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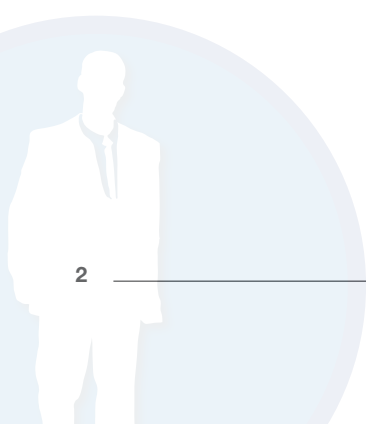
Patient Involvement in Research

A way to success



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Preface

Involving patients in research projects improves both the methodology and outcomes of the research, and offers invaluable additional insights. Contributions by patients to the design, implementation and evaluation of research leads to effectiveness, credibility, and often to more cost efficiency as well. It is essential to ensure that high quality research brings real benefits for patients and their daily lives.

Patient involvement can only be successful if patients are sufficiently prepared and supported to make a valuable contribution. To provide guidance to task force leaders and patient research partners, EULAR has developed recommendations for the inclusion of patient representatives in research: the 'EULAR Recommendations for the inclusion of patient representatives in scientific projects'. Furthermore, EULAR has supported the establishment of a PARE Network of 15 trained patient research partners, who have all been involved in numerous research projects after their training.

The involvement of patients in research should be an active and equal engagement between patients and researchers right from the start of the project. EULAR aims to ensure the effective involvement of patient partners in all the research projects that it is funding. Support for both patients and researchers is essential to optimise the research outcomes, and to find the best ways to involve patients.

'Patient Involvement in Research - A way to success' contains practical information for both parties. Using simple steps and advice, it shows how everyone involved can improve their collaboration. A set of reference cards is included in the package.

This collaborative approach is the only way to overcome barriers and fixed mind-sets. It will enhance the results of EULAR projects, and will lead to better study results because it is more realistic and is patient-centred. Most importantly, the results of this positive collaboration between patients and researchers will lead to improved quality of life for people with rheumatic and musculoskeletal diseases.

I should like to take this opportunity to thank the Task Force members for their excellent work and great initiative.

Marios Kouloumas

Vice President, EULAR,
representing People with Arthritis/Rheumatism
in Europe (PARE)

“These cards show the path that should be taken by patients and researchers alike. They emphasize the responsibility of the researcher to include patients from the very beginning, something that is not always done. They give good guidance to the patient, making it clear that their contribution is worthwhile. Patients are reminded to be open about their limitations and to recognize that they might not always be well enough to participate.”

Patient research partner





Introduction

Patient involvement in research is increasing. For many reasons patient representatives are engaging with researchers to improve methodology and research outcomes, to give credibility to the results and to acknowledge the fact that for ethical reasons patients should have a say in health care and health research when it is expected that decisions in these areas will have an impact on their daily life.

In the last decade patient involvement has been shown to be beneficial in different contexts of research¹⁻³. Also EULAR (European League Against Rheumatism) has recognized the pivotal role of patients in the development of recommendations and encourages task force leaders to include patient research partners in their projects. In particular, in the development of Patient Reported Outcomes, patients play a role in addition to that of study participants. They become collaborative partners in a process of co-production.

In 2009 EULAR initiated the development of recommendations for the inclusion of patient representatives and these have been published in “The Annals of the Rheumatic Diseases”⁴. They provide guidance for task force leaders and patient research partners setting up new partnerships and are included in reference card 2. EULAR, represented by the Standing Committee of People with Arthritis/ Rheumatism in Europe (PARE), also initiated the establishment of a network of fifteen trained patient research partners. Members of this network have been involved in many EULAR projects and in recent years reviewed grant applications for the EULAR call on Patient Reported Outcomes (2011) and on Pain (2012).

“An open dialogue requires that all participants are well informed and understand the issues at stake.”

Personal feedback from researchers as well as patients indicates that including the patient perspective in scientific projects is not easy. And although many people involved are convinced of the potential benefits of patient participation, they are still struggling with the question of ‘how to do it’. Patient involvement can only be successful if patients are sufficiently facilitated and supported to make a meaningful contribution⁵. Not only do patients need adequate support, but researchers also need help with practical tools and information about the conditions that make patients’ participation worthwhile. EULAR has recognized the fact that patient involvement in research is still a novelty and that its implementation needs appropriate stimuli, support and evaluation.

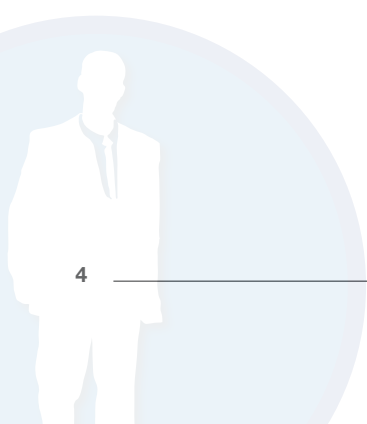
To this end EULAR has facilitated the Standing Committee of PARE to conduct an evaluation and implementation project to enhance the incorporation of the patient perspective in EULAR scientific initiatives.

The reference cards and this guide are the result of this project and we hope that they will find their way to all supporters of EULAR who have an interest in improving rheumatology research and the care for people with rheumatic and musculoskeletal conditions.

Nele Caeyers, project coordinator

Maarten de Wit, project convenor

June, 2013



The reference cards explained

Eular recommendations

Reference card 2

The “EULAR recommendations for the inclusion of patient representatives in scientific projects” have been developed by a group of seven patient experts and seven professionals. The process followed the EULAR standardized operational procedure for developing recommendations, including a literature search, two task force meetings and a *delphi method**. The recommendations were agreed on by EULAR in 2010 and were published in The Annals of the Rheumatic Diseases in 2011. The text of the recommendations is presented in the second reference card. The original manuscript can be found on the internet following this link:

<http://ard.bmj.com/content/70/5/722.full.pdf+html>

Definition of Patient Research Partner

- The task force who developed the recommendations has formulated a clear description of the term patient research partners: ‘Persons with a relevant disease who operate as active research team members on an equal basis with professional researchers, adding the benefit of their experiential knowledge to any phase of the project’. In this brochure Patient Research Partners will be mentioned as ‘Partners’ to ease the reading.

The EULAR PARE network of Patient Research Partners

To make sure the recommendations can be implemented at all levels, the EULAR Standing Committee of PARE has developed a network of competent, trained patient research partners. This network is used whenever there is a need for reviewers of scientific projects or the active participation of partners. Requests are received by the EULAR secretariat which then selects from the network the most suitable patient research partners for each specific project.

Researchers wishing to incorporate the patient perspective in their research project can ask for advice or an experienced Patient Research Partner from the EULAR PARE network. It will most certainly provide an extra perspective to the overall work.

For more information, please contact Florian Klett at the EULAR Secretariat at florian.klett@eular.org

“The cards contain valuable information and guidelines for all, experienced and newcomers. They will make a very useful tool for the future collaboration between researchers and patients.”

Patient research partner

* Words in italic are explained in the glossary





Preparation

Reference card 3

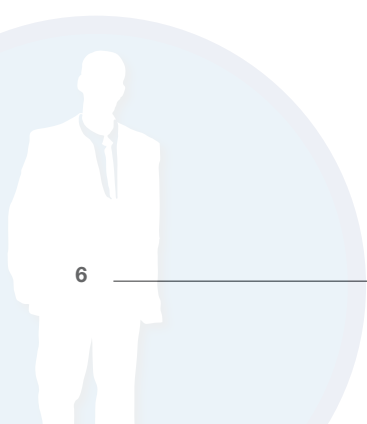
Starting a research project requires commitment, time and energy from all people involved. Patient participation adds extra workload to the already full agenda. But in time, these efforts will be rewarded. Ensuring all the people in the team are well prepared. This will save precious time and resources when things are underway.

For you as researcher or task force leader

- **Select** partners you consider to be best able to contribute to your project. Remember that 'the ideal patient' does not exist. The patient perspective is heterogeneous. For this reason you need at least **two partners**. The literature has provided much evidence that a minimum of two partners has several advantages. Selection can take place through the EULAR secretariat which keeps a record of all members of the EULAR network of patient research partners. They can help to identify the most appropriate partner for your project. You might also consider recruiting partners from your own department or your own country. Be aware of the **diversity** of people you can have on board. People from minority groups can provide valuable input that is often left out. Recruitment of partners from minority groups requires extra effort but is worthwhile to consider.
- If you have recruited new partners, be aware that their participation will be a **new experience** for them and they will need time to adjust to the team and to the jargon, culture and procedures. Allow patients to experience this learning curve. It will increase their motivation and the value of their input over time.
- Make sure your **expectations** are realistic and manageable. Often, the partner has a professional job outside this voluntary work. It is not always possible to get time off from work on weekdays for meetings. Discuss this issue before the project starts. Provide enough time for tasks which need to be done at home.
- Consider developing a **task description**. The partners need clear instructions about the purpose of the project and what is expected of them. This document can help to avoid misunderstandings in the future.
- Try to organise a **face-to-face introduction** with the partners an hour before a planned meeting. This will make all parties more confident and at ease, and provides opportunities to clarify uncertainties and to articulate and discuss mutual expectations.
- Pay attention to the **budget**. Having partners on board will incur additional costs for travel and accommodation. Partners cannot always rely on institutions' funds if needed. Sometimes partners need a personal assistant to accompany them.

“Partners need time to familiarize themselves with the research topic and to grow and become confident during the course of the project.”

Patient research partner



- Appointing a **contact person** or mentor for the partners will help them be better prepared for the first meeting. Make sure enough background information is available. The professionals in the team are experts in the field and familiar with the subject. Be aware the partners need more time and information to get acquainted with the subject and the goals of the project. The mentor should be available for any questions that might arise.
- When writing your project proposal, consider the items from the patient review form (reference card 7).

“I would have understood my role a lot earlier had I been given a set of these reference cards initially.”

Patient research partner

For you as patient research partner

- **Familiarise yourself** with the subject. Search and ask for additional information, make sure you understand what the project is about. Within this guide, you can find links to websites that contain a high standard of reference material.
- **Contact the task force leader** or appointed mentor. Make sure the expectations of both parties are clear.
- Try to **get in touch** with other partners in the project. You might want to set up a teleconference/Skype call before the start of the project to get to know each other and to discuss the project. Include the task force leader and/or mentor.
- Be clear about the time you can spend and the **workload** you can handle. If you have a day job, tell the task force leader whether or not you can take time off from work for meetings or teleconferences.
- Ask for **clarification** when things are unclear. The task force members should be able to explain in lay language what they mean.
- **Write down** any question or difficulty you have encountered when preparing for a meeting. Ask the mentor or task force leader to help you out with these issues before the actual meeting.
- Think creatively about potential events that could **educate** you in the area of this project. This might be a national symposium, a EULAR session or another type of training course that could be interesting for partners to attend. Discuss this with your mentor when budget is needed.





During Meetings

Reference card 4

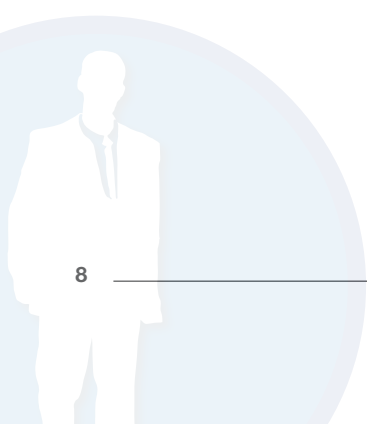
Having partners on board with a project, leads to a different way of meeting. Language has to be adapted to make sure all around the table understand each other. Mutual respect and the will to listen and learn from each other are crucial. Each person's contribution is valuable for the final result, a dialogue is the perfect way to get the best results.

For you as researcher

- Partners share their **own experiences** of their conditions and what they have heard from others. This can be different to what other patients go through. There is no such thing as 'the patient perspective', the partner cannot represent all patients with the studied illness. Look for multiple forms of patient participation to obtain representative data. The representativeness of the patient perspective is a team responsibility.
- Build up the **confidence** in the group. Make sure the partners feel at ease while sharing their, sometimes emotional, experiences. Give them enough opportunities and time to explain their point of view. Partners often have the feeling they cannot contribute enough to the discussions because they are not familiar with the way these meetings are organised or do not feel strong or secure enough to intervene. This can be avoided by repeatedly offering them a chance to ask questions or share their ideas.
- Offer the partners a seat somewhere **in the middle** of the group. By putting them at the end of the table or a little outside the group, you can discourage participation.
- Do something with the **input** given by the partners. Listening only is not enough. Create working points or extra research questions about the items they have put on the table. Add the issues to the final report.
- Shortly after the meeting, give **feedback** on the contribution. What was good? What could be even better?
- **Reflect regularly** on the quality of the collaboration. Are there learning points? Were expectations fulfilled on both sides? Use the opportunity to learn from each other for both to do better in the future.
- In the case of a **teleconference**, it is even more important to make sure the partners have time and the space to express their opinion. It is easy to overlook a person while on the telephone.
- Provide a **free line**, or reimburse the costs. Partners cannot use an institution's phone, they have to rely on a personal line. Costs for international calls can be high.

“I think smaller groups with a clear focus are very good to bring everybody's experience together.”

Task force leader



For you as a patient research partner

- **Speak up and share** your opinion. You were asked because of your experiences as a patient and to express your personal ideas and views on the matter: there are no 'rights' or 'wrongs', but do contribute with respect.
- Ask the members to give a **clarification** when something is unclear. They are experts in this field, so they might use terminology that is unfamiliar. There is no need to pretend you understand, if you do not.
- Be aware that your experiences might differ from those of other patients. Try to find a **good balance** between your own views and those of the larger group. They might be similar, but they might not.
- There is no such thing as *the* patient perspective. You might be asked 'how do patients look at this issue?'. However, it is not your responsibility to represent *the* patient perspective. Try to find appropriate methods with the entire group to **capture the heterogeneity** of the patient perspective. Patient participation should become an integral part of the project which requires patient involvement on different levels, for instance by the use of a survey, a Delphi method, interviews or focus group meetings, or a combination of methods.
- If there is a **disagreement** on an issue, make sure it is written down in the final report. You are supposed to be a co-author of the publication, if the result will be published. So if there are things in the paper you cannot agree with, it should be mentioned that it differs from the view of the patient research partner.
- If this is your first project you might feel not equal to all other members in terms of clinical or academic knowledge. You might even feel too inexperienced to be taken seriously. However, you are invited to participate because of your **experiential knowledge**. Your position and the value of your unique knowledge as a patient should be acknowledged. The presumed equality means that you are an equal member of the team.
- Sometimes when participating to such meetings you might feel intimidated or pressured, you might feel as if you are taking an exam and you might simply have a blockage. In this case you should not give up or feel ashamed. Use the coffee break to discuss potential feedback with someone you know. This might clarify whether your thoughts are relevant to bring in again.

“ Reality is we may ‘know’ what we should ideally be doing, but writing key points down as guidance such as these ensures both task force leader and patient partner to go the right direction when embarking on an initiative. ”

Task force leader



Debriefing

“If we’re ultimately going to instill a sense of confidence or trust it’s through a partnership and that means also educating one another.”

Task force leader

Reference card 5

Patient involvement is relatively new in the field. Both parties are likely to have doubts, uncertainties and reservations. It is most important to pause for a moment to share feedback on the collaboration. Have the expectations been met? Did this partnership go the way you thought it was going to go? Were there items you missed? Apart from looking back on the meeting, it is also crucial to stay in touch and keep each other informed of future steps.

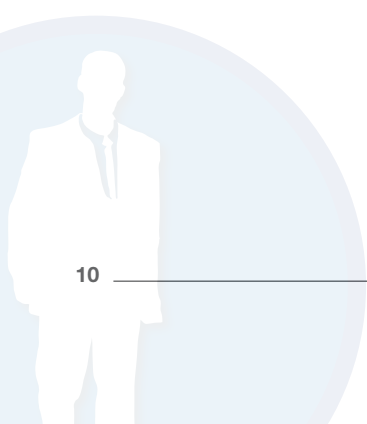
For you as researcher

- **Acknowledge the contribution** of patient research partners. They often miss feedback on their contribution and wonder: “Did I do my job well?”. Partners appreciate feedback on their input and may need reassurance. Let them know if their contribution was fruitful, and if not, what else could be done. This as a learning process for both parties.
- If issues that are important to patients cannot be addressed in your project, consider developing a research agenda. Patient items for which evidence is lacking might steer research initiatives in the future.
- Contact via email is fine, but **personal contact** either by telephone or face-to-face meeting can go into more detail and will give the partner a clearer view of his or her own input.
- Partners are not usually medically trained, which can make them feel insecure in a team of professionals. Constructive feedback will give them the opportunity to gain **confidence** towards future projects.
- It is perfectly possible and legitimate to acknowledge their contribution with co-authorship of the publication. The criteria for **co-authorship** are developed by the International Committee of Medical Journal Editors (ICMJE) and can be found on the following website: http://www.icmje.org/ethical_1author.html
- Share your intentions about future **follow-up** applications.

For you as a patient research partner

- Make your own **evaluation** and have a closer look at things that went well or could have been improved upon.
- It is important to think about how the results of the project might be **disseminated** among patient organizations.

Many recommendations are primarily focused on health professionals, to guide them to make evidence based decisions in situations that are often common. It might be beneficial for partners to start thinking about how research outcomes could influence patient educational materials, self-management courses or patient versions of the recommendations. If the information is new, it can be made available through the official website of national patient organizations or as printed brochures or magazines. Sometimes it is worthwhile to give a presentation about the findings.



-
- If during the evaluation new learnings occur about how patient participation might be improved, it is important to **share these experiences** and lessons learnt with other members of the EULAR network of patient research partners.
 - Share your **thoughts** with the task force leader and/or your mentor. Let them know how you felt during meeting(s). Were there moments when it seemed your input was not appreciated? Were other participants not willing to talk/share their opinions with you? Did your questions receive a proper answer? Was there an open atmosphere in the group? Were you involved in the discussions? Etcetera.
 - Use the feedback to **improve** your skills in the future. You are never too old to learn.
 - If you fulfil the requirements for co-authorship, your name should appear on the final publication. According to the official criteria you should at least provide a substantial contribution from a patient perspective to the project, you should critically review the draft manuscript, and approve the final version. For the exact criteria, visit the ECMJE homepage:
http://www.icmje.org/ethical_1author.html
 - If **further steps** are necessary during the process of the project, make sure they are clear for you.
 - You have been part of an interesting process, of which the outcomes will probably be valuable for other patients too. Try to find a way to share this new information with others and increase **implementation** of the findings.
 - If there is a **follow-up** study, show interest if you want to participate in this.

“Use the feedback to improve your skills in the future. You are never too old to learn.”





Grant review Process

“Although the patient research partners did not know what to expect when assessing a research proposal, the EULAR call coordinators were impressed by the high quality of the feedback from the patient research partners.”

Reference card 6

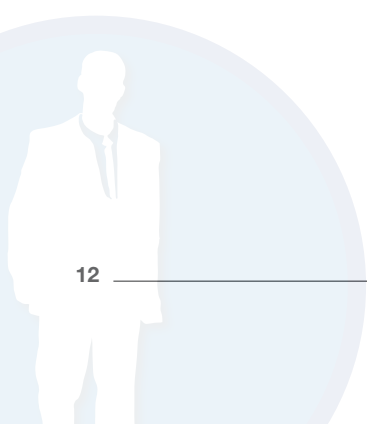
Since 2009 partners have been active and beneficial in EULAR task forces. Apart from the role as task force member, partners have become involved in the EULAR call for PRO (Patient Reported Outcomes) grant proposals (2011) and EULAR call for PAIN grant proposals (2012). This role was not foreseen and during our evaluation it became clear that partners need to be given instructions and prepare for the role of reviewer. Although the patient research partners did not know what to expect when assessing a research proposal, the EULAR call coordinators were impressed by the high quality of the feedback from the patient research partners.

For you as researcher

- Reviewing a grant application might be a new task and responsibility for partners. As in other research contexts, it takes them through a **learning curve**. Partners have to learn the review process and obtain the skills and abilities to assess the applications.
- Give partners clear **guidance**, an introduction and a review form to help them to assess the applications from a patient perspective. A teleconference with all patient reviewers in advance of the review process might be considered to give background information, to explain the overall objective of the call and to highlight specific patient issues. Appoint a contact person for future questions.
- Provide partners with **more than one** project proposal in order to enable them to compare applications and give discriminative assessments.
- Provide **feedback** on the review process, the final decisions about projects that are granted, and on the value of the patient input.

For you as a patient research partner

- Reviewing grant applications will take more **time** in the beginning. It requires time to become familiar with the procedures and to acquire skills to become discriminative in your advice and judgments.
- Try to assess proposals against the **background** of the EULAR call and the EULAR strategic objectives.
- When reviewing a grant proposal try to be **discriminative**, which means that you try to compare the relevance and quality of different proposals.
- It is important to be **critical and constructive**. To be critical does not mean to criticize but it encourages you to ask questions if particular sections are unclear or if you doubt whether a particular statement is true or whether there is sufficient evidence for a particular claim. To be constructive does mean that if you disagree with a particular approach or concept, that you try to formulate or provide an alternative approach or concept.
- Express your interest in a particular project for future involvement as a partner, if this is the case. It is no guarantee you will be taken on board, but it might be beneficial if future task force leaders are aware of your interests.



Patient review form

Reference card 7

In the past, project proposals within EULAR calls were always reviewed by professional with a scientific background. However, recently the value of the patient perspective has been acknowledged and partners are also asked to have a close look at grant applications and assess in particular the relevance of these proposals. As this is a rather individual task, partners appreciate clear guidance in this process. Reference card 7 contains specific questions to focus on while reading a project proposal. These questions guide the partners through the process of reviewing. A standard project evaluation rating form gathers all the feedback in a similar way, which eases the final decision making. You can find an example of such an evaluation form on the next pages.

For you as a patient research partner

- Patient reviewers should realize that their review is part of an advisory phase. In theory, it means that they should accept that their review has the status of an **advice** and that they are not directly involved in the decision making process. However, in the final decision parts of their advice should be reflected. If this is not the case partners may lose their motivation to continue reviewing grant applications.
- During our evaluation it became clear that partners found it difficult to distinguish between **design and feasibility**. By adding questions in the reference card we have tried to make the distinction more clear.
- Partners primarily assess relevance but may, depending on the level of their knowledge and experience, also comment on the quality of a study. Partners should however make sure that the main focus of their review is **the patient perspective**.

“I simply love this card! Knowing what questions to answer and what to look for when pursuing patients’ involvement and interest makes everything much easier.”

Patient research partner





Project evaluation rating form

Patient perspective

Call for proposals (if applicable):

Project:

Please evaluate the project from a patient perspective. Use the following criteria by giving your **brief** written evaluation as well as a numeric score for each criterion on a scale of 1 – 5 (please use 0.5 increments in your scoring if necessary). Your specific comments and suggestions are critical for an accurate evaluation and weighing of the scores. Please enter your assessment in the fields below.

1 (excellent) 2 (good) 3 (satisfactory) 4 (insufficient) 5 (poor)

1. Relevance to the subject matter of the call or the EULAR research strategy

Comments:
.....
.....

Score:

2. Feasibility

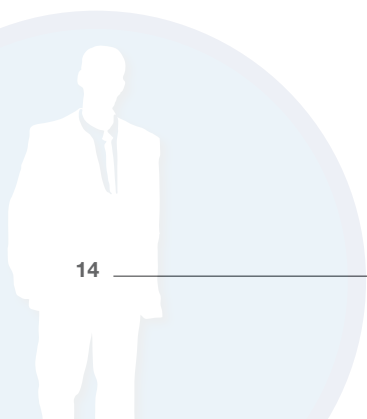
Comments:
.....
.....

Score:

3. Active participation of people with rheumatic diseases in the project

Comments:
.....
.....

Score:



4. Novelty and importance for the field of rheumatology

Comments: _____

Score: _____

5. Design

Comments: _____

Score: _____

6. Relevance to the EULAR objectives

Comments _____

Score: _____

TOTAL SCORE _____



EULAR objectives

Objective 1 – Research

By 2017, EULAR will be a central platform to facilitate and stimulate innovative basic and clinical research projects in rheumatic and musculoskeletal diseases.

Objective 2 – Education

By 2017, EULAR will be a pre-eminent provider and facilitator of high-quality educational offerings for physicians, health professionals in rheumatology, and people with rheumatic and musculoskeletal diseases.

Objective 3 – Congress

By 2017, the annual EULAR congress will be the top congress for rheumatic and musculoskeletal diseases and will have broadened its offerings and reach.

Objective 4 – Advocacy

By 2017, EULAR will have a significant influence on EU level, and assists actions on national level, towards improving research funding, social policy legislation, and quality of care.

Objective 5 – Standards of care

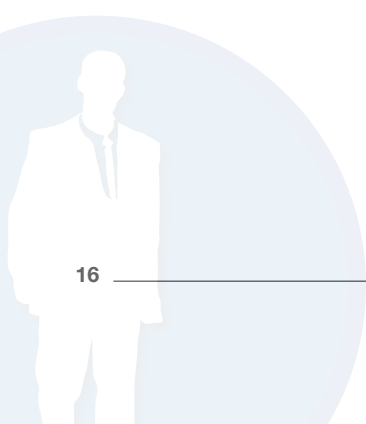
By 2017, EULAR will have raised standards of care by elaborating and actively promoting, disseminating and implementing EULAR recommendations and criteria for the most common rheumatic and musculoskeletal diseases.

Objective 6 – Profile

By 2017, EULAR will have raised its profile and visibility to patients and health care providers.

Objective 7 – National relations

By 2017, EULAR will have actively engaged all national societies as well as related organizations in key EULAR activities.



Appendixes

Methods

Glossary

Literature

Acknowledgements

METHODS

In May 2012 the pilot project 'PARE Network of patient research partners' had run for almost two years. We carried out a responsive evaluation of this pilot project and of the implementation of the recommendations for the inclusion of patient representatives in EULAR scientific projects. The findings were transferred into a practical guide and set of reference cards for patients as well as researchers. Data were collected through different channels.

Evaluation meeting

A 1,5 day training and evaluation meeting was held with eleven members of the PARE network, one guest speaker and one national delegate. The process and outcomes of the first two years of the pilot project were evaluated during this meeting which took place in June 2012, prior to the EULAR congress in Berlin. The group focused on the experiences in a variety of working groups and confirmed unanimously that it was good and important to have this follow up and to increase the impact of patient involvement in research. The participants received additional training on the research grant review process and provided suggestions on how to improve the quality of their contribution in task forces, as reviewers or otherwise.

Interviews

During the EULAR conference, four semi-structured interviews were conducted with EULAR Task force leaders who had already collaborated with patient research partners. The interviews were transcribed and then summarized in interview reports and sent to the interviewees for a responder check.

Survey

After the combined review of the training and evaluation meeting report and the four interview reports, the project coordinator and convener developed eight draft reference cards. The draft reference cards were distributed among a variety of stakeholders (patient research partners, researchers, Standing Committee chairs) following a modified Delphi method. The draft reference cards were sent to 46 people of whom 25 responded.

“Patient participation is quite new to everyone so it is quite a learning curve to do it. But with everyone's contribution, we certainly make a difference.”

Patient research partner



Glossary

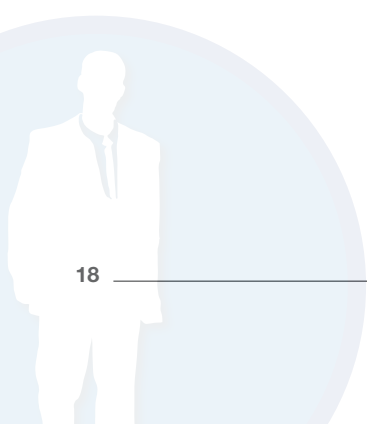
DAS – Disease Activity Score – The DAS is a scoring instrument widely used and adopted by *EULAR* to assess RA disease activity. It is a criteria set that combines information from the Ritchie Articular Index, joint counts for tenderness and swelling, the erythrocyte sedimentation rate (ESR) and patient global assessment of their disease activity. The DAS has been validated both for full (DAS 44) and limited joint counts (DAS 28: foot joints are excluded). A DAS score <3.2 is regarded as low-level disease activity, a score of 3.2-5.1 as moderate and a score >5.1 as high-level disease activity. The DAS is used as a criterion for eligibility to have anti-TNF, at least in the UK and the Netherlands. The DAS was developed by Desiree van der Heijde et al. First published: “Judging disease activity in clinical practice in RA: first step in the development of a disease activity score”. *Ann Rheum Dis* 1990; 49:916-20. Later: “Development of a disease activity score based on judgement in clinical practice by rheumatologists” *J Rheumatol* 1993;20;579-81.

Delphi method – The Delphi Process is a means of reaching consensus through a structured consultation between a group of people who may have very different perspectives and fields of expertise. It is particularly useful where there is little or no published information on the subject under consideration. Unlike more familiar consultation methods such as steering groups, the Delphi Process doesn't need participants to physically meet together and there is no limit on how many people can be involved. Since the process is anonymous, it avoids ‘power struggles’ because there is no opportunity for a strong individual to unduly influence the group. People can change their minds without losing face. The process also enables a combination of many opinions into a group response and can be completed in a short period of time.

EMA – The European Medicines Agency is a decentralized agency of the European Union, located in London. The Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union.

EULAR – The European League Against Rheumatism (EULAR) is the organisation which represents the patient, health professional and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. In line with UEMS, EULAR defines rheumatology as including rheumatic diseases of the connective tissue, locomotor and musculoskeletal systems.

EULAR is a truly pan-European organisation fostering a multitude of activities in areas of research, patient care, and education. To manage and promote its goals effectively, EULAR has set up a structure of committees and managerial bodies. The General Assembly is the highest authority of EULAR. It is composed of the members of the Executive Committee and delegates of the regular member organisations and corporate members. The General Assembly meets once a year on the occasion of the Annual European Congress of Rheumatology.



EUPATI – The consortium project “European Patients’ Academy on Therapeutic Innovation” (EUPATI), funded by the Innovative Medicines Initiative (IMI), will provide scientifically reliable, objective, comprehensive information to patients on medicines research and development. It will increase the capacities and capabilities of well-informed patients and patient organisations to be effective advocates and advisors in medicines research, e.g. in clinical trials, with regulatory authorities and in ethics committees. See also: www.patientsacademy.eu

HAQ – The Stanford Health Assessment Questionnaire – (the HAQ) was developed in 1980 by Fries et al. It is a measure of functional ability and is based on the belief that a patient desires to be alive, free of pain, functioning normally, experiencing minimal treatment toxicity, and financially solvent. A lot of patients have probably filled out the HAQ in clinic and it exists in 28 languages. Measurements are on a scale of 0 (best) to 3 (worst). It is a self-administered measure that evaluates four dimensions: disability, discomfort, drug side effects and costs. The disability section of the HAQ contains 20 questions about difficulties experienced with eight categories of activities of daily living, and four questions about the assistance used to perform these activities. The ‘Modified HAQ’, which contains only 8 of these questions, one from each category, is commonly used.

ICF – The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of environmental factors.

The ICF is WHO’s framework for measuring health and disability at both individual and population levels. The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21). Unlike its predecessor, which was endorsed for field trial purposes only, the ICF was endorsed for use in Member States as the international standard to describe and measure health and disability.

INVOLVE – INVOLVE is a national advisory group that supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by and part of the National Institute of Health Research (NIHR). INVOLVE shares knowledge and learning on public involvement in research. See: www.invo.org.uk

OMERACT – OMERACT stands for ‘Outcome Measures in Rheumatology’. The acronym OMERACT was coined at the first conference held in Maastricht, the Netherlands in 1992, limited to ‘Outcome Measures in Rheumatoid Arthritis Clinical Trials’. Since then, the OMERACT initiative has turned into an international informal network, working groups and gatherings interested in outcome measurement across the spectrum of rheumatology intervention studies. OMERACT strives to improve outcome measurement through a data driven, iterative consensus process. More information: www.omeract.org



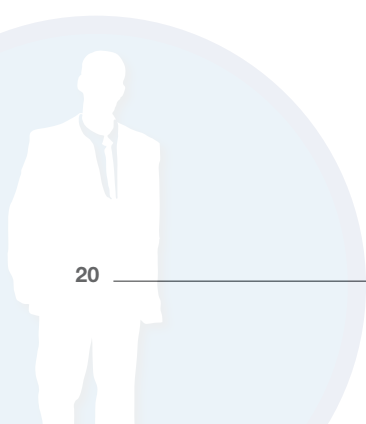
PARE Standing Committee – The national organisations of people with arthritis/ rheumatism across Europe (PARE) work together via the EULAR Standing Committee of PARE. Each member country is represented with one delegate in the committee. The standing committee meets twice a year on the occasion of the EULAR congress and the EULAR Autumn Conference (new name tbc) to review progress and plan future activities.

PRO – Patient Reported Outcome

SF36 – The Medical Outcome Study Short Form 36 measures three major health attributes (functional status, wellbeing, overall health) in eight subscales. These include PF (Physical function), RP (role limitations due to physical health), BP (bodily pain), GH (general health), VT (vitality), SF (social function), RE (role limitations due to emotional health), and MH (mental health). For each variable item scores are coded, summed, and transformed to a scale from 0 (the worst possible health state) to 100 (the best possible health state). Lit: Ware JE, Sherbourne CD “The MOS 36-item Short-Form Health Survey (SF-36) I. Conceptual framework and item selection”, in: Med Care 1992;30:473-83.

SOP – The EULAR Standardized Operating Procedures for the elaboration, evaluation, dissemination, and implementation of recommendations are officially endorsed by the EULAR standing committees. Their objective is to maintain and to homogenize a high level of intrinsic quality and comparability of EULAR studies. To achieve such an objective it appeared that the definition and publication of these standardized procedures might be a relevant and useful starting point. Obviously these SOPs should not be a barrier to acceptance of a project if not all points are satisfied but might be important to consider before starting a project. These SOPs are not mandatory in themselves but can be used flexibly. Dougados e.a. in: Ann Rheum Dis 2004;63:1172–1176. doi: 10.1136/ard.2004.023697

Some terms in this glossary are derived from the OMERACT glossary.



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