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Australian adaptation and external validation of Commissioning for Quality in Rheumatoid Arthritis-RA-Patient Reported Experience Measure (CQRA-RA-PREM)

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Abstract

Objectives: To evaluate the reliability and validity of an adapted Commissioning for Quality in Rheumatoid Arthritis-RA-Patient-Reported Experience Measure (CQRA-RA-PREM) for assessing care experience in an Australian rheumatology outpatient cohort.

Methods: Individual patient interviews were performed to check the language and completion time of the CQRA-RA-PREM before modification. Australian Rheumatology Association Database (ARAD) participants completed the CQRA-PREM-Australian version (CQRA-PREM-AU) (22 items, 5 domains), disease activity measure (RAPID-3, BASDAI) and Assessment of Quality of Life (AQOL-6D) index. Exploratory factor analysis (EFA) assessed item correlation. Cronbach's α assessed internal consistency.

Results: Individual patient interviews ($n = 8$, 62% male, mean age 50 years, mean disease duration 4.5 years) informed CQRA-RA-PREM modification. The ARAD survey response rate was 707/1124 (63%); 459 (65%) RA, 134 (19%) PsA, 114 (16%) AS; 67% female, mean age 62 years, mean disease duration 22 years. The median instrument completion time was 299 s (interquartile range 284–414). Scoring of responses allowed an averaged overall score. EFA extracted five factors: all items loading similarly onto factor 1, indicating validity of the overall score. The CQRA-PREM-AU score correlated with the AQOL-6D score ($\rho = 0.23$, $P < 0.01$); partial correlation with disease activity was not significant ($\rho = 0.03$, $P = 0.45$), indicating divergent validity. Reliability was comparable across disease subgroups (Cronbach's $\alpha > 0.94$). The mean overall score did not differ by disease subgroup [4.1 (S.D. 0.6, $P = 0.73$) and there was no floor/ceiling effect.

Conclusion: CQRA-PREM-AU is a valid and reliable instrument to measure self-reported care experience in Australian rheumatology patients and may be interpreted as an average overall numerical score.

Lay Summary

What does this mean for patients?
Patient-reported experience measures (PREMs) are surveys that gather information from patients about how their healthcare impacts them. Before a PREM can be used in clinics and health services, it should be field-tested in a group of people similar to those who will eventually use it. In this study, Australian people with rheumatological conditions were asked to consider an existing rheumatology PREM, called the CQRA-RA-PREM, which was adapted based on their feedback, and called the CQRA-PREM-AU. The research team then tested the CQRA-PREM-AU to ensure it remained statistically sound, showing it can be confidently used to collect information to improve care for rheumatology patients.

Keywords: patient experience, care quality, outcome measures, healthcare innovation.

Key messages

- Patient-reported experience measures (PREMs) capture patients' own perspectives of their healthcare.
- CQRA-PREM-AU reliability and validity was confirmed following Australian adaptation, including a novel overall score.
- Overall, the CQRA-PREM-AU score may be applied to follow change over time and compare cohort experience.

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Introduction

Patient-reported experience measures (PREMs) are surveys that capture patients' own perspectives of the healthcare they have received, through collection of data on the process, content and impact of care delivery [1–6]. PREMs capture domains of care including communication, interaction with clinicians, accessing information and logistics [1, 7–10]. Examining care experience from the perspective of patients, and understanding what matters most to patients, is a fundamental component of building and delivering patient-centred services and focusing quality improvement efforts [6, 8, 9, 11, 12]. Data of this nature must be gathered directly from patients, as no other source can reflect the true impact of care delivery on the individual [4, 6, 10, 11]. As such PREMs continue to gain recognition as important indicators of healthcare quality [1, 6, 13–15].

PREM use in clinical practice has been identified as a means of achieving rapid and sustained improvements in care, which enhance clinical effectiveness and patient safety [4, 6, 15]. Successful PREM application in practice necessitates selection of an appropriate instrument, which requires consideration of the validity and reliability, the clinical context in which it will be used and the domains it will address [1]. Validity of a measurement instrument is defined as the degree to which it measures the construct it intends to measure [16–18]. Reliability refers to the extent to which an instrument produces consistent scores under different conditions, between different responders and on different occasions [16–18]. Specific components of validation are important when an instrument is modified for language or cross-cultural use, including face validity (the degree to which an instrument looks to be a reflection of the construct to be measured [16–18]) and cross-cultural validity (the degree to which a culturally adapted instrument reflects the original and performs as intended). Both properties should be tested with a sample adequately representative of the target population to ensure relevant and meaningful data [19, 20].

A systematic review of PREMs used in the specialty of rheumatology has previously identified a paucity of instruments and broad heterogeneity of validation methods [21]. One of the better described and widely used PREMs is the Commissioning for Quality in Rheumatoid Arthritis-RA-PREM (CQRA-RA-PREM) [7, 22]. This survey was specifically intended for use by patients with RA, and following its development in the UK, it has been subsequently validated for use with other rheumatic conditions [23] and translated and validated into Dutch and Portuguese [7, 8, 24]. Arising from a specific framework for patient experience, the National Health Service (NHS) Patient Experience Framework (NPEF), the original CQRA-RA-PREM addressed eight domains, including respect, coordination and integration of care, information and communication, physical and emotional care and involvement of support people. Guidance on the interpretation of results of the original CQRA-RA-PREM is lacking in existing reports and previously a numerical score has not been applied to the original instrument.

While PREMs are in use in rheumatology care internationally, there has been no PREM validated for use with Australian rheumatology patients. Prior work with Australian rheumatology patients and healthcare professionals has identified that concepts of care coordination, respect and safety and information sharing are highly prioritized [12]. While these findings suggest the original CQRA-RA-PREM will likely be relevant to the Australian context, testing the instrument in the target population is an essential component of proving its potential benefit.

The aims of this study were to generate and test a modified version of the CQRA-RA-PREM instrument adapted to the Australian context, specifically, to test the face validity and cross-cultural validity with Australian patients, including language and comprehensiveness and to test psychometric properties of the modified instrument, including structural validity, internal consistency, divergent validity, test–retest reliability and interpretability.

Methods

Phase 1: Instrument modification for Australian use

Individual patient interviews were conducted to assess the face validity of the CQRA-RA-PREM and whether changes were required for Australian use. The time to complete the instrument was measured during the interview phase as a measure of feasibility. Patients were purposively recruited for interviews from two tertiary rheumatology outpatient clinics in South Australia. Informed consent was obtained.

Interview participants were shown the CQRA-RA-PREM and each of the 22 item statements was discussed in sequence. Guiding questions (Supplementary Fig. S1, available at *Rheumatology Advances in Practice* online) and 'think aloud' techniques were used to elicit views on the wording, structure and areas that participants felt required further clarification. Interviews were audio recorded and transcribed using a professional transcription service. Directed content analysis was performed (M.B.) to identify key concepts arising in the data [25]. Recurring concepts relative to wording and interpretation informed proposed changes to the original instrument. These were reviewed for consensus by study co-investigators (M.B., C.H. and R.J.B.). The modified instrument was thereafter referred to as the CQRA-PREM-Australian version (CQRA-PREM-AU) (Supplementary Fig. S2, available at *Rheumatology Advances in Practice* online). Additionally, numerical scores were assigned to the item responses on a 5-point Likert scale: 1, 'strongly disagree'; 2, 'agree'; 3,'neither agree nor disagree'; 4, 'disagree'; and 5, 'strongly agree'. This allowed an overall average score to be derived from the included items; higher overall scores indicating a better patient experience.

Phase 2: Validation of CQRA-PREM-AU psychometric properties

The CQRA-PREM-AU was tested in an Australian rheumatology patient cohort, the Australian Rheumatology Association Database (ARAD), a voluntary national database established to collect longitudinal outcome data from patients with inflammatory arthritis. Participants in this registry have a diagnosis of RA, AS, PsA or JIA. Enrolled participants complete online surveys at baseline and 6 months, then every 12 months, that collect health information including demographics, disease activity and quality of life, medication use and comorbidity status [measured by the Rheumatic Disease Comorbidity Index (RDCI)] [26].

Inclusion criteria for this study were adult participants currently registered with ARAD, active in completing an online ARAD questionnaire within the preceding 12 months,

currently attending rheumatology care and willing to complete online data collection. Excluded were participants <18 years of age or adult participants with a diagnosis of JIA.

Survey administration

ARAD participants meeting the inclusion criteria were invited by e-mail to participate in survey data collection in September 2022. Participation in the study was voluntary and respondents completed an online consent form. Questions were administered via the Research Electronic Data Capture (REDCap) platform. Participants who responded to the initial survey were invited to retest at 6 months in March 2023. Survey access remained open for 4 weeks in total, with a reminder e-mail sent to non-responders after 2 weeks. Responses were linked to existing ARAD data.

Data collection

Survey items included the proposed CQRA-PREM-AU, Assessment of Quality of Life score (AQOL-6D) [27], additional demographic data items for care type (private or public) and location (metropolitan or rural/remote) and a disease activity measure: the Routine Assessment of Patient Index Data (RAPID-3) [28] for participants with RA or PsA or the BASDAI [29] for patients with AS.

Analysis

Descriptive statistics were used to report demographic details of interview participants. Qualitative content analysis of individual interview data was performed using NVivo12 software (Lumivero, Denver, CO, USA).

For data obtained from ARAD survey administration, analyses to test the desirable properties for a satisfactory PREM were adopted from the COnsensus Based Standards for the selection of health status Measurement INstruments (COSMIN) standards for good measurement properties of Patient Reported Outcome Measures (PROMs), as no published standard exists specifically for PREM validation, although many principles of PROM validation are applicable [16–18].

The internal structure (degree of interrelatedness among items [16–18]) of the CQRA-PREM-AU was assessed by analysis of structural validity, internal consistency, divergent validity and measurement invariance. Exploratory factor analysis (EFA) was used to measure structural validity, defined as the degree to which the scores of an instrument are an adequate reflection of the dimensionality of the construct to be measured [16–18]. Additionally in this study, EFA determined whether the CQRA-PREM-AU could be interpreted as an overall numerical score. EFA was performed in Mplus version 8.8 (https://www.statmodel.com/) [30] with interpretation after orthogonal geomin rotations. The number of factors retained was selected by identifying the most parsimonious model that satisfied multiple stringent fit indices [root mean square error of approximation (RMSEA) $\leq$0.05, comparative fit index (CFI) and Tucker–Lewis index (TLI) both $\geq$0.97 and the standardized root mean square residual (SRMR) $\leq$0.1]. Evidence for structural validity of a scale or subscale is a prerequisite for interpretation of internal consistency analysis, another measure of the internal structure of an instrument. Cronbach's $\alpha \geq$0.70 was considered indicative of sound reliability for subscale items, as well as overall scores, of the CQRA-PREM-AU.

Divergent validity refers to evidence that measured constructs are discriminant rather than highly correlated [31]. In this study, divergent validity was assessed by evaluation of pairwise and partial correlations between the overall average CQRA-PREM-AU score and disease activity, AQOL-6D and RDCI. The rationale for analysing divergent validity by comparing the CQRA-PREM-AU with disease activity, quality of life and comorbidity indices was to illustrate the premise that patient experience is an independent dimension of care quality [32]. The RAPID-3 and BASDAI disease activity scores were first standardized to be expressed on the same scale and range, then standardized scores were combined into the one variable for this analysis. AQOL-6D scores range from 0 (death) to 1 (full health), with negative scores allowed and indicating a state worse than death. Measurement invariance was tested by analysing for the absence of significant differences found between group factors (age, sex, education level, diagnosis).

Test–retest reliability of CQRA-PREM-AU was estimated by the intraclass correlation coefficient (ICC) of the averaged score at 0 and 6 months, using a two-way random effects model [Fleiss ICC (2,1)].

A Bland–Altman analysis was performed to interrogate for systematic bias between measurement occasions at 0 and 6 months.

Other examined measurement properties included interpretability and floor/ceiling effects. Interpretability is defined as the degree to which clinical meaning can be assigned to an instrument score or change in score [16–18]. The minimum significant change in the averaged score for an individual patient was calculated from the 95% limits of agreement. Floor and ceiling effects were evaluated by estimating the proportion of observations expected to be $\geq$5 (ceiling effect) or $\leq$1 (floor effect), assuming a normal distribution and using an averaged PREM score measured on a scale of 1–5. Proportions >15% were taken to define a floor or ceiling effect [33].

Statistical analysis was performed using Stata version 16.1 (StataCorp, College Station, TX, USA) [34] and Mplus version 8.8 [30].

Patient and public participation

A patient representative, Timothy Collins, reviewed and approved the patient information and consent form and study protocol.

Results

Phase 1: Instrument modification for Australian use

Eight participants completed individual interviews. An additional 14 individuals were contacted and declined to participate: reasons included lack of interest in study aims and competing time commitments. Of the interview participants, five were male (62%), with a mean age was 50 years (s.d. 16.6). Diagnoses represented were AS [n = 4 (50%)], RA [n = 2 (25%)], PsA [n = 1 (12.5%)] and SLE [n = 1 (12.5%)]. The mean disease duration was 5.25 years (s.d. 3.85). One participant reported English as their second language. The median time to complete the CQRA-RA-PREM was 299 s (interquartile range 284–414). Concepts arising in interview data were analysed by qualitative content analysis [25]. This

informed modifications to the original CQRA-RA-PREM instrument. Participants continued to be recruited until data saturation of concepts was achieved. Modifications were confined to changes in the wording and definitions used (Supplementary Fig. S3, available at *Rheumatology Advances in Practice* online). All 22 items from the original instrument were retained. Consensus was reached by co-investigators (M.B., C.H. and R.J.B.) regarding final wording of the CQRA-PREM-AU instrument.

Phase 2: Validation of CQRA-PREM-AU psychometric properties

Survey respondents

The initial survey response rate was 707/1124 (63%) in September 2022; the majority of respondents were female [$n = 473$ (67%)], with a mean age was 62 years (s.d. 11) and a mean disease duration of 22 years (s.d. 12), and 161 (23%) reported a rural or regional location (Table 1). A diagnosis of RA was defined in 459 (65%) respondents, PsA in 134 (19%) and AS in 114 (16%). The majority of respondents were seen in private outpatient clinics [$n = 571$ (81%)]. Rates of private insurance were high [$n = 516$ (74%)]. The mean disease duration for RA was 22 years (s.d. 12), for PsA 20 years (s.d. 11) and for AS 25 years (s.d. 12). The majority of respondents [$n = 608$ (86%)] were using a biologic or targeted synthetic DMARD (b/tsDMARD); use in RA was 85% ($n = 388$), in PsA 84% ($n = 112$) and in AS 95% ($n = 108$). The number of females in the AS group was lower compared with other disease groups (38% in AS, 62% in PsA, 76% in RA), reflecting epidemiological trends of AS. There were no significant differences in disease diagnosis, gender, age and disease duration between survey responders and non-responders.

The mean RAPID3 score for respondents with RA was 11.3 (s.d. 6.8) and 10.5 (s.d. 7.0) for PsA. The majority of respondents with RA and PsA were classified in the high severity group for RAPID3, indicated by a score >12.0 [RA, $n = 205$ (45%); PsA, $n = 54$ (40%)]. The mean BASDAI score for respondents with AS was 3.0 (s.d. 2.2) and 33% ($n = 38$) of respondents with AS were classified in the active disease group, indicated by a score ≥4. The mean AQOL-6D scores were comparable between disease subgroups [0.73 (s.d. 0.19) in RA, 0.74 (s.d. 0.20) in PsA and 0.78 (s.d. 0.17) in AS; $P = 0.021$].

Analyses to test measurement properties of the CQRA-PREM-AU are summarized in Table 2.

Structural validity and internal consistency

EFA extracted five factors, with all items loading similarly onto factor 1, which thus can be taken to represent an overall score. The remaining factors broadly recapitulated the domains of the original instrument [7], noting that factor 4 equated to domain 3 ('Information about care'), but was best described by items 3c and 3d only, with items 3a and 3b not loaded onto this factor, and factor 5 equating to domain 4 ('Daily living') and domain 5 ('Emotional support') combined (Fig. 1).

Cronbach's α scores were >0.8 for all factors identified by EFA (Table 3). Cronbach's α 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. There was no significant difference in reliability of the overall score across disease subgroups (Cronbach's $\alpha = 0.95$ in RA, 0.94 in PsA and 0.95 in AS). The mean overall score [4.1 (s.d. 0.6)] did not differ by disease subgroup ($P = 0.73$).

Divergent validity

Partial correlation between the CQRA-PREM-AU score and standardized disease activity ($\rho = 0.03$, $P = 0.45$) and comorbidity index ($\rho = 0.04$, $P = 0.24$) was not significant, indicating divergent validity. The CQRA-PREM-AU score correlated with the AQOL-6D score ($\rho = 0.23$, $P < 001$).

Measurement invariance

Multivariable regression analysis of covariates demonstrated no significant differences in the CQRA-PREM-AU score by subgroup analyses: age [0.002 (IQR −0.002–0.007), $P = 0.29$], sex [−0.011 (IQR −0.110–0.088), $P = 0.83$], education level greater than secondary school [−0.067 (IQR−0.160–0.027), $P = 0.16$] or diagnosis compared with RA [PsA 0.030 (IQR−0.082–0.143), $P = 0.60$; AS −0.069 (IQR −0.198–0.060), $P = 0.30$].

Test–retest reliability

For the 6-month repeat survey, the survey response rate was 530/707 (78%). Test–retest reliability of the overall averaged CQRA-PREM-AU score was 0.74 (95% CI 0.70, 0.77). The ICC ranged from 0 to 1, and this value represents adequate reliability.

Bland-Altman analysis was performed to investigate agreement between measurements [35]. A mean difference of 0.00 indicated no systematic bias between measurement occasions (Supplementary Figure S4, available at *Rheumatology Advances in Practice* online).

Interpretability

The 95% limits of agreement indicate that a difference in the mean score of 0.85 is the minimum important change for the CQRA-PREM-AU for an individual patient.

Floor/ceiling effect

There was no floor or ceiling effect for the overall averaged CQRA-PREM-AU score.

Discussion

This study confirms the validity and reliability of the CQRA-PREM-AU instrument following adaptation from an original version for use in an Australian context for patients with RA, AS and PsA. It is the first instance of a rheumatology-specific PREM undergoing validation with an Australian patient population. Application of a numerical score to the modified instrument, as an overall averaged experience score, has been described for the first time, with relevance to evaluation, comparison and monitoring of rheumatology care delivery. A broader range of psychometric properties have been tested and demonstrated for this modified instrument than has previously been performed in original validation of the CQRA-RA-PREM, thus building on previous work. Furthermore, this study represents the largest validation performed for this instrument to date [7, 8].

PREMs require adaptation to a culturally appropriate context for best use in practice, and deploying a proposed instrument in a suitably representative cohort is an essential component of validation [20]. To demonstrate the relevance of the CQRA-RA-PREM for use with Australian patients, the

Table 1. Demographic data for ARAD survey respondents

Characteristics	AS	PsA	RA	All	*P*-value
Patients, *n*	114	134	459	707	
Female, *n* (%)	43 (38)	83 (62)	347 (76)	473 (67)	<0.001
Age, years, mean (S.D.)	58 (12)	61 (10)	63 (11)	62 (11)	<0.001
Disease duration, years, mean (S.D.)	25 (12)	20 (11)	22 (12)	22 (12)	0.005
Highest education, *n* (%)					
Did not complete high school	12 (11)	8 (6)	50 (11)	70 (10)	
Completed high school	19 (17)	31 (23)	112 (24)	162 (23)	
University/TAFE/CAE	83 (73)	95 (71)	297 (65)	475 (67)	
Rural/regional, *n* (%)	17 (15)	31 (23)	113 (25)	161 (23)	0.09
Public hospital outpatient, *n* (%)	23 (20)	27 (20)	86 (19)	136 (19)	0.90
Private health insurance, *n* (%)	81 (72)	102 (77)	333 (73)	516 (74)	0.68
Consults in the last 12 months, *n*, mean (S.D.)	2.5 (1.3)	2.8 (1.3)	2.9 (1.5)	2.9 (1.5)	0.05
Current medications, *n* (%)					
Methotrexate	21 (18)	56 (42)	265 (58)	342 (48)	<0.001
Other csDMARD	14 (12)	26 (19)	51 (11)	91 (13)	0.041
Prednisolone	15 (13)	15 (11)	135 (29)	165 (23)	<0.001
NSAID	56 (49)	53 (40)	199 (53)	308 (44)	0.31
b/tsDMARD, *n* (%)					
TNFi	97 (85)	71 (53)	197 (43)	365 (52)	
JAK inhibitor	3 (3)	12 (9)	86 (19)	101 (14)	
IL-6R blocker	0	0	50 (11)	50 (7)	
T cell inhibitor	0	1 (1)	34 (7)	35 (5)	
IL-17A blocker	8 (7)	18 (13)	3 (1)	29 (4)	
B cell depletion	0	0	18 (4)	18 (3)	
IL-12/IL-23 blocker	0	10 (7)	0	10 (1)	
None	6 (5)	22 (16)	71 (15)	99 (14)	
Total b/tsDMARD	108 (95)	112 (84)	388 (85)	608 (86)	
BASDAI score, mean (S.D.)	3.0 (2.2)				
BASDAI active disease (≥4), *n* (%)	38 (33)				
RAPID3 score, mean (S.D.)		10.5 (7.0)	11.3 (6.8)	11.1 (6.8)	0.24
RAPID3 severity group, *n* (%)					
Near remission (≤3)		24 (18)	68 (15)	92 (16)	0.58
Low severity (3.1–6.0)		22 (16)	61 (13)	83 (14)	
Moderate severity (6.1–12.0)		34 (25)	125 (27)	159 (27)	
High severity (≥12.1)		54 (40)	205 (45)	259 (44)	
AQoL-6D utility score, mean (S.D.)	0.78 (0.17)	0.74 (0.20)	0.73 (0.19)	0.74 (0.19)	0.021
RDCI, mean (S.D.)	2.1 (1.9)	2.3 (1.8)	2.8 (1.9)	2.6 (1.9)	<0.001

TAFE: Technical and Further Education; CAE: College of Advanced Education; TNFi: tumour necrosis factor inhibitor; JAK: Janus kinase; IL-6R: interleukin-6 receptor.

process of face validity and cross-cultural checking was addressed on two levels in this study. First, pre-testing of the instrument with individuals addressed the language, clarity and concept comprehensiveness of the original instrument [20, 36]. Modifications reflected in the CQRA-PREM-AU were confined to changes in wording and definitions relevant to Australian patients, and indeed the modified instrument closely resembles the original, yet this was an important part of cross-cultural adaptation. Second, the modified instrument was tested in the ARAD cohort because this sample has demographic features broadly reflecting the rheumatology patient population in Australia (Table 1). For this reason, we believe that the CQRA-PREM-AU will perform as anticipated in Australian rheumatology settings in the future. Time to complete the instrument was taken as a proxy measure of feasibility in this study. In this cohort, the median survey completion time of <5 min was considered acceptable, an important finding given that time constraints are a reported barrier to PREM implementation [9].

Importantly, the properties of structural validity and internal consistency have been confirmed for the CQRA-PREM-AU. EFA in this study confirmed that the domains of the modified instrument were broadly representative of the original, in which domains appear to have been constructed by expert opinion and have not been analysed in subsequent validation reports [7, 8]. EFA also identified similar loadings for the items loading strongly onto a specific factor, in this case factor 1 (Fig. 1), meaning that an average of these item scores is an estimate of the factor score on the same scale as the item responses. A high Cronbach's α value for this factor ($\alpha = 0.95$) also suggests reliability of an overall average score. In real-world terms, this indicates that an overall score for the CQRA-PREM-AU, averaged across all items, can be used to numerically represent patient-reported experience. This is a new application for the CQRA-PREM-AU and a novel aspect of this study. Potential applications of a numerical summary score for this instrument include the ability to monitor individual patient experience longitudinally, to perform analyses and comparisons between subgroups such as different disease cohorts, and to summarize and review patient experience within a health service more broadly. Aggregate experience scores may build into healthcare professional and patient understanding of how well services are meeting benchmarks for care, such as the Australian Rheumatoid Arthritis Clinical Care Standard, the Australian National Safety and Quality in Healthcare Standards or the

Table 2. Analyses of psychometric properties for CQRA-PREM-AU following modification

Measurement property	Analysis method; criteria	Finding
Face validity	Individual cognitive interviewing Pre-testing	
Feasibility	Completion time, seconds, mean, (IQR)	299 (130)
Structural validity	Exploratory factor analysis; IRT: CFI or TLI ≥0.97, or RMSEA ≤0.05 or SRMR ≤0.1	CFI 0.997 TLI 0.995 RMSEA 0.040 SRMR 0.015 Five factors extracted All items load similarly onto factor 1, as overall score
Internal consistency	Internal consistency of averaged CQRA-PREM-AU score; Cronbach's $\alpha > 0.7$	$\alpha = 0.948$
	Analysis by diagnosis	RA $\alpha = 0.95$ PsA $\alpha = 0.94$ AS $\alpha = 0.95$
Divergent validity	Correlation between overall averaged CQRA-PREM-AU score and disease activity	$\rho = 0.03$, $P = 0.45$
	Correlation between overall averaged CQRA-PREM-AU score and RDCI	$\rho = 0.04$, $P = 0.24$
	Correlation between overall averaged CQRA-PREM-AU score and AQOL-6D	$\rho = 0.27$, $P < 0.001$
Cross-cultural validity/measurement invariance	Multivariable regression analysis of covariates; coefficient (CI)	Age: coef = 0.002 (−0.002, 0.007), $P = 0.29$ Sex, female: coef = −0.011 (−0.110, 0.088), $P = 0.83$ Education level >secondary school: coef- = −0.067 (−0.160, 0.027), $P = 0.16$ Diagnosis (RA base): PsA coef = 0.030 (−0.082, 0.143), $P = 0.60$ AS coef = −0.069 (−0.198, 0.060), P = 0.30
Reliability	ICC of averaged overall CQRA-PREM-AU score	ICC 0.74 (95% CI 0.70, 0.77)
	Bland-Altman analysis for systematic bias	Mean difference 0.00 between measurement occasions 0 and 6 months
Interpretability	MIC; 95% limits of agreement	0.85
Floor/ceiling effect	Expected proportion of observations ≤1 or ≥5 exceeds 15%	Estimated proportion of observations ≥5 = 6.7% Estimated proportion of observations ≤1 = 0%

coef: coefficient; IRT: item response theory; RDCI: Rheumatic Disease Comorbidity Index; MIC: minimum important change.

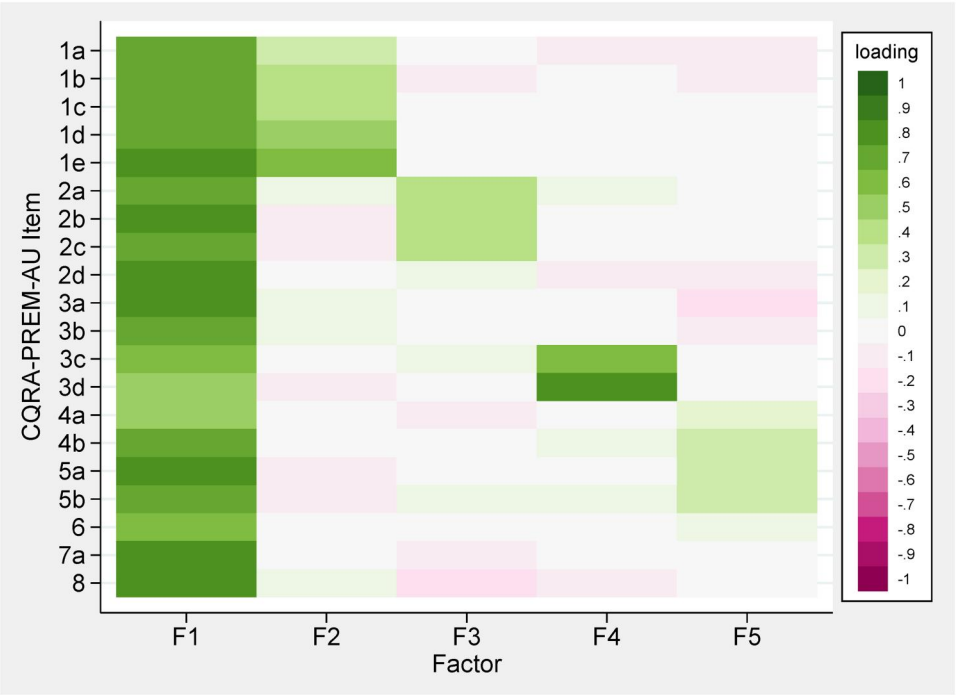

Figure 1. Orthogonal factor loadings for the five factors expressed in the CQRA-PREM-AU data

Table 3. Results of EFA and internal consistency of CQRA-PREM-AU items

Original CQRA-RA-PREM [7, 22]			CQRA-PREM-AU EFA following modification		
Domains	**Items**	α	**Factors**	**Items**	α
			Overall score	**All**	**0.948**
1: 'Needs and preferences'	1a, 1b, 1c, 1d, 1e	0.920	Domain 1	1a, 1b, 1c, 1d, 1e	0.920
2: 'Coordination of care'	2a, 2b, 2c, 2d	0.880	Domain 2	2a, 2b, 2c, 2d	0.880
3: 'Information about care'	3a, 3b, 3c, 3d	0.792	Domain 3 subset	3c, 3d	0.841
4: 'Daily living'	4a, 4b	0.631	Domain 4 + 5	4a, 4b, 5a, 5b	0.810
5: 'Emotional support'	5a, 5b	0.785			

Fundamental Standards of Care in the National Health Service [37–39].

Lastly, the capacity to represent CQRA-PREM-AU findings in a summary score lends practicality, another important consideration for uptake. It does not replace the need for careful review of PREM data for subscale items and the components of care experience they represent, which remains a prerequisite for ensuring meaningful service improvement. Rather, the numerical summary score is a fillip to the existing benefits of building PREM data into routine care. Defining absolute cut-off points for what constitutes excellent or suboptimal standards of care experience is a complex task, and beyond the scope of this study. However, describing the minimum important change in score for this instrument adds considerably to an understanding of how it can be used to follow change over time, and is a significant outcome of this study.

This study demonstrated a correlation between CQRA-PREM-AU scores and quality of life, in keeping with research reporting the association of patient experience and quality-of-life outcomes in long-term care [40]. Overlap exists between such AQOL-6D domains as independent living, relationships and pain and CQRA-PREM-AU domains such as physical and emotional care and involvement of support people. This positive correlation is therefore an expected finding. In contrast, the CQRA-PREM-AU score did not correlate with disease activity scores in this cohort, supporting the assertion that a positive patient experience can be achieved in spite of relatively high disease activity (and conversely, negative patient experience can occur despite sound disease control), confirming prior findings from real-world implementation of this instrument and other PREMs [8, 10].

Several limitations of this study are identified. First, there is no gold standard rheumatology PREM, and as such this study has not been able to compare CQRA-PREM-AU scores with a given standard, meaning criterion validity has not been tested. Furthermore, there are no published criteria for desirable measurement properties for PREMs in general, and while the COSMIN checklist is accepted as a proxy [1, 16–18], development of a dedicated standard for validating proposed PREMs would be appropriate. Second, a long time interval between collection of data detracts from the test–retest reliability findings. This was attributable in part to deploying the instrument in an existing patient database with guidance on the frequency of survey administration. It is plausible that changes to the clinical condition of an individual, or to care provision, may have occurred in this time. Third, as the demographic data for this sample indicate, many Australian rheumatology patients attend care in the private sector, although patients attending private rheumatology care were not represented in the individual interviews during face validity checking. Some elements of the instrument may be less applicable to private settings, e.g. where individual providers may not be co-located with other multidisciplinary team members and varying availability of or access to patient support programs. The authors note that purposive sampling was used in recruitment for individual interviews, following convention in qualitative methodology [41], to recruit varied participants representing the population of interest. It is possible that this sampling method can introduce potential bias. Despite these issues, we believe it is unlikely that the patient sample in individual interviews detracts from defining cross-culturally appropriate instrument items. Lastly, individuals with multisystem autoimmune diseases were not included in the study, due to the ARAD cohort comprising patients with inflammatory arthritis only. Further work will be necessary to validate the instrument for use with individuals in these cohorts.

Conclusion

PREMs add significant value to the existing use of outcome measures in rheumatology and regular appraisal of the patient experience is a key component of delivering high quality care. A modified instrument, CQRA-PREM-AU, has been defined for the Australian setting and has been demonstrated to be feasible for regular use and acceptable and relevant to patients in the Australian rheumatology setting. This study has confirmed the validity and reliability of the CQRA-PREM-AU and demonstrated the application of an overall averaged numerical experience score for the first time.

Supplementary material

Supplementary material is available at *Rheumatology Advances in Practice* online.

Data availability

The data underlying this article will be shared upon reasonable request to the corresponding author.

Authors' contributions

The study was designed by M.J.B., C.L.H. and R.J.B. Data collection was completed through the Australian Rheumatology Association, overseen by V.B. and M.J.B. Data analysis was performed by M.J.B., S.L., C.L.H. and R.J.B. M.J.B. drafted the manuscript, and all authors

contributed to its review. All agree to be accountable for all aspects of the work.

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