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.

You can read more about the Dialogue Model and some agenda setting projects in the following articles:

Abma TA and Broerse JEW Patient participation as dialogue: setting research agendas. Health Expectations, 2010. **13**(2):

p160-173

Broerse JEW et al, Involving burn survivors in agenda setting on burn research: An added value? Burns, 2010. **36**(2): p217-231

Elberse JE Changing the health research system. Patient participation in health research. PhD thesis, VU University Amsterdam (2012)

Elberse JE et al, Patient involvement in agenda setting for respiratory research in the Netherlands. European Respiratory Journal, 2012. **40**(2): p508-510

Elberse JE, Caron-Flinterman JF and Broerse JEW, Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives. Health Expectations, 2011. **14**(3): p225-239

Caron-Flinterman JF et al, Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands. Health Expectations, 2005. **8**(3): p253-263

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**