



## Consumer Participation Strategy

### Plan Implementation Period 2011-2013

Date: 24 December 2010

Developed by: NEMICS Directorate in consultation with

#### **Acknowledgements and thank you to:**

NEMICS Consumers, Dr Ian Roos (Cancer Voices, Victoria), Anna Mascitti (NEMICS Project Officer), Kathy Simons (NEMICS Manager)

## **Executive Summary**

---

The North Eastern Metropolitan Integrated Cancer Service (NEMICS) is one of three metropolitan and five regional integrated cancer services established by the Victorian Department of Health in 2005. The purpose of NEMICS as a networking organisation is to facilitate improvements in planning and delivery of cancer care within the north east region of Melbourne. This Consumer Participation Strategy 2011 – 2013, has been developed to guide how NEMICS engages with their dedicated consumers, carers and community members.

NEMICS is committed to consumer participation as a principle integral to its structure, core functions and service improvement initiatives. This Consumer Participation Strategy 2011 - 2013 has been developed in collaboration with consumers who are currently engaged with NEMICS and builds on its previous Consumer Participation Plan 2008 – 2010.

Our consumer participation vision is to work in partnership with consumers, carers and the community to facilitate access to best practice cancer care for our population, to achieve better outcomes for all patients.

Implementation of this strategy will guide how NEMICS engages with and supports consumer participation across all levels of participation: individual care, program / department, health service / organisation, and Department of Health. Consultations with consumers in the development of this strategy have highlighted areas of improvement, particularly in the areas of support and engagement with the community. These areas have been expanded upon in this new strategy.

## 1. Introduction

---

This document is an outline of the three year NEMICS Consumer Participation Strategy 2011 – 2013 and builds upon NEMICS commitment to consumer participation as being integral to all aspects of its work, improving cancer services across the north east region of Melbourne.

This strategic plan is a commitment by NEMICS to support and develop consumer participation in its service improvement initiatives and should be used by NEMICS Directorate to guide their consumer engagement activities.

## 2. The Broad Context

---

'Cancer is Victoria's biggest killer and the cause of considerable suffering of the Victorian Community'<sup>1</sup>. In recognition of the need to improve the delivery of cancer services and outcomes for cancer patients, the Victorian Government launched Victoria's Cancer Action Plan 2008-2011 (VCAP) as part of its ambition cancer service reform agenda.

VCAP recognises consumer participation as a tool to drive cancer service improvement initiatives. Action Area 4: Priority 1: 'create better experiences for cancer patients and carers', recognises that consumers have an important role in improving cancer care, not only through understanding and directing their own care but also by participating in policy development, service delivery and research. VCAP actions and targets include:

- Increase consumer participation in cancer care policy development, service delivery and research
- Work with consumer organisations in a range of tumour streams to support programs that train cancer consumer advocates.

Additionally, in 2009 the Victorian Department of Health (DH) released its policy document on consumer participation '*Doing it with us not for us: Strategic direction 2010-2013*'<sup>2</sup>. This document builds on the DH 2006 policy release '*Doing it with us not for us*' reinforcing its position that 'participation in health is an essential principle of health development, clinical governance, community capacity building and the development of social capital'. The 2010-2013 strategic direction 'targets the Victorian public health service system including acute, subacute, mental health, community health, and residential aged care facilities'.

In May 2010, the DH released a report following a review of consumer and carer participation in the Integrated Cancer Services<sup>3</sup>. This report highlighted a number of recommendations to improve consumer participation and included: sustained consumer and carer participation through

---

<sup>1</sup> Department of Human Services (2008). Victoria's Cancer Action Plan 2008-2011. Innovation in care – saving lives. Victorian Government Melbourne, Victoria

<sup>2</sup> Department of Health, 2009, '*Doing it with us not for us: Strategic direction 2010-13*', Rural and Regional Health and Aged Care Services Division. Victorian Government, Melbourne

<sup>3</sup> Department of Health (2010), Consumer and carer participation in the Integrated Cancer Services, Project Report May 2010. Victorian Government Melbourne, Victoria

the sharing of publications, resources, templates and learnings amongst ICS; linking with consumer advocacy organisations; undertaking regular needs analysis of consumer and carer training requirements; education for clinical staff to enhance awareness and acceptance of consumer and carer participation; and develop practical resources and tools to guide the engagement of consumers and carers in research.

In response to these recommendations and in collaboration with the CanNET Victoria project, the Integrated Cancer Services have recently established an ICS Consumer Participation Group to address these issues.

The NEMICS Strategic Directions 2010-2013 document builds on the work commenced within the 2008-2010 strategic directions document, focusing on increasing opportunities for consumers to participate, expanding our focus to support consumers and carers to participate effectively in their own care, and expanding our role for consumer and carer participation in research.

In relation to consumer participation, NEMICS Strategic Directions 2010 – 2013 are:

Strategic direction 3: Work with providers to improve consumer experiences and outcomes by:

- Continuing to develop the NEMICS consumer network and consider other structures for participation
- Providing opportunities for consumer participation at all levels
- Supporting the capacity of consumers & carers to participate effectively in their own care

### **3. Development of the NEMICS Consumer Participation Strategy 2011-2013**

---

In developing its consumer participation plan, the NEMICS Directorate has used the following definitions in accordance with current DH policy<sup>4</sup>.

*Consumers:* are people who are current or potential users of health services

*Carers:* are family and friends providing unpaid care to consumers.

*Communities:* are groups of citizens who have an interest in the development of an accessible, effective and efficient health service that best meets their needs.

*Consumer, carer and community participation* encourages consideration and debate through processes that allow people to be involved in decision making about their health care and that of the community. Through involvement, decisions are made that may accommodate a range of perspectives.

---

<sup>4</sup> Department of Health, 2007, 'A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services' Department of Human Services. Victorian Government, Melbourne

The NEMICS Consumer Participation Strategy 2011-2013 was developed using a four phase process:

1. review of the NEMICS Consumer Participation Plan 2008-2010
2. review of the evidence and current Victorian DH policy
3. review of local data
4. strategy development, and
5. workshop and consultation with consumers currently participating in NEMICS activities

### **Review of the NEMICS Consumer Participation Plan 2008-2010**

Our first Plan aimed to increase participation opportunities beyond representation on tumour groups to include participation opportunities at all levels within the NEMICS region; individual care level, program / department level, health service / organisation level and Department of Human Services level. To achieve this, our first plan focused on recruitment in order to expand the number of consumers we had to draw on, and the development of support and strategies to engage consumers at all levels within NEMICS.

### **Review of the evidence and current Victorian DH policy**

Consumer participation in healthcare occurs when "consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community"<sup>5</sup>. National and international literature indicates consumer participation is a valued contributor to health service planning and delivery. As a result it is being increasingly incorporated into the Australian health system through policy development and decision making by Australian governments, at both Federal and State levels. This strategic plan is based on the framework provided in the Department of Health's policy document '*A guide to enhancing consumer and carer participation in Victoria's integrated Cancer Services*'<sup>6</sup>

### **Review of Local Data**

#### ***Demographics***

The 2006 population in the north eastern metropolitan geographic region was 1.27 million and the total metropolitan Melbourne population was 3.74 million<sup>7</sup>. The geographic area of NEMICS is based on the following local government areas: Banyule, Boroondara, Darebin, Knox, Manningham, Maroondah, Nillumbik, Whitehorse, Whittlesea and Yarra Ranges. The implication of local demographics upon the provision of routine and systematic supportive care to cancer sufferers will be further analysed as part of the work underpinned by this strategy.

---

<sup>5</sup> Department of Health, 2009, '*Doing it with us not for us: Strategic direction 2010-13*', Rural and Regional Health and Aged Care Services Division. Victorian Government, Melbourne

<sup>6</sup> Department of Health, 2007, '*A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*' Department of Human Services. Victorian Government, Melbourne

<sup>7</sup> Australian Bureau of Statistics, 2006 Census QuickStats, downloaded from <http://www.censusdata.abs.gov.au> on 18<sup>th</sup> May 2010.

### ***Cancer Burden within NEMICS***

NEMICS inpatient public hospital activity data shows that in the 2008-2009 financial year, there were 31,921 inpatient admissions with a cancer diagnosis (malignant, in situ or unknown neoplasms) provided to 8,934 cancer patients. The number of patients admitted to one or more of the NEMICS public health services increased from 7,634 in 2004-2005 to 8,934 in 2008-2009.

In 2008-2009 there were 6104 cases of newly diagnosed cancer (excluding non-melanoma skin cancer) in patients that reside in the NEMICS geographic region<sup>8</sup>. This represents one new cancer diagnosis for every 200 residents in the region, most of which (74%) seek treatment within NEMICS health services.

The five year survival rate for people diagnosed with a cancer in 2004 for all Victorians was 61%. People residing within the NEMICS region have the highest five year survival rate of 64% (i.e. 64 in every 100 people with cancer have survived at least 5 years from their cancer diagnosis). This has a significant implication on service planning and improvement as it is recognised that survivorship is an important stage of patient journey, requiring development of appropriate follow up models of care<sup>9</sup>.

At this point in time we do not have access to data describing occasions of services provided to cancer patients in private hospitals within the north-east. The implication of cancer activity data within NEMICS upon the provision of routine and systematic supportive care to cancer sufferers will be further analysed as part of the work underpinned by this strategy.

### **Strategy development and workshop consultation**

During the workshop consumers were asked to reflect upon their engagement over the previous consumer participation plan and identify areas for future engagement and improvement. Consumers unable to attend the workshop were given the opportunity to provide written or verbal feedback on the draft Consumer Participation Strategy 2011-2013.

Areas identified for improvement include:

- education to facilitate greater contribution and engagement. Suggestions included policy development and implementation, public speaking and understanding ethics and quality improvement.
- greater involvement in service gap identification and project development using the establishment of a regularly meeting consumer group as one means to achieve this
- evaluation of the consumer role and its effectiveness
- education for health professionals throughout NEMICS who are working with consumers

---

<sup>8</sup>from latest incidence statistics available from The Victorian Cancer Registry (2006)

<sup>9</sup>Department of Human Services (2008). Victoria's Cancer Action Plan 2008-2011. Innovation in care – saving lives. Victorian Government Melbourne, Victoria.

There was agreement that the consumer participation journey has just commenced at NEMICS acknowledging that participation has been building over the past two years. To achieve effective and sustained consumer participation at all levels within NEMICS there remains a considerable amount of work to do; consumers expressed a commitment to working with NEMICS to achieve these aims.

#### **4. Purpose, Vision and Strategic Directions**

---

**Vision:**

NEMICS will work in partnership with consumers, carers and the community to facilitate access to best practice cancer care for our population, to achieve better outcomes for all patients.

**Aims:**

- Participation opportunities will be available for a diverse range of consumers at all levels of NEMICS activity
- Consumers will have input into decision making relating to service planning, review and evaluation
- People affected by cancer will have input into how their local services can be improved
- Participating consumers will be supported to optimise their effective and meaningful participation
- Collaborate within and across the ICS on consumer participation strategies

**Strategic Directions:**

The strategic directions for the NEMICS Consumer Participation Strategy 2011-2013 are:

1. Develop the NEMICS consumer network and consider other structures to participation
2. Consumer participation at all levels
3. Consumer and carer participation in research activities
4. Support the capacity of consumers and carers to participate effectively in their own care

## Strategic Directions

### Strategic Direction 1: Develop the NEMICS consumer network and consider other structures to participation

#### Recruitment

Aim:	Method:	Outcome	Responsibility	Timeframe
Ongoing recruitment of consumers, expanding the consumer network	NEMICS will continue to recruit consumers as required or as the opportunity presents Methods may include: <ul style="list-style-type: none"> <li>- advertising</li> <li>- engagement through community and cancer support groups</li> <li>- volunteering</li> </ul>	Consumers are available to contribute to all NEMICS service improvement initiatives	NEMICS Consumer Participation Officer	As required
Succession planning for consumer representatives on governance committees as required	Opportunities will be provided to existing consumers to develop skills required for NEMICS governance committees. This will ensure a ready pool of consumers is available if required	Timely replacement of consumers on key governance committees Organised succession planning	NEMICS Consumer Participation Officer NEMICS Manager	As required
NEMICS staff are aware of the processes involved in recruiting new consumers	Use of recruitment protocol by Directorate staff in the recruitment process of new consumers	Recruitment protocol developed All consumers are recruited to NEMICS following the protocol	NEMICS Directorate staff	May 2011
NEMICS Directorate consider consumer recruitment and engagement upon planning of all new projects	Inclusion of consumer recruitment and engagement in NEMICS generic project plan template	Consumers are engaged and consulted during the project planning phase	NEMICS Directorate staff	As required



Engagement				
Aim:	Method:	Outcome	Responsibility	Timeframe
Consumers are oriented prior to commencing participation	Individual/group orientation to be conducted as required Orientation kit available and updated All new consumers must complete an orientation session prior to commencing with NEMICS	Orientation kit updated Consumers are aware of their role and associated responsibilities Consumers are aware of the role and responsibilities of NEMICS Directorate staff towards them	NEMICS Consumer Participation Officer	April 2011 & annually As required
Increase broader community knowledge and awareness about NEMICS / goals / aims and cancer service improvement projects / strategies underway within the NEMICS region	Consumer engagement included in NEMICS stakeholder engagement and communication strategies Develop strategies to engage with community groups within the NEMICS region such as Probus, Red Cross, Lions club Develop strategies to engage with cancer support groups within the NEMICS region Work with organisations such as the Health Issues Centre to develop strategies to engage with Culturally and Linguistically Diverse (CALD) communities located within the NEMICS region	Increased awareness of NEMICS within the wider community and how to obtain cancer related information (websites, cancer council etc.) Increased community awareness of NEMICS activities and opportunities to participate NEMICS working groups will have a broader range of consumer members to consult with on activities	NEMICS Consumer Participation Officer	December 2011 and ongoing
Develop linkages with consumer participation initiatives within NEMICS health services	Maintain up-to-date copies of NEMICS health services' consumer participation strategies Maintain relationships with NEMICS health service Consumer Participation Officers Develop & maintain relationships with NEMICS health services Community Advisory Committees (CACs)	NEMICS will have greater awareness of existing and planned relevant consumer activities to reduce duplication, and encourage collaboration on projects, initiatives and quality improvement activities Health Service Consumer Participation Officers and CACs will have a greater awareness of cancer service initiatives being undertaken within their health service and the NEMICS region	NEMICS Consumer Participation Officer	Ongoing

Support				
Aim:	Method:	Outcome	Responsibility	Timeframe
Consumers are educated and confident in their ability to participate and advocate within their respective roles	<p>Regularly seek input from consumers in relation to their needs to undertake their role</p> <p>Keep consumers informed and up to date of potential training opportunities, including advocacy training</p> <p>Maintain links with organisations that provide consumer relevant training, development and resources, such as the Health Issues Centre &amp; Cancer Voices Victoria</p> <p>Consumers are aware of NEMICS professional development grants and that they are available for their use</p>	<p>2 x education sessions held annually or as required</p> <p>Newsletter is developed 2 x yearly detailing upcoming training opportunities, consumer related activities, and relevant cancer updates within and beyond NEMICS</p> <p>NEMICS professional development grants information is distributed to all consumers when available</p>	NEMICS Consumer Participation Officer	<p>May &amp; August annually</p> <p>March &amp; July annually</p> <p>As required</p>
Consumers clearly understand their participation role prior to commencing with a project	<p>Develop processes to ensure consumers are provided with clear parameters around their participation and contribution to a project prior to commencement.</p> <p>NEMICS Directorate staff are educated in these requirements</p>	<p>Guidelines and process are developed</p> <p>NEMICS Directorate staff understand and implement these guidelines and processes</p>	NEMICS Consumer Participation Officer	May 2011
<p>Consumers have the opportunity to:</p> <ul style="list-style-type: none"> <li>meet with other NEMICS consumers and those from other metropolitan Integrated Cancer Services (ICS)</li> <li>build relationships and offer each other support and guidance in their role</li> </ul>	<p>The NEMICS consumer group meet together 3 to 4 times each year</p> <p>A minimum of two consumers are present on any committees, workshops or focus groups</p>	<p>Consumer group to meet at the beginning of each year to plan their meetings and work for the year</p> <p>Consumers have a network of support mechanisms including other consumers and NEMICS Directorate staff</p>	NEMICS Consumer Participation Officer	<p>March 2011</p> <p>March 2012</p> <p>March 2013</p>

NEMICS Consumer participation Strategy 2011 - 2013

<b>Aim:</b>	<b>Method:</b>	<b>Outcome</b>	<b>Responsibility</b>	<b>Timeframe</b>
Consumers have the opportunity to meet with NEMICS Consumer Participation Officer yearly to review and discuss participation and ongoing contribution	Consumer Participation Officer to meet with consumers at the end of each year. This may be individual meetings or within a workshop situation	Consumers have the opportunity to discuss any issues / suggestions for improvement and ongoing participation with NEMICS	NEMICS Consumer Participation Officer	December 2011 December 2012 December 2013
To provide education / support to health professionals working with consumers within the ICS	Identify existing educational opportunities and disseminate information to NEMICS health professionals  Consider providing professional development opportunities in consumer participation  Work with the ICS Consumer Group working on educational needs	Health professionals have an understanding of the contribution and value that consumers can have to service improvement initiatives; and know how to best engage and support consumers  Implement ICS Consumer Group education working group recommendations	NEMICS Consumer Participation Officer & ICS Consumer Participation Group	Ongoing
Develop and extend the consumer webpage on the NEMICS website	Engage consumers in the development of the consumer webpage on the NEMICS website	Consumers will be able to readily access the NEMICS website to obtain relevant information  The consumer webpage is relevant to the needs of the NEMICS community	NEMICS Consumer Participation Officer	March 2011 and reviewed yearly

<b>Strategic Direction 2: Consumer and carer participation at all levels</b>				
<b>Aim:</b>	<b>Method:</b>	<b>Outcome</b>	<b>Responsibility</b>	<b>Timeframe</b>
<p>Increase the opportunities for consumers - current and future, to participate at a variety of levels. Including membership of:</p> <ul style="list-style-type: none"> <li>• Governance Committee</li> <li>• Reference group</li> <li>• Participation in project/ working parties</li> <li>• Consumer network</li> </ul>	<p>NEMICS members and groups are informed of the opportunities and benefits of consumer input into their work</p> <p>Recruitment to committees, project steering committees and network</p> <p>The NEMICS consumer group meet together 3 to 4 times each year to set priorities and develop a common voice</p>	<p>Consumers participate at all levels as recorded in the NEMICS consumer participation register</p>	<p>NEMICS Consumer Participation Officer</p>	<p>March 2011 and ongoing</p>
<p>Consumer participation within NEMICS is evaluated annually</p>	<p>Investigate methods and work with the ICS Consumer Participation Group to develop evaluation strategies</p>	<p>NEMICS consumer participation policies and strategies are effective and meet the needs of consumers</p>	<p>NEMICS Consumer Participation Officer</p>	<p>November 2011 and ongoing</p>

<b>Strategic Direction 3: Consumer &amp; carer participation in research activities</b>				
<b>Aim:</b>	<b>Method:</b>	<b>Outcome</b>	<b>Responsibility</b>	<b>Timeframe</b>
<p>NEMICS will facilitate engagement of consumers and carers to assist in developing research priorities and research proposals, conducting research and reviewing/disseminating research results</p>	<p>NEMICS Directorate to investigate research opportunities with other organisations such as Cancer Voices &amp; Victorian Cancer Agency (VCA). This will link with the overall NEMICS Strategic Plan to collaborate and foster research.</p> <p>Investigate research training opportunities for consumers</p>	<p>NEMICS Directorate has a system in place for identifying and engaging consumers in research</p> <p>Consumers are educated and able to contribute to research activities</p>	<p>NEMICS Consumer Participation Officer</p>	<p>November 2011</p>

<b>Strategic Direction 4: Support the capacity of consumers &amp; carers to participate effectively in their own care</b>				
<b>Aim:</b>	<b>Method:</b>	<b>Outcome</b>	<b>Responsibility</b>	<b>Timeframe</b>
Residents living within the NEMICS region know how to access cancer information and services	NEMICS to work with its consumers to investigate and develop its role within this area	NEMICS Directorate has a clearly defined role and understands its contribution to assisting consumers and carers to participate effectively in their own care	NEMICS Consumer Participation Officer	May 2011