

New patient empowerment and educational initiatives unveiled at EULAR 2014

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Five different presentations at the European League Against Rheumatism Annual Congress (EULAR 2014) have introduced new patient empowerment and educational initiatives, which are predicted to bring significant benefits to the many thousands of patients worldwide who suffer from a rheumatic disease.

These initiatives include:

- A new model of patient care involving self-monitoring and patient initiated follow-up¹
- An online learning resource to prepare patients and carers to actively engage in research, guideline development, advocacy and media activities²
- A new patient decision aid to better inform and involve patients in treatment choices³
- Video guides providing advice on living with a rheumatic disease⁴
- Patient Group support for patients wanting to become involved in guideline development and political committees⁵

Self-monitoring and patient-initiated follow-up reduces costs of treating patients with rheumatoid or [psoriatic arthritis](#) with no deterioration in outcomes

Following a brief period of training, patients with rheumatoid arthritis (RA) and psoriatic arthritis (PsA) receiving methotrexate were able to

understand and interpret their blood test results. Using this information, along with reports of their symptoms and side effects, they were then able to initiate appropriate treatment reviews with their rheumatology nurse.¹ At the end of the trial period participants in the intervention group had just over half the number of appointments with their rheumatology nurse specialist than those receiving usual care (p0.05).

According to lead author Ms. Hayley McBain of the School of Health Sciences, City University London, "this [new model](#) of care offers a viable alternative for established RA and PsA patients receiving disease-modifying anti-rheumatic drug (DMARD) therapy. It also has a positive impact in terms of reducing healthcare utilisation, with no detrimental effect on health outcomes," Ms. McBain added.

Online programme proven to successfully empower European patients with chronic medical conditions

Evaluation of a new free online course has shown that it is meeting its aim to enable and empower patients to advocate for themselves and others to shape future healthcare policy. The European Patient Ambassador Programme (EPAP) aims to provide patients with self-advocacy skills over six modules* to help them shape future healthcare policy. Out of 251 patients with chronic diseases, including arthritis/rheumatism, who had completed the EPAP, 80% felt they understood how decisions about healthcare were made, and 87% felt confident to interact with professionals, policy makers and the media.²

Ms Monica Fletcher, Chair of the European Lung Foundation (ELF) who developed the programme, explains why this new programme is needed, "as more people live longer with chronic conditions, such as arthritis and rheumatism, it is essential that they become involved in healthcare to help improve the patient's experience, identify patient priorities, reduce burden on services, and advance research."

ELF, who developed EPAP (<http://www.EPAPonline.eu>) with the help of patients, patient organisations, and professionals with expertise in each area, plan to work with partners across Europe to ensure this free online course is accessible to everyone. Introductory videos will be developed in all European languages, and full translations will be carried out wherever there is in-country interest.

New patient decision aid meets need to better inform and involve patients in treatment choices

Patients using a new Patient Decision Aid (PtDA) designed to educate them about DMARDs perceived that the PtDA was helpful in the decision-making process, allowing them to take a more active role in decision-making, and felt the final choice of medication to be more consistent with their personal values.³

According to Ms. Ingrid Nota of the Department of Psychology, Health and Technology, University of Twente, Netherlands, "our PtDA can be a valuable aid in improving patient participation in medical decision-making about anti-rheumatic drugs. We developed this new tool in response to research among Dutch arthritis patients, which showed a need for quality improvement in information provision about treatments, and a patient desire to be more involved in decision-making."

Arthritis patients who were facing the decision to initiate a (different) DMARD were invited to participate in the study. In the first year, patients received a questionnaire four weeks after consulting the rheumatologist (control group, n=158). In the second year, patients were referred to use the PtDA and also received a questionnaire 4 weeks after consulting the rheumatologist (intervention group, n=123).

The PtDA was used by 57% of respondents in the intervention group. Users rated the PtDA as useful, easy to use and easy to understand. Of

the patients who had used the tool, most stated that the PtDA contained new information (70%), that they learned a lot from it (71%), that it helped them to get insight into their preferences, worries, doubts and questions (70%), that it helped them discuss things with their rheumatologist (60%), and to make a decision about their medication (70%).

Compared to the control group, patients in the intervention group perceived a more active role in decision-making ($p=0.01$) and perceived the final choice to be more consistent with their personal values ($p=0.02$). No effects were found on satisfaction with the decision process, trust in physician, beliefs about medication, or adherence to medication. This project was financially supported by the Dutch Arthritis Association.

Video guides launched to help rheumatic disease patients live a better life

The Institute of Rheumatology in Warsaw, Poland has created a series of video-guides for people with rheumatic diseases and their relatives to provide simple tips and advice on how to make life with one of these conditions easier.⁴

Using the World Arthritis Day 2013 slogan "Living better, ageing well", these educational videos consist of five films: Kitchen of the rheumatic person, Bathroom for the rheumatic person, rheumatic person out shopping, rheumatic person on the stairs and rheumatic person in the car.

Speaking today at EULAR 2014, Ms. Jolanta Grygielska from the Department of Epidemiology And Health Promotion of Rheumatic Diseases at the Institute said, "minimising disability is the most important objective for people living with rheumatic diseases.

Adaptation of the rheumatic patient's environment to suit their needs and abilities is very important to reduce the impact on their quality of life.

"Video-guides are an easy and useful tool for health promotion, a good way to communicate with people with rheumatic disease, and to help them cope with the problems of everyday life," Ms. Grygielska explained.

The videos are available on YouTube and through links on the website of the Institute, on the websites of rheumatic disease patient organisations, and on the website maintained by Institute for Polish [patients](http://www.dzienreumatyzmu.pl) <http://www.dzienreumatyzmu.pl>. A second series is now in production, with the first video in this new series, launched last month, focusing on the rheumatic person travelling and addressing the challenge of travelling by city bus with sticks, cane and in a wheelchair.

German Rheumatology Patient Group supports patients' involvement in guideline development and political committees

Patient representatives with rheumatic diseases are actively taking part in guideline development and sitting on different political committees, helped by support from the patient organisation German League Against Rheumatism, the Deutsche Rheuma-Liga.⁵

Dr. Cornelia Sander, representing the Deutsche Rheuma-Liga based in Bonn, Germany said "we have set up a process to support and guide motivated patient representatives who want to bring the patient perspective to the table, and influence the health care system in favour of the patient. When they sit on healthcare related political committees, they will have to face professionals from the health care system and insurance companies," Dr. Sander explained.

In order to support those interested in working as a patient representative, or those already playing this role, the Deutsche Rheuma-Liga offers a 'work description' along with everything a patient representative would need to know, introductory workshops, ongoing research support and, where possible, provides a staff member to accompany new representatives to their first meeting.

"Despite the success of this initiative, we still need to find new ways to recruit younger people with rheumatic diseases as patient representatives, who may have less time to become involved in volunteer work," Dr. Sander concluded.

More information: Abstract Numbers: OP0086-HPR; OP0141; OP0299-HPR; OP0021-PARE; OP0121-PARE

Notes:

1 McBain H, Shipley M, Olaleye A, et al. A self-monitoring and patient-initiated follow-up service for patients with rheumatoid or psoriatic arthritis: a randomized controlled trial. EULAR 2014; Paris: Abstract OP0086-HPR

2 Masefield S. Development and evaluation of an online course on key skills in influencing healthcare. EULAR 2014; Paris: Abstract OP0141

3 Nota I, Drossaert C, Taal E, van de Laar M. The evaluation of a patient decision aid for anti-rheumatic drugs. EULAR 2014; Paris: Abstract OP0299-HPR

4 Grygielska J, Samel-Kowalik P, Komolka J, Raciborski F. YouTube video guides for people with rheumatic diseases. EULAR 2014; Paris: Abstract OP0121-PARE

5 Sander C. Patients become political – how to support patients' involvement in guideline work groups and the joint federal committee of physicians and health insurance companies (G-BA) EULAR 2014; Paris: Abstract OP0021-PARE

* 1 - being better informed; 2- improving public awareness; 3- enhancing treatment and care; 4- supporting research and development; 5- influencing health policy; 6- working with the media.

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