

# Trends in Patient-Focused Presentations at Scientific Congresses: A European Rheumatology Congress Case Study

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## ABSTRACT

### Objective

Patient engagement with medical research is gaining momentum and can provide a route to increasing the visibility of new research within the patient community.<sup>1</sup> This study aimed to investigate whether increased patient engagement in research has been reflected in the number of patient-focused presentations at a major international scientific congress.

### Research Design and Methods

The European League Against Rheumatism (EULAR) includes a patient-focused 'People with Arthritis and Rheumatism in Europe' (PARE) abstract category at their annual scientific congress. Using EULAR's abstract archives and congress reports, the number of accepted PARE abstracts (including oral and poster presentations) as a proportion of total submitted EULAR abstracts annually, from 2010–2019, was calculated. Each PARE abstract was reviewed and categorized into predefined abstract themes.

### Results

Overall, 352 PARE abstracts were identified. The number of accepted PARE abstracts/year increased from 16–45 between 2010–2019 (max=47 in 2017), resulting in the percentage of total submitted abstracts presented as PARE increasing from 0.46–1.05%. The greatest increase was between 2010–2013 with the number and proportion of PARE abstracts remaining stable thereafter (2013–2019 [min–max]: 39–47 PARE abstracts presented/year; 0.83–1.05% total abstracts/year). Most PARE abstracts fell under 'patient experience', 'patient organisation activities' and 'other' themes (31.25%, 30.11% and 20.45%, respectively). Abstracts discussing patient involvement in research or developing patient/public materials comprised 15.63% of abstracts; remaining abstracts reported case studies or controlled trial data.

### Conclusion

There has been an increase in the percentage of patient-focused abstracts presented at the EULAR congress, however, this has stabilised since 2013. Largely, these abstracts describe patient experience and patient organisation activities.

## Considerations for Medical Congresses with Patient Attendees

- The risk of being non-compliant by promoting prescription only medicine can discourage congresses from inviting patient attendees.
- EULAR offers reduced registration fees and travel bursaries to patients and patient organisations. These reduced rates only allow access to the 'EULAR Village' and prevent patients from accessing information about prescription only medicine.
- Patient-focused congress publications need to be written with the patient in mind by reducing the number of scientific words and providing a lay summary.

## Relevance To Medical Writers

- Medical writers can encourage the pharmaceutical industry and authors to consider patient readers and authors when writing publications and recommend congresses which focus on patient engagement.
- A solid knowledge of the industry standards and guidelines can help reassure pharmaceutical companies that they are involving patients in a compliant way.

## References

1. Utengen A. J Med Internet Res 2017;19:e280.

## Author Contributions

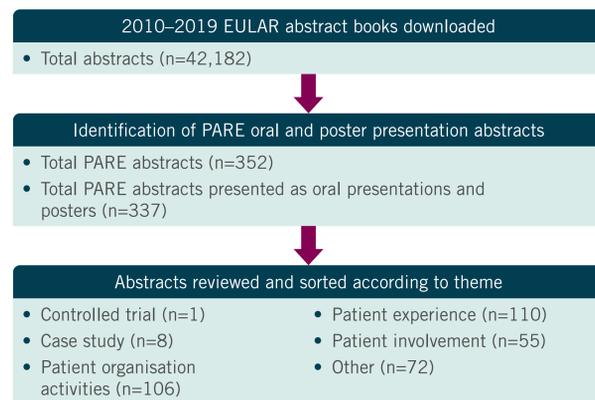
Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: EP, JS, OW, DN, SF; Drafting of the publication, or revising it critically for important intellectual content: EP, JS, OW, DN, SF; Final approval of the publication: EP, JS, OW, DN, SF.

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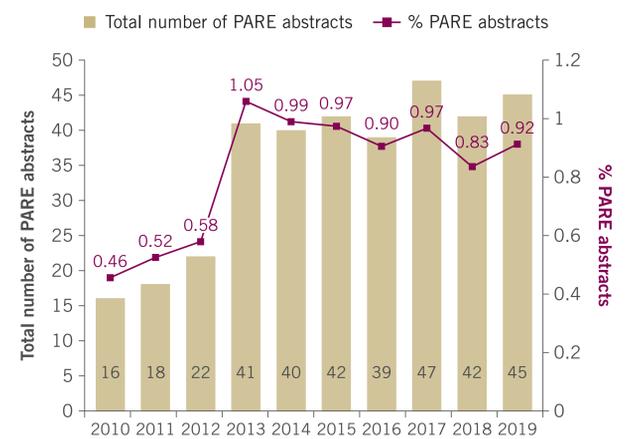
## RESULTS

### 1 Identification of People with Arthritis and Rheumatism in Europe (PARE) abstracts accepted for presentation at EULAR (2010–2019)



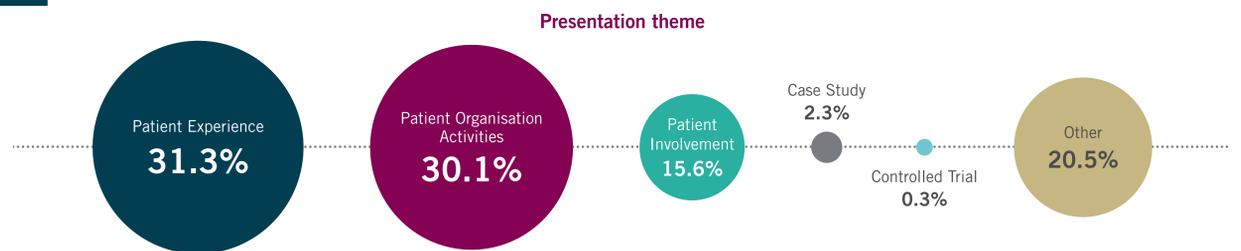
EULAR: European League Against Rheumatism.

### 2 Number of PARE abstracts presented at EULAR and as a proportion of total submitted EULAR abstracts over time



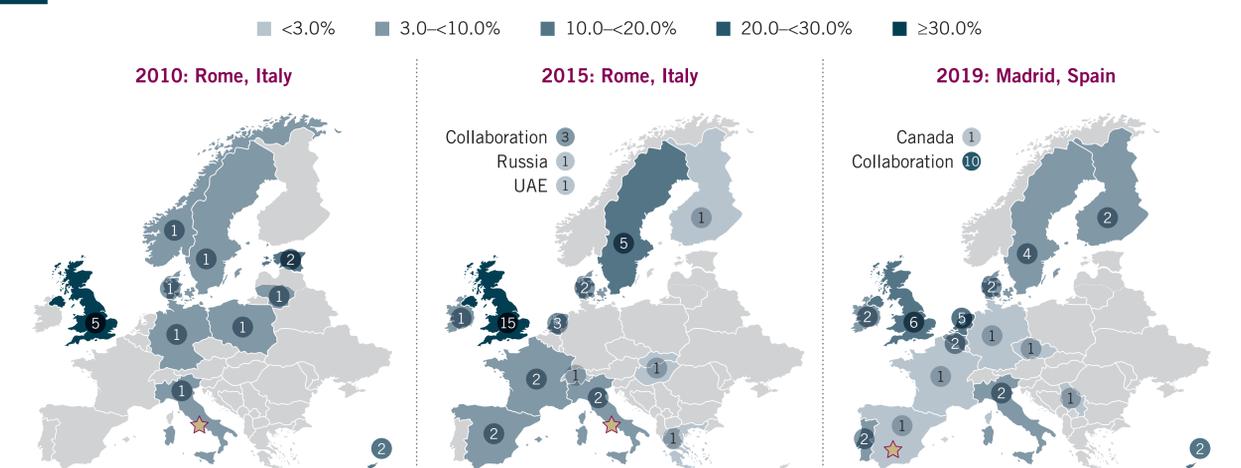
PARE: People with Arthritis and Rheumatism in Europe.

### 3 Percentage of total PARE presentations by presentation theme



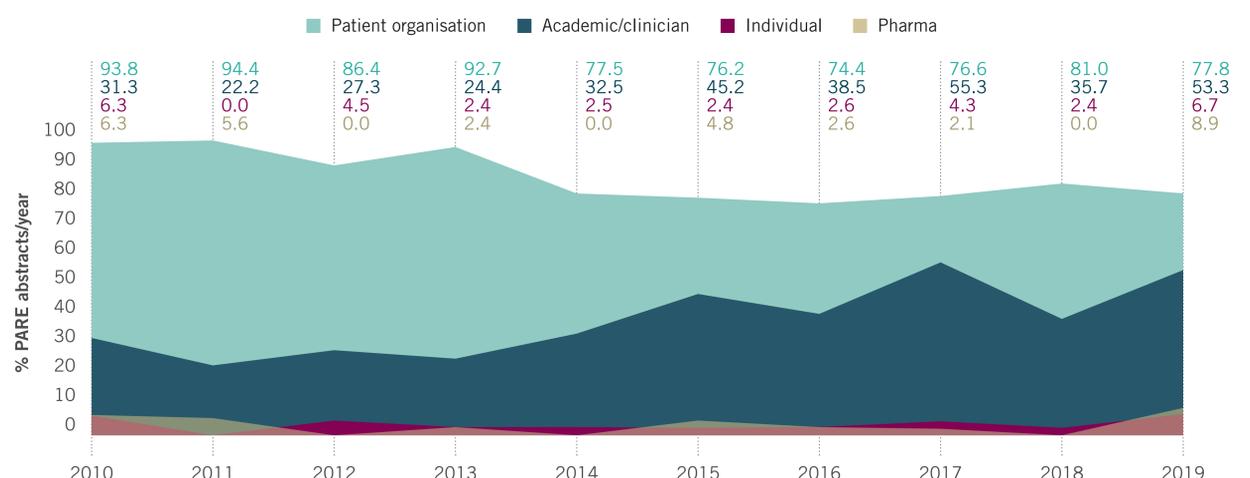
PARE presentations from 2010–2019 included. Most presentations in 'other' fell into the following themes: political lobbying; impact of awareness campaigns; education of patients, the public and employers; caregiver perspectives. PARE: People with Arthritis and Rheumatism in Europe.

### 4 Changes in the geographic distribution of authors of EULAR PARE presentations over time



The countries that PARE presentation authors were affiliated to were investigated to explore if the number of countries producing patient-focused presentations was increasing over time. Numbers in circles indicate the number of presentations from each country. If the authors on a single presentation were affiliated to multiple countries, the presentation was included in the collaboration category. Circles outside of the map indicate the number and percentage of collaborative or non-European country affiliated presentations. PARE: People with Arthritis and Rheumatism in Europe.

### 5 Changes in the distribution of different stakeholder groups involved in the authorship of PARE abstracts over time



Each abstract can have multiple authors so percentages for each year may >100%. PARE: People with Arthritis and Rheumatism in Europe.