

Jagiellonian University and allied rheumatology centers across the country have launched Poland's first registry on inflammatory rheumatic diseases

How the Real World Evidence Registry in Rheumatic Diseases in Poland has finally become a fact. A long, steep road successfully completed

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Dear Editor,

It was in early 2019 when a group of rheumatologists at Jagiellonian University Medical College had a vision of having Polish real world data instead of constantly quoting data from other countries. Such real world data are needed not only for scientific work, but also for improving the health care system and health care outcomes – our colleagues from the West have already seen this. Also big pharma listens to such data, which helps them set the pace for research and development of new drugs and improvement of drugs already in use by the rheumatology community. So, why do we not have our own registry in Poland?

We have a lot of patients with rheumatic chronic inflammatory diseases, and current worldwide progress in medicine has been established on two pillars – randomized controlled trials (RCTs) and real world evidence (RWE). These two are a bridge to joint research and improvement of clinical achievements. Since RCTs are the domain of pharmaceutical companies, RWE remains attractive for us. Doesn't such a large country deserve its own real world data in that case? Yes, of course – so that is why we decided to start.

We did not want to duplicate the scheme – “we have an idea of a RWE Registry and once you give us money we will arrange it”. No, we adopted a different approach – we wrote a project application with Norwegian partners and received funding of PLN 7 million from Norway Grants via the National Centre for Research and

Development in POLNOR Call 2019. The grant focused on improving health care and health outcomes of patients with inflammatory rheumatic diseases, both adults and children. Thus we got access to all Norwegian experience in RWE and their know-how in recording and navigating data flow for scientific but also practical purposes. Importantly, one of the key tasks was to create a high-quality register that would meet the requirements of data collection according to the philosophy of real world evidence that would be the basis for further scientific investigations and progress in clinical practice in Poland.

So, all hands on deck, two clinical departments – Jagiellonian University Medical College Department of Rheumatology and Immunology and Sorlandet Hospital Division of Rheumatology from Norway and two IT companies – KAMBU from Krakow and DiagraphIT from Kristiansand, and the work began in early 2021 as PolNor Rheuma Project (www.polnorrheuma.com).

The main undertaking at the beginning was to adapt a tool – the Norwegian IT program GoTreatIT (www.diagraphit.no) – for structured clinical data collection to the Polish environment. Once we had done this, we started enrolling patients in our database, and now we have more than 800 patients enrolled. For some, visits and data have been collected since the beginning of 2021. In the database we have evidence on the activity of the disease, imaging, treatment, side effects, accompanying diseases, and much more. In addition, we have a huge amount of data reported by the patients themselves, so

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called PROMs, e.g. as to the quality of life, health status, professional work, disability and a number of subjective symptoms.

We have data of patients with the most prevalent inflammatory rheumatic diseases – rheumatoid arthritis, ankylosing spondylitis, non-radiographic axial spondyloarthritis, peripheral spondyloarthritis, psoriatic arthritis and psoriatic arthritis with axial disease. This is the first wide-ranging undertaking in Poland covering real world data collected prospectively in a substantial and constantly growing number of patients, which would guide further analysis and research activities on inflammatory rheumatic diseases. Four other rheuma-

tology centers, including academic departments from Poznan, Bydgoszcz and two others from Krakow, have already joined the cooperation with us and are currently in the process of adapting their data collection systems.

Jagiellonian University Medical College is a part of the Jagiellonian University – the oldest higher education institution in Poland and one of the oldest in Europe. Since 2007, we have ranked first in the category of medical universities in Poland's most important annual university ranking. Our status in Poland and abroad is illustrated by widely recognized research activities, including the present pioneering efforts in real world data collection on inflammatory rheumatic disease.