National Renal Advisory Board

Wellington Airport Rydges Hotel
Held on Wednesday, 19 May 2021
9:30am – 2:00pm
ZOOM ID: 99679607285

Chairperson	Catherine Tracy
Board Members	Alex Gordon, Ashik Hayat, Balaji Jagannathan, Blair Donkin, Brett Butterworth, Caroline Chembo, David Semple, Jennifer Walker, Michael Campbell, Michael Collins, Nick Cross, Robin Erickson
Guests	Drew Henderson, Wing Cheuk Chan, Allister Williams, Ian Dittmer, Dee Alexander (MoH)
Apologies	Suetonia Palmer, Jennifer Walker, Jon Hosking, Ailsa Jacobson

MINUTES

Wednesday, 19 May 2021		
Ref	**Topic**	**Ref**
1.0	**Open Action Items - Previous Meeting (3 March 2021)**	
	NRAB Strategic Plan for 2021 / NRAB Work Programme: board members to think about what kind of strategic projects NRAB could focus on and bring that back to the next NRAB meeting in Aug • Some clarity is still needed around MoH rep role on the NRAB; would be helpful so that NRAB can align with any work they are doing • Catherine to speak with Ailsa again to see what their view is	Catherine
2.0	**Action Items**	
2a.	**Drew Henderson** • Patient Safety / Driving after Dialysis: Drew to find and circulate document on safety around driving after dialysis; drafted by someone in Australia **Brett Butterworth** • Consumer Rep: Some discussion around the Position Description; several suggestions made on fine tuning the wording were made; Brett to edit document to include these **Blair Donkin** • Tier 2 Work: Blair to send Caroline the March 2004 NRAB Workforce Standards Document to Caroline • RSA Nursing Advisory Group: Circulate update/report to the board **Catherine Tracy** • SGLT2 Inhibitors: NRAB does not support sending letter drafted by Dr Chris Hood regarding equity of access to diabetic medications; Board Chair to advise Dr Hood • Issues at Taranaki: Draft a letter from NRAB to Taranaki CEO stating high level of concerns about the impact of the staffing issues both on the individual SMOs involved and the patient care; inherent risk in employing junior consultant; letter to be cc'd to Ashley Bloomfield	

	ALL Board Members
	• Tier 2 Document
	  ○ NRAB asked to review Tier 2 document again and feedback to Ian/Caroline.
	• Current state of Automated Data Capture & Monitoring for CKD (Actions for NRAB to consider was received after the meeting was adjourned)
	  ○ Formally endorse the use of whole of system longitudinal lab results to support service improvement and development of optimal model of care and workforce mix, (to further advance the work plans at MOH).
	  ○ In the context of increasing prevalence of multi-morbidity, and overlapping clinical indications, consider supporting MOH to lead national clinical guidelines development (that covers macro and micro-vascular risk, diabetes and CKD concurrently etc) that would better support clinical workflow
	  ○ Advocate MOH to access whole of system clinically actionable information (which may involve changing service contracts by the DHB to enable mandatory reporting of lab results in an appropriate data standard.	

Ref	**Topic**	**Ref**
3.0	**General Business**	
3a.	**Previous meeting minutes accepted.**	ALL
3b.	**Lack of Creatinine Assay Standardisation Across Labs** • Robin and Suetonia met with IANZ • There is an advisory board that meets once a year in July; would be a good opportunity to present there if we want to bring about changes in the assays and standardising throughout the country • Robin and Suetonia putting together a continuation of the presentation that was given at NRAB previously to present to advisory board	Robin
3c.	**Funding for Taxi Service and Travel for Dialysis** • Board agreed that no letter should be sent to CEO's at this time	Catherine

3d.	**Consumer Rep**
	• Some wording was drafted for ToR around what could be expected from a consumer representative on the NRAB
	  ○ The Consumer Representative(s) will bring a broad consumer perspective to Board decision making and work with other members to build equitable solutions and policies that aim to improve the wellness and outcomes for constituents.
	  The consumer Representative role profile, recruitment process and on-boarding will be documented and reviewed prior to on-boarding each new representative
	  Where consumer input on specific tasks is outside the Consumer Representatives area of expertise, the Board will consider inviting guest consumers or groups to assist
	• Brett to form a sub-committee to look at scope, purpose, roles and come back to next meeting; Suetonia to be in the initial discussions; David, Robin and Michael Campbell keen to assist; includes more immediate task of making sure we have some resources for Tier 2
	  ○ Acknowledgement and thanks to David Semple, Michael Collins, Robin Erickson, Suetonia Palmer and Michael Campbell for their assistance
	• To improve the effectiveness of the Consumer Rep role the sub-committee have the
		Brett

	following recommendations for consideration: ○ The Position Description (PD), Recruitment and On-boarding process are documented; Note that the sub-committee have drafted a PD for consideration and subject to Board mandate, will proceed to draft the recruitment and on-boarding documents. ○ There is an overlap of 6-12 months between the outgoing and incoming representative to assist with continuity ○ An NRAB Board member is appointed as a "mentor" to support the Consumer Representative. Additional educational requirements are identified and provided ○ The Board Chair and Board members review information on how to maximise effectiveness of Consumer Representatives on Boards. The NZ Health and Safety Commission website can be used as a reference source • Discussion around overlapping; board might think about having 2 consumer reps • Also should consider having a standing item on the agenda for consumer rep • Consumer Input into the Tier 2 Specification ○ It is recommended that wording be included in the Tier 2 Specification specifying that each DHB Renal Service regularly consult with a cross section of users and that guidance on a "best practice" consultation process is provided as for reference ○ Some options for providing further consumer input into the Tier 2 Specification were discussed but further guidance from the Tier 2 sub-committee on the need and timetable is desirable before progressing these • Some discussion around the Position Description; Several suggestions on fine tuning the wording were made; Brett to edit document to include these.	
3e.	**Issues at Taranaki** • Meeting held between Catherine Tracy, Ashik Hayat, Chris Hood, Allister Williams and Brian Gub from Taranaki around staffing issues and patient risks; manager stated he was unaware of any issues and any risks to patients and were putting things into place • Agreed that there be a review of the services and how it's affecting their patients; letter to go out from NRAB to CEO • Discussion had around how many nephrologists are recommended per population for each DHB • NRAB agreed letter to be sent to Taranaki CEO from the board stating high level of concerns about the impact of the staffing issues both on the individual SMOs involved and the patient care; inherent risk in employing junior consultant; letter to be cc'd to Ashley Bloomfield • NRAB advocates for appropriate cover and adequate level of transplant experience	Catherine
3f.	**Support for Adolescent and Young Adult Transition** • Data shown to NRAB around youth transferred from Starship over the last 15 yrs or so • 2004-2020: 54 paediatrics patients with transplants were transferred to adult care throughout the country and 25 on dialysis; average age being 17.5 for transplant patients and 16 for dialysis patients • Of transplant patients those that are over 22 yrs of age, 1/3 have already lost their grafts, 1 has died; average time to graft loss post transplant is 8.5 yrs, meantime is 2.5 yrs after transfer; those still younger at time of data assessment were doing poorly already • Amongst dialysis patients 36% died before age 30 • Australians have done a project nationally look at the state of youth and young adult health and have come up with a number of service recommendations; government funded project; NZ has a few local programs (ad hoc) • Adolescents and young adults are a different patient population; transfer of care may be	Robin

	less of the issue than the patient population itself • Adolescent/young adult transition of care support will be part of the Tier 2 document; need to define what best practices are for youth and young adult population • Proposal made to the NRAB to endorse a multidisciplinary working group representing various adult renal units, patient advocacy groups and paediatrics; this could provide opportunities to also collaborate with other chronic disease groups • Discussion had around transition and challenges • Proposal endorsed by NRAB	
3g.	**Current state of Automated Data Capture & Monitoring for CKD** • Presentation around "Chronic kidney disease: population level analysis for the Auckland metropolitan region: The potential to use whole of system information to support clinical work flow at the point of care" • First line treatments for diabetes, cardiovascular disease or diabetic kidney disease are sub-optimally delivered in the community • The use of whole of system longitudinal lab results (to systematically define CKD, diabetes, albuminuria etc) to support proactive and opportunistic management is a game changer • Board was very pleased at the work being done by Wing • Discussion had around what the barriers might be at service level; can potentially break it down to primary care practice level; one of the challenges is how often people move • GP practices should be made aware of what we're doing • Actions for NRAB to consider (received after the meeting was adjourned): o Formally endorse the use of of whole of system longitudinal lab results to support service improvement and development of optimal model of care and workforce mix, (to further advance the work plans at MOH). o In the context of increasing prevalence of multi-morbidity, and overlapping clinical indications, consider supporting MOH to lead national clinical guidelines development (that covers macro and micro-vascular risk, diabetes and CKD concurrently etc) that would better support clinical workflow o Advocate MOH to access whole of system clinically actionable information (which may involve changing service contracts by the DHB to enable mandatory reporting of lab results in an appropriate data standard.	Wing (Zoom)
3h.	**SGLT2 Inhibitors** • A letter was drafted by Dr Chris Hood regarding equity of access to diabetic medications • Some discussion was held around the criteria for the medication • NRAB does not support sending the letter; Dr Hood is welcomed to send it on his own • Board Chair to advise Dr Hood	ALL
4.0	**On-going Business**	
4a.	**NZ Chapter of the ANZSN** • There will be some communication coming out noting that Suetonia is going to stand down as President elect due to health issues • David Johnston from Brisbane will be new President Elect • This leaves a space on the council for the second ANZSN member; once officially publically will send out EOI for someone to take over that role • Have a conference coming up which is being organised by David Voss to be held last week in Oct • Aotearoa NZ Nephrology meeting planning is well underway – Auckland themes are environmental sustainability. Registration website going live soon	Drew

	• Aotearoa NZ Nephrology meeting planning well underway – Auckland, themes are environmental sustainability. Registration website going live soon. • New Policy Quality Committee chaired by Martin Gallagher – and soon Peter Mount with Quality Indicators and Registries Sub-Committee, Deputy Chair - Jenny Walker • Basic Course 2021 is entirely online. 22 May and 19 June. https://cdesign.eventsair.com/2021-anzsn-education-courses/registration-portal/Site/Register • 2021 Annual Scientific Meeting 30 August to 1 September – virtual – registration open https://www.anzsnasm.com/home/registration. Early bird closes 16 July 2021. • Consumer engagement policy in progress to increase patient and consumer involvement at conferences • DNT Workshop entirely online in 2021 – adjacent to Annual Scientific Meeting (28-29 August 2021) • COVID-19 working group continuing advocacy for vaccine rollout and monitoring (largely in Australia)	
4b.	**ANZDATA** • A reminder that there is a working group in NZ which has a number of roles including oversight of the chapters that have reduced and review of data that come in in relation to NZ data usage; • Making the privacy and information forms publically available on the ANZDATA website; should be implemented soon; currently is not easily accessible • The chapters of the report are now published; if there are any requests for changes those changes can be made through the chapters • Dahlia to re-circulate Michael's presentation from the last NRAB meeting (March)	M Collins
4c.	**Australian & NZ Dialysis Board** • Renal Qualification: currently considering various options to get qualifications; also considering trainee model • AUT board of studies approved proposed renal physiology qualification and the new courses will be offered from 2022. • Continue to have challenges recruiting from overseas due to COVID. • Renal physiologist workforce project supported by NRA is on-going.	Balaji
4d.	**Kidney Health New Zealand** • Have 3 new board members at Kidney Health NZ • Just appointed a new part-time social media coordinator • Advertising currently for a Renal Educator in Christchurch • Working with NRAB, Starship and Kidney Kids around a new youth navigator; Kidney Kids are currently advertising it • Some concerns raised around driving after dialysis and patient safety; from a patient perspective what are the issues around it; • ANZSN had a request regarding this issue; someone in Australia is working on safety around driving after dialysis as a document; Drew to find document and circulate to NRAB • Trying to get some funds from MoH to fund promotion around transplant; blood service currently getting less funding than ADHB got previously	M Campbell

4e.	**National Renal Transplant Service**
	• Transplant Activity Report 2020 just released
	  ○ 187 Kidney Transplant in NZ
	  ○ 100 Deceased Donor
		Nick

	○ 81 Living Donor ○ Second equal highest year (187, like 2017), 2019 was 221 ○ Substantial reduction was written in report compared to 2019 ○ Second highest Live Donor total ○ Exceptionally difficult due to COVID so a remarkable achievement for health system • COVID had a dramatic effect on transplant ○ Wellington shut for 3 weeks; ○ limited deceased donation in that time (two kidneys, both allocated elsewhere); ○ marked reduction in activity for those months and workups with possible flow on effects on activity this year • Some discussion had around deceased donors and transplants • Thinking of incorporating another representative on the national leadership team who would be an equitable access representative of some sort; expert non-clinician vs. a specific patient representative there to keep an eye on what policies are likely to cause in terms of access equity problems • Also looking at making a specific approach to return to the KHNZ consumer council for an annual update on how we are doing on improving equity of access to transplantation and outcomes in New Zealand • Committed to making an effort to address the inequity of access to transplant in NZ	
4f.	**Renal IT System Presentation** • Renal Reality (RR1) (2014) and RR2 (2020) "in-house" versions successfully installed and running in Taranaki and Northland; under supervision of HA (Health Alliance for Northern DHBs). Retrieval of bloods, results and renal specific care plans fully automated for each patient every 20 minutes. • RR2.5 now upgraded with additional 72 enhancements following feedback from Northland DHB , with the additional ability to customize it for Starship as part of the RR2.5 roll out June 2021 using the HA shared data repository we using for Northland. • RR2.6 planned for October 2021 with full adaptation to a better result messaging service (as per HA contractual requirements) and to release customized versions for children (Starship) and Diabetics (DiabeticReality) as CKD subgroups. • RR3 now completed as a Microsoft Azure Cloud-based Renal IT solution at national level – as per MoH standards for cloud-based solutions in terms of Cyber Security ; Standardised data exchange (HL7 FHIR) and user-based roles. Awaiting HA Privacy impact and Cloud-risk assessments. • This technology is able to deal with changes to medical records should it happen in the future • System does not automatically link to ANZDATA as it is currently sits • Some board members expressed that a national Renal IT solution is needed however, are unsure if we have enough information to endorse any particular IT solution • Allister expressed that he would like a commercial company to take it over; preferably Microsoft • Discussion had around commercial company taking over and losing some of the renal for renal benefits if taken over by commercial company • Aliister - for the next 12 months need to first finalise the in-product; 12 months away from doing the commercial side; even if sold off or taken over then should continue to have clinical input at NRAB level • The preferred roadmap is now to obtain NRAB endorsement towards a national Renal IT solution – with RR3 User interfaces customized by the renal community, for the renal community (renal4renal); so that we as users can control and determine how our NZ renal IT solution will "look and feel" going forward.	Allister (Zoom)

4g.	**Tier 2 Working Group** • Thanks was given to the NRAB for the feedback/suggestions submitted on the Tier 2 document; some adjustments and added comments received have been made to the document; any additional feedback or comments are welcomed • Some bits need a bit more discussion such as pp 3.2 around Maori Health; it might be the best we can do at the moment and note that we will be taking further advice as appropriate • Jenny mentioned that current minister may not like current terminology "Tier 2" – will remain as Tier 2 doc until instructed otherwise; some comments made around use of terms and being in an environment where we are uncertain what the government is actually going to legislate and implement, etc • NRAB asked to review document again and feedback; may need to write more around consumer; following that will go back to Tier 2 working group to review document again • Should try to build in somewhere some specific reference to reporting data to the relevant registries as part of a service level specification; have plugged in a link to the ANZDATA KPI's • Discussion around whether or not we should have something about staffing in the Tier 2 document; Blair to send Caroline the March 2004 NRAB Workforce Standards Document	Ian
4h.	**RSA Nursing Advisory Group** • Report to be circulated after the meeting	Blair
4i.	**Ministry of Health** • Dr Dee Alexander, Principal Clinical Advisor from MoH attended the meeting in place of Ailsa: she has recently joined the long-term conditions team; • Ailsa is leaving MoH • No updates currently	Dee

Next Meeting: 11 Aug 2021