

# Making the invisible visible: investigating the views and experiences of frail, homebound and bedridden people

Before COVID-19, some members of our Australian community have been living with several health issues that do not allow them to leave their houses or their beds. They have reported the existence of many problems when trying to access care and the medical system. They argue that many other services and opportunities easily provided to other Australians have been extremely difficult to access for them: “I feel like we're just invisible. Like this problem isn't even on anybody's radar because nobody knows we exist.” - Ricky Buchanan.

Ricky Buchanan is the author of the report “Just Invisible: Medical Access Issues for Homebound/Bedridden Persons”. This report was a catalyst for developing and funding this Caring Futures Institute (CFI) research project: ‘Making the invisible visible: investigating the views and experiences of frail, homebound and bedridden people’. The CFI study is investigating consumers’ lived experiences and insights about the above-mentioned issues, as well as documenting potential healthcare disparities, social exclusion, and marginalisation. ‘Making the invisible visible’ is an important first step to tackle these types of reported problems:

- Reduction in overall health (frailty and increase in morbidity and mortality).
- Inability to recover from minor injuries or illnesses.
- Social isolation – “life becomes smaller”.
- Mental health decline.
- Episodic conditions feeding a health deterioration cycle.
- Diminished capacity to reach out to people, to work, to study, to participate in community and family life.

Dr Maria Alejandra Pinero de Plaza is the lead investigator of this project, which involves a multidisciplinary group of investigators: Dr Michael Lawless, Dr Mandy Archibald, Ms Penelope McMillan, Ms Alexandra Mudd, and Professor Alison Kitson. Ms Penelope McMillan (Chair, ME/CFS South Australia and a Director of ME/CFS Australia) is involved in this study as a consumer co-researcher, at peer level with the Flinders researchers. She shares an interest in further describing this population; particularly, those who are living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (includes CFS, ME or ME/CFS diagnoses), which has been defined as a severe, complex, acquired illness with numerous symptoms related mainly to the dysfunction of the brain, gastrointestinal, immune, endocrine and cardiac systems. It impacts the mobility, frailty levels and healthy aging of many Australians.

Identifying the circumstances and experiences that this self-described invisible population is facing is important. Researchers from the CFI believe that working in collaboration with people from these communities will create avenues to respond to their needs with evidence-based and innovative consumer-centred solutions. An online survey is available for one month, from this article’s publication, to capture people’s views and experiences in relation to the topic [https://qualtrics.flinders.edu.au/jfe/form/SV\\_8qW69nZrlqsdiB](https://qualtrics.flinders.edu.au/jfe/form/SV_8qW69nZrlqsdiB). The survey is exploring the different social and health issues that people, particularly those who are frail, homebound, and bedridden, are experiencing in Australia.

The survey will give homebound and bedridden participants the opportunity to provide a photograph of something that represents their lived experience alongside a written description. This information will be used to create a fully anonymous socio-scientific exhibition of posters to be rotated within different museums, social and community locations. The exhibition will be also be posted in an online gallery on the ME/CFS South Australia website and the CFI. Dr Pinero de Plaza was awarded a CFI accelerator grant to undertake this project and translate the findings of this study into a socio-scientific exhibition (posters), which will present better evidence of what it means to be frail and/or eventually become a homebound or bedridden person in Australia.

