



UNIVERSITY OF CALGARY

Division of Rheumatology

# Rheum4U

## Rheum4U Precision Health Registry: Better Care through Data

### Exciting News

The Rheum4U Team was awarded a grant for almost \$60,000 from Pfizer for their research titled, "Getting Inflammatory Arthritis Patients Access to Care for Mental Health Issues: Mapping and Developing Care Pathways". A literature search and interviews/focus groups with patients and healthcare providers will be conducted to understand current mental health questionnaires and practices around accessing care for mental health issues for patients with inflammatory arthritis. From the research, an appropriate mental health questionnaire will be used in Rheum4U and a recommended care plan will be developed.

### Vision

To conquer inflammation and arthritis and to prevent disability

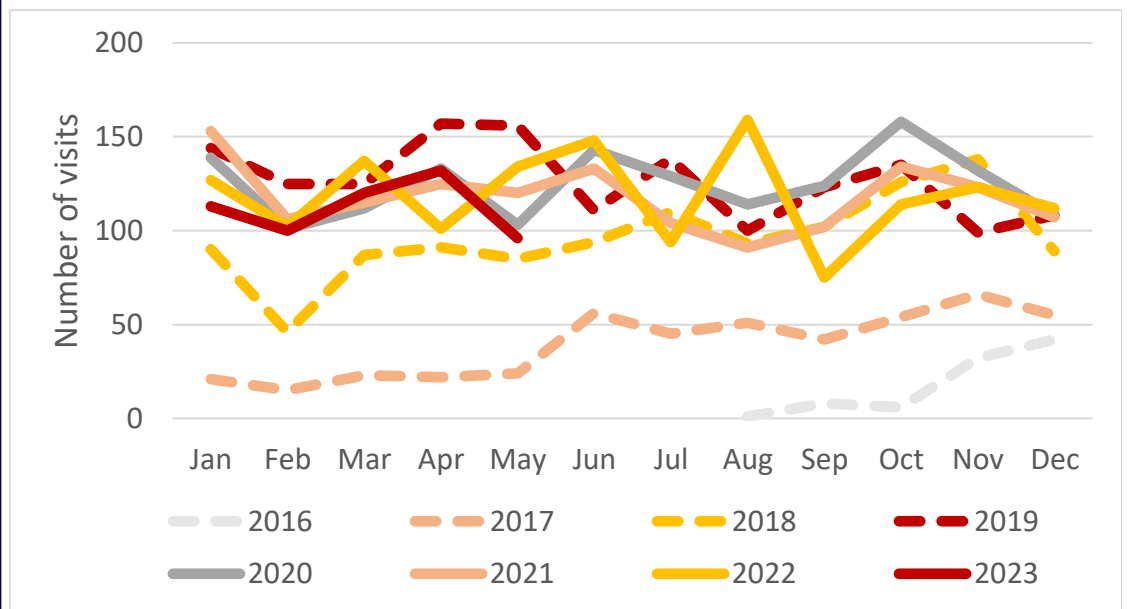
### Mission

We will optimize patient outcomes through early rapid disease recognition, fostering discovery, and initiating precision therapies, to accelerate new knowledge into practice

### Data Collection Update

As of May 2023, approximately 1,700 participants have contributed data to Rheum4U Precision Health Registry (Rheum4U). With 1,170 current active participants, Rheum4U has collected data on over 8,000 visits since 2016.

Since June 2022, 222 new participants have consented to the study. Over that same time, we collected data on more than 1,400 visits. On average, 18.5 new participants join the study each month and we collect data on 122 visits/month.

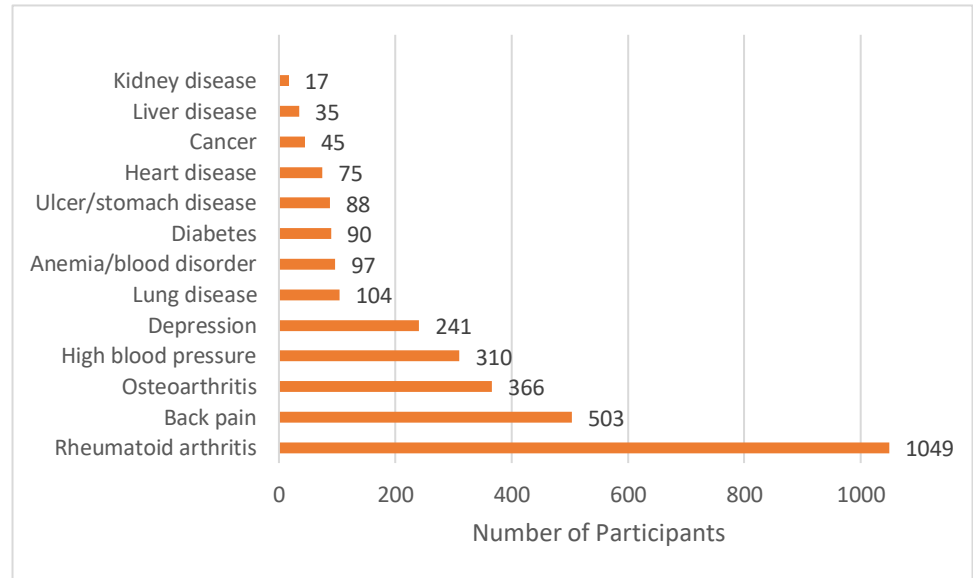


## Rheum4U Data What's collected?

- Demographic data
- Comorbidities
- Smoking Habits
- Alcohol Use
- Functional Assessment (ClinHAQ)
- Quality of Life Measure (EQ5D – 5L)
- Work Productivity (WPAI)
- Diagnosis
- Vitals (ht/wt/BP/HR)
- Blood Tests (ESR/CRP)
- Physician Global
- Swollen & Tender Joint Count
- Medications
- Spondyloarthritis Health History
- BASDAI
- Spondyloarthritis assessment

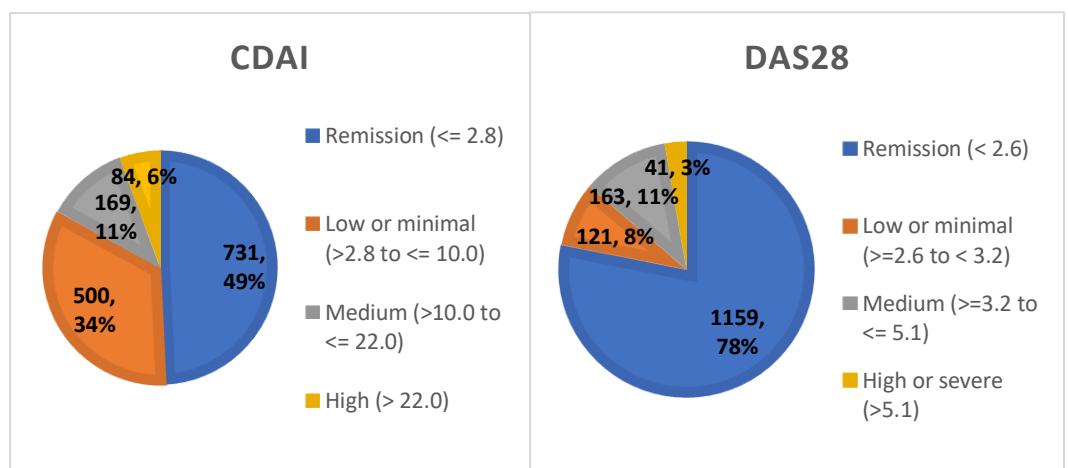
### Comorbidities of Our Participants

Upon study enrollment, 1,355 participants self-reported their comorbidities in Rheum4U. Participants reported an average of two comorbidities and 95% reported at least one comorbidity. The most common comorbidities reported were rheumatoid arthritis, back pain, osteoarthritis, high blood pressure, depression and lung disease.



### Participants in Remission on Enrollment

Upon study enrollment, 1,484 participants had an assessment documented in Rheum4U. Both DAS28 and CDAI showed around 85% of participants in remission or had low/minimal disease activity, however, DAS28 showed more patients in remission and less patients with low/minimal disease activity than CDAI.



# Rheum4U Research

Since its launch in clinic in August 2016, Rheum4U has streamlined recruitment and data collection processes in clinic as well as enabled the identification of potential research participants to support other research studies. Some of the research we are currently supporting are:

Researcher	Study	Description	Request
Barber	Patient-Initiated Care	Develop a care pathway for patient-initiated follow-up for rheumatoid arthritis patients who experience a flare or have urgent concerns.	<b>Recruit 12 participants</b> for gathering patient information in phase one and <b>recruit 72 participants</b> for the pilot in phase two
Jung/Luca	Smooth Transitions	Develop a multi-disciplinary virtual program for transitional care of AYAs with rheumatic disease in Southern Alberta using the information gathered from the existing literature, our needs assessment, and specific feedback from patients who have experienced a virtual transition meeting.	<b>Recruit 20 participants</b> ; conduct interviews; analyze data
Marshall	Biosimilar Switching	Understand the effects of the Alberta Biosimilar by examining switching patterns around the period of implementation and by demographics	<b>Data on over 7000 visits</b> collected over 5 years, 33 variables collected

## Next Steps for Rheum4U

- Patient-facing dashboard:
  - The Rheum4U team continues to work on developing a patient-facing dashboard that would show trends in disease management and allows patients to document their symptoms
  - The dashboard will enable shared decision-making, patient education, and can aid with triaging patient visits
  - Focus groups and interviews with patients, physicians and clinic staff will be conducted in a few months to provide insight on the design and layout of the content to build the prototype
- Linking Rheum4U to Connect Care :
  - The Rheum4U team is exploring how Rheum4U can be linked to the Connect Care electronic medical record system
  - The information collected in Rheum4U can be valuable for physician learning and improving the quality of patient care. Linking the data in Connect Care can support physicians and healthcare professionals to access the information and compliment administrative data
  - The Rheum4U team will carry out discussions with other research teams managing registries and Connect Care teams

## Participating Sites & Rheumatologists

- 2 Sites: RRDC & SHC
- 10 Rheumatologists

## Recent Publications, Abstracts, & Posters

- Mosher D, Gjata I, Benseler S, Stevenson M, Marshall DA on behalf of the Rheum4U Team, *Assessing the Diversity of Rheumatoid Arthritis Participants in the Rheum4U Precision Health Registry Cohort*. Canadian Rheumatology Association. Feb 2023
- Hazlewood GS, Colmegna I, Hitchon C, Fortin PR, Bernatsky S, Clarke AE, Mosher D, Wilson T, Thomas M, Barber C, Harrison M, Bansback N, Proulx L, Richards DP, Kaplan GG. Preferences for COVID-19 vaccination in people with chronic immune-mediated inflammatory diseases. *Journal of Rheumatology*. July 2023
- Pirhalova T, Sandhu N, Benseler S, Marshall D, Gjata I, Twilt M, Stevenson M, Olaosebikan O, Mosher D, on behalf of the Rheum4U Team. *Key factors for the development and implementation of a patient dashboard in rheumatology: review of literature*. Canadian Rheumatology Association. Feb 2022.
- Marshall, DA, Sandhu N, Benseler S, Twilt M, Guigue A, Gjata I, Stevenson M, Mosher D, on behalf of the Rheum4U Team. The relationship between disease activity measures and work productivity and activity impairment in patients with Rheumatoid Arthritis in the Rheum4U Precision Health Registry patient cohort. Canadian Rheumatology Association. Feb 2022.

# Rheum4U Research Request Process

## Did you know?

Since March 2020...

Rheum4U has supported  
17 research studies

Recruited or obtained  
consent to contact for  
over 240 participants

Shared data collected  
over 6 years and more  
than 5,000 visits

Rheum4U Precision Health Registry supports research and quality improvement initiatives. The Rheum4U Research Operations Committee will consider requests in support of the following:

- General inquiries such as patient cohort counts, data elements available, and retrospective availability. We support inquiries relating to grant submissions, LOIs and collaboration requests.
- Letters of support for researchers wishing to make use of data available in Rheum4U.
- Data access available for research and quality improvement projects, given appropriate Research Ethics Board (REB) approval. Rheum4U operates under a cost-recovery model, with concessions to students and new investigators.
- Data collection for research and quality improvement projects, given appropriate REB approval and the endorsement of the Rheum4U Research Operations Committee.
- Protocol development and ethics submission by providing expertise to researchers by developing research protocols and Research Ethics Board applications on a cost recovery basis.
- Participant recruitment and consent-to-contact for research studies by accessing our cohort of more than 1,500 participants.

Access to Rheum4U data and services involves the following steps:

- Submit a research request by completing the Research Request Form
- Meet with us to define research criteria
- Request is reviewed by the Rheum4U Research Operations Committee
- Sign Data Agreement
- Transfer Data

The list of Rheum4U data assets available to researchers can be found here:

[https://cumming.ucalgary.ca/sites/default/files/teams/323/Asset\\_2021.07.26.xlsx](https://cumming.ucalgary.ca/sites/default/files/teams/323/Asset_2021.07.26.xlsx)

For a broader overview of the research request process, the Research Request Form, and further description of how we can support research and quality improvement projects, please visit our website at:

<https://cumming.ucalgary.ca/department/s/medicine/division/rheumatology/rheum4u/researchers>

## Rheum4U Team

Research Operations Committee:

Dr. Dianne Mosher

Dr. Susa Benseler

Dr. Deborah Marshall

Rheum4U Support Team:

Wrechelle Ocampo O'Keefe, Project Manager

Martina Stevenson, Research Coordinator

## Contact Us

Dr. Dianne Mosher, Principal Investigator:

[dpmosher@ucalgary.ca](mailto:dpmosher@ucalgary.ca)

Wrechelle Ocampo O'Keefe, Project Manager:

[wbecampo@ucalgary.ca](mailto:wbecampo@ucalgary.ca)

## Website

[cumming.ucalgary.ca/rheum4u](https://cumming.ucalgary.ca/rheum4u)