Summary Paper

Proposed CKD Clinical Quality Registry and Support Unit

Workshop - 1st August 2017

Overview

The meeting on the 1st August was the first collaborative gathering of interested stakeholders in the development of an automated system to support primary health services in the care and management of people with chronic kidney disease. The forum and workshop followed individual presentations to government, Aboriginal community controlled and private health service providers. Attendees included representatives from the government and nongovernment primary care sectors, tertiary and specialist care, policy makers and experts in information and data management.

The broad representation of stakeholders and strong attendance reflects the intense interest and desire by all to determine sustainable and community inspired measures to address the increasing burden of kidney disease in the NT.

A list of attendees and organisations can be found in the appendices.

The format of the meeting was designed to:

- Provide an overview of:
    - The known level of kidney disease in the NT including resource impact of demand
    - National and International approaches to CKD management including evidence based strategies
    - The proposed system and possible feedback formats

- Encourage discussion and feedback throughout the presentations

- Identify barriers, opportunities and similar projects or duplication

- Identify issues for further discussion

- Determine the most suitable approach to progress the proposed project.

Seating configuration was designed to encourage participants to mix and share ideas with attendees they would normally have little contact with eg Tertiary service staff from Central Australia seated with primary health service staff from Top End.

Session One

Kidney Disease in the NT state of play: Alan Cass

This opening session described incidence and prevalence of chronic kidney disease (CKD) in the NT and impact of demand on service capacity and financial expenditure. Data on rates of early referral to a nephrologist and type of access on start of dialysis (reflecting patient preparedness for treatment) was also presented. A discussion followed on the opportunities for improving the patient journey.

National and international approaches

This session described approaches to CKD prevention and management nationally and internationally. Regions that have a CKD registry were listed and a recent report by the Australian Commission on Safety and Quality in Health Care (ACSQHC) outlined the quality improvement, clinical and economic benefits of clinical quality registries (CQR). Renal conditions were identified as a high priority for CQRs, due to the potential for serious health consequences and high cost to the health system.

A similar approach to the one being proposed has recently commenced in Canada focusing on diabetes care for first national communities. The program includes a centralised care coordinator and registry system (RADAR initiative).

The evidence supporting cost-effective measures to delay CKD progress as well as elements of effective CKD management programs were outlined and discussed in terms of how the proposed system would incorporate and support these approaches. This included screening of at risk people for early detection of CKD and intervention; optimal management of diabetes, hypertension and heart disease through adherence to evidence-based protocols; nurse-led, primary health services driven program; culturally appropriate patient education; intensive patient follow-up and early specialist referral.

Questions were then proposed to the group including how can we support services, will centralised data utilisation help, how will it improve efficiency, what is useful and what should it look like?

Progression of CKD and the patient journey: Asanga Abeyaratne

The complex patient journey was illustrated using graphs which highlighted the difficulty in identifying the real disease trajectory of a CKD patient from current reporting systems. The rate of progression is dependent upon many factors and understanding which patients are predicted to progress more rapidly, would be an advantage to prioritising patient care and focusing efforts.

An overview of how a centralised data collection system, coupled with a clinical decision support tool, could add value to current patient management provided by primary health services, was provided. This included identifying at risk groups for rapid progression, risk stratification, algorithms for individualised care, enhanced patient journey mapping and benchmarking for quality improvement. The proposed value of reporting at three levels was explained. This included population level, cluster level and individual level. Feedback to clinicians would be via current systems (PCIS/Comunicare) and in the same way pathology data would enter the system and require 'witnessing'. Example mock ups of feedback reports were shown including example: individual patient report with management recommendations; and an aggregate report from the NT KPI's.

It was stressed that the design of the system would not require additional data entry. Data contribution and feedback would occur through existing clinical systems such as PCIS and Communicare.

Proposed CKD Clinical Quality Registry and Support Unit

The objectives of the proposal were detailed, which stressed the need for a partnership approach if a meaningful and useful tool for supporting quality improvements in CKD care were to be developed. The proposal has a focus on improving the patient journey through better understanding of the disease trajectory. The proposal includes an evaluation of the program. A flowchart showing the four-pronged strategy was shown (see figure 1).
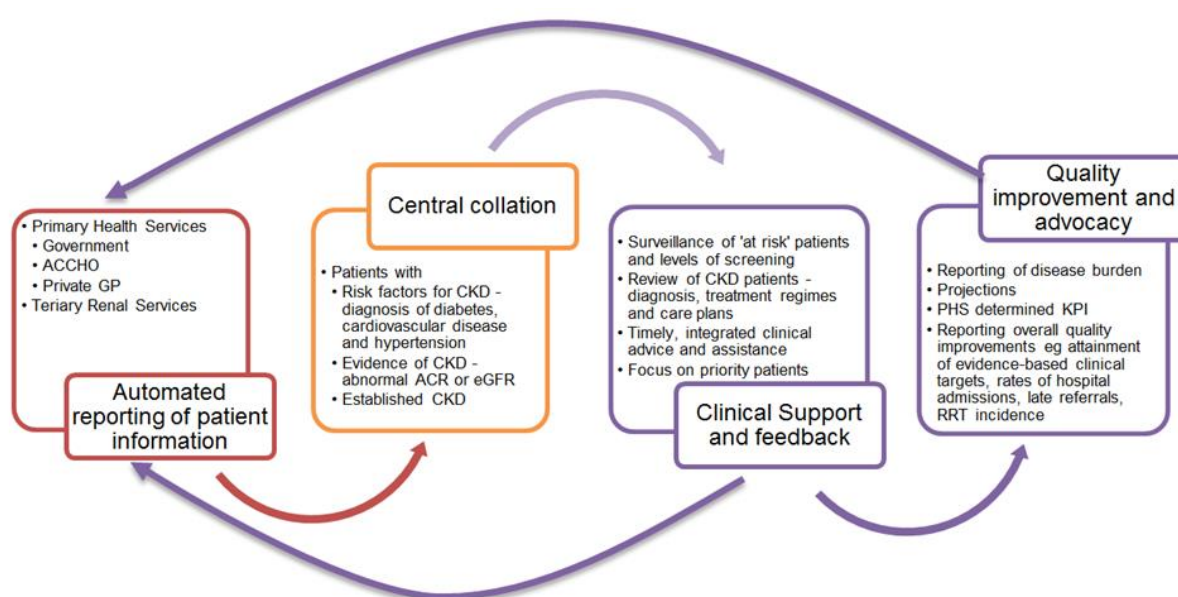

Figure 1 - Four-pronged strategy

Discussion – Issues raised during and after the presentation

Discussion was generated around whether a register was required and what additional value this project could produce.

Health services are already screening and managing CKD patients and have the suggested reporting capabilities in place. How will this system add value?

- Patients attend multiple services - primary (government and nongovernment) and tertiary - and information is siloed. The aim is to ensure information is accessible to all health care providers in a timely manner.
- Additionally, high staff turnover and an increasing chronic disease burden was noted as challenging health services in their ability to review data and prioritise patients to improve their journey and delay progression. An added clinical tool that could provide further information and reduce the burden of work would be useful for many services. However the emphasis is on enhancing existing initiatives including chronic disease care plans, screening, self-management and prevention.

Questions were raised on who would be making the clinical recommendations (provided in the feedback reports) and how would decisions be made.

- Recommendations regarding clinical decisions would be made by tertiary based specialists and based on national and International guidelines. The proposal includes a clinical support unit consisting of nephrologist and Nurse Practitioners who would undertake the monitoring of the data and provide feedback based on algorithms via existing systems to primary health clinicians eg as a HL7 report that enters the patients record and must be witnessed. It is anticipated that the clinical support unit would be integrated within the renal service.

If information is intended to be given back to the health services to be used immediately, is this mechanism/tool best described as a registry or a clinical decision support tool?

- The term registry is problematic as it clearly has connotations for many people of data collection for research purposes. The name should be changed to one that stakeholders are comfortable with. This is a decision for the Steering Committee once established.

The group discussed the possible locations that data could be stored and the governance arrangements, highlighting that this is a critically important issue.

- There was support for collated data to be hosted by the Department of Health

A discussion followed on the national Health Care Homes initiative and the contractual obligation to use shared care plans as part of the national My Health Record system. An attendee provided an overview of the shared care plan concept, which was received positively by the group as a useful tool. However, the national digital health plan, which will be released next month, will initially focus on child and maternal health and a renal care plan is not on the radar for some years.

It was noted that this proposal provides an opportunity for the NT to develop the requirements for a renal shared care plan (which incorporates atomised data), which if successful, could

then be adopted nationally. A meeting to discuss this with the Australian Digital Health Agency was proposed and agreed to be pursued.

An attendee provided details of *health coaching* which is an initiative that has been successful in First Nations communities in Canada and may address workforce gaps for the NT.

Primordial prevention was raised and a discussion on best evidence for public health followed.

The role of Aboriginal people in data governance and how this program of work can facilitate access to and understanding of clinical information by Aboriginal patients was identified as a potential positive.

Although a lot of information was presented, the areas that generated the most discussion related to: the name and main function i.e. a decision support tool or quality improvement tool rather than registry; a need to be clear on the value it would provide; the location of data storage and governance arrangements and whether individual consent was required.

Session Two

Group discussions - identifying the issues

Following the break, a list of potential discussion points was presented and attendees had the opportunity to add additional items they felt warranted further discussion. The final list of issues included:

- Meaningful data variables
- Feedback formats and systems
- Clinical support – how where when
- Health coaching and other non-clinical support – what else is useful?
- Patient journey/movement (patient identifier)
- Consent and confidentiality security
- Governance structure (examples AHForum/NT KPI)

Each table was asked to explore one or more issue using the following questions:

- What is the issue?
- What is the impact?
- What needs to be done?
- How can it be done?

Participants were asked to document the main points from their group discussions and present their 'findings' to the larger group later that afternoon.

Summary of group discussions

Group 1

The discussion focused on where the data could sit (preference for DoH) including clarifying data ownership and the need for strong governance. Suggesting that it is a CQI improvement initiative and should be community centred. Issues to be considered include factoring psychosocial needs into treatment/care plans, cross jurisdictional engagement (SA/WA) and the economic benefits of shifting focus upstream. The group explained that the scope of the system could be on CKD 1-5 initially, however it would be critical to review the risk/benefit of this in the longer term. It would only be possible to determine the level of consent required when the system and data location is proposed.

Group 2

This is a CKD decision support tool. The location of the data could be the NT DoH data warehouse. The tool would provide a link between ED and primary care, support specialists and primary care working together with a person centred approach; and could be a powerful resource for GPs with less experience working with patients with complex chronic conditions. To make this happen primary health services will need to agree to contribute data. The focus should be on CKD 3-5 initially and this could be achieved by reallocating existing resources, such as current CKD staff time. However there would need to be careful consideration of the impact of this approach on current workloads. The group discussed workforce implications and emphasised the importance of reviewing gaps in case management, recognising the impact of staff turnover and focusing on local workforce with new

initiatives, such as health coaching, which was mentioned earlier. As the tool would be used for clinical care, individual consent may not be required. The clinical data in the patient record in Communicare and PCIS is already being analysed by specialists and the proposed individual clinical support could provide opportunities to focus conversations more effectively during regular teleconference meetings. It is important that this proposal works with other initiatives such as the national shared care plan and doesn't create another silo. This tool could provide an improved understanding of preventable hospitalisations.

Group 3

The discussion focused on the issue of consent and it was agreed that the determining factor is the purpose and utilisation of the data being collected. If the purpose of the data collection is unclear than an alternative is the opt in consent model. It would be a patient decision support tool not a registry and the benefit of the tool should be informed decision making at the front-line and heavily hinged on an interactive shared care plan. It could also address the gap between primary and tertiary care. A scope of CKD 1-5 is too broad and may increase the burden on primary care. The tertiary services would benefit from broad use of the data for service planning but the benefit for primary health services must be at the individual level. A group discussion followed on the interaction between this and the shared care plans and the Core Clinical Systems Renewal Program (CCSRP). The shared care plan as part of the national My Health Record system is changing to an opt out model

from late 2018 and so this would eliminate the issue of consent. The CCSRP will commence rolling out in the Katherine region in 18 months and could provide an opportunity to drive change.

Group 4

The issues discussed included the change of focus to CQI and the need to improve patient outcomes. It could be used to breakdown the populations into manageable groups and identify gaps in following up care plans and access to medications/services and appropriate education. There is a need to determine what an appropriate service is, patient accessibility and the local workforce who can support this including clearly defined roles for community workers and career progression. This tool is an opportunity to improve the continuity of care and incorporate other initiatives such as health coaching across all stages of chronic conditions with a focus on the social determinants of health. The group discussed what noted the following:

- Changing role of AHP and less of a focus on brokerage and prevention
- Need to better understand primary health workflow to support services and system
- Need for lay person role in health coaching but also opportunity for health coaching at certificate level.
- Consider developing role description and a curriculum tailored to the NT context for health coaching - plan for integrating into the workforce to reduce the barriers that exist for current Aboriginal Health Practitioner training

A wider group discussion followed on the decreasing numbers of AHP, focus of AHP role and ability to change the

existing focus rather than creating a new role.

Group 5

This is a quality improvement collaboration not a registry. The issues discussed included how this could be integrated into current systems to add value and build on current processes, and the critical importance of data governance. The positive impact of this could be additional support for current processes. Communities will need to have confidence in the governance and the data ownership. To develop this, a systems approach to encourage best practice is required which will include 'change management' – make it difficult not to do the things that should be done. The DoH could host the data and there may be opportunities to link with existing initiatives including the CQI collaborative. There is a need to focus on 'value adding' and not duplication.

Group 6

The group consisted of technical stakeholders and focused on the systems that could be utilised. Systems integration with existing initiatives such as the shared care plan model should be reviewed. It was recommended to use a staged approach starting with the NT data warehouse with links to PCIS and Communicare for decision support. Engaging with the Australian Digital Heath Agency at the right time is required to emphasise that for the NT, CKD is our highest burden and a priority for addressing health outcomes. The national agenda is focussed on child and maternal health in the short term and to integrate any models created as part of this project it is important to engage early so that this can be incorporated into any future national plans. Regarding data

standard, the minimalist approach would use ICPC/HL7 however in the national space this is OEHR/HL7 models. Considering standards for future integration is important. Embedding clinical protocols is also important and it was suggested to review the iCare net project, risk stratification and algorithm tools. A consultation regarding the use of secondary use of data for the national My Health Record system will commence soon. If the intention is to possibly expand this nationally then it is essential to use the IHI identifier which has improved validation processes for matching patients.

Key themes from the group discussions

- The proposal is a clinical quality improvement strategy
- The design is based on a clinical decision support tool with clinical support
- There is general support for the establishment of the proposal
- There is acknowledgement that the DoH is the most appropriate place to host the data
- We should proceed to establish a Steering Committee to progress the project. The Steering Committee will:
    - Establish governance structure
    - Determine scope of data contribution – eg CKD 1-5
    - Determine name
    - Determine host location

Where to from here?

An overview of the development phase was presented (see figure 2). From now until the end of November an IT organisation has been engaged to complete a feasibility and scoping study for a possible build. There will be further workshops and meetings with stakeholders over the next few months. Expressions of interest will be sought for a steering group during this development phase. Key issues for further review include governance, system integration including data standards and location, the format of a decision support tool or shared care plan, existing/planned initiatives, consent, confidentiality and security. Feedback can be provided to the project team and regular email updates will be distributed to interested stakeholders.

Figure 2 Development Phase
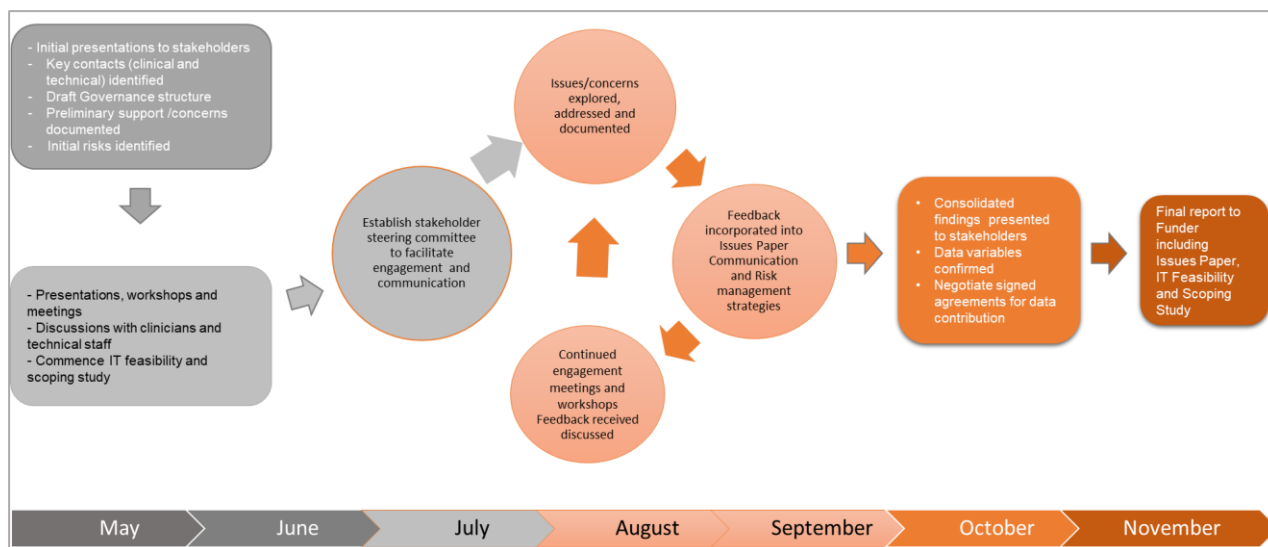
Workshop Feedback Summary

One week after the workshop 29% of attendees had submitted feedback via Survey Monkey or a paper form. Of the feedback received, 100% of attendees felt that the workshop was relevant to their work and would like to attend future workshops for this project. Feedback on the agenda, venue and length of workshop was positive. Comments received on aspects of the venue including the lack of curtains and difficulty with seeing from the back of the room will be addressed for future workshops. All feedback made positive mention of the attendees and felt that it was beneficial to have a cross section of participants from different areas of health.

Additional details that attendees would like included for the next workshop include:

- a more detailed background on CKD management across the NT
- the coaching concept
- precedents including registries, shared data storage/guiding principles
- further information on the 'to be decided' details
- a framework for Indigenous peoples in the set up and priority setting in this process

Suggestions for future workshops including involving more on the ground health professionals and having a solutions approach to group discussions. Opportunities to have workshops with this focus will be reviewed.

Additional feedback was received via email and has been answered in the Question and Answer section below:

Q. How could this be integrated into existing models of care. For example, who changes the prescription, is this completed at the primary care level and is there an opportunity to reduce the delay that can present between reviews and a patient consultation.

A. *The proposed tool is intended to provide additional recommendations to support prioritising patients and improving efficiencies. For example, the primary health care service may receive three patient alerts to recommend medication is reviewed including which medications are advisable. The proposed tool would not replace a patient record. Primary health care services would continue to manage and have ownership over patient care. The ability to have patient data reviewed by a specialist on a regular basis could reduce delays for patient's consultations, particularly patients living in remote locations. Additional funding is available for a small team of health professionals to work in the clinical support unit. It is anticipated that this unit would have close links to existing NT Renal Services Staff to avoid further duplication and silos.*

Q. There is a need for additional mechanisms to ensure that locums and primary health care professionals are appropriately skilled to understand risk and rapid progression for CKD and the need for active treatment. There could be opportunities to use monthly case conferencing with professional development with organisations such as the PHN or RAHC.

A. *The proposed project is intended to support the health system including governance, workforce, service delivery, financing, information and technology. There is funding available for initiatives that support the proposed tool including professional development. The governance arrangements would be responsible for determining the best approach and approving these supports.*

Documents

The following document is included as an attachment for circulation to attendees and attendees who were an apology for the workshop.

• Presentation slides 1 August 2017

The other documents – listed below - of interest to the attendees are available on the Renal Web page – no login required.

https://www.menzies.edu.au/page/Research/Projects/Kidney/CKD_clinical_quality_register_and_support_unit/

Attendees

Name	Organisation
Adam Whitehead	Radical Systems
Alan Cass	Menzies School of Health Research
Andrea Andrews	Sunrise Health Service
Anthony Burton	Department of Health
Asanga Abeyaratne	Top End Health Service
Beth Hore	Danila Dilba Health Service
Carol Farmer	Central Australia Health Service
Cherian Sajiv	Central Australia Health Service
Christine Connors	Top End Health Service
David Cooper	Aboriginal Medical Services Alliance Northern Territory (AMSANT)
Donna Ahchee	Central Australian Aboriginal Congress (CAAC)
Eddie Mulholland	Miwatj Health Aboriginal Corporation
Finlay Forbes	Aboriginal Medical Services Alliance Northern Territory (AMSANT)
Gill Gorham	Menzies School of Health Research
Ian Pollock	Department of Health
Jaqui Hughes	Menzies School of Health Research
Joe Parry	Radical Systems
John Boffa	Central Australian Aboriginal Congress (CAAC)
Julie Franzon	Northern Territory PHN
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Sally Banfield	Central Australia Health Service
Samuel Goodwin	Central Australia Health Service
Sarah Robinson	Department of Health

Sarena Ruediger	Northern Territory PHN
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