Disseminating and assessing implementation of the EULAR recommendations for patient education in inflammatory arthritis: a mixed methods study with patients' perspectives

Bethan Jones [1,2], Sarah E. Bennett [2,3], Ingrid Larsson [4,5], Heidi Zangi [6,7], Carina Boström [8], Kristien Van der Elst [9], Françoise Fayet [10], Mie Fusama [11], María del Carmen Herrero Manso [12], Juliana Hoeper [13,14], Marja Leena Kukkurainen [15], Suet-Kei Gladys Kwok [16], Elsa Mateus [17], Patricia Minnock [18], Tiziana Nava [19], Milena Pavic Nikolic [20], Jette Primdahl [21,22], Roopa Rawat [23], Mareen Schoenfelder [24,25], Matylda Sierakowska [26], Marieke Voshaar [27], Edgar Wammervold [28], Astrid van Tubergen [29], Mwidimi Ndosi [2,30].

1. School for Healthcare Sciences, Cardiff University, United Kingdom.
2. School of Health and Social Wellbeing, University of the West of England, Bristol, United Kingdom.
3. Translational Health Sciences, Bristol Medical School, University of Bristol, Bristol, United Kingdom.
4. School of Health and Welfare, Halmstad University, Halmstad, Sweden.
5. Spenshult Research and Development Centre, Halmstad, Sweden.
6. National Advisory Unit on Rehabilitation in Rheumatology, Diakonhjemmet Hospital, Oslo, Norway.
7. Faculty of Health, VID Specialized University, Oslo, Norway.
8. Department of Neurobiology, Care Sciences and Society, Division of Physiotherapy, Karolinska Institute, Stockholm, Sweden.
9. Department of Rheumatology, KU Leuven University Hospitals, Leuven, Belgium.
10. Department of Rheumatology, Clermont-Ferrand Teaching Hospital, Clermont-Ferrand, France.
11. School of Nursing, Takarazuka University, Osaka, Japan.
12. Servicio de Reumatología. Hospital Universitario 12 de Octubre. Madrid. España.
13. Center for Health Economics Research Hannover (CHERH), Leibniz University Hanover, Hannover, Germany.
14. Clinic for Rheumatology and Immunology, Hannover Medical School, Hannover, Germany.
15. The Finnish Society of Rheumatology Nurses, Helsinki, Finland.
16. Rheumatology and Clinical Immunology Unit, Grantham Hospital, Hong Kong.
17. Portuguese League Against Rheumatic Diseases (LPCDR), Lisbon, Portugal.
18. Rheumatic Musculoskeletal Disease Unit, Our Lady's Hospice & Care Services, Dublin, Ireland.
19. Department of Translational Medicine and Surgery, University of Milan–Bicocca, Milan, Italy.
20. Division of Internal Medicine, Rheumatology, University Medical Centre Ljubljana, Kamnik, Slovenia
21. Department of Regional Health Research, University of Southern Denmark, Odense, Denmark.
22. Danish Hospital for Rheumatic Diseases, University Hospital of Southern Denmark, Sønderborg, Denmark.
23. Indian Spinal Injuries Centre, New Delhi, India.
24. Österreichische Rheumaliga, Austria.

25. Sprachinstitut TREFFPUNKT, Bamberg, Germany.
26. Department of Integrated Medical Care, Medical University of Bialystok, Bialystok, Poland.
27. Department of Pharmacy, Radboud University Medical Center, Nijmegen, Netherlands.
28. Nordlandssykehuset, Bodø, Norway.
29. Department of Rheumatology, Maastricht University Medical Center, Maastricht, Netherlands.
30. Academic Rheumatology Unit, Bristol Royal Infirmary, University Hospitals Bristol and Weston NHS Foundation Trust, Bristol, United Kingdom.

Corresponding author:
Dr Mwidimi Ndosi University of the West of England, Bristol. Mwidimi.Ndosi@uwe.ac.uk
Twitter: https://twitter.com/ndosie

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Name	Email address	ORCID ID
1. Jones, Bethan	jonesb94@cardiff.ac.uk	0000-0002-7253-0751
2. Bennett, Sarah	sarah.bennett@bristol.ac.uk	0000-0001-7355-124X
3. Larsson, Ingrid	ingrid.larsson@hh.se	0000-0002-4341-660X
4. Zangi, Heidi A.	heidi.zangi@diakonsyk.no	0000-0001-6882-221X
5. Boström, Carina	carina.bostrom@ki.se	0000-0002-2506-687X
6. Van der Elst, Kristien	kristien.vanderelst@gmail.com	0000-0003-3504-0005
7. Fayet, Françoise	francoise.fayet139@orange.fr	0000-0002-5491-2262
8. Fusama, Mie	miefusama@gmail.com	0000-0002-6636-2835
9. Frazao Mateus, Elsa	elsafrazaomateus@gmail.com	0000-0003-0059-2141
10. Herrero Manso, María del Carmen	ojasintos@gmail.com	0000-0001-9223-7619
11. Hoeper, Juliana	jh@cherh.de	0000-0002-9937-9991
12. Kukkurainen, Marja Leena	marjaleenakukkurainen@gmail.com	0000-0001-6150-8252
13. Kwok, Suet Kei Gladys	kwoksk3@ha.org.hk	0000-0002-1032-5699
14. Minnock, Patricia	pminnock@olh.ie	0000-0002-4913-4320
15. Nava, Tiziana	tiziananava.job@outlook.it	0000-0001-9107-8441
16. Pavic Nikolic, Milena	milenapavic@gmail.com	0000-0001-9703-0182
17. Primdahl, Jette	jprimdahl@danskgigthospital.dk	0000-0002-1049-4150
18. Rawat, Roopa	rooparawat84@gmail.com	0000-0003-2641-2700
19. Schoenfelder, Mareen	mareen_schoenfelder@web.de	
20. Sierakowska, Matylda	matyldasierakowska@gmail.com	0000-0003-2816-8588
21. Voshaar, Marieke	marieke_scholte@hotmail.com	0000-0002-4161-0126
22. Wammervold, Edgar	edgar.wammervold@sbnett.no	
23. van Tubergen, Astrid	a.van.tubergen@mumc.nl	0000-0001-8477-0683
24. Ndosi, Mwidimi	mwidimi.ndosi@uwe.ac.uk	0000-0002-7764-3173

Abstract

Objectives

To explore patients' agreement and reasons for agreement or disagreement with the European Alliance of Associations for Rheumatology (EULAR) recommendations for patient education (PE) for people with inflammatory arthritis (IA).

Methods

This mixed-method survey collected data using snowball sampling. The survey had been translated into 20 languages by local healthcare professionals, researchers and/or patient research partners. It explored the degree to which patients with IA agreed with each recommendation for PE (0=do not agree at all and 10=agree completely), and their rationale for their agreement level in free text questions. Descriptive statistics summarised participants' demographics and agreement levels. Qualitative content analysis was used to analyse the free text data. Sixteen subcategories were developed, describing the reasons for agreement or disagreement with the recommendations, which constituted the categories.

Results

The sample comprised 2779 participants (79% female), with a mean (SD) age 55.1 (13.1) years, and disease duration 17.1 (13.3) years. Participants strongly agreed with most recommendations (Median 10 [IQR: 9 to 10] for most recommendations). Reasons for agreement with the recommendations included the benefit of using PE to facilitate collaborative care and shared decision making, the value of flexible and tailored PE, and the value of gaining support from other patients. Reasons for disagreement included lack of resources for PE, not wanting information to be tailored by healthcare professionals, and a reluctance to use telephone-based PE.

Conclusion

The EULAR recommendations for patient education have been disseminated among patients with IA. Overall, agreement levels were very high, suggesting that they reflect patients' preferences for engaging in collaborative clinical care, and using PE to facilitate and supplement their own understanding of IA. Reasons for not completely agreeing with the recommendations can inform implementation strategies and education of healthcare professionals.

Introduction:

Patient education (PE) is defined as "*a planned interactive learning process designed to support and enable people to manage their life with inflammatory arthritis and optimise their health and well-being*".[1] This broad definition of PE covers educational activities provided to patients, including health promotion and health education in clinics on topics such as mood, sleep, physical exercise, lifestyle behaviour, relaxation skills and communication.[1-3] PE is a crucial part of managing inflammatory arthritis and can contribute to patients' ability and willingness to take an active role in managing their health, as well as being a way to equip them with knowledge to make choices about their condition.[3 4]

In 2015, the European Alliance of Associations for Rheumatology (EULAR) developed evidence-based recommendations for PE.[1] They were intended to improve the quality of PE for people with Inflammatory Arthritis (IA) and increase understanding of PE for rheumatology healthcare professionals. Table 1 presents two overarching principles and the eight recommendations.[1]

Table 1: EULAR recommendations for patient education (PE) for people with Inflammatory Arthritis (IA)

Overarching Principles
• Patient education is a planned interactive learning process designed to support and enable people to manage their life with inflammatory arthritis and optimise their health and well-being
• Communication and shared decision making between people with inflammatory arthritis and their health professionals are essential for effective patient education
Recommendations
1. Patient education should be provided for people with inflammatory arthritis as an integral part of standard care in order to increase patient involvement in disease management and health promotion
2. All people with inflammatory arthritis should have access to and be offered patient education throughout the course of their disease including as a minimum; at diagnosis, at pharmacological treatment change and when required by the patient's physical or psychological condition
3. The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis
4. Patient education in inflammatory arthritis should include individual and/or group sessions, which can be provided through face-to-face or online interactions, and supplemented by phone calls, written or multimedia material
5. Patient education programmes in inflammatory arthritis should have a theoretical framework and be evidence-based, such as self-management, cognitive behavioural therapy or stress management
6. The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme
7. Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team
8. Providers of patient education in inflammatory arthritis should have access to and undertake specific training in order to obtain and maintain knowledge and skills

Dissemination is the initial stage in knowledge transfer. However, bringing about changes in practice requires an understanding of acceptability and applicability of recommendations to relevant stakeholders such as patients and healthcare professionals (micro-level), then analysis of the contextual factors including organisational context (meso and macro levels), as these are key to enabling implementation.[1 5 6]

This project aimed to disseminate the recommendations for PE across EULAR member countries and some countries in Asia to understand how acceptable and applicable they are. As the recommendations target patients with IA, it was important to assess acceptability (including reasons for agreement or disagreement with the recommendations) in patients as a stakeholder group.[5] A separate publication[7] reports the findings of the study with rheumatology healthcare professionals. The current paper reports the findings of agreement or disagreement with the recommendations from the patients' perspective.

Methods:

Design:

This was an explanatory mixed-methods research study. An abductive approach was used to explore patient agreement or disagreement with the recommendations using both quantitative and qualitative approaches for a more comprehensive understanding of patients' agreement.[8] The abductive approach involved moving back and forth between inductive and deductive approaches. The qualitative and quantitative data were collected in a single survey, and the findings offered an opportunity to review participants' agreement with the recommendations from different perspectives. This included considering how they used PE and preferred to receive PE in a clinical setting.

Data were collected in 23 countries using snowball sampling by distributing the survey link via social media, patient organisations and via rheumatology healthcare professionals. These countries were determined based on their membership of EULAR Study Group on Patient Education (STOPE) and country representatives being able and willing to participate.

Ethics approval:

The study was conducted in accordance with the Declaration of Helsinki. Participants were informed that their participation was voluntary, and that by submitting a completed survey

this implied their consent to participate. This study was approved by the University of the West of England, Bristol (HAS.18.11.066).

Procedure:

The study team included healthcare professionals and/or health researchers, patient research partners, rheumatologists, and methodologists. They contributed to designing the patient survey which comprised:

- Participant demographics (sex, age, diagnoses, disease duration, country of residence, highest academic qualification).
- Numerical rating scale of 0 to 10 (0 = I do not agree at all, 10 = I agree completely) capturing participants' agreement with each of the 8 individual recommendations.
- Free text for participants to report reasons for agreement or disagreement.

This survey was initially designed in English and then translated into other languages using a dual panel approach.[9 10] A UK study team co-ordinated the project, and local country representatives bilingual in English and the target language translated the survey. After this, a separate panel of people who spoke the target language reviewed the translation. The dual panel approach is efficient and has been shown to produce tools that are accurate, culturally adapted, and acceptable to users.[9 11] The survey was translated into 20 languages. Further details on the translation and the mixed-methods synthesis are reported elsewhere.[5] Data collection took place between July and September 2019. Data were collected in local languages using the translated surveys, and free text responses were then translated from other native languages back to English by the local collaborators. This created a single dataset for analysis.

Data analysis:

The mixed methods involved independent analysis of the quantitative and qualitative data to better understand both the level of- and reasons for agreement or disagreement with the recommendations.

Quantitative analysis

Descriptive statistics were used to summarise participants' characteristics and summarise their level of agreement with each recommendation, using medians with corresponding interquartile ranges (IQR).

Qualitative analysis

The free text responses for participants who completed the survey were imported into NVivo 12 (QSR International, Melbourne, Australia) and analysed using qualitative content analysis.[12] Content analysis focuses on classifying textual data into categories. Key features of this method of analysis include reviewing the data to develop familiarity, coding the data by attaching labels that describe the data, and developing categories that summarise the research topic.[12 13]

The free text was analysed in an abductive content analysis.[14 15] The first phase was deductive, where statements concerning barriers and facilitators to each EULAR recommendation were identified and were grouped together into content areas, agreement or disagreement as reported previously.[5] Statements concerning barriers and facilitators to each EULAR recommendation were identified. Next, an inductive content analysis was used, where each quote from participants constituted a meaning unit. The meaning units were coded and compared on the basis of similarities and differences and grouped into 16 subcategories, reflecting the central message contained in the free text, and described the reasons for agreement or disagreement with the recommendations. The last phase was deductive and the subcategories were linked to the EULAR recommendations, constituting the categories and manifest content, giving a two-level hierarchy.[12] The qualitative content analysis was performed by the second author (SB), in ongoing discussion with senior researchers (MN and IL). The findings were discussed with the STOPE team as part of a member checking exercise.

Mixed-method analysis

The quantitative and qualitative data were analysed independently, and the results are presented as a narrative where the qualitative findings explain the quantitative findings of patients' agreement or disagreement with the recommendations.

Results:

Participants and demographic information:

In total, 4912 participants accessed the survey but only 2779 provided fully completed responses (56.5%). Table 2 presents the characteristics of the participants and Table 3, participants by country.

Table 2: Characteristics of participants

Characteristic or variable	N (%), or Mean (SD)
Sex, N (%)	Female: 2193 (79)
	Male: 586 (21)
Primary diagnosis, N (%)	Rheumatoid Arthritis: 1258 (45.2)
	Ankylosing Spondylitis: 1019 (36.7)
	Psoriatic Arthritis: 427 (15.4)
	Not stated: 75 (2.6)
Age in years	55.1 (13.1)
Disease duration in years	17.1 (13.3)
Highest level of qualification	Certificate: 451 (16)
	Diploma: 812 (29)
	Bachelors: 488 (17.5)
	Masters: 463 (16.7)
	PhD: 399 (14.4)
	Not stated: 166 (9)

Table 3: Number of respondents by country

Country	Attempted	Completed
Austria	6	4
Belgium	151	117
Bulgaria	1	0
Czech Republic	1	0
Denmark	336	310
Estonia	2	1
Finland	150	120
France	653	505
Germany	9	5
Greece	3	2
Hong Kong	18	10
India	9	9
Ireland	49	12
Italy	304	269
Netherlands	57	34
Norway	405	310
Poland	81	62
Portugal	63	49
Slovenia	9	2
Spain	27	20
Sweden	773	690
Switzerland	2	1
UK	281	251

Not noted	1508	0
Total	4912	2779

Quantitative findings:

Table 4 summarises the levels of agreement with each of the recommendations. All median scores were 10 and the IQR for all recommendations were at least between 9 and 10, suggesting strong agreement with the recommendations.

Table 4: Levels of agreement with each recommendation

Recommendation	Median (IQR)
1. Patient education should be provided for people with inflammatory arthritis as an integral part of standard care in order to increase patient involvement in disease management and health promotion.	10 (10 to 10)
2. All people with inflammatory arthritis should have access to and be offered patient education throughout the course of their disease including as a minimum; at diagnosis, at pharmacological treatment change and when required by the patient's physical or psychological condition.	10 (9 to 10)
3. The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis.	10 (9 to 10)
4. Patient education in inflammatory arthritis should include individual and/or group sessions, which can be provided through face-to-face or online interactions, and supplemented by phone calls, written or multimedia material.	10 (9 to 10)
5. Patient education programmes in inflammatory arthritis should have a theoretical framework and be evidence-based, such as self-management, cognitive behavioural therapy or stress management.	10 (9 to 10)
6. The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme.	10 (9 to 10)
7. Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team.	10 (10 to 10)
8. Providers of patient education in inflammatory arthritis should have access to and undertake specific training in order to obtain and maintain knowledge and skills.	10 (10 to 10)

Qualitative findings:

The categories in this study were based on the eight EULAR recommendations for PE for people with IA and divided into content areas, reasons for agreement or disagreement. The

subcategories explained the core content of the patients' reasons for agreement or disagreement within each recommendation for patients with IA, presented in table 5.

Table 5: Reasons for agreement and reasons for disagreement, among patients

Reasons for agreement:
- PE facilitates collaborative care and shared decision making   - Patients are keen for PE to guide their own self-directed search for knowledge   - PE should be offered at every appointment   - PE needs to be flexible and tailored to individuals   - Using evidence-based PE to make informed choices   - Need to evaluate PE   - Benefits of getting PE from peers   - Training can help healthcare professionals to become more effective clinicians
Reasons for disagreement: - Lack of resources to deliver PE   - Managing IA without clear PE is difficult   - The timing of PE delivery matters   - Patients do not want information to be tailored by healthcare professionals   - Avoidance of phone-based PE and fears regarding group PE   - Concerns about PE evaluation   - Healthcare professionals may not be skilled at providing PE   - Preference for only healthcare professional-delivered PE

Reasons for agreement:

Recommendation 1: PE as an integral part of standard care

PE facilitates collaborative care and shared decision making:

Care for long-term conditions has been increasingly focused on the patient and healthcare professionals working as equal partners to make shared decisions. This was reflected in how participants wanted to use PE. They were keen to be treated as equal partners and involved in decision making:

"But - also ensure clinicians ask what we need/want. It should not be about them second-guessing is or assuming they know best. We're also experts, in our experiences so make it a joint enterprise please" [UK]"

"These are complex diseases that require active and positive patient management and the building of a real partnership… Each has a different, particular and important role to play in this regard" [France]

Recommendation 2: Patients offered PE throughout the course of their disease

<u>Patients are keen for PE to guide their own self-directed search for knowledge</u>

Some participants agreed with the timing discussed in recommendation 2 because they used PE to supplement their own personal research and study. Accessing PE that reinforced their independently gathered knowledge of their own condition was important to them.

"Personally, I get informed and read much. I have a very good and very sympathetic rheumatologist" [Italy]

Some felt they had a personal responsibility to educate themselves about their conditions:

"I think it is the individual's responsibility to learn about their disease and participate in the educations available" [Sweden]

<u>PE should be offered at every appointment</u>

While recommendation 2 proposed PE at key points throughout the course of their condition, some felt PE should be offered at each appointment to help them understand their health:

"The patient gets to know his disease better over time and this can raise new questions. The disease also evolves". [Denmark]

"Education needs to be repeated, especially as it is easy to forget some things" [UK]

"[I want to] get PE whenever the patient requires, not just when HCPs think it is needed" [Spain]

Recommendation 3: PE should be tailored to the individual

<u>PE needs to be flexible and tailored to individuals</u>

Participants were clear on the importance of tailored and flexible PE to best suit individual patients' needs, preferences, and abilities. Some participants mentioned the importance of information presented in accessible language:

"Patients are not expert in [the] medical field; It should be explained to them in depth, so that it's easier for them to understand." [Hong Kong]

"It should be based on fact but not [one] size fits all so what works for one may not for another" [UK]

Others discussed flexibility in PE delivery, with more generic information being suitable for group settings and more individualised PE in one-to-one appointments.

Recommendation 4: PE should be provided through face-to-face, individual and/or group sessions

Recommendation 7: PE should be delivered by competent health professionals and/or by trained patients

Benefits of getting PE from peers

Participants discussed the benefits they saw in peer-led PE support. This included their perceptions that lived experience of IA may be more valuable for delivering PE than formal training:

"The education is not always able to cover the experience." [Finland]

"Of course a patient knows more about pain than a physician who has no experience with arthritis pain himself" [Denmark]

They also discussed how patients can gain support from each other in PE groups. Some had a preference for group PE:

"Being newly diagnosed you often 'feel lonely with your disease' and in that case it good if you can meet someone in the same situation who understand you." [Sweden]

Recommendation 5: PE should have a theoretical framework and be evidence-based

Using evidence-based PE to make informed choices

Participants found this category reflected how they wanted to use PE to understand their medication. This included implications and side effects. They had a clear preference for PE to be informed by research.

"I believe that education should be rooted in theory and research. Experience-based practice is something we gain from fellow patients and that we try out ourselves." [Norway]

Recommendation 6: The effectiveness of PE should be evaluated

Need to evaluate PE

Participants agreed with recommendation 6 that PE should be evaluated, including understanding what benefits PE has for patients.

"You may find that there are other benefits to the patient than the ones you measure" [Denmark]

"Yes, we have to evaluate [PE], since it will have a cost, I would like to know if it is useful and relevant." [France]

Recommendation 8: Providers of PE should have access to, and undertake, training

Training can help healthcare professionals to become more effective clinicians

When reviewing recommendation 8, participants felt that training for healthcare professionals to deliver PE was important:

"It is important that they are continuously educated so their knowledge and awareness of the research is always up to date." [Sweden]

Reasons for disagreement:

Recommendation 1: PE as an integral part of standard care

Managing IA without clear PE is difficult

Participants recognised that managing their conditions without clear PE was particularly challenging. Some experienced a lack of support immediately post-diagnosis, despite the recommendations specifically suggesting PE at this point. They found this lack of PE made it challenging to manage their health. Those who sought information from the internet or support groups found that information they identified could be misleading.

"Often we don't know enough about our condition or we have to search for this ourselves. Doctor Google is NOT a good advisor!" [Belgium]

The timing of PE delivery matters

Some patients may not always want PE, and felt that their own self-care is sufficient. Similarly, participants also recognised that they may not want PE at each appointment.

"It depends in part on the level of culture and involvement that the patient himself wants to have" [Portugal]

"Should be systematically proposed but not imposed" [France]

The timing of PE was also important to consider, and patients may not be able to take in information immediately post-diagnosis.

"Often it's too much to take in when diagnosed at first, sometimes it feels like this is your diagnosis, these are the leaflets, job done! It can take time to assimilate the diagnosis, treatment and think of questions and what you really need to know." [UK]

Recommendation 2: Patients offered throughout the course of their disease

Lack of resources to deliver PE

In some cases, a lack of resources to deliver PE contributed to patient disagreement with the recommendations. Participants reported a lack of time within appointments to have PE

as part of normal care, and felt that personalised PE would be very time-consuming and resource-intensive to deliver in clinics.

"[the recommendations] it is probably not realistic due to resources" [Denmark]

"Again resource levels may limit this - the local rheumatologist helpline has been [cut] *right back over the last 18 months"* [UK]

"Only patients in the main centres will be able to benefit from it. And the others, far from everything? And what will be the quality of the service provided? Who will provide coverage? And at what cost for what final result?" [France]

Recommendation 3: PE should be tailored to the individual (and recommendation 5: PE should have a theoretical framework and be evidence-based)

<u>Patients do not want information to be tailored by healthcare professionals</u>

Despite the benefits and agreement of recommendation 3 discussed above, some participants did not want healthcare professionals to tailor the education they received. Instead, they wanted to receive comprehensive details to decide for themselves what was important:

"I want education from A to Z because if my situation would change later on, I would already know a lot." [Belgium]

"I do not agree at all with that. I think EVERYONE should get ALL the information. People really do pick up what is important to them personally. And you may hear/read things that you would never have known otherwise. Plus, who decides what the needs of someone else are?" [Netherlands]

Recommendation 4: PE should be provided through face-to-face, individual and/or group sessions

<u>Avoidance of phone-based PE and fears regarding group PE</u>

The mention of telephone calls in recommendation 4 contributed to disagreement from some participants. They were reluctant to receive PE via telephone, and preferred other modes of delivery instead:

"No information by telephone. It can easily be misunderstandings." [Sweden]

Some were not keen on the idea of group PE suggested in recommendation 4. They mentioned that others may not be comfortable discussing their conditions there, or that groups did not suit them personally:

"[Pressure of] Group can also be the reason that one does not dare to ask all questions." [Netherlands]

"I do not have any value from groups." [Finland]

"One to one may be better as people may feel intimidated in a group session." [UK]

Recommendation 6: The effectiveness of PE should be evaluated

<u>Concerns about PE evaluation</u>

Participants expressed some reservations about evaluating PE that led them to disagree. This included recognition of a lack of time to evaluate PE, uncertainty about how PE might be evaluated, and concern that evaluating PE may be stressful for patients:

"On what basis do you evaluate…What are the objectives of the programme?" [France]

"As long as there are patients evaluate whether or not the goal is met. Health professionals cannot decide what's effective and useful in a patients' life." [Norway]

Recommendation 7: PE should be delivered by competent health professionals and/or by trained patients

<u>Preference for only healthcare professional-delivered PE</u>

Some participants preferred not to receive PE from trained patients, and would rather receive their PE from healthcare professionals:

"I have poor experiences with patients as teachers - I do not need to hear about their disease. I need trained teachers who know what they are doing." [Denmark]

"[PE] Should only be provided by professionals." [Sweden]

Recommendation 8: Providers of PE should have access to, and undertake, training

<u>Healthcare professionals may not be skilled at providing PE</u>

Participants also recognised potential issues with the training recommended for healthcare professionals in recommendation 7. These issues contributed to disagreement with this recommendation. Participants had concerns about a lack of training for healthcare professionals and a recognition that even with training, healthcare professionals may not be skilled at delivering PE:

"A brilliant researcher is not necessarily a brilliant teacher. Some just can and some never learn it" [Denmark]

"Learning to educate and differentiate for each person is a high order skill that not all people can achieve" [UK]

Discussion:

The study objective was to disseminate the EULAR Recommendations for patient education with patients internationally, to understand their level of agreement with the recommendations, as well as reasons for agreement or disagreement. The recommendations were disseminated across many countries, resulting in 2779 completed surveys. These findings suggest that patients' agreement with the recommendations was very high.

The study has provided new knowledge on the reasons that contribute to patients' agreement and engagement with the PE recommendations. Understanding patient perceptions of the recommendations is important as it recognises them as key stakeholders of the intended change (improvement in PE provision), facilitating readiness for change and allows understanding of the potential impact of PE interventions. Patient participants' high agreement with the recommendations indicates the possibility of high engagement with PE delivered in line with these recommendations. This is in accordance with the principles of implementation science, which starts with identifying barriers and facilitators of change including patients, healthcare professionals and the wider contexts.[16]

While the recommendations give patients a sense of what to expect from educational interventions, by understanding patients' perspectives regarding these recommendations, clinical teams can implement them with confidence while understanding the reservations patients may have. Good quality PE delivered according to the recommendations can support patients to make informed choices about how to manage their IA.

The qualitative findings identified that participants were keen to receive PE as part of collaborative care. This allowed them to make decisions about their health as equal partners in collaborative self-management support.[17] These results support existing research suggesting that rheumatology patients use PE to supplement their own research, and appreciate evidence-based PE.[18]

Participants had a range of opinions on peer-led PE provided by expert patients. Some participants felt they would benefit from gaining support from peers, whereas others were

less comfortable with this and preferred PE only delivered by healthcare professionals. It is possible that these differences may have also been impacted by participants' home country and how common peer-led PE is in various locations. A study of peer mentor programme for patients with early RA,[19] reflects this range of views, where mentoring by peers is preferred in sensitive topics not easily discussed with professionals, yet caution is advised on other topics. The implementations will therefore consider the local contexts in each country.

Some participants expressed reservations about telephone-based PE and a preference for face-to-face PE. Our data were collected before the COVID-19 pandemic when largely, patients and professionals lacked experience and rarely used online information for health and care decisions. This agrees with previous studies looking at eHealth and Telehealth literacy in rheumatology.[20 21] Current studies[22 23] have shown that patients are open to mHealth technologies in care. Indeed, the area of mHealth is growing not least due to the changes accelerated by the COVID-19 pandemic. The long-term implications of post-COVID-19 clinical care provision will inform how patients receive PE in the future, as more patient education is delivered online.[24] In addition, as participants noted the importance of considering patient experiences in evaluating PE, incorporating the patient experience may be a key factor to consider when planning the evaluation of PE.

The sample was made up predominantly of women, and while this is common in health research,[25] it may contribute to differences in preferences in receiving patient education. The average disease duration of the sample was over 17 years, reflecting a great deal of experience self-managing rheumatic conditions and receiving patient education. Newly diagnosed patients are likely to have different patient education needs and preferences.[26 27]

Thus far, this study has given us a greater understanding of acceptability and applicability of recommendations to relevant patient stakeholders at an individual (micro) level. However, in order to enable effective implementation, contextual factors also need to be considered at the service or organisational (meso) level.[6] For example, the organisational context of PE is different across countries, and this will be important to understand in order to establish and sustain PE services, and enable routine evaluation as per Recommendation 6. Our participants were cautious about the idea of patient-led PE (Recommendation 7) and

thought that group-led PE might be intimidating (Recommendation 4). Future work at the policy (macro) level could focus on better understanding country-specific contexts, such as the national implementation of patients as partners in PE, and the training and support given to healthcare professionals who engage in PE.

This study has four key limitations. First, the data were collected using voluntary internet-based surveys which may allow selection bias (non-representativeness and volunteer effect).[28] Consequently, there were between-countries discrepancies in the number of respondents which means that some responses may have been driven by few countries. Given the high level of agreement with all the recommendations (at least IQR: 9 to 10), it is likely that they represent a true agreement in most countries surveyed. Further work will be required to understand agreement and applicability in countries that were not well represented in this survey. Selection bias may also explain the high levels of educational attainment in our sample, with 31.1% reporting a postgraduate qualification. Those with high literacy levels and access to digital tools and the internet are more likely to respond to online surveys than those with low literacy levels. This may also explain the finding that some patients would prefer not to have their PE tailored by healthcare professionals. Caution is needed in interpreting this finding as patients with lower educational attainment and health literacy may have different health needs, therefore may require more accessible, tailored information than those with higher educational attainment.[29] Second, the voluntary nature of this study allowed incomplete responses, with missing demographical details or enough data for analysis, it was not possible to understand the characteristics of the non-completers. Third, our findings represent barriers and facilitators at the individual patient (micro) level. While this is important, studying the contexts at the organisational (meso) and policy (macro) levels is necessary to enable successful implementation of the recommendations in different countries.[6] This could also focus on those countries that were less represented in this study. Last, this study was carried out before the COVID-19 pandemic which means the current developments in remote delivery of care with telehealth technologies were not captured. These remain the subject for future studies. There is also a need to update the EULAR recommendations for PE in light of these findings.

Conclusions:

The EULAR recommendations for PE in IA have been disseminated to patients across many countries in Europe. In those countries represented, agreement with the recommendations

is very high and qualitative findings suggest that they reflect patients' preferences for engaging in collaborative clinical care, using PE to facilitate and supplement their own understanding of IA. More studies are required to understand barriers at the micro level and the contextual factors in those countries not represented in this study, in order to facilitate implementation in all parts of Europe. The identified reasons for reservations or not completely agreeing with the recommendations can inform the implementation strategies and education of healthcare professionals.

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Competing interests

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Ethics approval

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