and increasing their ability to manage the disease. Furthermore, the pilot project aimed to close an important gap in the Swiss health care system.

Methods: A questionnaire was designed to measure the change in self-management abilities and the health status of patients. The questionnaire was given to patients at three points in time (t1=enrolment of patient, t2=last session of the self-management programme and t3= two months after the last session) and contained several validated scales such as the heQ. Self-Efficacy for Managing Chronic Disease 6-item Scale, RADAI-S and EQ-SD-SL. Descriptive statistics were applied to analyse the data by comparing the mean values of all relevant indicators at three points in time.

Results: In total 52 patients were enrolled in the pilot project. 48 patients completed the programme and 35 took part in the follow-up questionnaire. Overall, the results show a positive trend in self-management abilities and an improvement in the patients’ current health status. The slight increase in knowledge remained until the follow-up. Significant changes are seen in Skill and Technique Acquisition as well as in Self-Monitoring and Insight of the disease, which are two important components of self-management. Other components such as the knowledge and constructive attitudes and approaches also underwent a small but positive change that lasts up to two months after the last session of the self-management programme. Self-efficacy improved as well, but with a slight decrease during the follow-up. The disease activity also declined slightly over time. The results also indicate a small and steady improvement of the current health status. Using a visual analogue scale as part of the EQ-ED-EL, participants evaluated their current health status as 69 (t=1), 73 (t=2) and 74 (t=3). The quality of life has improved too, but the change doesn’t seem to be relevant. Furthermore, the use of health services indicates a slight decline after taking part in the self-management programme.

Conclusion: The comprehensive self-management programme designed by the Swiss League against Rheumatism embedded in outpatient rheumatological and general practitioner clinics proved to be successful. The three components of self-management in particular, i.e. knowledge, motivation to take action and skills to manage the disease improved significantly. The results also show a positive trend in the patients’ current health status, their quality of live and a decline in disease activity; however, based on the study design, it cannot be concluded that there is a correlation between the improved health status/quality of life and the self-management programme. For this purpose, a control group would be necessary to evaluate the programme’s effect on the health status and quality of life of people with rheumatic disease. Nevertheless, this pilot project represents an important foundation on which further services and programmes to strengthen self-management in rheumatology can be developed.

Disclosure of Interests: None declared


### Table 1. Avg assessment scores* by month, mean (SD)

<table>
<thead>
<tr>
<th>Pain Interv</th>
<th>Fatigue</th>
<th>Sleep Disturb</th>
<th>Physical Func</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Social Isol</th>
<th>Emot Support</th>
<th>Anger</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Period</td>
<td>63.3 (7.9)</td>
<td>62.6 (9.5)</td>
<td>58.1 (9.0)</td>
<td>37.7 (76)</td>
<td>60.8 (9.2)</td>
<td>62.4 (10.5)</td>
<td>619.10.2</td>
<td>40.8 (9.8)</td>
</tr>
<tr>
<td>May 2021</td>
<td>61.9 (8.2)</td>
<td>60.9 (9.7)</td>
<td>55.2 (8.8)</td>
<td>38.9 (8.5)</td>
<td>59.5 (9.2)</td>
<td>61.9 (8.8)</td>
<td>60.2 (13.3)</td>
<td>38.1 (8.3)</td>
</tr>
<tr>
<td>June</td>
<td>61.6 (8.9)</td>
<td>60.9 (9.5)</td>
<td>54.8 (8.9)</td>
<td>38.3 (7.8)</td>
<td>59.2 (10.0)</td>
<td>60.6 (9.6)</td>
<td>61.8 (12.0)</td>
<td>39.3 (10.3)</td>
</tr>
<tr>
<td>July</td>
<td>61.8 (7.4)</td>
<td>60.8 (10.2)</td>
<td>56.0 (8.5)</td>
<td>38.1 (7.9)</td>
<td>61.0 (7.8)</td>
<td>59.9 (12.1)</td>
<td>65.8 (8.5)</td>
<td>39.4 (9.7)</td>
</tr>
<tr>
<td>Aug</td>
<td>61.2 (8.5)</td>
<td>60.7 (10.4)</td>
<td>55.8 (8.6)</td>
<td>38.5 (8.5)</td>
<td>57.7 (79)*</td>
<td>58.2 (10.3)*</td>
<td>572.11</td>
<td>36.9 (12.2)</td>
</tr>
<tr>
<td>Sep</td>
<td>62.4 (8.5)</td>
<td>62.3 (10.0)</td>
<td>56.2 (8.3)</td>
<td>37.3 (76)</td>
<td>58.7 (8.0)</td>
<td>57.7 (11.3)</td>
<td>66.1 (12.8)</td>
<td>36.7 (12.1)</td>
</tr>
<tr>
<td>Oct</td>
<td>63.1 (8.4)</td>
<td>63.3 (9.9)</td>
<td>576 (8.6)</td>
<td>37.3 (8.0)</td>
<td>59.9 (13.1)</td>
<td>62.3 (9.0)</td>
<td>64.3 (10.3)</td>
<td>373 (11.4)</td>
</tr>
<tr>
<td>Nov</td>
<td>62.6 (6.8)</td>
<td>62.3 (10.0)</td>
<td>55.8 (8.6)</td>
<td>36.9 (70)</td>
<td>59.1 (8.8)</td>
<td>613.6 (8.8)</td>
<td>614.10 (9)</td>
<td>38.6 (11.7)</td>
</tr>
<tr>
<td>Dec</td>
<td>62.9 (8.3)</td>
<td>64.0 (9.6)</td>
<td>56.5 (8.4)</td>
<td>37.4 (8.1)</td>
<td>60.7 (8.4)</td>
<td>638 (8.3)</td>
<td>651 (7.5)</td>
<td>38.5 (13.5)</td>
</tr>
</tbody>
</table>

*PROMIS measures scored 0–100; mean 50 for general US population; 1SD = 10 points

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POS0088-PARE

CHANGES IN PATIENT-REPORTED OUTCOME SCORES DURING COVID-19 PANDEMIC: DATA FROM THE ARTHRITISPOWER REGISTRY

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Background: The COVID-19 pandemic causes concern among patients with autoimmune and rheumatic disease (ARD) due to increased risk of infection and heightened isolation from social distancing.

Objectives: Examine how mean patient-reported outcome (PRO) scores for mental, social and physical health fluctuated after COVID-19 vaccine availability was widespread in US.

Methods: We conducted and reported on an initial analysis of January 2020 – April 2021 where US participants (pts) of the ArthritisPower (AP) registry completed PROMIS measures of physical health (Physical Function, Pain Interference, Fatigue, Sleep Disturbance), mental health (Anger, Anxiety, Depression) and social health (Social Isolation, Emotional Support). Follow-up analysis was conducted May – December 2021. Only pts from initial analysis were included in follow-up. Null hypothesis was no change in monthly average scores across 23-month pandemic period. Analysis of means compared monthly assessment scores to mean overall score for each measure during study period. Pts with < 2 assessment time points and osteoarthritis with no ARD were excluded from analysis.

Results: Total of 49,940 PRO scores were contributed by 2,266 pts during 23-month period, with 8,393 of the scores contributed from May – December 2021. Mean (standard deviation, SD) number of observations per pt was 5.6 (12.5). Pts were 87.6% female, 86.7% white, mean age of 52.1 (12.7) years. Rheumatoid arthritis (n=1,131, 49.9%) was the most common condition. Most commonly reported measures were Pain interference, Fatigue, Sleep Disturbance and Physical Function, each with >11,000 total results (Table 1). Pts’ mental and social health assessment scores improved then worsened during last 8 months of 2021 (Figure 1). Overall mean scores were: Anxiety 62.4 (12.5), Social Isolation 61.9 (10.5), and Anger 61.5 (12.8). From July – August, Social Isolation decreased by 1 SD. Compared to overall assessment mean, Anger declined by >1/2 SD (53.3 [19.4]) in August and Anxiety declined by 1/2 SD (57.7 [11.3]) in September. By December, Anger rose by >1/2 SD (68.6 [5.0]) of assessment mean. Pain interference (mean 63.3 [7.8]), Fatigue (62.6 [8.9]), and Sleep Disturbance (58.1 [9.0]) scores were significantly lower in May, June, July and August compared to the assessment mean, though none decreased by >1/2 SD.

Conclusion: ARD members of AP had mental, social and physical health scores improve during summer of 2021, corresponding with widespread availability of vaccines. However mental and social health scores worsened by December as US faced new variants of the virus.

REFERENCES:

and private foundations. A full list of GHLF funders is publicly available here: https://www.ghlf.org/our-partners/.

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POSO089-PARE THE IMPORTANCE OF ACCURATE INCIDENCE AND PREVALENCE ESTIMATES FOR FAMILIES OF CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS

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Background: Juvenile Idiopathic Arthritis (JIA) is a heterogeneous group of autoimmune disorders characterised by chronic joint inflammation, affecting children and young people (CYP) under the age of 16. Recent analysis in the UK [1] has provided an update to the estimated incidence and prevalence of JIA.

Objectives: Whilst the policy and health-care benefits of accurate incidence and prevalence rates are understood, this patient- and parent-led qualitative project sought views from parents of CYP with JIA to understand whether knowing accurate estimates of incidence and prevalence are important to them.

Methods: Parents of CYP with JIA, all members of a small online group on social media, were asked whether knowing accurate rates of JIA were important to them, and why. Responses were collated and summarized.

Results: Whilst a few respondents felt it did not matter to them what the overall rates of JIA were, focusing instead on their own personal experience with the condition, the majority did want to know and gave consistent reasoning. They advised that, when your child is diagnosed with JIA, it is a very isolating experience. Most respondents have never heard of the condition before, and being told your child has arthritis is a frightening time (especially if you then become aware of some of the significant long-term effects, such as potential continuation of disease into adulthood and possible joint damage, and the side effects of treatment, and social impacts of the disease [2, 3]). Whilst direct support is available to families affected by JIA (www.jarproject.org/hope), understanding prevalence rates can help reduce mental health burdens on patients and parents and reduce feelings of isolation. Families also advised that they want to know numbers of children with JIA so we collectively can get a better understanding of the cause, the trends, and the possible reasons behind changes. Knowing accurately the numbers of children with JIA can help to raise awareness; current lack of awareness in society and primary care contributes to delays in diagnosis and potentially worse clinical outcomes [4]. In addition they reported the need for appropriate resourcing of paediatric rheumatology and support services, and the political and financial discussions that must take place to ensure that to happen need to be supported by evidence.

Conclusion: Overall, parents do want to know how many other children have JIA. It takes some of the isolation and anxiety away to know you are not alone. It matters because knowing there are other parents in the same situation as you can help reduce anxiety and loneliness. It matters, because knowing there are researchers focussing on JIA helps remind you that work is underway to better understand JIA, its causes, and improved treatments which will eventually lead to improved care for children with the condition. It matters, because it can help target resources appropriately. It matters, because raising awareness is more effective if we know how many people are affected by a chronic condition. And it matters, because as improved treatments are developed we want to be able to see the number of children categorised as having active JIA to reduce and health outcomes for each child to improve.

REFERENCES:


Disclosure of Interests: None declared


POSO090-PARE ORGANISATION, INFLUENCE, AND IMPACT OF PATIENT ADVISORY BOARD REPRESENTATION IN PRIVATE REHABILITATION INSTITUTIONS: AN EXPLORATIVE CROSS-SECTIONAL STUDY

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Background: Patient participation (PP) organised as patient advisory boards (PABs) is a statutory part of health care institutions in Norway [1]. There is limited agreement on how to engage PABs in a meaningful manner [2]. More knowledge on how PAB representatives experience patient engagement (PE) is needed.

Objectives: To explore how PAB representatives engage in PABs with regard to organisation, influence, and impact on decision-making processes and service delivery.

Methods: PAB representatives recruited from rehabilitation institutions, representing all four health regions in Norway completed a PE evaluation tool. The tool is tested for reliability and content validity with good results and comprises 35 items including four main domains policies and practices, participation culture, collaboration, and influence and impact that provided responses about PE-levels (3). Categorical data were summarized to modal scores using frequencies and percentages, and response categories were collapsed from five to three. The collapsed categories were divided into PE-levels: barrier, intermediate, and facilitator (Table 1). Free-text responses were analysed according to principles of manifest content analysis, summarized up, and used to complete the results of the scores. Free text responses were analysed using Quirkos version 2.4.

Results: Of the 150 contacted PAB representatives, 47 (32%) responded. PAB representatives’ mean age was 60.5 (min-max 30 - 80), 62% were female and a majority (81%) had prior experience with PP. The results showed that 75% of the participants agreed that patient-centered care was strengthened as a result of PE. Three out of four main domains scored indicating a facilitating PE-level (Table 1). The domain, influence and impact scored with an intermediate PE-level. Regarding influence and impact, half of the participants did not know if PE input had influenced management decisions, and 60% had rarely identified any PE contributions. The results from free text analyses showed that PE was coded as a facilitator seven times, and as a barrier to PE 26 times. The most frequent barrier was exclusion of PAB (13 codes), and the most coded facilitator was inclusion of PAB (3 codes).

Conclusion: Findings indicate that PAB representatives are satisfied with how rehabilitation institutions organise PABs. Unclear adherence to the values and principles of PP may hinder influence and visibility from PE contributions.

REFERENCES:


Table 1

<table>
<thead>
<tr>
<th>Modality (n)</th>
<th>Domain</th>
<th>PE-level</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n)</td>
<td>Policies and practices</td>
<td>Facilitating</td>
<td>125 (53.2)</td>
</tr>
<tr>
<td>8</td>
<td>Participatory culture</td>
<td>Facilitating</td>
<td>199 (53)</td>
</tr>
<tr>
<td>7</td>
<td>Collaboration</td>
<td>Facilitating</td>
<td>35 (36.5)</td>
</tr>
<tr>
<td>6</td>
<td>Influence and impact</td>
<td>Intermediate</td>
<td>125 (44.4)</td>
</tr>
</tbody>
</table>

Questions not presented in the table consist of background items, items related to final thoughts, and five questions with free text fields. A yes or no question related to the domain policies and practices is not included in the table.

Before collapsed, 15 items were valued: Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree, don’t know. Seven items valued 1-5: never, seldom, some of the time, all of the time, don’t know.

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