7 March 2023

Dr Mike Freelander MP
Chair of Standing Committee on Health, Aged Care and Sport
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Via email: health.reps@aph.gov.au

Dear Dr Freelander

RE: Academies expert roundtable on long COVID – additional information

As you are aware, on Friday 17 February, the Australian Academy of Science and the Australian Academy of Health and Medical Sciences convened a roundtable of experts on long COVID to provide evidence to the Committee's *Inquiry into Long COVID and repeated COVID infections*.

The Academies were pleased to use our convening power to provide independent and authoritative scientific and health advice, which we hope was helpful to you and the Committee members. Thank you again for the opportunity to host this meeting for the Committee.

We enclose additional information, including:
- a summary of the roundtable discussion;
- a copy of the slides used in the roundtable discussion.

These documents are provided to the Committee as supplementary information to inform the Committee's report. They outline the views expressed by the participants and should not be considered an official position of the Academies.

Please contact Chris Anderson, Director Science Policy, Australian Academy of Science   or Lanika Mylvaganam, Policy Manager, Australian Academy of Health and Medical Sciences   if you require further information. We also welcome any feedback on the process of working with the Committee and Committee secretariat for this roundtable.

Yours sincerely

Professor Chennupati Jagadish AC PresAA FREng FTSE   Professor Steven Wesselingh PresAHMS
President   **President**
Australian Academy of Science   Australian Academy of Health and Medical Sciences

National long COVID roundtable summary

Background

A national roundtable to discuss long COVID in Australia was held on Friday, 17 February 2023. It was jointly convened by the Australian Academy of Science and the Australian Academy of Health and Medical Sciences. The purpose of the roundtable was to bring leading experts in Australia together to provide evidence for the House Standing Committee on Health, Aged Care and Sport Inquiry into *Long COVID and repeated infections*.

The COVID-19 pandemic has had dramatic impacts globally. While much attention and action have focused on the acute phase of COVID, less is known about ongoing impacts, including the effects of long COVID and repeated infections.

Roundtable discussion summary

The roundtable group was comprised of experts from the research and health sectors, including individuals with lived experience. They discussed considerations for a definition of long COVID, key knowledge gaps and actions to address the impacts of long COVID in Australia.

This summary provides an overview of key discussion points and suggested actions that emerged from the discussion, captured by the Academies.

Definition

A suitable definition of long COVID is important for diagnosis, patient access to care and support, data collection, health system planning and consistency across research studies. The World Health Organization definition needs updating to incorporate new knowledge about the condition and to address ambiguities, for instance, the need for evidence of a confirmed SARS-CoV2 infection, the timeframe from acute COVID infection, quantifying impacts (e.g. functional impairment and quality of life) and measuring recovery.

A specific definition for children should be considered, particularly for those under 10 years of age, in whom there may be a potential interaction between long COVID and developmental milestones.

Australia should engage in current international efforts to establish and operationalise a definition of long COVID tailored to both the needs of patients and clinicians, and to the conduct of valid and meaningful research.

For research, a more stringent definition may be required, for example, a diagnosis of COVID proven by laboratory testing. However, an interim definition is critical for Australia's health system and researchers to respond to long COVID now.

The definition should evolve with new evidence, consider patients and consumers, and serve the needs of clinical care, research, access to social or disability support, public health, policy, and other areas.

Knowledge and implementation gaps

The group discussed critical knowledge and implementation gaps that need to be addressed to reduce or respond to the impacts of long COVID. Identified areas included:

Knowledge gaps

- Impacts of past infections, vaccination and treatments during the acute COVID phase on the development of long COVID.
- Most effective models of care, treatments and interventions (including vaccinations, antivirals and medications to alleviate specific expressions of long COVID, for example Postural Orthostatic Tachycardia Syndrome (POTS) when patients become dizzy on standing up), noting that current models of care are facing serious health system pressures.
- The most effective management approaches, including rehabilitation, mental health care and social support pathways.
- Identifying biomarkers for long COVID. Biomarker research contributes to understanding the underlying mechanisms of the disease, which could identify an increased risk of developing long COVID, offer insights into its trajectory, or corroborate the diagnosis of a particular subtype of long COVID based on clinical and/or functional criteria.

Implementation gaps

- Lack of long-term, ongoing monitoring of prevalence, severity, recovery and other aspects of long COVID in national statistics (the UK Office of National Statistics (ONS) survey is an exemplar that Australia could emulate). This kind of population survey can provide insight into the scale and distribution of affected people.
- Consistent and effective data collection, in particular, the Indigenous status of patients.
- Understanding who accesses support and how, and the barriers that exist to accessing support (e.g. disability support, rehabilitation, people unable to work), including cultural barriers to accessing care or recruitment to clinical trials.
- The support needed to assist GPs in providing continuity of care, including ready access to information and referral for specialist care and post-recovery support.
- Existing gaps in Medicare, Pharmaceutical Benefits Scheme (PBS) and National Disability Insurance Scheme (NDIS) for support for people experiencing long COVID.

Potential actions to address long COVID in Australia

The group discussed a range of actions that the Committee could consider, though time did not allow for the formulation of a consensus position. Some suggestions include:

National coordination and strategy

- A clinical definition of long COVID is required in the short to medium term to enable people to access the services they need. This definition must be communicated to all clinicians, especially in primary care and those located in regional, remote and Indigenous communities.
- Australia should engage with international collaborations to develop a consistent long COVID definition. The government can support relevant Australian experts to participate in global efforts. Equity and access are key considerations for the definition.
- Improve the strategic coordination of relevant research projects, for instance through a national strategy or knowledge mission (guided by a national advisory group of experts). This should

encompass fundamental research, through to translation, implementation and policy. A key component of this approach would be to coordinate strategic funding for research on long COVID, for instance through targeted calls to develop diagnostics, treatments and management strategies. Development of this research agenda needs to include engagement with individuals with lived experience and under-represented groups such as First Nations and Culturally and Linguistically Diverse communities. Research should be co-designed with individuals with lived experience and any programs in place must be evaluated for effectiveness.

- A national clinical trials network is needed to coordinate clinical research, together with a mechanism to support patients to access clinical trials. The National One Stop Shop may be relevant to achieving this. Special efforts should be made to improve equitable access and recruitment of under-represented groups into research and clinical trials to address long COVID knowledge gaps and ensure trials are reflective of our diverse population.

- Embed research in the health system so that research and its implementation can be progressed more efficiently.

- Provide clear public messaging that long COVID is real and burdensome and affects people of any age. This communication must be carefully nuanced with the message that most people who experience acute COVID have made a full recovery.

Infrastructure and data collection

- Establish a population survey of the prevalence of long COVID in the community, modelled on the methods used by the UK ONS. The Australian Bureau of Statistics would be a natural home for this.

- Support new or extend existing infrastructure (e.g. national networks of biobanks), platforms and research networks to enhance national coordination.

- Ongoing surveillance based on sustainable systems for relevant clinical, epidemiological and laboratory data collection, analysis and action. This system would be coordinated at a jurisdictional level with real-time information transfer to a national lead agency that informs government and connects internationally, a role which could be fulfilled by a future national Australian Centre for Disease Control.

Care, support and education on long COVID

- Consider options for how long COVID patients might access care and support, for instance, under Medicare, the NDIS and PBS.

- Explore existing models of care for implementation in the Australian context.

- Leverage existing mechanisms (e.g. medical colleges, National Clinical Evidence Taskforce) to develop and disseminate 'living' clinical care guidelines and evidence-based, integrated models of care and social support that are needed for people experiencing long COVID.

- Develop resources for self-care that may support patients who are in a position to make use of such resources (e.g. Your COVID Recovery in the UK is an exemplar).

- Address the urgent need for education and engagement across the general public and health professionals (GPs, allied health and others) to communicate what is known about long COVID. State-level public health units, primary public health networks and accredited training colleges (e.g. Royal Australian College of General Practitioners) can be utilised to educate the health workforce.

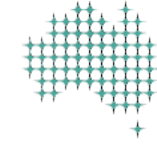# National roundtable: long COVID

Friday 17 February 2023

Australian Academy of Science and
Australian Academy of Health and Medical Sciences

Session 1

Principles for an updated definition of long COVID

Professor Tania Sorrell AM FAHMS

Professor Andrew Lloyd FAHMS

Session goals
- Determine key principles from which to develop a definition of long COVID post-roundtable
- Suggest actions that the Parliamentary committee can take towards establishing this definition

Out of scope
- Consideration of early post-acute COVID syndromes

Adopt the WHO definition?

- Primary purpose of case definition(s)
    - Research, surveillance, clinical care, access to social or disability support options, public health, policy development, health system planning (for impacted workforce and future needs)

- WHO definition has drawbacks
    - Developed as a clinical definition, has ambiguities, no operationalisation, no validation;
    - Has been adapted for many research studies but with different criteria – compromises comparisons

- Ambiguities
    - "probable or confirmed SARS CoV-2"
    - "usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months
    - "new onset following recovery from acute COVID 19 or ongoing from initial diagnosis"
    - "cannot be explained by an alternative diagnosis"
    - "overall having an impact on everyday functioning"

- Needs updating to account for new knowledge and pandemic stage
    - Comorbidities, Post acute COVID conditions eg cardiovascular, new diagnostics, quantify functional impairment, QoL

Adapting/updating WHO definition - key considerations

Experts' feedback

Account for variations in definition for clinical vs research purposes, including:

- What constitutes "proof" of acute COVID infection PCR/RAT/clinical syndrome
- Continuity of symptoms from acute illness (c.f. existing definition of "post-infective syndromes")

Consider incorporation of

- Pre-existing co-morbidities (eg obesity, diabetes)
- New onset post-COVID conditions (e.g cardiovascular disease)

Include new, validated biomarkers that improve clarity and specificity (likelihood/ certainty) of diagnosis

For Long-COVID phenotypes without diagnostic markers/abnormal test results:

- Operationalise with standardised, measurable assessments of functional impairment and quality of life

Children and young people

- Are current "phenotypes" truly different or influenced by developmental, family, social and other contexts?
- Impact of COVID/long COVID on developmental milestones?

Principles for a workable, standard definition that serves different end-users

*Long COVID is heterogeneous, with different underlying causes
- different phenotypes/subsets require different investigation, management, support*

Principles

- Workable, easily understood and meaningful to
  - practitioners, consumers with lived experience, the broader population (including First Nations, CALD and other vulnerable groups) and policy makers (children and young people?)

- Recognise that for research purposes, aspects of a clinical definition may be more stringent (eg proof of COVID)

- Be evidence-based and evolve with new evidence

- Align with international definitions

- Co-developed/modified in collaboration with lived experience, clinical and diagnostic discipline experts; researchers; public health and health planners; international colleagues

# Towards a workable definition of Long COVID – a model for discussion
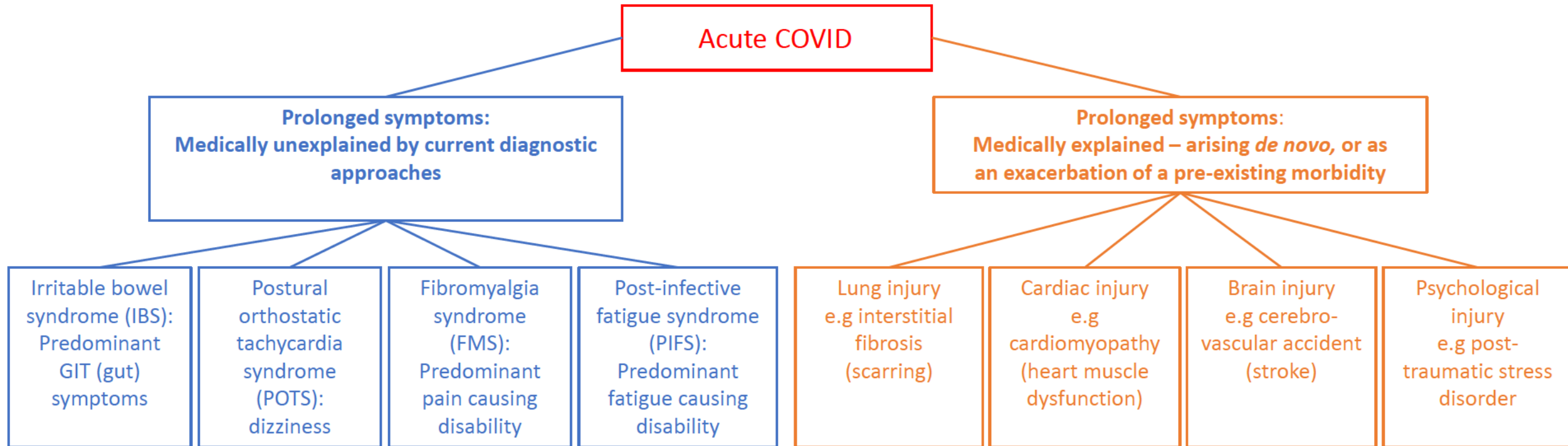
Notes:

- Clinical practice and research definitions will likely differ
- Syndromal (clinical subtype) diagnoses may be overlapping and may co-occur with medically explained conditions
- Validated questionnaires, protocolised evaluations are key for research definition
- Functional and quality of life impact measurements are important for operationalising clinical definitions
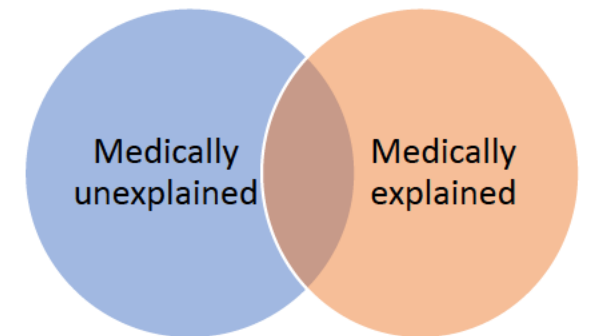
Towards a definition - Next steps?

- Ensure international alignment

- What about 'here and now' in Australia?

- Actions that Parliamentary Committee can take forward
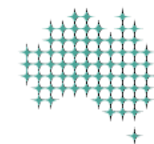
Session 2
Knowledge gaps

Session goals

Articulate key knowledge gaps requiring further research to ensure provision of

- Responsive clinical and supportive care that is equitable, of high quality and accessible to all
- Timely public health actions, preventive strategies
- Tailored, appropriate communications for all Australians
- Support for evidence-based policy development

Consider survey responses/additional issues

(These will feed into the next two sessions)

Knowledge gaps

Experts' feedback

- Treatments and interventions – which strategies are optimal and most effective?

- Prevalence and burden of disease, and natural history of long COVID
  - Interactions with pre-existing health conditions, quantifying severity, level of functional impairment,Impact of repeated infections

- Who is more at risk and why?

- Surveillance/monitoring
  - Lack of consistent, ongoing national surveillance of COVID-19 variants/waves and impacts, ICD code for long COVID

- Impacts of long COVID:
  - QoL, ability to work/study, relationships, mental health; on First Nations peoples, key populations e.g. CALD, rural/remote, vulnerable groups (paediatrics/children, elderly)

- Biomarkers and lack of diagnostic assessments/tools, how to make molecular information clinically actionable

- Prevention – how to reduce likelihood of long COVID, vaccination/antivirals

- What do we know from other post-infective fatigue states? Can this be applied to long COVID?

- What healthcare models work best to support recovery? What access do affected individuals have to services, and what are the outcomes e.g. rehabilitation?
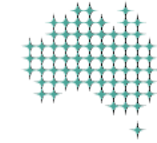
Session 3

# Actions to address knowledge gaps

Session goal

- Recommend actions that will address knowledge gaps and improve outcomes (themes of next two sessions)

Consider survey response summary/additional issues

Actions to address knowledge gaps

Areas of research needed

- More specific diagnostics and corroborative tests (laboratory and clinical)

- Research to validate new treatments or other interventions and public health predictions/interventions

- Effective management approaches including rehabilitation, mental health and social support pathways

- Up to date, cognate workforce – education, training and communication
    - Clinical workforce, public health, clinical/clinician/basic researchers, health planners

- Informed public (including communications/support tailored to First nations, CALD, other key populations)

- Adequate and sustained research infrastructure, platforms and networks

- Integrated national surveillance/analysis; co-ordinated national biobank; accessible "living" updates of impactful research, clinical and other advances

- Co-development of research with people with lived experience
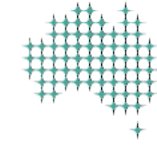
Session 3

How can the government, research and health sectors work to deliver actions?

Session goals

- How can stakeholders work together to deliver actions?

How can the government, research and health sectors work to deliver actions?

Actions under three key themes:
- Clinical care and communication with the community
- Research and evidence into policy
- Coordination and harmonisation

Theme: **Clinical care and communication with the community**

Ideas:
- Establish evidence-based models of care and social support
- Government and health authorities to improve communication approaches, including for CALD and First Nations peoples
- Information resources/guidance for patients and primary care, also for clinicians, researchers and policy makers

Theme: **Research and evidence into policy**

Ideas:

- Improve access/recruitment to treatment trials, consider a national clinical trials network in context of jurisdictional initiatives

- Targeted research funding for long COVID e.g. through MRFF or establishing CREs

- Support/coordination of infrastructure e.g. biobanks

- Patient-directed research, consumer research priority setting

- Establish an evidence base for research

- Maintain currency of international research outputs (e.g. regular systematic reviews)

- Assess effectiveness of interventions

- Ongoing mechanism to disseminate evidence, identify and prioritise gaps

- First nations-led research and mechanism for outcomes to be enacted into policy

Theme: **Coordination and harmonisation**

Ideas:

- Maintain or establish relevant taskforces/committees/advisory groups/national entities
  - National Clinical Evidence Taskforce
  - NHMRC Health Research Impact Committee
  - Consider role of an Australian CDC

- Harmonisation/standardisation of screening, laboratory tests, public health surveillance between state and federal governments

- Data collection – replicate UK ONS survey (ABS could do this), improve data sharing across jurisdictions, accurate coding of post-COVID conditions

- A 'knowledge mission' - representative advisory board of experts to develop strategy/plan/prioritise