Emerge Australia's submission to: Medical Research Future Fund Reducing Health Inequities Mission - National Consultation on the Roadmap and Implementation Plan

About Emerge Australia

Emerge Australia is the national patient organisation representing an estimated 600,000 people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), long COVID and associated conditions. We provide information, support and education; work with clinicians and researchers; and advocate for health and disability systems that are safe, accessible and informed by lived experience.

Consultation context

The Medical Research Future Fund Mission will invest $150 million over ten years from 2027-28 in research to reduce inequities in health outcomes and improve access to quality health services. Its priorities include health-system reform, monitoring drivers of inequity, intersectional disadvantage, lived-experience leadership, research translation and workforce development.

The documents identify people with disability and allow other populations experiencing health inequity to be considered. However, they do not clearly recognise health inequity arising from the systematic under-recognition of particular medical conditions. The proposed responses seek to close that gap.

Question 4

Are the priority areas for investment identified in the Implementation Plan the most effective way for delivering on the Reducing Health Inequities Mission's goal and aims?

Broadly, yes. However, the Plan should explicitly recognise people with under-recognised and poorly served disabling conditions, including ME/CFS and long COVID, as experiencing health inequity.

Rationale

The priority areas provide a sound framework, covering health-system barriers, access, coordination, disability, lived experience and translation. However, neither the Roadmap nor Implementation Plan provides a mechanism to identify or prioritise populations experiencing inequity because their conditions are poorly recognised or served. Without this, communities affected by stigma, unsafe or inappropriate care, limited services and research under-representation may continue to be overlooked.

The Mission should focus on access to appropriate, evidence-based care, not simply access to healthcare, and support research into service gaps, models of care and implementation, as well as de-implementation of ineffective or harmful practices. Earlier investment is also needed, as the most relevant funding opportunities begin from 2031–32 or later, these populations will continue to be neglected unless funding is issued sooner.

Question 5

Are there existing research activities which could be utilised to contribute to the Reducing Health Inequities Mission refreshed Roadmap and Implementation Plan aims and priority areas for investment? How can these be leveraged?

Yes. Emerge Australia's ME/CFS and long COVID Registry and Biobank, National Burden of Disease Survey, and Consumer Advisory Panel provide data, biospecimens and lived-experience expertise. They can support Mission-funded research through sustained infrastructure support, data linkage, co-designed studies and equitable partnerships with patient organisations.

Rationale

These established assets can support recruitment, longitudinal and health-services research, biospecimen-based studies, and research into disability and healthcare access. The Consumer Advisory Panel provides an established co-design mechanism. Sustained funding matters because Registry and Biobank funding is time-limited; equitable partnerships ensure patient organisations are appropriately resourced as genuine research partners, rather than only primarily relied upon as recruitment channels.

Question 6

Are the Evaluation approach and measures appropriate for assessing and monitoring progress towards the Reducing Health Inequities Mission's goal and aims?

Partly. The approach appropriately includes lived-experience feedback and impacts beyond academic outputs. However, measures such as increased partnerships, research activity or knowledge do not demonstrate whether health inequities have decreased.

Rationale

Measures should be disaggregated by condition, illness severity or functional impairment, geography and other intersecting factors, with clear baselines and targets. Evaluation should measure changes in access to appropriate care, diagnostic delay, unmet need, safety, patient experience and health outcomes, and assess whether inequity gaps are narrowing over time.

Evaluation must also be accessible to people across the full spectrum of illness severity, including people with severe and very severe ME/CFS who may be unable to participate in conventional research or consultation. Lived-experience input should therefore be adequately resourced and available through flexible, low-burden and asynchronous methods.