

PLAIN LANGUAGE REPORT

Our research team has a particular interest in understanding the experience of patients who attend rheumatology clinics around Australia. We acknowledge that people with rheumatic diseases are frequent, long-term attenders of healthcare services, that patients are expert consumers, and that they have vast experiential knowledge. To this end, understanding their care experiences is central to improving our healthcare services. To do this, we need a purpose-built survey to gather information from patients: a Patient Reported Experience Measure (PREM). We already collect information from patients about issues such as symptoms and test results, usually using surveys called Patient Reported Outcome Measures (PROMs), and have many of these surveys at our disposal. However, in the past we have lacked a PREM which is fit for use with Australian rheumatology patients. This is a gap in service delivery which we have sought to fill by undertaking this research.

To gather background information, we first met directly with patients to discuss their current experience of attending clinics, addressing both positive aspects and perceived shortcomings. We also engaged rheumatology clinicians to gauge opinion on what constitutes excellent care delivery. We found that patients' experience was affected by issues such as waiting times and lack of care continuity, and that while clinicians are prioritising important issues such as information sharing and patient advocacy, often this is not clearly evident to patients, and change is needed to improve this. The findings of this study have been published in medical literature.

After analysing the priorities and concerns of both rheumatology patients and clinicians, we were satisfied that the types of issues raised would be adequately surveyed using an existing rheumatology PREM, but with modifications in the language and layout for Australian patients. We have performed the statistical work on the adapted PREM, called the ACQRAPREM, which stands for Australian-Commission for Quality in Rheumatoid Arthritis (CQRA)- PREM. The tests performed have ensured that the ACQRA-PREM asks the right questions and is reliable when used in the Australian context; in other words that it is fit for the intended use. This research reports on the testing and performance of our proposed PREM, for future use in rheumatology clinics across Australia. We anticipate that the findings of this study will be published in medical literature in the coming months.

We are hopeful that the ACQRA-PREM will be used by rheumatology units around Australia to collect this information from patients on a regular basis. We believe there is great potential to routinely capture experience-related data: to review which parts of care are performed well, and which parts need improvement. This information can be used directly to reduce barriers to providing great care and improve patient services.

References

1. Bryant, M.J., et al., Joining forces to understand what matters most: qualitative insights into the patient experience of outpatient rheumatology care. *Rheumatology Advances in Practice*, 2023.
2. Starks, Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research* (interlibrary loans also available), 2007. 17(10): p. 1372-1380.
3. Braun, V. and V. Clarke, Using thematic analysis in psychology. *Qualitative Research in Psychology*, 2006. 3: p. 77-101.
4. Gale, N.K., et al., Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 2013. 13(1): p. 117.
5. Australian Commission on Safety and Quality in Healthcare., *Consumer Fact Sheet 1: Introduction to the National Safety and Quality Health Service Standards*. 2021.
6. Care Quality Commission. *The fundamental standards*. 2022; Available from: <https://www.cqc.org.uk/about-us/fundamental-standards>.
7. Institute of Medicine Committee on Quality of Health Care in America, in *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001, National Academies

Press (US), Copyright 2001 by the National Academy of Sciences. All rights reserved.: Washington (DC).

8. Bosworth, A., et al., Development and Validation of a Patient Reported Experience Measure (PREM) for Patients with Rheumatoid Arthritis (RA) and other Rheumatic Conditions. *Current Rheumatology Reviews*, 2015. 11(1): p. 1-7.

9. Beckers, E., et al., Validation and implementation of a patient-reported experience measure for patients with rheumatoid arthritis and spondyloarthritis in the Netherlands. *Clinical Rheumatology*, 2020. 39(10): p. 2889-2897.

10. Prinsen, C., et al., COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of Life Research*, 2018. 27(5): p. 1147-1157.

11. Terwee, C., et al., COSMIN methodology for evaluating the content validity of patient reported outcome measures: a Delphi study. *Quality of Life Research*, 2018. 27(5): p. 1159-1170