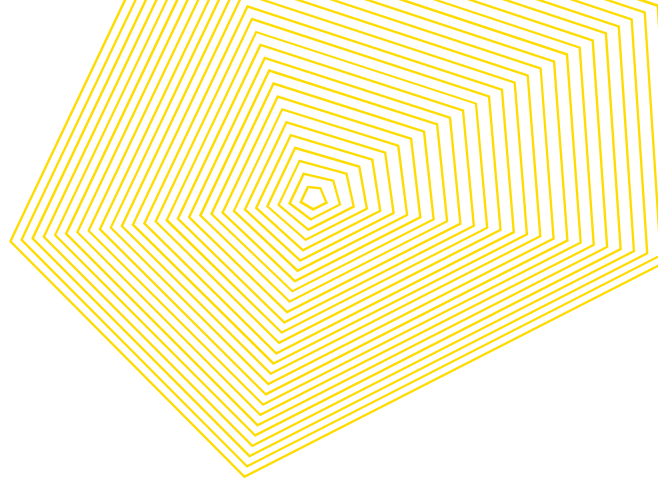




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**Assessments of public health and community
organisation responses to COVID-19 and other
infectious diseases by LGBTIQ+ people and those
living with blood-borne viruses**

Research briefing paper

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Abstract

This research briefing paper presents preliminary findings from the 'Diverse Experiences and Understandings of Immunity in the Pandemic Age' project, conducted in 2022-2023. The aim of this research was to identify how Australians from specific at-risk social and community groups experience and understand the relationship between immunity and good health in an era in which the serious risks to health posed by existing viral infections and diseases are now joined by those from novel diseases such as COVID-19 and mpox. Thirty semi-structured interviews were conducted with four key sub-groups: people identifying as LGBTIQ+ and people with lived experience of HIV, hepatitis B (HBV) and hepatitis C (HCV). These sub-groups were included in the study because they have extensive experience in dealing with infectious disease prevention and management. Furthermore, they are among those most at risk of further infection from other viruses. The paper covers the participants' responses to the question 'How have health communication, public health and community support initiatives helped or hindered participants' efforts to keep well?'. It includes recommendations for how these agencies and initiatives can better support people and social groups faced with discrimination and socioeconomic inequalities in the future.

Overview

The aim of the 'Diverse Experiences and Understandings of Immunity in the Pandemic Age' project was to identify how Australians from specific at-risk social and community groups experience and understand the relationship between immunity and good health in an era in which the risks posed by existing viral infections and diseases are now joined by those from novel diseases such as COVID-19 and mpox. It is a targeted qualitative study seeking to capture insights from four key sub-groups of the Australian population: people identifying as LGBTIQ+, people living with HIV, people living with hepatitis B (HBV), and/or people with lived experience of hepatitis C (HCV)¹. These groups are frequently marginalised in countries such as Australia, faced with entrenched stigmatisation and discrimination which complicates, and often impedes, their access to mainstream healthcare. Identifying the different experiences, impacts, causes and effects among these more marginalised, targeted and 'hidden' or 'hard to reach' populations is vital for a more comprehensive account of how public health and community responses to emerging infectious diseases are currently operating in Australia, and for identifying what improvements could be made in the future.

Recent outbreaks of communicable diseases have had an unequal impact on different population groups (Lupton, 2022; Bambra, 2022; Dionne and Turkmen, 2020), including in Australia (Flavel and Baum, 2022). Health and sexuality status are also contributing factors, particularly among groups who may be currently underserved by healthcare systems and public health initiatives. Socioeconomic and health inequalities combine with greater exposure to infection and co-infection risks for diseases such as hepatitis, COVID and mpox (McGowan and Bambra, 2022; Mitjà et al., 2023; McKee et al., 2018). Bambra (2022) outlined four main interconnected pathways linking inequality and infectious disease: unequal exposure, unequal transmission, unequal susceptibility and unequal treatment. Through these pathways, existing inequalities exacerbate the effects of emerging infectious disease outbreaks on those groups who are already more vulnerable to infection and reinfection, severe disease and lack of effective healthcare. Furthermore, they are among those most at risk of further infection from other viruses, such as the novel coronavirus that causes COVID-19, particularly in relation to Bambra's four pathways of inequality and transmission. At the same time, these communities have extensive experience in dealing with infectious disease prevention and management.

There is increasing recognition of the distinct health understandings and needs of people who have been positioned as at high risk of COVID infection: including those with chronic health conditions, people who are immunocompromised, and those who engage socially or sexually in close proximity to many others (Adab et al., 2022). Scientific evidence is emerging of the complex interrelationships between immunity, existing immunocompromise, chronic health conditions, and COVID infection and reinfection. For example, people with pre-existing health conditions or who are immunocompromised are at higher risk of developing severe COVID-19, long COVID and other subsequent health problems from infection, as well as death (Lin et al., 2021; Ssentongo et al., 2021; Hoffmann et al., 2021). COVID infection and reinfection can cause or worsen existing

¹ People living with HIV, hepatitis B, and/or hepatitis C have unique experiences owing to the biomedical and social natures of these blood-borne viruses, and therefore should not be collapsed or conflated into one group. However, they may share intersecting characteristics, and have crossovers with broader LGBTIQ+ communities.

chronic health conditions such as liver disease caused by hepatitis infection (Li et al., 2022). Those who are already immunocompromised due to existing viral infection are at higher risk of being infected with the mpox virus and progressing to severe disease (Saghazadeh and Rezaei, 2023).

COVID infection can itself damage immune responses, cause damage to organs, blood vessels and bodily systems (Parotto et al., 2023; Merad et al., 2022; Bowe et al., 2023). Some members of the LGBTIQ+ community are at higher risk of both COVID and mpox infection, including those who engage in frequent casual sexual contact (Prestage et al., 2022; Philpot et al., 2021; Holt et al., 2022). People with advanced HIV infection experience worse clinical outcomes and higher mortality if co-infected with the mpox virus (Mitjà et al., 2023). People living with HIV and/or gay, bisexual and other men who have sex with men have been identified as a major risk group for both COVID and mpox (May et al., 2023; MacGibbon et al., 2023; Murphy et al., 2023; Chow et al., 2023). However, they also often benefit from being part of communities that have a long history of successfully engaging members in successful and inclusive risk prevention activities in response to HIV, assisting COVID and mpox risk prevention (Murphy et al., 2023; Daroya et al., 2023; Chow et al., 2023).

The project's research questions are as follows:

- What does the concept of 'immunity' mean for the participants?
- Has this changed for them over their life course, and what experiences have contributed to this change?
- How does the concept of 'immunity' fit into their broader understandings of health or ill-health?
- What practices do they engage in to strengthen or protect their immune systems? (e.g. vaccination, medication, infection prevention practices, general good health practices)
- How have health communication, public health and community support initiatives helped or hindered participants' efforts to keep well?

A total of 30 semi-structured interviews were completed by Kerryn Drysdale with members of the four target groups between December 2022 and May 2023. The question on which this research briefing paper focuses is: *How have health communication, public health and community support initiatives helped or hindered participants' efforts to keep well?* Our findings contribute to better understandings of how recent major infectious disease outbreaks have influenced these communities' meanings and practices around immunity, and the role played by public health and community support initiatives.

Summary of key findings

Overall, the participants responded favourably to government initiatives and responses to the COVID pandemic, particularly those offered in the early stages to prevent the spread of the novel coronavirus SARS-CoV-2. For some participants, however, public health orders did not go far enough, especially for those who perceived themselves as immunocompromised or vulnerable to respiratory infections.

Participants were somewhat critical of the public health reliance on cultivating 'personal responsibility' for pandemic control measures. This approach was considered inadequate to protect more vulnerable Australians and as exacerbating existing health inequities. Several participants described continuing discrimination and marginalisation and called for more anti-stigma campaigns. Participants noted that the improved accessibility of COVID-related supports was also accompanied by greater acceptability on the part of community members. This was especially the case where such supports were community-oriented and promoted a sense of collective responsibility for self and others' health.

While COVID-related public health orders and initiatives were generally perceived favourably, there was some criticism of public health communication from government and mainstream health services. For example, participants noted the need for better accessibility for health-related information to ensure that 'information gets out'. Participants felt that there was an integral role for community organisations to play in relation to providing support and connection. While COVID-related public health orders and initiatives were generally perceived favourably, there was some criticism of public health communication from government and mainstream health services. In response, some participants felt that government and public health should 'hand over' complex health information and messaging to community organisations, as they are able to 'properly tailor' such messages.

In relation to other health concerns, participants called for more subsidies in and better access to health services. Trans and gender diverse people criticised the delays in gender affirming care caused by the pandemic. Participants also recommended new or alternative healthcare measures that focused on preventive health. Acknowledging the importance of strong personal data privacy and security protections, participants called for better tools to track/record and access to their health history, as well as automated reminder systems for upcoming vaccinations.

Beyond healthcare services, community organisations were seen as providing a valuable interface between a largely faceless public health system and the community. Participants felt that there was an integral role for community organisations to play in relation to providing support and connection. However, for some participants there was an increased perception of potential disenfranchisement from community organisations.

Finding ways for public health agencies and health communication campaign managers to work more closely and productively with trusted community organisations would strengthen prevention and education initiatives for COVID and other infectious disease prevention and treatment. Expanding free or low-cost healthcare for marginalised groups, including better information about and access to vaccines, would improve health promotion in these communities.

Methods

The 'Diverse Experiences and Understandings of Immunity in the Pandemic Age' study received approval from the UNSW Human Research Ethics Committee (HC220677) and from ACON's Research Ethics Review Committee (RERC202225). Letters of support for research provided by peak representative organisations Hepatitis Australia, Hep B Community, The National Association of People with HIV Australia, and LGBTIQ+ Health Australia. Participants were recruited to the study through both public facing (e.g., social media) and closed (e.g., email lists) advertisements by organisations who represented these distinctive, but often intersecting, sub-populations. The recruitment strategy used was underscored by the recognition that strong community ties and advocacy has been successful in managing past infectious diseases, and accordingly, representative organisational support was key to recruitment among these communities (Drysdale et al., 2023). Participants were eligible to participate if they self-identified as belonging to one or more of the target groups and were aged 18+ years of age and living in Australia. All participants provided informed consent (written or verbal) prior to the interview and were thanked for their time with a \$50AUD e-voucher.

Purposive sampling and screening ensured participant diversity in age, gender, ethnicity/race and geographical location. Table 1 (Appendix) provides the sociodemographic details of the participants. They ranged in age from 20 to 68 years of age. There was inclusive gender distribution among cis and trans men and woman, and non-binary people, and inclusive sexuality distribution among heterosexual, gay/lesbian, bisexual and other identities. The proportion of participants living in regional or rural areas, born in other countries, and speaking languages other than English also make this sample diverse.

The following questions were asked in the interview:

- Please describe to me how well you feel today? (e.g., great health, weak or poor health, a bit sick, really sick etc.) What is causing this state of health/illness for you right now? (e.g. current infection, rundown from past infections, engaging in health promoting behaviours such as eating well etc.) How does this relate to your experience of transmissible respiratory and/or close contact infections (COVID, mpox etc)?
- Please tell me about illnesses and infections you have experienced over your lifetime (as much as you can remember). How old were you at the time, how sick did you feel, what helped you recover, have you had any long-lasting effects or medication needed since then?
- Please tell me about any vaccinations you have had over your life. What were they for?
- Please tell me how you feel about vaccines in general? (e.g., strong support, weak support, ambivalent, anti-vax). Please explain your position on vaccines? Did your feelings change at any point along your life course?
- How would you describe your state of immunity to infectious diseases right now? (e.g., would you describe it as 'poor', 'weak', 'strong' etc?) What aspects of your life have influenced this state of your immunity, do you think?
- Do you think there's anything that the government, public health or the medical profession can do to improve your state of immunity and general health state right now?
- What about community organisations? Have they helped? In what ways can they help in the future?

- Is there anything else you would like to say about the topics we've just discussed?

Of the 30 interviews, 27 were conducted via video conferencing to enhance accessibility and COVID safety. The other three interviews were conducted face-to-face in local needle and syringe exchanges as preferred by these participants. The interviews ranged in length between 28 to 50 minutes. A timeline was constructed (hand drawn by Kerryn Drysdale), as participants responded to the questions, generating a chronological biographical record of participants' illnesses, infections and vaccination experiences over their lives to date, and serving as prompts to ask more detailed questions about periods of health or ill health over participants' life courses.

Findings

Accessibility and acceptability of public health initiatives

"I think it's a difficult situation, because it is a situation where I believe the majority would prefer not to be following [COVID protections]. And because it's the majority that don't feel like they are going to be as affected. But if you have people with disabilities or who have compromised immune systems, like they are the people and the families of those people who would want protections. ... And I feel like the people in the majority who would not want to wear masks and stuff would feel like personally slighted against for having to follow health recommendations, which would actually, like, save the lives of people."

Overall, participants responded favourably to government initiatives and responses to the COVID pandemic, particularly those that were offered in the early stages to prevent the spread of the virus. There was broad support of mask wearing mandates, temporary lock downs, and vaccination rollouts. Free access to COVID-related supports were also considered beneficial to maintaining good health. These included ready access to respiratory clinics and vaccinations as well as the temporary expansion of allied health services, such as increased sessions under Medicare-subsidised mental health plans, as well as improved avenues for accessing healthcare, including services that did not require Medicare cards.

For some participants, however, public health orders did not go far enough, especially for those who perceived themselves as immunocompromised or vulnerable to respiratory infection. For instance, some participants believed that the mask mandates were lifted too soon or were not uniformly enforced, and so Australia missed the opportunity to develop a strong mask-wearing culture such as that evident in some East Asian countries. Other participants felt that government may have capitulated too early, or have been too reactive, to negative press around mask mandates. While lockdowns were, on the whole, viewed favourably as necessary to prevent the spread of infection, criticism of made of the lack of wrap around supports, such as housing provision and financial support, that were perceived to be absent during periods of lockdowns. Two participants were also highly critical of state government decisions to reopen schools, highlighting the risk of infection faced by teachers and students.

In relation to other health concerns, participants called for more subsidies in and better access to health services. They suggested making HIV antiretroviral drugs free for all people living with HIV and increased rebates for other healthcare services in Medicare.

Participants suggested that the expansion of mental health plan sessions, pharmacies dispensing medicines and better bulk billing opportunities/access, better opportunities for those working traditional work hours to access vaccination clinics and healthcare, and more generalist healthcare access (as compared to specialist care that was perceived to be more accessible but more costly) would greatly contribute to protecting and maintaining good health in their communities. Trans and gender diverse people were especially critical of delays in gender affirming care caused by the COVID pandemic. There was a clear demand for more gender affirmation subsidies in healthcare, especially for those who wanted to medically affirm their gender.

The implementation of telehealth in the early stages of COVID was seen as highly positive. However, one participant who lived in a rural location pointed to the new levels of COVID infection risk they faced: despite the accessibility of telehealth, they still needed trips to the pharmacy to pick up their medications. Participants also recommended new or alternative healthcare measures that focused on preventive health. These suggestions included better streamlining of S100 prescribers and sexual health, better healthcare access and support for Aboriginal and Torres Strait Islander peoples, and incentives for people from stigmatised or marginalised communities to take better care of their health, such as people who use illicit or recreational drugs. For some people living with HIV, Australia's HIV prevention and treatment programs served as a good model for future integrated healthcare and public health responses. One participant specifically highlighted prison link-up services as another model that could be adapted to support other populations or diseases.

The relative visibility and use of the Australian Immunisation Register during the COVID vaccination rollout was viewed as ensuring easy access to vaccination information. However, several participants wished that all information on individuals' vaccinations from birth should be as easily accessible. Often participants did not recall all the vaccinations through their life course other than a belief that they must have had 'all the usual childhood vaccinations'. The difficulty of recollection was also exacerbated by different 'service app' requirements and availability in different state jurisdictions (with different access to immunisation registers).

Acknowledging the importance of strong personal data privacy and security protections, participants called for better tools to track/record and access health history, as well as automated reminder systems for upcoming vaccinations. The government's electronic health record My Health Record rarely came up in interviews as a way of keeping health records that people could refer to throughout their lives, suggesting either that this initiative has not been well advertised to the community or is being actively shunned.

Connection and support

"So one of the things I think that people learnt about [the AIDS response] is you have to temper the message. You can't sort of wag your finger and say 'No, you must not have sex.' Because that just sounds too preachy and people are just going to rebel against that – especially gay men who may have this history of being repressed and being, you know, ostracised. So it just needs to be more, 'What's in it for me, what's the win-win in doing this?'"

Participants noted that the improved accessibility of COVID-related supports was also accompanied by greater acceptability on the part of community members. This was

especially the case where such supports were community-oriented and promoted a sense of collective responsibility for self and others' health. Respiratory clinics, for instance, were seen as helpful beyond the healthcare that they offered; they were also seen as a version of community support, and there was a demand for more of them.

Participants were somewhat critical of the public health reliance on cultivating 'personal responsibility' for pandemic control measures, as this was seen as inadequate as a protection for more vulnerable Australians. This approach was perceived to create divisions between those who care about the health of others and so do the 'right thing' compared to those who wanted a swift return to 'normal'. Participants noted that this division exacerbated existing health inequities. They spoke of new divides between most Australians in good health versus those living with disabilities or chronic health conditions; between various states with differing public health orders, such as between Victoria and New South Wales; and between those who resided in 'fortressed' states, such as Western Australia, compared with the rest of the nation.

Several participants spoke of continuing discrimination and marginalisation and called for more anti-stigma campaigns. Particularly for people living with HIV and those living with HBV, stigma about their conditions had continued during the COVID pandemic. For people living with or affected by HCV, participants residing outside the populous capital cities in the eastern seaboard felt that the 'small town' syndrome, where everyone knows each other or are tightly networked, inhibited their access to targeted treatment due to lack of anonymity.

It was common for people to emphasise that there was an integral role for community organisations to play in relation to providing support and connection as well as providing services such as information and vaccinations. In particular, participants highlighted how community organisations promote and maintain a caring 'ethos' towards their community, evident by the numbers of people volunteering in these organisations. This extended to the support provided by community organisations, some of which kept open 'drop in spaces' which were perceived to be a great source of support and connection during COVID lockdowns. The perception of community support was amplified through the consistent social media presence (for example, their Instagram and Facebook accounts) that some community organisations maintained during the early phases of the pandemic.

AIDS Councils were seen as serving a wider community beyond those living with HIV, drawing on their knowledge of how to sensitively engage community members in ways that were non-judgemental and aware of community needs: for example, in relation to the prevention of mpox through education and vaccination provision. ACON in particular was specified as an important source of mental health support for those who were unable to access support services through mainstream health systems.

Beyond healthcare, community organisations were seen by many to serve as the interface between a largely faceless public health system and community. Here again ACON was singled out as taking the lead nationally over other state-based organisations. For people living with HBV, forums like the Hep B Community site were seen as sites of non-judgement, a credible source of information and the promotion of a sense of community among those who felt stigmatised or disenfranchised by mainstream services. The use of bilingual culturally and linguistically diverse community workers for HBV were seen as a strong source of support, similar to sentiment expressed for HIV-sector peer navigators.

However, there was an increased perception of potential disenfranchisement from community organisations. For example, this can occur when an individual has a negative interaction with a community organisation, is 'ejected from community spaces' or 'chewed up and spat out' in volunteering roles. One participant termed this an issue with 'lateral

violence' within the LGBTIQ+ community. While a minority of participants pointed to interpersonal dynamics in close-knit community groups, more held concerns around a lack of current representation in organisations more generally (that is, too many cisgender gay men), alongside recognition that such organisations cannot possibly represent all experiences and identities (for example, a bisexual Aboriginal man is likely to feel a lack of representation in community-run services). These problems were recognised as partially owing to a lack of secure, permanent funding, a reliance on volunteer labour, being too urban/city centric, and having too much focus on HIV prevention than the need to promote social connection and, for one participant, a lack of cancer-related attention.

Public health communication and education

"A community like ACON can help, I think, separate the overwhelming information. You know, because you have expert A on the ABC, you have expert B on at Channel 7, you have expert C on Channel 9, sort of saying different things, and then you have the government medical officers. I think an organisation like ACON can say, 'Well, we have taken all this and based on our medical experts, we think this is the approach to take.' And I think those types of organisations are probably better placed to give advice that the community will listen to – rather than, you know, different information from different sources and different people. So that's probably where I think it could be better done."

While COVID-related public health orders and initiatives were generally perceived favourably, there was some criticism of public health communication from government and mainstream health services. For example, participants noted the need for better accessibility for health-related information to ensure that 'information gets out'. This lack of accessibility is also complicated by what was perceived to be a lack of consistent messaging regarding COVID risk and precautions that could be taken. This was especially the case for participants from culturally and linguistically diverse backgrounds, who commented on the 'muddled' messaging around COVID vaccination types and eligibility. While the provision of COVID information was initially detailed and frequent, participants noted that there was an increasingly lack of availability of details such as case numbers over time, leading to the perception of declining public interest in COVID safe precautions. Some participants felt that this was due to a lack of visible respect in public forums for 'scientists'.

In response, some participants felt that government and public health should 'hand over' complex health information and messaging to community organisations, as they are able to 'properly tailor' such messages. Targeted, non-stigmatising advice that builds on LGBTIQ+ strengths was seen to be a role for community organisations. Such advice extends beyond the provision of COVID- or mpox-related information to sharing details about good experiences with allied healthcare, such as the circulation of information on LGBTIQ+ friendly services. The idea was that health information should be 'marketed by community' but 'funded by government'. Participants noted that using community or social events to distribute health information was a key strength of community organisations' communication strategies. Community-led campaigns resonate because ACON, especially, uses 'real people' in their campaigns and depend on the role of peers to disseminate information effectively. Participants felt that community organisations also shared practical, yet non-alarmist, information on mpox.

Despite the value of community-based information circulation, participants pointed to strategies for improvement. Their suggestions included community organisations needing to be more proactive in sifting through and distilling relevant information. People noted that resources can be hard to find they do not know where to look on websites and other information sources. Specifically, for those people living with HBV, there was generally broad support for government and public health initiatives over increasing awareness of accessibility of vaccinations, referral pathways to specialists, and free liver scans. Free and broad access to annual flu vaccines was also considered beneficial to good management of HBV symptomology and general good health. However, among these participants, there was recognition that HBV information and education around specific lifestyle recommendations and the availability of HBV vaccinations was lacking ('unnoticed') among the general public.

Recommendations

The members of the LGBTIQ+ community and people with lived experience of blood-borne viruses who participated in our study offered strong and helpful suggestions for how public health authorities and community organisations can work together to improve public health communication and services related to COVID-19, mpox, hepatitis, HIV, AIDS and other infections and communicable diseases. Returning to Bambra's (2022) pathways linking inequality and infectious disease (unequal exposure, unequal transmission, unequal susceptibility and unequal treatment), our participants' responses highlight how successful interactions between health communication strategies, inclusive health service delivery, social supports and public health protections, together with community organisations' services, education campaigns and other supports, can alleviate the impacts of these inequalities.

Health communication and healthcare services that recognise cultural and health diversity and offer clear, regular and updated advice that is non-judgemental and inclusive are highly important. Community organisations that recognise the diversity within their organisation membership and can focus on education and prevention related to the continuing COVID risks as well as the infectious diseases and other health risks with which they were more familiar offer the most helpful support. Finding ways for public health agencies and health communication campaign managers to work more closely and productively with trusted community organisations would strengthen prevention and education initiatives for COVID and other infectious disease prevention and treatment. Expanding free or low-cost healthcare for marginalised groups, including better information about and access to vaccines, would improve health promotion in these communities.

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Appendix: Sociodemographic details of participants

Characteristics	Total (n=30)
Age	
20-29 years	6 (20%)
30-39 years	9 (30%)
40-49 years	5 (17%)
50-59 years	7 (23%)
60-69 years	3 (10%)
Gender	
Man (cis and trans)	14 (47%)
Woman (cis and trans)	11 (37%)
Non-binary	5 (17%)
Sexuality	
Heterosexual	4 (13%)
Gay	10 (33%)
Lesbian	2 (7%)
Bisexual	4 (13%)
Queer	6 (20%)
Another term	4 (13%)
Indigenous status	
Aboriginal and/or Torres Strait Islander	2 (7%)
Not Indigenous	28 (93%)
Blood borne virus status*	
HIV	8 (27%)
HBV	2 (7%)
HCV	7 (23%)
No BBV	15 (50%)
*Categories not mutually exclusive	
Country of birth	
Australia	20 (67%)
Other	10 (33%)
Language spoken at home	
English	24 (80%)
Other	6 (20%)
State of residence	
Australian Capital Territory	1 (3%)
New South Wales	14 (47%)
Queensland	3 (10%)
South Australia	2 (7%)
Tasmania	4 (13%)
Victoria	4 (13%)
Western Australia	2 (7%)
Location of residence	
Urban	24 (80%)
Regional	4 (13%)
Rural	2 (7%)