**Problem, 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 experiences. 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 juvenile idiopathic arthritis, rheumatoid arthritis, psoriatic arthritis, MB. Bechterew, systemic lupus erythematoses, 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 those, 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 background, aim and design. Pre-meetings with Chair and post meeting support (debrief) were helpful. Two RUG members to attend for mutual support. PPI as a set agenda item and lay contribution encouraged throughout meetings. Awareness of role by other TSC members was helpful. Lack of training and knowledge of PPI as a set agenda item and lay contribution encouraged throughout meetings. PPI Support Worker attend meetings to support RUG members. Hand copies of paperwork sent, sections relevant to lay input highlighted.

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

**REFERENCE:**


**Acknowledgements:** We thank all RUG members for their contribution to our research, and P. 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 (KMF1-2014-03-002).

**Disclosure of Interest:** None declared

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**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 OP0294-PARE – Table 1:** Challenges and support of lay co-applicants and TSC lay members.

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

**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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**KWEEK BEGRIJP: THE LAUNCH OF OUR CREATIVE CAMPAIGN ACROSS THE NETHERLANDS ON WORLD ARTHRITIS DAY AIDS 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.
Methods: The Dutch Arthritis Foundation started its campaign on World Arthritis Day: ‘Grow awareness, plant a bulb!’ To ‘grow understanding’, we created two special tulip bulb fields, one online and one offline, for participants to plant the special ‘Anita Witziër’ tulip bulb. Anita Witziër is a well-known Dutch television host who suffers from rheumatoid arthritis. She has been ambassador for the Dutch Arthritis Foundation since 2001.

With the help from 70% of all local RMD patient organisations and a number of garden centres, we handed out a total of 10,000 bags of tulip bulbs across the Netherlands. The campaign kick-off was on World Arthritis Day. The event, held on a tulip breeder’s field, hosted presentations about incomprehension, and served to share real-life stories.

We also developed a website where people could plant bulbs digitally. Every week, participants receive a video, cartoon, update or article with information about RMDs. The campaign will run until 21 May 2018 when the (real-life) tulips will bloom in our RMD field. All participants can then visit the field to pick a bunch of flowers.

Results: The campaign received a great deal of national media attention on WorldArthritisDay, and featured on television programmes, in newspapers and on online platforms. 8000 people have since signed up for the online tulip field, sharing the information with others in their network. The campaign site drew 68,000 visitors between 120c and 310c tober. The campaign also resonated with people on Facebook. In October, our campaign posts reached 1,869,000 visitors, with more than 65,000 interactions (respond, share, like, watch video, conversion to campaign site).

Conclusions: Raising awareness for incomprehension can be difficult. A creative approach can help to kickstart a public debate. Responses generally show that people with RMDs appreciate this complicated subject being put on the map.

Disclosure of Interest: None declared


The Risk of Deliberate Self-Harm in Rheumatoid Arthritis and Ankylosing Spondylitis: A Population-Based Cohort Study

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Background: Inflammatory arthritis is associated with the development of mental health disorders. However, there is limited data on the risk of serious mental health outcomes following a rheumatoid arthritis (RA) or ankylosing spondylitis (AS) diagnosis.

Objectives: To estimate the risk of deliberate self-harm in patients with ankylosing spondylitis or rheumatoid arthritis compared with the general population.

Methods: We evaluated population-based cohorts of RA (n=53,240) and AS (n=13,964), each matched 1:4 by age, sex, and calendar year (at diagnosis) with non-RA comparator cohorts in Ontario, Canada. Individuals with a history of mental illness or prior episode of deliberate self-harm were excluded. The outcome was the first emergency room presentation for deliberate self-harm, subsequent to RA or AS diagnosis, between April 1, 2002 and March 31, 2016. We estimated hazard ratios (HR) and 95% confidence intervals (95% CI) for RA and AS, separately, versus the comparator groups, adjusting for demographic, clinical and health service utilisation variables.

Results: Individuals with AS were more likely to deliberately self-harm (incidence rate [IR] of 7.99/10,000 person years [PY]) compared to 3.19/10,000 PY in comparators, with an adjusted HR 1.33 (95% CI: 1.28 to 1.39) higher risk of deliberate self-harm. Deliberate self-harm was also increased for individuals with RA (IR 1.92/10,000 PY) only before (HR 1.43, 95% CI: 1.16 to 1.75), but not after covariate adjustment (HR 1.09, 95% CI: 0.88 to 1.36). The most frequent method of self-harm was poisoning (64% of attempts in AS, 81% in RA) or self-mutilation (36% in AS, 18% in RA).

Conclusions: There is a significantly increased rate of self-harm attempt in inflammatory arthritis and the risk is particularly elevated following a diagnosis of AS. These findings highlight the need for routine evaluation of self-harm behaviour as part of the management of chronic inflammatory arthritis. Understanding the mechanisms contributing to deliberate self-harm attempts will help tailor preventive strategies to reduce morbidity associated with this serious mental health outcome.

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