



UNIVERSITY OF CALGARY

Division of Rheumatology

# Rheum4U

## Rheum4U Precision Health Registry: Better Care through Data

### Vision

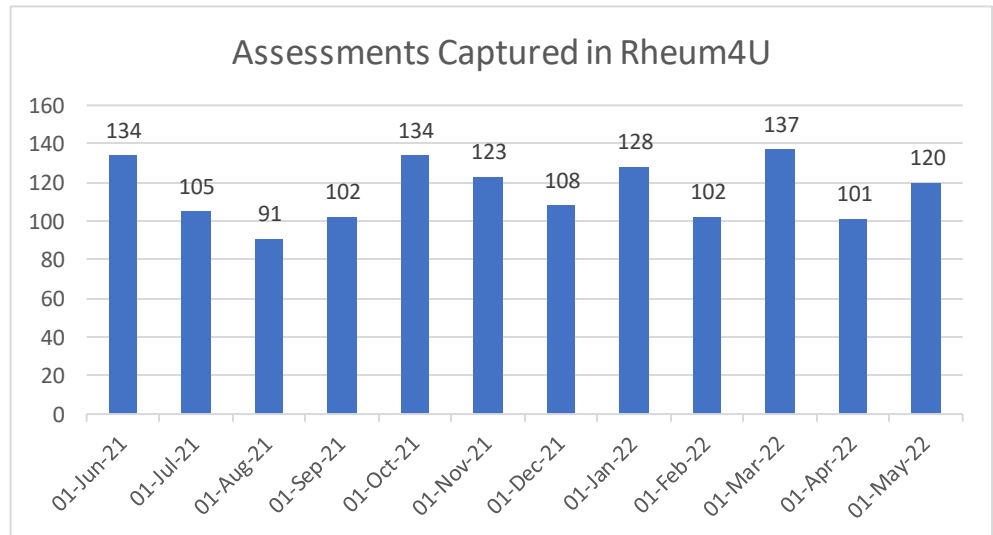
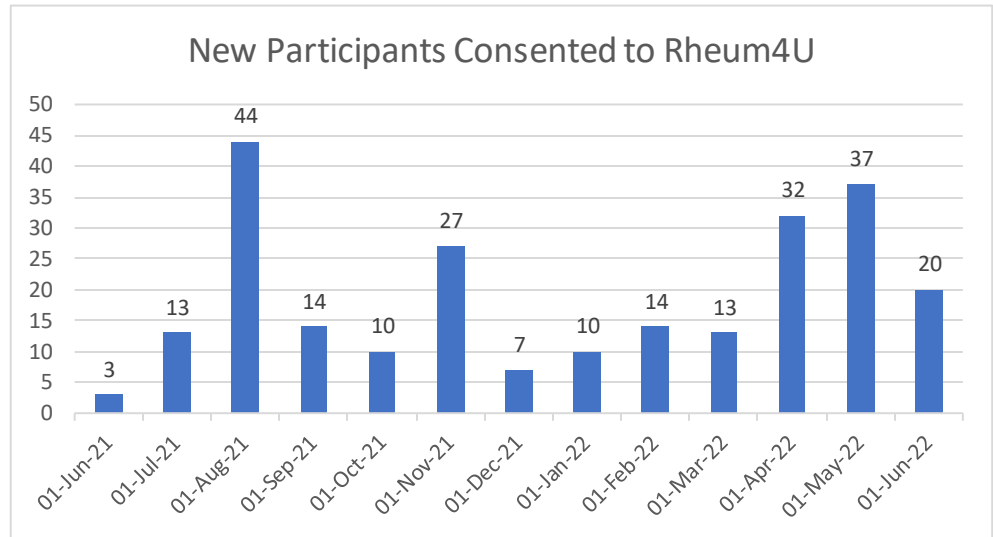
To conquer inflammation and arthritis and to prevent disability

### 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 Throughout the COVID-19 Pandemic

Over 1503 participants have contributed data to Rheum4U Precision Health Registry (Rheum4U). With 1042 current active participants, Rheum4U has continued to support new participant recruitment and data collection throughout the COVID-19 pandemic. Over the past 12 months (June 20, 2021 to June 20, 2022), 244 new participants have consented to the registry; 126 of those consented over the past six months. Each month, we collect data on over 100 patient assessments.

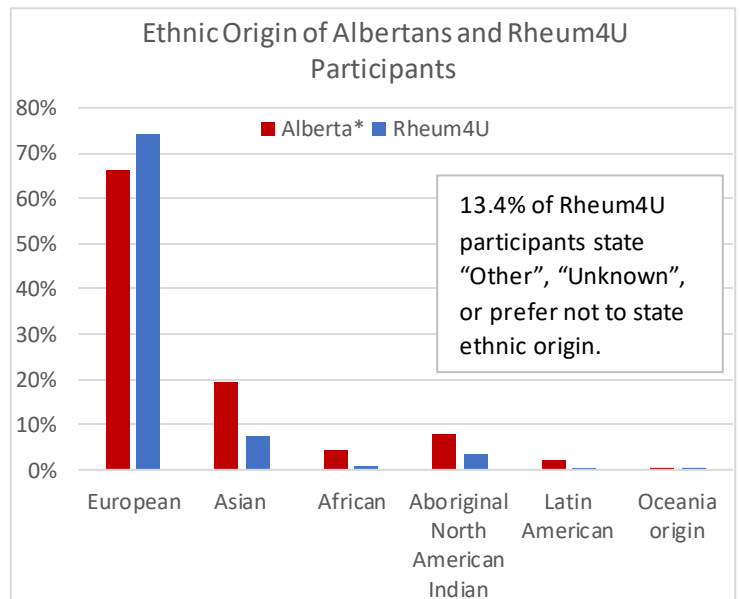
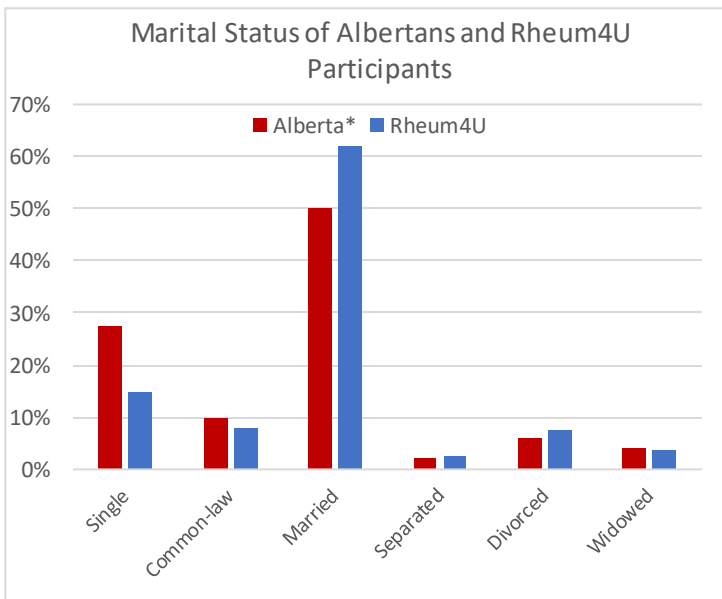
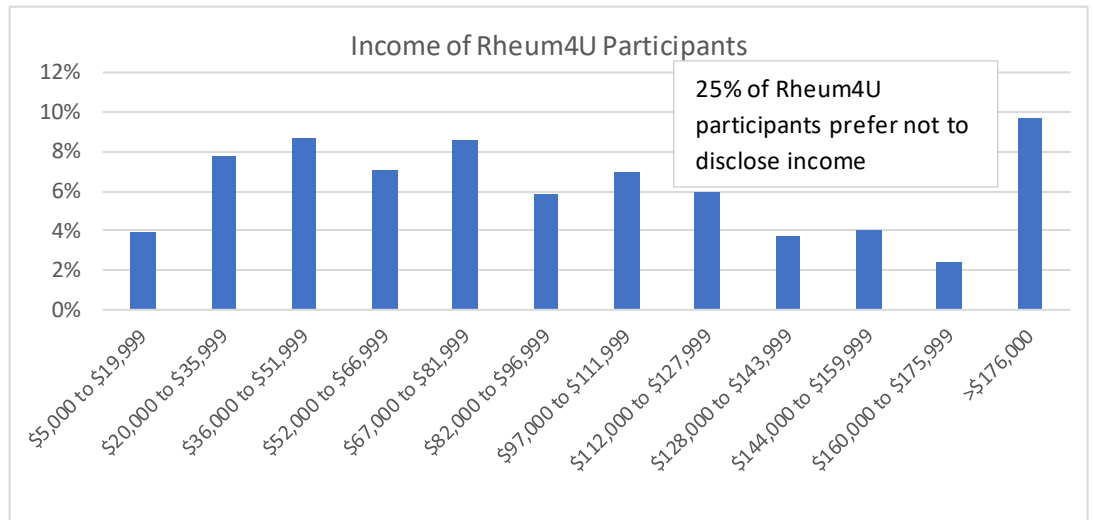
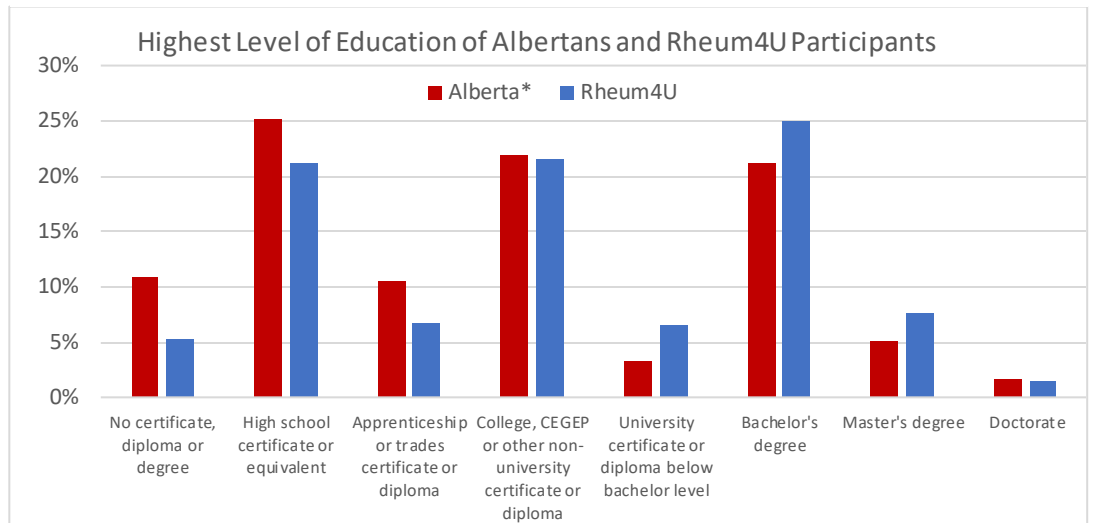


## Rheum4U Data What's collected?

- 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

### Rheum4U is a cohort representative of the population of Alberta

We compared the education level, marital status, ethnic origin of participants in Rheum4U to the larger Alberta population. Participants in Rheum4U are representative of the population of Alberta. The income of Rheum4U participants was also distributed throughout the different income categories.



\*Statistics Canada. 2017. *Alberta [Province] and Canada [Country] (table). Census Profile. 2016 Census.* Statistics Canada Catalogue no. 98-316-X2016001. Ottawa. Released November 29, 2017. <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E> (accessed June 8, 2022).

## Did you know?

Over the past 6 months...

**Rheum4U has facilitated recruitment for seven research projects**

**324 participants have been recruited, or are in the process of being recruited to these research studies**

# Rheum4U Development

Rheum4U in partnership with the Physician Learning Program (PLP) at the University of Calgary conducted focus groups and interviews with patients and health care providers to understand the utility of a Rheum4U data dashboard for patients. The dashboard would display disease progression over time accompanied by trends in medication use and patient-reported outcomes measures. The following major themes emerged:

- Patient portal – Rheum4U has the potential to be the *“MyHealth Alberta for Rheumatology, providing access to Rheumatology metric, patient resources and a hub for all RA related care needs”*. The patient portal to reduce burden of questions for the rheumatology clinic and improve clinic flow.
- Increase Data trends - All user groups want to see trends, rather than just a snapshot, including how changes in medication affect disease progression. Both patient and physician acknowledge the need for appropriate visual design to make it understandable and usable.
- Symptom and flare tracking - Patients indicate wanting to be able to track certain elements of their disease in a patient portal. All user groups indicate that the inclusion of flares in data collection would be of benefit to disease management.
- Data transparency and ownership - Both patients and physicians indicate the need for data transparency for patients. Access to personal data has the potential to increase patient autonomy and ownership. If the use of data is driven by a patient the likelihood of it being included in practice is higher. Rheum4U has the opportunity to provide a patient facing data dashboard, where patients are able to reflect and print/pull up a summary of their disease status to discuss with their physician.
- Patient education - Patient education should grow and evolve as the patients progresses throughout their journey with their chronic illness.

Over the next few months, we will work to:

- understand how PROMs, assessment, medication, and disease activity data collected in Rheum4U should be aggregated, displayed, and disseminated to support patient education, clinical care, and disease management
- understand how data collected in Rheum4U can be linked to ConnectCare
- compile a list of requirements that will inform the development of the dashboard
- engage all stakeholder groups in a co-design process
- develop a plan for usability, comprehension, and evaluation

## 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

Dr. Dianne Mosher, Principal Investigator:

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

Inelda Gjata, Project Manager:

[Inelda.gjata2@ucalgary.ca](mailto:Inelda.gjata2@ucalgary.ca)

# 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. We have contributed to the following studies:

Study	Principal Investigator	Rheum4U Support	Status
Pilot testing Online Data Entry by Division of Rheumatology Patients, Clinic Staff, and Physicians	Claire Barber, Rheumatology	Consented 131 participants between August 2016 – April 2017	Completed
A Balanced Scorecard Approach for Improving Care in Inflammatory Arthritis (CIHR & SPOR)	Claire Barber, Rheumatology	Consented participants between April 2017 to Sept 2019. Participants transitioned to Precision Health Registry study	Completed
The Precision Health Registry for Inflammatory Arthritis: Integrating Data Sources to Understand Disease and Improve Care for Rheumatology Patients in Alberta	Dianne Mosher, Rheumatology	Actively recruiting patients as of September 2019 with the implementation of Rheum4U v4.	In Progress
Optimizing Centralized Intake to Improve Arthritis Care for Albertans (PRIHS)	Deborah Marshall, Community Health Sciences	Contacted 27 participants; invited to complete an online survey	Completed
The relationship between sub-clinical inflammation and bony damage progression in rheumatoid arthritis (McCaig Institute)	Sarah Manske, Radiology	Recruited 10 participants; agreed to monthly visits for 6 months, completed baseline x-rays, HR-pQCT scan, and MRI Scan	Completed
Usability Testing of Methotrexate Decision Aid – Phase 2 (CIORA)	Glen Hazlewood, Rheumatology	Contacted 72 participants; invited to complete an online survey; provided Rheum4U-collected data on consented participants	Completed
Understanding Patient and Physician Choices for Tapering Treatment in Rheumatoid Arthritis (CIHR)	Glen Hazlewood, Rheumatology	Recruited 24 participants for focus group participation	Completed
Brain Dysfunction in Chronic Immune Mediated Diseases (CIHR)	Mark Swain, Gastroenterology	Actively recruiting patients; Targets: 15 patients on DMARD w/ no biologic; 15 patients on Enbrel (w/ or w/o DMARD); 15 patients on Actemra (w/ or w/o DMARD)	On hold
Advanced multi-modal imaging to predict early inflammatory arthritis progression: Assessing active	Sarah Manske, Radiology	Recruited 39 participants with RA and hand involvement. Provided Rheum4U collected data on consented participants.	Completed
Development of a Patient-Centered RA Quality of Care Survey and Testing Continuous Reporting of Established RA Quality Measures (U of C Dept of Medicine Clinical Analytics Award)	Claire Barber, Rheumatology	Recruited 50 participants using Rheum4U	Completed
Heterogeneity in Patient Characteristics and Differences in Treatment Across 4 Canadian Rheumatoid Arthritis Cohorts	Claire Barber, Rheumatology	Provided data on 709 rheumatoid arthritis participants.	Completed
A Better Match: Transforming rheumatoid arthritis care through tailored follow-up strategies based on disease activity and patient complexity	Claire Barber, Rheumatology	Recruited 25 participants for study participation	Completed
Preferences for COVID-19 vaccination in people with chronic immune-mediated inflammatory diseases.	Glen Hazlewood, Rheumatology	Recruited 32 participants to complete survey	Completed
Imaging the effects of sub-clinical inflammation on bone degeneration in rheumatoid arthritis remission	Sarah Manske, Radiology	Recruiting 100 participants for study participation.	In Progress
Canadian Early Arthritis Cohort (CATCH)	Glen Hazlewood, Rheumatology	Recruiting new participants and collecting data on active participants at Calgary site.	In Progress
Patient Acceptance of a Bone Marrow Transplantation as Treatment for Rheumatoid Arthritis	Deborah Marshall, Community Health Sciences	Recruiting 100 participants to complete survey	In Progress
Patient perspective in Biosimilar Switching	Deborah Marshall, Community Health Sciences	Recruiting 200-300 participants to complete survey	In progress
Virtual Health Methods in Transition	N Luca and M Jung, Rheumatology	Recruiting 20 participants for interviews	In Progress

## 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, Olaoosebikan 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.