



MARINA WADA

Department: School of Public Health and Health Systems at the University of Waterloo

Program: Master of Science

Project type: Thesis Project

Project funded by: NSERC

Project co-researchers: Dr. James Wallace, School of Public Health and Health Systems, HCI and Health Lab, Faculty

Rheumatoid arthritis (RA) is a chronic inflammatory joint condition that affects patients throughout their lifetime. For that reason, patients with RA must make several medication choices, each with long-term and short-term side effects that provide a complex basis for medication decision making. Our project employed user-centred design methodologies to collect qualitative data about RA patients' needs and desires: for example, we interviewed patients about how they'd envision integrating interactive technologies to existing medical practices, and learned about non-technology-based solutions the patients were developing for themselves.

We aimed to produce research-based suggestions for improving treatment plans for patients with RA that can inform the development of interactive technologies that integrate Shared Decision Making (SDM) elements, a medical approach that considers patient's individual needs and desires with the physician's expertise to reach a consensus on treatment. Ultimately, our study contributed the conclusion that designs in health technology to support RA patients with SDM may benefit by acknowledging the dynamic nature of RA as a chronic disease.

We gained valuable information from across these categories: chronic patient experiences, chronic disease management, lifestyle challenges associated with RA, and decision making. Exemplary findings included:

- 1) Mental health, sexual health, and family planning as it relates to RA patient experiences were overlooked.
- 2) Patient agency, which is the ability to exercise autonomy in decisions related to their own health was mentioned to be developed through social support, minor medical decision making, and gaining greater knowledge about RA.
- 3) Over time, participants recalled adapting to mental and physical lifestyle changes that RA demanded. This is important because every patient will go through their own journey in figuring out what works best for them as a coping adaptation to their disease; this also helps inform patient agency.

Interesting fact: We interviewed participants from the Canadian Arthritis Patient Alliance (CAPA), a national non-profit patient advocate organization. For more information go to <https://arthritispatient.ca>.