Territory Kidney Care

Six monthly progress Report

1st October 2020 – 28th February 2021

Table of Contents

Contact information

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

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 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.

Summary

The development of functionality within TKC has continued while we are implementing across services. There has been expanded interest from other specialties in the opportunities offered by TKC's integration of primary and tertiary data, particularly the automated summation of longitudinal information. This has led to a significant expansion in the number of users and variety of disciplines now accessing TKC.

We have continued to engage with Aboriginal medical services with several more services now in the process of implementation. COVID19 continues to play a part in the reduced travel around the NT, impacting on our ability to assist health services on the ground with implementation. However, we have continued to support services through virtual meetings using Zoom and Teams. More than 85% of Aboriginal Services are now partnering with TKC.

For those services where we have already implemented TKC, we are providing 6 monthly population health service reports through an iterative process that allows the health service to modify reports according to their needs. The data architect has been instrumental in developing a reporting pipeline that enables reports to be produced automatically and at regular intervals.

Demonstrations to the various groups and overseeing bodies across the NT Department of Health and NT Department of Corporate and Digital Development have raised the profile of TKC, ensuring TKC remains high on the priority of the development teams tasked with transitioning different data systems to the new clinical information system. This has been particularly important given advice to us late last year that the new Enterprise Data Warehouse (EDW) would be replaced with a Microsoft SQL Server (MSSQL) backend, contrary to the advice we were originally given that the current Oracle Database backend would remain.

As a result, the migration of the TKC backend from the Oracle Database to the new MSSQL Database has necessitated the rewriting and testing of all extraction, transformation and load scripts to ensure they function correctly against the new MSSQL database. A rewriting of scripts that operate within the database environment (the Rules Engine) which powers the advanced analytical capabilities of the TKC system is also required. However, this requirement has provided an opportunity to future proof TKC

by creating interoperability between systems through the rewriting of the code. Server space within the new warehouse for TKC has been made available.

In collaboration with the DoH, NT Primary Health Network and several GP practices we have developed and submitted a Medical Research Future Fund (MRFF) application to extend TKC to all preventable non-communicable diseases and urban private GP practices in the NT. If successful, it will offer the opportunity to develop a truly unique clinical decision support system for the NT population.

The formative evaluation has commenced after receiving ethics approval and the accuracy assessment (including specificity and sensitivity analysis) is almost complete. The analysis plan for the process evaluation is underway with the development of data capture and survey tools. Ethics approval will be sought from the relevant NT bodies including AMSANT.

The summative evaluation plan, examining the impact of TKC and comparing it with CKD management systems in Western Melbourne and Tasmania, will take some months to finalise. The ethics application will need to abide by the rules and regulation of three jurisdictions. However, an activity plan for this work has been completed and the quantitative analysis plan, which will compare the differences in data and outcomes between the jurisdictions is currently under review.

Phase Four Deliverables

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

Complete: Aboriginal medical 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 DoH to Aboriginal community controlled. TKC currently includes all primary health services under the Department of Health (56), the five tertiary hospitals and 12 Aboriginal medical services (Figure 1) Of the 20 services identified on the map, 12 are currently contributing data to TKC, four are either in the consultation or implementation phase and a further three in the early discussion stages.

We expect our coverage of the NT by mid 2021 to be nearly 90% of Territorians at risk of kidney disease or who have kidney disease.

Figure 1: Aboriginal medical services currently participating and consulting with TKC
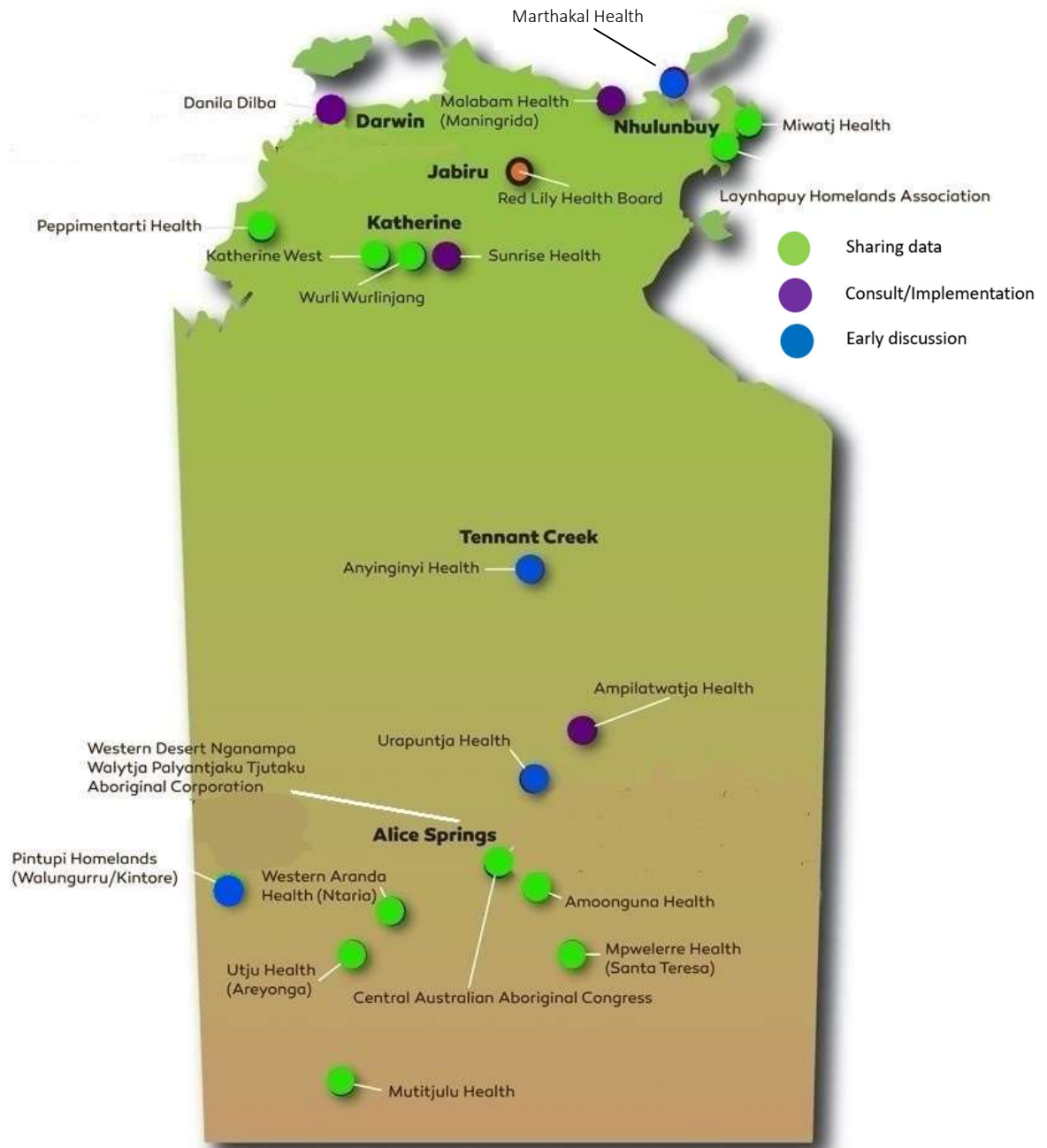
Deliverable Two: 6,000 CKD Patients within TKC Database

Complete: As of December 2020, there were just over 9000 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. As we achieve full coverage and integration with Aboriginal Medical Services across the NT our understanding of the burden of CKD will be enhanced. This information is now being shared with individual health services and the Department of Health in a process of validation.

**Figure 2: CKD by stage and district - identified by ICPC codes results**

Overall - CKD Clients by District
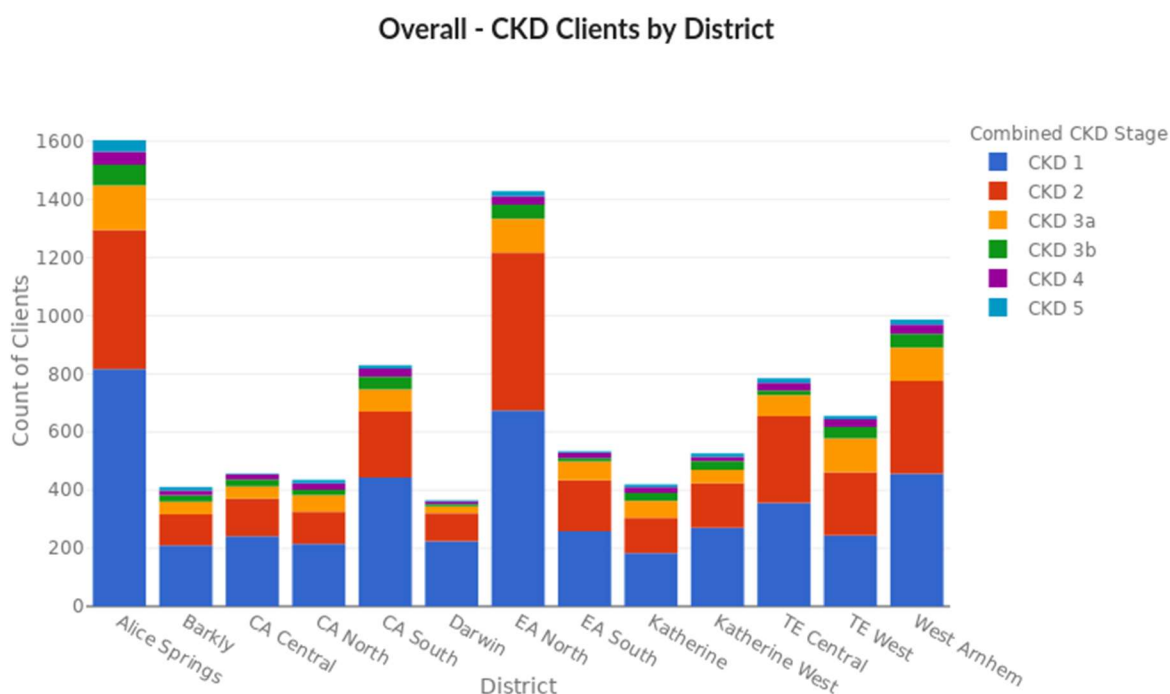
Deliverable Three: Nine Patients Saved from Dialysis.

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 prevent progression to dialysis. This is now possible through TKC. Patients with CKD in TKC are identified through classification based on pathology results, as well as recorded diagnoses in the electronic record system. This method aims to fill gaps where there had previously been significant delays in diagnosing patients and therefore 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, people in the very advanced stage of CKD ie CKD stage 5 are still being identified as having been undiagnosed. TKC simplifies and creates a time and resource efficient surveillance and monitoring process for the earlier identification of people with CKD. The Clinical Support Unit are now identifying these patients and referring them promptly and appropriately to the Nephrologists and GP. We expect to see the proportion of people with relevant ICPC codes missing to decrease over the next year.

Figure 3: Number of NT people with advanced stage of CKD - diagnosed and undiagnosed
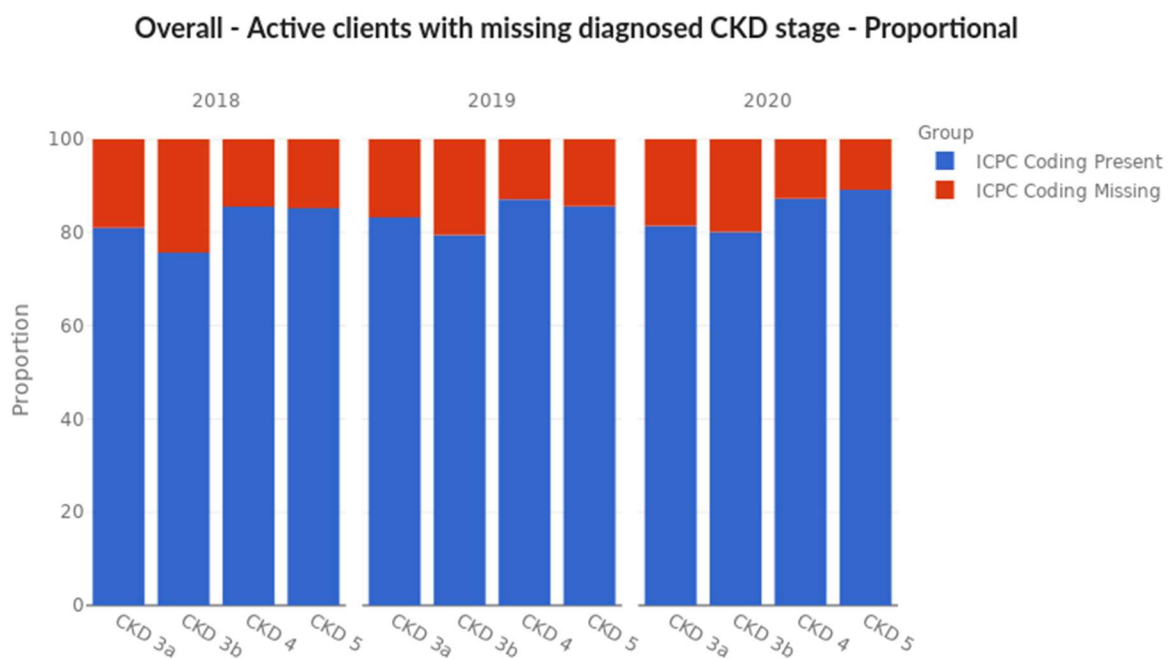
The progress of an individual from chronic kidney disease to end stage kidney disease and the requirement for dialysis, often occurs over several years with opportunities for intervention along the patient journey. However, the relationship between an intervention (such as the implementation of evidence-based treatment recommendations through TKC), and an outcome (such as the avoidance of dialysis), will not become fully evident immediately. The five-year evaluation, focusing on a number of key indicators, will provide the data points necessary to assess this metric.

# Deliverable Four: TKC Transitions to NT Health

In Progress: The transition to the Department of Health is in train but TKC will not be fully absorbed until the completion of the DoH's clinical information replacement program (Acacia). The DoH hosts

the system and provides the IT infrastructure, licensing, maintenance, security and technical support for the server. The gradual transition of positions to the Department has commenced with the time of the Clinical Lead/technical expert and Consultant Nephrologist and clinical staff based in Alice Springs no longer being supported by TKC. The Health Informatics RN will also be absorbed into business as usual by June 2021.

There is strong support for the continued development and expansion of TKC and opportunities to identify other funding sources to this end are being developed in partnership with stakeholders. We continue to engage with organisations, universities and industry (such as CSIRO) in other jurisdictions who have similar interests in developing integrated systems of care.

The worth of TKC, beyond the management of renal disease, is evidenced by the increasing number of clinicians from other specialties requesting access to TKC. There are over 100 registered users in TKC with approximately 75 using the system regularly to review patient data for clinical purposes.

**Figure 4: Number of TKC users by different providers**

TKC Production Users (Total Users: 90)
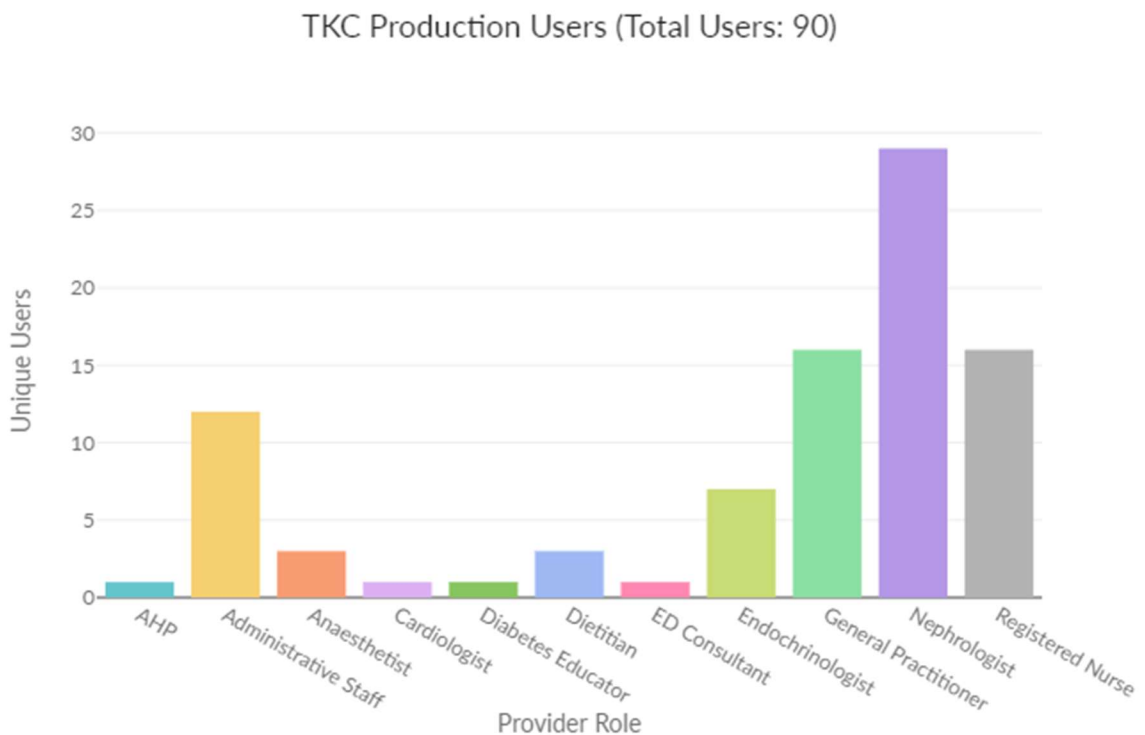
Deliverable Five: 1,191 Expected dialysis treatments avoided

In Progress: We cannot uniquely identify the number of treatments avoided by previously 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 progression 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.

We are now able to identify the number of people who have a hospital admission (by health service and district) and the frequency of hospital admissions per year. This will provide opportunities for health services to focus on patients with frequent admissions and target resources to reduce the number of avoidable admissions. The below graph shows the number of admissions per year, stratified by CKD status, for anyone who had a hospital admission (excluding Z49.1 the code for a same day dialysis admission).

Figure 5: Number of hospital admissions (excluding same day dialysis admission) per year by CKD status
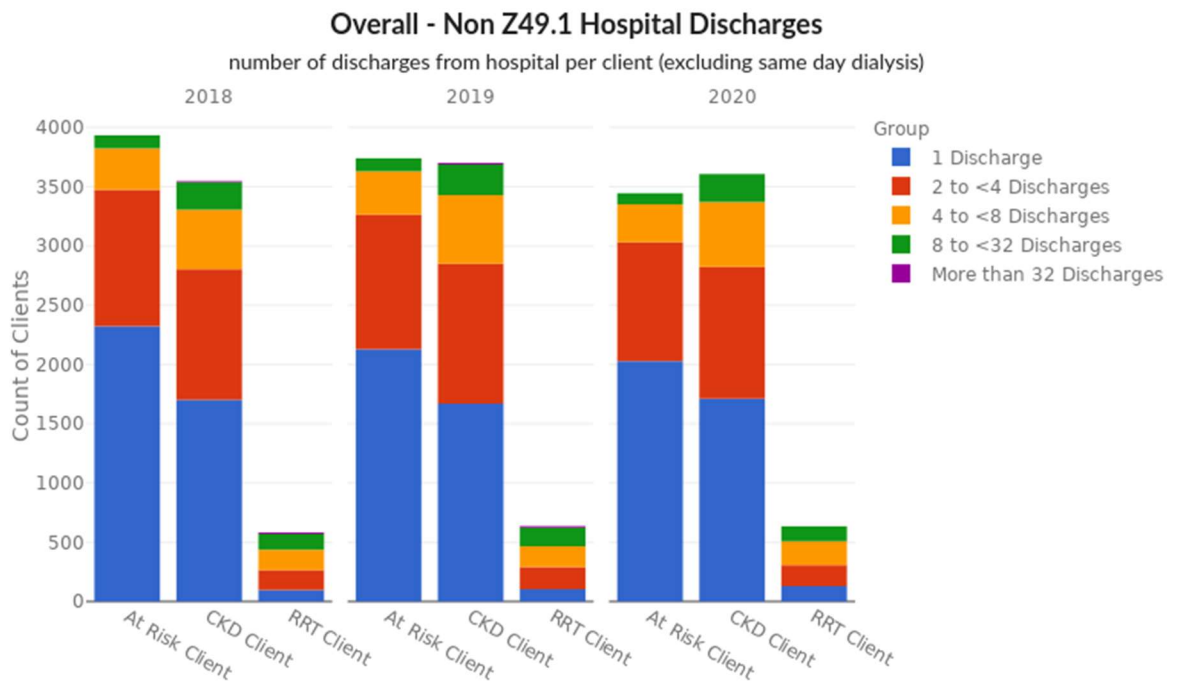
Communication Strategy

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 and we continue to offer face-to-face presentations for a variety of stakeholders. In November 2020 we held a Show and Tell for interested parties as part of a planning day for the TKC project team and Clinical Support Unit.

We have presented regularly to Department of Health senior executive, Clinical Leadership Team and the Department of Corporate and Digital Development.

We are currently reviewing our Governance structure to ensure we remain relevant and representative of our stakeholders.

Achievements and Next Steps

The profile of TKC is increasing and we continue to seek ways to partner and expand the capability of the system. There is a growing recognition that TKC offers a unique and innovative mechanism to improve integrated care between tertiary and primary health services and improve the clinical and patient experience.

Territory Kidney Care received recognition nationally when the Department of Health presented TKC under the banner of *Future of Health Care* at **the #GovAfterShock Silver linings: beyond the silos** event in November.

The high quality and impact of the Territory Kidney Care system was recognised with the awarding of the ***Northern Territory Digital Excellence Award for Community Benefit*** in November 2020.

We continue to talk with potential partners and seek funding to support the ongoing development and improvement of the system.

We have submitted a large funding application in collaboration with multiple partners (DoH, NT Primary Health Network, private GP practices, Radical Systems) to the Medical Research Future Fund (MRFF). This funding is aimed at improving Primary Health Infrastructure and seeks to improve the integration, embed within the new clinical system Acacia and linkage of patient data for the improvement in population analysis and evidence-based care. Our submission focuses on the extension of TKC to all preventable non-communicable diseases and urban private GP practices.