NT HEALTH

KIDNEY PLAN 2024–2029

NORTHERN TERRITORY GOVERNMENT

NT Health acknowledges the support and contributions of partner organisations and stakeholders in developing this Plan, particularly representatives from AMSANT, Menzies School of Health Research and Purple House. We also gratefully acknowledge the contribution and ongoing daily work of our clinical leaders throughout all regions of the NT and the Northern Territory Renal Clinical Network.

NT Health acknowledges the support and contribution of Professor JT Hughes in the developing of this Plan.

Professor Hughes brought an important and unique perspective to her contribution. She is a nephrologist working in the Territory, and Clinical Research Professor and an a proud Aboriginal woman of the Wagadagam tribe of Torres Strait who has lived in Larrakia Country (Darwin) since her childhood.

Acknowledgement of Country

NT Health respectfully acknowledges the Traditional Custodians of the Country on which we work and live throughout the Northern Territory. We recognise the deep connection Aboriginal people have with their lands, waters and communities. We pay our respects to Elders past and present whose ancestral land we provide health services upon. Throughout this document the term Aboriginal should be taken to include Torres Strait Islander people. The term Aboriginal has been used in recognition that Aboriginal people are the Traditional Owners of the Northern Territory.

CONTENTS

MINISTERIAL SUPPORTING STATEMENT 2

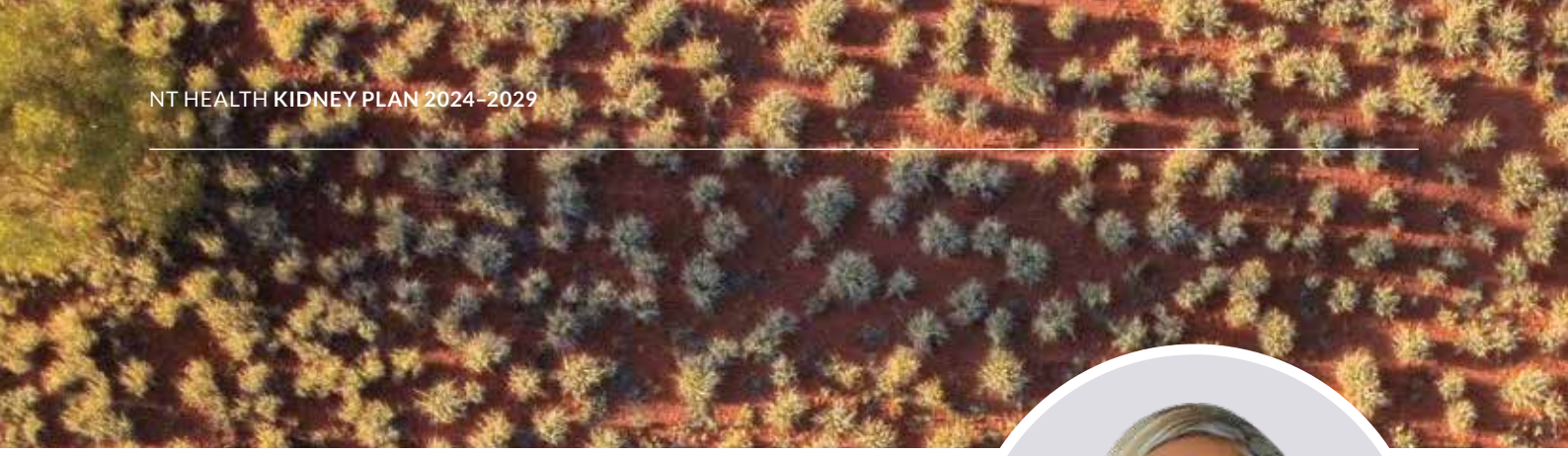
CHIEF EXECUTIVE SUPPORTING STATEMENT 3

INTRODUCTION 4

- How does this plan fit? 6
- Priority areas for action 8
- Context 10
  - *NT Renal Services*
  - *Chronic kidney disease (CKD)*
  - *Kidney disease in the NT: Our growing need*
  - *CKD contributing factors*
  - *Dialysis models of care*
  - *Our partnerships*

PRIORITIES 20

- Priority Area 1: Prevention, detection and health literacy
- Priority Area 2: Expanded models of care and support options
- Priority Area 3: Building renal support and workforce capacity
- Priority Area 4: Improved data and planning
- Priority Area 5: Kidney donation and transplantation



MINISTERIAL SUPPORTING STATEMENT

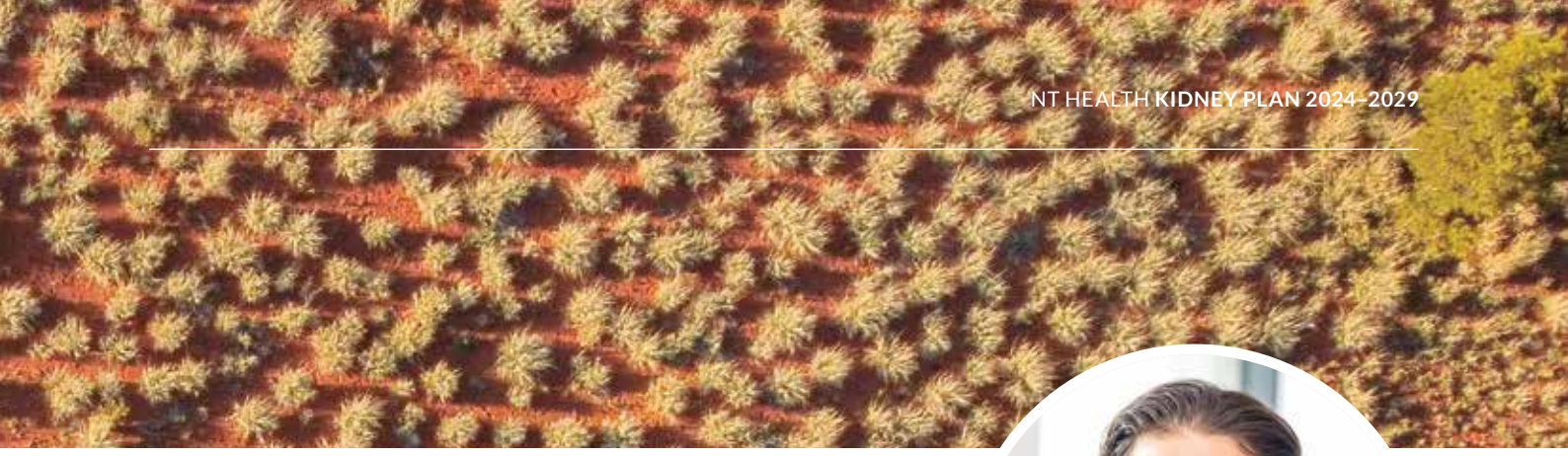
It is with great pride and a deep sense of responsibility that I introduce the new Kidney Plan 2024–2029 (the Plan) for the Northern Territory. Kidney disease is a silent yet devastating disease that disproportionately affects Territorians, particularly our Aboriginal population. The Plan represents our commitment to addressing this challenge and charting a path toward a healthier future and a system that lessens the impact of kidney disease on Territorians and their families.

We recognise the urgent need for a comprehensive approach that extends across prevention, management and the empowerment of our community to remain on Country. The Plan is a blueprint for this transformative journey.

To succeed, we will listen, engage and collaborate closely with communities, experts and stakeholders. Your voices will guide our decisions, ensuring the Plan is a collective endeavour for better health.

I would like to express my gratitude to our partners and the numerous individuals and organisations who have dedicated their time and knowledge to help shape this Plan and join us on this journey.

The Hon Selena Uibo MLA
Minister for Health



CHIEF EXECUTIVE SUPPORTING STATEMENT

Territorians are facing an unprecedented burden of kidney disease. With growing rates of chronic disease, especially diabetes, we expect to see rapid growth in the incidence and prevalence of chronic kidney disease over the coming years. NT Health's Kidney Plan 2024–2029 (the Plan) describes how we will partner and redesign our services and models of care to meet this growing clinical need.

We are committed to listening to Territorians with kidney disease and their families and communities to find better ways to prevent and manage the disease. This includes developing health literacy about prevention and improving understanding of treatment options such as kidney replacement therapy (haemodialysis and peritoneal dialysis), kidney transplantation, and supportive conservative management. These decisions require information, family and carer input, and an understanding of the social and cultural dislocation currently required for some treatments.

Our current models of care will not be able to meet the needs of the growing numbers of people needing kidney care and support. Redesigning and strengthening renal services requires us to work with openness and inclusivity with partnering organisations, communities and consumers. NT Health will undertake this at a regional level and work collaboratively to develop focused activities to respond to local needs.

This Plan sets out our high-level direction for the next five years to better support our systems and outcomes.

The NT Renal Clinical Network has been integral to the development of this Plan and will continue to oversee and guide its implementation. I thank them for their significant and vital contribution to building and planning services to deliver care as close to home as possible.

Dr Marco Briceno
Chief Executive Officer
NT Health

INTRODUCTION

The Northern Territory has the highest incidence and prevalence of kidney disease in Australia, at a rate 4 times higher than the national average. Aboriginal Territorians face a higher risk of developing kidney disease and subsequent mortality compared to non-Aboriginal Territorians.

The Plan focuses on providing greater access to care and more choices for how Territorians receive kidney care. The current context of workforce constraints, the rising prevalence of end stage kidney disease (ESKD) and the need for additional service capacity will require coordinated and collaborative efforts across government and non-government sectors and with consumers to achieve NT wide outcomes.

We are committed to making sure Territorians can get healthcare closer to home.

The Plan builds upon the achievements of the NT Health Renal Services Strategy 2017–2022 (NTRSS), which included positive outcomes such as enhanced service delivery through collaborations with various sectors, government services, and consumers. It also resulted in improved primary healthcare for chronic kidney disease (CKD), increased availability of dialysis services in regional and remote areas, and higher rates of kidney transplantation.

The Plan outlines specific steps that have been informed from the recommendations following the review of the NTRSS, which builds on the early successes of the Strategy, and improving health outcomes for Territorians.[1] These steps will be taken over the coming 5 years within various sectors, services, and the communities. It emphasises the necessity of collaborative partnerships involving Aboriginal Community Controlled Health Organisations (ACCHOs), government departments, service providers, communities, and their leaders throughout the Northern Territory. The goal is to collaborate on creative and innovative solutions in order to build upon successful renal service delivery and discover potential for new initiatives, services, and resources that promote cultural safety, create choices, and provide great health for all Territorians.

Our vision is for healthy kidneys for Territorians and more choices for those with kidney disease.

The foundation of the Strategy lies in the core principle of embracing cultural diversity. These principles are underpinned by the CARI Guidelines: Recommendations for Culturally Safe and Clinical Kidney Care for First Nations Australians. [2] NT Health acknowledges that creating a culturally inclusive environment hinges on mutual respect, building effective relationships, clear communication, shared expectations, and critical self-reflection. NT Health asserts that within such an inclusive setting, individuals of all cultural backgrounds can freely express their identities, opinions, and perspectives.

Inclusivity in practice is fluid and responsive. Cultural inclusiveness addresses and caters to the needs of individuals from diverse cultural backgrounds, while also recognising and appreciating their unique contributions. It entails continual efforts to raise awareness, where negotiations and compromises may be necessary. Simultaneously, individuals from diverse cultures must be supported in understanding the administrative and social norms of renal services. Above all, cross-cultural interactions should be seen as opportunities for mutual learning and growth.

1 *Northern Territory Renal Services Plan 2017–2022* Interim Review Report.
2 Recommendations for culturally safe kidney care for First Nations Australians. October 2022. CARI Guidelines.

Almost half of the Aboriginal population **aged over 50 years** in the NT have Chronic Kidney Disease or clinical biomarkers for Chronic Kidney Disease[3]

NT has the **highest proportion of population** receiving dialysis.

At the end of 2022 approximately **850 Territorians** were receiving haemodialysis treatment; **89%** of these people were Aboriginal[1]

3 Prevalence of chronic diseases in the Northern Territory, 2019 Health Statistics and Informatics, NT Health Page 3 of 7.

HOW DOES THIS PLAN FIT?

This Plan directly links to the following elements of *NT Health Strategic Plan 2023–28*:

- Keeping our population well to reduce demand on health care services and focus on prevention
- Empowering Territorians to improve health literacy through the availability of information and data
- Adopting new models of care that provide efficient, consistent and safe services to reflect best practice and contextually applied evidence-based care
- Harnessing technology to help overcome the physical and financial barriers of distance, and to improve decision making
- Establishing workforce solutions to improve the retention of skilled staff, attract talent and introduce new ways of working
- Building on our partnerships within communities, government and non-government organisations, particularly with the ACCHOs to address inequalities in remote areas
- Ensuring value and that "what matters to patients" is the basis for how care is provided.

This Plan also aligns with the National Strategic Action Plan for Kidney Disease.[4]

This Plan sets the direction for the development of annual action plans that will identify key actions and activities required within each region to achieve the outcomes of this Plan.

NT Health Strategic Plan 2023–2028

Provides the vision, outcomes and four strategic focus areas

Clinical Services Plan

Sets the direction and priorities for clinical services investment and design

Kidney Plan 2024–2029

Provides strategic guidance on priorities and outcomes for whole of NT kidney care

Annual action plan

Identify collaborative action with regional stakeholders and locally responsive activities to achieve the outcomes of the Kidney Plan

4 Kidney Health Australia 2019. *National Strategic Action Plan for Kidney Disease*.

PRIORITY AREAS FOR ACTION

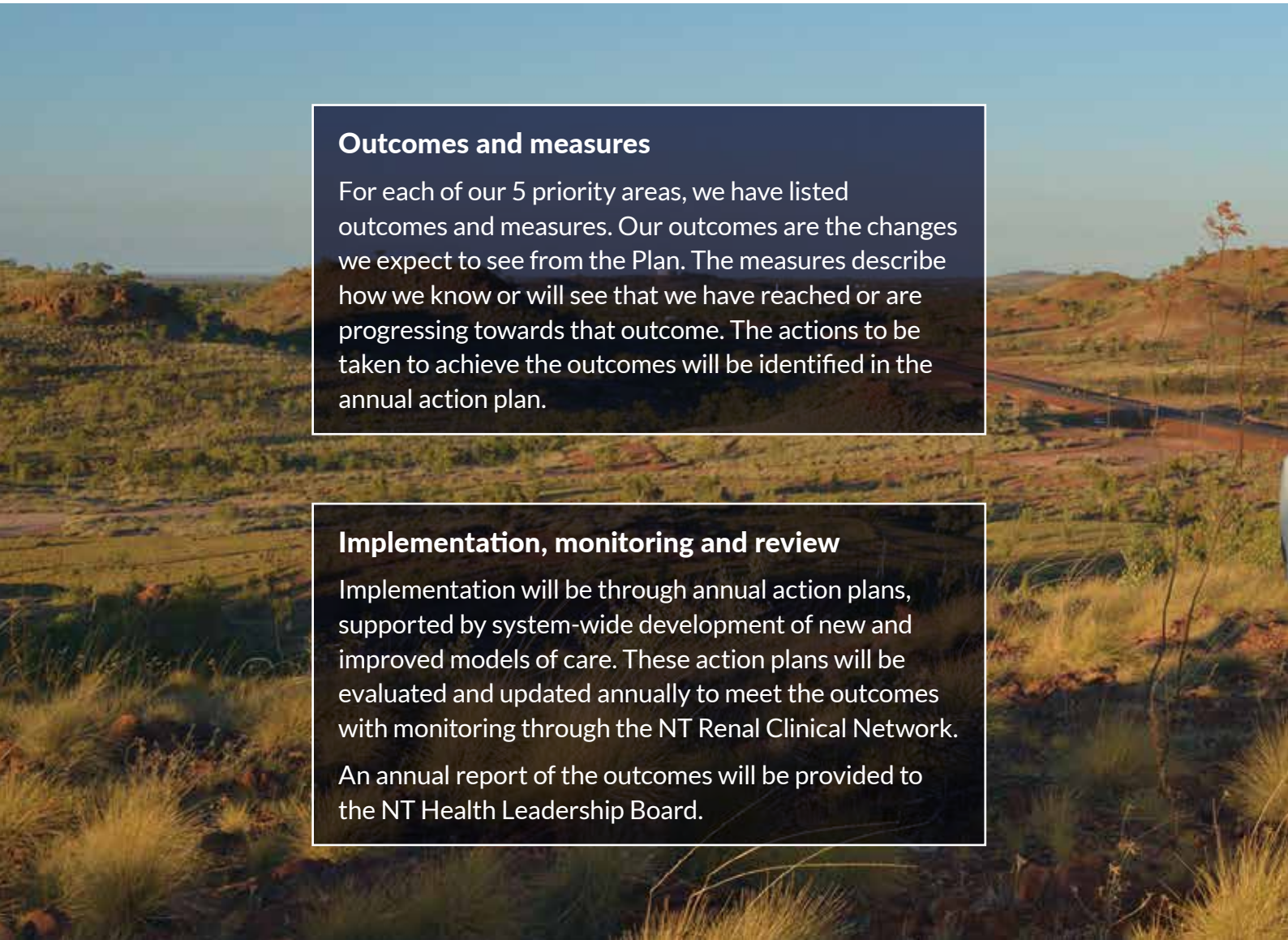
1
Prevention, detection and health literacy

2
Expanded models of care and support options

3
Building renal support and workforce capacity

4
Improved data and planning

5
Kidney donation and transplantation



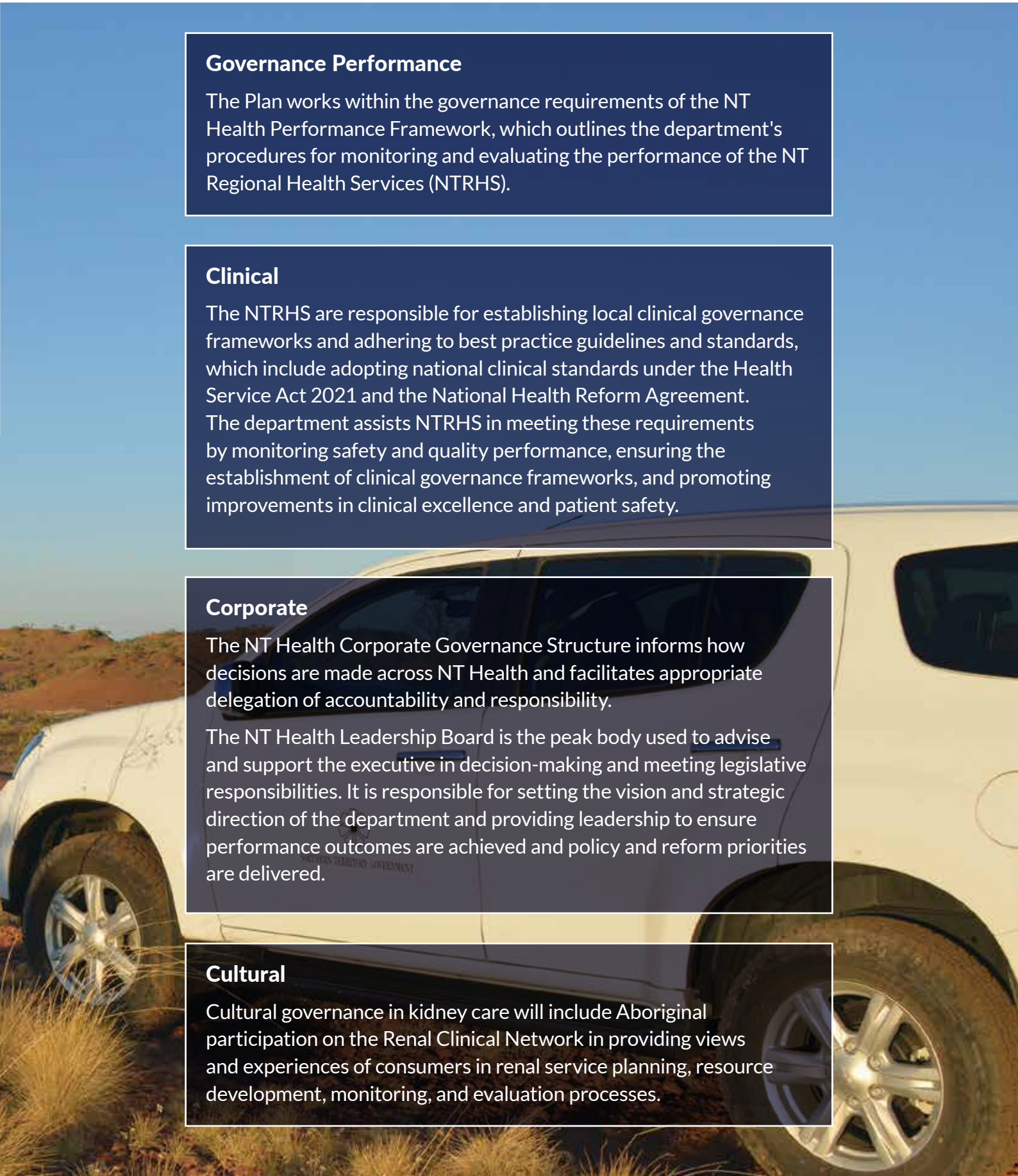
Outcomes and measures

For each of our 5 priority areas, we have listed outcomes and measures. Our outcomes are the changes we expect to see from the Plan. The measures describe how we know or will see that we have reached or are progressing towards that outcome. The actions to be taken to achieve the outcomes will be identified in the annual action plan.

Implementation, monitoring and review

Implementation will be through annual action plans, supported by system-wide development of new and improved models of care. These action plans will be evaluated and updated annually to meet the outcomes with monitoring through the NT Renal Clinical Network.

An annual report of the outcomes will be provided to the NT Health Leadership Board.



Governance Performance

The Plan works within the governance requirements of the NT Health Performance Framework, which outlines the department's procedures for monitoring and evaluating the performance of the NT Regional Health Services (NTRHS).

Clinical

The NTRHS are responsible for establishing local clinical governance frameworks and adhering to best practice guidelines and standards, which include adopting national clinical standards under the Health Service Act 2021 and the National Health Reform Agreement. The department assists NTRHS in meeting these requirements by monitoring safety and quality performance, ensuring the establishment of clinical governance frameworks, and promoting improvements in clinical excellence and patient safety.

Corporate

The NT Health Corporate Governance Structure informs how decisions are made across NT Health and facilitates appropriate delegation of accountability and responsibility.

The NT Health Leadership Board is the peak body used to advise and support the executive in decision-making and meeting legislative responsibilities. It is responsible for setting the vision and strategic direction of the department and providing leadership to ensure performance outcomes are achieved and policy and reform priorities are delivered.

Cultural

Cultural governance in kidney care will include Aboriginal participation on the Renal Clinical Network in providing views and experiences of consumers in renal service planning, resource development, monitoring, and evaluation processes.

CONTEXT

NT Renal Services

NT Health oversees the Northern Territory's public healthcare system, which encompasses the Regional Health Services.

The public health system comprises six public hospitals, with two located in Greater Darwin, and one each in Alice Springs, Tennant Creek, Katherine, and Gove.

Additionally, NT Health delivers community care through 39 primary healthcare centres and supports 133 clinics/services run by Aboriginal Community Controlled Health Organisations throughout the NT.

The current Renal Service within the NT public health sector operates on a hub and spoke model, with the Royal Darwin Hospital (RDH) serving as the hub for the Top End, Big Rivers and East Arnhem Regional Health Services and the Alice Springs Hospital as the hub for the Central Australia and Barkly Regional Health Services. This model facilitates a structured and sustainable transition for renal patients from acute facilities to community-based care, whether in urban or remote areas. The service hubs manage acute care services such as assessment, investigation, and intervention, and coordinate the management of renal patients along the continuum of care in collaboration with healthcare professionals from community and remote services.

ACCHOs play a primary role in preventing and managing kidney damage and disease within Aboriginal communities, with some partnering in the provision of dialysis services in remote areas. Additionally, there is interest and private sector involvement in the delivery of dialysis services in the Northern Territory.

The government directives during the COVID-19 public health emergency significantly affected health service delivery in the NT. One of the initial challenges was the limited availability of the workforce. In response, health services devised various strategies to ensure the ongoing provision of essential and urgent care, including renal services. These strategies encompassed the recruitment of generalist nurses and providing them with workplace support for on-the-job training, along with an expanded use of telehealth clinical services.

RENAL SERVICES AVAILABLE IN THE NORTHERN TERRITORY

Top End, Big Rivers and East Arnhem Regional Health Services

- Dedicated renal ward
- Acute haemodialysis and therapeutic plasma exchange
- Nightcliff satellite unit
- Palmerston satellite unit
- Tiwi Islands satellite unit
- Home haemodialysis training
- Drop in centre for home haemodialysis
- Renal ready rooms in community for home haemodialysis
- Peritoneal dialysis
- Transplantation
- Chronic kidney disease management
- Allied Health Services
- Conservative Care

Central Australia and Barkly Regional Health Services

- Dedicated renal ward
- Acute haemodialysis and therapeutic plasma exchange
- Flynn Drive satellite unit
- Tennant Creek renal unit
- Drop in centre for home haemodialysis
- Renal ready rooms in community for home haemodialysis
- Peritoneal dialysis
- Transplantation
- Chronic kidney disease management
- Allied Health Services
- Conservative Care

Partner Renal Services

Fresenius Kidney Care

- Private/public partnership – Katherine & Alice Springs

Purple House

- Respite Nurse Assisted Haemodialysis - Alice Springs & various remote communities throughout the NT.

Chronic kidney disease

Chronic kidney disease (CKD) leads to a gradual loss of kidney function. There are many causes of CKD including diabetes and high blood pressure, inherited conditions, inflammation of the kidney and recurrent infections, with diabetes being the leading cause nationally.

There are 5 recognised stages for CKD. A person's degree of functional loss can gradually progress to kidney failure.[5] End stage kidney disease (ESKD) occurs when the kidneys no longer function at the level required to sustain life. To prolong life, kidney replacement therapy (KRT) is then required. KRT includes dialysis (haemodialysis and peritoneal dialysis) or kidney transplantation.

Across Australia, around 860,000 people between the ages of 40 and 79 have stages 2–4 CKD. Of these, 780,000 are believed to be undiagnosed, and 51% of the population is thought to have additional cardiovascular disease or diabetes risk factors.[6]

It is possible to identify many people in the early stages of the disease and provide intervention and best practice care to halt or slow the progression of their disease. This can occur through kidney health checks and targeted screening and detection of those at high risk of CKD (patients with macroalbuminuria and comorbidities of diabetes and cardiovascular disease). Early identification and intervention can also decrease cardiovascular disease events, ESKD mortality, lower expenditure in the health system and reduce the burden of disease on individuals and communities.[6]

Table 1: Incidence of kidney failure with replacement therapy by modality and jurisdiction (per million people) 2021

State	Total Incident KRT Patients	Incident KRT Dialysis Patients	Pre-Emptive Transplant Patients
QLD	706 (135)	691 (132)	15 (3)
NSW*	955 (120)	933 (117)	22 (3)
ACT*	71 (106)	71 (106)	0 (0)
VIC	769 (116)	743 (112)	26 (4)
TAS	58 (107)	58 (107)	0 (0)
SA	236 (133)	224 (126)	12 (7)
NT	**118 (479)**	**118 (479)**	**0 (0)**
WA	368 (137)	361 (135)	7 (3)
Australia	**3281 (127)**	**3199 (124)**	**82 (3)**
New Zealand	708 (137)	669 (129)	39 (8)

*ACT and NSW population estimates adjusted for SE NSW Region.

Source; ANZDATA Registry. 45th Report, Chapter 1: Incidence of Kidney Failure with Replacement Therapy, Table 1.2. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2022.

5 Kidney Health Australia, https://kidney.org.au/your-kidneys/what-is-kidney-disease, accessed 19 April 2023.

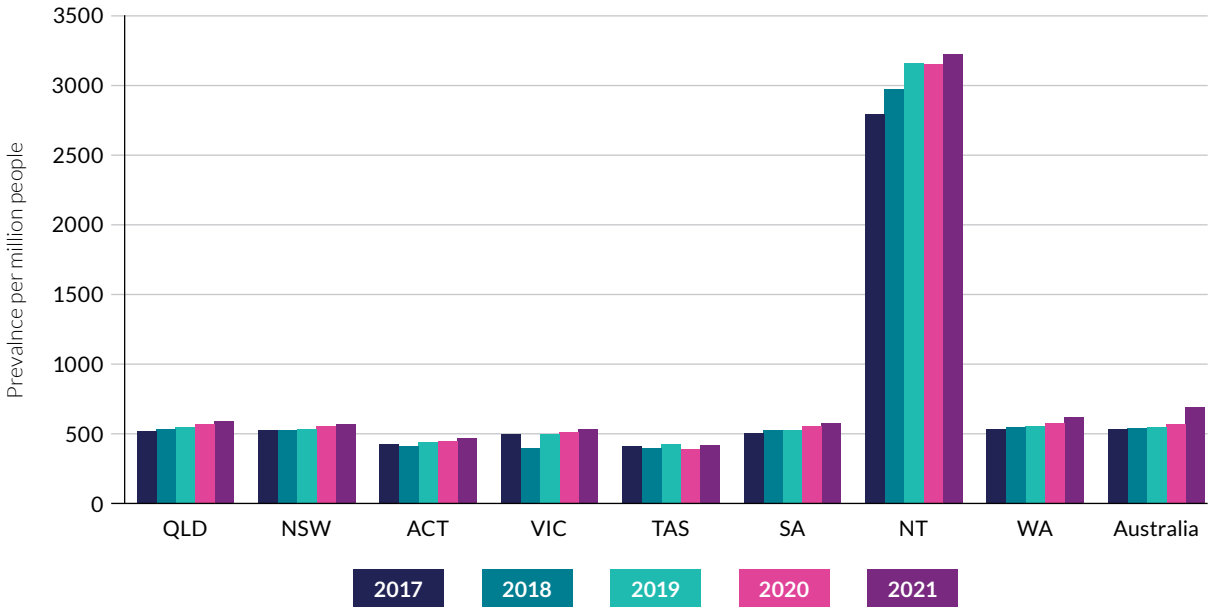
6 Deloitte Access Economics, *Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment* (report commissioned by Kidney Health Australia, February 2023).

Kidney disease in the NT: Our growing need

The NT has the highest incidence and prevalence of kidney disease in Australia. In 2021 the incidence rate for KRT per million people was 479 in NT, compared with 127 across Australia.[7]

In 2017-2021, the prevalence of dialysis (per million people) was also much higher in NT than other states.

Figure 1: Prevalence per million people of dialysis by State/Territory 2017–21



Source: ANZDATA Registry. 45th Report, Chapter 2: Prevalence of Kidney Failure with Replacement Therapy , Table 2.4. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2022.

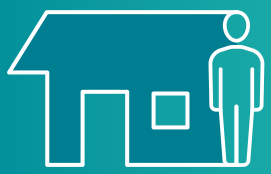
The lack of population representative data regarding incidence and prevalence of CKD and the rapidly growing burden of risk factors including diabetes and obesity happening at a younger age creates significant challenges to accurately predict future need. However, it is evident that the incidence of ESKD in NT Aboriginal populations will continue to grow. Our current models of care are not clinically, culturally or socially suited to manage ongoing and rapid increases in the number of people requiring treatment for ESKD.

7 ANZDATA Registry. 45th Report, *Chapter 1: Incidence of Kidney Failure with Replacement Therapy*. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2022. Available at: http://www.anzdata.org.au

CKD CONTRIBUTING FACTORS

Risk factors for CKD

- Family history of CKD
- Older age
- Diabetes
- Hypertension
- Obesity
- Smoking
- Established cardiovascular disease
- Medical histories of low birth weight



Social determinants of health

- Access to services (remoteness)
- Socioeconomic status
- Housing quality and security
- Employment opportunities
- Educational level attainment
- Food security
- Impact of generational colonisation

Strength-based cultural determinants of health and wellbeing

- Inclusion in decision making on health service design and development
- Access to culturally safe and relevant health services
- Access to health literacy resources in local languages
- Access to health services provided by Aboriginal health workers

Diabetes is the leading cause of CKD across Australian jurisdictions. Diabetes prevalence in adults 2018–2019 in Central Australia was 39.5%, and 24% in the Top End of NT.[8] People in remote Aboriginal communities have among the highest prevalence of diabetes recorded in any population worldwide.

Cardiovascular disease is the leading cause of morbidity and mortality in patients with CKD. Cardio-renal-metabolic conditions are interconnected disorders, including cardiovascular disease, CKD and type 2 diabetes. Diseases affecting one of these systems often exert negative effects on the others. Similarly, when a positive adjustment is made to one system it can have a favourable effect on the others. It is best practice to adopt integrated care strategies to address comorbidities and risk factors across all 3 systems, rather than treat single conditions in isolation.

The cause of the very high rate of CKD in Aboriginal people in the NT is multifactorial and significantly linked to social and economic disadvantage, which impacts on health outcomes.[9] Unstable living conditions and limited access to appropriate housing, health, employment and social services are well established risk factors in our remote and very remote communities. The National Agreement on Closing the Gap,[10] commits all governments to decrease mortality and morbidity gaps between Aboriginal and non-Aboriginal people. The Agreement requires action to address the social determinants of health and support the cultural determinants of health through Aboriginal people having a genuine say in how the services they use are designed and delivered.

Improving access to health services is more than just making them closer. It also includes addressing the viability of access based on cultural safety, responsiveness, shared communication and an understanding of a person's life and worldview. Culturally, people who remain close to kin and Country fare far better than people who have no options other than to relocate to urban areas to access dialysis.[11] This has been recently recognised through the advocacy for and development of a Medicare item number for assisted haemodialysis on Country.

Kidney replacement options in NT

Kidney transplant

Kidney transplant is the most cost effective and suitable therapy for many people with ESKD. Work-up for kidney transplant involves several components, a variety of practitioners and teams, and is completed over a period of time. Multiple barriers to transplant exist for Territorians including geographic location, infrequency of interstate transplant team visits to NT, and patients' complex health conditions that require medical intervention such as management of diabetes, heart disease, dental care, weight reduction interventions, smoking and alcohol use management.[12]

It is acknowledged that Aboriginal Territorians in remote areas have reduced access to timely waitlistings for transplants. While there has been an increase in the overall rates of waitlisting and transplantation among Aboriginal Territorians, significant disparities persist in comparison to non-Aboriginal people.[13] This Plan will be guided by the recommendations of the National Indigenous Kidney Transplantation Taskforce to ensure equitable outcomes for all Territorians.[14]

8 Hare MJL, Zhao Y, Guthridge S, et al. *Prevalence and incidence of diabetes among Aboriginal people in remote communities of the Northern Territory, Australia: a retrospective, longitudinal data-linkage study.* BMJ Open 2022;12:e059716. doi:10.1136/ bmjopen-2021-05971.

9 KHA-CARI guideline: *KHA-CARI adaptation of the KDIGO Clinical Practice Guideline for Acute Kidney Injury.* Langham RG1, Bellomo R, D' Intini V, Endre Z, Hickey BB, McGuinness S, Phoon RK, Salamon K, Woods J, Gallagher MP. Nephrology (Carlton). 2014 May;19(5):261-5. doi: 10.1111/nep.12220.

10 https://www.closingthegap.gov.au/national-agreement

11 Australian Institute of Health and Welfare (2022) *Indigenous Australians and the health system*, AIHW, Australian Government.

12 Final Report: the National Indigenous Kidney Transplantation Taskforce . https://www.nikkt.com.au/finalreport

13 Advancing accessible kidney transplantation for Aboriginal and Torres Strait Islander people: the National Indigenous Kidney Transplantation Taskforce https://www.mja.com.au/journal/2023/219/8/supplement

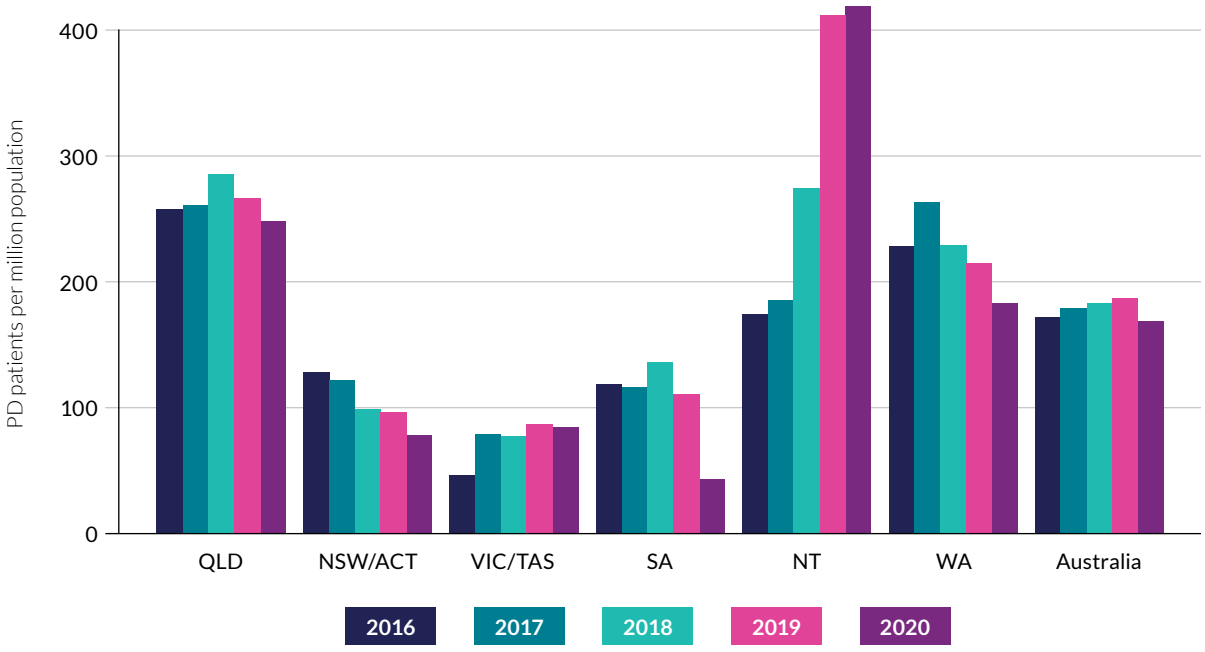
14 Final Report: the National Indigenous Kidney Transplantation Taskforce

Dialysis models of care

Haemodialysis is the most common form of KRT in NT. At the end of 2022, approximately 850 Territorians were receiving haemodialysis treatment, with 89% of these people identifying as Aboriginal.[15] Service delivery share of haemodialysis fluctuates; in January 2022 it was 70% NT Health, 24% private-public partnerships and 6% community controlled.[16]

While there are challenges for many people in being able to undertake peritoneal dialysis (PD), many Territorians have been successful in choosing this option and avoiding permanent relocation. NT showed an increase in PD over 2018–2020, and in 2020 recorded the highest national prevalence rate for PD.[17] Numbers of people using PD since 2020 have decreased, however PD is still a viable option for self-management of dialysis in remote areas. Whilst PD is a good option initially, in most longer term cases people will need to transition to HD in under 5 years.

Figure 2: Prevalent Indigenous Australian peritoneal dialysis patients



Source; ANZDATA Registry. 44th Report, Chapter 10: Kidney Failure in Aboriginal and Torres Strait Islander Australians, Figure 10.21. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2021.

15 *Northern Territory Renal Services Plan 2017–2022* Interim Review Report.
16 Majoni, Dr. W. 2023. NT Renal data statistics [PowerPoint presentation]. NT Health Renal Planning Day, 23 January 2023, Building Red 9, CDU Campus Casuarina NT.
17 ANZDATA Annual Report 2021 - *Chapter 10 – End Stage Kidney Failure in Aboriginal and Torres Strait Islander Australians.*

There are currently 7 described dialysis models of care (MoC) in the NT with many people having dialysis in hub services in hospitals, urban satellite units, or rural satellite units.

Table 2: Dialysis services in the NT characterised as Dialysis Models of Care[18]

Dialysis Model	Description	Characteristics
DxMoC0 Incentre dialysis	Hub service: situated in tertiary centre: acute and maintenance haemodialysis	Majority of patients commence treatment here: used for complex patients and overflow from satellite centres
DxMoC1 Urban Satellite Unit	Large facilities in urban areas: maintenance haemodialysis	All patients stabilised here: default service when rural and remote services at capacity
DxMoC2 Rural Satellite Unit	Smaller facilities: often co-located with regional hospitals: maintenance haemodialysis	Usually for stable patients: generally a waiting list
DxMoC3 Remote Satellite Unit	Small units isolated from hub by distance or geography: maintenance haemodialysis	Generally reserved for clinically well, physically mobile patients: generally a waiting list
DxMoC4 Remote CC Satellite Unit[a]	Aboriginal owned and determined; small remote based units providing permanent and respite dialysis with social support	Patient acceptance criteria less restrictive as more support services available: generally a waiting list
DxMoC5 SC HD[b]	Training and support for independent haemodialysis	Clinically stable, deemed capable and safe to deliver own care
DxMoC6 SC PD[c]	Training and support for independent peritoneal dialysis	Clinically stable, deemed capable and safe to deliver own care

[a]CC Community Controlled, [b]SC HD Self care haemodialysis, [c]SC PD Self care peritoneal dialysis

18 Gorham, G., Howard, K., Cunningham, J. et al. *Do remote dialysis services really cost more? An economic analysis of hospital and dialysis modality costs associated with dialysis services in urban, rural and remote settings*. BMC Health Serv Res 21, 582 (2021). https://doi.org/10.1186/s12913-021-06612-z.

The primary focus of action for the next 5 years is to increase ESKD care options in remote areas and allow greater independence and choice for consumers. This will require shifting resources to increase supports that are needed for home therapies and assisted dialysis.

Dialysis in the home (also known as home therapies) is administered by the patient and/or a carer enabling people to remain in their own home or on Country, connected to kin and culture. In recent years, for Aboriginal Territorians dialysis in the home has predominately been provided through peritoneal dialysis. Some self-haemodialysis units have been set up in NT remote communities, yet the uptake of this model is low. In February 2022, there was 9% self-dialysis and 91% nurse assisted dialysis[19] which was similar to national rates.[20]

Nurses have traditionally provided assisted dialysis, but this is becoming less viable due to national workforce shortages, which is further exacerbated in remote and regional areas.

This Plan identifies the important role of community members supporting assisted dialysis to widen the scope for innovative MoC and service and developing meaningful partnerships.

19 Majoni, Dr. W. 2023. NT Renal data statistics [PowerPoint presentation]. NT Health Renal Planning Day, 23 January 2023, Building Red 9, CDU Campus Casuarina NT.

20 ANZDATA Registry. 45th Report, Chapter 2: Prevalence of Kidney Failure with Replacement Therapy, Table 2.8. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2022.

Our partnerships

NT Health renal specialist services provide the underpinning support and medical supervision for people living with CKD and KRT across the NT. These speciality services partner with NT primary health care centres, urban and remote ACCHOs and GP practices to provide quality primary health and speciality care in prevention and management of CKD and related risk factors.

Dialysis services are provided directly by NT Health with public and private partners, and with Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (Purple House) in both urban and remote area dialysis.

Purple House has provided remote area dialysis for over 2 decades. Purple House services commenced in Central Australia, but in recent years they have established remote area renal units in partnership with NT Health and ACCHOs in the Top End. Purple House also provides wrap around services that include aged care, the National Disability Insurance Scheme (NDIS), primary health and social support services for people who have had to relocate for dialysis.

Fresenius Kidney Care operates dialysis clinics in Alice Springs and Katherine through a public-private partnership service delivery model within NT Health.

Baxter International Inc is the current supplier of dialysis products to NT Health dialysis services, including home therapies.

Menzies School of Health Research renal program has a focus on research into improving the renal health pathway. In partnership with the Northern Territory Government, Aboriginal Medical Services Alliance Northern Territory (AMSANT) and Northern Territory Primary Health Network (NTPHN) they have built an integrated clinical decision support tool for early CKD identification and management, named Territory Kidney Care (TKC). TKC aims to improve the integration of health data across disconnected health systems, facilitate efficiencies in data collation and analysis, and implement evidence-based protocols to enhance the patient journey and reduce the burden of CKD in the NT. As a clinical decision support system, TKC:

- improves the quality and comprehensiveness of data available to all clinicians providing care to a patient
- creates efficiencies in workflows through automated identification and summarisation
- assists GPs and remote-based clinicians with specialist support for the management of complex conditions
- assists with decreasing the rates of unplanned hospital admissions related to kidney disease
- provides comprehensive and robust data for advocacy, service planning and understanding resource demand.

ACCHOs are primary health care services situated throughout the NT, accountable to and operated by their local Aboriginal communities. They deliver holistic, comprehensive, and culturally appropriate primary health care. ACCHOs work with an understanding of the socio-economic inequities Aboriginal people experience which contribute to poor health outcomes including the risk factors for CKD and related chronic conditions. ACCHOs support the social, emotional, physical and cultural wellbeing of individuals, families and communities focusing on strength-based cultural determinants of health and action on the social determinants of health.

PRIORITY AREA 1

Prevention, detection and health literacy

The Territory's health system is facing long term challenges in addressing the growing prevalence and impacts of chronic diseases such as kidney disease. Non-communicable diseases are responsible for 70% of the gap in Aboriginal life expectancy.[21]

The burden of chronic conditions such as diabetes, heart, lung and kidney disease is more than 5 times greater than the Australian average for Aboriginal people in the NT.[22] Hospitalisation rates due to preventable chronic conditions are 4 times higher among Aboriginal Territorians.[23] Among those, 55.7% of Aboriginal people and 35.1% of non-Aboriginal people have multiple chronic conditions.[24]

Social and environmental conditions put populations at greater risk of chronic conditions. By addressing conditions that include housing, access to culturally safe and relevant health services, food security, education and employment opportunities, we can significantly reduce the burden of chronic diseases, including kidney disease on Territorians and our community.

The renewed NT Prevention and Early Intervention Framework for Chronic Conditions will drive cross-sector action to address this.

To reduce the impact of kidney disease on patients, their families and carers, and to maintain a sustainable health system, it is vital that we prevent as many Territorians as possible from developing kidney disease, and from progressing to the later stages of kidney disease. This will involve improving health literacy for our community about risk factors, regular checkups and ways to slow the decline in kidney functioning. Aboriginal Territorians and ACCHOS are best placed to lead the development of resources to increase community knowledge about prevention and management.

21 Theo Vos, Bridget Barker, Stephen Begg, Lucy Stanley, Alan D Lopez, Burden of disease and injury in Aboriginal and Torres Strait Islander Peoples: the Indigenous health gap, International Journal of Epidemiology, Volume 38, Issue 2, April 2009, Pages 470–477.
22 *Zhang X, Zhao Y, Guthridge S. Burden of Disease and Injury Study: impact and causes of illness, injury and death in the Northern Territory, 2004-2013. Department of Health, Darwin, 2018.*
23 Zhang X, Zhao Y. Potentially preventable hospitalisations in the Northern Territory 2005-06 to 2017-18. Department of Health, Darwin, 2021.
24 NT Health, Health Statistics and Informatics, Prevalence of chronic diseases in the Northern Territory, 2019. Fact Sheet.

No.	Outcome	Measure/Indicator
1.1	A documented Territory-wide approach to the prevention of chronic conditions with a strong emphasis on kidney disease, diabetes and cardiovascular disease agreed by NT Health, ANSAMT and NTPHN.	> Implementation of new NT Chronic Conditions Prevention and Management Framework > Consistency across NT guideline management algorithms (NT Health Pathways, Central Australian Rural Practitioners Association Standard Treatment Manual, CARI Guidelines, TKC and hospital guidelines)
1.2	Earlier detection and enhanced management of kidney disease and slowing disease progression	> Reduced rate of progression from CKD stages 1 and 2 to stage 5 > 90% people at risk of CKD undergo regular screening in a 24-month period > Improved NT Aboriginal Health Key Performance Indicators (NTAHKPI) screening rates for CKD, blood pressure and diabetes (1.10, 1.14, 1.18)
1.3	Improved community health literacy and ability to self-manage chronic kidney disease	> Number of community developed tools and Aboriginal language tools available about kidney disease
1.4	Improved knowledge and skills of primary care clinicians in detection and early management of kidney disease and its risk factors	> Uptake of TKC by primary care clinicians and renal teams > Annual review and promotion of renal NT Health Pathways by NT Renal Clinical Network partners
1.5	Clinical care pathways that support integrated chronic disease management are accessible and widely used across the health system	> 90% of clinical referrals to nephrologists align with agreed NT CKD pathways > 90% of people with CKD stages 4–5 and those on KRT have biannual primary care reviews

PRIORITY AREA 2

Expanded models of care and support options

Access to renal services remains challenging due to the demographics of the NT, with a small, culturally diverse population dispersed over a vast geographical area.

Care closer to home for kidney care and dialysis services refers to a tiered hierarchy of choices about where care is provided and by whom.
This involves:

- *Locations:* urban, regional centres, remote and very remote communities
- *Facilities:* homes, community dialysis units, primary health care renal ready rooms, regional centre satellite dialysis unit and hospital based renal unit services
- *Assisted by* self, carer, community workers, Aboriginal and Torres Strait Islander health practitioner (ATISHP) or Aboriginal and Torres Strait Islander health worker (ATISHW), remote area nurse, dialysis nurse
- *Method of support:* face to face; phone; video telehealth; remote monitoring devices

The Dialysis Model of Care Study[25] describes the range of current dialysis options in the NT from a quality and economic perspective. There are significant health and economic consequences for patients who have to relocate for dialysis treatment. This relocation results in low dialysis attendance and high hospital costs. There is also the full cost gap between regional and remote models, when the full needs of the patient beyond the dialysis treatment itself are considered.

A Medicare item incentivises provision of ATISHP, ATISHW and registered nurse assisted dialysis in remote settings, on behalf of a medical practioner.

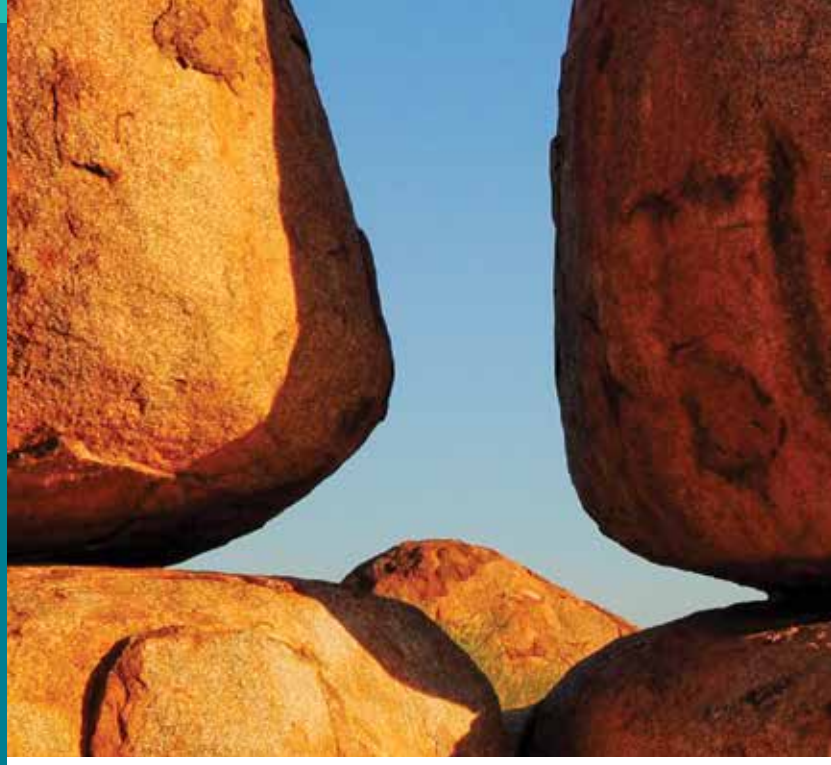
As patients with CKD progress toward ESKD they, and their families, require significant engagement, support and information on treatment options. Making decisions about the modality and suitability of KRT including the option of supportive or palliative care is challenging. For some people, particularly the older people or those with multi-morbidity, KRT may not be the preferred option. For this group of people and those who later in their KRT journey decide to cease therapy, it is critical that there are support pathways to manage symptoms and support decision making and care.

Home therapies (self/carer administered haemodialysis or peritoneal dialysis) enables people to remain on Country which is of significant cultural importance to Aboriginal Territorians. Supporting patients to choose home dialysis is a process that requires detailed and culturally appropriate assessment and resources to address possible barriers. These may include a suitable venue to undergo self-dialysis if home is not suitable. Working with communities to better support dialysis in remote settings through a hybrid model which is a mix of self, assisted and clinician led dialysis. This is critical for the provision of safe and culturally appropriate dialysis.

Our challenge is to work with Territorians to provide as much care as possible in their local communities, regional centres, health care centres or homes and to provide more choices. We will do this by piloting community kidney hubs where people can be supported in a range of ways to undertake a hybrid model of dialysis with virtual or onsite clinical and allied health support, matched to their individual needs. These hubs will support health literacy and the different management choices over a person's individual journey.

25 Gorham G, Howard K, Cunningham J, Barzi F, Lawton P, Cass A. *Do remote dialysis services really cost more? An economic analysis of hospital and dialysis modality costs associated with dialysis services in urban, rural and remote settings.* BMC Health Serv Res. 2021 Jun 17;21(1):582. doi: 10.1186/s12913-021-06612-z. PMID: 34140001; PMCID: PMC8212525.

No.	Outcome	Measure/Indicator
2.1	People with kidney disease have access to primary care support and management throughout their journey	> Care plans are adjusted to include primary care and specialist input for all people with kidney disease across all levels of care and include quarterly primary care clinic review for their holistic health and wellbeing needs and care
2.2	Dialysis appointments are fully utilised	> 10% annual decrease in missed dialysis, deferment and cancellation rates by region
2.3	Transition to care programs focus on individualised mapping of support needs to enable people to dialyse in supported community hubs	> 20% of CKD patients having dialysis in their community (through home dialysis or community kidney hub)
2.4	Community kidney hubs support people to dialyse with individualised support in community settings	> 10% annual increase in home therapies patients (self/ carer/community worker dialysis)
2.5	Patients have the knowledge and support required to make informed choices about ESKD care	> Feedback indicates that 80% of patients and their families understand their treatment options, and that a shared decision has been made about goals of care > Percentage of late referred (who commence KRT within 3 months of first renal consultation)
2.6	Culturally safe supportive care (not KRT) is available to those who choose this management pathway	> Development and implementation of a renal supportive care clinical guideline
2.7	Newly built dialysis facilities are designed to accommodate self-dialysis, "community kidney worker" assisted dialysis and nurse assisted dialysis onsite and through virtual care	> Newly built dialysis facilities are able to provide dialysis modalities to meet patient need



PRIORITY AREA 3

Building renal support and workforce capacity

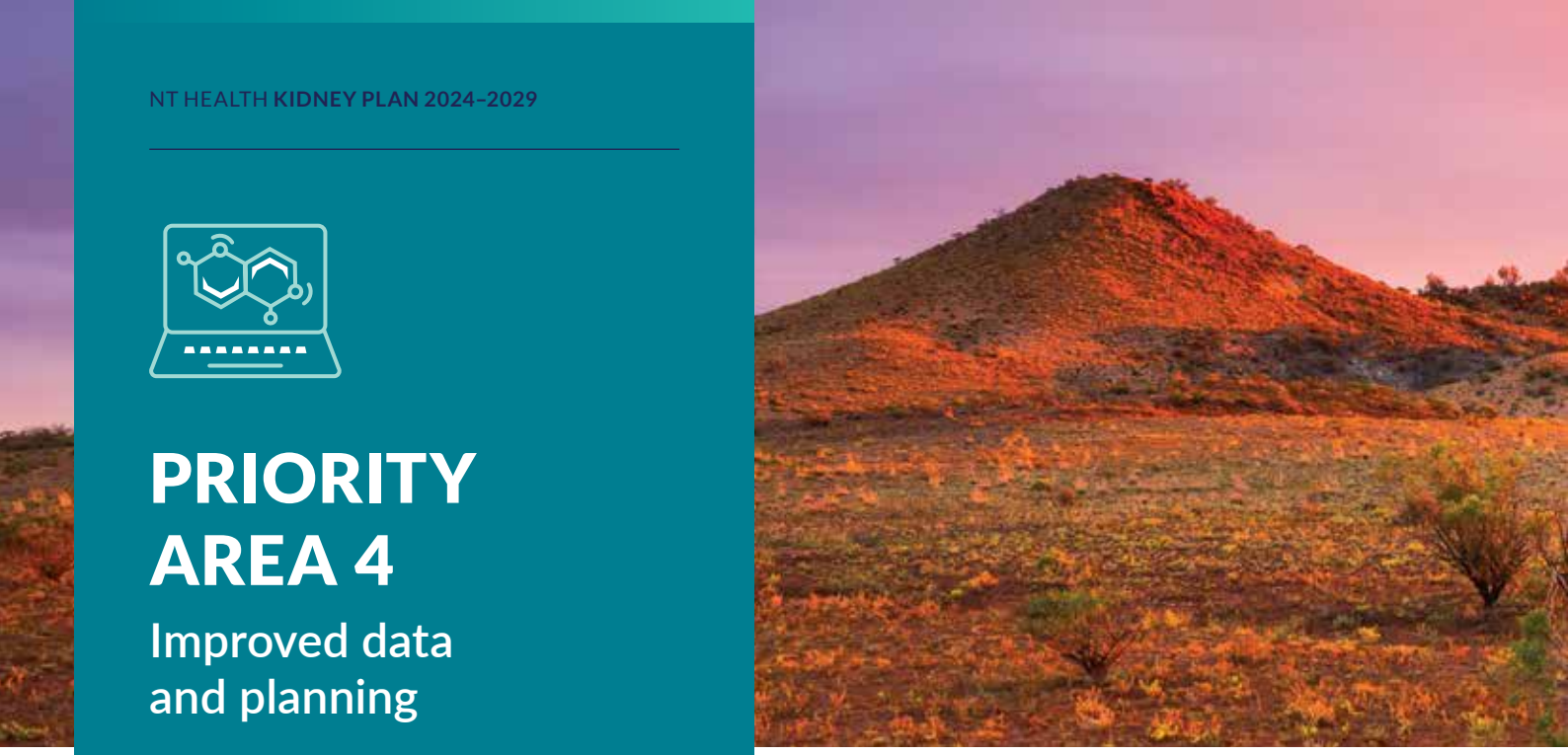
The recruitment and retention of a skilled workforce for renal services in the NT is a key priority. With growing numbers of people requiring renal care and the shortage of renal nurses nationally, a move to complement the current model of renal nurse assisted dialysis is necessary.

Multi-disciplinary teams are important in the management of renal patients across all stages from early intervention and education about CKD self-management and health literacy through to crisis management. This involves primary care providers, including allied health teams and dialysis support services. Given the growth in KRT demand, there is a need to increase the skills of a broader range of clinical and non-clinical staff in all aspects of kidney care including dialysis.

We will build a community-based workforce with the skills to support CKD patients through a coaching and supportive care model. We will work with communities and stakeholders to develop community kidney worker roles to meet the individual needs of patients and their families as they work through education, choices of care, and support of care including dialysis and pre- and post-transplant care. These roles will be piloted, and a micro-credentialling process utilised.

Virtual care will allow a distributed support model with centralised clinical oversight and support through nursing and allied health to the patients and community-based workforce. This range of workforce will support trials of hybrid community kidney hub models that are designed in partnership with care providers to accommodate individual requirements and changing needs for support.

No.	Outcome	Measure/Indicator
3.1	Communities have access to community kidney hubs where people can receive tailored face-to-face and virtual kidney support through multi-stakeholder and multidisciplinary teams (e.g. early kidney care, health literacy, dialysis support, telehealth support, post-transplant care, supportive care) can be supported throughout their journey	> Percentage of people who can undertake maintenance dialysis in their health service regions > Number of community kidney hubs established
3.2	Culturally safe care is provided across all renal services	> Clearly defined regional consumer feedback systems exist including quality, safety and consumer satisfaction and worries. > Annual analysis of consumer feedback is included in regional and system wide action plans > Formal consultation processes are instituted to consumer involvement in design and development of service provision at a local level
3.3	Pilots completed and reviewed by late 2025	> Micro-credentialled community kidney workers are piloted in satellite and remote community renal facilities
3.4	Renal patients have access to a range of allied health professional services focused on prevention and wellbeing strategies	> Increased percentage of CKD patients with allied health review in last 24 months
3.5	A multidisciplinary kidney care workforce supports prevention and management of CKD	> Increase the number of advance nephrologist trainees, and renal nurse practitioner positions. > Develop allied health outreach positions including occupational therapists, Aboriginal liaison officers, social workers and renal educators > Increased recruitment and retention of Aboriginal Health Practitioners in all renal service locations



PRIORITY AREA 4

Improved data and planning

High quality, accessible data is essential to making a difference in kidney disease prevention, management, treatment and research,[26] including capturing data in the very early stages of kidney disease.

Advancing real time access to clinical data about existing renal patients and improving the comprehensiveness and quality of data is key to improving patient outcomes and implementing forward planning. More robust data and projections will improve the ability of all service providers to plan and deliver services when and where clients need and want them.

Analysis of current infrastructure and operations of renal facilities across the NT and current and projected demand will help inform service planning for the future.

During the term of this plan, NT Health will work to embed data sovereignty principles in this work, by ensuring Aboriginal and Torres Strait Islander people have access to, and the capability to use, locally relevant data and information to monitor the implementation of the priority reforms, Closing the Gap targets and drive local priorities.

26 Kidney Health Australia 2019. *National Action Plan for Kidney Disease*. https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-kidney-disease?language=en, accessed 21 Apr 2023.

No.	Outcome	Measure/Indicator
4.1	Infrastructure is planned to meet service demand	> Annual and longer term infrastructure planning for renal services in NT
4.2	NT wide data is used to plan service delivery and resourcing	> Development of NT-wide renal dashboard
4.3	Improved quality of CKD and dialysis data across health care and community sectors	> Audits show improvement in data accuracy
4.4	Improved service planning through collaborative co-design efforts underpinned by data and human centered design principles	> 100% of new kidney services designed by NT Health have input from regional partners including consumers in design and model of care

PRIORITY AREA 5

Kidney donation and transplantation

Kidney transplantation is regarded as the most desirable management for ESKD from a financial and quality of life perspective.[27] A kidney transplant is a surgery where a healthy kidney from a living or deceased donor is placed into a patient with ESKD.

People with CKD approaching decisions for RRT will be considering transplantation. Since CKD commonly co-exists with other conditions (diabetes, cardiovascular disease and complex infections) it is important the health services provide MoC that create efficient transplantation assessment, optimisation and decision making for transplant suitability regardless of pre-existing complex conditions[28].Aboriginal Territorians are less likely to be added to the transplant wait list than non-Aboriginal Territorians during their first year of renal replacement therapy.[29]

Reasons for delays in wait listing encompass various factors such as missing appointments due to conflicting commitments and communication obstacles, difficulties in accessing and navigating complex pathways to specialist services, transportation issues, co-existing health conditions necessitating numerous tests and specialised services, and constraints on dialysis and hospital bed availability.[30]

Ultimately, obstacles to wait listing for kidney transplantation among Aboriginal and Torres Strait Islander Australians are multifaceted and could be mitigated through healthcare restructuring initiatives. These initiatives involve bolstering the Aboriginal and Torres Strait Islander healthcare workforce to be healthcare providers, offering education and assistance to navigate the healthcare system, enhancing communication, simplifying diagnostic procedures, and coordinating specialist services more efficiently.[31]

The inequity in accessing kidney transplants is experienced across Northern Australia and is the focus of national attention. Together with a lack of suitable organs and transplant capacity significant work is required to increase the access to suitable transplant organs for Northern Australian populations.

27 Australian Institute of Health and Welfare (AIHW) 2023, Chronic kidney disease: Australian facts, https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease
28 Garrard E, McDonald S. Improving access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander People in Australia: performance report. Sydney: Transplantation Society of Australia and New Zealand, 2019. https://tsanz.com.au/storage/NIKTT/TSANZ-Performance-Report---Improving-Indigenous-Transplant-Outcomes-Final-edited-1.pdf
29 Khanal, N., Lawton, P. D., Cass, A., & McDonald, S. P. (2018). *Disparity of access to kidney transplantation by Indigenous and non-Indigenous Australians.* Medical Journal of Australia, 209(6), 261-266.
30 Majoni S.W., Dole K, Hughes J.T. & Pain C. Review of current pathways to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander peoples with end-stage kidney disease in the Top End of Northern Australia. Australian Health Review, 2021. 45(2) 185-193 https://doi.org/10.1071/AH20011
31 Australian Health Review, 2021, 45, 185–193 https://doi.org/10.1071/AH20011.

No.	Outcome	Measure/Indicator
5.1	People with kidney disease have access to timely and supported information about the option of kidney transplantation	> Availability of lived experience education for people with kidney disease
5.2	A Northern Australian Alliance focussed on improving renal transplantation capability and support for Northern Australia is formed	> Formation and at least twice-yearly meetings of the Northern Australian Alliance
5.3	Improved access to waitlists for kidney transplantation	> Proportion of patients waitlisted for kidney transplantation within 2 years of commencing KRT
5.4	Improved access to kidney transplantation	> Increased annual percentage in kidney transplantation for NT patients
5.5	Post-transplantation people have access to ongoing primary health care supported by specialist services	> Post-transplantation survival rate improves by 5%
5.6	Northern Australian Transplant Unit economic and workforce feasibility study is undertaken through collaboration with other states and territories	> Completion of feasibility study

NT HEALTH

KIDNEY PLAN 2024–2029

health.nt.gov.au

NORTHERN TERRITORY GOVERNMENT