

Supporting the culturally safe disposal, storage and return of the limb (or part thereof) for Aboriginal and Torres Strait Islander patients undergoing amputation.

> DISCUSSION PAPER SEPTEMBER 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	April 2023
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ISBN: 978-0-6456437-1-8

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Colmer, K., Melchers, A., Morey, K. 2022, *Discussion paper: Supporting the culturally safe disposal, storage and return of the limb (or part thereof) for Aboriginal and Torres Strait Islander patients undergoing amputation,* 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.

The content is solely the responsibility of the authors and does not necessarily represent the views of the Government of South Australia.

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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 discussion paper uses the term 'Aboriginal' to describe the people and communities, for whose benefit this paper is written, in recognition of the traditional owners of the lands now called South Australia. The authors of the discussion paper 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 discussion paper is for the benefit of all, and the choice of terminology intends to respectfully acknowledge custodianship in accordance with Aboriginal traditions and customs. Other terms, including "Torres Strait Islander", "Aboriginal and Torres Strait Islander", "Indigenous", "First Nations" etc. are used where culturally appropriate, where reference is made to Aboriginal and / or Torres Strait Islander people at a national level and where they are used in position titles and source publications.

Acknowledgements for Contribution to the Paper

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 partner organisations and staff who have contributed to this paper:

- Aboriginal Priority Care Committee, Central Adelaide Local Health Network (CALHN)
- Aboriginal Community Reference Group, CALHN
- Clinicians and staff of CALHN
- South Australian Aboriginal Chronic Disease Consortium, South Australian Health and Medical Research Institute



Overview

This paper outlines seven recommendations and associated best practice principles, that could support Aboriginal and Torres Strait Islander patients undergoing amputation, to receive culturally appropriate information about the options for the disposal, storage, and potential return of their amputated limb (or part thereof). Implementation of the recommendations and best practice principles will ensure there is appropriate support of cultural and spiritual practices that relate to body integrity and/or the appropriate disposal of remains. The recommendations will require intersectoral collaboration across agencies and with Aboriginal community members to develop and implement clinical policy guidance and work instructions, patient information and training for relevant staff.

This discussion paper is one of the deliverables of a broader project which has sought to understand the enablers, needs and gaps along the amputation journey and identify health system improvements that will enhance amputation care for Aboriginal people receiving services in South Australia.

Aboriginal and Torres Strait Islander Australians experience comparatively high rates of diabetes (1) 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 (2). Rates also increased with increasing socioeconomic disadvantage and remoteness, with those living in remote and very remote areas being three times more likely to experience hospitalisation for lower limb amputation, compared to those living in major cities.

In South Australia, it has been identified by clinicians and Aboriginal community members, that the returning of an amputated limb to Country, may be very important for 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 (3).

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The literature highlights the need to 'normalise' the conversation for patients and provide clear options for people who would like their limb returned to them, or for those patients who just want to know what will happen, and be reassured that their limb will be treated with respect and dignity (4). The evidence also suggests, that the way in which a removed limb is disposed or handled can impact on a person's adaptation to amputation, however, the research is scarce. Many jurisdictions, including South Australia, lack the appropriate policies and procedures that are needed to effectively facilitate and navigate these sensitive conversations and options with patients.

This lack of policy guidance for returning tissue or body parts to patients in South Australia is making it particularly difficult for health services to meet the cultural needs of Aboriginal and Torres Strait Islander patients, resulting in potential negative consequences on health and social /emotional outcomes. Ideally consideration of disposal, storage and return would be part of a broader 'best practice clinical care amputation pathway', that considers all aspects of patient management including social emotional and cultural needs. Furthermore, clear policies and procedures are important to raise the awareness of the issue and provide guidance for staff and patients.

Recommendations

- That care of the amputated limb is explicitly built into the existing amputation care pathways and patient education resources are developed so that patients and staff are aware of its importance and the limb options available.
- 2. That SA Health and Local Health Networks develop and implement appropriate clinical guidance, consent procedures and relevant clinician resources for the disposal, storage and return of body parts, such as, limbs (overarching state-wide guidance as well as local work instructions).
- **3.** If a patient and/or their family are unable to be fully informed of their limb options or are unable to reach a shared consensus/decision in the pre-operative time frame the limb will be temporarily stored until that conversation can take place with the appropriate cultural and family supports.
- **4.** That SA Health explores current capacity and options for long term storage and tracking of body parts to support the cultural practices of patients who wish to be buried whole.
- **5.** That a risk and legal assessment for the safe transport of body parts is conducted to ascertain how and if patients can have their limb released directly to them.
- **5.** That culturally appropriate patient information sheets are developed with community.
- 7. That training packages for staff are developed and implemented relevant to need.

The Amputation Journey

1. Importance of Culturally Responsive Care

The loss of a limb is a life-changing event and existing literature suggests that the consideration of the disposal of the limb is part of the adaption process that patients may go through. Many patients have a desire to know how a part of their body will be disposed of and that this knowing may be an important part of their process of grieving and adaption to their new sense of self. However, the literature and anecdotal evidence highlight that these conversations do not routinely occur and that many patients feel uncomfortable asking about their limb/body part. The Australian and New Zealand Society for Vascular Surgery formally recognises the cultural significance for Aboriginal and Torres Strait Islander people in its web-based patient information sheet;

"For most patients the amputated body part is disposed by incineration with other medical waste. For some patients, notably Australian Aboriginal and Torres Strait Islanders, Muslim and Maori patients, it is important that all parts of the body are buried together and so these patients may retain their body parts either for subsequent burial in the event of their death or for temporary burial and subsequent relocation. If you wish to retain your amputated leg for cultural and religious reason, please let your surgeon and treating team know (5)."

Similarly, the Royal College of Pathologists in their 2018 guideline highlights the need to ensure respect for the human body and to ensure individuals are treated with dignity in respect to how their tissue is obtained and used (Royal College of Pathologists 2018). This needs to be done through a culturally appropriate informed consent process. The guideline states that (p5:2018) (6):

"Cultural differences may impact on the permissibility of provision of some tissues within some religious or cultural sub-groups e.g. foetal tissue. Honouring the individual's values, preferences and beliefs may preclude certain actions as much as permit others. Indigenous people have 'a unique attachment to their genetic resources since they are a vital part of their spiritual and cultural existence (cosmology)'. Sensitivities in the handling of tissue from Aboriginal and Torres Strait Islander people may therefore be encountered, including but not limited to genetic testing/ research. These should be explored on an individual basis with heightened awareness where the patient is from a traditional community."



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Whilst these statements provide some background information, they do not provide the treating team with clear instructions for returning body tissue at the local health service level. With no national guidance and variation existing across states, patients may not be informed of their options or their wishes may not be realised due to barriers at the level of a local hospital. Melissa Noonan, Chief Executive of Limbs for Life was quoted by Daily Mail to have stated:

"If people aren't offered the option to keep it, they probably wouldn't know they could (7)".

Best practice principle:

That all patients have their limb options explained to them as a routine part of the amputation care pathway.

The psychological impact of amputation is complex and varied, however, impacts on body image and self-identity are common (4). A recent narrative review by Hanna (2019) highlights a dearth of research related to the issue of disposal within the experience of amputation. The consideration of disposal of the limb is thought to be part of the adaption process that individuals may go through with patients viewing the amputated limb as something that is no longer 'me' but still definitively 'mine (4)'.

Gibson and Sobonya (2019) interviewed patients who had requested to have their specimens returned to them. They were interested in understanding, why patients chose to have their specimens returned and how that experience was for them. Of the 22 eligible patients, 8 were interviewed, one of whom a Native American had undergone a below knee amputation (8). The quotes below highlight just how important it was for this person to be buried whole and to follow his cultural beliefs and traditions (8);

"I am Native American and in our tradition we have a burial for amputated body parts. The burial is in the cemetery, so when we pass on, in the same spot, it will be in my next life".

"We dug a hole, 5 feet deep, not quite as deep as if you're burying a casket. But just like with a person. We covered my amputated leg with cactus pads, so no animals would dig up the gravesite. I was with immediate family and friends. We had a moment of silence, and a prayer or blessing and prayed the rosary. You know, a few prayers for me."

Emotions at the burial ceremony of a leg were described by one patient and his wife as,

"[We were] relieved to get it done with. We were really active, now I [patient's wife] am the only one that is active. The burial was a way to have it done. Now we are taking it day by day." The patient commented, "I don't know the words or how to explain it. I don't know how to put it into words. When the burial was happening, I felt good about the fact that someday I am going to be with my leg, as if it never happened." Overall the authors found that there was a spectrum of reasons for requesting tissue to be returned to them including cultural beliefs and a desire to be made whole again in the afterlife. Patients reported that by having their tissue returned they felt more equipped to process what had happened.

Aboriginal people have a cultural and spiritual connection to their land and consequently returning to 'Country' may be prioritised over their health care needs (9). A qualitative study, exploring death and dying, highlighted the importance of dying at home (10). Participants discussed how the soul and spirit is tied to the land as shown in the comment by one participant:

"If an older member or anybody wants to go home to die let's take them home. Don't leave them here because their soul and their spirit believe that if they don't die in their own country that spirit going to walkabout all the time... (It will be lost, yeah) Yeah, looking for home (10)."



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Best practice principle:

Cultural and emotional support is provided pre-amputation and that this care is person and family centred and culturally responsive.

Authors also highlight that personal belongings, such as, clothes worn at the time of death or hair shaved may need to be collected and stored appropriately so that they can be returned to the family (3), (9). However, it is important to acknowledge that burial and ceremonial practices vary widely amongst community groups and individuals and so this will not be relevant for all communities (3).

Community and Clinician Perspective – Enhancing Amputation Care for Aboriginal People Project

There is a lack of published literature that explores the experience of amputation from the perspective of Australian Aboriginal and Torres Strait Islander people. However, recent consultations as part of the 'Enhancing amputation care project' have provided further evidence of the need to ensure that disposal/storage and/or return of the limb is recognised as an integral part of the amputation pathway/journey. When asked about whether they would have liked the limb returned one community's members wife responded:

"I had thought about it...but at the time we were going through shock... if my husband passes away there are parts that won't be there".

She would have liked to have had the leg cremated so they could keep the ashes. Unfortunately, they were not given the choice and she:

"feels like when he is laid to rest, he won't be whole".

When discussing the amputation journey, several clinicians raised the cultural importance of Aboriginal patients having the option of their limb being returned to them. Clinicians understood the cultural significance of being buried whole and the impact that this can have on a person's social and emotional wellbeing. However, clinicians reported that there were many barriers and system challenges that made returning a limb difficult and, in some cases, impossible. They spoke about the negative impact this had on their patients social and emotional wellbeing and their healing.

Clinicians have highlighted numerous barriers/challenges that need to be overcome in South Australia in order to support a patient's wish to have a body part returned to them:

- There is no policy and procedural guidance for returning limbs making it difficult for staff to know what is legally and clinically required.
- When amputation is conducted as an emergency there may be inadequate time for the patient and family to be appropriately informed and supported to make a decision about the limb.
- The cost of cremation or burial is prohibitive to families.
- Some patients wish to have their body part stored until their passing, but options are currently limited.

Clinical examples from the consultation;

- Consultations with clinicians have highlighted the devastation for patients who have asked for their limb to be returned post amputation, only to be told that it had already been disposed. These situations were very upsetting for patients and the clinicians who were left trying to locate the limb.
- Some clinicians reported that they had successfully been able to negotiate return of the limb, with the patient arranging cremation. Clinicians also shared examples of patients who had told them that they wanted to have their limb returned but were unable to get the hospital to agree to arrange it.
- There have been instances in which a patient has been able to return interstate with the Royal Flying Doctor Service agreeing to take the limb with the patient. More recently, a patient has successfully arranged cremation through a funeral home in SA.
- Aboriginal staff have had an important role in facilitating the return of limbs. In one example the Aboriginal team were able to escalate the issue and arrange for their patient to have the body part returned to them and save a lot of distress for the patient and their family. The patient refused to be discharged without her body part, as this was extremely important to her. Aboriginal health practitioners report it is very important that people are empowered and that they have options available to them including being buried whole.

Recommendation 1:

That care of the amputated limb is explicitly built into the existing amputation care pathways and patient education resources are developed so that patients and staff are aware of its importance and the limb options available.

The Amputation Journey

2. Current Policy Context and Limb Care Options in South Australia

In Australia, the state based Human Tissue Acts govern the donation and use of tissue from living and deceased persons for different purposes. These statutes focus on how the tissue is obtained and not how are they stored, accessed or transferred. Each state within Australia has different regulations, guidelines and processes related to the return of body tissue and body parts. For example, the Northern Territory has a Waste Management Policy that provides some provision for discussing amputated limbs with patients. In Western Australia there are policies that guide return of tissue, but it does not explicitly refer to limbs. The most useful policy guidance is from NSW in their policy directive Donation, Use and Retention of Tissue from Living Persons (11). This policy directive provides a detailed procedure for the return of tissue including consent forms and letters for transporting the tissue in a private vehicle. South Australia does not have a return policy for body parts, but it does have a policy directive that guides the release of a placenta for private disposal (12).

From an Indigenous international perspective, New Zealand is leading the way with policies, that reflect the strong personal and cultural significance that may be attached to body tissue (13). New Zealand has implemented guidelines across the country to support return of tissue/body parts to patients. The policy/ procedure applies to all laboratory, mortuary, nursing, medical, orderly and clerical staff involved in the removal and return of tissue/body parts. The New Zealand guidance recognises that patients and their families have a right to have their tissue/body parts returned to them (minor or major). The policy also stipulates that no body part/tissue that is removed or obtained during the course of a health care procedure will be stored, preserved or used unless there is informed consent by the patient (14).

South Australia does not have an existing guideline or policy to support the culturally safe storage, disposal and return of the amputated limb for Aboriginal and Torres Strait Islander patients. This is in contrast to states, such as NSW, where the policy directive <u>Donation</u>, <u>Use and Retention of Tissue from Living Persons</u> provides guidance for situations where a patient may request that the tissue removed during their medical, surgical or dental treatment be returned to them for disposal. The policy outlines the conditions in which a patient can take home the tissue removed or expelled from their body while they are in hospital (11).

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SA policy and regulatory framework for tissue and body parts

The legalities and responsibilities of the patient and the health service when tissue or a body part is stored, released or disposed of are outlined in the relevant SA Acts and Regulations. The table below highlights the key documents that guide clinical practice in SA.

<u>Tissues Act - Transplantation and</u> <u>Anatomy Act 1983</u>

<u>South Australian Public Health</u> <u>Act 2011</u>	Is an Act to 'promote and to provide for the protection of the health of the public of South Australia and to reduce the incidence of preventable illness, injury and disability; and for other purposes' (16).
South Australian Public Health (Notifiable and Controlled Notifiable Conditions) Regulations 2012	The Public Health regulations outline the notifiable and controlled notifiable conditions within SA (17).
Burial and Cremation Act 2013 (the Act) and the Burial and Cremation Regulations 2014 (the Regulations)	The Act and its Regulations provide for and regulates the identification, handling, storage, transport, disposal and memorialisation of human remains (18), (19).

Recommendation 2:

That SA Health and Local Health Networks develop and implement appropriate clinical guidance, consent procedures and relevant clinician resources for the disposal, storage and return of body parts, such as, limbs (overarching state-wide guidance as well as local work instructions).

Options for limb care post amputation

It is important that patients understand their amputation journey and the options available to them in respect to the care of their amputated limb. Decision making regarding the amputation care pathway may not always rest with the patient themselves. It is important that patients and family are provided with the appropriate support and time to ensure that the 'right person' hears the 'right story' and that the Aboriginal health practitioner/worker has a key role to play (9). Maddocks and Rayner (2003) explain how the decision making processes in Aboriginal and Torres Strait Islander communities are collective and may take time. Family meetings may be large with some people travelling considerable distances to be involved. A patient facing surgery may wish to return to their community to discuss options and receive permission from family. Sometimes the person who has travelled with the patient may have been chosen due to their language skills but may not be appropriate for decision making in cultural terms, and it may take time for those people to arrive. Hospitals need to respect and support patients' and families' needs in culturally safe and responsive ways (3). If amputation is an emergency procedure, it may not be possible for patients to reach a decision, and in these situations temporarily storing the limb until the patient and the family can receive culturally appropriate counselling and cultural support, will ensure that limbs are not disposed of incorrectly. Based on the literature and the amputation project consultation, three options for the limb and the care of the limb have been identified and explored.

Recommendation 3:

If a patient and/or their family are unable to be fully informed of their limb options or are unable to reach a shared consensus/decision in the pre-operative time frame the limb will be temporarily stored until that conversation can take place with the appropriate cultural and family supports.

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Torres Strait Islander patients undergoing amputation.

OPTION 1: Disposal

Disposal of the limb is routine practice when a body part has been removed during surgery. It is important to note, that there is a difference between the way surgical material and bodily remains can be disposed. Legally, you cannot dispose of bodily remains through the normal medical waste channels, and hospitals have an obligation to conduct respectful cremation of bodily remains, but how this is achieved or defined is unclear. It is important that patient consent for disposal is obtained as part of the surgical consent process.

Best practice principle:

Hospitals should ensure that they are adopting respectful cremation of body parts and that explicit consent to dispose of the remains is obtained.

The decision to dispose of the removed limb needs to rest with the patient and their family. As part of pre-amputation care, patients should be counselled and provided with information about how their limb will be respectfully disposed of and provided with the options of storage or return should this be their wish (see option 2 and 3). If patients are unsure or unable to engage in a conversation before their amputation the limb can be temporarily stored until they have made a decision. This recommendation recognises that many patients undergo amputations as an emergency and are too unwell or too overwhelmed to make a decision about the care of their limb at that time. Furthermore, they may not have their next of kin or support person with them prior to surgery, or some patients may not realise that they want their limb stored or returned until after their procedure. Adopting a system of temporary storage and a follow up process may give patients the time needed to make an informed decision. All discussions should be documented and written consent for disposal, storage or return must be obtained.

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Best practice principle:

If the patient is unsure or unable to engage in a conversation about their limb prior to surgery then the decision to dispose of the limb should be delayed until the post amputation period. This will ensure that patients have time to make an informed and shared decision with their family.

OPTION 2: Long term storage

Some people will wish to store their body part until they pass away, so that they can then be buried whole. Within SA the only viable option for long term storage of a body part is the Royal Adelaide Hospital (RAH) Mortuary, but there is limited capacity which is unlikely to meet demand in the long term. Unfortunately, private funeral homes do not have the capacity to store limbs unless death is imminent, and country hospitals do not have any deep freeze available for storage.

A draft RAH Organisation Wide Instruction for storing limbs has been trialled over the past 12 months with uptake from Aboriginal and Torres Strait Islander patients being approximately 90% highlighting the potential demand for this service. A systematic follow up system is required to ensure that limbs are only being stored long term if patients request that service. Additionally, a robust system for following up and tracking the care of amputated limbs including storage (including ascertaining the length of time), respectful disposal and safe release will need to be implemented.

Recommendation 4:

That SA Health explores current capacity and options for long term storage and tracking of body parts to support the cultural practices of patients who wish to be buried whole.

OPTION 3: Return for cremation or burial

Some patients will arrange their own cremation or burial of the removed limb and will need to have their body part released from storage. There are usually significant costs associated with this e.g. transport, cremation and burial.

Cremation

In SA, the Burial and Cremation Act 2013 (18) supports the cremation of a body part, if certain criteria are fulfilled. It has been confirmed that a Funeral Home in Adelaide has facilitated the cremation of an amputated leg in the last 12 months and that the request was made for cultural reasons. According to the Funeral Home the cost to the patient was approximately \$900 and included collection of the limb and the permit for cremation (obtained from births, deaths and marriages). The leg is placed in an appropriately sized coffin and the ashes can be picked up by the family or posted to them.

An example Funeral Home process is below:

The funeral home needs a letter from the medical officer doctor as soon as practical with name, address, exact body part being removed and reason e.g. medical condition. Once amputation has occurred the funeral home should be advised as soon as possible so they can collect it. It will need to be appropriately packaged for collection. The person or their next of kin will need to complete the required paperwork either before or after amputation.

Burial

The Burial and Cremation Act 2013 (the Act) (18) requires human remains to be buried within a lawfully established cemetery or approved natural burial ground. Burial on private property may be permitted only if the property is located outside of metropolitan Adelaide or a township. Burial on private property is subject to the approval of the local council (or authority), and the permission of the landowner. The burial is subject to the requirements of the Burial and Cremation Regulations 2014 (the Regulations) (Health Protection Programs, SA Health Factsheet 2017).

Best practice principle:

It is important that patients and their family understand their obligations under the SA regulations and acts.

SA Health have developed a fact sheet to inform the legal, safe and dignified burial of human remains on private property (20). It is important that the person understands that if they bury on private land and the property is sold, they do not have rights to the buried remains. For more information refer to the SA Health Factsheet <u>Human remains</u> | <u>SA Health</u>.

There may be other cultural requests such as "smoking" rituals to purify an area or cleanse it of bad spirits, and this may also be important in the case of an amputated body part. There may be a request for this to occur in a hospital area (3).

Transporting human remains

In SA, human remains are not to be transported unless the remains are secured or restrained against movement within the vehicle; and the remains are kept in a compartment that (19):

- is physically separate from a part of the vehicle designed for the carriage of the driver and passengers; and
- is capable of being easily cleaned and disinfected; or
- are contained in a coffin, shroud or other container or wrapping from which no bodily discharges, contaminants or infectious substances may escape.

The above information is also outlined in the SA Health, Health Protection Programs factsheet on burying human remains (20). The National Pathology Accreditation Advisory Council <u>Requirements</u> for the packaging and transport of pathology specimens and associated materials (fourth Edition 2013) also provides information on packaging and the transport of tissue.

If the body part is small enough to fit in a large jar, it can be released although it is unknown how often or if this is occurring in South Australia.

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Recommendation 5:

That a risk and legal assessment for the safe transport of body parts is conducted to ascertain how and if patients can have their limb released directly to them.

The Amputation Journey

3. Next Steps

It is recommended that SA Health considers developing an overarching state-wide guideline that outlines all elements of disposing, storing and returning body parts/tissue, including limbs, post amputation. In addition, to ensure local hospital staff understand their obligations and responsibilities, work instructions relevant to the clinical area are required e.g. Draft CALHN Organisation Wide Instruction 'Amputated Limb Storage for Aboriginal and Torres Strait Islander Peoples'.

Additional clinical/consumer resources will be required as part of implementation and include:

- A consent form which includes agreement that the patient/family will follow the recommendations related to storage, burial and not removing the body part from the container is developed
- A template that can be used to certify human tissue for the purpose of cremation is available
- A template for transporting human remains (if needed)
- A culturally appropriate patient information sheet.

Recommendation 2:

That SA Health and Local Health Networks develop and implement appropriate clinical guidance, consent procedures and relevant clinician resources for the disposal, storage and return of body parts, such as, limbs (overarching state-wide guidance as well as local work instructions).

Recommendation 6:

That culturally appropriate patient information sheets are developed with community.

Training and support for staff

Amputation is a distressing and life changing time of a person's life and patients and their family require sensitivity, empathy and understanding as they come to terms with what lays ahead. For Aboriginal and Torres Strait Islander patients there will be additional considerations which have been described throughout this paper. It is critical that training and support is available for clinicians and other staff who may be involved in counselling and/or supporting patients through their journey. Staff will require the relevant knowledge, skills, attitudes and confidence to have difficult and sensitive conversations around the amputation journey including the options for the removed limb.

Recommendation 7:

That training packages for staff are developed and implemented relevant to need.

In conclusion, it is acknowledged that these are difficult conversations for both the patient and the clinical staff. However, without it being a routine question asked as part of the consent process patients may not know if it is an appropriate question, or they may feel afraid to ask. Patients may not know that they have any choices about what happens to their limb. Through the development and implementation of a procedure/guideline it is hoped that we can start to 'normalise' the conversation and provide culturally safe options for people who would like their limb returned or for those patients who just want to be reassured that their limb will be treated with respect and dignity.



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References

- 1. Gibson, O., Eltridge, F., Luz, Z., Stewart, H., Westhead, S. & Brown, A. 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/reports/diabetes-indicators-strategy-2016-2020/contents/summary</u>> (2018).
- 3. Maddocks, I. & Rayner, R. Issues in palliative care for Indigenous communities. MJA, 17-19 (2003).
- Hanna, E. "What Do You Want to Do With the Leg?" A Critical Narrative Review of the Understandings and Implications of Disposal in the Context of Limb Amputations. SAGE Open, 1-8, doi:DOI: 10.1177/2158244019859953 (2019).
- 5. Australian and New Zealand Society for Vascular Surgery. Amputation <<u>https://www.anzsvs.org.au/pa-tient-information/amputation/</u>> (Accessed July 2022).
- 6. The Royal College of Pathologists of Australasia. Ethical and Legal Issues in Relation to the Use of Human Tissue in Australia and New Zealand (2018). <<u>https://www.rcpa.edu.au/getattachment/ad0d4af1-901a-4056-af05-56bbc06167c1/Ethical-and-Legal-Issues-in-Relation-to-the-Use-of.aspx</u>>.
- 7. Bedo, S. They stuffed up': How the hospital lost my mum's arm. news.com.au (2018). <<u>https://www.news.</u> com.au/lifestyle/real-life/news-life/they-stuffed-up-how-the-hospital-lost-my-mums-arm/news-story/ b64025cce74d0d5f65889bfbe28b207d>.
- 8. Gibson, A. & Sobonya, R. Patients Who Take Home Their SurgicalPathology Specimens: A Preliminary Study. Academic Pathology 6, 1-4 (2019).
- 9. Waran, E., O'Connor, N., Zubiar, Y. & May, P. 'Finishing up' on country: challenges and compromises. Royal Australasian College of Physicians, 1108-1111 (2016).
- 10. McGrath, P. 'I don't want to be in that big city; this is my country here':Research findings on Aboriginal peoples' preference to dieat home. Australian Journal Rural Health 15, 264-268 (2007).
- 11. NSW Government. Donation, Use and Retention of Tissue from Living Persons. (Ministry of Health, NSW, 2016).
- 12. SA Health. Clinical Directive for the Management of the Release of a Placenta for Private Use (2016). <<u>https://www.sahealth.sa.gov.au/wps/wcm/connect/d197e5004d5176dfbd91ff4c56539eed/Managa-ment+for+the+Release+of+a+Placenta+for+Private+Use_02062016.pdf?MOD=AJPERES&CACHEID=-ROOTWORKSPACE-d197e5004d5176dfbd91ff4c56539eed-nJcxYK6>.</u>
- 13. New Zealand Medical Indemnity Insurance. Removal of body parts and informed consent, <<u>https://nzmii.</u> <u>co.nz/fact-sheets/removal-of-body-parts-and-informed-consent/</u>></u>
- 14. Mercy Hospital. Return or disposal of koiwi tangata/body parts and tissue policy. (2019). <<u>https://www.mercyhospital.org.nz/assets/Policies/Return-or-Disposal-of-Nga-Wahanga-Tinana-Body-Parts-Tissue-and-Substances.pdf</u>>.
- 15. Government of South Australia. Transplantation amd Anatomy Act 1983. (1983). <<u>https://www.sahealth.</u> sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/legislation/transplantation+and+anatomy+act/transplantation+and+anatomy+act+1983>.
- 16. Government of South Australia. South Australian Public Health Act. (2011). <<u>https://www.legislation.</u> <u>sa.gov.au/lz?path=%2FC%2FA%2FSouth%20Australian%20Public%20Health%20Act%202011</u>>.
- 17. Government of South Australia. South Australian Public Health (Notifiable and Controlled Notifiable Conditions) Regulations. (2012). <<u>https://www.legislation.sa.gov.au/lz?path=%2FC%2FR%2FSouth%20</u> <u>Australian%20Public%20Health%20(Notifiable%20and%20Controlled%20Notifiable%20Conditions)%20</u> <u>Regulations%202012</u>>.
- 18. Government of South Australia. Burial and Cremation Act 2013. (2013). <<u>https://www.legislation.sa.gov.</u> au/_legislation/lz/c/a/burial%20and%20cremation%20act%202013/current/2013.20.auth.pdf>.
- 19. Government of South Australia. Burial and Cremation Regulations 2014. (2014). <<u>https://www.legislation.</u> <u>sa.gov.au/lz?path=%2FC%2FR%2FBurial%20and%20Cremation%20Regulations%202014</u>>.
- SA Health. Public Health (Human Remains) Fact Sheet: Burial of human remains on private property. (2017). <<u>https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/public+health/human+remains</u>>.

Page 18 | Supporting the culturally safe disposal, storage and return of the limb (or part thereof) for Aboriginal and
Torres Strait Islander patients undergoing amputation.



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.

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For more information

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