



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

Goals

- Provide timely access to exemplary care
- Establish longitudinal data collection system to assess patient & system outcomes
- Develop a research team & align with University priorities
- Train world class health care professionals and students
- Become one of the top three Rheumatology residency training programs in the country
- Staff a full complement and highly coordinated team of rheumatologists and healthcare professionals

Rheum4U and Virtual Patient Care

Beginning in March 2020, the outpatient rheumatology clinic at Richmond Road Diagnostic and Treatment Center was impacted by the COVID-19 pandemic, limiting in-person clinic appointments to urgent cases only, while most patients attended phone consults. During this time, the Research Coordinator was able to support data collection remotely. As the clinic increased its capacity for more in-person visits, the Research Coordinator returned to the clinic two days/week, beginning in October 2020.

The ongoing COVID-19 world pandemic has highlighted the importance of providing safe and effective care for vulnerable rheumatology patients through virtual consults. The Rheum4U online platform allows patients to enter patient-reported outcome measures (PROMs) from the comfort of their home. 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.

The study team was able to capture a similar number of visits during the first six months of the pandemic (March-September) as the same period last year. The proportion of participants with an available Clinical Disease Activity Index (CDAI) score also remained consistent when compared to the same time last year. As fewer patients were able to complete laboratory tests during this time, we saw a decrease in the number of participants with a recent C-reactive Protein (CRP) or Erythrocyte Sedimentation Rate (ESR) values.

Rheum4U is an innovative tool that supports the collection of PROMs and facilitates effective monitoring of disease activity for both in-person and virtual consults.

Secure Data Storage and Sharing

The Rheum4U team has set up a Secure Compute Data Storage (SCDS) group that allows storing and sharing of Rheum4U data in a secure environment suited for restricted (level 4) data.

We have established processes for researchers to submit data requests, querying the Rheum4U cohort. All requests must be accompanied by an approved Research Ethics Board (REB) application. Following the review and approval of the request by the *Rheum4U Research Operations Committee*, data can be shared with internal and external collaborators in a secure manner.

Rheum4U Team

Rheum4U Research Operations Committee:

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

Rheum4U Support Team:

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

Contact Us

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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

The current version of the Rheum4U Platform focuses on collecting a core dataset for participants diagnosed with or who have a suspected diagnosis of rheumatoid arthritis. There is a need for a new module to record a core dataset for participants diagnosed with or who have a suspected diagnosis of ankylosing spondylitis, psoriatic arthritis, undifferentiated spondyloarthritis, enthesitis-related arthritis, juvenile onset ankylosing spondylitis, and IBD-associated arthritis.

The Rheum4U study team is in the process of developing and testing the following additions to the Rheum4U Platform:

- Spondyloarthritis Health History Questionnaire – completed by participants before every visit. 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) – completed by participants before every visit. A disease activity questionnaire that collects subjective symptoms in the week prior to their appointment.
- Spondyloarthritis page – completed by the healthcare provider during the assessment at each visit. Captures Bath Ankylosing Spondylitis Metrology Index (BASMI) and chest expansion measurements, as well as dactylitis, enthesitis, hip movement, psoriasis and uveitis data.

Manuscript Plan and CHI

The Rheum4U Research Operations Committee has prioritized the following four manuscripts to focus our efforts over the next year:

1. The primary objective of this paper is to report the correlation between patient-reported outcome measures (PROMs) and clinical measures for patients with inflammatory arthritis in the Precision Health Registry Rheum4U Cohort. The secondary objective is to assess the loss of work productivity in this population as it relates to PROMs.
2. The objective of this paper is to describe patterns over time for medication use and how they relate to disease activity.
3. The objective of this paper is to define how patient resource use relate to clinical outcomes and PROMs
4. The objective of this paper is to examine the transition cohort of those younger than 25 years old with JIA/RA.

The study team has engaged the Center for Health Informatics (CHI) at the University of Calgary to provide data analytics support for manuscripts 1 and 2. Additionally, CHI, will help develop a data management plan, as well as create continuously updating administrative tables that will help us monitor the cohort.

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)	In Progress
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

Rheum4U Statistics

Precision Health Registry Study Recruitment

- Began Sep 2019
- 752 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
- 10 Rheumatologists
- 1 Nurse Practitioner

Recent Publications, Abstracts, & Posters

Barber CEH, Mosher D, Dowling S, Bohm V, Solbak NM, MacMullan P, Pan B, Barnabe C, Hazlewood GS, Then KL, Marshall DA, Rankin JA, Li LC, Tsui K, English K, Homik J, Spencer N, Hall M, Lacaille D. Implementation and Evaluation of Audit and Feedback for Monitoring Treat-to-Target (T2T) Strategies in Rheumatoid Arthritis Using Performance Measures. *Rheumatol Ther.* 2020 Oct 9. doi: 10.1007/s40744-020-00237-0. Epub ahead of print. PMID: 33034861.