

Development and Validation of a Patient Reported Experience Measure (PREM) for Patients with Rheumatoid Arthritis (RA) and other Rheumatic Conditions

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Abstract: *Objectives:* Patient experience is not routinely measured in rheumatoid arthritis (RA) and no accepted standardised Patient Reported Experience Measures (PREM) tools currently exist. Commissioning for Quality in Rheumatoid Arthritis (CQRA) has developed, piloted and validated PREMs for RA and other rheumatic conditions.

Methods: Focus groups were held with RA patients to identify key elements of the patient experience. These were mapped against the UK Department of Health Patient Experience Framework and a PREM questionnaire developed with questions specifically relating to RA and rheumatology services. The RA PREM was piloted and Cronbach's alpha used to assess internal consistency. The PREM was modified to capture experience of patients with other rheumatic conditions and further validated.

Results: Ten UK sites and 524 patients were included in the RA PREM pilot and validation analysis. The RA PREM reliably captured RA patient experience and had good construct validity. Cronbach's alpha within the multiquestion domains ranged from 0.61 to 0.90 and the percentage agreement ranged from 22.5% to 70.4% with overall care. The modified PREM was evaluated in 11 UK sites and 110 patients with a range of rheumatic conditions. Cronbach's alpha ranged from 0.76 to 0.91 and the percentage agreement similarly ranged from 70% to 90% with the question on overall care.

Conclusions: The RA PREM and the modified PREM provide new valuable validated tools for capturing the patient experience in a range of rheumatic conditions. The RA PREM is currently being used in a UK National Clinical Audit of Rheumatoid and Early Inflammatory Arthritis.

Keywords: Patient Reported Experience Measure, rheumatoid arthritis.

INTRODUCTION

Rheumatoid arthritis (RA) represents a substantial health burden globally and ranks in the top 14% of highest contributors to global disability and has severe consequences in affected individuals [1]. The importance of incorporating the patient perspective and experience in assessments of quality of healthcare has long been recognised internationally [2, 3]. Improving patient experience and quality of care are also a priority in the UK. The Care Quality Commission (CQC) and National Institute for Health and Care Excellence (NICE) have published a Quality Standard that focuses on the patient experience [4], while the National Health Service's (NHS) Patient Experience Framework outlines the issues most important to patients' experience of the NHS [5]. In addition, payment through the Commissioning for Quality

and Innovation (CQUIN) scheme requires a patient experience element [6].

However, despite the increasing awareness of its potential value in improving quality of care, patient experience is not currently routinely measured in RA and there are, as yet, no consistent and uniformly accepted tools for capturing the patient experience. In response to this unmet need, Commissioning for Quality in Rheumatoid Arthritis (CQRA, a multidisciplinary group of stakeholders) has developed, piloted and validated Patient Reported Experience Measures (PREMs) for RA and for other rheumatic conditions. This paper focuses on the results from CQRA PREMs projects.

METHODS

PHASE I

Development, Pilot and Validation of a PREM for RA

The CQRA group agreed to use the NHS Patient Experience Framework (NPEF) [5] as a foundation for the RA

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#On behalf of Commissioning for Quality in Rheumatoid Arthritis (CQRA).

PREMs. The Framework was agreed by the National Quality Board (NQB) Patient Experience Sub Group and draws upon research published from the King's Fund and King's College London [7]. The NPEF is composed of eight separate domains that have been evidenced as being most important to patients' experiences of NHS services and can be used to direct efforts to improve services. The domains were used as a guide when devising which questions to ask patients that would give a true reflection of the service they are receiving across the care pathway. The eight domains are:

- Respect for patient-centred values, preferences, and expressed needs.
- Co-ordination and integration of care.
- Information, communication, and education.
- Physical comfort.
- Emotional support.
- Welcoming the involvement of family and friends.
- Transition and continuity.
- Access to care.

Scoping Project

It was decided that a focus group, convened and facilitated by the UK National Rheumatoid Arthritis Society (NRAS), on behalf of CQRA, would be the optimum method of scoping the above topics to gain patients' views and establish the priorities for patients with RA on their journey through the healthcare system.

Recruitment: Participants were invited to take part via the NRAS website and consent assumed following a response. Participants were all unpaid volunteers and were given full information about the project. Research was conducted in accordance with the ethical code prescribed by the British Sociological Association's Code of Ethics [8]. Participants were all NRAS members living with active RA and were over 18 years old. Selection was based on the need for inclusion of patients of different ages, with different lengths of time living with RA, differing treatment regimens (and including those receiving biologic therapy), and ability to travel to the focus group location.

Pilot and Focus Group: A pilot interview was first conducted with one participant to establish if the focus group would be able to elicit the information required. This was a one-hour telephone interview conducted with a female RA patient (aged 57) who had similar characteristics to the focus group participants. The convenience sample included seven additional participants (total 8 female participants), aged 37–71 years (median age 53 years). A thematic analysis was undertaken by recording and transcribing the interview and focus group. Using NVivo qualitative analysis software, data was subsequently coded and emerging themes grouped together. Similarities and differences between the responses were then identified.

The focus group took approximately two hours and was facilitated by SD, an NRAS Data Analyst and Research Intern. Participants were asked to comment on their personal experience related to the eight domains. A debrief opportu-

nity was offered to all participants allowing them to access the NRAS Helpline Team if they experienced any distress or upset during or after the focus group.

Results from the focus group scoping project informed the development of a PREM questionnaire by the CQRA group, aligned to the NPEF domains. A draft questionnaire was then piloted with NRAS members (n=20) and further refined. It was then reviewed and approved for clarity by the Plain English Campaign with award of the internationally recognised Crystal Mark (Crystal Mark 20589; approved May 2013). This approved questionnaire was piloted in rheumatology units who volunteered to take part in the survey. Details of participating units are shown in Table 1. Participating units were sent a project pack and a CQRA post-box for completed questionnaires to assure patient anonymity. Completed questionnaires were sent directly to CQRA for pooled analysis.

Statistical Analysis

The construct validity of the RA PREM was evaluated using Cronbach's alpha [9] to determine its ability to effectively measure the patient experience. Cronbach's alpha is commonly used over ordinal scales to measure internal consistency within a domain. A value of at least 0.7 is regarded as satisfactory [10]. In case of multiple questions per domain, responses were shown as a range. The percentage agreement with overall care over the 5-point scale for each question within a domain was also calculated. This provides another means of validation of each criterion against an overall score which should be a function of the individual components of care and therefore should exhibit good agreement with this overall score. The higher the agreement with overall quality, the more assurances that the question is valid.

Results from the Pilot and Validation of a PREM Questionnaire for RA

Ten units across England volunteered to participate in the pilot (Table 1). A total of 524 patients were included in the pilot and validation analysis. The median age of patients was 65 years (range 55–80 years), 377 (72%) were female and the median RA disease duration was 8 years (range 3.5–15 years). Respondent demographics are shown in Table 2. Responses for PREM questions across each domain are shown in Table 3.

On average 95% of respondents (range 91–99%) 'strongly agreed' or 'agreed' that their needs and preferences were being addressed, while 88% of respondents (range 83–92%) 'strongly agreed' or 'agreed' that co-ordination of care and communication was good. Cross team access did not generally score as highly as other questions although 92% of respondents were aware a team was looking after them. Overall, 69% of respondents (range 31–92%) 'strongly agreed' or 'agreed' that their information, education and self-care needs were being met. While 92% of respondents had been given timely information and had a good understanding of the treatments they were being offered, less than one-third (31%) had been offered an opportunity to attend a self-management programme and just over half (59%) had been told about patient groups or organisations.

Table 1. Units participating in the RA PREM and rheumatic conditions PREM.

Unit	Location	Type	Population served	RA PREM	Rheumatic conditions PREM
Guys and St Thomas' Hospital	London	Teaching hospital	750,000	Yes	Yes
James Paget University Hospitals NHS Trust	Great Yarmouth	Teaching hospital	230,000	Yes	Yes
Nuffield Orthopaedic Centre	Oxford	Teaching hospital	655,000	Yes	Yes
Pennine MSK Partnership Ltd	Oldham	Community-based musculoskeletal services provider	230,000	Yes	No
Queen Victoria Hospital	Blackpool	Teaching hospital	440,000	Yes	Yes
Royal Cornwall Hospital	Truro	Teaching hospital	450,000	Yes	Yes
Royal Lancaster Infirmary	Lancaster	Teaching hospital	300,000	Yes	Yes
Salford Royal NHS Foundation Trust	Salford	Teaching hospital	220,000	Yes	No
West Suffolk Hospital	Bury St Edmunds	Teaching hospital	280,000	Yes	Yes
Whipps Cross University Hospital	London	Teaching hospital	350,000	Yes	No
Brighton and Sussex University Hospital NHS Trust	Sussex	Teaching hospital	460,000	No	Yes
Royal Blackburn Hospital	East Lancashire Hospitals NHS Trust	Acute Trust	520,000	No	Yes
South Warwickshire NHS Foundation Trust	Warwick	Acute Trust	270,000	No	Yes
Wrightington Hospital	Wigan and Leigh NHS Foundation Trust	Acute Trust	310,000	No	Yes

Table 2. Respondent demographics for RA PREM survey*.

Characteristic		Number of respondents (%)
Age (n=512)	< 30 years	9 (1.76)
	30–40 years	23 (4.49)
	41–50 years	54 (10.55)
	51–60 years	117 (22.85)
	61–70 years	161 (31.45)
	> 70 years	148 (28.91)
Duration of RA (n=505)	< 2 years	42 (8.32)
	2–5 years	110 (21.78)
	6–10 years	122 (24.16)
	> 10 years	231 (45.74)
Ethnicity (n=512)	White	503 (98.24)
	Mixed	1 (0.19)
	Asian / Asian British	2 (0.39)
	Black, African, Caribbean or Black British	3 (0.59)
	Other	2 (0.39)
	Prefer not to say	1 (0.19)

*Data available from respondents completing each question.

Table 3. Responses for PREM questions by domain.

Domain	Question (Number of responders)	Percentage responders per response category (%)				
		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. Needs and preferences	Treated respectfully as an individual (n=518)	68.73	30.31	0.58	0.39	0.0
	Involved in decisions about care and treatment (n=518)	59.07	35.14	4.25	1.35	0.19
	Personal circumstances and preferences considered (n=507)	52.47	37.87	8.28	1.18	0.2
	Given understandable information (n=517)	59.19	37.52	2.51	0.77	0.0
	Given enough information (n=516)	53.29	39.73	4.65	2.13	0.19
2. Co-ordination of care	Made aware of health team looking after me (n=514)	53.70	38.13	4.47	3.31	0.39
	Able to access different health team members (n=505)	43.96	39.01	12.08	4.16	0.79
	Member of health team helps me access specialists (n=511)	44.62	40.12	11.55	3.72	0.0
	Health team fully up to date with my situation (n=516)	52.71	39.15	5.43	2.33	0.39
3. Information about care	Given information at the time I needed it (n=514)	50.19	42.22	5.64	1.75	0.19
	Good understanding of the treatments I am on/offered (n=518)	49.03	44.21	4.83	1.74	0.19
	Been told about patient groups/organizations (n=494)	25.91	33.00	28.34	12.75	0.0
	Offered opportunity to attend self-management programme (n=499)	13.63	17.64	35.67	27.66	5.41
4. Daily living	RA controlled enough to let me get on with daily life /usual activities (n=504)	36.11	39.09	14.09	9.33	1.39
	Able to get help quickly when I have had a flare (n=505)	34.26	40.59	16.44	7.13	1.58
5. Emotional support	Feel able to approach member of health team to discuss any worries about treatment or their effect on my life (n=506)	44.86	41.70	9.09	3.56	0.79
	Feel able to discuss personal / intimate issues with health team if I want to (n=498)	33.94	38.76	21.29	5.02	1.00
6. Family and friends	Feel able to take family members to appointments / become involved in decisions about my care (n=504)	46.43	39.29	12.70	0.99	0.60
7. Access to care	Enough time to cover everything during appointments (n=507)	49.31	42.01	5.33	2.76	0.59
	Have had clinic appointments cancelled unexpectedly (n=437)	20.59	28.15	10.53	29.98	10.76
	Have needed extra treatment or change of treatment (n=418)	27.27	41.15	15.31	8.61	7.66
8. Overall experience	Have had a good experience of RA care in the past year (n=513)	58.48	32.16	6.63	2.14	0.58

In terms of daily living and physical comfort, 72% of respondents ‘strongly agreed’ or ‘agreed’ that their RA was controlled enough to allow them to undertake their usual daily activities and a similar proportion (75%) ‘strongly agreed’ or ‘agreed’ that they were able to access help rapidly when experiencing a flare. However 11% of respondents ‘disagreed’ or ‘strongly disagreed’ that their RA was being controlled enough to let them get on with daily life, and a small proportion (9%) of respondents ‘disagreed’ or ‘strongly disagreed’ that they were able to get help quickly for flares. Regarding emotional support, on average 80%

(range 73–87%) of respondents ‘strongly agreed’ or ‘agreed’ that they were able to approach a member of their health team to discuss any worries. In general, fewer respondents ‘strongly agreed’ or ‘agreed’ they were able to approach a team member with intimate or relationship issues. The majority of respondents (86%) ‘strongly agreed’ or ‘agreed’ they felt able to involve family and friends in care decisions during outpatient appointments.

Access to care questions appeared to be poorly answered with some irregularities in data. Nevertheless, 91% of re-

spondents 'strongly agreed' or 'agreed' that their appointments were long enough. Regrettably 49% 'strongly agreed' or 'agreed' that appointments had been cancelled unexpectedly (55% were rescheduled within 3 weeks), while 68% 'strongly agreed' or 'agreed' that their treatment had been changed (with change occurring within 3 weeks for 73% of respondents). Overall, 91% of respondents 'strongly agreed' or 'agreed' that they had had a good overall experience of RA care over the past year; only a very small minority (3%) 'disagreed' or 'strongly disagreed'.

The Cronbach alpha co-efficients within the multi-question domains and their percentage agreement with the question on overall care are shown in Table 4. The access to care domain had the highest agreement with overall care (70.4%) while domains on information about care (22.5–66.4%) and daily living (33.2–53.4%) had the lowest agreement with overall care.

PHASE II

Development and Validation of a Rheumatic Conditions PREM

The validated RA PREM, with the same eight NPEF domains, was modified in series of workshops involving CQRA members. Each question within the PREM was reviewed and Group experience and judgement used to 'sense check' the PREM by evaluating specific wording and ensuring that questions were applicable, relevant and able to capture the experience of patients with other rheumatic conditions. Modification included amendment of any questions or phrasing specific or pertinent only to patients with RA. This "Rheumatic Conditions PREM" was then piloted in rheumatology units with patients diagnosed with a range of rheumatic conditions (which could also include RA) and validated, again using Cronbach's alpha [9]. Details of participating units are shown in Table 1.

Results of Pilot and Validation of a Rheumatic Conditions PREM

Eleven units (Table 1) volunteered to participate in the Rheumatic Conditions PREM pilot and 110 patients with rheumatic conditions were included in the final analysis. The median age of respondents was 60 years (range 18–84 years) and 69.7% were female and the majority of patients (63.3%) had a disease duration of \geq six years.

Respondents presented with a range of rheumatic conditions and may have had more than one diagnosis. Rheumatic conditions were: Sjögren's syndrome, fibromyalgia, systemic lupus erythematosus (SLE), gout, polymyalgia rheumatica, [adults with] juvenile idiopathic arthritis, chronic back pain, osteoarthritis, inflammatory polyarthritis, ankylosing spondylitis, psoriatic arthritis, and scleroderma (systemic sclerosis). The majority of patients (97%) were white.

The Cronbach alpha co-efficients within the multi-question domains and their percentage agreement with the question on overall care are shown in Table 5. Some domains (such as needs and preferences and emotional support) had higher agreement with overall patient experience. Cronbach's alpha within the multi-question domains ranged from 0.76 to 0.91 and their percentage agreement with the question on overall care ranged from 0.70 to 0.90. The modified PREM for patients with a range of rheumatic conditions proved to be practical to administer in a general rheumatology clinic. Results with the modified PREM were consistent with those obtained for the RA-specific PREM (0.76, 0.91) and (0.61 to 0.90), respectively. This modified PREM had good construct validity and was able to reliably capture the patient experience in rheumatic conditions other than RA.

DISCUSSION

The RA PREM was successfully piloted and validated in over 500 patients and proved practical to administer in typical UK RA units. Analysis using Cronbach's alpha demonstrated that the RA PREM has good construct validity, achieving a value of 0.7 or above in all but one domain (daily living, 0.61) and is a valid tool for measuring RA patient experience. Cronbach's alpha analysis of the modified PREMs for rheumatic conditions other than RA strongly supports the contention that the PREMs can also be used in this group of patients.

Data from the pilot study suggested areas of good patient experience of RA services, but equally revealed areas that may require a change in practice to improve the patient experience. For example, the data indicate that improvements are needed to ensure that patients are signposted to patient organisations and have adequate support for self-management. Furthermore, around one-quarter of patients felt that their RA was not being sufficiently controlled to allow them to get

Table 4. RA PREM validation: result of Cronbach's alpha analysis and agreement with overall care.

Domain	Number of questions	Alpha within domain	Agreement with overall care (%)
Needs and preferences	5	0.90	64.5–67.2
Co-ordination of care	4	0.87	59.1–69.1
Information about care	4	0.75	22.5–66.4
Daily living	2	0.61	33.2–53.4
Emotional support	2	0.84	53.5–68.9
Family and friends	1	–	61.8
Access to care	1	–	70.4

on with daily life or were unable to get rapid help for flare management, suggesting another priority area for improvement.

The data highlight the feasibility of using the PREM to benchmark patient experience between units, to provide data for clinical validation and re-validation of units and importantly to identify areas requiring improvement. Use of the PREMs alongside existing review of Patient Advocacy Liaison Service (PALS) concerns and complaints processes could help rheumatology units to identify specific local areas of challenge and aid the development and implementation of improvement action plans. Additionally, units would be able to record and monitor their own progress using the PREM tool and could potentially ask patients to complete a PREM once a year. The use of a standardised questionnaire also facilitates international benchmarking of units as well as national and regional comparison of patient experience.

To the authors' knowledge there has only been one previously reported PREM for inflammatory arthritis piloted in the UK healthcare setting [11, 12]. That PREM consisted of 32 questions covering five categories: journey to diagnosis, impact of the disease on the patients' everyday life, knowledge about the disease, hospital care and patient education and aftercare. The PREM and a PROM tool were evaluated in 183 participants attending a routine clinic with reproducibility and comprehensibility assessed using a test-retest method. A significant correlation was reported for the PREM's 'Arthritis and Life' domain with other clinically assessed disease activity parameters, though the level of correlation in other domains is not clear [11]. Though studies vary in the extent of correlation and the strength of association observed between patient experience and clinical outcomes, and differences between long-term conditions and acute conditions could affect correlations between PREMs and PROMs [13] it has been suggested that improving the patient experience may have a positive impact on patient outcomes [13, 14]. If so, this lends further support for the routine implementation of PREMs.

The current CQRA study has several strengths. Firstly, the PREMs were developed through a rigorous process including several revisions and refinements in consultation with patients with RA, ensuring the relevance of the final PREM questionnaire. Secondly, the survey and validation of the PREMs tools involved a large number of participants (over 600 for both PREMs) and included participation of 10–11 units across England. Furthermore, whilst the current PREMs pilots have been employed in the secondary care setting, there is potential for their use within the primary care setting, providing an opportunity for patient experience to be captured and monitored across the entire care pathway.

Authors acknowledge some potential limitations of the RA study. There is a possibility of bias in current PREMs results as focus group participants were all female NRAS members and as such may not fully represent the general RA population. Authors also acknowledge limitations in the ethnicity representation of the study sample such that findings may not be generalizable to all ethnic groups. Additionally,

subsequent volunteering rheumatology units may not represent the entire quality spectrum across the UK, and whilst authors requested respondents be consecutive patients (and as such randomly participating), this cannot be guaranteed. Dissemination of the PREMs and their wider use in a larger number of patients representative of the general population across a broad spectrum of rheumatic conditions would provide further important confirmatory evidence for the effectiveness of the PREMs.

The UK's Health Quality Improvement Partnership (HQIP) has a particular focus on increasing the impact that clinical audit has on healthcare quality in England and Wales. The RA PREM developed by CQRA has been incorporated into the HQIP National Audit for rheumatoid and early inflammatory arthritis commencing in 2014 for three years [15]. It has been mandated that all hospital trusts in England and Wales participate and the first quality report from the audit is expected in June 2015. However, as the audit only includes patients with early disease, a comprehensive assessment of patient experience would need to reflect the totality of the patient population, including those with established RA.

Given that the overarching aim of capturing the patient experience is to drive improvements in quality of care that may positively impact patient outcomes, future plans are to continue dissemination of the CQRA PREMs with the aim of increasing implementation. Use of the PREMs in more units across a wider range of patients will provide valuable data which can be used along with HQIP audit data to better understand current patient experience across the UK and help to embed routine data collection and analysis within units so that priority areas for improvement are identified and tangible plans put in place to address these areas. The effectiveness of improvement initiatives could be assessed through ongoing monitoring and potentially become an integral part of the validation/revalidation of rheumatology units. Furthermore, it is likely that with minor modification, the PREM has the potential to be relevant and useful in other long-term conditions beyond rheumatology.

In conclusion, both the RA and the modified PREMs for other rheumatic conditions have been validated for measuring and monitoring patient experience in rheumatology and implementation has been shown to be effective in identifying aspects of the patient experience which need review. They can provide data-based evidence for demonstrating quality of services and are practical and robust tools to enable commissioners and providers to monitor and improve patient experience of care under an integrated team for a long term condition. The PREMs are available for use and can be accessed from URL with <http://www.nras.org.uk/for-professionals>.

KEY MESSAGES

1. A Patient Reported Experience Measure (PREM) was successfully developed and validated for rheumatoid arthritis.
2. The Rheumatoid Arthritis PREM is currently being used in a UK-wide National Clinical Audit.

3. A modified PREM was also developed and validated for use with a range of rheumatic conditions.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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