



Territory Kidney Care Stakeholder Progress Report

1 July 2021 to 28 February 2022



Table of Contents

Project Overview	3
Summary	4
Participation of Aboriginal Health Services.....	5
Clinician Uptake and Usage.....	6
Number of CKD Patients in TKC	7
Filling the Gap between Diagnosed and Undiagnosed CKD.....	8
Looking at Preventable Hospital Admissions	9
Transition of TKC to NT Department of Health.....	10
Evaluation of TKC	11
Achievements and Next Steps	12

Contact information

Dr Gillian Gorham
Head Renal Health Program/TKC Program Lead
Gillian.gorham@menzies.edu.au

Dr Radwan Talukder
CKD Program Manager
Radwan.talukder@menzies.edu.au

Dr Asanga Abeyaratne
Nephrologist and TKC Clinical Lead
Asanga.abeyaratne@nt.gov.au

Paul Kamler
TKC Health Informatics RN
Paul.Kamler@nt.gov.au

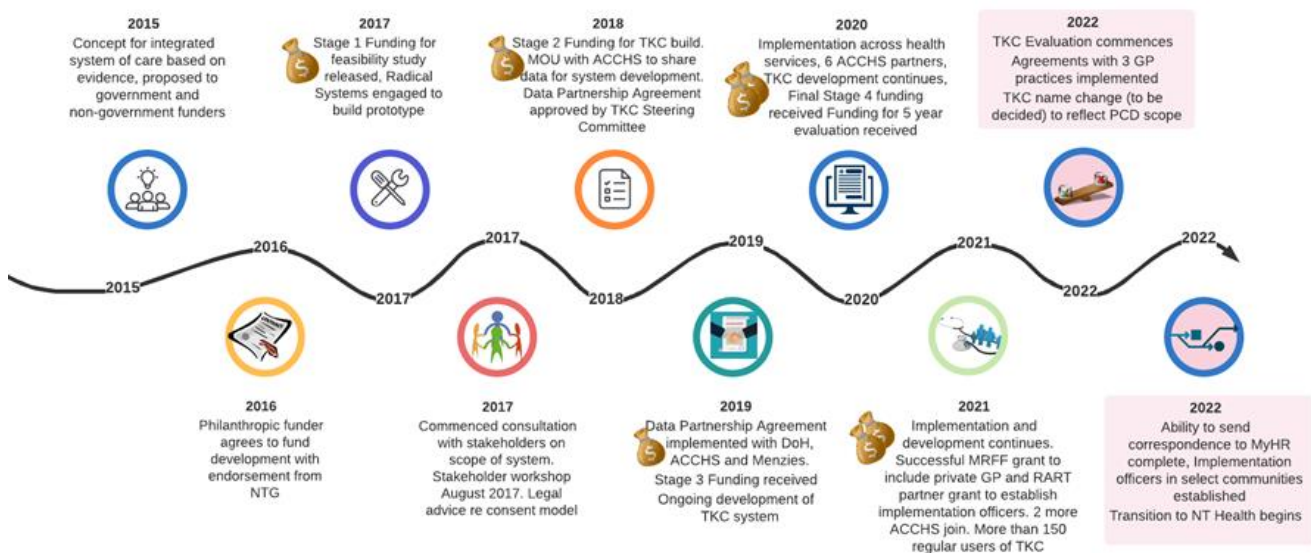
Project Overview

Territory Kidney Care (TKC) is an integrated clinical decision support tool that consolidates electronic health records (EHRs) from public hospitals, government-operated primary care services, participating Aboriginal Community Controlled Health Services (ACCHS) and private practices. TKC was developed to assist with the early identification and management of people with chronic kidney disease (CKD) to improve health outcomes and delay or prevent the requirement for dialysis. While TKC focuses on CKD, the platform has proved to have greater application and value for the management of related chronic diseases and complex conditions.

The majority funding for the design and development of TKC was secured from a non-government source with funds allocated in four stages based on the successful attainment of pre-determined milestones and deliverables. All funding for the program has been received and was initially expected to be fully expended by December 2020. In-kind support from the Northern Territory Department of Health (DoH), the Top End Health Service and the Central Australian Health Service has facilitated the efficient use of the remaining funds.

This report covers the activities from 1 July 2021 to 28 February 2022.

Figure 1. TKC Progress Timeline



Summary

Between July 2021 and February 2022, TKC's expansion into the remaining ACCHS slowed – largely due to the considerable impact of COVID-19 on remote communities. The capacity of health services and private practices has been significantly impacted by the COVID-19 pandemic; clinicians have been stretched beyond their capacity and are only now re-engaging with the TKC project team.

However, we have continued to support health services through virtual meetings using Zoom and Teams and regular emails and reporting. Nine of thirteen ACCHS and currently partnering in TKC and we are now working closely with three private practices – Pandanus Medical, Top End Medical Centre and NT Cardiac.

All government hospitals (six) and primary health services (approximately 56) contribute data to TKC. TKC's ability to integrate primary and tertiary data, particularly the automated summation of longitudinal information, has increased the number of users now accessing TKC. There are over 350 active users of various disciplines accessing the system for patient care, providing feedback on functionality and driving development to improve the user experience.

To transition TKC to a more sustainable model, the Department of Health has now taken the lead to identify the Business Owner for TKC and the appropriate department within the NT government for the ongoing funding and management of the system. This process is likely to involve a change in the governance structure with greater responsibility for oversight and integration of TKC within the strategic direction of the government's Health Integration Enterprise.

We continue to seek funding for implementation and development. In 2021, we received a Medical Research Future Fund (MRFF) grant for rapid translation. The *Top End Partners: translation research to improve health outcomes* (TOP R) grant allows the project to support TKC implementation officers in ACCHS to improve uptake and strengthen two-way communication, CQI and reporting into TKC.

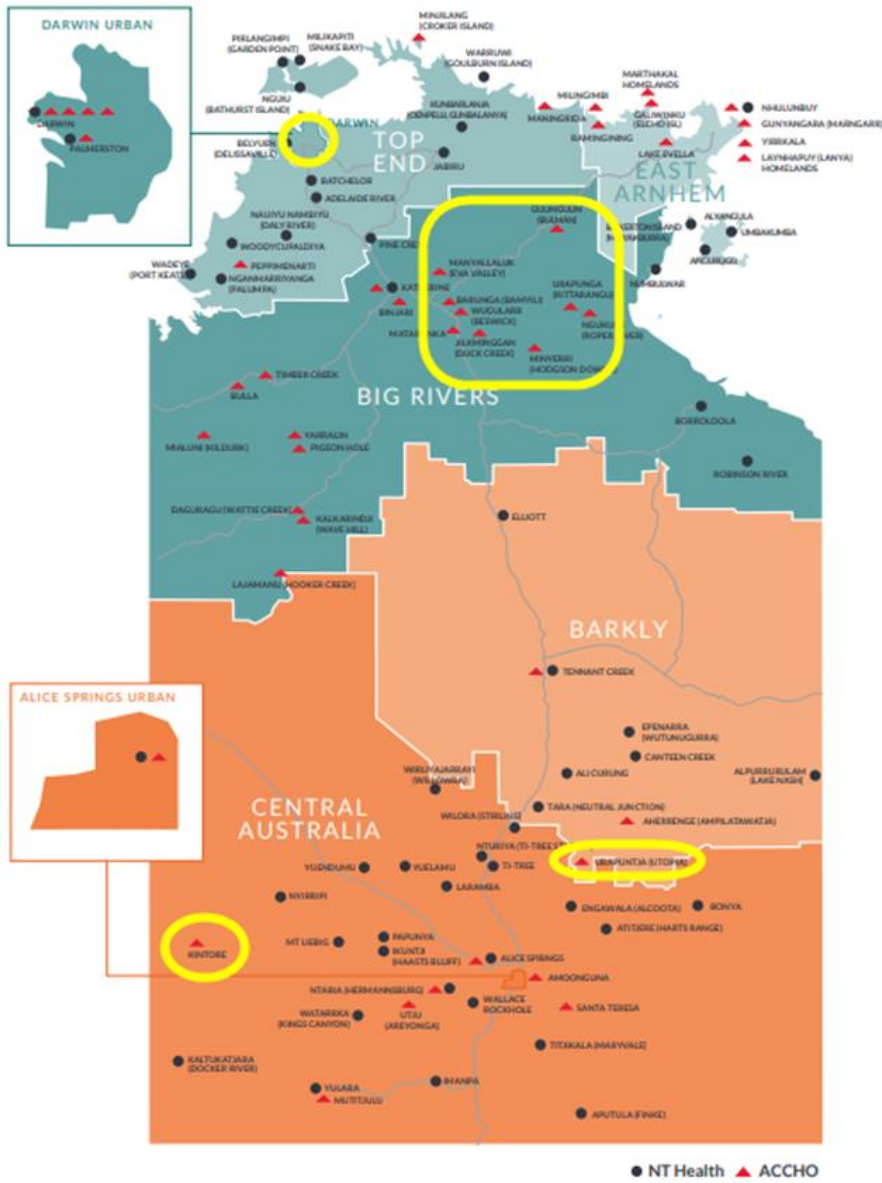
We are currently in the process of finalizing a contract with Department of Health and the Australian Digital Health Agency (ADHA) to create a link with the My Health Record so that TKC Summary Reports can be uploaded, providing greater access for patients and non-TKC partners to consolidated health information.

All necessary ethics approvals have been received from the relevant NT bodies for the TKC evaluation. The commencement of the process evaluation has been delayed due to COVID-19 restrictions and limited opportunities for engagement between clinicians/communities and the project team. However, baseline data analysis has now begun, and we expect qualitative data collection to commence shortly.

Participation of Aboriginal Health Services

Figure 2. Aboriginal Community Controlled Health Services participating in TKC (excluding highlighted health services)

NT HEALTH SERVICE LOCATIONS



NT Health Regions

- Top End (including Greater Darwin)
- East Arnhem
- Big Rivers (including Lajamanu, Pine Creek & Douglas Daly)
- Barkly (including Ampilatwatja)
- Central Australia

Source: Australian Bureau of Statistics

Aboriginal health services provide approximately 60% of primary health care services to Aboriginal people in the NT. This percentage is growing as more health care services transition from the Department of Health (DoH) to Aboriginal community controlled. TKC currently includes all primary health services under the DoH (56) as well as the six tertiary hospitals, nine ACCHS (overseeing care in approximately 20 health clinics).

For ACCHS participating in TKC, this partnership has been formalised through a Data Participation Agreement, which includes an implementation plan that is individualised to the specific context of each health service. Standard items in all implementation plans include communication with patients regarding data sharing and the opt-out process.

The project team provides six-monthly population reports to each health service and, through an iterative process, supports the health service to modify reports according to their needs.

As illustrated in Figure 2, TKC has broad coverage across the NT, with only four ACCHS currently not participating in TKC (circled and highlighted in yellow) due to capacity issues. These health services are determining the pace of engagement.

Clinician Uptake and Usage

Over the past year, the Department of Health has approved non-government access to the TKC system. Clinicians at partnering ACCHS and private GP practices can now access TKC via the NTG external access portal using an individual NTG LAN account (with VPN and multifactor authentication). This access enables two-way data sharing and increases the usage and application of TKC for integrated care.

Recognising that CKD requires an integrated and holistic management approach, an increasing number of clinicians from other specialties are utilising TKC for patient care, as illustrated in Figure 3. Access to TKC is vetted and only clinicians providing health care have access to the system. As specified in the Data Participation Agreements, the Agreed Uses for TKC include:

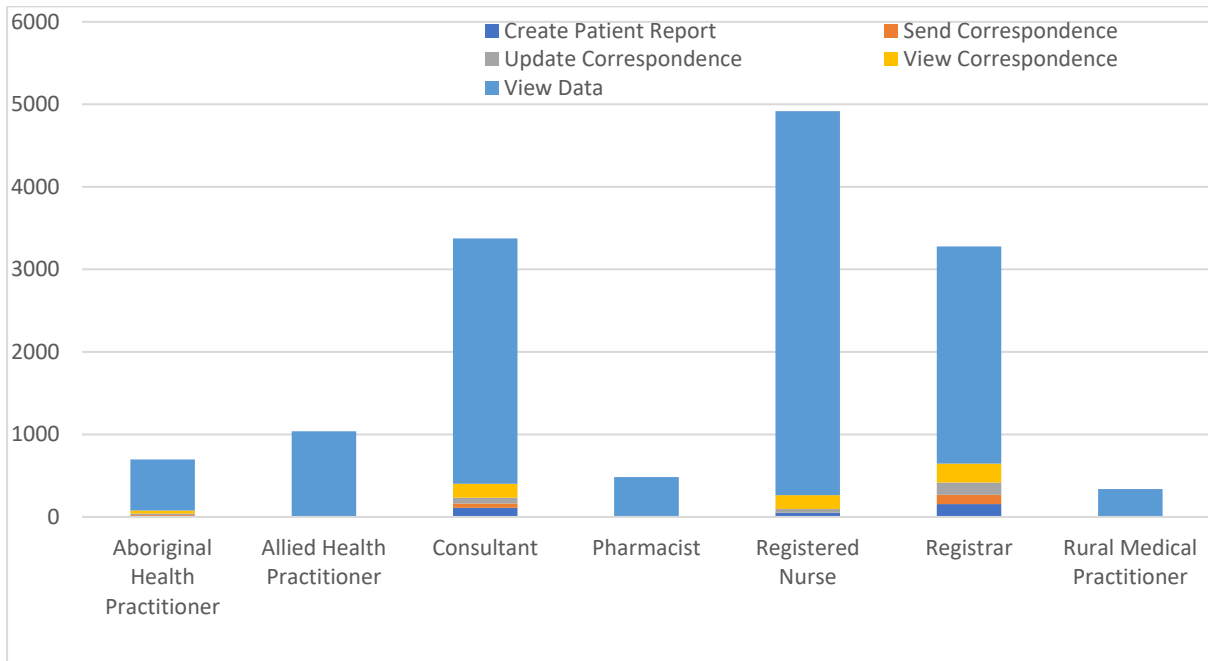
- Treatment for the provision, coordination or management of health care and related services;
- Health Care Operations to analyse shared data to develop a better understanding of the patient population and evaluate the impact of clinical interventions.

The health services also agree that their data will be used to improve the quality, coverage and scope of health services and protect the public health.

As of 28 February 2021, there were 367 active users with access to TKC. In the last three months, 99 users have used the system at least once for patient care.

Participating ACCHS have confirmed that they are aware clinicians other than nephrologists (including nurses and dieticians) are accessing TKC and endorse the use of data for patient care by clinical staff.

Figure 3: Usage of TKC by user group in December 2021



Number of CKD Patients in TKC

As of February 2022, there were just over 30,000 active CKD patients registered in TKC. The majority of these are in the early stages of the disease (CKD stage 1 and 2) and, with appropriate evidence-based care, progression to end stage kidney disease may be averted. Figures 4 and 5 identify the trend in patients at-risk of CKD (based on select co-morbidities) and the number of patients diagnosed with CKD based on stages, respectively.

As we expand coverage and integration with ACCHS and private practices across the NT, our understanding of the burden of CKD will be enhanced. This information is shared with individual health services and the DoH in a process of validation.

Figure 4: Active clients at-risk of CKD in TKC to December 2021

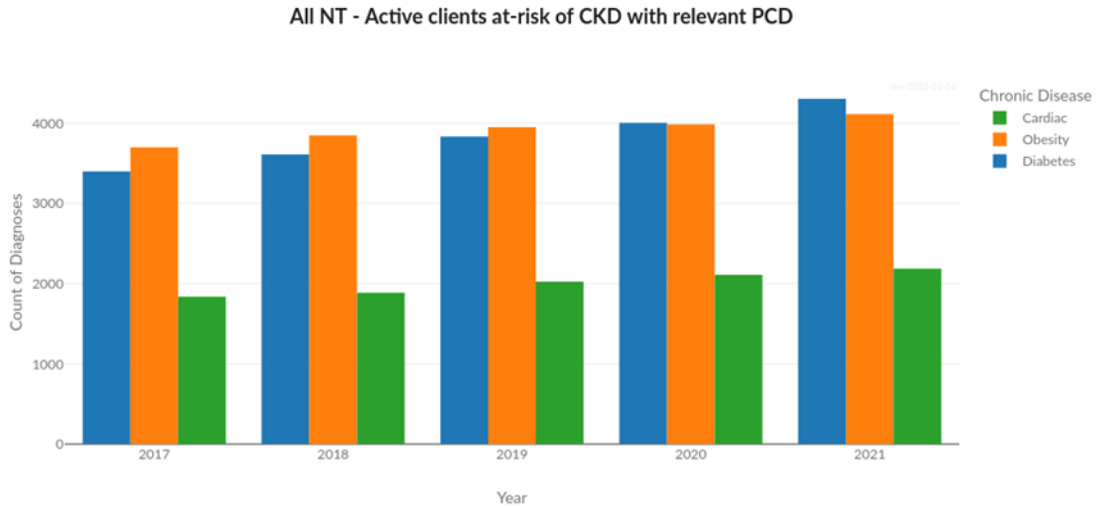
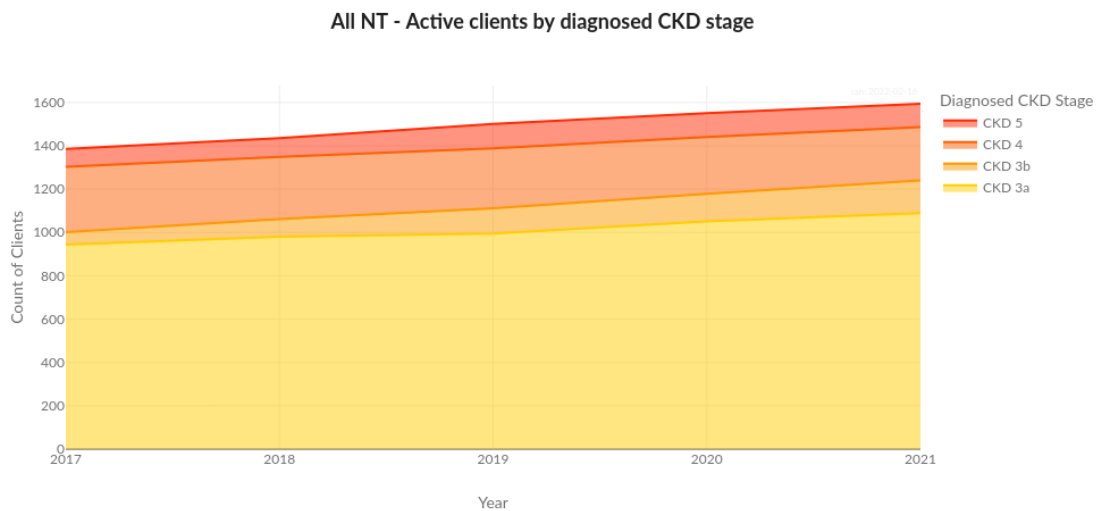


Figure 5: Active clients by diagnosed CKD stage in TKC to December 2021



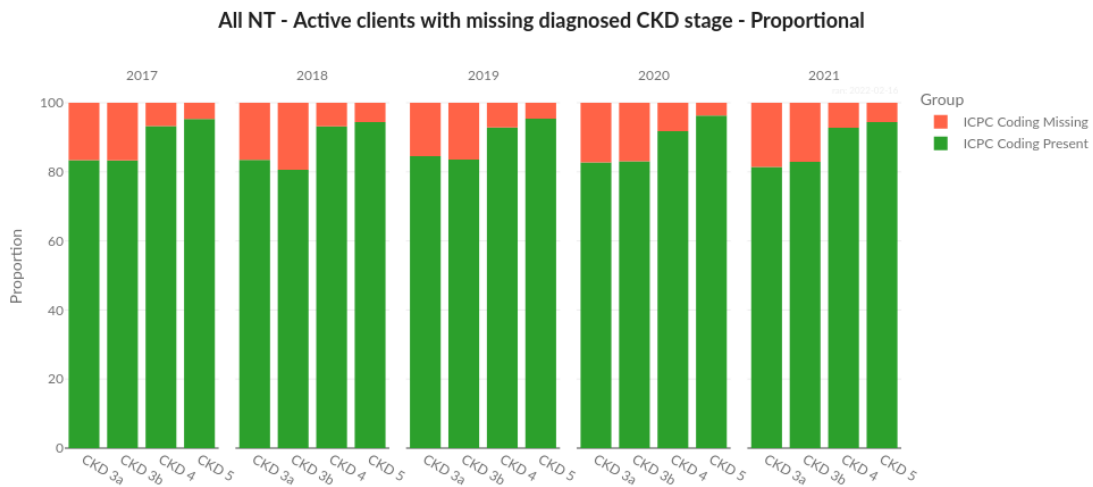
Filling the Gap between Diagnosed and Undiagnosed CKD

TKC enables the identification of early-stage CKD to inform interventions and evidence-based management strategies for people with CKD stages 3a and 3b to prevent progression to dialysis. Patients with CKD are identified through classification based on pathology results, as well as recorded diagnoses in the electronic record system. This method aims to fill gaps between diagnosed and undiagnosed CKD to facilitate earlier management.

Our analysis of ‘diagnosed’ CKD versus ‘undiagnosed’ CKD, based on pathology results has highlighted the number of people still falling through the gaps. Critically, a small number of people in the very

advanced stage of CKD, i.e. CKD stage 5, do not have a corresponding diagnosis in the source system. TKC simplifies the surveillance and monitoring process to efficiently identify people with CKD earlier. The Clinical Support Unit are now identifying these patients and referring them promptly and appropriately to their nephrologists and GPs. As shown in Figure 6, TKC identifies the proportion of active clients with missing diagnoses for advanced CKD stages.

Figure 6: Number of active clients with missing diagnosed CKD stage in TKC - proportional

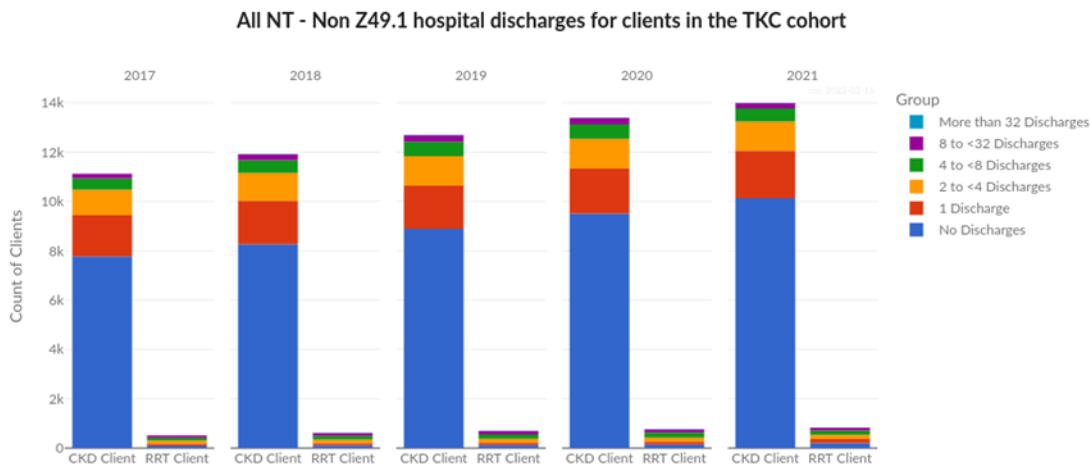


The progress of an individual from chronic kidney disease to end stage kidney disease and the requirement for dialysis often occurs over several years with opportunities for intervention along the patient journey. However, the relationship between an intervention (such as the implementation of evidence-based treatment recommendations through TKC), and an outcome (such as the avoidance of dialysis), will not become fully evident immediately. The impact evaluation of TKC at the five-year mark will focus on a number of key indicators and provide data points necessary to assess this metric.

Looking at Preventable Hospital Admissions

TKC can identify the number of people who have a hospital admission (by health service and district) and the frequency of hospital admissions per year. This provides opportunities for health services to identify patients with frequent admissions and target resources to reduce the number of avoidable admissions. Figure 7 shows the number of admissions per year, for CKD clients and RRT clients, excluding Z49.1, the code for a same day dialysis admission. In the long-term, this data will reveal trends in avoidable or preventable hospital admissions that may be addressed through early intervention.

Figure 7: Number of hospital admissions (excluding same day dialysis) per year for CKD and RRT clients



Transition of TKC to NT Department of Health

The DoH currently hosts the system and provides the IT infrastructure, licensing, maintenance, security and technical support for the server. As part of an NTG-wide policy, data management is being taken over by the Department of Corporate and Digital Development (DCDD). We are working with DoH and DCDD in this process and have prepared the following documentation for review:

- TKC Service Support Handover to ABS Group 1
- Attachment 1 – TKC Solution Architecture Document
- Attachment 2 – TKC Data Governance Overview
- Attachment 3 – TKC System Admin Guide
- Attachment 4 – TKC User Provisioning Guide
- Attachment 5 – TKC Risk Management Overview
- Attachment 6 – TKC Linkage Protocol

The transition of TKC to the Department of Health (DoH) is currently being negotiated with roles and responsibilities of each party being clearly defined. The DoH have drafted an Implementation Planning Study for Transitioning TKC System to Production Support, which has been reviewed by the TKC Executive Steering Committee before submission to the DoH Health Leadership Committee.

The gradual shut down of the Department's Oracle server and migration to the new MSSQL server, due to commence in April 2022, presents some technical challenges for TKC. The successful transition of the TKC database during this process requires additional work relating to rewriting and testing all data warehouse extraction scripts to ensure correct function against the new MSSQL database. Development and testing are currently on track.

Evaluation of TKC

We have received ethics approval from AMSANT and participating ACCHS for the evaluation of TKC. The evaluation will be conducted in phases and is made possible by funding from two project streams. Stream 1 funding will focus on a process evaluation and full outcome evaluation including economic impact of TKC. Stream 2 funding will focus on a comparative analysis of the impact of clinical decision support (CDS) systems on supporting adherence to CKD management guidelines across three jurisdictions in Australia. These CDS systems include TKC in the Northern Territory (NT), CD-Impact in Victoria and CKD.TASlink in Tasmania. These evaluations will inform the development, expansion, uptake, and transition of TKC to the Department of Health.

To assist with the evaluations, we have now engaged a Senior Biostatistician for three years as well as a casual appointment to commence the baseline analysis. An experienced qualitative evaluator has also joined our team and will be mentoring a First Nation researcher in evaluative techniques.

Achievements and Next Steps

The use and application of TKC is increasing and we continue to facilitate partnerships to expand the capability and functionality of the system. The Executive Steering Committee has been expanded to increase representation from clinicians at private practices and ACCHS and terms of reference for a Clinical Advisory Group to inform the Territory Integrated Care project have been drafted. We have also presented the TKC system to the new Chief Medical Officer of NT DoH and received support for our activities, including granting access to non-government health services.

To further develop TKC, we have submitted an application for the Medical Research Future Fund (MRFF) focused on 'applying machine learning to address data gaps in chronic disease care'. This funding application was submitted in partnership with NT DoH and the College of IT, Engineering & Environment at Charles Darwin University. If funded, the grant aims to develop, through engagement with clinical stakeholders, interpretable machine learning models to enable the integration of uncoded data (e.g. clinic attendances, text, medications) in Electronic Health Records. This will improve the completeness and quality of data available for the management of chronic disease.

We are also expanding the capabilities of the TKC project team, including the recruitment of a full-time senior biostatistician, part-time business analyst and evaluation specialists. We are committed to building the capacity and skill sets of our First Nations team members, currently focused in the areas of evaluation and data entry, and supporting ACCHS engagement with the project team.

During the COVID-19 pandemic, the Centre for National Resilience requested access to TKC as a comprehensive source of data in the Northern Territory. We added a banner to the patient synopsis page in TKC showing COVID-19 vaccination status to provide relevant information to clinicians accessing TKC, where available.