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1 **Outcome measures used in psoriatic arthritis registries and cohorts: a**
2 **systematic literature review of 27 registries or 16,183 patients**

3
4 **Running title:** Outcome measures in PsA registries

5
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1 **ABSTRACT**

2

3 **Introduction**

4 Psoriatic arthritis (PsA) is a multidimensional inflammatory disease for which multiple
5 outcome measures can be used to assess disease activity. In 2006, the OMERACT
6 has proposed the first core domain set in PsA. Since 2006, much work has been
7 performed on outcome measures in PsA.

8 **Objectives**

9 The purpose of this study was to assess outcome measures collected in recent PsA
10 registries or longitudinal cohorts.

11 **Methods**

12 A systematic literature review was performed in Pubmed Medline (PROSPERO
13 CRD42020175745) to identify all articles reporting on either registries or longitudinal
14 cohorts in PsA, published between 2010 and March 2020. Registries centered on
15 drugs or not PsA-specific, trials and long-term extension studies were excluded. The
16 data collection comprised patient characteristics and the clinical outcome measures
17 reported, including composite scores and patient reported outcomes (PROs). Statistics
18 were descriptive.

19 **Results**

20 Of 673 articles, 73 were analysed, reporting on 27 registries/cohorts. Overall, 16,183
21 patients were included, with a mean of 599 per study; 51% were men, weighted mean
22 age was 49.7±9.3 years and weighted mean disease duration was 6.8±0.2 years.
23 Overall, 58 different outcome measures were collected. Disease activity composite
24 scores were used in 20/27 (74%) registries through 8 different scores (most frequently
25 Minimal Disease Activity: 41%, DAS28: 33% and DAPSA: 30%). Among the domains
26 of PsA, joint involvement was reported in 26/27 (96%) registries (through the 66/68
27 joint count: 85%) and skin psoriasis in 93% (through PASI: 72%), whereas enthesitis,
28 dactylitis and axial involvement were less often reported (respectively, 77%, 74% and
29 52%). Furthermore, 22/27 (82%) studies reported HAQ; the other frequently reported
30 PROs were patient global assessment (70%) and pain (63%).

31 **Conclusions**

32 Data collection in PsA is very heterogeneous, reflecting the need for international
33 consensus on outcome measures.

34 **Keywords:** outcome measures; psoriatic arthritis; registries; cohorts.

1 1 INTRODUCTION

2 Psoriatic arthritis (PsA) is a heterogeneous and multidimensional inflammatory disease
3 with variable manifestations and progression.(1–3) Numerous outcome measures can
4 be used in PsA, some are specific to PsA such as Minimal Disease activity (MDA),
5 some are generic such as patient assessment of pain and some are borrowed from
6 rheumatoid arthritis (RA) such as the Disease Activity Score (DAS28).(2,4–6) There is
7 no consensus on the optimal instruments to measure disease activity and evaluate
8 treatment response in PsA.(7,8) We previously reported a lack of uniformity in PsA
9 evaluation of disease activity in randomised controlled trials (RCTs) in 2012.(9) In 58
10 clinical trials reviewed, 84 different outcome measures were used.(9)

11 In 2016, an updated PsA core set of domains to be assessed in all RCTs and
12 longitudinal observational studies (LOS) was proposed by the Group for Research and
13 Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and Outcome Measures in
14 Rheumatology (OMERACT).(10,11) Eight inner core set domains are recommended
15 to be assessed systematically in every RCT and LOS and include: musculoskeletal
16 disease activity (peripheral joints, dactylitis, enthesitis, and axial involvement), skin
17 disease activity, systemic inflammation and 5 patient reported outcomes (PROs):
18 fatigue, pain, patient’s global assessment, physical function, and health-related quality
19 of life.(11) Furthermore, several other domains are proposed in the core set as
20 important (but not mandatory) domains.(11)

21 Although the core set lists domains to be assessed in PsA, there is currently no
22 consensus on the best outcome measures to use.(11,12)

23 Another important aspect relates to composite scores. The treatment target in PsA is
24 remission or alternatively low disease activity (LDA);(7,8) several composite scores

1 allow the assessment of remission or LDA in PsA, without a current agreement on a
2 single score.(13–17)

3 Registries may provide important insights into the outcomes collected in PsA. By
4 definition, patient registries use “observational study methods to collect uniform data
5 (clinical and other) to evaluate specified outcomes for a population”.(18) Exploring
6 outcome measures collected in recently published registries or longitudinal cohorts
7 may provide a photograph of current clinical practices.(19)

8 The objective of this study was to assess outcome measures collected in ongoing PsA
9 registries or longitudinal cohorts, through a systematic literature review.

10

11 **2 MATERIAL AND METHODS**

12 This systematic review was conducted according to Cochrane guidelines.(20) The
13 protocol was registered on PROSPERO (CRD42020175745).(21)

14 **2.1 Search and selection strategy**

15 The search included all publications of cohorts or registries reporting any clinical data
16 in PsA published between March 1, 2010 and March 1, 2020. We searched the
17 electronic database PubMed MEDLINE using the terms "Arthritis, Psoriatic"[Mesh]
18 AND ("Registries"[Mesh] OR "Cohort Studies"[Mesh]). Although an EMBASE search
19 was initially planned, we only performed the search in PubMed due to limited added
20 value of EMBASE.(22) Publications concerning the same registry were analysed
21 together, publication used for demographic characteristics was the last published or
22 the one with the most patients. Three authors (KA, GM, and AR) independently
23 scanned the title, abstract and keywords of every record identified. In the event of
24 disagreement between the reviewers, disparities were discussed and resolved. If

1 needed, the registry correspondent was contacted and registries websites were
2 consulted.

3

4 **2.2 Inclusion criteria and participants**

5 Patients were adults with a confirmed diagnosis of PsA (using Classification Criteria
6 for Psoriatic Arthritis (CASPAR) or Moll and Wright criteria or according to the
7 physician's diagnosis). Registries or cohorts reporting at least one clinical outcome and
8 including at least 50 patients with PsA were selected. All the registries or cohorts
9 included patients with PsA, and some included patients with psoriasis and/or
10 spondyloarthritis.

11

12 **2.3 Exclusion criteria**

13 All biologic registries, registries centered on treatments or registries for health care
14 products, and post-marketing surveillance were excluded because they were not
15 specific to PsA, and thus did not reflect PsA-specific outcome measures. Papers not
16 reporting any clinical outcome measures (e.g., articles reporting only laboratory
17 outcomes, radiographic scores, or genetic analyses) were excluded. RCTs and long-
18 term extensions, retrospective and cross-sectional studies, case series, reviews, and
19 editorials were excluded.

20

21 **2.4 Data extraction**

22 The authors extracted relevant data from the included articles into a pre-defined case
23 report form (CRF). Only published outcomes measures were collected and analyzed.

1 **General data extraction** Descriptive data were extracted on the type of study
2 (international, nationwide or local) and patients' characteristics.

3 **Clinical outcomes** The outcome measures assessing the GRAPPA/OMERACT inner
4 core domain set were collected.(11) These include musculoskeletal disease activity
5 (peripheral joints, enthesitis, dactylitis, spine symptoms), skin disease activity, pain,
6 patient's global assessment, physical function, Health-related quality of life (HRQoL),
7 fatigue and systemic inflammation.(11) All the outcome measures relevant to these
8 domains were collected. Physical function measures were the HAQ, modified HAQ and
9 Bath Ankylosing Spondylitis Functional Index (BASFI). Spine symptoms were
10 assessed through the Bath Ankylosing Spondylitis Functional Disease Activity Index
11 (BASDAI), or through a binary score (yes/no) and/or. Skin disease activity was
12 assessed through Psoriasis Area Severity Index (PASI) and/or Body Surface Area
13 (BSA).

14 Health-related quality of life (HRQoL) was assessed through the 36-Item Short Form
15 Survey (SF-36), Short-Form 12 (SF-12), Dermatology life Quality Index (DLQI), Euro-
16 Qol 5 domain (EQ-5D), Psoriatic Arthritis Quality of Life (PsAQoL) and/or Ankylosing
17 spondylitis quality of life score(ASQoL).(5,13,17,23,24)

18 Then, we collected the domains considered important in the core set, i.e., economic
19 cost, emotional well-being, participation (work, leisure and social activities) and
20 structural damage. Finally, other outcomes of importance to patients and included in
21 the OMERACT research agenda, were collected, i.e., independence, sleep, stiffness
22 and treatment burden.(11) Physician global assessment was also collected.

23 Composite scores were collected: MDA, Very Low Disease Activity (VLDA), Disease
24 Activity Index for Psoriatic Arthritis (DAPSA), Composite Psoriatic Disease Activity

1 Index (CPDAI), Psoriatic Arthritis Response Criteria (PsARC), Psoriatic Arthritis
2 Disease Activity Score (PASDAS), Disease Activity Score (DAS28 CRP/EULAR
3 response), and ACR response, and Arithmetic Mean of the Desirability Function
4 (AMDF).(5,13,17,23,24)

5 2.5 **Statistical analysis**

6 A quantitative summary of findings was performed including frequencies of each
7 outcome. Risk of bias was not assessed because we were exploring outcomes
8 collected not results of outcomes. The frequency of reporting of domains in
9 cohorts/registries which had started the data collection before versus after 2007 (date
10 of publication of the first OMERACT core set) (10) was compared by the chi-square
11 test with Yates' correction.(10) Meta-analysis was not undertaken.

12

1 **3 RESULTS**

2

3 **3.1 Description of PsA registries/cohorts publications**

4 Of 673 articles, 73 were relevant for analysis, reporting on to 27 PsA-specific registries
5 or cohorts (**Figure 1 and Supplementary table S1**). The characteristics of the
6 registries, PsA-specific cohorts and patients evaluated are shown in **Table 1**. The total
7 number of patients was 16,183 with a mean of 599 per study. Overall, 8,224/16,183
8 (50.8%) were men, weighted-mean age was 49.7±9.3 years and weighted-mean
9 disease duration was 6.8±0.2 years. Most of the registries were established in Europe
10 (18/27, 66.7%) or North America (7/27, 25.9%) and 12/27 (44.4%) included patients
11 from a single center. Overall, 21/27 (77.8%) applied the CASPAR criteria,(25) and the
12 same number reported treatments.

13 **3.2 Composite scores**

14 Overall, 58 different clinical outcome measures were collected. Disease activity
15 composite scores were reported in 17/27 (63.0%) registries: of these, 11/27 (40.7% of
16 all registries) reported MDA, 9/27 (33.3%) DAS28 and 8/27 (29.6%) DAPSA; whereas
17 PsARC and PASDAS were reported each in only 7.4% of the studies. VLDA and AMDF
18 were never reported (**Figure 2**).

19 **3.3 PsA inner core set domains**

20 Eleven registries/cohorts collected all of the 2006 core set domains and only 2
21 registries/cohorts reported all of the 2016 updated 8 core set domains. The inner core
22 set domains were reported variably between 33.3% and 96.3% (**Table 2**). Joint
23 involvement was reported in 26/27 (96.3%) using variable joint counts, most frequently

1 the 66/68 joint count (in 20/23, 87.0% studies). Damaged joint count was less
2 frequently reported (7/27, 25.9%).

3 Skin psoriasis was reported in 25/27 (92.6%) registries, most frequently through PASI
4 in 18/27 (66.7%), and BSA in 12/27 (44.4%). Enthesitis was reported in 21/27 (77.8%)
5 registries, using most frequently Leeds Enthesitis Index (33.3%) and/or Maastricht
6 Ankylosing Spondylitis Enthesis Score (MASSES) (23.8%), whereas dactylitis was less
7 often reported (20/27, 74.1%), using mainly the number of digits (40.7%). Axial
8 involvement was reported in 15/27 (55.6%) through clinical binary assessment (yes/no)
9 (14/27, 51.9%) and/or BASDAI (9/27, 33.3%). Systemic inflammation was evaluated
10 mostly through CRP (90.4%).

11 Overall, 22/27 (81.5%) of the registries reported HAQ, and the other frequently
12 reported PROs were patient global assessment (70.4%) and pain (63.0%). HRQoL
13 was collected in 15/27 (55.6%) using mainly the SF-36 (46.7%), EuroQol-5 (46.7%),
14 and DLQI (46.7%). Fatigue was the least frequently reported core set domain, collected
15 in 9/27 (33.3%) studies (**Figure 2 and Table 2**).

16 3.4 Other domains reported

17 Among the domains considered as important by GRAPPA/OMERACT,(10) structural
18 damage was the most frequently reported (10/27, 37.0%), and was evaluated through
19 X-rays in 9/10 (90%) cases. Emotional well-being and participation were reported in
20 11.1% and 3.7% respectively.

21 Among the other outcomes, physician global assessment and work were the most
22 frequent, reported in 14/27 (51.9%) and 11/27 (40.7%) registries respectively. Stiffness
23 was reported in 4/27 (14.8%) whereas sleep, treatment burden and independence
24 were reported each in 1/27 (3.7%) study.

1 3.5 Comparison of more recent versus less recent registries/cohorts

2 Fifteen of the 27 PsA registries and cohorts were initiated after 2007. No significant
3 difference was seen in the frequency of reporting of domains in registries/cohorts which
4 were started before or after 2007 (**Table 2**, statistical comparisons not shown).

5

6 4 DISCUSSION

7

8 This systematic review puts to light an important heterogeneity in the assessment of
9 disease activity in PsA. In 27 recently published registries/cohorts, 58 different clinical
10 outcome measures were used. Disease activity composite scores were reported in 20
11 of 27 (74%) PsA registries: most frequently through MDA (41%), DAS28 (33%), and/or
12 DAPSA (30%). Almost all registries reported joint involvement and skin psoriasis, using
13 variable joint counts, most frequently the 66/68 joint count, whereas enthesitis (77%),
14 dactylitis (74%), and axial involvement (52%) were less frequently reported. The
15 OMERACT/GRAPPA 2016 inner core set domains (11) were assessed with a varying
16 frequency, from 96.3% for joint counts to 33.3% for fatigue.

17

18 This study has strengths and weaknesses. The literature search only screened papers
19 referenced in PubMed-Medline and used simple key words; however, given the
20 descriptive nature of this overview of outcome measures in PsA registries/cohorts, the
21 673 articles screened were sufficient to provide an informative snapshot of everyday
22 clinical practice in PsA; and the added value of other databases is under
23 discussion.(22) The search was limited to articles published in the last 10 years, which
24 may have missed some older publications. However, we wished to analyze current

1 practices and thus to concentrate on recent or ongoing PsA registries/cohorts and to
2 reflect outcome measures in the era after the publication of the OMERACT/GRAPPA
3 PsA core set of domains in 2006. (10,11) Only PsA-specific registries and cohorts were
4 selected; other registries including PsA patients along with other rheumatic diseases
5 were excluded to reflect data collection tailored for PsA. The selection of papers and
6 data collection were done separately by three authors. However, we often encountered
7 issues to identify and differentiate cohort studies from retrospective studies when
8 relying only on the methodology part. Therefore, besides collective agreement and
9 discussion between authors, study websites were consulted and key authors were
10 contacted when needed. Due to great heterogeneity in the outcomes used, classifying
11 the outcome measures was not always intuitive; e.g., BASDAI can be considered as a
12 PRO but also reflects axial involvement.(26) Only published outcome measures were
13 analyzed which can differ from the data collected in the registry/cohort. However, we
14 extracted data on outcome measures from all the papers available reporting on the
15 same registry/cohort. Finally, a meta-analysis was not performed, and risk of bias was
16 not assessed, due to the descriptive aim of this research and the heterogeneity of the
17 studies.

18

19 In the last decade, an increasing number of PsA-specific registries/cohorts have
20 emerged, with 15 of the 27 PsA registries and cohorts initiated after 2007. Interest has
21 grown among researchers regarding outcome measures in PsA, with the first PsA
22 GRAPPA-OMERACT core-set.(10) In parallel, registries and cohorts may be seen as
23 a source to understand the disease course and possibly reflect current practices better
24 than clinical trials.(19)

25

1 In the recent registries and cohorts reviewed here, peripheral joint counts and skin
2 involvement were the only domains which were almost systematically assessed. This
3 may reflect a consensus on the importance of these 2 key aspects of PsA, and/or
4 agreement on the scores to use. The 66/68 joint count was recently fully endorsed by
5 OMERACT in 2018 as the optimal instrument to measure peripheral arthritis, which is
6 a component of musculoskeletal disease activity in PsA.(27) The frequent use of the
7 66/68 joint count in our study indicates the agreement between practice and
8 recommendations.

9

10 Enthesitis and dactylitis were less often reported. The evaluation of enthesitis and
11 dactylitis in PsA is still unclear, as reflected by heterogeneity in clinical trials.(9,28)
12 Dactylitis is recognized as a poor prognostic factor in the EULAR
13 recommendations.(29) Data from the Corrona registry have shown that patients with
14 enthesitis and/or dactylitis had greater disease activity and were less likely to achieve
15 MDA.(30) Also, patients with enthesitis had a higher functional impairment, more pain,
16 and fatigue.(30) This underscores the need to better identify and assess these
17 manifestations in PsA.

18

19 Axial involvement was reported in PsA (55.6%). Overall, 15% of patients with PsA in
20 the Toronto cohort developed axial PsA over 10 years of follow-up.(31) Although a
21 clear distinction is not always possible in daily practice, a recent study has shown that
22 ankylosing spondylitis (AS) with psoriasis seems to be a separate disease from axial
23 PsA due to differences in the demographics, genetics, disease activity and disease
24 progression.(32,33) Although axial PsA had worse peripheral arthritis compared to AS,
25 AS patients had an earlier onset of their disease, a higher male predominance, were

1 more likely to be HLAB27 positive, to present with a more severe axial disease and
2 were more likely to be treated with biologics.(32) Therefore, for a better understanding
3 of this emerging entity, spinal involvement is an important aspect to measure in
4 patients with PsA. Our study has shown that spinal assessment was mostly done by
5 clinical evaluation of the physician in the majority of the registries/cohorts (90%), and/or
6 through the BASDAI questionnaire (60%), and never with MRI (0%). The assessment
7 of axial SpA should be further defined.(32)

8

9 In the present study, disease activity composite scores were reported in 74% of the
10 registries, mostly through MDA, DAS28 and DAPSA. DAS28 is adapted from RA and
11 is not recommended to evaluate disease activity in PsA.(34) A 2017 international task-
12 force on treat-to-target management recommended two PsA-specific instruments to
13 define the treatment target: MDA or DAPSA.(8) DAPSA is a unidimensional composite
14 outcome centered only on joint activity, whereas MDA is a binary measure of disease
15 state including skin, entheses and joints.(8) In the last GRAPPA meeting held in 2021
16 ASDAS was proposed as the composite score to use in clinical trials and MDA as the
17 treatment target.(35) Although not frequently collected in registries and cohorts,
18 PASDAS captures many aspects of PsA including joint counts, dactylitis, enthesitis,
19 systemic inflammation, SF-36 items for quality of life as well as the patient's and
20 physician's global assessment (36).

21 On the other hand, GRAPPA agreed that composite scores of disease activity such
22 as PASDAS or CPDAI should be modified to be feasible in routine clinical practice(37).
23 Therefore, shortened versions of these composite scores are being tested for use in
24 clinical practice and need further validation.(38)

25

1 Concerning PROs, more than $\frac{3}{4}$ of the registries reported HAQ and the other frequently
2 collected PROs were pain and patient global assessment which are all part of
3 MDA.(39) Fatigue was recently considered as an important topic mainly because of its
4 impact on quality of life.(40) It is also part of the main inner core-set; however, in our
5 study, fatigue was reported in only 1/3 of the PsA registries or cohorts. In Palominos'
6 systematic review on PsA RCTs, fatigue was described in only 15.5% of articles.(9)
7 Thus, it seems that fatigue is being increasingly collected. Fatigue has been studied
8 mainly in RA(41–43) and more comprehensive data is awaited in PsA.(44) The PsA
9 Impact of Disease score (PsAID) was not reported in the registries, probably because
10 the vast majority of the registries started before 2014, when the PsAID was first
11 developed.(45)

12

13 The present study highlights great heterogeneity in outcome measures in PsA. Similar
14 work on RCTs also evidenced heterogeneity in the evaluation of disease activity in
15 PsA.(9,28) However, registries and longitudinal cohorts may reflect more closely real-
16 world data than trials. In this regard, Radner et al observed heterogeneity in disease
17 activity outcomes in RA registries/cohorts. Such heterogeneity leads to difficulties in
18 comparing outcomes and studies.(19) Therefore, there is a need to obtain a consensus
19 on instruments to assess each domain and on outcome measures to be reported
20 homogeneously in studies and registries. This will enable a better evaluation and
21 comparability of the effectiveness of interventions, as well as improving the quality of
22 observational research. Only 11 registries/cohorts collected all of the 2006 core set
23 domains and only 2 registries/cohorts reported all of the 2016 updated 8 core set
24 domains. This finding shows a lack of implementation of the GRAPPA/OMERACT
25 consensus on important domains to assess in PsA.(11)

1

2 **5 CONCLUSIONS**

3

4 Overall, although there is an increasing number of PsA-specific registries and cohorts,
5 data collection is still very heterogeneous, reflecting the need for international
6 consensus on outcome measures. Consensus initiatives are ongoing and may allow
7 better standardisation in the future.(46)

8

9

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7 The protocol was registered on PROSPERO (CRD42020175745).

8 **AUTHOR CONTRIBUTIONS:**

9 **K. Aouad** contributed to: conceptualization, Methodology, Investigation, Formal
10 analysis and interpretation, Data curation, Writing- Original draft & Editing,
11 visualization, Project administration, Final approval of the version to be published.

12 **G. Moysidou, A. Rakotozafiarison** contributed to: Methodology, Investigation, Project
13 administration, visualization, Writing- Review & Editing, Final approval of the version
14 to be published.

15 **B. Fautrel** contributed to: Supervision, Validation, Writing- Review & Editing, Final
16 approval of the version to be published

17 **L. Gossec** contributed to: Conceptualization, Methodology, Validation, investigation,
18 Formal analysis and interpretation, Writing- Review & Editing, Supervision, Final
19 approval of the version to be published.

20

21

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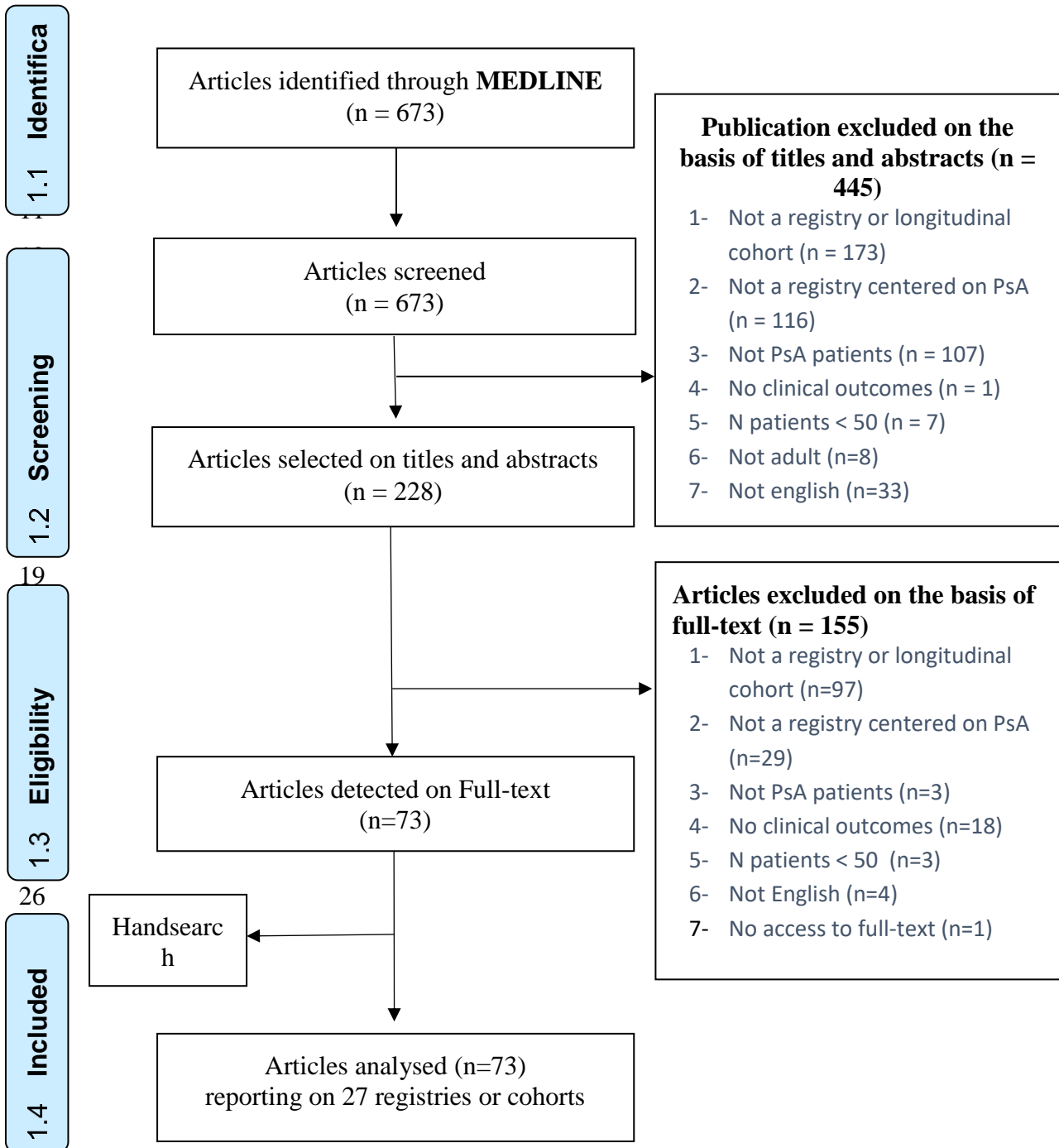
1 **7 TABLES AND FIGURES**

2

3 **Figure 1. Flow Diagram of PsA registries and cohorts published between 2010**
4 **and March 2020.**

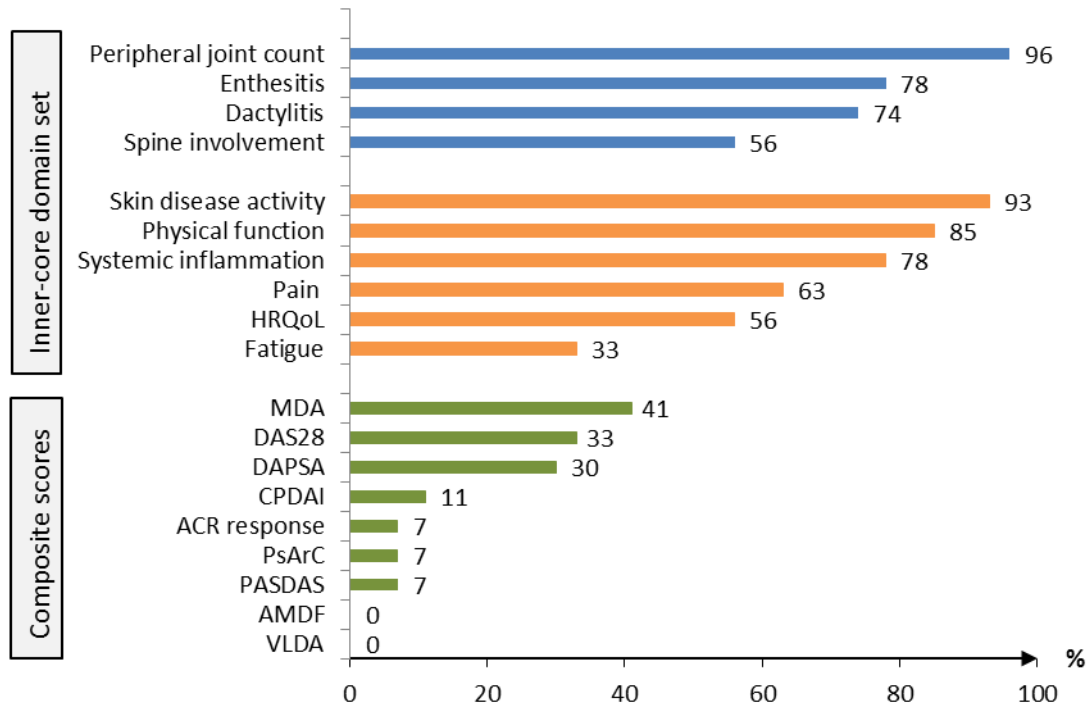
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1 **Figure 2. Frequency of reporting of different composite scores and outcome**
 2 **measures in 27 PsA registries/cohorts**

3



4 The bars represent the percentage of the 27 PsA registries/cohorts. The blue bars
 5 represent the musculoskeletal disease activity, the orange bars represent the other
 6 domains of the inner-core set, and the green bars represent the composite disease
 7 activity scores.

8

9 *ACR response: American College of Rheumatology response; AMDF: Arithmetic Mean of the*
 10 *Desirability Function; CPDAI: Composite Psoriatic Disease Activity Index; DAS28: Disease Activity*
 11 *Score 28; DAPSA: Disease Activity in Psoriatic Arthritis; HRQoL: Health-Related Quality of Life;*
 12 *PASDAS: Psoriatic Arthritis Disease Activity Score; PsArC: Psoriatic Arthritis Response Criteria; MDA:*
 13 *Minimal Disease Activity; VLDA: Very Low Disease Activity.*

14

1 **Table 1. Summary description of 27 PsA registries/cohorts**

2

	Total N =16,183 patients (n=27 registries)
Age of patients, weighted mean, years (SD)	49.7 (9.3)
Diagnosis based on CASPAR, N (%)	21 (77.8)
Gender, female, N (%)	7959 (49.2)
Disease duration, weighted mean, years (SD)	6.8 (0.2)
Study involving a single center, N (%)	12 (44.4)
Number of patients per study, mean (SD)	599 (578)
Inception cohorts for early disease (≤ 3 years), N (%)	4/26 (15.4)

3 *CASPAR: Classification Criteria for Psoriatic Arthritis (25).*

Table 2. Frequency of reporting of inner core set domains and outcome measures in 73 publications pertaining to 27 PsA cohorts/registries

PsA domains	Studies reporting the domain, n (% of 27 registries)	Cohort/registry starting before 2007, n (% of 12 registries)	Cohort/registry starting after 2007, n (% of 15 registries)	Main outcome measures used to assess each domain	Studies reporting the outcome measure, n (% of registries reporting the domains)
Inner core set domains					
Peripheral joint count¹	26 (96.3)	11 (91.6)	15 (100.0)	Tender joint count 68 Swollen joint count 66 Damaged joint count	14 (53.8) 14 (53.8) 7 (26.9)
Enthesitis²	21 (77.7)	9 (75.0)	12 (80.0)	Leeds enthesitis index MASES	7 (33.3) 5 (23.8)
Dactylitis³	20 (74.1)	9 (75.0)	11 (73.3)	Number of digits Leeds Dactylitis Index	11 (55.0) 1 (5.0)
Spine involvement	15 (55.6)	6 (50.0)	9 (60.0)	Physician assessment BASDAI	14(93.3) 9(60.0)
Skin disease activity⁴	25 (92.6)	11 (91.6)	14 (93.3)	PASI Body surface area	18 (95.7) 12 (48.0)
Physical function⁵	23 (85.2)	9 (75.0)	14 (93.3)	HAQ	22 (95.7)
HRQoL⁶	15 (55.5)	7 (58.3)	8 (53.3)	SF36 DLQI EuroQol-5 Domain	7 (46.7) 7 (46.7) 7 (46.7)
Fatigue	9 (33.3)	2 (16.6)	7 (46.6)	Fatigue analog scale	5 (55.6)
Systemic inflammation	21 (77.7)	10 (83.3)	11 (73.3)	CRP Erythrocyte sedimentation rate	19 (90.5) 17 (81.0)

Pain	17 (62.9)	7 (58.3)	10 (66.6)	Pain analog scale	17 (100.0)
Patient global assessment	19 (70.3)	7 (58.3)	12 (75.0)	PGA analog scale	19 (100.0)
Composite scores⁷	17 (63.0)	7 (58.3)	10 (66.7)		
MDA	11 (40.7)	6 (50.0)	5 (33.3)		
DAS28 or EULAR response	9 (33.3)	4 (33.3)	5 (33.3)		
DAPSA	8 (29.6)	4 (33.3)	4 (26.6)		

¹ binary assessment of joint count 4/27 (14.8%), tender and swollen joint count (28 and 44): 0% not reported

² Spondyloarthritis Research Consortium of Canada Enthesitis Index: 3/27 (11.1%)

³ Leeds dactylitis Index: 1/27 (3.7%)

⁴ Physician global assessment of psoriasis 4/27 (14.8%)

⁵ Bath Ankylosing Spondylitis Functional Index (BASFI): 4/27(14.8%), Modified HAQ: 1/27 (3.7%). Revised Leeds Disability Questionnaire, Advanced Activities of Daily Living Scale, Psoriasis Disability index (0%) were not reported.

⁶ Psoriatic Arthritis Quality of Life (PsAQoL): 4/27 (14.8%), Short Form 12 Health Survey: 1/27(3.7%), Ankylosing Spondylitis quality of life score: 1/27(3.7%), Comprehensive Assessment of the Psoriasis Patient (CAPP): 1/27(3.7%), Psoriatic Arthritis Impact of Disease (PsAID, 0%).

⁷ Other composite scores were: CPDAI: 3/27(11.1%), PASDAS: 2/27 (7.4%), American College of Rheumatology (ACR) response: 2/27 (7.4%), Psoriatic Arthritis Response Criteria (PsARC): 2/27(7.4%), other scores (VLDA, AMDF, 0%) were not reported.

AMDF: Arithmetic Mean of the Desirability Function; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; CPDAI: Composite Psoriatic Disease Activity Index; DAPSA: Disease Activity in Psoriatic Arthritis; DLQI: Dermatology Life Quality Index; HAQ: Health assessment Questionnaire; HRQoL: Health Related Quality of Life; MASES: Maastricht Ankylosing Spondylitis Enthesitis Score; MDA: Minimal Disease Activity; PASDAS: Psoriatic Arthritis Disease Activity Score; PASI: Psoriasis Area Severity Index; PGA: Patient's global assessment; SF-36: 36-item short-form health survey; VAS: Visual Analogue Score; VLDA: Very Low Disease Activity.

Supplementary Table S1 –

The 73 publications selected by the systematic literature review and reporting on 27 registries or longitudinal cohorts in psoriatic arthritis and published between 2010 and 2020.

Registry or Cohort Name/Abbreviation/Origin	Country from which the data originate	Reference
Adelphi PsA	18 countries	Alten R, Conaghan PG, Strand V, Sullivan E, Blackburn S, Tian H, et al. Unmet needs in psoriatic arthritis patients receiving immunomodulatory therapy: results from a large multinational real-world study. <i>Clin Rheumatol.</i> 2019 Jun;38(6):1615–26
		Furst DE, Tran M, Sullivan E, Pike J, Piercy J, Herrera V, et al. Misalignment between physicians and patient satisfaction with psoriatic arthritis disease control. <i>Clin Rheumatol.</i> 2017;36(9):2045–54.
BATH UK cohort	UK	Holland R, Tillett W, Korendowych E, Cavill C, Waldron N, Brooke M, et al. Validation of the Psoriatic Arthritis Impact of Disease (PsAID) Questionnaire and its potential as a single-item outcome measure in clinical practice. <i>Ann Rheum Dis.</i> 2018;77(3):343–7
BRAZIL PSA cohort	Brazil	Ferreira, M.F., Kohem, C.L., Xavier, R.M. et al. Treating psoriatic arthritis to target: discordance between physicians and patients' assessment, non-adherence, and restricted access to drugs precluded therapy escalation in a real-world cohort. <i>Clin Rheumatol</i> 2019; 38, 961–968
CAMPOBASSO	Italy	Lubrano E, Parsons WJ, Perrotta FM. Assessment of Response to Treatment, Remission, and Minimal Disease Activity in Axial Psoriatic Arthritis Treated with Tumor Necrosis Factor Inhibitors. <i>J Rheumatol.</i> 2016 May;43(5):918-23
		Lubrano E, Perrotta FM, Parsons WJ, Marchesoni A. Patient's Global Assessment as an Outcome Measure for Psoriatic Arthritis in Clinical Practice: A Surrogate for Measuring Low Disease Activity? <i>J Rheumatol.</i> 2015 Dec;42(12):2332-8
CARMA	Spain	García-Gómez C, Martín-Martínez MA, Fernández-Carballido C, Castañeda S, González-Juanatey C, Sanchez-Alonso F, González-Fernández MJ, Sanmartí R, García-Vadillo JA, Fernández-Gutiérrez B, García-Arias M, Manero FJ, Senabre JM, Rueda-Cid A, Ros-Expósito S, Pina-Salvador JM, Erra-Durán A, Möller-Parera

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CARVALHO PsA cohort	Spain	Carvalho PD, Savy F, Moragues C, Juanola X, Rodriguez-Moreno J. Axial involvement according to ASAS criteria in an observational psoriatic arthritis cohort. Acta Reumatol Port. 2017 Apr-Jun;42(2):176-182
COMPASS	USA	Dalal DS, Lin YC, Brennan DM, Borkar N, Korman N, Husni ME. Quantifying harmful effects of psoriatic diseases on quality of life: Cardio-metabolic outcomes in psoriatic arthritis study (COMPASS). Semin Arthritis Rheum. 2015 Jun;44(6):641-5
COPPAR	USA	Schneeweiss M, Merola JF, Karlson EW, Solomon DH. Rationale and Design of the Brigham Cohort for psoriasis and psoriatic arthritis registry (COPPAR). BMC Dermatol. 2017 Aug 16;17(1):11
CORRONA	USA	Mease PJ, Palmer JB, Hur P, Strober BE, Lebwohl M, Karki C, Reed GW, Etzel CJ, Greenberg JD, Helliwell PS. Utilization of the validated Psoriasis Epidemiology Screening Tool to identify signs and symptoms of psoriatic arthritis among those with psoriasis: a cross-sectional analysis from the US-based Corrona Psoriasis Registry. J Eur Acad Dermatol Venereol. 2019 May;33(5):886-892
		Mease PJ, Palmer JB, Liu M, Kavanaugh A, Pandurengan R, Ritchlin CT, Karki C, Greenberg JD. Influence of Axial Involvement on Clinical Characteristics of Psoriatic Arthritis: Analysis from the Corrona Psoriatic Arthritis/Spondyloarthritis Registry. J Rheumatol. 2018 Oct;45(10):1389-1396
		Kavanaugh A, Singh R, Karki C, Etzel CJ, Kremer JM, Greenberg JD, Griffith J. Disease activity and biologic use in patients with psoriatic arthritis or rheumatoid arthritis. Clin Rheumatol. 2018 Aug;37(8):2275-2280
		Harrold LR, Stolshek BS, Rebello S, Collier DH, Mutebi A, Wade SW, Malley W, Greenberg JD, Etzel CJ. Rebound in Measures of Disease Activity and Symptoms in Corrona Registry Patients with Psoriatic Arthritis Who Discontinue Tumor Necrosis Factor Inhibitor Therapy after Achieving Low Disease Activity. J Rheumatol. 2018 Jan;45(1):78-82
		Mease PJ, Karki C, Palmer JB, Etzel CJ, Kavanaugh A, Ritchlin CT, Malley W,

		<p>Herrera V, Tran M, Greenberg JD. Clinical and Patient-reported Outcomes in Patients with Psoriatic Arthritis (PsA) by Body Surface Area Affected by Psoriasis: Results from the Corrona PsA/Spondyloarthritis Registry. <i>J Rheumatol.</i> 2017 Aug;44(8):1151-1158</p> <p>Mease PJ, Karki C, Palmer JB, Etzel CJ, Kavanaugh A, Ritchlin CT, Malley W, Herrera V, Tran M, Greenberg JD. Clinical Characteristics, Disease Activity, and Patient-Reported Outcomes in Psoriatic Arthritis Patients With Dactylitis or Enthesitis: Results From the Corrona Psoriatic Arthritis/Spondyloarthritis Registry. <i>Arthritis Care Res (Hoboken).</i> 2017 Nov;69(11):1692-1699</p> <p>Harrold LR, Stolshek BS, Rebello S, Collier DH, Mutebi A, Wade SW, Malley W, Greenberg JD, Etzel CJ. Impact of prior biologic use on persistence of treatment in patients with psoriatic arthritis enrolled in the US Corrona registry. <i>Clin Rheumatol.</i> 2017 Apr;36(4):895-901</p> <p>Mease PJ, Lesperance T, Liu M, Collier DH, Mason M, Deveikis S, Accortt NA. Changes in Treatment Patterns in Patients with Psoriatic Arthritis Initiating Biologic and Nonbiologic Therapy in a Clinical Registry. <i>J Rheumatol.</i> 2017 Feb;44(2):184-192.</p> <p>Shrestha A, Bahce-Altuntas A, Mowrey W, Broder A. Active peripheral inflammation is associated with pro-atherogenic lipid profile in psoriatic arthritis. <i>Semin Arthritis Rheum.</i> 2016 Dec;46(3):286-290</p> <p>Reddy SM, Anandarajah AP, Fisher MC, Mease PJ, Greenberg JD, Kremer JM, Reed G, Chen R, Messing S, Kaukeinen K, Ritchlin CT. Comparative analysis of disease activity measures, use of biologic agents, body mass index, radiographic features, and bone density in psoriatic arthritis and rheumatoid arthritis patients followed in a large U.S. disease registry. <i>J Rheumatol.</i> 2010 Dec;37(12):2566-72</p>
CZECH COHORT	Czech Republic	<p>Mlcoch T, Tuzil J, Sedova L, Stolfa J, Urbanova M, Suchy D, Smrzova A, Jircikova J, Hrciarova T, Pavelka K, Dolezal T. Mapping Quality of Life (EQ-5D) from DAPsA, Clinical DAPsA and HAQ in Psoriatic Arthritis. <i>Patient.</i> 2018 Jun;11(3):329-340</p>
DEPAR PSA COHORT	The Netherlands	<p>Wervers K, Luime JJ, Tchetverikov I, Gerards AH, Kok MR, Appels CWY, van der Graaff WL, van Groenendael JHLM, Korswagen LA, Veris-van Dieren JJ, Hazes JMW, Vis M; Cicero. Time to minimal disease activity in relation to quality of life, productivity, and</p>

		<p>radiographic damage 1 year after diagnosis in psoriatic arthritis. <i>Arthritis Res Ther.</i> 2019 Jan 16;21(1):25</p> <p>Wervers K, Luime JJ, Tchetverikov I, Gerards AH, Kok MR, Appels CWY, van der Graaff WL, van Groenendael JHLM, Korswagen LA, Veris-van Dieren JJ, Hazes JMW, Vis M. Influence of Disease Manifestations on Health-related Quality of Life in Early Psoriatic Arthritis. <i>J Rheumatol.</i> 2018 Nov;45(11):1526-1531</p>
FEDERICO PSA COHORT	Italy	<p>Navarini L, Margiotta DPE, Caso F, Currado D, Tasso M, Angeletti S, Ciccozzi M, Scarpa R, Afeltra A, Costa L. Performances of five risk algorithms in predicting cardiovascular events in patients with Psoriatic Arthritis: An Italian bicentric study. <i>PLoS One.</i> 2018 Oct 11;13(10)</p> <p>Chimenti MS, Ortolan A, Lorenzin M, Triggianese P, Talamonti M, Costa L, Caso F, Favero M, Teoli M, Galluzzo M, Scarpa R, Punzi L, Perricone R, Ramonda R. Effectiveness and safety of ustekinumab in naïve or TNF-inhibitors failure psoriatic arthritis patients: a 24-month prospective multicentric study. <i>Clin Rheumatol.</i> 2018 Feb;37(2):397-405</p> <p>Costa L, Caso F, Ramonda R, Del Puente A, Cantarini L, Darda MA, Caso P, Lorenzin M, Fiocco U, Punzi L, Scarpa R. Metabolic syndrome and its relationship with the achievement of minimal disease activity state in psoriatic arthritis patients: an observational study. <i>Immunol Res.</i> 2015 Feb;61(1-2):147-53</p> <p>Di Minno MN, Iervolino S, Peluso R, Di Minno A, Ambrosino P, Scarpa R; CaRRDs Study Group. Hemostatic and fibrinolytic changes are related to inflammatory conditions in patients with psoriatic arthritis--effect of different treatments. <i>J Rheumatol.</i> 2014 Apr;41(4):714-22</p> <p>Di Minno MN, Peluso R, Iervolino S, Lupoli R, Russolillo A, Tarantino G, Scarpa R. Hepatic steatosis, carotid plaques and achieving MDA in psoriatic arthritis patients starting TNF-α blockers treatment: a prospective study. <i>Arthritis Res Ther.</i> 2012 Oct 4;14(5):R211</p> <p>Di Minno MN, Peluso R, Iervolino S, Lupoli R, Russolillo A, Scarpa R, di Minno G. Obesity and the prediction of minimal disease activity: a prospective study in psoriatic arthritis. <i>Arthritis Care Res (Hoboken).</i> 2013 Jan;65(1):141-7.</p>

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