



CONSUMER PARTICIPATION IN CANCER RESEARCH

A consumer resource

2010

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INTRODUCTION

This consumer resource aims to be a source of information that would support the work of consumers, carers and interested community members involved in cancer research in Victoria and nationally. As such it is to be read as a REFERENCE document to be consulted on an ongoing basis.

The resource was prepared by Health Issues Centre with funding from the Victorian Cancer Agency.

The resource contains the documents and links to other resources which were provided to consumer participants of the two day Consumer Participation in Research program. The Powerpoint presentations are available as a separate document. This program was part of the Victorian Cancer Agency funded project: *Training for consumer participation in cancer research*, undertaken between February 2009 and February 2010. Fourteen consumers participated in this program delivered over two weekends in July and August 2009 in Carlton, Victoria. The program was facilitated by Health Issues Centre and delivered through 18 sessions with the participation of 14 researchers, academics and consumers involved in research in Victoria.

In addition to the material offered during the program, Health Issues Centre included new material, mainly lists of resources and up to date Web links to further reading which would support the work of consumers, carers and community members involved in cancer research.

This resource has a companion resource for researchers: this aims to support clinical and academic researchers in working collaboratively with consumers, carers and community members in Victoria.

BACKGROUND

Health care consumers know that research and evaluation activities are essential to gaining new insights and knowledge, establishing the strengths and weaknesses of programs and interventions and ultimately to improving the health system and health outcomes. Worldwide, there has been a long-term commitment to involving consumers in research because of the belief that consumers can make a valuable contribution to translational research or activities that aim to advance evidence-based practice and improve health care.^{1 2}

Consumer and community participation in these activities also ensures that research and evaluation investigate and assess issues particularly relevant to consumers and asks the questions that consumers really need answered.³ The value of consumer participation in research is highlighted in the following extract:

Consumer groups have ... funded and initiated research and contributed to their own body of research on consumers' views, experiences and health outcomes. They have put previously unrecognised or misunderstood health issues on the agenda, including conditions such as sudden infant death syndrome and Alzheimer's disease. They have successfully challenged health care practices, and played a key role in getting information about health and health care to the community. Consumer groups have worked to make health care services more responsive to individuals' needs.⁴

The National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia (CHF) in their *Model framework for consumer and community participation in health and medical research*⁵ argued that “as the end users of health and medical research, consumers can provide valuable input to decisions about research policies and practices”. The *Framework* also emphasised that if research is to continue to provide high quality outcomes, it is important that consumer and community involvement in research and its ongoing development is facilitated. Research methods and results that are open to informed public scrutiny and debate also help to ensure the integrity of research, and accountability to the community for the quality of the research.

The United Kingdom NHS Research Support Unit⁶ and Macaulay et al.⁷ proposed the following reasons to support consumer and community involvement in research and evaluation activities:

¹ Project LEAD. The National Breast Cancer Coalition Fund's premier science training course for activists has created a revolution in the world of breast cancer research and public policy.

http://www.stopbreastcancer.org/index.php?option=com_content&task=view&id=395&Itemid=162

² INVOLVE (UK). *Involve are public participation specialists, bringing institutions, communities and citizens together accelerating innovation, understanding, discussion and change. breathing new life into institutions and communities in the UK and across the world; working with senior people in government and business as well as community activists* <http://www.involve.org.uk/index.cfm?fuseaction=main.viewSection&intsectionid=368>

³ Consumers' Health Forum of Australia. 2001. A guide for consumers doing health research. Canberra

⁴ Bastian, H 1998. Speaking up for ourselves: The evolution of consumer advocacy in health care, *International Journal of Technology Assessment in Health Care*, vol. 14, no. 1.

⁵ National Health and Medical Research Council [NHMRC] and Consumers' Health Forum of Australia [CHF]. 2004. A model framework for consumer and community participation in health and medical research. Canberra. http://www.nhmrc.gov.au/publications/synopses/_files/r33.pdf

⁶ Consumers in NHS Research Support Unit. 2005. Involving consumers in research and development in the NHS: Briefing notes for researchers. pp. 5 - 6

⁷ Macaulay A, Comanda LA, Freeman WL, Gibson N, McCabe ML, Robbins CM and Twohig PL. 1999. Participatory research maximises community and lay involvement. *BMJ* 1999, Vol. 319:774-778

- Consumers can help to ensure that issues which are important to consumers and therefore to [the organisation] as a whole are identified and prioritised.
- The knowledge, expertise and resources of the involved community are often the key to successful research and/or evaluation.
- The involvement of consumers can help to ensure that money and resources aren't wasted on research that has little or no relevance.
- Consumers can help to ensure that research doesn't just measure outcomes that are identified by and considered important for professionals.
- Consumers can help with the recruitment of their peers.
- Consumers can access people who are often marginalised.
- Consumers can disseminate the results of research and work to ensure that changes are implemented.
- Results of participatory research and evaluation can have both local applicability and transferability to other communities.

Consumer and community participation in health and medical research and evaluation also plays an important role in broadening researchers' perspectives, leading to deeper understanding of issues and contextual factors. For example, consumers and/or community representatives can provide valuable information to researchers about who to [or not to] approach, community politics, issues at a community level that could impact on the research activity, as well as the most effective way to engage with members of their community. They can also provide practical advice and guidance to support implementing the research, feeding back results and disseminating project information in ways that are meaningful to consumers.

There has been very little development work for health consumers involved in research in Australia. Some training of consumers has taken place in NSW to review research proposals; that is, "to support an independent consumer review of research grant applications".⁸ The Breast Cancer Network of Australia *Seat at the Table* program delivers training for women affected by breast cancer to be actively involved in programs and policy development as consumer advocates.⁹ In March 2008, an *Involving People in Research Symposium* was held in Western Australia and organised by the School of Population Health, The University of Western Australia and the Telethon Institute for Child Health Research. The Communiqué from the Symposium called on the NHMRC and Consumers Health Forum of Australia to take this initiative forward and put the *Statement on Consumer and Community Participation in Health and Medical Research* into action.

⁸ Saunders C, Girgis A, Butow P, Crossing S and Penman A. 2008: 'From inclusion to independence – Training consumers to review research'. *Health Research Policy and Systems*, 6 (3). <http://www.health-policy-systems.com/content/6/1/3>

⁹ Breast Cancer Network Australia, *Seat at the Table*. <http://www.bcna.org.au/content/view/723/1286/>

INTRODUCING THE VICTORIAN CANCER AGENCY

This section includes a presentation by Meredith Tucker-Evans from the Victorian Cancer Agency (VCA) outlining the aims and the work undertaken by the Agency.

From this presentation there would be some key learning points including:

- That the Victorian Cancer Agency is a Victorian-based organisation which was established in 2006
- That one of the main goals of the Victorian Cancer Agency is to accelerate transfer of new discoveries into better treatment and patient care
- That the Victorian Cancer Agency funds research, including through consumer grants

Linking research and patient care

Presentation by Meredith Tucker-Evans

The Powerpoint presentation is available as a separate document.

CONSUMER PARTICIPATION

Consumer participation is understood as the process of involving health consumers in decision-making about their own health care, health service planning, policy development, research, setting priorities and addressing quality issues in the delivery of health services. (Adapted from Consumer Focus Collaboration 2001:12)*

* Consumer Focus Collaboration. 2001. *Consumer Participation in Accreditation. Resource Guide*. Commonwealth of Australia

Definitions

Several definitions are used to refer to the people affected by a health condition such as cancer. These include users of health services, consumers, patients, survivors, clients. But generic definitions also include carers, family members, relatives, meaningful others, or members of the community. Terms used throughout this document are based on the Victorian Department of Human Services' Consumer Participation Policy *Doing it with us not for us**.

Consumers are people who are current or in some contexts potential users of health services.

Carers are family and friends providing unpaid care to consumers.

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

Representatives are consumer, carer or community members who are nominated by and accountable to an organisation of consumers, carers or community members.

Nominee is the term used to describe somebody who is not an exclusive representative or has special links with a particular group or groups.

Participation 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.

*Department of Human Services 2006, *Doing it with us and not for us. Participation in your health service system 2006 – 09: Victorian consumers, carers, and the community working together with their health service and the Department of Human Services*. Victorian Government Department of Human Services, Melbourne, Victoria, Australia. p. 3-4

Definitions used by the National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia (CHF) in their *Statement on Participation*** are:

Consumer — patients and potential patients, carers, organizations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services;

Consumer representative — a member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision making process on behalf of consumers. This person is usually nominated by an organisation of consumers and is accountable to them;

Community — a group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Within this definition, it is important to recognise that different types of communities are likely to have different approaches to participation in research.

** National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2002. *Statement on consumer and community participation in health and medical research*. Canberra. p. iv

Consumer Participation Resources

Below there is a list of valuable resources for the general area of consumer participation. These will be useful for consumers starting to be involved in consumer participation in general and in consumer participation in research specifically. The Web links to these resources were updated in November 2009.

Literature review

Conceptualising consumer engagement: A review of the literature. Dr Judy Gregory 2006
http://healthpolicystudies.org.au/component/option.com_docman/task.cat_view/gid,55/Itemid,145/

Planning and implementing consumer participation
Improving health services through consumer participation – a resource guide for organisations
http://www.healthissuescentre.org.au/documents/detail.chtml?filename_num=204596

Participation Indicators – participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services
http://www.health.vic.gov.au/consumer/pubs/participation_indicators.htm

Queensland Health, 2002. Community engagement handbook.
http://www.healthissuescentre.org.au/documents/detail.chtml?filename_num=204586

Central Northern Adelaide Health Service, 2005. Community and consumer participation framework
<http://www.publications.health.sa.gov.au/cgi/viewcontent.cgi?article=1002&context=comrel>

Southern Adelaide Health Service, 2005 Community and consumer participation framework
<http://www.southernhealth.sa.gov.au/aboutus/files/pages/CommunityParticipation.pdf>

Victorian Department of Human Services, 2006 How to develop a community participation plan
http://www.health.vic.gov.au/consumer/downloads/min_guidelines.pdf

WA Health Consumer, Carer and Community Engagement Framework: for health services, hospitals and WA health following consultations across WA health, 2007
http://www.health.wa.gov.au/hrit/publications/docs/wa_health_consumer_apr07.pdf

Health Issues Centre. Paying and reimbursing consumers, carers and community members to participate. 2008

<http://www.healthissuescentre.org.au/documents/items/2008/06/211201-upload-00001.pdf>

Health Issues Centre. Getting started. Involving consumers on committees. 2008

<http://www.healthissuescentre.org.au/documents/items/2008/07/222372-upload-00001.pdf>

Engagement

Engaging Consumers in Health Policy – roundtable discussion paper, November 2005.

www.aihps.org follow the “resources” link to “roundtables”.

Community engagement handbook – for Queensland Health District Health Council members

http://www.healthissuescentre.org.au/documents/detail.chtml?filename_num=204586

Aboriginal and Torres Strait Islander Partnerships: Communicating Across Cultures

<http://www.atsip.qld.gov.au/everybodys-business/protocols-aboriginal/>

Department of Victorian Communities, Indicators of Community Strength:

Framework and Evidence, 2006

<http://www.dvc.vic.gov.au/>

[Indicators of Community Strength: a framework and evidence \(2006\)](#)

[Indicators of Community Strength: a framework and evidence \(2006\) \(PDF 515 kB\)](#)

Department of Sustainability and Environment. Effective Engagement

[http://www.dse.vic.gov.au/DSE/wcmn203.nsf/childdocs/-](http://www.dse.vic.gov.au/DSE/wcmn203.nsf/childdocs/-0B996EB412EAB883CA2570360014F01A?open)

[0B996EB412EAB883CA2570360014F01A?open](http://www.dse.vic.gov.au/DSE/wcmn203.nsf/childdocs/-0B996EB412EAB883CA2570360014F01A?open)

Urban Research Program. URP Toolbox

<https://app.secure.griffith.edu.au/03/toolbox/>

Gregory, J., Hartz-Karp, J., & Watson, R. 2008 Using deliberative techniques to engage the community in policy development: A case study

Australia and New Zealand Health Policy 2008, 5:16 doi:10.1186/1743-8462-5-16

<http://www.anzhealthpolicy.com/content/pdf/1743-8462-5-16.pdf>

Quality and safety

Helping consumers improve quality and safety. Health Issues Centre Journal, No 72,

September 2002 www.healthissuescentre.org.au Follow “journal” links.

10 Tips for Safer Health Care – what everyone needs to know www.safetyandquality.org

Better quality, better health care – a safety and quality improvement framework for Victorian

Health Services <http://www.health.vic.gov.au/qualitycouncil/pub/improve/framework.htm>

Australian Council on Health Care Standards 2006. EQuIP 4. Table of Functions, Standards and Criteria: mandatory criteria available electronically from

http://www.achs.org.au/pdf/E4A3_poster.mandcriteria.pdf (accessed 26 November 2009)

Health Issues Centre 2006. Making space for the consumer voice in quality and safety. A resource guide for community advisory committees in public health services

www.healthissuescentre.org.au

Draper, Mary 1997, *Involving Consumers in Improving Hospital Care: Lessons from Australian Hospitals*, Commonwealth Department of Health and Family Services, Canberra (available for loan from the Health Issues Centre library collection).

Recruitment

NSW Department of Health, Guidelines to Selecting Consumer and Community Representatives, www.health.nsw.gov.au/archive/cib/circulars/2003/ Click on 2003/1 (bottom of list)

Finding Consumers and Carers. A guide to sourcing consumers, carers and community members for collaborative health service improvement
<http://www.health.vic.gov.au/qualitycouncil/pub/improve/finding.htm>

Department of Human Services

These documents are available from the Department of Human Services Consumer Information and Participation Program www.health.vic.gov.au/consumer/

Community advisory committee guidelines: Victorian public health services, 2006.
<http://www.health.vic.gov.au/consumer/pubs/cacg.htm>

Participation indicators – Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services, 2005.
http://www.health.vic.gov.au/consumer/pubs/participation_indicators.htm

Doing it with us and not for us. Participation in your health service system 2006 – 09: Victorian consumers, carers, and the community working together with their health service and the Department of Human Services, 2005.
<http://www.health.vic.gov.au/consumer/participate.htm>

Quality of care report guidelines and key messages 2005 – 06.
<http://www.health.vic.gov.au/consumer/pubs/guidelines0708.htm>

How to develop a community participation plan, 2005.
<http://www.health.vic.gov.au/consumer/pubs/howto.htm>

Responding to diversity

Centre for Culture, Ethnicity and Health 2003. Diversity in Hospitals Responding to the Needs of Patients and Client Groups from non-English speaking Backgrounds Policy and Resource Guide http://www.ceh.org.au/downloads/Diversity_in_Hospitals.pdf

Centre for Culture, Ethnicity and Health 2005. Consumer Participation and Culturally and Linguistically Diverse Communities. Melbourne.
http://www.ceh.org.au/downloads/Consumer_Participation_and_CALD_Communities.pdf

Centre for Culture, Ethnicity and Health 2005. A Practical Guide to CALD Consumer Participation http://www.ceh.org.au/downloads/CALD_Consumer_Participation.pdf

Centre for Culture, Ethnicity and Health 2004. CALD Consumer Participation Strategies Matrix http://www.ceh.org.au/downloads/Consumer_matrix.pdf

Culturally and linguistically diverse population profiles for disability services
www.dhs.vic.gov.au/disability

Health Issues Centre. Consumer Participation and Culturally and Linguistically Diverse Communities: A Discussion Paper.
<http://www.healthissuescentre.org.au/documents/items/2008/04/203594-upload-00001.pdf>

A model for CALD consumer participation in mental health
<http://www.health.qld.gov.au/pahospital/qtmhc/consumer.asp> click on “report” link

The Australian Health Rights & Equal Opportunity Commissions’ website:
www.humanrights.gov.au

Victorian Office of Multicultural Affairs website: www.voma.vic.gov.au
(see document Valuing Cultural Diversity)

Victorian Government Department of Human Services website:
<http://www.health.vic.gov.au/patientcharter/resources/materials>

Australian Commission for Safety and Quality in Health Care (formerly the Australian Council for Safety and Quality in Health Care)
www.safetyandquality.gov.au

Cochrane Consumers and Communication Review Group
www.latrobe.edu.au/cochrane/

Health Issues Centre: www.healthissuescentre.org.au

Consumers Health Forum of Australia: www.chf.org.au

Picker Institute: www.pickerinstitute.org

INVOLVE: www.invo.org.uk

International Alliance for Patients' Organisations: www.patientsorganizations.org

Carers Australia: <http://www.carersaustralia.com.au>

Chronic Illness Alliance: <http://www.chronicillness.org.au>

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CONSUMER PARTICIPATION IN RESEARCH

This section includes a presentation on consumer participation in research by Dr Tere Dawson from Health Issues Centre; an annotated bibliography on consumer participation in research; a list of definitions and links about a diverse range of types of research; a list of links to where to find definitions of clinical terms and acronyms; a table with potential areas for consumer participation according to the main types of research; responses from consumers about what would strengthen the relationship between consumers and researchers; and notes and resources about consumers reviewing research proposals.

Consumer participation in research

Presentation by Dr Tere Dawson

From this presentation there would be some key learning points including:

- That there has been national and international work done on the importance of consumer participation in research
- That in Australia since early 2000 there has been national interest in this area
- That the NHMRC has a policy of consumer participation in research
- That more work needs to be done to implement government policy
- That consumers are usually involved as 'subject' of research but that they can also be involved in other aspects of the research such as setting up research agendas and being members of research teams
- That there are benefits for researchers and for consumers if consumers are involved in research

The Powerpoint presentation is available as a separate document.

Annotated bibliography on consumer participation in research

Below there is a list of articles with a brief annotation and a web link. The web links were updated in November 2009.

Consumers in NHS Research Support Unit. 2001. Getting involved in research: a guide for consumers. Available at

<http://www.healthissuescentre.org.au/documents/items/2009/11/301436-upload-00001.pdf>

This is a practical guide for members of the public who want to become actively involved, as partners, in the research process. It includes reasons to be involved in research, how being involved has made a difference, terms used in research and examples of projects that involved consumers as active participants in the research.

INVOLVE. 2004. Involving the public in NHS, public health, and social care research: briefing notes for researchers. Available at

<http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf>

This is an introductory document designed for researchers with no previous experience of involving members of the public as active partners in research. The second edition includes the more recent work of INVOLVE in the Policy Research Program.

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2002. Statement on consumer and community participation in health and medical research. Canberra. Available at

https://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/r22.pdf

The statement was developed upon recognition that consumers can make contribution to health and medical research and it is their rights to do so. It includes background of the development, a checklist of research processes, and a guide to enable consumer participation, i.e. which consumers to involve and how to overcome bias.

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2002. Summary Statement on consumer and community participation in health and medical research. Canberra.

Available at https://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/r23.pdf

This is a summary of the statement developed upon recognition that consumers can contribute to health and medical research and it is their rights to do so. It includes objectives to guide consumer participation and putting these into practice.

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. A model framework for consumer and community participation in health and medical research. Canberra.

Available at http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/r33.pdf

This model framework was developed in order to better align health and medical research with community needs and improve the impact of research. It is intended for use by research funding bodies, organizations or teams who wish to develop consumer and community participation in their work. This document comprises three parts: an overview; consumer participation in various bodies, organizations and teams; and consumer participation in decision making processes.

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. Resource pack for consumers and community participation in health and medical research. Canberra. Available at

http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/r34.pdf

This resource pack accompanies the model framework for consumer and community participation in health and medical research, and is useful for consumers and community. It contains overviews of consumer and community participation, health and medical research in Australia, clinical trials, and research team or organizations.

Saunders C, Crossing S, Girgis A and Butow P. 2007. Operationalising a model framework for consumer and community participation in health and medical research. *Australia and New Zealand Health Policy*, 4:13.

Available at <http://www.anzhealthpolicy.com/content/pdf/1743-8462-4-13.pdf>

This paper describes how a large charity organization, which funds a significant proportion of Australian cancer research, operationalised the NHMRC model framework to demonstrate that it is both possible and reasonable for research to be considerate of public values.

Saunders C, Girgis A, Butow P, Crossing S and Penman A. 2008. From inclusion to independence—training consumers to review research. *Health Research Policy and Systems*. 6:3.

Available at <http://www.health-policy-systems.com/content/pdf/1478-4505-6-3.pdf>

This article describes a process for training consumers to independently review health and medical research.

Saunders C, Girgis A, Butow P, Crossing S and Penman A. 2007. Beyond scientific rigour: Funding cancer research of public value. *Health Policy*. 84 (2):234-242.

Abstract available at [http://www.journals.elsevierhealth.com/periodicals/heap/article/S0168-8510\(07\)00117-0/abstract](http://www.journals.elsevierhealth.com/periodicals/heap/article/S0168-8510(07)00117-0/abstract)

This article is based on a qualitative study aiming to identify the values deemed by cancer consumers and community members to be important in judging research. The findings of this study clarify consumer and community values regarding cancer research funding and offer a means to evaluate research that addresses these values.

Wright D, Corner J, Hopkinson J and Foster C. 2006. Listening to the views of people affected by cancer about cancer research: An example of participatory research in setting the cancer research agenda. *Health Expectations*. 9: 3-12.

Available at <http://www.ncbi.nlm.nih.gov/pubmed/16436157>

An article about the study that explored the views people affected by cancer have about cancer research and identified their research priorities, with a broader aim of ensuring an effective participation of consumers in the design and conduct of the study. The paper concludes that participatory research offers an effective means of involving consumers throughout the research process, thus strengthening the relevance of research findings and methods.

Staniszewska S, Jones N, Newburn M and Marshall S. 2007. User involvement in the development of a research bid: Barriers, enablers and impacts. *Health Expectations*. 10: 173-183. Available at

<http://www3.interscience.wiley.com/cgi-bin/fulltext/117991753/PDFSTART>

The paper aims to involve users in the development of a research bid to examine parents' experiences of having a pre-term baby, and to examine the barriers, enablers and impacts of user involvement. It concludes that researchers need to recognize the resource implications of involvement, and user groups will need to decide whether to participate when there is the greatest chance of influencing research but little or no funding.

O'Donnell M and Entwistle V. 2004. Consumer involvement in decisions about what health-related research is funded. *Health Policy*. 70: 281-290. Abstract available at

<http://www.journals.elsevierhealth.com/periodicals/heap/article/PIIS0168851004000818/abstract>

This article addresses issues of concerns of organisations that fund research. They have a variety of reasons for involving consumers in decisions about what research is funded, but also a number of concerns about doing so—particularly about the ways in which consumer input might 'distort' the research agenda.

Paterson C. 2005. How to involve consumers in your research team. *Complementary Therapies in Medicine*. 13: 61-64 [Not available on line]

This paper aims to offer practical advice about how to involve consumers in the research process, and to illustrate this with examples from the author's own and other people's experiences.

Lockwood S. 2004. "Evidence of me" in evidence based medicine? *BMJ*. 329:1033-1035. Available at <http://www.bmj.com/cgi/content/full/329/7473/1033?ecoll>

This article discusses the issue that most of the evidence-based medicine has been written from the perspective of clinical and research communities and that virtually no evidence-based literature considers the topics from the patients' perspective.

Entwistle V, Renfrew M, Yearley S, Forrester J and Lamont T. 1998. Lay perspectives: advantages for health research. *BMJ* 316: 463-6. Available at <http://www.bmj.com/cgi/content/full/316/7129/463>

This article outlines two basic reasons for incorporating lay perspectives into research and discusses some common objections. The article offers a framework to help clarify the dimensions of lay involvement in health research.

Griffiths K, Jorm A and Christensen H. 2004. Academic consumer researchers: a bridge between consumers and researchers. *Australian and New Zealand Journal of Psychiatry*. 38 (4):191-196. Abstract available at http://www.biomedexperts.com/Abstract.bme/15038796/Academic_consumer_researchers_a_bridge_between_consumers_and_researchers

This paper describes the contributions that consumers, particularly academic consumer researchers, can make to mental health research.

Horsfall J, Cleary M, Walter G and Malins G. 2007. Challenging Conventional Practice: Placing consumers at the centre of the research enterprise. *Issues in Mental Health Nursing* 28: 1201-1213. Abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/17987477>

This article provides an overview of factors that require consideration and action for collaborative research to be successful. The authors argue that actively involving consumers and carers in mental health research may improve the quality of research and has the potential to enhance clinical outcomes.

Oliver S, Clarke-Jones L, Rees R, Milne R, Buchanan P, Gabbay J, Gyte G, Oakley A and Stein K. 2004. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. *Health Technology Assessment* 8:15. Available at <http://www.hta.ac.uk/fullmono/mon815.pdf>

This article argues that productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices and identifies the barriers to, and facilitators of, meaningful participation by consumers in research identification and prioritisation.

Trivedi P and Wykes T. 2002. From passive subjects to equal subjects. *British Journal of Psychiatry*. 181: 468-472. Available at <http://bjp.rcpsych.org/cgi/reprint/181/6/468>

This article aims to demonstrate the challenges faced by joint research projects and concludes that the involvement of the user-researcher changed the focus of the study and its design and content. More attention was paid to the intervention itself and the way in which it was delivered.

Hanley B. 2002. Working partnerships, Consumers in NHS Research 3rd Annual Report. Consumers in NHS Research Support Unit. Available at http://www.invo.org.uk/pdfs/working_partnerships.pdf

The report also includes examples of research initiatives which have actively involved consumers, and quotes from those who are actively committed to consumer involvement in health research.

Macaulay C, Commanda L, Freeman W, Gibson N, McCabe M, Robbins C and Twohig P. 1999. Participatory research maximizes community and lay involvement. *BMJ*. 319: 774-778. Available at <http://www.bmj.com/cgi/reprint/319/7212/774.pdf>

This article argues that participatory research's goals can best be met by the community and researcher collaborating in the research as equals.

Warburton J, Bartlett H, Carroll M and Kendig H. 2009. Involving older people in community-based research: Developing a guiding framework for researchers and community organizations. *Australian Journal on Ageing*. 28 (1): 41-45. Available at <http://www3.interscience.wiley.com/cgi-bin/fulltext/122210565/PDFSTART>

This paper outlines the development of a guiding framework for both researchers and community organisations seeking to involve older people in research.

Wright D, Corner J, Hopkinson J and Foster C. 2006. Listening to the views of people affected by cancer research: an example of parliamentary research in setting the cancer research agenda. *Health Expectations*. 9: 3-12. Available at <http://www3.interscience.wiley.com/cgi-bin/fulltext/118575856/PDFSTART>

This study is currently exploring the views people affected by cancer have about cancer research and identifying their research priorities. Integral to this is the broader aim of ensuring an effective, collaborative participation of patients and carers in the design and conduct of the study.

Corner J, Wright D, Hopkinson J, Gunaratnam Y, McDonald JW and Foster C. 2007. The research priorities of patients attending UK cancer treatment centres: findings from a modified group study. *British Journal of Cancer*. 96(6):875-81. Abstract available at http://www.biomedexperts.com/Abstract.bme/17342090/The_research_priorities_of_patients_ending_UK_cancer_treatment_centres_findings_from_a_modified_nominal_group_study

This paper presents the findings of the first consultation to be conducted with UK cancer patients concerning research priorities. The study adopted a participatory approach using a collaborative model that sought joint ownership of the study with people affected by cancer.

Stryker J, Wray R, Emmons K, Winer E and Demetri G. 2006. Understanding the decisions of cancer clinical trial participants to enter research studies: Factors associated with informed consent, patient satisfaction, and decisional regret. *Patient Education and Counselling*. 63: 104-109. Abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/16242898>

This paper outlines a study to understand the psychosocial outcomes related to decision-making processes of individuals eligible for participation in clinical trials. The authors show that participants who enrol in clinical trials may not fully understand the implications of trial participation and in general those who do not fully understand the implications of trial participation, or who are less satisfied with their decision to enrol in the trial, may feel regret about their decision to participate.

Lindenmeyer A, Hearnshaw H, Sturt J, Ormerod R & Aitchison G. 2007. Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: a qualitative case study. *Health Expectations*. 10: 268-277. Abstract available at <http://www.ingentaconnect.com/content/bsc/hex/2007/00000010/00000003/art00007>

This article shows the results of a project assessing the benefits of involving health-care users in diabetes research. The authors show the feasibility, acceptability and effectiveness of a longstanding, experienced, lay-led research advisory group.

Cleary M, Matheson S, Walter G, Malins G & Hunt G. 2008. Demystifying research and evidence-based practice for consumers and carers: development and evaluation of an educational package. *Issues in Mental Health Nursing*. 29: 131-143. Abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/18293221>

This paper describes an educational initiative that sought to increase consumers' and carers' understanding of the way research is conducted and its role in evidence-based practice. The study also examined participants' attitudes towards research, knowledge about research practice and participation.

Fudge N, Wolfe C & McKeivitt C. Involving older people in health research. *Age and Ageing*. 2007. 36:492–500. Available at <http://ageing.oxfordjournals.org/cgi/reprint/afm029v1>

This is a systematic review of the literature about studies that involved older people in commissioning, prioritising, designing, conducting or disseminating research. That authors conclude that factors hindering the involvement of older people in research were the same as reported factors hindering involvement of younger people, suggesting that age, per se, is not a barrier. The definition of user involvement requires clarification, and systematic evaluation of research involving older people needs to be developed.

Wyatt K, Carter M, Mahtani V, Barnard A, Hawton A & Britten N. The impact of consumer involvement in research: an evaluation of consumer involvement in the London Primary Care Studies Programme. *Family Practice*. 2008. 25(3):154-161. Available at <http://fampra.oxfordjournals.org/cgi/reprint/25/3/154>

This paper presents the results of an evaluation of consumer involvement in the LPSCP and shows that consumers had an impact in the initial design of the study, in recruitment of the research subjects, in developing data collection tools, in collecting the data, in analysis and disseminating the findings.

Beresford P. 2007. User involvement, research and health inequalities: developing new directions. *Health and Social Care in the Community*. 15: 306-312. Abstract available at <http://www3.interscience.wiley.com/journal/117968414/abstract>

This paper looks at the role that user involvement research may play in health inequalities research. It examines the pressures for and against such user involvement research, its different expressions and ideological relations, and what particular contribution it may have to offer in researching health inequalities.

Rhodes P, Nocon A, Wright J & Harrison S. 2001. Involving patients in research. Setting up a service users' advisory group. *Journal of Management in Medicine*. 15: 167-171. Available at <http://www.emeraldinsight.com/Insight/viewPDF.jsp?contentType=Article&Filename=html/Output/Published/EmeraldFullTextArticle/Pdf/0250150205.pdf>

This article describes some of the issues raised by patients' involvement in the research process. The article presents the example of a service users' advisory group established as part of a diabetes service evaluation in the north of England. The main findings are: a precise role for the group should be specified at the outset; genuine user involvement is needed; wide and accurate representation of all relevant groups in society is essential; and, researchers must approach users with open minds with a view to shared decision making rather than control.

Hubbard G, Kidd L, Donaghy E, McDonald C & Kearney N. 2007. A review of literature about involving people affected by cancer in research, policy and planning and practice. *Patient Education and Counselling*. 65: 21-23. Abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/16860517>

This article presents the results of a systematic review of the literature on involving people affected by cancer in health care research, policy and planning and practice. The authors show that the USA, the UK, followed by Canada and Australia have promoted an agenda of involvement and argue that more research is needed on the impact of involvement and relationships between rationales for involvement and implementation.

Gibbs L, Gold L, Kulkens M, Riggs E, Van Gemert C & Waters E. 2008. Are the potential benefits of a community-based participatory approach to public health research worth the potential costs. *Just Policy*. 47: 54-59. [Not available on line]

This is an article about the benefits of community-based participatory research and the authors argue that this is a worthwhile approach provided that the community understands the investment required in terms of time and in-kind support.

Telford R, Boote J & Cooper C. 2004. What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations*.7: 209-220.
Abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/15327460>

This article describes the process undertaken to obtain consensus on the principles and indicators of successful consumer involvement in NHS research.

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Types of research

This is a list of the main types of research only and does not intend to be an exhaustive list of all types of research. The list includes the most common types of research and will help consumers to familiarise themselves with the diverse types of research by providing a short definition of each type.

Applied research

Applied research is original work undertaken in order to acquire new knowledge with a specific application in view. It is undertaken either to determine possible uses for the findings of basic research or to determine new methods or ways of achieving some specific and predetermined objectives. (Australian Bureau of Statistics definition)

Adapted from Department of Health and Ageing. Viewed 17 July 2009 at [http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/\\$File/appendix06_glossary.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/$File/appendix06_glossary.pdf)

Basic research

Basic research is experimental and theoretical work undertaken primarily to acquire new knowledge without a specific application in view. It consists of pure basic research and strategic basic research. Pure basic research is carried out without looking for long-term benefits other than the advancement of knowledge. Basic research is undertaken to address fundamental questions about the biological, behavioural and social mechanisms which underlie wellness and disease.

Adapted from Department of Health and Ageing. Viewed 17 July 2009 at [http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/\\$File/appendix06_glossary.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/$File/appendix06_glossary.pdf)

Biomedical research

Biomedical research is the area of science devoted to the study of the processes of life, the prevention and treatment of disease, and the genetic and environmental factors related to disease and health.

Adapted from New Jersey Association for Biomedical Research. Biomedical research definitions. Words used to describe different kinds of biomedical research. Viewed 17 July 2009 at http://www.njabr.org/programs/research_definitions/

Clinical research

Clinical research is undertaken to find better ways of identifying and caring for people in ill health. It has a more biological orientation than health services research.

Adapted from Department of Health and Ageing. Viewed 17 July 2009 at [http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/\\$File/appendix06_glossary.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/$File/appendix06_glossary.pdf)

Epidemiology research or population research

Epidemiological research is the study of how disease is distributed in groups of people and of the factors that influence this distribution.

Adapted from U.S. Department of Health and Human Services. Consumers' Cancer Dictionary for Peer Review. National Cancer Institute. p.15. Viewed 17 July 2009 at <http://deainfo.nci.nih.gov/PeerReview/DictionaryCompleteBook.pdf>

Evaluation research

Evaluation research is a social science activity directed at collecting, analysing, interpreting, and communicating information about the workings and effectiveness of social programs.

Adapted from Rossi P, Lipsey M and Freeman H. 2004. Evaluation: A Systematic Approach, 7th ed. Thousand Oaks, CA: SAGE Publications, p.] Viewed 17 July 2009 at http://books.google.com.au/books?id=8K3Ax5s7x5oC&pg=PA2&lpg=PA2&dq=%22a+social+science+activity+directed+at+collecting%22&source=bl&ots=LI7WuuKkyN&sig=Hs2IxuGxKW1s6PlexpTvsw2ryWM&hl=en&ei=qhpgSsSNNtOZkQWEz4nbDA&sa=X&oi=book_result&ct=result&resnum=1

Health services research

Health services research is the research into health services to examine ways of improving delivery of health services, e.g. cost benefit studies of health programs. Has more operational and economic orientation than clinical research.

Adapted from Department of Health and Ageing. Viewed 17 July 2009 at [http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/\\$File/appendix06_glossary.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/$File/appendix06_glossary.pdf)

Longitudinal study

Longitudinal study is a study that follows individuals over an extended period of time, gathering data at set intervals.

Adapted from Cancer Research UK. Glossary. Viewed 26 November 2009 at <http://info.cancerresearchuk.org/utilities/glossary/?letter=Lo>

Prospective studies

Prospective study is a study in which people are divided into groups that are exposed or not exposed before any outcomes have occurred, and who are then monitored for diseases such as cancer.

Adapted from Cancer Research UK. Glossary. Viewed 26 November 2009 at <http://info.cancerresearchuk.org/utilities/glossary/?letter=Pr>

Public health research

Public health research is a type of research involving communities or populations, typically outside health care institutions. It is undertaken to identify the factors which contribute to ill-health in populations and ways of influencing these factors to prevent disease. It includes epidemiology, social and behavioural sciences, and health services research on population-based health interventions.

Adapted from Department of Health and Ageing. Viewed 17 July 2009 at [http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/\\$File/appendix06_glossary.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/8F72CFAE3493111DCA257058007A16BE/$File/appendix06_glossary.pdf)

Randomized control trial

A randomized control trial (RCT) is a study in which participants are randomly (i.e. by chance) assigned to one of two or more treatment arms or regimens of a clinical trial. Occasionally, placebos are utilized. Randomization minimizes the differences among groups by equally distributing people with particular characteristics among all the trial arms.

Adapted from U.S. Department of Health and Human Services. Consumers' Cancer Dictionary for Peer Review. National Cancer Institute. p.41. Viewed 17 July 2009 at <http://deainfo.nci.nih.gov/PeerReview/DictionaryCompleteBook.pdf>

Translational research

Translational research is research focusing on the bridge between basic laboratory research application to settings involving patients and populations.

Adapted from U.S. Department of Health and Human Services. Consumers' Cancer Dictionary for Peer Review. National Cancer Institute. p.47. Viewed 17 July 2009 at <http://deainfo.nci.nih.gov/PeerReview/DictionaryCompleteBook.pdf>

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Definitions and acronyms

Consumers involved in cancer research often come across a series of acronyms and terms that are technical. If a list of definitions is not available from the specific research area the consumer is involved in, the consumer may be able to request one from the researchers or administrative support. Below there are some useful links that have some of the most commonly used terms and acronyms in health in general and in cancer specifically.

For a comprehensive list of terms used in the health sector in Australia see Department of Health and Ageing. Glossary at (re-direction currently in place): <http://www.health.gov.au/internet/main/publishing.nsf/Content/Glossary>

For a comprehensive list of terms related to cancer see a glossary available at <http://www.cancervic.org.au/glossary/default.asp>

Questions and answers about cancer can be accessed through the Cancer Council Australia web site (FAQs) <http://www.cancer.org.au/aboutcancer/FAQ.htm>

Types of health and medical research and potential areas of consumer and community participation

The table below was developed to summarise the potential areas of involvement of consumers, carers and community members according to main types of research.

Type of research*	Key characteristics	Potential areas of consumer and community participation
Biomedical	Laboratory-based Complex Controlled experimental designs Molecular, cellular	<ul style="list-style-type: none"> ▪ ethics ▪ member of a steering committee ▪ member of the project team ▪ communicating results broadly, in ways that are meaningful to consumers and community members
Clinical research	Laboratory based and/or human subjects Controlled experimental Designs Quantitative methods	<ul style="list-style-type: none"> ▪ ethics ▪ ownership or access to human tissue samples ▪ identifying areas for further research ▪ advocacy ▪ communicating results to participants and wider community in consumer-friendly ways ▪ member of a steering committee ▪ member of the project team
Public health/ population health research	Study of communities or populations Social setting Focus on epidemiology, health promotion and prevention, social and behavioural sciences, population based health interventions Quantitative and qualitative methods	<ul style="list-style-type: none"> ▪ identifying gaps in current knowledge ▪ identifying need ▪ contributing consumer focussed research ▪ advocacy ▪ informing policy development ▪ assisting/collaborating in research processes ▪ networking support and liaison ▪ communicating results ▪ translating results into practice ▪ member of a steering committee ▪ member of the project team
Health services, health economics & social research	Study of health-related institutions, including their operation within the broader system Systems/policy focus Complex social settings Quantitative and qualitative methods	<ul style="list-style-type: none"> ▪ identifying breakdown in systems ▪ feedback about quality, relevance and appropriateness of services ▪ collaboration in research processes ▪ contributing consumer focussed research ▪ research subjects ▪ member of a steering committee ▪ member of the project team ▪ providing consumer perspective on system issues ▪ networking support and liaison ▪ advocacy ▪ communicating results ▪ implementing results

NOTE: This table was developed by Dr Barbara Beacham (Flinders University PHCRED Program) for a policy paper commissioned to Health Issues Centre and Flinders University by the Primary Health Research and Development Strategy in 2005: *Strengthening the Participation of Consumers & Community Members in Research and Evaluation: Future directions for the Australian PHCRED Strategy*. Unpublished. p.10

*Adapted from NHMRC/CHF. Resource pack for consumers and community participation in health and medical research. Investing in Australian's health. Commonwealth of Australia. December 2004. p. 15 – 16

What would strengthen consumer participation in research?

This section includes the responses from 55 consumers surveyed in 2009 about consumer participation in research. Two questions are reported below because they represent important aspects that would strengthen the collaboration between consumers and researchers.

The main points here are:

- That having a dedicated staff member to support consumer participation and training for researchers and consumers would strengthen the collaboration between consumers and researchers
- That having an ongoing and transparent communication, clear goals and objectives, and a contact person is what consumers expect from working with a research team

Q: What do you think are the elements that would strengthen the collaboration between consumers and researchers? You may select more than one.

Total responses = 53

	Response Percent	Response Count
Dedicated staff to support consumer participation	83.0%	44
Training for researchers to improve their understanding of consumer participation in research	79.2%	42
Training for consumers to improve their understanding of consumer participation in research and how to participate effectively	77.4%	41
Evidence-based information about the benefits of consumer participation in research	71.7%	38
Time and allocated funding	62.3%	33
Examples of how is this done	56.6%	30

Q: As a consumer/carer participating in research, what would you expect from the cancer research/team you work with? You may select more than one.

Total response = 55

	Response Percent	Response Count
Open and ongoing communication	90.9%	50
Clear goals and objectives of my role in the research (briefing)	89.1%	49
Access to a contact person	87.3%	48
A sense of genuine partnership	78.2%	43
User friendly paper work and documents	78.2%	43
Receive information in time	76.4%	42
A sense that I belong	67.3%	37

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Reviewing research proposals

This section includes notes taken during the discussions held with consumer participants on the consumer participation workshop session held on Sunday 16 August 2009 about their own experiences of and expectations about reviewing research proposals; and an extract from a resource produced in the UK in 2006 to support consumers reviewing research proposals.

Consumers reviewing research proposals—notes from discussion

- Systems and structures need to be in place to support consumers and carers invited to participate in reviews of research proposals
- Key questions to ask: How is it going to be done? Why is this research to be done? When? Who will do it? With whom? When, How much will it cost? So what?
- Aspects that a consumer/carer should look into when reviewing a research proposal:
 - Aims and objectives of the research proposed
 - Impact of the proposal; is it new research or is it to reinforce/prove what is already known?
 - Does the submission have a synopsis in lay language?
 - Does it have enough background?
 - Does it include a note about the track record of the researchers' competency?
 - Does the proposal fit with the research guidelines?
 - What are the benefits/outcomes to the community? Does the proposal respond to a demonstrated need and demand?
 - What will be the impact on consumers?
 - Does it have an evaluation component? Or outcome measure? How is to be achieved?
 - Is the budget clear? Is it sustainable? Is there any "in kind" funding? What is the source of funding? Is there any bias or conflict of interest? (e.g. pharmaceuticals involved?)
 - Will the project be approved by an Ethics Committee?
 - Is it safe?
 - Is it collaborative?
 - Is it based on evidence? (including international evidence)
 - Does the proposal include community involvement and/or are consumers involved in research team?
 - Is there a communication strategy to communicate findings of the research to other researchers and to the community and/or the participants of the research (e.g. consumers in a RCT)?
 - Are the methodology and research methods (research tools) appropriate and acceptable?
 - Is there quality control of the reviewers of the proposal?

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Peer reviewing research proposals guidelines (INVOLVE)

In 2006 INVOLVE, a UK-based organization which supports consumer involvement in research, published a guideline to support the involvement of the public in reviewing research proposals. The *peer reviewing research proposals guidelines* are available at http://www.invo.org.uk/pdfs/P2peer_review.pdf

1. What is peer review?

Peer reviewing is the stage in the [funding] process where a research proposal or a report of research is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. Peer reviewers might be members of the public, researchers, or other professionals. Peer review helps to check the quality of a report or research proposal.

Members of the public who act as peer reviewers may choose to comment on:

- whether the research addresses an important and relevant question
- the methods used by researchers
- the quality of public involvement in the research.

2. Why should I be interested in getting involved?

Public involvement in peer review helps to ensure that research is relevant and important to people who use it. As a member of the public you will be asked to comment on the research from your perspective or the perspective of members of the public more generally.

Your input would be valuable to the peer review process as you would be able to offer:

- knowledge and experience of a particular condition or service relevant to the research topic
- a public perspective
- views about the best ways to involve other users and carers in research.

The benefits for you personally may include:

- influencing what research is funded
- opportunities for personal development including learning new skills
- getting involved in interesting work and increasing your knowledge about a topic.

The comments [funders] receive help them to decide which research grant application(s) to fund. Commissioners and other reviewers may not have the experience and knowledge that members of the public can bring and therefore your input is especially valued.

What will I be asked to consider when peer reviewing research proposals?

[Funders] will ask you to comment on the research proposal. You do not have to comment on all aspects of a proposal.

You may be asked to make specific comments on the proposal, for example:

- whether the research question is important to you/the people you represent
- whether you feel the methods would be appropriate and acceptable to the participants
- safeguarding the public interest
- the quality of the research
- how relevant the research is to members of the public
- whether the research is likely to contribute something new or significant
- ethical issues
- whether the study is designed well
- how the research could be improved
- whether the plans for public involvement are appropriate and organised to a high standard
- the skills and experience of the researchers
- whether the research offers value for money
- potential improvement to patients quality of life
- economic costs of participation—whether the appropriate costs of involving members of the public have been outlined, for example payment for their time and expenses (including carer costs where appropriate).

You may be asked to rank or score the proposals.

Prepared by Tere Dawson

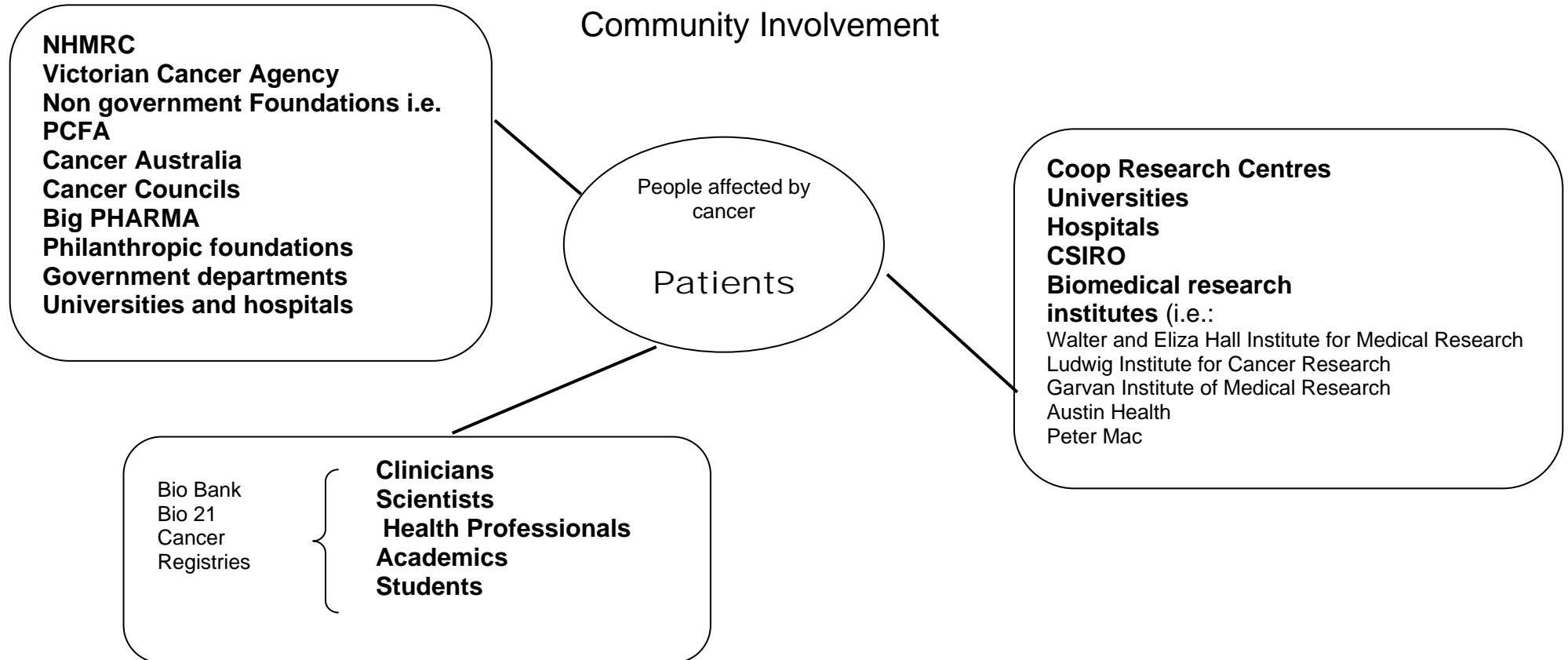
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WHAT ARE THE MAIN STAKEHOLDERS IN THE CANCER RESEARCH ARENA?

This diagram is based on the activity undertaken at the consumer participation in research workshops session facilitated by Ian Roos and Les Leckie from Cancer Voices Victoria on Saturday 25 July 2009 in Carlton, Melbourne

Community Involvement



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CANCER ORGANISATIONS AND CONTACT DETAILS

Below there is a list of Victorian, national and international cancer organisations with their contact details. This list was updated in December 2009 and contact details may need to be revised. This is not intended as an exhaustive list of cancer organisations.

Cancer Councils

<p>The Cancer Council ACT 5 Richmond Avenue Fairbairn ACT 2609 Tel: (02) 6257 9999 Fax: (02) 6257 5055 Email: reception@actcancer.org Website: www.actcancer.org</p>	<p>The Cancer Council NSW 153 Dowling Street Woolloomooloo NSW 2011 Tel: (02) 9334 1900 Fax: (02) 9358 1452 Email: feedback@nswcc.org.au Website: www.cancerCouncil.com.au</p>
<p>The Cancer Council Northern Territory Units 1-3, Casi House, Vanderlin Drive Casuarina NT 0810 Tel: (08) 8927 4888 Fax: (08) 8927 4990 Email: admin@cancernt.org.au Website: www.cancerCouncilnt.com.au</p>	<p>The Cancer Council Queensland 553 Gregory Terrace Fortitude Valley QLD 4006 Tel: (07) 3258 2200 Fax: (07) 3257 1306 Email: info@cancerqld.org.au Website: www.cancerqld.org.au</p>
<p>The Cancer Council South Australia 202 Greenhill Road Eastwood SA 5063 Tel: (08) 8291 4111 Fax: (08) 8291 4122 Email: tcc@cancersa.org.au Website: http://www.cancersa.org.au/</p>	<p>The Cancer Council Tasmania 180-184 Collins Street Hobart TAS 7000 Tel: (03) 6233 2030 Fax: (03) 6233 2123 Email: infotas@cancer.org.au Website: www.cancertas.org.au</p>
<p>The Cancer Council Victoria 1 Rathdowne Street Carlton VIC 3053 Tel: (03) 9635 5000 Fax: (03) 9635 5270 Email: enquiries@cancervic.org.au Website: http://www.cancervic.org.au</p>	<p>The Cancer Council Western Australia 46 Ventnor Avenue West Perth WA 6005 Tel: (08) 9212 4333 Fax: (08) 9212 4334 Email: inquiries@cancerwa.asn.au Website: www.cancerwa.asn.au</p>

Victorian Cancer Agency
<http://www.victoriancanceragency.org.au/Home/>

The Victorian Breast Cancer Research Consortium (VBCRC)
www.cancervic.org.au/vbcrc/

The Victorian Prostate Cancer Research Consortium (VPCRC)
www.vpcrc.org.au

The Victorian Cancer Biobank (VCB)
www.viccancerbiobank.org.au

Cancer Australia
www.canceraustralia.gov.au

Cancer Trials Australia (CTA)
www.cancertrialsaustralia.com

National Health and Medical Research Council
<http://www.nhmrc.gov.au>

NSW Cancer Institute (Cancer Institute NSW Standard Cancer Treatments)
<https://www.treatment.cancerinstitute.org.au>

National Cancer Institute. US National Institute of Health
<http://www.cancer.gov>

National Cancer Research Institute UK
<http://www.ncri.org.uk>

National Cancer Institute of Canada
<http://www.ncic.cancer.ca>

Australian Government, Cancer Australia Act, 2006, No35, 2006
[http://www.comlaw.gov.au/ComLaw/Legislation/Act1.nsf/0/C3DC6EEEDDD8C611CA2571690006919A/\\$file/035-2006.pdf](http://www.comlaw.gov.au/ComLaw/Legislation/Act1.nsf/0/C3DC6EEEDDD8C611CA2571690006919A/$file/035-2006.pdf)

The Senate. Community Affairs References Committee, June 2005. The Cancer Journey: informing choice. Report on the inquiry into services and treatment options for persons with cancer
http://wopared.parl.net/Senate/committee/clac_ctte/cancer/report/report.pdf

Australian Health Ministers' Conference, National Chronic Disease Strategy, 2005 (re-direction currently in place)
[http://www.health.gov.au/internet/wcms/publishing.nsf/Content/7E7E9140A3D3A3BCCA257140007AB32B/\\$File/stratal3.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/7E7E9140A3D3A3BCCA257140007AB32B/$File/stratal3.pdf)

Australian Health Ministers' Conference. National Service Improvement Framework for Cancer, 2005 (re-direction currently in place)
[http://www.health.gov.au/internet/wcms/publishing.nsf/Content/96C9CD63196A62ACCA25714100045165/\\$File/cancall.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/96C9CD63196A62ACCA25714100045165/$File/cancall.pdf)

Australian Lung Foundation www.lungnet.com.au

Australian Council of Stoma Associations www.australianstoma.com.au

Asthma Foundation of Australia <http://www.asthmaaustralia.org.au/>

Beyond Blue: the national depression initiative <http://www.beyondblue.org.au/>

Brain Foundation <http://www.brinaustralia.org.au/>

Brain Tumour Australia www.bta.org.au

Breast Cancer Action Group NSW www.bcagnsw.org.au

Breast Cancer Action Group VIC <http://www.bcag.org.au>

Breast Cancer Network Australia <http://www.bcna.org.au/>

BreastScreen Australia Program

<http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/breastscreen-about>

Cancer Voices Australia <http://www.cancervoicesaustralia.org.au/>

Canteen www.canteen.org.au

Guard Against Cervical Cancer <http://www.cervicalcancer.com.au/>

Gynaecological Cancer Society Queensland <http://www.gcsau.org/>

Kids Cancer Support Group <http://www.kcsg.org.au/>

Kylie Johnston Lung Cancer Network <http://www.kjlcn.org.au/> (Lung Cancer)

Leukaemia Foundation <http://www.leukaemia.org.au/>

Lions Australian Prostate Cancer Website <http://www.prostatehealth.org.au/>

Myeloma Foundation of Australia www.myeloma.org.au

My Parent's Cancer (Australia) <http://www.myparentscancer.com.au/>

National Breast Cancer Centre www.nbcc.org.au

National Ovarian Cancer Network <http://www.ovca.org.au/>

Ovarian Cancer Program <http://www.ovariancancerprogram.org.au/>

Prostate Cancer Foundation of Australia <http://www.prostate.org.au/>

Skin and Cancer foundation Australia <http://www.skin.com.au/>

Sydney Cancer Centre Foundation www.sydneycancer.com.au/

The Lymphoma Research Foundation of America <http://www.lymphoma.org/>

The Melanoma Foundation - <http://www.melanomafoundation.com.au/>

Cancer Voices

Cancer Voices Australia <http://www.cancervoicesaustralia.org.au/>

Cancer Voices New South Wales <http://www.cancervoices.org.au/>

Cancer Voices Victoria <http://www.cancervoicesvic.org.au/>

Cancer Voices Western Australia <http://www.cancerwa.asn.au/patients/cancervoices/>

Cancer Voices South Australia <http://www.cancervoicessa.org>

Cancer Voices Queensland <http://www.cancervoicesqld.org.au>

PARTICIPATORY ACTION RESEARCH

This section includes the presentation on this topic by John Kroschel, consumer advocate at Alfred Psychiatry, The Alfred Hospital, Victoria and the handout provided to participants of the consumer participation workshop held on Saturday 25 July 2009 at Carlton, Victoria. Bibliographic notes of examples of participatory action research are also included.

Participatory action research in mental health services

Essentially participatory action research (PAR) is research which involves all relevant parties in actively examining together current action (which they experience as problematic) in order to change and improve it. They do this by critically reflecting on the historical, political, cultural, economic, geographic and other contexts which make sense of it. Participatory action research (PAR) is not just research which is hoped that will be followed by action. It is action which is researched, changed and re-researched, within the research process by participants. Nor is it simply an exotic variant of consultation. Instead, it aims to be active co-research, by and for those to be helped. Nor can it be used by one group of people to get another group of people to do what is thought best for them—whether that is to implement a central policy or an organisational or service change. Instead it tries to be a genuinely democratic or non-coercive process whereby those to be helped, determine the purposes and outcomes of their own inquiry.

Wadsworth, Y. (1998)

Participatory – People who access the mental health service and people who deliver the mental health service are both participants and co-researchers

Action – Action is not just changes that are made, but also the formation of new knowledge and new understandings by both groups of people who currently hold differences of perspective of mental health service delivery and receipt.

Research – Research methodologies of triangulation of data, and test and re-test for validity checking are used. Grounded theory methodology and principles are also extensively used.

The 'Research Subject' is the service system of mental health service delivery.

Participatory action research

A group of people in coming together will form a collective identity, find common bondings by experiences, and find a common language. With any group this will happen. Sometimes some groups of people will start telling each other in the group some of their own personal histories and stories. This is a way people identify 'this is who I am, where I have come from and where I am currently at' to other people in the group. Outsiders to the group (service delivery staff, outside group facilitators or researchers) can sometimes experience this as 'the group being too negative' or 'not getting on with the tasks', or 'wasting group time'. It is an important step in the development of the 'community of interest' that must not be overlooked. The researchers are 'privileged visitors' to the group and witness (but not participate by

facilitating, directing or controlling) the group. Utmost respect for the group by researchers is paramount. The group of people, as they go through this initial 'group forming' process will be educating and teaching the researchers. The researchers learn the common language, common experiences and 'common world view' of the group.

First Action - The group decides which part or aspect of the groups common world view needs changing, altering, influencing, examining, inquiring into, researching etc. It may be the realm or facet of treatments, or the realm or facet of service delivery, or the realm or facet of research **not** yet looked at (holistic, alternatives to treatment, adjuncts to treatments, quality of life etc as opposed to treatments and clinical trials research). The group decides the topic, not the researchers.

The researchers then impart their knowledge to the group of all the possible research methodologies that could be used (focus groups, surveys, questionnaires, individual interviews, blinded trials, comparative trials, etc.). The group selects which methods will be used. The group learns about research methods from the researchers.

Research tools

Designing the research tools – The group designs the research tools, using the groups 'common language'. For example, in mental health the researchers and service staff language is 'the Acute Inpatient Unit' for describing hospital psychiatric wards; the community of interests language is 'the wards'. The use of the language of the community of interest increases participation rates in surveys, focus groups, and all other methods of research. It is also beneficial to use this language when advertising or inviting people to participate in the research.

Administration of the research tools – all members of the group receive experiential training from the researchers in the administration of the tools. All group members get to practice these skills prior to self selecting to take an opportunity to administer the tools. If there are limited opportunities for people to participate in the administering the tools in the research project (say 4 funded opportunities) and more people want to self select to take an opportunity (say 12 people) then the opportunities are rotated through all the people who are self selecting. This way everyone who wants to participate and use the skills is given the opportunity. Any other process of selection by skills or knowledge base is discriminatory and not inclusive. I have been challenged many times about the use of multiple researchers and whether this introduces an extra variable of inter-rater reliability to the research. We are not conducting psychological testing, or conducting 'observational research', we are conducting 'experiential research', that is finding out peoples' experiences. Each researcher is given the same questions to ask and sticks rigidly to asking only those questions that are part of the developed research tools. I find it quite confusing that the very same people who question the use of multiple researchers used in participatory action research are the ones who support the use of the 'clinical file' as a means of gathering longitudinal, retrospective historical clinical information when the file is written by multiple doctors and nurses making multiple entries, and the accuracy of inter-rater reliability of file entry is never questioned. The group members administer the research tools to people in the wider 'community of interest'.

Analysis of research results – The researchers provide experiential training (as for administration of research tools) to the group members. Members then self select to

being involved and conducting the analysis of results. Individuals from the group, remaining blinded from each other, conduct the analysis of the results. Their analysis is returned to the researcher who redistributes the results and analysis to each individual group member again. The process is repeated. This is similar to a 'Delphi' process where individuals with expertise in a particular field are given information from that field for comment on or for analysis. Each expert returns their information individually to a central point which then redistributes the entire information and every-one's analysis to each individual expert again. This process is repeated till either consensus is reached or for a predetermined number of times. This process builds rigour into the analysis.

The members of the group write up the research findings and present these findings.

Future work

Whilst most research ends here and the findings are presented in journals or at conferences, participatory action research is just really getting started at this stage. Remember when I previously said "The group decides which part or aspect of the group's common world view needs changing, altering, influencing, examining, inquiring into, researching etc. It may be the realm or facet of treatments, or the realm or facet of service delivery, or the realm or facet of research **not** yet looked at (holistic, alternatives to treatment, adjuncts to treatments, quality of life etc as opposed to treatments and clinical trials research)". Well this is where the research findings are presented, to the facet of the group's world view that needs changing.

The real action stage - There will be multiple discussions, planning, developing of changes to be made, etc between the group members and people from the facet of change. It might mean that new treatment services need to be supplied, or adjunctive therapies are included in treatment regimes etc.

Continuing research and documenting by the group members - The whole time this is taking place, the group members are also continuing to conduct an aspect of participatory action research. It is in researching the 'actions' that are taken as a result of the initial research, and researching how effective the initial research has been at making changes to the group's world view facet. All of this research is recorded and documented in post 'planning meeting' group discussion meetings, or in post 'development meeting' group meeting discussions. What is the response to the initial research findings? What barriers are being presented to making changes? What solutions are being presented to these barriers? What changes in attitude have occurred?

The group is also researching themselves – What new things are we learning?, What new knowledge are we gaining? What new knowledge about our world view facet do we now have that we didn't have before? How effective was our initial research at achieving the changes we wanted to make? What new knowledge do people in the 'world view facet' now have? What is the response to gaining this knowledge? How has this changed things in that facet?

The entire 'Research Project' is written and presented to the 'outside world' by members of the group. The group decides on and makes recommendations for new research methods to be used and tools to be trialled, if the necessary changes have not

been made. If they have, then the group members may select another facet of their 'world view' that they would like to research using participatory action research.

Benefits of participatory action research

Totally inclusive – Participatory action research has the maximum consumer participation in every facet of the research.

Benefits of bias – Whilst some researchers believe that bias detracts from the fidelity of the research, I would challenge the view that there is any research without bias. In participatory action research, the research is open and upfront about its inherent bias. There is bias in the language that is used, (by using the community of interest language) but this means that the people being asked any question will understand the question they are being asked, because it is in their own language. Research language and especially medical language can be a foreign language to people in the community of interest. You wouldn't ask people who speak French a question in German and expect the people to understand what they were being asked, would you?

Information given – There is also the possibility that the researchers are biased by having the same experiences as people in the community of interest. This bias enables information of a greater depth, having more meaning to people of the community of interest to be gathered. People who have had a car crash are more comfortable talking with other people who have had a car crash than they are with people who haven't had a car crash, and so will give more information, knowing that they will be better understood.

Analysis – There is bias in the analysis from the perspective of people in the community of interest. This means that the analysis has the priorities from this perspective, and this is the analysis that is most important. A person who has been homeless will place a higher priority on a comment "I had to miss a meal today" made by a person who is homeless than a person from a highly affluent part of society will. To the person from a highly affluent part of society missing a meal is no big deal, because they will know where their next meals is coming from and when that will be. A person who has been homeless will understand the importance of every meal because people who are homeless do not know where their next meal is coming from or when that will be—today, tomorrow, next week.

PAR is upfront and discloses its bias – How many research projects have you seen in journals, where there has been some form of 'interview of the research subjects' but the gender of the interviewer, or the age, or the social status or any other bias that the interviewer brings with them is not disclosed. All of these biases can and will influence the interview responses.

The primary purpose of all research is to benefit the people of the community of interest. With some research the findings are written into journal articles, these journal articles are used as reference material in the academic realm. This may influence the academic training of new service providers. New service providers may take this into the realm of working in the field. Their practice of working in the field may change as a result of their training and this may provide benefit to people in the community of interest. This whole process can be a five or ten year cycle. Participatory action research provides benefits to people in the community of interest even before

the research starts. People receive benefit from the first time a group meeting is held. The information sharing that goes on in the group provides immediate benefit, and there is the other benefit of letting other people in the group know they are not alone in their experiences. The first benefit is immediate.

Learning exchange –people in the group. The people in the group learn from each other and learn about each other and themselves. The people in the group learn from the researcher and learn about research. The people in the group learn more about the facet of their world view and learn about the people who operate in the facet of their world view.

Learning exchange –researcher. The researcher learns more about the community of interest by being amongst the group members, than they would by just administering research tools amongst people in the community of interest. It is like ‘living with people for a while’ as opposed to ‘visiting just to ask ten questions’. Researchers need to remember that to be invited into the group of people from the community of interest is a privilege. At all times respect the privilege and respect the people. The people are equal co-researchers.

Learning exchange –people in the facet of the world view of the community of interest. People in this facet will not only learn by hearing through the research from people in the community of interest, they will also learn by interacting with members of the group during the action stage.

Acknowledgement –participatory action researchers will always acknowledge all co-researchers by listing all names in all journal articles and conference presentations (unless co-researchers from the group request otherwise). We say things like ‘this is our work’ or ‘we found’ or ‘our recommendations are’. Individual researchers do not claim the work to belong to themselves using words of ‘this is my work’ or ‘I found’. Acknowledgement also means equal pay and equal opportunity. If the researcher is given the opportunity to present at a conference in England, all co-researchers deserve the same opportunity.

More info at NHMRC

Guidelines for Consumer Participation in Research

<http://www.nhmrc.gov.au/publications/synopses/r22syn.htm>

Participatory action research Presentation by Jon Kroshel

Some of the learning points of this presentation are:

- That the people who use mental health services and those who offer those services work together in research as a group
- That research is undertaken to improve or change the way things are done
- That what is researched and how it is researched is defined by the group
- That the group, including consumers, design the data collection tools, collect the data, analyse the data and disseminate the results

The Powerpoint presentation is available as a separate document.

Participatory action research examples

Below there are a few examples of participatory action research with an abstract.

Using participatory action research to build a priority setting process in a Canadian Regional Health Authority

San Patten, Craig Mitton, Cam Donaldson

Social Science & Medicine, (2006) Volume 63: 1121–1134

Abstract

Due to resource scarcity, every health system worldwide must decide what services to fund, and conversely, what services not to fund. In order to institute and refine a macro-level priority setting framework within a large, urban health authority in Alberta, Canada, researchers and decision makers together embarked on a participatory action research (PAR) project. The focus of this paper is the PAR process in this context, including reflections from PAR participants about the contribution of the research methodology to their own practice as health care managers and clinicians. The use of qualitative research in health economics—in this case, to refine the application of a macro-level priority setting model—is a relatively new advancement. PAR proved to be an appropriate and helpful approach to introducing a theoretically driven model of macro-level priority setting within a large, complex health organization. However, it is important that support for the change is sustained as long as necessary to embed the new practices into the organization.

Viewed from Science Direct on August 5th 2009

http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-4JGJJHW-2&_user=545344&_rdoc=1&_fmt=&_orig=search&_sort=d&_docanchor=&view=c&_acct=C000027898&_version=1&_urlVersion=0&_userid=545344&_md5=e277813d315d0f6dd72842ee37c348e6

Participative research in a remote Australian Aboriginal setting

Sue Kildea, Lesley Barclay, Molly Wardaguga, Margaret Dawumal

Journal of Action Research, (2009) Volume 7(2): 143–163

Abstract

This article describes the research process used to develop and evaluate an Internet-based resource aimed at improving access by health professionals to Australian Aboriginal cultural knowledge specific to pregnancy and childbirth. As a result of the research, women's stories from Maningrida were recorded and presented on the 'Birthing Business in the Bush Website' which provided a platform for Aboriginal Australian women from Maningrida to present cultural and other information to maternity care practitioners. In particular, this article describes the development of the participatory action research combined with an Aboriginal research process, and how this was guided by the Aboriginal co-researchers and participants.

Viewed from Science Direct on August 11th 2009

<http://0-arj.sagepub.com.alpha2.latrobe.edu.au/cgi/reprint/7/2/143>

Using technology and participatory action research to engage youth in health promotion

Sarah Flicker, Oonagh Maley, Andrea Ridgley, Sherry Biscope, Charlotte Lombardo, Harvey A. Skinner

Journal of Action Research, (2008) Volume 6(3): 285–303

Abstract

There is increasing interest in 'moving upstream' in youth health promotion efforts to focus on building youth self-esteem, self-efficacy and civic engagement. Participatory Action Research (PAR) can be a powerful mechanism for galvanizing youth to become active agents of this change. Engaging youth in PAR and health promotion, however, is not always an easy task. This article describes a model (e-PAR) for using technology and Participatory Action Research to engage youth in community health promotion. The e-PAR Model was developed iteratively in collaboration with 57 youth and five community partners through seven projects. The Model is designed to be used with a group of youth working with a facilitator within a youth-serving organization. In addition to outlining the theoretical basis of the e-PAR Model, this article provides an overview of how the Model was developed along with implications for practice and research.

Viewed from Science Direct on August 11th 2009

<http://0-arj.sagepub.com.alpha2.latrobe.edu.au/cgi/content/abstract/6/3/285>

Partners in Diabetes: Action research in a primary care setting

Tai J. Mendenhall, William J. Doherty

Journal of Action Research, (2008) Volume 5(4): 378–406

Abstract

Diabetes is a growing problem that threatens both individual health and health care systems throughout the industrialized world. This study analyzes the process and evolution of a collaborative project dealing with diabetes and employing action research methodology and the Citizen Health Care model. *Partners in Diabetes (PID)* was created through a democratic process among patients, families and providers in a primary care setting in the United States. Fourteen PID 'support partners' were nominated by their physicians to receive training and then reach out to other patients and families across a variety of contexts (e.g. home, clinic, telephone). We conducted qualitative analyses of detailed meeting process-notes spanning more than three years, and key-informant interviews with providers, patients and family members. We identified key developmental themes, including how providers and patients learned to overcome traditional hierarchy, how PID was designed and implemented, what challenges were encountered and what mistakes were made. Lessons for extending similar projects are highlighted.

Viewed from Science Direct on August 11th 2009

<http://0-arj.sagepub.com.alpha2.latrobe.edu.au/cgi/content/abstract/5/4/378>

Prepared by Dr Nicola Bruce

August 2009

CONSUMER PARTICIPATION ON COMMITTEES AND PRINCIPLES OF ADVOCACY

This section includes a reproduction of a Power Point presentation delivered by Ian Roos (Cancer Voices Victoria); a reproduction of a resource published in 2004 by the National Resource Centre for Consumer Participation in Health: *Consumer participation on committees*; and a list of other resources to support consumers in their work as consumer representatives on committees.

Working in a research committee as a consumer representative Presentation by Ian Roos

Some of the learning points from this presentation are:

- That it is important to know why are you participating on a committee
- That you should be aware of what roles you have in that committee
- That you should be clear if you are representing an organisation or not
- That you need to do some work before, during and after a committee meeting
- That creating partnerships is very important and that you cannot always win
- That working on a committee is hard work and that credibility is something you earn over time

The Powerpoint presentation is available as a separate document.

Information Series: consumer participation on committees



National Resource Centre for
CONSUMER PARTICIPATION in Health

On 1 September 2008 The National Resource Centre for Consumer Participation in Health (NRCCPH) closed. All resources from the NRCCPH website are now available on the Health Issues Centre website www.healthissuescentre.org.au

Purpose

This information sheet is designed to provide guidance to health services that are planning to involve consumers on committees. It explains the practical and theoretical issues involved in consumer participation on committees. It looks at the roles of health services and consumers and other issues such as resources, evaluation, and how to maximise the benefits to the health service while avoiding some common pitfalls.

Definitions

Representative

The word 'representative' is usually used in relation to consumers sitting on committees. The Consumers Health Forum, the national peak consumer organisation, uses the following definition:

*A consumer representative is a committee member who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. This person is usually nominated by, and is accountable to, an organisation of consumers.*¹

For reasons of clarity we use the overarching term 'consumers' when, in fact, we are talking about consumers, carers and communities. It is important to remember, however, that these three separate subgroups exist and may have different, even conflicting, interests.²

Context and issues

Understanding the different roles

A consumer on a committee will often but not always be there as a representative. The word 'representative' implies that the person has a constituency to which he or she is accountable.

When consumers are asked to 'represent' constituencies they must also be allowed to speak and liaise with those constituencies. Representation is impossible if committee discussions and materials are confidential.

Sometimes health services ask for representatives but are actually interested in something different. Health services may really be looking for people who will bring a different perspective (a consumer perspective) to the decision-making process. Rather than being representatives of a particular group or organisation, these kinds of consumers sit on committees as advocates or consultants. These are also important and useful roles. Consumers can have a significant part to play even when they don't have a constituency but it is important that the health service understands the difference.

Resourcing consumer participation^{3,4}

Consumer participation on committees costs money. A health service's willingness to fund consumer participation is an indication of commitment. Consumers should be compensated for sharing knowledge, experience and time. Health services should consult with the consumer members of committees about the form of compensation that best suits them.

An important area of resourcing is that of training. Consumers, through time, will develop skills in strategic questioning as part of their role on committees.^{5,6} Consumer organisations are best placed to provide training for consumer committee members but not all consumer organizations have funding to do this. Health services should budget for training from consumer trainers if needed.

Ensuring the committee is effective

The right number of consumers

Ideally there will be at least two consumers on a committee to prevent feelings of isolation and powerlessness. When consumers are asked to represent marginalised groups such as people from culturally and linguistically diverse backgrounds or parents with a disability, it is particularly important to ask several consumers to participate.

Clarity

A committee is most effective when the participants and the service provider are clear about the committee's role, authority and how the activity fits in with the service provider's broader decision-making and planning processes. It is useful to describe the role of the particular committee within the health service's overall consumer participation and consultation policy.

Openness, trust and respect

Consultation between members on a committee containing consumers should be based on openness, trust and mutual respect for the legitimacy and expertise of all participants. A committee is most effective when providers and consumers are able to see the value of each other's views and, ultimately, when all members are able to fuse consumer perspectives with health service issues to improve health services.

Planned processes

The service that is setting up the committee should include consumer input in the early stages of planning, especially around developing terms of reference and budget allocations. It is preferable, at this early stage, to enlist the help of consumer organisations or consumer consultants to inform the planning process. The checklist that follows lists other important elements in the planning process.

Managing creative tension

Consumers can have a powerful influence on the group dynamic of a committee. This effect arises from the fact that the consumer is an 'outsider' or 'other' and symbolises the committee's accountability to a wider constituency than is ordinarily present at the meeting. The influence on the group dynamic can be one of creative tension. This is positive and arises from the push for change or reform. Far less frequently this can lead to some degree of conflict where consumers may have objectives that differ from those of the balance of the committee. It's important to remember that conflict can be productive and isn't necessarily a sign that something is wrong.

Put conflict resolution in place right from the start when committees are being established. Also, set the committee up to bring out different viewpoints for productive debate, and systematically offer debriefing opportunities to all committee members. Sometimes an expectation of representativeness is made of consumers but not made of other members of the committee. This difference in the role can lead to tension, as can critical perceptions of the consumer role (e.g. 'too sick', 'not sick enough', 'not coming from "our" service'). Such perceptions have sometimes led to conflict or alienation and have thus limited the usefulness of having a consumer voice on the committee. It is important to prepare the committee to keep listening and resist the temptation to trivialise or discount what the consumer is saying.

Evaluation

Committees need to be evaluated to ensure they are producing effective outcomes and running smoothly. The committee should have an evaluation plan to assess its processes as well as the outcomes at regular intervals during its life. The values and priorities of consumers as well as the health service should inform the evaluation. The evaluation should also seek suggestions about how to improve the committee and feedback about how to modify those aspects that limited the committee's effectiveness.

The checklist

Setting up a committee that involves consumers

Checklist for service providers

Effective processes from planning to evaluation will help consumers and health services get the most out of consumer participation on committees.

1. Defining the role of the committee and the consumer

- ▶ How does this activity fit in with the broader organisational agenda?
- ▶ How does consumer involvement in this committee fit in with the organisation's consumer participation and consultation policy?
- ▶ What will be the role of consumers on this committee?
- ▶ What is the committee's authority (e.g. to advise only, to make recommendations only but not to decide; or to make decisions, regulate, control or set standards)?

2. Recruiting

How are we going to recruit consumer participants? By:

- ▶ working with consumer organisations
- ▶ contacting local services and organisations
- ▶ consulting people who have been concerned enough to complain to a health service
- ▶ contacting people who have expressed interest in the health service previously
- ▶ advertising in local newspapers
- ▶ placing an article in the service's newsletter
- ▶ developing fliers and pamphlets on consumer participation activities
- ▶ linking with the local council
- ▶ placing a notice on the service's website and other media
- ▶ What mechanisms are in place to enable marginalised groups to be untokenistically involved?

3. Planned processes

- ▶ What are the committee's goals, timelines and terms of reference?
- ▶ How have consumers been involved in drafting the terms of reference?
- ▶ How will you staff the committee, including reporting processes and minute-taking?
- ▶ How will you orientate committee members (including consumers)?
- ▶ What are the defined lines of communication between the organisation and the committee? E.g. Is there a designated liaison person within the health service for consumer committee members?
- ▶ Has the committee drafted a process for dispute resolution?

4. Resourcing the consumer role

- ▶ What resources has the service dedicated to support the committee (including time, budget, interpreters, etc.)? Is this sufficient and if not what does the service plan to do to get some more?
- ▶ What support will be provided for consumers (training, phone, postage, secretarial support, transport, childcare)? Is there a budget to provide this? If not, what are the funding plans?
- ▶ Has the organisation determined appropriate payment rates for consumer members (i.e., consultancy rates)? Do consultancy rates reflect preparation and debriefing time as well as the time necessary to inform and consult a constituency if the consumers on the committee are being expected to be representatives?

5. Evaluation

- ▶ How is this committee going to evaluate its work? What will be the roles of consumers and/or consumer organisations in the evaluation? How often will reviews take place?

Further resources

For more information about effective committees, see the Consumer Focus Collaboration study: *Enhancement of consumer and provider collaboration in the Metropolitan Health Service in Western Australia*. The study is focused on committees; it outlines lessons learnt and makes recommendations. Available from

http://www.healthissuescentre.org.au/documents/detail.chtml?filename_num=226172

See Victorian Mental Illness Awareness Council (VMIAC), *Consumer feedback and staff–consumer communication: consumer participation program orientation and job manual*, VMIAC 1996 p.81 for a discussion of the concept of 're-triggering' and why consumers sometimes choose to become involved in services which are not the ones in which they were 'patients'.

Department of Public Health, Flinders University & South Australian Community Health Research Unit 2000, *Improving health services through consumer participation: A resource guide for organisations*, A Consumer Focus Collaboration publication, Commonwealth Department of Health and Aged Care.

Consumers Health Forum of Australia 1999, 4th edn, *Guidelines for consumer representatives: Suggestions for consumer or community representatives working on committees*, Consumers Health Forum of Australia. (Available from the Consumers Health Forum of Australia web site)

Health Issues Centre 2005, *Getting involved. A kit for consumers interested in joining the Consumer Nominee Program*. This kit provides information about Health Issues Centre's Consumer Nominee Program and how it can help consumers to use their experience, wisdom, and ideas to 'make a difference' in Victoria. It includes information, advice, tips and resources to encourage consumers to get involved.

<http://www.healthissuescentre.org.au/documents/items/2008/07/220176-upload-00001.pdf>

Health Issues Centre 2006, *Making space for the consumer voice in quality and safety. A guide for community advisory committees in Victorian Public Health Services*. This guide aims to assist CACs to understand how decisions affecting quality and safety are made in public health services so that they can provide advice on how community participation can contribute effectively to quality and safety activities.

<http://www.healthissuescentre.org.au/documents/items/2008/04/204794-upload-00001.pdf>

Health Issues Centre 2008, *Getting started. Involving consumers on committees*. This resource is specifically designed to assist health professionals and organisations to include consumers on their advisory and other committees.

<http://www.healthissuescentre.org.au/documents/items/2008/07/222372-upload-00001.pdf>

SPICE Consulting 1998, *The kit: a guide to the advocacy we choose to do. A resource kit for consumers of mental health services and family carers*, Mental Health Branch, Commonwealth Department of Health and Family Services. (Available from Mental Health Council of Australia, PO Box 174, Deakin West, ACT 2600. \$35 includes postage)

Health Consumers' Council WA 2000, *Consumer representative skills training program handbook*, Health Consumers' Council WA. (Available from Health Consumers' Council of WA, GPO Box C134, Perth, WA, 6839 or phone (08) 9221 3422)

Walker, C. and Wohlers, M. 2001, 'A model of payment to consumers, carers and community representatives', *Health Issues*, No. 68 September, pp. 18–20

http://www.healthissuescentre.org.au/documents/detail.shtml?filename_num=204585

Victorian Government Department of Human Services 2000, *Community advisory committee guidelines: non-statutory guidelines for Metropolitan health services*.

<http://www.health.vic.gov.au/consumer/downloads/cacg.pdf>

Endnotes

1. Consumers Health Forum 1999, *Guidelines for consumer representatives* 4th Edition, Consumers Health Forum, Canberra, p. 3.
2. National Centre for Consumer Participation in Health 2003, *Information series: Introduction to consumer participation in health*, La Trobe University
<http://www.healthissuescentre.org.au/documents/items/2008/09/231150-upload-00001.pdf>
3. Peavey Fran 1992, *Strategic questioning: for personal and social change*, Lismore NSW.
4. Consumers Health Forum 1999, *Guidelines for consumer representatives* 4th Edition, Consumers Health Forum, Canberra, p. 3
5. Spink, J 2001, 'To pay or not to pay that is the Question', *Health Issues Journal* No. 68
6. Walker, C & Wohlers, M 2001, 'A model of payment to consumers, carers and community representatives', *Health Issues*, No. 68 September, pp. 18–20
http://www.healthissuescentre.org.au/documents/detail.shtml?filename_num=204585

List of resources

Below there is a list of further resources that would facilitate the work of consumers as representatives on research groups or committees.

Consumers Health Forum of Australia 1999, *Guidelines for consumer representatives*, 4th edn, Consumers Health Forum of Australia, Canberra, viewed 14 Jan 2008, <http://www.chf.org.au/resources-guidelines.php>

Adelaide Central Community Health Service 2003, *The little purple book of community rep-ing. Not just a token rep Project*, 3rd edn, Adelaide Central Community Health, Adelaide, viewed 26 November 2009, <http://www.healthissuescentre.org.au/documents/items/2008/08/226726-upload-00001.pdf>

Health Issues Centre. 2005. *Getting involved. A kit for consumers interested in joining the consumer nominee program.* <http://www.healthissuescentre.org.au/documents/items/2008/07/220176-upload-00001.pdf>

Health Issues Centre. 2006. *Making space for the consumer voice in quality and safety. A resource guide for community advisory committees in public health services.* <http://www.healthissuescentre.org.au/documents/items/2008/04/204794-upload-00001.pdf>

Health Issues Centre. 2008. *Getting started. Involving consumers on committees.* <http://www.healthissuescentre.org.au/documents/items/2008/07/222372-upload-00001.pdf>

HOW ARE CANCER RESEARCH AGENDAS PRIORITISED ON THE NATIONAL LEVEL?

This section includes a presentation by Dr Cleola Anderiesz to provide an overview of the methods and ways in which cancer research agendas are prioritized in Australia.

How are cancer research agendas prioritized on the national level?

Presentation by Dr Cleola Anderiesz

Several learning points in this presentation include:

- That there are several national and state based funding organisations and also charitable organisations that give money for research
- That funding for research is limited and that funding agencies need to consider the purpose of the funding and the best outcomes for the money invested
- That setting research priorities depends on the resources available and the aims of the funding
- That Cancer Australia involves consumers in setting research agendas together with a whole range of other stakeholders including consumers

The Powerpoint presentation is available as a separate document.

HOW ARE CANCER RESEARCH PROGRAMS DECIDED AT THE STATE LEVEL?

This section contains a presentation by Ms Vicki White from the Cancer Council Victoria on the way in which cancer research programs are decided in Victoria.

How are cancer research programs decided at the state level? Presentation by Vicki White

Some learning points from this presentation are:

- That the Cancer Council Victoria conducts all types of research
- That research priorities are based on the significance of the problem, the evidence that something can be done about it and the opportunities to match the research aims with the capacity to do the research
- That some of priorities are skin cancer, tobacco control, supportive care and most recently obesity

WHAT IS EVIDENCE-BASE AND THE COCHRANE SYSTEMATIC REVIEWS?

This section includes a presentation by Dr Nicola Bruce from Health Issues Centre on the Cochrane Collaboration and the concept of evidence base and information about the Cochrane Collaboration, the Cochrane Library, the Centre for Health Communication and Participation and the Health Knowledge Network.

What is evidence-base and the Cochrane systematic reviews?

Presentation by Dr Nicola Bruce

The main learning points of this presentation are:

- That the aim of medical evidence-based research is to provide rigorous and scientific information that helps with decision making about medical treatments and procedures
- That there are several types of evidence based research
- That the Cochrane Collaboration is a group of people who collect and analyse medical evidence-based research and disseminate this information to the world
- That there is a group from Cochrane, based at La Trobe University, that focuses on reviews of interventions affecting interactions between consumers and health professionals, health services and researchers

The Cochrane Collaboration



The Cochrane Collaboration is a global network of dedicated volunteers, supported by a small staff. The Cochrane Collaboration relies on grants and donations, and does not accept conflicted funding.

The Cochrane Collaboration aims to improving health care decision-making globally, through systematic reviews of the effects of health care interventions, published in the Cochrane Library. <http://www.cochrane.org/>

The Cochrane Library

The Cochrane Library contains high-quality, independent evidence to inform health care decision-making. It includes reliable evidence from Cochrane and other systematic reviews, clinical trials, and more. Cochrane reviews contain the combined results of the world's best medical research studies, and are recognised as the gold standard in evidence-based health care.

Centre for Health Communication and Participation



Cochrane Consumers and Communication Review Group

Systematic reviews of interventions affecting interactions between consumers and health professionals, services and researchers

Health Knowledge Network

A knowledge transfer service for health communication and participation

Effectiveness Research

Producing tools, resources and systematic reviews in Victorian health priority areas.

<http://www.latrobe.edu.au/chcp/>

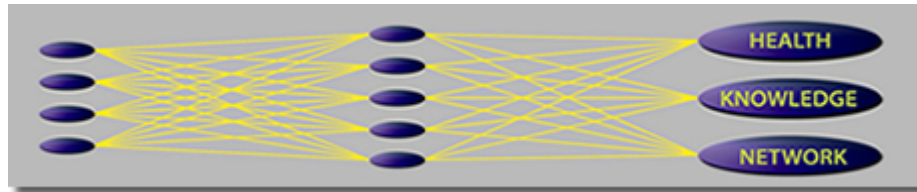
Health Knowledge Network

The Health Knowledge Network (HKN) fosters interest in, and awareness and use of effective and evidence-based strategies for consumer and carer engagement in health.

The Network's primary objectives are to:

- increase knowledge of evidence-based consumer and carer engagement among people in the Victorian health sector;
- share information on research and on practical strategies for health services to adopt in relation to good communication with patients and families about their health care;
- develop resources to assist people in the Victorian health sector to make evidence-informed decisions about people's participation in health care.

The Network provides a knowledge transfer service to consumers, professionals, researchers and policy makers in the health sphere.



Health Knowledge Network
Centre for Health Communication and Participation
Australian Institute for Primary Care, Faculty of Health Sciences
La Trobe University Victoria 3086
Australia
T: +61 (0)3 9479 5730
F: +61 (0)3 9479 5977
E: hkn@latrobe.edu.au
<http://www.latrobe.edu.au/chcp/hkn/index.html>

PRINCIPLES OF RESEARCH ETHICS, INFORMED CONSENT AND ISSUES OF CONFIDENTIALITY

This section includes two presentations: Virginia Tuckwell from the Division of Radiation Oncology of the Peter MacCallum Cancer Centre on *Principles of research ethics, informed consent and issues of confidentiality* and Jessica Faggian also from the Division of Radiation Oncology of the Peter MacCallum Cancer Centre on *Informed consent in clinical research*. A list of resources with links is also included.

Principles of research ethics, informed consent and issues of confidentiality

Presentation by Virginia Tuckwell

Some of the main learning points of this presentation are:

- That there is a series of historical events behind the development of research ethics
- That there are several codes of ethics and regulations and codes of ethics in Australia
- That the responsible bodies to regulate on ethics can be government, universities, research centres and the individual researchers themselves
- That human research ethics committees include lay people and researchers overseeing research and ensuring the protection and safety of research subjects

The Powerpoint presentation is available as a separate document.

Informed consent in clinical research

Presentation by Jessica Faggian

The main learning points from this presentation are:

- That clinical trials are studies to test the effectiveness and safety of treatments and procedures
- That there are risks and benefits of participating in a clinical trial
- That clinical trials must be approved by the Human Research Ethics Committee
- That participants in a clinical trial must give consent to participation and that participants can leave a clinical trial after it has started

The Powerpoint presentation is available as a separate document.

Further resources on ethics and privacy

Below there is a list of resources to follow up on issues related to ethics and privacy. This list was provided by Virginia Tuckwell and the web links were updated in November 2009.

Australian guidelines and regulatory bodies

1. National Statement on Ethical Conduct in Human Research (2007)
<http://www.nhmrc.gov.au/PUBLICATIONS/synopses/e72syn.htm>
2. Australian Code for the Responsible Conduct of Research
<http://www.nhmrc.gov.au/PUBLICATIONS/synopses/r39syn.htm>
3. National Health & Medical Research Council (NHMRC)
<http://www.nhmrc.gov.au/>
4. Therapeutic Goods Administration (TGA)
<http://www.tga.gov.au/>

Information on research codes of practice

5. Nuremberg Code
http://www.wesleyresearch.org.au/docs/nuremberg_code.pdf
6. Declaration of Helsinki 2008
<http://www.bioethics.org.au/Resources/Codes%20and%20Oaths/World%20Medical%20Association%20Declaration%20of%20Helsinki.pdf>
7. Belmont Report (1979)
<http://ohsr.od.nih.gov/guidelines/belmont.html>
8. The International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) Guidelines for Good Clinical Practice
<http://www.ich.org/cache/compo/276-254-1.html>
9. TGA Note for Guidance on Good Clinical Research Practice (CMPM/ICHI/135/95)
<http://www.tga.gov.au/DOCS/pdf/euguide/ich/ich13595.pdf>

Information on privacy

10. Commonwealth Privacy Acts (Privacy Act 1988)
http://austlii.law.uts.edu.au/au/legis/cth/consol_act/pa1988108/
11. National Health & Medical Research Council (NHMRC) Guidelines Approved Under Section 95A of the *Privacy Act 1988*
<http://www.nhmrc.gov.au/publications/synopses/e43syn.htm>
NHMRC Exploring what ethical research means
12. Victorian Privacy Commissioner
<http://www.privacy.vic.gov.au/>
13. Victorian Privacy Acts Information Privacy Principles
<http://www.privacy.vic.gov.au/privacy/web.nsf/content/information+privacy+principles>
14. Health Records Act Victoria 2000
http://www.dcgpa.com.au/_cms/CMS_images/resources/HPPs%20%20Summary%202001.367.doc
15. Information Privacy Act 2000
[http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubLawToday.nsf/a12f6f60fbd56800ca256de500201e54/cd652e34a04da6c2ca257505007ce686/\\$FILE/00-98a021.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubLawToday.nsf/a12f6f60fbd56800ca256de500201e54/cd652e34a04da6c2ca257505007ce686/$FILE/00-98a021.pdf)

DISSEMINATION OF RESEARCH FINDINGS AND HOW TO READ AND UNDERSTAND MEDIA REPORTS

This section includes a presentation by Annie Rahilly, the Public relations Manager at Peter MacCallum Research Centre on the importance of media for the dissemination of research findings.

Why the media matters?

Presentation by Annie Rahilly

Some of the main learning points of this presentation are:

- That media reports are useful to disseminate research findings
- That it is important to work collaboratively with the media to make the messages relevant to the public and to ensure that messages are not distorted

The Powerpoint presentation is available as a separate document.

QUALITATIVE RESEARCH METHODS AND ANALYSIS OF INFORMATION

This section includes a presentation by Robyn Faulkner from the Department of Nursing and Social Work at the University of Melbourne on qualitative research methods.

Qualitative research

Presentation by Robyn Faulkner

Some of the main learning points from this presentation include:

- Qualitative methods are used for research in the real world using a small number of people
- Qualitative research is used to enhance why interventions work, enhance the relevance of quantitative methods and to generate hypothesis
- That most analysis of qualitative data is done using words, that there are many interpretations of the data and that results cannot be made to apply to all cases, only the sample that was studied
- That qualitative methods complement quantitative methods
- Some data collection tools are observations, interviews and focus groups

The Powerpoint presentation is available as a separate document.

QUANTITATIVE RESEARCH METHODS AND ANALYSIS OF DATA

This section includes a presentation by Robyn Faulkner from the Department of Nursing and Social Work at the University of Melbourne about quantitative research methods.

Understanding quantitative research design Presentation by Robyn Faulkner

Some of the learning points from that presentation are:

- That quantitative research is logical, uses deductive reasoning and begins with an hypothesis
- That there are several sampling methods
- That there are several types of studies including case series, cross-sectional studies, case control and cohort studies
- That most analysis is based on statistical analysis (numbers)
- That there are several statistical terms such as p value, absolute risk, relative risk and 'numbers need to treat' (NNT).

The Powerpoint presentation is available as a separate document.