

CONSUMER AND COMMUNITY REPRESENTATIVES TRAINING

Workshop Report
26 February 2009

FEBRUARY, 2009

REPORT

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Background

Cancer Institute NSW

The Cancer Institute NSW is Australia's first state-wide, government-supported cancer control agency driving innovation in cancer care in NSW by working in partnership with key stakeholders to deliver best practice in cancer care.

The Cancer Institute NSW is committed to involving consumers in their program development and recognises the important contribution consumer representatives make to the outcomes of the NSW Oncology Group (NSWOG) and Cancer Institute NSW committees and the opportunities that exist to extend this role further and bring the consumer perspective to ensure a patient centred approach to Cancer Institute NSW programs.

Workshop: Being a Consumer/Community Representative with the Cancer Institute NSW - 2006

On 21 November 2006, the Cancer Institute NSW hosted its inaugural Consumer Workshop, facilitated by the Consumers' Health Forum of Australia (CHF) and planned with Cancer Voices NSW.

This workshop was designed to provide an interactive learning opportunity for consumer/community representatives and update them on the work of the Cancer Institute NSW. The day provided an opportunity for participants to understand the core skills needed to make an effective contribution from a consumer/community perspective. It also outlined strategies for representatives to put into practice and identified ways the Cancer Institute NSW could encourage and support the representatives in their role.

Evaluation of the workshop was positive; with high level interest and support for further training opportunities in the future.

Consumer training needs assessment

Plans to conduct a second training workshop for Cancer Institute NSW consumer representatives began in February 2008. In March 2008, an electronic survey was sent to all current Cancer Institute NSW consumer representatives to assess their training needs and identify the main areas and skills they would like addressed should another workshop be planned.

The common themes emerging from these results formed the basis of the workshop agenda. The workshop was originally planned for 2 December 2008, however due to low RSVP's and the approaching holiday season, was postponed to 26 February 2009.

MOU with Cancer Voices

The Cancer Institute NSW has a Memorandum of Understanding (MOU) with Cancer Voices, with agreement to consult with and invite input from CVN on matters of interest and concern to people affected by cancer in our state. Cancer Voices were consulted throughout all stages of planning for the workshop, with opportunities to present throughout the day.

A further aspect of the MOU is a requirement for the Cancer Institute NSW to invite a representative of Cancer Voices to sit on all relevant Cancer Institute NSW committees and working parties. These committees may also contain consumer representatives who are not Cancer Voices members.

A list of Cancer Institute NSW committees is included below:

- NSWOG Bone & Soft Tissue Sarcoma
- NSWOG Breast
- NSWOG Cancer Genetics
- NSWOG Child & Adolescent
- NSWOG Colorectal
- NSWOG Complementary Therapies
- NSWOG Executive
- NSWOG General Practice
- NSWOG Haematology Oncology
- NSWOG Head and Neck
- NSWOG Lung
- NSWOG Melanoma
- NSWOG Neuro-Oncology
- NSWOG Palliative Care
- NSW Joint Patient Information and Support
- NSW Joint Radiotherapy Advisory Committee
- NSWOG Rural Oncology
- NSWOG Upper GI
- NSWOG Urology
- GMCT Gynaecological Oncology Committee Advisory Committee
- Cancer Institute NSW Board
- Cancer Institute NSW Executive
- Clinical Services Advisory Committee
- Education & Workforce Advisory Committee
- Quality & Clinical Effectiveness Advisory Committee
- Population Health - Advisory Committees / Sub-Committees
- Cancer Information and Registries Advisory Committee
- Pap Test Registry Committee
- Standard Cancer Treatment Protocols: Steering Committee
- Standard Cancer Treatments - Dose Modification Reference Group
- Standard Cancer Treatments - Haematology Reference Group
- Standard Cancer Treatments - Medical Oncology Reference Group
- Standard Cancer Treatments - Nurses Reference Group
- Standard Cancer Treatments - Paediatric Reference Group
- Standard Cancer Treatments - Palliative Care Reference Group
- Standard Cancer Treatments - Radiotherapy Reference Group
- Central Cancer Registry Advisory Committee
- Clinical Cancer Registry (ClinCR) Steering Committee
- Prevention - Advisory Committees / Sub-Committees
- National Quit Group Teleconference
- National Health Warnings Steering Committee
- Cancer Research Advisory Committee
- Ethics Committee
- Grants Review Committee
- NSW Cancer Trials Group Executive Committee
- Screening - Advisory Committees
- NSW Cancer Screen Advisory Committee
- Bowel Cancer Screening Implementation Advisory Group

Alison Evans Consulting

The workshop was facilitated by Dr Alison Evans, an experienced healthcare communicator. Dr Evans has worked with consumer representatives, facilitating their input in both working and focus group settings to ensure optimal outcomes.

Workshop Summary

The second Cancer Institute NSW Consumer and Community Representatives workshop was held on 26 February 2009 at Australian Technology Park, Eveleigh. Consumer representatives from all Cancer Institute NSW committees, as well as nominated representatives from Cancer Voices NSW, were invited with nineteen consumer representatives present.

Other attendees included a representative from Cancer Australia, and members of the Quality and Clinical Collaboration team of the Cancer Services and Education Division, with a staff member on each of the tables for the duration of the workshop. The Quality and Clinical Collaboration team is responsible for the twenty NSW Oncology Groups, with a project officer dedicated to each Group. It was important for representatives to understand they have the support of this team, who are able to assist with any committee issues or queries.

The workshop agenda was split into two defined sessions. The morning session was themed 'how the system works', with the afternoon including a greater opportunity to scope 'how to be a representative'.

The following sections provide an overview of each session of the agenda.

Welcome & Introductions

Facilitator Alison Evans opened the day by welcoming participants, and presenting an overview of the aims and objectives of the day. The overall aim of the workshop was to help participants be effective consumer representatives of the Cancer Institute NSW. This was to be achieved by providing insight into:

- role, programs, structure and priorities of Cancer Institute NSW
- health system, cancer organisations and health policy
- oncology and meeting terminology
- communication skills

Consumers and Cancer Institute NSW staff were then invited to introduce themselves, the committee they are a member of and their expectations of the workshop.

Realities of being a consumer rep

Mark Anns, Manager of the Quality and Clinical Collaboration team of the Cancer Institute NSW welcomed attendees on behalf of the Cancer Institute NSW, and spoke of the challenges committee membership can often present. He encouraged members to utilise the support of the Cancer Institute NSW staff who run the committees, by asking questions, seeking background information and adding appropriate items to the agenda.

Consumer Participation – what's it all about?

Cancer Voices NSW Chair, Sally Crossing introduced the concept of being a consumer representative and how Cancer Voices fits into the big picture. She described the guiding principals of the Consumer Representatives best practice as derived from Consumers' Health Forum of Australia (CHF)¹.

¹ The Consumers' Health Forum of Australia is an independent member-based non-government organisation representing and involving consumers in health policy and program development.

The role of consumer representatives is defined by the CHF to:

- Protect the interests of consumers
- Present how consumers may think and feel about issues
- Contribute consumer experiences
- Ensure the committee recognises consumer concerns
- Ensure accountability to consumers

Launch of Cancer Australia Consumer Engagement Documents

John Stubbs, Executive Officer of Cancer Voices Australia officially launched four Consumer Resources, developed by the Health Issues Centre for Cancer Australia:

- Consumer participation guide
- Consumer training and mentoring guide
- Cancer Support Groups: A guide for peer facilitators
- Cancer Support Groups: A guide to setting up peer facilitated supports

These documents are available online, through the Cancer Australia website:

<http://www.canceraustralia.gov.au/consumer-support-and-information/overview.aspx>

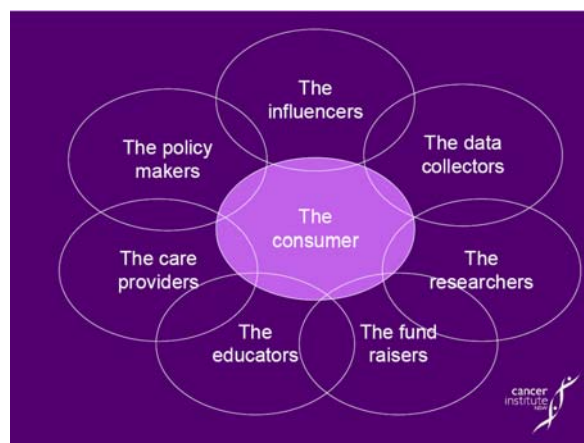
About us: Cancer Institute NSW

Professor Jim Bishop, Chief Cancer Officer and CEO of the Cancer Institute NSW highlighted the organisations objectives, divisions, current cancer projections, incidence and mortality data and current publications.

Pieces of the Puzzle: the NSW Health System

This interactive group activity was designed in response to the needs analysis survey, in which respondents sited difficulties understanding the intricacies of the NSW Health system. There were questions regarding who is who, how organisations relate to each other, how they are funded and by whom, and generally “*understanding the NSW cancer ‘world’*”.

This was achieved through a mapping exercise, in which tables were asked as a group to discuss a summary document listing a variety of organisations, and gauge any questions and/or uncertainties.



Discussion was facilitated around several organisations with similar names and objectives and consumers also sought information on whether organisations listed had consumers involved in any governing body or advisory group.

Facilitator, Alison Evans, presented a high-level summary as an example, grouping several organisations below:

Policy Makers	Influencers	Care Providers	Educators	Researchers	Fund raisers	Data collectors
<p>State government:</p> <ul style="list-style-type: none"> • NSW Health • Cancer Institute NSW <p>Federal government:</p> <ul style="list-style-type: none"> • Department of Health and Ageing <ul style="list-style-type: none"> ○ Therapeutic Goods Administration ○ Pharmaceutical Benefits Scheme <p>Private sector:</p> <ul style="list-style-type: none"> • Private Hospital Association 	<p>Independents:</p> <ul style="list-style-type: none"> • Cancer Council Australia • Consumer advocacy groups: eg Cancer Voices, BCNA, BCAG, CanTeen, Carers Australia • Professional Colleges eg RACS, RANZCR, RACGP • Other professional groups eg COSA, MOGA, CNSA • Industry <p>Government-funded:</p> <ul style="list-style-type: none"> • Cancer Australia • National Breast and Ovarian Cancer Centre • Cancer Institute NSW 	<p>Government:</p> <ul style="list-style-type: none"> • Area health services • Hospitals and clinics • Health professionals • Screening centres and programs <p>Private:</p> <ul style="list-style-type: none"> • Hospitals and clinics • Health professionals <p>Independent:</p> <ul style="list-style-type: none"> • Cancer Council NSW • Disease-specific groups eg Leukaemia Foundation • Information and support groups 	<ul style="list-style-type: none"> • Professional colleges • Other professional bodies • Cancer Australia - National Centre for Gynaecological Cancers • National Breast and Ovarian Cancer Centre • Cancer Council NSW • Cancer Institute NSW (CI-SCaT) • Clinical Information Access Program (CIAP) • Private organisations • Industry 	<ul style="list-style-type: none"> • NHMRC Clinical Trials Centre • CHERP, CHERE, CCORE • Cooperative clinical trials groups • Cancer Council NSW • National Health and Medical Research Council • Industry 	<ul style="list-style-type: none"> • Cancer Council NSW • National Breast Cancer Foundation • Prostate Cancer Foundation of Australia • Myeloma Foundation of Australia • Leukaemia Foundation • Cure Cancer Australia • McGrath Foundation 	<p>State:</p> <ul style="list-style-type: none"> • NSW Central Cancer Registry • Clinical Cancer Registry <p>National:</p> <ul style="list-style-type: none"> • Australian Institute of Health and Welfare • Australasian Association of Cancer Registries • Australian New Zealand Clinical Trials Registry

NB: This is a training exercise only and does not represent a comprehensive list of all key stakeholders.

In the Chair

Chair of the NSW Oncology Group (NSWOG) Neuro-Oncology Dr Kerrie McDonald presented an insightful overview of the importance of consumer input into committees. Dr McDonald presented a summary of the achievements of the NSWOG Neuro-Oncology, and outlined the priority areas of the Group in line with the activities and input of its consumer representatives.

There was discussion regarding the varying level of skill other committee Chairs have with involving consumer representatives in meetings. There was a suggestion the Cancer Institute NSW provide guidelines to Chairs, outlining methods to involve consumer representatives in meetings.

Learning the Lingo

Participants were encouraged to read the terminology handout provided within the workshop resources over lunch and address any uncertainties throughout the afternoon session.

Nothing about us without us – in practice (Consumers Health Forum and Cancer Voices NSW)

Opening the afternoon session was Sally Crossing, who elaborated on the role and history of Cancer Voices NSW:

- We are all volunteers who had experienced cancer, had a commitment to make a difference
- Shared very similar objectives, found many issues apply to most cancers – strength in a bigger voice
- Mentoring cancer specific groups which had no voice
- Shared common training, principles of operation, methods of communication, helped each other, saving energy & resources
- Providing a voice for cancer patient rights, access to best practice treatment; to better drugs; to good, timely information; to directories of specialists; to treatment & care plans, better financial assistance, and translatable research.

Participants were encouraged to read through the CHF Guidelines for Consumer Representatives, provided in the workshop pack. Sally noted the value of this document, as the best and only independent reference.

The Big C: Communication

This session was designed in response to consumers identifying a need for training in communication techniques. There were many representatives who cited the need for improved “*Confidence in "speaking out"*”. Drawing on the experiences of consumer representatives present, particularly those experienced in advocacy through Cancer Voices NSW, a set of scenarios was proposed for groups to discuss. Each table was to discuss a scenario (scenarios 4 & 5 combined), drawing on individual experiences and problem solving techniques.

Scenario	Feedback
How to be heard – having the confidence to speak and how to get your message across	Group felt that those with low confidence should reconsider their involvement on a committee
Managing conflict – how to manage 'difficult' situations, for example when you represent the minority view	Several techniques were suggested, including: <ul style="list-style-type: none"> • Discuss the issue with the Cancer Institute NSW project officer assigned to the group • Seek amendments to minutes • Take a note of what you say in meetings • Build your credibility
On the spot – what to do if you are asked to comment on something you're not prepared for	Group felt that members should come prepared, and if unsure, utilise the Cancer Institute NSW project officer for assistance.
All in the detail – when and how to seek clarification & right time, right place – ensuring relevance and choosing the right time to raise issues	Suggestions included: <ul style="list-style-type: none"> • Talk to the Chair of the Group, • Utilise the "new business" item of the agenda • Discuss the relevance of the item with the Cancer Institute NSW project officer beforehand – issue may be better placed with another committee. • Seek a lay summary from Cancer Institute NSW staff.

Mark Anns asked participants to consider new ways the Cancer Institute NSW could consult with its experts, outside the traditional meeting set-up.

These options included use of an online discussion board, a webinar² or a speciality formed subcommittees or panels.

The Group were asked to suggest specific areas they felt the Cancer Institute NSW could assist in their role on committees. Suggestions included:

- A set of guidelines when someone joins a committee, including the membership of the Group, who the Chair is, and a list of common meeting terminology.
- Provision of a lay summary for particularly complex agenda items, beyond the existing agenda coversheet.

Interactive Panel: Q & A Session

This consolidation session allowed participants an opportunity to re-address issues discussed in earlier sessions in more detail and also seek the direct input and advice of the panel.

Members of the panel included:

- Sally Crossing AM, Chair, Cancer Voices NSW
- John Newsom, Chair, Cancer Voices Australia
- Robyn Thomas, Project Officer, Cancer Institute NSW

² A webinar is a live online conference, in which participants are connected from their own computer to other participants and a presentation.

Highlights and actions of the interactive panel discussion included:

- Questions on how decisions are made on what research the Cancer Institute NSW funds and are consumers involved in this process?
- Participants felt there would be value in a non-scientific perspective to research priority-setting.
- A request to be involved in the planning and scoping of the next Cancer Plan.
- A need for more background information on what the Cancer Institute NSW does, with a lay overview of all its Divisions.
- The reinstatement of the NSWOG Newsletter, which will allow participants a better understanding on the activities of the tumour stream and discipline Groups, and enable identification of areas for collaboration or consumer involvement.
- Frustrations with the confidentiality agreements required on most committees.

Patient Information Review

A brief overview of the Cancer Institute NSW Standard Cancer Treatments (CI-SCaT) was presented, with participants encouraged to participate in a consumer reference committee for CI-SCaT. This committee would contribute to the development of patient resources to help health care professionals maximize limited teaching time and enable patients to better manage their cancer and cancer treatments and side effects.

Interested consumers were asked to contact:

Karen Eaton
Project Coordinator, Nursing/Patient Information
Standard Cancer Treatments Program
Ph 02 8374 5714
E-mail karen.eaton@cancerinstitute.org.au
www.treatment.cancerinstitute.org.au

Summary and Actions

Overall the workshop was a great opportunity for consumer representatives to network with each other, develop their skills and learn the systems and terminologies that will assist in ensuring the effectiveness of their contribution. Further, it provided the Cancer Institute NSW an opportunity to understand the needs of its consumer representatives and highlight the support offered by the Institute. The workshop reinforced the important perspective consumers bring to Cancer Institute NSW priorities and future direction.

The following represents the actions agreed for follow-up to the workshop:

- *Members requested a copy of Professor Jim Bishop's presentation be made available.*
- *Completed Health Organisations table to be circulated to attendees.*
- *Health Organisations list to include information on whether organisations have consumer involvement on governing bodies or advisory groups.*
- *Meeting Terminology document to be uploaded to the Cancer Institute NSW website.*
- *New Consumer Representatives to be sent a set of guidelines on the particular committee, including the membership of the Group, who the Chair is and a list of common meeting terminology.*
- *Cancer Institute NSW to provide guidelines to Chairs, outlining methods to involve consumer representatives in meetings.*
- *NSWOG Newsletter to be reinstated.*

Updates on the progress of these actions will be communicated to members as they develop.

Evaluation

Participants were required to complete an evaluation of the workshop, in order to feedback on the effectiveness of the workshop and identify needs for possible future sessions.

Participants enjoyed the opportunity to network with other cancer consumers, work with small groups and contribute to an open and informal discussion. Attendees highlighted value of the information provided, particularly regarding the role and function of the Cancer Institute NSW.

Sessions were evaluated as well structured, informative, engaging and of appropriate length. Speakers were said to be succinct in their presentations, with an overall good balance between formal input and small group activity. There was particular mention of the presentation Dr Kerrie McDonald provided describing an effectively functioning NSWOG.

Over 50% of respondents described the facilitation of the day as “excellent”. Attendees felt the day was interactive, well controlled and timed and kept on track.

There were minimal issues raised, with concern only around participant discussing personal health issues.

Participants were asked to offer suggestions for improvement, which included a request for more detail around successful Cancer Institute NSW research projects, and the opportunity to move around tables and work in a variety of small groups.

Suggested topics for a future workshop included a request for detail about the role and scope of Cancer Institute NSW. All respondents indicated they would like to attend any similar workshops in the future.

Overall, participant expectations were met. Many attended the workshop to learn and network and this opportunity was fulfilled.

Appendix Agenda

Time	Session
9.30am	Registration and Tea & Coffee
10.00am	Welcome & Introductions
10.20am	Realities of being a consumer rep <i>Mark Anns, Manager, Quality and Clinical Collaboration Cancer Institute NSW</i>
10.25am	Consumer Participation – What's it all about? <i>Sally Crossing AM, Chair, Cancer Voices NSW</i>
10.30am	Launch of Cancer Australia Consumer Engagement documents <i>John Stubbs, Cancer Voices Australia</i>
10.35am	About us: Cancer Institute NSW <i>Professor Jim Bishop, CEO and Chief Cancer Officer Cancer Institute NSW</i>
10.50am	Pieces of the Puzzle: the NSW Health System Interactive group activity Who's who and what do they do? The roles of cancer and health organisations in NSW and nationally explained.
11.20am. Morning tea (provided)	
11.40am	Report back: Pieces of the Puzzle: the NSW Health System
12.00pm	Learning the lingo Q&A session Your chance to clarify tricky cancer and meeting terminology
12.30pm	In the Chair <i>Dr Kerrie McDonald, Chair, NSWOG Neuro-Oncology</i> An insight into how meetings run and the importance of consumer input.
1.00pm. Lunch (provided)	
1.30pm	Nothing about us without us – in practice (Consumers Health Forum & Cancer Voices NSW) <i>Sally Crossing AM, Chair, Cancer Voices NSW</i>
1.45pm	The Big C: Communication Small group activity How can we manage difficult meeting situations?
2.50pm	Interactive Panel: Q & A Session Q&A session with a panel including experienced consumer representatives; Sally Crossing and John Newsom and Cancer Institute NSW representation.
3.25pm	Patient information review Overview on the review of patient information for CI-SCaT
3.40pm	Reflect and review Group discussion: key learning points & agreement on goals

