

# Long COVID care pathways: a systematic review

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**HTA Austria**

Austrian Institute for  
Health Technology Assessment  
GmbH

# Long COVID care pathways: a systematic review

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**Project team**

Project leader: Sarah Wolf, MSc

Authors: Sarah Wolf, MSc  
Judit Erdös, MA

**Project Support**

Systematic literature search: Tarquin Mittermayr, BA(Hons), MA

Hand searches: Sarah Wolf, MSc

Internal Review: Ingrid Zechmeister-Koss, Dr. rer. soc. oec., MA

External reviews: Primar Priv.-Doz. Dr. Karl Horvath, medical director of the Klinikum Bad Gleichenberg (Styria)  
Dr Diego Castanares-Zapatero, researcher at the Belgian Healthcare Knowledge Centre (KCE)

**Correspondence:** [sarah.wolf@aihta.at](mailto:sarah.wolf@aihta.at)

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Priv.-Doz. Dr. phil. Claudia Wild, managing director

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## List of abbreviations

ACS .....	Acute coronary syndrome
AOK .....	Allgemeine Ortskrankenkasse (engl. General Local Health Insurance)
AT .....	Austria
AUVA .....	Allgemeine Unfallversicherung (engl. Austrian General Accident Insurance)
BE .....	Belgium
bzgl. ....	Bezüglich (engl. regarding)
CDC .....	Centers for Disease Control and Prevention
CFS .....	Chronic fatigue syndrome
COVID .....	Coronavirus disease
engl. ....	English
GBA .....	Gemeinsamer Bundesausschuss (engl. Federal Joint Committee)
GER .....	Germany
GP .....	General practitioner
HDU .....	High dependency unit
HS .....	Hand search
IAPT .....	The Improving Access to Psychological Therapies
ICD-10 .....	International Classification of Diseases
ICU .....	Intensive care unit
INAHTA .....	The International Network of Agencies for Health Technology Assessment
IQWiG .....	Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (engl. the Independent Institute for Quality and Efficiency in Health Care)
IT .....	Italy
KCE .....	Belgian Health Care Knowledge Centre
MDT .....	Multidisciplinary team
NHS .....	National Health Service
NICE .....	National Institute for Health and Care Excellence
NL .....	The Netherlands
ÖGK .....	Österreichische Gesundheitskasse (engl. Austrian Health Insurance)
Pat. ....	Patient*innen
PCI .....	Personalised Care Institute
PICS .....	Post-intensive care syndrome
PPCS .....	Persistent post-COVID syndrome
Pts. ....	Patients
QoL .....	Quality of life
RCGP .....	The Royal College of General Practitioners
SARS-CoV-2 ....	Severe acute respiratory syndrome coronavirus 2
SIGN .....	The Scottish Intercollegiate Guidelines Network
SS .....	Systematic search
UK .....	United Kingdom
USA .....	United States of America
WHO .....	World Health Organization



# Executive summary

## Background and research aim

Long COVID presents a wide range of symptoms that can persist or reappear after a severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection including, fatigue, shortness of breath, high blood pressure, olfactory and gustatory disturbances, neurocognitive disorders or psychological complaints, such as anxiety and depression. In severe cases, organ damage, e.g. to the heart, lungs, or liver may also occur. Individuals of all ages and with all degrees of severity of the acute infection can suffer from long COVID which additionally may have an impact on the patients' everyday functioning. The exact number of patients suffering from long COVID is difficult to detect due to the broad prevalence ranges reported in the available evidence.

Due to the expected growing number of long COVID cases and the associated increasing average sick leave durations, it not only places a burden on the patients and their families but also the wider economy, in particular, the workforce. For this reason, long COVID care planning has gained more weight in political decisions.

The present systematic review aimed to support preparations and adjustments in the long COVID care planning in Austria by giving (1) an overview of recommendations about long COVID care pathways as well as (2) examples of already existing care structures in selected European countries.

## Methods

A systematic search in four databases and biweekly unsystematic hand searches were conducted to identify relevant guidelines, reviews and expert papers for answering both research questions. In addition, separate unsystematic hand searches were conducted on websites of relevant institutions and care facilities, as well as, experts of the selected European countries were contacted to retrieve further information about already existing long COVID care structures. Data were extracted into specially designed extraction tables and subsequently narratively summarised for each research question.

## Results

Based on the predefined inclusion criteria, in total 14 references including five guidelines, four reviews, one consensus paper and four clinical perspectives were included for answering both research questions. To answer the second research question, an additional 23 references including websites about patient organisations (n=4), healthcare facilities (n=12), social care services (n=6) and a newspaper article about relevant healthcare facilities (n=1) were considered.

In the included literature, it was recommended that the majority of long COVID-related healthcare should take place in primary care; however, including some differences in the served patient groups between countries. For example, in Austria and Germany, *all* long COVID patients including former hospitalised and non-hospitalised COVID-19 patients are advised to go to the general practitioner (GP) for a first clinical assessment. In contrast, for example in the United Kingdom (UK), former hospitalised COVID-19 patients, who suffer from ongoing or new symptoms after 12 weeks of dis-

**long COVID involves several different symptoms & impacts the wider economy, especially the workforce**

**→ long COVID care planning crucial for political decision-making**

**research questions: an overview of care pathways & examples of existing care structures in selected countries**

**systematic search in 4 databases, further unsystematic hand searches & expert consultation**

**14 references were included for both questions & 23 additional references for the 2. question**

**most of the long COVID care, particularly the first assessments, recommended to take place in primary care; difference in the served patient (pts.)-groups between the countries**

	charge, can go to secondary care outpatient departments or to primary care facilities for a clinical assessment.
<b>no life-threatening but complex long COVID symptoms can be reassessed in specialised long COVID outpatient assessment clinics</b>	The primary assessment is deemed to also identify serious, possibly life-threatening symptoms. These patients should then be referred to acute services. Patients with no serious but more complex symptoms persisting for four to 12 weeks after the acute infection are advised to be referred to so-called specialised long COVID outpatient assessment clinics. These multidisciplinary clinics can offer a second assessment and further referrals if needed. Some clinics are also intended to offer treatments, such as rehabilitative elements, themselves.
<b>pts. with 1 dominant symptom recommended being referred to respective specialists</b>	Patients with one dominant symptom are recommended to be referred to secondary assessment by the respective specialist, e.g. pulmonologist, cardiologist, neurologist or psychologist. Subsequently, depending on the patients' needs, they can be referred to multidisciplinary inpatient, partial inpatient or outpatient rehabilitation programmes including physical, cognitive and/or psychological rehabilitation, community health services or single-discipline non-medical healthcare providers, such as physiotherapists and occupational therapists. The timing of the referral to these services should depend on the severity of the symptom.
<b>other options: rehabilitation, community health services and/or non-medical healthcare providers</b>	Besides, self-management presents a crucial part of the long COVID management recommendations including exercising at home, nutritional management and stress reduction but also the participation in long COVID online programmes. According to the guidance documents, it can function as a single therapy for milder long COVID symptoms or supportive in addition to other treatments for moderate to severe symptoms.
<b>self-management &amp; good communication are further crucial aspects</b>	Likewise, good communication between healthcare professionals and the patients including inclusive communication (e.g. by offering translated materials) and the right balance in the detail of provided information to avoid unnecessary uncertainty is another crucial aspect in long COVID care.
<b>same additional (social) services as for other diseases</b>	Concerning additional (social) services, the same services as for other diseases are recommended also for long COVID patients including the same sick leave procedures, social services such as social prescribing and/or support for employees, like a phased return or transitional allowance. Long COVID-specific services or benefits could not be identified in the literature.
<b>existing care structures correspond to the identified recommendations</b>	It has been shown that the identified existing care structures in the selected European countries started to follow the recommendations summarised in the present systematic review. Out of the investigated countries, in particular, the UK succeeded in rapidly adapting their healthcare structures through prompt implementation of long COVID specific care facilities.
<b>no significant differences in long COVID care between the analysed countries; small differences due to differences in the healthcare system</b>	Furthermore, no significant differences in the recommendations and the respective established long COVID care structures could be identified between the analysed countries. Some small differences can be mainly described through the differences in the healthcare systems. For example, in most of the investigated European countries, the long COVID care structures are organised on a regional level due to federalism, whereas, only the UK developed a national plan for the organisation of long COVID care structures, the so-called NHS "5-point plan for long COVID support". However, in the end, some aspects of this plan are still executed on a regional level, like the specialised long COVID outpatient assessment clinics. Therefore, the exact number of the existing specialised long COVID outpatient clinics or rehabilitation programmes in each country is difficult to estimate.

## Discussion and preview

Overall, multidisciplinary, a personalised approach and shared decision-making have been named as key factors for successful long COVID care. However, it needs to be considered that long COVID care is also accompanied by some hurdles. For example, one major challenge in long COVID healthcare lies in the uncertainty in the diagnosis of long COVID for practitioners. Therefore, providing education for physicians about the disease itself, its diagnosis and management including communicational aspects is crucial.

Moreover, long COVID care can differ from other care offers. For example, rehabilitation programmes for long COVID patients should involve support for a successful return to work, because a large proportion of the long COVID patients are in their working age. Moreover, long COVID rehabilitation should focus on the concept of careful exercising (“pacing”).

Regarding suggested self-management, it needs to be taken into account that it can place a lot of responsibility on the patients, which might cause an additional burden to them. Further physical, emotional and/or financial burden on the patients can also be caused by multiple doctor visits and therefore need to be outweighed in the decision for a next referral.

From an economic point of view, the planning of long COVID care structures can also trigger concerns about resource capacities (e.g. long waiting lists). Moreover, it needs to be discussed if patients should be able to directly contact e.g. their physiotherapist or psychotherapist instead of the GP. In doing so, the burden on the GPs, who have a primary role in long COVID care, could be eased.

The quality of the included guidelines and reviews is limited in its methodological quality due to the novelty of this topic and the associated urgency for research. Hence, an update with more rigorous data and guideline development that fulfils the methodological standards are recommended.

Furthermore, the scope of the present systematic review was limited to care pathways for adult long COVID patients and hence do not include specific treatment recommendations or recommendations e.g. for children and adolescents. High-quality clinical trials and systematic reviews are needed to further investigate long COVID management options, as well as, the safety and effectiveness of potential treatments and interventions for various patient groups. In addition, the systematic collection of real-world data on long COVID surveillance is advised to be set up across countries in the near future to gather further information e.g. on the duration and severity of long COVID or possible consequences in terms of sick leave. Thereby, long COVID care planning can be facilitated.

**hurdles of  
long COVID care:**

**uncertainty in the  
diagnosis → further  
education needed**

**adjusted rehabilitation  
programmes for long  
COVID pts. recommended**

**additional burden due  
to self-management or  
multiple referrals possible**

**concerns about  
resource capacities  
→ e.g. physiotherapists  
also possible first points  
of contact?**

**evidence of limited quality  
→ update data fulfilling  
methodological standards  
is needed**

**more evidence on  
specific management  
recommendations &  
real-world data on  
long-COVID surveillance  
are crucial**

# Zusammenfassung

## Hintergrund und Projektziel

**Long-Covid umfasst mehrere verschiedene Symptome & geht häufig mit Einschränkungen im Alltag einher**

**Daten zu Long-Covid Prävalenzen sehr variabel**

Long-Covid umfasst ein breites Spektrum an Symptomen, die nach einer akuten Coronavirus-Erkrankung (SARS-CoV-2-Infektion) bestehen bleiben oder nach einer gewissen Zeit erneut auftreten können. Mögliche Long-Covid Symptome sind beispielsweise Müdigkeit/Erschöpfung, Kurzatmigkeit, hoher Blutdruck, Geruchs- und Geschmacksstörungen, neurologische Störungen oder psychische Beschwerden wie Ängste und Depressionen. In schweren Fällen können auch Organschäden, z. B. an Herz, Lunge oder Leber, auftreten. Long-Covid Symptome können unabhängig vom Lebensalter und Schweregrad der akuten Infektion auftreten und gehen häufig mit Einschränkungen im Alltag einher. Aufgrund der variablen Prävalenzen, die in den Studien berichtet werden, ist es schwierig, die zu erwartende Anzahl an Long-Covid Patient\*innen zu ermitteln. Eine belgische systematische Übersichtsarbeit zeigte beispielsweise, dass die Prävalenzen für Long-Covid bei nicht-hospitalisierten Covid-19 Patient\*innen drei bis sechs Monate nach der akuten Infektion zwischen 2 und 21 Prozent und bei ehemals hospitalisierten Patient\*innen zwischen 13 und 92 Prozent lagen.

**Long-Covid auch gesellschaftliche Auswirkungen → die Planung geeigneter Long-Covid Versorgungsstrukturen wichtiger Bestandteil politischer Diskurse**

Die Tendenz einer steigenden Anzahl an Long-Covid Patient\*innen in mehreren Ländern kann unter anderem zu durchschnittlich längeren Krankheitsständen führen, wie eine deutsche Analyse festgestellt hat. Dadurch belastet Long-Covid nicht nur die Patient\*innen sowie deren Familien, sondern auch die Gesellschaft, insbesondere den Arbeitsmarkt. Aus diesem Grund ist die Planung geeigneter Versorgungsstrukturen für Long-Covid Patient\*innen ein wichtiger Bestandteil aktueller politischer Diskurse. Zu den möglichen Versorgungsstrukturen zählen z. B. medizinische sowie therapeutische Angebote, aber auch sozial-rechtliche Leistungen.

**Forschungsfragen (FF):**

Vor diesem Hintergrund war es das Ziel der vorliegenden systematischen Übersichtsarbeit, die Long-Covid Versorgungsplanung in Österreich zu unterstützen. Die Übersichtsarbeit bietet demnach einen Überblick zu den aktuell verfügbaren Empfehlungen, wie Long-Covid Patient\*innen am besten versorgt werden könnten. Konkret geht es dabei um folgende zwei Fragen:

1. Überblick zu Long-Covid Versorgungspfaden &
2. Beispiele zu bereits bestehenden Versorgungsstrukturen in ausgewählten europäischen Ländern

1. Wo sollen Long-Covid Patient\*innen im ersten Schritt untersucht werden?
2. Welche weiteren Versorgungsschritte sind im Anschluss für welche Patient\*innen-Gruppen anzudenken?

Darüber hinaus präsentiert die vorliegende systematische Übersichtsarbeit einzelne Beispiele zu bereits bestehenden Versorgungsstrukturen ausgewählter europäischer Länder, darunter das Vereinigte Königreich, Belgien, Italien, Deutschland und Österreich.

## Methode

**FF1 & FF2: systematische Suche in 4 Datenbanken & unsystematische Handsuchen bis Anfang August 2021**

Den Anfang bildete eine systematische Literaturrecherche in vier Datenbanken (Cochrane, Embase, Medline und HTA-INAHTA) Ende April 2021. Im Anschluss an die systematische Literatursuche wurden bis Anfang August alle zwei Wochen weitere unsystematische Handsuchen durchgeführt, um aktuelle Informationen zu berücksichtigen. Zur Beantwortung der beiden Forschungsfragen wurden basierend auf den vorab definierten Einschlusskrite-

rien Leitlinien, Übersichtsarbeiten und Expert\*innen-Papiere ausgewählt. Als zentrales Einschlusskriterium galten beispielsweise, dass die Empfehlungen für Erwachsene mit Symptomen, die mehr als vier Wochen nach Beginn der akuten SARS-CoV-2 Infektion anhielten, waren.

Für die Beantwortung der zweiten Forschungsfrage wurden zusätzlich Websites relevanter Institutionen (z. B. Long-Covid Patient\*innen-Organisationen) und Versorgungseinrichtungen (z. B. Long-Covid Spezialambulanzen und Rehabilitationen) durchsucht. Darüber hinaus wurden interdisziplinäre Expert\*innen mit unterschiedlichen Rollen in Bezug auf Long-Covid (z. B. praktizierende Ärzt\*innen, Patient\*innen-Vertreter\*innen, politische Beratung) aus den ausgewählten europäischen Ländern kontaktiert. Somit konnten nähere Informationen zu bereits bestehenden Long-Covid Versorgungsstrukturen in den jeweiligen Ländern identifiziert werden.

Die Daten aus den identifizierten Quellen wurden in speziell entworfene Tabellen extrahiert und anschließend für jede Forschungsfrage narrativ zusammengefasst.

## Empfehlungen zur Long-Covid Versorgung

### Eingeschlossene Literatur

Insgesamt 14 Referenzen konnten aus den ursprünglich 754 Zitaten für die Beantwortung beider Forschungsfragen eingeschlossen werden. Dabei handelte es sich um fünf Leitlinien, vier Übersichtsarbeiten, ein Konsenspapier und vier klinischen Perspektiven, die vor allem aus dem Vereinigten Königreich und den Vereinigten Staaten von Amerika stammten. Einzelne Referenzen waren auch aus den Niederlanden, Deutschland und Österreich. Darüber hinaus konnten für die Beantwortung der zweiten Forschungsfrage zusätzlich 23 Referenzen identifiziert werden, darunter Websites von vier Patientenorganisationen, 12 Gesundheitseinrichtungen, sechs Einrichtungen im Sozialbereich und ein Zeitungsartikel über relevante Versorgungseinrichtungen.

### Erste Anlaufstelle für Long-Covid Patient\*innen

Der eingeschlossenen Literatur zufolge soll der Großteil der Long-Covid Versorgung in der Primärversorgung stattfinden. Es gibt jedoch Unterschiede zwischen den analysierten Ländern, für *welche* Patient\*innen-Gruppen das gilt. Generell wird in der Literatur zwischen *allen* Long-Covid Patient\*innen unabhängig davon, wo sie während der akuten Infektionsphase behandelt worden waren, den *ehemals hospitalisierten* und den *ehemals nicht-hospitalisierten* Covid-19 Patient\*innen unterschieden. Für Österreich und Deutschland wird empfohlen, dass Patient\*innen mit Long-Covid Symptomen, die länger als vier Wochen nach der akuten Infektion anhalten, für die erste Untersuchung ihren Hausarzt/ihre Hausärztin oder Primärversorgungszentren aufsuchen. Im Vergleich dazu wird beispielsweise im Vereinigten Königreich für ehemals hospitalisierte Covid-19 Patient\*innen eine Nachuntersuchung via Telefon oder Videoanruf durch medizinisches Fachpersonal aus der Sekundärversorgung (z. B. Krankenhaus) 12 Wochen nach der Entlassung empfohlen. Halten die Symptome länger als 12 Wochen an oder treten nach der 12. Woche neue Symptome auf können die ehemals hospitalisierten Covid-19 Patient\*innen entweder die Krankenhausambulanz oder die/den Hausarzt\*in aufsuchen.

### FF2:

**weitere unsystematische Handsuchen & Expert\*innen-Konsultation für nähere Informationen zu bereits bestehenden Versorgungsstrukturen**

**aus insgesamt 754 Referenzen 14 für FF 1 & FF2 eingeschlossen**

**für FF2 noch zusätzlich 23 Quellen**

**Großteil der Long-Covid Versorgung (vor allem Erstuntersuchungen) sollten in den Praxen der Hausärzt\*innen oder in Primärversorgungszentren stattfinden**

**→ Unterschiede zwischen den Ländern welche Pat.-Gruppen betreffend**

### Mögliche weitere Überweisungen

<b>Pat. mit komplexen Long-Covid Symptomen können an Long-Covid Spezialambulanzen überwiesen werden</b>	Patient*innen, bei denen schwerwiegende bzw. lebensbedrohliche Symptome während der Erstuntersuchung festgestellt werden, sollten direkt an die Notaufnahme zugewiesen werden. Patient*innen ohne lebensbedrohliche, jedoch mit mehreren und/oder unspezifischen Symptomen (z. B. Müdigkeit/Erschöpfung), die über vier bis 12 Wochen nach der Infektion anhalten, können an sogenannte „Long-Covid Spezialambulanzen“ (z. B. im Vereinigten Königreich, Deutschland und Österreich) überwiesen werden. Diese multidisziplinären Ambulanzen dienen einer weiteren umfassenden Untersuchung und können die Patient*innen bei Bedarf weiter überweisen. In manchen Fällen können Behandlungen, z. B. rehabilitative Maßnahmen, auch direkt in den Ambulanzen angeboten werden.
<b>bei Pat. mit 1 dominanten Symptom → Überweisung an entsprechende Spezialist*innen empfohlen</b>	Patient*innen mit <i>einem</i> dominanten Symptom sollten zur weiteren Abklärung an den/die jeweilige/n Facharzt*in überwiesen werden, z. B. Lungenfacharzt*in, Neurolog*in oder Psychiater*in. Nach Abschluss weiterer Untersuchungen können die Patient*innen, je nach Bedarf, z. B. an multidisziplinäre stationäre, teilstationäre oder ambulante Rehabilitationsprogramme einschließlich physischer, kognitiver und/oder psychologischer Rehabilitation überwiesen werden. Eine andere Option sind Überweisungen an sogenannte „Community Care Networks“, wie die „Community Nurses“ im Vereinigten Königreich oder Italien. Diese haben das Ziel, die Patient*innen bei der Bewältigung ihrer Erkrankung zu unterstützen (z. B. durch Hausbesuche) und dadurch die Selbstständigkeit der Patient*innen zu fördern. Darüber hinaus können Long-Covid Patient*innen auch an einzelne nicht-ärztliche Gesundheitsdienstleister (z. B. Physiotherapeut*innen, Ergotherapeut*innen) überwiesen werden. Der Zeitpunkt für solche Überweisungen sollte vom Schweregrad des Symptoms abhängig gemacht werden.
<b>anschließende Optionen, z. B. Rehabilitation, Community Care Networks</b>	

### Selbstmanagement von Patient\*innen

<b>Selbstmanagement: wesentlicher Bestandteil der Empfehlungen zur Long-Covid Versorgung</b>	Ein wichtiger Bestandteil der Empfehlungen zur Long-Covid Versorgung stellt das Selbstmanagement dar. Dies umfasst z. B. Bewegungstherapie zu Hause, Ernährungsmanagement und Stressabbau, aber auch die Teilnahme an Long-Covid-spezifischen Onlineprogrammen, wie „The Your COVID Recovery Platform“ in dem Vereinigten Königreich. Für die Teilnahme an diesem Programm ist jedoch eine Überweisung notwendig. Den Empfehlungen zufolge kann Selbstmanagement entweder als alleinige Therapie bei milderen Long-Covid Symptomen eingesetzt werden oder als Ergänzung zu anderen Behandlungen bei moderaten bis schweren Symptomen hilfreich sein.
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### Weitere wichtige Aspekte in der Long-Covid Versorgung

<b>inklusive Kommunikationen &amp; richtiger Detailgrad an Information sind zu berücksichtigen</b>	Eine gute Kommunikation zwischen den Ärzt*innen bzw. Therapeut*innen und den Patient*innen stellt ein weiterer wichtiger Aspekt der Empfehlungen zur Long-Covid Versorgung dar. Eine gute Kommunikation berücksichtigt beziehungsweise minimiert dabei beispielsweise kulturelle Unterschiede oder Sprachbarrieren. Darüber hinaus, ist es wichtig, den passenden Detailgrad der bereitgestellten Informationen zu finden, um unnötige Verunsicherung bei den Patient*innen durch zu viel oder zu wenig Informationen zu vermeiden.
<b>dieselben zusätzlichen (sozialen) Leistungen wie für Pat. mit anderen (chronischen) Krankheiten ...</b>	Bezüglich den zusätzlichen (sozialen) Leistungen haben Long-Covid Patient*innen die gleichen Ansprüche wie Patient*innen mit anderen (chronischen) Erkrankungen z. B. für arbeitsbezogene Leistungen, wie Krankenstand, Wiedereingliederungsteilzeit oder Umschulungsprogramme. Ergänzend können auch soziale Unterstützungsleistungen, wie z. B. das „Social

Prescribing“ angedacht werden: Dabei werden den Patient\*innen je nach Bedürfnis soziale Tätigkeiten, wie z. B. Singen oder Gärtnern in der Gruppe, verschrieben. Empfehlungen zu Long-Covid-spezifischen Sozialleistungen oder Beihilfen konnten in der Literatur nicht identifiziert werden.

... auch für  
Long-Covid Pat.  
empfohlen

#### Umsetzung in der Praxis: Unterschiede zwischen den Ländern

Bezüglich den identifizierten bereits bestehenden Long-Covid Versorgungsstrukturen in den ausgewählten europäischen Ländern war ersichtlich, dass diese grundsätzlich den beschriebenen Empfehlungen folgten. Unter den analysierten europäischen Ländern wurden vor allem im Vereinigten Königreich rasche Anpassungen im Gesundheitswesens, etwa die Errichtung von Long-Covid Spezialambulanzen, durchgeführt.

bestehende Long-Covid  
Versorgungsstrukturen  
entsprechen den  
Empfehlungen → rasche  
Anpassungen in UK

Des Weiteren konnten keine bedeutsamen Unterschiede in den Empfehlungen und den jeweiligen bestehenden Long-Covid Versorgungsstrukturen zwischen den einzelnen Ländern festgestellt werden. Kleinere Unterschiede zwischen den Ländern können vor allem durch die Unterschiede in den Gesundheitssystemen erklärt werden. So sind die Long-Covid Versorgungsstrukturen in den meisten der analysierten Länder aufgrund des Föderalismus auf regionaler Ebene organisiert. Nur das Vereinigte Königreich entwickelte einen nationalen Versorgungsplan für Long-Covid Patient\*innen, den so genannten „5-point plan for long COVID support“. Manche Aspekte dieses nationalen Plans wurden jedoch trotzdem auf regionaler Ebene umgesetzt, z. B. die Etablierung der Long-Covid Spezialambulanzen. Aufgrund dieser regionalen Versorgungsplanung ist die Anzahl an bestehenden Long-Covid Versorgungseinrichtungen (z. B. Spezialambulanzen oder Rehabilitationsprogramme) in den einzelnen Ländern schwierig zu erheben.

keine bedeutsamen  
Unterschiede in der  
Long-Covid-Versorgung  
zwischen den untersuchten  
Ländern → geringe  
Unterschiede auf  
Unterschieden im  
Gesundheitssystem  
zurückzuführen

#### Diskussion und Ausblick

Einer der Schlüsselfaktoren einer erfolgreichen Long-Covid Versorgung betrifft die Zusammenarbeit unterschiedlicher medizinischer und therapeutischer Disziplinen aus dem Gesundheits- und Sozialbereich (Multidisziplinarität). Dabei sollte die individuelle Situation des/der Patient\*in stets mitberücksichtigt werden (personalisierter Ansatz). Zudem sollten Behandlungsentscheidungen immer gemeinsam von den Ärzt\*innen und den Patient\*in getroffen werden (Shared-Decision Making).

Schlüsselfaktoren:  
Multidisziplinarität,  
personalisierter Ansatz &  
Shared-Decision Making

#### Mögliche Herausforderungen in der Long-Covid Versorgung

Eine große Herausforderung bei der Versorgung von Long-Covid Patient\*innen liegt beispielsweise in der Unsicherheit bezüglich der Diagnosestellung von Long-Covid. Aus diesem Grund sind weitere Schulungen zur Diagnose und/oder zu möglichen Long-Covid Managementstrategien für die praktizierenden Ärzt\*innen anzudenken.

Unsicherheit bei der  
Diagnosestellung →  
Schulungen für Ärzt\*innen  
notwendig

Darüber hinaus sind häufig konkrete Versorgungsangebote für Long-Covid Patient\*innen notwendig. Beispielsweise sollte die Vorbereitung für die Rückkehr an den Arbeitsplatz ein wichtiger Teil eines Long-Covid Rehabilitationsprogramms ausmachen, da ein Großteil der Patient\*innen im arbeitsfähigen Alter ist. Ebenso sollte der Schwerpunkt der Rehabilitation auf das Konzept des vorsichtigen Bewegungstrainings mit langsamen Leistungssteigerungen („Pacing“) gelegt werden. Im Gegensatz dazu sind bei herkömmlichen physikalischen Rehabilitationsprogrammen fixe Leistungssteigerungen vorgesehen.

Rehabilitationsprogramme  
sind an Bedürfnisse von  
Long-Covid Pat.  
anzupassen, z. B. Pacing

**mehrere Überweisungen  
→ zusätzliche Belastungen  
für Pat. (zeitlich, finanziell,  
emotional)**

Es gibt unterschiedliche Möglichkeiten, wohin Long-Covid Patient\*innen nach einer Diagnose überwiesen werden können: an Long-Covid Spezialambulanzen, Fachärzt\*innen, Rehabilitationsprogramme und/oder nicht-ärztliche Therapeut\*innen. Bei der Entscheidung über eine Überweisung sollte jedoch mitberücksichtigt werden, dass mehrere Überweisungen zu unterschiedlichen Ärzt\*innen bzw. Therapeut\*innen mit einer zusätzlichen Belastung für die Patient\*innen einhergehen können. Diese Belastungen können zeitlicher (z. B. erhöhte Anfahrtszeiten), finanzieller (z. B. zusätzliche Anfahrtskosten) oder emotionaler (z. B. gegensätzliche Meinungen von unterschiedlichen Ärzt\*innen) Natur sein.

**Selbstmanagement  
kann belastend sein**

Auch das empfohlene Selbstmanagement kann mit einer großen Verantwortung und daher mit einer zusätzlichen Belastung für die Patient\*innen einhergehen.

**Erfahrungen zu Beihilfen  
& Unterstützungen von  
anderen Erkrankungen  
hilfreich**

Entscheidungssträger könnten, was die weiteren (sozialen) Leistungen, etwa arbeitsrechtliche Regelungen, betrifft auf Erfahrungen bei anderen Erkrankungen, die ebenfalls mit längeren Ausfällen einhergehen (z. B. psychische Erkrankungen, Krebs), zurückgreifen. Dies ist empfehlenswert, weil es zu Long-Covid bisher noch keine entsprechenden Regelungen gibt.

**bei Ressourcenengpässen  
→ mögliche alternative  
erste Anlaufstellen, z. B.  
Physiotherapeut\*innen?**

Aus wirtschaftlicher Sicht kann die Planung von Long-Covid Versorgungsstrukturen auch Ressourcenengpässe (z. B. lange Wartezeiten für einen Untersuchungstermin) auslösen. Diesbezüglich sollte diskutiert werden, ob z. B. Physiotherapeut\*innen oder Psychotherapeut\*innen ebenfalls als erste Anlaufstelle in Frage kommen könnten. Auf diese Weise könnten die Hausärzt\*innen, denen in der Long-Covid Versorgung eine primäre Rolle zugeteilt wird, entlastet werden.

#### Zukünftiger Forschungsbedarf

**Update der Leitlinien &  
Reviews notwendig um  
qualitativ hochwertigere  
Empfehlungen zu erzielen;  
weitere Evidenz zu  
spezifischen**

Die Qualität der berücksichtigten Leitlinien und Übersichtsarbeiten ist aufgrund der Aktualität des Themas und des damit verbundenen dringenden Forschungsbedarfs eingeschränkt. Eine Aktualisierung der Leitlinien und Übersichtsarbeiten unter Berücksichtigung der methodischen Standards ist wichtig, um zukünftig qualitativ hochwertigere Empfehlungen generieren zu können.

**Behandlungsempfehlungen  
& internationale Long-  
Covid Register empfohlen**

**→ als Unterstützung  
für die Long-Covid  
Versorgungsplanung**

Darüber hinaus fokussierte sich die vorliegende systematische Übersichtsarbeit lediglich auf Versorgungspfade für erwachsene Long-Covid Patient\*innen. Spezifische Behandlungsempfehlungen und Empfehlungen für z. B. Kinder und Jugendliche konnten in diesem Bericht nicht berücksichtigt werden. Qualitativ hochwertige klinische Studien und systematische Übersichtsarbeiten sind erforderlich, um die Behandlungsmöglichkeiten für unterschiedliche Long-Covid Patient\*innen-Gruppen (z. B. unterschiedliche Altersgruppen), sowie die Sicherheit und Wirksamkeit potenzieller Behandlungen und Interventionen weiter zu untersuchen.

Zudem werden internationale Long-Covid Register empfohlen, um anonymisierte Patient\*innen-Daten zur Dauer und den Schweregraden von Long-Covid oder zu potentiellen Auswirkungen langer Krankenzustände sammeln und dadurch die Planung der Long-Covid Versorgungsstrukturen unterstützen zu können.

# 1 Background

## Disease profile

In December 2019, the first cases of the severe acute respiratory syndrome coronavirus 2 [SARS-CoV-2] were detected in China [1]. On January 30 2020, the World Health Organization (WHO) declared SARS-CoV-2 a public health emergency of international concern [2]. The viral disease encompasses a wide spectrum of severity from asymptomatic to fatal courses of infection. A SARS-CoV-2 infection can occur in all age groups and genders, although some persons might be at higher risk for a severe course, e.g. elderly individuals, men, obese (body mass index >30) people and people with certain pre-existing conditions including, for example, the cardiovascular system, chronic lung diseases and patients with a weakened immune system [2, 3]. According to the International Classification of Diseases (ICD-10), a confirmed acute SARS-CoV-2 infection is assigned the code U07.1 and a suspected case is assigned the code U07.1/2 [4].

Already a few months after the first SARS-CoV-2 cases had appeared, international patient organisations were founded and drew attention to possible late effects of the acute infection. These organisations also initiated the first research steps in the field of sequelae after SARS-CoV-2 infections [5]. The first research results showed that several long-lasting symptoms can persist or reappear after the acute infection and that new symptoms can be developed after several months. These long-lasting symptoms are often summarised under the term “long COVID”. However, other terms, such as “post-acute COVID condition”, “long-term COVID”, “post-acute COVID syndrome”, “post-acute COVID symptoms”, or “chronic COVID” can also be found in the literature [6, 7].

The wide range of possible long COVID symptoms includes common symptoms, such as fatigue, shortness of breath, high blood pressure, olfactory and gustatory disturbances, neurocognitive disorders or psychological complaints, such as anxiety and depression. In severe cases, organ damage, e.g. to the heart, lungs, or liver may also occur [6, 7]. Sometimes only one symptom persists, while in other cases multiple symptoms can occur simultaneously. Moreover, the symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. They may also fluctuate or relapse over time. Besides, international data indicates that individuals of all ages and regardless of the severity of the acute SARS-CoV-2 infection can experience long-term symptoms that generally can have an impact on the patients’ everyday functioning [8-10].

## Definition

In December 2020, the National Institute for Health and Care Excellence (NICE) in the United Kingdom (UK) proposed a definition of long COVID, which includes all symptoms that occur after the acute SARS-CoV-2 infection and cannot be associated with any other cause. The definition distinguishes between different time points after disease onset [11]:

- **“Ongoing symptomatic COVID-19”** including patients with signs and symptoms from four to 12 weeks after the acute SARS-CoV-2 infection.
- **“Post-COVID-19 syndrome”** includes patients with signs and symptoms that develop during or after the acute infection, continue for more than 12 weeks and are not explained by an alternative diagnosis.

**Dezember 2019 erste SARS-CoV-2- Fälle in China, Januar 2020 WHO erklärt SARS-CoV-2 zu einem internationalen Gesundheitsnotfall**

**Risikofaktoren für schweren Verlauf z. B.: höheres Alter, Übergewicht, Vorerkrankungen**

**vermehrter Fokus auf langfristige Folgen einer SARS-CoV-2 Infektion**

**Long-Covid umfasst zahlreiche unterschiedliche neue oder bestehende Symptome**

**mehrere Long-Covid Symptome gleichzeitig möglich, auch bei jüngeren Personen oder nach einem milden SARS-CoV-2 Verlauf → Auswirkungen auf alltägliches Leben**

**NICE unterscheidet zwischen: anhaltender Covid-19 Symptomatik (>4-12 Wochen), Post-Covid-19 Syndrom (>12 Wochen)**

durch einen Test bestätigte  
SARS-CoV-2 Infektion  
keine Voraussetzung, um  
Definition zu erfüllen

NICE also proposed that the presence of a positive test for SARS-CoV-2 should not be necessary to meet the long COVID definition, because, on the one hand, not all long COVID patients might have access to a test at the time of the acute infection, e.g. due to the lack of availability. On the other hand, some of the COVID-19 patients might choose not to be tested due to the fear of possible consequences (e.g. termination as a result of the obligated self-isolation) [5].

WHO Post-Covid-Definition:  
≥3 Monate nach  
Infektionsbeginn

In October 2021, the WHO published a clinical case definition of the **post-COVID-19 condition**, which has been developed by Delphi methodology. According to this definition, a 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** and that last for at least 2 months and cannot be explained by an alternative diagnosis [10].

Long-Covid Definition  
eines Cochrane Reports  
umfasst 4 Kategorien,  
von denen zumindest  
1 erfüllt sein muss

Another definition of long COVID is presented by a Cochrane Rehabilitation Review. According to this definition, long COVID involves at least one of the four categories [12, 13]:

- Symptoms that persist from the acute SARS-CoV-2 infection or its treatment.
- New symptoms that occur after the end of the acute SARS-CoV-2 infection but are understood to be a consequence of the acute infection.
- Symptoms that have resulted in a new health limitation.
- Worsening of a pre-existing underlying condition.

## Diagnosis

Januar 2021 Long-Covid  
ICD-10 Code: U09.9

Since January 2021, the ICD-10 catalogue of the WHO includes a separate diagnosis code for long COVID, namely U09.9 [14].

Schwierigkeiten mit der  
Diagnosestellung in der  
klinischen Praxis, z. B.:  
fehlendes Wissen bei  
Ärzt\*innen, einfache  
klinische Tests nicht  
vorhanden → objektive  
Diagnose schwierig

However, even though long COVID has become a separate diagnosis, some difficulties may arise in clinical practice. To date, not all of the practising physicians are yet more familiar with the diagnosis of long COVID. Furthermore, there are no simple clinical tests to diagnose long COVID. The clinical diagnosis is based on the history of the past SARS-CoV-2 infection and the incomplete recovery, including the development of some already known long COVID symptoms and no obvious alternative cause. Accordingly, an objective diagnosis is almost impossible, because, on the one hand, the severity of some common long COVID symptoms like fatigue is difficult to detect. On the other hand, it is difficult for many unspecific symptoms to identify whether they are caused by the virus directly or whether there is another reason for them (e.g. mental health problems might also be triggered by the pandemic management measures, such as social distancing). For these reasons, the trustful relationship between the patient and the practising physician plays a special role in the diagnosis of long COVID [15].

Empfehlung für  
Diagnosestellung:  
Berücksichtigung  
zusätzlicher  
Diagnosecodes für  
betroffene Organe  
(wenn möglich)

Due to the great variety in long COVID symptoms and the associated difficult diagnosis, it is recommended to list other specific (organ)diagnoses on an ICD-basis in addition to the single ICD-10 code for long COVID if possible. For example, the following ICD-10 codes can be added [13]:

- **F06.7** Cognitive disorder
- **F32.** Depressive disorder
- **F41.** Anxiety disorder
- **F43.** Adjustment disorder

- **G62.80** Critical Illness Polyneuropathy
- **G93.3** Chronic Fatigue Syndrome
- **R00.2** Palpitations
- **R06.0** Dyspnea
- **R26.** Disorders of gait and mobility
- **R42.** Vertigo
- **R43.** Disorders of sense of smell and taste
- **R51.** Headache
- **U50.** Motor function impairment
- **U51.** Cognitive functional impairment

## Aetiology

The exact causes and risk factors leading to long COVID symptoms are currently unknown. Due to the great variety of different symptoms, it can be assumed that several causes are interwoven. For example, the Belgian Health Care Knowledge Centre (KCE) distinguishes two categories [16]:

- Long-term symptoms due to organ damage that happened during the acute infection phase (e.g. damage to the lung or heart due to the infection). It is assumed that these damages are more common in more severe SARS-CoV-2 courses.
- Persistent or residual symptoms without evidence of organ damage.

In addition, long COVID must be differentiated from other diseases or causes, such as the “Post-intensive care syndrome” (PICS) that describes long-term physical, psychological and cognitive impairments (e.g. damage to the lungs after prolonged artificial respiration) that are similar to long COVID symptoms in patients who were previously treated in an intensive care unit (ICU). In addition, it should be distinguished from chronic comorbidities that worsen in the aftermath of acute illness [16].

## Epidemiology

In the first part of the long COVID project, the prevalence of long COVID in adults was investigated in cooperation with the Belgian institute KCE. Overall, 28 studies showed that five to 36 per cent of the COVID-19 patients, who had never been hospitalised during the acute SARS-CoV-2 infection, and 39 to 72 per cent of hospitalised COVID-19 patients suffered from persistent symptoms one to three months after the onset of the acute infection. After three to six months, the prevalences slightly decreased in both patient groups (2-21% versus 51-68%). Six months after disease onset, still, 13 to 25 per cent of the non-hospitalised and up to 60 per cent of the hospitalised COVID-19 patients reported ongoing symptoms. Even if there are wide ranges in the long COVID prevalences of symptoms, the study results indicate that the COVID-19 patients, who had been treated in the hospital during the acute infection, generally have a higher risk to suffer from persistent symptoms long COVID compared to COVID-19 patients with mild to moderate infections [17, 18].

Regarding the most reported symptoms, the included studies showed that the long COVID patients most frequently reported fatigue, shortness of breath and headache one to three months after the onset of the acute infection. After three to six months, the most reported long COVID symptoms were fatigue, cognitive disorders and pulmonary difficulties [17, 18].

**genaue Ursachen von Long-Covid noch nicht bekannt;**

**KCE unterscheidet zwischen Symptomen aufgrund von Organschäden & Symptomen ohne vorliegende Organschäden**

**Abgrenzung von Long-Covid zu anderen Erkrankungen/Ursachen mit ähnlichen Symptomen & Komorbiditäten**

**Teil 1 zur Epidemiologie (n=28 Studien): Anzahl der Patient\*innen (Pat.) mit Long-Covid Symptomen nimmt im Laufe der Zeit ab**

**ehemals hospitalisierte Covid-19 Pat. häufiger von anhaltenden Symptomen betroffen**

**am häufigsten berichteten Symptome: Müdigkeit/Erschöpfung & Atemwegsprobleme**

<b>anhaltende Symptome bei Kindern und Jugendlichen nicht nur auf akute Infektion zurückzuführen</b>	Besides, long COVID can also occur in children and adolescents, although studies on frequency and symptoms have not been systematically summarised so far. In general, long COVID in children and adolescents seems to occur less frequently, with less severe symptoms and shorter duration than in adults, as children and adolescents have a lower risk for severe SARS-CoV-2 infection and hospitalisation. Moreover, comparative studies have demonstrated that some symptoms children and adolescents described occurred in children with a previous and without a previous SARS-CoV-2 infection suggesting that a part of the symptoms are not caused by the virus but have other origins (e.g. social distancing, school closures) [19, 20].
<b>andere Ursachen, wie z. B. Auswirkungen der Pandemiemaßnahmen ebenso möglich</b>	
<b>bis Anfang August 2021 19 Studien zur Epidemiologie hinzugekommen</b>	On October 26 2021, the Belgian institute KCE published an update of the systematic review about long COVID prevalences. By August 2021, in total 47 studies/48 publications (28 <i>existing</i> + 19 <i>new studies</i> ) could be identified. The 47 studies included 36 cohort studies, one case-control study and eleven cross-sectional studies. Despite the consideration of the 19 new studies, the updated prevalence rates still show substantial variations:
<b>&gt;1 bzw. &gt;3 Monaten: keine neuen Prävalenzen für nicht-hospitalisierte Pat. &amp; größere Schwankungen bei Prävalenzen zu hospitalisierten Pat.</b>	Beyond one month and three months, no new evidence could be identified for the prevalence rates of the mostly non-hospitalised COVID-19 patients. However, the ranges of the prevalence rates for mainly hospitalised COVID-19 patients had even increased with the upcoming evidence: <ul style="list-style-type: none"> <li>■ after one to three months: 32 to 78 per cent (versus 39 to 72 per cent),</li> <li>■ and after three to six months: 13 to 92 per cent (versus 51 to 68 per cent).</li> </ul>
<b>&gt; 6 Monaten: sehr variable Prävalenzen</b>	Six months after disease onset, still, 13 to 53 per cent of mostly non-hospitalised and up to 50 to 93 per cent of the mostly hospitalised COVID-19 patients reported ongoing symptoms. However, the studies with a follow-up longer than six months are still limited.
<b>keine wesentlichen Änderungen bzgl. den am häufigsten berichteten Long-Covid Symptomen</b>	Regarding the most reported symptoms, the results did not change significantly by considering the 19 new studies. Only the first three months, also smell or taste disorders were newly reported as one of the most common symptoms among long COVID patients, next to the afore mentioned fatigue, dyspnea and headache.
<b>mögliche Risikofaktoren: z. B. mehrere Covid-19 Symptome unter den nicht-hospitalisierten Pat.</b>	Regarding possible risk factors, there are new indications in those who were not hospitalised that a higher number of symptoms at the acute phase of the disease may be a risk factor for developing long COVID. Moreover, six studies showed an association between female gender and the likelihood to develop long-term symptoms [21].

## Impact of long COVID

On the one hand, long COVID comes with a burden to the affected individuals and their families. The systematic review about long COVID epidemiology, for example, showed that 41 to 61 per cent of long COVID patients experienced impairments in activities of daily living [17, 18].

On the other hand, the increasing number<sup>1</sup> of long COVID cases is also an issue for society as a whole. In particular, because of its impact on the workforce [8, 9]. For example, an analysis by the Scientific Institute of the General Local Health Insurance (AOK) in Germany found that employees who had to be hospitalised during the acute SARS-CoV-2 infection missed, on average, more than two months of work during the nine months after their hospital admission. The average sick leave during the nine months after the hospitalisation were 61.4 days, which is four times as much as the average of 15 days of sick leave among employees in general [22]. Moreover, reports from the UK have shown that the National Health Services (NHS) are also impacted by long COVID because many of the healthcare workers were infected with SARS-CoV-2 themselves and are struggling with the long-lasting symptoms. This has led to reduced workability (e.g. part-time work) or even inability to work within the NHS healthcare professionals. Similar consequences are expected to occur in other professional groups, such as teachers.

Due to the high impact of long COVID not only on an individual level but also on the wider economy, it needs to play a significant role in healthcare planning [9].

**Auswirkungen auf  
alltägliche Aktivitäten der  
Pat. & dessen Familien  
...**

**... & gesellschaftliche/  
ökonomische  
Auswirkungen:**

**längere Krankenstände  
(z. B. Deutschland:  
Krankenstand vervierfacht)**

**Ausfälle wichtiger  
Berufsgruppen, wie  
Gesundheitspersonal**

**Long-Covid wichtiger  
Faktor bei der Planung der  
Gesundheitsversorgung**

---

<sup>1</sup> Due to the constant increase in total SARS-CoV-2 cases, the number of long COVID patients is also expected to grow. However, a quantification of the expected long COVID cases in Austria is currently not possible. The reasons for this are the great heterogeneity in long COVID prevalences for hospitalised and non-hospitalised COVID-19 patients, as well as the lack of data that do not allow a precise disaggregation between hospitalised and non-hospitalised SARS-CoV-2 infected persons in Austria. Currently only the total number of all registered SARS-CoV-2 cases is known for Austria (as of 08.07.2021: 651,000 SARS-Cov-2 infected persons), which makes an estimation of long COVID cases impossible.



## 2 Aim and research questions

This project aims to provide a systematic review of recommendations about long COVID healthcare pathways and additional (social) services for adults. Furthermore, a rough overview of already existing long COVID care structures of selected European countries will be given. The presented results are deemed to support preparations for and adjustments in the long COVID care planning in Austria including the healthcare sector and social-legal aspects.

An overview of recommendations about specific treatments and/or interventions for long COVID patients, as well as, effectiveness and/or safety analysis of different treatment or rehabilitation options is NOT the aim of the present project. Also, this project does not include an analysis of the previous management of long COVID patients in Austria. Until now, evidence on the specific management of long COVID is still evolving. Hence, healthcare systems have proposed transient pathways and await more robust evidence to adapt and implement them.

This report presents the second part of the long COVID project. The first part provided a systematic review about long COVID prevalences published at the end of June 2021 (see <https://eprints.aihta.at/1321>).

The following research questions arise from the defined project aims:

1. What are the current recommendations concerning long COVID healthcare pathways and additional (social) services?
2. Which medical care structures and additional (social) services for long COVID patients have already been established in Austria and selected European countries?

**Ziel:**

**Überblick zu  
Empfehlungen bzgl.  
Long-Covid  
Versorgungspfaden &  
Beispiele etablierter  
Versorgungsstrukturen**

**KEINE spezifischen  
Therapieempfehlungen**

**KEINE Versorgungsanalyse  
für Österreich**

**2 Forschungsfragen (FF):  
Empfehlungen zu  
Versorgungspfaden;  
Beispiele zu etablierten  
Versorgungs-strukturen**



### 3 Methods

#### Literature searches

From 27<sup>th</sup> to 29<sup>th</sup> April 2021, a systematic literature search was performed in four databases (Cochrane, Embase, Medline, HTA-INAHTA) for the present systematic review on long COVID recommendations concerning healthcare pathways and other (social) services as well as on already existing long COVID care structures of selected European countries. In addition, several unsystematic hand searches were conducted in PubMed and google scholar on a biweekly basis to gather further information (last hand search: 02.08.2021).

More details on the systematic search strategy are presented in the Appendix (see Search strategies).

**systematische Suche in  
4 Datenbanken Ende  
April 2021 & weitere  
unsystematische  
Handsuchen bis Anfang  
August 2021**

**Details zur systematischen  
Suchstrategie im Anhang**

#### Inclusion and exclusion criteria

For the selection of the literature, predefined inclusion and exclusion criteria were considered according to the PICO scheme. These criteria are presented in the following table.

**Ein- & Ausschlusskriterien  
nach dem PICO-Schema**

Table 3-1: Inclusion and exclusion criteria according to the PICO scheme

	Inclusion criteria	Exclusion criteria
Population	Adults with long COVID symptoms lasting $\geq 4$ weeks after disease onset <i>Keywords: post-COVID condition, late-lasting COVID-19 symptoms, post-acute COVID syndrome, chronic COVID syndrome, post-acute sequela of SARS-CoV-2</i>	Children & adolescents with long COVID
Intervention	-	-
Control	-	-
Outcomes	<b>Research question 1:</b> <ul style="list-style-type: none"> <li>Recommendations concerning long COVID healthcare pathways</li> <li>Recommendations regarding other services for long COVID patients (e.g. social, financial, vocational)</li> </ul> <b>Research question 2:</b> Examples of already existing care structures for long COVID patients in selected European countries	-
Study design	<b>Research question 1:</b> Guidelines, reviews, expert opinions in the form of consensus statements and clinical perspectives <b>Research question 2:</b> <ul style="list-style-type: none"> <li>Same references as for research question 1</li> <li>Websites of e.g. patient organisations, care facilities, social services</li> </ul>	Primary studies
Publication period	Until the beginning of August	From August 2021 onwards
Countries	<b>Research question 1:</b> Europe, North America, Australia <b>Research question 2:</b> selected European countries (e.g. UK, Belgium, Germany, Italy, Austria)	Other countries (e.g. Asia, South America)
Language	German and English	Other languages

Abbreviations: COVID – Coronavirus disease, e.g. – for example, UK – United Kingdom

## Literatur selection process

754 Referenzen standen  
zur Abstract-Durchsicht  
zur Verfügung

aus 67 Volltexten,  
14 für die qualitative  
Synthese (hauptsächlich  
FF1) eingeschlossen

Auswahlprozess &  
Ausschlussgründe in  
Abbildung 3-2 dargestellt

After deduplication, a total of 754 sources including guidelines, reviews, consensus statements and clinical perspectives were available for the literature selection on an abstract basis. The literature was reviewed independently by the two authors (SW, JE). Only studies published until the beginning of August 2021 were considered. Differences were resolved through discussion and consensus or the involvement of a third person.

After the screening of all 754 abstracts, 67 references were considered for further investigation on full text basis. Out of these 67 full texts, a total of 14 references including five guidelines, four reviews, one consensus statement and four clinical perspectives met the pre-defined inclusion criteria and were primarily included to answer the first research question. Nevertheless, relevant information from the 14 references was also considered for the second research question.

The detailed selection process, including the reasons for the exclusion of 53 full texts is shown in Figure 3-1.

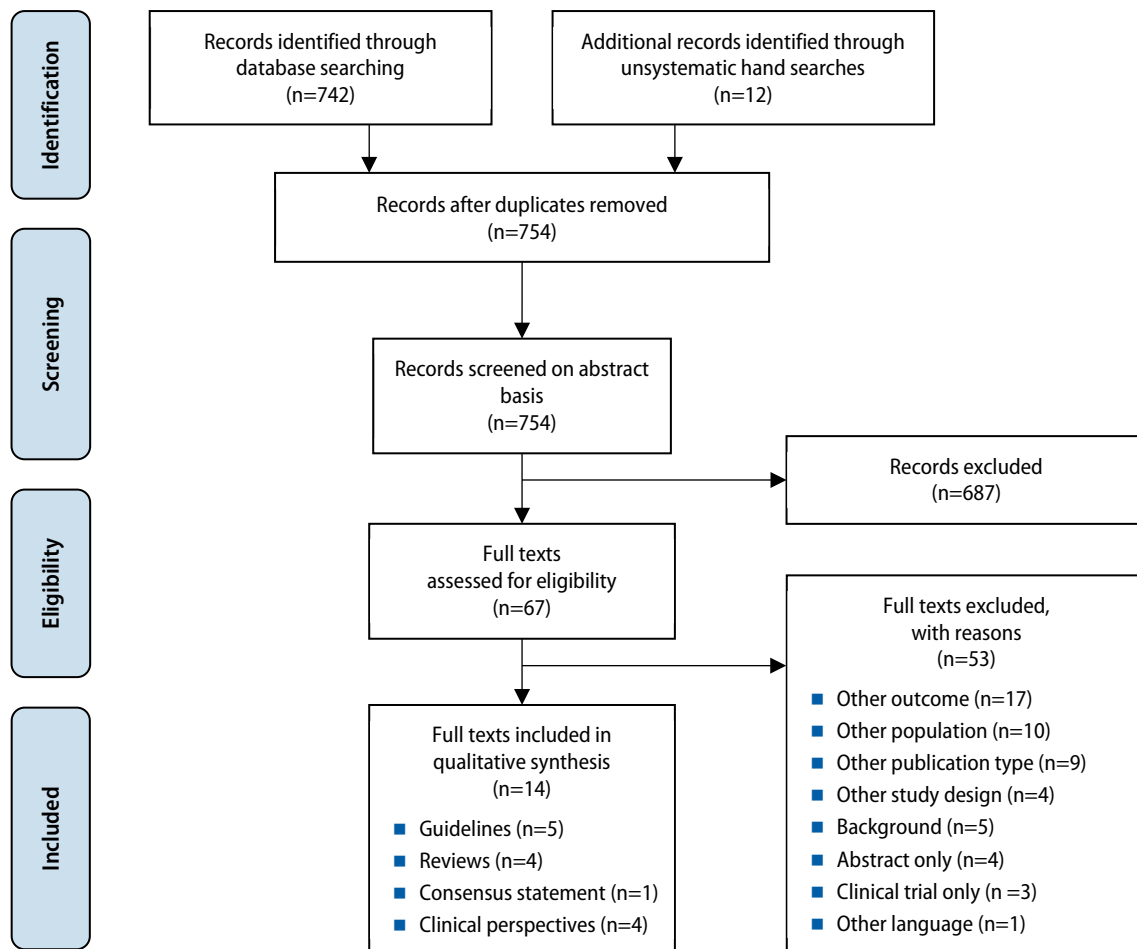


Figure 3-1: Representation of the selection process (PRISMA Flow Diagram)

## Additional sources for answering the second research question

Separate unsystematic hand searches and expert consultations were conducted to yield additional sources, next to the 14 included references, to answer the second research question about already existing long COVID care structures in selected European countries (UK, Belgium [BE], Italy [IT], Germany [GER], Austria [AT]). This further information was obtained from websites about relevant institutions including patient organisations, long COVID healthcare facilities and social care services, as well as, from newspaper articles about relevant healthcare facilities. The selected European countries represent different geographic locations (north, middle and south Europe) and different healthcare systems (national health services and social health insurance system). In order not to go beyond the scope of this report, no other European countries (e.g. Spain or France) could be considered. Experts with different access to long COVID (e.g. practising physicians, patient representatives or political consultancy) were found within networks to national experts and through contacts between healthcare and health technology assessment agencies.

**weitere Quellen  
für die Beantwortung  
der 2. FF durch weitere  
unsystematische  
Handsuchen &  
Kontaktaufnahme  
mit Expert\*innen**

### Expert consultation

In total, 13 experts from the selected European countries were contacted between May and August 2021 via e-mail regarding further information about examples of already existing long COVID care structures in their country. However, only five of the contacted experts replied (UK [n=1/1], BE [n=1/5], IT [n=1/2], GER [n=2/3] and AT [n=0/2]).

**13 Expert\*innen zwischen  
Mai & August kontaktiert,  
von 5 Antwort erhalten**

More information about the experts and their answers is presented in the Appendix (see Expert consultation Table A-13).

### Data extraction process

The data of 14 included references and the additional information from websites or experts were extracted by using specially designed data extraction tables. Thereby, separate extraction tables were created for each sub-question, namely

**Datenextraktion mit Hilfe  
von Extraktionstabellen**

four extraction tables for the first research question:

- Characteristics of the included literature
- First point of services
- Possible referrals
- Additional (social) services

**1 Extraktionstabelle  
pro Sub-Frage**

and two extraction tables for the second research question:

- Current long COVID care structures in Austria
- Current long COVID care structures in selected European countries.

While only data from the 14 included references were taken into account in the extraction tables for the first research question, the additional information from websites and contacted experts were only considered in the extraction tables for the second research question.

The extraction tables are presented in the Appendix (see Extraction tables).

<p><b>keine Qualitätsbewertung der eingeschlossenen Leitlinien &amp; Reviews durchgeführt, deren Qualität jedoch limitiert</b></p> <p><b>Konsenspapiere &amp; Expert*innen- Einschätzungen → niedrigste Evidenzstufe</b></p>	<p><b>Quality assessment</b></p> <p>In this systematic review, no systematic quality assessment of the included guidelines or reviews was performed, because most of the retrieved articles were conceptual and therefore did not fit for a classical quality evaluation. However, it has to be pointed out that due to the topicality of long COVID and the urgency for research regarding its management, the quality of the available evidence is limited. For example, most of the included guidelines are presented as “living guidelines” that are deemed to be updated regularly. Furthermore, the included reviews on long COVID management do not present classic systematic reviews.</p> <p>Besides, expert opinions in the form of consensus statements or clinical perspectives – which present the lowest level of evidence – were also taken into account in the present systematic review in order not to overlook any potentially relevant information.</p>
<p><b>narrative Zusammenfassung der Ergebnisse pro Sub-Frage</b></p>	<p><b>Narrative data synthesis</b></p> <p>Following the data extraction, the characteristics of the included references were narratively described in a first step. In the next step, the extracted information was narratively summarised for each sub-question (first point of contact; possible referrals; additional [social] services; examples of long COVID care structures in Austria and selected European countries).</p>

## 4 Results

In the following chapter, firstly, recommendations concerning long COVID care pathways from available guidelines, reviews and expert papers of five countries (UK, USA, the Netherlands [NL], GER, AT) are summarised. Subsequently, a broad overview of the current long COVID care structures in Austria is given and finally complemented by some models from selected European countries (UK, BE, IT, GER).

**Überblick über  
Empfehlungen zu  
Versorgungspfaden  
& aktuellen  
Versorgungsangeboten  
in AT & ausgewählten  
Ländern**

### 4.1 Recommendations about long COVID care pathways

#### 4.1.1 Included evidence

##### Guidelines

In total, five guidelines were identified in the systematic search and additional hand searches:

- two guidelines from the UK: the guideline of the NICE, the Royal College of General Practitioners (RCGP) and the Scottish Intercollegiate Guidelines Network (SIGN) [11]; the NHS clinical guidance [23],
- one guideline from the USA: the Centers for Disease Control and Prevention (CDC) guidance [24],
- one guideline from Germany: the S1 guideline Germany [13] and
- one guideline from Austria: the S1 guideline Austria [25].

**insgesamt 5 Leitlinien  
aus UK, USA, GER & AT  
eingeschlossen**

Overall, the guidelines aimed at identifying and assessing the management of long COVID symptoms and thereby giving advice to healthcare professionals on how to organise, establish, but also maintain long COVID (healthcare) services.

**3/5 der Leitlinien sollen  
regelmäßig upgedated  
werden**

Three of the five included guidelines [11, 24, 25] were declared as living/ interim guidelines, which means that they are updated if new evidence and/or recommendations occur. In four of the five guidelines, the presented recommendations were based on expert consensus, while one guideline did not report how the recommendations were conducted [24]. Funding was not reported in any of the five included guidelines and only the Austrian S1 guideline declared no conflict of interests of guideline authors [25].

**bei 4/5 Leitlinien,  
Empfehlungen  
basierend auf  
Expert\*innen-Konsensus**

All guideline recommendations, except the ones from the CDC guideline, applied to ongoing symptomatic COVID-19 (persistent symptoms of four to 12 weeks) as well as post-COVID syndrome patients (persistent symptoms of >12 weeks). The CDC guideline did not report to which long COVID definition the recommendation relate. Also, the CDC guideline did not report to which patient population their recommendations relate [24], while the recommendations of the other guidelines hold for both, hospitalised and non-hospitalised COVID-19 patients. The S1 guideline from Austria specified that they considered hospitalised COVID-19 patients, except for those who were admitted to the ICU.

**4/5 der Leitlinien zu  
hospitalisierten &  
nicht-hospitalisierten Pat.  
mit anhaltenden  
Symptomen >4 Wochen  
nach Krankheitsbeginn**

## Reviews

**4 Reviews aus UK, USA &  
1 zu mehreren Ländern  
identifiziert**

**Empfehlungen für  
hospitalisierte & nicht-  
hospitalisierte Pat. in  
2 Reviews**

**Empfehlungen für  
anhaltende Symptome  
über >4 bzw. >6 Wochen  
in 2 Reviews**

**Methode nur in  
1 Review beschrieben**

**Finanzierung &  
Interessenskonflikte nur  
in 2 Reviews dargelegt**

In addition, four reviews were identified in the systematic search and unsystematic hand searches: two from the UK [8, 26], one from the USA [27] and one from several European countries (including UK, BE, IT, GER) [28]. Among other things, the included reviews aimed at presenting recommendations for healthcare pathways for long COVID patients. Two of the four reviews presented recommendations for both hospitalised and non-hospitalised SARS-CoV-2 infected [8, 26], while the other two reviews did not report for which patient population the presented recommendations were meant [27, 28].

While one review considered all symptoms persisting more than four weeks after the beginning of the SARS-CoV-2 infection [26], another report focused on recommendations for ongoing symptoms of at least six weeks after disease onset [28]. The two other reports did not report on which long COVID definition they relied on [8, 27]. Only in one out of the four included reviews, it was reported that the presented recommendations were evidence-based, but not systematically searched [8], while the other reviews did not describe the applied methods [26-28].

Two of the four included reviews reported on funding and conflict of interests, from which one declared one conflict of interest [26] and the other review reported on conflict of interests of two authors of the report [28].

## Expert papers

**Expert\*innen-Papiere  
berücksichtigt:  
Konsenspapier (n=1)  
& Expert\*innen-  
Einschätzungen (n=4)**

**1 Expert\*innen-  
Einschätzung berichtete  
Interessenskonflikte**

**Konsenspapier mit  
Empfehlungen zur  
Rehabilitation physisch  
aktiver Post-Covid-19 Pat.**

**Expert\*innen-  
Einschätzungen mit  
Empfehlungen für  
Gesundheitspersonal zu  
Rehabilitation, Sport &  
Nachuntersuchungen**

Due to the topicality of this theme and the therefore limited available evidence, also expert papers in the form of consensus statements or clinical perspectives were considered. In total, one consensus statement from the UK [29] and four clinical perspectives from the UK [30], the Netherlands [31] and Germany [32, 33] were identified in the systematic search and additional hand searches.

Only one clinical perspective reported conflict of interests in the form of grants to the first author [31]. The other clinical perspectives [30, 32, 33] and the consensus statement [29] had no conflict of interests to declare.

The consensus statement aimed at providing current evidence-based recommendations for likely requirements of a post-COVID rehabilitation in a primarily physically active patient population [29]. The clinical perspectives aimed at giving consensus-based perspectives for healthcare professionals on where and how to manage long COVID symptoms including recommendations on rehabilitation, exercise/sports and other follow-up treatments [30-33]. One clinical perspective thereby focused on hospitalised and non-hospitalised patients with ongoing symptoms of more than four weeks after disease onset [30], while another clinical perspective only focused on former COVID-19 patients that were treated in hospital during the acute infection and had long-lasting symptoms of more than four weeks but less than 12 weeks after disease onset [31]. The other two clinical perspectives did not report on which long COVID definition they relied on. One of the two clinical perspectives [33] reported that they presented recommendations for hospitalised and non-hospitalised COVID-19 patients.

More information about the characteristics of the included literature is presented in the Appendix (see Table A-1 and Table A-2).

#### 4.1.2 Recommendations for possible long COVID healthcare pathways

##### First point of contact

Table A-3 and Table A-4 in the Appendix present detailed information about the first points of contact for long COVID patients.

##### Primary care

In most of the analysed countries (e.g. UK, USA, GER, AT), the primary care sector, including GPs and primary care centres, is recommended as the first point of contact for former symptomatic or asymptomatic SARS-CoV-2 infected with persistent symptoms for at least four weeks after the acute infection [11, 13, 23-25, 27, 30]. Importantly, healthcare services should thereby be not restricted to patients with a positive SARS-CoV-2 test result, because not all persons may have had access to a test when they were infected [9, 19, 24].

However, in some countries (e.g. UK, USA, NL), for some long COVID patients not only the primary care sector is responsible in the first step. For example, in the UK, a healthcare professional from secondary care are advised to follow-up on former hospitalised COVID-19 patients via video or phone to check for new or ongoing symptoms or complications at 12 weeks after discharge. Besides, former hospitalised COVID-19 patients who suffer from ongoing or new symptoms after 12 weeks of discharge can go to secondary care outpatient departments or primary care facilities for a clinical assessment [11, 23, 30].

Nevertheless, most of all, the GPs or respective healthcare professionals in primary care centres should carry out the primary assessment including a comprehensive clinical history, the examination of persistent physical, cognitive, psychological and psychiatric symptoms as well as functional abilities. In addition, it should be differentiated between long COVID symptoms due to organ damage and functional disorders. Furthermore, existing comorbidities, other differential diagnoses as well as the socio-economic circumstances of the patients need to be considered within the primary assessment [13, 23, 25, 27, 30].

At the beginning of the first assessment, the GPs or respective healthcare professionals in primary care centres should identify any possible life-threatening complications (e.g. acute respiratory insufficiency, pronounced frizz instability or suspected cardiogenic chest pain) and in case they find any, refer the patients to acute services. Subsequently, other non-severe symptoms that are likely to be caused by the initial SARS-CoV-2 infection can be identified by using standard operating procedures [13, 23, 25, 27, 30]. For example, the GPs or respective healthcare professionals in primary care centres can make use of different questionnaires and scales, which can help them in their diagnosis. Possible questionnaires and scales are [11, 13, 25, 31]:

- **The EQ-5D and the Short-Form 36** to assess the generic health status of the patients [34, 35].
- **The Klok Scale** to assess, inter alia, long COVID-related individual distress and level of impairment [36].
- **The Newcastle Post-COVID Syndrome Follow-up Screening Questionnaire** to identify patients who may benefit from a comprehensive face to face multi-disciplinary assessment if symptoms persist for ten to 12 weeks after the acute illness [37].

**Hausärzt\*innen generell als erste Anlaufstelle für Long-Covid Pat. empfohlen, jedoch in manchen Ländern (UK, USA, NL) nicht für alle Long-Covid Pat.**

**Primärversorgung nicht immer erste Anlaufstelle, z. B. für ehemals nicht-hospitalisierte Covid-19 Pat. → in UK z. B. auch Krankenhausambulanzen**

**Erstuntersuchung vor allem durch Hausärzt\*innen empfohlen: Berücksichtigung von Komorbiditäten bzw. anderen Ursachen wichtig**

**1. Ausschluss potentiell lebensgefährlicher Symptome**

**2. Identifizierung potentieller Long-Covid Symptome z. B. mittels standardisierten Fragebögen & Skalen, wie die Klok-Skala**

Informationen  
zur Einnahme von  
Nahrungsergänzungsmitteln,  
etc. wichtig

3. Planung weiterer  
Vorgehensweise,  
z. B.: Self-Management,  
symptomatische Therapie,  
„Abwarten & Beobachten“  
bei milden bis moderaten  
Symptomen

bei komplexen  
Symptomen bzw.  
Zustandsverschlechterung  
Überweisung an  
z. B. Long-Covid  
Spezialambulanzen

multidisziplinäre  
Rehabilitationsprogramme  
oder Einzeltherapien auch  
möglich

in manchen Ländern  
Sekundärversorgung auch  
als 1. Anlaufstelle für  
ehemals hospitalisierte  
COVID-19 Pat. empfohlen

Zeitpunkte der  
Kontaktaufnahme in  
z. B. USA & NL zwischen  
1-8 Wochen nach  
Entlassung

- **The COVID-19 Yorkshire Rehabilitation Screening Tool** to find out if the patients are experiencing problems related to the recent illness with COVID-19 [38].
- **The Hospital Anxiety and Depression Scale, the Patients Health Questionnaire 9, the General Anxiety Disorder 7 or the Depression Anxiety Stress Scale 21** to assess anxiety and/or depression [39-42].
- The **Medical Research Council Dyspnoea Grading Scale** to measure breathlessness [43].
- The **Montreal Cognitive Assessment** for a cognitive screening [44].

Furthermore, the GPs or respective healthcare professionals in primary care centres should always inquire about any unprescribed medications, herbal remedies, supplements or other treatments that patients may be taking for their long COVID conditions to avoid potential interactions with recommended treatments [24].

In the next step, the GPs or respective healthcare professionals in primary care centres can propose self-management strategies and/or prescribe treatments to alleviate symptoms depending on the patients' needs [23, 27, 30]. In the German and Austrian long COVID guidelines also a wait-and-see approach under the supervision of the respective doctor is proposed (also known as watchful waiting). This means that after the exclusion of severe symptoms, further assessments and referrals can be postponed as some long COVID symptoms may disappear over time, while symptomatic treatments are still possible if needed. However, in the case of symptom deterioration or persisting symptoms of more than 12 weeks, the need for further diagnostics is mandatory [13, 25].

For patients with (a) more complex long COVID symptom(s) or clinical worsening, the GPs or respective healthcare professionals in primary care centres can also make appropriate referrals to, for example:

- multidisciplinary specialised long COVID outpatient assessment clinics (e.g. in the UK, GER, AT) [11, 13, 23, 25] or
- to a specialist of a single discipline (UK, USA, NL, GER, AT) [11, 13, 23-25, 28, 30, 31].

Besides, consultations with multidisciplinary rehabilitation programmes or non-medical healthcare providers, such as physiotherapists, occupational therapists, psychotherapists, speech therapists, nutritional counsellors or nurses can be initiated if necessary (UK, USA, NL, GER, AT) [11, 13, 23-25, 31].

### Secondary care

As described previously, in a few countries (e.g. UK, USA, NL), the secondary care sector can also be recommended as the first point of contact for patients who had been hospitalised during the acute SARS-CoV-2 infection. Hence, follow-up consultations of the patients' condition can also be planned as phone or video consultations by a healthcare professional in secondary care or secondary care outpatient department. These consultations should include a check for new or ongoing symptoms and ruling out life-threatening symptoms or other non-COVID-19-related conditions. Subsequently, it should be assured that the patients are discharged to the appropriate setting (e.g. home, rehabilitation centre, nursing home). The timing of the first follow-up visit varies between the countries. For example, in the USA, the first follow-up consultation should take place six to eight weeks after hospital discharge [11, 24], while in the Netherlands, it is recommended within one to two weeks of hospital discharge [31].

In the UK, services also differentiate between former hospitalised COVID-19 patients in general and patients who had been treated in an ICU or high dependency unit (HDU). For the latter, the first multidisciplinary assessment of rehabilitation needs should already take place at the point of a step down to other inpatient facilities. Inpatient rehabilitation should therefore begin as soon as the patient is capable of it. After the inpatient rehabilitation and on discharge from the hospital, an assessment of the patients' ongoing needs is recommended including appropriate community service referrals if needed. Subsequently, a multidisciplinary clinic re-assessment should be undertaken at four to six weeks post-discharge, including referral if needed, e.g. to rehabilitation or mental health services. If the patients continue to improve further, the next assessment is recommended 12 weeks after the hospital discharge [23].

### Possible referrals from first point of contact

#### Acute services (e.g. emergency)

Several guidelines (e.g. UK, GER, AT) point out that referral to the relevant acute service is recommended if acute or life-threatening complications, such as severe hypoxaemia, oxygen desaturation on exercise, signs of severe lung disease, cardiac chest pain or unexplained or newly appeared neurological abnormalities are diagnosed during the primary assessment. This also includes acute psychiatric services for patients with severe psychiatric symptoms with a risk of self-harm [11, 13, 23, 25].

#### Specialised long COVID outpatient assessment centres/clinics

In some countries (e.g. UK, GER, AT), patients with no acute or life-threatening complications, but with more complex possibly SARS-CoV-2-related symptoms should be referred to so-called specialised long COVID outpatient assessment centres/clinics. In such outpatient centres/clinics, a second assessment of the patients' clinical history and current health status is recommended. Thereby, the patients are provided access to multidisciplinary teams including professionals of e.g. neurology, psychiatry, psychosomatic, cardiology, pneumology, rheumatology, otorhinolaryngology, dermatology and/or endocrinology. If the assessment results in the need for further assessments and/or therapies, the centres/clinics can also forward the patients to appropriate services, such as specialists for specific disciplines or multidisciplinary rehabilitation programmes or some may also offer treatment options themselves. The timing of a referral to a specialised long COVID outpatient assessment clinic/centre is recommended at any time from four weeks after the onset of the disease, but mostly if symptoms last for more than 12 weeks. [11, 13, 23, 25].

In chapter 4.2.3, examples of already existing specialised long COVID outpatient assessment clinics are presented in more detail.

#### Specialist care

In all investigated countries (UK, USA, NL, GER, AT), patients with a dominant long COVID symptom, e.g. a specific organ dysfunction, should be referred to the relevant specialist. The referral can come directly from the doctor who did the first clinical assessment or from a specialised long COVID outpatient assessment clinic after the second assessment. Possible specialists are, for example, pulmonologists, cardiologists, neurologists and psychologists.

**in UK spezieller  
Nachbeobachtungsprozess  
für Intensivstation-Pat.:**

- 1. Assessment bei  
Verlegung auf andere  
Station,**
- 2. bei Entlassung,**
- 3. 4-6 Wochen danach,**
- 4. >12 Wochen**

**bei akuten oder  
lebensgefährlichen  
Symptomen  
→ Überweisung in die  
Notaufnahme empfohlen**

**bei nicht akuten, jedoch  
komplexen Symptomen  
→ weitere Untersuchung  
in Long-Covid  
Spezialambulanzen  
empfohlen, meistens bei  
Long-Covid Symptomen,  
die >12 Wochen anhalten**

**manche  
Spezialambulanzen  
bieten auch selbst  
Behandlungen an**

**bei 1 dominanten  
Symptom, z. B. organ-  
spezifisch → Überweisung  
an relevante(n)  
Spezialist\*in empfohlen**

anschließend, weitere  
Überweisungen möglich

The timing of the referral to a specialist should be based on the individual patients' needs and the discretion of the assessing clinician; however, mostly it happens if symptoms persist for more than 12 weeks. Subsequently, the specialists can also make further referrals if needed, e.g. to appropriate rehabilitation programmes or other care offers, such as community nursing, to support the patients and wider family members with the treatment process [11, 13, 23-25, 28, 30, 31].

#### Multidisciplinary rehabilitation

Überweisung zu  
stationärer, teilstationärer  
oder ambulanter  
Rehabilitation,  
meistens wenn Symptome  
>12 Wochen anhalten

In all investigated countries (UK, USA, NL, GER, AT), the long COVID patients can be referred to multidisciplinary inpatient, partial inpatient or outpatient rehabilitation programmes if necessary. The referrals can be performed directly by the doctors who made the first clinical assessment, specialists or by specialised long COVID outpatient assessment clinics [8, 13, 23-25, 31]. The timing of the referral depends on the severity of the symptom(s). For example, early rehabilitation should be offered to ICU and HDU patients already during the hospital stay if the patients are capable of it. For patients with mild to moderate symptoms, rehabilitation should be usually indicated if the symptoms last for more than 12 weeks [23, 25].

generell Pat.-orientierte,  
multimodale Rehabilitation  
empfohlen, inklusive  
z. B. physikalischen,  
kognitiven und/oder  
psychologischen  
Elementen &  
Berücksichtigung des  
Lebensstils der Pat.

Overall, the rehabilitation for long COVID patients should be patient-centred and tailored to the individual needs of the patients, given the wide variety of symptoms and the possible presents of comorbidities. The programmes should also be multimodal and include some of the following elements [8, 11, 13, 23-25, 29-32]:

- **Physical elements:** e.g. pneumological rehabilitation, cardiological rehabilitation, physiotherapy, speech and language therapy, muscle strengthening programmes, especially for patients who had been treated at the ICU.
- **Cognitive elements:** e.g. physiotherapy and exercise for patients with motor deficits, but also for support in restoring the cognitive function or, if not possible, in developing new ways of organising information.
- **Psychological elements:** e.g. high-intensity psychological interventions from clinical psychologists, psychiatry and/or psychological therapies.
- **Lifestyle components:** e.g. advice on nutrition, sleep and stress reduction.

#### Community health services and non-medical healthcare providers

weitere Optionen:

“Community Care  
Networks” wie z. B.  
Community Nurses

Depending on the needs of the patients, they can also be referred to community care networks by the GP, specialists or specialised long COVID outpatient assessment clinics (e.g. in the UK). These networks involve, for example, community nurses, nursing homes or healthcare hotels and aim to support the other long COVID healthcare service providers by offering support for patients (e.g. via home visits) [23, 28].

nicht-medizinisches  
Gesundheitspersonal,  
z. B. Physio- bzw.  
Psychotherapeut\*innen

Moreover, in many countries (e.g. UK, GER, AT), for patients with a mild to moderate symptom that can be treated by one specific discipline, it is recommended to refer them to outpatient non-medical healthcare workers, such as physiotherapists, psychotherapists, occupational therapists, speech therapists or nutritional counselling. Besides, non-medical healthcare services can be suggested for patients with more severe symptoms in addition to other treatments (e.g. respiratory physiotherapy) [11, 13, 25, 26].

## (Supported) self-management

In most of the countries (UK, USA, NL, AT) it is recommended to advise the patients on how to self-manage their symptoms besides other treatments. This can include information about the self-check of clinical parameters (e.g. by oximetry) or self-monitoring by documenting the changes in health conditions and symptom severity (e.g. in a diary). Besides, also recommendations about how to improve the general well-being through an appropriate diet, enough sleep or stress reduction might be helpful for some patients. Furthermore, supported online programmes can be offered to the patients where available. For example, in the UK, an online self-management programme for long COVID patients was introduced by the NHS, namely the Your COVID-19 Recovery Platform (see more detail in chapter 4.2.3) [8, 11, 24, 25, 29-31].

zusätzlich  
Selbstmanagement-Tipps  
empfohlen,  
z. B. Dokumentation des  
Symptomverlaufs oder  
Hinweis zu speziellen  
Online-Programmen

More detailed information about possible referrals after the first point of contact is presented in the Appendix (see Table A-5 and Table A-6). Figure 4-1 presents a summarised overview of the possible long COVID healthcare pathways.

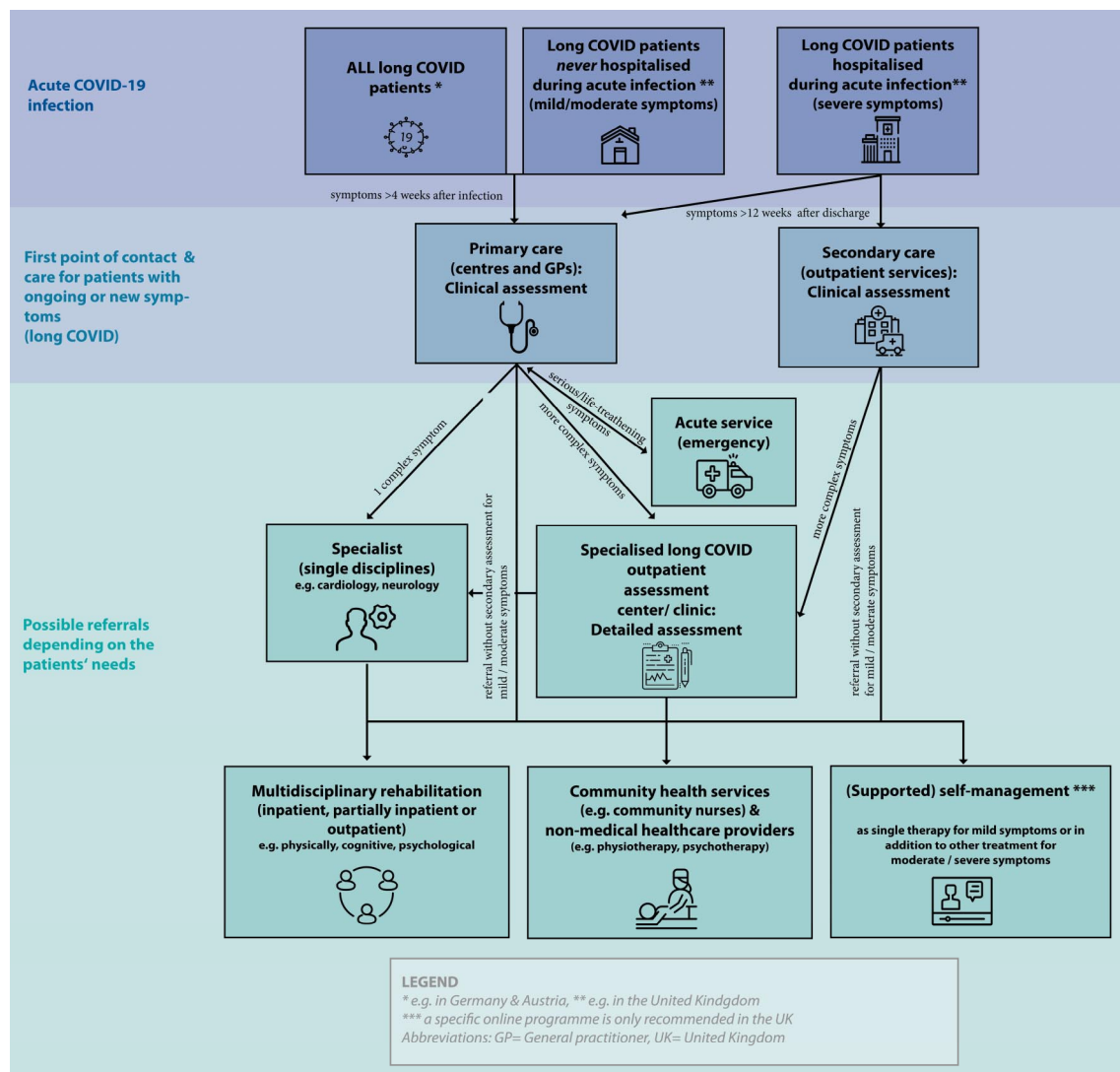


Figure 4-1: Possible long COVID healthcare pathways

### 4.1.3 Possible additional (social) services

#### Cash payments

**keine Long-Covid-spezifischen Leistungen, z. B. selber Prozess bei Krankenstand**

Two included guidelines (GER, AT) reported on the topic of cash payments for long COVID patients and recommended that the process to receive sick leave due to long COVID should be the same as for other (chronic) diseases. However, the diagnosis for receiving sick leave for long COVID should be rather based on the main clinical symptom instead of the “broad” long COVID diagnosis if possible [13, 25].

#### Contributions in kind

##### Social care services

**Informationen zu weiteren Unterstützungsmöglichkeiten wichtig, z. B. Austausch mit Pat.-Organisationen**

In general, delivering information to the patients and their families about where to find additional support is important. This can be, for example, suggestions to the patients made by the GP about community offers, such as patient organisations (e.g. UK, BE, GER, AT), faith groups or online support groups (e.g. via Facebook). If appropriate, patients can also be referred to social activities, also called social prescribing (UK) [11, 13, 23, 25, 30].

**ebenso sind Unterstützungsmöglichkeiten für Angehörige zu bedenken**

Moreover, recommendations about further support services for the families of long COVID patients can be envisaged including, for example, mental support or social services, such assistance in financial issues, family illness, bereavement and caregiving (e.g. UK, USA, NL, GER) [23-25, 30, 31].

##### Employment-specific services

**keine spezifischen Long-Covid Leistungen für Arbeitnehmer\*innen empfohlen, sondern übliche Leistungen, wie bei anderen Erkrankungen, z. B. Möglichkeit Arbeitsbedingungen anzupassen**

In the analysed literature, no recommendations about long COVID-specific services for employees could be identified. In general, the services are the same as for other diseases. For example, two included guidelines (UK, AT) emphasised that adjustments of the workplace and working conditions should be possible to facilitate the patients' come back to work [11, 25]. According to the German and Austrian long COVID guidelines, the severity of the acute infection and the individual requirements at work should be discussed with the relevant occupational health staff in the company (e.g. the safety specialist or company doctor) and the relevant institutions (e.g. labour inspectorate or respective insurance) before starting to work again [13, 25]. Besides, the patients can contact employee protection agencies or case managers from the health insurance, who provide support in organising the reintegration into work [13].

A more detailed overview of the additional (social) services is given in the appendix (see Table A-7 and Table A-8).

#### 4.1.4 Further recommendations for practising physicians regarding decision-making and communication

As recommended in the included literature, empathy towards patients, a holistic and person-centred approach and shared decision-making between healthcare professionals and patients should be key factors in long COVID care [11, 23-25, 29, 30]. For example, the NHS provides training programmes about “personalised care” for health and care staff by offering them access to the Personalised Care Institute. This institute provides high-quality eLearning and training resources in this regard [23, 24].

Furthermore, it is recommended that healthcare professionals should always update themselves on evolving guidance on long COVID management to be able to inform the patients with the latest information on the disease itself, the possible recovery periods and therapies [24]. In particular, information about self-management strategies and symptoms when to better look out for professional help should be part of the provided information to the patients [11].

Besides, good communication between healthcare professionals and the patients presents another important aspect in long COVID care. On the one hand, the practising physicians should consider and minimise possible health inequalities, such as cultural differences, language barriers, mental health conditions, mobility or sensory impairments, learning disabilities by offering special support (e.g. providing translated materials on long COVID) [11, 23, 24]. On the other hand, good communication also involves the right balance in the detail of the provided information to avoid unnecessary anxiety and uncertainty in patients, e.g. through overdiagnosis [25].

A more detailed overview of the additional (social) services is given in the appendix (see Table A-9 and Table A-10).

**Empathie, ganzheitlicher & personenzentrierter Ansatz, sowie Mitbestimmungsrecht  
→ Schlüsselfaktoren**

**behandelnde Ärzt\*innen sollten immer auf dem neuesten Stand bzgl. der Behandlungsempfehlungen sein**

**gute Kommunikation wichtig, z. B.:**

**Berücksichtigung von Sprachbarrieren,**

**richtiger Detailgrad an Informationen**

## 4.2 Examples of already existing long COVID care structures

### 4.2.1 Included evidence

The same 14 references that were considered for answering the first research question were also used to answer the second research question about examples of already existing long COVID care structures. The 14 references had thus already been described in the previous chapter (see chapter 4.1.1).

In addition to the 14 references, further relevant information was obtained by separate unsystematic hand searches and expert consultations. In total, information from four patient organisations (UK, BE, GER, AUT) [45-48], 12 websites about different long COVID healthcare facilities including rehabilitation programmes [49-55] or specialised long COVID centres [56-60], six websites about social care services (e.g. Fit2work) [61-66] and from one newspaper article about relevant healthcare facilities [67] were taken into account to answer the second research question. Details about the extracted information are presented in the related tables in the Appendix (see Table A-11, Table A-12 and Table A-13).

**dieselben 14 Referenzen wie für FF 1 für FF 2 herangezogen**

**zusätzliche 23 Quellen durch weitere unsystematische Handsuchen & kontaktierte Expert\*innen erhalten**

## 4.2.2 Overview of current long COVID care structures in Austria

österreichische Long-Covid  
Gesundheitsversorgung  
hauptsächlich regional &  
im niedergelassenen  
Bereich organisiert

In Austria, the long COVID healthcare provision is mainly organised and executed on a regional level including, in particular, outpatient treatment offers, such as primary care physicians, specialists and multidisciplinary rehabilitative offers, e.g. dietary counselling, physiotherapy and psychotherapy. Only if the required therapy is not available locally, inpatient facilities further away from the patient's residence are considered [56]. A large proportion of the long COVID care in Austria, in particular, the first clinical assessments, thus takes place in primary care centres or GPs' offices [13].

komplexere Fälle:  
Überweisung an Long-Covid  
Spezialambulanzen für  
weitere Untersuchungen  
möglich

For patients with more complex symptoms and the need for additional clinical consultations, specialised long COVID outpatient assessment clinics are available across Austria. The exact number of such clinics is not known, as they are also organised and implemented on a regional level.

Unterscheidung zwischen:

In general, it can be distinguished between:

Ambulanzen, die weitere  
Untersuchungen  
durchführen &  
gegebenenfalls für  
zusätzliche  
Untersuchungen und/oder  
Therapien an andere  
Fachrichtungen  
überweisen

- Specialised outpatient assessment clinics that have been adapted and now also offer *detailed clinical assessments and additional assessment and/or treatment recommendations for long COVID patients*. Depending on the patients' needs, these outpatient clinics can also refer them to other specialists. Some examples of such specialised outpatient assessment clinics are:

- **The outpatient assessment clinics of the Austrian Health Insurance**, which are located in several federal states across Austria and now also offer special consultation hours for long COVID patients [57].
- The specialised long COVID outpatient assessment clinic as part of the cardiac outpatient clinic of the University Hospital of Vienna, which offers clinical assessment and support hours once a week, on Wednesdays. Within this clinic, patients can also participate in a long COVID study [45].
- The long COVID outpatient assessment clinic as part of the Department of Internal Medicine of the state hospital in Graz (Styria) that offers secondary assessments for former COVID-19 patients with symptoms that persist for at least 12 weeks. Depending on the patients' needs, the secondary assessments can also include recommendations about further assessments or treatments. The patients need a referral from the GP or a specialist to receive an appointment in this clinic [45].

versus Ambulanzen,  
die neben weiteren  
Untersuchungen auch  
selbst Behandlungen  
anbieten

- And specialised long COVID outpatient centres that have been adapted and now also offer *treatment programmes themselves* besides the secondary clinical assessments. Some examples of such clinics are:
  - **The long COVID outpatient programme of the psychosomatic department of the "Barmherzigen Schwestern" in Vienna**, which offers a six-week outpatient programme for long COVID patients. The multidisciplinary programme takes place two times a week from 08:30 until 15:30 and consists of various psychotherapeutic modules, medical consultations, physical exercise, relaxation and individual psychotherapy [45].
  - **The psychotherapeutic outpatient clinic in Vienna**, which offers conversation group therapy for long COVID patients [45].

The GPs, primary care centres, specialists or specialised long COVID outpatient clinics can refer patients to multidisciplinary rehabilitation programmes. Such specialised outpatient and inpatient rehabilitation programmes are organised and implemented regionally across Austria. Some examples are:

- **The 15 inpatient and two outpatient rehabilitation centres of the Pension Insurance Institution**, which offer, inter alia, rehabilitation for long COVID patients across Austria. For example, the two inpatient programmes, the centres in Hohegg (Lower Austria) and Weyer (Upper Austria) provide rehabilitation for cardiovascular diseases, respiratory diseases and diseases of the musculoskeletal system. After the inpatient rehabilitation programme, many patients receive a training plan to continue careful exercising at home [67].
- **The long COVID inpatient rehabilitation “Klinikum Bad-Gleichenberg”** in Styria [49].
- **The rehabilitation clinic “Tobelbad”** in Styria (led by the Austrian General Accident Insurance) that provides a three-week inpatient rehabilitation programme for patients with long COVID as an occupational disease. Within the clinic, the long COVID rehabilitation programme belongs to the department of occupational diseases and occupational medicine [50].
- **The Hospital “Herz-Jesu”** in Vienna, which offers an acute rehabilitation programme for COVID-19 patients who were treated at the ICU during the acute infection. This department comprises an interdisciplinary team of the following specialties: internal medicine, physical medicine and rehabilitation, pulmonology, radiology, dietology, clinical psychology, pastoral care and discharge management [51].
- **The long COVID six-week outpatient rehabilitation programme** in Bruck (Styria) [52].

For patients with a dominant symptom that can be treated by a specific discipline, GPs or other specialists can also refer them to outpatient therapies of relevant local non-medical healthcare professionals, such as physiotherapists, psychotherapists or occupational therapists [25].

Concerning additional (social) services, there is the Austrian patient organisation “Long Covid Austria” that keeps the long COVID patients updated regarding information about new long COVID research results and recently opened long COVID care structures [45].

Besides, no long-COVID specific services could be identified in Austria. Generally, the same services as for other (chronic) illnesses also apply for long COVID, e.g. the usual sick leave procedure [61]. Other examples include services that help the patients to return to work, such as:

- **The gradual reintegration** after an illness (“Wiedereingliederungsteilzeit”), which enables the patients to reduce their working time by up to 50 per cent and thus, facilitates the patients’ come back to work. During this time of gradual reintegration, the health insurance compensates for the loss of income [62]. This concept was originally requested by the Austrian Cancer Aid and now applies also to other diseases [68].
- **The fit2work programme**, which is a government-funded programme that helps patients to promote, maintain or restore their ability to work or discover other fields of activities that are more suitable to their condition [63].

wenn notwendig,  
Überweisung an  
ambulante oder stationäre  
Rehabilitationsprogramme  
möglich

Rehabilitationszentren  
in Österreich auf  
Bundesländerebene  
organisiert & ausgeführt

weitere Option:  
direkte Überweisung  
an spezifische  
Therapeut\*innen

Pat.-Organisation  
als Informationsträger  
für Long-Covid Pat.

keine Long-Covid-  
spezifischen  
(Sozial-)Leistungen in  
Österreich identifiziert

es gelten dieselben  
Leistungen wie bei  
anderen (chronischen)  
Erkrankungen, z. B.  
Wiedereingliederungs-  
teilzeit, Fit2work

### 4.2.3 Examples of existing long COVID care structures of selected European countries

#### UK: nationaler 5-Punkte-Plan zur Long-Covid Gesundheitsversorgung:

1. NICE Leitlinie
2. Selbstmanagement-  
Plattform
3. Long-Covid  
Spezialambulanzen
4. Forschungsförderungen
5. NHS Long-Covid  
Taskforce

#### in BE, IT, GER Long-Covid Versorgungsstrukturen aktuell regional organisiert

Of the four European countries that were investigated in addition to Austria in this systematic review, UK is the only country that organises long COVID healthcare structures also on a national level. For example, the “5-point plan for long COVID support” was introduced by the NHS in October 2020 and includes the following aims [58]:

1. The creation of the NICE guideline on long COVID.
2. The creation of the Your COVID Recovery Online Platform.
3. The foundation of designated specialised long COVID outpatient assessment clinics.
4. Funds for long COVID research by the National Institute for Health Research (NIHR).
5. The establishment of the NHS long COVID task force, which involves long COVID patients, medical specialists and researchers.

According to the included literature and contacted experts, the other three investigated countries (BE, IT, GER), conversely, have no national plans for the establishment of long COVID healthcare structures yet. Currently, the long COVID healthcare structures in these countries are organised and implemented on a regional level.

#### Primary care

#### in allen 4 Ländern, Primärversorgung meistens 1. Anlaufstelle

In all four investigated countries (UK, BE, IT, GER), the clinical assessment of long COVID patients generally takes place in the primary care sector including primary care centres and GPs [13, 28]. However, in some countries (e.g. UK), the primary care sector is mainly responsible for former COVID-19 patients who had never been hospitalised during the acute infection [11].

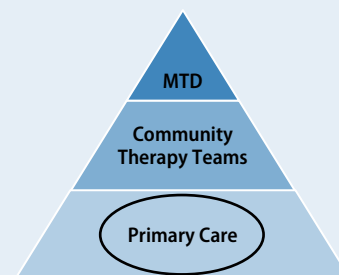
#### manchmal regionale Zulassungskriterien für Erstuntersuchung

Furthermore, in primary care, there can be region-specific selection criteria for the first clinical assessment. For example, even if the UK has a national long COVID support plan, the selection criteria for primary assessment can also be specified on a local level (see Example 1) [26].

#### Example 1: Primary care

##### Local healthcare pathway in Leeds, UK:

In Leeds, an integrated healthcare pathway was developed by the Leeds Primary Care Services, the Leeds Community Healthcare NHS Trust and the Leeds Teaching Hospital NHS Trust in autumn 2020. This pathway aligned itself to the NHS “5-point plan for long COVID support” and was the first pathway of its kind to be set up in the UK. Overall, it comprises a three-tier service model with the **first tier** presenting the primary care for a primary assessment in patients with typical long COVID symptoms lasting one to two months and are likely to be resolved with supported self-management.



Abbreviations: COVID – Coronavirus disease, NHS – National Health Service, UK – United Kingdom

## Specialised long COVID outpatient assessment centres/clinics

The first specialised long COVID outpatient assessment clinics were founded in the UK as part of the NHS “5-point plan for long COVID support” to complement existing primary, community and rehabilitation care. Currently (August 2021), around 90 such specialised outpatient assessment clinics exist across England. They are organised in different ways (e.g. centrally, decentrally or virtually) depending on the needs of the patients and the structures of existing services. However, mostly they function as outpatient “one-stop-clinics”, where specialist assessments, diagnoses and treatments including rehabilitation are offered if necessary. In these clinics, the patients have access to multidisciplinary teams including professionals of, e.g. neurology, psychiatry, psychosomatic, cardiology, pneumology, rheumatology, otorhinolaryngology, dermatology and endocrinology [29]. In general, the clinics are intended for patients with long COVID symptoms that persist for more than 12 weeks [23].

A local example of an integrated specialised long COVID assessment clinic is presented in Example 2 [26].

**erste Long-Covid  
Spezialambulanzen  
in den UK gegründet:  
ca. 90 Ambulanzen  
(Stand: August 2021)**

**Organisation zentral,  
dezentral oder virtuell  
organisiert möglich**

**meist als multidisziplinäre  
„One-Stop-Ambulanz“  
geführt**

### Example 2: Specialised long COVID outpatient assessment services

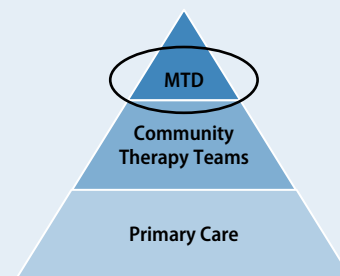
#### Local healthcare pathway in Leeds, UK:

The local healthcare pathway in Leeds for long COVID patients comprises a three-tier service model. The *third tier* involves **specialised multidisciplinary team (MDT) outpatient services** that, on the one hand, offer services to patients with COVID-19-related symptoms lasting more than 12 weeks. On the other hand, services are offered for patients with more complex symptoms lasting less than 12 weeks but requiring input from two or more healthcare professionals.

Most referrals to the MDT outpatient services comes from the primary care sector (*first tier*) or also from community therapy teams (*second tier*). Few referrals come directly from hospital services.

The specialised MDTs are multidisciplinary including consultants with a speciality in rehabilitation medicine, respiratory medicine and/or cardiology, physiotherapy, neurological and occupational therapy, nursing and nutritional counselling. They offer the usual process of assessment, clinical reasoning and intervention planning in a first step, also possible via home visits or phone interviews. Subsequently, the patients can be linked to appropriate pathways of investigation and treatment if necessary. For example, the patients can receive a prescription to the online self-management programme “The Your COVID Recovery Platform”.

For patients with severe medical concerns, the specialised MDTs hold a virtual meeting, where these cases are discussed as a priority once a week.



*Abbreviations: COVID – Coronavirus disease, MTD – Multidisciplinary team, NHS – National Health Service, UK – United Kingdom*

in anderen Ländern  
(IT, GER) Long-Covid  
Spezialambulanzen  
meist in Form von  
Long-Covid-spezifischen  
Sprechstunden

in GER ca. 50 solcher  
Ambulanzen (August 2021)

Other countries (e.g. IT, GER) have also established some kind of specialised long COVID outpatient assessment clinics. In fact, in these countries, the specialised long COVID assessment clinics mostly present outpatient clinics that offer special long COVID consultation hours once or twice a week (*similar to the specialised long COVID outpatient assessment clinics in Austria, see chapter 4.2.2*). Moreover, in these countries, such clinics pop up in different regions without a national plan behind their establishment. Thus, the exact number of these clinics is difficult to estimate. The German long COVID patient organisation estimated that there are approximately 50 long COVID outpatient assessment clinics across Germany (August 2021) [expert information]. In Table A-12 in the Appendix, some examples of specialised long COVID outpatient assessment clinics in Italy and Germany are presented.

BE:  
einzelne Krankenhäuser  
bieten unspezifisches  
Angebot für  
Long-Covid Pat.

Almost no information could be identified regarding specialised long COVID assessment clinics in Belgium. From around 55 Flemish hospitals, some provide unspecified offers for long COVID patients. Based on their own hospitals' initiatives some hospitals only accept patients who had been hospitalised during the acute SARS-CoV-2 infection, while others also accept patients who have not been hospitalised [expert information].

### Multidisciplinary rehabilitation

in allen 4 Ländern:  
stationäre, teilstationäre  
oder ambulante  
Rehabilitationsprogramme  
angeboten

In all four investigated countries (UK, BE, IT, GER), multidisciplinary rehabilitation programmes are offered to long COVID patients if needed. These programmes vary from inpatient through partial inpatient to outpatient programmes and are established on a regional level. Sometimes rehabilitation is also provided within the specialised long COVID outpatient assessment clinics [28, 29, 46].

genaue Anzahl an  
Rehabilitationsprogramme  
n pro Land nicht bekannt

The exact number of rehabilitation programmes in each country offering therapies for long COVID patients is currently unknown. The German long COVID patient organisation estimated that there are around 15 providers of long COVID inpatient rehabilitation programmes across Germany (August 2021). Mostly these programmes involve a three to six-week-stay including specialised therapies for long COVID patients [expert information]. Sometimes the rehabilitation programmes are specialised in one specific symptom, for example, some German rehabilitation clinics focus on chronic fatigue syndrome [54]. Another example of a long COVID rehabilitation is the Italian non-profit organisation AbilityAmo (see Example 3) [28].

in GER geschätzte  
15 Anbieter für stationäre  
Programme

Beispiel 3 zu Italien

#### Example 3: Rehabilitation

##### AbilityAmo, Italy:

The AbilityAmo in Italy is a non-profit organisation that provides rehabilitation interventions for post-COVID disability and fragility. It offers specialist interventions, such as psychological support as well as neurological, respiratory and/or cognitive post-admission rehabilitation both, in hospitals or at home (including telemonitoring systems).

Abbreviations: COVID – Coronavirus disease

### Community health services and non-medical healthcare providers

UK & IT:  
zusätzlich unterstützende  
"Community Health  
Services"

In some countries (e.g. UK, IT), the above-mentioned healthcare structures are facilitated through community care networks, like reconverted community hospitals, healthcare hotels, nursing homes and/or low-intensity residential facilities [28].

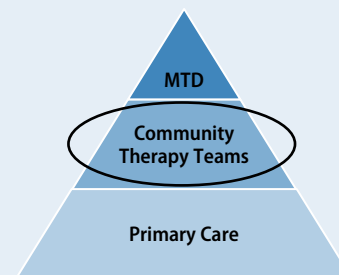
Besides, in all four investigated countries (UK, BE, IT, GER), locally organised non-medical healthcare providers offer specialised outpatient therapies, such as physiotherapy, occupational therapy, psychotherapy, speech therapy, nutritional counselling and nursing services, which can be attended as a single therapy or in addition to other services (see Example 4) [13, 23, 26]. In Belgium, for example, all patients including long COVID patients have access to outpatient physiotherapy (18 sessions per year) and consultations with psychologists (8 standard sessions that can be extended) [expert information].

**in allen 4 Ländern:  
nicht-medizinische  
Therapien als weitere  
Unterstützung möglich**

#### Example 4: Community therapy teams

##### Local healthcare pathway in Leeds, UK:

The local healthcare pathway in Leeds for long COVID patients comprises a three-tier service model. The **second tier** involves **community therapy teams** for long COVID patients with low to moderate symptoms that can be adequately met by a single discipline. Possible disciplines include occupational therapy, physiotherapy, dietetics or speech and language therapy.



Abbreviations: COVID – Coronavirus disease, UK – United Kingdom

#### (Supported) self-management

In many countries, there are long COVID patient organisations (e.g. UK, BE, GER) that provide information and support to the patients, inter alia, on how to self-manage their symptoms [46-48]. Besides, in the UK, a specific online self-management programme for long COVID patients was developed as part of the NHS “5-point plan for long COVID support” (see Example 5) [53].

**nur in UK: spezielles  
Online-Selbstmanagement-  
Programm für Long-Covid  
Pat.**

#### Example 5: The Your COVID Recovery Platform (UK)

##### The online self-management platform consists of two versions:

**The Your COVID Recovery Website**, which was launched in July 2020 and provides the latest advice on long COVID management including:

- general information about the disease COVID-19,
- tips on how to self-manage different long COVID symptoms,
- tips on how to improve general wellbeing (e.g. by adapting eating, sleeping and moving habits) and
- tips for the way back to daily activities or work.

This website is publicly available and continuously updated.

**The Your COVID Recovery Online Programme**, which is a password-protected web app available on a computer, tablet device or smartphone. The programme contains four stages with a variety of tasks helping the patients to set realistic goals to handle their long COVID symptoms and to organise the right resources to achieve these goals. In addition, the programme provides information to the patients (written or video) about supporting mental health, movement, symptom management and nutritional effects. Patients can also participate in an activity challenge, use the offered symptom tracker and/or the chat, where they can directly contact healthcare professionals or just join the community forum. In order to receive access to this online programme the patients need a referral from a healthcare professional.

Abbreviations: COVID – Coronavirus disease, UK – United Kingdom

<p>keine Long-Covid-spezifischen (Sozial-)Leistungen in den 4 Ländern identifiziert; es gelten dieselben Leistungen wie für andere Erkrankungen, z. B.:</p> <p>selber Prozess bei Krankenstand,</p> <p>soziale Unterstützungsleistungen wie Social Prescribing (siehe Beispiel 6),</p> <p>Wiedereingliederungsteilzeit,</p> <p>Umschulungen</p>	<p><b>Additional (social) services</b></p> <p>Similar to Austria, long COVID-specific additional (social) services could not be identified in the four other investigated European countries (UK, BE, IT, GER) either. In general, the same services as for other (chronic) diseases are also available for long COVID patients in these countries [64]. Such services are for example:</p> <ul style="list-style-type: none"> <li>■ <b>Social care services</b> like <b>social prescribing</b>, which can be also applied in long COVID if deemed appropriate (see Example 6) [65, 69].</li> <li>■ <b>Different services for employees with (chronic) diseases</b>, which facilitate the come back to work, including, for example: <ul style="list-style-type: none"> <li>■ <b>The fit for work programme</b> (UK): a government-funded service that offers free impartial work-related health advice [64] (<i>similar to the fit2work programme in Austria, see chapter 4.2.2</i>). Likewise to Austria (see chapter 4.2.2), in other countries (e.g. UK, GER), there is also the possibility of a <b>phased return</b>. Thereby, the patients are supported to gradually return to work after an illness [11, 66].</li> <li>■ <b>The transitional allowance</b> (e.g. GER) that enables the patients to switch the field of work if the previous working place does not fit anymore after the illness. The German Pension Insurance, thereby, provides special support to the patients, such as financing necessary (re-)training(s) [13].</li> </ul> </li> </ul>
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#### Example 6: Social prescribing

Social prescribing has its' origin in the UK. It presents a way for local agencies, like general practice, pharmacies, multi-disciplinary teams, hospital discharge teams, allied health professionals, fire service, police, job centres, social care services, housing associations, etc. to refer people to so-called link workers. The social prescribing link workers take the time to focus on what matters to the people in need and, thereby, follow a holistic approach to people's health and wellbeing. Depending on the persons' needs, they can also connect the people to community groups and/or statutory services for practical and emotional support. The spectrum of such services is wide including, for example:

- locally available health promotion measures,
- sports and exercise programmes,
- nutritional counselling,
- social, debtor, employment and/or housing counselling,
- as well as community activities such as senior dances, hiking groups, and neighbourhood networks.

In recent years, the interest in the principle of "social prescribing" has also increased in other European countries (e.g. AT) but so far, they have not been specifically linked to long COVID.

*Abbreviations: COVID – Coronavirus disease, UK – United Kingdom*

## 5 Discussion

Changes that had been introduced to the healthcare system in response to the severe acute respiratory syndrome coronavirus 2 [SARS-CoV-2] pandemic, including prioritisation of severely ill patients or remote care where possible, paradoxically do not fit the purpose of managing the heterogenous sequelae of this disease. Patients with long COVID, independent of symptom severity, may rather benefit from careful clinical assessments and monitoring over time as well as a good therapeutic relationship with healthcare professionals for emotional and clinical support to avoid chronification [70].

Besides, long COVID not only comes with a burden of disease for the individuals but also affects the wider economy. For example, the average time of sick leave has been longer compared to other infectious diseases and some patients may even require ill-health retirement due to their inability to work [71]. Thus, already a few months after the first SARS-CoV-2 cases had appeared, national patient organisations highlighted the importance of structural adaptations in (health)care. Since then, long COVID (health)care structures are continuously being discussed and organised in and across several countries [5].

Against this background, the present systematic review aimed to provide, on the one hand, an overview of recommendations about long COVID care pathways (research question 1) and, on the other hand, presents examples of already existing long COVID care structures of selected European countries (research question 2).

### Included evidence and its limitations

In total, five guidelines (UK, USA, GER, AT) [11, 13, 23-25], four reviews (UK, USA, BE, IT, GER) [8, 26-28], one consensus paper (UK) [29] and four clinical perspective papers (UK, NL, GER) [30-33] were included in the present systematic review to answer both research questions. In addition, information from relevant websites, e.g. of long COVID patient organisations or long COVID care facilities as well as information from the contacted experts (see Table A-13) were taken into account for answering the second research question.

The quality of the included evidence is limited due to the topicality of the theme and the urgency for research in this regard. Most of the recommendations of the included guidelines were preliminary and based on expert consensus. Therefore, many guidelines were presented as “living guidelines” that are deemed to be updated when new evidence rises. Moreover, the included reviews do not present classic systematic reviews (including a systematic literature search and data synthesis) and thus are limited in their methodology. Furthermore, experts have rapidly organised care structures in their local healthcare system and networks due to the emergent nature of long COVID. Thus, expert recommendations in the form of consensus papers or clinical perspectives are highly biased and present the lowest level of the evidence pyramid. Besides, the information from websites of single institutions is also biased.

**unterschiedliche Versorgungsstrategien bei akuter Infektion versus Langzeitfolgen; bei Letzteren: Vermeidung von Chronifizierung wichtig**

**Long-Covid hat ökonomische Auswirkungen: z. B. aufgrund der Arbeitsunfähigkeit → Anpassung der Versorgungsstrukturen notwendig**

**Projektziel: Überblick über Empfehlungen zu Versorgungspfaden & Beispielen zu etablierten Strukturen**

**5 Leitlinien, 4 Reviews, 1 Konsenspapier & 4 Expert\*innen-Einschätzungen eingeschlossen; für FF 2 zusätzliche Quellen berücksichtigt**

**limitierte Qualität der vorhandenen Evidenz aufgrund der Aktualität des Themas & des Zeitdrucks in der Forschung: z. B. vorläufige Leitlinien, unsystematische Reviews**

## Possible long COVID care pathways

## First point of care

<p><b>Primärversorgung deckt Großteil der Long-Covid Versorgung ab, jedoch unterschiedliche Auswahlkriterien welche Pat.-Gruppe betreffend</b></p>	<p>In most of the guidance documents, the primary care sector is recommended for the first clinical assessment. However, the selection criteria which patient group receives which services can differ between the investigated countries. In some countries (e.g. AT, GER), the primary care sector is recommended as the first point of contact for <i>all</i> long COVID patients with persistent symptoms of at least four weeks (including former hospitalised and non-hospitalised COVID-19 patients). In contrast, in some countries (e.g. UK, USA, NL), for some long COVID patients not only the primary care sector is responsible in the first step. For example in the UK, former hospitalised COVID-19 patients who suffer from ongoing or new symptoms after 12 weeks of discharge can also go to secondary care outpatient departments for a clinical assessment [11, 13, 23-25, 27, 30].</p>
<p><b>Hürden: Schwierigkeiten für Pat., richtige/n Ärzt*in zu finden</b></p>	<p>Regarding the primary care sector, however, some difficulties might occur at the first point of contact in clinical practice: Long COVID patients can experience hurdles in finding the right GP or primary care centre. In some countries (e.g. AUT, BE) patients are not assigned to one GP, which makes the search even more difficult.</p>
<p><b>praktizierende Ärzt*innen unsicher in der Diagnosestellung von Long-Covid (z. B. objektive Diagnose schwierig)</b></p> <p>→ Auswirkungen auf Ärzt*in-Patient*in-Beziehung</p>	<p>To date, not all of the practising physicians are fully familiar with the difficult diagnosis of long COVID. In the absence of simple clinical tests, practising physicians need to rely on other diagnostic measures, like the history of the past SARS-CoV-2 infection and the incomplete recovery accompanied by possible long COVID symptoms. The diagnosis of long COVID becomes even more complicated for former asymptomatic COVID-19 patients. Moreover, the recommended long COVID-specific questionnaires and scales that can be used for the diagnosis (e.g. the Klok Scale [36], the Newcastle Post-COVID Syndrome Follow-up Screening Questionnaire [37] and the COVID-19 Yorkshire Rehabilitation Screening Tool [38]) are non-validated diagnostic tools that have been developed out of necessity and are only available in English. Besides, the severity of some common long COVID symptoms, like fatigue, is hard to detect, which makes an objective diagnosis almost impossible [72]. These uncertainties of physicians can lead to patients feeling misunderstood and consequently starting to self-manage their symptoms by taking several expensive supplements instead of receiving treatments from health-care professionals [72].</p>
<p>→ Weiterbildungen bzgl. Diagnose &amp; Therapiemöglichkeiten wichtig</p>	<p>For these reasons, the practising physicians should receive further information and training about the disease itself, but also about its diagnosis and management. For example, the GPs should be informed about how long COVID symptoms can be differentiated from similar symptoms with other causes. Moreover, the GPs need to be informed about different options, such as symptomatic treatments, watchful waiting for milder symptoms or possible further referrals [73].</p>
<p>Liste zu Long-Covid Spezialist*innen hilfreich für Überweisungen</p>	<p>Apart from that, in Germany, the development of lists of long COVID specialists in the outpatient and inpatient sectors has been proposed. Such lists should help GPs to refer patients to specialised outpatient clinics or specialists [74].</p>

### Possible referrals

After the primary assessment, it is recommended to refer patients with more complex symptoms that last more than 12 weeks (but without any acute or life-threatening symptoms) to so-called specialised long COVID outpatient assessment clinics for a second assessment (e.g. UK, GER, AT). The first of these clinics were founded in the UK, mostly as a “one-stop clinic”, where further diagnosis and/or treatments, including rehabilitation, was offered [23]. Thereby, the main aim was to avoid multiple referrals to different professionals and thus minimise the burden to the patients [23, 29].

After the clinical assessments and depending on the patients’ needs, different referral options are suggested. For example, for long COVID patients with more complex symptoms who need multidisciplinary therapies, inpatient, partially inpatient or outpatient rehabilitation is recommended. The rehabilitation programmes for long COVID patients are advised to have a wider scope compared to usual rehabilitation programmes. On the one hand, the age group of the long COVID rehabilitation population can differ from the usual rehabilitation population, as a large proportion of the affected persons are of their working age. Thus, the rehabilitation programmes should also involve support for a successful return to work [31]. On the other hand, the programmes should be adapted to the divergent needs of long COVID patients. For example, the emotional burden caused by the acute COVID-19 disease (e.g. through social isolation) should be taken into account in the programmes. Moreover, in the included literature, the concept of “pacing” was recommended as one of the most important aspects of a long COVID rehabilitation. This concept enables the patients to manage their physical, cognitive and emotional energy within their limits through careful planning. Thus, it has been suggested that fixed incremental increases in physical exercise as with the usual physical rehabilitation should not be used in long COVID rehabilitation [8, 24-26, 29, 30, 32].

Besides, some patients can experience uncertainties regarding their return to their daily life, for example, after an inpatient rehabilitation programme. Hence, it is recommended to develop specific follow-up strategies, such as a practice plan for continuing exercises at home, the referral to outpatient non-medical healthcare therapies or the support through social workers [75].

If the patients suffer from one dominant symptom with the need of a specific discipline, a referral to a specialist for further assessment and/or treatment or a specific non-medical healthcare outpatient therapist, such as physiotherapist, psychotherapist, occupational therapist, speech therapist or nutritional counselling can be suggested [11, 13, 25, 26].

However, it is crucial to take into account that many referrals involve multiple doctor visits and thus, can place an additional physical, emotional and/or financial burden (e.g. accumulated travel times) on the patients [24]. Therefore, also non-medical aspects, such as the geographical distance between the patient’s residence and the treatment location and private co-payments especially for non-medical healthcare therapies need to be taken into account in the decision about a referral. Alternatively, where appropriate and possible, virtual consultations may be suggested to eliminate additional travel time and costs [13, 24, 25, 30, 32]. Apart from that, several referrals can also increase the risk of contradictory medical advice causing uncertainty in the patients [24].

**bei komplexeren Symptomen Überweisung an Long-Covid Spezialambulanzen empfohlen**

**abhängig von den Pat.-Bedürfnissen auch weitere Überweisungen empfohlen, z. B. zur multidisziplinären Rehabilitation**

**Long-Covid Rehabilitation sollte sich von üblichen Programmen unterscheiden, z. B.: Anpassung an jüngere Pat.-Population & angepasstes Rehabilitationsprogramm (“pacing”)**

**Unterstützung bei der Rückkehr in den Alltag für manche Pat. empfohlen**

**bei einzelnen spezifischen Symptomen Überweisung an z. B. Spezialist\*innen sinnvoll**

**viele Überweisungen mit zusätzlichen Belastungen für die Pat. & erhöhtem Risiko für gegensätzliche Empfehlungen verbunden**

**Empfehlungen zu Selbstmanagement kann mit zusätzlicher Verantwortung verbunden & belastend sein**

The included literature in the present systematic review also presented advice on how to self-manage the symptoms and improve the condition by boosting the general wellbeing through appropriate nutrition, sleep management, stress reduction and/or the exchange with other long COVID patients. However, self-management can also place a lot of responsibility on the patients, which might cause an additional burden to them [70, 76]. Moreover, the exchange with other long COVID patients (e.g. within a forum) is not helpful for all patients. Hearing bad experiences of others might increase anxiety in some patients [72].

#### Additional (social) services

**dieselben Empfehlungen zu Sozialleistungen wie bei anderen Erkrankungen**

Concerning additional (social) services for long COVID patients, no recommendations regarding long COVID specific offers could be identified in the included literature. In general, the same services as for other (chronic) illnesses, like sick leave, social prescribing or gradual re-integration, were also suggested for long COVID [61, 64].

**Überlegungen zur Beantragung eines Behindertenpasses für Long-Covid Pat. um Kündigungsschutz zu erlangen → Nachteile berücksichtigen!**

However, these services also have some weaknesses. For example in Austria, sick leave, including long-term sick leave, does not automatically protect against termination. For this reason, in the case of long COVID that is expected to last for more than six months, some experts even recommended applying for notice of assessment regarding the degree of disability. An employee with a degree of disability of at least 50 per cent is, thereby, protected from dismissal [77]. Nevertheless, the possible consequences of such suggestions, like negative impacts on pension claimants or the return to work, needs to be discussed and taken into account. For this reason, knowledge about further socio-legal services from patient groups of other conditions that also involve long-term work loss (e.g. cancer or mental illnesses) should be taken into account when discussing long COVID-specific options.

**Erfahrungen mit langen Ausfällen bei anderen Erkrankungen eventuell hilfreich**

**Social Prescribing in Österreich im Primärsektor angesiedelt → Zugang zu Long-Covid Pat.**

Regarding the increasing interest in social prescribing of some European countries (e.g. UK, AT), it needs to be considered that none of these initiatives has been specifically linked to long COVID. However, in Austria, social prescribing could also be considered for long COVID patients, as the social prescribing pilot projects are mainly located in the primary care sector where most of the long COVID care is deemed to take place [5].

**Long-Covid muss gegebenenfalls als Berufskrankheit gemeldet werden**

Besides, it needs to be considered if long COVID counts as an occupational disease, e.g. for healthcare or welfare professionals. As with other occupational diseases, these cases must be reported to the responsible Employer's Liability Insurance Association by the employer or the attending physician to increase the financial benefits for the patient [33, 61].

#### Implementation of the recommendations in practice

**etablierte Long-Covid Versorgungsstrukturen scheinen den identifizierten Empfehlungen zu entsprechen**

The present systematic review showed that the existing care structures that could be identified in the selected European countries generally follow the recommendations summarised in the present systematic review. Hence, in general, multidisciplinary, a personalised approach and shared decision-making between healthcare professionals and patients are key factors for successful long COVID care [8, 11, 24, 28-31]. Out of the investigated countries, in particular, the UK succeeded in rapidly adapting their healthcare structures by fastly implementing long COVID-specific care facilities. For example, only the UK implemented a specialised online programme for long COVID patients, the Your COVID Recovery Platform [3].

**→ rasche Umsetzungen in UK**

Furthermore, no significant differences in the recommendations and the respective established long COVID care structures could be identified between the analysed countries. Some small differences can be mainly described through the differences in the healthcare systems. For example, in most of the investigated European countries, the long COVID care structures are organised on a regional level due to federalism, whereas, only the UK developed a national plan for the organisation of long COVID care structures, the so-called NHS “5-point plan for long COVID support”. However, in the end, some aspects of this plan are still executed on a regional level, like the specialised long COVID outpatient assessment clinics [23]. Moreover, the specialised long COVID outpatient assessments clinics can be organised slightly differently between the analysed countries. While in the UK, these clinics are mostly managed as so-called “one-stop-shops” including clinical assessment and treatment services, in other countries such as Germany or Austria, they present outpatient clinics that only offer special consultation hours for detailed clinical assessments and recommendations about further specialist assessments and/or treatments [16, 25, 57].

#### Further recommendation for practising physicians concerning shared decision-making and communication

In the included guidance documents, it was additionally emphasised that the communication between the healthcare professionals and the long COVID patients is crucial. Good communication should consider inclusive communication (e.g. by reducing language barriers), as well as, the avoidance of over-diagnosis and/or over-medication by finding the right balance in the detail of the provided information to avoid causing unnecessary anxiety and uncertainty to the patients [11, 23-25, 73]. In addition, empathy towards patients and continuous support over time in every disease stage are crucial to building up a trustworthy relationship [70, 72].

#### Concerns from a healthcare perspective

From an economic point of view, the organisation of long COVID care structures triggers concerns about resource capacities. Within the healthcare systems, for example, long waiting lists might exist for a first appointment in a specialised long COVID outpatient assessment clinic or a place in a rehabilitation programme. One reason for such capacity shortages might be that specialised rehabilitation centres are sparse in some countries and the access is classically restricted to patients with other indications than long COVID, such as stroke or head trauma. Another reason payers of services have reported are patients preferences: the geographical distance to the care facility might hinder a patient and eventually cause refusal of a rehabilitation place. As a consequence, more and more private providers appear on the market offering full all-around packages with shorter waiting times and various destinations. However, thereby, the two-tier healthcare system is further enhanced [75].

Besides, it needs to be analysed if there are enough GPs available, considering the expected increase in long COVID patients and their primary role in long COVID care. From this point of view, it should also be discussed if patients should have the possibility to directly contact non-medical healthcare providers, such as physiotherapists or psychotherapists, in a first step. In doing so, it could ease the burden on the GPs.

Overall, the costs and the sustainability of long COVID care need to be assessed in the future.

→ keine wesentlichen Unterschiede hinsichtlich der Long-Covid Versorgung;  
kleine Unterschiede auf Unterschiede im Gesundheitssystem zurückzuführen, z. B.:

Spezialambulanzen in den Ländern unterschiedlich organisiert

gute Kommunikation zwischen Ärzt\*in & Pat. wesentlich

Empathie & langfristige Unterstützung → Vertrauensaufbau zu Pat.

Long-Covid Versorgung  
→ Bedenken hinsichtlich der Ressourcenkapazitäten

immer mehr private Anbieter → Verstärkung der Zwei-Klassen-Medizin

praktizierende Ärzt\*innen möglicherweise überlastet  
→ direkter Zugang zu z. B. Physiotherapeut\*innen möglich?

<b>Limitationen des systematischen Reviews:</b>	<b>Limitations of the present review</b>  This systematic review addresses a topic of high public interest by summarising recommendations for long COVID care pathways as well as presenting examples of already existing long COVID care structures of selected European countries. However, it is also limited in some aspects.
<b>keine Empfehlungen zu Long-Covid Versorgungsstrukturen speziell für Kinder und Jugendliche oder vulnerable Gruppen aufgrund von Sprachbarrieren möglicherweise nicht alle relevanten Informationen identifiziert</b>	Firstly, the present systematic review only focused on adult long COVID patients in general. Long COVID care pathways for children and adolescents or vulnerable groups, such as socially disadvantaged persons were not considered in this review. However, as the aforementioned groups may require different professional groups and care structures than adults in general, this needs to be investigated separately in the future.  Secondly, only German or English information could have been considered to answer the two research questions. It is possible that due to the omission of information e.g. in Spanish, French, and Italian, relevant information on care pathways may have been overlooked.
<b>Fokus lediglich auf Versorgungspfade, nicht auf spezifischen Therapieempfehlungen</b>	Thirdly, the present systematic review only addresses care pathways for long COVID patients. Detailed management recommendations about how the different long COVID symptoms should be treated including specific drug and/or intervention recommendations were not part of this review. Other reviews focused on recommendations for specific long COVID treatments [29, 78]. Another review also reported on the results of the first effectiveness studies of long COVID treatments [79].
<b>keine systematische Qualitätsbeurteilung der eingeschlossenen Leitlinien &amp; Reviews, Expert*innen-Papiere trotz Limitationen berücksichtigt</b>	Fourthly, the quality of the included guidelines and reviews was not systematically assessed, e.g. by using specific risk of bias assessment tools. However, it has been pointed out previously that the included literature is limited in its nature due to the novelty of this topic and the associated urgency for research. This limited quality of evidence comes along with several consequences, as Stamm et al. pointed out: “An insufficient consideration of appropriate methodologies in the guideline development process could lead to misleading information, uncertainty among the professionals, and potentially harmful actions for patients” [80, p. 126]. Furthermore, given the sparsely available evidence on long COVID management, expert papers in the form of consensus papers or clinical perspectives were also taken into account in the present systematic review, even if they present the lowest level of the evidence and, thus, are associated with a high risk of bias.
<b>keine Antwort von einigen der kontaktierten Expert*innen</b>	Fifthly, many experts (mainly practitioners), who were contacted for further information on already existing long COVID care structures did not answer our request (see Table A-13). Thus the information retrieved from experts is limited.
<b>Begriffe standardisiert, um Lesbarkeit zu verbessern → unterschiedliche Bedeutungen eines Begriffes, wie z. B. “Long-Covid Spezialambulanzen” nicht sofort ersichtlich</b>	Sixthly, in the present systematic review, the terminologies of the original references were standardised to improve readability. Thus, small differences in the meaning of some terminologies may not be visible at a glance. For example, the described specialised long COVID outpatient assessment clinics, on the one hand, present clinics that offer further assessments and diagnoses as well as recommendations to further treatments in the form of long COVID-specific consultation hours once or twice a week (e.g. GER, AT). On the other hand, in some cases, these clinics can also offer treatments, such as rehabilitation, themselves (e.g. UK). On top of that, the standardisation of terminologies was more difficult when German terminologies needed to be translated. Again, the specialised long COVID outpatient assessment clinics provide a perfect example. In the end, the different German terminologies, such as
<b>zusätzliches Verzerrungspotential durch Übersetzungen</b>	

“Long-Covid Spezialambulanzen” and “Long-Covid Kliniken” were summarised to the standardised terminology “specialised long COVID outpatient assessment clinics”.

Seventhly, due to the methodology applied in this review (systematic search at the end of April 2021 and biweekly unsystematic hand searches until the beginning of August 2021) and the rapidly emerging evidence on this topic, possibly not all relevant publications could be identified. For example, one of the external reviewers suggested a further relevant Canadian rapid systematic review about long COVID care models, which was published in June 2021 [81]. This rapid systematic review included two references that have also been included in the present systematic review [23, 26]. Overall, 12 long COVID care models were identified in the Canadian review. Similar to the present report, the identified care models were designed for the discharge and long-term follow-up of hospitalised COVID-19 patients and/or for non-hospitalised COVID-19 patients. Moreover, the Canadian review also identified primary care (in 9/12 models), specialised clinics (8/12) and rehabilitation services (12/12) as main aspects of long COVID care. In contrast to the present report, the Canadian report suggested a centralised referral system.

**möglicherweise nicht alle  
relevanten Publikationen  
identifiziert**

**z. B. systematischen  
Review aus Kanada zu  
Long-Covid  
Versorgungsmodellen**

**→ kanadischer Bericht  
empfiehlt zentrales  
Überweisungssystem**



## 6 Conclusion and preview

This systematic review shows that there are recommendations for long COVID care pathways including country-specific guidelines, reviews and also expert papers. Furthermore, it presents examples of some meanwhile established healthcare structures for long COVID patients. Overall, both, the national recommendations and the first implementations are based on the already existing healthcare infrastructure of the respective country. Thus, not all recommendations are useful for all countries and not all implemented services are convertible in each country. For this reason, it is recommended to develop contextually appropriate guidelines, where this is needed, or adapt existing guidelines to the healthcare system of a respective country [28]. Additionally, the weak evidence base of the existing guidelines calls for an update with more rigorous data and for applying processes of guideline development that fulfil the methodological standards to avoid unintended harms for patients.

Besides, the exact epidemiology of long COVID – e.g. how many patients are suffering from it – is still not clarified. These epidemiological data are urgently needed for efficient long COVID care planning and hence, to reduce the likelihood of overwhelming the medical system in the future due to long COVID or vice versa establishing inappropriate or excess care facilities [2, 28]. However, the collection of epidemiological data via clinical trials is challenging [82].

For this reason, the collection of real-world data on the long COVID surveillance is recommended [5]. For example, long COVID registries could be set up to collect data on the duration and the severity of persistent symptoms after acute SARS-CoV-2 infection in males relative to females, for different comorbidities and in different age groups [2, 28]. Moreover, such registries could help to obtain further information about e.g., long COVID symptoms that turned out to be another indication, the number of justified and unjustified emergency department consultations including subsequent hospitalisation and/or possible consequences in terms of sick leave. Patients should be ideally involved in the research planning to ensure a patient-centred approach [5, 83, 84]. Last but not least, the collection of such real-world data would benefit from international cooperation, as these data are disease-specific and might not significantly differ between countries [28].

Moreover, to date, little evidence about possible treatment options for long COVID patients, their safety and effectiveness is available. Therefore, more high-quality clinical trials and systematic reviews summarising the results of clinical trials are needed to investigate the safety and effectiveness of potential treatments and interventions for long COVID patients (e.g. the impact of the COVID-19 vaccine on long COVID, the identification of the preferred type of rehabilitation or specific treatments for children and adolescent with long COVID) [2, 8, 13, 28].

**Empfehlungen:  
Entwicklung  
kontextgerechter Leitlinien  
bzw. Anpassung  
bestehender Leitlinien  
an jeweilige Länder**

**& Update der aktuell  
limitierten Leitlinien  
notwendig**

**epidemiologische  
Daten für effiziente  
Versorgungsplanung  
notwendig, Erhebung  
durch Studien schwierig**

**“Real-World“-Daten für  
mehr Informationen über  
Long-Covid z. B. zur Dauer  
empfohlen → Aufsetzen  
von internationalen  
Long-Covid Registern  
anzudenken**

**qualitativ hochwertige  
klinische Studien  
& systematische  
Übersichtsarbeiten zur  
Effektivität & Sicherheit  
von Long-Covid Therapien  
notwendig**



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# Appendix

## Extraction tables

### Characteristics of the included literature

Table A-1: Characteristics of the included literature (A)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
Country	UK	UK	UK	UK	Overview of several countries (mostly England)	UK	UK
Identified through	SS	HS	HS	SS	SS	SS	HS
Publication type	Living guideline	Guideline	Review	Review	Review	Consensus statement	Clinical perspective/ expert opinion
Evidence basis	Consensus-based	Consensus-based	Evidence-based	Not reported	Not reported	Consensus-based	Consensus-based
Funding & declaration of interest	Not reported	Not reported	Not reported	<b>Funding:</b> Leed Clinical Commissioning Group, University of Leed Medical Research Council Confidence in Concept grant <b>Conflicting interests:</b> none	<b>Funding:</b> National Institute for Health Research (NIHR), Applied Research Collaboration East Midlands (ARC EM), NIHR Leicester Biomedical Research Centre (BRC) <b>Conflicts of interest:</b> KK is Chair of the Ethnicity Subgroup of SAGE, KK & MM are members of Independent SAGE	<b>Funding:</b> No funding <b>Conflicts of interest:</b> None	<b>Funding:</b> Not reported <b>Conflict of interest:</b> None
Aim	Identifying, assessing & managing the long-term effects of COVID-19; advice for healthcare professionals on organising services for long COVID.	Inform the commissioning of post-COVID syndrome assessment clinics by assisting local healthcare systems in establishing and maintaining post-COVID assessment services.	One of several aims of the NIHR review was to evaluate the treatment of people with long COVID.	Description of a functioning comprehensive multidisciplinary rehab pathway in Leed (a city in England) for those experiencing long-term impacts after COVID-19 to help inform the development of these services in the UK & worldwide.	Overview of several countries affected by long COVID & their long COVID health systems.	To provide an overarching series of recommendations by assimilating the current evidence-base for & likely requirements of rehabilitation post-COVID-19	Clinical perspective intended for primary care clinicians relates to pts. who have delayed recovery from an episode of COVID-19 that was managed in the community or a standard hospital ward
<b>Publication characteristics</b>							
Long COVID definition	Ongoing & post-COVID symptoms (>4 wks.)	Ongoing & post-COVID symptoms (>4 wks.)	Not reported	Ongoing & post-COVID symptoms (>4 wks.)	Ongoing symptoms (>6 weeks)	Not reported	Ongoing & post-COVID symptoms (>4 wks.)
Patient population	Pts. treated at home & hospital	Pts. treated at home & hospital	Pts. treated at home & hospital	Pts. treated at home & hospital	Not reported	Active pt. population including military personnel and athletes	Pts. treated at home & hospital

Abbreviations: COVID – Coronavirus disease, e.g. – for example, HS – hand search, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, SS – systematic search, UK – United Kingdom

Table A-2: Characteristics of the included literature (B)

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
Country	The Netherlands	USA	USA	Germany	Germany	Germany	Austria
Identified through	SS	HS	SS	HS	SS	SS	HS
Publication type	Clinical perspective/expert opinion	Living guideline	Review	Guideline	Clinical perspective/ expert opinion	Clinical perspective/expert opinion	Living guideline
Evidence basis	Consensus-based	Not reported	Not reported	Consensus-based	Consensus-based	Consensus-based	Consensus-based
Funding & declaration of interest	<b>Funding:</b> Not reported <b>Conflict of interest:</b> MA. Spruit reports grants from Netherlands Lung Foundation and Stichting Astma Bestrijding, grants and personal fees from AstraZeneca and Boehringer Ingelheim, outside the submitted work. AE. Holland has nothing to disclose. SJ. Singh has nothing to disclose. T. Tonia acts as an ERS methodologist. KC. Wilson reports other possible conflicts of interest as ATS Chief of Guidelines and Documents, and as developer of the CORE process, outside the submitted work. T. Troosters has nothing to disclose.	Not reported	Not reported	Not reported	<b>Funding:</b> Not reported <b>Conflict of interest:</b> None	<b>Funding:</b> Not reported <b>Conflict of interest:</b> None	<b>Funding:</b> Not reported <b>Conflict of interest:</b> None
Aim	Interim recommendations for rehabilitation in the hospital & post-hospital phases in COVID-19 & post-COVID-19 pts.	Evaluating the caring for pts. with post-COVID conditions.	One aim of the review was to present a framework of strategies for the management of pts. with suspected or confirmed persistent post-COVID syndrome.	A clinical-practice guideline that provides clinical diagnostic-therapeutic orientation for post/long-COVID specific symptoms.	Clinical guidance on exercise & sports after COVID-19.	Recommendations for the follow-up care for pulmonary COVID-19 sequeale	Information for primary care physicians and other first-contact medical providers, as well as all, physicians who deal with long COVID affected individuals.
<b>Publication characteristics</b>							
Long COVID definition	Ongoing symptoms (4-12 wks.)	Not reported	Not reported	Ongoing & post-covid symptoms (>4 wks.)	Not reported	Not reported	Ongoing & post-COVID symptoms (>4 wks.)
Patient population	Pts. treated at the hospital	Not reported	Not reported	Pts. treated at home & hospital	Not reported	Pts. treated at home & hospital	Pts. treated at home & hospital (but no ICU pts.)

Abbreviations: CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, HS – hand search, ICU – Intensive care unit, pts. – patients, SS – Systematic search, United States of America

## First point of contacts

Table A-3: First point of contacts for long COVID patients (A)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
Country	UK	UK	UK	UK	Overview of several countries (mostly England)	UK	UK
Identified through	SS	HS	HS	SS	SS	SS	HS
Publication type	Living guideline	Guideline	Review	Review	Review	Consensus statement	Clinical perspective/ expert opinion
<b>Results – Healthcare pathways</b>							
<b>First point of contact</b>							
<b>Primary care investigation: General practitioner (GP) consultation</b>	First consultation for pts. treated at home without referral to the hospital → check for new or ongoing symptoms & exclude life-threatening diseases and other non-COVID-19-related conditions Screening questionnaires (e.g. Yorkshire rehab questionnaire, Newcastle screening tool) should be part of the initial consultation, however, not used to decide the need for further assessment, as there are no validated questionnaires for this use.	Pts. <i>never</i> admitted to hospital with their acute illness but managed independently or in the community: 1) Pts. with persistent symptoms >4 weeks after the infection will be signposted to contact their GP via community pharmacies, the NHS website, Test and Trace service, Your COVID Recovery Phase 1 (if already member). 2) Assessment carried out by the GP, using a holistic, person-centred approach, including comprehensive clinical history, appropriate examination (physical, cognitive, psychological, psychiatric symptoms & functional abilities). 3) Test & investigations tailored to pts.'s signs & symptoms used to rule out life-threatening complications & find out symptoms that are likely to be caused by long COVID. 4) If further investigation or support is required → referral to a post-COVID assessment service or referral to mental health support or specialists for other specific needs possible. The timing is based on individual needs & is at the discretion of the assessing clinician (mostly after 12 weeks). <i>Hospitalised pts.</i> whose symptoms persist after the 12-week follow-up can be reviewed by their GP (or secondary care outpatient service) → if no alternative diagnosis can be made, then the pts. should be referred to the post-COVID assessment clinic, which should keep the GP updated with the ongoing process.	Not reported	Not reported	England: See NICE guideline which pts. have which the first point of contact. Standard operating procedures for the assessment of pts, their documentation and long-term follow-up, is necessary at the clinics serving as the first point of contact for pts who were hospitalised during acute infection.	Not reported	Generally, pts. can be divided into those who may have serious sequelae (such as thrombo-embolic complications) & those with a non-specific clinical picture. A positive test for COVID-19 is not a prerequisite for a long COVID diagnosis. Long COVID management in primary care includes assessment & initial management of pts. with continuing symptoms. It requires a whole-patient perspective. 1) Clinical assessment: full history from date of first symptom (clinical testing not always needed, but can help to pinpoint causes); current symptoms (nature & severity); considering co-morbidities (e.g. diabetes, hypertension, kidney disease or ischaemic heart disease); considering social & financial circumstances of pts. 2) Medical management including symptomatic treatment, the control of long-term conditions, listening & empathy. 3) Propose self-management strategies.

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
<b>Secondary care investigation</b>	Not reported	<p><i>Hospitalised COVID-19 pts. in general:</i></p> <p>1) should undergo a video or phone follow-up consultation at 12 weeks after discharge by a health-care professional in secondary care including a check for new or ongoing symptoms or complications</p> <p>2) An assessment and investigation of new or ongoing symptoms after 12 weeks, in secondary care outpatient services or (in primary care) should rule out alternative diagnoses → otherwise referral to post-COVID assessment services if needed.</p> <p><i>Pts. cared for in ICU or HDU:</i></p> <p>1) Multidisciplinary assessment of rehabilitation needs at the point of step down to other inpatient facilities. Inpatient rehabilitation with defined goals should begin immediately.</p> <p>2) On discharge from hospital, an assessment of ongoing needs with appropriate community service referral if needed.</p> <p>3) Then, a multidisciplinary clinic re-assessment should be undertaken at 4-6 weeks post-discharge, including early referral to rehabilitation or mental health services, if needed.</p> <p>4) If pts. continue to improve then they attend the general 12-week post-hospital discharge assessment done by a healthcare professional in secondary care (phone/video).</p>	Not reported	Not reported		Not reported	Not reported
<b>General aspects</b>	The panel emphasised that access to services should not be restricted by the need for a positive SARS-CoV-2 test.	Not reported	The complexity of long COVID mirrors the need of people with multiple long-term conditions who benefit from a holistic, integrated approach rather than symptom by symptom management. Care should be multidisciplinary preferably in a one-stop COVID clinic. Some pts. will require full rehab programmes & others may benefit from psychological services. Others will need long-term support in the community, including help with self-management strategies.	Not reported	<p>England:</p> <p>NICE guidelines advise that assessment &amp; management should be tailored to individual's problems, after excluding any co-existing illness that may be giving rise to the symptoms reported. For example, this would include a chest X-ray in those with respiratory symptoms, checking for postural drop in blood pressure in those with dizziness &amp; urgent referral to the appropriate specialist for those with chest pain, palpitations or mental illness.</p>	Not reported	Many long COVID pts. will recover without specialist input through a holistic & paced approach in primary care and through interprofessional, community-facing rehabilitation services, which embrace self-management & peer support & the potential of video & other remote technologies.
<p><i>Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HDU – High dependency unit, HS – hand search, NIHR – National Institute for Health Research, ICU – Intensive care unit, NHS – National Health Service, NICE – National Institute for Health Care Excellence, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, SS – systematic search, UK – United Kingdom</i></p>							

Table A-4: First point of contacts for long COVID patients (B)

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
Country	The Netherlands	USA	USA	Germany	Germany	Germany	Austria
Identified through	SS	HS	SS	HS	SS	SS	HS
Publication type	Clinical perspective/ expert opinion	Guideline	Review	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
<b>Results – Healthcare pathways</b>							
<b>First point of contact</b>							
<b>Primary care investigation: General practitioner (GP) consultation</b>	<p>For the assessment of physical &amp; psychosocial outcomes that allow the identification of unmet rehabilitation needs core outcome sets are recommended, e.g.:</p> <ul style="list-style-type: none"> <li>■ EQ-5D and Short-Form 36 (assess generic health status)</li> <li>■ Hospital Anxiety and Depression Scale; Patients Health, Questionnaire 9; General Anxiety Disorder 7; the Depression Anxiety Stress Scale 21 (assess anxiety/depression)</li> <li>■ Impact of Events Scale Revised</li> <li>■ the Medical Research Council dyspnoea grading scale (measure breathlessness)</li> <li>■ Montreal Cognitive Assessment (cognitive screening)</li> </ul>	<p>Many post-COVID conditions can be managed by primary care providers, incorporating a patient-centred approach to optimise the QoL &amp; function of affected pts.</p> <p>First clinical assessment: Healthcare professionals should inquire about any unprescribed medications, herbal remedies, supplements or other treatments that pts. may be taking for their post-COVID conditions.</p> <p>Referral to multidisciplinary post covid centres for additional care, where available, can be considered.</p>	<p>1) Physician examination of pts. includes mapping of current symptomatic status or medical concerns. A COVID-19 exposure status &amp; potential disease history through oral history &amp; possible clinical testing is established. In addition, screening for possible non-COVID-19 comorbidities or chronic medical conditions should also be considered.</p> <p>2) After physician examination, administer appropriate medical treatments for acute symptoms or established underlying chronic conditions.</p>	<p>1) Primary care diagnosis: detailed pts. history &amp; physical examination including basic laboratory diagnostic, the assessment of neurological, psychological and functional status &amp; existing comorbidities. Particular attention to any new symptoms or increased symptoms due to COVID-19 is recommended. Generally, psychological symptoms and illnesses should also be considered in the planning &amp; implementation of post/long-COVID-19 treatment or rehabilitation, including the treatment of fatigue &amp; stress symptoms. A validated questionnaire developed by Klok et al can be used to better characterise adult pts. in the primary care setting and also to assess, for example, existing or impending incapacity for work, education, or school due to post/ long-COVID syndrome [36].</p> <p>2) In the absence of clinical deterioration, a wait-and-see approach (= watchful waiting) under GP supervision should initially be considered.</p> <p>3) If there are warning signs in the basic diagnosis as well as a possible clinical worsening → more in-depth diagnostics and/ or a referral to acute services or specialists should be offered for symptom-oriented therapy &amp; psychosocial care.</p>	Not reported	Not reported	<p>Primary care physicians are the first point of contact for the classification and clarification of symptoms (in particular functional disorders) that may be related to previous SARS-CoV-2 infection including treatment planning and targeted referral to appropriate cooperation partners. Referral to other health professionals such as physiotherapists, psychotherapists or occupational therapists is possible, if necessary. Essential to referral decisions is the assessment of impairment of daily living and working capacity.</p> <p>Not every symptom requires immediate comprehensive workup. After exclusion of potential “red flags” (e.g. acute respiratory insufficiency, pronounced frizz instability or suspected cardiogenic chest pain) &amp; after an appropriate baseline examination with exclusion of organ damage, a wait-and-see approach can be followed in the case of mild symptoms. Only if symptoms persist for more than 12 weeks, further diagnostics should be sought.</p> <p>Wait-and-see approach enables pts. enough recovery time (e.g. sick leave). However, the need for re-presentation in case of symptom deterioration must be pointed out in a documented manner.</p>

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
<b>Primary care investigation: General practitioner (GP) consultation</b> (continuation)				4) Close cooperation with authorities, health insurance companies and pension insurance providers should be sought. 6) Follow-up treatment, e.g. structured GP care and treatment planning together with pts. and/or their relatives or caregivers (limitations of the pts. performance should be discussed).			For some symptoms, there is a limit in time of wait-and-see approach, e.g. for cough the limit of watchful-waiting is 8 weeks. Objectification of individual distress and level of impairment is provided by the Post-COVID-19 Functional Status Scale ("Klok Scale").
<b>Secondary care investigation</b>	For hospitalised COVID-19 pts. an evaluation at hospital discharge is recommended to ensure that pts. are discharged to the appropriate setting (e.g. home, rehabilitation centre, nursing home). A follow-up assessment 6-8 weeks after discharge (including physical, emotional & cognitive functioning & return to work) is only recommended in symptomatic pts. with limitations in daily functioning.	For pts. who were hospitalised for COVID-19, follow-up visits should be arranged optimally within 1-2 weeks of hospital discharge including medication reconciliation, discussion of the clinical course before, during & after hospitalisation & a comprehensive physical examination. Additionally, evaluation for other specific illnesses, such as impaired renal function, critical myopathy & polyneuropathy, residual cardiac or pulmonary manifestations & psychiatric sequelae should be assessed. Healthcare professionals should consider additional follow-up visits as indicated by ongoing needs.	Not reported	Not reported	Not reported	Not reported	Not reported
<b>General aspects</b>	Limited access to treatments for disadvantaged communities needs to be considered.	Many post-COVID conditions can be diagnosed based on medical history & findings of physical examination. However, objective laboratory or imaging findings should not be used as the only measure or assessment of pts. wellbeing. Nevertheless, workup & testing should not be delayed when there are signs & symptoms of urgent & potentially life-threatening clinical conditions (e.g. pulmonary embolism, myocardial infarction, pericarditis with effusion, stroke, renal failure). Symptoms that persist beyond 12 weeks should prompt further evaluation.	Management strategies for the treatment of persistent post-COVID syndrome will vary greatly depending on the symptomatic profile & needs of each pt. Management strategies should account for prior pre-existing medical conditions & care teams should provide regular follow-up for each pt. until symptoms subside & for some time thereafter.	If (new) symptoms or complaints after a survived SARS-CoV-2 infection lead to the suspicion of a post/long-COVID syndrome, other differential diagnoses should be considered & if necessary, ruled out.	A clinical examination has to be performed in all individuals after COVID-19 before starting a rehabilitation program or an individualised training program.	Consistent collection of a detailed history & acute symptoms (e.g. SF-12 questionnaire or mMRC dyspnea score for pulmonary symptoms). In this way, psychiatric & neurological disorders, as well as limited quality of life, can also be recorded.	Treatment, guidance, and monitoring should be provided in any case, even if the symptoms appear unclear and/or a causal relationship with COVID-19 is not certain. Differentiation between symptoms due to organ damage and functional disorders (that might be reversible) need to be considered in planning pts. return to physical activities (e.g. profession, sport or other daily activities).

Abbreviations: CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HS – hand search, ICU – Intensive care unit, pts. – patients, QoL – Quality of life, SS – Systematic search, United States of America

## Possible referrals

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Table A-5: Possible referrals after the first assessment in primary or secondary care (A)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
Country	UK	UK	UK	UK	Overview of several countries (mostly England)	UK	UK
Identified through	SS	HS	HS	SS	SS	SS	HS
Publication type	Living guideline	Guideline	Review	Review	Review	Consensus statement	Clinical perspective/ expert opinion
<b>Different medical service options depending on the pts. needs</b>							
<b>Acute services (e.g. emergency)</b>	Pts. with signs of acute or life-threatening complications (e.g. severe hypoxaemia/oxygen desaturation on exercise, signs of severe lung disease, cardiac chest pain) referred urgently to the relevant acute services; Acute psychiatry services for pts. with severe psychiatric symptoms or at risk of self-harm/suicide.	People with ongoing systematic COVID-19 or suspected post-COVID-19 syndrome should be urgently referred to the relevant acute services if they have signs or symptoms that could be caused by an acute or life-threatening complication, including (but not limited to): severe hypoxaemia or oxygen desaturation on exercise, signs of severe lung disease, cardiac chest pain.	Not reported	Not reported	Not reported	Not reported	Not reported
<b>Specialised long COVID outpatient assessment centres/clinics</b>	Post-COVID assessment clinics: Pts. with no acute or life-threatening complications and no alternative diagnosis referred to integrated multidisciplinary assessment services any time from 4 weeks after the onset of the disease.	Post-COVID assessment clinics: Act as “one-stop shops” that provide specialist assessment, diagnosis & treatment (avoiding multiple referrals). <ul style="list-style-type: none"> <li>■ Ensure coverage for all.</li> <li>■ Are available, following GP or other clinicians, referral.</li> <li>■ Access is predicated upon an assessment framework (e.g. Equality and Health Inequalities Assessment Framework).</li> <li>■ Access is monitored via clinic data and health equity audit.</li> <li>■ Access is acted upon urgently if discrepancies are identified.</li> <li>■ Internal &amp; external communication plan for raising awareness with clinical community &amp; key stakeholders (pts. &amp; public, primary care networks, community, secondary care &amp; mental health services).</li> <li>■ Access to a multidisciplinary team of professionals.</li> </ul>	Not reported	Not reported	Not reported	Not reported	Not reported

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
<b>Specialised long COVID outpatient assessment centres/clinics</b> (continuation)		<ul style="list-style-type: none"> <li>■ Access to diagnostic tests recommended by NICE.</li> <li>■ Support collaboration across localities.</li> <li>■ The post-COVID assessment clinics refer pts. with symptoms lasting &gt;12 weeks according to their needs to:</li> <li>■ Self-management/supported self-management (e.g. Your COVID Recovery Phase 2, interactive rehab).</li> <li>■ Post-COVID multidisciplinary rehabilitation (physical – psychological – psychiatric – vocational): Tailored rehabilitation packages for long COVID pts., which are delivered by therapists working in the post-COVID assessment clinics.</li> <li>■ Specialists for specific conditions within the clinic.</li> </ul>					
<b>Self-management advise and/or supported self-management</b>	Pts. get advice (in addition) on ways how to self-manage the symptoms & on sources of support including patient organisations, (online) support groups, social prescribing, online forums, apps.	<p>Options to enable pts. (mostly with milder symptoms) with self-care:</p> <ul style="list-style-type: none"> <li>■ Signposting to Your COVID Recovery online platform.</li> <li>■ Techniques such as shared decision-making, health coaching, virtual group consultations for peer support &amp; social prescribing.</li> <li>■ Linking with the third sector in recognition with the whole-person biopsychosocial needs using Patient Activation Measures (PAM) to help to determine the level of support required.</li> </ul>	Some pts. will need long-term support in the community, including help with self-management strategies.	Not reported	Not reported	Pts. should be given strategies on how to manage recovery.	<p>Self-management can include:</p> <ul style="list-style-type: none"> <li>■ daily check of clinical parameters (e.g. oximetry)</li> <li>■ attention to general health (diet, sleep, quitting smoking, limiting alcohol, limiting caffeine) <ul style="list-style-type: none"> <li>■ rest &amp; relaxation</li> </ul> </li> <li>■ self-pacing &amp; gradual increase in exercise if tolerated</li> <li>■ setting achievable targets <ul style="list-style-type: none"> <li>■ Patient organisations emphasise wellbeing, mindfulness, social connection, self-care (including diet &amp; hydration) &amp; peer support.</li> </ul> </li> </ul>
<b>Multidisciplinary rehabilitation services</b> (e.g. inpatient or outpatient)	<p>Rehabilitation prescription includes a personalised rehabilitation &amp; management plan:</p> <p>Areas of rehabilitation &amp; interventions</p> <p>Symptom management for all presenting symptoms</p>	<p>After the post ICU multidisciplinary clinic re-assessment at 4-6 weeks post-discharge referral to early rehab or mental health services, if needed.</p> <p>A multidisciplinary team should tailor support &amp; rehab:</p> <ul style="list-style-type: none"> <li>■ Enable pts. access to clinical review in primary care &amp; more specialist advice or rehab, if needed.</li> </ul>	The Stanford Hall expert consensus statement: All pts. requiring rehab following COVID-19 should have a functional assessment & those with post-intensive care syndrome should receive psychological, physical & cognitive rehab.	Not reported	Not reported	Rehabilitation must be patient-centred and tailored to individual needs, taking into account comorbidities.	Referral to a specialist rehabilitation service does not seem to be needed for most pts. who can expect a gradual, if sometimes protracted, improvement in energy levels & breathlessness, aided by careful pacing, prioritisation & modest goal setting.

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
<b>Multidisciplinary rehabilitation services</b> (e.g. inpatient or outpatient) (continuation)		<ul style="list-style-type: none"> <li>Development of individual care plans for physical, mental &amp; social needs</li> <li>Including support through the Your COVID Recovery interactive online rehab platform.</li> </ul>					Where needed, rehabilitation can also be delivered by various virtual models, including video linked classes & home education booklets with additional telephone support.
<b>Physical rehab</b>	Physiotherapy & rehabilitation medicine	Pneumological rehabilitation <ul style="list-style-type: none"> <li>Cardiological rehabilitation</li> <li>Physiotherapy for pts. with breathlessness, de-conditioning, fatigue &amp; dizziness including specific guidance on pacing, rest &amp; recovery time</li> <li>Occupational therapy for pts. with cognition, delirium, mental health &amp; functional difficulties</li> <li>Co-morbidity management, e.g. for diabetes (dietetics &amp; nutrition services)</li> <li>Speech &amp; language therapists for pts. with cognitive (brain fog), swallowing, voice &amp; respiratory difficulties.</li> </ul>	A key element of physical rehab is exercise, but individuals have different levels of exercise tolerance → rehab exercise needs careful prescription & monitoring! E.g. for pts. with chronic fatigue syndrome (CFS) exercise should be personalised & overseen by a physiotherapist or occupational therapist with specialist training & expertise. Fixed incremental increases in physical exercise should not be used.  For other symptoms/ conditions, exercise therapy/physical activity may be helpful: pacing is important!	To improve strength & endurance, exercise programmes should be prescribed but with caution, especially where pts. may experience ongoing fatigue problems.	Not reported	Pulmonary rehabilitation programmes can be delivered within a hospital setting, outpatient, home-based or even remotely supervised. Another consideration is dosage of exercise – pacing.	Most but not all pts. who were not admitted to hospital recover well within 4-6 weeks of light aerobic exercise, gradually increasing in intensity as tolerated.  For example, pulmonary rehabilitation is defined as a multidisciplinary intervention based on personalised evaluation & treatment that includes, but is not limited to, exercise training, education & behavioural modification & designed to improve the physical & psychological condition of people with respiratory disease.  For some symptoms (e.g. fatigue), exercise should be undertaken cautiously & cut back (pacing) if pts. develops fever, breathlessness, severe fatigue or muscle aches.
<b>Psychological and/or psychiatric rehab</b>	Clinical psychology, psychiatry & psychological therapies (e.g. occupational therapy) for pts. with common mental health symptoms (e.g. mild anxiety, mild depression).	Improving Access to Psychological Therapies (IAPT) & other mental health services including cognitive management. Psychologists can provide assessment of cognition, mental health, services such as IAPT.	High-intensity psychological interventions from clinical psychologists are essential in multidisciplinary rehab programmes.  The British Psychological Association Society (2020) recommended a structured, stepped approach to the psychological interventions as part of integrated, multidisciplinary rehab → this has been incorporated into the NHS “Your COVID Recovery” programme as support for their rehab.	Not reported	Not reported	Not reported	While the minority of pts. may benefit from referral to mental health services, it is important not to pathologise the majority.  Mental health contributions should include continuity of care, avoidance of inappropriate medicalisation, and longer appointments for pts. with complex needs (face to face if needed).

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
<b>Neurological and cognitive rehab</b>	Not reported	Not reported	Neuropsychological interventions (e.g. for cognitive impairments, brain fog) should either restore the cognitive function or if that is not possible, compensate by developing aids & new ways of organising information to ensure that the person can function.	Not reported	Not reported	Not reported	For neurological sequelae (e.g. ischaemic stroke, seizures, encephalitis & cranial neuropathies) supportive management & symptom monitoring is in particular recommended in primary care but also in rehabilitation.
<b>Specialist care for (symptom)-specific complications, if necessary</b>	Depending on the need of the pts.: e.g. rheumatology, neurology, cardiology.	After the post ICU multidisciplinary clinic re-assessment at 4-6 weeks post-discharge referral to mental health services, if needed.  Referral from the post-COVID assessment clinic or directly from the GP for some pts. who need further therapeutic input (mental health services, specialists for specific conditions). The timing is based on individual needs & is at the discretion of the assessing clinician (mostly after 12 weeks).  Referral pathways for the following specialised services should be possible: Specialist lung disease services including referral to pulmonary rehab. Cardiac services include referral to cardiac rehab. Referral to neurology, rheumatology, dermatology, gastroenterology & psychologists e.g. for pain management & fatigue services.	Not reported	Not reported	Those who need further care should be referred to specialists for input in more complex cases of specific organ dysfunction.	Not reported	However, specialist referral may be indicated, based on clinical findings, e.g.: <ul style="list-style-type: none"> <li>■ Respiratory if suspected pulmonary embolism, severe pneumonia.</li> <li>■ Cardiology if suspected myocardial infarction, pericarditis, myocarditis or new heart failure.</li> <li>■ Neurology if suspected neurovascular or acute neurological event.</li> </ul>
<b>Community health services &amp; non-medical healthcare providers</b>	Depending on the need of the pts.: dietetics, speech & language therapy, nursing & pharmacy.	Specialist nursing functions such as district nursing, community nursing, psychiatric nursing, clinical nurse specialists & general practice nurses can support treatment of pts. and wider family members where appropriate.	Not reported	Not reported	Not reported	Not reported	Not reported
<b>Additional medical guideline recommendations</b>							
<b>Follow-up monitoring</b>	Shared decision with the pts. how often follow-up & monitoring is needed. Consider supported self-monitoring at home to measure, e.g. blood pressure or heart rate.	Not reported	Not reported	Not reported	Not reported	Pts need to be followed up closely.	Not reported

Abbreviations: CFS – Chronic fatigue syndrome, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HDU – High dependency unit, HS – hand search, NIHR – National Institute for Health Research, ICU – Intensive care unit, NHS – National Health Service, NICE – National Institute for Health Care Excellence, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, SS – systematic search, UK – United Kingdom

Table A-6: Possible referrals after the first assessment in primary or secondary care (B)

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
Country	The Netherlands	USA	USA	Germany	Germany	Germany	Austria
Identified through	SS	HS	SS	HS	SS	SS	HS
Publication type	Clinical perspective/ expert opinion	Guideline	Review	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
<b>Different medical service options depending on the pts. needs</b>							
Acute services (e.g. emergency)	Not reported	Not reported	Not reported	Referral to acute inpatient treatment if clear warning signs (e.g. poor general health, significant weight loss, unexplained or newly appeared neurological deficits/abnormalities, new pain symptoms, poor or worsening somatic or psychological findings & unexplained abnormalities in the basic diagnostics) could be diagnosed via basic diagnostics by the GP.	Not reported	Not reported	Not reported
Specialised long COVID outpatient assessment centres/clinics	Not reported	Not reported	Not reported	Post-COVID ambulances should involve several disciplines next to primary care, e.g. neurology, psychiatry, psychosomatic, cardiology, pneumology, nephrology, rheumatology, otorhinolaryngology, dermatology, endocrinology.	Not reported	Not reported	Second assessment in a specialist long COVID outpatient clinic forms more complex symptoms.
Self-management advise and/or supported self-management	Self-management or education modules may also need to be considered.	Healthcare professionals should encourage pts. to report any new or changing symptoms & to discuss any changes in activities or routines. Pts. diaries & calendars might be useful to document changes in health conditions & symptom severity, especially in relation to potential triggers such as exertion (physical or cognitive), foods, menstruation and treatments or medications.	Not reported	Not reported	Not reported	Not reported	<p>If there are long-lasting symptoms, self-management including connection with patient organisations can be helpful.</p> <p>Self-management can also include:</p> <ul style="list-style-type: none"> <li>■ Self-management of the symptoms ("What helps me?")</li> <li>■ Self-control (e.g. diary, heart rate monitor) or self-monitoring (e.g. Borg-Scale)</li> <li>■ Salutogenese (concentration of the healthy parts)</li> <li>■ Support from friends and relatives</li> <li>■ Recommendations for trustworthy websites ("self-education")</li> </ul>

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
<b>Multidisciplinary rehabilitation services</b> (e.g. inpatient or outpatient)	<p>Comprehensive rehabilitation programmes are recommended considering that the programme will potentially be wider in scope than current rehabilitation programmes, because of</p> <ul style="list-style-type: none"> <li>■ the additional burden of COVID-19 (e.g. consequences of social isolation, emotional burden).</li> <li>■ the different age group to the “usual” (pulmonary) rehabilitation population, thus supporting successful return to work should be part.</li> </ul> <p>Rehabilitation must be made to pts. in a personalised &amp; targeted manner to maximise the likelihood of acceptance.</p>	<p>Multidisciplinary post-COVID care centres based in a single physical location can provide a comprehensive &amp; coordinated treatment approach to COVID-19 aftercare.</p> <p>Established partnerships with specialists for physical &amp; mental healthcare including comprehensive rehabilitation services are useful.</p> <p>Creating a comprehensive rehabilitation plan may be helpful for some pts. &amp; might include physical &amp; occupational therapy, speech &amp; language therapy, vocational therapy, as well as neurologic rehabilitation for cognitive symptoms.</p> <p>Optimising management of underlying medical conditions might also include counselling on lifestyle components such as nutrition, sleep and stress reduction (e.g. meditation).</p> <p>Approaches that incorporate telemedicine, including phone calls &amp; virtual visits, can be helpful for ongoing follow-up &amp; might lessen the burden on pts. with limited energy from post-COVID conditions or who have other concerns about personal Vitis. Evaluation &amp; care should not be delayed if only telemedicine options are available. For example, telemedicine may be helpful for pts. with barriers to transportation, childcare or paid sick leave given that they live in rural areas with broadband access.</p>	Not reported	<p>After primary care diagnosis, primarily outpatient “Heilmittel<sup>2</sup>” are recommended, if these are not sufficient, multimodal (partial) inpatient rehabilitation is required. (Partial) inpatient rehabilitation is always a phase of (more intensive) rehabilitative treatment, which often requires outpatient continuation. Persistent consequences of the disease with a threat to the ability to work or to provide for oneself or restrictions on participation in daily activities are decisive criteria for a need for rehabilitation.</p> <p>Generally, the guideline differentiates between the “Anschluss-Heilbehandlung” (AHB), “Anschluss-Rehabilitation” (AR) &amp; “Medizinische Rehabilitation auf Antrag” (MRA, also referred to as “Heilverfahren” [HV]) that can also be offered to COVID-19 pts. with mild to moderate acute infections.</p> <p>If, for example, pulmonary, neurological or cardiological damage (“impairment”) is the cause of the need for rehabilitation, the patient should undergo pneumological, neurological or cardiological rehabilitation according to the specific indication. Depending on the individual symptoms, accompanying or basic psychosomatic, psychiatric and/or psychological-psychotherapeutic treatment offers are indicated.</p>	<p>See physical &amp; neurological rehab</p> <p>Support by telemedicine should be considered as an additional tool to increase long-term adherence to rehab programs.</p>	Not reported	<p>Outpatient or inpatient rehabilitation is possible, e.g. in case of persistent symptoms for longer than 12 weeks or even earlier in case of severe impairment. The rehabilitation should be indication-specific and multimodal.</p> <p>The concept of “pacing” is important for several symptoms and presents a person-centred process that can enable pts. to manage their physical, cognitive, and emotional energy within individual limits, through careful planning of where and how to use available energy.</p> <p>The stress limits (physical &amp; emotional) must be explored under medical supervision or in the context of rehabilitation (e.g. before returning to everyday activities): Estimation of the expected daily workload versus individual capacity.</p>

<sup>2</sup> „Heilmittel“ are medical services that can be prescribed by contracted physicians and dispensed by specially trained therapists. These include physiotherapy, occupational therapy, voice therapy, speech therapy, swallowing therapy, podiatry and nutrition therapy. ([https://www.gkv-spitzenverband.de/krankenversicherung/ambulante\\_leistungen/heilmittel/heilmittel.jsp](https://www.gkv-spitzenverband.de/krankenversicherung/ambulante_leistungen/heilmittel/heilmittel.jsp)).

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
<b>Physical rehab</b>	Pulmonary rehabilitation is defined as a comprehensive intervention that is based on a thorough assessment followed by patient-tailored therapies including, but is not limited to: exercise & training and education & behaviour change (e.g. nutritional support); Thereby, it should improve the physical & psychological condition of people with chronic respiratory diseases & promote long-term adherence of health-enhancing behaviours. Muscle-strengthening programmes, especially for pts. previously treated at the ICU. Muscle strength needs to be assessed before commencement, to enable accurate prescription & tailoring of the programme.	A conservative physical rehabilitation plan might be indicated for some pts.; consultation with physiatry for cautious initiation of exercise & recommendations about pacing may be useful.	Not reported	Pneumological rehabilitation, e.g. for dyspnoea or fatigue Cardiological rehabilitation, e.g. for pulmonary artery thrombosis, myocarditis, or an acute coronary syndrome (ACS).	Exercise programs for post-COVID-19 pts. are mandatory; Exercise programs should be integrated into rehabilitation programs, e.g. supervised rehab in the beginning (e.g. group exercises) & non-supervised training in a home-based setting or fitness gym later on. Exercise training has to be individually tailored to optimise the balance between strain & adaption processes based on disease state & exercise performance. Concerning training structure: first frequency, then duration & finally intensity should be increased.	Not reported	–
<b>Psychological and/or psychiatric rehab</b>	–	–	Not reported	Psychological rehabilitation, e.g. for adjustment disorder, depression, anxiety disorder, somatisation disorder, obsessive-compulsive disorder, psychosis. Psychotherapeutic treatment is indicated when a clinically relevant diagnosis is confirmed or the subjective distress is so great that the quality of life and daily burden are significantly reduced.	Not reported	Not reported	–
<b>Neurological and cognitive rehab</b>	–	–	Not reported	Neurological rehabilitation e.g. neurological disease after a severe SARS-COV-2 infection (e.g. strokes, encephalomyelitis, Guillain-Barré syndrome, Miller Fisher syndrome, cranial nerve neuritis syndrome, cranial nerve neuritis, myositis, myasthenia gravis and plexopathies) & neurological disease after mild to moderate primary	Resuming or starting exercise is also highly desired from a neurological standpoint & should be encouraged in all pts. Pts. with motor deficits need to be assessed according to their functional	Not reported	–

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
<b>Neurological and cognitive rehab</b> (continuation)				infections (e.g. hyposmia or anosmia decreased psychophysical resilience, peripheral paralysis, cognitive deficits such as impaired coordination, concentration, word-finding, forgetfulness), and/or headache or muscle pain).	state & most likely benefit from exercise & physical therapy under professional supervision.		
<b>Specialist care for (symptom)-specific complications, if necessary</b>	Those pts. who show high levels of anxiety or depressive symptoms need to be referred to a psychologist or psychiatrist for further assessment. Treatment may be indicated when symptoms continue to exist after 10-12 weeks.	Based on clinical evaluation & response to treatment, healthcare professionals might also consider a stepwise approach to other specialist referrals. However, multiple visits may place additional burdens (e.g. financial, time, psychological burden) on pts., as well as the possibility of fragmented care that can increase the risk of contradictory medical advice.	Not reported	Further specialist clarification may be indicated if, after SARS-CoV-2 infection, symptoms persist for more than 3 months. E.g. if neurological focal signs, epileptic seizures or confusion (delirium) occur after the infection. If olfactory and gustatory disturbances or cognitive impairments persist for more than 3 months.	Not reported	Not reported	The treatment of specific symptoms can be conducted by a specialist or also in the primary care setting depending on the pts. situations.
<b>Community health services &amp; non-medical healthcare providers</b>	Not reported	Not reported	Not reported	If needed, pts. can be referred e.g. by the GP to healthcare professionals, such as physiotherapists, psychotherapists or occupational therapists speech therapy, nutritional counselling, or nursing services (also in addition to other healthcare services).	Not reported	Not reported	For pts. with mild to moderate symptoms that can be treated by one specific discipline, outpatient therapies of non-medical healthcare providers (e.g. physiotherapy, occupational therapy, psychotherapy, speech therapy, nutritional counselling, nursing services) are recommended also in addition to other treatments.
<b>Additional medical guideline recommendations</b>							
<b>Follow-up monitoring</b>	Not reported	For pts. who were hospitalised for COVID-19, healthcare professionals should consider additional follow-up visits based on pts. needs.  Pts. with asymptomatic infection to moderate illness might benefit from follow-up within 3-4 weeks from initial infection, if they experience or new symptoms.  Further follow-up visits with a healthcare professional might be considered every 2-3 months, with the frequency adjusted based on the needs.	Follow-up & encouraging pts. to seek medical care at the onset of worsening symptoms are recommended.	Follow-up consultations are often the responsibility of GPs.	In case of good tolerability of the exercise program, re-evaluation on an individual basis is recommended routinely after 12 months & earlier if needed.	The optimal time to begin COVID-19 follow-up depends on the severity of persistent symptoms. Usually, an interval of 4-6 weeks after the acute infection or hospital discharge is recommended, with further follow-up checks approximately every 3 months.	An examination before restarting daily and professional activities is recommended, especially for physically demanding activities. This should include the planning of an appropriate resuming & monitoring. Overall, follow-up should be planned on an individual basis also considering psychosocial circumstances. For hospitalised pts., a follow-up depending on the individual situation should be already planned in the course of discharge.

Abbreviations: CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HS – hand search, ICU – Intensive care unit, pts. – patients, QoL – Quality of life, SS – Systematic search, United States of America

## Additional (social) services

Table A-7: Additional (social) services for long COVID patients (A)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
Country	UK	UK	UK	UK	Overview of several countries (mostly England)	UK	UK
Identified through	SS	HS	HS	SS	SS	SS	HS
Publication type	Living guideline	Guideline	Review	Review	Review	Consensus statement	Clinical perspective/expert opinion
<b>Additional (social) services</b>							
Cash payments (e.g. sick leave, early retirement)	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
<b>Contributions in kind</b>							
Social care services (e.g. daycare)	Not reported	Post-COVID assessment clinics should ensure referral to appropriate services if needed (e.g. social prescribing).	Not reported	Not reported	Not reported	Not reported	Offers in the community, such as community link workers, patient peer support groups, attached mental health support service, cross-sector partnerships with social care, community services, faith groups → community level, cross-sector collaborations may be needed to develop locally relevant solutions.
Employment	Employers should be willing to put workplace modifications in place. These modifications are known as 'reasonable adjustments' for disabled people and employers must consider this if an employee is disabled under the Equality Act 2010 (e.g. phased return to work). A fit note may make suggestions about workplace modifications ( <a href="https://www.yourcovidrecovery.nhs.uk/your-road-to-recovery/returning-to-work/">https://www.yourcovidrecovery.nhs.uk/your-road-to-recovery/returning-to-work/</a> ).	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported

Abbreviations: COVID – Coronavirus disease, e.g. – for example, HS – hand search, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, SS – systematic search, UK – United Kingdom

Table A-8: Additional (social) services for long COVID patients (B)

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
Country	The Netherlands	USA	USA	Germany	Germany	Germany	Austria
Identified through	SS	HS	SS	HS	SS	SS	HS
Publication type	Clinical perspective/ expert opinion	Guideline	Review	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
<b>Additional (social) services</b>							
Cash payments (e.g. sick leave, early retirement)	Not reported	Not reported	Not reported	Sick leave is issued according to the known principles, the criterion is the actual ability to work of the affected person. The diagnosis should refer to the respective dominant symptom.	Not reported	Not reported	The process to receive sick leave due to long COVID is the same as for other illnesses. The main criterium should be the inability to work. The diagnosis should be based on the main clinical symptom instead of the broad symptom "long COVID".
<b>Contributions in kind</b>							
Social care services (e.g. daycare)	Also, consider psychological assessment and/or support for the family of pts.	Connecting pts. to social services when available, to assist in other hardships (e.g. financial, family illness, bereavement, caregiving) & in resources on disability & in reasonable accommodations for work or school & connections to support groups.	Not reported	Multimodal treatment of patients is central including the involvement of self-help groups & social interventions.	Not reported	Not reported	Not reported
Employment	Not reported	When material, employment or other social support needs are identified, healthcare professionals should consider (if they are knowledgeable & able) engaging a social worker, caseworker, community health worker or similarly trained professionals to assist.	Not reported	The 4-P rule can be helpful (pacing, planning, prioritizing, positioning). Stress limits & occupational aptitude in the case of persistent severe limitations should be assessed during rehabilitation & depending on the situation, discussed with the responsible preventive staff in the company (safety specialist, company doctor) and the responsible institutions (labour inspectorate) before starting work.  Also, contacting employee protection agencies (trade unions) should be advised to those affected. Case managers from the health insurance funds can provide support in organising reintegration, if available.	Not reported	See FF5	Stress limits and job suitability should be tested during rehabilitation, before going back to work. The severity of the acute infection and the persistent symptoms, as well as the individual requirements at work, need to be considered and discussed with the relevant preventive staff in the company (safety specialist, company doctor) and the relevant institutions (labour inspectorate, AUVA).  Adjustments of the working place or working conditions should be possible to facilitate the coming back.

Abbreviations: AUVA – Allgemeine Unfallversicherungsanstalt (engl. general accident insurance), CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HS – hand search, ICU – Intensive care unit, pts. – patients, QoL – Quality of life, SS – Systematic search, United States of America

## Further information for practising physicians regarding decision-making and communication

Table A-9: Information for practising physicians (A)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (Dec. 2020) [11]	NHS Clinical Guidance (April 2021) [23]	NIHR Review (2021) [8]	Parkin et al (2021) [26]	Policy Brief 39 (Rajan et al. 2021) [28]	Barker-Davies et al. (May 2020) [29]	Greenhalgh et al (2020) [30]
Country	UK	UK	UK	UK	Overview of several countries (mostly England)	UK	UK
Identified through	SS	HS	HS	SS	SS	SS	HS
Publication type	Living guideline	Guideline	Review	Review	Review	Consensus statement	Clinical perspective/ expert opinion
<b>Results – Information for practising physicians</b>							
<b>Further information for practising doctors in long COVID care</b>	National guidance on communication, providing information & shared decision making (NICE's guideline on patient experiences in adult NHS services) should be followed. Health inequalities (language barriers, mental health conditions, mobility or sensory impairments, learning disability, cultural differences) need to be considered by providing extra support and raising awareness.	Healthcare systems can utilise existing communica- tion platforms, including formal NHS platforms, membership bodies & voluntary organisations. NHS England & NHS Improvement will support communication to pts., relevant communication plans should also be developed to raise awareness amongst pts. & the public, ensuring these commu- nications are targeted at audiences from all back- grounds & thus ensure equity of access to services. Minimising health inequalities, e.g. special support to those with visual & hearing impairments, learning disabilities, autism, mental health problems or to ethnic minority groups (e.g. language & cultural barriers), etc. To help health & care staff with the knowledge, skills & confidence to deliver personalised care, they can access the <b>Personalised Care Institute (PCI)</b> platform including access to PCI accredited eLearning, view accredited training providers & programmes, high-quality resources (to support learning).	Not reported	GPs are made aware of the Community COVID-19 MDT service through usual communica- tion avenues such as the internal bulletin briefings.	Not reported	Holistic approach is needed where the physical, psycholog- ical and cognitive issues are tackled.	Support should be personalised (especially for older pts.) with input from a multi-professional team (e.g. general practitioner, district nurse, social worker, rehabilitation teams & occupational therapists, if needed).
<b>Important information submitted to the pts.</b>	Written advice for all confirmed or sus- pected COVID-19 infected about most common new or ongoing symptoms. The advice should also include the information that there are different recovery times (unpredictable changes in new & ongoing symptoms are possible), but mostly the symptoms last 12 weeks. Information about self-management programmes and symptoms to look out for professional help is also crucial. copy of the care plans including discharge letters, clinical records and rehabilitation plans & prescriptions should be given to the pts.	Not reported	Nor reported	Not reported	Not reported	Education is also important: implications of the disease & consequences must be discussed with pts.	Not reported
<p><i>Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HS – hand search, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, SS – systematic search, UK – United Kingdom</i></p>							

Table A-10: Information for practising physicians (B)

Reference (author, month, year)	Spruit et al. (2020) [31]	CDC interim guidance [24]	Oronsky et al. (2021) [27]	S1 guideline (July 2021) [13]	Halle et al. (2021) [32]	Leo et al (2020) [33]	S1 guideline (July 2021) [25]
Country	The Netherlands	USA	USA	Germany	Germany	Germany	Austria
Identified through	SS	HS	SS	HS	SS	SS	HS
Publication type	Clinical perspective/ expert opinion	Guideline	Review	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
<b>Results – Information for practising physicians</b>							
<b>Further information for practising doctors in long COVID care</b>	Not reported	Understanding of post-COVID conditions remains incomplete & guidance for healthcare professionals will likely change over time as the evidence evolves. Healthcare professionals should continue to check for updates on evolving guidance for post-COVID conditions. Healthcare professionals & pts. should set achievable goals through shared decision-making & treatments should focus on specific symptoms & conditions. Particularly among persons who belong to marginalised or vulnerable groups, sensitivity & awareness of stigma, completing a full clinical evaluation & maintaining an attitude of empathy/understanding can help to address these concerns.	Not reported	Not reported	Not reported	Not reported	Holistic & person-centred approach is necessary, considering the results of the first general diagnostic, the subjective burden of the disease, as well as pts. wishes and possibilities. It is crucial to avoid causing unnecessary anxiety and uncertainty in pts., as well as overdiagnosis or over-medicalisation.
<b>Important information submitted to the pts.</b>	Not reported	Healthcare professionals should advise pts. that post-COVID conditions are not yet well understood & assure them that support will continue to be provided as new information emerges. Tools for cross-cultural communication & language access, including translated materials on post-COVID conditions & interpreter services, could help address health literacy & improve communication effectiveness.	Pts. should be educated by physicians in the possible manifestations of persistent post-COVID syndrome.	Not reported	Not reported	Not reported	Pts. should be informed about the good prognosis of functional disorders.

Abbreviations: CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HS – hand search, pts. – patients, SS – Systematic search, United States of America

## Current long COVID care structures in Austria

Table A-11: Current long COVID care structures in Austria (August 2021)

Country	Austria
<b>Medical service offer</b>	
Organisation	Mostly organised on the local level [25].
Primary care: GPs or primary care centres	The first point of contact for long COVID pts. is the primary care sector (primary care centres & GPs) [25].
Secondary care	No examples
Specialised long COVID (outpatient) assessment centres/clinics	<p><i>National level:</i> Long COVID should be primarily treated locally involving multidisciplinary treatment offers (e.g. primary care physicians, specialists &amp; other disciplines such as dietary counselling, physical therapy &amp; psychotherapy). If not possible specialised inpatient offers are relevant [56].</p> <p><i>Local examples:</i> <b>Specialised regional outpatient clinics of the Austrian health insurance</b> across Austria offer secondary assessments for long COVID pts. if necessary after the primary assessment. Pts. are further referred to other specialists for appropriate treatment [57].</p> <p><b>Specialised long COVID outpatient assessment clinic in Vienna (AKH)</b> founded by Frau Prof. Mariann Gyöngyösi, first in Austria. Offer: clinical assessments and support hours once a week (Wednesday). Pts. can also participate in the study that is conducted there [45].</p> <p><b>Long COVID outpatient clinic of the "Barmherzigen Schwestern Wien" in Vienna:</b> an outpatient programme for 6 weeks twice a week (08:30-15:30). It consists of various psychotherapeutic modules, medical consultations, physical exercise, relaxation &amp; individual psychotherapy [45].</p> <p><b>Long COVID outpatient clinic in the LKH Graz II Standort West (Styria):</b> referral from the GP or a specialist necessary. For pts. with long COVID symptoms that last at least 12 weeks. Offer: secondary assessment &amp; recommendations about further assessments &amp; appropriate treatments [45].</p> <p><b>The psychotherapeutic outpatient clinic in Vienna</b> offers conversation group therapy [45].</p>
Self-management or supported self-management services (e.g. online, tele- and/or home-based services)	Patient organisation: Long Covid Austria [45].
Multidisciplinary rehabilitation clinic/Centre (inpatient/partially inpatient/outpatient)	<p>Long COVID rehabilitation offers are regulated on the local level.</p> <p><i>Local examples:</i> <b>15 inpatient rehabilitation centres and two outpatient centres for rehabilitation of the Pension Insurance Institution also for long COVID pts.</b> E.g. the centres in Hohegg (Lower Austria) and Weyer (Upper Austria) offer inpatient rehabilitation for cardiovascular diseases, respiratory diseases and diseases of the musculoskeletal system. Many pts. receive a training plan for continuing at home after the inpatient programme [67].</p> <p><b>Long COVID inpatient rehabilitation "Klinikum Bad-Gleichenberg" (Styria)</b> [49].</p> <p><b>Rehabilitation clinic "Tobelbad" (AUVA)</b> department of occupational diseases and occupational medicine (Styria): 3-week inpatient rehabilitation for pts. with COVID-19 as an occupational disease [50].</p> <p><b>Hospital "Herz-Jesu" in Vienna</b> offers acute rehabilitation for ICU-COVID-19 pts. A specially established interdisciplinary team is made up of the following specialties: internal medicine, physical medicine &amp; rehabilitation, pulmonology, radiology, dietology, clinical psychology, pastoral care, discharge management [51].</p> <p><b>Long COVID outpatient rehabilitation "Bruck" for 6 weeks (Styria)</b> [52].</p>
Specialised care offers	List of psychotherapists, psychologists, counsellors with support for long COVID pts. [45].
Community health services and non-medical healthcare providers	If needed, pts. are referred e.g. by the GP to healthcare professionals, such as physiotherapists, psychotherapists or occupational therapists [25].
<b>Additional (social) services</b>	
Cash payments (e.g. sick leave, early retirement)	Same sick leave procedure than for other diseases [61].

Country	Austria
Contributions in kind	
Social care services	No examples
Employment	<p><b>No long COVID specific offers, same offers as for other illnesses, e.g.</b></p> <p><i>National level:</i></p> <p><b>Fit2work:</b> a government-funded programme that helps to promote, maintain or restore the ability to work, secure the employees' job with solutions that also convince the company, discover other fields of activities &amp; quickly get back to work [63].</p> <p><b>Gradual reintegration</b> after illness ("<b>Wiedereingliederungsteilzeit</b>"): e.g. working time can be reduced by up to 50%. Health insurance cushions the loss of income [62].</p> <p>In principle, any suspicion of occupational illness must be reported by the employer or by the attending physicians according to the law [61].</p>

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, ICU – Intensive care unit, pts. – patients

## Current long COVID care structures in selected European countries

Table A-12: Current long COVID care structures in selected European countries (August 2021)

Country	United Kingdom (UK)	Belgium (BE)	Italy (IT)	Germany (GER)
<b>Medical service offer</b>				
<b>Organisation</b>	<p>Mostly organised on a national level, but locally executed.</p> <p><i>The NHS Improvement's 5-Point plan for long COVID support (national level) involves [58]:</i></p> <ol style="list-style-type: none"> <li>1) NICE guideline on long COVID</li> <li>2) the Your COVID Recovery online rehabilitation programme</li> <li>3) designated post-COVID assessment services</li> <li>4) funds for long COVID research by the NIHR</li> <li>5) an NHS long COVID task force which includes patients with long COVID, medical specialists and researcher</li> </ol>	<p>Not many established healthcare structures for long COVID, if any, then mostly organised on the local level.</p>	<p>Mostly organised on the local level.</p>	<p>Mostly organised on the local level.</p>
<b>Primary care: GPs or primary care centres</b>	<p><i>National level:</i></p> <p>First point of contact for pts. never hospitalised during COVID-19: primary care sector [11].</p> <p><i>A local example (e.g. Leeds):</i></p> <p>Integrated care pathway developed by Leeds Primary Care Services, Leeds Community Healthcare NHS Trust and Leeds Teaching Hospital NHS Trust. The pathway aligns itself to the NHS England "Five-point plan for long COVID support". The pathway was the first of its kind to be set up in the UK and comprises of a <i>three-tier service model</i>:</p> <ol style="list-style-type: none"> <li>1. tier) <b>Primary care</b> for pts. with typical long COVID symptoms lasting 1-2 months &amp; likely resolve with supported self-management [26].</li> </ol>	<p>Current situation:</p> <p>GP's don't know enough about long COVID &amp; often don't know to which clinics pts. can be referred to (expert information).</p>	<p>Long COVID management generally takes place in primary &amp; secondary care.</p> <p>GPs also coordinate services that include domiciliary care possibly supported by telemonitoring and new community nurses [28].</p>	<p>First point of contact for long COVID pts. primary care sector (primary care centres &amp; GPs) [13].</p>
<b>Secondary care</b>	No examples	No examples	No examples	No examples

Country	United Kingdom (UK)	Belgium (BE)	Italy (IT)	Germany (GER)
<b>Specialised long COVID outpatient assessment centres/clinics</b>	<p><i>National level: Integrated multidisciplinary post-COVID assessment outpatient clinics</i> across England are set up as one part of the <i>NHS Improvement's 5-Point plan for long COVID support (n=89)</i>. These services are designed to complement existing primary, community and rehabilitation care in the form of specialist assessments, diagnosis &amp; if possible treatment. There will be several different ways that these services are implemented depending on the needs of local patients &amp; the configuration of existing services (<a href="https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/">https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/</a>). For example, they can function as a "one-stop clinic" for further testing, investigations &amp; support for managing physical/mental health symptoms including rehabilitation. However, services can also be delivered across multiple sites or – where appropriate – virtually [29].</p> <p><i>A local example (e.g. Leeds):</i> Part of the <i>three-tier service model</i>:  <b>3. tier) Specialist multidisciplinary team (MDT) services:</b></p> <ul style="list-style-type: none"> <li>■ For pts. with prolonged COVID-19 symptoms for &gt;3 months, complex symptoms with impact on daily life &amp; functioning <i>requiring input from 2 or more professionals</i> (also &lt;3 months) &amp; for post-discharge pts. with complex needs. <ul style="list-style-type: none"> <li>■ Most referrals to the MDT services from the GPs (tier 1) or also from Community therapy teams (tier 2), few referrals directly from hospital services (complex cases).</li> </ul> </li> <li>■ The MDT service is multidisciplinary, e.g. allied health professionals, pathway coordinators, physiotherapists, occupational therapists, consultants with a specialism in rehabilitation medicine, respiratory medicine &amp; cardiology; additional support comes from respiratory nurses, respiratory physiotherapists, dieticians &amp; neurological occupational therapists.</li> <li>■ Offered interventions: the usual process of assessment, clinical reasoning &amp; intervention planning including home visits for assessments &amp; reviews (also phone interviews); prescription to exercise programmes, e.g. NHS England's online "Your COVID Recovery Programme". <ul style="list-style-type: none"> <li>■ Severe medical concerns (e.g. unexplained chest pain) discussed as a priority within the <i>weekly specialist MDT meeting (virtual)</i> → linking pts. to appropriate pathways of investigation &amp; treatment &amp; reduce the number of outpatient clinic attendances as the MDT rationalise the need for investigations &amp; most appropriate &amp; effective management approach [26].</li> </ul> </li> </ul>	<p><i>National situation:</i>  Of the 30 Flemish hospitals, 20 offer "something" to long COVID pts. Different offers between the clinics &amp; inclusion criteria which pts. receive interventions is diverse, e.g. some clinics only accept pts. who were hospitalised in their clinic during COVID-19 (expert information).</p> <p>Specialised long COVID services mainly focus on pts. who were admitted to ICU during COVID-19 including programmes dedicated to the management of Post-Intensive Care Syndrome (e.g. services at home or in a specialised or a geriatric hospital with a multidisciplinary team of doctors, nurses, physiotherapists, occupational therapists, sports therapists, psychologists, speech therapists and social workers) [28].</p>	<p>Specialist long COVID assessment outpatient clinics are regulated on the local level.</p> <p><i>Local-level (e.g. Rome):</i>  <b>Post-COVID-19 Day-Hospital</b> including a multidisciplinary team of an infectious disease physician &amp; specialists for pneumological, ophthalmologic, otolaryngologic, neurologic, psychiatric, cardiovascular, nutritional, gut and rheumatologic assessments [28].</p>	<p><i>National level:</i>  The "Deutsche Bundestag" calls on the Federal Government to anchor <b>outpatient long COVID assessment clinics</b> as a new § 116c in the Fifth Book of the Social Code (SGB V) within the limits of the available budget [59].</p> <p>Currently, there are approximately 50 long COVID outpatient clinics of various specialities at clinical institutions across Germany (expert information).</p> <p><i>Local examples:</i>  The <b>University Hospital Essen</b>: 2 special outpatient clinics (part of the neurology &amp; infectiology departments) for the assessment &amp; follow-up of long COVID pts. Offer: twice a week special, consultation hours for long COVID pts. [56].</p> <p><b>Charité fatigue centre</b> (Berlin) offers post-COVID consultation hours [60].</p> <p><b>Max-Planck-Institute of Psychiatry</b> (Munich): neurological-psychiatric post-COVID outpatient clinic for further diagnosis &amp; treatment [55].</p> <p><b>Jena University Hospital &amp; Hanover Medical School:</b> a post-COVID outpatient clinic (since July 2020) including a multidisciplinary team of neurologists, cardiologists, pneumologists, psychiatrists, gastroenterologists, occupational physicians, internists &amp; ear, nose and throat doctors providing interdisciplinary care [28].</p>
<b>Self-management or supported self-management services</b> (e.g. online, tele- and/or home-based services)	<p><i>National level:</i>  <b>"NHS Your COVID Online Recovery Plattform"</b> was set up as part of the NHS Improvement's 5-Point plan for long COVID support [53].</p> <p>The <b>Your COVID Recovery website</b> launched in July 2020: provides the latest advice on recovering from COVID-19 including general information about COVID-19; tips on how to manage different long COVID symptoms; general aspects about wellbeing (e.g. eating, sleeping, moving habits) &amp; tips for the way back to recovery (e.g. after a hospital stay; how to manage daily activities; how to go back to work). The information website is <b>available to all</b> and is continuously updated.</p>	<p>Patient organisation:  Post-COVID Gemeenschap [48].</p>	<p>Domiciliary care is often supported by telemonitoring [28].</p>	<p>Patient organisation: Long COVID Deutschland [46].</p>

Country	United Kingdom (UK)	Belgium (BE)	Italy (IT)	Germany (GER)
<b>Self-management or supported self-management services</b> <i>(e.g. online, tele- and/or home-based services)</i> <i>(continuation)</i>	<p><b>The Your COVID Recovery Online Programme:</b> a password-protected web app available on a computer, tablet device or smartphone. Access is only available after a referral to the programme by a healthcare professional who provides patients with a unique code for registration. The programme contains:</p> <ul style="list-style-type: none"> <li>■ 4 stages with a variety of tasks guiding pts. through the programme.</li> <li>■ Encouragement to set goals &amp; learn to choose the resources to achieve the goals.</li> <li>■ 14 resources packed full of information and videos to aid recovery, e.g. about supporting mental health, supporting movement, symptom management &amp; nutritional advice.</li> <li>■ Optional activity challenge.</li> <li>■ Symptom thermometer: tracking the changes in the persistent symptoms.</li> <li>■ Chat: directly with a healthcare professional or joining in the community forum.</li> </ul> <p>Patient organisation: Long COVID Support [47].</p> <p><i>Local-level (e.g. Leeds):</i> In addition to the national “Your COVID-19 Recovery Platform”, other online sources are offered on the local level. Mainly symptom-specific offers, e.g. in Leeds: “Leeds COVID rehab guide”, “Leeds Mental Well-being Service”, “Coping with COVID-19”, “8-week Virtual Fatigue Management Course” [26].</p>			
<b>Multidisciplinary rehabilitation clinic/centre (inpatient/partially inpatient/outpatient)</b>	<p>Rehabilitation is mostly offered on a local level, e.g. the post-COVID assessment outpatient clinics sometimes offer rehabilitation themselves [29].</p> <p><i>Local-level (e.g. Stanford):</i> <b>The Defence Medical Rehabilitation Centre</b> at Stanford Hall is running a 2-week residential intervention for long COVID pts. &amp; a concurrent research study to evaluate the programme [8].</p>	<p><i>National level:</i> The Federal Center for Healthcare did a call in May to supply funding for rehabilitation programs for long COVID patients. In October, they will decide who gets the money (expert information).</p>	<p>Long COVID rehabilitation offers are regulated on the local level.</p> <p><i>Local-level (e.g. Lombardy):</i> San Raffaele Hospital have <b>post-COVID rehabilitation wards</b> for COVID-19 pts. who had experienced prolonged admission to ICU [28].</p> <p><i>Another local example:</i> Other services e.g. by <b>AbilityAmo</b>, a non-profit organisation, provide <b>rehabilitation interventions</b> for post-COVID disability and fragility: specialist interventions (both in hospitals &amp; at home), psychological support, neurological, respiratory &amp; cognitive post-admission rehabilitation &amp; telemonitoring systems [28].</p>	<p><i>National level:</i> Currently, there are around 15 providers of long COVID inpatient rehabilitation programmes. Generally, 3-6 week-stays are offered at rehabilitation clinics of various specialities including specialities in long COVID (expert information). E.g. there are rehabilitation clinics specialised in chronic fatigue pts. [54].</p>
<b>Specialised care offers</b>	No examples	No examples	No examples	No examples
<b>Community health services &amp; non-medical healthcare providers</b>	<p>Community health services are regulated and offered on the local level. For example, specialist nursing functions such as district nursing, community nursing, psychiatric nursing, clinical nurse specialists and general practice nurses support the treatment of pts. and wider family members where appropriate [23].</p>	No examples	<p>Generally, long COVID management in primary &amp; secondary care is facilitated through <b>community care networks</b> including a combination of reconverted community hospitals,</p>	<p>Especially, for pts. with mild to moderate symptoms that can be treated by one specific discipline, outpatient therapies of non-medical healthcare providers (e.g. physiotherapy, occupational therapy, psychotherapy, speech therapy, nutritional counselling, nursing services) can be applied [13].</p>

Country	United Kingdom (UK)	Belgium (BE)	Italy (IT)	Germany (GER)
<b>Community health services &amp; non-medical healthcare providers</b> (continuation)	<i>A local example (e.g. Leeds):</i> Part of the <i>three-tier service model</i> : 2. tier) <b>Community therapy teams</b> for long COVID pts. with low/moderate symptoms that are adequately met by a single discipline, such as occupational therapy, physiotherapy, dietetics, speech & language therapy. Community therapy teams primarily address usual discharge support for hospitalised pts. or needs primarily arising from other pre-existing conditions [26].		healthcare hotels, nursing homes (new role of community nurses) & low-intensity residential facilities [28].	
<b>Additional (social) services</b>				
<b>Cash payments</b> (e.g. sick leave, early retirement)	The <b>usual rules for sickness absence &amp; sick pay</b> apply when someone is off work because of COVID or long COVID [64].	No information available	No information available	No information available
<b>Contributions in kind</b>				
<b>Social care services</b>	<b>Social prescribing</b> people are referred to a link worker, who gives people time, focusing on 'what matters to me' and taking a holistic approach to people's health and wellbeing. People are connected to community groups & statutory services for practical and emotional support, e.g. locally available health promotion measures, sports & exercise programmes, nutritional counselling to social, debtor, employment and housing counselling, debt counselling, employment counselling, and housing counselling, as well as community activities, such as senior dances, hiking groups, and neighbourhood networks [65].	No examples	No examples	No examples
<b>Employment</b>	No long COVID specific offers, same offers as for other illnesses, for example: <i>National level:</i> <b>Fit for work</b> is a government-funded service that offers free expert & impartial work-related health advice. Anyone looking for guidance about work-related health issues can call the free telephone advice line [64]. <b>Fit note:</b> if off work for >7 days & fit enough to work. The doctor or other healthcare professional will give a fit note if the person's health affects their fitness to work. If the employer agrees, a similar document can be provided by a physiotherapist, podiatrist or occupational therapist instead. This is called an <b>Allied Health Professional (AHP) Health and Work Report</b> [58]. <b>Phased return:</b> Possible support for pts. in discussions with their employer(s) or colleague(s) about returning to work (NICE's guideline on workplace health: long-term sickness absence and capability to work).	No examples	No examples	No long COVID specific offers, same offers as for other illnesses, for example: <i>National level:</i> <b>Transitional allowance:</b> The "Deutsche Rentenversicherung" (DRV) provides services to facilitate participation in working life, e.g. by financing further training & re-training [13]. <b>Gradual reintegration</b> after illness (also "Hamburger Model"): If employees are unable to work for >6 weeks or repeatedly, they have the right to the employer's support in gradually returning to work [66]. <b>Occupational disease:</b> Long COVID is also an occupational disease, e.g. in healthcare or welfare workers. Corresponding benefits come from employer-financed occupational accident insurance associations, which are often greater than those provided by health insurance funds. If the occupational disease is suspected a report must be made to the responsible employers' liability insurance association in accordance with No. 3101 of Annex 1 to the Occupational Diseases Ordinance [33].

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, ICU – Intensive care unit, MDT – Multidisciplinary team, NHS – National Health Service, NICE – National Institute for Health and Care Excellence, pts. – patients

## Expert consultation

Table A-13: Experts contacted about examples of already existing long COVID care structures in their countries

Country	Field of activity	Contacted	Answer	Information
UK	An expert from the NHS	May 2021	19.05.2021	Information about NHS Improvement's 5-Point plan including NHS Your Covid Online Recovery.
Belgium	Practitioner	07.07.2021		No answers
	Practitioner	07.07.2021		No answer
	Practitioner	07.07.2021		No answer
	Practitioner	07.07.2021		No answer
	Patient organisation	11.08.2021	17.08.2021	<p>At the moment, there aren't a lot of established structures for Long COVID in Belgium, but I'll do my best to give an overview:</p> <ul style="list-style-type: none"> <li>■ <b>Primary care:</b> GP's don't know enough about long COVID and often don't know to which clinics they can refer people. Existing info on the subject isn't passed on to those in the field. There is quite some confusion in primary care.</li> <li>■ <b>Guidelines:</b> There is a governmental assignment to write guidelines on how to treat people who've had COVID in primary care, but these guidelines aren't ready yet. The deadline is May 2022. The guidelines are restricted to people who were hospitalised after COVID.</li> <li>■ <b>Hospitals:</b> Of the 30 Flemish hospitals, 20 offer "something" to people who had COVID. What they offer is different from clinic to clinic and the inclusion criteria are also diverse. Some clinics only allow people who were hospitalised in their clinic.</li> <li>■ <b>Rehabilitation programs:</b> The Federal Center for Healthcare did a call in May to supply funding for rehabilitation programs. In October, they will decide who gets the money.</li> <li>■ <b>General:</b> If healthcare workers know long COVID exists, their knowledge is often still fragmented. This causes a lot of misunderstandings in the field and can cause harm to patients.</li> </ul>
Italy	An expert from the Ministry of health	06.07.2021	02.08.2021	The Italian health system provides some centralised guidance while leaving the deployment and implementation of services very much up to the single regional health system. Therefore it is quite difficult to pinpoint someone that could provide you with an overall picture. I am attaching a recently published document from the Istituto Superiore di Sanità (which is a national body that provides guidance). It is in Italian. You will see that it is mainly a reproduction of the UK guidance on Long-COVID. You can contact the first author of the document. From my end, the Emilia-Romagna Region, we are going to develop an update of the initial regional guidance (which had initially focused only on the follow-up of patients who had been hospitalised and experienced quite severe illness).
	An expert from the National Institute of Health ( <i>suggested first author</i> )	02.08.2021		No answer
Germany	An expert from the IQWiG	06.07.2021	06.07.2021	<p>Plans for structuring the care algorithm for long COVID (GBA):</p> <p><a href="https://www.bundestag.de/dokumente/textarchiv/2021/kw23-pa-gesundheit-longcovid-844332">https://www.bundestag.de/dokumente/textarchiv/2021/kw23-pa-gesundheit-longcovid-844332</a></p> <p><a href="https://dserver.bundestag.de/btd/19/292/1929267.pdf">https://dserver.bundestag.de/btd/19/292/1929267.pdf</a></p> <p><a href="https://dserver.bundestag.de/btd/19/292/1929270.pdf">https://dserver.bundestag.de/btd/19/292/1929270.pdf</a></p>
	Practitioner ( <i>suggested by the IQWiG expert</i> )	07.07.2021		No answer

Country	Field of activity	Contacted	Answer	Information
Germany (cont.)	Patient organisation	11.08.2021	12.08.2021	An overview of the outpatient long COVID services established in Germany can be found here ( <a href="https://longcoviddeutschland.org/post-covid-19-ambulanzen/">https://longcoviddeutschland.org/post-covid-19-ambulanzen/</a> ). Currently, there are about 60 dedicated outpatient clinics of different specialities at clinical institutions. The aim is that outpatient care for long COVID patients in Germany is primarily provided by physicians in private practice. A guideline for this has recently been published ( <a href="https://www.awmf.org/leitlinien/detail/II/020-027.html">https://www.awmf.org/leitlinien/detail/II/020-027.html</a> ). An overview of inpatient rehabilitation services can be found here ( <a href="https://longcoviddeutschland.org/post-covid-19-rehabilitation/">https://longcoviddeutschland.org/post-covid-19-rehabilitation/</a> ). These are usually 3-6 week stays at rehabilitation clinics of various specialities, which are increasingly specialising in post-COVID patients. I would recommend that you also take a look at what the NHS has to offer ( <a href="https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/">https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/</a> ). In addition, I would like to refer you to our partner initiative in Austria: <a href="https://www.longcovidustria.at">https://www.longcovidustria.at</a> . Please contact the responsible persons of the initiative (if there is no exchange yet), who can give you an assessment of the needs in Austria.
Austria	An expert from the ÖGK	06.08.2021		No answer
	Patient organisation	11.08.2021		No answer

Abbreviations: COVID – Coronavirus disease, GBA – Gemeinsamer Bundesausschuss, IQWiG – Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen, NHS – National Health Service, ÖGK – Österreichische Gesundheitskasse, UK – United Kingdom

## Search strategies

### Search strategy for Cochrane

Search date: 29/04/2021	
ID	Search
#1	("long covid*") (Word variations have been searched)
#2	(Post-COVID-19 syndrom*) (Word variations have been searched)
#3	("post covid*" NEAR (syndrom* OR disease* OR disorder* OR condition* OR illness* OR sickness* OR trauma*)) (Word variations have been searched)
#4	((("long-term" OR "long-lasting" OR "long haul*" OR chronic OR sequela* OR "post-acute" OR postacute) NEAR (covid* OR "SARS-CoV*" OR "coronavirus disease 2019" OR "corona-virus disease 2019")):ti,ab,kw (Word variations have been searched)
#5	#1 OR #2 OR #3 OR #4 (Word variations have been searched)
Total: 106 Hits	

### Search strategy for Embase

No.	Query Results	Results	Date
#6.	#5 AND ([english]/lim OR [german]/lim)	554	27 <sup>th</sup> April 2021
#5.	#1 OR #2 OR #3 OR #4	555	27 <sup>th</sup> April 2021
#4.	('long-term' OR 'long-lasting' OR 'long haul*' OR chronic OR sequela* OR 'post-acute' OR postacute) NEAR/2 (covid* OR 'sars cov*' OR 'coronavirus disease 2019' OR 'corona-virus disease 2019')	347	27 <sup>th</sup> April 2021
#3.	'post covid*' NEAR/6 (syndrom* OR disease* OR disorder* OR condition* OR illness* OR sickness* OR trauma*)	128	27 <sup>th</sup> April 2021
#2.	'post-covid-19 syndrom*'	24	27 <sup>th</sup> April 2021
#1.	'long covid*'	137	27 <sup>th</sup> April 2021

### Search strategy for Medline via OVID

Database: Ovid MEDLINE(R) and In-Process & Other Non-Indexed Citations and Daily <1946 to April 23, 2021>, Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <2017 to April 23, 2021>	
Search Strategy:	
1	long covid*.mp. (259)
2	Post-COVID-19 syndrom*.mp. (44)
3	(post covid* adj (syndrom* or disease* or disorder* or condition* or illness* or sickness* or trauma*)).mp. (37)
4	((long-term or long-lasting or long haul* or chronic or sequela* or post-acute or postacute) adj2 (covid* or SARS-CoV* or coronavirus disease 2019 or corona-virus disease 2019)).mp. (681)
5	1 or 2 or 3 or 4 (916)
6	limit 5 to (english or german) (900)
7	remove duplicates from 6 (501)
Search date: 27.04.2021	

### Search strategy for HTA-INAHTA

Search step: Search query, "Hits", "Searched At"	
3	("post-covid*") OR ("long covid*"), "0", "2021-04-29T13:53:52.000000Z"
2	"post-covid*", "0", "2021-04-29T13:53:52.000000Z"
1	"long covid*", "0", "2021-04-29T13:53:52.000000Z"
Search date: 29.04.2021	



**HTA Austria**

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