

4. **Claire Adams¹**, Brett Thombs¹.

Elsa-Lynn Nassar¹, Danielle B. Rice², Amanda Wurz³, Jill T. Boruff¹.

¹McGill University, Montreal, QC; ²McMaster University, Hamilton, ON; ³University of the Fraser Valley, Abbotsford, BC.

Patient Engagement in Rheumatic Research: State of the Evidence.

Meaningful engagement of patients in health research involves active partnership between patients and researchers across the research process. Effective engagement can improve the quality and relevance of research, translation of findings, and generate trust in results. This presentation will describe a series of studies reviewing the evidence on patient engagement in rheumatology research. The objectives are to: 1) Evaluate the proportion of studies published in high-impact rheumatology journals that reported whether they engaged patients, and actually engaged patients, in the studies; 2) Synthesize evidence through an overview of systematic reviews to identify advantages and disadvantages of methods for recruiting and engaging patients in applied health research; 3) Review advantages and disadvantages of patient engagement in rheumatology research and form recommendations for patient engagement practices.

A 12-member Patient Engagement Advisory Team helped guide this work. 1) We reviewed studies published in rheumatology journals with an impact factor of ≥ 5 . We searched Medline and Scopus for eligible articles. 2) We searched medical and health databases using a systematic search strategy designed by an expert librarian to identify systematic reviews of patient engagement in health research. DistillerSR was used for study screening and data extraction by two reviews independently. 3) References on patient engagement in rheumatology research were identified through searches of medical and health databases and Google Scholar using keywords from our overview search strategy, searching of reference lists, and searches of the authors own files.

Only 9% of rheumatology studies (12 of 141 included) published in prominent journals report engaging patients. When patients were engaged, it was most commonly at the lowest level of decision-making, consult (73%). Based on an author survey of included studies, we estimated 29-44% of studies likely engaged patients. In our overview, 13 reviews were included. One was specific to rheumatology; of the 52 individual studies, 11 were opinion pieces, 18 were qualitative research or surveys of opinions, 9 were reports from annual meetings and working groups, 3 provided anecdotal evidence from case studies, none provided evaluative evidence.

Evidence on advantages and disadvantages of recruitment and engagement methods for patient engagement is commonly of low quality. More work is needed to establish evidence-based practices. The available evidence presented can be used by researchers, clinicians, patients, and the public to make decisions on how they can work together across the research process to generate useful and relevant research.