



## 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

#### Rheum4U and Virtual Patient Care

Rheumatology care in outpatient clinics has been significantly impacted by the COVID-19 pandemic, highlighting the importance of providing safe and effective care for vulnerable rheumatology patients through virtual consults. Although new patient recruitment is limited, Rheum4U continues to facilitate data collection for participating patients attending in-person and virtual consults.

The Rheum4U online platform allows patients to enter patient-reported outcome measures (PROMs) from the comfort of their home before each appointment. Similarly, healthcare providers use Rheum4U to capture assessment data and changes to medications at each visit, regardless of whether the patient is seen in clinic or remotely.

#### Rheum4U Participants Before and During the COVID-19 Pandemic

The table below compares number of cases, disease activity, and patient reported outcomes captured in Rheum4U over a six month period before and during the COVID-19 pandemic.

	Pre-Pandemic (Mar-Sept 2019)	During Pandemic (Mar-Sept 2020)	Change (%)
Unique participants (n)	645	592	▼8
Visits (n)	793	755	▼5
Baseline visits (n)	157	61	▼61
EQ5D-5L VAS (mean score, SD)	73 (20.7)	72 (21.4)	▼1
CDAI score available (n, %)	778 (98%)	685 (91%)	▼7
Remission (CDAI ≤2.8) (n, %)	327 (48%)	434 (63%)	▲21
Low/Moderate (CDAI >2.8 - ≤22) (n, %)	403 (52%)	234 (34%)	▼18
High (CDAI >22) (n, %)	48 (6%)	17 (2%)	▼4
DAS28CRP score available (n, %)	573 (72%)	226 (30%)	▼42
Remission (DAS28CRP <2.6) (n, %)	394 (69%)	155 (69%)	◀▶
Low/Moderate (DAS28CRP ≥2.6 - ≤5.1) (n, %)	165 (29%)	68 (30%)	▼1
High (DAS28CRP >5.1) (n, %)	14 (2%)	3 (1%)	▼1

## 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

## What new functionality will be added?

Reporting Module to show patient-specific trends of disease activity scores, functional status, patient & physician reported outcomes, and CRP/ESR values

# Rheum4U Development

## Platform development

In February 2021, our team deployed a new module on the Rheum4U platform to support data collection for participants with diagnosed or suspected ankylosing spondylitis, psoriatic arthritis, undifferentiated spondyloarthritis, enthesitis-related arthritis, juvenile onset ankylosing spondylitis, and IBD-associated arthritis.

The following forms are now available on the Rheum4U platform:

- Spondyloarthritis Health History Questionnaire – Collects data on previous diagnosis (inflammatory bowel disease, iritis, or psoriasis) and family history of disease (ankylosing spondylitis, psoriasis, Crohn's disease, and iritis).
- BASDAI (Bath Ankylosing Spondylitis Disease Activity Index) – A disease activity questionnaire that collects subjective symptoms in the week prior to a patient appointment.
- Spondyloarthritis page – Captures Bath Ankylosing Spondylitis Metrology Index (BASMI) and chest expansion measurements, as well as dactylitis, enthesitis, hip movement, psoriasis and uveitis data.

## Supporting Research and QI

The Rheum4U study team supports researchers, student projects, and quality improvement (QI) initiatives through:

- granting access to Rheum4U data using our secure data environment for ethics-approved projects.
- recruiting study participants or obtaining consent to contact on behalf of researchers.
- supporting in-clinic data collection and developing data collection tools on behalf of researchers.
- developing study protocols and preparing ethics applications.
- providing Letters of Support and addressing inquiries in support of grant submissions.

If you or a student you support would like to initiate a project with Rheum4U, please contact Inelda Gjata at [Inelda.gjata2@ucalgary.ca](mailto:Inelda.gjata2@ucalgary.ca).

## Rheum4U Team

Rheum4U Research Operations Committee:

- Dr. Dianne Mosher
- Dr. Susa Benseler
- Dr. Deborah Marshall
- Dr. Marinka Twilt

Rheum4U Support Team:

- Inelda Gjata, Project Manager
- Namneet Sandhu, Research Coordinator
- Martina Stevenson, Research Coordinator

## Rheum4U Online Resources

We are in the process of developing online resources which will support patients and providers in using the Rheum4U platform in clinic and for virtual consults. Additionally, we are creating information guides on how Rheum4U can facilitate Continuing Medical Education activities, research projects, and quality improvement initiatives. Stay tuned!

## Contact Us

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# Rheum4U: Supporting Research Studies

Since its launch in clinic in August 2016, Rheum4U has supported recruitment and data collection for 9 different studies for PI's from Rheumatology, Community Health Sciences, Radiology, and Gastroenterology. Use of Rheum4U has streamlined recruitment and data collection processes in clinic as well as enabled the identification of potential research participants.

Study	Investigator	Rheum4U Support	Status
Pilot testing Online Data Entry by Division of Rheumatology Patients, Clinic Staff, and Physicians	Claire Barber, Rheumatology	Consented 131 participants from August 2016 – April 2017; collected study data using Rheum4U	Completed
A Balanced Scorecard Approach for Improving Care in Inflammatory Arthritis (CIHR & SPOR)	Claire Barber, Rheumatology	Recruited participants Apr '17 – Sep '19; collected study data using Rheum4U. Recruitment completed. Participants transitioning to Precision Health Registry study	Completed
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; 28 completed (39%)  Provided Rheum4U-collected data on the 28 participants who completed the online survey	Completed
Understanding Patient and Physician Choices for Tapering Treatment in Rheumatoid Arthritis (CIHR)	Glen Hazlewood, Rheumatology	Recruited 24 participants for focus group participation; 12 participated (50%)	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)	Pending
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
Advanced multi-modal imaging to predict early inflammatory arthritis progression: Assessing active Rheumatoid Arthritis with HR-pQCT and Ultrasound	Sarah Manske, Radiology	Actively recruiting 39 participants with RA and hand involvement	In Progress

## Precision Health Registry Study Recruitment

- Began Sep 2019
- Over 750 patients consented to date

## Balanced Scorecard Study Recruitment

- Apr 2017 – Sep 2019
- 914 patients consented

## Pilot Study Recruitment:

- Aug 2016 – Apr 2017
- 131 patients consented

## Participating Sites & Rheumatologists

- 2 Sites: RRDC & SHC
- 12 Rheumatologists
- 1 Nurse Practitioner

## Recent Publications, Abstracts, & Posters

Mosher D, Benseler S, Twilt M, MacMullan P, Gjata I, Sandhu N, Stevenson M, Brose A, Omotajo D, Marshall DA on behalf of the Rheum4U Team. The Rheum4U Precision Health Registry Platform: Enabling quality care for patients with inflammatory arthritis during the COVID-19 pandemic in two outpatient rheumatology clinics. Canadian Rheumatology Association Conference. February 2021.