

# **Territory Kidney Care Progress Report**

**November 2018**



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## 1. Background

In 2017 Menzies School of Health Research negotiated with a philanthropic organisation to fund the establishment of an integrated clinical information system to support early identification and improved management of people with kidney disease. Previous proposals to Government/s had noted the unrelenting and increasing demand for dialysis services in the NT, the escalating treatment costs and that the limited understanding of the current and future burden of chronic kidney disease (CKD) had prevented effective forward planning. Recent collaborations with both the Department of Health and Aboriginal health services examining CKD management, along with national and international evidence, suggested improvements in early identification and management were not only possible but critical to stemming the tide of people entering end stage kidney disease (ESKD).

Menzies proposed a strategy to stakeholders: evidence translation in the form of an integrated clinical information system that included a clinical decision support tool. The system, incorporating a secure and automated extract from participating health services (to limit impact on health services), consolidates a patient's record across multiple government and non-government health services, thereby closing the information gap. Risk stratification identifies patients at various stages of disease progression and clinical decision support, based on evidence based best practice guidelines from renal specialists, ensures primary health clinicians are provided with timely and relevant information.

The Agreement with the Funder was conditional on Menzies obtaining support from the NT Minister of Health and the NT Department of Health for the long-term sustainability of the system, should it prove effective.

The delivery of this project is unusual for a number of reasons:

- Menzies involvement is not as a research organisation but as a facilitator of evidence translation and coordinator of stakeholders.
- The Funder has taken a substantial risk in committing significant funds (over \$3M) for a health project with no commercial value, no economic gain for them, no Intellectual Property rights and no prospect of future ownership.
- As the Funder wants to remain anonymous, there is no benefit for them in terms of profile raising or media attention.
- By committing to deliver a successful outcome (based on the belief that health service providers share a common goal to improve the care of people with chronic and kidney disease) in return for the funds, Menzies has also assumed a significant risk.

Funding for the development of TKC has been allocated in stages over 4 years, with each funding allocation dependent on the successful attainment of pre-determined milestones and deliverables. This report covers the activities and outcomes for Phase 2 of the Project.

## 2. Overview

The TKC project has progressed from the finalisation of a feasibility study to the successful completion of the Proof of Concept. We are currently in the build and testing phase of the system

development. TKC operational governance structures are in place with the establishment of the Steering Committee, Clinical Reference Group and the Technical Reference Group.

The TKC is being built and hosted within the DoH data warehouse environment. Once implemented Menzies staff will not have access to the system. TKC currently has MOUs in place with four individual Aboriginal Community Controlled Health Services (ACCHO) for the build and test phase, although only data from two health services is currently being used in the test system. This has enabled the testing of the amalgamation and consolidation of patient records from different health systems.

The decision to participate in TKC will be the decision of individual ACCHO health services. Patients may also Opt-out of TKC. Partnership Agreements and data governance protocols are being developed.

Over the last few months the Menzies Project team have focused on specific activities related to the build and testing of TKC. These activities have included:

- Development of the TKC Business Rules and Data Dictionary to document TKC system design and data quality protocols
- Development of clinical decision trees and clinical decision rules
- Mapping the clinical decision rules to TKC data components
- Embedding clinical risk mitigation and management protocols in the system
- Expansion of the TKC Governance structure to include the Clinical Reference Group
- Establishing the Clinical Decision Support Team
- Testing and validating assumptions with clinical users.

A significant amount of work has been completed in relation to the development of the clinical decision support system. The aim is to develop a computerised clinical knowledge base that can make patient-specific assessments or recommendations based on the individual clinical characteristics of a patient. The technical translation of clinical decision trees and risk stratifications is key to this work and is critical to developing an accurate computerised knowledge base. It is an iterative and incremental process that requires broad consultation.

Some delays in other areas of system development, which are dependent on stakeholder activities, have enabled broader consultation with national and international experts in the field. Agreement on translation language and the initial rules-based engines have been reached while development around knowledge engineering, which will result in patient recommendations, is ongoing.

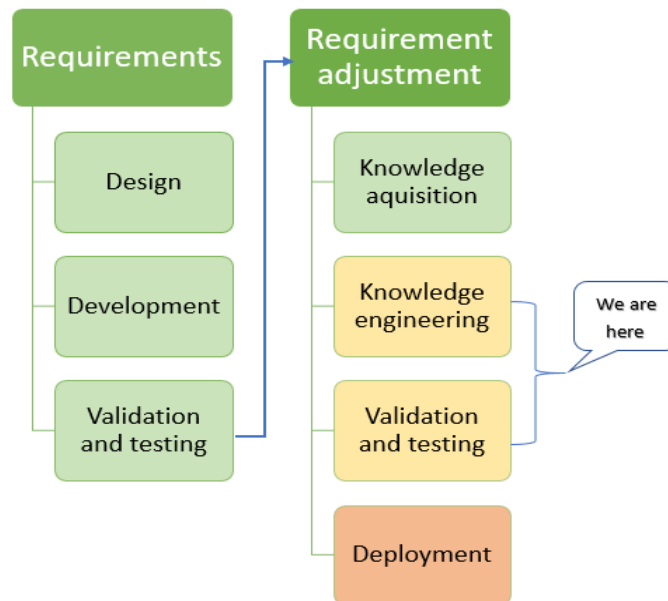
The TKC team is currently working with health services to validate outputs from the test data and define reporting parameters and formats. Testing of secure data extraction via Argus is dependent on health sites using Communicare upgrading to Communicare version 18.2 or 18.3.

Development and testing of TKC outputs delivered via secure messaging is in progress and is dependent on assistance for Communicare and DoH systems.

However the system will operate in conjunction with current manual communication channels.

Current development status is represented in Figure 1.

Figure 1: Steps and status of TKC Development



### 3. Governance

The Governance Structure includes a Steering Committee consisting of broad representation of primary health clinicians, service providers and organisations; tertiary service clinicians, policy makers and technical staff including data managers and representatives from Acacia (Core Clinical System Renewal Program). Representation is evenly split across the regions. A Clinical Reference Group and Technical Working Group have also been established to advise the Steering Committee and guide system development. A Consumer Reference Group will complete the Governance Structure.

Through this structure, the development of the governance framework for phase 3 of the project has commenced. This has included the development of a Draft Participation Agreement including data governance and access protocols for when the system is implemented. Consultation with stakeholders is still at the preliminary stage as the full requirements of an Agreement, ostensibly for clinical patient care and not research, are still unclear. However, there is acknowledgement that the model of participation developed must be sustainable and address all areas of concern for participating health services. Once endorsed, the Agreement will enable health services to participate with confidence in TKC.

### 4. Project Progress

#### 4.1. IT Build Contract Awarded

The IT Build contract was awarded to Radical Systems on 15 August 2018. Radical Systems are a well-established company in the NT with a strong background in health information system design and business intelligence. They were engaged initially to undertake a Feasibility Study and, after demonstrating their sound knowledge and understanding of the project requirements, developed the Proof of Concept.

The TKC design and build phase has adopted the following quality cycle activities:

- I. Requirements adjustment – functionalities for subsequent clinical tasks refined
- II. Knowledge acquisition – evidence based best practice clinical guidelines interpreted by clinicians and defined as rules
- III. Knowledge engineering – translation of clinical rules
- IV. Validation and testing – User acceptance testing and stakeholder feedback
- V. Deployment – task dependencies within partnering organisations have delayed deployment.

## 4.2. System Development

### Requirements Adjustment - functionalities for subsequent clinical tasks refined

Data provided by the participating health services during the Proof of Concept phase is continually reviewed to refine the Patient Consent model, inclusion components and clinical tasks to be performed.

Specific areas of refinement included:

- i. candidate selection criteria
- ii. patient identity matching protocols
- iii. demographic data protocols
- iv. component data elements
- v. data conformity rules
- vi. development of an Opt-out solution for individual patients and health services
- vii. reporting requirements.

### Knowledge acquisition - evidence-based best practice clinical guidelines interpreted by clinicians and defined as rules

Evidence-based guidelines<sup>1</sup> were interpreted by renal specialists, defined as rules or algorithms and mapped within TKC. The aim of TKC is to:

- i. identify patients at high risk of CKD and those with undiagnosed CKD
- ii. classify CKD patients according to International Guidelines
- iii. stratify the risk for patients progressing to End Stage Kidney Disease (ESKD)
- iv. estimate time to ESKD based on longitudinal data
- v. evaluate the care and management of CKD patients
- vi. identify patients currently undergoing Renal Replacement Therapy (RRT).

### Knowledge engineering - translation of clinical rules

Significant effort has been placed on the design of the Clinical Decision Support Systems (CDSSs) within TKC. The accurate translation of clinical rules is critical as it forms the basis of all further analysis and subsequent recommendations made by the Clinical Support Unit. Nationally and

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<sup>1</sup> KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease

internationally recognised classifications and language have been used for standardising and coding data extracts eg METeOR, ICD and ICPC.

All developmental aspects of the system have been documented in the TKC Business Rules and Data Dictionary. This living document is continuously updated as TKC is developed. The document provides safeguards for quality assurance and clinical risk management, ensures a completely transparent developmental process and enables replicability.

It is important that TKC is integrated into the workflow of the Renal Services and that the advice and recommendations (decision support) are delivered at the time and place of need; that is the patient record in the primary health service. These recommendations must be actionable and aid health professionals in their clinical practice and therefore must also meet the workflow requirements of primary health services.

This component of the development is iterative and requires ongoing communication and workshops with clinical users and the clinical reference group.

#### Validation and testing - User acceptance testing and stakeholder feedback

User acceptance testing (UAT) is currently underway and includes the development of the Clinical Support Unit interface. The recruitment of the TKC Informatics Nurse, currently in progress, will support the development of this crucial aspect of the TKC system. Audit log review and error testing is essential to evaluate and validate TKC processes.

Draft example reports for the three levels of information have been developed for validation and UAT by the Clinical Reference Group and participating health services. These include individual patient recommendations, operational reports for individual health services of 'at risk' patients ie those declining rapidly and prevalent reports useful for planning and reporting requirements eg CKD patient numbers, by disease stage and undiagnosed. Stakeholder engagement sessions are scheduled with clinicians and health services to further inform the design, development and implementation of reporting.

#### Deployment

Preparation for the move into the production environment is underway but full operational deployment of TKC is dependent on the completion of three critical tasks.

1. Upgrade to Communicare V18.2 or 18.3 by Aboriginal health services to enable the extraction and secure delivery of scheduled reports, via Argus to the DoH. The upgrade has been stalled by issues in the 18.2 version unrelated to the transfer functionality developed for TKC.
2. Development of the HL7 message format from TKC to health services which requires input and possible resource allocation by the DoH for configuration and testing.
3. Meet DoH requirements (technical and governance standards) for moving to the production environment. The TKC project and technical team continue to engage and work with DoH corporate services to ensure the final TKC system design, functionality and documentation, meet the DoH approval process.
4. Deployment is also dependent on attaining consensus from stakeholders and participating health services in relation to:
  - TKC Participation Agreement and Data Governance and Security Protocol

- TKC Participant Health Service Implementation Plan(s)

These foundation documents are currently in *draft for consultation*. Menzies has allocated funding for Aboriginal health services (or AMSANT on the behalf of their health service members) to seek independent legal advice regarding the Partnership Agreement.

#### **4.3. TKC Current Test State**

The TKC test data base currently contains 58,470 consolidated patient registrations although this is likely to contain a number of deceased individuals. Patient records have been extracted from government and non-government primary health source systems as well as the Department of Health (DoH) Tertiary Care system. The DoH primary health care systems include all primary health services in the NT. Two Aboriginal Community Controlled Health services have also contributed a one off data set to the test system.

Only patient records that meet the TKC selection criteria are extracted from each source system, and only the identified TKC data components are extracted for each record (if available).

Patient matching audit logs indicate the vast majority of records arise from a single source system eg Caresys or PCIS, which is expected. 13.9% of TKC registrations have been linked across two source systems while 2% are linked across three or more. Audits also noted a small proportion of patients, with the same name and date of birth, were not linked due to missing or unmatched HRNs. Many of these appear to be data entry issues and opportunities exist to present this information as a data quality improvement exercise.

Work with the clinical user group is ongoing in terms of validating data and developing reporting parameters.

### **5. Risk management**

The TKC Risk Register is maintained and reviewed by the Steering Committee at each meeting. A number of risks have been closed and new risks have been added with mitigation strategies. The Risk Register is available for review.

### **6. Communication Strategy**

The TKC project team continues to maintain the Stakeholder Engagement Database identifying key stakeholders and communication strategies. Monthly project updates are provided to the TKC Steering Committee. Bi-monthly updates on project progress are provided in summary to all stakeholders via email lists and the Menzies TKC Project webpage. Detailed progress reports are provided to key stakeholders to ensure project governance and oversight is maintained. The TKC Frequently Asked Questions (FAQs) is a living document that is continuously updated to provide clear information in response to questions raised during stakeholder consultations and engagement sessions. It is available on the TKC Project webpage and can be emailed on request.



## 7. Appendices A: Data Flow

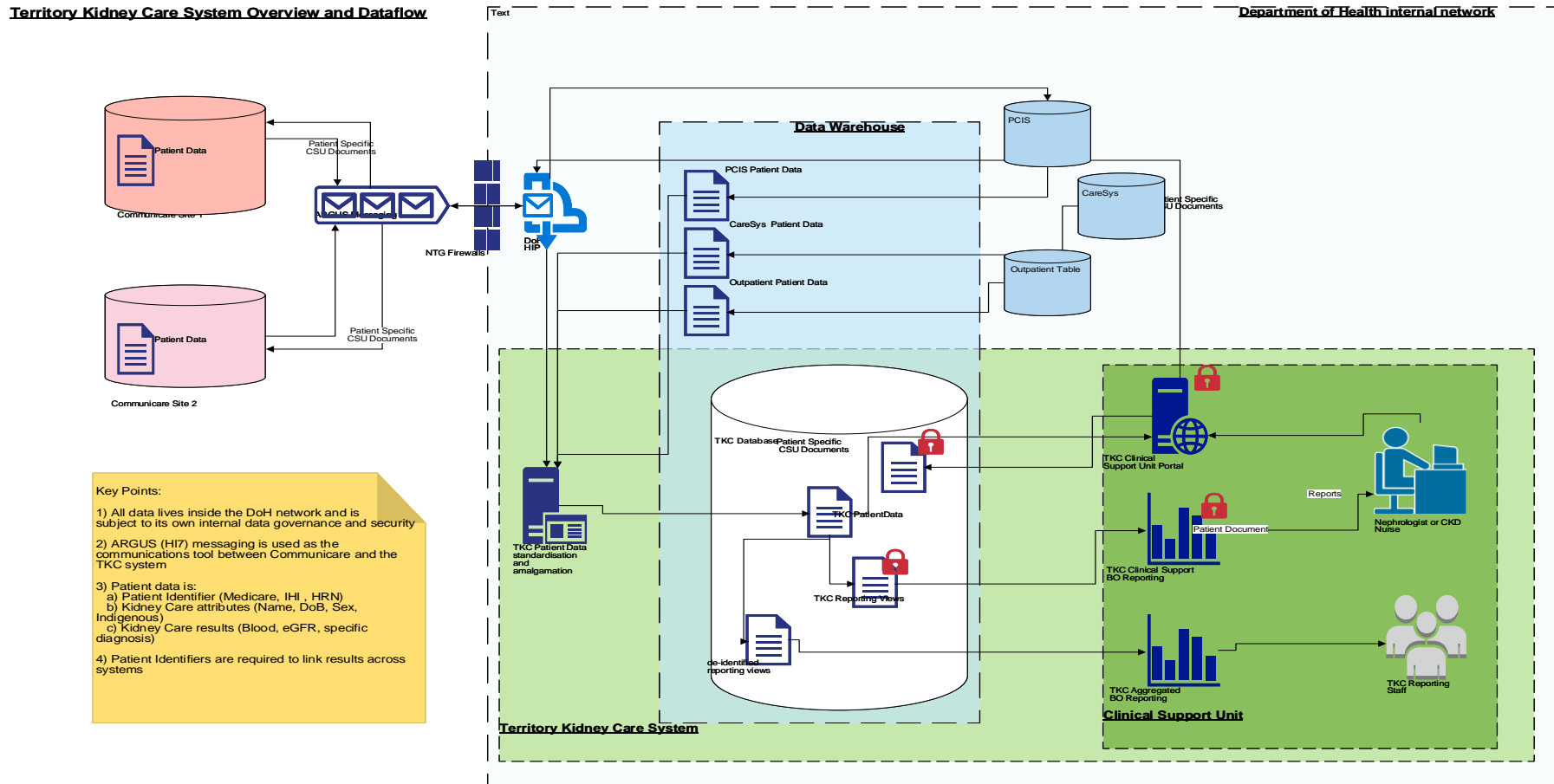


Figure 2: Territory Kidney Care Data flow

## 8. Appendices B: Process Map Example

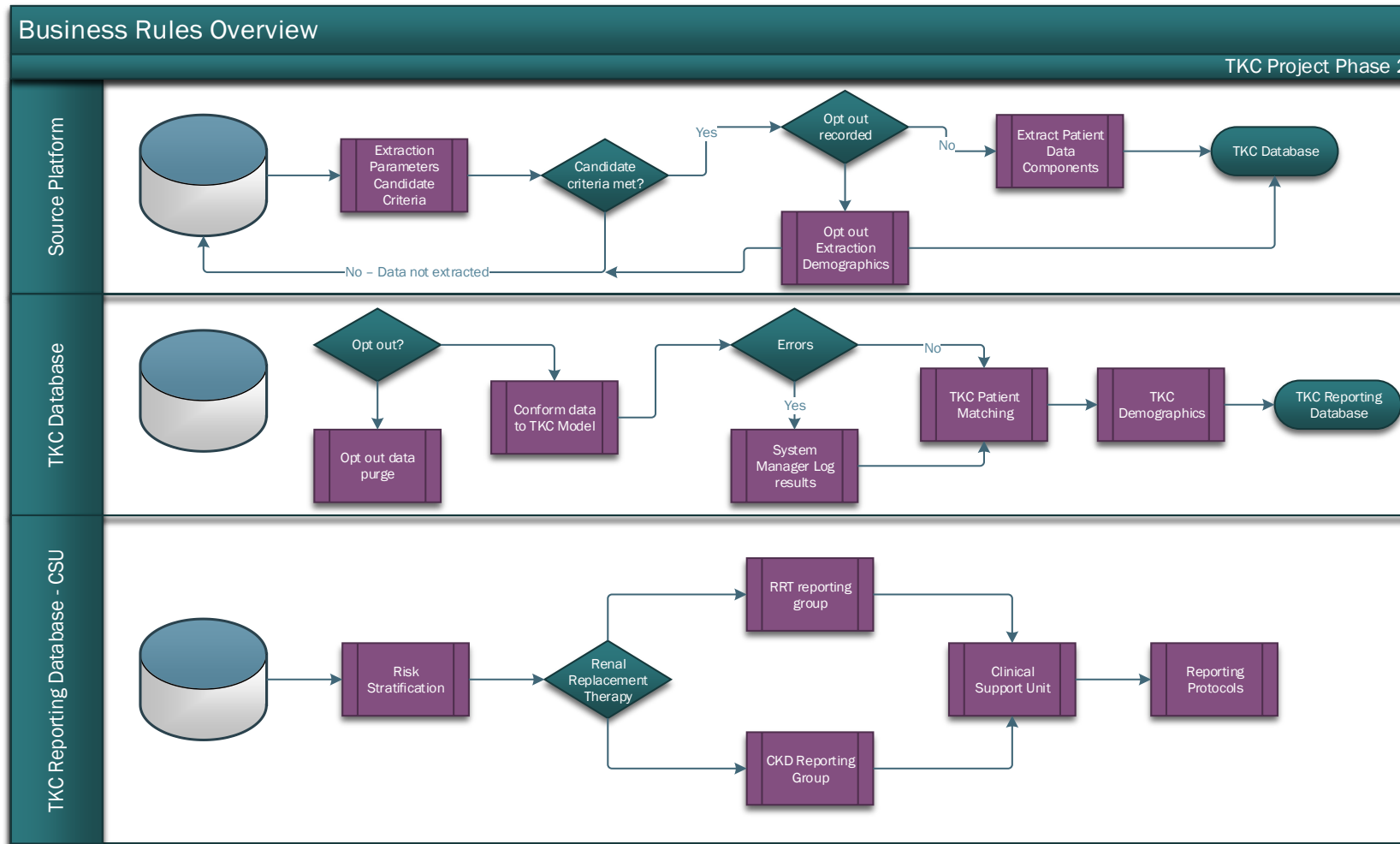


Figure 3: Territory Kidney Care Process Map