

The road towards PPI in research in Denmark

By Mogens Hørder

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.

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