



# PATIENT INVOLVEMENT IN RESEARCH

A way to success

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This set of reference cards comes with a brochure which contains more detailed information about the “**Patient involvement in research project**”. If you prefer to have the information electronically and/or if you wish to work with patient research partners, please contact the EULAR Secretariat: [eular@eular.org](mailto:eular@eular.org)

## Patient involvement in research

Congratulations! Soon you will be starting a research project in which researchers and patient research partners (further on described as 'partners') will work together. In order to improve this collaboration and enhance your contributions, a set of guidelines was developed with the support and input of a stakeholder group being active in the field of rheumatology research.

The guidelines are for you to consider and are not binding. We trust on your insights and willingness to gain from this unique partnership. Should there ever be any questions, please feel free to contact the EULAR Secretariat: [eular@eular.org](mailto:eular@eular.org)

More detailed information as well as the full "EULAR recommendations for the inclusion of patient representatives in scientific projects" can be found on the EULAR website: [http://www.eular.org/st\\_com\\_pare\\_prp.cfm](http://www.eular.org/st_com_pare_prp.cfm)

*Ann Rheum Dis* 2011;70:722–726. doi:10.1136/ard.2010.135129

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## Recommendations

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- Participation of Partners is strongly recommended for clinical research projects and for the development of recommendations and guidelines, and should be considered for all other research projects.
- Participation of Partners should be considered in all phases of the project to provide experiential knowledge, with the aim of improving the relevance, quality and validity of the research process.
- A minimum of two Partners should be involved in each project.
- Identification of potential Partners should be supported by a clear description of expected contributions.
- The selection process of Partners should take into account communication skills, motivation and constructive assertiveness in a team setting.
- The principal investigator must facilitate and encourage the contribution of Partners, and consider their specific needs.
- The principal investigator must ensure that Partners receive information and training appropriate to their roles.
- The contribution of Partners to projects should be appropriately recognised, including co-authorship when eligible.

## Preparation Task force leader

- Patient involvement requires a commitment of time for preparation
- Invite a minimum of two partners and guarantee adequate budget
- Appoint one contact person or mentor who will answer all the partners' questions
- Involve partners as early in the process as possible
- Plan in advance and be open about the amount of time, meetings and teleconferences the project will take and when and where these will happen
- Think about the criteria for the partners in terms of diagnosis, competences and attitude
- Provide the partners with
  - background information on the aim and context of the study, including the project protocol
  - a task description with clear information about the expected input
  - a list of other participants in the task force and their background
- Provide information in lay language
- Provide a face-to-face meeting or personal call in advance of the first meeting to address any questions from both sides
- Consider different ways of patient involvement, apart from the partners in your team
- If you do not involve partners, please explain in the protocol why

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## Preparation Patient research partner

- Involvement in research requires a commitment of time for preparation
- Ask for a contact person or mentor who is available to answer your questions
- Ask the Task force leader for a well-defined task description in clear language
- Familiarise yourself with the subject, ask for the study protocol and other background information
- Make sure you understand the objectives, methods and expected outcomes of the project
- Consult the internet and glossaries for terms and abbreviations you do not know
- Prepare for a meeting or teleconference by writing down questions or topics that are of importance for you or that are unclear
- If possible, take part in a short introductory talk with the Task Force Leader and/or contact person
- Consider the amount of time you can offer to the project. Be open about your limitations in available time, mobility, access to information
- Make sure you are available for the next steps of the process: consider time, travelling, days off work if necessary

## During the meeting Task force leader

- Do not expect partners to present 'the patient perspective'. They do not represent all patients with the studied condition
- Create an open atmosphere where partners feel confident to contribute
- Introduce partners at the start of the meeting, or let them introduce themselves
- Encourage partners to participate in the discussions and regularly invite them to give their opinions
- Promote open dialogue and attentive listening
- Create smaller group discussions if possible
- Explain jargon without being asked and give extra information if needed
- Treat all team members equally
- Consider how partners can be informed and supported along the way
- Acknowledge the input of partners
- Respect confidentiality and adhere to ethical rules
- If possible provide a toll free number for teleconferences, or reimburse the costs

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## During the meeting Patient research partner

- Introduce yourself to the group
- Take part in the discussions, give your view on the subjects when possible. Your input is surely valuable, no matter how small it is
- Do not assume that what you think or feel is obvious to the others
- Ask for clarification if something is unclear. There are no such thing as stupid questions
- Make notes during the discussions. These might help in a later stage
- Ask for the slides of any presentations when relevant
- Try to balance your personal views and experiences, and that of the larger group of patients with your condition
- Respect confidentiality and apply to ethical rules
- Ask for a toll free number in case of a teleconference
- If there is anything you cannot agree on, make sure it is written in the report



## Debriefing Task force leader

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- Give feedback on contributions
- Acknowledge the partner's contribution
- When partners fulfil the International Committee of Medical Journal Editors criteria for co-authorship, they should become co-authors
- Guarantee that reimbursements are made as soon as possible
- Reflect on and evaluate the experiences of collaboration for future improvements
- Discuss possible learning points for all stakeholders
- Involve partners in the development of follow-up applications

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## Debriefing Patient research partner

- Ask for feedback on your contribution
- Reflect on and evaluate the experiences of collaboration, for future improvements
- Discuss possible learning points for all stakeholders
- Make sure next steps to be taken are clear
- Try to think how the results of the project might be disseminated among patient organisations
- Try to think how you can support the implementation of study outcomes
- Consider involvement in follow-up studies

## Review process Task force leader

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- Allow enough time to provide feedback on the research applications
- Send the text of the EULAR call in time to all patient reviewers
- Provide patient reviewers with more than 1 project proposal in order to be able to compare
- Prepare partners on the review process. Provide a clear guide for assessing the research proposals and give sufficient background information in lay language. Explain terminology and abbreviations
- Be available for questions arising during the review process
- Review the current EULAR Patient Review Form
- Inform all patient reviewers about the final decisions
- Provide feedback on the review process and on the value of the partner's input

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## Review process Patient research partner

- Ask the EULAR Secretariat for clear instructions on the review process
- Consider any conflict-of-interest when you are involved in the application that you are asked to review
- Try to be discriminative by comparing different applications
- Try to be critical but do so constructively
- Write down questions when a paragraph is not clear to you
- Respect confidentiality and observe to ethical rules

# The patient version Project review form

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## Relevance

- Why is this project important for patients?
- Does the study address patient reported needs or interests?
- Will this research result in practical benefits for patients?
- Would you be willing to participate as a study participant yourself?

## Feasibility

- Is the application written in an understandable language?
- Is there a structured and realistic plan? Timing? Funding?
- Is the burden for the study participants acceptable?

## Novelty and importance for rheumatology

- Does this project improve the quality of health care?
- Does it reduce the impact of the disease and improve quality of life?

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## The patient version Project review form

### Active participation of people with rheumatic diseases

- Have patients been involved in the development of this application?
- Are patients research partners involved in all phases of the project?
- Is implementation foreseen on a patient's level?

### Design

- How will the research be performed?
- Is the right patient group included in this study?
- How are the study participants recruited?
- Will the outcomes measured really matter to patients?

### Relevance to the EULAR objectives

- Is this project in line with the strategy of EULAR for the coming years?

### General comments

- What is good and what is not good?
- Any suggestions to make the project better?

## Useful links

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- [www.eular.org](http://www.eular.org)
- [www.omeract.org](http://www.omeract.org)
- [www.invo.org.uk](http://www.invo.org.uk)
- [www.clinicaltrialsregister.eu](http://www.clinicaltrialsregister.eu)
- [www.clinicaltrials.gov](http://www.clinicaltrials.gov)



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