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Cancer Consumer Representation Training –Midland Region Final Report

Background

This training programme for cancer consumer representatives has been a work in progress for many years - including from the early days when Cancer Voices, through the Cancer Society, put together training for cancer consumer representatives - to the recent development of this modular training programme. The development of this training programme was overseen by the National Cancer Consumer Representative Advisory Group, supported by the four Regional Cancer Networks.

People who have been affected by cancer bring a unique perspective to, and can provide valuable input on, how cancer services can be improved. Cancer representatives need to be 'sitting at the table, at the time' so they can contribute across the spectrum of health, from policy to delivery of services and in governance roles at local, regional and national levels.

Integral to the success of the cancer consumer representation is the need to ensure that representatives are appropriately supported, trained and have the relevant skill set to contribute at the various levels their role may require.

Purpose of the Training

The aim of this training is to provide participants in their role as cancer consumer representatives with the knowledge, skills and resources to contribute in a range of cancer settings from service delivery policy to governance. It is also designed to enhance their confidence by providing them with the tools and resources to seek further information and network amongst other cancer consumer representatives.

The Module Training Programme

The concept of the modular training programme has been designed to provide the facilitator with the tools and resources to deliver training for cancer consumers who are in representative roles. It also allows for flexibility; including if appropriate hosting on a marae. Each module comprises of a one day training programme, and can be adapted to account for regional differences and group member's experience.

An ideal number to undertake the training is 6 – 8 per session. This number is an important aspect of a training day as it relates to the way group members interact, the time this takes and the ability of participants to work with the material in a timely way.

The programme includes a guide for the facilitator as well as four power-point sets – one for each module – on a USB enclosed with the guide. The training programme is contained within a framework of four modules. Each module provides advice and guidance for facilitators undertaking the training programme.

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The Modules

Module One: Cancer Context, includes topics on the New Zealand health setting, the cancer policy environment and consumer advocacy.

Module Two: Experience Base, focuses on using stories to support the consumer role, and how to effectively engage with health clinicians and managers.

Module Three: Evidence Base, focuses on what is cancer and how cancer develops, Maori health and inequalities and inequities, and cancer research.

Module Four: Focuses on Partnership, leadership, co-design and peer support.

Training for the Midland Cancer Network Cancer Consumers

Organising the training programme involved teleconferences with Rawiri Blundell, Equity Manager MCN and emails to set timetables and discuss appropriate guest speakers.

The four modular training programme was delivered to cancer consumer representatives in Hamilton over two days on October 2nd and 3rd 2014 and November 13th and 14th 2014. HER Solutions Sue Ellis and Dr Chris Walsh delivered the four modules.

Rawiri Blundell, and Hayley Goodall, Community Service Manager from the Hamilton Cancer Society also attended the 4 days.

These days were supported by guest speakers Dr Nina Scott, Waikato DHB Chronic Conditions Advisor on October 2nd who spoke on the health and cancer policy environment and Jan Smith manager MCN who spoke about local contexts. Helena Stewart from the Cancer Society Hamilton spoke about the biology of cancer and Wendy Thomas, charge nurse oncology unit Waikato hospital delivered the session on clinical trials on 13th November.

Evaluations

The completed evaluations with participants comments are attached in appendix one.

Evaluations for Modules One and Two – October 2nd and 3rd 2014

Ten cancer consumer representatives took part in the first two-day training and all completed evaluations for both days. Eight of these identified as Maori. Most, but not all participants answered all questions.

Participants ranked the days overall as excellent, though the first day was possibly a little hard going for three who noted that day as average. Many commented on the relaxed and enjoyable learning environment while also gaining lots more knowledge. They particularly identified getting to know more about the Ministry of Health, the complexity of cancer and how processes in the cancer environment interplay. On the second day many enjoyed the

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sharing of stories and commented on the learning gained from this. The group noticeably gelled together through this exercise.

Evaluations for Modules Three and Four – November 13th and 14th 2014

Nine cancer consumer representatives took part in the 2 day training and nine completed evaluations for module three, seven for module four. Eight participants identify as Maori. Most, but not all participants answered all questions.

All participants ranked both days as excellent, apart from one on the first day who found it very good. Getting the information packs up to date and better aligned with the power points was an improvement for the next training programme noted by some participants. This was due mainly to the short time frame between modules when updating the material and aligning it proved challenging. The format of the days suited everyone.

Participants commented on the clarification they gained about aspects of evidence based concepts, cancer trials and more understanding of inequities in cancer. They enjoyed the practical information shared and the discussions. Some of the participants particularly liked the session on leadership and once again the sharing of knowledge rated highly.

Overall Outcomes

I would like to take this time to thank you both for the impact you both and the course has helped to influence change and doors opening for me since then and I hope will lead to career opportunities.

Tapeka Tanirau
E mail correspondence
Participant cancer consumer training, MCN 2014

The above message (reprinted with permission from Tapeka) is a clear and tangible outcome of the training programme. Tapeka has been selected to be on the group that will provide operational advice to the Ministry of Health on implementing the additional psychological and social services for people with cancer announced in budget 2014. The first meeting for this group is in mid-December 2014.

From the training Midland Cancer Network participants received, the group expressed enthusiasm for their role, more clarity around expectations of what a consumer representative can do, appreciation of the new knowledge gained and how this gave them more confidence to speak at all levels of service and governance and importantly a sense of cohesiveness as a group which they now called their whānau.

By the end of this training all participants would recommend this training to others and also expressed interest in undertaking more training if it was offered.

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Recommendations

It is recommended that:

1. That the Midland Cancer Network trainee participants be brought together again in twelve months to reassess how their training has contributed to their cancer consumer representative role.
2. That 2-3 of the trainees give presentations to the local cancer consumer networks about how the training has influenced their role as a cancer consumer representative
3. A system is put in place to support those who are engaged as cancer consumer representatives and networking occurs

Dr Chris Walsh and Sue Ellis
Directors
HER Solutions

11th December 2014

Appendix one

Evaluations of cancer consumer representative training

Module one

How would you rank the day overall?

Excellent 7

Average 3

Poor

Comments:

- The duration of the course was fully information based. I enjoyed the balance of representatives comments/feedback
- Only sat through half the journey at this stage
- Still on my journey of cancer, its networks, the dynamics and to be given the opportunity to learn more. I am more aware and still wanting to know more
- Relaxed stimulation conversation
- It may be good to start with explaining what a cancer consumer role means
- New representative within this area, felt out of depth of some content of course

How much practical knowledge have you gained from today?

- The whakapapa of all stakeholders aligned with the Minister of Health, where everybody sits. I see my role as a representative at the forefront for all patients I support.
- Some knowledge in the networks was useful. Great being with a big group of consumers

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- An insight into the structures and complexities of the cancer 'world' in NZ
- A practical introduction to the cancer community
- Finding way around Ministry system
- Enjoyed group discussions
- Knowledge base has improved on 'jargon'
- Still learning
- Better understanding of how processes work and whose who up the top ladder
- Gained perspective on midland Cancer Network workings; gained knowledge of consumer group workings

What were the major strengths from the day that you feel helped you?

- My networks have been strengthened and knowledge based information has increased
- I enjoyed the discussion on advocacy, Nina's presentation and the robust discussion
- Knowledge and information-tools for future
- Feeling part of a team
- Group input
- Group discussions
- Safety for the group to share
- More understanding of processes
- By the end of the day the group became a whanau
- Gaining knowledge of medical networks; meeting group participants; shared information

What can we improve on for the next module?

- Invite other groups within the region that contribute to supporting cancer patients
- Trying to bring all the participants out a little more
- Nothing special springs to mind
- Maintain formula
- I had no goals, therefore I had no expectations, enjoyed the easy pace
- Still learning; unsure where this course was taking me but now have a better understanding of all the stakeholders
- Try to limit discussion but enjoyed the interaction of robust conversation
- Introduction to consumer as the start for new representatives
- Not sure

Were the goals met for you? If not, why not?

- Yes, it was an extension to my current role
- Yes
- Yes-had an open mind coming in with no set expectations
- Yes
- Was grateful just to learn pathway, especially structure to Ministry
- Learning more each time; I come on the course to learn more which I have; no goal in mind
- I didn't come with any goal setting
- Still learning
- Yes
- Have not had enough experience to gauge whether goals were met, still a learning curve in this area

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Will you attend the second module training? If not, why not?

- Yes, primarily because I am a representative for WDHB Te Puna Oranga
- Yes please, for 3 and 4
- Yes
- Undecided

Would you recommend this type of training programme to others?

- Yes
- Yes
- Yes
- Yes
- Yes
- Yes, excellent interaction
- Too early to evaluate
- Yes
- Yes, to the rest of my staff
- Yes, would definitely recommend this type of training especially if participants have not been involved in this type of training previously

Module two

How would you rank the day overall?

Excellent 10

Average

Poor

Comments:

- Enjoyed today more; it fitted in with yesterday and where one is as a consumer, on track now
- Great group
- Learning personal events that has affected their journey through cancer; very emotional

How much practical knowledge have you gained from today?

- All good practical stuff
- A lot more than what I thought-the power of a consumers stories
- How long is a piece of string? There was much learnings from the day and I was able to take on a number of ideas and processes to assist me going forward
- More awareness
- Wow, good strong practical interaction on sharing stories; thank you for no time limit to present
- A greater insight as to a consumers stance
- It has given me new tools on how other ways can support our clients
- Learning from others has enriched my kete of knowledge
- There should be someone to contact to talk to about a similar diagnosis

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- Gained knowledge from group involvement and discussions

What were the major strengths from the day that you feel helped you?

- Again feeling part of a team
- The roles and responsibilities was a major strength plus the group exercise, amazing 'aha' moment
- Everyone sharing their journeys and experiences has reinforced why and what I am doing in the cancer continuum
- Telling my story and making me aware that our stories need to be shared
- You have a story others are interested and it could change someone's perspective to having treatment to choices
- Sharing
- Sharing stories; emotional contact with
- Realisation of other realities
- Listening to each story
- Sharing of stories, compassion, sharing of knowledge

What can we improve on for the next module?

- More balloons!
- I can't think of anything in particular
- Stick to the formula used today i.e. good levels of attendee participation by way of workshops and/or games
- Retrace what we have learnt
- Well-constructed, no changes here
- Nothing really
- Have therapeutic music and visualisation as a breaking point
- Programme is very well planned, no improvements necessary

Were the goals met for you? If not, why not?

- Yes
- Yes
- Yes
- As per training course, yes; understand and know/aware of what it is I do and know which consumer group I fit
- Yes, well meet; participants were interacting which helped
- Compassion, togetherness of the group
- Yes, it is a very powerful moment for all sharing experiences; heartfelt thanks to all
- Yes
- Yes

Will you attend the third module training? If not, why not?

- Yes
- Yes if offered
- Yes
- Undecided

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Would you recommend this type of training programme to others?

- Yes
- Yes
- Yes
- Yes
- Yes, just found module one heavy
- Yes
- The rest of my staff; Na mihi Kia Korua; Ka pai toa mahi-te Hei Mauri ora
- Yes
- Yes
- Yes

Module three

How would you rank the day overall?

Excellent 8

Very good 1

Average

Poor

Comments:

- Happy to be part of a group who share commonalities in a wider group-cancer patients; whanau, hapu, iwi
- This would be the most informative module yet in the training

How much practical knowledge have you gained from today?

- Adequately resourced and more knowledge to my basket
- Getting a better understanding of different cancers
- From all the courses I have attended this one has made me more aware; everything now falling into place e.g. inequities, inequalities etc
- Heaps
- Good understanding of all presentations
- What is evidence based cancer and how to identify this; also what and how to do an action plan
- I had clarification of aspects of cancer trials and research jargon
- A far greater understanding of resources available to gain additional information and knowledge e.g. Cochrane Consumer Network
- More information on consumer involvement; a greater understanding of inequalities

What were the major strengths from the day that you feel helped you?

- Research; clinical trials and barriers; opportunity to strengthen and broaden knowledge in support of patients we support
- Tools to strengthen our voice as consumers
- More knowledgeable; understand more; now more confident and feel I am able to converse with people with confidence
- An insight into information available and how it can be used
- Today's presentation was very practical; able to relate to most subjects
- Identifying a contact person when clients ask about clinical trials; hearing the process into research

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- I enjoy the sharing from the group; reinforces some thoughts and clarifies things you are shy to talk about
- Discussions around inequalities/inequities and research
- Background in cancer causes and types; inequalities

What can we improve on for the next module?

- More interactive; less information-persons talking about roles
- More tools are always helpful; different stories for different focus
- Still learning; looking forward to going over what we have learnt in the previous 3 modules in the one tomorrow
- Improve technology; get gear working ok
- More of this
- More interactive work in each module
- At this time I think the first half up to lunch should be in module one because I work on the ground; I understand it best and relaxes me to the more clinical aspects coming forward
- Continue with the same approach/format
- Not so much on the RCT's; programme more time for discussion

Were the goals met for you? If not, why not?

- No, some of the content was complex due to ethnicity and cultural barriers
- Yes
- Yes
- Yes
- Yes
- Yes
- Yes they were
- Yes
- Yes

Will you attend the fourth module training? If not, why not?

- Yes
- Yes
- Yes
- Yes
- Yes
- Yes
- Of course
- Yes
- Yes

Would you recommend this type of training programme to others?

- Yes, the information is useful to groups, newly diagnosed and require knowledge of what is cancer to participation in clinical trials
- Yes
- Yes
- Selected participants
- Yes
- I would have to make sure they can cope at this level

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- Yes
- Yes
- Yes

Module four

How would you rank the day overall?

Excellent 7

Average

Poor

Comments:

- Comfortable safe korero through the day
- The knowledge gained over the duration of all modules has been significantly meaningful to my role and how this can be implemented in support of the consumers I support

How much practical knowledge have you gained from today?

- Knowledge around co design and peer support
- All totally relevant to what will do in the community
- Greater understanding of a consumer
- Lots; gaining confidence to do a presentation; assurance; sharing; taking ownership
- Enjoyed listening to other consumers sharing their knowledge on leadership; have been inspired from today's module 4 to return and consult with staff and support group to co design a plan where to from here
- The information will build my skills based practice and supported from information received today
- A good second part to the first day

What were the major strengths from the day that you feel helped you?

- A reminder of what is involved with leadership and all things that being a leader entails; the use of video was particularly pertinent
- Good explanations, robust discussions, relaxed facilitators who now know our personalities
- Interaction of group
- Leadership, co design, peer support, from stress to inspiration
- Reviewing my leadership skills; love the co design graph, will be using this co design when required
- To share knowledge has broadened my networks; a strong voice for iwi, Maori and a diverse culture
- Discussion on leadership

What can we improve on for the next training programme?

- Continuation of existing format, more video content perhaps
- Sadly not having the right papers to the power point was a distraction to keeping up with the facilitator
- Not sure
- To ensure the information required is available in our packs
- Up to date material or slides
- Keep with practical modules

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Were the goals met for you? If not, why not?

- Yes-depending on timing
- Yes
- Yes
- Yes
- Yes, awesome
- Yes; professionally it is beneficial to my role. Personally when I first attended the course I did not know what the role entailed fully in regards to why was I here and now I know the purpose-it is to teach and to provide a safe practice
- Yes

Will you attend another cancer consumer training programme if one is offered? If not, why not?

- Yes- depending on timing
- Of course, upskilling is important, things change
- Yes
- Yes
- Yes
- Yes, primarily because I would like to enhance further and extend on my knowledge in the future work in a health and disability role on a national level to support iwi Maori
- Yes

Would you recommend this type of training programme to others?

- Yes
- Yes
- Yes
- Yes
- Yes
- Yes
- Yes