

collaboration between patients and researcher sustained in the process of implementation? To this end, we recently finished a two-year evaluation study on ten different multi-stakeholder agenda setting projects in the Netherlands, which used the Dialogue Model.

Several of the evaluated research agendas have been translated into funding programmes and two strategies for processing research agendas were identified. Some funding agencies translated the results of the research agenda into a funding programme without making changes. Other funding agencies used the obtained experiences with patient involvement to adapt their general policy. Also a combination of both strategies has been carried out by a few funding agencies. Some research agendas had not been programmed at all. Programming and implementation of research agendas, including patients' perspectives, cannot be taken for granted and effectiveness is dependent on a multitude of factors. Three main categories of factors could be recognised: (1) factors that influence programming (for example research climate), (2) those that influence implementation (for example assessment criteria) and (3) factors regarding the context in which agenda setting, programming and implementation occur (for example support, attitudes, collaboration). However, several examples were found of research topics identified and prioritised by patients that were picked up by researchers.

Although patient involvement in the programming and implementation phases is gaining more attention nowadays, it was very limited at the time of programming and implementation of the evaluated research agendas. This shows that collaboration between patients and researchers is hardly sustained. Only a few funding agencies carried out continued patient involvement and this was restricted to the implementation phase. For example, the Netherlands Asthma Foundation established a group of trained patients to assess research proposals. The judgement of this group was taken into account in the final decision of the scientific advisory board about which research proposals were funded. The Dutch Diabetes Organisation has formed a mixed selection committee consisting of patients, patients' relatives and experts.

Although our findings suggest that patient involvement is not always sustained and patients' topics are seldom picked up, it would be too easy

to conclude that our results are disappointing. Our findings clearly illustrate that patient involvement in research agenda setting is constantly improving and further developing. During our evaluation we observed that organisations are currently adjusting their procedures to further improve their patient involvement activities regarding research funding (for example appointing patient reviewers and advisory committees of patients actively matching research topics identified by patients to research institutes).

Based on the findings, two practical decision models were developed which can be used by funding agencies and patient organisations to realise or improve patient engagement in the programming and implementation of research agendas. The models take the context of organisations into account, as well as their potential to invest in patient involvement. The findings also led to further improvement of the Dialogue Model.

The results of our two-year evaluation are expected to be published later this year. The study was financed by ZonMw/VSB Fonds.

Contact: **Janneke Elberse, PPI researcher, VU University Amsterdam**

Email: [jannekeelberse@hotmail.com](mailto:jannekeelberse@hotmail.com)

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## University of Western Australia Consumer and Community Participation Program

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**By Anne McKenzie**

Consumers and community members having a 'voice' at all levels and in all stages of health research has underpinned the Consumer and Community Participation\* Program at the University of Western Australia's School of Population Health (the School) and the Telethon Institute for Child Health Research (the Institute). The Program, which began in 1998, was first established in response to community concerns about research being undertaken using Department of Health data without community knowledge. It became a joint initiative between the School and the Institute in 2002 and follows the principles outlined in the



National Health and Medical Research Council and the Consumers Health Forum of Australia's joint 'Statement on Consumer and Community Participation in Health and Medical Research'.

I commenced in the role of Consumer Advocate in 2004 and my key task is to support consumer and community involvement at both organisations by providing processes and links between researchers and the community. As a first step I developed a long-term plan to manage organisational and cultural change at both organisations. Workshops were held with staff and community members and the plan was inclusive of the goals and values of both groups. This early work has resulted in a strong, sustained Participation Program that has the following components: senior level champions, dedicated positions, policy and framework, Consumer and Community Advisory Councils, training, resources and well established links with the community.

The activities of the Participation Program have arisen from a wide variety of events, forums, workshops, presentations, training sessions and delegations. Attendees at these diverse events and activities have included researchers, students, consumers, community members and staff from government agencies and non-government organisations.

Since 2004, over 1500 consumers and community members have attended events to provide input into planning and priorities for research, strategic planning activities and seminars. The steady increase of consumers and community members in attending these events supports the increase in involvement of consumers and community members in research teams. Currently there are 149 consumer and community members actively involved in research programmes and projects across both organisations. Many of these projects use data sets that are routinely collected by a range of government agencies.

As consumer and community participation is not standard practice in research in Australia, my early support was gained from contact with the wonderful staff at INVOLVE. I have also been privileged to attend five INVOLVE conferences which, along with ongoing support from the INVOLVE staff, has allowed me to develop strong relationships and collaborations with many skilled and experienced people who are involved in patient and public involvement in the UK.

One such example of this is the collaborative work that I have undertaken with Bec Hanley following an introduction from INVOLVE. Firstly to write about the Participation Program in a resource manual for researchers: McKenzie and Hanley (2007). Then in response to requests from researchers we developed a range of training workshops on the 'how and why' of implementing consumer and community participation in research. Since 2007 over 900 researchers, students, health professionals, consumers and community members from across Australia have attended 19 workshops. 85% of researchers who have attended the workshops state they intend to change their practice. The steady increase in requests for support from researchers validates this feedback.

At the 2010 INVOLVE conference I met Hayley Haines (formerly from the South Central Research Design Service) prior to her travelling to Perth on a 12-month working holiday. Hayley now lives in Perth and works with me in the Participation Unit. She started with a short-term contract to work with me to develop a series of Fact Sheets. A further short-term contract saw Hayley using her considerable IT skills to develop the 'Involving People in Research' website to house the Fact Sheet Series [www.involvingpeopleinresearch.org.au/index.php/resources/fact-sheets](http://www.involvingpeopleinresearch.org.au/index.php/resources/fact-sheets). The success of these two initiatives has led to Hayley being sponsored to work in Australia for a further three years.

These two introductions with Bec Hanley and Hayley Haines initiated by INVOLVE, have made a substantial and enduring contribution to the growth and development of a Consumer and Community Participation Program that is recognised across Australia as a best practice model.

My hope for the future is that as Australia moves towards greater consumer and community involvement, our Program will expand and continue to provide support for consumers, community members and researchers working together to enhance research and its results. [www.involvingpeopleinresearch.org.au](http://www.involvingpeopleinresearch.org.au)

\* Patient and public involvement in the UK is referred to as consumer and community participation in Australia.

Contact: **Anne McKenzie, Consumer Advocate, University of Western Australia School of Population Health and the Telethon Institute for Child Health Research**  
Email: [anne.mckenzie@uwa.edu.au](mailto:anne.mckenzie@uwa.edu.au)