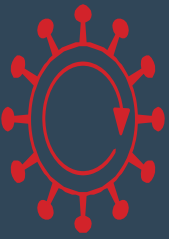


Summary of the Long COVID Forum

Long COVID forum update
9 - 10 December 2020
Dr Gail Carson, GloPID-R &
ISARIC

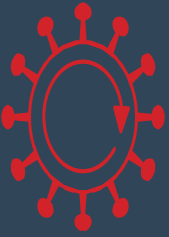


Nothing about us without us

Fantastic to hear from people living with Long COVID, clinicians and researchers from around the world (16 countries, agenda). Co chairs included research funders and the WHO. Joined by almost 900 people (1,400 registered) over the 2 days and over 7,400 views on YouTube so far.

Dr Tedros opened the meeting and used the three R's in relation to Long COVID:

- **Recognition**
- **Research**
- **Rehabilitation**



‘Nothing about us without us’

1) What is causing my illness?

Why me? Why did I get it? Why do others recover quickly?

Is the virus still there? Autoimmunity? What investigations do I need?

2) How do I recover?

Can somebody help me? How do I get my life back? Medications? Rehab? What? Where? How to get? Some people have to pay for their health care or medication. What should I do NOW? Can we be re-infected? What about Vaccination? Shielding?

3) Concern for others

How many others are affected? How to prevent others from getting this? Can early treatment lessen the severity of Long COVID?

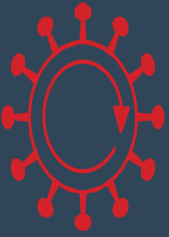
4) How to define Long COVID (case definition and clinical features) count it?

Need a systematic way to define cases - Does the case definition for COVID testing need to be broader?

One/many conditions?

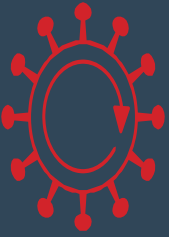
Patterns to predict progression?

Long-term disability and mortality?



‘Nothing about us without us’

- 5) Children and Long COVID does occur but less well recognised
- 6) Long COVID and people living with other conditions, e.g. HIV, TB.
 - Lessons learnt from following up other illnesses such as Ebola, HIV, chikungunya
- 7) Mental health impact possibly direct effect of virus, and consequence of effect on quality of life, loss of earnings, relationship breakdown etc.
- 8) The need for early interventions studies – (e.g. ANTICOV, Principle study)



Whilst so much good work is being done, it is **striking how much we do not know**:

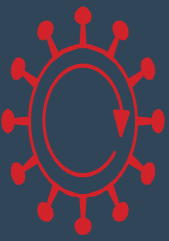
Only **45/5000+** COVID-19 research projects are looking at Long COVID

How many of these are focused only on post-hospitalised patients?

Not a single study into the long-term effects in children!

Results from living systematic review:

- *Need clear **case definition***
- *High quality **case-controlled studies** to establish causal links*
- *Need to **include younger patients and children, data from LMICs and those managed in the community***



Long COVID forum 9 - 10 December 2020

Lancet ID Feb 4th 2021

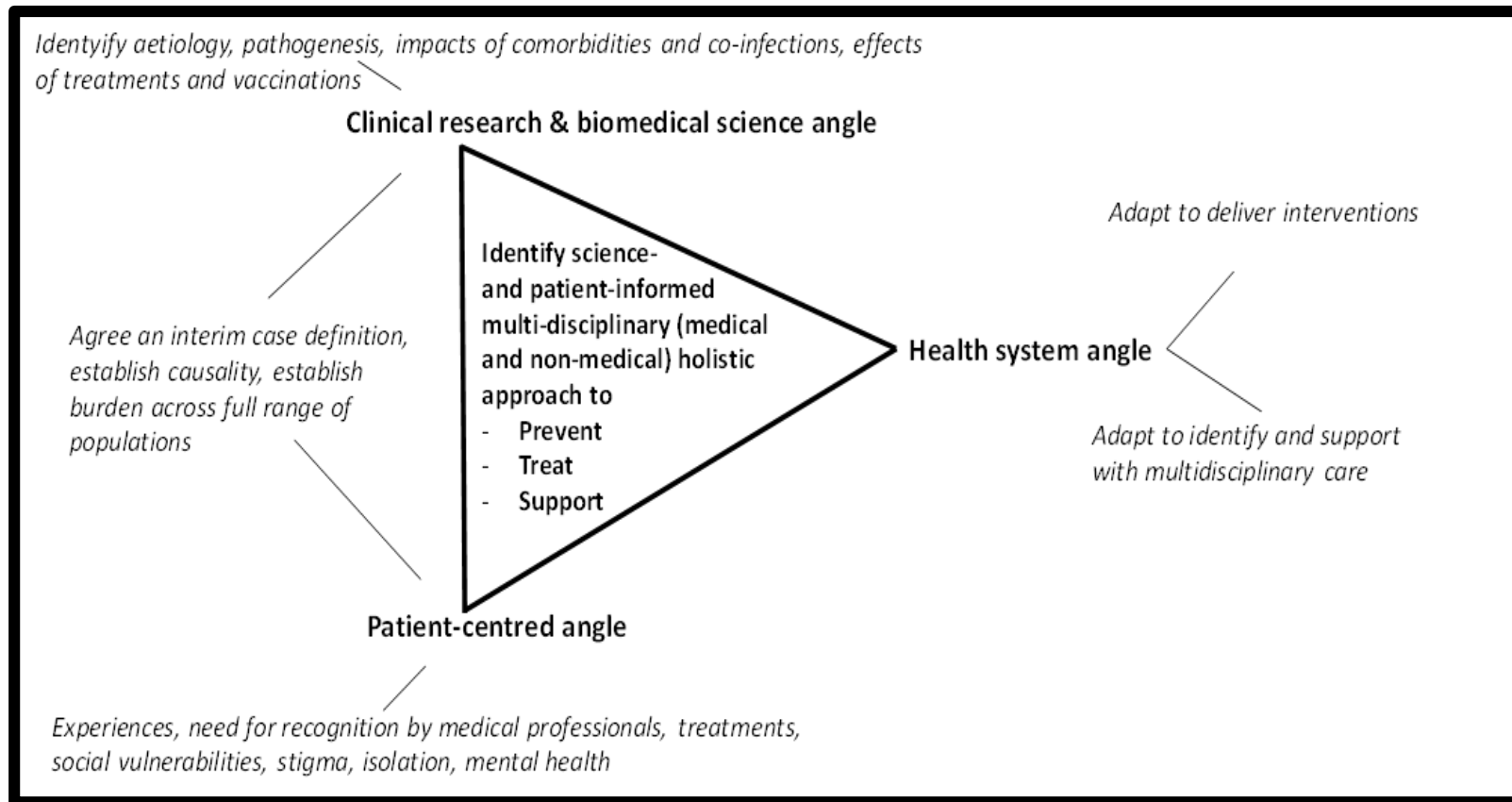


Figure 1: Research priorities identified at the Long Covid Forum

Framework for identifying research needs from the Long COVID Forum

Research priorities (aligned to the WHO mid-term & long-term Research Priorities: 2019 Novel Coronavirus (4))	Identified sub- priority for Long Covid	Populations (multi-country studies needed)
Virus: natural history, transmission and diagnosis	<ul style="list-style-type: none"> - Identify pathogenesis - Investigate impact of co-infections 	Hospitalised patients; non-hospitalised patients; clinical diagnosis only, individuals; children; vulnerable communities; resource constrained populations
Epidemiological Studies	<ul style="list-style-type: none"> - Define the clinical presentations of Long Covid and Characterise the burden and spectrum of Long Covid across populations according to clear case definition - Determine any associations between host genetic factors and Long Covid 	
Clinical characterization and management	<ul style="list-style-type: none"> - Agree case definition and diagnosis - Establish causality - Relationship between acute disease and Long Covid development - Identify aetiology - Investigate pathogenesis to explain e.g. thrombotic tendencies, organ impairment - Investigate impact of co-infections & co-morbidities - Characterise mental health and neurological impacts 	
Candidate therapeutics R&D	<ul style="list-style-type: none"> - Investigate antiviral and anti-inflammatory therapeutics and therapeutic timings to prevent Long Covid - Investigate therapeutics to treat Long Covid symptoms and non-pharmaceutical interventions 	
Candidate vaccines R&D	<ul style="list-style-type: none"> - Investigate the impact of vaccination on people with Long Covid - Investigate whether vaccination prevents Long Covid - Investigate re-infection in people with Long Covid and impact on vaccine priority list 	
Social sciences in the outbreak response	<ul style="list-style-type: none"> - Health systems research on identifying & supporting Long Covid cases (through holistic care) 	



Thank you

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