

## **Study Results: Patient Priorities in RA Research: An Exploration of Perspectives from those Enrolled in a Canadian RA Clinical Cohort**

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RA patients enrolled in OBRI were invited to participate in 1 of 3 patient sessions held in 2014. In each session, small group discussions were facilitated by a moderator. Patients were asked to discuss their priorities for RA research, identify gaps they felt were present in OBRI data collection, and complete a questionnaire on their use of social media. In total, 48 RA patients participated in a facilitated discussion. Four research priorities were identified:

1. A need for qualitative research focused on patient experiences with RA including: journeys to diagnosis, symptoms, treatment side effects and challenges/concerns
2. A need to research patient satisfaction with rheumatology care including: accessibility, communication, and disease management
3. A need for OBRI research questions addressing patient social support networks, strategies for coping with flares, diet and exercise, and the use of alternative therapies
4. A need for more information from rheumatologists on medication risks and side effects

Although the majority of patients reported using social media, only 54% preferred to receive research related communication through email. This study identified patient preferred communication methods and the need to expand OBRI data collection methods to include more experience based information.