

## **AGENDA**

### **Reference Group Meeting**

**Friday 5 May 2017**

**10.00am-4.00pm**

**Novotel, Auckland Airport**

**Attending:** Caroline Folland, Anne Morgan, Jan Millar, Kirsten Ballantine, Melissa Wilson, Scott MacFarlane, Amanda Lyver, Pru Etcheverry, Claudine Young, Deepika Singh, Mal Joyce, Robyn Kiddle, Amber Conley, Dawn Wilson, Heidi Watson, Emma Tonks

**Welcome:**

**Chair:** Amanda Lyver

### **Summary of Action Items**

1. Scott to raise issue with Haematology Working Group on Thursday 11 May
2. Siobhan to continue to log haematological enquiries to build up picture of issue.
3. Haematology to remain on agenda of next reference group meeting.
4. Scott to seek ongoing updates from Sarah Hunter regarding 2018 ANZCHOG and update the Reference Group.
5. NCCN to advise Shared Care centres of availability and allocation process for financial support for Nurses to attend ANZCHOG.
6. Melissa to circulate draft work plan for more detailed consideration and feedback.
7. Melissa to finalise reserves available for projects in 2018/19 and circulate with work plan.
8. Melissa to source and distribute reports from Summer Studentships
9. Melissa to routinely notify shared care teams of availability of Reference Group minutes.
10. Melissa to review Service Agreement to see where the EVIQ platform can be included, eg safe handling.
11. Melissa to develop section on NCCN website that provides access to relevant paediatric oncology research and papers.

### **1. Apologies**

Lochie Teague, David Hamilton, Fiona McGill, John Sanders, Karen Smith

### **2. Welcome**

Welcome to Dawn Wilson (Manager, Cancer Services, Ministry of Health), Emma Tonks (Senior Advisor, Cancer Services, Ministry of Health) who are the new Ministry representatives on the Reference Group.

### 3. Previous Minutes and Actions

- No amendments to minutes for previous meeting held on 18 November 2016
- Action items 1,2,3,4,6 to be addressed in upcoming agenda items

Action Item 18.12.16	Update
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	Kirsten has investigated data sources and provided information to inform development of research proposal.
Scott and Melissa to propose more robust research question and scope of research and distribute to Reference Group for feedback and approval.	Research proposal has been drafted. Applications are being drafted for grants to fund this piece of research.
Sarah to follow up data request for cross referencing NZCCR data with NZCR with MOH.	Cross referencing has now been completed.

### 4. Clinical Advisor Cancer Services Update – Scott Macfarlane

- Scott provided an update on priorities and activities of the Ministry’s Cancer Team. He observed that the availability of resources to address the complexity of issues within the programme was challenging.
- Scott highlighted three tumour standards that are relevant to paediatric oncology – Sarcoma, Melanoma and Thyroid Cancer, commenting that there is little relevance for paediatrics in the other main tumour standards. He observed that while the Tumour Standards have been in circulation for the past three years, there have been no specific programmes or requirements in the Minister’s letters of expectation to operationalize the standards. A project is underway to review the standards. This will involve pulling out a number of generic elements that occur in all standards to form a core set of standards. This will allow the specific tumour standards to be more relevant and act as a catalyst for change.
- In response to a question, Scott clarified that there is no specific cut off age for paediatric patients in the standards, applicability is driven by where the patient is treated – in either paediatrics or adult oncology.
- Scott introduced the Cancer Health Information Service (CHIS) which works alongside the cancer team to consider IT solutions for the integration of existing information

sources. Connecting information sources is considered critical to improvements in service provision and the ability of the sector to generate feedback about how services are developing and performing.

- Scott provided an overview of the 4 new Advisor positions within the Ministry who have been appointed to provide clinical advice to the Ministry: Scott Macfarlane, Suzanne Beuker, Kim McAnulty and Natalie James.

## **5. Non-malignant Haematology – Scott Macfarlane**

- Follow up to discussion held at previous Reference Group meeting in November regarding NCCN's mandate with regards to Non-malignant Haematology.
- Scott described a lack of enthusiasm across the broader paediatric oncology group for the development of a set of clinical guidelines analogous to the oncology guidelines.
- He acknowledged a lack of clear definition between adult and paediatric haematology in New Zealand.
- Key issue is the fact that we have only one paediatric haematologist based in the South Island (Siobhan Cross) who is on call 1 in 4 weeks, meaning that paediatric haematology expertise is available after hours, only 25% of the time in the South Island.
- In her absence, Siobhan has a phone message that directs enquiries to Starship.
- With Starships rosters, there is a 50% chance that the person on call will be a haematologist.
- Is it appropriate, in regions where there is no paediatric haematologist available, for the local adult haematologist to be the first port of call for a general paediatric service providing care for a child with a haematology problem. The issue is that adult haematologists have been informed that paediatric expertise is most appropriate to deal with paediatric problems and many have no paediatric training and are unwilling to provide care to the younger age group. A resolution is required.
- Scott will discuss the issue with the Haematology Working Group who are scheduled to meet Thursday 11 May 2017.
- Caroline Folland and Anne Morgan discussed the fact that in the Southern DHB, adult haematology have refused to provide these services to paediatric patients for the past 12 months.
- Amanda recognized that while oncologists are sometimes able to answer queries, more complicated enquiries require specialist haematological input. She acknowledged that paediatric oncologists have a legitimate concern regarding the provision of haematological advice when this is not their area of specialty.
- Scott reiterated that the Network has no mandate to deal with non-malignant haematology. While a lot of the haematology work that takes place is malignant haematology and clearly within the scope of paediatric oncology there are elements that fall outside.
- Deepika advised that Waikato have an adult haematologist who provides paediatric haematology services. She queried whether it is a good model to involve adult

haematology in the provision of emergency support for these haematological patients.

- Amanda acknowledged that a lot of management in this area is relational, involving local agreements regarding involvement of adult haematology service when necessary.
- Scott queried whether a set of haematology guidelines would reduce the need for calls and allow paediatricians to deal with non-complex issues directly.
- Discussion regarding separation of haematology and oncology teams. Tends to happen once number of specialists in each area reaches a critical mass. The only place there is potential for this to happen in New Zealand is Auckland. The Starship team has deemed that such a separation is not currently advantageous for their overall service. In response to a question, Scott confirmed that the specialist team at Starship was currently fully staffed and thus this situation is unlikely to change in the near future.
- General agreement that there is an issue but there is currently no obvious solution that doesn't involve a small number of haematologists covering a national service.

#### **Agreed Actions**

- 1. Scott to raise issue with Haematology Working Group on Thursday 11 May**
- 2. Siobhan to continue to log haematological enquiries to build up picture of issue.**
- 3. Haematology to remain on agenda of next reference group meeting.**

#### **6. ANZCHOG Meeting June 2019**

- Scott provided an update on ANZCHOG – local collegial multidisciplinary meeting that runs an annual scientific meeting that moves between seven locations including New Zealand.
- While this meeting used to be a high priority for paediatric oncologists, this general oncology meeting has become less attractive in recent years as paediatric oncologists have become increasingly specialized.
- The meeting is typically expensive to attend. Australian Nurses' attendance is funded by an Australian federal grant that can not be spent on travel to New Zealand. Thus, ANZCHOG is likely to only be hosted in Australia in the future. This may lead to further reduction in New Zealand participation which is considered regrettable.
- Amanda confirmed that if the meeting is to be hosted in New Zealand then Christchurch is willing and able to organize the event.
- Sarah Hunter is the New Zealand representative for ANZCHOG and we will seek ongoing updates from her.
- Scott acknowledged the funding support that CCF provide to enable nurses to attend ANZCHOG.
- Deepika queried whether there could be greater transparency regarding the allocation of available funds to nurses with a view to increasing the participation of Shared Care Nurses. The group agreed that increased transparency would be

beneficial and that NCCN should play a role in informing Shared Care nursing teams of funding that is available and how to apply.

### Agreed Actions

4. **Scott to seek ongoing updates from Sarah Hunter regarding 2018 ANZCHOG and update the Reference Group.**
5. **NCCN to advise Shared Care centres of availability and allocation process for financial support for Nurses to attend ANZCHOG.**
  
7. **“Drugs in the News” - dinutuximab, dexrazoxane, the new melanoma antibodies, PHARMAC’s pipeline for dealing with new agents and PHARMAC now dealing with devices – Scott Macfarlane**
  - Group agreed that it is useful to have NCCN acting as central point for managing these issues.
  - Scott provided an update on the supply of Dinutuximab which is summarized in the attached document. This statement is available on the NCCN website and enquiries can be directed to it.
  - The new European supply of the drug is expensive (approximately \$300,000 per patient). NCCN have discussed with High Cost Funding pool who have confirmed that their fund is for procedures that are not available in New Zealand. PHARMAC have also confirmed that they are unable to contract for supply. Thus, cost lies with DHBs.
  - NCCN agreed to maintain an up to date statement on their website regarding the status of supply of this agent.
  - Scott provided an update on Dexrazoxne a cardiac protective agent that is now available. There has been enthusiasm for using this with patients who receive higher doses of anthracyclines However early information raised doubts about the safety of the preventative agent related to an association with increased risk of other malignancies.
  - There are differing views on whether the agent should be used even though many of the safety issues have been dispelled.
  - There are several trials where the agent is now mandated as part of paediatric protection. NCCN has moved to make Dexrazoxne an approved drug funded by PHARMAC and it is in the process of coming through.
  - Scott highlighted the efficiency of PHARMAC in following up on new agents such as this, despite high profile media cases that suggest otherwise. They have a good eye on future drugs and there are appropriate steps that they follow to examine drugs for suitability. Recent changes mean PHARMAC is now also responsible for the funding of devices as well. They have also started doing analyses on the impact of funding drugs looking at the up and downstream impacts of approving agents.



Immunotherapy  
High-Risk Neuroblastc

### 8. Executive Management Team Report



Executive Report

- Melissa tabled and spoke to Executive Management Report.
- Discussion regarding process for scrutinizing budget allocations and reporting and it was agreed that the Reference Group Chair could ask the Executive Management Team to leave the room if the Reference Group would like a closed discussion regarding budgets or finances.
- Discussion regarding budget and justifications for expenditure managed in group with Executive Management Team present. Closed discussion not required.

## 9. Mini Symposia

- Scott provided an update on the Mini Symposia that had been proposed in this year's work programme. There has been luke warm interest in these topics and it has been agreed to keep them on the back burner as potential items of interest with the potential to perhaps deliver as an adjunct to a paediatric society meeting for example where there may be a broader interested audience. This particularly applies to vascular anomalies where there is a likelihood of wider interest.



## 10. Counseling Framework

Counseling  
Framework

- Melissa provided an update on the counseling framework.
- In addition to tabled report Robyn reported that CCF have been successful in securing \$25k towards the pilot from ANZ Staff Foundation. These funds will be used as soon as possible to develop or modify a screening tool to be used by referrers to the Counseling Network. It was noted that such screening tools already exist and Melissa and Scott indicated that they believed Massey would be using these as foundation information when developing NZ's specific tool.

## 11. Family information

- Amber provided an update on the project to review the existing family information folder. The information is currently provided in paper format to families with the material replicated on the KidsHealth website. We will be moving to a more electronic version with the option of printable pdfs for families who prefer a hardcopy.
- The review will seek to integrate applicable elements of the COG and PIC versions with the existing version.



## 12. Educational Support

Educational Support

- Melissa tabled an update on the three projects being carried out by the Educational Support Working Group.

## 13. 2017/18 Workplan

- Melissa presented a draft work programme for NCCN for 1 July 2017 to 30 June 2018.
- There is some uncertainty at this stage regarding the amount of reserves that will be available at the end of this financial year in A+ Trust for allocation to projects. Melissa will circulate the actual figure as soon as it is available.
- No additional suggestions were made with regards to new work to include in the work programme.

#### Agreed Actions

6. Melissa to circulate draft work plan for more detailed consideration and feedback.
7. Melissa to finalise reserves available for projects in 2018/19 and circulate with work plan.

#### 14. Child Cancer Foundation Update

- Robyn reported a slightly quieter year with 24 referrals/24 diagnosis compared with 49 in the same period last year. CCF providing support to 226 families. 3 bereavements compared to 11 last year.
- CCF concentrating on delivering a different model of service with family support co-ordinators increasingly working in teams rather than as sole providers.
- CCF continue to support and facilitate the development of NCCN's Education and counseling projects.
- Have just completed a speaker's tour with Professor Matt Sanders delivering presentations on positive parenting. Topic originated from survey of parents asking them to identify hot topics. They reported strong interest in strategies to assist with parenting through the cancer experience.
- Working on counselling and educational support project
- A bereavement support program has been successfully piloted in Auckland and the Waikato.
- Currently developing nutritional support program to replace traditional approach of giving food vouchers. Looking to provide nutritional advice and education for families.
- Major fundraising initiative is being planned for 2018 – the Big Hoot art project. This is taking a lot of resource but is receiving excellent support.

#### 15. Starship Update

- Amber reported that Starship has been slightly less busy than the intensively busy period towards the end of last year. This is providing staff with the opportunity to regroup and deal with the building project that is now underway at Starship and due for completion at the end of next month.
- With less numbers, Oncology has been able to assist with outliers from other areas.
- While numbers less intense, the complexity of patients is increasing and workload reflects this.

- Jessie Butler, Starship's Shared Care Nurse, has recently moved to Tauranga. This is a significant change for the service as Jessie was a long standing and pivotal member of the team. Amanda Cleland has taken over her role and will be travelling to the regional centres to meet Shared Care teams in upcoming months.
- There is currently a vacancy for a part-time educator as Bridget Smith has taken on part of the LEAP role as Kathy Yallop has reduced her working hours.
- There is a fellow in place for the first time in around a year - Wing-Chi Leung – who will be here until December before going to the States. Starship will be advertising for a Fellow shortly.
- The CRA team is at full strength after losing some long-term staff. This is important in terms of the services ability to keep up with priorities for opening trials.
- A Business Case has been submitted for increasing nursing and CRA FTEs for the service. This case is based on overall increases in the acuity and dependency of the patient cohort.
- Successful planning day was held in March with all senior nurses and doctors. An increase in the number of patients has allowed for an increase in the number of senior staff and thus the sub specialization of the team. This has led to increased diversity in the way that people do things and a greater need for processes to drive consistency in practice.

## **16. Christchurch Update**

- Amanda provided an update on the CHOC service, noting that while there has been somewhat of a lull in new cases in the last quarter this is not reflected in workload due to changes in the CHOC team and service.
- The implementation of MedChart (electronic prescribing software) has created complications with different systems between inpatients and outpatients.
- CHOC is being credentialed as part of the DHB's credentialing this year which creates a significant administrative workload.
- Major building projects both inside and outside the hospital continue and are not scheduled for completion until 2019.
- Summer studentships have completed work looking at delays in Sarcoma diagnosis and differences in revaccination practice between the South and North Island services. Melissa will distribute a copy of these reports.
- An innovative piece of virtual reality technology is being utilized in the radiology department to support children to have MRI's without GAs. Trial has been very successful and has eliminated waiting times for MRIs. Radiologist optimistic that they can employ the technique with children as young as four years.

## **Agreed Actions**

### **8. Melissa to source and distribute reports from Summer Studentships**

## **17. Waikato Shared Care Update**

- Deepika reported that despite a recent lull in the number of oncology inpatients the shared care service remains busy.



- Danielle Polyblank is due to go on maternity leave at the end of June and Lisa van Walraven will fill in for her.
- There have been significant efforts to push the implementation of EVIQ and get staff buy-in.
- Deepika has been involved in an assessment of paediatric oncology patients in ED, with a drive to have all patients assessed in ED.
- The Shared Care service is keen to investigate the option for electronic prescribing based on Starship charts in line with what is happening in other parts of the country.
- Deepika pointed out that the implementation of NCCN's Shared Care Agreement process has eliminated some of the need for the Shared Care paediatricians on the Reference Group to be soliciting input from other shared care centres as they are regularly engaging with NCCN. Agreement to provide Shared Care Centres with access to Reference Group minutes to keep them abreast of what is happening nationally.

### Agreed Actions

9. **Melissa to routinely notify shared care teams of availability of Reference Group minutes.**

### 18. Wellington – Shared Care Update

- Mal provided an update on the shared care service at Wellington, highlighting the impact of a long-standing staff member moving on. With a new SMO in place – Ros Woods – there is a full complement of shared care consultants.
- System of rotating nurses from the paediatric ward through oncology is working well, assisting with the familiarity of both staff and families.

### 19. Update Leukaemia and Blood Cancer New Zealand

- Pru provided an update on LBC operations. She reported that they currently have 7 Support Co-ordinators, 6 of whom are nurses and 1 from a social work background.
- LBC opened a research unit several years ago at Auckland University which now boasts approximately 17 people. Conversations to support the vision to have a focus and collaboration with Starship and around the country are now happening.
- Pru reported an ongoing desire to work collaboratively with other NGOs wherever possible, emphasizing that the NGOs offer different services and it is not a case of patch protection. Their desire is to see all families hearing about and benefitting from all three NGOs.
- LBC continue to advocate for enrolment in clinical trials, particularly in the adult sector and promoting growth in enrolment remains a focus.
- Have introduced a back-to-workforce programme. This is a big issue for patients and L&BC NZ has been working with PWC to consider workforce and legal issues for example.
- Health literacy remains a focus and the organisation is gradually working through existing booklets to improve accessibility.

- Participating in global coalition on lymphoma – considering what patient-centered means, trying to define and publish what it looks like. This will enable organisations to assess how they are performing and to be held to account.
- Pru drew attention to the fact that L&BC NZ offers travel and research grants that Nurses could be accessing to attend things like ANZCHOG.
- Currently at busy time in fundraising cycle – have just completed shave for a cure and have the Sky City step challenge in the next few weeks.

## 20. CanTeen Update



CanTeen Update

- Claudine tabled update on CanTeen

## 21. Pacific

- Scott provided an update on the activities of the Pacific working group.
- He highlighted that NZ has now had 10 years of twinning with Pacific Countries.
- In summary while Lautoka and Tonga both continue to be high functioning twinning partners, services are variable in Suva.
- Suva is currently struggling with a lack of consistent senior level clinical support. There is anxiety about whether the service is performing at a level that is required to deliver paediatric oncology care.
- Simon Lala and Scott are meeting with Fiji's Minister of Health shortly to assess whether there is support for an external review of services. Anticipate that any review is likely to identify a need for improving the general level of paediatric care provided in Suva.

## 22. Tumour Staging

- Scott provided an update of a meeting he attended in Wellington looking at Tumour staging. He reported general agreement that it is important to have staging information recorded in NZCR and to link this information with quality improvement programmes.
- To achieve this, we require a means of notification of stages – staff at cancer registry are data enterers not clinical, they need to be provided with consistent sources of staging information which will most likely need to come from MDT meetings – will require templating and submitting this information alongside currently mandated histology reports.
- There are differences of opinion regarding most appropriate approach to staging.

## 23. NZCCR Update



NZCCR Snapshot

- Kirsten tabled the latest NZCCR annual report (2016). She highlighted issues regarding timing of consent whereby there can be a delay between diagnosis and

receiving consent. Hoping to include NZCCR information in the family information folder to improve this. Also, looking at how the list of protocols can be refined to make it easier for CRAs to manage.

#### **24. Protocols Update**

- Scott highlighted the fact that Starship and CHOC now have a full contingent of CRAs and there is no lag between clinical decision to open a protocol and CRA's ability to progress. This is a significant step forward from previous times when a delay of months was standard.

#### **25. Professional Development**

- Jan Millar provided an update on the activities of the Professional Development Working Group. The focus has been on the development of national standards for chemotherapy and cytotoxic credentialing. She reported significant breakthrough with having the EVIQ module uploaded onto learning platforms in most DHBs. Most the learning is online with follow up study days to consolidate learning. The system provides a 3-year reminder for recertification.
- Anne reported that Christchurch is using the modules and working through some teething problems. They have reinstated education sessions with shared care centres to provide them with access to the platform.
- Some of the modules are broadly applicable and may be suitable for use by Registrars and ancillary staff (eg safe handling module).
- Discussed the value of including some reference to the platform in the NCCN Service Agreements.

#### **Agreed Actions**

10. **Melissa to review Service Agreement to see where the EVIQ platform can be included, eg safe handling.**

#### **26. AYA Cancer Network Aotearoa New Zealand**

- Heidi provided an update of the activities of the AYA Cancer Network. Her current focus is on the Launch planned for next week, of the AYA Standards of Care. This event will be a celebration of achievements to date, a focus on next steps and an opportunity to raise awareness of the needs of young people. The launch will be very young person-focused and 150+ people are expected to attend.
- The AYA Standards are now published with hard copies and printable online versions. A consumer version has also been produced with significant input from young people. It is 10 short videos that aim to empower and enskill young people to advocate on their own behalf.
- The Network's website is nearly completed and will serve as a one-stop shop for AYA care. It has 2 streams of information, one for young people and one for service providers. The clinical guidance section is still under development but will include resources, guidelines, research, links etc. that are relevant to the various clinical areas included in the standards.

- Discussion regarding the idea of highlighting paediatric research and presentations on the NCCN website in the same way that AYA plans to. Amanda suggested that useful for NGOs, clinicians, families etc. to be aware of the work that is going on.
- The AYA Keyworker data set has now been agreed and will allow Key Workers to consistently collect data. This will be implemented from 1 June.
- The AYA standards self-assessment tool has been developed and is designed as an implementation model for the standards. The tool and the process that surrounds it will allow regions to understand what is working well, what areas require further development and what needs to be included in local development plans.
- Heidi commented that in general there seems to be a real turn in the sector across the country with much greater engagement with the Network and its activities and the whole notion of services for AYAs.

### **Agreed Actions**

11. **Melissa develop section on NCCN website that provides access to relevant paediatric oncology research and papers.**