OP0293-PARE PROBLEMS, GOALS AND URGENT WISHES OF YOUNG AUSTRIANS DIAGNOSED WITH RHEUMATIC DISORDERS: A REPORT

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Background: The Austrian Rheumatism League provides information about rheumatic disorders in order to improve the quality of life. It helps to get in contact with professional health caregivers and supports the sharing of personal experience. Because we suspected that young patients often have very different problems, goals and urgent wishes than their older counterparts, we conducted a survey addressing these questions.

Objectives: We sent a questionnaire to young people between 15 and 35 years old diagnosed with 'rheumatism' and in order to get information about their diagnosis, their daily lives, their problems, goals and urgent wishes.

Methods: 52 persons between 15 and 35 years old and diagnosed with juvenile idiopathic arthritis, rheumatoid arthritis, psoriatic arthritis, Mb. Bechterew, systemic lupus erythematosus, Sjögren-Syndrome, Sharp-Syndrome or fibromyalgia filled out a questionnaire. The subjects were divided into two groups (15–25, 25–35 years). The questions covered gender, province of residence, education, job, retirement, pregnancies/family as well as the problems and goals of the subjects. We also asked where they obtain necessary information about their condition (doctor, web).

Results: 55% of the participants were 15–25 years old and 45% were between the age of 25–35 years. 72% were female. Of these, 15 live in the province of Salzburg, 15 in Upper Austria and 15 in Vorarlberg. There were 5 participants each from other provinces (Vienna, Lower Austria, Styria, Carinthia, Tyrol and Burgenland). Most young adults got their information from their doctors (50%) or from the internet (39%). 39% graduated with A-level, 27% graduated at university and 34% completed specialised job training. 78% of these young Austrians were able to earn their living; 22% were not able to work. 29% never got the chance to start working. 35% had enough support to get pregnant and to manage a family. There was a strong desire (81%) for a meeting (which was never held before in Austria). 50% expressed willingness to help us or to run their own group. The most urgent wish of young people diagnosed with a rheumatic disorder is to be healed or to receive the ideal therapy in order to go into remission. The participants felt that there is a lack of understanding and appreciation of young people with painful chronic diseases. Some participants would like to be treated by younger rheumatologists. They feel that this would facilitate 'eye level' consultations. There is also a lack of understanding and support in schools, in civil service settings and in government agencies. A big issue mentioned was inflexible thinking, especially in job settings. Applicants with rheumatic disorders must compete with healthy individuals for forty-hour jobs. For people with a rheumatic disorder a forty-hour job is often too much, but they can do good work in a job with shorter working hours. Young people feel it is necessary to force our society and our doctors to feel responsible for the concerns of young people with rheumatism.

Conclusions: Following the positive feedback the Austrian Rheumatism League organised a first meeting for those young people with rheumatism. A program of sports and relaxation in a beautiful natural setting was planned with the aim of enhancing positive, constructive thinking and well-being. We must encourage young people with rheumatic disorders to participate in the activities of the Austrian Rheumatism League, and encourage our society to give up black and white thinking. Everyone should be educated to accept and appreciate handicapped colleagues in their work setting, and to treat them as equals. Furthermore, our government should make it possible for persons with rheumatic disorders to stay at work and with their families even if they are not able to work forty hours a week. All doctors working with rheumatic patients should be familiar with their thoughts, beliefs, aims and problems in order to support them not only with drug prescriptions but also with understanding.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.1208

OP0294-PARE ADDRESSING KEY CHALLENGES OF LAY INVOLVEMENT IN MUSCULOSKELETAL RESEARCH: CO-APPLICANTS AND TRIAL STEERING COMMITTEES

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Background: Patient and Public Involvement (PPI) in research is a requirement of funding in the UK. It has shown to improve the relevance and quality of research. For over 10 years, a Research User Group (RUG) of over 100 patients with musculoskeletal and other long term conditions who actively work with a Research Institute.¹ Researcher and anecdotal feedback from RUG members and researchers have highlighted two challenging PPI roles: lay co-applicants on research grants and lay membership of trial study steering committees (TSCs).

For some RUG members, this has resulted in a less positive experience and a disinterest in having these important roles in the future

Objectives: To address the challenges of involving RUG members as co-applicants and as members of TSCs, and to describe ways of supporting RUG members in these roles.

Methods: Information to improve understanding of the challenges of these roles were gathered during group meetings and informal conversations with 13 RUG members, and a workshop with 35 researchers. PPI and researcher perspectives were captured on flipcharts, notes and meeting minutes. This information shaped the development of resources and approaches to support RUG members as lay co-applicants and TSC members.

Results:

Abstract OP0294PARE – Table 1. Challenges and support of lay co-applicants and TSC lay members

	Challenges	Support provided
Lay co-applicant	Understanding the role and time commitment Managing expectations Difficulties with online grant submission process Research jargon	Guidance and advice provided for RUG members and research teams Early meetings encouraged between research teams and RUG members to discuss and agree roles Personal and technical support provided for lay members during the grant submission process Glossary
Lay members of TSCs	Understanding the role and process of TSCs Understanding study background, aim and design Sustaining interest during extended periods between meetings Uncertainty about what, how and when to contribute in meetings Awareness of role by other TSC members Lack of training Teleconference meetings Volume of emails and paperwork to review Research jargon	Training module for RUG members Guides for Chairs, RUG members and researchers Pre-meetings with Chair and post meeting support (debrief) Two RUG members to attend for mutual support PPI as a set agenda item and lay contribution encouraged throughout meetings PPI Support Worker attend meetings to support RUG member Hard copies of paperwork sent, sections relevant to lay input highlighted Glossary

Conclusions: Providing support to RUG members and researchers can sustain active and long-term lay involvement in these challenging yet important research roles.

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[1] Jinks, et al. *Res Involv Engagem* 2016;2:1.

Acknowledgements: We thank all RUG members for their contribution to our research, and R Taylor, C Ingram, C Walker, S Dent, P Callaghan for their input to training and guidance. We thank the Primary Care Consortium and Arthritis Research UK for supporting the RUG. KD is part-funded by a NIHR Knowledge Mobilisation Research Fellowship (KMRF-2014–03–002).

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.6328

OP0295-PARE 'KWEK BEGRIP': THE LAUNCH OF OUR CREATIVE CAMPAIGN ACROSS THE NETHERLANDS ON WORLD ARTHRITIS DAY AIMS TO INCREASE AWARENESS ABOUT RMDs IN GENERAL AND PEOPLE LIVING WITH RMDs IN PARTICULAR

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Background: With two million patients, RMDs are one of the most common chronic diseases in the Netherlands. A 2016 Nivel survey showed that 50% of all RMD patients deal with people who know too little about RMDs in order to understand their situation. RMDs are not always visible, and symptoms may vary from day to day. This often leads to friends, colleagues, neighbours and even relatives showing incomprehension. For RMD patients this can lead to loneliness, insecurity and a sense of not being accepted. Understanding RMDs and being able to show compassion starts with knowing about RMDs.

Objectives: By launching a national creative campaign about incomprehension, the Dutch Arthritis Foundation aims to raise general awareness of RMDs to promote understanding of people with a RMD and to reduce their sense of loneliness.