

Newsletter 1 • September 2009

Editorial

CancerVOICES has come a long way since our inauguration as a Charitable Trust back in 2004. We have achieved recognition in the New Zealand cancer community and are establishing ourselves as a key body in the field of cancer community representation.

Our redeveloped website heralds the beginning of a new era for us, as it becomes the site for consumer representatives nationwide. It is a significant advance over our previous website, providing links to cancer information, an ability to electronically sign up as a CancerVOICES member or register interest in consumer representation, and an online forum for Cancer Consumer Representatives (CCRs).

This is the first newsletter of what will become a quarterly publication on our website. We intend that each edition will have a theme; this first edition is dedicated to consumer representation.

Long-term funding for the training of consumer representatives has been secured; we have a three-year contract with the Ministry of Health to provide two courses each financial year.

The support we have had from the Cancer Society in the development and initial funding of the training has been incalculable. In particular, we would like to thank Bronwen Laurenson for her vision and drive and Dr. Jan Pearson for the superb work she has put in helping to develop and manage the programme; her management of the evaluation report on the first two courses combined with her steering of the approval process through the Cancer Control Council and the Ministry of Health contributed massively to our securing of funds for the programme.

The first two courses have been funded by the New Zealand Cancer Society with a \$10,000 contribution from the Derrick Ward Memorial fund in the Manawatu Cancer Society. Without this support, we would not have been able to get the training off the ground.

CancerVOICES now has a number of members participating on various committees, working parties and advisory groups as consumer representatives, and the Ministry of Health is asking us for our input into policy documents.

So our future is assured, and our place firmly established where it should be: at the forefront of cancer consumer representation in New Zealand.

Our third course took place on 21 and 22 February 2009 and 14 March 2009.

Another course was held 25/26th July and 15th August 2009.

What our representatives do

CancerVOICES now has 39 CCRs trained and willing to undertake consumer representation work. They work within the Central Cancer Network and on other committees, and are also available for consultation on policy formation. So what sort of work do they do?

Working within the Central Cancer Network

The four Regional Cancer Networks around the country are the engines that drive the implementation of the Cancer Control Strategy. Each network must work across the cancer control continuum of prevention, screening and early detection, diagnosis and treatment, support and rehabilitation, palliative care and research and surveillance. Most importantly, this means that each network must involve and truly consult with representatives from each of these areas, that is, primary health, the DHBs in their region, NGOs and palliative care organisations and they must involve consumers.

Each regional network uses a different representation model. For example, the Northern Network consults with a collaboration of reference groups representing a wide range of stakeholders; consumers form one of these groups. The governance board of the Central Cancer Network (CCN) includes representatives from most of its nine DHBs, primary health, the Cancer Society and palliative care, plus Maori and Pacific peoples. CancerVOICES has a CCR on this board.

The governance board of each network determines where improvements need to be made, how they should be funded and the priority accorded to each. Its work is divided into workstreams, one for each of the six areas of the cancer control continuum, and each workstream is populated with a group which determines how the improvements directed by the governance board are going to be implemented. The diagnosis and treatment workstream is split into a project for each major type of tumour. The first of these tumour workstreams to be tackled by the Central Cancer Network focuses on lung cancer. Project teams will be looking at streamlining the treatment and care of lung

cancer patients, and the addition of support measures to ease the patient's journey.

CCRs have the opportunity to work on any of these work-stream projects.

Working on other committees

We also have representatives working on the Medical Imaging Guidelines committee, the national genito-urinary committee and on DHB cancer network groups. Representatives have contributed to the development of guidelines for melanoma and the supportive care for adult people with cancer. Requests for consumer representatives are coming ever more regularly.

Consultation on MOH policy documents

Recently, the Ministry of Health contacted CancerVOICES to request consumer input into a draft protocol on the public interface with private radiation oncology services. Our input resulted in four significant changes to the document.

This is the first time that true consultation with consumers has taken place, which augurs well for future consumer involvement.

How CCRs are trained

A bit of history

Back in November 2005, CancerVOICES submitted a proposal to the Ministry of Health in response to their Request for Proposal for the implementation of the Cancer Control Strategy Action Plan. Specifically, we proposed that we could create and deliver a training programme for Cancer Consumer Representatives.

We saw this as an opportunity for CancerVOICES to become a leader in the field for which we were created, namely:

To influence the process to ensure excellence and equal-

ity in the provision of and access to treatment of all cancer patients

To be a bridge between cancer patients, policy makers and cancer service providers.

At the time and for the next year or more, the Ministry of Health saw us as too much of a risk, given our lack of runs on the board and so, without funding, we were unable to follow through on our proposal. However, in early 2007, the New Zealand Cancer Society agreed to support us with funding and administrative expertise to implement a training course.

A workshop was held in Auckland with representatives from CancerVOICES, and the CANGO group (a group of six cancer NGO's under the leadership of the Cancer Society). From there, a training package was developed and facilitators and presenters secured for the first course, which was held in November/December 2007. Since then, a second course has been held and a third is planned for July/August 2008.

Course content

The three-day course is held over two weekends, three weeks apart.

Day One presents information on cancer, its diagnosis and treatment, and the cancer health system.

Day Two discusses the cancer journey, identifies issues that might occur during that journey and improvements that can be made to the health system. The Maori perspective is also presented.

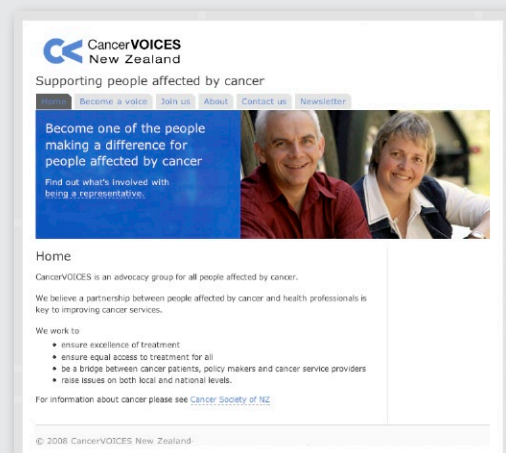
Day Three focuses on the role of consumer representation. There is pre-reading before the first workshop and homework between the two weekend workshops. We ask people to obtain information on their local Cancer Society and the cancer planning of their local DHB, and also to attend a formal committee (preferably one from their local DHB).

Visit our new website

The new website for CancerVOICES is has been designed to be much more responsive to the needs of people affected by cancer.

It provides access to information of importance or of interest to those people who are representing cancer consumers within the health system. Importantly, it also provides a forum for CCRs to discuss issues that have arisen during their work, ask questions, contribute ideas and communicate with others doing similar work.

We hope that you enjoy it and make use of it.



Visit the new website at www.cancervoices.org.nz.

A Consumer Representative's view of the training

The second CCR (Cancer Consumer Representative) training was successfully completed on 29 and 30 March and 19 April 2008 in Palmerston North, with many of the trainees already nominated to participate in regional cancer network committees and projects.

To quote the Guidelines for Consumer Representation on a Committee or Working Party, one of the key principles of the New Zealand Cancer Control Strategy is that "all activities undertaken to meet these purposes [being the reduction of the incidence and impact of cancer and the reduction of inequalities with respect to cancer] should actively involve consumers and communities". As part of satisfying this principle, there is a need for a Cancer Consumer Representative (CCR) on many health committees and working parties.

It is clear that this role is not

- where a particular cause can be pursued, but rather one requiring negotiation with other committee members to achieve better conditions for the cancer consumer; nor
- where personal experience forms the basis of a position taken with other committee members; but rather - one where personal experience provides the basis for a general view of issues affecting cancer consumers

CCR Responsibilities are:

- consumer representation
- co suggest improvements for cancer patient care
- to protect the interests of cancer consumers
- to ensure cancer concerns are recognised
- to report to the consumer community
- to obtain feedback from the consumer community, where appropriate.

And the CCR takes particular account of the need to ensure the following principles relating to treatment and supportive care are adhered to:

- All patients nationwide should have equity of access to treatment and supportive care.
- Cancer patients are entitled to be made aware of the range of treatment options available for their cancer and the advantages and disadvantages of each option.
- Full information should be made available to cancer patients on all aspects of their treatment, the expected impact it will have on their cancer, its possible side effects and the progress made in meeting treatment objectives.

- During their treatment, cancer patients should be entitled to full support including: management of side effects; the presence of a support person; emergency contact information and information about the support services available to them.
- Cancer patients should be able to expect a regular follow-up by a specialist for a reasonable period during and after their treatment.
- All patients nationwide should be made aware of support available to them for any aspect of their lives during their cancer journey'

As CCRs may participate alongside oncologists, radiologists, specialists, surgeons, consultants, project managers, nursing and allied health professionals, there may be self-doubt concerning their nominated right to be there. Yet the CCR position has just as much credence as any, in respect of knowledge and experience. After all we are the experts in the field of cancer consumerism – having been there, done that and got the scars to prove it!

Certainly the role is not without its challenges – among them, the possibility of discussion triggering thoughts and emotions from your own experience. How would you feel if the specialist on the group was your oncologist? Having completed a Myers-Briggs Type Indicator, trainees are given further insights into their personality - how this impacts on you, on others. Do you base decisions on objective analysis and logic or on values and people-centred concerns (are you a thinker or a feeler?). You have to be honest with yourself...are you ready for this? Could there be a potential conflict of interest? You need to determine your own health considerations and how these may impact.

Despite all that, a winning angle is the coaching from Denise Robbins and her Team being both practical and encouraging, as it includes mentors, annual refresher courses and a forum for discussion on the Cancer-VOICES website.

While the label 'Cancer Consumer' does not evoke imagery that would automatically bring a smile to the dial, the intent and focus of what this position represents is setting a new precedent within our District Health Board environments. And it ultimately brings a smile to the face of every cancer survivor in Aotearoa in smoothing the path for ourselves and those who will follow.

Jacqui Thomas

Cancer Consumer Representative