EXTENDED REPORT

EULAR recommendations for patient education for people with inflammatory arthritis

Heidi A Zangi,[1] Mwidimi Ndosi,[2] Jo Adams,[3] Lena Andersen,[4] Christina Bode,[5] Carina Boström,[6] Yvonne van Eijk-Hustings,[7,8] Laure Gossec,[9,10] Jana Korandová,[11] Gabriel Mendes,[12] Karin Niedermann,[13] Jette Primdahl,[14,15,16] Michaela Stoffer,[17] Marieke Voshaar,[18] Astrid van Tubergen[19]

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For numbered affiliations see end of article.

Correspondence to Dr Heidi A Zangi, National Advisory Unit on Rehabilitation in Rheumatology, Department of rheumatology, Diakonhjemmet Hospital, PO Box 23 Vinderen, Oslo 0319, Norway; heidi.zangi@diakonsyk.no

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ABSTRACT

Objectives The task force aimed to: (1) develop evidence-based recommendations for patient education (PE) for people with inflammatory arthritis, (2) identify the need for further research on PE and (3) determine health professionals' educational needs in order to provide evidence-based PE.

Methods A multidisciplinary task force, representing 10 European countries, formulated a definition for PE and 10 research questions that guided a systematic literature review (SLR). The results from the SLR were discussed and used as a basis for developing the recommendations, a research agenda and an educational agenda. The recommendations were categorised according to level and strength of evidence graded from A (highest) to D (lowest). Task force members rated their agreement with each recommendation from 0 (total disagreement) to 10 (total agreement).

Results Based on the SLR and expert opinions, eight recommendations were developed, four with strength A evidence. The recommendations addressed when and by whom PE should be offered, modes and methods of delivery, theoretical framework, outcomes and evaluation. A high level of agreement was achieved for all recommendations (mean range 9.4–9.8). The task force proposed a research agenda and an educational agenda.

Conclusions The eight evidence-based and expert opinion-based recommendations for PE for people with inflammatory arthritis are intended to provide a core framework for the delivery of PE and training for health professionals in delivering PE across Europe.

INTRODUCTION

Patient education (PE) is recommended as an integral part in established recommendations for the management of early arthritis and ankylosing spondylitis (AS).[1,2] PE comprises all educational activities provided for patients, including aspects of therapeutic education, health education and health promotion.[3] Previous systematic reviews on various PE interventions in patients with rheumatoid arthritis (RA) documented significant short-term improvements in knowledge, coping behaviour, pain, disability and depression, but long-term effects were inconsistent.[4–7]

During the last decades there has been an ongoing development within healthcare, moving away from the view of health professionals (HPs) as the only experts and providers of knowledge and patients as passive recipients towards a more collaborative approach. Patients have been recognised as active agents in managing their illness and own healthcare.[8] The principle of 'shared decision making' allowing patients and their providers to make healthcare decisions together, based on the best scientific evidence available, as well as the patient's values and preferences, is increasingly accepted.[9] The primary goal of PE is no longer only knowledge transfer and disease control, but also to enable patients to manage their illness, adjust to their condition and maintain quality of life.[10,11]

Moreover, PE has been influenced by scientific developments and changes in society. Biomedical advancements, new pharmacological treatment options, and better knowledge about the risk for developing comorbidities require new approaches to communicate with patients in a timely and meaningful way.[12,13] In several countries, larger healthcare teams with more specialised HPs have been established to meet the complexity of the healthcare needs of patients with rheumatic diseases.[14,15] Furthermore, the development of e-health and the use of mobile telehealth platforms have introduced new possibilities for communication and delivery of information, which are increasingly applied in PE. Finally, the increase in immigration and cultural diversity in many European countries is challenging for planning and facilitating effective PE for all patients.[8]

Informal discussions among multidisciplinary HPs at the European League Against Rheumatism (EULAR) annual congress in 2012 and succeeding email correspondences revealed that great variety exists in the content and modes of delivery of PE across European countries. In some countries PE is still limited to providing knowledge in order to improve patients' adherence to treatment. Additionally, there seems to be a large variation in HPs' involvement in PE.[15] To what extent different HPs participate in PE is likely to depend on their competency, availability and education, as well as the organisation of the healthcare system.[16] Based on these initial discussions, an EULAR task force was convened with the following objectives: (1) to develop a set of recommendations for PE for people with inflammatory arthritis (IA) (2) to identify the need for further research and (3) to define

HPs' educational needs for providing evidence-based PE. The recommendations would allow standardisation and improvement of PE for people with IA across Europe. The target groups for the recommendations are rheumatology HPs including rheumatologists, patients with IA, policy makers and patient and professional organisations.

METHODS

The EULAR standardised operation procedures for the elaboration, evaluation, dissemination and implementation of recommendations[17] were followed.

The task force

The multidisciplinary task force comprised 15 experts including three patients, five nurses, two occupational therapists (OTs), two physiotherapists (PTs), a psychologist and two rheumatologists/epidemiologists with clinical experience and/or academic knowledge in the field of PE. They represented ten European countries (Austria, Czech Republic, Denmark, France, the Netherlands, Norway, Portugal, Sweden, Switzerland and UK). People who had taken part in the initial discussions, but were not included in the task force, were invited to participate in a 'consultation group'. This group comprised 20 HPs, such as OTs, PTs, nurses and rheumatologists, but no patients were included.

Before the first task force meeting in 2013 one of the members was tasked with reviewing the literature of existing PE definitions. An overview was presented and thoroughly discussed during the meeting. Common elements in the definitions were identified and the following definition was formulated, based on consensus among the task force members: "PE is a planned interactive learning process designed to support and enable people to manage their life with IA and optimise their health and well-being." This interactive learning process includes a wide range of educational activities, such as provision of knowledge, written material, e-health, self-management programmes (SMPs), cognitive behavioural therapy (CBT), mindfulness, stress management, individual consultations with HPs, sharing experiences among patients, motivational discussions, exercise counselling, lifestyle change interventions and self-help courses. Moreover, the task force agreed that the recommendations should be based on the principle of shared decision making.[9] Following this consensus process, the task force formulated 10 research questions to guide the systematic literature review (SLR) (see online supplementary file 1).

Systematic literature review

An extensive systematic literature search in Medline, Embase, PsycINFO, Cochrane Library and CINAHL from January 2003 up to September 2013 of publications in English, German, French or Spanish describing any kind of PE activities, was conducted (details provided in online supplementary file 2). No limitations regarding study type or research design was applied. The inclusion criteria were IA, confined to RA, AS and psoriatic arthritis (PsA) and adults (age ≥18 years). All abstracts were independently read by two reviewers, and by a third reviewer in case of disagreement. The papers of the included abstracts were reviewed in full-text. Papers were excluded if they did not include any formal PE intervention (as defined above) or did not address the patient perspective on PE. The task force members were asked to review the final list of included papers and could add studies that were not captured by the SLR.

Developing the recommendations

The results of the SLR were presented and discussed during the second task force meeting in 2014 and eight recommendations were developed. The strength of each recommendation was based on the categories of evidence defined by the EULAR standardised operation procedures, graded from A (highest) to D (lowest)[17] (see online supplementary file 3). The recommendations were emailed to each task force member for final independent voting and approval. The level of agreement was recorded on a 0–10 point scale (0=no agreement at all; 10=full agreement, table 1). In addition to the task force, the consultation group was invited to independently rate their level of agreement with each recommendation to obtain an indication of the agreement among people who are supposed to use the recommendations in clinical practice.

RESULTS

Figure 1 shows the flow chart of the SLR. In total, 115 publications were included, comprising 11 systematic reviews/meta-analyses, 36 randomised controlled trials (RCTs) (reported in 44 papers), 7 controlled clinical trials (CCTs), 9 pre-post-test studies, 23 cross-sectional surveys and 21 qualitative studies. The majority of patients in the included studies was female (58–100%), diagnosed with RA (82%) and had relatively long disease duration (mean 6–16 years). Ten studies included patients with AS and/or PsA and five studies included only patients with early disease duration (<2 years).

Recommendations

Two overarching principles and eight evidence-based and expert-opinion based recommendations were developed, four of which achieved strength A. A high level of agreement was achieved for all recommendations; mean range 9.4–9.8 in the task force and 8.2–9.2 in the consultation group (table 1).

Recommendation 1: PE as an integral part of standard care

The task force agreed that PE should be an integral part of standard care for people with IA. Category I evidence showed that various individual and group educational interventions had beneficial short-term effects in patients with RA.[3] [7] Three RCTs[18–20] and one CCT[21] showed that individual or group PE enhanced adherence with pharmacological treatment and knowledge of medication side effects. Moreover, one meta-analysis and four RCTs concluded that group educational programmes significantly improved disease knowledge, coping skills and physical and psychological health status.[22–25] Several RCTs[26–31] and CCTs[32] [33] demonstrated that PE supplementary to physical therapy or joint protection exercises had positive influence on physical function and activity, and reduced pain. Furthermore, consistent evidence showed that CBT and stress management programmes improved psychological health after intervention and at follow-up (4–18 months).[34–42]

Finally, there was consensus in the task force that PE would increase patients' involvement in their disease management, but this was only supported by one cross-sectional study,[43] in which high levels of perceived knowledge of the disease were positively associated with involvement in healthcare.

Recommendation 2: PE throughout the course of the disease

The task force emphasised the importance of offering timely PE. Individual patients' educational needs may vary, related to their disease stage and to fluctuations in their physical and

Table 1 Recommendations for patient education for people with inflammatory arthritis

Overarching principles
1. 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
2. Communication and shared decision making between people with inflammatory arthritis and their healthcare professionals are essential for effective patient education

Recommendations	Category of evidence	Strength of recommendation	Level of agreement mean (SD) Task force	Consultation group
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	1A–2B	A–C	9.6 (0.8)	9.2 (1.8)
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	3–4	C–D	9.6 (0.7)	9.1 (1.8)
3. The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis	1B	A	9.8 (0.6)	9.1 (2.3)
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	1A–B	A	9.5 (0.7)	8.9 (2.4)
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	1A–B	A	9.5 (0.9)	8.8 (2.2)
6. The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme	4	D	9.6 (0.8)	8.3 (1.8)
7. Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team	3	C	9.5 (0.8)	8.4 (2.0)
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	3–4	C–D	9.4 (0.8)	8.2 (1.6)

psychological health condition. Educational needs may be identified by the patients themselves as well as by HPs and should be regularly monitored. Educational and support needs may be most salient at times when patients are more likely to be experiencing change or pressure, such as in the early stages of their disease, when new pharmacological treatment is initiated and when their everyday life is affected.[44,45] Differing educational needs may also appear when patients experience flares, worsening or comorbidities, and when the disease interferes with daily activities, life events and family roles.[46–48]

Recommendation 3: tailored and needs-based PE

The task force stated that PE should be tailored to the individual patient's needs. Several RCTs supported that individual counselling with a competent HP, either in one-by-one consultations or in combination with group sessions had beneficial health effects.[19,29,37,49–51] Cross-sectional and qualitative studies exploring patients' needs and expectations described a wide range of educational needs, such as knowledge and management of the disease, knowledge of side effects and risk factors, non-pharmacological treatment, pain control and self-help methods, as well as activity regulation, physical exercises and behaviour change.[44,47,52–60] In general, patients' levels of knowledge about the disease were low to moderate and patients expressed they had received insufficient information.[47,61,62] Patients with IA wanted to be recognised as more than their disease, to be enabled to use their own resources and to re-engage in previously abandoned activities.[55,57,63–65] Moreover, PE should include discussion on emotional issues and support from HPs in coping with emotional distress.[64–66]

Recommendation 4: modes of delivery of PE

The SLR showed that PE is provided in various modes; individual face-to-face-meetings,[19,20,23,26,30,37,42,67–73] groups,[24,25,28,34–36,38–41,74–79] a combination of the two[27,29,49,50,80] and online.[81–83] Category I evidence was found for individual counselling. Interactive individual education by rheumatologists improved adherence to medication regimen.[19,20] Individual counselling by OTs and PTs led to increased use of self-management strategies, such as hand exercises, joint protection and activity regulation.[26,71,72] Individual counselling by psychologists reduced depression, anxiety and total use of healthcare.[37,42,69] Individual counselling supplementary to physical exercise improved health status, adherence with exercise programmes and physical activity recommendations.[29,50,51,80,84] Individual counselling by nurses, supplementary to group education improved disease knowledge, well-being, pain and self-management behaviours.[27,49]

Various group interventions focusing on active coping with emotional distress and daily life stressors improved functional and emotional health status, patients' coping strategies[28,31,34–36,38–41,74,76] and perceived social support.[85] Finally, two RCTs[80,82] and one pre-post-test study[83] demonstrated that interactive online programmes contributed to improvement in health status, pain, physical limitations and levels of physical activity.

Recommendation 5: theoretical framework and evidence for PE

The task force agreed that PE should be based on a theoretical framework and be evidence-based. Four categories of PE interventions were described in the included studies: educational programmes (32 studies),[18–21,23–33,49,50,70,71,73,76–78,80,83,86–91] SMP (7 studies),[74,75,82,92–95] CBT (9 studies)[34–39,42,68,96] and stress management programmes (6 studies).[34,40,41,69,97,98] The educational programmes mainly aimed to enhance knowledge, adherence to treatment, performance of physical function, joint protection and healthy lifestyle. The methods used were primarily didactic, instructions, counselling and practical exercises. These programmes were typically based on clinical experience and knowledge and were not underpinned by a theoretical framework. In contrast, the SMP and CBT interventions were based on

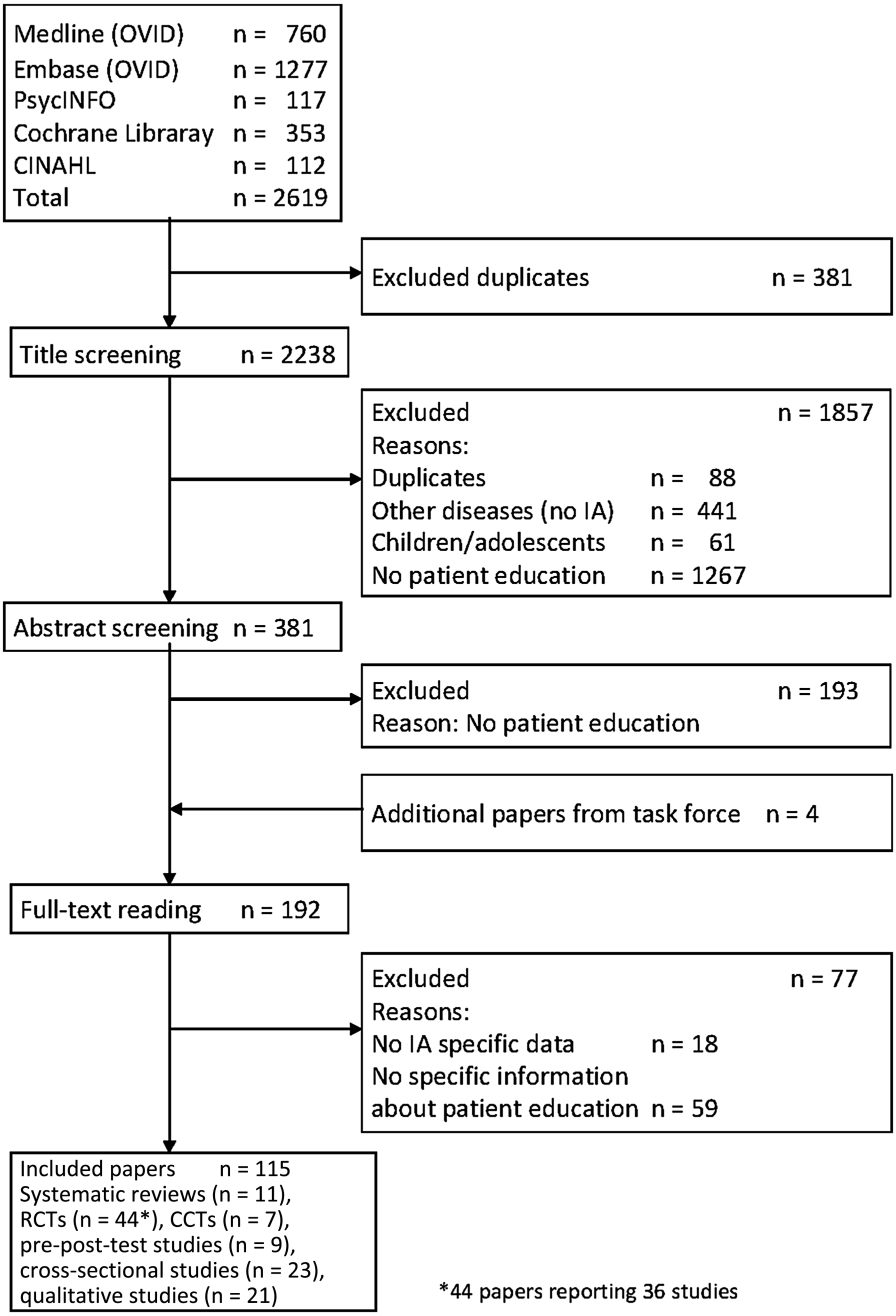

Figure 1 Flow chart of the systematic literature review (SLR). CCT, controlled clinical trial; IA, inflammatory arthritis; RCT, randomised controlled trial.

frameworks derived from social cognitive theory[99] and cognitive behavioural theories.[100] In addition to provision of knowledge, these programmes were targeted at improving coping and psychological health status, facilitating behaviour change and adoption of health promoting behaviours. Participants were actively involved in goal-setting, problem-solving, group discussions and in preparing action plans. Furthermore, CBT interventions focussed on cognitive restructuring of beliefs.[100 101] The stress management programmes were mainly adapted from ancient Buddhist practices including yoga and breathing exercises, training of mindfulness meditation and acceptance.[102] The main aims of these programmes were to enhance well-being by improving stress management skills, alleviate emotional distress,[34 40 41 69] and promote a constructive relationship with positive and negative emotions.[102]

Recent systematic reviews have concluded that various group programmes (SMP, CBT and stress management) demonstrated small, but positive impact on self-reported physical activity levels, pain, disability, depressive symptoms, anxiety[22 103] and fatigue[104] at follow-up (4–18 months).

Recommendation 6: outcomes of PE

The task force agreed that in order to provide evidence-based PE, the various PE programmes need to be evaluated. To ensure valid evaluation the outcomes must reflect the programme objectives. The SLR revealed a great variation in evaluation criteria and use of outcome measures in the included studies. The specific educational objectives of the programmes were not always clear, making it difficult to judge whether the reported outcomes were matched to the educational objectives. For example, some studies reported the disease activity score with 28 joint counts (DAS-28), which are unlikely to be directly influenced by PE.[25 74 75]

Many of the PE programmes can be characterised as complex interventions, which intend to influence various aspects of the disease impact on life. It is challenging to find the outcome measure(s) that best capture these aspects and the outcome measures need to be carefully reviewed before evaluation studies are conducted.

Recommendation 7: competency in delivery of PE

The task force agreed that PE should be delivered by competent HPs and patients. The majority of the studies included, comprised PE interventions delivered by HPs within a healthcare context. However, PE may also be delivered by trained patients and in community settings.[92] Sixteen of the PE programmes were delivered by multidisciplinary HPs,[25,28,31,33,38,41,76–78,88–90,93,95,96,98] and 10 programmes were delivered by two different professionals, that is, OT and PT (3 studies),[26,30,50] nurse and rheumatologist (1 study),[21] OT and rheumatologist (1 study),[24] psychologist and nurse (1 study),[39] psychologist and OT (1 study),[36] pharmacist and nurse (1 study),[91] and nutritionist and OT (1 study).[79] Trained patients were involved in, or delivered two SMPs,[75,82] two online programmes[82,83] and one patient-led interactive workshop.[89] The remaining interventions were provided by one HP.[18–20,23,27,29,34,35,37,40,42,49,67–71,74,80,86,87,97] Which professionals should be involved, and how many, will depend on the aim, the topic and the context for the education. For example, physical exercise programmes provided by PTs may be combined with group educational sessions by other HPs, as appropriate[50,76] and some CBT programmes are provided by psychologists only.[34,37,42,67,68] Other programmes are independent of profession, but require specific training in methods, such as CBT techniques[36,38] and mindfulness.[40,41]

Recommendation 8: training competency for delivering PE

The task force agreed that teaching competence is necessary alongside clinical expertise to deliver high quality PE. Only a few studies reported what skills and training providers of PE need. Qualitative studies exploring patients' perspectives on PE indicated requirements for knowledge and skills by educators. For example, patients wanted to receive clear explanation about test results, medication and self-management techniques.[105] HPs should have the ability to provide emotional support[59,64] and to focus on acceptance of the patient's illness and its consequences.[106] Moreover, patients experienced that the use of creative learning methods, such as guided discovery, metaphors, poetry, music and visual materials in groups facilitated their emotional and behavioural change processes[57,65] and they wanted to have the possibility to exchange knowledge and experiences with other patients.[56,65] HPs, on the other hand, perceived that their delivery of knowledge and advice was influenced by their own attitudes and their abilities to interact with the patients.[107]

Research and educational agendas

Box 1 presents the research agenda proposed by the task force, based on areas with only weak or limited evidence for PE. The two overarching principles (see table 1) should be applied when addressing each of these topics.

Box 2 presents the educational agenda, which encourages the development of training programmes to enhance and support HPs' opportunities to improve their educational competencies.

Box 1 Research agenda for patient education (PE)

- To evaluate, harmonise and/or further develop existing patient education outcomes, such as educational needs, goal attainment, etc, and if needed develop new outcomes, such as outcomes reflecting health literacy, health promotion, activity pacing, patients' needs, etc
- To develop guidelines on how to conduct and report studies in patient education
- To investigate which modes of delivery are best suited to meet which objectives of patient education, including the time point (in the disease trajectory) at which patient education is likely to produce maximum effects
- To study PE in other rheumatic conditions than rheumatoid arthritis
- To investigate educational needs in specific subgroups (ie men, patients with minority ethnic backgrounds and patients with lower literacy levels)
- To develop and evaluate PE for significant others (partners, spouses, family and carers)
- To conduct economic evaluations of PE interventions (using PE-sensitive outcomes and effects in relation to healthcare resource use).
- To investigate the long-term effects and cost-effectiveness of PE
- To gain insight into the working principles of PE—that is, the mechanism by which PE produces its effects; whether directly, or by modifying or mediating its effects through other outcomes
- To investigate how to best provide online/e-health PE programmes
- To investigate cross-cultural acceptability of PE programmes/modes of delivery across Europe
- To define training requirements for PE provider

DISCUSSION

Eight recommendations for PE for people with IA were developed based on a SLR and expert opinions. The recommendations were formulated to be practical and feasible for providing evidence-based PE across all European countries. The strength of evidence supporting the recommendations varies and a research agenda is proposed for areas with lack of evidence. A high level of expert agreement was achieved for all recommendations. An educational agenda was also formulated to support the development of competencies of HPs providing PE.

The included studies showed a trend towards greater inclusion of behavioural, cognitive and emotional aspects in the PE programmes during the last decade. This trend is reflected in the PE definition that the task force formulated as an overarching principle, stating that PE should enable people to manage their *life with IA* and *optimise their health and well-being* rather than be limited to the disease. Some previous PE definitions have stated that PE is designed to improve patients' health behaviours. However, the patient representatives in the task force felt that

Box 2 Educational agenda for providers of patient education (PE)

1. Increase health professionals' knowledge on the process and practicalities of delivering and evaluating effective PE
2. Regular updating of PE skills/training is necessary to ensure provision of state of the art effective PE
3. Develop training programmes for health professionals within the European League Against Rheumatism (EULAR)

this was rather patronising and therefore it was not included in the consensus definition. The definition emphasises that PE is an *interactive learning process*, not a one-way delivery of knowledge. Substantial evidence has shown that interactive counselling, either in combination with group sessions or in one-by-one consultations with a competent HP, has beneficial effects in terms of adherence to treatment regimens, behavioural change, use of self-management strategies and well-being.[19 37 49 72 108] In order to ensure the application of shared decision-making, HPs need to develop their communication skills, and patient representatives should be involved in all phases of designing, implementing and evaluating the interventions.

Surprisingly, the SLR included only a limited number of studies on online PE programmes, but these showed promising results on health status and levels of physical activity.[82 84] In our rapidly growing digital world, one may foresee that face-to-face-meetings will be more frequently replaced by online programmes, the impact of which will need evaluation.

A limitation to the generalisability of the recommendations is that the majority of patients who participated in the included studies was female, diagnosed with RA and had relatively long disease duration. The task force recognises that at present there is limited evidence for patients with AS and PsA. It is therefore suggested that the recommendations should be regarded as “points to consider” for this population. Furthermore, little is known about special educational needs for men, patients with minority ethnic backgrounds and patients with lower literacy levels, which needs attention in future research. A great diversity in the type of educational programmes was observed, varying from interventions with a primary focus on increasing knowledge and improving performance, to more therapeutic oriented interventions aiming at behavioural change and improving mental health status.[3 5 103] Also, a wide range of outcome measures was used and most studies reported multiple outcomes, limiting comparison of the effectiveness of the programmes. To be able to evaluate the programmes more stringently and to compare relevant interventions, the task force recommends harmonisation of outcomes, tailored to the programme goals and content and to the patients needs. Furthermore, the task force has proposed that existing outcomes should be evaluated, and new outcome measures should be developed, if needed. The task force was not aware of any unpublished studies with negative results. Nevertheless, due to publication bias some positive effects of PE may potentially have been overestimated.

A methodological limitation of the SLR is that the task force decided to include all types of studies that could give insight in PE, resulting in a great methodological variety. Consequently, it was not possible to use one formal quality scoring system. Four recommendations were of strength A and the remaining four were of strengths C to D, that is, based on qualitative and cross-sectional studies or expert opinions. However, the qualitative studies may provide valuable insight into the individual patient’s needs and expectations, which should be regarded as the core of PE programmes.

The use of a multidisciplinary task force, including patients, is one of the strengths of this study. Ideally, the task force should also have included a dietician and a pharmacist as the educational activities comprise lifestyle changes and adherence to medication. However, we believe that these issues have been addressed by the comprehensive SLR. Another strength is the high level of agreement with the recommendations among the members of the task force and the consultation group. However, the level of agreement will have to be further evaluated in a wider population of patients and HPs with interest and expertise in this field during the dissemination and evaluation of the recommendations.

The task force agreed on a research agenda to gain further insight in the qualitative and quantitative aspects of PE, including working mechanisms of PE, developing and harmonising PE outcomes, economic evaluations and cross-cultural acceptability of PE programmes across European countries. The educational agenda states that providers of PE need regular updates of their skills in order to deliver effective PE. The task force proposes that training of educational skills should be integrated in EULAR courses for HPs and rheumatologists.

Effective dissemination, implementation and evaluation of these recommendations across European countries demand a clear implementation strategy. Barriers and facilitators for implementation of PE as an integral part of standard care for all people with IA must be assessed within each country and appropriate support and education must be provided. This strategy will need further support from EULAR.

In conclusion, eight evidence-based and expert-opinion-based recommendations for PE for people with IA were developed. The dissemination and application of the recommendations should allow establishment of core standards for PE across Europe. Further evaluation will be necessary to ensure relevance and effective application.

Author affiliations

[1]Department of Rheumatology, National Advisory Unit on Rehabilitation in Rheumatology, Diakonhjemmet Hospital, Oslo, Norway
[2]School of Healthcare, University of Leeds, Leeds, UK and Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, Leeds, UK
[3]Centre for Innovation and Leadership in Health Faculty of Health Sciences University of Southampton Highfield, Southampton, UK
[4]Nyborg, Denmark
[5]Department of Psychology, University of Twente, Health & Technology, Enschede, The Netherlands
[6]Division of physiotherapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden
[7]Department of Patient & Care/ Department of Rheumatology, Maastricht University Medical Center, Maastricht, The Netherlands
[8]CAPHRI, School for Public Health and Primary Care, University of Maastricht, Maastricht, The Netherlands
[9]Sorbonne Universités, Institut Pierre Louis d’Epidémiologie et de Santé Publique, Paris, France
[10] Department of rheumatology, AP-HP, Pitié Salpêtrière Hospital, Paris, France
[11]Institute of Rheumatology, Prague, Czech Republic
[12]Department of National Team, Portuguese Cycling Federation, Lisbon, Portugal
[13]Institute of Physiotherapy, School of Health Professions, Zurich University of Applied Sciences, Winterthur, Switzerland
[14]Institute for Regional Health Research, University of Southern Denmark, Odense, Denmark
[15]Hospital of Southern Jutland, Aabenraa, Denmark
[16]King Christian X’s Hospital for Rheumatic Diseases, Graasten, Denmark
[17]Division of Rheumatology, Department of Medicine 3, Medical University of Vienna, Vienna, Austria
[18]Department of Psychology, Health and Technology, University of Twente, Enschede, The Netherlands
[19]Department of Medicine, Division of Rheumatology, Maastricht University Medical Center, Maastricht, The Netherlands

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Contributors HAZ was the research fellow for the project, undertaking the SLR; MN and AvT were the project convenors, AvT being the epidemiologist directing the SLR. All authors have contributed substantially by participating in the development of the recommendations, revising the manuscript critically for important intellectual content and approved the final version for publication.

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Online supplementary file 1 Definition of patient education and research questions for the systematic literature review

Definition of patient education:

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

Research questions:

1. How is PE organized in published studies from 2003 – to date? (availability, accessibility, frequency, duration, by whom)
2. What content is used in PE programs? (If any, which theories and models are used?)
3. What are the learning goals for PE described in the literature?
4. Which techniques are used in PE? (i.e. self-help courses, books, e-health, SMP, CBT, mindfulness, goal management, stress management, individual consultations with HPs, peer contacts, role models, motivational (interview) discussions, exercise therapy, lifestyle changes)
5. Which modes and methods of delivery are used for PE? (Individual, group, e-health, face-to-face education, etc.)
6. Who (professionals, lay persons, organisations) deliver what type of PE (see question 1) and what skills or qualifications (in the subjects and pedagogics) do they have?
7. Which patients have participated in PE studies? (demographics, disease characteristics, health literacy)
8. Which outcomes are reported for evaluation of PE? (including cost-effectiveness)
9. What are the effects of PE on knowledge, skills, attitudes and coping abilities?
10. What are the patients' needs/expectations/preferences for PE?

PE = patient education, SMP = self management program, CBT = cognitive behavioural therapy, HP = health professional

Online supplementary file 2: Systematic literature search

The systematic literature search was conducted by the research fellow (HAZ) and a medical librarian, guided by an epidemiologist (AvT). The following databases were searched: Ovid Medline, EMBASE, Cochrane Library, PsycInfo and CINAHL. Relevant keywords, free text words and terms were selected and defined for a search strategy combining patient education (PE) AND patients with inflammatory arthritis (IA). The search was limited to studies on adults (age ≥ 18), published between January 2003 and September 2013 (date of search), written in English, German, French or Spanish. No limitations regarding geographical area was applied

Systematic reviews and meta-analyses

A separate search was conducted for systematic reviews and meta-analyses in the databases Ovid Medline and EMBASE. The same search terms were applied as well as the limitations regarding languages and years of publication. However, the studies were not limited to adults because relevant studies may be indexed without age-specifications.

Medline search strategy. (The same strategy, with an adjustment to the correct thesaurus, was used in searching the other databases)

1. exp Behavior Therapy/
2. self management.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
3. exp Health Behavior/
4. cognitive behavioural therapy.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
5. behaviour change.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
6. exp Self Efficacy/
7. exp Relaxation Therapy/
8. Stress, Psychological/
9. stress management.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
10. exp "Power (Psychology)"/
11. empowerment.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
12. exp Counseling/
13. exp Exercise Therapy/

14. exp Health Promotion/
15. exp Information Dissemination/
16. exp Pamphlets/
17. exp Patient Education as Topic/
18. exp Patient Participation/
19. exp Patient-Centered Care/
20. exp Professional-Patient Relations/
21. exp Self Care/
22. exp Teaching/
23. exp Teaching Materials/
24. (educat: adj (patient: or consumer: or health:)).tw.
25. (information adj (patient: or consumer: or health:)).tw.
26. (advice adj (patient: or consumer: or health:)).tw.
27. consumer health information.tw.
28. (shared decisionmaking or informed choice).tw.
29. (patient adj3 education).ti,ab.
30. (patient adj3 information).ti,ab.
31. (education adj2 program$).ti,ab.
32. (leaflet$ or booklet$ or pamphlet$ or poster$).ti,ab.
33. ((written or printed or oral) adj3 information).ti,ab.
34. academic detailing.ti,ab.
35. training program$.ti,ab.
36. (professional patient relation: or physician patient relation: or doctor patient relation: or nurse patient relation: or physical therapist patient relation: or physiotherapist patient relation: or occupational therapist patient relation).tw.
37. (professional patient interaction: or physician patient interaction: or nurse interaction: or physiotherapist patient interaction: or physical therapist patient interaction: or occupational therapist patient interaction).tw.
38. (patient physician communication: or patient doctor communication: or patient nurse communication: or patient physical therapist communication: or patient physiotherapist communication: or patient occupational therapist communication).tw.
39. (patient professional relation: or patient physician relation: or patient doctor relation: or patient nurse relation: or patient physical therapist relation: or patient physiotherapist relation: or patient occupational therapist relation).tw.
40. (patient professional interaction: or patient physician interaction: or patient doctor interaction: or patient nurse interaction: or patient physical therapist interaction: or patient physiotherapist interaction: patient occupational therapist interaction).tw.
41. or/1-40

42. exp arthritis, rheumatoid/
43. ((rheumatoid or reumatoid or revmatoid or rheumatic or reumatic or revmatic or rheumat$ or reumat$ or revmarthrit$) adj3 (arthrit$ or artrit$ or diseas$ or condition$ or nodule$)).tw.
44. (felty$ adj2 syndrome).tw.
45. (caplan$ adj2 syndrome).tw.
46. still$ disease.tw.
47. bechterew$ disease.tw.
48. exp Spondylarthropathies/
49. (ankylos$ or spondyl$).tw.
50. (bekhterev$ or bechterew$).tw.
51. (Marie adj struempell$).tw.
52. exp Arthritis, Psoriatic/
53. (psoria$ adj (arthriti$ or arthropath$)).tw.
54. ((arthriti$ or arthropath$) adj psoria$).tw.
55. undifferentiated oligoarthritis.tw.
56. (inflamm$ adj5 (arthrit$ or arthrop$)).tw.
57. or/42-56
58. 41 and 57
59. exp clinical trial/ or comparative study/ or consensus development conference/ or evaluation studies/ or meta-analysis/ or multicenter study/ or twin study/ or validation studies/ or exp epidemiologic study characteristics as topic/
60. study.ti.
61. trial.ti.
62. 59 or 60 or 61
63. 58 and 62
64. limit 63 to "review articles"
65. 63 not 64
66. limit 65 to (french or english or german or spanish)
67. limit 66 to last 10 years
68. limit 67 to ("adult (19 to 44 years)" or "young adult and adult (19-24 and 19-44)" or "middle age (45 to 64 years)" or "middle aged (45 plus years)" or "all aged (65 and over)"

Online supplementary file 3: Categories of evidence and Strength of recommendations

Categories of evidence

Category	**Evidence**
1A	From meta-analysis of randomized controlled trials
1B	From at least one randomised controlled trial
2A	From at least one controlled study without randomisation
2B	From at least one type of quasi-experimental study
3	From descriptive studies, such as comparative studies, correlation studies, or case control studies
4	From expert committee reports or opinions and/or clinical experience of respected authorities

Source: Dougados et al. EULAR standardised operating procedures for the elaboration, evaluation, dissemination, and implementation of recommendations endorsed by the EULAR standing committees. Ann. Rheum. Dis. 2004;63(9):1173

Strength of recommendations

Strength	**Directly based on**
A	Category 1 evidence
B	Category 2 evidence or extrapolated recommendations from Category 1 evidence
C	Category 3 evidence or extrapolated recommendations from Category 1 or 2 evidence
D	Category 4 evidence or extrapolated recommendations from Category 2 or 3 evidence

Source: Dougados et al. EULAR standardised operating procedures for the elaboration, evaluation, dissemination, and implementation of recommendations endorsed by the EULAR standing committees. Ann. Rheum. Dis. 2004;63(9):1174

Online supplementary file 4: List of papers included from the systematic literature review

Systematic reviews

Albano MG, Giraudet-Le Quintrec JS, et al. Characteristics and development of therapeutic patient education in rheumatoid arthritis: analysis of the 2003-2008 literature *Joint Bone Spine* 2010;**77**:405-10*.*

Badamgarav E, Croft JD, Hohlbauch A, et al. Effects of disease management programs on functional status of patients with rheumatoid arthritis. *Arthritis Rheum* 2003;**49**:377-87.

Christie A, Jamtvedt G, Dahm KT, et al. Effectiveness of nonpharmacological and nonsurgical interventions for patients with rheumatoid arthritis: an overview of systematic reviews. *Phys Ther* 2007;**87**:1697-715.

Cramp F, Berry J, Gardiner M, et al. Health behaviour change interventions for the promotion of physical activity in rheumatoid arthritis: a systematic review. *Musculoskeletal Care* 2013;**11**:238-247.

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Niedermann K, Fransen J, Knols R, et al. Gap between short- and long-term effects of patient education in rheumatoid arthritis patients: a systematic review. *Arthritis Rheum* 2004;**51**:388-98.

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Savelkoul M, de Witte L, Post M. Stimulating active coping in patients with rheumatic diseases: A systematic review of controlled group intervention studies. *Patient Educ Couns* 2003;**50**:133-43.

Warsi A, LaValley MP, Wang PS, et al. Arthritis self-management education programs: A meta-analysis of the effect on pain and disability. *Arthritis Rheum* 2003;**48**:2207-13.

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EULAR RECOMMENDATIONS

Education for people with inflammatory arthritis

INTRODUCTION

Patient education is a planned interactive learning process designed to support and enable people with inflammatory arthritis to manage their life and optimise their health. Patient education activities include giving help and advice on healthy living and how to stay well. Receiving patient education helps people to manage their own illness and to have better health and well-being.

EULAR recommendations give advice to doctors and patients about the best way to treat and manage diseases. EULAR has published in 2015 recommendations on patient education for people with inflammatory arthritis. Inflammatory arthritis is a group of conditions where the joints become stiff and painful due to the immune system attacking the body’s own tissues and causing inflammation. The main conditions include rheumatoid arthritis, spondyloarthritis/ankylosing spondylitis and psoriatic arthritis.

Doctors, nurses, health professionals and patients worked together to develop these recommendations. Including patients in the team ensured that the patient point of view was integrated in the recommendations. The authors looked especially at the evidence on what type of patient education is provided, who provides it and how it is provided. They also looked at the evidence on how well patient education works.

WHAT DO WE ALREADY KNOW?

The concept of patient education has changed over the years. In the past, patient education meant that doctors provided information and patients were passive recipients of this information. Nowadays, patient education means more than just giving information, and patients are encouraged to be more involved in decisions about their care. Patient education can improve people’s knowledge and ability to cope with their disease.

WHAT DO THE RECOMMENDATIONS SAY?

The recommendations fall under two main principles. The first is that patient education should be interactive and designed to support people in managing their disease and to improve their health and quality of life. The second is that communication and shared decision-making are essential. This means that patients should have a say in their treatment and management of their disease and be encouraged to take decisions with their doctor and other health professionals.

Overall, there are eight recommendations. Each recommendation is based on available scientific evidence or expert opinion. The more stars a recommendation has the stronger the evidence is and the more important it is that you and your doctor follow it.

One star (*) means it is a weak recommendation with limited evidence.
Two stars (**) means it is a weak recommendation with some evidence.
Three stars (***) means it is a strong recommendation with some evidence.
Four stars (****) means it is a strong recommendation with a lot of evidence.

- **Patient education should be a part of normal care for people with inflammatory arthritis.****
  This will make sure that you understand your disease and that you are involved in your care and decisions about your treatment. Informed patients are more likely to be able to manage it.

- **Patient education should be offered more than once.****
  You should get patient education when you are first diagnosed, and again each time you change your medicine or if your health condition or personal needs change.

- **The content of patient education should be designed according to the needs for each person.******
  The patient education you get should be tailored to your personal needs and expectations. Some people will want to know more about certain aspects of their disease than others.

- **Patient education might be given in a variety of different ways.******
  Some people might respond best to one-to-one education, while others might learn best in a group or online, and further support. Phone calls or written materials may also be needed.

- **Patient education should be based on theory and evidence.******
  Some patient education may be supported by scientific evidence or educational theories. Others may be based on ancient practices such as yoga or meditation. The aims of each are to improve well-being.

- **Patient education should be evaluated.***
  Patient education programmes should be evaluated. When the evaluation is done, the outcomes used must reflect the programme objectives.

- **Patient education should be delivered by health professionals e.g. doctors, nurses, psychologists, physiotherapists and/or trained patients as part of a team.****
  It is important that the people giving patient education are trained in proper techniques.

- **People providing patient education should be trained and maintain their knowledge and skills.****
  It is important that the people giving patient education are trained and have the right knowledge and skills in order to provide high-quality education.

Overall, the recommendations say that it is important for you and your doctor or health professional to work together to manage your disease and get the best possible results from treatment. If you have an inflammatory arthritis these recommendations will give you some guidance on what to expect from providers of patient education.

If you have any questions or concerns about your disease or your medication, you should speak to your doctor or a health professional involved in your care.

This is the patient version of the EULAR recommendations for patient education in people with inflammatory arthritis. The original publication can be downloaded from the EULAR website: www.eular.org.

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