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Shame and stigma barriers to COVID-19 testing for young Australians and culturally diverse communities, new research finds

Shame and stigma are preventing young Australians and key community groups from deciding to be tested for COVID-19 in situations where testing is warranted, new collaborative research led by Burnet Institute found.

The Optimise Study, a research partnership led by Burnet Institute and the Peter Doherty Institute for Infection and Immunity (Doherty Institute), has been following a group of over 300 participants from key groups for the past six months. The latest findings reveal stigma as a pervasive and significant barrier to COVID-19 testing that transcends age and cultural differences in the Australian community.

“Testing is a critical component of the public health response to COVID-19, and this latest report focused on reasons for non-testing among people who reported symptoms,” Dr Alisa Pedrana, Burnet Senior Research Fellow, said.

“Ninety-three percent of participants reported symptoms but did not test on at least one occasion during follow-up. The majority (85 per cent) had declined to get a test as they considered their symptoms to be unrelated to COVID-19, while 14 per cent declined to get a test because they had mild symptoms.

“When we spoke with community members, fear, anxiety and stigma played a prominent role in their decision to get a test and were identified as common barriers for very different groups – young Australians in their teens and 20s, and people from culturally and linguistically diverse (CALD) communities.”

The Optimise Study report: *COVID-19 testing and strategies to improve testing uptake*, noted concerns that ‘sensationalised’ media portrayals of individuals who tested positive as selfish, irresponsible or reckless made study participants feel they too would be judged or ridiculed for testing positive. In addition, young people also feared the impact of isolation and not being able to survive.

Participants noted that people who were identified as having COVID-19 are ‘bombarded with hate’ and noted the use of social media hashtags such as #covidiot to publicly shame and harass others who have supposedly ‘done wrong’. And for young people at school, if there is a ‘COVID scare’, there is intense focus on identifying the person who had COVID-19, but less interest in knowing whether that person is OK.

“In some CALD communities, family groups and communities can blame and stigmatise individuals who try to get tested by asking ‘What have you been doing to get COVID-19? Who are your friends?’ which may discourage them from seeking out testing in the future,” report co-author, Dr Bronwen Merner, La Trobe University Research Fellow with the Centre for Health Communication and Participation, said.

“And people who may have had COVID-19 many months ago noted their experience of shame when required to declare it, with results sometimes discussed in a waiting room in front of others.”

The Optimise report identified a range of other barriers to testing for young people including:

- Impact on employment and financial security
- A testing system that is uncaring and impersonal
- Worries about how they would provide for themselves if forced to isolate.

“It is harder for young people to fit testing into their lives – they are less likely to be able to work from home, less likely to have their own transport, and less likely to feel that their lives and needs are reflected in government information and advice,” report co-author, Dr Angela Davis, Burnet Institute Research Fellow said.

“Young people often felt like it was not important or appreciated if they engaged with testing. Interactions during testing felt cold, impersonal and dismissive.”

Other barriers to testing identified in the report for people from key community groups include:

- Reluctance to stand for hours in a queue just for a ‘scratchy throat’
- Older people unable to stand for long periods
- Lack of awareness of call-to-test services
- Language barriers for people who speak languages other than English.

The Optimise Study researchers outlined a number of potential solutions based on participants’ recommendations including:

- A booking system for testing to avoid long queues
- Designated testing times for older people and vulnerable community members
- Integrate general practitioners into the process for advice and support on testing
- More information on walk-in testing centres and better accessibility
- Thank-you cards to promote community engagement while linking people to information and support
- An expanded health concierge model to support young people through testing and isolation.

The Optimise Study:

A partnership between Burnet Institute and Doherty Institute in collaboration with University of Melbourne, Swinburne University of Technology, Monash University, La Trobe University, Murdoch Children's Research Institute, the Centre for Ethnicity and Health, and the Health Issues Centre.

The Optimise Study aims to better understand how the community is managing and responding to COVID-19 and the measures introduced to stop its spread. It assesses the level of community cooperation to government COVID-19 directions and measure’s the effectiveness of government restrictions while identifying unintended consequences of the restrictions.

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