Clinical Reference Group Workshop Feedback Summary Report

This report summarises the feedback from the Clinical Reference Group Workshop held on the 22nd November 2018. Attendees included primary health representatives from both government and non-government services as well as renal service clinicians and the project team. Workshops were held at both Alice Springs and Darwin on the same day and connected via webex.

This report also includes the feedback and input from attendees at subsequent health service presentations conducted in the following week.

The intention of the workshop was to ensure primary health services and clinicians at the coal face, had the opportunity to provide input into the development of the feedback and reporting mechanisms developed in TKC and validated clinical knowledge acquisition processes. From a development perspective it was important that:

- The project team fully understands the differences in the way clinical information systems are used across services, to ensure clinical components extracted are treated equally.

- Clinicians provide feedback on what information would be useful to help them achieve their clinical objectives and what components are required to deliver this.

- Clinicians provide advice on how this information should look and where it should be received.

An overview of progress to date was provided and discussion took place on the following aspects of the TKC Business Rules and system development:

- TKC Patient Selection Criteria

- TKC Identity Matching Protocols

- TKC Consent Model and Opt-out functionality

- Evidence based best practice – TKC Clinical Decision Trees – Derived Components

- TKC Reporting Protocols.

The workshop is a starting point for the discussion and collaboration required to inform development of the three levels of reporting to be provided by TKC. Business rules developed as outcomes of this workshop will be documented in the TKC Business Rules and Data Dictionary. Further work will also be undertaken with individual health services to design reports that are unique to the health service.

TKC Patient Consent Model

The TKC Patient Consent Model was presented and discussed – general feedback included acknowledgement of the TKC opt-out functionality developed within the Communicare system and the promise of assistance to develop a TKC awareness campaign for health services.

Patient selection criteria

Patient inclusion criteria for TKC follows national guidelines for people who are 1. at high risk of developing CKD and 2. those with CKD either documented with a diagnosis or calculated on blood results.

Exemptions discussed:

- Although Aboriginality is a risk factor for CKD, it has not been included in the selection criteria for fear it is too broad.

- Smoking was raised and discussed but attendees agreed this was poorly documented in terms of currency.

- Children - age is limited to individuals over 16 years - Discussion on certain conditions occurring in children (SLE/PSGN and Diabetes) - agreed that numbers are quite small and perhaps can be considered at a later stage.

- Other indicators/risk factors: Cancer, Lupus. Currently not included at this stage but maybe considered at a later stage

Early validation/evaluation of risk factors conducted on test data have shown that for ACCHO patient records extracted into TKC, by far the majority of individuals have more than one documented risk factor. Based on patient selection criteria, only 254 individual records contained one risk factor (less than 1.73% of all records) with no other components recorded.

TKC Identity Matching protocols

TKC Identity matching protocols were presented and discussed. TKC is committed to embedding clinical risk mitigation and management protocols in the system. External data validation and patient matching evaluation is in progress to provide audit and confidence measures on matching protocols. Risk mitigation strategies for patient matching are based on erring on the side of caution. However, TKC will include feedback reports to individual health services, identifying possible patient matches where linking of records did not occur due to possible data entry errors eg transposed numbers or missing digits. Health services may then address the data entry issues and correct records as they see fit.

Clinical Decision Trees, TKC Derived Components.

The clinical decision trees were presented and explained to attendees. Clinical decision processes have been mapped by senior clinicians and engineered within TKC based on National and International best practice guidelines. Information/data required at each point along the patient journey to inform clinical and management decisions were discussed. Discussions then focused on the type of information required for immediate patient clinical decision support (level 1) and patient management (level 2) reports.

The following is a summary of the feedback, but individual responses have been collated on a separate spreadsheet and are available on request.

Level 1 Reporting – Clinical Decision Support

What information should these messages contain

The general consensus was that Level 1 information should focus on clinical decision support for patients that required 'immediate' attention based on a sentinel event; acute decline, trend detection indicating negative change eg undiagnosed CKD which is rapidly progressing.

Specific advice might include: further investigations needed; medication changes; recommendations. Attendees also acknowledged that information that can be actioned is more useful such as warnings of potential drug interactions, ways to minimise harm, translation of new information eg drug

interactions or changes in dosing requirements.

Attendees acknowledged that they can see high value in specialist support and information without the patient having to see the specialist.

Attendees also noted that the graphics illustrating clinical changes or how the different clinical components fitted together (spider map) were instructive and might be useful for explaining disease progression to patients.

All recommendations arising from TKC needed to identify the nephrologist making the recommendation, their contact details and link to resources (Evidence based guidelines and patient education information).

Where should information go and which Position would action

There was agreement that Level 1 information needed to be witnessed by a delegated clinician in the primary health services. As some services were reliant on visiting officers, it was determined that individual health services should determine where the information was sent – generic *Documents in-tray*, Clinic manager or GP. Therefore, the health service processes would determine who was responsible for witnessing and actioning information.

Should there be an ability to feed back to the CSU after receiving a message

Normal communication channels will remain open, primary health staff can still discuss via email or phone with the renal physician servicing their catchment area. They can also contact the nephrologist that provided the recommendation, for further information or clarification in the same manner.

In the same way GPs can still request a file review for patients that may not yet be categorised or identified as high-risk CKD (eg someone with poorly controlled BP already on three agents).

Level 2 Reporting – Lists

What clinical information should be included/ where are the information gaps

Level 2 reports are intended to easily identify previously unknown CKD clients and changes in known CKD clients. The lists are intended to improve operational aspects of care and allow a reprioritising of workload. It is an alternative/complimentary form of OPD management for the CKD patient cohort.

In theory, clinics can report on high risk CKD patients themselves but due to multiple conflicting priorities 'we often rely on reports generated by others (eg "traffic Light" reports) to identify at risk patients'. The reports generated by TKC are intended to value-add to current reports and use longitudinal information as well as more than one risk factor component to identify patients eg a patient with poorly managed diabetes and previous admission for AKI.

Level 2 reports can be individualised per health service and attendees described the value of creating "worry lists" ie those with CKD who can improve with intervention; lost to follow up; with acute kidney injury event (date and severity), or a summary profile of the health services population eg CKD by risk, stage, aetiology, dialysis by category.

Where /which position should these reports be directed

Again, there was agreement that individual health services should determine to whom and where these reports are sent as they contain identified information. Attendees suggested a variety of individuals including the clinic manager (who would forward to appropriate position), Chronic disease

coordinator or CKD Nurse if available.

It was also suggested that for the DoH, the information flow should follow the same path as per the Chronic Conditions Management Model (CCMM) for TLRs dissemination: CQI facilitators, preventable Chronic Conditions clinicians(PCCEs), District managers, Outreach Allied Health, RMPs and others. However, as level 2 lists are meant to support patient management (and therefore should result in patient review at some stage) this list may be more appropriate for level 3 reporting.

When / how often

There was some difference in opinion regarding frequency of these reports with some attendees indicating monthly to counter the lag in the current TLR; 3 to 4 times a year if there was enough change in the population group and their disease to warrant this frequency where others thought services may find twice a year is enough. Reporting frequency can be customised to community or region especially for those with higher rates of disease or numbers of dialysis clients.

Level 3 Reporting – Aggregate Reports

What sort of reports

Level 3 reports provide population reviews and are intended to be used by health services for annual reporting, planning and advocacy purposes. They can be customized to each health service although a suite of standardized reports will be developed to be delivered at pre-determined intervals.

Feedback suggested adhoc reports may be required which are at different levels eg NT wide, TE and CA, regional, community etc. There was strong support for better understanding of demand for dialysis services, uptake and occupancy rates through this reporting.

Where should they go / How often

Director of Medical Services for each HS

6 - 12 monthly / Yearly

See level 2 reporting for DoH as well.

General Comments / Implementation

General discussions acknowledged the value of screening however, providing the additional information does not automatically translate to improved outcomes. Current barriers to PHC preventive interactions is health literacy – lack of resources.

Report graphics need to be simple, eye catching and would be very helpful to use imagery that can be taken to community to give feedback to the community on this data.

Menzies could support the development of culturally appropriate resources/programs for use by PHC/Chronic disease Nurses with patients eg through complimentary programs aimed at translation of evidence into practice.

Health services could use the information to support a prioritization of education and preventive interactions at the clinic level. Attendees acknowledged the ongoing conflict for staff between Acute Care vs Chronic Disease Management. Prior to implementation Menzies will work with health services to develop appropriate plans that include indicators for evaluation to ensure a comprehensive approach to chronic disease management.