

CANCER VOICES

A large, stylized white letter 'V' is positioned between the words 'CANCER' and 'VOICES'. The 'V' is composed of two thick, curved strokes that meet at a sharp point at the bottom. The background is a gradient of blue, transitioning from a lighter shade at the top to a darker shade at the bottom. In the bottom right corner, there are several overlapping, curved white and light blue shapes that suggest a rising sun or a stylized horizon.

*Advocacy for those affected  
by Cancer*

Ian Roos

Chair

Cancer Voices Victoria

*“Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place”*

*Susan Sontag, **Illness as Metaphor***

# The Patient Journey

*Learning*



*Meaning*

*Identity*



# The Expertise of Consumers

## Patients

- experience of illness
- social circumstances
- attitude to risk
- habits and behaviours
- values
- preferences

## Clinicians

- diagnosis of disease
- etiology
- prognosis
- treatment options
- preventative strategies
- outcome probabilities

*“Both types of knowledge are needed to manage illness successfully”*

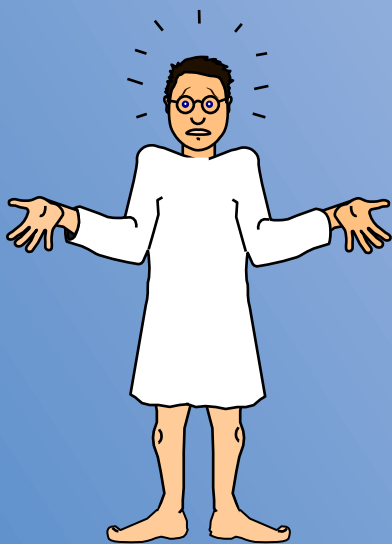
*Coulter A (2002) Qual & Safety in Health Care 11:2, 186-188*

# Why Involve Consumers?

***"when patients become co-equal with care providers in controlling care, making decisions, and treating themselves with coaching..... outcomes improve, costs fall, satisfaction rises, and even physiological measures look better."***

Don Berwick - Professor of Health Care Policy, Harvard Medical School  
& President Institute for Healthcare Improvement.

# Some Consumer Roles



- **As patients, carers and partners with experiences and knowledge**
- **As advisers and experts with skills developed from that experience and knowledge**
- **As partners in developing safe and coordinated cancer services**
- **As consumer advocates for improved services**

# Advocacy Networks

Specialist Cancer Groups e.g.

BCNA

PCFA

Canteen

LF

OvCA

**Cancer Council**

Cancer  
Consumer  
Advocacy

Non Cancer Specialist Groups e.g.

Continece

Stoma

Support Groups

Local Groups

Vic

NSW

Qld

WA

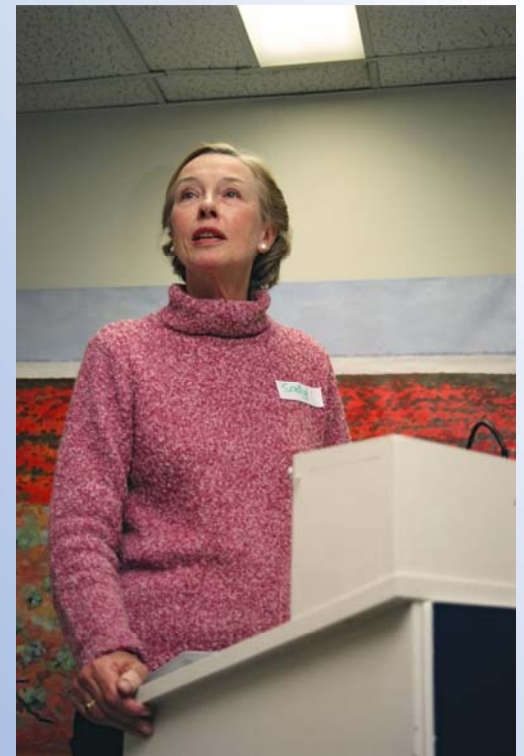
Tas

ACT

Advocacy Groups in Other States

# Cancer Voices

- Started by the MacMillan Trust in the UK [www.cancervoices.org.uk](http://www.cancervoices.org.uk)
- Cancer Voices NZ 2004  
[www.cvnz.org.nz](http://www.cvnz.org.nz)
- Cancer Voices NSW 2002  
[www.cancervoices.org.au](http://www.cancervoices.org.au)
- Cancer Voices groups now in most Australian States
- Cancer Voices Australia as a Peak Body



# Cancer Voices Victoria



- Started following an approach to Cancer Council Vic by Sue Lockwood
- CCV set up Working Group

# Cancer Voices Victoria



- Public Meeting Called June 2005
- Agreed to establish a Consumer Advocacy Group
- Steering Committee Elected

# Group Work on Issues



# CV Victoria Steering Group



Steering committee at Advocacy Training

# Early Development

- Early on identified bodies to work with
- Took part in workshops - DHS reform of cancer services
- Set up a group to develop objectives
- Set up group to work on Logo
- Intensive advocacy training - HIC/DHS/CCV
- Established profile

# Early Profile

- National Education Project Steering Committee
- Representation on Ministerial Task Force
- Paper on Survivorship
- Paper on consumer views for ONJCC
- Involvement with Integrated Cancer Services - consumer advisors and tumour working groups

# Early Results

- Information needs of patients included in PMF's
- Cancer Voices seen as a source of advice from consumers - Pratt Foundation Project

# Ongoing Development

- Logo
- Brochure
- Incorporation
- Consumer Survey prepared
- Website established – [www.cancervoicesvic.org.au](http://www.cancervoicesvic.org.au)
- Newsletter in draft
- Looking forward to launch

*None of this would have been possible without the support of the Cancer Council Victoria and DHS*

# Lessons Learned

- Work as a team, not a one person band - a slower process, but more thorough
- Advocacy is not a rapid process
- Enrol others in the task
- Know what to tackle and what to send elsewhere

*Never Assume that Matters Observed are Lessons Learned*

*Bill Kricker CEO Westmead Hospital*

# Think Long Term

- First Major project - information needs
  - Information collection: we thought three months, so far it has been six!
- Breast Cancer Action Group
  - Establishing single point for funding of prostheses - took four years

# Be Prepared to Act Short Term

- A comment at a Task Force meeting - information being included as a need in PMF's
- A chance sighting of an email - submission to a Senate Enquiry
- Network, Network, Network!!



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QUESTIONS?