

# Benchmarking Care in Psoriatic Arthritis — The QUANTUM Report: A Report from the GRAPPA 2016 Annual Meeting

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**ABSTRACT.** Members of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), in partnership with KPMG LLP (UK), conducted interviews at selected research centers around the globe to analyze the process of care in psoriasis and psoriatic arthritis (PsA): pre-diagnosis, referral and diagnosis, treatment, and followup. Ten major challenges emerged, many of which were universally recognized across centers; the top 4 included limited awareness of PsA among non-rheumatologists, a disparate approach to care, late referral and diagnosis, and an inadequate management of comorbidities. (J Rheumatol 2017;44:674–8; doi:10.3899/jrheum.170142)

## Key Indexing Terms:

PSORIATIC ARTHRITIS PSORIASIS QUALITY OF CARE OUTCOMES GRAPPA

Psoriatic arthritis (PsA) is a form of chronic inflammation associated with psoriasis, with a worldwide prevalence of 0.16% to 0.25%<sup>1,2,3</sup>. The condition occurs in up to 30% of patients with psoriasis, around 10 years after psoriasis onset<sup>1,4</sup>. Clinically, it is characterized by peripheral or axial joint inflammation, which may be associated with varying levels of pain, swelling, and stiffness of joints in the hands, feet, knees, neck, spine, and elbows<sup>1</sup>.

Over the last decade, the management of PsA has been improved through the introduction of new treatment options.

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However, despite this progress, there is considerable variation in the quality of care patients receive from the point of diagnosis and referral, to treatment initiation and followup care<sup>5</sup>. As a consequence, the longterm outcomes for patients with PsA are poor, marked by disease progression, reduced function, and increasing disability<sup>6</sup>, in addition to low health-related quality of life<sup>5,7,8</sup>.

To understand these challenges and to analyze potential strategies and interventions to optimize care delivery, an independent observational research project was undertaken during March–July 2016. Expert advisors from the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) oversaw the project, forming a multidisciplinary working group including rheumatology and dermatology specialists from centers in Europe, North America, South Africa, and Hong Kong.

The primary goal of the research was to collate information on key interventions to improve care for patients in multiple centers worldwide. Researchers aimed to identify, document, and share consistent practices; to help increase the awareness of PsA, promote timely and accurate diagnosis, and increase the consistency of care; and ultimately to improve outcomes of patients with PsA. Our paper summarizes the research findings.

The project focused on clinical, behavioral, social, and structural interventions to optimize care for the patient with PsA, so the target audience for our review includes healthcare providers (HCP), service and program managers, policy makers, and disease organizations involved in developing programs and implementing care.

## MATERIALS AND METHODS

*Face-to-face interviews.* Semistructured interviews were undertaken with experts from a variety of specialties located in 7 research centers across the

globe. Centers and interviewees were selected by members of the GRAPPA KPMG Steering Committee, based on set criteria including clinical and academic merit and innovative practices and to represent a variety of geographies and healthcare systems. Participating centers included Brigham and Women's Hospital, Boston, Massachusetts, USA (Dr. Joseph F. Merola), Toronto Western Hospital, Toronto, Ontario, Canada (Dr. Dafna D. Gladman), Groote Schuur Hospital, Cape Town, South Africa (Dr. Asgar Kalla); Prince of Wales Hospital, Hong Kong (Dr. Lai-Shan Tam); Guy's and St. Thomas' UK National Health Service Foundation Trust, London, UK (Dr. Bruce Kirkham); Hospital Italiano de Buenos Aires, Buenos Aires, Argentina (Dr. Enrique Soriano); and the University Hospital Schleswig-Holstein, Lübeck, Germany (Dr. Diamant Thaci). We also interviewed Professor Alice Gottlieb from the Tufts Medical Center in Boston, Massachusetts, USA.

An interview guide was created to facilitate structured collection of quantitative and qualitative insights on PsA care throughout the patient's journey, which was combined with open questions. All questions were concise, specific, and nonleading. Topics covered ranged from current practice and key challenges to valuable and unique strategies used by the center, patient centrality, and the effect of interventions.

All interviews were completed 1:1 over a duration of about 1 h. Before beginning the interview, all participants were given an overview of the project objectives. In total, > 50 experts were interviewed, including specialists in rheumatology and dermatology, primary care physicians (PCP), nurses, researchers, pharmacists, managers, patients, and patient groups.

Interview responses were systematically analyzed for insights and patterns. Thematic analysis was undertaken to identify all challenges and interventions, which were subsequently validated through virtual review of the multidisciplinary working group consisting of clinicians, academics, and patient representatives.

## RESULTS

Overall, 10 key challenges and unmet needs in PsA care were identified (Table 1). Many of these challenges were universally recognized across centers, with all interviewees reporting that limited awareness of PsA among non-rheumatologists was a key challenge, followed by a disparate approach to care (86%), late referral and diagnosis (71%), and an inadequate management of comorbidities (57%).

In total, 24 innovative strategies and interventions were used to address these challenges and drive improved quality of care (Table 2); selected examples are described below. The working group identified interventions to raise awareness of PsA, reduce misdiagnosis and delays in diagnosis, improve treatment coordination and quality of care, reduce disease progression, and improve care of comorbidities.

*Raising awareness of PsA.* Interviewees noted that limited HCP awareness of PsA and the risk of developing musculoskeletal disease in patients with psoriasis is likely driven by a lack of clinical training in rheumatology. In addition, patients with psoriasis often receive limited education on the possibility of developing PsA later in their lives<sup>9</sup>. As a result, physicians who are not familiar with PsA are less likely to screen for the condition<sup>5</sup>, and patients may not recognize the signs of onset. Experts agreed that development of formal and informal structured education programs should be undertaken and targeted at those most likely to encounter PsA in clinical practice, e.g., PCP and dermatologists, as well as the patients themselves. Rheumatologists should

develop these programs by sharing their knowledge and clinical experience.

In practice, we observed researchers at Brigham and Women's Hospital who developed a simple teaching tool to promote awareness of PsA, the key feature of which is the use of the acronym "PSA" to serve as a mnemonic to help non-rheumatologists remember the main hallmarks of PsA (Pain, Swelling or Stiffness, Axial disease). The tool has been observed to help with early recognition of PsA symptoms<sup>10</sup>. In addition, at the Groote Schuur Hospital in Cape Town, South Africa, specialists run peer-education programs to support PCP and medical students in recognizing the symptoms of PsA and identifying which patients would benefit from referral. Overall, these programs may contribute to reduced time to diagnosis and referral, in addition to empowerment of patients.

*Reducing misdiagnosis and delays in PsA diagnosis.* PsA is often underdiagnosed in clinical practice, and patients may experience a delay in diagnosis of up to 2 years<sup>11,12</sup>; interviewees reported that this is likely driven by a lack of awareness, combined with short consultation times preventing a thorough clinical examination<sup>9</sup>. To overcome this issue, experts agreed that centers should use regular screening of patients with psoriasis, in addition to the routine use of screening tools to help identify early symptoms of PsA.

Several screening tools have already been developed, including the Psoriatic Arthritis Screening and Evaluation, Toronto Psoriatic Arthritis Screening, Psoriasis Epidemiology Screening Tool, Psoriasis and Arthritis Screening Questionnaire, and Early Arthritis for Psoriatic Patients, which demonstrate comparable sensitivity and specificity for PsA<sup>13,14,15</sup>. In practice, they have been observed to improve diagnosis and referral times. However, further refinement and development of new screening tools to improve sensitivity is critical to improve uptake<sup>5</sup>. Development of a tool consisting of the most discriminatory aspects from established PsA screening questionnaires is under way to create a more sensitive and specific PsA screening test<sup>16</sup>.

Patients also experience a delay in referral to a rheumatologist<sup>9,17</sup>. Experts established that the development of standard referral pathways, in addition to the creation of formal and informal networks to support the transition to rheumatologist care, can markedly improve the speed of referral. Community clinics in Toronto have developed specific forms to ensure that patients are referred in a timely manner with all required tests completed before seeing a rheumatologist; at the Women's College Hospital in Toronto, patients with psoriasis can self-refer to a rheumatologist. Both interventions may drive earlier diagnosis of psoriasis patients with PsA.

*Improving PsA treatment coverage and quality of care.* Given the characteristics of PsA, patients need to be seen by a range of HCP, including dermatologists and rheumatologists, to

Table 1. Challenges persisting across the journey of patients with PsA.

Stage of Patient Journey	Challenge	Definition
Pre-diagnosis	Limited awareness	Some HCP are not aware of the risk of musculoskeletal disease in patients with psoriasis
Referral and diagnosis	Lack of screening	There is a lack of regular screening among patients with psoriasis
	Delayed referrals	Patients are often referred to a rheumatologist several years after symptom onset
Treatment initiation and diagnosis	Challenges with differential diagnosis	Following a referral, diagnosis of PsA can remain challenging even to experienced rheumatologists
	Siloed approach to care	Although PsA affects both joints and skin, there is limited coordination of care between different specialties
	Gaps in clinical management	Although many effective PsA therapies have been introduced over the last decade, many patients do not respond to their treatment or may lose the initial response over time
	Challenges with the use of biologics	Access to effective therapies can be reduced or delayed, especially in lower income areas
Followup	Lack of patient centricity	As patients become more engaged in healthcare, they want to be empowered to manage their own health. However, many centers could do more to be truly patient-centric
	Inadequate management of comorbidities	There is a lack of regular screening and management of comorbidities among patients with psoriasis
	Lack of regular followup	In current practice, some patients may not be followed up and their disease not monitored after their initial consultation

PsA: psoriatic arthritis; HCP: healthcare professional.

Table 2. Interventions to address challenges across the journey of patients with PsA.

Stage of Patient Journey	Challenge	Interventions
Pre-diagnosis	Limited awareness	1) Education of PCP and specialists
Referral and diagnosis	Lack of screening	2) Education of patients with psoriasis
	Delayed referrals	3) Regular screening
	Challenges with differential diagnosis	4) Refinement and development of new screening tools
		5) Early referrals
Treatment initiation and diagnosis	Siloed approach to care	6) Networks and referral pathways
		7) Consistent assessment criteria
	Gaps in clinical management	8) Interdisciplinary approach
	Challenges with the use of biologics	9) Use of diagnostic equipment
		Lack of patient centricity
Followup	Inadequate management of comorbidities	11) Development of networks and relationships with community centers
		12) Use of protocols and treatment algorithms
	Lack of regular followup	13) Development and validation of new outcome measures in PsA
		14) Enrollment of patients into clinical trials
	Inadequate management of comorbidities	15) Development of relationships with commissioners
		16) Improved communication between HCP and patients, and engagement of patients in their care
		17) Development of educational programs for patients
		18) Patient education by the medical office staff
		19) Collaboration with patient associations
		20) Peer and patient education
21) Nurse-led clinics		
22) Regular monitoring		
23) Use of databases and electronic medical records		
24) Patient education		

PsA: psoriatic arthritis; PCP: primary care physician; HCP: healthcare professional.

effectively manage their disease. However, interviewees noted that there is often a disconnect between the specialties, affecting timeliness and appropriateness of decision making regarding diagnosis, treatment, and symptom management. Improving the relationship between dermatology and rheumatology teams was recognized as key in providing comprehensive and holistic care for patients with PsA.

There are several models for improving collaboration between the 2 specialties that require different levels of resources and commitment to ensure consistent management and optimal outcomes. These range from informal HCP communication and knowledge-sharing to combined rheumatology-dermatology clinics. A preferred solution is to form multidisciplinary teams (MDT) that retrospectively assess patients on a case-by-case basis. This holistic yet flexible approach involving a range of specialists requires a moderate level of time and planning commitment, but experts encourage the establishment of such teams where possible and appropriate, as the best approach to providing comprehensive PsA care.

Examples of an MDT approach to PsA care were observed at The Comprehensive Centre for Inflammation at the University Hospital Schleswig-Holstein in Lübeck, Germany, and Guy's and St. Thomas' in London, UK. Both centers run weekly MDT meetings involving dermatologists, rheumatologists, and gastroenterologists, combined with joint clinics plus monthly meetings that may be attended by other specialists depending on the patients being discussed. In Lübeck, specialists from across the country may attend the meetings through teleconference or video conference. At Guy's and St. Thomas', rheumatologists and dermatologists run a weekly combined clinic for patients with PsA to improve the management of difficult-to-treat patients by having both specialists present at the same time. These interdisciplinary and collaborative approaches help address the whole spectrum of patients' needs, thereby providing more individualized patient care.

However, a survey conducted by the US National Psoriasis Foundation of more than 5000 patients with PsA revealed that about 50% were not satisfied with their treatment<sup>18</sup>. Therefore, consensus among experts was also to encourage centers to provide adequate patient education and engage patients in their own care. Educational programs can be delivered by several different trained medical staff, including medical assistants, and should include education on the disease, treatment options, and their risks and benefits. A structured program of education should be considered to ensure patients receive adequate and consistent information.

At Toronto Western Hospital, a number of initiatives are undertaken to educate and engage patients, including an annual patient newsletter<sup>19</sup>, a patient advisory committee, and an annual patient education symposium. It is hoped that these activities help drive improved quality of life and empowerment of patients.

*Improving effective management of disease progression and care of comorbidities.* Outcomes for patients with PsA are varied, with many patients experiencing disease progression and increasing severity of symptoms<sup>9,20</sup>. Therefore, experts agreed that regular and comprehensive assessment of the clinical symptoms of PsA should be performed. Followup care should be supported using electronic medical records (EMR), where possible, and databases that enable specialists to identify detailed data and make better-informed decisions. For example, Hospital Italiano de Buenos Aires has implemented an EMR that links the hospital's network with peripheral centers, enabling use throughout all centers belonging to the same health maintenance organization. Both specialists and general practitioners (GP) belong to this network; therefore, the system enables specialists, GP, and patients themselves to have access to relevant patient information.

Patients with PsA also have a high risk of comorbidities, including hypertension, cardiovascular (CV) diseases, Type 2 diabetes, obesity, and gastrointestinal disorders<sup>8</sup>, which may be overlooked by clinicians who focus solely on treating cutaneous and joint manifestations of PsA. Interviewees noted that this may be due to lack of awareness in addition to limited resources for screening and management of comorbidities. Experts agreed that specialists should strive to perform regular monitoring of patients' comorbidities, which may be achieved through nurse-led clinics where appropriate. At the Prince of Wales Hospital in Hong Kong, rheumatology nurses assist doctors in an outpatient setting<sup>21</sup>. Responsibilities include monitoring disease activity and adverse reactions, and management of longterm comorbidities, including an annual assessment of CV risk, to support overall improved quality of care for all conditions.

## DISCUSSION

Despite the availability of several treatment options for patients with PsA, unmet needs remain. To improve quality of care for patients, experts recommend that centers evaluate their own gaps in care and select appropriate interventions. We observed improvements in both clinical outcomes and patient satisfaction at all centers because of implementation of relevant interventions.

Limitations of the current research include the small sample size and observational methods undertaken to gather data. A wider spectrum of centers, in different healthcare systems, might have highlighted other areas of unmet need. In addition, limited quantitative data were available at center level to objectively measure the effect of interventions detailed in our review. Therefore, centers are encouraged to consider the use of standardized outcome measures to develop baselines, to monitor the outcome of specific initiatives, and to compare care across centers.

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