

newsletter

Spring 2013

Welcome to the INVOLVE Spring 2013 newsletter, which has an international theme. We begin with news of an exciting new online resource.

invoDIRECT

By Ade Adebajo,
Chair of the invoDIRECT task
and finish group



What is invoDIRECT?

At INVOLVE, we know that there are many national and international groups and organisations involved in working on public involvement in research. In fact, there are so many that it can be difficult to

know which groups are interested in particular topics or which organisations work in a particular geographical area.

To address this issue we have developed a new online resource called invoDIRECT. This resource, which is viewable on INVOLVE's website, is a searchable map which shows groups and organisations that support public involvement in research.

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If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

How was it developed?

I was the Chair of the INVOLVE task and finish group responsible for advising on this work. The group met a few times over the course of the past year and it was exciting to see ideas for this resource develop into the online map. The group, which included members of the public and researchers, thought through the features which would be most useful and how to make the map user-friendly.

Who is it for?

I believe that invoDIRECT will be particularly useful for anyone or any group wanting to find other groups or organisations that support or work in public involvement in research. Contact details are available to encourage people to get in touch with others on the map to discuss shared interests.

The map also encourages groups and organisations to let others know that they are out there and supporting or working in public involvement in research.

Key features

invoDIRECT is searchable by keyword or geographical location. It shows whether groups or organisations cover a local area or have national coverage. An exciting feature of invoDIRECT is a 'worldwide' area which displays groups and organisations working on public involvement in research outside the UK. This issue of the newsletter showcases the work of some international organisations and groups - in Australia, Denmark, the Netherlands and the United States. We will encourage these organisations and others to add their information to the map.

Add your information

To add your own details please visit www.invo.org.uk/find-out-more/invodirect You will need to follow the links to 'Add your details' and complete the form. You will then receive a password enabling you to add or change the information about your group or organisation.

Visit invoDIRECT

You can view the resource at www.invo.org.uk/find-out-more/invodirect

INVOLVE Coordinating Centre news

Research project database

Our Research project database is an online resource of published and unpublished research projects in health, public health and social care that have or plan to actively involve members of the public. Visit our website to browse over 250 projects in the database, read about the ways people are involved or to add your own project details.

www.invo.org.uk/resource-centre/research-project-database/

New information cards

There are three new additions to our series of A5 information cards, highlighting our Research project database, Plain English summaries for researchers and invoDIRECT. For copies of these and other cards in the series please send your name and address together with details of how many cards you would like to admin@invo.org.uk or phone us on 023 8065 1088.

www.invo.org.uk/posttypenews/involve-postcards/

Plain English summaries update

A new area on our website contains information and advice on writing a plain English summary. It includes our report on improving the quality of plain English summaries in National Institute for Health Research (NIHR) funded research, together with links to our Jargon buster and tips from other organisations. Further information and examples will be added in the future.

www.invo.org.uk/resource-centre/plain-english-summaries/

EUPATI

We were excited about attending the European Patients' Academy on Therapeutic Innovation (EUPATI) conference in Rome on 19 April 2013. The conference included sessions on the vision for patient involvement by 2020, public awareness about medicines development and building knowledge and competences for involvement. Lucy Simons from INVOLVE contributed to this last session with a brief presentation about the cross-NIHR working group on learning for involvement. More information about EUPATI is available at

www.patientsacademy.eu

INVOLVE response to Commons Select Committee inquiry

In February we welcomed the opportunity to submit written evidence to the House of Commons Science and Technology Select Committee inquiry into clinical trials and disclosure of data. Read our response at www.invo.org.uk/posttypeorgpub/involve-response-to-commons-select-committee-inquiry-into-clinical-trials/

INVOLVE Advisory Group members

Who are our Advisory Group members? INVOLVE has around 30 members encompassing a broad mix of individuals who use health and social care services, carers, people from voluntary organisations, and health service and social care practitioners, managers and researchers.

You can download a list of current INVOLVE Advisory Group members or read their detailed biographies by visiting the INVOLVE members' page on our website: www.invo.org.uk/about-involve/who-are-involve/members-information/

Welcome to Meraid and Marisha



We are delighted to welcome Meraid Griffin to the INVOLVE Coordinating Centre. Meraid is our new Business Manager and will have a leading role in strategic direction and management of

the operation of the Coordinating Centre. She has previously managed a Citizens Advice Bureau in Northern Ireland and is a keen sailor.

We are also delighted to welcome Marisha Palm, who has joined us on a three-month part-time contract until the end of June 2013. Marisha will be assisting with several projects including one to briefly review existing work on principles and standards for public involvement in research. Marisha may be known to some of you through her work as Facilitator for the North West People in Research Forum and with Nowgen at the University of Manchester.

Twitter

Are you following us on Twitter? Don't miss out on the latest news and information on public involvement in research [@NIHRINVOLVE](https://twitter.com/NIHRINVOLVE)

Interesting articles and publications

Do not forget the professional – the value of the FIRST model for guiding the structural involvement of patients in rheumatology research

Martin P T de Wit, Janneke E Elberse, Jacqueline E W Broerse and Tineke A Abma
Health Expectations, January 2013, advance e-publication

The FIRST model comprises five practical components that enable equal collaboration between patients and professionals in clinical rheumatology research: facilitate, identify, respect, support and training. This paper assesses the value of the FIRST model as a framework for setting up and guiding a network of patient research partners and clinical rheumatology departments in the Netherlands. The authors conclude that FIRST is a good model to implement sustainable relationships between patients and researchers and that it would benefit from further refinement.

www.ncbi.nlm.nih.gov/pubmed/23363240

Designing a placebo device: involving service users in clinical trial design

Rachel Gooberman-Hill, Clare Jinks, Sofia Barbosa Boucsas, Kelly Hislop, Krysia S Dziedzic, Carol Rhodes, Amanda Burston and Jo Adams
Health Expectations, January 2013, advance e-publication

This article describes and reflects on the process of involving service users in splint selection and the design of a placebo splint with the aim of enhancing the design of a future clinical trial. Two fora of service users discussed their experience of hand splints for thumb-base osteoarthritis (OA), identified the design features of a variety of alternative splints and developed a potential design for a placebo splint. The authors conclude that service users are increasingly involved in product and device design and are ideally placed to identify features to make a placebo credible.

www.ncbi.nlm.nih.gov/pubmed/23311756

Why collaborate with children in health research: an analysis of the risks and benefits of collaboration with children

Deborah Bird, Lorraine Culley
and Monica Lakharpaul

Archives of Disease in Childhood: Education and Practice Edition, January 2013, e-publication

Over the last 15 years children have become increasingly engaged in research and there has been a shift from research on children to research with children. This article discusses collaboration with children in health research: what this means and why (or why not) to do it. The definition of collaboration is discussed and the lines among collaboration, involvement, participation and participatory research are considered. The authors review the risks and benefits of collaboration and look towards the future.

www.ncbi.nlm.nih.gov/pubmed/23303525

How to develop a patient and carer advisory group in stroke care research

Sarah Sims, Sally Brearley, Gillian Hewitt,
Nan Greenwood, Fiona Jones, Fiona Ross
and Ruth Harris

Nurse Researcher, January 2013, volume 20,
number 3, pages 6-11

This paper reflects on the process of developing a stroke patient and carer advisory group as part of a research study. It discusses the challenges and the benefits of developing the group and offers advice to other researchers undertaking a similar process. The authors conclude that with careful planning and consideration and the allocation of sufficient time and resources, stroke patients and their carers can be effectively involved. <http://tinyurl.com/cotj5m8>

To what extent can people with communication difficulties contribute to health research?

Rebecca Palmer and Gail Paterson
Nurse Researcher, January 2013, volume 20,
number 3, pages 12-16

People with communication disorders are often precluded from involvement in research due to the high level of communication skills required. This paper describes creative techniques used to help an advisory group of people with aphasia and their carers to collaborate in research at all stages. Those involved reported increased confidence in communicating, stimulation and feelings of empowerment.

<http://tinyurl.com/brxemev>

BPSU PPI Guidance for Researchers

By Rachel Winch

The British Paediatric Surveillance Unit (BPSU) undertakes national epidemiological surveillance of rare diseases of childhood. Unlike many research projects, patients or their parents are not approached, so its studies are undertaken without consent and have to obtain approval from the National Information Governance Board for Health and Adult Social Care (NIGB) as well as a Multicentre Research Ethics Committee (MREC). Patient and public involvement (PPI) is especially important in research which does not involve individual consent, to ensure openness, transparency and accountability to the public.

After an extensive review of the impact of PPI on its research activity, the BPSU has produced a guidance document for researchers on how to involve patients and the public in their research. This document has been designed to be an accessible and practical guide for researchers carrying out research through the BPSU, but we also hope it will be useful to a wider audience who are grappling with PPI in similar types of epidemiological surveillance. It offers practical advice on how to involve people, and provides examples of where PPI has been effective in BPSU studies. The guidance was developed by TwoCan Associates in collaboration with a steering group of BPSU Scientific Committee members, including its lay representatives.

www.rcpch.ac.uk/bpsu/ppi

Contact: **Richard Lynn, BPSU Scientific Coordinator, Royal College of Paediatrics and Child Health**

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Tel: **020 7092 6173**

If you have written or know of any articles or publications relevant to public involvement in research that might be of interest to readers, please contact Helen Hayes at the Coordinating Centre with details: hhayes@invo.org.uk

The Center for Evidence-based Policy at Oregon Health & Science University

By Cathy Gordon, Pam Curtis and Valerie King

“This is not going to be solved with idealism and by saying that you’re ‘patient-centered and that consumers are going to be involved here’ [That] **isn’t** going to get it done. There is going to need to be a well-organized, reasonably funded, pretty sophisticated effort to do this. It’s not going to happen on its own.”

Patient Advocate, Patient Centered Outcomes Research Institute (PCORI) Expert Interviews Project

The Center for Evidence-based Policy (Center) at Oregon Health & Science University is a national leader in evidence-based decision making and policy design. While the importance of public involvement in research is gaining recognition in the US, there are still relatively few avenues for researchers and members of the public to engage in meaningful work together. Many Center projects are focused on bridging the cultural divide between the public, policymakers and researchers in the US.

Our Stakeholder Engagement Team works with state and federal policymakers, and has collected rich data and experience on best practices in patient and public involvement that we have used to produce tools designed to assist researchers in their work engaging the public. Many of our products are available in the public domain including key process elements for public engagement, a facilitation primer and online training programme for researchers interested in working with the public:

www.ohsu.edu/policycenter

A recent example is the Expert Interviews Project (EIP) for the newly established Patient Centered Outcomes Research Institute (PCORI). The EIP identified best practices in public involvement through in-depth qualitative interviews with nearly 90 national and international experts and a dozen discussion groups with members of the general public across the US. While many of the findings are simple common sense for those who are experienced in patient engagement, we heard many examples in which basic principles of engagement had not been employed to the detriment of the research and patients.

Our initial analysis identified three broad thematic areas essential for effective public involvement in research:

1. mutually respectful relationships among all participants
2. effective communication practices
3. dedicated resources to conduct engagement activities.

These themes, along with findings from other work we have done, informed the development of a framework for effective public engagement (Figure 1). The framework focuses on four overarching systemic components necessary for effective engagement, and five steps to ensure all elements are present.

Planning for engagement involves determining project goals and rationale for engagement; understanding patient and community needs; determining points of engagement; creating transparency; and identifying logistical requirements.

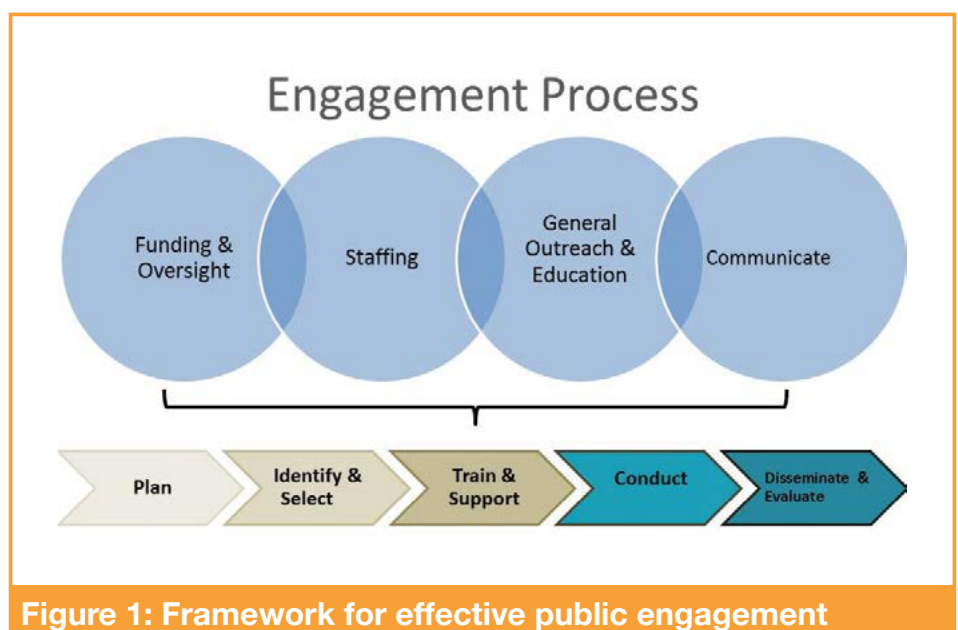


Figure 1: Framework for effective public engagement

Identifying and selecting participants involves identifying relevant stakeholders; recruiting and selecting stakeholders; and matching stakeholders with points of engagement identified in planning.

Training and supporting participants includes providing orientation; training and building participant and researcher capacity for involvement; providing support to participants; and mentoring stakeholders.

Conducting the project may involve various forms of public or patient engagement from focus groups and surveys to committees, boards and as co-producers of research.

Evaluation and dissemination includes the distribution of findings; evaluation of both the processes for public engagement and the results of the research; creating participant feedback loops; and using findings to inform future public or patient engagement.

Conclusion

Patient and public involvement in research is a relatively new phenomenon in the US. Despite the US being a 'consumer' economy, the patient-citizen actually has few opportunities for engagement or involvement. The EIP assisted PCORI to develop standards for effective patient and public engagement with recommendation for inclusion of these standards into research funding and conduct:

1. patient involvement across the spectrum of research activities
2. dedicated resources for patient and other stakeholder involvement
3. stakeholder identification and selection
4. support for patient engagement
5. communication with patients and other stakeholders
6. transparent involvement processes.

Plans are underway to continue development of the EIP into a toolkit for use by researchers and the public. We hope that the combined 'pull-push' of funding and education will help to increase the involvement of US patients in the research that so importantly influences their lives and health.

We welcome enquiries regarding our work and potential collaborations.

Contact: **Cathy Gordon, Pam Curtis** or **Valerie King, The Center for Evidence-based Policy, Oregon Health & Science University, Portland, Oregon**

Email: gordonc@ohsu.edu or curtispa@ohsu.edu or kingv@ohsu.edu

The road towards PPI in research in Denmark

By **Mogens Hørdér**

The road was not always towards the active involvement of patients

Health research in Denmark has a high ranking in international comparisons of performance within research, in particular within clinical research – the kind of research that involves the participation of patients.



However, there has been growing concern, from clinical researchers as well as pharmaceutical companies, that the number of clinical trials would fall due to failure in the recruitment of patients into trials. This concern was addressed during 2008-9 by the National Forum for Health Research and many initiatives were undertaken to counteract the fall.

It was, unexpectedly, out of these initiatives that the focus was turned towards 'active involvement' rather than a focus on measures to increase the number of 'passive trial participants'. A parallel to this 'renewed' awareness of the role of patients and the public was expressed by the European Science Forum in the 2010 publication, Implementation of Medical Research in Europe:

"Patient and public involvement in clinical trials is founded on the belief that a collaborative approach to testing treatments is vital if the uncertainties that matter most to patients are to be reduced. Patients may be involved in the sense that they are invited to participate as

‘passive trial participants’ or may be involved actively as co-researchers in the research process itself, working alongside other health professionals throughout the project.”

The turn in the road

In late 2010 the National Forum for Health Research decided to establish a working group on patient and public involvement (PPI) in research. The Forum reports to the Ministry of Health and its members represent a broad range of stakeholders from the health service, universities, health science societies, research councils, patient organisations, and the medico and pharmaceutical industry.

The working group made contact with INVOLVE, which was identified as the obvious organisation to learn from. In 2011 INVOLVE arranged a study tour to a number of research networks in England that had all actively gained experience of patient and public involvement in research.

In late 2011 the study group was able to present a report and recommendations to the National Forum for Health Research. In May 2012 the report and recommendations were launched at a national conference chaired by the Minister of Health. The aim of the recommendations is two fold: to raise awareness about PPI to a broader audience and to serve as a starting platform for implementation of PPI among a number of actors.

Recommendations at national level:

- The experiences of ways of implementing PPI and its outcomes should be coordinated and evaluated.
- Peers among researchers and civil society should be identified and engaged as ambassadors for PPI.
- PPI should be implemented in the education of health professionals and, in particular, in the training of PhDs.
- The legal and ethical issues of PPI should be addressed separately.

Recommendations at the level of the individual research project:

- PPI should be considered early enough to play a potential role in the planning as well as during the establishment and conduct of the project.
- The added value of PPI, if any, should be made visible.

Recommendations at the level of councils and boards:

- Research councils, boards and other bodies should develop mechanisms for PPI in the preparation of research strategies and as an advisory function for decisions of funding research projects.

The road ahead

The road is bumpy and sometimes steep. PPI in research represents a significant change of culture and new roles for the researcher as well as for the ‘lay’ researcher. Good examples are crucial. Since the launch of the PPI concept in May 2012 awareness has been growing and questions are being asked in many contexts about why, what and how to implement PPI.

Funding bodies are developing ways of integrating PPI into their decisions about funding and councils are inviting ‘lay’ researchers to become members and suggest the need for the type of research to be funded. Research groups are telling how they have included PPI elements in their research, both before and since the ‘launch’ of PPI in 2012.

No traffic on the road without road signs

Currently an initiative is under way, supported by the Ministries of Health and of Science and Innovation, to establish a coordinating function or secretariat. The role will be to serve as advisor for the implementation of PPI in various settings, to monitor and evaluate and to exchange experiences about PPI internationally.

Contact: **Mogens Hørdér, Professor at the University of Southern Denmark and Head of Working Group for Patient and Public Involvement in Health Research, Denmark**

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Deadline for contributions for our next newsletter: **3 June 2013**

If you have any questions on contributing to the newsletter, please contact Paula Davis
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Patient and health consumer involvement at ZonMw

By Meralda Slager



Introduction

The Netherlands Organisation for Health Research and Development (ZonMw) is a funding agency for health research. It also stimulates the use of the knowledge developed to help improve health and healthcare in the Netherlands. In

this connection it is vital that relevant stakeholders are included. In order to make active involvement of patients and health consumers possible at ZonMw, certain conditions had to be created, for patients and health consumers, and for researchers, health professionals and policy makers. In this article I will explain how ZonMw is working to establish the conditions necessary to allow active and effective participation by patients and health consumers.

Participation as the cornerstone

Since ZonMw was established in 1998, the participation of patients and health consumers has always played an important role. ZonMw's main task is to improve health and healthcare. For it to do so, it must generate knowledge. It is equally important that people use that knowledge. For people to use knowledge, research must address the needs and requirements of patients and health consumers.

Throughout the history of ZonMw, new programmes had been developed by involving various stakeholder groups to analyse the state of play, to articulate the aims and goals of programmes and to set priorities. This mostly occurred at expert meetings and conferences. The findings were put together to create a programme that included a plan of action setting the direction for developments in research and

healthcare. A special committee was appointed for each programme. The main task of this committee was to advise on the research proposals submitted, monitor the programme in terms of its aim and goals, and make sure the knowledge generated was transferable. Patients and representatives of patients' organisations always played an important role in this process.

ZonMw realised, however, that more had to be done to make patient participation structural. The feedback ZonMw received from patients and patients' organisations and relevant stakeholders, such as researchers, suggested that more support was needed. To make patient participation structural there was a need for training, to share experiences and develop more knowledge of question articulation and of methods and techniques. There was also a need to experiment with various forms of patient involvement. In the following sections I will explain what ZonMw has done to create the conditions necessary for structural participation.

Supporting patients

In 2003 ZonMw started with a conference on patient participation in scientific research. This was organised specially for patients and representatives of patients' organisations. They needed to learn more about participation in scientific research and have an opportunity to share their experiences. A specific wish arising from this conference led to the publication of a guide for patients involved in scientific research. The guide was presented at the third conference. The conference is held every year and important aspects of patient participation have been addressed over the years. Other groups such as researchers and policymakers from various health and patients' organisations have also participated. The conference themes are determined with representatives of patients' organisations.

ZonMw has also organised training for patients who are involved in scientific research or want to become involved. The training is provided by Maarten de Wit, one of the main authors of the guide and an experienced patient research participant.

Developing a research programme

One important issue was the need for more knowledge about the effectiveness of patient participation. What are the prerequisites for successful patient participation? What methods

and techniques are effective? These questions were addressed in a programme funded by the VSBfund, a Dutch capital fund. The programme was launched in 2008 and will finish by the end of 2013. It has two important cornerstones. One is the evaluation of existing participation by means of formative evaluation. Formative evaluation means that the outcomes of the research can be implemented immediately. The second cornerstone is research into the necessary conditions and feasibility for patient participation.

Throughout the execution of the programme, patients have played an important role at the various different stages, both at programme level and in terms of determining which proposals were accepted. In the second call for proposals patients' organisations were asked to take the lead and to operate as main applicant.

Structural participation

Over the past few years ZonMw has noticed a growing desire to make patient participation more specific and to adapt it to the specific needs of individual ZonMw programmes. This also requires specific knowledge and experience. In order to meet this desire, ZonMw has appointed an officer to support this development. This will also help to combat tokenism. Patient participation is no longer seen as one patient on one committee alongside a whole battalion of research representatives. It is now considered an important means of addressing health problems and improving the quality of health research.

Exchanging international knowledge

ZonMw considers exchanging knowledge on patient participation as an important step forwards. It held a conference on 11 and 12 April with European researchers and representatives of various organisations called "Exchanging knowledge on participation by EU health consumers and patients in research, quality and policy". One goal was to jointly assess the state of play in patient and health consumer participation, but another important goal was how to achieve structural exchange of knowledge in Europe. More information about this conference will be available on www.zonmw.nl/en/

Contact: **Meralda Slager, Senior Programme Officer, ZonMw**

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Patient involvement in setting research priorities in the Netherlands

By Janneke Elberse

Patients are increasingly involved in health research in the Netherlands. For the last six years I have been working as a patient and public involvement (PPI) researcher at the Athena Institute, VU University Amsterdam. My work mainly focuses on improving patient involvement in health research, stimulating a drive towards a more needs-oriented health research system. I have attended the last three INVOLVE conferences and always learn a lot, meet interesting people and come back with new ideas on how to improve patient involvement.

In the last ten years, there has been growing interest among patient organisations and funding agencies in the Netherlands to involve patients in setting research priorities, a so-called research agenda. To correspond with this development the Athena Institute (VU University Amsterdam) and Metamedica (VU University medical centre) have developed the 'Dialogue Model'. This model operationalises collaboration between health professionals, researchers and patients and is based on several participatory and interactive methodologies. Research is not framed by experts' interests, but is developed through interaction and dialogue among all stakeholders. The model has an emergent design in practice and is comprised of the following six phases: (1) initiation and preparation, (2) consultation, (3) prioritisation, (4) integration, (5) programming, and (6) implementation. Since 2003, the Dialogue Model has been used to formulate research agendas for several conditions including spinal cord injuries, burns, asthma/chronic obstructive pulmonary disease, neuromuscular diseases, congenital heart diseases, renal failure, diabetes, intellectual disabilities, dementia, and Parkinson's disease, leading to the further development and validation of the model.

Although it is now well documented that patient involvement leads to new topics from a patients' perspective being included on the research agenda, little is written about what happens next. Are the topics that are considered important by patients taken up by researchers? And is the

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.

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University of Western Australia Consumer and Community Participation Program

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. 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

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

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noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in research and development. If you would like to put an item on our noticeboard please contact the Coordinating Centre.

Be Involved – a new PPI website

South Yorkshire Collaborations in Leadership in Applied Health Research and Care (CLAHRC) have launched an exciting new website designed with a small group of service users and carers.

Visit the website to:

- view a film about why the voice of the public is vital in health research and to the work of CLAHRC for South Yorkshire
- find out how members of the public are working with researchers when they are planning their research
- find out how you can share your experiences and ideas with cutting-edge researchers developing treatments and services within the CLAHRC for South Yorkshire
- find out who was involved in developing the website.

<http://beinvolved-sy.org.uk/>

Patient, carer and public involvement seminar series

Elaine McNichol from the University of Leeds has received funding from the Higher Education Academy to coordinate a series of five seminars about patient, carer and public involvement in health, education and research. Three seminars have already taken place and the next two are coming up in May and June 2013. A few places are left at each one and there is a waiting list in case of cancellations. If you can't get along in person, there is a collection of web-based resources to catch up on topics, presenters and discussions.

www.healthcareconferences.leeds.ac.uk/conferences/details.php?id=10

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Involvement4Access

A new web resource has been launched to support patients having a say in health research as a treatment choice in their local NHS hospital or health centre. Involvement4Access aims to encourage initiatives that support patients as 'Research Ambassadors' to help improve access to health research in the NHS locally.

The new web resource is the first step in creating a 'community of practice' to support the patient voice for research in the local NHS. It outlines what Involvement4Access is and what you can do locally, supported by hot tips, examples and resources. It also invites you to log your plans or initiative online.

Phase 2 of the web resource will see it becoming increasingly interactive with sharing of local initiatives across the country and the opportunity to interact with the people involved in them as part of a developing community.

www.crnc.ac.uk/ppi/why_is_research_important/involvement4access

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