

Consumer Involvement in Victorian Cancer Service Reform: The SMICS consumer perspective

**Presentation at Participate in Health
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****Presenters***

Presentation Overview

- The consumer perspective
 - Val Johnstone

- Structures and processes for involving consumers in cancer service reform
 - Jane Miller

- Consumer involvement at SMICS
 - Val Johnstone

The Cancer Service Reform Agenda

- **Fighting Cancer Policy (2002)**
 - Upgrading and expanding services
 - Improving cancer service coordination
- **Cancer Services Framework for Victoria (2003)**
 - Establishing Integrated Cancer Services
 - Delivering clinical treatment and care through 10 major tumour streams

Gynaecological	Genito-Urinary
Head & Neck	Haematological
Upper Gastro-Intestinal	Neurological
Colorectal	Breast
Lung	Skin

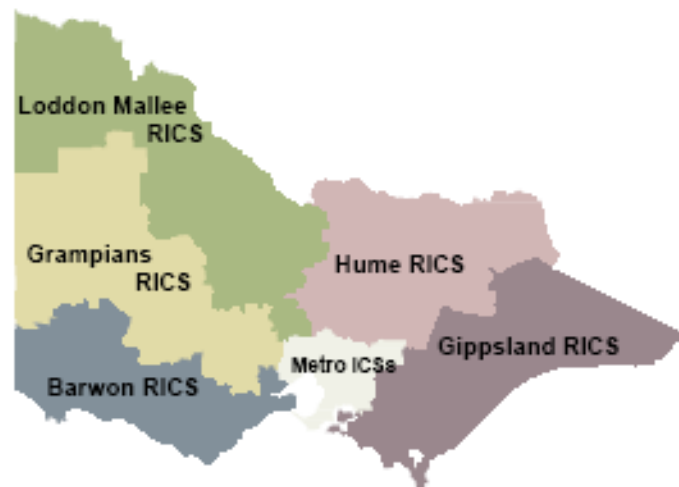
Victorian Integrated Cancer Services

■ Three Metropolitan ICS

- North Eastern
 - Austin Health, Eastern Health, Northern Health, Mercy Hospital for Women
- Southern Melbourne
 - Bayside Health, Peninsula Health, Southern Health
- Western Central
 - Melbourne Health, Peter MacCallum Cancer Centre, Royal Women's Hospital, Western Health, St. Vincent's Health, Werribee Mercy

■ Five Regional ICS

- Barwon South Western
- Gippsland
- Grampians
- Hume
- Loddon Mallee



CURRENT Cancer Service System	INTEGRATED Cancer Service System
Health service planning focussed on the needs of health services	Health service planning focused on the needs of the population
Health services work independently to deliver services	Health services work together to deliver cancer services
Treatment and care options delivered by location	Treatment and care options planned by streams along the patient pathway
Clinical treatment based on local practice and interpretation of clinical practice guidelines	Clinical treatment based on state-wide standards of practice
Unexplained variation in practice across Victoria	Agreed best practice implemented across Victoria
Management of resources for treatment and care by individual health services	Management of resources for treatment and care integrated cancer services along the patient pathway
Level and scope of service delivery historical or based on individual experience and expertise	Levels and scope of service delivery based on agreed standards and needs of populations

Source: Cancer and Palliative Care Unit, DHS - www.health.vic.gov.au/cancer

DHS Priority Cancer Reform Areas

■ **Multidisciplinary Care**

- All patients diagnosed with cancer have access to multidisciplinary care planning

■ **Care Coordination**

- All patients (including family and/or carers) experience cancer care that is connected and coherent

■ **Supportive Care**

- All patients receiving cancer treatment receive appropriate supportive care services

■ **Reducing Unwanted Variations in Care**

- Processes and outcomes of cancer treatment and care are measured and benchmarked (using a range of clinical indicators and performance measures) and this information is used to enhance services



SMICS Vision

Bayside Health, Peninsula Health and Southern Health will work together and with health professionals, community, primary and palliative care services and consumers/carers to provide **s**eamless, **m**ultidisciplinary care that **i**mproves the patient journey and outcomes for people affected by **c**ancer in **s**outhern Melbourne.



Partnering with Consumers

Getting it right from the start ...

A known limitation to involving consumers is that health service managers develop the processes designed to facilitate consumer participation without consulting with consumers.

Types of Consumer Participation

Information	<ul style="list-style-type: none"> • Support participation • Convey facts and educate
Consultation	<p><i>Consultation is only participation when information gathered can influence subsequent policy, care, etc.</i></p> <ul style="list-style-type: none"> • Gauge reaction to proposal and invite feedback
Partnership	<ul style="list-style-type: none"> • Involve in aspects of government or health service organisational decision making • Involve in healthcare or treatment decision-making
Delegation	<ul style="list-style-type: none"> • Hand control to a board of community representatives within a specified framework • Ensure policy options are formulated at arms-length from partisan politics
Control	<ul style="list-style-type: none"> • Hand control of an issue to the electorate • Hand control to consumer of healthcare

Source: 'Doing it with us not for us' – DHS (2006)



Optimising Consumer Participation

- **SMICS Optimising Consumer Participation in Cancer Services Project**
 - Funding received from **Cancer & Palliative Care, Department of Human Services**
 - Two-year project (May 2005 – June 2007) being conducted in collaboration with **Health Issues Centre**
 - Project aims to develop strategies to support consumers to contribute to cancer service improvement activities in southern Melbourne

Project Objectives

- Develop a framework for consumer participation in quality improvement within cancer services
- Implement strategies to enable recruitment, selection, support and training consumers to participate in SMICS
- Establish processes for gathering feedback from consumers regarding their cancer journey to assist with identifying opportunities for improvement and evaluating of activities to improve the quality of cancer services
- Develop strategies and tools to support health professionals to work together with consumers to improve cancer service delivery

Model for Consumer Recruitment & Mgmt

- Developed a 'tool kit' to support SMICS practically and appropriately:
 - Define consumer roles and responsibilities
 - Recruit consumers
 - Prepare consumers for their first SMICS Tumour Group meeting
 - Support and mentor consumers
 - Provide opportunities for consumer networking, training and skill development
 - Reimburse consumers' costs
 - Evaluate consumer recruitment and management

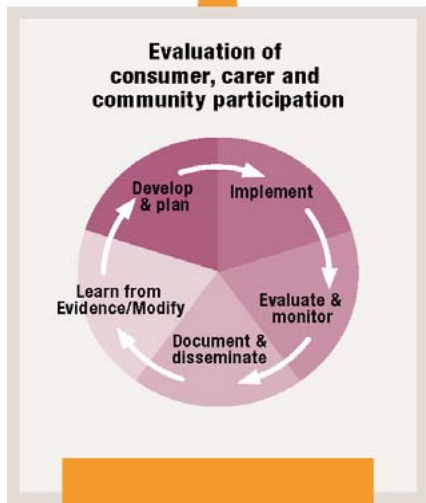
Consumers on SMICS Tumour Groups

■ Key outcomes

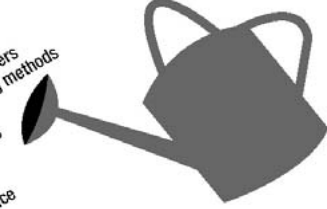
- *I got involved hoping to make a difference ... the longer I have been involved, the more I feel this is starting to happen.*
- *It is an empowering experience ... I have learnt so much.*
- *We have only met four times this year ... but when I look back, we've come a long way.*
- *It has given me an appreciation of others' (health professionals') views.*

Model for Consumer Participation in QI

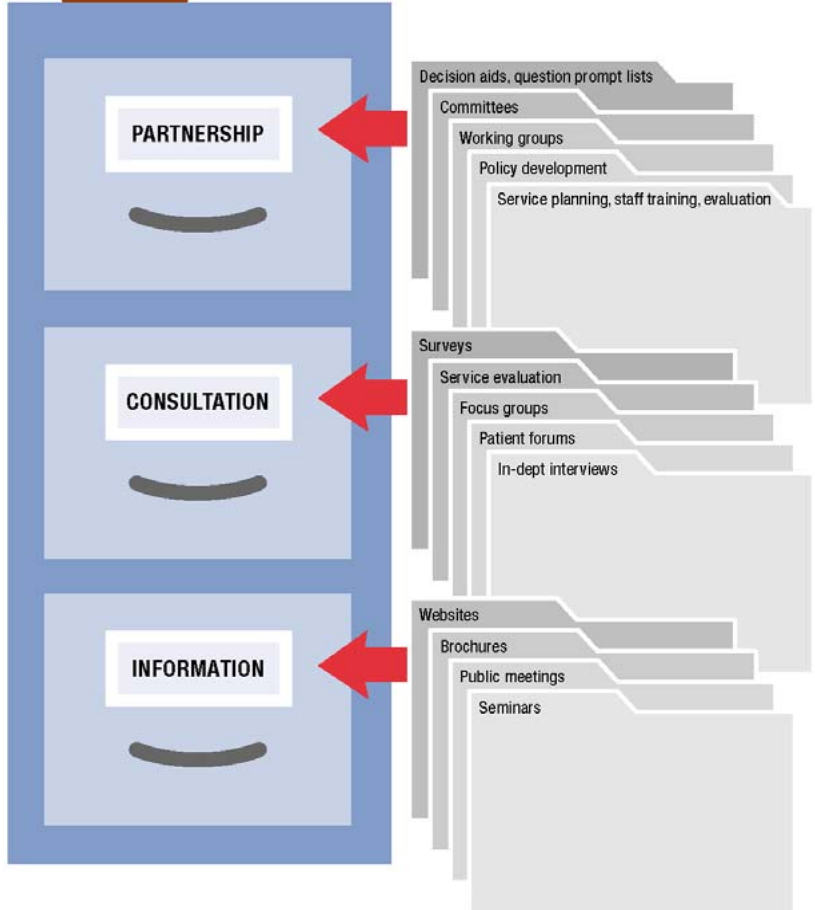
- Identify consumer participation methods for SMICS Tumour Groups to apply when involving consumers in quality improvement initiatives
- Identify roles to support implementation of these participation methods
- Pilot methods with SMICS Tumour Groups (December 2006 – May 2007)
- Evaluate pilot and finalise the Model
- Make Model widely available to SMICS stakeholders



Know your consumers and carers
 Involve consumers in selecting methods
 Use a range of methods
 Use previously trialed methods
 Monitor and evaluate
 Document and disseminate
 Recognise the cancer experience



DRAFT





Planned SMICS Tumour Group Activities 2007

Gynaecological

- Enhancing referral pathways
- Improving patient information*

Breast

- Enhancing multidisciplinary teams
- Enhancing communication with GPs
- Enhancing access to mammography

Skin

- Enhancing multidisciplinary teams*
- Improving patient information*

Haematological

- Improving management and support of potential / actual fertility issues*
- Understanding current access to clinical trials

Lung

- Enhancing care coordination
- Enhancing multidisciplinary care
- Improving access to home oxygen

Head & Neck

- Enhancing care coordination*
- Improving patient information*

Upper GI

- Enhancing multidisciplinary teams
- Scoping delays in accessing scans (CT & MRI)*

Colorectal

- Improving patient information*
- Enhancing multidisciplinary teams

Genito-Urinary

- Improving management and support for treatment morbidity: incontinence and impotence*
- Enhancing multidisciplinary care

Neurological

- Enhancing multidisciplinary care
- Strengthening links with health service providers in Gippsland

Optimising consumer participation in cancer services acknowledges and values the lived experiences of those who have experienced the cancer journey and encourages / supports consumer input into the planning and delivery of quality cancer services in southern Melbourne.

For More Information

We can do better,
it's all about...



*listening to the
views of consumers.*

Nicola
Consumer

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