

# Are patient partners a necessity in research?

June 14 2024

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	YES	NO
Q1. Have you felt that the presence of patients hindered the advancement of the project due to the lower scientific/medical literacy?	/	4,8 %	/	47,6 %	47,6 %		
Q2. Do you attribute the same value to the inputs from patients' partners on their disease as you would to the input from expert medical professionals?	23,8 %	61,9 %	9,5 %	/	4,8 %		
Q3. In future research projects, would you consider involving a patient association as a collaborating partner without any prior obligation?						95,2 %	4,8 %
Q4. During meetings, do you feel that you are able to speak freely even if patients are attending?						100 %	0 %

Credit: *People with Arthritis and Rheumatism in Europe Abstracts* (2024). DOI: 10.1136/annrheumdis-2024-eular.2931

The European Alliance of Associations for Rheumatology has long recognized the pivotal role of patients in the development of recommendations, and the role of patients in research is also evolving. But collaboration with patients in this way is relatively new, and trials or effectiveness studies are not yet available.

Now, new [survey data](#) shared at the 2024 EULAR congress in Vienna shine a light on the views of the scientific community—specifically in

the drive to find new outcomes and treatments for people with primary Sjögren's disease.

Sjögren's disease is a systemic autoimmune disorder that often causes sicca symptoms—or dryness of the eyes and mouth, alongside many other complications such as fatigue, pain, and neurological manifestations. There are treatments that help with symptoms, but none that address the underlying disease processes.

One key issue in developing new treatments is that Sjögren's can differ from person to person—and that makes it hard to measure and compare outcomes in a clinical trial.

NECESSITY is an interventional trial looking at new clinical endpoints in Sjögren's disease. This is an international project involving eight European countries, and coordinated by Professor Xavier Mariette. The aim is to identify sensitive endpoints that could be used in [clinical trials](#) to assess the efficacy of new medicines. In addition, the project hopes to find biological markers that could be used to identify specific subgroups of people with different disease types.

Unusually, the project has gathered a consortium of 25 partners across academia and industry—including representatives from patient associations. This is a challenging initiative, but one which could add value and highlight patients' unique experience and expertise around Sjögren's and its numerous unmet needs.

To assess the merits of working with patient advisory groups in this way, a survey was sent to each of the other partners. The intention was to collect a scientific point of view, as well as to identify obstacles and areas for improvement.

The main challenges identified included differences in perspectives and

perceptions of Sjögren's [disease](#), as well as the need to go beyond strictly scientific considerations in order to include patient opinions and implement their ideas. Another concern was to ensure that patients find their place within the consortium among scientists, and about the time sometimes needed to explain technical aspects to ensure effective collaboration. Addressing these challenges will be important for future projects.

But when looking at the benefits of working with patient partners, there were some noteworthy findings. For example, a majority of respondents favored working with patients to validate unmet needs—especially those around symptoms and care expectations.

Some people also expressed the view that patient partners provide moral support, boost motivation, and retain empathy within the consortium. Over 95% of respondents stated they would be willing to seek out patient partners in the future, and view them as genuine research partners.

Overall, the NECESSITY consortium appears to have been a success, and could provide the basis for a collaborative model to address clinical research in the future, helping to answer questions from the perspective of both the patient and the medical community.

**More information:** C. Bouillot et al, OP0286-PARE Myths vs realities: An honest feedback from the scientific community on collaboration with patients partners in the necessity research project, *People with Arthritis and Rheumatism in Europe Abstracts* (2024). [DOI: 10.1136/annrheumdis-2024-eular.2931](https://doi.org/10.1136/annrheumdis-2024-eular.2931)

Provided by European Alliance of Associations for Rheumatology  
(EULAR)

Citation: Are patient partners a necessity in research? (2024, June 14) retrieved 18 June 2024  
from <https://medicalxpress.com/news/2024-06-patient-partners-necessity.html>

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