



SHORT COMMUNICATION

Patient and public involvement in health research: A Nordic perspective

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Abstract

Patient and public involvement (PPI) in health research is of increasing interest internationally, as well as being a means to enhance the quality and relevance of research. PPI was one of the main themes and parallel sessions at The Nordic Health Research and Innovation Networks in Oslo in 2017. In this short comment/debate article, we outline some of the experiences from the event. Importantly, there are many common challenges. More collaboration across the borders could ensure a broader range of experience in the field and provide better ways of developing and evaluating PPI in health research.

Keywords: *patient and public involvement, health research quality and relevance, Nordic collaboration*

Introduction

Patient and public involvement (PPI) is a topic of increasing interest and relevance internationally, as well as in health research [1–3]. PPI is quite a new concept and is often used interchangeably with terms such as patient engagement or empowerment, participatory health care, co-researching, co-production and many more [4,5]. However, in the context of clinical research, ‘patient and public involvement’ seems to be the preferred term. There are two main reasons for involving patients and members of the public in research. One is as means of enhancing quality and relevance in research; the other is as part of democratic principles. In the case of the latter, PPI is also regarded as a way of empowering people who use health and social care services [6]. When aiming at reduced waste and increased value in research, the needs of the potential users of the research should be of particular interest for the research communities [7]. Major funding bodies, such as the European Research Council, encourage or require PPI in health research in their calls, depending on the topic [8].

Based on existing literature and the experiences from The Nordic Health Research and Innovation Networks (NRI) conference in Oslo in 2017, we briefly report some of the main features of PPI. Furthermore, we describe how the Nordic countries are approaching the field and propose possible benefits of more Nordic collaboration.

Internationally, the UK has been a leading nation in developing good systems for PPI. One important initiative is the James Lind Alliance (JLA) [9]. The JLA is a non-profit-making initiative where patients, carers and clinicians meet to discuss key uncertainties in health research in the UK. In this way, all these groups can influence research priorities. The government-funded organisation INVOLVE [6] was established back in 1996, aiming to support public involvement in health and social care research. The INVOLVE website updates information on areas such as practical guidelines for researchers and inspiring examples of collaborations in the field. PPI is defined by INVOLVE as ‘research being carried out “with” or “by” members of the public instead of “to”, “about”

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or “for” them’ [6]. Patients or members of the public are present as important stakeholders when research funding and prioritising are discussed. On a more practical level, patients give their advice when researchers discuss and plan methodology and study design. The users of research are commonly defined as patients or next of kin, but on some occasions they are simply members of the public. The nature of the research and the research question will decide which kind of involvement is relevant. How to recruit the right patients is a matter of continuous discussion. Most commonly, patient and user organisations form the basis for recruitment. Frequently mentioned challenges are questions of capacity, payment, training and a non-desirable development of ‘professionalism’ of patients involved in PPI. Hence, it is of crucial importance that PPI is well organised in order actually to support involvement and remove possible barriers. However, a major issue is also that so far the evidence for added value from PPI in research is limited, and it should therefore be investigated further [2].

Nordic countries: status

Among the Nordic countries, only Norway has introduced considerations for PPI as mandatory for research funding by the Regional Health Authorities [10]. The Research Council of Norway and the Norwegian Cancer Society also emphasise the value of PPI and follow the same practice. Denmark and Sweden have so far not institutionalised general guidelines, but PPI is on the agenda, especially as a prerequisite for research funding. According to information from the Academy of Finland, PPI is not a prerequisite for research funding in Finland [11].

In Denmark, a report published back in 2011 gave recommendations about how PPI can be an important part of research [12]. However, according to reports from a national conference in 2017, there is a concern that the pharmaceutical industry is now partly dominating the field. As such, traditional roles in the research field are challenged as a result of PPI, thereby creating a need for new competence for both professionals and patients [13].

In Sweden, collaborators at The Centre for Ageing and Supportive Environments (CASE) at Lund University have written a report on PPI and patient involvement, published by the Swedish Research Council for Health, Work and Welfare [14]. The report confirms that PPI is increasingly acknowledged as an important part of health research. However, it is questioned whether the researchers really value the effort and contribution from participants. According to the authors of the report, PPI must be scientifically grounded.

Patient initiatives

In order to succeed in involving patients in research, it is necessary to build patient-led organisations. In Finland, Siskot (sisters) is an independent organisation founded and run by women living with cancer. Siskot focuses on the need for information when participating in clinical trials. In order to receive better treatment, patients need to be able to contribute and not be over-protected in health research [15].

In Norway, research networks in mental health offer training and have involved service users or patients as co-researchers. This initiative has resulted in hypotheses on how participatory research can be fruitfully organised [16]. The European Patients’ Academy on Therapeutic Innovation (EUPATI) is another patient-led initiative, coordinated by The European Patients’ Forum [17]. The main goal is to develop and disseminate objective, credible, user-friendly and up-to-date information regarding the development of new treatments. Offering training and education for patients involved in PPI is important for the initiative. Several nations in Europe have established national platforms of EUPATI. Denmark, Norway and Finland have now established their arms of the network.

The way ahead: Nordic collaboration

In order to increase and enhance PPI, it is important that initiatives come from patient organisations as well as the researcher communities and health authorities. According to the presentations and the debate at the NRI conference, PPI activities in the Nordic countries have so far been largely dominated by top-down initiatives, such as reports and guidelines initiated by the government. Several participants at the conference highlighted the importance of more bottom-up initiatives. In this regard, national initiatives such as Siskot in Finland and the internationally oriented EUPATI hold promising potential.

Furthermore, Nordic collaboration could ensure a broader range of experiences for developing and evaluating PPI. One possible area for collaboration is by arranging courses and training for researchers with participants from all the Nordic countries, for example as part of PhD education.

When aiming at better use of PPI and thereby enhancing relevance and quality in health research, it is crucial to build a culture of mutual trust and a better understanding of the concept. Exchanging views and experiences in the field at the NRI conference convinced us that more initiatives are needed to bring the stakeholders closer together. It is our hope that the Nordic health research community recognises this need and integrates the matter of PPI in all

aspects when planning and facilitating of research are on the agenda.

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