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# Evaluation of participation- what does it mean?

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Health Issues Centre

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# Health Issues Centre

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- ❑ Independent NGO
- ❑ Board = consumers and health professionals / researchers
- ❑ [www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)
- ❑ [www.participateinhealth.org.au](http://www.participateinhealth.org.au)
- ❑ Health Issues journal, eNews, library

# Main approaches

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## Policy

from a consumer perspective

## Research

consumer-focussed research

## Supporting consumer participation

support, information, training for providers  
and consumers

# Aims of session

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- ❑ To explore evaluation as a tool to learn more about consumer participation
  - ❑ To give some examples of evaluation of consumer participation (CP)
  - ❑ To increase understanding about the diversity of evaluation activities
  - ❑ TO ENCOURAGE US ALL TO DO MORE
  - ❑ To give some examples of consumer participation in evaluation

# Evaluation is...

- ❑ Research 'that assesses the **VALUE** of things around us, or things we do, using the same logic and sequence of steps as does ...research process...
- ❑ A more or less easily accomplished facet of our daily life
- ❑ The more we engage in regular small scale ..evaluations, the less we need...large formal evaluations..
- ❑ Key ... is to hear and voice consumer (and other end-beneficiary) issues and concerns
- ❑ Wadsworth, Evaluation on the Run, 1990

#1850  
ERwad1

# EVERYDAY EVALUATION ON THE RUN

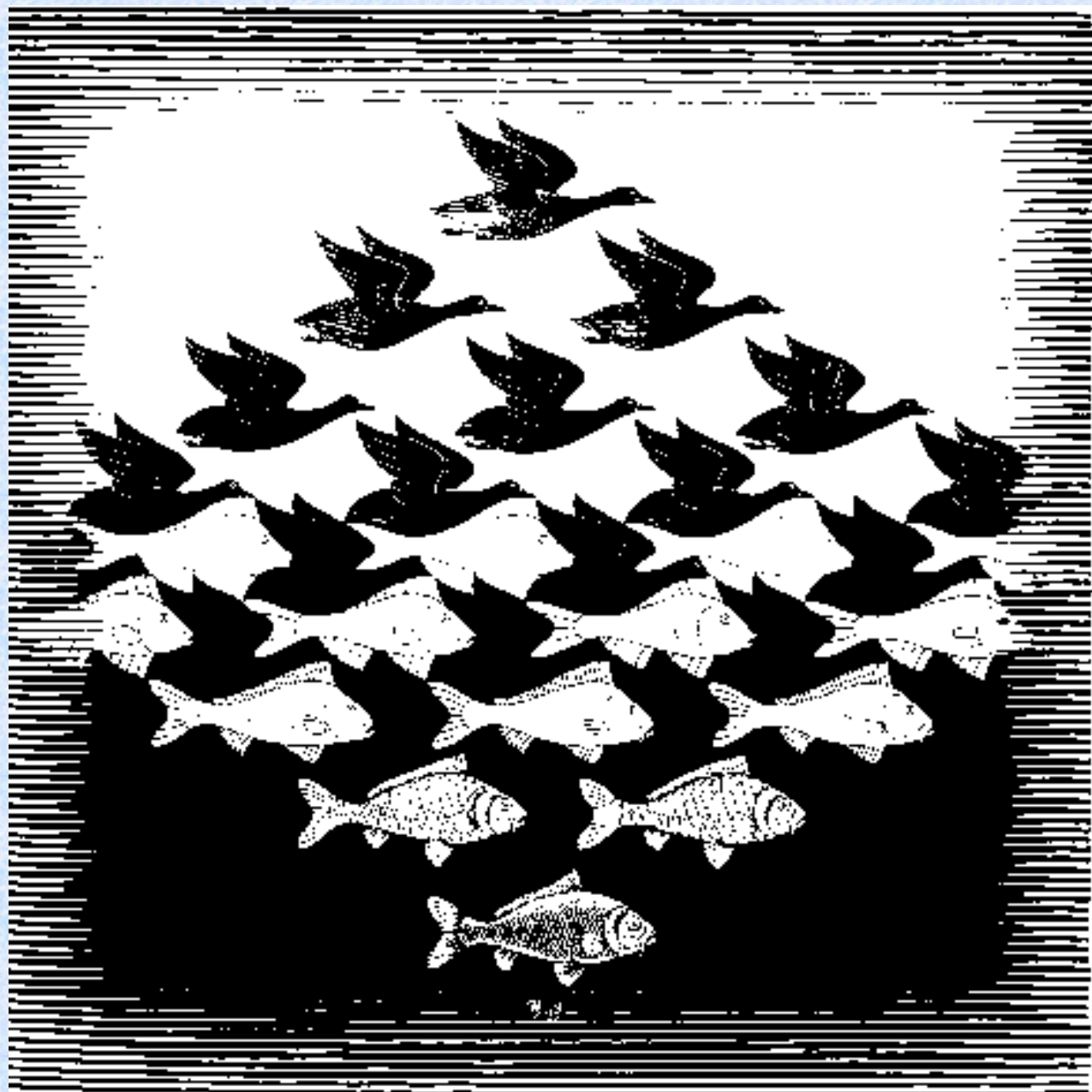
2ND EDITION

Yoland Wadsworth



ALLEN & UNWIN





# Little evaluation done to date

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- ❑ Cochrane Review (Nilsen 2006) found very little research done on consumer involvement in healthcare decisions at the population level
- ❑ Hence little evidence so far from comparative studies re effect of such participation

# Your turn

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- ❏ What are the key questions you have about evaluating consumer participation?
  - ❏ What do you want to find out?

# Common questions #1 (from health staff)

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- ❑ How can we show that participation has been worthwhile in this activity / committee / service development / project?
- ❑ What impacts did it have?
- ❑ Upon whom? In what way?
- ❑ How do we measure the effects of consumer participation on a program or across organisation? Are we using the 'right' strategies

# Common questions #2 (from health staff)

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- ❏ Are we organising / supporting our participation in the most effective way?
  - ❏ How do you make sure you have the 'right' consumers involved?
  - ❏ How do you ensure consumers are really involved in decision making?
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- ❏ How do we engage consumers in the evaluation of a project?

# Common questions #3 (from consumers)

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- ❏ What impact did my (and other consumers') involvement have on this service / project / activity?

# We will look at some common examples

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- ❑ Audit of what happening
  - ❑ Finding baseline pre-planning
- ❑ Self assessment of a committee (CAC)
- ❑ Evaluation of information development
- ❑ Evaluation of individual involvement in decision-making about own care

# Evaluation – two emphases

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- ❑ Evaluation of consumer participation
  - ❑ Eg assessment of impact of consumers being involved in development of health information
  - ❑ *(may or may not actively involve consumers)*
- ❑ vs.
- ❑ Participation of consumers in evaluation
  - ❑ consumers as partners in assessing ED processes
  - ❑ *(focus of study may not be participation)*

# Austin Health Consumer Participation Audit 2005



1. How do you engage with consumers in your area?
  - (choice of 30+ options given, eg Advisory Group / Committee, Complaints Handling etc)
2. Who is undertaking the work with consumers in your area?
  - (choice of Wards, Depts, Quality Co-ordinator etc)
3. What have you learnt from the experience of working with consumers and what changes have you put in place?
4. Did anyone attend training last year?

# CAC Self- Assessment Tool 2006

- ❑ Survey to enable CAC to self assess its processes and impacts
- ❑ Tool is simple, practical, action-oriented
- ❑ Has meaning to each CAC as its Resource Officers & consumer members identified need
- ❑ Collaborative development process, inc HIC
- ❑ 3 - 4 key questions per theme
- ❑ Tool piloted by 3 CACs
  
- ❑ Final version available to all Victorian CACs

# Questions focussed on:

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- ❑ Communication and relationship between CAC and Board/management
- ❑ Support needed by CACs
- ❑ Meeting structure and processes
- ❑ CAC relationship to the community
- ❑ Role of CAC and members' understanding of it
- ❑ **Impacts and Outcomes**

# Citizen and consumer engagement



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# Your turn again

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☐ What will this tell us?

☐ What will this NOT tell us?

# Types of evaluation

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☐ **Process**- how did we involve consumers?

☐ Did we implement strategy effectively?

☐ **Impact** –short term effects of having involved consumers?

☐ eg what impacts on system, participants

☐ **Outcomes** – long term effects?

☐ eg on service received by future consumers

# PEP 2 – Evaluation of consumer participation in information development

Austin Health, Health Issues Centre

## Phase One

- ❑ Consultation with patients re existing information about colorectal cancer care
- ❑ Focused on experiences of receiving pre-operative and discharge information
- ❑ Led to recommendations about changed content and delivery

# Phases 2 and 3

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- ❑ Development of a new package of information in partnership with consumers
- ❑ Guidelines for consumer participation in development of information across the hospital
- ❑ Evaluation of impact of the new information on patients' experiences of care
- ❑ Showed information was more relevant, useful and readable

# You again

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☐ What will this tell us?

☐ What will this NOT tell us?

# Evaluation of CP in Staff Selection Strategy at Northern Area Mental Health Service

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## Purpose of Evaluation (2003)

- ☐ Briefly describe development of strategy, etc
- ☐ Consider achievements re **goals and objectives**
- ☐ Assess effectiveness of processes
- ☐ Identify factors which may have assisted / constrained
- ☐ Consider findings .. and implications for future..

# Respecting Patient Choices

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- ☐ Advance care planning
- ☐ Evaluations of consumer experiences of implementation of processes and outcomes built into project
- ☐ Mainly interviews with consumers/carers but also providers

# What questions raised?

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- ☐ If you didn't reach goals:
  - ☐ was implementation as good as it could have been
  - ☐ were the goals the right ones (eg feasible and/or supported by staff and consumers)?

# Lots of evaluation of participation at individual level

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## Cochrane Reviews

(<http://www.cochrane.org.au/>) on

- Decision aids ( O'Connor AM 2002) found 30+ evaluations
- Audio-taped or written summaries (Scott JT 2003)
- Most studies used standard research methodologies (eg RCTs, comparative studies)

# Lots more examples at page 49 of Doing it with us, not for us

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- ☐ By different levels & for process / impact / outcome, eg
  - ☐ Check if VQC checklists for participation achieved
  - ☐ Evaluate if participation in decision-making at care level having an impact
  - ☐ Assess if consumer participation plan goals achieved

# So what can we learn from these various examples?

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- ❑ Evaluation of CP still rare – we need to do lots more
- ❑ Planning evaluation needs to happen at early stages, not towards end
- ❑ Evaluation of CP not necessarily the same as participation in evaluation



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# Things to consider

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- ❑ Planning an evaluation can help clarify goals and assumptions
- ❑ Evaluation by whom (and according to whose values)?
- ❑ Done by external or internal evaluators or both?
- ❑ We can evaluate process / impact / outcomes (mostly first two)
- ❑ Factors influencing participation

# More to think about

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- ❑ Tailored evaluation, linked to the complexity of participation
- ❑ Evaluation can take place at very different scales and foci – we need to clarify exactly what we want to assess/judge
- ❑ Structured process
- ❑ Linking evaluation to planning

# Why do it?

## does it lead to better outcomes?

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- ☑ Demonstrates its value
  - ☑ Contributes to improving how we involve consumers in the health system
  - ☑ Contributes to the long- term sustainability and success of programs

# Health Issues Centre can

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- ☐ Help you plan your evaluation
- ☐ Find audit or develop survey tools

Thank you

[www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)

[www.participateinhealth.org.au](http://www.participateinhealth.org.au)

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- ☐ Look up yolandes stuff – what can learn from her approach?
  - ☐ Cath s stuff n policy And Indicator paper
  - ☐ Look at Entwistle, Vikki (1999), *Towards Constructive Innovation And Rigorous Evaluation: A New Series On Methods For Promoting And Evaluating Participation*, in *Health Expectations*, 2, pp 75-77.