks and 12 weeks) after the acute phase of COVID-19.

Definitions that are used in the following countries belong to the second group: Australia, Belgium, Cyprus, Croatia, France, Iceland, Italy, Malta, Slovenia, and Spain. The definitions that were found from these countries describe Long COVID in terms of persistent symptoms without strictly defining a specific duration.

In response to the review round of the current report, the French NELC member exemplified that French medical authorities insist on the fact that a variety of symptoms may exist and that there is a need to exclude differential diagnosis. In addition, the French NELC member underlined that recommendations are not intended to define a disease but rather to determine from when clinicians might need to initiate diagnostic or therapeutic measures, because symptoms following the acute phase are abnormally prolonged. The French Health Authority does not recommend how to define Long COVID; rather, they specify the date from which it is deemed important to eliminate differential diagnoses and initiate management of persistent symptoms.

While there are variations in the definitions of Long COVID across countries, a number of elements overlap in their descriptions. These are common elements found in many definitions in addition to the duration criteria as outlined above:

- 1. Ongoing or persistent symptoms:** Many definitions highlight the presence of ongoing or persistent symptoms beyond the acute phase of COVID-19, including the definitions found for: Austria, Australia, Belgium, Bulgaria, Denmark, Estonia, Germany, Greece, France, Ireland, Romania, Norway, Malta, Luxembourg, and the UK.
- 2. Wide range of symptoms:** Definitions often encompass a wide array of symptoms, both respiratory (e.g., shortness of breath, persistent cough) and non-respiratory (e.g., fatigue, muscle aches, cognitive dysfunction). This is the case for the definitions that were found for: Australia, Bulgaria, Croatia, France, Germany, Latvia, Malta, the Netherlands, Portugal, Romania, and Slovenia.
- 3. Not explained by alternative diagnosis:** Several definitions emphasise that Long COVID symptoms should not be explained by an alternative diagnosis, indicating the need to rule out other potential causes. This includes the definitions found for: Australia, Cyprus, Ireland, France, Germany, Latvia, Portugal, Romania, UK.

Differences

Notable differences between the definitions of Long COVID across countries include the following:

- 1. Impact on daily life:** Some definitions highlight the impact of Long COVID on daily life or functioning, including the definitions used in Australia, Croatia, Germany, and Norway, while many others focus more on the duration and nature of symptoms.
- 2. Organ system involvement:** The extent to which definitions emphasise multisystem involvement in Long COVID varies. Some explicitly mention impacts on respiratory, cardiovascular, neurological, and musculoskeletal systems, including the definitions from Croatia, Czechia, Belgium, Germany, and Slovenia. Others may provide a more general description.
- 3. Severity of acute COVID-19:** The mention of the severity of the acute phase of COVID-19 as a factor in defining Long COVID differs between definitions. For example, the Spanish definition distinguishes Long COVID as affecting those with a history of severe acute COVID-19 that required hospitalisation.

Some countries, like the United States, refer to persistent symptoms after a COVID-19 infection by various names such as Post-COVID Conditions, Long-haul COVID, post-acute COVID-19, Long-term effects of COVID, and chronic COVID.

Meanwhile, new developments have taken place with respect to the definition of Long COVID, for instance within the [ORCHESTRA](#)-study. This study provided new evidence that long COVID syndrome can be classified according to the combination of symptoms, with a different impact on physical and mental quality of life and different pathogenetic mechanisms. These insights led to the development of the following definition:

“The post-COVID-19 syndrome occurs in individuals with a history of SARS-CoV-2 infection, usually within 3 months from diagnosis, with symptoms that last till 24 months and can be differentiated in 4

clusters: respiratory, chronic fatigue like, chronic pain, and neurosensorial. Severe long COVID is defined by persistence of at least 3 clusters at 12 month of diagnosis with substantial impact on physical and mental individuals quality of life.” (Gentilotti et al., 2023).⁹

3.2. Long COVID guidelines for diagnosis and treatment

The second topic that was addressed in this mapping study, concerns the availability of Long COVID guidelines for diagnosis and treatment. For a total of 21 of the 34 countries that were part of our search, we found guidelines for diagnosis and/or treatment of Long COVID. Annex 2 provides an overview of the titles, the type of care providers that are addressed, the objectives, and the sources of the guidelines that were found.

Common elements

Common elements across the guidelines that were found include the following:

- 1. Multidisciplinary approach:** Several guidelines emphasise a multidisciplinary approach involving various healthcare professionals such as physiotherapists, occupational therapists, psychologists, and specialists in pulmonology, cardiology, neurology, etc. This includes for example the guidelines that were found in Germany, Spain, and Sweden.
- 2. Central role for primary care:** The guidelines often focus on primary care providers, such as general practitioners, as their target audience. This is for example the case in the guidelines that were found for Australia, Austria, Belgium, Canada, Denmark, Estonia, France, Germany, the Netherlands, Poland, and Spain.
- 3. Rehabilitation:** Rehabilitation is a key topic often referred to in the guidelines, including for example the guidelines from Belgium, Norway, Poland, and Sweden. In Germany there is even a distinct guideline on rehabilitation.

Differences

Notable differences between the guidelines that were found include the following:

- 1. Referral and follow-up:** Some guidelines provide recommendations for referral to specialised care when necessary and outline follow-up procedures to monitor the progress of patients with Long COVID. This is the case in the guidelines from Belgium and France.
- 2. Target group:** Some guidelines include recommendations for secondary (specialised) care (Belgium, Denmark, Germany, the Netherlands, Poland), for decision makers (Italy, Sweden), for healthcare providers in general (Austria, Canada, Greece, Latvia, Norway, Portugal, UK, US) and for interdisciplinary support involving municipalities (Denmark) or social services (Sweden).
- 3. Specific symptoms addressed:** Guidelines may focus on specific symptoms or organ systems affected by Long COVID. For example, the guideline from Ireland specifically addresses breathing discomfort, fatigue, cognitive symptoms, pulmonary symptoms, neurological manifestations, and cardiovascular symptoms.

Some countries, such as Canada, referred to the [living guidelines](#) as published by the WHO (last updated in January 2023), which contains the most up-to-date recommendations for the clinical management of people with COVID-19, including people with Long COVID. The guidelines are regularly updated as new evidence emerges.¹⁰

⁹ Gentilotti E, Górska A, Tami A, Gusinow R, Mirandola M, Rodríguez Baño (...), Tacconelli E. Clinical phenotypes and quality of life to define post-COVID-19 syndrome: a cluster analysis of the multinational, prospective ORCHESTRA cohort. *EClinicalMedicine*. 2023 Jul 21;62:102107.

In addition to the above collected national guidelines, we found several publications with *proposals* for guidelines for specific medical specialties and ways of treatment. We provide a preliminary list of recent articles on *proposed* guidelines found by searching PubMed for 'Long COVID and guidelines' (Annex 3).

3.3. Long COVID surveillance systems

The third topic that was addressed in this study, was the mapping of existing Long COVID surveillance systems. In our first approach the term 'surveillance system' was used in the search. Since this term did not lead to any results, the term 'registry' was used instead. This led to the finding of seven Long COVID registries from: Australia, Germany, Spain, Sweden, the Netherlands, New Zealand, and the United States. In addition, the Czech NELC member provided input on a registry in Czechia when the current report was shared by NELC members for their review. The German representative of the NELC also provided input on a second registry in Germany, leading to a total of nine registries from eight different countries.

Findings

In **Australia** the [Australian ME/CFS Biobank and Registry](#) (You+ME Registry) of Emerge Australia (association providing support to people with ME/CFS), was expanded in 2023 to collect vital data and biosamples from people who experience Long COVID symptoms. The mission of this registry is to provide biomedical researchers with access to high-quality patient biospecimens and a comprehensive data to facilitate impactful research into Long COVID and post-infection diseases.

The Registry is patient-driven, created by and for the people who use it, collecting detailed demographic and health information from individuals living in Australia. Using a secure web-based portal, registry participants can provide data regarding their diagnosis, symptoms, medications, and lived experiences. This information is then made available to approved researchers in a de-identified format.

Carers and supporters of those with Long COVID are also welcomed to contribute to the You+ME Registry as healthy volunteers. Healthy volunteers (aka: "controls" or people without Long COVID).

The Czech NELC member exemplified that in **Czechia** the Information System of Infectious Diseases (ISID) contains a post-COVID module with data on more than four thousand persons with post-COVID symptoms as registered by 44 pneumology outpatient clinics (which is 10% of all pneumology outpatient clinics in Czechia). Furthermore, the [National Registry of Reimbursed Health Services](#) (NRHVS) contains data on a large number of patients that are diagnosed with post-COVID by physicians based on ICD10 code U09.

The [Long COVID registry in Germany](#) covers the whole country and is being carried out jointly by scientists from different clinics and institutes at the Martin Luther University Halle-Wittenberg, the Technical University of Munich and the Otto von Guericke University Magdeburg. To date there is no data available from this registry. As part of this registry, long-term COVID symptoms, their progression, severity, and relief through individual therapies will be recorded. In addition, links between Long COVID and other diseases as well as gender and age can be investigated. The research is an online questionnaire survey, with follow-up measurements every 6 months.

In addition, the German NELC member exemplified that the German Central Institute of Statutory Health Insurance (Zi) has been continuously monitoring the number and characteristics of patients in Germany for whom post COVID-19 condition (ICD-Code U09.9) was documented in routine ambulatory health care data.

In **the Netherlands** there is an ongoing [Long COVID study](#) among children and adults, which is not labelled as register, but which has very similar features compared to the other registries described in this paragraph. The aim of the study is to investigate over a longer period how many people develop long-term health complaints after COVID, what the complaints are, how long they last, and whether they are different from people who have not had corona. People (with and without a positive test for the coronavirus) can enrol and have to fill out a questionnaire five times a year about their health, whether and when they have been vaccinated, the use of care and medicines, and the

occurrence of any complaints. The study is conducted by the National Institute for Public Health and the Environment (RIVM).

In **New Zealand** the [Long COVID Registry Aotearoa New Zealand](#) was set up by the University of Auckland and launched in 2023. The aim of this registry is to provide data to better understand: the burden of long COVID on patients, including learning more about symptoms; the impact of long COVID on quality of life; the different pathways and possible complications to receiving diagnosis and treatment; the impact of long COVID on work and caregiving; the cost of long COVID on individuals and our wider society; the distribution of this burden; and whether the impacts improve or worsen over time.

The registry aims to recruit 3.000 New Zealand adults (aged 18+) with self-reported Long COVID. Data on quality of life will be collected via monthly online surveys. At the start and six months after registration, participants will be asked to complete a larger survey covering several topics, including symptoms, diagnosis, and work.

The registry data will be linked to Stats NZ's Integrated Data Infrastructure (IDI) – a large research database containing de-identified microdata about people and households, including data on health, education and training, housing, income and work, benefits and social services, and census information.

In **Spain** the [REGICOVID-AP Clinical Registry](#) was announced by the Spanish society of general and family physicians (SEMG), on 3 February 2022. The aim of this registry was to identify clinical and genetic risk factors associated with the development of Long COVID. The REGICOVID-AP registry is a multicentre and nationwide registry, including a cohort of patients diagnosed with COVID-19 and conducting a follow-up aimed at detecting the development of long COVID. The recruitment would be carried out by primary care professionals, with the participation of the associations of patients affected by COVID-19, Long COVID ACTS, and with the rest of the professionals involved in the care of these patients.

The professionals would collect information related to the personal history of the patients and to the diagnosis and follow-up of COVID-19, in addition to performing a genetic analysis and an exome analysis on a subgroup. With the set of the above variables, a risk estimation model based on clinical and genetic variables of the host will be built to identify those patients who have a higher risk of developing this disease. Variables related to quality of life, disability, and patient experience would also be collected to complete the profile of those affected by long COVID, as well as the use of health resources, from the onset of symptoms. To date, it remains unclear to what extent this registry is put in place.

In **Sweden** the ongoing project called “Swedish Covid-19 Investigation for Future Insights – a Population Epidemiology Approach using Register Linkage ([SCIFI-PEARL](#))” started in 2020, led by the University of Gothenburg. SCIFI-PEARL is a nationwide register, that includes Swedish residents with Covid-19 and links to a broad range of national and regional healthcare data for a comprehensive longitudinal view of the Covid-19 pandemic. By combining high-quality national registers with short time delay and continuous repeated linkage and updating, the register brings timely and internationally relevant data for epidemiological research on SARS-CoV-2. Based on this registry, a [prospective cohort study](#) was conducted, including a two-year follow-up of patients with post-COVID-19 condition in Sweden. This study was led by Linköping University.

In the **United States** a registry called [Western New York Community-Based Long COVID Registry](#) among others from the University at Buffalo was launched in 2023. However, little information on this registry can be found. The registry (also known as the UBCoV registry) is a survey that can be completed by persons who think they have Long COVID. The aim of the registry is to help clinical researchers understand Long COVID in the community. There is another [registry by the University of Florida](#) for people who have experienced new, ongoing or returning symptoms after initial COVID-19 infection and who are interested in learning about current or upcoming IRB-approved research related to Long COVID.

Common elements

The registry from Sweden stands out from the other registries, as it is a nationwide registry, not specifically designed for the study of Long COVID, but for the study of Covid-19 and based on linked

administrative data (meaning that only existing data is used). Czechia and Germany have registries based on routinely recorded health data from healthcare practitioners. A **shared feature** of the other six registries is that all are specifically designed to study Long COVID. Furthermore, as far as it is reported, all these six registries collect data via online surveys. Thirdly, these registries are all based on self-registration of participants, except the Spanish registry. The Spanish registry involves primary care professionals recruiting participants.

Differences

One of the **differences** between the registries, is that only the Australian registry allows that carers of persons with Long COVID can register. Furthermore, the linkage of registry data to other data sources was only mentioned in the registries from New Zealand and Sweden. Thirdly, the Spanish registry seems the only registry to include genetic analysis and exome analysis for a subgroup of patients. This aspect is not explicitly mentioned in the other registries. Fourthly, only for the registries from Sweden and New Zealand a specific number of registry participants was mentioned, while the size of the other registries is not explicitly mentioned.

So far, the websites of most of these registries do not provide any information on insights that were gained based on the registry data, nor any expected dates on which insights can be expected. The German monitoring based on ICD-10 code for post COVID-19 is an exception. Furthermore, information about certain registries (specifically the US registry) is limited, making it challenging to provide detailed insights into its structure and goals compared to the other registries.

Additional studies

Although there is a limited number of Long COVID registries, there are several ongoing **longitudinal cohort studies and an even larger number of clinical trials** on the long-term progression and effects of potential therapies of COVID 19. The cohort studies offer important insights, for instance in the development of Long COVID symptoms over time. These insights could be very meaningful for the future development of surveillance systems. A couple of examples of such studies are:

- The [COVIMPACT project](#) as conducted by Sciensano in **Belgium**, aims to compose a cohort of people that were tested positive for COVID-19 and follow up their mental and physical condition in the long run, including factors that are associated with a positive or negative disease progression.
- The [quality database](#) for late sequelae of covid-19 from **Denmark**, established under the auspices of the Regions' Clinical Quality Program (RKKP). The database aims to support national data collection and is central to supporting research in Denmark. Among other things, a diagnosis code has been created: DB948A 'Following covid 19'.
- The German NELC member exemplified that in **Germany** there are multiple relevant cohort studies, for instance the [NAPKON \(National Pandemic Cohort Network\)](#) patient cohort studies investigating long-term health consequences of SARS-CoV-2 infection including large cohorts of patients admitted to university hospitals all over Germany as well as population-based cohorts of adults with confirmed SARS-CoV-2 infection in three regions. Data on mental and physical health trajectories are collected. Deep phenotyping including imaging studies and biomarker studies is possible in a subset.

The National Pandemic Cohort Network (NAPKON) was initiated in July 2020 as part of the University Medicine Network (NUM) and bundles previously decentralised national research activities into a common framework of cohorts and infrastructures. Patients are observed from the beginning of their infection with the SARS-CoV-2 virus and up to 3 years after infection. In addition to the collection of data, image data and biosamples, questionnaires and scores are collected to record symptoms or quality of life. The data is collected in three complementary cohorts: The High Resolution Platform (HAP), the Cross Sector Platform (SÜP) and the Population Based Platform (POP). While each cohort has its own focus, a harmonised data set is created as well with more than 12,000 data elements. This provides a unique opportunity to elucidate mechanisms that lead and contribute to the development and persistence of post-COVID.

- In addition the German NELC member stated that Germany has a Post-COVID-19 Monitoring in Routine Health Insurance Data (POINTED) program. The POINTED consortium (six large German sickness funds, health care services research institutions, Robert Koch Institute) has

been conducting matched cohort studies based on routine health care data in Germany.¹¹ Pre-defined long-term health sequelae as documented in health records are compared among adults, children and adolescents with and without documented SARS-CoV-2 infection. Furthermore, the German representative of the NELC referred to several population-based controlled studies of Long COVID¹² embedded in the national and regional COVID-19 [monitoring program at the Robert Koch Institute](#).

- The Irish NELC member stated that in **Ireland**, the ongoing [Follow-up After Disease Acquisition \(FADA\)](#) study is a retrospective cohort study of a nationally representative randomised sample of adults notified to the Irish Health Service Executive (HSE) as confirmed cases of COVID-19 between March 2020 and January 2022. “Fada” is also the Irish word for long. All individuals selected were invited to complete a self-reported online survey which was launched in March 2023. This study seeks a comprehensive understanding on long COVID in Ireland, with an initial focus on estimating the prevalence of long COVID and exploring its symptoms, nature, and impact. FADA survey invitations were disseminated via SMS, linking to an online survey covering demographics, COVID-19 history, long COVID symptoms, severity, duration, medical comorbidities, COVID-19 vaccination status, and lifestyle factors. Validated scores like the Modified Covid-19 Yorkshire Rehabilitation Score and the EQ-5D-5L were included. The FADA study dataset links to a diverse array of regional and national healthcare data, providing a comprehensive perspective on recovery of individuals from COVID-19.
- The [“Analysis and strategies of response to the Long-term effects of CoViD-19 infection \(Long-CoViD\)”](#) project, coordinated by the Istituto Superiore di Sanità (ISS) in **Italy**. The project involves Italian Regions (Tuscany, Apulia, and Friuli), Clinical networks (Neuroscience and Neurorehabilitation, Aging, Cardiological IRCCS (Scientific Institute for Research, Hospitalisation and Healthcare) networks) and the Catholic University of sacred Heart. Aims of the project are to define the dimensions of Long-Covid, to map number, characteristics, and distribution Long-Covid care centers in Italy, to define the best practices, to set up a Long-Covid surveillance system, and to structure a national clinical network.
- The [“CoVaLux”](#) (COVID-19, Vaccination & Long-term health consequences of COVID-19 in Luxembourg) study in **Luxembourg**, which is coordinated by Research Luxembourg and a consortium of Luxembourgish research institutions, including the Luxembourg Institute of Health (LIH). Overall, this unique project is providing important results that are helping to improve the understanding and Long-term impacts of COVID-19, while also leading to improvements in patient care.
- In **the Netherlands** a large-scale [Long-COVID study](#) started in October 2021, based on a combination of data sources and methods. Specific attention is paid to vulnerable groups within this study, which is lead by Nivel, University of Groningen, Radboud University, Maastricht University and Dutch Hospital Data. Besides that, an [observational cohort study](#) from the Netherlands aimed to analyse the nature, prevalence, and severity of long-term symptoms related to COVID-19, while correcting for symptoms present before SARS-CoV-2 infection and controlling for the symptom dynamics in the population without infection. The study is based on data collected within the Lifelines project, a multidisciplinary, prospective, population-based, observational cohort study examining the health and health-related behaviors of people living in the north of the Netherlands.

¹¹ See for instance: Roessler M, Tesch F, Batram M, Jacob J, Loser F, Weidinger O, (...), Schmitt J. Post-COVID-19-associated morbidity in children, adolescents, and adults: A matched cohort study including more than 157,000 individuals with COVID-19 in Germany. *PLoS Med.* 2022 Nov 10;19(11):e1004122. doi:<https://doi.org/10.1371/journal.pmed.1004122> ; Tesch F, Ehm F, Vivirito A, Wende D, Batram M, Loser F, (...), Schmitt J. Incident autoimmune diseases in association with SARS-CoV-2 infection: a matched cohort study. *Clin Rheumatol.* 2023 Oct;42(10):2905-2914. doi: <https://doi.org/10.1007/s10067-023-06670-0>

¹² See for instance: Heidemann C, Sarganas G, Du Y, Gaertner B, Poethko-Müller C, Cohrdes C, (...), Scheidt-Nave C. Long-term health consequences among individuals with SARS-CoV-2 infection compared to individuals without infection: results of the population-based cohort study CoMoLo Follow-up. *BMC Public Health.* 2023 Aug 21;23(1):1587. doi: 10.1186/s12889-023-16524-8. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10440884/>; Wurm J, Finkel B, Iwanowski H, Jordan S, Sandoni A, Kubisch U, (...), Loss J. Day care study showed no differences in long-term symptoms in children who were and were not infected during COVID-19 outbreaks. *Acta Paediatr.* 2024 Jan;113(1):116-118. doi: 10.1111/apa.17014.

- The [LOCUS study](#) (Long Covid – Understanding Symptoms, Events, and Service Usage in Portugal) from **Portugal**, which aims to contribute to the understanding of Long-term COVID (post-COVID-19 condition). The main goal is to determine how many people in Portugal are suffering from Long-term COVID-19 and what their characteristics are. This includes patients who were hospitalized due to COVID-19 and those being monitored in the community. The study also seeks to understand the experiences related to Long-term COVID-19 through three components: severe events in patients hospitalised due to COVID-19, mild symptoms among community cases of COVID-19, experiences of patients with Long-term COVID, and professionals following these patients. Participation in the study is by invitation only based on clinical records or national COVID-19 surveillance systems.
- The [RECOVER initiative](#) from the **United States**, where large numbers of Long COVID patients will be enrolled in clinical trials.

4. Reflections

It is evident that the three topics explored in this mapping study, definitions, guidelines, and surveillance systems, are closely intertwined. Without a clear definition, the development of guidelines for diagnosis and treatment and the establishment of surveillance systems becomes challenging, as these necessitate a clear understanding of who should be included and monitored. The development of a definition is, however, complex due to the diverse range of symptoms experienced by those who suffer from Long COVID.

The definition as proposed by the ORCHESTRA project, distinguishing multiple types of Long COVID based on clusters of symptoms and patient characteristics, might contribute to the development of more refined guidelines for diagnostics and treatment as well as the development of surveillance systems.

Regarding guidelines for diagnosis and treatment of Long COVID, certain countries have guidelines spanning across medical disciplines, while others have guidelines for specific disciplines, such as occupational therapists. For many countries guidelines are lacking or difficult to find.

As for surveillance systems, there is currently a lack of comprehensive systems. A few countries have established registries to track and follow Long COVID patients, although little is known about how these registries function in practice and what knowledge is gained from them so far. Participation in most of these registries is voluntary and five of the seven are based on self-registration, which introduces the caveat that not all individuals enrolled may have received an official Long COVID diagnosis.

Some countries, including Bulgaria, Italy, Germany, and Ireland, have implemented clinical centers for Long COVID patients¹³ from which data can be collected that may serve as an alternative source of information on the Long COVID population.

Similarly, several countries have implemented or are implementing cohort studies for Long COVID patients or clinical trials, which could serve as alternative sources of information from registries. Clinical trials often deal with attempts to cure or care for specific post COVID symptoms and conditions that often are the object of medical specialties, such as cardiology, neurology, pulmonology, or pediatrics. They are an essential element of a comprehensive surveillance system and provide the possibility to learn from best medical practices.

A limitation of the current rapid mapping exercise is that the term 'Long COVID' was translated into national languages using machine translation. It might be possible that the correct terminology or frequently used synonyms that are used in specific countries was not applied and that information, particularly on guidelines, but also on definitions and registries or surveillance systems, might have been missed.

¹³ Survivor Corps: <https://www.survivorcorps.com/pccc-europe>

5. Conclusion

Based on this rapid mapping of publicly available information, it can be concluded that in most EU Member States guidelines for the diagnosis and treatment of Long COVID need to be developed or need to be made publicly available. Member States in which guidelines are available could serve as an example. Simultaneously, guidelines for more specific aspects of Long COVID and its possible treatment are still in development.

Furthermore, although many efforts seem to have been undertaken to study Long COVID in cohort-based studies and clinical trials, surveillance systems are not yet in place in EU Member States and further developments in this respect could be a joint effort.

Annex 1 Overview of definitions per country

Country	Definition	Source
Australia	The term Long COVID is generally used to describe both: ongoing symptomatic COVID-19 – COVID-19 symptoms lasting more than 4 weeks and post-COVID-19 condition/syndrome – COVID-19 symptoms after 12 weeks that are not explained by an alternative diagnosis.	Government of Australia
	<p>Long COVID is defined by the World Health Organization as: “a condition that occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually: three months from the onset of COVID-19; AND with symptoms that last for at least two months and cannot be explained by an alternative diagnosis”. Note that both of these criteria are required. A number of other terms are sometimes used to describe long COVID such as ‘post-acute COVID-19’ or ‘post COVID-19 syndrome’. These terms are not synonymous with long COVID, as they may also describe symptoms that persist immediately following acute COVID-19 illness.</p> <p>The World Health Organization states “common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial illness. Symptoms may also fluctuate or relapse over time”.</p>	New South Wales Government
Austria	“Long-COVID”: complaints that occur or persist longer than four weeks after infection, “Post-COVID”: complaints that occur or persist longer than 12 weeks after infection.	Gesundheit.gv.at
	In an Austrian Long COVID guideline, published by Karl Landsteiner University, the NICE (National Institute for Health and Care Excellence) definition is adopted: Acute COVID-19: Symptoms of COVID-19 up to 4 weeks. Persistent COVID-19: 4-12 weeks. Post-COVID syndrome: Symptoms that occur during infection with SARS-Cov-2, but similar to symptoms observed before COVID-19, lasting Longer than 12 weeks and no other identifiable causes.	Karl Landsteiner University
Belgium	People who have experienced COVID-19 and have persistent symptoms for at least 4 weeks after the acute infection. This includes patients who have been hospitalized during the COVID-19 infection, as well as patients who have experienced the COVID-19 infection at home.	Evikey Network
	Sciensano refers to the NICE (National Institute for Health and Care Excellence) definition: Acute COVID-19: Symptoms of COVID-19 up to 4 weeks. Persistent COVID-19: 4-12 weeks. Post-COVID syndrome: Symptoms that occur during infection with SARS-Cov-2, but similar to symptoms observed	Sciensano

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	before COVID-19, lasting Longer than 12 weeks and no other identifiable causes.	
Bulgaria	Usually, the symptoms of COVID-19 resolve within 4 weeks of the onset of the disease – the so-called “acute COVID-19” phase. If the complaints continue after the fourth week (or reappear), we are now talking about so-called “Long COVID-19”. The “Long COVID-19” itself is divided into two periods: from the 4 th to the 12 th week is the “proLonged symptomatic COVID-19”, and after the 12 th week we speak of the “post-COVID-19 syndrome”. It includes symptoms such as shortness of breath, easy fatigability, persistent cough, joint and muscle pain, cardiovascular complaints, impaired kidney and liver function, depression, brain fog and even hair loss. Evidence has recently emerged of recorded cases where symptoms do not resolve even 6 months after cure.	Bulgarian Cardiac Institute
	Long COVID, also referred to as “Long-Haul COVID or Post-COVID syndrome” is a condition where a person continues to experience symptoms of COVID-19 after their body has defeated the virus. Long COVID is a Post-COVID condition, which the Centers for Disease Control and Prevention (CDC) of the United States describes as “new, returning or ongoing health problems” caused by the disease more than a month after infection.	Department of Medical Chemistry and Biochemistry, Medical Faculty, Trakia University, Stara Zagora, Bulgaria
Canada	Post COVID-19 condition is when the symptoms of COVID-19 persist for more than 12 weeks after the infection. It’s also known as Long COVID, and can affect both adults and children.	Government of Canada
Croatia	In addition to acute manifestation, an increasing number of people show proLonged symptoms after recovering from COVID-19 – this is called Long COVID, and it can last for several weeks and even months after recovery. These proLonged symptoms are most often manifested as respiratory symptoms, but can also be symptoms –f damage to other organ systems - cardiovascular, neurological, and musculoskeletal, often also accompanied by psychological effects and sometimes even cognitive disorders, which all leads to decreased functioning in daily activities and impacts quality of life.	Zdravlje.gov.hr
Cyprus	Long – COVID’ also referred to as post – COVID conditions, post – COVID syndrome, or post-acute sequelae of SARS-Cov-2 infection (PASC), generally refers to symptoms that develop during or after acute COVID-19 illness, continue for > 4 weeks, and are not explained by an alternative diagnosis.	Kounnis Zacharias Cardiology Center
	Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of	Long Covid Outpatient Clinic, State Health Services Organization

	<p>breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.</p>	<p>Unit for Surveillance and Control of Communicable Diseases, Medical and Public Health Services, Ministry of Health</p> <p>Information provided by Cypriot NELC member</p>
Czechia	<p>Post-COVID syndrome is a collection of respiratory and non-respiratory symptoms that persist for 12 or more weeks after the onset of COVID-19, which are pathophysiologically related to this condition and cannot be explained by another cause [NICE 2020]. Recently, it has become evident that not all patients with post-COVID changes in respiratory system function (as assessed by pulmonary diffusion and stress testing) and/or changes in lung structure (as assessed by HRCT of the chest) are symptomatic. Therefore, a broader term, post-COVID impairment, is sometimes used. Analogies to post-COVID impairment have been found in patients with SARS and swine flu.</p>	<p>Position paper of the Czech Pneumological and Phthisiological Society</p>
	<p>a. Signs of objective impairment of respiratory function or structure of the lungs or other organs, with or without subjective symptoms;</p> <p>b. The presence of prior PCR/Ag-confirmed COVID-19 disease at least 12 weeks prior to the onset of these complaints;</p> <p>c. While excluding any other cause of these difficulties.</p>	<p>Information provided by Czech NELC member</p>
Denmark	<p>Inspired by a guideline from NICE from December 2020, the Danish Health Authority considers symptoms that have persisted for 4 weeks or Longer after the onset of the disease as a Long-duration course of COVID-19. If these persistent symptoms last for 12 weeks or more, they are considered as Long-term consequences</p>	<p>Danish Health Authority</p>
Estonia	<p>In the primary care guidelines as published by an Estonian health insurer, the NICE (National Institute for Health and Care Excellence) definition is adopted: Acute COVID-19: Symptoms of COVID-19 up to 4 weeks. Persistent COVID-19: 4-12 weeks. Post-COVID syndrome: Symptoms that occur during infection with SARS-Cov-2, but similar to symptoms observed before COVID-19, lasting Longer than 12 weeks and no other identifiable causes.</p>	<p>Primary care guidelines Estonian health insurance</p>
Finland	<p>The symptoms last for at least two months and cannot be explained by any other diagnosis.</p>	<p>Finnish institute for health and welfare</p>
France	<p>Presence of at least one of the initial symptoms, for over 4 weeks following the start of the acute phase of the disease. Initial and Long-term symptoms are not</p>	<p>HAS Sante</p>

	explained by another diagnosis with no known relationship with COVID-19.	
	Persistent symptoms after an initial symptomatic episode of COVID-19, confirmed or probable, with the presence of at least one of the initial symptoms for more than 4 weeks after the onset of the acute phase of the disease and not explained by another diagnosis unrelated to COVID-19.	HAS Sante
Germany	Long COVID refers to the general, long-term health problems after an infection of the Corona virus. These symptoms go beyond the acute illness phase of 4 weeks or arise newly or again after this phase. Post COVID refers to symptoms, which are still present even after 12 weeks or arise newly or again after a Corona virus infection. The symptoms last for at least 2 months and cannot be explained otherwise. Furthermore, the Long haulers are generally affected in everyday life.	Federal Ministry of Health / BMG Long COVID Initiative / Robert Koch Institute
Greece	The Hellenic Thoracic Society adopted the NICE (National Institute for Health and Care Excellence) definition: Acute COVID-19: Symptoms of COVID-19 up to 4 weeks. Persistent COVID-19: 4-12 weeks. Post-COVID syndrome: Symptoms that occur during infection with SARS-Cov-2, but similar to symptoms observed before COVID-19, lasting Longer than 12 weeks and no other identifiable causes.	Hellenic Thoracic Society
Hungary	Post-COVID symptoms are first identified at least four weeks after infection.	National public health center
Iceland	Long-term mental and physical health consequences of a COVID-19 infection.	COVIDMENT project
Ireland	You may be diagnosed with Long COVID if your symptoms continue 3 months after you were infected with COVID-19, are present for at least 2 months – symptoms can come and go and have an impact on your day-to-day life.	Health Services Executive Ireland
	Based on NICE. The following clinical definitions for the initial illness and Long COVID at different times: Acute COVID-19: signs and symptoms of COVID-19 for up to 4 weeks. Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4 to 12 weeks. Post-COVID-19 syndrome: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.	HSE Health library Ireland
Italy	If more than four weeks after infection with SARS-CoV-2, despite the negative test, some symptoms persist, we speak of Long-CoViD. This condition, which precludes a full return to the previous state of health, can affect, according to a study published in Nature Medicine, up to one in two people, and can leave a trail even months later. Despite the vast	ISS

	<p>impact on the population, and although it has been recognized as a specific clinical entity, knowledge about Long-CoViD is still scarce and subject to numerous investigations.</p>	
Latvia	<p>The Post-COVID-19 condition occurs in individuals who have had a possible or confirmed SARS-CoV-2 infection, typically within 3 months after Covid-19. Symptoms can last for at least 2 months and cannot be explained by any other alternative diagnosis. The most common symptoms include a feeling of fatigue, shortness of breath, cognitive dysfunction, but other symptoms are also possible, and they usually significantly affect daily activities. Symptoms may reappear after recovery from an acute episode of Covid-19 or persist from the onset of the illness. Over time, the symptoms may have a fluctuating or recurring nature</p>	<p>Riga University</p>
Lithuania	<p>No definition was found.</p>	
Luxembourg	<p>The COVID-19 infection manifests itself through a diverse array of symptoms, varying in type and intensity and consequently resulting in very different outcomes for affected patients. One outcome that has become increasingly clear over the past year is the onset of persistent symptoms after the initial acute infection, which has been widely referred to as 'Long COVID'. Despite this now being a well-known potential outcome of COVID-19, little is still known about this debilitating disease.</p>	<p>Luxembourg Institute of Health</p>
Malta	<p>"It became evident quite early on that some infected individuals were experiencing persistent symptoms beyond the acute phase due to prolonged viral involvement affecting multiple organs. These individuals were labelled as experiencing Long COVID."</p>	<p>Cuschieri et al., 2023 – University of Malta; Mater Dei Hospital Malta</p>
	<p>"Long COVID has been defined in several ways. Recently, the World Health Organization used the Delphi method to agree on a definition. Observations from various studies have indicated a significant variation in reported symptoms ranging from fatigue, dyspnoea, joint pains, chest pain, headaches, hair loss and changes in hearing with or without tinnitus to psychological disorders such as memory loss, anxiety, depression, disorders of sleep and concentration and attention disorders."</p>	<p>Baruch et al., 2022 – Ministry of Health Malta; European Centre for Disease Prevention and Control Sweden</p>
Netherlands	<p>Some people have Long-term symptoms after a SARS-CoV-2 infection. This is referred to as 'Long COVID' or 'PASC': Post-Acute Sequelae of SARS-CoV-2. These symptoms may persist for several weeks after COVID-19, but could sometimes last several months. People with Long COVID may experience such symptoms as: fatigue, shortness of breath, chest pain, muscle aches, headaches, heart palpitations, proLonged loss of smell, or suffer from depression or memory problems – often called 'brain fog'.</p>	<p>National Institute for Public Health and the Environment</p>

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New Zealand	Long COVID describes the symptoms that continue or develop after your initial COVID-19 symptoms. You can experience these symptoms more than 12 weeks after you are first infected.	New Zealand Government
Norway	The term “late sequelae of covid-19” (or post or Long COVID) is used to describe the condition of patients who experience persistent symptoms beyond 4-6 weeks after being ill.	Directory of Health
	People who have symptoms that affect their daily life and have lasted for at least 2 months, are diagnosed with “Post-COVID-19 condition	Norwegian Institute of Public Health
Poland	Long COVID – COVID-19 symptoms lasting from 4 to 12 weeks. Post-COVID – COVID-19 symptoms lasting Longer than 12 weeks.	Agency for health technology assessment and tariff system
Portugal	Post-COVID-19 condition, also known as Long COVID-19, occurs in people who have had COVID-19, usually 3 months after the onset of the acute phase and lasting at least 2 months. Symptoms can arise during or after an acute COVID-19 infection, impact the quality of life of the affected person and are not explained by an alternative diagnosis. More than 50 symptoms have been described associated with this condition. The most common are fatigue, breathing difficulties, changes in smell and taste, headache, chest pain, changes in concentration and memory.	NOVA National School of Public Health
Romania	<p>The National Institute for Health and Clinical Excellence, the Royal College of General Practitioners, and the Scottish Intercollegiate Guidelines Network define the different forms of COVID based on the duration of symptoms as follows: Acute COVID-19 infection – signs and symptoms of COVID-19 that can last up to 4 weeks. Ongoing symptomatic COVID-19 – signs and symptoms of COVID-19 that persist between 4 and 12 weeks. Post-COVID-19 syndrome – signs and symptoms that develop during or after COVID-19, lasting more than twelve weeks and not explained by an alternative diagnosis. It typically presents as a group of diverse symptoms, often overlapping, which can fluctuate and change over time and affect various systems in the body. Post-COVID-19 syndrome can be considered even before 12 weeks, while the possibility of an alternative disease is also evaluated.</p> <p>Another classification proposed for Long COVID includes: Post-COVID syndrome ICU follow-up; Post-viral fatigue syndrome; Persistent organ damage; Long-term COVID syndrome.</p>	REGINA MARIA Private Health Network
Slovakia	The recovery time from COVID-19 is different for everyone. For some people, symptoms can last for weeks or months after experiencing COVID-19. If various health problems arise for more than 4 weeks,	NZIP

	<p>we can already speak of the so-called “Long covid”. Post-covid syndrome (also called chronic covid) is a set of symptoms that last twelve or more weeks after infection with SARS-CoV-2.</p>	
	<p>The exact medical definition of post-covid syndrom is still in development, but most experts suggest that the symptoms persist for more than twelve weeks and are not explained by other diagnoses.</p>	<p>Ministerstvo Práce, Sociálních Vecí A Rodiny Slovenskej Republiky</p>
Slovenia	<p>“One of the enduring repercussions of the COVID-19 pandemic, which has persisted for the past 3 years, is a phenomenon referred to as ‘long COVID’ or ‘long-haulers’ within the medical community. This is a post-COVID condition defined as an umbrella term for a complex multisystem illness.¹ Cook et al noted that long COVID is related to a variety of diseases and symptoms, such as fatigue, dyspnoea, cardiovascular abnormalities, mental health problems, olfactory and gustatory dysfunction, and pulmonary symptoms.”</p>	<p>Rotar Pavlic et al., 2023 – University of Ljubljana; Primary Healthcare Research and Development Institute Ljubljana; University Clinical Center Ljubljana.</p>
Spain	<p>Post COVID: a history of severe COVID-19 in its acute phase, often requiring hospitalization, even in critical care units, and presenting symptoms resulting from later sequelae to the structural damage of the complications suffered</p> <p>Long COVID: A multiorgan symptomatic complex that affects those patients who have suffered from COVID-19 and who remain symptomatic after the considered acute phase of the disease, past 4 and up to 12 weeks, with symptoms persisting over time</p>	<p>SEMG, Spanish society for general practitioners and family doctors</p>
Sweden	<p>The Swedish Board of Health and Welfare (Socialstyrelsen) describes patients with Postcovid as individuals exhibiting proLonged symptoms, or experiencing new relevant symptoms after the acute phase of COVID-19 infection. While the severity of symptoms will diminish over time for most individuals (such individuals do not need assistance from healthcare during the recovery), some individuals experience symptoms that are debilitating and need treatment, rehabilitation, and other follow-up medical care.</p>	<p>The Swedish Board of Health and Welfare</p>
United Kingdom	<p>The Long-term effects of COVID-19 are often referred to interchangeably as Long COVID and post COVID syndrome. The National Institute for Clinical Excellence (NICE)/Scottish Intercollegiate Guidelines Network/Royal College of General Practitioners guidance on managing Long-term effects of COVID-19 (updated November 2021) gives the following clinical definitions below:</p> <p>ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from four to 12 weeks</p> <p>post COVID-19 syndrome: signs and symptoms that develop during or after COVID-19 and continue for more than 12 weeks and are not explained by an alternative diagnosis.</p>	<p>NHS England</p>

United States

Some people who have been infected with the virus that causes COVID-19 can experience Long-term effects from their infection, known as Long COVID or Post-COVID Conditions (PCC). Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after acute COVID-19 infection. This definition of Long COVID was developed by the Department of Health and Human Services (HHS) in collaboration with CDC and other partners. People call Long COVID by many names, including Post-COVID Conditions, Long-haul COVID, post-acute COVID-19, Long-term effects of COVID, and chronic COVID. The term post-acute sequelae of SARS CoV-2 infection (PASC) is also used to refer to a subset of Long COVID.

[Centers for Disease Control and Prevention](#)

Annex 2 Overview of available guidelines per country

Country	Name of the guideline	Target audience	Purpose	Source
Australia	<p>Clinical practice guide for assessment and management of adults, children and young people with symptoms of long COVID</p> <p>Guidance for NSW health clinicians</p> <p>November, 2023</p>	<p>Clinicians who provide care to adults, young people and children with a history of COVID-19 diagnosis, regardless of severity or COVID-19 variant of concern.</p>	<p>Clinical practice guide for assessment and management of adults, children and young people with symptoms of long COVID for New South Wales health clinicians.</p> <p>This guide is intended for use together with the Long COVID Model of Care, which outlines a four-stage approach through which people with symptoms of long COVID may receive care. Together, this guide and model of care are designed to: minimise the risk of fragmented delivery of care; avoid potential over-investigation and over-treatment; and identify people who would benefit from further assessment and management.</p> <p>This information is not a substitute for a healthcare provider's professional judgement and is intended to provide additional guidance for the assessment and management of symptoms of long COVID, after usual clinical assessment and care.</p>	<p>New South Wales Government</p>
Austria	<p>Guideline S1 for the treatment of post-viral conditions, using the example of post-COVID-19.</p>	<p>The emphasis is on practical applicability at the primary care level, which is understood as an appropriate place for initial access and for</p>	<p>Differential diagnosis and treatment strategies.</p>	<p>Rabady et al., 2023 – Karl Landsteiner University</p>

		primary care and treatment.		
	The Long COVID guideline (as mentioned in the previous row) was transferred into a practical point-of-care tool.	All medical doctors who deal with Long COVID patients or who are interested in the clinical picture. Yet the main aim is to support general practitioners, who are the central point of care and the first point of contact.	To provide information and decision support. The tool is suitable for use at the point of need - also during the consultation - as well as for reference and research.	Developed by the Austrian health professional board for "general practitioners" (ÖGAM) and the Austrian Karl Landsteiner University
Belgium	Guideline 'Follow-up and rehabilitation of patients with persistent symptoms after COVID-19 in primary care'	The intended users of the guideline are frontline healthcare workers dealing with patients with persistent complaints after COVID-19: general practitioners, physiotherapists, occupational therapists, clinical psychologists, speech therapists and dieticians. The guideline is also relevant for other healthcare workers such as social workers and healthcare providers in the second line (pulmonologists, cardiologists, rehabilitation physicians,	Healthcare workers can use this guideline when making decisions about the follow-up and rehabilitation of patients with complaints after COVID-19. Specifically, this guideline provides recommendations for diagnostics, rehabilitation therapies, follow-up and referral of patients with persistent (≥ 4 weeks) symptoms of COVID-19 in primary care. The goal is to offer efficient solutions to ongoing COVID-related health issues.	Dillen et al., 2022 - Evikey Netwerk

				<p>pneumologists , ear, nose and throat physicians, neurologists, psychiatrists and geriatricians), because it describes the current care for these patients.</p>
Bulgaria	No guidelines were found.			
Canada	<p>Post COVID-19 Condition: Guidance for Primary Care. January, 2023</p>	Physicians	To support assessment and management of symptoms.	Ontario Health, Government of Ontario
	<p>Website Post-COVID Recovery Care 2023</p>	Healthcare providers	This page provides healthcare providers with a centralized resource for the latest evidence and recommendations for managing post-COVID symptoms.	Provincial Health Services Authority of British Columbia
Croatia	No guidelines were found.			
Cyprus	<p>No guidelines were found. Guideline development is under consideration. The Cyprus Federation of Patients' Associations (CyFPA) has published some manuals regarding specific issues of Long COVID (rehabilitation manual, dietary advice, returning to work),</p>			Cyprus Federation of Patients' Associations (CyFPA)
Czechia	No guidelines were found, but the Czech Society of Pneumology and Phthisiology			Newssite Lidovky.cz

	is preparing clear instructions on how to effectively care for symptomatic patients after COVID.			
Denmark	<p>Senfølger ved covid 19 - Recommendations for the organisation of care for patients with long-term symptoms of COVID-19.</p> <p>August, 2023</p>	Healthcare providers working in general practices or in hospitals as well as municipalities.	To provide recommendations for the organisation of care for patients with Long-term symptoms of COVID-19 as well as recommendations for examination and treatment in general practice and the management of long-term symptoms in hospital. It also contains recommendations for interdisciplinary support and the role of municipalities.	Danish Health Authority
Estonia	Treatment guidelines for Long COVID-19 for primary care.	Primary care providers.	Describing management of patients with suspected Long-COVID 19 complaints based on specific symptoms and comorbidities and different sex and age groups.	Primary care guidelines Estonian health insurance
Finland	No guidelines were found. According to the Finnish Institute for Health and Welfare, there is no generally accepted medical treatment for the disease. Several different drugs are used to treat the symptoms. The doctor may try different drug treatments on his Long covid patients in order to find a drug that this particular person will benefit from.			Finnish Institute for Health and Welfare
France	Toolkit guide titled: Rapid responses in the	Primary care providers.	To provide guidance for diagnosis, clinical assessment, additional	HAS Sante

	context of COVID-19: Prolonged symptoms following acute COVID-19 in adults — Diagnosis and management February, 2021		tests, communication with the patient, referral to secondary or tertiary specialist advice, follow-up and organisation of care.	
Germany	The German Society of Pneumology initiated in 2021 the AWMF S1 guideline Long COVID/PostCOVID.	Healthcare providers working in primary and secondary care settings.	The clinical recommendations describe current Long COVID/Post-COVID symptoms, diagnostic approaches, and therapies.	German Society of Pneumology
	Long COVID guidelines for patients and related persons	Long COVID patients and related persons.	Recommendations on what post-COVID is, causes and possible therapies.	AWMF online
	Guideline about rehabilitation of Long COVID patients	Healthcare professionals.	Recommendations on rehabilitation for Long COVID patients.	AWMF online
	Guideline about fatigue (including ME/CFS)	Healthcare professionals.	Recommendations on treatment of fatigue in persons suffering from Post-COVID-19-Syndrom.	AWMF online
	Guideline concerning neurologic manifestations of COVID-19 (living guideline to be updated)	Healthcare professionals.	Guideline on diagnostics and treatment of neurological problems following a COVID-19 infection, with a specific chapter on neurological problems during Post-COVID-19-Syndrom.	AWMF online
Greece	Long/Post Covid diagnostic and therapeutic approach.	Healthcare professionals.	Diagnosis and treatment of Long COVID.	Hellenic Thoracic Society
Hungary	No guidelines were found.			
Iceland	No guidelines were found.			
Ireland	International review of clinical guidelines and models of care for Long COVID	No specific target audience.	Guidelines/care models on diagnosis and management of Long COVID or on a specific sequelae of Long	Health Information and Quality Authority Ireland

	December, 2022		COVID including: breathing discomfort; fatigue; cognitive symptoms; pulmonary symptoms; neurological manifestations; cardiovascular symptoms.	
Italy	Italian good practice recommendations on management of persons with Long-COVID (research paper).	Patients with Long-COVID, healthcare professionals and the healthcare system.	To develop good practice recommendations for the clinical management of patients with Long-COVID in order to provide guidance and improve quality of care. These recommendations could contribute to standardize on a national basis the assistance provided - in terms of diagnosis, care and services organization - by the clinical centers and to strengthen their interactions.	Giuliano et al., 2023 - National Center for Global Health, Istituto Superiore di Sanità (a total number of 27 organisations were represented by the authors of this article).
Latvia	Clinical Pathways for Adults	Medical doctors.	To offer assessment and decision support for doctors when suspecting patients to have Long COVID.	Riga University
Lithuania	No guidelines were found.			
Luxembourg	No guidelines were found.			
Malta	No guidelines were found, but in the national health systems strategy it was mentioned that specific services and specialist care may need to be set up to meet the needs of persons with Long COVID.			A National Health Systems Strategy for Malta 2023 - 2030
Netherlands	Long-term complaints after COVID-19. March, 2022	General practitioners	Long COVID diagnosis and policy.	Dutch Society of General Practitioners

	<p>Multidisciplinary care after COVID-19.</p> <p>March, 2022</p>	<p>Care professionals from multiple disciplines, including: general practitioners, rehabilitation doctors, geriatricians, occupational physicians, insurance doctors.</p>	<p>Guideline on how to design multidisciplinary treatment of long-term complaints after COVID-19.</p>	<p>Federation of Medical Specialists, Long Alliance Netherlands and the Dutch Society of General Practitioners</p>
	<p>Recovery & reintegration for workers with Post-COVID Syndrome.</p> <p>June, 2022</p>	<p>Occupational physicians</p>	<p>Guideline on recovery and reintegration of workers with Post-COVID Syndrome.</p>	<p>NVAB, the Netherlands Society of Occupational Medicine</p>
	<p>Guide to occupational therapy for clients with the post-COVID-syndrome</p> <p>October, 2022</p>	<p>Occupational therapists working in primary care that treat clients in the context of paramedical recovery care for COVID-19. The guide also offers points of reference for secondary care, to shape the treatment of Long COVID.</p>	<p>The purpose of this document is to provide treatment guidance for occupational therapists if COVID-19 post-infectious complaints persist.</p>	<p>Occupational therapy Netherlands</p>
New Zealand	<p>No guidelines were found. The governmental website of New Zealand states that researchers and healthcare providers are still working out the best ways to manage Long COVID and that there are currently no specific treatments.</p>			<p>New Zealand Government</p>
Norway	<p>Rehabilitation after COVID-19,</p>	<p>Healthcare providers.</p>	<p>Advice on post COVID-19 rehabilitation.</p>	<p>Directory of Health</p>

December 2021				
Poland	Recommendations for Long COVID/Post-COVID	Patients, family doctors, outpatient specialist care providers.	<p>To inform family doctors on so-called 'red flags' that require the consideration of referring patients to hospital or outpatient care and on diagnostic and therapeutic procedures.</p> <p>To provide pulmonologists, cardiologists, neuropsychiatrists on symptoms and management of patients with Long COVID/post-COVID.</p> <p>To provide information on rehabilitation.</p>	Agency for health technology assessment and tariff system
Portugal	<p>On the website of Ordem Dos Médicos Região do Sul (order of doctors of the southern region), a reference is made to the NICE guideline: COVID-19 rapid guideline: managing the long-term effects of COVID-19 [NG188].</p> <p>December, 2020 (Last updated: November 2021)</p>	Healthcare providers working in all healthcare settings.	<p>This guideline covers identifying, assessing and managing the long-term effects of COVID-19, often described as 'long COVID'. It makes recommendations about care in all healthcare settings for adults, children and young people who have new or ongoing symptoms 4 weeks or more after the start of acute COVID-19. It also includes advice on organising services for long COVID.</p>	<p>NICE - COVID-19 rapid guideline: managing the long-term effects of COVID-19</p> <p>This guideline has been developed jointly by NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP).</p>
Romania	No guidelines were found.			
Slovakia	No guidelines were found.			
Slovenia	<p>https://www.zdravniskazbornica.si/informacije-publikacije-in-analize/obvestila/2023/01/10/dolgoro%C4%8Dne-posledice-covid-19-dolgi-covid</p> <p>Usmeritev bolnikom po</p>	Healthcare professionals that participate in services provided to Long-COVID 19 patients.	Guidelines cover identifying, assessing and managing the long-term effects of COVID-19	University Medical Centre, Ljubljana (department of infectious diseases)

	<p>prebolelem covidu-19 Nijz</p> <p>https://nijz.si/wp-content/uploads/2022/02/smernice_obravnav_a_covid_zvc_ckz-1.pdf</p>			National Institute of Public Health
Spain	<p>Long Covid-19: proposed primary care clinical guidelines for diagnosis and disease management.</p>	<p>Primary care providers.</p>	<p>To provide guidance for diagnosis and management of Long-COVID.</p>	<p>Sisó-Almirall et al., 2021 - Permanent Board of the Catalan Society of Family and Community Medicine (CAMFiC) (a total of 10 Spanish research and hospital departments contributed to this publication).</p>
	<p>Clinical guide for the care of patients with Long COVID/persistent COVID</p> <p>May, 2021</p>	<p>Healthcare professionals and assistants of any discipline of specialization that participate in services provided to Long-COVID 19 patients.</p>	<p>To improve the health of Long COVID-19 patients and increase visibility of the condition. Increase knowledge on Long COVID-19 patients, evaluate according to common criteria, apply scientific evidence and patient experiences to a clinical guideline and homogenise clinical practice.</p>	<p>SEMG, Spanish society for general practitioners and family doctors</p>
Sweden	<p>Post COVID-19 – effective treatment and rehabilitation. A systematic review and assessment of medical and economic aspects.</p> <p>August, 2022</p>	<p>Staff and decision-makers in health care and social services.</p>	<p>To provide insight into treatments are effective for post COVID-19.</p>	<p>SBU, Swedish Agency for Health Technology Assessment and Assessment of Social Services</p>
	<p>Postcovid – residual or late symptoms after covid-19</p> <p>Support for decision-makers and staff in health care (part 2).</p> <p>April, 2021</p>	<p>Decision-makers and staff in health care.</p>	<p>To provide recommendations on care for post-COVID.</p>	<p>The Swedish Board of Health and Welfare</p>

United Kingdom	<p>NICE guideline: COVID-19 rapid guideline: managing the long-term effects of COVID-19 [NG188].</p> <p>December, 2020 (Last updated: November 2021)</p>	<p>Health and care practitioners.</p>	<p>To provide guidance for identifying, assessing, and managing the Long-term effects of COVID-19.</p>	<p>National Institute for Health and Care Excellence (NICE)</p>
United States	<p>Webpage: Post-COVID Conditions: Information for Healthcare Providers</p> <p>Last updated: September, 2023</p>	<p>Healthcare providers.</p>	<p>To provide key information on post-covid conditions, including information on the assessment and testing for post-covid conditions, the physical examination and vital signs of post-covid, and recommendations for basis diagnostic laboratory testing as well as specialised diagnostic laboratory testing.</p>	<p>Centers for Disease Control and Prevention</p>

Annex 3 Proposed Long COVID guidelines

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