



Piotr Kuzmiersz<sup>1,2</sup>, Mariusz Korkosz<sup>1,2</sup>

<sup>1</sup>Department of Rheumatology and Immunology, Jagiellonian University Medical College, Krakow, Poland

<sup>2</sup>Division of Rheumatology and Immunology, University Hospital, Krakow, Poland

## UJCM registry of rheumatic diseases launched

With the advancing process of digitization in modern medicine and access to a dynamically growing amount of data, it seems clear that information technology as well as the processes of data collection and management will play an increasingly important role in improving the quality of diagnostics and treatment. Data from randomized clinical trials are now the backbone of evidence-based medicine and largely shape current recommendations in all fields of medicine. However, information from randomized clinical trials is often very selective and limited to a small group of patients with specific entry criteria, which may lead to an underestimation of treatment effects in a wider patient population. This problem has resulted in increasing attention to the data collected as part of Real World Evidence (RWE) [1].

RWE is data from everyday clinical practice that has been collected to determine the effectiveness and safety of drugs and other therapies under real conditions of use. RWE provides a more realistic and useful picture of how drugs and other therapies work in different patients and situations. RWE is increasingly important in modern medicine as it enables physicians and patients to make more informed and data-driven decisions about treatment and healthcare. It also supports regulatory processes and helps assess the safety and effectiveness of drugs and therapies in the real environment of use [2].

RWE can come from many sources, including patients, physicians, disease registries and healthcare databases. It enables the assessment of the effectiveness of drugs and therapies in patients with various conditions and in various situations, which is difficult to obtain in the controlled conditions of clinical trials.

Thus, in order to take advantage of all the benefits of RWE analyses, it is necessary first of all to create qualitative clinical data registries

that will allow to collect data on the incidence, progression and treatment of diseases, better understand them and improve patient care.

In recent years, many countries in North America, Europe and Asia have implemented national registries of rheumatological diseases, which, thanks to systematically collected prospective data from the daily practice of a rheumatologist, enabled not only the creation of databases and conducting scientific research, but also significantly influenced the shaping of health policy.

The ambition of the POLNOR Rheuma project, launched in 2019 at the Division of Rheumatology Immunology, Jagiellonian University Medical College, is to improve the quality of patient care and the effectiveness of their treatment, as well as to develop scientific research in the field of rheumatology in Poland. As part of this project, the Division established international cooperation with the Sorlandet Hospital in Kristiansand in Norway and with IT companies, using the experience of Norwegian centers in the development of the national register of rheumatic diseases. The implementation of this project was based on funds obtained from a grant under the “Applied Research” program of the Norwegian Financial Mechanism 2014–2021, operated by the National Center for Research and Development.

The starting point for the creation of the Polish register of rheumatic diseases was the implementation of new IT software allowing for the collection of key clinical information in a structured manner. The advantage of this solution is the possibility of using the software for everyday medical practice and keeping patients’ visas, collecting data remotely reported by the patient as part of the so-called PROMs (Patient-Reported Outcome Measures) and simultaneously analyze this data to both assist

**Address for correspondence:**

Piotr Kuzmiersz, MD  
Department of Rheumatology  
and Immunology,  
Jagiellonian University  
Medical College  
Jakubowskiego 2  
30–688 Kraków, Poland  
e-mail: piotr.kuzmiersz@uj.edu.pl

in making clinical decisions and conducting scientific research.

Despite the progressing digitization in Polish health care, the data collected in the conditions of everyday clinical practice still does not allow for the creation of a qualitative register of rheumatological diseases. The software used in Polish medical facilities is not adapted to collect structured data, often does not allow for the integration and exchange of clinical data and does not have advanced mechanisms supporting therapeutic decisions. Also, the central treatment monitoring program introduced along with the development of therapeutic programs is not able to provide comprehensive clinical data and is limited only to a small group of patients with rheumatological diseases treated with biologics disease-modifying anti-inflammatory drugs.

The GoTreatIT software, designed by Norwegian rheumatologists, overcomes these difficulties and has successfully served as a platform for the creation of a qualitative register of rheumatic diseases in Norway. As part of the POLNOR Rheuma project, we adapted this IT tool to Polish conditions and successfully implemented it in the daily practice of doctors at the Rheumatology and Immunology Clinic at the University Hospital in Kraków. This resulted in the registration of over 800 patients of our clinic, including the data of some patients have been collected prospectively since 2021. Implementation of this solution in further rheumatology centers, including academic units in Poznań, Bydgoszcz and two in Kraków together with building an IT infrastructure for sending anonymized data from networked units created the basis for launching the first Polish register of rheumatic diseases.

The development of these solutions will be crucial for assessing the Polish perspective on the quality of care for patients with rheumatological diseases and will enable the evaluation of patients' treatment in real conditions. The registry of rheumatic diseases will allow for a better understanding of the epidemiology, risk factors, progression and outcomes of rheumatic diseases. This will allow physicians and healthcare teams to monitor the progress of treatment and adapt to current recommendations and guidelines, and base their decisions on the treat to target strategy. The registry will

also make it possible to assess the effectiveness and safety of the therapies used in a wider population of patients, which will help in making decisions regarding therapeutic recommendations in the future.

Another key aspect of implementing the registry is the ability to monitor and assess the impact of these conditions on patients' quality of life, allowing them to tailor care and support patients in disease management. The key role in this process is played by the so-called PROMs, which make available to assess the quality of life of patients from their own point of view. The PROMs used in the project allow for the collection of information about patients' experiences and their symptoms, such as pain, loss of function, stress and other factors affecting quality of life, as well as assessment of the impact of their diseases on productivity at work, quality of life and mental health. In rheumatology, PROMs are particularly important because rheumatic diseases often affect a patient's quality of life and cause permanent damage to joints and other tissues.

It should also be remembered that access to real data can significantly improve the management of public funds allocated to the care of rheumatological patients. The registers allow for the monitoring and evaluation of the effectiveness of the use of public funds for the treatment of rheumatic diseases, which enables optimization of expenses and savings of public funds. In addition, thanks to the registers, rheumatologists have access to current data on the effectiveness and efficiency of therapy, which allows for the introduction of more effective and effective therapies and reduction of treatment costs.

Taking into account all these benefits from the use of the analysis of data collected in the register, the implementation of such a solution in the Polish health care system, in addition to improving the access to modern drug therapies, is currently one of the greatest opportunities for real improvement in the quality of care for rheumatological patients.

## CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

## References

1. Misra DP, Agarwal V. Real-world evidence in rheumatic diseases: relevance and lessons learnt. *Rheumatol Int.* 2019; 39(3): 403–416, doi: [10.1007/s00296-019-04248-1](https://doi.org/10.1007/s00296-019-04248-1), indexed in Pubmed: [30725156](https://pubmed.ncbi.nlm.nih.gov/30725156/).
2. Knevel R, Liao KP. From real-world electronic health record data to real-world results using artificial intelligence. *Ann Rheum Dis.* 2023; 82(3): 306–311, doi: [10.1136/ard-2022-222626](https://doi.org/10.1136/ard-2022-222626), indexed in Pubmed: [36150748](https://pubmed.ncbi.nlm.nih.gov/36150748/).