Territory Kidney Care Meeting Summary Paper

Purpose of meeting:

The meeting on the 15th of March was an opportunity to bring together representatives from primary health care services across the Northern Territory to discuss the progress of Territory Kidney Care. The agenda remained flexible to allow for rich discussions so that benefits, challenges, opportunities and collaborations could be explored as a group. Presentations to initiate discussions included:

- Renal Health Pathways - Christine Lesnikowski
- NT Renal Services - Cherian Sajiv
- Patient Journey - Asanga Abeyaratne

A demonstration of the Clinical Support Unit interface was provided to help attendees visualise the format of reporting that is possible.

A list of attendees and organisations can be found on page 5.

Overview of project:

Territory Kidney Care is a proposed integrated clinical decision support system for the management of chronic kidney disease in the NT. The aim is to improve the identification and management of *all* people with kidney disease across the Territory to slow the progression to dialysis.

Since commencing in April 2017 the project team have engaged with health services and technical staff to discuss the concept and seek feedback. The Steering Committee continues to meet monthly and early planning to establish the operational governance structure is underway.

A proof of concept is in progress with the Department of Health (DoH) to test the concept and identify any challenges. Territory Kidney Care aims to be available for primary health care services across the Territory however initial development is focused on connecting with PCIS, CareSys and Communicare. Future development includes Medical Director, Best Practice, Genie and Trakcare.

Outcomes from the proof of concept together with the level of support from Communicare sites will be reviewed to determine if Territory Kidney Care should progress to full development – Phase 2.

Meeting Summary:

Technical Comments

Ian Pollock, Chief Data Officer provided an update on the Department of Health's (DoH) involvement in the project. The DoH can support the hosting requirements for TKC on the existing platform. Technically the solution is simple to implement and the approach is similar to the national My Health Record opt-out. The system would be governed by its own governance and data sharing arrangements.

TKC will use any existing patient identifiers (i.e., multiple HRN or IHI/Medicare Care) to link patients. It is important that pilot sites that potentially share patients are tested to confirm the ability to link patient records. Hospital pathology is within the technical scope of TKC. The possibility of uploading the individual patient TKC report to the national My Health Record was discussed as being of value and potentially being utilised until pathology is added to the national My Health Record and a shared care plan is available.

Actions:

- Review feasibility of document upload to My Health Record
- Identify pilot sites to test patient linking through identifiers
- Include hospital pathology in TKC

Patient Journey Comments

An overview of, renal disease and service provision in the NT, growth in demand for dialysis treatment and the challenges faced by NT Renal Services was presented by Cherian Sajiv, Head of Renal Services. The presentation highlighted the number of people with CKD that are crash-landers (50% commencing dialysis unprepared) into renal services and the resulting poor outcomes and cost impacts. The group discussed potential reasons for this but noted disengagement of patients from health services was a recurring theme and ways to improve this needed to be identified. Cross border issues and engaging health services in these border regions as part of TKC was discussed.

It was noted that many communities are planning for dialysis services but do not know how many community members are receiving care in urban facilities or the number that may want to return home. Additionally many primary health services are managing the primary care of dialysis patients and their clinical information from tertiary services would be useful.

Christine Lesnikowski presented on the Renal Health Pathways that are being completed by the NT PHN. They are being tailored to the context of the Northern Territory and any existing resources can be forwarded to Christine to be included (Christine.Lesnikowski@ntphn.org.au). TKC will link to the pathways as part of the patient specific decision support provided to health services. In the future TKC information will be included in the pathways.

Asanga Abeyaratne, the Clinical Lead for TKC, presented an example patient journey where the detail of the clinical history would have made a difference to patient management. The example identified where a 'flag' could be raised in TKC, with the potential to change clinical management and improve the patient journey. TKC would allow communication between tertiary and primary care earlier in the patient journey when opportunities to impact on the trajectory of CKD are greatest (for example early CKD with severe Acute Kidney Injury).

The group discussed the value of including patients on dialysis or with acute renal failure so that the patient journey to return home to their community and initiate a plan for this is possible. The success of TKC was discussed as being dependent upon all or the majority of health services participating to ensure that the patient journey is as complete as possible.

Actions:

- Review feasibility of cross border health service participation for TKC.
- Scope of TKC to include dialysis and acute kidney failure.

TKC Project Comments

Gillian Gorham confirmed that resources have been allocated in the project funding to provide the capacity for staffing the Clinical Support Unit. Dedicated and quarantined funding that is closely integrated with NT Renal Services will ensure that decision support is timely and focussed. Sarah Giles commented that it will need to be clear how the healthcare home for a patient is decided to avoid receiving alerts or reports for people that are not based at a particular service. Joe Parry confirmed that TKC would present the patient with the list of health services and it would allow the Clinical Support Unit to determine which health service is accessed on a regular basis or most recently. This can be detailed in the business rules.

The group discussed the future of TKC and the critical importance of demonstrating the value to ensure that it is considered in future planning for DoH. Including a target statement for the project early is important. Areas where improvements are likely to occur include:

- less direct patient contact with tertiary service and therefore reduced patient travel, reduced staff outreach and less cost
- an improved referral system benefiting from improved information enabling triaging
- more timely and targeted information
- reduced hospital admissions
- better prepared patients for ESKD; and
- improved best practice care.

Demonstrating health service support is required for the funder. The DoH has indicated their support through a Letter of Support from the Minister of Health and the establishment of good working relationship with Menzies and a commitment to establish the host system.

The funder is keen to understand the current level of engagement from non-government primary health services including Aboriginal Community Controlled Health Organisations (ACCHOs). An MOU outlining Health Services willingness to participate in the design and development of TKC has been drafted for circulation. This is a non-binding document and does not commit any organisation to contributing patient information to the system.

The MOU is intended as a means to demonstrate support from this sector to the funder and as a mechanism to seek feedback on TKC.

Future development will include private general practices, however demonstrating their support at this stage is not currently required.

Phase 2 of TKC from April to September will require clinician input to ensure appropriate functionality of the system. Discussion on the make-up of this group indicated that participants should be practicing GPs and RNs who will be the end users of the system. Expressions of interest are currently being sought by Karen Thomas, Project Manager. When Phase 2 funding is confirmed further details will be provided.

Actions:

- MOU to be circulated to ACCHOs for feedback and endorsement
- Ensure adequate testing through live pilot sites to ensure system meets needs of users
- EOIs for clinical user groups to be circulated and nominations returned to Karen Thomas
- To draft the Business Rules for TKC early
- To consider the CQI collaborative in the future
- To build in support where possible for primary health services to improve and increase patient engagement

General Comments

Alan Cass provided an update on the National Renal Roadmap that was announced at the recent Renal Roundtable in Darwin with Hon Ken Wyatt. Alan Cass and Gillian Gorham have been part of discussions to advocate for an MBS item that is adequate for dialysis and these are ongoing. Gillian and Karen have been working with a number of primary health services and non-government organisations on a funding proposal to support community determined initiatives around the implementation of TKC. This has a particular focus on increasing patient engagement with health services, health promotion, and training and employment opportunities.

Date: 8:30am-12:30pm Thursday 15th March 2018
Venue: Seminar Room JMB Menzies RDH Campus, Darwin

Attendee	Organisation
Liz Moore	Aboriginal Medical Services Alliance NT
Leo Curran	Anyinginyi Health Aboriginal Corporation
John Boffa	Central Australian Aboriginal Congress
Leslie Manda	Central Australia Health Service
Sarah Giles	Danila Dilba Health Service
Tamsin Cockayne	Northern Territory PHN
Cherian Sajiv	Central Australia Health Service
Ian Pollock	Department of Health
David Chatterton	Radical Systems
Joe Parry	Radical Systems
Kym Davis	Sunrise Health Service Aboriginal Corporation
Paul Burgess	Top End Health Service
Dana Fitzsimmons	Top End Health Service
Alan Cass	Menzies School of Health Research
Gillian Gorham	Menzies School of Health Research
Asanga Abeyaratne	Top End Health Service/TKC Clinical Lead
Karen Thomas	Menzies School of Health Research
Margaret Cotter	Aboriginal Medical Services Alliance NT
Steve Buchanan	Menzies School of Health Research