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Long COVID care pathways and structures: an updated scoping review

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Long COVID care pathways and structures: an updated scoping review

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Project team

Project leader: Sarah Wolf, MSc

Authors: Sarah Wolf, MSc

Project Support

Hand searches: Sarah Wolf, MSc

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

Correspondence: sarah.wolf@aihta.at

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List of abbreviations

ACS .....Acute coronary syndrome
ANZICS .....Australian and New Zealand Intensive Care Society
AOK .....Allgemeine Ortskrankenkasse (engl. General Local Health Insurance)
AT.....Austria
AUS .....Australia
AUVA.....Allgemeine Unfallversicherung (engl. Austrian General Accident Insurance)
BE.....Belgium
bzgl. .....bezüglich (engl. regarding)
ca. .....zirka
CAN .....Canada
CDC .....Centers for Disease Control and Prevention
CFS .....Chronic fatigue syndrome
CH.....Switzerland
COVID.....Coronavirus disease
DE .....Deutschland (Germany)
engl.....English
ESCMID .....European Society of Clinical Microbiology and Infectious Diseases
ES .....Spain
EWMHS.....Emotional Wellbeing and Mental Health Service
FF.....Forschungsfrage
GBA.....Gemeinsamer Bundesausschuss (engl. Federal Joint Committee)
ggf.....gegebenenfalls
GP.....General practitioner
HDU.....High dependency unit
HS.....Hand search
IAPT.....The Improving Access to Psychological Therapies
ICD .....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
MIS-C.....Multisystem inflammatory syndrome in children
NHS.....National Health Service
NICE.....National Institute for Health and Care Excellence
NIHR .....National Institute for Health Research
NIPH.....Norwegian Institute of Public Health
NL .....The Netherlands
NO.....Norway
NZ .....New Zealand

ÖGK .....Österreichische Gesundheitskasse (engl. Austrian Health Insurance)
Pat. .....Patient*innen
PCI .....Personalised Care Institute
PICS .....Post-intensive care syndrome
PIMS .....Paediatric inflammatory multisystem syndrome
PPCS .....Persistent post-COVID syndrome
Pts.....Patients
QoL .....Quality of life
RACGP .....Royal Australian College of General Practitioners
RCGP .....The Royal College of General Practitioners
SARS-CoV-2 ....Severe acute respiratory syndrome coronavirus 2
SENDco .....Special Educational Needs and Disability Coordinators
SIGN .....The Scottish Intercollegiate Guidelines Network
SS.....Systematic search
TA.....Techniker Krankenkasse
UK.....United Kingdom
USA.....United States of America
vs.....Versus
WHO .....World Health Organization

Executive summary

Background and research aim

Long COVID involves 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. 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. However, especially in children and adolescents, the prevalences remain uncertain. In addition to long COVID, children may, in rare cases, suffer from multisystem inflammatory syndrome (MIS-C), a rare but severe condition in which different body parts become inflamed, including the heart, lungs, kidneys, brain, skin, eyes, or gastrointestinal organs.

long COVID involves several different symptoms

prevalences, especially in children & adolescents, are uncertain

a few children may suffer from MIS-C

The disease can impact the patients' everyday functioning, including long absenteeism in school, training or work. Thereby, it may also affect the broader economy. For these reasons, long COVID care planning has gained more weight in political decisions.

long COVID can impact the broader economy → care planning is crucial

The present scoping review aimed to update the recommendations on care pathways and other support services for adult long COVID patients and add recommendations for children and adolescents. In addition, it presents identified long COVID care structures of selected European countries for children, adolescents and adults.

updated recommendations for adults + newly identified recommendations for children & adolescents

Methods

Next to the systematic search and additional hand searches conducted for the original report published in October 2021, update hand searches were performed until the beginning of July 2022 to identify further guidelines. In order to retrieve more information about existing long COVID care structures, websites of relevant institutions and care facilities were searched (last update: August 2022). In addition, experts from the selected European countries (UK, Norway, Belgium, Germany, Switzerland, Italy and Spain) were contacted. The newly identified information extended the data extraction tables of the original report. Overall, the total body of information was narratively summarised for each research question.

systematic & hand searches from the original report + update hand searches & contact with further experts

Results

Based on the updated inclusion criteria, 24 references, including 15 (standardised) guidelines (2 updates and 10 new ones), as well as four reviews and five expert papers from the original report, were considered. Thirteen of the 15 guideline documents included recommendations for adult patients and nine documents for children and adolescents. Two of the nine documents focused solely on children and adolescents. The information about existing long COVID care structures was updated for the UK, Belgium, Germany and Italy and newly added for Norway, Switzerland and Spain.

15 guideline documents (10 new ones): 13/15 for adults, 9/15 for children & adolescents

3 additional countries

primary care is recommended as the first point of contact for most long COVID patients (pts.)

The included literature recommended that most long COVID-related healthcare should take place in primary care (e.g. general practitioners, primary care centres or paediatricians). However, in some countries (e.g. the UK, the Netherlands, Italy, Spain and the USA), former hospitalised COVID-19 patients, who suffer from ongoing or new symptoms 12 weeks after discharge, can also go to hospital outpatient departments for a clinical assessment.

caregivers are crucial in long COVID care for children

Regarding long COVID care for children and adolescents, practising physicians should acknowledge the parents and caregivers as one of the most important pillars and support them with all necessary information about the diagnosis and treatment of the disease, as well as useful social and financial support.

referral to specialised long COVID centres for pts. with more complex symptoms,

"one-stop assessments" especially for children

Patients with possibly life-threatening symptoms, e.g. adults with severe lung disease or children with the MIS-C, should be referred to acute services. Patients with no severe but more complex symptoms persisting for four to 12 weeks after the acute infection can be referred to specialised long COVID outpatient assessment clinics, if available. Thereby, "one-stop assessments" where consultations with various specialists and diagnostic tests are concentrated on a single day are particularly recommended for children and adolescents to avoid multiple referrals.

further referrals to specialists, rehabilitation or specific therapies are possible when needed

psychological support for caregivers of affected children should also be considered

Patients, including children and adolescents with one dominant symptom that persists for more than four weeks post-infection should be referred to the respective specialist for further assessments and treatments, e.g. pulmonologist, cardiologist, neurologist or psychologist. In addition, depending on the patients' needs and the availability of care, they can be referred to multidisciplinary inpatient, partial inpatient or outpatient rehabilitation programmes. These programmes can include physical, cognitive and/or psychological elements. Besides, the patients can be referred to specialised therapies, such as psychotherapy, physiotherapy and speech therapy. Psychological support may also be necessary for parents and caregivers of affected children and adolescents.

self-management is another important aspect for successful long COVID care

Next to primary care, self-management is often recommended to long COVID patients and/or caregivers, including exercising at home, nutritional management and stress reduction, but also participation in long COVID programmes online or via App. According to the recommendations, self-management can function as a single therapy for milder long COVID symptoms or supportive in addition to other treatments for moderate to severe symptoms.

same (social) support as for other diseases suggested for long COVID pts.

Concerning additional (social) support for long COVID patients, no recommendations regarding long COVID-specific offers could be identified. In general, the same support as for other (chronic) illnesses, including financial and social support, such as sick leave, support groups and social prescribing, as well as employment- or school-specific services, like gradual re-integration, were also suggested for long COVID patients.

existing care structures correspond to the identified recommendations

Most of the existing long COVID care structures in the seven analysed countries complied with the identified recommendations. In particular, the UK rapidly adapted its healthcare structures by fastly implementing long COVID-specific care facilities. Nevertheless, the other countries have caught up on developing their specialised centres. In particular, online programmes or apps supporting the patients in self-management have increased.

In many countries, most long COVID care structures were built based on existing healthcare infrastructure. For example, in Germany, Switzerland and Austria, specialised long COVID centres were often integrated into hospital outpatient clinics that offer special consultation hours for detailed clinical assessments and recommendations about further specialist assessments and/or treatments.

long COVID care is often integrated into existing healthcare infrastructure

Discussion and conclusion

This update on recommended long COVID care pathways and existing support structures demonstrates once more that different medical and non-medical services are required for long COVID patients depending on their individual needs. In particular, primary and non-institutionalised care – including supported self-management – play an important role. However, apart from sufficient availabilities of services, one of the key factors of successful long COVID care is the cooperation of different medical and therapeutic disciplines from the health and social care sector (multidisciplinarity). Thereby, the patient's situation should always be considered (personalised approach). In addition, treatment decisions should always be made jointly by the doctors, therapists, patients, and, if necessary, caregivers (shared decision-making).

sufficiently available & appropriate offer of services is crucial

other key factors: multidisciplinarity, personalised approach & shared decision-making

Furthermore, good communication between physicians/therapists and patients/caregivers is another crucial aspect of successful long COVID care. Good communication takes into account or minimises, for example, cultural differences or language barriers. Moreover, it is essential to find the appropriate level of detail in the information provided to avoid unnecessary uncertainty among patients due to too much or too little information. This is especially important when communicating with younger patients. All necessary information should also be discussed with the children and adolescents, considering age-appropriate language.

inclusive and age-appropriate communication & right level of detail of information need to be considered

However, not all practising physicians are thoroughly familiar with the difficult diagnosis of long COVID. In particular, the severity of some common long COVID symptoms, like fatigue or psychological issues, is hard to detect. The diagnosis of long COVID becomes even more complicated for younger children who have difficulties in expressing their symptoms. For these reasons, practising physicians should receive continuous training about the disease itself, its diagnosis and management as soon as new evidence occurs. Several countries (e.g. Germany) offer specific training courses.

long COVID diagnosis difficult to make, especially in younger children → regular training for physicians necessary

Besides, there are different possibilities where long COVID patients can be referred to after the diagnosis, e.g. to specialised outpatient clinics, medical specialists, rehabilitation programs and/or therapists. Thus, when deciding on a referral the doctors should consider that several referrals to different physicians or therapists can be associated with additional stress for the patients and/or caregivers. These burdens can be because of increased travel time, additional travel costs or emotional stress due to conflicting opinions of different doctors. Moreover, the recommended self-management can also be associated with great responsibility and an additional burden for the patients.

multiple referrals can cause additional burdens for patients

self-management can also be stressful

From an economic perspective, setting up long COVID care structures, particularly in the primary care sector, can lead to resource shortages (e.g. long waiting lists). Hence, additional human resources need to be considered, such as providing primary care centres with other support staff in the areas concerned most (e.g. rehabilitation, mental health).

concerns about resource capacities → further staff needed?

long COVID care = interplay of different, fragmented systems, e.g. healthcare, social care, employment/education system & family

Overall, long COVID care comes with the interplay of various systems next to the healthcare system, including the social care system, employment or education system and the family. This interplay is essential when it comes to the care of children and adolescents. Therefore, planning long COVID care structures requires coordinating support across these different and usually fragmented systems and guaranteeing care that addresses the individual needs of patients and their families. However, further high-quality evidence on the long-term prevalence, especially in children and adolescents, is needed for accurate long COVID care planning.

Detailed overview of what is new

New evidence

Two updates of previously included documents (NICE, CDC) and 10 additional documents from Italy, Spain, the ESCMID, USA, Canada, Australia, New Zealand and the WHO were newly identified. 2/10 new documents (Italy and USA) focused on long COVID care recommendations for children and adolescents.

Recommendations on possible first points of contact

- GPs and primary care centres remain the first point of contact for all patients with persistent symptoms in most of the countries. Children and adolescents or their caregivers may also consult primary care paediatricians.
- Next to the UK, in the USA, the Netherlands, also in Italy and Spain, former hospitalised COVID-19 patients can contact the hospital outpatient departments as a first step.
- „Healthcare appointment checklists" are recommended to show patients how to best prepare for the appointment, e.g. which documents and types of information are needed from the doctors. Thereby, such checklists can support physicians in saving time during assessments.
- Regarding long COVID care for children and adolescents, GPs should acknowledge that the parents and caregivers as the most important pillar and support them with all necessary information about the diagnosis and treatment of the disease but also about useful social and financial support.

Recommendations on possible referrals

- Apart from long COVID, a few children might suffer from the multisystem inflammatory syndrome after the acute SARS-CoV-2 infection. For those, the admission to paediatric or cardiac ICU might be necessary. However, for most children and adolescents who have persistent symptoms after the infection, primary care and self-management is expected to be sufficient.
- For patients with 1 dominant symptom and the need of a specific discipline, a referral to a specialist for further assessment and/or treatment is also recommended in the newly identified documents. For children and adolescents, specialist peadiatric advice should be considered if symptoms persist for >4 weeks post-infection.
- For patients with more complex symptoms persisting >12 weeks post-infection, a referral to a specialised long COVID outpatient assessment clinic is indicated, also according to the newly identified documents. In the UK and Italy, „one-stop assessments" are recommended to avoid multiple referrals, especially for children and adolescents.
- Multidisciplinary rehabilitation (inpatient or outpatient) can be recommended to children, adolescents and adults with more complex persisting symptoms as the first preference or as bridging operation until specialised services are available.
- Concerning long COVID self-management, advice for adult patients or families with affected children can come directly from practicing physician or from Apps, online programmes or support groups. When apps are recommended, potential limitations should be considered, including e.g., applicability and adherence issues, data protection issues, missing evidence on effectiveness and safety, and potential conflicts of interest of providers.

Recommendations on additional services

It emerges that long COVID care, especially for children and adolescents, require the interplay of different systems including the healthcare system (GPs and/or specialists), the school (e.g. administrators, counselors and/or nurses), social care (e.g. financial support, social workers), the employer of the caregiver and the family.

Further recommendations for practicing physicians

- Especially when working with children and adolescents, shared decision-making between doctors, patients and caregivers is crucial to avoid unnecessary investigations that can cause anxiety. Thus, empathy towards the patients and person-centred approaches are key factors for successful long COVID care.
- As practicing physicians need to continuously be updated on new evidence regarding the long COVID diagnosis and management, several countries have developed or are developing trainings and tools. For example, there are trainings at the University Hospital Charité in Berlin and in Belgium and Spain, long COVID guidances for healthcare workers are currently in development.

Newly implemented long COVID structures

- Next to care offers for adults, there are also specialised offers for children and adolescents, including for example, specialised long COVID outpatient centres in the UK, Germany, Switzerland and Italy, multidisciplinary rehabilitation in Switzerland, and children specific support groups for parents and caregivers in the UK, Germany and Switzerland.
- In the last year, German speaking apps were introduced to support long COVID patients in self-management, such as the „Long-Covid Tagebuch App" and „INSELhealth Cofit app" from Switzerland and the „FIMO-App" from Germany.
- In addition, different support networks have been introduced to offer guidance for several stakeholders, including employers, managers, schools, patients and caregivers.

Zusammenfassung

Hintergrund und Projektziel

Long-Covid umfasst mehrere verschiedene Symptome,

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. Vor allem bei Kindern und Jugendlichen ist die Prävalenz jedoch nach wie vor unsicher. In seltenen Fällen kann bei Kindern unabhängig von Long-Covid nach einer akuten Infektion ein multisystemisches Entzündungssyndrom auftreten. Dabei handelt es sich um eine seltene, aber schwere Erkrankung, bei der sich verschiedene Körperteile entzünden können, darunter Herz, Lunge, Nieren, Gehirn, Haut, Augen oder Magen-Darm-Organe.

Häufigkeit von Long-Covid insbesondere bei Kindern noch unsicher

einzelne Kinder können am multisystemischen Entzündungssyndrom leiden

Long-Covid neben individuellen auch gesellschaftliche Auswirkungen

Long-Covid kann mit erheblichen Einschränkungen im Alltag einhergehen, einschließlich langer Fehlzeiten in der Schule oder Arbeit. Eine Analyse der deutschen Techniker Krankenkasse zeigte, dass Long-Covid Betroffene vergleichsweise lange krankgeschrieben sind. Im Jahr 2021 lag eine Krankschreibung für Long-Covid bei durchschnittlich 105 Tagen, während die durchschnittliche Krankschreibung aller Versicherter nur rund 15 Tage betrug. Dadurch belastet die Erkrankung nicht nur die Patient*innen sowie deren Familien, sondern auch die Wirtschaft, 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.

→ Planung geeigneter Versorgungsstrukturen wichtiger Bestandteil politischer Diskurse

Update der empfohlenen Long-Covid-Versorgungspfade & der bestehenden Strukturen für Erwachsene & ergänzend für Kinder & Jugendliche

Der vorliegende Bericht bietet ein Update zu den aktuellen Empfehlungen möglicher Versorgungspfade für erwachsene Long-Covid Patient*innen. Zusätzlich fasst dieser Bericht auch die Empfehlungen für Kinder und Jugendliche zusammen.

Darüber hinaus präsentiert der vorliegende Bericht einzelne Beispiele zu bereits bestehenden Versorgungsstrukturen ausgewählter europäischer Länder für Kinder, Jugendliche und Erwachsene, nämlich aus dem Vereinigten Königreich (UK), Norwegen, Belgien, Deutschland, Österreich, Schweiz, Italien und Spanien.

Methode

systematische Suche & Handsuchen des Originalberichts + Update-Handsuchen bis Anfang Juli 2022

Neben der systematischen Suche und den Handsuchen, die für den Originalbericht 2021 durchgeführt wurden, wurden bis Anfang Juli 2022 Update-Handsuchen durchgeführt, um weitere Long-Covid Leitlinien zu identifizieren.

zusätzlich: gezielte Recherchen nach Versorgungsstrukturen (Letztstand: August 2022)

Darüber hinaus wurden zahlreiche Internetrecherchen nach relevanten Institutionen (z. B. Long-Covid Patient*innen-Organisationen) und Versorgungseinrichtungen (z. B. Long-Covid Spezialambulanzen und Rehabilitationen) in den ausgewählten europäischen Ländern bis Anfang August 2022 durchgeführt. Für weitere nicht publizierte Informationen 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 Länder kontaktiert.

Die Daten aus den identifizierten Quellen wurden in die Tabellen des Originalberichts integriert und anschließend für jede Forschungsfrage narrativ zusammengefasst.

Update der originalen Datenextraktionstabellen

Empfehlungen zur Long-Covid-Versorgung

Eingeschlossene Literatur

Basierend auf den angepassten Einschlusskriterien für diesen Update-Bericht konnten insgesamt 24 Referenzen eingeschlossen werden. Dabei handelte es sich um 15 teilweise standardisierte Leitlinien, darunter zwei Updates und zehn neue, sowie vier Übersichtsarbeiten und fünf Expert*innen-Papiere aus dem Originalbericht. Dreizehn der 15 Leitliniendokumente enthielten Empfehlungen für erwachsene Patient*innen und neun Dokumente für Kinder und Jugendliche, wobei zwei der neun Dokumente ausschließlich auf Kinder und Jugendliche fokussiert waren.

insgesamt 24 Referenzen, darunter 15 Leitlinien (2 Updates & 10 neue), 4 Reviews & 5 Expert*innen-Papiere

Für die Beantwortung der Fragen hinsichtlich den bestehenden Long-Covid-Versorgungsstrukturen wurden die Beispiele zu Versorgungsstrukturen in dem UK, Belgien, Deutschland und Italien upgedated und weitere Beispiele aus Norwegen, der Schweiz und Spanien ergänzt.

Beispiele zu Versorgungsstrukturen aus drei neuen Ländern ergänzt

Erste Anlaufstelle für Long-Covid Patient*innen

Der eingeschlossenen Literatur zufolge soll der Großteil der Long-Covid-Versorgung in der Primärversorgung (z. B. bei Allgemeinmediziner*innen, in Primärversorgungszentren oder bei niedergelassenen Kinderärzt*innen) stattfinden. In einigen Ländern (z. B. im UK, in den Niederlanden, in Italien, Spanien und den USA) können Covid-19-Patient*innen, die während der akuten Infektion im Krankenhaus behandelt wurden und 12 Wochen nach ihrer Entlassung unter anhaltenden oder neuen Symptomen leiden, zur klinischen Beurteilung auch in die Krankenhausambulanzen gehen.

Großteil der Long-Covid-Versorgung sollte im Primärsektor stattfinden

Eltern und Erziehungsberechtigte sind eine der wichtigsten Säulen in der Long-Covid-Versorgung von Kindern und Jugendlichen. Demnach sollten Entscheidungen gemeinsam mit Kindern bzw. Jugendlichen, Eltern bzw. Erziehungsberichtigen und Ärzt*innen getroffen werden und alle Beteiligten ausreichend über die Diagnose und Behandlung der Erkrankung, sowie über mögliche soziale und finanzielle Unterstützungen informiert werden.

Shared Decision-Making zwischen Ärzt*innen, Eltern & Kindern wichtig

Mögliche weitere Überweisungen

Patient*innen, bei denen schwerwiegende bzw. lebensbedrohliche Symptome während der Erstuntersuchung festgestellt werden, z. B. schwerwiegende Lungenerkrankungen bei Erwachsenen oder das multisystemische Entzündungssyndrom bei Kinder, 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“ überwiesen werden. Diese multidisziplinären Ambulanzen dienen einer weiteren umfassenden Untersuchung und können die Patient*innen bei Bedarf weiter überweisen. In manchen Ländern (z. B. Italien und den USA) bieten diese Spezialambulanzen sogenannte „One-Stop Assessments“ an, bei denen Konsultationen mit verschiedenen Fachärzt*innen und

Pat. mit komplexen Symptomen können an Spezialambulanzen überwiesen werden

„Ein-Tages-Untersuchungen“ insbesondere für Kinder & Jugendliche empfohlen → Vermeidung von Mehrfachüberweisungen

diagnostische Tests an einem Tag durchgeführt werden. Solche „Ein-Tages-Untersuchungen" werden insbesondere für Kinder und Jugendliche empfohlen, um multiple Überweisungen zu vermeiden.

bei Pat. mit 1 dominanten Symptom → Überweisung an entsprechende Spezialist*innen empfohlen

Patient*innen, einschließlich Kinder und Jugendliche, mit *einem* dominanten Symptom sollten zur weiteren Abklärung an den/die jeweilige/n Fachärzt*in überwiesen werden, z. B. Lungenfachärzt*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. Darüber hinaus können Long-Covid Patient*innen auch an einzelne nicht-ärztliche Gesundheitsdienstleister (z. B. Physiotherapeut*innen, Ergotherapeut*innen, Logopäd*innen) überwiesen werden. Auch für die Eltern und Erziehungsberechtigten der betroffenen Kinder und Jugendlichen kann eine psychologische Unterstützung hilfreich sein. Der Zeitpunkt für solche Überweisungen sollte vom Schweregrad des Symptoms abhängig gemacht werden.

anschließende Optionen, z. B. Rehabilitation oder spezifische Therapien, eventuell auch für betreuende Erziehungsberechtigte

Selbstmanagement von Patient*innen

Selbstmanagement: wesentlicher Bestandteil der Empfehlungen zur Long-Covid-Versorgung

Neben der Primärversorgung stellt das Selbstmanagement einen weiteren wichtigen Bestandteil der Empfehlungen zur Long-Covid-Versorgung 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 oder die Teilnahme an Programmen, die mittels spezifische Apps angeboten werden. Den Empfehlungen zufolge kann Selbstmanagement entweder als alleinige Therapie bei milderen Symptomen eingesetzt werden oder als Ergänzung zu anderen Behandlungen bei moderaten bis schweren Symptomen hilfreich sein.

Weitere (soziale) Leistungen

dieselben zusätzlichen (sozialen) Leistungen wie für Pat. mit anderen (chronischen) Krankheiten auch für Long-Covid Pat. Empfohlen

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. Für Schüler*innen werden Unterstützungsmöglichkeiten für die Rückkehr an die Schule empfohlen. Dazu zählen beispielsweise eine schrittweise Rückkehr, mehr Pausen im Schulalltag, mehr Zeit für Tests oder besonderes Equipment.

z. B. schrittweise Rückkehr an Arbeitsplatz oder Schule

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.

Long-Covid-Versorgungsstrukturen in Europa

bestehende Long-Covid-Versorgungsstrukturen entsprechen den Empfehlungen → rasche Adaptierungen im UK

Bezüglich den identifizierten bestehenden Long-Covid-Versorgungsstrukturen in den ausgewählten europäischen Ländern war ersichtlich, dass diese grundsätzlich mit den beschriebenen Empfehlungen übereinstimmten. Unter den analysierten europäischen Ländern wurden vor allem im UK rasche Anpassungen im Gesundheitswesens, etwa die Errichtung von Long-Covid Spezialambulanzen, durchgeführt. Die anderen Länder haben mittlerweile jedoch bei der Entwicklung von spezialisierten Zentren aufgeholt. Besonders die Angebote von Online-Selbstmanagement-Programmen oder Apps wurden ausgebaut.

In vielen Ländern wurden Long-Covid-Versorgungsstrukturen unter Berücksichtigung der bereits bestehenden Infrastruktur aufgebaut. In Deutschland, der Schweiz und Österreich wurden beispielsweise Long-Covid Spezialambulanzen oft an Krankenhausambulanzen angegliedert, die nun spezielle Sprechstunden für Long-Covid Patient*innen anbieten. In solchen Sprechstunden werden Empfehlungen zu umfangreichen klinischen Untersuchungen und/oder Behandlungen diskutiert.

Long-Covid-Versorgungsstrukturen oft in bestehende Infrastrukturen integriert

Diskussion und Konklusion

Dieses Update der Empfehlungen zu Long-Covid-Versorgungspfaden zeigt unverändert, dass für eine bedarfsorientierte Versorgung unterschiedliche medizinische und nicht-medizinische Leistungen erforderlich sind. Dabei spielen insbesondere die Primärversorgung und die nicht-institutionalisierte Versorgung (inklusive unterstütztem Selbstmanagement) sehr wichtige Rollen. Abgesehen von einer ausreichenden Verfügbarkeit von Versorgungsangeboten ist jedoch ein Schlüsselfaktor einer erfolgreichen Long-Covid-Versorgung 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, Therapeut*innen, Patient*in und wenn nötig den Erziehungsberechtigten getroffen werden (Shared Decision-Making).

ausreichende Verfügbarkeit von notwendigen Versorgungsstrukturen wichtig

weitere Schlüsselfaktoren: Multidisziplinarität, personalisierter Ansatz & Shared Decision-Making

Eine gute Kommunikation zwischen den Ärzt*innen bzw. Therapeut*innen und den Patient*innen bzw. Erziehungsberechtigten stellt einen weiteren wichtigen Aspekt einer erfolgreichen 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. Dies ist insbesondere bei der Kommunikation mit jüngeren Patient*innen wichtig. Alle notwendigen Informationen sollten immer auch direkt mit den betroffenen Kindern und Jugendlichen in verständlicher Sprache besprochen werden.

inklusive bzw. altersgerechte Kommunikation & richtiger Detailgrad an Information sind ebenso zu berücksichtigen

Eine große Herausforderung bei der Versorgung von Long-Covid Patient*innen liegt jedoch in der Unsicherheit bezüglich der Diagnosestellung. Insbesondere Symptome, wie Müdigkeit/Erschöpfung oder psychische Störungen, sind nicht einfach objektiv zu erfassen. Noch komplizierter wird die Long-Covid-Diagnose bei jüngeren Kindern, die Schwierigkeiten haben, ihre Symptome umfassend zu äußern. Aus diesem Grund sollten praktizierende Ärzt*innen regelmäßige Schulungen mit aktuellen Informationen zur Diagnose und/oder zu möglichen Long-Covid-Managementstrategien erhalten. Einige Länder (z. B. Deutschland) bieten solche bereits konkret an.

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

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 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*in-

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

Selbstmanagement kann auch belastend sein

nen) Natur sein. Auch das empfohlenen Selbstmanagement kann mit einer großen Verantwortung und daher mit einer zusätzlichen Belastung für die Patient*innen einhergehen.

eventuelle Ressourcenengpässen → weiteres Personal notwendig

Aus wirtschaftlicher Sicht kann die Bereitstellung von Long-Covid-Versorgungsstrukturen, insbesondere im Bereich der Primärversorgung, auch Ressourcenengpässe (z. B. lange Wartezeiten für einen Untersuchungstermin) auslösen. Daher sollten auch zusätzliche Personalressourcen diskutiert werden, wie etwa die Bereitstellung von zusätzlichem Personal für die am häufigsten betroffenen Bereiche in der Primärversorgung (Rehabilitation, psychische Gesundheit, usw.).

Long-Covid-Versorgung = Zusammenspiel von teilweise stark fragmentierten Sektoren

weitere Prävalenzdaten notwendig

Alles in allem benötigt die Versorgung von Long-Covid Patient*innen ein Zusammenspiel verschiedener Systeme, darunter das Gesundheitssystem, Sozialsystem, Beschäftigungs- oder Bildungssystem und die Familie. Dieses sektorenübergreifende Zusammenspiel ist insbesondere hinsichtlich der Betreuung von Kindern und Jugendlichen von entscheidender Bedeutung. Die Planung von Long-Covid-Versorgungsstrukturen erfordert daher eine gute Koordinierung zwischen den verschiedenen und in der Regel stark fragmentierten Systemen und die Gewährleistung, dass die Versorgung auf die individuellen Bedürfnisse der Patient*innen und ihrer Familien eingeht. Für eine akkurate Versorgungsplanung sind jedoch weitere qualitativ hochwertige Daten zur Langzeitprävalenz, insbesondere bei Kindern und Jugendlichen, erforderlich.

Was ist neu? Eine detaillierte Übersicht

Neue Evidenz

Es wurden zwei Updates von bereits eingeschlossenen Leitlinien (NICE, CDC) und 10 zusätzliche Leitliniendokumente aus Italien, Spanien, der ESCMID, den USA, Kanada, Australien, Neuseeland und der WHO neu identifiziert. 2/10 neuen Dokumente (Italien und USA) fokussierten sich ausschließlich auf Empfehlungen für Kinder und Jugendliche mit Long-Covid.

Empfehlungen zu möglichen ersten Anlaufstellen

- In den meisten Ländern sind Hausärzt*innen und Primärversorgungszentren nach wie vor die erste Anlaufstelle. Bei Kindern und Jugendlichen können auch niedergelassene Kinderärzt*innen kontaktiert werden.
- Neben dem UK, den USA und den Niederlanden können auch in Italien und Spanien Krankenhausambulanzen erste Anlaufstellen für ehemalige hospitalisierte COVID-19 Patient*innen sein.
- "Checklisten für Arzttermine", die den Patient*innen bei der Vorbereitung auf den Termin helfen, werden empfohlen. Die Checklisten informieren z. B. darüber, welche Unterlagen und Informationen von den Ärzt*innen benötigt werden. Dadurch kann während den Untersuchungsterminen Zeit eingespart werden.
- Bei der Long-Covid Versorgung von Kindern und Jugendlichen sollten die Hausärzt*innen die Eltern und Erziehungsberechtigte miteinbinden und ihnen alle notwendigen Informationen zur Diagnose und Behandlung der Erkrankung, aber auch zu nützlichen sozialen und finanziellen Unterstützungsleistungen geben.

Empfehlungen zu möglichen Überweisungen

- Manche Kinder können nach einer SARS-CoV-2-Infektion auch an einem multisystemischen Entzündungssyndrom leiden und die Aufnahme in eine pädiatrische oder kardiologische Intensivstation benötigen. Für die meisten Kinder und Jugendliche mit anhaltenden Symptomen nach der akuten Infektion dürfte die Primärversorgung bzw. Selbstmanagement jedoch ausreichend sein.
- Für Patient*innen mit einem dominanten Symptom und der Notwendigkeit einer spezifischen Disziplin wird in den neu identifizierten Dokumenten auch eine Überweisung an eine/n Spezialist*in empfohlen. Bei Kindern und Jugendlichen mit anhaltenden Symptomen >4 Wochen sollte eine Überweisung an eine/n Fachärzt*in für Kinderheilkunde angedacht werden.
- Für Patient*innen mit komplexeren Symptomen, die >12 Wochen nach der Infektion fortbestehen, ist eine Überweisung an eine Long-Covid Spezialambulanz angezeigt, auch gemäß den neu identifizierten Dokumenten. Im UK und in Italien werden "One-Stop-Assessments" insbesondere bei Kindern und Jugendlichen empfohlen, um Mehrfachüberweisungen zu vermeiden.
- Eine multidisziplinäre Rehabilitation (stationär, teilstationär oder ambulant) kann Kindern, Jugendlichen und Erwachsenen mit komplexeren anhaltenden Symptomen als erste Wahl oder als Überbrückungsmaßnahme empfohlen werden.
- Selbstmanagementtipps können direkt vom/von der behandelnden Ärzt*in, von Apps, Online-Programmen oder Selbsthilfegruppen an die Patient*innen weitergeleitet werden. Werden Apps empfohlen, sollten potenzielle Limitationen berücksichtigt werden, z. B. Fragen der Anwendbarkeit, der Adhärenz und des Datenschutzes, fehlende Belege für die Wirksamkeit und Sicherheit, sowie potenzielle Interessenkonflikte der Anbieter.

Empfehlungen zu zusätzlichen Leistungen

Die Long-Covid Versorgung von Kindern und Jugendlichen fordert eine ressortübergreifende Zusammenarbeit zwischen dem Gesundheitssystem (Allgemeinmediziner*innen und/oder Fachärzt*innen), dem Sozialsystem (z. B. finanzielle Unterstützung, Sozialarbeiter), der Schule (z. B. Verwaltungsangestellte, und/oder Berater*innen), der Arbeitgeber*innen und der Familie.

Weitere Empfehlungen für praktizierende Ärzt*innen

- Vor allem in Bezug auf Kinder und Jugendliche ist eine gemeinsame Entscheidungsfindung zwischen Ärzt*innen, Patient*innen und Erziehungsberechtigten wichtig, um unnötige Untersuchungen zu vermeiden, die Ängste auslösen können. Einfühlungsvermögen gegenüber den Patient*innen und ein personenzentrierter Ansatz sind daher Schlüsselfaktoren für eine erfolgreiche Long-Covid Versorgung.
- Mehrere Länder haben Long-Covid Schulungen und Programme für praktizierende Ärzt*innen entwickelt oder sind dabei, diese zu entwickeln. Das Universitätsklinikum Charité in Berlin bietet beispielsweise Schulungen an. Auch in Belgien und Spanien werden derzeit Long-Covid Leitfäden für Gesundheitspersonal entwickelt.

Kürzlich aufgebaute Long-Covid Versorgungsstrukturen

- Neben den Versorgungsangeboten für Erwachsene gibt es auch spezialisierte Angebote für Kinder und Jugendliche, z. B. Long-Covid Spezialambulanzen im UK, Deutschland, der Schweiz und Italien, multidisziplinäre Rehabilitationszentren in der Schweiz und kinderspezifische Selbsthilfegruppen für Patient*innen und Erziehungsberechtigte im UK, Deutschland und der Schweiz.
- Es gibt deutschsprachige Apps, die die Patient*innen und auch Erziehungsberechtigte beim Selbstmanagement unterstützen, z. B. die "Long-Covid Tagebuch App" und "INSELhealth Cofit App" aus der Schweiz und die "FIMO-App" aus Deutschland.
- Es wurden auch verschiedene Long-Covid Netzwerke eingerichtet, die für verschiedene Akteure, wie Arbeitgeber*innen, Manager*innen, Schulen, Patient*innen und Pflegekräften, hilfreich sein können.

1 Background

Disease profile

In December 2019, the first cases of severe acute respiratory syndrome coronavirus 2 [SARS-CoV-2] were detected in China [4]. On January 30 2020, the World Health Organization (WHO) declared SARS-CoV-2 a public health emergency of international concern [5]. The viral disease encompasses a broad spectrum of severity from asymptomatic to fatal courses of infection. A SARS-CoV-2 infection can occur in all age groups and genders. However, some persons might be at higher risk for a severe course, e.g. elderly, 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 [5, 6]. 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 [7].

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

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 [8]. Research showed that several long-lasting symptoms can persist or reappear after the acute infection, and new symptoms can develop 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 [9, 10].

Fokus auf langfristige Folgen einer SARS-CoV-2 Infektion

Long-Covid umfasst zahlreiche neue oder bestehende Symptome

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 [9, 10]. Sometimes only one symptom persists, while multiple symptoms can occur simultaneously in other cases. Moreover, the symptoms may be new 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, regardless of the severity of the acute SARS-CoV-2 infection, can experience long-term symptoms that impact their everyday functioning [11-13].

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

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 after the acute SARS-CoV-2 infection which cannot be associated with any other cause. The definition distinguishes between different time points after disease onset [1, 14]:

NICE unterscheidet zwischen:

- "**Ongoing symptomatic COVID-19**" includes patients with signs and symptoms from four to 12 weeks after the acute 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.

anhaltender Covid-19 Symptomatik (>4-12 Wochen),

Post-Covid-19 Syndrom (>12 Wochen)

positiver Test sollte keine Voraussetzung sein, 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 COVID-19 patients might choose not to be tested due to the fear of possible consequences (e.g. termination due to the obligated self-isolation) [8].

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 three months from the onset of COVID-19 and that last for at least two months and cannot be explained by an alternative diagnosis [13].

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

A Cochrane Rehabilitation Review presents another definition of long COVID. According to this definition, long COVID involves at least one of the four categories [15, 16]:

- 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.

ESCMID Definition berücksichtigt die Dauer der anhaltenden Symptome & die Wahrscheinlichkeit einer tatsächlich stattgefundenen SARS-CoV-2 Infektion

In February 2022, the European Society for Clinical Microbiology and Infectious Disease (ESCMID) published a definition of long COVID that takes into account the time of persisting symptoms and the certainty of the original acute COVID-19 infection (see Table 1-1) [17].

Table 1-1: ESCMID definition of long COVID

Time from acute COVID-19 diagnosis	Typical symptoms of acute COVID-19, positive laboratory results*	Typical symptoms, negative laboratory results*, suggestive epidemiology	Typical symptoms, negative laboratory results and negative epidemiology
4-12 weeks	Confirmed post-acute COVID	Probable** post-acute COVID	Possible** post-acute COVID
>12 weeks	Confirmed persistent long COVID	Probable** persistent long COVID	Possible** persistent long COVID

* *Confirmed diagnosis is considered a positive PCR test in a relevant epidemiological setting.*

** *The syndrome can be definite, probable or possible, according to the level of certainty of the original acute COVID-19 infection.*

Abbreviations: COVID – Coronavirus disease, ESCMID – European Society of Clinical Microbiology and Infectious Diseases; Source: [17]

Diagnosis

Since January 2021, the ICD-10 catalogue of the WHO includes a separate diagnosis code for long COVID, namely U09.9 [18].

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

Although long COVID has become a separate diagnosis, some difficulties may arise in clinical practice. Not all practicing physicians are yet thoroughly familiar with the diagnosis. 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 apparent alternative cause. Accordingly, an objective diagnosis is almost impossible. On the one hand, the severity of some common long COVID symptoms, like fatigue, is challenging to detect. On the other hand, it is difficult to identify whether some unspecific symptoms were caused by the virus directly or if there was another reason (e.g. pandemic management measures, such as social distancing). Thus, long COVID is a diagnosis of exclusion [19, 20], which requires a trustful relationship between the patient and the practicing physician [21].

Hürden bei der Diagnosestellung,

z. B.: fehlendes Wissen bei Ärzt*innen, einfache klinische Tests nicht vorhanden → objektive Diagnose schwierig

Long-Covid = Ausschlussdiagnose

Due to the tremendous 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. For example, the following ICD-10 codes can be added [16]:

Empfehlung für Diagnosestellung: Berücksichtigung zusätzlicher Diagnosecodes für betroffene Organe

- **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

When it comes to young children, the diagnosis can be particularly challenging. Therefore, specific signs could give a hint about possible long COVID symptoms. For example, feeding behaviour changes and previously well-tolerated food now avoided by the child could indicate changes in smell or taste resulting from COVID-19 [22].

Diagnose bei Kleinkindern oft besonders schwierig

Aetiology

The exact causes and risk factors causing long COVID symptoms remains unclear. Due to the great variety of different symptoms, it can be assumed that several causes are interwoven.

genaue Ursachen von Long-Covid noch nicht bekannt;

For example, the Belgian Health Care Knowledge Centre (KCE) distinguishes two categories [23]:

Unterscheidung zwischen ...

... Symptomen aufgrund von Organschäden & Symptomen ohne vorliegende Organschäden

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

z. B. Nervenschäden mögliche Erklärung für anhaltende Symptome ohne Organschäden

An updated publication of the KCE report suggests that autonomic nervous system damage could account for many symptoms without clear evidence of organ damage. In addition, immune dysregulation, auto-immunity, endothelial dysfunction, occult viral persistence and coagulation activation are other expected underlying pathophysiological mechanisms [24].

Studien zu Long-Covid nach Covid-19 Impfung notwendig

Besides, a few persons may suffer from long COVID-like symptoms after the COVID-19 vaccine. However, no published studies show a correlation between long COVID and the COVID-19 vaccination [25].

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

Moreover, long COVID must be differentiated from other diseases or causes, such as the "post-intensive care syndrome" (PICS). It describes long-term physical, psychological and cognitive impairments in patients who were previously treated in an intensive care unit (ICU) that are similar to long COVID symptoms [24]. Also, rare and/or severe diseases in children and adolescents can cause similar symptoms as long COVID, such as the multisystem inflammatory syndrome in children (MIS-C) or celiac [16, 26].

Risk factors

mögliche Risikofaktoren: z. B. mehrere Komorbiditäten, psychiatrische Vorerkrankungen, höheres Risiko für Frauen

Regarding possible risk factors for long COVID, evidence suggests that a higher number of symptoms at the acute phase of the disease may be a risk factor for developing long COVID. Moreover, there seems to be an association between female gender and the likelihood of developing long-term symptoms [27]. Furthermore, smokers, overweight or obese persons and people with a wide range of comorbidities were associated with an increased risk for long COVID [28]. Recent studies also showed that patients with a prior history in depression or anxiety have a higher risk in developing long COVID [29, 30].

ähnliche Risikofaktoren bei Kindern & Jugendlichen

Similarly, in children and adolescents, females, those with allergic problems or with other chronic underlying diseases and those with severe symptoms during the acute SARS-CoV-2 infection are deemed to have an increased risk of long COVID. Besides, a trend towards a greater chance of developing long COVID was found in overweight/obese children and adolescents [26].

Epidemiology

Adults

KCE-Bericht 2021: 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

A systematic review of the KCE was published in October 2021 and included 47 studies/48 publications. Overall, the 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 32 to 78 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% vs 13-92%). Six months after disease onset, 13 to 53 per cent of the non-hospitalised and up to 50 to 93 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 compared to COVID-19 patients with mild to moderate infections [27].

die häufigsten Symptome: Müdigkeit/Erschöpfung & Atemwegs-probleme

Regarding the most reported symptoms, the KCE report 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 [27].

NIPH-Bericht 2022 bestätigt Ergebnisse

These results are confirmed by a recent review of the Norwegian Institute of Public Health (NIPH) that included nine controlled studies [31] and a meta-analysis and systematic review about the global long COVID prevalence, including 50 studies [32].

Children and adolescents

Long-Covid Prävalenz bei Kindern & Jugendlichen noch unsicher

Long COVID can also occur in children and adolescents. However, systematic reviews on the prevalences in children and adolescents are rare and present uncertain results.

2 systematische Reviews 2021: Kontrollgruppen berichten die meisten Symptome ähnlich häufig als die SARS-CoV-2 positiven Gruppen

Two systematic reviews from 2021 [33, 34] reviewed studies that reported persistent symptoms following SARS-CoV-2 infection in children and adolescents. Both reviews showed that the frequency of the majority of reported persistent symptoms was similar in SARS-CoV-2 positive cases and controls (n=5). One of the two systematic reviews [33], however, found statistically significantly higher prevalence rates for cognitive difficulties (pooled risk difference: 3%), headache (5%), loss of smell (8%), sore throat (2%) and sore eyes (2%) in the SARS-CoV-2 positive groups. Both review highlighted the importance of controlled studies on long COVID in children and adolescents to consider long-term SARS-CoV-2 infection-associated symptoms but also pandemic-associated symptoms.

1 systematischer Review 2022: SARS-CoV-2 positive Kinder haben höheres Risiko für Atemnot, Fieber, etc.

In contrast, another recent systematic review published in June 2022 [35] included 21 studies and reported that children infected by SARS-CoV-2 had a higher risk of persistent dyspnea, anosmia/ageusia, and/or fever compared to controls.

Impact of long COVID

Auswirkungen auf alltägliche Aktivitäten, Lebensqualität & finanzielle Situation

On the one hand, long COVID comes with a burden to the affected individuals and their families. A recent systematic review and meta-analysis, including 12 studies, showed that long COVID is associated with a poor health-related quality of life, particularly amongst long COVID patients with previous intensive care unit admission and with fatigue as the primary symptom [36]. In addition, long COVID can impact the quality of life of patients, as well as parents/caregivers and siblings of affected children and adolescents [3]. Next to physical and mental difficulties, long COVID can also cause financial insecurities for patients and/or families, e.g. for adult patients when the entitlements for sickness benefits have expired and the application for early retirement has not yet been approved [37], but also for parents and caregivers if they need to reduce working hours to care for the child [3].

Rückkehr zur Schule, Lehre, etc. oft schwierig

Furthermore, children and adolescents with long COVID often have difficulties returning to school, training or work, which can affect the future of the patients in the mid to long term [26].

gesellschaftliche/ ökonomische Auswirkungen:

längere Krankenstände insbesondere bei schweren SARS-CoV-2 Verläufen

On the other hand, the increasing number of long COVID cases and its impact on the labour market is also an issue for society as a whole [11, 12]. A recently published health report from the German "Techniker Krankenkasse" (TA) showed that long COVID has accounted for only a relatively small proportion of total sick leave among the employed. However, those affected are on sick leave for a comparatively long time. In 2021, the average duration of sick leave in long COVID patients was 105 days, while the average sick leave of each person insured by the TK was only 14.6 days. The TK also sees a difference in the duration of sick leave depending on the severity of the acute SARS-CoV-2 infection. While long COVID patients with mild to moderate acute disease had an average sick leave of 90 days in 2021, patients who were submitted in the hospital for more than seven days had an average sick leave of 168 days [38].

Ausfälle wichtiger Berufsgruppen, wie Gesundheitspersonal möglich

This increase in sick leaves may impact whole institutions. For example, reports from the UK showed that in the National Health Services (NHS), many healthcare workers were infected with SARS-CoV-2 and are still struggling with the long-lasting symptoms. This has led to reduced workability (e.g. part-time work) or even the inability to work for NHS healthcare professionals. Similar consequences are expected in other professional groups, such as teachers.

Long-Covid wichtiger Aspekt in der aktuellen Gesundheitspolitik

Due to the potentially high impact of long COVID on an individual and societal level, including healthcare, social care and the labour market, it plays a significant role in current healthcare policies [12, 39].

2 Aim and research questions of this update

This scoping review aims to update the original report published in October 2021 [40, 41]. The recommendations on care pathways and other support needs for adult long COVID patients will be updated and added for children and adolescents. In addition, newly identified long COVID care structures of selected European countries for children, adolescents and adults will be presented. The updated results are intended to support preparations or adaptations in planning long COVID healthcare (e.g. primary care, rehabilitation) and social-legal care (e.g. sick leave, vocational reintegration).

Ziel:
Update zu Empfehlungen bzgl. Long-Covid-Versorgungspfaden & Beispiele etablierter Versorgungsstrukturen für Kinder, Jugendliche & Erwachsene

This update neither includes an efficacy and safety analysis of the different long COVID treatments or rehabilitation interventions nor an analysis of the implementation of long COVID care pathways. The update also does NOT describe the actual long COVID care situation in Austria, as the "Gesundheit Österreich GmbH" is currently working on it.

KEINE spezifischen Therapieempfehlungen & Versorgungsanalyse für Österreich

The following research questions arise from the defined project aims:

aus den Projektzielen ergaben sich 4 Forschungsfragen

1. What are the new recommendations on long COVID care pathways and other support options for adult patients?
2. What are the recommendations on long COVID care pathways and other support options for children and adolescents?
3. Are there any newly established long COVID care structures for adult patients in the selected European countries?
4. What are the existing long COVID care structures for children and adolescents in the selected European countries?

3 Methods

Literature searches

Literature searches of the original report

For the original report published in October 2021 [40, 41], a systematic search in four databases (Cochrane, Embase, Medline, HTA-INAHTA) was conducted in April 2021. In addition, several hand searches were performed in PubMed and Google scholar biweekly until the beginning of August 2021. More details on the systematic search strategy can be found in the original report [40].

Originalbericht vom Oktober 2021: systematische Suche in 4 Datenbanken & zusätzliche Handsuchen

Updated literature searches

For this update, several hand searches were conducted in Google, Pubmed, the Trip database, Prospero and the Guideline International Network from May to the beginning of July 2022 to identify updated or new long COVID guidelines and guidances. The following search terms were used: *long covid/post-covid guidelines, long covid/post-covid guidances, long covid/post-covid care, long covid/post-covid care recommendations, long covid/covid care in children*. In addition, the reference lists of potential literature were searched for further guidelines and guidance.

Update: Handsuchen nach upgedateten & neuen Leitlinien

letzte Suche Ende Juni 2022

Additional internet searches were performed until August 2022 to identify websites and documents of existing long COVID care structures for children, adolescents and adults. The selected European countries represent different geographic locations (north, middle and south Europe) and healthcare systems (national health services and social health insurance systems). In total, one northern European countries (Norway), three central-European countries (Belgium, Germany and Switzerland), two southern-European countries (Italy and Spain) and the UK were selected (see Figure 3-1), whereby Norway, Switzerland and Spain were newly added in this update.

weitere Internetrecherchen zu bestehenden Versorgungsstrukturen in Europa; letzte Suche Anfang August 2022; Norwegen, Schweiz & Spanien neu dazu gekommen

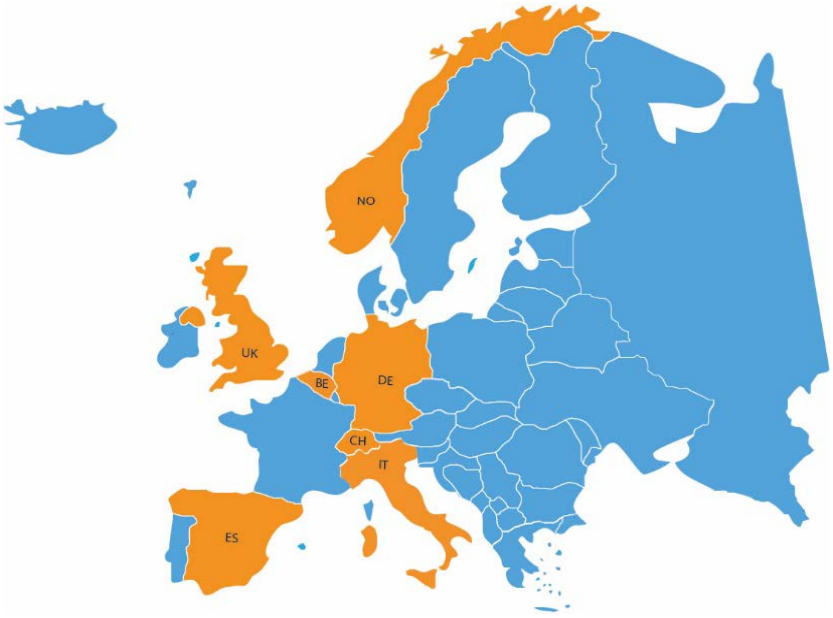


Figure 3-1: Selected European countries (source: own figure)

Kontaktaufnahme mit Expert*innen

Moreover, one to two experts per country were contacted to obtain further unpublished information about the national long COVID care structures.

Original and updated inclusion criteria

Ein- & Ausschlusskriterien nach dem PICO-Schema

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

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

	Original inclusion criteria	Updated inclusion criteria
Population	Adults with long COVID symptoms lasting ≥4 weeks after disease onset	Children, adolescents and adults with physical, neurological/ cognitive, or psychiatric long COVID symptoms beginning ≥4 weeks after the start of the acute SARS-CoV-2 infection
Intervention	-	-
Control	-	-
Outcomes	**Research question 1:** ■ Recommendations concerning long COVID healthcare pathways ■ Recommendations regarding other services for long COVID patients (e.g. social, financial, vocational) **Research question 2:** Examples of already existing care structures for long COVID patients in selected European countries	**Research questions 1 and 2:** ■ New recommendations on long COVID care pathways and other support options (e.g., social, financial, legal) for adults ■ Recommendations on long COVID care pathways and other support options (e.g., social, economic, legal) for children and adolescents **Research questions 3 and 4:** ■ Examples of newly identified long COVID care structures for adults in selected European countries ■ Examples of already established long COVID care structures for children and adolescents in selected European countries
Study design	**Research question 1:** Guidelines, reviews, expert opinions in the form of consensus statements and clinical perspectives **Research question 2:** ■ Same references as for research question 1 ■ Websites of e.g. patient organisations, care facilities, social services ■ Experts	**Research questions 1 and 2:** ■ Clinical guidelines ■ Guidances (no standardised clinical guidelines)* **Research questions 3 and 4:** ■ Same references as for research questions 1 and 2 ■ Websites of, e.g. patient organisations, care centres, social institutions ■ Further experts
Publication period	Until the beginning of August 2021	**Research questions 1 and 2:** Until the beginning of July 2022 **Research questions 3 and 4:** Until the beginning of August 2022
Countries	**Research question 1:** Europe, North America, Australia **Research question 2:** selected European countries (UK, Belgium, Germany, Italy, Austria)	**Research questions 1 and 2:** Europe, North America, Australia **Research questions 3 and 4:** selected European countries (UK, Norway, Belgium, German, Switzerland, Italy, Spain**
Language	German and English	

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

blue = Changes in inclusion criteria compared to the inclusion criteria from the original report (October 2021) [40, 41].

** In this update, reviews, consensus statements and clinical perspectives were not considered for answering research questions 1 and 2, as more guidelines and guidance papers have been published in the last months.*

*** The selected European countries represent different geographic locations (north, middle and south Europe) and healthcare systems (national health services and social health insurance systems).*

Literature selection processes

Literatur selection process of the original report

The systematic literature search of the original report yielded 754 sources after deduplication. Of the 754 references, 14 were considered, including five guidelines, four reviews, one consensus statement, and four clinical perspectives. Further information about existing long COVID care structures were obtained through hand searches and from five experts with different access to long COVID (e.g. practising physicians, patient representatives or political consultancy). The detailed selection process can be obtained from the original report [40, 41].

Originalbericht 2021: 14 Referenzen zu Versorgungsempfehlungen & zusätzliche Quellen zu bestehenden Versorgungsstrukturen

Updated literatur selection process

Hand searches

Twenty-nine potentially relevant references were identified through the update hand searches. Of these, 15 met the inclusion criteria and were included for answering research questions 1 and 2 about recommendations for long COVID care pathways for children, adolescents and adults. Five of the 15 guideline documents were already included in the original report [40, 41], and ten were newly identified. The other 14 references did not fulfil the inclusion criteria and thus were not included to answer research questions 1 and 2. The main exclusion reasons were different study design (e.g. review or corresponding letter), another country (e.g. India) and other outcomes (e.g. recommendations about specific treatments). Nevertheless, three of the 14 excluded references could be considered for answering research questions 3 and 4 about already existing long COVID care structures. Figure 3-2, Chapter 4.1.1 (adults) and Chapter 4.2.1 (children and adolescents) give a more detailed overview of the literature for long COVID care pathway recommendations.

Update-Bericht 2022: aus 29 Referenzen, 15 Leitlinien zu empfohlenen Versorgungspfaden (FF 1 & 2) identifiziert, davon 10 neue

For answering research questions 3 and 4 about existing long COVID care structures for children, adolescents and adults in the selected European countries, information was obtained from the 15 included guideline documents and additional sources identified through internet searches, including reviews, as well as websites of patient organisations, support groups, long COVID networks (e.g. Post-Covid Netzwerk Charté Berlin Germany, Altea Netzwerk Switzerland) and long COVID care offers, such as specialised outpatient clinics or social care offers. Chapter 4.4.1 describes the references of existing long COVID care structures in more detail.

Informationen zu bestehenden Strukturen (FF 3 & 4) aus den 15 Leitlinien, von Reviews, unterschiedlichen Websites

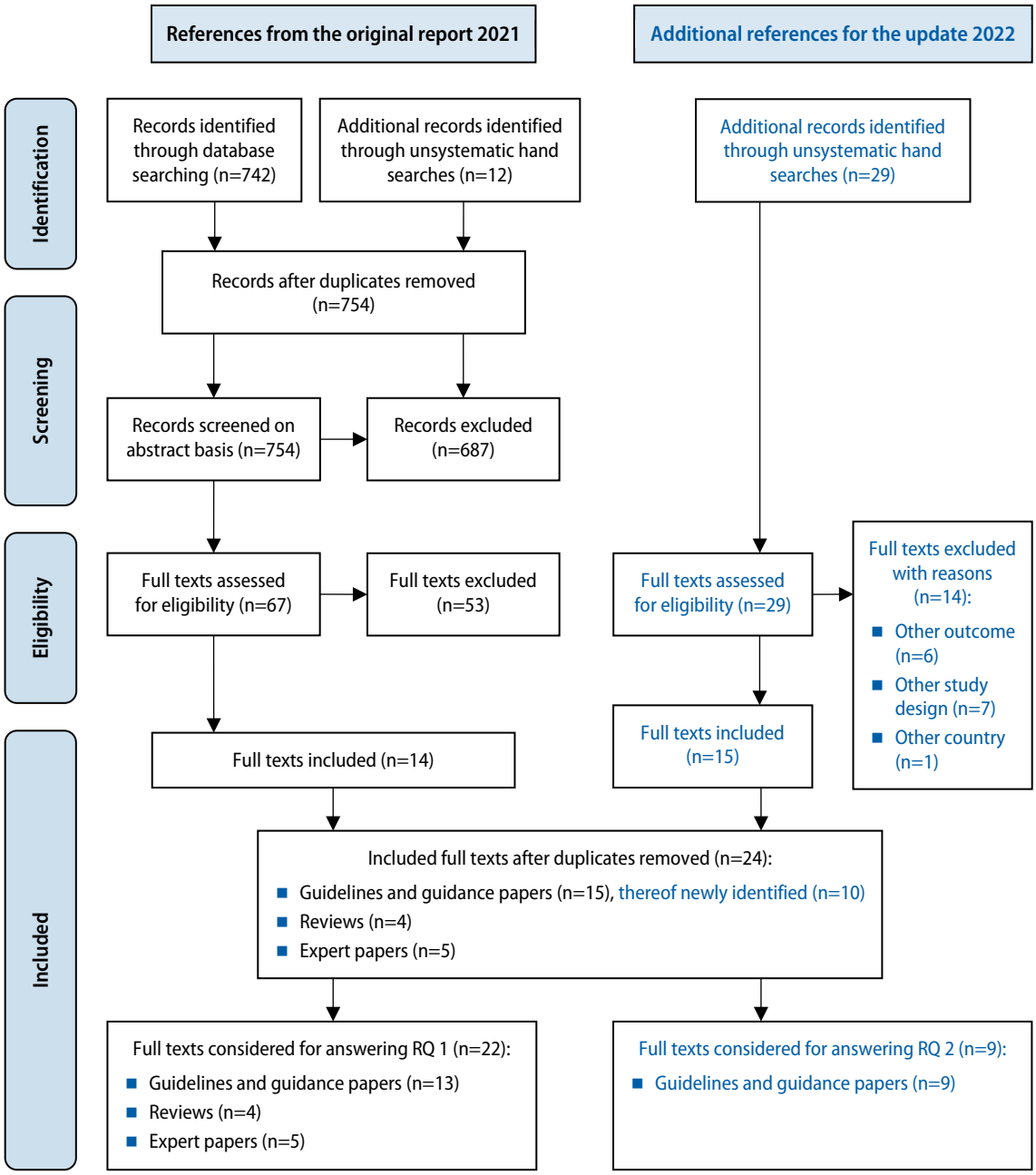


Figure 3-2: Presentation of the literature selection process for research question 1 & 2 (PRISMA Flow Diagram)

Expert consultation

For this update, seven experts from UK, Norway, Belgium, Switzerland and Spain were contacted via e-mail regarding further information about examples of existing long COVID care structures in their countries. As in the original report, the experts were found within networks of national experts and through contacts between healthcare and health technology assessment agencies. Of the seven experts, six experts replied: UK (n=1/1), Norway (1/1), Belgium (1/1), Switzerland (2/3) and Spain (1/1). For Germany and Italy, no further experts were contacted in this update, as the documents and additional sources were detailed enough. The Appendix (see Table A-20) gives more information about the experts and their answers.

7 weitere Expert*innen für Update kontaktiert, davon 5 Antworten erhalten

für Deutschland & Italien Literatur ausreichend

Quality assessment

In the original review [40, 41], no systematic quality assessment of the included guideline documents or reviews was performed because most of the retrieved articles were conceptual and therefore did not fit for a classical quality evaluation. Thus, in this updated review, the quality of the newly identified guideline documents was also not assessed. Indeed, the quality of the evidence regarding long COVID care pathway recommendations is limited due to the topicality of long COVID and the urgency for research regarding its management. However, several included documents are presented as "living or interim guidelines", which will be updated regularly when new evidence rises.

Qualität der eingeschlossenen Leitlinien nicht bewertet

einige Leitlinien werden regelmäßig upgedated

Updated data extraction

In this review, the updated and newly identified recommendations about long COVID care pathways for adults (research question 1) were added to the existing extraction tables of the original report [40, 41]. Thereby, separate extraction tables were created for the UK, European and non-European countries. Information on the following categories was extracted:

- Characteristics of the included literature
- First point of services
- Possible referrals
- Additional services
- Further information for practising physicians regarding decision-making and communication

Update der Extraktionstabellen zu empfohlenen Versorgungspfaden für Erwachsene

In addition, a new data extraction table was built to summarise the recommendations about long COVID care pathways for children and adolescents (research question 2).

neue Tabelle zu Kindern & Jugendlichen

Concerning research questions 2 and 3, the information about existing long COVID care structures for children, adolescents and adults in the UK, Belgium, Germany and Italy were updated, and new information about the care structures in Norway, Switzerland and Spain was added to the extraction tables of the original report [40, 41].

Update der Tabellen zu bestehenden Versorgungsstrukturen für Kinder, Jugendliche & Erwachsene

The updated extraction tables are presented in the Appendix (see Table A-1 to Table A-19).

Narrative data synthesis

Ergebniskapitel mit neuen Informationen zu Versorgungspfaden & -strukturen upgedated

The narratively summarised recommendations about long COVID care pathways for adult patients of the original review [40, 41] were updated with newly identified information. Moreover, a new chapter about possible long COVID care pathways for children and adolescents was added to this updated report.

neues Kapitel zu Kindern & Jugendlichen

Regarding the existing long COVID care structures in selected European countries, the information from the UK, Belgium, Germany and Italy was updated and information from Norway, Switzerland, and Spain, as well as details on existing care structures for children and adolescents were added in this update.

All steps (update of the literature search and selection, the data extraction, and the narrative description) were performed by one author (SW).

in Extraktionstabellen, & speziellen Info-Boxen neue Informationen hervorgehoben

Overall, this update provides an overview of all recommendations on possible long COVID care pathways, as well as on established long COVID care structures in the selected European countries for children, adolescents and adults. The data extraction tables and special info boxes complementary to the summaries will highlight the key results about recommendations on care pathways, especially for children and adolescents, and about newly identified care structures.

4 Updated results

4.1 Recommendations about long COVID care pathways for adults

4.1.1 Included evidence

Guideline documents

In total, 13 long COVID documents [1, 2, 16, 17, 39, 42-49] were identified in the systematic search and additional hand searches with recommendations for adult patients, of which nine were standardised clinical guidelines [1, 2, 16, 17, 42, 44, 47-49] and four [39, 43, 45, 46] were guidance papers. Two documents had already been included in the original report [16, 42], three had been updated since August 2021 [1, 2, 49], and eight were newly identified [17, 39, 43-48].

insgesamt 13 Leitlinien zu erwachsenen Pat. eingeschlossen (davon 8 neue)

Eight documents are from European countries (UK [1, 2], Austria [AUT] [42], DE [16], IT [43], ES [44] and from a supranational European document [17]), and six from non-European countries (United States of America [USA] [45, 49]), Canada [CAN] [39], Australia [AUS] [46], Australia and New Zealand [NZ] [47]) and one of the WHO [48].

aus dem UK, 6 europäischen & 6 nicht-europäischen Ländern, sowie von der WHO

Overall, the documents aimed at identifying and assessing the management of long COVID symptoms, thereby advising healthcare professionals on how to organise, establish, and maintain long COVID (healthcare) services. The Austrian document [42], the Spanish document [44], one document from the USA [45] and the Australian document [46] focused on recommendations for the primary care sector. Two documents [47, 48] addressed the management of COVID-19 with sub-chapters about long COVID. Only the long COVID sub-chapters were considered in this review.

Empfehlungen zu Versorgungspfaden für Gesundheitspersonal, 4 Leitlinien mit Fokus auf Primärversorgungssektor

Six documents [1, 17, 42, 43, 48, 49] were declared as living/interim documents, which means that they are updated if new evidence and/or recommendations occur. In six documents [1, 2, 16, 17, 42, 47], the presented recommendations were based on expert consensus, while in three documents [39, 45, 48], the recommendations were based on a mix of evidence and consensus and in one documents [44], the recommendations were evidence-based. Three documents did not report how the recommendations were conducted [43, 46, 49]. Other three documents [17, 44, 45] reported no funding was received, and six documents [17, 42, 44-46, 48] declared no conflicts of interest of the authors. The other included documents did not report on funding or conflicts of interest.

bei 6/13 Leitlinien, Empfehlungen basierend auf Expert*innen-Konsensus

in den meisten Leitlinien keine Interessenskonflikte der Autor*innen

All recommendations, except the ones from the CDC document, applied to ongoing symptomatic COVID-19 (persistent symptoms of 4-12 weeks) as well as post-COVID syndrome patients (persistent symptoms of >12 weeks). The CDC document did not report to which long COVID definition and patient population the recommendations relate [49]. In contrast, most documents' recommendations hold for hospitalised and non-hospitalised COVID-19 patients. The S1 guideline from Austria specified that they considered hospitalised COVID-19 patients, except those admitted to the ICU. The recommendations of the Spanish document [44] addressed patients that were treated at home, and the document from Australia and New Zealand [47] addressed former hospitalised COVID-19 patients.

12/13 der Leitlinien zu hospitalisierten & nicht-hospitalisierten Pat. mit anhaltenden Symptomen >4 Wochen nach Krankheitsbeginn

Reviews

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

In addition to the identified guideline documents, four reviews were identified in the systematic search and unsystematic hand searches of the original report: two from the UK [11, 50], one from the USA [51] and one from several European countries (including UK, BE, DE, IT) [52]. Among other things, the reviews presented recommendations for healthcare pathways for long COVID patients. Two of the four reviews presented recommendations for both, former hospitalised and non-hospitalised SARS-CoV-2 infected [11, 50], while the other two reviews did not report for which patient population the presented recommendations were meant [51, 52].

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

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

While one review considered all symptoms persisting more than four weeks after the beginning of the infection [50], another report focused on recommendations for ongoing symptoms for at least six weeks after disease onset [52]. The two other reports did not report on which long COVID definition they relied on [11, 51]. Only one of the four included reviews reported that the presented recommendations were evidence-based but not systematically searched [11], while the other reviews did not describe the applied methods [50-52].

Methode nur in 1 Review beschrieben

Finanzierung & Interessenskonflikte in 2 Reviews dargelegt

Two of the four included reviews reported on funding and conflicts of interest, from which one declared one conflict of interest [50] and the other review reported on the conflicts of interest of two authors of the report [52].

Expert papers

5 Expert*innen-Papiere aus Europa berücksichtigt

Due to the topicality of this theme and the limited available evidence, expert papers in the form of consensus statements or clinical perspectives were considered in the original report. In total, five documents from the UK [53, 54], the Netherlands [55] and Germany [56, 57] were identified in the systematic search and additional hand searches. These expert papers were also considered for this update.

unterschiedliche Pat.-Populationen eingeschlossen

Two documents focused on former hospitalised and non-hospitalised patients [53, 57], while another one only focused on former hospitalised COVID-19 patients [55]. Another document focused on a primarily physically active patient population [54]. The fifth document [56] did not report on whether hospitalised and/or non-hospitalised COVID-19 patients were considered.

1 Dokument berichtete Interessenskonflikte

Only one document reported conflicts of interest in the form of grants to the first author [55]. The other documents [53, 54, 56, 57] had no conflicts of interest to declare.

More information about the characteristics of the included literature is presented in the Appendix (see Table A-1, Table A-2 and Table A-3).

4.1.2 First point of contact

Table A-4, Table A-5 and Table A-6 in the Appendix present detailed information about the first point of contact for adult long COVID patients.

Primary care

Identifizierung von Long-Covid Pat.: z. B. durch Hausärzt*innen oder Eigeninitiative

Long COVID patients can be identified proactively through healthcare records or hospital records focusing on patients with a high risk for long COVID, by the general practitioner (GP) or primary care centre during routine assessments or by the initiative of the patients themselves [43].

Hausärzt*innen generell erste Anlaufstelle für alle Long-Covid Pat.,

erste Untersuchung >4 Wochen nach der akuten Infektion empfohlen

In most of the analysed countries (e.g. UK, USA, DE, AT, IT, ES, CAN, AUS, NZ), the primary care sector, including GPs and primary care centres, is recommended as the first point of contact for former hospitalised or non-hospitalised, symptomatic or asymptomatic SARS-CoV-2 patients with persistent symptoms for at least four weeks after the acute infection [1, 16, 39, 42-49, 51, 53]. According to the ESCMID document [17], for patients with persistent symptoms four to 12 weeks after diagnosis, clinical assessment can also be considered on a case-by-case basis, depending on the severity and course of symptoms. However, if the symptoms persist for more than 12 weeks, all patients require an assessment. In Spain, for example, three visits to the GP are recommended for each patient, including the first clinical assessment after more than four weeks from diagnosis, a second assessment to make differential diagnoses after nine to ten weeks and the third evaluation of long-term symptoms and re-evaluations of possible causes after 13 to 14 weeks [44].

Primärversorgung nicht immer erste Anlaufstelle, z. B. für ehemals hospitalisierte Covid-19 Pat. im UK, Italien & Spanien Krankenhausambulanzen auch zuständig

However, in a few countries (e.g. UK, USA, NL, IT, ES), for some long COVID patients not only the primary care sector is responsible for the first assessment. For example, in the UK, a healthcare professional from secondary care is advised to follow-up on former hospitalised COVID-19 patients via video or phone to check for new or ongoing symptoms or complications 12 weeks after discharge. Former hospitalised COVID-19 patients who suffer from persistent or new symptoms for 12 weeks after discharge can go to secondary care outpatient departments or primary care facilities for a clinical assessment [1, 49, 53]. Also, in Italy and Spain, patients admitted to the hospital during the acute infection can visit the hospital outpatient department in the first step if symptoms persist or reoccur [43, 44].

Erstuntersuchung vor allem durch Hausärzt*innen empfohlen

Berücksichtigung von Komorbiditäten bzw. anderen Ursachen, & der sozialen bzw. finanziellen Situation des Pat. wichtig

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. It is recommended to move away from conducting many clinical tests and only apply the most relevant tests for the patient (case-by-case decisions). In addition, it should be differentiated between long COVID symptoms due to organ damage and functional disorders. Furthermore, existing comorbidities and other differential diagnoses must be considered within the primary assessment, as long COVID is considered a diagnosis of exclusion. Apart from that, social determinants, such as financial stability, discrimination, social exclusion, available support and the family/social situation, need to be taken into account by the GPs [16, 17, 39, 42-48, 51, 53].

1. Ausschluss potentiell lebensgefährlicher Symptome

2. Identifizierung potentieller Long-Covid Symptome z. B. mittels standardisierten Fragebögen & Skalen

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, suspected cardiogenic chest pain). In case they find any, referral of the patients to acute services is recommended [16, 17, 39, 42, 49, 51, 53]. Some other symptoms, such as arthritis, myositis, pancreatitis, or other neurological, renal, haematological, endocrine and systemic autoimmune manifestations also require early suspicion and guidance [44]. Besides, other non-severe symptoms likely to be caused by the initial SARS-CoV-2 infection can be identified using standard operating procedures [16, 17, 42, 51, 53]. For example, the GPs or, e.g. nurses can use different questionnaires and scales, which can help them in their diagnosis. Some aspects may also be collected directly from the patients by asking them to fill out a questionnaire. Possible questionnaires and scales are [1, 16, 42-44, 48, 55]:

- **The EQ-5D** and **the Short-Form 36** to assess the generic health status of the patients [58, 59].
- **The Klok Scale** to assess, inter alia, long COVID-related individual distress and level of impairment [60].
- **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 [61].
- **The COVID-19 Yorkshire Rehabilitation Screening Tool** to find out if the patients are experiencing problems related to the recent illness with COVID-19 [62].
- The **Hospital Anxiety and Depression Scale** [63], the **Patients Health Questionnaire 9** [64], the **General Anxiety Disorder 7** [65] or the **Depression Anxiety Stress Scale 21** [66] to assess anxiety and/or depression.
- The **Medical Research Council Dyspnoea Grading Scale** to measure breathlessness [67].
- The **Montreal Cognitive Assessment** for a cognitive screening [68].

Informationen zur Einnahme von Medikamenten, Nahrungsergänzungsmittel, etc. wichtig

Checkliste zur Vorbereitung für Untersuchung hilfreich

Furthermore, the GPs or respective healthcare professionals in primary care centres should always inquire about 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 [49]. A healthcare appointment checklist could help patients prepare important information for the GP, e.g. information about necessary paperwork, medications and supplements, symptoms, and open questions they would like to ask the physician. Consequently, such a checklist can help the GPs to save time [49].

3. Planung weiterer Vorgehensweise, z. B.: Selbstmanagement, symptomatische Therapie, Pacing, „Abwarten & Beobachten"

kein positives Testergebnis notwendig für Diagnose

The GPs can manage patients with low clinical complexity [43]. They can propose self-management strategies and/or prescribe treatments to alleviate symptoms depending on the patient's needs [51, 53]. The patients should be informed about the concept of pacing, meaning that they should increase their exercise workload gradually and that they need to prioritise activities of daily living over a return to exercise if they do not have the energy to manage both [39]. The doctors should also discuss the likelihood of spontaneous recovery with the patients and their expectations, e.g. patients should not expect to return to pre-infection baseline but rather obtain good quality of life [17, 39]. In the German and Austrian documents, also, a wait-and-see approach was proposed under the supervision of the respective doctor (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 [16, 42].

According to the documents, healthcare services should not be 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 [1, 43, 53].

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

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, e.g.:

- multidisciplinary specialised long COVID outpatient assessment clinics [1, 16, 42, 49] or
- to a specialist of a single discipline [1, 16, 42, 49, 52, 53, 55].

Überweisungen an multidisziplinäre Rehabilitationsprogramme oder Einzeltherapien weitere Möglichkeit

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 [1, 16, 42, 47, 49, 55].

For more information about referral options, see Chapter 4.1.3.

Folgeuntersuchungen & notwendige Unterstützungen sollten durch Hausärzt*innen koordiniert werden

In addition, the GP should coordinate follow-up care (through personal visits or telemedicine tools), including reviews for the return to work [43, 47]. Thereby, mental health and well-being should be reinforced by recommendations for further social support, mutual assistance and other collective or community-based measures [17, 44].

Secondary care

in manchen Ländern Krankenhausambulanzen auch als 1. Anlaufstelle für ehemals hospitalisierte Covid-19 Pat. möglich

As described previously, in a few countries (e.g. UK, USA, NL, IT, ES), the secondary care sector can also be recommended as the first point of contact for patients who have been hospitalised during the acute SARS-CoV-2 infection [2, 43, 44, 49, 55]. The follow-up consultations can be planned as phone, video or personal consultations [2]. These consultations should include a check for new or ongoing symptoms and rule out life-threatening symptoms or other non-COVID-19-related conditions. Subsequently, it should be assured that the patients had been discharged to the appropriate setting (e.g. home, rehabilitation centre, nursing home) and that necessary referrals are coordinated (e.g. to multidisciplinary long COVID assessment clinics or non-medical therapies). The timing of the first follow-up visit varies between countries. For example, in the USA, the first follow-up consultation should occur six to eight weeks after hospital discharge [1, 49]. In the Netherlands, it is recommended within one to two weeks of hospital discharge [55].

Zeitpunkte der Kontaktaufnahme zwischen 1-8 Wochen nach Entlassung

im UK spezieller Nachbeobachtungsprozess für Intensivstation-Pat.: 1. Assessment bei Verlegung, 2. bei Entlassung, 3. 4-6 Wochen danach, 4. nach >12 Wochen

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 occur 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 discharge from the hospital, an assessment of the patient's ongoing needs is recommended, including appropriate community service referrals if needed. Subsequently, a multidisciplinary re-assessment should be undertaken at four

to six weeks post-discharge, including referral to, e.g. rehabilitation or mental health services. In case the patient continues to improve further, the next assessment is recommended 12 weeks after the hospital discharge.

4.1.3 Possible referrals

Acute services

bei akuten oder lebensgefährlichen Symptomen → Überweisung in die Notaufnahme

Several documents (e.g. UK, DE, AT, ES, ESCMID, CAN, RACGP-AUS, WHO) pointed out that referral to the relevant acute service is recommended if acute or life-threatening complications, "red flags", such as severe hypoxaemia, oxygen desaturation on exercise, signs of severe lung disease, thromboembolic events, cardiac involvement, such as myocarditis, heart failure, cardiac chest pain, or unexplained or newly appeared neurological abnormalities are seen during the primary assessment. This also includes acute psychiatric services for patients with severe psychiatric symptoms with the risk for self-harm [1, 16, 17, 39, 42, 44, 46, 48].

Specialised long COVID outpatient assessment centres/clinics

bei nicht akuten, jedoch komplexen Symptomen → weitere multidisziplinäre Untersuchungen in Spezialambulanzen empfohlen, meistens bei Symptomen, die >12 Wochen anhalten

manche Spezialambulanzen bieten auch selbst Behandlungen an

In several countries (e.g. UK, DE, AT, IT, ES, USA, CAN, AUS), patients with no acute or life-threatening complications but with more complex possibly SARS-CoV-2-related symptoms can be referred to so-called specialised long COVID outpatient assessment centres/clinics by the GP or related specialist. In Italy, for example, the GPs need to stay in contact with the clinic during the treatment [43]. In the centres/clinics, a detailed assessment of the patient's clinical history and current health status should be conducted. Thereby, the patients should be provided access to multidisciplinary teams including professionals of, e.g. neurology, psychiatry, psychosomatic, cardiology, pneumology, rheumatology, otorhinolaryngology, dermatology and/or endocrinology. The centres can also offer "one-stop assessments", where consultations with various specialists and diagnostic tests are concentrated on a single day [43]. If the assessments result 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 offer treatment options (e.g. UK). 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. [1, 16, 39, 42-46, 49].

Chapter 4.4 presents examples of existing specialised long COVID outpatient assessment clinics.

Specialist care

bei 1 dominanten Symptom, z. B. organspezifisch → Überweisung an relevante(n) Spezialist*in empfohlen

In most investigated countries (UK, USA, NL, DE, AT, IT, ES, AUS, NZ), patients with a dominant long COVID symptom should be referred to the relevant specialist for further investigations or treatments. For example, patients with persistent generalised pain should be referred to the pain unit or a rheumatologist, patients with persistent dyspnea should be referred to a pulmonologist or otolaryngologist, and patients with persistent headache should consult a neurologist [44, 45, 48, 49]. The referral can come directly from the doctor who did the first clinical assessment, the rehabilitation team, or a specialised long COVID outpatient assessment clinic after detailed assessments.

The timing of the referral to a specialist should be based on the individual patient's needs and the discretion of the assessing clinician; however, it mostly 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 [1, 16, 42, 43, 49, 52, 53, 55].

anschließend, weitere Überweisungen möglich

Multidisciplinary rehabilitation

In many countries (UK, USA, NL, DE, AT, IT, ES, CAN), long COVID patients can be referred to multidisciplinary inpatient, partial inpatient or outpatient rehabilitation programs. The referrals can be performed directly by the doctors who made the first clinical assessment, the specialists or by specialised long COVID outpatient assessment clinics [11, 16, 39, 42-45, 49, 55]. 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 patient is capable of it. For patients with mild to moderate symptoms, rehabilitation should usually be indicated if the symptoms last more than 12 weeks [42, 47]. In the USA, for example, rehabilitation is also recommended for patients with persistent complex symptoms (e.g. neurological impairments) who wait for a place in a specialised clinic [45].

Überweisung zu stationärer, teilstationärer oder ambulanter Rehabilitation,

meistens wenn Symptome >12 Wochen anhalten

Overall, the rehabilitation programmes should be patient-centred and tailored to the patient's individual needs, taking into account the patient's persisting symptoms, their functional and sustainable occupational goals for activities of daily living and the availability of healthcare resources. The programmes should involve multidisciplinary teams including, e.g. medical doctors, occupational therapists, physiotherapists, psychologists and specialists for fatigue or respiratory symptoms. The programmes should also be multimodal and include some of the following elements [1, 11, 16, 39, 42-46, 48, 49, 53-56]:

generell Pat.-orientierte, multimodale Rehabilitation empfohlen, inklusive z. B. physikalischen, kognitiven und/oder psychologischen Elementen

- **Physical elements:** e.g. rehabilitation medicine, pneumological rehabilitation, cardiological rehabilitation, physiotherapy, occupational therapy, speech and language therapy, and muscle strengthening programmes, especially for patients who had been treated in the ICU. Return to exercise should always be guided by the symptoms.
- **Cognitive/neurological elements:** e.g. physiotherapy and exercise (e.g. memory exercises, puzzles, games, reading), but also for support in restoring the cognitive function or, if not possible, in developing new ways of organising information (e.g. lists and notes).
- **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

Depending on the needs of the patients, they can also be referred to community care networks by the doctor who did the first assessment, specialists or specialised long COVID outpatient assessment clinics. These networks involve, for example, community nurses (UK, IT, AT), nursing homes or healthcare hotels (IT) and aim to support the other long COVID healthcare service providers by offering support for patients (e.g. via home visits) [42, 52]. Community nurses can also help coordinate care delivery in more complex cases [43].

weitere Optionen:

"Community Care Networks" wie z. B. Community Nurses

nicht-medizinische Therapien, z. B. Physio- bzw. Psychotherapie

Moreover, in many countries (e.g. UK, DE, AT, ES, USA, CAN, AUS), for patients with mild to moderate symptoms 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. For patients with persistent anosmia and/or dysgeusia, a referral to specific olfactory training therapy may be helpful [39, 44]. Furthermore, given the impact distress can have on persistent symptoms, the threshold for a referral to psychotherapy should be low [45]. Besides, non-medical healthcare services can be suggested for patients with more severe symptoms in addition to other treatments (e.g. respiratory physiotherapy) [1, 16, 17, 39, 42, 44-46, 49, 50].

(Supported) self-management

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

In several countries (UK, NL, AT, IT, ES, USA, CAN, AUS), it is recommended that the GP advise the patients on how to self-manage their symptoms besides other treatments. This can include information about possible services (e.g. healthcare or social services), the self-check of clinical parameters, such as heart rate, blood pressure, pulse oximetry, sleep surveillance, or self-monitoring by documenting the changes in health conditions and symptom severity (e.g. in a diary, such as the "My post-COVID symptom diary" [46]). Education about the disease plays another critical role in self-management. Especially patients with fatigue need to learn the balance between engaging in modified daily activity and adopting strategies to limit exertion, e.g. by introducing short rests. Besides, recommendations about improving general well-being through an appropriate diet, enough sleep or stress reduction might be helpful for some patients. Supported online programs or apps can also provide such information and advice. 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 4.4.2). In addition, exchanging with patient organisations or support groups might help [1, 11, 39, 42-44, 46, 48, 49, 53-55].

More detailed information about possible referrals is presented in the Appendix (Table A-7, Table A-8 and Table A-9). Figure 4-1 presents a summarised overview of the possible long COVID healthcare pathways.

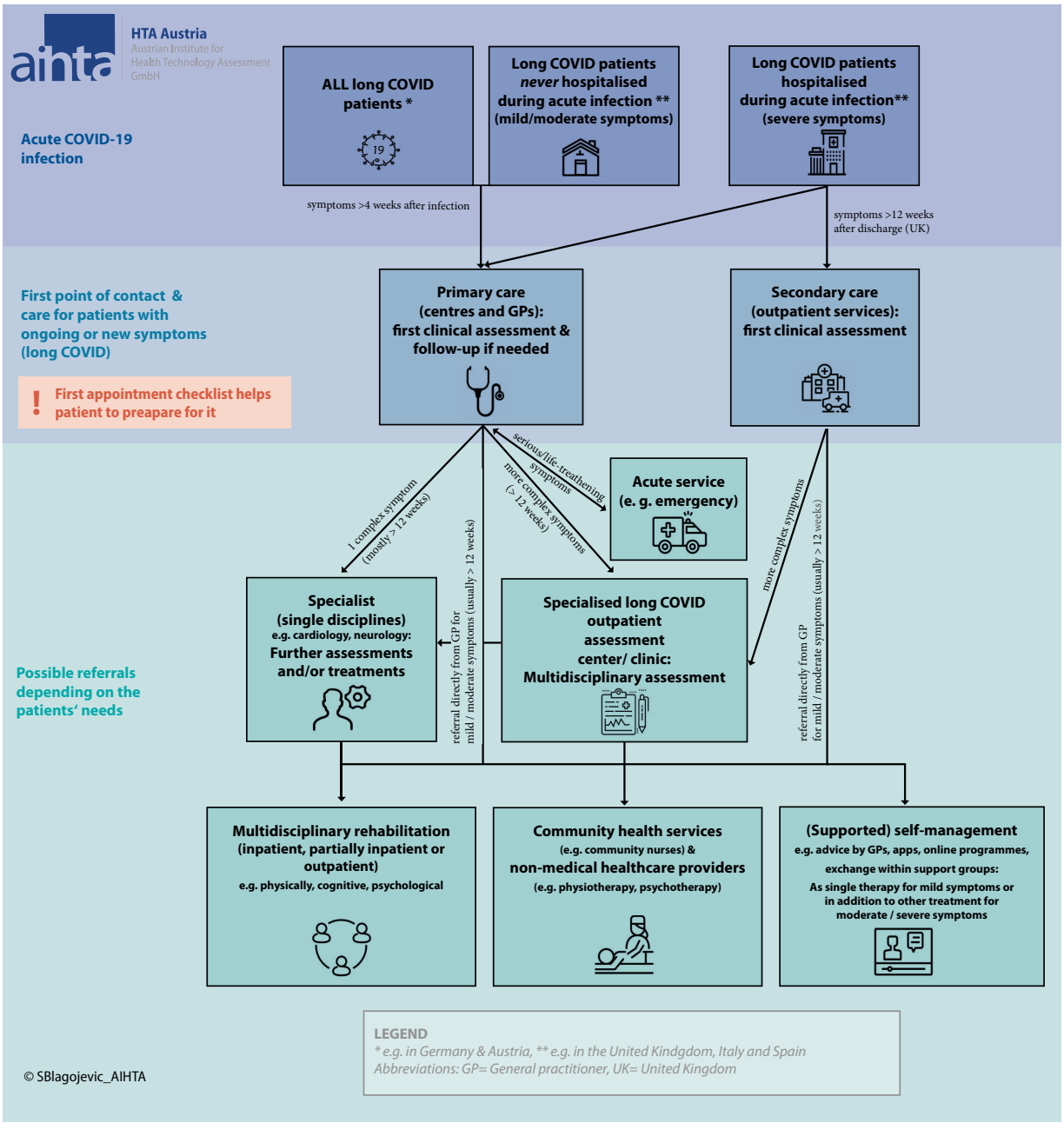


Figure 4-1: Possible long COVID healthcare pathways (updated) (source: own figure)

4.1.4 Possible additional services

Cash payments

keine Long-Covid-spezifischen Leistungen, z. B. üblicher Krankenstandprozess

Two included documents (DE, AT) reported on cash payments for long COVID patients. They recommended that the process of receiving 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 instead based on the main clinical symptom instead of the "broad" long COVID diagnosis if possible [16, 42].

Contributions in kind

Social care services

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

In general, it is essential to deliver information to the patients and their families about where to find additional support. This can be, for example, suggestions to the patients about community offers, such as patient organisations, faith groups, online support groups (e.g. via Facebook) made by the GPs. In some cases, patients can also be referred to social activities, known as social prescribing (e.g. UK) [1, 16, 42, 46, 53].

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, assistance with food preparation and delivery or cleaning or assistance with activities of daily living (e.g. UK, USA, NL, DE) [42, 49, 53, 55].

Employment-specific services

keine Long-Covid-spezifischen Leistungen für Arbeitnehmer*innen, sondern übliche Leistungen empfohlen

z. B. Anpassung der Arbeitsbedingungen

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 documents (UK, AT) emphasised that adjustments to the workplace and working conditions should be possible to facilitate the patient's return to work [1, 42]. The Italian and Australian/New Zealand (ANZICS) documents mentioned that patients should receive support for interviews with their employer before returning to work [43, 47]. According to the German and Austrian documents, 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 individual insurance) before starting to work again [16, 42]. In addition, the patients can contact employee protection agencies or case managers from the health insurance, who provide support in organising the reintegration into work [16].

A more detailed overview of the additional services is given in the Appendix (see Table A-10, Table A-11 and Table A-12).

4.2 Recommendations about long COVID care pathways for children and adolescents

4.2.1 Included evidence

insgesamt 9 Leitlinien mit Empfehlungen zu Kindern & Jugendlichen, davon 4 neu

In total, nine long COVID documents [1, 2, 16, 22, 26, 42, 43, 46, 49] were identified with recommendations for children and adolescent patients, of which four were standardised clinical guidelines and five [22, 26, 43, 46, 49] were guidance papers.

Of the nine documents, two had already been included in the original report [16, 42], three had been updated since August 2021 [1, 2, 49], and four were newly identified [22, 26, 43, 46].

2 Leitlinien aus Italien & den USA speziell zu Kindern & Jugendlichen

Two documents, one from Italy [26] and one from the USA [22], solely focused on managing long COVID in children and adolescents. The other seven documents [1, 16, 42, 43, 46, 49, 69]) included recommendations primarily for adults and marginally for children and adolescents. These seven documents were already described in chapter 4.1.1.

evidenzbasierte Empfehlungen (USA) & evidenz-& konsensusbasierte Empfehlungen (IT)

Of the children and adolescents-focused documents, the US document [22] was declared as an interim document. In the US document [22], the recommendations were evidence-based, whereas, in the Italian document [26], the recommendations were based on a mix of evidence and expert consensus. The Italian document [26] declared no funding and authors' conflicts of interest. The US document [22] did not report on it.

Leitlinie aus IT mit Fokus auf nicht-hospitalisierte Kinder & Jugendliche, US-Leitlinie: hospitalisierte & nicht-hospitalisierte Pat.

The US document [22] involved recommendations for ongoing as well as post-COVID, while the Italian document [26] did not report on which long COVID definition the recommendations relate. The Italian document [26] mainly focused on children and adolescents who had been treated at home during the acute infection. In contrast, the US document [22] also looked at children and adolescents who had been admitted to the hospital.

4.2.2 First point of contact

Hausärzt*innen & niedergelassene Kinderärzt*innen erste Anlaufstelle

In most of the investigated countries (UK, DE, AT, IT, USA, AUS), the primary care sector, including GPs and paediatricians, is recommended as the first point of contact for children and adolescents with persistent symptoms after the acute SARS-CoV-2 infection [16, 42, 43, 46, 49, 69]. The initiation for a first assessment can come from many routes, including the school, community child-development services, community therapies, primary care or parents/caregivers [69]. Especially, worse performance or absenteeism at school, training or work should be seen as "red flags" and indicate a first assessment [1, 26]. Early assessments and treatments are essential for children and adolescents to avoid physical, cognitive and/or mental difficulties in the medium to long term [43].

rasche Untersuchungen wichtig, um Langzeitfolgend zu vermeiden

erste Untersuchung wenn Symptome länger als 4-12 Wochen anhalten; bei milden-moderaten Symptomen telemedizinische Anamnese möglich

A first assessment should be considered between four to 12 weeks from the COVID-19 diagnosis. It should include a comprehensive clinical history, an appropriate examination of physical, cognitive, psychological and psychiatric symptoms, and functional abilities – similar to first assessments in adult patients. According to the US document for children and adolescents, the assessment should be in person for children and adolescents who had a moderate to severe acute infection. In contrast, a phone or video call for patients

who had a mild acute infection may be sufficient [22]. There are questionnaires that may help the practising doctors with the diagnosis, e.g. the NICE questionnaire that contains questions on the most common symptoms of paediatric long COVID [26, 69].

Rolle der Eltern sehr wichtig

The role of parents and caregivers is essential in long COVID for children and adolescents. They need to offer lots of love and affection, establish and maintain the usual daily routine as much as possible and reassure of positive solutions [26]. Therefore, the GPs or primary care paediatricians should inform the parents/caregivers about the natural course of the disease. They need to address that in general, the symptoms heal within a few days of diagnosis but in some cases the symptoms may persist for more than four weeks or if disappeared can reappear with the same or different characteristics. In addition, parents and caregivers should be informed about alarming symptoms they need to recognise in their children so that targeted interventions by specialists can be fastly indicated [26, 43].

Informationen über die Erkrankung & mögliche alarmierende Symptome sollten an die Eltern übermittelt werden

Mehrheit der Kinder & Jugendlichen brauchen keine spezialisierte Behandlung

Overall, most children and adolescents are expected to be managed by their GP or primary care paediatrician with simple measures including common symptomatic treatments and investigations but also advice on enough sleep, how to handle exercise and possible solutions with school, training or work [2]. The depth and type of investigations recommended by the GP or primary care paediatrician should depend on the clinical relevance and type of manifestation [26].

niedergelassene Ärzt*innen sind für notwendige Nachuntersuchungen verantwortlich

In addition, the GPs or primary care paediatricians are responsible for appropriate follow-up assessments if necessary. The Italian document for children and adolescents, for example, recommended a check-up three months after the diagnosis of the acute infection to confirm normality or address emerging problems [2, 26]. Routine follow-ups for one year after admission is recommended for children and adolescents who had been hospitalised with severe COVID pneumonia [2].

4.2.3 Possible referrals

manche Pat. benötigen weiterführende Untersuchungen & Therapien

As with adult patients, some children and adolescents may need further healthcare, e.g. specialist investigation or treatment, psychological support or rehabilitation [2].

neben Long-Covid Symptomen: einzelne Kinder können das MIS-C bekommen → Intensivbehandlungen können notwendig sein

Even if it does not fall under long COVID, a few children have been seen to develop other syndromes after the acute SARS-CoV-2 infection that need treatment or can even be life-threatening, e.g. the multisystem inflammatory syndrome (MIS-C). These patients have several multisystemic manifestations, including fever, the gastrointestinal tract, the skin and mucous membranes and the cardiovascular system, which are the most common. Symptoms, such as vasogenic shock, myocardial dysfunction or infarction, coronary artery or arrhythmias require admission to the paediatric/cardiac ICU [22, 26, 42, 46].

Überweisung an jeweilige Fachärzt*in speziell bei Verdacht auf Organschäden

Depending on the individual needs and especially those children and adolescents with symptoms indicating organ involvement, further specialised assessments and treatments might be necessary, including, e.g. a pulmonary, cardiological, neurological, ear, nose and throat or psychiatric consultation [16, 26]. According to the Australian document, children and adolescents with persisting symptoms for four weeks post-acute infection should be considered for specialist paediatric advice [46].

Children and adolescents can also be assessed in a multidisciplinary manner by specialists adequately trained to recognise the possible late manifestations and complications in an outpatient clinic or day hospital [43]. For example, children and adolescents with neurocognitive changes, such as inattentiveness, slower in reading or processing, requiring more repetition in learning, less endurance and/or requiring more breaks when reading or performing other cognitive tasks, should be referred to a neuropsychological evaluation to identify symptoms and develop a multidisciplinary treatment plan [22]. The US document for children and adolescents recommended a referral to a multidisciplinary post-COVID clinic if the symptoms persist for more than 12 weeks [22].

Überweisung an multidisziplinäre Long-Covid Ambulanzen, z. B. wenn Symptome >12 Wochen anhalten

Furthermore, for children and adolescents with long COVID but also for their families, dedicated psychological and neuropsychiatric support programmes should be provided [43]. For example, the Italian document outlined that children and adolescents with severe mental health problems that persist beyond 12 weeks after the diagnosis require psychological interventions, e.g. continuous psychological support by existing local services [26]. Besides, depending on the type of symptoms, occupational therapy, physiotherapy, speech and language therapy or support through a dietician/nutritionist can be recommended to the patients if necessary [1].

ggf. psychologische & neuropsychiatrische Unterstützung für die Pat. & deren Familien

Überweisung an andere Therapien, wie z. B. Psychotherapie

In addition, rehabilitation programmes may be helpful for some children and adolescents [43].

weitere Option: Rehabilitation

As the following example will show, often, a combination of several care offers is required [22]: If the child or adolescent experiences delays or changes in cognitive, language, motor or mood and behavioural domains, referral to a neurodevelopmental neurologist, developmental and behavioural paediatrician or neuropsychologist should be indicated. In addition, the referral to a speech-language pathologist, psychologist, and/or physical or occupational therapist may be helpful.

in den meisten Fällen multimodaler Ansatz notwendig

4.2.4 (Supported) self-management

Self-management strategies can be suggested to children, adolescents and their families, e.g. while awaiting referral to other care services. This includes advice about, e.g. enough sleep, healthy nutrition, pacing and exercises, and stress reduction. In addition, it is crucial to show children and adolescents how they can speak up and talk about their feelings and symptoms. Writing a symptom diary might be helpful for them [2].

Selbstmanagement alleine oder begleitend zu anderen Therapien empfohlen

For parents and caregivers, it is important to ask for and accept help and to look after themselves as well, as nobody can care if energy is gone. Telecommunication tools or telemedicine programmes may be supportive, especially for parents with fragile children or children with pre-existing health conditions who have difficulty accessing healthcare facilities [43].

Unterstützung für Eltern ebenso wichtig, z. B. Erleichterung durch telemedizinische Tools

4.2.5 Possible additional services

andere Unterstützungsmöglichkeiten:

For children and adolescents with long COVID and their families, additional services might be necessary:

Anpassung des Schulalltags, z. B.: schrittweise Rückkehr, mehr Zeit für Tests, extra Pausen

gemeinsame Entscheidungen (Pat., Eltern, Ärzt*innen, Schule)

- It is crucial to find a way for children and adolescents affected with long COVID to return to school, training or work. Thereby, a gradual return could be one solution that is discussed between the family, the GP or paediatrician and the school. In addition, a transport service could be considered. Furthermore, school administrators, counsellors, nurses, and social workers can help families and healthcare professionals identify necessary adjustments for the patients, particularly those experiencing thinking, concentration or physical difficulties. Such adjustments could include extra time on tests, scheduled rest periods throughout the day, a modified class schedule or specialist equipment in the classroom. In case specific adjustments were agreed upon, they need to be transparently shared with the other pupils in class [22, 26].
- Similar adjustments could also be requested outside school for activities, such as daycare, tutoring, sports or scouting, to reinforce social activities of the child and adolescent [26].

Unterstützungsmöglichkeiten für Eltern, z. B.: Selbsthilfegruppen, Pflegeurlaub, flexible Arbeitszeiten

As parents and caregivers often play the most significant role in long COVID care, support for them should also be guaranteed, including information about the disease and possible self-management tips, exchange with other affected families, work-related adjustments, such as flexible working hours or filial leave. Furthermore, it is essential to educate the parents/caregivers on how to handle the long COVID condition of one child within the family, e.g. how to explain it to the child's siblings [26].

Figure 4-2 illustrates recommended care elements for children and adolescents with long COVID.

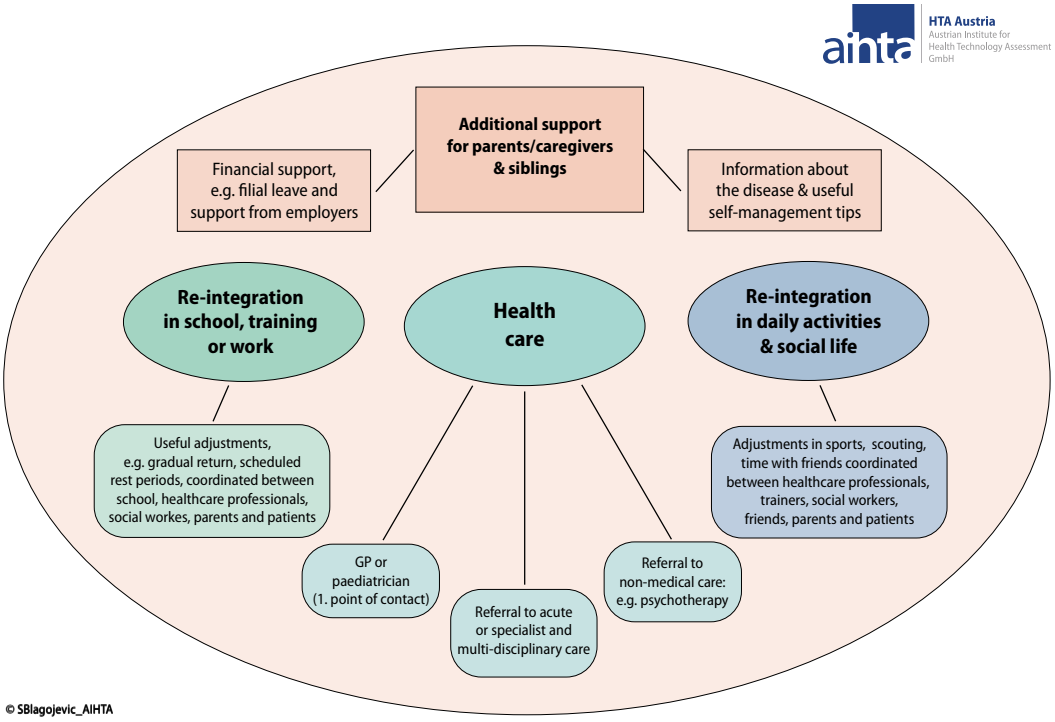


Figure 4-2: Recommended long COVID care structures for children and adolescents (source: own figure)

4.3 Further recommendations for practising physicians regarding decision-making and communication

Empathie, ganzheitlicher & personenzentrierter Ansatz, sowie Mitbestimmungsrecht → Schlüsselfaktoren

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 [1, 39, 42, 46, 49, 53, 54]. Especially when working with children and adolescents, shared decision-making is crucial to avoid unnecessary investigations that could lead to anxiety [1]. 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 [49]. In addition, GPs should recognise the patients' health beliefs, that their symptoms are real and acknowledge the mental health impacts [46].

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

Furthermore, it is recommended that healthcare professionals should always update themselves or be updated through training on evolving guidance on long COVID management to be able to inform patients and/or parents with the latest information on the disease (including possible aetiologies of symptoms), the expected recovery periods and available therapies [39, 43, 45, 49]. In particular, information about self-management strategies and symptoms when to better seek for professional help should be part of the provided information to the patients [1].

gute Kommunikation wichtig, z. B.:

Berücksichtigung von Sprachbarrieren,

richtiger Detailgrad an Informationen

Besides, good communication between healthcare professionals and patients (and parents/caregivers) presents another important aspect in long COVID care. On the one hand, practicing physicians should consider and minimise possible health inequalities, such as cultural differences, language barriers, mental health conditions, mobility or sensory impairments, and learning disabilities, by offering exceptional support [1, 46, 49]. For example, written advice for patients about the most common new or ongoing symptoms (possibly in different languages) can be provided by GPs or community services or by secondary care for people who were in hospital [1]. On the other hand, good communication also involves the right balance in providing detailed information without causing unnecessary anxiety and uncertainty in patients, e.g. through overdiagnosis [42].

wichtige Aspekte bei der Kommunikation mit Kindern & Jugendlichen: altersgerechte Sprache wählen, Fragen ehrlich beantworten, etc.

In addition, it is crucial to show children and adolescents how they can speak up and talk about their feelings and symptoms. The information box below summarises crucial aspects for a good communication with children and adolescents [2].

How to talk to children about long COVID [1-3]:

- Choose the right time
- Pick a quiet space
- Find out what they already know
- Use a clear language appropriate to the child's age
- Allow any reactions, questions and feelings
- Answer questions honestly
- Reassure them that you will support them as best you can
- Encourage them for additional support, e.g. healthcare(their willing is key)

4.4 Examples of existing long COVID care structures in selecten European countries

4.4.1 Included evidence

dieselben 24 Referenzen wie für FF 1 & 2 herangezogen

The same 24 references that were considered for answering the research questions about recommendations for long COVID care pathways for children, adolescents and adults were also used to answer the research questions about examples of existing long COVID care structures. The 24 references had thus already been described in the previous chapters (see chapters 4.1.1 and 4.2.1).

zusätzliche Informationen von Reviews & Websites ...

Further information was obtained from reviews [3, 70, 71] and websites of, e.g.:

- patient organisations (UK, NO, BE, DE, CH) [19, 72-75] and platforms (UK and CH) that focused on children and adolescents with long COVID and their parents/caregivers [3, 76].
- several long COVID healthcare facilities, including specialised centres (e.g. [50, 77-79]), rehabilitations (e.g. [80, 81]), social care services (e.g. social prescribing [82] or fit to work programmes [83]) and long COVID networks (e.g. [84-86]).

Details about the examples of existing care structures are presented in the related tables in the Appendix (seeTable A-18 and Table A-19).

... & Expert*innen-Konsultationen

In addition, unpublished information was retrieved from expert consultations. In the original report, the answers of five experts from the UK, Belgium, Germany and Italy were considered. For this update, further information from four experts from Norway, Belgium, Spain and Switzerland was taken into account. Table A-20 gives an overview of the experts and their answers.

4.4.2 Examples of existing long COVID care structures of selected European countries

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

Of the seven European countries, the UK is the only country that organises long COVID healthcare structures 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 [83, 87]:

1. NICE Leitlinie (+ Updates)

1. The creation of the NICE guideline on long COVID (including regular updates).

2. Selbstmanagement

2. The creation of the Your COVID Recovery Platform.

3. Spezialambulanzen

3. The foundation of designated specialised long COVID outpatient assessment clinics.

4. Forschungsförderungen

4. Funds for long COVID research by the NIHR.

5. NHS Long-Covid Taskforce

5. The establishment of the NHS long COVID task force, which involves long COVID patients, medical specialists and researchers.

in den anderen untersuchten Ländern Versorgungsstrukturen aktuell lokal organisiert

According to the considered literature and contacted experts, the other investigated countries (BE, NO, DE, CH, IT, ES) have no national plans for establishing long COVID healthcare structures. Currently, the long COVID healthcare structures are organised and implemented locally or nationally in these countries. Italy, for example, is separated into different regions, such as the Emilia-Romagna Region, the Abruzzi Region, the Tuscany Region and the Liguria Region. And each region has its long Covid programme [43].

Primary care

in allen 7 Ländern, Primärversorgung meistens 1. Anlaufstelle

In all seven investigated countries (UK, BE, NO, DE, CH, IT, ES), the clinical assessment of long COVID patients generally takes place in the primary care sector, including primary care centres and GPs [16, 52, 70]. For children and adolescents, the primary care paediatrician is also responsible for the first assessment [43, 87]. However, in some countries (e.g. UK, IT, ES), the primary care sector is mainly responsible for COVID-19 patients who had never been hospitalised during the acute infection [1, 43, 44].

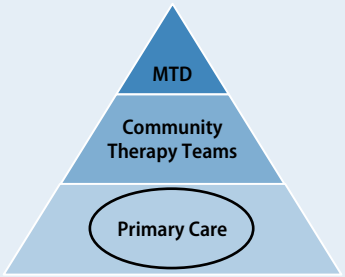
manchmal regionale Zulassungskriterien für Erstuntersuchungen

Furthermore, there can be region-specific selection criteria for the first clinical assessment in primary care. For example, even if the UK has a national long COVID support plan, the selection criteria for the primary assessment can also be specified on a local level (see Example 1) [50].

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 the 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

Trainings & Unterstützungsangebote für Ärzt*innen des Primärsektors werden angeboten (DE) bzw. sind in Entwicklung (BE, ES)

Listen zu Long-Covid-Versorgungsangeboten in DE & CH

In several countries, there are or will be training and tools that help physicians with the first assessment and the diagnosis of long COVID. For example, the University Hospital Charité in Berlin offers training for healthcare professionals in Germany [88]. In Spain, training for physicians with access to university, a long COVID diagnostic tool and a long COVID app that shows the guideline's content are in development [44]. Also, in Belgium, guidance for healthcare workers on detecting and treating long COVID is in development [70]. In addition, in some countries, lists that summarise the outpatient clinics that offer long COVID consultation hours are available or in development (DE, CH) [79] [expert information]. These lists can be helpful for primary care physicians if further investigations or treatments are necessary after the first assessment.

Specialised long COVID outpatient assessment centres/clinics

erste Long-Covid Spezialambulanzen für Erwachsene im UK gegründet: ca. 90 Ambulanzen (Stand: Juli 2022)

Organisation zentral, dezentral oder virtuell möglich

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 (July 2022), around 90 specialised outpatient assessment clinics for adult patients 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, they mainly 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.

meist als multidisziplinäre „One-Stop-Ambulanz" geführt

neurology, psychiatry, psychosomatic, cardiology, pneumology, rheumatology, otorhinolaryngology, dermatology and endocrinology [54]. The clinics generally aim for patients with long COVID symptoms that persist for more than 12 weeks [2]. Recent data analyses showed over 1,500 referrals to these clinics per week [87].

A local example of an integrated specialised long COVID assessment clinic is presented in Example 2 [50].

Example 2: Specialised long COVID outpatient assessment services

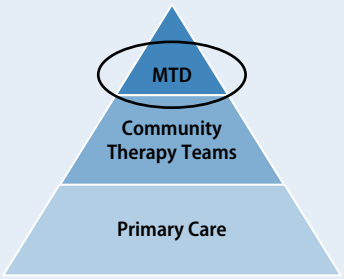
Local healthcare pathway in Leeds, UK:

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 come from the primary care sector (first tier) or community therapy teams (*second tier*). Few referrals come directly from hospital services.

The specialised MDTs are multidisciplinary, including consultants with a seciality 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".

The specialised MDTs hold a virtual meeting for patients with severe medical concerns, 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

Long-Covid Hubs für Kinder & Jugendliche (ca. 15 in UK): Untersuchungen & Koordination weiterer Behandlungen

For children and adolescents, there are approximately 15 so-called long COVID hubs in the UK [3]. These specialist hubs consist of multidisciplinary teams that provide assessment services and remote support to other clinicians to ensure an ongoing holistic support. The hubs also coordinate care for children and young people (up to 16 years of age) across various services [87].

in anderen Ländern Long-Covid Spezialambulanzen meist in Form von Long-Covid-spezifischen Sprechstunden

Other countries (e.g. BE, DE, CH, IT, ES) also established specialised long COVID outpatient assessment clinics primarily for adult patients. In fact, in these countries, the specialised long COVID assessment clinics mainly present outpatient clinics that offer additional long COVID consultation hours. 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 challenging to estimate.

in DE ca. 80 solcher Ambulanzen (Stand Juli 2022)

The German long COVID patient organisation estimated that there are approximately 80 long COVID outpatient assessment clinics of various specialities across Germany (July 2022) [74]. A few outpatient clinics also offer long COVID consultation hours for children and adolescents [74, 79].

in der Schweiz ca. 40 Ambulanzen mit Long-Covid Sprechstunden, 4 für Kinder & Jugendliche

In Switzerland, there are approximately 40 clinics offering long COVID consultation hours [19]. The offers might differ between the clinics: While for some clinics, a referral is needed, other clinics can be contacted directly; some clinics report their availability for consultation hours on their website, while others share their care offers only to physicians who make the referrals [expert information]. For children and adolescents, approximately four clinics offer consultation hours across Switzerland [19].

Anzahl der Ambulanzen in BE, IT & ES unklar

in IT auch Ambulanzen mit Angeboten für Kinder & Jugendliche

Also, in Belgium, Italy and Spain, some clinics offer long COVID consultation hours, but the number of such clinics remains unclear. In Belgium, some hospitals specialised in managing long COVID patients on their initiatives. Frequently, these hospitals are involved in research projects and receive additional funds [expert information]. According to the Italian guideline, two hospitals also offer consultation hours for children and adolescents, one in Rome and one in Sicily [43].

Norwegen: ein paar multidisziplinäre Kliniken für Long-Covid Pat. – Anzahl unbekannt

Concerning Norway, one paper addressed that Norway was asked to establish one outpatient clinic for long COVID patients for each of the four healthcare regions [70]. According to the contacted expert, the regional health authorities in Norway – responsible for specialist services – have established some clinics focusing on patients with long COVID (senfølgeklinikker). These clinics offer multidisciplinary assessment and treatment, and possibly also services to children and adolescents [expert information].

In Table A-18 and Table A-19 in the Appendix, the examples of the specialised long COVID outpatient assessment clinics are presented for each country.

Multidisciplinary rehabilitation

stationäre, teilstationäre oder ambulante Rehabilitationsprogramme in einigen Ländern vorhanden

In many investigated countries (e.g., UK, NO, DE, CH, IT), multidisciplinary rehabilitation programmes are offered to long COVID patients if needed. These programmes vary from inpatient through partial inpatient to outpatient programmes (including digital home-based options) and are established on a regional level [2, 43, 74, 80, 81, 84]. Sometimes rehabilitation is also provided within the specialised long COVID outpatient assessment clinics [52, 54].

genaue Anzahl an Rehabilitationsprogrammen pro Land nicht bekannt

The exact number of rehabilitation programmes in each country offering therapies for long COVID patients is currently unknown:

UK entwickelt standardisierte Reha-Pakete

- In the UK, rehabilitation is offered to long COVID patients. Also, the post-COVID assessment outpatient clinics can offer rehabilitation themselves. Currently, standard rehabilitation pathway packages to treat the most typical long COVID symptoms are in development [87].

Norwegen: Rehabilitation macht großen Anteil der Long-Covid-Versorgung aus

- In Norway, most of the rehabilitation care happens in primary care, with self-management and GP support. Those patients needing further help are admitted to rehabilitation services in secondary care, e.g. in the hospital as an integral part of the treatment or in dedicated rehabilitation departments. In the municipalities, rehabilitation is provided in institutions, such as interdisciplinary home rehabilitation, rehabilitation at various daycare facilities, everyday rehabilitation or, e.g. at private physics institutes [expert information].

in Deutschland ca. 44 Anbieter für stationäre & niedergelassene Programme

- The German long COVID patient organisation estimated that there are around 44 providers of long COVID inpatient and outpatient rehabilitation programmes across Germany (July 2022) [74]. The inpatient programmes involve a three to six-week stay, including specialised therapies for long COVID patients [expert information]. Some-

times the rehabilitation programmes specialise in one symptom; for example, some German rehabilitation clinics focus on the chronic fatigue syndrome.

in der Schweiz 25 stationäre & niedergelassene Angebote (ein paar auch für Kinder)

- In Switzerland, there are approximately 25 inpatient and outpatient specialised rehabilitation programmes for adult long COVID patients. A few of these rehabilitation centres also treat children with long COVID [expert information].

in Italien gibt es auch Reha-Angebote für Long-Covid Pat.

- In Italy, there is, for example, the Italian non-profit organisation AbilityAmo that offers rehabilitation for long COVID patients (see Example 3) [52].

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: zusätzliche 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 [52].

in den meisten Ländern: nicht-medizinische Therapien als weitere Unterstützung möglich

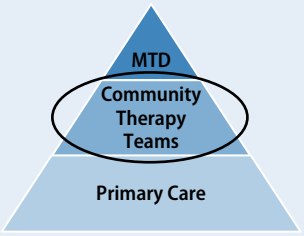
Schweiz: INSELhealth Cofit App zur Unterstützung für Therapiepläne

Furthermore, in most of the investigated countries (e.g. UK, BE, DE, CH, IT), 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) [2, 16, 50]. 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 Switzerland, the INSELhealth Cofit app (available in German) proposes treatment plans based on the patients' health data and thus can be helpful for, e.g. physiotherapists [89].

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 a single discipline can adequately meet. Possible disciplines include occupational therapy, physiotherapy, dietetics or speech and language therapy.



Abbreviations: COVID – Coronavirus disease, UK – United Kingdom

(Supported) self-management

Patient*innen-Organisationen & Selbsthilfegruppen in mehreren Ländern verfügbar

In many countries, long COVID patient organisations (e.g. UK, NO, BE, DE, CH, ES) provide information and support to the patients, inter alia, on how to self-manage their symptoms [19, 44, 71-75]. In addition, some countries have support groups or long COVID networks for adult patients, children, adolescents and their parents/caregivers (e.g. DE, CH) [84-86, 90]. In Norway, there is a platform for the public [75] that provides information about long COVID, including videos and WHO fact sheets, also available in different languages [expert information].

Unterstützung durch Long-Covid Apps, z. B. 2 aus der Schweiz & 1 aus Deutschland

During the last year, long COVID apps have been developed. For example, in Switzerland, there are two German-speaking apps available: The "Long-Covid Tagebuch App" helps the patients to make notes about their symptoms and changes in symptoms and thus can help them to learn from symptoms. The app, the "INSELhealth Cofit app", can be used by therapists and patients. It proposes exercises that can be done at home without a therapist. In addition, the app provides information about the disease, self-management and useful contact addresses [89]. In Germany, the "Techniker Krankenkasse" refunds the app, "Fimo" (German-speaking). This app supports long COVID patients with fatigue, including a symptom diary, clinical questionnaires, exercises adapted to individual needs and the possibility to export the health data, e.g. to the GP [91].

Long-Covid-spezifisches Online-Programm aus dem UK

In the UK, a 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) [92]. So far, it is the most famous long COVID-specific online programme.

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 for children, adolescents and adults, 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. Recent analyses showed that there have been made over 1.5 million visits to the website [87].

The Your COVID Recovery Online Programme is a password-protected web app available on a computer, tablet, or smartphone. The programme contains four stages with various tasks helping the patients set realistic goals to handle their long COVID symptoms and 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 using the offered symptom tracker and/or the chat, where they can directly contact healthcare professionals or join the community forum. To receive access to this online programme, the patients need a referral from a healthcare professional.

Abbreviations: COVID – Coronavirus disease, UK – United Kingdom

zusätzliche Unterstützungsangebote für Kinder, Jugendliche & Eltern aus UK:

z. B. Long Covid Kids Website & Apps zur Unterstützung der mentalen Gesundheit

In addition to this programme, there are also other specialised support systems for children and adolescents with long COVID and their parents/caregivers in the UK. For example:

- **Longcovidkids:** This website provides comprehensive information about the disease in children and adolescents, possible consequences and available support systems to the patients and caregivers [3].
- **Young Minds Website:** This website offers self-management recourses for children, adolescent and their parents/caregivers. It is not restricted to long COVID [93].
- **The Kooth app:** This app provides mental health support for children and adolescents between ten and 25 years and is freely available, also for long COVID patients [94].
- **The Emotional Wellbeing and Mental Health Service (EWMHS):** This initiative provides online self-management advice and support to children, young people and their families who need help with their emotional wellbeing or mental health difficulties. It is not restricted to long COVID [95].

Additional services

keine Long-Covid-spezifischen (Sozial-)Leistungen identifiziert;

es gelten dieselben Leistungen wie für andere Erkrankungen, z. B.:

soziale Unterstützungsleistungen wie Social Prescribing (siehe Beispiel 6),

Wiedereingliederungs-teilzeit,

Anpassungen der Arbeitsbedingungen

Umschulungen

Long COVID-specific additional services could not be identified in the investigated European countries (UK, NO, BE, DE, CH, IT, ES). Nevertheless, the same services as for other (chronic) diseases are generally available for long COVID patients in these countries. Such services include, for example:

- ***Social care services*** like **social prescribing** that can also be offered to long COVID if deemed appropriate (see Example 6) [82].
- ***Work-related services*** that facilitate the come back to work, including, for example:
  - **The fit for work programme** (UK): a government-funded service that offers free impartial work-related health advice [83].
  - There is also the possibility of **a phased return** (UK) or **gradual reintegration** (DE). The patients are supported to gradually return to work after an illness [1, 96, 97]. In addition, there are also support networks that offer guidance for employers and managers on how to help employees return to work (e.g. UK, CH) [97-99]. For example, adjustments to working conditions can be discussed, including, alteration to timings (work start and finishes and breaks), altered hours (e.g. shorter days or days off between workdays), alteration to workload and additional support (e.g. extra time for healthcare appointments, home office) [100, 101].
  - **The transitional allowance** (e.g. DE, UK) enables the patients to switch the field of work if the previous work does not fit after the illness. The German Pension Insurance, thereby, provides exceptional support to the patients, such as financing necessary (re-)training(s) [16, 97].

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 but so far, they have not been specifically linked to long COVID.

Abbreviations: COVID – Coronavirus disease, UK – United Kingdom

nicht-medizinische Unterstützungsangebote für Kinder, Jugendliche & deren Familien, z. B. finanzielle Unterstützungen ...

Also when children and adolescents suffer from long COVID, additional social care services might be necessary. In the UK, for example, the local council is responsible for providing services in the local areas, such as additional services for disabled children. Thereby, the carer's assessment looks at the need for family support, including help at home, support for parents and caregivers with work and/or planning for emergencies. Furthermore, in most countries, there are helplines and tools that support parents and caregivers of a child with long COVID with the application of available financial benefits [3].

... & spezielle Netzwerke für die Unterstützung bei der Rückkehr an die Schule, Lehre oder den Arbeitsplatz

Similar to adult patients, children and adolescents with long COVID might require special arrangements in school, training or work, e.g. to support the comeback. For example in the UK, the Special Educational Needs and Disability Coordinators (SENDco) oversee the needed changes for the children. In addition, clinical commissioning groups ensure that health services cooperate with schools to support patients with medical conditions [3]

5 Discussion

Adults but also children and adolescents can suffer from long COVID even if the prevalence rates vary between the studies and remain uncertain. The reasons are the heterogeneous studies concerning the design, inclusion and exclusion criteria, follow-up duration, and long-term clinical manifestations' assessment. Furthermore, most epidemiological studies had significant methodological limitations, e.g. the collection of information via questionnaires and subjective responses of patients or caregivers and the absence of a control group. In addition, data on pre-existing medical conditions, including mental health problems, were rarely reported. Overall, the correlation between the reported symptoms in positively tested study groups and the acute SARS-CoV-2 infection could not always be ensured, especially in children and adolescents, because controlled studies showed similar prevalences of the same symptoms in SARS-CoV-2 positive and control groups [26, 102-104].

Long-Covid Prävalenzen noch unklar – insbesondere bei Kindern & Jugendlichen

methodische Limitationen in den Studien

vor allem für betroffene Kinder & Jugendliche rasche Diagnose & Behandlung wichtig, um Langzeitfolgen zu vermeiden

Nevertheless, particularly for those children and adolescents who experience persisting symptoms after an acute SARS-CoV-2 infection, early diagnosis and treatments are crucial to prevent physical, cognitive and mental difficulties in the medium to long term [43].

Next to the individual consequences of long COVID, the effect on the broader economy must also be considered. For example, the average sick leave time for adult patients has been longer compared to other infectious diseases. Some patients may even require ill-health retirement due to their inability to work [38, 105]. Furthermore, parents and caregivers of affected children and adolescents might also need adjustments to provide informal care, e.g. reduced working hours or filial leave [3].

Long-Covid hat ökonomische Auswirkungen: z. B. aufgrund der Arbeitsunfähigkeit oder -reduktion

Thus, long COVID has forced structural adaptions in health and social care. Against this background, the present update aimed to provide an overview of recommendations about long COVID health and social care pathways for adults (*updated*) and children and adolescents (*new*). Furthermore, this update presents examples of existing long COVID care structures in selected European countries for children, adolescents and adults.

Projektziel: Update der empfohlenen Versorgungspfade & Beispielen zu etablierten Strukturen; neu: Kinder & Jugendliche

Included evidence and its limitations

In total, 15 long COVID guideline documents (UK, DE, AT, IT, ES, ESCMID, USA, CAN, AUS, NZ, WHO) [1, 2, 16, 17, 22, 26, 39, 42-49] were included, of which 13 documents were summarised for recommendations about long COVID care pathways for adults and nine documents for children and adolescents. Two of the nine documents focused on children and adolescents specifically [22, 26], while the other seven were more general guidelines from which we extracted information on children and adolescents.

15 Leitlinien, davon 13 mit Empfehlungen für Erwachsene & 9 mit Empfehlungen für Kinder & Jugendliche

In addition, the four reviews (UK, USA, BE, IT, DE) [11, 50-52] and five expert papers (UK, NL, DE) [53-57] that were already included in the original review were still considered in this update. However, the adapted inclusion criteria included no new reviews or expert papers.

keine neuen Reviews & Expert*innen-Papiere eingeschlossen

limitierte Qualität der Evidenz aufgrund der Aktualität des Themas: Empfehlungen meistens auf Expert*innen-Konsensus basierend

The quality of the included guideline documents is limited due to the topicality of the theme and the urgency for research in this regard. Most of the recommendations of the included documents were preliminary and based on expert consensus. Therefore, many documents were presented as "living documents" that are deemed to be updated when new evidence arises. Moreover, the included reviews and expert papers of the original report are limited in their methodology and present the lowest level of the evidence pyramid, respectively.

zusätzliche Informationen zu bestehenden Strukturen von Websites & Expert*innen → nicht vollständig

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-20), were considered for answering the third and fourth research questions. The information from websites might be incomplete, and the information from experts could be biased due to the low number of contacted experts per country.

Recommended long COVID care pathways and possible difficulties

First point of care

Primärversorgung deckt Großteil der Long-Covid-Versorgung ab,

In most of the analysed countries, the primary care sector, including GPs, primary care centres and primary care paediatricians, is recommended for the first clinical assessment in former hospitalised and non-hospitalised patients between four to 12 weeks after the diagnosis of SARS-CoV-2.

in manchen Ländern auch Krankenhausambulanzen für ehemals hospitalisierte Pat.

However, the selection criteria, which patient group receives which services, can differ between the investigated countries. In some countries (e.g., UK, USA, NL, IT, ES), the hospital outpatient departments can also be the first point of contact for former hospitalised COVID-19 patients if symptoms persist [1, 16, 42-44, 49, 51, 53].

Eltern spielen wichtige Rolle in der Versorgung von Kindern & Jugendlichen

Concerning long COVID care for children and adolescents, the treating physicians should also focus on the parents and caregivers, as they present the most critical pillar. Therefore, the GP or primary care paediatrician has to inform them about the disease and possible treatment steps and where they can receive additional social and/or financial support if needed [26, 43].

mögliche Hürden:

Regarding the primary care sector, however, some difficulties might occur at the first point of contact in clinical practice:

Difficulties with the diagnosis

Diagnosestellung „Long-Covid" sehr komplex, noch schwieriger bei Kindern

To date, not all practicing physicians are thoroughly familiar with the difficult diagnosis of long COVID. In the absence of simple clinical tests, practicing physicians need to rely on other diagnostic measures, like the history of the past SARS-CoV-2 infection, the incomplete recovery accompanied by possible long COVID symptoms, and the exclusion of another diagnosis. The diagnosis of long COVID becomes even more complicated for younger children who have difficulties in expressing their symptoms.

fehlende medizinische Unterstützung – Pat. probieren nicht-evidenzbasierte Empfehlungen aus

These uncertainties of physicians can lead to patients or parents of affected children feeling misunderstood and consequently starting to self-manage the symptoms by following non-evidence-based suggestions from the internet at their own expense, e.g. taking expensive supplements. Some even have undergone privately paid dialysis following recommendations from untrustworthy sources [106, 107].

Besides, the severity of some common long COVID symptoms, like fatigue or psychological issues, is hard to detect. Multiple issues need to be disentangled before the diagnosis can be made. It needs to be considered that not only the actual SARS-CoV-2 infection can cause persistent symptoms such as fatigue, depression or anxiety, but also the consequences of the global pandemic (e.g. isolation, unemployment, fear of infection) can do so. Furthermore, fatigue, depression and anxiety are primarily measured through self-reported, sometimes non-validated surveys, which makes an objective diagnosis almost impossible. Indeed, this does not diminish the mental symptoms' impact on the patients, but needs to be considered for the diagnosis [38].

manche Symptome, wie Mündigkeit, besonders schwierig zu diagnostizieren

Fragebögen zur Diagnostik nur teilweise validiert

For these reasons, practicing physicians should receive continuous training about the disease itself, its diagnosis and management as soon as new evidence occurs. For example, in Austria, a web tool based on the Austrian long COVID guideline (available in German) was developed by the Karl Landsteiner University [108]. The tool provides recommendations for the workup and assignment of symptoms temporally associated with the SARS-CoV-2 infection. It considers the exclusion of long COVID from other causes, the recognition of organic-structural causes as a consequence of the infection and the recognition of a worsening of pre-existing underlying diseases in the wake of SARS-CoV-2. In addition, the web tool provides recommendations for treating the assigned disorders and complaints, possible care and coping strategies, and rehabilitation needs and options.

Weiterbildungen bzgl. Diagnose & Therapiemöglichkeiten wichtig

Beispiel: Webtool der Karl Landsteiner Universität (Österreich) basierend auf der S1 Leitlinie

Apart from that, in Germany and Switzerland, the development of lists of long COVID specialists in the outpatient and inpatient sectors is in process. Such lists can help – especially GPs – to refer patients to specialised outpatient clinics or specialists in the surrounding area [109].

Listen zu Long-Covid Spezialist*innen in Deutschland & Schweiz in Bearbeitung

Resource capacities

Considering the expected increase in long COVID patients and the primary role of the primary healthcare sector in long COVID care, each country needs to analyse if there are enough GPs available [44]. From this point of view, it should also be discussed if additional human resources to serve this group of patients is necessary, e.g., providing primary care centres with other support staff in the main areas needed (rehabilitation, mental health, etc.) [44].

Ärzt*innen möglicherweise überlastet → Arbeitsteilung mit anderen Disziplinen möglich?

On the other hand, small steps, such as offering patients so-called "healthcare appointment checklists" that help them to be optimally prepared for the first assessment, can also help GPs save time and thus see more patients [49].

Vorbereitungs-Checklisten für Pat. können Zeit einsparen

Besides the need for primary care, in more complex cases, long COVID patients also require specialist care. However, especially in the countryside, these specialists are rare, causing long waiting times and long travel distances and often, only private specialists are available [110].

insbesondere in den ländlichen Gegenden, wenig Fachärzt*innen verfügbar

Possible referrals

mögliche Überweisungen

After the first clinical assessment and depending on the patients' needs, different referral options are suggested:

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

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

- If the patient suffers from one dominant symptom with the need for a specific discipline, a referral to a specialist for further assessment and/or treatment or a non-medical healthcare outpatient therapist, such as a physiotherapist, psychotherapist, occupational therapist, speech therapist or nutritional counselling is recommended in most of the countries [1, 16, 42, 50]. For children and adolescents, respective child and adolescent specialists are recommended [16, 26]. However, 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 or parents/caregivers of affected children [49]. Therefore, practicing physicians also need to consider non-medical aspects in the decision about a referral. For example, the geographical distance between the patient's residence and the treatment location, as well as private co-payments, especially for non-medical healthcare therapies, need to be taken into account. Alternatively, where appropriate and possible, virtual consultations may be suggested to eliminate additional travel time and costs [16, 42, 49, 53, 56]. Apart from that, several referrals can also increase the risk of contradictory medical advice causing uncertainty in the patients [49].

komplexe Symptome: Überweisung an Spezialambulanzen empfohlen

1-Tages-Aufenthalte insbesondere für Kinder sinnvoll

- Furthermore, GPs or specialists can refer patients with more complex but non-severe symptoms that last more than 12 weeks to specialised long COVID outpatient assessment clinics for further assessments. In the UK and Italy, the centres often offer "one-stop assessments" where consultations with various specialists and diagnostic tests are concentrated on a single day to avoid multiple referrals [2, 43]. Such "one-stop assessments" have been helpful especially for children and adolescents [43].

weitere Überweisungsmöglichkeit: multidisziplinäre Rehabilitation

Unterscheidung zu üblichen Reha-Programmen, z. B.: Anpassung an jüngere Pat.-Population & individuelles Trainingsprogramm ("Pacing")

Follow-up Strategien für zuhause für viele Pat. hilfreich

- For children, adolescents and adults with more complex persisting symptoms who need multidisciplinary therapies, inpatient, partially inpatient or outpatient rehabilitation may be useful. In some countries (e.g. USA), rehabilitation can also be suggested while waiting for a place in a specialised clinic [45]. The rehabilitation programmes for long COVID patients are advised to have a broader scope than usual. On the one hand, the age group of the long COVID rehabilitation population can differ from the regular rehabilitation population, as a large proportion of the affected persons are of working age. Thus, rehabilitation programmes should also support a successful return to work [55]. On the other hand, the programmes should be tailored to the patient's needs. For example, pacing needs to be considered, while usual fixed incremental increases in physical exercise should not be recommended for long COVID rehabilitation [11, 42, 49, 50, 53, 54, 56]. Furthermore, rehabilitation programmes should include specific follow-up strategies to support the patients' dismissal. Such strategies could involve a practice plan for continuing exercises at home, the referral to outpatient non-medical healthcare therapies or support through social workers [111].

(Supported) self-management

Empfehlungen zu Selbstmanagement kann mit zusätzlicher Verantwortung verbunden & belastend sein

Besides, self-manage advice from the practicing physician or via apps, online programs or support groups about how to improve the symptoms by boosting the general wellbeing through appropriate nutrition, sleep management, stress reduction and/or the exchange with other long COVID patients is recommended [1, 11, 39, 42-44, 46, 48, 49, 53-55]. In addition, self-management strategies can be useful for families with affected children [2, 43]. However, self-management can also place a lot of responsibility on the patients and caregivers, which might cause an additional burden on them [112]. Moreover, exchanging 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 [106].

mögliche Limitationen der Apps sollten berücksichtigt werden, z. B.

Datenschutzprobleme, fehlende Evidenz zur Wirksamkeit & Sicherheit oder Interessenskonflikte der Anbieter

Moreover, even though there is a "hype" of long COVID self-management apps popping up, potential limitations of such apps need to be discussed, e.g. [113, 114]:

- Are the apps user-friendly and are the patients adherent to using the apps for a longer time?
- Is the health-related data protected adequately?
- Are the recommendations for these apps based on effectiveness and safety evidence?
- Are there any conflicts of interest of the app provider?

Additional services

dieselben Sozialleistungen wie bei anderen Erkrankungen empfohlen

Regarding additional services for long COVID patients, no recommendations regarding long COVID specific offers could be identified in the literature. In general, the same services as for other (chronic) illnesses, including social services, such as support groups or social prescribing, and financial or employment-specific services, like sick leave, gradual re-integration or re-training, were also suggested for adult long COVID patients [1, 16, 42, 46, 53, 98].

Erfahrungen mit langen Ausfällen bei anderen Erkrankungen eventuell hilfreich

However, these services also have some weaknesses. For example, sick leave, including long-term sick leave, might not automatically protect against termination. Thus, 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.

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

Regarding the increasing interest in social prescribing in some European countries, 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 recommended to take place [115].

Long-Covid muss ggf. 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 [57].

Long-Covid-Versorgung für Kinder = multidisziplinäres Zusammenspiel von unterschiedlichen Sektoren

Additional services for children and adolescents can include support to return to school or hobbies (e.g. gradual return or specific arrangements) and financial or employment-specific support for the parents and caregivers [22, 43]. Thereby, it emerges that long COVID care for children and adolescents

comprises the interplay of different systems, including the healthcare system (GPs and/or specialists), the school (e.g. administrators, counsellors and/or nurses), the social security (e.g. financial support, social workers), the employer of the caregiver and the family.

Further recommendations concerning shared decision-making and communication

gute Kommunikation zwischen Ärzt*in & Pat. wesentlich

insbesondere bei Kinder & Jugendliche unnötige Unsicherheiten vermeiden

Communication between healthcare professionals, patients and/or caregivers is crucial in long COVID care, including empathy and shared decision-making between doctors and patients. Especially when working with children and adolescents, the right balance in providing information to avoid causing unnecessary anxiety and uncertainty to the patients and their caregivers is important. In addition, good communication should consider inclusive communication (e.g. by reducing language barriers) [1, 39, 42, 46, 49, 53, 54].

Long COVID care recommendations implemented in Europe

Long-Covid-Versorgung in den meisten Ländern regional organisiert → Überblick unvollständig

Of the seven analysed European countries (UK, NO, BE, DE, CH, IT, ES), UK is the only country that organises long COVID healthcare structures nationally (see the 5-point plan for long COVID support in chapter 4.4.2). In contrast, other countries are currently managing and implementing long COVID care structures on a regional level. Thus, no overviews of all existing long COVID care structures are available for these countries, making identifying all structures almost impossible.

etablierte Versorgungsstrukturen stimmen mit Empfehlungen überein

rasche Umsetzung im UK – andere Länder haben aufgeholt

Most of the identified long COVID care structures in the seven analysed countries comply with the recommendations in the identified literature. However, it was noticeable that, in particular, the UK succeeded in rapidly adapting its healthcare structures by fastly implementing long COVID-specific care facilities. For example, the UK was the first country to implement specialised long COVID outpatient clinics and develop a specialised online programme for long COVID patients, the Your COVID Recovery Platform [92]. Up to now, the other countries have been caught up on developing their specialised centres and offering online programmes or apps supporting the patients in self-management.

in den meisten Ländern Long-Covid-Versorgung in bestehende Infrastruktur integriert

In many countries, most long COVID care structures were built based on existing healthcare infrastructure. For example, in Germany, Switzerland and Austria, specialised long COVID centres were introduced in hospital outpatient clinics that offer special consultation hours for detailed clinical assessments and recommendations about further specialist assessments and/or treatments. In comparison, in the UK, the specialised long COVID outpatient centres are mainly managed as so-called “one-stop-shops” including clinical assessment and treatment services.

Strukturen für Kinder & Jugendliche im Aufbau wo notwendig → weitere Prävalenzdaten notwendig

The offer of care structures, particularly for children and adolescents, might not yet be fully developed. For example, not all analysed countries have specialised long COVID outpatient centres or rehabilitation programmes for children and adolescents. However, further evidence on the long-term prevalence of long COVID in children and adolescents is needed to estimate better the need for specialised long COVID care for the youngest.

Evidence gaps and ongoing research

Next to this update on long COVID care pathways and structures, there is an ongoing systematic review of the NIHR about long COVID care models, which is planned to be published in December 2022 [116].

laufender NIHR Review zu Long-Covid-Versorgungsmodellen

Besides, several reports, e.g. by the Swedish Agency for Health Technology Assessment and Assessment of Social Services [117], the National Research Action Plan on Long COVID of the Department of Health and Human Services in the USA [118] and the Italian long COVID guideline [43], highlighted that various long COVID-related questions are not yet answered and need further research in the future:

mehrere Berichte aus USA, Schweden & Italien betonten weitere Forschungs-bedarfe

- The underlying cause of the various patterns of long COVID symptoms is still not fully understood. Maybe different immune responses, e.g. T-cell responses, antibodies to COVID-19 or autoimmunity, influence the risk of developing long-term symptoms.

  Pathophysiologie von Long-Covid

- So far, an objective diagnosis of long COVID is still impossible. Further research on optimising the diagnosis of long COVID, e.g. by developing sub-groups, is crucial to improve treatment strategies and prevent future complications.

  objektive Diagnose schwierig → Definition von Subgruppen hilfreich?

- Furthermore, the exact epidemiology of long COVID is still not fully clarified. Therefore epidemiological data are urgently needed, especially for children and adolescents, to plan long COVID care efficiently. However, collecting epidemiological data is challenging as these studies should involve control groups and consider the external context of isolation and societal changes during the pandemics as well [38]. For these reasons, collecting real-world data on the long COVID surveillance is recommended. In the UK and Spain, a national long COVID registry is developing [2, 44]. The UK's registry is planned for patients attending post-COVID assessment clinics [2].

  Long-Covid Prävalenzen noch nicht vollständig geklärt, insbesondere bei Kindern & Jugendlichen

  Long-Covid Register im Aufbau (UK & ES)

- Moreover, high-quality evidence (controlled clinical studies, systematic reviews and meta-analysis) is needed on the effectiveness and safety of possible long COVID treatments and interventions, including, e.g. medication rehabilitation programmes and vaccination. Especially, the recommendations for specific long COVID therapies in children and adolescents are rare.

  gute Evidenz zur Wirksamkeit & Sicherheit von Interventionen notwendig

- Besides, the sustainability of long COVID care, including intervention costs and indirect costs caused by e.g. unemployment, need to be assessed in the future. For example, a currently ongoing systematic review of the NIHR investigates the burden of post-COVID-19 syndrome, including the risk of long-term sequelae, the impact on health-related quality of life and direct and indirect costs compared to non-COVID-19 controls [119]. The anticipated completion date was the 30th June 2022, but until now, the systematic review has not been published.

  Erhebung der direkten & indirekten Kosten einer Long-Covid-Versorgung wichtig, laufender NIHR-Report

Limitations of the present report

Limitationen des Berichts:

This scoping review addresses a topic of high public interest by summarising recommendations for long COVID care pathways and presenting examples of existing long COVID care structures of selected European countries. However, it is also limited in some aspects.

aufgrund von Sprachbarrieren möglicherweise nicht alle relevanten Informationen identifiziert

Firstly, we could only consider German or English to answer the research questions. Due to the omission of information in other languages, relevant recommendations or information on care pathways may have been overlooked. For example, in December 2021, the Norwegian Directorate of Health published an updated guidance to healthcare professionals on rehabilitation recommendations for people with lasting symptoms after the acute SARS-CoV-2 infection; however, it is only available in Norwegian [80].

Fokus lediglich auf Versorgungspfade, nicht auf spezifischen Therapieempfehlungen

Secondly, the present systematic review only addresses care pathways for long COVID patients. Other open questions were not part of this review, such as specific drug and/or intervention recommendations (see the chapter "Evidence gaps and ongoing research"). Other reviews focused on recommendations for specific long COVID treatments [54, 120] or also reported first results of effectiveness studies of long COVID therapies [121].

keine systematische Qualitätsbeurteilung der eingeschlossenen Leitlinien & Reviews,

einige Leitlinien werden regelmäßig upgedated, wenn neue Evidenz vorliegt

Thirdly, as in the original report [40, 41], the quality of the newly included guideline documents was also not systematically assessed. 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" [122, p. 126]. Nevertheless, the identified living documents are planned to be updated regularly when there is new evidence.

fehlende Antworten der Expert*innen → Informationen sind limitiert

Fourthly, some experts (mainly practitioners) who were contacted for further information on existing long COVID care structures did not answer our request (see Table A-20). Thus the information retrieved from experts is limited.

Begriffe standardisiert, um Lesbarkeit zu verbessern → standardisierter Begriff umfasst mehrere Bedeutungen

zusätzliches Verzerrungspotential durch Übersetzungen

Fifthly, as in the original report [40, 41], in this update, the terminologies of the original references were sometimes standardised to improve readability. Thus, minor 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, diagnoses and treatment recommendations in the form of long COVID-specific consultation hours (e.g. DE, AT). In other 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, such as the different German terminologies "Long-Covid Spezialambulanzen" and "Long-Covid Kliniken" that were summarised to the standardised terminology "specialised long COVID outpatient assessment clinics".

6 Conclusion

This updated scoping review summarises the broad spectrum of recommendations for long COVID care pathways in various countries. It shows the comprehensive long COVID care structures established in selected European countries during the last two years.

Überblick zu Empfehlungen & etablierten Versorgungsstrukturen

Long COVID care structures were established based on national recommendations and existing healthcare infrastructures. For these reasons, the recommendations of the national guideline documents and the implemented services might slightly differ between countries and may not be fully convertible between countries. Nevertheless, primary care and self-management are recommended as the main pillars in long COVID healthcare in most of the analysed countries, complemented by specialist care, non-clinical therapies and rehabilitation if necessary. This holds for adults but also children and adolescents.

Versorgungsstrukturen basieren auf nationalen Empfehlungen & Infrastrukturen → Primärsektor größter Anteil

Furthermore, a multidisciplinary and person-centred approach, empathy towards the patients and caregivers, and shared decision-making between doctors, patients and/or caregivers were suggested as key factors for successful long COVID care. Especially for children and adolescents, finding the right balance of necessary treatments and interventions is crucial to avoid unnecessary uncertainty and anxiety.

Schlüsselfaktoren für Long-Covid-Versorgung: z. B. multidisziplinärer & individueller Ansatz

Overall, long COVID care comes with the interplay of various systems next to the healthcare system, including the social care system, employment or education system and the family. This interplay is essential when it comes to the care of children and adolescents. Therefore, planning long COVID care structures requires coordinating support across these different and usually fragmented systems and guaranteeing care that addresses the individual needs of patients and their families. Especially in countries with numerous different funding bodies and organisations responsible for the care structures, such as Austria, the necessity for patient-oriented coordination is particularly important.

Zusammenspiel mehrerer Systeme, Gesundheits- & Sozialsystem, Arbeit/Schule & Familie → Pat-orientierte Koordination wichtig

Besides, the limited evidence base of the existing documents calls for regular future updates with more rigorous data. In addition, several open questions regarding the pathophysiology, prevalence, treatments and costs of long COVID remain and need further research. Thereby, inclusive, representative and diverse patient participation is crucial to receive research results applicable to the wide range of long COVID patients.

weitere Forschung zu Long-Covid notwendig → Berücksichtigung diverser Pat. um anwendbare Ergebnisse zu erzielen

7 Literature

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Appendix

Recommendations for long COVID care pathways

Characteristics of the included literature

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

Reference (author, month, year)	NICE, RCGP, SIGN guideline (updated: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]	Parkin et al (2021) [50]	Barker-Davies et al. (May 2020) [54]	Greenhalgh et al (2020) [53]	Policy Brief 39 (Rajan et al. 2021) [52]
Country	UK						Overview of several countries (mainly England)
Publication type	Living guideline	Guideline	Review	Review	Consensus statement	Clinical perspective/ expert opinion	Review
Evidence basis	Consensus-based	Consensus-based	Evidence-based	Not reported	Consensus-based	Consensus-based	Not reported
Funding & declaration of interest	NR	NR	NR	**Funding:** Leed Clinical Commissioning Group, University of Lees Medical Research Council Confidence in Concept grant **Conflicting interests:** None	**Funding:** None **Conflicts of interest:** None	**Funding:** NR **Conflict of interest:** None	**Funding:** National Institute for Health Research (NIHR), Applied Research Collaboration East Midlands (ARC EM), NIHR Leicester Biomedical Research Centre (BRC) **Conflicts of interest:** KK is Chair of the Ethnicity Subgroup of SAGE, KK & MM are members of Independent SAGE
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.	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	Overview of several countries affected by long COVID & their long COVID health systems.
Long COVID definition	Ongoing & post-COVID symptoms (>4 wks.)	Ongoing & post-COVID symptoms (>4 wks.)	NR	Ongoing & post-COVID symptoms (>4 wks.)	NR	Ongoing & post-COVID symptoms (>4 wks.)	Ongoing symptoms (>6 weeks)
Patient population	Pts. treated at home & hospital (children, adolescents and adults)	Pts. treated at home & hospital (children, adolescents and adults)	Pts. treated at home & hospital (adults)	Pts. treated at home & hospital (adults)	Active pt. population including military personnel and athletes (adults)	Pts. treated at home & hospital (adults)	NR (adults)

Abbreviations: COVID – Coronavirus disease, e.g. – for example, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-2: Characteristics of the included literature – updated (European countries) (part 1)

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Country	Germany			Austria
Publication type	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
Evidence basis	Consensus-based	Consensus-based	Consensus-based	Consensus-based
Funding & declaration of interest	NR	**Funding:** NR **Conflict of interest:** None	**Funding:** NR **Conflict of interest:** None	**Funding:** NR **Conflict of interest:** None
Aim	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 sequelae.	Information for primary care physicians and other first-contact medical providers & physicians who deal with long COVID-affected individuals.
Long COVID definition	Ongoing & post-covid symptoms (>4 wks.)	NR	NR	Ongoing & post-COVID symptoms (>4 wks.)
Patient population	Pts. treated at home & hospital (children, adolescents and adults)	NR (adults)	Pts. treated at home & hospital (adults)	Pts. treated at home & hospital (but no ICU pts.) (children, adolescents and adults)

Abbreviations: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. ICU – Intensive care unit, NR – not reported, pts. – patients

Table A-2: Characteristics of the included literature – updated (European countries) (part 2)

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Italian intersociety consensus on management of long COVID in children (March 2022) [26]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Country	Italy		Spain	Netherlands	Europe
Publication type	Interim guidance	Guidance	Guideline	Clinical perspective/ expert opinion	Living guideline[1]
Evidence basis	NR	Evidence- & consensus-based	Evidence-based	Consensus-based	Consensus-based
Funding & declaration of interest	**Funding:** NR **Conflict of interest:** NR	**Funding:** None **Conflict of interest:** None	**Funding:** None **Conflict of interest:** None	**Funding:** NR **Conflict of interest:** Some authors reported minor conflicts of interest.	**Funding:** None **Conflict of interest:** None
Aim	Recommendations on the subject of long COVID provided by the World Health Organisation were adapted to the Italian situation.	Guidance on how to identify and manage children with long COVID.	Clinical practice guideline for the management of long COVID developed by the Catalan society of Family and Community Medicine.	Interim recommendations for rehabilitation in the hospital & post-hospital phases in COVID-19 & post-COVID-19 pts.	Overview of guidelines for physicians of any medical discipline who are taking care of pts. after acute SARS-CoV-2 infection, with emphasis on those with persisting symptoms after >12 weeks since diagnosis.
Long COVID definition	Ongoing & post-covid symptoms (>4 wks.)	NR	Ongoing & post-covid symptoms (>4 wks.)	Ongoing symptoms (4-12 wks.)	Ongoing & post-covid symptoms (>4 wks.)[2]
Patient population	Pts. treated at home & hospital (children, adolescents and adults)	Most children & adolescents with COVID-19 are treated at home (children & adolescents)	Pts. treated at home[3] (adults)	Pts. treated at the hospital (adults)	Pts. treated at home & hospital (adults)

Abbreviations: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. ICU – Intensive care unit, NR – not reported, pts. – patients

[1] The panel will meet monthly regarding the need for updates.
The panel members will perform an updated search every three months and will update the guidelines once substantial evidence for changing any recommendation is observed.

[2] In the article, it is called post-acute COVID (4-12 weeks after diagnosis) and long COVID (>12 weeks).

[3] The clinical practice guideline focused on patients with long COVID not requiring hospitalisation, whose diagnosis and follow-up has been made in primary care (probably >80% of affected people). It does not focus on hospitalised patients, whose follow-up and management will be carried out by the hospital outpatient department.

Table A-3: Characteristics of the included literature – updated (non-European countries)

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Guidance for Primary Care Physicians (November 2021) [45]	Post-COVID Conditions in children and adolescents (December 2021) [22]	Oronsky et al. (2021) [51]	COVID-19 Scientific Advisory Group Rapid Evidence Report Post-COVID (July 2021) [39]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS COVID-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Country	USA				Canada (Alberta)	Australia	Australia & New Zealand	WHO
Publication type	Living guideline	Guidance	Interim guidance	Review	Guidance	Guidance	Guideline	Living guideline
Evidence basis	NR	Evidence- & consensus-based	Evidence-based	NR	Evidence- & consensus-based	NR	Consensus-based	Evidence- & consensus-based
Funding & declaration of interest	NR	**Funding:** None **Conflict of interest:** None	NR	NR	NR	NR	NR	**Funding:** NR **Conflict of interest:** None
Aim	Evaluating the caring for pts. with post-COVID conditions.	Post-COVID management guidance for primary care physicians as a quick reference guide.	Directions for paediatricians to navigate the follow-up care of infants, children & adolescents.	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.	Recommendations about the optimal management for pts. with post-COVID conditions occurring after acute SARS-CoV-2 infection.	Providing advice & support to GPs & teams when caring for pts. with post-COVID-19 conditions; to encourage the development of individualised plans for ongoing management.	Guidance on the identification and treatment of pts. with COVID-19 *(only the section about long-term impairments is extracted here).*	Guideline about COVID-19 management, including chapters about care & rehabilitation after COVID-19.
Long COVID definition	NR	Ongoing & post-covid symptoms (>4 wks.)	Ongoing & post-covid symptoms (>4 wks.)	NR	Ongoing & post-covid symptoms (>4 wks.)	Ongoing & post-covid symptoms (>4 wks.)	Acute – post-covid symptoms (>12 wks.)	Ongoing & post-covid symptoms (>4 wks.)
Patient population	NR (children, adolescents and adults)	Pts. treated at home & hospital (adults)	Pts. treated at home & hospital (infants, children and adolescents)	NR (adults)	Pts. treated at home & hospital (adults)	Pts. treated at home & hospital (children, adolescents and adults)	Pts. treated at hospital (adults)	Pts. treated at home & hospital (adults)

Abbreviations: ANZICS – Australian and New Zealand Intensive Care Society, CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – general practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, RACGP – Royal Australian College of General Practitioners, USA – United States of America, WHO – Word Health Organization

Long COVID care pathways for adults

First point of contact for adult long COVID patients

Table A-4: First point of contact for adult long COVID patients – updated (UK) (part 1)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (updated: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]
Country	UK		
Publication type	Living guideline	Guideline	Review
Healthcare pathways			
First point of contact			
Primary care investigation: GP consultation	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. *never* 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 a member). 2) Assessment carried out by the GP, using a holistic, person-centred approach, including comprehensive clinical history, and appropriate examination (physical, cognitive, psychological, psychiatric symptoms & functional abilities). 3) Tests & 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). *Hospitalised pts*. 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.	NR
Secondary care investigation	NR	*Hospitalised COVID-19 pts. in general:* 1) should undergo a video or phone follow-up consultation at 12 weeks after discharge by a healthcare professional in secondary care including a check for new or ongoing symptoms or complications 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. *Pts. cared for in ICU or HDU:* 1) Multidisciplinary assessment of rehabilitation needs at the point of step down to other inpatient facilities. Inpatient rehabilitation with defined goals should begin immediately. 2) On discharge from hospital, an assessment of ongoing needs with appropriate community service referral if needed. 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. 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).	NR

Reference (author, month, year)	NICE, RCGP, SIGN guideline (updated: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]
General aspects	The panel emphasised that access to services should not be restricted by the need for a positive SARS-CoV-2 test. The trend to move away from conducting lots of clinical tests towards a model where discussion is held with the individual to determine what matters to them and what their goals are (identify most appropriate tests for the pts.)	NR	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.

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HDU – High dependency unit, ICU – Intensive care unit, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NIHR – National Institute for Health Research, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-4: First point of contact for adult long COVID patients – updated (UK) (part 2)

Reference (author, month, year)	Parkin et al (2021) [50]	Barker-Davies et al. (May 2020) [54]	Greenhalgh et al (2020) [53]	Policy Brief 39 (Rajan et al. 2021) [52]
Country	UK			Overview of several countries (mainly England)
Publication type	Review	Consensus statement	Clinical perspective/expert opinion	Review
Healthcare pathways				
First point of contact				
Primary care investigation: GP consultation	NR	NR	Generally, pts. can be divided into those who may have serious sequelae (such as thromboembolic 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.	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.
Secondary care investigation	NR	NR	NR	NR
General aspects	NR	NR	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.	England: NICE guidelines advise that assessment & management should be tailored to individual's problems, after excluding any coexisting 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 & urgent referral to the appropriate specialist for those with chest pain, palpitations or mental illness.

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HDU – High dependency unit, ICU – Intensive care unit, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NIHR – National Institute for Health Research, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-5: First point of contact for adult long COVID patients – updated (European countries) (part 1)

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Country	Germany			Austria
Publication type	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
Healthcare pathways				
First point of contact				
Primary care investigation: GP consultation	1) Primary care diagnosis: detailed pts. history & physical examination including basic laboratory diagnostic, the assessment of neurological, psychological and functional status & 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 & implementation of post/long-COVID-19 treatment or rehabilitation, including the treatment of fatigue & 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 [60]. 2) In the absence of clinical deterioration, a wait-and-see approach (= watchful waiting) under GP supervision should initially be considered. 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 & psychosocial care. 4) Close cooperation with authorities, health insurance companies and pension insurance providers should be sought. 5) 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).	NR	NR	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. 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) & 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. 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. 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").

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Secondary care investigation	NR	NR	NR	NR
General aspects	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 on 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: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life

Table A-5: First point of contact for adult long COVID patients – updated (European countries) (part 2)

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Country	Italy	Spain	Netherlands	Europe
Publication type	Interim guidance	Guideline	Clinical perspective/expert opinion	Living guideline
Healthcare pathways				
First point of contact				
Primary care investigation: GP consultation	Multidimensional evaluation including clinical, functional, cognitive, psychological & nutritional aspects persisting for >4 weeks from acute infection: full medical history (history of COVID-19 & other health conditions, previous & current symptoms, timing & duration of symptoms, current & previous drug treatment), evaluation of specific signs of long COVID, assessment of activity level of pts. (daily living), assessment of psychological, cognitive & nutritional impact. Assessment can be collected by healthcare professionals or self-completed by questionnaires. For pts. who may have difficulty reporting signs & symptoms, it is important to involve a family member or caregiver in the assessment.	3 consecutive visits in primary care planned: V1: history, examination & complementary tests to study possible underlying causes of symptoms (>4 weeks after the diagnosis of the acute infection): personal medical record, the acute infection, physical examination, laboratory studies, etc. – with active support from nurses. V2: aim to make differential diagnosis if necessary (9-10 weeks after the diagnosis).	For the assessment of physical & psychosocial outcomes that allow the identification of unmet rehabilitation needs core outcome sets are recommended, e.g.: ■ EQ-5D and Short-Form 36 (assess generic health status) ■ Hospital Anxiety and Depression Scale; Patients Health, Questionnaire 9; General Anxiety Disorder 7; the Depression Anxiety Stress Scale 21 (assess anxiety/depression) ■ Impact of Events Scale Revised ■ the Medical Research Council dyspnoea grading scale (measure breathlessness) ■ Montreal Cognitive Assessment (cognitive screening)	First step: assess clinical history to rule out previous underlying conditions and iatrogenic causes or complications related to the acute infection. For pts. with persistent symptoms 4-12 weeks after diagnosis, assessment should be considered on a case-by-case basis, according to severity & course of symptoms. For pts. with persisting symptoms >12 weeks after diagnosis, assessment is necessary. Long COVID is a diagnosis of exclusion. After ruling out other conditions, assessment should assess symptom severity and impact on QoL.

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Primary care investigation: GP consultation *(continuation)*	Pts. with low clinical complexity can be coordinated & managed by the GP. The structuring of the care should be led by a GP with expertise and experience in COVID-19. Treatment program must include appropriate follow-up.	V3: evolution of long-term symptoms and re-evaluate possible causes (13-14 weeks after diagnosis). Some symptoms require early suspicion and guidance, e.g. arthritis, myositis, pancreatitis, or other skin, neurological, renal, haematological, endocrine & systemic autoimmune manifestations.		
Secondary care investigation	There should be appropriate specialist support & local programs in which primary & specialist care are also integrated with multidisciplinary & hospital rehabilitation services.	For pts. that were treated in hospital the hospital outpatient departments are the first point of contact.	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.	NR
General aspects	Positive molecular or antigen swab & a positive antibody test for COVID-19 are not a prerequisite for diagnosis.	Considering the key role of social determinants such as poverty, discrimination & social exclusion. Isolation itself can lead to reduced physical activity & greater isolation, which may be particularly problematic in older adults → potential increase in mental health problems. Mental health & well-being should be reinforced by increased social solidarity, informal social support, mutual assistance & other collective or community-based measures.	Limited access to treatments for disadvantaged communities needs to be considered.	Clinicians should discuss the likelihood of spontaneous recovery with pts. GPs should be aware of the substantial incidence of psychological sequelae of COVID-19 of any severity and, whenever relevant, refer pts. for assessment & therapy.

Abbreviations: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life

Table A-6: First point of contact for adult long COVID patients – updated (non-European countries) (part 1)

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Guidance for Primary Care Physicians (November 2021) [45]	Oronsky et al. (2021) [51]	COVID-19 Scientific Advisory Group Rapid Evidence Report – Post-COVID (July 2021) [39]
Country	USA			Canada (Alberta)
Publication type	Living guideline	Guidance	Review	Guidance
Healthcare pathways				
First point of contact				
Primary care investigation: GP consultation	Many post-COVID conditions can be managed by primary care providers, incorporating a patient-centred approach to optimise the QoL & function of affected pts. 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. Referral to multidisciplinary post covid centres for additional care, where available, can be considered.	Primary care physicians mostly the first point of contact; First assessment: detailed history (new symptom vs continuation of a prior symptom) & physical & judicious test ordering as needed.	1) Physician examination of pts. includes mapping of current symptomatic status or medical concerns. A COVID-19 exposure status & potential disease history through oral history & possible clinical testing is established. In addition, screening for possible non-COVID-19 comorbidities or chronic medical conditions should also be considered. 2) After physician examination, administer appropriate medical treatments for acute symptoms or established underlying chronic conditions.	Recommended GP assessments: ■ Complete Assessment including functional & physical assessment, patient history & testing to rule out differential diagnosis & continued close surveillance, especially among those with pre-existing conditions. ■ Identification of red flags. For some symptoms (e.g. neurological) the management by the GP is largely supportive, including setting patients' expectations (e.g. never returning to pre-infection baseline) but ensuring pts. safety.
Secondary care investigation	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.	NR	NR	NR
General aspects	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.	NR	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.	Pts. with long COVID will need to increase their exercise workload gradually. Pacing & energy conservation strategies are very important in this population. Pts. may need to prioritise activities of daily living over a return to exercise if they do not have the energy to manage both.

Table A-6: First point of contact for adult long COVID patients – updated (non-European countries) (part 2)

Reference (author, month, year)	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS Covid-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Country	Australia	Australia & New Zealand	WHO
Publication type	Guidance	Guideline	Living guideline
Healthcare pathways			
First point of contact			
Primary care investigation: GP consultation	GPs should conduct a comprehensive clinical history & appropriate examination that involves assessing physical, cognitive, psychological, psychiatric symptoms & functional abilities. Pats. Assessment should include: ■ History of acute infection & other health conditions ■ Nature & severity of previous & current symptoms ■ Timing & duration of symptoms since the start of the infection ■ Mental health & wellbeing ■ Available supports	2-6 weeks post-discharge, pts. should be re-assessed by their GP: ■ General health review ■ Review functional & mental health impairments previously identified at hospital discharge ■ Refer to rehabilitation if needed ■ Engage with carer & link with supports ■ Review return to work Pts. should be re-screened through their GP at 12 weeks post-COVID-19 symptom onset to monitor for ongoing symptoms & problems. Screen for new functional or mental health impairments: ■ A cognitive assessment test (e.g. Montreal CAT) ■ Anxiety & depression scale ■ Post-traumatic stress (e.g. Impact of event scale) ■ 6-minute walk ■ EuroQoL-5D5L	If any one or more of the symptoms persist, or pts. develop new or changing symptoms, then seek medical care according to national (local) care pathways (GP, relevant specialists, rehabilitation professionals, mental health & psychosocial providers, social care services). Screening includes a full history, evaluation of pre-existing health conditions, observation of the patient performing functional tasks, a symptom-based questionnaire or an easily administered screening tool. When resources permit, define & clinically assess impairment types by functional domains, including respiratory function (spirometry, diffusing capacity of the lungs for carbon monoxide, Medical Research Council dyspnoea scale), cardiovascular function (6 minutes walking distance), swallowing function (such as dysphagia severity scale), musculoskeletal function (such as hand grip strength, Medical Research Council sum score), cognitive functioning (Montreal Cognitive Assessment, Mini-Mental State Examination), & mental functioning (Hospital Anxiety and Depression Scale, PTSD checklist-5, Impact of Event Scale-Revised). Screening tools: ■ Timed Up and Go test for physical function ■ Whooley questions for depression, ■ Generalized Anxiety Disorder 2-item for anxiety, ■ Mini-Cog for cognition
Secondary care investigation	NR	NR	
General aspects	A consultation with the GP is recommended within six weeks from isolation for all pts. It is important to reassess the family/social situation, as the carer's leave & financial stability can become an increasing concern.	NR	NR

Abbreviations: ANZICS – Australian and New Zealand Intensive Care Society, CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life, RACGP – Royal Australian College of General Practitioners, USA – United States of America, WHO – World Health Organization

Possible referrals for adult long COVID patients

Table A-7: Possible referrals after the first assessment in primary or secondary care for adult long COVID patients – updated (UK) (part 1)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (update: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]
Country	UK		
Publication type	Living guideline	Guideline	Review
Different medical service options depend on the pts. needs			
Acute services (e.g. emergency)	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.	NR
Specialised long COVID outpatient assessment centres/clinics	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). ■ Ensure coverage for all. ■ Are available, following GP or other clinicians, referral. ■ Access is predicated upon an assessment framework (e.g. Equality and Health Inequalities Assessment Framework). ■ Access is monitored via clinic data and health equity audit. ■ Access is acted upon urgently if discrepancies are identified. ■ Internal & external communication plan for raising awareness with clinical community & key stakeholders (pts. & public, primary care networks, community, secondary care & mental health services). ■ Access to a multidisciplinary team of professionals. ■ Access to diagnostic tests recommended by NICE. ■ Support collaboration across localities. ■ The post-COVID assessment clinics refer pts. with symptoms lasting >12 weeks according to their needs to: ■ Self-management/supported self-management (e.g. Your COVID Recovery Phase 2, interactive rehab). ■ 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. ■ Specialists for specific conditions within the clinic.	NR

Reference (author, month, year)	NICE, RCGP, SIGN guideline (update: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]
Self-management advise and/or supported self-management	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, and apps.	Options to enable pts. (mostly with milder symptoms) with self-care: ■ Signposting to Your COVID Recovery online platform. ■ Techniques such as shared decision-making, health coaching, virtual group consultations for peer support & social prescribing. ■ Linking with the third sector in recognition of the whole-person biopsychosocial needs using Patient Activation Measures (PAM) to help to determine the level of support required.	Some pts. will need long-term support in the community, including help with self-management strategies.
Multidisciplinary rehabilitation services (e.g. inpatient or outpatient)	Rehabilitation prescription includes a personalised rehabilitation & management plan: Areas of rehabilitation & interventions Symptom management for all presenting symptoms	After the post-ICU multidisciplinary clinic re-assessment at 4-6 weeks post-discharge referral to early rehab or mental health services, if needed. A multidisciplinary team should tailor support & rehab: ■ Enable pts. access to clinical review in primary care & more specialist advice or rehab, if needed. ■ Development of individual care plans for physical, mental & social needs ■ Including support through the Your COVID Recovery interactive online rehab platform.	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.
Physical rehab	Physiotherapy & rehabilitation medicine	Pneumological rehabilitation ■ Cardiological rehabilitation ■ Physiotherapy for pts. with breathlessness, de-conditioning, fatigue & dizziness, including specific guidance on pacing, rest & recovery time ■ Occupational therapy for pts. with cognition, delirium, mental health & functional difficulties ■ Co-morbidity management, e.g. for diabetes (dietetics & nutrition services) ■ Speech & language therapists for pts. with cognitive (brain fog), swallowing, voice & respiratory difficulties.	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!
Psychological and/ or psychiatric rehab	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 psychological interventions as part of integrated, multidisciplinary rehab → this has been incorporated into the NHS "Your COVID Recovery" programme as support for their rehab.

Reference (author, month, year)	NICE, RCGP, SIGN guideline (update: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]
Neurological and cognitive rehab	NR	NR	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.
Specialist care for (symptom)-specific complications, if necessary	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.	NR
Community health services & non-medical healthcare providers	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.	NR
Additional medical guideline recommendations			
Follow-up monitoring	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.	NR	NR

Abbreviations: CFS – Chronic fatigue syndrome, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HDU – High dependency unit, NIHR – National Institute for Health Research, ICU – Intensive care unit, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-7: Possible referrals after the first assessment in primary or secondary care for adult long COVID patients – updated (UK) (part 2)

Reference (author, month, year)	Parkin et al (2021) [50]	Barker-Davies et al. (May 2020) [54]	Greenhalgh et al (2020) [53]	Policy Brief 39 (Rajan et al. 2021) [52]
Country	UK			Overview of several countries (mostly England)
Publication type	Review	Consensus statement	Clinical perspective/expert opinion	Review
Different medical service options depend on the pts. needs				
Acute services (e.g. emergency)	NR	NR	NR	NR
Specialised long COVID outpatient assessment centres/clinics	NR	NR	NR	NR
Self-management advise and/or supported self-management	NR	Pts. should be given strategies on how to manage recovery.	Self-management can include: ■ daily check of clinical parameters (e.g. oximetry) ■ attention to general health (diet, sleep, quitting smoking, limiting alcohol, limiting caffeine) ■ rest & relaxation ■ self-pacing & gradual increase in exercise if tolerated ■ setting achievable targets ■ Patient organisations emphasise wellbeing, mindfulness, social connection, self-care (including diet & hydration) & peer support.	NR
Multidisciplinary rehabilitation services (e.g. inpatient or outpatient)	NR	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. Where needed, rehabilitation can also be delivered by various virtual models, including video-linked classes & home education booklets with additional telephone support.	NR
Physical rehab	To improve strength & endurance, exercise programmes should be prescribed but with caution, especially where pts. may experience ongoing fatigue problems.	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.	NR

Reference (author, month, year)	Parkin et al (2021) [50]	Barker-Davies et al. (May 2020) [54]	Greenhalgh et al (2020) [53]	Policy Brief 39 (Rajan et al. 2021) [52]
Physical rehab *(continuation)*			For some symptoms (e.g. fatigue), exercise should be undertaken cautiously & cut back (pacing) if pts. develop fever, breathlessness, severe fatigue or muscle aches.	
Psychological and/ or psychiatric rehab	NR	NR	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).	NR
Neurological and cognitive rehab	NR	NR	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.	NR
Specialist care for (symptom)-specific complications, if necessary	NR	NR	However, specialist referral may be indicated based on clinical findings, e.g.: ■ Respiratory if suspected pulmonary embolism, severe pneumonia. ■ Cardiology if suspected myocardial infarction, pericarditis, myocarditis or new heart failure. ■ Neurology if suspected neurovascular or acute neurological event.	Those who need further care should be referred to specialists for input in more complex cases of specific organ dysfunction.
Community health services & non-medical healthcare providers	NR	NR	NR	NR
Additional medical guideline recommendations				
Follow-up monitoring	NR	Pts need to be followed up closely.	NR	NR

Abbreviations: CFS – Chronic fatigue syndrome, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, HDU – High dependency unit, NIHR – National Institute for Health Research, ICU – Intensive care unit, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-8: Possible referrals after the first assessment in primary or secondary care for adult long COVID patients – updated (European countries) (part 1)

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Country	Germany			Austria
Publication type	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
Different medical service options depend on the pts. needs				
Acute services *(e.g. emergency)*	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.	NR	NR	NR
Specialised long COVID outpatient assessment centres/clinics	Post-COVID ambulances should involve several disciplines next to primary care, e.g. neurology, psychiatry, psychosomatic, cardiology, pneumology, nephrology, rheumatology, otorhinolaryngology, dermatology, and endocrinology.	NR	NR	Second assessment in a specialist-long COVID outpatient clinic forms more complex symptoms.
Self-management advice and/or supported self-management	NR	NR	NR	If there are long-lasting symptoms, self-management, including connection with patient organisations can be helpful. Self-management can also include: ■ Self-management of the symptoms ("What helps me?") ■ Self-control (e.g. diary, heart rate monitor) or self-monitoring (e.g. Borg-Scale) ■ Salutogenese (concentration of the healthy parts) ■ Support from friends and relatives Recommendations for trustworthy websites ("self-education")
Multidisciplinary rehabilitation services *(e.g. inpatient or outpatient)*	After primary care diagnosis, primarily outpatient "Heilmittel[4]" 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.	See physical & neurological rehab Support by telemedicine should be considered as an additional tool to increase long-term adherence to rehab programs.	NR	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.

[4] „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).

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Multidisciplinary rehabilitation services *(e.g. inpatient or 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. Generally, the guideline differentiates between the "Anschluss-Heilbehandlung" (AHB), "Anschluss-Rehabilitation" (AR) & "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. 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.			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. The stress limits (physical & 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.
Physical rehab	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.	NR	NR
Psychological and/ or psychiatric rehab	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.	NR	NR	NR

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Neurological and cognitive rehab	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 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).	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 state & most likely benefit from exercise & physical therapy under professional supervision.	NR	NR
Specialist care for (symptom)-specific complications, if necessary	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.	NR	NR	The treatment of specific symptoms can be conducted by a specialist or also in the primary care setting depending on the pts. situations.
Community health services & non-medical healthcare providers	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).	NR	NR	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, and nursing services) are recommended also in addition to other treatments.
Additional medical guideline recommendations				
Follow-up monitoring	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: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life

Table A-8: Possible referrals after the first assessment in primary or secondary care for adult long COVID patients – updated (European countries) (part 2)

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Country	Italy	Spain	Netherlands	Europe
Publication type	Interim guidance	Guideline	Clinical perspective/expert opinion	Living guideline
Different medical service options depend on the pts. needs				
Acute services *(e.g. emergency)*	NR	Some symptoms may need coordinated primary & hospital care: ■ pulmonary sequelae ■ pleural involvement ■ cardiac involvement, e.g. myocarditis ■ pericardial effusion	NR	In symptomatic pts., other serious/life-threatening conditions (e.g. malignancy, thromboembolic events, myopericarditis, encephalitis) should be ruled out prior to considering long COVID.
Specialised long COVID outpatient assessment centres/clinics	One-stop assessment: concentrating the consultation with the various specialists & the diagnostic tests on a single day, e.g. long COVID day hospital. In more complex pts., treatment can be managed in another context (e.g. day hospital) → direct contact with the GP must exist.	Pts. with long-term fatigue (>6 months): referral to the corresponding multidisciplinary unit.	NR	NR
Self-management advice and/or supported self-management	Advice on self-management is important, including information on the healthcare services. Self-management programs provided either formally by patient organisations & support groups online, or provided informally during visits by the GP or other specialists & health professionals. Information & training on self-management include setting realistic goals, sources of support (support groups, social services, online forums, apps), and financial support.	Advice & information on self-management of symptoms, self-monitoring at home (heart rate, blood pressure, pulse oximetry, sleep surveillance)	Self-management or education modules may also need to be considered.	NR
Multidisciplinary rehabilitation services *(e.g. inpatient or outpatient)*	Multidisciplinary rehabilitation programs include physical, psychological & psychiatric aspects of rehabilitation. Tailored rehabilitation plans must be based on multidimensional assessment. The programmes involve a multidisciplinary team, e.g. medical doctors, occupational therapists, physiotherapists & psychologists & to provide specialist skills for fatigue & respiratory symptoms.	A central role for multidisciplinary rehabilitation support (physical, psychological & psychiatric aspects) with occupational therapy, physiotherapy, clinical psychology & psychiatric therapy & rehabilitation medicine.	Comprehensive rehabilitation programmes are recommended considering that the programme will potentially be wider in scope than current rehabilitation programmes, because of ■ the additional burden of COVID-19 (e.g. consequences of social isolation, emotional burden). ■ the different age group to the "usual" (pulmonary) rehabilitation population, thus supporting successful return to work should be part. Rehabilitation must be made to pts. in a personalised & targeted manner to maximise the likelihood of acceptance.	Clinicians should follow available consensus statements regarding multidisciplinary rehabilitation in the post-acute stage until further evidence about the effectiveness and safety of rehabilitation accumulates.

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Physical rehab	NR	NR	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.	NR
Psychological and/ or psychiatric rehab	NR	NR	NR	NR
Neurological and cognitive rehab	NR	NR	NR	NR
Specialist care for (symptom)-specific complications, if necessary	NR	Pts. with long-term generalised pain: referral to the pain unit or rheumatology department. Pts. with long-term dyspnea: referral to pulmonology or otolaryngology. Pts. with long-term headache: possible neurology consultation. Pts. with long-term digestive signs & symptoms: referral to digestive department.	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.	NR
Community health services & non-medical healthcare providers	In order to coordinate the delivery of care in more complex cases, community nurses can be used.	Pts. with long-term anosmia//dysgeusia: referral to otolaryngology & specific olfactory training therapies. If needed, psychological care.	NR	E.g. olfactory training should be suggested for all pts. due to its simplicity and safety..
Additional medical guideline recommendations				
Follow-up monitoring	Appointments for regular follow-up exams in order to monitor their clinical performance, e.g. also, through telemedicine tools, are needed.	NR	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life

Table A-9: Possible referrals after the first assessment in primary or secondary care for adult long COVID patients – updated (non-European countries) (part 1)

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Guidance for Primary Care Physicians (November 2021) [45]	Oronsky et al. (2021) [51]
Country	USA		
Publication type	Living guideline	Guidance	Review
Different medical service options depend on the pts. needs			
Acute services *(e.g. emergency)*	NR	NR	NR
Specialised long COVID outpatient assessment centres/clinics	NR	Pts. with neurological symptoms that have not lessened since initial treatment, or neurology, psychology and/or physical medicine and rehabilitation	NR
Self-management advice and/or supported self-management	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.	NR	NR
Multidisciplinary rehabilitation services *(e.g. inpatient or outpatient)*	Multidisciplinary post-COVID care centres based in a single physical location can provide a comprehensive & coordinated treatment approach to COVID-19 aftercare. Established partnerships with specialists for physical & mental healthcare including comprehensive rehabilitation services are useful. Creating a comprehensive rehabilitation plan may be helpful for some pts. & might include physical & occupational therapy, speech & language therapy, vocational therapy, as well as neurologic rehabilitation for cognitive symptoms. Optimising management of underlying medical conditions might also include counselling on lifestyle components such as nutrition, sleep and stress reduction (e.g. meditation). Approaches that incorporate telemedicine, including phone calls & virtual visits, can be helpful for ongoing follow-up & might lessen the burden on pts. with limited energy from post-COVID conditions or who have other concerns about personal Vitis. Evaluation & 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.	If the specialised clinic is not available, pts. with neurological symptoms that have not lessened since initial treatment, receive rehab	NR
Physical rehab	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.	Including physical medicine & treatment	NR
Psychological and/or psychiatric rehab	NR	and psychology medicine & treatment	NR
Neurological and cognitive rehab	NR	and neurology medicine & treatment	NR

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Guidance for Primary Care Physicians (November 2021) [45]	Oronsky et al. (2021) [51]
Specialist care for (symptom)-specific complications, if necessary	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.	Pts. with cardiac complications (myocarditis, pericarditis, myocardial infarction, dysrhythmia) should be evaluated by cardiology. Referral for formal neuropsychological evaluation: severe or persistent symptoms (e.g. brain fog, memory difficulties)	NR
Community health services & non-medical healthcare providers	NR	Reference only to evidence-based therapies, e.g. cognitive behavioural therapy, acceptance and commitment therapy, etc. Neuropsychological symptoms: threshold for referral for psychotherapy should be low, given the impact distress can have on functional cognition. For mood symptoms, psychotherapy should be considered a first-line treatment.	NR
Additional medical guideline recommendations			
Follow-up monitoring	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 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.	NR	Follow-up & encouraging pts. to seek medical care at the onset of worsening symptoms are recommended.

Abbreviations: ANZICS – Australian and New Zealand Intensive Care Society, CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life, RACGP – Royal Australian College of General Practitioners, USA – United States of America, WHO – World Health Organization

Table A-9: Possible referrals after the first assessment in primary or secondary care for adult long COVID patients – updated (non-European countries) (part 2)

Reference (author, month, year)	COVID-19 Scientific Advisory Group Rapid Evidence Report – Post-COVID (July 2021) [39]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS: Covid-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Country	Canada (Alberta)	Australia	Australia & New Zealand	WHO
Publication type	Guidance	Guidance	Guideline	Living guideline
Different medical service options depend on the pts. needs				
Acute services *(e.g. emergency)*	Treatment of "red flags" that need acute care.	Pts. with "red flags" (severe, new onset or worsening breathlessness or hypoxia, syncope, unexplained chest pain, palpitations or arrhythmias, new delirium or focal neurological signs) might require urgent care in a hospital emergency or by ambulance services.	NR	Counselling about acute life-threatening complications, such as pulmonary embolism, myocardial infarction, dysrhythmias, myopericarditis and heart failure, stroke, seizures and encephalitis.

Reference (author, month, year)	COVID-19 Scientific Advisory Group Rapid Evidence Report – Post-COVID (July 2021) [39]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS: Covid-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Specialised long COVID outpatient assessment centres/clinics	A wide spectrum of multisystem long COVID symptoms may require multidisciplinary clinics.	"The local Health Pathways" might have referral pathways for specialist clinics.	NR	NR
Self-management advice and/or supported self-management	Clinicians should also promote healthy eating, healthy sleep hygiene & appropriate exercising. Pts. education: balance between engaging in modified daily activity & adopting strategies to limit exertion (especially for fatigue), e.g. frequent short rests, energy conservation, quality sleep, self-awareness & pacing.	GPs should support the pts. pragmatically, e.g. how to maximise their personal wellbeing through diet, exercise & sleep.	NR	Pts. should be provided with education and support for the self-management of breathlessness & resumption of activities, peer-to-peer groups, stress management, stigma mitigation & home modification if necessary. All rehabilitating pts. should be educated about resuming everyday activities conservatively at an appropriate pace that is safe & manageable for energy levels within the limits of current symptoms & should not be pushed for post-exertional fatigue. A gradual increase in exercise should be based on symptoms.
Multidisciplinary rehabilitation services *(e.g. inpatient or outpatient)*	A wide spectrum of multisystem long COVID symptoms may require multidisciplinary rehabilitation services. Programmes require tailoring to best match individual needs, taking into account the availability & use of healthcare resources, the attention to symptom management over time & the functional/sustainable occupational goals for activities of daily living.	For pts. with severe acute infection, rehabilitation can be suggested at the follow-up consultation 6-8 weeks after discharge.	GP can refer pts. to rehabilitation if required 6 or 12 weeks after hospital discharge.	NR
Physical rehab	NR	e.g. pulmonary rehabilitation	NR	Exercises that support recovery in daily functioning. Start with active range of motion exercises, & when tolerated, proceed with progressive muscle strengthening, typically offered with resistance training. Return to physical exercise should always be guided by symptoms.
Psychological and/or psychiatric rehab	NR	NR	NR	Basic mental health & psychosocial support by appropriately trained health or non-health workers should be provided.
Neurological and cognitive rehab	NR	NR	NR	Education should be provided, & advice on strategies to help establish expectations & to alleviate stress and anxiety. Cognitive restorative rehabilitation may support cognitive exercises (such as memory exercises, puzzles, games, and reading) & compensation tools such as prompts (e.g. lists and notes) and breaking down activities.

Reference (author, month, year)	COVID-19 Scientific Advisory Group Rapid Evidence Report – Post-COVID (July 2021) [39]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS: Covid-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Specialist care for (symptom)-specific complications, if necessary	NR	NR	If.e.g. neurocognitive dysfunction is identified by the GP 12 weeks after hospital discharge, pts. should be referred to specialists	Rehabilitation or health staff should be alerted & refer to specialists as part of multidisciplinary, coordinated care pathway. For pts. with persistent pain, a multidisciplinary approach is recommended in order to provide pain management according to the principles of the biopsychosocial model.
Community health services & non-medical healthcare providers	Psychotherapy is preferred initial approach for anxiety & depression with a focus on addressing triggers & managing the impact of symptoms. Pharmacotherapy may play a role in selected pts. Referral to a sleep disorders programme may be prompted when primary care resources are insufficient to resolve pts. concerns.	Referral to a speech pathologist for management of chronic cough, hoarse voice or dysphagia. Referring to a practising dietitian if symptoms interfere with nutrition. A monitored return to exercise can be supported by exercise physiology, physiotherapy or rehabilitation referral Referral to mental health services or online support if needed.	NR	NR
Additional medical guideline recommendations				
Follow-up monitoring	NR	For pts. with severe acute infection: formal assessment of physical & emotional functioning 6-8 weeks post-discharge	Follow-up consultations for pts. treated at the hospital: ■ ICU discharge ■ Hospital discharge ■ 2-6 weeks post-discharge ■ 12 weeks post-discharge	NR

Abbreviations: ANZICS – Australian and New Zealand Intensive Care Society, CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life, RACGP – Royal Australian College of General Practitioners, USA – United States of America, WHO – World Health Organization

Additional services for adult long COVID patients

Table A-10: Additional services for adult long COVID patients – updated (UK)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (updated: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]	Parkin et al (2021) [50]	Barker-Davies et al. (May 2020) [54]	Greenhalgh et al (2020) [53]	Policy Brief 39 (Rajan et al. 2021) [52]
Country	UK						Overview of several countries (mostly England)
Publication type	Living guideline	Guideline	Review	Review	Consensus statement	Clinical perspective/ expert opinion	Review
Financial support							
Cash payments *(e.g. sick leave, early retirement)*	NR	NR	NR	NR	NR	NR	NR
Contributions in kind							
Social care services *(e.g. daycare)*	NR	Post-COVID assessment clinics should ensure referral to appropriate services if needed (e.g. social prescribing).	NR	NR	NR	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, and cross-sector collaborations may be needed to develop locally relevant solutions.	NR
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 (https://www.yourcovidrecovery.nhs.uk/your-road-to-recovery/returning-to-work/).	NR	NR	NR	NR	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-11: Additional services for adult long COVID patients – updated (European countries) (part 1)

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]
Country	Germany			Austria
Publication type	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline
Financial support				
Cash payments *(e.g. sick leave, early retirement)*	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.	NR	NR	The process of receiving 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".
Contributions in kind				
Social care services *(e.g. daycare)*	Multimodal treatment of patients is central, including the involvement of support groups & social interventions.	NR	NR	NR
Employment	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.	NR	NR	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 to the working place or working conditions should be possible to facilitate the coming back.

Table A-11: Additional services for adult long COVID patients – updated (European countries) (part 2)

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Country	Italy	Spain	Netherlands	Europe
Publication type	Interim guidance	Guideline	Clinical perspective/expert opinion	Living guideline
Financial support				
Cash payments *(e.g. sick leave, early retirement)*	NR	NR	NR	NR
Contributions in kind				
Social care services *(e.g. daycare)*	NR	NR	Also, consider psychological assessment and/or support for the family of pts.	NR
Employment	Support should be provided to the pts. for interviews with their employer, school or university regarding return to work or teaching activities, for example, by providing for a gradual resumption of activities.	NR	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life

Table A-12: Additional services for adult long COVID patients – updated (non-European countries)

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Guidance for Primary Care Physicians (November 2021) [45]	Oronsky et al. (2021) [51]	COVID-19 Scientific Advisory Group Rapid Evidence Report – Post-COVID (July 2021) [39]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS: Covid-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Country	USA			Canada (Alberta)	Australia	Australia & New Zealand	WHO
Publication type	Living guideline	Guidance	Review	Guidance	Guidance	Guideline	Living guideline
Financial support							
Cash payments *(e.g. sick leave, early retirement)*	NR	NR	NR	NR	NR	NR	NR
Contributions in kind							
Social care services *(e.g. daycare)*	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. 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.	NR	NR	NR	Need for short-term social support, e.g.: ■ assistance with food preparation & delivery ■ cleaning or assistance with activities of daily living ■ support groups	NR	NR
Employment	NR	NR	NR	NR	NR	The GP should help patients with a return to work plan or refer them to supportive agencies.	NR

Abbreviations: ANZICS – Australian and New Zealand Intensive Care Society, CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, ICU – Intensive care unit, NR – not reported, pts. – patients, QoL – Quality of life, RACGP – Royal Australian College of General Practitioners, USA – United States of America, WHO – World Health Organization

Long COVID care pathways for children and adolescents

Table A-13: Long COVID care pathways for children and adolescents (UK and European countries) (part 1)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (updated: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	S1 guideline (July 2021) [16]	S1 guideline (July 2021) [42]
Country	UK		Germany	Austria
Publication type	Living guideline	Guideline	Guideline	Living guideline
Healthcare pathways				
First point of contacts	Worse performance or absenteeism at education, work or training is seen as a "red flag". Many children experience anxiety caused by lots of investigations and referrals to different specialists → shared decision-making to avoid unnecessary investigations.	Referral for a first assessment may be from many routes, including School, community child-development service, community therapies, primary care, etc. Early holistic medical assessment by the GP is important to identify the need for further specialist input & management of organ impairment → prevent decreasing QoL First assessment = comprehensive clinical history + appropriate examination of physical, cognitive, psychological and psychiatric symptoms and functional abilities. Many children and adolescents can be managed by their GP with simple measures including advice (sleep, exercise, liaison with school), common investigations and treatments. Selbst management will also be offered to children and adolescents and their families while awaiting referral.	Primary assessment is similar to that for adults.	First assessment similar to first assessment for adult pts. with a special focus on psychological causes of the symptoms.
Acute services *(e.g. emergency)*	NR	For children and adolescents who had been hospitalised with severe COVID pneumonia or PIMS, routine follow-up for one year following admission is recommended.	NR	Few pts. suffer from Mis-C/PIMS-TS for which acute services are needed.
Possible referrals	NR	As with adults, some children and adolescents may need further care, e.g. rehabilitation, psychological support, specialist investigation or treatment. Referral to a local general paediatrician is recommended if there are ongoing concerns which are not settled with simple interventions. Some children and adolescents might need further investigation and support within the 12 weeks after the acute infection.	Possible referrals for further diagnostic based on the pts. needs: ■ Pulmunoary consultation ■ Cardiological consultation with specialist child and adolescent cardiologists ■ Consultation at the neuropaediatrics ■ Consultation at the ear, nose and throat specialist ■ Child and adolescent psychiatrists	NR
Financial support & contributions in kind	NR	NR	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-13: Long COVID care pathways for children and adolescents (UK and European countries) (part 2)

Reference (author, month, year)	Interim Guidance on Long-COVID management (July 2021) [43]	Italian intersociety consensus on management of long COVID in children (March 2022) [26]
Country	Italy	
Publication type	Interim guidance	Guidance
Healthcare pathways		
First point of contacts	Essential role of primary care paediatricians: first interlocutors of parents. Long COVID must be recognised & treated adequately to avoid physical & mental difficulties in children, their cognitive development & mental health in the medium-long term. Parents must be informed about the discomfort & alarming symptoms they need to recognise in their children → role of parents is essential in the early identification of risk signals to allow targeted intervention by specialists when necessary. It would be desirable to offer primary care paediatricians guidelines & training courses for the diagnosis & management of long COVID.	Long COVID symptoms cannot be explained by an alternative diagnosis. Between 4-12 weeks from diagnosis, all children with previously suspected or documented COVID-19 must be checked by the primary care paediatrician → e.g. NICE questionnaire containing questions on the most common symptoms of pediatric long COVID. Further check-ups by the primary care paediatrician should be scheduled 3 months after the diagnosis of SARS-CoV-2 infection to confirm normality or to address emerging problems. Children without clinical manifestations suggesting long COVID should be discharged without any immediate investigation but with recommendation of a new visit in case of development of symptoms of any type. Partnership between families and paediatricians are priority for better care. Children with physical symptoms must be evaluated according to the characteristics of the clinical manifestations. The depth and type of investigation to be requested will depend on the clinical relevance & type of manifestations. All pts. with suspected or documented COVID-19 and even if asymptomatic at the time of diagnosis, and their parents must be informed of the natural course of the disease, of the fact that it generally heals within a few days of diagnosis but that in some cases, the symptoms may persist for more than 4 weeks or, if disappeared, reappear with the same or with different characteristics → absence from or poor performance in education may be associated with poor outcomes for children and young people with symptoms of long COVID. The role of parents is essential: They must offer lots of love and affection, establish and maintain the usual daily routine as much as possible, and be positive and reassuring about the positive solution of all the pandemic-related problems.
Acute services *(e.g. emergency)*	NR	Some pts. suffer from MIS-C. These pts. present with several multisystemic manifestations, among which those involving the gastrointestinal tract, the Skin & the mucous membranes, and the cardiovascular system are the most common. The latter is the most dangerous as a vasogenic shock, myocardial dysfunction or infarction, coronary artery dilation or aneurysm, & arrhythmias can lead to admission to ICU.
Possible referrals	Dedicated psychological & neuropsychiatric support programs for children, adolescents & their families must be provided. Design of telecommunication tools or telemedicine programmes may be a support for parents with fragile children or children with pre-existing health conditions for whom access to healthcare facilities is difficult. Outpatient clinics & day hospitals: children can be assessed in a multi-disciplinary manner by specialists adequately trained to recognise the possible late manifestations & complications. In addition to providing rehabilitation programmes, when necessary.	The subjects who present symptoms of any organic problem must undergo a thorough evaluation of the same. For few children that present very severe mental problems and persist beyond 12 weeks after diagnosis, psychological intervention with continuous psychological support becomes mandatory (e.g. by existing local services).
Financial support & contributions in kind	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-14: Long COVID care pathways for children and adolescents (non-European countries)

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Post-COVID Conditions in children and adolescents (December 2021) [22]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]
Country	USA		Australia
Publication type	Living guideline	Interim guidance	Guidance
Healthcare pathways			
First point of contacts	NR	All pts. with acute SARS-CoV-2 infection should have at least one follow-up conversation with primary care paediatricians: Moderate – severe acute infection: in-person visit Asymptomatic – mild disease: visit by phone or video may be sufficient Aim: return to activities of daily living (return to learning, play or employment): ■ Paediatrician visit prior to return to physical activity ■ Moderate – severe acute symptoms: Intensive preparticipation sports examination (e.g. electrocardiogram or cardiology evaluation)	GP
Acute services	NR	Pts. with multisystem inflammatory syndrome (MIS-C) should be followed and cared for in a hospital with tertiary pediatric/cardiac intensive care units.	Pts. with paediatric inflammatory multisystem syndrome (PIMS-TS) must be considered. Common symptoms include fever, abdominal pain, gastrointestinal symptoms, neurological symptoms and/or rash.
Possible referrals	NR	Pts. >6 years with persistent respiratory symptoms should receive pulmonary function testing. Changes or delays in cognitive, language, academic, motor or mood/behavioural domains: age-specific history & evaluation for neurodevelopmental impairment is recommended → referral to neurodevelopmental neurologist, developmental & behavioural paediatrician, neuropsychologist, speech-language pathologist, psychologist, and/or physical or occupational therapists. Neurocognitive changes, e.g. inattentiveness, slower reading or processing, requiring more repetition in learning, less endurance and/or requiring more breaks when reading or performing other cognitive tasks → referral to targeted neuropsychological evaluation to identify symptoms & development of multidisciplinary treatment plan. Reconditioning programmes for postviral fatigue are mostly led by a physical therapist or a multidisciplinary team. Existing mental/behavioural illness may be exacerbated by COVID-19 → team-based approach including primary care paediatrician & other medical, surgical, occupational and behavioural specialists. Symptoms persisting >12 weeks, additional diagnostic testing needed → referral to a multidisciplinary post-COVID clinic.	Pts. with post-COVID-19 symptoms at four weeks post-acute infection must be considered referring them for specialist paediatric advice
Financial support & contributions in kind	School administrators, school counsellors and school nurses can work with families and healthcare professionals to provide learning accommodations for pts., particularly for those experiencing thinking, concentrating, or physical difficulties. For example, extra time on tests, scheduled rest periods throughout the day, modified class schedule, etc. Similar accommodations can also be requested for activities outside of school, daycare, tutoring, sports, scouting, etc.	Possible additional support: ■ Gradual return to school ■ Cognitive activities based on tolerance & cognitive "rest periods" throughout the school day ■ Close monitoring & communication by family, school & paediatrician	NR

Abbreviations: CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, NR – not reported, pts. – patients, RACGP – Royal Australian College of General Practitioners, USA – United States of America

Further information for practising physicians regarding decision-making and communication

Table A-15: Information for practising physicians – updated (UK) (part 1)

Reference (author, month, year)	NICE, RCGP, SIGN guideline (updated: March 2022) [1]	NHS Clinical Guidance (updated: July 2022) [2]	NIHR Review (2021) [11]
Country	UK		
Publication type	Living guideline	Guideline	Review
Information for practising physicians			
Further information for practising doctors in long COVID care	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 communication 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 communications are targeted at audiences from all backgrounds & 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 Personalised Care Institute (PCI) platform, including access to PCI accredited eLearning, view accredited training providers & programmes, high-quality resources (to support learning).	NR
Important information submitted to the pts.	Written advice for all confirmed or suspected COVID-19 infected about the most common new or ongoing symptoms must be provided by GPs or community services or by secondary care for people who were in hospital. 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.	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-15: Information for practising physicians – updated (UK) (part 2)

Reference (author, month, year)	Parkin et al (2021) [50]	Barker-Davies et al. (May 2020) [54]	Greenhalgh et al (2020) [53]	Policy Brief 39 (Rajan et al. 2021) [52]
Country	UK			Overview of several countries (mostly England)
Publication type	Review	Consensus statement	Clinical perspective/expert opinion	Review
Information for practising physicians				
Further information for practising doctors in long COVID care	GPs are made aware of the Community COVID-19 MDT service through usual communication avenues such as the internal bulletin briefings.	Holistic approach is needed where the physical, psychological 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).	NR
Important information submitted to the pts.	NR	Education is also important: implications of the disease & consequences must be discussed with pts.	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, NIHR – National Institute for Health Research, NHS – National Health Service, NICE – National Institute for Health Care Excellence, NR – not reported, pts. – patients, RCGP – Royal College of General Practitioners, SIGN – Scottish Intercollegiate Guidelines Network, UK – United Kingdom

Table A-16: Information for practising physicians – updated (European countries)

Reference (author, month, year)	S1 guideline (July 2021) [16]	Halle et al. (2021) [56]	Leo et al (2020) [57]	S1 guideline (July 2021) [42]	Interim Guidance on Long-COVID management (July 2021) [43]	Primary Care Clinical long COVID Guidelines (April 2021) [44]	Spruit et al. (2020) [55]	ESCMID rapid guidelines for assessment & management of long COVID (2022) [17]
Country	Germany			Austria	Italy	Spain	Netherlands	Europe
Publication type	Guideline	Clinical perspective/ expert opinion	Clinical perspective/ expert opinion	Living guideline	Interim guidance	Guideline	Clinical perspective/ expert opinion	Living guideline
Information for practising physicians								
Further information for practising doctors in long COVID care	NR	NR	NR	Holistic & person-centred approach is necessary, considering the results of the first general diagnostic, the subjective burden of the disease, as well as pts. wish and possibilities. It is crucial to avoid causing unnecessary anxiety and uncertainty in pts., as well as overdiagnosis or over-medicalisation.	Long COVID can be identified: ■ Proactively through healthcare records or hospital records → focus on population at high risk for long COVID (including phone calls) ■ By the GP or primary care paediatricians during the routine assessments Pts. initiative through their GP, primary care paediatricians or local long COVID clinics & services.	If symptoms persist & no aetiology reasonably explains the persisting symptoms & complementary tests at V3 are unaltered, the diagnosis of long COVID is confirmed.	NR	NR
Important information submitted to the pts.	NR	NR	NR	Pts. should be informed about the good prognosis of functional disorders.	NR	NR	NR	NR

Abbreviations: COVID – Coronavirus disease, e.g. – for example, ESCMID – European Society of Clinical Microbiology and Infectious Diseases. GP – General practitioner, NR – not reported, pts. – patients

Table A-17: Information for practising physicians – updated (non-European countries) (part 1)

Reference (author, month, year)	CDC interim guidance (updated: March 2022) [49]	Guidance for Primary Care Physicians (November 2021) [45]	Oronsky et al. (2021) [51]
Country	USA		
Publication type	Guideline	Guidance	Review
Information for practising physicians			
Further information for practising doctors in long COVID care	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.	Primary care physicians should be prepared to assess long COVID symptoms systematically & address them accordingly; they should be equipped to evaluate alternative aetiologies of symptoms, validate symptoms as potentially related to long COVID & provide support as needed.	NR
Important information submitted to the pts.	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. A healthcare appointment checklist could help the pts. to prepare for the first assessment at their GP, which also helps the GPs to save time. The checklist includes what to prepare before the appointment (paperwork, medications/supplements, questions, etc.), during the appointment (symptoms/issues, next steps) and after the appointment (further appointments, journal, etc.).	NR	Pts. should be educated by physicians on the possible manifestations of persistent post-COVID syndrome.

Table A-17: Information for practising physicians – updated (non-European countries) (part 2)

Reference (author, month, year)	COVID-19 Scientific Advisory Group Rapid Evidence Report – Post-COVID (July 2021) [39]	RACGP: Caring for patients with post-COVID-19 conditions (December 2021) [46]	ANZICS Covid-19 Guidelines (September 2021) [47]	WHO Clinical management of COVID-19 (chapter 19 & 24) (June 2022) [48]
Country	Canada (Alberta)	Australia	Australia & New Zealand	WHO
Publication type	Guidance	Guidance	Guideline	Living guideline
Information for practising physicians				
Further information for practising doctors in long COVID care	The GPs assessment should be tailored to the pts. and involve shared decision-making. Ongoing exchange of knowledge, skills and training would benefit primary care & other healthcare providers in the community to identify appropriate assessments & interventions.	General practitioners should use a holistic, person-centred approach (shared decision-making) for the first assessment. GPs should: ■ Recognise the pts. health beliefs ■ Symptoms are real ■ Acknowledge the mental health impacts ■ Consider barriers, language & health literacy	NR	NR
Important information submitted to the pts.	NR	Information that long-term symptoms do not mean that the pts. are still infectious & that the symptoms & severity can fluctuate over time. Pts. can use the "my post-COVID-19 symptom diary" available on the "Managing post-COVID-19 symptoms" resource platform.	NR	NR

Abbreviations: ANZICS – Australian and New Zealand Intensive Care Society, CDC – Centers for Disease Control and Prevention, COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, NR – not reported, pts. – patients, RACGP – Royal Australian College of General Practitioners, USA – United States of America, WHO – World Health Organization

Current long COVID care structures in selected European countries

Long COVID care structures

Table A-18: Current long COVID care structures in selected European countries – last update July 2022 (Examples in central and south Europe)

Country	Germany	Switzerland	Italy	Spain
Organisation	Mainly organised on the local level	Organised per Katon	Organised on the local level **Regional programmes: [43]** ■ Emilia-Romagna Region (GP & specialist outpatient clinics for severe cases); ■ Abruzzi Region (GP and multidisciplinary outpatient clinics for hospitalised pts.); ■ Tuscany Region (GP and hospital for hospitalised pts.); ■ Liguria Region (healthcare plan for all hospitalised pts.: day hospital or short stay units)	Organised on the local level. Clinical long COVID registry in development.
Medical service offer				
Primary care: GPs or primary care centres	First point of contact for long COVID pts. primary care sector (primary care centres & GPs) [16]. **University Hospital Berlin Charite:** recommendations for training for healthcare professionals; list of outpatient clinics for possible referrals [88]. **Multidisciplinäry post-COVID-Centre University:** list of outpatient clinics for possible referrals [79].	See expert information	Long COVID management generally takes place in primary (non-hospitalised COVID-19 pts.) & secondary care (hospitalised COVID-19 pts.). GPs also coordinate services that include domiciliary care possibly supported by telemonitoring and new community nurses [52]. For children and adolescents: primary care paediatrician [43].	In development for the practising physicians [44]: ■ Long COVID diagnostic tool ■ Long COVID app that shows the content of the guideline ■ Training for physicians with access to university
Secondary care	No examples	No examples	No examples	No examples
Specialised long COVID outpatient assessment centres/clinics	***National level:*** The "Deutsche Bundestag" calls on the Federal Government to anchor **outpatient long COVID assessment clinics** as a new § 116c in the Fifth Book of the Social Code (SGB V) within the limits of the available budget [123]. Currently, there are approximately 80 long COVID outpatient clinics of various specialities at clinical institutions across Germany [74].	Approximately 40 clinics across Switzerland offer long COVID consultation hours for adults [19]. The consultation hours differ: for some, a referral is needed, for some not; some list their long COVID care offer on their website, and some only report their care offers to physicians who makes the referrals (expert information). ***Local example:*** **Clinic Solothurm:** interdisciplinary clinic for the treatment of long COVID patients; referral needed [19].	Specialist long COVID assessment outpatient clinics (day hospitals) are regulated on the local level. The long COVID project has foreseen a survey to collect data in order to define the number and characteristics of centres assisting patients with long COVID manifestations in Italy. This activity is ongoing, and results will be analysed and published [126]. ***Local examples [43]:*** **Post-COVID Day Hospital at the Agostino Gemelli IRCCS University Hospital Foundation** (Rome): multidimensional assessment for hospitalised & non-hospitalised pts.	***Local examples [127]:*** **Andalusia:** 4 outpatient clinics with long COVID sections + 1 neurological & cardiological long COVID consultation hours. **Málaga:** 3 outpatient clinics with long COVID sections. **Sevilla:** 1 outpatient clinic with long COVID section. **Valencia:** long COVID department in the main hospital & university hospital.

Country	Germany	Switzerland	Italy	Spain
Specialised long COVID outpatient assessment centres/clinics *(continuation)*	***Local examples:*** The **University Hospital Essen:** multidisciplinary outpatient clinics (infectiology, anaesthesiology and intensive care, pneumology, psychosomatic medicine, psychotherapy) for the assessment & follow-up of long COVID pts. Consultation hours Monday to Friday 09:00-12:00 [78]. **Charité fatigue centre** (Berlin) offers post-COVID consultation hours for pts. with persistent symptoms >6 months [88]. **Max-Planck-Institute of Psychiatry** (Munich): neurological-psychiatric post-COVID outpatient clinic for further diagnosis & treatment [124]. **Jena University Hospital:** Post-COVID outpatient clinic (for adults), including psychiatric and psychotherapeutic care [79]. **Psychosomatic clinic in Munich and Magdeburg:** therapies for physical symptoms and pain, therapies for psychological symptoms and social care interventions [125]. ***Local examples for children:*** **Jena University Hospital:** child and adolescent psychiatry, psychosomatics and psychotherapy offer consultation hours for children and adolescents.	***For children:*** Approximately 4 clinics across Switzerland offer long CoVID consultation hours for children [19].	**Infectious Disease and Pneumology Outpatient Clinic of the University Hospital of Modena:** multidimensional diagnosis & treatment program (>5 weeks after discharge). **Post-COVID Day Hospital at the ASST St. Gerard Hospital of Monza** (day hospital): multidisciplinary assessment → further diagnoses, treatment & rehabilitation by needed specialist for hospitalised pts. **San Martino Hospital of Genoa** (day hospital): assessment after 6 months, if needed, referral to relevant specialist. **COVID-19 Follow-up Day Clinic at the ASST Niguarda Metropolitan Hospital in Milan (**day hospital): assessment 3 months after discharge → referral to a needed specialist and/or rehabilitation. ***Local examples for children [43]:*** **Bambino Gesù Children's Hospital** (Rome): day hospital, management & surveillance of paediatric COVID pts. Clinic is open for all pts., while the day hospital is reserved for pts. with moderate to severe forms of COVID-19 requiring follow-up.[5] **San Marco Hospital of Catania (Sicily):** paediatric outpatient clinic for children 0-16 years of age, a referral from the primary care paediatrician necessary.[6]	**Castellón:** 2 long COVID outpatient clinics. **Madrid:** departments for acute SARS-CoV-2 infection shall be changed to long COVID departments.
Self-management or supported self-management services (e.g, online, tele- and/or home-based services)	**Patient organisation:** List of post-COVID consultation hours [74]. **List of COVID support groups:** [90] **Overall information platform** including präsentations of physicians [74] **Jena University Hospital** offers a biweekly support group guided by a doctor [79].	**Support group Long Covid Schweiz** [19] **Altea network:** self-management guide and list of treatment offer (primary physician always first step) [84, 89]. **RAFAEL:** first interactive information and digital exchange platform for long COVID pts.; chatbot for the general public and healthcare professionals, answering questions and providing information on post-COVID symptoms; in French only [85].	No long COVID patient organisation or support groups could be identified. Domiciliary care is often supported by telemonitoring [52].	**Regional long COVID patient organisations Spain "Asociación Covid Persistente"** with information for children, adolescents and adults. Example of a fact sheet with information about long COVID for pts. [128].

[5] Multidisciplinary day hospital team: paediatrician, infectious disease specialist, rheumatologist, bronchopneumologist, cardiologist, neurologist, physiatrist & psychologist/psychiatrist.

[6] Investigations: patient history, assessment of persistent symptoms, physical examination, blood sampling, skin allergy tests, global spirometry, quality of life questionnaire, ect. → basis for personalised therapeutic program.

Country	Germany	Switzerland	Italy	Spain
Self-management or supported self-management services (e.g, online, tele- and/or home-based services) *(continuation)*		***Apps:*** **Long COVID Tagebuch APP** (German): make notes about symptom changes and learn from them [89]. **INSELhealth Cofit APP** (German): data collection, exercise based on personal needs without therapist, and information about disease, management and contacts [89]. ***For children:*** **Support group Long Covid Kids** [76]		
Multidisciplinary rehabilitation clinic/centre (inpatient/ partially inpatient/ outpatient)	***National level:*** Currently, there are around 44 different inpatient and/or outpatient rehabilitation clinics [74]. E.g. there are rehabilitation clinics specialised in chronic fatigue pts. The new network "DiAGNOSTIK, ReHABILITATION und NaCHSORGE (DiReNa)" of several inpatient and outpatient rehabilitation clinics, payers, expert and medical associations in Brandenburg Germany [86].	Approximately 25 in- & outpatient specialised rehabilitation for adults (expert information) **Long COVID rehabilitation at home** [81] ***For children:*** A few rehabilitation centres that also treat children with long COVID [19].	Long COVID rehabilitation offers are regulated on the local level. ***Local examples:*** **San Raffaele Hospital** have post-COVID rehabilitation wards for COVID-19 pts. who had experienced prolonged admission to ICU [52]. Other services e.g. by **AbilityAmo**, a non-profit organisation, provide rehabilitation interventions for post-COVID disability and fragility: specialist interventions (both in hospitals & at home), psychological support, neurological, respiratory & cognitive post-admission rehabilitation & telemonitoring systems [52].	No examples
Specialised care offers	No examples	**No examples**	No examples	No examples
Community health services & non-medical healthcare providers	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, and nursing services) can be applied [16].	**INSELhealth Cofit APP** (German): proposed treatment plans can also help physiotherapists [89].	Generally, long COVID management in primary & secondary care is facilitated through **community care networks**, including a combination of reconverted community hospitals, healthcare hotels, nursing homes (new role of community nurses) & low-intensity residential facilities [52].	No examples
Financial support				
Cash payments (e.g. sick leave, early retirement)	No information available	Information about social and legal aspects, e.g. sick leave for chronic diseases, long COVID as an occupational disease and refunds for clinical rehabilitation [98].	No information available	No examples

Country	Germany	Switzerland	Italy	Spain
Contributions in kind				
Social care services	No examples	No examples	No examples	No examples
Employment/ school	No long COVID-specific offers, same offers as for other illnesses, for example: ***National level:*** **Transitional allowance:** The "Deutsche Rentenversicherung" (DRV) provides services to facilitate participation in working life, e.g. by financing further training & re-training [16]. **Gradual reintegration** 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 [96]. **Occupational disease:** 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 [57].	No examples	No examples	No examples

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – general practitioner, pts. – patients

Table A-19: Current long COVID care structures in selected European countries – last update July 2022 (Examples in UK and northern Europe)

Country	United Kingdom	Norway	Belgium
Organisation	Mainly organised on a national level but locally executed. The NHS Improvement's 5-Point plan for long COVID support (national level) involves [87]: 1) NICE guideline on long COVID 2) the Your COVID Recovery online rehabilitation programme 3) designated post-COVID assessment services 4) funds for long COVID research by the NIHR 5) an NHS long COVID task force which includes patients with long COVID, medical specialists and researcher A long COVID registry for patients attending the post-COVID assessment clinic is established [87].	Organised on the regional level.	See expert information.
Medical service offer			
Primary care: GPs or primary care centres	***National level:*** First point of contact for pts. never hospitalised during COVID-19: primary care sector [1]. In England, any child with ongoing symptoms of COVID for 4 weeks or more can be referred for paediatric assessment by the GP or paediatrician. Referral's can be made by the GP general local paediatric team or a long COVID Hub [87]. ***A local example** (e.g. Leeds):* 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 comprised of a three-tier service model: 1. tier) **Primary care** for pts. with typical long COVID symptoms lasting 1-2 months & likely resolve with supported self-management [50].	National action plan also includes the development of guidance for healthcare workers on how to detect & treat people having long COVID symptoms [70].	Primary care initiative from NIHDI about a tool that should make it easier for primary care workers to plan rehabilitation for pts. Including a financial compensation plan for pts. who visit psychologists, dieticians or physiotherapists [70].
Secondary care	No examples	No examples	No examples
Specialised long COVID outpatient assessment centres/clinics	***National level:*** **Integrated multidisciplinary post-COVID assessment outpatient clinics** across England are set up as one part of the *NHS Improvement's 5-Point plan for long COVID support* (**n=89**). These services are designed to complement existing primary, community and rehabilitation care in the form of specialist assessments, diagnosis & if possible treatment. There will be several different ways that these services are implemented depending on the needs of local patients & the configuration of existing services [87]. For example, they can function as a "one-stop clinic" for further testing, investigations & support for managing physical/mental health symptoms, including rehabilitation. However, services can also be delivered across multiple sites or – where appropriate – virtually [54]. Data showed increases to over 1500 referrals a week [87]. ***For children:*** There are approximately 15 long COVID hubs for children and adolescents [3]. These specialist hubs consist of multidisciplinary teams that can provide assessment services and remote support to other clinicians to ensure ongoing holistic support. The hubs also coordinate care for children and young people across a range of services. Considerations for assessment & treatment [87]: ■ impact of illness on pts. and family, possibly wide-ranging & fluctuating symptoms ■ considering alternative diagnosis ■ consider transition services for young people aged over 16	Hospitals are asked to establish outpatient clinics for pts. One for each health region (n=4) exists [70].	See expert information

Country	United Kingdom	Norway	Belgium
Specialised long COVID outpatient assessment centres/clinics *(continuation)*	***A local example*** *(e.g. Leeds):* 3. tier) **Specialist multidisciplinary team (MDT) services:** ■ For pts. with prolonged COVID symptoms for >3 months, complex symptoms with impact on daily life & functioning requiring input from 2 or more professionals (also <3 months) & for post-discharge pts. with complex needs. ■ Most referrals to the MDT services from the GPs (tier 1) or also from Community therapy teams (tier 2), and few referrals directly from hospital services (complex cases). ■ The MDT service is multidisciplinary, e.g. allied health professionals, pathway coordinators, physiotherapists, occupational therapists, consultants with a specialism in rehabilitation medicine, respiratory medicine & cardiology; additional support comes from respiratory nurses, respiratory physiotherapists, dieticians & neurological occupational therapists. ■ Offered interventions: the usual process of assessment, clinical reasoning & intervention planning, including home visits for assessments & reviews (also phone interviews); prescription to exercise programmes, e.g. NHS England's online "Your COVID Recovery Programme". ■ Severe medical concerns (e.g. unexplained chest pain) discussed as a priority within the weekly specialist MDT meeting (virtual), linking pts. to appropriate pathways of investigation & treatment & reduce the number of outpatient clinic attendances as the MDT rationalises the need for investigations & most appropriate & effective management approach [50].		
Self-management or supported self-management services (e.g, online, tele- and/or home-based services)	***National level:*** "**NHS Your COVID Online Recovery Plattform**" was set up as part of the NHS Improvement's 5-Point plan for long COVID support. **The Your COVID Recovery website**, 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 of wellbeing (e.g. eating, sleeping, moving habits) & 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 available to all and is continuously updated. **The Your COVID Recovery Online Programme:** 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: ■ 4 stages with a variety of tasks guiding pts. through the programme. ■ Encouragement to set goals & learn to choose the resources to achieve the goals. ■ 14 resources packed full of information and videos to aid recovery, e.g. about supporting mental health, supporting movement, symptom management & nutritional advice. ■ Optional activity challenge. ■ Symptom thermometer: tracking the changes in the persistent symptoms. ■ Chat: directly with a healthcare professional or by joining the community forum. Over 1.5 million visits have been made to the patient information section of the Your COVID Recovery website; over 100 rehabilitation services have been trained to support patients by using the specialist online rehabilitation support element. Over 1.5 million visits have been made. [87].	The national action plan also focuses on providing information about the condition of pts. [70].	**Patient organisation:** post-COVID Gemeenschap [73].

Country	United Kingdom	Norway	Belgium
Self-management or supported self-management services (e.g, online, tele- and/or home-based services) *(continuation)*	**Patient organisation:** Long COVID Support. ***Local-level (e.g. Leeds):*** In addition to the national "Your COVID-19 Recovery Plattform", 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" [50]. ***For children and adolescents: [3]*** Information for caregivers Pacing for children Mental health support: ■ www.kooth.com (app, 10-25 yrs., free) ■ www.themix.org.uk (live chat, discussion boards, 10-25 yrs.) ■ Young Minds Textline (24/7 text support across UK, answers by trained volunteers supported by experienced clinical supervisors) ■ The Emotional Wellbeing and mental Health Service: support for children, adolescents & families		
Multidisciplinary rehabilitation clinic/centre (inpatient/ partially inpatient/ outpatient)	Rehabilitation is mostly offered on a local level, e.g. the post-COVID assessment outpatient clinics sometimes offer rehabilitation themselves [54]. Standard rehabilitation pathway packages to treat the commonest symptoms of long COVID will be developed [87]. ***Local-level** (e.g. Stanford):* **The Defence Medical Rehabilitation Centre** at Stanford Hall is running a 2-week residential intervention for long COVID pts. & a concurrent research study to evaluate the programme [11].	No examples	See expert information
Specialised care offers	No examples	No examples	Long COVID pts. can be referred to usual specialist care if needed.
Community health services & non-medical healthcare providers	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. ***A local example** (e.g. Leeds):* 2. tier) **Community therapy teams** 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 [50].	No examples	Based on the pts. needs, they can be referred to physiotherapy, psychotherapy, etc.
Financial support			
Cash payments **(e.g. sick leave, early retirement)**	The **usual rules for sickness absence & sick pay** apply when someone is off work because of COVID or long COVID [99]. Help for parents and caregivers [3]: ■ Local authorities can arrange help needed, such as support at home and financial support (e.g. cost of living allowance)	No examples	No examples

Country	United Kingdom	Norway	Belgium
Contributions in kind			
Social care services	**Social prescribing** 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 [82].	No examples	No examples
Employment/ school	No long COVID-specific offers, same offers as for other illnesses, for example: ***National level:*** **Fit for work** 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 [99]. **Fit note:** 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 **Allied Health Professional (AHP) Health and Work Report** [83] **Phased return:** 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). Help for parents and caregivers [3]: ■ Employers can allow parents and caregivers time away from work to provide care for a child in an emergency; the possibility of other arrangements: flexible working hours. Support at school [3]: ■ Special Educational Needs and Disability Coordinators (SENDco): oversee the needed changes – reasonable adjustments – that help to come back and stay in school. ■ Class teachers should be informed about the adjustments. ■ Educational psychologist: specialised in supporting children with more needs. ■ School nurses can provide a full assessment of all health needs and can refer to professionals ■ Clinical Commissioning Groups ensure that commissioning is responsive to pts. needs & health services are able to co-operate with schools supporting pts. with medical conditions.	No examples	No examples

Abbreviations: COVID – Coronavirus disease, e.g. – for example, GP – General practitioner, KCE – Belgian Healthcare Knowledge Centre, MDT – Multidisciplinary team, NHS – National Health Service, NICE – National Institute for Health and Care Excellence, pts. – patients

Expert consultation

Table A-20: Experts contacted about examples of existing long COVID care structures in their countries (updated)

Country	Field of activity	Contacted	Answer	Information
United Kingdom	Expert from the NHS	May 2021	19.05.2021	Information about NHS Improvement's 5-Point plan, including NHS Your Covid Online Recovery.
		June 2022	08.06.2022	Updated information about long COVID care in the UK, including information about offers for children and adolescents: ■ Updated guideline [1] ■ Updated NHS guidance [2] ■ Platform for children and adolescents [3]
Norway	Expert from the Public Health Institute in Norway	July 2022	26.08.2022	Detailed description of the long COVID care situation in Norway, including several documents (unfortunately in Norwegian): The Norwegian Directorate of Health has taken the initiative to a follow-up assessment of the rehab, establishing a working group with the mandate to give professional advice and assist the Directorate in assessing the need for new/updated guidance or changes in available information based on scientific evidence and experiences from the field. National plan for rehabilitation after COVID-19 [80]: 6 main objectives for rehabilitation: ■ Patients with functional impairments following COVID-19 disease receive rehabilitation in accordance with current knowledge and best practice in the area. ■ Patients who need rehabilitation after having had COVID-19 disease receive information about what rehabilitation services are available in meetings with health personnel both in the municipalities and in the specialist health service. ■ Groups with an increased risk of needing rehabilitation after COVID-19, or groups that are particularly difficult to reach with information measures, are given priority. ■ The use of terms related to patients who need rehabilitation after COVID-19 disease is uniform and quality assured. ■ There is good registration of COVID-19 rehabilitation in the health and care services at both service levels as part of increasing knowledge in the field. ■ A continuous and systematic summary of knowledge based on existing research is ensured, as well as stimulation of new research on rehabilitation after COVID-19. ■ Routines and agreements on interaction and message exchange cover all actors in the patient process across the municipalities and the specialist health service in the rehabilitation area. Long COVID rehabilitation guidance to healthcare professionals (in Norwegian, last update December 2021) [80]: The main principle is that people with long COVID should consult with their GP (in Norway, there is a list patient system, so every citizen is entitled to have their personal GP). Patients in need of rehabilitation after COVID-19 must follow normal referral routines and rehabilitation procedures. The rehab service offered should be adapted to individual needs. Patients who have been admitted to the hospital are recommended for early assessment and start of rehab measures. The patient should be assessed by a multidisciplinary rehabilitation team during the hospital stay. **Most of the rehabilitation happens in primary care, with support and GP support. Those in need of further support are admitted to rehab services in secondary care**. Rehabilitation in the specialist health service can be provided at: ■ hospital as an integral part of the treatment in the relevant (emergency) medical department or in dedicated rehabilitation departments ■ outpatient (possibly per digital home follow-up or video consultation) ■ private rehabilitation institutions

Country	Field of activity	Contacted	Answer	Information
Norway *(continuation)*				**The rehab clinics for people with long COVID are also offering their services to children and adolescents.** A platform with health information for the public, Helsenorge.no, provides information about long COVID. The site provides videos showing patients with long COVID telling their stories and relevant information, including access to a leaflet in several languages from the WHO [75].
Belgium	Practitioner	July 2021	No answers	
	Practitioner		No answer	
	Practitioner		No answer	
	Practitioner		No answer	
	Patient organisation	August 2021	17.08.2021	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: ■ **Primary care:** GPs 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. ■ **Guidelines:** 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. ■ **Hospitals:** 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 clinics. ■ **Rehabilitation programs:** 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. ■ **General:** 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.
	Expert from the KCE	June 2022	10.06.2022	Update about long COVID care structures in Belgium: No dedicated long COVID structures exist but are integrated into existing care. Projects about long COVID care pathways and the development of a tool for primary care physicians to plan long COVID care are ongoing. Belgium's National Institute for Health and Disability Insurance (NIHDI) is currently finishing the care pathway for long COVID pts. focus mainly on GPs who will refer patients to specialists or other healthcare staff like physiotherapists. In practice, no long COVID clinics per se will be set up. However, some hospitals have, on their own initiative, specialised in the management of long COVID. Frequently, they are involved in research projects, and KCE is funding 3 projects running in 3 hospitals. However, there is no list of hospitals active in long COVID management.
Italy	An expert from the Ministry of Health	July 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 (*suggested first author*)	August 2021	No answer	
	As the Italian long COVID guideline was available in English for this update review, no further experts needed to be contacted.			

Country	Field of activity	Contacted	Answer	Information
Spain	Expert from IQVIA human data science	May 2022	20.05.2022	Overview of the long COVID care structure in Spain (regional structures). Ongoing long COVID projects, e.g. clinical registry, training & diagnostic tool, apps [127, 128]
Germany	An expert from the IQWiG	July 2021	06.07.2021	Plans for structuring the care algorithm for long COVID (GBA): https://www.bundestag.de/dokumente/textarchiv/2021/kw23-pa-gesundheit-longcovid-844332 https://dserver.bundestag.de/btd/19/292/1929267.pdf https://dserver.bundestag.de/btd/19/292/1929270.pdf
	Practitioner *(suggested by the IQWiG expert)*	July 2021	No answer	
	Patient organisation	August 2021	12.08.2021	An overview of the outpatient long COVID services established in Germany can be found here (https://longcoviddeutschland.org/post-covid-19-ambulanzen/). 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 (https://www.awmf.org/leitlinien/detail/ll/020-027.html). An overview of inpatient rehabilitation services can be found here (https://longcoviddeutschland.org/post-covid-19-rehabilitation/). 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 (https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/). In addition, I would like to refer you to our partner initiative in Austria: https://www.longcovidaustria.at. 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.
	No further experts needed to be contacted, as enough information was available online.			
Switzerland	Patient organisation	June 2022	No answer	
	Expert from the ministry of health	June 2022	15.06.2022	Further contacts for more information.
	Expert from the "Bundesamt für Gesundheit Schweiz"	June 2022	29.06.2022	Detailed overview of the long COVID care structures in Switzerland, including links to specific care offers [19, 76, 84, 85, 98] First contact for pts: GPs can also make referrals for a consultation hour in a clinic. List with long COVID care offers for each Kanton is planned; helpful for the physicians to see which care offers are close.

Abbreviations: COVID – Coronavirus disease, GBA – Gemeinsamer Bundesausschuss, GP – General practitioner, IQWiG – Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen, NHS – National Health Service, NIHDI – National Institute for Health and Disability Insurance, ÖGK – Österreichische Gesundheitskasse, UK – United Kingdom

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