

MINUTES

Reference Group Meeting

Friday 24 November 2017

10.00am-4.00pm

Novotel, Auckland Airport

Attending: Anne Morgan, Jan Millar, Kirsten Ballantine, Scott Macfarlane, Amanda Lyver, Claudine Young, Deepika Singh, Amber Conley, Dawn Wilson, Heidi Watson, Lochie Teague, Fiona McGill, John Sanders, Emma Barker, Claire Gooder, Elizabeth Ryan.

Chair: Amanda Lyver.

Summary of Action Items

1. Elizabeth to follow up with Stephen Laughton, Amber and Lochie regarding Supportive Care Guideline – Medicinal Cannabis Use.
2. Elizabeth to ensure that Claire's research (return to social activities) and implications are adequately described in the work plan going forward.
3. Elizabeth to remove item 7 from work programme (measuring delays in time to receive treatment).
4. Professional Development Working Group to circulate eviQ and professional development opportunities to all Shared Care Centres.
5. Elizabeth to let NGO partners know for communications purposes about the reimmunisation protocol change.
6. Elizabeth to let Shared Care Centres know about the reimmunisation protocol change so that they can manage family expectations.
7. Scott to explore with the Immunisation Advisory Committee the NIS issues raised (e.g age limits).
8. Elizabeth to add development of new Shared Care Agreements to next year's work programme.
9. Elizabeth to add the 2019 ANZCHOG Conference as an agenda item for the next meeting.
10. Amanda as Chair to formally invite Stephen Evans to join the NCCN Reference Group.
11. Updated TOR to be drafted by Amanda, Scott and Elizabeth, then circulated to the reference group for feedback, and signed off by CPLB.
12. Elizabeth to add TOR update to the work plan.
13. Scott and Elizabeth to update the National Plan for Child Cancer Services as per suggestions (achievements and current work plan).

14. Amanda to seek formal support from her team at CHOC and feed back to Scott for publication of new Non-malignant Haematology guideline.
15. Elizabeth and Scott to email the seven Shared Care Centres being visited in 2018 with suggestions about format and an invitation to discuss the most appropriate format once meetings start to be scheduled.
16. The Reference Group to formally acknowledge and thank CCF for their contribution and ongoing commitment to the success of the Counselling Framework initiative.
17. Elizabeth to follow up with Emma and Pru about whether LBC is able to share their survey results with the reference group.
18. Elizabeth to assess and confirm 2018 meeting dates with Reference Group.

1. Apologies

David Hamilton, Karen Smith, Caroline Folland, Pru Etcheverry, Mal Joyce, Emma Tonks, Emma Maddren, Robyn Kiddle.

2. Introductions

Welcome to Claire Gooder and Elizabeth Ryan. Claire is a researcher doing a piece of work around return to school /social activities who commenced in October. Elizabeth is the new Programme Manager for NCCN, who joins the Executive Management Team from Counties Manukau Health.

3. Chair Update

4. Previous Minutes and Actions

- No amendments to minutes for previous meeting held on 5 May 2017.
- Action items 1-5 to be addressed in upcoming agenda items. Items 7-10 have been actioned.

Action Item 5 May 2017	Update
6. Melissa to circulate draft work plan for more detailed consideration and feedback.	Work plan to be discussed (item 5). Need to consider whether additional items are required for inclusion and prioritised. Work plan for 2018/19 needs to be finalised by Scott and Elizabeth April/May 2018.
11. Melissa to develop section on NCCN website that provides access to relevant paediatric oncology research and papers.	There is now a tab on NCCN website for research /other work.

5. 2018 Work Programme

A summary of the key discussion and action points is contained in the table attached.



SUMMARY OF
PRIORITIES 2017 UPI

Regarding new initiatives for 2017/18 (right hand column of table) more detailed discussion points were raised as follows:

Child Cancer Website. Access is not as easy as desired (due to increased firewall measures following ransomware /hacking scare). Scott and Elizabeth to get advice re improving access and promotion of site. Upgrades to website are likely to be expensive (noting that current platform is provided free of charge) and Heidi noted that with the AYA website update adding more features (e.g videos, interactive) brings additional complexity and potentially more technical issues.

There was discussion about who the key audience is for the site and whether access issues more closely relate to the portal and member section as opposed to the open access part of the site. For the portal there are two levels of security relating to the protection of protocols (to clinicians) and also to Service Level Agreement access for relevant DHBs.

Need to promote website more and ensure that linkages to and from related sites are operational (e.g KidsHealth, Starship). It represents the “electronic face” of NCCN. The Family Information folder should also contain link a to the NCCN website so that interested family members can access if desired.

Family Information. Led by Amber this work is ongoing and assisted by adapting existing resources, including COG and PICS (Paediatric Integrated Cancer Service, www.pics.org.au) from Victoria, Australia. The Victorian team are allowing us to link to their resources (e.g podcasts), which is generous and saves development time and cost. The information is being re-written section by section (tests and procedures section complete). Treatment section to be finalised by end-2017. Electronic platform preferred but acknowledge that in order to maintain and improve equity of access for families hard copy options for some key sections need to be retained.

Some discussion about development of an app as the way of the future. At present the plan is to show families the information by way of a session on an i-pad. There could be potential to seek funding for app development (e.g Genesis). Also consideration of developing wallet cards with key phone numbers printed. Not all in agreement that these are effective.

Professional Development Framework. Jan noted that the framework is more comprehensive now and should lead to better results with respect to attraction and retention of high-quality nurses (career pathways enhanced). Training programme is in place and this work is transitioning towards BAU for 2018/19. No additional resource is required. To date this has covered Nursing only but scope could be extended to other roles including non-regulated (e.g cleaners). Amanda noted it is an expectation for Registrars in Christchurch to use it. Modules are on HealthLearn for South Island and KALearn for North Island.

Dental Research. Paediatric dentists completing research (against a grant). Outcomes are expected in 2018, including incidence and late effects data.

NZCCR. Ongoing.

Differences in Outcome by Ethnicity. From the 2005-2014 data analysed and peer-reviewed there appears to be a possible trend towards a difference between Maori and Pacific and non-Maori/non-Pacific survival rates for the first time. Comparative outcomes by ethnicity remains a key piece of analysis for NZCCR and increasing numbers may reveal differences which we have previously not seen.

Measuring Delays in Time to Receive Treatment. Has been considered by NZCCR WG. Can't do on retrospective basis (data not in form required) so needs to be removed from the work programme.

Counselling Framework. Ongoing.

Educational Support. Ongoing. The Cognitive Assessment and Reporting Work Group is led by Psychologist Rebecca Slykerman and is working with the Ministry of Education on a new format for

neurocognitive reports. This specific piece of work continues alongside the more generic education interface work.

Pacific Island. Scott gave an update regarding issues with the Pacific Child Cancer Registry (PCCR) in terms of ownership and access. There are also complexities with respect to the proposed MOU. The proposal moving forward is for the registry to be presented to each country individually and they can use it as they see fit. NZ can provide some support but not as owner.

Plan to establish Community Nurse positions (ongoing) to bridge the gap between the inpatient unit (Lautoka) and care at home. Funding was approved, including a car from World Child Cancer Charitable Trust. The MOU which took 18 months to finalise has been approved by Cabinet. The government (Fiji) has to pick up the ongoing costs once funding expires.

Scope for 10 year review of paediatrics twinning in Fiji. Fiji have been offered a resourced review but there have been some issues getting the relevant parties to meet since July. This work is ongoing and will continue over the longer term.

Discussion:

Amanda emphasised that members can still contribute to the work plan after today's meeting (e.g via email). There was also a brief discussion regarding the importance of Claire Gooder's research and that it is not currently distinguishable in the work plan (refer agenda item 17 for more detail). Dawn (MoH) noted that the two-page summary of the NCCN work plan (with some context) would be good to send to the CPLB.

Agreed actions:

- 1. Elizabeth to follow up with Stephen Laughton, Amber and Lochie regarding Supportive Care Guideline – Cannabis Use.**
- 2. Professional Development Working Group to circulate eviQ and professional development opportunities to all Shared Care Centres.**
- 3. Elizabeth to remove item 7 from work programme (measuring delays in time to receive treatment)**
- 4. Elizabeth to ensure that Claire's research (return to social activities) and implications are adequately described in the work plan going forward.**

6. Clinical Advisor Cancer Services Update (Dawn Wilson / Scott Macfarlane)

- Dawn talked briefly about the priorities of the new government for health being centred around mental health in the first instance and medicinal cannabis. Details around the proposed Cancer Agency are unknown at this point but at present it is BAU for cancer-related services, with major changes to funding for NCCN seen as unlikely. This feedback was supported by Scott as Clinical Advisor.
- Dawn noted that equitable access is likely to be a key priority for the new Minister, as will leadership and governance. The Cancer team are unlikely to see the Minister until at least March 2018.
- Dawn noted that the three-year contract between MoH and ADHB (NCCN) is likely to be rolled over after 2017/18, with the potential of having one agreement to cover NCCN and the AYA Cancer Network likely to be proposed.
- Scott also acknowledged the strong position of child cancer services relative to our adult counterparts. e.g good access to treatment, strong workforce, shared care arrangements. The onus is to continue with strong performance and offer access to others interested in what NCCN does, how we do it etc. Examples of good work also include AYA's new Standards of Care, self-

assessment tool as well as the work of CHIS in ensuring nationally consistent data in the cancer space.

- Scott noted that there is lots of work being done on tumour-specific standards (e.g bowel standard being updated), as well as with respect to Faster Cancer Treatment (children <16 not included). Adolescents (>16) are included in the FCT targets with the target for percentage of eligible patients receiving treatment within 62 days increasing from 85% to 90%. Unlikely to see the introduction of targets for paediatric cancer.

7. Immunisation Protocol



Immunisation WG
report to NCCN ref gr

- Scott noted Siobhan Cross has done a lot work in this area in recent years. A key focus has been investigating the utility of continuing with a serology-based immunisations catch up programme for patients coming off cancer treatment.
- An investigation was undertaken and the individualised approach (current practice) was found to result in some delays to immunisation, leading to exposure to avoidable risks. Therefore a recommendation has been made to change the immunisation programme so that everyone is immunised as soon as they are eligible post-treatment and for the whole panel of immunisations. The protocol has been re-written and needs to go up on the website.
- There are likely to be 1-2 additional needle sticks as a result of the change in guideline, and there is no disadvantage from being immunised for diseases you already have immunity for.
- Deepika noted that for some families this change may be challenging and they may prefer the status quo approach. Scott noted that that would need to be a doctor to patient/family conversation.
- The change is expected to be cost-neutral (may also be cost saving though this is unrelated to the reasons for change).
- There is also potential confusion arising from contradictory information contained in the current NIS, especially around age limits (e.g whether over-18 year olds are excluded) but the expected guidance is “anyone treated as AYA is eligible” which should cover off that small group of patients.
- The research is being written up by Siobhan’s student for publication and Amanda highlighted it as a great piece of work.

Agreed actions:

5. Elizabeth to let NGO partners know for communications purposes about the reimmunisation protocol change.
6. Elizabeth to let Shared Care Centres know about the reimmunisation protocol change so that they can manage family expectations.
7. Scott to explore with the Immunisation Advisory Committee the NIS issues raised (e.g age limits).

8. Service Level Agreements (SLAs) with Waitemata, Counties Manukau and Wellington and Starship.

- Lochie gave an update about discussions which have commenced with Counties Manukau and Waitemata DHBs around introducing SLAs. This has been an increasing issue over the last year, with Starship struggling to manage all paediatric cancer patients for the metro-Auckland region, especially during winter. e.g patient load peaked at 30 which meant 11 patients had to be outlied to other areas of Starship.

- The plan is to establish Shared Care Centres, with agreement in principle to progress the idea following recent meetings. Clinical champions need to be confirmed for each DHB (Counties Manukau still to confirm theirs). Lochie has visited Waitemata's paediatric facilities and they are very impressive. This represents a major piece of work as paediatric clinicians at Counties Manukau and Waitemata have never managed paediatric oncology patients before.
- It is envisaged that rollout will start with outpatients and the appointment of a 0.2FTE Paediatrician at each DHB. Immersion time at Starship would follow, and then on-treatment patients for some cancer types (e.g Wilms Tumour). After some time service delivery would expand to inpatient services and potentially chemotherapy.
- Expectation is that preliminary outpatient services to be established within six months and that by winter 2019 inpatient services would commence.
- This initiative is about providing a high standard of care to patients closer to home. At present the patients (in terms of domicile) are split around 1/3: 1/3: 1/3 across Auckland, Waitemata and Counties Manukau.
- Amanda noted that there will need to be a lot of staff investment (both clinical and admin) initially and a process of confidence building for families.
- The Shared Care Centres will need to be credentialled.
- Amanda noted a request has been made by Capital and Coast paediatric Shared Care Service for establishment of a shared care agreement between CCDHB and Starship Blood and Cancer Centre in recognition of the fact that there are a significant number of patients shared between the two centres. This was raised at the recent CHOC/CCDHB service level agreement review but there is yet to be formal communication between Lochie also added that he has yet to be formally contacted around ongoing arrangements between CCDHB and Lochie as Service Clinical Director at SBBC.

Agreed actions:

8. Elizabeth to add development of new Shared Care Agreements to next year's work programme.

9. Pacific Review – Outcomes of 10 years investment in Pacific

- Note this has already been covered under item 5.

10. ANZCHOG – 2019 Conference, Funding for Executive Functions

Executive functions:

- Lochie noted ANZCHOG executive request for funding of A\$10,000 per year per centre for executive activities. Amanda and Lochie have both indicated their intention to comply (using unit research funds) so as to enable full participation. May need support from NGO partners in future.
- ACCT annual membership (\$30,000) is currently generously provided by CCF, which is equivalent to Australian support provided.

2019 Conference:

- Amanda gave the group an update on plans to date for Christchurch to host ANZCHOG in 2019. Timing and facilities are still to be confirmed. Queenstown had been suggested as potential venue but not proceeding as more expensive and poses more of a flight risk (if bad weather) for international delegates. Numbers could be around 150.
- NGOs need to be aware so can think about stands and having a presence at the conference.

Agreed actions:

9. Elizabeth to add the 2019 ANZCHOG Conference as an agenda item for the next meeting.

11. National approach to end of treatment report

- CHOC has a consistent style End of Treatment letter and after being provided with some examples, a small working group from Starship has proposed a similar style for Starship Consultants to use.
- Lochie noted he was unsure whether consultants were using the suggested template.
- It was noted that a consistent approach to discharge letters was beneficial to the broader care team, including families, GPs and local Shared Care Centres as well as to LEAP Nurses and for NZCCR data accuracy,
- At CHOC the Nurse Specialists assist with the letter content.
- Lochie noted that it was a workload issue at Starship and that staff needed to be convinced to use it. Amanda noted that the process is relatively straightforward and works well. It also provides a signal to the family about items that may be about to cease (e.g taxis).
- Amber noted that staff are keen to do adopt the template, it just needs to be launched.

12. Terms of Reference – NCCN Reference Group



TOR 2011.pdf

- Scott noted that the Terms of Reference (TOR, 2011) has been an agenda item for the last three meetings and need to be updated. Changes over recent years need to be reflected. e.g the surgical appointee has only attended one meeting due to other priorities, and has suggested a potential replacement – Stephen Evans (Starship).
- A small sub-group was suggested to undertake a line-by-line review of the TOR (Scott/Elizabeth/Amanda) and then circulate via email to the group.

Agreed actions:

10. Amanda as Chair to formally invite Stephen Evans to join the NCCN Reference Group.
11. Updated TOR to be drafted by Amanda, Scott and Elizabeth, then circulated to the reference group for feedback, and signed off by CPLB.
12. Elizabeth to add TOR update to the work plan.

13. National Plan for Child Cancer Services in NZ



National Plan for
Child Cancer Services

- Scott noted that a large part of what was contained in the Plan is either redundant (e.g reviewing service specifications) or has been achieved (putting in place SLAs).
- The group agreed that there seemed to be little point in revisiting the plan but several pages could be added to outline achievements to date and a summary of NCCN's current work plan, which could then be discussed with the MoH Cancer Team and confirmed through the CPLB.

Agreed actions:

13. Scott and Elizabeth to update the National Plan for Child Cancer Services as per suggestions (achievements and current work plan).

14. Non-malignant haematology

- As discussed at previous NCCN Reference Group meetings there have been questions around NCCN's overview /stewardship with regards to Non-malignant Haematology, and a lack of enthusiasm for taking on this role.
- There has been ongoing confusion about specialist advice for Non-malignant Haematology available in the SI after-hours.
- Scott presented a summary of the issues and proposed a way forward to the Haematology Working Group on 23 November, as follows:

“Children and young people presenting acutely to a paediatric service outside of Christchurch and Auckland with a non-malignant haematological problem will, where possible, be dealt with by the paediatric service using available Starship Clinical Guidelines. If additional assistance is required, this should be sought in the first instance from the local haematologist if one is available, since many non-malignant haematology problems in young people have similar investigation and management strategies as the same condition in adult patients.

In the case of a transfusion medicine related problem, the local transfusion service specialist should be able to deal with the problem.

If the assistance of a paediatric haematologist is required after involvement of these 2 local specialty services, then contact can be made as appropriate with Starship Blood and Cancer Service through the on call Haematologist/Oncologist (in the case of centres who have a shared care paediatric oncology contract with Starship) or CHOC through the on-call Oncologist/Haematologist (for centres who have a paediatric oncology shared care contract with CHOC). Both of these services have their call rosters filled by either paediatric oncologist or paediatric haematologist, but if the person on call is an oncologist, he/she may be able to provide advice or will know how to make contact with a paediatric haematologist for that advice.

In all instances where the assistance of a specialist paediatric haematologist is sought, both local paediatrician and adult haematologist should have first been involved and contact should be consultant to consultant.”

- The mechanism for disseminating this statement is through:
 - Starship Clinical Guidelines after agreement is reached at Starship and CHOC.
 - Haematology Working Group (MoH's advisory body on Haematology).
 - A notification to paediatric centres through the NCCN communication tree.
- There was some discussion around wording for the process to be followed (as per what was described in the draft statement). Fiona noted that inclusion of the word “local” is important. The SI staff should talk to CHOC in the first instance if their local clinician (e.g haematologist) is not available, not Starship.

Agreed actions:

14. Amanda to seek formal support from her team at CHOC and feed back to Scott for publication of new Non-malignant Haematology guideline.

15. Executive Management Team Report



Executive Report
November 2017.pdf

- Elizabeth tabled and spoke to Executive Management Report.
- Discussion about whether the seven site visits planned for 2018 needed to be the all-day version (which hasn't occurred in six years) or more of a "lite" version.
 - o John noted that the meeting provides a good kick start to get the team organised and focussed.
 - o Fiona added that an all-day meeting was probably not necessary but means that tasks that may have fallen off the radar get attention and audit activities completed. If the Centre had to report on a set of audit activities in advance of the meeting, and they have a good Shared Care Agreement, then it should not take more than a half-day.
 - o Scott suggested perhaps a 45-min overview session where the team presents (all invited) followed by several smaller meetings with key clinicians.
 - o Amanda noted her support for a "hybrid" approach.
 - o With respect to the budget Elizabeth noted the 40k (unallocated) for ongoing development of educational resources. There is potential to use this money towards website redevelopment if an agreed priority.

Agreed actions:

- 15. Elizabeth and Scott to email the seven Shared Care Centres being visited in 2018 with suggestions about format and an invitation to discuss the most appropriate format once meetings start to be scheduled.**

16. Counselling Framework



Counselling
Framework Nov 2017

In Robyn's absence Scott spoke to this item.

- There was a reasonably high expectation that a detailed application to Sky City Community Foundation for over \$200k (three years) to fund the Counselling Framework pilot project would be successful but unfortunately the application was unsuccessful.
- CCF has been submitting other funding options (e.g Sky City Waikato Foundation). Meanwhile Massey University has been contracted to develop a distress screening tool by CCF using a separate \$25k grant from the ANZ Foundation).
- If the Waikato application is successful then a Waikato-based pilot would be the likely result. If these other applications are not successful CCF has agreed to fund implementation costs for this project, which is a fantastic contribution.
- The aim for the project is to provide more appropriate counselling options, including providing training and professional supervision for counsellors on the database.
- Two key elements are Massey's coordination of the counselling service as well as NGOs being able to better direct clients identified as potentially benefiting from counselling.
- There was some discussion about longer term funding options.
 - o NGOs may be able to secure grants (NB: given the niche market Fiona commented that counsellors are unlikely to want to pay for their own training).

- Ongoing costs could also be picked up by the government as part of the wider mental health funding programme.
- Lochie noted that AYA and Late Effects were funded by NGOs before being picked up by health services (MoH).
- Longer term funding of the infrastructure required by NGOs is probably not the preferred option, although funding for counselling sessions over and above what is offered by DHB-based services will likely remain an ongoing area for NGO support.

Agreed actions:

16. The group to formally acknowledge and thank CCF for their contribution and ongoing commitment to the success of the Counselling Framework initiative.

17. Educational support project



Educational Support
Nov 2017.pdf

- 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).
- Claire took the group through the proposed objectives of the research as per the draft Study Protocol, noting these have been slightly updated since the draft was circulated.
 - The wording “back to school” has been altered to read “back to social activity” as we are considering a broader cohort (e.g 4 year olds who then start school).
 - Most of the interviews will be carried out in Auckland or Christchurch, with some phone/skype calls outside the main centres.
- Claire noted that the reason for the research was to look into the differences in approach that currently exist with respect to when children in the two main specialist centres (Auckland and Christchurch) are recommended to return to social activities/school.
- Lochie asked a question relating to whether differences were centre-specific or clinician-specific, noting that there is some variation between clinicians’ practice in Auckland.
- The age band is 0-13 years old reflecting that this is the bracket capturing most of the ALL patients and the need for at least three years of data (some may have left school after 16).

17. Pacific Working Group



Pacific WG Report
.pdf

- A report from Jane Skeen was tabled.

18. LEAP



LEAP working group
report - November 20

- A report from Kathy Yallop was tabled.

19. NZCCR



NZCCR Working
Group Report Novem

- Kirsten tabled the NZCCR report for 2017 and reviewed the highlights.
- More research needs to be added to the NCCN website. Just recently the Australasian Prostate Society saw the site and wanted more information about the Network.
- Summer studentships are planned for the two main centres.
- Rates of survivorship have improved. Increasing patient numbers will allow scrutiny of ethnic and other differences which may not previously have been possible.
- Lochie advised caution in drawing conclusions over small differences where statistical significance had not been reached.
- Kirsten is planning to attend two University of Otago Public Health Summer School courses; 'Data Ethics' & 'Health Research in the Stats NZ Integrated Data Infrastructure (IDI)', contingent on funding. Amanda also recommends the courses.

20. Protocols update



NCCN working group
report May-Oct 2017

- Lochie tabled the Protocols Working Group report.
- The Starship febrile neutropenia protocol has been updated and is in the process of being ratified to become the national protocol (to Amanda for sign off – tracked changes version being circulated to Shared Care Paediatricians). Shared Care Centres will then need to be informed.
- From a workforce planning perspective Fellow WingChi Leung goes to the US in December (Houston: Baylor). A Fellow in Vancouver may be keen to return to Auckland/Christchurch. There is no business case to expand the workforce.
- \$5000 donation will be used to fund a visiting speaker in 2018, but a topic is required (e.g thyroid, melanoma, resilience).

22. Professional Development

- Jan has already spoken to this work in the work plan (agenda item 5) but updated the group that with respect to cytotoxic credentialing. She noted that the eVIQ modules are suitable for a wider group of clinicians beyond Nursing (including doctors and Allied Health).

21. TP53



Tp53 WG report to
NCCN ref grp 24.11.1

- Scott tabled the TP53 report and noted the WG recommendation to remain focussed solely on TP53.

22. Proton Therapy



Proton Beam WG
report to NCCN ref gr

- Scott tabled the Proton Therapy report.

25. Dental



Dental WG report to
NCCN ref grp 24.11.1

- Scott tabled the Dental report.

26. AYA Update



AYA Cancer Network
October 2017 Update

Heidi tabled the AYA report (which is their latest newsletter) and highlighted:

- o Successful launch of Standards of Care (two versions, one for health professionals and one for young people).
- o Updated website – now a “one stop shop” including videos etc.
- o Online self-review tool – the plan is to review 8 of the standards in the first round (two standards can be chosen by the provider). By mid-March expect to have completed all 20 DHBs. The focus is more about quality improvement than benchmarking/compliance which assists with buy in.

27. CanTeen Update



Canteen Report to
the National Child Car

- Claudine tabled the Canteen report and noted the increase in offspring referrals.
- In terms of referral source she also noted that “LEAP clinic” numbers may be currently under-reported, but this will be addressed moving forward.
- Listen Up (two-year leadership /advocate programme) is being expanded to a new group of young people.
- Peer support numbers are lower as there was no camp this year.
- Street appeal is under review as getting harder over time.

28. CCF Update



CCF NCCN Update
Nov 2017.pdf

- A report from Robyn was tabled.

29. Leukaemia and Blood Cancer NZ (LBC) Update



LBC NCCN report
November 2017.pdf

- Emma Barker tabled the LBC report on behalf of CEO Pru Etcheverry.
- Staff are expanding with an extra person now in Auckland and Dunedin.
- Will run another forum in 2018.
- KIDS Club has started up in Hamilton. This is a therapeutic workshop for children and siblings of those going through a blood cancer. Scott noted an organisation which shares a similar name, "Kids Foundation" (Immune Deficiencies Foundation of NZ) focussed on helping children immune deficiencies.

LBC conducted a survey of 4,000 service users and got 700 responses. Scott noted it would be good if LBC was able to share the results of the survey and Emma confirmed that they would be very keen to share the results of the survey once they come through.

Agreed actions:

17. LBC to share results of their nationwide survey with the Reference Group when results are finalised.

30. Starship Update

- Lochie noted that a new Fellow joins Starship from Israel in April 2018.
- Amanda Cleland is the new Shared Care Nurse (update meeting occurring 30 November).

31. Christchurch Update

- Chrissy Bond has retired and has been replaced by Jenny Gardener (ex-CRA).
- Megan Brown has resigned and finishes in December.
- Credentialling took place in August with involvement from Scott Macfarlane, Alison Pearce, and QC Fraser Cook. Draft report is positive.
- Non-malignant Haematology referral pathway highlighted as important along with IT solutions.
- Physical move to new building likely to be early-2019.

32. Shared Care Centre Updates

John noted that Taranaki had had a good year with stable staffing. He noted the loss of their CCF Family Support Coordinator and some challenges with the new person being based in Wellington.

Proposed meetings 2018

The group discussed potential Reference Group meeting dates of 11 May 2018 and then either 2 or 9 November 2018. Elizabeth to assess numbers and confirm dates.

Agreed actions:

18. Elizabeth to assess and confirm 2018 meeting dates with Reference Group.