# Innovations in Data Collection in Rheumatology

By Denis Choquette, MD, FRCPC

Rhumadata™ celebrates its 25th year of existence in 2023. When it was started, it collected data on rheumatoid arthritis (RA) only. With time and progressive subsequent technological improvements, the registry now collects information on axial (AxSpA) and peripheral (pSpA) spondyloarthropathies, including arthritis associated with inflammatory bowel diseases. All visits with rheumatologists (total 15) are included in the database. Data collected include demographics, disease history, comorbidities, and disease activity scoring (disease activity score [DAS], clinical disease activity index [CDAI], simplified disease activity index [SDAI], the ankylosing spondylitis disease activity score [ASDAS], psoriatic disease activity [DA], and more). Patient-reported outcomes (PROs) are collected through different channels such as in-clinic visits with the help of a nurse or directly by the patient on a tactile screen or tablets. Patients can also access their questionnaires online, following an invitation reminding them to answer before their clinic visit. All medications and comedications are also collected with start and stop dates, and with reasons for discontinuation, if this is the case. All pertinent labs are also accessible and directly input to the database if patients are residents in the Optilab region of Montreal. Rhumadata can also be used as an electronic medical record (EMR), can generate lab, imaging, and consult forms, and retain historical data. It is also a self-evaluation and practice self-reflection tool, allowing one to compare one's practice to that of the other members of the registry.

Rhumadata is also connected to another EMR as of the last 5 years, from which we can also extract data from patient visits. Other rheumatologists desiring to participate have only to sign off on chart access approval. This way, our database managers will be able to retrieve the data if, and only if, the patient has signed an informed consent form.

There are multiple facets to a tool like Rhumadata. Of course, it is an important research medium exploring efficacy, safety and pharmacoeconomic questions. But it is also an instrument to optimize rheumatology practice and follow practice pattern evolution over time.

For example, in partnership with the International Psoriasis and Arthritis Research Team (IPART), a consortium of registries on SpA across Canada, we examine the residual burden of diseases in RA, psoriatic arthritis (PsA), and ankylosing spondylitis (AS). More than a thousand patients were included in the analysis, and we found out that many patients are left with significant residual disease activity at the 6- and 12-month time points. This information should be of great interest to the rheumatologic community, as it illustrates a significant gap in treatment optimization. Many reasons are suspected but time constraints are certainly an area to evaluate. More and more administrative work to access biologic treatments is required by the payers, increasing the work burden on rheumatologists. Another example has been published by the Rhumadata team: Which subsequent treatment offers the best sustainability after a first anti-TNF failure? Certain therapeutic choices show a higher likelihood of retention, and also demonstrate pharmacoeconomic advantages. The evidence thus shows that a medication with a different mechanism of action should be used in this situation. Lastly, a Canadian Institute of Health Research (CIHR)-supported project was accepted for a poster at the 2022 American College of Rheumatology (ACR) meeting in Philadelphia, comparing originator and biosimilar biologics. Similar efficacy and safety profiles were shown. This is reassuring for both practitioners and patients.

Rhumadata also participates in a pan-Canadian initiative comparing the different registries in Canada. There is some heterogeneity from one to another, leading to interpretation challenges.

As more and more rheumatologists are using EMRs, participation for everyone should soon be possible. It should and will become part of usual practice, as it permits each of us to reflect on the quality of their practice, and will eventually be used for maintenance of competence purposes as suggested by the *College des Médecins du Québec.*

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