Impact on amputee treatment and care due to Covid-19 restrictions

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Limbs 4 Life
Empowering Amputees

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Glossary

ALS	State-based Artificial Limb Schemes/Services
Amputee	A person living with limb loss, due to the absence or surgical removal of a limb or limbs
Assistive technology	Adaptive, and rehabilitative devices for people with disabilities to assist them to lead independent lives (e.g. prosthesis, wheelchair, walker, cane)
CRPD	The Convention on the Rights of Persons with Disabilities
Limb loss	Acquired absence of a limb or limbs
NDIS	National Disability Insurance Scheme
OT	Occupational Therapist
Prosthesis (artificial limb)	A device which helps to replace the mobility or functionally of a missing limb/s
Prosthetic provider	A trained clinical practitioner who manufactures prosthetic devices (artificial) limbs
Socket	The interface which connects the prosthesis to the individual
Stump	Residual limb

Executive Summary

While Limbs 4 Life acknowledges that COVID-19 was a novel pandemic, after two years of restrictions it became apparent that people with limb loss experienced considerable impacts on their treatment and care prohibiting sound health based outcome and impeding their recovery. This lack of care should raise serious concerns amongst governments, health-based administrators, and other key stakeholders. The lack of care and support must be reviewed and addressed. The barriers to amputee rehabilitation, care and treatment failures, careless practices and mistakes raised in this report should influence discussion and create opportunities to strategically plan for future-proofing of vital healthcare services.

During restrictions Limbs 4 Life fielded hundreds of calls from distressed and concerned amputees. Callers identified as people who had recently undergone an amputation, while others were people who had lived with amputation for the longer-term, for up to 71+ years in some cases. Based on the anecdotal feedback it was imperative that a formal consultation be conducted to capture personal experiences in relation to the lack of treatment and access to services for this cohort of people with significant physical disability. The national survey qualitatively responded to by 274 amputees, coupled with literature, are documented in this report.

Overarchingly, people with limb loss experienced significant structural, personal, environment, economic and policy barriers which, in many cases, prevented their ability to access rehabilitation treatment and prosthetic supports during this time. Tragically, in some cases this led to increased existing or emerging physical health, anxiety and wellbeing impacts which they may never recover from. At a human and disability rights perspective denial or poor provision of amputee-tailored rehabilitation, habitation, treatment and care for individuals living with limb loss, outlines that many hospital departments and healthcare practitioners across Australia contravened Articles 5, 9, 20, 25 and 26 in the Convention on the Rights of Persons with Disabilities to which our nation is a signatory.

In the case of respondents who underwent major limb amputations during the restrictions, there was often a denial, poor provision or delay in critical sub-acute in-patient rehabilitation. Some respondents were sent directly home following surgery, which meant that there was no basic rehabilitation support provided at all, failing the ‘duty of care’ that healthcare facilities adhere to. These individuals were discharged from hospitals, often without a prior home assessment, and left to fend for themselves at home without the necessary tools in place to ensure their safety. Those amputees did not receive training to develop basic skills to transfer from wheelchair to bed and toilet, given access to vital aids and equipment (assistive technology) was not provided, nor was other healthcare management strategies to assist with basic mobility and safe home transitioning practice. Many indicated that this created a greater sense of personal vulnerability, undue stress, anxiety, burdens on family (where available) which led them to feel high degrees of challenging mental health impacts. At the time of this report, it is noted that in some cases those who were sent home are still waiting to be contacted for prosthetic assistance and management.

In the case of amputee respondents who have a long term history of lived limb loss experience, delays or lack of access to prosthetic providers, mobility device provision, allied health services and other critical supports, countering their amputee-specific needs, were raised. It is relevant that many people in who have undergone amputation in Australia is due to health comorbidities, such as Type 2 Diabetes, and lack of access to prosthetic services can have additional lasting health implications.

Respondents expressed significant delays or lack of access to prosthetic providers for replacement, repairs and maintenance to this crucial device, reduced ability to access mobility devices such as wheelchairs, or use of more risky alternative mobility aids if prosthetic or other assistive technology devices couldn't be used. They conveyed inability or difficulty mobilising in the home or community, increased levels of pain, unnecessary injuries and hospital re-admissions, the introduction of new chronic health conditions, economic and employment impacts, and compromised ability to care for dependents. De-classification of immediate allied health care need from 'urgent' or 'emergency' to a lesser categorisation, border closures which prevented access to prosthetic services (e.g. Albury and Wodonga), and delayed surgical treatments were raised as significant impediments to amputees' physical and emotional wellbeing.

Many respondents indicated that they felt abandoned by healthcare systems, experienced social isolation that was further compounded by their disability, concerns that lack of access to allied health and assistive technology might lead to long-lasting physical and potentially irreversible health conditions, regression in physical competence, increased dependence on family members, loss in independence, disability marginalisation, and poor psycho-social wellbeing.

This national consultation has enabled Limbs 4 Life to identify recommendations in the hope that restrictions to healthcare services for amputees never happens again.

Recommendation 1
Recognise that people who undergo a major amputation should never be discharged home without services and supports in place. Acknowledge that failure to provide individual and purpose-built rehabilitation is denial of critical healthcare treatment after acquiring limb loss and developing a physical disability.

It is recommended that all health systems work to ensure that people with the newly acquired disability of limb loss receive tailored amputee rehabilitation in a clinical setting.

Recommendation 2
Recognise that individuals who are prosthetic users rely on essential assistive technology to walk, function, and participate socially and economically. Understand that the delay in fitting a prosthesis will result in negative outcomes and major setbacks for the individual.

It is recommended that amputees receive access to allied health supports in an effective and efficient manner for the provision of prosthetics, which is in no way detrimental to their long-term health-based outcomes.

Recommendation 3

Recognise that during the restrictions many public prosthetic clinics were, for a variety of factors, closed and/or not responding to general enquiries. Phone calls were often not responded to or were answered but after a long delay, putting amputees' physical and mental health at significant risk, despite the fact that these government services and public servants are there to support public healthcare.

It is recommended that calls and enquires made to public prosthetic clinics never go unanswered and are responded to in a timely manner. There also needs to be serious consideration paid to sharing prosthetic services among private providers when public ones deny, or are completely inaccessible for, essential patient health treatment.

Recommendation 4

Recognise that due to fragmented funding services some amputees have no choice or control over their provider and consequently receive prosthetic care and treatment across state borders. Additionally, consideration should be paid to the fact that some amputees are able to exercise their rights of 'choice and control' to access to interstate healthcare services, which should not be prohibited, and they may struggle to source a new one if they cannot attend their usual practitioner.

It is recommended that no governments ever deny Australian amputees from accessing essential healthcare services due to border closures. Border closures should never have happened nor happen again, and while a service such as telehealth may work in some settings it is not applicable in in the manufacture, fit or supply of a prosthetic device, meaning that crossing state lines for prosthetic treatment and care is critical.

Recommendation 5

Recognise that lower limb amputees are reliant on other mobility devices, such as wheelchairs, to achieve independence and remain mobile and safe within home, employment and community settings. Understand that only certain practitioners, such as occupational therapists, can prescribe and fit this assistive technology. Acknowledge that amputees in need of mobility devices became house bound due to the inability to ambulate, because they were unable to gain access to practitioners for assessments, prescriptions and ordering during restrictions.

It is recommended that all amputees must be prioritised for urgent practitioner assessment. If they require access to assistive technology and the person's regular practitioner, whether government-funded or private, is unavailable they should be assisted by the relevant health service and/or industry body to source an alternative provider.

Recommendation 6
Recognise that due to clinical closures of state-funded prosthetic facilities during restrictions, funds provided to these clinics for the provision of prosthetics would have remained unspent. Publicly funded services should be required to provide financial transparency, declare where monies were expended and how saved costs can be reinvested in public health.

It is recommended there should be greater levels of transparency in relation to state-based artificial limb schemes expenditure, number of patients treated and funds retained during COVID-19 lockdown and restriction periods. Serious consideration should be paid to reallocating savings to invest in amputees denied access to adequate support over this period so that they can achieve better quality of life outcomes.

Recommendation 7
Recognise that the provision of and access to amputee rehabilitation, habitation, assistive technology, health services, personal mobility and a good quality of life is ratified in The Convention on the Rights of Persons with Disabilities. Acknowledge that governments likely failed to meet Articles 5, 9, 20, 25 and 26 within the Convention, and therefore didn't adequately protect the health and human rights of all amputees in Australia.

It is recommended that the Federal Government and Australian Human Rights Commission recognise that amputees were a disabled cohort disproportionally affected by restrictions, some of which counter Articles within the Convention on the Rights of Persons with Disabilities. The importance of human rights must be recognised and realised so as not to impact the health and disability rights of any individual.

1. About Limbs 4 Life

Limbs 4 Life's mission is to provide information and support to amputees and their families while promoting an inclusive community.

Our philosophy is to *empower amputees with knowledge and support to make a real difference, because no one should go through limb loss alone*.

Limbs 4 Life is the peak body for amputees in Australia and provides services to thousands of amputees and their care givers, who rely on its programs and support for assistance prior to or after a limb amputation. Limbs 4 Life is supported by 200 trained Peer Support Volunteers, located across Australia, who provide one-on-one support pre or post amputation surgery.

Limbs 4 Life advocates for amputees by initiating or taking part in research, provides recommendations to government, responds to submissions, and educates the community about amputation. For more information visit www.limbs4life.org.au

2. Report background and purpose

Over the course of the COVID-19 lockdowns and restriction periods in Australia Limbs 4 Life became anecdotally aware of amputees' challenges in relation inadequate or lack of access to treatment, care and support from the healthcare system and essential services. Not surprisingly, the largest number of responses came from those living in the state whereby people experienced the longest lockdowns in the world.

Considering this, and given that Limbs 4 Life was only receiving information informally (e.g. via phone, email and social media), we identified the need for a formal consultation to capture first-hand accounts from members of our community (people with limb loss) regarding their experiences during the restrictions.

2.1 Methodology and design

The 'Impact on amputee treatment and care during COVID-19 restrictions' was a qualitative survey. People with limb loss located across Australia were invited to participate between April to June 2022. The survey was shared directly via email, social media and Limbs 4 Life's publication.

Respondents did not need to identify. However, some key non-identifiable details were sought. Respondents were broken into two groups:

a) those who experienced their amputation immediately prior to or during COVID-19 restrictions to enable them to respond to questions related to post-amputation rehabilitation
b) those who had experienced limb loss in a period prior to the COVID-19 pandemic, with this cohort generally classified as 'longer-term amputees'.

The survey consisted of ten questions, nine of which were open-ended. A thematic analysis approach was used to examine respondents' questionnaire content and generate a series of coded themes. The survey did not build upon an existing questionnaire framework.

2.2 Limitations

The most notable limitation is that the survey is not a representative survey, and thus caution should be used when generalising findings to the broader Australian population of amputees. Convenience sampling was used to recruit participants in this survey, as the survey was promoted on an opt-in basis via an array of communication channels.

Because of this approach, and that the survey was only offered via a few channels, the resulting respondent sample is likely to only represent those with the confidence and capacity to partake in

an online survey. Therefore, those lacking internet confidence, who are socially isolated, affected by low literacy, and/or have none or limited access to the internet are less likely to have participated and may have led to some response bias.

3. Amputee population

Amputation is defined as the surgical removal of a limb, limbs or partial limb/s due to injury, illness or disease. The aetiology of surgical amputation of major or minor limbs (upper and/or lower limbs) in Australia is varied and diverse, with the main causative factors including diabetes-related complications, cardiovascular disease, trauma, cancer, and infections. Such limb loss can occur at any stage within an individual's lifetime. In addition, members of the amputee community comprise those born with congenital deficiencies of limbs, which sees this cohort experience a lifetime of living with limb loss. It is reasonable to say that people living with limb loss make up the largest physical disability group in Australia today.

The KPMG 'Socio-economic burden of limb loss in Australia'[1] report, Australia's very first such study which was commission by Limbs 4 Life, reveals the most up-to-date data in relation to population size, prevalence, incidence, cause, and socio-economic costs. It recognised that *"the burden of amputation is arguably one of the least known and often under-appreciated health problems in Australia."*

Until this study was undertaken, due to lack of consistent and harmonised data collection at both individual states and national levels, even governments were unaware of this clear evidence and the staggering figures. Sadly, without significant intervention, the amputee population is conservatively estimated to grow at a rate of 2.2% per annum.

- **Population.** 160,395 amputees live in the Australian community in 2019/20, with this population group expected to reach 305,146 by 2049/50.
- **Rate.** Every three hours a person loses a lower limb in Australia, due to the effects of Type 2 diabetes.
- **Age.** The risk of amputation increases with age, with 60% of amputees aged 65 years and over in 2019/20.
- **Gender.** Males are more likely to undergo an amputation when compared to females, with 73% of amputees being men and 27% being women in 2019/20.
- **Ethnicity.** Aboriginal and Torres Strait Islander peoples are twice more likely to experience amputation than their non- Aboriginal and Torres Strait Islander people counterparts. But Aboriginal and Torres Strait Islander people aged 50 over years of age, are nearly three times more likely to experience limb loss.
- **Re-amputation risk.** It is estimated that if amputation is due to disease, the risk of re-amputation after an initial one is significant. Indeed, it is estimated that the probability of a re-amputation is 10% the year after the initial amputation and 23% within 10 years.

Concerningly, the probability of a second re-amputation is 15% in the first year after the first re-amputation and 33% within 10 years after the first re-amputation procedure.

4. The Convention on the Rights of Persons with Disabilities

It is critical that governments in Australia adhere to The Convention on the Rights of Persons with Disabilities, not solely because Australia is a signatory to this, but because Article 1 of the Convention states that its purpose *"… is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."* [2]

However, in reviewing other Articles within the Convention it would appear that Australian governments failed to meet their obligations during the COVID-19 restriction periods in relation to people who experienced amputation during this period or could be classified as a longer-term amputee. These have been broken down into two clusters of Articles, which Limbs 4 Life firmly believes were not met.

Articles 9, 20, 25 and 26 relate to 'rehabilitation and habitation' and other areas such as accessibility, standard of health and independence, which connect to those people who experienced amputation just prior to or during the COVID-19 restriction period. Articles 5, 9, 20, 25 and 26 relate to 'assistive technology' and other areas such as service access, health, independence and equal inclusion, which strongly correlate with those people who lived with limb loss prior to the COVID-19 pandemic reaching Australia.

Detailed information about the aforementioned Articles is provided in section 7.

Drawing upon respondents' feedback and the barriers they raised strongly suggests that Australian governments failed to meet the objectives and principles within each of these Articles.

5. Rehabilitation treatment and care for new amputees during the restrictions

5.1 Background to amputation recovery and rehabilitation

The loss or surgical removal of a limb is considered a major health event which can impact on a person's mobility and independence.

Rehabilitation is considered to be the sum of treatment approaches aimed at raising a person's capacities to maximum, reducing dependencies and improving quality of life after disablement.[3] Considerable research attests that well planned rehabilitation, in particular that which follows lower limb amputation and often within inpatient settings, is aimed at:

- minimising phantom pain and residual limb pain

- improving health outcomes
- reducing limb contracture
- balance and stability training
- improving muscle strength
- developing wheelchair skills ability and confidence
- facilitating prosthetic prescription and fabrication, as well as concurrent successful prosthetic training and ambulation if suitable
- improving independence
- developing daily living and self-care activities and duties
- reducing dependency
- increasing vitality
- planning for socio-economic re-entrance into the community
- planning for funding services and supports
- peer support which validates experiential knowledge, promoting self-determination and empowerment, fostering choice and control, and, encouraging strengths and connectivity
- improving quality of life. [4,5,6,7,8,9,10,11,12]

With respect to lower limb amputations, it is estimated that overall recovery post-amputation occurs over a 12 - 18 month period and is inclusive of activity recovery, reintegration into society, and prosthetic management and training.[13]

Conversely, poor rehabilitation of a person who has experienced a recent amputation affects health outcomes, physically and mentally.[14]

5.1.1 Rehabilitation in Australia

In Australia, much lower-limb amputation rehabilitation is conducted in a mix of sub-acute inpatient facilities or, to a lesser degree, outpatient treatment. In the case of individuals who experience upper-limb amputations, rehabilitation is predominately provided in an outpatient treatment setting. Examples of minimum state-based government or agency guidelines and standards of care which reflect this include ones such as the 'Model of Amputee Rehabilitation in South Australia'[15] and the 'NSW Minimum Standards: Care of the Person following Amputation'[16].

Inpatient rehabilitation may be conducted in a public or private specialised rehabilitation facility specifically designed for amputees, often colloquially referred to as an 'Amputee Rehabilitation Clinic'. At such a clinic each patient receives 24-hour nursing care and a comprehensive individualised program designed by a multidisciplinary team often comprised of a specialist doctor, physiotherapist, prosthetist, occupational therapist, dietician, social worker and other relevant healthcare workers. The goal of this is to achieve the treatment outcomes noted in the aforementioned literature.

In-patient rehabilitation at a sub-acute facility is usually over the course of a 3 – 4 week period. This time allows for new amputees to adjust to their condition while receiving ongoing medical treatment, such as wound dressing, skills to transfer safely using one leg, lessons about traversing in wet-areas, toileting, and showering, along with basic daily living skills (e.g. dressing). Sub-acute rehabilitation is also a time whereby the amputee is prepared for prosthetic training, learns exercise skills to enhance the accommodation of a prosthesis, wheelchair drills and balancing.

Following an initial rehabilitation program it is not uncommon for new amputees to transferred home for a short period of time while final wound healing takes place, however this usually only happens once basic skills have been taught and adopted, their residence has been assessed for access and safety and if there is a partner and carer who can support the process.

Individuals discharged from hospital and admitted to outpatient rehabilitation will attend appointments sessions with a multidisciplinary team at their closest Amputee Rehabilitation Clinic, although for some this can mean considerable travel distance. Others may be receiving rehabilitation in the home, whereby health practitioners will attend the person's home, albeit absent of the array of tools and equipment available in the clinic.

5.1.2 Home assessments and provision of assistive technology prior to discharge

Regardless of whether the person has completed inpatient rehabilitation or discharged home post-surgery in all cases their residence should be assessed for access and safety prior to discharge. Each hospital has a duty of care when discharging patients to their home.

Indeed, the NSW Minimum Standards of Care states that "all persons receive a home safety review delivered by an occupational therapist" as part of 'Standard Practice S5 – Falls Prevention'.[17]

It is notable that regardless of whether or not a person will be a prosthetic user, most Australians who experience a lower limb amputation will be prescribed a manual wheelchair to support independence and mobility; making the provision of and training in the use of a wheelchair prior to discharge critical.[18] Any mobility device should be prescribed by practitioners, such as physiotherapists or occupational therapists, to ensure that the assistive technology takes account of the person's specific limb loss, ability and needs.[19] Failure to provide the person with mobility devices that are fit-for-purpose and puts the person at risk of injuries and unnecessary hospital admissions.

Provision of rehabilitation, assistive technology, home modifications and other relevant supports to assist a person adjust to recent amputation is critical for safety, mobility and functionality, and also facilitates access to societal participation, places of learning, workplaces and services. Denial of rehabilitation in an appropriate manner contravenes the basic rights outlined in Articles 9, 20, 25 and 26 in the Convention on the Rights of Persons with Disabilities.

5.2 Informal feedback regarding amputation rehabilitation during the COVID-19 restrictions

It became apparent that individuals who experienced an amputation just prior to or during the COVID-19 pandemic, and in need of rehabilitation to achieve functionality, mobility and independence have been impacted. Those particularly affected were individuals in jurisdictions that experienced lockdowns and restrictions, leading to lack of access to or reduced rehabilitation facilities and services.

Prior to conducting the survey Limbs 4 Life received an abundance of calls from people who had experienced amputations during the restriction periods, family members and some healthcare providers who were distressed and expressed concerns that access to appropriate rehabilitation was being denied, limited and/or not in accordance with standard health practices.

Limbs 4 Life became aware that significantly more individuals who would ordinarily be transferred to an amputee-specific inpatient (sub-acute) rehabilitation setting were instead discharged home. Furthermore, these individuals were not offered outpatient rehabilitation due to restrictions in rehabilitation facilities, bed and ward closures, or staff furloughs. In addition, if confined to the home a lack of allied health staff availability meant they could not receive even basic in-person rehabilitation in the home environment. Collectively, these individuals were missing out on the early intervention effectiveness of rehabilitation, and associated prosthetic provision and training, that offers the greatest likelihood of successful long-term physical and emotional outcomes.

Limbs 4 Life was informed that prior to a home discharge many individuals did not have a standard occupational assessment of their living environment. As such, their overall safety, physical health and emotional wellbeing was compromised.

We were told by several lower limb amputees that they were discharged without basic adequate aids, equipment and assistive technology needed to safely mobilise and ambulate in the home environment, an abandonment of duty of care by various hospitals. Some were provided with aids and equipment (e.g. manual wheelchair, anti-slip mats, shower chair) but had received none or insufficient training in how to safely use these.

Prior to conducting the survey Limbs 4 Life received considerable feedback outlining concerns in relation to lack of access to assistive technology providers and healthcare services from amputees who had lived with limb loss for a considerable time. Many callers were deeply concerned and distressed, as were some of the people and organisations that support them.

A mere two examples of significant and distressing personal issues and incidents in relation to lack of proper rehabilitation, expressed to Limbs 4 Life via a phone call, included:

- Two men in their thirties had been sent home in wheelchairs. Both men were trying to maintain automotive employment working in wheelchairs repairing vehicles, because they had no other sources of income and were desperately waiting on their prosthesis.
- A man who was bought to tears because he had his amputation and was sent home to his seventy-year-old wife and she was unable to lift/ help him to move and access basic toileting. Follow up from the rehabilitation facility was never provided to this couple.

5.3 Formal responses regarding rehabilitation treatment and care during the COVID-19 restrictions

Of the 274 survey respondents, 14 percent experienced amputation in the two-year COVID-19 restriction period and provided responses to the rehabilitation-specific questions asked in segment one of the survey, more specifically six open-ended questions.

During this period, 69 percent of people (n=26) who experienced an amputation were NOT transferred from hospital to a rehabilitation facility. Instead, they were discharged from the hospital post-surgery to their home or residential care facility. The remaining 31 percent (n=12) were transferred to a rehabilitation facility connected to the hospital.

A review of the survey responses highlights that both cohorts experienced challenges and barriers due to the impacts that restrictions imposed regardless of whether or not they went into rehabilitation. However, those who were NOT transferred into rehabilitation post-surgery expressed a greater sense of vulnerability and imposed barriers and challenges to healthcare service access.

Responses to the rehabilitation-related questions were coded to generate themes, identifying structural, personal, environmental, economic and policy barriers which impacted on their ability to adapt to life post-amputation.

5.3.1 Barriers experienced by those who experienced amputation during COVID-19 restrictions and were transferred from hospital to inpatient rehabilitation

Twelve respondents identified as having been transferred from hospital to inpatient rehabilitation.

Barriers in relation to this post-amputation experience were drawn from the polar Question 6 which enabled the person to answer yes or no, followed by an open-ended Question 7 which sought comments to the query “If your amputation was just prior to or during the COVID-19 restrictions, were you transferred from hospital to rehabilitation?”.

Respondents expressed concerns that they spent unnecessarily extended periods in acute hospital settings post-surgery, undertook incomplete rehabilitation, had to urgently appeal to government leaders and advocates for access to basic health rights, and were left to make surgical decisions or face the post-amputation challenges without adequate psycho-social support which led to rising levels of isolation and anxiety.

Structural barriers resulted in some individuals who experienced their amputation surgery spend unnecessary extended periods in acute hospital settings, discharge from rehabilitation prior to full program completion because of facility lockdowns, and necessity to appeal to government for vital healthcare access.

"Sent to <name withheld> rehab centre after 9 weeks in <name withheld> private hospital. Had to stay longer in hospital as rehab were not taking anybody because of Covid 19." (65-74 year lower-limb amputee, Victoria)

"Still waiting for rehabilitation to be completed." (35–44 year old, lower-limb amputee, Victoria)

"Rehab was eventually after waiting 99 days for a bed & requesting assistance and intervention from the Minister for Health. I received 16 days as an inpatient." (65–74 year old lower-limb amputee, Victoria)

Personal barriers left several individuals having to make surgical decisions or face the post-amputation challenges without adequate psychosocial support; ones which contributed to increasing levels of anxiety and social isolation.

"The period of my hospitalisation was from Aug 21 to mid Dec 21. During that time strict Covid restrictions were in place. A total ban on visitors existed. In hospital I was rarely allowed out of my room. That was for a period of 99 days. I had to make vital decisions regarding my treatment alone or through zoom or FaceTime." (65-74 year old lower-limb amputee, Victoria)

Policy barriers resulted in one respondent directly appeal to government for a vital healthcare service, that would ordinarily form part of their standardised recovery with medical and allied health professionals, because the facility was shut down.

"It was shut down so had to take case to Minister of Health to get access to rehabilitation services." (45-54 year old lower-limb amputee, Victoria)

5.3.2 Barriers experienced by those who experienced amputation during COVID-19 restrictions and were NOT transferred from hospital to inpatient rehabilitation

Respondents who were denied access to or received limited rehabilitation provision during the restriction periods commented on an array of barriers and challenges. It became apparent that the impact of these barriers had immediate effects but may also have longer term consequences on their psycho-socio and economic wellbeing.

Responses to the following five open-ended survey questions facilitated analysis and then composition of key barrier themes.

5.3.1.1 Barriers raised in response to 'Question 8: If you didn't attend in-patient rehabilitation after surgery, please tell us about your experience?' and 'Question 9: If you were sent home, which services were provided?'

Respondents who did not attend rehabilitation after their surgery expressed concerns in relation to their discharge and recovery in the home. Many felt that a lack of access to coordinated rehabilitation programs, services and associated allied health practitioners, coupled with limited information, placed undue stress and burdens on the individuals and their unpaid carers. Many also expressed that lack of provision of basic mobility devices, home modifications and prosthetics limited their progression and recovery.

Structural barriers left some respondents feel despondent due to a lack of re-structured rehabilitation service availability, no home visits to conduct rehabilitation programs, lack of access to allied health services due to re-structures and staff limitations, lack of communication from public hospital departments, and denial of basic home care which in some cases increased burdens on informal carers. Some also felt the need to privately self-fund services as a direct result of inaccessibility to publicly funded services.

"Sent home and basically left to get on with life… good old Covid hit and everything stopped as we were advised that the <name withheld> hospital was only doing home visit to Metro NOT regional. So basically left without any support… Feel very let down by the system." (65-74 years lower limb amputee, Victoria)

"Although I qualified for physio and prosthetic services they could not be provided. Covid & staffing were cited as the reason why." (65-74 year old low-limb amputee, Victoria)

"Was told by the Physio that there was no face-to-face appointments during Covid." (65-74 years upper-limb amputee, Western Australia)

"Allied health telehealth appointments only." (35-44 year old upper-limb amputee, NSW)

"Yes, sent home and could only have telehealth appointments with OT and Surgeon." (35-44 years upper-limb amputee, NSW)

"Needed support of my husband who is in his 70s and has his own health issues." (65-74 year old amputee, Victoria)

"None. Had to get cleaning and home help myself." (35-44 year old lower-limb amputee, Victoria)

"I was sent home, with a promise of a referral to Queensland Health, heard nothing for almost 3 months." (55-64 years lower-limb amputee, Queensland)

"I am having to go private for rehab." (45-54 year old lower-limb amputee, Western Australia)

"I took charge of my own rehab through private services not state." (45-54 year old lower-limb amputee, South Australia)

Environmental barriers occasioned a lack of basic access to aids and equipment and the fitting of an interim (first) prosthesis. This was a lack of access to assistive technology which should form part of any 'first world' rehabilitation program and discharge process, both to ensure the person is progressing and also returning to a home and lifestyle that can safely accommodate their needs.

"I was due to start being fitted (for a prosthesis) when Covid started so I have no idea when I will start being fitted for prosthetic." (65-74 years lower limb amputee, Victoria)

"Sent to nursing home, no rehab yet, no idea when I get fitted for leg." (65-74 year old amputee, Victoria)

"I was left largely to my own devices. My home required modifications to the bathroom that no one funded except for the fitting of handrails. I had to get the bathtub removed and a shower stall installed. All at my own cost and without any help." (65-74 years lower limb amputee, South Australia)

5.3.1.2 Barriers raised in response to 'Question 10: If you were eligible for a prosthesis, did you experience any delay in getting your first limb?'

Respondents comprised of a mix of those who were transferred from hospital to rehabilitation after surgery as well as those immediately discharged to their home. They expressed concerns about lengthy delays in the fitting of their first prosthesis or disclosed that such a critical mobility device had not been fitted at all.

Environmental barriers resulted in new amputees either experiencing lengthy delays for their first prosthesis or, even worse, no fitting of a prosthesis at all.

"I was discharged in early December 2021 received my first limb at the start of March 2022." (65-74 year old lower-limb amputee, Victoria)

"After my surgery in June 2021 I only received my first prosthetic in the last month (June 2022)." (35-44 year old upper-limb amputee, NSW)

"Still have not received a limb." (25-34 year old lower-limb amputee, SA)

"Unable to see clinic." (35-44 year old lower-limb amputee, Victoria)

"I had to use crutches." (45-54 year old lower-limb amputee, SA)

5.3.1.3 Barriers raised in response to 'Question 11: If you experienced delays in access to prosthetic or other healthcare services (e.g. physiotherapy, occupational therapy, social work) how did these wait times affect you?'

Respondents comprised of a mix of those who were transferred from hospital to rehabilitation after surgery as well as those immediately discharged to their home.

Respondents expressed concerns about lack of access to or unsuitable provision of a variety of allied health services, increased falls and accidents due to home discharge without rehabilitation, decline in physical and psycho-social capacity because of poor service access, and inability to be fitted with a prosthesis within the adequate timeframe. Some felt abandoned by the public system, had to draw upon personal finances to make even basic home safety modifications and access in-home rehabilitation, and could not access health practitioners to conduct assessments in order to submit clinical justifications for assistive technology funding under the National Disability Insurance Scheme (NDIS). When considered collectively, respondents' comments highlighted that some, who had recently acquired a physical disability, were living in situations and conditions that did not meet even a very basic quality of life.

Structural barriers resulted in some respondents' experience absence of access to allied health services due to re-structures and staff limitations leading to accidents and falls, lack of access to traditional inpatient rehabilitation leading to lack of progression in phased physical and assistive technology development, and re-structured online support and development services unsuited to their needs.

"No private OT availability, still on a waiting list. No physio due to lack of availability. Social work pretty non-existent due to local demands. I left rehab on my own, have lived in an unmodified home and been hospitalised 3 times due to injuries from falls." (55-64 year old lower limb amputee, ACT)

"Very frustrated having no idea if I will ever get help. Never got a prosthetic appointment. Stuck at start of process, stuck in wheelchair in nursing home." (65-74 year old lower-limb amputee, Victoria)

"OT and prosthetic input to rehab all had to be done via video and phone linkups which affected the quality of the therapy." (65-74 year old upper limb amputee, WA)

Personal barriers left several respondents feel concerned that as a direct result of lack of access to rehabilitation, psycho-social and prosthetic services their physical, mental health and overall capacity was compromised and/or in considerable decline.

"I had my surgery on 1st March 2022. I got home on 6th. Didn't see or hear from anyone for about 2 weeks after I phoned them several times. I felt unsure about lots of things, wound, stiffness, lack of support and general uneasiness that I might be missing the opportunity to rehab well and quickly." (65-74 year old upper-limb amputee, WA)

"Mainly mental anxiety due to lack of social work and psychology." (45-54 year old lower-limb amputee, Victoria)

"Made everything a struggle, financially, mentally, physically. Felt like I was on my own." (45-54 year old lower-limb amputee, SA)

Environmental barriers left several respondents who became amputees immediately prior to pandemic or during the restrictions experience considerable difficulties to progress from being fitted with their interim (first) prosthesis to their definitive (second) prosthesis. An interim prosthesis is considered a temporary limb fitted during the rehabilitation phase to assist with basic mobility, gait training, regaining balance, confidence building, prevent prolonged bed rest, and allow the residual limb to naturally shrink and shape post amputation. The definitive prosthesis is fitted once the residual limb has stabilised and accommodates an individual's weight and movement, and activity level. If a person does not progress to the definitive prosthesis phase within a reasonable timeframe they risk considerable physical, social, psychological and economic impacts.

"2020 - Delayed my new legs, unable to walk long distances, exercise, unable to have a waterproof leg, generally unable to function at the level I wanted to. 2021 - I was unable to wear my prosthetic leg as the socket became so big and was causing pain. I need to use my wheelchair. I was unable to go for walks and had limited access to my workplace as it is not 100% accessible." (45-54 year old lower-limb amputee, Victoria)

"I have been waiting now 3 months for my second leg due to Covid (on-going delays to gain a lengthy prosthetic appointment) my first leg no longer fits. My first leg which I have had for 12 months is now not fitting properly even after several attempts at re packing so it is not

comfortable or safe to wear it has fallen off a few times." (65-74 year old lower-limb amputee, WA)

Economic barriers resulted in some respondents feeling abandoned by the government system/s because of a necessity to draw upon individual finances to reduce physical safety risks, to coordinate home modifications, and access unavailable basic rehabilitation services due to immediate discharge from hospital.

"I have had to organise & fund the conversions necessary for me to safely return home myself. There was no wait for social work but they couldn't provide anything for me. I couldn't even get someone to do my floors & bathrooms once a fortnight. I feel abandoned by the system." (65-74 year old lower-limb amputee, Victoria)

"From discharge I've received NO SERVICES until I hired private OT & PT services. Delayed my rehab progress almost 3 months." (55-64 year old lower-limb amputee, Queensland)

Policy barriers born out of COVID-19 health system re-structures resulted in several respondents unable to access healthcare providers necessary to make assessments and submit clinical justifications for assistive technology under the National Disability Insurance Scheme (NDIS), leaving participants without vital aids and devices to live a basic quality of life.

"Living in Gippsland the OT waitlists were very long 6 months and mine was put an urgent list but I still needed to wait 2 months. This meant without having an OT functional capacity assessment I was not able to purchase the equipment I needed through my NDIS plan. In reality this looks like me not being able to do the basics in life showering, getting dressed and toileting in a potty it was humiliating. I was stuck in my house unable to get out. I did not have a ramp this needed OT approval and quotes it's been an absolute nightmare." (45-54 year old lower-limb bilateral amputee, Victoria)

"No OT services available out of hospital for assessment for funding." (45-54 year old lower-limb amputee, Victoria)

5.3.1.4 Barriers raised in response to 'Question 12: If you experienced delays in accessing services, did these delays affect your overall physical and mental health and wellbeing?'
Respondents comprised of a mix of those who were transferred from hospital to rehabilitation after surgery as well as those immediately discharged to their home environment.

Respondents expressed concerns that due to lack of rehabilitation the ability to walk was no longer a possibility nor something to aspire to. Some had experienced increased falls and

accidents as no home modifications were made prior to discharge, others had lost a sense of independence due to lack of access to prosthetic servicing, and some experienced amputee-related surgical delays because of government-imposed hospital restrictions.

Personal barriers left several respondents feel that they are living with a genuine sense that their 'new normal' and challenging physical disability will now result in a lifelong inability to walk; whereas had a rehabilitation program been made available then mobility and ambulation outcomes may have been achieved.

"Feel totally let down and lost the drive to even think I will walk again." (65-74 year old lower-limb amputee, Victoria)

"Mobility with a wheelchair only now." (55-64 year old lower-limb amputee, Victoria)

"Just had to tough it out and accept that is what it is. Was disappointing knowing I lost the small chance to walk again but nothing was going to change it." (55-64 year old lower-limb amputee, Tasmania)

"Yes frustration and not being able to go places as trying to walk on crutches … my mental health was impacted even more than dealing with the amputation itself." (45-54 year old lower-limb amputee, SA)

Environmental barriers resulted in several respondents lacking access to basic home modifications to ensure safety. This resulted in serious injuries, reduced independence due to return to alternative but less accessible mobility devices because of prosthetic clinic closures, and inability to have vital prosthetic adjustment.

"Yes, my independence was affected because I couldn't get my prosthetic leg adjusted and had to use a wheelchair. My ability to socialise because I couldn't access the staff room at work. I was in pain. I felt very frustrated. I was unable to exercise which normally helps to keep me feeling strong and positive." (45-54 year old lower-limb amputee, Victoria)

"I know there's others worse off, but when you're lying on your bathroom floor because it's not designed for your new context, with 4 cracked ribs it's easy to feel sorry for yourself." (55-64 year old lower-limb amputee, ACT)

Policy barriers born out hospital surgery restrictions placed by state or territory governments saw some respondents, while still in need of amputation or re-amputation, placed into 'elective' categories and experience stressful holds, delays or cancellations over those periods.

"My surgery was delayed 3 times and there was no psychological support either during the delays or since." (65-74 year old lower-limb amputee, SA)

6. Treatment, care and support for longer-term amputees during the restrictions

6.1 Background to treatment, care and support for longer-term amputees

The capacity to independently mobilise is regarded by health-related measures as a key indicator for quality-of-life measures[20], underscoring the need to provide assistive technology enablers for amputees.

Most amputees are suitable candidates for a prosthesis, a device which aims to restore function, improve mobility, increased quality of life and associated with a greater likelihood of entering into or sustaining employment.[21]

However, due to health conditions some people may not be suitable prosthetic candidates, or unable to suspend a prosthesis because their level of amputation is so high that it prevents a secure fit, in which case other types of assistive technology will be offered. In the case of lower limb amputees this is usually a wheelchair or crutches, and in upper limb amputees it may be nothing at all.

Any prosthetic product or alternative assistive technology solution, coupled with adequate training and tailored customisation, does not just target increased personal mobility or functionality but also provides access to societal participation, places of learning, workplaces and services. Furthermore, they must be fitted at appropriate times to ensure the person is using or being prescribed a product that helps to ensure their safety and wellbeing. Failure to achieve all the above contravenes Articles 5, 9, 20, 25 and 26 in The Convention on the Rights of Persons with Disabilities.

6.1.2 Prosthetics

It is widely reported that the goal for a person with limb loss, in particular lower limb amputees, is to secure a prosthesis that aids in returning what is missing in a functional manner.[22] Indeed, the role of prosthetics and advances in these over recent decades provide amputees with a wide range of options that can improve function, assist in preventing further health complications and enable an optimal quality of life. [23]

The type of prosthesis that a person utilises is contingent on the individual; taking account of the cause of amputation, location of the missing limb, height, weight, any other health considerations, and their desired goals.[24] Consequently, prosthetic limbs must be custom made by qualified prosthetists, who work to manufacture and fit a device that best meets the individualised mobility and functional needs of their client.

Amputees utilising prosthetics are users of some of the most complex and technical assistive technology available. Considerable engineering and biomechanical advancements in recent decades have led to the manufacture of sophisticated feet, knee and arm units which utilise dynamic response, microprocessor, bioelectric or bionic technology. The benefits to users of advanced prosthetics are better controllability, improved balance, fall reduction, reduced osteoarthritis incidence, and decreased energy expenditure.[25,26] Furthermore, recent trends in such assistive technology point to a more seamless integration of the capabilities of the user and the assistive technology they use, and lead to transformative mobility and participation capacity benefits. [27] While not all amputees are eligible for the more advanced technology, predominately those not eligible for the NDIS, it is important to note that such evolutions have enabled more amputees access fit-for-purpose devices which deliver impactful psycho-social-economic outcomes.

The fitting and ongoing maintenance and repairs of prosthetics are vital for amputees to remain safe and able to contribute socially and economically. As noted in the World Health Organization's 'Standards for Prosthetics and Orthotics', the provision of person-centred readily accessible maintenance and repair services ensures optimal functioning and comfort of products, maximises product lifespans, reduces the need for frequent renewals, is important for restoring functioning and preventing secondary deformities and avoidable impairments, improves user satisfaction, increases the cost–effectiveness of services, and ensures that more people are assisted.[28]

6.1.1.1 Prosthetic servicing across Australia

The provision of prosthetic services is complex and fragmented in Australia. Those who are eligible NDIS participants or insurance compensation clients can choose their provider. Whereas those ineligible for the NDIS (generally people who experience amputation over the age of 65 years) are reliant on state-based artificial limb schemes and providers eligible to deliver services under that scheme are often restricted.

Artificial Limb Scheme Services

Government regulations in the following jurisdictions have determined the following in relation to those amputees' ineligible for the NDIS and needing prosthetic provision. Publicly funded limb schemes are fragmented and not nationally consistent in Australia.

- Australian Capital Territory and Tasmania: amputees can only attend publicly funded prosthetic providers (situated in rehabilitation facilities with only one provider in each state/territory, so no choice whatsoever).
- New South Wales, Queensland and South Australia: amputees can attend all public and privately funded providers.
- Victoria and Western Australia: amputees can attend publicly funded providers and limited private prosthetic providers.
- Northern Territory: amputees can only attend publicly funded providers (no private prosthetic providers available in that jurisdiction).

A person from a rural or regional community and reliant on artificial limb scheme funding will not have travel costs funded. Therefore they must either wait for a visiting service to attend their home town (or one nearby) or be out-of-pocket and cover transport and related costs to attend a central service as required (with the exception of Queensland residents).

NDIS-funded and insurance scheme prosthetic servicing

NDIS provision, on the other hand, is a competitive marketplace with a mix of private prosthetic providers and public facilities (e.g. hospitals) servicing NDIS participants. The NDIS has provided amputee participants with significant choice and control in relation to their prosthetic provider and the ability to access services outside of their immediate community. Where there is no choice of a local or close provider, travel costs to attend a clinic in a capital city is provided.

6.1.1.2 Impacts if prosthetic servicing is delayed or not treated within critical timeframes

Amputees who are prosthetic users are critically reliant on prosthetic providers for support. It requires a specific skillset because prosthetic devices are all custom made for each individual.

Significant delays or failure to manufacture and fit a new prosthesis, service, repair an existing one, and undertake assessments for the purpose of funding applications can have wide-ranging physical and psycho-social impacts on amputees.

Such delays can cause preventable complications that affect long-term effective use of a device, such as skin breakdowns, musculoskeletal overuse injuries, muscle atrophy, loss of flexibility, and flexion contractures.[29] People may continue wearing an ill-fitting prosthesis which can have dire consequences or lead to rejection of prosthetic wear and return to using a wheelchair resulting in loss of mobility and confidence. Considered collectively all can have physical and mental health impacts, lead to greater risks of falls and hospital re-admissions which, in addition to affecting the individual and their support network, also have downstream economic impacts on government health budgets.

As access to prosthetic providers was significantly reduced or denied altogether during COVID-19 restriction periods these impacts were expressed to Limbs 4 Life either anecdotally or in response to the survey.

6.1.2 Mobility devices

For those amputees who are unsuitable candidates for prosthetics, primary mobility and locomotion is enabled through other assistive technology. Predominate alternative mobility devices include wheelchairs and/or crutches. Various studies have identified that the determinant of prosthetic non-use and utilisation of alternative mobility devices includes

factors such as: physical health (amputation level, comorbidities, degenerative changes to the intact limb); demographic characteristics (age, residential aged care); length of time between amputation and prosthesis fitting; bilateral amputations; and/or, prosthesis abandonment due to low satisfaction.[30]

The degree to which the person will use the device, how and where it will be used, health considerations, personal preference and recommendation/ prescription from healthcare providers will influence the choice of device. For example, an older amputee reliant on a wheelchair may find that a manual chair is too difficult to use in terms of unsustainable energy expenditure, falls risk and manoeuvrability, and thus more suited to a power-assisted chair. Whereas another amputee who primarily uses their prosthesis throughout the day may be better suited to a manual wheelchair when temporarily not wearing their prosthesis and/or the need to ambulate during the night when they are sleepy and feeling unstable on their prosthesis.

Mobility devices require fitting by a professional practitioner. Most commonly this will be conducted by occupational therapists. Prescription is most often not something than can be done without the two parties being in the same room, and not via an online service such as telehealth.

6.2 Informal feedback regarding treatment, care and support during the COVID-19 restrictions

It became apparent that longer-term amputees, some who have lived with limb loss for as long as 71+ years, struggled during the restrictions. For the purpose of this report Limbs 4 Life is using the term 'longer-term amputee' to separate out those who did not experience amputation during the restrictions from those who did.

Prior to conducting the survey Limbs 4 Life received considerable feedback outlining concerns in relation to lack of access to assistive technology providers and healthcare services from amputees who had lived with limb loss for a considerable time. Many callers were deeply concerned and distressed, as were some of the people and organisations that support them. Some examples of personal issues and incidents included:

- As access to services were impacted, in some cases amputees advised that they could only see a healthcare provider if it was an emergency and would avoid hospital admission.
- People working in community organisations who couldn't access prosthetic appointments for clients, meaning the person that they cared for went without.
- Some amputees lacked ability to use transportation as they could not utilise their prosthetic device due to lack of access for repairs.
- Some amputees were being treated in carparks because the public hospital prosthetic clinic/facility would not allow access into the building.

- Some public hospital prosthetic providers used answering machines, rather than have staff speak to amputee callers, and continually failed to return calls.
- Inability for amputees living in regional areas to cross borders to access prosthetic providers, and other related health services, in a timely manner.

6.3 Formal responses regarding longer-term amputee treatment, care and support during the COVID-19 restrictions

Of the 274 respondents, 86 percent (n=236) had been living with limb loss for between two years to 71+ years, with these 'longer-term' amputees providing feedback to any or all questions posited in this segment of the survey.

A review of the survey responses highlights longer-term amputees experienced a mix of consistent and varied challenges and barriers due to the restrictions. Responses to questions posed to this amputee community were coded to generate themes, enabling identification of structural, personal, environmental, economic and policy barriers which impacted on their ability to live through this novel period in our lifetime.

6.3.1.1 Barriers raised in response to 'Question 13: If you are a longer-term amputee, did you experience any difficulties visiting your prosthetist for any type of treatment (e.g. maintenance, repairs, fitting of a new prosthesis, other)?

Of the 236 respondents categorised as longer-term amputees, 76 percent (n=179) responded to this open-ended question.

Respondents expressed significant delays or lack of access to prosthetic providers, countering their amputee-specific healthcare need. Some respondents indicated that these delays had a direct impact on their health and wellbeing, reduced levels of independence, led to disability marginalisation, resulted in infections and unnecessary hospital admissions, and the voiding of assistive technology warranties. Some recognised that the impacts were caused by border closures and others felt it inappropriate that some hospitals where prosthetic services are located de-classified immediate prosthetic care to only those they deemed 'urgent' or 'emergency' even when the amputee felt it could be categorised as either of those.

Prior to exploring singular barriers three clustered comments highlighted amputees' hurdles in relation to accessing prosthetic treatment.

> *"I was unable to access prosthetist and other services such as podiatrist and also complications resulting in the manufacture of a new device taking an excessive amount of time and resulted in the device not fitting and also injury to myself resulting in further complications and prolonged issues."* (45-54 year old lower-limb amputee, Victoria)

"Yes. My clinician is interstate and I was unable to have the required maintenance done on my prosthesis meaning that without a service I was unable to control the device and make changes as needed. My warranty was voided resulting in a $135K cost to government. I also use an orthotic device to walk, the clinic who usually manages my needs advised me that because my shoe repairs were not an emergency, and therefore would not give me an appointment. Worth noting, I cannot walk, drive, attend work or provide carer services without these necessary footwear repairs." (55-64 year old lower-limb amputee, Victoria)

"Yes I still don't have a completed upper-limb prosthetic and have had to keep wearing an ill-fitting prosthetic that needs to be replaced. Mental health impacted, being unable to wear my prosthetic to work as I was unable to wash my hand effectively with it on so I just stopped wearing it to work." (55-64 year old upper-limb amputee, Queensland)

Structural barriers resulted in some respondents indicate that they experienced significant wait times to attend prosthetic appointments for vital repairs, servicing and adjustments, an inability to participate in face-to-face appointments despite the necessity for an in-person healthcare approach, an obligation to change prosthetic provider, and inadequate levels of communication.

"Had to put up with an ill-fitting leg for almost 12 months." (75+ years lower-limb amputee, Victoria)

"Yes, 12 months appointment delay." (45-54 year old lower-limb amputee, Victoria)

"Wait for appointment changed from 1 week to 7 weeks. Spent a lot of time with my prosthesis off, waiting." (65-74 year old lower-limb amputee, Victoria)

"Yes, due to shut down of my prosthetic company in Melbourne I was unable to access prosthesis maintenance and upgrades." (45-54 year old lower-limb amputee, Victoria)

"It was difficult as they were working a week at time from home. They staggered who worked from the clinic. So it was difficult to get in." (45-54 year old lower-limb amputee, Victoria)

"Yes, the clinic was closed for long periods of time." (45-54 year old lower-limb amputee, Victoria)

"Took 3 months to get my prosthetic foot repaired." (25-34 year old lower-limb amputee, SA)

"Yes, wait times for leg production were majorly blown out" (35-44 year old lower-limb amputee, ACT)

"Had to wait, all the treatment had to be done over the phone, shocking as they (prosthetists) could not see the problem." (45-54 year old lower-limb amputee, NSW)

"Yes it has been rubbish I had to change provider mid-pandemic." (35-44 year old lower-limb amputee, Victoria)

"One month to get a booking." (75+ year old lower-limb amputee, NSW)

"Not sure how a clinician even thinks that they can successfully treat a patient from their car?" This service is a joke!" (66 year old lower-limb amputee, Victoria)

Personal barriers left some respondents feel that the restrictions led to significant rise in pain, discomfort and infection, a reduction in levels of personal independence, diminished ability to fulfil unpaid carer responsibility, and marginalisation due to receipt of prosthetics which were not 'fit-for-purpose'.

"It was difficult to get prosthetic appointments. I needed a new socket and the delay caused my pain and discomfort." (35-44 year old lower-limb amputee, Victoria)

"Couldn't access services when I needed them the most. It's hard enough on a day-to-day basis, but when things start go wrong it doesn't take long for skin integrity to break down causing wounds that take days to weeks to heal and these play on your mental heath and ability to remain independent." (35-44 years lower limb amputee, SA)

"Frustrating, walking pattern changed which created pain in neck, shoulders and lower back." (35-44 year old lower-limb amputee, Victoria)

"Yes - delays in modifications to my prosthetic resulted in wounds and chronic cellulitis and a hospitalisation." (25-34 year old lower-limb amputee, Victoria)

Environmental barriers resulted in some respondents revealing they were unable to be cast and fitted with a new prosthesis; such a device vitally important for an amputee's independence, mobility, participation capacity and accessibility.

"Waiting for a new prosthetic for almost 12 months. Only got in this week for a new casting." (55-64 year old lower-limb amputee, Victoria)

"I could not get a new prosthetic (I had grown out of my old one) for quite some time." (17 or younger upper-limb amputee, NSW)

"Yes - new legs were started, but had to be put on hold for a whole year." (45-54 year old lower-limb amputee, Victoria)

Economic barriers resulted in some respondents feeling so abandoned by their public hospital government prosthetic service provider that they elected to privately self-fund, and

others recognised that government-imposed inability to attend prosthetic appointments within a designated timeframe has voided the warranties associated with their costly assistive technology.

"My current prostheses are ill fitting and I'm still waiting for new prostheses. I've decided to leave the public system as it could not accommodate me and I'm now going private." (55-64 year old lower-limb amputee, Victoria)

"Yes, difficult to get an appointment unless an urgent problem (i.e. no regular or periodic warranty checks)." (55-64 year old amputee, ACT)

Policy barriers born out of some jurisdictions imposing border closures and some state health guidelines classifications under which a person's health situation could or would eliminate access to vital in-person prosthetic service in government or private facilities resulted in some respondents feel particularly impacted at limited or lack of availability to this critical assistive technology.

"Yes, as I live in NSW and prosthetist is in Vic when borders were shut no chance of getting things fixed etc." (45-54 year old lower-limb amputee, NSW)

"2.1 year delay. Appointment due February 2020 - Appointment held March 2022." (55-64 year old lower-limb amputee, Victoria)

"Border closures delaying prosthetic care." (35-44 year old lower-limb amputee, ACT)

"Yes if the legs don't fit properly I'm in trouble as I live by myself. Mildura has nothing here for amputees. If I need something done to my legs I have to go to Adelaide or maybe Melbourne, but because I live across the border in NSW when the borders were shut I suffered because I could not go across. And now I have an ulcer on my left stump which I have had now for 12 months." (55-64 year old lower-limb amputee, NSW)

"Yes, I was in desperate need of a new socket as my residual limb had shrunk quite significantly. I wasn't able to get to my prosthetist in Vic so just had to make do with what I had. Due to my socket not fitting I had multiple blisters and my leg was painful to wear" (35-44 year old lower-limb amputee, Tasmania)

"Access to prosthetic limb maintenance denied as it wasn't "essential" or an "emergency"." (45-54 year old lower-limb amputee, Victoria)

"Yes. Frustrating, worrying as a fault in a prosthetic can cause discomfort/pain without being considered an "emergency." (45-54 year old lower-limb amputee, Victoria)

"Attendance at prosthetics refused as not "emergency"." (45-54 year old lower-limb amputee, Victoria)

6.3.1.2 Barriers raised in response to 'Question 14: If you use other aids/ equipment/ assistive technology (e.g. wheelchair, mobility devices) did you experience delays visiting an allied health practitioner for treatment or prescription?'

Of the 236 respondents categorised as longer-term amputees, 69 percent (n=163) responded to this open-ended question.

Respondents who are users of everyday assistive technology conveyed difficulties in relation to the aids, equipment and devices needed for independence, mobility, safety and accessibility. They expressed concerns that their ability to access new or maintain use of existing assistive technology was impeded by difficulty to gain support from allied health practitioners. They noted that lack of access to appropriate assistive technology led to use of more risky alterative mobility devices, and that drawing upon personal finance was at times the only means of acquiring access to aids and equipment for basic mobility and comfort. Some also felt that that the government-imposed de-classification of immediate allied health care need from 'urgent' or 'emergency' to a lesser categorisation was inappropriate, particularly in light of the fact that many of the amputees who were then 'demoted' were actually living with a disability and major health concerns that should have been classified as something of critical concern by the health system.

Structural barriers left some respondents feel that that they experienced significant delays in receiving allied health practitioner assessments and prescriptions essential to meet assistive technology needs, delays and/or cancellations in assistive technology maintenance and repairs, product transport wait-time implications, and product shortages due to supply chain challenges and weaknesses.

"Yes – delays in access to OT appointments for wheelchair prescription." (25-34 year old lower-limb amputee, Victoria)

"Accessing repair and adjustment, cancelled clinics in Hobart due to lockdown and outbreaks." (55-64 year old lower-limb amputee, Tasmania)

"Delays in prescription times due to lack of supply." (45-54 year old lower-limb amputee, Victoria)

"I had a wheelchair replaced and had to wait extended time for delivery. The company I used could not deliver so I had to travel over 120km to pick up my chair (which failed within 2 weeks). I then had to wait a further 6 weeks before repair could be carried out." (45-54 year old lower-limb amputee, Queensland)

"Couldn't use wheelchair so very limited walking with a walker." (55-65 year old lower-limb amputee, Victoria)

Economic barriers left some respondents reveal that they had no choice but to draw upon personal finances to ensure access to the assistive technology needed for basic mobility and comfort.

"I have had delays getting my mobility scooter fixed and it costed me to hire one on a regular basis." (65-74 year old lower-limb amputee, Victoria)

"Using a wheelchair never got a prescription for the chair which took all of my money." (65-74 year old lower-limb amputee, Victoria)

Policy barriers whereby some state health guidelines classifications under which a person's health situation could or would not facilitate a person's access to in-person allied health service facilities resulted in some respondents feel particularly impacted by lack of professional practitioner accessibility during restrictions.

"Unable to see my orthotist because my needs were not deemed an emergency." (55-64 year old lower-limb amputee, Victoria)

6.3.1.3 Barriers raised in response to 'Question 15: If you experienced delays accessing allied health and support services, did these delays affect your overall physical and mental health and wellbeing?'

Of the 236 respondents categorised as longer-term amputees, 67 percent (n=158) responded to this open-ended question.

Long-standing amputees are often heavily reliant on a range of allied health support services to meet their physical needs, ranging from prosthetic, physiotherapy, exercise physiology, podiatry and occupational therapy to name a few. Furthermore, amputees, where appropriate, are encouraged by medical and health professionals to participate in safe levels of community activity to benefit their ongoing physical and mental health and development.

Respondents expressed concern that inability to access or be offered poor prosthetic and allied health servicing played a significant role in physical and mental health decline, and in some cases led to impaired physical abilities and the introduction of new chronic health conditions. Some also indicated that government-imposed lockdowns which restricted travel and the ability to participate locally impacted on physical and mental health, and in some cases the reduction in independence compromised their capacity to maintain responsibilities as an unpaid carer of dependents.

Prior to exploring singular barriers three clustered comments highlighted amputees' hurdles in relation to accessing allied health support and the impact this had on their mental health and wellbeing.

"Yes - poor fitting prosthesis = additional pain; reduced mobility and capacity to engage in social and sporting activities. Leading to poor self-worth." (55-64 year old lower-limb amputee, NSW)

"Couldn't access exercise physio - fitness and weight deteriorated so the prosthetic cast didn't fit." (45-54 year old lower-limb amputee, Victoria)

"Yes. Mental health declined without being to go to physio. Telehealth is not the same." (45-54 year old lower-limb amputee, Victoria)

Structural barriers left some respondents feel that non-existent or inadequate prosthetic servicing and a lack of availability to other allied health support led to a consequential sense of isolation and decline in physical and mental health.

"Yes, I couldn't go out as I'm blind and double amputee and rely on services to take me out. I felt isolated." (65-74 year old lower-limbs amputee, NSW)

"Yes, really badly I waited a year for a new leg and I was depressed and angry." (45-54 year old lower-limb amputee, Victoria)

"Mental health, worry anxiety all increased. Access to critical services (for an amputee access to a prosthetist means being able to walk)." (45-54 year old lower-limb amputee, Victoria)

"My physical ability to move deteriorated due in inability to access in-person physiotherapy." (35-44 year old lower-limb amputee, ACT)

"Yes, lack of progress with OT and lack of equipment from prosthetic company." (17 years or younger upper-limb amputee, Victoria)

Personal barriers left several respondents feel concerned that as a direct result of lack of access to prosthetic services and other allied health care supports their physical health and ability was in decline or had even led to other longer-term chronic conditions.

"Yes, serious back issues due to ill-fitting leg because I was unable to access prosthesis maintenance and upgrades." (45-54 year old lower-limb amputee, Victoria)

"I was waiting a lot of time for my new prosthetic as my old was not fitting any more, I was in a lot of pain." (18-24 year old lower-limb amputee, Victoria)

"Yes, due to being unable to access <name withheld> rehab, developed injury on stump which is now chronic." (75+ year old lower-limb amputee, Victoria)

Environmental barriers resulted in some respondents feel that their lack of access to assistive technology was not only frustrating but led to a weakening of their physical and mental health.

"Yes, found it increasingly frustrating waiting for things to be approved. Having to be active around the home and not access supports or get specific equipment was hard." (35-44 year old lower-limb amputee, Victoria)

"Just waiting for the equipment and that takes ages - getting weaker and more depressed." (65-74 year old lower-limb amputee, Queensland)

"Not being able to do activities due the parts not being available." (25-34 year old lower-limb amputee, NSW)

Policy barriers whereby some states placed lockdown restrictions on individuals' ability to travel within local areas, attend local businesses for personal reasons and participate in the local community left some respondents feel that their physical and mental health was compromised, independence was reduced and capacity to maintain responsibilities as an unpaid carer of dependents was compromised.

"Physically, muscle atrophy and because of the restriction on movement general fitness declined. Mentally, stress, depression, anxiety and probably a lot more." (45-54 year old lower-limb amputee, Victoria)

"Impact on health due to ability to exercise being restricted." (45-54 year old lower-limb amputee, Victoria)

"The delays did not affect my mental health but COVID restrictions certainly did." (55-64 year old lower-limb amputee, Victoria)

"Unable to walk, drive, shop, go to work and therefore struggled to care for my elderly father." (55-64 year old lower-limb amputee, Victoria)

"Drastically affected my mobility independence this went on for over six months and impacted my mental health like it never has before. Reduce mobility, the inability to live my life day to day, reduced independence and the ability to meet my children's needs, the inability to participate in the community. Mental health decline." (45-54 year old lower-limb amputee, Victoria)

6.3.1.4 Barriers raised in response to 'Question 16: Looking back at the period of COVID-19 related restrictions, what were some of the major impacts on your life?'

Of the 236 respondents categorised as longer-term amputees, 77 percent (n=182) responded to this open-ended question. As this question was quite broad, naturally respondents provided wide ranging replies. However, for the purpose of this report responses have been coded to isolate those that are predominately amputee or disability-specific in nature.

Overall, respondents' feedback suggested that the restrictions played a role in raising levels of stress, anxiety, relationships, pain and discomfort, and overall quality of life when connected to specific barriers.

At a structural level they expressed feeling a sense of abandonment by allied health care services within the timeframe. Barriers at a personal level were voiced in relation to feeling overwhelmed by social isolation compounded by disability, concerns that a reduced ability to ambulate might have a long-lasting effect, pain was heightened by lack of access to health practitioners, and that increased levels of dependency on family and friends was indicative of a loss in precious independence. Barriers at an economic level were stated as resulting in a loss of workforce participation and financial implications as a direct result in lack of access to essential prosthetic servicing, and inability to offer meaningful volunteerism contribution. Policy barriers born out of state government/s restrictions and guidelines were conveyed as the key reasons for limiting access to local services, delaying surgical treatments, and cross-border prosthetic care had the collective effect of poor physical and mental health impacts.

Prior to exploring singular barriers four clustered comments highlighted amputees' hurdles in relation to variable major impacts that restrictions had on their lives.

"These restrictions and the impacts that they had on people were dreadful. There was little to no consideration given for people with physical disability needs by the state government and/or the health services in question." (55-64 year old lower-limb amputee, Victoria)

"Loss of freedom: As an amputee, a major part of recovery and maintaining a lifestyle is returning to normal activities prior to the amputation and restrictions prevented this. Reliance on others: having to ask for help and loss of independence returned. Isolation: as a single person living alone, loneliness was detrimental to my mental health." (65-74 year old lower-limb amputee, NSW)

"Had to change prosthetic provider mid pandemic. I couldn't walk for quite a while. It has put me in a pretty fragile state where I was not confident to go to work, and was coming home in tears from pain." (35-44 year old lower-limb amputee, Victoria)

"Like many being stuck at home during lockdowns, treatment by those in power left a lot to be desired. Mental health is now more relevant to me than in the past when I first lost my leg 1985." (55-64 year old lower-limb amputee, Victoria)

Structural barriers left some respondents feel they were abandoned by critical prosthetic and allied health care services within the timeframe and via support methods required by amputees which contributed to increasing levels of anxiety, worries and mental health concerns.

"Really badly I waited a year for a new leg and I was depressed and angry. My quality of life has been impacted by not having a prosthetic." (45-54 year old lower-limb amputee, Victoria)

"Attending most services ie: physio, prosthetist, social, longer than usual waiting on my provider providing new prosthetic leg, loneliness, my depression/anxiety became much worse. It had a major impact." (55-64 year old lower-limb amputee, Victoria)

"It took longer to get service due to staff shortages, therefore suffered more pain and discomfort waiting for that service that was required." (75+ year old lower-limb amputee, Victoria)

"Stress, anxiety, depression and lack of any form of treatment availability." (45-54 year old lower-limb amputee, Victoria)

"No OT or PHYSIO could come to house" (45-54 year old lower-limb amputee, NSW)

"Some services were telehealth only and didn't feel appropriate to my issues." (35-44 year old lower-limb amputee, ACT)

Personal barriers resulted in some respondents feel that restrictions led to social isolation and marginalisation, increased levels of pain due to lack of access to health services, and greater levels of dependency to mitigate reduction in physical independence.

"Infrequent purpose for and use of prosthesis. "Shuttered" existence like so many others whether amputees or not." (75+ year old lower-limb amputee, Victoria)

"Isolation, with a disability." (55-64 year old lower-limb amputee, WA)

"Lack of social interaction. Walking around the same area for two years set me back in terms of resilience in tackling new areas, buildings with stairs etc. I feel as though I have had to start again with my mobility." (55-64 year old lower-limb amputee, Victoria)

"Delays in an appropriate prosthetic and wheelchair resulted in a dramatic decrease in my physical capacity due to a period of 3 months of being unable to walk - I am still rebuilding

strength. Weight gain - which also affected my prosthetic fit due to limited activity." (31-40 years lower-limb amputee, Victoria)

"Mobility decreased." (45-54 year old lower-limb amputee, Victoria)

"Physio has been hard to get, so physio has been challenging. Started to get bilateral contractures." (55-64 year old lower-limb amputee, NSW)

"Stopped walking and now basically confined to walking short distances, 10 - 20 meters only due to pain." (75+ year old lower-limb amputee, Victoria)

"Stump break down due to not been able to get services when needed." (35-44 year old lower-limb amputee, Victoria)

"Weight gain and isolated from friends, amputee support network." (35-44 year old lower-limb amputee, NSW)

"Total routine disruption, working from home caused being sedentary and over eating and alcohol." (45-54 year old lower-limb amputee, Victoria)

"I can't follow my physiotherapy as scheduled and others healthcare services like dentist, endocrinology etc. I gained some more weight, so I couldn't use my prosthetic." (45-54 year old lower-limb bilateral amputee, NSW)

"Inability to go to the gym (for ongoing rehab)." (55-65 year old lower-limb amputee, NSW)

"Now having to depend on friends to do shopping, medical appointments etc." (65-74 year old lower-limb amputee, Victoria)

Economic barriers left one respondent lose employment because of lack of access to prosthetic servicing and another without the ability to uphold personal volunteerism contributions due to restrictions.

"Loss of access to services- resulting in inability to perform duties and tasks that could maintain my job resulting in loss of income and loss of ability to afford the necessary repairs and upkeep of my prosthetic. Was very hard and extremely depressing and was unable to access my doctor or services to talk to about it." (54-54 year old lower-limb amputee, WA)

"Changed from regular voluntary work since 1970 to fiddling my fingers stuck in nursing home on the scrap heap." (65-74 year old lower-limb amputee, Victoria)

Policy barriers born out of state governments placing lengthy lockdown restrictions on individuals' ability to attend local businesses for personal and essential reasons, unexpected changes to elective surgery treatment and cross-border closures resulted in some respondents feel consequential decline in physical wellbeing, quality of life, and mental health during restriction periods.

"Stress, pain and weight gain (5 kg). Twice weekly community sport activity mostly cancelled. Gym closure etc. Back pain, headaches and low mood result." (45-54 year old lower-limb amputee, Victoria)

"Inability to access any type of shopping or other places in my electric buggy." (75+ year old lower-limb amputee, Victoria)

"I needed to visit Melbourne for surgical assessment. This has been delayed by 2 years. I have spent a further 2 years of my life confined to a wheelchair and associated restrictions." (45-54 year old lower-limb amputee, Queensland)

"The major issue was not being able to get a surgery date for daughter's bone shortening surgery and having to go to a private hospital." (17 years or younger lower and upper limb amputee, Queensland)

"I am still waiting for further surgery on my stump for a large neuroma. Very painful. Thumb and shoulder joints are giving out from overuse. I am told the wait list has been made worse because of Covid. So I remain in my wheelchair." (65-74 year old lower-limb amputee, Queensland)

"Couldn't see my prosthetist at all because of the cross-border issue. I was in real trouble." (45-54 year old lower-limb amputee, NSW)

7. Articles within The Convention on the Rights of Persons with Disabilities

The Australian Government is a signatory to the United Nation's Convention on the Rights of Persons with Disabilities. The Convention recognises the barriers that people with a disability may face in realising their rights. Various state and territory legislation, policies, programs, disability plans or strategies aim to comply with Australia's obligations in the Convention.

It is of grave concern that at Commonwealth and state levels, amputees faced considerable barriers which contravened practical obligations within the Convention. The 'rehabilitation and habitation' and 'assistive technology' Articles, as well as related matters in other Articles, and summarised associated barriers experienced by amputees during the restriction period are detailed below.

7.1 Articles related to rehabilitation and habitation

Barriers raised by respondents which affected their ability to participate in any or incomplete rehabilitation programs, no qualified home assessments prior to discharge from

hospital post amputation surgery or no home modifications to accommodate their new physical disability needs suggest that objectives and principles within Articles 9, 20, 25 and 26 of the Convention were not met.

- Article 9 of the Convention establishes that people with disability have fully participate in all aspects of life, whether that is at a personal or public environment:

  "1. … on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
  a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
  b) Information, communications and other services, including electronic services and emergency services."[31]
- Article 20 of the Convention requires that State Parties take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities (such as during early intervention and rehabilitation timeframe periods), including:

  "a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
  b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
  c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities"[32]
- Article 25 of the Convention establishes that people with disability have the right to enjoy the highest attainable standard of health without discrimination, taking into account health-related rehabilitation, including:
  "b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
  d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care"[33]

- Article 26 of the Convention establishes the right of people who acquire a loss in function as a direct result of acquiring a disability to regain maximal function, relearn how to perform daily activities, compensate for the loss or absence of a function or limitation and equip people to achieve a higher level of independence, including taking:

  "1. … effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
  a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
  3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation."[34]

7.2 Articles related to assistive technology

Limited, delayed or lack of access to various assistive technology aids, equipment and devices, as well similar impacts on maintenance and timely reviews, from prosthetists of other allied health practitioners raised by respondents suggest that objectives and principles within Articles 5, 9, 20, 25 and 26 of the Convention were not met.

- Article 5 of the Convention recognises that all people with disability are considered equal before and under law and therefore entitled without any discrimination to equal protection. This includes access to adjustments, such as assistive technology, which does not impose disproportionate or undue burden. The Article includes State Parties taking:

  "3. … all appropriate steps to ensure that reasonable accommodation is provided."[35]

- Article 9 of the Convention requires that State Parties take appropriate accessibility measures. This encompasses ones that eliminate barriers and obstacles restricting individuals' access to assistive technology practitioners for services, treatment and product prescription aimed at facilitating mobility, independence and safety. The Article includes measures:

  "a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
  b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;

c) To provide training for stakeholders on accessibility issues facing persons with disabilities"[36]

- Article 20 of the Convention requires that State Parties take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including:

  "a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
  b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
  c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
  d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities."[37]
- Article 25 of the Convention establishes that people with disability have the right to enjoy the highest attainable standard of health. One purpose of this is to minimise and prevent further disabilities or chronic conditions, and it could be argued that lack of access to critical assistive technology which enhances health is not only a risk to individuals' health and wellbeing but also a potential example of benign neglect. The Article recognised that State Parties:
  "b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
  d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care"[38]
- Article 26 (3) of the Convention advocates for the provision of effective and appropriate measures to enable persons with disabilities to attain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. Clearly lack of access to or use of inadequate or unsafe assistive technology contravenes this, so inability to access services to mitigate this is not only impactful physically and psycho-socially but only potentially discriminatory. The Article indicated that:

  "3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation."[39]

8. Recommendations

A range of recommendations are proposed to ensure that people with a disability gain access to the critical healthcare services they need in a timely manner. Furthermore, given that many of these are preventative treatments they should be considered as a means of basic healthcare. While we understand that the initial impact of COVID-19 turned the world into turmoil, surely now governments and healthcare providers can safely and effectively provide and deliver services to those most in need and at risk. Closing and cancelling services should never happen again.

Limbs 4 Life believes that the recommendations should be considered by governments, health-based administrators and other key stakeholders as part of their practical, policy and future-proofing strategic planning processes.

Recommendation 1
Recognise that people who undergo a major amputation should never be discharged home without services and supports in place. Acknowledge that failure to provide individual and purpose-built rehabilitation is denial of critical healthcare treatment after acquiring limb loss and developing a physical disability.

It is recommended that all health systems work to ensure that people with the newly acquired disability of limb loss receive tailored amputee rehabilitation in a clinical setting.

Recommendation 2
Recognise that individuals who are prosthetic users rely on essential assistive technology to walk, function, and participate socially and economically. Understand that the delay in fitting a prosthesis will result in negative outcomes and major setbacks for the individual.

It is recommended that amputees receive access to allied health supports in an effective and efficient manner for the provision of prosthetics, which is in no way detrimental to their long-term health-based outcomes.

Recommendation 3
Recognise that during the restrictions many public prosthetic clinics were, for a variety of factors, closed and/or not responding to general enquiries. Phone calls were often not responded to or were answered but after a long delay, putting amputees' physical and mental health at significant risk, despite the fact that these government services and public servants are there to support public healthcare.

It is recommended that calls and enquires made to public prosthetic clinics never go unanswered and are responded to in a timely manner. There also needs to be serious

consideration paid to sharing prosthetic services among private providers when public ones deny, or are completely inaccessible for, essential patient health treatment.

Recommendation 4
Recognise that due to fragmented funding services some amputees have no choice or control over their provider and consequently receive prosthetic care and treatment across state borders. Additionally, consideration should be paid to the fact that some amputees are able to exercise their rights of 'choice and control' to access to interstate healthcare services, which should not be prohibited, and they may struggle to source a new one if they cannot attend their usual practitioner.

It is recommended that no governments ever deny Australian amputees from accessing essential healthcare services due to border closures. Border closures should never have happened nor happen again, and while a service such as telehealth may work in some settings it is not applicable in in the manufacture, fit or supply of a prosthetic device, meaning that crossing state lines for prosthetic treatment and care is critical.

Recommendation 5
Recognise that lower limb amputees are reliant on other mobility devices, such as wheelchairs, to achieve independence and remain mobile and safe within home, employment and community settings. Understand that only certain practitioners, such as occupational therapists, can prescribe and fit this assistive technology. Acknowledge that amputees in need of mobility devices became house bound due to the inability to ambulate, because they were unable to gain access to practitioners for assessments, prescriptions and ordering during restrictions.

It is recommended that all amputees must be prioritised for urgent practitioner assessment. If they require access to assistive technology and the person's regular practitioner, whether government-funded or private, is unavailable they should be assisted by the relevant health service and/or industry body to source an alternative provider.

Recommendation 6
Recognise that due to clinical closures of state-funded prosthetic facilities during restrictions, funds provided to these clinics for the provision of prosthetics would have remained unspent. Publicly funded services should be required to provide financial transparency, declare where monies were expended and how saved costs can be reinvested in public health.

It is recommended there should be greater levels of transparency in relation to state-based artificial limb schemes expenditure, number of patients treated and funds retained during COVID-19 lockdown and restriction periods. Serious consideration should be paid to

reallocating savings to invest in amputees denied access to adequate support over this period so that they can achieve better quality of life outcomes.

Recommendation 7
Recognise that the provision of and access to amputee rehabilitation, habitation, assistive technology, health services, personal mobility and a good quality of life is ratified in The Convention on the Rights of Persons with Disabilities. Acknowledge that governments likely failed to meet Articles 5, 9, 20, 25 and 26 within the Convention, and therefore didn't adequately protect the health and human rights of all amputees in Australia.

It is recommended that the Federal Government and Australian Human Rights Commission recognise that amputees were a disabled cohort disproportionally affected by restrictions, some of which counter Articles within the Convention on the Rights of Persons with Disabilities. The importance of human rights must be recognised and realised so as not to impact the health and disability rights of any individual.

8. Concluding comments

This report, drawing upon consultation with amputees across Australia, highlights a wide range of barriers and challenges experienced by this cohort during the COVID-19 restrictions.

While Limbs 4 Life acknowledges that the pandemic was a novel crisis in Australia, we are concerned that people living with limb loss were put at significant physical, psychological and socio-economic risks during the restriction periods. These were even more challenging given the unique type of disability that amputees live with, and their heavy reliance on healthcare systems to live a safe and equitable life at all times; something that was further exacerbated during restrictions.

Limbs 4 Life strongly feels that this report and resulting recommendations are invaluable from systemic and policy consideration perspectives. We intend using these learnings and direct feedback from amputees to facilitate discussion with key decision makers so that the matters raised can be addressed during the ongoing COVID-19 pandemic and influence how issues are appropriately handled in the event of potential future restrictions and crises.

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