

Long term effects of COVID-19 – maintaining a 'living' approach to guidance

5.1.2e

NICE National Institute for
Health and Care Excellence



NICE's role in the system

As set out in the
Regulations

NICE

Our regulatory foundation

Health and Social Care Act 2012 - Established as a non-departmental public body.

Our remit

- Give advice and guidance on matters relating to the provision of NHS services, public health services or social care in England.
- Deliver education & training on therapeutics and medicines management to healthcare professionals.
- Provide advisory services to bodies e.g. devolved administrations & pharmaceutical companies.



NICE guidelines make **evidence-based recommendations** on a wide range of topics, from preventing and managing specific conditions to providing social care and support to adults and children

NICE

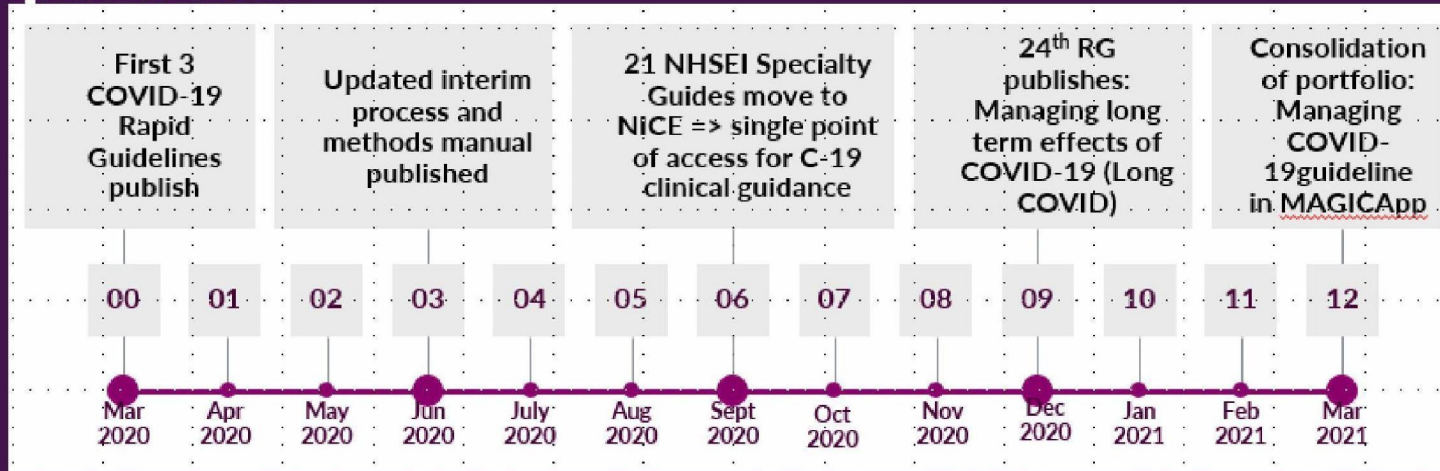
Process stages



Development time

- Old world: 12-24 months
- During height of early pandemic: compressed timescale of 5-10 days
- Future: our new strategy builds on our learnings from COVID-19 with focussed, rapid, living guidelines

Timeline of our growing C-19 guidance portfolio

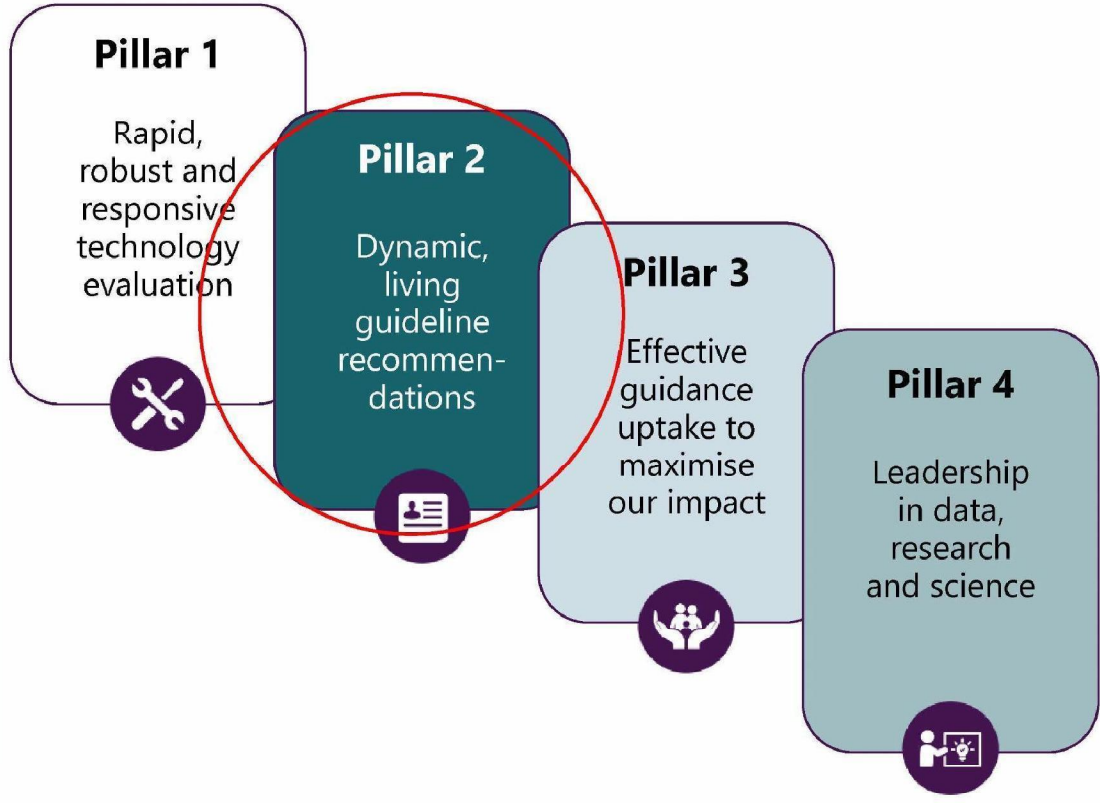


NICE

Four strategic pillars

Underpinned by internal transformation

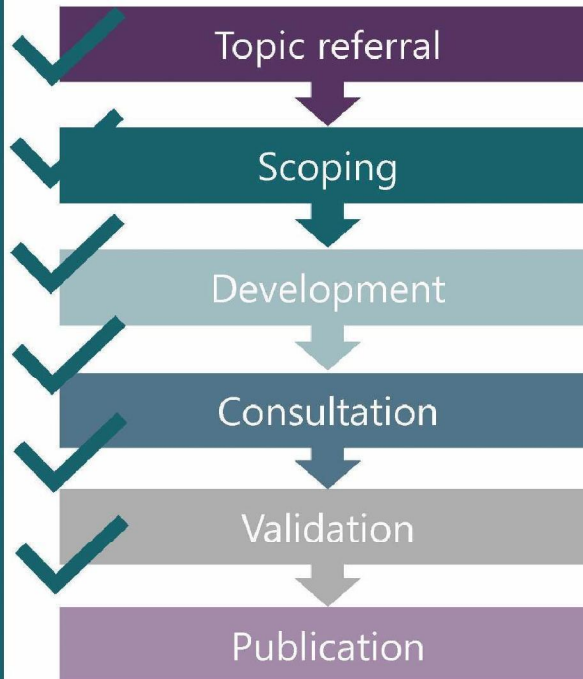
NICE



NICE guidelines make **evidence-based recommendations** on a wide range of topics, from preventing and managing specific conditions to providing social care and support to adults and children

NICE

Standard process



Rapid process for long-term effects

Case definition and coding
 Developing key questions
 Rapid recruitment – including people with lived experience

Reviewing the evidence base/real world evidence/expert consensus

Targeted peer review

Quality assurance

Scope of rapid guideline

Development began

- October 2020
- Collaborative approach – SIGN and RCGP

Inclusion of case definitions

- Acute COVID-19 infection (up to 4 weeks)
- Ongoing symptomatic COVID-19 (from 4 weeks up to 12 weeks)
- Post COVID-19 syndrome (Long COVID) (signs/ symptoms beyond 12 weeks)

Population

- Adults, young people and children diagnosed with COVID-19, based on signs and symptoms, with or without a positive SARS-CoV-2 test whose symptoms continue for more than 4 weeks from start of infection



NICE National Institute for
Health and Care Excellence



Key areas of the guideline: Recommendations

- Identification
- Assessment
- Investigations and referral
- Planning care
- Management
- Follow-up and monitoring
- Sharing information and continuity of care
- Service organisation

NICE



Area of guidance		Evidence
Identification	• Initial presentation and consultation	Patient experience evidence
	• Understanding symptomatology	Under representation in data
Investigations and referral	• Testing	Limited evidence, use of consensus
Assessment	• Presentation and likelihood	Limited and uncertain evidence
Planning and Management	• Self-management	Patient experience evidence and consensus
	• Therapeutics	Gap in evidence
	• Rehabilitation	Limited evidence, consensus and expert testimony
Follow-up and monitoring	• Follow-up	Limited evidence – largely in hospitalised settings
	• Continuity of care	Patient experience evidence
Service organisation		Limited evidence, use of consensus and expert testimony

Research recommendation 5

NICE

Risk factors

What factors influence the risk of developing post-COVID-19 syndrome
What factors influence the trajectory of post-COVID-19 syndrome?

Interventions

What are the most clinically effective interventions?
How do these vary across different population groups
Do any symptoms of post-COVID-19 syndrome predict the need for specialist intervention?

Prevalence

What is the prevalence and incidence of post-COVID-19 syndrome?
Does it differ from the prevalence and incidence across different population groups

Impact

- NHSE commissioning guidance
- 500,000 views, 23,000 website downloads
- >20,000 use of SNOMED codes in primary care systems
- Evidence sharing with other guideline producers e.g. WHO, Australia
- Extensive media coverage and debate

NHS warns against Gwyneth Paltrow's 'kombucha and kimchi' Covid advice

Hollywood actor urged to stop spreading misinformation after promoting 'intuitive fasting'

- Coronavirus - latest updates

See all our coronavirus coverage

5.1.2e

A Gwyneth Paltrow ad on the blog that long Covid could be treated with an 'infused seaweed' among other things. Photograph: Enea Montini/Getty Images

NICE

Three tips for how to deal with long Covid

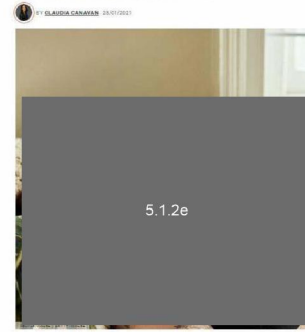


Three tips for how to deal with long Covid

Getting Covid is bad enough, but dealing with long Covid can be a physical and psychological nightmare. GQ's Life Coach has some advice...

Long Covid: What Are the Symptoms, Who Is Most at Risk and What Does It Feel Like?

Sufferers report radical, life-changing health issues



5.1.2e

When news of a virus, one which affected your lungs and travelled via particles of saliva passed on by those infected, began to percolate this January, the consensus

NICE defines 'long Covid' as symptoms lasting more than 12 weeks



enormous commonly known as long Covid has been it of the development of the first UK guideline for managing the newly emerging condition.

COVID
to fill the many gaps in this new "living advice"

...it is defined as a collection of symptoms that last for more than 12 weeks after the acute phase of the infection has resolved. The symptoms can be physical, mental, or both, and can significantly impact a person's quality of life. The guideline covers a range of symptoms, including fatigue, breathlessness, and brain fog. It also provides advice on how to manage these symptoms and when to seek help.



'Living' recommendations

- ✓ Active surveillance
- ✓ Identification of 'hot topics'/noise
- ✓ Weekly evidence sift
- ✓ Codesets of interest
- ✓ Expert panel
- ✓ Rapid updating

Research to access pathway for investigational drugs for COVID-19 (RAPID-C19)

A multi-agency initiative to enable safe and timely patient access to medicines showing evidence of benefit in treating symptomatic COVID-19 patients in current and any future waves

Interim 'group' approach, significantly streamlining and accelerating the standard patient access pathway

Identifies and prioritises technologies currently in research with most promising signals for rapid regulatory consideration and interim clinical policy development. Technologies continue to collect data to support licensing and HTA approval whilst in use



NICE

NICE, working with NIHR, coordinate horizon scanning activities and the process for identifying the most promising candidate medicines

Next steps



- Continuing surveillance of new evidence
- Threshold for updating – challenging/changing recommendations and strengthening evidence
- Addressing gaps – e.g. young people and PIMS/ Therapeutics/ Rehabilitation
- NIHR funded work into long term effects of COVID-19 in non-hospitalised patients
 - case definition
 - translation of guideline into practice
- National & international collaboration

NICE

NICE National Institute for
Health and Care Excellence

Any questions?

© NICE [2021]. All rights reserved. Subject to [Notice of rights](#).