Rheum4U

UNIVERSITY OF CALGARY
Division of Rheumatology

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 Precision Health Registry: Better Care through Data

Rheum4U and Virtual Patient Care

The ongoing COVID-19 world pandemic has highlighted the importance of providing safe and effective care for vulnerable rheumatology patients through virtual consults.

Rheum4U Precision Health Registry (Rheum4U) enables real-time reporting of disease activity scores for rheumatoid arthritis (RA) patients. The web-based Rheum4U platform automatically calculates and displays the disease activity score (DAS), DAS 28-ESR, DAS28-CRP and Clinical Disease Activity Index (CDAI) score to physicians.

Similarly, for each consult, physicians can record the pharmacotherapeutic management of patients, indicating changes in medications, dose, or frequency. Recording and reporting disease activity and medication use over time allows rheumatologists to monitor disease progression, assess the safety and efficacy of interventions, and make adjustments as necessary.

Providing the right information at the right time enables clinicians to engage with their patients and make the most informed decisions about next steps in both in-person and virtual consults.

Linking to Administrative Datasets

Rheum4U is envisioned as a unique data collection platform in six key areas: (1) allow seamless integration into clinic operations, (2) data collection and patient progress tracking along the continuum of care, (3) patient care transitions from pediatric through to adult life, (4) include multiple rheumatic diseases, (5) provide data for real-time decision-making during clinic visits, and (6) enable continuous improvement through identification of variation in practice and subsequent outcomes.

To this end, the study team has initiated a collaboration with the Center for Health Informatics at the University of Calgary to link Rheum4U Precision Health Registry data to administrative datasets within Alberta Health Services.

By virtue of its integrated nature and ability to link various data sources, Rheum4U will provide a wealth of data to answer research questions pertaining to topics in advanced diagnostics and biomarkers, clinical epidemiology, clinical trials, models of care, health services delivery, patient outcomes, and health economics. Importantly, the systematic collection of data in Rheum4U will be used to identify gaps between knowledge and practice that can then be addressed through quality improvement initiatives.

- 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

What new functionality will be added?

- Ankylosing Spondylitis-specific data collection
- Biologics Summary page
- 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

Version 4 of Rheum4U was implemented in September 2019, adding significant changes to the medication module. Now, clinicians can better capture medication stop and start dates, as well as modifications to dose and frequency to better reflect changes in care. The study team is working to deploy version 4.1 of the platform which addresses the feedback received from clinicians. With this new version, clinicians will be able to record the first instance the medication was prescribed, including starting dose and frequency.

In the coming months, Rheum4U version 5 will see the addition of the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI). Additionally, design is underway for physician and patient dashboards reporting patient-specific trends of Disease Activity Scores, Functional Status, Patient & Physician Reported Outcomes, and CRP/ESR values.

From Balanced Scorecard to Precision Health

Following the end of recruitment for the Balanced Scorecard study ("*Development and testing of a balanced scorecard approach to improve quality of care in adult and pediatric arthritis patients*") in September 2019, participants have been invited to continue their involvement by consenting to participate in the Precision Health Registry study ("*Precision Health Registry for Inflammatory Arthritis: Integrating Data Sources to Understand Disease and Improve Care for Rheumatology Patients in Alberta*").

Over the next few weeks, Study Coordinators will contact participants who have yet to be invited to the Precision Health Registry Study. Consenting participants will have the opportunity to continue completing their medical questionnaires online before each physician consult. This will not only contribute data to research and quality improvement, but it will also provide physicians with valuable information about disease progression and patient outcomes.

Chart reviews

While patient enrollment in Rheum4U Precision Health Registry is still ongoing, currently, more than 1,000 patients have consented to participate and have contributed data. To ensure the accuracy and completeness of patient data, Study Coordinators have already completed chart reviews on >90% of cases. This process will allow for the accurate capture of historical disease presentation and medication data.

Team

Rheum4U Oversight 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; Damilola Omotajo, Research Coordinator

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; 942 active participants. Recruitment completed. Participants transitioning to Precision Health Registry study	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; 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
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	• Approximately 50 RA patients will be recruited using Rheum4U • Patient-Centered survey will address gaps in RA quality measurement brought to light by Balanced Scorecard Project • Testing continuous reporting of quality measures is based on data captured in Rheum4U	In Progress

Rheum4U Statistics

Precision Health Registry Study Recruitment
- Began Sep 2019

Balanced Scorecard Study Recruitment
- Apr 2017 – Sep 2019
- 942 patients consented
- >80% consenting to be contacted for future research

Pilot Study Recruitment:
- Aug 2016 – Apr 2017
- 131 patients consented

Participating Sites & Rheumatologists
- 2 Sites: RRDTC & SHC
- 12 Rheumatologists
- 1 Nurse Practitioner

Publications, Abstracts, & Posters
- Poster presented at ACR November 2019: *Testing Rheumatoid Arthritis Performance Measures to Optimize Treat to Target Strategies*

- *Rheum4U: Development and testing of a web-based tool for improving the quality of care for patients with rheumatoid arthritis* (Barber CEH et al) Clin Exp Rheumatol. 2018 Aug 29