

GRANT-IN-AID RECIPIENT AND FINAL REPORT

Funded by:	Australian Rheumatology Association (\$15,000)
Recipient:	Dr Madeleine Bryant
Intended Department:	Department of Rheumatology, The Queen Elizabeth Hospital
Project:	Validation and integration of Patient Reported Experience Measures in outpatient rheumatology care in Australia

We are very grateful for the grant funding received from Arthritis Australia in support of our project "Validation and integration of Patient Reported Experience Measures in outpatient rheumatology care in Australia".

Overview

The research team have been extremely thankful for the opportunity to undertake this project with the support of an Arthritis Australia Grant In Aid. We believe the outcomes of our project will have a tangible effect on improving the experience of care that our patients receive when attending rheumatology clinics across Australia. We have modified and validated a Patient Reported Experience Measure (PREM) with Australian patients, meaning this instrument may now be used to routinely capture experience-related data. Sitting alongside other outcome measure instruments, the modified PREM will enable providers to qualify factors relating to the process, content and impact of care, directly capturing the perspectives of consumers.

Phase 1

The objectives of Phase 1 of this project have been fully realised and published in rheumatology literature [1]. In this work, we sought to capture the current lived experience of patients and healthcare professionals receiving and providing care in rheumatology clinics, and to explore patient and health-care professional (HCP) views on what constitutes high quality, patient-centred care. This is a foundational component of establishing the role and remit of a purpose-designed PREM to routinely build experience-related data into quality improvement systems within rheumatology as a specialty in Australia.

We conducted a non-interventional, qualitative study comprising five semi-structured, facilitated focus groups. Participants included rheumatology outpatients (n=16) of two tertiary teaching hospitals (The Queen Elizabeth and Royal Adelaide Hospitals), and healthcare professionals (n=14) (rheumatologists, rheumatology trainees, physiotherapists, specialty nurse, pharmacist). Participants explored priorities when attending outpatient services, real experiences, and aspirations for improving future care. Focus groups were audio-recorded, professionally transcribed verbatim, and coded using inductive and deductive thematic analysis by the research team [2-4]. Conceptual links between individual perspectives were explored both within and between the patient and clinician groups. Potential key themes were identified as those repeatedly raised and explored in depth during the focus groups [4]. The study was approved by the Central Adelaide Local Health Network Human Ethics Committee (reference 13846). Written informed consent was obtained, including consent for audio recording and transcription.

Results: Seven key themes were identified. These included smooth flow of technical processes, care coordination, individualised care, information sharing, clinical excellence, patient empowerment and comprehensive care. Such themes were conceptually aligned with quality standards in Australia and worldwide [5-7]. Overall we identified that patient and HCP cohorts are concerned with the same issues, though prioritisation is different between groups. Several disparities were noteworthy; the foremost of which being a discord in appreciation of the impact on logistics on the overall care experience. To this end, the most highly prioritised themes for patients pertained to processes and technical aspects of care. Issues of waiting time and appointment inflexibility were demonstrated as universal patient concerns, and their negative impact on care was grossly evident in patient cohort data. HCPs focused on themes relating to non-technical aspects of service provision: another noteworthy difference in prioritisation and conceptualisation between cohorts. Information sharing, individualisation of care, patient advocacy and empowerment were frequently occurring and deeply explored themes in the HCP cohort. HCPs described many different manifestations of empowerment, such as the importance of facilitating patient selfadvocacy, acknowledging patient ownership

of health information, and adjusting care to account for individual health literacy. This theme was explored in detail by HCPs and was given high priority in descriptions of high quality care, but was not as strongly evident in patient focus group data. Participants from both patient and HCP cohorts highlighted the importance of mutual respect and pursuit of therapeutic partnership.

Summarily, this study captured valuable insights into the current experience of outpatient rheumatology care from the perspective of patients and healthcare professionals. It informs a collective understanding of differing and shared priorities, positives of current care, and areas requiring improvement.

Citation: Bryant MJ, Munt R, Black RJ, Reynolds A, Hill CL. Joining forces to understand what matters most: qualitative insights into the patient experience of outpatient rheumatology care, *Rheumatol Adv Practice*, 2023, rkad068, <https://doi.org/10.1093/rap/rkad068>

This work has been distributed in the following forums:

1. Oral presentation, Patient Reported Measures Research Symposium, Commission for Excellence and Innovation in Health (CEIH), Adelaide, 18 March 2022.
2. Oral presentation, Australian Rheumatology Association Annual Scientific Meeting, Sydney, 20 May 2022. Awarded Best Clinical Free Paper.
3. Oral presentation, Basil Hetzel Institute Research Expo, Adelaide, 21 Oct 2022. Awarded best oral presentation, best lay summary.
4. Online report, The Limbic rheumatology. Available at <https://thelimbic.com/rheumatology/what-do-rheumatology-patients-value-most-during-clinic-visits/>

Phase 2

Data collection and analysis for Phase 2 of this project have been realised, with a report now in the editing phase and anticipated to be submitted for publication by end 2023.

In this project, we undertook the necessary steps to evaluate the reliability and validity of an adapted version of the Commissioning for Quality in Rheumatoid Arthritis-PREM (CQRAPREM), for assessment of the patient care experience in an Australian mixed rheumatology patient cohort. Building on the findings of Phase 1 work, we identified that the priorities and concerns of Australian rheumatology patients and HCPs represented in our sample were reflected in the domains of an existing proposed survey instrument, the CQRA-PREM, a rheumatology-specific PREM originating in the United Kingdom. This instrument has been validated post publication for use with other rheumatic conditions [8], and translated into and validated in Dutch [9]. We have now undertaken this process with an Australian cohort.

The candidate instrument was first presented to participants in individual patient interviews (n=8). The purpose of individual interviews was to check the language, relevance, comprehensiveness, and completion time of the original CQRA-PREM, the latter as a measure of feasibility [10, 11]. Interviews were audio recorded, transcribed and content analysis was performed to identify recurring reflections on the language and comprehensiveness of the original instrument questions. Proposed changes to the original instrument were discussed among the research team and consensus was achieved. The modified instrument was thereafter referred to as the Australian-CQRA-PREM (ACQRAPREM).

The validation project was conducted in collaboration with the Australian Rheumatology Association Database (ARAD), a voluntary national database established to collect longitudinal outcome data from patients with inflammatory arthritis, administered by the Australian Rheumatology Association (ARA). Individual registrants of ARAD over 18 years of age, active in completing an unrelated online ARAD questionnaire within the preceding 12 months, and currently attending rheumatologist care, were invited by email to participate voluntarily in online survey data collection in September 2022. Participants who responded to the initial survey were invited to re-test at 6 months in March 2023. Participants completed the proposed ACQRA-PREM, a disease activity index relevant to their rheumatological diagnosis (Routine Assessment of Patient Index Data-3 for patients with Rheumatoid Arthritis, or Bath Ankylosing Spondylitis Disease Activity Index for patients with Ankylosing Spondylitis or Psoriatic Arthritis), a quality of life index (Assessment of Quality of Life score-6D), demographic survey items, and responses were linked to a comorbidity index (Rheumatic Diseases Comorbidity Index). Statistical analyses performed included

exploratory factor analysis (EFA) and tests of reliability, validity, floor and ceiling effects, and minimum significant change value for the ACQRA-PREM instrument. Electronically signed informed consent for participation was obtained. The study was approved by the Central Adelaide Local Health Network Human Ethics Committee (reference 16836).

Results: The survey response rate was 707/1124 (63%) at the first data point (0 months) in September 2022. 459 (65%) respondents had a diagnosis of Rheumatoid Arthritis, 134 (19%) Psoriatic Arthritis, and 114 (16%) Ankylosing Spondylitis. The majority of respondents were female (n= 473, 67%), mean age was 62 years (SD= 11), mean disease duration 22 years (SD= 12). There were no significant differences in disease diagnosis, gender, age, disease duration between survey responders and non-responders. Median completion time (feasibility) of ACQRA-PREM was 299 seconds (IQR 130). Exploratory factor analysis extracted 5 factors, with all items loading similarly onto factor 1, indicating validity of an overall score for the ACQRA- PREM, averaged across all items. Remaining factors broadly recapitulated the domains of the original instrument. Cronbach's alpha scores were > 0.8 for all factors identified by EFA, indicating internal consistency. Cronbach's alpha for an average score of all item responses was 0.948, indicating reliability of the average score as an overall measure of the patient's reported experience. The partial correlation between ACQRA-PREM score and standardised disease activity was not significant ($\rho=0.03$, $p=0.45$), indicating divergent validity. There was no floor or ceiling effect for the average score. For the 6 month datapoint in April 2023, the survey response rate was 530/707 (78%). The test-retest reliability of the averaged PREM score, estimated by the intraclass correlation coefficient from a 2-way random effects model (Fleiss ICC [2,1]) was 0.74 (95% CI 0.70, 0.77). The ICC ranges from 0,1, and this value represented adequate reliability. Bland-Altman analysis was performed to investigate the agreement between measurements. Mean difference 0.00 indicated no systematic bias between measurement occasions. The 95% limits of agreement suggested that a difference in the mean score of 0.85 may be the least significant change for the ACQRA-PREM for an individual patient.

In summary, this study has field-tested the ACQRA-PREM, a modified rheumatology-specific PREM, with a large population of Australian patients, and has confirmed it as a valid and reliable instrument to measure self-reported care experience this cohort. As a novel application not previously reported, we have also demonstrated the utility of an overall, averaged PREM score for this instrument, which we propose can be used to follow patient reported experience longitudinally.

Future work: Following submission for publication, it is anticipated that the ACQRA-PREM will be distributed for use by rheumatology units around Australia. We intend to analyse the implementation process and report on the findings of the first data tranches from routine capture of experience data.

This work has been presented or will be presented at the following forums:

1. Poster presentation, University of Adelaide Florey Postgraduate Research Conference, Adelaide, 2 August 2023.
2. Future: Accepted abstract, Basil Hetzel Institute Research Expo, Adelaide, 19 Oct 2023.

This work will be submitted for consideration of presentation at:

3. Future: Australian Rheumatology Association South Australia Annual Scientific Meeting, Adelaide, 27 Oct 2023.
4. Future: Australian Rheumatology Association Annual Scientific Meeting, Christchurch, May 2024.

Once again we express sincere gratitude to Arthritis Australia for funding this important work.