MyNIAR Psoriatic Arthritis

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MALAYSIA NATIONAL INFLAMMATORY ARTHRITIS REGISTRY-Psoriatic Arthritis (MyNIAR-PsA) Report

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CONTENTS

CONTENTS

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INTRODUCTION

MyNIAR-PsA registry

The MyNIAR-PsA registry was established in 2020 to capture the demographics, clinical information, management and treatment outcome of Psoriatic Arthritis (PsA) patients utilising the public healthcare system in Malaysia. Majority of hospitals with Rheumatology service under the Ministry of Health (MOH) Malaysia participated in this registry.

The information obtained from this registry reflected real-world data, hence may be useful to guide future disease management by answering clinical questions arising from the day-to-day rheumatology practice. Moreover, the registry data may give insights pertaining to the PsA disease burden in hospitals under MOH which may be useful to all relevant stakeholders for treatment budget planning and projections.

OBJECTIVES

- To determine the incidence and prevalence of PsA in Malaysia
- To obtain data pertaining to PsA patient demographics, disease patterns and manifestations
- To study the clinical management of PsA of patients under MOH
- To assess the patient outcome, disease activity, and impact of PsA on quality of life (work productivity and activity impairment)

DISTRIBUTION OF CASES ACCORDING TO HOSPITAL

Data were obtained from January 2020 to February 2022. A total of 14 MOH hospitals were involved in the data collection. As a newly established registry, 687 data entries were made in the early stage. The total number of patients is projected to increase over the next few years which will facilitate epidemiologic studies of the disease in the country.

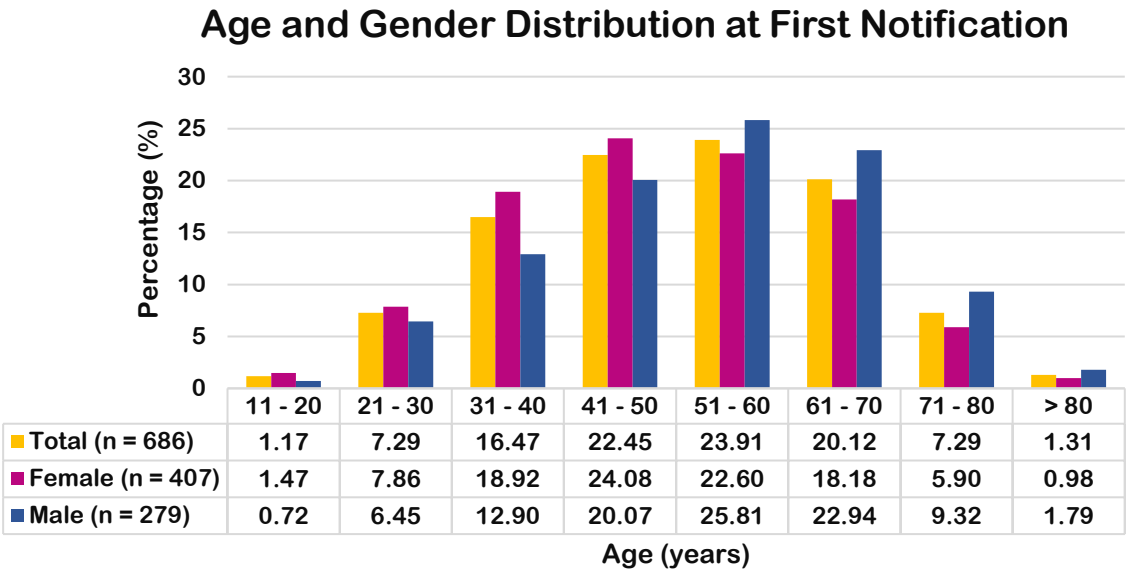
Table 1: Distribution of cases reported in the MyNIAR according to hospitals (n = 687)

No	Hospital	Year			Total (%)
		2020	2021	2022	
1	Hospital Pulau Pinang	148	10	-	158 (23.00)
2	Hospital Tuanku Jaafar, Seremban	39	62	1	102 (14.85)
3	Hospital Selayang	37	43	-	80 (11.64)
4	Hospital Tengku Ampuan Rahimah, Klang	5	50	23	78 (11.35)
5	Hospital Umum Sarawak	-	78	-	78 (11.35)
6	Hospital Tengku Ampuan Afzan, Kuantan	26	43	3	72 (10.48)
7	Hospital Putrajaya	25	16	-	41 (5.97)
8	Hospital Melaka	4	23	2	29 (4.22)
9	Hospital Sibu	-	23	-	23 (3.35)
10	Hospital Sultanah Bahiyah, Alor Setar	14	1	-	15 (2.18)
11	Hospital Raja Perempuan Zainab II, KB	3	3	-	6 (0.87)
12	Hospital Sultan Ismail	-	2	1	3 (0.44)
13	Hospital Raja Permaisuri Bainun	1	-	-	1 (0.15)
14	Hospital Sultanah Fatimah, Johor	-	1	-	1 (0.15)
	Total	**302**	**355**	**30**	**687**

CHAPTER 1: DEMOGRAPHICS

1.1 Age and Gender Distribution at Notification

The mean age of the total patient population was 51.19 ± 14.20 years old - Female: 49.76 ± 14.06 years; Male: 53.28 ± 14.17. A vast majority of the patients (82.94%) were between 31 – 70 years old (Figure 1). Gender distribution was 59.24% and 40.76% for females and males, respectively (Figure 2).



	11 - 20	21 - 30	31 - 40	41 - 50	51 - 60	61 - 70	71 - 80	> 80
Total (n = 686)	1.17	7.29	16.47	22.45	23.91	20.12	7.29	1.31
Female (n = 407)	1.47	7.86	18.92	24.08	22.60	18.18	5.90	0.98
Male (n = 279)	0.72	6.45	12.90	20.07	25.81	22.94	9.32	1.79

Figure 1: Age distribution of patients with psoriatic arthritis at first notification (n = 686)

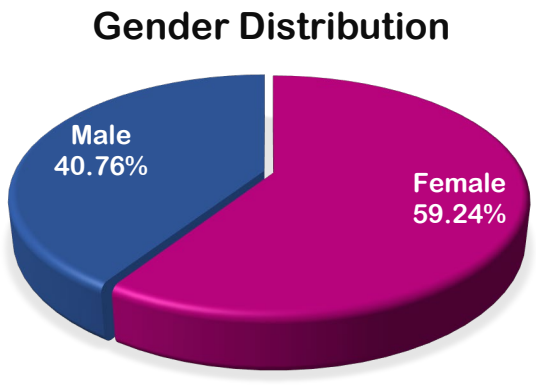


Figure 2: Gender distribution of patients with psoriatic arthritis (n = 687)

1.2 Ethnic Group Distribution

A vast majority of patients in this cohort were Malay (46.29%), followed by Indian (26.49%) and Chinese (21.98%) (Figure 3).

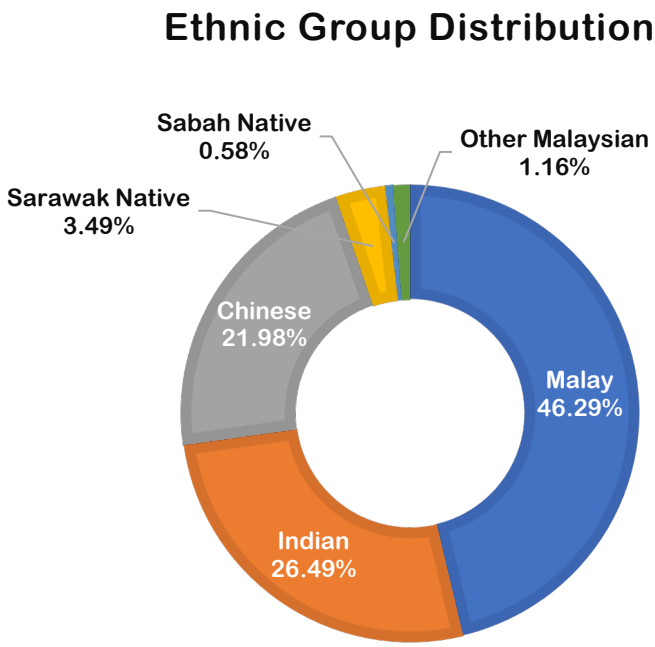


Figure 3: Ethnicity distribution of patients with psoriatic arthritis (n = 687)

1.3 Duration of Disease at Notification

The mean duration of disease at first notification for the patient population was 6.66 ± 5.99 years. More than half (54.74%) of the patients had a disease duration of less than 6 years (Figure 4).

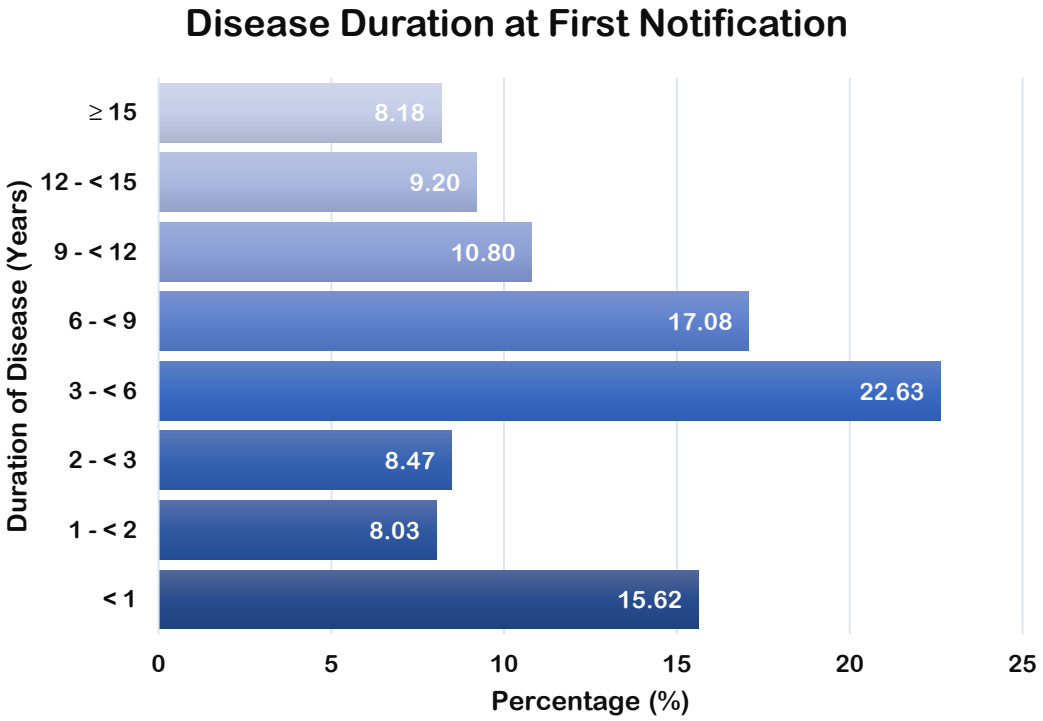


Figure 4: Disease duration of patients with psoriatic arthritis at first notification (n = 685)

1.4 BMI Distribution

Mean Body Mass Index (BMI) of the patient population at first notification (kg/m^2) was 28.17 ± 5.56 - Female: 28.39 ± 5.74; Male: 27.84 ± 5.29. More than two-thirds of the patients had BMI above the normal range with 18.14% and 68.22% being overweight and obese, respectively (Figure 5).

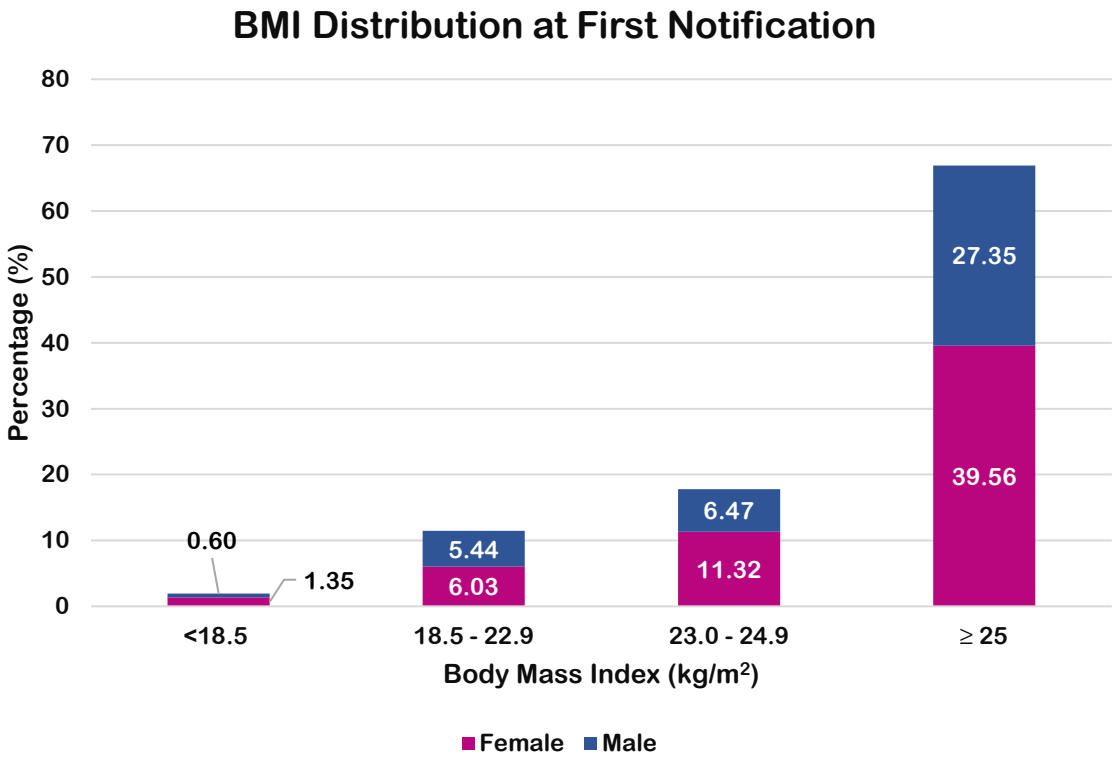


Figure 5: Body Mass Index of patients with psoriatic arthritis at first notification (n = 667)

CHAPTER 2: SOCIOECONOMIC STATUS AND SMOKING

2.1 Education Level

A vast majority of the patients (44.83%) had secondary education. Approximately a quarter (27.07%) of them had tertiary qualifications while those with primary or no formal education accounted for 10.19% and 1.60%, respectively (Figure 6).

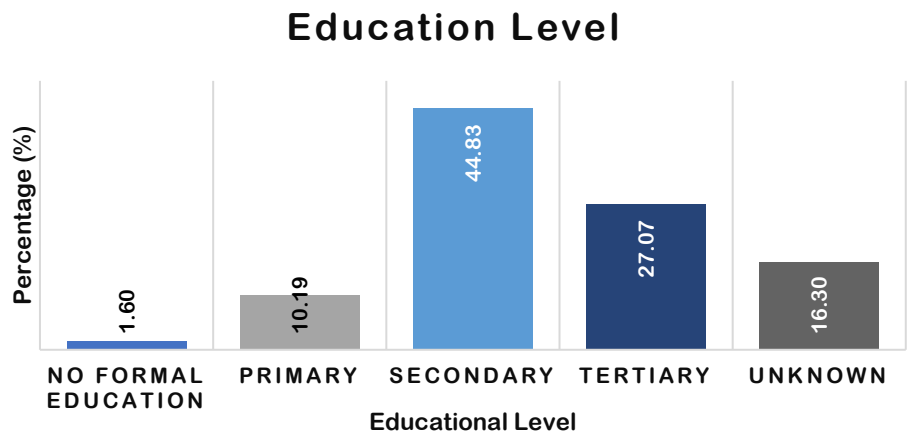


Figure 6: Education level of patients with psoriatic arthritis (n = 687)

2.2 Employment Status

Over half (51.82%) of the patients were unemployed with 4.67% (n = 32) attributing the cause of unemployment directly to psoriatic arthritis (Figure 7).

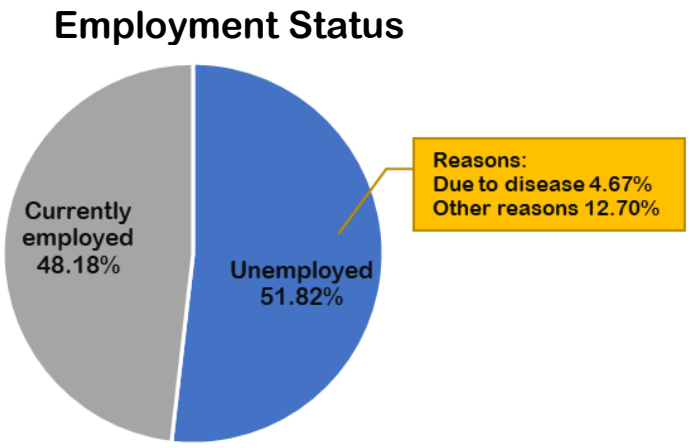


Figure 7: Employment status of patients with psoriatic arthritis (n = 685)

2.3 Household Monthly Income

Approximately 45.56% of the patients fell under the National Poverty Line Income (PLI) category (i.e., less than RM 2208.00/month) according to the revised PLI in July 2019 (The Star 2020). The most common household income bracket was RM1001 - RM3000 with 31.30% of them falling into this category (Figure 8).

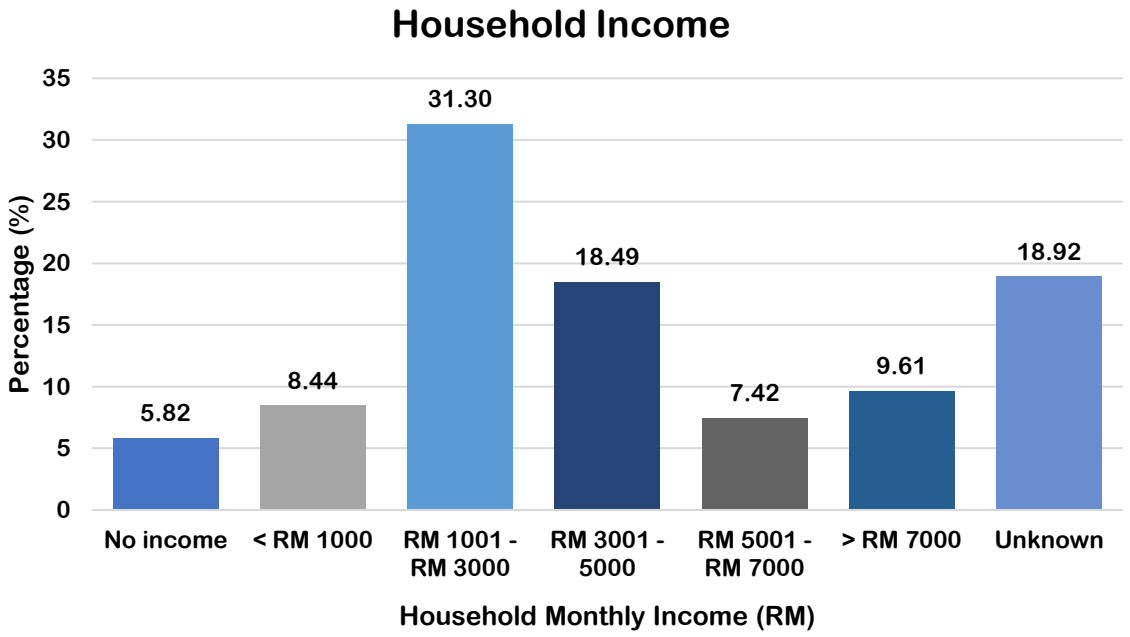


Figure 8: Household income of patients with psoriatic arthritis (n = 687)

2.4 Medical Insurance

More than half of the patient population did not have medical insurance (58.37%), whilst only 23.29% of patients were medically insured (Figure 9). This might be attributed to the registry being based on data from public hospitals in Malaysia.

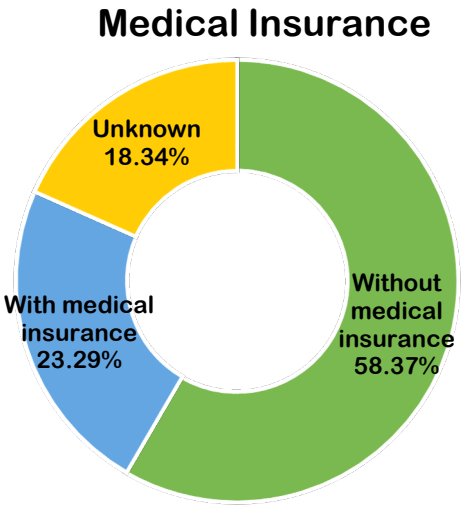


Figure 9: Medical insurance of patients with psoriatic arthritis (n = 687)

2.5 Smoking Status

Most of the patients (70.25%) were non-smokers. Only 6.13% and 7.13% were 'current smokers' and 'ex-smokers', respectively (Figure 10).

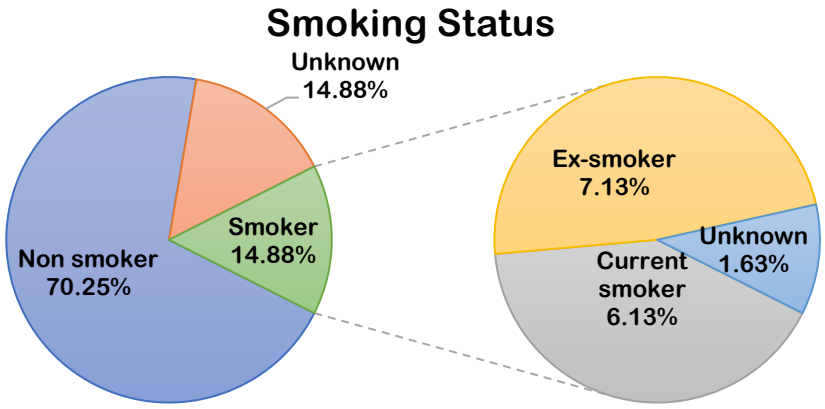
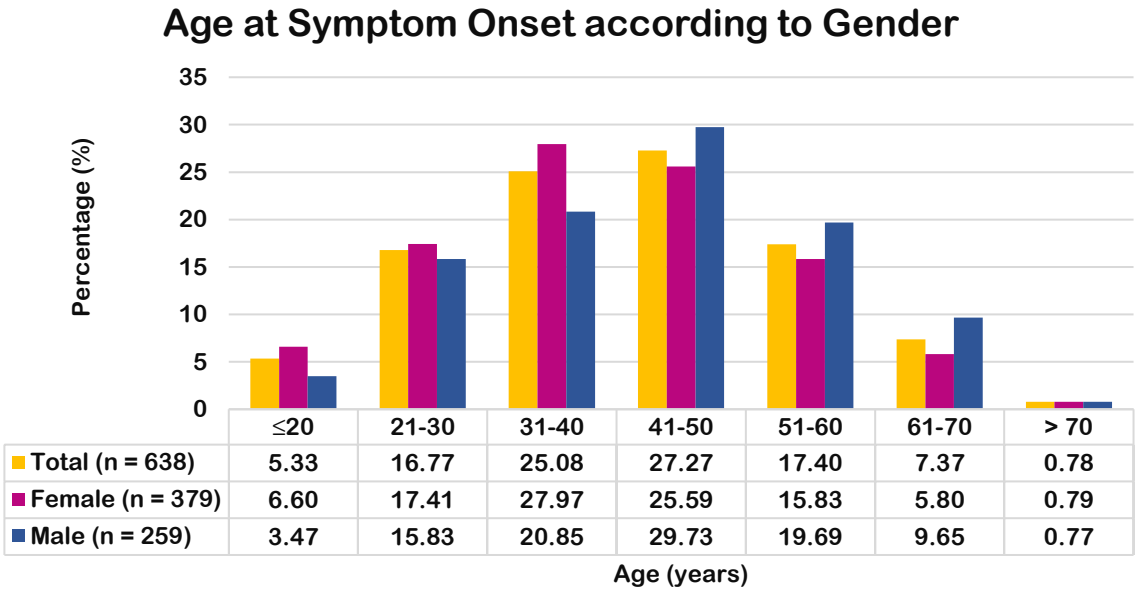


Figure 10: Smoking status of patients with psoriatic arthritis (n = 687)

CHAPTER 3: DISEASE PATTERN AND MANIFESTATIONS

3.1 Age of Disease Onset and Diagnosis

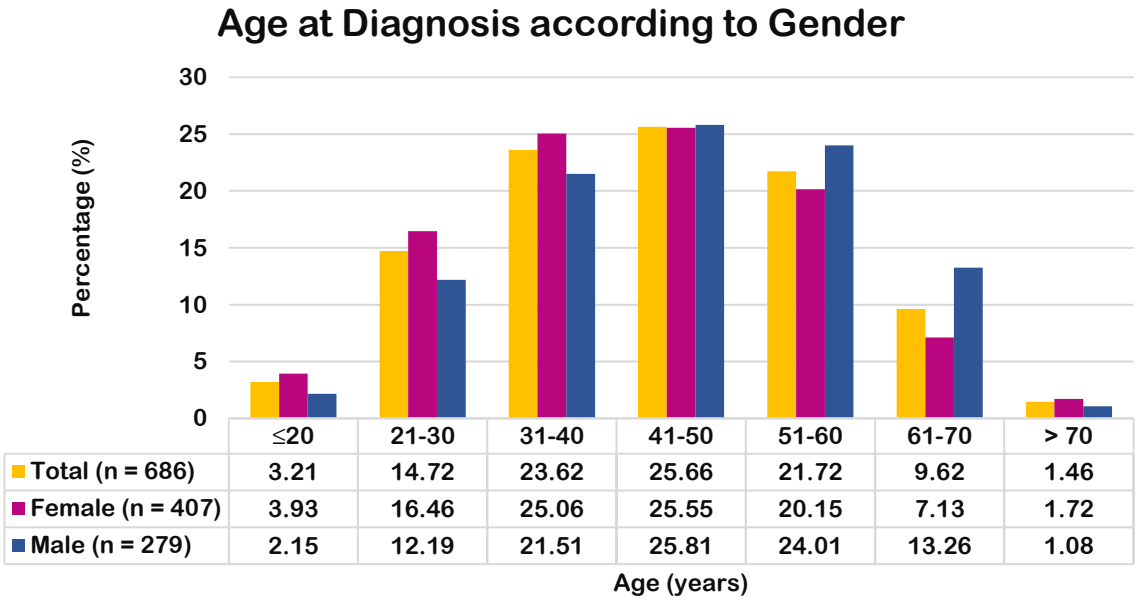
The mean age of symptoms onset for the patient population was 41.46 ± 12.97 years old – female: 40.15 ± 12.83 years; male patients: 43.39 ± 12.96 years. More than half of male patients (59.85%) had symptom onset after 40 years old while 51.98% of females had symptom onset before or at age of 40 (Figure 11).



	≤20	21-30	31-40	41-50	51-60	61-70	> 70
Total (n = 638)	5.33	16.77	25.08	27.27	17.40	7.37	0.78
Female (n = 379)	6.60	17.41	27.97	25.59	15.83	5.80	0.79
Male (n = 259)	3.47	15.83	20.85	29.73	19.69	9.65	0.77

Figure 11: Distribution of age at symptom onset according to the gender of patients with psoriatic arthritis (n = 638)

The mean age at diagnosis was 43.70 ± 13.11 years old while female patients were diagnosed slightly earlier than their male counterparts (42.40 ± 12.98 years vs 45.58 ± 13.08 years, respectively). More than half of male patients (64.16%) were diagnosed after 40 years old whilst 71.01% of females were diagnosed before or at age of 50 (Figure 12).



	≤20	21-30	31-40	41-50	51-60	61-70	> 70
Total (n = 686)	3.21	14.72	23.62	25.66	21.72	9.62	1.46
Female (n = 407)	3.93	16.46	25.06	25.55	20.15	7.13	1.72
Male (n = 279)	2.15	12.19	21.51	25.81	24.01	13.26	1.08

Figure 12: Distribution of age at diagnosis onset according to the gender of patients with psoriatic arthritis (n = 686)

3.2 Duration of Symptoms Prior to Rheumatology Visit and Prior to Diagnosis

The mean duration of psoriatic arthritis symptoms prior to visit to rheumatology clinic was 3.82 ± 5.57 years. On average, it took 2.27 ± 3.65 years from symptom onset to a psoriatic arthritis diagnosis. Approximately one-third (34.86%) of patients were diagnosed as early as 6 months of symptoms onset whereas more than half (51.92%) were diagnosed within one year of symptoms (Figure 13).

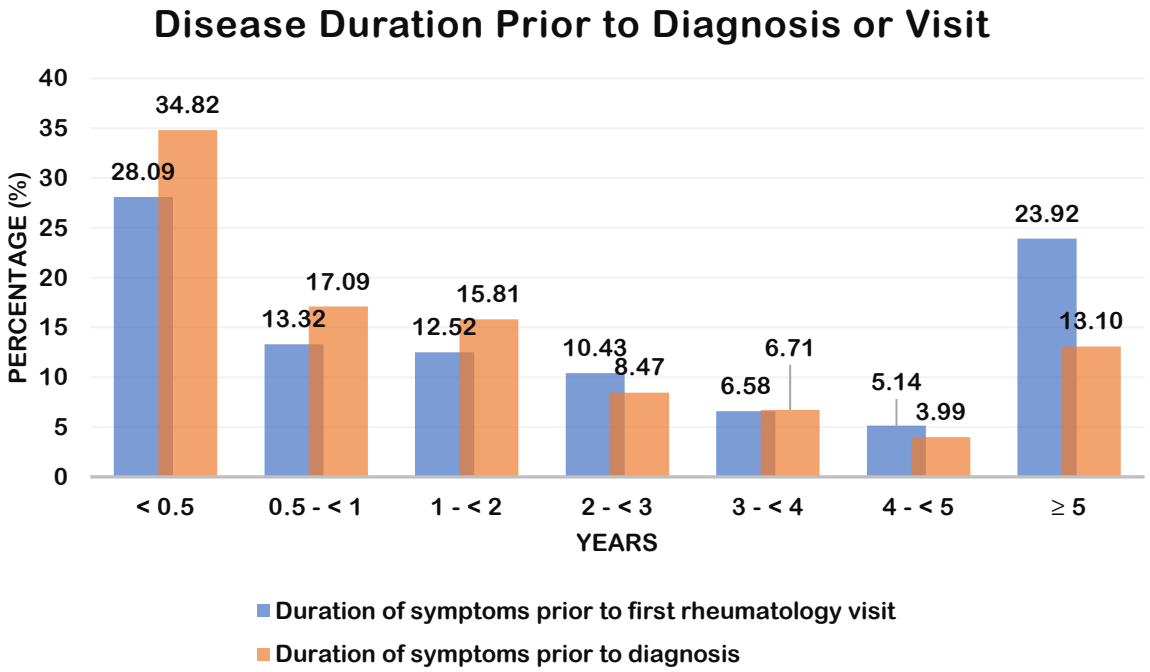


Figure 13: Duration of symptoms prior to rheumatology visit (n = 623) and prior to diagnosis (n = 626) among patients with psoriatic arthritis

3.3 Classification Criteria for Psoriatic Arthritis (CASPAR) Criteria at Presentation

Psoriasis (92.72%) was the most common presentation, followed by nail lesions (69.72%). Many patients also had negative rheumatoid factor (45.71%) and dactylitis (41.19%) as shown in Figure 14.

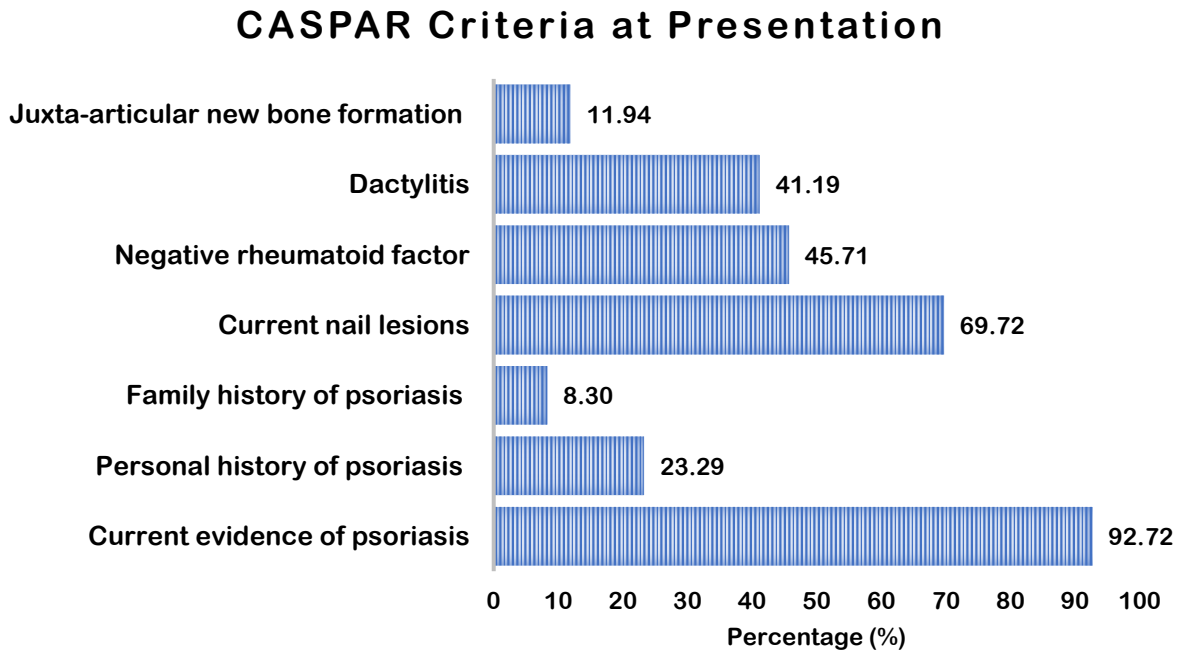


Figure 14: Disease presentation of patients with psoriatic arthritis according to CASPAR criteria (n = 687)

3.4 CASPAR Score at Presentation

The mean CASPAR score at presentation was 3.86 ± 1.09. Approximately 90.08% of patients fulfilled 3 or more CASPAR score at diagnosis (Figure 15).

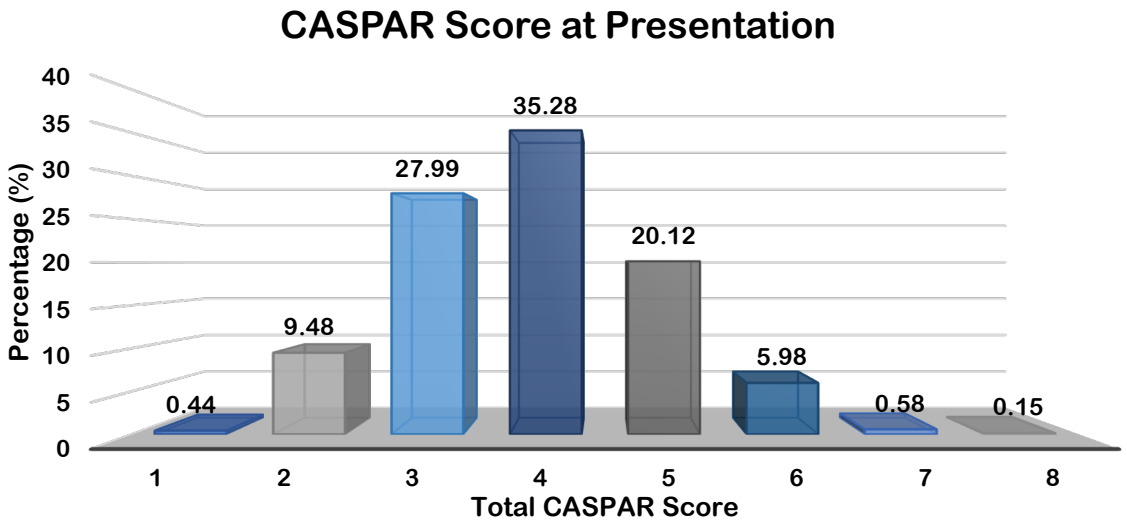


Figure 15: Total score of patients with psoriatic arthritis at presentation according to CASPAR criteria (n = 686)

3.5 Joint Involvement

Over two-thirds (81.51%) of the patient cohort had only peripheral joint affected by the disease while 16.16% had both axial & peripheral joint involvement. A minority (2.33%) of the patients had only axial disease (Figure 16(a)). Different joint involvement among the patients with only peripheral disease is shown in Figure 16(b). Among those presented with peripheral joint involvement, the prevalence of synovitis was the highest (76.36%), followed by dactylitis (46.19%) and enthesitis (23.47%) as depicted in Figure 16(b). About 38.37% of patients presented with more than one peripheral manifestation, dactylitis + synovitis (19.37%) being the commonest followed by dactylitis + synovitis + enthesitis (7.64%). Among those presented with synovitis, polyarticular aymmetrical arthritis (56.59%) was the commonest followed by oligoarticular arthritis (33.66%) (Figure 16(c)).

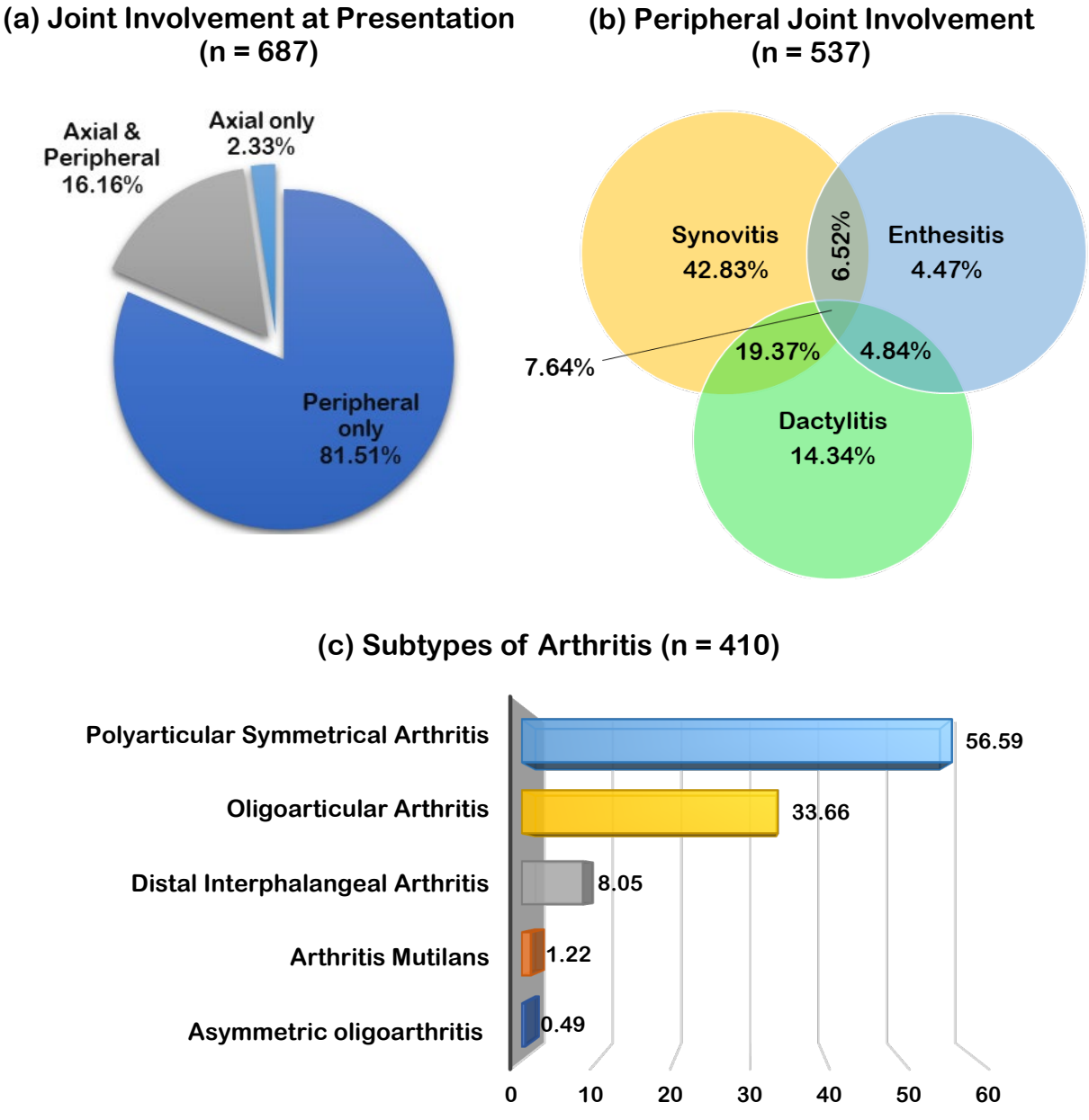


Figure 16: Joint involvement of patients with psoriatic arthritis at presentation (n = 703). (a) Overview of joint involvement; (b) Presentation of peripheral joint involvement; (c) Subtypes of arthritis.

3.6 Extra-articular Manifestations

Most of the patients had extra-articular manifestations with 88.06% having skin involvement, 1.75% with interstitial lung disease whilst 0.87% had uveitis. Approximately 7 out of 10 patients with skin involvement had skin manifestation before joint symptoms whereas 8.15% had joint symptoms preceding the skin condition. Simultaneous skin and joint manifestations occurred in 7.28% of these patients (Figure 17).

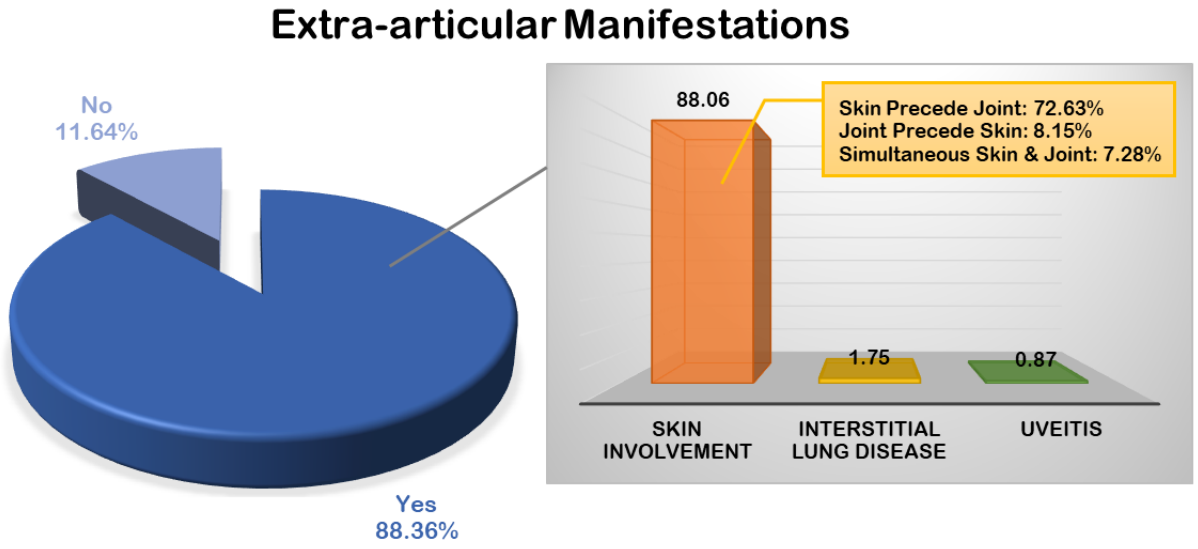


Figure 17: Extra-articular manifestations of patients with psoriatic arthritis (n = 687)

CHAPTER 4: COMORBIDITIES

4.1 Medical Comorbidities

The most common comorbid conditions were obesity (66.23%), hypertension (46.72%), dyslipidaemia (40.90%), diabetes mellitus (27.66%) and non-alcoholic fatty liver disease (12.08%). This alluded to the fact that cardiometabolic comorbidities were common among this group of patients (Figure 18). On average, the cohort of patients have 2.15 ± 1.51 medical comorbidities (Figure 19). Over half of the patients (60.40%) have 2 or more comorbidities while 86.75% of the patients have at least 1 comorbid condition.

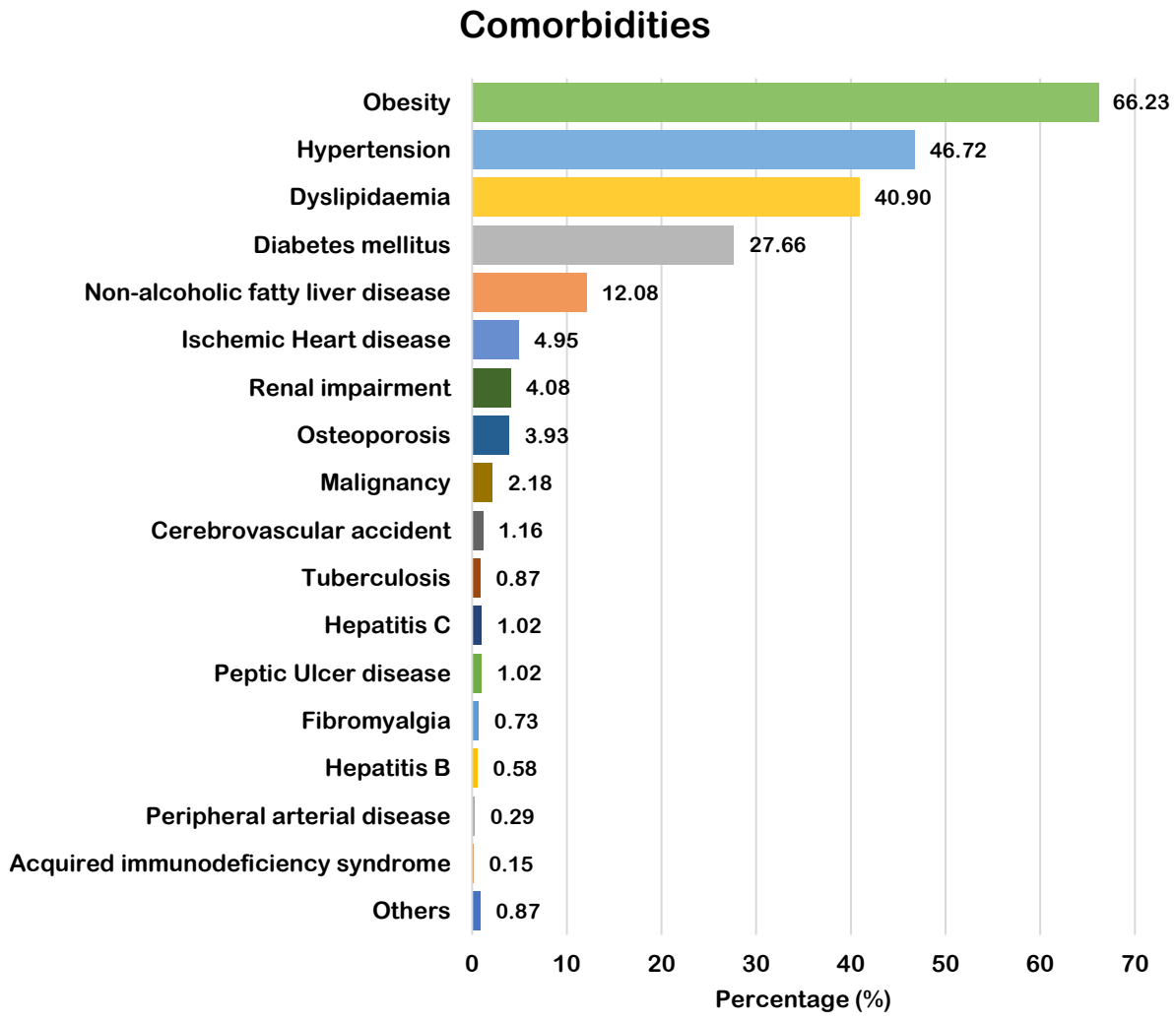


Figure 18: Medical comorbidities of patients with psoriatic arthritis (n = 687)

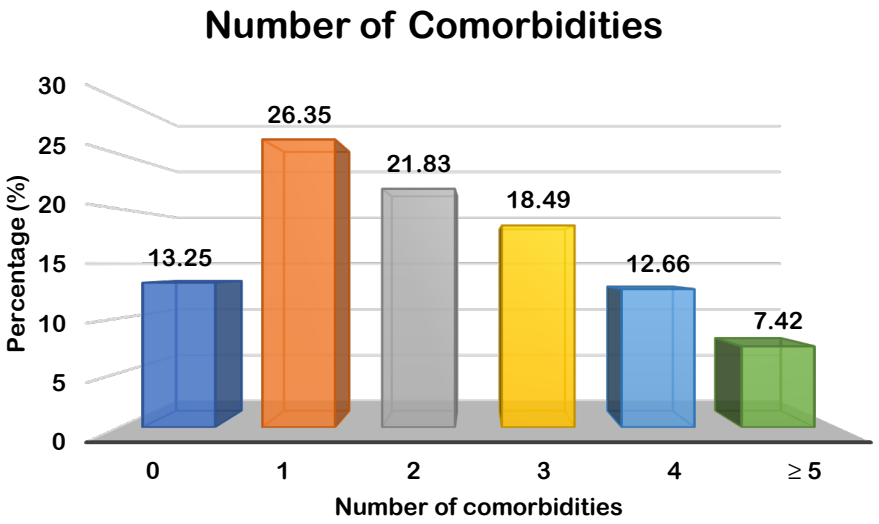


Figure 19: Total number of medical comorbidities of patients with psoriatic arthritis (n = 687)

CHAPTER 5: DISEASE ACTIVITY STATUS

5.1 Disease Activity Score

The cohort of patients was assessed using different disease activity assessment tools, DAS-28 CRP, DAS-28 ESR and DAPSA, with some being scored using more than one tools. The disease activity score according to different assessment tools used are shown in Table 1.

The proportion of patients in different disease states for those who had undergone all three assessments was shown in Figure 20. The percentage of patients in remission was clearly different between the composite scores used, with DAPSA being the most stringent (27.98%), followed by DAS-28 ESR (32.64%) and DAS-28 CRP (51.3%). The DAS-28 includes 28-SJC and 28-TJC in addition to patient global assessment and ESR or CRP values. While the DAS-28 assessments are well-accepted and validated in Rheumatoid arthritis, in PsA, a more complete joint evaluation is needed. DAPSA includes 68-SJC and 68-TJC, CRP, patient global assessment and patient pain assessment and it is a validated tool for the assessment of PsA (Schoels et al., 2016). As such, all subsequent data in this report would be based on DAPSA assessment. The mean DAPSA score of the patient population was 12.09 ± 11.56 (Figure 20). Over one-third (29.53%) of the patient were in 'high disease activity' or 'very high disease activity' state.

Table 2: Disease activity score reported according to different assessment tools

Disease activity	Percentage (%)		
	DAS-28 ESR score*	DAS-28 CRP score*	DAPSA score**
Total, n	**264**	**226**	**259**
Remission	29.92	54.42	32.05
Low disease activity	27.65	17.26	40.54
Moderate disease activity	34.47	25.22	19.31
High disease activity	7.95	3.10	8.11

*Disease Activity Score (DAS-28) is a composite calculation of four parameters which includes tender joint count (TJC) and swollen joint count (SJC) (based on 28 joints assessment), ESR (or CRP) and patient global assessment (PGA) using a visual analogue scale (VAS) 0-100mm). Definition of disease activity: Remission: ≤ 2.6; Low disease activity: > 2.6 to ≤ 3.2; Moderate disease activity: > 3.2 to ≤ 5.1; High disease activity: > 5.1.

**Disease Activity Index for Psoriatic Arthritis (DAPSA) is a composite measure based on a summation of 5 variables: TJC (68 joints), SJC (68 joints), Patient pain assessment (10 cm on a VAS), PGA (10 cm on a VAS) and CRP. Definition of disease activity: Remission: 0 – 4; Low disease activity: 5 – 14; Moderate disease activity: 15 – 28; High disease activity > 28.

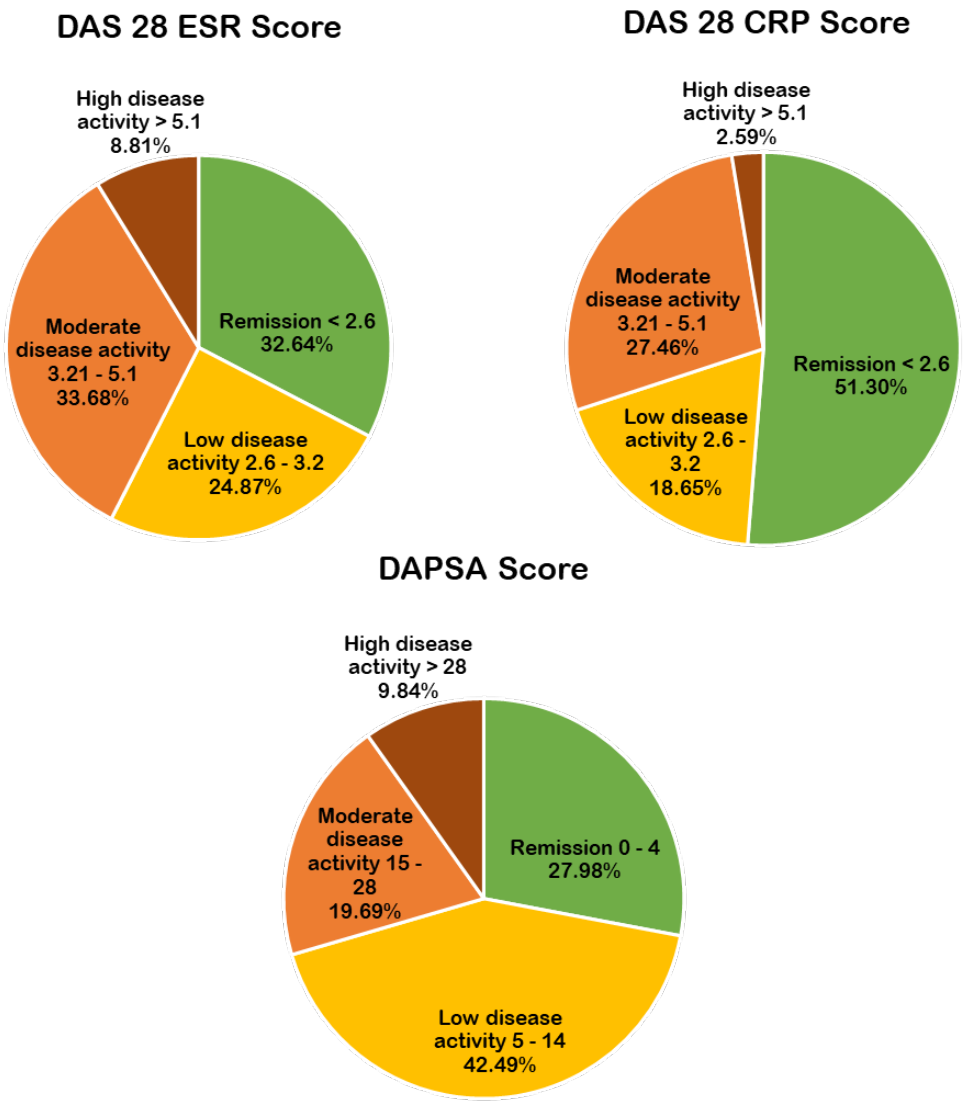


Figure 20: Disease activity scores of patients with psoriatic arthritis (n = 193). This includes only those had all three assessments in the disease activity score. Components assessed by different tools in the calculation of disease activity: DAS-28* - Tender joint count (28), swollen joint count (28), ESR/CRP, Patient Global VAS; DAPSA** – Tender joint count (68), swollen joint count (668), CRP, Pain VAS, Patient Global VAS.

*Disease Activity Score (DAS-28) is a composite calculation of four parameters which includes tender joint count (TJC) and swollen joint count (SJC) (based on 28 joints assessment), ESR (or CRP) and patient global assessment (PGA) using a visual analogue scale (VAS) 0-100mm). Definition of disease activity: Remission: ≤ 2.6; Low disease activity: > 2.6 to ≤ 3.2; Moderate disease activity: > 3.2 to ≤ 5.1; High disease activity: > 5.1.

**Disease Activity Index for Psoriatic Arthritis (DAPSA) is a composite measure based on a summation of 5 variables: TJC (68 joints), SJC (68 joints), Patient pain assessment (10 cm on a VAS), PGA (10 cm on a VAS) and CRP. Definition of disease activity: Remission: 0 – 4; Low disease activity: 5 – 14; Moderate disease activity: 15 – 28; High disease activity > 28.

5.2 MASES Enthesitis Score and Disease Activity Score

Approximately 7% of the patients presented with enthesitis at notification. The mean MASES enthesitis score of the patient population was 0.15 ± 0.65 (Figure 21). Of these, more than half of patients present with 2 or more enthesitis score. This population of patients appear to have higher disease activity with a mean DAPSA score of 18.49 ± 9.75. More than half of patients (55.55%) had either moderate or high disease activity (Figure 22).

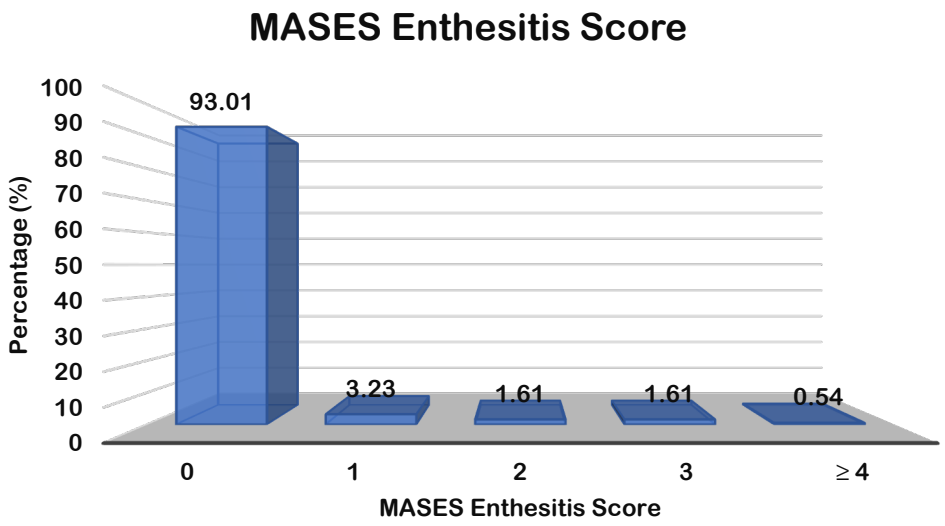


Figure 21: MASES Enthesitis score* of patients with psoriatic arthritis (n = 186).

*MASES Enthesitis score is an enthesitis index is a grading of tenderness (0/1) at 13 sites (bilateral 1st and 7th costochondral joints, anterior and posterior superior iliac spines, the iliac crests, 5th lumbar spinous process and proximal insertion of Achilles tendon

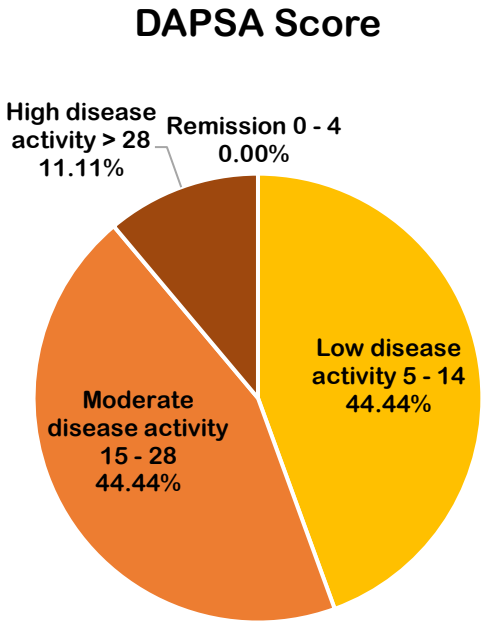


Figure 22: Disease activity for psoriatic arthritis patients with enthesitis (n = 9)

5.3 Presence of Dactylitis and Disease Activity Score

Approximately 15.35% of patients presented with dactylitis with an average of 2.73 ± 3.75 digits involved (Figure 23). This subgroup of patients appeared to have higher disease activity with a mean DAPSA score of 15.56 ± 11.55. Almost half of them (44.83%) had either moderate or high disease activity (Figure 24).

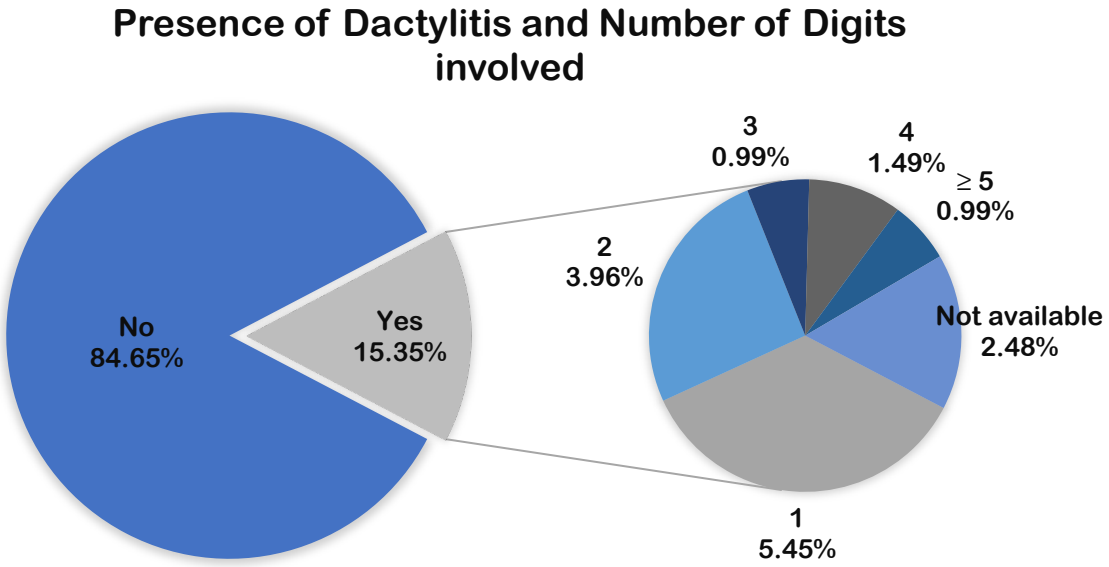


Figure 23: Presence of dactylitis in patients with psoriatic arthritis (n = 204).

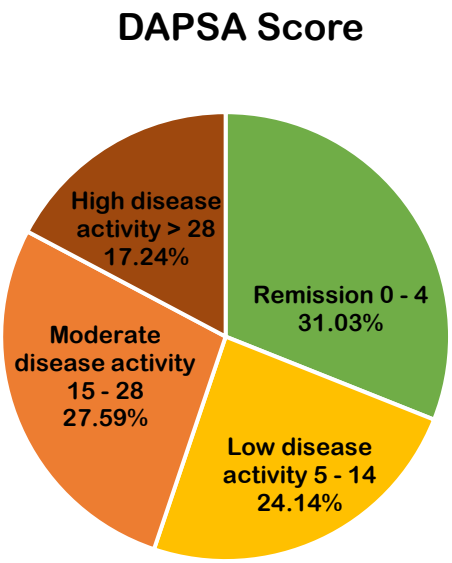
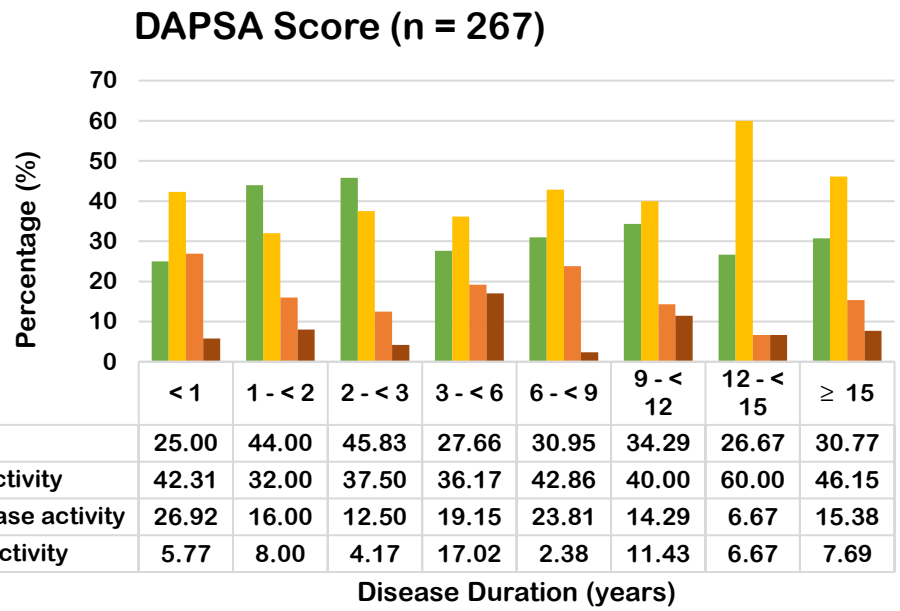


Figure 24: Disease activity for psoriatic arthritis patients with dactylitis (n = 29)

5.4 Relationship of Disease Activity Score and Disease Duration at Notification

The relationship of disease activity scores based on different assessment tools and disease duration at notification is depicted in Figure 25. Patients included in the registry were notified at various stages of their disease and some of the patients were being treated by various disciplines before being referred to Rheumatology for expert management. As such, there was no clear disease trend observed.



	< 1	1 - < 2	2 - < 3	3 - < 6	6 - < 9	9 - < 12	12 - < 15	≥ 15
Remission	25.00	44.00	45.83	27.66	30.95	34.29	26.67	30.77
Low disease activity	42.31	32.00	37.50	36.17	42.86	40.00	60.00	46.15
Moderate disease activity	26.92	16.00	12.50	19.15	23.81	14.29	6.67	15.38
High disease activity	5.77	8.00	4.17	17.02	2.38	11.43	6.67	7.69

Figure 25: Relationship of DAPSA scores and disease duration at notification

CHAPTER 6: TREATMENT

6.1 Time to Initiate DMARDs After Diagnosis

Mean time to disease-modifying antirheumatic drugs (DMARDs) initiation after disease diagnosis was 5.66 ± 30.91 months. Over two-thirds (68.64%) would be started on DMARDs treatment in less than a month. Meanwhile, DMARDs treatment was started in 14.64% of patients for other clinical conditions prior to PsA diagnosis (Figure 26).

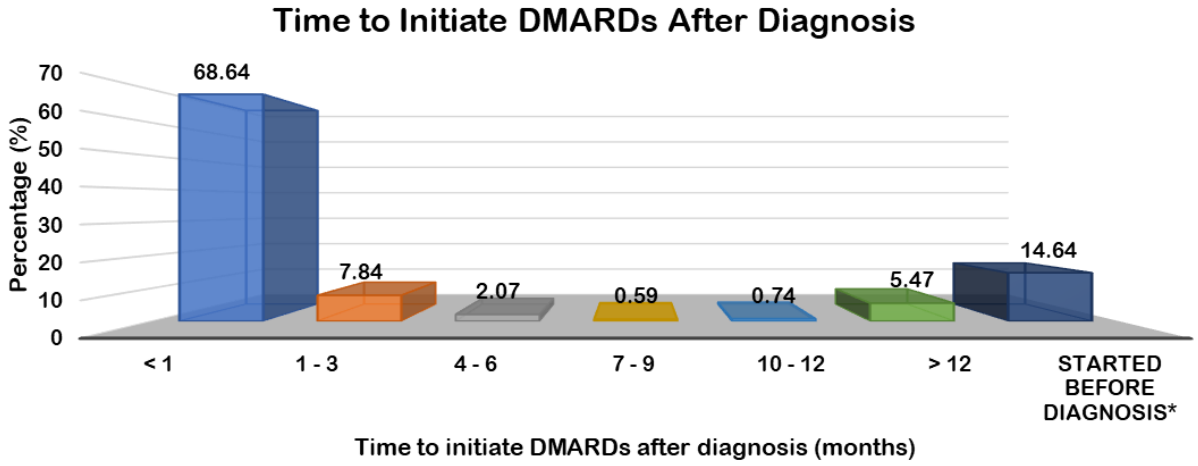


Figure 26: Time to initiate DMARDs after diagnosis among patients with psoriatic arthritis (n = 689). *DMARDs were started before diagnosis for other indications.

6.2 Type of Therapy

The most prescribed DMARDs were methotrexate (92.18%), suphasalazine (42.54%) and leflunomide (25.18%). Meanwhile, the commonly used biologics were secukinumab (8.31%), adalimumab (5.13%) and infliximab (2.20%). Low doses of prednisolone (<7.5mg) were prescribed more frequently compared with high doses of prednisolone (>7.5mg) among PsA patients (Figure 27).

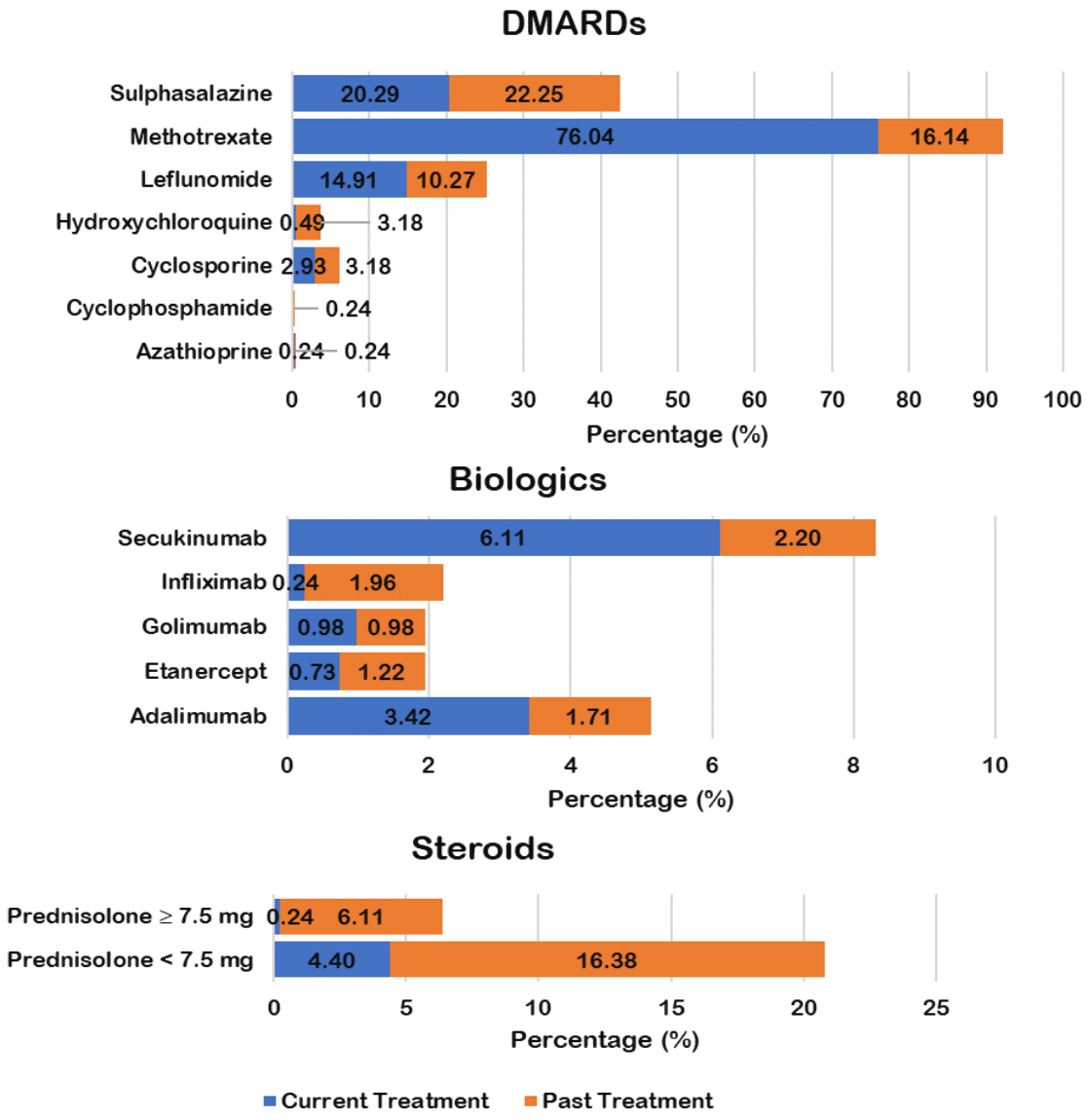
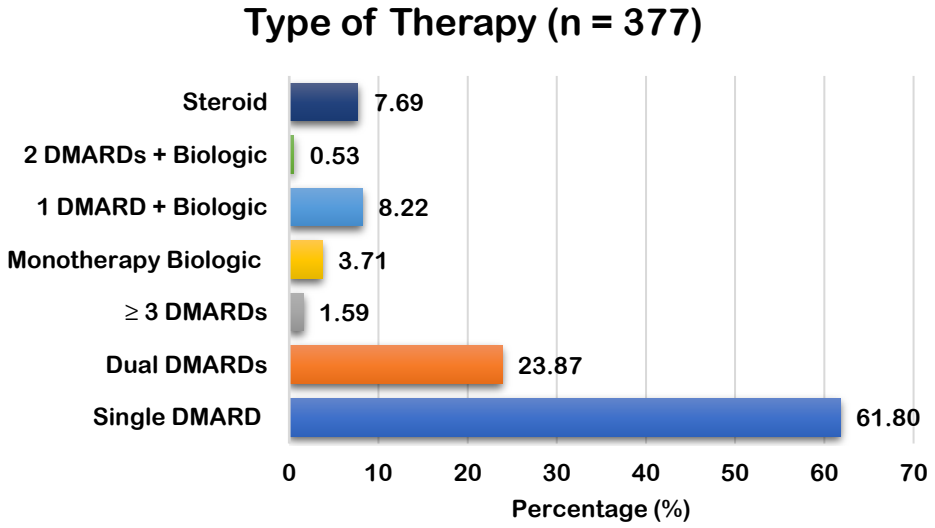
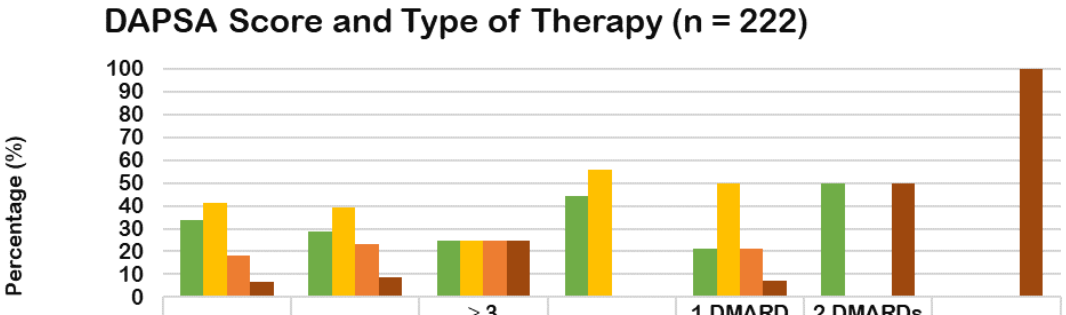


Figure 27: Type of therapy for patients with psoriatic arthritis (n = 409)

6.3 Relationship between Types of Current Therapies and Disease Activity

Most of the patients were on either one (61.80%) or two DMARDs (23.87%) while 1.59% had used at least 3 DMARDs. Biologic accounted for 12.46% of the total prescribed therapies either as monotherapy (3.71%) or in combination with DMARDs (8.75%). A higher percentage of patients in the biologic-prescribed groups appeared to attain a state of low disease activity or remission than those on DMARDs or steroid (Figure 28).





	1 DMARD	2 DMARDs	≥ 3 DMARDs	1 Biologic	1 DMARD + Biologic	2 DMARDs + Biologic	Steroid
Remission	33.82	28.57	25.00	44.44	21.43	50.00	0.00
Low disease activity	41.18	39.29	25.00	55.56	50.00	0.00	0.00
Moderate disease activity	18.38	23.21	25.00	0.00	21.43	0.00	0.00
High disease activity	6.62	8.93	25.00	0.00	7.14	50.00	100.00

Figure 28: Relationship type of current therapy and disease activity

6.4 Treatment History Prior to Biologic Usage

The average number of DMARDs used prior to first biologic therapy was 2.19 ± 1.08. Approximately a third (31.15%) of patients had used one DMARD before biologic therapy while more than half of them would have been prescribed with ≥ 2 DMARD (Figure 29(a)). The most common treatment prior to biologic usage was methotrexate monotherapy (44.44%), to be followed by two combination therapies i.e. methotrexate + leflunomide (14.29%), methotrexate + sulphasalazine (12.70%) as shown in Figure 29(b) and three combination therapies of methotrexate + sulphasalazine + leflunomide (6.35%).

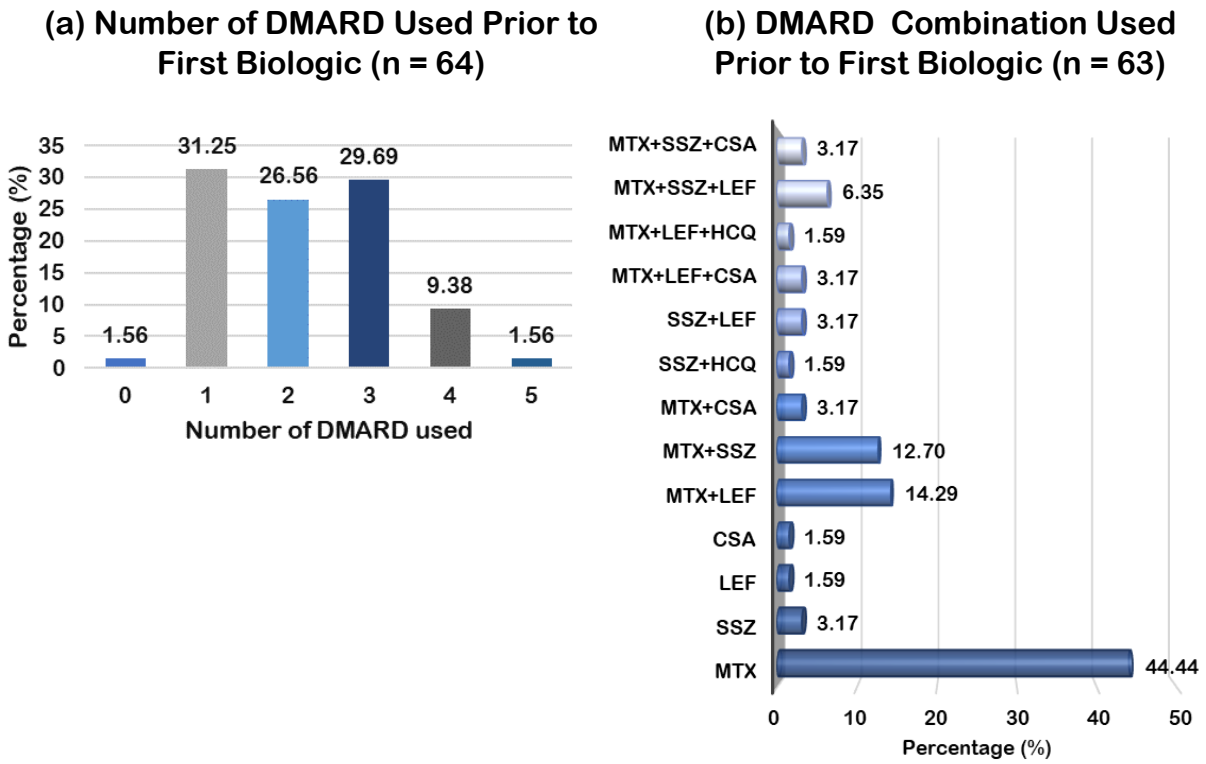
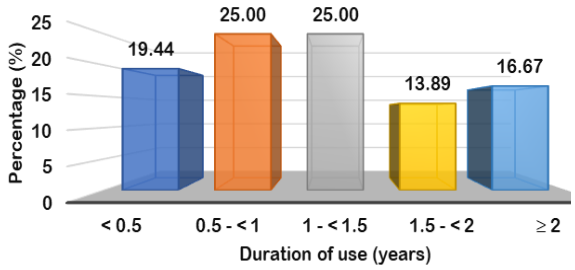


Figure 29: The number of DMARD(s) used (a) and the DMARD combination used prior to the first biologic treatment (b). MTX: methotrexate; SSZ: Sulphasalazine; LEF: leflunomide; CSA: cyclosporine; HCQ: hydroxychloroquine.

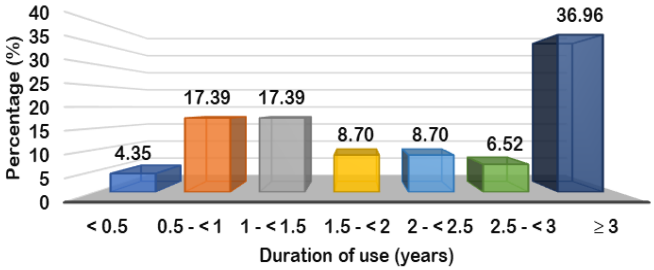
6.5 Biologic Usage Pattern

The mean duration of biologic usage among the patient population was 2.30 ± 2.28 years whereas the mean duration of biologic use for those who had stopped biologic therapy was 1.67 ± 2.14 years. For those who were still on biologic therapy at present, the average duration of use was 2.79 ± 2.28 years (Figure 30).

(a) Duration of Biologic Use among Those who had Stopped Biologic Treatment (n = 36)



(b) Duration of Biologic Use among Those who are Currently on Biologic Treatment (n = 46)



(c) Overall Duration of Biologic Use (n = 82)

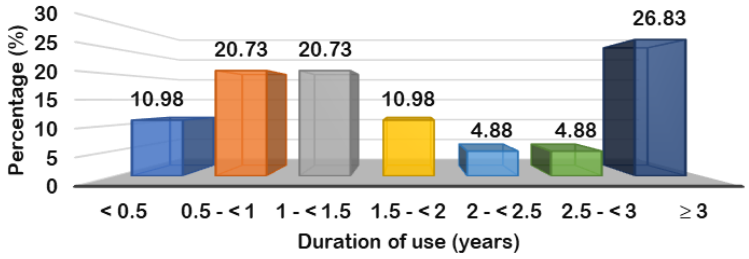


Figure 30: The duration of biologic use (a) among those who had stopped biologic treatment; (b) those who are currently on biologic treatment and (c) overall duration.

6.6 Reasons for Treatment Discontinuation

The most common reasons for DMARDs discontinuation were side effects (33.84%) followed by lack of effectiveness (25.10%) (Figure 31). Among those patients who discontinued DMARDs treatment due to side effects, majority (53.93%) of them were on methotrexate, followed by sulphasalzine (22.47%) and leflunomide (15.73%) (Figure 31).

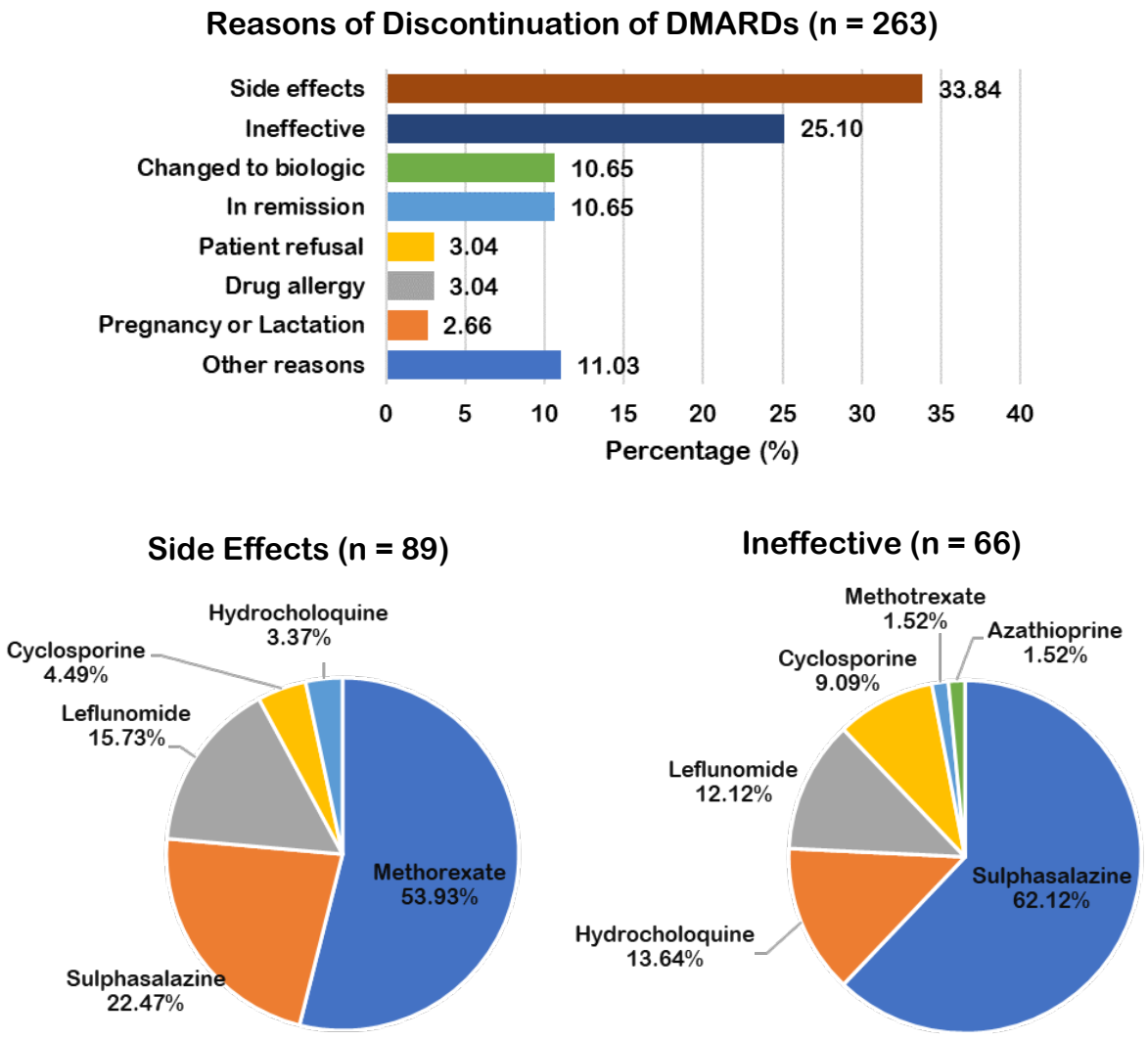


Figure 31: Reasons for discontinuation of DMARDs among patients with psoriatic arthritis

The key reasons for biologics discontinuation were lack of funding (29.73%) and ineffectiveness (29.73%). Only 2.70% of patients discontinued biologics due to side effects (Figure 32). Among those patients who discontinued biologic treatment due to ineffectiveness, approximately one-third of patients (36.36%) had used or failed biologic treatment before.

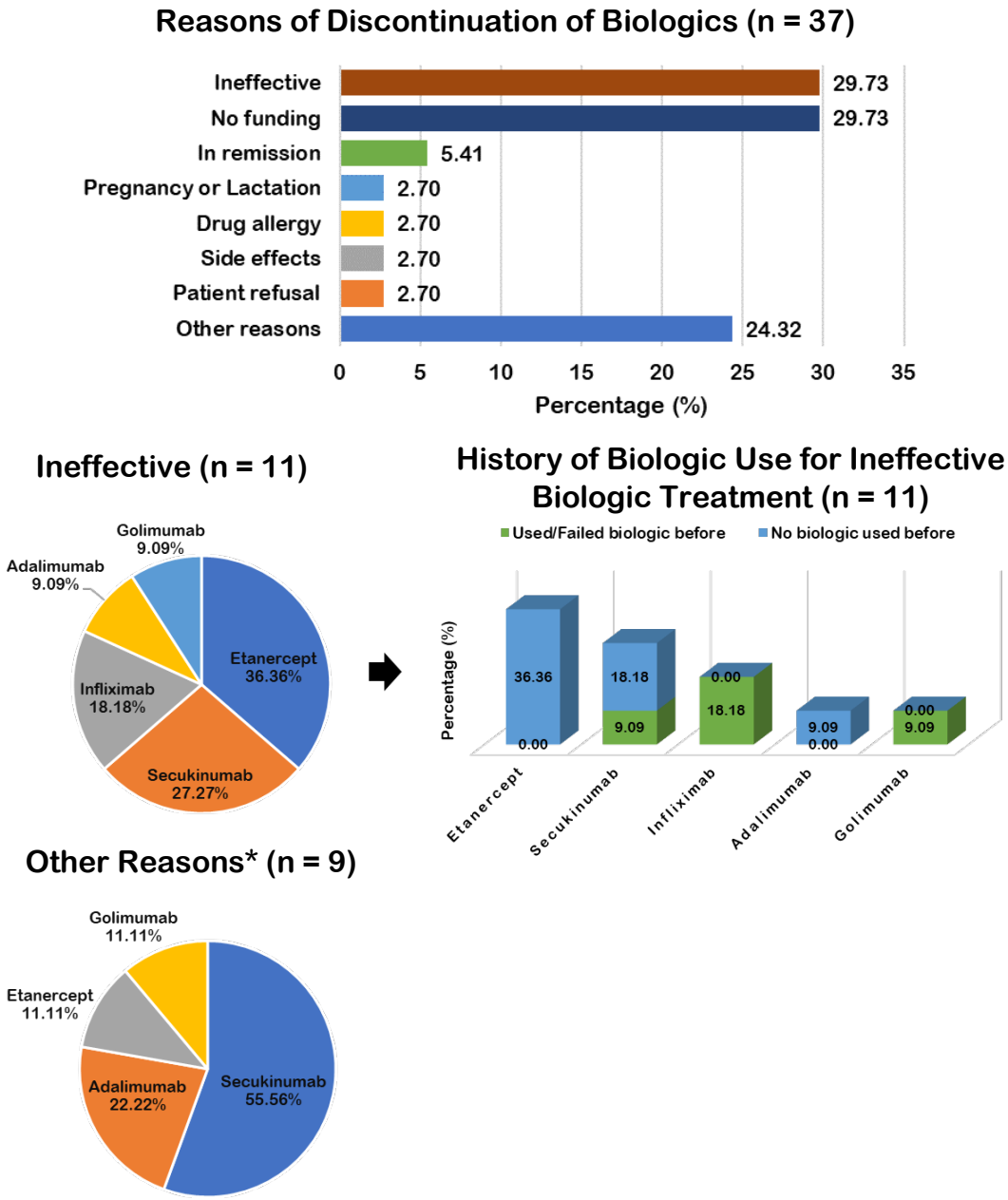


Figure 32: Reasons for discontinuation of biologics among patients with psoriatic arthritis

*Other reasons might include patients completed industry-sponsored RCTs, industry assisted patient access program or self-pay patients that decided to stop treatment.

6.7 Indication for Biologic Therapy

Among patients in whom biologic therapies were indicated (18.21%), only slightly over half of them were started with biologics. The most common reasons for the delay in biologic therapies was due to pending funding approval (41.18%) or the absence of fund (11.76%). Meanwhile, some patients would choose not to start treatment due to personal preference (17.65%) as shown in Figure 33.

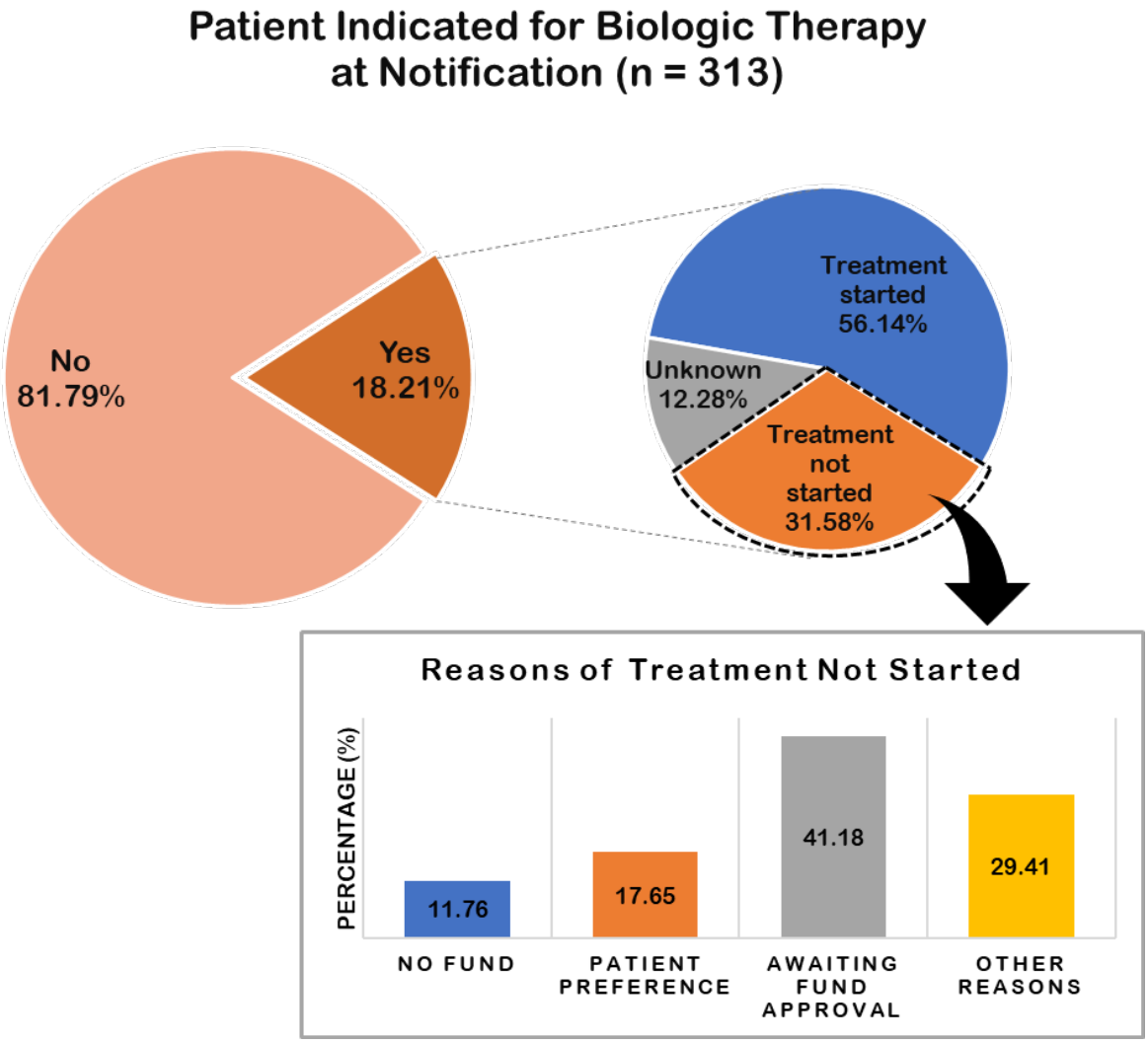


Figure 33: Indication for biologic therapy and reasons for treatment not initiated among patients with psoriatic arthritis (n = 313)

6.8 The Use of NSAIDs and Incidence of Adverse Reactions among Patients

The most common non-steroidal anti-inflammatory drug (NSAID) used among patients with PsA was cyclooxygenase 2 (COX-2) inhibitor (44.69%). First generation NSAIDs were prescribed to 31.15% of this patient cohort (Figure 34). Approximately 1 in 10 patients experienced adverse events from the use of NSAIDs (Figure 35).

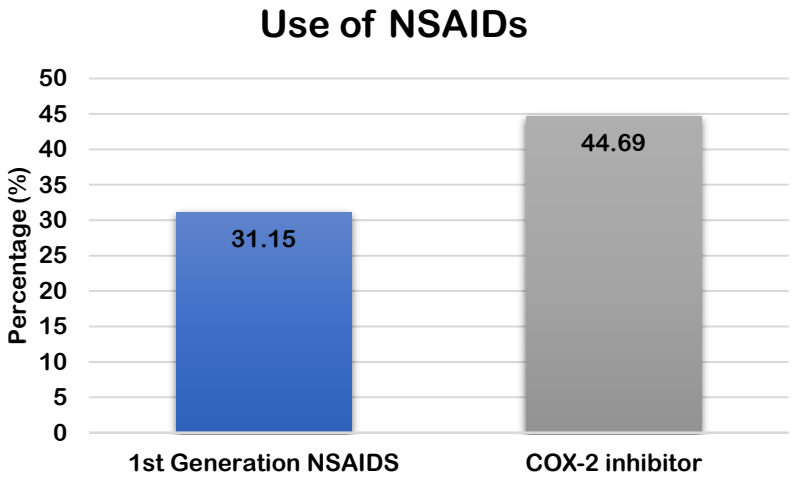


Figure 34: The use of NSAIDs among patients with psoriatic arthritis (n = 687)

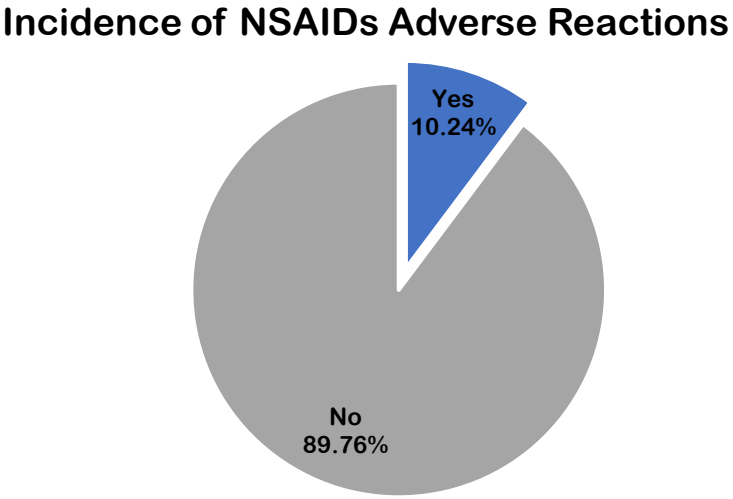


Figure 35: The incidence of NSAIDs adverse reactions among patients with the use of NSAIDs (n = 293)

6.9 Traditional and Complementary Medicines

A vast majority (88.94%) of the patients were not using any traditional and complementary medicines. Of those who were taking unorthodox treatment concurrently, most were using unprescribed supplements (33.33%), followed by Chinese Traditional Medicine (24.44%), Malay Traditional Medicine (20%) as well as Acupuncture (17.78%) and Ayurvedic (13.33%) as shown in Figure 36.

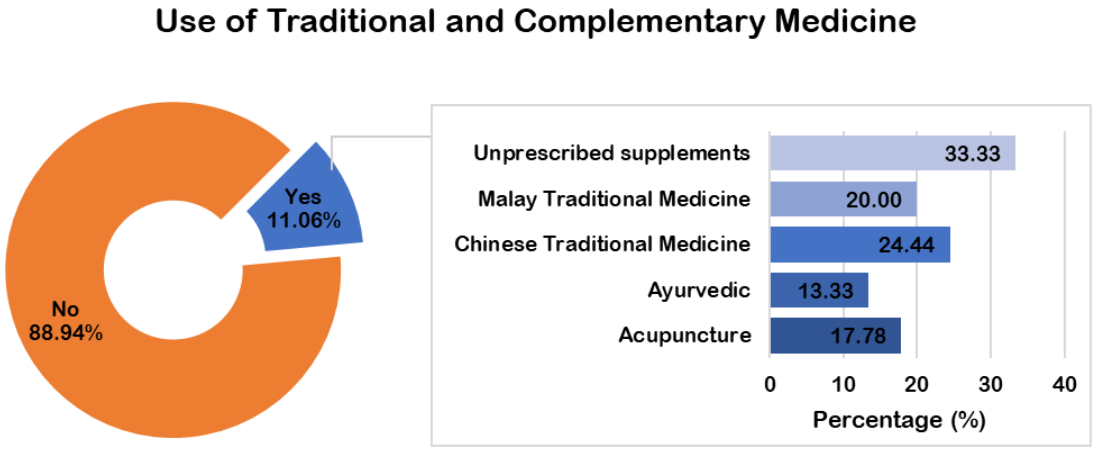


Figure 36: The use of traditional and complementary medicines among patients with psoriatic arthritis (n = 407)

6.10 Surgeries

A small number of patients required surgeries, namely arthroplasty (1.46%), spinal surgery (0.58%), synovectomy (0.44%) and arthrodesis (0.29%) as shown in Figure 37.

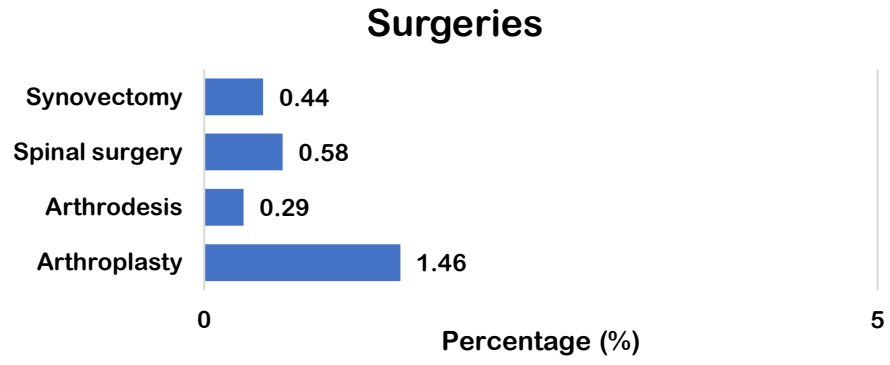


Figure 37: Surgeries performed on patients with psoriatic arthritis (n = 687)

CHAPTER 7: Quality of Life

7.1 Work Productivity and Activity Impairment Questionnaire (WPAI)

Among patients with reported employment status (n = 246), approximately half of them were working. The mean percentage of worktime missed, overall impairment and overall work impairment were 44.74 ± 36.69%, 31.69 ± 27.21% and 39.01 ± 29.37 %, respectively. The mean percentage of activity impairment was 31.30 ± 26.92% (Figure 38).

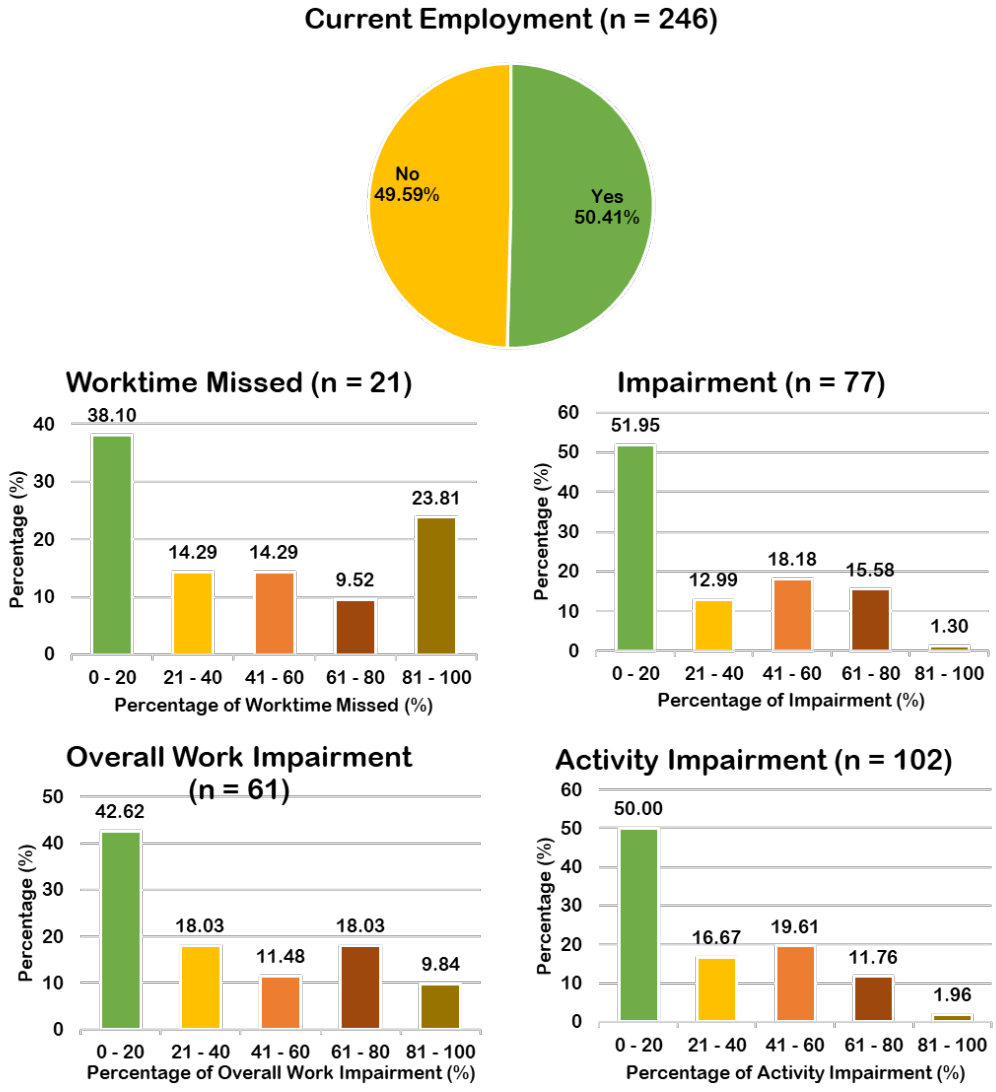


Figure 38: Work productivity and activity Impairment* (WPAI) among patients with psoriatic arthritis.

*Work Productivity and Activity Impairment (WPAI) questionnaire measures impairments in pain work and unpaid work, absenteeism, presenteeism, as well as impairments in unpaid activity because of health problems during the past 7 days.

7.2 Health Assessment Questionnaire Disability Index (HAQ-DI)

The patient cohort had a mean HAQ-DI score, HAQ-DI pain score and HAQ-DI health score of 1.24 ± 0.56, 32.04 ± 23.60 and 33.34 ± 24.60, respectively (Figure 39).

HAQ-DI scores of 0 to 1 generally represent mild to moderate difficulty, 1 to 2 represent moderate to severe disability, and 2 to 3 indicate severe to very severe disability. The estimated population mean HAQ DI was 0.25 (95% confidence interval 0.22-0.28) in general population (Krishnan et al., 2004).

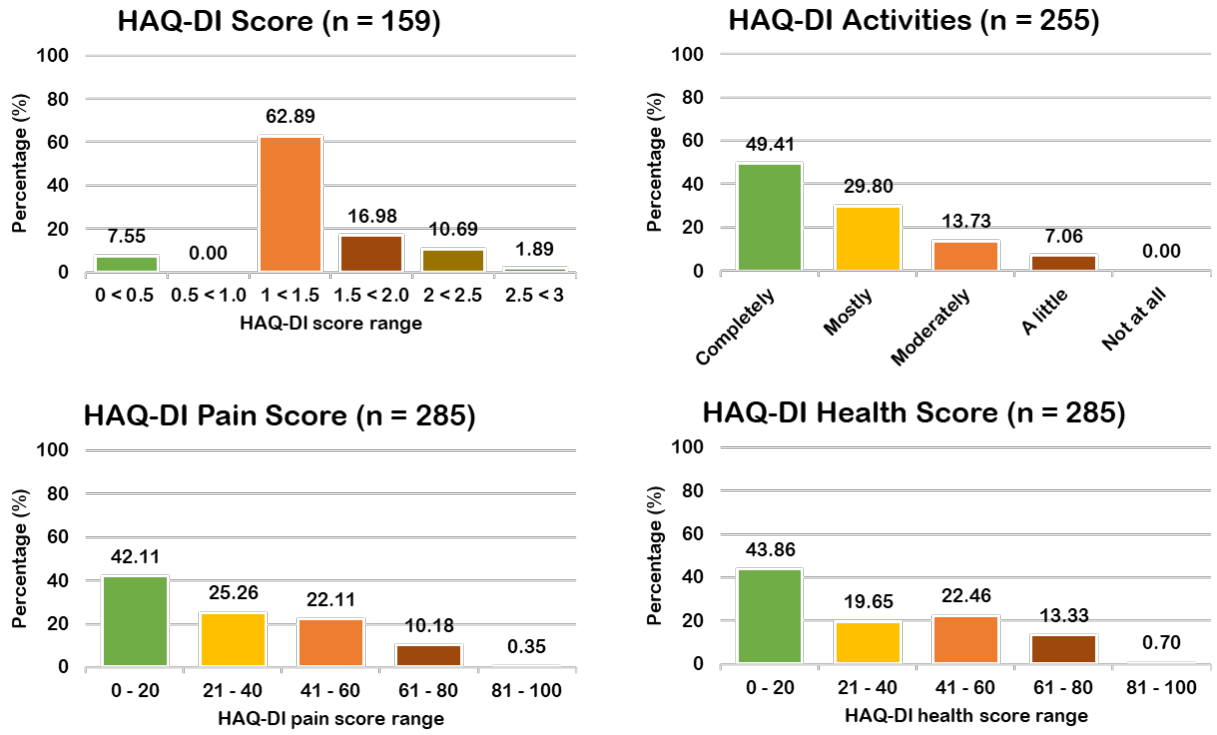


Figure 39: Health Assessment Questionnaire Disability Index* (HAQ-DI) among patients with psoriatic arthritis.

*HAQ is a patient-filled questionnaire to assess functional status in adults with arthritis, specifically 20 specific functions to evaluate patient difficulty with activities of daily living over the past week; it covers eight categories including dressing and grooming, arising, eating, walking, hygiene, reaching, gripping and, errands and chores, as well as the use of specific aids or devices and the need for assistance from another person.

7.3 American College of Rheumatology (ACR) Functional Status

Among patients with recorded data pertaining to American College of Rheumatology (ACR) functional status, 73.33% reported having normal functional status. For those with reported limitations in physical activities, 19.05% faced limitations in social activities, 6.35% had limitations in avocation/vocational activities whilst a minority of them (1.27%) were either wheel-chair bound or bedridden (Figure 40).

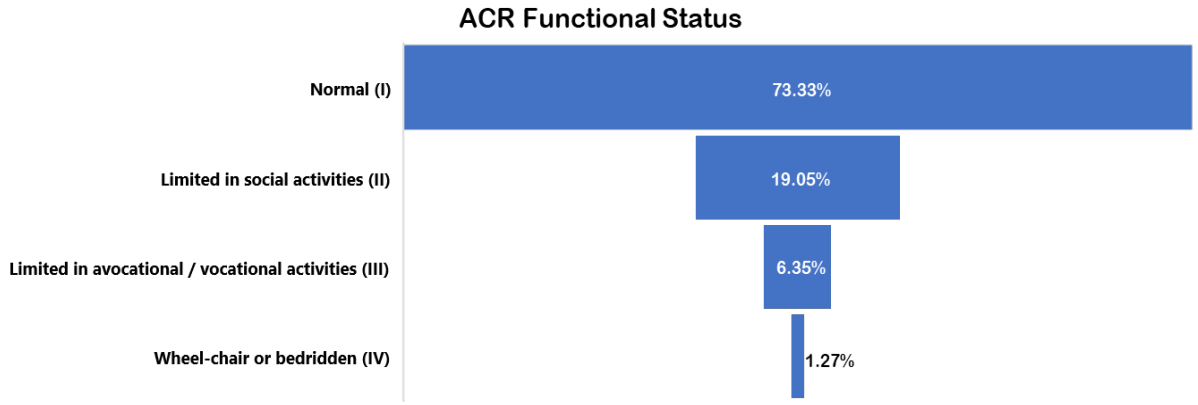


Figure 40: ACR functional status of patients with psoriatic arthritis (n = 315*). *There were 54.15% missing values of ACR functional status.

7.4 Assessment of Spondyloarthritis: ASAS Health Index (ASAS-HI)

The mean ASAS-HI score for patients with axial joint involvement was found to be 6.28 ± 5.21. Overall, slightly less than half (47.22%) of the patients had ASAS-HI score of ≤ 5 with approximately a quarter of patients having either moderate or poor scores (Figure 41).

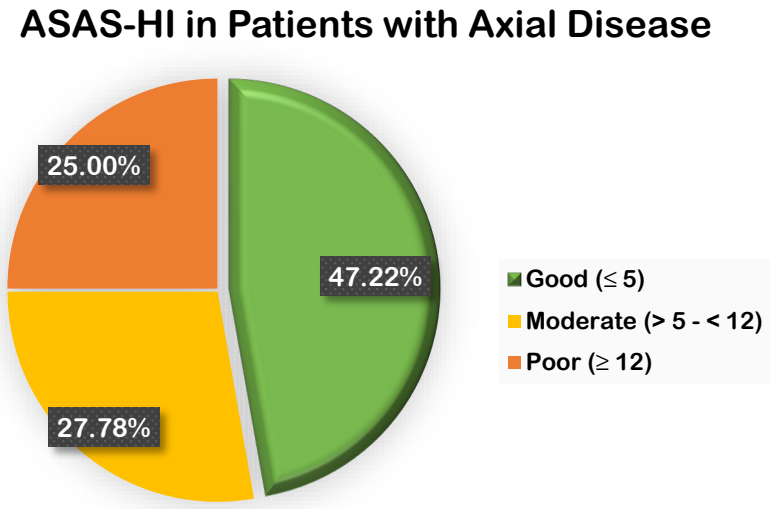


Figure 41: Assessment of Spondyloarthritis Health Index (ASAS-HI)* among patients with axial joint involvement (n = 36).

*ASAS-HI is a self-reported questionnaire to measure functioning and health across 17 aspects of health and 9 environmental factors in patients with spondyloarthritis.

DISCUSSION

The MyNIAR Psoriatic Arthritis (PsA) registry is a relatively new registry under the MOH, established back in 2020. At present, a total of 14 MOH hospitals are involved in the data collection of PsA patients, representing the majority of hospitals with Rheumatology service in Malaysia. A total of 687 PsA patients are included in this registry report. This is likely to be grossly under-reported due to factors such as non-mandatory notification and limited resources at the hospital level. This is further compounded by the fact that the registry was launched during the COVID-19 pandemic. Therefore, the prevalence and incidence of PsA at the national level cannot be estimated. Nevertheless, there was an increasing number of cases being notified to the registry from 2020 to 2021.

Malaysia is a multi-ethnic country with three major ethnic groups i.e. Malay, Chinese and Indians. The Indian population appeared over-represented in this registry with a total percentage of 26.5%, which is in stark contrast with the 6.7% as reported in MYCENSUS 2020 (Department of Statistics Malaysia, 2022). Some plausible explanations for this ethnic preponderance include a higher number of Indian patients utilising public healthcare services or the genetic predisposition among this ethnic group leading to the development of PsA. The latter warrants further investigations.

More than half of the patient cohort had secondary education level and below. Half of them were unemployed whilst 45.6% of them fell under the National Poverty Line Income (PLI) category (i.e., less than RM 2208.00/month) according to the revised PLI in July 2019 (The Star, 2020). More than half (58.37%) of the patient population were not medically insured. This poses a financial challenge when advanced therapies are required for severe disease conditions. Despite the good accessibility to the public healthcare system, the availability of costly advanced therapies like biologics remains limited due to funding issues.

The mean age of symptoms onset reported in this cohort of patients was 41 years whereas the mean age of diagnosis was 43. This age group is usually the prime age for work productivity, thus measurement of this outcome is very important. It has been shown that work disability among PsA patients is high, with reported rates ranging from 16 to 39% (Tillett et al., 2012). In this cohort, among patients who were employed, a significant number of them experienced work impairment (39%) or missed work time (44.7%) and this could pose a significant socioeconomic burden to the country if left unaddressed. In addition, approximately one-quarter of the patients also reported at least a certain degree of limitation in their social activities. Early diagnosis and treatment are therefore crucial given the socioeconomic and psychosocial impacts caused by the disease.

Primary care doctors and dermatologists play an important role in recognising and referring PsA patients early. In our cohort of patients, it took an average of 2.3 years from symptoms onset to a psoriatic arthritis diagnosis while it took nearly 4 years for patients to be seen in a rheumatology clinic. Early diagnosis and treatment can make a difference to the prognosis of the disease, either delaying or preventing disease progression which otherwise will lead to irreversible joint damage. Hence, early referral of PsA patients to rheumatology clinics is of utmost importance. Approximately 8 out of 10 patients had psoriatic skin manifestation which, in most cases preceded the joint disease. This warrants a closer collaboration and multidisciplinary management between dermatologists and rheumatologists. Proactive screening of psoriasis patients for signs of joint involvement coupled with early co-management by both specialties may lead to a better disease outcome. Disease awareness among patients should also be reinforced so that they would seek treatment early in addition to being compliant to prescribed treatments.

Comorbidities are common among PsA patients (Gupta et al., 2021; Pantano & Ruscitti, 2022). This was also observed among our cohort of patients, who on average had 2.2 comorbidities, with over half of them having at least two comorbidities. Cardiometabolic comorbidities were common with a cohort prevalence of 46.7% for hypertension, 40.9% for dyslipidaemia and 27.66% for diabetes mellitus, being about three times higher than the national prevalence of 15.9%, 13.5% and 9.4%, respectively for the adult population as reported by the 2019 National Health and Morbidity Survey (NHMS, 2019). In addition to that, nearly two-thirds of these patients appeared obese while 1 in 10 were having non-alcoholic fatty liver disease. Of note, the comorbidities burden of our cohort appeared to be higher compared with the reported pooled prevalence of hypertension (34%), hyperlipidaemia (24%), diabetes mellitus (12.9%) and liver disease (3.4%) in over 150,000 PsA patients (Gupta et al., 2021). This is an interesting observation which warrants further research in ascertaining the correlation between cardiometabolic comorbidities with PsA outcomes. Nevertheless, regular screening and early treatment of PsA patients for high blood pressure, high cholesterol, obesity and diabetes are advisable. Moreover, the European League Against Rheumatism (EULAR) task force recommended that PsA disease activity should be controlled optimally with the aim to lower CVD risks (Agca et al., 2017).

The prevalence of cancer among our cohort of patients was 2.2%. This was significantly higher than the national cancer prevalence (5-year) of 0.40% (Globocan, 2020). As such, regular cancer screening should be encouraged among PsA patients.

Psoriatic arthritis (PsA) is a chronic inflammatory disease with heterogeneous manifestations encompassing peripheral arthritis, enthesitis, dactylitis, psoriasis, nail disease and axial disease (FitzGerald, et al., 2021). The commonest presentations as per CASPAR criteria in our cohort of patients were psoriasis (92.7%), followed by nail lesions (69.7%) and dactylitis (41.2%). Over three quarters had only peripheral joint involvement (peripheral synovitis, enthesitis and dactylitis) while 16.2% had both axial and peripheral joint involvements, 2.3% had only axial involvement. Among those who presented with peripheral joint manifestations, close to 40% presented with concurrent synovitis, enthesitis and/or dactylitis. This highlights the heterogeneity of PsA domain manifestations in our cohort. It was reported that PsA patients with multidomain disease presentation were associated with worse disease activity, quality of life, and work productivity measures (Ogdie et al., 2021). Therefore, it is important to assess and treat all PsA domains for optimal patient outcomes as recommended by the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) treatment recommendations (Coates et al., 2021).

This cohort of patients was assessed using different disease activity assessment tools, DAS-28 CRP, DAS-28 ESR and DAPSA. This is due to the fact that disease assessment is not standardised and CRP is not widely available in all centres. There is variation in the proportion of patients in different disease states based on the assessment tools used. In the analysis of patients scored by all three tools, DAPSA, a validated tool in PsA disease assessment may reflect a more reliable remission in view of more joints being assessed compared to DAS-28 assessment. For patients with moderate-to-high disease activities, DAPSA and DAS-28 CRP showed similar results with 29.5% and 30.1%, respectively. However, DAS-28 ESR showed a higher percentage of moderate-to-high disease activities, 42.5%. It is also noteworthy that both DAS-28 and DAPSA do not assess other psoriatic disease domains and thus might underestimate disease activity from other manifestations, such as skin, dactylitis, enthesis, nail and axial components. The MDA criteria, which assess multiple domains of the disease, is also a validated tool in PsA disease activity assessment that is recommended by both the treat-to-target international task force and the GRAPPA/OMERACT group (Coates et al., 2018; Smolen et al., 2018).

Treatment should be commenced as soon as the diagnosis is established to avert a poor disease prognosis (Haroon et al., 2015). Current PsA treatment guidelines also put forward the importance of the treat-to-target approach in the management of PsA (Gossec et al., 2020). While the average time to DMARDs initiation post-diagnosis was about 5.7 months, approximately two-thirds of patients were started with DMARDs in less than a month. The most prescribed DMARD was methotrexate, followed by sulphasalazine and leflunomide.

The most common reason for DMARDs discontinuation is treatment side effects (33.8%) and methotrexate accounts for over half of the cases. Lack of efficacy led to the discontinuation of DMARDs in about a quarter of the patients, and sulphasalazine accounts for over half of the cases. Most of the patients were on monotherapy (61.8%) or two DMARDs (23.8%). A small percentage of patients (1.6%) were on at least 3 DMARDs despite recommendations by treatment guidelines to escalate treatment to biologic after one or two DMARDs failures. These were difficult to treat cases that would have necessitated biologic therapy but were not initiated, either because of difficulties in access to biologics or were awaiting biologic fund approvals, hence the third DMARD was given in the absence of other treatment modalities.

About 18% of the patients in this cohort required biologics, but only slightly over half of the patients were started with the advanced treatment. Since registry notification was highly encouraged especially among patients who were put on biologics, the overall biologic usage noted in this current report is very likely to be over-represented. Biologic usage varied among MOH hospitals depending on the availability of funding in view of the high cost of this advanced therapy. The most common reasons for the delay in biologic therapies was due to the waiting time for funding approval (41.2%) or absence of fund (11.8%). Based on EULAR task force recommendation, PsA patients who have an inadequate response to at least one DMARD are indicated for biologics (Gossec et al., 2020). Patients may be rotated to a second DMARD if they are with mild disease activity or without worse prognostic factors. However, in the current patient cohort, only one-third of the patient moved on to a biologic after a single DMARD, about a quarter after two DMARDs and over 40% of patients used three or more DMARDs prior to the first biologic therapy. Of note, there was considerable usage of cyclosporin and hydroxychloroquine although there is a lack of evidence pertaining to their efficacies in treating PsA.

Biologics were prescribed to this cohort of patients, either as monotherapy (3.7%) or in combination with DMARDs (8.8%). A higher percentage of patients in the biologic-prescribed groups appeared to achieve the state of low disease activity or remission compared with those on DMARDs and steroids. One of the key reasons for biologics discontinuation was the lack of funding (29.7%). As such, it is imperative for new sources of funding to be identified to ensure continuous treatment for patients who need biologic therapies.

CONCLUSION

As a relatively young registry, the MyNIAR PsA registry provides valuable insights on the burden of PsA and its current management in MOH hospitals. Although the actual prevalence and incidence of the disease could not be estimated, the data from this registry allows a greater understanding of the disease patterns among PsA patients who were treated in public hospitals. The registry highlights several key findings, including the psychosocial and socioeconomic burdens posed by the disease as well as the need for greater adoption of the treat-to-target approach using a validated tool with the goal of achieving low disease activity or remission status in all patients. Pertinent to this is the sources of funding required to allow all eligible patients to be treated with advanced therapies in a sustainable manner to ensure a good long term prognosis. The high prevalence of numerous comorbidities i.e. cardiometabolic and cancer compared to the general population also warrants attention.

The registry could benefit from the participation of all rheumatology centres not only under MOH but all hospitals including those in the private and universities. In order to achieve this goal, greater collaboration among all relevant stakeholders is vital.

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LIST OF ABBREVIATIONS

ACR	:	American College of Rheumatology
ASAS-HI	:	Assessment of Spondyloarthritis Health Index
BMI	:	Body Mass Index
CASPAR	:	Classification Criteria for Psoriatic Arthritis
COVID-19	:	Coronavirus disease
COX-2	:	Cyclooxygenase 2
CRP	:	C-reactive protein
CVD	:	Cardiovascular disease
DAPSA	:	Disease Activity Index for Psoriatic Arthritis
DAS	:	Disease Activity Score
DMARD	:	Disease-modifying antirheumatic drug
ESR	:	Erythrocyte sedimentation rate
EULAR	:	European League Against Rheumatism
GRAPPA	:	Group for Research and Assessment of Psoriasis and Psoriatic Arthritis
HAQ-DI	:	Health Assessment Questionnaire Disability Index
MASES	:	Maastricht Ankylosing Spondylitis Entheses Score
MDA	:	Minimal disease activity
MOH	:	Ministry of Health
NSAID	:	Non-steroidal anti-inflammatory drug
OMERACT	:	Outcome Measures in Rheumatology
PGA	:	Patient global assessment
PLI	:	Poverty Line Income
PsA	:	Psoriatic Arthritis
SJC	:	Swollen joint count
TJC	:	Tender joint count
VAS	:	Visual analogue scale
WPAI	:	Work Productivity and Activity Impairment

APPENDICES

Appendix A: Information on Patient Confidentiality

Appendix B: MyNIAR Forms

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) NOTIFICATION FORM (PsA)

Date of Notification		Date 1st Visit to Rheumatologist	

SECTION 1 PATIENT DEMOGRAPHIC			
Name			
MyKad/MyKid		Old IC	
Other ID Document			
Specify Document Type (if Others)	◯ Passport ◯ Birth Certificate ◯ Police ID	◯ Armed Force ◯ Army ID ◯ Others, specify :	◯ Foreigner ID ◯ Unregistered
Address			
Contact Number	Home :	HP :	
Gender	◯ Male	◯ Female	
Date of Birth		☐ Estimated/presumed year	Age
Ethnic Group			

SECTION 2 EDUCATION, OCCUPATION			
Education Level	◯ No formal education ◯ Tertiary	◯ Primary ◯ Unknown	◯ Secondary
Work Status	◯ Not employed	◯ Unemployed/Retired : ◯ Home-maker ◯ Student	◯ Due to disease ◯ Other reasons
	◯ Currently Employed (Self Employed)	◯ Full-time	◯ Part-time
Household Income (RM)	◯ Less than RM1000 ◯ RM5001 - RM7000 ◯ No Income, on social welfare :	◯ RM1001 - RM3000 ◯ Above RM7000 ◯ Yes ◯ No	◯ RM3001 - RM5000 ◯ Unknown ◯ Unknown
Has Medical Insurance	◯ Yes	◯ No	◯ Unknown

SECTION 3 DIAGNOSIS		
Diagnosis	◯ Rheumatoid Arthritis ◯ Psoriatic Arthritis ◯ Connective Tissue Disease	◯ Ankylosing Spondylitis/Spondyloarthropathy ◯ Juvenile Idiopathic Arthritis ◯ Gout
Connective Tissue Disease		

SECTION 4 DIAGNOSIS CRITERIA (PsA)				
CASPAR Criteria	a. Current evidence of psoriasis b. Personal history of psoriasis (if current psoriasis not present) c. Family history of psoriasis (if personal history of psoriasis or current history of psoriasis is not present) d. Current nail lesions, including pits or onycholysis e. Negative rheumatoid factor f. Dactylitis g. Juxta-articular new bone formation detected on hand and foot radiographs	◯ Yes ◯ Yes Applicable ◯ Yes Applicable ◯ Yes ◯ Yes ◯ Yes ◯ Yes	◯ No ◯ No ◯ No ◯ No ◯ No ◯ No ◯ No	◯ Unknown ◯Unknown/Not ◯ Unknown/Not ◯ Unknown ◯ Unknown ◯ Unknown ◯ Unknown
	TOTAL SCORE:			
Date of Diagnosis		Date of Onset of Symptom		
Date DMARD)				
Joint Involvement	☐ Peripheral ☐ Synovitis ☐ Dactylitis ☐ Enthesitis	☐ Axial Involvement		

SECTION 5 COMORBID CONDITIONS (RA)			
Comorbid Conditions			
◯ No ◯ Yes	☐ Hypertension ☐ Hyperlipidaemia ☐ Diabetes Mellitus ☐ Ischemic Heart Disease (HD) ☐ CVA ☐ Peptic Ulcer Disease ☐ Entrapment neuropathy ☐ Malignancy Type: ☐ Haematology ◯ Leukemia ◯ Lymphoma ☐ Others ☐ Lung ☐ Stomach ☐Uterus/Ovary ☐ Breast ☐ CNS ☐ Bladder ☐ Colorectal ☐ Liver ☐ Skin ☐ Endocrine ☐ ENT ☐ Unknown ☐ Others, specify: _____	☐ Hepatitis B ☐ Hepatitis C ☐ Fatty Liver ☐ Renal Impairment ☐ Osteoporosis ☐ TB ☐ Demyelination ☐ Thyroid Disease ☐ Others, specify: _____	
Smoking Status	◯ Never	◯ Yes ◯ Ex ◯ Current	
Weight (kg)		Height (cm)	BMI

SECTION 6 EXTRA-ARTICULAR FEATURES AT PRESENTATIONS (PsA)		
Comorbid Conditions		
◯ No ◯ Yes	☐ Fever ☐ Eye inflammation ☐ Sicca ◯ Eye ◯ Oral Cavity ◯ Both ☐ Pleural effusion ☐ Interstitial lung disease ☐ Pericarditis/effusion ☐ Entrapment neuropathy ☐ Mononeuropathy ☐ Polyneuropathy ☐ Uveitis ☐ Cardiovascular Disease ◯ Aortic Regurgitation ◯ AV Conduction Block	☐ Cutaneous vasculitis ☐ Raynaud's ☐ Lymphadenopathy ☐ Skin involvement (psoriasis) _____ ☐ Amyloidosis ☐ AA subluxation ☐ Cervical myelopathy ☐ Anaemia (due to disease activity) ☐ Pulmonary Fibrosis ☐ Renal Disease ◯ Amyloidosis ◯ Glomerulonephritis ☐ GI Disease ◯ Crohns Disease ◯ Ulcerative Colitis ☐ Others, specify: _____

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) JOINT ASESSMENT

Patient Name			
NRIC Number		Date of Assessment	

SECTION 1 JOINT ASSESSMENT

Joint Evaluation-Upper Extremities

RIGHT SIDE				LEFT SIDE		
Not Evaluable ☐	Yes ◯ No ◯	Yes ◯ No ◯	*JOINT	Not Evaluable ☐	Yes ◯ No ◯	Yes ◯ No ◯
Not Evaluable Yes	Tenderness	Swelling		Not Evaluable Yes	Tenderness	Swelling
☐	Yes ◯ No ◯	Yes ◯ No ◯	Temporomandibular	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Sternoclavicular	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Acromioclavicular	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Shoulder	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Elbow	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Wrist	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	IP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯

Joint Evaluation-Lower Extremities						
RIGHT SIDE				LEFT SIDE		
Not Evaluable ☐ Yes	Yes ◯ No ◯ Tenderness	Yes ◯ No ◯ Swelling	*JOINT	Not Evaluable ☐ Yes	Yes ◯ No ◯ Tenderness	Yes ◯ No ◯ Swelling
☐	Yes ◯ No ◯		Hip	☐	Yes ◯ No ◯	
☐	Yes ◯ No ◯	Yes ◯ No ◯	Knee	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Ankle	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Tarsus/Mid Tarsal	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	IP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯

28 Joint Count (Tenderness)		28 Joint Count (Swelling)	
Total Joint Count (Tenderness)		Total Joint Count (Swelling)	

ACR functional status	◯ Normal (I) ◯ Limited in social activities (II) ◯ Limited in avocational / vocational activities (III) ◯ Wheel-chair or bedridden (IV)
Radiographic erosion at assessment	◯ Yes ◯ No ◯ Not available/Not Done
MASES Enthesitis score	
Dactylitis	◯ Yes, Number of digits involved ◯ No

◯ Not Applicable for this section

BASDAI	
a. How would you describe the overall level of fatigue/tiredness you have experienced?	
b. How would you describe the overall level of AS neck, back or hip pain you have had?	
c. How would you describe the overall level of pain/swelling in joints other than the neck, back or hips you have had?	
d. How would you describe the overall level of discomfort you have had from any areas tender to touch or pressure?	
e. How would you describe the overall level of morning stiffness you have had from the time you wake up?	
f. How long does your morning stiffness last from the time you wake up?	
g. Total Score	

ASDAS	
a. How would you describe the overall level of AS neck, back or hip pain you have had during the last week?	
b. How long did your morning stiffness last from the time you wake up during the last week?	
c. How active was your rheumatic disease on average during the last week?	
d. How would you describe the overall level of pain/swelling in joints other than neck, back or hips you have had during the last week?	
e. ◯ C-reactive protein (mg/l) ◯ C-reactive protein (mg/dl) Erythrocyte sedimentation rate (mm/h)	
MASES Enthesitis score	
Dactylitis	◯ Yes, Number of digits involved ◯ No

◯ Not Applicable for this section

BASMI	
a. Tragus to wall (score)	
b. Lumbar side flexion (score)	
c. Lumbar flexion (modified Schober's) (score)	
d. Cervical rotation (score)	
e. Intermalleolar distance (score)	
f. BASMI Score	

◯ Not Applicable for this section

BASFI	
a. Putting on your socks or tights without help or aids (eg sock aid).	
b. Bending from the waist to pick up a pen from the floor without aid.	
c. Reaching up to a high shelf without help or aids (eg helping hand).	
d. Getting up from an armless chair without your hands or any other help.	
e. Getting up off the floor without help from lying on your back.	
f. Standing unsupervised for 10 minutes without discomfort.	
g. Climbing 12-15 steps without using a handrail or walking aid.	
h. Looking over your shoulder without turning your body.	
i. Doing physically demanding activities (eg physiotherapy exercises, gardening or sports).	
j. Doing a full day activities whether it be at home or at work.	
k. BASFI Score	

SECTION 2 INVESTIGATIONS			
Blood test	Result		
ESR	☐ (mm/hr)	☐ Not Available	
CRP	◯ ☐ mg/L	◯ ☐ mg/dL	◯ Not Available ◯ Unknown
HLA B27	◯ Positve	◯ Negative	◯ Not Available
X-ray Pelvis	◯ Sacroilitis Grade 0 ◯ Sacroilitis Grade 3	◯ Sacroilitis Grade 1 ◯ Sacroilitis Grade 4	◯ Sacroilitis Grade 2 ◯ Not done
X-ray Spine	☐ Cervical Xray	◯ Syndesmophyte Present ◯ Not done	◯ Syndesmophyte Absent
	☐ Lumbo-sacral Xray	◯ Syndesmophyte Present ◯ Not done	◯ Syndesmophyte Absent
	☐ MRI	◯ Done	◯ Not done

SECTION 3 DISEASE ASSESSMENT		
How active was your arthritis during the past week?		
Activity	Measurement	
Patient global health assessment (PaGA)	(mm)	Value : 0 - 100
Physician's global health assessment (PrGA)	(mm)	Value : 0 - 100
Patient's Assessment of Disease Activity and Pain		
*How active was your rheumatic disease on average during the last week? 0-10 (0 not active; 10 very active)	◯0 ◯1 ◯2 ◯3 ◯4 ◯5 ◯6 ◯7 ◯8 ◯9 ◯10	
*How would you describe the overall level of joint pain during the last week? 0-10 (0 none; 10 very severe)	◯0 ◯1 ◯2 ◯3 ◯4 ◯5 ◯6 ◯7 ◯8 ◯9 ◯10	

SECTION 4 DISEASE ACTIVITY SCORE		
Clinical Variable	Value	
DAS 28 ESR SCORE	☐	◯ Remission < 2.6 ◯ Low disease activity >2.6 - 3.2 ◯ Moderate disease activity 3.21 - 5.1 ◯ High disease activity >5.1
DAS 28 CRP SCORE	☐	◯ Remission < 2.6 ◯ Low disease activity >2.6 - 3.2 ◯ Moderate disease activity 3.21 - 5.1 ◯ High disease activity >5.1
DAP SA SCORE	☐	◯ Remission 0 - 4 ◯ Low disease activity 5 - 14 ◯ Moderate disease activity 15 - 28 ◯ High disease activity > 28
BA SDAI SCORE	☐	◯ Inactive disease < 1.3 ◯ Low disease activity 1.3 - 2.1 ◯ High disease activity 2.1 - 3.5 ◯ Very high disease activity > 3.5
ASDAS SCORE	☐	◯ Inactive disease < 1.3 ◯ Low disease activity 1.3 - 2.1 ◯ High disease activity 2.1 - 3.5 ◯ Very high disease activity > 3.5

SECTION 5 INDICATION FOR BIOLOGIC THERAPY			
Indication for biologic	◯ No		
	◯ Yes	◯ Treatment Started	
		◯ Treatment Not Started	Reason : ☐ No fund available ☐ Patient preference ☐ Awaiting fund approval ☐ Other Reason

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) TREATMENT

TREATMENT				
Drug		Ongoing ☐	Reason for stopping	
Date started		Date stopped		
Drug		Ongoing ☐	Reason for stopping	
Date started		Date stopped		
Drug		Ongoing ☐	Reason for stopping	
Date started		Date stopped		
Drug		Ongoing ☐	Reason for stopping	
Date started		Date stopped		
Drug		Ongoing ☐	Reason for stopping	
Date started		Date stopped		

OTHER THERAPY		
Ever on ☐ NSAIDs ☐COX2 inhibitors?	◯ No	
	◯ Yes	Adverse reaction ever
		◯ No ◯ Yes ☐ Allergy ☐ Peptic ulcer disease (confirmed on OGDS) ☐ Dyspepsia ☐ Renal impairment

Traditional Complementary, medicine	◯ No	◯ Yes ☐ Acupuncture ☐ Ayurvedic ☐ Chinese traditional medicine ☐ Malay traditional medicine ☐ Unprescribed supplements

SURGERY		
Arthroplasty	◯ No	◯ Yes
Arthrodesis	◯ No	◯ Yes
Spinal surgery	◯ No	◯ Yes
Synovectomy	◯ No	◯ Yes
Other surgery, specify	◯ No	◯ Yes
	◯ Not given treatment	Specify reason :
	◯ No	

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) OUTCOME

Patient Name		Date of Outcome	

SECTION 1 PATIENT STATUS			
Patient Status	◯ Alive		
	◯ Death	Date of Death	
		Primary cause of Death	◯ RA related, specify the cause: ◯ Infection secondary to RA drugs ◯ Lung fibrosis ◯ IHD etc ◯ Unknown
	◯ Transfer to a new centre	Date of Transfer	
		Centre	a) Centre code
			b) Name of New Centre
		Reason	
	◯ Lost to Follow Up		

◯ Not Applicable for this section

SECTION 2 WORK PRODUCTIVITY AND ACTIVITY IMPAIRMENT QUESTIONNAIRE (WPAI)	
Work Productivity And Activity Impairment Questionnaire (Wpai)	
a. Are you currently employed (working for pay)?	◯ Yes ◯ NO
b. During the past seven days, how many hours did you miss from work because of problems associated with your Ankylosing Spondylitis? Include hours you missed on sick days, times you went in late, left early, etc., because of your Ankylosing Spondylitis. Do not include time you missed to participate in this study.	☐ HOURS
c. During the past seven days, how many hours did you miss from work because of any Other Reason, such as annual leave, holidays, time off to participate in this study?	☐ HOURS
d. During the past seven days, how many hours did you actually work?	☐ HOURS
e. During the past seven days, how much did your Ankylosing Spondylitis affect your productivity while you were working?	◯0 ◯1 ◯2 ◯3 ◯4 ◯5 ◯6 ◯7 ◯8 ◯9 ◯10
f. During the past seven days, how much did your Ankylosing Spondylitis affect your ability to perform your normal daily activities, excluding your job?	◯0 ◯1 ◯2 ◯3 ◯4 ◯5 ◯6 ◯7 ◯8 ◯9 ◯10
Percentage work time missed due to problem:	
Percentage impairment while working due to problem:	
Percentage overall work impairment due to problem:	
Percentage activity impairment due to problem:	

◯ Not Applicable for this section

EVENT OF SPECIAL INTEREST (after baseline notification)	
☐ Infection requiring hospitalization Total Number of Hospitalization: ☐	☐ Pneumonia ☐ Skin and Soft Tissue (Exclude Herpes Zoster) ☐ Septic Arthritis ☐ Septic Arthritis ☐ Urinary Tract Infection ☐ Septicaemic Shock ☐ Others - specify ☐
☐ Herpes Zoster	
☐ Tuberculosis	☐ Pulmonary ☐ Extra-pulmonary
☐ Cardiovascular Event	☐ Ischemic Heart Disease ☐ Cerebrovascular Disease ☐ Pulmonary Embolism ☐ DVT
☐ Pregnancy	◯ Live Birth ☐ ◯ Normal ◯ Congenital Malformation ☐ ◯ Miscarriage ☐
☐ Malignancy	
☐ Interstitial Lung Disease	Type: ☐ Haematology ◯ Leukemia ◯ Lymphoma ☐ Other ◯ Lung Stomach Uterus/Ovary ◯ Breast CNS Bladder ◯ Colorectal Liver Skin ◯ Endocrine ENT Others, specify: ☐ ☐ Unknown
☐ Hepatitis B	
☐ Hepatitis C	
☐ Osteoporosis	
☐ Diabetes Mellitus	
☐ Hypertension	
☐ Dyslipidaemia	

◯ Not Applicable for this section

ASSESSMENT OF SPONDYLOARTHRITIS (ASAS-HI)			
Please answer all statements by placing one check mark per statement to indicate which response best applies to you at this moment in time taking into account your rheumatic disease (the term "rheumatic disease" contains all forms of spondyloarthritis including Ankylosing Spondylitis).			
Questions	Agree/not Agree		
Pain sometimes disrupts my normal activities.	◯ Agree	◯ Not Agree	
I find it hard to stand for long.	◯ Agree	◯ Not Agree	
I have problems running.	◯ Agree	◯ Not Agree	
I have problems using toilet facilities.	◯ Agree	◯ Not Agree	
I am often exhausted.	◯ Agree	◯ Not Agree	
I am less motivated to do anything that requires physical effort.	◯ Agree	◯ Not Agree	
I have lost interest in sex.	◯ Agree	◯ Not Agree	◯ Not Applicable
I have difficulty operating the pedals in my car.	◯ Agree	◯ Not Agree	◯ Not Applicable
I am finding it hard to make contact with people.	◯ Agree	◯ Not Agree	
I am not able to walk outdoors on flat ground.	◯ Agree	◯ Not Agree	
I find it hard to concentrate.	◯ Agree	◯ Not Agree	
I am restricted in traveling because of my mobility.	◯ Agree	◯ Not Agree	
I often get frustrated.	◯ Agree	◯ Not Agree	
I find it difficult to wash my hair.	◯ Agree	◯ Not Agree	
I have experienced financial changes because of my rheumatic disease.	◯ Agree	◯ Not Agree	
I sleep badly at night.	◯ Agree	◯ Not Agree	
I cannot overcome my difficulties.	◯ Agree	◯ Not Agree	
ASAS-HI SCORE			

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ-DI)				
Please select in the button which best describes your abilities OVER THE PAST WEEK:				
Questions	Without Any Difficulty	Without Some Difficulty	Without Much Difficulty	Unable to Do
Dressing & Grooming				
Are you able to dress yourself, including shoelaces and buttons?	○	○	○	○
Are you able to shampoo your hair?	○	○	○	○
Arising				
Are you able to stand up from a straight chair?	○	○	○	○
Are you able to get in and out of bed?	○	○	○	○
Eating				
Are you able to cut your own meat?	○	○	○	○
Are you able to lift a full cup or glass to your mouth?	○	○	○	○
Are you able to open a new milk carton?	○	○	○	○
Walking				
Are you able to walk outdoors on flat ground?	○	○	○	○
Are you able to climb up five steps?	○	○	○	○
Please check any AIDS OR DEVICES that you usually use for any of the above activities:				
☐ Devices used for Dressing (button hook, zipper pull, etc. ☐ Special or built up chair. ☐ Cane ☐ Walker			☐ Built up or special utensils. ☐ Crutches. ☐ Wheelchair	

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:			
☐ Dressing and Grooming.	☐ Arising	☐ Eating	☐ Walking
Please select in the button which best describes your abilities OVER THE PAST WEEK:			

Questions	Without Any Difficulty	Without Some Difficulty	Without Much Difficulty	Unable to Do
Hygiene				
Are you able to wash and dry your body?	○	○	○	○
Are you able to take a tub bath?	○	○	○	○
Are you able to get on and off the toilet?	○	○	○	○

Reach				
Are you able to reach and get down a 5 pound object (such as a bag of sugar) from above your head?	○	○	○	○
Are you able to bend down to pick up clothing from the floor?	○	○	○	○
Grip				
Are you able to open car doors?	○	○	○	○
Are you able to open previously opened jars?	○	○	○	○
Are you able to turn faucets on and off?	○	○	○	○
Activities				
Are you able to run errands and shop?	○	○	○	○
Are you able to get in and out of a car?	○	○	○	○
Are you able to do chores such as vacuuming or yard work?	○	○	○	○

Please check any AIDS OR DEVICES that you usually use for any of the above activities:

☐ Long-handled appliances in bathroom.
☐ Bathtub Bar.
☐ Jar opener (for jars previously opened).
☐ Raised toilet seat.
☐ Long-handled appliances for reach.
☐ Bathtub Seat.

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

☐ Hygiene. ☐ Reach. ☐ Gripping and Opening Things. ☐Errands and Chores.

HAQ-DI Score	

Your ACTIVITIES:

To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

○ Completely. ○ Mostly. ○ Moderately. ○ A Little. ○ Not At All.

Your PAIN:

How much pain have you had IN THE PAST WEEK? On a scale of 0 to 100 (where zero represents “no pain” and 100 represents “severe pain”), please record the number below.

Your HEALTH:

Please rate how well you are doing on a scale of 0 to 100 (0 represents “very well” and 100 represents “very poor” health), please record the number below.