



UNIVERSITY OF CALGARY

Division of Rheumatology

# Rheum4U

## Rheum4U Precision Health Registry: Better Care through Data

### Vision

To conquer inflammation and arthritis and to prevent disability

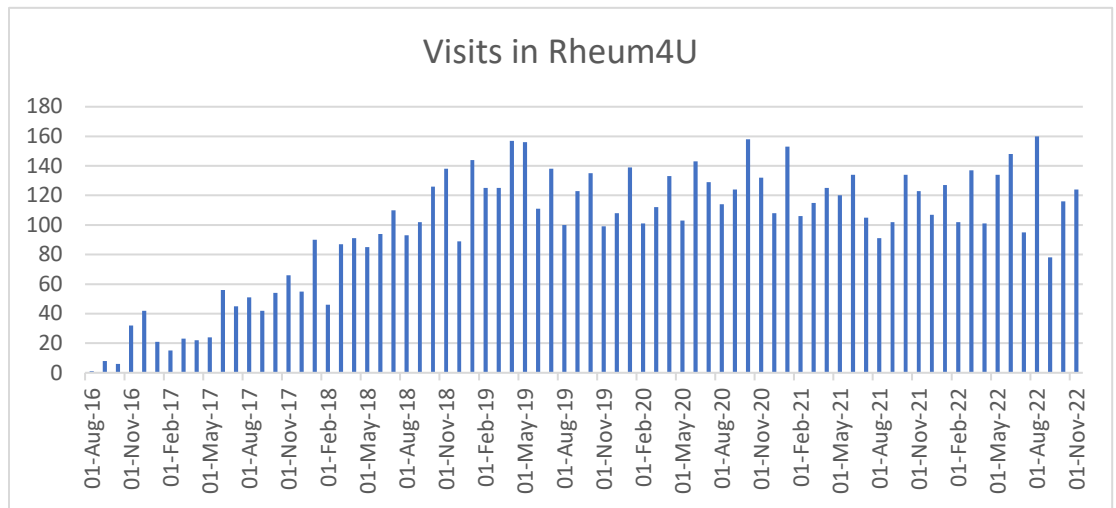
### Mission

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

Approximately 1500 participants have contributed data to Rheum4U Precision Health Registry (Rheum4U). With 1130 current active participants, Rheum4U has collected data on over 7400 visits since 2016.

Since January 2022, 199 new participants have consented to the study. Over that same time, we collected data on more than 1,300 visits. On average, 18 new participants join the study each month and we collect data on 120 visits/month.



	Consents	Visits
Year to date, count	199	1322
Year to date, monthly average	18.1	120.2

## 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

### Where do our participants live?

We queried postal codes provided by Rheum4U participants with a diagnosis of Rheumatoid Arthritis (RA) to determine their geographic distribution. The majority of Rheum4U participants, 66%, live in metro areas (i.e., Calgary) or areas with moderate metro influence (i.e., Cochrane or Okotoks), 14%. Participants in urban (i.e., Lethbridge, Medicine Hat) or moderate urban influence areas comprise 7% of our cohort. Rural participants represent 10% of those with RA in Rheum4U.

Previous research by Marshall et al. [1] revealed that RA prevalence rates were significantly higher in rural and remote areas of Alberta compared with urban areas. Our research team is interested in investigating further:

- What proportion of clinic patients live in metro, urban and rural areas?
- Are patients in rural areas being seen in clinic?
- Are patients from rural communities less likely to participate in Rheum4U than metro/urban participants?

Answers to these questions will inform whether there is a discrepancy in access to clinic resources and participation in research studies for rural participants.

[1] Liu X, Barber CEH, Katz S, Homik J, Bertazzon S, Patel AB, Robert J, Smith C, Mosher D, Marshall DA. **Geographic Variation in the Prevalence of Rheumatoid Arthritis in Alberta, Canada.** *ACR Open Rheumatol.* 2021 May;3(5):324-332. doi: 10.1002/acr2.11251. Epub 2021 Apr 1. PMID: 33793090; PMCID: PMC8126758.

### Participant Diagnosis

Patients with either confirmed or suspected inflammatory arthritis (IA) are eligible to participate in Rheum4U. We also collect diagnosis date and the most responsible diagnosis.

Through the Health History Questionnaire and Spondyloarthritis Health History questionnaire participants also report on other diagnosis, such as heart disease, diabetes, and cancer.

The most common diagnosis for participants in Rheum4U is Rheumatoid Arthritis, followed by Psoriatic Arthritis, Juvenile Idiopathic Arthritis, and Ankylosing Spondylitis.

# Rheum4U Research Request Process

## Did you know?

Since March 2020...

Rheum4U has supported  
10 research studies

Recruited or obtained  
consent to contact for  
over 200 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:

Inelda Gjata, Project Manager

Martina Stevenson, Research Coordinator

## Contact Us

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## Website

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

# Rheum4U: Supporting Research Studies

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. In 2022, we have supported the following studies:

Researcher	Study	Description	Request
Barber	A Better Match	Investigating strategies to optimize care for patients with rheumatoid arthritis (RA). Assess the content validity of the INTERMED Self-Assessment Questionnaire to measure clinical complexity of RA.	<b>Recruit 50</b> Rheum4U participants to complete interviews
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</b> participants; conduct interviews; analyze data
Hazlewood	CATCH	Study the real-world effectiveness of recommended treatments and treatment paradigms for patients with inflammatory arthritis.	<b>Data collection</b> and participant recruitment
Manske	ACTUS	Determine how joint swelling is related to the progression of bone damage and function in the hands.	<b>Recruit 39</b> participants with RA and hand involvement; <b>data on 330</b> visits collected over 6 years, 44 variables collected
Manske	RAIR	Determine the relationship between multi-modal imaging with bloodwork analysis to quantitatively evaluate the effects of subclinical levels of inflammation on bone progression within patients in RA remission.	<b>Recruit 30</b> Rheum4U participants
Marshall	Patient Acceptance of Bone Marrow Transplant	Survey using discrete choice experiment methodology to examine patient preferences for a potential new treatment for RA (bone marrow transplant) and how patient would trade-off between the benefits and risks.	<b>Recruit 10</b> participants for the pre-test and <b>100</b> participants for the main study

## Participating Sites & Rheumatologists

- 2 Sites: RRDC & SHC
- 7 Rheumatologists

## Recent Publications, Abstracts, & Posters

- 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.
- 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. Submitted. Pending Publication.
- Hazlewood GS, Bombardier C, Li X, Movahedi M, Choquette D, Coupal L, Bykerk VP, Schieir O, Mosher D, Marshall DA, Bernatsky S, Spencer N, Richards DP, Proulx L, Barber CEH, OBRI, RHUMADATA, CATCH Investigators, the Rheum4U Team. Heterogeneity in Patient Characteristics and Differences in Treatment Across 4 Canadian Rheumatoid Arthritis Cohorts. *J Rheumatol*. 2021 Aug 1;jrheum.201688. doi: 10.3899/jrheum.201688. Epub ahead of print. PMID: 34334357.