Patients as partners in research – The challenges for researchers of patient involvement

Patients are the beneficiaries of medical research. Yet, in the past, patients were regarded solely as passive objects in research-based development of new treatments and medicines. Research happened ‘for’ or ‘to’ patients, who played no active part in the research process. In recent years, however, there has been a shift in research practices. Patient involvement in research, also known as Patient and Public Involvement (PPI), is increasingly recognised as a valuable part of healthcare research. Rather than ‘for’ or ‘to’, research is now ‘with’ or ‘by’ the patient.

In PPI, patients are treated as research partners rather than simply recipients. The patient’s perspective on the research process is invited and can influence the direction taken by the research. Living with the condition being studied allows patients to offer unique and personal insights at all stages of the process, from planning and design of the study to communicating the results. THE CHALLENGES OF PPI

While most researchers recognise the potential value of PPI, actually achieving this potential in practice can throw up many challenges. For many scientists, embracing PPI requires a shift in mindset. Some researchers believe that “science is for scientists”, perhaps understandably, a scientist who has dedicated years to their chosen specialism may struggle with the idea of sharing ownership of their work with a non-expert. There is also the issue of identifying exactly what contribution is requested or expected from the patient: is it solely their experience of living with the disease or condition? Or could they offer more? How should patients be selected for participation – should the researcher aim for patients who are most representative of the patient population, or should those who are most willing or able to contribute be selected?

PPI represents a relatively new way of working. As such, some institutions may not have the right support in place for researchers to make best use of PPI. Project leaders may need guidance on how to involve the patient. Even simple things such as ensuring the patients are included in project meetings can require careful planning. Finally, both scientist and patient may need to learn how best to communicate with each other to get full benefit from the partnership. Most patients will not have a scientific background or be familiar with the research process, creating a ‘language barrier’ that must be overcome.

HOW DOES PPI AFFECT THE TRADITIONAL RESEARCH PROCESS?

Most scientific, medical and clinical research follows a well-established path. The traditional research process – which includes, for example, generating a hypothesis, designing a study, collecting data and analysing results – is robust and reliable. While incorporating PPI does not mean that this process will be overturned, it does mean that it might be approached in new ways. In PPI, the patient’s perspective informs the research goals. When researchers are open to this, the view of the patient can steer the direction of the research, reveal overlooked issues, influence study design – and, crucially, ensure that the outcome is patient-centred. This has been particularly successful in arthritis research, in which patients have driven a new focus on quality-of-life measures such as chronic fatigue and sleep problems.

Prof Hørder and Prof Nielsen found that, according to many researchers, the potential of PPI varies according to the type of study. While PPI might be smoothly included in clinical research – in which there has always been patient involvement, even if only as research subjects – it is less relevant to basic research (which seeks to expand knowledge, rather than lead directly to a new treatment, for example). The success of PPI may vary from project to project, most researchers expressed a view that they are themselves changed by the process. For example, working closely with patients can force researchers to discuss their work in more accessible language, avoiding scientific jargon. As a result, researchers improve their
For successful PPI, both researcher and patient may need training. For the patient, this may include familiarising themselves with the fundamental ideas of the research process.

Second, researchers should guide and mentor those who are new to the task. Both researchers and patients may need training in PPI. For the patient, training in communication – and taking overall responsibility – it is important that the roles of each participant are clearly defined. This should be done as early in the project as possible, so that realistic expectations can be set. With the support of their institution, researchers could even consider written ‘job descriptions’ for both themselves and patient participants in order to clarify roles. Another possibility is for researchers experienced in PPI to guide and mentor those who are new to the task.

Finally, researchers agree that institutions should offer practical support in place to allow researchers to address these points. Both researchers and patients may need support in PPI. For the patient, this could cover the fundamental ideas of the research process: that research builds up knowledge that is based on data, that methodology is based on certain principles and theoretical assumptions, for example. For the researcher, training in communication – which could cover everything from discussing methods and results to chairing meetings – is likely to be beneficial. Researchers and patients could even participate in training together, which would help to build their relationship. If PPI is to have value, the commitment of the researcher is key. There are many challenges for the researcher in successfully implementing PPI. Prof Hørder and Prof Nielsen believe that, as yet, these challenges have received little attention.

To overcome problems and sustain the motivation of both researcher and patient participant, the support of the institution is crucial. With the right support in place, researcher and patient will be able to work together in a constructive and mutually beneficial way. At its best, this collaboration will contribute to new scientific discoveries. A positive experience of PPI will lead the researcher to develop new skills and a richer level of experience, thereby enhancing the value of their future work.

PPI will likely reveal new issues or problems to consider – and perhaps solutions to investigate by research.

Behind the Research

Professor Mogens Hørder and Associate Professor Marie Konge Nielsen examine how patient involvement impacts research projects.

Research Objectives

Mogens Hørder
J.B. Winslewovv 9 B. 1.
Dept. of Public Health Research Unit on User Perspectives
University of Southern Denmark
5000 Odense C.
Denmark

Bio
Mogens Hørder is currently Professor at the Department of Public Health, University of Southern Denmark, the Unit for User Perspective. His main research interests are the development, implementation and evaluation of Patient and Public Involvement in Research (PPI) at project as well as institutional level. He focuses on the roles of the researcher and the patient in PPI and the interaction of the two as partners. Since 1964, Hørder has published more than 200 publications within clinical application of basic biochemical and molecular knowledge and on health services research – most recently on patient involvement in research (h-index 33).

Marie Konge Nielsen’s research focus has been on the researchers’ and patients’ perspectives. Recently she has been working with patient empowerment and involvement in telemedicine. She has a background in anthropology and is an Associate Professor at the Department of Public Health, Research Unit on User Perspectives, University of Southern Denmark.

Funding
Danish Board of Health supported Mogens Hørder’s project on the mapping of PPI in Denmark 2016-2019

Collaborators
• Knowledge Center for Patient Involvement in Denmark, VIBIS
• Collaborators
• Knowledge Center for Patient Involvement in Denmark, VIBIS

References

Personal Response

In your opinion, what factor is most important in helping researchers to tackle the challenges of PPI? Of major importance is to get started, to gain experience with PPI, to ensure feedback from patients and to share experiences among colleague researchers. “The researcher does not know what she does not know until she has asked the patient.” (Kristina Staley).

www.researchoutreach.org

www.researchoutreach.org