

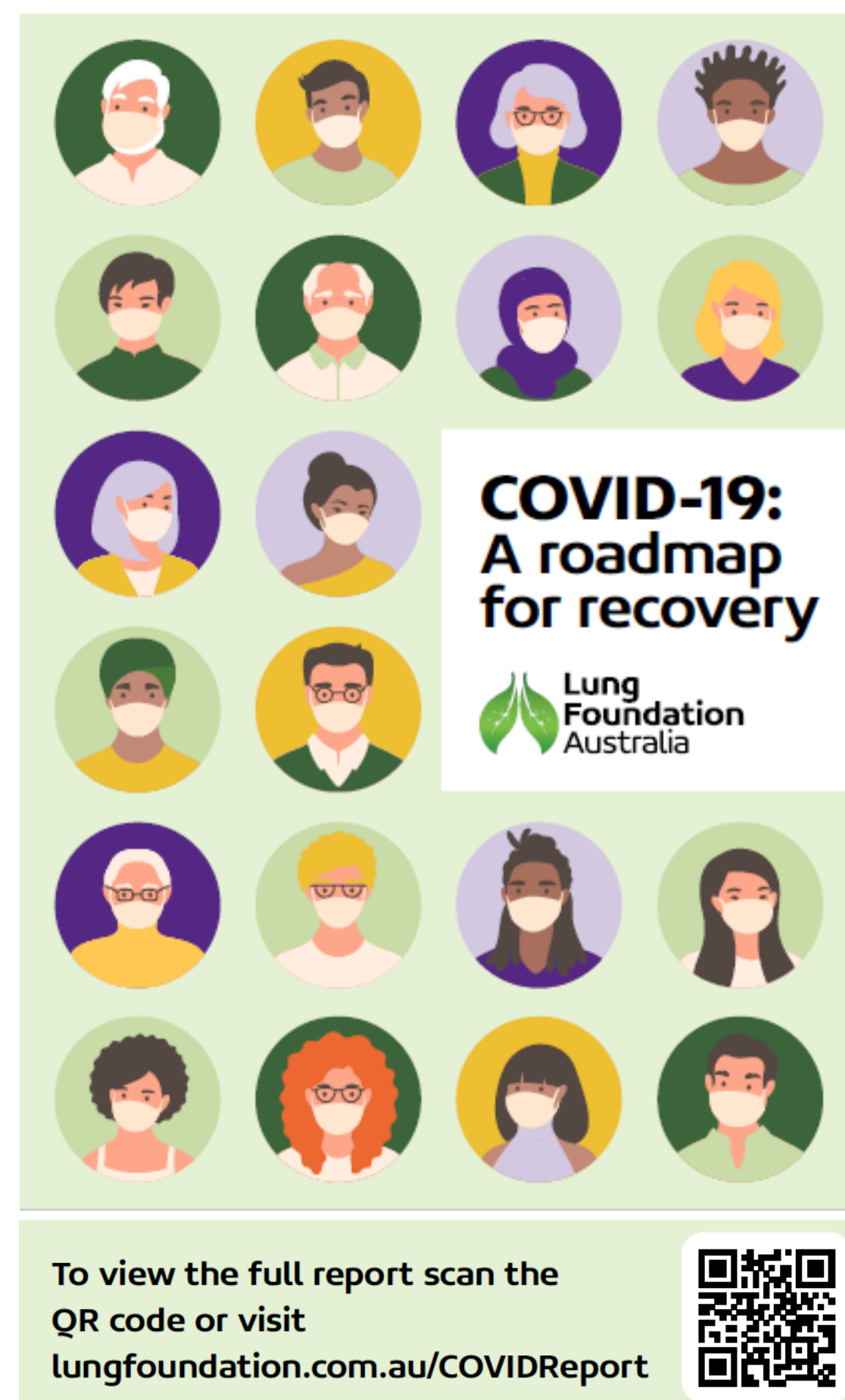
Designing a resource hub for people living with long COVID



- Imogen Page, Lung Foundation Australia

Background

Long COVID is a multisystem illness that affects everyone differently. For some people it may be categorised by having symptoms such as breathlessness and fatigue whereas other people may experience memory or thinking issues (often referred to as brain fog). Following a Lung Foundation Australia community survey of over 2000 Australians



and scoping literature review, it was identified that there is a lack of consistent and holistic information (with many existing resources for people with long COVID addressing each symptom in isolation). To address community need, we developed a project plan to fill this gap and create comprehensive long COVID resources for both clinicians and patients with long COVID.

Key stakeholders

Consumer representative group

- Six Australian representatives, four living with long COVID and two with other conditions
- Convened to help guide the COVID project and ensure all outputs were designed with consumers in mind.
- Met two times on average (range = 1-5) over the six-month period

Expert working group

- 12 Australian clinicians and researchers from a range of disciplines who all have a special interest in long COVID.
- Other clinicians were engaged with on an ad hoc basis to cover disciplines not in the formal expert working group (n=5)
- Three formal meetings plus out of session engagement over the six-month period

"When you have long COVID you can't exactly avoid the crashes, the thing that does change is how severe they are and the quality of life you get in between. Pacing gives me a quality of life that I didn't have before and allows me to do things I enjoy - like gardening."

Lisa, TAS resident living with long COVID.

Outputs

- Comprehensive long COVID booklet resource
- Five new long COVID webpages
- Blog on long COVID
- Resource for parents and caregivers of school-aged children with a chronic health condition, to help them navigate the school environment.

Outcomes

Resources have been disseminated via key stakeholders, long COVID clinics, healthcare professionals, peak bodies, PHN HealthPathways, Healthdirect, long COVID Facebook groups and more.

"I used to bounce out of bed in the mornings, but with long COVID, I wake up exhausted, and no amount of sleep seems to make any difference; even thinking about getting out of bed causes me anguish, but of course I do drag myself out of bed each morning... and everything is related. For example, my fatigue affects my lifestyle choices - if I'm exhausted then I don't have enough energy to cook a healthy meal and will end up having bickies and cheese."

Elizabeth, SA resident living with long COVID.

Long COVID: a tale of frustration and hope
Read the personal story from someone living with long COVID



Learn more about Long COVID at Lung Foundation Australia

Access the resource here:



Understanding long COVID

