Table 1. AUCs (95% CI) for performance of outcomes in discriminating between flare and non-flare.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>AUC (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAID score</td>
<td>0.88 (0.82, 0.93)</td>
</tr>
<tr>
<td>PGA</td>
<td>0.92 (0.86, 0.96)</td>
</tr>
<tr>
<td>DAS</td>
<td>0.94 (0.90, 0.99)</td>
</tr>
<tr>
<td>CRP</td>
<td>0.77 (0.68, 0.84)</td>
</tr>
</tbody>
</table>

Acknowledgements: We thank the ARCTIC REWIND study group and patient representatives for contributing to this study.

Disclosure of Interests: Karen Holten Consultant of: UCB, Nina Paulshus Sun-daliser: None declared, Joseph Sexton: None declared, Lena Nordberg: None declared, Till Utlah Speakers bureau: Lilly, Galapagos, Pfizer, UCB, Consultant of: Lilly, Galapagos, Pfizer, UCB, Tore K. Kiven Speakers bureau: Grunenthal, Sandoz, UCB, Consultant of: AbbVie, Amgen, Celtrion, Gilead, Novartis, Pfizer, Sandoz, UCB, Grant/research support from: AbbVie, Amgen, BMS, Galapagos, Novartis, Pfizer, UCB, Espen A Haavardsholm Speakers bureau: Pfizer, UCB, Consultant of: AbbVie, Boehringer-Ingelheim, Eli Lilly, Gilead, Sirc Lillegraven Grant/research support from: Boehringer Ingelheim, Anna-Birgitte Aga Speakers bureau: Abbvie, Eli Lilly, Novartis, Consultant of: AbbVie, Eli Lilly, Novartis, Pfizer, UCB.

DOI: 10.1136/annrheumdis-2023-eular.620

Keywords: Outcome measures, Quality of life, Patient reported outcomes

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Background: Glucocorticoids are used in the treatment of a broad range of rheumatic conditions but can have a significant impact on health-related quality of life[1]. In-depth qualitative interviews with patients have experience of glucocorticoid treatment for their rheumatic disease, from the UK, USA and Australia, were used to develop candidate items for a treatment-specific Patient Reported Outcome Measure (PROM): the Steroid PRO.

Objectives: We aimed to complete the development and validation of the Steroid PRO through use of a cross-cultural validation study.

Methods: This was a cross-sectional online study of adults taking glucocorticoids for a rheumatic disease, from the UK, USA, Australia and New Zealand. A steering committee comprising methodologists, clinicians and patient research partners (PRPs) oversaw the study. The survey was distributed via social media with support from patient groups. Baseline data included: (i) demographics - age, gender, country, ethnicity, educational level; (ii) clinical information - diagnosis, glucocorticoid dose; (iii) 40 candidate items for the Steroid-PRO, developed in a previous qualitative study; (iv) EGS-EL: Optional follow-up data collected 3-5 days later: (i) the Steroid PRO candidate items; (ii) a condition change question. After descriptive analysis, iterative testing with Rasch measurement model and exploratory factor analysis (EFA) informed item reduction and established structural validity, reliability and unidimensionality of the final Steroid PRO. Item reduction was based on clinical importance, lack of fit to the Rasch model, and redundancy. Evidence of discriminative validity of the Steroid PRO was established by comparing its scores for participants receiving lower dose glucocorticoid (up to 10 mg) versus higher dose (>10 mg). Intraclass correlation (ICC) between baseline and follow-up was calculated for patients who reported ‘no change’ compared with 3-5 days ago.

Results: A total of 946 patients returned complete responses at baseline (follow-up: 447 responses). They were from UK, n= 743 (78.5%); USA, n= 139 (14.7%); Australia, n= 59 (6.2%). Their mean age was 57.6 (SD=13.6); 833 (88%) were women. They were treated for inflammatory arthritis (n=194), connective tissue disease and/or vasculitis (n=398), and giant cell arteritis and/or polymyalgia rheumatica (n=341). A total of 25 items were removed due to floor effects and lack of fit to the Rasch model. Iterative discussions between statisticians, clinicians and PRPs ensured that items of high clinical importance were retained. The remaining 15 items showed a satisfactory fit to the model. EFA suggested a scale structure with four domains: Participation (4 items), Appearance (3 items), Psychological (5 items), and Treatment concerns (3 items). PRPs were involved in naming the domains. The 4-domain structure was supported by the Rasch model, confirming construct validity; χ2=47.82 (DF=36), p=0.899; and reliability (Person Separation Index, PSI=0.757). Total scores also fitted the Rasch model, therefore both domain and total scores will be psychometrically appropriate for use as a repeated measure. A good fit to the Rasch model was also seen across the disease groups with items distributed equally across the three groups. Patients on a lower glucocorticoid dose had lower Steroid PRO domain scores than those receiving higher dose (discriminant validity). ICC between baseline and follow-up ranged from 0.892 to 0.942 (95% CI 0.868 to 0.953) suggesting excellent (test-retest) reliability.

Conclusion: The final Steroid PRO is a 15-item, valid and reliable 4-domain scale measuring the impact of glucocorticoid therapy on HRQoL of people with rheumatic diseases.


Acknowledgements: NIL.

Disclosure of Interests: Susan Bridgewater Grant/research support from: Vifor Pharma, Mwidi Ndos Grant/research support from: Vifor Pharma, Jill Dawson: None declared, Pamela Richards: None declared, Christine Silverthorne: Nonfinancial support, Emma Durey Grant/research support from: Vifor Pharma, Sarah Mackie Consultant of: UCB, Grant/research support from: Novartis, Catherine Hill: None declared, Sarah Mackie Speakers bureau: Roche/Chugai, Vifor Pharma and Pfizer on behalf of her institution (no personal remuneration), Consultant of: Roche/Chugai, Sanofi, AbbVie, AstraZeneca and investigator on clinical trials for Sanofi and GSK on behalf of her institution (no personal remuneration), Grant/research support from: Vifor Pharma as research grant co-applicant (partial salary support) paid to her institution, Joanna Robson Speakers bureau: Vifor Pharma, Consultant of: Vifor Pharma, Grant/research support from: Vifor Pharma.

DOI: 10.1136/annrheumdis-2023-eular.3705

Keywords: Patient-led research, Best practices

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Background: Financial and Human Resources are 2 key issues faced by European federations of Patient organisations and limiting their impact. This reality is

PARE Abstract Session.

Keywords: Lupus Europe's Patient Advisory Network - A Huge Double Success

also a vicious circle as volunteers are needed to deliver the projects, themselves forming the basis to fund the organisation. When preparing its 2018-2023 strategic plan, Lupus Europe was confronted with this frustrating reality with incomes stagnating around 40,000€/year, just enough to cover its basic operations, convention and few limited size projects.

Objectives: To step change Lupus Europe’s development and unlock both the funding and volunteering recruitment bottlenecks by creating an energising Patient Advisory Network.

Methods: As part of its 2018-22 strategic plan discussions, the Lupus Europe designed the structure of a Patient Advisory Network (PAN) as a key way to reach its objectives, in a way that combined both volunteers and sponsors motivation factors. For volunteers, the PAN offered an opportunity to move from a victim of the disease position to that of an actor of the change, working together with other fellows, equally motivated. Initial patients were selected based on their positive energy and desire to change things and grow skills. We identified (web based) opportunities to grow the needed skills, and encouraged participation. Finalising the team charter, drafted by the board, became the first exercise of the team, which then dedicated itself to support projects from academics, clinicians or industry, and work on own lupus Europe projects. The visibility of the PAN quickly became an additional motivator, and many applications to join were received. PAN members agreed that potential remuneration for their work would accrue to Lupus Europe and be used to motivate and reward the group. For sponsors, we redesigned our partnership proposal, using the PAN to step change engagement levels. We asked our sponsors for a leap of faith that we could drive this to success, and that they would benefit from it as much as we would by making our community more vibrant. We also offered to all a sample of what the team could do to support key projects. We engaged with academics to identify valuable project ideas, and asked them to give training to the team. In parallel, we invested some of our savings to fund initial costs, and provided soft skills training for the group. Two years later, we applied and obtained EMA recognition as EMA eligible entity. Early successes boosted the team’s morale and helped reach out to more partners. This in turn allowed us to “put the program on steroids”, multiplying our support to the group and the number of projects generated by Lupus Europe. Things we had never imagined being able to do by ourselves, like the Living with Lupus project, were “suddenly” all feasible. In 2022 we recognised most experienced members as Fellows offering an aspirational “path for growth” to all, from trainee to ambassador to expert and Fellow.

Results: 5 years after its start, the PAN is now rich of 23 highly motivated members working on 25 projects (50/50 industry/non-industry) including some of our own design. It is recognised as a best in class organisation, and keeps growing, enabling us to achieve results we could not have dreamed of 5 years ago. Lupus Europe’s funding jumped from 40k in 2017 to more than 300k in 2021, allowing to do more projects, invite PAN members to SL Euro or EULAR and professionalise some of our support. It also increased our independence from pharma, as we feel free to say no to any funder we don’t fully feel happy with (and we did it already twice!).

Conclusion: The PAN project as transformed lupus Europe from a minimalistic federation to the key voice and support of people living with lupus in Europe. Acknowledgements: Many thanks to LUPUS EUROPE’S Patient Advisory Network members whose enthusiasm and commitment has been critical for the success of this project.

Disclosure of Interests: None Declared.

DOI: 10.1136/annrheumdis-2023-eular.2950

OP0282-PARE

WORLD ARTHRITIS DAY, A UNIQUE CAMPAIGN

Keywords: Best practices

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Background: Since its establishment in 1996, World Arthritis Day is celebrated every year on the 12th of October, across the world and in my country as well. Several events-campaigns, take place aiming to raise awareness among the general public, stakeholders, politicians and people with Rheumatic and Musculoskeletal diseases, health care professionals, elected officials and the relevant governmental authorities. Giving the message to the public about the early symptoms, the importance of early diagnosis, the importance of proper therapy and the importance of managing the disease is the aim of the campaign. For the 2022 campaign, our organisation traditionally for this day, organizes big Campaigns among all the above in addition to achieve recognition of the Organization in the General Public. In 2021 for the first year, we established very successfully a new campaign called, <Wear me>-. In this campaign, the idea was to engage People and Companies to wear a T-shirt for us. In 2022 the target was bigger than the previous year. The idea was to create text through a photo. As we all know, picture talk more to people than words. These days, with the internet overseer and Social Media’s role in our lives, words and pictures pass in front of us, in hundreds every day. We wanted a strong IMAGE to make people curious about RMDs and about our organisation.

Objectives: The major objectives were:

- To raise awareness of WAD.
- To increase the Prevention of RMDs.
- To make our league more popular.
- To become more familiar and recognizable with our new name and logo.

We got involved in the campaign more people than in 2021.

Methods: Six months before the WAD, a Task Force for the campaign was established, to build the Action Plan. Without a very good plan, we can’t have a successful campaign. After several meetings and discussions, the action plan was ready four months before the WAD. Main target: to involve 2000 People (we had 1400 people in 2021), to wear a t-shirt with our logo on the 12th of October 2022. In addition, our prompt was to take a photo, post it on their social media, use the hashtag (#) and the name of our organisation. The Action plan had four Phases: First, contact the people and the companies, by writing two letters, one for those that they participated in the previous year to ask them to stand with us, again and the second one for new companies or people that we wanted to approach for participating in this year campaign. Second, to find funds for the campaign and for purchase the T-Shirts. Third, to deliver all the T-shirts on time and fourth, to be able to Post or Re-Post all the photos on organisation’s FB page.

Results: Our results were over and above our expectations! Achieving goals: We contact many small and medium local companies, coffee chains, hairdressing salons, gyms, physiotherapists, health insurance companies, pharmacies etc… Schools and municipality employees. We involved doctors, nurses, famous people, athletes, actors, singers, journalists, football players, athletes’ teams, politicians and the president of Cyprus Parliament. A lot of TV’s and Radio Channels cover the campaign, even some of them wore our T-shirts during the shows all day. We reached over and above our target of the use of T-Shirt 2700 people wore the t-shirt with the logo of our organisation, on the 12th of October 2022. The FB results were extremely positive! The organisation’s FB page reached 30000 views, the whole week. The FB page had an average of 219% increase in visiting compared to the previous week.

Conclusion: Compare to the previous year, almost twice the number of participants wore our t-shirt. Engagement on Facebook was satisfactory. The hashtag was applied as a caption to the pictures taken. There was a big discussion on social media and TV shows about the campaign. A lot of people were asking to buy the t-shirt to support our league. A lot of people were calling our offices to get information about our services and our programs. The general conclusion is that the need of raising awareness for RMDs is still high.

REFERENCES:
[1] FB page of the Organisation

Acknowledgements: NIL.

Disclosure of Interests: None Declared.

DOI: 10.1136/annrheumdis-2023-eular.1519

OP0283-PARE

HELLENIC LEAGUE’S AGAINST RHEUMATISM’S SCHOOL OF HEALTH EDUCATION

Keywords: Quality of care, Patient information and education, Best practices

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Background: The more time healthcare professionals spend with patients the better the health outcomes become. Therefore, education seems to play a crucial role for the quality of life not only for the patients but also for the health care costs and the future cost projections that depend on the health outcomes of everyone.

Objectives: To provide a platform of the School of Health Education is to give the opportunity to participants to familiarize themselves with frequently used terminology in everyday clinical practice, to become accustomed in using the common medical language when describing their symptoms to their doctors so that they will have a common ground. Basic goal of this education is for every patient to understand a bit more about concepts such as medications, adverse events, pharmacovigilance etc.