

Knowledge Transfer Programme report

Poland-Netherlands-Sweden

Three national patient organizations for RMDs from Poland, The Netherlands and Sweden received financial support from EULAR (European League Against Rheumatism) for a Knowledge Transfer Program on patient participation. This meant that representatives of our organizations visited each other in the past months to exchange experiences and to be inspired.

Three partner organizations participated in the Knowledge Transfer Program:

- 1) Polish Rheuma Federation "REF"
- 2) National Association ReumaZorg Nederland
- 3) Reumatikerförbundet - Swedish Rheumatism Association

The purpose of the Knowledge Transfer Program was to be acquainted with the experience of partner organizations. The Netherlands and Sweden in the scope of the inclusion the representatives of patient organizations in the research process as experts at every stage of the organization, realization, publication and promotion of the research results, and recruitment of medical professionals for cooperation.

KPT was implemented in three phases:

- 1) June 30 - July 7, 2019 – The Netherlands
- 2) August 27 - September 1, 2019 – Sweden
- 3) September 30 - October 4, 2019 – Poland

The Netherlands

In the first stage, guests of the KTP Program get acquainted with the activities of the Dutch organization: its goals, how to obtain funds, projects and their implementation. In the Netherlands, Groesbeek village were held the courses for the REF group and the training organization in the form of lectures and workshops, on July 1-4, 2019.

The meetings were divided thematically: the first day concerned the cooperation issues with the patient's perspective, the second - researchers, the third - networking, fourth – medical students.

As part of the meetings, apart from representatives of the Dutch organization, actively participating in the Patient Partner program, there were: representatives of researchers, lecturers, staff from medical universities, including Patient Partners and students of these universities.

The first training day highlighted patient participation from the perspective of patients. Why is it important to involve patient partners in research and education? And as a patient

partner, in which stages of a project can you be involved, and which roles can you have in a project?

During the second training day, patient participation was highlighted from the perspective of researchers. Presentations of this day were focused on questions such as: How do you involve patient partners in setting up a research agenda? How do you set up a coaching program that trains medical students to become coaches for patients in shared decision making? Or how do you involve the patients' perspective in setting up a new e-Health initiative? Researchers shared their projects and talked about the benefits but also about the challenges of involving patient partners in research

To involve patient partners in research and education, network of patients who have been trained to contribute to projects as a patient partner is needed. How do you set up such a patient partner network? How do you get people interested in becoming a patient partner? What training is needed to train patients partners? How do you ensure diversity in your patient partner network in terms of cultural background, gender, age and educational level? Is it possible to keep a network of patient partners up and running on a voluntary basis? Is it important to evaluate patient partners annually? And what about reimbursing patient partners for their efforts? These questions formed the basis of an inspiring brainstorming session between the participants.

During fourth training day, patient participation was highlighted from the perspective of healthcare providers (in training such as medical students). How can patient partners be involved in training medical students but also in training care providers who have been in the profession for years? Best practices from the Radboud University in Nijmegen were discussed.

When finishing the lectures, the Polish participants had the opportunity to get acquainted with the principles of medical activities at the University Medical Center in Nijmegen, the oldest city in the Netherlands.



Workshop in the Netherlands



Meeting in the Netherlands

Sweden

The second stage of the KTP program was the visit of representatives of Poland and the Netherlands to Sweden, which took place from August 27 - September 1, 2019.

The courses in the form of lectures and outside meetings, lasted from 28 to 30 August 2019, in Stockholm at the headquarters of Reumatikerförbundet: at Karolinska University hospital and at the biological treatment center.

The participants got acquainted with the activities of the Swedish organization and also met with the representatives dealing with education and Scientifics research association.

KTP in Stockholm starts in Reumatikerförbundet office from an introduction by Stina Nordström, secretary general about activities of Swedish partner and from a summary of the meeting in the Netherlands in July. During this day delegates participated in study visit in the Center for Rheumatology, where they had opportunities to learn about organization of Center, treatment of rheumatic diseases and cooperation with patients' organizations in Sweden.

Second day was devoted to research project from beginning to end. Participants learnt about activities of the James Lind Alliance (JLA) – a non-profit organization bringing patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and priorities the Top 10 unanswered questions or evidence uncertainties to agreement of all three parts.

Participants could hear about experiences in collaboration of both sides of Research Partner Project: research partner and a researcher presented.

Swedish Rheumatism Association presented its involving in research giving good examples of initiatives, collaboration, funding and building significant position in research by patient organization.

Last day of KTP in Stockholm participants had occasion to learn about initiatives SRA devoted for patients with rheumatoid arthritis like Reuma direct – helpline for patients. There were presented results of survey among users high rating this type of support. RA instructors presented their experiences.

This day representatives visited clinical Hospital of Karolinska, where they met a patient partner instructor and participated in presentation of typical lecture for medical students connected with practical examination of patient with rheumatoid arthritis. Participants act here as patients. After it delegates walked around to show the premises at the Rheumatology clinic in Karolinska University hospital.



Meeting in Sweden



Workshop in Sweden

Poland

The third stage was a meeting in Poland on 30 September - 3 October.

For this stage of KTP representatives of the member associations of the Polish Rheuma Federation "REF" were invited to participate at the meeting which was held at the National Institute of Geriatrics, Rheumatology and Rehabilitation in Warsaw. The participants from the Netherlands got acquainted with the organization of health care in Poland, with the activities of the Federation and the organizations members. Specially prepared video with a rheumatologist doctor, who has been cooperating with members of the local patients' association for years, in terms of adopting a chronically patient by physiotherapy, students' perspective was presented and discussed among participants.

The delegates visited the institute, and in the establishment of radiology, rehabilitation, pediatric clinics and rheumatologic. In rheumatological clinic they met with deputy head of it and discussed together problems of active patient participation in research and treatment.

Presentations about research in Poland from idea to realization and about works of Ethical Committee in hospital refill educational part of program.

Participants also took an active part in rehabilitation exercises at the Warsaw branch Association of People with Rheumatism and their Friends – member association of Federation REF.

Polish delegates learnt about activities and initiatives of Dutch partner and discussed possibilities to transfer some ideas to Poland. Dutch participants had an opportunity to know unmet needs of Polish students of medicine and young physicians during a meeting with a doctor doing medical specialization in rheumatology in Institute. It was Q&A session.

After visits

After finishing the educational visits in the Netherlands and Sweden there were diagnosed the conditions of the possibility of achieving the objectives of the project in Poland. Currently, it is difficult due to the reorganization of health care and education. There is also no tradition of medical professionals working together with representatives of patient organizations.

The presentations of the best practices provided a lot of food for thought. Poland, the Netherlands and Sweden are culturally different from each other. Dutch people, similar like Swedish people, are used to speaking out and sharing their opinion, also when it comes to their wishes in treatment and health care. In partnership model of healthcare shared decision making is a principle in communication between patient and physician. In Poland, healthcare is still fairly paternalistic; the caregiver takes care of the patient and determines what the patient should do.

The Polish participants would like to change this by starting with the medical students in Poland. They are the doctors of tomorrow. Patient partners can be involved in the curriculum

of these medical students and bring about change in this way. Patient partners can also educate patients and make them aware of their own responsibility for their health.

During last months in Warsaw there have been attempts to students interest of medicine and physiotherapy lectures for patients under the project of early diagnosis of rheumatoid arthritis: Students who have courses and internships at the institute are regularly invited to complete their compulsory classes, with additional activities through participation in open lectures for patients taking place 1-2 times a month. Through participation in these lectures, students have the opportunity to learn the transfer form of knowledge to patients and also to know the patients' perspective on the disease. The audience could ask questions about the disease, its treatment, diet, physiotherapy, which allows to know the interests of patients. Each meeting was attended by representatives of the Federation which was a partner of the Institute in this project in the part of educational and information for patients.