

## Background/Purpose

- Improving patient experience is important in all diseases, but most important in patients with chronic rheumatic diseases like rheumatoid arthritis
- To date there have been no specific patient reported experience measures (PREMs) in rheumatology. This would be a method of ascertaining that the patient has an optimum experience when attending for their care
- A multi-disciplinary group, commissioning for quality in rheumatoid arthritis (CQRA) was established to develop the first PREM in RA
- This group was supported under the terms of a joint working agreement with Roche Products Ltd. (Ailsa Bosworth, Chief Executive, NRAS, Joint Chair Rheumatology Futures Group; Graeme Johnston, NRAS, Chair of the Trustees; Dr. Marwan Bukhari, Consultant Rheumatologist, Royal Lancaster Infirmary; Maureen Cox, Clinical Nurse Specialist in Rheumatology, Nuffield Orthopaedic Centre (NHS Trust); Anne O'Brien, Lecturer in Physiotherapy - Keele University Staffordshire; Prof. Peter Jones, Senior Statistician at the Health Services Research Unit, and Emeritus Professor of Statistics, Keele University; Paul Carroll, Assistant Director Commissioning, Ashton, Leigh and Wigan PCT; Dr. Alan Nye, Director Pennine MSK Partnership; Alison Elliott, Strategic Funding Manager-Speciality Care, Roche Products Limited; Ify Sargeant, Medical Writer, ismedica Ltd.)
- A series of focus groups were held with patients from the UK National Rheumatoid Arthritis Society (NRAS) to determine which elements of the patient experience was deemed most important
- This was mapped against the UK Department of Health Patient Experience Framework which comprises 8 domains
- A questionnaire was then developed using the same 8 domains, but with questions developed specifically relating to RA and Rheumatology Services
- This questionnaire was then piloted across ten UK sites
- The final question asked respondents to evaluate their overall level of care
- All questions were graded from strongly agree to strongly disagree

Figure 1. Map of UK showing participating unit locations (white dots)



## Aim

To determine the construct validity of the PREM questionnaire developed by the CQRA group, to determine its ability to measure the patient experience

## Methods

- Cronbach's alpha<sup>1</sup> (Bland & Altman (1997)) was chosen to measure construct validity. It is commonly used over ordinal scales to measure internal consistency within a domain or how closely the individual questions are related. A value of at least 0.7 is regarded as satisfactory. The percentage agreement with overall care over the 5 point scale for each questions within a domain 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

## Results

- 524 patients were included in the analysis
- Median age was 65 years (IQR 55,80 years)
- 377 (72%) were female
- Median RA disease duration was 8 years (IQR 3.5, 15 years)
- The Cronbach alpha co-efficients within the multi-question domains and their percentage agreement with the question on overall care are shown in table 1

- This demonstrated good within domain agreement and agreement of each domain with overall experience of care

Table 1. Result of Cronbach's alpha analysis and their 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                            |

## Conclusion

- The PREM has good construct validity and is a valid tool for measuring RA patient experience
- Some domains have higher agreement with overall patient experience
- This could provide a useful future tool for measuring patient experience
- Modification of the tool to use in other rheumatic conditions is underway

## Reference

1. M. Bland & D. Altman Statistics notes: Cronbach's alpha BMJ 1997;314:572

## Acknowledgements:

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## The PREM questionnaire

| Section                                    | Statement   | Strongly agree   | Agree                 | Neither agree nor disagree | Disagree              | Strongly disagree     |
|--|---|--|-----------------------|----------------------------|-----------------------|-----------------------|
| 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"/> |
|  | 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"/> |
|  | 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"/> |
|  | 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"/> |
| 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"/> |
| 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"/> |
| 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"/> Yes<br><input type="radio"/> No  | <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"/> <1 week<br><input type="radio"/> 1-3 weeks<br><input type="radio"/> 4-6 weeks<br><input type="radio"/> 7-12 weeks<br><input type="radio"/> >12 weeks | <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"/> Yes<br><input type="radio"/> No  | <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"/> <1 week<br><input type="radio"/> 1-3 weeks<br><input type="radio"/> 4-6 weeks<br><input type="radio"/> 7-12 weeks<br><input type="radio"/> >12 weeks | <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"/> |

The length of time you have had rheumatoid arthritis, 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.

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?  
 Under 30     30 to 40     41 to 50     51 to 60     61 to 70     Over 70

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

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