PATIENT EDUCATION IN THE EUROPEAN REFERENCE NETWORK ON RARE AND COMPLEX CONNECTIVE TISSUE AND MUSCULOSKELETAL DISEASES (ERN RECONNET): UNMET NEEDS FROM THE HEALTH CAREPROVIDERS SIDE AND FROM THE PATIENTS’ SIDE

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Background: The ERN ReCONNeT (European Reference Network on Rare and Connective Tissue and Musculoskeletal Diseases) is the ERN aimed at improving the management of Rare Connective Tissue and Musculoskeletal Diseases across the European Union (EU). The ERN ReCONNeT involves 26 health care providers (HCPs), from eight different EU countries: Belgium, France, Germany, Italy, the Netherlands, Portugal, Romania, Slovenia and 7 European Patient Advocacy Group (ePAGs). An intense collaboration has been established between HCPs and ePAGs. Patient Education (PE) was defined in 1998 by the World Health Organization as a continuous process including organized awareness information, self-care learning and psychological support regarding the disease, treatment, care and health care setting. It is designed to help patients to maintain or improve their quality of life with specific PE programmes designed to help them acquiring new skills.

Objectives: To evaluate PE practice in the ERN ReCONNeT based on a survey send to the HCPs members and to the patients of the corresponding countries.

Methods: A questionnaire designed on a google form was send to the HCPs members asking about their practices in PE in their department and an other one was send to ePAGs who translated the patients’ survey in the different languages. Various versions of the same questionnaire was then send to patients’ associations in the different countries.

Results: 33 HCPs members or representatives answered the survey. 52.9% (18) had no specific staff members dedicated to PE. In the department with staff trained in patient education, 33% (4) had no specific PE programmes. In the HCPs with dedicated staff for PE, 83.3% (10) estimated care providers are insufficient to meet the patients’ needs. 1608 patients answered the patient survey (France, n=246; Germany, n=23; Italy, n=500; Portugal, n=339; Slovenia, n=240; Belgium, n=190; the Netherlands, n=42), mostly women (84.5%, n=1359), around 48.5 years old (SD=13.6). Patients suffered mostly from Connective Tissue Diseases and Ehler-Danlos disease. 68% (1093) of the patients had never heard about PE and were for 74% (844) interested in taking part in a PE programme. In the remaining patients who had heard about PE, 66% (342) never took part in a programme. For patients who had already taken part in a PE programme, they expressed satisfaction in several domains listed in the following bar chart: For all respondents, patients expressed needs for a better knowledge in disease and symptoms, treatments, well-being, nutrition, exchanging experiences with other patients, and daily life with the disease.

Conclusion: Based on the EULAR recommendations for PE (Zangi HA et al.), PE should be apply in all EU countries. E-learning on PE for staff members and ePE for patients will be developed by the ERN ReCONNeT.