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Commonalities and differences in set-up and data collection across European spondyloarthritis registries — results from the EuroSpA collaboration

The study investigates the commonalities and differences in data collection across 15 European spondyloarthritis (SpA) registries, including almost 34,000 patients with axial spondyloarthritis (axSpA) and psoriatic arthritis (PsA). Key findings highlight significant variability in registry design, data availability, and the wording and recall periods of patient-reported outcome measures (PROMs). Interestingly, data completeness for PROMs (such as assessments of pain, fatigue and the BASDAI score) has improved since 2015.

This study is important for rheumatologists as it emphasizes the challenges in pooling data from different registries for collaborative research, suggesting that differences in how data are collected might affect study outcomes. For patients, the findings underline the increasing focus on incorporating patient-reported measures in treatment assessment, with the aim of improving personalized care. Overall, the study provides valuable insights that can guide future research efforts toward more standardized data collection methods in SpA registries.

Link to the publication: Commonalities and differences in set-up and data collection across European spondyloarthritis registries — results from the EuroSpA collaboration at https://doi.org/10.1186/s13075-023-03184-7