

## **AGENDA**

### **Reference Group Meeting**

**Friday 18 November 2016**

**10.00am-4.00pm**

**Novotel, Auckland Airport**

- Attending:** Scott Macfarlane, Melissa Wilson, Kirsten Ballantine, Amber Conley, Anne Morgan, Mal Joyce, Heidi Watson, Robyn Kiddle, Amanda Lyver, Caroline Folland, Fiona McGill, Lochie Teague, Sarah Eames, Heidi Watson, John Sanders, Emma Barker (for Pru Etcheverry)
- Apologies:** David Hamilton, Deepika Singh, Andy Simpson, Karen Smith, Pru Etcheverry, Emma Maddren, Jan Millar, Bruce Pilbrow
- Chair:** Amanda Lyver


### **Summary of Action Items**

1. Sarah to discuss proposal of NCCN coordinating paediatric nonmalignant haematology with Chair of National Haematology Working Group
2. Scott to raise at meeting of National Haematology Working Group in March 2017
3. Kirsten to investigate what data is available to quantify patient population involved with nonmalignant haematological conditions
4. Scott to discuss formation of NCCN Haematology Guidelines Working Group with Lochie
5. Scott and Melissa to consider priority of Vascular Malformations update once scope of haematology work set out.
6. Reference group to nominate planning committee and develop tentative timelines for ANZCHOG 2019 Conference at meeting in April 2017
7. Kirsten to investigate what information is available via the Ministry of Education to support research project investigating differences in morbidities relating to return to school
8. Scott and Melissa to propose more robust research question and scope of research and distribute to Reference Group for feedback and approval.
9. Sarah to follow up data request for cross referencing NZCCR data with NZCR with MOH.



**Previous Minutes**

Minutes 8 April 2016

<b>Action Items 8 April 2016</b>	<b>Update</b>
1. Melissa and Scott to consider strategy for reinvigorating membership of Working Groups.	A number of new working groups including educational support and family information along with ad hoc technical working groups have provided opportunities to introduce new members to working groups including newly appointed medical team members.
2. Catherine Thompson to update the Reference Group on any progress with regards to the establishment of radiation services in the Pacific, if and when updates are available.	Scott in Fiji earlier this year and met with officials and found that Fijian Government had developed an interest in developing radiation services stimulated by Taiwan and International Atomic Energy Agency who are interested in setting up radiation facility in Suva. It looks as if something may happen with regards to radiation services in the Pacific however there are many complexities that require consideration for example availability of experts to interpret scans.
3. Catherine to request an overview of the recent changes and emerging structures from Cancer Programme team, to present to Reference Group.	Email update provided by Andrew Simpson 20 April 2016  Email Update Andrew Simpson.pdf
4. Melissa and Scott to incorporate feedback from Reference Group in Work Programme for the year and circulate plan by email for comment.	Work programme circulated, amended and presented to Ministry for finalization.
5. CCF to link to provide link to the report on their website.	Link currently not available.
6. Mal, Deepika, and Kirsten to send Melissa information regarding contacts.	Contacts received and invitations to Educational Support workshop

	were sent.
7. Melissa to discuss with Heidi and CanTeen use of Listen Up network to seek the views of young people.	Ongoing opportunities for input from Listen Up Network – NCCN to continue to collaborate with AYA Network and CanTeen.
8. Melissa to attempt to get a SENCO teacher to attend.	Workshop held in May with over 35 participants from health, education, Ministry and NGOs. Parent representative also attended.

## 1. Executive Management Team Report

- Report tabled



Executive Report

## 2. Clinical Advisor Cancer Services

- Scott has been appointed as Clinical Advisor Cancer Services.
- He is one of 4 part-time appointees to this new position within the Ministry.
- The role holders have replaced Andrew Simpson who has held the role of National Clinical Director within the Ministry of Health for several years. In this role Andrew provided advice to the Ministry's Cancer Team which includes approximately 15 people, as well as providing advice to the Director General of the Ministry of Health and the Minister of Health on all things related to cancer.
- Approximately a year ago, Andrew was seconded to the role of Chief Medical Officer within the Ministry to replace Don Mackie Andrew remains in this role and thus there has been a gap in the provision of oversight and support for the Ministry's cancer programme.
- The Ministry received a large number of Expressions of Interest for the temporary Cancer Advisor Role and chose to appoint a number of applicants from medical, nursing, radiology and urology backgrounds.
- The four appointees have been allocated portfolios of responsibility and will act as an interface and interpreter between the clinical workplace and policy creators.
- The recent adverse publicity surrounding Southland services for glaucoma monitoring provide a good example of the need for these role holders to attempt to join up services and develop systems for understanding what goes on between silos – both within a pathway and across pathways.

### 3. Non Malignant Haematology

- Scott Macfarlane led a group discussion regarding NCCN's role with regards to Haematological services.
- NCCN's terms of reference and the National Plan for Child Cancer Services make no mention of haematology.
- There is a significant overlap between the workforce providing care to child cancer patients and those supporting children with non-malignant conditions. By default those responsible for providing services to children with cancer are linked to delivery of services for children with blood conditions.
- Given NCCN's success in putting national infrastructures, guidelines and processes in place for paediatric oncology, and that haematology largely involves the same group of service providers, should NCCN adopt a similar role for haematology services.
- Paediatric oncology already includes malignant haematology; the question is whether we should be involved with non-malignant haematology.
- Leukaemia and Blood Cancer New Zealand currently provide services for non-malignant haematology and would be interested in partnering if we included these conditions under the NCCN banner.
- Management of haematological conditions has become problematic in Christchurch with only one qualified haematologist on staff. Increasingly receive referrals from shared care centres who manage a lot of general conditions but tend to refer on more complex cases. There is not a good streaming of how we deliver these services or definition of what conditions should be referred to tertiary centres. Currently have no idea of scope of work or the level of involvement we should be having.
- Heidi highlighted the inequity of access to support services and different levels of care for children with haematological conditions. The allocation of AYA key workers is a prime example of this.
- Amber confirmed that while children on the floor at Starship are not differentiated between there is a difference in access to NGO support.
- It was estimated that there are over 20 different places children with haematological conditions might be treated in New Zealand – an analogy was drawn with how AYA services are provided.
- Fiona highlighted the importance of managing these children in a way that maintain links with paediatricians and other specialist groups who are critical to their care.
- Difficult to estimate numbers involved in these conditions as there are grey areas around conditions to include. Work needs to be done to define what is included.
- Robin highlighted the successful partnerships that exist in New Zealand between medical and NGO providers for children with cancer and the concern about whether NGOs including CCF would have the capacity to provide similar levels of support to a wider group of children if haematological conditions were included.

- Scott pointed out that a critical element of our national approach to child cancer services has been the lack of debate about what constitutes a paediatric oncology patient. The lines are much blurrier with haematological conditions which exist on more of a continuum.
- Scott reflected on the fifteen-year legacy of POSG that provided a strong foundation for the success of NCCN. It is impossible to go from nothing to this level of cohesion overnight for haematology. However, it is possible to create a collaborative environment among the five paediatric haematologists and their adult colleagues through national standards with regards to access paediatric advice for example.
- It is important to consider the downstream impacts of assigning tertiary centres with responsibility for any specific group of patients.
- Amanda proposed that a service could be largely consult based with children seen at clinic and sent back with a plan with the support of national guidelines. With patients remaining the responsibility of regional services. Virtual FSA as with cardiology.
- Sarah confirmed that the Ministry Cancer Programme do provide some support to the National Haematology Work Group, but that they are on the edge of the cancer programme. While they have some oversight of their work programme they are largely self-directed. Would be beneficial to have discussion with chair of this working group and consider how it fits with their work programme.
- Scott is attending their Working Group planned for March 2017 and Sarah is organizing a phone conversation with the Chair. These are two opportunities to begin the discussion.
- Kirsten proposed doing some work to get a better sense of the numbers involved. A diagnostic search would not tell you about severity but it is possible to get patient data if desired.
- Amber confirmed that Starship maintain a list of non-malignant patients that are seen at Starship regularly and there are approximately 20 on the list who require monthly or more frequent infusions.
- Would need to consider how to capture cohort of patients who aren't seen in person but who are consulted about via phone.
- Consensus was that NCCN could take a lead role in developing a national framework for managing this group of patients. This might include developing standards of care and guidelines for referral for example.

### **Actions**

1. Sarah to discuss proposal with Chair of National Haematology Working Group
2. Scott to raise at meeting of National Haematology Working Group in March 2017
3. Kirsten to investigate what data is available to quantify patient population
4. Scott to discuss formation of NCCN Working Group with Lochie

#### 4. Mini Symposium

- Scott led discussion on proposal to hold mini symposia looking at thyroid cancer, vascular malformations and/or melanoma. Three areas that are currently being dealt with in an ad hoc manner.
- There is money in NCCN's current budget for undertaking these, however need to gauge level of interest.
- General feeling that this was less important than potential new work on Haematology and needed to be weighed up against this priority once the scope of the work had been better defined.
- Suggestion that shared care centres may find vascular malformations an interesting topic and could be looked at in the context of Shared Care Updates.

#### Action

5. Scott and Melissa to consider priority of Vascular Malformations update once scope of haematology work set out.

#### 5. ANZCHOG Meeting

- New Zealand is down to host the 2019 ANZCHOG meeting.
- It is Christchurch's turn to host.
- Appropriate for NCCN to play an oversight role in preparations but will be primary responsibility of hosting centre.
- Both Christchurch and Auckland have new conferencing facilities that will be available in time so there is no issue with capacity.
- Anticipate between 180-250 delegates.

#### Actions

6. Reference group to nominate planning committee and develop tentative timelines at meeting in April 2017.

#### 6. Counselling Framework

- Report tabled
- The three NGOs approach counseling and consider framework differently:
  - CCF engage external counselors
  - Leukaemia and Blood Cancer NZ have trained nurses who have some counseling skills and refer to external providers.
  - CanTeen has well developed internal capacity.
- The three NGOs have agreed to collaborate on a bid to fund the pilot programme and CCF are taking the lead in preparing applications for three trusts.
- CanTeen are interested to collect data and use that information to consider the wider implications for supporting the families of their young people in the future.



Counselling  
Framework

- In the future LBC may consider how the framework could be used to support their adult patients.
- NGOs are confident they will receive some level of funding and have agreed to address any shortfall once they have completed funding rounds.

## 7. Education Support Working Group

- Report tabled



Educational Support

- Discussion regarding proposed research project to look at different morbidity levels for children treated at Starship and CHOC with regards to recommendations to return to school.
- Consensus that this is a relatively significant piece of work and could not be completed as a summer research project.
- Proposal to seek university input as a PHD project discussed however agreement that this is an urgent piece of work that would need to progress faster than a PHD process would allow.
- Agreement that this is retrospective research as it avoids risk of practice changing because of the investigations being undertaken.
- Cognitive subgroup met last week to consider how resources are being used to undertake neurocognitive assessments and how the reports produced can be used more effectively to facilitate parents' and teachers' understanding of a child's cognitive abilities and to mobilise appropriate education support.
- A detailed neurocognitive assessment takes approximately 20 hours and these reports do not necessarily translate into the intended support that is necessary for children.
- A critical issue is that the reports are not written using language that is easily interpreted or consumed by the education sector. Tendency is to focus on deficiencies, diagnoses etc. while the education sector looks at competencies, skills, attributes, curriculum. The working group needs to develop a framework that allows the same problems to be voiced in a different way.
- Main outcome of the working group is going to be a reporting framework that incorporates the insights of both education and clinical psychologists and uses language that educators can respond to in an effective way.
- Educational psychologists have suggested that paediatric oncologists may not be the right people to identify who would benefit from this level of assessment and the referral pathway needs to be reconsidered.

### Actions

7. Kirsten to investigate what information is available via the Ministry of Education

8. Scott and Melissa to propose more robust research question and scope of research and distribute to Reference Group for feedback and approval.

## 8. Survivorship Working Group

- Scott, Kathy Yallop and Heidi Watson attended a Survivorship Working Group that was jointly run by the Central Cancer Network, the Cancer Society and College of Oncology Nurses.
- They were seeking support for a proposed survivorship model that could be rolled out nationally.
- Presentations indicated that insufficient was being done from early after diagnosis to support survivors to remain in their communities and normal lives.
- Meeting raised many questions and highlighted that there is no single model that will meet the needs of all.
- Meeting acknowledged the work done with LEAP programme that are embedded in paediatric oncology practice and the AYA standards of care.
- Lack of definition of survivorship within the adult world was a significant hurdle to making progress. The broad definition that was adopted made the topic unwieldy.

## 9. Pacific Working Group



- Report tabled
- In collaboration with SIOP and World Health Organisation attempted to get a meeting in Fiji which was scheduled for same time hurricane struck. Meeting now going ahead 1-2 December in Nadi. It will predominantly be an education forum for our pacific colleagues.
- Expecting a significant contingent from parent support groups.
- Forum is largely funded by WCCCT and will be attended by most NZ members of pacific working group
- Recent detailed article in Mindfood on child cancer in the Pacific.
- Michael McHugh talking about his visit to Tonga with World Child Cancer Charitable Trust <http://www.mindfood.com/podcast/mindfood-radio-michael-mchugh-on-the-november-issue/>

## 10. LEAP



- Report tabled
- LEAP now completely embedded as business as usual
- Very well established with original ring fenced funding rolled into baseline
- DHBs who provide LEAP services are embedded as integral component of service with no fear of service being removed



- Feeling that they would like to see some academic analysis of growing survivorship data and one of pieces of work that is going to be enabled through NZCCR and Kirsten's analysis of 2<sup>nd</sup> malignancy.

## 11. NZCCR



- Report tabled
- Jane presented the matching of NZCCR with NZCCR data at SIOP in November
- Kirsten attended the International Agency for Cancer Registries in April providing an excellent networking opportunity. She met with the Australian Paediatric Registry which is quite different from our own and involves a person visiting each hospital to collect data. They are probably 10 years away from being able to do any detailed analysis.
- The Toronto staging guidelines project provides a consistent way of staging paediatric cancers. Being piloted in Australia and we are now looking at a summer research project in Christchurch, New Zealand.
- We are behind schedule for the next wave of NZCCR analysis due to significant delays in MOH's response to data requests. Do not want to report survival analysis until data has been cross referenced as a small number of missed deaths can have a large impact on our results.
- Reminder that Kirsten is available as a resource to do analysis as well as extracting data.
- Cancer health information strategy is looking at the mindful ownership of data and data sharing including ethical considerations. Trying to join up sources and make a raft of cancer information sources available in ways that are clinical usable.
- Discussion regarding misreporting of cancer data in the media using recent UK Telegraph example. Consensus that responding can further fuel discussions however there are occasions where it is useful. Robyn highlighted the importance and opportunity to be more proactive and lay strong foundations of information base.

### Actions

9. Sarah to follow up data request with MOH.

## 12. Professional Development

- The Cancer Nurses College of the New Zealand Nurses Organisation with the support of the Cancer Team has developed national standards for chemotherapy administration in New Zealand.
- <http://www.health.govt.nz/system/files/documents/pages/national-nursing-standards-for-antineoplastic-drug-administration-nz.pdf>

- ADHB and other DHBs are now moving to eviQ to provide a platform for training nurses to administer chemotherapy.
- Challenge remains to ensure that there is a paediatric voice in DHB-wide policies.

### 13. AYA Network Aotearoa Update

- Heidi provided an update on the AYA Network Aotearoa
- AYA Standards of Care are due for publication next week.
- They have gone through a significant consultation and editing process.
- Heidi acknowledged the work and leadership of Tristan Pettit in his role as Chair of the group developing the standards.
- The intended audience for the standards is service providers who work with young people. They are not intended for consumer use. However, the Network is currently working with CanTeen to develop a version of the standards that is applicable for consumers. Young people have been extensively consulted on the development of this resource and indicated a dislike of brochures, a preference for video format and a desire to hear from professionals themselves.
- Heidi reflected that significant progress has been made in engaging with AYA service providers to raise awareness of the distinct needs of AYA age groups. While it is difficult to measure the impact, there is a sense that the question of who and what AYA are is becoming less common. There has also been an increase in the number of approaches from those within the sector to learn more about the Network and to participate in relevant forums.
- A launch for the standards is planned for the end of February. Importance is being placed on providing service providers with tools that enable them to implement the standard. This will involve the development of an online self-review process. This will ensure the sector understand what is working well and to identify those areas where further development is required. This information will feed into local service delivery plans. The emphasis isn't on compliance or benchmarking but on local development.
- Project is also underway to redesign the website to provide easy access to information and vetted resources. Will become a one-stop-shop for AYA over time. It will bring together information for service providers. It will link to consumer resources but not replicate the many excellent websites already available.
- Project looking at data collection and reporting has been put on hold. Significant issues remain with consistency and definitions.

### 14. CanTeen Update

- Report tabled.



CanTeen Update

### 15. CCF



CCF Update

- Report tabled
- Robyn highlighted that historically, CCF have had to manipulate their fundraising database to do case management. They are now considering CanTeen's approach which would impact positively on transition between CCF and CanTeen.
- CCF have noted a higher number of relapses this year and have been very busy over winter supporting families financially.
- Janet Masina is working with Family Support Co-ordinators to improve the consistency of practice with regards to how families are being supported.
- CCF considering how they can best support their FSCs. Assessing a team-based approach with the possibility of Co-ordinators working from a hub with regular travel to regional areas. This proposal does not entail a change in the level of care provided.
- Working on major fundraising initiative involving owl sculptures, have enjoyed a high level of interest from authorities who have been approached to participate in the event and are beginning to bring sponsors on board. Event will involve a month-long fundraising and awareness campaign.

#### **16. Leukaemia and Blood Cancer NZ Update**

- Currently have 3370 active clients of which 76 are children and 106 are AYA
- Over the past 12 months there have been a total of 1000 referrals of which 48 are children, the vast majority of which come from Starship.
- Very few referrals received from CHOC – this is an area of focus for the future.
- There are 200 support groups held across New Zealand every year, seeking to reach additional regional areas to provide support to as many as possible.
- Working on a health literacy project which involves updating information resources and putting them through a health literacy lens.
- Kidsclub is a therapeutic group for offspring and siblings. There are regular groups held in Auckland and one will be starting in Waikato soon with a view to moving down the country.
- Increased focus on Māori and pacific resources with translations of all our books.
- 12 Monkey in the Chair programmes put in place throughout the country this year.
- Regular mindfulness groups and star supporters for partners and carers are held.
- Focus on upskilling 8 national support service co-ordinators, including ACP training, Privacy Act training, triaging of mental health issues, facilitation etc.
- A Patient Advisory Board is being established and will meet for the first-time next year.
- Conducting nation-wide survey to assess needs of service users in the first quarter of 2017.

- Planning to hold blood cancer patient forum next year in Auckland. This will include a day of speakers and breakout workshops for our patients and their families.

### 17. Starship Update



Starship Update

- Report tabled
- Discussions under way with regards to creation of 2-3 Nurse Practitioner roles and 1 MSO role. Nurse Practitioner will be able to do routine lists for example approximately 4 lists for lumbar punctures. Currently registrars do these procedures, however they move on and take their knowledge and expertise with them. May also be able to do elective admissions for set chemotherapy cycles and all the associated charting, blood counts etc. This will free up Registrars to do new patient assessments and deal with complications as well as attending outpatient clinics which is currently impossible due to workload.
- These roles are likely to be filled by existing staff who will be trained in their roles.
- Roles will need to be cost-neutral but believe this is possible.
- Senior workforce is stable but nursing turnover remains high and it is a priority for Amber to ensure a safe nursing workforce.



CHOC Update

### 18. CHOC Update

- Report tabled
- Electronic records being rolled out for inpatients, however does not include those receiving chemotherapy or outpatients. This will be problematic for those transferring from inpatient to outpatients.

### 19. Shared Care Centre Updates

- Fiona observed the impact that Shared Care Agreements have had on generally improving the consistency of practice and quality of services. She also commented on the improvement in communications due to the collection of information in a single point with the implementation of Health Connect South.
- Idea of combining Shared Care Updates across North and South mooted. This is an area for ongoing discussion in the next year. Enthusiasm was also expressed for recording updates so they could be made available for those who cannot attend in person.

## **20. Next Meeting**

- Friday May 5
- Friday November 24