

# MODIFICATION OF A VALIDATED PATIENT REPORTED EXPERIENCE MEASURE TOOL FOR RHEUMATOID ARTHRITIS FOR USE IN OTHER RHEUMATIC CONDITIONS: RESULTS OF A PILOT STUDY

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## Background

- To date there have been no specific patient reported experience measures (PREMs) for rheumatology. PREMs would be a method of ascertaining that patients have an optimum experience when attending for their care
- A multidisciplinary group Commissioning for Quality in Rheumatoid Arthritis (CQRA) developed a PREM for RA in 2012
- A series of focus groups were held with patients from National Rheumatoid Arthritis Society (NRAS) to determine which elements of the patient experience were deemed most important. This was mapped against the UK Department of Health Patient Experience Framework which comprises 8 domains
- A PREM questionnaire was then developed using the same 8 domains, but with questions developed specifically relating to RA and rheumatology services. The final question asked respondents to evaluate their overall level of care. All questions were graded from strongly agree to strongly disagree using a 5-point scale

- The PREM questionnaire was piloted across ten UK sites (Bosworth et al. 2013)<sup>1</sup> and construct validity evaluated (using Cronbach's alpha to assess internal consistency or how closely the individual questions are related). This confirmed that the PREM has good construct validity and is a valid instrument for measuring RA patient experience (Bukhari et al. 2013)<sup>2</sup>

- This PREM is being used nation-wide in the current Healthcare Quality Improvement Partnership (HQIP) National Clinical Audit of Rheumatoid and Early Inflammatory Arthritis<sup>3</sup>

## Methods

- The RA PREM was modified to capture the experience of patients with other rheumatic conditions (including Sjögren's syndrome, fibromyalgia, systemic lupus erythematosus, gout, polymyalgia rheumatica, [adults

with] juvenile idiopathic arthritis, chronic back pain, osteoarthritis, inflammatory polyarthritis, ankylosing spondylitis, psoriatic arthritis, and scleroderma) using the same eight domains

- Cronbach's alpha (Bland, Altman 1997)<sup>4</sup> was again chosen to measure construct validity. It is commonly used over ordinal scales to measure internal consistency within a domain
- A value of at least 0.7 is regarded as satisfactory, as it demonstrates the questions that correlate with each other (Tavakol, Dennick 2011).<sup>5</sup> The percentage agreement with overall care over the 5-point scale for each question within a domain estimating reliability of test scores was also calculated
- Additionally, for each question the percentage agreement with the overall assessment on the five point scale was calculated
- In case of multiple questions per domain, the responses are shown as a range. The modified PREM was piloted and validated

## Results

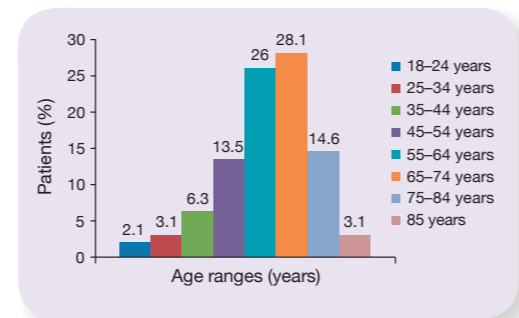
- Eleven units volunteered to participate in the pilot (Figure 1)

Figure 1. Illustrates map of UK showing participating unit locations



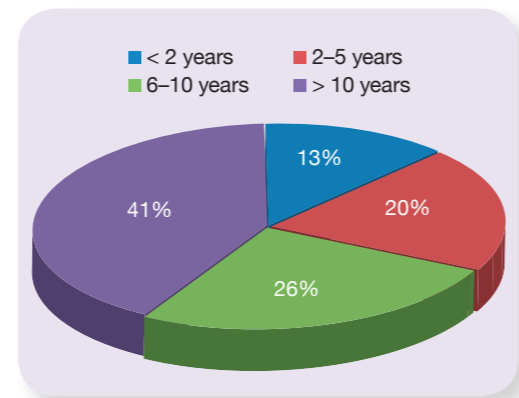
- 110 patients with rheumatic conditions were included in the analysis
- Median age was 60 years (range 18–84 years) (Figure 2)

Figure 2. Illustrates the age range of patients (n=96)



- 69.7% were female
- The majority of patients had a disease duration of ≥6 years (Figure 3)

Figure 3. Illustrates the duration of rheumatic condition (n=90)



- Patients presented with a range of rheumatic conditions and included: rheumatoid arthritis; Sjögren's syndrome; SLE / lupus; (adult with) juvenile idiopathic arthritis; gout; fibromyalgia; polymyalgia rheumatica; chronic back pain; osteoarthritis; inflammatory polyarthritis; ankylosing spondylitis; psoriatic arthritis; and scleroderma
- The patient population and the range of rheumatic conditions were representative of what is generally seen in the clinic
- The majority of patients (97%) were caucasian
- The Cronbach alpha co-efficients within the multi-question domains and their percentage agreement with the question on overall care are shown in Table 2
- 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.
- These results are consistent with those obtained for the RA-specific PREM (0.61–0.90) and (0.56, 0.81), respectively (Bukhari et al. 2013)<sup>2</sup>

Table 2. Illustrates the 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	0.91	90
Co-ordination of care	4	0.81	84
Information about care	4	0.77	79
Daily living	2	0.76	81
Emotional support	2	0.85	88
Family and friends	1	-	70
Access to care	1	-	78

## Conclusions

- The modified PREM was practical to administer in a general rheumatology clinic, demonstrated good construct validity and was able to reliably capture the patient experience in rheumatic conditions other than RA
- Some domains (such as needs and preferences and emotional support) had a higher agreement with overall patient experience
- Both the RA and the modified PREMs provide valid and valuable tools for measuring and monitoring patient experience in rheumatology and aim to drive improvements in patient experience of care

## References

- Bosworth A, et al. Rheumatology 2013;52 (suppl 1): i56-i94 (Abstract 93. Poster presentation)
- Bukhari M, et al. Arthritis Rheum 2013;65:S952 (Abstract 2239. Poster presentation)
- Healthcare Quality Improvement Partnership (HQIP) National clinical audit for rheumatoid and early inflammatory arthritis. Available at: [http://www.rheumatology.org.uk/resources/audits/national\\_ra\\_audit/information\\_pack.aspx](http://www.rheumatology.org.uk/resources/audits/national_ra_audit/information_pack.aspx). Patient data collection form - follow up at 3 months (accessed March 2014)
- Bland M, Altman D. Statistics notes: Cronbach's alpha BMJ 1997;314:572
- Tavakol M, Dennick R. Int J Med Ed 2011; 2:53–55

## Acknowledgements

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## The PREM questionnaire

Section	Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable
1. Your needs and preferences	a) Whenever I attended a clinic, I felt that I was treated respectfully as an individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	b) I was involved as much as I wanted to be in decisions about my treatment and care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	c) My personal circumstances (see note 1 below) and preferences were taken into account when planning and deciding on my treatment and care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	d) I was given information in a way that I could understand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	e) I was given enough information to help me make decisions about my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2. Co-ordination of care and communication	a) I was made aware that there is a team of health professionals (see note 2 below) looking after me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	b) When I needed help I was able to access different members of my health team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	c) There is a member of my health team who can help me to see other specialists in the team if I need to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	d) I feel that the people I see at the clinic are fully up to date with my current situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Information, education and self-care	a) I feel that I was given information at the time I needed it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	b) I feel that I have a good understanding of the treatments I am on or being offered	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	c) I have been told about patient organisations or groups that can help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	d) I have been offered an opportunity to attend a self-management programme suitable to my needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Daily living and physical comfort	a) I feel that my rheumatoid arthritis is being controlled enough to let me get on with my daily life and usual activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	b) If I have had a 'flare' (when my symptoms get much worse), I have been able to get help quickly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Emotional support	a) I feel able to approach a member of my health team to discuss any worries about my condition and my treatment or their effect on my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	b) I feel able to discuss personal or intimate issues about relationships with my health team if I want to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
6. Family and friends	a) I feel able to take members of my family to outpatient appointments to become involved in decisions about my care if I want to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
7. Access to care	a) At appointments, I feel that I have enough time with the healthcare professional to cover everything I want to discuss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	b) I have had clinic appointments cancelled unexpectedly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	c) If yes, how long have you had to wait for a new appointment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	d) I have needed extra treatment or a change of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	e) If yes, how long did it take for this to happen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Overall experience of care	a) Overall in the past year, I have had a good experience of care for my rheumatoid arthritis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Your rheumatic condition, the length of time you have had the condition, your age, sex and ethnic background may affect the kind of care you have experienced and affect your answers to the questions. To help us fully understand your answers, please fill in the section below.

9. What rheumatic condition(s) do you attend the rheumatology clinic for?  
 Rheumatoid arthritis     Sjögren's syndrome     Fibromyalgia     SLE / lupus     Adult with juvenile idiopathic arthritis     Gout  
 Polymyalgia rheumatica     Chronic back pain     Osteoarthritis     Don't know     Inflammatory polyarthritis  
 Scleroderma     Ankylosing spondylitis     Psoriatic arthritis     Other (please specify)

How long have you had rheumatoid arthritis?  
 Less than 2 years     Between 2 and 5 years     Between 6 and 10 years     More than 10 years

How old are you?  
 18–24     25–34     35–44     45–54     55–64     65–74     75–84     85 and over

How old are you?  
 male?     female?

What is your ethnic group?  
 White     Mixed     Asian or Asian British     Black, African, Caribbean or Black British     Other     Prefer not to say

Note 1: Examples of 'personal circumstances' could be whether you work or have carer responsibilities. Note 2: The type of health professionals in the team will vary from region to region but should include a consultant, a nurse specialist, an occupational therapist and a physiotherapist, as well as access to a podiatrist.

Thank you for taking the time to fill in this questionnaire.