
Report for the Child Cancer Counselling Working Group

**Evaluation of a Proposed
Counselling Network Model for
Child Cancer**

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“Actually after treatment had finished it was almost the hardest... the fear, worry and exhaustion... could no longer be hidden by the 'doing'.”

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Executive summary

Background

Three Non-Government Organisations (NGOs), the Child Cancer Foundation, CanTeen and Leukaemia and Blood Cancer New Zealand, along with the National Child Cancer Network are testing a proposal for a new National Network of Child Cancer Counselling Providers for:

- Young people aged between 0 and 24 years when they have their diagnosis of cancer and;
- Family members and friends of the young people with cancer.

In addition to the above two groups, key stakeholders involved in testing the proposal are:

- Potential referrers (the three NGOs); and
- Potential providers (counsellors or counselling agencies).

The impetus for change is that there is a gap in referrers knowing how and who to refer to for quality counselling for the range of needs and ages needed and types of counselling required. Also, there are geographic and equity of access issues as well as potential quality issues.

The proposal in summary shows that there would be a robust application and selection process for potential providers, training for providers and referrers and an oversight of the Network as it develops.

Methodology

This was a qualitative review involving a sampling of key stakeholders via individual interviews, focus groups and an e-survey (via Survey Monkey). There were 258 responses to the e-survey and 56 individuals involved in interviews or focus groups. Combined, the inputs were from:

- 51 (17 percent) young people (age 16 years or over) with a diagnosis;
- 239 (76 percent) family members;
- 11 (3 percent) referrers; and
- 13 (4 percent) potential providers.

The field site locations were pre-determined by the Child Cancer Counselling Working Group and included the wider Auckland region (the three District Health Board areas) and Southern District Health Board (which included Otago and Southland).

Consolidated Interview findings

Counselling means many things to people

Although this proposal is targeted at formally qualified and potentially registered counselling people felt strongly that mental and psychosocial wellbeing supports come in many forms. Counselling is but one tool in the continuum of supports. For some this is vital, for others it is of less use and they prefer other supports, e.g. peer supports.

Confidentiality, trust and keeping counselling separate from the medical team are very important for most people interviewed, while only important for about half of those in the e-survey.

Counselling offers vary and / or people don't remember

Having received an offer of counselling varied in people's recollections. Some don't know if they were offered it and others recalled they did, but they were not sure if it was the right time. Overwhelmingly people felt a "pop-in" follow up should have been given. Timing in the process of diagnosis and treatment and how the option of counselling is offered is imperative to how people receive it and are open to the option, or not, in their own time.

Normalise counselling

Actually, being in such a time of need, or distress, means that for most, if not all people, it is "normal" to need a person to talk to / counselling. The advice from people is don't wait until people are in desperate need and feel like they are failing. But normalise it and be proactive.

Young people findings

Of the young people interviewed they were between age 16 and 24 years now, and there was a relatively similar split (e.g. around quarter each) of age at diagnosis of cancer between preschool, primary school years, secondary school and older years. The majority were of New Zealand European descent.

Overall the young people felt peer support was the most beneficial. When they did have formal counselling that was useful, it was vital to have a counsellor that gave good strategies, respected confidentiality and the young person could trust them. Being separate from the "medical team" was very important as people see themselves as compartmentalised between cancer specific treatment and conversations and their overall wellbeing and interactions.

Family findings

The family interview findings were remarkably similar to the young people findings in terms of:

- Peer support being important;
- Confidentiality and trust of counsellors being vital; and
- Counselling being separate from the medical team.

However from the e-survey the family (mother) findings were about half felt the hospital counselling option was alright.

Referrer findings

Other than two referrers interviewed, referrers require a more robust and assurance quality system than is in place now. Referrers are overall keen on the proposal.

Questions referrers had relate to system or operational parts of the proposal:

- Would use of the Network be mandatory;
- What criteria could be in place if you want to use a provider who is not in the Network;
- How would providers be exited from the Network and what is the tenure;
- Risk of reducing choice for some families;
- Make the system clear and simple to use; and
- Clear criteria for consistent prioritisation and urgency of referrals.

Potential provider findings

Potential providers interviewed (n=13) overall felt a network is a great idea. Most of those interviewed represented an agency, not just themselves. So overall a lot more than 13 counsellors were represented.

65 percent said the network was a positive idea and 85 percent said it was very important who selects the suppliers who were elected to go on the network. 62 percent said all costs (other than fees) should be borne by the individuals or organisations applying for the network, whilst 85 percent said some form of additional training is likely to be needed. Mostly, 69 percent, said this was related to high level cancer knowledge, in terms of treatment types, impact on families, time of treatment etc. It was not related to the clinical inputs or technicalities of treatment. 31 percent felt some additional training on grief might be necessary. It will be individual.

62 percent said additional supervision is not needed (as they already have clinical supervision). 69 percent believed that use of technology (e.g. phones and skype) is possible as part of the mix for the future but it should be bed on individual circumstances and preferences.

54 percent believed that the hourly or session rate would be between \$100 and \$150 per session but interestingly 54 percent also thought that maybe \$150 plus per session is reasonable.

54 percent said that home and hospital visits are a reasonable expectation but caveats such as privacy and professional boundaries will be important. Both with the person themselves but also with the wider family in their own environment.

E-survey findings

158 people responded to the e-survey. This has given depth to the interviews and analysis for the evaluation. The majority of respondents to the survey were New Zealand European mothers of children with a diagnosis of cancer. The respondents were mainly from Auckland and Wellington, with Canterbury next highest. There was a response from every region in New Zealand. There was a 15 percent response rate of Māori. There were 57 male

responses, 41 of these were fathers of a diagnosed person, and eight were those who were diagnosed. The others were a sibling and two friends, and not otherwise defined.

Mostly the child cancer was diagnosed in pre-school years. Half of the respondents were offered counselling and 60 percent of those accepted it. The number of sessions was mainly between one and six sessions.

It was reported that the immediate family is most likely to receive counselling from a registered professional counsellor (39 percent), the hospital (26 percent), or a support agency (20 percent). School counsellors are often a source of counselling for the diagnosed, siblings and friends. There are also other avenues for counselling such as employee assistance programmes through a person's work, and specialist programmes such as the Massey Psychology clinic.

Those outside the family appear less likely to benefit from the counselling.

Talking to someone was the most useful, access to free counselling was also the issue raised as what they didn't have access to now (19 percent).

Findings: Counselling needs to be appropriate and accessible

Overall the key themes from all of these questions was that counselling needed to be appropriate and accessible, and for the life course of the patient. Counsellors need to be specially trained for a variety of issues that can arise for child/youth cancer patients and their friends and families which include the stress and strain it puts on them individually and as a family. Different methods for interacting with patients and their siblings including single, partner and group sessions, cognitive behaviour therapy (CBT), and play therapy. Relationship counselling was also an area that was noted several times throughout the survey, but potentially this again needs to be from the cancer perspective as it is directly linked to the cancer journey.

Counselling is not a one off event

Out of the 258 responses and 26 questions a general view can be formed about the gap in current service provision, and potential ways that it can be addressed.

Firstly it would seem that cancer is a journey which does not end with treatment, and involves everyone around the diagnosed person. Counselling isn't for everyone, and many do not understand what it is or how it can help. The need for counselling can be at any time, now or in to the future.

Counselling needs to be integral and normalised

One way in which to address this and de-stigmatise counselling would be to incorporate it as part of the treatment journey, considering an 'opting out' rather than 'opting in' methodology. As in to "normalise" part of what most people will need to do is "talk to someone".

This is a very individual need

Some want counselling to cope with the diagnosis, and some wish to have it to support the aftermath of treatment, some want it connected to the hospital to help navigate the treatment process, and others want it separate and confidential. It is a very individual response that is based on experience, preferences and need.

Counsellors need to be professional, specialised and provide choice

Counselling is provided to varying degrees and quality. Overwhelmingly there is a need for high quality professional specialised counsellors, easily accessible, and available to support the whole family. Different people will require varying degrees of support and will respond to different techniques and methods. Counsellors need to be experienced with children and young people, and cancer. Age and gender appropriate counsellors who can flex the support to meet the needs of the families are important.

Technology for counselling should be an option

Many respondents were open to the idea of technology, as one method of support. This could be a useful tool as part of a ‘maintenance’, or ‘checking in’ package. It could be used once a relationship has already been established to support families when they return home, when they live in rural situations or those that choose to such as when they have other children.

Upskill others in cancer, especially schools

As this is particularly focused on children and young people, the entities that their lives revolve around are extremely important, schools need support in addressing cancer diagnosis of the children and young people they support.

Recommendations

It is recommended that:

1. The proposal for a national Child Cancer Counselling Network be progressed, including clear and simple application, referral and communication processes, as well as exit strategies / criteria
2. The NGO referrers be more proactive and “normalise” counselling for people with a diagnosis and their families, and that the offer of counselling be repeated over time
3. Special effort be taken to identify and recognise the individual needs of people potentially needing counselling, especially at known transition points
4. A plan is made as to what level of education or skills be required on the Network, by what number (volume), in what locations
5. Consider how the peer supports that people report as being so important can be fostered more
6. Provide education and knowledge of what counselling is and can offer, being careful with terminology, and then how to get it later if you need it (follow up, by whom)
7. Consideration of what supports might be needed to enable people to access counselling, e.g. child care, transport
8. Develop a process for people who have had a cancer diagnosis to link in to counselling leading up to and post 24 years of age; and / or for their partners

1. Background

1.1 Testing a proposal for a network of counsellors and testing the current gap

This report summarises the findings of a project testing a proposal for a network of counsellors for children and young people with cancer, who were diagnosed between the ages of 0 and 24 years, and their families and friends (the proposal). The project also explored what is currently in place and any gaps that might exist, or how services and supports could be improved.

Three NGO's (the Child Cancer Foundation, CanTeen and Leukaemia and Blood Cancer New Zealand) working with the National Child Cancer Network engaged Jo Esplin and Hazel Rook, as independent reviewers of the proposal. The concept of the proposal has been tested and views of a sample of key stakeholders canvassed about past and current counselling experiences, preferences, services and gaps.

The key stakeholder groups involved were:

- Young people aged 16 years and older, who have had a diagnosis of cancer;
- Family members of young people with cancer;
- Potential referrers (the three NGOs);
- Potential providers (counsellors or counselling agencies); and
- The Working Group for the project.

1.2 Why change is needed

The current situation is that young people who are diagnosed with cancer and / or their families may be referred or access counselling or support services via:

- Inpatient District Health Board (DHB) services e.g. referred via the Ward they are on, e.g. to consult liaison teams, psychologist, nursing staff, social worker etc.
- The three NGOs who may refer to “free” services or fund them via a fund themselves, and / or;
- People pay privately.

It is difficult for the referrers to know who to refer to.

Not everyone is offered or accepts counselling, and some people who might need it, to reduce the overall burden of the cancer experience for children and families, are not aware of the services available or how to access them.

A key assumption underpinning the proposal and the need for this evaluation is that this approach is relatively ad hoc and not all referrers have a repertoire or directory of quality

providers to refer to. There are service gaps in some areas and a need for improved equity of access and assurance of quality services overall.

1.3 The proposal summarised

The following is a summary from the full proposal¹.

A National Network of Counselling Providers is proposed

The three NGO's working with the National Child Cancer Network have proposed establishing a new national Network (the Network) of counselling providers to deliver funded counselling services to children and youth with a diagnosis of cancer and/or their whānau and friends. In some cases, multiple family members may choose to access counselling services. The Network aims to improve access to counselling support and reduce the overall burden of the cancer experience for people and their families.

The Network could be made up of a variety of counselling providers who will provide support for those affected by childhood and young adult cancer, alongside their existing caseload.

These providers will be carefully screened and receive foundation training before becoming part of the Network to ensure they:

- Know about the impact of child cancer on children and their families;
- Can deliver high quality services; and
- Can provide the relevant service in a timely manner.

There will be ongoing evaluation to make sure the services are meeting expected standards and delivering what is required by the young people and the families.

As there is unlikely to be enough work in most areas to employ providers specifically for child cancer counselling the Network will contract private providers who are responsible for their own clinical work and maintain their usual client base. The Network will provide these contractors with education regarding counselling for children with cancer and will also assist providers to receive appropriate additional supervision, if required.

How providers will be selected to join the Network

There will be a clear set of expectations about the experience and expertise that providers require to be selected to join, and remain in, the Network. A multi-stage process will be used to screen and select applicants against these expectations, including:

- A web based application;

¹ Ross, K.J. and Baken, D.M. (2014). Proposal for a National Network of Providers of Psychosocial Support for Children, Young People and their Families. Cancer Psychology Service, Massey University and MidCentral District Health Board.

- Two referees; and
- An interview.

Applicants may already provide services to the three child cancer NGOs, or may be new. It is expected they will be counsellors or psychologists² etc., who may work in sole practice or be part of a larger practice. It is proposed that specific training will be mandatory (especially Foundation Training) and there would be agreed guidelines to follow; e.g. period in which a the person or the family should be seen, need for availability of home or hospital visits, systems and processes to use, such as discharge letters to go to specific list of people.

The budget and remuneration for counselling provided to children, young people and their families who are referred will be via the three NGOs.

Who will train and support providers

The Network will retain the services of a small number of specialists in providing psycho social support to children and families dealing with a cancer diagnosis to co-ordinate the Network. They will be responsible for developing resources and guidelines to train and support counselling providers. They will also screen, select and train providers and ensure they continue to meet expected standards of care.

Referrers to be educated too

Individuals and organisations who are likely to refer people to the Network will also receive education. This will ensure they are aware of the Network and can make informed decisions about who would benefit from the services available and how and when to make referrals. As the three NGOs hold the budgets they will be the key referrers.

A group will oversee the development and management of the network

A governance group of key stakeholders will meet regularly to measure the success of the Network and help resolve any individual or Network issues that arise in a consistent and coordinated way. The governance group is likely to include consumers (young people who have had a diagnosis of cancer and / or their families), support organisations, child cancer specialists and other referrers.

² Part of the review was to test what qualifications and experience stakeholders felt would be needed. So the Network may be broader than counsellors and psychologists, e.g. psychiatrists, psychotherapists, play or music therapists, etc.

2. Methodology

2.1 Mixed methods

2.1.1 Sampling and methods

This was a qualitative review gathering the views of various stakeholders on a proposal for counselling services for children, young people diagnosed with cancer and their families. A mixed methods qualitative approach was utilised.

The scope included two field sampling geographic sites of Auckland and Southern New Zealand³. All inputs are confidential and anonymised with thematic analysis undertaken.

Interviews took place over the period of 11th August to the 11th September 2015. The e-survey was open from 5th August till 17th August 2015. It was then extended for an additional week to 26th August 2015 to provide additional opportunities for young people to respond, as there was a dominance of parental responses.

The following table summarises the stakeholder groups, sampling methodology and interview methods. Note the people interviewed in the young people and family categories were given a \$30 thank you fee to acknowledge their time and experience.

Table 1 Stakeholders, sampling methodology and interview methods

Stakeholder Group	Sampling methodology	Interview method
Young people: age 16 and over who had had a diagnosis of cancer between age 0 and 24 years	Consent gained via CanTeen for names and contact details to be given to Sapere Research Group. CanTeen arranged focus groups of members in Auckland, Dunedin and Invercargill.	Face to face, one on one interviews and focus groups

³ Auckland district covered the three District Health Boards in the Auckland District of Waitemata, Auckland and Counties. Southern District Health Board covered Southland and Otago districts.

Stakeholder Group	Sampling methodology	Interview method
<p>Family members: age 16 years and over, of young people diagnosed with cancer</p>	<p>Consent gained via the Child Cancer Foundation and Leukaemia and Blood Cancer New Zealand for names and contact details to be given to Sapere Research Group</p> <p>Sought three to five members from each NGO in both Auckland and Southern districts</p>	<p>Face to face or telephone one on one interviews with family members</p> <p>In addition two family members were interviewed a second time to validate the findings of the project</p>
<p>E-survey: young people aged 16 years and over with a cancer diagnosis and / or their families and friends</p>	<p>The three NGOs loaded the e-survey link on their face book pages</p>	<p>Web based survey</p>
<p>Referrers</p>	<p>Key interviewees at each of the three NGOs were identified and offered an interview</p>	<p>Focus groups, face to face and telephone interviews with referrers from the three NGOs</p>
<p>Potential counselling providers for the Network: a sample of potential providers who may, or may not, enter a Network model in the future</p>	<p>A mixed methodology was used to get a neutral sample. This included:</p> <ul style="list-style-type: none"> • Sample of names / organisations given from current referrers • Google to get some random sample • Additional names given to Sapere by interviewees 	<p>Mixed method of telephone interviews, email responses and face to face</p>

2.1.2 Number of stakeholders

The following table summarises the number of stakeholder inputs.

Table 2 Summary of stakeholder numbers

Method	Face to Face	Focus Group ⁴	Telephone	e-survey	Total	% of Grand total
Stakeholder						
Person with diagnosis	1	18	0	32	51	17%
Family member / friend	11	0	2	226	239	76%
Referrer	2	7	2	0	11	3%
Provider	3	0	10 ⁵	0	13	4%
Total	17	25	14	258	314	100%

Combined, young people and families made up 94% of stakeholder responses.

2.2 Format of this report

This is a qualitative report and is organised into sections that reflect the various stakeholder inputs and conclusions separately and then brings an overall conclusion together. This is then used to make recommendations based on the original proposal for the future.

Every effort has been taken to ensure anonymity of all results and quotes in this report. Stakeholder quotes are used to emphasise points made and are italicised.

2.3 “Counselling” or support, means many things to young people and their families

For the purposes of this review the proposal referred to formal counselling by trained, and potentially all registered, people. However what became evident throughout the evaluation was that young people and their families see wellbeing as holistic and very individual.

⁴ Focus groups were also in person

⁵ Target of 10; waiting to hear back from 3

Therefore “counselling” in their terms may be made up of a range of supports e.g. the formal counselling referred to in the proposal, peer supports (e.g. via CanTeen, parent face book pages, parent support groups), practical help (e.g. travel and accommodation assistance, filling in financial application forms), talking to their contact people at the NGOs, hospital nurses and social workers, or a range of others in their life. Even people “checking in” with them at various times are seen as a huge support.

It is important to note that some interview answers oscillated between what might be deemed formal counselling and other forms of listening, assistance or support. Also, not everyone answered every question and sometimes people answered on behalf of themselves and other members of their family. Therefore numbers do not add up to the same totals throughout this report.

3. Interview findings

3.1 Young people

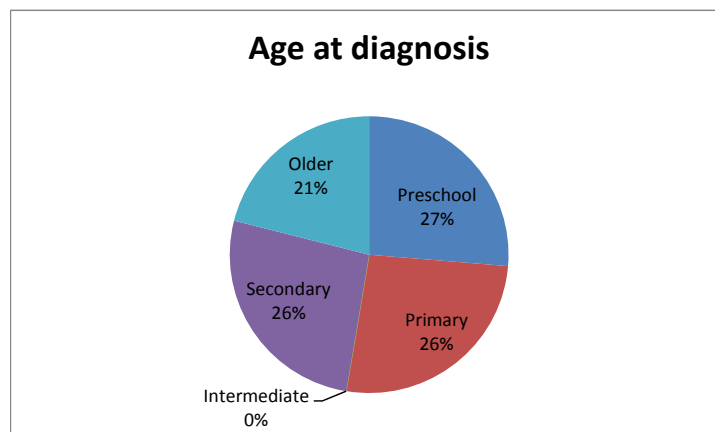
3.1.1 Demographics

19 young people were interviewed of which:

- 7 (37 percent) were male;
- 12 (63 percent) female;
- One individual interview and the rest in three focus groups;
- Current ages ranged from 16⁶ years to 24 years.

Age at diagnosis was relatively evenly spread across preschool, primary school, secondary school and older than secondary school, e.g. at University, working or polytechnic.

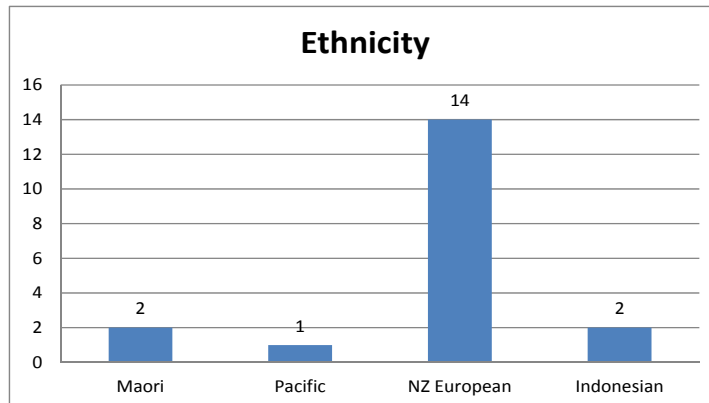
Graph 1 Age at diagnosis



Graph 2 indicates ethnicity as self-reported by the young people, with 74 percent NZ European and 26 percent others.

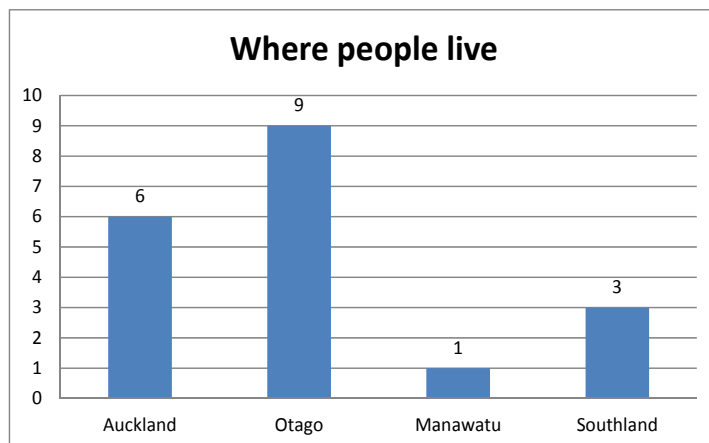
⁶ Scope was limited to age 16 years and over for reasons of informed consent.

Graph 2 Ethnicity of young people



Graph three shows where young people who were interviewed live. This was based on the scope of the review focussing on Auckland, Otago and Southland. The person from Manawatu happened to be in Auckland the day of the CanTeen focus group and was able to join in, which was very beneficial.

Graph 3 Where people live

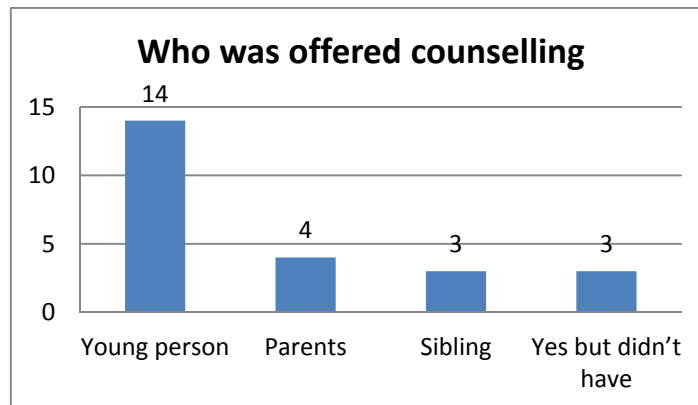


3.1.2 Young people: past experiences of counselling

Difficult for some people to remember if they had been offered counselling

Interviewees were asked if they or any of their family or close friends had been offered counselling. Some people couldn't remember or felt they may not have known if their parents had been offered or had counselling.

Graph 4 Who was offered counselling



Of the 14 who were offered counselling, six (43 percent) declined. Five attributed the decline to the fact that their family dealt with things as a family, or it was a cultural difference.

“No. We [family] just don’t do things like that [counselling].”

“Our family just needed to go through it together. We are quite close.”

“My mum and I are really close. We had each other.”

The number of sessions available needs to vary by individual circumstance

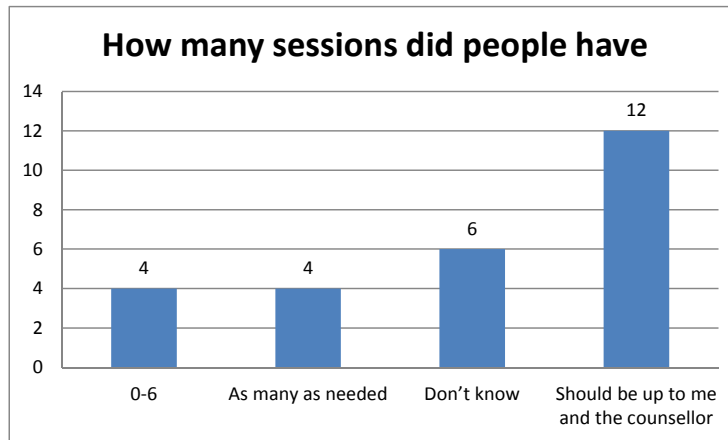
Looking to the future it is desirable to understand number of counselling sessions and how this might correlate to how people experienced the outcome. However the answers could not determine any correlation. Of interest however, is that the young people felt that the number of sessions should be based on their need and not be pre-determined, or constrained by budget.

Currently there is a variation in the number of sessions that can be funded by the three NGOs. For example, CCF fund up to six sessions (but can extend if necessary), and CanTeen fund up to \$600 (so depending on the cost of the sessions it may change the number of sessions).

“Actually, I know there are budget limits, but really..... the number of sessions should be up to me and my counsellor.”

“I was starting to really get something from the sessions. But then I turned up on the sixth session and she said this was my last as that was all that could be paid for. It was lucky my counsellor was able to get that extended.”

Graph 5 How many sessions did people have



Who the counsellors are and their qualifications

People were not clear on the exact qualifications of their counsellor. “Psych” was given as a proxy for a range such as psychiatrist, psychologist and psychotherapist. Note: as detailed elsewhere in this report, answers to specific questions may differ to the more free ranging discussion in the overall interviews and focus groups.

A strong finding is that overall school counsellors were not considered helpful, and were perceived to make things worse in some circumstances. All young people from the interviews who had seen the school counsellor, had poor experiences⁷. Others had been offered but refused, or wouldn't even consider the school counsellor. The key theme was that the school counsellors don't understand cancer and what people are going through / have been through.

“They are useless.”

“They are the biggest school gossips – everyone would know what I had said.”

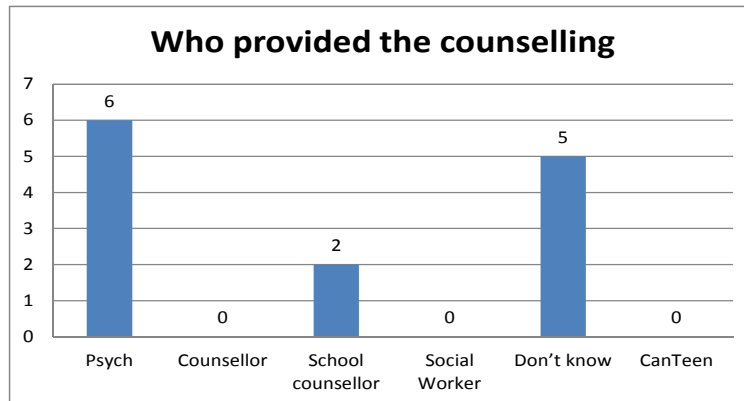
“No way! They have no idea.”

“She was the worst. She wouldn't even use the word cancer. just wanted to say “The BIG C”. I have cancer. That is what I needed to talk about”.

Graph six shows who people thought they had counselling from. However it is not clear that it was always understood who did provide the counselling.

⁷ Note this was not the same finding as in the e-survey.

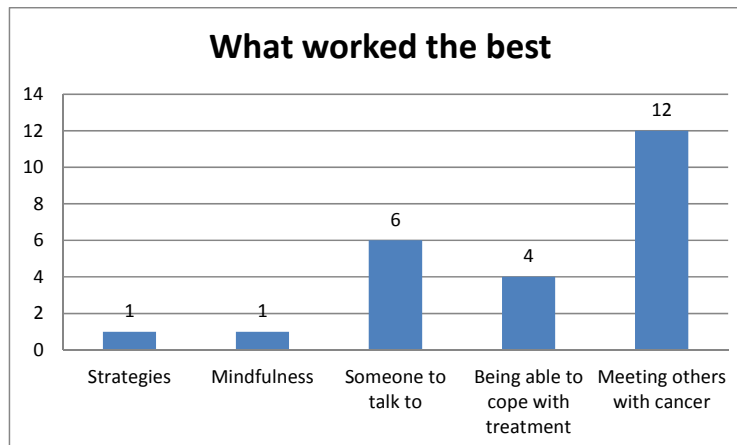
Graph 6 Who provided the counselling



Mixed views on the outcome of the counselling

People were asked to consider what they got the most from, or what worked best in the counselling they had had. 12 (63 percent) noted meeting with others with cancer (peers) was the best form of support, yet note in Graph Six that no one said they had counselling from peers. Being able to cope with treatment included, needle phobia and fear of doctors or treatment. Five (42 percent) people considered the counselling had met their needs and seven didn't.

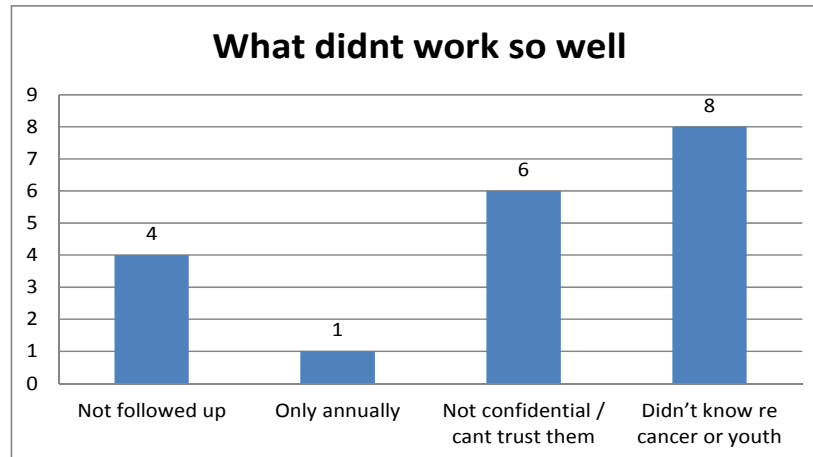
Graph 7 What worked the best from counselling



Perceived trust and confidentiality are issues

We then asked what didn't work so well from the counselling. Of note combined 14 responses said it wasn't confidential / can't trust them and / or they didn't understand youth issues.

Graph 7 What didn't work so well from counselling



Summary

From the responses from people who had been offered and / or received counselling the key findings are:

- Emotional and psychological wellbeing requires a variety of support mechanisms;
- If counselling is offered, it needs to be followed up; re-offered;
- The number of sessions needed varies by person and should be based on need not budget;
- Counselling options may need to be reoffered at a later time;
- People need to trust the counsellor;
- Trust includes: building rapport, confidentiality, understanding of youth issues / needs and some understanding of cancer.

“Empathy not sympathy.”

“I don't know who to trust anymore. I had two really bad counsellors and the school counsellor was even worse. There is no confidentiality. They all just spread everything I say around everywhere. I can't trust anyone.”

3.1.3 Future

Strong personal characteristics would make good counsellors for the future

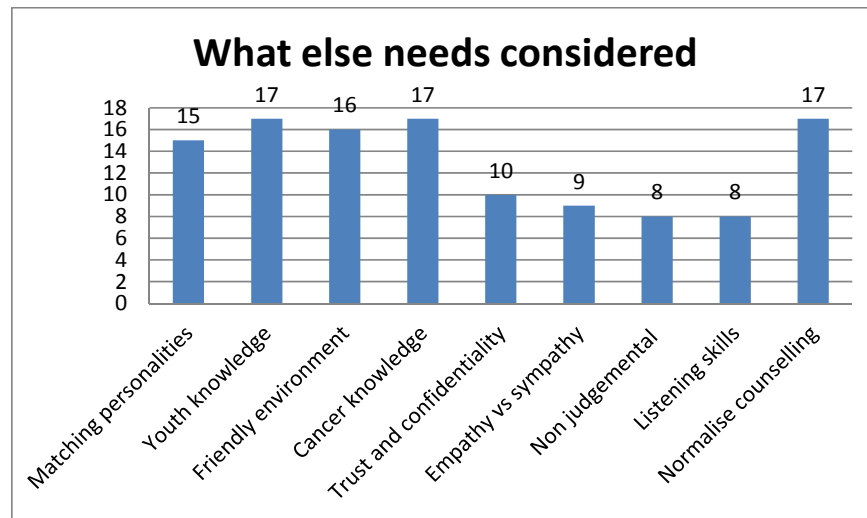
Then people were asked about the future. What would they want for people like themselves, their family and potentially others who get a cancer diagnosis, in the future? Some of the following responses also inform the previous section in terms of what was useful etc., and are considered together in the conclusion section of this report.

A strong theme was that the type of people who are counsellors, their personal characteristics, is vital to enable the young people to build rapport and trust them. In addition a youth friendly environment was very important.

“The place needs to be friendly and warm. Maybe with bean bags and a whiteboard for drawing on. I don’t want a clinical white space.”

Graph eight lists the features the young people reported to be important.

Graph 8 What else needs to be considered for the future / what type of people



The answers were clear that counsellors must have a variety of strong personal attributes. The top three areas of youth knowledge, cancer knowledge and normalise counselling were 17 (89 percent) each. Other attributes included a sense of humour, good listener and don’t link it to the medical team.

Normalising counselling related to various things but can be summarised in to two key themes:

- Make it just part of what happens for people on this journey, so people don’t feel “different”, or don’t have to get in to a bad space / crises before counselling is offered⁸;
- How can the terminology of the word “counselling” be changed as it carries a stigma.

“If it was offered to everyone then it might seem normal. Not like you are the odd one and can’t cope.”

“I got bullied at school..... not because of having cancer but because I was seen as weak when I had to go to counselling.”

“Change the word [counselling] then more people might do it. It has a stigma.”

“We need people who understand us [youth] AND understand that cancer is not a death sentence.”

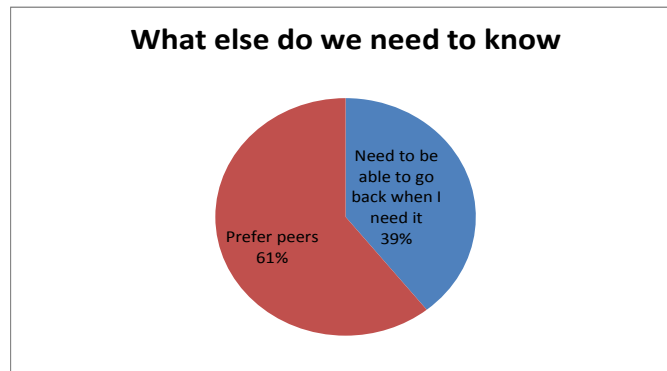
⁸ This was strongly supported in the family interviews and the e-survey as well. As in offer an “opt-out” approach as opposed to an “opt-in”.

“People really p... me off when they think they know what it is like. They don’t. It is not the same as their dog having cancer.”

What else do we need to know: Peers are preferred over counsellors but counselling should be re-offered at future dates

When asked what else we might need to know for counselling services for the future, there were two key themes. These are in Graph nine.

Graph 9 What else do we need to know



“Early on we have bigger fish to fry. I was super focussed on treatment. So follow up re someone to talk to is important.”

Additionally, another point raised by many was that their friends and family didn’t know what to say or how to respond, so many walked away.

“It’s hard when your friends don’t know what to say and exit the scene. Some come back months later but others don’t. It would be good if we could hand them a blurb on cancer, like, what to not say and what not to do!”

Young people would approach CanTeen if they needed help in the future

16 people said they’d approach CanTeen first and one person said their Adolescent and Young Adult key worker. The latter was due to the person turning 24 years of age so no longer was part of CanTeen.

People were very clear they would not approach their GP first. No one appeared to have a strong relationship with their GP and some reported it being too expensive to go.

Peers as providers of support and understanding were viewed as very important.

“In the peer group it is more relaxed. The discussion re cancer and how we are just comes up organically.”

⁹ This person had someone say they knew what they were going through as their own dog had had cancer.

Use of tele-options for counselling should be an individual choice

10 people felt telephone would be fine, only one felt skype would be alright and seven said it should be up to the individual. The main reason for not using skype was the current unreliability of it and the potential for it to “drop out” mid-session. As technology improves this may be less of an issue.

Four people felt there could be also a confidentiality issue with skype, as other people might be in the room and they wouldn't know it.

How far people are willing to travel to counselling in individual as well

The answers varied but overall the theme was it depends on the individual circumstance:

- Close to the bus stops (n=2);
- Depends on individuals (n=5);
- Not too far (n=4); and
- The closer the better (n=6).

“It depends on where you live, what you are used to¹⁰, the money you have, if you have a drivers licence and a car, if not, can your mum take you, is she at work..... so many things.”

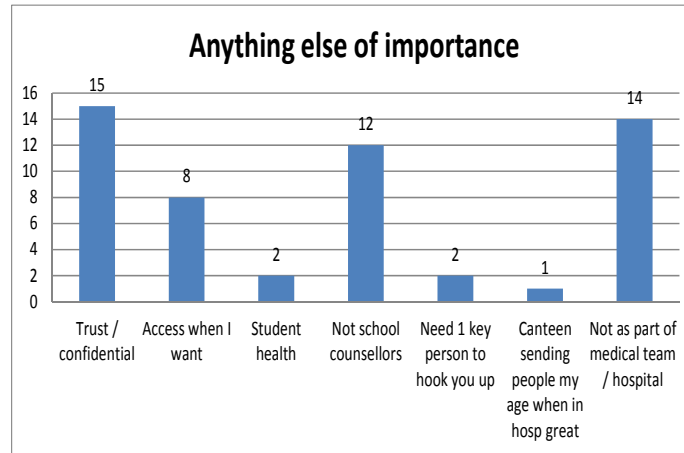
The personal attributes of the counsellors were reinforced as was confidentiality

People were asked was there anything else of importance that hadn't been covered yet. This question was designed to capture a summary for people of what had arisen during the session, for them. The top three items were:

- The counsellor needs to be trustworthy and keep confidentiality;
- Do not use school counsellors; and
- Counsellors should not be part of the medical / hospital team.

¹⁰ E.g. the difference between a large city, provincial towns and rural.

Graph 10 Anything else of importance



“Counsellors need to be confidential between us and them, and not talk to your medical team, or your parents. That is separate.”

“I heard her talking about me to my doctors in the corridor. I wouldn’t go back to her. She is not trustworthy.”

One thing that isn’t known is, if the counsellors who talked to the medical teams were actually part of the hospital multi-disciplinary team, or not. However this appears to be a significant barrier to young people engaging with a counsellor.

3.1.4 Summary

Overall the analysis of this section leads to the following conclusions:

- Counselling needs to be individualised – not one size fits all;
- Counsellors need to have specific personal skills and knowledge (especially around confidentiality, knowledge of cancer and youth issues) and generic counsellors, e.g. school counsellors, without upskilling, are not the right people;
- Counselling needs to be normalised, and access needs to be when people need it, and they need to go back if needed;
- Importantly, there were significant number and depth of reports of not feeling like the counsellor would keep confidence; and
- Peers are a very important part of wellbeing and support.

3.2 Families

3.2.1 Demographics

13 family members from 12 families were interviewed of which:

- One was a father of a child who had been diagnosed with cancer;
- One a grandmother of a child with cancer; and
- 11 were mothers of a child or young person with cancer.

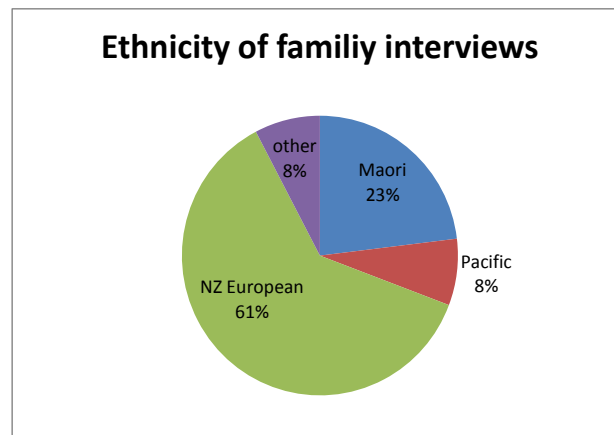
All were individual interviews either in person (n=11) or by telephone (n=2), at their choice.

The age of their child when the cancer was diagnosed was:

- 10 preschool (including two at birth);
- One primary school; and
- One at secondary school age.

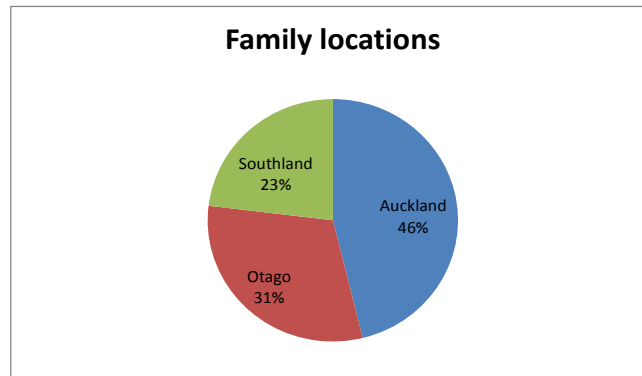
Self-reported ethnicity of the family member being interviewed is detailed in Graph 11 below.

Graph 11 Ethnicity of family members



The locations of where families live were 46% in the wider Auckland region and 54% across Otago and Southland regions.

Graph 12 Location of family members



Nine people were offered counselling

Nine people said they were offered counselling, three young people with the cancer were, two siblings, one grandparent and three didn't know.

Three people declined the offer of counselling and the reasons given were they were scared or vulnerable, didn't want to be assessed, or that the timing was wrong.

“If I was told that on this journey most people need to talk to someone..... Like it was normal..... then I might have been more open. And in hindsight I did need counselling.”

“I won't see anyone with “psych” in their name. I don't want to be assessed..... If I let all this out they may think I am not coping and CYF will take my kids off me.”

“Once I start opening up I don't know where it will lead to. I need to keep it inside. I need to keep it from the medical team.”

“The medical team are very judgemental and write things about you in the notes. You have to pretend you are strong even though this is the worst time of your life.”

“Timing is everything. Maybe it [the offer of counselling] needs to be followed up as I might have said yes the next time. It needs to be more normalised and proactive.”

3.2.2 Families: past experiences of counselling

Six said counselling didn't meet their needs and they may have needed more sessions

Five people had between zero and six sessions, two said as many as is needed and one said it should be up to the person and the counsellor. Three said they did have enough sessions and four said they didn't. Two said it met their needs and six said no, it didn't. Of those six there were a variety of reasons including:

- The counsellor didn't know about cancer so couldn't empathise;
- It was at the wrong time (e.g. too early in diagnosis and treatment) so couldn't really engage; and
- Wrong person; couldn't link with them (three said this).

"She just ended up down loading her troubles on me. I didn't need that!"

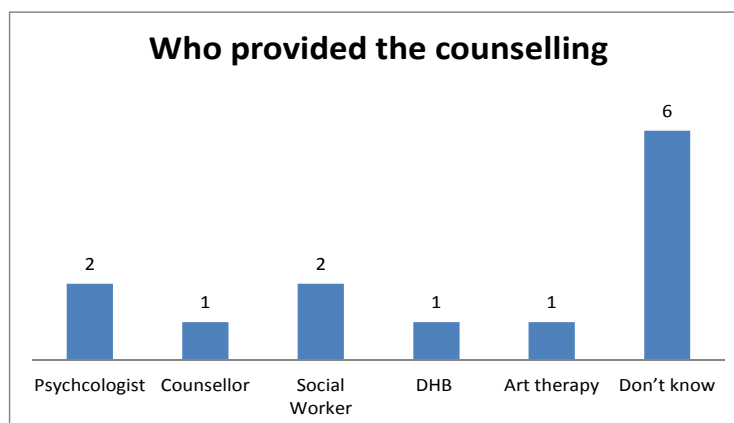
"She just kept crying when I told our story..... that didn't help. It was a big disaster."

"They had no idea what we had been though, what we were going through. They didn't understand about any of the medical parts..... I don't think they need to be an oncologist, but they need to understand cancer."

People were not clear what qualifications the counsellor had

People were not clear of the qualifications of the person who provide the counselling. Even for some who thought they could name the person they might have guessed at their role or qualification.

Graph 13 Who provided the counselling



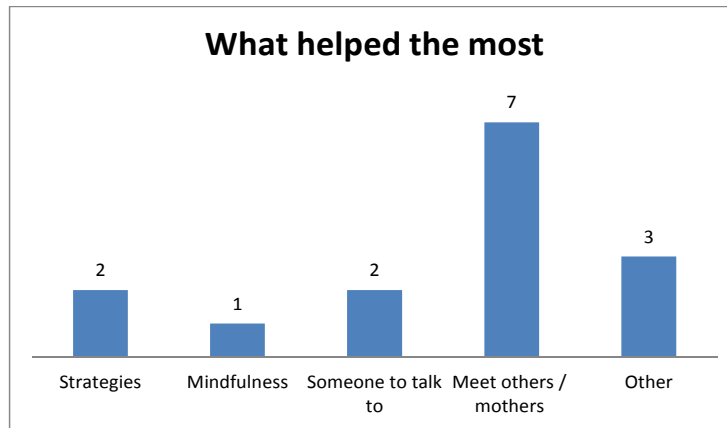
Counselling is one tool on a continuum of supports; peer supports are important

However, families were clear that a variety of things helped them, the best being other family / parent support and strategies. Like the young people, counselling was not tightly defined for the family members. Seven said that meeting others in the same circumstances e.g. other mothers, was the most useful. This is because they understand what each other have been through. Seven said that having support groups or using the dedicated and closed Facebook

page for mothers, or friends of the ward, where medical staff couldn't see what they were asking about or writing, was very helpful.

When asked what helped the most via the counselling, people mainly referred back to reflecting on peer supports.

Graph 14 What helped the most from counselling



The two that said strategies helped, related to managing their children's changing behaviours due to treatment.

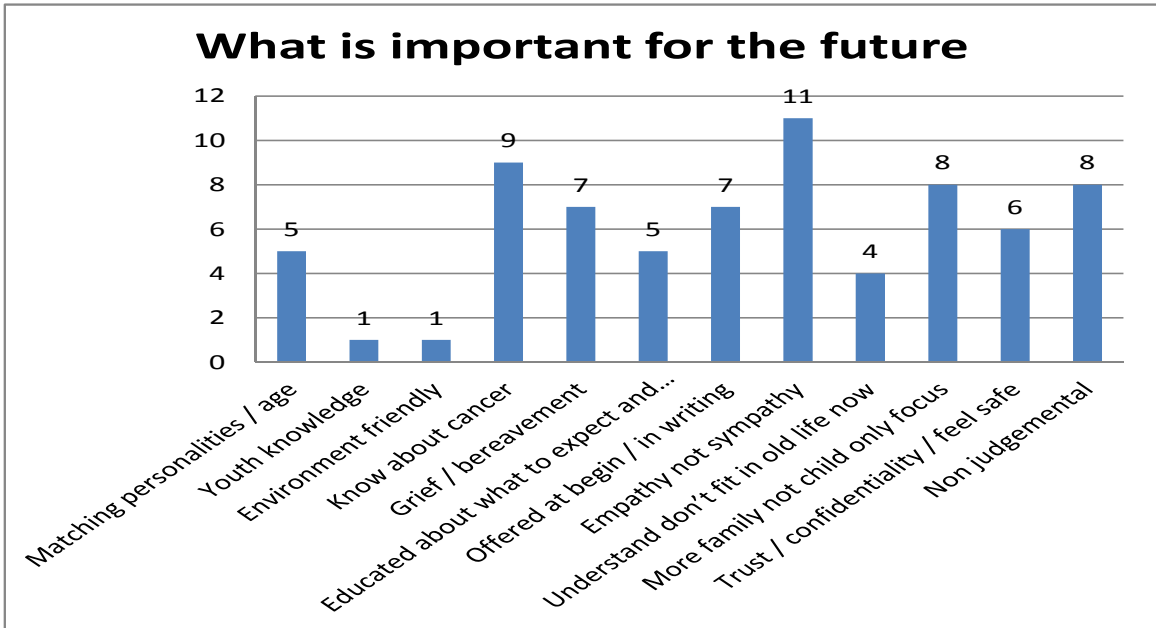
“When she was on steroids she was like a... monster – not her normal self at all. I didn't know what to do. The counsellor gave me some very helpful strategies.”

3.2.3 Future

The right person, at the right time, is key

People were asked what would be good for the future, or could be improved, to make counselling services accessible and of benefit for them. In summary the “right” person at the right time with an understanding of cancer, irrelevant of qualifications, was the most important.

Graph 14 What is important for the future



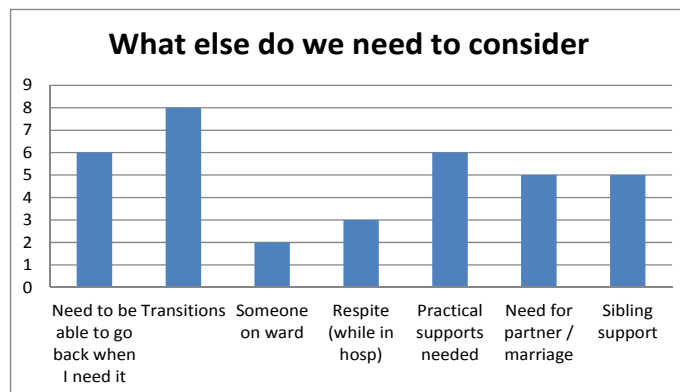
“It [counselling] may have been offered but we were dealing with so much at the time. It is necessary for people to come back and build rapport. They need to offer it again.”

“Someone popped in to the hospital and said if I needed to talk to anyone they were there. But, I never saw them again and I didn't know who they were. They need to build relationships, like.... Pop their head in weekly and then when I was ready I could talk then. It would have been really good to have someone to talk to.”

Proactive identification of supports at transition points is needed

People were then asked what else needs to be considered for the future.

Graph 15 What else needs to be considered



A very clear point was that at the point of transitions things got more difficult and stressful and counselling / someone to talk to should be offered at these times. Most of these transition points can be proactively identified and planned for.

Examples of transitions given included:

- Immediately post diagnosis and start of treatment;
- Going back home after being away for treatment, both if you lived in the same town as treatment and more so if you had to travel for treatment;
- The child starting preschool or school;
- Someone you are on the ward with dying (either while you are on the ward or later) therefore:
 - Dealing with a bereavement in the face of your own child living / being at risk also
 - Feeling guilty your child is living
 - Losing your support person (their parent may have been your main support person)
- Finishing treatment; and
- Transitioning out of oncology to a different service or part of the hospital.

“It is in the aftermath of the busy time; the hurricane when everything is happening and everyone is coming at you..... that is when you have time to reflect and think, “Did that really just happen over the last few weeks.....?”, that is when you really need someone to talk to.”

“Going home from CHOC was a big, big shock. It was so hard. I had been living in a bubble in the hospital for months and my life was changed for ever. But when I got home I was expected to be like I was before. But everything had changed.”

“When you are in hospital, although it is hard, you feel supported. It was so scary even going on our first few days’ leave. It would have helped to have someone checking in – just a phone call or two to see how we were doing.”

“Going home after so long away was very difficult. We were just sent home after months away with nothing in place but a referral to a name we didn’t know.”

“They build you up to celebrate the end of treatment. But then you leave the hospital and you are alone. You’ve gone from having a team of experts around you, to it being just you. You don’t know what to do, when to call a doctor, what is normal? I was so scared and alone.”

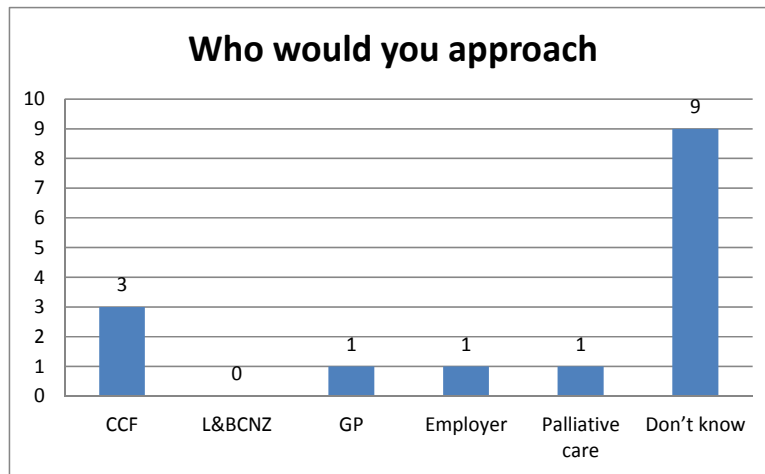
“It was so hard letting her go to pre-school. I don’t know what to expect and I am on egg shells all the time.”

“We went from a wraparound service with a social worker helping me, to an adult ward. No one spoke to me, there was no one to talk to. It was awful and stressful.”

64 percent of people don’t know who they’d ask for help in the future

People were then asked, if they needed counselling in the future who they would go to first to ask for help. Nine (64 percent) family members didn’t know who to approach.

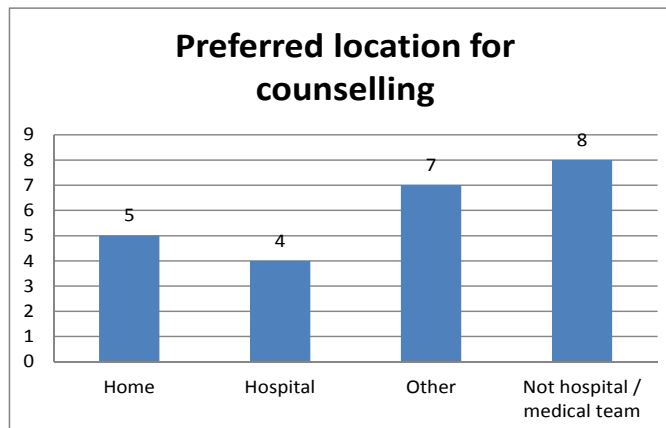
Graph 16 Who would you approach first



Preferred location for counselling varied; but 62 percent said not with the medical team

In thinking about where they would prefer to have counselling in the future, eight (62 percent) were clear that it must be separate from the medical team and not at the hospital. There were some caveats on responses such as in the home but would need to be after hours so the children are in bed. The term “Other” referred to in counsellors’ offices, at CCF or they weren’t sure.

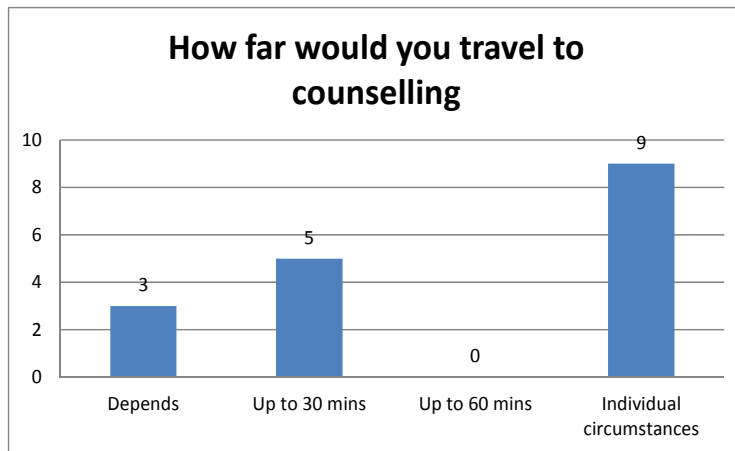
Graph 17 Preferred location



Travel distances are based on individual circumstances

When asked how far people would be prepared or could travel to get counselling 12 (92 percent) said it depends on circumstances at the time or it would be up to the individual.

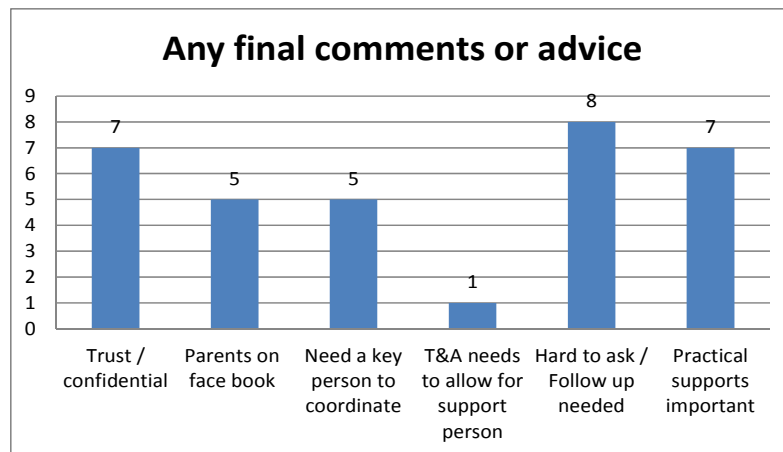
Graph 18 How far would you be prepared to travel



Proactive supports with trusted counsellors most important

Lastly people were offered the opportunity to add any final comments or thoughts for the future. Once again the trust and confidentiality aspect of counselling came up. Eight (62 percent) said that it is very hard to ask for help and that the opportunity for counselling should be offered proactively, and more than once.

Graph 19 Final comments



Key: T&A = Travel and Accommodation assistance

3.2.4 Summary

Please read this summary in conjunction with the summary from the e-survey.

Overall people reported they:

- Had not had much benefit from counselling;
- They may not have been offered it or couldn't recall if they had been;

- That the offer of counselling should have been more proactive and followed up, even several times, at different times, especially at times of transition;
- That counselling, or someone to talk to, should be normalised;
- Timing is very individual and important to note that it changes over time;
- Having the right person as the counsellor is more important to people than their qualifications and ensuring trust and confidentiality is key. They need to know about cancer, have empathy and not sympathy or pity, and be non-judgemental;
- Counselling is only part of a continuum of supports with linking with other parents / peers a strong support. Understanding that others are going through the same experiences as you and that what you experience is “normal” is very important; and
- Separating emotional or psychosocial supports from the hospital medical team is seen as important. There is a strong correlation to this and the confidentiality point.

3.3 Referrers

3.3.1 11 referrers interviewed

Referrers work in the three NGOs and have access to some funds, each held nationally by all three NGOs, for referring their clients / members to counselling. 11 referrers were interviewed either individually or in a focus group; two by telephone.

3.3.2 Current situation

It is difficult for most referrers to know who to refer to

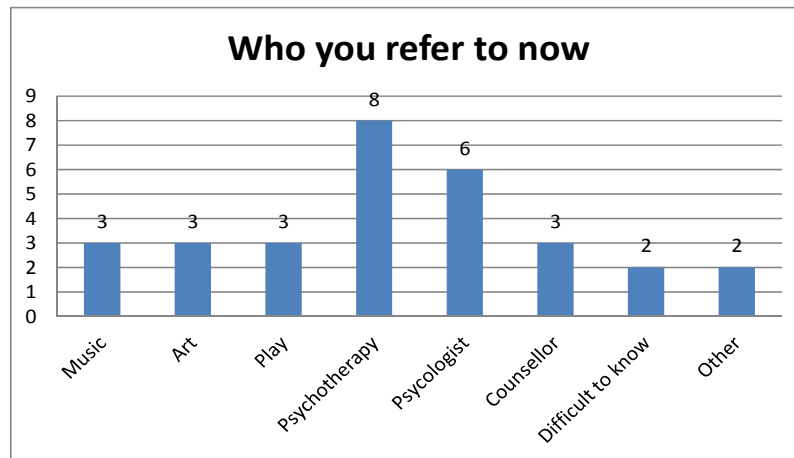
No systematised list or network of counsellors for child cancer is currently in place. Referrers in each centre mainly have one or a few counsellors they have used and found successful, as evidenced by patient or family feedback. However if they get a need in a new geographic location, or a different type of need, they may not have a contact. In this instance, most referrers report googling and trying to find an appropriate counsellor online, if they don't already know someone.

“It is a bit like a needle in a haystack scenario. How do we know who is a good one and who isn't. I'd hate to do harm.”

A range of counsellors is important

There is a range of disciplines referrers refer to now, based on their assessment of the person's need.

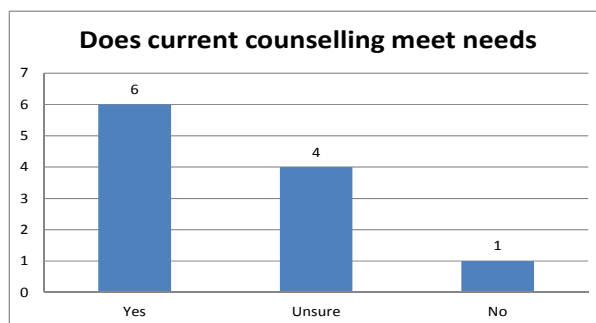
Graph 20 Who you refer to now



Nearly half weren't sure if the counselling met needs

When asked if current counselling meets the needs of the people they refer, some said yes, from family or young person feedback, and others weren't so sure.

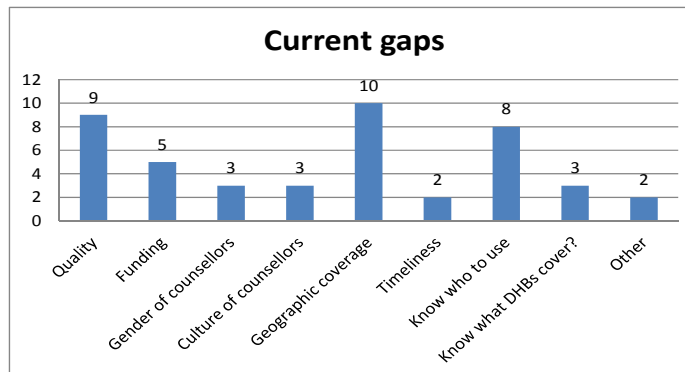
Graph 21 Does counselling currently meet needs



Geographic coverage, quality and knowing who to use are the biggest gaps

There were a variety of gaps in counselling services perceived by most of the referrers. Added together the theme is about not really knowing who to use, quality of counsellors and who is most appropriate e.g. cultural, gender etc.

Graph 22 Current gaps in counselling services



Referrers are generally comfortable to know when to refer

Eight referrers felt they are generally comfortable knowing when to refer, three not always and a few said it should be earlier for people. Overall knowing who to refer to is the issue. The reasons they felt comfortable knowing when to refer was a mix of being clinical people themselves and / or general experience.

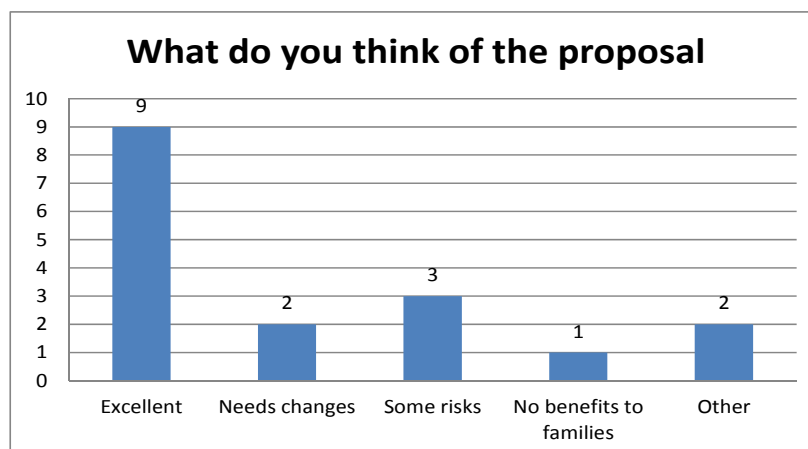
“We need to get in early and work as a system. Counselling should be normal and just one part of the information, treatment and support. Make it normal.”

3.3.3 Future

Majority of referrers very enthusiastic about the Proposal

The majority of referrers (all but two) were enthusiastic about the Proposal of a screened and quality network of providers. They felt this would give better outcomes for their clients and secondly make their job easier finding and matching the right provider with their client.

Graph 23 What do you think of the proposal



Only one referrer felt this was a negative approach and two thought this might take away choice for clients. In addition there was discussion and questions around, if there was a Network developed:

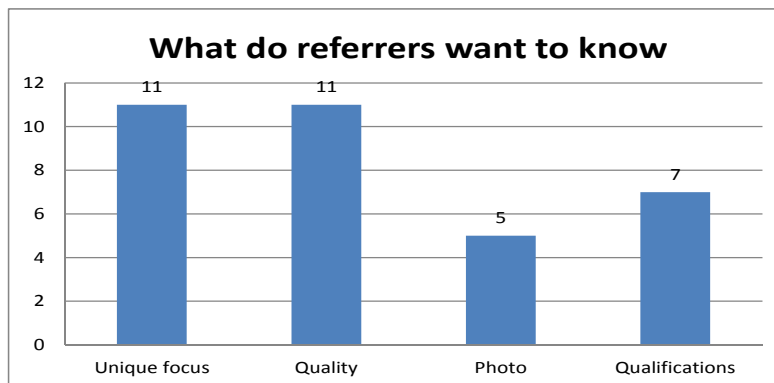
- Can other providers who choose not to, or can't “make the grade” be used in individual circumstances;
- What criteria would need to be developed and used if a referrer wanted to use a provider outside of the Network; and
- What is the tenure, when, and under what circumstances, providers would be exited from the Network.

In general there was agreement that there should be defined criteria for when a referrer could / would use a provider not on the Network, and how they would identify and select them. Choice should still be available for the people.

Referrers want to know what providers offer and that they are high quality

Referrers have several features they wish to know about the providers in the future, before they would refer to them. The unique focus is what they specialise in e.g. grief, play therapy, family counselling etc. Quality relates to the application process providers would need to follow to become part of the Network.

Graph 24 What referrers want to know about providers



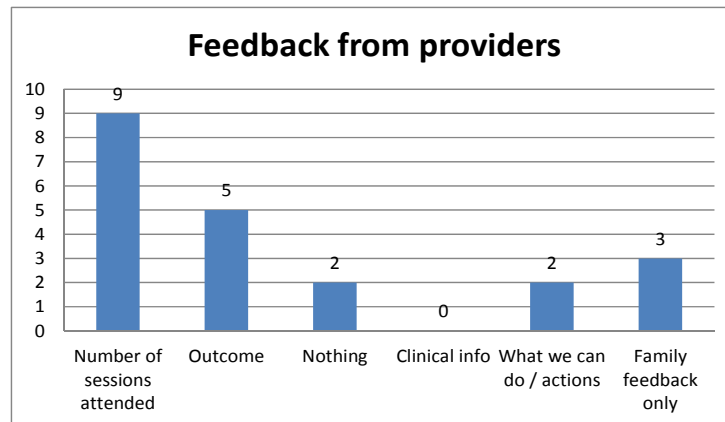
All referrers want to know the skills of the providers. Eight want to meet with the list of providers and build relationships, so they get a better understanding of which provider might best “fit” or meet the needs of the person they are referring.

In addition a directory or easy to access information or website were important.

Referrers want very little feedback from providers

No referrers want to breach confidentiality and know what was spoken about in the sessions (clinical information). Nine of the 11 (82 percent) do want to know what number of sessions the people attended and any “no shows” that may require follow up. They would like some accountability to ensure that the people they are referring are receiving the services that have been paid for.

Graph 25 What feedback referrers want to know from providers



“Once they are referred the relationship is between them and the counsellor. We don’t need anything. It is private.”

Keep the Network simple and build local relationships

Two felt there was a better way than a national network, as in building local networks themselves. Three were cautious of a Network becoming too complicated and that it should be simple to use. Three felt having a coordinated Network and referrals provided an opportunity to use data for research on volumes, costs, “no shows”, number of sessions, who was being referred, etc.

Providers may need additional training

The list of additional training, or specific training, referrers thought providers might need included:

- Building family resilience;
- Mindfulness for parents;
- Understanding the cancer journey – grief, hope, treatment regimes, impacts of treatment;
- An overview of different types of cancer;
- Youth;
- Understanding of the ripple effects across families and the impact on lives, including:
 - Life will never be the same
 - Relationships
 - Marriage challenges
 - Siblings and extended family
 - Financial impacts
 - Parenting

- Transitions
- Staying in hospital for long periods

Key implementation issues relate to ensuring quality

The implementation issues that were identified mostly relate to ensuring quality providers and good coverage. Coverage relates to both choice of provider and equity of access for people seeking counselling. There were questions on who would run the Network and how would ongoing management of the database, updates, promotion and quality control is undertaken.

The two key risks identified were:

- Ensuring professional boundaries are adhered to, especially if hospital and home visits are included; and
- Ensuring a choice of counsellors for young people and families.

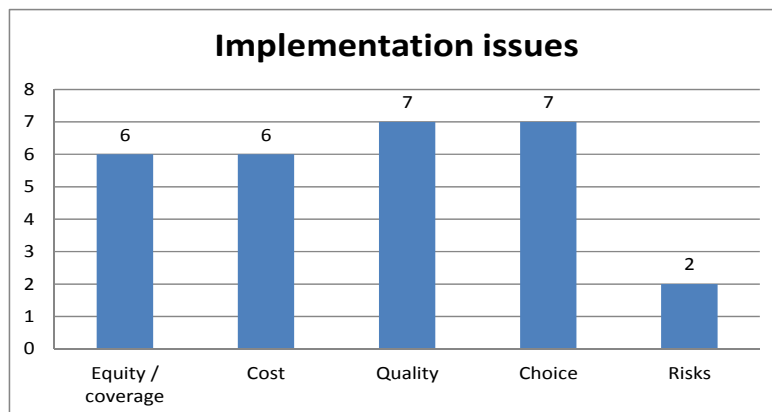
Two referrers gave an example of reducing choice for families related to what if a provider was not on the Network but a family wanted to use that one, whereas the rest said it would increase choice. For example, there may have been a previous relationship, it might be in a small town and / or the provider just didn't see applying for the network as important.

Ensuring or trying to achieve geographic coverage and therefore equity of access was also important for referrers, as was ensuring a cost effective solution. There was also a suggestion by most that clear guidelines and referral processes and forms would be useful.

One referrer felt that having a "mandated network" would open up risks to the three NGOs as they had been the ones to mandate them, and what if they didn't do a good job.

Conversely many others felt that having a screening process would improve confidence in the quality of providers.

Graph 26 Key implementation issues

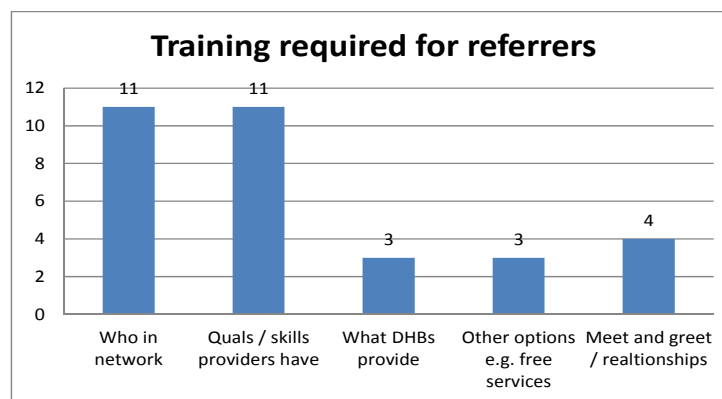


Training for referrers includes who is on the network and what they do

The proposal notes that training for referrers will be required also. When asked about what type of training the responses are in the graph below, notably information about who the providers are and the skills they have.

Once again the meeting of the providers to build relationships was seen as important by four of the referrers.

Graph 27 Training required for referrers



Session fees only should be funded by the Network for providers; training and supervision to be at their own cost

All referrers interviewed felt that session fees should be funded by the NGOs / Network. No one agreed that training costs, supervision or application costs should be at the cost of the Network.

“This opportunity is potentially giving them more business. They need to pay for that themselves.”

“Don’t they already have to undertake supervision and training anyway?”

Technology should be an option for some, but individual choice

Seven said yes that technology could be used for some counselling, one said skype only and five said it should be the choice of the person and the counsellor. One potential option offered was a mix of face to face and technology, e.g. every second or third session to be in person.

Other referrers, e.g. hospital wards, paediatricians, would need to refer via the three NGOs

This question provoked much thought. Overall however, eight felt that no, this couldn’t work due to the three NGOs holding the budget and how coordination would occur. Three were not sure and two said it was a good idea, but not sure how this could work.

Some discussion was had on maybe there is a middle ground where for example, wards and paediatricians are educated about the Network and how referrals get made, and then can

refer to the three NGOs, who would then screen and prioritise. It was less clear about the role of GPs in this.

An optimum amount of session numbers depends on types and complexity of needs

Four felt six was an optimum or limit to the number of sessions, six felt this needs to be flexible and can be reviewed if more needed and two didn't know.

A conclusion is that each NGO may be referring for different needs, and varying needs have different amount of sessions required. For example some are short term issues such as learning strategies to deal with children's immediate behavioural issues versus longer term and reoccurring issues of deep set phobias, living with cancer personally or relationship / marriage issues.

Unclear what level of qualifications Providers need

Five said they were unsure / not clinically qualified to comment and five said a variety / choice of qualification and areas of discipline are needed.

Home visits and ward visits could be part of the future, with some caveats

There was a variety of responses to this, but in general the outcome was "it depends" on the individual and their needs and circumstances at the time. The few that disagreed were concerned about professional boundaries, whereas others were assuming registered professionals would be able to manage boundaries well.

A few were concerned about privacy if counselling was to happen on the ward, while others thought a private space might be possible.

Network providers may require additional specific training

People generally felt this would depend on the criteria used to get providers in to the Network and therefore what skills, experience and training they already had. Topics canvassed included grief, bereavement, youth, and cancer.

System issues need to be considered for the Proposal too

There were a variety of additional comments to this question.

- Six wanted to know how providers would be exited – what criteria?;
- Four wanted the system to be very easy and simple to use;
- Three wondered about how to prioritise referrals; and
- Three suggested that the providers need to know who the referrers are too.

3.3.4 Summary

Overall the analysis of this section leads to the following conclusions:

- The current situation is that referrers often are unsure of the right people to refer to. Most applaud the option of having an identified network of screened quality providers to refer to, as long as there is choice of providers in local areas;
- Good geographic coverage and options for gender and culture of providers is also important;

- Some questions of process were raised such as would referrers only be able to use those on the Network or would there be defined criteria for when a referrer might use a different provider. Also, once on the Network, how and when providers would be exited;
- Generally referrers felt the qualifications and skills of the providers needed to vary, but most felt they didn't have the clinical knowledge to say what qualifications or level of study should be sought;
- All felt that the NGOs should only pay for the session fees, not for supervision or training, which the counsellors should already have in place; and
- Lastly, the number of sessions that should be available to individuals should vary based on need and age and stage of the person / family.

3.4 Potential providers

Potential providers interviewed (n=13) overall felt this network proposal was a great idea. Most of those interviewed represented an agency, not just themselves. So overall a lot more than 13 counsellors were represented.

65 percent said the network was a positive idea and 85 percent said it was very important who selects the suppliers who were elected to go on the network. 62 percent said all costs (other than fees) should be borne by the individuals or organisations applying for the network, whilst 85 percent said some form of additional training is likely to be needed. Mostly, 69 percent, said this was related to cancer knowledge, in terms of treatment types, impact on families, time of treatment etc. It was not related to the clinical inputs of treatment. 31 percent felt some additional training on grief might be necessary.

62 percent said addition supervision is not needed (as they already have clinical supervision). 69 percent believed that use of technology (e.g. phones and skype) is possible as part of the mix for the future.

54 percent believed that the hourly or session rate is between \$100 and \$150 per session but interestingly 54 percent also thought that maybe \$150 plus is reasonable.

54 percent said that home and hospital visits re a reasonable expectation but caveats such as privacy and professional boundaries are important.

Table 3 Comments on the proposal

Positive comments	Not agreeing with the proposal comments (one provider)
<ul style="list-style-type: none"> <i>This is an awesome idea!</i> <i>I would greatly value such a Network, especially if we got to know our local colleagues. This could help with problem solving and peer supervision going forward</i> <i>This is an excellent idea and I would like to be part of it. This is a complex area of work and to have an oversight of a network of providers is sensible. This will help ensure consistent quality</i> <i>This is the same sort of model ACC uses for preferred suppliers</i> <i>It is a reality these days that we need to demonstrate our skills and experience. I would be more than happy to belong to such a network</i> <i>We are a small provider so the process wouldn't need to be onerous. But we see the networking as a great advantage</i> 	<ul style="list-style-type: none"> <i>We already have professional associations, so there is no reason to have to belong to another network. We would not be interested</i> <i>We are all highly trained at Master's levels so I don't think more training is needed</i>

Source: Interviews

Of the seven two were individual practitioners and the rest are part of a larger practice / group, therefore a larger number of counsellors than seven have been represented. One was a psychiatrist; three psychologists, one psychotherapist and two said they had a mix of disciplines in their practice.

A summary of responses to the questions is in the Table below. Of note the provider interviews were relatively brief (10 to 30 minutes) with one response via email. Not all answered all questions.

Table 4 Potential provider responses

Question	Response
Implementation issues	<ul style="list-style-type: none"> How will the application process work? Who is on the selection panel and their clinical qualifications is vital They (on the panel) must be very highly clinically skilled; the knowledge and skill of these people is very important

Question	Response
<p>What would need to be in place to interest you applying</p>	<ul style="list-style-type: none"> • Simple and easy application process • Good networking • Build relationships with the referrers and other providers locally
<p>What qualification levels should providers have</p>	<ul style="list-style-type: none"> • Consistent advice that all must registered to a professional body <i>“Registration ensures a Code of Ethics and that the person will be receiving professional supervision.”</i> • Varying views on qualification levels ranging from: <ul style="list-style-type: none"> – All must be at least Masters level – A range of qualification levels – Not all people requiring this counselling will have the same level or type of need, so a range of qualifications would be appropriate
<p>What costs should be borne by the network</p>	<ul style="list-style-type: none"> • Two thought the training and supervision costs should be borne by the Network • The rest said this is part of their professional development and CME¹¹ anyway • No one felt additional supervision was necessary but maybe some peer forum on line / phone, particularly in the early phases of the Network. Could also discuss whether the referrals are appropriate and feedback to the referrers
<p>Would you be prepared to participate in on line supervision forums</p>	<ul style="list-style-type: none"> • This was not so much supported, although three said in the initial phase maybe. Key reason being supervision relationships are already in place.

¹¹ Continuing Medical Education (CME)

Question	Response
Additional training that might be useful	<ul style="list-style-type: none"> • Three said oncology / cancer; <ul style="list-style-type: none"> – <i>“The biology of cancer would be useful”</i> – <i>“An overview of cancer treatment so we know what to expect for the person and families.”</i> • Two re grief • Two re youth issues • Four said it would be good to meet and build relationships with the local referrers, and two with other local providers
Can technology be used for ongoing counselling	<ul style="list-style-type: none"> • Four said yes, the others didn’t comment • Two said a mixed model of face to face and technology might be useful <i>“Psychologists working for the Employer Assistance Programme already do counselling via phone.”</i>
Remuneration levels	<p>This ranged depending on disciplines, experience and type of counselling</p> <ul style="list-style-type: none"> • Generally stated to be between \$100 to \$180 per hour. One noted they are likely to be higher in Auckland • Student health is funded separately so fees are already covered for enrolled students, but additional non student time or non CME expectations would need to be covered
Home and hospital visits	<ul style="list-style-type: none"> • There was a mixed but generally positive response to this question. • A concern is the professional boundary issue, one said they’d take a second counsellor with them to the home • Some felt the hospital setting is not private enough and / or the child is still in the room if the counselling is for the parent

Source: Interviews

3.4.1 Summary

In summary:

- All but one of the potential providers interviewed thought the Proposal of a network had merit and that they would want to participate;

- There are no major issues with the details of the Proposal other than on line supervision doesn't seem to be required. However some on line forum, especially in the implementation phase does seem to be a good idea; and
- Who runs the application process and selects the counsellors is seen to be vital, with interviewees stating it needs to include highly skilled and qualified counsellors.

4. E-survey summary

Following is a summary of the e-survey responses. The full survey analysis report can be found in Appendix Two.

4.1 Summary

Methodology and respondents: 158 people responded

To help inform the development and testing of the counselling proposal process, an online survey (e-survey), in conjunction with the field work / interviews, was developed and launched to understand what experience young people with cancer and their families have had with counselling services, and what they may have liked to receive, in the past and into the future.

The survey was open to all people age 16 and over, who have had cancer, or known someone who had cancer diagnosed between the age of 0 and 24 years of age. It was a short survey with 26 multiple choice questions, with options to comment or skip any or all of the questions. The survey was posted on the Facebook pages of the three NGOs:

- CanTeen;
- Child Cancer Foundation; and
- Leukaemia and Blood Cancer New Zealand.

The survey was live for three weeks and by the closing time there had been 258 respondents in total to the survey.

The majority of respondents were New Zealand European mothers of children with a diagnosis of cancer. The respondents were mainly from Auckland and Wellington, with the Canterbury region the next highest. There was at least one response from every region in New Zealand. There was a 15 percent response rate from Māori. There were 57 male responses, 41 of these were fathers of a diagnosed person, and eight were those who were diagnosed, the others were a sibling and two friends, and not otherwise defined.

The majority of the respondents are referring to a cancer diagnosis that was made while the person was less than 10 years of age and their experience with cancer occurred between two and 10 years ago. There were a few who had been diagnosed within the last year and some had their experience one to two years ago. Over 78 percent had received their main treatment in Starship or Canterbury specialist centres.

4.2 Findings

Females more likely to have counselling than males

A key finding of the survey is that the responses are very much based on individual experience and using different filters such as Māori, fathers, the person with the diagnosis did not alter the overall findings, probably due to the size of the cohort that were mothers. Despite a good response rate from fathers (47 responses) their experiences with counselling services are low (with only nine actually receiving counselling sessions). Fathers are also less

likely to seek counselling if not offered it (only one did). This would point to perhaps alternate ways of engaging fathers in the process may be required e.g. an activity based option.

Just over half offered counselling took it up

Just over half of the respondents were offered counselling and just over half took it up. Those that did not take up the offer mainly said they spoke to family, friends, the church or a support group or they didn't need it. There were some that were unsure about it. Only a few respondents said that issues of cost, time off work or travel distances were an issue. Of those 81 people that weren't offered counselling, 24 still went on to have counselling. Fathers were less likely than mothers to seek counselling if it wasn't offered.

Up to six counselling sessions appears enough for family and friends

Of those that received counselling 66.5 percent of them received between one and six sessions of counselling. Due to the structure of the survey we can't directly link the number of sessions to whether they were enough as respondents answered on behalf of other people. However 41 percent felt that the number of session they received was enough, but 34 percent did not. It is not known how many sessions that 34 percent received. Further analysis within specific cohorts revealed that mothers were most satisfied with the number of sessions they received when they had between six and twelve sessions. Of the small number of fathers who had received counselling they mainly had between two and five sessions and were generally satisfied with this amount.

The immediate family is most likely to have received counselling from a registered professional counsellor (39 percent), the hospital (26 percent), or a support agency (20 percent). School counsellors are often a source of counselling for the diagnosed, siblings and friends. There are also other avenues for counselling such as employee assistance programmes through a person's work, and specialist programmes such as the Massey Psychology clinic.

Support agencies first port of call for most

When asked if they wanted support in the future, most respondents would seek help from a support agency first such as CanTeen; Child Cancer Foundation; or Leukaemia and Blood Cancer New Zealand, followed by their family doctor, but many did not know who to seek support from. Equally large proportions (119 responses) felt most comfortable receiving counselling from either a registered professional counsellor or a support agency, followed by a hospital based counsellor (60 responses).

Counselling did not meet the needs of those outside the immediate family

On exploring the 'not at all' responses for the highest rates of dissatisfaction with counselling services, that is that the services did not address their issues at all, were from those outside the immediate family. For the immediate family we find that there is little pattern between those receiving sessions, the number of sessions or the providers and satisfaction levels. The immediate family all had the majority of responses in the 'mostly' dealt with their issues category.

4.3 The Future

The future: Quality counselling and supports key

Many key themes were repeated through a number of open ended questions that were asked to see if there was any correlation between what people found helpful who had received counselling, what people would find helpful who hadn't received counselling, what people wanted access to in the future, what could be improved and any other considerations for a counselling service. The top priorities within those themes are below:

- Access – free, local, availability of appointments, post treatment
- Peer support – understanding of what families with cancer are going through
- Quality – experienced, specialist, appropriate
- Family support – counselling for family members as required
- Proactive counselling – automatic referral, follow up

Counselling is provided to varying degrees and quality. Overwhelmingly there is a need for high quality professional specialised counsellors, easily accessible, and available to support the whole family. Different people will require varying degrees of support and will respond to different techniques and methods. Counsellors need to be experienced with children and young people, and cancer. Age and gender appropriate counsellors who can flex the support to meet the needs of the families are important. Peer support also has a role to play.

Normalise counselling and explain the benefits

Counselling isn't for everyone, and it appears many do not understand what counselling is or how it can help. One way in which to address this and de-stigmatise counselling would be to incorporate it as part of the treatment journey, considering an 'opting out' rather than 'opting in' methodology. This would help address those that feel too busy to organise this themselves, and also tries to put the emphasis on the counsellor to ensure the person is alright (checking in) rather than the people to chase appointments. This is a very different situation than normal medical or counselling appointments when patients may choose not to engage. Some of this is due to the situation people find themselves in, that is being busy with appointments and treatments away from home, and therefore active follow up for the offer of counselling may be necessary.

Technology for counselling has a place

Some respondents were open to the idea of technology, as one method of support. This could be a useful tool as part of a 'maintenance', or 'checking in' package. It could be used once a relationship has already been established to support families when they return home, perhaps those that live in rural situations or those that choose to such as when they have other children or commitments and find it hard to attend in person.

Schools need education and support

As this proposal is particularly focused on children and young people, the entities that their lives revolve around are extremely important. For example, schools need support in addressing cancer diagnosis amongst their pupils, siblings and friends, as well as supporting those returning to school after treatment.

5. Overall conclusions and recommendations

5.1 Overall conclusions

5.1.1 This is about individuals with individual needs

The cohort needing counselling is not homogenous

Due to the fact that those who may need counselling have a huge variety of individual based needs and preferences, ages and developmental stages, the network of counsellors needs to provide for a range of skills, levels of experience and types of counselling. For example various therapies for young children, adolescent needs, siblings, marriage and family needs, behavioural strategies for parenting, grief, depression, etc.

Within this, individual levels of need and number of sessions also need to be considered. The general feedback from interviewees was that some, especially adolescents and young adults or families in long term treatments, will typically require more sessions than others, and may require it again later in their life.

“All your attention is going on looking after someone else – your kid. So, someone needs to look after you. You can’t look after your kid if you are not well yourself.”

“I didn’t need counselling about having cancer. It was about my dysfunctional family. Having my cancer just tipped me over and I couldn’t cope with that and my family.”

“This journey is not ending. It is going on forever and ever. Now that I think about it there are various points where my husband, myself and her siblings could have done with some help. It has been a very, very hard road for us all. And we are still on that road.....”

It was clear, and supported, that this proposal is about young people with a diagnosis and their family (e.g. parents, siblings, extended family) but a “gap” that was raised several times was that for the offspring of a parent diagnosed with cancer.

Normalise the need for someone to talk to, and offers of counselling need to be early, regular and proactive; especially when transitions are coming up / have occurred

People reported the fact that there is a social stigma with the word “counselling” and many felt that they were being judged as not coping if they needed counselling. Overwhelmingly people wanted counselling, or talking to someone, to be made as being a normal part of having cancer, or supporting / caring for someone with cancer. As in, everyone is offered an opportunity for counselling or talking to someone and you are told that this is normal to want to talk to someone, e.g. a counsellor.

“This is the worst time of your life..... being told you have cancer and then starting treatment. You get bombarded with information, people, and treatment. It is a frantic time. I might have been offered counselling, but I can’t recall. What would have been great would have been for someone to pop in a few

times, build a rapport with me and then be proactive about offering me someone to talk to. I would have done it then. That would have been so good.”

“It is really, really hard to ask for anything. Someone offering me something several times, in a proactive way, would have been really useful. I did, and probably still do, need someone to talk to – someone to let me know what I was thinking and feeling, my anxiety and such, was normal.”

Peer supports are the most highly regarded

For both the young people and family members they reported that peer supports are the most useful. CanTeen provides forums for this to occur for young people but it was felt by interviewees that potentially more could be done to arrange parent groups and support for younger people with cancer and siblings. This might be part of the continuum of supports of a National Network.

How the referrers work and offer counselling is critical

The referrers’ role is critical in identifying and supporting individual needs and offering counselling. There appear to be several triggers over time that may prompt referrers to offer support or counselling such as just after diagnosis (some were clear that this is the wrong time for them), at the end of treatment, when a person loses their support person in hospital (e.g. a death of someone else on the ward so their family leaves and may have been your main support) and other major transitions e.g. going home, starting school, relapse, end of a marriage, bereavement of others, etc. Proactive and regular offers of counselling, over time, and in preparation for transitions, appear to be needed.

What happens when a young person turns 24 years? And Partners?

If the scope of this counselling is for people diagnosed between age 0 and 24 years, but acknowledging that the need for counselling might be after age 24 years, what system needs to be in place to enable a young person to seek funded counselling? For example CanTeen goes to age 24 years, so who would the young person approach after that time.

In addition what about for young people who have partners? What counselling is available for them? This can be an important support network for young people.

5.1.2 Feedback on the proposal

Strong support for the proposal

There is strong support to develop a national network of a range of highly skilled and trained counsellors. This network needs to be accessible, flexible and provide for a range of needs. It should address the current gaps of having confidence in a set of highly skilled counsellors, surety of quality and geographic access. In addition access to more male and cultural (Maori and Pacific) counsellors is desirable.

Who decides on the applicants is critical

Potential providers and the referrers were clear that there needs to be skilled experienced counsellor professionals on the selection team to decide who can be on the Network. There also needs to be criteria and flags for an exit process. Examples given were ask local referrers why no one has been referred for a defined period, e.g. six months, have a

(electronic) flag on the system when no referrals have been made to an individual counsellor for a defined period, have a system for referrers to flag poor outcomes / dissatisfaction.

Keep it simple and easy to use

For referrers and providers alike they asked for the system around the Network to be simple and easy to use. Some felt a simple online (easy to access) directory of counsellors on the Network, along with a photo of them and a simple list of their areas of expertise and their locations would suffice. Others wanted a more defined system including common referral forms, criteria for when you might refer to a provider outside the network and criteria for when a provider might exit the network.

To attract providers to apply the application process needs to not be too onerous (time and cost).

Providers have various incentives to belong to this Network

There were various reasons given by potential providers as why they would consider applying for and belonging to such a network. For some they felt that they are already doing some of this work but are isolated and need more specific knowledge around cancer and how the system works for young people and families. Others felt that this would ensure quality and they would like to be part of a quality network for young people with cancer and their families and this could be a point of difference for their business.

Training

There was a variety of responses on the need for additional training over and above what professionals already have. Some felt there may be additional cancer biology training needed but overall there was varying opinion of what else might be required. Mostly people felt that qualified providers would already know about grief, bereavement, youth and various other issues people might need to talk about.

Referral processes need to be widely understood

As the Network develops care needs to be taken to ensure those in touch with people and cancer in the desired cohort, know who and how to refer to for counselling. Notably at this stage, it is via the three NGOs.

On line forums and technology

Mostly potential providers didn't feel they would need additional on line forums / supervision over and above what they already have as supervision. Some felt it might be useful for a discussion forum in the implementation phase.

All but one provider believed that use of telephone or skype would be suitable for counselling, especially if the first session was face to face. Various examples of this already occurring e.g. for EAP counselling, Youth Line were given.

Funding

Overall interviewees felt that potential providers should fund their own way in to the Network. Especially as training CME and supervision was part of their current practice anyway. Two potential providers noted if the network requirements were a lot over and above current requirements then the Network would need to fund those.

5.2 Recommendations

It is recommended that:

1. The proposal for a national Child Cancer Counselling Network be progressed, including clear and simple application, referral and communication processes, as well as exit strategies / criteria
2. The NGO referrers be more proactive and “normalise” counselling for people with a diagnosis and their families, and that the offer of counselling be repeated over time
3. Special effort be taken to identify and recognise the individual needs of people potentially needing counselling, especially at known transition points
4. A plan is made as to what level of education or skills be required on the Network, by what number (volume), in what locations
5. Consider how the peer supports people report as being so important can be fostered more
6. Provide education and knowledge of what counselling is and can offer, being careful with terminology, and then how to get it later if you need it
7. Consideration of what supports might be needed to enable people to access counselling, e.g. child care, transport
8. Develop a process for people who have had a cancer diagnosis to link in to counselling leading up to and post 24 years of age; and / or for their partners

Appendix 1 Interview questions

For young people and families



Child Cancer
Counselling Proposal I

For referrers



Child Cancer
Counselling Proposal I

For providers



Child Cancer
Counselling Proposal I

Appendix 2 E-Survey analysis report



Child Cancer
Counselling E-Survey