# **National Renal Advisory Board**

Middlemore Hospital, Staff Centre, Rm 2-3 Held on Wednesday, 3 March 2021 9:00am – 2:00pm ZOOM ID: 94203210373



Chairperson	Catherine Tracy
<b>Board Members</b>	Ashik Hayat, Balaji Jagannathan, Blair Donkin, Brett Butterworth, Caroline Chembo, David Semple, Jennifer Walker, Michael Campbell, Michael Collins, Robin Erickson, Suetonia Palmer, Ailsa Jacobson, Chris Hood, Ian Dittmer
Guests	Scott Crawford, Terry O'Donnell
Apologies	Jon Hosking, Nick Cross, Alex Gordon

## **MINUTES**

#### Wednesday, 3 March 2021

# 1.0 Open Action Items - Previous Meeting (11 Nov 2020)

A letter was prepared by Robin to IANZ expressing concern around the clinical impact around lack of creatinine assay standardisation across labs; letter was sent out by the NRAB; response was received from Sharon Thomas, Senior Operations Manager for Healthcare Programmes at IANZ wanting to meet to discuss options.

 Robin will reply to Sharon; David Semple and Suetonia Palmer expressed willingness to also attend a meeting.

### 2.0 Action Items

#### **ALL Board Members**

 With regard to the 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

#### **Catherine Tracy**

- Speak to Margie Apa about the letter drafted by NRAB which supports continued use of taxi service and travel for dialysis to see who it should be sent to
- Clarify in ToR what the role of the MoH Representative should be on NRAB
- Discuss with Ailsa: need a mechanism by which NRAB can communicate issues to MoH; would MoH pay for a room at the airport Wellington to hold next NRAB meeting if MoH room is unavailable

#### Suetonia

- Maori Representation on NRAB: Suetonia to generate a role proposal which would also include remuneration to bring back to next NRAB meeting
- Suetonia to clarify what information from the ANZDATA Registry Annual Report would be most useful

#### **Brett Butterworth**

- Draft some wording (ToR) around what could be expected from a consumer
- 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
- Ian and Robin to touch base with Kidney Kids around what we should be putting into the Tier 2 schedule



#### **Michael Collins**

• A letter has been drafted with regard to ANZDATA and the reporting of NZ data re COVID – Michael to liaise with Ian about who to discuss it with further

## Norman Panlilio - MidCentral DHB

- Need more info on risks and what is being done to mitigate risks given in DHB Update:
  - Not enough chairs to future proof it for another 5 years; with the current increase it is practically full
  - o No surgical capacity for AV fistula
  - o No renal clinic capacity (patients are on the waiting list)

### Ashik Hayat - Taranaki DHB

• Set up meeting with Catherine, Chris, and Michael Campbell to discuss cover for SMO Sabbatical (1 year); need to detail all of the issues and can then send letter to CEO advising that this has been brought to the attention of the NRAB and that this is an unsafe unit, etc

Ref	Topic	Ref
2.0	General Business	
2a.	<ul> <li>Maori Representation on the NRAB</li> <li>Previously proposed that NRAB consider Maori representation on the board</li> <li>An EOI could be sent out to DHBs to see if there is any interest and availability to support the Board; could include Tier 2 work</li> <li>NRAB endorses this approach</li> <li>Suetonia to generate a role proposal which would also include remuneration to bring to next meeting</li> </ul>	Suetonia
2b.	<ul> <li>Strategic Plan for 2021 &amp; NRAB Work Programme</li> <li>Current strategic plan should be reviewed to see what could be moved over to 2021</li> <li>In-Centre Dialysis Capacity in NZ (Pilot Survey) – could be something that the NRAB includes in its plan</li> <li>Work around NTA</li> <li>Monitoring of the Simpson Report and the actions that MoH may take to move that along as it could have an impact on Renal patients; may need to think about allocating resources</li> <li>On-going support in relation to access and capacity for dialysis</li> <li>Workforce and Renal Physiologists is a piece of work NRAB needs to support and work on</li> <li>At the next NRAB meeting group should think about what kind of strategic projects NRAB could focus on; good to think ahead about what the board may want to do next</li> <li>Once a strategic plan is put together the NRAB could consider forming a small group to review it</li> </ul>	Catherine
2c. 2d.	<ul> <li>Joint Position Statement (vaccinations for Renal patients)</li> <li>NRAB agrees that they are an advisory group not an advocacy group and therefore does not wish to advocate on prioritising vaccinations for Renal patients.</li> <li>Renal patients are not more a priority than any other group with long-term conditions</li> <li>Request for Reporting NZ Data re COVID (ANZDATA)</li> </ul>	Catherine
zu.	<ul> <li>Letter has been drafted by lan and board had endorsed it</li> <li>Michael Collins to liaise with lan about who to discuss it with further</li> </ul>	Catherine
2e.	<ul> <li>Letter to Jo Brown that supports continued use of taxi service and travel for dialysis has been drafted by Ian Dittmer; board endorses this letter</li> </ul>	Catherine/ Ian



2f.	<ul> <li>Further discussion had around who the letter should be sent to (MoH or DHBs).</li> <li>Catherine to speak to Margie Apa (CEO CMDHB) to see what her thoughts would be on who it should go to;</li> <li>Michael Campbell to send Catherine issues they've identified as a group so that it can be included in letter.</li> <li>Board suggests that MoH be advised to consider that assistance needs to be across all services rather than just Renal; letter to MoH to be circulated out of session for the board to review before the next meeting</li> <li>Once a response is received from MoH organisations on the board can choose how they advocate</li> </ul> Consumer Representation on the Board	Brett
	Presentation given by Brett Butterworth around the role of a consumer representative	
	<ul> <li>and having one on the NRAB</li> <li>Discussion around having additional consumer reps participating in various board tasks</li> <li>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</li> <li>lan and Robin to touch base with Kidney Kids around what we should be putting into the Tier 2 schedule</li> </ul>	
2g.	Equity within In-centre HD Populations	Scott
	<ul> <li>Scott Crawford, Nephrologist, Bay of Plenty DHB (BOP DHB) - presented a short paper on "In-Centre Dialysis Capacity in NZ" and asked whether the NRAB would help facilitate sending out a survey to the Heads of unit as a means to collect some basic raw data</li> <li>Until recently BOP DHB renal was looked after as a satellite unit of Waikato requiring patients to go to Tauranga for clinic weekly and Whakatane hospital monthly; 4 nephrologists were employed to slowly develop the service within the DHB in order to be increasingly self-sufficient however since January have taken over the care of all Whakatane patients</li> <li>Increasingly having to send notable number of patients to a different DHB in order to undertake in-centre HD due solely to capacity issues at both Tauranga and Whakatane</li> <li>Data would be used to inform wider renal community about the current state of service but also as a way to benchmark BOP DHB's current position against what is routinely undertaken in other centres and as stimulus to drive discussions with planning and funding.</li> <li>NRAB advised during the discussion that end goal is not clear and suggested that it may be good to visit Jenny Walker at Northland who has already done this to gain some further insight;</li> </ul>	Crawford
3.0	On-going Business	
3a.	PHARMAC	Terry
	<ul> <li>Nipro has been listed as of Dec</li> <li>Agreement with Fresenius has been signed; seeking feedback on a proposal to list a range of haemodialysis equipment and products; consultation closes 2 March</li> <li>Agreement with Medtronic signed; consultation going out in the next week</li> <li>B Braun – have an agreement with them for signing; should have it sorted within the next week; go out for consultation later this month; looking at a 1 June listing; this is the final agreement in the Haemodialysis category</li> <li>Agreement with Baxter for their Peritoneal Dialysis signed; to go live on Pharmaceutical Schedule 1 April</li> <li>If DHBs are experiencing problems they should advise NRAB</li> <li>Suetonia happy to communicate with HODs and Nephrologists once contracts have come</li> </ul>	
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	through and advise them to communicate any issues to NRAB so that NRAB can raise the issue(s) with PHARMAC	
3b.	NZ Chapter of the ANZSN	Suetonia
	<ul> <li>The New Zealand group annual meeting is approved to take place in Auckland on October 29-30. Full details to follow. Local organising committee led by Dr David Voss.</li> <li>Governance of NZ Chapter has been reviewed. Few changes substantive. For review by</li> </ul>	
	<ul> <li>Council.</li> <li>The ANZSN annual scientific meeting set for Christchurch in 2022 will now take place in</li> </ul>	
	<ul> <li>2023 at Te Pae in Christchurch.</li> <li>The 2021 annual scientific meeting and DNT will be fully virtual including update course.</li> <li>Require a replacement for Dr Carolyn Clarke on the Scientific Program and Awards Committee. Will be sending out further EOI to NZ members.</li> </ul>	
	<ul> <li>PHARMAC responded to nearly all recommendations made by the ANZSN on expanded rituximab use in primary membranous nephropathy, indicating this is an effective approach to improving treatment for patients, 7. ANZSN COVID-19 working group is generating position statement on COVID 19 vaccination, with RSA and KHNZ with release early next week 8. New awards policy including Leadership award.</li> <li>New Quality Improvement subcommittee with Drew Henderson as NZ member</li> </ul>	
3c.	<ul> <li>Summary of data from the ANZDATA Registry 43<sup>rd</sup> annual report given by Dr Michael Collins (NZ Representative, ANZDATA Advisory Committee); sits on the NRAB as ex-officio member</li> <li>Rate of new KRT patients is tracking slightly ahead of population growth</li> <li>Have been big improvements in access to transplantation in recent years</li> <li>Home HD is falling as a proportion of haemodialysis</li> <li>Maori and Pasifika people in particular experience a high burden of Kidney Failure</li> <li>Maori and Pasifika people experience worse outcomes         <ul> <li>High proportion of patients have Diabetes</li> <li>Less access to kidney transplantation, higher mortality</li> <li>This is despite being young in age when they start KRT and not being referred late</li> </ul> </li> <li>We need to do considerably better and the need to address the inequity in KRT outcomes for different ethnicities in NZ is critical and urgent</li> <li>Report was also presented by Suetonia to the Chief Medical Officer at MoH; there was some interest shown there; was not aware report existed</li> <li>ANZDATA can provide NRAB with any data needed it would just need to be specifically requested – Michael Collins is main point of contact; Suetonia to clarify what information would be most useful</li> </ul>	M Collins
3d.	Australian & NZ Dialysis Board	Balaji
	<ul> <li>Update given about CPRB (Clinical Physiologists Registration Board) decision to actively pursue MoH recognition of self-regulation for now and consider HPCAA option in the future; discussion held suggested to pursue possibility of going under HPCAA</li> <li>Ponal Qualification: currently considering various entions to get qualifications; also</li> </ul>	
	<ul> <li>Renal Qualification: currently considering various options to get qualifications; also considering trainee model</li> </ul>	
	<ul> <li>NRAB to write support letter supporting Balaji:         <ul> <li>Otago University – run other qualifications for cardiac, respiratory and sleep; renal is accepted in principle but haven't progressed further</li> <li>James Cooks University, Queensland for Renal Physiology qualification program accepted and started in Feb 2021</li> <li>Challenges to recruit qualified from overseas due to COVID</li> </ul> </li> </ul>	



	Letter can be addressed to Balaji then he can present it to the next CPRB board meeting	
3e.	National Renal Transplant Service	Nick
	Apologies given for meeting; no report received	
3f.	Kidney Health New Zealand	М
	<ul> <li>KHNZ commenced a road show in June 2020 which has been well received with KHNZ staff providing free public kidney health checks supported by either/both local nurses/student nurses</li> <li>KHNZ has also attended other events for testing; plans to be at the Pasifika festival next weekend (COVID permitting)</li> <li>KHNZ is working with a GP practice at present to identify how they can best test for CKD and KHNZ hopes that a model can be developed to be shared with other GP practices and PHOs</li> <li>KHNZ has collected data on the testing undertaken and over the 9 months tested 550 people of whom 55 had kidney issues underlining that "one in ten" have some form of kidney disease; will continue to monitor this data</li> <li>During March KHNZ is investing in excess of \$50,000 to raise the profile of kidney disease in a range of media including billboards, newspapers, social media and media commentary</li> <li>A Christchurch based patient has also decided to embark on an epic fundraiser – Eugene Sanders (Umpire for Canterbury Cricket) was diagnosed with kidney disease and before he is unable, he wants to scooter from Picton to Bluff in the South Island; Action Requested is that Renal units circulate Eugene's challenge to their DHBs and kidney patients (if</li> </ul>	Campbell
	<ul> <li>KHNZ has upgraded the e-newsletter and hope that renal units would forward these to patients and encourage patients to join their local support group</li> <li>With the retirement of Dr John Collins, KHNZ are working with the NRAB to develop the role of Medical Advisor with Ian Dittmer and as an interim measure have appointed Dr Andy Salmon until a replacement for Dr Collins is found. A process and scope is being worked on and will be communicated to the NRAB and renal community once available.</li> </ul>	
3g.	<ul> <li>RSA Nursing Advisory Group</li> <li>ToR last reviewed in 2018 is currently being re-reviewed</li> <li>Nephrology Nursing Skills Framework published a few years ago is actively under review; hope to have it updated soon</li> <li>Workforce survey started 2016, long overdue to have that done</li> <li>Looking at where current focus needs to be; how that can tie in with NRAB, a collaborative effort</li> </ul>	Blair
3h.	Ministry of Health	Ailsa
	<ul> <li>A lot of extra time is currently going into COVID response at the moment</li> <li>The long term conditions team is looking at the areas that they need to increase focus on (renal is one of those) – have approval for clinical leader for renal to provide support and are developing EOI that will be sent out to some interested parties (NRAB may suggest who); this person could also make contribution to NRAB (attending meetings, etc)</li> <li>Send ToR to Ailsa to review; need to look at ministry's role in NRAB</li> <li>Ailsa to follow-up on issues around NTA</li> <li>Dahlia to set up a time with Ailsa to discuss other issues with Catherine</li> <li>Any issues that need to be raised with MoH can be send to Ailsa</li> </ul>	



#### 4.0 Regional Roundup – DHB Updates

#### **4a.** MidCentral DHB (Norman Panlilio)

Need more info on risks and what is being done to mitigate risks

#### Taranaki DHB (Ashik Hayat)

- Dr Allister Williams covering renal and general medicine
- SMO Sabbatical will be covered by long-term locum from June 2021 and intermittent renal locum cover once Dr Allister Williams is also away
- Issue is that the renal doctors are doing more and more work in Medicine and other subspecialties, they have to be on wards for 6 weeks covering General Medicine and off ward for another 6 weeks alternately covering renal which seriously impacts continuity of renal services, causes delays in patients appointments for new patients, delays in follow up of HD, PD and TX resulting in long waiting times
- Rostering does not work for renal as we have a continuous flow of renal patients including HD and PD, with non-stop problems
- Have been unable to cope with daily General Medicine ward rounds for 5 days a week for 6 weeks and then switching back to renal; alternative is to take time off; current working conditions are unstable for renal work
- Set up meeting with Catherine, Chris, and Michael Campbell to discuss cover for SMO
  Sabbatical (1 year); need to detail all of the issues and can then send letter to CEO
  advising that this has been brought to the attention of the NRAB and that this is an unsafe
  unit, etc

## 5.0 Other Business

- Some discussion around access criteria to SGLT2 inhibitors
- Chris Hood to prepare a document outlining concerns to be circulated to NRAB for consideration and further discussion; NRAB will then get a consensus from HODs and as to whether a letter from NRAB should be sent to PHARMAC once document is received
- Thank you to Ian Dittmer and Chris Hood who are no longer on the board for their support and contributions to the NRAB
- In the event that MoH does not have a room for the next NRAB meeting in August,
   Catherine to check if they would pay for a room for the board to use at the airport in
   Wellington (Rydges Hotel)
- Meeting closed 3:25pm