

MINUTES

Reference Group Meeting

Friday 11 May 2018

10.00am-4.00pm

Novotel, Auckland Airport

Attending: Anne Morgan, Kirsten Ballantine, Scott Macfarlane, Amanda Lyver, Laverne Robinson, Deepika Singh, Amber Conley, Heidi Watson, Lochie Teague (from noon), Elizabeth Ryan, David Hamilton, Pamela Baines, Steve Evans, Emma Tonks, Emma Maddren (until 1.00pm), Robyn Kiddle, Mal Joyce.

Chair: Amanda Lyver.

Summary of Action Items

1. Elizabeth to incorporate any last feedback and finalise the 2018/2019 Work Plan by 30 May 2018.
2. Elizabeth to discuss financial arrangements regarding primary care representation on Reference Group with MoH, with a view to approaching the College of GPs to seek a representative if financially feasible.
3. Elizabeth to lead a membership review in consultation with other Executive Team members, taking into account refreshment of roles (where applicable) over the next 18 months.
4. Elizabeth to invite nominations for new member to represent Radiation Oncologists (ideally from Christchurch).
5. Elizabeth to incorporate Working Groups activities into the TOR.
6. Elizabeth to note Working Group Convenors in upcoming NCCN newsletter, and to request that each Working Group Convenor reviews the membership and TOR of their group for their next meeting.
7. Elizabeth to add as standing agenda item updates from Radiation Oncologist and Paediatric Surgeon.

1. Apologies

Claudine Young, Fiona McGill, John Sanders, Karen Smith, Dawn Wilson, Jan Millar.

2. Introductions

Welcome to Pamela Baines (Service Manager, Southern DHB) and Steve Evans (Paediatric Surgeon, ADHB).

3. Chair Update

4. Previous Minutes and Actions

- No amendments to minutes for previous meeting held on 24 November 2017.

- Action items 4, 9, and 17 addressed in upcoming agenda items. An update on items 1, 7 and 13 is provided below. All other items have been actioned.

Action Item 24 November 2017	Update
1. Elizabeth to follow up with Stephen Laughton, Amber and Lochie regarding Supportive Care Guideline – Medicinal Cannabis Use.	Stephen Laughton and Radhika Sandilya (Pharmacist) are progressing this. It may need to be a general Starship Guideline, not oncology-specific.
7. Scott to explore with the Immunisation Advisory Committee the NIS issues raised (e.g age limits).	Issues have been raised with the Committee. There are also numerous ambiguities in the Handbook which will be corrected in the next electronic version. The NIR is not a reliable source of re-immunisation data (only 1 place to record in NIR). Refer agenda item 21 for more detail.
13. Scott and Elizabeth to update the National Plan for Child Cancer Services as per suggestions (achievements and current work plan).	Plan is outdated and focussed on NCCN “set up” phase. Scott will have further discussions with Dawn Wilson regarding timing and logistics of potential update.

Minutes approved by Scott, seconded by Robyn.

5. Election of Officers (Chair)

- [Amanda Lyver left the room].
- Scott noted Amanda’s current term finishes this month and asked for Chair nominations from the Reference Group. There were no nominations. Amanda was offered a second term as Chair (she accepted) which was confirmed unanimously by the Reference Group, who thanked her for her ongoing commitment as Chair.

Approved: Scott Macfarlane *Seconded:* David Hamilton

6. Chair Update

Amanda introduced the agenda and noted the extent of content to be covered during the meeting.

7. Clinical Advisor Cancer Services Update

- Scott as one of three Ministry clinical advisors sits across all key working groups.
- The Minister of Health has agreed to review and renew the NZ Cancer Strategy as recommended by CPLB. This is likely to have less impact on children/AYAs but presents an opportunity for NCCN. We need to have ideas ready to insert (e.g last time LEAP/AYA/trials membership were ready). Process will be shorter than last time, with less consultation in the initial round to form a draft strategy. Draft will be produced by end-June and distributed for feedback, with Cancer Services Team coordinating development of accompanying Action Plan.
- Cancer Health Information Strategy still being pursued, particularly to address gaps for adults. Issues include variable staging information, 15% of diagnoses made clinically, opportunity to record additional details on histology reports /data from MDTs. Disparate systems across NZ

leads to multiple workarounds and duplication versus a clinical information system where source data is retrievable. A standalone system (e.g EPIC) is costly.

- Radiation oncology data set is due to be released in June which is significant and has involved agreement from 6 DHBs and 3 private providers to share data, broken down by domicile, ethnicity etc. Will allow for better detection and analysis of variation.
- Scott gave an update re Tumour Standards (x10). It is different for adults in that there is not always consistent treatment by condition guided by protocols as it is for children. Although released for voluntary adoption in 2013 the standards are not measurable and have varying influence on practice. Clinical indicators are being developed (e.g bowel cancer pilot). Relatively small impact on NCCN.
- Idea of cancer agency noted in the Labour Party's manifesto. The aim is to strengthen governance, ensuring consistent practice, evidence based treatment, and equity of access both to services and outcomes. Scott was an invited speaker at the Central Cancer Network meeting earlier in the week and presented the NCCN model of care. Use of the entire model may not be applicable across the cancer sector, but there are useful elements (e.g shared care agreements, guidelines, protocols) which could be incorporated.
- Some discussion from Reference Group about work done in the past that was not fully implemented (e.g minimum data set project 2003-13). Complete data sets with patient reported outcomes do exist elsewhere (e.g Australian national prostate dataset), head and neck database in parts of NZ, but they are expensive.

8. Executive Management Team Report



7. Executive Management Team Report

- Elizabeth tabled and spoke to Executive Management Report.
- The team has been busy organising site visits to 7 of the 14 shared care centres, with visits to Rotorua and Whangarei already completed (April).
- Guideline usage is showing the normal trends with drug dosage guidelines the most commonly accessed. Scott noted that guidance on drugs now references directly to the NZF guidelines, except where there are valid reasons to deviate.
- In terms of the year-end financial position a modest surplus of around \$12k is forecast. This is mainly due to an underspend on projects, partially offset by increased salary costs. Also noted was the surplus currently sitting in the A+ Trust Fund (\$60k) which will reduce further over the coming year. As a result of funding pressures NCCN is becoming increasingly reliant on joint funding of initiatives, in particular from NGO partners such as CCF.
- Emma (Tonks) noted that details around the upcoming renewal of the NCCN contract with ADHB are before the Funding Board, but a four-year term has been proposed, both for NCCN and the AYA Network.
- There was discussion about the length of term given current funding and activity levels. Other options may need to be considered (e.g decreased support for meeting activities).
- The Reference Group's Terms of Reference refers to one representative from professional groups such as Service Managers, Shared Care Nurses and Shared Care Paediatricians attending meetings.
- Funding of travel costs also needs to be reconsidered. NCCN is unique in its current funding to attend meetings of its Reference and Working groups. In future only non-DHB employees may be funded to attend. It was noted that this is likely to be more challenging for Allied Health and Nursing staff.

- The importance of the Working Groups also needs to be recognised – the model to form a group around an issue, resolve that issue and then disband the group has meant valuable ongoing contributions to the outcomes of NCCN.
- The role of technology (e.g VCs) should also be considered as is more cost-efficient and can be done from PCs in some cases. e.g professional Skype which CCF uses.

9. 2018/2019 Work Plan



8. DRAFT Work Plan
1 July 2018 to 30 Jun

- Elizabeth gave an overview of the draft 2018/19 NCCN Work Plan and invited comment from the Reference Group. In a change from previous years new columns have been inserted in the detailed work plan table (p.g 14 onward) to note achievement of objectives and any amendments to objectives required as a result.
- Participants are requested to send final feedback to Elizabeth. If no further feedback is received by 30 May, the Work Plan will be finalised as it stands.

Agreed actions:

1. Elizabeth to incorporate any last feedback and finalise the 2018/2019 Work Plan by 30 May 2018.

10. NCCN Reference Group Terms of Reference (TOR): 2018 Update



9. NCCN TOR 2018
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- Elizabeth tabled the updated Terms of Reference (draft) for the Reference Group, the first update that has occurred since 2011.
- Amanda noted that section 5 refers to relationships that NCCN has with organisations (e.g Royal New Zealand College of General Practitioners) which do not currently exist. Feedback had been received on the draft TOR from the Ministry that primary care needed to be included as part of the Reference Group, hence the addition of the College and a primary care representative to the member list.
- Discussion of issues around how to increase involvement, understanding and communications from primary care, acknowledging that GPs are not all of primary care.
- Scott noted that he has presented at multiple GP fora in recent years, emphasising aspects most relevant to GPs such as:
 - diagnosis
 - ongoing support for the family through treatment
 - re-introduction to the practice (e.g at time of re-immunisations)
 - transition out of late effects programmes
 - addressing palliative care needs
- Elizabeth also sought input on the issue of primary care representation from Barnett Bond (Primary Care Director, ADHB) who noted that there are other ways to forge closer relationships with GPs, such as surveying them to assess their needs, and ensuring some level of communication is maintained throughout a child's cancer treatment, even if the child is rarely at the practice. This enables the relationship to be more easily re-established at the end of treatment, which is enhanced by a strong end of treatment letter.

- Not all families have a close relationship with their GP, and the set up of practices combined with timing issues often mean that a patient sees a range of GPs, or goes to an after-hours A&E facility.
- GPs need to be able identify signs of cancer early, and having a named GP facilitates better transfer of information.
- Emma (Tonks) noted that it is common practice for there to be primary care representation on national groups funded by the Ministry and that further work could be done.
- Finding and funding a representative GP to attend Reference Group meetings is challenging.
- Amanda noted the lack of reference to Working Groups in the TOR.
- The Shared Care Paediatricians (Deepika) agreed to coordinate between themselves who would attend future meetings.
- General agreement made to review and refresh the Reference Group membership in the context of having a number of long serving members and the desire to give others the opportunity to provide input.
- Service Managers agreed that having one manager attend future meetings is sufficient (as was discussed at their national meeting earlier in the week).
- David Hamilton offered to stand down in favour of an alternative radiation oncology representative, likely to be Christchurch based.
- Working Groups should also have the opportunity for refreshment. These are “opt-in” but not everyone may be aware of the various groups so it is a good opportunity to promote the groups and their respective convenors.

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4. Elizabeth to invite nominations for new member to represent Radiation Oncologists (ideally from Christchurch).
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11. ANZCHOG – 2019 Conference Update

- Date 13-15 June, Christchurch. Theme not yet confirmed but “cancer and families” a potential contender. Need to cater to medical audience as well as broader stakeholders.
- ANZCHOG will replace Shared Care Update Day for CHOC. Lochie will consider options re Starship Shared Care Update days in 2019.
- ANZCHOG likely to fund one international speaker with the Child and Adolescent Trust Board confirming \$10k of funding which could fund a second speaker. Also potential to align with CCF visiting speaker.
- Amanda has started a local organising committee which includes CHOC staff, Scott, Elizabeth, Robyn Strong, plus the event manager. CCF invited to join.
- Numbers could be around 130. Less people likely from Australia but may attract more NZ participants.
- CCF to approach Mary McGowan (Oceania representative on CCI) about potential options.

12. Counselling Framework



11. Counselling Framework May 2018

- Elizabeth reiterated that the application to Sky City Community Foundation to fund the entire Counselling Framework pilot project was not successful but that development of the distress screening tool (a discrete piece of work) was successful in gaining \$25k of funding from the ANZ Staff Foundation.
- Massey University has developed a distress screening tool (following an extensive literature review) and trained 10 Family Support Coordinators in Auckland (March 2018). Training included context about why the tool is being introduced, how to present it to families, and the evaluation process.
- Unfortunately due to major staff shortages in Auckland CCF are unlikely to be able to commence the screening tool pilot until July.
- CCF has agreed to fund implementation costs for the remainder of the Counselling Framework project, which is a significant contribution.
- The aim remains to provide more appropriate counselling options (funded by CCF), including providing training for counsellors on the database.
- David noted a counselling pilot undertaken in Wellington (nurse-led) where uptake of counselling offered has been low (about 2%).
- Canteen noted their Youth Assessment Tool (YAT) which is used in conjunction with their own distress screening tool. They are also developing a Psychosocial Manual to offer more guidance to staff.

13. Educational support project



12. Educational Support May 2018.pc

- Elizabeth tabled this report which provided updates on three initiatives, the Cognitive Assessment and Reporting Working Group, Educational Support Resources, and the Educational Support research project (led by Claire Gooder).
- Of note the research on “return to social activities/ school” for ALL patients is now at the stage where “opt out” letters have been sent to families, and the work done to achieve this milestone by both Starship and CHOC was acknowledged.
- The Qualtrix licence has also been purchased by the AYA Network and the sharing of this survey tool is important for the survey components of Claire’s research.

14. Pacific Working Group



13. Pacific Working Group Report April 20

- A report from Jane Skeen was tabled.
- Tonga continues to utilise screening tools well, Samoa practice more variable.
- Fiji continuing to work towards commencement of Community Nurse.
- Vanuatu formally admitted as 4th partner – Starship has had several of their patients recently.
- For Sydney ANZCHOG Mike (Sullivan) is leading a Pacific half-day.

15. LEAP



14. LEAP working group report - 26.04.

- A report from Kathy Yallop was tabled.

16. NZCCR



15 (a) NZCCR Snapshot 2017 (FINA Group Report April 2018)



15. NZCCR Working Group Report

- Kirsten tabled the NZCCR report for 2017 and reviewed the highlights.
- Abstract submitted for October 2018 SIOP meeting shows comparable child cancer survival by domicile and treatment centre, also by deprivation level. Three achievements highlighted by Scott in the latest child cancer research:
 - NZCCR data is reliable (complete and accurate).
 - No statistically significant difference to survival rates by ethnicity.
 - Same survival rate regardless of where you live.
- Opportunity to publicise these results more fully after SIOP meeting.

17. Protocols update



16. Protocols Working Group.pdf

- Lochie tabled the Protocols Working Group report.
- Noted timing of next meeting to coincide with LEAP (proposed for 31 October) as Rob Corbett retiring.

18. Professional Development



17. Professional Devt Report NCCN M&I

- A report from Jan Millar was tabled.

19. TP53



18. TP53 WG report to Ref Grp 11.5.18.ppt

- Scott tabled the TP53 report.

20. Proton Therapy



19. Proton beam WG report for ref grp 11.

- Scott tabled the Proton Therapy report.

21. Dental



20. Dental WG report to ref Grp 11.5

- Scott tabled the Dental report.

22. Immunisations



21. Imms WG Report 21 (a) Immunisation for Ref Grp 11.5.18. record example.pdf

- Scott presented the example of an “immunisation of children after cancer therapy” form completed and signed by the GP that the patient can bring back to their specialist. This is the best available way of recording accurate re-immunisation information.

23. AYA Update

- Heidi spoke to recent AYA activities and highlighted:
 - o Online self-review tool (standards of care). By mid-June expect to have completed all 20 DHBs. Results will inform national strategy development and the model of care.
 - o Developing patient experience survey based on the standards of care, collaborating with University of Auckland to access health faculty/tablets. Conducting focus groups at present. Results of the survey will be presented by young people. The age group is 16-32 (12-30 treatment age) to better understand how experiences differ for older ages.
 - o Early identification working group has completed a literature review (Claire Gooder) and is initiating further research, looking further into primary care aspects.
 - o Obtaining good quality data remains a focus area.

24. CanTeen Update



23. Canteen Report _NCCN April 2018.pdf

- Laverne tabled the Canteen report and noted the case management model category system they use to deliver services.
- Also working on a new leadership model (with Australia).

25. Child Cancer Foundation (CCF) Update



24. CCF Report
NCCN May 2018.pdf

- Robyn tabled the report from CCF.
- Noted a significant shortage of Family Support Coordinators in the Auckland area with senior staff having to cover gaps.
- Working on a new “fit for purpose” database, hoping to go live in August.
- Excited to be launching new research with CureKids (5 years, \$1,250,000) to be led by Dr Andrew Wood, focussed on developing an advanced genomics diagnostic test to improve treatment, survival, and quality of life for NZ paediatric cancer patients. The project is called “Precision Paediatric Cancer Project (PPCP)”.
- Conclusion of the “Haier Big Hoot” with the auction on 29 May.

26. Leukaemia and Blood Cancer NZ (LBC) Update



25. LBC NCCN report
April 2018.pdf



LBC Nationwide
survey presentation.

- The LBC report was tabled. Note that the new CEO Peter Fergusson commences 14 May.
- Results from LBC’s survey of 4,000 service users (700 responses) were also tabled for members to read.

27. Starship Update

- Lochie noted that no replacement fellow (for Israel fellow who fell through) has been found which has been challenging.
- Unit is full with two outliers at present (19 inpatients).
- A major change in the staff model means there are now two consultants on call, meaning staff have a maximum of 3 days on call at a time (versus current situation of up to 7 days). Expect some impacts on out-patient clinics but manageable.
- Still working on changes to the Senior Nursing team and a business case for an AYA Nurse Specialist.
- There is a new Radiation Oncologist coming mid-year with a paediatrics focus.
- Delay in discussions with Counties Manukau and Waitemata DHBs re shared care arrangements as at the regional level there are moves to align other sub-specialties (e.g gastro) under the same framework.
- The Adult Oncology Centre is on hold.
- A new Oncologist joins the team (Michelle Wilson).

28. Christchurch Update

- CHOC has a new Charge Nurse Manager (Jenny Gardner), who has been lead CRA in the past.
- Other changes with an outpatients nurse moving to inpatients.
- A successful Shared Care Update Day held recently with successful use of VCs for centres that were unable to send staff, and a good presentation by Nyree Cole (Starship) on post-stem cell transplant care.
- 2019 Shared Care Update Day will be replaced by ANZCHOG.
- MRI /virtual reality programme development continues (can mean avoidance of anaesthesia).

29. Shared Care Centre Updates

- Hamilton is busy, and looking forward to the return of Danielle Finn in June (Lisa Van Walraven has been covering).
- Many families requiring psychosocial support.
- Both Mal and Deepika referred to examples of intensive palliative care treatment happening outside hospital (e.g hospice) and challenges that brings for staff.
- Lochie noted his intention to talk with Alison (Pearce) re how to further improve communications between Wellington and Starship, ensuring a smooth patient journey.

30. General Business

- David noted ongoing workforce issues for Radiation Oncologists (particularly with a paediatric specialty).
- A suggestion was made to add updates from the Reference Group Radiation Oncologist and Paediatric Surgeon for future meetings.

Action

- 7. Elizabeth to add as standing agenda item updates from Radiation Oncologist and Paediatric Surgeon.**

Next meeting: Friday 2 November 2018.