

Guidance for the Initial Assessment of
Patients with Post-infection and Associated
Complex Chronic Syndromes (PACCS), such
as Long COVID,
Myalgic Encephalomyelitis/Chronic Fatigue
Syndrome (ME/CFS)
Postural Tachycardia Syndrome (PoTS),
Post Treatment Lyme Disease (PTLD)
and similar conditions

National Strategic Network for the Long-Term Effects of
COVID 19

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Review: March 2028

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Guidance for Initial Assessment of Patients with Post-infection and Associated Complex Chronic Syndromes (PACCS) such as Long COVID, ME/CFS, PoTS, PTLD and similar conditions

1. Introduction

1.1 Aim of this Guidance

This guidance has been developed to support healthcare professionals across Primary and Secondary Care in Scotland to undertake an initial assessment of patients with Post-infection and Associated Complex Chronic Syndromes (PACCS).

1.2 Role of the Long COVID Network

This guidance has been developed by the National Strategic Network for the Long-Term Effects of COVID 19 (Long COVID Network) within NHS National Services Scotland (NSS). The Long COVID Network is a collaboration of stakeholders involved in care of people with Long COVID. The aim of the Network is to facilitate effective communication and collaboration between relevant stakeholder to improve healthcare services for people with Long COVID.

Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively.

1.3 Status of this Guidance

Guideline for GP Assessment of Adults with Suspected Long Covid (NSS version 4.1) was approved by the Strategic Oversight Board of the Strategic Network for the Long-term effects of COVID 19 on 6th March 2024.

18 months of practical use since March 2024 has identified potential gaps, ambiguities, and practical implementation challenges.

Understanding of Long Covid continues to develop rapidly with new research on pathophysiology, diagnostic criteria, and management approaches that required integration into current clinical guidance. The governance process for evaluation has evolved since this guideline was developed and therefore a review was timely.

This Guidance has therefore been expanded to support an Initial Assessment of Patients with PACCS.

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Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve.

Adherence to this guidance will not ensure a successful outcome in every case, nor should this guidance be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidance derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

1.4 Intended Audience

Primary Audience

- Primary and Secondary care Practitioners across Scotland
- GP registrars and resident doctors
- Nurse practitioners involved in Long Covid assessment
- Allied Health Professionals (AHPs) working in Long COVID services.

Secondary Audience:

- Practice managers and administrative staff
- Pharmacists in primary care settings
- Long Covid service coordinators.

1.5 Methodology

This guidance has been produced using the NHS NSS's guidance development process. It included the establishment of a development/review group of doctors, feedback from the lived experience and wider clinicians mentioned above. The document has been approved by the Network's Steering Group and Oversight Board

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2. Guidance

2.1 Scope

This guidance has been developed to support the assessment of people with PACCS.

Post-infection and Associated Complex Chronic Syndromes(PACCS) is used here as an umbrella term for Long COVID, PoTS, PTLD, ME/CFS and similar conditions such as post treatment Lyme disease, noting that the underlying aetiology of ME/CFS remains unknown. Severity is defined by functional impairment, not test abnormalities. These syndromes have a disproportionate impact on working-age adults, especially women and those with fewer resources to rest or reduce work.

Post-COVID-19 condition (Long COVID) (LC) is the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.

Myalgic encephalitis/Chronic fatigue syndrome (ME/CFS) is an acquired fatigue syndrome characterised by post exertional malaise for the full definition see NICE Guideline 206 [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#) Post treatment.

Lyme disease (PTLD) is a condition characterised by persistent symptoms such as fatigue, joint pain and cognitive difficulties that can occur after completing treatment for Lyme disease. Consider Lyme disease testing in patients with persistent fatigue if there is a risk of tick exposure. Assess risk based on clinical history, recent tick bites, occupational or recreational activities in endemic areas.

If a diagnosis of a PACCS is being considered, it is vital to exclude co-morbidities or other reversible causes. Long-term conditions should be optimised prior to referral, if possible. These conditions present with multi-system symptoms. This guidance is not exhaustive and symptoms should be investigated according to presentation.

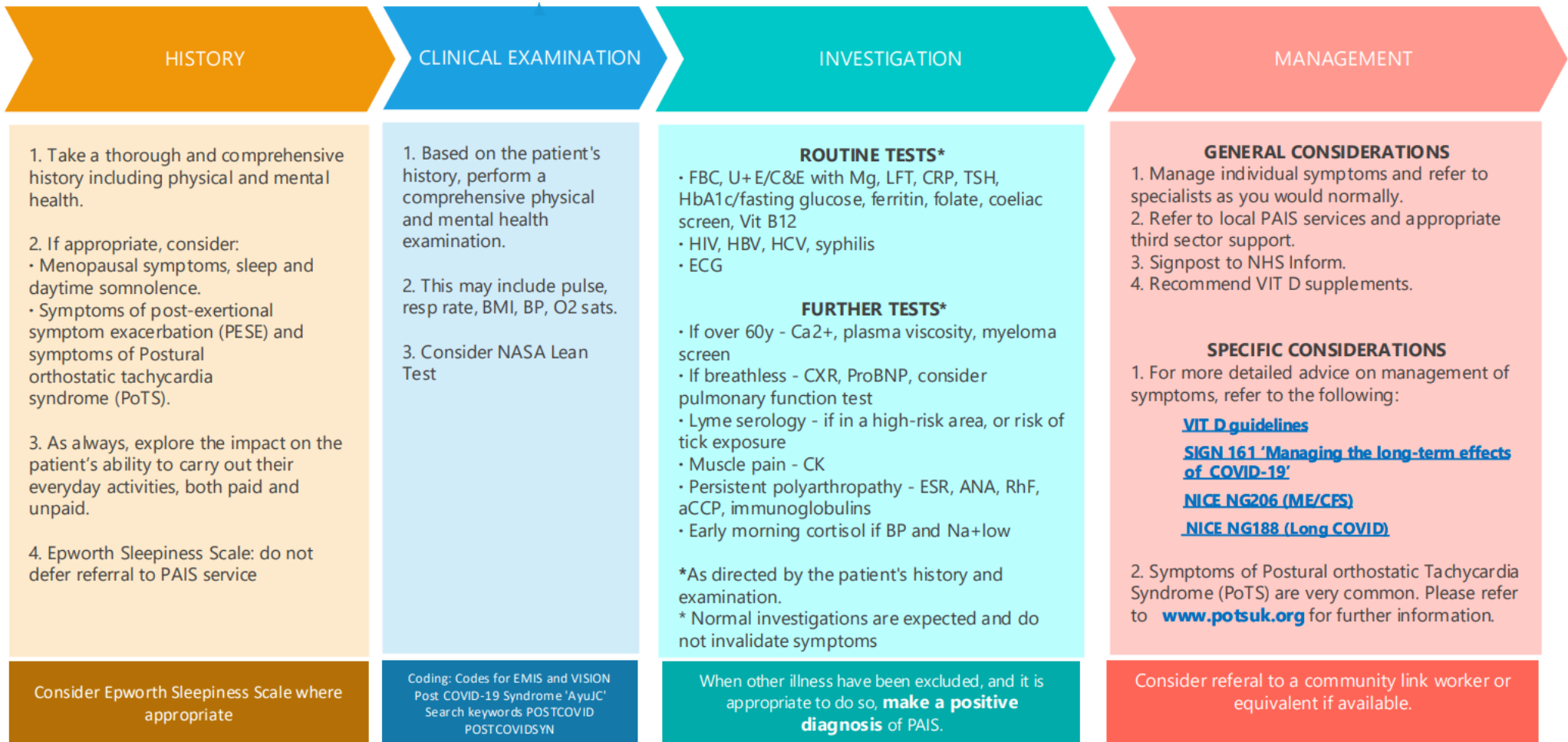
If under 16, consider paediatric input if required.

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2.2 Pathway



For more detailed management, consult:

- Public Health Scotland (2025) [Vitamin D and you](#)
- SIGN 161 (2021) [Managing the long-term effects of COVID-19](#)
- NICE (2021) NG206 [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#)
- NICE (2020) NG188 [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#)

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Initial Assessment

- This guidance builds upon the NICE guideline '*Assessment of Tiredness/Fatigue in Adults*' 2021. Whilst PACCS is an emerging field, assessment and management of symptoms is not new, symptoms may be addressed as normal.
- Although a positive diagnosis of a Long COVID or ME/CFS isn't made until 12 weeks following an infection, this is no reason to delay investigation of symptoms.
- Consider investigating suspected long COVID after 4 weeks.

Making a diagnosis

- If a diagnosis of a PACCS is suspected, it remains vital to exclude other comorbidities and reversible causes. Long-term conditions should be optimised prior to referral where possible.
- A deterioration in a long-term condition should not be attributed to the PACCS without thorough assessment.
- Common alternative or concurrent diagnoses are obstructive sleep apnoea, COPD, deterioration of asthma or diabetes, anaemia, haematological malignancies. More unusual diagnoses include destructive arthropathies, ischaemic heart disease, arrhythmias, Addison's disease and myasthenia gravis.

Consider PACCS in your differential diagnosis of fatigue.

New and Emerging symptoms

These syndromes present with many symptoms, but patients with a PACCS can still develop other conditions.

New and emerging symptoms should therefore be investigated appropriately, independent of the PACCS diagnosis.

Postural Tachycardia Syndrome (PoTS) can be common in PACCS and symptoms may not be typical. Whilst the history remains the most important part of a PoTS assessment, consider a NASA Lean Test. Many symptoms can be alleviated by non-pharmacological measures which can be started in primary care.

Please refer to www.potsuk.org for further information.

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Appendix 1 – Stakeholder Involvement

Document Development

The following stakeholders developed this document:

Name	Designation	Organisation
Dr Janet Scott	Clinical Lead, Long COVID Network Consultant in Infectious Diseases	NHS NSS NHS Highland
Dr Carolyn Forsyth	GP- GPwER Long Covid	NHS Highland
Dr Alison Hunter	Rehabilitation Medicine Consultant	NHS Lothian
Dr Gouri Bhat	GP	Barrhead
Dr Scott Jamieson	GP Clinical Lead	Primary Care NHS Tayside
Dr Stuart Sutton		

Consultation

Individuals and groups consulted – representatives of all stakeholder groups should at least be consulted

Name	Designation	Organisation
Long COVID Steering Group	Steering Group	NHS Scotland long COVID Network
Strategic Oversight Board	Board Members	NHS Scotland long COVID Network

Approval

This Guidance was approved by the long COVID Network Steering Group on 25th February 2026 and the Oversight Board on 3rd March 2026.

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References

NICE (2020) *COVID-19 rapid guideline: managing the long-term effects of COVID-19*

NICE (2021) *Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management* Guideline 206

POTS UK [www.potsuk](http://www.potsuk.com)

Public Health Scotland (2025) *Vitamin D and you*

SIGN (2021) *Managing the long-term effects of COVID-19*

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