

# Enhancing Amputation Care for Aboriginal People in South Australia

NOVEMBER 2022

Aboriginal and Torres Strait Islander readers should be aware that this document may contain culturally sensitive issues.





### **Version History**

Version 1.0 First publication June 2023	
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ISBN: 978-0-6456437-2-5

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Colmer, K., Agius, J., Wilson, S., Davey, S., Fitridge, R., Morey, K. 2022, *Enhancing Amputation Care for Aboriginal People in South Australia*. South Australian Health and Medical Research Institute, Adelaide.

The South Australian Aboriginal Chronic Disease Consortium Coordination Centre is funded by the Department for Health and Well being, Aboriginal Health.

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# Acknowledgements

# Acknowledgement of Country

We acknowledge Aboriginal people as the traditional custodians of country throughout South Australia. We respect their continuing connection to land, waters, kinship and community, language, lore/law and ceremony. We also pay our respects to the cultural authority of Aboriginal and Torres Strait Islander people from other areas of Australia who reside in South Australia.

# Use of the Term 'Aboriginal'

The report uses the term 'Aboriginal' to describe the people and communities in recognition of the traditional owners of the lands now called South Australia. The authors of the report acknowledge the diversity of the people, families and communities, who live in South Australia, which includes people from various Aboriginal and / or Torres Strait Islander backgrounds. The impacts of colonisation and past policies, still felt by many Aboriginal and Torres Strait Islander people today, have resulted in some complexities associated with traditional ownership, country and a sense of home and belonging. The authors would like to iterate that this report is for the benefit of all, and the choice of terminology intends to respectfully acknowledge custodianship in accordance with Aboriginal traditions and customs. The term Torres Strait Islander is specifically used where reference is made to Aboriginal and/or Torres Strait Islander people at a national level or where it is used in position titles and titles of publications and programs.

# Acknowledgements for Contribution to the Project

The Aboriginal and Torres Strait Islander Diabetes-related Foot Complications Program is funded through the Indigenous Australians' Health Programme (IAHP), a Commonwealth Government initiative.

We would like to acknowledge the clinical staff and the community members who generously participated in this project.

This project is a collaboration between:

- Aboriginal Health Council of South Australia (AHCSA)
- Central Adelaide Local Health Network (CALHN)
- South Australian Aboriginal Chronic Disease Consortium, South Australian Health and Medical Research Institute



# **Executive summary**

Diabetes is the leading cause of preventable amputation with Indigenous Australians experiencing far higher rates of hospitalisation for lower limb amputation. These rates were eleven times higher among Indigenous females and five times higher among Indigenous males, when compared to their non-Indigenous counterparts.<sup>2</sup>

Aboriginal people undergoing and recovering from amputation require services that are high quality, evidence-based, culturally responsive, coordinated, accessible, equitable and person and family centred. There is a paucity of information about the care that Aboriginal people in South Australia are receiving both pre- and post-amputation and more specifically their access and experience in mainstream rehabilitation services. It is important that the cultural significance of losing a limb and the cultural needs throughout the journey are understood and built into amputation pathways and service delivery models. The aim of this project was to understand the Aboriginal patient journey for amputation and identify opportunities for enhancements.

## **Objectives:**

- To identify health system needs and gaps for Aboriginal people undergoing an amputation in South Australia
- Define the elements of evidence-informed, high quality, culturally responsive health care across the continuum
- Define how the elements of culturally responsive health care can be implemented into practice and systems (including prehabilitation, acute care, rehabilitation and ongoing long-term care).

## Method:

- Service mapping templates were completed to understand what services and resources were available in each SA Health Local Health Network
- Key clinician and/ or service manager interviews were conducted to understand the needs and gaps (n=32)
- Community member and carer interviews (n= 3).

## **Results:**

- 1. Service and resource mapping
- 2. The amputation journey
- 3. Enablers identified during the consultation
- 4. Gaps or needs grouped against amputation best practice care principles; and
- 5. Health system recommendations (summarised page 6)

The findings in this project provide further evidence and detail for targeted health service improvements across each phase of the amputation journey as described in the system recommendations (summarised page 6). By delivering amputation care that is culturally safe and responsive, person and family centred, integrated and coordinated Aboriginal people will experience improved health and wellbeing outcomes.

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# Summary of recommendations

Best practice care	Recommendations
1. Culturally safe and responsive care	1.1 Facilitate processes that enable Aboriginal staff to meet patients in emergency department or ward.
	1.2 Early referral to Aboriginal health practitioner (AHP) offered to all patients.
	<ol> <li>Care of the amputated limb is explicitly built into local health network (LHN) amputation pathways.</li> </ol>
	1.4 Training and support package for non-Aboriginal clinicians.
2. Prevention, early identification,	2.1 Implement national evidence-based pathways for diabetes-related foot risk stratification.
management and escalation	2.2 Increase the awareness of all staff and community members about the seriousness and urgency of active foot disease and how to escalate patients to specialist services.
3. Access and equity	3.1 Offer flexible follow up options for patients who are from rural and remote locations.
	3.2 Explore telehealth options and where possible expand the use of telehealth.
	3.3 Improve financial support for families who need to travel for care.
	3.4 Advocate for increased accommodation options.
	3.5 Consider access and equity issues as part of comprehensive care planning ensuring social workers are engaged early.
	3.6 Establish stronger partnerships between health services (primary, secondary and tertiary care).
	3.7 Return of amputated limb to Country is supported by LHNs, with financial support in built.
4. Counselling and psychological support	4.1 Social and emotional wellbeing and trauma aware-healing approaches should be strengthened.
	4.2 Amputation clinical pathway should include access to social and emotional support for patients and their family members pre-operatively and beyond.
	4.3 Explore best practice mental health screening tools and look for opportunities to systematically implement them at the appropriate time points along the continuum of care and escalate as needed.
5. Patient education and support	5.1 Increase access to culturally appropriate diabetes and preventative foot education.
	5.2 Develop and implement culturally appropriate amputation resources.
	5.3 Ensure that patients and carers are at the forefront of the decision-making process and have access to prehabilitation services where possible.
	5.4 Increase access to relevant and culturally appropriate amputation education and support.
	5.5 Education and support for patients to understand when and who to call if they have concerns.
	5.6 Use of interpreters should be offered at all stages of the amputation continuum.

6. Care coordination	<ul> <li>6.1 Interdisciplinary teams have access to minimum level of recommended disciplines.</li> <li>6.2 That an appropriately trained and resourced AHP is formally recognised and included in the amputation interdisciplinary team as early as possible.</li> <li>6.3 Consider models that promote continuity of care and integration e.g. navigator role.</li> </ul>
7. Comprehensive care	<ul> <li>7.1 Develop a guiding document that supports comprehensive care planning.</li> <li>7.2 Comprehensive care plans are developed with patient and family and include issues around equity and access, be strengths based and recognise holistic health and wellbeing.</li> <li>7.3 Aboriginal cultural considerations and support for the cultural determinants of health are built into existing amputation clinical care pathways and procedures.</li> <li>7.4 Consider workforce models that enhance continuity of worker/clinician.</li> <li>7.5 Ensure links are made with local Aboriginal support workers to assist with the transition home following amputation.</li> </ul>
8. Peer Support	<ul><li>8.1 Explore options to partner with amputee charities and other support groups to develop an Aboriginal Peer Support Program.</li><li>8.2 Increase access to group therapy e.g. telehealth group.</li></ul>
9. Discharge planning / transfer of care	<ul> <li>9.1 Explore options for a state-wide care coordinator role that could provide oversight/coordination of patients who have undergone an amputation.</li> <li>9.2 Explore options for improving support for Aboriginal patients to access all funding effectively.</li> <li>9.3 Develop clear guidance for transfer of care (e.g. clinical handover) for patients as they transition between services.</li> </ul>
10. Monitoring amputation care and outcomes	<ul><li>10.1 Explore opportunities for increased data collection including the use of Australasian Rehabilitation Outcomes Centre and PREMS/PROMS.</li><li>10.2 Develop an amputation register that enables a methodical system of data collection.</li></ul>
11. Strengthening the workforce	<ul> <li>11.1 Enhance capability of clinicians working in primary, acute and rehabilitation settings.</li> <li>11.2 Explore innovative models to build the Aboriginal workforce including volunteer roles that could enhance the amputation care journey.</li> <li>11.3 Strengthen the cultural awareness and capability of the non-Aboriginal workforce involved in amputation care.</li> </ul>

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# Introduction

Recognising the burden of diabetes-related foot disease (DFD) and amputation experienced by Aboriginal people, the project has sought to understand the needs and gaps along the amputation journey and identify health system improvements that will enhance amputation care. The Central Adelaide Local Health Network (CALHN) and the Aboriginal Health Council of South Australia (AHCSA) have collaborated with the South Australian Health and Medical Research Institute (SAHMRI) to deliver the project. The Enhancing Amputation Care project is part of a broader program of work that is funded through the Indigenous Australians' Health Programme, a Commonwealth Government initiative.

The most severe cases of diabetes-related foot disease can lead to amputation of the affected toes, foot or lower leg. Aboriginal and Torres Strait Islander Australians experience comparatively high rates of diabetes<sup>1</sup> and data which informed the AIHW Diabetes indicators for the Australian National Diabetes Strategy 2016-2020 showed that in 2015 and 2016 Indigenous Australians experienced far higher rates of hospitalisation for lower limb amputation. These rates were eleven times higher among Indigenous females and five times higher among Indigenous males, when compared to their non-Indigenous counterparts.<sup>2</sup>

Aboriginal people undergoing and recovering from amputation require services that are high quality, evidence-based, culturally responsive, coordinated, accessible, equitable and person and family centred. There is a paucity of information about the care that Aboriginal people in SA are receiving both pre- and post-amputation and more specifically their access and experience in mainstream rehabilitation services. It is important that the cultural significance of losing a limb and the cultural needs throughout the journey are understood and built into amputation pathways and service delivery models.

The aim of the project was to understand the Aboriginal patient journey for amputation and identify opportunities for enhancements. The objectives were:

- To identify health system needs and gaps for Aboriginal people undergoing an amputation in South Australia
- Define the elements of evidence-informed, high quality, culturally responsive health care across the continuum
- Define how the elements of culturally responsive health care can be implemented into practice and systems (including prehabilitation, acute care, rehabilitation and ongoing long-term care).

# Background

The prevalence of diabetes continues to increase globally, leading to a rising incidence of foot complications.<sup>3</sup> As the leading cause of lower limb amputation with high rates of associated mortality, diabetes-related foot disease (DFD) complications are a major but poorly recognised health care burden in Australia, estimated to cost in excess of \$1.6 billion annually.<sup>4</sup> DFD is defined as infection, ulceration or destruction of tissues of the foot associated with neuropathy and/or peripheral artery disease in the lower extremity of a person with diabetes.<sup>3</sup> Each year in Australia, DFD causes an estimated 27,600 public hospital admissions, 4,400 lower extremity amputations and 1,700 deaths.<sup>5</sup>

Diabetes is the leading cause of non-traumatic related amputation. High blood glucose levels can lead to damage to the nerves (neuropathy) and narrowing of the blood vessels which results in poor circulation (peripheral vascular disease) in the lower limbs, leading to ischemia, gangrene and impaired wound healing. These complications can lead to ulcers and infections and most seriously, amputation.<sup>6</sup> Up to 85% of diabetes-related amputations are preceded by ulceration and are preventable if problems are detected early and managed appropriately.<sup>7,4</sup> Amputation is classified as "major" if it is above the ankle and "minor" if it is limited to the foot.

Diabetes-related amputations have a huge personal and financial cost to individuals, families, productivity and employment, and the broader health system. The loss of a limb is a life changing event and often occurs as the final procedure after numerous hospitalisations, and attempts to save the foot, with major amputation having a substantial impact on a person's physical and psychological health.<sup>8</sup> For people with diabetes, amputation outcomes are poorer with fifty percent of single diabetes-related amputees developing a serious problem with their remaining limb within two years.<sup>9</sup> Access to timely rehabilitation along with an interdisciplinary team approach is essential.

People move through the amputation journey at different rates and it can take 12-18 months for the limb to stabilise.<sup>10</sup> The care pathway begins with the acute hospital phase, during this time patients begin training in transferring, limb positioning and mobility. The challenge of transitioning from hospital and/or inpatient rehabilitation to home cannot be underestimated. Radenovic et al (2021) highlight that these challenges have been explored for people with stroke, acquired brain injury and spinal injury but there is little known about amputation. In their study, participants who had undergone amputation described the importance of rehabilitation in preparing them for integration back into community. The extent to which the participants felt adequately prepared for discharge varied. Participants highlighting areas for improvement, such as; provision of individualised care, discussions around expectations, and better access to ongoing community support.<sup>11</sup> Columbo et al (2018) had similar findings, with participants reporting that they did not feel adequately prepared to live with an amputation and found the transition from inpatient care to home particularly difficult.<sup>8</sup> Whilst the qualitative findings in these studies are of interest they will not reflect the experience of Aboriginal and Torres Strait Islander Australians. A desktop review of the literature was unable to identify any amputation papers specific to Aboriginal and Torres Strait Islander peoples or Indigenous peoples, other than those reporting prevalence and outcomes.

# The amputation journey

The amputation journey has been divided up into four phases but the way and the time in which people move through the phases varies considerably.

# Phase 1 - Pre-amputation (includes pre-habilitation)

In this report the pre-amputation phase refers to the immediate lead up to amputation i.e., amputation becomes a viable clinical option for the person's management. It is important that patients understand their options and are involved in the decision-making including being given culturally safe options for the care of their amputated limb. For Aboriginal and Torres Strait Islander peoples the returning of an amputated limb to Country may be an important part of healing and of their cultural values and belief system. A pre-amputation consultation should include discussion of realistic rehabilitation goals that are patient and family centred, options for prosthetic use, and early advice/assessments from the occupational therapist and physiotherapist.<sup>9</sup>

"Prehab" is a preventative risk management strategy to prime the individual and their family to improve their understanding of the care needed pre/post major limb amputation. It helps to reduce the concerns the patient and family may experience while awaiting major limb surgery. Amputee pre-habilitation is a comprehensive interdisciplinary program carried out by a rehabilitation team before major limb amputation. The pre-habilitation phase is an opportunity to improve post-surgical outcomes by focusing on optimising preoperative conditions. This includes, optimising blood glucose levels, exercise programs, psychological status and identifying potential barriers or issues that may need to be addressed in a culturally sensitive manner. Unfortunately, many amputations occur as emergencies, thus, there is minimal or no preparation time, but opportunities for optimising care should be examined and encouraged at every contact. Preparing patients and families by introducing the rehabilitation staff and explaining key information about what to expect after amputation and during the rehabilitation phase is extremely important.

## Phase 2 – Amputation (Acute care)

The acute care phase refers to the period in which the patient is admitted to hospital and includes preparation for surgery and the acute hospital postoperative stage. The CALHN Clinical Pathway for Major Limb Amputation has the expected length of stay as 3-4 days, however, anecdotal evidence and Australasian Rehabilitation Outcomes Centre (AROC) data has highlighted longer lengths of stay. During the acute care phase, patients should be supported by a wide range of health professionals, such as, surgeons, amputee nurses, nurses, physiotherapists, occupational therapists, orthotists/prosthetists, podiatrists, acute pain services, dietitians, psychologists, social workers, National Disability Insurance Scheme (NDIS) case workers, Aboriginal liaison or health practitioners, Limbs4Life peer support and rehabilitation physicians. Together these professionals provide inpatient care, education and care coordination during the acute care stay.

## Phase 3 – Rehabilitation

The aim of rehabilitation is to enable the patient to achieve maximum functional independence, taking into account the persons pre-amputation lifestyle, their expectations and limitations.<sup>9</sup> There are different options for rehabilitation depending on where the person lives, whether they will be using a prosthesis and of course their personal preferences. During this phase, the person is again supported by a wide range of health professionals such as rehabilitation physicians, physiotherapists, occupational therapists, orthotists/prosthetists, podiatrists, dietitians, psychologists, social workers, Aboriginal health practitioners and the persons diabetes team.

## Phase 4 – Lifelong care

Once there is relative limb stabilisation, the person enters the long-term phase where the focus is on review and maintenance. The limb will continue to change to some degree (up until 12 to 18 months). In this stage the prosthesis will require occasional adjustments and over time people move toward community reintegration and higher functional training with increasing independence. Regular podiatry review and consideration of appropriate footwear is critical to prevent further ulceration or ulceration on the contralateral foot.<sup>9</sup> Various medical specialists in collaboration with the diabetes interdisciplinary team, will also be key to supporting the person to achieve their optimal glucose and cardiovascular targets.

## Burden of disease for diabetes related lower limb amputation - South Australia

In 2019, the Prevention and Population Health Branch (Wellbeing SA) prepared a report on diabetes-related lower limb amputation in South Australia.<sup>12</sup> The data in the report was based on people aged 20 years and above from all South Australian metropolitan and country public hospitals for the financial years 2011-2012 to 2017- 2018. All of the ICD 10 codes (medical codes) for diabetes and amputation were retrieved.<sup>12</sup> The data showed that Aboriginal people are over-represented in those who have a diabetes-related lower limb amputation.

Between the period July 2011 – June 2018, there were 93 Aboriginal people aged 20 years and over residing in South Australia who had a diabetes-related lower limb amputation. While accounting for 1.5% of the South Australian population, Aboriginal people accounted for 4.9% of those who had an amputation. The rate of amputation in the Aboriginal population over this period was 8.1 per 1000 people/year, 3.4 times greater than the non-Aboriginal rate of 2.4 per 1000 people/year.

## Gender

Men were more likely to have had an amputation compared to women in both the Aboriginal and non-Aboriginal populations. Aboriginal men were 2.2 times as likely to have had an amputation compared to women. This rate ratio is lower than that seen in the non-Aboriginal population (rate ratio: 2.7).

## **Place of residence**

Figure 1 shows the proportion of Aboriginal people who undergo amputation by their place of residence (LHN).<sup>12</sup> Almost one third (31%) of Aboriginal people who had an amputation were from the Flinders and Upper North LHN. CALHN accounted for the second highest number of Aboriginal people who had an amputation (26%). The distribution of population varied between Aboriginal and non-Aboriginal populations.

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**Figure 1:** People with diabetes-related lower limb amputation by place of residence (LHN) (%), people aged 20 years and over, SA, 2011-12 to 2017-18 by Aboriginal status\*

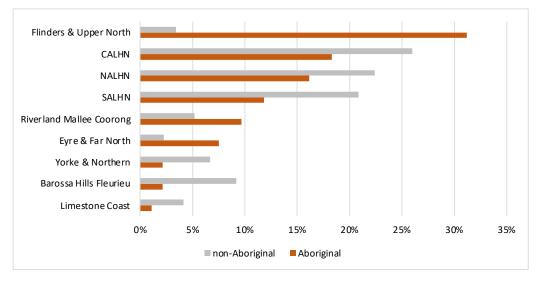
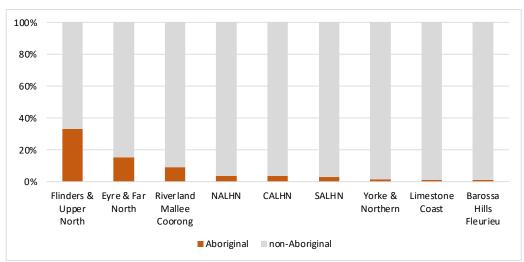


Figure 2 shows the proportion of clients by Aboriginal status within each LHN.<sup>12</sup> Of those people having a diabetes-related lower limb amputation in Flinders and Upper North LHN, Aboriginal people accounted for one third of clients (33%). Aboriginal people in Eyre & Far North LHN accounted for 16% of all people having an amputation.

**Figure 2:** Proportion of Aboriginal and non-Aboriginal people with diabetes-related lower limb amputation within each LHN, aged 20 years and over, SA, 2011-12 to 2017-18



The Australasian Rehabilitation Outcomes Centre (AROC) is the national rehabilitation medicine integrated outcomes centre of Australia and New Zealand. The AROC data provides high level information about the number of amputation episodes and the impairment outcomes for a small number of these episodes. It does not provide any detail or breakdown in relation to Indigenous status. It is unknown how many services are utilising the AROC data centre but public amputation data numbers for SA are very small.

\*The data has been compiled according to postcode. People with unknown LHN or interstate residence address have been excluded. The population presented in this report may not accurately represent the overall SA Aboriginal population

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# Methodology

The project team included:

- Manager/Co-Theme Lead Wardliparingga and Senior Project Officer (SAHMRI)
- Aboriginal Health Practitioner (in training) CALHN
- Prosthetics and Orthotics Manager (CALHN)
- Vascular Surgeon (CALHN)
- Registered Nurse and Credentialled Diabetes Educator (AHCSA)

Ethics approval was granted by the Aboriginal Health Research Ethics Committee (AHREC) and the CALHN Ethics Committee.

All amputation related health services within South Australia were in scope for the project. Whilst the focus of the project was South Australia, we have also included feedback relating to services within the Far West of NSW and Northern Territory due to the high volume of patients that access CALHN for their initial and long-term management of amputation. Although the focus was diabetes-related amputation, we received some feedback relating to a person who had a non-diabetes related amputation, and this has also been included. Detailed analysis of services such as the National Disability Insurance Scheme (NDIS) was not within the scope of this project.

## Mapping of services and resources

Current health service availability, health professional resources that support clinical practice and Aboriginal consumer education resources were mapped by stage of care and Local Health Network (LHN).

## Health service provider interviews

Key clinician/service manager interviews (n= 32) were conducted to understand the needs and gaps including the mapping of a small number of patient journeys. Clinicians were asked to map the patient journey across the phases of amputation care using a case example from their own clinical practice. Most clinicians were only able to discuss aspects of the journey in which they were directly involved. The project team adapted the Lowitja Institute Strategic Mapping Tool to prompt clinicians as they moved through the health journey. This tool has been used for similar purposes in other areas such as cardiac and renal health services.<sup>13</sup> Ten different journey examples were described as part of the conversations. Note: It was not within the scope of this project to cross check information provided by clinicians about patient journeys i.e. against medical records or with the client themselves.

## **Community consultation and engagement**

The CALHN Aboriginal Consumer Reference Group and the SA Health Senior Officers Aboriginal Health provided advice and guidance for community and Aboriginal clinician engagement within their local areas.

We sought to engage with community members and their significant others who have lived experience of amputation. An infographic was developed to aid the discussions with community members about their amputation journey. Community members were approached, if they were attending the Royal Adelaide Hospital for one or more of their amputation services (Community members n= 2, carer n= 1).

## **Broad consultation on the findings**

The data from the interviews with health care providers and community members was analysed with draft enablers, gaps and recommendations developed. Staff who were part of the first round of consultation were invited to provide feedback either in written form or participate in an online discussion. Additional stakeholders were also identified and invited to provide feedback. Feedback was reviewed and changes made accordingly. In total seventeen individual practitioners (n= 17) provided feedback either in written form or at the online meeting.

Health service provider	Number
Physiotherapist	2
Social worker	2
Prosthetist	5
Aboriginal health practitioner/cultural consultant /manager	8
Occupational therapist	1
Registered nurse/enrolled nurse/amputee nurse/credentialled diabetes educator/rehabilitation nurse	7
Podiatrist	2
Rehabilitation physician	2
Manager	3
TOTAL	32

Organisations engaged with across the phases	
Rehabilitation services	Queen Elizabeth Hospital, Hampstead Rehabilitation Centre, Modbury Hospital Rehabilitation Centre, Whyalla Hospital and Health Service, Rural Support Service (SA Health), Repat, Berri Hospital and Health Service
Acute care	Royal Adelaide Hospital (RAH), Flinders Medical Centre (FMC)
Aboriginal Community Controlled Health Services	Pt Lincoln Aboriginal Health Service, Nunkuwarrin Yunti
Aboriginal health services (SA Health)	Royal Adelaide Hospital, Flinders Medical Centre, Modbury, Riverland
Non-government organisations	Limbs4Life, NDIS, University of SA

# **Findings**

The data collected from the service mapping, health care provider/manager consultation and community member interviews were analysed by the project team and the results have been summarised below.

# Mapping of services and resources

In 2012 the 'Model of Amputee Rehabilitation in South Australia' was published and provided a roadmap for amputation care for the next 7 years. The model was developed to support service change and best care across the state and was developed by the State-wide Rehabilitation Clinical Network. With the devolution of the state-wide network, the implementation of the model has been left to individual services and is now significantly out of date.

Some of the SA Health LHNs have developed their own amputee pathway (NALHN, SALHN) but there is no state-wide pathway for amputation and there is no specific resource or pathway for Aboriginal patients undergoing amputation. In addition, South Australia does not have any Aboriginal information/education resources that can support the amputation discussion and decision making.

Amputation guidelines/consumer resources in SA;

- SA Health Amputee Model of Care 2012
- Amputee pathway
- Limbs 4 Life Peer Support Program and consumer resources
- SALHN Lower Limb Major Amputation Guideline
- CALHN Lower Limb Major Amputation Guideline
- NALHN Rehab Model of Care 2017
- Metro Amputee pathway Major Limb Amputation
- NALHN Partial Foot Amputee Pathway
- NALHN Country Amputee Pathway
- Amputees requiring prosthetic rehab, country to SALHN Guideline

The mapping activity highlighted inequities in access to services for people living in rural and remote SA including:

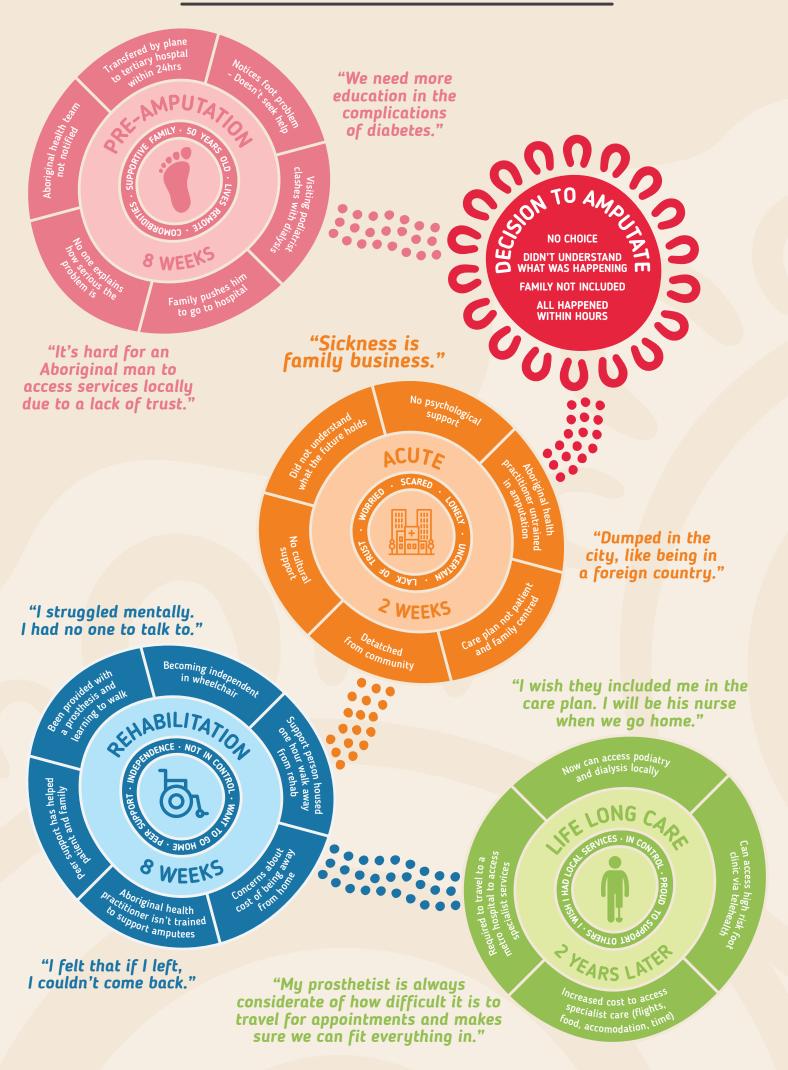
- Interdisciplinary high-risk foot services (iHRFS)
- Podiatrists
- Orthotics and prosthetics
- Specialised rehabilitation services
- Accommodation for country patients attending day rehabilitation in another country or metro location
- Appropriate transport options
- Counselling services

A full summary of the available services can be viewed in Appendix 1.

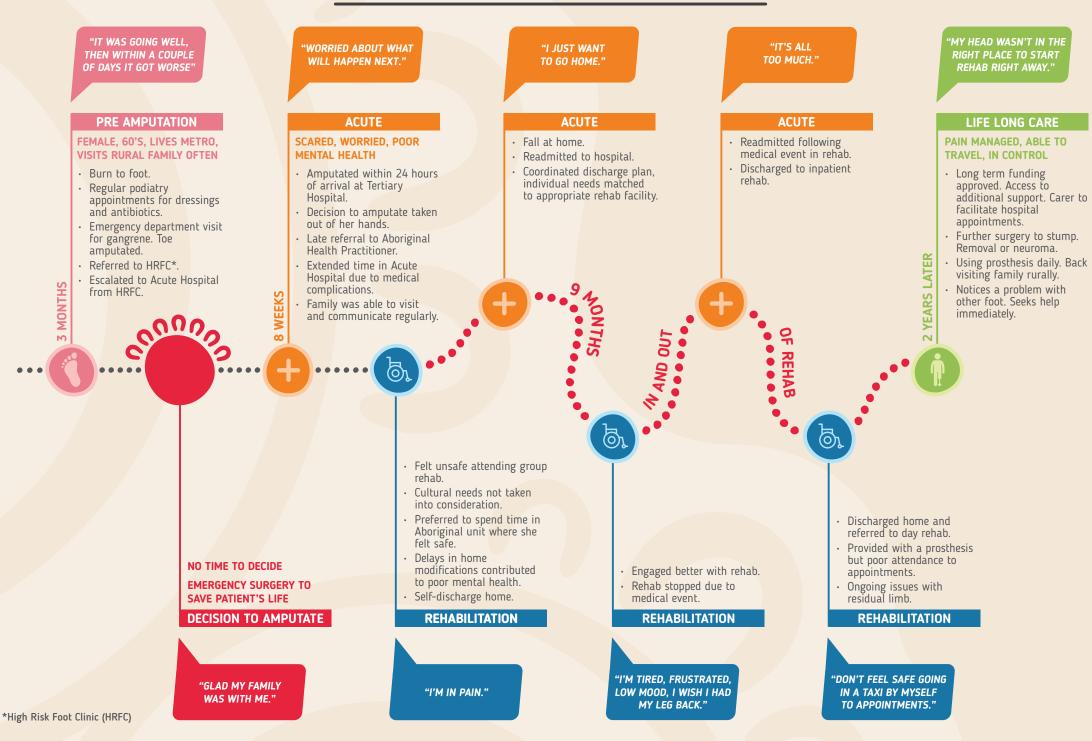
## The amputation journey

Members/carers with lived experience (n=3) highlighted the complexity and variability of the amputation journey. Amputation is traumatic and life changing, but both health care providers and community members shared stories of hope, strength and determination. In many of the journeys community members spent many months away from community and family, because they could not access the services they needed locally or they had complex medical needs. Some had to face the prospect of amputation of the other leg within 12-18 months of the loss of their first leg. The strength of culture, community and family was a common theme and are highlighted in the example journeys and enablers below. Note: to ensure confidentiality data was synthesised from more than one journey.

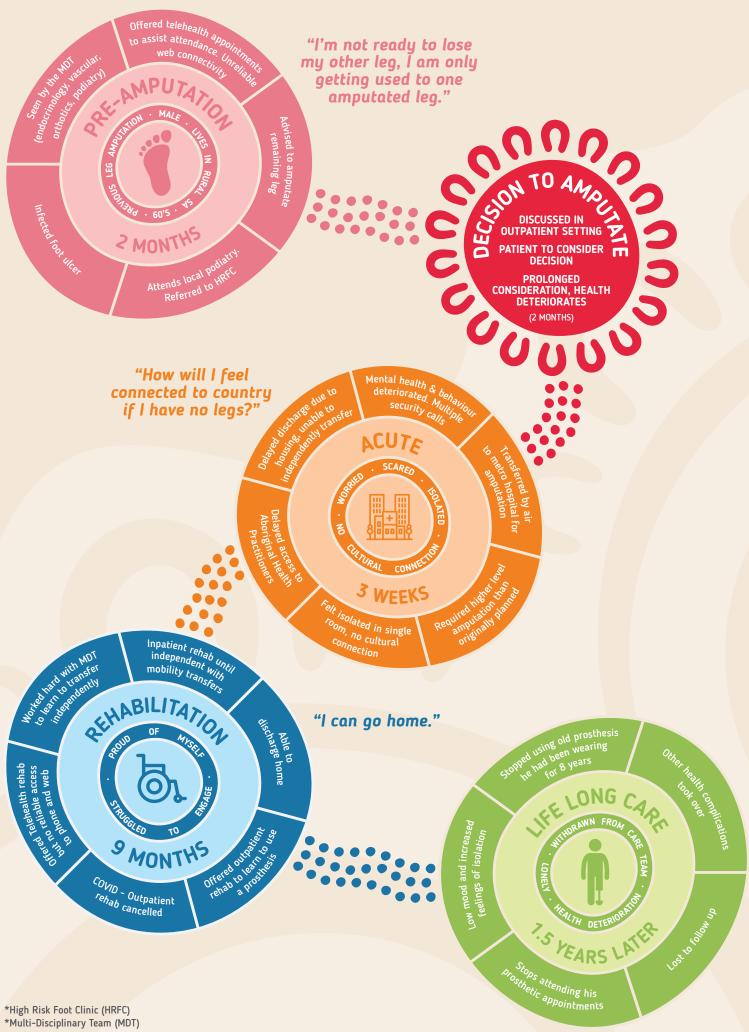
# **Patient Amputation Journey 1**



# **Patient Amputation Journey 2**



# Patient Amputation Journey 3



## The health team

Consultation highlighted the breadth and complexity of the team involved in supporting an individual and their family through the amputation journey.

General practitioner	Pharmacist	Physiotherapist
Visiting podiatrist	Anaesthetist	Occupational therapist
Primary health Aboriginal team	High risk foot service team	Orthotists/prosthetists
Diabetes team (endocrinologist, dietitian, credentialled diabetes educator)	Renal team	Podiatrist
Local emergency department	Acute pain team	Dietitian
Radiographers	Theatre staff	Clinical psychologists
South Australian Ambulance Service	Social work	National Disability Insurance Scheme (NDIS) support workers
Royal Flying Doctor Service	Rehab consultant	Limbs4Life peer support worker
Community nurse	Aboriginal health practitioner	Accommodation services
Tertiary ED	Aboriginal liaison officer	Transport services
Vascular surgeon	Aboriginal cultural consultant	Royal District Nursing Service
Ward nursing staff	Dialysis team	Infectious diseases team
Amputee nurse	Inpatient rehab team	Spiritual care
Cardiac team		^

## **Enablers**

There were many enablers that are critical to providing high quality, safe and culturally appropriate care identified during consultation. Most of the examples have come from clinicians who shared patient journey examples. Some examples have come verbatim from the community interviews.

## **Enablers**

Community members feel empowered through self- management knowledge and skills

Clinicians identified that when clients understand their own risks, there was more active engagement in the care, e.g. a gentleman with a foot ulcer was referred to home nurses for wound care but his appointments were repeatedly cancelled by the agency. He was concerned about his wound and so booked himself an appointment with a podiatrist at the local Aboriginal community-controlled health service (ACCHS).

Aboriginal workforce supporting patients cultural and/or health care needs across the continuum of care

- Patient journeys described by clinicians and community members highlighted, how much the Aboriginal health area of the hospital were valued and seen as a safe place.
- Aboriginal staff were seen as critical members of the team and are highly utilised by staff who consult with them to better understand how to meet cultural needs, having an important role in case conferencing, clinical handover to community services and supporting transition to other services.

#### The non-Aboriginal workforce provides culturally safe and responsive care

- Clinicians reported that whilst some patients were initially hesitant, establishing relationships helped them to feel more comfortable.
- One carer spoke about one of the clinicians "She's lovely, she explains things, she gives us time". (carer)

### Peer support from others going through the same thing is invaluable

All three community members found the support from others who had a lived experience invaluable

- "Excited to see other patients start to walk and how helpful it was to see other patients a bit further down the track... all going through this together... doesn't matter if they black or white...got close...no matter old or young" (carer)
- *"When I seen couple of others walking I couldn't wait to do it"* (community member)
- "Being able to talk to others, what helps and be part of the amputee community" (community member)

#### Culture is considered as part of the comprehensive care plan

Clinical staff were aware of the importance of culture e.g. the health service was able to help organise a Ngangkari (accessed privately) for their client, staff were able to offer flexible delivery of care to meet their needs and a Aboriginal cultural consultant was utilised to provide advocacy, cultural and discharge support.

#### Continuity of care and care coordination

Clinicians highlighted the importance of having someone who is a constant, a cultural support and someone who they can trust throughout the journey and someone to coordinate the care including NDIS.

### The importance of connection to Country

Clinicians understood that being connected to Country helps with healing and gave examples of how they worked hard to get their patients as close to home as possible and back home as soon as possible.

### Wherever possible include family as part of any education (patient and family centred care)

We need to remember that it is the family who often provides the care when they go home and so they need to be included in the education so they have the knowledge and the skills ..."it is a family business with any sickness" (carer)

#### People need hope and understanding

"Make sure that people get the information so they know what will happen e.g. that they can get another leg if they want to" (carer).

"Keep positive, be happy, because no matter what happens you still you" (community member)

#### Community / primary health organisations are key members of the interdisciplinary team

Clinicians valued the role of community services highlighting; the Aboriginal Community Controlled Health Service (ACCHS) was important for transport and other social and health supports and the NDIS worker was integral in supporting attendance at appointments because the patient was not comfortable going alone. 0

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#### **Clinical handover**

One clinician described a new handover tool that is being used to summarise the cultural needs of the patient at discharge. The tool is making a real difference to patients and staff alike.

### Facilitating effective communication between hospital and primary care community services

Some ACCHS have a Chronic Disease Team that reviews the discharge letters / referrals from hospital and develop the care plan accordingly. The team also receives inpatient notifications that get flagged with the doctor on a daily basis.

### **Returning limbs to Country**

Clinicians and community members recognise that it is very important that people are empowered and that they have options available to them including the limb being returned to Country. Some clinicians have experienced extremely positive outcomes for patients who have been able to have limbs returned.

### **Identified gaps and needs**

The data from the health service provider interviews and the community interviews were analysed with the identified gaps and/or needs mapped against best practice care for amputation.

Best practice care was informed by the following key documents;

- National Aboriginal and Torres Strait Islander Health Plan 2021-2031<sup>14</sup>
- Australian evidence based guidelines for diabetes-related foot disease (2021)<sup>15</sup> and National Foot Forward 'Foot Risk Stratification and Triage' and 'Active Foot Disease' Integrated Diabetes Foot Care Pathways (2020)<sup>16</sup>
- NSW 'Care of the person following amputation Minimum standards of care' (2017)<sup>17</sup>

The NSW 'Care of the person following amputation - Minimum standards of care' has been written to guide clinicians and health services in their care of people experiencing limb loss.<sup>17</sup> The standards were based on the findings from a rapid review evidence check conducted by the Sax Institute in 2015. The review identified 16 guidelines that covered various aspects of amputation care.<sup>18</sup>

The standards are written at both the service level and the person level and include elements such as care coordination, comprehensive care, counselling and psychological support, peer support, falls prevention, discharge planning, care of the residual limb, education and pain management. The standards include a self-assessment tool that can be used by clinicians and services to reflect on areas for improvement.

Key elements at the health service level;<sup>17</sup>

- Care is coordinated, multispecialty, and interdisciplinary across all phases
- A comprehensive care plan is developed and updated throughout the care journey
- Counselling and psychological support is available across all stages of care
- Referral is offered to a managed peer support program

- Education and training on falls prevention and safety, including how to get up from the floor in the event of a fall is provided to persons and their valued others
- Discharge planning and transfer of care arrangements commence as early as possible with communication between all key stakeholders.

Key elements at the individual level;<sup>17</sup>

- Care of the residual limb and management of risk factors for further amputation are addressed.
- Education begins in the preoperative phase and continues across all phases of care.
- Pain is assessed, managed and monitored at all stages of care.
- The Aboriginal liaison worker/health practitioner or similar are part of the interdisciplinary team for persons of Aboriginal or Torres Strait Islander background from the decision to amputate or earlier.

Best practice care	Identified gaps or needs across the phases of amputation care
<ol> <li>Culturally safe and responsive care</li> <li>Mainstream services are capable of providing high quality, culturally safe, trauma-aware, healing informed and responsive care (National Aboriginal and Torres Strait Islander Health Plan 2021-2031)</li> </ol>	<ul> <li>There were examples of a lack of cultural safety or trust in mainstream services that led to delays in accessing care and disengagement with services.</li> <li>Culturally safe and responsive care of the amputated limb including return to Country is not easily accessible. This was due to a lack of understanding of the cultural significance, absence of procedural guidance in SA, financial cost and minimal options for long term storage.</li> <li>Patients are not routinely being offered cultural support services such as Aboriginal health practitioner (AHP) i.e. care may be reactive rather than proactive.</li> <li>The role of the Aboriginal health worker/practitioner is not well defined and consequently underutilised by the multidisciplinary team.</li> <li>Difficulties with recruitment and retention have led to extended periods where AHP position has been vacant.</li> <li>There is limited access to publicly funded Ngangkari in some areas.</li> </ul>
<ul> <li>2. Prevention and early identification, management and escalation</li> <li>Diabetes Feet Australia and Australian Diabetes</li> <li>Society, Australian evidence-based guidelines for DFD (2021)</li> <li>National Foot Forward</li> <li>'Foot Risk Stratification and Triage' and 'Active Foot Disease' Integrated</li> <li>Diabetes Foot Care Pathways (2020)</li> </ul>	<ul> <li>Community members are frequently presenting late with active foot issues, such as, ulcers and burns with negative consequences.</li> <li>Patients presenting with foot complications may face delays in accessing responsive acute medical care due to delays in transport (e.g. RFDS) and bed availability.</li> <li>The identification and escalation of active foot problems by clinicians may not be consistent with the Diabetes Feet Australia and National Foot Forward evidence informed pathway.</li> </ul>

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<b>3. Access and equity</b> Receiving culturally responsive care when and where they need it (National Aboriginal and Torres Strait Islander Health Plan 2021-2031)	<ul> <li>People living in rural and remote locations often need to leave home for extended periods of time to access specialist amputation related services. Specialist amputee and prosthetic rehabilitation is predominately provided in the metro area with limited access to outreach services.</li> <li>There is limited access to timely podiatry and vascular specialist services and tertiary level iHRFS in rural and remote areas.</li> <li>There is underutilisation of telehealth across the continuum of amputation care with current funding models, technology (bandwidth, software and hardware) not meeting the needs of service users and clinical staff.</li> <li>There are financial barriers to attending health services including rehabilitation e.g. PATS does not cover transport to rehabilitation only to medical appointments and there are limited options for accommodation near rehabilitation services.</li> <li>Financial costs associated with long term care in Adelaide are high and cause significant stress for patient and their families.</li> <li>There are limited rehabilitation options for patients who are experiencing homelessness or insecure housing.</li> </ul>
4. Counselling and psychological support Counselling and psychological support should be available across all stages (NSW Care of the person following amputation Minimum Standards 2017)	<ul> <li>There are multiple stressors that impact on patients and families particularly those who need to travel from rural and remote locations, yet access to psychosocial support is limited.</li> <li>Despite many patients exhibiting signs of experiencing social and emotional distress, access to specialised counselling services post amputation is variable and psychological support is not currently routinely offered pre-amputation.</li> <li>Patients previous trauma associated with an acute inpatient experience may contribute to behavioural challenges during admission. This can be further exacerbated by separation from family and the trauma of amputation.</li> </ul>
5. Patient education and support Education and support is available across all stages of care (NSW Care of the person following amputation Minimum Standards 2017)	<ul> <li>There is a lack of understanding about the seriousness and urgency of active foot problems and that foot disease can be prevented.</li> <li>Often community members have a limited understanding of the need for amputation or their options, leading to delays in care and decision making.</li> <li>Lack of understanding of the patient journey may be leading to disengagement if patients' expectations are not able to be met or the patient does not know what to expect.</li> <li>There is often confusion and limited understanding navigating the funding resources available e.g. NDIS, My Aged Care, SA Amputee Limb Service (SAALS).</li> <li>Access to culturally responsive diabetes education based on need and disease progression is variable.</li> </ul>
<b>6. Care coordination</b> 'care is coordinated, multispecialty, and interdisciplinary across all phases' (NSW Care of the person following amputation Minimum Standards 2017)	<ul> <li>Care coordination and access to the full multidisciplinary team (MDT) is variable depending on the health service, and the personnel involved, with some patients not understanding their journey or knowing what to expect.</li> <li>Aboriginal health staff, such as, AHPs are not being involved early enough or proactively enough as core members of the MDT.</li> <li>There is no dedicated resourcing for coordination that occurs across the phases to ensure a culturally safe and seamless transition between services and phases.</li> <li>Ad hoc care coordination contributes to some patients being lost to follow up.</li> </ul>

<ul> <li>7. Comprehensive care</li> <li>'comprehensive care plan</li> <li>is developed and updated</li> <li>throughout the care</li> <li>journey'</li> <li>(NSW Care of the person</li> <li>following amputation</li> <li>Minimum Standards 2017)</li> </ul>	<ul> <li>An integrated, holistic person and family centred, interdisciplinary care plan may not be available across all health services or phases.</li> <li>There is often fragmentation of care across the phases and across systems.</li> <li>A lack of continuity of care with health professionals may contribute to disengagement.</li> <li>When patients transition home following amputation, there is limited emotional and/or home support.</li> <li>There is no guiding document to assist health care professionals in the long-term management of amputees in primary care.</li> <li>Family members needs may not be factored into the comprehensive care planning e.g. culturally safe accommodation, financial needs, transport, emotional and social support, and amputation education.</li> </ul>
8. Peer Support – referral is offered to a managed peer support program (NSW Care of the person following amputation Minimum Standards 2017)	<ul> <li>Limbs 4 Life peer support was highly valued but not always an option, and there are currently no Aboriginal peer support people available.</li> <li>Due to Covid -19 group sessions for education and rehabilitation have been limited or stopped which has reduced the opportunities for patient and families to have that informal peer support which they find invaluable.</li> <li>Patients may feel very isolated in their care i.e. single rooms.</li> </ul>
9. Discharge planning / transfer of care <ul> <li>discharge planning and transfer of care</li> <li>arrangements commence</li> <li>as early as possible with</li> <li>communication between</li> <li>all stakeholders (NSW Care</li> <li>of the person following</li> <li>amputation Minimum</li> <li>Standards 2017)</li> </ul>	<ul> <li>The NDIS is difficult to navigate for patients, carers and clinicians and often contribute to delays in discharge.</li> <li>Health system issues related to home modifications, funding, bed availability and housing instability are leading to delays in discharge and / or self-discharge.</li> <li>Local country services have limited resources and clinical information to support their clients who have undergone amputation and have returned to the community early.</li> <li>There is a lack of understanding about when to seek help and who should be contacted with some patients becoming lost to follow up.</li> <li>There is a lack of systemised integrated care and robust recall systems leading to a heavy reliance on individual clinicians and patients.</li> <li>Community health and Aboriginal health teams are not consistently engaged early in the discharge planning process and are also unable to access discharge information through electronic systems. Hospital discharge letters are often not accessible by all health professionals involved in the patients care. This leads to a lack of community health.</li> </ul>
<ul> <li>10. Monitoring amputation care and outcomes</li> <li>Employ continuous monitoring of type</li> <li>2 diabetes and its associated complications at a population level (Aboriginal Diabetes Strategy 2017-2021)</li> </ul>	<ul> <li>There is a lack of measurable data on the quality of amputation services or outcomes across the continuum of care.</li> <li>There is a lack of data available on the events leading up to the amputation.</li> <li>There is lack of data on the patient related experiences of amputation care.</li> </ul>
11. Strengthening the workforce	<ul> <li>Many generalist staff such as, Aboriginal health practitioners do not feel adequately prepared to support patients who are in the pre or post amputation phase.</li> </ul>

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# Recommendations

# **Best practice care**

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### Recommendations

<ol> <li>Culturally safe and responsive care</li> <li>Mainstream services are capable of providing high quality, culturally safe, trauma-aware, healing informed and responsive care (National Aboriginal and Torres Strait Islander Health Plan 2021-2031)</li> </ol>	<ol> <li>1.1 Facilitate processes that enable Aboriginal staff to meet patients in the Local Health Network (LHN) emergency department or ward to facilitate a culturally safe and responsive introduction to the health service environment.</li> <li>1.2 Early referral to AHP offered to all patients as a core component of a culturally responsive amputation pathway.</li> <li>1.3 That care of the amputated limb is explicitly built into LHN amputation pathways and procedures so that all patients understand their options and can have their limb returned to Country should this be their wish.</li> <li>1.4 The development and implementation of a training and support package that enables non-Aboriginal clinicians to develop the knowledge, skills and attitudes needed to provide high quality, strength based, culturally safe, trauma-aware, healing informed and responsive amputation care across all phases of the amputation pathway.</li> </ol>
<ol> <li>Prevention and early identification, management and escalation</li> <li>National Foot Forward</li> <li>'Foot Risk Stratification and Triage' and 'Active</li> <li>Foot Disease' Integrated</li> <li>Diabetes Foot Care</li> <li>Pathways (2020)</li> </ol>	<ul> <li>2.1 Implement Foot Forward Pathways (Foot Risk Stratification and Triage and Active Foot Disease) across SA Aboriginal primary care services (requires health system enhancements and sustainable training and support).</li> <li>2.2 Increase the awareness of all staff working within the health care system and community members about the seriousness and urgency of active foot disease and how to escalate patients to specialist services.</li> </ul>
<b>3. Access and equity</b> Receiving culturally responsive care when and where they need it (National Aboriginal and Torres Strait Islander Health Plan 2021-2031)	<ul> <li>3.1 Offer flexible follow up options for clients who are from rural and remote locations e.g. coordinating appointments, so they can occur in one trip if possible.</li> <li>3.2 Explore telehealth options and where possible expand the use of telehealth across the continuum of amputation care – potential for allied health/AHP to visit patients in their home supported by telehealth.</li> <li>3.3 Improve financial support for families who need to travel for care.</li> <li>3.4 Advocate for increased accommodation options to ensure patients and family members can access hospital and rehabilitation services as required.</li> <li>3.5 Access and equity issues need to be considered as part of the comprehensive care planning with social workers engaged early</li> <li>3.6 Establish stronger partnerships between acute hospital with regional and metropolitan step-down services.</li> <li>3.7 Return of limb to Country is supported by LHNs, with financial support in built.</li> </ul>

<ul> <li>4. Counselling and psychological support</li> <li>– counsellizg and psychological should be available across all stages (NSW Care of the person following amputation Minimum Standards 2017)</li> </ul>	<ul> <li>4.1 Social and emotional wellbeing and trauma aware-healing approaches should be strengthened and further explored within the amputation space.</li> <li>4.2 Amputation clinical pathway should include access to social and emotional support for patients and their family members pre-operatively and beyond.</li> <li>4.3 Explore best practice mental health screening tools and look for opportunities to systematically implement them at the appropriate time points along the continuum of care and escalate as needed.</li> </ul>
<b>5. Patient education</b> <b>and support</b> Education and support is available across all stages of care (NSW Care of the person following amputation Minimum Standards 2017)	<ul> <li>5.1 Increase access to culturally appropriate diabetes and preventative foot education for patients and family.</li> <li>5.2 Develop and implement culturally appropriate amputation resources that are pictorial and in language and describe the amputation journey including options for care of the amputated limb.</li> <li>5.3 Ensure that patients and carers are at the forefront of the decision-making process and have access to pre-hab services where possible.</li> <li>5.4 Increase access to relevant and culturally appropriate amputation education and support across all phases of the journey.</li> <li>5.5 Education and support for patients to understand when and who to call if they have concerns.</li> <li>5.6 Use of interpreters should be offered at all stages of the amputation continuum to support patient education and understanding.</li> </ul>
<b>6. Care coordination</b> 'care is coordinated, multispecialty, and interdisciplinary across all phases' (NSW Care of the person following amputation Minimum Standards 2017)	<ul> <li>6.1 To provide optimal care ensure that all interdisciplinary teams have access to minimum level of recommended disciplines as per NSW Amputation Minimum standards 2017.</li> <li>6.2 That an appropriately trained and resourced AHP is formally recognised and included in the amputation interdisciplinary team as early as possible, across the phases and according to the patient and families wishes.</li> <li>6.3 Consider models that promote continuity of care and integration e.g. an Aboriginal coordinator/navigator based in community who can support the client across all phases including transition back to community.</li> </ul>
<ul> <li>7. Comprehensive care</li> <li>'comprehensive care plan</li> <li>is developed and updated</li> <li>throughout the care</li> <li>journey'</li> <li>(NSW Care of the person</li> <li>following amputation</li> <li>Minimum Standards 2017)</li> </ul>	<ul> <li>7.1 Develop a guiding document that supports comprehensive care planning that meets the needs of clients as they transition from the acute amputation phase to living life in the community.</li> <li>7.2 Comprehensive care plans should include issues around equity and access, be strength based, recognise holistic health and wellbeing and include family.</li> <li>7.3 Aboriginal cultural considerations and support for the cultural determinants of health are built into existing amputation clinical care pathways and procedures.</li> <li>7.4 Consider workforce models that enhance continuity of worker/clinician.</li> <li>7.5 Ensure links are made with the local Aboriginal support workers to assist with the transition home following amputation.</li> </ul>

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8. Peer Support – referral is offered to a managed peer support program (NSW Care of the person following amputation Minimum Standards 2017)	<ul><li>8.1 Explore options to partner with amputee charities and other support groups to develop an Aboriginal Peer Support Program.</li><li>8.2 Increase access to group therapy e.g. telehealth group.</li></ul>
<ul> <li>9. Discharge planning / transfer of care <ul> <li>discharge planning</li> <li>and transfer of care</li> <li>arrangements commence</li> <li>as early as possible with</li> <li>communication between</li> <li>all stakeholders (NSW Care</li> <li>of the person following</li> <li>amputation Minimum</li> <li>Standards 2017)</li> </ul> </li> </ul>	<ul> <li>9.1 Explore options for a state-wide care coordinator role that could provide oversight/coordination of patients who have undergone an amputation.</li> <li>9.2 Explore options for improving support for Aboriginal patients to access all funding effectively.</li> <li>9.3 Develop clear guidance for transfer of care (e.g. clinical handover) for patients as they transition between health services (primary, secondary and tertiary).</li> </ul>
<ul> <li>10. Monitoring amputation care and outcomes</li> <li>Employ continuous monitoring of type</li> <li>2 diabetes and its associated complications at a population level (Aboriginal Diabetes Strategy 2017-2021)</li> </ul>	<ul><li>10.1 Explore opportunities for increased data collection including the use of Australasian Rehabilitation Outcomes Centre and PREMS/PROMS.</li><li>10.2 Develop an amputation register that enables a methodical system to monitor and track amputation outcomes leading to improved care for Aboriginal people.</li></ul>
11. Strengthening the workforce	<ul> <li>11.1 Enhance capability of; <ul> <li>Primary care clinicians to provide support for people undergoing amputations</li> <li>Enhance capability of primary care clinicians to identify and appropriately escalate active foot disease</li> <li>AHPs working in acute care to support the clinical, social, emotional wellbeing of the patient undergoing amputation.</li> </ul> </li> <li>11.2 Explore innovative models to build the Aboriginal workforce including volunteer roles that could enhance the amputation care journey.</li> <li>11.3 Strengthen the cultural awareness and capability of the non-Aboriginal workforce in amputation care.</li> </ul>

# Discussion

This project has highlighted several significant gaps and needs for Aboriginal people experiencing amputation. It has long been recognised that the current structure and design of the health system is not meeting the needs of Aboriginal people. Previous rehabilitation reports have also found that there are limited culturally appropriate local rehabilitation options, especially for Aboriginal people who live in rural South Australia.<sup>19,20</sup>

Aboriginal people have a cultural and spiritual connection to their land and consequently returning to Country may be prioritised over their health care needs.<sup>21</sup> Amputation will require patients and families to travel to Adelaide to access treatment leaving them isolated from family, local supports and culture, often for lengthy periods. There are numerous challenges in achieving successful discharge home, especially for those who live in rural and remote locations. This is due to inadequate access to equipment, home modifications and ongoing therapy services and specialist medical outreach services.<sup>19</sup> Given this, it is not surprising that uptake and completion rates of rehabilitation post amputation are anecdotally much lower than for non-Aboriginal patients. Unfortunately, there is a lack of data pertaining to health outcomes, service use, and patient reported measures across all phases of the amputation journey.

It is critical that patients understand their options and are involved in decision-making including being given culturally safe options for the care of their amputated limb. For Aboriginal and Torres Strait Islander peoples, the returning of an amputated limb to Country may be an important part of healing and the promotion of social and emotional wellbeing. Whilst, there is limited published literature describing the Aboriginal patient experience of amputation including their views around care/disposal, the literature on death and dying highlights the importance of cultural practices, such as, all parts of a "body" being sent back to the person's homeland/Country.<sup>22</sup>

The SA Model of Amputee Rehabilitation<sup>20</sup> recommends an integrated clinical pathway for individuals that includes; assessment, intervention and regular review of independence, physical and psychosocial wellbeing, functioning and quality of life be developed and implemented. In addition, the model proposed a number of strategies to assist in delivering culturally appropriate services, all of which have been identified during this current project<sup>20</sup> e.g.

- Ensuring health information is communicated in a manner that is acceptable and easily understood.
- Involvement of extended family, Aboriginal health workers/practitioners and healers as appropriate.
- The need for early supported discharge programs to minimise length of stay in hospital and facilitate discharge to a more culturally appropriate environment.
- Increase the use of technology to minimise the need to have to leave their communities.
- Provide more flexibility with appointments and attendance at clinics.
- Acknowledgment of the many factors that may influence ongoing health care choices, including extended family relationships and home environment.
- Building the cultural understanding and awareness of the non-Aboriginal health workforce
- A supported pathway for accessing ambulatory rehabilitation and prosthetic services for metropolitan and country Aboriginal clients should be developed and implemented.

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Low uptake of rehabilitation amongst Aboriginal and Torres Strait Islander peoples has been found in other conditions such as stroke.<sup>23</sup> One study involved interviews of 32 Aboriginal people, highlights the importance of acknowledging cultural identity and strengths through involvement of extended family and Aboriginal health staff. They found that access to language and proximity to Country were all central to rehabilitation planning for Aboriginal people.<sup>24</sup>

# Conclusion

The 2012 SA Model of Amputee Rehabilitation highlighted several gaps and system recommendations. The findings in this project build on this work and provide further evidence and detail for targeted health service improvements across each phase of the amputation journey. By delivering amputation care that is culturally safe and responsive, person and family centred, integrated and coordinated Aboriginal people will experience improved health and wellbeing outcomes.



# References

- 1. Gibson, O. et al. The South Australian Aboriginal Diabetes Strategy 2017-2021. (Wardliparingga Aboriginal Research Theme, South Australian Health and Medical Research Institute, Adelaide, 2016).
- 2. AIHW. Diabetes indicators for the Australian National Diabetes Strategy 2016-2020, <<u>https://www.aihw.gov.au/</u> reports/diabetes/diabetes-indicators-strategy-2016-2020/contents/summary> (2018).
- 3. International Working Group on the Diabetic Foot. IWGDF Guidelines on the Prevention and Management of Diabetic Foot Disease. (2019).
- 4. Chuter, V., West, M., Hawke, F. & Searle, A. Where do we stand? The availability and efficacy of diabetes related foot health programs for Aboriginal and Torres Strait Islander Australians: a systematic review. Journal Foot Ankle Research 18 (2019).
- 5. Van Netten JJ et al. Australian diabetes-related foot disease strategy 2018-2022: The first step towards ending avoidable amputations within a generation. 1-43 (Diabetic Foot Australia and Wound Management CRC, Brisbane, 2017).
- 6. AIHW. Diabetes <<u>https://www.aihw.gov.au/reports/diabetes/diabetes/contents/hospital-care-for-diabetes/</u><u>hospital-procedures-for-diabetes-complications</u>> ( 2020).
- 7. Jupiter, D., Thorud, J., Buckley, C. & Shibuya, N. The impact of foot ulceration and amputation on mortality in diabetic patients: From ulceration to death, a systematic review. International Wound Journal (2015).
- 8. Columbo, J. et al. Patient Experience of Recovery After MajorLeg Amputation for Arterial Disease. Vascular and Endovascular Surgery 52, 262-268 (2018).
- 9. British Society of Rehabilitation Medicine. Amputee and Prosthetic Rehabilitation Standards and Guidelines (3rd Edition). 1-90 (British Society of Rehabilitation Medicine, London, UK, 2018).
- 10. American Academy of Orthotists and Prosthetists. Standards of Care. Journal of Prosthetics and Orthotics 16, S6-S12 (2004).
- 11. Radenovic, M. et al. Understanding transitions in care for people with major lower limb amputations from inpatient rehabilitation to home: a descriptive qualitative study. Disability and rehabilitation (2021).
- 12. Prevention and Population Health Branch, W. S. Lower Limb Amputations in South Australia. 1-15 (Government of South Australia, Adelaide, 2019).
- 13. Lowitja Institute. Health Journey Mapping, <<u>https://www.lowitja.org.au/page/services/tools/health-journey-mapping</u>>
- 14. Australian Government. National Aboriginal and Torres Strait Islander Health Plan 2021–2031. (Department of Health, Canberra, 2021).
- 15. Lazzarini, P. et al. Australian evidence-based guidelines 2021 for diabetes-related foot disease. (Diabetes Feet Australia, Australian Diabetes Society, Brisbane, 2021).
- 16. National Diabetes Services Scheme. Integrated Diabetes Foot Care Pathway (Foot Forward for Diabetes, 2020).
- 17. NSW Agency for Clinical Innovation (ACI). Care of the Person following Amputation: Minimum Standards of Care. (NSW, 2017).
- David Tivey, Joanna Duncan, Anje Scarfe, Robyn Lambert & Cameron, A. . Amputee care standards: an Evidence Check rapid review brokered by the Sax Institute <u>www.saxinstitute.org.au</u>) for the NSW Ministry of Health, 2015., (NSW, 2015).
- 19. Statewide Service Strategy Division. Statewide Rehabilitation Service Plan 2009-2017. (Department of Health, , Adelaide, 2009).
- 20. Statewide Rehabilitation Clinical Network. Model of Amputee Rehabilitation in South Australia. (SA Health, Adelaide 2012).
- 21. Waran, E., O'Connor, N., Zubiar, Y. & May, P. 'Finishing up' on country: challenges and compromises. Royal Australasian College of Physicians, 1108-1111 (2016).
- 22. Maddocks, I. & Rayner, R. Issues in palliative care for Indigenous communities. MJA, 17-19 (2003).
- 23. Armstrong, E., Hersh, D., Hayward, C. & Fraser, J. Communication disorders after stroke in Aboriginal Australians. Disability and rehabilitation 37, 1462-1469 (2015).
- 24. Armstrong, E., Coffin, J., Hersh, D., Katzenellenbogen, J. & al, e. "You felt like a prisoner in your own self, trapped": the experiences of Aboriginal people with acquired communication disorders. Disability and Rehabilitation (2019). <<u>https://www.tandfonline.com/doi/abs/10.1080/09638288.2019.1686073</u>>.

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# **Appendices**

### **Appendix 1: Amputation Service Mapping**

## Phase 1 Aboriginal primary health services: SA Health and Aboriginal communitycontrolled health services (ACCHS) offering a range of chronic disease services Pre-amputation including general practitioners (GPs) and visiting nurse and medical specialists, (Including pre-hab) such as, credentialled diabetes educators (CDE), endocrinologists. Podiatry: SA Health, ACCHS, Rural Doctors Workforce Agency (RDWA), Country Outback Health (COB) or privately through a GP Care Plan or via private health insurance. Interdisciplinary high-risk foot services (iHRFS): Central Adelaide Local Health Network (CALHN), Northern Adelaide Local Health Network (NALHN) and Southern Adelaide Local Health Network (SALHN) have National Associated Diabetes Centre (NADC) accredited iHRFS services with CALHN providing iHRFS across the state as well into Broken Hill and Wilcannia. Vascular services: CALHN has a visiting vascular specialist service (country and NALHN) CALHN operates a vascular nurse led wound clinic SALHN provides a visiting vascular service to Mt Gambier Transport (emergency and non-emergency): Royal Flying Doctor Service (RFDS), SA Ambulance, Patient Assisted Transport Scheme (PATS), community vans. Red Cross volunteer car and shuttle bus. Pre-habilitation: SALHN offers a multidisciplinary pre-habilitation clinic that includes the Amputee Nurse Practitioner, Rehab Consultant, Prosthetist, Amputee Day Rehabilitation Service, Amputee Physiotherapist. CALHN offers an interdisciplinary pre- rehabilitation program for patients coordinated by the Amputee Nurse. NALHN provides a limited prehab service that is offered through Specialist Ambulatory and Rehabilitation Centre (SpARC) or through the Amputee Nurse at RAH. Prehab is limited by the funding availability i.e. home modifications cannot be done until funding comes in. Health and wellbeing:

- SA Health hospitals have a range of Aboriginal services delivered by Aboriginal health practitioners, liaison officers and social work.
- Aboriginal Community Controlled Health Services provide a range of culturally safe health and wellbeing services.

# **Appendices**

Phase 2	Amputation surgery:
Amputation (Acute care)	<ul> <li>CALHN: RAH provides a state-wide service for minor and major amputations including servicing Alice Springs and Broken Hill. Most amputations conducted in SA occur at the RAH.</li> </ul>
	FMC: minor and major amputations.
	Vascular Nurse led clinic (RAH) – foot wound reviews
	<b>Multidisciplinary team:</b> Surgeon, amputee nurse (RAH), Amputee Nurse Practitioner (FMC), nurses, medical officers physiotherapy, rehabilitation physician, occupational therapist, dietitian, diabetes educator, social worker, psychologist, Aboriginal health practitioner (RAH, FMC)
	Prosthetics and Orthotics:
	• CALHN (manufacture interim and long term prosthetics at QEH)
	NALHN (interim prosthetics management first 6-9months)
	SALHN Orthotics and Prosthetics South Australia (OPSA)
	• The Whyalla Hospital and Health Services Inc interim only. Provide outreach to FUN, EFN and Yorke Peninsula.
	Accommodation:
	CALHN:
	• Kangawodli
	Luprin Hostel
	Scotty's Motel
	NALHN:
	<ul> <li>Sfera's/Mawson lakes accommodation – accommodation is paid for but not transport or food – usually stay for two weeks and come in Monday to Friday for rehab.</li> </ul>
	Wound care and home support:
	Hospital in the home
	RDNS (has an Aboriginal team)
	Private nurses
	Community health
	Aboriginal health
	Disability SA
	CICC-CALHN integrated care coordination CALHN integrated care coordinator - connecting hospital and community services - CALHN.
	Peer support - Limb 4 Life:
	• NDIS
	• PATS

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Stage 3	CALHN:
Rehabilitation	Hampstead (inpatients)
	QEH Day rehab
	QEH Hospital in the Home (HITH)
	NALHN:
	Modbury Hospital Rehabilitation Unit (inpatients).
	<ul> <li>Aged Care, Rehabilitation and Palliative Care services NALHN (Aboriginal Cultural Advisor).</li> </ul>
	• Specialist Ambulatory and Rehabilitation Centre (SpARC) – includes multi d team (Prosthetist, physio, OT, Social worker, rehab physician, podiatrist
	Rehab in the Home.
	SALHN:
	• FMC Flinders Medical Centre Rehabilitation Ward- Kokoda and Repat Health Precinct- Rehab V (inpatients).
	Rehab in the home.
	Day rehab program based at FMC.
	Country:
	In country all the postcodes have been divided up and are allocated a rehabilitation facility. The Rural Support Service Nurse Consultant for rehabilitation works with the metropolitan services to coordinate care post amputation.
	<ul> <li>Mt Gambier Rehabilitation – inpatient and outpatient service with outreach provided by SALHN and Rural Support Service (RSS) and access to visiting prosthetics.</li> </ul>
	Berri – inpatient and outpatient rehab with physician visiting from NALH
	<ul> <li>Whyalla Rehab – Inpt and day rehab (outreach services provided by SALHN Amputee Nurse Practitioner and Rehab Consultant). Visiting endocrinology (Pika Wiya), visiting rehab medicine (Whyalla), podiatry, prosthetics, dietetics, diabetes education, social work, psychology, OT, physio, visiting amputee nurse. Outreach prosthetic service across FUN, EFN and Yorke Peninsula.</li> </ul>
	• Telerehab - RSS.
	Pre-habilitation not an option because most country patients are not linked to vascular.

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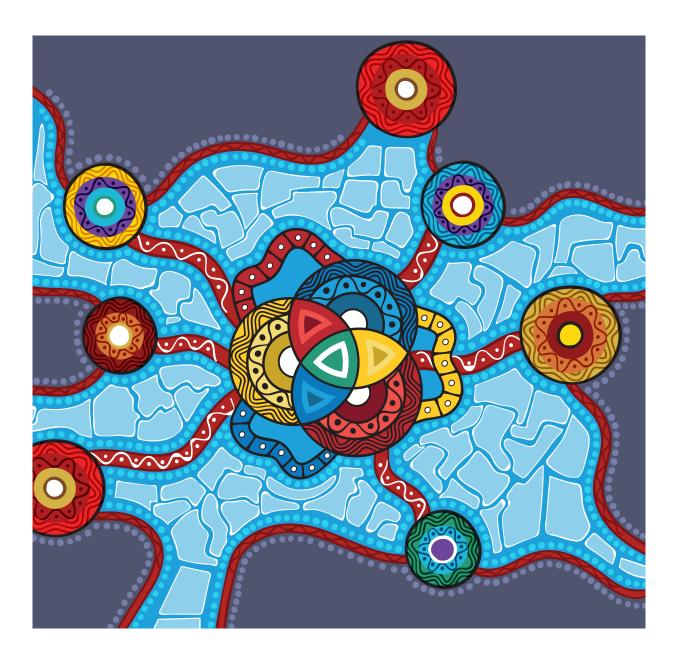
Stage 4	Podiatry and diabetes services:
Lifelong care	• ACCHS
	General Practice
	Closing the gap - Integrated Team Care - Aboriginal Health - <u>Sonder</u>
	SA Health High risk foot clinics in metro and podiatrists across country
	<ul> <li>Endocrinology and allied health diabetes teams at each of the metro hospitals. Diabetes educators across community health in country with visiting endocrinologist services in many sites including ACCHS.</li> </ul>
	Orthotics and prosthetics:
	CALHN - Prosthetic clinic QEH
	SALHN – ongoing prosthetic services available through OPSA
	• Private

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**JORDAN LOVEGROVE** is an Indigenous Artist from Dreamtime Creative. Jordan is a Ngarrindjeri young man who combines intimate knowledge of Aboriginal communities and illustration skills to develop outstanding Indigenous artwork which is applied to a range of print and online communications.

This artwork represents the South Australian Aboriginal Chronic Disease Consortium and the interdependence of prevention, care and after care to achieving the best health outcomes for Aboriginal and Torres Strait Islander people. The three central overlapping meeting places signify the across plan priorities of the three plans. Diabetes is depicted by the blue meeting circle; heart and stroke by the red meeting circle; and cancer by the yellow meeting circle. The red, blue and yellow paths show the three plans collaborating and coming together to achieve the best health outcomes and the red paths show the Consortium reaching out to other organisations and communities, represented by the outer meeting circles, which are working together to maximise the effectiveness of the three plans. The small dots are the people going to the organisations and communities and being assisted by the work of the Consortium, and the pale blue puzzle pieces represent the organisations and communities giving the Consortium important feedback.

# For more information

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