



This is an update on the work of the Norfolk Arthritis Register. Now in its 27th year, NOAR continues to recruit and follow up people who develop **Inflammatory Polyarthritis (IP)**. Overleaf is a list of publications resulting from NOAR research which can be found online at <http://research.bmh.manchester.ac.uk/Musculoskeletal/research/CfE/noar/noarinfo/publications>. If you would like a copy of any of these, please contact us at the NOAR Office, Room 2.22, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Tel: **01603 597204/5**.

Our continuing thanks to all NOAR participants who are helping improve our understanding of IP and how it affects their lives.

The Team: The NOAR team is based in the Norwich Medical School at the UEA, with NOAR Chief Investigator, Rheumatology Consultant Professor MacGregor, based in the new Bob Champion Research Education (BCRE) building opposite A&E at the hospital.

The NOAR staff are: Karen Durrant, Administrator, who is the first point of contact for any queries about appointments and responsible for the day-to-day running of the NOAR office (Monday, Wednesday, Thursday and Friday); Jackie Chipping is Clinical Nurse Manager, with Alison Lincoln and Pearl Claydon, research nurses.

In the last two years we have expanded recruitment to include people registered with GPs *mainly* within the Clinical Commissioning Groups (CCGs) of NHS Norwich, North and South Norfolk. Newly recruited participants will be followed up for five years .

Please contact NOAR if you would prefer an evening or Saturday appointment.

01603 597204/5 www.uea.ac.uk/noar

Funding

NOAR continues to receive its core funding from **Arthritis Research UK**, the leading medical charity for research into musculoskeletal disorders. Further information about arthritis and other musculoskeletal conditions can be found on their website: www.arthritisresearchuk.org

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Currently two NOAR papers are under review:

One shows that early treatment (within 6 months after disease onset) is associated with reduced disability over the course of two decades. This paper was presented at the British Society for Rheumatology meeting 2016.

The second describes surgical orthopaedic interventions over the course of 20 years, showing that 17% of patients underwent at least one major surgery during that time.

Other projects currently being worked on with NOAR data:

One is comparing the 10 year outcome of two groups of patients, recruited before and after the treatment revolution (use of methotrexate, and treating patients as early as possible). Although this shows that disease activity and mortality are reduced in the group recruited after the treatment revolution - disability has not improved. This work will be presented at the British Society of Rheumatology meeting 2017.

Another project involves looking at how depression and stress change over the course of five years in patients with IP. We have shown that the average level of depression and stress is remarkably constant in patients over this period and is not related to disease activity. However it is predicted by pain and disability at the current assessment and disability one assessment prior. This work has been submitted as an abstract to EULAR 2017. (European League against Rheumatism).

In October we started to look at outcomes over time in patients with moderate disease activity. This is a study funded by Arthritis Research UK and in collaboration with BSRBR-RA and ERAN.

Other studies:

RAMS is the Rheumatoid Arthritis Medication Study and looks at the response to Methotrexate by people with Inflammatory Arthritis who are about to start taking it for the first time, either on its own or in combination with other medication. Methotrexate is the drug most used to treat people with IP. The study aims to understand which patients benefit most from this treatment. RAMS is taking place at various sites throughout the country, so far we have recruited 220 participants. Nationally we are the second highest recruiter. <http://www.rams-study.net>

PREVeNT RA is looking for 'first degree' relatives of people with, or who have had, **rheumatoid arthritis** (eg mother, father, brother, sister, son, daughter, half brother or half sister). They must: **NOT** have rheumatoid arthritis or any inflammatory arthritis but **MUST** be:

- aged over 30
- resident in the UK
- willing to consent to complete questionnaires
- willing to give a blood sample
- willing to inform the study centre if they develop symptoms which may be related to rheumatoid arthritis

https://www.aruk.manchester.ac.uk/tacera_preventra/

NOAR PUBLICATIONS – CONTRIBUTORS 2016

Ajeganova S, Humphreys JH, Verheul MK, van Steenberg HW, van Nies JA, Hafstrom I, Svensson B, Huizinga TW, Trouw LA, Verstappen SM, van der Helm-van Mil AH. Anticitrullinated protein antibodies and rheumatoid factor are associated with increased mortality but with different causes of death in patients with rheumatoid arthritis: a longitudinal study in three European cohorts. *Ann Rheum Dis* 2016; **75**(11): 1924-1932.

Askling J, Berglind N, Franzen S, Frisell T, Garwood C, Greenberg JD, Ho M, Holmqvist M, Horne L, Inoue E, Michaud K, Nyberg F, Pappas DA, Reed G, Tanaka E, Tran TN, Verstappen SM, Yamanaka H, Wesby-van SE, Symmons D. How comparable are rates of malignancies in patients with rheumatoid arthritis across the world? A comparison of cancer rates, and means to optimise their comparability, in five RA registries. *Ann Rheum Dis* 2016; **75**(10): 1789-1796.

Cook MJ, Diffin J, Scire CA, Lunt M, MacGregor AJ, Symmons DP, Verstappen SM. Predictors and outcomes of sustained, intermittent or never achieving remission in patients with recent onset inflammatory polyarthritis: results from the Norfolk Arthritis Register. *Rheumatology (Oxford)* 2016; **55**(9): 1601-1619.

Gwinnutt J, Symmons DPM, MacGregor AJ, Chipping JR, Marshall T, Lunt M, Verstappen SMM. Disease activity, disability and surgery in a prospective inception cohort of inflammatory arthritis patients followed for 20 years: results from the Norfolk Arthritis Register. *Rheumatology (Oxford)* 2016; **55**(suppl 1): i36.

Gwinnutt J, Symmons DPM, MacGregor AJ, Chipping J, Marshall T, Lunt M, Verstappen SMM. Have Outcomes of Patients with Inflammatory Arthritis Improved in the New Millennium? a Comparison of the 10 Year Outcome in Cohorts Recruited in 1990-4 and 2000-4. *Arthritis & Rheumatology* 2016; **68**(Supplement S10): Abstract Number: 25.

Humphreys JH, Verheul MK, Barton A, MacGregor AJ, Lunt M, Toes RE, Symmons DP, Trouw LA, Verstappen SM. Anticarbamylated protein antibodies are associated with long-term disability and increased disease activity in patients with early inflammatory arthritis: results from the Norfolk Arthritis Register. *Ann Rheum Dis* 2016; **75**(6): 1139-1144.

Ling SF, Viatte S, Lunt M, Van Sijl AM, Silva-Fernandez L, Symmons DP, Young A, MacGregor AJ, Barton A. HLA-DRB1 amino acid positions 11/13, 71 and 74 are associated with inflammation level, disease activity and the Health Assessment Questionnaire disability index in patients with inflammatory polyarthritis. *Arthritis Rheumatol* 2016; **68**(11): 2618-2628.

Michaud K, Berglind N, Franzen S, Frisell T, Garwood C, Greenberg JD, Ho M, Holmqvist M, Horne L, Inoue E, Nyberg F, Pappas DA, Reed G, Symmons D, Tanaka E, Tran TN, Verstappen SM, Wesby-van SE, Yamanaka H, Askling J. Can rheumatoid arthritis (RA) registries provide contextual safety data for modern RA clinical trials? The case for mortality and cardiovascular disease. *Ann Rheum Dis* 2016; **75**(10): 1797-1805.

NOAR is the world's first community-based study of new onset cases of inflammatory polyarthritis, which has been carrying out research into inflammatory arthritis for over 20 years. Currently more than 4000 people are taking part. NOAR collects information (data) about you and we need to be fair, transparent and honest with you about what we do with the data. Identifiable information about you will be held by the NOAR nurses team at UEA (such as name, address, NHS and hospital number) and is kept separately in password-protected databases. Researchers not directly involved with you but involved in analysing your data know only your unique NOAR study number.

Information held by the Health and Social Care and other UK NHS bodies (Hospital Episodes Statistics) may be given to the researchers and be used to provide data about your health status and hospital admissions. To obtain information this information we will need to provide them with your NHS number, date of birth and gender and your unique NOAR ID. Once they link with these records they will remove the personal information and send us back the information for analyses.

When presenting information in research articles, your personal information is never revealed. More information about NOAR including informed consent can be found on the NOAR website www.uea.ac.uk/noar