

## How patient experiences can guide the development of Long COVID health policy

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Long Coronavirus Disease (COVID) is a growing public health challenge in Australia. People with Long COVID have a reduced ability to perform their normal daily activities due to debilitating symptoms that affect multiple body systems. However, the burden of Long COVID on people living with the condition and Australia's healthcare system is poorly described, meaning care and support resources cannot be allocated appropriately.

Australia's public health guidance for Long COVID is inconsistent. There is no single, nationally accepted case definition for Long COVID in Australia and public health messaging differs across each state and territory. This complicates an already challenging diagnostic process.

To ensure that Australians with Long COVID are recognised and supported with adequate and appropriate person-centred healthcare, social, and disability services, a number of key priority areas must be addressed.

### Recommendations

#### Identification

Broaden surveillance by developing a national Long COVID registry, establishing a national minimum data set for chronic illnesses, and expanding electronic health data collection and sharing.

Co-produce accessible and inclusive public health advice about Long COVID using a consensus case definition and consistent terminology.

#### Recognition

Acknowledge the disabling nature of Long COVID at a federal policy level and within the design and provision of care and support services.

Develop a co-produced approach in consultation with consumers to reduce stigma and discrimination against people with Long COVID in Australia.

#### Consumer engagement

Understand the care and support needs of Australians with Long COVID by expanding research using appropriate patient-reported experience and outcome measures at a national level.

Establish an intersectional, consumer-driven advisory group for Long COVID to be regularly consulted by policymakers.

Increase care accessibility by adequately resourcing GPs with co-produced care pathways that align with the care and support needs of Long COVID consumers.

