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Long COVID: Summary of the Desk Research

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‘A Different Perspective’ on the NHS and Social Care by Shani Shamah, Citizen Reader

You just have to care – to make a difference in someone’s life, you don’t have to be brilliant, rich, beautiful or perfect.

Giving peace of mind is a priority – help people to make deliberate life choices to protect mental, emotional and spiritual state.

Help fight the demons – waking-up every morning to continue fighting the demons is so tiring and demands continual bravery

Holding the hand-wonderful people who can guide and support are needed to help find oneself again. It is the minimum – I achieved because I had my husband to hold my hand to guide, encourage and push me to take control and self-manage to move forward.

Maintain a sense of normality – even in times of trauma trying to maintain a sense of normality is called surviving.

Everyone deserves a life that is worth living

A UNIQUE OPPORTUNITY TO DEVELOP CARE THAT STARTS IN PEOPLE'S HOMES

First Contact

we need services to be kind. we need to trust you

Flexible

a flexible approach that adapts to my changing needs

Collaborate

design services at a local level, working together with patients and communities that everyone can access

Waiting

Check the waiting list for people at increased risk of certain conditions

Learn

Learn locally and with other services. Share the learning widely with others.

Having and then living with Long COVID is to live with uncertainty. Any model of provision needs to understand and support people to live with uncertainty.

Long COVID

CHANGING ATTITUDES

- Listen and don't assume
- As a new condition people's experience is paramount
- Be honest about the uncertainty
- Be supportive and compassionate
- Long COVID is NEW.

INTEGRATE

- Close to home
- Located in Primary Care
- Coproduced with people living with Long COVID and their families
- Detect and treat other illnesses, disabilities, or complications

WHOLE JOURNEY

- Prevention + detection
- Diagnosis + treatment
- Living With packages of support

COLLABORATE

Holistic approach

WORKING TOGETHER WITH PEERS + COMMUNITIES TO FIND SOLUTIONS

As an emerging service, Long COVID services vary from place to place.

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drawn by GRAPHIC CHANGE

This desk research has been commissioned by the Joint Programme for Patient, Carer and Public Involvement in COVID Recovery.

Established in September 2020, the Joint Programme for Patient, Carer and Public Involvement in COVID Recovery is a partnership between Guy's and St Thomas' NHS Foundation Trust (GSTT) including Evelina London Children's Hospital and Royal Brompton and Harefield hospitals (RBH) and King's College Hospital NHS Foundation Trust (KCH). It is funded, over two years, by GSTT Charity and supported by KCH Charity to ensure the involvement of patients, carers and the public in ongoing changes and the development of services necessitated by the COVID pandemic.

The programme is working with patients, carers and the public to understand:

- shifts in public attitudes and behaviours toward accessing care in different parts of the healthcare system and the risk that patients and the public may retract from accessing the care they need now or in the future
- how changes made, or being made, continue to affect patients, their families and carers experiences' of accessing care, using new or rapidly changing models of care
- variations in experience of care between different protected characteristics
- how we can improve and further develop services

As part of the programme's activities, an extensive scoping, identification and prioritisation exercise was carried out to refine the focus of the programme. This resulted in the prioritisation of the following three projects:

- Virtual access to care
- Waiting for treatment and self-management
- Long COVID

London South Bank University's Health Systems Innovation Lab and People's Academy will support the delivery of the three projects outlined above.

This desk research report provides background information and context to help shape and inform the project.

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1. Scope of this desk research

This is a summary of the desk research conducted by the academic team on Long COVID. The desk research questions were:

1. What support or interventions would be helpful (e.g., clinical treatment, peer to peer support, self-management/supported self-management, advice, and guidance) and how can these services be as accessible as possible to patients?
2. How can partners help patients manage their symptoms, access services, and alleviate anxiety?

The search question was therefore:
"What support, services or interventions are available to help manage the symptoms of Long COVID?"

It should be noted that Long COVID is known by other terms (see below), there is wide heterogeneity in studies on Long COVID and the availability of evidence is very low (Siso-Almirall et al, 2021). Some have classed Long COVID as symptoms persisting at 3 weeks whereas others argue this is the case for many viral illnesses and make the case for using a much longer milestone. In addition, many have argued that a diagnosis of COVID-19 (or presence of antibodies) should not be required to suspect Long COVID. The NICE, SIGN and RCGP (2020) criteria definition is: "signs and symptoms that develop during or following an infection consistent with COVID-19, continue for >12 weeks and are not explained by an alternative diagnosis."

Long COVID is also referred to as:

- Post COVID syndrome
- Incident clinical sequelae
- Long COVID
- Post COVID
- Post-COVID-19
- COVID long-haulers

We use the terms **'person/people'** rather than 'patients', except when quoting other sources.

2. Key messages from the desk research

1. This is a unique opportunity to design an integrated asset-based approach (Malby et al, 2019) with people and communities; rebuilding trust and developing a model of care that starts in people's homes. Learning from previous integration experiments is useful. Spreading the learning from Long COVID model development will be beneficial to many other services.
2. This requires the NHS to address the attitudes held by some professionals to people with Long COVID, moving to a position of listening, belief, partnership and shared solution finding. It needs the NHS to advocate to the wider system to recognise the impact of Long COVID (e.g. on work and income).
3. It also requires a peer-based approach to solution finding, bringing in the whole system of care and support from informal carers to clinicians. This is not a hospital-led model of care. It is important to consider however, that non-medical support offers can sometimes make people feel that they are being 'fobbed off' (National Voices, 2021) and care needs to be taken to find joint solutions.
4. As Long COVID treatment, support and recovery is co-dependent on community-based resources and assets (such as the voluntary sector and peersupport), development of Long COVID models need to be as local as possible – developed at a Borough level and supported by national standards (NICE, 2020). This has the added benefit of working with communities to ensure no one is left behind.
5. Having, and then living with Long COVID is an uncertain world. Integral to any model provision is appreciation of and support for living with uncertainty.Any model of Long COVID support is relational – people need people.

The Model of Provision

1. **Collaborate**: Long COVID requires a collaborative holistic approach between people and their families; multiple NHS specialities and professions across hospital and community settings; social care and third sector services; and communities. This is a challenge to the traditional siloed ways of organising NHS care, and to a dominant medical model. Evidence suggests that Long COVID represents a variety of post COVID health problems which include multi- organ

morbidity, increased risk of morbidity (cardiac, diabetes) and psychological and social issues.

2. **Integrate:** This is a unique situation; the opportunity to develop an integrated model from scratch. Long COVID requires a fully integrated model, provided as close to home as possible, primarily located in primary care. The model should be co-produced with people living with Long COVID and their carers, and should exclude red flag conditions, detect and treat comorbidities or complications, support symptomatic management, resilience and recovery.
3. **Whole Pathway:** Should include ‘Prevention and Detection’ (working with communities), ‘Diagnosis and Treatment’ (with a case management model to support integration) and ‘Living with Long Covid’ packages of support that bring communities and services together.
4. **First Contact:** People need a warm approach with people they trust. Many have lost trust and need to rebuild their relationship with services. Communities should be integrated into any new model.
5. **Adapt:** Any approach needs to be flexible and adaptive to the changing needs to people with Long COVID. Long COVID can also be a relapsing-remitting condition with different issues at different stages of the syndrome.
6. **Waiting:** Triage people waiting for Long COVID clinics. Almost 70 Long COVID clinics (NHSE, 2021) have been set up across the country, but the literature suggests there may be a long wait for these and that they may lack multidisciplinary or specialist input (Sivan et al, 2021). For this reason, the evidence suggests that people waiting for treatment must be triaged to check for ‘red flags’ as people living with Long COVID are at higher risk of developing certain conditions (such as heart and liver failure) and may need tests and investigations whilst they wait for treatment.
7. **Coproduce Locally:** With people, their families and carers, their communities, health care, social care, third sectors. Take an asset-based approach that is adaptive to emerging knowledge and addresses the wide range of needs. It needs the assets of people and communities and will be best designed at Borough level, with clear standards set nationally/regionally to ensure universality.

8. **Learn:** Locally within the emerging model and with others developing Long COVID provision. Spread learning into wider services as this will be the exemplar for integration.

Changing Attitudes

9. **Recognition:** As a new condition, people's experience is paramount. People living with Long COVID need to be heard and believed. Some clinicians still believe that Long COVID is largely psychological, but the evidence contradicts this, as differences have been found between other post viral illnesses and post COVID-19 pathology - many people have said they just want to be 'believed'.
10. **Attitude**: Long COVID is not 'Chronic Fatigue Syndrome' or 'Fybromyalgia'. People and health professionals who live with Long COVID arefrustrated about the comparisons made with Chronic Fatigue Syndrome and arekeen for it not to be treated as the same, as the aetiology of Long COVID is still unknown.
11. **Listen Don't Assume:** Long COVID requires a highly personalised and holistic (including family/ context) approach to work. The importance of coproduction of both services and guidelines with people living with Long COVID (see below) was highlighted in the literature.
12. **Be Honest:** People living with Long COVID live in a world of uncertainty, they need clarity about the potential futures, and support and compassion to cope with this.

Fairness

13. **Universality:** As an emerging service there are a multiplicity of Long COVID services. Clinics follow a variety of models, and services offered are not standardised nor widely available, which is an inequality in healthcare provision. The type of care provided may also reflect research priorities and grants as well as professional beliefs about what is needed. For example, there are reports that some service models offer mainly psychological input whereas others offer specialist investigations as well as treatment options. National and local needs should inform place-based coproduced models.
14. **Equity:** It is yet to be determined whether those who are disproportionately affected by COVID (e.g., key workers, transport workers, people with learning disabilities and ethnic minorities) are proportionately receiving support in specialist Long COVID services locally. Local services need to collect data on

these characteristics to address inequalities and must make adjustments, such as including providing information in a range of languages and formats.

15. **Impact:** The physical, mental, social, and financial impact of Long COVID is different for different people, but these factors are not supported to the same extent by professionals or Long COVID services. Appropriate services should be offered to reflect impact on physical, mental, financial, and social health.

The infographic at the start of this document summarises the key messages.

3. Contextual information

3.1 Background from our citizen reader

“The effects of COVID -19 are going to continue for some time. Although it is clear that there will be no return to ‘normal’, at least in the near future, the experience of COVID-19 has demonstrated the need to reconsider the way that the NHS has traditionally delivered services. Additionally, COVID-19 has exposed the widened existing inequalities in health and care throughout the country.

At the early stages of the pandemic, the British media were already covering what people called “Long-COVID”. Several people who had experienced an initial COVID-19 infection and recovered, experienced relapsing symptoms. For some people recovering from COVID-19 symptoms will prevent them from working orcaring for their loved ones or create anxiety about fulfilling responsibilities.

There is a recognition that patients throughout the country recovering from COVID-19 need rehabilitation services that should be holistic and should consider that each patient is a person with individual rehabilitation needs that span across health and social care, ‘One-size does not fit all’.

It is high time to LISTEN, co-designing and evaluating self-management support with and for people living with Long COVID (Bridges Self-Management, 2021). An article in the Lancet further points to the rising profile of Long COVID (‘a modern medical challenge’) while none other than the Director-General of the WHO callson countries worldwide to prioritise recognition, rehabilitation, and research into the long-term consequences of COVID-19.

People with experience of Long-COVID have developed considerable expertise on their condition; they have organised and mobilised, they have already had an important influence on research; and they can and must be fully involved in solutions to help improve their lives.”

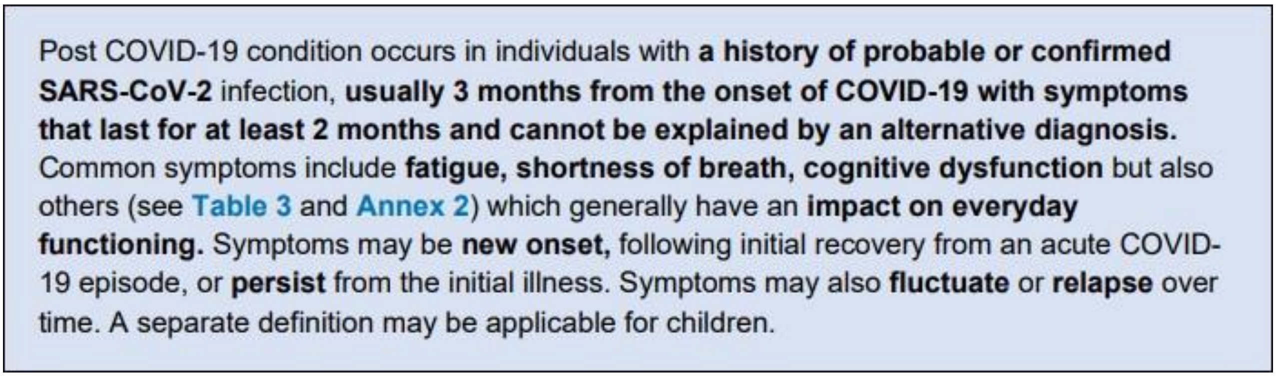
3.2 Context

The National Institute for Health and Care Excellence (NICE) (2020) defined the various forms or possible stages of COVID-19 infection as follows:

1. *Acute COVID-19: Signs and symptoms of COVID-19 for up to 4 weeks.*
2. *Ongoing symptomatic COVID-19: Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.*
3. *Post-COVID-19 syndrome: Signs and symptoms that develop during or after an infection consistent with COVID-19 continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time andcan affect any system in the body. Post-COVID-19 Syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.*
4. *Long COVID: In addition to the clinical case definitions, the term 'Long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and Post-COVID-19 syndrome (12 weeks or more)*

The World Health Organisation (2021) refer to Long COVID as Post-COVID condition. The full definition is below (figure 1).

Figure 1: World Health Organisation (2021) definition of post-COVID condition



Post COVID-19 condition occurs in individuals with **a history of probable or confirmed SARS-CoV-2** infection, **usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis.** Common symptoms include **fatigue, shortness of breath, cognitive dysfunction** but also others (see **Table 3** and **Annex 2**) which generally have an **impact on everyday functioning.** Symptoms may be **new onset,** following initial recovery from an acute COVID-19 episode, or **persist** from the initial illness. Symptoms may also **fluctuate** or **relapse** over time. A separate definition may be applicable for children.

The Office for National Statistics (ONS) reported in November 2021 that in the UK:

- 1.2 million people have Long COVID symptoms

- 65% say their symptoms impact on their day-to-day activities and almost 20% say their activities have been impacted ‘a lot’
- Over 70% have had ongoing symptoms 12 weeks after their symptoms first began
- 35% have had symptoms for over a year

This data is being continuously updated.

Groups suggested to be disproportionately impacted by Long COVID and/or have increased prevalence of self-reporting are (Sykes et al, 2021; ONS, 2021; Raveendran et al, 2021; Oronsky et al, 2021):

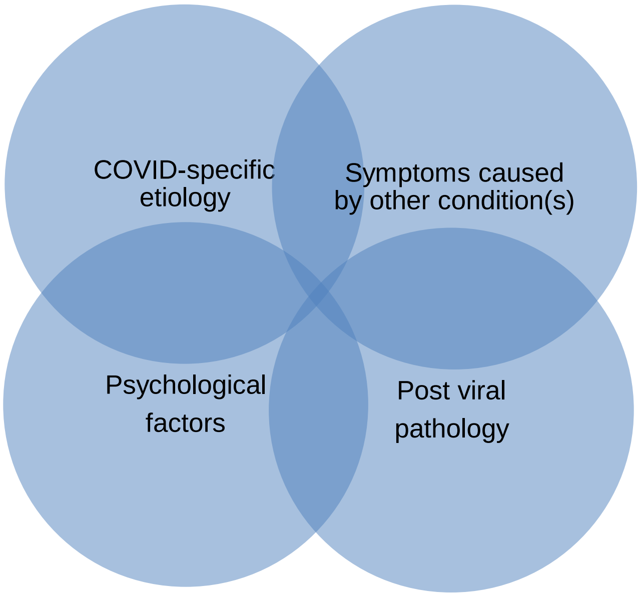
- Women
- People living in more deprived areas
- Key workers, including those working in health and social care
- People with existing co-morbidities (whether these are known or not)
- People living with another activity-limiting health condition or disability
- People of working age and in particular those aged 35 to 69 years

It is possible that other specific groups, such as people with learning disabilities who are disproportionately impacted by COVID in relation to infection, severity and death (Flynn et al, 2021) are also disproportionately impacted by Long COVID but are not picked up in self-reported prevalence data. It is yet to be determined whether those who are disproportionately affected by COVID (e.g., key workers, transport workers, people with learning disabilities and ethnic minorities) are proportionately receiving support in specialist Long COVID services locally. Local services need to collect data on these characteristics to address inequalities and make adjustments.

The desk research identified 4 ‘Schools of Thought’ on the underlying factors connected to experiencing Long COVID, seen in figure 2. These are likely to:

- Overlap
- Change with time (following initial infection)
- Present to a different extent from one person to another
- Require a holistic approach to care

Figure 2 'Schools of thought' on the causes of Long COVID (Sykes et al, 2021; Siso-Almirall et al, 2021; Maxwell and Radford, 2021)



Presentation and consequences

The symptoms of Long COVID include fatigue, dyspnoea, cardiac abnormalities, cognitive impairment, sleep disturbances, symptoms of post-traumatic stress disorder, muscle pain, concentration problems, and headache (Crook et al 2020). The literature proposes mechanisms for some of symptoms experienced in relation to the brain, circulatory, respiratory, gastrointestinal and other systems (Crook et al 2020).

Public Health England (Amin-Chowdhury et al, 2021) has identified three different clusters of symptoms:

- sensory (ageusia, anosmia, loss of appetite and blurred vision)
- neurological (forgetfulness, short-term memory loss and confusion/brain fog)
- cardiorespiratory (chest tightness/pain, unusual fatigue, breathlessness after minimal exertion/at rest, palpitations).

The key themes we came across in relation to the questions ‘What may be missing; what else might help?’ were as follows:

- Being ‘believed’ and that Long COVID is sometimes not recognised as an independent and emerging health problem.
- Barriers to accessing Long COVID services.
- The accessibility and availability of services or support for the physical, mental, financial and social health impact of Long COVID.
- The importance of addressing inequalities, including providing information in a range of languages and formats.
- The importance of coproduction of both Long COVID services and guidelines, with people living with Long COVID.
- Under-reporting of Long COVID in some groups (i.e., the elderly).

This project is a unique opportunity to design an integrated asset-based model of care with local people and communities, to deliver services that support physical, mental, financial, and social health.

4. Useful resources

Resources for people living with Long COVID:

- NHSE (2021) Long COVID | Your COVID Recovery
  And: Your COVID Recovery | Supporting your recovery after COVID-19
- University College London Hospital (2021) Living with Long COVID: University College London Hospitals NHS Foundation Trust (uclh.nhs.uk)
- University College London (2021) Mental health resources for COVID-19: https://www.ucl.ac.uk/psychiatry/COVID-19-mental-health-resources
- NHS Inform (2021) Longer-term effects of COVID-19 (nhsinform.scot)
- COVID-Aid Charity (2021): COVID: aid – The UK's National COVID-19 Charity – CoronavirusSupport| COVID: aid (COVIDaidcharity.org)
- The Health Education England webpage (no date) links to a range of professional organisations with information on treatment options and rehabilitation: Long COVID; Post-COVID syndrome - Knowledge and Library Services
- Patient.info (2021) Self management advice and specialist options: Long COVID: what support is available? | Patient
- The British Lung Foundation and Asthma UK have developed a website with a Long COVID assessment tool (2021) ‘My Long COVID Needs’: https://mylongcovid.org.uk
- NHSE (2021) ‘Your COVID Recovery’ What Next? | Your COVID Recovery. A new digital programme designed to support recovery. This is not yet live but will have an ‘ask the healthcare professional’ facility to allow people direct access to local staff who answer questions related to recovery. NHS organisations can express an interest to sign up to this now.

Professional resources in addition to those referenced in sections 2 and 3:

- RCGP (2021) COVID Resource Hub: Course: COVID-19 Resource Hub (rcgp.org.uk) Post-COVID syndrome Information and resources for GPs supporting patients through recovery from COVID-19.
- NHSE (2021) Initial safety netting for people suffering with first signs of COVID: https://www.england.nhs.uk/coronavirus/publication/suspected-coronavirus-

COVID-19-important-information-to-keep-you-safe-while-isolating-at-home/

- AHSN (2021) COVID oximetry and virtual wards - AHSN Network This is a new programme of work run by the AHSN for managing COVID at home using virtual care.
- Ladds et al (2021) ‘Developing services for Long COVID: Lessons from a study of wounded healers. This study includes a coproduced care model with healthcare workers impacted by Long COVID.
- National Long COVID research centres (GOV UK, 2021): New research into treatment and diagnosis of Long COVID - GOV.UK (www.gov.uk)
- McCorkell et al (2021) ‘Patient-led research collaborative: Embedding patients in the Long COVID narrative’. This paper includes detailed considerations for Long COVID care.

5. References

Amin-Chowdhury, Z., Harris, R. J., Aiano, F., Zavala, M., Bertran, M., Borrow, R., ... & Ladhani, S. N. (2021). Characterising Long COVID more than 6 months after acute infection in adults;prospective longitudinal cohort study, England. medRxiv.

Bridges Self-Management (2021). High time to LISTEN: co-designing and evaluating self-management support with and for people living with long Covid. Available online at: https://www.bridgesselfmanagement.org.uk/high-time-to-listen/ Accessed on 26-01-22.

Crook, H., Raza, S., Nowell, J., Young, M. and Edison, P. (2021) Long COVID—mechanisms,risk factors, and management. Bmj, 374.

Flynn, S., Hayden, N., Clarke, L., Caton, S., Hatton, C., Hastings, R. P., Abbott, D., Beyer, S.,Bradshaw, J., Gillooly, A., Gore, N., Heslop, P., Jahoda, A., Maguire, R., Marriott, A., Oloidi, E., Paris, A., Mulhall, P., Scior, K., Taggart, L., & Todd, S. (2021). Coronavirus and people with learning disabilities study Wave 3 Results: September 2021 (Full Report). Coventry, UK: University of Warwick. ISBN: 978-1- 871501-37-7

Ladds, E., Rushforth, A., Wieringa, S., Taylor, S., Rayner, C., Husain, L. and Greenhalgh, T. (2021) Developing services for Long COVID: Lessons from a study of wounded healers, Clinical Medicine,21(1), pp.59.

Lancet, T. (2021). Understanding long COVID: a modern medical challenge. Lancet (London, England), 398(10302), 725.

Malby, R., Boyle, D., Wildman, J., Omar, B.S. and Smith, S. (2019). The Asset Based HealthInquiry: How best to develop social prescribing. London South Bank University.

Maxwell, E. and Radford, M. (2021) Long COVID and the ghost of nursing theory, Journal of Research in Nursing, 26 (5), pp. 362-366. DOI: 10.1177/17449871211037473.

McCorkell, L., Assaf, G. S., Davis, H. E., Wei, H. and Akrami, A. (2021) Patient-led research collaborative: Embedding patients in the Long COVID narrative, Pain Reports, 6 (1).

National Voices (2021). A multi-agency framework for supporting people with Long Covid. Unpublished manuscript shared by National Voices.

Newman, M. (2021) Chronic fatigue syndrome and Long COVID: Moving beyond the controversy, Bmj, 373

NICE (2020). COVID-19 rapid guideline: managing the long-term effects of COVID-19. Available online at: https://www.nice.org.uk/guidance/ng188

NHSE (2021). Long COVID patients to get help at more than 60 clinics. Available online at:https://www.england.nhs.uk/2020/12/long-COVID-patients-to-get-help-at-more-than-60- clinics/ accessed 24-11-21

Office for National Statistics (2021). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK. Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronavirusCOVID19infectioninthe uk/4november2021 accessed 23-11-21

Oronsky, B., Larson, C., Hammond, T. C., Oronsky, A., Kesari, S., Lybeck, M. and Reid, T. R.(2021) A review of persistent post-COVID syndrome (PPCS), Clinical Reviews in Allergy & Immunology, pp. 1-9.

Raveendran, A. V., Jayadevan, R. and Sashidharan, S. (2021) Long COVID: An overview, Diabetes & Metabolic Syndrome: Clinical Research & Reviews.

Sisó-Almirall, A., Brito-Zerón, P., Conangla Ferrín, L., Kostov, B., Moragas Moreno, A., Mestres, J., Sellarès, J., Galindo, G., Morera, R. and Basora, J. (2021) Long

COVID-19: Proposed primary care clinical guidelines for diagnosis and disease management, International Journal of Environmental Research and Public Health, 18 (8), pp. 4350.

Sivan, M., Rayner, C., & Delaney, B. (2021). Fresh evidence of the scale and scope of long covid. BMJ, 373.

Sykes, D. L., Holdsworth, L., Jawad, N., Gunasekera, P., Morice, A. H. and Crooks, M. G. (2021) Post-COVID-19 symptom burden: What is long-COVID and how should we manage it?Lung, 199 (2), pp.113-119.

World Health Organization (2021) A clinical case definition of post COVID-19 condition by aDelphi consensus, 6 October 2021. Available online at:https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition- Clinical_case_definition-2021.1 Accessed om 23-11-21.