

EULAR PARE: Knowledge Transfer Programme

Bożena Moskalewicz¹, Jolanta Grygielska²

¹Department of Monitoring and Analysis of Population Health, The National Institute of Public Health – National Institute of Hygiene (NIPH-NIH), Warsaw, Poland

²Department of Gerontology, Public Health and Didactic, National Institute of Geriatric, Rheumatology and Rehabilitation, Warsaw, Poland

Dear Editor,

The national organizations of people with arthritis/rheumatism across Europe work together via the EULAR Standing Committee of PARE. PARE organizes high-quality activities as the Knowledge Transfer Programme. Last year representatives from Poland learned in the Netherlands and Sweden fascinating examples of successful patient involvement in scientific projects, which could be inspiring for your readers.

“I have worked on the best way to treat rheumatic arthritis (...) and in particular to do so in a way which is rigorous but also relevant and meaningful for patients. This has led to publications on ways to interact with patients as partners in research and the promotion of patient and public involvement” says the renowned rheumatologist Professor John Kirwan from Bristol University. Professor Kirwan has been the patient partner coordinator for OMERACT (Outcome Measures in Rheumatology) since 1998 and has led the extensive involvement of patients as research and teaching partners.

Collaboration between patients and professionals in research is relatively new, claim authors de Wit et al. [1] in the European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. Their recommendations on patient participation in clinical research include defining the role of patient representatives in research, as well as the phase(s) of research to include patients, the recommended number of patient participants in a project and the recruitment and support of patient research partners. They came to these recommendations in several steps. After a systematic literature review, a task force group of 15 experts found 38 points to consider when actively involving patient representatives in projects. Out of these 38 points to consider, all task force members eventually agreed on a set of eight. Next, a wider group of experts, professionals and patient representatives

discussed and formulated the recommendations. Finally the level of agreement was re-evaluated. The most important recommendation members agreed upon is the statement of the patient’s role: “Participation of patient research partners is strongly recommended for clinical research projects and for the development of recommendations and guidelines, and should be considered for all other research projects” [1].

The question how patient participation in projects works in everyday practice was a main goal of the EULAR Knowledge Transfer Programme in which Poland, Sweden and the Netherlands participated in the period from June to October 2019. Four people, representing the Polish Rheuma Federation “REF” participated in workshops during the programme. The first part of the programme was organized by the National Association ReumaZorg Nederland (RZN) in Groesbeek (the Netherlands) and the second part by Reumatiker Förbundet in Stockholm, Sweden (the Swedish Rheumatism Association – SRA). During this period Polish representatives had the occasion to learn about the practice of patient partner inclusion in the therapeutic process, in medical education programmes and in scientific research. By participating in this EULAR Knowledge Transfer Programme we learnt what “patient inclusion” means. We started the project with a traditional view, where patients are research objects, rather than subjects, for revealing new clinical knowledge. We soon learned about the innovative definition that patients are persons with relevant disease experience who are able to act as a research team member.

The Netherlands

In an introduction to *Faces behind Rheumatoid Arthritis* [2], a book presenting several Dutch patients’ fascinating stories, we could read that people with RA can experience fatigue every day without having worked hard or exercised. This is a key difference compared to

Address for correspondence:

Bożena Moskalewicz, National Institute of Public Health, 24 Chocimska St., 00-791 Warsaw, Poland, e-mail: bozena.moskalewicz@gmail.com

Submitted: 14.02.2020; Accepted: 14.03.2020

“normal” fatigue. The severity of fatigue is completely disproportionate to the activity or the effort that has been made. Many people with RA have learned to say nothing during a flare and simply accept the pain and fatigue. But patient-partners of National Association ReumaZorg Nederland, the national patients’ organization of people with rheumatic and musculoskeletal diseases (RMDs) in the Netherlands, are well prepared to say a lot about the patient’s perspective. They have years of experience building a network of patient experts. Patient participation in research and also in educating medical students and health professionals about rheumatic diseases is growing in the Netherlands. At present an excellent network of 60 trained “patient-partners” covers a country, supports research projects and meet 4 times a year during the network meetings to develop their skills. Patient-partners can grow from being a patient (experiencing an RMD), to being a patient-informant (being able to talk about personal experience with an RMD), to being a patient-partner (being able to talk about experiences of people with RMDs) to eventually becoming a patient advocate (being able to talk about experiences of people with RMDs and to advocate change). Patient-partners differ with regards to the stage in which they feel comfortable. Basic principles of patient participation in research for researchers, as commissioned by the National Association ReumaZorg Nederland, are the following:

- each patient-partner has his/her own experience,
- the representative of all patients does not exist!
- there is an important difference between “getting involved” as a patient partner which leads to a passive role of patient-partners in projects and “being involved”, which means an active role of patient-experts in relation to the researcher.

An interesting approach of the Dutch association is to explain the practice of patient involvement to researchers with a guideline for researchers in the form of a main questions. “Why do I want to involve patients in my project? Why does a patient want to be involved in my project? What kind of result do I want to achieve by involving a patient in my research project? At what point in the research circle do I involve a patient in my project? What role does the patient have in my research project? (gathering information, expert, interviewer...). Which patient with which characteristics do I involve in my research project? (experienced expert, trained – untrained, level of experience; with the condition, caregiver, parent; age, gender, residence, education, work situation). Which method? (brain storm session, patient panel, focus group, focus group online, talk with patient organization, interview, observation, workgroups, patient diary, patient board, theater – role play, questionnaire).

Which requirements? What conditions apply to the collaboration? Draw up a written agreement. Describe the timeline including deadlines, the communication moments and the evaluation possibilities. Reimbursement of costs incurred by the patient: travel, parking, food, lodging. Which appreciation? Consult with the patient involved, perhaps he/she has different ideas about an appreciation than you have as a researcher. Describe the appreciation the patient receives for his/her involvement and input. What can go wrong?” (A research question can change during the project. The needed contribution of a patient-partner to a specific phase of the research cycle can change. The patient wants a different role, but the role is given to a professional. The patient becomes ill, dies, stops, etc. The tasks for the patient-partner turn out to be too time-intensive, not doable. There is a conflict and one of the parties wants to revise the conditions. The patient does not get to be a co-author in the publication).

The Dutch Association also works with a simple check-list when patient-partners are asked to evaluate a research proposal. This checklist consists of questions such as: Is the research question clearly defined? Is the aim or the project applicable in everyday care/practice? Does the research contribute to better diagnostics? Are the risks for the participants clearly defined? The checklist can help patient-partners in their final judgement: is the research proposal worthy of funding from a patient perspective?

Sweden

As Swedish medical scientists say, patient involvement can optimize the ethics, relevance, accountability and transparency, communication, promotion and implementation of research outcomes.

In 1988 Peter Lipsky [3], University of Texas, described the first example of the positive impact of arthritis patient educators in rheumatology care practice. In Sweden, patient research partners (PRPs) have been educated to participate in research projects since 2008. In total 60 PRPs have been educated. At the moment 40 PRPs are actively involved in research projects. All have participated in a two-day basic education course. Every year the basic education is provided for new PRPs. A continuation course for present active patient partners is provided every year. Both the basic and continuation course include group exercises and activities where experienced PRPs share their knowledge with newly educated PRPs.

The Swedish Rheumatism Association (Reumatiker Förbundet) funds scientific research in rheumatology. Last year – 2019 – it distributed 1.55 million EUR to 96 research projects. In Sweden PRP involvement in research is becoming more common. The PRPs participate

in activities to identifying research gaps that are important and relevant to persons with rheumatic disorders. In a cooperative initiative the Reumatiker Förbundet, the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) and researchers work to develop a systematic literature overview article with the goal to reveal the scientific evidence and knowledge gaps regarding the effects of rehabilitation in rheumatic diseases. We have heard that funding research without mapping existing research is like going shopping without checking what you already have in the cupboard. The SBU carries out James Lind Alliances activities including patients and health care professionals to identify and prioritize the most important evidence gaps for that patient group. Also, the SBU evaluates scientific evidence gaps to be found in the literature. These activities presents research questions that are of importance to “the end users”.

During the seminar in Stockholm “A short guide, for researchers, to successful patient involvement in EU funded research” was presented [4]:

- When getting started you should involve patients as soon as possible, already in the planning phase.
- Ask patients to support you in the recruitment process.
- Train patients to represent themselves successfully.
- Train healthcare professionals to understand the importance of patient involvement.
- During the project communicate regularly and clearly.
- Ask patients to act as ambassadors of the project. The patients’ voice is strong politically and helps to explain why certain aspects of a project are so important.

Patricia Pennings from the Netherlands urges: “Patients want their voice to be heard from the very start of a research project, even before the first research proposal is actually written, even before research funds decide what to use their funding for”.

We firmly believe that the time has come to learn a lesson from the practice of patient participation in the Netherlands and Sweden. Health care is changing in Poland. There is a shift from the focus on disease to a focus on health, prevention and life style. Chronic diseases, such as rheumatic conditions, require personalized health care and patient participation in decision making. However, the health professional in Poland today is not yet prepared for this change. Innovative education programmes for medical students in Poland promise professional development. New generations of medical doctors will be enabled to see the patient’s perspective and gain valuable patient interaction skills.

Funding: EULAR PARE: Knowledge Transfer Programme.

References

1. De Wit MPT, Berlo SE, Aanerud GJ, et al. European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. *Ann Rheum Dis* 2011; 70: 722-726, DOI: 10.1136/ard.2010.135129.
2. Faces behind Rheumatoid Arthritis. Amsterdam 2017.
3. Mittleman BB, Lipsky PE. Patient – centered outcomes: a bridge too far? *Nat Rev Rheumatol* 2006; 2: 457.
4. Patient Involvement in Research. A way to success. EULAR, Brussels 2017.