RES00034.Wales COVID-19 Evidence Centre. A rapid evidence summary of the cost impact of demands due to Long COVID on NHS and social care services

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Published: 01/04/2022

Publisher's PDF, also known as Version of record

Wales COVID-19 Evidence Centre (WCEC)
Rapid Evidence Summary

What is the cost impact of demands due to Long COVID on NHS and social care services? A rapid evidence summary.

Report number – RES00034 (April 2022)

TOPLINE SUMMARY

What is a Rapid Evidence Summary?

An **interim evidence briefing** to inform further work and provide early access to key findings. They are based on a **limited search of key resources** and the **assessment of abstracts**. Priority is given to studies representing robust evidence synthesis. No quality appraisal or evidence synthesis are conducted, and the summary should be interpreted with caution.

Background/Aim of the Review

Long COVID is a term used to describe signs and symptoms in adults or children that persist or develop after acute COVID-19. As of March 2022, an estimated 2.4% of the UK population (1.5 million) reported COVID-19 symptoms lasting more than 4 weeks after a confirmed or suspected case of COVID-19 (Office for National Statistics, 2022).
It is important to understand the cost implications of Long COVID on NHS and social care services to inform resource use planning.

Key findings

Extent of the evidence base

- Searches revealed 8 peer-reviewed articles, including systematic reviews (n=2, including one living review), cohort studies (n=2), a modelling paper (n=1), a Mixed-method study (n=1), a rapid clinical guideline (n=1), and a qualitative survey study design (n=1).
- Two broad themes were identified: the **economic impact** of Long COVID and the variance of **patient demand** for Long COVID treatment services.

Recency of the evidence base

- All 8 articles were published 2020-22.

Evidence of impacts

- **Evidence is limited**
  - **There was limited evidence for the cost impact of demands due to Long COVID** on the NHS**.** For **social care services no evidence of cost impact of demands due to Long COVID** was found.
- Two papers were found relevant to the **economic impact of Long COVID**:
  - One paper modelled that 299,730 Quality Adjusted Life Years (QALYs) were lost within 1 year of infection (90% of this loss is attributable to COVID symptoms and 10% is due to permanent injury) and 557,764 QALYs lost within 10 years of

infection (49% of this loss is attributable to COVID symptoms and 51% is due to permanent injury). **The UK Government expressed a willingness-to-pay of £17.9 billion and £32.2 billion to avoid the QALY losses, respectively based on QALY valuation of £60,000 per QALY gained. The current QALY valuation has since increased to £70,000 per QALY in 20/21 prices** (HM Treasury, 2022)**.**
    - A second paper found that Long COVID had a **financial impact** on Belgian patients due to **loss of income, increased healthcare expense and loss of money due to foregone activities**.

- Five papers were found relevant to the **variance in patient demand for Long COVID services** and highlighted the importance of: collecting service use history; determining treatment based on symptoms; and investigating implementation, outcomes and cost-effectiveness.
    - A Canadian based living systematic review found the five most common **care model principles** for Long COVID treatment include: **multidisciplinary teams (90%), integrated care (50%), continuity or coordination of care (50%), self-management (50%) and evidence-based care (35%)**. The five most common **care model components** include: **standardised symptoms assessment (95%), a referral system (80%), a follow-up system (75%), virtual care (70%), and home-based care (50%).**

Policy implications

- The cost of demands due to Long COVID on the NHS and social care services are unclear due to a lack of evidence, **ongoing NIHR studies** may provide further evidence.
- Future research should focus on the following:
    - **Economic modelling** of resource allocation of health and social care services to potential diagnosis, treatment and care pathways to estimate the cost of Long COVID per patient. The economic model should be multidirectional, given that Long COVID symptoms vary between patients.
    - **Evaluating costs and benefits** of resource allocation to potential diagnosis and treatment pathways, and which regions require them, taking into account that regions are variable in capacity for providing Long Covid services. The effects of Long COVID on children and young people, with data disaggregated from adults.

Strength of the evidence

- It was not possible to provide an indication of the strength of evidence as only the abstracts of the included papers were assessed for relevance.

This rapid review should be cited as:
RES00034.Wales COVID-19 Evidence Centre. A rapid evidence summary of the cost impact of demands due to Long COVID on NHS and social care services. April.2022.
http://www.primecentre.wales/resources/RES/RES00034-Wales_COVID-19_Evidence_Centre-Rapid_evidence_summary_of_the_cost_impact_of_Long_COVID_on_the_NHS_social_care-April-2022.pdf

This report can be downloaded here:
https://healthandcareresearchwales.org/wales-covid-19-evidence-centre-report-library

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Report number – RES00034 (April 2022)

Rapid Evidence Summary

FULL REPORT

1. What is a Rapid Evidence Summary?

Rapid Evidence Summaries are designed to provide an interim evidence briefing to inform further work and provide early access to key findings. They are based on a limited search of key resources and the assessment of abstracts. Priority is given to studies representing robust evidence synthesis. No quality appraisal or evidence synthesis are conducted, and the summary should be interpreted with caution.

2. Production of this Rapid Evidence Summary

The following individuals were involved in the Rapid Evidence Summary process and production of this report:

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3. Requesting stakeholder group(s)

The research question was submitted by the Policy Modelling subgroup of the Technical Advisory Group, Welsh Government.

4. Context / Background

As of March 2022, an estimated 2.4% of the UK population (1.5 million) were experiencing self-reported COVID-19 symptoms lasting more than four weeks after a confirmed or suspected case of COVID-19 (Office for National Statistics, 2022a). Individuals between the ages of 35-49 had the greatest self-reported prevalence of Long COVID. In addition, females, those working in social care, health care, teaching and education, along with individuals living in more deprived areas as well as those with activity-limiting health conditions also reported a greater prevalence (Office for National Statistics, 2022b).

Definition of Long COVID

Long COVID affects adults and children. The majority of Long COVID research is from adult populations, given that gaining ethical approval to conduct research on under 18s is a more rigorous than for adults (Thomson, 2021). 12.9% of UK children aged 2 to 11 and 14.5% of 12 to 16 year olds still have COVID-19 symptoms five weeks after infection (Office for

National Statistics, 2022a).When COVID-19 symptoms last for a sustained period after initial COVID-19 infection, this is known as post-COVID-19 syndrome or more commonly as Long COVID (NHS, 2022). The definition of Long COVID according to the National Institute for Health and Care Excellence (NICE) (National Institute for Health and Care Excellence, 2021) is:

1. **Acute COVID-19** denotes signs and symptoms of COVID-19 for up to 4 weeks after initial infection
2. **Ongoing symptomatic COVID-19** denotes signs and symptoms of COVID-19 from 4 weeks – 12 weeks
3. **Post-COVID-19 syndrome** denotes signs and symptoms that develop or after infection consistent with COVID-19, which persist for more than 12 weeks. It typically presents with a number of symptoms that can change over time and affect any system in the body. A diagnosis of post-COVID-19 syndrome could be considered before 12 weeks whilst alternative diagnoses are under review. The consensus clinical case definition for Long COVID is a syndrome that describes signs and symptoms that persist or develop after acute COVID-19, this includes ongoing symptomatic COVID-19 and post-COVID-19 syndrome (National Institute for Health and Care Excellence, 2021).

Long COVID in children and young people

The Children and young people with Long COVID (CLoCK) study is an ongoing longitudinal study with aims to track the effect of Long COVID on the mental health of children, young people and their families (Public Health England, 2020). The CLoCK researchers worked with a patient and public involvement group (PPI) of 11-17 year olds with long COVID to derive a definition appropriate for children (National Institute for Health Research, 2022). The study will conclude in January 2024.

Their definition of Long COVID is a condition in which a child or young person has symptoms (at least one of which is a physical symptom) that:

- Have continued or developed after a diagnosis of COVID-19 (confirmed with one or more positive COVID tests)
- Impact their physical, mental or social wellbeing
- Are interfering with some aspect of daily living (e.g. school, work, home or relationships)
- Persist for a minimum duration of 12 weeks after initial testing for COVID-19 (even if symptoms have fluctuated during that period)

An early publication from the CLoCK study of 3065 11-17 year olds testing positive for COVID-19 following a PCR test were paired with a matched control group of 3739 11-17 year olds testing negative for COVID-19 over a three month period (Stephenson et al., 2022). Provisional data from the publication print indicates that after an average of 15 weeks after their PCR test, one in seven (14%) more young people in the positive group had three or more symptoms than the negative test group. One in 14 (7%) of children in the positive group had five or more symptoms.

An analysis of a COVID symptom study app (for mobile phones and tablets) found that Long COVID affects one in ten 18-49 year olds, and 22% of over 70 year olds (Sudre et al., 2020). This analysis also reported that older people, women, and those that experienced five or more symptoms within the first week of infection were most likely to develop Long COVID.

COVID-19 vaccination status, Long COVID symptoms and treatment pathway

Long COVID affects both vaccinated and unvaccinated populations. A UK Health Security Agency (UKHSA) review found that those individuals infected with COVID-19 after two doses of Pfizer, AstraZeneca, Moderna, or one dose of the Janssen vaccine saw a 50% reduction in developing COVID-19 symptoms lasting beyond 28 days (UK Health Security Agency, 2022). The review also found that being vaccinated reduced experiencing COVID-19 symptoms for up to six months.

Long COVID may affect any system in the body, therefore potential Long COVID symptoms are many. Subsequently, there are many secondary care specialists that can be engaged in Long COVID patient treatment. Data from Digital Health and Care Wales show that, by January 2022, just over 2,400 people had been diagnosed with Long COVID by their GP or healthcare professional in Wales, and 2,226 people were referred into Long COVID rehabilitation services in the last year. This number is smaller than the self-reported Office for National Statistics estimates of the number of people with Long COVID in Wales, and it is not yet clear what the long-term impact of omicron will be on the number of people experiencing Long COVID symptoms (Welsh Parliment, 2022). There are up to 90 NHS managed Long COVID clinics in the UK (NHS England, 2022), and the UK government announced a £6.6 billion package of funding in March 2021 to support health and care services which included an allocation of funds support to Long COVID services (UK Government, 2021). The Adferiad (recovery) programme (launched in June 2021) is a £5 million Welsh Government a package of services for Long COVID patients in Wales, for treatment and rehabilitation (Welsh Government, 2021a). A report outlining NHS running costs by the NHS Confederation and NHS Providers found that 38% of 116 NHS trusts (54% of the sector) believe that Long COVID costs will persist until the end of 2024/2025 financial year (NHS Confederation & NHS Providers, 2021).

Box 1: A list of Long-COVID symptoms compiled from a systematic review (Lopez-Leon et al., 2021)

Ageusia
Anorexia
Anosmia
Anxiety-Mental Health
Attention disorder
Blood clots
Chest pain or tightness
Chills or shivering
Cough
Cutaneous signs
Depression and anxiety
Diabetes
Diarrhoea
Difficulty concentrating
Digestive disorders
Discontinuous flushing
Dizziness
Dysphoria
Ear pain
Edema of lower limbs
Extreme tiredness (fatigue)
Fatigue
Feeling feverish, Nausea
Feeling sick
Hair loss
Headaches
Heart palpations

High temperature Joint or muscle pain loss of appetite Loss of sense of taste or smell Memory loss Myalgia Myocarditis New hypertension OCD Palpitation Pins and needles Polypnea Problems with memory and concentration (brain fog) Pulmonary fibrosis Rash Red eyes Reduced pulmonary capacity Renal failure Resting heart rate increase Runny nose Shortness of breath Sleep apnoea Sleep disorder Sore throat Stomach aches Stroke Sweat Sweats Tinnitus or earaches Vision issues Weight loss PTSD Paranoia

The National Health Service Trusts in the UK have developed treatment pathways for Long COVID (Welsh Government, 2021b). Patients will first consult their GP who will recommend them to the appropriate secondary care services after extensive questions on day-to-day wellbeing, pre-existing health conditions, symptoms, changes in mood, behaviour, emotions and mood and may result in diagnostic tests if required. The diagnostic tests can include: blood tests, blood pressure, heart rate, oxygen levels, chest X-Rays. In certain NHS Trusts, patients are referred to designated Long COVID clinics.

This will involve each part of the country designating expert one-stop services in line with an agreed national specification. Post-COVID services will provide joined up care for physical and mental health, with patients having access to:

- A physical assessment, which will include diagnostic testing, to identify any potential chronic health issues.
- A cognitive assessment, to assess any potential memory, attention, and concentration problems.
- A psychological assessment, to see if someone is suffering potentially from depression, anxiety, post-traumatic stress disorder (PTSD), or another mental health condition. Patients could also then be referred from designated clinics into specialist lung disease services, sleep clinics, cardiac services, rehabilitation services, or signposted into Improving Access to Psychological Services (IAPT) (in England) and other mental health services.

Patients with specific Long COVID symptoms can be referred to the following specialties:

- Cardiology
- Dermatology
- Ears Nose and Throat department
- Gastroenterology
- Haematology
- Physiotherapy
- Neurology
- Occupational Therapy
- Pathology
- Psychiatry
- Psychological Services
- Respiratory department
- Speech and language therapy

Due to the complexity and range of symptoms, Long COVID treatment can incur a number of costs. Non self-reported diagnosis of Long COVID calls on a number of secondary care specialists which vary from case to case (Scottish Government, 2021).

Aim of the review

It is important to understand the cost implications of Long COVID on NHS and social care services to inform resource planning. This Rapid Evidence Summary aimed to inform a decision-making about progress to a rapid review.

5. Research question(s)

Review question	
What is the cost impact of demands due to Long COVID on NHS and social care services?	
Participants	Patients with suspected or confirmed Long COVID (children and adults)
Intervention / exposure	Suspected or confirmed Long COVID-19
Comparison	Any or no comparator (as this is a rapid evidence summary)
Outcomes	**Cost of treatment or diagnostic testing** **Cost-effectiveness** **NHS services demand (or use)** **Cost of social care services associated with Long COVID**
Other Study Considerations	
Primary, secondary, grey literature, preprints	

6. Summary of the evidence base

Using the PICO framework outlined above, COVID-19 database searches were conducted to look for relevant papers within the time period from March 2020 to March 2022.

6.1 Type and amount of evidence available

Eight publications were included in this Research Evidence Summary (RES). All the included publications (n=8) were peer reviewed publications. The themes which emerged from the searches include: firstly, the economic impact of Long COVID, and secondly, the variance of patient demand in Long COVID treatment services.

Of the included publications there were systematic reviews (n=2), cohort studies (n=2), a modelling paper (n=1), a mixed-method study (n=1), a rapid clinical guideline (n=1), and a qualitative survey study design (n=1).

6.2 Key findings

Economic impact of Long COVID

Evidence is limited on the cost impact of demands due to Long COVID on the NHS and **no evidence was found about the cost impact of demands due to long COVID on social care services.**

Two publications were included in the theme of economic impact of Long COVID (Castanares-Zapatero et al., 2021; Martin, Luteijn, Letton, Robertson, & McDonald, 2021).

The modelling paper by Martin et al (2021) investigated lost Quality Adjusted Life Years (QALYs) of the UK population from Long COVID symptoms (Martin et al., 2021). This paper modelled that 299,730 QALYs were lost within 1 year of infection (90% of this loss is attributable to COVID symptoms and 10% is due to permanent injury) and 557,764 QALYs lost within 10 years of infection (49% of this loss is attributable to COVID symptoms and 51% is due to permanent injury). **The UK Government expressed a willingness-to-pay of £17.9 billion and £32.2 billion to avoid the QALY losses, respectively, based on valuing QALYs at £60,000.** The HM Treasury Green Book valuation of QALYs has since increased to £70,000 per QALY (HM Treasury, 2022). A model framework is outlined in the paper that encourages proactive and tailored interventions, prioritisation of prevention over cure, and introduction of flexible working arrangements to accommodate workers.

The report by Castanares-Zapatero et al 2021 found that Long COVID had a financial impact on Belgian patients due to **loss of income**, **increased healthcare expense** and loss of money **due to foregone activities** (Castanares-Zapatero et al., 2021). As there is no one test for the diagnosis of Long COVID, patients had to undergo a number of diagnostic tests which were not fully reimbursed before finding the appropriate treatment. For the Belgian population, having private insurance would help offset some of these costs.

The variance of patient demand in Long COVID treatment services

Six papers were in this theme (Davis et al., 2021; Décary et al., 2021; Duncan et al., 2020; MacPherson et al., 2022; Sykes et al., 2021; Yelin et al., 2022), as described below:

In order to be accurate in specialist referral, **it is important to collect client service use history to rule out underlying conditions** (Yelin et al., 2022)

Long COVID treatments are determined by individual symptoms, making standardised care challenging for care providers (MacPherson et al., 2022).

A qualitative survey study conducted by Duncan et al (2020) provided a national picture of community rehabilitation for people with Long COVID in Scotland in 2020 (Duncan et al., 2020). 14 health boards were solicited for this survey, and it was found that 13/14 health boards delivered rehabilitation. Fatigue (11/14) and respiratory conditions (9/14) were cited as the two most prevalent symptoms of patients. Each health board outlined different services that their rehabilitation services engaged for patient care, this included:

- Health board A: providing fatigue management, confidence building, muscle strengthening, anxiety management, nutritional advice, breathing re-education, and activities to support individuals to regain function
- Health board B: used a combination of pulmonary rehabilitation and community reablement
- Health board C: providing individualised goal setting based on symptomatic presentation

  Duncan et al **highlighted the need for investigation of implementation, outcomes, and cost-effectiveness** of differing models of community rehabilitation for patients with Long COVID.

- A Canadian based living systematic review found the five most common care model principles for Long COVID treatment include**: multidisciplinary teams (90%), integrated care (50%), continuity or coordination of care (50%), self-management (50%) and evidence-based care (35%)**. Equally, the five most common care model components include: **standardised symptoms assessment (95%), a referral system (80%), a follow-up system (75%), virtual care (70%), and home-based care (50%).** None of the included studies in the systematic review provided impact analysis or costs. As of 4th December 2021, this living review has been **completed** and **there will be no further updates**.

- The most commonly reported symptoms were anxiety, fatigue, post-exertional malaise, cognitive dysfunction. and myalgia (Davis et al., 2021; Sykes et al., 2021)

Bottom line:

It is unclear what the definite costs of demands due to Long COVID on the NHS and social care services are, due to a lack of evidence. However, individual health boards can model costs by creating multidirectional treatment pathways that are responsive to changes in symptoms including standardised assessment and diagnostic testing, referral to secondary care, follow-up, and virtual and home-based care.

Although one study outlines what the UK Government would be willing to pay to avoid loss of QALYs due to Long COVID, further research would be required to determine how these funds should be allocated and which regions require them (Martin et al., 2021).

6.3 Areas of uncertainty

Remaining uncertainties include:

- In areas without Long COVID clinics, patients will be sent back to their GP before they can be redirected to the appropriate secondary care specialist. Furthermore, it is unclear how the costs increase in the event of misdiagnosis. Not all regions in the

UK have designated Long COVID clinics, and those that do not have the same treatment pathway. Therefore, costs may vary from region to region.

- The RES did not find any evidence of the economic impact of Long COVID on children and adolescents.
- The full extent of the economic impacts of demands due to Long COVID on the NHS and social care services are unknown. However, in 2021 the National Institute for Health Research (NIHR) and the UK Research and Innovation (UKRI) awarded £19.6 million and commissioned 15 studies to understand and treat Long COVID. Researchers that have received this funding are in the early stages of their research or currently recruiting participants. At least four of fifteen studies will investigate the cost implications of Long COVID:
    - Effectiveness and cost-effectiveness of a personalised self-management support intervention for non-hospitalised people living with Long COVID ISRCTN36407216 Current status: Ongoing and Recruiting Overall trial dates 01/08/2021 - 31/07/2023 (Busse, 2021)
    - LOCOMOTION: Can we optimise the treatments and services provided across the NHS for Long COVID? ISRCTN15022307 Current status: Ongoing and Recruiting Overall trial dates: 01/08/2021 - 31/12/2023. Includes Evaluating cost-effectiveness of current and alternative care pathways (Paley, 2021)
    - Remote Diet Intervention to Reduce Long COVID symptoms Trial: Does weight management improve Long COVID symptoms in people with Long COVID and obesity? ISRCTN12595520 Overall trial dates: 31/03/2021 - 01/11/2023. Includes Cost-effectiveness of the intervention assessed using an economic evaluation (Haggerty, 2021)
    - Quality-of-life in patients with Long COVID: harnessing the scale of big data to quantify the health and economic costs NIHR award ID: COV-LT2-0073 Overall trial dates: 01/08/2021 – 31/08/2023 (Eggo, 2021)
- A summary produced by the WCEC outlines Active and Prospective Long COVID research in Wales and provides more detail of these aforementioned studies commissioned by the NIHR (Peters, Edwards, Law, & Cooper, 2021).

Although there are no current general pathology tests available to diagnose patients with the symptoms of Long COVID, there are NHS pathways for Long COVID (Welsh Government, 2022).

There is a significant evidence gap in relation to social care provision as there is a current emphasis on healthcare related matters. Newly funded NIHR studies are also focused on healthcare despite the fact that there might be increased need for social care to manage symptoms associated with Long COVID. Both physical and mental issues have arisen due to Long COVID and this is currently under-researched. Costs of increased demand on social services due to Long COVID are not clear due to a lack of published full economic evaluations.

6.4 Options for further work

Due to the lack of economic evaluations in the area of Long COVID, future research should focus on economically modelling potential diagnosis and treatment pathways in order to make a calculation of the cost of Long COVID per patient, based on service unit costs. The economic model would need to be multidirectional, given that Long COVID symptoms vary between patients. More studies are required specifically on the effects of Long COVID on children and young people with data disaggregated from adults.

7. Next steps

In view of the limited available evidence the cost impact of demands due to Long COVID on NHS and social care services, it was decided, in consultation with the stakeholders, not to

proceed to a (more detailed) rapid review. It is anticipated that ongoing research, in particular those funded by the National Institute for Health Research, will be able to provide further evidence to inform practice or policy in the near future.

It was agreed to progress with a further Rapid Evidence Summary work focussing on the cost impact of Long COVID on employment and caring responsibilities.

8. Acknowledgements

The Wales COVID-19 Evidence Centre (WCEC) would like to thank the stakeholders from the Welsh Government: Mark Walker, Heather Payne, Brendan Collins, and Tracey Williams as well as Lisa Trigg from Social Care Wales, and Mari James and Alexandra Strong (WCEC Public Partnership Group (PPG)) members for their advice and guidance in developing this research question.

9. Methods used in this Rapid Evidence Summary

COVID-19 specific and general repositories of evidence reviews noted in our resource list were searched on 11th and 14th March 2022. An audit trail of the search process is provided within the resource list (Appendix). Searches were limited to English-language publications and did not include searches for primary studies if secondary research relevant to the question was found. Search hits were screened for relevance by a single reviewer.

Priority was given to robust evidence synthesis using minimum standards (systematic search, study selection, quality assessment, appropriate synthesis). The secondary research identified was not retrieved as full text or formally quality assessed. The included research may vary considerably in quality and the degree of such variation could be investigated during rapid review work which may follow-on. Citation, recency, evidence type, document status and key findings were tabulated for all relevant secondary research identified in this process.

As secondary evidence was limited, a further targeted search for primary studies was conducted to inform options for further work. Findings from such studies have not been tabulated but an indication is given of the amount of literature for different aspects of the question.

Date of Search	March, 2022
Search Concepts Used	Chronic Chronic disease

	Cost of treatment Cost* Cost-effectiveness Demand Excess cost* Long COVID-19 Long COVID-19 diagnostic Long COVID-19 test* NHS services demand Pathway* Post COVID-19 syndrome Symptoms Long COVID-19 Unmet
Search Completed by	Abraham Makanjuola, Kalpa Pisavadia, Jacob Davies; BIHMR

The asterisks seen in the above table denote search terms (*) broader search terms beyond the stem word (i.e. test* tests and testing)

10. Results

Table 1. Summary of review evidence identified

Evidence type	Total identified	Comments
Systematic reviews (SRs)	2	Including an ongoing living review
Rapid reviews (RRs)	0	
Clinical Guidelines (CGs)	1	A rapid clinical guideline
Protocols for reviews that are underway	0	
Economic evaluations (EE)	0	
Primary Studies	4	Including cohort studies and qualitative study designs
[Other..]	1	A modelling paper

A more detailed summary of included evidence can be found in Table 2.

Table 2: Summary of included evidence

Primary /Secondary / Tertiary research						
Resource	**Citation**	**Recency (Search dates)**	**Evidence Type***	**Status****	**Key findings from abstracts**	**Reviewer comments**
Economic Impact						
WHO Global Coronavirus Database	Castanares-Zapatero et al (2021) Long COVID: Pathophysiology – epidemiology and patient needs. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2021. KCE Reports 344. D/2021/10.273/31.	2021	Mixed-method study	Published	This publication reports on the increasing number of patients reporting Long-term effects of COVID-19. Report focuses on three main areas of research: **Research area 1: Literature review on epidemiology and pathophysiology of Long COVID (to understand definition, frequency, common symptoms, risk factors and underlying pathophysiological mechanisms of Long COVID).** • Hospitalised patients during the acute phase, the median reported percentage of persistent symptoms within the first 3 months was 32% (ranging from 5 to 36%). • In studies in which almost all patients have been hospitalised, the median was higher (51%, ranging from 32 to 78%). • Evidence on the prevalence of Long COVID remains limited and insufficient to formulate conclusions. The high heterogeneity of symptoms and	**Belgium based study** • Although this publication does not specifically address the cost impacts of Long COVID, it does provide insight into reimbursable Long COVID treatments in Belgium, as well as offering a comprehensive review of existing Long COVID literature. • This review conducted primary research via interviews and online surveys to assess the needs and experiences of patients suffering with Long COVID complaints. • Given the differences between the Belgian and UK health systems, the **findings of research area 3 are not transferrable to this context.**

					high variance of reported prevalence offer difficulties. • There is still no clear widely accepted definition of Long COVID. Long COVID encompasses distinct phenotypes. • In the **first three months**, the most commonly reported persistent symptoms in the group of Long COVID patients are fatigue (up to 98%), dyspnoea (up to 88%), headache (up to 91%) and taste/smell disorders (up to 55%). **Beyond 6 months,** fatigue (median 51%) and dyspnoea (median 30%) are still reported. • Risk factors to developing Long COVID are still unclear. Those who were not hospitalised reported a higher number of symptoms at the acute phase may be a risk factor. • Although Long COVID is prevalent across all age categories, people aged 35 to 69 years appear to be more likely to be affected. Females seem to be more likely to develop Long COVID than males. **Research area 2: Patient survey and interviews (what are the needs and experiences of patients with Long COVID complaints)?** • Several patients self- diagnosed LCOVID. Some interviewees	

					self-diagnosed by recognising themselves in stories on Facebook or internet reports without any certainty or formal diagnosis. • Patients felt there was a lack of awareness on the part of physicians. Uncertainty and lack of awareness of a clear Long COVID diagnosis is having an impact on adequate management of Long COVID-19. • Diagnostics often conducted on a symptom-by-symptom basis. Some patients reported searching for unconventional therapies when traditional medicine is not working. • Variety of symptoms and many uncertainties around Long COVID results in unstandardised treatment approaches, described some interviewees. • Some patients noted Long COVID having a life changing impact due to the associated symptoms. Some patients have had to adapt their activity levels, others face incapacity to work or face difficulties to restarting work. Some patients felt they could no longer resume in their same career function at the same capacity or at all. • **Costs:** some patients reported physicians prescribing several not (fully) reimbursed treatments, raising personal	

					costs. Costs of ambulatory expenses and medical exams have an impact on household budgets of patients. • Patients reported adverse psychological symptoms such as heightened anxiety. **Research area 3: Analysis of current Belgian legislation and reimbursement rules**	
PubMed/L*OVE primary studies Secondary research resources for (non-COVID-19) reviews	Martin et al (2021) A model framework for projecting the prevalence and impact of long-COVID in the UK 10.1371/journal.pone.0260843	Up to December 2020	Modelling paper	Published	• Scope includes QALYs lost to symptoms, but not deaths, due to acute COVID-19 and Long COVID. • The prevalence of symptomatic COVID-19, encompassing acute symptoms and Long COVID symptoms, was modelled using a decay function. • Permanent injury as a result of COVID-19 infection, was modelled as a fixed prevalence. • Both were combined to calculate QALY loss due to COVID-19 symptoms. Assuming a 60% final attack rate for SARS-CoV-2 infection in the population. • Modelled 299,730 QALYs lost within 1 year of infection (90% due to symptomatic COVID-19 and 10% permanent injury) and 557,764 QALYs lost within 10 years of infection (49% due to symptomatic COVID-19 and 51% due to permanent injury). **The UK Government willingness-to-pay to avoid these QALY losses would be £17.9 billion and £32.2 billion, respectively.**	**UK based study** Presents a model framework for calculating the health economic impacts of symptoms following SARS-CoV-2 infection which can aid in quantifying the adverse health impact of COVID-19, Long COVID and permanent injury following COVID-19.

The variance of patient demand in Long COVID treatment services						
PubMed Secondary research resources for (non-COVID-19) reviews	Davis et al (2021) Characterizing long covid in an international cohort: & months of symptoms and their impact doi.org/10.1016/j.eclinm.2021.101019	September 6 2020 to November 25 2020	Cohort study	Published	• Time to recovery exceeded 35 weeks for 91% of respondents. • Participants experienced an average of 55.9+/- 25.5 (mean+/- STD) symptoms, across an average of 9.1 organ systems. • **The most frequent symptoms after month 6 were fatigue, post-exertional malaise, and cognitive dysfunction.** • Symptoms varied in their prevalence over time, 85.9% of participants (95% CI, **84.8% to 87.0%) experienced relapses, primarily triggered by exercise, physical or mental activity, and stress.** • 86.7% (85.6% to 92.5%) of unrecovered respondents were experiencing fatigue at the time of survey, compared to 44.7% (38.5% to 50.5%) of recovered respondents. 1700 respondents (45.2%) required a reduced work schedule compared to pre-illness, and an additional 839 (22.3%) were not working at the time of survey due to illness. • **Cognitive dysfunction or memory issues were common across all age groups** (~88%). • Except for loss of smell and taste, the prevalence and trajectory of all symptoms were similar between groups with confirmed and suspected COVID-19.	**UK and USA based study** Study analysed responses from 3762 participants with confirmed COVID-19, from 56 countries, with illness lasting over 28 days. Estimates the prevalence of 203 symptoms in 10 organ systems and traced 66 symptoms over seven months measuring the impact on life, work, and return to baseline health. Patients with Long COVID report prolonged, multisystem involvement and significant disability. By seven months, many patients have not yet recovered (mainly from systemic and neurological/cognitive symptoms), have not returned to previous levels of work, and continue to experience significant symptom burden.

VA-ESP	Decary et al (2021) Care Models for Long COVID – A Living Systematic Review. First Update – December 2021. SPOR Evidence Alliance, COVID-END Network	2021	Systematic Review	Ongoing (Living Review)	In the first update of this ongoing Review, the **five most common principles in Long COVID-19 care models included multidisciplinary teams, integrated care, continuity or coordination of care, self-management and evidence-based care.** The **five most common components included standardized symptom assessment, referral system, follow-up system, virtual care, and home-base care**. For **staffing rehabilitation, the three most common professions were physiotherapy, psychiatry/psychology and occupational therapy**. For **staffing primary care, the three most common professions were social work, family physicians and nursing.** The **most common medical specialties included pulmonary/respiratory, cardiovascular and neurology**. Impact and costs of care models for Long COVID remain largely unknown. **Care Models principles** The five most common principles remain the same and include multidisciplinary teams (90%), integrated care (50%), continuity or coordination of care (50%), self-management (50%) and evidence-based care (35%). **Care Models' Components** The five most common components remain standardised symptoms assessment (95%), referral system (80%), follow-up system (75%), virtual	**Canadian based Review** Offered insight into the most common make-up of Long COVID care within Canada. The components of which and the associated medical/healthcare specialists are also defined. As of 4th December 2021, this living review has been **completed** and **there will be no further updates**.

					care (70%), and home-based care (50%). **Healthcare Professionals and Medical Specialties Included in Care Models** We identified all healthcare professionals and medical specialties included in care models and combined evidence from the initial and updated search (Table 4). We initially found a total of 32 healthcare professionals and medical specialties proposed to staff Long COVID care models. No new medical specialty or healthcare professional was identified in the update. We divided specialties and professionals according to their care setting (i.e. rehabilitation, primary care and specialty care). For the review update, for rehabilitation staffing, the three most common professions were physiotherapists (80%), psychiatrists/psychologists (80%) and occupational therapists (60%). For primary care staffing, the three most common professions were social workers (60%), family physicians (55%) and nurses (50%). The most common medical specialties included pulmonary/respiratory (90%), cardiovascular (80%) and neurology (70%). **Impact and Costs** Similar to the initial report, none of the included studies in the update provided impact analysis or costs.	

PubMed/ Cochrane COVID-19 Study Register Secondary research resources for (non-COVID-19) reviews	Duncan et al (2020) A national survey of community rehabilitation service provision for people with long Covid in Scotland 10.12688/f1000research.27894.2	14 October 2020 to 6 November 2020	Quantitative study	Published	• Almost all Health Boards (13/14) currently deliver rehabilitation for people with Long Covid within pre-existing services. Fatigue (11/14) and respiratory conditions (9/14) were the two most common presenting problems of patients. • Most Long Covid community rehabilitation services are delivered through a combination of face-to-face and digital contact (13/14). • One respondent described their service as providing fatigue management, confidence building, muscle strengthening, anxiety management, nutritional advice, breathing re-education, and activities to support individuals to regain function. • One respondent stated that their service used a combination of pulmonary rehabilitation and community reablement. • A final respondent described their service as providing individualised goal setting based on symptomatic presentation. Survey provides a national picture of current community rehabilitation for people with Long Covid in Scotland.	**Scotland based study**
VA-ESP	Macpherson et al, (2022) Experiences of living with long COVID and of accessing healthcare services: a qualitative systematic review. *BMJ Open*. 2022;12(1):e050979. Published 2022 Jan 11.	2022	Qualitative Systematic Review	Published	It appears that greater knowledge of Long COVID is required by a number of stakeholders and that the design of emerging Long COVID services or adaptation of existing services for Long COVID patients should take account of patients' experiences in their design. Evidence showed that people with Long COVID experience a wider range of	**Studies from any country and any setting included**. Offered insight into patients' experiences living with Long COVID. As detailed in other literature, these experiences and symptoms are very heterogeneous.

	doi:10.1136/bmjopen-2021-050979				symptoms than the three symptoms officially recognised as acute COVID-19: high temperature, new continuous cough and change or loss of sense of smell or taste. For many patients, there was a feeling that their self-identity was affected by Long COVID. People reported an impact on how they viewed themselves, before and after their illness. The phrase 'compared with how I used to be' was used by multiple participants in Kingstone *et al*'s study, while Ladds *et al* commented on the concept of a 'spoiled identity' where an identity as previously 'healthy, independent and successful' was perceived to be threatened. Interviews by Ladds *et al* with doctors and other clinicians who had experienced Long COVID showed that many were worried about the impact of cognitive deficits on their ability to perform their jobs Across most of the studies, participants expressed concerns relating to the lack of knowledge, information and understanding about Long COVID among healthcare professionals. While the reason behind this lack of knowledge was understood, there was a general feeling that there needed to be acknowledgement of this gap within the healthcare community. There is a need for greater understanding and communication about Long COVID at a number of levels (public, policy and healthcare professional). This Review's findings	Participants expressed concerns relating to the lack of knowledge, information and understanding about Long COVID among healthcare professionals, outlining issues in practice, the lack of a clear Long COVID definition.

					suggest that people with Long COVID are well placed to co-create this understanding and communication. Our findings can also be used by those currently developing services for people with Long COVID to ensure that they meet patients' needs. The varied and fluctuating symptoms and emotional consequences experienced by people with Long COVID indicate a need for multidisciplinary services, which provide holistic patient-centred assessment, appropriate management and specialist referral where indicated.	
PubMed Secondary research resources for (non-COVID-19) reviews	Sykes et al, 2021, Post-COVID-19 symptom burden: What is long-COVID and how should we manage it? 10.1007/s00408-021-00423-z	2021 (publication date)	Cohort study	Published	• Assessed symptom burden of patients with COVID-19 pneumonia discharged from a large teaching hospital trust at follow-up using a standardised data collection technique during virtual outpatient clinic appointments. • Eighty-six percent of patients reported at least one residual symptom at follow-up. No patients had persistent radiographic abnormalities. • The presence of symptoms at follow-up was not associated with the severity of the acute COVID-19 illness. • **Females were significantly more likely to report residual symptoms including anxiety ($p = 0.001$), fatigue ($p = 0.004$), and myalgia ($p = 0.022$).** • The presence of long-lasting symptoms is common in COVID-19 patients.	**UK based study** Authors suggest that the biopsychosocial effects of COVID-19 may play a greater role in the aetiology of Long COVID-19

					Phenomenon of Long COVID may not be directly attributable to the effect of SARS-CoV-2.	
L*OVE COVID-19	Yelin et al (2022) ESCMID rapid guidelines for assessment and management of Long COVID, Clinical Microbiology and Infection, https://doi.org/10.1016/j.cmi.2022.02.018	2022	Journal	Published	**Who should be assessed for Long COVID?** Recommendation: As a first step, it is suggested to collect specific clinical history to rule out previous underlying conditions, as well as iatrogenic causes or complications related to the acute episode. Hence, any patient with persisting or new symptoms that last over 12 weeks after acute COVID-19, should be referred to medical care. For patients 4-12 weeks following acute infection, assessment should be considered on a case-by-case basis, according to the severity and course of symptoms. **What assessment is needed for individuals with Long COVID?** Recommendations are made on assessment options for the following specialties: Pathology, cardiology, pulmonology, neuroimaging, psychology, psychiatric evaluation, and general practice. **Management of patients with Long COVID.** Recommendations are made on management options for the following Long COVID symptoms and treatments: Post-discharge extended) thromboprophylaxis, physical or pulmonary rehabilitation, persistent pulmonary symptoms/signs, persistent cough, smell and taste	Used to compile list of Long COVID specialties as part of Long COVID rehabilitation, assessment, and management.

					disturbances, fatigue, neurological/cognitive Long COVID sequelae and emotional/psychiatric Long COVID sequelae.	

* RR Rapid review; CG Clinical guideline; EE Economic Evaluation; HTA health technology assessment; SR systematic review [delete / add as appropriate]

* Caution: Preprints are preliminary reports of work that have not been certified by peer review. They should not be relied on to guide clinical practice or health-related behaviour.

11. About the Wales COVID-19 Evidence Centre (WCEC)

The WC19EC integrates with worldwide efforts to synthesise and mobilise knowledge from research.

We operate with a core team as part of Health and Care Research Wales, are hosted in the Wales Centre for Primary and Emergency Care Research (PRIME), and are led by Professor Adrian Edwards of Cardiff University.

The core team of the centre works closely with collaborating partners in Health Technology Wales, Wales Centre for Evidence-Based Care, Specialist Unit for Review Evidence centre, SAIL Databank, Bangor Institute for Health & Medical Research/ Health and Care Economics Cymru, and the Public Health Wales Observatory.

Together we aim to provide around 50 reviews per year, answering the priority questions for policy and practice in Wales as we meet the demands of the pandemic and its impacts.

Director: Professor Adrian Edwards

Contact Email:
WC19EC@cardiff.ac.uk

Website: https://healthandcareresearchwales.org/about-research-community/wales-covid-19-evidence-centre

All reports can be downloaded from the website library:
https://healthandcareresearchwales.org/wales-covid-19-evidence-centre-report-library

12. APPENDIX – Resources searched during Rapid Evidence Summary

A single list of resources has been developed for guiding and documenting the sources searched as part of Rapid Evidence Summary. Where relevant, all 'priority resources' will be searched, but not all resources will be searched. Some sources will be searched as part of the subsequent Rapid Review (or Rapid Evidence Map).

Each resource will be recorded as being:

- *searched; nothing found*
- *searched; results found*
- *not searched; not relevant*
- *not searched, maybe relevant*

Resource	Success or relevancy of the retrieval
Priority COVID resources for reviews	
Cochrane COVID Review Bank https://covidreviews.cochrane.org/search/site	Searched, nothing found
WHO Global Coronavirus Database https://search.bvsalud.org/global-literature-on-novel-coronavirus-2019-ncov/	Searched, results found
L*OVE – COVID-19 https://app.iloveevidence.com/loves/5e6fdb9669c00e4ac072701d?population=5e7fce7e3d05156b5f5e032a&classification=systematic-review	Searched, results found
VA-ESP https://www.covid19reviews.org/index.cfm	Searched, results found
Additional COVID resources for reviews *(Tailor the list according to the topic and potential evidence base. In some cases, it may be preferable to scan the main (generic) source rather than COVID-19 specific product; listed under secondary research)*	
LitCovid https://www.ncbi.nlm.nih.gov/research/coronavirus/	Searched, nothing found
Rolling collaborative review of Covid-19 treatments - Eunethta (Not a searchable database but a list of living reviews) https://eunethta.eu/covid-19-treatment/	Searched, nothing found
EPPI-Centre - Living map of the evidence of studies on COVID-19 identified in MEDLINE and EMBASE, that groups the evidence into broad themes https://eppi.ioe.ac.uk/eppi-vis/Review/Index	Searched, nothing found
For technology / treatment questions	
International HTA database (ITS-HTA) (for technology questions only) https://database.inahta.org/	Not searched, not relevant
EUnetHTA – COVID 19 response (not a searchable database but a lists of evidence covering diagnostics and treatments) https://eunethta.eu/services/covid-19/	Not searched, not relevant
For topic specific / focused review questions	
COVID-END– Evidence summaries (McMaster Health Forum) (Incorporates multiple COVID-19 resources, including many listed here. May be useful for topic specific/focused questions; may not be useful for border questions) https://www.mcmasterforum.org/networks/covid-end	Searched, nothing found
COVID-19 Evidence Alerts from McMaster PLUS™ Usefulness dependent on topic; may not be user friendly for broad/complicated questions https://plus.mcmaster.ca/COVID-19/	Searched, nothing found

Additional COVID resources for primary studies	
L*OVE primary studies https://app.iloveevidence.com/loves/5e6fdb9669c00e4ac072701d?population=5e7fce7e3d05156b5f5e032a&classification=primary-study	Searched, results found
Cochrane COVID-19 Study Register https://covid-19.cochrane.org/	Searched, results found
LitCovid https://www.ncbi.nlm.nih.gov/research/coronavirus/	Searched, results found
Secondary resources for reviews relevant to local/UK context	
United Kingdom Health Security Agency's (UKHSA's) COVID-19 Rapid Reviews https://ukhsalibrary.koha-ptfs.co.uk/covid19rapidreviews/	Not searched, maybe relevant
NICE resources for COVID reviews *Any queries regarding ongoing or planned reviews contact Chris Connell: Chris.Connell@nice.org.uk*	Not searched, maybe relevant
Healthcare Improvement Scotland – COVID-19: Evidence for Scotland (not a searchable database but a lists Once for Scotland guidance, rapid evidence reviews, NICE rapid guidelines evidence covering diagnostics and treatments) http://www.healthcareimprovementscotland.org/our_work/coronavirus_covid-19/evidence_for_scotland.aspx	Not searched, maybe relevant
Ireland, HSE Library, Covid-19 Summaries of Evidence not a searchable database but a list of all summaries of evidence that HIQA have been asked to address) https://hselibrary.ie/covid19-evidence-summaries/	Not searched, maybe relevant
HIQA Health Information and Quality Authority (Ireland) – Rapid reviews https://www.hiqa.ie/reports-and-publications/health-technology-assessment/rapid-review-public-health-guidance	Not searched, maybe relevant
SAGE https://www.gov.uk/government/organisations/scientific-advisory-group-for-emergencies	Not searched, maybe relevant
Secondary resources for reviews produced by key international organisations	
NCCMT COVID-19 rapid reviews (Canada): https://www.nccmt.ca/covid-19/covid-19-rapid-evidence-service	Not searched, maybe relevant
ECDC European Centre for Disease Prevention and Control (COVID-19 outputs) https://www.ecdc.europa.eu/en/publications-data	Not searched, maybe relevant
CDC centre for Disease Control and Prevention - Guidance for COVID-19 (US) https://www.cdc.gov/coronavirus/2019-ncov/communication/guidance.html	Not searched, maybe relevant
AHRQ Agency for Healthcare Research and Quality (US) https://www.ahrq.gov/coronavirus/health-systems-research.html	Not searched, maybe relevant
NASEM The National Academy of Sciences Engineering Medicine - Coronavirus Resources Collection (US) https://www.nap.edu/collection/94/coronavirus-resources	Not searched, maybe relevant
Australian National COVID-19 Clinical Evidence Task Force - Living Guidelines; mainly treatment https://covid19evidence.net.au/ (*also incorporated in Trip*)	Not searched, maybe relevant
Secondary research resources for (non-COVID-19) reviews (*Tailor the list according to the topic and potential evidence base, talk to stakeholder before proceeding with this type of search*)	

Trip (Trip Pro can be accessed by an institutional based subscription based via institution, otherwise use Trip) https://labs2020.tripdatabase.com/ Link to search for COVID-19 related research: https://www.tripdatabase.com/search?criteria=%22covid+19%22+OR+%22novel+coronavirus%22 (As a **covid resource for guidelines** - add an additional COVID search term and filter by UK guidelines, covers NICE, and SIGN. Can also filter for non-UK guidance)	Searched, nothing found
Cochrane Database of Systematic Reviews (CDSR) https://www.cochranelibrary.com/cdsr/reviews	Searched, nothing found
Campbell Collaboration https://www.campbellcollaboration.org/better-evidence.html	Searched, nothing found
JBI (via OVID) (Subscription based service – WCEBC has a subscription)	Searched, nothing found
Epistemonikos https://www.epistemonikos.org/en/advanced_search	Searched, nothing found
PROSPERO https://www.crd.york.ac.uk/prospero/	Searched, nothing found
Pubmed Clinical Queries https://pubmed.ncbi.nlm.nih.gov/clinical/	Searched, nothing found
PubMed Filter by systematic reviews, reviews or meta-analysis once search undertaken https://pubmed.ncbi.nlm.nih.gov/	Searched, results found
Additional resources searched	
Google Advanced Search https://www.google.co.uk/advanced_search	Searched, nothing found

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