

Management of long COVID

- This webinar will start at 8.30pm IST / 4pm UK.
- You can watch the recording on the [AHSN Network](#) and SAHF YouTube channels afterwards.
- Please use the chat to submit your questions.

Panellists



- **Dr Sarah Ali**, Consultant in Endocrinology, Royal Free London NHS Foundation Trust



- **Dr Amitava Banerjee**, Associate Professor in Clinical Data Science and Honorary Consultant Cardiologist, University College London



- **Dr Nisreen Alwan**, Associate Professor in Public Health for Medicine at the University of Southampton



- **Dr Shashank Joshi**, Dean Indian College of Physicians ICP (Academic wing of the API) Covid task force key member for the Maharashtra State, Consultant Endocrinologist, Lilavati Hospital Mumbai



- **Professor Dhruva Chaudhry**, Professor of Respiratory Medicine & Critical Care at PGIMS, Rohtak, India



- **Professor Mahesh Kappanayil**, Professor of Paediatric Cardiology, Amrita Institute of Medical Sciences, India



- **Dr Manoj Sivan**, Associate Clinical Professor and Honorary Consultant in Rehabilitation Medicine, University of Leeds, WHO Consultant in Covid Rehabilitation for Europe



- **Dr Amit A Saraf**, Head Quality Control & Patient Safety. Director Department of Internal Medicine, Jupiter Hospital, Mumbai



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Welcome

The webinar is about to begin.

Dr Sarah Ali

Consultant in Endocrinology, Royal Free London

NHS Foundation Trust

Overview of webinar

- What is long COVID?
- Setting up a long COVID clinic in India
- Implications and barriers for long COVID
- Reducing risk of impact of long COVID
- Managing long COVID
- Question and answer session

Long COVID: the pandemic after the pandemic

Dr Nisreen Alwan

Associate Professor in Public Health for Medicine at the
University of Southampton

Long Covid: the pandemic after the pandemic

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20 May 2021

Healthy

ill

dead

Survival \neq Recovery

World view



By Nisreen A. Alwan

A negative COVID-19 test does not mean recovery

Pandemic policy must include defining and measuring what we mean by mild infection.

Eight months into the global pandemic, we're still measuring its effects only in deaths. Non-hospitalized cases are loosely termed 'mild' and are not followed up. Recovery is implied by discharge from hospital or testing negative for the virus. Ill health in those classed as 'recovered' is going largely unmeasured. And, worldwide, millions of those still alive who got ill without being tested or hospitalized are simply not being counted.

Previously healthy people with persistent symptoms such as chest heaviness, breathlessness, muscle pains, palpitations and fatigue, which prevent them from resuming work or physical or caring activities, are still classed under the umbrella of 'mild COVID'. Data from a UK smart-phone app for tracking symptoms suggests that at least one in ten of those reporting are ill for more than three weeks.

“Once recovery is defined, we can differentiate COVID that quickly goes away from the prolonged form.”

quantifying and characterizing COVID-related illness in those not hospitalized. The consequences of failing to do so are significant. Some people, especially the young and healthy, might not see a need to follow preventive measures, because they expect only a few days of flu-like symptoms at the worst. Sick people might not get the support they need, and the true human and economic costs of the pandemic will not be correctly estimated.

As long as 'long COVID' is labelled as anecdotal, it will not be taken seriously, and public communication will neglect it. We need to quantify it properly and accurately. We must measure recovery in those not presenting with severe disease at the outset.

Let us start simple. With other common viral illnesses, such as flu, we would expect recovery to mean going back to pre-infection levels of functionality and quality of life. This means we must follow up all patients with confirmed (by test) or highly probable (by symptoms) COVID and find out whether they have returned to their previous normal within a specified time from the onset of their symptoms.

<https://www.nature.com/articles/d41586-020-02335-z>

What is Long Covid?

- Patient-made umbrella term
- Not fully recovering from covid-19 (not going back to baseline health) for several weeks and months (different time cut-offs)
- Even in so-called mild covid-19 cases
- Can be very debilitating
- Very wide range of symptoms

How common is Long Covid?

- Very common in those initially hospitalised
- 1 in 8 deaths and 1 in 3 re-admitted within 20 weeks of discharge (Ayoubkhani et al)
- Mild/moderate initial disease:
 - Around 1 in 3 after 2-6 weeks
 - 1 in 10 to 1 in 4 after 3 months
- Varying degrees of severity and disability
- Difficult to accurately measure:
 - relapsing nature
 - lack of lab confirmation
 - representative follow-up

Table 2: Percentage of study participants reporting any symptom at 12 weeks by sex and age group

UK, 26 April 2020 to 6 March 2021

Group	Estimate	Lower 95% confidence limit	Upper 95% confidence limit
Males	12.7	9.8	16.4
Females	14.7	10.7	20.3
Age 2 to 11 years	7.4	5.3	10.5
Age 12 to 16 years	8.2	5.7	11.8
Age 17 to 24 years	11.5	7.8	16.8
Age 25 to 34 years	18.2	14.1	23.4
Age 35 to 49 years	16.1	11.8	22.0
Age 50 to 69 years	16.4	12.0	22.4
Age 70 years and over	11.2	8.4	14.8

Source: Office for National Statistics

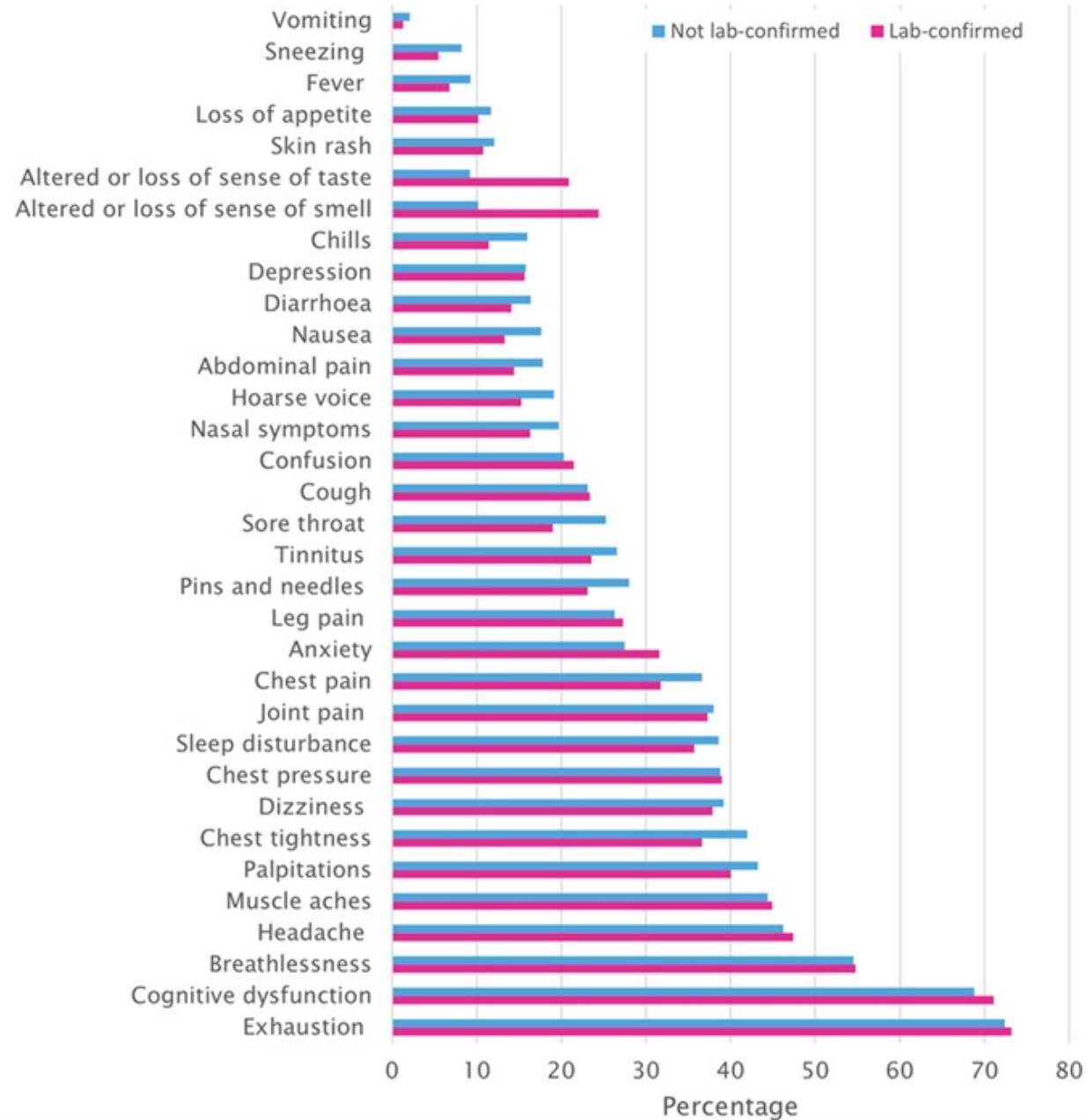
Potential mechanisms/causes

- Fibrosis/scarring
- Inflammatory response
- Immune reaction (autoimmune)
- Persistent virus (GI biopsies)
- Endothelial damage
- Role of genetics?

Long Covid survey (non-hospitalised in first 2 weeks)

- Co-produced with people living with Long Covid
- 2550 participants, support groups & general social media, 80% UK
- 27% lab-confirmed (PCR or antibody), mean age 47 (45) years
- 83% (85%) women, 77% (78%) university degree, 93% (90%) White
- Duration 7.2 (6.2) months
- 90% (91%) with good, very good or excellent health before infection
- 47% (50%) pre-existing conditions
- 84% symptoms affecting at least 3 organ systems
- Pattern: 75% (74%) fluctuating/relapsing/ 'comes and goes'

Ziauddeen N, Gurdasani D, O'hara M, Hastie C, Roderick R, Yao G & N A Alwan. Characteristics of Long Covid: findings from a social media survey



Common triggers:

- Physical activity
- Stress
- Sleep disturbance
- Cognitive activity

What effect does Long Covid have on daily life?

- 32% (28%) unable to live alone without assistance at 6 weeks
- 66% (72%) taken time off sick (median 60 days)
- 37% (33%) loss of income due to illness
- Being ill affected respondents' ability:
 - self-care 50% (42%)
 - domestic chores 84% (80%)
 - work 75% (78%)
 - childcare 36% (33%), caring for other adults 26% (25%)
 - mental health 64% (65%)

What effect does Long Covid have on daily life?

- Fatigue Severity Scale mean 5.5 (SD 1.4)
- Score ≥ 4 86% (84%)
- Post Covid-19 Functional Status Scale:
 - No functional limitations 0.7% (0.7%)
 - Negligible 10% (12%)
 - Slight 23% (26%)
 - Moderate 35% (34%)
 - Severe 32% (28%)

What can research tell us?

- Who's more at risk
- Who's more likely to recover from LC
- What are the pathophysiological mechanisms
- What are the clinical patterns
- Do they predict progression and recovery
- What is the treatment(s)
- What can stop acute covid from progressing into LC
- Role of vaccine
- Likelihood of re-infection
- Inequalities and stigma
- Economic and health service burden
- Long Covid in children

Reporting

Recognition

Research

Case definitions

Prevention of Long Covid

Primary

Prevent acute infection

Secondary

Prevent progression from acute to LC

Tertiary

Prevent complications and disability, Improve quality of life



Marija Pantelic and Nisreen Alwan: The stigma is real for people living with long covid

Long covid stigma will have long lasting detrimental outcomes for patients, services, and society as a whole

- Testimonial injustice: concerns & symptoms dismissed by service providers
- Exacerbated by pre-existing structural inequities
- Internalised stigma: ‘ashamed of own illness’

What is needed from healthcare

- Listening
- Recognition (even if no immediate fix)
- Proper clinical assessment and investigations
- A solid diagnosis (employment rights)
- Treatment of treatable pathology
- Rehabilitation

Dr Shashank Joshi

Dean Indian College of Physicians ICP (Academic wing of the API) Covid task force key member for the Maharashtra State, Consultant Endocrinologist, Lilavati Hospital Mumbai



Long COVID-19

Mumbai / Maharashtra

20nd May 2021

Dr Shashank R Joshi MD,DM,FRCP,FACP,FICP
Member ,Maharashtra COVID Task force
Shashank.sr@gmail.com

Nomenclature: Long Covid

- Post COVID Viral syndrome,
- “Long Haulers”,
- Persistent COVID symptoms
- Ambiguity in the definition.
 - Any patient in whom symptoms persist for more than 2 to 3 weeks and even beyond 60 days
 - Symptoms recur after recovery

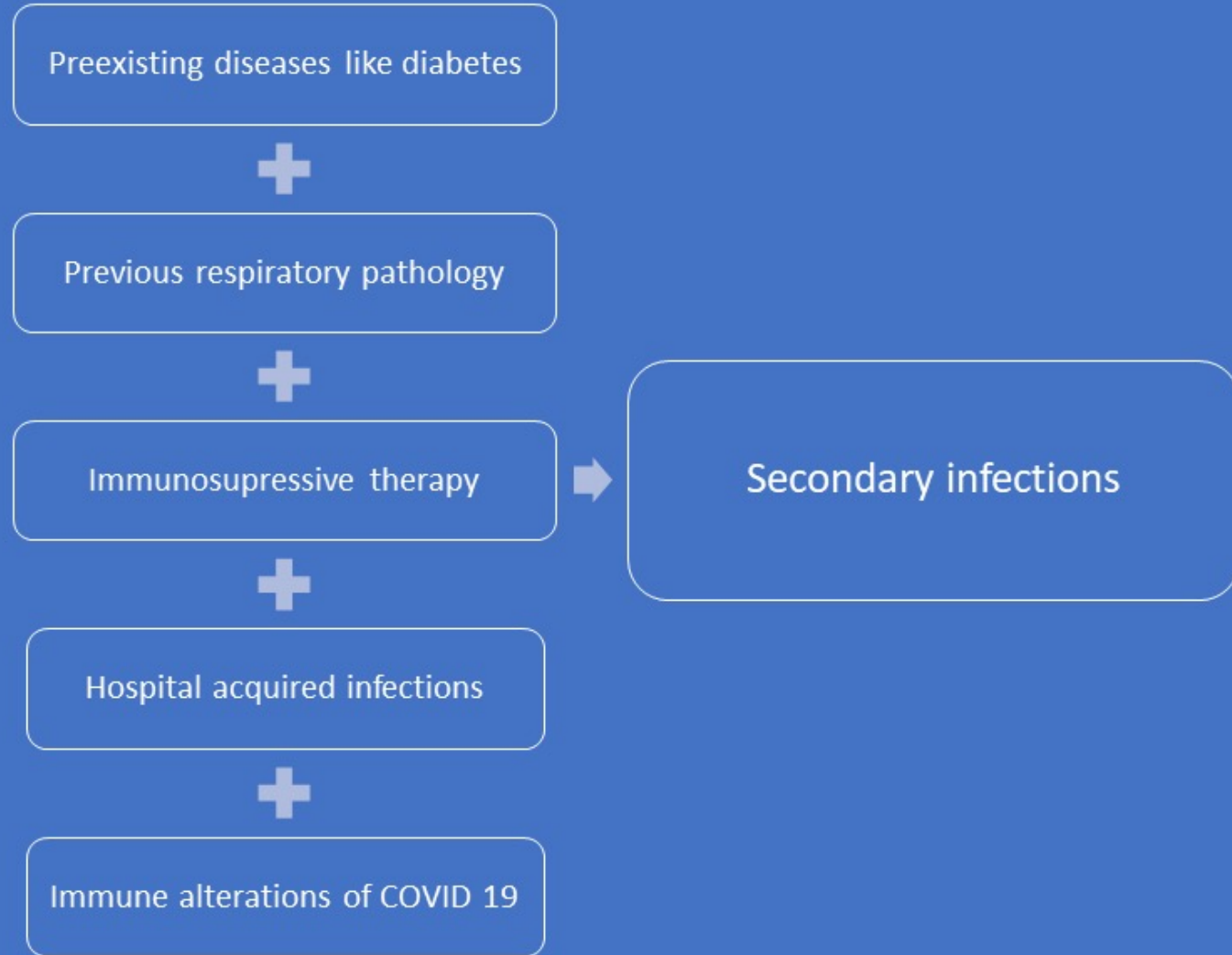


Long Covid 19



- **Vulnerable population – Characteristics**
- **How Big is the problem ?**
 - Cardiac
 - Tachycardia, arrhythmias, CHF, myocarditis etc. warranting the need to do regular cardiac enzymes and 2 D echo. A few patients had normal echos but had myocardial injury picked up on Cardiac MRI
 - Seen in even those patients who had no cardiac conditions prior
 - Neurological and Musculoskeletal
 - Fatigue similar to the Chronic Fatigue Syndrome
 - Exhaustion
 - Neuropathy (Tingling Numbness)
 - Poor Hand brain coordination leading to being clumsy and even falls
 - GBS
 - BRAIN FOG leading to lack of enthusiasm, concentration and poor memory
 - Psychiatric Disturbances
 - Fear of Death
 - PTSD
 - Pulmonary
 - Due to lung fibrosis especially in those with initial pulmonary affection and or need for MV
 - SOB
 - Impaired Quality of Life -
 - Worsened QOL by more than 10 points from baseline using the EUROCOL scale (0– 100 points)
 - Metabolic and Endocrine
 - Diabetes ,Steroids
 - Thyroiditis,Hypocortisolism

Steroids, Diabetes and Mucor Mycosis: unholy trinity !



Steroids, Diabetes and Mucor Mycosis: unholy trinity !



- Widespread use of steroids against COVID-19 may lead to the development / exacerbation of preexisting fungal diseases
- Physicians should be aware of the possibility of invasive secondary fungal infections in patients with COVID-19 infections
- Use of therapeutic agents should be monitored to achieve a therapeutic effect at the lowest dose and shortest durations
- Use of broad-spectrum antibiotics, especially in the absence of infection, should be re-evaluated.

Long Covid 19



- Post COVID syndrome (PCS) is common and affects nearly 80% of the COVID affected patients
- Its understanding may be similar to the diverse pathophysiology of Chronic Fatigue Syndrome
- PCS affects men and women equally and also affects all age groups making it an ailment to watch out for.
- Symptoms vary from mild ones to debilitating ones and leads to poor Quality of life in nearly half the patients.
- A multi-pronged approach is important to treat this group of patients
- Recognizing the entity of Post COVID syndrome, is the first step to its containment



COVID-19 Long Covid

BE RESPONSIBLE

20 May 2021

PREDICTABLY UNPREDICTABLE
SAVE LIVES

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Professor Dhruva Chaudhry

Professor of Respiratory Medicine & Critical Care at PGIMS,
Rohtak, India

The emerging global healthcare crisis of long Covid

Dr Manoj Sivan

WHO Consultant Covid Rehabilitation Europe

Associate Professor, Rehabilitation Medicine, University of Leeds

Consultant Rehabilitation Medicine, Leeds Teaching Hospitals NHS trust and Leeds Community Hospitals NHS Trust

President-Elect British Society of Rehabilitation Medicine (BSRM)



British Society of
Rehabilitation Medicine
Promoting quality through
education and standards



Leeds Long Covid (LC) service

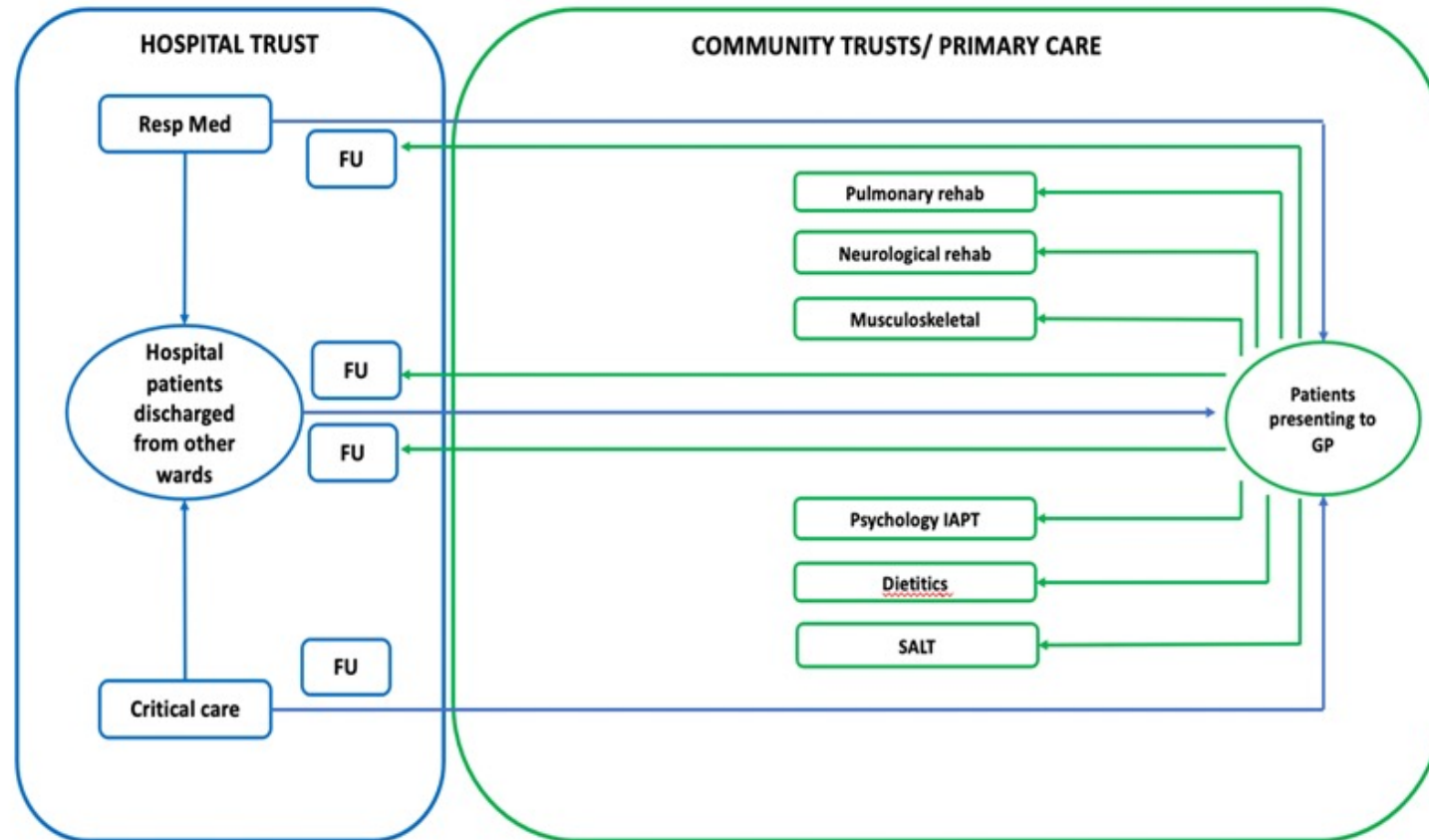
- UK's first COVID-19 follow-up study (Halpin et al JMV 2020)
- One of the first LC services to be set up (Sivan et al JRM 2020)
- World's first LC PROM (C19-YRS) (Sivan et al ACNR 2020)



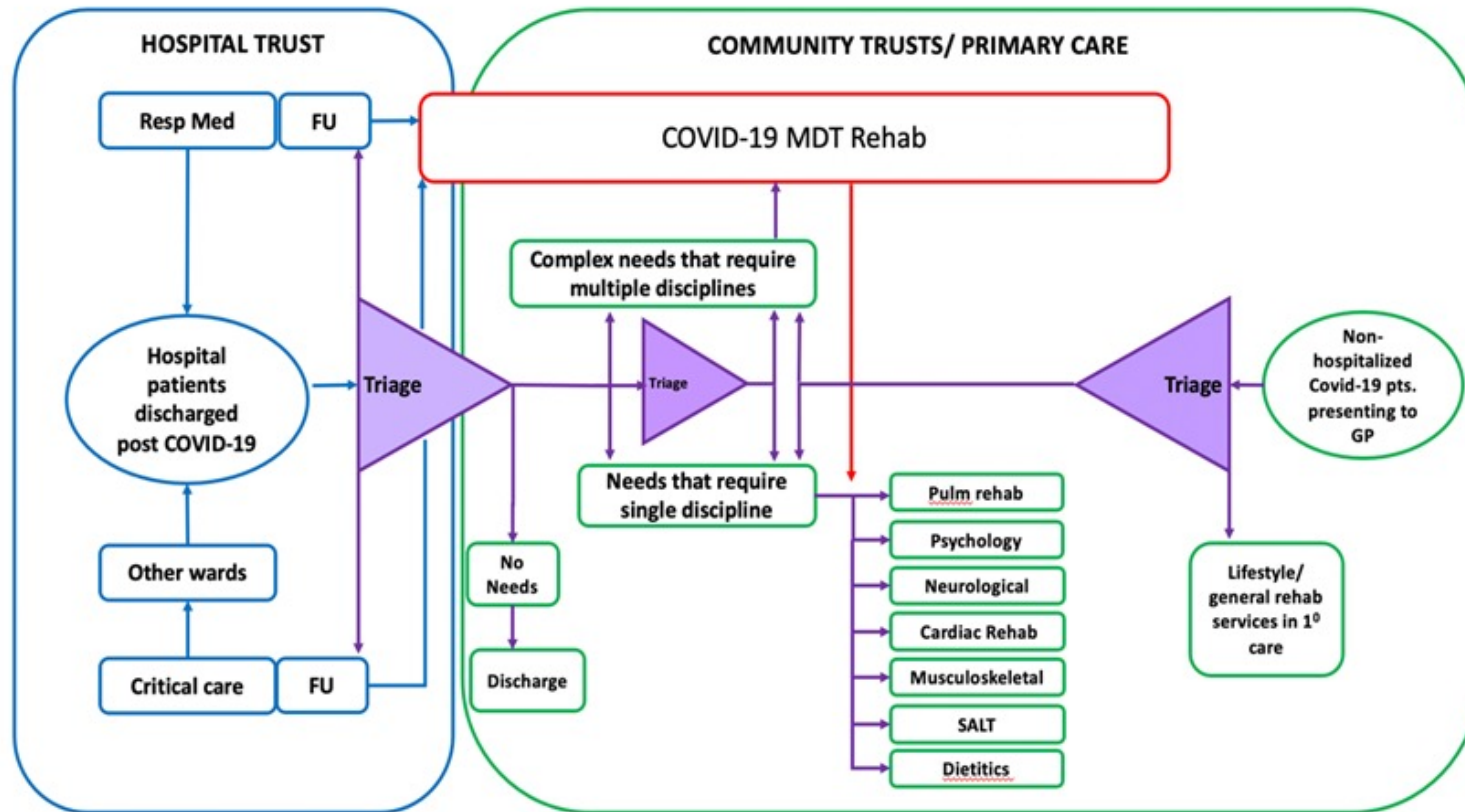
The screenshot shows the top navigation bar of The Guardian website. It includes the 'Support the Guardian' logo, navigation links for 'News', 'Opinion', 'Sport', 'Culture', 'Lifestyle', and 'More', and a search bar. Below the navigation bar, there is a featured article in the 'Opinion' section titled 'People with long Covid urgently need help. Why can't we access it?' by Joanna Herman. The article is categorized as 'Long Covid' and includes a small image of the author, Joanna Herman, in a laboratory setting.

This isn't a representative survey - and I know that some long Covid clinics are offering excellent care to patients like me. The Leeds clinic, led by a rehabilitation consultant, seems to have the right approach: its multidisciplinary team provides guidance and support to those with long Covid, helping them manage their everyday lives with the symptoms they have. For a disease that has no specific treatment, and whose underlying processes are not yet known, such practical help is essential.

NHS conventional pathways



Novel Leeds Covid Rehabilitation Pathway



Need for Integrated care pathways



EDITORIALS

Fresh evidence of the scale and scope of long covid

The NHS must reconfigure services to manage enduring multimorbidity following covid-19

Manoj Sivan,¹ Clare Rayner,² Brendan Delaney³

The SARS-CoV-2 pandemic in the UK has so far affected more than four million people, with more than 450 000 admitted to hospital and 30% in-hospital mortality.¹ The UK's health service has risen to the twin challenges of managing waves of acute covid-19 and the vaccination effort, with rapid reconfiguration of both services and physical space. Beneath the daily headlines of admissions, deaths, and vaccinations is, however, hidden an iceberg of long term illness—known as long covid, post-covid syndrome, or post-covid sequelae.

dysautonomia, mast cell dysfunction, and neurological diagnoses.³ This is a problem for management, as common long covid symptoms (fatigue, cognitive dysfunction, wheeze, inappropriate tachycardia, gastrointestinal disturbance, for example) have multiple differential diagnoses spread across multiple specialties.

The NHS has always operated on a single specialty referral model, with general practice as the gatekeeper. With notable exceptions in elderly care, pain, and cancer services, hospital services are

LC ideal management approach

- Comprehensive medical assessment
- Red flags
- Individualised management plan
- MDT approach
- Rehabilitation interventions
 - 1:1 treatments
 - Group therapy programmes

MDT approach

Parkin et al

3

Table 1. Composition of Level I COVID-19 MDT (Banding Levels as per NHS Agenda for Change).

Rehabilitation therapists

- Band 8a pathway co-ordinator (1.0 whole time equivalent, WTE)
- Band 7 physiotherapist (2.0 WTE)
- Band 7 occupational therapist (2.0 WTE)

Specialist Allied Health Professionals

- Band 6 respiratory nurse (1.0 WTE)
- Band 6 respiratory physiotherapist (1.0 WTE)
- Band 7 dietitian (0.2 WTE)
- Band 6 dietitian (0.5 WTE)
- Band 7 neuro occupational therapist (0.5 WTE)
- Band 6 neuro occupational therapist (0.2WTE)

Medical

- Consultant in rehabilitation medicine (0.1 WTE)
- Consultant in respiratory medicine (0.1 WTE)
- Consultant cardiologist (0.1 WTE)

Research

- Consultant in rehabilitation medicine (research) (0.1 WTE)
- Band 6 AHP researcher (1.0 WTE)

Others

- Project manager (0.1 WTE)
- Admin support (0.1 WTE)
- Post doctoral clinical psychologist trainee (0.5WTE)

Digital outcome measures

C19-YRS

COVID-19 Yorkshire Rehabilitation Scale

A digital assessment and monitoring tool to help manage individuals with Long COVID





Continue assessment >

Assessments completed: 1

More
Assessments

Symptoms severity score



Functional disability score

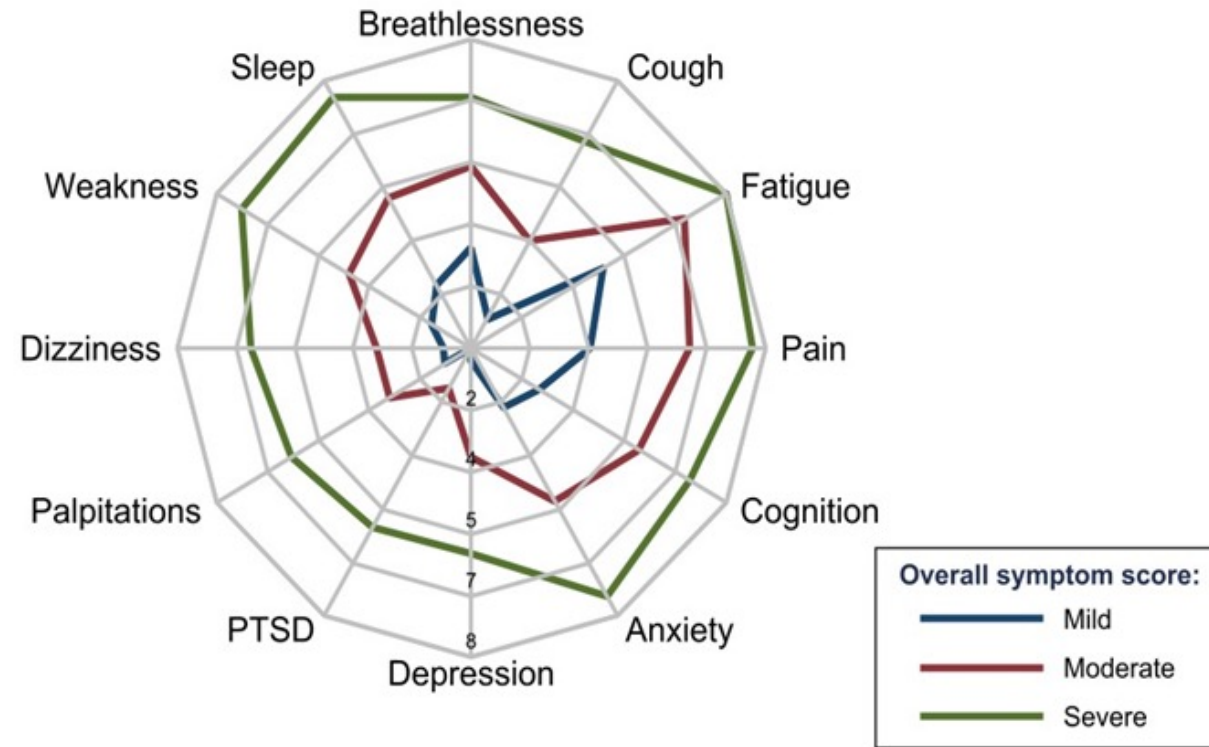


Overall health score

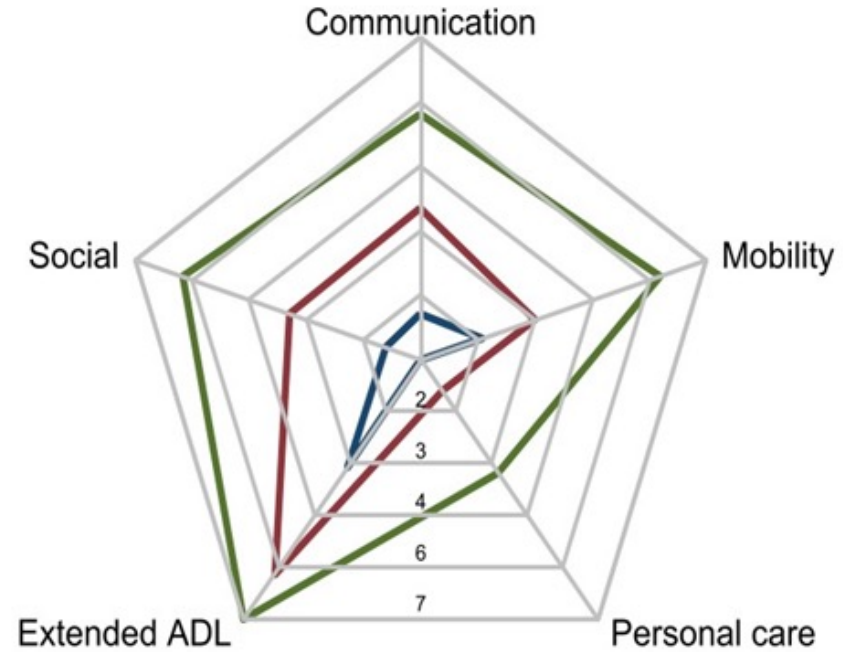


	Before COVID	Now	Total Score
Symptom severity			
1. Breathlessness	0	6	39/100
2. Cough / Voice Change / Noisy Breathing	0	0	
3. Swallowing / Nutrition	0	0	
4. Fatigue	0	9	
5. Continence	0	0	
6. Pain / Discomfort	2	5	
7. Cognition	0	6	
8. Anxiety	2	4	
9. Depression	1	7	
10. PTSD Screen	0	2	
Functional disability			
11. Communication	0	4	25/50
12. Mobility	0	3	
13. Personal-Care	0	4	
14. Other activities of daily living	0	6	
15. Social Role	0	8	
Overall health			
16. Overall Health	8	3	3/10
Other Symptoms			
Rate the severity of any Dizziness you've encountered	-	6	
Rate the severity of any Palpitations you've encountered	-	7	
Rate the severity of any Weakness you've encountered	-	2	
Rate the severity of any Sleep Problems you've encountered	-	7	
Rate the severity of any Fevers you've encountered	-	0	
Rate the severity of any Skin Rash you've encountered	-	0	
Overview			
	Before COVID	Now	
Symptom severity (out of 100)	5	39	
Functional disability (out of 50)	0	25	
Overall health (out of 10)	8	3	

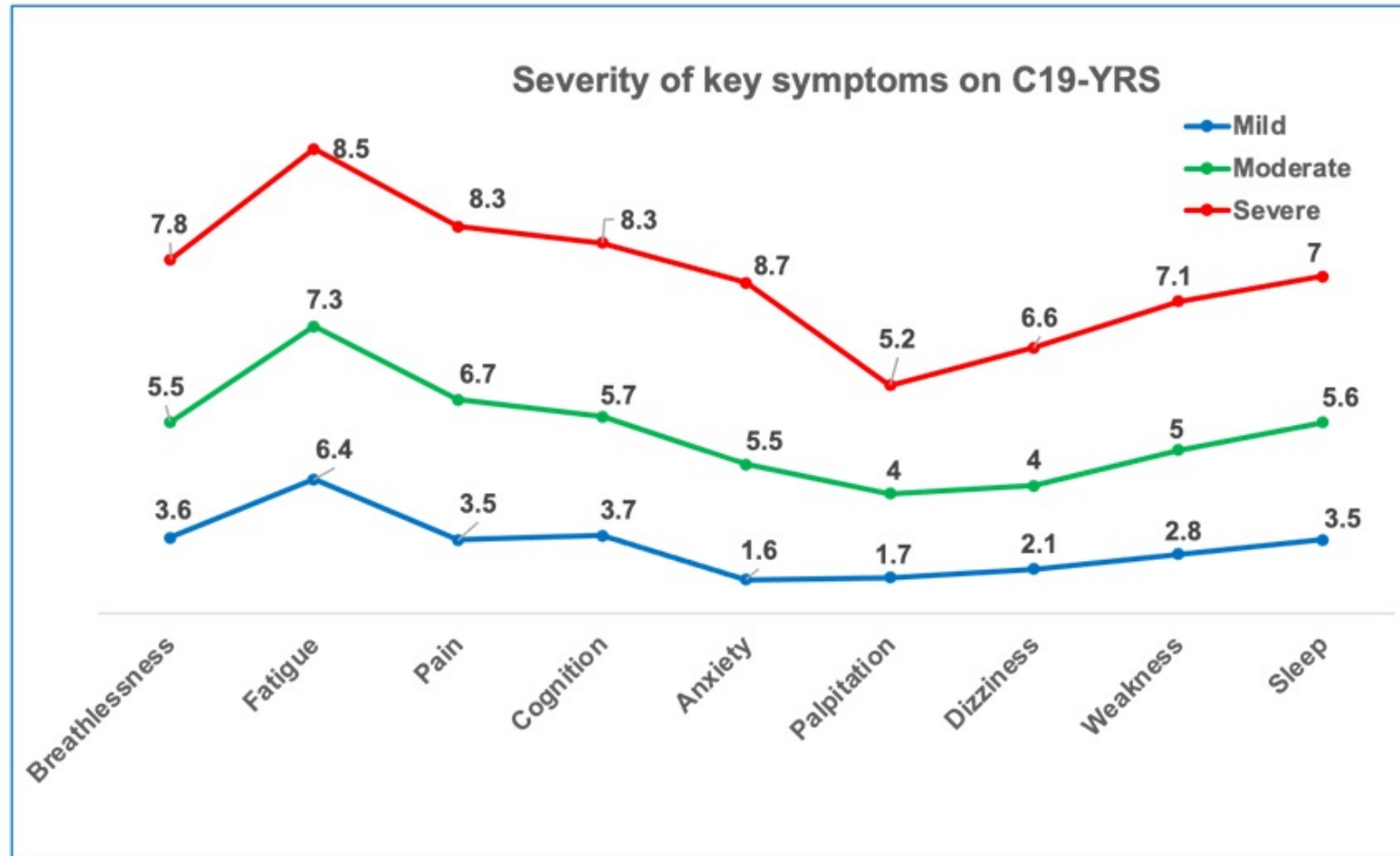
Phenotypes



Phenotypes



Phenotypes



Rehabilitation interventions

Parkin et al

5

Table 4. Symptom and Interventions.

Symptom	Example interventions considered:
Chest and pleuritic pain	<ul style="list-style-type: none"> • Education of self-management strategies (avoiding over exertion) • Medical management occasionally required such as electrocardiogram (ECG) screening to rule out potentially life threatening diagnoses
Repeated chest infections	<ul style="list-style-type: none"> • Secretion clearance strategies • Swallowing screen for aspiration then medical management if required • Medical management to optimize underlying respiratory conditions may be required
Muscular and joint pain	<ul style="list-style-type: none"> • Hot/cold therapy • Exercise prescription for pain related deconditioning • Multi-disciplinary team discussion if potentially neuropathic pain
Shortness of breath at rest	<ul style="list-style-type: none"> • Assessment of breathing pattern to rule out Breathing Pattern Disorder • Use of Borg Rating of Perceived Exertion Scale (RPE) and oximetry • Breathing retraining (Diaphragmatic and nasal) • Assessment of N-terminal pro-brain natriuretic peptide (NT-proBNP) if indicated • Diffusing capacity for carbon monoxide (DLCO) and overnight pulse oximetry warranted in a minority of complicated cases
Shortness of breath on exertion	<ul style="list-style-type: none"> • Breathing techniques whilst moving • Purse lip breathing strategies if nasal breathing effortful • Positioning • Use of fan • Using Borg-RPE scale and oximetry with activity to guide and educate patient to safe level exercise
Desaturation on exertion	<ul style="list-style-type: none"> • Assessment of NT-proBNP if indicated • Use of pulse oximetry to relate to breathlessness score on Borg-RPE scale, and recovery time • Review how patient manages desaturation • Grade up activity gradually starting with non-de-saturation tasks • Education of self-management and breathing control for recovery/managing desaturation • Positioning • Assessment of NT-proBNP if indicated • Assessment of need for further respiratory investigation

MDT rehabilitation programmes

Table 5. Virtual Fatigue Management Course Modules.

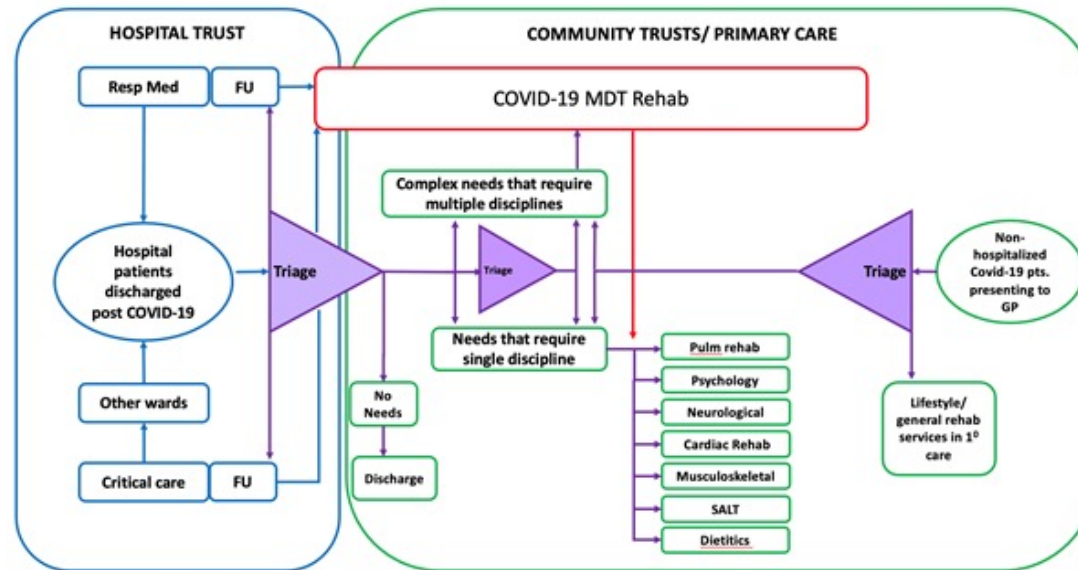
Week	Module	Facilitator	Facilitated discussion questions
1	Overview and understanding fatigue	Occupational therapist and other MDT members	<p><i>Are you able to recognize when you are becoming fatigued, and how?</i></p> <p><i>Can you identify what may trigger your fatigue?</i></p> <p><i>What would you like to get out of the programme in order to improve your quality of life and best manage your levels of fatigue?</i></p>
2	Thinking about activity	Occupational therapist	<p><i>What activities have people found manageable or more challenging?</i></p> <p><i>Have people had experience of using an activity diary? How has this been incorporated into daily routines? How useful have these been?</i></p>
3	Activity grading	Occupational therapist	<p><i>How do you ensure you have a combination of activities?</i></p> <p><i>Do you know when your stopping point is, or do you tend to only stop when your body tells you to do so?</i></p>
4	Fatigue and exercise	Physiotherapist	<p><i>What daily exercise are people managing now?</i></p> <p><i>Has anyone tried to return to higher level exercise? How did this affect your fatigue levels and ability to do other activities?</i></p>
5	Diet and nutrition	Dietician	<p><i>Have you noticed a pattern between your fatigue and what you eat?</i></p> <p><i>Have you altered your diet to try and improve your fatigue? What did you try and did it help?</i></p>
6	Sleep hygiene	Neuro occupational therapist	<p><i>What do you find works well to improve your sleep to recover for the next day?</i></p>
7	Cognition and communication	Neuro occupational therapist	<p><i>What difficulties are you having with your memory, attention or communication?</i></p> <p><i>Can you see any strategies that would be beneficial within your daily routines?</i></p>
8	Mindfulness	Neuro occupational therapist	<p><i>Can you see any strategies that would be beneficial within your daily routines?</i></p>


Summary

- Next biggest healthcare crisis for all of us
- Needs urgent joined up integrated care pathways
- Primary/ community care needs upskilling
- Better understanding of clinical phenotypes
- Personalised rehabilitation interventions
- Global strategy

References

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Long COVID.

What we know and what we don't know

Dr Amitava Banerjee

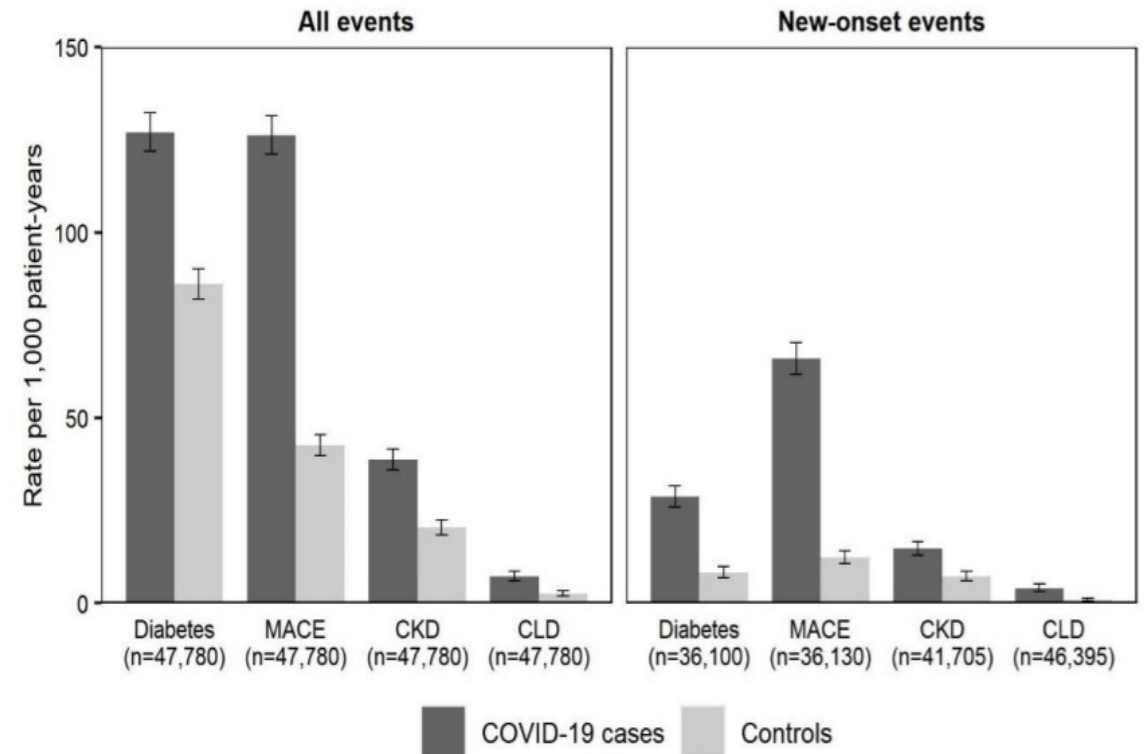
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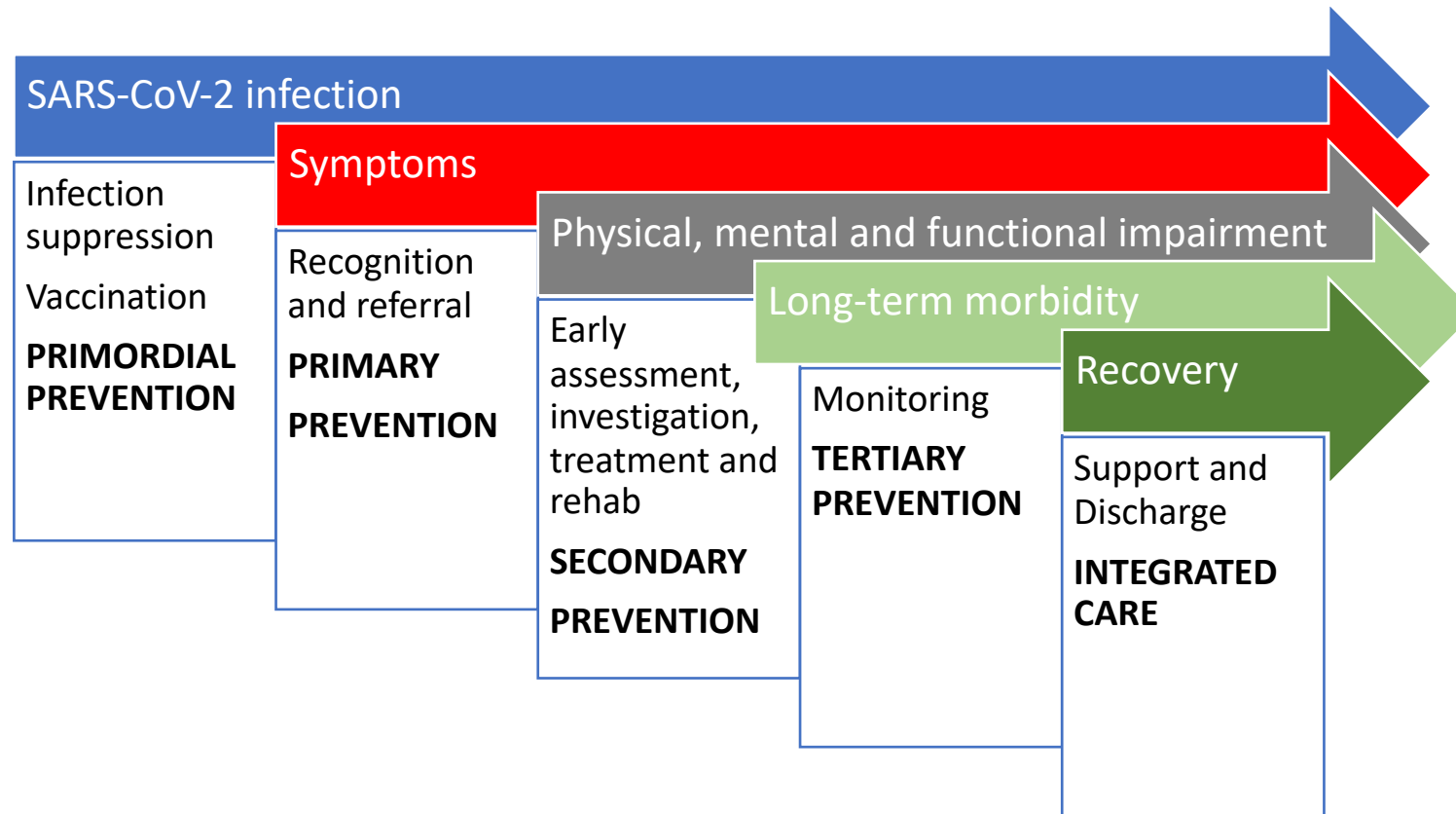
Long COVID

- Pandemic context
- Long-term impact on organ function
- Long-term impact in different cohorts
- Long-term impact on overall function
- Predictors are not known
- No proven treatments

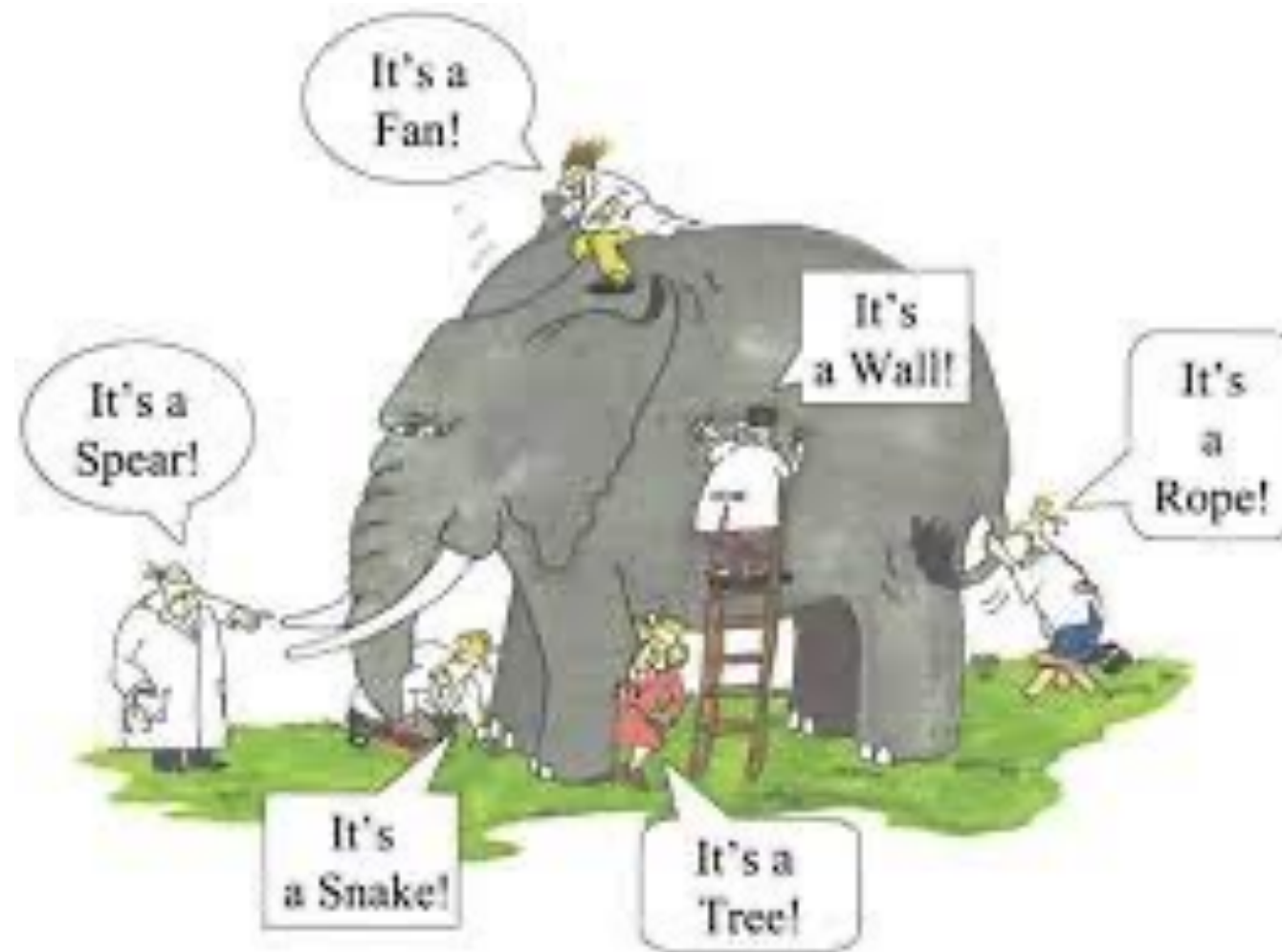


Ayoubkhani et al. BMJ. 2021.

Management spectrum: Long COVID

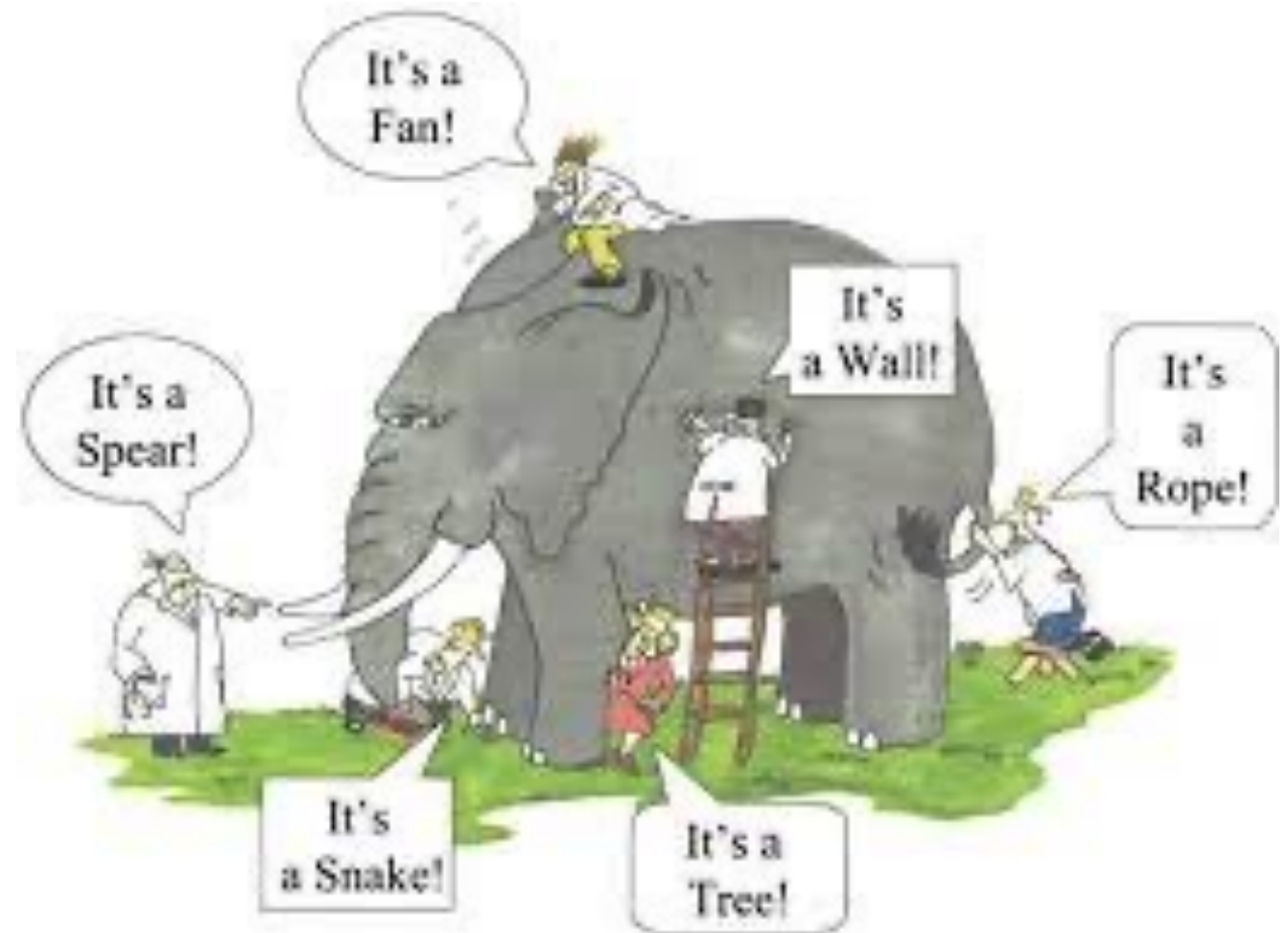


Need for Integrated Care Pathways



Conclusions

- Prevention is best
- Wide-angle lens
- Joined up approaches
- Global thinking
- Parity for funding
- Patient-driven is the only way



Q&A session

Led by Dr Alison Tavaré, West of England Regional Clinical Lead for COVID Oximetry @home

Please ask any questions using the chat function.



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SAHF/AHSN UK-India COVID-19 webinar series TO UPDATE



MANAGEMENT OF LONG COVID

Thursday 20 May 8.30-9.30pm (India Standard Time) / 4-5pm (UK BST)

This is the sixth in a series of UK-India COVID-19 webinars from the South Asian Health Foundation, Academic Health Science Network (AHSN Network) and Learn with Nurses, sharing NHS experiences of COVID-19 specifically regarding the identification, implications and management of long COVID, with health and care professionals in other countries.

- What is long COVID
- Setting up a long COVID clinic in India
- Implications and barriers for long COVID
- Reducing risk of impact of long COVID
- Managing long COVID



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Further information:

Panellists will include:



- **Dr Sarah Ali**, Consultant in Endocrinology, Royal Free London NHS Foundation Trust



- **Dr Amitava Banerjee**, Associate Professor in Clinical Data Science and Honorary Consultant Cardiologist, University College London



- **Dr Nishreen Alwan**, Associate Professor in Public Health for Medicine at the University of Southampton



- **Dr Shashank Joshi**, Dean Indian College of Physicians ICP (Academic wing of the API) Covid task force key member for the Maharashtra State, Consultant Endocrinologist, Lilavati Hospital Mumbai

Register:

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Thank you