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SELECT COMMITTEE ON THE COVID-19 2021 PANDEMIC RESPONSE

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Submission Cover Sheet

Inquiry into the COVID-19 2021 pandemic response

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into the COVID-19 2021
pandemic response**

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Health Care Consumers' Association

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Background

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

We sought input from a range of consumer members and organisations, including:

- HCCA's Health Policy and Research Advisory Committee
- Women With Disabilities ACT (WWDACT)
- Advocacy for Inclusion (AFI)
- Carers ACT
- Women with Disabilities Australia (WWDA)
- National Ethnic Disability Alliance (NEDA)

We have also drawn on our experiences in working with and talking with consumers during the COVID pandemic to shape the issues raised in this submission.

HCCA members are grateful for and appreciative of the work and commitment of members of the ACT Government and their officials as well as clinicians and health services staff for the effective response. While the health response has been highly successful, there has been unintended and significant consequences for consumers and our families in navigating a very different healthcare landscape. In this submission we recognise the things that have worked well and also identify those issues that point to areas for improvement.

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1. General comments –

Overall, HCCA has been impressed with the COVID response by the ACT Government to the pandemic. The collaboration across sectors and services has been good to see and we feel that learnings from 2020 have been able to be applied in 2021. The Government has been working closely with our community organisations to try and respond to the needs of those people who have been disproportionately affected by the pandemic.

We know that health care workers and policy makers have put in an enormous effort to responding to many urgent issues that have arisen during the pandemic. There has been a demonstrated commitment by our health services to meet the challenge of balancing health and safety during the pandemic, alongside the many ongoing needs for consumers in our healthcare system. The responses at Condamine Court, Ainslie Village, as well as the establishment of the Ragusa Quarantine facility are examples of successful collaborations between health services and the community sector during the ACT's pandemic response.

Since March 2020, with the first wave of the pandemic, HCCA has worked closely with health services in the ACT to develop the clinical response. Our organisation is committed to the principle of consumer empowerment and for us that means people being in charge of our own health. We're also very focused on the delivery of safe, high quality healthcare. We want a system where consumers are actively involved in decision making and to feel supported to ask questions and then get the answers in a way we understand. We have been applying this approach to what's happening in our clinical and community response to COVID-19.

The HCCA Executive Director is a member of the Clinical Health Emergency Coordination Centre (CHECC). This group provides advice to the Chief Health Officer regarding the clinical response to COVID-19. The CHECC was established in April 2022 and prior to that HCCA was represented on the Canberra Health Services COVID-19 Task Force. Its members are senior leaders of the ACT health public health and hospital system. The HCCA role is NGO and Community Liaison and involves talking with consumers and community organisations about their experience of COVID-19 and ensuring this is considered in CHECC decision making.

For this outbreak there has been an improvement in communication with consumers and communities, which has been pleasing. We have been encouraged to see ACT Health and Canberra Health Services using social media to help spread messages out to the community. For example, the use of Facebook posts helped to keep consumers up to date with the latest data, safety advice, access to services (such as COVID-19 testing and vaccination) and changes to restrictions. There have been responses to many individual questions and comments from consumers via social media. Facebook links have also provided easy access to press conferences, which was particularly important to consumers during the ACT's lockdown period. We also appreciate that the Government has attempted to provide materials for those people who do not use social media.

We know that Commonwealth decisions have had an impact on the ACT Government's COVID response, particularly in relation to vaccination. The ACT Government, along with the primary care sector and the support of the Capital Health Network, has done a good job in delivering our allocated supply of vaccines as this has become available. We should be very proud of the vaccination rate achieved in the ACT, which has been outstanding. The rate of COVID vaccination in the ACT bodes well for helping limit severe illness and death amongst our population as the pandemic continues.

COVID has changed the way we access health care and it will continue to affect the way we do business as usual across our health system. For example we have seen an increase in the use of telehealth. This has been an effective option to reduce the transmission of the virus. While the situation may become more challenging in the coming months as restrictions ease, we hope to see the collaborative work with community organisations continue in COVID environment. HCCA looks forwards to a continuing role in this important work.

The power of evaluation and reflection is often undervalued. We think it is even more important in times of crisis, like now. We need to take the time to think back on what's worked well and consumer what we need to change to improve our individual and collective response to a situation. We see this Inquiry as an opportunity for us all to reflect on what has been happening and think about changes we can make to ensure that people get equitable access to the health care and social supports they need to stay safe.

The pandemic has presented a range of opportunities for research, not only around COVID-19, but how we manage pandemics in health care and society more broadly. HCCA supports the valuable role of consumer-based research, involving consumers at all levels and stages of the research process. This will help ensure that results of research help support improvements in safety and quality, as well as health outcomes. We cover this in more detail later in our submission.

We are often critical of the glacial pace of reform in the health system but the way we have all worked together to respond to a significant threat has been extremely satisfying. It shows that change and reform is possible. HCCA is interested in building on the positive aspects of what happened in the clinical and health response post-COVID. There are numerous opportunities to improve our health system and address health inequity, and ultimately leading to a more sustainable health system.

2. Key Issues

The following sections cover a range of key consumer issues identified by and raised with HCCA during the COVID-19 pandemic.

As part of our submission, we have de-identified quotes from consumer and carers. Input from other community organisations have also helped to shape our submission.

2.1 Consumer experience of care during the pandemic

HCCA advocates for consumer-centred care as the foundation of the way healthcare is provided in the ACT. Consumer-centred care can be understood as an approach that attempts to dissolve the structures of power inherent in healthcare, moving towards a non-hierarchical partnership between consumers, their support systems and professionals. Consumer-centred care is grounded in autonomy and frames the consumer as an active participant in decision making around their health care. It is also deeply attentive to the personal context of the consumer as well as the social determinants of health which underscore their experience of health and wellbeing. At its core, it is care that 'meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals'¹.

HCCA has consistently received feedback about the need for health systems in the ACT to create relationships of trust with the community in order to truly deliver consumer-centred care. Consumer-centred care is not only about the individual clinical experiences of consumers, but also the broader structures within our health system which embed a robust and diverse consumer representation throughout all stages of planning and decision making. The COVID-19 pandemic has demonstrated the key importance of consumer voices in emergency planning, the delivery of public health outcomes and safeguarding positive clinical experiences for consumers.

We need to ensure that a diverse range of consumer voices are integrated into health service planning. Liaising with consumer representatives is not always sufficient, and can feel shallow and tokenistic if this is the only attempt at consumer engagement by health services. As reflected by one consumer:

'Health systems forget the high level of mistrust and pain experienced by marginalised people in health settings. They often forget the specificity of people's experiences and connection to community, which is absolutely vital to building strong relationships. There needs to be targeted and specific efforts to engage with diverse communities. Whilst ACT Health has liaised with the Disability Reference Group, the DRG is not wholly representative of the disability community, just as the Multicultural reference group is not a surrogate for the multicultural community.'

We know that consumers are not homogenous and there is significant variation in our skills, motivations, needs and resources. We saw evidence that traditional public health measures were not working with people who were more at risk of poor outcomes if they contracted the virus or were in need to quarantine. We were pleased to see the public health team liaise with colleagues in NSW and Victoria for advice and adjust their approach. An important aspect of this was recognising the expertise and knowledge that rests within communities and community organisations.

The impact of restrictions on visitation on the experience of care and patient safety

The introduction of restrictions on visitors to patients in hospital and other health services has been a necessary but challenging element of the COVID-19 response. While these restrictions are essential to infection prevention and control, they create other risks for patient safety and quality of care, which must be actively managed by health services. Specifically, there is clear evidence that the presence of family and carers in health services improves patient outcomes on a range of measures and reduces adverse patient outcomes. Patient visitors play an important role in the care process, and advocate for patients². Given the high vaccination rates in the Canberra community and the use of PPE in high-risk settings, many consumers have struggled to understand why visitation continues to be so restricted. How do we balance the risk of infection with the risk of harm because consumers do not have the support they need while they are in hospital? HCCA suggests that health services could safely and responsibly manage infection risk, while easing visitor restrictions.

Visitor restrictions have been very hard for those accessing health care as well as their families. One member of the multicultural community in Canberra noted:

'There were many restrictions to accessing services in Canberra during the pandemic. If somebody is unwell or in hospital, as part of our culture everybody wants to go and visit in order to provide support. We are a very tight-knit community and rely upon each other. Rightly these decisions (to restrict visitation), were about protecting people, but it wasn't communicated clearly to our communities. People felt a bit targeted and like the government didn't understand our forms of cultural support.'

HCCA understands that the restrictions are about keeping people safe, and are designed to prevent the spread of the virus and ensure the safest environment possible for patients and health care workers. But we also know that visitor restrictions can create unintended risks for patient and staff safety.

Without family and carers with us, patients may be more at risk of falls, pressure injuries, not being able to eat our food or there being delayed recognition of deterioration. A recent systematic review found that patients affected by visitor restriction report an increase in pain levels and a reduced ability to care for themselves³. This review also reports that in geriatric care “the nutritional status of long-term patients decreased due to reduced oral intake during the visitor restriction period”. HCCA is interested to know to what extent visitor restrictions have similarly impacted people in the ACT. Family and carers can play a role in the management of challenging behaviours often associated with delirium. They can settle patients when they are agitated⁴. We are interested to know if there was an increase in agitation and aggressive behaviours during the visitor restriction period. Was there an increase in the prescription of antipsychotic medication or other restrictive practices in the ACT?

As well as these negative impacts on patients, visitor restrictions place additional strain on staff, especially nurses⁵. When carers are unable to participate as key members of the health care team, the need for support shifts to staff and can exacerbate professional stress levels and place additional strain on health system functioning more broadly. Numerous studies have found hospital performance falls when visitation is restricted. For example, one study found that hospitals “with closed visitations saw most pronounced deficits in their performance with regard to patient ratings of medical staff responsiveness, fall rates and sepsis rates”⁶. HCCA calls on the ACT Health Directorate to complete an analysis of the impact of visitor restrictions on patient safety and consumer experience in public and private hospitals and report the findings publicly.

Consumers and families have accepted the restrictions, but in return we seek assurance that staff are able to involve family in bedside handover, discharge planning, medical rounds and other important interactions. This demands that staff are creative and proactive in finding ways to communicate with carers and family, involving us in care to the extent that patients wish, despite visitor restrictions. Unfortunately, this has not been as smooth as we need it to be. It takes time and planning to involve family and friends in this way, and health service staff have been working under incredible pressure. Yet involvement of carers remains a crucial component of safe care during COVID-19 and staff must be supported to do this work.

Visitor restrictions also exacerbate inequities among patients and families who may not have access to the technologies that we need to connect virtually. HCCA is interested to know how family members have been supported to participate in care, and communicate with patients and the care team, including remotely where this has been necessary.

The role of carers

For care to be consumer-centred across our health system, it is vital to recognise the key role of carers in supporting health consumers. We know that the kinds of care people used changed dramatically during the pandemic, particularly during lockdown when access to services was often difficult. As care transformed and consumers adapted, needs emerged around carers and their structures of support as roles also changed. It is clear that not all people who provide care are linked into support organisations such as Carers ACT and it is consequently important that public health campaigns also broaden their scope to include the caring community. As reflected upon by a consumer:

'There was a presumption that individuals who needed care would have already been linked into networks of support, whereas the restrictions around COVID-19 meant that many people experienced a drastic shift in their caring responsibilities as other forms of support became unavailable. For example, people may have acted in a care capacity to support people to doctor's appointments, but suddenly they found themselves being responsible for medications and medical care. This also meant that people who weren't already linked to existing support services weren't necessarily provided all of the supports that they needed in order to perform the new kinds of care they found themselves doing.'

Taking on new kinds of care, or adapting to existing care needs, without structural support can lead to detrimental impacts both on carers and those receiving their care. One consumer reflected on the way in which there can often be power imbalances in relationships of care. Without further support for both carers and those being cared for, these changes in dynamics can lead to strains in relationships, increasing the possibility for violence, abuse and neglect to occur.

'Caring roles in the home were stepped up so that people wouldn't need to be admitted to hospitals. There's no consideration of the burdens this places on carers as deputised nurses, doctors and psychologists. It also puts family relationships in jeopardy as family relationships are transformed into focusing on enforcing and enabling medical tasks. People have reported feeling more unsafe in their family home as these new caring responsibilities saw different hierarchies of power emerge in a domestic context.'

2.2 Health Inequity and COVID-19

The pandemic has had an unequal impact on our communities. It has exposed & compounded long-standing inequities that negatively impact the health and wellbeing of many Canberrans. We have been pleased with the Government's focus on supporting those people most at risk of poor outcomes if they have COVID-19. This

is a key difference between 2020 and 2021. This year during the outbreak the needs of our people experiencing disadvantage were front of mind.

Collaboration with the community sector improved in 2021. There was recognition that those people most affected by the impact of COVID-19 were often likely to seek assistance from community and non-government organisations (NGOs). This includes people living in poverty, people who are experiencing homelessness, or living in overcrowded houses, people who have dependencies on alcohol or other drugs, as well as people who have recently migrated to Australia. It is vital that our public health responses include cross-sector collaboration as a key method of developing and sustaining health equity beyond the pandemic.

The exploration of options to provide financial support and security to community sector organisations during this period was positive. In September 2021, the ACT Government announced a boost to funding⁷ for mental health, alcohol and other drug services and primary health care, to support wellbeing needs of consumers during the lockdown, as well as to provide longer term funding for local mental health and community health support programs. This measure provided \$3.6m in additional support⁸, including both CAHMA and Directions Health Services. This is an essential recognition of the value that NGO collaboration brought to COVID-19 response.

Health Literacy

We provide information sessions and workshops to consumers and community groups to build understanding of the health system. This is part of HCCA's work in the area of health literacy. Health literacy describes the knowledge, skills, confidence and motivation that people need to make sound decisions about their health in the context of everyday life. It is essential to:

- find, understand, and use health information
- be involved in decisions about our care
- access the services we need and
- navigate health and social support systems⁹

Across our communities our health literacy has increased during the pandemic. Consumers learned the language of the pandemic: flatten the curve, surge capacity, PPE, double dose, TTIQ, epidemiology, breakthrough infections. So many terms we now find ourselves using in conversation.

We are more attune to health messages. At HCCA, we have provided significant feedback to Government on messaging for health communities, the importance of using plain language, minimising the use of technical terms and medical jargon.

Experience during the pandemic has demonstrated that health literacy is a modifiable determinant of health – it can change over time, and increases with

support, education and lived experience of a condition. It is a “state, not a trait”¹⁰. Most people in the ACT community will face health literacy challenges at some in their life. The best available national data indicates that around 44% of adults in the ACT have a level of health literacy that can make it difficult to get and use health information in daily life¹¹ – for example, to calculate the safe recommended dose of an over-the-counter medication, follow a health care professional’s advice about how to self-manage a long-term condition, or to assess the risks and benefits of COVID-19 vaccination.

While health literacy challenges can affect anyone, people experiencing socioeconomic disadvantage are more likely than others to have low health literacy skills confidence and motivation. This includes people who did not complete high school, people earning low incomes, people from migrant and refugee backgrounds, people with multiple chronic conditions, and people who are disconnected from social and health services¹². Young people in complex circumstances and experiencing disadvantage face additional challenges in getting and understanding health information, and making good health decisions. Socioeconomic disadvantage is a risk factor for poor health outcomes, and low health literacy compounds this risk. People with low health literacy are also more likely to experience avoidable adverse events when using health services and to be disconnected from preventative health programs (such as risk screening for disease) and health promotion education¹³. Supporting good health literacy, including in relation to COVID-19, is part of a health equity agenda that seeks to provide everyone the opportunity to have the best health possible.

A study by Prof Kirsten McCaffrey and colleagues from University of Sydney¹⁴ found that

People with inadequate health literacy had poorer understanding of COVID-19 symptoms (49% vs 68%; $p < 0.001$), were less able to identify behaviours to prevent infection (59% vs 72%; $p < 0.001$), and experienced more difficulty finding information and understanding government messaging about COVID-19 than people with adequate health literacy. People with inadequate health literacy were less likely to rate social distancing as important (6.1 vs 6.5; $p < 0.001$) and reported more difficulty with remembering and accessing medicines since lockdown (3.6 vs 2.7; $p < 0.001$). People with lower health literacy were also more likely to endorse misinformed beliefs about COVID-19 and vaccinations (in general) than those with adequate health literacy. The same pattern of results was observed among people who primarily speak a language other than English at home.

This underscores the critical importance we must place on addressing the health literacy, language and cultural needs of the community in public health messaging about COVID-19.

Aboriginal and Torres Strait Islander Communities

We know that around eleven per cent of COVID-19 cases in the ACT during the outbreak in the last few months have identified as Aboriginal and/or Torres Strait Islander people¹⁵. Children in the ACT's Indigenous community have been disproportionately affected, with more than sixty children under 12 diagnosed with COVID (who are not eligible for the vaccine). The median age of the approximately 200 COVID-19 cases in the Indigenous community has been 19 years. We note that with the concentration of cases in younger people, it is understandable that 77 per cent of the total group were not yet vaccinated¹⁶.

HCCA has been pleased to hear that ACT Health has been working with Winnunga Nimmityjah Aboriginal Health and Community Services in rolling out the COVID-19 Vaccination Program. We note that the Chief Health Officer reported¹⁷ that a key area of focus for the ACT's vaccination program is the uptake of COVID-19 vaccines across the Aboriginal and Torres Strait Islander community, having heard through our networks that there has been a lag in vaccination rates compared to the general population. HCCA emphasises the importance of transparency in reporting. Communities, such as our Indigenous population in the ACT, need regular and clearly communicated updates to see the data. Consumers need to understand how our communities are being impacted, and what actions to take next.

Justice health is a key health equity issue for ACT's indigenous community. HCCA echoes a key issue raised by Julie Tongs, CEO at Winnunga Nimmityjah, emphasising the dangers posed to inmates due to a lack of inclusion of frontline staff at the Alexander Machonochie Centre as part of the COVID-19 vaccine mandate for essential workers.¹⁸ In a closed, carceral settings, the possibility for inmates to undertake the same sorts of COVID-19 safe precautions is extremely limited.¹⁹ For this reason it is crucial that ongoing public health efforts have a specific focus on justice health, providing increased protections for inmates, visitors and staff.

HCCA also sees cultural safety as fundamental to the health outcomes of the ACT Indigenous community. The Cultural Respect Framework 2016–26 defines cultural safety as 'the individual's experience of care they are given, ability to access services and to raise concerns'²⁰. This framework 'identifies that health consumers are safest when health professionals have considered power relations, cultural differences and patients' rights. Part of this process requires health professionals to examine their own realities, beliefs and attitudes.'²¹

In order to address the health inequities experienced by Indigenous communities in the ACT during the pandemic and beyond, there must be clear strategies to embed cultural safety at the core of all mainstream health services.²²

Culturally and Linguistically Diverse Communities

We have had more positive feedback about how the Government engaged with multicultural communities in 2021, especially during the most recent outbreak. The most significant improvement has been the increased level of collaboration with community leaders and organisations.

The Health Directorate and Community Services Directorate (CSD) worked closely with the community leaders to ensure families had access to culturally appropriate food, particularly for those households where the women were either in hospital or too unwell to cook. This was particularly an issue for those cultural groups where men generally do not cook. They also provided COVID -19 resources in community languages to explain lockdown, quarantine, as well as testing and vaccination.

Some community members, who were fully vaccinated, were given exemptions so they could conduct contactless welfare checks and food deliveries to those families in quarantine or who had unwell members in their homes. They were given the Personal Protective Equipment (PPE) they needed and were trained in donning and doffing to ensure they were safe.

Other members of culturally and linguistically diverse communities expressed concern that there was a lack of comprehensive health information produced by authoritative sources that were provided in languages other than English and that addressed community concerns. This suggests that we need to review what community languages were selected for the translation of materials and the dissemination methods.

'It's clear that messaging was aimed at English speakers who are born here, or people who have obtained permanent residency. Whilst there was some information for CALD communities, it felt like an afterthought. There need to be more engagement with community leaders to get the messaging about vaccinations out.'

Some members of culturally and linguistically diverse communities also expressed that their communities can find it difficult to know where and how to access information, and what information they should rely on.

'the information is not reaching our communities and if it doesn't reach our communities how can we know to get help?'

While the ACT Government did produce some information in a variety of languages (and this was positively received), translation itself isn't enough to counteract alternative, inaccurate information community members were accessing in more culturally relevant and easy to access and understand forms. One health care consumer who is a member of the Vietnamese Australian community reflected:

'Part of the issue is that the government relies on traditional modes of communication, but there are other forms of communication that the multicultural community is linked into, like local religious groups and WhatsApp or Wechat groups, which often don't get leveraged...In Canberra part of the strategy needs to be leveraging these connections that already exist. The ACT health system needs to find a way to connect with and leverage our communities in a consistent sense, not just when there's an emergency.'

Production of health literate, accessible and targeted resources should be a standard component of all ACT Government communication plans.

2.3 Partnering with consumers during the pandemic

The voice of health consumers has been influential in shaping ACT's effective response to COVID-19. This was possible for a range of factors including:

- the willingness consumers and carers to share their experiences during the pandemic,
- strong advocacy from consumer and carer peak bodies, and
- responsive leaders in health services, government agencies and non-government organisations.

For over 40 years HCCA have been a critical friend of governments and provided consumer insights. Our experience and established networks meant we were well placed to provide the consumer perspectives needed to shape response and policies to meet needs. We also were able to play a critical role in connecting the community sector with the health response.

Clinical Health Emergency Coordination Centre

The HCCA Executive Director is a member of the Clinical Health Emergency Coordination Centre (CHECC). This group provides advice to the Chief Health Officer regarding the clinical response to COVID-19. The CHECC was established in April 2002 and prior to that HCCA was represented on the Canberra Health Services COVID-19 Task Force. Its members are senior leaders of the ACT health public health and hospital system. The HCCA role is NGO and Community Liaison and involves talking with consumers and community organisations about their experience of COVID-19 and ensuring this is considered in CHECC decision making.

HCCA supports a consumer representative on the CHECC Clinical Governance Committee. This Committee has been engaged in developing Key Indicators to measure the outcomes of an individual who has contracted COVID-19 from diagnosis to recovery. The committee includes representation from all areas of ACT

health services and NSW Southern Local Hospital District. It currently meets weekly while smaller Indicator Working Groups are held between the larger group meetings.

NGO Leadership Group and Working Group

The HCCA Executive Director is a member of the ACT Health NGO Leadership Group. Early in the outbreak a working group was convened to identify issues that consumers, carers and communities that needed to be addressed. This was cross-Directorate and included ACT Health and CSD. This groups met several times a week initially and the frequency reduced as the situation settled.

This included access to services including to testing and vaccination, communications, workforce issues and changes to cross border patient exemptions. It was a valuable forum. Membership included HCCA, CEO of Carers ACT, CEO of ACTCOSS and later the CEO of Mental Health Community Coalition also joined. The Directorate staff liaised with Public Health to have our questions answered.

Consumer and community participation decision making about Public Health response

We have received positive feedback about the role we have played on CHECC. We are strongly of the view that an equivalent NGO and Community Liaison role is needed for the Health Emergency Control Centre (HECC).

Often there were issues raised with us by NGOs and consumers that fell outside the remit of CHECC. Escalating these issues was not always straightforward. This included in reach testing for those people who were experiencing homelessness and were in hotel accommodation, as well as transport to testing for people who were symptomatic and did not have their own private transport. A link with the Public Health Unit would have made raising and resolving these issues easier.

An example was a case of a woman whose adult son was in hotel accommodation (via OneLink). The young person has complex needs. He spent time with a positive case and became symptomatic. He was mixing with other people and was not isolating. He did not have access to private transport and needed support to get tested. While he was located in Tuggeranong, within walking distance of the Lakeview respiratory clinic, this service required a booking and his mother was concerned that he was unlikely to follow through. He never was tested although he became unwell. The mother monitored him by ringing every day, but because he didn't get tested as she recommended, he wouldn't respond. Fortunately he recovered, but it is likely that he mixed with many others because he was still going out and getting food, He later went to the immunisation drop-in centre and is now doubly vaccinated. However, getting tested when he was sick didn't happen because he had to ring and make an appointment at Lakeview and this is very

difficult for him. He also appears to have had concerns that if he was found to be positive, he would be taken away “somewhere”. He has low trust in authorities from other life experiences. Despite extensive lobbying to get assistance, this did not happen.

We would like to see increased engagement with key stakeholders by the Chief Health Officer and their team in planning for the response. The COVID-19 pandemic has emphasised the importance of community engagement in tackling disease outbreaks²³. Community engagement is not a one-off event. It needs clear structures and commitment for it to be sustained. The ACT is well-placed as we have many well-established community organisations and advocacy groups who have strong connections to grass roots and decision makers. HCCA demonstrated the important role we can play to in advocating for consumers and communities. Our trusted relationships and good standing meant we could build a bridge between members of communities less likely to trust governments.

We would encourage the Government to explore the establishment of an NGO and Community Liaison role in Public Health to collaborate on work around the services needed by those who are the most vulnerable in a pandemic. Providing emergency accommodation during the lock down period of the pandemic was a good strategy, but it seemed to lack a depth of understanding about the lack of trust and complexity of people who spend much of their time in insecure housing, living in their cars, couch-surfing or homeless. The expectations that they have “choices” and can decide or not whether to look after themselves completely misunderstands their predicament. Their lived experience is that they will be harassed by figures of authority. They don’t trust government messages or don’t see them as relevant to them as “outsiders”. They often access information through their own informal networks, which may or may not be accurate sources of information. They don’t feel comfortable asking call centres or strangers about important public health questions like “Can you catch COVID-19 by sharing a bong with someone?”.

The post-testing messages sent to some people, who had tested positive but had not answered their phones, were unclear. living at the edges of our society will often not answer a call if they don’t know the number or caller ID is blocked. One parent sought advice from HCCA on such a phone message received by a young person and it took many phone calls by HCCA senior staff to discover that this message was sent when phone contact had not been possible. However, the message did not tell the person they were COVID positive, or to ring Public Health for contract tracing purposes. The message was ambiguous and simply said to isolate without saying why and to enrol in the Government’s COVID monitoring arrangement. People who live at the margins are unlikely to do this, unless it’s clearly explained that people are trying to help look after them.

Community organisations who work with those at the margins are likely to better understand how to get information to their consumers and be able to provide

ongoing assistance to ensure the messages are known and acted upon. We would like to work with the Chief Health Officer to explore ways to increase consumer and community engagement.

Impact of COVID-19 on consumer representation

During the initial stages of the pandemic and lockdown in early 2020 there was an overall decrease in consumer representation on health committees. Health service resources were diverted to pandemic-related work, meaning that some committees did not meet and their work was postponed. Additionally, the shift to an online-only format for committee meetings did not suit all consumer representatives.

Following the easing of restrictions in the second half of 2020, many committees resumed their work. However, the continued uncertainty about the ongoing COVID-19 pandemic and the mental load of managing life and wellbeing in pandemic conditions has continued to impact people's availability and willingness to take on consumer representation roles.

By early 2021 consumer participation opportunities were once again offered by health services and there was an increase in in nominations for consumer representative roles, compared to the previous year. In some instances, multiple nominations were received for opportunities. This period also saw a number of newly trained representatives nominating for committees following interest generated by the HCCA consumer representative training run in early 2021.

The extended lockdown in mid to late 2021, due to the COVID-19 outbreak in the ACT, once again saw an impact on consumer representation with some committees again postponing or cancelling meetings due to the lockdown and the redeployment of some health service staff into COVID-19 related operations such as testing clinics. During the lockdown, any committees that continued to meet, met online and while this still may not have been suitable to all representatives (particularly those faced with technological barriers), by this time there was an increased level of familiarity with online participation in many aspects of life. Consumer representatives, on the whole, adapted well. For some, it made participation in consumer advocacy more accessible than it had been before.

It currently remains to be seen whether there will be a resurgence of consumer representative activity and opportunities in the new year of 2022, following the easing of restrictions both in the ACT and nationally as well as the resumption of international travel in late 2021.

2.4 Public information about COVID-19

COVID-19 has underscored how important it is to tailor key public health messages to diverse populations in the community. There was, and is, significant variation in public knowledge and understanding of COVID-19, and diverse populations have specific needs for how information is presented and shared²⁴. This relates both to information needs, and the distribution channels that people use.

In this context a key issue that consumers have raised is that while online communication (such as websites and social media) are an essential tool for sharing information with the public, over-reliance on online platforms to communicate with the community excludes many who are not as digitally literate or who have chosen not to use specific social media platforms. For example, information about exposure sites was largely updated through the ACT Health website and social media. Given constant changes to this information, health consumers who readily access information online had a greater opportunity than others to monitor for exposure, get tested and protect their health and wellbeing. Over-reliance on online platforms to the exclusion of other ways of communicating with people risks compounding health inequity affecting people do not have access to this technology or prefer not to engage?

It is important that health information, however complex, is conveyed in simple and easy to understand language. It is also important to provide a variety of formats to expand access. HCCA advocated strongly for the ACT Government to develop materials to meet the information needs of different communities. During this outbreak this was done much better than previously, with regular newsletters, webinars, Q&A sessions for community members and workers. Social media has been an important communication channel that meets the needs and preferences of many. However, we continue to encourage all agencies involved to be mindful of also being responsive to the information requirements of people who do not have access to the internet.

Accessibility and Targeting of Health Information

Some consumers, and even some community organisations, reported finding it difficult to identify the authoritative source when faced with conflicting advice. This happened regularly as the outbreak, and the response to it, evolved quickly.

'Frequently changing advice, and inconsistent advice, and lack of clear 'authorised' advice (advice coming from a clearly authoritative or official source) made following information and understanding advice too complex for people with a disability.'

ACT Health and Canberra Health Service also need to move beyond an individualist understanding of health, to focus on the providing targeted health communications for specific communities that consumers are deeply embedded in.

For instance, ACT Health did not produce Easy English resources to effectively communicate with the Disability community. This resulted in community groups such as Advocacy for Inclusion (AFI) producing resources to bridge this gap. AFI, Women with Disabilities ACT and Disabled People's Organisations across the ACT have expressed continuing desire to collaborate with governments to produce targeted, consumer tested health information.

Awareness of outbreaks in the disability sector

Consumers with disabilities and those connected to the disability community in the ACT also spoke of the feelings of panic during the outbreak, particularly when a cluster of cases emerged in the disability sector. Health consumers reported being informed of these cases first through informal sources such as family and friends, but that they received no direct confirmation or assistance from the ACT Government until many days after the initial outbreak. The lack of clear, direct communication with affected communities also saw a significant burden placed on service providers and the social sector to provide information, advice and mental health support.

'Awareness of the Covid outbreak in the disability sector preceded official recognition by ACT Health. Community knew on Friday, but it wasn't officially commented on until the press conference on Monday. This filled the community with fear and panic. It was up to overwhelmed service providers to manage panicking people with disabilities, carers, family and workers.'

Feedback from community also outlined the material consequence for people with disabilities and their carers due to the lack of communication. The withdrawal from essential supports compromised the health and wellbeing of people with disabilities at the time when it was most needed. There is also a clear sense that absence of communication compromises a sense of trust in the government and its public health response.

'Lack of information about where outbreaks in disability sector had occurred prompted distress and fear in our community, particularly with transient workforce. People withdrew from essential supports because of fear that support workers may be exposed in outbreaks and no transparency.'

COVID-19 Helpline

Consumers consistently raised issues regarding the ACT Government COVID-19 helplines, with key concerns regarding the difficulties in accessing this service due to long wait times, inaccuracies in the information provided. Whilst raising these issues, consumers were cognisant of both the breadth of information that staff members needed to be aware of, as well as the constantly evolving nature of the situation. One key case of concern involved a consumer whose family members had tested positive for COVID-19, calling the helpline for advice for information on what arrangements were in place to assist their family:

'When two of three of us tested positive, and I tested negative, I phoned the call centre to confirm the arrangements, and was told (by one of these poorly-trained staffers) that they weren't going to do that. She asked if I could stay in my bedroom and work from home "until I got sick". I was completely appalled that she couldn't be bothered looking into the situation, or arranging the move to the ANU, and that she just expected me to stay with infected people and catch the virus.'

This health consumer later tested positive for COVID-19 and reported further difficulties in accessing important health information from the helpline during their illness:

'There was a dedicated phone line for COVID-positive families, but the number was never given to me by anybody in the pandemic response team. The wait times on the public number were often hours, and I had no option but to sit on hold with the rest of Canberra...while I had urgent things I needed answers for...The call centre staff could have done with some serious empathy training. I found a lot of them downright dismissive and rude. I even had a few complain to me about being busy. The thing is, when you're speaking to someone who actually has the virus, this isn't good enough. For me, COVID was life-altering and almost fatal, and the staff should have been better at dealing with people in that situation. To be honest, they should have been polite and helpful no matter who was on the other end of the phone. It was their job.'

The COVID-19 help line is a key source of health information which informs the behaviours of health consumers and impacts their capacity to protect both themselves and their communities. Consumer feedback has evidenced a clear need for further staff training in order to provide accurate, timely and relevant advice.

There was also concern that the disability specific helpline that was established to provide targeted support for the disability community was ineffective. Consumers reported being unaware of how to access the disability COVID-19 helpline. Additionally, consumers with a disability who were able to access the helpline also reflected a lack of disability specific health information. The generalist nature of

information provided by this helpline failed to take into account the specific health needs of people with disabilities and mitigated the usefulness of what should have been established as a specialised service.

‘(the) disability specific phone number that was then provided late in the pandemic, didn’t work as there were long delays and call centre staff were not able to answer lots of questions. (the phone line) needed to be resourced enough to prevent these delays of sometimes hours waiting on line and also specific disability awareness training. A well-resourced and well-informed disability specific Covid contact line is best set up in the beginning with call centre staff being able to follow up on questions they can’t answer. There was a need to get back to consumers rather than giving the wrong information or no answer at all. Call centre staff need to be able to have a mechanism to get answers to all questions even if they must get back to the caller.’

2.5 Access to Vaccination and Testing

One of the key successes by ACT Health has been vaccination rollout. The ACT has led the nation in our vaccine rollout, and it has been the key mechanism our community has protected itself from impacts of the pandemic. This has been possible due to ACT Health having an efficient and effective vaccine rollout through the Garran Surge Centre, AIS mass vaccination hub and the encouraging of vaccination through health systems that consumers already interact with and are connected to, namely general practitioners and pharmacies. These structural supports have been key to the ACT’s vaccination success.

We are aware that the ACT has maintained a low wastage rate for COVID-19 vaccine doses. We understand that the Commonwealth Government published vaccine utilisation rates across jurisdictions often has the ACT as the national leader in this area of low vaccine wastage rates²⁵.

Additionally, there have been some key pieces of feedback from consumers in relation to their experiences of vaccination that provide further nuances experience of vaccination and testing in the ACT.

Vaccine Rollout

During vaccine rollout, consumers expressed confusion over the vaccination policy, particularly around eligibility. This confusion meant that vaccine uptake for eligible consumers was delayed. One consumer of mental health services in the ACT noted:

As a person with a psychiatric disability, I found the health messaging about my vaccine eligibility to be extremely confusing. It was stated that only people with ‘severe’ mental illness qualified, but there was no definition of severity. Even after calling HealthDirect, I wasn’t provided with any clear guidance. I

ended up speaking to my GP who wrote a support letter for me to get vaccinated, but I would have done so much earlier during the rollout to protect myself and the people around me.

There was also a sense that the ACT Government public health response was also best when it not merely echoed federal health messaging but sought directly to respond to gaps in health communications. This has been particularly important in targeting priority communities in an embedded and local sense, particularly those in aged care and disability care.

Rollout of phase 1 a to people with disability by the commonwealth was severely compromised and meant that PwD (people with disabilities) felt neglected and ignored. This caused obvious distress, confusion, and safety risks. The ACT Health response to this federal neglect was appreciated

Physical Access to Vaccination Centres

Consumers with disabilities also provided feedback regarding the lack of accessibility at vaccination hubs and testing facilities. It is vital that the ACT Government takes into consideration the potential access needs of all demographics of consumers, particularly those with potential mobility issues, such as people with disabilities and older people. Concerns were raised particularly over the accessibility of the Garran Surge Centre:

'The accessible ramp at the entrance to the mass vaccination hub at the Canberra Hospital was a steep incline and some of those with mobility restrictions including older and frail persons, and wheelchair users, found this difficult or impossible without assistance. Bus access to the mass vaccination hub at the Canberra Hospital for those consumers using mobility aids such as wheelie walkers or wheelchairs impossible/unsafe due to having to walk/wheel across a gravelled busy carpark with no pathway. Gravelled surfaces are not accessible and winding through a carpark unsafe for all especially those at a different height.'

It is pivotal that planning around physical accessibility in health settings is considered a core part of all clinical planning. Whilst the ACT Government had set up the Access and Sensory clinic, it is also important that consumers should feel empowered to attend any vaccination or testing facility with the expectation that it will be structured to fully meet all of their accessibility and health needs.

Better support for people with COVID-19

The lived experiences of people who have had COVID-19 needs to form part of ACT's emergency planning. These experiences complement systemic consumer

advocacy and are valuable in information the public health response to the COVID-19 pandemic, as well as future response planning.

From consumer feedback received by HCCA, people who have had COVID-19 reflected a clear need for greater supports in managing their illness and accessing quality health information. Providing specialised support and guidance for COVID-19 positive consumers would also contribute to the adherence to public health measures, including testing and quarantining. One consumer noted the desire for priority access to health supports for COVID-19 positive consumers and households:

"I really feel that people from COVID-positive houses should have been given some sort of priority testing. The call centre people seemed to think there was a protocol in place for us, and that we'd be tested faster, but that wasn't the case. The reality was, we had to drive across town to EPIC for the test, and were there for six hours, in the queue with everyone else. We were guaranteed to be COVID-positive, but weren't prioritised that way.

Half the time we were waiting there we were on the phone to ACT Health to set up our case files, and talking to contact tracers etc.'

It is also fundamental that people who had COVID-19 receive supports to manage both their recovery as well as ongoing health and wellbeing. With the process of understanding the continuing health impacts of COVID-19 ongoing, consumers need to assured that health monitoring and supports do not cease once the acute period of the illness as passed. One person who had COVID-19 also highlighted the need for a focus on the dimensions of lived experience in vaccine provision:

'For people who've had the virus, there's no assistance or medical advice on offer surrounding vaccination. There's conflicting information about how soon after being sick we should get vaccines/booster shots. And it's only overseas that there are studies and warnings that the vaccines tend to make people who've had COVID extremely sick. The side effects are often far worse—debilitating. After getting a shot (because of everything else, I couldn't get vaccinated until the end of October), I spent the better part of a week bedridden and sicker than I was when I actually had the virus. Some guidance and warning would have been nice'

Health services also need to consider establishing procedures for care for consumers experiencing serious post-COVID-related illness, when no longer testing positive for COVID-19. A consumer told us of a difficult experience in accessing care in this situation:

'Unfortunately, the second ambulance guy—the one who took me to hospital—seemed to think I was being a hypochondriac. He told me not to bring my bag with me because I'd "be home in a couple of hours". I would

have thought the word “COVID” might have been enough for him to take me seriously, but obviously not. He was so unconvinced I was sick, he tried to make me walk up the stairs and then up the hill to the road at 3am because he couldn’t be bothered going to get the stretcher ... I don’t know if that influenced the way I was treated in Emergency, but I was left there for a long time (a couple of hours—maybe more) before anyone came to see me. Older patients, who I overheard being sent home because there was nothing wrong with them, were given priority, even though I was throwing up blood, had two black eyes from the organ failure, and couldn’t sit up! When a doctor eventually got to me, everyone panicked because they realised how sick I was. Suddenly there were doctors everywhere. I definitely felt that I was not treated well until the moment my blood test results came back and they realised my whole body had stopped working.’

We need to ensure that the right systems are in place to provide appropriate care for consumers experiencing serious post-COVID-related illness.

Mandatory vaccinations

The vaccine mandate, both federally and by the ACT Government in health, disability aged care and education sectors were largely received positively by consumers. These mandates on particular professions that interact with consumers who are most at risk of either contracting COVID-19, or suffering from severe health complications, are key in assuring that health consumers are protected into the future. It is important that as the ACT begins to lessen restrictions, that vaccination policy for relevant workforces continues to be updated.

HCCA has received feedback from consumers with disabilities who spoke of people in the disability community withdrawing from essential supports during the pandemic because there was no legislation ensuring that support workers would be vaccinated. Particularly considering the outbreak of COVID-19 in the disability sector in 2021, it is important to provide ongoing assurances and protections for those at risk.

‘The vaccination status of special needs transport drivers, cleaners, and personal support staff caused significant amounts of distress, awkward and difficult conversations, and safety concerns for PwD (people with disabilities) reliant on them. Currently only the mandated vaccination of these workers is only relevant under the declared health emergency but once this is lifted this same requirement won’t be in place. There is a need to communicate what happens when this is lifted in the future as there are some with disabilities and others who can never get vaccinated and are therefore incredibly vulnerable to both catching and having worse outcomes from COVID. Feedback across the disability sector overwhelmingly supports the mandated status of these workers.’

Consumers also highlighted the role of disability workforce contingency planning to ensure that people with disabilities continue to receive all necessary assistance through their support workers.

'Confusion around support worker provision and what to do when PwD had been to hotspots, exposure sites, and / or needed to quarantine. There was no plan in place and support workers were removed over night with no plan in place leaving PwD without support staff.'

Access and Sensory Clinic

The establishment of the Access and Sensory Clinic has also been a good demonstration of partnering with consumers, carers and advocates to respond to community need. This clinic provides vaccinations for people with disability, with mental health conditions and to those needing additional support in a quieter, less rushed and more accessible venue. Most of the feedback received about the clinic has described it as being a positive and supportive environment. HCCA's colleagues at Carers ACT have heard numerous stories of staff going above and beyond to make the vaccination process as accessible as possible, including closing down parts of the clinic, vaccinating people in cars and taking long periods of time to comfort people who are scared of needles. The flexibility and compassion of staff, face to face at the clinic, answering the phones and developing the service delivery behind-the-scenes should be commended. Colleagues at AFI provided the following feedback regarding the Access and Sensory Clinic:

'This was a welcome initiative, both for impact on people with disability, and also because it was a very strong example of good consultation and collaboration with people with disability, representatives, and the community. Would really like to highlight that this is a positive case study, and development was cooperative and responsive. Quite proud of this as a community/government project. The model was also positively viewed by advocates nationally, and has also been advocated for by others in other jurisdictions (to reproduce the model in other states) and has been advocated for as a good model and way to work with other hard-to-reach communities, such as Aboriginal and Torres Strait Islander communities.'

Whilst the Access and Sensory clinic at the Australian Institute of Sport was responsive to consumer needs, HCCA has also received feedback that the relocation of the clinic to Weston Creek lacked the same level of consumer input in its service provision. One consumer noted:

'The Disability specific vaccination clinic worked well giving the choice for a more accessible entrance and a quieter more appropriate area for those who needed it. This is because the voices and experiences of people with disability

shaped the setting up of this space. However, when this clinic was moved, the same level of consultation wasn't sort and this space didn't work well at first and complaints from PwD were received, and this then resulted in changes that should have shaped infrastructure and service provision it from the beginning of this second set up. It is an obvious example of the benefits of seeking feedback in the setting up stage is being clearly better for the service provider and the consumer rather than reactive retrospective actions'

Overall, the Access and Sensory clinic collaboration has been an exemplary demonstration of consumer-centred care in practice. This has resulted in better outcomes for consumers and carers, and better experiences of care. We want that this spirit of collaboration and inclusive access to be maintained going forward in health service development.

2.6 Impact of COVID-19 on the health system

Consumer feedback overwhelmingly reflected the sense that the ACT health system is in a position of precarity, with the health workforce at capacity and unable to absorb the additional strains of the pandemic. Consumers regularly reflected that they were grateful to their doctors, nurses and other clinical support staff as they often continued to receive high quality care during difficult circumstances. They similarly reflected fears that the quality of their care could become compromised.

'Whilst I was in hospital having surgery for my Cochlear Implant, it seemed like it wouldn't take much for the health system to be completely overwhelmed. Politicians are saying there are no issues with public health systems, but media reports from health practitioners saying health systems are at capacity, some hospitals had to resort to getting casual nurses in for shifts. It was really clear how much stress doctors and nurses were under and it made me feel really overwhelmed being in hospital at that time.'

A COVID-19 positive consumer also reflected the impacts of COVID-19 on the health workforce during their time in hospital:

'At various times while I was there the kitchen staff, the wardsmen, the dieticians, and the neurology department were all sent into quarantine because of exposure to positive cases'

ACT health system and workforce planning needs to take into account the high levels of stress that staff are under in a pandemic environment, and the flow-on impacts this has on delivering safe and quality health care to consumers. The Grattan Institute has highlighted workforce planning as an issue across Australia, in being prepared for future 'surge' capacity²⁶. This is particularly important in the ACT due to ongoing health workforce shortages.

Hospital integration and continuity of care

Integration of care was identified as an issue for several consumers we spoke with. They reflected the sense that forms of care, particularly in a hospital setting were siloed, with a lack of open communication between different departments and professionals overseeing patient. A lack of clinical integration can lead to negative health system experiences for consumers. A consumer who had been hospitalised with COVID-19 shared their experience with HCCA:

‘There is NO communication between different parts of the hospital. None. I was dragged out of life-saving dialysis for a random and unnecessary X-ray (and the X-ray people didn’t even know I was a dialysis patient, let alone that I was meant to be in treatment right then!). I missed so many meals because different departments were dragging me off all over the hospital between 7am and 8pm! And many of the specialists came to see me (or other patients) for all of two minutes before ordering risky/invasive procedures.’

Continuity of care, including care between different health services, is a key predictor of 'positive patient experiences, greater patient satisfaction, increased treatment adherence and improved patient outcomes.'²⁷ Consumer feedback to HCCA has reflected the lack of continuity of care experienced by some consumers during the pandemic.

‘I have had to quarantine due to being exposed to covid in Calvary ED Red stream when I was taken there by ambulance and had a kidney infection and UTI. Meant I couldn’t be transferred to National Capital and they wanted to treat me in the covid respiratory ward. I refused to go and had Hospital in the Home for nine days of intravenous antibiotics. Everyone in full PPE. Shouldn’t have happened.’

Fragmentation is a key issue for consumers. Health system integration is fundamental to maintaining the quality clinical standards and in ensuring that services can effectively deliver whole-person care.^{28,29}

COVID Care@Home

It has been good to see work on developing the COVID Care@Home program. This will be an important health service for consumers through both ACT Health and primary care as we move into this next 'living with COVID' stage of the pandemic response in the ACT. We are very pleased to see the module of the EPIC Digital Health Record in use to support patient care.

Consumers want to see an increase in public information about the COVID Care@Home program. A consumer told us:

'I see people getting this mixed up with NSW's "Hospital at Home" program, where extremely sick people were forced to stay home and treat themselves. This was NOT the case in the ACT. Monitoring at home was for people with mild, manageable symptoms. Anybody who needed it could go to hospital.'

It is difficult to find anything about the ACT's COVID Care@Home program online. We know that NSW have published their model of care³⁰ and we would like to see the ACT's model of care for the COVID Care@Home program, and other relevant patient information material, readily available. This is important because we will increasingly be managing COVID in the community. The more consumers know about the process, the clinical tools provided and help available, the better placed we are to respond well if we are diagnosed or supporting someone with COVID.

It is also vital for consumers to know, when monitoring symptoms at home, if and when to escalate and seek medical help. The advice around 'mild' symptoms may differ from the lived experience of consumers or carers.

Digital Health and Telehealth

Over the course of the pandemic, ACT Health has introduced and expedited a range of digital (public) health solutions. This includes the Check-in CBR application, developed in-house by ACT Health and subsequently used in other jurisdictions. It also includes fast tracking My Digital Health Record functionality to monitor patients under COVID Care@Home and to manage vaccination bookings. With these projects, ACT Health has demonstrated that they have the capacity to respond swiftly and effectively with digital solutions. They are to be commended for this work. One area where this has not been as effective is the development and expansion of public telehealth services.

An effective telehealth system will have benefits far beyond its use during the COVID-19 pandemic. Telehealth can enable easier access to health care services for consumers across the ACT, as well as those living in neighbouring regional areas³¹. Research has shown that benefits associated with virtual care experiences include convenience, saving time and feeling at ease in their own home/surroundings³². Telehealth will facilitate a move to a more flexible and sustainable health workforce. And it will pave the way for future digital health innovations to both encourage and simplify communication between clinicians and consumers. It can also play a role in reducing burgeoning wait times, which have grown due to service interruptions during certain phases of the pandemic.

While we know that public health services in the ACT have telehealth guidelines in place for staff and nominally offer a telehealth model of care, to date, they have not invested in the information technology systems and compulsory education of clinicians that would make telehealth a genuine alternative for suitable patients.

HCCA has had numerous discussions with health service staff about the reasons for limited use of telehealth for outpatients' appointments. Our perspective is that:

- some CHS clinics were simply not set up physically and technologically for telehealth
- some doctors have been reluctant to establish telehealth options because they were not confident with the technology and/or because they do not have sufficient clinical space to conduct telehealth appointments.

The temporary nature of the Medicare funding for telehealth has not helped. Without assurance of an ongoing revenue stream from the investment, it was not financially viable for clinicians to upgrade private practice systems, which would have enabled them to conduct public health appointments from their own rooms. We recognise that Medicare funding decisions are not the responsibility of the ACT Government, however, embedding telehealth capacity into public clinics should be an ACT Government priority. All consumers should have the option of accessing the benefits of telehealth, which include, but are not limited to, enhanced COVID safety.

Some consumers are more susceptible to serious health impacts from COVID-19. This can lead to increased anxiety and cause people to defer both acute and routine care. The option of accessing care online is an important addition to the models of care provided by ACT Health, to ensure ongoing access for vulnerable or anxious consumers, particularly during COVID-19 but also beyond the pandemic.

Many consumers have responded positively to health services that have implemented telehealth. In late 2020, HCCA published a report into the experiences of people with long term conditions: *"There's what your doctors say, and then there's the real world" People's experiences of long-term conditions self-management and support in the ACT, including during COVID-19.*³³ This project found that despite limited uptake of telehealth, model of care changes enacted in response to COVID-19 had prompted expansion of digital health services that have unexpectedly served to support self-management of long-term conditions. Most participants in the study regard telehealth and e-prescribing as more convenient, accessible, and safer due to the reduced risk of contracting viral illnesses.

However, consumers have also raised with us the challenges they have encountered accessing telehealth. In some cases wanting to receive care via telehealth meant needing to change provider. As one consumer notes:

'Some GPs didn't offer telehealth with the result that some consumers had to use GPs that weren't familiar to them and didn't know their history. Alternatively, it forced them to visit the surgery causing distress and risking contact with COVID'

Despite its recognised benefits, telehealth is not the right fit for all consumers and it is vital that telehealth is only one of a variety of health care modalities in use - both during the ongoing public health emergency and subsequently during business-as-usual. Consumers have expressed concern about the lack of choice of model of care available, particularly for those more at risk of poor health outcomes:

'Whilst I was able to have a telehealth appointment with my GP, there were services that were deemed inessential that didn't translate well. I have regular appointments with my physical therapist as I have Cerebral Palsy which was transitioned to telehealth. Whilst I understand the need to keep people safe, I felt it (physical therapy appointments) are necessary for my health.'

If telehealth is to be effectively deployed in a diversity of populations, consideration must be given to preparing all consumers, including those with low technological literacy, to use these services confidently. Early and well-targeted communication about what to expect and ongoing support to access the services must be part of any telehealth model of care.

'For those with intellectual disability, older persons, and those with some specific physical disability this [telehealth] was difficult / impossible to access, and mid-pandemic caused distress and confusion.'

HCCA hopes that, despite a slow start, ACT health services continue to promote, support and invest in telehealth, in recognition that it offers superior accessibility, convenience and safety for many people, particularly for routine health care matters. Telehealth's benefits include convenience (less waiting, no travel time) and removing accessibility barriers for people with disabilities or limited mobility. It also limits potential exposure to viral illnesses – colds and influenza as well as COVID-19.

There is also a role for telehealth to play in facilitating support for consumers who have their consultation in-person, but need the support of a person who is not physically present. It is important that consumers know they can still have support in appointments or as an inpatient, even when their support person cannot physically attend. Visitor restrictions have been a significant source of anxiety for people accessing care in the COVID environment. Administrative staff and clinicians need to know how to offer and facilitate attendance by an online support person, and have available the technology to do so.

Models of care implemented for COVID, such as the COVID Care@Home program, provide a useful model for delivery of telehealth-supported home-based care for consumers who consent to using the model. The COVID Care@Home program delivers thermometers and oximeters to patients who are under the care of CHS but are supported to monitor their own health at home using My Digital Health Record. The model provides for escalation of care for consumers where monitoring indicates deterioration or increased needs.

At a broader level, ongoing research and evaluation of a range of telehealth initiatives will be required to monitor the pros and cons of telehealth models, and where these can be best used to improve consumer access and health outcomes. We hope to see learnings shared for the wider implementation of telehealth across our health care system.

Impact of consumers delaying health care during the pandemic

During the COVID-19 pandemic, there was a significant drop in access to healthcare services for non-COVID health issues in Australia. We know that health services have been faced with the difficult task of balancing the need for elective procedures and the need to protect patients and staff from COVID-19. Patients with other urgent needs, such as cancer treatment, also needed to be weighed with the risks of delayed diagnosis and treatment and the risks of exposing immunocompromised patients to the virus. We are aware that consumer fear of infection, along with temporary closures of services or staff redeployment, has led to a drop-in routine health care and screening³⁴. All these factors may result in poorer health outcomes in the long-term, due to delay of treatment for diseases and conditions already diagnosed, and delayed diagnosis and care for undiagnosed conditions³⁵.

As we move into the new 'living with COVID' environment, it is important to communicate to consumers that delays in diagnosis and treatment may provide greater health risks than COVID-19. It is important that health services both practice and communicate their commitment to patient safety, and ensure that appropriate infection prevention and control measures are in place as health services reopen towards 'business as usual'³⁶.

Physical design of hospital spaces

Consumers often raised with us the need to improve indoor air quality and expressed concerns about the ventilation in hospitals. We are very aware of the ventilation and air quality issues that impacted our hospitals during the 2019/20 bushfires. We had regular reports from consumers about smoke in the wards, especially in the tower block.

We are supportive of the advocacy of OzSAGE, a multi-disciplinary network of Australian experts³⁷. They have identified the critical need for Safe Indoor Air (Ventilation) and state that there is "a substantial body of scientific evidence on Safe Indoor Air (Ventilation) and the risk of airborne infections, generated by engineering, science and medical researchers"³⁸. We are interested to know what action the government is taking to improve ventilation in hospitals to address the risk of airborne infections.

2.7 Isolation and Quarantine

The lockdown had a disproportionate impact on people who already living with disadvantage although we acknowledge this was an essential public health measure necessary to protect our communities.

Impact on mental health

Many consumers have raised with us the detrimental impacts that the pandemic and consequent lockdowns in the ACT have had on collective mental health and wellbeing. Whilst the pandemic has raised the awareness mental health support services, many consumers still face barriers to accessing support.

Feedback to HCCA details the way in which there continue to be many barriers to accessing mental health services. Many consumers are still relying on informal networks of care, seeking support through family and friends. One consumer outlined the need for mental health care to be integrated into all aspects of the pandemic response:

There is inadequate mental health support, especially for the multicultural community that I am a part of. Most of our mental health supports are our family and friends Talking to the people in my community there is a very real feeling that good health cannot be achieved unless mental health is focused on and included as the basis of all forms of health. Our communities are ready to reach out and ask for help for our communities. If the support is there and we are informed of the existence of supports, we will reach out.

Whilst the additional funding for Canberrans needing mental health services was welcome. It is also important that other structural impediments to accessing mental health care are taken into consideration.

Mental health workforce planning is key to providing access to mental health services for consumers. Many consumers have reflected the inaccessibility of mental health support, both due to the shortage of mental health professions in servicing growing demand, but also due to the unaffordable nature of care.

'When my psychologist went on parental leave, I was unable to find a psychologist that had their books open and was taking on clients, let alone trying to find a psychologist that was affordable and wasn't charging a substantial gap payment. I'm a carer for my partner with mental health issues and it has been so challenging for us to access the help that we know we need. I don't need awareness campaigns and to be told that it's okay not to be okay, I need to be able to access services that can help me'

It is also important to rethink the kinds of mental health care that are available to consumers. Often consumers with mental health issues or who are experiencing

distress are unable to access consistent and extended support. It is crucial that funding for mental health is not merely focused on critical emergency care, but also focuses on preventative and community embedded mental health care. As such, HCCA sees the \$14 million commitment by the ACT government to fund a variety of targeted and community based mental health services as a key strength.³⁹

Many consumers welcomed the doubling of Medicare subsidised psychologist sessions, accessible through a GP mental health care plan, from ten sessions to twenty as part of the Better Access Pandemic Support initiative. It is greatly concerning that this expansion in support is only available until 30 June 2020.⁴⁰

It is important that federally and territory funded mental health services are able to meet the increased mental health needs of consumers. The recent select committee report on Mental Health and Suicide Prevention has also emphasised the need for whole of government collaboration for both the structural planning and funding of mental health services.⁴¹ We particularly hope the Health National Reform Committee will see greater levels of cohesion in the workforce planning and funding of mental health services across Canberra.

As an example of this, HCCA welcomes the commitment to providing territory funded subsidies for young people and those on low incomes to assist with gap payments that consumers often face when accessing mental health services.⁴²

Approach to Quarantine

Quarantine facilities are an important aspect of the response. The facilities at the Australian National University have been very useful to support people to quarantine. For some this experience was very positive and they felt supported:

'... It was also a free and voluntary service to try and stop more people becoming infected. It was all done discreetly. A woman from ACT Health drove to the house in her own car, handed over hospital-grade protective masks, and then the people going into quarantine drove their own car behind her to the ANU... Nurses were available to help move into the apartment. It was a really big place, with a decent kitchen and even a roped-off garden. A "welcome basket" of food was provided to get people through the first few days.'

We know that several complaints were made by residents in public and social housing complexes about rolling quarantine orders. The Human Rights Commission (HRC) published a factsheet that explains the rights of residents during a full lockdown of public and social housing complexes. This was a useful document⁴³.

There are issues about ending quarantine and the use of rolling quarantine. This will be challenging for residents in public and social housing complexes. There have

been questions about the extent to which this violates human rights of residents. It is important for Public Health to be working with the HRC on this.

While many Canberrans have the resources to quarantine successfully there are some people for whom this is challenging. The managed quarantine facilities were established for those who may have struggle to comply with public health directions and they liaised with NSW and Victoria for advice on how to support these people and communities. The advice was to establish a suitable managed quarantine and isolation facility. We are very pleased the government took the decision to establish the Ragusa Quarantine Facility.

Government set up a multi-agency planning group to develop an operational plan for the facility. We advocated strongly for the support services to be designed with NGO partners, organisation who had a solid understanding of the challenges that many of the people may need support with. HCCA, alongside CAHMA, Directions Health Services, ACT Shelter, and YWCA, worked with government to develop the model of services for Ragusa. We drew on our recent experience of Condamine Court and Ainslie Village.

There were difficulties experienced by residents where a whole site is declared for close contact, at the same time as movement into and around the site is unable to be limited. In addition, some sites are built in a way that does not easily lend itself to people isolating or quarantining. This causes significant uncertainty for residents due to uncertainty about the end date of quarantine arrangements.

The response in social and public housing clearly demonstrated the importance of working with community organisations who understand the challenges many of these people face. We need to hear the voices of community leaders and community members. We cannot make assumptions about what people need. And work with those people they trust who can give them a voice. We need to address the judgment and stigma many people face.

Organisations like CAHMA - the Canberra Alliance for Harm Minimisation and Advocacy - has long been recognized in the public health area as an important organisation supporting people who use drugs. Peer support made a real difference in helping people feel safe and talk about their needs in a non-judgemental way. Directions Health Service provides drug and alcohol health treatment. They have successfully worked alongside the clinical staff from Canberra Health Services. Directions have been an important service to roll out vaccination to tenants of public and social housing and clients of homelessness services.

Proposed amendments to the Public Health Act

We understand that the Government is considering legislative amendments to the *Public Health Act 1997* to enable the ongoing management and response to the COVID-19 pandemic. HCCA support amendments that:

- include consumer consultation,
- take a human rights-based approach, partnering with the Human Rights Commission
- are fit-for-purpose, and
- ensure transparency and accountability.

Going forward, it is important for consumers to be able to engage with the COVID-19 response by having access to the underlying evidence and reasoning taken into account to justify the adoption of particular settings and measures.

2.8 Opening up and the return to 'COVID normal'

Consumers have generally been comfortable with the gradual easing of restrictions taken by the ACT Government in 'opening up' from the lockdown. Understandably, there have been various levels of anxiety and perceptions of risk around the easing of restrictions, given that COVID-19 is still circulating in the community at this time. Increased travel from other jurisdictions, particularly NSW and VIC, where higher rates of transmission and COVID infection have been experienced. It is important that as a community across the ACT, we can focus more on forms of collective care and support, rather than health as an individualised metric.

Concerns from people who are immunocompromised

Many immunocompromised people feel that they must continue to quarantine themselves as the population comes out of government-imposed lockdown. In some cases immunocompromised people are unable to be vaccinated due to health risks but in most cases they have been vaccinated but remain concerned that the level of protection this afford them may not be sufficient. For example, they may be taking medications which impact the effectiveness of vaccines.

'Anecdotally I have heard from two people with organ transplants who had double vaccines who had the test done. One had got Covid immunity and one had not. I have a family member who has had an organ transplant, and although double vaccinated, we have been in self-imposed isolation because we do not know if they have any immunity. He has asked his doctor, but he was not able to provide any information.'

Immunocompromised people have found it hard to access information that takes into account their unique situation. HCCA has also found this difficult when supporting members with questions around compromised immunity, as well as COVID related policies and arrangements. It seems, from the comment above, that this is also true for some clinicians. Specific messaging targeting people in recognised risk categories is important to enable them to make informed and safe decisions about their health and lifestyle in the context of COVID-19 and community transmission.

'Overall I think there needs to be more information given for people who are immunosuppressed.'

The lifting of lockdown does not bring the same levels of freedoms for all people. For some it has transferred the responsibility for protecting their health onto their shoulders alone. This can result in social isolation, economic hardship and psychological distress. People who are immunosuppressed need to be supported to take steps to assure themselves that they are safe to participate in their community.

'I have not found any further information about the availability of the tests to check immunity levels. There is some information around about antibody tests but it is hard to distinguish between tests for Covid and if people have immunity. It would be good to have a reliable source of information about where one can get the test and which tests are reliable.'

'So far in Australia they have not approved the giving of a booster shot - after the third shot - for immunosuppressed people.'

There needs to be recognition that the protections in place are not sufficient to keep everyone safe and that the benefits of opening up experienced by most may not apply to everyone.

Long-Covid

Whilst the clinical response to COVID-19 has mainly focused on the acute phase of the virus, it is also important that the growing body of evidence drawn from consumer experience about 'long-covid' is taken into consideration in informing health system supports.

Long-Covid can be understood as the experience of COVID symptoms, weeks or months after being infected. Many people who develop Long-Covid will experience a diverse range of symptoms such as respiratory symptoms, fatigue, pain and cognitive dysfunction such as 'brain fog'.⁴⁴ A recent study published in the journal *Critical Care* found that over a third of survivors had new disability, which was widespread across all areas of functioning⁴⁵. In responding to consumer experiences of Long-Covid, the World Health Organisation has noted that the amorphous nature of clinical presentations has caused great difficulty in mapping out the aetiology of

this condition. WHO states that: "The absence of both a single terminology and a clinical case definition have been repeatedly signalled as drawbacks to advance on research and management of these patients"⁴⁶.

The variation in consumer experiences of long-covid highlight the need for clearer forms of clinical monitoring and ongoing support those experiencing long-covid. One consumer who developed COVID-19 expressed their concerns to HCCA that the ongoing impacts of COVID-19 were largely being ignored, resulting in a lack of support for consumers.

'As far as I'm aware, there isn't any kind of monitoring or record of people who had the virus but didn't miraculously recover at the two-week mark. For people with longer-term effects from it... We're all classed as "recovered", according to the government. It seems to be a nationwide issue: nobody is recording the real effect the virus is having on hundreds or even thousands of us.'

From initial population studies, one in three people diagnosed with COVID-19 will report symptoms of Long-Covid between three to six months after diagnosis.^{47 48} This data suggests the importance of monitoring and researching the ongoing and sometimes disabling impacts of COVID-19. It is also clear that due to the multifaceted nature of Long-Covid, treatment will need to be framed in an interdisciplinary sense.⁴⁹

It is important to note that Long-Covid emerged as a clinical concept from the consumer movement and as a result of consumer activists who advocated for health systems across the world to broaden their understanding of consumer experiences of COVID-19.⁵⁰ It is imperative that the ACT Government, in providing ongoing structures of care for those who develop Long-Covid, continues to connect with health consumers and health consumer organisation to co-design⁵¹ models of care that are not only consumer-centred⁵², but consumer-led.

Booster doses

After reaching a commendably high level of COVID-19 vaccination in the ACT, consumers now have access to booster doses, six months after their second dose was given. We know that COVID-19 vaccine coverage can wane over time. Getting a booster dose will help consumers across the ACT community to maintain a good level of immunity. Research is demonstrating that boosters work at improving immunity against current variants, including the Delta strain, and particularly in our older population who are more at risk from COVID 19⁵³.

Consumers have shared with HCCA their confusion between the terms 'booster' and 'third dose'. Some people are eligible for a third dose under certain requirements particular to immunocompromised communities. Does this mean that some consumers would receive both a third and a booster dose? It would be helpful to clarify this in messaging to consumers.

It has been good to see ACT Health encouraging the uptake of booster doses. Sites for booster doses include public health COVID vaccination centres, along with many GPs and pharmacies in our primary care sector. We have seen a number of pop-up vaccination clinics around Canberra promoted through social media which has been a useful approach to encouraging vaccination and booster doses.

Emerging medications for Covid-19 treatment

Evidence has been emerging around the effectiveness of certain medicines that, if delivered early in COVID-19 infection, can greatly reduce the severity and length of illness for consumers. It is important that once health services are using these kinds of treatments as part of COVID-19 models of care, that there is equitable access and health literate consumer information available for consumers. It would also be useful to communicate information more broadly about the use of these treatments in the community, so that consumers can be aware and encouraged that early testing may lead to better health outcomes if they do end up contracting COVID-19.

2.9 Schooling and the impact of opening up on children and their families

While many families are relieved that children are returning to on site schooling, there is also significant anxiety in the community about the growing number of infections among children. While children are less likely to suffer from severe illness this does not mean they will not become unwell. Currently children make up around 30% of COVID infections in Australia. Available research suggests that approximately 2% of those children who contract COVID, regardless of the variant, will be admitted to hospital. There are many parents for whom this risk is too great, particularly those whose children have underlying conditions which make COVID potentially more dangerous. It can be financially onerous to choose to keep unvaccinated children at home.

The risks to unvaccinated children and young people need to be a key consideration in planning safety measures for early childhood settings and primary schools. These risks as well as the psychological safety of children need to be addressed in any risk/benefit analysis of potential safety measures and decisions about school attendance.

‘Opening up’ and significant relaxing of restrictions also means many anxious parents are being directed to return to their workplace rather than continue work from home. Many others who could not work from home due to the requirements of their role are also faced with their children now attending school with a larger cohort of children and the associated increased infection risk.

Following re-opening, it is reasonable to expect that school-based exposures will be a regular occurrence until a safe vaccine is available to children under 12. This could mean a significant period of anxiety and/or financial pressure for families.

School-based exposures can result in anything from a short closure for cleaning to children being quarantined at home for 14+ days. In addition to time off resulting from exposure, the concern around COVID infection means children are required to be tested and quarantined until cleared for symptoms of minor illnesses and hay-fever. For some children this is happening regularly.

While the ACT Government has chosen to continue work from home for its staff where possible, many other employers – including some federal government departments – have required a return to on-site work for staff who have been working from home throughout lockdown. This has a variety of negative impacts. It drives even more parents to make difficult decisions about sending children to school while exhibiting minor symptoms they should be tested for, so parents can attend their workplace and avoid taking (potentially) unpaid leave. Alternatively, it forces more parents to make adhoc care arrangements for potentially Covid positive children – such as grandparent care – again potentially increasing the spread of Covid beyond the household.

While schools have implemented a range of mitigation measures to reduce the potential for infection, including segregating cohorts, ventilation improvements, and mask requirements for staff and older children, school remains a high-risk environment. Many families remain concerned about the risk of severe illness in not just their children but other immunocompromised members of their community.

Rapid Antigen Testing (RAT) is being considered by many jurisdictions as a way of limiting school closures and family quarantine requirements. There are many complex ethical and logistical considerations at play with any decision to adopt large scale testing of minor children. These considerations must be balanced with the risks of continuing to use the extant trace, test and isolate model as well as a risk/benefit analysis of COVID vaccines in children under 12. Within the Australian context - a largely vaccinated adult population, and the mild form of COVID illness experienced by the majority of children it is possible the risk analysis may weigh against the use of existing vaccines in young children. This could occur either because ATAGI elects not to recommend their use or because parents and guardians do not feel confident that vaccination is in the interests of their children.

Regardless of any decision by ATAGI on vaccinations for under 12 year-olds, it is uncertain whether Australian children will be offered vaccination prior to the commencement of the 2022 school year. Schools and families will likely be navigating these issues and the anxiety they bring for some time to come. For this reason it is important to keep the children and families impacted by these decisions at the centre of considerations.

While the economic, educational and psychological benefits of returning to school are significant for many children, many more are finding that the supports and accommodations that assisted them to attend school have been reduced or removed. This includes the removal of access to therapies during school hours (such as sessions with external occupational therapists and speech therapists), ceasing use of shared breakout and sensory spaces, exclusion of parents from school premises, and the requirement for children to remain in classrooms regardless of sensory or emotional overload. This places children with a disability or neurodivergence at a significant disadvantage.

It would be helpful for families to be given more information about the reasons behind decisions taken around reopening schools and the protections in place. Families also need clarity about the level of risk involved, and what to expect when quarantine arrangements are put in place. They would also benefit from clear advice about what they can expect if their child is diagnosed with COVID, what their child may experience in terms of illness (what does 'mild illness' mean in terms of the range of symptoms and severity) and what supports are in place to help families safely manage their child's illness at home. This would allay some fears and assure parents that these public health decisions are being made in their children's best interests. Consumers told us:

'One of my children is in quarantine at home, along with the rest of her class, after a school exposure. I did not know what to expect but I am learning a lot along the way. I have been getting messages from many friends, having seen the school exposure list. They are checking in to see if we are ok, but also wanting to know, in quite some detail, how the process works. I think this is because most parents are assuming that they will experience a school quarantining arrangement at some point, and they want to be prepared, knowing what to expect. It would be good to see a bit more transparency about this. I have some feedback to give on the process so I hope there will be some evaluation or an opportunity to provide ideas for improvement at the end of the quarantine period!'

'I have had a child at home for two weeks quarantine due to school exposure. We found out about the need to quarantine with an SMS and email from the school, along with a general letter from ACT Health, one afternoon around 4pm. We were told which classes were affected, and those to stay at home, and that ACT Health would contact us the next day if we were considered a close contact. We went for testing straight away that afternoon, even though it was not clear from the advice whether we should do that. Twenty-four hours later, we received an SMS from ACT Health with the close contact advice and details on what to do next. I was surprised this took so long if it only required a text message. It would have been good to understand to expect contact from ACT Health within 24 hours, rather than waiting expectantly all day for advice.'

It is a significant adjustment to suddenly need to try to maintain 'appropriate separation' from your child for two weeks at home, and to have one parent unexpectedly need to be at home for this time. I am lucky that we can work from home with little notice, but I know that it's not as easy for everyone.'

Although there are economic imperatives at play, it is vital that the wellbeing of children and families is prioritised. Families want to know that there are plans in place for the ongoing safety of schooling and childcare and this needs to be evident in communication.

2.10 Environmental Sustainability

Australian healthcare is responsible for 7% of national carbon emissions, “with hospitals and pharmaceuticals the major contributors”⁵⁴. Other countries, such as the United Kingdom, are taking action to reduce emissions from healthcare but Australia’s healthcare footprint is increasing. The AMA says we need carbon neutral healthcare by 2040⁵⁵. In the ACT we have committed to carbon neutrality by 2050 and there is no exemption for healthcare. We are concerned, however, about the impact of the outbreak on environmental sustainability, in particular the use of single use plastics⁵⁶ which undermines our efforts to reduce plastic pollution.

The levels of plastics use “have increased significantly in connection with the consumption of plastic-based materials associated with the treatment of patients and general health care associated with COVID-19. This was mainly attributed to the discarding of single use personal protective equipment (PPE) which are most made of plastic. This includes disposable gloves and masks.” One study found that “the amount of medical waste generation containing significant percentages of plastics showed a rise of 370% during the pandemic”⁵⁷.

There has been an increase in unrecyclable clinical waste. We are aware of work underway at St Vincent’s in Sydney⁵⁸ where there is a program to recycle plastic tips of vaccination syringes. This is part of a demonstration project⁵⁹ with NSW Circular where plastic waste is recycled and turned into plastic parts for wind turbines and roller doors. In just three months, they collected more than 80,000 pieces of clinical waste plastic. This has been taken on by Hunter New England LHD who reporting recycling 70kg in four weeks. We would like to see this be explored in the ACT.

2.11 Evaluation and Research

There are significant lessons learned for us to consider from the pandemic. Organisations had to make quick and difficult choices on policies and processes, staff worked under sustained pressure and often exhausted, supply chains for PPE and other equipment were interrupted and the way care was delivered was different.

We were all forced to reflect on realities of healthcare in ways we have not before. All these issues warrant evaluation, reflection and research.

HCCA believes in the value of consumer-based research. The HCCA Consumer-Based Research Framework⁶⁰ defines and presents our ideal of consumer-based research. It explains what HCCA, as a consumer organisation, does to support and encourage consumer-based research.

HCCA believes that consumer-based research involves consumers at all levels and all stages of the research process. Ideally, consumers are not just subjects of research but want to participate fully, and be involved, in the governance and conduct of research. Consequently, they are involved from the early stages of deciding what and how to research, through undertaking the research, to disseminating the findings and deciding what to do next. Involving consumers in this way increases the likelihood that the research will be relevant to community needs, deliver greater public awareness of research findings, and deliver better health outcomes.

We are hearing more about the impact of COVID-19 infection on chronic conditions and new disability for many people. There is much to learn about these impacts and we are keen to see the research agenda developed. The ACT Health and Wellbeing Partnership Board could play a role in overseeing the development of this work.

HCCA encourages all COVID-19 care providers to work with consumers and their representative organisations to develop an approach to collecting satisfaction and experience data on exit from time-limited COVID-19 care programs; and an approach to medium and longer-term satisfaction/experience data collection including collection of qualitative experience data. HCCA is well placed to establish a COVID-19 consumer reference group to begin building the infrastructure to support consumer involvement in work of this kind.

In discussions this year consumers have identified the following areas for research with HCCA:

1. Understanding the consumer experience of COVID-19 care (both strengths, and opportunities to improve safety, quality, experience and outcomes). This includes consumer experience of support through primary care, Covid Care at Home, as inpatients at public hospitals as well as rehabilitation.
2. Learning from and sustaining COVID-19 driven innovations in patient care, in particular telehealth and virtual health care delivery.
3. Understanding and responding to the long-term needs for care of people with COVID-19 related disability in particular "long COVID" / "post-COVID syndrome". Across this research agenda consumer involvement and leadership will be crucial to ensuring health service innovation is sustained and better health outcomes for patients and consumers are achieved.
4. Understanding the gendered impacts of COVID-19 and how to address these impacts.

3. Concluding remarks

We thank you for the opportunity to provide a submission to the Inquiry into the COVID-19 2021 pandemic response.

HCCA members are grateful for and appreciative of the work and commitment of members of the ACT Government and their officials as well as clinicians and health services staff for the effective response.

While the health response has been highly successful, there has been unintended and significant consequences for consumers and our families in navigating a very different healthcare landscape. In this submission we recognise the things that have worked well and also identify those issues that point to areas for improvement.

HCCA is happy to be contacted to clarify any issues we have raised in our submission, or to discuss our submission further.

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