Consumer and Community Participation Program

Anne McKenzie and Kirsten Alpers
Acknowledgments

Many people have been involved in bringing together a report that covers 16 years of the Consumer and Community Participation Program at The University of Western Australia School of Population Health and the Telethon Kids Institute (formerly the Telethon Institute for Child Health Research). Kirsten Alpers has worked diligently and tirelessly to ensure that the information is accurate and fully reflects the comprehensive and varied aspects of the Program. Others have had roles in providing editorial advice and proof-reading:

D’Arcy Holman         Michele Kosky
Jan Payne             Emma Fuller
David Preen           Anna Kemp
Colleen Fisher        Margaret Mathews
Deborah Lehmann       Alison Carleton
Bec Hanley

Hayley Haines, Ngaire McNeil and Tammy Gibbs have worked together to create a final product we are proud of. Thanks to the many people who have willingly contributed quotes and case studies. Finally sincere thanks to the Chief Investigators of the National Health and Medical Research Council Program Grant (2010 – 2014) at the Institute: Fiona Stanley, Steve Zubrick, Carol Bower, Nick De Klerk, Helen Leonard and Sven Silburn for providing the funding for the report.

About this book
The font is set at Arial 12 point as recommended by Vision Australia.
Acronyms have been avoided with the exception of the following:

NHMRC        National Health and Medical Research Council
WA           Western Australia
UWA          The University of Western Australia
UK           United Kingdom
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It is pleasing that a report detailing and describing the activities and achievements of the Consumer and Community Participation Program (the Program), developed and hosted jointly by the School of Population Health at UWA and the Telethon Kids Institute (formerly Telethon Institute for Child Health Research) has been produced. Those who proposed, developed and grew the Program are to be congratulated for their vision. The passion for inclusionary research practices of those who currently work for the Program, or have done so in the past, is also integral to its growth.

At one level, this report is a showcase of the commitment of the two organisations to the involvement of consumers and community members in health-related research. This involvement is evident through the impressive scope and breadth of Program activities documented in the report. The report also acts as an historical record, and will be available in perpetuity for those seeking to replicate or learn from its successful development.

The purpose of this report primarily is to enable evaluation of the Program. Clearly demonstrating its utility is an important next step in the ongoing evolution and development of the Program. To this end, the report provides a comprehensive document from which activities can be evaluated - at least at two levels. Firstly, the report provides documentation through which the impact and value of the Program to the School of Population Health and Telethon Kids Institute can begin to be assessed. Additionally, it enables assessment of its impact and value to researchers, the community and collaborations outside of these organisations. As such, the report has saliency to a number of other organisations locally, nationally and internationally.

Community and consumer participation in research is a rapidly developing area and one in which individuals and groups have a vested interest. Evaluation of the Program has the potential to feed directly into the growing of inclusive research into the future, and hence, potentially improved outcomes for consumers and communities.
FOREWORD

Carol Bower

Given that health research is funded by public money and is conducted ultimately for the benefit of the population as a whole, involving consumers and the community at every stage of the research seems absolutely the right thing to do. While ‘being the right thing to do’ is sufficient reason to involve consumers and the community, it is also the right thing to do to evaluate whether and how and in what ways that involvement affects the value of the research. It is also important to assess the value of consumer and community participation to organisations and to consumers and community members themselves.

This report is the first step in a process to do just that. The report charts the history of the Consumer and Community Participation Program at The UWA School of Population Health and at the Telethon Kids Institute over more than a decade. In addition, the report describes methods that influenced how researchers have come to consider it second nature to work alongside consumers and the community. The influence of the work of the Program has spread beyond the two institutions and the state of Western Australia, resulting in national and international recognition.

The NHMRC Program Grant at the Institute funded, in part, the development of the Participation Program during the past five years, and I count it the best among many achievements of the Program Grant. Anne McKenzie and her small team have done us proud and it is gratifying to see their hard work and successes documented so clearly in this report. It is now important that we capitalise on these achievements and ensure that the participation of consumers and the community in research continues to grow and evolve and that researchers are guided and supported to work in partnership with them.

Professor Carol Bower
Research Fellow
Telethon Kids Institute, December 2014
## SUMMARY OF PROGRAM OUTPUTS
### 1998 - JULY 2014

### PUBLICATIONS & RESOURCES
- 27 journal articles and published reports
- 2 book sections
- 2 editions of the Green Book
- 1 Fact Sheet series
- 1 Prospectus
- 4 Network newsletters
- 1 Website

### TRAINING WORKSHOPS FOR CONSUMERS
- **2** national with 39 attendees
- **9** local with 188 attendees

### TRAINING WORKSHOPS FOR RESEARCHERS
- **13** national with 204 attendees
- **16** local with 310 attendees

### FORUMS, WORKSHOPS AND COMMUNITY CONVERSATIONS
- **57** held with 1263 attendees

### PRESENTATIONS
- **23** international
- **36** national
- **22** local
- Lectures & tutorials

### GRANT INVOLVEMENT
- **1** international
- **15** national
- **6** local

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### TRAINING WORKSHOPS FOR CONSUMERS

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<td>Local</td>
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### TRAINING WORKSHOPS FOR RESEARCHERS

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### GRANT INVOLVEMENT

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The Consumer and Community Participation Program (the Program) was established in 1998 at The UWA School of Population Health (the School). This was a direct result of community concerns about the establishment of the Data Linkage Unit at the WA Department of Health. The Program became a joint initiative with the Telethon Kids Institute (the Institute), formerly the Telethon Institute for Child Health Research, in 2002. The Program has evolved from the efforts and commitment of senior level champions and leaders, Program staff and many consumers, community members and stakeholders since 1998.

The increased awareness of consumers, community members and researchers has resulted in the tangible and intangible outputs of the Program. Some outputs are easily quantifiable and others are not easy to measure. These include goodwill, better communication and valuable collaborations that have improved levels of respect and understanding between researchers, consumers, community members and stakeholders. There is increased awareness of the Program and its activities in the local, national and international research community.

The influence and value of the Program’s activities are reflected in quotes from consumers, community members, researchers and policy makers that are included in this report. A measure of the success of the various activities may be indicated by the increase in number and scope of the key components and

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**Figure 1: Program components and key deliverables**

![Diagram of Program components and key deliverables]
deliverables over time. Increased support for consumer and community participation in research is evident and justifiable.

The four interconnecting areas of work that were present in 1998 were community links, advocacy, education and leadership. These remain the key deliverables of the Program. In 2004 a strategic plan was developed to provide a framework for the activities of the Program. Activities performed during 1998 - 2003 were built upon and expanded in a structured way from 2004 onwards.

In 2011, a diagram showing components and key deliverables of the Program was developed by Program staff with input from UK patient and public involvement experts Bec Hanley and Philippa Yeeles. The diagram (Figure 1) illustrated all components of the Program, including four key deliverables, which have underpinned the Program since 1998, and six components that were further developed between 2004 - 2011. Figure 1 describes a focused framework for the activities that were being conducted in 2011 and for the work of the Program since then.

For the purposes of this report, we have described the foundations of the Program (1998 - 2003) separately and used the six components of the Program to organise our description of activities since 2004. Some Program activities bridge multiple components, for example advocacy and advice, training and community interaction may all contribute to a method of participation. Advice and support, networking and the development and implementation of resources are aspects of many Program activities.

The breadth of work undertaken by Program staff is illustrated in Appendix 1 by the outputs for one year, from March 2012 to March 2013, which address all components of the Program. As the Program is not a research project, research outputs are not demanded of Program staff or consumers and community members but their contributions are valued and acknowledged. Research outputs in collaboration with researchers, however, have been numerous. Some collaborations have involved the funding of and publishing of studies about consumer and community participation activities and benefits.

**Summary of Program activities**

Using the six Program components in Figure 1 to organise the descriptions of activities that took place from 2004 to July 2014 to showcase the development of Program achievements within specific focus areas. This also allows readers of the report to concentrate on their area of interest. Program activities did take place within distinct stages defined by major events such as the development of governance frameworks, the provision of funding, personnel changes and additions and increased capacity. The following is a chronological summary of important Program achievements.

**Stage one (1998 - 2003): Foundations**

- Awareness of the need for consumer and community involvement in health and medical research and the potential benefit to research projects
- Appointment in 1998 of a Consumer Liaison Officer at the School, the first position of its kind in a research institution in Australia
- Willingness to provide financial and mentoring support for the role of Consumer Liaison Officer despite scepticism and criticism from peers
Responsiveness to consumer and community concerns

Breaking down barriers and fear by establishing and building relationships, acknowledging different points of view and utilising existing communication strategies while planning for improved ones

Raising awareness and sharing knowledge through lectures at the School on consumer and community participation since 1999

The Duty to Care Project in 2001 and the survey of consumers with chronic illness

Executive endorsement in 2002 of a proposal to increase consumer and community participation at the School and the Institute followed by a joint Program funded by NHMRC Capacity Building Grant

Stage two (2004 - 2006): Development and implementation of Strategic Plan and Policy

A dedicated consumer advocate employed at the School and the Institute

Consultation in 2004 with senior administration and research staff, consumers and community members; development of a governance and policy framework

Endorsement in 2004 of the joint Consumer and Community Participation Strategic Plan at the School and the Institute

Endorsement in 2005 of the joint Consumer and Community Participation Policy at the School and the Institute

Establishment in 2006 of the Consumer and Community Advisory Councils (Councils) at the School and the Institute

Commencement in 2006 of a consultancy service to advise researchers on the inclusion of budgeted participation activities in research grant applications

The development of a range of good-practice methods for consumer and community participation

Training events relevant to participation for consumers and community representatives

Forums that brought researchers, service providers, consumers and community members together

Collaboration with UK counterparts working in the area of patient and public involvement in research

Increase in consultancy, advice, advocacy, collaborations and input into policy

Expanded consumer representative positions at state and national levels

Establishment of consumer reference groups

Stage three (2007 - 2010): Training and resource development

Ongoing support and advocacy from the Councils for researchers, consumers and the community, including input into strategic planning at the School. Development of an award to recognise good practice

Publication in 2007 of Consumer and Community Participation in Health and Medical Research: a practical guide for health and medical researchers (the ‘Green Book’)

Development and facilitation, since 2007, of training workshops for consumer and community members on basic research information
• Provision of a consultancy service for researchers during grant application periods to assist with grant sections relating to consumer and community participation
• Organisation in 2008 of the national Involving People in Research Symposium on consumer and community participation in health and medical research
• Development and facilitation of training workshops for researchers on implementing consumer and community participation, piloted in 2009
• Expansion of community forums to include community conversations from 2009
• Development in 2010 of Minimum Standards for consumer and community participation at the School and the Institute
• Expanded community and international collaborations, particularly with UK patient and public involvement advocates
• Increased undergraduate, postgraduate and Summer School teaching
• Increased invitations to speak at community forums and at state, national and international conferences
• Involvement of consumer and community groups in dissemination of research results
• Extended state, national and international consumer and community networks
• Development and implementation of a range of methods for consumer and community participation in different research projects
• A steady increase in participation activities across the School and the Institute

• Ongoing support to existing community reference groups and establishment of new groups
• Advocacy with federal agencies such as the Commonwealth Department of Health and the Therapeutic Goods Administration

Stage four (2011 - 2014): Increased capacity
• Memorandum of Understanding signed in 2011 between the School and the Institute
• Development in 2011 of the website www.involvingpeopleinresearch.org.au
• Formalisation of the Participation Network in 2012
• Development in 2011 and publication in 2012 of the Fact Sheet Series
• Audits conducted in 2013 on participation activities at the School and the Institute
• Addressing issues of sustainability with a Participation Centre Proposal and a Lotterywest grant
• Increased demand nationally for information, support and training workshops, including for the Population Health Research Network, Australian Primary Health Care Research Institute and the National Breast Cancer Foundation
• Consumer and community training workshops organised and facilitated for organisations external to the School and the Institute, including Alzheimer’s Australia, Perth North Metro Medicare Local and Better Treatments 4 Kids
• Continued support from the Councils including contribution to audits of participation activities and strategic planning at the School and the Institute
• Increased national profile of the Program, including the invitation to
join the working committee to draft the second joint NHMRC and Consumers Health Forum Statement on Consumer and Community Participation

✦ Submissions to the Strategic Review of Health and Medical Research (McKeon Review)
✦ Publicity in the media about activities of the Program
✦ Invited presentations at international conferences and new collaborations with Denmark and Canada
✦ Increased input into research projects
✦ Discussions with researchers on how to evaluate the Program and its impact on research at the School and the Institute
✦ Organisation of community conversations and forums
✦ A Community Expo organised at the School in 2013 and at the Institute in 2014
✦ Increasing international recognition of the Program as a good practice model including, in the UK, by Swansea University Health Information Research Unit and the National Institute for Health Research’s Review of Patient and Public Involvement
✦ Network News (four issues 2012 - July 2014)
✦ Media interviews and articles
✦ Prospectus: Involving the Community in Health Research
✦ Reviews of, and contributions to, national and state government policy documents
✦ Two research projects undertaken

The Program has been highly successful in influencing awareness of consumer attitudes within research. Translation of research findings (to maximise community benefit) is now recognised globally as a critical component of research development and the consumer perspective is a vital part of the process. The nucleus of the WA Program’s impact has been within the School of Population Health at UWA and the Telethon Kids Institute, but its influence on consumer-research developments has spread nationally (through training programs and committee representation) and internationally through collaboration. The gradual increase of awareness and acceptance has resulted in a cultural shift within research that will enhance population health generally.

Elizabeth Geelhoed
The School, 2015

The Consumer and Community Participation Program provided a unique opportunity to maximise the relevance and impact of research on the health of our kids, while actively involving consumers in the research. It was my privilege to be able to champion this Program and secure funds to support its expansion.

Moira Clay,
MC Consulting, Perth, 2015
CHAMPIONS AND CONTRIBUTORS

Many people have contributed to the development of the Program at a local, national and international level since 1998. Champions and contributors include people from academia, research organisations, health professions, government agencies, non-government agencies and consumer and community organisations. The following people have had significant involvement with the Program and are listed in chronological order of their initial involvement, with their current titles and affiliations.

Researchers and members of government and non-government organisations

Local

Emeritus Professor D’Arcy Holman AM, School of Population Health, UWA

Professor Fiona Stanley AC, Telethon Kids Institute

Professor Carol Bower, Telethon Kids Institute

Professor Steve Zubrick, Telethon Kids Institute

Professor Matthew Knuiman, School of Population Health, UWA

Professor Nick de Klerk, Telethon Kids Institute

Emeritus Professor Michael Hobbs, School of Population Health, UWA

Dr Garth Kendall, Curtin University

Dr David Lawrence, Telethon Kids Institute

Professor Max Bulsara, University of Notre Dame Australia

Professor James Semmens, Curtin University

Dr Emma Glasson, Telethon Kids Institute

Ms Diana Rosman, Data Linkage Branch, WA Department of Health

Professor John Finlay-Jones, Edith Cowan University

Professor David Preen, School of Population Health, UWA

Dr Jan Payne, Telethon Kids Institute

Professor Sven Silburn Menzies School of Health Research

Ms Heather D’Antoine, Menzies School of Health Research

Heather O’Malley, WA Department of Health

Ms Leanne Scott, Telethon Kids Institute

Ms Elizabeth Chester, Telethon Kids Institute
Clinical Associate Professor Deborah Lehmann AO,
Telethon Kids Institute

Dr Helen Leonard,
Telethon Kids Institute

Clinical Professor Jon Emery,
UWA and the University of Melbourne

Associate Professor Caroline Bulsara,
University of Notre Dame Australia

Associate Professor Frank Sanfilippo,
School of Population Health, UWA

Professor Angus Cook,
School of Population Health, UWA

Professor Jane Heyworth,
School of Population Health, UWA

Assistant Professor Anna Kemp,
School of Population Health, UWA

Ms Margaret Mathews,
School of Population Health, UWA

Dr Melissa O'Donnell,
Telethon Kids Institute

Professor Colleen Hayward AM,
Edith Cowan University

Dr Daniel McAullay,
Dan McAullay Consulting

Assistant Professor Peter Franklin,
School of Population Health, UWA

Professor Peter Sly,
Queensland Children’s Medical Research Institute, The University of Queensland

Ms Jenny Mountain,
School of Population Health, UWA

Adjunct Associate Professor Rachael Moorin,
School of Population Health, UWA

Professor Elizabeth Geelhoed,
School of Population Health, UWA

Mr Glenn Pearson,
Telethon Kids Institute

Dr Hannah Moore,
Telethon Kids Institute

Ms Victoria Gray,
School of Population Health, UWA

Dr Merran Smith,
Population Health Research Network

Dr Felicity Flack,
Population Health Research Network

Dr Michael Wright,
Telethon Kids Institute and Curtin University

Dr Rebecca Glauert,
Telethon Kids Institute

Professor Moira Clay,
MC Consulting Perth

Professor Ian Puddey,
Faculty of Medicine, Dentistry and Health Sciences, UWA

Professor Colleen Fisher,
School of Population Health, UWA

Associate Professor Rosemary Saunders,
School of Population Health, UWA

Professor Jonathan Carapetis,
Telethon Kids Institute

Associate Professor Tom Briffa,
School of Population Health, UWA

Ms Cecily Strange,
School of Population Health, UWA

Professor John Challis,
School of Population Health, UWA
National

Dr Norman Swan,
Australian Broadcasting Corporation Radio National

Professor Warwick Anderson AM,
National Health and Medical Research Council

Mr Mick Gooda,
Aboriginal and Torres Strait Islander Social Justice Commissioner

Mr Glen Rees AM,
Alzheimer’s Australia

Ms Geraldine McDonald,
Telehealth Strategy and Development, Department of Health Victoria

Dr Michelle Banfield,
Australian Primary Health Care Research Institute, Australian National University

Dr Robert Wells,
Australian National University and Sax Institute

Mr Chris Rathbone,
South Australia-Northern Territory Datalink

Associate Professor Terry Findlay,
Australian Primary Health Care Research Institute, Australian National University

Dr Lesley Russell,
Australian Primary Health Care Research Institute, Australian National University

Professor William Tarnow-Mordi,
The University of Sydney

Professor Jonathan Craig,
The University of Sydney

Dr Alison Butt,
National Breast Cancer Foundation

Ms Pam Smith,
Flinders University, South Australia

Dr Libby Tropp,
Cancer Council New South Wales

Ms Sally Crossing AM,
Cancer Voices New South Wales

Ms Helen Hopkins,
National Rural Health Alliance, Canberra

Mr John Stubbs,
CanSpeak Australia

Ms Carol Bennett,
Alzheimer’s Australia

Ms Liza Newby,
Health Issues Centre

Melinda Cruz,
Miracle Babies Foundation

Ms Kylie Pussell,
Miracle Babies Foundation, New South Wales

Ms Deborah Smith,
Community Council for Australia, Canberra

Ms Darlene Cox,
Health Care Consumers Association of the ACT, Canberra

International

Dr Rosemary Barber,
School of Health and Related Research, University of Sheffield

Dr Jill Thompson,
School of Nursing and Midwifery, University of Sheffield

Professor Ronan Lyons,
Health Information Research Unit, Swansea University

Professor David Ford,
Health Information Research Unit, Swansea University

Dr Kerina Jones,
Health Information Research Unit, Swansea University
Consumers and community members

Local

Ms Michele Kosky AM,
Director of MMK Consulting

Ms Karen Carey,
consumer advocate and Chair of the
NHMRC Community and Consumer
Advisory Group

Ms Ann White,
mental health consumer advocate

Ms Margaret Cook,
mental health consumer advocate

Ms Ginger Gordy,
mental health consumer advocate

Ms Jackie Softly,
Down Syndrome Australia

Mrs Barbara Daniels,
consumer advocate

Mr Ben Horgan,
Perth North Metro Medicare Local

Mr Matthew Hunt,
WA Department of Local Government and
Communities

Ms Dot Henry,
Aboriginal community member

Ms Margaret Culbong,
Aboriginal community member

Ms Kathie McLure,
Health Consumers’ Council WA

Ms Rosemary Caithness,
Health Consumers’ Council WA

Ms Maxine Drake,
consumer advocate

Ms Lorraine Powell,
mental health consumer advocate

Mr Mitch Messer,
consumer advocate

Ms Stephanie Newell,
health consumer advocate

Ms Julie Ireland,
Down Syndrome WA

Mr Bill Fox,
community member

Dr Rachel Skoss,
disability advocate

Mr Ian Hill,
community member

Ms Sara Elliot,
mental health consumer advocate

International

Ms Bec Hanley,
Co-director of TwoCan Associates UK

Ms Helen Hayes,
Knowledge and Communications Manager,
INVOLVE Coordinating Centre England

Ms Philippa Yeeles,
Director of Involvement and Engagement,
National Institute for Health Research
Central Commissioning Facility UK

Ms Maryrose Tarpey,
Assistant Director, INVOLVE Coordinating
Centre England
Past and present Council members

The Consumer and Community Advisory Councils at the School and the Institute were established in 2006. Further details are in Appendix 8.

Jan Adams
Anne Atkinson
Michelle Atkinson de Garis
Georgia Banton
Pip Brennan
Siobhan Brennan
Liz Buckton
Elizabeth Chester
Moira Clay
Robyn Coleman
Margaret Culbong
Anne Cordingley
Beatriz Cuestra-Briand
Barbara Daniels
Jenny Downs
Sara Elliot
John Finlay-Jones
Judith Finn
Colleen Fisher
Bill Fox
Belinda Frank
Sarah French
Catherine Gangell
Mike Garlepp
Elizabeth Geelhoed
Caitlin Green

Jennifer Hafekost
Melanie Hawkes
Dot Henry
Ian Hill
D’Arcy Holman
Ben Horgan
Helena Iredell
Julie Ireland
Sarra Jamieson
Kristina Johns
Heather Jones
Anna Kemp
Vivien Kemp
Garth Kendall
Mary Kepert
Matthew Knuiman
David Lawrence
Eric Leotta
Rebecca Lubansky
Andrew Markovs
Valerie Mather
Sandy McKeirnan
Kathie McLure
Mitch Messer
Jan Payne
Glenn Pearson

Lorraine Powell
David Preen
Frank Prokop
Angela Rate
Charlie Rook
Bronwyn Rose
Caroline Rugdee
Cheryl Rugdee
Hilary Rumley
Frank Sanfilippo
Rosemary Saunders
Catherine Searle
Ruth Simms
Rachel Skoss
Fiona Smith
Cecily Strange
Fiona Stanley
Louise Stewart
Janet Wale
Phil Weinstein
Margaret Wood
Wendy Wright
Rae Young

We also acknowledge that there are many other consumers and community members who have contributed to the Program by serving on a wide range of committees at the School and the Institute. We apologise if there are any omissions.
STAFF PROFILES

The following people have held dedicated positions within the Program, 1998 - 2014.

**Rebecca Coghlan**  
**Consumer Liaison Officer 1998 - 2003**

Rebecca established the inaugural role of Consumer Liaison Officer and laid the foundations for the future work of the Program. This included raising awareness, conducting lectures on consumer and community participation at the School and contributing to research projects. Her years of experience with the Health Consumers’ Council WA and Consumers Health Forum of Australia helped to bring researchers, consumers and community members together to establish the relationships that are the basis of the Program.

**Anne McKenzie AM**  
**Consumer Advocate and Manager of the Consumer and Community Participation Program 2008 - present (Formerly known as Consumer Research Liaison Officer 2004 - 2007)**

Anne’s key role is to support and facilitate active consumer and community participation in the research and teaching programs at the School and the Institute. She has a long history as a consumer advocate and has been involved on numerous state and national health-related committees. She established and occupied the role of Parent Advocate at Princess Margaret Hospital for Children. Anne is a life member and former Chairperson of the Health Consumers’ Council WA and a senior consumer representative for Consumers Health Forum of Australia. Her early collaborations with counterparts in the UK led to the development of innovative training programs that built capacity in researchers, consumers and community members and promoted the work of the Program.

**Hayley Haines**  
**Project Officer 2011 - present**

Hayley’s responsibilities are to develop and implement resources, systems and processes to support the aims of the Program at the School and the Institute. In this capacity she has been integral to the development of the Participation Network and a dedicated website. Hayley previously worked at the UK National Patient Safety Agency and the South Central Research Design Service (Universities of Southampton, Oxford and Portsmouth) where she established systems to increase patient and public involvement in health and social care research. Her skills and experience have extended links with the UK and brought an international perspective to work undertaken in Australia. Hayley is a consumer representative for the Health Consumers’ Council WA and Perth North Metro Medicare Local.
Rachel Skoss
Consumer Development Officer 2011

Rachel brought her research experience to the development of resources and planning for a short-term role in the Program. A key achievement was the development of the submission for the Fact Sheets Series, accepted for publication on the CES4Health, a peer reviewed website for dissemination of health-related community-engaged scholarship, based in the USA. Her advocacy roles include membership on the Board of the Disability Services Commission and Disability Health Network Executive Advisory Group, and chairing the Ministerial Advisory Council on Disability and the WA Register for Developmental Anomalies Consumer Reference Group. She continues her involvement with the Program as Chair of the Consumer and Community Advisory Council at the Institute.

Ngaire McNeil
Administration Officer 2011 - present

Ngaire has responsibility for the administrative and communications functions of the Program. These include management of the Program’s network and database, publication of the quarterly newsletter and providing support to the Councils at the School and the Institute. An important aspect of her role is the organisation of consumer and community events including forums, community conversations and training workshops.

Kirsten Alpers
Research Assistant 2013 - present

Kirsten has researched and prepared the report on the activities of the Consumer and Community Participation Program from 1998 to July 2014. She has been involved in a range of epidemiological and public health projects at the Institute since 2003, including facilitating consumer and community participation in infectious disease studies.

Hayley Haines, Anne McKenzie, Kirsten Alpers, Ngaire McNeil
COLLABORATIONS

Collaborations with consumers, community members, research organisations, government and non-government organisations have been a fundamental part of the Program since it began. Early collaborations, particularly with the Health Consumer’s Council WA, Consumers Health Forum Australia, the WA Department of Health and the NHMRC have continued and strengthened over the past sixteen years. With the expansion of activities and networks there was a steady increase in recognition of the Program. This has resulted in increased opportunities for collaborations with consumer organisations, universities and research organisations at state, national and international levels. The following descriptions of the Program’s major collaborations are organised in chronological order of initial involvement.

INOLVE

The Program’s Consumer and Community Strategic Plan (2004) and Participation Policy (2005) were, in part, informed by the work of INVOLVE in England. The INVOLVE support unit was established in 1996 and is part of, and funded by, the National Institute for Health Research in the UK to support active public involvement in National Health Service, public health and social care research. Ongoing relationships with INVOLVE staff were first established via email in 2004 and then through attendance by Program staff at INVOLVE’s bi-annual national conferences. Guidance and support for the Program’s activities and direction was provided by former and current INVOLVE staff Helen Hayes, Philippa Yeeles and Maryrose Tarpey. INVOLVE staff have also facilitated introductions to a wide range of invaluable contacts throughout the UK as well as Denmark, Canada and the United States of America.

TwoCan Associates

An introduction by INVOLVE staff in 2006 to Bec Hanley, founding Director of INVOLVE and now Co-director of TwoCan Associates, has resulted in an ongoing collaboration between Bec Hanley and the Program. Her contribution in the form of mentoring, advice and support has had a significant impact on the Program. In 2007 Bec Hanley co-authored the Program’s first publication entitled Consumer and Community Participation: a Practical Guide for Health and Medical Research Organisations. In 2008 she was involved in planning for the Program’s inaugural Involving People in Research Symposium and was a keynote speaker. In 2009 she worked with the Consumer Advocate to develop and facilitate training workshops for researchers on implementing consumer and community participation. She was involved in developing the Program’s resources and website and worked with Program staff on a further publication, entitled Planning for Consumer and Community Participation: a guide for health and medical researchers, published in December 2014.
The School of Health and Related Research, Sheffield University

Introductions by INVOLVE staff to Rosemary Barber and Jill Thompson from Sheffield University provided additional international links for the Program. In 2008, Rosemary Barber and Jill Thompson were plenary speakers at the *Involving People in Research Symposium*, organised by Program staff and collaborators. The Consumer Advocate was invited to attend a researcher and consumer meeting in 2010 at Sheffield University to make a presentation about the developing activities of the Program. Ongoing contact has been maintained and opportunities for Jill Thompson to be involved in evaluation of the Program are being explored.

Kulunga Aboriginal Research Development Unit

The Kulunga Aboriginal Research Development Unit, formerly the Kulunga Research Network, was formed in 1999 and is dedicated to improving the health and wellbeing of Aboriginal children, families and communities while enabling Aboriginal people to conduct research. The Program has worked closely with many Aboriginal researchers associated with Kulunga since 2004, exchanging knowledge, experiences and support to foster greater involvement by all Australians in the research effort. The Program has been supported and encouraged by good practice examples of community consultation and involvement undertaken by Kulunga.

Cancer Voices NSW and Cancer Council NSW

Networks established via Consumers Health Forum of Australia, initially with Cancer Voices NSW and then with Cancer Council NSW, have resulted in a range of collaborations with the Program. At the *Involving People in Research Symposium* in 2008, good practice consumer participation undertaken by these two organisations was highlighted as a showcase project. In 2009, invited attendance by Program staff at a ‘community conversation’ facilitated by Cancer Council NSW on consumer priorities for research informed the development of participation methods by the Program. The Community Conversations have become a major component of the work of the Program. In 2014 a formal agreement was developed between Cancer Council NSW and UWA for Program staff to provide a consultancy service for the development of new modules for their consumer training.
Swansea University

In 2009 the Consumer Advocate was invited by Professor Ronan Lyons to make a presentation about the Program to a research network meeting associated with the Health Information Research Unit at Swansea University in Wales. During a subsequent visit to Perth by Professor David Ford and Dr Kerina Jones in 2010, there were further discussions about the Program and the possibility of establishing a Consumer Council at the Health Information Research Unit, based on the model developed by the Program. The Consumer Advocate provided advice and support during the establishment of a Consumer Council and has since attended Council meetings in 2012 and 2013 at the Health Information Research Unit.

Australian Primary Health Care Research Institute

Michele Kosky, former Executive Director of the Health Consumers’ Council WA, highlighted the Program’s training workshops to the Australian Primary Health Care Research Institute Board in 2010. Their commitment to support consumer and community participation in primary health care research has resulted in an ongoing collaboration. This has included researchers attending a training workshop at the School in 2010 and Program staff facilitating bespoke workshops at the Australian National University in Canberra for researchers who receive Australian Primary Health Care Research Institute funding. Over 50 researchers have now attended workshops between 2010 - 2014. Evaluation of the training will take place in 2015 and a report will be produced.

National Breast Cancer Foundation

Program staff and Dr Alison Butt, Director of Research Investment at the National Breast Cancer Foundation, developed a relationship following an introduction by Professor Moira Clay (former Acting Director of the Institute) in 2012. Program staff also provided advice on consumer participation in a breast cancer research project funded by the Foundation that was conducted at the School. In 2013 Program staff facilitated a bespoke training course in Melbourne for researchers and consumers on implementing consumer participation in research funded by the Foundation.

Westmead International Network for Neonatal Education and Research

Professor William Tarnow-Mordi, Foundation Director of Westmead International Network for Neonatal Education and Research at the University of Sydney’s Clinical Trials Unit made contact with the Program in 2011. Conversations about the work of the Program led to Program staff being invited to present at a conference in May 2012 at the Westmead Hospital in Sydney and at a parent training workshop in October 2012. A project led by Professor Tarnow-Mordi and funded by the NHMRC included a Program staff member as an associate investigator.
The Program established links with Miracle Babies Foundation, an organisation that supports premature and sick newborns, their families and the hospitals that care for them, when presenting at Westmead Hospital’s Neonatal Conference in 2012. The co-founders of Miracle Babies, Melinda Cruz and Kylie Pussell actively support the work of the Program and have made contributions to training workshops (as consumer presenters) and Program publications.

In 2013, a meeting between Program staff and Jonathan Craig, Professor of Clinical Epidemiology at the School of Public Health and Associate Dean (Research), Sydney Medical School, led to an ongoing collaboration which included an invitation to join a team of researchers and community organisations developing a grant application for a Centre of Research Excellence funded by the NHMRC. Although unsuccessful in securing funding, Program staff have had further involvement with this group as they continue to pursue opportunities for consumer-driven research.

Professor Craig was instrumental in enabling two training workshops, facilitated by Program staff, to be held in 2014 in Sydney for researchers and consumers involved in the research activities of the Better Treatment 4 Kids Research Network. The Network is a collaboration of research clinicians based in NSW children’s hospitals.

Consumer and Community Participation program is committed and a valuable advocate for public involvement in research in Australia and in the International arena. Colleagues at INVOLVE have established strong relationships with Anne, we keep in close contact and follow with interest and respect the continuing development of public involvement in research in the University and in Australia. We widely disseminate information about the expertise, work and training carried out by the consumer and community participation program.

Helen Hayes
INVOLVE, 2015
SECTION TWO
THE CONSUMER AND COMMUNITY PARTICIPATION PROGRAM

INTRODUCTION

During the development of the WA Data Linkage System (1995 - 1997), the Foundation Chair in Public Health at the School, Emeritus Professor D’Arcy Holman, became aware of concerns emerging within the health consumer movement about data linkage. A meeting took place between Professor Holman and the Executive Director of the Health Consumers’ Council WA, Ms Michele Kosky. It was agreed that, commencing in 1998, the School would fund a part-time Consumer Liaison Officer position, located in the School yet with considerable independence. The Consumer Liaison Officer would work closely with the Health Consumers’ Council WA, keeping the Council well informed on data linkage developments. Ms Kosky and Professor Holman jointly recruited and selected the first occupant of the position, Ms Rebecca Coghlan. It was the first time that a position of this type had been established in an Australian academic institution.

In 2002, the School collaborated with the Institute in a successful joint application to the NHMRC for a Capacity Building Grant (2002 - 2007) entitled Better Health Outcomes Through New Research Methods and Population Data (Capacity Building Grant). This grant was the first of its type in Australia and included support to fund a full-time Consumer Liaison Officer, who continued to collaborate with the Health Consumers’ Council WA and facilitate a joint initiative at the School and the Institute. This was the first time that a consumer and community participation theme had been included in a major NHMRC research initiative. Leadership of the theme changed when Ms Anne McKenzie was employed in 2004 as the Consumer Advocate (formerly the Consumer Research Liaison Officer).

Capacity Building Grant awarded – West Australian Newspaper article

The Program evolved from having a limited strategic focus to ongoing development and implementation of a strategic plan that provided the framework for activities and facilitated change. A Strategic Plan developed in 2004, described in the section on Governance and Services (see Appendix 5), supported the aim of consumer and community participation becoming standard practice in research and teaching activities across the School and the Institute. A Memorandum of Understanding outlining the commitment of the School and the Institute to work together to strengthen the Program was signed in 2011. Currently, funding of the Program is a shared responsibility of the School and the Institute.

High-level support from senior leaders and champions, and dedicated positions in the
Program at the School and the Institute has contributed to the success of the Program. Strong local, national and international collaborations and growing recognition of the importance of consumer and community involvement in research has supported this. As awareness of the value of consumer and community involvement has grown, so too has the demand for resources, advice and training. This increased demand has been largely driven by the Program actively identifying areas of need and being responsive to feedback from stakeholders.

The current Program is a dynamic and marketable asset of the School and the Institute with a far reaching influence, as summarised by the following factors:

- Interest in the Program, within the School and the Institute and externally, has grown as a result of a general increase in awareness and uptake of consumer and community participation activities across both organisations and the wider research community.
- Increased requests for advice on developing and implementing participation activities have been directly attributed to attendance at the Program’s training workshops.
- A website and other resources have been developed and these are accessed by a wide range of researchers, consumers and community members, not just locally and nationally, but also internationally.
- The formalisation of community networks has strengthened collaboration.
- There have been changes to funding body requirements for researchers to actively involve consumers and community members in their research.
- Increased requests for Program representation on state and national committees is due to the recognition and credibility of the Program.
- Increased requests for advice from external agencies are currently provided on a goodwill basis; externally requested training workshops are facilitated as a fee-for-service activity.

Ethos of the Program

Program activities, including the preparation of this report, have been guided by the ethos of consumer and community participation in research being an active and respectful partnership that

John Finlay-Jones
Edith Cowan University, 2015
supports consumers, community members and researchers working together to make decisions about research priorities, policy and practice. Undertaking research with consumers and the community has benefits that are varied and far reaching for all involved, more so than research that is conducted on, about or for consumers and the community.

Scope of this report

This report describes activities of individuals, institutions and the broader communities of researchers, consumers and community members from the start of the Program in 1998 to July 2014 and is intended as an historical record of the Program, showing the breadth of activities and collaborations over time.

Evaluation is fundamental to the principles of continuous quality improvement, which underlie the Program’s activities. Reporting on the documented uptake and growth of activities and resources is the first step in evaluation of the Program. Further work will be needed to assess the extent of impact, which can be hard to define and measure due to the subtlety and gradual nature of cultural and behavioural change. A complex interplay of factors contributed to the paradigm shift in attitudes that has occurred over the years covered in this report, leading to a research environment that is more responsive and meaningful to the needs and interests of consumers, the community and all other stakeholders.

This report will support and enable future evaluation of the Program and other consumer and community participation initiatives at the School and the Institute. Additionally, it serves as a framework for future Program work and describes a model for implementing an organisation-wide consumer and community participation strategy to the wider Australian research community. Ultimately, research outcomes arising from this participative model have a stronger community mandate, a more powerful legitimacy and are more likely to enjoy the support of the political constituency necessary to influence health policy and practice. The Program has been, and still is, at the forefront of this cultural change and is in a position to describe the narrative and quantifiable evidence generated over more than a decade that shows the impact on attitudes, behaviour, policy and practice apparent in the current health and medical research environment.

Factors that influenced the development of the Program

The Virtuous Cycle: Working together for health and medical research\(^1\) (also known as the Wills Review) was produced in 1998. It was the result of a comprehensive review of the state of Australian health and medical research commissioned by the Commonwealth Minister for Health and Aged Care. This strategic review aimed to identify threats, investigate future opportunities and make recommendations for optimum health outcomes for Australia, including suggested actions to engage and involve the community as stakeholders in the research effort. The Consumers Health Forum of Australia, established in 1987, made several submissions to the review.

The Consumers Health Forum recommendations, incorporated into the Wills Review\(^1\), included:

- Opportunities for consumers to participate in decisions on research priorities
- Research outcomes to be communicated to consumers who took part
That researchers involve the community in the research process and communicate about the role, benefits and results of research

The NHMRC funded the Consumers Health Forum to conduct a consultation process in 2000 which generated 60 submissions from research and health service organisations, consumers and the community from around Australia and involved roundtable discussions on the draft report in four cities in 2001. The resulting recommendations contributed to the joint NHMRC and Consumers Health Forum Statement on Consumer and Community Participation in Health and Medical Research in 2002 and can be found in detail in the final report by the Consumers Health Forum, Developing a Statement on Consumer and Community Participation in Health and Medical Research. The Consumer Focus Collaboration, a national body consisting of representatives from consumer, professional, private sector and health departments promoted active partnerships in health services. They provided reports and educational material through their National Resource Centre for Consumer Participation in Health. These resources were summarised in The Evidence Supporting Consumer Participation in Health, published in 2001. The NHMRC and Consumers Health Forum resource: A Model Framework for Consumer and Community Participation in Health and Medical Research was published in 2004 and aimed to build on the ethos and principles espoused in the 2002 Statement by providing researchers with guidance on implementing consumer and community participation.

The Program capitalised on the birth of the consumer movement in health and medical research in Australia and the strong gains in consumer involvement initiatives in health service delivery over the previous decades. It addressed early barriers of a lack of knowledge and understanding of the value of consumer and community participation and developed working methods based on national and international evidence which could be adapted to suit changing needs. The ground-breaking work undertaken by the Consumer Liaison Officer during 1998 - 2003 increased levels of confidence and trust, enabling the development of a structured program of innovative practices at the School and the Institute. The initial role created to bring together consumers, community members and researchers changed over the years. As the Program became more involved in advocacy, the title of the role was changed to Consumer Advocate in 2008.

The Program commenced from humble beginnings with a single person employed to bring together the community and researchers in an environment that was often not receptive to the value that community input could bring to research. Over the years the Program has evolved into a leading champion for increasing the community voice. This has facilitated and ever-increasing acceptance and incorporation of consumer participation by researchers all over the country.

The UWA Centre for Health Services Research has benefited from this evolution of change. The Centre now has embedded consumer participation into its strategic plan as an integral part of its activities and has a dedicated Community Reference Group to provide the community perspective.

David Preen
The School, 2015
The establishment of the WA Data Linkage Unit in 1995 raised issues and concerns about privacy with members of the Health Consumers’ Council WA. These issues were proactively addressed by two key initiatives in 1998:

- The appointment of a consumer representative to the WA Data Linkage Management Committee
- Funding of a part-time Consumer Liaison Officer position at the School

Ms Rebecca Coghlan, supported by the Health Consumers’ Council WA, was appointed to the role of Consumer Liaison Officer at the School. This initiative aimed to increase dissemination and accessibility of research results and forge links with community members and groups. The position was the first of its kind in a research institution in Australia and was met with some scepticism from within the research community about the benefits of such a role.

Wider support for the role was hard won through activities such as a survey conducted by the Consumer Liaison Officer in 2000 with chronic illness groups to identify what they wanted from health services research. A report on the findings was produced and used to inform subsequent research grant applications.

Between 2000 and 2001 the Consumer Liaison Officer:

- Conducted lectures and awareness-raising sessions for consumers and researchers/service providers
- Held positions on national committees and attended meetings and consultations at the School
- Participated in NHMRC workshops on the National Statement on Ethical Conduct in Research Involving Humans and Evidence Based Clinical Practice Research
- Undertook training in The Scientific Basis of Health Services and Background to Linked Databases
- Conducted seminars for staff at UWA and other organisations on how to involve consumers in health decision making
- Was a speaker at the National Privacy Principle Debate at the Institute’s Away Day annual scientific meeting
- Participated in the Consumers Health Forum and NHMRC process for developing a Statement on Consumer and Community Participation in Health and Medical Research and the 2001 National Prescribing Service Planning Day
- Published articles in Health Matters, the newsletter of the Health Consumers’ Council WA

Duty to Care Report
In Australia and internationally at this time, the research culture, in which the Consumer Liaison Officer position was developing, became more conducive to the inclusion of consumer and community contributions. From 2001 at the School, the scope of the Consumer Liaison Officer’s activities expanded and the potential benefits of having this role were identified. Consumer groups were involved with the Duty to Care Project in 2001, a project funded by the NHMRC which looked at the physical health of mental health consumers and which was identified by the Consumer Liaison Officer as a priority for consumer involvement. The research teams met with consumers to validate findings, develop a greater understanding of the issues and identify weaknesses in health data utilised. The various stakeholders worked together and displayed a flexible approach, developing a technical report, stakeholder summary and consumer summary for dissemination to the appropriate recipients.

To date, the Duty of Care project remains one of the most exemplary demonstrations of how a linked data project has the capacity to influence and change health policy and in part that was due to the systematic involvement of consumers in all aspects of the project.

Emma Fuller
WA Department of Health, 2014

Consumer organisations assisted with the launch and the resulting media coverage. Reporting the findings in this way (as opposed to publishing in scientific journals only) had wide ranging impact, from policy implications in WA following consumer lobbying, to the distribution of material to over 150 countries and translation into French and Spanish. The sharing of knowledge and experience led to benefits for consumers in the form of social justice, to researchers through the greater distribution of their findings and to the community through greater transparency of publicly funded research.

Greater priority was given to mental health on the political agenda following the Duty to Care Project. The Holman Review of the 1996 Mental Health Act in WA recommended physical health checks for mentally ill patients. The majority of the recommendations from the Holman Review were later accepted by the WA Government and incorporated into draft legislation for a new Mental Health Bill. A new project, Healthright, was conducted at UWA and provided an intervention program using peer advocates to assist people with mental illness to gain better access to high quality care for physical conditions.

During the 1990s, there was a strong commitment at the Institute to engage with families, particularly with research into Aboriginal health and in the area of disability research. The NHMRC Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research, produced in 1991, provided researchers with guidance for the responsible and respectful conduct of their projects. Research with Aboriginal people at the Institute had included involvement, consultation and communication since the establishment of the Institute in 1987. There was an expectation from the Aboriginal people that this research would include community involvement. The Bibbulung Gnameep Project, which began in 1994 at the Institute, emanated from community concerns voiced through health service organisations. Aboriginal staff employed on the project included a research coordinator who was also a chief investigator and research assistants. The project reached out to the community with positive health
messages expressed through a community art competition and included the establishment of a community reference group that provided overall guidance and ensured the appropriateness of research outputs.

In 1999, Institute researchers published the first journal article to discuss the establishment of community reference groups as a good practice model for research projects involving Aboriginal people\(^{(13)}\). The article also included policy and practice guidelines, which had been developed in collaboration with community members. Aboriginal leaders involved in the project challenged Professor Fiona Stanley, founding Director of the Institute, to extend the good practice community involvement into all research being undertaken at the Institute.

Disability research at the Institute included consultation with community groups prior to the publication in 1996 of *Disability Counts: A profile of people with disabilities in Western Australia*\(^{(14)}\). This report stated that ‘Collaboration with, and involvement of, people with disabilities in determining what information to collect, how to collect it and from whom, is essential if the information is to be relevant to all stakeholders’. Research was undertaken at the Institute in response to, and in collaboration with families involved in the Rett Syndrome Association of Australia since 1992, and the Down Syndrome Association of WA since 1997. The Western Australian Cerebral Palsy Register, established in 1979, was housed at the Institute when, in 2000, the Register’s Advisory Committee made the decision to recruit two parent representatives, both of whom served on the Committee for more than ten years.

In 2000, Dr Garth Kendall, Executive Officer for the *Western Australian Pregnancy Cohort (Raine)* Study at the Institute, travelled to the UK where he visited the *Avon Longitudinal Study of Parents and Children in Bristol* and observed the novel ways in which the participants (both parents and children) engaged with the research teams. This contact resulted in Dr Kendall seeing the potential benefits of establishing a consumer liaison position for the Raine Study. Following his return to the Institute he developed a proposal that the Institute:

- Appoint a liaison/communication officer
- Establish a committee to facilitate consumer and community participation
- Develop a policy on consumer and community participation

**Rett Study Community Forum**

The proposal was accepted by the Institute’s Executive Committee in 2002. It was anticipated that the proposal would enable the Institute to build on existing consumer and community participation activities and a perceived need for a more robust program. Dr Kendall arranged for the Communications Manager of the Avon Longitudinal Study of Parents and Children, Ms Pam Holmes, to visit the Institute in 2004 and provide advice on establishing a similar program of consumer and community participation for the Raine Study. Ms Holmes also assisted in the establishment in 2004 of the Consumer
Reference Group for the *Rett Study*. This group has been an important part of Rett Syndrome research at the Institute since that time and the model for subsequent reference groups working with international Rett Syndrome researchers.

As senior staff, researchers and administrators at the School and the Institute became more aware of the added value that consumer and community participation can bring to research projects, the enthusiasm for and acceptance of consumer and community participation increased. The success of earlier initiatives prompted the inclusion of a specific consumer and community participation theme in a joint application by the School and the Institute for a NHMRC Population Health Research Capacity Building Grant. This was an innovative step as it was the first time a non-scientific theme was included and was accomplished despite uncertainties among some researchers as to the value of inclusion. The 2002 - 2007 Capacity Building Grant enabled the Consumer Liaison Officer position to be funded full time and shared as a joint initiative across the School and the Institute.

The Capacity Building Grant Theme Six had stated aims of:

- Continuing education in the form of seminars and in undergraduate medical and health science courses
- Consultation with consumer groups concerning priorities for health services research
- Maintaining a consumer library to ensure relevant consumer material was available to both researchers and consumer groups
- Involvement of community and consumer groups in the dissemination of and response to research results and in major new research developments

These themes aligned with the expected outcomes of Theme Six which were to:

- Increase knowledge of consumer and community participation amongst graduates
- Increase participation of consumer and community groups in research priority setting and translation of results
- Improve research field performance, with higher response rates and fewer complaints

Existing collaborations continued with the support and mentoring of the Health Consumers’ Council WA; services and relationships were enhanced and extended as the profile of the Program increased.

The Consumer Liaison Officer expanded the teaching role to include lectures to The UWA Faculty of Medicine and Dentistry and Health Science undergraduate students in 2002 and established the Consumer Library. Advocacy activities continued as did participation by the Consumer Liaison Officer in National Prescribing Service Planning Days in 2002 and 2003 and the publication of an article in the New South Wales Public Health Bulletin. When the Consumer Liaison Officer ceased employment in 2003 there was a strong foundation for the expansion and future development of the Program.

With the Capacity Building Grant funding came a higher profile, attracting attention from those in Australia and overseas who were interested in consumer and community participation. Champions at the School and the Institute ensured that the potential was not wasted and that the Program was integral to the short term and long term planning, functioning...
and success of research projects at both organisations. In January 2004, Anne McKenzie was appointed to the position of Consumer Advocate at the School and the Institute and brought strong networks and extensive experience to the role.

A dedicated position, proven advocacy skills, existing networks and support from champions at the School and the Institute were the vital elements that allowed the continuity of advocacy, community links and teaching roles while the process to place the Program on a more structured and permanent footing began. These careful preparations laid the groundwork for the future success of the Program activities and built trust and understanding between researchers and stakeholders to ensure sustainable partnerships.

The School has been committed to producing the next generation of researchers for whom consumer and community participation in research is the norm and who have the skills to incorporate effective participation in research. We would not have been able to do this without the work of Anne McKenzie and Hayley Haines. They put together a program that integrated really nicely into our public health major and that allows students to build their knowledge and skills over the three years. We have had very positive feedback from students who have gone on to work in the Program on a voluntary basis. Former students have also attended researcher training workshops at the School and the Institute to further build their knowledge.

Jane Heyworth
The School, 2015

Consumers and community members having a say
Theme Six: Community Participation in Population Health Research funded by the NHMRC Capacity Building Grant (2002 - 2007) at the School and the Institute, supported the extension of existing activities and the development of innovative strategies and practices at both institutions. The four key deliverables of community links, advocacy, education and leadership were expanded to encompass additional activities and aims from 2004. The activities of the Program from 2004 onwards are described using the six components of work conducted by the Program (Figure 1).

These are:
- Advocacy and advice
- Building the evidence
- Community and stakeholder interaction
- Methods of participation
- Governance and services
- Teaching and training

While certain activities can be clearly categorised, many others are the product of efforts in two or more areas of work and all are the result of collaborative relationships between stakeholders that developed over time and that underpin the Program. Many people have contributed to the development and implementation of the governance frameworks, stakeholder networks, increased resources, interactive methods of participation, exchange of knowledge and evaluation potential that define the Program in 2014. To avoid conflicts of interest, a variety of perspectives have been sought in all Program activities.

In 2005 I was asked by the Health Consumers Council WA to attend a meeting with a view to establishing a consumer reference group for the Telethon Institute and the UWA School of Population Health. The meeting was facilitated by Anne McKenzie and speakers were Professors Fiona Stanley and D’Arcy Holman. This resulted in a steering committee being formed to establish an Advisory Committee for Research at both institutions. I was appointed to the committee and some very lively discussions followed till in 2006 it was decided that there were too many fundamental differences between the way the two institutions operated so it was agreed to form separate Councils for each institution.

I agreed to Chair the Council at the School of Population Health. There followed a lengthy period of recruiting members, developing Terms of Reference, determining the parameters of the work of the Council and beginning to develop relationships with the staff and students at the university.

Barbara Daniels
Council Chair, the School, 2015
ADVOCACY AND ADVICE

The Program has provided advocacy and advice to researchers internally at the School and the Institute and externally to government and non-government agencies, consumer and community organisations and research institutions. In addition, the Program has advocated nationally for greater consumer and community participation in research.

In order to provide researchers with advice and support to implement greater consumer and community participation, there was a need to develop strong networks and collaborations with consumer organisations at the local and national level. It was also apparent in 2004 that countries such as the UK had well-established processes and resources for supporting consumer and community participation in research. Contact was made with INVOLVE, a public and patient involvement support group in England. This early contact was fundamental in establishing the supportive and collaborative relationship that developed over the years 2004 - 2014. In addition, state and national consumer networks were developed and increased through a range of activities including attendance at forums and meetings, such as the Data Linkage Australia Pharmaceutical Research Network inaugural meeting in 2005, and support for consumer representative positions on committees.

Advocacy and advice at the School and the Institute

The Capacity Building Grant (2002 - 2007) enabled the development of a planned, long-term approach to increasing consumer and community participation across both the School and the Institute. Certain events provided opportunities for innovative activities to be developed in tandem with the aims of the grant. Advocacy and advice were frequently provided in response to an identified need or to unanticipated requests. For example, the Head of the School identified that there were no processes or policies in place at the School to deal efficiently and quickly with complaints received from the community. Through the implementation of a ‘customer’ complaint policy at the School in 2005, the Program increased the opportunities for consumers and community members to articulate their concerns in a systematic way and for researchers to become more aware of issues. Over 70 staff attended a training seminar on complaints handling at the School.

Contributions made by the Program staff at the School led to involvement in other activities at UWA. As a direct result of implementing the complaints policy at the School, the Consumer Advocate was invited to be part of a review by The

Raine Study Community Reference Group
UWA Grievance and Complaint Review Working Party of complaints policies and practices across the University. This resulted in the School’s Complaint Policy being recommended as the model for the University’s external complaint policy. Advice was given in 2006 on the establishment of a consumer and community participation reference group at The UWA Department of General Practice.

At the School in 2006 - 2007, support and advice were provided for two Masters Dissertations on consumer and community participation in health research. Support was ongoing for the duration of the projects and included assistance with recruitment into one study of 35 consumer participants who completed the study survey on community priorities for health research. A consultancy service was provided to researchers during the 2006 grant application period. At least six applications at the School proposed expanded consumer and community participation activities, including appropriate budgets. Two large NHMRC grant applications included significant participation activities with an aim of developing a ‘good practice model’ for involvement. A consultancy service that advised researchers at the Institute in 2006 resulted in proposed consumer and community participation activities being expanded in four grant applications.

Establishment and expansion of local, national and international networks

Maintaining and increasing existing networks with consumers, community members and representatives of advocacy organisations and government departments was essential for the growth of the Program. Two major collaborations developed were with the Health Consumers’ Council WA and with patient and public involvement advocates in the UK. The Involving People in Research Symposium in 2008 highlighted the strength of existing Program networks and helped to establish new relationships.

The Health Consumers’ Council WA

The Health Consumers’ Council WA provided a strong mentoring and advisory role during the early stages of the Program. Commitment to consumer and community participation in health research by the Health Consumers’ Council WA played a pivotal role in supporting plans for consumer and community participation at the School and the Institute. A summary of Program activities conducted in 2004 was featured in the NHMRC’s A Model Framework for Consumer and Community Participation in Health and Medical Research. This was the result of the Executive Director of the Health Consumers’ Council WA bringing the work of the Program to the attention of the NHMRC and Consumers Health Forum of Australia.

Health Consumers’ Council WA

The Health Consumers’ Council WA was influential in the establishment of the Councils at the School and the Institute in 2005 - 2006. The establishment of
Councillors was part of the implementation of the Consumer and Community Participation Strategic Plan, detailed in the section on Governance and Services. The Health Consumers’ Council WA also collaborated with researchers from the Institute in the community consultation processes in 2006 for achieving statutory notification of birth defects and cerebral palsy in WA\(^{(15)}\). Advocating for and supporting the Health Consumers’ Council WA to lobby the WA Department of Health to establish a working party to raise community awareness about state health data collections was a significant step in addressing consumer concerns about data linkage processes and activities. The resulting committee, of which the Consumer Advocate was a member, developed a series of consumer-friendly resources in 2006 about the data collections, including a website, booklet, brochure and poster.

Continued collaboration during 2007 - 2010 resulted in:

- Researchers writing three articles for *Health Matters* (the Health Consumers’ Council WA newsletter)
- Presentations by researchers at two consumer meetings at the Health Consumers’ Council WA
- Involvement between the Health Consumers’ Council WA, Kwinana Community Action Groups and the School in 2008 in the preparation of grant applications to Lotterywest and Healthway; although these applications were unsuccessful, subsequent funding was provided by the WA Department of Health to the Institute for the Kwinana Children’s Respiratory Health Study
- The inaugural *Involving People in Research Symposium* in 2008
- Development of training workshops for researchers in 2009
- Support for the Consumers Health Forum consumer consultations in WA on quality use of medicines and electronic health records in 2009 and 2010

There was growing awareness in the late 1990s, amongst active health consumers, about the extent of the information collected about Western Australians in the many databases held within Health. This data store was being accessed by researchers and Ethics Committees were being called upon to consider both research questions and methods. UWA made the leap to employ a Consumer Consultant to bring a new view and a different voice to the enterprise of population health research. Involving an ‘outsider’ reflected an openness, maturity and accountability to the community that represented a new era for public health research.

At the same time there was growing activism of mental health consumers, speaking of the destructive and often anti-therapeutic effects of mental health ‘care’ and the harm caused by the stigma of mental illness. The data linkage research that led to the Duty to Care Report involved health consumers in the research and dissemination processes in an unprecedented way. Once this partnership had begun, there was no way that public health researchers in WA could return to conducting research without some level of engagement with the community as partners.

Maxine Drake
Consumer advocate, WA, 2015
The collaborative relationship with the Health Consumers’ Council WA continued to strengthen after 2010 and allowed the sharing of resources and tools for advocacy and advice. The Health Consumers’ Council WA has maintained representation on key committees supported by the Program, such as the Councils at the School and the Institute and the Developmental Pathways Project at the Institute.

**United Kingdom collaborations**

A particularly successful and significant collaborative partnership with patient and public involvement advocates in the UK began with the Consumer Advocate’s attendance at the biennial INVOLVE conference held in Nottingham UK in 2004. Presentations at the INVOLVE conferences in 2006 and 2008, as well as the development of ongoing relationships with INVOLVE and UK patient and public involvement consultant Bec Hanley, strengthened the collaboration.

International interest in the Program and strong collaborative relationships with UK counterparts were further developed with the attendance of UK advocates and researchers at the Involving People in Research Symposium in 2008. Bec Hanley, Research Fellow Dr Rosemary Barber and PhD candidate Jill Thompson from Sheffield University presented at this Australian national symposium organised by the Program. As a result of their attendance, the Consumer Advocate was invited to speak at The School of Health and Related Research at Sheffield University and the Exeter University Service User Program Workshop in 2009. Also in 2009, the Consumer Advocate attended the Swansea University Health Information Research Unit Research Forum.

**National Symposium**

The inaugural Involving People in Research: A National Symposium on Consumer and Community Participation in Health and Medical Research was held in March 2008. The event advocated for consumer and community participation in research and was held at UWA. Sponsorship was received from the NHMRC, the Health Consumers’ Council WA, the WA Department of Health, UWA, Edith Cowan University, Curtin University and Murdoch University. Dr Norman Swan, host of the Australian Broadcasting Corporation’s The Health Report and Tonic radio programs, facilitated the Symposium which featured local, national and international speakers. There were 57 concurrent presentations, a
I would like to thank you for the opportunity and funding that attending the symposium gave me. I remember returning exhausted, that three hour east to west to east really throws the body clock out. My brain was scrambled as I listened intently to the talks but could not stop to take notes; else I feared I would lose thread of the discussion. The Symposium assured me consumer involvement was the right and legitimate and invaluable way to go. There have been inroads since 2008 and your work is no doubt part of that momentum. I look forward to hearing more should you organise another event.

Jan Mumford
Consumer advocate, NSW, 2013

facilitated interactive workshop session and poster presentations. New collaborations between researchers, students and consumer and community advocates were created and existing partnerships were strengthened. Attendance at the two-day Symposium included 115 consumers, community members and members of community and non-government organisations, 23 students and 120 researchers, clinicians, administrators and representatives from funding bodies. Participants at the workshop session suggested barriers to consumer and community participation could be addressed by:

+ The establishment of a national co-ordinating body
+ A national training strategy
+ NHMRC reform in this area
+ Research on the benefits of participation
+ Tools to evaluate participation
A communiqué to the NHMRC developed at the conclusion of the Symposium called for ways to further support consumer and community involvement in research (see Appendix 3).

The Councils made a commitment to have the issues raised at the Symposium regarding formal consumer involvement in research design, priorities, funding and dissemination discussed at an appropriate national forum. The NHMRC hosted a post-Symposium meeting in Melbourne in August 2008. Senior consumer and community advocates from across Australia attended the meeting and a presentation on recommendations from the Symposium was given. The NHMRC did not support the establishment of structures to formally provide funding and training in consumer and community participation but agreed to continue the dialogue with their internal consumer group about the way forward.

Ongoing consultations have been held over the ensuing years with the NHMRC, enabling the Program to advocate for greater consumer and community participation in health research.

**Advocacy and advice in an expanding Program**

Increasing the profile of the Program locally, national and internationally was important in the support of advocacy activities. During 2008 - 2014 awareness of the Program increased. This can be attributed to a range of factors that include researchers from across Australia attending training workshops developed and facilitated by the Program (detailed in the section on Training and Teaching). Other contributing factors were Program representation on national committees and invitations to present at national conferences and workshops. Recognition and promotion of Program activities by individuals and organisations enabled information about the Program to be widely disseminated. Requests for advice increased with the Program’s efforts to promote activities and with media attention that followed some events. Interest in the Program from overseas organisations was a factor in the increased opportunities for collaboration and strong relationships with international research and consumer organisations. To acknowledge the increasing advocacy role, the Consumer Research Liaison Officer became known as the Consumer Advocate in 2008.
Local and national advocacy 2006-2014

Projects funded by the NHMRC at the School entitled *Chronic Disease Outcomes and Enhanced Primary Care in Seniors* and *Improving Medication Safety in Seniors* (the Seniors Projects) began in 2006 (featured as a Case Study on page 45). Consumer consultations raised issues of safety and the quality use of medicines. Subsequent media attention enhanced the profile of the Program and contributed to the Consumer Advocate’s involvement nationally with the Consumers Health Forum and Department of Health’s *National Medicines Policy Conference* in Canberra in 2008, and as a plenary speaker at the *National Prescribing Service’s National Medicines Symposium* in 2010.

Example of branding confusion on prescription medicines

A Radio National Health Report interview by Dr Norman Swan with the Consumer Advocate and a consumer on consumer issues about packaging and labelling of prescription medicines was broadcast in 2009. These important safety issues were raised in correspondence and meetings at a state level with the WA Department of Health and Therapeutic Advisory Group. Nationally, the issues were raised with the Australian Medical Association, National Medicines Policy Committee, Therapeutic

ABC Health Report interview

Goods Administration, Medicines Australia, National Prescribing Service, Pharmacy Guild and Council, Royal Australian College of General Practice, Commission on Safety and Quality, Commonwealth Department of Health, Consumers Health Forum and the Federal Minister for Health. In 2011 the Consumer Advocate was invited to join a Therapeutic Goods Administration committee established to review packaging and labelling of medicines. A submission was made by Program staff on behalf of the Consumer Panel of the Seniors Projects to the *Therapeutic Goods Administration Medicines Labelling and Packaging Review* in 2012, incorporating information collected from consultations since 2006.

It was great catching up with you again in Sydney. I came away so inspired! My head full of ideas and hopes to make some changes and undertake some initiatives. I sat on the plane making a list of things that I need to do and I have to admit I was a little overwhelmed.

Janine Fisher
Consumer advocate, Victoria, 2012
The Program was one of the ‘notable cases of consumer involvement in Australian health research’ featured in an article in the Health Promotion Journal of Australia in 2011(16). Further media interest in the Program included an interview with the Consumer Advocate on the importance of consumer and community participation in research on the Australian Broadcasting Corporation’s Tonic News program in 2011 and an interview for the *Women, Leaders and Social Change Project: women leaders in the consumer movement* (17) in 2012. The West Australian newspaper’s Health + Medicine supplement featured an article in 2012 entitled *Researchers Tap Lived Experiences* (18) that publicised the establishment of the Participation Network, an initiative of the Program designed to match consumers and community members with suitable research projects. As mentioned in the article, there were 143 community representatives on nineteen committees at the School and the Institute at that time. The article contained interviews with the Consumer Advocate, the Chair of Public Health at UWA and a senior consumer representative from the Seniors Projects. The article also highlighted safety issues with medications raised by consumers involved in the projects.

The Population Health Research Network was established in 2009 to create Australia’s first national data linkage network and was an initiative of the Australian government as part of the National Collaborative Research Infrastructure Strategy. Involvement by the Program began in the planning stages. The Program provided expertise and advice on the consumer and community participation strategy, including the development and facilitation of tailored training on consumer and community participation in 2011 and 2012 for researchers at the Population Health Research Network data linkage units. The Consumer Advocate served as one of two consumer representatives on the Population Health Research Network’s Ethics, Privacy and Consumer Engagement Advisory Group.

Five community members and the Consumer Advocate attended the Dialogue on Data Linkage workshop at UWA in 2010. The workshop was co-sponsored by the Australian Bureau of Statistics, UWA and the Population Health Research Network to discuss plans for linking Commonwealth and state information, particularly health information. The organisers expressed appreciation for the consumer attendance.

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**Consumer participation in the Dialogue on Data Linkage workshop was very valuable. It was clear from discussions that consumers support the linkage of data for population health research because they value the benefits that flow from the research.**

*Merran Smith*

*Population Health Research Network, 2015*

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The consumers raised issues that had not been raised previously. For example, privacy issues that were discussed as a barrier to releasing Commonwealth data were not seen by consumers as the main issue. Consumers were generally more concerned about benefits and relevance of research and having open and accountable processes for the use of public money on research. There was also concern about bureaucracy impeding the release of data so research could be conducted. Generally, consumers and community members expected that privacy issues would be dealt with appropriately. It was evident that there was a lack of consumer and
Council Chairs support the Discoveries need Dollars campaign

Council Chairs support the Discoveries need Dollars campaign. Community input at a Commonwealth level into the area of Commonwealth data linkage. The Councils at the School and the Institute were active in the Discoveries Need Dollars campaign, lobbying the federal government for health and medical research funding and using networks to encourage consumers and community members to support research. A joint letter was prepared and sent to the NHMRC and the Prime Minister in 2011. A Program staff member worked with researchers in the preparation of an editorial on the involvement of consumers in the campaign. This was submitted, but not accepted, for publication in the Medical Journal of Australia as it was not deemed relevant to the research community at the time, illustrating the difficulty of publishing on consumer and community participation in Australia. Other issues raised at Council meetings and subsequently brought to the attention of the Federal Health Minister at a meeting in 2011 included delays in the provision of cross-jurisdictional health data leading to waste of public funds and establishing interest in the concept of a national Participation Centre. The Minister was very interested in the work of the Program and commented that this was the first time a research organisation had brought a consumer advocate to a meeting. Submissions were made by the Councils to the Commonwealth of Australia’s Strategic Review of Health and Medical Research (also known as the McKeon Review) in March 2012 and June 2012 (supplementary). Program staff and the Chair of the Council at the Institute attended a public consultation and submitted a response in October 2012.

Excessively long wait times for the provision of data to researchers from the WA Department of Health was identified by researchers at the School and the Institute as an issue needing to be addressed. This complex issue was discussed by the community reference group of the Developmental Pathways in WA Children Project (Developmental Pathways Project) at the Institute and at 2011 Council meetings at the School and the Institute.

Developmental Pathways Project Community Reference Group

It was decided that the Council Chairs would write to the Director General of the WA Department of Health expressing concern about waiting times for data but the issue was brought to the attention of the Data Linkage Branch management and the situation was improved to some extent. The length of time waiting for the release of state and Commonwealth data is an ongoing concern to the Councils as they consider this to be a waste of money and time that could be used in a more appropriate way.
The Consumer Advocate was invited to participate in a consumer participation workshop hosted by the NHMRC in 2011. At this workshop the issue of a lack of criteria to assess researcher responses to questions about consumer and community participation in grant applications was raised. A letter to the NHMRC regarding assessment criteria was prepared with input from the Councils. In 2012 another invitation was extended to join the working committee to draft the second joint NHMRC and Consumers Health Forum Statement on Consumer and Community Participation in Health and Medical Research. In addition to participation in the drafting group, a presentation on the Program was made at the national consumer consultation run by the Consumers Health Forum in 2012. Involvement continued with appointment to the NHMRC Community and Consumer Advisory Group and attendance at the inaugural meeting and workshops held in 2013. The key focus of this group was the translation of research into policy and practice and to provide timely, high level, strategic advice to the Chief Executive Officer of the NHMRC.

Advice on consumer and community participation has been given freely, on request, to many individuals and organisations in Australia since the Program began. This continues to be the case, such as the ongoing assistance provided to the clinical project manager of the Princess Margaret Hospital for Children Diabetes Research Group regarding their consumer engagement strategy and inaugural community forum held in 2013.

**International advocacy 2010 - 2014**

The ethos, knowledge and activities of the Program were promoted during 2010 - 2014 in a variety of settings outside Australia. In 2010, the Consumer Advocate attended the Community-Campus Partnerships for Health Conference in Portland, Oregon and made contact with US and Canadian counterparts. Program staff attended the Community-Campus Partnerships for Health Conference in Houston, Texas in 2012.

The Consumer Advocate was invited to join a multi-national panel of senior researchers and clinicians at the INVOLVE Conference Public Involvement in Research: Innovation and impact, in Nottingham.

**Women who attended focus groups in China**

The Lu Cha Research Collaboration between the School and Zhejiang Medical School in Hangzhou, China, conducted three parallel case-control studies, funded by the NHMRC, of breast cancer, colorectal cancer and adult leukaemia. This was part of the Green tea polyphenols and cancer prevention: Use of biomarkers and population controls to elicit causal pathways project. The Consumer Advocate travelled to China in 2010 with Professors Min Zhang and Max Bulsara to visit Hangzhou and Shenyang Cancer Hospitals. With Professor Zhang providing interpreter services, a Program-facilitated focus group was conducted at each hospital with patients who were involved in the research projects. Patients discussed why they decided to participate in research. Clinical staff attended the focus groups to hear patients’ feedback.
UK in 2010. Discussions were held on implementing an organisational strategy to increase consumer and community participation in health and medical research. A presentation was made on the use of training to promote a culture of involvement, based on the experience of developing training workshops for researchers at the School and the Institute. In addition, two workshop sessions were co-facilitated: ‘What to do when things go wrong’ and ‘International perspectives on consumer and community participation’. During this visit to the UK, presentations were made at Sheffield University, the INVOLVE support unit in Southampton and the National Cancer Research Institute Consumer Group.

In 2012, Program staff attended the INVOLVE conference to present posters on the work of the Program and conduct a workshop session on barriers to participation, including comparison and discussion of differences between issues raised in focus groups at the School and the Institute, and those in the UK. An invited presentation on the Program was given at the international session with the USA and Canada. While in the UK, the Consumer Advocate was invited to visit Swansea University to meet with the Consumer Panel for the Health Information Research Unit and with the Deputy Director of the Unit to discuss opportunities for collaboration, particularly regarding training and the development of online training. The Health Information Research Unit Consumer Panel had been established as a result of meetings in 2009 and 2010 with Swansea University staff at which information about the Program and advice were provided.

A prospectus\(^{20}\) describing the range of services and resources available from the Program was produced in 2012. This included promotion of the School and
Collaborations with the UK led to further international recognition of the Program

the Institute as innovators in the area of consumer and community participation in research using linked data, a Program overview, services provided, details of methods used and an outline of the existing evidence base. The Program was invited to submit the prospectus to the Health Information Research Unit at Swansea University as part of advice given by Program staff in 2012 on establishing a consumer advisory panel for the grant titled Centre for the Improvement of Population Health through E-records Research (CIPHER)\(^{[21]}\). The grant is supported by a consortium of UK government and charity funders led by the UK Medical Research Council. It is a multinational research collaboration led from Swansea University, with investigators from other UK universities (Brighton, Bristol, Leicester, Sussex) and overseas universities and institutions (Australia: Curtin University, Monash University, UWA; Canada: Ottawa University; Finland: National Institute for Health and Welfare). In this 2012 - 2017 £9.3 million Centre of Excellence Grant with aims of scientific research, methodological development, capacity building, public engagement, governance and industrial innovation, the Participation Program was used as an exemplar model for consumer involvement.

Other international advocacy and advice activities of the Program include the development of relationships with counterparts in Canada and Denmark. Discussions about the Program with the Director of Community Engagement for the Canadian Institutes of Health Research have continued since initial contact was made in 2010 and the Program has provided advice and resources.

The second International Health Data Linkage Conference in Vancouver, Canada in 2014 was attended by Program staff. A presentation on Implementing the ‘community voice’ in linked data research was made. Following this presentation several meetings were held with researchers and community organisations to further discuss the Program.

\[\text{A decade ago we were strongly opposed to data linkage, after 10 years of coming to understand exactly where the risks lie, and more importantly where they don’t, we are now the strongest supporters of using data to conduct meaningful research}\]

Karen Carey
Consumer advocate, 2014

\[\text{Data linkage does to health research what genealogy does to family history research. Both connect records together making a far richer and more useful picture than was possible before linkage}\]

Jenni Ibrahim
Consumer advocate, 2014
In 2011, the Consumer Advocate was invited by Bec Hanley to join a meeting in London with a study group from Denmark, led by Professor Mogens Horder. This group was looking into good practice methods for patient and public involvement. Following the meeting, a senior researcher from the Danish Cancer Society, who had been part of the group, requested further information and examples of consumer and community participation. International initiatives focusing on examples from the UK and the School and the Institute were used in a presentation about consumer involvement at the Danish National Forum for Health Care Research. The presenters gave feedback that they considered the meeting to be successful as their Minister for Health gave a commitment to actively support consumer involvement in research. Ongoing contact with Professor Horder has been maintained with joint presentations in an international session at the INVOLVE Conference in 2012 and in 2014, as part of an international group invited to take part in the Review of Patient and Public Involvement in the National Institute for Health Research in England.

The Consumer Advocate’s contribution to the INVOLVE 2010 conference was invaluable, sharing with enthusiasm and passion her approach to public involvement in research at the School and the Institute. She expertly co-facilitated a session for delegates to explore the development of good practice in situations where the planning and delivery of public involvement activities has not gone to plan.

Helen Hayes
INVOLVE, 2015
Western Australian Audit of Surgical Mortality 2001 - 2005

In 2000, surgeon James Atkin from Edinburgh approached the Health Consumers’ Council WA seeking consideration and support for an audit of death and injury after surgery. The Health Consumers’ Council WA, strongly committed to patient safety, was pleased to support the proposal. In 2001 a research project entitled the Western Australian Audit of Surgical Mortality began as a collaboration between the School, the Royal Australasian College of Surgeons and the WA Department of Health. The project adopted a model from Scotland and was part of the WA Safety and Quality of Surgical Care Project, funded by the NHMRC.

The project addressed calls by patient and community organisations for a framework of accountability for improving surgical safety. The Consumer Advocate collaborated with the Health Consumers’ Council WA in 2004 to bring together consumers and community members to discuss the WA Audit of Surgical Mortality and the first Annual Report. The Consumer Roundtable Meeting held in July 2004 was attended by 22 consumers and community members. Aggregate data from the project was reported to consumers and community members attending the Roundtable Meeting. The consumers and community members were supportive of the audit and provided recommendations to the Board of the Health Consumers’ Council WA for endorsement and then to the Chair of the WA Audit of Surgical Mortality. These recommendations were included in a peer-reviewed publication co-authored by the Consumer Advocate in the Australian and New Zealand Journal of Surgery in 2006.(34)

The collaborative process of providing input into the recommendations from consumers and community members increased trust between stakeholders and led to a consumer representative position being established on the WA Audit of Surgical Mortality Management Committee. Consumers and community members who were involved in the Roundtable Meeting in 2004 later lobbied the Health Consumers’ Council WA to write to the government of Western Australia to reconsider a decision to cut funding to the WA Audit of Surgical Mortality. This decision was ultimately reversed and, as stated on their website: ‘The Royal Australasian College of Surgeons’ Council is committed to a bi-national surgical mortality audit program that has been modelled on the successful Western Australian Audit of Surgical Mortality’. 
CASE STUDY

‘Chronic Disease Outcomes and Enhanced Primary Care in Seniors’ and ‘Improving Medication Safety in Seniors’ Projects 2005 - 2009

Two projects funded by the NHMRC entitled Chronic Disease Outcomes and Enhanced Primary Care in Seniors and Improving Medication Safety in Seniors began at the School in 2006 and included a strategy, developed in 2005, of innovative, planned and budgeted participation activities. These projects were influential in the Program’s development of good practice methods for participation. The Consumer Advocate organised and facilitated, in collaboration with the Health Consumers’ Council WA, two community forums at UWA in 2006 and one in Rockingham in 2007.

The community forums, attended by 104 people, aimed to raise awareness of the research and to seek input into the research questions. Feedback led to further ethics approval being sought to include additional questions about the role of the pharmacist and carers in managing chronic disease and medication safety. Participants were also invited to nominate for a position on the project steering panel. Subsequently, a Seniors Consumer Panel (steering group) was established in 2007 and met regularly with researchers and clinicians for the duration of the projects. The Seniors Consumer Panel members identified two major safety issues. One issue was confusion about the use of brand names rather than active ingredients on prescription medicine packaging. The second issue identified was the use of non-specific dosing information on prescription medicines with potential for adverse events such as ‘Take as directed by doctor’. This resulted in extensive publicity and raised awareness at a national policy level across Australia with agencies such as the Commonwealth Department of Health, Therapeutic Goods Administration and the National Prescribing Service. Six focus groups were held in 2008 to explore issues raised in the community forums which related to three core themes: the safe use of medicines, packaging and labelling, and generic medicines.

National advocacy has continued with a range of government agencies and health professional, consumer and non-government organisations to address safety issues related to medicines raised by consumer and community members at these events. The success of the consultation processes used for these projects informed the development of the ‘community conversation’ method of participation developed by the Program. The Program surveyed researchers, health professionals and members of the consumer panel involved with the two projects in 2009 to see if their expectations for the consumer and community participation activities held for the projects had been met. The survey asked questions about expectations of activities when the projects commenced, expectations at the time of the survey and whether the respondent’s expectations had changed. A further question on overall expectations required a response on a scale of 0 to 4 where 0 was ‘not met’ and 4 was ‘exceeded’ expectations.
As can be seen in Figure 2, there were no respondents who felt that their expectations were ‘not met’ and a majority indicated that their expectations were more than ‘met’ by choosing 3 or 4 on the scale.

![Figure 2](image.png)

Figure 2: Survey of researchers and consumers on their expectations of consumer and community participation activities in NHMRC projects on medication safety and chronic illness in seniors. Responses to Question 4: Were your overall expectations of the consumer and community participation activities met?

Quotes from survey respondents

What were your expectations of the consumer and community participation activities when the projects commenced?

✚ ‘I thought that we would be merely subjects for researchers but welcomed the opportunity to contribute’

✚ ‘Lacked any major expectation due to no real experience with consumer participation’

✚ ‘I hoped to hear what consumers and the community opinions truly were, in comparison to what health professionals assumed they were’

✚ ‘Very little. I thought it would be like every other inquiry, lots of talk and no action’

What are your expectations of consumer and community participation now?

✚ ‘Completely changed’

✚ ‘Their experiences could potentially provide some ideas as to why we are observing certain results’

✚ ‘I now believe that consumer input can make a difference’

✚ ‘That consumer participation is established and legitimised and added so much value in such a common sense way’
In the early stages of the Program’s development from 1998 - 2004, it was not considered necessary to apply a formal structure to the work being conducted. The experiences and benefits of actively involving consumers and community members in research are not widely published in peer review journals in Australia. In other countries, such as the UK, a culture of knowledge transfer had developed and publication of community involvement activities and initiatives are expected and encouraged. As the Program developed and expanded, it became increasingly apparent that there was a need to build evidence of the value, importance and impact of consumer and community participation. The evidence gathered from activities conducted during 2004 - 2014 enabled the Program to document changes in research processes at the School and the Institute. Activities conducted during 2004 - 2014 have primarily been modelled on a community development framework using continuous improvement principles that include evaluation of all activities to improve future planning. A long-term strategy for sustainability, including priority setting, ongoing planning and management and resource provision, is an intended outcome of Program evaluation.

**Changes in awareness, attitudes and behaviours**

Nationally and internationally, between 2004 - 2014, there was increased interest in the work of the Program, indicating an increase in acceptance of consumer and community participation in research. Internationally, there were publications acknowledging this increasing acceptance and the corresponding need for an evidence base\(^{22}\). Much of the literature described benefits from consumer and community involvement in health service provision rather than impact on research. Interest in detailed evaluation of the Program has grown with greater awareness of the value of the accumulated quantitative and qualitative data collected by the Program since it began. There are opportunities for the dissemination of findings after analyses of these data which may also provide valuable information for researchers, consumers, community members and other stakeholders.

**Raising awareness**

Between 2004 and 2009 there was anecdotal evidence reported at the School and the Institute of changes to researchers’ awareness, attitudes and behaviours relating to consumer and community participation. Following the implementation of training workshops in 2009 (detailed in the section on Training and Teaching), there was an increase in demand within the School and the Institute to develop a range of participation activities and resources. This increased demand provided evidence of changes to the processes of consumer and community involvement that researchers were implementing. Evaluation of participation activities was undertaken in order to describe and report on the extent of changes to awareness, attitudes and behaviours of researchers within the School and the Division of Population Sciences at the Institute. Audits, qualitative research projects and feedback forms from training workshops were among the evaluation methods used.
The ladder of participation stays with me, reminding me that there are not only multiple ways of involving consumers and the community, but there are also multiple levels of engagement. Some projects are more suited to one over the other, and not to feel that you can only be all in or all out for research participation. Makes it possible to take small steps rather than being overwhelmed.

Workshop attendee, 2012

Changing attitudes

Since 2004, in keeping with principles of continuous quality improvement, feedback has been sought from participants at events organised by the Program. Evaluation forms provided to all participants contain three key questions. These questions are:

- What worked well?
- What didn’t work well?
- What changes can be made to improve future events?

Based on the feedback, changes are incorporated into planning for future events organised by the Program. Feedback from the first five researcher training workshops held in 2009 showed that 83% of attendees intended to change their practices as a result of attending a workshop. All subsequent researcher training workshops have had over 80% of attendees intending to change their practices. The Program received increased requests for assistance from researchers following their attendance at training workshops. This has shown that intentions were acted upon, validating the training as a method of influencing attitudes and behaviours.

Feedback from the researcher training workshops during 2009 - 2011 led to a participation planning form being developed and piloted in 2012. The Program staff conducted interviews with eight researchers from the Institute’s NHMRC Program Grant during 2012 using the draft planning form to guide discussions on current and potential planning activities. The aim of the planning form is to enable structured mentoring, advice and support for researchers on implementing consumer and community participation in research. Questions asked on the form are the same questions that are used in the part of the training workshops dedicated to participation planning activities. Further details of the training workshops can be found in the section on Training and Teaching.

It is anticipated that changes in attitudes and knowledge can be documented over time. The feedback from researcher training workshops continues to be a resource for the refinement and development of strategies and resources to
development of strategies and resources to assist researchers. For example, a series of questions on planning for participation have been developed into a template to guide researchers. This template is available in a new Program publication entitled Planning for Consumer and Community Participation: a guide for health and medical researchers, published in December 2014.

In 2011 - 2012, two research projects that looked at researchers’ attitudes to consumer and community participation were conducted by Program staff in collaboration with Bec Hanley, Professor Jane Heyworth from the School, Health Sciences student Cindy Phoung and external researcher Dr Caroline Bulsara.

The projects were:

- **Researchers’ perceptions of barriers to consumer and community participation**\(^{(23)}\); this qualitative study used in-depth interviews and focus groups at the School and the Institute. It was found that researchers involved in qualitative research had a greater appreciation of the value of consumer and community participation than researchers involved in epidemiology or laboratory research. Despite this difference, all the participants felt that there was value to having meaningful consumer involvement.

- **An evaluation of the effectiveness of the training workshops for researchers**; a survey of training workshop participants aimed to assess changes in awareness, attitudes and behaviours before and after undergoing the training. Surveys were sent to 160 researchers, students, clinicians and administrators who had attended training workshops between 2009 and 2012 and 100 of these were returned. Of the 74 respondents who answered the question ‘How relevant was consumer and community participation in research to you prior to...
the workshop and since attending the workshop?”, only 24% answered ‘very relevant’ prior to the training, while 57% found participation to be very relevant after training. Of these respondents, 77% considered that the workshop helped explore ideas to overcome barriers to participation.

**Changing behaviours**

An organisational strategy on consumer and community participation was developed in 2004 by Program staff with support from Professor Holman, Head of School, and Professor John Finlay-Jones, Deputy Director of the Institute. Details of this strategic plan can be found in the section on Governance and Services. The strategic plan included an audit of current activities which was conducted with selected researchers at the School and the Institute in 2004, along with other consultation processes.

You were very encouraging and gave great examples of how to involve consumers and the community. The evidence for how consumers and community participation enhanced research in the UK and Australia was compelling and inspiring.

**Workshop attendee, 2012**

The audit questions were developed with a two-fold aim of assessing current activities and providing opportunities for researchers to consider ways to increase consumer and community participation in future projects. The audit was conducted by the Consumer Advocate who met with the selected researchers. They discussed and completed the audit questionnaire together.

Overview of responses to the audit in 2004:

**Leadership:** Prominent researchers need to facilitate cultural acceptance of consumer and community participation and publicly acknowledge value

**Advocacy:** School and the Institute-wide platform and guidelines are required for consumer and community participation

**Education:** Strategies and checklist for consumer and community participation to be considered and budgeted for in infrastructure and projects

**Community links:** Continue the dedicated role of Consumer Advocate to facilitate collaboration

A joint School and the Institute workshop on consumer and community participation was held in September 2004 and was attended by eighteen researchers. There was a presentation of findings from the audit, a summary by the Deputy Director of the Institute and discussion on forward planning.

The Heads of the nine research groups at the School completed a second audit of participation activities in 2010. The Council at the School then developed a series of recommendations from the audit responses, which were included in a final report of the audit in 2011. These were gradually implemented across some research and teaching programs at the School and can be found in Appendix 4.
Some of the recommendations which related directly to the evaluation of the Program included:

- Encouraging researchers who have consumer and community participation in their projects to include descriptions and/or acknowledgement of such activities in their publications.
- Developing processes and templates for consistent annual reporting of consumer and community participation activities, evaluation of consumer and community participation activities, sharing of stories and good practice examples.
- Implementing a system of ‘buddying’ a Council member with a research group to provide ongoing individual advice and expertise.

A repeat of the 2010 audit of consumer and community participation activities in research was carried out with researchers at the School in 2013. The audits were compared to see if there had been changes in activities and attitudes over time.

![Figure 3: Comparison of the responses to survey questions in the 2010 and 2013 audits at the School, averaged over nine research areas.](image-url)
The same audit was conducted in 2013 with researchers at the Institute who were involved in the NHMRC Program Grant *Early developmental pathways linking health, disability, education, welfare and justice* (2010 - 2014). The audits were used for future planning of the Program.

The audits in 2010 and 2013 at the School consisted of a questionnaire that was sent to the heads of the nine research groups. Responses were scored according to an assigned value of 0-5 depending on the level of consumer and community participation reported, with 0 being no participation and 5 being the highest level of participation. Non-applicable questions were not assigned a value. Appendix 4 contains details of the questions and scoring system. Comparison of the responses from the 2010 and 2013 audits at the School found that almost half of the respondents scored a high level of participation in 2013 compared to a quarter in 2010. There was a decrease in responses scored as low participation in 2013, compared with 2010. More research groups had a stated policy or demonstrated commitment to consumer and community participation in 2013 than in 2010. A comprehensive report of the comparison of 2010 and 2013 audit responses has been prepared by Program staff. As can be seen in Figure 2, the levels of participation, averaged over all nine research groups surveyed at the School, increased from 2010 to 2013.

Other evidence-building activities

The Program has been involved locally, nationally and internationally in various methods of building evidence to support consumer and community participation in research. These include initiatives of the Program, such as the research buddy trial at the School. In addition, there has been involvement of Program staff in collaborative activities that have, and will, assist in evaluation of the work of the Program and evaluation of broader changes in awareness, attitudes and behaviours.

The concept of a consumer research buddy was new to us. We elected to participate so as to deepen consumer involvement in our research program. It has proved to be a very positive step for us, and this was partly due to the enthusiasm of the consumer who put her hand up to be the buddy in our group. We now have a new national grant that includes consumer participation and the consumer buddy is a named associate investigator. We will continue to recruit more consumer buddies as required in all aspects of our research.

Frank Sanfilippo and Tom Briffa
The School, 2015

Research buddies

The research buddy method, which involves pairing consumers or community members with researchers for the purpose of ongoing advice and support, was successfully trialled with the Cardiovascular Research Group at the School in 2012. Responses from the audit in 2013 of consumer and community participation
at the School showed a marked increase in consumer and community participation activities for this group, attributed by the audit respondents to input from the research buddy.

**Promotion of events to consumers and the community**

The Institute held two community conversations in 2013 to seek community feedback on research that looked at the impact of school attendance on academic performance. The community conversations provided an opportunity to compare methods of inviting consumer and community attendees to forums and events. The Program’s strategies of advertising and promotion through community networks and the Participation Network database attracted eight times more attendees to the community conversations than a telephone survey. This telephone survey involved a random sample of Perth metropolitan residents and had been put forward as an alternative method of informing consumers and the community of upcoming events.

**Shared learning**

The Consumer Advocate was invited in 2013 to participate in a UK study that aims to develop consensus-based guidance for reporting on the involvement of patients and the public in health and social care research. Results of the three electronic surveys that inform the development of the *Guidance for Reporting Involvement of Patients and Public Checklist*\(^{(25)}\) will be published and the resulting guidelines will assist researchers worldwide with reporting of consumer and community participation activities.

**Launch of the Lotterywest WA Data Linkage Infrastructure project WA**

Planned evaluation is part of a grant entitled *Data Linkage Australia: Development and expansion of data linkage infrastructure for Western Australia to support health research*. This collaboration between the WA Department of Health and academic partners at Curtin University, UWA and the Institute was funded by Lotterywest in 2013. The grant provides the Program with independent funding in 2013 - 2016 for *Program 3: Consumer participation in linked data research*. Outcomes of Program 3 will include the development of online training specifically targeting researchers using linked data and expansion of the Program’s network and website. The outcomes will be evaluated to inform future activities of the Program.

*Let’s Get Smart Community Conversation*
Publications

Increased awareness of the need to develop an evidence base led to advocating for publications focussing specifically on methods and impacts of participation. Also, the Program offered assistance to researchers to support discussion of their consumer and community participation experiences within their publications. This could include the particular participation activities they utilised and benefits or issues arising during their research. Publications on participation methods and experiences (15, 26, 27) were made available via the Involving People in Research website. This is one aspect of a diverse consumer and community participation strategy that emphasises transparency and open access to information in addition to adding to the evidence base.

Consumers facilitating at forums

Consumers and community members having a say
CASE STUDY

Western Australian Register of Developmental Anomalies
2006 - 2012

Voluntary notification to the Western Australian Birth Defects Registry and Cerebral Palsy Register in Western Australia had been in place for many years prior to the establishment of the WA Register of Developmental Anomalies.

In order to allay concerns about privacy and ensure consistency and confidentiality of data, a request for statutory notification was made by data custodians to the WA Minister for Health. Community consultation was considered essential and the Minister required consensus between participating stakeholders and consumers.

Professor Carol Bower, in her capacity as Head of the Birth Defects Registry, came to the Program seeking support for community involvement in the statutory notification process. A workshop was organised and facilitated by the Consumer Advocate in May 2006 which involved nineteen invited attendees from consumer support groups, the Health Consumers’ Council WA, the Genetic Support Council of WA, the Ministerial Advisory Council on Disability, WA Department of Health staff, registry staff and registry advisory committees.

A second workshop was held in October 2006 with consumers and community groups. At this workshop participants reached a unanimous decision in favour of statutory notification. This was conditional upon including consumer input in the development of the statutory notification and that comprehensive and open information would be provided to consumer groups and the community.

Agreement was also reached on the name change for the new, combined register to the WA Register of Developmental Anomalies. Some workshop attendees continued their involvement by becoming members of the consumer reference group formed in 2007 and ensured that the agreed conditions for statutory notification were met. The legislation was enacted in 2011.

To inform consumers and community members of the changes to the reporting process following the legislation and to receive feedback, a community conversation was held in Perth in 2011. A second conversation was held in Broome in 2012. The two events had a combined attendance of 45 parents, carers, health service providers and community members. The reference group continues to provide support and advice to researchers and disseminate information to the wider community.
CASE STUDY

Evaluating Costs, Accessibility of Care and Availability of Support Networks for Catastrophically Injured Persons and Those Involved in Their Care in Western Australia 2008 - 2010

A research project conducted at the School and funded by the Insurance Commission of WA entitled Evaluating Costs, Accessibility of Care and Availability of Support Networks for Catastrophically Injured Persons and Those Involved in Their Care in Western Australia used a methodology that involved consumers as equal partners in the research process. The Consumer Advocate was a chief investigator on the research team. A thirteen member Steering Panel which was convened in 2008 included consumers, carers, Consumer and Community Advisory Council members, researchers, government agency representatives, members of service provision organisations and members of the Health Consumers’ Council of WA. The Steering Panel provided invaluable input into all aspects of the project, particularly around the sensitive issues about how the data would be collected. Data collection through surveys and interviews with injured persons, carers and service providers in 2009 resulted in a report being published in 2010 by the Australian Centre for Economic Research and The UWA Centre for Health Services Research. Contained in the report is acknowledgement of the influence of consumer and community participation in research, as outlined in the following quote:

This project embraced the philosophies of this work and developed a unique approach to investigating the issues from a consumer and community perspective. In order to achieve this, consumers, carers and researchers were equal partners throughout the entire research process. Since consumer and community participation from the outset has been essential to the success of this project, a steering panel was formed with responsibility for all aspects of the project: design, data collection, analysis and interpretation, and dissemination of results. The role of the panel was to identify relevant and appropriate research issues that fall within the mandate of the project, determine how best to gather and interpret information about these issues from consumers and carers, and determine appropriate strategies for disseminating the results of the study.

The report was later disseminated to local and national disability advocates working on the National Disability Insurance Scheme.
COMMUNITY AND STAKEHOLDER INTERACTION

Community interaction was integral to the planning and development of the Program. Ensuring that involvement benefited consumers, the community, researchers and other stakeholders, guided the development of the Program components from 2004 - 2014. Mutually respectful partnerships have developed from the ongoing relationships between consumers, community members and researchers. Implementation of the Program’s strategic framework, details of which can be found in the section on Governance and Services, commenced in 2004 in conjunction with consultation workshops and forums for researchers, consumers and community members.

My work on Rett syndrome was really partly instigated by Bill Callaghan, the president of the Rett Syndrome Association of Australia (the family group) wanting information about Rett syndrome in Australia in 1992. I could not have initiated or undertaken this research without the inspiration and involvement of this group at a very early stage.

Helen Leonard
The Institute, 2014

Community interaction 2004 - 2006

A consumer and community meeting was held in December 2004 to seek community input into ways to increase participation in research and engender greater trust in the research process at both organisations. Participants also discussed the type of supports required to enable this. Twenty five of the 31 attendees wanted to continue being involved in consumer and community participation activities. These interested consumers and community members provided their contact details to the Consumer Advocate. The collation of a list of contact details over the ensuing years ultimately led to the establishment of the Participation Network in 2012.

The findings and recommendations from this meeting were to:

✦ Establish consumer/community roles in steering groups for current research projects
✦ Develop plans to implement consumer and community participation in all current and future research projects
Address communication strategies, remuneration for consumers, training for researchers and consumers, budgets for consumer and community participation

Invite interested consumers and groups to participate in steering groups responsible for development and implementation of the Consumer and Consumer Advisory Councils at the School and the Institute

Identify areas of need such as training for researchers and consumers, funding and communication

Establish the Consumer and Community Advisory Councils (Councils), a policy on consumer and community participation and researcher and consumer training in 2005

Establishing an environment for researchers, consumers and community members to express concerns and consider solutions to address them provided the foundations for strong, ongoing relationships. The issues or barriers identified by researchers, consumers and community members were critical in the planning and development of the Program. Consumers and community members discussed issues about language, lack of information about

research projects, remuneration, relationships and trust as being important. Researchers were concerned about clearly defined roles for consumers, the lack of guidance and support from funders, financial resources and evidence and value of the benefits. Whilst these concerns were raised consistently in early workshops and forums, all participants at the workshops remained supportive of the concept of increasing consumer and community participation and highlighted the need for training, support and targeted activities and resources. The potential for the barriers, real or perceived, to hold back widespread acceptance by researchers for increased consumer and community participation across the School and the Institute was acknowledged by the Program. Addressing the barriers informed the development of a range of Program resources for researchers such as the Green Book, entitled Consumer and Community Participation: a Practical Guide for Health and Medical Research Organisations\(^{(10)}\), which was published in 2007.

Relationships between researchers, consumers and community members were strengthened by initiatives that began in the period 2004 - 2006, particularly the establishment of the Councils, detailed in the section on Governance and Services. Community interaction with researchers
and other stakeholders increased capacity and confidence in the Program. This increased capacity and confidence supported the development of the structured methods detailed in the Methods of Participation section of this report. Case Studies within this report provide details on selected good practice examples in 2004 - 2006 such as *The Western Australian Audit of Surgical Mortality* and Seniors Projects at the School and The Developmental Pathways Project and *Western Australian Register of Developmental* Anomalies at the Institute.

**Community interaction 2007 - 2010**

During the period 2007 - 2010, consumer and community participation as standard practice was being promoted by champions at the School and in the Division of Population Sciences at the Institute. The Councils provided opportunities for consumers and community members to interact with researchers and administration staff at the School and the Institute. These opportunities included senior staff regularly attending the quarterly Council meetings to provide updates and seek input on activities such as the development of a NHMRC Program Grant application. This demonstration of leadership by champions was enhanced by an increase in senior level support for consumer and community participation thus contributing to the development of good practice examples which valued consumer and community contributions.

Within the Division of Population Sciences at the Institute, the Infectious Diseases Community Reference Group and the Child Development Study Steering Group (which included two Council members) were formed in 2007. Support and involvement with existing reference groups continued.

*Infectious Diseases Community Reference Group*

Three focus groups were held in 2007 with parents who participated in the *Down Syndrome Needs Opinions Wishes Study* to seek input into the issues they wanted highlighted in the final report of the study. Consumer and community participation was included in the strategic planning activities for the Division.

*Proper consumer and community participation is an essential element of world class research. It grounds the research in the reality of those who should be the first beneficiaries. To better understand the world that we live in should not just be the domain of researchers, instead it should be a process that essentially celebrates our common humanity and encourages us to use new discoveries to effect positive change - be that at a policy, program or at an individual and family level.*

_Glenn Pearson_  
The Institute, 2015
A workshop was held in 2008 with researchers from the Centre for Health Services Research at the School to discuss and develop a list of priorities for future research. Following this workshop, members of the Council at the School were presented with the researcher’s priorities and asked to list their top ten priorities. The difference in priorities is shown in Figure 4.

In 2009, Council members at the School were involved with the development of the School’s Strategic Plan 2009 - 2013\(^{(28)}\). Equal value was given to staff, student and consumer input. Council members were invited to undertake a process of identifying priorities.

Strategic initiative 9, Building an ethos of participation, was the result of this process and included three goals:

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**Researcher Priorities**

1. Cancer prevention and treatment
2. Complementary therapies
3. State and national health priorities
4. Obesity
5. Mental health conditions
6. Pharmacoepidemiology
7. New and emerging issues
8. General health services utilisation
9. Geographic based research
10. Clinical trials of interventions

**Community Priorities**

1. Aboriginal health
2. Mental health conditions
3. General health services utilisation
4. Research on consumer participation
5. Primary and community care
6. Diagnostic imaging
7. Aged care
8. Cancer prevention and treatment
9. Complementary therapies
10. Emergency medicine

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*Figure 4: Comparison of researcher and community priorities in 2008*
✔ To develop community participation as standard practice
✔ To establish a community participation centre
✔ To facilitate community participation research

A collaboration between the Health Consumers’ Council WA, the Kwinana Community Action Group, Dr Angus Cook (an environmental researcher at the School) and the Consumer Advocate was formed in 2008 to seek funding for a participatory action research project to explore health issues within the Kwinana area. Attempts to secure funding were not successful and the research was not conducted. An ongoing relationship between the Program and members of the Kwinana Community Action Group was formed at this time. Members of the Kwinana Community Action Group have been strong advocates for consumer and community involvement in research and for research funding, such as during the Discoveries Need Dollars campaign in 2011 when they wrote letters and circulated information to their networks.

In 2009, the WA Department of Health funded a project at the Institute, the Kwinana Children’s Respiratory Health Study, which looked into respiratory health of children living within the Kwinana area. The knowledge gained from the earlier work with the Kwinana Community Action Group and the ongoing relationships that had resulted assisted in the establishment of a community reference group for the new study. The joint nature of the Program facilitated the transfer of knowledge between the School and the Institute. The Kwinana Children’s Respiratory Health Study Community Reference Group had input into the questionnaire, the data collection and the dissemination of the report to the community. Associate Professor Peter Franklin, one of the lead researchers in the project who worked at the School and the Institute at the time, received a Consumer and Community Participation Award from the Councils in recognition of his work with the community reference group. His work to ensure that all views were aired and respected even if not all ideas could be fully implemented in the project was considered by the Council as a good practice example of working with the community and other stakeholders.

The Growth and Development Study at the Institute established a reference group following a meeting with 25 interested community members in 2009. The Growth and Development Team decided to take advantage of technology and explored the use of blogs and Facebook to better...
engage with the reference group and community members. Whilst the consumer and community participation activities in this project were fully supported by the researcher’s commitment to increasing involvement in the project, the limited uptake by community members meant planned activities could not be fully implemented.

Following the success of community forums held in 2006 and 2007, a structured process to increase the community voice and enable researchers to make connections with consumers and community members was developed and piloted by the Program in 2009. Three community conversations were held in 2009, one of which was for the Raine Study at the Institute. This community conversation for study participants aged 17 to 20 years of age was featured in a West Australian newspaper Health + Medicine supplement in 2009 and included interviews with participants and Institute and Program staff(29). The Community Conversation, as a method of interaction between researchers, consumers, community members and other stakeholders became an important and influential component of the Program in subsequent years. Feedback from attendees is used by the Program to plan for future conversations. Details of Community Conversations held at the School and the Institute 2009 - 2014 can be found in Appendix 2 and a proposal to support community conversations at the Institute is included as Appendix 9.

Community interaction 2011 - 2014

Consultation with consumers and community members continued in diverse ways throughout this period. Community Conversations and forums were organised and facilitated. Details can be found in the Methods of Participation section. Some

Wow, this is a tremendous resource. You are really dissolving that barrier between researchers and the community in such a friendly way. I love the simplicity of the website and yet it’s information-rich. Well done.

Emma Glasson
The Institute, 2011

This is excellent! Well done! It is very clear, informative, accessible and thorough, as well as being engaging and friendly. I enjoyed reading it. I’ll pass this on to interested people, including INVOLVE.

Rosemary Barber
Sheffield University, UK, 2011

I am delighted to see this website - it is great and just right

Fiona Stanley
The Institute, 2011
reports on Community Conversations were made available on the Involving People in Research website, the Program’s online resource repository and information hub. Launched in 2011, the website contains the Fact Sheet Series (2011), the book Consumer and Community Participation, a Practical Guide for Health and Medical Research Organisations (2007) and many other resources. The website www.involvingpeopleinresearch.org.au facilitates a culture of shared learning and promotes community interaction.

Institute Council members provided a community perspective to the Institute’s 2011 grant applications and review process, which included a community member (Chair of the Council) on the grant application review panels that provided support and feedback to researchers submitting grant applications in 2011 and 2012.

Facilitating greater community involvement by providing advice and resources to researchers in establishing reference groups continued from 2011. This was supported by the development of the Participation Network, a database established by the Project Officer to house the details of consumer and community representatives. The Participation Network was developed with input from the Councils at the School and the Institute and launched in February 2012.

I think it is a fantastic to set up this network – it is much needed in WA and the matching service is wonderful. I would absolutely use it and I think it would remove a lot of the main barriers to collaboration for researchers and community members – well done!

Anna Kemp
The School, 2012

Delighted to become involved in this Network

John Stubbs
CanSpeak, 2012

The Participation Network strengthened links with consumers and community members in various ways that has increased knowledge and awareness of research and consumer and community participation. These included:

- Provision of information on hot topics and issues of interest
- Promotion of opportunities to be involved in research projects
- Details of current and new research projects
- Advertising of training workshops for consumers and community members
- Promotion of community events and forums

Participation Network members
By May 2014 the Participation Network had 160 registered members from across Western Australia with links to 86 consumer and community organisations also registered on the Network. Additionally, the database contained contact details of 400 consumers, community members and researchers who receive information about the Program and associated issues. A national Alliance Network was established to inform consumers and community organisations throughout Australia of the Program’s activities and a quarterly newsletter (Network News) is distributed to members.

A workshop on issues relating to participation, facilitated by the Consumer Advocate and Bec Hanley, was held in 2012 with consumers, community members and researchers. Issues identified and discussed included boundaries and roles, dealing with hostile or neutral co-researchers, challenging consumers, and how consumer and community participation can move forward.

For the 2013 Better Practice Conference of the Aged Care Standards and Accreditation Agency in Perth, the Program had input into a presentation on the School’s Beyond the Teaching Nursing Home: a Community Partnership of Learning and Care Project. This contribution, regarding the consumer and community participation aspects of the project, was enhanced by the participation of two senior consumers in the presentation. The project is an example of researchers, consumers and community members and the facilitators who support the partnerships benefitting from collaboration. Further details on this project can be found in the Case Studies.

The official launch of the newly renamed Telethon Kids Institute took place with a community celebration in March 2014. Consumers and community members of the Council and those who took part in the strategic planning process were invited. A Community Research Expo was held at the Institute in July 2014 to raise awareness in the community of research being undertaken at the Institute. Sixty consumers, community members and their families attended to hear presentations on research projects being conducted, view posters of research studies and have opportunities to talk to researchers. Additionally, consumers and community members expressed their interest in taking part in future research activities. Eleven community members subsequently joined the Program’s Participation Network.

Participation Network members at the Telethon Kids Institute Launch and at the Strategic Planning Forum
CASE STUDY

Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder Research 2006 - 2013

The research project at the Institute funded by Healthway and entitled Alcohol in Pregnancy: Health Promotion for Health Professionals was an example of a study that included a strategy of planned and funded consumer and community participation activities.

Collaboration with Program staff occurred at all stages of the research, from inclusion on the grant application to publication of the results. Two Community Reference Groups (one Aboriginal and one non-Aboriginal) were established to provide consumer and community perspectives on the conduct of the research, the development of resources for health professionals and the translation of the results. Consumer and community participation in the project was evaluated and published in the journal Health Research Policy and Systems in 2011(27).

For the Alcohol in Pregnancy: Health Promotion Messages That Work project, a consumer and community reference group advised on aspects that included a state-wide media campaign on alcohol in pregnancy.

A national project to develop a screening tool for diagnosing Fetal Alcohol Spectrum Disorder (FASD) in Australia followed. The FASD: Development of a Screening Diagnostic Instrument for Australia was funded by the Commonwealth Department of Health and Ageing and led by Institute researchers. Consumers and community members were involved in all aspects of the project, including the steering group. At this project’s community conversations, held in Perth in 2010 and in Cairns in 2011, feedback was sought from women about how they would like health professionals to discuss alcohol consumption during pregnancy. This feedback informed the development of a Delphi Survey conducted with health professionals.

The Australian FASD Collaboration was responsible for the project and included community members, clinicians, epidemiologists, researchers and policy makers. Consumer and community involvement was considered integral to the success of the project. As stated in a 2013 article (25) in Health Research Policy and Systems ‘Consumer and community participation was considered essential to good research practice that makes research relevant to the community and gives researchers a real passion and sense of relevance to their work’. Staff involved with these projects received the Health Consumers’ Council WA Excellence Award in 2009.
CASE STUDY

Developmental Pathways in WA Children Project 2005 - 2015

The Developmental Pathways Project, a collaboration between the Institute, UWA and multiple WA government jurisdictions, was funded by two consecutive Australian Research Council Linkage Grants with contributions from collaborators. Initial funding in 2005 was followed by funding in 2010 for five years.

The cross-agency collaboration linked de-identified, population-based data to investigate pathways to health and wellbeing of children and youth in WA using data on education, disability, child maltreatment and juvenile offending outcomes. Research into the determinants of these outcomes and their interrelationships informed planning, practice and policy initiatives affecting children, their families and communities in culturally appropriate and cost effective ways.

Discussion about the involvement of community members in the project was ongoing for a number of years. Project staff and PhD students attended an awareness-raising session about the value of consumer and community participation in 2005 and met with community members. Some students sought input from these community members for the duration of their projects. A forum for staff, PhD students and consumer representatives was conducted in 2006. Later, researchers sought consumer and community input into the development of the second Australian Research Council grant application.

A community conversation held in 2009 involved the presentation of questions and grant proposal details from the steering group for feedback. This feedback and the community priorities had an impact on the final grant application, including proposing the addition of housing data, which had not been considered for the initial application. Community members felt that this was an important factor in developmental pathways.

In 2011, 60 consumers and community members attended two community forums to discuss data linkage and the preferred model for a community advisory group. The second forum was organised in response to consumer and community requests for additional information. A reference group was established and included sixteen community members who were involved with or had an interest in the government agencies which were part of the project collaboration. They provided community support for this large data linkage project and for the translation of findings with implications for future policy and practice.
The early development of the Program’s methods of consumer and community participation in research drew on participation experiences and methods of increasing involvement in health service delivery. These experiences were able to be adapted to suit a research environment. Examples from America and the UK were looked at and a review was conducted in 2004 of organisations that incorporated or advocated for consumer and community participation. A continuous quality improvement model of ‘Plan-Do-Check-Act’ was agreed upon after input had been sought from key stakeholders such as researchers, students, the Health Consumers’ Council WA and consumer and community representatives from a range of community organisations. Establishing some benchmarks regarding attitudes, understanding and barriers were priorities in the planning of Program activities.

Conducting workshops for staff at the School and the Institute and for consumer

In my area of research as a PhD student, the most important outcome I hope to achieve is to influence in some small way policy and practice that will support families with young children in local communities. I now understand that involving consumer and community representatives will assist this. I have experienced, through attending Anne’s workshop and as a member of the Consumer and Community Advisory Council in SPH, several light bulb moments to do with the benefits of involving consumers and community members across different areas of health research. Involvement doesn’t have to be huge to be effective – it is important to have consumer and community involvement appropriate to the research area and particular study. I have observed many happy campers (researchers and consumer/community members) where consumer and community involvement has been embraced!

Cecily Strange
The School, 2015

and community members was identified as a priority for achievement of the aims of the Program, as stated in the Consumer and Community Participation Strategic Plan 2004 (refer to Appendix 5), which were to:

- Acknowledge the various levels of participation
- Understand and respect the contributions of each party
- Willingly share knowledge and power
Consultations and forums were held in 2004 and 2005 at the School and the Institute where work began on developing strategies and a range of participation methods for individual research projects. These methods would prove to be varied and flexible, adding to the expertise and broadening scope of the Program. This range of methods was developed in conjunction with expanding collaborations with the Health Consumers’ Council WA, support groups and community organisations. A Western Australian Audit of Surgical Mortality Consumer Roundtable Meeting was held in 2004 as part of research conducted at the School (included as a Case Study on page 44). Collaboration with the Western Australian government Office of Children and Youth was established to increase opportunities for young people to be more involved in research, including holding a workshop in 2005. Also in 2005, the Raine Study Consumer and Community Participation Forum was held at the Institute for parents and study participants. There were 40 attendees and a Youth Reference Group was subsequently established. The Program supported the Rett Syndrome Project at the Institute to establish an Australia-wide parent group which had input into the 2006 Rett report and other activities. A pool of consumer and community representatives available for positions and consultation was established and, in 2006, a consultancy service commenced for researchers writing about proposed consumer and community participation in grant applications.

As uptake of the ethos of consumer and community participation by researchers at the School and the Institute increased, collaborations and networking opportunities between consumers, community members and researchers expanded, as did planned and funded activities in grant applications. The increase in collaborative networks and dedicated funding enabled the development of methods specifically designed to address the needs and barriers identified at community and researcher forums.

Methods of participation developed and supported by the Program include:

- Writing or commenting on documents
- Consumer and community forums
- Consumers and community members in research teams
Research buddies  
Reference groups  
Steering groups  
Consumer and community researchers  
Consumer and Community Advisory Councils (Councils)

The national Involving People in Research Symposium, hosted jointly by the School and the Institute in 2008, was another method of participation that showcased the Program, established and reinforced networks and informed the development of later resources. Further details of the Symposium can be found in the section on Advocacy and Advice. Influential case studies describing methods of participation used by a range of research projects are included in this report.

Council involvement with the Strategic Plan at the School began in 2007 with a forum that included Council community members and the School Executive Committee. As part of the consultation process for the 2009 - 2013 Strategic Plan, the Council was involved in planning processes, including the development and implementation of Strategic Initiative 9: Building an Ethos of Participation. Equal weighting was given to input and voting on strategic goals from staff, students and the Council. In 2013 a community conversation was held to seek input from the Council, community members and stakeholders from government and community organisations on the development of the 2014 - 2017 Strategic Plan. The feedback from the community conversation informed the development of the goals, which were then circulated to staff, students and...
Ready accessibility to a consumer perspective as a resource for research planning, governance and dissemination is what I value most about having a Consumer Council associated with our academic School. It’s the immediacy of the capacity to interact with an independent consumer voice, which also knows enough about research and how it works, that makes the difference.

D’Arcy Holman
The School, 2012

attendees from the community conversation for ranking and prioritisation. Again, ranking from the Council, community members and stakeholders was given equal weighting to that of the staff and students.

The Council at the Institute was involved in strategic planning during 2012 and 2013. A community conversation was held in 2012 regarding the strategic plan for the Institute. Current and past Council members attended. The Director of the Institute, Professor Jonathan Carapetis, told the Council in March 2013 that the community input was reflected in changes made to the original plan, including the vision statement, ensuring the community perspective was integrated into the Institute’s *Working Together* Strategic Plan 2013 - 2017.[30] One point of the Strategic Goal 2 ‘We will work together with stakeholders to achieve the best health and well-being outcomes for children’ is outlined in the following commitment:

‘We will further develop our community and consumer involvement programs, and establish other forums between stakeholders and researchers, to ensure a two-way dialogue with relevant sectors of the community and recognise the importance of the people’s voice in making research relevant’

![Research Buddy facilitating a Community Conversation](image)

**Research buddies**

The Council at the School was influential in the development of a ‘buddy’ method of participation trialled in 2012 with the Cardiovascular Research Group. A Council member took on the role of the research buddy for this group and provided advice as required. Contributions from the research buddy included...
inclusion as an Associate Investigator on a grant application and involvement, with research study staff, in the project’s participation activities. Researchers from the Cardiovascular Research Group, in their response to the audit of consumer and community participation activities at the School in 2013, attributed increased consumer and community participation activities to input from the research buddy.

Steering groups and reference groups

Steering Panel workshop for research on Costs Associated with Catastrophic Injury

Between 2004 and 2014 Program staff provided assistance and advice with the establishment of many steering and reference groups for projects at the School and the Institute and externally. Assistance was often ongoing and in many cases input began in the planning stages with advice on inclusion of planned and funded consumer and community participation activities in grant applications.

A steering group has involvement with the direction of the research and may include members who are researchers, clinicians, policy makers, health administrators, consumers and community members and representatives of advocacy or non-government organisations. A reference group is a group of consumers and community members that can be consulted throughout the duration of the research project. Reference groups can provide advice for all or part of the research and members of the research team may also be included and report to the reference group on research progress and issues. Reference groups can be particularly helpful in getting information out to a large number of people who may have an interest in the research conduct or findings. Providing adequate support in the form of training and remuneration for community members is vital to the success of this method of participation as it addresses potential barriers of inequality and mutual respect.

Further information about steering groups and reference groups can be found on the Program’s website, www.involvingpeopleinresearch.org.au.

Community forums and events

The early forums, meetings and workshops which were facilitated by the Program were not planned using specific methods but were influential in the subsequent development of participation methods. The Community Forums in 2006 and 2007 for the Seniors Projects at the School (refer to Case Study on page 45) and attendance by the Consumer Advocate at a consumer event...
A forum on priority setting for research held by Cancer Council NSW informed the development of community conversations. Feedback from Seniors Project forums, which had a combined attendance of 104 consumers and community members, was particularly helpful in the development of this method of participation. The aim of a community conversation is to inform consumer and community members about current research projects and to seek their input in identifying any perceived gaps and priorities for future research. Community conversations were organised and facilitated by the Program from 2009.

Two workshops were held in 2006 for Institute researchers and other stakeholders to consult with consumers and community members about proposed changes to the Western Australian Birth Defects Registry and Cerebral Palsy Register (refer to Case Study on page 55).

Community forums were held at the Institute in 2007 for parents involved in Rett Syndrome research and for the Growth and Development Study (which held a second forum in 2009). Three stakeholder focus groups for the Down Syndrome Needs Opinions Wishes Study at the Institute were held in 2007 to ensure the needs of parents, the Down Syndrome Association, service providers and policy makers were taken into account in the development of the final report\(^\text{[31]}\). In 2008 an initial community forum with researchers from the School and representatives of the Kwinana Community Action Groups established relationships that helped in the subsequent funding to the Institute in 2009 for the Kwinana Children’s Respiratory Health Study; this study held community forums in 2009 and 2011.

The community conversation method of participation has enabled planning and resource development for the Program and
for individual research projects as well as opportunities for community interaction. Details of community conversations held between 2009 and 2013 highlight this method of participation at the School and the Institute and can be found in Appendix 2. A significant issue raised at Institute community conversations in 2009 was the need for easy access to information about research projects, research findings and translation of those findings into policy and practice. This feedback influenced the Institute in the subsequent development of processes for dissemination of information to consumers and community members, including at two community meetings in 2013 to seek feedback from consumers and the community on the accessibility and usability of the proposed Institute building.

Funding for the community conversations on disability, infectious diseases and the Raine Study was generously provided by the Collaboration for Applied Research and Evaluation at the Institute. Funding for all other community conversations has been provided either by the individual research projects or the Program.

**Community Expos**

A community expo, as a method of participation developed by the Program, is a forum that raises awareness in the community of current research at the School and the Institute. It is an opportunity for consumers, community members and other stakeholders to learn about research projects, talk with researchers and look for opportunities to work together. The Centre for Health Services Research at the School held a Community Expo in 2013.

**Community Expo**

The 21 community members who attended provided very positive feedback, as did the researchers who attended. Researchers made contact with new consumer and community organisations and some were subsequently invited to present about their research at community meetings. A Centre for Health Services Research community reference group was established in 2013 to provide input into strategic planning, ongoing advice and support to projects and enable researchers to establish new community links.

This method was used at the Institute in 2014 for a Community Research Expo.
sponsored by the 2010 - 2014 Program Grant and the Developmental Pathways Project. Sixty consumers, community members and their families attended the Expo to hear presentations, view posters of research projects and talk to researchers from the sponsoring groups. Eleven of these community members expressed their interest in taking part in future research activities by joining the Program’s Participation Network. The Expos have been a method of participation that facilitates knowledge translation between community members and researchers and enables information about research and research findings at the School and the Institute to be disseminated.

Knowledge sharing

The Program has facilitated a variety of methods of participation that enable consumers and community members to share their knowledge and experience with researchers and other stakeholders. These methods include providing comments on documents and project materials, developing grant applications, membership on committees and being consumer researchers on project teams. Input from consumers, community members and researchers also informed the development of the Program’s training workshops and resources, such as the Green Book. This book, entitled *Consumer and Community Participation: a Practical Guide for Health and Medical Research Organisations*[^10], was published in 2007 and contains contributions from consumers. The first and second editions have been in high demand from researchers. The Green Book is available from the Program’s website, www.involvingpeopleinresearch.org.au and the TwoCan and INVOLVE websites. The 1600 printed copies of the Green Book have been distributed to consumers, community members and researchers locally, nationally and internationally.

Community Expo

A Fact Sheet

The *Fact Sheet Series*, published in 2011 and also available from the Program’s website, evolved from an earlier resource, *Useful tips for researchers*, and addresses needs and barriers which were identified at consultations and training workshops. The 22 Fact Sheets offer assistance in different methods of involving consumer and community members in research, including setting up steering and reference groups and organising consultation forums.
I absolutely love the discipline of 1 side of A4 for all your Fact Sheets. This is going to be a brilliant resource for us to link through to when we re-launch our website with a new Training and Support section.

Philippa Yeeles
INVOLVE, 2011

The Program’s website, established in 2011 with the aim of supporting consumers, community members and researchers to work together in partnership to make decisions about research priorities, policies and practice, has encouraged the exchange of knowledge and information. More information on all the Program’s methods of participation can be found on the website, including journal articles describing consumer and community participation in specific research projects.

It was a humbling experience to explain my research to members of the wider community, most of whom support research through the taxes they pay. I was immediately taken from the world of research questions, and methods, and data to the world of people living their lives – some of whom suffer the very conditions I research. I learned that interaction between consumers and researchers does several things. It deepens the sense of urgency and responsibility to produce usable results; it builds relevance into the practice of science; and it creates invaluable advocacy for research and researchers.

Steve Zubrick
The Institute, 2015

FORUMS, WORKSHOPS AND COMMUNITY CONVERSATIONS

were organised and facilitated by the Program between 2004 and July 2014. Total attendance by consumer and community members was 1263.
Beyond the Teaching Nursing Home: A Community Partnership of Learning and Care 2011 - 2014

Beyond the Teaching Nursing Home: A Community Partnership of Learning and Care, also known as the Bethanie Project, was a collaborative partnership between The UWA Faculty of Medicine, Dentistry and Health Sciences and the Bethanie Group Inc. (Western Australia’s largest not-for-profit aged care provider). A refurbished facility in a Bethanie residence housed a clinical learning environment that facilitated the teaching of medicine, nursing, social work and podiatry students.

The project was funded by Health Workforce Australia and the Commonwealth Department of Health with key partners including the Central Institute of Technology, the West Coast Institute of Training and Leading Age Services Australia (WA). Discussions and consultations with the researchers, stakeholders and Program staff led to a process of community consultation in 2011. This included a community conversation facilitated by Program staff that was attended by 60 consumers and community members from the Bethanie hostel and independent living centre. A key part of this learning and training program was the contribution of senior consumers to health professional education and therefore their feedback and input into the conduct of the community partnership was vital to the success of the Bethanie Project.

Attendees at the community conversation were invited to nominate for membership of the reference group. The project was launched in 2012 with guidance and oversight provided by the project’s reference group. Membership of the Reference Group included Bethanie residents, Bethanie staff and a student representative. A project advisory committee was also established and included two members of the reference group and members from each partner group. Suggestions from the Reference Group which were adopted by the project included feedback forms and a participant charter.

In 2012, the Chief Investigator of the Bethanie Project, Professor Rosemary Saunders, received the School’s Award for Consumer and Community Participation from the Consumer and Community Advisory Council. The Bethanie Project was the recipient of The UWA Faculty of Medicine, Dentistry & Health Sciences Excellence in Teaching Award 2014 for Educational Partnerships and Collaborations with other organisations.
CASE STUDY

Consumer and Community Participation in Infectious Disease Research 2007 - ongoing

Infectious disease researchers at the Institute, with the assistance of the Program, established the Infectious Diseases Community Reference Group in 2007. Researchers, consumers, community members and representatives from the WA Department of Health and non-government organisations have met four times a year since then. Researchers demonstrated a commitment to inform the community about research activities undertaken and those planned for the future. Feedback and input from consumers and community members are considered central to a broader community understanding of the reasons behind research into infectious diseases. The group was funded by allocations specifically dedicated to consumer and community participation within the budgets of infectious disease research projects. Consumers and community members from rural WA were supported to participate in the reference group and Aboriginal membership was always considered essential to ensure that community interests and values were as widely represented as possible. The members have provided practical assistance to researchers in the form of feedback on proposed studies and letters of support to accompany ethics applications. From 2014, continuing support is being provided by the Wesfarmers Centre of Vaccines and Infectious Diseases at the Institute. Researchers, consumers and community members are jointly involved in preparing plain language summaries of all infectious disease projects at the Institute. Organisers of the reference group received the Consumer and Community Participation Award in 2011 from the Consumer and Community Advisory Council for their commitment to facilitating consumer and community participation within the infectious diseases research area.

The establishment of the Infectious Diseases Community Reference Group has opened a whole new dimension to our research. We have been both challenged and supported by this highly committed group of people from diverse backgrounds, ranging from young mothers to grandmothers, and representing minority groups, including Aboriginal people, refugees and those with disabilities. The group has asked us to provide them with information about specific diseases while, in other instances, has identified areas they would like researchers to research in the future. There is no doubt that the research has gained from learning what is important to consumers and community members and how to communicate research plans and outcomes of our research.

Deborah Lehmann
The Institute, 2014
In 2004, Program stakeholders recognised the need for a sustainability framework to bring about institutional change, enabling consumer and community participation to become part of standard research practice. The Head of the School, Professor D'Arcy Holman, and the Deputy Director of the Institute, Professor John Finlay-Jones provided guidance and mentoring in the preparation of the resulting organisational strategy for consumer and community participation. In May 2004, the School’s Executive Committee and the Institute’s Executive Committee endorsed the resulting Consumer and Community Participation Strategic Plan (Strategic Plan). This was followed by the development and endorsement in July 2005 of the Consumer and Community Participation Policy (Participation Policy). These documents are included as Appendix 5 and Appendix 6 of this report and while the School and the Institute have endorsed them through their individual governance frameworks, the content of the documents is identical at each institution.

The aims of the 2004 Strategic Plan and Participation Policy were to:

- Support the ethos of the NHMRC and Consumers Health Forum Statement on Consumer and Community Participation in Health and Medical Research
- Develop and implement strategies to expand and enhance current consumer and community participation and partnerships

Figure 5: Consumer participation planning cycle
Manage organisational change inclusive of staff and community values and ideas

Address NHMRC accreditation requirements

The intended outcomes were to:

- Audit current activities and conduct workshops to discuss goals and vision for enhanced consumer and community participation
- Establish a steering committee to develop plans
- Conduct staff awareness-raising sessions
- Establish Consumer and Community Advisory Councils (Councils)
- Provide reports on Program achievements

Consultation workshops and forums for researchers, consumers and community members commenced in 2004 to inform and support the implementation of the Strategic Plan. Planning was a cooperative process and input was sought from all interested parties and all organisational levels. The Participation Policy recognised the central role of health consumers and community members in research. The Participation Policy aims to foster partnerships in which consumers, community members and researchers shape decisions about research priorities, goals, methodologies, questions and dissemination of results. As a written document adhering to the Statement on Consumer and Community Participation in Health and Medical Research(2), the Participation Policy addressed a requirement for NHMRC accreditation as an Independent Research Institute.

In 2004 there was support from champions and senior research staff at the School and the Institute who accepted the importance of consumer and community participation and the potential for beneficial impact on their research. Consumers and community members were also interested and supportive, despite a lack of awareness, of the way research is funded, the ethics approval process, and the time required to develop and complete a research project. There was also a lack of understanding of terminology used by researchers.

Researchers expressed concern about the potential for adverse impact on their research projects from the possible involvement of consumers and community members who lacked fundamental knowledge of research processes or have an agenda or issue.

Consultations held in 2004 with consumers, community members and researchers, informed not just the implementation of the Strategic Plan but also the subsequent direction and priorities of the Councils and the development of participation methods and training to address issues which were raised at the consultations. An audit of
consumer and community participation activities, which was one of the intended outcomes of the Strategic Plan and Participation Policy, was conducted in 2004 with senior researchers at the School and the Institute. Details can be found in the section on Building the Evidence.

Establishing the Councils

A consumer and community meeting was held in 2005 regarding the establishment of the Councils at the School and the Institute. There were eighteen attendees and commitment for future involvement from others who were unable to attend. Recommendations from the meeting were to:

- Establish a steering committee
- Develop training for consumers to gain a basic understanding of research
- Compile a list of existing research projects
- Prepare a glossary of research terms

A joint School and the Institute steering committee tasked with developing a Council for each organisation was established. The steering committee met during 2005 – 2006 and was composed of senior staff from the School and the Institute and consumers and community members associated with the following groups:

- Health Consumers’ Council WA
- Down Syndrome Association of WA
- Arthritis Foundation of WA
- Diabetes WA
- Cochrane Consumer Network
- Cancer Council WA
- Aboriginal health organisations

The steering group made the decision to include senior researchers and students on the Councils. This was an innovative change to the original plan for the Councils but the steering group felt it was important to show leadership with consumers, community members and researchers working in partnership to enhance research through consumer and community participation.

As the inaugural Chair of the Consumer and Community Council at the Telethon Kids Institute I am extremely proud of the work that has been done and the continuing opportunities for the future. With the many research projects now collaborating alongside consumers and community and the continuing feedback through Community Consultations the landscape of research in this state has changed considerably for the better.

Ben Horgan,
Council Chair, the Institute, 2014

The development of a Council business plan was completed by December 2005. The Business Plan can be found in Appendix 7. The Councils were responsible for terms of reference, membership, guidelines, glossary of research terms and remuneration for members. Awareness-raising sessions with School and the Institute staff were conducted, including providing updates on consumer and community participation activities to the School’s Executive Committee and the Institute’s Board of Management.

The steering group applied the principles stated in the Participation Policy to the establishment of the Councils. Each Council was chaired by a community member and comprised community members, researchers, students,
administrators and the Consumer Advocate. The process of recruiting members included development of selection criteria and application forms, advertising in newspapers, interviewing applicants and making recommendations to the Head of the School and Director of the Institute.

Our Council received tremendous support from a succession of Deans of the School and in 2009 the new Strategic Plan included a Strategic Initiative specifically relating to the meaningful involvement of consumers and the community in research by the School. The Council was also recognised and asked to take part in the School’s Accreditation Review where, at our interview, the Panel were extremely interested in this unique initiative.

When I finally retired from the Council I looked back with great pride at the things we had accomplished, not least of which was a change of mind set by many researchers where inclusion of consumers and community members has become part of their “core business” leading to much more relevant and meaningful research and an attitude of partnership from all participants.

My involvement with the Council has been a very satisfying experience.

Barbara Daniels, Council Chair, the School, 2015

The role of each Council included:

- Contribute consumer and community perspectives on research undertaken at the School and the Institute
- Create links between consumers, the community and researchers
- Provide advice and expertise on consumer and community issues and priorities for research
- Advocate on behalf of consumers and the community
- Implement the Participation Policy for consumer and community representatives involved in research
- Have input into evaluation and reports on consumer and community participation
- Comment on the strategic planning and governance structures relating to consumer and community participation in research at the School and the Institute

Aboriginal involvement was integral to the ethos of the Councils and the Program. The Terms of Reference for each Council stated that the membership should include at least one Aboriginal community member. The early involvement with Aboriginal representatives on the Councils was the basis for long-term, ongoing relationships between the Program and Aboriginal community members.

Council and staff planning workshop at the School
Contributions of the Councils

The first meeting of the Councils was held jointly in December 2006. The Head of School addressed the meeting, supporting this important initiative and noting the potential for the Councils to play a key role in developing good practice methods as an example for other research organisations. Openness, accountability and transparency, particularly regarding reporting and implementation of research results, were seen as important. Statements on research being meaningful, responsible to the community and relevant were accompanied by an intention to break down barriers between researchers and consumers and the community. The contributions of the Councils to the directions and viability of the Program during 2006 - 2014 have been wide-reaching and varied.

Council activities 2007

The Councils identified needs which included lists of current research projects, potential areas where Council input would be beneficial and a glossary of terms and acronyms. The Councils were permitted to modify for Australian use the ‘Jargon Buster’ internet resource, developed by INVOLVE. At the Institute, opportunities were provided for the Council Chair to be on other Institute committees. Council activities were discussed at Executive and Board meetings. High level support at the School and the Institute increased the Councils’ profile, relevance, opportunities and motivation.

The Chair of the Institute Council presented with the Consumer Advocate at an Institute Scientific Forum in 2007 on the composition, role and potential of the Council, including ways to work with researchers to address sections of grant applications related to consumer and
community involvement. A consultancy service for researchers at the School and the Institute during the 2007 grant-writing period resulted in at least twelve grant applications being submitted with expanded consumer and community participation activities. The ‘Tips for Researchers’ resource was being developed at this time in response to the need for advice, enabling researchers to have a more informed perspective on the grant application requirements about consumer and community participation.

Serving on the Council was an opportunity to encourage collaboration between consumers and researchers. To be able to have an impact at a strategic level in a research institute and promote active consideration of consumer input was rewarding. The Participation Program has taken a series of strategies and ideas, and packaged them with practical examples and tools that make it easier for researchers and consumers to work together to have input into the design, implementation and practical application of a research project.

Julie Ireland, Council Chair, the Institute, 2014

The Council at the School contributed to planning for the School Review throughout 2007, including a delegation of Council community members meeting with the Review Team. The Council also advocated for an increased consumer and community participation component in teaching programs at UWA and during 2007 conducted lectures on consumer and community participation in research for students in the following courses:

- Bachelor of Health Sciences - 2nd, 3rd and 4th years
- Post Graduate Medicine - 3rd year
- Master of Public Health
- Summer School - Clinical Epidemiology

Presentations were made to the Councils by School and the Institute staff in 2007 on strategic planning and other areas of governance as well as existing and proposed research projects, enabling Council feedback to inform activities and a culture of reciprocity to be fostered. The Council’s input was integral to the development of the program and planning for the national Involving People in Research Symposium, details of which can be found in the section on Advocacy and Advice. The lack of criteria for the NHMRC to assess responses to questions in grant applications on consumer and community participation was recognised by the Councils as an area that needed to be addressed; a letter on this issue was prepared and sent to the Chief Executive Officer of the NHMRC. The Councils provided direct input into the recommendation and selection of consumer representatives for research reference groups. At the Institute, the Council had input into the proposed Mandurah Peel Study, and made recommendations for the Institute’s Quinnquennial Review.

The Council at the Institute provided a community perspective on the Division of Population Science’s Confidentiality Policy which later became an Institute-wide policy. The Consumer Advocate recommended that the School consider the Institute’s Confidentiality Policy and it was subsequently adapted and adopted, illustrating the synergy between the activities of the Councils and organisations they work with. The bridging function of the role of Consumer Advocate across both
Councils and as a member of committees external to the School and the Institute facilitated collaborations and enabled timely exchanges of information.

Researchers made presentations to the Councils on their projects and received feedback from Council members. In 2007 a process to evaluate the effectiveness of the advice given to researchers was discussed, developed and implemented. An evaluation form was given to all staff who had received Council advice. There was a low response from researchers in returning the forms which may have been due to the early developing relationships between the Councils and the researchers.

Appointment to and participation in an Advisory Council is a wonderful experience, the members bring a range of talents and perspectives along to meetings, and there are some very constructive interactions in both the strategic and decision-making activities. The academic members and other staff bring great value, providing presentations and insights often not otherwise available, and last though not least, Anne and her Consumer Advocate team provide very valuable professional advice, assistance and continuity. I am very confident the School, and indeed all of us, benefit greatly from this unique and constructive participation framework.

Ian Hill
Council Chair, the School, 2014

The Capacity Building Grant, which finished in October 2007, enabled the establishment and enhancement of many consumer and community participation activities. There were more than 60 community representatives engaged in the Council activities 2008-2013

An ongoing issue highlighted by the Council at the School was the limited information, readily available and accessible, about research being undertaken at the School. The Council continued to advocate for an overview of all research projects, including plain language summaries and research results, to be compiled and made available on the School’s website. The issue was
addressed at the Institute by the Infectious Diseases Community Reference Group, established in 2007, which subsequently worked with researchers to develop plain language summaries of the numerous projects being conducted by Institute researchers in this research area.

My first task was to grasp the language/the euphemisms. It was a bit like being washed up in a foreign land. I had the same feeling when I started sociology at uni. We developed Terms of Reference. We listened. The brave asked questions. Gradually we developed the idea that this was to be a two way street. It gradually became clear that, given a reasonable understanding of the research process, we might be able to demonstrate and deliver on how involving consumers and community in research would benefit all parties. I’m pleased to say that, for their part, Institute staff members on (and off) the Advisory Council continue to educate us and keep us informed and (mostly) relevant. With the passage of time and considerable work, I believe that we now fit much more into the scheme of things - it feels as though we are more integrated as a group and more integrated into the Institute’s thinking. Our input feels more sought after and more valued.

Bill Fox
Council Chair, the Institute, 2013

An increased level of Council influence at the School in 2008 is demonstrated by the following:

- Input into the School’s Strategic Planning process and later contribution to implementation of the Strategic Initiative Building an Ethos of Participation
- Advocacy for enhanced consumer and community perspectives to be part of The UWA teaching program
- Offers from Council members to be guest lecturers
- A presentation by the Consumer Advocate and two community members at the School Seminar Series
- A Council member was the first consumer representative to be involved in the WA Department of Health research funds allocation process
- The issue of barriers to the dissemination of research results led to the submission and publication of a letter to the Editor of the Australian and New Zealand Journal of Public Health

There was also recognition by the Councils of the importance of knowing the extent and type of consumer and community participation activities being implemented across both organisations. This challenging and ongoing task made slow progress during the early years of the Program, but was assisted by additional staff and the development of the Program’s website www.involvingpeopleinresearch.org.au launched in 2011.
The Program had organised and facilitated forums in 2006 and 2007 for the Seniors Projects at the School (detailed in a Case Study on page 45). The knowledge gained at these forums informed the development and planning for a series of ‘community conversations’ undertaken in 2008 in consultation with the Council at the Institute. This method has proven to be an influential aspect of the Program and is detailed in the section on Methods of Participation and Appendix 2.

In 2008 the Councils sought to address a perceived lack of acknowledgement for researchers conducting good practice in their projects. A process to acknowledge commitment to consumer and community participation was initiated and the result was the Consumer and Community Participation Award, first presented in 2010. The Award showcased outstanding commitment to good practice principles of consumer and community participation at the School and the Institute. These awards are an ongoing, annual event.

Recipients of the Award are as follows:

At the School:
❖ 2011 D’Arcy Holman
❖ 2012 Rosemary Saunders
❖ 2013 Anna Kemp

At the Institute:
❖ 2010 Jan Payne
❖ 2011 Deborah Lehmann, Hannah Moore and Kirsten Alpers
❖ 2012 Fiona Stanley, Carol Bower, Steve Zubrick, Helen Leonard, Sven Silburn, Jan Payne, Leanne Scott and Peter Franklin
❖ 2013 Rebecca Glauert

Additionally, the Councils successfully nominated the Institute’s Alcohol in Pregnancy Project staff in 2009 and Professor Holman in 2010 for the Health Consumers’ Council of WA Excellence Awards.
Over the past 4 years of my involvement with the Program, we have seen a lot of change at the Institute. With the opportunity to have input into the new strategic plan and the new focus areas, the Consumer & Community Advisory Council is helping to bring a voice to the Institute which will ensure grounded research that has links with the community, rather than research occurring in an isolated ivory tower.

Rachel Skoss, Council Chair, the Institute, 2015

The Council at the Institute had discussions with senior research staff in 2008 and 2009 regarding the development of an application for a NHMRC Program Grant titled Early developmental pathways linking health, disability, education, welfare and justice. Following the success of the application, further discussions were held with the Council about the integration of consumer and community participation activities across this program of research. The Program Grant (2010 - 2014) has had a consumer and community participation ethos integrated into the two research themes of Mapping developmental disorders and child mental health and Child health and human developmental pathways. Thirty three of 35 staff supported by this Program Grant have attended training on consumer and community participation and have developed a range of participation activities.

A workshop to discuss Council priorities at the Institute was held in 2011. The Council prioritised proposed activities at this planning session and discussed implementation of the top three priorities.

Activities voted as highest priority to lowest priority were:

1. Raising the profile of the Council within the Institute’s Board of Management and the organisation as a whole
2. Community reporting and advocacy
3. Oversight role for Council of consumer and community participation at the Institute
4. Audit of consumer and community participation activities
5. Minimum standards for consumer and community participation
6. Policies
7. Guidelines

Council members provided community perspective on the Institute’s grant application and review process in 2011, including having a community member on the review panels that were established to provide support and feedback to researchers who intended to submit grant applications in 2012. In 2013, Program staff attended a grant proposal workshop for researchers to give feedback from a consumer and community perspective.

In 2012 - 2013 the Council at the School continued to have input into implementation of the goals of the School’s Strategic Plan 2009 - 2013\(^{(28)}\), particularly the goal of...
making consumer and community participation standard practice for research projects at the School. A planning workshop was held in 2013 and various contributions and collaborations made progress toward the achievement of this goal. Practical support was provided for the research ‘buddy’ trial with the Cardiovascular Research Group. There was involvement by Council members with the Community Expo organised by Program staff at the School in 2013 to promote research being undertaken in the Centre for Health Services Research. Council members also attended a community conversation in 2013 with other stakeholders on the development of the School’s 2014 – 2017 Strategic Plan.

An annual combined meeting of the Councils to foster closer working relationships and exchange of information between the two groups was first held in 2012. This annual event is ongoing and supports the joint nature of the work of the Councils and of the Program. The sustainability of the Program has been the subject of ongoing discussions between senior staff and the Councils in 2013 - 2014.

Development of Minimum Standards

The School’s Strategic Plan 2009 - 2013 included a Strategic Initiative on Building an Ethos of Participation which included three goals to support the initiative:

- Community participation as standard practice in teaching and research activities
- Funds to establish a participation centre to provide training and resources to researchers and the community
- Funds to establish a research area for the Program

The Centre for Health Services Research at the School worked towards implementing these goals, including addressing them at a planning workshop in 2010. To assist researchers in implementing consumer and community participation as standard practice, this workshop included a session on writing in plain language. Research projects on the Centre for Health Services Research web page include a short, plain language explanation of each project.

In 2010 the Council at the Institute, at the request of investigators on the 2010 - 2014 NHMRC Program Grant, worked with the Program to develop a set of minimum standards for consumer and community participation in all projects supported by the grant. These minimum standards included support and resources for researchers to implement participation activities.

At an organisational level, researchers had access to:

- Training on consumer and community participation
- Examples of good practice methods and methods for consumer and community participation
- Networks and links to consumers and community members
- A register of community priorities for research including access to feedback from ‘community conversations’
- The Consumer and Community Advisory Council
- Support from the Program staff

At a program and project level researchers were required to:

- Develop and document a plan for consumer and community participation activities that included dissemination of research findings to the community
Attend training on consumer and community participation

Develop a plain language summary for each research project

The Program Grant and the Developmental Pathways Project at the Institute accepted these minimum standards as a blueprint for their consumer and community participation activities. Initiatives in 2010 to support researchers to implement these minimum standards included workshops on writing plain language summaries and training workshops on implementing consumer and community participation. This collaborative work between the Council at the Institute and these two major research programs is considered by both the Chief Investigators and the Council to have set a good practice benchmark for future participation activities throughout all research areas at the Institute.

Figure 6: Governance structure for the NHMRC Program Grant and Australian Research Council Linkage Grant showing their relationships to the Consumer and Community Advisory Council, Chief Investigators Meeting and the Combined Research Communication Forum.
Program support of related Institute-wide initiatives at this time included involvement with potential future Institute leaders in the Research Leadership Program. This involvement, since the start of the Leadership Program in 2011, has included membership of the selection committee and organisation of annual workshop sessions on leadership and consumer and community participation.

**Funding, capacity and sustainability**

A key factor in the growth and development of the Program was recognition by senior champions and leaders at the School and the Institute of the potential benefits that increased consumer and community involvement can bring to research outcomes, as well as to community members and organisations. This has been demonstrated through the ongoing support and funding from the School and the Institute.

Historical funding support for the Program was provided by Professor Holman at the School and, from 2008, from the Centre for Health Services Research and infrastructure funds at the Institute. In 2010, after attending the two-day training workshop on consumer and community participation at the Institute, the Institute’s Deputy Director, Professor Moira Clay, took a lead role in seeking sustainability and expansion for the Program. She collaborated with Professor David Preen, the Director of the Centre for Health Services Research, and the Consumer Advocate to plan for an expanded Program. In 2011, Professor Preen provided funding to employ Hayley Haines on a temporary three-month contract to work with the Consumer Advocate to develop fact sheets on consumer and community participation. Following the development of the Fact Sheet Series, Professor Clay successfully advocated for increased funding from Professor Ian Puddey, the Dean of The UWA Faculty of Medicine and Dentistry. This was matched with funding from the Institute’s Program Grant and provided for a full time Project Officer and a part time Development Officer for six months.

The funding of these positions enabled further development of support and resources and increased the flexibility of the Program to respond to requests for advice and assistance. In October 2011, the Program Grant at the Institute allocated funding for the Project Officer and an Administration Officer for three
years, supporting the work of the Program at the School and the Institute and the implementation of plans to embed consumer and community participation within the Program Grant at the Institute. It was anticipated that the participation activities in the Program Grant projects would be reported on and evaluated for potential implementation across the Institute and the School. To further this aim, the position of Research Assistant was funded and has enabled the production of this report. The Centre for Health Services Research co-funded the Consumer Advocate position with the School in 2012, leading the School to place the position on the core School budget, increasing the certainty and sustainability of funding.

A Memorandum of Understanding was signed in 2011 outlining the commitment of the School and the Institute to work together to strengthen the Program. Funding arrangements were addressed with the following statement:

‘At different times each organisation has, and will contribute to the Participation Program with funding, resources and support. These contributions are made according to needs and availability of funding. At different times both the School and the Institute has been a principal funder sharing their program resources with the other organisation. These contributions are made in the spirit of improving and supporting our joint Participation Program.’

Council members at a Joint Council meeting

A workshop facilitated by the former Chair of the Consumers Health Forum of Australia, Ms Karen Carey, was held in 2013 with senior staff from the School and the Institute, Council Chairs and Program staff. The meeting addressed planning for the Program; ongoing issues of capacity, sustainability and funding; the lack of a research agenda; and the increased demand for services, particularly from external agencies. Consensus was reached on the need for a business case to underpin support for the establishment of a Participation Centre. A workshop report was prepared and a commitment given for the development of a business case and action plan. Meetings regarding sustainability of the Program between the Head of School and Director of the Institute were held in December 2013. Discussions have been ongoing within UWA and the Institute in 2014.
CASE STUDY

NHMRC Program Grants at the Telethon Kids Institute 2005 - 2014

Chief investigators on the 2005 - 2009 NHMRC Program Grant, entitled *Determinants of Child Health and Development: Populations, Partnerships, Pathways and Prevention*, supported consumer and community participation activities in research projects within the Division of Population Sciences at the Institute. Senior staff regularly attended meetings of the Consumer and Community Advisory Council at the Institute to provide updates and receive feedback during the development of their subsequent NHMRC Program Grant application.

The interaction with the Council in 2008 and 2009 continued after the success of the application for continued funding. The 2010 - 2014 NHMRC Program Grant, entitled *Early Developmental Pathways Linking Health, Disability, Education, Welfare and Justice*, had a consumer and community participation ethos integrated into the two research themes of *Mapping Developmental Disorders and Child Mental Health* and *Child Health and Human Developmental Pathways*.

The Consumer Advocate was invited by chief investigators to join them as a member of the Governance Committee. In 2010 the Council at the Institute, at the request of chief investigators, worked with the Consumer Advocate to develop a set of minimum standards for consumer and community participation in all projects supported by the Program Grant.

The expectation of participation as standard practice was supported by staff attendance at training workshops on consumer and community participation. Funding from the Program Grant was provided for additional Consumer and Community Participation Program staff from 2011, increasing resources, flexibility and the potential for participation as standard practice to be more widely implemented with researchers at the Institute.

Program Grant research leaders consider the Consumer and Community Participation Program to be a successful outcome of the 2010 - 2014 Program Grant. Bringing staff together and ensuring the provision of appropriate training and support led to widespread benefits in project governance and outcomes. Champions of participation among senior Program Grant staff were vital to this success.

The 2005 - 2009 Program Grant was recognised as one of the *Ten of the Best Research Projects of 2011* by the NHMRC. The 2010 - 2014 NHMRC Program Grant chief investigators received the Award for Consumer and Community Participation from the Consumer and Community Advisory Council in 2012.
CASE STUDY

Improving Rural Cancer Outcomes 2009 - 2015

The Improving Rural Cancer Outcomes project, a partnership between the School, the UWA School of Primary, Aboriginal and Rural Health, Cancer Council WA and the WA Health Department, investigated why regional cancer patients in WA experience 20 - 30% poorer survival rates than metropolitan patients and ways to address this disparity.

The first phase included identifying factors that affect outcomes in rural and remote patients with colorectal, lung, breast and prostate cancers. In the second phase, the team developed a ‘best prospects’ package of community and general practitioner interventions. A consumer representative was appointed to the project management team in 2009 and members of the management team attended training workshops run by the Program. Consumer and community participation on the steering committee resulted in feedback about information sheets and consent forms which the researchers considered to have increased recruitment. A community conversation held in 2010, assisted by the Program, was attended by 50 consumers and community members. Feedback from the community conversation identified gaps and barriers for consumers accessing services and informed development of the aims and content of the Find Cancer Early community campaign, coordinated by Cancer Council WA. Project officers who delivered the campaign used a community engagement approach.

Whilst evaluation of the study is still underway, early success in uptake of Find Cancer Early messages has been attributed to the significant input from regional communities. With generous support from the AH Crawford Cancer Treatment Society, this initiative will continue in 2014/2015 in regional areas, including a television commercial to create awareness about symptoms and encourage people to consult their local doctor.

Involving cancer patients and other community members in helping us steer the development of this research has been so essential that I have no hesitation in saying that it would have been professionally negligent and incompetent not to go down that track. There is no substitute in designing a major community intervention than grass roots input from the very type of people that the intervention is intended to benefit. Academic researchers don’t have a clue how most members of the general public think about cancer awareness issues or what approach to communication would work best for them. We invested two whole years in trying to understand the issues from their perspectives and I think we have avoided falling into some big black holes as a result.

D’Arcy Holman
The School, 2011
Education has been integral to the Program since it began. Resources and teaching activities established by the Consumer Liaison Officer at the School during 1998 - 2003, such as the consumer library and undergraduate lectures, continued and were enhanced from 2004. Lectures and tutorials to postgraduates and medical students were included from 2004 and, in 2006, they were given to Health Science students and as part of Master of Public Health and Master of Nursing Science courses. Guest lectures on Consumer and Community Participation in Health were also given to undergraduates at the Curtin University School of Nursing in 2007 and 2008. These were expanded to include Curtin University School of Pharmacy fifth year students in 2009 - 2012.

Ongoing lecturing commitments have continued throughout subsequent years. All lectures have been conducted by a Program staff member or a member of the Councils to ensure consumer and community perspectives are not tokenistic. Topics covered include consumer and community participation in health and in health research, research design, the evolution of the consumer movement and health consumer advocacy. The opportunity to inform future health professionals, health administrators and researchers of the benefits of consumer and community participation has also resulted in involvement with student projects, work experience and mentoring within the School and the Institute.

A workshop for researchers and a consumer and community meeting were held at the Institute in 2004. Researchers, consumers and community members identified the need to address concerns about the capabilities of consumers as being very important. The result was a set of recommendations to the School and the Institute Executive Committees, detailed in the section on Community Interaction, which acknowledged a need for training for consumers and community members. Addressing this perceived need led to a process in 2007 of developing training workshops tailored to the requirements of consumers and community members. These workshops were developed and facilitated by the Consumer Advocate with advice on topics provided by the Councils at the School and the Institute.

The Consumer Advocate and Bec Hanley developed the training workshops for researchers on implementing consumer and community participation in research. This was in direct response to the feedback from the attendees at the Involving People in Research Symposium in 2008, who identified the need for training as a priority for taking consumer and community participation forward. Details of the
Training workshop facilitators

Symposium can be found in the section on Advocacy and Advice. Bec Hanley has co-facilitated many of the workshops with the Consumer Advocate with support and extra facilitation provided by the Project Officer. The workshops have primarily been held at the School and the Institute and, more recently, at interstate organisations. Increased demand from organisations outside the School and the Institute has highlighted the flexibility of the workshops, which can be modified to suit a range of training requirements. The first external training workshop occurred in October 2010 at Arthritis Victoria in Melbourne. Training workshops have become a core component of the support provided to researchers and, in Australia, are offered only by the Program.

Training for consumers and community members

Consumer and community members involved with projects at the School and the Institute and the Councils attended the first training day on basic research information in 2007. Senior research staff, consumer representatives and the Consumer Advocate presented on topics such as grant application and funding processes, the ethics approval process, terminology, data linkage processes, types of research and being an effective community representative. Positive feedback was received from the 30 attendees. Evaluation of the training assisted in the refinement of future training workshops for consumers and community members. A second training workshop on basic research information, attended by 27 consumers and community members associated with the School’s and the Institute’s research projects, was held in 2008.

Training workshops for consumers and researchers

11 training workshops for consumers were held between 2007 and July 2014 with 227 attendees.

29 training workshops for researchers were held across Australia between 2009 and July 2014 with 514 attendees.
A half-day workshop on data linkage was attended by twenty consumers and community members in 2011 and two training workshops facilitated by the Consumer Advocate and the Project Officer were held in 2012, one at the School with eighteen attendees and one at the Institute with twenty attendees.

Training workshops for consumers and community members external to School and the Institute research projects were conducted by the Program during 2009 - 2014, including one-day workshops at the Health Consumers’ Council WA in Perth in 2009 and 2010 and in Rockingham in 2011. A one-day workshop attended by 30 consumers and community members was organised in Brisbane in 2011 for Alzheimer’s Australia. In Sydney in 2014, a one-day consumer and community workshop was conducted for Better Treatments 4 Kids Research Network in addition to the researcher training workshop held the following day.

Training for researchers

Requests for training at the Involving People in Research Symposium in 2008 and the growth of the Program at the School and the Institute highlighted a lack of tools and training to support researchers to confidently and effectively implement consumer and community participation. Pilot workshops were developed and conducted in 2009 and covered topics such as planning, methods and the benefits of and barriers to participation. The three pilot workshops were attended by 53 students, early-career and senior researchers from the School and the Institute. Feedback suggested a one-day workshop did not give time for researchers to fully develop plans to implement consumer and community participation in their research.

A two-day workshop was subsequently developed and first conducted as part of The UWA Summer School in December 2009. There were 44 attendees from Western Australia, South Australia, New South Wales, Victoria and the Australian Capital Territory. The combined feedback response from the two workshops conducted was that 83% of attendees intended to change their practices as a

Consumer and community training workshop

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A greater confidence in following through with consumer and community involvement’

Workshop attendee, 2010

‘It was really eye opening. I think I will be eager to participate with consumers in all stages of my research’

Workshop attendee, 2009

‘I think this has made involving consumers in my research more practical, convenient, and attainable therefore easier for me to implement’

Workshop attendee, 2013

New South Wales, Victoria and the Australian Capital Territory. The combined feedback response from the two workshops conducted was that 83% of attendees intended to change their practices as a
result of attending the workshops. This response has remained similar in subsequent workshops.

Writing in Plain Language workshops were introduced in 2010 with 30 researchers involved in the Program Grant and Developmental Pathways Project at the Institute. The series of workshops culminated in a masterclass and competition in September with seven researchers presenting their summaries to a judging panel consisting of the Chair of the Council and a Public Relations department staff member. Additional workshops attended by 48 researchers in total were held at the School and the Institute in 2010 and 2012.

Two further two-day workshops on implementing consumer and community participation in research, facilitated by the Consumer Advocate and Bec Hanley, were held in 2010 and were attended by 40 researchers, administrators and students. Some attendees were from interstate research organisations, including the research manager from Alzheimer’s Australia. As a result of this attendance, Program staff were invited to conduct a half-day consumer and community training workshop in 2011 in Brisbane with Alzheimer’s Australia.

By 2011 there had been enquiries about training workshops with researcher and consumer aspects from a range of organisations including the Australian Primary Health Care Research Institute at the Australian National University, Arthritis Victoria, the Health Consumers’ Alliance South Australia, Alzheimer’s Australia, Partnerships and Citizen Engagement Division of the Canadian Institutes of Health and the Health Quality Council at the Saskatchewan Ministry of Health. While all workshops address consumer and community participation in health

*Researcher training workshop*
research, they are adapted to suit specific requirements. Discussions were held among stakeholders at this time on how to capture the important anecdotal evidence of changing attitudes and increased acceptance of consumer and community participation. As the training workshops for researchers were the only ones of their kind in Australia, plans were made to conduct an evaluation of their influence on awareness, attitudes and behaviour. More information on this survey, conducted in 2012, is in the section on Building the Evidence.

Researcher training workshop, South Australia

As part of their commitment to provide support and training in consumer and community participation for people involved in their work nationally, the Population Health Research Network engaged the Program to deliver training workshops. Workshops for staff at Population Health Research Network data linkage units were held during 2011 and 2012 in South Australia, Victoria, New South Wales and the Australian Capital Territory.

A workshop was held by the Program at the Australasian Epidemiology Association Conference in Perth in 2011 and at the International Data Linkage Conference, also in Perth, in 2012. Twenty seven people attended these two workshops. An Introduction to Consumer and Community Participation half-day workshop took place at the Institute in 2012.

Training workshops co-facilitated with Bec Hanley during 2011 - 2013 included the following:

- Two workshops at the Australian Primary Health Care Research Institute in Canberra in 2011 at which there were 30 attendees
- Two Summer School workshops at the School in 2011. Of the 51 attendees, ten students were subsidised by the School, the Institute funded Program Grant researchers and Edith Cowan University also subsidised researchers to attend
- A two-day workshop for researchers at the Institute in 2013. Of the 22 attendees, eighteen stated that they intended to make changes as a result of the training
- The first workshop designed for laboratory based researchers, held at the Institute in 2013

Workshops external to the School and the Institute organised by the Program in 2013 included a one-day workshop for Perth North Metro Medicare Local, a two-day workshop at Flinders University in Adelaide and a one-day workshop for the National
Breast Cancer Foundation in Melbourne. By June 2014 workshops had also been held in Sydney for Better Treatments 4 Kids and in Canberra for the Australian Primary Health Care Research Institute.

Training and teaching resources

Tools and resources developed by Program staff have included:


- A brochure outlining Program achievements to 2011, produced to enhance the profile of the consumer and community participation work that had been done and to advertise the aims of the Program from 2011 onwards.

- The Fact Sheet Series of 22 information sheets to assist researchers with consumer and community participation, launched in 2011 and accepted for publication in 2012 by CES4health, an American online organisation publishing peer-reviewed products of health related, community engaged scholarship that are not journal articles.

- The Involving People in Research website, launched in 2011. The website houses guides, advice and information, making resources easily accessible to School and the Institute staff as well as external groups and individuals. By July 2014 the website had received over 7000 visits from 4671 visitors in 95 countries. It had been accessed by 211 universities world-wide, including four of the top ten and 44 of the top 100 universities as ranked by the Academic Ranking of World Universities and been viewed by 162 organisations of interest including government departments, education departments, health services and research organisations.

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I just wanted to thank you again for the fantastic training program you ran. The feedback to me has been excellent and I met with Jeff Fuller yesterday to talk about how we ensure it becomes an embedded practice.

**Pam Smith**

**Flinders University, 2013**

Program staff collaborated in 2014 with the National Breast Cancer Foundation on the publication *From Application to Outcomes: consumer and community participation in health and medical research*[^33]. This resource includes several of the Program’s Fact Sheets, information about the Program and information from a training workshop conducted by the Program for
the National Breast Cancer Foundation in 2013 on barriers to consumer and community participation.

**Training the next generation**

The Program, since 1998, has worked with teaching staff at the School and other universities in Western Australia to inform students of many aspects of consumer and community participation. Lectures increase awareness and give students resources and confidence to apply consumer and community participation in their field. Hopefully, this will lead to mutually respectful partnerships between consumers, community members and the next generation of researchers, health professionals and health administration staff. Program staff contributed to the development of the new medical degree curriculum at the UWA Faculty of Medicine, Dentistry and Health Sciences from 2012 onwards.

The range of lectures conducted by Program staff or consumers or community members within the Faculty of Medicine, Dentistry and Health Sciences at UWA since 2004 are:

- Introduction to Consumer and Community Participation
- Consumer and Community Participation in Health - Leadership and Management of Health Services
- Consumer and Community Participation in Health Research - Foundations of Epidemiology
- Consumer Participation Lobby Groups & Stakeholder Perspectives
- Consumer and Community Participation - Research Design
- Consumer and Community Participation in Health

- Consumer and Community Participation in Health Research
- Consumer and Community Participation in Health - Social Work Knowledge, Theories and Values
SUMMARY OF TRAINING WORKSHOPS 2007 - 2014

CONSUMER TRAINING WORKSHOPS

5 School and Institute
3 Health Consumers Council
1 Perth North Metro Medicare Local
1 Alzheimer’s Australia Brisbane
1 Better Treatment 4 Kids Sydney

RESEARCHER TRAINING WORKSHOPS

18 School and Institute
1 South Australia
  • Flinders University School of Nursing
2 Melbourne
  • Arthritis Victoria
  • National Breast Cancer Foundation
3 Canberra
  • Australian Primary Healthcare Research Institute
1 Sydney
  • Better Treatment 4 Kids
4 Population Health Research Network
  • South Australian Northern Territory Data Link
  • Victorian and Tasmanian Data Linkage Units
  • Australian Institute of Health and Welfare
  • Centre for Health Record Linkage & The SAX Institute
CASE STUDY

Consumer Co-payments for Prescription Medicines: Impact on Access and Health Outcomes 2007 - 2010

A project entitled Consumer Co-payments for Prescription Medicines: Impact on Access and Health Outcomes was funded by the NHMRC and conducted at the School to investigate the impact of rising costs of prescription medicines on medicine use and health outcomes of consumers by using linked health and pharmacy data.

From the beginning of the project in 2007, a consumer and community representative sat on the Project Advisory Committee. The research team found that recent increases in co-payments (the portion of the cost of medication that is borne by the consumer), for medicines that were subsidised under the Pharmaceutical Benefits Scheme, led to substantial falls in the use of many essential medicines by consumers. In response to this finding, the researchers were asked by journal editors and research peers to make policy recommendations to the Commonwealth government and also to prescribers and pharmacists to ease the impact of increased co-payments on consumers.

The researchers responded by organising a community forum, facilitated by the Program in conjunction with the Health Consumers’ Council WA, at UWA in 2011. In addition to Health Consumers’ Council staff and researchers, the forum was attended by 69 consumers and community members after being promoted by the Health Consumers’ Council and through radio and local newspaper advertising in Western Australia. Consumer and community input at the forum contributed to the generation of a number of feasible policy recommendations. These recommendations were presented to policy makers at Medicare Australia, part of the Australian Government Department of Human Services which administers health-related programs, including the Pharmaceutical Benefits Scheme.

One of the project’s researchers, Professor Libby Roughead, commented ‘the level of engagement we had from the community members was fantastic – we learned a great deal from talking to them’, and Michelle Kosky, Director of the Health Consumers’ Council WA at the time, said she was ‘impressed with the range and depth of issues consumers identified’. A report outlining the forum’s discussions was distributed across Western Australia via the newsletter of the Health Consumers’ Council and the Program’s Participation Network.
CASE STUDY

The ‘Participate’ Project: Preparing Children with Acquired Brain Injury for Integration into Community Recreation and Leisure Activity 2012 - ongoing

Following a presentation at the WA Department of Health Clinical Senate in 2012, the Consumer Advocate was approached by Dr Catherine Elliott from Princess Margaret Hospital for Children about establishing a steering group for a research project for children with acquired brain injury. Inspired by a world class rehabilitation program in Norway, the research aims to develop an intervention to improve participation outcomes.

Members of the research team took part in the Program’s training workshops at the Institute to support the effectiveness and relevance of a steering group to the research and the community. Supported by the Program, a steering group was established in 2012 to assist in developing and directing the project. The Steering Group comprises parents of children and adolescents with an acquired brain injury, a young adult with an acquired brain injury, clinicians, policy makers and representatives from non-government organisations and the community.

The Steering Group guides the development of studies within the larger project and validates their results. The researchers consider the contributions of the Steering Group to be invaluable, ensuring that research reflects the needs of the community while empowering the community to respond to those needs. The Steering Group has improved the relevance and suitability of a measurement tool, contributed to and validated a literature review that played an integral role in guiding the research and developed interview guides. The topics and questions in the guides were used in interviews conducted by the researchers with children, parents, clinicians and local service providers in Norway.

Ultimately, the Steering Group will be expanded to contribute to all research and service delivery within the Department of Paediatric Rehabilitation at Princess Margaret Hospital for Children. Fostering linkages between the community, UWA, Princess Margaret Hospital for Children and collaborators at Curtin University and in Norway was considered essential to improving outcomes for children with acquired brain injury and their families.

Claire Willis, a PhD candidate on the research team, received the Mindlink Brightwater Interdisciplinary Focussed Research Award at the Australasian Society for the Study of Brain Impairment 37th Annual Conference in May 2014. This award recognises and encourages innovative, interdisciplinary collaborative research approaches with the capacity to carry over into long term service delivery.
Concluding Thoughts

Fiona Stanley

It is somewhat strange that it took us so long as a group of health and medical researchers to realise the power and importance of a real engagement with consumers. In our work with Aboriginal communities in the 1980s and 1990s we developed excellent ways to involve them to overcome the barriers to research resulting from a hundred years of exploitation. In fact we worked more closely with them than with our non-Aboriginal research participants! All that changed with our NHMRC public health capacity building grant in which one of the six themes was totally dedicated to consumer and community engagement. The impact on our research questions and methods, the relevance, the translation and the importance to the community changed dramatically. Ideas came streaming in, support for research previously considered unacceptable to consumers and the community (such as linking individual health records and registers of disease) became something that people demanded and participation in research projects was more popular as the population wanted to make a difference. Opening the research door to the community has been hugely mutually beneficial. And we had much more fun! Our meetings with our Raine cohort kids were informative and hilarious! Preconceived myths about DNA research were challenged and whole new areas of research made possible as these kids and their families realised the value of what we were doing.

I believe that engaging the community in our research has been of enormous benefit; none of us now feel that we can do research without this input; it is just not right to exclude those who are our research participants and the communities in which they live from having their say in how this work should be done. This activity still needs to be fostered, funded sustainably and become embedded in our research culture. We need to lobby for granting agencies to appreciate this and to fund both the input of consumers and to build the capacity of both researchers and consumers to work together effectively. We need research on how best to do this and to conduct trials of how best to work with consumers in everything from basic science to translational research. We must not lose the momentum and the gains that have been made over the last sixteen years.

Professor Fiona Stanley AC FAA FASSA
Patron, Telethon Kids Institute
December 2014
Michele Kosky

It is a pleasure to write a conclusion for this report that charts the concept, development, implementation and growth of the Consumer and Community Participation Programme at the School and the Institute. The Program has been characterised by all those features articulated in the NHMRC Consumer Participation Statement 2002, particularly the vision of consumers and researchers working in partnerships based on understanding, respect and a shared commitment to research that will improve the health of humankind.

Consumers have long held the view that community members, carers and consumers have the right to participate at all stages and every level of the health research enterprise. This view was developed in the 1980s and was exemplified in Australia by the involvement of HIV positive people, injecting drug users, men who have sex with men and sex workers in the HIV/AIDS research agenda from the beginning of the epidemic in Australia. In addition, Aboriginal people tired of being the “subjects” of research became active partners and participants in research in the 1990s. The Consumer and Community Participation Program at the School and the Institute was cognisant of this history and like much in life, really built on the shoulders of the people who went before.

Rebecca Coghlan, as the first staff member of the Program in 1998, laid solid foundations in consumer knowledge and participation and the research, writing and publication of the Duty to Care Report was a landmark achievement of consumers and researchers working together. Anne McKenzie and her team have continued to build, develop and expand an outstanding model of consumer and community participation, the only one of its kind in Australia and a model that all Western Australia can be proud of. This report is a testament to the vision, the hard work and the influence of the Program over the past sixteen years. Looking forward, the Program has the capacity to further develop at local, national and international levels with good governance, sustainable funding and the support of the community.

Finally, thanks and recognition must be given to the School and the Institute for their commitment over time to consumer and community involvement, embracing the challenge of change and disruption; a very fitting approach in the 21st century.

Michele Kosky AM
Executive Director, Health Consumers’ Council WA 1994-2012
December 2014
OUTPUTS

Publications

6. McKenzie A. Health Consumers’ Council of WA and Western Australian Audit of Surgical Mortality Consumer Roundtable Meeting Report. The University of Western Australia Faculty of Medicine and Dentistry 2004
15. McKenzie A. Seniors have a say in research on medication safety. Health Matters 2010;81:45-47
16. Bulsara CE, Cuesta-Briand B, Moorin R, McKenzie A. Evaluating costs, accessibility and availability of services for those with catastrophic injury in Western Australia. Australian Centre for Economic Research and the Centre for Health Services Research, The University of Western Australia; 2010
23. McKenzie A. Involving the community in health research. Consumer and Community Participation Unit, The University of Western Australia School Population Health & Telethon Institute for Child Health Research 2012


33. McKenzie A. UWA Consumer and Community Participation Program. INVOLVE Newsletter Spring 2013 p 10-11

34. McKenzie A. The University of Western Australia School of Population Health and The Telethon Institute for Child Health Research Consumer and Community Participation Program workshop: Discussion paper July 2013

35. McKenzie A. The Consumer and Community Participation Program’s Next Steps Workshop Report. The University of Western Australia School of Population Health Sep 2013

Presentations

1. Coghlan R. Consumer involvement in the Centre for Health Services Research. Symposium on Health Data Linkage: Its value for Australian health policy development and policy relevant research, Sydney March 2002
2. Coghlan R. Barriers to community and consumer participation. LEAP’03 WA Health Promotion Conference, Fremantle April 2003
5. McKenzie A. Increasing consumer and community participation in research. School of Population Health and Telethon Institute for Child Health Research consumer meeting, December 2004
11. McKenzie A. Invited speaker. A consumer perspective of data linkage in WA.
14. McKenzie A. For the people, by the people, with the people. INVOLVE Conference: People In Research, Hatfield, Hertfordshire UK September 2006


26. McKenzie A. Invited speaker. Developing an organisational strategy to increase participation. INVOLVE Conference: Public involvement in research: Getting it right and making a difference, Nottingham UK November 2008


30. Bulsara C, McKenzie A, Emery J. “Blimey, I was only in there five minutes!”: the significance of GP continuity of care in ensuring medications safety in seniors. General Practice and Primary Health Care Research Conference, Melbourne July 2009

31. McKenzie A. Invited speaker. Consumer and community participation at The University of Western Australia and the Telethon Institute for Child Health Research. The School of Health and Related Research Sheffield University, Sheffield UK November 2009

32. McKenzie A. Invited speaker. Consumer and community participation at The University of Western Australia and the Telethon Institute for Child Health Research. Swansea University Health Information Research Unit Research Forum, Swansea Wales November 2009
33. McKenzie A. Invited speaker. Consumer and community participation at The University of Western Australia and the Telethon Institute for Child Health Research. Exeter University Service User Program Workshop, Exeter UK November 2009


35. McKenzie A (invited workshop presenter), Bulsara C, Solich B, Piu M. Consumer and community participation: adding value to research. Primary Health Care Research Conference - Primary health care research and health reform: Improving care, Darwin June 30-July 2 2010. Two consumer panel members was funded to attend and co-present at this workshop session


39. McKenzie A. Invited speaker. Consumer and community participation at The University of Western Australia and the Telethon Institute for Child Health Research. WA Department of Health Data Linkage Unit Workshop, Perth June 2010

40. McKenzie A. Invited speaker. Hangzhou Women’s Hospital Workshop, Hangzhou China July 2010

41. McKenzie A. Invited speaker. Shenyang University Hospital Workshop, Shenyang China July 2010

42. McKenzie A. Invited speaker. Seniors have a say about medicines. National Prescribing Service Consumer Advisory Group Workshop, Sydney August 2010

43. Hanley B, McKenzie A (Invited speaker). Can training promote a culture of involvement within a research organisation or department? INVOLVE Conference: Public involvement in research: Innovation and impact, Nottingham UK November 2010

44. McKenzie A. School of Health and Related Research, University of Sheffield UK November 2010

45. McKenzie A. National Cancer Research Institute Consumer Group, School of Health and Related Research, University of Sheffield UK November 2010

46. McKenzie A. INVOLVE support unit, Southampton UK November 2010

47. McKenzie A. Medicines packaging and labelling: Seniors have a say. Consumers Health Forum Workshop, Sydney December 2010

49. McKenzie A. Alzheimer’s Australia National Consumer Workshop, Brisbane May 2011
54. McKenzie A. Invited speaker. Consumer participation in health. School of Pharmacy Curtin University, Perth March 2012
58. McKenzie A. Invited speaker. The University of Western Australia Academic Health Science Workshop, Perth May 2012
59. McKenzie A. Invited speaker and panellist. WA Department of Health Genetics and Ethics Symposium, Perth May 2012
60. McKenzie A. Invited speaker. Presentation to The Aboriginal Collaborative Council Advising on Research and Evaluation, Perth June 2012
63. McKenzie A. Invited speaker. Westmead International Update on Controversies in Perinatal Care, Sydney June 2012
64. McKenzie A. Invited speaker. Consumers Health Forum Consumer and Community Leaders’ Workshop, Perth August 2012
66. McKenzie A. Packaging and labelling of medicines – is a regulatory solution going to deliver what is desired? Scientific Congress of ARCS Australia Ltd: a professional development association for people working in the development of therapeutic goods, Canberra September 2012
67. McKenzie A. Australian College of Nursing Community and Primary Health Care Nursing Conference: Shaping and influencing primary health care, Perth October 2012


69. McKenzie A. Invited speaker. Westmead Hospital Clinical Trials Unit: Equipping parents and clinicians as partners in perinatal trials national workshop, Sydney October 2012

70. McKenzie A. Invited speaker. NHMRC and Consumers Health Forum Public Consultation Workshop: Draft Statement on Consumer and Community Participation in Research, Sydney November 2012


72. McKenzie A. Invited speaker. Embedding public involvement in health services research. INVOLVE Conference: Putting People First in Research, Nottingham UK November 2012

73. Haines H, McKenzie A. Establishing a community participation network. INVOLVE Conference: Putting People First in Research, Nottingham UK November 2012

74. Haines H, McKenzie A. Resources to support consumer participation. INVOLVE Conference: Putting People First in Research, Nottingham UK November 2012

75. McKenzie A. Invited speaker. Swansea University Health Information Research Unit Community Forum, Swansea UK November 2012

76. McKenzie A. Invited speaker and workshop panellist. Australian and New Zealand School of Government Institute for Governance at the University of Canberra and Health Care Consumers’ Association of the ACT. Health Activism and the Knowledge Society: Engaging Consumer/Citizens in Shaping Health, Canberra April 2013


78. McKenzie A. UWA School of Psychiatry and Clinical Neurosciences, Fremantle July 2013


80. McKenzie A. University of Notre Dame Health Sciences School, Fremantle September 2013


83. McKenzie A. Invited speaker. Swansea University Health Information Research Unit Consumer Council Forum, Swansea UK November 2013
84. McKenzie A. Invited speaker. Swansea University Health Information Research Unit Researcher Forum: Public involvement in linked data research, Swansea UK November 2013
85. McKenzie A. The University of Western Australia Research Development Workshop, Perth December 2013
86. McKenzie A. Implementing the ‘community voice’ in linked data research. International Health Data Linkage Conference Vancouver, Canada, May 2014

**Grant Involvement**


4. NHMRC Project Grant #403928. Chronic disease outcomes and improved care in seniors: A cross-jurisdictional linkage project. CI: Holman CDJ, Hobbs MST, Emery JD, Preen DB, Kelman CW, Rosman DL. AI: McKenzie A. 2006 - 2009 $1,012,100


7. Insurance Commission of Western Australia. Evaluating costs, accessibility of care and availability of support networks for catastrophically injured persons and those involved in their care in Western Australia. CI: Moorin R, McKenzie A, Preen D, Holman D. 2009 - 2010 $198,000


21. Invited consultancy. UK Medical Research Council consortium Centre of Excellence Grant. Centre for the Improvement of Population Health through E-records Research (CIPHER). 2012 - 2017 £9,300,000

Research projects

1. The University of Western Australia School of Population Health and the Telethon Institute for Child Health Research 2012. Consumer and community participation in health and medical research training workshop evaluation. McKenzie A, Hanley R, Heyworth J, Phuong C


Committee involvement and awards

External committees

Consumer Advocate, current member

✦ National Health and Medical Research Council Community and Consumer Advisory Group
✦ Canadian Institutes of Health Research, Pool of Experts Focused on Patient Engagement
✦ Population Health Research Network Privacy, Ethics and Consumer Participation Committee
✦ Western Australia Data Linkage Infrastructure Project Board of Management
✦ National Prescribing Service Consumer Advisory Group
✦ Commonwealth Department of Health Medical Services Advisory Committee, Protocol Advisory Sub-Committee
✦ National Prescribing Service RADAR Editorial Group
✦ Medicines Australia Code of Conduct Committee
✦ Silver Chain Human Research Ethics Committee
✦ Western Australian Register of Developmental Anomalies Advisory Group
✦ Western Australian Register of Developmental Anomalies Community Reference Group - former Chair
✦ The UWA Faculty of Medicine, Dentistry and Health Science Selection Committee

Consumer Advocate, past member (national)

✦ National Health and Medical Research Council Wind Farms and Human Health Reference Group 2012 - 2014
✦ Commonwealth Department of Health Codes of Conduct Advisory Group 2014
✦ National Health and Medical Research Council Consumer Participation Statement Working Committee 2012 - 2013
- Therapeutic Goods Administration Labelling and Packaging Review External Reference Group 2013
- Consumers Health Forum Our Health Our Community Reference Group 2012 - 2013
- National Prescribing Service Consumer New Medicines Editorial Group Subcommittee - Chairperson 2005 - 2013
- National Health and Medical Research Council Harmonisation of Research Ethics Review Committee 2009 - 2012
- Consumers Health Forum Quality Use of Medicines Project Reference Group 2008 - 2010
- National e-health Transition Authority Clinician and Consumer Discussion Forum 2006 - 2007
- National Heart Foundation and Beyond Blue Cardiovascular Disease and Depression Advisory Panel 2007
- Medicines Australia Code of Conduct Appeals Committee 2005 - 2006
- National Health and Medical Research Council and Australian Health Ministers’ Advisory Council Priority Driven Research Program 2006
- Department of Health and Ageing Informed Financial Consent National Taskforce 2004 - 2005
- Australian Safety and Quality Council Adverse Medicine Events Line Steering Committee 2004 - 2005
- Australian Health Ministers’ Advisory Council National Portability of Medical Registration Taskforce Expert Working Group 2003

Consumer Advocate, past member (state)
- Health Consumers’ Council WA Board of Management – former Chair and Board Member 2006 - 2012
- WA Department of Health Clinical Senate and Senate Executive Committee 2009 - 2012
- Western Australian Audit of Surgical Mortality Committee, Royal Australasian College of Surgeons 2006 - 2011
- Royal Perth Hospital Intensive Care Research Alliance 2006 - 2010
- Western Australian Primary Health Care Research Evaluation and Development Advisory Committee 2005 - 2009
- WA Department of Health:
  - State Health Executive Forum Information Communication and Technology Principle Committee 2008 - 2012
○ Chairperson, e-Health Community Reference Group 2010 - 2012
○ Clinical Senate and Senate Executive Committee 2010 - 2012
○ WA Department of Health Child and Adolescent Network and Community Data Awareness Committee 2004 - 2006
○ Child and Youth Health Clinical Network 2006 - 2009

Project Officer, current member
✦ Injury Control Council of Western Australia Fetal Alcohol Spectrum Disorder Community and Stakeholder Reference Group
✦ Perth North Metro Medicare Local Community Reference Group
✦ WA Department of Health Patient Satisfaction Survey Reference Group Research Assistant, current member
✦ SIDS and Kids Western Australia Scientific Advisory Committee

Awards
✦ McKenzie A. Honorary Life Membership, Health Consumers’ Council of Western Australia October 2012
✦ McKenzie A. People’s Choice Award for Best Concurrent Presentation, Australasian Research Management Society Conference September 2012
✦ Haines H. Mike Schon-Hegrad Incentive Award, Telethon Institute for Child Health Research 2013
APPENDICES

Appendix 1

Outputs from March 2012 to March 2013

The following outputs address all components of the Program and illustrate the breadth of Program activities

Outputs included:

• Providing assistance to researchers in the development of new participation activities in eighteen grant applications
• Providing ongoing support and advice for 21 research project committees and reference groups
• Continuing support for the Consumer and Community Advisory Councils, established at the School and the Institute in 2006, and facilitation of Council advocacy activities
• Training workshops and seminars. Seven were conducted while eleven enquiries or requests for training workshops from external agencies were received
• Continuing provision of lectures and tutorials at the School with ten being delivered in this period
• Ten community forums which involved over 200 consumers, community members and researchers thus increasing interaction and allowing structured evaluation of a range of activities
• Presentations totalling seven internal, nine local and thirteen (ten invited) at national and international conferences. Additionally, four conference abstracts were accepted
• Publication of resources for researchers, including the Factsheet Series and the second edition of the Green Book, in addition to ten other publications and three submissions
• Two research projects on consumer and community participation
• Collaborations with sixteen local, national and international agencies, extending the links between consumers, community members and stakeholders
• Establishment of the Participation Network. Membership rose to over 500 members and contacts and three Network Newsletters were produced
• An increase in utilisation of the Involving People in Research website which had 1700 visitors from 37 countries (including 32 of the top 100 universities as ranked by the Academic Ranking of World Universities)
• Involvement in funding schemes beyond Program-specific grants, highlighting the Program’s reputation at institutions external to the School and the Institute
Appendix 2

Community Conversations 2009 - 2014

The following events were organised and facilitated by the Program

• The *Understanding Disability* community conversation in 2009 was attended by 25 consumer and community members who identified research priorities of: family and carer isolation; resilience and functioning; transition from child to adult health services; fertility, pregnancy and depression for young adults with disability; cultural views and issues relating to disability; and gaps in service delivery. Feedback was used to inform research projects at the Institute and, in regard to health service delivery, provided to the WA Department of Health Clinical Senate’s workshop to inform the development of recommendations for the establishment of a state-wide Disability Network. A Network was established and the Deputy Chair of the Council at the Institute was appointed as community member of the Network team.

• The Raine Study at the Institute held a community conversation in 2009 attended by nineteen Raine Study participants seventeen to twenty years old. Issues relating to mental health, addiction and substance abuse, fertility and cyber-bullying were identified by participants as priorities for future research.

• The Developmental Pathways Project community conversation in 2009 gained community input into the development of research questions for a major grant application. Researchers and community members discussed the research being undertaken within the project at the Institute and their ideas for future projects. Two additional forums were conducted in 2011 to discuss the data linkage aspects of the research and the establishment of a community reference group.

• As part of a study at the School, in collaboration with the Cancer Council of Western Australia, a community conversation attended by 50 consumers and community members was held in 2010. Feedback identified gaps and barriers for rural cancer patients accessing services and informed the next stages of the intervention trial. Other participation activities included key members of the management team attending training workshops run by the Program and a consumer representative being appointed to the project management team.

• The *Infectious Diseases* community conversation in 2010 attracted twenty consumers and community members to hear about infectious diseases research at the Institute. Vaccination issues and others, such as the dissemination of information to the wider community about infectious diseases, were raised at a workshop session. Feedback led to a subsequent community conversation in 2011 on informed consent for childhood vaccinations, part of a project for the Centre for Applied Research and Evaluation at the Institute and the WA Department of Health which included a consumer on the project team.

• Two community conversations on Fetal Alcohol Spectrum Disorders (FASD) research at the Institute were held, one in Perth in 2010 which attracted 25 attendees and a second in Cairns in 2011. Feedback was sought from women about how they would like health professionals to discuss alcohol consumption during pregnancy.
Beyond the Teaching Nursing Home: A Community Partnership of Learning and Care held a community conversation in 2011. The project, known as the Bethanie Project, is a collaboration between the School and the Bethanie Group of aged care providers. It was launched in 2012 and is a learning and training program in which senior consumers contribute to health professional education. Feedback from the community conversation informed all aspects of the teaching program and the research. Attendees were invited to nominate for a position on the project’s reference group.

A Community Conversation on mental health in 2011 discussed the findings of research undertaken at the School about physical health issues for mental health consumers. The research was complementary to the earlier *Duty to Care* research conducted in 2001 and looked at whether people with mental illness are adequately and appropriately serviced by primary medical care in general practice. Sixteen consumers, mental health consumer advocates and researchers attended the forum and recommended a larger forum be held with consumers, service providers and government and non-government agency staff.

Sixty nine consumers and community members attended the Medicines Costs Community Conversation at the School in 2011. Key aims were to seek feedback from the community on health system changes which would help to manage the costs of medicines and priorities for future research. The feedback informed policy recommendations.

The Western Australian Register of Developmental Anomalies, led by Institute researchers, held community conversations in Perth in 2011 and Broome in 2012 to inform the community about legislative changes regarding statutory notification of birth anomalies and the change of name from the *WA Birth Defects Registry* and *WA Cerebral Palsy Register*.

The second Mental Health Community Conversation was held in 2012 and attended by 35 people who discussed findings from research at the School and developed a series of policy recommendations. The draft report on the forums is under discussion by mental health consumer advocates.

A community conversation on stress in pregnancy was held in 2012 at the Institute to look at sources of stress, the influence of media messages and how researchers can better provide these messages to consumers.

The *Pre-term birth* community conversation, held at the Institute in 2012, looked at the information provided to parents on causes and risks of pre-term births and enabled discussion of priorities for future research.

The *What’s Our Vision* community conversation held in 2012 brought together Council members, senior consumer representatives and community leaders from a wide range of non-government organisations to have input into the development of the Institute’s Strategic Plan. A second forum was held in 2013 for input on the draft Strategic Plan; there was a combined attendance of 57 consumers and community members.

In 2013 community members and stakeholders attended a community conversation on the development of the School’s 2014 - 2017 Strategic Plan.
• Two community conversations were held in 2013 at the Institute to seek community feedback on research that looked at the impact of school attendance on performance and provided an opportunity to compare methods of recruiting consumer and community participants. The Program’s established strategies for recruitment attracted eight times more participants than the alternative method of inviting people as part of a telephone survey to a random sample of Perth metropolitan residents.

• Seventeen consumers attended the School’s community conversation in July 2014 to inform a research project: *Investigating the long-term use of medications to treat heart disease*, about the reasons why consumers continue or stop taking heart medications.
Appendix 3

Involving People in Research Symposium Communiqué

March 5th & 6th 2008
Perth Western Australia

Call to Action

We acknowledge and appreciate the National Health and Medical Research Council (NHMRC) for providing funds and supporting the opportunity to bring consumers and researchers together at this inaugural symposium.

• This symposium recognises the enormous value and potential for consumer involvement to improve Australian health and medical research outcomes
• We recognise that there are tens of thousands of consumers already formally involved in groups, networks and non-governmental agencies
• We strongly advise that consumers are meaningfully involved at all stages and all levels of the research process

These consumer resources should be more formally involved in research design, priorities, funding and dissemination.

The NHMRC can ensure this happens by finding ways to fund or support the creation of an independent coordinating body which would include consumers, carers, funders and researchers.

This body will develop:
• A strategy and program to advocate and market consumer participation.
• Advise NHMRC, other funding bodies and agencies on changes needed to their structures, funding, and processes to support this body.

This work should begin within the next twelve months.

We call on the NHMRC and Consumers’ Health Forum of Australia to take this forward and put the Statement on Consumer and Community Participation in Health and Medical Research into action

Thursday March 6th 2008
Appendix 4

The UWA School of Population Health

Report on the Audit and Evaluation of Consumer and Community Participation Activities in 2010

Anne McKenzie and Hayley Haines

Recommendations

In order for the School to address the findings of the audit and ultimately achieve the goals of Strategic Initiative 9 (School of Population Health, 2009) it is recommended the following initiatives be considered:

• Develop a series of professional development seminars specifically aimed at increasing understanding and awareness of the importance, value and benefits of consumer and community participation

• Promote awareness of consumer and community participation resources and activities through the whole-of-School meeting process

• Increase awareness of training opportunities to all staff and research students

• Encourage researchers who have consumer and community participation in their projects to include descriptions and/or acknowledgment of such activities in their publications

• Implement minimum standards of consumer and community participation for the School of Population Health. Hold a meeting/workshop, in the first instance, with senior research leaders and the Consumer and Community Advisory Council to discuss the principles surrounding developing minimum standards and identify potential minimum standards for different types of research. This will encourage ownership and champions

• Encourage shared learning and raise awareness by developing processes and templates for:
  • Consistent annual reporting of consumer and community participation activities
  • Evaluation of consumer and community participation activities
  • Sharing of stories and good practice examples

• Implement a system of ‘buddying’ a Council member with a research group to provide ongoing individual advice and expertise
Example of Audit Questionnaire and Scoring Criteria

The UWA School of Population Health Audit of community engagement activities in research programs August - September 2010

Questions Asked

Scored questions:

1. Does your research group have a stated policy on community and/or a commitment to consumer participation?

2. Are consumers and/or community members (separate from focus group and study participants) involved in projects in the following areas:
   2a. Developing the goals, topics or questions for the project?
   2b. Developing the study design methods?
   2c. Developing study instruments such as questionnaires, recruitment advertisements, consent forms and information sheets?
   2d. Data collection/conducting the research?
   2e. Commenting on results/inputs into the reports?
   2f. Dissemination of information and results?

3. If consumers / community members (separate from focus group and study participants) have a role in your research:
   3a. How are they informed of their role in the project?
   3b. What training or support is provided?

Additional questions:

Do you want assistance with recruiting, training and supporting consumer / community members?

Please comment on how involvement has benefitted your research program and if there were any problems or issues.

Describe any current evaluation or future plans to evaluate your research group’s consumer and community participation activities.

Do you want assistance with evaluation?

What can SPH provide or how can SPH better support consumer and community participation in your research?

Are you aware that SPH has a Consumer and Community Advisory Council?

If so, please describe any interaction your group has had with the Council and your reflections on this interaction.

Any further comments?
<table>
<thead>
<tr>
<th>Number</th>
<th>Name</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No Participation</td>
<td>• There was no involvement of consumers and community members in the research process though they may have been participants of the research project</td>
</tr>
</tbody>
</table>
| 1      | Low Participation| • Minimal involvement of consumers and community members in the research process  
• No influence on decision making  
• Little or no documentation, support or systems established for consumers and community members  
• Consumer and community participation infrequently utilised and for small tasks that are selected by the researcher |
| 2      | Low-Mid Participation| • Increased involvement of consumers and community members in the research process  
• Limited influence on decision making  
• Little documentation, support and few systems established for consumers and community members  
• Consumer and community participation utilised at times throughout the project which is usually decided by the researcher |
| 3      | Mid Participation| • Variable involvement of consumers and community members in the research process  
• Consumers and community members may have influence on decision making  
• Some documentation, support and systems established for consumers and community members including peer support  
• Consumer and community participation can be utilised at various stages of the project |
| 4      | Mid – High Participation| • Consistent involvement of consumers and community members in the research process  
• Influence and some responsibility for decision making  
• Numerous documentation, support and systems for consumers and community members including peer support and payment systems  
• Consumer and community participation utilised consistently throughout the project |
| 5      | High Participation| • Extensive involvement of consumers and community members in the research process  
• Equal responsibility for decision making  
• High levels of documentation, support and systems for consumers and community members including training, payment systems, and peer support  
• Consumer and community participation fully integrated into project |
Appendix 5

Consumer and Community Participation Strategic Plan
Telethon Institute for Child Health Research
May 2004

Background

In 2001 the National Health and Medical Research Council and the Consumers’ Health Forum of Australia Statement on Consumer and Community Participation in Health and Medical Research (the Statement) describes:

Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind.

This Statement identified opportunities for the Telethon Institute for Child Health Research (the Institute) to further develop existing relationships with the community of Western Australia. In July 2002 the Institute Executive accepted the following proposal:

1. Appoint a liaison/communication officer
2. Develop a committee to facilitate consumer and community participation
3. Develop a policy on consumer and community participation in research

Implementation of Point 1

A National Health and Medical Research Council Capacity-Building Grant enabled the shared appointment of a Consumer Liaison Officer between the Institute and the School of Population Health. The current incumbent commenced in January 2004.

Proposed Implementation of Point 2 & 3

The Institute was recently re-endorsed as a National Health and Medical Research Council Accredited Independent Research Institute. In future Research Institutes will be required to demonstrate adherence to the Statement by having written consumer policies in place. Also the National Health and Medical Research Council now require final project reports to state evidence of consumer participation.

In order to address the multi-faceted requirements of a consumer participation strategy for the Institute it is proposed to develop and implement a plan that will:

• Support the ethos of the Statement
• Expand and build on current consumer and community participation, in particular widen the established strengths of the Kulunga Research Network to other areas of the Western Australian community
• Manage organisational change through a series of steps that are inclusive of both staff and community ideas and values
• Address accreditation requirements
The Aim

The consumer participation strategy will increase participation by building the capacity of the Institute’s staff to: acknowledge the various levels of participation; understand and respect the contributions of each party; and willingly share knowledge and power. By adopting a planned long-term approach that is inclusive and seeks to address issues as they arise, risks will be minimised of implementing a policy that is tokenistic and has little added value to the staff, the community and the quality of research.

The proposed strategy will not only demonstrate adherence to accreditation requirements but will also take maximum advantage of: high community support and exposure, willingness of dedicated staff to try new ideas and the dedicated resource of a Consumer Liaison Officer.

How Consumer Participation Adds Value

The Statement presents the background, vision, and some of the relevant literature concerning consumer participation in research. Part of the aim of establishing a Consumer and community Advisory Council (the Council) at the Institute will be to evaluate the evidence that it adds value to the research programs.

Approach

The consumer participation strategy will follow an ongoing long-term approach with three main phases:

Phase 1: ascertain current organisational capacity and goals concerning consumer participation

Phase 2: establish a steering committee to develop plans and policies

Phase 3: establish Consumer and Community Advisory Group

Each phase will incorporate planned incremental changes ultimately to enable the School to maximise consumer participation.

Planning Framework

As with any strategic direction, to start the process, it is necessary to adopt a framework to guide the organisation through the various stages of assessment and planning. The framework below describes the various stages of the cycle. (Diagram source: Improving Health Services through consumer participation)
Phase One: Assess the current situation

1. Conduct half-day workshop with senior staff at the Institute to discuss goals and vision for enhanced consumer participation
2. Conduct an audit of current consumer participation

The information gathered from the workshop and audit will provide the basis to develop the goals and vision for enhanced consumer participation and the terms of reference for a steering committee.

Phase Two: Establish a Steering Committee

Community members and staff members (‘champions’) will be invited to form a steering committee.

Community members may be representatives from organisations such as Friends of the Institute, Western Australian Health Consumers’ Council, or relevant Support Groups. The steering committee will be sponsored by the Executive and will report to the Executive through the Consumer Liaison Officer on a bi-monthly basis. The establishment of a steering committee will have a two-fold purpose, firstly it will be a formal point of reference for the Executive and secondly it will provide support and focus during planning and developmental phases of the strategy. During this phase the Consumer Liaison Officer will conduct a series of consumer participation awareness-raising sessions with staff.

Phase Three: Establish the Council

It is envisaged that the steering committee will have a relatively short life and be phased out with the establishment of a Council which will report directly to the Board.

The Council will have responsibility for developing organisation-wide policies on:

- Consumer participation
- Seeking consumer feedback
- Consumer complaints
- Consumer Rights and Responsibilities

Evaluation

As part of its function, the Council will maintain a summary of the ways in which it has added value to research at the Institute. This will be used in a biennial evaluation of its effectiveness by the Board, and for inclusion in the quinquennial scientific review of the Institute.

Funding

The initial phases of planning and conducting a workshop and audit will not require any additional funding as this will be conducted by the Consumer Liaison Officer. Areas that will eventually require an allocation of funds are:

- Running costs for a steering committee and the Council
- Payment of sitting fees for consumers
• Out of pocket expenses for consumers
• Training for staff and consumers

As phases two and three are implemented, staff may require both financial and mentor support as they increase their capacity to engage with consumers. The allocation of appropriate funding for a consumer participation strategy sends a clear message of importance, commitment and support to both staff and the community.

Conclusion

Whilst there are numerous articles on the benefits of actively involving consumers in research there is little written evidence about the most successful way of implementing an organisation-wide consumer participation strategy. By adopting and implementing a planned strategy that is based on continuous improvement principles, accreditation requirements and the ethos of the Statement, the Institute has the opportunity to:

• Take proactive steps to address the National Health and Medical Research Council’s thrust to fully involve consumers and the community in research
• Lead the way in Australia by developing a best practice model for implementing consumer participation

Time line - 2004

Sept 2004 Workshop with senior staff
July-Aug 2004 Audit conducted by Consumer Liaison Officer
Sept-Oct 2004 Steering committee and terms of reference established
Dec 2004 Steering committee to meet and commence development of goals and vision

Recommendations

The following recommendations are for endorsement by the Executive:
3. Endorse in principle the proposed plan to enhance consumer participation at the Institute
4. Endorse and support to conduct a workshop and audit
5. Endorse an Executive sponsored steering committee to operate during the developmental and implementation phases of the proposal
6. Consider future budget requirements and strategies for enhancing consumer participation at the Institute

References

Statement on Consumer and Community Participation in Health and Medical Research. Joint statement of the National Health and Medical Research Council and the Consumers’ Health Forum of Australia.

Appendix 6

Consumer and Community Participation Policy
The UWA School of Population Health
July 2005

Aim

The UWA’s School of Population Health (the School) recognises the central role of health consumers and community members in its research programs. Our aim is to build partnerships in which consumers, community members and researchers shape decisions about research priorities, goals, methodologies, questions, and dissemination of results.

This aim is aligned with the National Health and Medical Research Council and Consumers Health Forum of Australia’s Statement on Consumer and Community Participation in Health and Medical Research.

Scope

This policy covers all research projects undertaken at the School. It is acknowledged that each research project is unique and there will be varying levels of consumer and community participation depending on the research project.

Definitions

The National Health and Medical Research Council and Consumers Health Forum of Australia define consumers as

- Patients and potential patients
- Carers
- Organisations representing consumers’ interests
- Members of the public who are targets of health promotion programs
- Groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services

The National Health and Medical Research Council and Consumers Health Forum of Australia define community as

- A group of people sharing a common interest – for example, cultural, social, political, health, economic interests – but not necessarily a particular geographical association

Principles

- Consumers and the community will be acknowledged as a key stakeholder in all research projects undertaken at the School
- Consumers, the community and researchers will work together to add value to research at the School
- Partnerships between consumers, the community and researchers will be based on mutual respect for one another’s different knowledge and experience.
- Partnership roles will be decided by consultation between consumers, community and researchers
- Consumers and community members will be provided with all information related to fulfilling these roles
- Consumers and community members will be required to comply with The University’s policy on Intellectual Property and the National Privacy Principles
- Remuneration for consumer and community participation is to be allocated in research project planning and budgets
- Consumer and community participation will be evaluated in consultation with consumers, community members and researchers, and made available to the public

**Governance and Ethics**

- A Consumer and Community Advisory Council will be established and supported by the Consumer Liaison Officer
- The Consumer Liaison Officer will provide regular reports on the activities of the Council to the Head of School and Executive Committee
- Consumer and Community Advisory Council membership and terms of reference will be decided by consultation between consumer and community representatives and researchers
- The Consumer Advisory Council will establish a link to the School Ethics Committee through the Consumer Liaison Officer

**Benefits**

The establishment of effective partnerships between consumers, the community and researchers will:

- Add value to evidence based research at the School
- Facilitate and enhance understanding of consumer and community priorities, perspectives and issues
- Enhance the planning, conduct and analysis of the School’s research programs
- Enhance the dissemination of research findings and increase translation into policy and practice
- Provide increased opportunities to obtain funding for research which addresses the needs and priorities of the community
Appendix 7

The UWA School of Population Health
Telethon Institute for Child Health Research

Establishing a Consumer and Community Advisory Council
Business Plan
Dec 2005

Background SPH

The establishment of a Consumer and Community Advisory Council is the culmination of the following initiatives undertaken over a number of years aimed at increasing consumer and community participation in research conducted at The UWA School of Population Health (SPH):

1. Appointment of a consumer representative to the WA Data Linkage Management Committee in 1998
2. Appointment of a part-time Consumer Research Liaison Officer in 1999
3. Appointment of a consumer representative to the Australian Cross-Jurisdictional Data Linkage Steering Committee in 2004
4. Inclusion of an initiative for working with consumers and the community in the 2003 – 2007 Strategic Implementation Plan

A NHMRC Capacity Building Grant (2003) enabled the shared appointment of a Consumer Research Liaison Officer between The UWA School of Population Health and the Telethon Institute of Child Health Research.

In 2004 a plan to address the multi-faceted requirements of a consumer and community participation strategy for SPH was developed by the Consumer Advocate and endorsed by the School Executive Committee. The plan aimed to:

• Support the ethos of the NHMRC/Consumers Health Forum Statement
• Expand current consumer and community participation
• Manage organisational change

The three phases of the plan will enable increased consumer and community participation by supporting consumers, the community and researchers to work in partnership to add value to research at SPH.

• Phase One: assessed the current situation through staff and community workshops and consultation
• Phase Two: convened a Steering Committee to develop plans for a Consumer and Community Advisory Council
• Phase Three: establish the Consumer and Community Advisory Council

In 2005 a Policy on Consumer and Community Participation was developed and endorsed by the School Executive Committee. Currently policy guidelines and procedures are being developed by the Consumer Advocate in collaboration with the Steering Committee.
Background TICHR

The establishment of a Consumer and Community Advisory Council is the culmination of initiatives undertaken over a number of years aimed at increasing consumer and community participation in research conducted at the Telethon Institute for Child Health Research (TICHR). In July 2002 the TICHR Executive accepted the following proposal:

- Develop a committee to facilitate consumer and community participation at TICHR
- Appoint a liaison/communication officer
- Develop a policy on consumer and community participation in research at TICHR

A NHMRC Capacity Building Grant (2003) enabled the shared appointment of a Consumer Research Liaison Officer between TICHR and The UWA School of Population Health.

In 2004 a plan to address the multi-faceted requirements of a consumer and community participation strategy for TICHR was developed by the Consumer Advocate and endorsed by the Executive. The plan aimed to:

- Support the ethos of the NHMRC/Consumers Health Forum Statement
- Expand current consumer and community participation
- Manage organisational change
- Address NHMRC accreditation requirements

In 2005 a Policy on Consumer and Community Participation was developed and endorsed by the Executive, the Board and the Scientific Advisory Committee. Currently policy guidelines and procedures are being developed by the Consumer Advocate in collaboration with the Steering Committee.

Objectives of the Consumer and Community Advisory Council

The Council will be a link between consumers, the community and SPH/TICHR and will:

- Provide advice and expertise on consumer and community participation
- Facilitate access to consumer and community networks
- Advocate on behalf of consumers and the community;
- Provide support to consumer and community representatives involved in research
- Support the Consumer Advocate to:
  - Obtain feedback on research priorities from consumers and the community
  - Evaluate and report to SPH/TICHR and the community on consumer and community participation
  - Provide feedback to SPH/TICHR on consumer and community issues and perspectives
  - Provide feedback on strategic planning and governance relating to consumer and community participation in research
**Membership**

The Council membership will aim to reflect the diversity of the people involved in research by having representatives from the following groups:

- The general community
- Consumer organisations linked with research at SPH/TICHR
- Researchers and participants involved in established research projects
- Health Consumers’ Council of WA

The Consumer Advocate will have ongoing membership and the Head of School/Director (or nominee) will have ex-officio membership to provide support and advice when required.

Membership numbers will be:

- 6 – 8 consumer / community members
- 2 – 3 researchers / staff
- Consumer Advocate (convener / secretariat)
- Head of School/Director (or nominee)

Expressions of interest for community and consumer membership will be advertised in local / community newspapers, as well as by direct notification to organisations representing the relevant health consumers. Consumer and community members and researchers involved in research projects at SPH/TICHR will be notified of membership vacancies. Selection processes will be overseen by the Steering Committee, who will make appointment recommendations. Appointments will be for a two year term. The Chair of the Council will be a consumer / community member and the Council will have the authority to co-opt other members as required. The Council may establish working parties for specific approved projects from consumer and community representatives who are involved in research projects but are not necessarily members of the Council. Administration support will be provided to the Council by (date to be added).

**Governance**

The Council will have Executive sponsorship from the Head of School/Director of SPH/ TICHR.

The Council will establish links with Ethics Committees associated with research at SPH/ TICHR.

Terms of Reference for the Council will be developed by the Steering Group and endorsed by SPH/TICHR.

The Consumer Advocate will provide support and guidance to the Council.
Target and Benefits

The Council has the potential to have influence about consumer and community participation in all research conducted at SPH through offering a wide range of services and functions such as:

- Providing advice about when and where to include consumer and community participation and budget costs in grant applications
- Providing advice and assistance in developing strategies to disseminate research results
- Facilitating access to consumer and community groups
- Collaborating with researchers to ensure translation of research into policy and practice
- Collaborating with researchers to explore funding opportunities
- Overseeing the process of obtaining consumer and community feedback on perspectives, priorities and understanding of research conducted at SPH/TICHR

The Council will provide a pivotal point of access for both the community and researchers, to increase opportunities for greater engagement and increase consumer and community knowledge and support for research being undertaken at SPH/TICHR.

Outputs

The council will meet four times per year.

The Council will report on its activities through the Consumer Advocate Committee on an annual basis. These reports will be made available to the community.

The Council will support the Consumer Advocate in:

- Providing feedback from the community on research priorities and consumer and community participation outcomes
- Developing guidelines, role statements and payment structures for consumer and community representatives
- Developing training courses on consumer and community participation for researchers and consumer and community members
- Facilitating consumer and community consultation in the research grant application process

Goals, Milestones and Evaluation

In the first instance the goals, vision and milestones of the Council will be developed by the Steering Committee and endorsed by the School Executive Committee and will directly relate to the stated outputs. Milestones will be reviewed annually.

All activities of the Council will be aligned to the National Health and Medical Research
Council and Consumers Health Forum of Australia National Statement on Consumer and Community Participation in Health and Medical Research.

Evaluation of the activities of the Council will be done by measuring:

- Increases in consumer participation activities or representatives in research projects due to the existence and influence of the Council
- How many researchers utilise the services of the Consumer and Community Panel during the grant application round/s
- Attendance at training courses by consumers, community members and researchers
- Requests for access to consumer and community groups
- Attendance at Council events by consumer and community member

**Communication**

The Council will develop a communication strategy that will increase knowledge of their existence and purpose to both researchers and the wider community.

**Constraints**

The Council will not be involved in operational matters, consultancy activities, or service provision activities of SPH/TICHR.

**Related Projects**

The Council will be supported by and work in close collaboration with the Consumer Advocate.
## Appendix 8

### Membership of the Consumer and Community Advisory Councils

**Current members at the School**

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Role</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara Elliot</td>
<td>Mental health consumer advocate</td>
<td>Chair</td>
<td>2012</td>
</tr>
<tr>
<td>Vivien Kemp</td>
<td>Mental health, primary care</td>
<td></td>
<td>2012</td>
</tr>
<tr>
<td>Rebecca Lubiansky</td>
<td>Cancer Council WA</td>
<td></td>
<td>2014</td>
</tr>
<tr>
<td>Andrew Markovs</td>
<td>Men’s health, mental health</td>
<td></td>
<td>2014</td>
</tr>
<tr>
<td>Mitch Messer</td>
<td>Health consumer advocate</td>
<td></td>
<td>2014</td>
</tr>
<tr>
<td>Ruth Simms</td>
<td>Ishar Multicultural Women’s Health Centre</td>
<td></td>
<td>2013</td>
</tr>
<tr>
<td>Colleen Fisher</td>
<td>School staff</td>
<td></td>
<td>2010</td>
</tr>
<tr>
<td>Anna Kemp</td>
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<td>Frank Sanfilippo</td>
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<tr>
<td>Rosemary Saunders</td>
<td>School staff</td>
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<tr>
<td>Cecily Strange</td>
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<tr>
<td>Anne McKenzie</td>
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<td>Acting Chair 2006 - 2007</td>
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<tr>
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Current members at the Institute

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<tr>
<th>Name</th>
<th>Affiliation</th>
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<tr>
<td>Rachel Skoss</td>
<td>Disability advocate</td>
<td>Chair</td>
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<tr>
<td>Michelle Atkinson de Garis</td>
<td>Consumer advocate</td>
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<tr>
<td>Belinda Frank</td>
<td>Health consumer</td>
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<tr>
<td>Caitlin Green</td>
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<tr>
<td>Dot Henry</td>
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<tr>
<td>Kristina Johns</td>
<td>Genetic Support Council</td>
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<tr>
<td>Frank Prokop</td>
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<td>Bronwyn Rose</td>
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<td>Catherine Searle</td>
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<tr>
<td>Rae Young</td>
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<td>Margaret Wood</td>
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<tr>
<td>Elizabeth Chester</td>
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<tr>
<td>Georgia Banton</td>
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<td>Heather Jones</td>
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## Past members at the School

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Kathie McLure</td>
<td>Health Consumers’ Council, Chair 2008</td>
</tr>
<tr>
<td>Barbara Daniels</td>
<td>Diabetes WA, Chair 2009 - 2012</td>
</tr>
<tr>
<td>Ian Hill</td>
<td>City of Mandurah, Chair 2013</td>
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<tr>
<td>Anne Atkinson</td>
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<tr>
<td>Liz Buckton</td>
<td>Cancer Council WA</td>
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<tr>
<td>Margaret Colbung</td>
<td>Aboriginal health</td>
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<tr>
<td>Anne Cordingley</td>
<td>Health consumer</td>
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<tr>
<td>Beatriz Cuesta-Briand</td>
<td>Cancer Council WA</td>
</tr>
<tr>
<td>Valerie Mather</td>
<td>Community member</td>
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<tr>
<td>Sandy McKeirnan</td>
<td>Cancer Council WA</td>
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<tr>
<td>Lorraine Powell</td>
<td>Mental health consumer advocate</td>
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<tr>
<td>Charlie Rook</td>
<td>Disability advocate</td>
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<tr>
<td>Caroline Rugdee</td>
<td>Health Consumers’ Council</td>
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<tr>
<td>Cheryl Rugdee</td>
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<tr>
<td>Hilary Rumley</td>
<td>Disability First Stop</td>
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<tr>
<td>Janet Wale</td>
<td>Cochrane Consumer Network</td>
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<tr>
<td>Matthew Knuiman</td>
<td>Head of School</td>
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<td>Phil Weinstein</td>
<td>Head of School</td>
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<tr>
<td>Judith Finn</td>
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<td>Sarah French</td>
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<tr>
<td>Elizabeth Geelhoed</td>
<td>Head of School</td>
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<tr>
<td>D’Arcy Holman</td>
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<td>Helena Iredell</td>
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<td>Fiona Smith</td>
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<tr>
<td>Louise Stewart</td>
<td>School student representative</td>
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### Past members at the Institute

<table>
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<tr>
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<tbody>
<tr>
<td>Ben Horgan</td>
<td>Arthritis WA, Chair 2007 - 2008</td>
</tr>
<tr>
<td>Julie Ireland</td>
<td>Down Syndrome WA, Chair 2009 - 2012</td>
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<tr>
<td>Bill Fox</td>
<td>Health Consumers’ Council, Chair 2013</td>
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<tr>
<td>Pip Brennan</td>
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<tr>
<td>Robyn Coleman</td>
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<td>Melanie Hawkes</td>
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<td>Mary Kepert</td>
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<tr>
<td>Eric Leotta</td>
<td>Juvenile diabetes</td>
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<tr>
<td>Wendy Wright</td>
<td>Association for the Welfare of Children in Hospital</td>
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<tr>
<td>Fiona Stanley</td>
<td>Institute (Director)</td>
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<tr>
<td>Moira Clay</td>
<td>Institute (Acting Director)</td>
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<td>John Finlay-Jones</td>
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<tr>
<td>Mike Garlepp</td>
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<tr>
<td>Jan Adams</td>
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<td>Siobhan Brennan</td>
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<td>Jenny Downs</td>
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<td>Catherine Gangell</td>
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<td>Sarra Jamieson</td>
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<td>Garth Kendall</td>
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<tr>
<td>Angela Rate</td>
<td>Institute staff</td>
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Appendix 9

Consumer and Community Advisory Council

Community Conversations Proposal – November 2008

Background

The National Health and Medical Research Council Statement on Consumer and Community Participation was developed as a result of the Wills Report in 1999. The Wills Report endorsed the Consumers Health Forum of Australia recommendations that:

- Consumers be given the opportunity to participate in decisions about what types of research should have priority
- Consumers who take part in research be told about the outcomes of that research
- Researchers involve the community in the research process

The consumer and community participation strategy for the Institute, developed in 2004 and which included the establishment of the Consumer and Community Advisory Council, has been underpinned by the NHMRC Statement and principles. Since forming in 2006, the Consumer and Community Advisory Council has had ongoing discussions about the most appropriate way to facilitate community input into research priorities. Some of the issues identified and discussed have been:

- Events such as this may raise unrealistic community expectations – particularly if there is not funding available to carry out new areas of research
- The general public may not be interested and a general forum may attract people that have a different agenda or interest

In August 2008 a Council sub-committee met with staff from the Development Office to discuss the issues and ideas for community consultations. Following are some points considered at the meeting;

- Consultations were likely to have better outcomes if informed and interested consumers / community groups attend i.e. disease specific groups and Council members
- There is a need to promote more widely what research is done at the Institute – annual reports and websites may not get to everyone. Forums would showcase current research projects

Proposal

The sub-committee proposed that a series of seminars based around the research themes of the Institute be held in 2009. These seminars could be called ‘community conversations’. Informed consumers/community members will be invited to join senior researchers from the theme for a half-day workshop at the Institute. Researchers will
present an overview of current work followed by a group workshop session to discuss community perspectives on any gaps/priorities within the theme areas.

It is envisaged the seminars will provide valuable community perspectives around the work currently being done at the Institute without running the risk of raising unrealistic expectations that new and different work can or will be undertaken.

The aim is to hold one or two seminars each quarter and have 20 – 30 attendees at each session. Rural and remote community members will be invited wherever possible. The proposal was endorsed in principle by the Council at the August meeting with the recommendation that funding and sponsorship be sought.

**Funding**

Funding has kindly been provided by the Collaboration for Applied Research and Evaluation and will cover catering and honorariums for attendees.

**Plans**

It is planned to hold a pilot community conversation in March 2009. This will be based on the theme Understanding Disability and will be led by Helen Leonard. The pilot will enable feedback from the researchers and attendees to be incorporated into future seminars. Negotiations with other theme Heads are currently underway and it is envisaged that two more seminars will be held before mid 2009.

It is anticipated that the Consumer and Community Advisory Council will have a role in developing and supporting opportunities for the feedback from the community consultations to be implemented. These seminars will provide the Institute with an opportunity to lead the way in Australia by seeking to engage the community in all areas of the research agenda.

Executive Group support and sponsorship for the community conversations is requested.

Anne McKenzie
Consumer Advocate
REFERENCES


28. School of Population Health. Partnerships that make a difference: Strategic Plan 2009-2013. Perth: The UWA School of Population Health and Faculty of Medicine, Dentistry and Health Sciences 2009.


