

**Minutes**

**National Renal Transplant Leadership Team Meeting**

**Strategic Group**

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| **Date:** | 1 February 2019 |
| **Time:** | 9.45am – 3.15pm |
| **Location:** | Jet Park Conference Centre, Mangere, Auckland |
| **Attendees:** | Andrew Henderson, Andrew McNally, Chanel Prestidge, Claire Beckett, Denise Beechey, Dilip Naik, Heather Dunckley, Ian Dittmer, Jane Potiki, Janice Langlands, Jo Brown, John Irvine, John Kearns, John Schollum, Karen Lovelock, Karen McLeod, Kristin Wilson, Nick Cross, Philip Matheson, Ralph La Salle, Jane Presto |
| **Guest:** | Jo Burton |
| **Apologies:** | Justin Roake, Stephen Munn |

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|  | **Agenda Item** | **Discussion** |
| 1. | Welcome/Introductions/Coffee | Meeting started at 10.10am due to late arrival of a flight.  New attendees; Andrew Henderson, Andrew McNally, Karen McLeod, Jane Presto |
| 2. | COI | Request to sign a COI declaration form if not already done so. |
| 3. | Minutes of previous meetings | Strategic Group (25 May 2018)  Moved Ian Dittmer, seconded Kristen Wilson;  Operational Group (21 Sep 2018)  Moved Ian Dittmer, seconded Philip Matheson |
| 4a | Actions Register | 1. From 7/7/17 - Long Term Suspended Review   Provide patient details on those delayed surgery (parathyroidectomy) so the circumstances can be investigated with the surgical DHB. (Ongoing)  Jane as retrieved relevant NHIs. Given to Trisha.  **Action:** **Ian** is to ask Tricia if Jane needs to do anything more.   1. From 24/3/17 - Multiple Live Donor Assessments for Single Individual.   Develop National Guideline for multiple live  Donor assessments for a single individual.  No update.   1. From 21/9/18 – QIM 4 Recipient ‘work-up’ time.   (No metrics presented at this meeting).  Defer to a future meeting.   1. From 21/9/18 - Should NZ offer every donor the opportunity for Kidney Exchange programme?   **Ian** – ongoing development of protocol. |
| 4b | Professor Palmer’s mail out | Nick will continue to use this mail out as a method for NRTS updates.  As the email only goes to doctors, it will need to be distributed further to other relevant staff.  **Action:** **Nick** will ask Suetonia if it’s possible to communicate her mail update directly with all relevant nephrology staff. |
| 5 | CD Report  Transplant Assessment | **Calendar Year 2018 Activity Report**  Tables reviewed and explained.  Audience  1) DHBs Senior Management / Clinicians – prompt for discussions.  2) MOH reporting NRTS vs target.  Summary:   * Ongoing steady growth overall in kidney transplantation:   Deceased donor kidneys   * + 5/5 years greater than 5 year moving average   Live donor kidneys   * + 4/5 years greater than 5 year moving average * Local differences can affect patient flow e.g. timeframes to complete tests. * MoH needs to know about barriers to patient flow. * Drivers of the numbers are complex. * Drivers of deceased donor and live donor numbers are different – may be helpful to represent live donors separately.   **Action:** Create the Transplants by DHB of Domicile and Donor Type. **(Nick)** |
|  | Decisions By Ethnicity (CDHB) | Tables from the study “Ethnicity and assessment for Kidney Transplantation: A single transplant centre retrospective analysis” was reviewed and explained.  Summary – Data showed that ethnicity did not determine if the patient was offered assessment or not. |
| 6 | Projections of transplant activity in NZ | Table “Target and Observed Kidney Transplantation in NZ by donor source and year” was reviewed and explained.  Review target for annual increases– agreed 10 -14 per year increase may be reasonable balance to meet need and be deliverable.  Numerator and denominator options reviewed.  Wait list vs incident options reviewed.  Regional adjustments considered.  Effect of increment to be considered.  **Action**: NRTS/MOH to develop volume indications for annual increases per incident ESKD patient, per year, for 5 years for referring and transplanting DHBs for distribution in March/April to DHBs. |
| 7 | Final versions of:  NRTS Atlas of Process Maps (2018)  NRTS Continuous Improvement Resource (2018) | Both publications are complete and ready for distribution to DHBs; i.e. senior management and renal clinicians.  For distribution - include a short note to explain the purpose of the documents and reason for distribution.  Helpfully explain the pathways for DHBs who want to make changes and DHBs who should consider making changes based on the documentation.  If performance concerns are reported to NRTLT the matter can be escalated to the MoH.  **Action:** Nick and Jane to discuss MOH label prior to circulation (with projections from item 6) to managers; for circulation to CDs/Coords. |
| 8 | Tissue Typing Issues  a) Attribution of costs to DHBs  b) Overseas recipients HLA typing  c) Overall costs (SM comment, letter from PF 2017)  d) Histotrack data error report | 1. Infrequently, donors from NZ are typed for overseas recipients (5-10 times per year) and many are from Australia which does not charge for the reverse. NZBS wish to invoice for this work, agree that DHB of domicile of donor would be appropriate.   **Action:**  **Nick/Heather/Ian** to write to CDs/Coords   1. All approaches to NZBS for tissue typing for live donors that do not come via renal units/coordinators should be referred to renal units and not proceed until they request the same **Action:** as action for a) 2. Noted that tissue typing costs per test had reduced somewhat with increased volume. 3. Investigation undertaken by Heather and Ian tabled and reviewed by group. Corrective action taken noted. |
| 9 | NZKE/AKX Collaboration Progress | Further meeting took place in December 2018. Australia is interested in cooperating with kidney exchange. Start July 2019.  ANZKX is proposed name, clinical governance is via RACOS (subcommittee of RTAC) and proposal (for ratification) is for RACOS to have two NZ reps.  NZKE remains independent and governed by NRTLT.  Details about costs and shipment and 3rd party responsibility for transit to be worked out. |
| 10 | DHB Support for travel for overseas based donors | NTA will fund travels for overseas based donors whilst in NZ. International travel to NZ remains discretionary by individual GM P&F or delegate.  When finalised, document is to go to GMs funding group.  For coordinators’ information – add visa type required, and that overseas donor should have travel insurance and that donor should not be pursued for bills.  **Action:**  Finalise document **(Nick/Jo)** for presentation at GM”s Planning and Funding body **(Jo/Nick)** |
| 11 | Declaration of Istanbul Update | Some aspects of 2018 update highlighted – re: organ trafficking and transplant tourism.  Website: <https://www.declarationofistanbul.org/> |
| 12 | Allocation Algorithm Update - pre-emptive deceased donor listing criteria  (Including deceased donor delisting following acceptance of live donor - patient feedback) | Two material changes proposed:   1. Eligibility criteria for DD list pre-emptively 2. Suspension criteria for listed person who subsequently has a live donor (including feedback from a patient to Ian, John K and Nick)   Various issues discussed.  Patient point of view letter read.  Update proposed:  “Patients who are active on the deceased donor waiting list are suspended when they have a directed live donor accepted by the transplant unit. Patients who are transplanted are removed from the deceased donor waiting list.”  **Action: Nick** will   * Update document - Allocation Algorithm. * Request upload of updated document on MoH site then include in emailed update to CDs and coords * Respond to patient letter & cc Ian and John Kearns. |
| 13 | Printing the LKD and recipient books | Kidney Health NZ is considering if it will be responsible for publication and distribution of the books.  Books need to be reviewed and updated.  Survey of coordinators views on the books is underway.  **Action: Denise/Claire/Karen** will gather views (including paediatric relevance) for suggested updates and then pass on to physicians for their views (via Nick). Coordinators will have an update on this ready for 29th of March meeting. |
| 14 | Live donor guidelines update   * Entry into KE * Assessing donors for other centres | Updates discussed and agreed  Summary – Service should offer KE to non-directed donors, and directed donors who are a cross-match.  **Action: Nick** will update live donor guidelines and circulate to coords/CDs. |
| 15 | Hepatitis C Positive Deceased Donors | Study planned in Australia discuss, agreed that analogous study in NZ appropriate.  **Action:** **John Schollum and Drew Henderson** agreed to review protocol and suggest changes for use in NZ  **Action:** After wording established, **Nick** will send to Stephen Streat and Janice Langlands to inform the deceased donor protocol development. |
| 18 | Bridge Donors in Kidney Exchange | Jo Burton described process / role of ‘bridge donors’ in the kidney exchange context. There was general agreement that this was appropriate in the NZ context.  Question – how long to ‘hold on to’ a bridge donor?  Suggested – 1-2 match runs. |
| 19 | Possible Transplantation Meetings in NZ (TTS 2022/TSANZ 2021) | Idea of hosting Transplantation Meetings in NZ discussed.  **Action: Ian** will progress. Discuss with chair of TSANZ and feedback to Tourism NZ |
| 20 | Other Business   * A) Retrievals * B) ODNZ location * C) Social media inspired offers to donate kidney | A) **Ian** that there is a risk that there will be no retrieval in Auckland in a period in April because of surgical availability. Work is ongoing to try and avert this. This could see deceased donors offered to Australia for retrieval.  **B) Janice** advised that ODNZ will likely be housed at NZBS following the end of the current contract with ADHB in June 2020.  C) Consensus that there should be a relationship between the donor and the recipient for a directed offer to be made, but method and definition of relationship was likely to be different in the era of social media. There was agreement that the operational group would discuss this further to develop a national policy |

**Next Meeting: Operational Group, Friday 29 March 2019**

**Ministry of Health 133 Molesworth St, Wellington**