

## EULAR Study group on Longitudinal Observational Registers and Drug Studies

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#### Background

Over time, the number of European biologics registers has expanded. Some have accrued substantial number of patients and treatments. Several new registers are currently being launched. The existing and planned registers increasingly differ by size, design, and methodological “maturity”. This shift away from a harmonised approach led to the recently completed EULAR Taskforce on Biologics Registers, whose objectives were to establish points to consider when establishing, analysing and reporting results from such studies, ensuring that existing and emerging registers share best practice. Ongoing work is necessary to ensure the continued sharing of experience and establishment of best practice, particularly as the complexity of this field increases.

In parallel with the increasing number of registers launched, data from registers have come to play an increasingly important role in the evaluation of drug safety, real world effectiveness, and of treatment strategies in clinical practice. It is important to ensure registers are able to maintain this role. The complexities have increased along with more available treatment options and switching between therapies. As a consequence, issues that might have been addressed by a single register for the early biologic drugs will now only lend themselves to study through collaborative approaches as fewer patients have any given treatment pattern. Similarly, many of the recently established registers are not likely, within the coming years, to accrue large enough patient datasets to allow for within-registry analyses. The significant efforts to collect large amounts of information from clinical practice, as is increasingly mandated by regulators, will only prove meaningful if collaborative analyses are made possible with sound methodology.