INVOLVING THE COMMUNITY IN HEALTH RESEARCH
◊ Consumer and community participation in research is about the active involvement of consumers, community members and researchers working together to make decisions about health research priorities, policy and practice.

◊ It is an active partnership that is sensitive to changing needs and priorities. It is about being part of the process as well as observing or commenting.

◊ Fundamentally, it is a commitment to conducting research that is with the community rather than to or for the community.

◊ This approach results in greater transparency, openness and accountability and research that is more relevant to the community.

The University of Western Australia School Population Health and Telethon Kids Institute is committed to upholding these values in their research and teaching programs.

‘Patient and public involvement’ in the United Kingdom and ‘community engagement’ in Canada and the United States is referred to as ‘consumer and community participation’ in Australia.
WHO WE ARE

THE UNIVERSITY OF WESTERN AUSTRALIA: SCHOOL OF POPULATION HEALTH

The University of Western Australia (UWA) is recognised internationally as an excellent research-intensive university. Established in 1911, the University is renowned for its ground-breaking research, quality academic staff and state-of-the-art facilities. UWA ranks 88th in the world in the highly respected Shanghai-Jiao Tong University’s Academic Ranking of World Universities.

UWA is the only Western Australian university to belong to the Group of Eight – a coalition of the top research universities in Australia – and it is one of only two Australian universities to belong to the Worldwide Universities Network, a partnership of 18 research-led universities from Europe, North America, North Asia, Australia and Africa.

The School of Population Health (the School) in the Faculty of Medicine, Dentistry and Health Sciences has a reputation for a strong evidence-based approach to the research disciplines and is committed to the discovery and communication of knowledge that will influence health policies and practices. The School offers world-class research training leading to the degrees of Master of Public Health (by research), Master of Nursing Research and Doctor of Philosophy.

TELETHON KIDS INSTITUTE

The Telethon Kids Institute (the Institute) is one of the largest, and most successful medical research institutes in Australia, comprising a dedicated and diverse team of more than 500 researchers, staff and students.

Established in 1990 the Institute was among the first to adopt a multidisciplinary approach to major health issues. Clinical research, laboratory sciences and epidemiology are all under the one roof, to enable researchers to tackle complex diseases and issues in a number of ways.

Research at Telethon Kids is grouped around four Research Focus Areas:

- Aboriginal Health
- Brain and Behaviour
- Chronic Diseases of Childhood
- Early Environment

Located in Subiaco, Western Australia, the Institute has strong affiliations with Princess Margaret Hospital for Children and all the major Western Australian universities, particularly The University of Western Australia and Curtin University.

The Institute is independent and not-for-profit and is committed to translating the results of its research into policy and practice to improve the lives of children and families.

THE WESTERN AUSTRALIAN DATA LINKAGE SYSTEM

The WA Data Linkage System was established in 1995 and has been developed under a coordinated, collaborative partnership between the Department of Health Western Australia, The University of Western Australia, Telethon Kids Institute and Curtin University.

The WA Data Linkage System brings together 40 years of data from over 30 population-based health collections and has expanded to encompass health and welfare data sets, and the ability to put together information about families, communities and the environment.
CONSUMER AND COMMUNITY PARTICIPATION PROGRAM

OUR JOURNEY

The joint Consumer and Community Participation Program (Participation Program) at The University of Western Australia’s School of Population Health (School) and Telethon Kids Institute (Institute) was initially established at the School in 1998 and then joined by the Institute in 2002, to provide community transparency and accountability for data linkage research projects.

Adopting a planned long-term approach that was inclusive and flexible in addressing issues as they arose has enabled the development of sustained and effective partnerships between researchers and the community.

The gradual increase in involvement of researchers, consumers and community members in the Participation Program has resulted in the School and Institute being recognised as national leaders in this area.

During the past 16 years the Participation Program has developed a range of strategies, systems and methods to successfully involve consumers and community members in a variety of research projects. These include laboratory based, epidemiological, clinical, and data linkage projects ranging from student and individual projects to large multi-million dollar programs of research.

THE PARTICIPATION PROGRAM

The Participation Program facilitates and enables consumer and community participation to become standard practice in research and teaching programs.

The Participation Program includes the following key components:

- Senior level support and champions
- Dedicated positions to support and develop:
  - Governance and policy frameworks
  - Consumer and Community Advisory Councils
  - A range of models with budgeted participation activities
  - Training for researchers, consumers and community members
  - Community links, networks and forums
  - Resources, publications and a website to support participation
THE PARTICIPATION PROGRAM TEAM MEMBERS

ANNE MCKENZIE has worked as the Consumer Advocate at the School and the Institute since 2004. Anne leads the Participation Program and her key role is to develop an organisation-wide program to enhance and increase consumer and community participation in health and medical research at both organisations.

In this role she has developed extensive collaborations in the United Kingdom, Canada and the United States with organisations that promote and support the active involvement of consumers and community members in health and social-care research. The UK collaborations have led to the development of unique resources and a suite of training workshops. Anne has a long history of consumer advocacy roles and is involved on key state and national health committees.

HAYLEY HAINES is the Consumer Project Officer and commenced in 2011. Hayley’s responsibilities are to develop and implement resources, systems and processes to support the aims of the joint Participation Program at the School and the Institute.

Hayley is a consumer representative for the Health Consumers’ Council and serves on committees for the Western Australian Department of Health and Perth North Metro Medicare Local, a non government organisation enhancing primary health in the community.

Hayley previously worked at the South Central Research Design Service in England where she established systems to increase patient and public involvement in health and social care research.

KIRSTEN ALPERS is a research assistant who is employed in writing a report on the Participation Program activities from 1998 – 2014. She has been involved in a range of epidemiological and public health projects at Telethon Kids Institute since 2003, including contributions to studies of infectious diseases and child mortality.

NGAIRE MCNEIL is the Participation Program administration officer who has responsibility for the day-to-day functions of the Program including overseeing the consumer and community network and database, publication of the quarterly newsletter, support to the Consumer and Community Advisory Councils and organising consumer and community events.

Involving People In Research
WHAT CAN THE PARTICIPATION PROGRAM OFFER?

The Participation Program has been developed over many years to encompass the multi-faceted needs of two diverse research organisations. Experiential learning has enabled robust systems and methods to be developed that have the flexibility to be implemented in a manner that is sensitive to the demands of the specific culture of any organisation.

Potential collaborators will benefit from the shared learning opportunities available from this effective and sustainable program.

The Participation Program offers:

- A suite of training courses and workshops for researchers and consumers and community members
- Resource and template development
- Access to state and national consumer and community networks
- Expertise and guidance on:
  - Establishing participation programs and activities
  - Governance models
  - Stakeholder relationship building
  - Engagement strategies
  - Facilitation and event organisation

The diagram below describes the key elements of the Participation Program which aspires to consumer and community participation in research becoming standard practice at the School and the Institute.
Services provided by the Participation Program include but are not limited to:

**ADVOCACY AND ADVICE**

◊ A credible service that is accessed by researchers, students, consumers and community members for support and advice on implementing participation activities. Our strategies to develop relationships with all stakeholders have been successfully implemented across a diverse range of research projects. We are able to demonstrate an incremental increase of consumer and community participation activities at the School and Institute. The Participation Program also provides strategic advice at an organisational level on ‘hot topics’ and important issues of concern to consumers and the wider community.

◊ A series of one-of-a-kind resources to support consumer and community participation that have demonstrated effectiveness in providing meaningful information on involving consumer and community members in research:

  - Consumer and Community Participation in Health and Medical Research: a practical guide for health and medical research organisations. McKenzie and Hanley (2007). Also known as ‘The Green Book’, this comprises a practical guide to establishing consumer and community participation at an organisational level as well as providing guidance and shared experience of involving people in individual research projects. It is now available online from the Participation Program’s website.

  - Consumer and Community participation in Health and Medical Research: Fact Sheet Series. McKenzie and Haines (2011). The Series was developed in direct response to requests from researchers for short simple ‘tools’ to support the implementation of consumer and community participation in health research.

  - A series of templates to support the planning and implementation of participation activities. These include terms of reference, information sheets, the Participation Planning Form and consent forms.

  - A new publication: Planning for Consumer and Community Participation in Health and Medical Research: a practical guide for researchers, which will be published in December 2014.

◊ Responsiveness to regular requests for information and advice and invitations to present about the Participation Program from research organisations and universities across Australia, the United Kingdom, Canada and Denmark.

◊ Advocacy on a range of ‘hot topic’ issues to external organisations and government agencies. This has included making submissions on behalf of consumers and community members involved in the Participation Program to:


  - The Australian Government Department of Health and Aging Strategic Review of Health and Medical Research in Australia (2012)

  - The National Health and Medical Research Council and Consumers Health Forum of Australia’s Draft Statement on Consumer and Community Involvement in Health and Medical Research (2014)

*Consumer concerns raised at community forums at The University of Western Australia about medication safety, specifically packaging and labelling of prescription medicines, led to major safety issues such as branding confusion and non-specific dosing instructions on prescription medicines gaining a high national profile and being discussed at national policy forums and conferences. National advocacy in this area has been ongoing with a range of government agencies, health professional organisations and consumer and non-government organisations.*
OUR WEBSITE

A dedicated website (www.involvingpeopleinresearch.org.au) for the Participation Program was launched in 2012 to provide researchers, consumers and community members with: ready access to resources, information about topical issues, training opportunities and events. The website has proven to be an effective tool in promoting shared learning locally, nationally and internationally. Since its inception there has been a steady increase of ‘hits’ and it has received over 5000 visitors from 96 countries. It has been accessed by 210 universities internationally, including 5 of the top 10 and 37 of the world’s top 100 universities according to the Academic Ranking of World Universities. The website has also been viewed by 131 organisations of interest including government departments, education departments, health services, research institutions and research organisations.

BUILDING AN EVIDENCE BASE

◊ An audit tool was developed at the School in 2010 in consultation with the Consumer and Community Advisory Council and researchers to assess the extent of participation activities across the School. In 2013 the audit was repeated at the School and showed a marked improvement in the uptake of participation activities. The audit tool is transferable to other organisations as demonstrated by its adoption at Telethon Kids Institute in 2013.

◊ All activities of the Participation Program are evaluated to measure effectiveness and identify opportunities for improvement. The feedback is utilised to improve the Participation Programs services and resources.

◊ A research project has been conducted to explore barriers to consumer and community participation. Researchers from the School and Institute participated in one of two focus groups or took part in an in-depth interview. The data is currently being analysed and is expected to be submitted for publication later in 2014. The results of this will inform the development of future services of the Participation Program.

◊ Research is being conducted to evaluate the effectiveness of the researcher training workshops in changing knowledge, attitudes and behaviours of researchers regarding consumer and community participation. It is anticipated this will also be submitted for publication in 2014.

◊ In addition to the publication of ‘The Green Book’ and the Fact Sheet Series, the Participation Program has collaborated with researchers from the School and Institute on a number of other academic publications. Participation Program staff have been co-authors on a range of publications which directly relate to collaborating with consumers. All researchers who use the Program’s services are encouraged to incorporate their participation activities into their publications. For more information see: http://www.involvingpeopleinresearch.org.au/index.php/publications/ourpublications.

Consumer and Community Reference Group members of the Alcohol and Pregnancy Project at the Institute, offered their comments and perspectives on all documents associated with the project such as: consent forms and information sheets; topic guides for focus groups; educational resources for health professionals; reports and PowerPoint presentations; and grant applications for future research. Researchers considered consumer and community participation gave the project credibility and was vital for the development of educational resources. A publication about evaluation of the project can be found at http://www.involvingpeopleinresearch.org.au/index.php/publications/ourpublications
COMMUNITY INTERACTION

◊ Over 138 consumer and community members are contributing to research policy and practice on a diverse range of research teams and committees at the School and the Institute.

◊ A database of consumer and community representatives, known as the Participation Network, was developed in March 2012. The Participation Network currently has over 220 members registered on the Network along with over 350 contacts. National consumer and community organisations have also been invited to join an ‘Alliance’ to enable shared learning and knowledge transfer.

◊ Network members are sent information via a quarterly newsletter ‘Network News’ which covers hot topics and current issues, training opportunities and vacancies on research committees.

◊ From 2004 to the end of September 2014 the Participation Program has facilitated 59 community events which have been attended by 1307 people. These events have identified research priorities and issues and have influenced changes to policy at both the School and Institute and externally at state and national levels.

‘Community Conversations’ have been held at the Institute since 2009 and have discussed a wide range of topics including disability, infectious diseases and vaccinations, genetics, pre-term births, stress in pregnancy, the Cerebral Palsy register, alcohol in pregnancy, research priorities and strategic planning. Feedback from these community conversations has been used to make improvements at an organisation-wide level as well as planning for individual research projects.

A research project to look at the impact of increasing patient costs for medicines provided through the Pharmaceutical Benefit Scheme (a system of subsidising the cost of most prescription medicines in Australia) was conducted at the School. Requests to the researchers for policy recommendations to address the findings led to researchers and the Health Consumers Council of Western Australia holding a large consumer forum to seek input into the recommendations. A report outlining the forum’s discussions was distributed across Western Australia via the Health Consumers Council newsletter and the Participation Program’s network. A report about the community forum; Kemp A. Report of the Health Consumers Council Health Issues Group Community Forum on prescription medicines costs, can be found at www.involvingpeopleinresearch.org.au/index.php/publications/auspublications
GOVERNANCE AND SERVICES

◊ Community oversight is an integral aspect of the Participation Program. The School and the Institute established Consumer and Community Advisory Councils in 2006 to enhance the quality and relevance of research activities. Council membership includes community members, senior staff member and researchers. The Councils meet quarterly to provide advice and a community perspective on organisational issues such as strategic planning and research programs. Additionally, the meetings enable consumer and community issues and concerns to be raised.

◊ The Participation Program is underpinned by a Consumer and Community Participation Policy which was first endorsed by Executive Committees at the School and The Institute in 2005. This Policy meets the National Health and Medical Research Council’s requirements for accreditation of independent research institutes.

◊ The Participation Program has developed robust minimum standards for consumer and community participation in collaboration with researchers and the Consumer and Community Advisory Councils. These standards are applicable and transferable to all types of health research. The support systems and structures are underpinned by a good-practice governance framework that is aligned with national principles and enables effective partnerships.

◊ A Memorandum of Understanding was signed between the School and the Institute in 2011. The purpose of the Memorandum is to ensure that the foundation work of the Program is carried forward with acceptance and acknowledgement of the varying contributions from both the School and the Institute.

Following two workshops with staff and community members a Consumer and Community Participation Strategy was developed and endorsed in 2005 at the School and the Institute. The second phase of the Strategy included establishing a joint Steering Committee to undertake the necessary planning and development associated with establishing Consumer and Community Advisory Councils for each organisation. The Steering Committee was to have a short life and be phased out with the establishment of the Councils. Convening a Steering Committee with short-term specific goals meant the group was focused and outcome orientated.

‘Early on we recognised that we wouldn’t succeed if we went for a “one size fits all” arrangement, and so we aimed to establish an Advisory Council that could accommodate diversity in the ways in which consumer and community participation could enhance research programs’. Professor John Finlay-Jones

‘I agreed to join the Steering Committee on the proviso that it would be of value. I only wanted to be involved if it was going to make a difference. I felt it worked really well – there was a good balance of researchers and consumers, there was a commitment from everyone to make it work’. Jackie Softly - consumer

‘I think the steering committee has developed a model that is useful, sustainable and practical. The Steering Committee enabled researchers and consumers to get behind a concept that was realistic and, to work through our disagreements.’ Ben Horgan - consumer
METHODS OF PARTICIPATION

◊ The Participation Program has developed a range of tried and tested working methods for involving consumers and community members in research. Our ‘one size does not fit all’ policy means these methods can be modified to suit a wide range of projects.

The methods promoted by the Participation Program have the flexibility to suit a range of projects from individual projects through to large programs that undertake multiple projects. Each method has been developed using the minimum standards for consumer and community participation.

The Participation Program currently supports consumer and community members on 23 research projects at the School and the Institute. Since its inception, the Participation Program has supported the use of the following methods to implement consumer and community participation at an organisational, program and individual project level:

- Consumer and Community Advisory Councils
- Community conversations / forums
- Steering groups
- Reference groups
- Consumer representatives
- Research buddies
- Community researchers
- Grant reviewers

A disability research group at the Institute sought input from the community about their research program in three key areas: gaps in current research, priorities for future research and general concerns and issues. A key issue raised by parents related directly to gaps in service delivery. This feedback was subsequently provided to the Western Australian Department of Health’s Clinical Senate to inform recommendations for the establishment of a state wide disability network. A Network has been established and the Chair of the Consumer and Community Advisory Council at the Institute was appointed as the community member of the Network team.

The Rural Cancer Project, Improving Rural Cancer Outcomes (IRCO) Trial, conducted at the School appointed a Consumer representative to the project management team in 2009. Four community conversations were held in the first phase of the project to inform the development of the intervention phase of the research.

‘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’.

Professor D’Arcy Holman – November 2011
TRAINING AND TEACHING

Training is a fundamental aspect of the shared learning philosophy of Participation Program. In direct response to requests from researchers and community members for training, a range of one and two day bespoke training workshops has been developed. Over 700 researchers, students, health professionals, administrators, consumers and community members from have attended forty workshops on the ‘how and why’ of implementing consumer and community participation in research from across Australia. These workshops are one-of-a-kind in Australia and have been developed in collaboration with a UK consultant.

- **Researcher training workshops:**
  Researchers, students, health professionals and administrators from universities and research organisations across Australia have attended 30 one and two day courses since 2009. The workshops have applicability to all areas of research including primary health, clinical and epidemiology. Modules include: foundations, principles, planning, methods and case studies.

  Evaluation of the workshops has been very positive with 83% of attendees stating they intend to change their practice following the workshops. Increases in requests for support coupled with the increase in the number of events and committees validate these intentions.

- **Plain language writing workshops:**
  A workshop on writing in plain language has been developed and facilitated at the School and Institute. Seventy-five researchers and students have attended half day workshops since 2010.

  Training workshops on writing in plain language have been held at the School and the Institute since 2010. Researchers have since reported the training was useful for developing lay summaries for grant and ethics applications, scholarship and bursary applications and presenting to community audiences. The Centre for Health Service Research at the School has included a plain language summary for each project on the Centre's website. A key task for the Infectious Diseases Research Group’s Community Reference Group at the Institute was to work with researchers on plain language summaries of all research projects.

- **Laboratory based research workshops:**
  In 2013 a pilot training workshop on implementing consumer and community participation in laboratory-based research was held at the Institute. The pilot workshop was developed in collaboration with a UK consultant, the Consumer Advocate and researchers at the Institute. Feedback from the pilot will inform the development of further workshops for laboratory-based researchers.

- **Consumer training workshops:**
  Consumers and community members have attended 10 workshops on research information. Topics covered include, funding and ethics processes, research terminology, the data linkage process and being an effective member of a research team. Presentations are made by researchers and community members.

  Bespoke training courses have been developed for community organisations such as Alzheimer’s Australia, Cancer Council New South Wales and Arthritis Victoria.
• Lectures and Tutorials:
The Participation Program team delivers lectures and tutorials on consumer and community participation in research to students in undergraduate and postgraduate courses across the Faculty of Medicine and Dentistry at the University of Western Australia and Curtin University.

• Online training:
An on-line training course specific to data linkage research is currently being developed in collaboration with a UK colleague and it is anticipated that this will be available for use in 2015/16.

CONTACT DETAILS

Please contact Anne McKenzie to discuss opportunities for collaboration, training workshops or resource development.

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Researchers from the Australian Primary Health Care Research Institute (APHCRI) at the Australian National University attended a two-day training workshop facilitated by the Participation Program at in 2010. Subsequently a collaborative agreement between the School, the Institute and APHCRI has enabled a series of bespoke training workshops to be conducted. These workshops on implementing consumer and community participation in primary healthcare research are for researchers who receive APHCRI funding. This is in line with their ongoing organisational commitment that aligns with the National Primary Health Care Strategy.

The Beyond the Teaching Nursing Home Project is a collaborative project between Nursing Education at the School and the Bethanie Group Inc. (a not-for-profit aged care provider). A process of community consultation with senior consumers followed by wider stakeholder consultation culminated with the launch of a teaching, learning and training program. A Reference Group of consumers, staff and students has provided ongoing guidance for the project. This project has given senior consumers a say on health professional education. More information can be found at http://www.sph.uwa.edu.au/community/consumer-and-community-participation/research-involving-the-community.