Table 1 – Results of the surveys, across different countries, concerning patient perspective on the efficacy and risks of glucocorticoids in patients with RA.

	All	Brazil	USA	UK	Portugal	Germany	NL	Others**
GCs are or have been very useful to me								
Agree	58	64	56	62	42	51	68	54
Slightly agree	20	20	21	11	12	30	10	18
Neutral	6	4	8	7	5	6	6	10
Slightly disagree	3	4	5	1	4	0	3	3
Disagree	4	3	7	3	1	4	3	3
Missing	9	6	1	15	25	9	9	12
At a GC dose of 5 mg/day:								
-Are very effective in the control of signs and symptoms of RA								
Agree	41	48	42	40	31	28	46	38
Slightly agree	25	25	15	20	26	45	20	38
Neutral	12	11	24	8	12	12	16	12
Slightly disagree	5	7	6	6	4	0	4	4
Disagree	5	4	7	6	1	6	5	7
Missing	12	6	3	19	25	9	9	15
-Improve RA symptoms within days								
Agree	41	45	44	37	34	37	44	39
Slightly agree	23	23	19	19	20	33	23	24
Neutral	12	12	18	8	13	8	12	9
Slightly disagree	6	6	7	7	7	0	6	7
Disagree	8	8	8	10	1	3	5	7
Missing	11	6	3	19	25	9	9	15
I have suffered very SAEs due to GCs								
Agree	29	40	44	13	15	18	18	29
Slightly agree	3	0	0	0	0	0	32	18
Neutral	14	15	12	15	17	4	7	11
Slightly disagree	1	0	0	0	0	0	7	2
Disagree	44	40	43	56	43	58	27	41
Missing	9	6	1	15	25	9	9	12
N (% of total)	432 (100)	104 (24)	211 (49)					117 (27)
How serious do you consider these SAEs								
Life threatening	9	NA	55	32	NA	NA	NA	13
Serious impact in my QoL	36	NA	39	38	NA	NA	NA	23
Minor impact in my QoL	27	NA	28	52	NA	NA	NA	17
Mid and well tolerated	29	NA	18	50	NA	NA	NA	32

Numbers indicate %.

***Others (% of total): Italy 1.9%; Spain 1.7%; Romania and Canada, each one 1.4%; Belgium 0.6%; France, Australia and Venezuela, each one 0.2%; Algeria, Angola, Argentina, Belize, Cyprus, India, Ireland, Japan, Mauritius, Mexico, Mozambique, Moldova, Nicaragua, Norway, Sweden and Switzerland each one with 0.1%.

*The Portuguese, German and Deutschland version as well as the English survey through MedGuard.org. didn't have this question due to legal constraints (% of answers per frequency category).

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AB1336-HPR NON-PHARMACOLOGIC TOPICS RELEVANT FOR CLINICAL RESEARCH IN RHEUMATIC DISEASES: THE PATIENT PERSPECTIVE

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Background: The research approach on Rheumatic diseases (RDs) is challenging and patient involvement as partners in medical research is an emerging force to obtain relevant information and to add unique skills, values and experiences to research. Despite growing interest in non-pharmacologic aspects of clinical research in RDs, the patients' perspective is currently poorly explored.

Objectives: To identify and rank the priorities for clinical research according to patients' perspective.

Methods: A structured face-to-face meeting between physicians and a patient representative was convened to list the non-pharmacologic topics relevant to RD patients. A cross-sectional no-profit on-line anonymous survey was devised to evaluate opinions of RD patients. They were asked to rate the following topics: food/nutrition, air pollution, smoking, work activity, social participation, physical activity, emotional well-being/stress, alternative medicine, and patient-physician relationship. Moreover, patients were asked to explain for which reason a topic was considered important (disease prevention, halting disease progression, symptoms control and disease cure). The survey was disseminated by ALOMAR (Lombard Association for Rheumatic Diseases) between June and October 2019.

Results: 200 rheumatic patients completed the survey: 130 inflammatory arthritis, 50 connective tissue diseases/vasculitis, and 20 among osteoarthritis, gout, condrocalcinosis, polymyalgia and primary fibromyalgia. Respondents were 178 female with median age of 50 years and median disease duration of 7 years. Among the nine topics identified, the one most rated by patients was the doctor-patient relationship; 188 (94%) of respondents considered this topic very or extremely important (see table below). In descending order, patients rated very

or extremely important: psychological well-being/stress 185 (92.5%), physical activity 155 (77.5%), nutrition, eating habits and alcohol 150 (75%), alternative therapies 144 (72%), work activity 144 (72%), environmental pollution 134 (67%), social life 121 (60.5%) and cigarette smoke 119 (59.5%). The topics considered relevant was perceived to be able to influence disease symptoms. Regarding RD prevention, environmental pollution and cigarette smoking were considered the most important topics, while fewer patients believed that research on other topics could help to stop disease progression or to achieve disease healing.

Ranking	Topic	Not or quite important	Very or extremely important
1	Doctor-patient relationship, n (%)	12 (6.0)	188 (94.0)
2	Psychological well-being/stress, n (%)	15 (7.5)	185 (92.5)
3	Physical activity, n (%)	45 (22.5)	155 (77.5)
4	Nutrition/eating habits/alcohol, n (%)	50 (25.0)	150 (75.0)
5	Alternative therapies, n (%)	56 (28.0)	144 (72.0)
6	Work activity, n (%)	56 (28.0)	144 (72.0)
7	Environmental pollution, n (%)	66 (33.0)	134 (67.0)
8	Social life, n (%)	79 (39.5)	121 (60.5)
9	Cigarette smoke, n (%)	81 (40.5)	119 (59.5)

Conclusion: This survey highlights the relevance of several unmet needs. The holistic approach, in terms of medical consultation and psychological well-being, is considered the most important component able to influence disease perception. By capturing patient opinions on non-pharmacological topics for clinical research, this survey indicates that the active patient involvement is essential to design successful translational studies and improve clinical outcomes.

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AB1337-HPR PATIENTS' EXPERIENCE OF INVOLVEMENT IN A RHEUMATOLOGY OUTPATIENT CLINIC

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Background: Involvement in own treatment and care is a wish from patients and a vision from politicians in Denmark. (1,2) In outpatient rheumatology patient involvement also leads to increased patient satisfaction, better quality of treatment and better utilization of resources in health care. (3,4,5) On the basis of this we ought to involve our patients at our Outpatient Clinic in Svendborg, but are we?

Objectives: To gain knowledge about how patients with rheumatoid arthritis experience involvement in treatment and care in the Rheumatology Outpatient Clinic, Svendborg.

Methods: An interview study of six patients with subsequent analysis based on Ricoeur. (6) Patient inclusion: patients with rheumatoid arthritis in remission by DAS28 for more than 2 years. The participants elected were 3 males and 3 female at the age of 30 – 78 visiting the clinic during Marts and April 2019. They were asked about their experience of involvement from time of diagnosis until present time.

Results: The study provided knowledge that patient involvement was new to the participants. This is also found in other literature about patient involvement. (7,8) All participants in this study felt involved in own care and treatment. The involvement was based on being seen and heard as persons with individual needs and not just as patients with arthritis. The way the participants experienced involvement showed that there are individual differences in how to provide the experience. In order to clarify what involvement meant for each patient, relationship with the health professional was necessary, as other studies also shows. (7,8) The relationship was conditioned by continuity, trust, care and mutual respect. For all the participants informed consent was equal to involvement. Disease activity or fear of this was the main reason for feeling involved this way. Literature describes the same: amongst other factors, the severity of the disease is significant for the patients desire to be involved. (7,8)

Conclusion: The participants experienced involvement in own care and treatment. The relation to the health professional was important providing this experience. All defined involvement as informed consent as it also is to many healthcare professionals. (9) All participants needed time to reflect on what

involvement meant as none of them had heard of it before. Patient involvement needs education of both patients and healthcare professionals to be taken further than informed consent.

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AB1338-HPR

GLOBAL PATIENT PERSPECTIVE ON TOP CHALLENGES IN LUPUS CARE AND RESEARCH PARTICIPATION

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Background: The Addressing Lupus Pillars for Health Advancement (ALPHA) Project is a global consensus initiative to identify, prioritize and address top barriers in lupus drug development, clinical care and access to care. The Lupus Foundation of America convenes ALPHA with Tufts Center for the Study of Drug Development and a Global Advisory Committee of lupus experts representing clinician-scientists, industry and patients.

Objectives: Collect global patient input to determine alignment with the lupus clinician-scientist community on prior published consensus of top lupus barriers.

Methods: A 23-question online Qualtrics survey was developed to identify challenges across lupus diagnosis, clinical care and research participation. The survey, available in English, Spanish, Korean and simplified Chinese, was fielded in November 2019 to people with lupus and caregivers of children <18 with lupus. SPSS 26 and SAS 9.4 were used for descriptive statistics and sub-analysis.

Results: Analysis included only consented responses with ≥ 68% survey completion (n=3,447) received across 83 countries. 95% were female with a mean age of 45. Respondents reported being White (57%), Black or of African descent (14%), Hispanic or Latino (18%) and Asian (10%). 65% resided in the US while 35% resided in countries outside of the US. 97% were people with lupus while 3% were caregivers to children <18 with lupus.

Highest ranked challenges were similar globally and across children and adults: medication side effects, lack of treatment options and high out-of-pocket costs. Managing side effects ranked significantly higher (p<.05) outside of the US (48%) compared to US (40%). 50% of caregivers reported managing side effects as the top challenge for children compared to 43% of adults (p<.05). Research participation was low (24%) and lower among children (16%). The top reason for not participating in a clinical trial was not being asked by their doctor.

Conclusion: This global survey revealed that medication side effects and lack of effective treatments are top challenges for people with lupus, including children. Most respondents were never asked by their doctors to participate in a clinical trial, which may explain difficulties in trial recruitment. These barriers are consistent with prior published barriers identified by the clinician-scientist community.

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AB1339-HPR

SAFETY AND ADHERENCE OF THE JAK INHIBITORS IN CLINICAL PRACTICE IN RHEUMATOID ARTHRITIS

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Background: The Janus Kinase (JAKi) inhibitors Baricitinib (BAR) and Tofacitinib (TOF) are indicated for moderate to severe active rheumatoid arthritis (RA). Data about safety, effectiveness in refractory patients and adherence in real clinical practice in our population are scarce.

Objectives: An evaluation of safety, adherence and reasons to consider suspension of JAKi in routine clinical practice.

Methods: Retrospective observational study of patients with RA treated with BAR and TOF according to usual clinical practice between September 2017 - December 2019. Data were collected from the electronic medical record and from the Dominion® Outpatient Drug Dispensing program.

Demographic, clinical, laboratory and treatment-related variables were collected, including reasons for discontinuing JAKi (inefficiency and toxicity). Adherence was calculated using the Compliance Questionnaire on Rheumatology (CQR-5), and the average possession ratio (RMP), which is defined as the number of days with treatment dispensed between the total days of the period analyzed, considering the adherent patient when RMP had a ≥ 0.8.

Laboratory abnormalities were defined according to normal limit values (NLV) and specifications of data sheet. A descriptive analysis was performed using proportions, medians and interquartile ranges (IQR) using the SPSS v.15 program.

Results: Thirty patients were included in treatment with BAR and nine with TOF. The median age was 62.9 (RIQ 49.9-74.4), 34 (87.2%) were women, 28 (71.2%) anti-CCP and 32 (82.1%) were rheumatoid factor positive, with erosive disease in 34 (87.2%) patients. In the previous treatment, 9 (23.1%) were naive to biological, 6 (15.4%) had received 1 biological, 18 (46.1%) 2 biologicals, and 6 (15.4%) ≥ 3 biologicals. The median treatment time was 8.4 months (RIQ 6.5-20.3) in BAR and 13.2 (RIQ 3.9-20.7) in TOF.

The reasons for consider suspension shown in Table 1.