

Assessing acceptability and identifying barriers and facilitators to implementation of the EULAR recommendations for patient education in inflammatory arthritis: a mixed-methods study with rheumatology professionals in 23 European and Asian countries

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ABSTRACT

Objectives: To disseminate and assess the level of acceptability and applicability of the EULAR recommendations for patient education among rheumatology professionals across Europe and 3 Asian countries, and identify potential barriers and facilitators to their application.

Methods: A parallel convergent mixed methods research design with an inductive approach was used. A web-based survey, available in 20 different languages, was distributed to health professionals by non-probability sampling. The level of agreement and applicability of each recommendation was assessed by (0 to 10) rating scales. Barriers and facilitators to implementation were assessed using free-text responses. Quantitative data were analysed descriptively and qualitative data by content analysis and presented in 16 categories supported by quotes.

Results: A total of 1159 participants completed the survey; 852 (73.5%) were women. Most of the professionals were nurses (n=487), rheumatologists (n=320), physiotherapists (n=158). For all recommendations, the level of agreement was high but applicability was lower.

The four most common barriers to application were: lack of time, lack of training in how to provide patient education, not having enough staff to perform this task and lack of evaluation tools. The most common facilitators were: tailoring patient education to individual patients, using group education, linking patient education with diagnosis and treatment, and inviting patients to provide feedback on patient education delivery.

Conclusions: This project has disseminated the EULAR recommendations for patient education to health professionals across 23 countries. Potential barriers to their application were identified and some are amenable to change, namely training patient education providers and developing evaluation tools.

Keywords: Patient education, Inflammatory arthritis, Recommendations, Dissemination, Implementation

Key Messages

What is already known about this subject?

- Patient education is an integral part of the management of inflammatory arthritis. An international task force of health professionals, researchers and patients, developed evidence-based EULAR recommendations for patient education in inflammatory arthritis in 2015.

What does this study add?

- This study disseminated the recommendations for patient education to healthcare professionals in rheumatology across Europe, India, Hong Kong and Japan.
- The levels of agreement with the recommendations among healthcare professionals was very high, the level of applicability was lower for each corresponding recommendation.
- The top three barriers to application were lack of time, lack of training in how to provide patient education, and not having enough staff to perform this task.

How might this impact on clinical practice?

- Patient education delivered according to the recommendations can support patients to make informed choices about how to manage their inflammatory arthritis and optimise their health.

Background

Patient education (PE) is recommended as an integral part of standard care for patients with inflammatory arthritis (IA).¹⁻³ PE has been defined as “*a planned interactive learning process designed to support and enable people to manage their life with a disease and optimise their health and wellbeing*”.⁴ It can include health education, self-management programmes, psycho-educational programmes (such as stress management, relaxation techniques, strategies to manage psychological distress and social functioning), and health promotion by healthcare providers.⁴

Using an evidence-based and expert opinion-based approach, EULAR recommendations for patient education⁴ were developed in 2015 to increase the awareness of and improve the quality of PE for people with IA across Europe. The recommendations comprised two overarching principles and eight recommendations which address the content of PE, when and how this should be provided, the need for evaluation of PE and training of the providers (Table 1).

Table 1: Recommendations for patient education for people with IA.

Overarching Principles
<ul style="list-style-type: none">• 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
<ol style="list-style-type: none">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 promotion2. 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 condition3. The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis4. 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 material5. Patient education programmes in inflammatory arthritis should have a theoretical framework and be evidence-based, such as self-management, cognitive behavioural I therapy or stress management6. The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme7. Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team8. Providers of patient education in inflammatory arthritis should have access to and undertake specific training in order to obtain and maintain knowledge and skills

While developing evidence-based recommendations is essential, successful implementation in practice is crucial to obtain the desired improvements in quality of care and patient outcomes.⁵⁻⁷ Implementation is a dynamic, iterative process comprising planning, analysis of the context, assessing barriers and facilitators, designing strategies and evaluation.⁷⁻¹⁰ It occurs at three levels, the micro-level (individual clinicians, clinical teams and patients or carers), the meso-level (institution, organisation or local government) and the macro-level (national or regional/continental). Dissemination of the recommendations to all stakeholders and assessing acceptability, feasibility and identifying barriers and facilitators to implementation is the first crucial step in the implementation process.⁶⁻¹⁰

To facilitate implementation, it is essential to assess acceptability to various stakeholders, feasibility in different health systems, the cost and sustainability if applied in practice.¹¹ PE is usually organised by rheumatology nurses¹²⁻¹⁵ although all professionals in the care of people

with IA (rheumatologists, physiotherapists, occupational therapists, psychologists and social workers) deliver PE as part of their role in a multidisciplinary team.¹⁶⁻¹⁸ Patients with IA have also been successfully involved in the design and delivery of PE to other patients.¹⁹⁻²¹ Therefore, all these groups are the target of the dissemination and implementation.⁴ We have disseminated these recommendations to patients with IA in Europe and overall, their agreement levels were very high, suggesting that they reflect patients' preferences for engaging in collaborative care.²²

The objectives of this study were to: (i) disseminate the recommendations to professionals across Europe and 3 countries in Asia (ii) assess the level of acceptability and applicability and (iii) identify potential barriers and facilitators to implementation of the recommendations.

Methods

Design

We applied a parallel convergent mixed methods research design with an inductive approach. Quantitative and qualitative data were collected concurrently and then merged and integrated during analysis and interpretation. Since both quantitative and qualitative methods can provide complementary data on the same research problem, a mixed methods design was used to provide a more comprehensive understanding of the dissemination including awareness, and barriers and facilitators to the implementation of the recommendations across Europe.²³

The study was conducted in 20 European countries, Hong Kong, India, and Japan. The research team comprised 31 multidisciplinary members; including a methodologist, patient research partners, researchers and/or health professionals within each collaborating country.

Quantitative data collection

The survey developed by authors comprised two sections: (i) personal characteristics (age, sex, country) and professional background (profession, qualification, work setting and experience in rheumatology) and (ii) items regarding the eight recommendations. For each of the recommendations, numerical (0 to 10) rating scales were used to assess participants' level of agreement and application of the recommendations. Example:

Recommendation 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

- *Do you agree with this recommendation? (Please indicate the level of your agreement: 0 "I do not agree at all" and 10 "I agree completely")*
- *Do you provide patient education as it is advocated in this recommendation? 0 "No, not at all" and 10 "Yes, entirely".*

All the items are presented in the supplementary material.

Qualitative data collection

The two overarching principles were stated using bullet points, and for each of the eight recommendations, respondents were invited to add free text comments on reasons for not agreeing entirely and/or barriers to application of the recommendation.

Translation of the survey

Investigators in each country translated the survey into their national language using a dual panel approach.²⁴⁻²⁶ This approach involves a consensus translation produced by a primary (professional) panel of bilingual people familiar with the target language, followed by review by a second panel who speak the target language, in order to ensure acceptability and understanding of the wording for prospective participants. Any discrepancies in translation were resolved using a group consensus approach. This approach has been shown to produce translations that are easier to understand, compared to the forward-backward translation approach.²⁴⁻²⁶ In total, 20 different language options were available for the survey respondents to select from a drop-down menu.

After data collection was complete, investigators in each collaborating country were sent the free-text responses from their corresponding languages. These were translated back into English and sent to the study coordinator for analysis.

Participants

The target participants for this survey were all professionals involved in the care of people with inflammatory arthritis. From July to September 2019, collaborators from the 23 countries disseminated the web-based survey to their colleagues and national rheumatology organisations using a snowball sampling technique.²⁷

Data analysis

Quantitative analysis

Descriptive statistics were used to summarise the levels of agreement and application of each of the recommendations. IBM SPSS Statistics version 20 (IBM, New York, USA) software was used.

Qualitative analysis

Translated free text responses were imported into NVivo 12 (QSR International, Melbourne, Australia) and analysed with a manifest qualitative content analysis with an inductive approach. This qualitative method involved coding, creating categories and data abstraction.²⁸ Each translated dataset was read through repeatedly by the first author (SB) to gain a greater understanding of the whole data.²⁹

The text was first divided into barriers and facilitators for each of the 8 EULAR recommendations, and into positive and negative opinions, relating to the overarching principles.²⁹ Although the survey items asked about barriers to implementation of the recommendations, many participants gave examples of instances where they had successfully implemented recommendations in their practice, and exemplars of how they had achieved this. These were coded as facilitators for each recommendation. Phrases and words containing information relevant to the aims of the study were identified, extracted and labelled with a code.²⁹ For each barrier and facilitator, codes with similar underlying meanings were grouped into subcategories. Each subcategory was organised, and named using words and phrases characteristic of the data, such as “not enough time”. Subcategories with similar content and incidences were grouped together into broader main categories, giving a two-level hierarchy.²⁸ Data analysis was conducted by the first author (SB), with a critical discussion of codes, subcategories, and main categories with the principal investigator (MN) and input of a qualitative methodologist (IL).

Mixed-method analysis

After independent analyses of the quantitative and qualitative data, the results were paired side by side for comparison and identification of similar and different categories between and within the eight recommendations in order to validate the results.²³ The categories were correlated and thereafter ranked within each recommendation (Figure 1).

Figure 1: Parallel convergent mixed-methods model

Ethical considerations

Participating in this study was voluntary. Survey respondents were advised that completing and submitting the survey implied that they had read the information sheet, and consented to taking part. The study was approved by the Faculty of Health and Applied Sciences Research Ethics Committee at the University of the West of England, Bristol, UK (UWE REC REF No: HAS.18.11.066).

Results

Participants

A total of 1510 responses were received 1159 of which were complete responses. This may be due to the in-built feature of Qualtrics® survey, where incomplete responses were saved automatically after 2 weeks. The respondents comprised 487 nurses, 320 rheumatologists, 158 physiotherapists, 75 occupational therapists, 22 pharmacists, 8 nutritionists, 8 medical assistants, 3 psychologists, and 78 'other' professionals. Most were women (852; 73.5%) and median duration of clinical experience was 13 (IQR: 6 to 23) years of which 5 (IQR: 1 to 7) years were in rheumatology. Table 2 presents the number of respondents by country.

Table 2: Number of respondents by country.

Country	Number attempted survey	Number completed survey
1. Austria	17	11
2. Belgium	99	71
3. Bulgaria	9	8
4. Czech Republic	1	0
5. Denmark	57	45
6. Estonia	1	0
7. Finland	70	61
8. France	156	128
9. Germany	32	26
10. Hong Kong	14	12
11. Hungary	90	75
12. India	17	13
13. Ireland	24	18
14. UK	51	41

15. Italy	85	63
16. Japan	214	169
17. Latvia	3	3
18. Netherlands	36	28
19. Norway	55	42
20. Poland	36	29
21. Portugal	245	171
22. Slovenia	1	1
23. Spain	60	46
24. Sweden	136	97
25. Switzerland	1	1
TOTAL	1510	1159

Cross-cultural adaptation

The adaptation of the questionnaire into target languages was largely seamless except for professional characteristics, training and educational background, which differs across countries. In Hong Kong, the term "theory" in the context used in recommendation 5 was difficult to understand therefore this was modified to "scientific based approved information as a component in patient education". In Spain, the word "designed" in recommendation 3 was substituted for 'tailored' as this was considered more personal. In addition, examples of "personal needs" in recommendation 2 were expanded to give examples of the nature of those needs (such as work or pregnancy). As the recommendations were often described in long sentences, it was necessary in some languages to break into two sentences in order to retain the intended meaning. In the Norwegian translation, the adaptation included shortening the number of words in the information section.

Quantitative results

Level of agreement and application of the recommendations

Table 3 presents the level of agreement and application of the recommendations. Overall, there was high agreement (median=10, IQR: 8 to 10) across all recommendations. However, the level of applicability was generally lower compared to each corresponding agreement level, especially for recommendation 6, which states that the effectiveness of patient education should be evaluated (median=6, IQR: 4 to 8). Lack of an effective evaluation tool was the most often mentioned barrier to implementation for recommendation 6. For

recommendation 4, the most cited barrier was limited access to phone or internet-based PE. For recommendation 5, a lack of training in theoretical frameworks, self-management or cognitive behaviour therapy was a common barrier.

Table 3: Levels of agreement and applicability of each recommendation.

	Agreement		Applicability	
	Median	IQR	Median	IQR
Recommendation 1	10	10 to 10	8	7 to 10
Recommendation 2	10	10 to 10	8	6 to 10
Recommendation 3	10	9 to 10	8	7 to 10
Recommendation 4	10	8 to 10	7	5 to 10
Recommendation 5	10	8 to 10	7	5 to 9
Recommendation 6	10	8 to 10	6	4 to 8
Recommendation 7	10	9 to 10	8	5 to 8
Recommendation 8	10	10 to 10	8	5 to 8

Qualitative findings:

Barriers to implementation

Table 4 presents the 10 categories and selected quotes that illustrate perceived barriers to implementation of the recommendations.

Table 4. Quotes for respective category supporting barriers to implementation

Quote number (Q)	Category (bold) /Illustrative quotes	Quoted by
Lack of time		
1	<i>“Medical file, medical history, clinical assessment, lab tests, imaging, medication ... there is often a lack of time, consequently, patient education is provided but in a less optimal way.”</i>	Rheumatologist, Belgium
2	<i>“Not all the needs of patients can be extracted within the set time of current PE.”</i>	Nurse, Japan
3	<i>“It is ideal to meet various needs, but on the other hand, increasing the burden on the provider side is an issue.”</i>	Rheumatologist, Japan
4	<i>“Evaluation is never performed, no time is allocated to it.”</i>	Registered Nurse, Belgium
Lack of training		
5	<i>“Lack of training in the area on my part; little time available.”</i> [Recommendation 1]	Registered Nurse, Portugal
6	<i>“Inflammatory chronic disease nursing and nurse specialist in this field have not been established. Therefore, as information, and knowledge and skills of</i>	Nurse Educator, Japan

nurses are insufficient, nurses may not be able to take care of patients based on the personal situation.” [Recommendation 3]

- 7 “Ignorance of the [EULAR] recommendations” [Recommendation 1] Registered Nurse, Portugal
- 8 “I think we don't do it because we don't know how to do it. Especially [CBT] and stress management” [Recommendation 3] Rheumatologist, France
- 9 PE [may] varies depending on the years of experience of the nurse. [Recommendation 1] Nurse, Japan
- 10 “Not enough training providers in our country” [Recommendation 6] Rheumatologist, Bulgaria
- 11 “Finding appropriate patients and training them to be trainers are all challenges” [Recommendation 7]. Registered Nurse, Hong Kong

Lack of staff

- 12 “We do not currently have the resources to incorporate CBT or stress management strategies into patient self management. We do refer some patients to the pain team service ...however waiting lists are very lengthy” [Recommendation 5] Registered Nurse, UK

Lack of assessment tools

- 13 “At follow up with the patient it will emerge what the patient needs to be re-informed about and what is missing, but we don't use any tool for this evaluating..” [Recommendation 6] Registered Nurse, Sweden].
- 14 “No framework for follow-up” [Recommendation 6] Rheumatologist, Belgium
- 15 “Lack of time to organize follow-up and evaluation consultations” [Recommendation 6]. Family Doctor, Portugal

Limited resources

- 16 “Not all patients have access to the Internet” [Recommendation 4] Nurse, Finland
- 17 “Face-to-face online support and telephone support at a general hospital like ours are not possible” [Recommendation 4] Nurse, Japan
- 18 “Group sessions and online cannot be used due to institutional restrictions.” [Recommendation 4] Occupational Therapist, Japan

Concerns about online PE

- 19 “My preferred method to answer patients’ questions is absolutely individually and face-to-face, online contact and written material can be misunderstood; however, this (online/written) is possible for most patients in case of sharing more general information [Recommendation 3] Rheumatologist, Belgium
- 20 “Online interaction seems not an ideal approach in my opinion. For example, information shared via email could be misinterpreted wrongly.” [Recommendation 4] Rheumatologist, Belgium
- 21 “Online self-learning can be misleading” [Recommendation 3] Rheumatologist, Japan

Concerns about patient-delivered PE (Recommendation 7)

- 22 “It is mandatory that the physician should control over the information provided to the patient. [Recommendation 7] Rheumatologist, France

23	“The presence of non-healthcare personnel would open the door to dubious situations.” [Recommendation 7]	Rheumatologist, Italy
Lack of systematic PE		
24	“Not systematic” [Recommendation 2]	Occupational Therapist, Norway
25	“Very rare monitoring of patients with [IA]” [Recommendation 2]	Registered Nurse, Portugal
26	“The focus is on newly diagnosed patients, <i>there is no organised PE aside from ordinary doctor- and nurse visits</i> ” [Recommendation 2]	Rheumatologist, Sweden
27	“Patients come often spontaneously to PE after reading a poster, receiving a flyer etc... Not enough on doctor's initiative...[not] according to a defined agenda.” [Recommendation 2]	Pharmacist, France
28	“It's up to me to keep me updated about appropriate pedagogics” [Recommendation 8]	Nurse, Sweden
29	“I do not think we do [PE] according to the most up-to date research findings” [Recommendation 8].	Physiotherapist, Hungary
Lack of funding		
30	“The money for training costs is reduced year by year” [Recommendation 8].	Nurse, Finland
31	“Do not have the money” [Recommendation 8].	Physiotherapist, Hungary
Lack of patient participation in disease management		
32	“Patient with incorrect beliefs, patient thinking that only treatment is important, patient not wanting or unable to change their everyday life activities” [Recommendation 1].	Occupational Therapist, France
33	“The patient is not willing to come to the nurse's office. All patients do not understand that there is something to be done by the caregiver in treating the patient.” [Recommendation 1].	Nurse, Finland
34	I always offer it, and the rheumatologist always offers this, however, when the patient indicates that he or she does not want to be ready for this, it will not happen. We do not see all patients with inflammatory arthritis, so [PE] is not standard care [Recommendation 1].	Specialist Nurse, The Netherlands

1. Lack of time

The most cited barrier to the implementation of PE as part of standard care was a lack of time. Patient consultations were subject to competing demands (Q1) and health professionals found it difficult to tailor information (Q2). While it was good to meet the needs of patients this created additional work (Q3). Activities such as evaluation of PE were not always prioritised due to lack of time (Q4).

2. Lack of training

Many described a lack of knowledge and training (Q5-Q7), which prevented participants from offering self-management training or cognitive behavioural therapy (Q8, Q10). Whether

patients received PE varied, depending on the experience of the provider (Q9). Similarly, identifying and training patients to deliver PE could be challenging (Q11).

3. Lack of staff

Often, there were not enough staff with specialised expertise, such as trained nurses, to provide PE to patients. Many indicated that there was a lack of psychological support such as cognitive behavioural therapy (CBT) or stress management interventions to support self-management in patients with IA (Q12).

4. Lack of assessment tools

The lack of a reliable evaluation tool was cited as a significant barrier. Some had evaluation activities in place for the effect of PE, but no tool to evaluate whether PE had been successfully achieved (Q13). Staff had difficulties remembering to evaluate PE, and a lack of structure made it difficult to check up with patients (Q14-Q15).

5. Limited resources

Respondents cited a lack of resources to provide patients with PE during the course of their disease. Examples of resources mentioned were both patient-facing (lack on internet access) and staff-facing (online support, telephone and institutional internet restrictions (Q16 - Q18).

6. Concerns about online PE

Some respondents raised their reservations about delivering PE online as written information could be misunderstood. They preferred face-to-face interactions for PE delivery (Q19-Q21).

7. Concerns about patient-delivered PE

Others felt that health professionals should be the only providers of PE. Some had concerns that non-healthcare providers (such as patients) could risk providing misinformation (Q22-23).

8. Lack of systematic PE

Health professionals described some PE as lacking in organisation. Monitoring of PE was unusual, and patients were not always referred sufficiently (Q24-Q27). The need for participants to attend training was not always recognised or seen as a priority. Many had to

rely on “self-study” instead (Q28). As a result, their practice may not be as informed as it could be (Q29).

9. Lack of funding

A lack of funding was cited as a barrier in terms of employing enough staff (to evaluate PE) as well as for supporting training (Q30-32).

10. Lack of patient participation in disease management

Lack of patient involvement was cited as a barrier as patients had to be open and willing to engage with PE. Some respondents described patients as ‘uninterested’ when PE was offered (Q32 - Q34).

Facilitators for implementation

Table 5 presents the 6 categories and selected quotes that illustrate facilitators of implementation of the recommendations.

Table 4: Quotes to illustrate the respective category supporting facilitators to implementation.

Quote number (Q)	Category /Illustrative quotes	Quoted by
	Tailoring PE	
35	<i>“Some [are] more in need of information than others and are more “dependent” on information to move forward”</i> [Recommendation 1].	Occupational Therapist, Norway
36	<i>“Informed... on their disease(s) and treatment(s) and options”</i> [Recommendation 1].	Rheumatologist, Belgium
37	<i>“Life’s situations are changeable, which the teaching should be targeted for”</i> [Recommendation 1].	Authorised Nurse, Denmark
38	<i>“Therapy compliance, self-management and treatment objectives”</i> [Recommendation 1].	Nurse, The Netherlands
39	<i>“PE must...always be customized to the patients’ needs and resources and limitations. The feasibility for the different platforms for the patient education must always be considered.”</i> [Recommendation 4]	Occupational Therapist, Sweden
40	<i>“We have psychologist, group therapy... nurses and physiotherapists trained in pain and trained in drug education.”</i> [Recommendation 5].	Rheumatologist, France
41	<i>“Common basis for all patients and a personalized part, 50/50”</i> [Recommendation 3]	Rheumatologist, Belgium
42	<i>“General instructions ... After that, individual instructions will be given”</i> [Recommendation 3]	Physiotherapist, Finland

	Using group education	
43	<i>"Group interaction and experience sharing can be very enriching"</i> [Recommendation 3]	Nurse, France
	Linking patient education with diagnosis and treatments	
44	<i>"We provide education at diagnosis, at the start of pharmacological and non pharmacological interventions and periodically depending on individual patient needs. Sometimes limited clinic time can act as a barrier, however, I believe, as a department, we do strive to give good quality education via a multi-disciplinary approach."</i> [Recommendation 2]	Registered Nurse, UK
45	<i>"Life's situations are changeable, which the teaching should be targeted for"</i> [Recommendation 2].	Authorised Nurse, Denmark
46	<i>"Regularly organised education programs (by and for patients)"</i> [Recommendation 1].	Rheumatologist, The Netherlands
47	<i>"Patient education is ... the basis for standard treatment"...I want to think of patient education like "soil ploughing" for standard treatment to "grow" or develop."</i> [Recommendation 1].	Physiotherapist, Japan
	Maintaining face-to-face PE delivery and inviting feedback	
48	<i>"Asking the patient verbally ... not by means of questionnaires"</i> [Recommendation 6].	Rheumatologist, Belgium
49	<i>"[This method] makes it possible to check whether the information is understood, the other forms do not"</i> [Recommendation 4]	Nurse, The Netherlands
	Accessing multidisciplinary teams and patient organisations	
50	<i>"Patients are being asked to take care of [PE] especially if we are moving towards general health education that does not require very specialized knowledge"</i> [Recommendation 7]	Rheumatologist, France
51	<i>"More awareness about avenues for patients to get trained in PE should be created"</i> [Recommendation 7]	Educationist, India
52	<i>"The patient organizations are important players and should have a more eminent role, both for the patients but also for education of the professionals"</i> [Recommendation 7]	Rheumatologist, Sweden
	Accessing training from different providers	
53	<i>"For me, it is the same as for the patients: competencies need to be maintained over time"</i> [Recommendation 8]	Rheumatologist, France
54	<i>"I had a training course with the support of private funding (pharma companies)"</i> [Recommendation 8]	Nurse, France
55	<i>"Specific training is ...provided by the physiotherapy association"</i> [Recommendation 8]	Physiotherapist, Belgium

1. Tailoring PE

Respondents cited tailoring PE to individual patients' needs as important (Q35, Table 5).

Providing one-to-one PE enables patients to ask questions, and gain information (Q36).

The need for flexibility in patient access to PE was emphasised (Q37). Offering PE when required supported patient independence (Q38). Others described adapting PE with brochures and education materials tailored to patients' needs (Q39). The need to support each patient to manage their mental and physical health was recognised (Q40). Others suggested providing standardised PE as a baseline, and offer extra elements that could be personalised and tailored to individual patients according to need (Q41, Q42).

2. Using group education

Some respondents described how they used a combination of group education alongside one-to-one (Q43) as patients could learn from, and support each other in a group setting.

3. Linking PE with diagnosis, treatment and multidisciplinary care

Many agreed that PE should be scheduled regularly (Q44). PE was often offered at the start of drug interventions, with annual review clinics cited as an excellent opportunity for education. The need for flexibility in patient access to PE was emphasised (Q45). Successful PE included regularly organised programmes (Q46). PE was cited as fundamental to increasing patient knowledge and understanding (Q47).

4. Maintaining face-to-face PE delivery and inviting feedback

Benefits of face-to-face PE were acknowledged. In addition to allowing tailoring PE and patients to learn from one another in group setting, face to face delivery facilitated PE evaluation by inviting feedback and checking whether the information is understood (Q48, Q49). To facilitate evaluation participants also suggested sending out evaluation forms, planning follow-up sessions and providing telephone support as needed.

5. Accessing multidisciplinary teams and patient organisations to deliver PE

Ability of patients to provide PE was acknowledged together with training opportunities (Q50-Q51). Patient organisations were identified as important players in providing PE and also in training patients as PE providers (Q52).

6. Accessing training from different providers

Participants acknowledged the importance of obtaining and maintaining knowledge and skills (Q53) and accessed training from a variety of sources including private and professional organisations (Q54, Q55).

Mixed methods results

The mixed-methods analysis revealed similarities in barriers and facilitators for implementation across the recommendations. For example, lack of time, lack of training was seen in 6/8 recommendations. In the suggested facilitators, tailoring PE was suggested in 5/8 recommendations (Table 6).

Table 5: Similarities in the barriers and facilitators to implementation by recommendation.

Barriers

	1. Lack of time	2. Lack of training	3. Lack of staff	4. Lack of assessment tools	5. Limited resources	6. Concerns about online PE	7. Concerns about patient-delivered PE	8. Lack of systematic PE	9. Lack of funding	10. Lack of patient participation in disease management
Recommendation 1	●	●	●					●		●
Recommendation 2	●	●	●		●			●		
Recommendation 3	●	●	●		●					
Recommendation 4	●		●		●	●			●	
Recommendation 5		●	●							
Recommendation 6	●			●				●	●	
Recommendation 7		●	●		●		●			
Recommendation 8	●	●						●	●	

Facilitators

	1. Tailoring PE	2. Using group PE	3. Linking PE with diagnosis, treatment and multi-disciplinary care	4. Maintaining face-to-face PE delivery and inviting feedback	5. Accessing multi-disciplinary teams and patient organisations to deliver PE	6. Accessing training from different providers	

Recommendation 1	●		●				
Recommendation 2	●		●				
Recommendation 3	●	●					
Recommendation 4	●	●		●			
Recommendation 5	●				●		
Recommendation 6				●			
Recommendation 7					●	●	
Recommendation 8						●	

Legends: The dots indicate how the barriers and facilitators relate to the recommendations.

Discussion

This study disseminated the recommendations for PE in IA and assessed their acceptability and barrier and facilitators for implementation across 23 countries. This substantial project achieved good dissemination of the recommendations; providing a total of 20 translations of the recommendations. The responses (including textual data) suggest an expansive awareness and engagement with the recommendations, and identifies issues of implementation across the countries.

The findings suggested a very high level of agreement with all recommendations (median 10), but the self-reported application in clinical practice was rated consistently lower (median scores between 6 and 8). This difference illustrates the commonly known gap between knowledge or agreeing with the evidence and application in practice, the latter requiring efforts to address individual, organisational and societal barriers to change.⁷⁻¹⁰

The common barriers to implementation were lack of time, lack of training and inadequate staff. This agrees with literature which suggests that work pressure, lack of time, and perceived lack of training are the common reasons why clinicians find it hard to apply recommendations into clinical practice.^{30 31} While those three factors interact with each other, efforts directed toward (cross-disciplinary) training of professionals and patients to deliver PE may help improve the perceived lack of time and staff. However, it is important to highlight that training also needs funding, time and effort, thus needing a change at all (individual professional, institution and policy) levels. Training of PE providers was also identified as an education agenda of the current recommendations.⁴

The mixed-methods approach has made it possible for the qualitative findings to explain the quantitative results. For example, recommendation 6 (the requirement for outcomes of PE to be evaluated) was rated the lowest in applicability to practice and the corresponding qualitative findings explain the possible reasons for this such as perceived lack of time, lack of structure and oversight about the effectiveness of PE, including a lack of a reliable assessment tool. This meant that evaluation of PE was often overlooked.

There were notable differences in responses across countries, in terms of applicability of the recommendations. For example, participants from Ireland, Denmark, Hong Kong, Japan and Portugal indicated that the technology and Internet access provided by hospitals might not be sufficient to offer supplementary online PE support. A previous UK study found while internet-based video consultations in outpatient care were found to be safe, time-efficient and convenient, there was strong resistance from hospital Information/technology departments, as videoconferencing was anticipated to require costly updates and increased technical support.³² In light of changes to service delivery as a result of COVID-19, hospitals across the world have quickly adopted virtual (video or phone-based) appointments in response to restrictions in face-to-face interactions, therefore showing potential for faster development in the delivery of PE in virtual environment. Evaluation of how departments adopt these changes will inevitably inform future training and developments in the delivery of PE.

Interestingly, some responses on recommendation 7 from France, Italy, Portugal and Japan expressed concerns that there would not be enough trained patients to deliver PE, or patients might give inaccurate information and who would be responsible for this information. A study with General Practitioners in the UK³³ highlighted similar tensions between supporting increased patient self-management and professional responsibility. It took confidence from both the doctor and the patient to ensure that control and responsibility were shared.³³ Developing targeted training for patients who deliver PE may help address some of the above concerns and this could be championed by patient and professional organisations.

The main strength of this study is its extensive reach across 23 countries including those with less established rheumatology multidisciplinary team care or focus on PE. Collaborating with leaders of professional organisations in these countries facilitated the dissemination. Second, the response from such a number of diverse health professionals suggests multidisciplinary engagement with the recommendations. Third, efforts were made to gain textual responses which ensured rich data on specific barriers, or facilitators for implementing each recommendation. The mixed-methods design has provided a unique opportunity to obtain a deeper understanding of the issues needed to address for a successful implementation of

these recommendations. Last, our data can be used to develop practitioner-informed quantitative scales to measure the level of applicability of future recommendations.

This study has four key limitations. First, there is limitation of external validity, as the voluntary nature of the study meant that the responses were not uniform across countries, with some countries having higher response rates than others. Therefore, the results can only represent the views of respondents to our survey, and may not be representative of all professionals in rheumatology across all 23 countries. Further work will be required to assess country-specific barriers and facilitators, especially in the regions that were under-represented in this study. Second, data were collected between July and September 2019, a typical summer vacation time in some countries, which could have affected the response rates. Third, some participants started the online survey but did not complete. Our analysis focused on completed data only as our survey platform (Qualtrics®) captures all the data and it is impossible to tell if participants with incomplete data went ahead to complete the survey using a different device. All this suggests that a degree of selection bias cannot be excluded. Last, this study identified the barriers and facilitators to implementation at the individual practitioners and institutional (micro and meso) levels. Further study of the wider policy context (macro) level in each country will be required to ensure sustainable implementation and improvements in the quality patient education.⁶⁻⁹

In conclusion, the EULAR recommendations for PE in IA have been disseminated across 23 countries and a range of barriers and facilitators to their implementation have been identified. A high level of agreement with all the recommendations is encouraging although addressing the barriers at the individual, organisation and societal level will be important to ensure successful application to practice. Some barriers to application are amenable to change, such as addressing training needs of providers and developing evaluation tools for PE. Further targeted implementation activities may be required in different countries, taking account of their healthcare systems to promote integration of the recommendations in practice and thus improve the outcome of patients with IA.

Authors Contribution

Sarah Bennett, coordinated the study, collected the data, undertook the analysis, drafted the manuscript and revised it for intellectual content. Mwidimi Ndosu is the Principal Investigator, designed the study, led the grant application, oversaw the project and interpretation of the results and revised the study report for intellectual content. Heidi Zangi codesigned the study, contributed to the grant application, interpretation of the results and revised it for intellectual content. Astrid van Tubergen is the Methodologist for this project, co-designed the study, contributed to the grant application, interpretation of the results and revised it for intellectual content. Ingrid Larsson, provided methodological advice, contributed to adaptation of the questionnaire in Sweden, interpreting the data and reviewing the manuscript for intellectual content. The following co-investigators were involved in the dual-panel adaptation of the questionnaire from English into their respective countries, disseminating the survey, interpreting the results, and revising the manuscript for intellectual content: Carina Boström, Sweden; Andrea Domján, Hungary; Jette Primdahl, Denmark; Patricia Minnock, Ireland; Tiziana Nava, Italy; Ricardo J. O. Ferreira, Portugal; Mie Fusama, Japan; Kristien van der Elst, Belgium; Maria del Carmen Herrero Manso, Spain; Roopa Rawat, India; Catherine Beauvais Valeyrie, France; Mariela Geneva-Popova, Bulgaria; Kristen Hoeper, Germany; Yvonne van Eijk-Hustings, Netherlands; Marja Leena Kukkurainen, Finland; Matylda Sierakowska, Poland; Michaela Stoffer, Austria; Gladys Kwok, Hong Kong; Heidi Zangi, Norway.

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Competing interests

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Ethics approval: This study involves human participants and 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. The ethics approval was obtained from Faculty of Health and Applied Sciences Research Ethics Committee, University of the West of England, Bristol, UK (UWE REC REF No: HAS.18.11.066).

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Figure captions and legends:

Figure 1: Parallel convergent mixed-methods model