Minutes of 2015.1 DNT Sub-Committee teleconference held on Monday 16th February 2015, commencing at 2PM, EDST.

<table>
<thead>
<tr>
<th>Chair</th>
<th>Stephen May (KHA)</th>
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<tbody>
<tr>
<td>ANZSN Members</td>
<td>Jeffrey Barbara, Hilton Gock, Robert Walker, Steven McTaggart</td>
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<tr>
<td>KHA Members</td>
<td>Evan Eggin, Allyson Manley, Henry Pleass, Matthew Jose</td>
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<tr>
<td>Ex-officio</td>
<td>Fiona Brown (HDAC), Matthew Jose (ANZDATA), Carmel Hawley (AKTN), Tim Mathew, John Kanellis (RTAC)</td>
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<tr>
<td>Correspondence</td>
<td>Aviva Rosenfeld/Anna Golebiowski, ANZSN 145 Macquarie Street Sydney NSW 2000 Ph: +61 2 9256 5461 Fax: +61 2 92414083 Email: <a href="mailto:anzsn@nephrology.edu.au">anzsn@nephrology.edu.au</a> <a href="mailto:admin@nephrology.edu.au">admin@nephrology.edu.au</a></td>
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1. Welcome and Apologies
The meeting commenced at 2.03PM. Present at the meeting were: Stephen May, Jeffrey Barbara, Matt Jose, Carmel Hawley, Hilton Gock, Timothy Mathew, John Kanellis, Martin Gallagher, Stephen McTaggart, Robert Walker and ANZSN administrative support Aviva Rosenfeld and Anna Golebiowski.

Apologies were accepted from Evan Eggin, Allyson Manley, Fiona Brown and Henry Pleass.

2. Declaration of Conflicts of Interest Related to the Current Agenda
There were no conflicts to declare.

3. Minutes of the Previous Meeting
The minutes of the DNT teleconference 2014.4 held on 24th November 2014 were accepted as a true and accurate record.- no vote taken

4. Business arising from the Minutes of previous meeting
Live donation follow up consent form- This form will be similar to the ANZDATA consent form but for follow up of live donors. A/Prof John Kanellis will liaise with Prof Matthew Jose and A/Prof Henry Pleass regarding the form. Leave on the agenda.

DNT TOR’s- The final DNT TORs are on file and posted on the ANZSN website.

DNT tab on ANZSN website- DNT page open to the membership has been approved by ANZSN Council ACTION: Dr Steve May to send through domains to ANZSN admin to organise a new tab on the ANZSN site.

Funding for DNT meetings- DNT meetings will be funded from the DNT account which includes the costs of travel, room hire and catering. If funds run low it will fail to KHA and ANZSN to top up the account.
KHA Consumer rep: There has been the suggestion of having a KHA consumer group as a contact for committees which can be consulted in issues relating to kidney disease. A/Prof Tim Mathew has on numerous occasions raised the issue with KHA. The matter is ongoing and will be discussed at the National Consumer Council of KHA meeting which will be held Saturday 21st February. The NCC may assist in setting up the sub group.

ACTION: A/Prof Tim Matthew will contact Mr Evan Egging re: consumer rep on DNT.

TTP Position Paper: In 2014 Dr Shlomo Cohney suggested starting a working group which was referred onto DNT from ANZSN Council. Dr Cohney suggested to set up the working group to obtain nephrological input to draft guidelines and assist with position statements for treatment of TTP. It was thought it would be a multi-disciplinary group. A/Prof Jeff Barbara agreed to moving this issue forward by establishing a working group after calls of EOI from ANZSN members. Prof Matthew Jose added Dr Cohney chairs the TTP registry, which has three significant nephrological representation already, being Dr Coheny, A/Prof Nikki Isbel and Dr Josh Kausman. As their governance group covers haematologists and transfusion specialists, the proposed working group could link in with the TTP Registry that already exists. The role of DNT in assisting setting up this working group was questioned as it seemed unnecessary to being another separate group when it could fall under the TTP registry but if the position paper is to have DNT badging then involvement in process is important.

ACTION: A/Prof Jeffry Barbara is to continue coordinate with Dr Cohney to convene the TTP working group. There would need to have TOR re aims of group and any level of DNT support required.

DNT Position on ANZDATA KPI’s: to be discussed at the 2015 DNT Workshop.

2015 Workshop program: to be discussed later in teleconference.

2015 Workshop Sponsors: Sponsorship has been finalised. No other sponsors have been secured. The registration fee has essentially been increased by charging for the Monday night dinner currently costed at $25000.

Direction of Future Workshops: Dr Steve May has created a questionnaire which has been sent for comment, then will be sent to the ANZSN membership after the DNT Workshop.

ACTION: The committee is to make changes to the questionnaire then it is to be sent to the membership via the ANZSN Office.

ANZDATA Steering Committee TOR’s: The steering committee TOR’s are still presently with ANZSN Council to be approved.

KHA- HDAC continued support: Associate Prof Tim Mathew confirmed that up to $15k has been approved to fund HDAC committee meetings.

5. DNT Funds
The DNT funds sit at $248k.

6. DNT Membership
It will be up to ANZSN Council to appoint the new DNT members after A/Prof Hilton Gock’s and Dr Steve McTaggart’s terms finish at the DNT Workshop. Dr Steve May will hand over to Prof Matthew Jose at the DNT Workshop and a new KHA representative will need to be found.

ACTION: S May to notify council that it will need to replace the two retiring ANZSN DNT members

7. Action Points from previous DNT Workshop
Several points have been actioned. The remaining items will be spoken about at the upcoming DNT workshop.

Next Workshop
7.1 Local Organising Committee Report
7.2 PCO Report
7.3 Timeline
7.4 Program- The program has been circulated with only slight changes since November ie a title change is to be made for one of the sessions. There is a speaker which has not registered which needs to be confirmed. Chairs need to come up with Action and discussion points.
7.5 Sponsors
7.6- Budget- There is still a $20-$30k shortfall even after asking attendees for the extra $150 for the Monday night dinner. Prof Matthew Jose suggested there should be further discussions at the Workshop regarding future meeting arrangements of the event as there will more than likely be a shortfall for this meeting.
7.7 Invites- numbers/ allocation- The numbers remain at 155-160px to attend the 2015 DNT Workshop.

8. Position statements on ANZSN Website
Position statements will be tabled and will be discussed at the first face to face meeting with Prof Matthew Jose as the new Chair or DNT. The position statements will be reviewed once a year to be updated or archived.

9. HDAC Report
No report in Dr Brown’s absence. Assoc Prof Tim Mathew reported that The Committee is meeting Friday 27th February. The biannual Home Dialysis meeting has been cancelled because of the ISPD Conference in 2016. Therefore the next HDAC meeting will not fall until 2018. Prof Matthew Jose suggested in 2016 there is a combined APCN meeting in Perth and there could be a satellite Home Dialysis meeting held which would involve all of Asia. The idea was supported by the committee.
ACTION: A/Prof Tim Mathew will suggest satellite meeting to KHA committee although the September dates conflict with the meeting which is normally held in February.

10. AKTN Report
A/Prof Carmel Hawley reported AKTN has been operating for 10 years and it is time to look at it strategically as this has not been done before. AKTN will be presenting at the DNT Workshop with updates.

Trials:
CKD- FIX- on going.
IMPROVE- on going
FAOURED- Finished. Reporting this year.
HERO – ancillary papers to be published
HONEY POT- ancillary papers to be published
BLOCKADE- reporting this year.

Awaiting official confirmation of the Program Grant that will last 5 years. This grant will be a significant achievement to the nephrological community. The grant will not be available until 2016. AKTN sit financially sound for 2015. A/Prof Carmel Hawley added it would be right not to require ANZSN/ KHA committed funding after 2015 due to the expected project grant. The grant will also involve Cochrane and the Registry.

In recent months AKTN has implemented a strategic initiative to address research priorities and issues in the kidney care setting. Special interest groups have been convened to develop trial ideas in the major disciplines of nephrology; glomerulonephritis and chronic kidney disease[ low salt, AKI], transplantation[ BK, AMR], haemodialysis[ Spironolactone, Dialysate Na,plastic needles, catheter locks] and peritoneal dialysis[teaching PD teachers], in addition to a working group that relates to research methodology. It is anticipated that each discipline will develop a trial proposal for NHMRC project grant submission in 2015.

In summary: The main challenges are to secure the right trials and engage the nephrological community so they remain enthusiastic about trials.

11. RTAC Report
There was a meeting in December and the summary of the meeting will be soon circulated.
Ethical Guidelines - The Guideline is open for commentary until 6th March.

Clinical Guide process heading for version II. The Guideline will reflect current practice and issues to be resolved, which may not be currently in practice, and other items from the last document. The Guideline is proposed to be completed by the end of 2015. Prof Steve Chadban and Dr Philip Clayton are involved.

A/Prof John Kanellis is presently involved in setting up the following sub committees of RTAC:

**Clinical Oversight Committee** is already set up and has been running well with established

Allocation Sub Committee will be involved in reorganising donor allocation and processes. This committee will be looking at current challenges, improvements to allocation, national and international systems. The group is yet to become fully established. The subcommittee will include Dr Fiona Mackie, a consumer, RTAC, ANZDATA and lab representatives.

**Histocompatibility and Sensitisation sub Committee**

‘NOMs Modernisation Project’. The DWS Group is contracted to scope out options re future costs and a wish list for the future. The group will look to replace the functionality of NOMs as it stands and will seek out to move to a more modern platform including software. There will be large costs involved as the presently systems used involve complex software which needs to be replaced. The group will look at enhancements and improvements of NOMs and this will be fed back to the NOMs governance committee.

An additional issue was raised by Dr Hilton Gock regarded the fall in numbers for live kidney donors. RTAC has no plans to look at this but maybe related to increasing DD rate.

12. **ANZDATA Report**

The current ANZDATA report is from November 2014. The next steering committee meeting will be a teleconference to be held Friday 20th February.

There was an ANZDATA executive teleconference the morning of 16th February. From an operational point of view there are currently three vacancies within ANZDATA, resulting in a fall of 30% of staff. The fall in staff is causing delays from data requests to receiving data. Thus, the Annual ANZDATA report from 14 months ago is still yet to be published. Dr Philip Clayton, Editor of the ANZDATA Report, does not currently have administration assistance which is a significant lack of support. The process to find replacement staff is taking months which is very disruptive to ANZDATA.

Real time incident reports will be presented at the DNT Workshop. At the Workshop the proposal to release the real time report as at 31st December, in February as an interim report will be made. Currently real time reporting is 90% accurate for new patients and 60% for deaths. One private Canberra unit has requested funds for submitting data. This request was not welcome and declined by ANZDATA.

There has been a delay in presenting the ANZDATA Steering committee TOR’s as this is presently with ANZSN Council.

13. **KHA Report**

World Kidney Day. Theme: Kidney Health for All - The event has an international date of March 12th and the Australian date of March 26th with a parliamentary breakfast event. World Kidney Day will be widely advertised. Prof Alan Cass will chair the event.

Kidney Health Week will be held the last week in May.

There was a hearing on Friday 13th February with the senate selection committee on Health. KHA presented on Indigenous Kidney Disease. Prof Alan Cass also helped to prepare the presentation.

14. **CARI Report**

There hasn’t been a steering committee meeting to date in 2015.
CARI Review: The CARI review is currently been undertaken by Catherine Martin and Prof Carol Pollock. They have visited the CARI office and they have begun interviewing. If any members want to make a contribution to the review, they are encouraged to meet with Catherine Martin and Prof Carol Pollock as they are consulting extensively regarding the review. Dr Steve May will organise to speak with Carol Pollock.

There is an invitation to a KDIGO meeting in Cape Town. Prof Robert Walker volunteered for the meeting as he will be attending the WCN.

15. RSA Report
No discussion held

16. First Nations Report
There was no report requested from Dr Jacquie Hughes for the DNT teleconference. Dr Steve May suggested for Prof Mat Jose to keep in contact with Dr Hughes in order to keep up to date with any ATSI to report on at future meetings.

ACTION: Dr Steve May suggested the DNT minutes to be circulated to Jacqui Hughes.
Ask Jacqui re ATSI term.

17. Correspondence
No discussion held

18. New Business
18.1 Agenda items from membership- No items were raised

19. Next Meeting
2015 dates are to be set for the year though doodle polls and promptly confirmed.

Dr Steve May thanked the committee at his last meeting as chair and the committee thanked Dr Steve May for his efforts of the committee.

The meeting ended at 3.51PM
### Action points from 2015.1 DNT TC on 16th February 2015

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<thead>
<tr>
<th>Item</th>
<th>Who</th>
<th>Action</th>
<th>Status</th>
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<tbody>
<tr>
<td>Live Donor Consent Form</td>
<td>JK</td>
<td>John to liaise with Matt to finalise form</td>
<td></td>
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<tr>
<td>Consumer Rep</td>
<td>TM</td>
<td>A/Prof Tim Matthew will contact Mr Evan Eggins re: consumer rep on DNT.</td>
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<tr>
<td>TTP Working Group</td>
<td>JB</td>
<td>Jeff to convene TTP working group with Schlomo Cohney</td>
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<td>DNT Workshop questionnaire</td>
<td>SM</td>
<td>The committee is to make changes to the questionnaire then it is to be sent to the membership via the ANZSN Office.</td>
<td>Done</td>
</tr>
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<td>DNT Members</td>
<td>SM</td>
<td>Contact Council to replace retiring members</td>
<td>Done</td>
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<tr>
<td>Position Statements</td>
<td>MJ</td>
<td>Discuss position statements at next face to face.</td>
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<td>9 HDAC</td>
<td>TM</td>
<td>2016 HDAC meeting. A/Prof Tim Mathew will suggest satellite meeting to KHA committee although the September dates conflict with the meeting which is normally held in February.</td>
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<td>16 ATSI</td>
<td>SM</td>
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<tr>
<td>19 Next meeting dates</td>
<td>AG</td>
<td>Send Poll</td>
<td>completed</td>
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<td>DNT site on ANZSN website</td>
<td>AG</td>
<td>Establish DNT Tab on ANZSN site</td>
<td>ongoing</td>
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<tr>
<td>DNT site on ANZSN website</td>
<td>SM</td>
<td>Send list of domains for DNT website to Anna</td>
<td>ongoing</td>
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<tr>
<td>Replace Steve May position</td>
<td>TM</td>
<td>DNT Membership replacements. 1x KHA</td>
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