Patient Education Survey -HPs, Version 2, 19th Dec 2018

Project title: Dissemination and assessing implementation of the EULAR recommendations for patient education for people with inflammatory arthritis across Europe

Dear colleague,

We invite you to take part in our research about EULAR recommendations.

The European League Against Rheumatism (EULAR) is a collaboration of Rheumatology scientific societies, Rheumatology Health Professional organisations and patient organisations. Its aim is to improve the quality of care for patients with rheumatic diseases across Europe.

Eight EULAR recommendations for patient education for people with inflammatory arthritis (rheumatoid arthritis, ankylosing spondylitis or psoriatic arthritis) were developed in 2015 by a Task Force of health professionals in rheumatology (nurses, physiotherapists, occupational therapists and psychologists), rheumatologists and patients across Europe.¹

What is the purpose of the study?
Differences exist in the provision of patient education across Europe. If you are involved in caring for people with inflammatory arthritis, we would like to know your views about the recommendations. We particularly want to know if you:

1. agree or disagree with each of the recommendations. If you disagree with any, why is this?
2. provide the patient education as advocated in the recommendations. If you do not, why is this?

Why have I been invited to take part?
We are inviting all professionals involved in the care of people with inflammatory arthritis. Participating in this study is voluntary. Completing and submitting the survey implies that you have read this information sheet, you are over 18 and consent to take part. It will take between 10 and 15 minutes to complete the survey.

What am I expected to do if I decide to take part?
If you decide to complete:

a. First, please answer the questions about yourself and where you work.
b. For each recommendation: choose a number indicating how much you agree or disagree with it.
   For example, 0 means you do not agree at all and 10 means you completely agree with the recommendation. If you disagree, or partly disagree, with the recommendation, you may want to write down your reasons in the space provided.
c. Also, for each recommendation: choose a number indicating the level or degree at which you currently provide that type of patient education. If you do not, or only partly, provide that type of patient education, you may want to write down the reasons or barriers to application.

Will my taking part in this study be kept confidential?
Yes. Your questionnaire will be marked with a number, not your name. All information which is collected about you during the research will be kept strictly confidential and will not be disclosed outside of the project team.

Do I have to take part?
No, taking part is voluntary. If you decide not to take part, you do not have to give a reason.
Can I withdraw from the study?
If you decide to withdraw from the study, you may exit the survey at any point before submitting the survey. If you wish, you may delete your responses by backtracking through the survey before the exit point. **Please note: withdrawal of responses is not possible once the survey has been submitted.**

What will happen to the results of the research study?
The results of this research will likely be used in scientific journal articles, poster presentations and oral presentations to publicise the results and better improve care. No identifiable information will be shared.

Who is organising, funding and reviewing the research?
The University of the West of England (UWE) Bristol is the official sponsor of this research. Funding is provided by the European League Against Rheumatism (EULAR). This study has been approved by the Faculty Research Ethics Committee (FREC) at the University of the West of England Bristol.

Thank you for your time.

Dr Mwidimi Ndosi (Principal Investigator)
University of the West of England
Email: Mwidimi.Ndosi[at]UWE.ac.uk

Section 1: Questions about you

1. What is your sex? Male___ Female ___
2. What is your profession? □ Registered Nurse □ Registered Physiotherapist □ Occupational Therapist □ Psychologist □ Pharmacist □ Rheumatologist □ Nutritionist □ Other profession (please specify) _______
3. What year were you born? ______
4. In which country are you currently working? (Option to select from the dropdown list)
5. Please tick your highest degree/academic qualification (tick one only)
   □ Certificate □ Diploma □ Bachelors □ Masters □ PhD □ other (please specify) ______
6. How many months/years of clinical experience do you have within rheumatology care? ______
7. What type of setting do you work in? (you can give more than 1 answer)
   □ inpatient □ outpatient □ community/primary care □ other (please specify) ______

Section 2: Questions on the recommendations:

Overarching principles

- Patient education is a planned interactive learning process designed to support and enable people to manage their life with inflammatory arthritis and optimise their health and well-being
- Communication and shared decision making between people with inflammatory arthritis and their healthcare professionals are essential for effective patient education

8. You can write here any comments you would like to make regarding the overarching principles

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

1A. Do you agree with this recommendation? (Please indicate the level of your agreement)

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I do not agree at all

I agree completely

1B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

1C. Do you provide patient education as it is advocated in this recommendation?

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No, not at all

Yes, entirely

1D. If you do not or cannot entirely provide patient education as specified in this recommendation in your daily practice, please write down the reasons or barriers.
**Recommendation 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.

2A. Do you agree with this recommendation? (Please indicate the level of your agreement)

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I do not agree at all

I agree completely

2B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

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2C. Do you provide patient education as advocated in this recommendation?

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No, not at all

Yes, entirely

2D. If you do not or cannot (entirely) provide patient education as advocated in this recommendation in your daily practice, please write down the reasons or barriers.

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**Recommendation 3.** The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis.

3A. Do you agree with this recommendation? (Please indicate the level of your agreement)

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I do not agree at all

I agree completely

3B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

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3C. Do you provide tailored, needs-based patient education as recommended above?

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No, not at all

Yes, entirely

3D. If you do not or cannot (entirely) provide tailored, needs-based patient education, please write down the reasons or barriers to this.

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**Recommendation 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

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I do not agree at all

I agree completely

4B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

4C. Do you provide patient education as advocated in this recommendation?

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No, not at all

Yes, entirely

4D. If you do not or cannot (entirely) provide patient education as advocated in this recommendation, please write down the reasons or barriers.

**Recommendation 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

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I agree completely

5B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

5C. Do you provide patient education as advocated in this recommendation?

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No, not at all

Yes, entirely

5D. If you do not or cannot (entirely) provide patient education that meets this recommendation, please write down the reasons or barriers.
**Recommendation 6.** The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme.

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I do not agree at all | I agree completely

6B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

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No, not at all | Yes, entirely

6D. If you do not evaluate the effectiveness of patient education as recommended, please write down the reasons or barriers to this.

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**Recommendation 7.** Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team.

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I do not agree at all | I agree completely

7B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

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7D. If you do not or cannot (entirely) provide patient education as advocated in this recommendation, please write down the reasons or barriers to this.
**Recommendation 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

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I do not agree at all

I agree completely

8B. If you have one or more reasons for (partly or completely) disagreeing with this recommendation, please write down your reasons in the space provided.

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8C. Do you undertake continuous education or training as advocated in this recommendation?

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No, not at all

Yes, entirely

8D. If you have not undertaken continuous education to maintain your knowledge and skills, please write down the reasons or barriers to this.

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Thank you for your time and your valuable contribution which will contribute to improvement of patient education in inflammatory arthritis across Europe.

\End.