



Long COVID and repeat COVID infections in children and adolescents



Prepared for: The House of Representatives Standing Committee on Health, Aged
Care and Sport
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Dr Mike Freeland | Chair of the House of Representatives Standing Committee on Health, Aged Care and Sport

Dear Mike,

Thank you for the invitation to provide a submission on the impacts of long and repeat COVID. The Murdoch Children's Research Institute (MCRI) has an ongoing commitment to address the needs of children and adolescents resulting from the pandemic. Our team of internationally recognised researchers and clinicians in infectious disease, vaccinology, and public/global health have undertaken over 120 research projects in prevention and treatment of COVID, understanding infection and transmission, and responding to the mental health and wellbeing needs - unique to children.

The impact of COVID on children and adolescents is far-reaching. While acute infection is less likely to cause severe disease in children compared with adults, long COVID is an important medical sequela. Being able to accurately diagnose long COVID, understand its clinical course, investigate treatment options, and predict long-term effects is essential to the health and wellbeing of our next generation of adults.

Whilst we appreciate the focus of this committee is long and repeat COVID, most children have been impacted by the indirect effects of the pandemic. These impacts are disproportionately felt by children and families living in adversity. We note that Recommendation 12 from the Senate Enquiry into COVID addressing this impact has not yet been actioned. The outstanding paediatric leadership within this enquiry also highlights a lack of paediatric leadership within the federal government - and we wonder if it might not be timely to appoint a Chief Child Health Medical Officer within the Department of Health to drive and inform policy and clinical issues such as long COVID.

Long and repeat COVID - what we know:

- Long COVID affects a proportion of children and adolescents, with a minority experiencing significant functional impact which limits their daily activities.
- The health, social, educational, and economic impact of long COVID and repeat COVID infections are inherently different in children and adolescents compared to adults.
- A set of questions, unique to children and adolescents need answering to improve their long-term health and wellbeing, as repeat infections with new variants occur.
- The Melbourne Children's campus is the place to co-ordinate the implementation of recommendations relevant to best practice for prevention, diagnosis and treatment of Australia's children and adolescents.

This submission builds upon Associate Professor Shidan Tosif's presentation to your committee. It describes the evidence available on long and repeat COVID in children and offers 10 recommendations that may ultimately provide the government with the evidence needed to drive vaccine delivery and prevention strategies. The MCRI would welcome an opportunity to discuss the submission with the committee and wishes you all the best with the inquiry.

Yours sincerely,

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RECOMMENDATIONS

Recommendation 1. *The voice, health and wellbeing of children, adolescents and their families be visible in outcomes of the inquiry.*

Recommendation 2. *Development of national diagnosis and management guidelines for children and adolescents with long COVID.*

Recommendation 3. *Development of national resources for children and families effected by long COVID.*

Recommendation 4. *Acknowledge the research needed to improve the care of long COVID and repeat infections – that is unique to children and adolescents.*

Recommendation 5. *Advocate for dedicated clinics to support primary care with the diagnosis and treatment of children and adolescents with long COVID.*

Recommendation 6. *Population level longitudinal cohort studies to elucidate the true prevalence of long COVID and repeat infections in children and adolescents to drive policy decisions on vaccine requirements and prevention strategies.*

Recommendation 7. *National data collection of long COVID and repeat COVID infections to assist the development of targeted and effective clinical care*

Recommendation 8. *Ongoing systemic data collection and assessment of the health social and educational impact on children and adolescents who developed/develop long COVID and have experienced repeat COVID infections.*

Recommendation 9. *Support shared data across state borders to improve understanding and impact of long COVID in children and adolescents.*

Recommendation 10. *Appoint a Chief Child Health Medical Officer within the Department of Health*

GLOSSARY

We acknowledge there are different terminologies for COVID in younger populations. For this submission, terms are defined as the following:

Term	Definition
Childhood	0 to 12 years of age
Adolescent	12 to 18 years of age
Young adult	18 to 24 years of age
Paediatric long COVID	Presence of one or more new, persistent physical symptoms, which may fluctuate and relapse, that lasts at least 12 weeks after confirmed initial SARS-CoV-2 infection and impairs daily function.
Repeat COVID	Subsequent infections after recovery from an initial COVID infection, of any given strain.
Chronic illness	Medical, neurodevelopmental, and acquired conditions associated with persisting challenges for health and well-being.
Mental health	A state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to their community.
Mental health problems	A catch-all term to describe mental health issues that can be of any severity, but in the context of the submission, relates mainly to mild-moderate symptoms.
Equity	Health equity is the principle underlying a commitment to reduce and, ultimately, eliminate disparities in health and in its determinants, including social determinants. Pursuing health equity means striving for high health standards for – whilst focusing on the needs of those at greatest risk.

RESEARCH EVIDENCE SUPPORTING RECOMMENDATIONS

TERMS OF REFERENCE 1: EXPERIENCING LONG COVID AND REPEAT COVID INFECTIONS

- A PATIENT'S PERSPECTIVE



The number of Australian children and adolescents living with long COVID remains unknown. Meet 13-year-old Shaun*, who has been affected for almost a year.

Before COVID Shaun enjoyed PE at school, hanging with his friends and playing basketball. He was in the throes of optimising a blood condition when he and his parents contracted COVID. Despite being fully vaccinated Shaun experienced symptoms of extreme fatigue and breathlessness, which remain to this day.

After the **acute COVID infection** Shaun's symptoms of light headiness, shortness of breath and fatigue intensified. Ten months on he manages as much school as he can but returns home completely fatigued. His education has been modified and his learning greatly impacted due to multiple absences, and his inability to retain information. He cannot exercise and has had to miss out on 'normal' everyday activities – some days just climbing a flight of stairs is daunting and exhausting.

For Shaun, it's impossible to predict the physical, mental, social and emotional limits each day. Shaun has also experienced increased susceptibility to other infections since COVID, and when he does contract an illness the long COVID symptoms flare up and his recovery is slow.

The social and emotional impact of long COVID on Shaun is equally as devastating as the physical. "I do not socialise with my mates and am scared of going out in case my body lets me down and I need help". His experience has caused ongoing anxiety that together with the physical symptoms control all aspects of his life. Shaun knows that it's hard for other people to grasp his situation, and often puts a mask on to make people think he is ok.

Shaun now receives psychological support. You can hear the sadness in his voice when asked about his future. "It's really hard, I have been going through this for so long now I feel useless – I worry about what people say about me when I am not at school, and how much of my life will be like this – no one can tell me."

"I am worried, how much of my life will I be like this? – no one can tell me" [Shaun 13]

*"The unknown is frightening - we need to know if he will have a normal life again"
[Shaun's mum]*

Shaun's **diagnostic journey** involved more than 10 GPs and specialists with no answers or co-ordination of care. As the weeks turned into months Shaun and his family felt that no-one was really listening. The long COVID clinic at the RCH was the last stop for Shaun, where he at least felt listened too and understood. Shaun has subsequently been diagnosed with long COVID and chronic fatigue syndrome and will continue to receive paediatric care, as long as the clinic remains funded.

Shaun's **advice to other adolescents** is to find someone that believes you and don't give up until you get some help. "Just because its new and many doctors don't know how to treat it – does not mean it's not real. Find doctors that will listen to you and ask for referrals to specialists if you think it will help."

A key take home **for the inquiry committee**. Long COVID in children is real – its physically and emotionally exhausting and socially debilitating. Children, and their families need better care to improve their lives.

Recommendation 1. The voice, health and wellbeing of children, adolescents and their families be visible in outcomes of the inquiry.

Recommendation 2. Development of national diagnosis and management guidelines for children and adolescents with long COVID.

Recommendation 3. Development of national resources for children and families effected by long COVID.

TERMS OF REFERENCE 2: SUPPORTING CHILDREN WITH LONG COVID AND REPEAT COVID

– A PAEDIATRICIAN'S PERSPECTIVE



Associate Professor Shidan Tosif
Clinical Lead - Post COVID clinic
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The RCH COVID-19 clinic has been in place since August of 2020 and has managed the care of 100's of children and their families. Whilst initially the clinic was established to provide acute clinical care and support vulnerable families, children with post-COVID-19 conditions are now the focus of the clinic.

In the last 10 months, we have seen approximately 115 children with a range of long COVID symptoms. Many have mild symptoms resulting in mild-moderate functional impact, that improve or make a full recovery within 3-6 months. However, a small proportion have more debilitation symptoms and are unable to attend school or engage in regular activities.

The mainstay of management has been supportive, holistic care, with symptom control, and assessment of treatable complications. We try to **hear the patient's story and validate the experience of the family.**

Unlike other conditions where we may offer a medication or treatment, the approach here is one of holding and support

The experience for children with long COVID is varied and challenging. **Children and families often reflect feeling unheard, misunderstood and miss labelled.**

The subjective nature of the symptoms can be dismissed by others and underrecognized by healthcare providers.

As clinicians, not having a cure or a defined treatment approach presents a challenge. We try to provide context, support, and reassurance where possible. Unlike other conditions where we may offer a medication or treatment, the approach here is one of holding and support. We provide a framework for the patient and their family based on current best practice for long COVID and our experience with other post-viral fatigue syndromes.

Importantly, the COVID-19 pandemic has had a major impact on children overall. Whilst COVID-19 infection is less likely to be severe in kids, the indirect impacts from lockdowns, isolation, and family strain have caused high rates of anxiety and wellbeing concerns, social and educational disruption. These pandemic associated symptoms at times can overlap and make it difficult to distinguish from long COVID. Concern regarding long COVID is high in caregivers, who understandably fear its implications.

Unfortunately, research and resources for children and families are limited, and more data is needed to improve our understanding and management of this condition. We have published a paper on an early cohort of children and adolescents and their recovery and are part of an international collaboration to build evidence for long-COVID in children. In addition to active research, we have had meetings with Victorian paediatric units, and last month a joint seminar was held to harmonise efforts with QLD and NSW paediatric units looking after children with long COVID. Our ongoing funding for the clinic and remains in question.

Recommendation 4. Acknowledge the research needed to improve the care of long COVID and repeat infections – that is unique to children and adolescents.

Recommendation 5. Advocate for dedicated clinics to support primary care with the diagnosis and treatment of children and adolescents with long COVID.

TERMS OF REFERENCE 3: RESEARCH INTO EFFECTS, CAUSES, RISK FACTORS, PREVALANCE, MANAGEMENT AND TREATMENT IN AUSTRALIAN CHILDREN AND ADOLESCENTS.

What we know

The World Health Organisation **defines** long COVID as the presence of one or more new, persistent physical symptoms, which may fluctuate and relapse, that lasts at least 12 weeks after confirmed initial COVID infection and impairs daily function. Over 200 **symptoms** have been attributed to long COVID. Many of these symptoms are challenging to distinguish from pandemic-related symptoms and other chronic conditions. (1-3)

Most research into long COVID had been undertaken in adults. Studies involving children and adolescents report a prevalence of anywhere between 4 to 66%. This variation is a result of major study limitations that not only prevent the aggregation of data but suggest that outcomes from individual studies should be treated with a high level of caution. (4)

Major limitations of currently studies on risk and prevalence of long and repeat COVID in children (1).

- Many studies have small *numbers* of participants making interpretation to the wider population difficult.
- Studies have used *non-standardised methods* for identifying and classifying infection and persistent symptoms, including patient reported infection in non-controlled settings, and selection biases.
- Studies vary in their *definition* of long COVID and inclusion of symptoms. Some reporting on persistent physical symptoms, while others using the broader definition including an array of mental health and non-specific symptoms.

Inherently difficult issues in studying the risk and prevalence of long and repeat COVID

- The *attribution of persistent symptoms* to a COVID infection alone is inherently difficult. Nearly all persistent symptoms reported by children and adolescents infected with COVID are also reported at a similar frequency in those without evidence of infection; including cough, fatigue, headache, sore throat, nasal congestion, diarrhea, rhinorrhoea, altered taste or smell, insomnia, shortness of breath, lack of concentration, weight loss, persistent muscle pain.
- Many if not all *control groups* collected are likely contaminated with children who have been infected with COVID but were not tested or who did not seroconvert.
- Furthermore any evaluation of long COVID a single time point is likely to miss transitory or intermittent symptoms of long COVID.

Data on the true prevalence, risk factors, and immune response of long covid and repeat infections are critical for implementing prevention and vaccination strategies for Australian children and adolescents.

In many children and adolescents, acute COVID is less severe than in adults. (5), however we know that adults with mild infections can experience debilitating long COVID. As a result, many **parents and carers have focused** their concerns less on the acute infection and more on the potential long-term effects of infection/s. The absence of reliable data in younger age groups compared to adults in this space makes policy decisions on vaccines and prevention strategies problematic.

A **study** looking at outcomes in 151 children with mild and asymptomatic COVID seen at Melbourne's Royal Children's Hospital COVID clinic reported ongoing of mild post-viral cough and fatigue symptoms in 8% of children. By six months symptoms had resolved in all 151 children. (6).

What we know we don't know

Some of the key questions – unique to children and adolescents - that we don't know include:

- What are the optimum modalities/approach for the treatment of long COVID in children?
- How much are persistent symptoms in children and adolescents from the COVID infection itself, or from the indirect effects of the pandemic more broadly? For example, are persistent mental health issues and lack of concentration, due to the COVID infection itself, other infections/illnesses, or due to pandemic related factors such as lockdowns and isolation?
- What are the immune system characteristics and biomarkers that are associated with long COVID?
- Can we generalise across the ages of all children and adolescents? The immune response and severity of COVID infections vary with age, thus should we expect the risk and prevalence of persistent symptoms to also differ across the age span?
- What long term effect will repeat COVID infections have on susceptibility of severe COVID, the developing immune systems, susceptibility to other infections and exacerbation of existing co-morbidities (e.g., asthma and respiratory health)?

What we need to know

The following list research questions that need to be understood to improve the prevention, diagnosis, treatment and long-term outcomes for children and adolescents.

What we need to know	Why is this important
The true risk of persistent symptoms because of COVID infection/s in children and adolescents from well-designed studies and better data.	Long COVID is an important factor in the risk benefit equation for decisions on vaccines and COVID-19 infection prevention strategies for children and adolescents.
The immune differences of children and adolescents that experience persistent symptoms due to long or repeat COVID infections.	Mechanisms underpinning the risk of long COVID will guide development of treatment strategies, inform care, and deliver improved outcomes.
The impact of age, disease severity and duration, virus strain, and other factors on the risk of long COVID in children and adolescents.	Children and adolescents respond differently to COVID infection/s and its imperative that we develop age-appropriate care for those with persistent and recurring symptoms.
The role of testing to identify cases of reinfection and measure community levels of infection.	the interplay between repeat infections and vaccination status in will be crucial to optimise protection across the life span and minimise multiple infections in Australia's children and adolescents.

Recommendation 6. Population level longitudinal cohort studies to elucidate the true prevalence of long COVID and repeat infections in children and adolescents to drive policy decisions on vaccine requirements and prevention strategies.

Recommendation 7. National data collection of long COVID and repeat COVID infections to assist the development of targeted and effective clinical care.

TERMS OF REFERENCE 4: THE HEALTH, SOCIAL, EDUCATIONAL, AND ECONOMIC IMPACTS IN AUSTRALIA ON INDIVIDUALS WHO DEVELOP LONG COVID AND/OR HAVE REPEATED COVID INFECTIONS, THEIR FAMILIES, AND THE BROADER COMMUNITY, INCLUDING FOR GROUPS THAT FACE A GREATER RISK OF SERIOUS ILLNESS DUE TO FACTORS SUCH AS AGE, EXISTING HEALTH CONDITIONS, DISABILITY, AND BACKGROUND.

There is no Australian data on the health, social, educational, and economic impact of repeat and long COVID infections in children and adolescents.

The indirect effects of pandemic control measures on children and adolescents have been addressed in previous senate inquiries – but briefly include mental health issues, wellbeing, disruption to family income, increased family violence, delayed medical attention and loss of face-to-face socialisation and learning. These issues have also amplified existing inequalities, by increased effects on sub-populations that are already disadvantaged and have been brought to the attention to senate COVID inquiry by MCRI. (7-12) There is no direct evidence in a specific cohort of those with repeat infections or long COVID.

Recommendation 8. Ongoing systemic data collection and assessment of the health social and educational impact on children and adolescents who developed/develop long COVID and have experienced repeat COVID infections.

TERMS OF REFERENCE 6: BEST PRACTICE FOR PREVENTION DIAGNOSIS AND TREATMENT

Management approaches for children with COVID are limited due to few clinical trials of chemotherapeutics in children. Thus, proposed management of is based in evidence from adult trials that utilise medications licensed for efficacy and safety in children. (13)

Current management for children and adolescents with long COVID is like other post-viral fatigue syndromes and focuses on lifestyle modification, sleep hygiene, limited screen time, exercise and activity modification, with encouragement of participation in school and social activities.

Current best practice for prevention includes vaccination, reducing obesity and asthma control. However, much needs to be done to establish a national best practice that is applicable to all children and adolescents including:

- Nationally agreed diagnostic criteria for children with emphasis on functional impact, and exclusion of other medical or psychosocial conditions which can cause similar symptoms.
- National guidelines/resources for self-management, clinical diagnosis and treatment.
- Dedicated long COVID clinics in paediatric settings.
- Support primary care by providing multidisciplinary clinics for secondary assessment, diagnosis, and treatment.
- Shared Data across States to allow improved understanding of long COVID incidence and impact.

Recommendation 9. Support shared data across state borders to improve understanding and impact of long COVID in children and adolescents.

Recommendation 10. Appoint a Chief Child Health Medical Officer within the Department of Health

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