ORIMA

Australian Government
Department of the Prime Minister and Cabinet

Final Report on Qualitative Research with Specific Cohorts on their Lived Experiences with the COVID-19 Pandemic

Informing the Commonwealth Government's COVID-19 Response Inquiry

29 July 2024

Quality and Compliance Statement

This project was conducted in accordance with the international quality standard ISO 20252, the international information security standard ISO 27001, as well as the Australian Privacy Principles contained in the Privacy Act 1988 (Cath). ORIMA Research also adheres to the Privacy (Market and Social Research) Code 2021 administered by the Australian Data and Insights Association (ADIA).

Acknowledgments

ORIMA pays respect to Aboriginal and Torres Strait Islander Peoples past and present, their cultures and traditions and acknowledges their continuing connection to land, sea and community.

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Key take-outs

1

Individual experiences of the pandemic were highly negative, and some impacts have continued

Across all cohorts in the research, there were one or more impacts from the pandemic identified in relation to people’s physical, mental, social, relational, educational/ developmental and/or economic wellbeing. The pandemic has continued to have residual impacts on people/ their families, leaving unresolved emotions and resentment.

2

Perceptions and experiences of the government response to the pandemic changed over time

There was initial openness and willingness to comply with the response measures. However, over time, there was increased polarisation of perceptions of the pandemic management, with many becoming increasingly frustrated, distressed and angry, particularly as measures were felt to be predominantly “negative”, “punitive” and “forceful”.

3

Pandemic information and measures often did not meet the needs of Australia’s heterogenous population

People often found pandemic information contradictory, overwhelming and/or mismatched from their personal experience, leading to disengagement, anxiousness and distrust. The were gaps in the supports available which meant some people across all cohorts missed out or did not have access to supports that were appropriate or accessible for them.

4

There was expectation of greater Federal Government oversight of a pandemic

Overall, there was felt to be limited Federal leadership during the pandemic leading to a perceived lack of fairness, consistency, coordination and unity across Australia’s response to the pandemic – resulting in divisiveness within Australia as a result of States/ Territories leading their own responses to the pandemic.

5

Negative experiences during the pandemic have disrupted some factors contributing to the societal fabric of Australia

There was erosion of trust, social license and goodwill in governments and institutions. Resentment towards what was lost (i.e. choice, connections, “freedoms” and autonomy) has led some mainstream audiences to become more sceptical and critical of government policies and decision-making. There is a need to repair and rebuild these elements of the social fabric.

Executive Summary

BACKGROUND AND METHODOLOGY

In September 2023, Prime Minister Anthony Albanese launched the **Commonwealth Government's COVID-19 Response Inquiry** to identify lessons learned from the pandemic and enhance Australia's future pandemic preparedness. As part of the initiative, the Australian Government Department of the Prime Minister and Cabinet commissioned ORIMA Research to conduct **large-scale qualitative research** on people's experiences of the COVID-19 pandemic in Australia. The research focused on understanding the range of attitudes and perceptions towards the government's COVID-19 response across 11 different audience groups:

1. People with disabilities
2. Culturally and linguistically diverse (CALD) communities
3. First Nations communities
4. Parents/ carers of school children
5. Mental health support services users
6. International students
7. People who participated in quarantine
8. Rural and remote communities
9. People who experienced homelessness
10. Vaccine hesitant/ sceptical individuals
11. People who experienced long COVID

The research was conducted between **21 May** and **24 June 2024** with a total of **176 people**. It consisted of: 9 face-to-face focus groups; 6 online focus groups; 5 mini focus groups; 1 kinship in-depth interview; 2 paired in-depth interviews; and 15 in-depth interviews.

This report presents the overall findings from the research, findings relating to each response measure (drawing out relevant cohort differences), and overall key learnings that were commonly and strongly identified in the research. Appendix B presents summaries of findings by each audience cohort.

OVERALL PANDEMIC EXPERIENCES ACROSS COHORTS AND LOCATIONS

The research found that pandemic experiences were **largely negative across all cohorts** – characterised by frustration, stress, isolation and fear. Negative impacts of the pandemic spanned multiple aspects of people's lives and were evidenced at the **individual, family/ community** and **structural/ system-wide** levels, including social disconnection, breakdown in personal relationships, reduced physical and mental health, disruption to education/ developmental progress, and ongoing emotional and economic challenges. The research identified considerable **negative residual emotions** from the pandemic, making discussions about the pandemic and the possibility of future health emergencies an emotive topic.

Pandemic experiences **varied substantially by location**, with more intense negative impacts reported more commonly in Victoria, New South Wales, metropolitan areas and specific localities where there were longer lockdowns or larger outbreaks. These differences were largely influenced by differences in local restrictions, case numbers, State/ Territory-specific government information and the capacity of local health services. Some participants in areas with higher case numbers, including some from CALD backgrounds living in high-density metropolitan areas, felt stigmatised and unfairly treated, leading to a **sense of disunity**; while those in regional/ remote areas reported frustration with measures that they perceived as being designed for metropolitan regions without consideration to their situation.

OVERALL FINDINGS ABOUT THE PANDEMIC RESPONSE MEASURES

The research identified **limited understanding of the roles and responsibilities** of different levels of government in responding to the pandemic. Most participants did not clearly distinguish between State/ Territory and Federal Government interventions/ measures, **leading to widespread confusion** about who was responsible for the various aspects of Australia's response and a perceived lack of national leadership and coordination.

While many acknowledged that COVID-19 was unexpected and challenging for governments to navigate, overall perceptions of the Federal Government's management were largely negative. Participants felt that governments **lacked a cohesive, united and transparent approach in managing the pandemic** – which led to uncertainty, confusion, anxiety and fear; resulting in reduced social cohesion, scepticism about government intentions and an erosion of trust in government and its institutions. The research suggested that this **could undermine public compliance** with future health regulations and pandemic responses.

Overall, participants felt that there had been **insufficient national reflection** and acknowledgement from government regarding the pandemic and people's experiences. The research suggested that these perceptions have contributed to **widespread unresolved emotions about COVID-19**, hindering recovery.

FINDINGS ABOUT PANDEMIC INFORMATION AND COMMUNICATIONS

Throughout the pandemic, the research indicated that there was **high demand for information** across all cohorts, driven by uncertainty and rapidly changing circumstances. However, most participants reported experiencing **contradictory information from various sources**, including official government communications. This contributed to widespread feelings of overwhelm, confusion and distrust, particularly as the pandemic progressed. Overall, the research found that pandemic communications were largely **ineffective at keeping participants informed, confident and reassured**. The research found heightened anxiety, diminished trust in government and scepticism towards official information over time due to "fear-based" messaging, a "patronising" tone, politicisation, and a perceived complexity of health guidelines.

FINDINGS ABOUT BORDER CLOSURE MEASURES

The research found **strong support for international border closures**, which were felt to be effective at preventing or slowing the spread of COVID-19 in Australia. However, there was lower support for domestic State/ Territory closures, which were felt to increase divisiveness in Australia and be less effective at limiting spread. Some viewed internal border restrictions as **inconsistent** and/or **poorly communicated**. Generally, most felt that refining approaches to the implementation of border closures could improve their appropriateness and **reduce negative impacts on mental and social wellbeing**. Key learnings included: the need for clearer and timely communication; national co-ordination of domestic border restrictions; flexible exemptions to facilitate the return of overseas citizens; and accommodations to minimise mental health impacts stemming from a perceived "lack of compassion".

FINDINGS ABOUT THE QUARANTINE PROGRAM

Participants were **generally supportive of the role of quarantine** in controlling the spread of COVID-19. While the purpose of quarantine was well understood, there was a perception for many that quarantine was poorly managed and did not appropriately adjust for individual circumstances. Common concerns included inadequate consideration for larger families, those from lower socio-economic backgrounds or individuals with existing health challenges, as well as insufficient consideration of and support for mental wellbeing. Key learnings included: improving communication about quarantine protocols; enhancing the quality and accessibility of hotel quarantine facilities; increasing access to specific accommodations; and reducing financial burden.

FINDINGS ABOUT FINANCIAL MEASURES

The research found **widespread support for financial assistance measures** such as JobKeeper and increased JobSeeker payments across cohorts. These were seen as valuable "lifelines" for meeting basic needs and sustaining businesses. However, some **felt overlooked and struggled financially**, including international students, single parents, people with disabilities and people with micro-small businesses. In addition, some struggled to readjust to the decline of their financial situation following the removal of payments. Key learnings included: maintaining the overall approach of providing financial support for people to meet their living expenses and retain employment; ensuring targeted and tailored support for specific cohorts; considering how to reduce the negative impacts of decreases in financial support in the design phase of financial assistance measures.

FINDINGS ABOUT SUPPLY AND LABOUR MEASURES

Most participants had **limited awareness of government measures aimed at supporting industries** during the pandemic, which negatively impacted their perception of the government's response. Common experiences included grocery shortages, limited access to medicines and difficulties in filling labour shortages. Participants felt that purchasing limits often did not meet the needs of larger families, those living remotely or individuals on tight budgets. Key learnings included: enhancing communication and transparency about government measures; and ensuring that support measures are effectively targeted and reach those most in need.

FINDINGS ABOUT PREVENTATIVE HEALTH MEASURES

The research indicated **strong general support for the range of preventative health measures** implemented during the pandemic, including PCR and RAT testing, mask-wearing, social distancing, hygiene practices, PPE and contact tracing. Participants felt that these measures were typically easy to access and implement, particularly when provided for free or covered by Medicare. However, access issues were noted for a few, including the cost of masks and tests, accessibility for people with disability (e.g. vision impairment), supply shortages, and long wait times for PCR testing. There were also interruptions to important rituals and cultural practices due to limitations on numbers at events. Key learnings were: continuing and expanding approaches to ensure affordability and accessibility, and giving particular consideration to the impacts of measures for culturally and linguistically diverse communities and people with disabilities.

FINDINGS ABOUT NON-COVID PHYSICAL AND MENTAL HEALTH MEASURES

Participants emphasised the importance of **maintaining access to non-COVID health services** during the pandemic to prevent compromising other areas of physical and mental health. Despite telehealth measures and increased Medicare-funded psychologist sessions, **access remained challenging** for many participants. Delays in diagnosis and treatment, coupled with high demand and perceived inadequacies in service delivery, exacerbated physical and mental health issues. Participants highlighted the need for culturally appropriate care and reported highly distressing experiences due to hospital visitation restrictions and a lack of support for First Nations and CALD communities. Key learnings included: considering opportunities to maintain in-person visits in combination with telehealth when required; expanding the size and capacity of the health care workforce; ensuring access to culturally appropriate services; and minimising delays in non-COVID medical procedures/ treatments and preventative assessments.

FINDINGS ABOUT VACCINATION MEASURES

Many participants **supported securing access to vaccines as an effective and necessary pandemic response**. There was good awareness of vaccine access, and the rollout was generally seen as effective albeit delayed in its implementation in Australia. However, **vaccine hesitancy was**

identified across all cohorts, and **limited support was identified for vaccine mandates**. Key information gaps and misconceptions contributed to this hesitancy (including about why vaccines were mandated, their potential risks and the number of required doses) as did personal experiences of adverse reactions to vaccines and the removal of the Astra Zeneca vaccine from the market. Vaccine hesitancy was also fuelled for some by the **perceived commercial influence** of pharmaceutical companies, low perceived severity of COVID-19 and exposure to contradictory information about vaccines. The research suggested that these perceptions may **reduce future compliance** with public health directives if unaddressed. Key learnings included: adopting positive and empowering approaches to communicating about vaccines; increasing transparency of information; and providing targeted communications.

1. Introduction

1.1. Background

In September 2023, Prime Minister Albanese launched the Commonwealth Government's **COVID-19 Response Inquiry** (the Inquiry) – an independent review aimed at enhancing Australia's future pandemic preparedness. The Inquiry is led by an independent panel and supported by a taskforce (the Taskforce) from the Department of the Prime Minister and Cabinet (the Department). The Inquiry was tasked with **evaluating the government's response to the COVID-19 pandemic and identifying opportunities to improve Australia's response to future pandemic events**.[1]

SCOPE OF THE INQUIRY:

COVID-19 posed significant challenges across health, social and economic dimensions in Australia and **required close collaboration between governments, community groups and industry**. Due to the diverse impacts across different sectors and communities, the Inquiry's scope is **government wide**. This includes the broad spectrum of health and other non-health-related measures introduced, as well as the roles and responsibilities of the Commonwealth, State/ Territory governments, and other governance mechanisms like the National Cabinet.

When calls for submissions to the Inquiry were opened in November 2023, the Taskforce received over 2,000 public submissions in a little over a month, including nearly 300 submissions from peak bodies and community organisations. Stakeholder consultation is currently ongoing and has thus far included over 50 interviews with representatives from government, research and academia.

The Inquiry's terms of reference also recognise the disproportionate effects of the COVID-19 pandemic on particular communities and aims to explore ways to improve supports for these cohorts in the future. In recognition of this aim – ORIMA Research was commissioned by the Department to conduct **qualitative research** with the following **11 cohorts of people about their experiences of the COVID-19 pandemic in Australia**:

1. People with disabilities
2. Culturally and linguistically diverse (CALD) communities
3. First Nations communities
4. Parents/ carers of school children
5. Mental health support services users
6. International students
7. People who participated in quarantine
8. Rural and remote communities
9. Homelessness support service users
10. Vaccine hesitant/ sceptical individuals
11. People who experienced long COVID

1.2. Research objectives

The primary objective of the research was to inform better **understanding of the lived experiences** of people from the 11 cohorts regarding the government's pandemic response. This included:

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[1] Australian Government Department of Prime Minister and Cabinet. Commonwealth Government COVID-19 Response Inquiry: https://www.pmc.gov.au/domestic-policy/commonwealth-government-covid-19-response-inquiry

- Understanding **the perceptions and attitudes of each cohort** regarding the various response measures that were implemented by government during the pandemic;
- Identifying **the challenges experienced by each cohort** in relation to the COVID-19 pandemic, including their unique information and support needs; and
- Informing **future strategies and solutions to address these challenges**, including strategies tailored specifically to the support needs of each cohort.

1.3. Research methodology

The qualitative research was conducted between **Tuesday 21 May** and **Monday 24 June 2024** with a total sample of **176 people**. Figure 1 (overleaf) presents the adopted research design.

Participants were recruited via **local ISO-accredited specialist qualitative research recruiters** and ORIMA **First Nations community interviewers**. The demographic profile of research participants in Appendix A shows that people from a range of demographic backgrounds participated in the research.

Participants received the following payments in recognition of their time and contribution:

- Participants in **face-to-face full or mini focus groups** received $120 payments;
- Participants in **online focus groups, individual and paired/ kinship interviews** received $100 payments; and
- Participants in **online interviews** received $80 payments.

This project was reviewed and approved by the ORIMA Research Human Research Ethics Committee (HREC) on 14 May 2024 in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2023) (Reference Number: 0032024).

Research discussions were focused on direct personal experiences of individuals and their immediate family and friends (rather than hearsay, media reporting or from extended indirect networks).

ANALYSIS APPROACH

A **manual, systematic but tailored approach** to qualitative analysis was adopted. The same team of specialist consultants conducted all the moderation, analysis and reporting to ensure the **analysis was done with a full appreciation and understanding of the context in which responses were provided** (e.g. non-verbal cues, language and tone). The qualitative analysis process was based on grounded theory – whereby hypotheses are formed based on the data collected through observation and interviews/ focus groups, allowing insights and patterns to emerge through inductive reasoning.

For each session, **extensive verbatim notes and quotes were taken by a note-taker**. Regular analysis sessions were run and attended by all consultants involved in the project to **cross-check and validate emerging findings**. These involved indicative **thematic analysis of results**, which then formed the basis for building on and validating emerging findings and insights. As the research progressed, key themes and findings were iteratively developed and refined, to draw out deeper insights.

Figure 1: Qualitative research design

	Metropolitan			Regional			Remote	Mixed Locations			
	Melbourne VIC	Parramatta NSW	Sydney NSW	Bendigo VIC	Cairns QLD	Darwin NT	Port Lincoln SA	Online WA	Online TAS	Online (National)[2]	**Total**
Face-to-face focus groups (FG) n=8-10 participants; Online focus groups (OFG) n=6-8 participants; Mini focus groups (MFG) n=4-5 participants; Kinship in-depth interviews (KIDI) n=3 participants, Paired in-depth interviews (PIDI) n=2 participants, In-depth interviews (IDI) n=1.											
General Public, n=15											
Single, living alone	1 x FG	-	-	-	-	-	-	-	-	-	1 x FG 1 x OFG
Partnered, no children	-	-	-	-	-	-	-	-	-	1 x OFG	
CALD audiences, n=22											
Female	1 x FG	-	-	-	-	-	-	-	-	6 x IDI (with interpreter)	1 x FG 1 x MG 6 x IDI
Male	-	-	-	-	-	1 x MG	-	-	-		
Parents/ carers, n=21											
Primary school aged children during pandemic	1 x FG	-	-	-	-	-	-	-	1 x PIDI	-	2 x FG 2 x PIDI
High school aged children during the pandemic	-	-	-	-	-	-	1 x FG	-	-	1 x PIDI	
Mental health care users, n=15											
Private practice and support from non-government organisations	-	-	-	-	-	-	1 x MG	1 x OFG	-	-	1 x MG 1 x OFG 2 x IDI
Specialist community/ hospital services	-	-	-	-	-	-			1 x IDI	1 x IDI	
International students, n=12											
Attended tertiary institution	-	1 x MG	-	-	-	-	-	-	-	-	1 x MG
Attended vocational training institution	-	-	-	-	-	-	-	1 x OFG	-	-	1 x OFG

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[2] Interview participants were from the following locations: very remote Queensland, Brisbane, Ballarat, Geelong, Perth, Sydney and Tasmania.

Figure 1: Qualitative research design (continued)

	Metropolitan			Regional			Remote	Mixed Locations			
	Melbourne VIC	Parramatta NSW	Sydney NSW	Bendigo VIC	Cairns QLD	Darwin NT	Port Lincoln SA	Online WA	Online TAS	Online (National)[3]	**Total**
People with disability, n=12											
Physical disability	-	-	-	-	-	-	-	-	-	1 x OFG	1 x OFG 7 x IDI
Sensory disability	-	-	-		1 x IDI	-	-	-	-	2 x IDI	
Cognitive/ intellectual disability	-	1 x IDI	-	2 X IDI	-	-	-	-	-	1 x IDI	
First Nations, n=23											
Female	-	-	-	-	1 x FG	-	1 x KIDI	-	-	-	2 x FG 1 x KIDI
Male	1 x FG	-	-	-	-	-		-	-	-	
Experiencing homelessness, n=13											
Female	-	-	1 x MG	-	-	-	-	-	-	-	2 x MG
Male	-	-	-	-	-	1 x MG	-	-	-	-	
People who experienced quarantine, n=18											
39 years and under	-	-	-	-	-	-	-	-	-	1 x OFG	1 x FG 1 x OFG
40 years and over	-	1 x FG	-	-	-	-	-	-	-	-	
Vaccine hesitant, n=17											
Female	-	-	-	-	1 x FG	-	-	-	-	-	1 x FG
Male	-	-	-	-	-	-	-	-	1 x OFG	-	1 x OFG
People who experienced long COVID, n=8											
	1 x FG	-	-	-	-	-	-	-	-	-	1 x FG
Total	5 x FG	1 x FG 1 x MG 1 x IDI	1 x MG	2 x IDI	2 x FG 1 x IDI	2 x MG	1 x FG 1 x MG 1 x KIDI	2 x OFG	1 x OFG 1 x PIDI 1 x IDI	3 x OFG 10 x IDI 1 x PIDI	9 x FG 6 x OFG 5 x MG 15 x IDI 2 x PIDI 1 x KIDI **n=176**

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[3] Interview participants were from the following locations: very remote Queensland, Brisbane, Ballarat, Geelong, Perth, Sydney and Tasmania.

1.4. Presentation of findings

The research was qualitative in nature and hence the results and findings are presented in a qualitative manner, with the aim of delving deeply into the complexities of human behaviours, perceptions and experiences. The following terms used in the report provide a qualitative indication and approximation of the size of the target audience who held particular views:

Most – refers to findings that relate to more than three quarters of the research participants.

Many – refers to findings that relate to more than half of the research participants.

Some – refers to findings that relate to around a third of the research participants.

A few – refers to findings that relate to less than a quarter of research participants.

The most common qualitative findings are reported except in certain situations where only a few have raised particular issues, but these are nevertheless considered to be important and to have potentially wide-ranging implications/ applications.

PARTICIPANT QUOTES AND STORIES

Participant quotes have been provided throughout the report to support the main findings under discussion. Each chapter of the report also contains 'participant stories' that summarise specific participant experiences with the various COVID-19 response measures. These stories have been de-identified and use pseudonyms (denoted by an asterisk*), but they encapsulate the direct experiences of participants as was shared during the research sessions.

1.5. Limitations

This research was qualitative in nature and therefore **aimed to gain insights on the breadth and depth** of participants' experiences. However, given the nature of qualitative research, several limitations should be noted when interpreting the findings:

- **Limitations due to the selective sampling of targeted cohorts in the sample design** – beyond the 11 cohorts targeted in the research design, there are other demographic cohorts in the wider community that have not been covered by the research (e.g. younger and older Australians). Therefore, this means that there may be **perspectives and experiences of cohorts in the population that are not addressed in this report**;
- **Limitations in quantifying the size and prevalence of people's experiences and issues raised** – due to the qualitative nature of the research, the findings **cannot be quantified or extrapolated to the broader population** as the sampling method was not based on a statistically valid quantitative approach; and
- **Scope and budget constraints** – the project scope and budget determined the size of the research design that was used. The methodology included a mix of face-to-face and online

sessions to maximise geographic and audience coverage. However, in some instances, more than one focus group was not able to be conducted to test the consistency of experiences in that cohort (e.g. people with long COVID and specific CALD communities) or across different locations.

1.6. Report structure

This report is organised around four **key parts**:

- **Chapters 2 and 3** – present the **overall research findings;**
- **Chapters 4 to 11** – present findings in relation to each **government response measure (drawing out relevant cohort differences),** specifically: communications; border management; quarantine; financial support; measures to support labour/ supply chain issues preventative health; non-COVID health and mental wellbeing; and vaccination.
- **Chapter 12** – presents overall **key learnings** that were commonly and strongly identified in the research across all cohorts; and
- **Appendix B** – presents individual **cohort summaries** for each of the eleven audience groups covered in the research.

Chapter 1 provides context for the research (objectives, research methodology and design), Chapter 13 presents the conclusions from the research, and the profile of research participants can be found in Appendix A.

2. Overall findings about pandemic experiences

Key takeouts

- The pandemic **negatively impacted people's physical, mental, social, relational, educational/ developmental and financial wellbeing**.
- There remain **unresolved emotions and ongoing issues** associated with the pandemic which have impacted people at the individual, family/ community and structural/ system levels, and some of these impacts are still being experienced.
- Without **acknowledgement of the negative impacts and a focus on recovery/ healing**, experiences of the pandemic are likely to negatively **shape personal responses to future health emergencies** and reduce the likely effectiveness of future management strategies.
- There was a **large degree of consistency and overlap between cohorts in terms of their perceptions and experiences of the different pandemic response measures**.

2.1. Overview of pandemic experiences

"I had to basically stay home for an entire three years because I am medically unable to take the vaccine. My cancer treatment was delayed, and the depression and anxiety really hit me. Being on disability support, I had little money and very little to live for" – Partnered participant with no children, Australia-wide

Overall, the research found that experiences of the COVID-19 pandemic were **largely negative**, which was not surprising due to the adverse nature of a pandemic. Participants' experiences were influenced by their **own personal attitudes and needs** as well as by the **context of their circumstances** and the **external environment impacting them**.

"It was really difficult for me because I wasn't able to go to programs and spend time with friends… I felt quite powerless" – Participant with a disability, Bendigo

Most participants reported that their overall experiences were characterised by negative emotions and sentiments, including "**frustration", "stress", "isolation"** and **"fear"** (as shown in the word-cloud in **Figure 2** overleaf). While some participants expressed gratitude that their experiences were not "as bad" as those experienced by others – especially in terms of exposure to, or impacts from, the virus for themselves or loved ones – others found it difficult to find any positivity from the pandemic experience. **Across all cohorts** in the research, there were **one or more impacts** identified in relation to physical, mental, social, relational, educational/ developmental and/or financial wellbeing (Figure 3).

"We still feel the impacts of COVID today, especially the children" – Participant with long COVID, Melbourne

The research found that the strength of negative experiences during the pandemic and their emotional impact meant that **negative residual emotions and resentment remained** for many participants. Given this context, communicating with people about the COVID-19 pandemic must be done with sensitivity and acknowledgement of the need for further healing and recovery.

Figure 2: Words used by participants to summarise their experiences of the COVID-19 pandemic

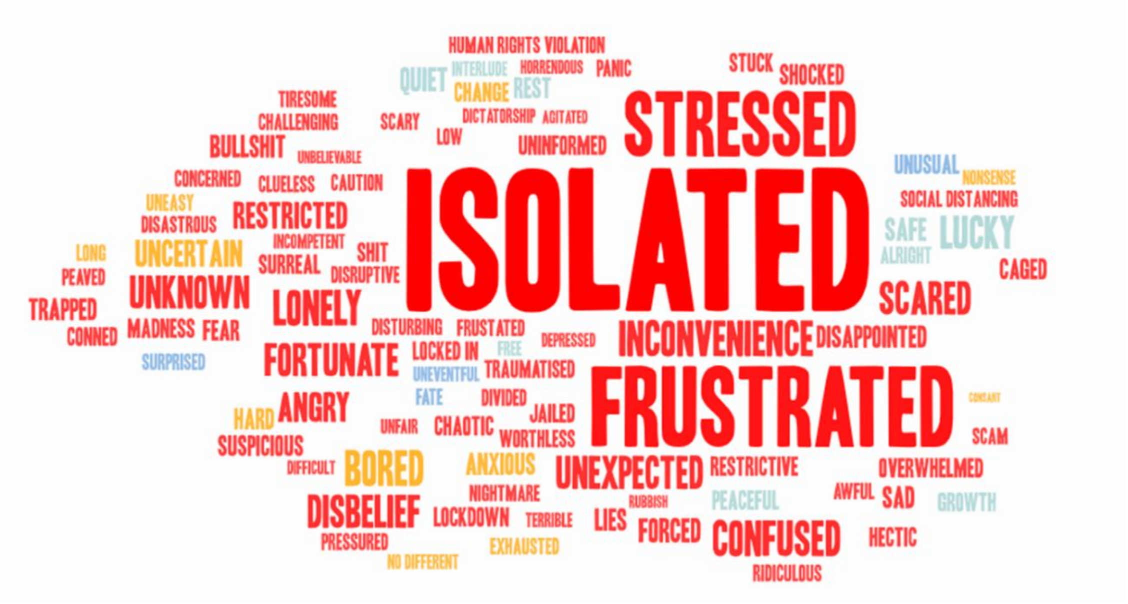
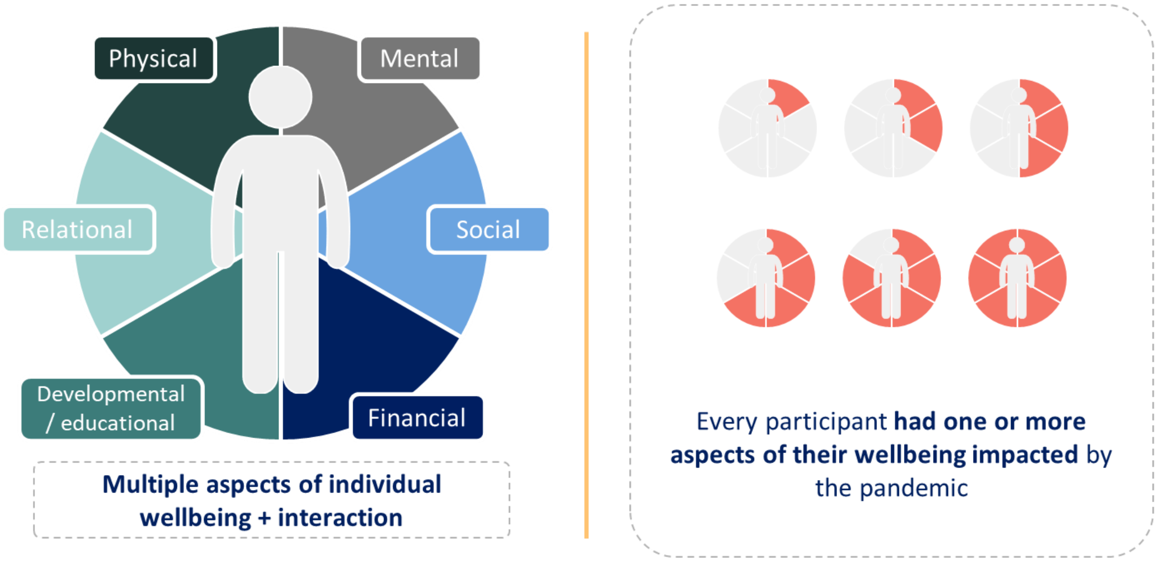


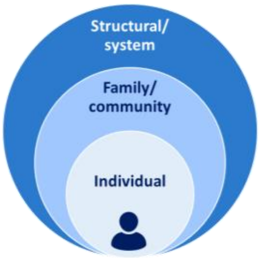
Figure 3: Negative impacts of pandemic experience on individual reported wellbeing



Multiple aspects of individual wellbeing + interaction

Every participant **had one or more aspects of their wellbeing impacted** by the pandemic

2.2. Personal impacts and outcomes



The research found that the **impacts** of the pandemic on participants' lives **were extensive and spanned across many domains**. While a few positive impacts were mentioned, most were negative. The research found that the impacts of the pandemic were evidenced at the **individual**, **family/ community** and **structural/ system-wide** level.

2.2.1. Individual-level outcomes

The research identified the following **positive individual-level outcomes** from the pandemic among some research participants:

- **Greater acknowledgment and acceptance of the importance of mental health** and the **normalisation** of discussions about, as well as help seeking for, mental health conditions;
- **Increased ability to save money during the pandemic,** as they spent less on their normal activities and, in some cases, earned more due to increased government payments; and
- **Improved health prevention and personal hygiene behaviours** – strategies to prevent the spread of illness continued to be adopted by the public including regularly "washing hands" and "covering up when sneezing/ coughing". Also, businesses/ employers have continued to provide hand sanitisers and encourage people to stay at home when sick. This was particularly appreciated by older participants and those who were immunocompromised.

> *"A lot more people are aware now of mental health… they didn't even realise anxiety or depression was a thing before"* – Participant who uses mental health care, Melbourne

> *"People are more hygienic and everything is being cleaned regularly, like trains and door handles… which is a good thing"* – Parent/ carer of primary school aged child, Port Lincoln

> *"Lots of children have gotten mental health issues…my son was doing [online] school and he was finding that hard due to the isolation… he's developed some mental health issues"* – Participant experiencing homelessness, Sydney

> *"I literally cried every time I turned on the TV, I thought it was the end of the world so drank myself silly almost every*

However, most **individual-level impacts** tended to be **negative,** resulting in the following outcomes:

- **Poor mental health** – this included mental health issues being triggered or exacerbated by social isolation or other restrictions, loss of control/ autonomy, fear of illness, disruptions to, or missing out on, important life events, being unable to care for loved ones in need, triggering of past trauma (e.g. for those who had lived under authoritarian governments) or barriers to accessing mental health care services. For some participants, the mental health impacts were ongoing for themselves or their loved ones, with many reporting impacts on children and young people in their lives. This was found to impact social and emotional wellbeing, as well as capacity to effectively participate in education, work and/or caring responsibilities. For some participants, especially existing mental health care users and people experiencing homelessness, worsening mental health issues contributed to the misuse of alcohol and other drugs (AOD), which the research suggested is likely to increase the ongoing need for AOD services;

- **Poor physical health** – due to delayed or interrupted care as a result of restrictions on treatments and therapies, as well as limited access to physical exercise (e.g. attending the gym or organised sports), ongoing impacts from COVID-19 infection and/or perceived impacts from the vaccination. This has led to ongoing health impacts and/or reduced physical fitness;
- **Negative emotions** – associated with specific elements of the pandemic experience. This included continued **grief** from not being able to “say goodbye” or attend funerals of loved ones and/or **guilt** for decisions made during the pandemic, including in relation to decisions to vaccinate or encourage vaccination and concern about the potential negative health impacts. For a few, there was also continued heightened **fear** and **anxiety** relating to illness;
- **Reduced financial security** – including due to using savings or superannuation to meet daily living expenses during the pandemic period, particularly for small business owners and those who lost work/ were made redundant;
- **Reduced social skills and developmental maturity** – parent/ carer participants reported that their children and young people struggled to maintain friendships and regular social lives due to periods of isolation where they were unable to interact with peers in a face-to-face setting. Furthermore, parents/ carers and participants who were teachers indicated that children/ young people had not developmentally progressed, showing signs of immaturity and behavioural problems; and
- **Delays and challenges in education and broader skills development** – parent/ carer participants reported challenges transitioning to home schooling, particularly for large families with multiple school aged children, those with work commitments, those with limited English language proficiency and those in remote communities reliant on boarding schools. They also reported challenges later re-engaging children in school, resulting in some children falling behind in their education and/or struggling socially or emotionally. Some adult participants also reported interruptions to their professional growth due to missing out on promotions, internships or opportunities (e.g. to work abroad). This included international students who felt that the quality of their education was adversely impacted by the shift to online delivery methods.

day” — First Nations participant, Port Lincoln

“I got COVID three years ago, but even now I’m so fatigued all time… I have to take half days at work because by 3pm I can’t even stand” — Participant with long COVID, Melbourne

“We missed a funeral of an Elder… we tried to get a pass [exemption] but couldn’t… the whole family just had to watch online... it was so upsetting” — First Nations participant, Cairns

“The kids are just disengaged from school now and get caught committing offences” — Parent/ carer of high school aged child, Port Lincoln

Physical and mental health impacts of the pandemic

Lara* has been suffering from a rare deteriorating muscular disorder since the age of nine. She relies on essential therapy a few times a week which enables her to maintain muscle strength and continue to walk. When COVID-19 hit, all the places where she accessed her therapy closed. While she initially was paying for a physiotherapist to come to her so she could keep up her exercises, she quickly used up her NDIS funding and had to completely stop. When the vaccine came out, she tried to find information about how it would impact her, given her unique condition. She tried talking to her GP about the issue and he simply dismissed her concerns and continued pushing her to get vaccinated – she ultimately decided not to take the vaccine in case it had a negative impact. During this time, she felt immensely alienated by the government, health care workers and even friends who questioned her decisions. Since she was not vaccinated, many of her essential therapy services were not available to her, so she had a year before she could re-access the therapies she had been receiving prior to the pandemic. During this time her muscles deteriorated significantly – she went from being able to walk at least four kilometres at a time, to not being able to walk at all without assistance. The impact on Lara's life is profoundly negative and she has to continue living with limited mobility. Lara felt that she was abandoned, had no one to rely on and received no additional supports. She still feels resentful and distrusting of government today.

Impacts of online schooling and isolation on students

Noor* is a teacher at an Islamic school and had been teaching for 12 years when the pandemic occurred. When teaching went online during the pandemic, she was teaching a Year 1 class and she noticed that her students struggled to pay attention and keep up with the content she was teaching. The students suffered from the isolation they experienced from their friends and teachers. Noor felt that she was unable to adequately help them to learn and develop at the critical juncture of their schooling experience. These students spent their first school year in online classes due to the extended lockdowns. Noor now finds that these students, who are currently in Year 4, are still struggling not just academically but also socially and psychologically.

2.2.2. Family/ community level outcomes

At the **family/ community-level**, the research identified the following **positive outcomes from the pandemic** among some participants:

- **More quality time with family** as a result of the "slower lifestyle" during the pandemic;
- **Greater visibility of communities supporting each other** (e.g. delivering groceries to people in isolation and sharing items); and
- Increased instances of organisations implementing **targeted programs to support wellbeing** (e.g. workplaces and universities).

"Because of work from home I could spend more time with the kids and re-establish our relationship" – Parent/ carer of a primary school aged child, Melbourne

However, most **family/ community-level outcomes** were **negative** including:

- **Breakdown of relationships** – this included:
    - **Romantic and close family relationships**, with increased strain due to the high stress environment and extended time either "locked down" together or being separated. Some participants also reported strain due to changed family dynamics, including increased time at home, loss of jobs and income, and limited access to extended social networks. A few participants reported increased domestic and family violence in their homes due to this increased pressure in the home environment, or having no option but to live with a violent or volatile partner/ ex-partner;
    - **Other family or friends**, with participants commonly reporting disagreements and arguments about vaccinations or other elements of the pandemic response. Some participants had lost friendships or cut off relationships completely due to opposing opinions. In addition, a few First Nations participants reported strain in their households due to overcrowding as a result of extended family members who had lost their jobs or were transient moving in during the pandemic;
    - **Between parents/ carers and children** – particularly for parents/ carers who did not live with their children, whose children lived interstate and for foster and out-of-home care families for whom travel restrictions interrupted regular visitations;
- **Reduced community cohesion** – due to experiences of aggressive behaviour to those required to enforce restrictions (e.g. health care and hospitality workers) and people in neighbourhoods "policing" each other in relation to restrictions (e.g. mask wearing and social distancing). This led to mistrust and conflict in communities. In addition, a few reported that established community networks, such as social, support or volunteer groups "fell apart" during this period, with many yet to re-establish. Reduced community cohesion was felt to have a particularly negative impact for participants in rural and remote communities who felt that this was an important protective factor for mental and social wellbeing; and
- **Further stigmatisation and marginalisation of communities** – particularly in instances where increased case numbers or community discourse negatively affected particular cohorts that were already marginalised, including migrant populations or those of lower socioeconomic status.

"I had my entire family move back in with me… including my ex-partner who was abusive and the whole situation was just so traumatising" – Participant experiencing homelessness, Sydney

"I had lots of arguments with my family about the vaccine, they thought I was a crazy conspiracy theorist" – Participant who uses mental health care, Melbourne

"Everyone was a jailor to their fellow neighbour… always watching people… assaulting them…like an Orwellian future… it was Australian vs Australian" – Participant experiencing homelessness, Darwin

Loss of community spirit via local clubs

James* and others in the focus groups mentioned that during the COVID-19 pandemic some of the sporting clubs in his regional town had ceased operating due to the inability to gather in groups/ have sporting matches and train. This was and continues to be a significant blow to the community as these clubs had been a key means for community to gather, support each other and foster local community spirit. He mentioned that those clubs have not yet been revived and it's been a great loss to the community.

Frontline workers facing abuse and hostility

Tess* worked in hospitality before and during the COVID-19 pandemic and said she loved her job. She reported that she and other frontline workers received a lot of verbal "abuse", "rudeness" and "hostility" on a daily basis during the three years of the pandemic. She felt that this was largely due to the anger, frustration and fear that many people in her regional community experienced due to the mask mandates, vaccination and social distancing requirements. Frontline workers became the avenue through which people vented their frustrations at governments across Australia mandating these restrictions. She believed that governments did a "very poor job" of communicating the reasons for the mandates, which led to heightened and "uncontrolled" emotions. The whole experience left her feeling "broken" and "hating" her job, so she quit, vowing to never return to the industry again.

2.2.3.Structural/ system-level outcomes

"A positive is that COVID has changed the way we work… you've got work from home, telehealth… virtual access to everything" – Parent/ carer of a primary school aged child, Melbourne

The research identified **more effective use and integration of digital technologies** as a **positive structural/ system-level outcome** from the pandemic. The research found that, as a result of the forced reliance on online technologies during the pandemic, technology was used (and continues to be used) to more effectively facilitate work, study, telehealth and other types of service delivery. This increased use of technology in workplaces and organisations was reported to have increased ease of access to services and improved work-life balance.

"I'm not a fan of how it was handled, it was very aggressive… we had no freedom of choice or bodily autonomy… I have less trust in government and health officials now" – Participant who experienced quarantine, aged under 39 years, Australia-wide

However, **structural/ system-level outcomes** tended to be **negative,** including:

- **Erosion of trust and faith in government** – due to perceptions that responses were "too heavy handed", "lacking in justification", "controlling" and/or not in the best interest of individuals. This was particularly evident in response to measures such as lockdowns, curfews, movement restrictions and vaccination mandates. This was found to be exacerbated by circumstances and actions by government post-pandemic that were perceived to contradict the efficacy of these responses (e.g. withdrawal of Astra Zeneca and the continuation of high prevalence of COVID-19 cases in the community following the vaccination roll-out). Furthermore, for some, exposure to "conspiracy"-based information which questioned the intentions, actions and decisions made by governments further fuelled the decline of trust (e.g. Bill Gates, Jeffrey Sachs or the pharmaceutical industry being responsible for the virus for profit maximisation reasons);

- **Erosion of trust in medical science and public health advice** – due to exposure to high levels of health information during the pandemic which was felt to be "contradictory", "changing" and/or misaligned with personal experiences, and therefore was not felt to be true or transparent. This was particularly in relation to vaccinations; and
- **Increased cost of living** – due to the perceived downstream economic impacts of the pandemic which many felt had played a role in the current "cost of living crisis", "housing crisis", inflation and supply shortages.

"COVID has completely changed my views on the medical field and profession… my trust is at rock bottom, gone completely" – Vaccine hesitant participant, Tasmania

"Everything is getting more expensive, housing prices are going up dramatically, I don't have any more savings, or even money for food" – Participant experiencing homelessness, Darwin

2.3. Enduring impacts from the pandemic

While most participants reported "continuing on" with their lives, many felt the effects from the pandemic continued to impact themselves and/or their families and friends. It was felt that, overall, there was **limited acknowledgement** of, or **national reflection** on, what people had experienced **through the pandemic**. This was felt to hinder social and emotional recovery and "healing" (See Figure 4, overleaf).

The research found that unresolved feelings and emotions (e.g. anger and resentment) relating to pandemic management would likely **shape reactions and responses to future health emergencies**. Specifically, the research found that experiences of the COVID-19 pandemic have adversely affected factors underpinning to pro-social behaviour which influence whether people are likely to follow/ comply with government advice and direction in future emergencies, including:

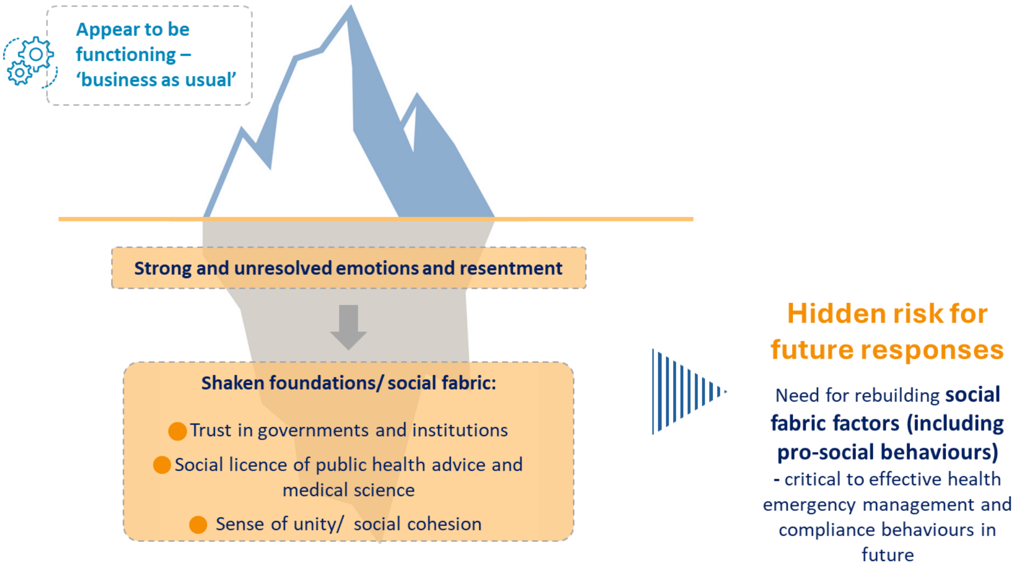
- Levels of **trust** in governments and institutions;
- **Social licence** of public health advice and medical science; and
- Sense of **unity/ social cohesion**.

The research found that there was a need for repair and rebuilding of these essential social fabric factors to support successful health emergency management and compliance behaviours in the future.

"I'm still dealing with things now because I can't think of what my life was like before the pandemic. It is like my life started again, I had a terrible time, and my mental wellbeing took a huge hit" – First Nations participant, Cairns

"If a pandemic happened again, and they take a similar response, it would be frustrating and annoying... I would be less likely to listen… maybe not overtly rebel, but I'll just do my own thing" – Participant from a CALD background, Brisbane

Figure 4: Negative and ongoing wellbeing impacts



2.4. Differences in lived experiences by location

> *"I travelled to Melbourne from Tasmania… I was so shocked… those guys had it really bad compared to us… they had police choppers out after 9pm"* – Vaccine hesitant participant, Tasmania

Overall, the research found that **where people lived** impacted the **intensity of their experience** of the pandemic, with **differences noted between States/ Territories,** as well as by **remoteness**. Participants in Victoria, New South Wales and metropolitan areas, as well as in a few specific Local Government Areas (e.g. Western Sydney) typically reported more intense negative experiences than those in other locations (**Figure 5**).

The research found that locational differences in relation to lived experiences were largely driven by how participants' day-to-day lives were impacted by the local restrictions, as well as their access to services and information. Specifically:

> *"The lockdown itself created a lot of fear... we didn't get to visit relatives or see them. Because the lockdown was so long, it felt like it was the end of the world"* – CALD participant with lower English language proficiency, Ballarat

- **Local restrictions** in place to prevent the spread of COVID-19 – in particular the extent and duration of 'lockdowns' or other restrictions impacting individual autonomy (e.g. curfews and restrictions on distance allowed from home), which participants reported had highly negative impacts on their and their loved ones' wellbeing;
- **Case numbers** – as case numbers in locations tended to correlate with severity of restrictions (i.e. in terms of amount and length of time of these), it is not surprising that research participants from locations with higher case numbers tended to have more negative lived experiences of the pandemic than those in areas with fewer and shorter restrictions;
- **Access to essential services and workforce capacity constraints** – participants living in regional and remote locations particularly noted the difficulty in accessing health

care, mental health care, education support and other frontline services largely due to internal border restrictions as well as limitations to transport options (e.g. decreased internal flights) and increased costs (e.g. airfares); and

- **Tone of information delivery** – different Premiers were perceived to take a different tone and messaging in their approach and management of the pandemic in each State/ Territory. This approach influenced how information and updates about the pandemic were received, including how confident participants felt about how the pandemic was managed, as well as how fearful they became of COVID-19. The outcome of the diversity of approaches shaped the experiences of people in different States/ Territories.

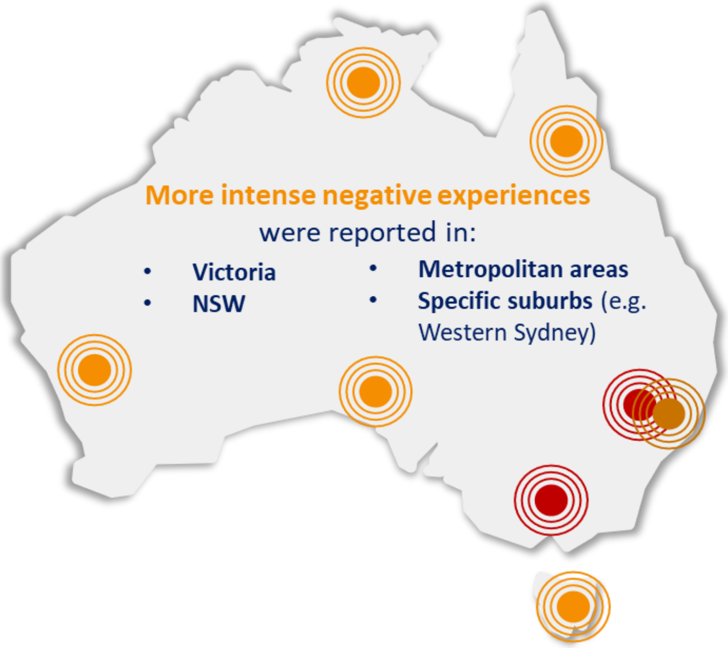
"The big boss from Adelaide [State Premier] was on TV 24/7 and just made all the issues seem really bad. I was too scared to turn on and watch because of what I was seeing" – First Nations participant, Port Lincoln

A consistent finding across all focus groups and interviews was a concern about the management of the pandemic being "left to the States/ Territories" rather than being managed by the Australian Government – resulting in perceptions of "unfairness", "inconsistency", "disparity" and a sense of "disunity" between States/ Territories and across Australia. Some participants living in areas with higher case numbers which experienced more severe restrictions also reported feeling "**stigmatised" and/or "villainised"**. This was particularly true for some participants from CALD backgrounds, who felt that localised lockdowns and restrictions **"targeted"** areas with larger CALD communities.

"After Christmas, certain suburbs were shut down, there was lots of discrimination and racism, lots of police patrolling the area and fear… people were treated like criminals" – Participant with a disability, Parramatta

Most participants reported that the negative impacts of this division continue to adversely impact their perceptions of Australia as an inclusive and united country.

Figure 5: Differences in lived experiences by location



2.5. Difference in lived experiences by cohort

Overall, there was a **large degree of consistency and overlap between cohorts in terms of their perceptions and experiences of the different pandemic response measures**. Many measures were experienced in a similar way among the different cohorts. As such, Chapters 4-11 of this report are structured based on the response measures (with specific differences in cohort experiences of these measures noted within these chapters where they are relevant).

The cohort differences tended to be due to variances in contextual factors and communications needs. Summaries of pandemic experiences by cohort are included in Appendix A.

3. Overall findings about pandemic response

Key takeouts

- Overall, there was perceived to be a **lack of national leadership** during the pandemic which was largely driven by observations of a **lack of a cohesive, fair and coordinated approach** to the pandemic across Australia. This lack of national leadership was perceived to have led to **divisiveness and reduced social cohesion**, as well as concern that a clear plan or pathway forward was lacking – which eroded confidence and increased participants' sense of uncertainty and fear.
- Broadly, the **types of measures** introduced by governments during the pandemic were felt to be **suitable**. However, many felt that the measures were not implemented in an effective way, as they did not fully consider individual circumstances/ needs and did not appropriately balance priorities that were felt to be important (e.g. physical, social, emotional and financial wellbeing). These gaps in the implementation of measures led to many participants having **negative experiences**.

3.1. Overview of experiences of the pandemic response

Overall, the research found that there was **limited understanding of the roles and responsibilities of different levels of government** in responding to the pandemic. Most participants did not clearly delineate between which measures were from the State/ Territory governments versus the Federal Government. There was limited understanding of what powers each level of government had as well as their respective roles in delivering the response measures. As such, when recalling the pandemic, there was not always a clear understanding among participants of which level of government was responsible for different aspects of the response or what was in the Federal Government's remit.

"COVID was a difficult time, but it was better here in Australia than back home in the Philippines" – Vaccine hesitant participant, Tasmania

While many participants **acknowledged that the COVID-19 pandemic was unexpected and difficult to navigate** for governments, some questioned why the governments were not better prepared (especially as they felt that the risk of a pandemic occurring was high given recent experiences with SARS and Ebola). While some participants felt that Australia did comparatively better than some other countries at preventing serious illness and high death rates from COVID-19, some others believed that the rates of serious illness and death were the same between countries that had locked down and those that did not.

"It didn't feel like the Federal Government did anything… it was like all the States were at war, 'we can do what we want, and you can do what you want'… it was divisive" –

Overall perceptions of the Federal Government's pandemic response tended to be largely negative, especially in terms of **pandemic management over time**. In particular, participants felt that there was a lack of a cohesive, united approach to the pandemic in Australia which contributed to limited confidence and greater uncertainty about the future, negative impacts for

Participant who uses mental health care, Melbourne

Australia's social cohesion and scepticism about whether approaches taken were in the best interest of people living in Australia. The research found that these perceptions appeared to have undermined trust and **social licence of governments** and institutions. This is likely to reduce **people's willingness to comply** with directions and advice in future health emergencies, like pandemics.

Desensitisation due to lengthy lockdowns

Frederico* lives in a local government area (LGA) in Sydney that was "in constant lockdown". He was "lucky" because he managed to work from home, but his partner lost his job. They managed to make ends meet, especially with his partner qualifying to receive the JobSeeker payment for which they were very grateful. They felt "psychologically trapped" as the restrictions were very stringent. He felt that people around his area eventually broke the rules because the restrictions kept going for so long (he thought it was for around a year) and became desensitised to threats of fines. He felt that people living in the LGA were unfairly portrayed as being "bad people", were constantly chastised for breaking the rules by politicians and the media and that there was little understanding shown to "vulnerable people who needed to work". While he supported the need for local targeted lockdowns to control disease spread, he felt that when it turned into a "never ending lockdown", the effectiveness of the measure weakened.

3.2. Perceptions of the Federal Government's response

"The Federal Government was not doing their job… we kept hearing excuses but that's their job, to have a plan in the draw to deal with an emergency" – Participant with long COVID, Melbourne

Based on their experiences, most participants felt that **national leadership was lacking** during the pandemic. The research found that there was support for tailoring the delivery of responses to specific locations based on local needs of communities and their unique circumstances. However, they expected the Federal Government to take a leadership role in establishing and communicating a **clear plan and pathway** for Australia through the pandemic and **supporting general consistency** in the underlying approach to pandemic management. This was due to the national significance and seriousness of a pandemic.

"Different rules between states… pits states against each other… it creates anger and fragmentation" – Participant who experienced quarantine, aged 40+ years, Parramatta

The research found that the perceived lack of Federal Government leadership was due to perceptions that there was a **lack of a cohesive, fair and coordinated approach to the pandemic across Australia**, leading to **"**division" and "fragmentation". This was based on State/ Territory Premiers and Chief Health/ Medical Officers being the primary communicators during the pandemic, pandemic management responses differing greatly between States/ Territories (including their introduction and application) and the perceived lack of shared learning across the different States/ Territories. While some participants were aware of the National Cabinet, they did not believe that the process was one of sharing information and learnings, but rather a process used by the different State/ Territory Premiers and/or the Federal Government to "compete" or "grand-stand" against each other for political reasons.

Common negative **perceptions about the Federal Government's response** centred around the following issues:

"The response needs to be more balanced between education, health and economy, which was not present. There was a panic approach to physical heath" – Parent/carer of a primary school aged child, Melbourne

- **Lack of a measured and balanced approach** – most participants felt that limiting the impact of COVID-19 infection in Australia was important to protect people's physical health, particularly those with existing health conditions and older people (especially in the early-mid stages of the pandemic when little was known about the seriousness of the illness). However, many felt that these measures were often adopted without sufficient consideration of other aspects of people's lives including mental, social, economic and developmental (i.e. educational for children and professional for adults) wellbeing. Participants reported that the negative impacts of the pandemic on these aspects of their lives continued to the present day and in some cases had exacerbated over time;

"It was a little bit hard to get information because it wasn't set out properly for screen-readers… so I just missed out on hearing what was happening" – Participant with a disability, Bendigo

- **Lack of person-centred approach** – many participants felt a "broad brush" approach was taken in the introduction and implementation of response measures which meant that they often did not give sufficient consideration to the needs and circumstances of individuals. This approach resulted in situations where many participants could not find the information relevant to them, which impacted some in a highly negative, unforeseen way. These participants felt "forgotten" and overlooked by the government's responses. Additionally, participants in rural and remote areas felt that measures introduced in metropolitan areas were not always appropriate for regional and remote settings;

"I was so scared, I was hearing about so many people dying [in the updates]… we could not do anything, everything was no, no, no, so I was too scared to even talk to people and to touch people" – Participant from a CALD background, Sydney

- **Underpinned by negative, fear-based and punitive approaches** – many participants felt that the messaging and tone during the pandemic heightened fear, worry or concern about the pandemic without providing a sense of optimism, empowerment or hope. This resulted in some participants disengaging from credible sources of information, contributed to perceptions of divisiveness across the country and reduced trust in governments;

"It was very frustrating and annoying, there was so many inconsistencies… the news was like 'the police are checking everyone at the borders', but they weren't checking… it made it feel like they weren't communicating" – Participant from a CALD background, Brisbane

- **Lack of a clear, central source of information** – most participants reported that they felt "overwhelmed" and "confused" by information during the pandemic as there was "a lot information" across multiple channels including from different levels of governments. This resulted in uncertainty about the credibility and believability of some of the information, especially when much of the information was perceived to be inconsistent, contradictory and lacking in objectivity;
- **Lack of transparency and accountability** – many participants reported that politicisation in messaging and wide variation in

the response measures across the country undermined trust and confidence in pandemic management;

- **Limited self-determination and agency** – many CALD and First Nations participants felt there was a lack of representative leadership in pandemic decision-making and the design and implementation of key measures. This resulted in insufficient consideration of important community needs regarding information, health, and wellbeing; and
- **Limited, evidence-based learning and integration from overseas experiences** – some participants felt there was a lack of communication about the rationale for the measures taken in Australia and whether these reflected international best practice, particularly given that other countries had been exposed to COVID-19 before Australia and hence, there was opportunity to learn from their experiences.

"It should have been handled more like the Europeans. Slow down and learn before doing things" – Participant experiencing homelessness, Darwin

Impacts of fear-based messaging and "scare tactics"

Kathryn* is a First Nations Elder who lives in a remote area. She works in childcare and has lived with social anxiety for much of her adult life. The abrupt shutdown triggered severe panic for Kathryn, leading her to stay at home and "drink heavily almost every day". During the focus group, Kathryn explained that she genuinely believed that COVID-19 would be the "end of the world". Daily news coverage of the devastation overseas overwhelmed her, especially the constant footage of hospitals "wheeling out the dead bodies" en masse. Terrified of COVID-19 reaching her hometown, Kathryn told the group that she would cry every time she watched government officials give an address. Kathryn eventually decided to turn off the TV and disengage from COVID-19 information altogether. The trauma of those early days still lingers over her. She now believes that the portrayal of deaths as being primarily due to COVID-19 was exaggerated to instil fear and that the "scare tactics" went too far. She reported that at the time, she would have appreciated more outreach from local Aboriginal health organisations to explain the situation to her in a more balanced way and provide more measured information about how she could keep herself safe.

3.3. Perceptions of pandemic responses over time

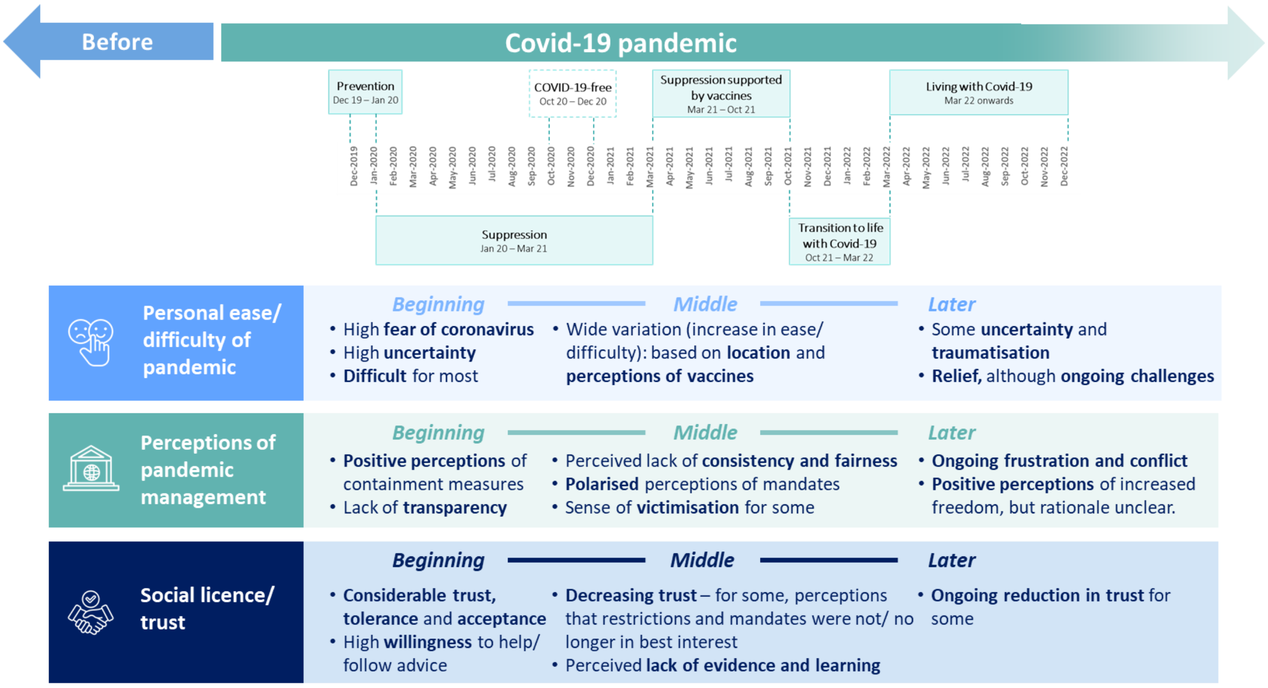
The research found that **perceptions of the government response to the pandemic changed over time**. Personal experiences were reported to have become more negative over the course of the pandemic because living with the restrictions became harder and more challenging. As the challenges with the lived experience increased, so did negative perceptions of governments' management of the pandemic. In turn, these perceptions appeared to slowly erode trust and confidence in governments' management, especially among those who felt the pandemic was poorly managed.

"We don't have any information about COVID in our community now, or about why the borders opened… there's nothing about it but people are still getting COVID?" – Participant with long COVID, Melbourne

As shown in Figure 6

Figure 6, there was initial openness to the responses being implemented by government, with people willing to comply with measures. However, the research found that **over time there was increased polarisation of perceptions of the pandemic management**, with many becoming increasingly frustrated, distressed and angry. When reflecting on the pandemic, many participants were unclear about how and why Australia shifted "back to normal" after being under restrictions and mandates, given that COVID-19 was still in the community. This led some to question the legitimacy of the original measures and others to feel fearful about whether their health was being compromised.

Figure 6: Change in perceptions of government response over time



	Beginning	*Middle*	*Later*
Personal ease/ difficulty of pandemic	• High **fear of coronavirus** • High **uncertainty** • **Difficult** for most	• Wide variation (increase in ease/ difficulty): based on **location** and **perceptions of vaccines**	• Some **uncertainty** and **traumatisation** • **Relief,** although **ongoing challenges**
Perceptions of pandemic management	• **Positive perceptions** of containment measures • Lack of **transparency**	• Perceived lack of **consistency and fairness** • **Polarised** perceptions of mandates • Sense of **victimisation** for some	• **Ongoing frustration and conflict** • **Positive perceptions** of increased freedom, but rationale unclear.
Social licence/ trust	• **Considerable trust, tolerance** and **acceptance** • High **willingness** to help/ follow advice	• **Decreasing trust** – for some, perceptions that restrictions and mandates were not/ no longer in best interest • Perceived **lack of evidence and learning**	• **Ongoing reduction in trust** for some

3.4. Overall experiences of the pandemic measures

"The restrictions and LGA lockdowns went on for a long time, so eventually people just did what they wanted" – Participant who experienced quarantine, aged 40+ years, Paramatta

Overall, the research found that governments' pandemic response (Federal and State/ Territory) was perceived to have adopted a **predominantly "punitive" and "forceful" (i.e. 'stick-based')** rather than incentivising and encouraging (i.e. 'carrot-based') approach. The 'stick' approach was felt to be appropriate in the initial stages of the pandemic when the perceived risks of COVID-19 were high and there was acceptance of the need to act quickly. However, over time this approach led to increased **resistance to accepting and complying with advice** due to increasing frustration and personal challenges at being under restrictions, as well as a perceived lack of fairness and justification of need. In addition, many participants felt this approach was inappropriately **based on**

the assumption that people would ‘do the wrong thing’ which led to anger, shame or resentment towards each other and the governments. Such an approach was believed to have resulted in reduced community trust and “goodwill”, weakened personal relationships and eroded social cohesion.

In general, while many of the **types of measures implemented by governments during the pandemic were felt to be appropriate,** participants felt there was a need to better balance the ‘stick’-based approach to implementing these measures with ‘carrot’-based approaches where possible. In addition, many felt that the measures did not fully consider individual circumstances, nor did they appropriately balance other important priorities beyond the health-focus.

Participants’ perceptions of the effectiveness of government pandemic measures were based on their lived-experiences, and were informed by:
- **Awareness, understanding** and **access** – i.e. knowledge of the availability and purpose of the measure, as well as how easy/ difficult it was to use or apply the measure;
- **Perceived impact** – i.e. whether measures were perceived as being successful; and
- **Extent to which measure met needs and perceived gaps** – i.e. whether the measure met individual needs (including for specific cohorts) or were there gaps.

Overall, the research found that those who had greater **responsibilities** for others tended to have more negative experiences and perceptions of the pandemic response measures than other people. Similarly, those who were **dependant or reliant** on other people and/or had **significant vulnerabilities** tended to have more negative experiences.

Chapters 4-11 of this report discuss participants’ experiences with specific measures in more detail.

4. Findings about pandemic information and communications

Key takeouts

- There were **high levels of information seeking** during the pandemic. However, many participants reported that government communications about COVID-19 were **slow**, **contradictory**, **overwhelming and lacking in balance**, leading to confusion and distrust. Dissatisfaction with government information was reported to increase reliance on word-of-mouth and social media as alternative sources.
- The research found that information delivery was not suitable for some participants from First Nations communities, CALD backgrounds and those with disabilities. This included **limited access to information through trusted and known sources**, contributing to information gaps, confusion and vulnerability to mis/ dis/ mal-information.
- In general, participants perceived government communications about the pandemic to be **overly fear-based and complex**, contributing to widespread distrust, anxiety and scepticism.

4.1. Overview of findings

"What I was hearing was not what I was seeing. Everyone had COVID but no one was dying but Australian government was saying everyone was dying… there were a lot of conspiracy theories and I think there was a lot of information that was not shared by the Australian Government" – Participant who experienced quarantine, aged under 39 years, Australia-wide

Overall, the research found a **high level of reported information-seeking during the pandemic** due to a high degree of uncertainty about the virus and the rapidly changing circumstances. However, participants reported that communications were **often contradictory**, even when comparing "official information" from State/ Territory leaders, public health experts and the Federal Government and its agencies (e.g. Department of Health and Services Australia). Many also felt that the information lacked balance in terms of portraying the full information. These perceptions, along with extensive fear-based messaging and changing guidelines, led many participants to feel **overwhelmed, confused and distrustful** of COVID-related information and government communications as the pandemic progressed.

"There needs to be one central source of information, so it's black and white and easy to understand" – Parent/ carer of a primary school aged child, Melbourne

In general, the research indicated that there was a need for a clear, central source of live information that **provided straightforward guidance on what to do and why**. Additionally, there was a perceived need to improve delivery of information for more **isolated or hard-to-reach cohorts**.

4.2. Access

Overall, the research found that there was a **high level of engagement with information** related to COVID-19 and the response measures, particularly in the early stages of the pandemic. Participants were commonly looking for information about the nature of the COVID-19 illness, what specific advice and restrictions were implemented, how to protect themselves and what was likely to happen next.

Most participants reported **engaging with information from multiple sources**. However, government and news media were the most commonly reported sources.

"I was getting my information from the Premier… his conferences were as popular as a rock concert" – Participant who experienced quarantine, aged under 39 years, Australia-wide

Participants reported engaging with information from the following:

- **Government** – e.g. daily updates from State/ Territory Premiers and Chief Health Officers in press conferences, as well as State/ Territory and Federal government websites and apps (e.g. Department of Health). Overall, participants reported receiving more information from their State/ Territory Governments than the Federal Government;
- **News media** – e.g. news stories, current affairs programs, interviews and editorials via radio, TV channels and social media;
- **Workplaces and schools** – e.g. directives from employers and updates from school leaders (particularly for parents/ carers and those in rural and remote areas). However, a few participants who worked in schools reported a need for more support for schools during the pandemic to help them stay up-to-date and keep families informed;
- **Scientific/ health community** – e.g. updates from epidemiologists, virologists, the World Health Organisation (WHO), university publications and information from GPs and other health specialists;
- **Social media** – e.g. online forums, influencers and podcasters; and
- **Word-of-mouth** – e.g. through family and friends (both local and overseas) and support workers (for people with disability).

"The news was on all day every day with the numbers and the deaths… it was too much for me, so I just shut off from everything. I stopped believing it… it didn't make sense. I was asking people if they knew anyone who had died, and they didn't know. Where are all these people dying? Nobody knew anyone who had died" – Participant who used mental health care, Melbourne

Some participants reported that over time they became **frustrated with more official and mainstream sources of information** (e.g. government sources and news media). They reported that they did not feel like the information they were receiving from these sources was transparent, balanced or aligned to their personal experiences, and that the **tone of the information was highly negative.** Furthermore, some also felt that the content was biased towards achieving compliance with government public health directives, thereby supporting "the government's agenda". These participants reported that they began to disengage with these sources and **relied more strongly on direct word-of-mouth information or searched more broadly online** (including international sources) for information that aligned more with their personal experiences and/or their perceptions and feelings.

Mistrust of pandemic information

During the early stages of the COVID-19 pandemic in Victoria, John* spent considerable time watching TV to stay up-to-date with the latest government announcements about the virus. However, as time went on, John grew increasingly distrustful with what he perceived as sensationalised media reports that did not align with his personal experience. From what he witnessed, he did not feel that the virus was as serious as was being reported. As such, he grew increasingly frustrated with the mandates, particulalry lockdowns and curfews. He lost his job early in the pandemic and was "pushed deep into isolation".

Trying to make sense of his situation, he turned to alternative "streamers" on platforms such as Facebook, Instagram and Telegram for information about the pandemic. He increasingly distanced himself from his family and friends who he felt blindly supported government mandates. The pandemic exacerbated John's poor mental health, leading him to resort to harmful coping, such as heavy drinking. Now, he describes feeling "tired and confused", uncertain about what to believe as COVID-19 discussions by governments and authorities have "faded away completely" (even though the virus is still prevalent in the community) and it is unclear to him why people had to "suffer" through the restrictions.

4.3. Perceived effectiveness

Overall, participants felt that **information and communications were not consistently effective** at keeping people informed, confident or reassured over the course of the pandemic. Most participants felt that communications were generally effective at providing information about the local measures in place, particularly through regular announcements from State/ Territory Premiers. However, they reported that information was less effective in relation to providing the rationale for different measures, how measures applied in specific circumstances and the overall plan for managing the pandemic in Australia. This led to reduced trust in how the pandemic was being managed and scepticism toward official information for some.

Participants reported that the following aspects of the pandemic information and communications **reduced their effectiveness**:

- **Lack of unified messaging across Australia** – many participants reported that there was a high volume of information from many sources about the pandemic which differed between States/ Territories, as well as between scientific experts asked to provide opinions. In addition, they reported that they needed to use multiple sources to find relevant information as it was not all available in one place. This led to some participants perceiving information as "contradictory" and "politicised", which eroded the credibility of the messaging and created confusion;

"There were mixed messages from a lot of different sources… it could change daily, and there was a lot of misinformation coming out at the time too… it was too much" – Parent/ carer of a primary school aged child, very remote Queensland

- **Lack of clear rationale and forward plan** – many participants felt that information about the pandemic response measures lacked clear explanations of the rationale for why they were being implemented and what information and evidence had contributed to decision-making, which undermined confidence in decisions;
- **Primarily deficit and "fear based" messaging** – while this was initially effective at "scaring" people into complying with public health advice, over time many reported that this type of messaging: was overwhelming; resulted in them losing hope and feeling disempowered; exacerbated poor mental health; and caused them to disengage from official information, in some instances turning to less reliable sources;

"Dan Andrews was very condescending, he talked down to us a lot… it makes you zone out and turn the TV off" – Single participant living alone, Melbourne

- **"Disempowering", "patronising" or punitive tone** – many felt that government messaging often assumed the worst rather than appealing to people's goodwill. Many reported that this was "off-putting", "condescending" and over time reduced receptiveness to the information;
- **Overly complex information** – some participants felt that complex information was not effectively conveyed in a manner that supported shared understanding and clarity, particularly for information about health principles underpinning decision-making and vaccine information;

"The government kept saying the vaccine was great but there were lots of stories of people dying… I really struggled with that" – Parent/ carer of a primary school aged child, Tasmania

- **Lack of acknowledgment of differing experiences of people on the ground** – some participants reported becoming sceptical of official sources of information which were perceived to "manipulate" information to ensure compliance with measures (e.g. felt to exaggerate the seriousness of COVID-19 or downplay potential side-effects of the vaccines). This was particularly for people who had been exposed directly either personally or through family/ friends to mild cases of COVID-19 or perceived negative vaccine side-effects; and

"[When we called to get advice] we got idiots at the end of the phone, they were misinformed about the rules. They tried to give you an answer but it's wrong… 'this is what we know, and we can't take into account everything'" – Vaccine hesitant participant, Cairns

- **Lack of detailed information for people's specific circumstances** – for example, some participants reported that they had sought information to identify if a particular restriction or measure would affect them or not (e.g. international students, regional/ remote Australians and people with a disability). They reported that they could not find this information and when they had tried to call to speak to someone, the person providing telephone support was also unsure of the answers. This resulted in participants' questions being unanswered and loss of confidence about whether the pandemic was being managed properly.

"There was no consistency between states… it tells me the government is unorganised… they all lost a little bit of credibility" – Participant from a CALD background, Brisbane

Overall, the research found that this led to **negative outcomes**, including: heightened levels of anxiety and uncertainly; loss of confidence that the government was managing the pandemic effectively; and increased scepticism and concerns regarding the transparency and accountability of official information sources. Such negative experiences with information and communications also contributed to eroding the level of trust and confidence in governments and their delivery/ service agencies more broadly.

Turning off from messaging

Eliza* worked in a dental clinic at the beginning of the pandemic, in a regional area. She felt terrified by all the messaging about the risks of COVID-19 – “it made us feel like if we touched a mouth we would die”. At the time, all non-essential dental operations had been cancelled, but one day she was called back in for a patient who required emergency open mouth surgery. Eliza felt so anxious and scared about being exposed that she cried after the operation was done.

After a while Eliza became fed up with hearing the case numbers each day and feeling terrified of COVID-19. She stopped watching the regular updates and began to ignore the public health messaging. Even when she felt confused and uninformed, she still chose to ban all COVID-19 news channels in her house.

After a while, Eliza began to feel suspicious about the information she had received at the beignning of the pandemic. She felt her experiences and the experiences of those around her didn’t match up with what she had been told at the beginning. She didn’t have any direct experiences of people in her life becoming severely unwell or dying from COVID-19. “It was the government pushing things. They take six cases and make it sound like 6,000, making out we’re all going to die… it was just scare tactics”. On reflection, she felt that the level of fear evoked about COVID-19 and the extent of the restrictions and mandates were unecassary. She admitted that if the situtation were to happen again, she would be less likely to follow rules and mandates as she would be sceptical of the need for them.

4.4. Extent to which information and communications met needs and perceived gaps

Overall, participants felt that there was **lack of a clear and consistent messaging** during the pandemic. They reported that this led to confusion and difficulty in keeping up with rapidly changing guidelines. Participants felt that a single, reliable source of information would have improved clarity and trust in the governments’ communications.

In addition, participants felt that there were **key information gaps** that were not addressed in government communications, which led to further negative emotions, negative perceptions of pandemic management and more confusion. Specifically, information about:

- **Rationale/ reasons** for measures and responses (i.e. the ‘why’?) and how the measures inter-related;
- **Clear and holistic forward plan/ goals**;
- Feedback on **impacts of measures** and their effectiveness (positive and negative), as well as information about what other countries were doing successfully; and
- **Available supports** and how to access these supports.

“In the future we need more transparency which means more trust… they need to communicate more, for example why we are doing this or stopping this” – Parent/ carer of a primary school aged child Melbourne

Overall, the research found that available information lacked appropriateness for some cohorts in particular, including:

> *"Use more visuals, than words... it was all too wordy and First Nations people don't like that… how do you expect us to understand that?"* – First Nations participant, Cairns

- **First Nations peoples** – who felt that there was a lack of information being delivered through trusted sources (e.g. Aboriginal-controlled community organisations) and that information was often presented in formats that were difficult to engage with (e.g. used language that was "too complex"). In addition, fear-based messaging about the seriousness of COVID-19 had particularly negative impacts for First Nations participants as they were also receiving messages about being more vulnerable to the illness which led to very high levels of fear, anxiety and panic;

> *"Sometimes I would watch the news in English, then I would have to get dictionary out to understand words I didn't know… I was frustrated because I couldn't fully understand what they were saying and I'm sure I misunderstood lots of information"* – CALD participant with lower English language proficiency, Sydney

- **People from CALD backgrounds** – many participants from CALD backgrounds (particularly those with limited English language proficiency) reported that COVID-19 lockdowns and restrictions interrupted their access to community networks, which were a primary source of information for them. This led to high levels of confusion and fear due to difficulty accessing relevant information about COVID-19 and relevant measures, including vaccination information. This was heightened for those who had limited literacy and therefore relied on verbally shared information. Participants reported a range of misunderstandings about COVID-19 and the measures during the pandemic due to not receiving the relevant information (e.g. what to do if they were unwell and what local restrictions were in place). In addition, strong fear messaging about COVID-19 and a lack of clear rationale about why borders were closed to certain countries was felt to exacerbate stigmatisation towards some CALD communities; and

> *"A lot of websites were inaccessible with screen readers, so that made it difficult, and I couldn't read which made it hard to get information"* – Participant with a disability, Bendigo

- **People with disability** – many participates reported limited availability of information in accessible formats, such as auditory (e.g. radio or podcasts), screen reader accessible or visual/ easy English formats. There was also felt to be a lack of information from expected channels, such as peak bodies, service providers and the NDIS. In addition, some reported feeling overly reliant on others (e.g. support workers/ carers) to access and understand key information, which impacted their ability to make informed decisions, including about vaccinations and the availability of supports, such as mental health services.

> *"I had WeChat where Chinese people translated government information, but it's not official, so we were influenced by a lot of biased information. It would have been better to have government translated information"* – CALD participant with lower English language proficiency, Sydney

This meant that information was often being generated and disseminated via non-government channels for these cohorts, including community organisations, service providers and support workers. Many participants in these cohorts therefore relied more on **word-of-mouth** for information about changing guidelines and were **more vulnerable to mis/ mal/ dis-information** and less likely to have access to accurate information to inform their decisions. This included a heavy reliance on information from family and friends, particularly for CALD community members with limited

English language proficiency (e.g. first-generation refugees who relied on information solely from their children or case workers).

Navigating the pandemic with limited information

Nya* is a mother of five from South Sudan, who has lived in the west of Melbourne for the past 10 years. She usually relies on word-of-mouth from her community for information, including from family and friends. During the pandemic, the closure of community gatherings, including her church, isolated Nya and limited her access to information. Nya also reported not being provided with information in her native language, Dinka. This left her feeling confused, frightened and isolated, especially in the early stages of the pandemic. It was only when her children's school closed that Nya first learnt about COVID-19 and began to grasp the severity of the pandemic. Prior to this, she was unaware of the virus and had inadvertantly failed to follow public health advice.

Nya often relied on sporadic information from friends, her husband and her children who relayed information they had received at work/ school, leading to misunderstandings and an increased risk of infection. Even now, Nya remains uncertain about the current status of COVID-19 and the remaining rules and restrictions. She felt let down by the lack of timely and accurate information provided to her to help her protect herself, her family and her community.

4.5. Key learnings

Key learnings for improving government communications identified by participants included:

- **Establishing a central source of live information** that provides straightforward and consistent guidance on guidelines;
- **Adopting a more hopeful, supportive and empowering tone that enhances individual wellbeing and self-efficacy** and avoids predominantly fear-based messaging – especially for audiences already accustomed to deficit-based government messaging (e.g. First Nations and CALD audiences);
- **Addressing key information gaps** to ensure people understand what is happening and know how to access supports, including information that is tailored to the individual circumstances of specific audiences; and
- **Improving accessibility and appropriateness of information for diverse communities** by providing more in-language and simple resources, and more widely leveraging known and trusted channels such as community leaders, pre-established community partnerships and support workers.

“We needed more officially translated information… we had no reliable information, it felt like the world was ending. All the information was too overwhelming and confusing…”
– Participant from a CALD background, Melbourne

5. Findings about border management/ closure measures

Key takeouts

- Overall, **international border** management was perceived as being an appropriate measure to prevent COVID-19 from entering Australia. However, the process for returning Australian citizens was felt to be ineffective.
- While **State/ Territory and internal metropolitan/ regional border closures** were felt to be appropriate in certain circumstances, they had significant and ongoing negative impacts on social and psychological wellbeing, with a more measured and nationally consistent approach being preferred.
- Across all types of border management/ closures, there was a **clear gap in allowing for reasonable exceptions based on compassionate grounds**. This gap had ongoing negative impacts on social and psychological wellbeing for some participants.

5.1. Overview of findings

> *"I agreed with the international border closures... Australia is lucky it's a single island, good to protect... I was very scared of COVID, and I think the government should have closed the border more quickly to protect [people]"* – CALD participant with lower English language proficiency, Sydney

Overall, the research found that international border closures were **generally supported and felt to be appropriate** to limit the spread of COVID-19 in Australia. This was despite the negative experiences for some who were impacted by these closures.

In contrast, many participants **felt more negatively about State/ Territory border closures**. While the strategic use of State/ Territory borders was felt to be a suitable measure to reduce the spread of COVID-19, some felt there were instances where these were unjustified, inconsistent, inequitable and/or poorly communicated or managed. Similarly, some participants also **felt negatively about closures of specific postcode areas in metropolitan locations or restrictions between metropolitan and regional areas within a State/ Territory**, which were seen as "disruptive" and/or "confusing", especially for people who regularly worked or travelled across those zones.

The research suggested that, while **the purpose and rationale for border closures were well understood by participants**, most felt the implementation of these closures could be improved to increase the appropriateness of measures and reduce the negative impacts faced by some. This applied to each type of border closure (i.e. international, State/ Territory and local).

5.2. Awareness, understanding and access

The research found that there was **generally good awareness of border closures** as these were regularly communicated in the

"I don't see why there should be internal as well as international border closures. What did they do? What were they designed for?" – Participant who uses mental health care, WA

media and most "paid attention" to the information as it had direct implications for themselves and/or their family and friends. The **overall purpose of these measures was well understood** as being to limit the number of COVID-19 cases entering Australia (international closures) and reducing the spread of COVID-19 within Australia (State/ Territory and local area closures).

In contrast, there was **more limited understanding of the government's decision-making process regarding when, how and to whom the borders were closed**. This contributed to the perception that closures were **inconsistent, confusing and unfair** for some participants. These perceptions negatively impacted trust and confidence in government decision-making and contributed to feelings among some participants of "frustration", "helplessness" and a lack of "fairness".

5.3. Perceived effectiveness

"They did it too slowly [international closures] … considering they knew everything happening overseas, they shouldn't have let people in" – Partnered participant with no children, Australia-wide

"In Perth we were lucky, we didn't get locked down that much, our world was peaceful… but it was intense and very different in Melbourne. I had a girlfriend from Melbourne who rang every day, and I dreaded it, because I could hear how she was getting worse and worse each day" – Participant who uses mental health care, WA

"We were told we needed to produce a negative test to travel interstate, they made a big deal of it and said the police were checking at the borders, but they weren't… it was very frustrating, I had to wait in line for three hours to get tested, but others didn't have to… it was so inconsistent" – Participant from a CALD background, Brisbane

Overall, participants perceived that the **international border measures** were effective at reducing the number of COVID-19 cases entering Australia. However, some felt that these border measures would have been more effective if they had been implemented sooner, to minimise the risk of COVID-19 entering by better leveraging Australia's advantage as a sperate continent.

Perceptions of the effectiveness of **State/ Territory border closures** were more mixed and varied by State/ Territory. Many participants from Western Australia, South Australia and the Northern Territory felt that closures of their State/ Territory borders had reduced the impact of COVID-19 in their area, which in turn reduced the impact of illness and the requirements for severe restriction of movement within their States/ Territory. In contrast, many participants in Victoria, New South Wales, and Queensland felt that the closures in their States lasted too long. They questioned the effectiveness of these measures, as COVID-19 cases continued to rise despite the restrictions.

Regardless of location, there was agreement among most that internal border closures were **not applied consistently or communicated clearly across Australia**, and this created confusion and substantial disruption (see Section 5.4 below). Furthermore, a few participants indicated that there existed "loopholes" that enabled the bypassing of borders unchecked, thereby reducing the effectiveness of the border restrictions. There was widespread agreement across research participants that this lack of consistency and coordination adversely impacted Australia by causing unnecessary division between States/ Territories and heightening feelings of inequity between citizens. There was widespread support for a more standardised national approach to border closures to improve their effectiveness if required and implemented in the future.

5.4. Extent to which measure met needs and perceived gaps

While participants felt that closing borders was justified in the early to mid-stages of the pandemic, many felt that **the implementation** of these closures was not always appropriate or fair. In particular, some participants reported “missing out on” significant events (e.g. birth of a child, farewelling the sick or a funeral) and/or major disruptions to their personal lives as a result of the border closures. These participants reported that this experience had highly negative impacts on their mental and social wellbeing, with ongoing consequences.

Specific **perceptions** of border control measures reduced the perceived appropriateness of these measures, including:

“My mother-in-law passed away [interstate] and I couldn’t go to the funeral, I had to attend online. It was such a terrible way to say goodbye” – Participant experiencing homelessness, Sydney

- **Limited access to reasonable exemptions** – many participants felt that there was a need for greater flexibility to cross State/ Territory borders on compassionate grounds, such as attending funerals or visiting severely unwell family members. They felt that this was appropriate with reasonable precautions in place (e.g. home isolation and/or testing). A few participants who had attempted to seek exemptions found the process difficult to navigate and unsympathetic to individual circumstances;

“The sudden lockdowns weren’t a good thing, there was not enough time to prepare” – Participant with long COVID, Melbourne

- **Overly abrupt closures with limited notice** – the “suddenness” of some closures (for both international and interstate borders) was found to contribute to feelings of stress and anxiety, with participants reporting they were concerned about being “stranded” and/or separated from family and friends. This was particularly true for some international students, who felt increasingly isolated from their family and friends overseas with limited clarity on when these closures would be lifted. A preference was reported for earlier communication and more gradual escalation where possible;

“It took me six months to figure our flights from India with my newborn son, while my husband was here in Australia… and it was so expensive” – Participant who experienced quarantine, aged 40+ years, Parramatta

- **Ineffective processes for returning citizens** – a few participants who were caught overseas at the time of international border closures, or knew those who were, reported that their return home had been delayed, confusing, and/or costly. Many felt that repatriating citizens should be a key priority for the Australian Government when implementing border closures;
- **Lack of consideration for the implementation of internal and cross-border closures for workers** – some reported the border closures between metropolitan and regional areas as well as State/ Territory borders for cross-border communities were

particularly disruptive, especially for workers required to travel locally. They reported long wait times to cross borders and challenges with exemption processes. This further compounded the stress and frustration caused by broader border management policies;

- **Lack of consideration for accessing services for regional and remote communities** – some regional and remote community participants indicated that the border closures between metropolitan and regional/ remote areas had limited their access to essential services in capital cities, including health care. These participants felt that there was not sufficient consideration given to accommodate their needs (see Chapter 10 for more detail); and
- **Limited transparency around selective border closures for specific countries** – a few participants felt that international borders were closed to certain countries (e.g. India and China) but not others (e.g. USA and UK), even when case numbers were similar. This perceived inconsistency resulted in feelings of unfairness and exclusion, especially among international students and participants from CALD backgrounds. The unclear rationale behind these selective closures was found to contribute to confusion and mistrust towards authorities among these participants, affecting their sense of feeling welcomed and included in Australia.

> *"Border closures are not a bad measure… the only thing I objected to is opening borders to certain countries and closing to others… I don't know why there was a differentiation… some parts of the world could come, and others couldn't"* – Participant from a CALD background, Sydney

Getting home during a pandemic

Sandra* was on a cruise to Brazil when the global lockdowns began. None of the ports or surrounding countries would take them in and they were floating from place to place. Eventually they were sent to a port in Portugal and told to get off the boat. They were put on buses and sent to a tarmac. They were shuttled onto a plane but were not told where they were going. The plane landed in London. They were not expected in London when they arrived, and there were no follow-up plans for the people on the plane. She managed to find an inn and stayed overnight (illegally, to her knowledge).

The next day she went back to the airport and found someone from Qantas. She was told the last flight to Australia was about to leave. With no other choice, Sandra quickly handed over her credit card and just paid whatever the amount was to get home. She felt she was extremely lucky that she was there in time to get the last flight home and that she had enough money available to buy the ticket, but she realised just how vulnerable she was in that moment and how close she had come to being stuck overseas during a pandemic. She heard of others who had not made it back and had struggled to return.

During the focus group, Sandra grew increasingly upset while recalling the "trauma" she went through and told stories of other Australians she had heard about who were unable to afford a ticket home in time and were left separated from their loved ones overseas at the beginning of the pandemic.

Stranded overseas with no prospects for returning home

Sania* was visiting her family in India to introduce them to her infant son when the international borders were closed, two days before her booked departure date. She received a text notification stating that her flight was cancelled and after hours on the telephone trying to contact the airline, was told that "no one knew when flights would resume to Australia". She kept contacting the Australian Embassy, Qantas and other airlines on a daily basis to try to get a ticket to return home to her husband. After six months, she was told that she couldn't fly to Sydney as there were no quarantine beds available and her only option was to fly to Darwin. So she secured flights to Darwin, where she and her son went into quarantine for two weeks then finally returned to Sydney.

She described the whole experience as being "frustrating", "fearful" and "stressful". While she was supportive of the need for quarantine, she was angry that Australian citizens were not allowed to return home and was disappointed by the lack of compassion. She felt that she and her husband missed out on significant time bonding with their baby as a new family due to the length of time it took to return home. Furthermore, she felt that had she not been on maternity leave, she may have lost her job.

Impacts of interstate border closures

During the pandemic, Jessica* was living in Victoria while her mother was living in NSW. As a result, they were separated during the height of the pandemic. When her mother fell seriously ill, Jessica attempted to secure an exemption to travel and be by her side, but she found the process challenging to navigate. This left Jessica feeling confused and distressed. Despite her efforts, she was unsuccessful in obtaining an exemption, leaving her uncertain if she would ever see her mother again. This ordeal had a significant impact on both Jessica and her mother's mental health, which deteriorated dramatically at the height of the pandemic. Jessica ultimately spent two years without seeing her mother and felt that she had missed out on caring for her mother when she was needed the most. During the focus group, Jessica shared how she felt she had "failed" to be there for her mother when she was in pain and explained that her "guilt" still followed her.

Creating a new life in Australia in the midst of the pandemic

Parisa* came to Australia with her husband and daughter on a skilled worker visa in February of 2020, with the plan to go back home to Iran after four months. When international borders closed, she was unable to return and stayed here continuing to work. She was worried about her family back home as well as her sickly pet which she had to leave behind. Back in Iran, her father was hospitalised twice, and anytime she missed a call from her family, she was worried it was because something terrible had happened. She felt helpless to do anything. Parisa and her husband did everything they could to adjust to their life in Australia, but with extended lockdowns they felt stranded and alone in a new country. She lost her job four times during the pandemic and her husband could only manage to get short-term contract jobs. Her daughter had to attend kindergarten online in a country where she barely knew the language which only increased her anxiety and worries. Parisa experienced anxiety attacks for the first time during that period, where she would have “difficulty breathing” and could “hear her heart beating really loudly”. She still experiences these attacks now and fears she'll have to live with this forever.

5.5. Key learnings

Key earnings identified in the research in relation to border closure measures included:

- Ensuring **early and strict international border controls**, whilst allowing for the repatriation of citizens in a timely and affordable manner;
- Taking a **nationally consistent approach** to interstate and more localised border closures/ movement restrictions – a targeted and localised approach was preferred (e.g. only closing when required and with clear and consistent thresholds and rationale);
- Striving to balance more **localised border closures with maintaining access to the protective influence of family and community networks** in supporting wellbeing, particularly among First Nations and CALD communities;
- Allowing **reasonable exemptions** on compassionate grounds, (e.g. caring for unwell relatives and Sorry Business), for those living across border towns, and for those needing to travel for work (e.g. essential workers); and
- Ensuring **timely communications** to, wherever possible, reduce the suddenness of closures and allow for planning.

“I was very scared of COVID, and I think the government should have closed the border more quickly to protect [people]” – CALD Participant with lower English language proficiency, Sydney

"You should do border closures, but maybe... give people time to come back [to Australia], the closures need to be more considerate” – Participant who experienced quarantine, aged 40+ years, Parramatta

6. Findings about the quarantine program

Key takeouts

- Overall, most participants perceived quarantine measures as **valuable and appropriate,** balancing the need for certain travel requirements with limiting the spread of COVID-19. There was a clear preference for home-based over hotel quarantine.
- There were concerns about the **lack of flexibility in hotel quarantine arrangements**, particularly in meeting the individual needs and circumstances of some participants.
- **Negative experiences with hotel quarantine providers**, **unsuitable quarantine facilities**, **unclear communication about quarantine requirements** and **high costs** associated with quarantining were issues highlighted by participants.

6.1. Overview of findings

Overall, the research found that participants **generally supported having a quarantine program** as it was **felt to be an appropriate measure that controlled the spread of COVID-19** in Australia, while allowing people mobility between locations when required. There was a clear preference for home-based quarantine over hotel quarantine.

"Mental health was low, I was feeling distressed, isolated and alone [during hotel quarantine], at one point you lose track of time… I looked at the balcony and thought should I jump?" – Participant who experienced quarantine, aged under 39 years, Australia-wide

However, while the purpose of quarantine was well understood by most, experiences of hotel quarantine were variable and often negative. This was due to a perceived **lack of accommodation** and **suitable facilities available** to meet individual needs and circumstances, as well as the financial burden incurred. For those who had experienced hotel quarantine, negative impacts included **social disconnection**, **reduced mental health** and **financial stress**.

In general, the research suggested that the **implementation of hotel quarantine could be improved** to increase the appropriateness of this measure and reduce negative impacts.

6.2. Awareness, understanding and access

"I understand quarantine was so people don't go out in public and infect others, it protected the community but there was no transparency about how long was going to be, I was more scared of quarantining then getting COVID" – Participant who experienced

Most participants had **good general awareness of the purpose of quarantine measures**. They understood that the intention of these measures was to prevent people from spreading COVID-19 when travelling between locations.

From the research, home-based quarantine was felt to be a far simpler and easier process than hotel-based quarantine.

quarantine, aged under 39 years, Australia-wide

In terms of hotel quarantine, participants reported limited awareness and understanding of:

- **The duration** of the quarantine period – with a few participants indicating that their time was extended beyond two weeks even though they did not have COVID-19;
- Where to find **up-to-date, consistent and clear information** – including about the **range of travel routes** that would result in the hotel quarantine requirements;
- Procedures for **sourcing and securing** hotel quarantine accommodation, as well as for **making complaints** about negative experiences/ hotel quarantine providers;
- The availability and ability to request and confirm **different room arrangement, food and appliance options** to meet individual needs and circumstances when in quarantine – e.g. multiple rooms to accommodate larger families, toaster or microwave for food preparation, food requirements to meet particular cultural or dietary requirements, and rooms with opening windows or balconies for people who get anxious in small spaces and/or with neurological disabilities or conditions; and
- What **processes were in place for reducing COVID-19 spread within hotels** – which caused concern for some who felt they were at increased risk as they did not feel adequate measures were being adopted.

"My son was especially effected… they didn't have baby food and he would go hungry…I had to get food delivered" – Participant who experienced quarantined aged over 40 years, Parramatta

Some participants felt that the hotel quarantine program had **limited availability** and hence, resulted in some people not being able to access it in a timely manner, or at all. For some, this had a significant impact as it restricted their ability to return home sooner or visit sick family members.

The **lack of information and availability of hotel quarantine** led to feelings of confusion, anxiety and frustration, with some participants reporting difficulties making informed decisions about their travel arrangements and plans. These experiences were reported to impact the physical and mental wellbeing of these participants and their families, which added stress on their relationships with spouses/ partners and children.

Attempting to find information about quarantine

Sarah* fell pregnant with her second child during the pandemic. She and her husband felt that it was important for them to move back to Queensland to be close to family and friends as a vital support network to help them adjust to life with a second child.

Sarah was nervous about getting the vaccine while pregnant, but was told that if she didn't, she and her husband would need to quarantine for two weeks. She began seeking information about quarantine programs and whether they would be able to accommodate her family situation and her husband's disabilities. Sarah looked online and rang around to try to find the answers she needed. She reported that no one was able to give her a "straight answer" and she kept being given contradictory information, but it seemed unlikely any facility would be able to accommodate her family's needs. She reported feeling "incredibly stressed and confused" about the lack of options available to her.

In the end, Sarah felt that her only available option was to get the vaccine. She became emotional and cried as she told this story because she still held strong feelings of guilt and sadness about her decision to take the vaccination when she was pregnant, and held ongoing concern about the potential longer-term impacts that the relatively untested vaccine would have on her child and his life going forward.

6.3. Perceived effectiveness

"To be honest, hotel quarantine was a good way to stop people travelling without a good reason… I was glad the government brought it in" – Participant from a CALD background, Darwin

Overall, participants felt that isolating people traveling back from higher risk locations was an **effective approach to limiting the spread of COVID-19**. While there was a clear preference for quarantining at home over hotels, generally participants accepted the need for hotel quarantine in the early stages of the pandemic, and when there were no other options available. This included participants who travelled to Australia or moved interstate without pre-arranged accommodation, when houses had immunocompromised individuals living in them who would likely be severely impacted if infected and/or when people were infected and did not have permanent housing/ were sleeping rough and needed somewhere to isolate.

6.4. Extent to which measure met needs and perceived gaps

Overall, the quarantine measures met the needs of some but not others.

"My daughter was isolating at home and got called four times a day during online classes... it got so out of hand with children. They shouldn't be calling the children, call the parent" – Participant with long COVID, Melbourne

In terms of **home-based quarantine**, experiences of monitoring processes appeared to be quite varied. While some participants indicated that they had limited monitoring, others indicated that monitoring of themselves or family members was excessive. A few participants felt that the extent of monitoring they received was based on either racial or socio-demographic profiling by the police/ military, which made them feel stigmatised and disrespected. For those who reported excessive monitoring (e.g. being called up to "seven times a day" or having the police and/or army visit their homes regularly), a few were concerned by the focus of this monitoring and checking on their children in quarantine (i.e. insisting on personally talking to their children on the telephone or visually sighting them rather than taking the word of the parent/ carer). A few with negative past experiences or perceptions of the police or military (e.g. First Nations community members, those escaping family violence) also reported it to be overly intimidating and to negatively impact their emotional or psychological wellbeing.

"I'm still traumatised to this day, it was awful… my son who's almost six [years] still remembers it… there was no communication, and we were treated like absolute pigs" – Participant who experienced quarantine, aged under 39 years, Australia-wide

The research found that negative experiences of **hotel quarantine** tended to be largely **due to structural barriers or discrepancies** which resulted in a **lack of flexibility** in **meeting individual needs and circumstances**. A lack of **consistency was reported among participants in relation to the quality and suitability** of quarantine facilities, staff and quality of food and services, leading to disparity in the level of hardship of the quarantine experience.

The research also identified **negative and distressing experiences** of the quarantine program among a few participants, as illustrated in the case studies later in this chapter.

In terms of **hotel quarantine**, participants **appreciated the regular calls they received to check on their physical and mental health**. A few indicated that these calls were made by social workers due to their circumstances (e.g. existing mental illness or fleeing from domestic violence), which was felt to be appropriate. However, a few felt consideration and flexibility should be provided in relation to the timing of these check-in calls, which tended to be "very early in the morning". This time did not suit all, disrupting sleep for a few, particularly parent/ carer participants who had been "up all night" with their children, those who felt too anxious to sleep or those working to overseas time zones.

More **significant experiences** of the hotel quarantine program which reduced the perceived appropriateness of the measure included:

"I felt psychologically trapped in that small room" – Participant who experienced quarantined aged over 40 years, Parramatta

- **Limited suitable accommodation that supported health and wellbeing needs** – participants reported that quarantine was highly distressing without facilities that offered natural light and access to fresh air, especially for people with psychosocial/ neurological conditions or disabilities and younger children;
- **Limited suitability of facilities for families with younger children** – particularly in relation to the limited space (i.e. small, tight rooms), number of rooms available or rooms with natural light and access to outdoor space. These limitations were found to lead to high strain on families and negative mental and physical health impacts for parents/ carers and children;
- **High hotel quarantine costs** – many felt that hotel quarantine was too expensive, which had a substantial financial impact on individuals and families and/or forced those with lower financial means to make difficult decisions (e.g. foregoing travel to funerals or visiting sick loved ones), which created perceptions of inequality;

"I had to go to NSW for a funeral and couldn't get back for three months. I was stranded there, unless I chose three or four weeks of hotel quarantine at my own expense, up to $500 a night… which I

wasn't going to choose" – Partnered participant living alone, Melbourne

    - In contrast to this, some felt that the high financial costs associated with hotel quarantine were necessary to deter unnecessary travel. A few also appreciated that costs were covered for those with no other options (e.g. when released from prison or when required to isolate without permanent housing/ when sleeping rough); and

"We weren't treated like humans, even the health professionals didn't want to get close to you. It was like we had leprosy" – Participant who experienced quarantine, aged under 39 years, Australia-wide

- **Negative experiences with quarantine providers** – some participants reported having experienced negative and unsupportive or disrespectful staff at their hotel quarantine facilities. Some also indicated that wellbeing supports for those struggling with mental health issues were lacking. This limited support, as well as a lack of awareness of or ability to make official complaints about the circumstances they were experiencing, compounded the negativity of the experience for these individuals.

Challenging hotel quarantine experiences

Katie* was in America at the start of the pandemic due to her husband's work. However, when her father became very unwell, she and her family decided to move back to Sydney. Travelling back was easy, but on arrival her family was required to go into hotel quarantine. The extended time in a closed, cramped hotel room with no opening windows, two toddlers (one with a disability) and her husband was mentally, emotionally, relationally and physically exhausting for Katie. She had to entertain two "overstimulated" toddlers during the day without proper sleep as her husband had to work online during the night. She was also scared and worried that she may not get to see her father as his health was deteriorating. The experience was overwhelming for her, and she is still angry about the entire situation, particularly when she recalls the conditions she and her family had to live through for two weeks, as well as the "unfriendly" and "abrupt" way the staff at the hotel treated them.

A positive quarantine story

Kabir* was in India visiting family when the international borders were slowly closing in early 2020. He became increasingly nervous about the closures, as his girlfriend was alone in Melbourne and needed his support. When he arrived back, Kabir was told he had to complete hotel quarantine. However, as there was no more space in the hotel quarantine program in Melbourne, he was instead sent to Canberra. There he was provided with "a nice, spacious serviced apartment with a balcony" all to himself and was able to get his choice of groceries and take-away food delivered to the hotel. As a result of the accommodation facility, hotel quarantine had minimal impact on him (aside from being separated from his girlfriend for an extended period). He almost feels as if "it was an extended holiday".

Extended quarantine

Jenna* found out that someone in her gym class had tested positive for COVID. At 10pm, she received a call from NSW Health informing her that she needed to complete hotel quarantine. Jenna was unable to quarantine at home, as she only had one bathroom between her husband and herself. She was told an ambulance would come to pick her up in 30 minutes, however it did not arrive until 12pm the following day. After completing her quarantine for three weeks, she found out that her husband also tested positive and had to commence his quarantine period at home. This meant that she was "forced to stay at the hotel" for a further two weeks. Overall, the extended time in quarantine away from her husband negatively impacted her mental health and enhanced feelings of isolation and despair. She is still very angry and upset about the entire experience. She does not understand why she and her husband could not have remained at home in quarantine together.

Police check-ins

Yasmin* has two children, a 10-year-old son and a 15-year-old daughter, who both had to quarantine at home during the pandemic because they had contracted COVID-19. During the two weeks of quarantine, police officers would "consistently" knock on their door and ask to see her young children as proof they were actually in the house. This scared her children, and they kept asking Yasmin to tell the police to leave and to respond on their behalf. Yasmin felt that the constant check-ins on her young children only added to the fear they were feeling throughout the pandemic, resulting in anxiety and negative perceptions of the police and other authority figures.

6.5. Key learnings

Learnings for quarantine measures identified by the research included:

- Using **home-based quarantine** over hotel-based quarantine for people in Australia whenever possible, and consider hotel-based quarantine only for those coming into Australia from high-risk international locations or for those who do not have a home they can reasonably quarantine in. Ensure **monitoring of those in home-based quarantine is not excessive** for particular individuals/ cohorts of the community, and does not overly focus on children;
- Ensuring quarantine measures are **flexible enough to accommodate the diverse needs and circumstances** of individuals, especially for families, people with mental illness and people with disabilities/ neurological conditions;
- Ensuring **communications about quarantine requirements and procedures, including complaints procedures,** are **clear, consistent and transparent.** Also, that such information is

"My husband has a disability so he could not cope with one room [in hotel quarantine]" – Vaccine hesitant participant, Cairns

easily available before people enter quarantine so that their expectations are clear;

- Having dedicated quarantine facilities that can be quickly mobilised in the event of an emergency, including ensuring **facilities are suitable, staff well trained and support services are set-up ahead of the quarantine program implementation;**
- Exploring **options to reduce the financial burden** of hotel quarantine, particularly for individuals facing financial hardship who have important reasons to travel (such as on compassionate grounds); and
- Ensuring **support is offered to people in quarantine** through telephone calls or online, and with **qualified professionals** (e.g. social workers) for those who require this support due to their circumstances (e.g. existing mental illness or fleeing from domestic violence). Where possible, enable choice in the timings of these support check-ins.

"The psychologist was calling daily at 7am, when my son was sleeping well and I asked him to call later but he didn't... he kept calling at 7am" – Participant who experienced quarantine, aged under 39 years, Australia-wide

7. Findings about financial measures

Key takeouts

- Overall, financial supports made available during the pandemic were **viewed positively and supported people to meet** their living expenses in a time of crisis and when unable to work.
- Some **gaps were identified in the delivery of the available financial supports for some cohorts.**
- The main challenge for some participants related to **adjusting back to reduced income levels** after the cessation of pandemic-related payments.

7.1. Overview of findings

"For people who lost jobs… JobKeeper was a lifeline" – Participant who uses mental health care, Port Lincoln

"I lost my job as an international student. I wasted all my savings trying to survive…. neither the Australian Government nor my home country supported me" – Participant from a CALD background, Darwin

Overall, the research found that there was **strong support for the financial measures** provided during the pandemic, in particular the introduction of JobKeeper and the increased JobSeeker payments. These were felt to be a "lifeline" that enabled individuals to meet their basic living needs and expenses, and allowed businesses to retain staff. However, some participants felt that they were **not adequately supported by the financial measures**, including international students, people with disability and micro businesses. These participants reported feeling overlooked by governments and struggled to meet their basic living expenses, leading to considerable financial and mental stress during the pandemic.

7.2. Awareness, understanding and access

"I knew about JobKeeper and JobSeeker… it was a good thing… JobKeeper helped the employer pay us" – Participant who experienced quarantine, aged 40+ years, Parramatta

Overall, the research found that there was **good awareness of the key financial measures available** during the pandemic, in particular JobKeeper, JobSeeker and one-off disaster payments. There was also reasonable awareness of the option for early access to superannuation, as well as other non-government financial supports offered in relation to mortgage/ loan repayments, utility bills and rental tenancy payments, such as deferring or discounted payments. However, a few single parent participants had limited awareness of increases to their payment which resulted in participants feeling like they had "missed out" and/or were "excluded".

The **overall purpose of providing financial assistance measures was well understood** as being to support people whose livelihoods were impacted by the exceptional circumstances of being in a pandemic and the measures in place to protect people's health which prevented them from earning an income through working.

"If I want any payment like that, I would usually go to the Centrelink office, but I had no idea what payments were available... and during COVID you couldn't even get them on the phone, because everyone was trying to ring Centrelink" – CALD participant with lower English language proficiency, Sydney

Most participants reported personally accessing financial supports during the pandemic. Overall, they reported the process of accessing payments as individuals and/or businesses as being **easy and "straightforward"**. However, a few participants with limited English language proficiency reported that they had found it difficult to access Services Australia during the pandemic to organise income support due to language barriers experienced with online services as they were not able to access services in-person.

In addition, a couple of participants felt that there could have been additional **checks or support for people accessing their superannuation**. While most participants valued being able to draw on their superannuation, a few felt that it would have been useful to discuss this choice to better understand and make an informed decision as to what the longer-term benefits and drawbacks would be for them.

7.3. Perceived effectiveness

"Financial supports helped me; it meant that money was coming in for me. I wasn't able to work, and this was necessary to support myself" – Partnered participant with no children Australia-wide

Overall, participants reported that the financial measures implemented by the government were **effective at decreasing financial hardship** experienced during the pandemic. Participants also felt that by ensuring people were financially supported, the spread of COVID-19 was minimised as it reduced their need to "take risks to earn an income" and they were able to adhere to restrictions. The research also indicated that addressing identified gaps in financial support for specific cohorts (outlined in Section 7.4), would have further increased the success of these measures.

Income support payment reducing pandemic stress

At the time of the pandemic, Caitlin* lived in regional Tasmania with her two teenage daughters. When the pandemic first began, she was very nervous about the risk of infection as she was a cancer survivor and immune-compromised. She tried to stay isolated as much as possible. She was doing limited work at the time as she was a disability support worker and primarily worked face-to-face with clients who also had health issues. As such, she received the JobKeeper payment which she reported was easy to access as the "employer did it" and provided her with a more stable income than her regular work. Caitlin reported that she felt she was in a better financial position during the pandemic than she had been previously. She was incredibly grateful for this as it meant that she could focus on keeping herself healthy and looking after her daughters, particularly as one of her daughters had existing mental health issues that were exacerbated by the pandemic. She doesn't know how they would have coped without the financial support.

7.4. Extent to which measure met needs and perceived gaps

> *"I had a friend escaping DV [domestic violence] during the pandemic, and the Super access was a godsend. She was early 40s, really bad break up, and that saved her, she was able to leave and be free"* – Participant who uses mental health care, WA

> *"Everyone got JobSeeker payments… you were getting double the money you usually made and when it stopped pretty much everyone wanted to commit suicide because it stopped so suddenly. How the fuck am I supposed to live on this? It caused a lot of mental health struggles"* – Participant experiencing homelessness, Sydney

Many participants reported that financial measures **met their needs and expectations**, allowing them to subsidise their loss of income and keep up with living expenses. It was felt to be a **compassionate approach** by the government at a time of need, and reduced the financial pressure and stress they were under. However, a few participants found it **difficult to re-adjust back to their previous income levels after the pandemic payments had ceased**, particularly casual and part-time workers and those who had experienced homelessness. In some instances, participants' income had doubled during the pandemic and therefore the sudden reduction resulted in reduced ability to meet living expenses, such as groceries and housing-related bills – leading to worry, anxiety and depression.

Most participants felt that **JobKeeper was an appropriate** financial measure to support businesses to retain workers during the pandemic. However, a few were concerned about some **larger businesses "taking advantage"** of the broad payment eligibility criteria and receiving payments despite still being able to make large profits. In addition, a few participants who employed people in small community organisations felt that the payments **lacked flexibility** to ask staff to work the hours they were paid for (instead of maintaining their normal part-time hours for increased pay), leading to "overpaid" workers who they reported developed "unrealistic wage expectations" thereafter.

Participants reported that there were gaps in the available financial supports available during the pandemic for the following cohorts:

- **International students** – despite loss of work and income, most reported being unable to access income support payments or other financial supports such as utility freezes due to their visa status. Many also did not know whether they were protected under tenancy acts. This led a few to drop out of their study entirely and switch to a working visa in order to work and afford living expenses. Others reported being reliant on families, friends, universities and charity organisations for financial support and felt purposefully "left-out" by government, "unwelcome" and "isolated";

> *"My friend was not even in Australia, and she still had to pay rent, the tenancy rules were only for residents not international students"* – International student, WA

- **People with disability** – who reported that there was no increase in the Disability Support Pension, despite perceived increases in living expenses (e.g. needing to pay for delivery of groceries and in-home therapies/ health care professionals) which led to financial pressure;
- **Freelance/ contract workers** – who reported being unable to access, or unaware if they could access, the level of financial support they needed due to their less structured employment situation; and

> *"I got a once off payment for being a casual worker… I didn't know if I could get the rest"* –

Participant experiencing homelessness, Sydney

- **Micro-small businesses** – participants working in micro family businesses reported that they were not eligible for JobKeeper as they did not have any employees. They reported experiencing substantial loss of earnings and some had needed to break the restrictions to continue to earn an income during the pandemic.

The research found that exclusion of particular cohorts from being able to access financial support resulted in **financial hardship** for these individuals and/or reduced their confidence in government supporting the needs of all members of the Australian community**.**

In addition to the above cohorts, a few participants who worked at or who had close family/ friends who worked at **universities** reported that the absence of access to JobKeeper payments impacted the sector and saw increases in staff being "let go". This was exacerbated by the reduction in the numbers of international students, which reduced overall income for universities.

Limited flexibility of JobKeeper hindered community improvement

Diane* is the local football club manager in her town in remote Australia. She (and other focus group participants) indicated that the local football club was integral to the health of their community as it was the main hub for community activities and for people from all around the town to come together and socialise. Diane mentioned that, while her club was grateful for JobKeeper because it kept their casual employees engaged with the club and working during the pandemic, she was frustrated by the rules of the payment. The JobKeeper payment was at a full-time rate even though her staff only worked a maximum of 6-8 hours per week. Diane had asked her staff to extend their hours of work to help with getting other chores and improvements done at the club. She and her fellow volunteer club committee members felt that this was a good opportunity to make improvements to their club as they could finally get more paid assistance. However, the staff had said that the JobKeeper requirements only required them to work the same hours and refused to do more hours. She felt that this was inappropriate and suggested that in the future if any such payments were made, it should enable employers to appropriately access the services of people for the duration they were being paid for (i.e. up to full-time hours), especially in their remote town where there was limited risk of COVID-19 infection. She felt that the lack of flexibility on the part of the employer "was not a good use of taxpayer funds".

Limited access to financial supports as an international student

Jia* moved to Australia just one month before the pandemic began. Isolated and lacking a support network, she found the government's lack of support for international students particularly difficult. "We got nothing as students", Jia said, "I was relying on my husband and my savings". While Jia felt relieved that the country avoided a high death toll compared to her home country, she was frustrated by the lack of support for international students like her.

Impacts for small businesses

Janette* is an accountant who had many small family business clients that “started to go under” during the pandemic. Her smaller clients were ineligible for support payments as they didn’t have employees and told her that they couldn’t afford to close for the seven days required to isolate. As such, they did not test or report when they got sick. She is still very concerned about the number of small businesses that have closed down (and continue to close down) and the impact of this on the economy, with many businesses still struggling to “get back on their feet” due to a reduction in their “reserves” as a result of having drawn on their savings during the pandemic.

Loss of small business

Bruce* was on the Age Pension and owned a small business before the pandemic. When lockdowns began, he was forced to stand down all his staff, as he was unable to access any financial support from the government. He came out of retirement to work in his business but was not allowed to visit his warehouse as it was outside of his five-kilometre radius and he was not considered an essential worker. However, out of desperation Bruce took the risk multiple times to get to his warehouse and was stopped by the police each time and handed a $1,700 fine. At this point, he was lonely, frustrated and had no support from anyone, as his wife and daughter were stuck in the Philippines due to border closures. Eventually he lost his business, including his warehouse and all the stock in it. Now, Bruce is left trying to pay off all his debts and feels that the government was “very incompetent” in managing the pandemic via the lockdowns. He is also angry that he couldn’t receive any financial support for his small business during the pandemic because he was on the Age Pension, which resulted in him losing his business.

7.5. Key Learnings

Key learnings identified by participants in relation to the financial measures included:

- **Maintaining the overall approach** of providing financial support for people to meet their living expenses and retain employment, as it was felt to be a highly needed and effective;
- **Ensuring targeted and tailored support for the cohorts** specified in Section 7.4, with a focus on ensuring that at least basic needs of food and shelter could be met; and
- **Considering opportunities to reduce the negative impacts of sudden decreases in financial support in the design phase of financial measures** (e.g. gradual phasing in payment reduction).

8. Findings about supply and labour measures

Key takeouts

- There was **limited awareness of government measures to support Australian industries during the pandemic**.
- Many participants identified **challenges associated with labour and supply issues**. These included food and grocery shortages, difficulties accessing medicines and staffing shortages which affected service delivery.
- Many felt that **labour shortages and increased costs have continued to be a problem** since the pandemic.

8.1. Overview of findings

Overall, the research found that participants had **limited awareness of measures** introduced by government to support industries and businesses during the pandemic, beyond the Job Keeper financial measure. Participants' perceptions of industry measures were largely based on whether or not they were able to access the products and services they needed, and for employer participants, their ability to get staff. Many participants reported instances of not being able to access what they needed during the pandemic with ongoing impacts post-pandemic. This concern contributed to the perception that the government did not adequately meet the needs of industries, nor did it sufficiently support supply chains to continue operating satisfactorily – thereby heightening the **economic challenges and impacts** as a result of the COVID-19 pandemic.

8.2. Awareness, understanding and access

> *"The government needed to step in and support food supply shortages"* – Participant from a CALD background, Melbourne

While most participants were aware of **purchasing limits** being applied for certain grocery items, they were **largely unaware of industry measures** introduced to address labour shortages and supply chain issues during the pandemic (e.g. changes to visa arrangements – with the exception of international student participants, who were somewhat aware of visa changes and had accessed these in some instances - and government working groups supporting industry). Overall, most reported limited understanding of how government was responding to labour market and supply chain constraints, contributing to a **perception that this was a gap** in government's response measures.

8.3. Perceived effectiveness

Overall, participants felt that labour market and supply chain issues were not effectively addressed due to their lived experiences in relation to the following:

- **Grocery and other shortages** – many participants reported that certain supplies were not available in their local stores which meant they had to go without, wait extended periods of time or travel long distances to obtain what they needed. Some participants felt that this situation was exacerbated by "fear messaging" in the media, which they reported led to increased "panic buying" and fuelled further shortages. While this only had minor impacts for some, it created considerable worry, stress and inconvenience for those unable to purchase important products such as staple food items (e.g. milk, toilet paper, flour and bread), baby formula, child-friendly foods, or specific foods that their children would reliably eat. Despite purchasing limits, the availability of certain supplies remained limited, with participants in regional and remote areas more commonly reporting these issues and experiencing greater inconvenience;
- **Access to medicines and prescription drugs** – a few participants reported not being able to access their regular medications. They reported that these medications were important for their health and wellbeing, and were "not supposed" to be ceased abruptly. This had negative impacts on their physical health or mental health and caused fear and concern. A few participants indicated that they had to "swap" essential medicines with other people they knew or online due to low availability;
- **Other essential supplies** – a few participants reported not being able to access other essential resources required for their business or work, such as timber and other building/ construction supplies; and
- **Labour shortages** – participants in rural and remote areas in particular reported difficulty maintaining local workforce due to an already limited supply of workers, and this being exacerbated by decreased availability of backpackers, fly-in-fly-out workers, seasonal workers and some choosing not to vaccinate. In addition, participants who were business owners or involved in resourcing at their workplaces experienced difficulties filling positions, which they attributed to the perceived disincentive to work created by JobSeeker and the lack of access to international workers. A few also indicated that their part-time or casual staff "refused" to increase their hours of work because they were receiving a higher income on JobKeeper. These employers reported that such staff shortages "jeopardised" their ability to run their organisations and meant they were short-staffed, including in important

"I really struggled with getting baby formula and had to go to multiple supermarkets and chemists… and my youngest son has an eating disorder and only eats one type of chicken nuggets, and I had to drive 30 minutes to buy one type of chicken nugget… it was stressful and not ideal with a baby" – Participant who uses mental health care, WA

"The chronic maintenance of my health became a real problem… we had a Facebook group that traded medications illegally. We were taking them every three days to ration them as a group" – Participant with a disability, Australia-wide

"There was no labour hire because they didn't need to work, people were getting paid more to sit at home than to work… we had so many vacancies, but we couldn't fill any of them" – Vaccine hesitant participant, Cairns

frontline and community service functions (e.g. providing health and family support services and aged-care);

- However, a few international student participants reported that the opportunity to extend visas had a positive impact on them, as it had encouraged them to stay and they were able to easily secure work.

Access to medications

Amanda* is on a Disability Support Pension for both physical and mental health conditions. During the pandemic, she had difficulty accessing her regular medications. She said "the chemist just wasn't getting stock… I went two weeks without my autoimmune medications. It says to not stop taking suddenly – I thought I was going to die". To get by, she joined a Facebook group that illegally shared medications which she knew had risks and was not good practice. She felt that ensuring a supply of medications for people who relied on them should be a key priority during health emergencies.

Lack of supplies in the funeral industry

Dan* worked in a funeral business. At the start of the pandemic, when non-essential workers were being asked to stay at home, funeral services were not listed as an essential service. After some lobbying, the essential services list was revised to include funeral services, and he was able to return to work. However, as the pandemic progressed, he found that they were running out of supplies, such as timber for coffins. He was told that many of the supplies were "on boats at sea", unable to enter Australia due to border closures/ quarantine measures. He felt that maintaining essential supplies, such as wood for the construction of coffins, needs to be a central consideration should Australia find itself in a similar situation again.

Labour shortages for small businesses

Barbara's* brother ran a hospitality business in Cairns. Businesses like theirs relied on having access to seasonal workers and international backpackers so travel restictions during the pandemic led to labour shortages in their industry. Barbara felt that it was also difficult to find domestic workers who were willing to work in hospitality over that time, especially if they didn't want to get the vaccine or were receiving more money through JobSeeker than they would in low paying hospitality roles. She reported that the lack of staff "put pressure on her brother to keep the business running on his own". This meant that if he got sick, he did not self-isolate or get tested, and was forced to run the risk of spreading illness to others. This pressure to continue working was compounded by financial challenges to the business during the pandemic as a result of having fewer customers, which meant he could not afford to close the business and isolate.

8.4. Extent to which measure met needs and perceived gaps

Purchasing limits on grocery items in supermarkets was the main supply chain measure that participants were aware of. For many, rationing of grocery supplies did not accommodate their needs, especially for:

- **Larger families** – where parents/ carers generally needed to purchase a higher volume of grocery items to meet their family's basic needs;
- **Those living out of town** – who travelled long distances (e.g. an hour) and therefore needed to "stock up"/ buy in bulk to cover themselves for a week or more and "reduce multiple trips into town"; and
- **Those on tight budgets** – those who tended to shop after receiving their paycheques who bought enough to ensure their family could "eat until their next pay".

> *"I have five kids… I always have a full trolley for the week, but people were asking me why I was stocking up and taking all the stuff off the shelves" –* Parent/ carer of high school aged, Port Lincoln

While a few participants indicated that they developed workarounds to deal with rationing by "trading" groceries with other shoppers to get what they needed within the limits, most others had not done so. For the above cohorts, purchasing limits created **considerable inconvenience and "stress"**, compromising their ability to feed themselves and their families, and to budget appropriately.

> *"People in the line would ask me to buy extra toilet paper for them… and they would get more milk for me"* – Parent/ carer of a primary school aged child, Melbourne

However, participants responded positively about **specific shopping hours in supermarkets** available for older Australians, people with disability and essential workers to allow them to purchase their groceries safely and support their access to essential items.

> *"Coles and Woolworths had special times for people with disability, that was really good"* – Participant with disability, Paramatta

Purchasing limits for large families

Myra* was living with her husband and four children at the time of the pandemic. With a large family to feed, Myra was very nervous when she started hearing news of shortages of grocery supplies and seeing evidence of empty shelves in her local supermarket. She understood why purchasing limits were put in place but felt that they did not consider larger families like hers. Myra reported that they easily got through two litres of milk every day, so she was needing to go to the supermarket once a day while also juggling home schooling, her own work and the stress of a public health emergency. To help reduce this burden, she reported that she and other shoppers would "trade" supplies depending on what items their family needed and could be purchased under the limits.

8.5. Key learnings

Key learnings in relation to labour market and supply chain pandemic measures from the research included:

- **Enhancing communication and transparency** of government measures to support industries and manage labour market and supply chain issues during crises;
- **Ensuring that support measures (e.g. purchasing limits), are effectively targeted and reach those most in need**, including consideration for regional/ remote location disparities, people's needs and specific industry challenges;
- **Designing financial assistance measures** (e.g. JobSeeker and JobKeeper) to incentivise work rather than disincentivising labour participation which exacerbates labour shortages; and
- **Facilitating quicker and easier access to domestic and international workers** where possible, to ensure a greater supply of workers is available in the labour market.

9. Findings about preventative health measures

Key takeouts

- Overall, there was generally good support for the range of **preventative health measures** – as they were felt to be effective in reducing the spread of COVID-19, while allowing people to continue to interact with others more safely.
- However, a few felt that their **circumstances and needs were not adequately considered** in the design and implementation of some measures – including people with disability, First Nations people and people from CALD backgrounds.
- While mandating certain preventative health measures was considered appropriate, some participants experienced **affordability and accessibility barriers** to adhering to mandated health measures, such as masking and testing.

9.1. Overview of findings

Health prevention measures discussed in the research included **COVID-19 testing** – Polymerase Chain Reaction (PCR) and Rapid Antigen Testing (RAT); **mask wearing and other personal protective equipment (PPE)**, including mandates for certain locations; physical distancing (e.g. in public places); **promotion of hygiene behaviours** – including hand washing and hand sanitising; **contact tracing** and isolation as required; and **attendance limits at public places and events** (e.g. restaurants, weddings and funerals).

"If there was an outbreak at work, it was good to get tested to know I was not sick" – Single participant living alone Melbourne

Overall, the research found that there was **general support for the range of preventative health measures implemented and promoted** during the pandemic as a means of reducing the spread of COVID-19. However, a few felt that their circumstances were not adequately considered in the implementation of some measures, reporting a need for better accessibility to these measures across the community.

9.2. Awareness, understanding and access

"There were signs everywhere about hand washing, hand sanitiser, wearing masks… the 1.5 meters [social distancing], how many people were allowed in places" – Participant from a CALD background, Brisbane

The research found that there was **generally good awareness of the range of preventative health measures**, as these were commonly communicated in the media, visibly sign-posted and/or mandated for use in certain circumstances. The **overall purpose of these measures was well-understood** as being to limit the spread of COVID-19 cases and to allow people to interact more safely. However, some participants had **limited understanding of why** certain health measures had been mandated or why certain limits had been set (e.g. the number of people who could attend an event). This lack of understanding of the rationale decreased support for, and/or confidence in, these measures, leading to frustration and uncertainty for some participants.

Overall, most participants reported that health measures like testing, mask wearing and contact tracing systems were accessible for them, which supported adherence to and uptake of these measures. They reported that access was supported by:

- **Being cost-free** – for example, free masks or hand sanitisers available at venues or health services, and PCR testing and PPE (for those on NDIS) being covered by Medicare;
  - However, a few participants reported that when items, such as masks and RAT tests were **not provided for free**, they had not been able to afford them and were either unable to access certain venues and/or did not test or wear masks;
- **Being easy to use** – for many participants using QR codes for contact tracing purposes was easy and straightforward, as were many of the basic hygiene practices promoted;
  - However, a few participants had **older mobile telephones** that could not scan QR codes or download apps, or no access to a mobile telephone or internet connectivity. A few of these participants (including people who were homeless) felt compelled to purchase newer phones or larger plans to enable such applications if they wanted to access essential services and public facilities (e.g. supermarkets), causing significant financial burden due to the high cost of smart telephones and the required larger data plans.
  - In addition, one participant who was visually impaired reported they had to give other people access to their phone to scan on their behalf which created security and privacy risks for them; and
- **Having physical signage** – which was a clear visual cue to support physical distancing in public places and a reminder to practice good hygiene.

"The initiative of supplying PPE to NDIS participants was good and useful" – Participant with disability, Geelong

"Everyone had to upgrade their phones for the apps and certificates to work" – Participant who experienced quarantine, aged 40+ years, Parramatta

Some participants experienced barriers to accessing certain preventative measures, including:

- **Supply shortages or long wait times** – such as long wait times (4+ hours) at peak periods for PCR testing, or shortages in supply of masks, RAT tests and PPE. In some instances, this led to participants not testing; and
- **Lack of accessibility of testing for some people with disability** – specifically:
  - Drive-through PCR testing did not account for those with physical or sensory disabilities who could not drive themselves to the testing site;
  - In-person PCR testing did not account for those who had psychosocial or neurological conditions that made it difficult to wait in line with others for long periods; and

"RAT kits were hard to get, so it was good to have clinics, but there wasn't enough of them either" – Participant from a CALD background, Brisbane

"I am fully blind… how am I going to get to the testing station? That was horrendous trying to find how to do that" – Participant with a disability, Geelong

  - Mask mandates did not account for those with asthma or breathing difficulties, or with a sensory disability who relied on lip reading or smell. A few participants reported feeling “stressed”, “concerned” and “panicked” at being “abused” or “yelled at” by strangers for not wearing their masks for these reasons.

In summary, barriers to access resulted in some people being unable to follow public health requirements and/or experiencing a substantial financial or emotional burden to do so.

Overlooking disability when accessing preventative health

Nirel* is a person with multiple disabilities, who faced substantial challenges accessing necessary health support during the pandemic. As she explained in the focus group, some people with disabilities “need support on the ground that is brought to [them]”. However, Nirel felt that face-to-face support became severely compromised during the pandemic. Unable to drive and being severely immunocompromised, Nirel found herself in a difficult situation when she felt unwell and needed a COVID-19 test. She couldn’t use a drive-through testing site because no one from her support network was available or allowed to drive her, due to restrictions on being in close contact with anyone outside her household bubble.

In an urgent bid to get tested, Nirel contacted an old support worker who arranged for an official to come to her apartment and administer the test in the front car park of her building. Though the experience was “embarrassing” and “undignified” (with the official in full PPE and all her neighbours watching), it was her only option. Nirel believes the government overlooked people with disabilities during the pandemic, assuming everyone was able-bodied and fit. Without the advocacy of her former support worker, Nirel feared she would have been left without any means to get tested and properly protect her health and the health of others.

9.3. Perceived effectiveness

Overall, most participants reported that the implemented preventative health measures were **effective at decreasing the spread of COVID-19** during the pandemic, **while also allowing people to continue to interact with others more safely**. In particular, most felt that PCR and RAT testing were convenient and safe (particularly PCR drive-through testing), provided reassurance when they were fearful about having COVID-19, and allowed for strategic self-isolation (i.e. only having to isolate when required). In addition, a couple of participants who had COVID-19 and had been monitored through contact tracing reported receiving “compassionate” follow-up through local health care teams to check that they had the supplies that they required.

“Once I got it, the follow-up from the Austin Hospital was incredible… I was alone so the check-ins were good” – Single participant living alone, Melbourne

However, a few felt the effectiveness of preventative health measures was undermined by:

- **Lack of accessibility of all measures** – discussed previously, as this meant that not all could adopt these measures; and
- **Concern about the safety of the in-person PCR queues** – as participants felt that they were more likely to catch COVID-19 from others in the queue and further risked increasing viral spread.

> *"The queue times were so long, so even if you didn't have COVID you would get it from waiting in line so might as well stay home and try my luck to get better"* – CALD participant with lower English language proficiency, Sydney

9.4. Extent to which measure met needs and perceived gaps

Overall, participants felt the **range** of preventative health measures were generally **appropriate**. However, some First Nations, CALD and some other participants reported that limits on the number of people who could attend events meant that they were **unable to partake in important rituals or cultural practices**, such farewelling the deceased, attending 'Sorry Business' and spending time with family after the death of a loved one. This was felt to be "unfair", "uncompassionate", culturally inappropriate and led to poor personal and social outcomes. In addition, some participants reported that they did not adhere to the preventative measures/ rules as partaking in rituals and cultural practices was more important to them than avoiding COVID-19 infection.

In addition, long COVID participants reported that the testing mandates (i.e. requirements to isolate if testing positive) did not account or provide sufficient exemptions for those who were not contagious or symptomatic but tested positive due to their long COVID. As such, they were unable to access travel, work or face-to-face services or venues when proof of a negative test was required.

> *"Ten people at gathering is not enough… community always have to go to funerals and help the family, it's one of the most important things for us… but we had to follow the rules…it was too hard"* – Participant from a CALD background, Melbourne

Navigating important cultural norms during the pandemic

Lual* is from South Sudan and talked about the significant challenges she faced navigating important cultural traditions during the COVID-19 pandemic. In her community, attending the funeral of a deceased community member is a central and deeply engrained cultural obligation. Showing solidarity and support for grieving families is a crucial part of Lual's culture, including visiting the homes of families of the deceased to offer physical comfort and practical assistance. However, strict limitations on in-person gatherings, specifically when only ten people were allowed to attend funerals, posed significant hurdles to honouring this cultural tradition and led to internal tensions about what to prioritise.

Lual shared that many people she knew felt compelled by their cultural duty to provide support in person. This often-led people to defy the regulations and risk legal consequences in favour of upholding the custom. Lual believes this contributed to the early spread of the virus within her community. However, she did not feel that the degree of importance of these customs was considered in the implementation of restrictions during the pandemic.

9.5. Key learnings

Key learnings in relation to preventative health measures from the research included:

- **Continuing to adopt preventive health measures** such as masks, hygiene promotion, social distancing and access to testing;
- **Expanding strategies to ensure the affordability and accessibility** of specific measures which are required to access essential services, facilities, venues, work and travel – such as provision of free masks, hand sanitisers and RATs, as well as access to PCR testing via Medicare;
- **Accommodating the unique needs of people with disabilities** in the design of suppression health measures;
- **Allowing exemptions on the size of social gatherings on a case-by-case basis** (with appropriate preventative measures in place) for important rituals and cultural practices, especially for certain cultural communities, and/or communicating the importance of these restrictions in a culturally sensitive manner; and
- **Allowing for exemptions for those with long COVID** to ensure appropriate access to face-to-face services (i.e. if testing positive, but not contagious).

10. Findings about physical and mental health measures

Key takeouts

- Overall, many participants experienced **challenges accessing related physical and mental health care** during the pandemic, resulting in delayed diagnoses, cancelled surgeries, deteriorating physical health and increased mental health challenges.
- While **knowledge of telehealth was prevalent**, some participants felt this service did not always align with their needs. This was especially the case for CALD communities, First Nations participants, those with disabilities and older people who were not comfortable or confident using technology.
- There was a reported need for **greater access to in-person care**, an **expanded health care workforce**, access to **culturally appropriate services** and **minimised delays** for procedures.

10.1. Overview of findings

"Getting emergency surgery was impossible… they weren't operating in the theatres because there were no beds… they wanted me to sleep in the emergency chair when I was in terrible pain, I just went home instead" – Participant with a disability, Australia-wide

Overall, participants felt that maintaining **access to physical health services and care** during the pandemic was important to ensure that physical health was not compromised. However, many reported that health care services had narrowed their focus to only preparing for and managing the "expected storm" of COVID-19 cases which did not eventuate. Given this perceived single focus, many felt that their health care needs were not met during the pandemic, as they could not access timely and appropriate curative and preventative health care. While telehealth supported access to some health care services, it was not able to facilitate all health care needs, especially for people who found it difficult explaining their ailments and for more complex cases. Commonly reported challenges included: delays in diagnosis and treatment; deterioration of physical health and fitness; extended time in discomfort or pain; and delays in preventative care that led to more serious/ chronic conditions or diseases.

"The gap in the mental health system was worse during COVID… one of my daughters rang Kids' Helpline but was on hold for hours and hours… she just went without" – Participant who uses mental health care, Tasmania

In addition, the research found that there was an **increased need for mental health care** during and following the pandemic due to the impacts on emotional and social wellbeing. Most participants felt that mental health care services and supports were not able to meet demand both during and after the pandemic. While access to additional Medicare funded sessions supported access for some, participants reported missing out on the care they needed due to lack of awareness, long waitlists, negative experiences with time-poor providers or difficulty with the telehealth mode of service delivery for their condition. These challenges had continued to adversely impact many participants' and/or their families' psychological, physical and social wellbeing, and for some, their willingness to re-engage with services after the pandemic. Negative impacts of these barriers to access were especially pronounced amongst pre-existing mental health care users who faced barriers to accessing their regular services and supports during a challenging time.

10.2. Awareness and understanding

Overall, the research found that there was **good awareness of the availability of telehealth consultations** for various types of health care. Participants understood that the intention of telehealth access was to reduce face-to-face interactions in health care settings to reduce the risk of COVID-19 infection. Many participants were also aware of the **suspension of non-essential health services**, with some reporting that their treatments, procedures or surgeries were delayed during the pandemic. Participants understood that the rationale was to reduce pressure on the health care system and reduce COVID-19 infections in hospitals. However, they did not understand how particular types of care were deemed 'non-essential', as they felt that delays had highly negative immediate or longer-term consequences on their health and wellbeing, and in some cases were detrimental to their lives.

"My treatments got pushed back or cancelled because they were viewed as "elective" even though it wasn't really elective, but that's how they viewed it. Dealing with ongoing pain issues, it was frustrating" – Participant who uses mental health care, WA

There was general awareness of **helpline access and supports** (e.g. Lifeline and Kids Helpline). In contrast, there was mixed awareness of the **increased number of psychologist sessions funded through Medicare**, with some having accessed these sessions and others unaware of the change. There was also limited awareness of the availability of mental health care services and processes and how to access them. While these concerns were prevalent across all cohorts, they were particularly evident among those from CALD and First Nations backgrounds, people with disability, those with younger children who were struggling to cope and those who were homeless. This lack of awareness led to perceptions of the government being "too slow" or "neglectful" in addressing mental health issues in the community, especially for conditions that were believed to be directly brought-on or exacerbated by the fear-based and "punitive" restrictions of the pandemic (e.g. anxiety and depression).

"I didn't even know there were extra sessions under Medicare, I would have used them if I knew" – Participant experiencing homelessness, Sydney

On a more positive note, it was generally felt that **public awareness of mental health issues** and **normalisation of help-seeking behaviours** had improved as a result of the pandemic. This was largely attributed to better direct exposure to, and personal understanding of, the challenges of experiencing mental health issues as well as the increased discourse of the topic in the media and among social networks.

10.3. Access

Overall, most participants felt that **access to both physical and mental health care was hindered** during the pandemic. Telehealth supported safe access and was convenient for some cohorts accessing some services by reducing the need to travel to a doctor and see them face-to-face. However, it was not always effective as discussed in Section 10.4. Participants reported that **long wait times and limited availability of services** were experienced for both physical and mental health care services.

"Our medical centre shut and that created more pressure on the emergency department… even if you had horrible symptoms, you couldn't get into the hospital" – First Nations participant, Cairns

In relation to **physical health**, participants reported that **hospital-based emergency care, surgeries and in-person therapies were particularly difficult to access** – which was perceived to be due to suspension of non-essential health services, and closure or reduction of other types of health services which increased demand on hospitals. Examples cited during the research included:

- Being turned away from emergency departments;
- Delays in receiving important treatments and therapies (e.g. cancer treatments, surgery, root canal and therapies for chronic conditions); and
- Cessation of preventative care assessments (e.g. skin cancer, breast and bowel screening).

Participants reported feeling **worried and fearful about their prognosis and quality of care**, living in pain for extended periods of time, experiencing regression of their pre-existing conditions and/or dealing with more acute conditions which could have been detected earlier.

In addition, some **international students** reported that their international health insurance did not cover basic health care and that they therefore avoided going to hospital or accessing health services due to the prohibitive financial cost, including when they had COVID-19 symptoms.

"Increasing sessions was good but just that is not enough… there was a 6-month waitlist and you just had to find your own way to cope" – Single participant living alone, Melbourne

In relation to **mental health**, some participants reported that **waitlists were over six months long to see a mental health care professional**. Participants reported that some services had shorter wait times than others, but these were **not affordable due to the additional gap fee** required beyond the Medicare subsidised amount. A few participants also reported being unable to get hospital-based support for mental health. First Nations participants reported being unable to access First Nations mental health care professionals to whom they would have felt comfortable talking. In addition, participants who had contacted helplines (e.g. Beyond Blue or Kids Help Line) reported extended periods of time on hold and not receiving call-backs that had been promised, leading to further despair and helplessness.

“It wasn’t enough… people went from one-hour face-to-face sessions to 10-minute zoom calls” – Participant experiencing homelessness, Sydney

Those who could access services reported that **appointments often felt rushed or inadequate** and some reported **longer times between appointments**. These negative experiences with services exacerbated mental health issues and reduced willingness to continue to seek help.

Extended wait times for mental health supports

Lucy* was in Queensland at the time of the pandemic and began feeling isolated, depressed and anxious being separated from her family in Melbourne, particularly after she lost her job and was relying on her parents for financial support. She reached out for help but found there was a 6-month waitlist to see a psychologist. She soon “gave up on getting help from mental health services”. Her condition kept deteriorating and she tried to cope as best she could. She felt extremely let down, “helpless” and alone.

Struggle with unmet mental health needs in the home

During the COVID-19 pandemic, Justine* and her family faced significant challenges caring for her elderly grandmother, who was suffering from recently diagnosed schizophrenia. When mental health facilities stopped admitting patients, Justine's mother, whose condition deteriorated rapidly, had to be cared for at home. This placed an immense burden on Justine and her mother, who were also managing their own physical disabilities. Justine and her family took on the responsibility of providing constant care to someone with complex care needs during the height of the pandemic.

Over time, Justine’s grandmother’s symptoms worsened dramatically. She refused medication, was physically violent, neglected personal hygiene and began defecating herself. Despite their efforts to secure assistance from four different mental health units within a three-hour drive, they were repeatedly turned away. The lack of professional, in-person support left Justine feeling overwhelmed and abandoned, unable to provide the necessary care her grandmother urgently needed. While Justine found the experience highly personally taxing, she was even more concerned about how confused, frightened and distressed her grandmother would have been, reporting “it must have been hell in her head”.

Giving birth prematurely during the pandemic

During the pandemic Sara* gave birth to a premature baby. Her son was born at home, ten weeks early, amidst the strict pandemic restrictions. When paramedics arrived, they were hesitant to enter the home due unclear procedures due to social distancing requirements. The situation was “chaotic”, with her husband “becoming increasingly upset and angry” as the paramedics struggled to decide how to proceed and whether to treat Sara or not. Neither Sara nor her husband had COVID, yet there was a reluctance by paramedics to act because they were uncertain of the protocols due to the restrictions. Sara was scared and concerned about what was going to happen to her and her baby.

Sara and her premature baby spent nine weeks in the neonatal intensive care unit. Sara believes that clear policy guidelines and better training for emergency responders and more flexible hospital policies are necessary to improve the situation for new mothers in similar circumstances. She is still very shaken-up about the experience and says her husband is still very angry about what happened.

10.4. Perceived effectiveness

Overall, most participants felt that **physical and mental health needs were not effectively met during the pandemic**. Specifically, they felt that there was inadequate support for acute and specialised needs, and that mental health supports did not meet demand.

"It was really difficult to see a doctor in person and it's not the same to do it online" – Participant who experienced quarantined, aged under 39 years, Australia-wide

Telehealth was felt to be **effective for routine, minor health care appointments** as it enabled convenient access to care while reducing the likelihood of the spread of COVID-19 in high-risk settings. However, the research highlighted that **the effectiveness of telehealth was limited** for individuals with **acute needs, surgical requirements or those needing face-to-face examinations**. Participants reported that telehealth consultations sometimes lacked the thoroughness and rapport of in-person visits, which was considered important for those with ongoing conditions. Due to the demand for these services, appointments felt "rushed" and "less caring". Additionally, technical issues, such as poor internet connectivity and a lack of digital literacy, further hindered the effectiveness for a few participants. The reduction of in-person care options for these cases was felt to be a gap in the pandemic response and led to ongoing care needs post-pandemic.

Struggle with drug recovery during COVID-19

Mary* has battled drug dependency for many years. Before the pandemic, she enrolled in a drug rehabilitation program with the support of her caseworker. She found the face-to-face sessions highly supportive, providing the strength she needed to combat her addiction. However, when COVID restrictions took effect, the rehabilitation program moved online. Mary struggled to get the same level of support and value from the program due to the lack of face-to-face interaction. This shift compromised her recovery journey completely, placing Mary back into drug dependency. She couldn't understand why such essential programs needed to move online once they had already started: "They needed to keep it going; shutting us out just hurt the most vulnerable".

Appropriateness of telehealth psychology

Julie* was seeing a psychologist through face-to-face sessions before COVID-19 started. She felt that she had a good relationship and rapport with her psychologist until her sessions were changed to go online when the pandemic started. Over time, her service provider became swamped with patients and an excessive workload, and Julie was no longer guaranteed to be able to see the same psychologist. She felt that she had to retell her story to each new professional she saw, and that her sessions became rushed. Julie lost trust in her provider, making it harder to feel supported and to get the care she needed. She stopped going to psychology appointments altogether and hasn't returned since, even though she knows she's "not in a good place" and "getting worse". Julie blames her negative experiences with telehealth mental health services as the primary cause of her reluctance to seek help.

10.5. Extent to which measures met needs and perceived gaps

"It was the hardest time for me, because I just had my second baby, but no one was allowed into my room. I needed support during that time. I was feeling very alone" – Participant who experienced quarantined, aged under 39 years, Australia-wide

"They should extend the mental health measures even after COVID because it's now that you're feeling the effects of COVID" – Participant experiencing homelessness, Sydney

"The health system was culturally inappropriate… I asked the midwife if I can have my partner here and she said no (crying)… we're in 2024 and I still live with that trauma now" – First Nations participant, Cairns

Overall, many participants felt that their **needs in relation to physical and mental health care were not appropriately met** during the pandemic. In addition to not being able to access care when needed, participants reported:

- **Negative experiences with hospital visitation restrictions** – some, particularly parent/ carer participants, reported experiencing distressing separations from their families due to stringent visitation limits. This resulted in circumstances which participants felt were "unacceptable" such as children being alone in hospital, and people not receiving the support they required such as being alone in mental health wards for extended periods of time, leading to high levels of distress and compromised care;
- **Lack of ongoing mental health support following the pandemic** – many participants felt that it was not appropriate for access to the increased number of Medicare funded sessions to be reduced immediately after pandemic restrictions had been lifted. They felt that this failed to recognise the continued mental health impact of the pandemic and did not take a recovery-orientated approach;
- **Insufficient cultural consideration** – many First Nations and CALD participants reported that Western medical services generally lacked cultural appropriateness which was further exacerbated during the pandemic when opportunities to have support people present were reduced and staff were under additional pressure which inhibited their ability to build rapport and have more sensitive interactions. This led to feelings of isolation from services and supports, and avoidance of help-seeking;
- **Lack of consistent approach to supports for people with disability** – participants with disability reported highly mixed experiences in relation to their ability to access support

workers and allied health professionals during the pandemic. While some providers had maintained their services, others did not, leaving participants unsure as to why this was the case. This led to frustration and negative health impacts from being unable to undertake preventative care (e.g. physiotherapy, rehabilitation and counselling);

- **Insufficient targeted health and mental health care for those with long COVID** – participants with long COVID reported that health professional did not know how to address their complex and chronic symptoms, leaving them feeling helpless and unable to effectively manage their condition; and
- **Insufficient consideration and support for international students** – many international students felt isolated and distant from their usual support networks but were unaware of mental health supports or unable to access them through their private health funds which resulted in unmet mental health needs. This included ineligibility for the Medicare rebate scheme, which limited access to professional support despite the heightened impact on mental health for this audience due to common feelings of isolation and uncertainty.

"My therapist refused to see me… and I couldn't go to the gym to do my rehab" – Participant with a disability, Paramatta

"The only mental health support I got was phone calls from my university" – International student, WA

Separation from daughter during a late-night hospital visit

Bobi* is a mother of two children under the age of five years and lives in a remote area. When her young daughter was rushed to the hospital in an ambulance late at night with COVID-19, Bobi experienced a daunting ordeal. Upon arrival, Bobi said that she was "treated rudely by hospital staff", who were "clearly overwhelmed" by fear of the virus. Bobi's frightened daughter was wheeled inside for treatment, while Bobi was forced out of the hospital.

In the middle of the night, Bobi was left waiting by herself "sitting in the gutter" in the hospital car park. Sitting alone and desperate for news, Bobi was unable to be by her daughter's side. She was distraught and felt completely helpless. She could empathise that hospital staff were under pressure and visitation rules were in place to try to protect people. However, she felt it was completely inappropriate to be separated from her young child with no ability to provide comfort or stay updated about her condition. Bobi and other parents in the focus group felt that no matter how serious the illness was, they would always prioritise being able to support their child.

10.6. Key learnings

Key learnings in relation to the physical and mental health measures from the research included:

- **Ensuring clear and widespread sharing of information** about mental health supports, especially for CALD and First Nations communities, people with young children, those experiencing homelessness and those with long COVID;

"Next time, continue telehealth, but for severe cases there has to be exemptions to have face-to-face consultations" – Participant who experienced quarantine, aged 40+ years, Paramatta

"When my daughter went to hospital and I couldn't see her, that was my entire support system gone… I know when sistagirl [friend in community] went to hospital in Adelaide to drop-off her son, when she got home the nurse rang to tell her he'd died, and that she couldn't come back to see him because of COVID" – First Nations participant, Port Lincoln

- **Designing measures that include hybrid models of care** that **combine telehealth and in-person visits**, especially for people requiring more intensive or specialised care;
- **Ensuring ongoing access to support workers able to provide in-person support for people with disability** – including ensuring adequate supply and affordability of PPE through the NDIS and greater access to training and pandemic specific information for support workers and carers;
- **Implementing strategies to allow for better prioritisation and continuation** of curative and preventative medical procedures and care (e.g. based on individual risk assessment);
- **Ensuring delivery of culturally appropriate health services and supports** to better meet the needs of First Nations and CALD communities;
- **Facilitating the continuation of in-person rehabilitation group-based programs where possible,** especially where these programs are central to an individual's pre-existing mental health care treatment plan;
- **Continuing to support access to mental health care after the emergency event** (ideally for up to three to five years) to account for the prolonged mental health impacts of the pandemic;
- Ensuring **health professionals are equipped with information to appropriately support those with long COVID** and assist in managing the ongoing impacts of this condition; and
- **Building and strengthening the physical and mental health care workforce** to enable more capacity to effectively and quickly respond during health emergencies, including in rural and remote areas and in the area of mental health care for children.

11. Findings about vaccination measures

Key takeouts

- Overall, **securing vaccines for Australians was felt to be a positive and effective measure** which allowed for the community to “open up”. However, there were **strong negative perceptions of the vaccine mandates and some scepticism about the efficacy of the vaccines in reducing the spread and severity of COVID-19**.
- Vaccine hesitancy was evident across all participant cohorts, primarily due to the perceived ‘newness’ of the COVID-19 vaccines and the limited availability of information that was perceived to be “balanced” – many felt their **fears and anxieties about the risks were “dismissed”** in the push to get the community vaccinated, and as such, they felt “forced”, “frustrated”, “disempowered” and/or “angry” in relation to vaccine mandates.
- The research suggested that the negative perceptions and experiences of the vaccine mandates negatively **impacted trust in government and medical science** as well as potentially on **social licence** to implement vaccine mandates and public health advice in the future.

11.1. Overview of findings

> *“Getting the vaccine meant we could go back to normal… it rolled out pretty quick out here, and there were plenty of avenues to get it”* – Parent/ carer of a primary school aged child, very remote Queensland

> *“I don’t trust the vaccination, there was no proper transparency about side effects, how it can change your body, we don’t know how many we needed to get, it was done very quick, other vaccinations take years and years”* – International student, WA

> *“I got vaccinated straight away but then got terribly sick with COVID, which changed my thinking. I get fevers now more than I ever have before… it’s made me stop wanting to take other medicines and vaccines”* – Participant from a CALD background, Darwin

Overall, the research found that the general **principle of vaccination was understood and supported** and **felt to be an appropriate and effective health response measure** in a pandemic. **Some participants felt safer and more reassured** as a result of having the vaccine. For those who were comfortable getting the vaccine, there was **good awareness of how to access vaccines**, and the rollout was felt to be **effective and easy to access**.

However, the research also identified **strong negative perceptions and limited retrospective support for mandating the COVID-19 vaccines**. The research identified **fear and worry about the potential impacts of the vaccines due to their “newness”** among participants **across all cohorts**, with some having personally experienced, or heard of close family/ friends experiencing, negative side-effects. This led to many feeling **“forced”** (e.g. by employment mandates) **or “tricked”** (e.g. by access mandates) into getting vaccinated against their will. Some were hesitant about the vaccines from the beginning of their introduction, while others become increasingly hesitant over time as they were exposed to more negative experiences and information. These participants relied on their personal experiences and observations as evidence to confirm their feelings about the vaccines and mandates.

Additionally, the research indicated that **confidence** in future pandemic-related health advice is likely to be negatively impacted by negative experiences of the vaccination mandates, perceived lack of "balanced" advice on COVID-19 vaccine side-effects and negative personal knowledge/ experience with vaccine reactions (including the withdrawal of the Astra Zeneca vaccine from the market). These factors have led to **increased questioning** of novel vaccines and **weakened trust** in medical science and government.

11.2. Awareness, understanding and access

There was generally **good awareness of the availability of COVID-19 vaccinations and who was eligible to receive them.** In addition, there was good awareness of the consequences of not receiving vaccinations under vaccine mandates, including being unable to work in most industries or attend certain places. Overall, participants reported being aware of the need for, and availability of, vaccinations due to: extensive media coverage; information provided through workplaces and health services; and due to the requirements for proof of vaccination status in places that they frequented.

"Some jobs wouldn't let you back if you weren't vaccinated, teachers wouldn't get vaccine and couldn't come back" – Participant from a CALD background, Brisbane

Overall, among those who wanted to receive the vaccine, participants reported that the **COVID-19 vaccines were easy to access later on but not in the initial stages**. Many participants reported that it was "straightforward" to book and receive a vaccine after the early stages. It was felt that delays in Australia securing a vaccine supply had resulted in initial limited availability of vaccines. Given that early supplies were limited, there was agreement that giving priority vaccine access to those most at risk from COVID-19 (e.g. older people and frontline workers) was fair and appropriate.

"The vaccine rolled out pretty quick out here, there were clinics at school, plenty of avenues to get it" – Parent/ carer of a primary school aged child, very remote Queensland

The research found that there were some key information gaps and misconceptions in relation to vaccinations, some of which contributed to hesitancy to get the vaccines. These included:

- **Why the vaccines were mandated** – especially for those who were less at risk of being infected with COVID-19 or who could potentially experience adverse or unknown reactions from the vaccines (e.g. young people, people with allergies and cancer sufferers with weak immune systems). While most participants were aware of the term 'herd immunity', there was limited understanding of what this meant or how it was related to the vaccination mandate;
- **What testing had been undertaken to ensure vaccine safety** – particularly whether vaccines were safe for pregnant people and unborn babies, immunocompromised people, people with specific health conditions, minority ethnic groups (e.g. First Nations and certain CALD communities) and children;
- **What were the risks** of the vaccine – participants wanted to feel that they were receiving "balanced" and "full" information to allow them to make informed decisions and have "real choice", especially in relation to the side-effects of

"The government was saying I had to get vaccinated to protect someone else… the biggest lie I've ever heard" – Vaccine hesitant participant, Tasmania

"I was pregnant and wasn't sure how it would affect my baby in the long-term" – Participant who experienced quarantine, aged under 39 years, Australia-wide

the vaccines, likely contra-indications, efficacy rates and duration in the body; and

- **How many vaccine doses were/ would be required** – including whether people would be "forced" to have COVID-19 vaccines indefinitely.

The research found that the following were **barriers to engaging with and understanding** information about vaccinations:

- **Having too much information from competing sources** – many participants reported that there was a large amount of information available about vaccinations and differing opinions which made it difficult to navigate and know what information to trust;
- **The divisive nature of the topic** – many participants reported that the topic of vaccinations became divisive due to their mandated nature and differing opinions. As such, participants reported a reluctance to discuss the topic and share legitimate sources of information with others;
- **Not being able to find answers to specific queries** – some participants reported not being able to find answers to their targeted vaccination questions (e.g. the potential impacts of the vaccine on unborn babies and children, people with specific diseases, conditions and allergies, and minority groups);
- **Information being overly complex or difficult to understand** – for example, information that had "too much text", used difficult language or was hard to translate (for a few CALD participants); and
- **Feeling that information was not trustworthy and lacked transparency** – specifically, many felt that potential risks or side effects were "being hidden" or were disregarded in the push to get people vaccinated. Additionally, some reported directly experiencing/ seeing adverse reactions or hearing information from official sources that contradicted their personal experience (e.g. people experiencing side effects that were not being acknowledged or reported via official sources).

"Because of the controversies I didn't know what was in the vaccination… who would be accountable if something happened to my baby after getting the vaccine… I don't think anyone should be forced to choose between getting vaccinated or not having your baby at a hospital…. you feel powerless when you aren't given choice" – Participant who experienced quarantine, aged under 39 years

"We didn't have any translations… sometimes there's no word in my language for English words so I had to use Google translate… especially about vaccination and medical terminology" – International student, WA

Encouraging vaccination uptake in a First Nations community organisation

Rhanee* was classed as an essential worker because of her work at an Aboriginal community organisation. She found this incredibly challenging, as she had her own children, her sister and her children, and her elderly mother all living in the house with her. Because she felt she was constantly being told how First Nations people and Elders were "vulnerabe" and at "high risk", Rhanee was terrified of killing her family by bringing COVID-19 back home, but she also wanted to continue supporting her community.

When she was offered early access to the vaccine as a First Nations essential worker, she felt some trepidation about how safe an "untested" vaccine was, but she wanted to protect her family and community. She was able to sympathise with others who felt unsure or hesitant about getting the vaccine, but reported that there was a push to get staff and community members who were accessing their service vaccinated. On the one hand, she felt guilty and unsure about making others get the vaccine if there was a chance of adverse health reactions, but on the other hand, she felt it was important to protect Elders and vulnerable community members from COVID-19. She felt the mandates had put community organisations in a difficult position, and that the topic became so divisive that other staff and community members would become hostile when the vaccines were discussed.

11.3. Perceived effectiveness

"My husband got COVID… he wasn't vaccinated… but he survived… they just sensationalised it making it out we were all going to die" – Vaccine hesitant participant, Cairns

"I've had three doses [of the vaccine] and a couple of boosters as well… but I've had COVID now three or four times now, and I feel like the jabs haven't protected me from COVID unfortunately" – Participant with a disability, Perth

Overall, many felt that the COVID-19 **vaccines were generally effective** at allowing the community to "open up". However, there was **some scepticism about the efficacy of the vaccines in reducing the spread and severity of COVID-19.** This was due to continued (and continuing) large waves of COVID-19 cases following the introduction of the vaccines, and/or perceptions that it was just a "very bad flu", with most people recovering well from it without a vaccine. Some participants reported feeling doubtful about the effectiveness of specific COVID-19 vaccine brands due to shifting expert and media advice about vaccine efficacy and vaccines being "pulled from the market". Across all cohorts in the research, some participants felt that vaccines had been ineffective because they still contracted COVID-19 after being vaccinated. Some long COVID participants indicated that their long COVID symptoms (e.g. loss of smell, muscle pain and fatigue) returned when they got vaccinated, thereby making them question the efficacy of the vaccine.

While the **vaccine mandate measures** were successful from a systemic perspective by achieving the target number of vaccinations across the population, the research identified potential negative impacts on longer-term effectiveness of vaccination mandate approaches. Specifically, there were strong negative perceptions in relation to the appropriateness of mandating vaccines (see Section 11.4) which negatively impacted **trust in government and medical science** as well as potentially on **social licence to support vaccine mandates and public health advice** in the future (potentially impacting future vaccine take-up).

Impact of vaccine mandates

Charlie* was in jail during part of the COVID-19 pandemic and was concerned about getting the vaccine. He had heard about the potential side effects and was sceptical about the amount of research that had been done to prove its safety, given the short period over which it was developed. However, he reported that if he did not get it, he would have been placed in a more isolated, higher security area with other prisoners he considered to be more dangerous, potentially putting his life at risk. As such, he felt that he was threatened into getting the vaccine.

After being released from jail, he spoke to his other friends about the vaccine. Charlie and his friends were young men and lived in Darwin – where they felt that the risk from COVID-19 was low and the risk of getting the vaccine seemed unknown and potentially high. His friends reported also feeling "forced" into being vaccinated, as not being vaccinated would have meant that they would be unable to work and financially support themselves.

They wondered why there was such a strong push for them to be vaccinated. Charlie became increasingly concerned about the government's motives for "pushing vaccinations" and became substantially less trusting of government decision-making, not only in relation to COVID-19 but also more broadly.

11.4. Extent to which measure met needs and perceived gaps

"I wasn't worried about the vaccine itself… the mandate was an issue, different people have different reasons to not take it" – International student, WA

"My mum is from the Czech Republic… she came here to escape the communists and had the same feeling she had back then… I'm not against the vaccine but there needs to be a choice" – Participant with a disability, Paramatta

Many participants felt that it was **appropriate for the government to secure vaccines** for use in Australia to help protect people from COVID-19. However, many felt that **mandating the vaccine was not appropriate** as it took away individual's "right to choose", particularly for those who had concerns about the vaccines. For some this caused feelings of "frustration", "loss of control", "disempowerment" and "anger", which **negatively impacted on their mental health and their perception of government and public health advice**. This feeling was exacerbated for those who reported feeling previously disempowered by government decisions which negatively impacted them (e.g. First Nations participants, those who had experienced homelessness and participants who were vaccine hesitant prior to the pandemic).

"The whole thing made you question the vaccine's effectiveness in the long term… we were just guinea pigs" – Parent/ carer of a primacy school aged child, Melbourne

"They labelled us as high risk, so we had to be guinea pigs to test it… I felt discriminated against" – First Nations participant, Cairns

Overall, the research found that perceptions of COVID-19 vaccines tended to be **more positive** among those who had an **understanding of, and confidence in, the health system** and the **Therapeutic Good Administration's (TGA) processes for developing and regulating** vaccines. However, perceptions of the vaccines were **more negative** among participants who perceived the following:

- **The COVID-19 vaccines to be "too new" or "experimental"** – many participants were concerned that the vaccines were not sufficiently tested and that the potential impacts were unknown due to the short time frame between the emergence of the COVID-19 virus and the vaccines. This concern was exacerbated for cohorts who felt the vaccines had not been tested on other people similar to them, including pregnant people, those with disability or health conditions, First Nations peoples and people from some CALD backgrounds. A few participants who had early access to a vaccine due to their higher risk status (e.g. First Nations peoples) reported feeling like they were being treated as the "test guinea pigs" for the rest of the community, given the newness of the vaccines;

- **Pharmaceutical companies** to have "too much influence" in promoting vaccinations – some participants felt sceptical of the need for and the safety of vaccines due to the commercial nature of COVID-19 vaccinations, which was emphasised by the wide-scale discussion of different vaccine brands from different companies. This led to an assumption that commercial interests had influenced vaccination information and requirements. A few participants reported that they had not had a choice about which vaccine they received (e.g. Pfizer, Moderna or Astra Zeneca) and felt that they were forced to take "riskier" vaccines as that was all that was available to them at the time;
- **COVID-19 to be of low severity** – some reported that the health impacts of COVID-19 were overstated in the media or that they were not personally at risk (e.g. younger or healthier participants). This was particularly the case for participants who had direct experience themselves or among their family/ friends of having only mild symptoms from COVID-19, and meant they were less likely to see a personal benefit in being vaccinated;
- **The information and rules to be contradictory or shifting** – this undermined confidence in, and the credibility of, information and measures being put in place. For example, when vaccine mandates, advice or information about the side effects changed (e.g. including the withdrawal of the Astra Zeneca vaccine), participants assumed that prior information had been incorrect or misleading; and
- **The vaccines to have adverse side effects** – as discussed above, a few participants reported that they had experienced negative side effects (e.g. a few with long COVID reported reoccurring symptoms post-vaccination) or had known people who had negative side effects from the vaccine and had become unwell, which contributed to high levels of concern about the vaccines.

"I thought 'this has now turned into big pharma thing, this is now a financial roll out'. Big pharma basically own the AMA" – Participant with a disability, Cairns

"To this day I don't know if COVID was a real thing… what did I get vaccinated for?" – First Nations participant, Cairns

"I was forced to get the vaccine to pay my mortgage, but now they say the vaccine is bad for you" – Parent/ carer of a secondary school aged child, Port Lincoln

Many participants had (and continued to have) genuine **fear and "anxiety"** about the potential unknown long-term impacts of receiving the vaccines. Participants who had concerns reported feeling that these were often **"dismissed' or "not taken seriously"** in the push to get the community vaccinated, and as such they felt "forced". Many also reported feeling "stigmatised" by health professionals and others in the community who they felt treated them with suspicion or disapproval if they communicated their hesitancy or concerns. This resulted in distrust in government and public health experts, with some perceiving that these institutions were too short-term focussed and were not acting in the best interest of the Australian community.

"There wasn't enough information about how it would impact my condition [rare muscular disorder]… my GP was very against me not getting vaccinated, but he didn't give me any information" – Participant with a disability, Parramatta

Even participants who tended **not to be concerned about receiving the vaccines personally** could understand why others were hesitant. They were **not supportive of the mandate and the lack of choice,** but reported that in some instances they had to help enforce it in their workplaces. This led them to feel guilty and upset, and in some instances had resulted in them losing friendships with colleagues who were reluctant to take the vaccines.

A few participants also experienced **challenges having vaccination exemptions recognised**. These participants reported having legitimate exemptions from their doctors doubted and being questioned by others which led them to miss out on access to venues and services.

Using personal anecdotal evidence of vaccine effectiveness

When COVID-19 vaccinations became available, Mikey* trusted the advice of his support coordinator, his doctor and his family and got three COVID-19 vaccines plus the booster vaccine. Mikey thought that the vaccines would help to prevent him from getting COVID-19. However, he became unwell with the virus four times after getting vaccinated. This led him to become highly sceptical about whether the vaccines actually worked. He reported that he had seen “conspiracy theories” about the vaccines being harmful and, while he didn’t believe these, he did feel that vaccines were not as effective as they had been made out to be by government and the media. In hindsight, he felt that the vaccine rollout had been rushed, and that it was unfair to “take away the choice of a person” when it hadn’t protected him from COVID-19 in the end.

“The one thing I would do differently if we had the pandemic again is letting people make the choice of whether to get the COVID jab or not. It’s their life, their choice, and they shouldn’t lose a job if they’re not vaccinated. I feel like the jabs haven’t protected me from COVID”

Challenges with vaccine exemptions

Alice* found the pandemic to be an incredibly challenging period, particularly for her mental health. During this time, she was undergoing cancer treatment, which was severely disrupted. "Our normal health system just went out the window" she shared. Alice's treatment was delayed, and she felt like it was “put on the backburner”.

To complicate matters, Alice's doctor advised her against getting the COVID-19 vaccine. This meant she had to stay home almost entirely. "Despite my exemption letter from my oncologist, places either didn't believe me or didn't know what the rules were" she recounted. As a result, Alice and her husband were confined to their home, unable to work, and struggling with depression and anxiety. "We both weren’t able to work. I just felt like my life was going downhill fast".

The Salvation Army provided crucial support by delivering food packages weekly. However, Alice believes the government needed to introduce a national exemption letter for those unable to take the vaccine and communicate clearly about who was exempt and why. The lack of clear information left Alice feeling isolated and abandoned.

11.5. Key learnings

Key learnings in relation to the vaccination measures from the research included:

- **Adopting more positive and empowering approaches and tone** to support vaccination uptake (including communicating ‘why’ vaccination is important and being more open and transparent about the side-effects);
- **Ensuring clearer and more timely information is available** about vaccinations well before their roll-outs;
- **Having avenues to make people feel that their concerns are heard and being responded to** (e.g. open public discourse and discussion with health professionals);
- **Ideally, implementing an opt-in incentivised approach** (with extensive education and communication) **before moving to a mandated approach** for vaccine roll-outs;
- **Taking deliberate efforts to build-up and enhance trust and social licence in public health advice, experts and vaccinations** in preparation for potential future events; and
- **Providing targeted communications for different audiences to address concerns about vaccine testing and vaccine harms** – e.g. First Nations peoples, people from non-European backgrounds, pregnant women and children.

12. Future pandemic expectations and learnings

The research found that, if there was to be a future pandemic, people's expectations, attitudes and behaviours would be shaped by their experiences of the COVID-19 pandemic. **All participants** indicated that their wellbeing was at least in some way negatively affected by the pandemic. Given this, it is not surprising that there were some clear and common themes emerging from the research in relation to expectations and learnings for any future pandemic-like events in Australia.

Overall, the research found **overwhelming (unprompted) expectation and support** across **every cohort** for the following:

1. **A co-ordinated national, consistent and fair response led by the Federal Government** – with such a response having a shared vision and input from State/ Territory governments but with **clear national leadership** for managing, co-ordinating and directing the plan and pathway forward. The States/ Territories can be responsible for the application and implementation of the **nationally agreed consistent measures** on the ground. Examples of **national leadership qualities** included:
    - Providing ongoing and up-to-date **evidence and reassurance** that Australia has a **plan and pathway** for managing the pandemic, including clear key performance indicators;
    - **Checking** that the overall plan and approach to the implementation of pandemic measures in Australia were being **consistently and fairly applied** across States/ Territories;
    - Ensuring there is a **clear, central source of pandemic information** which provides information about the rationale for Australia's approach and overall plan; is transparent about knowns and unknowns; and ensures that all content is factual and evidence-based including acknowledging positive and negative perspectives;
    - **Communicating messages in a tone** that is positive, respectful and encouraging – that supports a sense of **unity, cohesion, collaboration and hope**;
    - Avoiding **politicising messaging or narratives** about pandemic management or State/ Territory governments to reduce scepticism, divisiveness and confusion; and
    - After the pandemic, "close-the-loop" by **acknowledging the challenges and helping people recover and heal** from the "fall-out" of their negative experiences, by demonstrating learnings and having a clear plan for next time.

2. Governments to have **a more prepared, proactive and effective approach to managing and implementing measures** – based on past (and in a crisis, real-time) learnings from the COVID-19 pandemic in Australia and overseas. Participants expected government to be better prepared with a plan of action to be able to mobilise quickly and activate measures that reduced the burden on individual citizens and residents.

3. Adoption of a **holistic and balanced response to health emergencies** – whereby equal input, consideration and focus is given to physical, mental, relational, social, educational and economic wellbeing outcomes (rather than the perceived over-focus on physical COVID-19 health outcomes only).

4. **Measures that are designed to be flexible, responsive and adaptable** – so that implementation can accommodate individual exceptions, the changing nature of the virus over time and evidence-based changes in knowledge and experience from overseas and in Australia. Suggestions from the research when implementing measures include:

  - Considering the **breadth and diversity of people who will be impacted by measures (i.e. the heterogeneous nature of the population)** and ensuring their needs and circumstances can be reasonably met via allowing case-by-case exemptions;
  - Utilising **pre-established partnerships/ relationships with relevant community organisations** that can be leveraged to communicate important information to the community and receive feedback about measures, including for First Nations, CALD and disability communities;
  - **Allowing for measures to be introduced gradually via opting-in** (with incentives, education and communication) and then only **escalating gradually**. Ideally, avoiding mandating requirements until a clear case is evident and it is supported by a clear and saturated explanation of the rationale with key indicators for loosening them. Limit the duration of time that mandates and punitive enforcement of measures are adopted, especially in relation to fines for the most vulnerable;
  - **Continuously reviewing and improving** the individual and combination of measures used and implemented in line with the evolving situation, evidence and community feedback; and
  - Sharing regular **feedback about the effectiveness** of different measures and why they are being continued, amended or stopped.

5. A focus on the **post-pandemic recovery**, including: reflection and acknowledgement from government regarding the pandemic and people's experiences; consideration that **government supports** (e.g. financial) may need to be **withdrawn gradually** to enable people to adapt to their changed circumstances; and **extension of health supports** for longer periods of time to help individuals and families heal, recover and bounce-back.

A clear and consistent finding from the research was that there **now exists less tolerance and likely acceptance of any future mandatory/ "punitive" measures in response to a pandemic** – as these were perceived to be reactive, only suitable in the short-term and were viewed as having significant longer-term negative impacts. Participants reported that they would expect the government to be prepared to adopt more nuanced and supportive measures based on the learnings from the COVID-19 pandemic. In addition, loss of trust in government and public institutions among some has further reduced willingness to comply.

While some participants felt that if another pandemic occurred in their lifetime, they would have an understanding of what to expect and would likely cope better, most others stated that they would be psychologically "triggered" and would likely react "badly" or negatively (e.g. become non-compliant, vociferously protest, "leave the country" or "riot").

Key learnings relating to each pandemic measure have been presented at the end of the relevant chapters (see Chapters 4 to 11).

13. Conclusions

Overall, the research found that **individual experiences of the pandemic were highly negative** which was not surprising due to the adverse nature of a pandemic. Across all cohorts in the research, there were one or more impacts identified in relation to people's **physical, mental, social, relational, educational/ developmental and economic wellbeing**.

Pandemic experiences were influenced by people's own **personal attitudes and needs** as well as the **context of their circumstances** and the **external environment** impacting them. Overall, the research found that those who had greater **responsibilities** for others tended to have more negative experiences and perceptions of the pandemic response measures than other people. Similarly, those who were **dependant or reliant** on other people and/or had **significant vulnerabilities** tended to have more negative experiences.

Overall, there was a **large degree of consistency and overlap between the audience cohorts** in terms of their perceptions and experiences of the different pandemic response measures. Many measures were experienced in a similar way among the different cohorts.

In general, the research found that **where people lived** impacted the **intensity of their experience** of the pandemic, with **differences noted between States/ Territories,** as well as by **remoteness**. Participants in Victoria, New South Wales and metropolitan areas, as well as in a few specific Local Government Areas (e.g. Western Sydney) typically reported more intense negative experiences than those in other locations. The research found that locational differences in relation to lived experiences were largely driven by **how participants' day-to-day lives were impacted by the local restrictions**, as well as their **access to services and information**.

The research found that **perceptions of the government response to the pandemic changed over time**. Personal experiences were reported to have become more negative over the course of the pandemic because living with the restrictions became harder and more challenging. As the challenges with lived experience increased, so did negative perceptions of governments' management of the pandemic. In turn, these perceptions appeared to slowly erode trust and confidence in governments, especially among those who felt the pandemic was poorly managed.

Overall, the research found that governments' pandemic response (Federal and State/ Territory) was perceived to have adopted a **predominantly "punitive" and "forceful" (i.e. 'stick-based')** rather than incentivising and encouraging (i.e. 'carrot-based') approach. The 'stick' approach was felt to be appropriate in the initial stages of the pandemic when the perceived risks of COVID-19 were high and there was acceptance of the need to act quickly given the uncertainty/ unknowns. However, over time this approach led to increasing **resistance to accepting and complying with advice** due to increased frustration and personal challenges at being under restrictions, as well as a perceived lack of fairness and justification of need.

There was initial openness to the pandemic response measures being implemented by governments, with people willing to comply with measures. However, the research found that **over time there was increased polarisation of perceptions of the pandemic management,** with many becoming increasingly frustrated, distressed and angry. While there were **some positives, there were strong negative perceptions about the pandemic response**. The types of measures adopted were generally felt to be suitable. However, many felt that the implementation of measures was not appropriately tailored, balanced, consistent or person-centred to cater to the diversity of individual circumstances and the changing nature of the pandemic.

Awareness of, and access to, supports were variable. There were gaps in the supports available which meant some cohorts missed out or did not have timely access to supports that were appropriate or accessible for them. For some, there was also limited awareness of the availability of, and how to access, such supports.

Experiences of **pandemic information** were found to be **often confusing and overwhelming.** People relied on a broad range of sources for information about the pandemic which could be contradictory, overwhelming and/or mismatched to their personal experiences. This led to anxiousness, disengagement, scepticism and distrust.

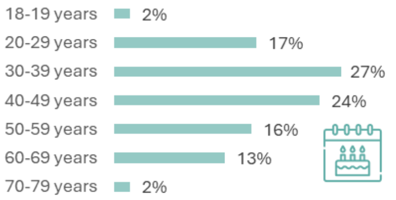
There was **a clear expectation of greater Federal Government oversight of a pandemic**. Overall, there was felt to be limited Federal Government leadership and visibility, with States/ Territories leading their own responses. This led to a perceived lack of fairness, consistency, coordination and unity across Australia's response to the pandemic – resulting in divisiveness within Australia.

The research found that the pandemic has continued to have residual impacts on people/ their families, leaving **unresolved emotions and resentment**. The widespread negative experiences during the pandemic have disrupted some of the essential factors contributing to the societal fabric of Australia as being a united, compliant and cohesive society. Erosion of trust, social licence and goodwill in governments and institutions were commonly and overwhelmingly reported as having resulted from the pandemic experience. Furthermore, resentment towards what was lost (i.e. choice, connections, "freedoms" and autonomy) has led some mainstream audiences to become more sceptical and critical of government policies and decision-making. In turn, this has led to greater vaccine hesitancy and openness to misinformation.

There is a need to **repair and rebuild these essential social fabric factors** to support successful health emergency management and compliance behaviours in the future.

APPENDIX A: Demographic profile of participants

AGE



GENDER

50%
Male

48%
Female

2%
Other

BACKGROUND

34%
CALD

19%
Aboriginal and/or Torres Strait Islander

43%
Neither of the above

LANGUAGES SPOKEN

Arabic
Bangla
Bengali
Burmese
Cantonese
Chinese
Creole
Croatian
Czech
Dutch
English
Gujarati
Hindi
Indonesian
Italian
Jawoyn
Kriol
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Punjabi
Sinhalese
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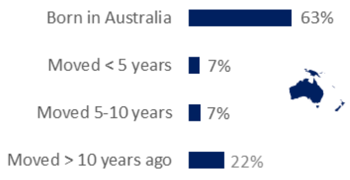
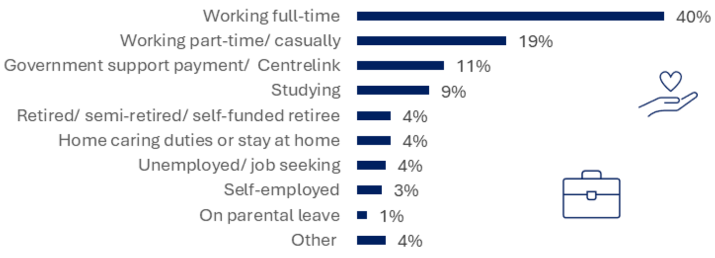
Urdu
Vietnamese

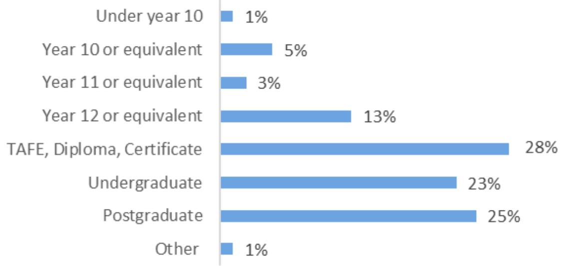
LIVING IN AUSTRALIA



LIFE SITUATION IN 2020-21



EDUCATION LEVEL



PARENT/ CARER

27%
Yes - primary school age child (in 2020-21)

15%
Yes - high school age child (in 2020-21)

62%
No

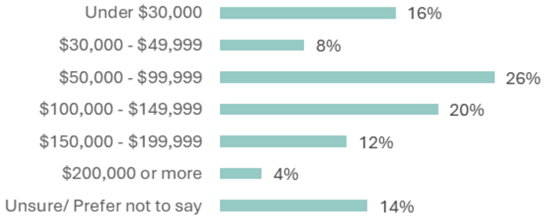
DISABILITY

17%
Yes

79%
No

4%
Prefer not to say

ANNUAL INCOME



QUARANTINED IN 2020-21

63%
Yes home

13%
Yes hotel

23%
No

2%
Prefer not to say

USED HOMELESS SERVICES IN 2020-21

3%
Yes

96%
No

2%
Prefer not to say

EVER USED MENTAL HEALTH SERVICES

46%
Yes

52%
No

3%
Prefer not to say

INTERNATIONAL STUDENT IN 2020-21

17%
Yes

84%
No

VACCINATION STATUS

88%
Yes

10%
No

3%
Prefer not to say

*Note: Percentages may not sum to 100% due to rounding or questions permitting multiple responses (n=176).

APPENDIX B: Cohort profiles

First Nations

FACTORS IMPACTING PANDEMIC EXPERIENCES

Overall, **First Nations participants** consistently reported negative experiences of the COVID-19 pandemic, with most feeling that the pandemic had adverse impacts on them, their families and communities – particularly on their mental and social wellbeing.

> *"[Measures] need to be culturally appropriate… consult black fellas…. include us in the conversation and action… helping community to help ourselves… working together instead of against us"* — First Nations participant, Melbourne

> *"There needs to be sympathy with funerals, especially in Indigenous communities. When one person dies it affects all of us, we all feel it… it was an attack on our Culture, community and our way of life"* — First Nations participant, Melbourne

> *"The deaths… were a scare tactic, they went a bit too far"* — First Nations participant, Port Lincoln

> *"The health system was culturally inappropriate… I asked the midwife if I can have my partner here and she said no (crying)… we're in 2024 and I still live with that trauma now"* — First Nations participant, Cairns

> *"So much fear… news of people dropping dead, so we didn't even want to send the kids to school"* — First Nations participant, Cairns

- **Reduced ability to connect to family, community and Culture** – most reported that connections to family and community as well as connection to Country and cultural practices functioned as a strong protective factor to mental health and wellbeing. However, most experienced increased social isolation and separation from family networks and were unable to practice important Customs (e.g. Sorry Business) due to COVID-19 restrictions (e.g. lockdowns, travel restrictions), which negatively impacted their mental and social wellbeing. In addition, most reported there was limited availability of culturally appropriate mental health care or tailored supports to address this gap for First Nations peoples.
- **Deficit and "fear-based" approach to information and messaging** – many reported that messaging about COVID-19 continuously emphasised that First Nations peoples were "more vulnerable" to death or serious hospitalisation which created high levels of anxiety and reduced openness to engaging with COVID-19 information – this was exacerbated for frontline workers who felt additional fear due to potentially exposing their family to risk.
- **Challenges accessing information from trusted sources** – many reported having limited trust in government information and found that official sources were not tailored to their needs. They reported relying on word-of-mouth information from others in community. They felt there was an increased risk of misinformation being shared due to community sources not being supplied with accurate information in easy-to-understand language or formats.
- **Perceived lack of self-determination and governance** – many felt that there was a lack of First Nations leadership included in decision making as well as the design and development of key measures. They felt this led to a lack of consideration of community needs in delivery of measures (e.g. could not bring a family member/ support person or access to First Nations staff in "mainstream" hospital and health settings, and financial supports that did not account for larger households with multiple dependants).
- **Perceived inappropriateness of vaccination mandate** – many felt stigmatised by the heavy focus on vaccinating First Nations peoples due to being the "most vulnerable". In addition, they were concerned about the lack of testing of vaccines on First Nations people before the roll-out. They also felt the mandate created conflict and put community workers in a difficult position by relying on them to push vaccinations in communities that were hesitant.
- **Limited housing availability and affordability** – some reported having additional family members move in with them during the pandemic (e.g. transient family members or family members who had lost jobs and could not afford housing). This resulted in overcrowding, and a few reported that these family members still could not afford housing after the pandemic.

CASE STUDIES

Experiences of culturally inappropriate healthcare

Sara* was due to give birth in the first few months of the COVID-19 pandemic in 2020. At the time, strict suppression measures were still in place in all hospitals and healthcare settings, restricting visitors. She was already anxious about giving birth, having had negative experiences with non-Aboriginal health services in the past. When she went into labour, she was rushed to the closest general hospital. Sara was terrified. She asked the midwife if she could have her partner there during the birth, but the midwife said "no". There were no First Nations staff around to provide culturally informed support.

As she retells this story, Sara begins to cry. Others in the group rally around and try to help Sara explain that this is a common experience for First Nations women, and things may have gone differently if there had been an Aboriginal midwife, or someone present who understood their Cultural needs – *"that's another trauma she's got to live with now".*

Restrictions preventing *Sorry Business*

Haden's* brother passed away from illness in the middle of the Victorian lockdowns. At the time, there was a ban on holding any type of gathering so Haden had to "put his brother on ice" and wait until they could hold a funeral. It wasn't until a month later that restrictions were partially lifted that Haden was able to hold a funeral for his brother. Unfortunately, at the time there were still caps on the number of people who could attend funerals, so they were only able to hold a small event.

Haden shared how distressing, disturbing and upsetting it was seeing his brother's body after a month, and to miss out on the opportunity to say goodbye and grieve properly with all his family. He felt that decisions about caps and restrictions were based on "Western" understandings of funerals and felt there was no compassion or understanding of the importance of Sorry Business.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Access to information and services via a wider range of trusted sources and channels to reach people on the ground (e.g. beyond just AMSs and ACCHOs for those not accessing these health services)

Need for factual, non-fear based, culturally appropriate and tailored information with **clear and simple guidance on what to do and why**

Identifying and having **pre-established relationships with local community organisations and leaders** who can provide advice on the roll-out of measures, and to support communications across communities.

Increased consideration of cultural differences and needs in all aspects of measure design – including accounting for:

- A range of family sizes and structures
- Protective role of family/ community networks in supporting wellbeing
- Negative experiences and attitudes towards government sources and reliance on word-of-mouth or trusted community networks
- Inappropriateness of mainstream hospital and health care settings for some First Nations peoples
- Prior and ongoing negative impact of deficit-based messaging on individual wellbeing and self-efficacy

People with disability

FACTORS IMPACTING PANDEMIC EXPERIENCES

Overall, there was **wide variation in experiences** due to the **diversity in support needs, differences in response across disability providers**, and the extent to which **measures, and information were accessible for people with different disabilities** (e.g. sensory and cognitive disabilities).

> *"All my therapies were stopped for over a year. I didn't get the vaccine so the therapist wouldn't see me. My condition has deteriorated, and I can't walk now"*— Person with physical disability, Parramatta

> *"Personally, I do not like that the vaccine was forced on us... It hasn't been tested on people like me. It wasn't tested pretty much at all – but especially not on people like me. Totally unknown"*— Person with physical disability, Ballarat

> *"Some of us need help on the ground – access to face-to-face support was really compromised. No one was allowed to drive me to get tested"*— Person with physical disability, Sydney

> *"People with disability had a real hard time getting information… once Barwon Health came on board with putting on a disability liaison person things were so much easier, there was a number and place to go if you had disability... But it wasn't easy in the beginning"*— Person with sensory disability, Geelong

> *"I was alright, I had the support people around me. I got what I needed, but I know some people that didn't have that, and it was hard for them"*— Person with cognitive disability, Perth

- **Heightened concern about physical health and safety** – some participants reported having health conditions that made them more vulnerable to illness and therefore appreciated the focus on limiting COVID-19 spread (despite some participants being negatively impacted by the design of some response measures).
- **Variable access to support workers** – while some participants retained access to their support workers during the pandemic, others reported that they did not which resulted in challenges in daily living (e.g. cooking, reading mail, cleaning), getting to key services (e.g. health appointments, PCR testing) and maintaining social wellbeing.
- **Limited and/or delayed access to information** – many reported limited availability of information in audio (e.g. on-demand radio/ podcasts), screen reader accessible or in visual or easy English. Some reported feeling overly reliant on others (e.g. support workers/ carers) to access and understand key information which **impacted their ability to make informed decisions**, including about vaccinations. They also reported not knowing about and therefore **missing out on available supports**, such as mental health care.
- **Reduced access to allied health services** – some participants were unable to access services such as psychologists, counsellors, rehabilitation, physiotherapy, gyms and hydrotherapy which led to deterioration in physical and mental health. However, a few reported having health professionals willing to continue their in-person care.
- **Inappropriateness of vaccination mandate** – many were concerned about the impacts of the vaccine, particularly if they were immunocompromised. However, they felt that their concerns were not appropriately addressed and that they or their support workers should not have been "forced" to get vaccinated.
- **Insufficient consideration for maintaining social wellbeing** – many participants reported increased social isolation due to being cut off from support workers and support groups, particularly where this was their only social outlet and/or they could not interact online. Additionally, a few reported that contact with staff was highly restricted and impersonal due to health restrictions.
- **Inaccessibility of testing measures** – e.g. for some who could not drive themselves or get transport to PCR testing facilities, who had a psychosocial disability which made it difficult to stand in line for testing, or sensory disabilities which made it difficult to see result of RAT tests.
- **Interrupted access to medication** – a few had access to medications disrupted due to supply shortages which had detrimental health outcomes.
- **Limited increase in financial support** – for a few participants the pandemic led to additional daily living expenses (e.g. pre-made meals, one-on-one in-person therapy), but the disability support pension did not increase.

Cohort summary

People with disability

CASE STUDIES

No access to support workers

Janet* has a visual impairment and an acquired brain injury. She lives with her husband who is also visually impaired. They rely on their support worker to assist them with everyday tasks such as cooking, reading the mail or shopping. During the pandemic she was told by her provider that support workers could not do home visits or provide in-person support. She felt frustrated because she was not provided with a clear reason for why this support was not possible. Even once restrictions started easing, she found there was a shortage of workers who were willing to return to work in-person, including because they didn't want to get the vaccine. Because she could not cook or shop without support, Janet was reliant on frozen meals for the duration of the pandemic period. Janet noticed that over time she began to feel physically weaker due to a lack of proper nutritious food.

Medicine shortages

Dianna* requires a specific medication which helps with managing her lupus, an auto-immune condition. While the drug is not only for lupus and can be accessed over the counter, it is often prescribed by doctors as an auto-immune medication. Unfortunately, during the pandemic, a public figure claimed that the medication could stop you from getting COVID. As a result, more people began to purchase this medication which created a supply shortage. While Dianna's chemist had tried to put aside some bottles for Dianna and his other customers with auto-immune conditions, he still struggled to get the medications for those who needed it. When Dianna had to stop taking the medication due to limited supply, she got ill.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs:

- How to stay safe from COVID
- Why you should get vaccinated
- The potential risks of getting vaccinated (for different conditions)
- What services are available and how to access (e.g. mental health and wellbeing supports)

Key information sources:

- Support workers
- Carers
- Disability organisations and peak bodies – e.g. Vision Australia radio/ podcasts
- NDIS & disability providers
- Government websites (screen reader compatible)

Information is needed in **a range of formats** and in **easy English** to account for different disabilities and needs

Other supports and resources:

- **Ongoing access to support workers** – including ensuring adequate supply and affordability of PPE through the NDIS to help ensure support workers can provide in-person support
- **Maintained access to health care** – including therapies, allied health and medication
- **Training and consistency** in the provision of pandemic specific information for support workers/ carers
- **Ensure physical and sensory accessibility** of testing

OVERVIEW OF PANDEMIC EXPERIENCES

Overall experiences of the pandemic were **largely negative** for participants from CALD backgrounds, particularly those **with limited English language proficiency** and/or with close friends/ family overseas. However, some participants were grateful to be in Australia during the pandemic as they saw more negative impacts of COVID-19 from their family/ friends living in other countries.

- **Challenges accessing information and government communications** – many participants from CALD backgrounds (particularly those with limited English language proficiency) reported that COVID-19 lockdowns and restrictions interrupted their access to community networks, which was their primary source of information. This led to high levels of confusion and fear due to difficulties accessing relevant information about COVID-19 and relevant measures, including vaccination information. This was heightened for those who had limited literacy and therefore relied on information shared verbally.
- **Heightened stigmatisation and marginalisation** – some participants reported that the pandemic exacerbated social exclusion and discrimination. This was due to localised lockdowns and other measures which targeted areas with larger CALD communities, as well as suspicion placed on people from countries that had been perceived to be targeted by border closures (e.g. India and China).
- **Uncertainty about international border closures** – some perceived a lack of consistency and transparency in relation to international border closures, resulting in confusion, frustration and feelings of "unfairness". This was particularly evident when borders closed "abruptly" and without clear justification for why people from specific countries were restricted. This led to separation from overseas family/ friends for "indefinite" periods of time – heightening stress, fear and isolation.
- **Disruption to protective family and cultural factors** – some participants reported that COVID-19 measures interrupted their ability to participate in important cultural customs, including observing mourning customs with extended family after the death of a loved one. Additionally, some participants reported strain due to changed family dynamics, including increased time at home with larger families and limited access to extended family. The impacts of this were felt to be ignored by governments, leading to feelings of unfairness and cultural insensitivity. Participants felt that this contributed to poor mental health impacts and increased pressure on families.
- **Limited support for mental and social wellbeing** – the above factors contributed to heightened negative mental health and social wellbeing impacts for those from CALD backgrounds. Many were unaware of available mental health supports.

> *"I heard about things from family members who speak English, but the information was never given to me directly. The government needed to find a way to translate information and give verbal direction, or use community leadership to get the information out"*—Participant from CALD background, Ballarat

> *"Ten people at gatherings is not enough… community always have to go to funerals and help the family, it's an important thing for us… but we had to follow the rules, it was too hard"*—Participant from a CALD background, Melbourne

> *"I'm Hindu, and once somebody passes away, we bring the body back home into the house, do rituals, say goodbye in the house and do cremation. When my uncle passed, his last wish was to come home and it wasn't fulfilled, so of course it impacts you"*— Participant from a CALD background, Sydney

> *"My mental health suffered but I did not know who to tell and what to do about it... I just suffered by myself without knowing about any mental health services"*— Participant from a CALD background, Sydney

Cohort summary

CALD

CASE STUDIES

Lack of access to information

Jane* is a South Sudanese refugee living in regional Victoria. She didn't speak English and couldn't read or write in her first language. She was not aware there was a pandemic until her children were sent home from school. During the pandemic, she relied solely on her children for updates on restrictions and services available. At one point, she became sick with COVID-19 and feared she might infect her family and community so didn't leave her bedroom for any reason. She spent two weeks confined to her room and relied on "home remedies like ginger and lemon". Some nights, Jane was terrified she wouldn't make it through until morning but didn't know how to get medical advice. Her children shared her fear and were worried she would die. When Jane finally came out of isolation, she felt immense relief. Her children were overjoyed to see her again. Jane wishes there had been services and information to better support her during this time.

Navigating isolation and the struggles of family separation

Kamal* and his family are from India and have lived in Australia for 9 years. In the months prior to COVID-19, Kamal and his wife flew back home to Delhi for family support for their newborn child. In January 2020, Kamal needed to return to Sydney to begin work, leaving his wife and newborn behind. However, soon after his departure, international borders closed abruptly, separating Kamal from his family. Despite being an Australian citizen, his family could not return from Delhi and he was unclear about why they couldn't return when those from other countries could. He assumed this was due to negative stereotypes about India. Isolated and concerned for both his young family and his mother, who was alone following his father's passing, Kamal grappled with anxiety, mounting debts and the responsibility of sending money back home. The inability to fulfill cultural rites, especially when two family members succumbed to the virus in India, added to his stress. Kamal could "only pray for the health" of his family and was separated from them for six months.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs:

- How to stay safe from COVID
- How to access tailored in-language information from official sources
- What services are available for mental health and wellbeing supports
- The rationale and benefits of health suppression measures, including border closures, local area lockdowns and event caps

Key information sources:

- Community networks and leaders (e.g. faith networks)
- Family and friends
- CALD media
- Social media and community forums
- Government websites
- People working in settlement services / migrant resource centres and GPs

Information needs to be more widely shared or easily sharable through **established community networks** (e.g. community organisations, faith groups and social media). Information is needed **in-language** and **in a wide-range of formats** (e.g. both audio and written).

Other supports and resources:

- Ensure that Australia citizens **can return home** from overseas and that there are compassionate exemptions available where appropriate
- Establish pre-existing relationships with local community organisation to support **communications and provide feedback** on appropriateness of different measures

International students

FACTORS IMPACTING PANDEMIC EXPERIENCES

Overall, experiences of the pandemic were **largely negative for international students** due to financial pressures, impacts of isolation on wellbeing and uncertainty about the impact on their education.

> *"If you have COVID, you need to stop working, but then you don't have money... when I was working and thought I might have COVID I was scared to get tested... I kept working without getting tested"*— International student, Parramatta

> *"The health insurance aspect was quiet daunting, you have to pay for your health… there's a financial burden if you need to go to emergency or the hospital"* — International student, Parramatta

> *"The only thing I remember was the Prime Minister saying that international students can move out of the country because they don't have any supports for international students... You felt like an outsider"*— International student, Parramatta

> *"We didn't have any translations… sometimes there's no word in my language for English words so I had to use 'Google Translate'… especially about vaccination and medical terminology"*— International student, WA

> *"There was a lot of uncertainty and worry… we didn't know what the future was going to be.. I was scared that my level of education would be lower since I couldn't go into university to do certain components of my degree"*— International student, WA

- **Limited awareness of and access to financial supports** – most participants reported losing work and income due to the pandemic. They struggled to afford necessities, such as food, accommodation and other household essentials. However, due to their visa status, they were ineligible for income support payments (e.g. JobSeeker) and were not aware of financial aids (e.g. utility payment suspensions and protection under tenancy laws). Some reported that, without income, they had to drop out of study and switch to a working visa, impacting their education and career pathways.
- **Isolation and border closures** – participants reported that international border closures exacerbated their sense of isolation from family/ friends overseas, as they knew if they left Australia, they would not be able to come back. They relied heavily on local support from other students but reported that these were disrupted by 'lockdown' measures. As such, they felt lonely and unsupported.
- **Limited affordability and access to health services** – some participants reported that their international health insurance did not cover basic healthcare. As such they avoided going to hospital or accessing health services, including when they had COVID-19 symptoms, due to the financial cost, which put their health at risk. In relation to mental health, they were ineligible for the Medicare rebate and could not afford private services. This was a particular concern for participants given the impact on mental health due to isolation, uncertainty and being told to "return home" by the Australian Government (when many felt unable to do so). However, a few participants reported universities had set up helplines for them for information and support, which they valued.
- **Challenges navigating complex information** – many participants who had limited English reported found it hard to follow complex health information (e.g. about quarantine, medical terms and vaccinations). They reported that these topics were difficult to translate. This led to them missing out on key information and relying on international sources for information. In addition, a few participants reported that there was a lack of specific information aimed at international students.
- **Negative impacts of restrictions on quality of education** – a few participants were forced to study online or return to their home country. Those who were studying degrees which relied on practical components (e.g. clinical or lab-based components) were annoyed or concerned about the impact of online learning on education quality and how this would impact future employment.
- **Access to visa extensions** – a few were grateful for visa extensions during the pandemic which gave them some short-term certainty about where they would live. However, a few reported that who got these extensions and how long for was unclear and felt "ad hoc".

CASE STUDIES

Financial burdens
Khuswant* lost his part time work during the pandemic and was unable to access income supports. He could not meet his day-to-day living expenses without work so decide to pivot to UBER driving. However, he needed to take out a loan to buy a car suitable for this line of work. This put him in considerable debt while also trying to pay for his degree, leading to significant financial stress throughout the pandemic.

Isolation during the pandemic
Ranveer* started university in Australia shortly before the pandemic began. He had very little opportunity to make friends in Australia before being required to go into lockdown in his small dormitory. He went for long periods of time without seeing anyone. Ranveer felt very alone and terrified of being infected with COVID-19. During this challenging time, he reported that the Australian Government messaging towards international students was negative and unsympathetic which made him feel unwelcome and unsupported. His mental health deteriorated over time, exacerbated by his worry about his family in India. Ranveer didn’t get any mental health support in Australia and felt he could not express his mental struggles to his friends and family back home for fear of upsetting them, further increasing his despair and sense of isolation. He felt abandoned, and uncertain about how he would survive the pandemic, especially as lockdowns continued.

When restrictions eased, he was able to quickly make friends who had been in the same position and found that they had all struggled as well. He reported that he was unsure whether he wanted to continue living in a country that he perceived cared so little about him during such a difficult time.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Ensure financial supports are available to enable international students to meet their basic living needs particularly food, accommodation and health services.

Increase awareness of and access to mental health supports for international students

Communication needs:

- **Ensure more technical/ medical information is translated** in different formats
- **Provide specific information for international students**, including what supports and services are available and whether they are eligible
- **Adopt a more inclusive and compassionate tone**
- **Provide clear information for visa extensions,** including about opportunities and eligibility

Cohort summary

Mental health care users

FACTORS IMPACTING PANDEMIC EXPERIENCES

Mental health care users reported **overwhelmingly negative experiences** during the pandemic, with major impacts on their social and mental wellbeing. These challenges were particularly pronounced in regional and remote areas where accessing services posed additional difficulties.

> *"There were absolutely no psychologists available where we live. I ended up waiting eight months to see someone who only offered telehealth. It ended up being too impersonal and there was no guarantee I'd get the same psych each time"*— Participant who uses mental health care, Port Lincoln

> *"All of the control and manipulation from government just built up and just tipped me completely over the edge. When they took away going to the football and taking myself out for ramen, that's when I'd had enough and wanted to kill myself"*— Participant who uses mental health care, Melbourne

> *"My doctor went straight to telehealth… it was an ok experience, but I had mental health issues that required treatment in hospital. When dealing with those issues, it is frustrating to try and use telehealth"*— Participant who uses mental health care, WA

> *"I was hospitalised last month; a friend picked me up and took me. If that had of been back during COVID, none of the support would have been available and I would have definitely killed myself"*— Participant who uses mental health care, regional Tasmania

- **Barriers to accessing mental health services** – many mental health care user participants reported difficulties accessing services which prevented them from getting the support they needed, especially in regional and remote areas. They reported that this was due to long waitlists, workforce shortages, limited awareness of extended Medicare rebates and closure of services (e.g. group therapies and rehabilitation clinics). Some participants reported that due to the public system being overwhelmed, they were forced to access high-cost privatised supports, which limited ongoing access for most.
- **Exacerbation of conditions due to the impacts of pandemic containment measures** – many reported that pandemic restrictions (e.g. lockdowns and border closures) reduced their access to crucial protective factors which were often central to their treatment plans and ongoing recovery, such as socialising, activities they enjoyed, access to support networks and religious or pastoral care.
- **Challenges with the suitability of telehealth** – while telehealth improved service access for some, it was often felt to be inadequate for those with more complex mental health conditions due to perceived difficulties in establishing rapport and the "impersonal" nature of virtual sessions. Some expressed frustration over having to "retell" their stories to new providers each session and shared negative experiences with "time-poor" professionals online. A few reported "giving up" on care entirely due to the insufficiencies of telehealth, leading to the exacerbation of poor mental health.
- **Lack of post-pandemic supports** – the research suggested a need for extended mental health supports post-pandemic, as many participants felt "abandoned" after the initial crisis period. "Fear-based" messaging during the pandemic was felt to have heightened anxieties and poor mental health, increasing the demand for ongoing support.
- **Impacts on substance abuse issues** – some participants reported that their worsening mental health issues contributed to misuse of alcohol and other drugs (AOD), which the research suggested is likely to increase the ongoing need for AOD services. This was particularly evident for mental health care users experiencing homelessness, and participants reliant on face-to-face group care which was interrupted during the pandemic.

Mental health care users

CASE STUDIES

Struggle for mental health care in regional Australia
Julie* was seeing a psychologist through face-to-face sessions before COVID-19 started. She felt that she had a good relationship and rapport with her psychologist until her sessions were changed to go online when the pandemic started. Over time, her service provider became swamped with patients and Julie was no longer guaranteed to be able to see the same psychologist. She felt that she had to retell her story to each new professional she saw, and that her sessions became rushed. Julie lost trust in her provider, making it harder to feel supported and to get the care she needed. She stopped going to psychology appointments altogether and hasn't returned since, even though she knows she's "not in a good place" and "getting worse". Julie blames her negative experiences with telehealth mental health services as the primary cause of her reluctance and barriers to seeking help.

Isolation and mental health during the pandemic
John* is a self-described introvert in his early 30's who struggled with mental health issues prior to the pandemic. Once the pandemic hit, John was made redundant, and his mental health declined dramatically. This pushed him further into isolation, where he would spend his days alone in his room. He began to drink heavily and immersed himself in online content and social media about the pandemic. The strain of differing viewpoints on the pandemic led to rifts in his relationships, further isolating him from much-needed support networks.

Despite reaching out to crisis lines for support on multiple occasions, John experienced long wait times and unfulfilled promises of callbacks – which left him feeling hopeless and angry. Eventually, John's mental health deteriorated to the point where he fled from Victoria to Queensland. He lied to police and said he was homeless to be allowed to cross the border. His relationships have yet to recover and the confusion and anger persist today.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs:

- How to access mental health services and supports for both adults and children
- How to access government rebates or concessions
- Empowering, reassuring and motivating government communications that supports hopefulness, optimism and help-seeking behaviours
- Information communicated verbally and in simple English to reduce cognitive load for those with complex mental health needs

Information sources:

- GPs and mental health service providers
- Family and friends
- NDIS (e.g. for those with psychosocial disabilities)
- Community health services and organisations

Other supports:

- Limit the use of measures which impinge on important protective factors like exercise and access to social networks
- Facilitate continuation of in-person rehabilitation group-based sessions where possible
- Seek opportunities to build the mental health workforce and increase resilience in an emergency
- Continue increased mental health support beyond the cessation of the pandemic

FACTORS IMPACTING PANDEMIC EXPERIENCES

Most parent/ carer participants faced numerous challenges during the pandemic, influenced by factors such as the age of their children, their financial and employment situations and their location in Australia. Compared to other cohorts, parent/ carer participants reported more **negative experiences** and **additional stressors** due to COVID-19, particularly to their mental, social and financial wellbeing.

- **Disruption of the social development of their children** – many reported that their children experienced substantial disruptions to their social development, driven by measures such as school and sporting club closures and social distancing requirements. This contributed to ongoing issues for their children, including school refusal and social anxiety (particularly among younger children). The long-term impacts on children's mental, social and educational/developmental health were a major concern for this cohort, and many felt that these issues were not appropriately considered in the government's response.
- **Challenges accessing healthcare services** – many faced barriers to accessing healthcare, both for themselves and for their children. This was exacerbated by higher demand, especially among young children and new parents. Common barriers included long wait times, limited availability of psychologists, "inundated helplines" and stringent hospital protocols. Telehealth improved access for some health needs but was not felt to be suitable for all types of care (e.g. acute mental health needs, emergency surgeries) or for children who needed rapport building or could not effectively explain their symptoms online.
- **Difficulties transitioning to online school** – many faced challenges shifting to online schooling, including balancing the role of teaching their children while managing their own work from home; additional stress and pressure with a "cramped household"; and extra financial costs associated with purchasing digital devices. These challenges were especially pronounced for parents/ carers with larger families, limited English proficiency and those from remote communities who relied on boarding schools for their children. The research also found variation in the level of support offered by different schools. While some pivoted quickly and were well-resourced, others struggled, leaving families to fill the gap in their children's education. This inconsistency added to the stress experienced by parents/ carers, who expected more support from governments to help schools transition to online schooling more smoothly.
- **Travel restrictions and visitation rights** – for foster and out-of-home care families, travel restrictions interrupted regular visitations with biological parents. Similarly, families with children who had been adopted out experienced difficulties maintaining access to their children, including parents/ carers experiencing homelessness. This led to significant negative strain on the relationship between these parent/ carers and their children.
- **Marital/ partner relationships** – many reported that the heavy load from the above factors had put significant strain on their personal relationships with their partners, resulting in frequent arguments and disagreements, which adversely affected their relational wellbeing and mental health.

> *"The fall out of it still affecting parents. We are battling financially and trying to get back lost time. My child has ADHD and struggled with homeschooling, and is now anxious to go back to school"*— Parent/carer of a primary school aged child, Tasmania

> *"I just had my second baby, but my family wasn't allowed into my hospital room… I was feeling very alone"*— Participant who experienced quarantined, aged under 39 years, Australia-wide

> *"As a single mum, COVID was madness. I have five kids and was pulling my hair out trying to home-school. I needed to cope myself and I also need to provide for them financially and get groceries and keep them safe and happy"*— Parent/ carer of a secondary school aged child, Port Lincoln

> *"I was struggling with what was happening. The daily updates didn't make sense compared to other states. It was frustrating being locked-down so much, because it felt like it depended on where you lived as to how messed up you and your kids were"*— Parent/carer of a primary school aged child, Melbourne

CASE STUDIES

Navigating remote learning

During the pandemic, Chris* was living in with his wife and two children, Mia (aged 7) and Nate (aged 10). His heart sunk when he heard that Victorian children would need to shift to home-schooling. His family was living in a small apartment at the time, and he was working full-time from home. His wife was a frontline worker, so it was up to Chris to manage home schooling.

The only work and study space in their home was the master bedroom so each day Chris and his kids crammed into one room on their laptops – Chris at his desk, Nate next to him and Mia on the floor. Nate was able to keep up with his remote lessons independently, but Mia really struggled. Mia needed a lot of help from Chris to keep up with her mathematics learning, but Chris needed to also uphold his work responsibilities so was often only able to help her after work hours. There were many days when Mia ended up in tears because she was not able to keep up with her lessons and was anxious about getting behind. This left Chris guilty and distressed. While Chris' family is coping now, there was a large amount of strain and tension placed on him and his relationships with his wife, children and work colleagues.

Separated from child during pandemic

James* is a father living in regional Northern Territory. During the focus group, James shared the difficulty he experienced due to three years separation from his daughter, who lives with her mother interstate. The stringent movement restrictions, which James felt were excessive for his area of the country, prevented in-person visits between James and his daughter for the majority of the pandemic. James was limited to contacting his daughter via an occasional FaceTime call, which made it difficult to build rapport and strengthen their relationship. James is also unvaccinated, which meant he faced additional hurdles as restrictions eased, exacerbating his frustration and isolation from his child. He felt betrayed by the government, believing they misled the public about the necessity of the stringent measures, resulting in significant emotional pain and a deep sense of mistrust.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs:

- What supports are available and how to access them, both for self and children
- Clear rationale for implementing and lifting restrictions and lockdowns – that can also help communicate the situation to children

Key information sources:

- Schools and educators
- Family and friends
- Official government websites
- Local health officials

Measures must consider children as a particularly vulnerable group in relation to **social, educational/ developmental and emotional impacts of social isolation** and account for added **burdens on parents/ carers**.

Other supports and resources:

- **Initiatives for children's social development** – e.g. to address social anxiety and school refusal, especially for younger children and new parents.
- **Ongoing access to mental health care** – e.g. availability of child psychologists and mental health hotlines during and after the pandemic.
- **Government-funded devices and resources** – to alleviate financial burdens on families (e.g. to facilitate remote learning).
- **Supports and resources for schools** – to effectively manage transitions to and from home schooling for families in a range of situations.

OVERVIEW OF PANDEMIC EXPERIENCES

Overall, there was **wide variation in experiences** for participants from rural and remote communities. This was driven by variation in case numbers, differences in the capacity of local health services, varied impacts of labour and supply shortages and the protective influence of local community connectedness. On balance, **most participants reported largely negative experiences**. However, a few in remote communities reported less impact or change in their lives compared to those in larger cities/towns.

> *"My son snapped his arm, and we spent more time outside hospital than we did inside... even if you had no symptoms, had driven hours and were in a lot of pain, you had to wait to see someone because of all the rules and how stressed doctors were"*—Parent/carer of a primary school aged child, very remote Queensland

> *"I work in disability support and things were totally hectic for me. It felt never ending. People could only access support if it was a mega emergency"*—Vaccine hesitant participant, Cairns

> *"A lot of sporting clubs folded entirely. Community sport has changed for good now, and we've lost a real sense of community, all because of the stupid restrictions on regional clubs"*— Participant who uses mental health care, Port Lincoln

> *"Everybody looked after one another, which lessened the impact of COVID. People knew who the vulnerable were and supported them all the way"*—Parent/carer of a primary school aged child, very remote Queensland

- **Challenges accessing healthcare services** – many participants reported barriers to accessing health care during the pandemic, including travel restrictions limiting access to hospitals in major towns/ cities and long wait times for accessing over-burdened healthcare services. Participants noted that services were already strained pre-pandemic and that COVID-19 further exacerbated this pressure. Telehealth improved access for some types of care. However, it was not suitable for all types of care (e.g. specialised/ intensive physical and mental health care).
- **Strain on local community connectedness** – community connectedness was an important protective factor for wellbeing in regional and remote communities. Some participants reported that during the pandemic people "checked-in" on more vulnerable neighbors and shared supports and information with each other, which led to more positive pandemic experiences overall. However, others reported substantial and ongoing negative impacts on social wellbeing due to the disruption to important community social hubs (e.g. sporting clubs, gyms and shopping centres), as well as heightened tensions in otherwise tight-knit communities (e.g. increased judgement and neighbourhood reporting for non-compliance).
- **Labour and supply shortages** – compared to other cohorts, participants in regional and remote communities reported difficulty obtaining supplies such as basic grocery items. They reported this being particularly disrupted due to longer distances to travel to stores. In addition, participants commonly reported difficulty maintaining the local workforce due to an already limited supply of workers, and this being exacerbated by decreased availability of backpackers, fly-in-fly-out and seasonal workers and some choosing not to vaccinate. This led to under resourcing, including in essential services like education and health care.
- **Insufficient tailoring of measures and information** – some participants felt that government directives were designed for high density metropolitan areas, with less relevance to regional/ remote communities, preferring responses to be more flexible to the circumstances of regional/remote areas of Australia. In addition, those from more remote areas reported that it was difficult to find localised information about pandemic response measures and relied on local community leaders (e.g. educators and local councils) to find and share relevant information. This increased pressure on community leaders who did not feel supported in this role.

Rural and remote

CASE STUDIES

Sandy's role in communicating with her community
Sandy*, a long-time teacher at a remote boarding school in far-north remote Queensland, has always been a pillar of her small community. While continuing her duties at the school, she tirelessly worked to keep her community informed and safe amidst the rapidly changing guidelines, fielding phone calls and emails all day without additional pay. The constant stream of inquiries, coupled with the confusion and misinformation spreading through word-of-mouth and social media, left her exhausted and overwhelmed. As the situation became more complex, Sandy grew frustrated and often directed people to official government messaging, saying, "I don't know what to tell you anymore - this is just what the government are telling us to do". She expressed how much her community meant to her and highlighted the collective effort of her neighbors in supporting vulnerable members. "Keeping an eye out for community is what we do", noting that solidarity and communication was a significant factor in helping people navigate the pandemic safely.

Lack of timely access to child mental health services
Steph* lives in regional Australia with her husband and three children. Her son developed anxiety early in the pandemic. She tried to get mental health care for him but could not get timely access to any help. She was told that the waiting time was over a year in her town, and she could not access the nearest capital city due to travel and service restrictions. Her son's condition kept deteriorating, and she felt scared and helpless. Steph kept calling different health services, her son's school, mental health hotlines and her GP to see if they could facilitate quicker or alternative access, but to no avail. While she received lots of empathy and sympathy, no one was able to help. Her son then started self-harming and developed other more complex psychological conditions, before finally receiving access to medical help. She feels that her son's condition kept compounding and snowballing because of the delays and that the help came too late to prevent this. This had severe ongoing mental, social and physical wellbeing consequences for her other children, her partner and herself.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Learnings in relation to communications – produce and share resources with community leaders and tailor information about the rationale for introducing measures in regional and remote areas.

Reduce the negative impact of measures on community connectedness where possible – consider continued access to community hubs and social supports.

Access to healthcare services – consider opportunities to expand and build the resilience of local healthcare workforces.

Avoid a one-size-fits all approach to measures where possible – i.e. measures introduced in metropolitan areas may not be necessary or suitable for regional and remote parts of Australia.

Consider added burden for border towns – e.g. address unique challenges for those needing to travel across borders, including to access groceries or services. This also involves improving the exemption process for essential workers required to cross borders for work.

Homelessness

FACTORS IMPACTING PANDEMIC EXPERIENCES

Overall, participants experiencing homelessness during the COVID-19 pandemic reported **considerable challenges** over this period of time, with limited access to services, precarious or dangerous living situations and negative post-pandemic financial and employment impacts. While there were a few unexpected benefits for some, the overall feedback from this cohort was largely negative.

> *"We were treated like animals [in temporary housings]. Police would visit 3 times a day to check on us and lock us up if we weren't there. I got back into smoking after being clean for a year, mainly because I was staying with ex-cons who weren't doing well and were violent"*— Participant experiencing homelessness, Sydney

> *"I was working at a pub and lost my job, which started a downward spiral. One big thing was that I didn't have a fancy phone and so I couldn't sign in or get vaxxed"*— Participant experiencing homelessness, Sydney

> *"I haven't seen my daughter in three years because of the lockdowns. I've given up completely on the government now"*— Participant experiencing homelessness, Darwin

- **Limited accessibility of services and supplies** – most experiencing homelessness during the pandemic reported difficulties accessing preventative health supplies (e.g. masks), tailored information and resources, and mental and physical health care. They reported that access to charities and food banks were strained due to social distancing requirements and a reduced volunteer workforce. While telehealth provided some support, it was not suitable for all health and wellbeing needs. This model of care was felt to be less effective for group activities like Alcoholics Anonymous (AA) meetings and other rehabilitation supports.
- **Temporary housing solutions –** many reported being housed in hotels and shelters at different points throughout the pandemic, which provided warmth and regular meals. However, with increased efforts to ensure people were in accommodation during the pandemic, some female participants reported heightened safety concerns and experiences of violence, aggression and sexual harassment from others sharing the same accommodation. In addition, many participants reported that help-seeking and escape from dangerous situations was made more difficult due to restrictions on movement enforced through fines and punitive policing, as well as limited awareness of available options.
- **Incarceration and post-release challenges** – some who experienced incarceration during COVID-19 faced challenges upon release. With limited options, many had to move in with family, leading to heightened volatility and unhealthy situations for some participants and their families. Additionally, they felt that the pandemic had negatively impacted the economy which added to their challenges finding work, meeting basic living expenses and reintegrating into the community.
- **Financial challenges post-pandemic** – many accessed financial supports which helped them support themselves during the pandemic. However, participants reported that the abrupt cessation of payments following the pandemic led to increased financial instability and difficulty re-adjusting to life on a lower income again. This had substantial impacts on the wellbeing of this audience.
- **Technology barriers** – reliance on technology during COVID-19 posed various challenges accessing services for this audience. Many relied on cheaper models of mobile phones that were incompatible with QR codes and digital vaccination certificates. As such, some were required to purchase expensive smartphones and data plans to participate in daily life, which added to the financial and emotional burden of the pandemic.
- **Limited contact with children and family** – some struggled to maintain contact with their children, especially when their children lived in foster care. For these participants, restrictions on visitations and the impersonal nature of online interactions increased disconnection from family, leading to more fractured relationships.

Homelessness

CASE STUDIES

Struggle with reintegration
Hamish* is a 45-year-old man experiencing homelessness in a regional town outside of Darwin. He was incarcerated at the beginning of the pandemic: “We were like dogs locked in cages, starving and isolated”. He reported that those running the prisons “knew nothing about COVID-19” – leaving people confused and uncertain. After leaving prison, Hamish found himself couch surfing at his ex-wife's place which strained their relationship and created animosity. "I had no outlets," Hamish explains. "I couldn't go outside, I couldn't work, I couldn't get my life back together." Isolated and without constructive support, Hamish relied on substance use to cope. A lack of post-release supports, compounded by trauma and restrictions, severely hindered Hamish's ability to reintegrate into society and maintain stability.

Heavy policing and drug addiction
Maria* has experienced homelessness for many years and has battled an intense drug dependency. Grappling with agonising withdrawals at the height of the lockdowns, Maria struggled to access resources and supports. Daily trips to the clinic for methadone treatment became a daunting task and she grew fearful of moving around due to intense policing and limited access to masks, which led to a $5,000 fine from law enforcement. This extra financial burden compounded her distress, as she lacked the means to pay such fines while already struggling to meet basic needs like food and shelter. Maria was plunged further into despair when the JobSeeker payments were abruptly withdrawn – at this point she told the group she battled with suicidal ideation daily. She knew friends who killed themselves throughout this time, due to no income and mounting fines and debt. Maria spoke of her feelings of isolation, distrust and abandonment, and felt that the heavy policing of marginalised communities typified her experiences with the government throughout the pandemic.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs

- How to access essential services and supports
- How to stay safe from COVID-19
- Information about the vaccines – including why it is useful

Sources of information

- Largely found to not seek information about the pandemic, indicating a substantial need for push communications
- Crisis housing organisations

Other supports

- Provide free masks, COVID-19 tests and other preventative health supplies
- Continue providing targeted recovery supports and services post-pandemic
- Offer financial support for devices and data plans
- Design financial aid to minimise negative impacts of sudden income changes
- Consider the gender composition of temporary housing to ensure safety
- Allow exemptions from certain restrictions for families fleeing domestic violence situations
- Implement compassionate grounds for fines imposed on people experiencing homelessness
- Classify charities and key volunteers (e.g. food banks, shelters) as essential workers

Vaccine hesitant

FACTORS IMPACTING PANDEMIC EXPERIENCES

Overall, the research identified vaccine hesitant attitudes and behaviours **across all cohorts in the research**. Among those who were most hesitant, the research found that there were two groups of people: those who **were suspicious or concerned about the COVID-19 vaccine before the pandemic**, and those who **gradually became more suspicious or concerned during the pandemic**. Across both groups, most felt that what they saw or personally experienced in relation to vaccines was inconsistent with what they were being told by government sources, which heightened distrust of official sources.

Already vaccine hesitant

These participants were **concerned about the vaccine prior to the pandemic** and never planned to receive it.

Factors driving hesitancy:

- **Pre-existing concerns about vaccine safety** – e.g. they were already concerned about vaccines generally, felt they were at risk of vaccine related harm (e.g. due to a health condition); or felt the vaccine was "too new".
- **Pre-existing suspicion of pharmaceutical companies and funders** and their commercial influence in driving vaccinations via public health actions and advice.
- **Limited trust in government or the public health system** – especially among those who had previous negative experiences with the health system/ vaccines.

Factors impacting experiences:

- **Feeling that their safety concerns were "dismissed" or "ignored"** in the push to get people vaccinated.
- **Feeling "stigmatised"** – many reported health professionals or others in the community **treated them dismissively or disapprovingly** if they communicated their hesitancy or concerns.
- **Having their "right to choose" removed** – most felt "frustrated" or "distressed" by being "forced" or "coerced" to choose between risks to their health, or to their financial or mental wellbeing if they did not get the vaccine. Some who had vaccinated themselves or their children reported that they still felt "guilty", "scared" or "anxious". Others who did not get vaccinated reported losing work, being socially isolated, or feeling stigmatised by others in the community.

> *"COVID has completely changed my views on the medical field and profession… my trust is at rock bottom, gone completely"* – Vaccine hesitant participant, Tasmania

Grew hesitant over time

These participants held more positive attitudes towards vaccinations generally before the pandemic but **became increasingly concerned/ sceptical about the COVID-19 vaccine over time**.

Factors driving increased hesitancy over time:

- **Gradual exposure to side effects** – through their own or others experiences of vaccine injuries, blood clotting, loss of senses, or other side effects. This led to concerns that the vaccine was too "new" and "untested".
- **Vaccinated individuals getting COVID-19/ long COVID** – which contributed to the perception that the vaccine was ineffective.
- **Exposure to misinformation** – e.g. that it can "change your DNA".
- **Limited understanding about rationale for changes to vaccines and vaccine mandates** – including confusion about why mandates were lifted when COVID-19 was still prevalent in the community, and why AstraZeneca was removed from the market. This contributed to the perception that the vaccine and vaccine mandates had been harmful, ineffective or unnecessary.

Among this groups, some **chose to "wait and see" before deciding if they would get the vaccine**, while others got the vaccine, but **regretted it** or felt they would be **unlikely to get a "new" vaccine again in future**.

> *"I got suspicious because a lot of the things didn't add up with the vaccine and why they were pushing it down people's throats when it wasn't tested"* – Vaccine hesitant participant, Cairns

Cohort summary

Vaccine hesitant

CASE STUDIES

Impacts of vaccination mandate

Sarah* fell pregnant with her second child during the pandemic. They needed to move back to their home in Queensland from interstate. She was nervous about getting the vaccine while pregnant, but was told that if she didn't, they would need to quarantine for two weeks. After contacting different hotels, she was unable to find anywhere that could accommodate her husband's disability. She felt her only option available was to get the vaccine – she cried as she told this story because she still felt fearful, anxious and guilty about her decision to vaccinate her unborn child, and the potential long-term impacts of a new and untested vaccine on a baby.

Declining trust in government information

Donald* was reluctant to receive the vaccine due to its perceived novelty and limited information available about it. He believed the information he was receiving from the Australian Government was lacking and went seeking information from international sources. He found individuals advocating the use of ivermectin to treat COVID and opposing the available COVID vaccines, explaining that the vaccine altered people's DNA. The information he was finding only increased his apprehension about the vaccine. He held off on getting the vaccine to see how it would affect others first.

Soon after receiving her vaccine, Donald's mother suffered from serious blood clots and had to be taken to the hospital. One of his friends had a heart attack shortly after getting the vaccine and was also hospitalised. Seeing these adverse reactions in his loved ones, he decided not to get vaccinated. He noticed all the information the Australian Government disseminating about the vaccine was overly positive and felt that the possible side effects were never properly disclosed.

Later, when he found that Australia was not withdrawing the AstraZeneca vaccine despite many countries doing so, his trust in Government reduced and he thought that other overseas sources of information were more reliable. He also believed that people were coerced into taking the vaccine and there was never really a choice, as people risked losing their jobs if they weren't vaccinated. Even today, Donald's mistrust in the Australian Government continues and he continues to seek his information from international sources. He believes the Government to be "grossly incompetent" and has "built a large community with other like-minded individuals" who have lost trust in government as well as institutions (e.g. health, pharmaceutical, universities, police) in Australia.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES IN RELATION TO VACCINATION

Information needs

- **Encouraging and empowering information** which communicates **'why'** vaccination is important and what the **risks and benefits** are
- Ensure people feel their concerns are **heard and responded to appropriately**
- **Ensure clear, timely and tailored information is available** before the roll-out

Implement strategies to **build broader trust and social license** in vaccinations and public health advice in preparation for future events

Ideally, implement an **opt-in incentivised approach** (with extensive education and communication) before moving into a mandated approach for vaccine roll-outs

Hotel quarantine

FACTORS IMPACTING PANDEMIC EXPERIENCES

Participants who experienced hotel quarantine during the pandemic reported **widely varied and often negative experiences**. This was driven by a perceived lack of flexibility to meet individual needs, negative experiences with hotel quarantine providers and a lack of clear and consistent information. Overall, structural barriers within the hotel quarantine program contributed to notable disparities in the level of hardship experienced by participants, with some facing more severe challenges than others.

> *"We were put on level 22 and I have three kids under five [years]. They were all overstimulated and we couldn't open windows or move around"*— Participant who experienced quarantine, aged under 39 years, Australia-wide

> *"I spent five months in Kenya and kept checking prices. It was expensive to pay for a hotel, so I waited ages"* — Participant who experienced quarantine, aged 40+ years, Parramatta

> *"The transparency was the issue… not knowing how long. I was more scared of quarantining than getting COVID"*— Participant who experienced quarantine, aged under 39 years, Australia-wide

> *"I felt trapped, clueless and scared. It was awful, like I was in jail. Being isolated from family and friends really took a toll on my emotional wellbeing"*— Participant who experienced quarantine, aged 40+ years, Parramatta

- **Limited flexibility and tailoring to meet individual needs** – many participants reported rigid hotel quarantine arrangements that limited their choices and failed to accommodate their individual needs. The hotel facilities and services provided to participants often did not meet important requirements, such as the need for multiple rooms when quarantining with larger families, specific dietary requirements or accessible accommodations for people with mental health conditions and/or physical or neurological disabilities. This was a significant source of stress and dissatisfaction for these participants, who felt they were given limited agency, independence and availability to choose suitable arrangements.
- **High costs and variation in financial coverage** – the high financial cost associated with hotel quarantine (and or travelling back to Australia) was a major concern for many, who felt that the financial burden on individuals was substantial and inequitable. Some participants reported that the high costs led them to forgo "important travel", such as visiting dying family members or attending funerals. However, a few participants acknowledged that the cost was necessary to deter non-essential travel, and that incurring financial costs was reasonable when non-essential travel was a personal choice. Additionally, a few participants noted that hotel quarantine costs were covered for those with no other choice (e.g. people released from prison returning to their home State/ Territory) and felt that this reduced inequities.
- **Limited awareness and information** – many reported gaps in understanding and limited access to clear and up-to-date information about the hotel quarantine process. These participants reported confusion about the duration of quarantine, procedures for securing accommodation and how to make complaints about negative experiences with hotel quarantine providers. The perceived lack of consistent and clear information added to stress and anxiety for many participants, affecting their ability to make informed decisions about travel plans.
- **Negative impacts on mental health and wellbeing** – the research found that social disconnection and isolation experienced during hotel quarantine had a notable negative effect on some participants' mental health. These participants reported feelings of heightened anxiety, frustration and stress – which were exacerbated by the above concerns. Unsuitable quarantine conditions, including a lack of natural light and fresh air, were common drivers of mental ill-health. Regular check-in calls from social workers were therefore appreciated by some.
- **Negative experiences with hotel quarantine providers –** some participants reported poor experience with hotel providers. Issues included poor quality facilities, unclear communication about quarantine requirements from staff and unsupportive and at times "disrespectful" staff.

Hotel quarantine

CASE STUDIES

Hotel quarantine with two children

Katie* was in America at the start of the pandemic due to her husband's work. However, her father became very unwell, so she and her family decided to move back to Sydney. Travelling back was easy, but on arrival her family was required to go into hotel quarantine. The extended time in a closed, cramped hotel room with no opening windows, two toddlers (one with a disability) and her husband was mentally, emotionally, relationally and physically exhausting for Katie. She had to entertain two "overstimulated" toddlers during the day without proper sleep as her husband had to work online during the night. She was also scared and worried that she may not get to see her father as his health was deteriorating. The experience was overwhelming for her and she is still angry about the entire situation, particularly when she recalls the conditions she and her family had to live through for two weeks, as well as the "unfriendly" and "abrupt" way the staff at the hotel treated her and her family.

Isolation and trauma in hotel quarantine

Sofia* experienced hotel quarantine alone with her three-year-old son, and said she was entirely unprepared. With no prior information on how to prepare, they were taken from their home by ambulance without any explanation. Sofia only learned upon arrival at the hotel that they would be confined to their room for ten days. A few days into the quarantine, a friend thankfully sent toys for her son. Sofia's son, now almost six, still clearly remembers the traumatic experience. Sofia described feeling like they were "treated like absolute pigs", with minimal communication and no information. Meals were delivered with a knock at the door, which excited her son, but he was unable to open the door or say hello. The lack of support and understanding from staff left Sofia and her son feeling isolated and traumatised.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs

- Why hotel quarantine is required
- How to prepare for quarantine
- How to self-care in quarantine (e.g. mental health care)
- What options and choices are available for quarantine facilities
- The mental health supports available for hotel quarantine users

Other support needs and resources

- Consider more **home-based quarantine** options over hotel quarantine facilities where appropriate
- Consider the flexibility of hotel facilities to **accommodate the diverse needs** of families, people with mental or physical illness and those with disabilities
- Have **dedicated quarantine facilities and trained staff** that can be quickly mobilised in the event of an emergency
- Ensure **clear and consistent communication** about hotel quarantine requirements, procedures and complaints processes, especially before entering quarantine
- Provide **options to reduce financial burden**, especially for those facing existing financial hardships or travelling on compassionate grounds
- Ensure **support is offered to people in quarantine** through telephone calls or online, and with qualified professionals

Long COVID

FACTORS IMPACTING PANDEMIC EXPERIENCES

Participants experiencing long COVID-19 reported **major challenges and negative experiences** throughout the pandemic with ongoing residual impacts. These challenges were driven by persistent health issues and a perceived lack of support from government and medical professionals.

> *"It felt like I got hit by a ten-tonne truck, and that stayed for about two years. I started finishing work at 3:00pm and was too tired to get myself home. Constant nausea, too sick to even watch TV"*— Participant with long COVID, Melbourne

> *"They needed to bring in exemptions for [people with long COVID who would kept testing positive] so that we weren't impacted so heavily by the lockdowns… me and my family still feel the impacts now [from so long in isolation]"* — Participant with long COVID, Melbourne

> *"I'm always sick now, I've gained weight and developed pretty bad anxiety. I would cry every day for six months and started feeling like I should just die. I honestly wanted to die; it was excruciating"*— Participant with long COVID, Melbourne

> *"I was told by doctors not to come in because there was nothing that they could do about it. They told me to look online for other medications, which was really terrifying"*— Participant with long COVID, Melbourne

- **Chronic health impacts** – most participants who experienced long COVID reported ongoing physical symptoms, such as loss of smell and taste, prolonged respiratory issues (e.g. coughing and breathlessness), muscle spasms/ restlessness, extreme fatigue and mental fog. These resulted in reduced mental and physical capacity, negatively impacting their ability to maintain normalcy in daily life (including work, family responsibilities and relationships). The overall lack of effective treatments was disheartening for many. During the pandemic access to telehealth was beneficial for some, but many reported it did not adequately address the complex needs associated with long COVID.
- **Negative perceptions of restrictions and testing** – compared to other cohorts, participants with long COVID were less supportive of isolation requirements during the pandemic, particularly those who continually tested positive to COVID-19 despite not having severe symptoms or being contagious. Prolonged isolation led to heightened anxiety, depression and stress at a time they were already struggling. Some felt these restrictions did not adequately account for those with long COVID, and created an "unfair" barrier to accessing face-to-face services and social supports.
- **Impact on mental health and challenges accessing mental health care** – the enduring nature of long COVID symptoms compounded mental health challenges for many, with a few resorting to unhelpful coping mechanisms (e.g. smoking and alcohol). Feelings of helplessness were exacerbated by the lack of effective treatments. Many reported limited awareness of available mental health supports and challenges accessing Medicare rebates for mental health treatments which reduced access to valuable supports.
- **Information gaps** – participants reported that there was limited information tailored to managing long COVID symptoms, contributing to a sense of helplessness for many. Most felt that the ongoing impact of long COVID required more tailored government supports and greater public awareness. A few reported accessing alternative medicines and exploring alternative information online as a way of filling this gap.
- **Increased vaccine hesitancy** – some experienced negative reactions from the COVID-19 vaccine and re-occurring COVID symptoms post-vaccination, contributing to vaccine hesitancy.

Cohort summary

Long COVID

CASE STUDIES

A young mum's long COVID journey at home with her daughter
Brooke* experienced long COVID during the pandemic that lasted almost two years. Stricken with debilitating symptoms, Brooke spent most of this time bedridden – grappling with severe physical and mental health deterioration. The relentless struggle took a toll on her wellbeing to the extent that she found herself in the depths of despair, contemplating suicide. Brooke told the group that she would cry daily and was unsure if she would ever recover. Brooke now struggles with her weight and has been diagnosed with anxiety and depression. The consequences of this prolonged period of major illness also affected her daughter. With Brooke unable to provide the level of support she wanted to due to her health, her daughter fell significantly behind at school. Her daughter now faces challenges adjusting to school life again, suffering from "separation anxiety" and struggling academically.

LEARNINGS FOR FUTURE HEALTH EMERGENCIES

Information needs

- Reassuring, constructive and tailored information about long COVID
- Positive, hopeful and informative government communications
- Vaccine impacts for those with long COVID and rationale for vaccines

Other supports

- Improved access to healthcare services that cater specifically to the complex and enduring symptoms of long COVID, including more research into the causes, treatments and long-term implications
- Address gaps in mental health support and clear pathways to access treatments covered by Medicare
- Policies that accommodate changes in work schedules and physical capacity due to long COVID symptoms
- Educating healthcare providers, employers and the public about the realities of long COVID to improve understanding and support for this audience
- Consider exemptions for those with long COVID to ensure appropriate access to face-to-face services (especially when testing positive but not contagious)