

Summary

Course Name	1st EULAR Online Course for Patient Research Partners
Module Title	Module 1- Principles of collaborative research

Basic Learning

- It is important for PRPs to be aware of the value of their experiential knowledge in the context of medical research. It is knowledge based on introspection and the shared reflection of illness experiences and is considered a valid source of knowledge. It covers all domains of life; rather than knowledge about the illness, it comprises knowledge of the impact of the illness on daily life.
- In health research, patients can choose between different roles that represent different types of input and different amounts of influence.
- The strategies for patient involvement should always be tailor-made; there is no concept that fits all research initiatives. However, the participation matrix is a helpful framework to develop, organise and evaluate patient involvement strategies.
- Combining methods of consultation with the involvement of patients as collaborative partners in the research team provides face and content validity to research findings.
- Patient involvement often requires multiple forms of participation at different phases of the research. This will enhance the preservation and representativeness of the patients' perspective.
- A structural approach guarantees sustainability.

Advanced Learning

- Patient research partners must be an integral part of the research team with the same rights and opportunities to participate in the entire process as other participants. It is essential that they are included from the very beginning when decisive choices are made.
- PRP involvement in the protocol design stage may impact research objectives, questions and methods, and raise the level of attention for the dissemination of outcomes. Using experiential expertise during all phases of the project can contribute to the relevance, quality and validity of the research outcomes.
- A critical and constructive attitude is mandatory for effective collaboration. Good communication skills are needed to express personal experiences to professionals in a compelling and useful manner. Willingness for mutual learning is a key to success.
- The primary responsibility of PRPs is to provide a patient perspective in all its diversity on the *design, conduct and dissemination* of the research project and to ensure that the patient perspective is preserved throughout the research process. It is not the primary role of PRPs to be fully representative for the target patient group. The entire research team needs to ensure that a representative sample of patients is engaged in the study to fully capture the diversity of the patient's perspective.
- The role of the principal investigator is key in providing adequate support to PRPs. PRP involvement always requires an extra effort in terms of time, money and energy. Information, training, support, feedback and acknowledgement are important features of the EULAR recommendations. PRPs should ask for them and researchers should provide them (and vice versa!).