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Best Practice Indicators in Psoriatic Disease Care

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ABSTRACT: Background. In 2016, members of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), in collaboration with KPMG LLP (United Kingdom), conducted a study to benchmark care in psoriatic arthritis (PsA). A key finding was that centres do not usually have processes in place to measure the impact of improved quality of care.

Objectives. To identify and select best practice indicators to enable PsA caregivers to assess and monitor the outcomes of specific initiatives aimed at improving care in 4 focus areas: (1) shortening time to diagnosis, (2) improving multidisciplinary collaboration, (3) optimising disease management, and (4) improving disease monitoring.

Methods. (1) Structured review of scientific and grey literature to obtain evidence for a long list of 100 potential indicators across the 4 focus areas.

(2) Survey expert rheumatologists and dermatologists to review the long list and identify the most meaningful and feasible indicators for use in day-to-day practice.

(3) Consensus discussion to identify a shortlist of indicators based on pre-defined selection criteria.

(4) Electronic group discussion to refine definitions of shortlisted indicators and targets.

(5) Review of the shortlisted indicators at the annual GRAPPA meeting in July 2018 to ensure the indicators meet the preliminary criteria.

Results. The expert group arrived at a consensus with a shortlist of 8 best practice indicators across 4 key focus areas aligned with the patient pathway.

Conclusions. There were 8 evidence-based best practice indicators and respective targets that were identified to enable the monitoring of quality of care and target improvements.

Key Indexing Terms: Psoriatic Arthritis, Psoriasis, Quality of Care, GRAPPA, Quality Indicators, Diagnosis

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INTRODUCTION

Psoriatic arthritis (PsA) is a chronic inflammatory musculoskeletal disease that affects peripheral joints, entheses, axial skeleton, skin, and nails. PsA is also associated with other comorbidities with the impact of the disease extending beyond skin and joint symptoms. PsA impairs physical and mental function, negatively affects quality of life, results in reduced work productivity, and leads to high rates of healthcare utilisation.(1, 2)

In 2016, members of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) in collaboration with KPMG LLP (United Kingdom) conducted a study to benchmark PsA care at treatment centres around the world.(3) The benchmarking study identified 10 key challenges in the care of PsA patients as well as practices to improve these challenges. The top 4 challenges were late referral and diagnosis, limited awareness of PsA among non-rheumatologists, a disparate approach to care, and an inadequate management of comorbidities.

A range of practices was identified to address these challenges in 4 corresponding focus areas:

1. Shorten time to diagnosis to ensure patients receive timely and appropriate screening.
2. Improve multidisciplinary collaboration to ensure PsA patients receive appropriate care.
3. Optimise disease management to ensure level of care is adjusted as required.
4. Improve disease monitoring to improve management of comorbidities.

Although the benchmarking study observed a range of practices that could improve care for patients at treatment centres globally, it also suggested that PsA

treatment centres do not usually have processes or metrics in place to measure quality of care.(3)

The objective of the present study was, therefore, to develop a set of indicators to enable PsA caregivers in the rheumatology and dermatology setting to objectively assess delivery of care while focusing on the 4 challenges and treatment practices discussed above. Such a set of indicators would be the first step in developing an objective measure of the impact of interventions aimed at improving care and to target future efforts.(4)

METHODS

Ethical approval for this study was not sought.

PsA expert panel composition. To ensure practical relevance in a range of PsA care settings, this study was supported by a panel of international experts consisting of 5 rheumatologists and 3 dermatologists across 3 geographies (Europe, North America, and South America). The panellists were all GRAPPA members and were recruited to reflect treatment centres with leading care practice and a range of care environments.

Based on panel input, a set of principles was defined to guide the identification and definition of a set of quality-of-care indicators. Namely, that each indicator should be: (1) relevant to the key challenges in PsA care; (2) evidence-based, (3) feasible and measurable to be of practical use to PsA treatment centres around the world in both the rheumatology and dermatology care settings, and (4) formulated in a clear, concise, and sufficiently general way. The study comprised 4 phases to achieve these objectives, which are highlighted in Figure 1 and described in detail below.

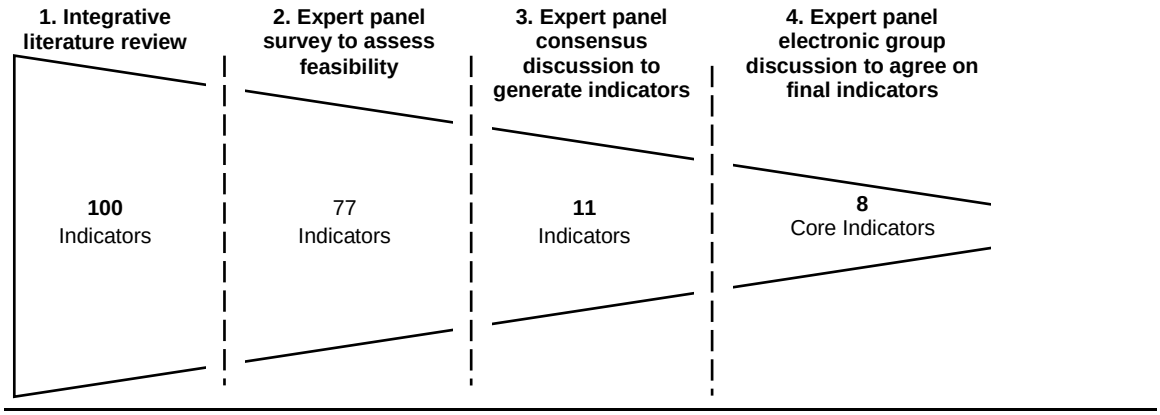

Figure 1. Study approach to identify PsA best practice indicators that are evidence-based and of practical use to treatment centres.

Phase 1 consisted of an integrative literature review to identify a long list of 100 potential indicators. In Phase 2, through an online survey, the expert panel assessed the long list based on predefined feasibility criteria to identify a set of 77 indicators that would be practical to collect at the centres. In Phase 3, in a consensus discussion, the expert panel evaluated the resulting 77 indicators, focusing on relevance and reliability, to arrive at a shortlist of 11 indicators. Finally, in Phase 4, through electronic group discussion, a list of 8 core indicators was refined and attributed targets based on evidence from literature.

Phase 1: Integrative literature review. The study used an integrative literature review approach to identify relevant literature as an evidence base for best practice indicators. A search in PubMed and online search engines was complemented with literature suggestions from the expert panel. The review covered both academic articles and grey literature, such as relevant guidelines and policy documents, that discussed PsA, additional arthritides, and other chronic diseases. This structured approach has been employed in similar studies in arthritis and nursing and allows

rapid triage to arrive at the most relevant literature.(5, 6) Figure 2 summarises the literature review process.

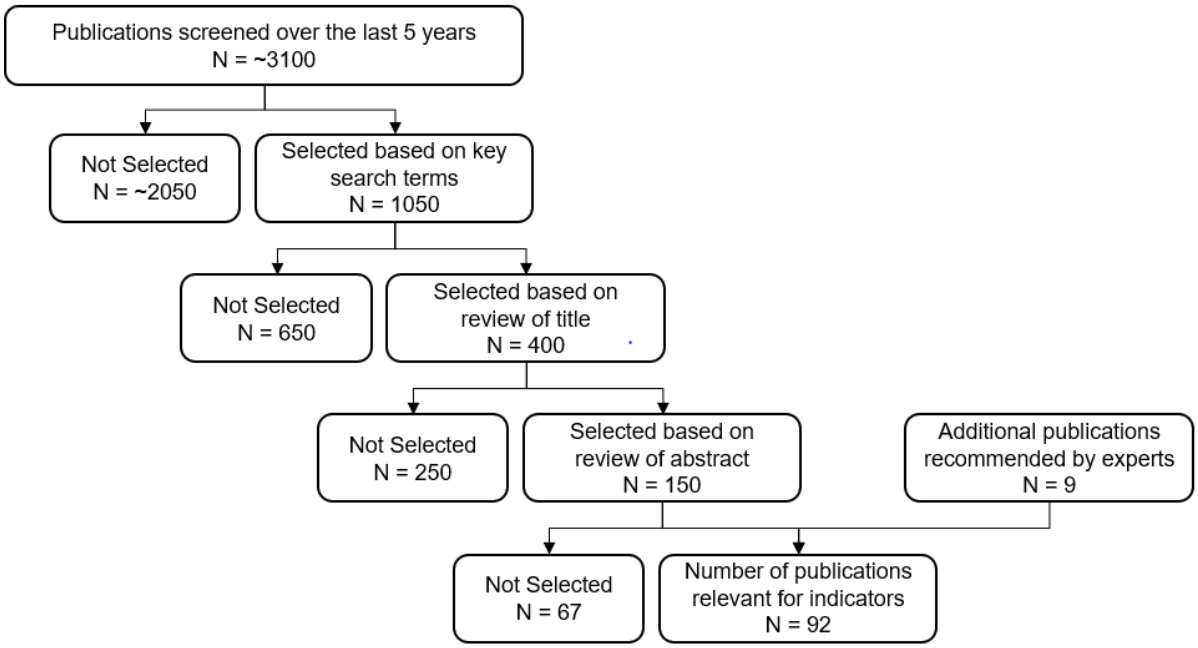

Figure 2. Studies identified in the integrative literature review. N: number.

Academic literature search. A database search for articles in PubMed related to best practice indicators using a combination of prioritised search terms (Table 1) was conducted to identify existing best practice indicators. Additional articles were retrieved through the citation-tracking of original articles and based on recommendations from the expert panel.

High priority search term / group of search terms	**Search Results (Last 5 years)**
Psoriatic arthritis / psoriatic arthritis management / management of psoriatic arthritis / management of psoriasis	3126
Patient outcomes / patient-reported outcomes / patient outcome / patient-reported outcome measures / patient satisfaction	31

Treatment / treatment challenges / treatment guidelines / guidelines / treatment recommendations	74
Indicator / quality indicator / quality of care / quality of life / patient quality of life	91
Screening / diagnosis / delayed diagnosis / diagnostic delay / referrals / referral / symptoms	34
Disease burden / multidisciplinary care / comorbidity	58

Table 1. Prioritised search terms.

Grey literature search. The publicly available grey literature was examined by applying prioritised search terms in search engines (Table 1). Non-English language references were excluded unless there was sufficient explanatory text in English.

The time allotted for the grey literature search was 1 hour or until saturation was reached, whichever came first. Saturation was defined as not identifying new literature to include in analysis for 30 minutes or 5 consecutive search pages, whichever came first. The predefined time limit/saturation was set as a pragmatic limit while allowing a comprehensive search to be performed. After the academic and grey literature searches were completed, the literature list was supplemented through engagement with the expert panel and PsA care practitioners.

Overall, the searches of academic and grey literature returned approximately 3126 studies over the last 5 years, of which 288 were prioritised based on key search terms. Of the 288 studies, 183 were selected following a relevancy check by conducting a title review in which overlapping literature was eliminated. Subsequently, a review of the abstracts and additional findings from the expert panel and grey literature established a total of 143 relevant publications to be further evaluated. Finally, based on reviews of the full articles, 92 publications were considered relevant for identifying the indicators.

Identification of indicator long list. A review of the 92 selected academic and grey literature sources led to the identification of 100 potential indicators across the 4 focus areas. To support evaluation in subsequent phases of the study, an initial definition was constructed for each indicator in terms of a measure with a unit, a target where available, and support by a rationale for measurement. To structure the analysis, the indicators were categorised into 3 groups: adoption of clinical practice, process measures (such as duration), and clinical and nonclinical outcomes. Figure 3 summarises the distribution of indicators across these categories. For example, for "Shorten Time to Diagnosis", a potential indicator in the category "Process measures" was tentatively defined as "Average duration from the onset of symptoms (such as joint pain, skin manifestations, etc.) to a diagnosis of PsA", measured in months, with a target of less than 5 years. In the following phases, the definition of selected indicators was refined iteratively based on the expert panel's review.

Focus area / Sub-group	Shorten time to diagnosis	Improve multidisciplinary collaboration	Optimise disease management	Improve disease monitoring	Total
Adoption of clinical practice	5	6	11	7	29
Process	18	3	9	2	32
Outcomes	7	3	20	9	39
Total	30	12	40	18	**100**

Figure 3. Mapping of long list of potential quality indicators.

Phase 2: Expert panel survey to assess indicator feasibility. In Phase 2, the panel of 7 experts was asked to complete a survey to identify the most feasible indicators for use in day-to-day practice. For each of the long listed 100 potential indicators, the

panel assessed whether data required to measure the indicator would be available and whether the cost to retrieve these data was acceptable. The decision process to retain an indicator for detailed evaluation is outlined in Figure 4. Specifically, an indicator would be retained if:

1. The majority of experts (at least 4 out of 7) agreed that the indicator is currently captured or can easily be captured; or
2. 2 or more experts agree that the indicator is currently captured, and 3 or more agree it could be easily captured in the future.

Of the 100 potential indicators from the initial long list, 77 were retained based on feasibility. Of the 23 indicators, 16 were discarded based on limited feasibility to collect the underlying data and were clinical and nonclinical outcomes. A primary concern regarding outcomes-related data was the ability to aggregate data either from patient reporting or health records in line with the effort reported in other studies required to collect patient-reported impact of PsA on quality of life.(1)

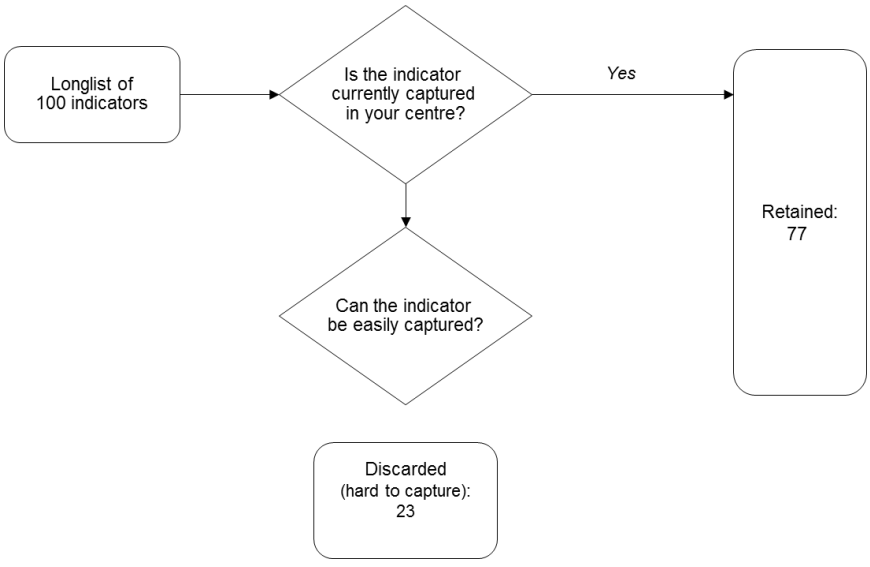

Figure 4. Feasibility Expert Panel Survey.

Phase 3: Expert panel consensus discussion. In Phase 3, a group discussion involving the expert rheumatologists and dermatologists from the panel followed.

The panel assessed the 77 retained indicators in detail to identify a shortlist based on 2 criteria:

1. Relevance of the indicator for PsA best practice: Does measuring the indicator help evaluate delivery of care to identify potential for improvement?
2. Reliability of measurement: Does the indicator provide a consistent measure?

The panel also suggested the following key points to consider in the selection and definition of the indicators to ensure they would be of practical use in the PsA care setting:

- Retain as few indicators per focus area as possible (maximum of 4 per focus area).
- Ensure indicators are defined in a sufficiently general and simple way.
- Clearly communicate distinction between aggregate indicator (e.g., percent over all patients at treatment centre) and the checklists (e.g., per individual patient) required to get individual data points.

Each of the 77 indicators was reviewed and comments were captured to refine the indicator definition and target, as well as to provide further evidence. The full list of 100 potential indicators was kept at hand to allow for reassessment of specific discarded indicators in case panel members deemed these sufficiently

important. In particular, the indicator related to application of treat to target,(7) which had initially been discarded, was re-included. Furthermore, 2 new indicators that were not originally part of the top 100 were added based on panel suggestions.

The panel discussion led to a shortened list of 11 quality indicators for PsA care. The other 68 indicators were discarded because they were considered too detailed, could be combined into an overarching indicator (e.g., the duration of an intermediate step between presentation and diagnosis), or were not a direct or reliable measure of quality of PsA care.

Phase 4: Indicator generation. In Phase 4, a final electronic group discussion among the experts was conducted to refine the shortlist of 11 indicators, including their respective definitions and targets, and to provide supplementary evidence to support the rationale for inclusion in the final set. Specifically, the indicators were once more reviewed based on the guiding principles determined by the expert panel. Based on this review, 3 indicators were rejected because of limited feasibility or current lack of supporting evidence. For example, despite being a promising solution, a measure related to fast-tracking patients based on PsA risk score would first require a validated risk score to be established.

RESULTS

The expert group arrived at a consensus with a shortlist of 8 indicators across each focus area, listed in Table 2.

Indicator	**Target**
1. Shorten time to diagnosis	
Average duration from presentation to HCP to confirmed PsA diagnosis(8)	Less than 6 months

Percent of patients with psoriasis in a year who receive a PsA screening test (a suitable validated tool such as PEST, CONTEST, or other questionnaires)(9)	PsA screening test to be conducted at least once a year
2. Improve multidisciplinary collaboration	
Multidisciplinary PsA assessment is available (Y/N)(10)	Multidisciplinary collaboration should be available in centres
Does the centre provide suitable training for HCPs, nurses, etc. to increase awareness of PsA disease symptoms (Y/N)(11)	100% of staff should have followed suitable training on PsA each year
3. Optimise disease management	
Average number of PsA evaluations done by HCP per patient in a year (depending on the specialty), assessing 6 core domains of PsA: musculoskeletal, skin, function, pain, patient's global assessment, and Quality of Life(12)	1-2 evaluations per year to monitor disease activity
Percent of PsA patients on whom T2T strategy is applied(7)	All patients with new onset disease should be offered a T2T strategy
4. Improve disease monitoring	
Percent of PsA patients who received full disease assessment for comorbidities, e.g., comorbidity index at least once every year(13)	All patients should have at least an annual assessment for comorbidities
Availability of short-term, unscheduled appointments (Y/N)?(14)	Maximum wait time for unscheduled appointment should be 2 weeks

Table 2. Best practice indicators for PsA. HCP: healthcare providers; PsA: psoriatic arthritis; PEST: Psoriasis Epidemiology Screening Tool; CONTEST: CONTEST Screening Tool; Y: yes; N: no; T2T: Treat to Target.

Review at the annual GRAPPA meeting. In addition to the PsA expert panel, the final list of indicators was presented at the 2018 annual GRAPPA meeting where approximately 150 participants, including expert rheumatologists, dermatologists, and patient research partners, evaluated the indicators and associated targets to assess their ability to improve PsA care. Figure 5 depicts the voting results from the workshop held at the meeting specific to the topic.

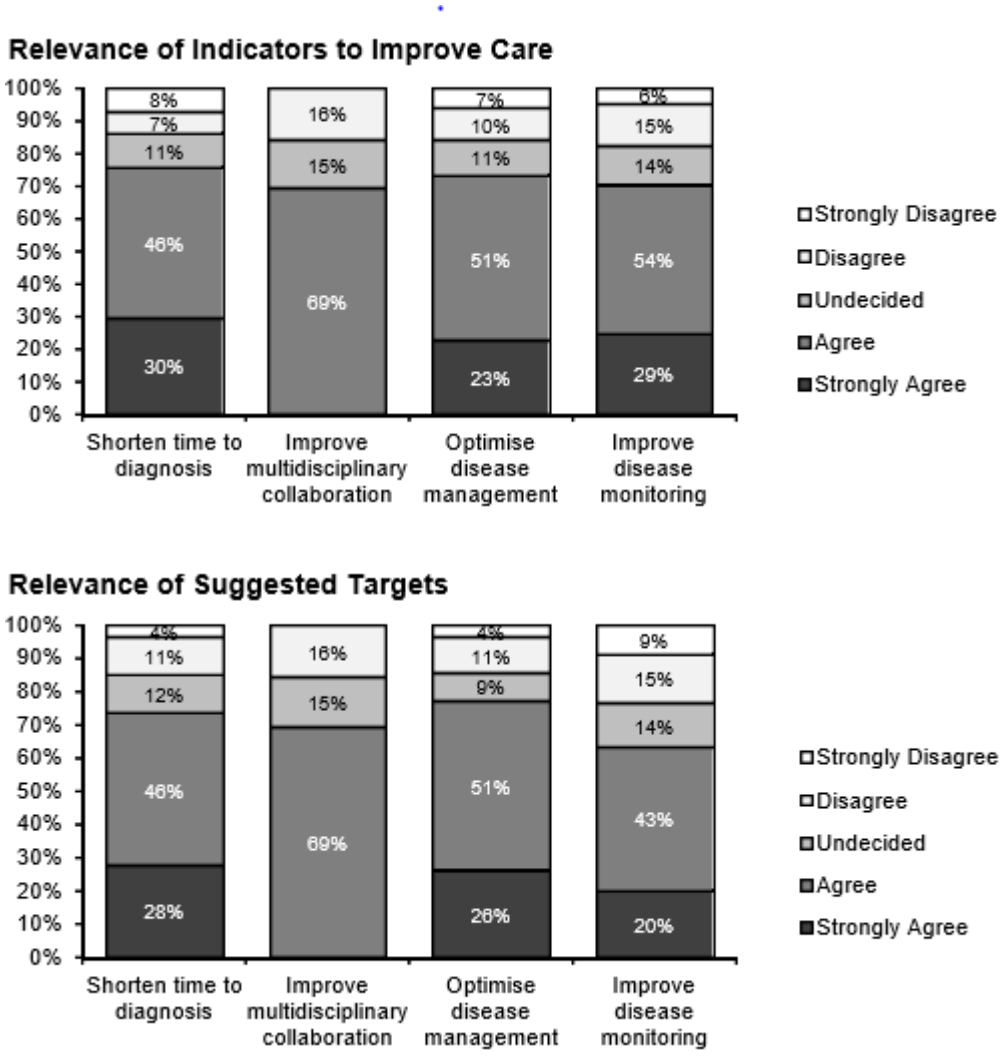

Figure 5. Voting Results, Annual GRAPPA Meeting.

As part of the workshop, the 8 core indicators were re-evaluated to seek patient perspective and input from a larger group of rheumatologists, dermatologists,

and industry experts. Overall, the feedback was positive with approximately 70% of the participants agreeing with the relevance of presented indicators and respective targets to improve care for patients. The consensus view suggested the indicators would be useful measures for clinical practice, but that they should be repositioned from “Quality Indicators” to “Best Practice Indicators”.

Detailed focused group discussions suggested that minor modifications to the existing indicators can provide greater clarity of measures. As a result, some of the Best Practice Indicators were further refined to enable ease of adoption in clinical practice, as shown in Table 3.

Indicator	**Target**
1. Shorten time to diagnosis	
Average duration from presentation to HCP to confirmed PsA diagnosis(8)	Less than 6 months
Percent of patients with psoriasis in a year who receive PsA screening tests (clinical or a suitable validated tool such as PEST, CONTEST, or other questionnaire)(9)	PsA screening test to be conducted at least once a year
2. Improve multidisciplinary collaboration	
Multidisciplinary PsA assessment is available (Y/N)(10)	Multidisciplinary collaboration should be available in centres
Does the centre provide training to increase awareness of symptoms associated with psoriatic disease and upskill HCPs, nurses, etc. to conduct disease assessment?(11)	100% of staff should have followed suitable training on PsA each year
3. Optimise disease management	
Average number of evaluations conducted in a year for psoriatic patients who have visited HCP more than once, assessing 6 core domains of PsA: musculoskeletal, skin, function, pain, patient’s global assessment, and Quality of Life(12)	1-2 evaluations per year to monitor disease activity

Percent of new PsA patients who are treated using the T2T strategy or with an agreed treatment goal(12)	All patients with new onset disease should be offered a T2T strategy
4. Improve disease monitoring	
Percent of psoriatic disease patients who received full disease assessment for comorbidities at least once every year (e.g., comorbidity index can be leveraged to conduct disease assessment)(13)	All patients should have at least an annual assessment for comorbidities
Availability of short-term unscheduled appointments for new patients (Y/N)(14)	Maximum wait time for unscheduled appointment should be 2 weeks

Table 3. Refined list of Best Practice Indicators. HCP: healthcare providers; PsA: psoriatic arthritis; PEST: Psoriasis Epidemiology Screening Tool; CONTEST: CONTEST Screening Tool; Y: yes; N: no; T2T: Treat to Target.

In addition to the refined list of core indicators included above, members at the GRAPPA workshop were also asked to evaluate the long list of 77 indicators that were originally reviewed by the expert panel. As a part of this exercise, members were asked to suggest additional potential indicators that may be valuable for PsA care. As a result, 7 additional indicators were put forward as shown in Table 4.

Additional Indicators Suggested at GRAPPA	
1. Shorten time to diagnosis	
	Average time from the first contact with HCP to a rheumatology or dermatology referral
	Average time from the HCP referral to a dermatology appointment
	Average time from the HCP referral to a rheumatology appointment
2. Improve multidisciplinary collaboration	

	Percent of PsA staff at the centre who participated in at least 1 PsA-related training session in last year
	Number of educational and collaborative meetings organised between dermatologist, rheumatologist, and other specialists (such as cardiologist, ophthalmologist, etc.) in each quarter
	Percent attendance at the multidisciplinary networking and community-based meetings every quarter
4. Improve disease monitoring	
	Percent of PsA patients on whom a comprehensive risk/benefit and long-term side effects assessment is conducted in a year (in follow up period)

Table 4. Additional potential indicators that may be relevant to measure. GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; HCP: healthcare providers; PsA: psoriatic arthritis.

DISCUSSION

In this study, we present an initial set of concise indicators for best practice in PsA resulting from an integrative literature review, electronic survey, and consensus discussions among an international panel of dermatology and rheumatology experts followed by a review at the annual GRAPPA meeting by a larger group of physicians and patients. These indicators are preliminary and can serve as benchmarks for delivering quality care in the clinical setting and may enhance the care of patients with psoriatic disease worldwide. It is clear that the indicators relate more to PsA than psoriasis, although it could be argued that they cut across these 2 specialities and may serve to monitor and enhance care for patients with both conditions.

We acknowledge a number of limitations to this study and highlight a number of potential next steps. First, patient involvement in the project occurred late. At the

2018 annual GRAPPA meeting, a patient voice at the outset may have changed the prioritising of the indicators. Second, to ensure the PsA best practice indicators would be of practical use to health care professionals, in phase 2 of this study only potential indicators that the panel deemed feasible to collect were retained. As a result, 23 indicators were discarded in Phase 2 because the panel presumed limited availability of data for these and/or effort required to collect these prohibitive. Because of this, potentially relevant indicators may have been discarded based on a subjective evaluation of data availability. A next step would be to review the discarded indicators for relevance, followed by a pilot study to assess data availability. Additionally, for best practice indicators to be useful and meaningful, they must also depict an array of attributes: feasibility, acceptability, reliability, and validity. In this study we have only tested indicators based on feasibility to capture data and availability of target evidence.

The current definition of targets for some of the 8 indicators could benefit from tailoring to current practice. For example, it may not be feasible to achieve annual PsA screening for 100% of patients with psoriasis, and a different target may be more appropriate. Although, in general, patient research partners were reluctant to reduce the targets in order to force the maintenance of higher standards of quality care.

In some cases, indicators were not used because they were not yet evaluated in the literature or because there is no consensus on desired clinical practice. As PsA care is further standardised and new information from research is available, it may be worth revisiting and expanding the shortlist of indicators.

The indicators are currently aimed at supporting best practice care for PsA patients to aid health care professionals to set up a measuring framework and to

give them the opportunity to identify gaps in the quality of their care that otherwise might remain undetected. The indicators may also benefit from additional, more targeted measures of care. For example, with respect to delays in time to diagnosis, the indicator currently measures the overall time to diagnosis from first presentation to healthcare providers. Modification of the indicator may unravel delay along specific steps of the patient pathway, which may also be useful to record to highlight further opportunities for improvement.

CONCLUSION

This project has identified 8 best practice indicators for PsA care across 4 practice areas. The respective targets are evidence based, feasible, measurable, and meaningful for PsA care providers. These indicators may be used in practice to further assess the delivery of care and to allow for the identification of areas for improvement.

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