Consumer Participation – Practice Examples

This includes examples of organisations and people putting consumer participation into practice.

A "healthy" consumer/community partnership - key success factors.

Presented by Elaine Hillis at the Consumers Reforming Health Conference 2011.

A Matter of Forethought

Over the last 30 years or so, changes in the application of consumer law and health promotion have led to a more inclusive and better informed society. Though for roughly 20% of the population – those Australians with disabilities – the question is: has this social change really been effective? This article looks at the work of the Disability Advocacy and Information Service, and the regional groups its supports, in bring change to local communities.

A perspective on the patient's role in treatment decisions

Medical Care and Research Review. This article describes some of the tools currently available to help support better decisions and looks at some of the challenges to the implementation and dissemination of these efforts.

Aboriginal and Torres Strait Islander Hospital Accreditation Project Community Report

The Aboriginal and Torres Strait Islander Hospital Accreditation Project aims to obtain accurate data about the use of hospitals by Koori patients and to help develop more accessible and culturally appropriate hospital services. This report looks at the problems and successes of the project and makes suggestions for improvement.

Alice Springs Hospital: Implementing consumer feedback into a continuous quality improvement framework

Following a review of current and past research, and individual and group discussions with Aboriginal consumers and health workers, several potential tools were identified, including development of a culturally appropriate questionnaire, face to face interviews, posters, pamphlets, training sessions and presentations, and creation of an Aboriginal consumer advisory group. The ‘Alice Springs Hospital Consumer feedback questionnaire and Guide for Interviewers’ is also available from the Publications section of this website.

Bayside Health Community Advisory Committee: Making it Work
The establishment of Community Advisory Committees (CACs) within the Metropolitan Health Services in Victoria has increased the scope of hospitals' consultative processes with consumers, carers and the wider community. CACs aim to achieve a shift in culture to embed the opinions and views of consumers, carers and the community into health services' decision making and planning processes. This article records the account of one CAC's attempts to establish its role within the health service.

**Cancer Australia - Cancer Support Groups**

A guide to setting up peer-facilitated supports for peer facilitators.

**Cancer Australia consumer training and mentoring guide**

**Cancer Support Groups: a guide to setting up peer-facilitated supports and Cancer Support Groups: a guide for facilitators**

**Citizens Juries: A Model for Involving the Community in Health**

Increasingly, consumer participation in treatment decisions has become a focus of health care management. Interest is now shifting to models of participation by consumers not just as patients but as citizens with a right to participate in resource allocation and other health policy concerns. This article examines a Western Australian attempt to adapt the concept of citizens' juries as a model to broaden the range of consumers engaged in policy development in Australia.

**Cochrane Consumer Network**

Cochrane Consumer Network
This Network is an example of how consumers can participate in assessing the evidence of what really works in health interventions. Consumers throughout the world communicate via a moderated email list. The site gives examples of how consumers are contributing in a range of ways to the reviews undertaken by Cochrane Collaboration teams.

**Communities working for health and wellbeing: success stories from the Aboriginal community controlled health sector in Victoria**

The philosophy of Aboriginal community control is particularly strong in Victoria and the stories collected here represent only a small portion of the positive outcomes achieved by Victorian Aboriginal community controlled health services.

**Community Advisory Committees and their Communities of Interest**

The Victorian Department of Human Services requires public health services to set up Community Advisory Committees (CACs) which among other responsibilities, are required to obtain community views, comment on community issues and enhance community
participation. But just what is ‘The Community’ and how can CAC’s engage with ‘it’ to undertake these obligations? This paper looks at how a CAC can identify local ‘communities of interest’ through its own membership so bringing a wide range of community views to its responsibilities.

Community Engagement as Easy as ABCD

This paper describes the experiences of the South Metropolitan Public Health Unit and the City of Fremantle working with Indigenous communities to plan future actions. They used an assets-based community development (ABCD) approach called Appreciative Inquiry, to engage an Indigenous community and local services to evaluate a cultural community development program.

Paper presented at the 15th National Health Promotion Conference convened by the Australian Health Promotion Association held at the National Convention Centre, Canberra 13-16 March 2005
Leeann Murphy, Penny Kordyl, Marie Thorne

Community Participation in Action

In September 2003, Southern Health held a forum where four methods of consumer participation (written survey, discussion group, nominal technique and citizens’ jury) were used to explore community opinions on funding, providing resources, and setting priorities for public health. The forum aimed to compare decisions and ideas produced by each method to determine what was best able to produce “meaningful community input”.

Community Participation in the Design of Health Related Information

The California Wellness Guide is a health information and referral resource designed to provide information on how to stay well and where to find help on health related topics for a socially and culturally diverse population of 10 million people in the USA. This article describes how community participation played a central role in the development of the content and format of the Guide. Both the process of developing the resource and the final product suggest strategies useful to the development of health information resources in Australia.

Community Participation: A Bottom Up Approach

This article describes how the Mallee Division of General Practice developed a consumer participation strategy, which started with just nine focus groups and led to a network of ongoing groups working, and succeeding at improving health and health services over several years.
Community consultation and participation resource kit for area health service managers and project leaders

A resource kit designed to assist Area Health Service Managers and project leaders in establishing and maintaining community and consumer input into planning, policy development and service monitoring.

Community participation in action and working with the community to assess needs and develop information support on issues of Family Violence and Family Safety


Community participation in rural primary health care: intervention or approach

Published in the Australian Journal of Primary Health.

Consumer Checklist

The Victorian Clinical governance policy framework is the Department of Health’s policy on clinical governance. This checklist is a tool to assist consumers to understand how they can participate in safety and quality activities as outlined in the policy. It may be used as a guide to the roles and responsibilities that consumers have in facilitating effective implementation of the policy.

Consumer Participation Guide

The aim of this guide is to support consumers and carers participating in national advisory and reference groups of Cancer Australia.

Consumer Participation at Women’s and Children’s Health

Consumer participation at Women’s and Children’s Health (the Royal Women’s Hospital and the Royal Children’s Hospital) has been undertaken at a variety of formal and informal levels for a number of years. Participation strategies have included community consultation for service planning, community advisory committees, consumer liaison/advocate positions, development of charters of consumers’ rights and responsibilities, patient satisfaction surveys and focus groups. This article gives a snapshot of past and present consumer oriented activities at Women’s and Children’s Health, together with the findings of a survey conducted to explore staff views about consumer participation.
Consumer Participation in Cancer Research June 2010

Resources developed for the 2009-2010 project with the Victorian Cancer Agency.

Consumer Participation in Health: Translating Policy into Practice

Many health services find themselves wishing or needing to develop consumer participation programs and integrate them into their organisation’s structure. This article contains two models, the first describes how any health service could begin to develop a consumer participation program that is driven by the consumers that access its service. The other example provides greater detail of the model used by Alfred Psychiatry and two of the projects that have developed from it.

Consumer Participation in Staff Selection Strategy

At the Northern Area Mental Health Services a Consumer Participation in Staff Selection Strategy was initiated by consumers and involved the recruitment, training and participation of consumers in staff selection processes. The evaluation two years later found that it had ‘profoundly influenced the culture of the service’ (p. 6), not just in employment processes, but in terms of relationships between staff and consumers.

Consumer Participation in the Sharing Health Care Initiative Demonstration Projects

The Sharing Health Care Initiative (SHCI) is part of the Commonwealth Department of Health and Ageing Enhanced Primary Care Package of 1999-2000. Twelve demonstration projects, including five Indigenous projects were conducted. Each project focused on enhancing self-management of complex health conditions by testing and evaluating chronic condition self-management service delivery models. This article describes the lessons learnt from consumer participation in the ACT and Queensland SHCI demonstration projects.

Consumer and Community Participation in Metropolitan Health Services

This is a report of workshop held by Health Issues Centre on the 30 April 2001 that involved the Executives and Boards of the 12 Metropolitan Health Services. Issues examined include: the community’s capacity to engage; skills and competencies of organisational staff; dominant professional service culture within organisation; overall organisational ethos and culture; and dynamics of the local and national political systems.

Consumer and provider partnerships: what makes them work

Twenty-two diverse projects were conducted in all states and territories in a variety of acute and community health settings, both public and private. This report of the project highlights key elements of successful partnerships including good processes which lead to successful
outcomes. The case studies (Chapter 4) provide examples in real-life contexts and the project as a whole demonstrated some important learnings for how future funding of similar programs should be structured.

**Consumer experiences of participation in Community Advisory Committees**


**Consumer participation in Australian Divisions of General Practice: a case study**

A General Practice Division is a local network of General Practitioners. There are 123 of them across Australia. Many of these Divisions of General Practice have involved consumers and the community in the planning and implementation of their work. The case studies document the rationale for involving consumers; describe the desired outcomes of consumer involvement; the methods employed to involve consumers and the enablers and barriers to consumer participation efforts from both the Division and consumer's perspectives.

**Consumer participation in accreditation: project report**

The four pilot studies undertaken during this project provided an opportunity to demonstrate how consumers could be engaged effectively in accreditation processes either at the health facility level or as reviewers and surveyors in an accreditation team. Elements of the project included a literature search, an international survey of accreditation agencies, and interviews with consumer and provider participants in earlier accreditation studies. The report makes recommendations for achieving widespread and long-term involvement of consumers in accreditation and quality assurance processes.

**Consumer participation in healthy partnerships**

Presented by Sophy Athan at the Consumers Reforming Health Conference 2011.

**Consumer participation in sharing health care initiative project: a case study report**

Each Sharing Health Care demonstration project focuses on enhancing self-management of complex health conditions by testing and evaluating chronic disease self-management service delivery models. These case studies projects cover rural, urban and remote settings, and involve a wide range of communities including Aboriginal and Torres Strait Islander communities in Queensland and the Australian Capital Territory.
Consumer self-rated outcome measures in mental health: A report to the Mental Health Branch

A comparative analysis of the consumer self-rating outcome measures now in use in mental health services throughout Australia, identifying international best practice, and making recommendations towards a uniform national approach.

Consumer voices in clinical review


Consumers Have their Say in the Management of Hypertension

This article describes the Take the Pressure Down Project that aimed to improve health outcomes and quality of life for consumers with, or at risk of, hypertension in the Banyule and Nillumbik Shires. As part of the commitment to engaging consumers in the planning, development and delivery of this project, a Consumer Reference Group was established. The article covers the establishment of the Consumer Reference Group, the support provided and key lessons learnt from this model of consumer participation.

Consumers Improving Equity of Access to Services

Presented by Fidye Westgarth at the Consumers Reforming Health Conference 2011.

Consumers and Carers’ Experiences of the Acute Phase of Stroke Care

This project involved Health Issues Centre conducting a review of the literature surrounding consumer issues in stroke care as well as focus groups and individual interviews to provide insight into the consumer experience of stroke care at Monash Medical Centre and West Gippsland Hospital. This report contains the findings of this project.

Consumer’s Voices in Victorian Primary Care Partnerships

In 2002, the Victorian Department of Human Services commissioned Health Issues Centre to conduct the Enhancing Consumer, Carer and Community Participation in Primary Care Partnerships project. The project’s aim was to enhance the Primary Care Partnership’s (PCP) capacity to undertake effective consumer, carer and community engagement strategies. During the course of the project Health Issues Centre received a request that the voices of the consumers participating in PCPs also be heard in the project. This paper outlines the methodology and findings of a small study conducted to capture the views of consumers participating in PCPs.
Convenient Care: Consumers as Partners in Healthcare Decision-Making?

This is a video stream, with a panel discussing the issue of consumers as partners in healthcare and decision making. It is talking about health care in the US. Are health care consumers being empowered and positioned for success or manipulated and positioned for failure? How consistently and how fairly do we deliver quality care to all parts of our population?

Creating Decision Support Tools That Work

Produced by the California Healthcare Foundation. This report outlines possible ways to overcome the problems that some consumers faced when using decision aids, including the issue of low literacy and the context where the decision making process takes place.

The report outlines processes used to recruit and train community representatives, examines the complexities of consumer representation and discusses outcomes and lessons learned from the project.

Eastern Health 2010 CAC Forum Presentation

Developing a new framework at Eastern Health for consumer, carer and community engagement.

Education and training for consumer participation in health care: resource guide

The guide does not provide a formula on how to undertake education and training for consumer participation. Instead it is a guide to what other people have done with some commentary on the processes used and principles that might have underpinned those processes.

Embracing a strong consumer participation model in research at Arthritis Victoria.


Encouraging consumer demand for qualified interpreters for health appointments.


Enhancement of consumer and provider collaboration in the Metropolitan Health Service in Western Australia

This project aimed to enhance consumer participation in the four metropolitan health authorities located in Perth. Specifically the project aimed to achieve a clearer direction for
community advisory councils established by health services and hospitals. Activities of the project included interviews, focus groups and forums conducted with service providers, staff and represented and non represented consumers. The project highlighted a lack of commonality in approaches to consumer participation. Outcomes of the project included the development of a Community Advisory Council Participation Plan. The plan is included as an appendix to this report.

**Enhancing consumer participation within psychiatric nursing academia**

The aim of this consumer/provider partnership was to promote consumer participation in the education of mental health professionals through the creation of a 'consumer academic' staff position at the Centre for Psychiatric Nursing Research and Practice, University of Melbourne. This report outlines the processes through which this position was implemented, details activities undertaken by the consumer academic, and examines key learnings of the project.

**Executive Conversation Rounds incorporating a Consumer Constant Model**


**FAQ: Frequently asked questions about consumer participation in health (Illawarra Area Health Service and Illawarra Consumer Health Council)**

A question and answer approach is taken in presenting the information from the Illawarra Consumer and Provider Partnerships Project. Key to the Illawarra approach was the appointment of a Consumer Advocate whose role was to focus exclusively on the cultural change needed to develop effective working relationships between the service and the community. Relationship building occurred at many levels and the Illawarra Area Health Service now supports a number of consumer participation mechanisms, and consumers are represented on a number of consumer support groups. The model is not a static one but is continually developing.

**Getting it right: involving consumers in policy development for diabetes**

The project aimed to develop a network of consumers with diabetes who had an interest in shaping the services they use, and who could lobby for changes in service provision and support for people living with diabetes.

**Guidelines for Consumer Representatives 4th Edition**

Published by the Consumer Health Forum.
Health Advocacy Framework Queensland Health 2011

The Health Advocacy Framework: Strengthening health advocacy in Queensland aims to inform stakeholders about health advocacy and provide a framework to assess and strengthen health advocacy.

Healthy Hawkesbury: Improving accountability and responsiveness to consumers

Reports a project which aimed to enable consumers to participate in defining, evaluating and reporting on the quality of health service provision by the Hawkesbury District Health Service, NSW.

How are Community Advisory Committees meeting the 'Doing it with us not for us' Policy

19 Community Advisory Committees (CACs) across Victoria are asked to identify one objective/action in Community Participation Plans (CPP) and discuss how it relates to the priority actions and standards in 'Doing it with us not for us' Policy.

Illawarra consumer confidence mechanisms and model of consumer participation

Final report of the Illawarra Consumer and Provider Partnerships Project, a partnership between Illawarra Area Health Service and the Illawarra Consumer Health Council. The project aimed to develop consumer confidence mechanisms within the health service. See related report on this website ‘FAQ: Frequently asked questions about consumer participation in health’.

Improving health services through consumer participation: a resource guide

The guide is for people working in health care organisations who want to increase consumer participation in the planning, management and evaluation of those organisations. This is in a zip file and includes Sections 1 to 7 plus Appendices. To open a zip file you need to save the zip in your desktop and then right click to open. Each of the sections are also available separately in pdf format (see separate entries in this website).

Information series. An introduction to participation in health

Consumer participation is increasingly being linked with improvements in the quality of health care and improved health outcomes, and as a result is being encouraged by Commonwealth, State and Territory governments. This information sheet provides a brief overview including definitions, examples of consumer participation in action; benefits of consumer participation in health and what's on the horizon for consumer participation.
Information series. Key resources and tools for participation in health

Resources are listed in this information sheet according to themes including: introductory resources; resources that support consumers; resources that support health service providers; resources for self-assessment; resources in education and training; resources with a focus on hospitals and resources that help identify methods and models of participation; accreditation; consultation; resources focusing on specific groups of consumers; policy examples; practice examples and participation in research.

Information series. Methods and models of consumer participation

This information sheet provides a brief introduction to the various methods of consumer participation. This information sheet provides an overview of the various degrees of participation from participation at the level of individual health care through to participation at an organisational level.

Involving people in research

Resources and information support increased consumer and community participation in health research.

Making the best of consumer participation

Melbourne Health 2010 CAC Forum Presentation

A CAC project on accessing quality health information on the Internet.

Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review) - 2010

This is a 2010 updated Cochrane review from 2006. There is moderate quality evidence that involving consumers in the development of patient information material results in material that is more relevant, readable and understandable to patients, without affecting their anxiety. This 'consumer-informed' material can also improve patients' knowledge. There is low quality evidence that using consumer interviewers instead of staff interviewers in satisfaction surveys can have a small influence on the survey results. There is low quality evidence that an informed consent document developed with consumer input (potential trial participants) may have little if any impact on understanding compared to a consent document developed by trial investigators only. There is very low quality evidence that telephone discussions and face-to-face group meetings engage consumers better than mailed surveys in order to set priorities for community health goals. They also result in different priorities being set for these goals.
New additions March 2011 - The concept of consumer participation

Nicola Bruce 2010 CAC Forum Presentation

Consumer voices contributing towards health workforce policy and planning.

Promoting Consumer Participation Consumer Participation in Mental Health Research: in Mental Health Research: A National Workshop

The workshop were designed to provide policy perspectives on consumer participation in mental health research, background information about stakeholder views about benefits, barriers and priorities for action to promote consumer participation in research and models for active consumer involvement in research.

Queensland Health: consumer and community participation toolkit

This kit is intended for use by staff who want to increase consumer and community participation in their area of Queensland Health. This is an user-friendly, easily accessible resource which contains information, case examples, methods, tools and resources which are relevant and meaningful to their organisational context.

Real Lives Real Jobs - Developing a sustainable consumer workforce in the mental health sector.


Real lives, Real jobs – Developing good practice guidelines for a sustainable consumer workforce in the mental health sector, through participatory research.

This report summarises the finding of research conducted on consumers working in mental health or related organisations. The report includes a series of recommendations to strengthen the mental health consumer workforce.

Southern Health 2010 CAC Forum Presentation

Consumer Participation training for managers at Southern Health.

TasCOSS - HACC Client Engagement Toolkit

Tasmania Council of Social Services. 2011. HACC Model for Client Engagement – Tool Kit. Hobart. This Tool Kit was developed to support the implementation, monitoring and documentation of consumer engagement in the aged care sector.
**Telling it like it is: Project report**

This is the final report of a project designed to improve the breadth and depth of consumer input into service management. A consumer of the mental health services initiated this project.

**The Advocacy Toolkit for Consumers Queensland Health 2011**

The Advocacy Toolkit gives consumers an easy to use resource that supports better discussions with their healthcare professionals and help them to take an active role in decision-making about their own health care.

**The El Paso Collaborative Health Literacy Curriculum, 2001**

The five step model
The Five Step model is built on using learner-generated topics, information-gathering involving reading and discussion, and a learning process that engages reading, writing, speaking, listening, and critical thinking resulting in practical out-of-the-classroom English language use (action activities). Philosophically, the approach builds on whole language theory while addressing learner needs for practical instruction that works.

**The Mental Health Culturally & Linguistically Diverse Consumer Refernce Group of Victoria**

Presented by Evan Bichara at the Consumers Reforming Health Conference 2011.

**The Role of a Consumer as a Member of the Surgery Model of Care Redesign Working Group at Peninsula Health**


**The effectiveness of consumer-led training for community health staff by people living with co-occurring mental health and substance use issues.**


**Victorian good practice example- Northern Health**

One of the ways that Northern Health celebrates Community and Consumer Participation is through an annual Community Participation Week. Since 2005, five Community and Consumer Participation Weeks have been conducted which have provided a platform for staff education about consumer and community participation. This has demonstrated Northern Health’s commitment to the relevance and importance of involving consumers across the different levels of participation.
Voices heard: Queer community advise health service.


What Consumer say about consultation.

Health Issues Centre recently asked consumers on our HIC Consumer Register to reflect on their experience of being consulted. Here are some of their comments.

blueVoices - beyondbule's model of national consumer and carer participation