



Consumer & Community Health Research Network

***Report on the first year
July 1st 2016 - 30th June 2017***



**THE UNIVERSITY OF
WESTERN
AUSTRALIA**

Founding partners

**TELETHON
KIDS
INSTITUTE**
Discover. Prevent. Cure.

lotterywest
supported

Overview

The WA Consumer & Community Health Research Network (the Network) is an enabling platform of the Western Australian (WA) Health Translation Network and was formerly known as the Consumer and Community Involvement Program. It was established in 1998 at The University of Western Australia's School of Population and Global Health and Telethon Kids Institute (founding partners). It is considered an international best practice model for consumer and community involvement. Three-year funding provided by WA's Lotterywest in July 2016, has enabled the expansion of the program of work across the WA Health Translation Network.

This exciting initiative, which is a first for Australia, has seen the Network expand across the WA Health Translation Network's partner organisations i.e. five universities, seven research institutes, tertiary health services, private hospitals and the WA Department of Health.

The new structure for the Network features a Delivery Team and a Development Team. The Delivery Team of three consumer advocates currently provides on-the-ground support to researchers, clinicians, students, consumers and community members in six partner organisations: The University of Western Australia (UWA), Telethon Kids Institute, Curtin University, Edith Cowan University, Harry Perkins Institute of Medical Research and Princess Margaret Hospital. The Development Team provides 'back-of-house' support for the consumer advocates as well as support services and resources for all partner organisations across the WA Health Translation Network.

The Network's Strategic Framework has a three-phased approach and 97% of outcomes for the first year have been successfully achieved, with a Community Advisory body for the Network being the only task not completed. A sharp increase in activity in the second half of the year is supported by the increased staffing levels.

159 Projects supported

Grant applications supported

97

13 Events attended by 189 consumers and community members

Training workshops

15

534 Meetings attended

Applications received for 159 positions **213**

Program of work

The Network has a comprehensive program of work with the following core components: advocacy and advice; building the evidence; community and stakeholder interaction; governance and services; methods of involvement and; teaching and training.

A significant benefit of the expanded Network is the ability to provide extra experienced staff from the Development Team to support a range of events at a partner organisation. Examples of the value of the availability of increased staff include:

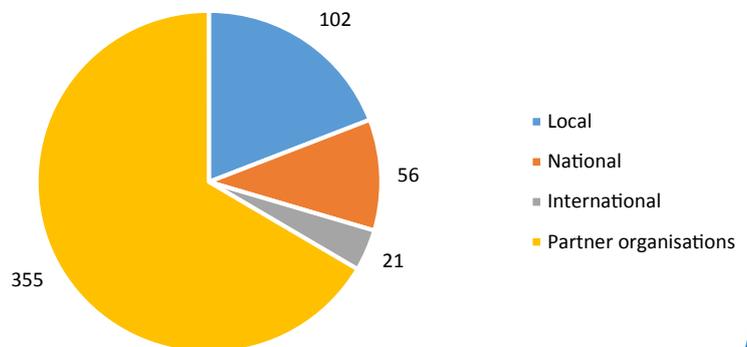
- Six staff members meeting with 23 researchers at the 'drop in centres' at the Telethon Kids Institute and the Harry Perkins Institute of Medical Research
- Six staff members organising and facilitating a community conversation about 'Opt-in consent for research' at Sir Charles Gairdner Hospital

Advocacy and advice

Advocacy and advice was provided to researchers at the WA Health Translation Network partner organisations in the following ways:

- Negotiations with senior staff at the six partner organisations regarding the jointly funded appointment of the consumer advocates
- Attendance at partner organisation's management meetings to introduce the Network and the consumer advocate
- One-on-one meetings with researchers to support consumer and community involvement in new and existing research projects
- 159 projects were supported in the first year, 56 of which had involvement activities that were initiated prior to the start of the Network

Network meetings



National and international advocacy

The Network is able to influence consumer and community involvement in research in the national and international arena; in the first year the Networks Head and Senior Project Officer attended 56 national and 21 international meetings.

Other activities undertaken by the Head of the Network include:

- Organising and facilitating events in Canada that involved researchers, patients and their families with an aim of increasing patient engagement
- Reviewing patient engagement activities in grant applications for the Canadian Institutes of Health Research

National reference group

The Fetal Alcohol Spectrum Disorder Research Australia Centre of Research Excellence established an eighteen member national community reference group to gain input and advice from consumers and community members. The Network provided advice on the structure of the reference group and advertised the positions nationally. A total of 31 applications were received from consumers and community members from all Australian states and territories. The Centre of Research Excellence is in the process of planning a priority setting partnership to identify community priorities in the area of alcohol consumption in pregnancy and fetal alcohol spectrum disorder.

- Developing an 'International Consensus Statement for Patient Engagement' with UK collaborators about involvement activities in linked data research
- Being invited to present the opening plenary at the INVOLVE conference in the UK in November 2017

Building the evidence

The first year has seen the establishment of standardised systems to collect outputs from the consumer advocates. It is anticipated these outputs will form the basis of future data collection for potential research in consumer and community involvement and to measure the impact of the Network.

A research project, *Barriers to community involvement in health and medical research - Researchers perspectives on consumer and community involvement in research: a qualitative study*, undertaken in 2012 was published in September 2016.

Audits of consumer and community involvement activities in partner organisations will be undertaken in year two of the Network's program of work. Whilst base line audits were envisaged for year one, priority was given to meeting the initial demand for project support from the partner organisations which was higher than anticipated.

Discussions with UK collaborators regarding the evaluation of the Network's program of work have been ongoing and it is envisaged this will continue into year two. The Network produced three publications and two newsletters for the first year.

Community priorities for research

The Family and Domestic Violence Priority Setting Partnership Project was undertaken in September 2016. The project was a collaboration between the Network, the UWA School of Population and Global Health, Telethon Kids Institute, Anglicare WA, and Crowe Associates UK. It was established to seek community input into priorities for future research in the area of family and domestic violence. The Family and Domestic Violence Priority Setting Partnership Project Report documents a new method of involvement for the Network, which seeks consumer and community priorities for research. This is adapted from the UK's James Lind Alliance Priority Setting Partnership Process. This priority setting partnership process will be used as a new method of involvement for other areas of research across WA Health Translation Network.

A new method of involvement: Family and Domestic Violence Priority Setting Partnership

Priority setting partnerships are a new process in Australia and aim to seek the views of the community to identify research priorities within a specified area. In 2016 the Network trialled an abridged version of the UK's James Lind Alliance process. Our aim for the priority setting partnership was to:

- Identify the issues and questions that consumers and community members consider are important about family and domestic violence
- Develop a list of community priorities that will be used to inform future research in this area
- Ensure that people who have experienced family and domestic violence are included in the development of priorities for research in this area

The project consisted of a survey to identify the issues and questions important to people who have experienced family and domestic violence and those who support them. The survey was followed up by a consensus workshop to prioritise the issues and questions identified. A list of the 'top ten' priorities was developed. A separate 'top ten' list was also developed by Aboriginal people who attended the workshop.

Community & stakeholder interaction

The number of consumers and community members providing input into research has continued to grow with 395 people having input into 55 research projects or programs. The rise in demand for support for new projects has increased the number of opportunities for consumer and community members to be involved. In the first year, 213 consumer and community members applied for 159 vacancies on 38 projects.

The Network organised and facilitated thirteen events with 189 consumers and community members attending to have a say about a range of topics including; family and domestic violence, linked data research; opt-in consent for research, early childhood; cancer prevention and health conditions such as muscular dystrophy and familial hypercholesterolemia.

The Involvement Network (a database of consumers, community members and researchers with an interest in consumer and community involvement), established in 2012, has seen strong growth in the first year and has exceeded its target of 1500 members. Contact with our members is maintained through weekly updates, newsletters and social media.

The Network has extended its reach into the community through increased presence on a number of social media platforms including Facebook, Twitter and Instagram. We have exceeded our target of 400 Twitter followers and 200 Facebook likes by the end of the first year.

Community involvement strategy

The Western Australian Pregnancy Cohort (Raine) Study is one of the worlds largest longitudinal studies of pregnancy, childhood, adolescence and early adulthood. In 2016 the Raine Study underwent a restructure and approached the Network for advice on a consumer and community involvement strategy to support study retention. A structured approach was developed to include a community reference group and two community members joining the study's Unincorporated Joint Venture Board. The Network managed the application process and 30 applications for the community reference group and 23 applications for the Board positions were received. The calibre, skills and expertise of applicants was considered to be very high by the Raine Management which resulted in all consumer positions being filled within the new structure.

High calibre of applicants for vacancies

The Cancer Division's Translational Cancer Research Program at the Harry Perkins Institute of Medical Research needed two 'research buddies' to assist them in developing an ethics application. After advertising this vacancy, the Network received seven outstanding applications which were presented to the Head of the Cancer Division. The quality of the applicants was exceptional and all were invited to form a reference group for the Cancer Division. A further four consumers, who were already working with various researchers in the Cancer Division, were also invited to join the reference group. The inaugural Cancer Division Reference Group was established in June 2017 with eleven members.

A resource for consumer and community members involved in research, namely the *Ten Top Tips for Consumers and Community Members* about Involvement, was developed in collaboration with consumers and community members from key committees within the Network at a skill-building workshop held in March 2017.



256 posts
and liked by
237 people



252 tweets
and 253 new
followers



43 posts
and 134
followers

Governance and services

A *Strategic Framework*, *Consumer Advocate Manual* and online Advocate Portal for reporting of outcomes have been developed to support the expansion of the Network across the WA Health Translation Network.

The *Consumer Advocate Manual* was developed to support the consumer advocates to deliver the Network's program of work across the partner organisations in a standard and consistent way. Two training workshops for staff in the Network were held as part of an intensive induction process. The consumer advocates have also been provided with ongoing one-on-one support in addition to shared learning opportunities at weekly team meetings.

Methods of involvement

The Network has developed and implemented a range of methods of involvement during the last two decades. Over 150 activities have been implemented across the partner organisations using these methods since January 2017.

The Network is using two new methods of involvement: 'drop in centres' and 'priority setting partnerships'. The 'drop in centres' provide individual support to researchers developing grant applications during peak grant writing seasons in the partner organisations. A staff member of the Network and an experienced consumer consultant met with researchers in the 'drop-in-centres' to provide feedback and advice about plans for consumer and community involvement.

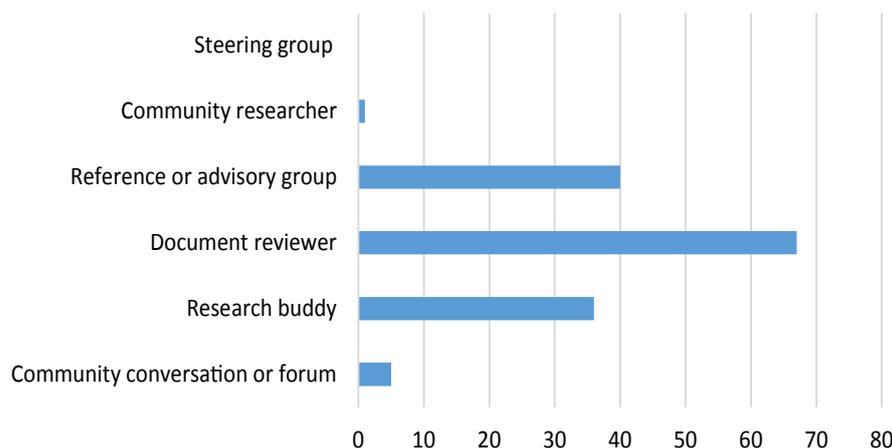
Assessing consumer and community involvement in grant review processes

In 2017, the Perth Children's Hospital Foundation has included consumer and community involvement as a new scored element of their grant application process following discussions with Network staff. The Network was involved in the development of:

- Application questions focusing on the role consumers had in preparing the grant and any ongoing involvement
- Criteria for assessing consumer and community involvement which looked for evidence of a budgeted plan for involvement activities, that the proposed research meets a community need, a planned budgeted strategy for involvement activities

Consumer and community involvement accounted for 10% of the final score. All 40 applications were reviewed by Network staff. It is planned to have consumers and community members fulfil the role of grant reviewers in 2018.

Consumer and community involvement activities by type since January 2017



Priority setting partnerships are a method of eliciting consumer and community priorities for research. The Network established an abridged version of the James Lind Alliance process in Australia in collaboration with a UK consultant. The process was successfully trialed in the sensitive area of family and domestic violence. Two priority setting partnerships are currently being undertaken and will be completed in the second half of 2017.

Teaching and training

The Network's target of six training workshops has been exceeded in the first year with fifteen training workshops being facilitated. This has included:

- Eight researcher training workshops including two held at the South Australian Health and Medical Research Institute
- Three 'Introduction to research' workshops for consumers and community members
- Two introductory workshops for students
- One skill-building seminar for consumers and community members
- One 'Writing in plain language' workshop for researchers

The training workshops have gained increased exposure at a national level. Requests for training workshops have been received from other national organisations in Sydney, Brisbane and Tasmania. Six lectures have also been delivered to undergraduate and postgraduate students at UWA.

Bespoke training workshops

The Network ran a bespoke researcher training workshop at the School of Occupational Therapy and Social Work at Curtin University for its staff and PhD students. The workshop included presentations from researchers within the school who have involved consumers in their projects. Researchers spoke of working with consumers in the UK and Queensland and their experience of the Network supporting their grant application. An infographic presented at the workshop is now being used on the Network's website as a case study of how researchers can be supported when developing grant applications. The feedback from the event was extremely positive and led to an invitation to return and deliver another training module on 'Writing in plain language'

Supporting increased uptake of consumer and community involvement

The Edith Cowan University School of Nursing and Midwifery has implemented a more inclusive strategy to involve consumers and community members. The Associate Dean has approved the inclusion of consumer representatives across the existing School committees to undertake the following tasks:

- Identify areas of research need and opportunities for collaborative research initiatives
- Advise the School Executive on all matters relating to research priorities and to monitor the directions and outcomes of research and research training
- Provide advice on appropriate involvement strategies for current research projects around and opportunities for new research projects

Thank You

The Consumer and Community Health Research Network would like to thank:

- Lotterywest for providing the funding that has enabled the expansion of the Network across Western Australia
- The partner organisations who have provided joint funding for consumer advocates and supported the implementation of increased involvement activities
- Consumers and community members who have joined the Involvement Network to provide a 'lived experience' perspective to research in WA



Contact the Team

Central phone number: 6488 8176

E-mail: admin@involvingpeopleinresearch.org.au



www.InvolvingPeopleInResearch.org.au