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A multicentre nominal group study to rank outcomes important to patients and their representation in existing composite outcome measures for psoriatic arthritis

W. Tillett[1,2], E. Dures[3], S Hewlett[3], P.S .Helliwell[4], O. FitzGerald[5], M. Brooke, J. James, J. Lord, C. Bowen, M de Wit[6], A Orbai[7], N.McHugh[1,2] on behalf of the PROMPT study group

[1]Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, Bath, UK

[2]Department of Pharmacy and Pharmacology, University of Bath, Bath, UK

[3]University of the West of England, Bristol, UK

[4]LIRMM, University of Leeds, Leeds, UK

[5]St. Vincent's University Hospital and the Conway Institute, University College Dublin (UCD), Dublin, Ireland

[6]Department of Medical Humanities, Patient Research Partner, VU University Medical Centre, Amsterdam, the Netherlands

[7]Division of Rheumatology, Johns Hopkins University School of Medicine, Baltimore, Maryland, USA

Corresponding author

Dr William Tillett

Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, Bath, BA11RL, UK

Tel: 44 (0) 1225 448444

E-mail: w.tillett@nhs.net

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Objective

To rank outcomes identified as important to patients with psoriatic arthritis and examine their representation in existing composite measures.

Methods

Seven Nominal Group Technique (NGT) meetings took place at four hospital sites. Two sorting rounds were conducted to generate a shortlist of outcomes followed by a group discussion and final ranking. In the final ranking round patients were given 15 points each and asked to rank their top five outcomes from the shortlist. The totals were summed across the seven NGT groups and are presented as a percentage of the maximum possible priority score.

Results

Thirty one patients took part;16 men and 15 women, the mean age was 54 (range 24-77; standard deviation (SD) 12.2), the mean disease duration was 10.3 years (range 1 - 40; SD 9.2) and mean HAQ: 1.15 (range 0 - 2.63; SD 0.7). The highest ranked outcomes which patients wished to see from treatment were pain with 93 points (20.0%), fatigue 62 (13.3%), physical fitness 33 (7.1%), halting/ slowing damage 32 (6.9%) and quality of life/ wellbeing 29 (6.2%). Reviewing existing composite measures for psoriatic arthritis demonstrated that no single measure adequately captures all these outcomes.

Conclusion

Pain and fatigue were ranked as the outcomes most important to patients receiving treatment for PsA and are not well represented within existing composite measures. Future work will focus on validating composite measures modified to capture outcomes important to patients.

Introduction

Psoriatic arthritis (PsA) is an inflammatory arthritis affecting up to 20% of people with psoriasis.[1] PsA is now well recognised to be progressive and destructive in the majority with considerable impact in quality of life and there is building evidence from observational studies that delay to diagnosis is associated with worse radiographic and functional outcome.[2-4] This has prompted the hypothesis that early detection and treatment may improve outcome in the long term for patients. The 'early detection to improve outcome in patients with undiagnosed psoriatic arthritis' (PROMPT) study is a programme of studies to investigate the effect of enhanced surveillance for the early detection of arthritis amongst patients with psoriasis (RP-PG-1212-20007). An important aspect of this study is to assess outcomes that are meaningful to patients.

Considerable efforts have been made in recent years to improve the assessment of treatment response in PsA. Work within the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and Outcome measures in Rheumatology (OMERACT) led to the development of a core set of domains of disease to be assessed in Randomised Controlled Trials (RCT's) and Longitudinal Observational Studies (LOS) in 2006,[5] recently updated in 2016.[6] There is however no consensus as yet on the optimal method for assessing treatment response.[7, 8] It is well established that PsA may affect many domains including arthritis, enthesitis, dactylitis, spondylitis, uveitis and other extra articular manifestations such as the metabolic syndrome. There have been efforts to develop a composite outcome measure of disease activity to capture all aspects of PsA in a continuous activity measure. It is important to distinguish an activity measure from a response criteria such as the Minimal Disease Activity (MDA)[9], PsA response criteria (PsARC)[10, 11] or the American College of Rheumatology (ACR)[12] criteria that defines a disease state that is either achieved or not. A disease activity measure has the benefit of grading response and tracking of activity over time, furthermore cut points of high, moderate, low disease activity and remission can be developed to derive a response criteria. An activity measure is also distinct from an impact of disease measure, such as the Psoriatic Arthritis Impact of Disease (PSAID), which more widely covers concepts of activities and participation.

Several candidate activity measures have now been developed including the Composite Psoriatic Arthritis Disease Activity Index (CPDAI),[13] GRACE measure (initially named the Arithmetic Mean of Desirability Function- AMDF then re-named the GRACE after the original development study), Psoriatic Arthritis Disease Activity Score (PASDAS)[14] and Disease Activity in Psoriatic Arthritis (DAPSA)[15]. It has become apparent that these measures were developed with little patient involvement. This raises the issue that without representation of the lived experience of PsA through patient involvement we may be missing important aspects of disease thereby calling into question the validity of the composites.[16]

As part of the PROMPT programme we set out to establish whether existing composite activity measures capture outcomes of treatment important to patients or whether modifications may be necessary. Any modified versions would need validation in a prospective study and shortened, more feasible versions derived (based on sensitivity to change) for use in routine care. The first stage previously reported was to identify which outcomes from treatment were thought important by patients in a UK multicentre focus group study.[17] Qualitative data captured many outcomes important to patients, ranging from specific physical symptoms to the psychological, social and emotional impact on wellbeing and daily life. The objective of this present study was to rank these outcomes identified as important to patients and examine their representation in existing composite measures.

Materials and Methods:

Nominal Group Technique

A Nominal Group Technique (NGT) was applied in order for patients to rank the previously identified outcomes in relation to importance. A NGT is a structured group process with a focus on solution generation and decision-making. It encourages contributions from all participants by asking each individual for their opinion and their vote in the ranking exercise. To ensure an appropriately wide range of views and experience, patients who took part in the initial focus group studies to identify domains[17] were not eligible to take part in this present NGT ranking study.

Seven NGT groups took place at four hospital sites in Bristol, Bath, Stoke and Weston. Patients were identified from routine clinic appointments by their treating physician. To be eligible to take part patients were over 18 years old, have a physician diagnosis of PsA and have sufficient English language to participate in discussions. Efforts were made to recruit a sample of patients with a spectrum of phenotype and activity.

Prior to the start of the nominal groups, patients were asked to complete data on demographics, medications, and a Health Assessment Questionnaire score (HAQ)[18] as a measure of physical function. Nominal groups lasted for approximately one hour, were co-facilitated by two members of the study team (ED and SH) and were audio-recorded to keep an audit trail of the process. The nominal groups began with patients individually sorting a pack of laminated cards listing the 68 outcomes from previous UK focus group studies,[17] as well as five additional outcomes generated from a concurrent international focus group study.[6] Data from both these focus group studies contributed to the updated Outcome Measures in Rheumatology (OMERACT) psoriatic arthritis core set of domains.[6] The questions asked in these focus group studies addressed the same themes but exact wording differed:

UK focus groups were asked:

- Which symptoms have the most effect on your well-being?
- What do you want from your treatment?
- What are the benefits and drawbacks of treatment for you personally?
- 'How do you know when you are in a flare?'

International focus groups were asked:

- How does PsA affect your life?
- Has your life changed since PsA?
- How do you know you are in flare/remission?

In round one of the NGT patients were asked to rank with the instruction: 'What outcomes would you want from a treatment for your psoriatic arthritis?' Outcomes were categorised into four groups: not important/not applicable, important, very important, and most important. In round two, patients then identified the top five of their "most important outcomes" and these

were shared with the group, listed on a board and each one discussed and debated by the group, supported by facilitators. In round three, patients were asked to individually rank the top outcomes from the group list and overall ranking scores were calculated. The five top outcomes scored five points down to one according to priority order. Points were then summed across all seven nominal groups giving a potential total of 465 points. Data are represented as total points and percentage of the maximum possible score.

This study was approved by the National Research Ethics Service Committee North West-Haydock (reference: 15/NW/0609) and has been conducted in accordance with the Declaration of Helsinki. All participants signed informed consent.

Representation in existing composite measures

The final ranked outcomes from the NGT were then mapped against those included in the CPDAI, PASDAS, DAPSA and GRACE by one investigator (WT). These data were then presented at an investigators meeting to discuss; a) how each outcome was represented in the existing composite measures, b) identify the highest ranked outcomes important to patients that were missing and c) discuss which instruments could be added to capture these important missing domains to modify composites. The PASDAS, which was derived through a regression analysis and as such cannot be modified retrospectively, has been included in this study for completeness. The CPDAI, GRACE and DAPSA are modular and hence amenable to modification. At the mapping meeting there were three Patient Research Partners (PRP's) MB, JJ, JL, four clinicians; WT, NM, OFG, PH and two qualitative researchers, ED and SH.

Composite measures

The Composite Psoriatic Arthritis Disease Activity Index (CPDAI).[13] The CPDAI measures disease activity in five domains: peripheral joints [68 tender and 66 swollen joints, and Health Assessment Questionnaire (HAQ)][19], skin [Psoriasis Areas and Severity Index- (PASI)[20] and Dermatology Life Quality Index (DLQI)[21]], enthesitis (Leeds Enthesitis Count[22] and HAQ), dactylitis (number of tender dactylitic digits and HAQ), and spine [Bath Ankylosing Spondylitis Disease Activity Score (BASDAI)[23] and Ankylosing Spondylitis QOL index ASQoL)[24]]. Within each domain, severity is graded as 0 (none), 1 (mild), 2 (moderate), and 3 (severe), according to predefined cut offs.

The GRACE measure.[14] The GRACE measure is derived from the tender and swollen joint count, HAQ, patient global, skin and joint VAS scores, PASI and Psoriatic Arthritis Quality of Life (PsAQoL). Scores are transformed into linear functions ranging from 0 (totally unacceptable state) to 1 (normal) based on established desirability functions.[14] The eight transformed variables are then combined using the arithmetic mean giving a score from 0 to 1 the GRACE measure is a transformed version where scores range from 0 (low disease activity) to 10 (high disease activity).

The Disease Activity in Psoriatic Arthritis (DAPSA).[15] The DAPSA is a measure derived from the 68 tender and 66 swollen joint count, C Reactive Protein (CRP), patient global and pain visual analogue scales.

Psoriatic Arthritis Disease Activity Score (PASDAS).[14] The PASDAS is a weighted index comprising assessments of joints, function, acute-phase response, quality of life (QOL), and patient and physician global by Visual Analogue Scale (VAS).

Results

Nominal Group Technique

Thirty one patients took part in seven nominal groups at four hospital sites. There were a total of 16 men and 15 women, the mean age was 54 (range 24-77; standard deviation SD 12.2), the mean disease duration was 10.3 years (range 1-40; SD 9.2) and mean HAQ: 1.15 (range 0-2.63; SD 0.7). Patients had current or previous disease activity in the following domains; peripheral arthritis (n=29), psoriasis (27), spondyloarthritis (5), enthesitis (5), uveitis (1). The 68 outcomes important to patients discussed in round one are listed in Table 1. The round two shortlists from each of the seven NGT's are reported in Table 2. The final ranking of outcomes important to patients from round three are listed in Table 3. The top five ranked outcomes from treatment were pain with 93 points (20.0%), fatigue 62 (13.3%), physical fitness 33 (7.1%), halting/ slowing damage 32 (6.9%) and quality of life/ wellbeing 29 (6.2%).

Representation of outcomes in existing composite measures

It was not feasible to examine the representation of all 68 outcomes in the composite measures (CPDAI, PASDAS, GRACE, DAPSA). Examining the data there appeared to be a natural separation in the prioritisation of the top 10 ranked outcomes as compared to those ranked as less important (table 3). As a result the top ten ranked outcomes from the NGT were mapped to the composite measures and compared to the OMERACT core set of domains in Table 4. None of the existing composite measures captured all ten priority outcomes. Discussion at the investigators meeting focused on the two modular composites, the CPDAI and GRACE which are amenable to the additon of new outcomes. The top ten outcomes from the NGT are mapped to the CPDAI and GRACE in Figures 1 and 2 respectively. Pain (93 points) and fatigue (62 points), were ranked considerably more important by patients than the other outcomes in the NGT, and it is notable that neither pain or fatigue are represented independently in the CPDAI or GRACE composte measures.

The remaining eight out of the top ten outcomes identified in the NGT were then discussed. Physical function, quality of life and fitness were felt to be captured within the HAQ and PsAQol, ASQol. Damage is an important concept captured in the NGT and represented in the OMERACT core set of domains but given the irreversible nature of damage it was agreed this was not suitable to include in an activity measure, rather it should be measured seperately using a different instrument. Work, independence and mood are not independently or well captured in the existing composite activity measures. Of interest many of the outcomes not captured by the activity measures are reflected in the Psoriatic Arthritis Impact of Disease (PSAID) instrument (give reference) that was developed as a measure of impact rather than activity (Figures 1 and 2).[25] Medication side effects are captured as adverse events in RCT's but not in Longitudinal Observational Studies. The group recognised that it would not be feasible to add all outcomes in to a modified composite measure and that pain and fatigue appeared clearly separate in the rankings from other outcomes. It was also noted that pain and fatigue were included in the OMERACT core domain set and therefore there was agreement that they should be represented in the composite measures moving forward in a planned validation study, within the PROMPT programme.

Potential measures for pain and fatigue were discussed. There are data supporting the use for the Functional Assessment of Chronic Illness – Fatigue (FACIT-Fatigue) patient reported questionnaire for physical fatigue in PsA.[26] The PSAID instrument has fatigue and pain items (0-10) but the PSAID needs further validation as an activity measure.[25] A standard pain Visual Analogue Scale 0-100 was also considered. It was agreed to incude these measures in the prospective study and select the best performing measure (in terms of sensitivity to change).

Discussion

We report a multicentre study ranking outcomes important to patients and how they are represented in existing composite measures of disease activity in PsA. None of the composite scores in their existing form capture the top ten outcomes important to patients identified in this study. Pain was ranked most highly by patients in this study and is not well represented in the existing composite measures. The DAPSA is the only composite to independently measure pain using a visual analogue scale. The CPDAI, GRACE and PASDAS may capture pain indirectly, such as through the tender joint count, enthesitis/ dactylitis counts, the patient global VAS score or within a component questionnaire. For example the CPDAI includes pain questions within the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)[23] and the Ankylosing Spondylitis Quality of Life Index (ASQoL).[24] However indirect measurement of an outcome in this way has disadvantages, such as the inability to perform specific analyses and reduced representation of an outcome within the overall score. The BASDAI, for example, is reported as single score and not by its component parts, making separate analysis of pain difficult. Deterioration of other components within the BASDAI (such as stiffness or fatigue) may also mask improvement in another component, in this case pain. Indirect measurement in this way also diminishes the representation of pain within the total composite score. Pain (the most highly ranked outcome to patients in this study) is included as a component of the BASDAI, as a subcomponent of the CPDAI, only contributes a small amount to the total score and therefore impacts on the face validity of the composite.

Fatigue was ranked second highest by patients but, like pain, is not well represented in composite measures. Fatigue is also represented indirectly in the CPDAI (in the BASDAI and ASQoL) and PASDAS (PsAQoL).[27] The individual questions of the BASDAI, ASQoL and PsAQoL are not designed to be separately reported and as a result fatigue cannot be easily

studied independently. The same problem arises with independence which was ranked in the top ten outcomes and is represented in PsAQoL and ASQoL but not independently reported.

Skin disease was ranked as a low priority in our study which is discordant with other qualitative studies of outcomes in PsA. The studies conducted for the development of the Psoriatic Arthritis Impact of Disease (PSAID) impact measure ranked skin symptoms as third highest behind pain and fatigue.[25] In an international study to update the psoriatic arthritis OMERACT core set twenty four focus groups were conducted to identify domains of PsA important for patients as part of the update of the OMERACT core set for PsA.[6] Skin psoriasis symptoms were ranked by patients as important but, as in our study, slightly lower than other outcomes (placed 17th out of 39 in the first Delphi round, and 6th out of 15 in the second round). The low ranking of skin symptoms in this study may reflect low levels of psoriasis amongst the cohort of patients in this study, but we did not specifically record participants levels of psoriasis activity before the focus groups. With regards to skin representation in the composite measures skin activity is captured in the GRACE, PASDAS and CPDAI but not in the DAPSA measures.

We recognise that many of the outcomes important to patients in our study are captured in the PSAID impact measure. Outcomes identified as important to patients cover impact and activity supporting the view that patients do not distinguish between the two concepts when describing the influence of the disease.[17] Only damage and treatment side effects are not included. The PSAID is a patient reported questionnaire in two versions, twelve or nine questions capturing aspects PsA such as pain, fatigue, work, function and participation. Therefore should the PSAID be validated as a measure of disease activity as well as impact?

When interpreting the findings of this study it is important to recognise that concurrent fibromyalgia or depression amongst study participants was not recorded for sub-analysis. It is therefore not possible to determine the influence these comorbidities (or other contextual factors such as coping or self-management) on the NGT rankings. In a recent study by Brikman *et al* concomitant fibromyalgia was found to be associated with 'worse' scores in all patient reported, clinical and composite PsA measures.[28] This is an important consideration when selecting (or modifying) a composite measure of disease activity where individual components

of composite scores may be more susceptible to influence by contextual factors such as fibromyalgia.

Composite activity measures are developed to capture all components of psoriatic arthritis disease activity, although component parts may be used to assess how individual aspects of disease are influenced by treatment. In a disease such as PsA, with diverse manifestations this is of considerable importance as, for example, a treatment may influence one domain but not another. A well-constructed composite measure should therefore capture all domains of disease yet allow sub-analysis of individual domains. Fatigue has been rated highly in the current study and now sits in the inner core of the recently updated OMERACT core set of domains.[6] Little is understood about the underlying cause of fatigue in PsA or the effect of treatment, in large part because fatigue is infrequently measured in RCT's.[29] There is now an opportunity to incorporate pain and fatigue in a modified composite measure for PsA, either using the fatigue/ pain VAS scores from the PSAID questionnaire or the FACIT-fatigue scale.

Conclusion

In this NGT study we ranked outcomes of treatment important to patients and examined their representation in existing composite outcome measures that have been developed without significant input from patients. The top five outcomes ranked by patients were; pain with 93 points (20.0%) and fatigue with 62 (13.3%), physical fitness 33 (7.1%), halting/ slowing damage 32 (6.9%) and quality of life/ wellbeing 29 (6.2%). Pain and fatigue were ranked most highly as outcomes important to patients and are not adequately captured within existing composite measures. Future work will focus on validating composite measures modified to capture outcomes important to patients.

Ethics

The study was approved by the National Research Ethics Service Committee North West-Haydock (reference: 15/NW/0609) and has been conducted in accordance with the Declaration of Helsinki. All participants signed informed consent.

OUTCOMES IDENTIFIED IN UK FOCUS GROUPS[17]
1. Reduce the pain in my joints, for example hands, wrists, hips, and/or knees
2. Reduce the pain in my back
3. Reduce pulsating or sharp nerve pain, for example in my hands
4. Reduce the pain in my muscles
5. Reduce tenderness, for example tendons at back of my foot
6. Reduce inflamed and burning joints
7. Reduce swelling, for example in my hands and/or feet
8. Reduce sausage toes and/or sausage fingers
9. Reduce the variation in my body temperature
10. Reduce stiffness, for example in my hands/thumbs, feet, and/or other joints
11. Have less physical fatigue, for example not feel so tired
12. Have less mental fatigue, for example be able to think more clearly
13. Have less emotional fatigue, for example not get so cross and/or upset due to tiredness
14. Have improved mobility, for example be able to walk more easily
15. Have hands that do not lock or claw
16. Have feet that do not feel so heavy
17. Have increased strength, grip and dexterity in my hands
18. Have less grinding and/or creaking in my bones and joints
19. Have better/improved sleep
20. Have skin that is less red
21. Have skin that is less itchy and uncomfortable
22. Have skin that is less flaky
23. Have fewer fungal nail infections and\or split nails
24. Have less variability in the different joints in my body that are affected on different days
25. Have less variability in the number of my joints that are affected on different days
26. Generally feel less unwell
27. Not be in constant pain
28. Have more stamina and/or energy
29. Not lose the sense of touch and feeling in my fingers
30. Not gain weight gain, for example due to reduced activity
31. Not lose physical fitness
32. Not have to cover up my skin in sunshine and/or wear high factor sun creams
33. Feel in a better mood
34. Feel less depressed
35. Feel less anxious
36. Feel less frustrated
37. Feel less inadequate
38. Feel less guilty
39. Feel less angry
40. Feel more confident
41. Feel less embarrassed because of visible psoriasis
42. Feel less isolated
43. Be more sociable
44. Feel more able to commit to activities and/or make plans
45. Be able to keep up with my peers and/or friends
46. Not sacrifice my home life
47. Be able to remain in work
48. Not have my work/job affected by my psoriatic arthritis
49. Be able to maintain my independence/ not be dependent on others to help me
50. Not feel nauseous and/or sick after taking treatments
51. Not experience side effects (from treatments)
52. Not be worried about long-term effects (of treatments)
53. Not have reduced or lowered immunity (due to treatments)
54. Not experience reduced concentration and/or brain fog after taking treatments
55. Have treatments that I find easy to take
56. Feel better after taking treatments, compared to before taking treatments
57. Have treatments that do not interact with medications for other health conditions
58. Have treatments that do not require regular monitoring and/or blood tests
59. Halt/slow down the progression of my symptoms, for example not lose strength and/or flexibility in my joints
60. Enable me to be and/or return to 'normal'
61. Reduce the long-term damage to my joints
62. Give me greater disease control, for example fewer flares
63. Improve my quality of life and wellbeing

ADDITIONAL OUTCOMES IDENTIFIED FROM INTERNATIONAL FOCUS GROUPS [6]
64. Able to carry out my daily activities/tasks
65. My condition is easier to self-manage (deal with)
66. My condition has less impact on my role within the family
67. Able to do my usual leisure activities
68. Improved blood tests for inflammation

Table 1
List of 68 outcomes for discussion and ranking in round one of the NGT

Group 1	Group 2	Group 3	Group 4
Work	Treatments stop things deteriorating	Pain	Pain –constant, dull
Leisure activities	Not to be in constant pain	Fatigue	Mobility
Daily activities	To maintain independence	Stiffness	Fatigue – emotional, mental, physical
Quality of life – wellbeing	Feeling less isolated	Sleep	Quality of life
Medicines side effects/interactions/immunity	Side effects of treatment	Emotions/anxiety/mood	Impact and ability to work
Feel better after treatment	Long terms effects of treatment	Mobility/walk	Variability and control
Physical fitness	Reduce pain in my muscles	Drug side effects/interactions	Being able to exercise more
Touch and feeling in fingers	Frustrated	Less variability	Side effects and lowered immunity
Fatigue/stamina/mental fatigue	Variations in body temperature	Better immunity	Grip, strength, dexterity
Mobility	Enable me to be/return to normal	Skin	Confidence, mood, emotions, depression
Pain in back/joints	Be able to remain in work	Self-confidence	Weight
Mood/anger/frustration	Quality/continuity of clinician	Work	Joint damage
Stiffness	Treatments that don't interact with other medications	Slow progression	Pain –constant, dull
Independence			
Self-management easier			

Group 5	Group 6	Group 7
Treatments stop things deteriorating	Side effects/anxiety about symptoms	Quality of life
Not to be in constant pain	Everyday activities	Lose of sense of touch/feeling
To maintain independence	Pain	Skin
Feeling less isolated	Variability	Sleep
Side effects of treatment	Inflammation	Pain
Long terms effects of treatment	Fatigue (physical and mental)	Frustration
Reduce pain in my muscles	Burden of treatment (especially blood tests)	Maintain independence
Frustrated	Physical fitness and not gaining weight	Lowered immunity
Variations in body temperature	Impact on work	Mobility/walk about more easily
Enable me to be/return to normal	Getting back to normal	Flare (and anxiety about flare)
Be able to remain in work	Keeping up with peers	Stress
Quality/continuity of clinician	Mobility	Fatigue – physical, mental (concentration), emotional
Treatments that don't interact with other medications	Clearer skin (to avoid embarrassment because of other people)	

Table 2 Individual group shortlists of important outcomes from round two of the Nominal

GRACE

Joint
Patient Global
Skin

GRACE

Physical Function
HRQoL

Damage
Fatigue*
Independence*
Pain
Mood
Work
Side effects

NGT

Grey- in PSAID
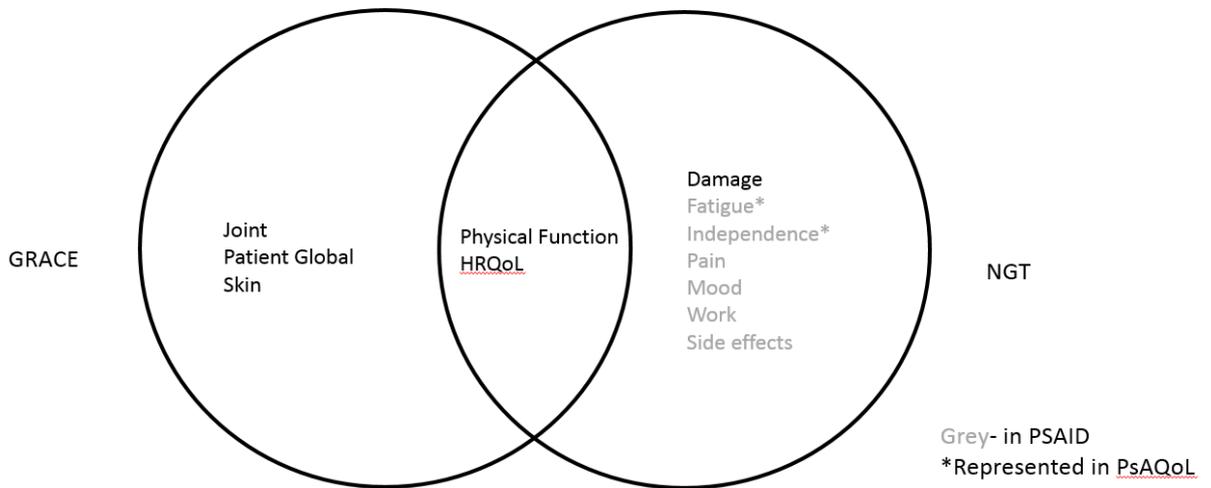*Represented in PsAQoL

Figure 1 Representation of outcomes Important to patients in the current NGT study and the GRACE measure
Nominal Group Technique (NGT), Health Related Quality of Life (HRQoL), Psoriatic Arthritis Impact of Disease (PSAID), Psoriatic Arthritis Quality of Life (PsAQoL)

CPDAI

Joint
Enthesitis
Dactylitis
Axial Symptoms
Skin

CPDAI

Physical Function
HRQoL

Damage
Pain*
Fatigue*
Independence*
Mood
Work
Side effects
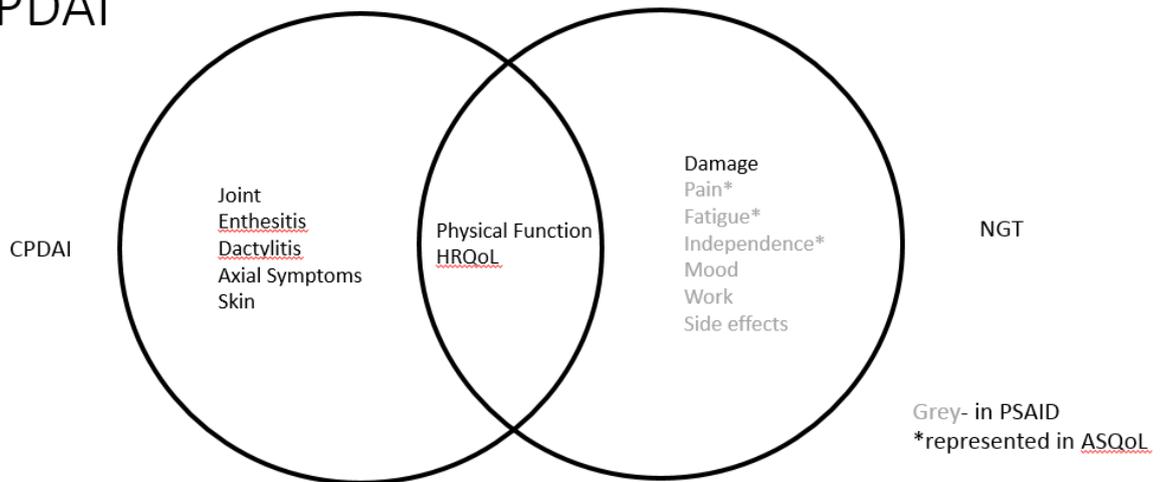
NGT

Grey- in PSAID
*represented in ASQoL

Figure 2 Representation of outcomes Important to patients in the current NGT study and the CPDAI measure
Nominal Group Technique (NGT), Health Related Quality of Life (HRQoL), Psoriatic Arthritis Impact of Disease (PSAID), Psoriatic Arthritis Quality of Life (PsAQoL)

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