The Finnish Rheumatology Register (FRR; ‘Reumarekisteri’)

15th November 2020

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Background

Structured follow-up data regarding inflammatory rheumatic diseases has been collected in the Finnish rheumatology units for several years already. This data has been gathered and analyzed nationally based on the ROB-FIN (the Finnish register of Biological Treatment) research permit.

The Government Decree from 2017 on the organization of specialist care stated that the Pirkanmaa Hospital District is responsible for the nationwide planning and coordination of diagnostics and treatment of inflammatory rheumatic diseases. The Coordination Center for Rheumatic Diseases (Reumasairauksien koordinaatiokeskus) was established for this purpose. It aims to assess the diagnostics, treatment and achieved treatment outcomes of rheumatic diseases both nationally and regionally. A national rheumatology quality register is a prerequisite for the Center to accomplish this aim.

The Finnish Society for Rheumatology has set an aim of building a national rheumatology quality register that would follow the examples of other Scandinavian countries.

Svensk Reumatologis Kvalitetetsregister, www.srq.nu

Svenska barnrheumaregistret, www.barnreumaregistret.se

In 2018, the Finnish Institute for Health and Welfare (THL) started a pilot project on national quality registers. The aim of the pilot was to gather experiences that would form the basis for continuous development and maintenance of national health quality registers. The Rheumatology Register was chosen as one of the pilot registers in this project, and the project was carried out in collaboration with THL and the Finnish Society for Rheumatology. Also representatives from patient organizations took part in the planning of this project. Among other things, experts from THL developed ICT solutions and compatibility between The Finnish Rheumatology Register and other national registers. The pilot project ended on 31 October 2020. Currently, the Finnish Society for Rheumatology is waiting for a Decree on national registers from the Ministry of Social Affairs and Health (STM). The Decree will determine whether The Finnish Rheumatology Register will be maintained and funded by THL in the future.

Purpose of the register

The primary purpose of the Finnish Rheumatology Register is to help rheumatologists and pediatric rheumatologists make treatment decisions concerning rheumatic diseases according to the treat-to-target strategy, which has been shown to improve treatment outcomes in numerous studies. The register aims to improve the quality, effectiveness and safety of patient care. In addition, it helps to unify diagnostics which at the moment can be heterogeneous. Register data can be utilized locally in rheumatology clinics to evaluate and improve operations.

Furthermore, the quality register enables comparisons between different regions and rheumatological units in Finland. Collected data can also be utilized in scientific research on the effectiveness and safety of different treatments as well as in developing new drugs. The quality register also enables the monitoring of the efficacy and safety of new antirheumatic drugs, such as biosimilars.

Content of the register

The register contains information on all patients who have been diagnosed with an inflammatory rheumatic disease in Finland and who qualify for special reimbursements for medicine expenses according to the Social Insurance Institution of Finland (KELA) (ICD-codes: K50.9, K51.9, L40.5, M02, M05, M06, M08, M13.9, M30–M35, M45, M46.1, M46.9, M94.1. M09.0*L40.5). Approximately 100 000 patients (2% of Finns) suffer from a rheumatic disease that requires long-term treatment. The largest patient group is rheumatoid arthritis (approximately 0.8% of Finns). Other major rheumatological diseases are ankylosing spondylitis and non-radiographical axial spondylarthritis (together 0.5 %), psoriatic arthritis (0.3%) and juvenile idiopathic arthritis (0.2%; < 16-year-olds).

Data content of the register includes the patients' identification data, demographics and life style and occupational information. The register also contains information on the diagnosis, diagnostic findings, comorbidities, treatment and disease activity during follow-up visits. Patient reported outcomes (PROs) form an essential part of the data content.

Implementation

Rheumatologists, nurses and quality secretaries in rheumatology units collect patient information using different register platforms: GoTreatIt (GTI), BCB and RaiQu. Rheumatologists participate in improving the data content of the register platforms together with the software providers. Information from these register platforms have already been transferred to THL where preliminary analyses have been performed as a basis for national peer-review.

In the future, the aim is to combine data from the Finnish Rheumatology Register with the data from other national registers, such as the KELA registers on medicine purchases, rehabilitation and pensions and sickness allowance, the Care Register for Health Care (HILMO), Statistics Finland's register on causes of death and the Finnish Centre for Pensions' pension register, among others.

Publications (ROB-FIN)

- Huoponen S, Aaltonen KJ, Joensuu JT, Rutanen J, Relas H, Taimen K, Puolakka K, Sokka T, Nordström DC, Blom M. The cost-effectiveness of abatacept, tocilizumab, and tnf-inbitors as compared with rituximab as a second-line biological therapy for the treatment of rheumatoid arthritis in Finland. PLOSOne,Published:July 24, 2019
- Lindström U, Glintborg B, Di Giuseppe D, Nordström D, Aarrestad Provan S, Gudbjornsson B, Askling J, Lund Hetland M, Aaltonen K, Krogh NS, Geirsson AJ, Jacobsson LTH. Treatment retention of infliximab and etanercept originator versus their corresponding biosimilars in 2334 biologics-naïve patients with spondyloarthritis – a Nordic collaborative observational study. RMD Open. 2019 Oct 23;5(2).

- Chatzidionysiou K, Lukina G, Gabay C, Hetland ML, Hauge EM, Pavelka K, Nordström DC, Canhão H, Tomsic M, Rota Z, Lie E, Kvien TK, Vollenhoven RF, Saevarsdottir S. Smoking and Response to Rituximab in Rheumatoid Arthritis – Results from an International European Collaboration. Scand J Rheumatol 2018; 27:1-7.
- Chatzidionysiou K, Lund Hetland M, Frisell T, Giuseppe D, Hellgren K, Glintborg B, Nordström DC[6], Aaltonen K, Törmänen M, Kristianslund EK, Kvien T, Provan SA, Gudbjornsson B, Dreyer L, Kristensen LE, Jørgensen TS, Jacobsson L, Askling J. Opportunities and challenges for real world studies on chronic inflammatory joint diseases through data enrichment and collaboration between national registers: the Nordic example. RMD Open, 2018 Apr 12;4(1):e000655. doi: 10.1136/rmdopen-2018-000655. eCollection
- Lauper K, Nordström DC, Pavelka K, Hernandez K, Kvien TK, Kristianslund EK, Santos MJ, Rotar Z, Iannone F, Codreanu C, Lukina G, Gale SL, Sarsour K, Luder Y, Courvoisier DS, Gabay C. Comparative effectivenessa of tocilizumab as monotherapy versus TNF inhibitors in combination with csDMARDs for rheumatoid arthritis after the use of at least one bDMARDs. Ann Rheum Dis. 2018; 77:1276.
- Lauper K, Mongin D, Iannone F, Kristianslund EK, Kvien TK, Nordström DC, Pavelka K, Pombo-Suarez M, Rotar Z, Santos MJ, Codreanu C, Lukina G, Courvoisier DS, Gabay C. Comparative effectiveness of subcutaneous tocilizumab versus intravenous tocilizumab in a pan-European collaboration of registries. RMD Open. 2018; 5;4 (2):000809.
- Glintborg B, Lindström U, Aaltonen KJ, Kristianslund EK, Gudbjornsson B, Chatzidionysiou K, Askling J, Nordström DC, Hetland ML, Di Giuseppe D, Dreyer L, Kristensen LE, Jørgensen TS, Eklund K, Grondal G, Ernestam S, Joensuu JT, Törmänen M[1], Skydsgaard H, Hagfors J, Kvien TK, Lie E, Fagerli K, Geirsson AJ, Jonsson H, Provan SA, Krogh NS, Jacobsson L. Biological treatment in ankylosing spondylitis in the Nordic countries during 2010-2016: a collaboration between five biological registries. Scand J Rheumatol. 2018; Aug:1-10.
- Aaltonen KJ, Joensuu JT, Pirilä L, Kauppi M, Uutela T, Varjolahti-Lehtinen T, Yli-Kerttula T, Isomäki P, Nordström DC, Sokka T. Drug survival on tumour necrosis factor inhibitors in patients with rheumatoid arthritis in Finland. Scand J Rheumatol. 2017;46(5):359-363.
- Aaltonen KJ, Ylikylä S, Joensuu JT, Isomäki P, Pirilä L, Kauppi M, Rannio T, Eklund K, Blom M, Nordström DC. Efficacy and effectiveness of tumour necrosis factor inhibitors in the treatment of rheumatoid arthritis in randomized controlled trials and routine clinical practice. Rheumatology. 2017;56(5):725-735.
- Joensuu JT, Aaltonen KJ, Aronen P, Sokka T, Puolakka K, Tuompo R, Korpela M, Vasala M, Ilva K, Nordström DC, Blom M. Cost-effectiveness of biologic compared with conventional synthetic disease-modifying anti-rheumatic drugs in patients with rheumatoid arthritis: a Register study. Rheumatology. 2016;55(10):1803-1811.
- Heinonen AV, Aaltonen KJ, Joensuu JT, Lähteenmäki J, Pertovaara MI, Romu M, Hirvonen HE, Similä AK, Blom M, Nordström DC. Effectiveness and Drug Survival of TNF Inhibitors in the Treatment of Ankylosing Spondylitis: A Prospective Cohort Study. J Rheumatol. 2015;42(12):2339-46.
- Aaltonen KJ, Joensuu JT, Virkki LM, Sokka T, Aronen P, Relas H, Valleala H, Rantalaiho V, Pirilä L, Puolakka K, Uusitalo T, Blom M, Konttinen YT, Nordström DC. Rates of serious infections and malignancies among patients with rheumatoid arthritis receiving either tumor necrosis factor inhibitor or rituximab therapy. J Rheumatol. 2015;42(3):372-378.
- Aaltonen KJ, Virkki LM, Jämsen E, Sokka T, Konttinen YT, Peltomaa R, Tuompo R, Yli-Kerttula T, Kortelainen S, Ahokas-Tuohinto P, Blom M, Nordström DC. Do biologic drugs affect the need for and outcome of joint replacements in patients with rheumatoid arthritis? A register-based study. Seminars in Arthritis and Rheumatism. 2013;43(1):55-62.
- Virkki L, Valleala H, Takakubo Y, Vuotila J, Relas H, Komulainen R, Koivuniemi R, Yli-Kerttula U, Mali M, Sihvonen S, Krogerus M-L, Jukka E, Nyrhinen S, Konttinen YT, Nordström DC. Outcomes of switching anti-TNF drugs in rheumatoid arthritis--a study based on observational data from the Finnish Register of Biological Treatment (ROB-FIN). Clinical rheumatology. 2011;30(11):1447–54.

- Virkki LM, Sumathikutty B, Aarnio M, Valleala H, Heikkilä R, Kauppi M, Karstila K, Pirilä L, Ekman P, Salomaa S, Romu M, Seppälä J, Niinisalo H, Konttinen YT, Nordström DC. Biological therapy for psoriatic arthritis in clinical practice: outcomes up to 2 years. The Journal of rheumatology. 2010;37(11):2362– 8.
- Virkki L, Aaltonen [1], Nordström DC. Biologiset reumalääkkeet – käytännön kokemukset rekisteritulosten valossa. Duodecim.2010;126:1487–95.
- Virkki LM[1], Konttinen YT, Peltomaa R, Suontama K, Saario R, Immonen K, Jäntti J, Tuomiranta T, Nykänen P, Hämeenkorpi R, Heikkilä S, Isomäki P, Nordström D. Cost-effectiveness of infliximab in the treatment of rheumatoid arthritis in clinical practice. Clinical and experimental rheumatology. 2008;26(6):1059–66.
- Konttinen L, Tuompo R, Uusitalo T, Luosujärvi R, Laiho K, Lähteenmäki , Puurtinen-Vilkki M, Lanteri R, Kortelainen S, Karilainen H, Varjolahti- Lehtinen T, Nordström D. Anti-TNF therapy in the treatment of ankylosing spondylitis: the Finnish experience. Clinical rheumatology. 2007;26(10):1693–700.
- Konttinen L, Kankaanpää E, Luosujärvi R, Blåfield H, Vuori K, Hakala M, Rantalaiho V, Savolainen E, Uutela T, Nordström D. Effectiveness of anakinra in rheumatic disease in patients naive to biological drugs or previously on TNF blocking drugs: an observational study. Clinical rheumatology. 2006;25(6):882–4.
- Konttinen L, Honkanen V, Uotila T, Pöllänen J, Waahtera M, Romu M, Puolakka K, Vasala M, Karjalainen A, Luukkainen R, Nordström DC. Biological treatment in rheumatic diseases: results from a longitudinal surveillance: adverse events. Rheumatology international. 2006;26(10):916–22.
- Nordström DC, Konttinen L, Korpela M, Tiippana-Kinnunen T, Eklund K, Forsberg S, Ilva K, Kaipiainen-Seppänen O, Malmi T, Ylä-Kerttula T, Honkanen V. Classic disease modifying anti-rheumatic drugs (DMARDs) in combination with infliximab. The Finnish experience. Rheumatology international. 2006;26(8):741–8.