

News Rheum



Edition 10:
Evidence-Based Patient Care
Autumn 2021

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

Welcome to the autumn 2021 edition of News Rheum. The theme of this edition is Evidence-Based Patient Care

IN THIS ISSUE

Since our last edition of News Rheum, our researchers and patient partners have been busy with grant applications and returning to campus. Following a short break in the summer, our Rheumatology research seminar series is back this semester. We are looking forward to hosting our annual conference (online) in November. We hope to see you there! The UCD Centre for Arthritis Research Steering Committee for 2021 consists of 10 committee members including three are patient representatives. The 2021 representatives are

Wendy Costello (Paediatric and Rare Disease), John Sherwin (Degenerative Arthritis) and Stacey Grealis (Inflammatory Arthritis) .



We hope you are well and enjoy this issue of News Rheum. If you would like to get involved, please contact us at:

patientvoicearthritis@ucd.ie

- *“IMPlmentation of osteoArthritis Clinical guidelines Together” (IMPACT) Project*, Dr Clodagh Twomey, University of Limerick
- UCD Centre for Arthritis Research Annual Conference 2021: Registration
- *The ROSE clinic: enhancing the care of women with rheumatic diseases during pregnancy* by Á. Gorman, L. Moore, Prof D. Veale
- UCD Centre for Arthritis Research Annual Conference 2021: *Clarity in Research Call for Abstracts*
- UCD Centre for Arthritis News

“IMPLementation of osteoArthritis Clinical guidelines Together” (IMPACT) Project

IMPACT



Implementation of osteoArthritis Clinical Guidelines Together

What is the IMPACT project?

A bit of background

The IMPACT research project aims to understand why all people with osteoarthritis are not being offered appropriate care for their joint pain and what we can do about it. It is a four-year Health Research Board funded project based in the University of Limerick, that will tackle these questions. Osteoarthritis affects 1 in 8 Irish people as they get older and this figure is expected to double within one generation. Most people with the disease in their hips or knees are likely to experience some level of pain as well as difficulty carrying out work or activities. Replacing the joint is a common treatment strategy and is normally a final resort.

Despite this, waiting lists for orthopaedic surgery in Ireland are at their highest ever and many patients are not given the recommended management options in the meantime. Clinical guidelines worldwide tell us that all patients with osteoarthritis should be treated with exercise, education and weight management strategies (if needed) as the first line of treatment. However, most people do not adequately trial the first line of treatment and this research aims to understand why.

The ‘Together’ part of IMPACT

To achieve the project aims, a participatory health research approach will bring together a group of expert researchers, people with osteoarthritis, healthcare professionals and policy makers to help understand the barriers, decide on the best strategy to deliver an evidence-based programme for osteoarthritis in Ireland, and also make sure it continues to be available once the research is over.

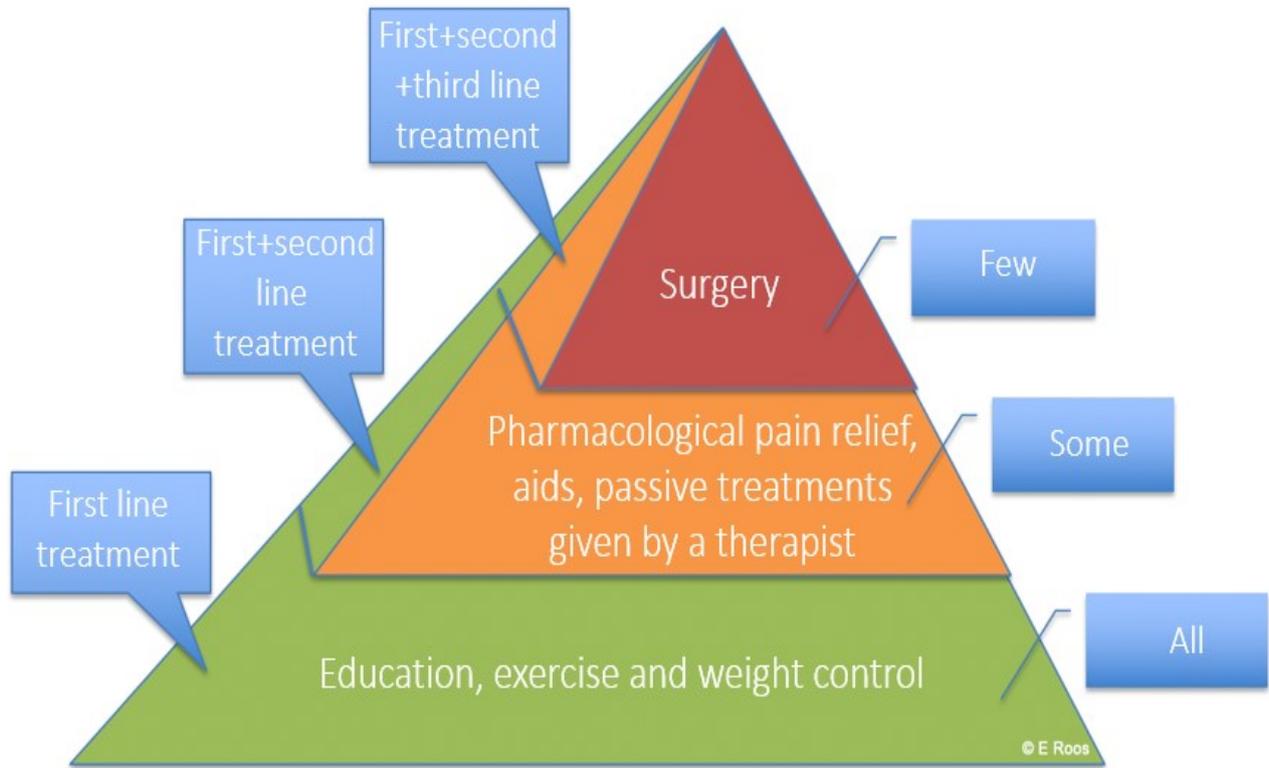
The GLA:D Ireland Programme

Once a plan to implement the programme has been decided on, physiotherapists around Ireland will be trained to deliver the [Good Living with osteoArthritis Denmark \(GLA:D®\)](#) programme in public and private health settings. The GLA:D programme consists of two main compo-

nents: evidence-based patient education and a six-week physiotherapist-supervised neuromuscular exercise training programme. Recent data from 9,825 patients in the GLA:D registry showed improved pain intensity and quality of life at 3 months and 12 months after starting the programme.

Furthermore, physical function and activity improved, fewer patients took painkillers (-24%), and fewer patients were on sick leave (-44%) after 12 months compared with the year prior. Based on this success, the programme has expanded and now has over 3,700 trained physiotherapists and more than 55,000 registered patients globally. We will monitor how feasible and acceptable the programme is in Ireland as well as how effective it is at improving patient health outcomes and reducing the personal and economic cost of disease.





We need your help

Before the programme is implemented, we need to understand the barriers! We are seeking input from people who live in Ireland with hip or knee osteoarthritis, to take a 10 minute survey on your experiences with osteoarthritis and exercise. The survey can be found at this [link](#). Please see the infographic and send to other family members or friends with hip or knee pain!

The IMPACT team includes primary investigator, Dr. Clodagh Toomey, PhD Student Avantika Bhardwaj, Co-investigators Prof Norelee Kennedy (all School of Allied Health, UL), Prof Anne MacFarlane, Prof Liam Glynn, Prof

John Forbes (all School of Medicine, UL), Prof Ewa Roos (University of Southern Denmark), and the IMPACT Steering Committee.

What if I have more questions?

For more information about the project, contact the primary investigator, Dr. Clodagh Toomey at clodagh.toomey@ul.ie.





Osteoarthritis Survey:

Researchers at the University of Limerick want to know about your experiences with hip or knee osteoarthritis. Please consider taking the following **10-minute** survey



If you:



have HIP or KNEE pain
(for at least 6 months or more)



are living on the island of Ireland



are 30 years or older



have **NOT** had **joint replacement surgery** on **at least one** of your painful hips or knees



Use the link below or take a **photo** of this QR code using a **smartphone**

<https://bit.ly/3ffUUOz>

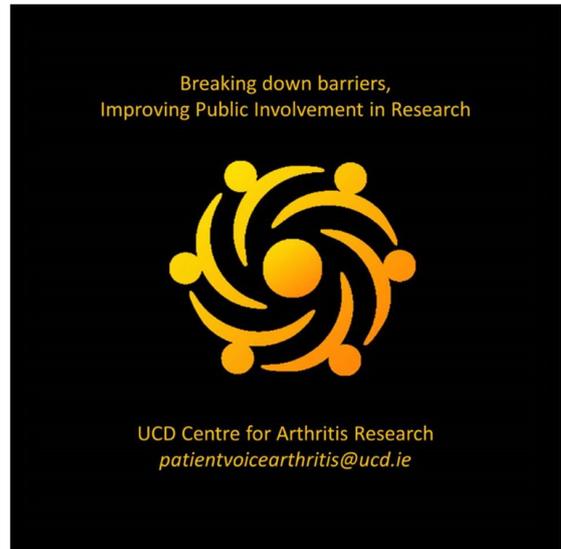


Participation is entirely voluntary and all answers are anonymous.
Ethics approval number: 2020_12_13_EHS. More information can be found using the link above or contacting the principal investigator at clodagh.toomey@ul.ie

IMPACT



Implementation of
osteoArthritis Clinical
Guidelines Together



New Treatments for Rheumatic Diseases

UCD Centre for Arthritis Research Annual Conference 2021

Wednesday 17th November
9:30am – 2pm



<https://www.ucd.ie/medicine/research/researchcentres/ucdcentreforarthritisresearch/events/>

The ROSE clinic: enhancing the care of women with rheumatic diseases during pregnancy

Á. Gorman¹, L. Moore², Prof D. Veale¹

1 The Centre for Arthritis and Rheumatic Disease, EULAR Centre of Excellence, St. Vincent's University Hospital and University College Dublin, Ireland
2 Our Lady's Hospice and Care Services, Harold's Cross, Dublin, Ireland

Rheumatic and musculoskeletal diseases (RMD) include a wide range of inflammatory conditions such as connective tissue diseases (CTD), primary systemic vasculitis, rheumatoid arthritis (RA), psoriatic arthritis (PsA) and ankylosing spondylitis (AS).

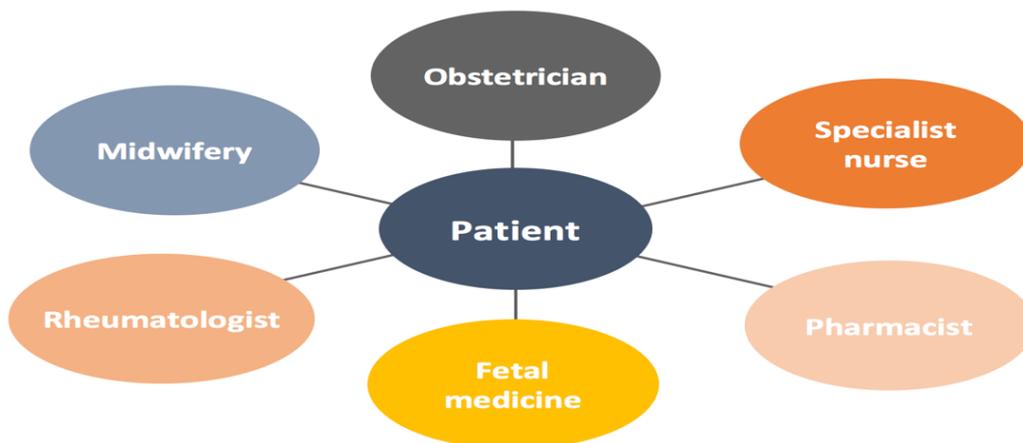
The history of the ROSE clinic

Rheumatic Musculoskeletal Diseases (RMD) affect women 2-3 times more often than men, occurring most frequently in the 30-40 age range therefore they commonly occur around the reproductive years. Active disease in pregnancy is potentially associated with adverse outcomes for both mother and baby such as low birth weight, pre-term delivery and pre-eclampsia. As a result, careful planning, combined management and good disease control before and throughout the pregnancy are essential to achieve the improved outcomes for all.

In a previous survey, it was revealed that the majority of clinicians (74%) had no local guidelines for pregnancy-related care in RMD patients. In this study, only 55% of rheumatologists consulted directly with their counterparts in obstetrics, and many were did not want to take medication during and after their pregnancy. Most respondents were unsure when medication should be discontinued before pregnancy or if medications were considered safe during pregnancy. Patients reported different approaches to management between centres, with a lack of shared care and few opportunities to discuss reproductive health in busy clinics. The result was that many young women considering starting a family were confused and frustrated at the lack of clear medical advice and guidance.

In 2013, the first designated multidisciplinary team in Ireland - the Reproductive Health Service was established. In March 2017, the Rheumatology Obstetric Service (ROSE) clinic, dedicated to providing the highest quality maternal medicine care for pregnant women with RMD, started at the National Maternity Hospital, Holles Street. The healthcare team has grown to meet patient's needs. This service includes rheumatology and obstetric consultants, specialist registrars, clinical nurse specialists, maternal medicine midwives and a dedicated pharmacist at the clinic.

Team members in the Rheumatology Obstetric Service (ROSE) Clinic



Patients are reviewed at the pre-pregnancy planning phase and in each trimester or more frequently if necessary. The patient is the central focus of the ROSE clinic.

The ROSE clinic aims to achieve the best disease control and outcomes for mother and baby. The importance of a key person to contact has been a recurring theme in feedback from patients. In our service, the key case manager is an experienced advanced nurse practitioner. Having a key contact leads to improved communication between everyone involved. The pathway begins with a pre-pregnancy planning visit with team members where the main aim is disease control, and a medication review is performed. Information is provided about medications guidelines, vaccinations, breastfeeding, and other advice such as nutritional advice. Another important aspect of this visit is giving the patient time to ask questions. Regular patient reviews, access via telephone or email, and a time for queries are central to providing a quality person-centered service. In those with an unplanned pregnancy, they access the pathway at whatever stage they present.

The ROSE Clinic

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Ongoing education and support is provided to the patient and they are referred to other multidisciplinary team members in anesthesiology, physiotherapy, occupational therapy, and medical social work if required.

The postnatal review is an essential aspect of the pathway as the postpartum period can be difficult for the patient. A common concern for patients with a RMD is having a flare at any point during pregnancy but especially after pregnancy, as it will impact their ability to look after their newborn. There is an increased rate of disease flare after pregnancy. After delivery, complications such as a wound infection may lead to RMD medication being withheld or a delay occurring in restarting medication after delivery. Patients are followed up at their original rheumatology clinic unless they are planning a further pregnancy within one year.

The ROSE clinic so far

To date, 136 patients have attended the ROSE clinic: 40 with Rheumatoid Arthritis, 5 with Vasculitis, 22 patients with Connective Tissue Diseases and 69 patients with other inflammatory types of inflammatory arthritis. Pre-pregnancy reviews were carried out with 15% of patients. This enabled us to assess if the patients' disease is in remission and if current medications were compatible with pregnancy. In terms of treatment, 9% of patients received steroids during their pregnancy with an average dose of 8mg, with 36% of patients receiving a conventional synthetic disease-



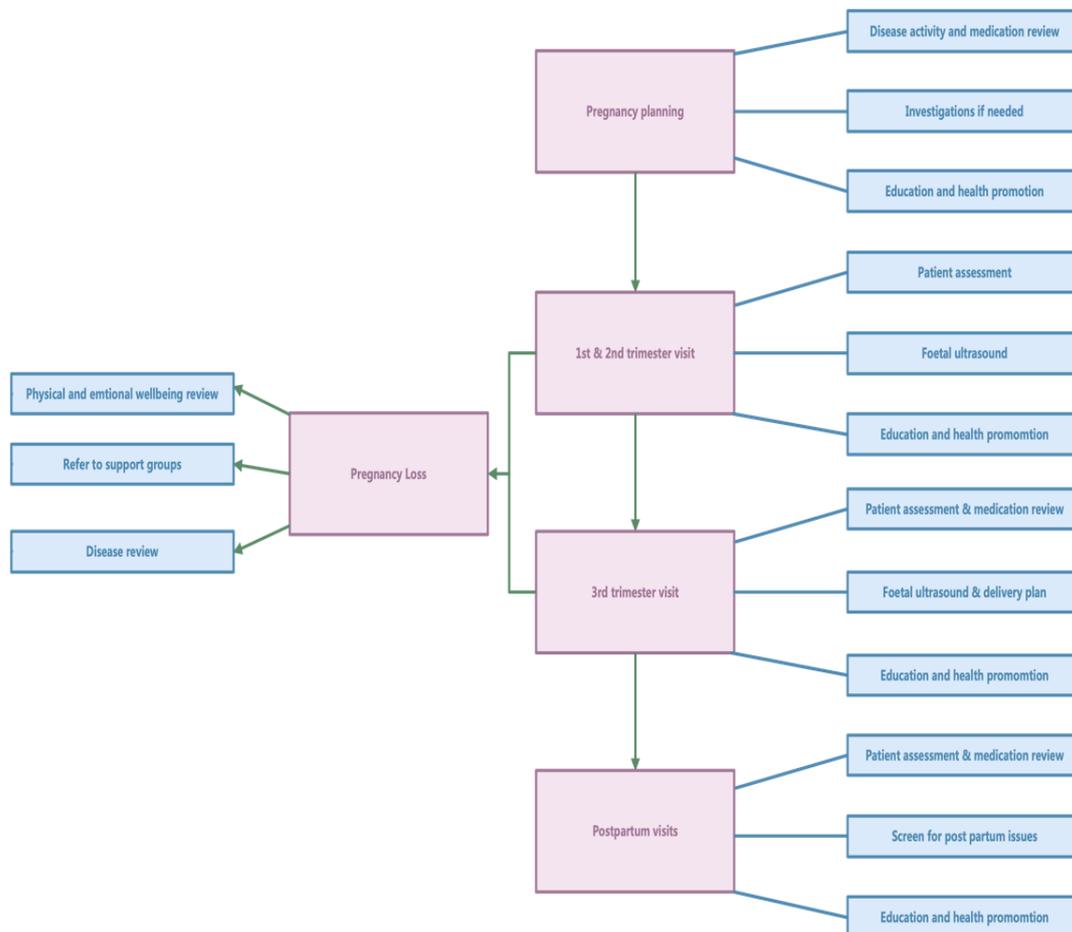
modifying antirheumatic drug (csDMARD) such as hydroxychloroquine. 62.5% of patients with inflammatory arthritis remained on a biologic agent during pregnancy. The patient is reviewed postpartum to assess disease activity and possible flare, as well as providing support. Over time, demand for our service has increased; in 2019, 43 patient visits occurred. In contrast, in 2020, this increased to 110 patient visits. Over 90% of patients were "very satisfied" with the service.

Research and the ROSE Clinic

Another focus of the ROSE clinic is to improve maternity outcomes in the future. The ability to predict disease course in pregnancy and pregnancy outcomes is based on previous pregnancy morbidity, disease activity prior to pregnancy and the presence of specific autoantibodies. During pregnancy, the mother's immune system is altered. Some RMD patients spontaneously im-

prove while pregnant. Studies have shown that RA patients can improve during pregnancy. In contrast, AS patient can remain active or deteriorate.

One important cell type is regulatory T-cells (T-cells). Previous studies have demonstrated T-cells protect from autoimmune RMD during pregnancy. There is an increase in circulating T-cells in pregnancy which declines after pregnancy. In studies in non-pregnant patients with RA, decreased levels of T-cells are present during active RA. While previous studies have focused on T-cell response in pregnant RA patients, there is a lack of data on T cell responses in pregnant patients. Our aim is to perform T-cell analysis to see if it is possible to predict a patient's disease course during pregnancy. This could help us decide on a treatment plan during pregnancy and improve outcomes for mother and baby.





Clarity in Research Medal Award

Call for Abstracts

The '**Clarity in Research**' Award is a patient-judged competition which will be held at the upcoming 2021 Annual UCD CAR Conference.

We are now accepting submissions in fields pertaining to rheumatic diseases. All submissions will be judged for clarity and use of plain English in research. We welcome both abstracts and posters.

The submission deadline is 5pm, ***Friday 15th October 2021***.

Further information about the Call for Abstracts is available on the UCD Centre for Arthritis website.

New Treatments for Rheumatic Diseases

UCD Centre for Arthritis Research



Annual Conference 2021

9:30am – 2pm, Wednesday 17th November

UCD Centre for Arthritis Research News

2021 has been a busy year so far for the UCD Centre for Arthritis Research with a successful research seminar series, research collaborations and new publications. We hope to continue this activity throughout the rest of 2021.

Research Seminar Series

The Centre for Arthritis Research—Rheumatology Research Seminar Series started again this semester for 2021. The seminar series hosted a number of world class academics during the first semester of 2021.

The first seminar of this semester took place on Friday 17th September with a superb presentation on PPI by UCD Professor of Health Systems Management Thilo Kroll.

If you would like to attend our seminars, please keep check on our [twitter page](#) for updates. We remain very grateful to our guest speakers and audience members. We look forward to welcoming you to future seminars.



Annual Conference 2021

This years' UCD-CAR Annual Conference is scheduled to take place on Wednesday 17th November. The conference theme for 2021 is "New Treatments for Rheumatic Diseases". The online event will feature speakers from academia, industry and patient partners. A draft programme is available on the Centre for Arthritis Research [website](#).

IMI Grant Award

Congratulations to Professor Oliver Fitzgerald and Professor Stephen Pennington on the launch of HIP-POCRATES, a new EU and Industry funded Psoriatic Arthritis research project.



The Patient Voice in Arthritis Research

The Patient Voice in Arthritis Research is a public and patient involvement (PPI) initiative, co-ordinated by the UCD Centre for Arthritis Research. It aims to ensure



that the real-life experiences of patients and their families are considered in research decision-making. If you would like to become involved, please contact patientvoicearthritis@ucd.ie

iCAN: Irish Children's Arthritis Network

The [iCAN Network](#) is a national support network for children with arthritis and their families. If you would like to become involved, please contact iCAN at icanireland@gmail.com

Arthritis Ireland

[Arthritis Ireland](#) works to support people with arthritis by providing access to healthcare, treatments and minimising the effects of arthritis on their quality of life. If you would like to become involved, please [contact](#) Arthritis Ireland. <https://www.arthritisireland.ie/>

**Thank you for working with The Patient
Voice in Arthritis Research this year!**

**If you would like to become involved in
our research, please contact us at
rheumatology@ucd.ie**



Questions? Ideas?

Would you like to write for
News Rheum?

We are always happy to hear from you. If you have an idea to share, a question to ask please do not hesitate to get in touch. We are always happy to hear from people who would like to contribute to News Rheum and what we cover. Get in touch at patientvoicearthritis@ucd.ie

If you would like a printed version of News Rheum, please contact us ((0)1 716 6728 or patientvoicearthritis@ucd.ie





Centre for Arthritis Research Rheumatology Research Seminar Series 2021

CONTACT US

UCD Centre for Arthritis Research
The Conway Institute
University College Dublin
Belfield, Dublin 4, Ireland

Tel +353 (0)1 716 6728

Email patientvoicearthritis@ucd.ie

Tweet at us @UCD_CAR



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