Minutes

National Renal Transplant Leadership Team Meeting
Strategic Group

Date: 24 May 2019

Time: 9.45 am – 3.15 pm

Location: Sudima Christchurch Airport, 550 Memorial Avenue, Christchurch

Attendees: Nick Cross, John Irvine, Heather Dunckley, Janice Langlands, Denise Beechey, Ian Dittmer, Jane Potiki, Jo Brown, Kristin Wilson, John Schollum

Apologies: Andrew Henderson, Andrew McNally, Chanel Prestidge, Claire Beckett, Dilip Naik, Helen Pilmore, Jane Presto, John Kearns, Justin Roake, Karen Lovelock, Karen McLeod, Philip Matheson, Ralph La salle, Stephen Munn

	Agenda Item	Discussion
1.	Welcome/introductions/ coffee	Quorate
2.	COI	No conflicts of interest to declare. Request to sign a COI declaration form if not already done so.
3.	Minutes of previous meetings	Minutes strategic group 1 February 2019 – moved Ian / seconded John S Minutes operational group 29 March 2019 – moved Ian / seconded John S FU question on nucleic acid testing protocol- deferred pending discussion with ODNZ/NZBS. Impact is additional time to organise a donor. Preferable to have result prior to transplant, but should not be mandatory. Most problematic for DCD donors where families more likely to proceed urgently. **Action:** Ian/Janice/Heather to have further discussion and report back.
4a	Actions register	1. Transplant volumes: Letters prepared for transplant units, and the renal centres. Will be sent on 31 May. Will go to CE, copied COO, GM P&F, transplant surgeon and renal CD. a. In the covering email, will include note of any issues we are aware of. b. CQI toolkit will be loaded on website when letters sent. 2. Error checking in NZKAS Waitlist. Development ongoing. Heather will provide coordinators with information for error checking. Agreed Coordinators will need to return email to confirming it is accurate. 3. Provision of Waiting List Data (NZBS) to ANZDATA. Data/privacy security concern about ANZDATA from NZBS privacy officer concern. Concerns about data security in ANZDATA and consent. ANZDATA now opt out for participation, after advice from Privacy Commissioner's office that express consent not required.

		a. **Action:** Jane to send Heather the security template b. **Action:** Set up meeting between Ian, Heather, NZBS Privacy officer and Ministry's registry lead to discuss data security requirements for data sent to ANZDATA and ANZOD to agree minimum standards. 4. Activity report – break down report by live and deceased donors, by DHB of dom – deferred for 2019 report. 5. Biopsy process for deceased donor kidneys – significant event led to question of value of biopsy. Aim to reduce number of biopsies through criteria changes, following research project underway (Ian). Also discussed prior issues of delay in samples getting to labs and length of biopsy process. ODNZ very happy to address delays if reported to them. 6. Vigilance and safety event report created in Australia by OTA to track and follow up sentinel events. NRTLT seeking access to the reports so can be considered in NZ context and protocols changed if required. May also consider providing information from NZ back to OTA. Third step would be NZ involvement in the committee. Nick still working on this. ODNZ would value receiving this information also. **Action:** Nick progress and cc Janice in on him communication on this.
4b	Correspondence	Select Committee submission discussed.
5	NKAS Clinical Director's report	

	Improving equity of access to transplant	Nick presentation at OTA
		
		Outline: access to transplantation differs by ethnicity
		
		• Drivers, process and population
		• Confounder or cause (inherent bias), and does it matter?
		• Argument for and against more live donors
		• Higher rates of dialysis for Māori and Pasifika, and a reduction in Asian rates
		• Pre-emptive transplant is very low for Māori and Pasifika
		• Variation by DHB, different demographic and geographic challenges
		  ○ Different outcomes/rates of transplant depending on where you live
		  ○ Deprivation another key determinant of transplantation
		• In Australia deprivation associated with less live donor transplant, but not deceased donor transplant (no difference)
		• Work undertaken based on ANZDATA (Dr S Donellan, Prof S Palmer), preliminary findings not yet published, but submitted in abstract and presented at conferences
		• Access to LD transplant varies by ethnicity (higher for NZE compared to others), after adjustment for deprivation and comorbidity in recipient
		• Access to DD transplant does not vary by ethnicity, after adjustment for deprivation and comorbidity
		
		Important to develop skills/expertise in these units, and to work more closely with transplant centres. Local champions to focus activity.
		
		• What can be done:
		• Patient level – remove barriers to engagement
		• Increase health literacy
		• Health practitioners
		  - Community health workers
		  - Cultural competency

		- Guidelines and decision tools Data from CMDHB suggest for live donors that come forward, ethnicity has minimal impact on eventual donation. Pacific children more likely to donate to a parent compared to other ethnicities. Risk to donor differs related to ethnicity – US study shows African American donors have higher risk of ESKD later in life.
	NKAS Report (Ian)	Waiting list relatively unchanged, but slightly lower. Suspended – 200 people activated and currently suspended Waikato has increased list in recent years. Palmerston North has reduced number listed, as has Hawke's Bay – these DHBs have the lowest physician/patient ratios. Increase in high PRAs in past two years. Over 95 least likely to be transplanted. **Action:** Heather to talk to Colleen to split highest PRA groupings at the upper end – 81-94 and 95-98, 99-100 . Waiting list by month –relatively the same. Deceased donor transplants lower than previous year, but still higher than previous years. Kidneys by rank: change in algorithm had desirable affect. 25-30% allocated by match, rest on waiting time. Waiting time by rank– rank 3 (predominantly waiting time) average wait time improved. Use of "Rank" might be confusing in this context as that term is used for individual kidney allocation (ie recipients are ranked from 1 to 15, kidney offered first to person on rank 1, then rank 2 etc). **Action:** Nick to change "Rank" to "Tier" in published Allocation document.
6	Long term suspended	Ian has liaised with coordinators and updates provided. 36 patients, up from 27 in 2016. Longest 6 years. - 1 transplanted in January - 7 relisted in April - 1 appeal against non-listing (successful) and being presented - 1 cancer stand down – to be presented - 1 parathyroidectomy - to be presented - 9 delisted permanently - 1 moved overseas 3 years ago - removed - 1 lost to different DHB (in prison) - removed - 1 died - 5 in active assessment - 2 awaiting parathyroidectomy - One each of other problems – adherence, no fixed abode, etc Coords find this a positive exercise to provide surety about status of patients and get a definitive outcome. Decided to change to an automatic "validation check" for everyone who is suspended, at the point they have been suspended for 2 years.

		Action: Ian/Denise describe process coords to go through when a person is suspended for more than 2 years. Heather can provide an alert for people waiting 2 years (included in the error checking spreadsheet).
7	Tissue typing study days	NZBS providing study days. Orientation to process and requirements. First on 11 June. Plan to do this twice per year. Open to all solid organ coordinators. 20 registered. Already have some registrars in lab regularly and can extend this to nephrology registrars.
8	Coordinator study day	Discussed under 7) **Action:** Denise/Heather to consider including tissue typing to the agenda of the DLC study day. **Action:** Nick to consider options to include on registrar training days at October Nephrology Meeting.
9	NRTLT supporting or being involved in assessment decisions	CQI concept: Donor assessment with three phases - enquiry/preassessment; assessment (must be quick, reliable); Planning for donation. Cross matching occurs variably during assessment, but usually once donor well engaged and after preliminary testing. It is done twice (at least) for each successful live donor transplant, and at least once for each assessed donor who undergoes transplant who does not proceed. Based on DHB related cross match info from NZBS, and live donor transplantation six months later, there is a reasonably constant relationship. Key message: On average, for every 4 x-matches, there will be one live donor transplant in subsequent six month period. Discussion about whether this might provide ability to plan – probably too short a time horizon to adequately plan transplants.
10	Hep C study	Progress on protocol discussed. **Action:** John S - Protocol and patient information sheet to be updated and circulated, subsequently include in NZ newsletter (Sway Palmer). **Action:** John S to provide advice to Ministry CMO (Andy Simpson).
11a	Overseas based donor complication	Specific case discussed in committee of donor who developed complications, and the relative ability of different agencies to effectively compensate. ACC is not able to provide corrective surgery outside of NZ where required, and loss of wages beyond 12 weeks compensation is not available under the Live Donor Compensation Act. **Action:** Develop guidance for all donors on complications and risks related to compensation, ACC entitlements and benefit options. Additional material for overseas donors noting non-eligibility for ACC earnings compensation. **Action: Nick/Ian** Letter to Ashley to request financial compensation to cover this situation. **Action: Nick/Ian** Provide advice to donor coordinators to update their information to overseas donors pending provision of the guidance document.

11b	Financial support for travel for overseas based donors	GMs have agreed to protocol, with the approval to be finalised in June. Additional information provided on complications as requested. **Action:** Jane – provide formal minute to Nick which confirmed, and have material posted on website.
12	QIM 3-5	Challenging: Data collection Data quality and checking Work processes to clean data Analysis Report production (all manual) Options are to change the process, and more support is required to provide these. **Action:** Nick to discuss analytical support with Ralph. If no resolution, will revert to annual report.
13	NRTS/DLC contracts	Expire in June next year. Recommendation to Ministry funding board will be to roll over NRTS contract, and to devolve DLC contracts (ie allocation to DHBs). Future of the service and agreements may be dependent upon the scope of the National Agency when established. DLCs: options would be shift to National Agency, continue to contract or devolve funding. NRTS CD: same as above. If not shifting to National Agency a change in CD is proposed, and the scope of the group should be considered.
14	NZ Donation & Transplantation Authority & NRTLT	At this stage, unclear what the national agency scope is. Discussion about the pros and cons of NRTLT being involved in a National Agency. Nick/Ian put in a submission, on behalf of the NRTLT, as agreed at the last meeting.
15	LKDA printing	KHNZ interested in printing resources. Response from DHBs on number of books wanted was not sufficient for KHNZ to print. **Action:** Denise to check with KHNZ on which DHBs said no, and who the offer was made to. FU with Drew and Andy on whether there is any amendment to content.
16	ANZKX	Making progress. Donor reimbursement, surgery start times and governance issues to be resolved.
17	LOS and DHB of Dom at ADHB	Analysis shows no material difference when outliers taken out, and that length of stay is similar irrespective of referring DHB. This suggests there isn't a systematic issue caused by variability in discretionary support from referring DHBs to provide funding (notwithstanding that individual cases may be challenging for the teams to find accommodation for, due to a mismatch of funding and available accommodation).
18	Other business	Ian interested in a project to look at people on waiting list for four years and whether they got a transplant or not. Ethics approval required. Will work with NZBS on project.

	Next meeting	**Operational Group - Friday 2019** **Ministry of Health 133 Molesworth St, Wellington**