

Territory Kidney Care

Six monthly progress Report

1st April – 30th September 2020

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1. Project Overview

Territory Kidney Care (TKC) is an integrated clinical information system that assists primary health services with the early identification and management of people with chronic kidney disease (CKD) thus improving health outcomes and delaying or preventing the requirement for dialysis.

The majority funding for the design and development of TKC was secured from a non-government source with funds allocated in stages based on the successful attainment of pre-determined milestones and deliverables. This report covers the activities for Phase Four of the Project.

Significant in-kind support has also been provided by the Department of Health (DoH), the Top End Health Service and the Central Australian Health Service.

2. Summary

The development of functionality within TKC has continued while we are implementing across services. In the last six months, largely due to the impact of Covid19, the project has faced barriers to implementation and facilitators to development. Both the project team and the clinical teams of nephrologists and CKD nurses have not been able to travel to communities. While this has hindered the implementation, it has resulted in a far greater reliance on telehealth clinics for the clinicians. It has increased usage of the system and assisted in identifying shortcomings and/or functionalities that are useful for the GPs, nephrologists and patients.

Our Project Officer June Fairless retired and we have chosen to employ a data architect to develop the architecture for the pipeline and permanent reporting interface. He will also assist with the more complicated analysis relating to projections and estimations of disease burden. This is an important milestone as it is critical to providing accurate, timely and frequent reporting with minimal impact on resources.

Menzies has secured funding to undertake two evaluations of TKC. A long term cost effective analysis of TKC will begin in November and will occur over 5 years. In collaboration with Tasmania and western Melbourne we will also undertake a comparative analysis of CKD information and management systems used in each jurisdiction. This will provide important information to the Australian kidney community on effective mechanisms for the monitoring and management of people with kidney disease.

In collaboration with the DoH we are developing an application to NHMRC for an Ideas Grant to increase the technical capability of TKC and extend the system to other conditions and possibly other sites. The ongoing development of the system is supported by the DoH.

All of this work involves strong collaborative partnerships and it is expected that Menzies will retain a role in the ongoing development and evaluation of TKC beyond June 2021.

Although TKC has not been fully implemented across the NT and some refinement and development continues, the system has proved to be extremely useful to GPs and Specialists. Specialists are

advocating for the expansion of the system to other chronic conditions and we regularly receive positive reports (See email in appendix).

3. Phase Four Deliverables

3.1. Deliverable One: 85% AMS to have Agreements in Place.

In Progress: Aboriginal community-controlled 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 to community controlled. Currently there are over 50 primary health clinics managed by the Department of Health and all, including tertiary services, are contributing data to TKC.

Currently TKC has coverage of over 70% of Aboriginal people who have chronic kidney disease in the NT. There is some support from Central Australian clinicians to include health services across the SA and WA borders in TKC. There is considerable patient traffic between these remote health services and the NT DoH facilitates and there would be significant benefits to both patients and services with the expansion of TKC into these locations.

Moreover, two large private GP practices (one in each region of Top End and Central Australia) have indicated interest in joining TKC. This will take considerable work in relation to the consent model and automation of data extraction scripts and will be investigated further as resources allow.

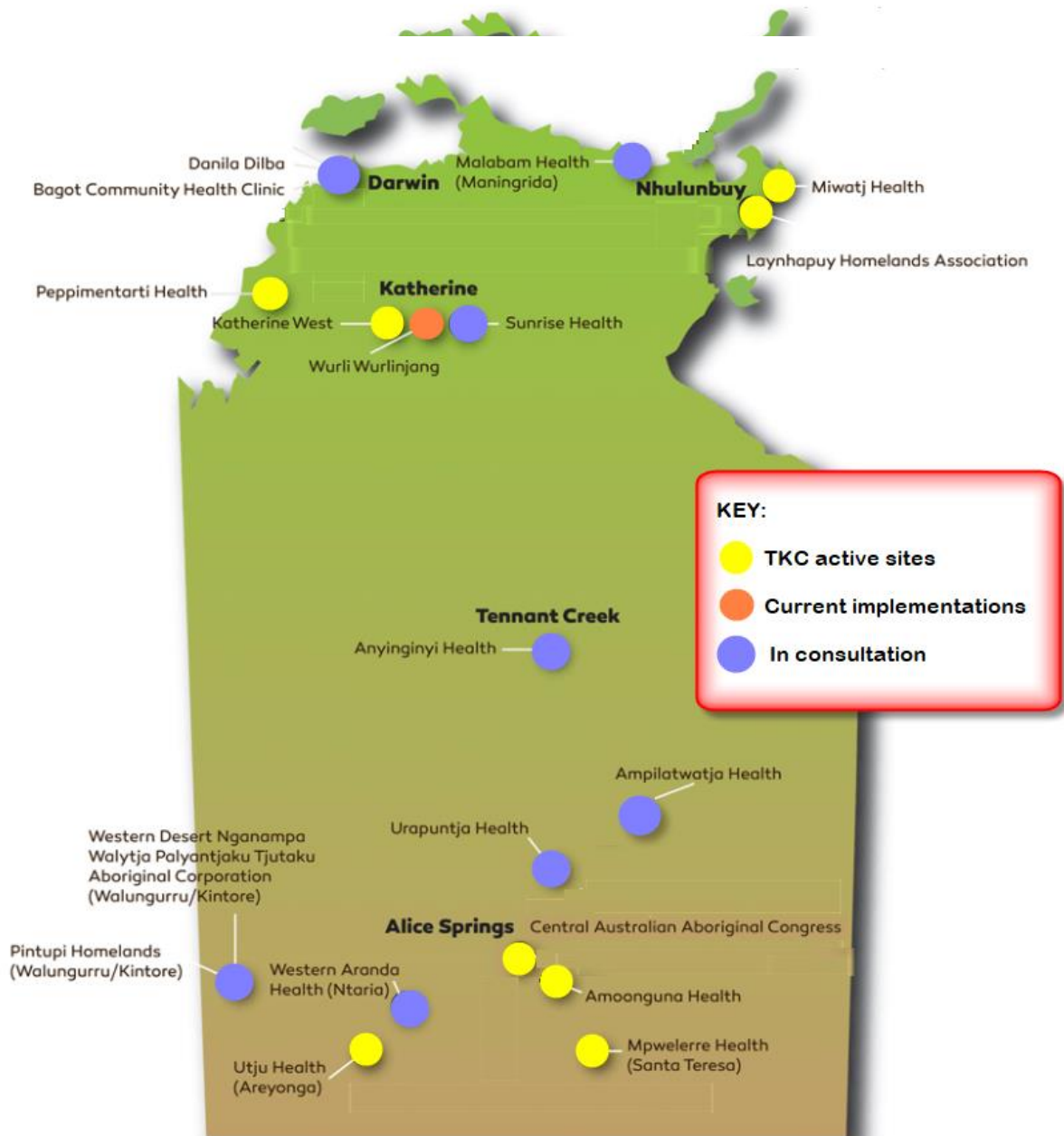
Figure 1 shows the Aboriginal organisations and their locations in the NT that are currently delivering primary health services and Figure 2 shows the Aboriginal health services currently contributing information to TKC, and those that we are actively engaged with regarding implementation. Some Aboriginal health services are still in the consultation phase.

Our coverage of the NT by the end of 2020 will ensure that the majority of Territorians at risk of or with kidney disease, will receive the benefit of TKC.

Figure 1: Aboriginal controlled health services in the NT



Figure 2: Aboriginal controlled health services currently participating and consulting with TKC

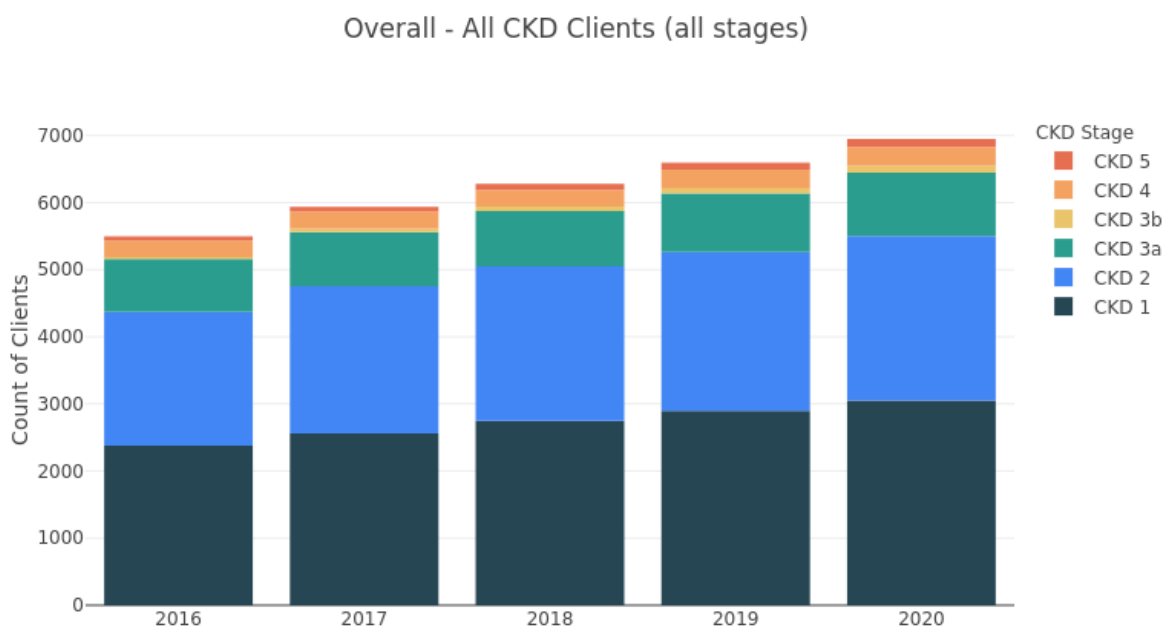


3.2. Deliverable Two: 6,000 CKD Patients within TKC Database, Disease Progress and CKD Management Monitored.

In Progress: As of September 2020, there were nearly 7000 active CKD patients registered in TKC. The vast majority of these are in the early stages of the disease (CKD stage 1 and 2) and, with appropriate evidence-based care, may never progress to end stage kidney disease. Until the system is fully integrated with all health services across the NT, some uncertainty will persist regarding the complete community burden of CKD.

However, patient numbers are higher than numbers held in data bases currently maintained by NT Renal Services and reflect the concerns of nephrologists that the true extent of chronic kidney disease in the NT is under-recorded.

Figure 3: CKD by stage and year - identified by ICPC codes results



3.3. Deliverable Three: Nine Patients Saved from Dialysis.

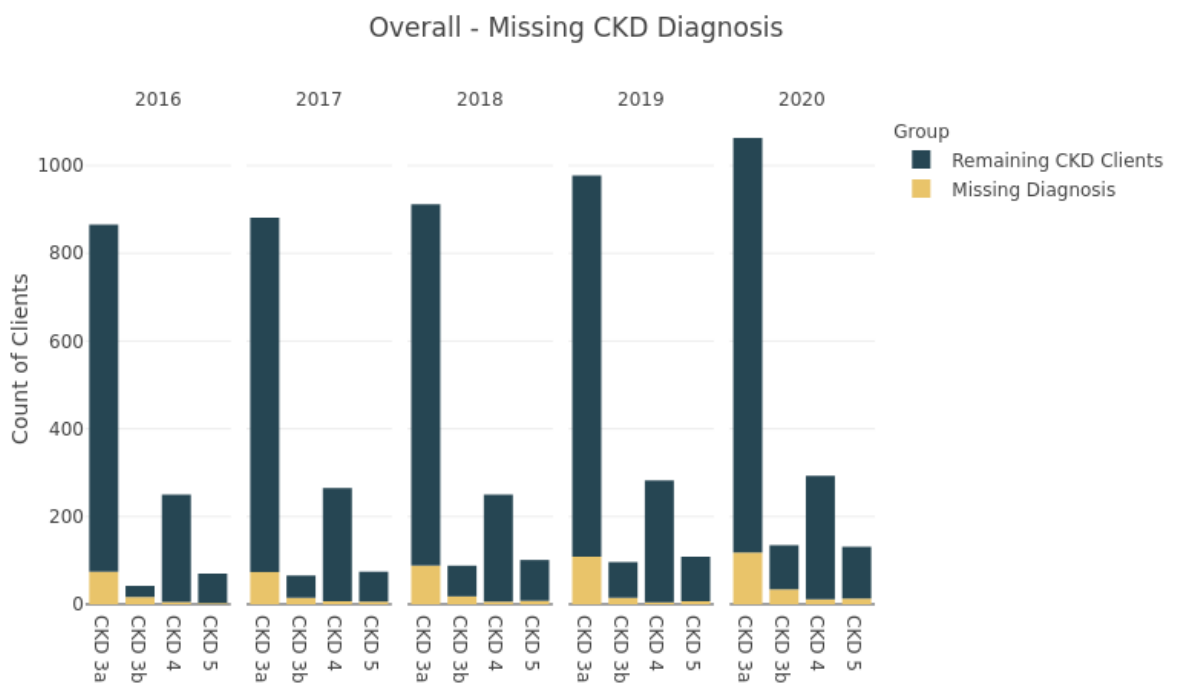
In Progress: The earlier identification and implementation of evidence-based management strategies for people with CKD stages 3a and 3b is the best method to avoid the requirements for dialysis. This is now possible through TKC. Patients with CKD in TKC are identified through calculation of pathology results, as well as recorded diagnoses in the system. This method aims to fill the gaps where there might be latency in diagnosing patients and therefore facilitate earlier management. CKD

management needs an integrated approach between primary care and tertiary care. TKC upholds this principle by facilitating appropriate and targeted specialist involvement through earlier identification of people with kidney disease.

Our analysis of ‘diagnosed’ CKD versus ‘undiagnosed’ CKD, based on pathology results has highlighted the number of people still falling through the gaps. Critically, people in the very advanced stage of CKD ie CKD stage 5 are still being identified as undiagnosed. This has been confirmed by staff in the Clinical Support Unit (CSU) who report regularly that TKC has identified patients in remote communities with advanced CKD that they were previously unaware of.

The CKD Nurses in the CSU have a special role in TKC, responsible for active surveillance of the system. They ensure critical information is conveyed promptly to the nephrologists who communicates with the GP, and then follow up appropriately with the primary health service caring for the patients.

Figure 4: Number of NT people with advanced stage of CKD -diagnosed and undiagnosed



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 multiple opportunities for intervention along the patient journey. The avoidance of dialysis might occur for a variety of reasons. However, the relationship between an intervention (such as the outputs from TKC), and an outcome (such as the avoidance of dialysis) in terms of causality, will not be immediate and in the case of kidney disease, can only meaningfully be assessed after a reasonable passage of time.

The five year evaluation due to commence in November, will provide the data points necessary for a robust analysis regarding the impact on health service utilisation.

3.4. Deliverable Four: TKC Transitions to NT Health for ongoing management and maintenance.

In Progress: The transition to the Department of Health will occur gradually over the next six to twelve months. The DoH continues to provide significant in-kind support for the IT infrastructure, licensing and security. The gradual transition of positions to the Department has commenced with the time of the Consultant Nephrologist and technical expert no longer being supported by TKC. The Health Informatics RN and remaining clinical staff based in Alice Springs, will also be absorbed into business as usual by June 2021.

The Department is still in the development and release phase of their large Clinical Information System (ACACIA), and we have been advised that TKC is on a priority list of systems that are to be integrated with ACACIA. We are receiving support to transition our extraction scripts for primary health care data from the legacy system to the new data warehouse tables which is to be completed by the end of the year. The Department has also advised that they will continue paying the licenses for legacy environments they no longer require, until TKC is able to make the full transition.

There is strong support for the continued development and expansion of TKC.

3.5. Deliverable Five: 1,191 Expected Treatments Avoided

In Progress: We cannot uniquely identify the number of treatments avoided by the number of unidentified individuals with advanced stage of CKD, who are now receiving care according to evidence-based guidelines. We will continue to monitor and track rates of kidney disease and incidence rates of RRT over the next five years. Nevertheless, evidence from the NT and more broadly has confirmed that unidentified people with advanced stages of CKD are those people who have the longest and most costly hospital admissions, resulting in the poorest health outcomes. Through earlier identification of CKD, TKC will reduce those who have these most challenging, unplanned and costly transitions to end-stage kidney disease care.

4. Communication Strategy

The TKC project team maintains a Stakeholder Engagement Database which is continuously added to. Regular updates are provided in the way of progress reports and presentations. A planned 'Show and Tell' mid year has been deferred although the TKC team has continued to provide demonstrations to smaller groups using the online platforms (Teams or Zoom).

We have presented regularly to Department of Health senior executive, Clinical Leadership Team and have been invited to present to the First Assistant Secretary Gavin Matthews, Indigenous Health Division, Australian Government.

5. Barriers and Facilitators

The TKC Project team acknowledges that the development and implementation of TKC has taken longer than initially anticipated. Our expectation for Phase four was to be fully implemented across the NT and that we would now be in the evaluation stage.

The reasons for slow progress relate largely to the time taken to negotiate with the key Aboriginal Health Service representative body on the consent model and data sharing agreement. The organisation has a duty of care to their members and is naturally risk averse and the negotiation has resulted in a strong partnership and support for TKC. Importantly the processes involved determined a significant component of the design and development of TKC. The approach to the collaboration and the outcome of a Data Partnership Agreement have also been recognized as a model for other cross-organisation clinical services wishing to establish partnerships.

Secondly, Covid19 has severely restricted our ability to work with health services in remote areas with an embargo on travel to communities. Health services have also been focused on other priorities related to Covid19 preparedness plans. However, this has provided us with time to develop the system based on feedback and include newly released codes used by primary health services to the extraction script such as those for the identification and management of people with Covid19 and the MBS item for staffed dialysis in a remote area.

The development of the DoH clinical information system and the unexpected transition of key DoH IT departments to the Department of Corporate Information Services, has had some impact on TKC progression. The constant turnover of key contacts within the Departments we are required to work with, slowed negotiation and progression of TKC, particularly where TKC interfaces with the Department of Health. Although TKC is fully supported, all NT Government personnel are keenly focused on the development and implementation of ACACIA .

Although the time frames have extended, we have excellent engagement with health services across the NT and we remain on track to deliver an innovative and unique system that will make significant differences to the health and care of Aboriginal people with kidney disease in the NT. The system is already proving to be exceptional by any standards.

This is reflected in the strong support for expansion of TKC to other chronic conditions and other specialties. The Cardiology team have been trialing the use of TKC in their clinics and the anesthetic department has also expressed an interest in exploring the functionalities of TKC for their work.

More primary health service GPs are using TKC with excellent feedback. Please see Appendix A

6. Appendix

6.1. Testimonial

From: Donald Reed <Donald.Reed@nt.gov.au>
Sent: Thursday, October 15, 2020 12:44:30 PM
To: Gillian Gorham <Gillian.Gorham@menzies.edu.au>
Cc: Paul Kamler <Paul.Kamler@nt.gov.au>
Subject: TKC Very valuable use for RMPs in remote communities.

Hello Gillian,

The Renal Physicians are able to use the information to provide improved renal care.

I would argue that the benefit of TKC would be even greater. As the SRMP (Senior Remote Medical Practitioner) involved with the TKC in Central Australia I need to express my astonishment!

I attend various remote clinics in Central Australia on a regular basis.

The use of the TKC platform enables me to review patient care immediately while the patient is present.

It enables me to provide a higher level of medical care.

The information provided allows me to assess and treat most medical conditions with the information provided.

to RMPs in community.

It is very challenging treating patients with multi organ pathology. With the information provided by TKC the treatment of such patients is vastly improved.

An example of this is, a patient who needs a simple antibiotic for a simple infection, can turn out to be very complicated without the full history of renal function, cardiac status, BP status or allergy status. TKC provides all this information and more, immediately.

At present I am involved with a program in one of our communities to try and improve the control of diabetes. Part of my approach to this challenging problem is to use the TKC platform. Without the ability to use this platform our ability to find ways of improving diabetes care will be severely limited.

As diabetes control improves it is expected that renal function, vascular pathology including the microvascular structure of the eyes will improve greatly.

Improvement in macro vascular conditions like Cerebro Vascular Accidents (CVA), Myocardial Infarctions (MI) etc. are expected with the information provided by the TKC platform.

I look forward to the ongoing progress of TKC to the point of all RMPs being able to use it in communities.

Regards

Don Reed

Dr Donald Reed | Senior Remote Medical Practitioner. Lead Supervisor Registrars.
Primary Health Care | Central Australia Health Service