



Ministry of Health Malaysia
National Dermatology Registry
(DermReg)

THE TWELFTH REPORT OF THE MALAYSIAN PSORIASIS REGISTRY 2020–2022

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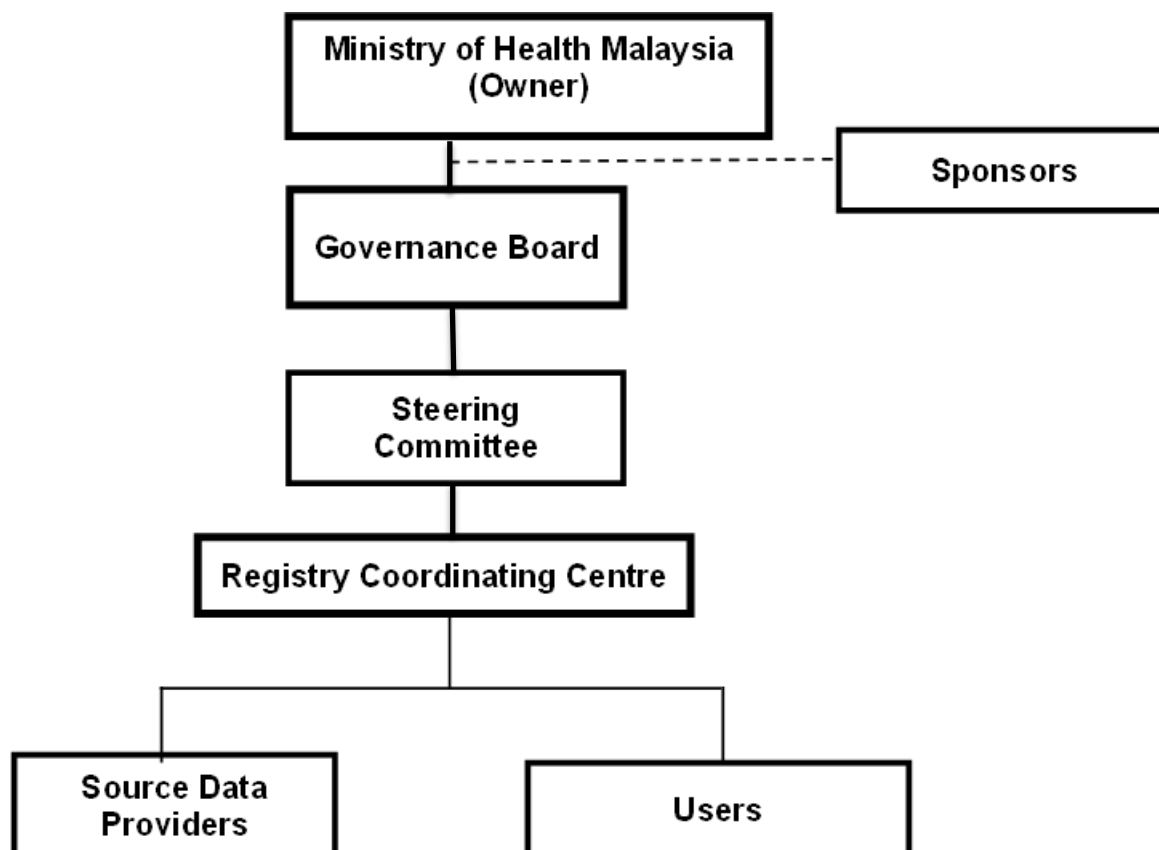
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ABBREVIATIONS

ACE	Angiotensin-converting enzyme
AIDS	Acquired immunodeficiency syndrome
ARP	Aplikasi Registri Pesakit
BBUVB	Broadband ultraviolet B
BMI	Body mass index
BSA	Body surface area
CDLQI	Children's Dermatology Life Quality Index
CRC	Clinical Research Centre
CRF	Case report form
DermReg	National Dermatology Registry
DLQI	Dermatology Life Quality Index
eCRF	Electronic case report form
eDermReg	DermReg web application
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
IC	Identity card
ICT	Information and communications technology
MOH	Ministry of Health
MPR	Malaysian Psoriasis Registry
MyHDW	Malaysian Health Data Warehouse
NA	Not available
NBUVB	Narrowband ultraviolet B
NHMS	National Health and Morbidity Survey
NSAIDs	Nonsteroidal anti-inflammatory drugs
PASI	Psoriasis Area Severity Index
PI	Principal Investigator
PUVA	Psoralen and ultraviolet A
QoL	Quality of life
RCC	Registry Coordinating Centre
SC	Site Coordinator
SD	Standard deviation
SDP	Source data provider
SPSS	Statistical Package for the Social Sciences
SQL	Structured Query Language
UM	Universiti Malaya
UKM	Universiti Kebangsaan Malaysia

ORGANISATION OF THE MPR

The organizational structure of the MPR consists of the Ministry of Health Malaysia, sponsors, Governance Board, Steering Committee, Registry Coordinating Centre, Source Data Providers (SDPs) and users.



SPONSORS

The MPR is sponsored by:

1. Ministry of Health, Malaysia
2. The Dermatological Society of Malaysia

GOVERNANCE BOARD

The **Governance Board of the MPR** is a committee established by the sponsors. Its roles are:

- to ensure that the MPR stays focused on its objectives
- to ensure its continuing relevance and justification

1. Dr. Suganthi Thevarajah (Chairperson)
National Head of Dermatological Services and Senior Consultant Dermatologist
Department of Dermatology
Hospital Kuala Lumpur
2. Dr. Sabeera Begum
President of the Dermatological Society of Malaysia, and
Senior Consultant Dermatologist
Department of Dermatology
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No.	Name	Institution
1.	Dr. Suganthy Robinson	Hospital Kuala Lumpur
2.	Associate Professor Dr. Kwan Zhenli	University of Malaya Medical Centre
3.	Dr. Rajalingam Ramalingam	Hospital Tengku Ampuan Afzan, Kuantan
4.	Dr. Voo Sook Yee @ Michelle	Hospital Queen Elizabeth, Kota Kinabalu
5.	Dr. Tang Min Moon	Hospital Umum Sarawak
6.	Dr. Latha Selvarajah	Hospital Sultan Ismail
7.	Associate Professor Dr. Adawiyah Jamil	Hospital Canselor Tuanku Muhriz Universiti Kebangsaan Malaysia
8.	Dr. Tan Wooi Chiang	Hospital Pulau Pinang

REGISTRY COORDINATING CENTRE

The **MPR Registry Coordinating Centre (RCC)** is based at the Department of Dermatology, Hospital Kuala Lumpur. It coordinates the data collection among the source data providers and collaborates with the Clinical Research Centre (CRC) that provides epidemiological and statistical support.

Registry Manager

Dr. Muhammad Jaya Aiman Bin Muhammad Muthaiah

Database Administrator

Health Informatics Centre
Planning Division
Ministry of Health, Malaysia

SOURCE DATA PROVIDERS (SDP)

Source data providers (SDPs) are centres that contribute data to the registries.

Source Data Providers for the MPR 2020-2022

No.	Source Data Provider	Investigator
1.	Hospital Kuala Lumpur	Dr. Suganthy Robinson
2.	Hospital Pulau Pinang	Dr. Tan Wooi Chiang
3.	Hospital Sultanah Bahiyah	Dr. Wong Siu Bee
4.	Hospital Tuanku Fauziah	Dr. Khoo Voon Ling
5.	Hospital Sultanah Fatimah	Dr. Evelyn Yap Wen Yee
6.	Hospital Tuanku Jaafar	Dr. Preamala Gunabalasingam
7.	Hospital Queen Elizabeth	Dr. Voo Sook Yee @ Michelle
8.	Hospital Sungai Buloh	Dr. Norli Marwyne Mohd Noor
9.	Hospital Tengku Ampuan Afzan	Dr. Rajalingam Ramalingam
10.	Hospital Permaisuri Bainun	Dr. Tang Jyh Jong
11.	Hospital Umum Sarawak	Dr. Tang Min Moon
12.	Hospital Tengku Ampuan Rahimah	Dr. Ng Ting Guan
13.	Hospital Melaka	Dr. Lee Choon Sian
14.	Hospital Miri	Dr. Tang Min Moon
15.	Hospital Sultan Abdul Halim	Dr. Loo Yin Pin
16.	Hospital Sultanah Aminah	Dr. Wong Kit Wan
17.	Hospital Canselor Tuanku Muhriz UKM	Associate Professor Adawiyah Jamil
18.	UM Medical Centre	Dr. Kwan Zhenli
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20.	Hospital Ampang	Dr. Kwan Jing Wern
21.	Hospital Selayang	Dr. Teeba Raja
22.	Hospital Putrajaya	Dr. Nazatul Shima Abdul Rahim
23.	Hospital Serdang	Dr. Lee Sut Enn
24.	Hospital Sultan Ismail	Dr. Latha Selvarajah
25.	Hospital Sultan Haji Ahmad Shah	Dr. Rajalingam Ramalingam
26.	Hospital Jerantut	Dr. Rajalingam Ramalingam


No.	Source Data Provider	Investigator
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28.	Hospital Sultanah Zahirah	Dr. Nor Azura Mohamad
29.	Hospital Duchess of Kent	Dr. Voo Sook Yee @ Michelle
30.	Hospital Tawau	Dr. Voo Sook Yee @ Michelle
31.	Hospital Lahad Datu	Dr. Voo Sook Yee @ Michelle
32.	Hospital Kuala Lipis	Dr. Rajalingam Ramalingam
33.	Hospital Tunku Azizah	Dr. Sabeera Begum
34.	Hospital Taiping	Dr. Lee Hock Leng
35.	Hospital Rompin	Dr. Abdul Rahman Che Abdul Rahim
36.	Hospital Sibul	Dr. Teo Hock Gin
37.	Gleneagles Hospital Kota Kinabalu	Dr. Voo Sook Yee @ Michelle
38.	Hospital Muadzam Shah	Dr. Abdul Rahman Che Abdul Rahim
39.	KPJ Pahang Specialist Hospital	Dr. Rajalingam Ramalingam

UM = Universiti Malaya

UKM = Universiti Kebangsaan Malaysia

OFFICIAL WEBSITE OF MPR

<http://www.dermatology.org.my/DermReg/index.htm>

MPR	Malaysian Psoriasis Registry
	WELCOME
	
Home	Welcome to Malaysian Psoriasis Registry (MPR)
About MPR	The Malaysian Psoriasis Registry (MPR) is a skin disease clinical registry. It is a nationwide ongoing systematic collection, analysis and interpretation of data pertaining to psoriasis and related services in Malaysia. This information is useful in assisting the Ministry of Health, non-governmental organizations and private healthcare providers and industry to plan, develop and improve services and facilities in the management of psoriasis.
Governance Board	
Steering Committee	
Coordinating Centre	
Source Data Providers	
Publications	
Data Request	Sponsors
Data Collection Forms	<ol style="list-style-type: none">Ministry of Health, Malaysia<ul style="list-style-type: none">Pusat Informatik KesihatanDepartment of Dermatology, Hospital Kuala LumpurHead of Dermatology Services, MalaysiaDermatological Society of MalaysiaIndustrial Sponsors:<ul style="list-style-type: none">Abbot Malaysia - 2011Leo Pharma (Malaysia) - 2010, 2011, 2013, 2014Janssen (Malaysia) - 2011, 2015 - 2017Abbvie - 2013 - 2016Novartis - 2017
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ABOUT THE MALAYSIAN PSORIASIS REGISTRY (MPR)

Introduction

Psoriasis is a chronic, T-cell mediated skin disorder characterized by erythematous scaly plaques. It runs a chronic relapsing course with variable degrees of severity, and causes significant physical, psychosocial and economic impact on the patient. As psoriasis is a long-term disease, it can be associated with poor patient adherence especially to treatment which will further compromise the overall management of the disease.

The Malaysian Psoriasis Registry (MPR) is a skin disease clinical registry. It is a prospective collection of data pertaining to patients with psoriasis. The main objective of setting up the MPR was to have accurate data on the various aspects of psoriasis in Malaysia. This would help in assessing the true magnitude of the problem in Malaysia, including demographic data, types of psoriasis, severity, aggravating factors, associated joint and nail disease, comorbidities and the various types of therapies used. Having a psoriasis registry would also help in research work and more importantly in improving the overall management of the patients.

Preliminary work on the MPR started in 1998 by a group of dermatologists, which culminated in the First Malaysian Psoriasis Symposium on 17th May 1998. This registry consisted of information on patients with psoriasis in Malaysia and is under the umbrella of the National Dermatology Registry (DermReg). A case report form (CRF) was developed, and data collection started as a pilot project in March 2000. A preliminary report of the registry (March 2000 to July 2005) was published in the Malaysian Journal of Dermatology in the August 2005 issue.

In 2007, the MPR was extensively revamped under the guidance of the Clinical Research Centre (CRC) Malaysia and with financial support from the Ministry of Health (MOH) Malaysia, a new CRF was introduced. A web-based centralised database was established to facilitate multi-centre data collection. The preliminary report of the newly revised MPR was published in the Medical Journal of Malaysia in September 2008. The First Annual Report of the MPR 2007-2008 was published the following year.

With the arrival of biological agents in Malaysia, additional CRFs for data collection of patients receiving biologic agents were introduced in 2011. In 2020, the MPR database became a part of the Malaysian Health Data Warehouse (MyHDW) under the purview of the Health Informatics Centre, Planning Division of the MOH, Malaysia. The CRF also underwent another revision in the same year to further improve data collection in terms of comorbidities, symptoms and assessment of disease severity.

Objectives

The MPR has the following objectives:

- Primary objective:
To obtain accurate data on various aspects of psoriasis in Malaysia.

- Secondary objectives:
 1. To determine the sociodemographic profiles of patients with psoriasis.
 2. To determine the disease burden attributed to psoriasis.
 3. To provide information for planning of medical services, facilities, human resource and training related to the management of psoriasis.
 4. To stimulate and facilitate research on psoriasis and its management.

Scope of MPR

The MPR is intended to be a truly national population-based disease and treatment registry. Hence it seeks the participation of all providers of dermatological services in both the public and private sectors in Malaysia.

The MPR collects:

- Demographic data
- Clinical data including patients' history, comorbidities, symptoms and clinical examination findings
- Quality of life assessment i.e. Dermatology Life Quality Index (DLQI) and Children's Dermatology Life Quality Index (CDLQI)
- Modalities of treatment used

Outcomes of interest include:

- Course of the disease
- How the disease affects quality of life
- Disease improvement with treatment
- Association with other diseases

Inclusion criteria:

All patients who are clinically diagnosed to have psoriasis by a dermatologist or by a medical practitioner under the supervision of a dermatologist are included. The confirmation of diagnosis by histopathologic examination is optional.

Exclusion criteria:

Patients whose diagnosis is in doubt are excluded.

EXECUTIVE SUMMARY

Stock and Flow

As of December 2022, 39 centres (35 government hospitals, 2 private centres and 2 university hospitals) had registered with the Malaysian Psoriasis Registry (MPR) as data providers. During the period of January 2020 to December 2022, a total of 8,813 patients with psoriasis from 34 dermatology centres (30 government hospitals, 2 private centres and 2 university hospitals) were enrolled into the MPR.

Demographic Characteristics

For the adult patients, the male-to-female ratio was 1.2:1. Ethnic distribution is as follows: Malay 59.4%, Chinese 17.8%, Indian 14.6%, and other ethnic groups 8.2%. The mean age at notification was 44.83 ± 16.12 years. Most patients (99.3%) were Malaysian citizens.

For the paediatric patients, the male-to-female ratio was 1:1.2. Ethnic distribution is as follows: Malay 75.5%, Chinese 4.7%, Indian 10.3%, and other ethnic groups 9.5%. The mean age at notification was 13.06 ± 4.33 years. Most patients (99.8%) were Malaysian citizens.

Among the adult patients, 16.2% were current smokers compared to 1.5% of the paediatric patients. The most frequent type of substance use among the adults was alcohol (65.9%) followed by vape (26.7%) and illicit drugs (7.4%). Among the adults with substance use, methamphetamine was the most frequently used illicit drug.

Psoriasis History

In adult patients, the mean age of onset for psoriasis was 34.1 years. Family history of psoriasis was present in 24.6% of patients. Among those who had a positive family history, 41.7% had either parent affected, 33.6% had siblings with psoriasis and 8.9% had children with psoriasis.

In the paediatric population, the mean age of onset for psoriasis was 10.3 years. At least one family member was affected with psoriasis at 24.4%. Of these, 46.1% had either parent affected with psoriasis.

Both populations (53.8% of adults and 38.9% of paediatric patients) reported one or multiple factors which aggravated their psoriasis. The common aggravating factors were stress (66.9% of adults, 51.2% of paediatric patients), excessive sun exposure (28.8% of adults, 38.0% of paediatric patients) and infection (10.1% of adults, 12.2% of paediatric patients).

Comorbidities

Among the adult psoriasis patients, 62.9% had a body mass index (BMI) of 25 or more, 28.5% had hypertension, 22.7% had hyperlipidaemia, 19.2% had diabetes mellitus, 4.9% had ischaemic heart disease, 1.6% had suffered a prior stroke and 3.4 % had fatty liver. Only 2.2% of the paediatric group had a comorbidity which was mainly obesity.

Clinical Presentation

The most common clinical type of psoriasis in adult and paediatric patients was plaque psoriasis (94.4% and 90.0%, respectively). Itch was present in 77.5% of adults and 76.8% of children. In the adult group, the mean body surface area (BSA) involvement was 12.2% whereas for the paediatric group it was 11.6%. The mean psoriasis area severity index (PASI) score was 6.5 in adults and 6.6 in children. Psoriasis affecting special sites (face, scalp, genital, tongue and eyes) were noted in 33.8% and 26.9% of adult and paediatric patients respectively.

Psoriatic arthropathy was reported in 18.8% of the adults and 2.7% of the paediatric population. The most common type of psoriatic arthropathy in adults was distal hand joint arthropathy (32.1%) followed by oligo/monoarthropathy (30.4%) and rheumatoid-like symmetrical polyarthropathy (28.7%). In contrast, in paediatric patients, the most common type of psoriatic arthropathy was oligo/monoarthropathy (46.7%), followed by distal hand joint arthropathy (20.0%) and rheumatoid-like symmetrical polyarthropathy (20.0%).

Of the adult patients 57.7% had nail changes associated with psoriasis. Among the patients who had nail disease, pitting was the most frequent (69.9%), followed by onycholysis (49.3%). Total nail dystrophy was found in 5.8% of the adult patients with nail disease. In the paediatric group, 42.3% had nail involvement with pitting most frequently encountered (83.2%) followed by onycholysis (29.3%).

Systemic treatment received in the past 6 months

Most patients (89.3% of adults and 84.2% of paediatric patients) were on topical treatment. Topical corticosteroids were the most frequently prescribed topical medication (93.6% of adults and 90.9% of paediatric patients), followed by emollients (84.0% of adults and 78.1% of paediatric patients), and tar preparations (63.1% of adults and 55.6% of the paediatric group). Phototherapy was administered to 2.9% of adults and 1.6% of the paediatric group. Systemic therapy was given to 32.1% of adult patients and 13.5% of paediatric patients. The most frequently used systemic therapy was methotrexate (73.9% of adults and 58.1% of paediatric patients), followed by acitretin (23.4% of adults and 41.9% of paediatric patients).

Biologic treatment received in the past 6 months

Biological therapy was used in 377 adult patients (4.6%) and 9 (1.6%) paediatric patients with psoriasis. The most prescribed biologics were secukinumab (54.9%) followed by ustekinumab (25.1%) and adalimumab (6.5%). Of these, 42 patients (11.1%) had received biologic therapy as first line treatment and 62 patients (16.4%) had received prior biologic therapy (7 patients had missing data for previous treatment used). Concomitant systemic treatment was used in 111 patients (29.8%) receiving biologic treatment of which the most common was methotrexate (65.7% of adults and 83.3% of children). This was followed by acitretin (17.1% of adults and 16.7% of children) and ciclosporin (12.4% of adults).

The most common indication for initiating biologic therapy was treatment failure to phototherapy and conventional systemic agents (79.6% of adults and 88.9% of children). Most patients received biologic therapy via funding from the Jabatan Perkhidmatan Awam (JPA) (32%) followed by government hospital funding (17.4%).

Adverse events were encountered only in the adult population which included worsening of psoriasis, (10, 43.5%) and infections (9, 39.1%). None of the patients experienced major adverse cardiac events (MACE) or skin cancers. Biologic treatment was discontinued in 6.8% due to primary failure (6, 30%), secondary loss of efficacy (5, 25%), financial restrictions (4, 20%), sample stock availability (3, 15%) and adverse events (2, 10%).

Quality of Life

In the last six months, measurement of quality of life using the Dermatology Life Quality Index (DLQI) or Children's DLQI (CDLQI) was performed in 8,296 patients aged 17 years and above and 407 patients aged 4-16 years respectively. The mean DLQI score was 8.9 and the mean CDLQI was 7.9.

A DLQI of more than 10 was reported by 35.9% of patients, and 21.8% of patients reported a CDLQI of more than 12, indicating a significant impact on their quality of life (QoL) due to psoriasis or its treatment. "Symptoms and feelings" was the domain most affected for both DLQI (38.9%) and CDLQI (36.9%) assessments where patients scored 2 points or more per question in this domain.

Outcomes

Treatment outcomes were assessed for the different types of treatment, i.e. phototherapy, systemic treatment, biologic agents, phototherapy with concomitant systemic therapy and biologics with concomitant systemic treatment. Overall, the median PASI for adults had reduced from a baseline of 4.5 to 3.0 at 6 months and remained at 3.0 at 12 months. Similarly, the median BSA in adults improved from 8.0 at baseline to 5.0 at 6 months and 5.0 at 12 months for all types of treatment. The greatest improvement for both median PASI and BSA for adults was seen in the biologic group with PASI improving from 14.2 at baseline to 2.0 at 6 months

and 2.5 at 12 months, and BSA improving from 33.5 to 2.5 at 6 months and 3.0 at 12 months. For the paediatric patients, the median PASI at baseline was 8.1 which improved to 6.1 at 6 months and 5.2 at 12 months while the median BSA at baseline was 10.0 which improved to 5.5 at 6 months but subsequently increased to 10.0 at 12 months.

For all patients, the median DLQI at baseline was 6.0 and this improved to 4.0 at 6 months and remained at 4.0 at 12 months. Good response to treatment (as defined as a reduction of at least 5 points in the DLQI score) was achieved by 23% of patients at 6 months and 20.4% at 12 months. At 6 months, patients on phototherapy with concomitant systemic therapy reported the highest proportion of patients achieving a good response (37.0%) followed by patients on biologic agents (32.0%) and phototherapy alone (30.8%). At 12 months' follow-up, the category with the greatest proportion of patients achieving good response was biologic agents (35.9%) followed by biologics with concomitant systemic treatment (24.5%).

CHAPTER 1

STOCK AND FLOW

Chapter 1

Stock and Flow
Dr Suganthi Robinson

From January 2020 to December 2022, a total of 8,813 patients were notified to the registry. Of these, 6.4% (n=561) belonged to the paediatric age group (≤ 18 years old) and 93.6% (n=8,252) belonged to the adult group (> 18 years old). As of 1.1.2023, a total of 28,795 patients had been enrolled in the MPR from 39 centres (35 government hospitals, 2 private centres and 2 university hospitals) (**Figure 1.1**).

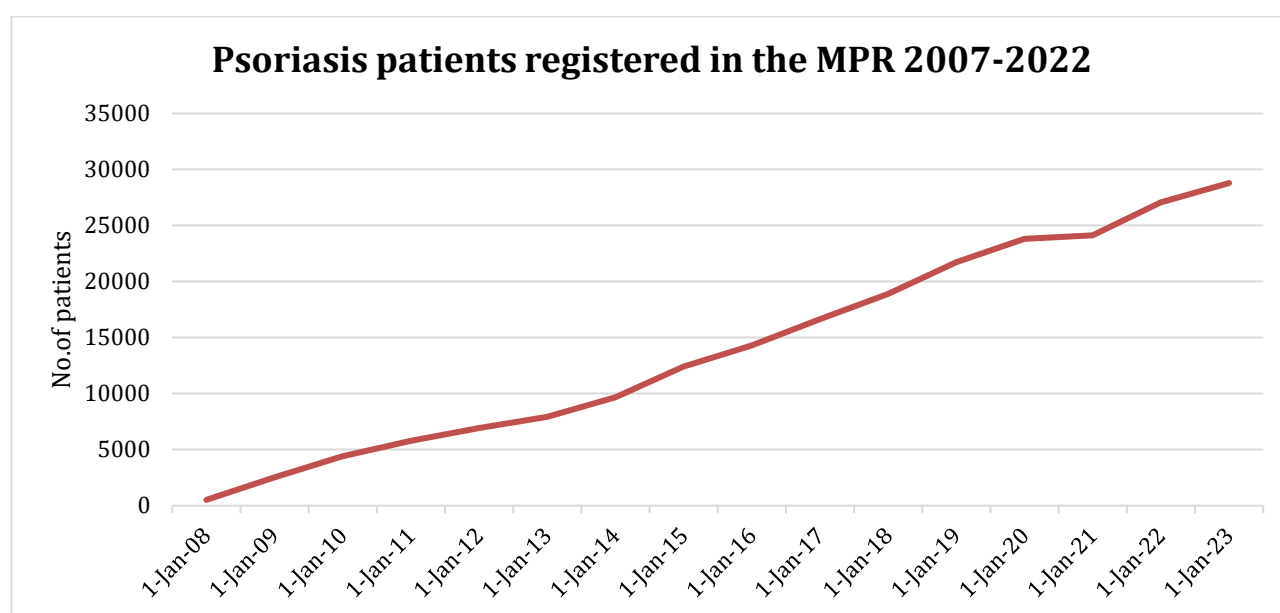


Figure 1.1 Number of psoriasis patients notified to the Malaysian Psoriasis Registry 2007-2022

A total of 34 centres (30 government hospitals, 2 private centres and 2 university hospitals) contributed to the MPR from January 2020 to December 2022. The number of patients notified for the adult and paediatric groups are shown in **Table 1.1** and **Table 1.2**. **Table 1.3** and **Table 1.4** depict the number of patients notified for biologic treatment for the adult and paediatric groups respectively.

Table 1.1 Number of adult patients with psoriasis notified from each participating centre

No.	Reporting Centre	No. of patients			Total
		2020	2021	2022	
1	Hospital Kuala Lumpur	286	402	283	971
2	Hospital Tuanku Jaafar	246	387	64	697
3	Hospital Umum Sarawak	188	199	233	620
4	Hospital Sultan Ismail	212	202	155	569
5	Hospital Sultanah Aminah	41	247	241	529
6	Hospital Raja Permaisuri Bainun	119	221	183	523
7	Hospital Queen Elizabeth	133	160	211	504
8	Hospital Pulau Pinang	171	203	86	460
9	Hospital Tengku Ampuan Rahimah	159	139	146	444
10	Hospital Sultanah Bahiyah	146	91	178	415
11	Hospital Tengku Ampuan Afzan	181	115	107	403
12	Hospital Melaka	82	180	64	326
13	Hospital Sultanah Nur Zahirah	51	82	159	292
14	Hospital Putrajaya	124	93	45	262
15	Hospital Raja Perempuan Zainab II	97	63	91	251
16	Hospital Sultanah Fatimah	67	61	99	227
17	Hospital Taiping	162	41	14	217
18	Hospital Selayang	1	35	107	143
19	Hospital Serdang	49	11	40	100
20	Hospital Tuanku Fauziah	31	27	17	75
21	Hospital Sungai Buloh	1	5	63	69
22	KPJ Pahang Specialist Hospital	-	35	23	58
23	Hospital Kuala Lipis	7	4	9	20
24	Gleneagles Hospital Kota Kinabalu	5	6	5	16
25	University Malaya Medical Centre	9	1	4	14
26	Hospital Ampang	0	0	14	14
27	Hospital Sultan Haji Ahmad Shah	6	0	0	6
28	Hospital Muadzam Shah	4	0	2	6
29	Hospital Sultan Abdul Halim	5	0	0	5
30	Hospital Lahad Datu	1	0	4	5
31	Hospital Duchess of Kent	-	1	3	4
32	Hospital Tawau	-	-	4	4
33	Hospital Canselor Tuanku Muhriz UKM	0	2	0	2
34	Hospital Tunku Azizah	0	1	0	1
Total		2584	3014	2654	8252

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Table 1.2 Number of paediatric patients with psoriasis notified from each participating centre

No.	Reporting Centre	No. of patients			Total
		2020	2021	2022	
1	Hospital Kuala Lumpur	21	16	14	51
2	Hospital Tuanku Jaafar	6	21	1	28
3	Hospital Umum Sarawak	8	13	35	56
4	Hospital Sultan Ismail	11	11	12	34
5	Hospital Sultanah Aminah	6	19	17	42
6	Hospital Raja Permaisuri Bainun	2	7	8	17
7	Hospital Queen Elizabeth	7	16	14	37
8	Hospital Pulau Pinang	2	8	4	14
9	Hospital Tengku Ampuan Rahimah	12	8	10	30
10	Hospital Sultanah Bahiyah	13	12	12	37
11	Hospital Tengku Ampuan Afzan	12	14	7	33
12	Hospital Melaka	5	2	4	11
13	Hospital Sultanah Nur Zahirah	5	7	15	27
14	Hospital Putrajaya	9	3	2	14
15	Hospital Raja Perempuan Zainab II	10	8	4	22
16	Hospital Sultanah Fatimah	10	4	14	28
17	Hospital Taiping	9	6	3	18
18	Hospital Selayang	0	0	3	3
19	Hospital Serdang	6	2	1	9
20	Hospital Tuanku Fauziah	4	5	2	11
21	Hospital Sungai Buloh	0	0	7	7
22	KPJ Pahang Specialist Hospital	-	1	1	2
23	Hospital Kuala Lipis	0	0	1	1
24	Gleneagles Hospital Kota Kinabalu	0	1	1	2
25	University Malaya Medical Centre	1	0	0	1
26	Hospital Ampang	0	0	1	1
27	Hospital Sultan Abdul Halim	3	0	0	3
28	Hospital Tunku Azizah	14	8	0	22
Total		176	192	193	561

Table 1.3 Number of adult psoriasis patients notified for biologic treatment from each participating centre

No.	Reporting Centre	No. of patients			Total
		2020	2021	2022	
1	Hospital Kuala Lumpur	8	33	17	58
2	Hospital Tuanku Jaafar	2	13	1	16
3	Hospital Umum Sarawak	8	8	10	26
4	Hospital Sultan Ismail	17	21	11	49
5	Hospital Sultanah Aminah	0	22	18	40
6	Hospital Raja Permaisuri Bainun	5	12	18	35
7	Hospital Queen Elizabeth	6	5	3	14
8	Hospital Pulau Pinang	2	3	0	5
9	Hospital Tengku Ampuan Rahimah	3	0	0	4
10	Hospital Sultanah Bahiyah	3	8	5	16
11	Hospital Tengku Ampuan Afzan	6	12	6	24
12	Hospital Melaka	3	8	0	11
13	Hospital Sultanah Nur Zahirah	4	4	6	14
14	Hospital Putrajaya	3	5	0	8
15	Hospital Raja Perempuan Zainab II	7	6	1	14
16	Hospital Sultanah Fatimah	2	3	22	27
17	Hospital Taiping	4	1	0	5
18	Hospital Selayang	0	2	4	6
19	Hospital Tuanku Fauziah	1	0	0	1
20	KPJ Pahang Specialist Hospital	0	0	1	1
21	Gleneagles Hospital Kota Kinabalu	0	2	0	2
22	University Malaya Medical Centre	0	0	1	1
Total		84	169	124	377

Table 1.4 Number of paediatric psoriasis patients notified for biologic treatment from each participating centre

No.	Reporting Centre	No. of patients			Total
		2020	2021	2022	
1	Hospital Tuanku Jaafar	0	1	0	1
2	Hospital Umum Sarawak	0	0	3	3
3	Hospital Sultan Ismail	1	0	0	1
4	Hospital Raja Permaisuri Bainun	1	0	0	1
5	Hospital Sultanah Bahiyah	0	0	1	1
6	Hospital Sultanah Nur Zahirah	0	2	0	2
Total		2	3	4	9

A total of 11,779 notifications of new and follow-up patients with psoriasis were received from January 2020 till December 2022. Of these, 11,144 (94.6%) notifications were from adult patients and the remaining 635 (5.4%) notifications were from paediatric patients. From the total number of adult patients, 6,545 (79.3%) were notified only once and 1,707 (20.7%) had one or more follow-up notifications (**Table 1.5**). For the paediatric population, 511 (91.1%) patients were notified only once and 50 (8.9%) patients had one or more follow-up notifications (**Table 1.6**).

Table 1.5 Number of notifications for adult patients with psoriasis

No. of notifications	No. of patients	%
Entry notification	6545	79.31
Entry and 1 follow-up notification	1021	12.37
Entry and 2 follow-up notifications	376	4.56
Entry and 3 follow-up notifications	184	2.23
Entry and 4 follow-up notifications	86	1.04
Entry and 5 follow-up notifications	20	0.24
Entry and 6 follow-up notifications	17	0.21
Entry and 7 follow-up notifications	3	0.04
Total	8252	100.00

Table 1.6 Number of notifications for paediatric patients with psoriasis

No. of notifications	No. of patients	%
Entry notification	511	91.09
Entry and 1 follow-up notification	36	6.42
Entry and 2 follow-up notifications	8	1.43
Entry and 3 follow-up notifications	3	0.53
Entry and 4 follow-up notifications	2	0.36
Entry and 5 follow-up notifications	1	0.17
Total	561	100.00

CHAPTER 2

DEMOGRAPHIC CHARACTERISTICS

Chapter 2

Demographic Characteristics*Dr Voo Sook Yee @ Michelle*

Among the 8,813 patients registered to the Malaysian Psoriasis Registry between 2020 to 2022, 53.6% were males and 93.6% were adults. The mean age of all patients at notification was 42.8 years ranging from 15 months to 91 years. In terms of nationality, Malaysians made up 99.4%. Among the Malaysians, more than half (60.4%) were Malays, 16.9% were Chinese, 14.3% were Indians, 8.3% were ethnic groups of Sabah and Sarawak and 0.1% were Orang Asli (Figure 2.1).

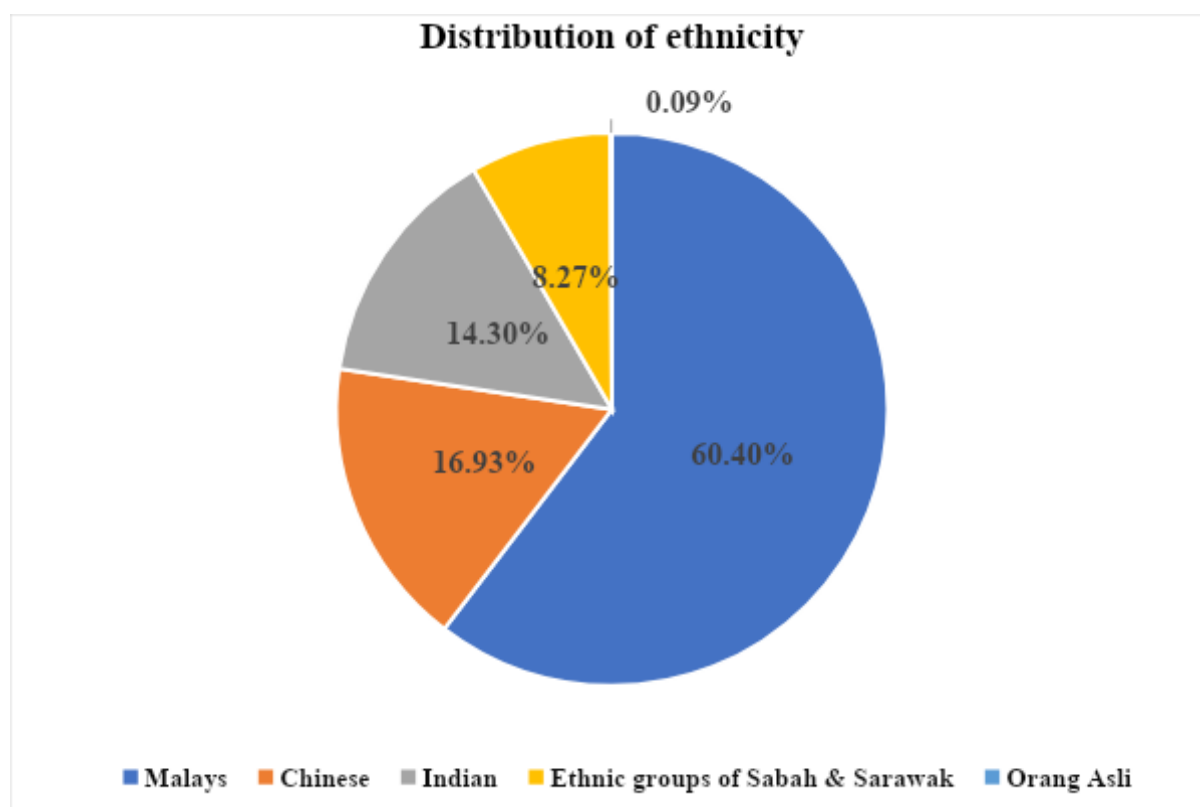


Figure 2.1 Ethnic distribution of the Malaysian patients with psoriasis

In the adult group, 59.4% were Malays, 17.8% were Chinese, 14.6% were Indians. Males comprised 54.1% (Figure 2.2). The majority (67.4%) were married. Of the females, 4.2% were pregnant at the time of notification (Table 2.1).

In the paediatric group, 75.5% were Malays, 4.7% were Chinese, 10.3% were Indians. Males comprised 45.5%. (Figure 2.3).

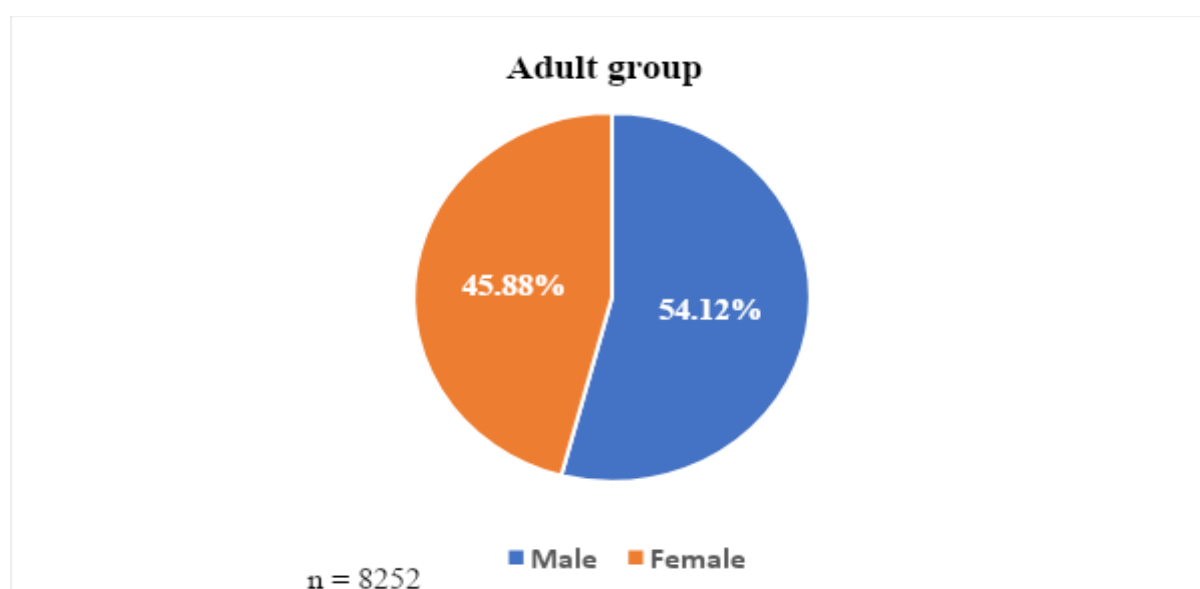


Figure 2.2 Gender distribution among the adult psoriasis patients

Table 2.1: Demographic characteristics of the adult and paediatric patients with psoriasis

Patients' characteristics		Adult		Paeds		
		n	%	Paeds	%	
Nationality (n = 8813)	Malaysian	8198	99.35	560	99.82	
	Non-Malaysian	54	0.65	1	0.18	
Ethnicity (n = 8670)	Malay	4818	59.37	419	75.50	
	Chinese	1442	17.77	26	4.68	
	Indian	1183	14.58	57	10.27	
	Ethnic groups of Sabah & Sarawak					
	Dusun	117	1.44	13	2.34	
	Kadazan	95	1.17	1	0.18	
	Bajau	92	1.13	9	1.62	
	Murut	23	0.28	2	0.36	
	Other bumiputera of Sabah	121	1.49	8	1.44	
	Kedayan	10	0.12	0	0	
	Iban	102	1.26	8	1.44	
	Melanau	8	0.10	0	0	
	Bidayuh	88	1.08	11	1.98	
	Other bumiputera Sarawak	9	0.11	0	0	
Orang Asli	7	0.09	1	0.18		
Gender (n = 8813)	Male	4466	54.12	255	45.45	
	Female	3786	45.88	306	54.55	
Marital status (n = 8813)	Single	2318	28.09	560	99.82	
	Married	5561	67.39	1	0.18	
	Divorced	177	2.14	0	0	
	Widowed	196	2.38	0	0	

Data on cigarette smoking status and substance use were available for 8,736 and 8,674 patients respectively. Among the adult patients, 16.2% were current smokers compared to 1.5% of the paediatric patients. A total of 516 adults and 5 paediatric patients reported substance use. The most frequent type of substance use among the adults was alcohol (65.9%) followed by vape (26.7%) and illicit drugs (7.4%). On the other hand, alcohol use (50%) and vaping (50%) were equally reported among the paediatric patients (**Table 2.2**). Among the adults with substance use, methamphetamine (13 patients) was the most frequently used illicit drug followed by heroin (8 patients), marijuana (4 patients), ‘ketum’ and morphine (3 patients each) and cocaine (1 patient).

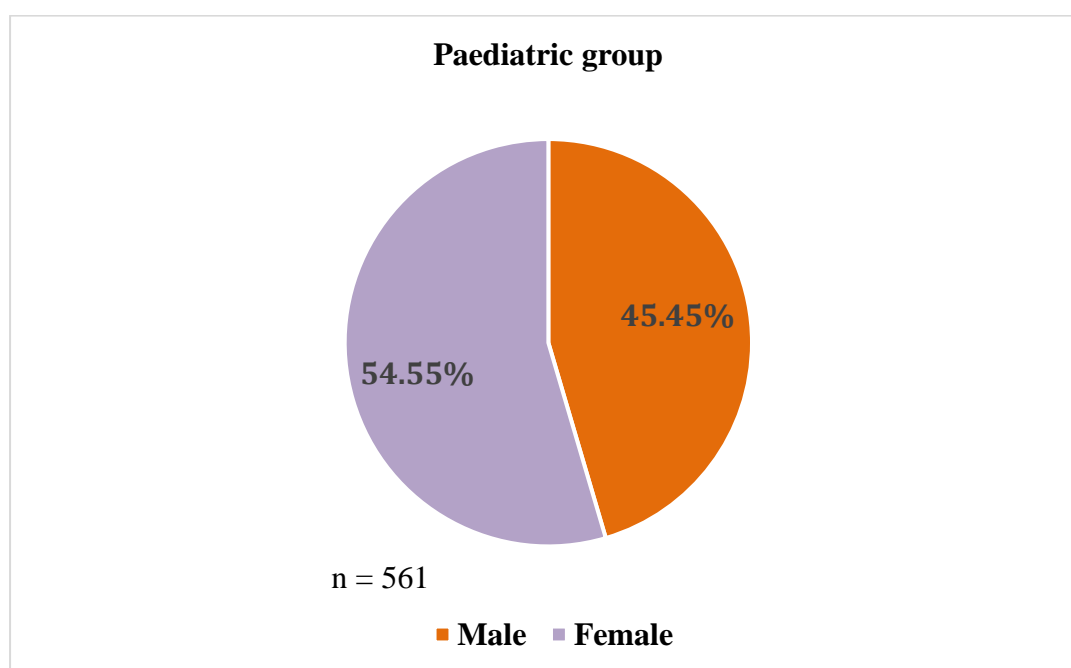


Figure 2.3 Gender distribution among the paediatric psoriasis patients

Table 2.2: Cigarette smoking and substance use in adult and paediatric patients with psoriasis

Cigarette smoking and substance use		Adult		Paediatric	
		n	%	n	%
Smoking status (n = 8736)*	Current smoker	1327	16.20	8	1.46
	Ex-smoker	1038	12.68	4	0.73
	Never smoked	5824	71.12	535	97.81
Substance use (n = 505) [©]	Alcohol	329	65.93	3	50.00
	Vape	133	26.65	3	50.00
	Illicit drug	37	7.41	0	0

*n = 8189 for the adult group and 547 for the paediatric group

[©]One patient may report more than one substance use

[©]n = 449 for the adult group and 6 for the paediatric group

CHAPTER 3

MEDICAL HISTORY

Chapter 3

Medical History*Associate Professor Dr Adawiyah Jamil***Age of psoriasis onset and age at diagnosis**

Patients aged ≤ 18 years were included in the paediatric cohort. The mean age of psoriasis onset in paediatric patients was 10.3 ± 4.5 years. The mean age of onset in adult patients was 34.1 ± 16.3 years. Psoriasis was diagnosed about 1 year following disease onset in paediatric patients with a mean age of 11.5 ± 4.4 years when diagnosis was made. Diagnosis of psoriasis in adults was made slightly later. The mean age of diagnosis in adults was 37.9 ± 16.0 years, about 1.5 years after the mean age of onset of symptoms at 36.4 ± 16.1 years. Almost half of the adult patients developed psoriasis between the ages of 11 to 30 years. **Table 3.1** summarizes the age of psoriasis onset according to the age groups in adult and paediatric patients.

Table 3.1 Age of psoriasis onset in adult and paediatric patients.

Adult psoriasis patients		Paediatric psoriasis patients	
Age, years	n=8187 n (%)	Age, years	n=547 n (%)
0-10	259 (3.16)	0-5.99	99 (18.10)
11-20	1767 (21.58)	6-10.99	154 (28.15)
21-30	2001 (24.44)	11-15.99	230 (42.05)
31-40	1496 (18.27)	16-18	64 (11.70)
41-50	1181 (14.43)		
51-60	885 (10.81)		
61-70	461 (5.63)		
71-80	122 (1.49)		
>80	15 (0.18)		

Family history of psoriasis

Data on family history of psoriasis was available for 8,187 adult patients and 547 paediatric patients. Family history of psoriasis was reported by 2,016 (24.6%) of adult patients and 139 (25.4%) of paediatric patients. For adult patients, the most common family member affected by psoriasis was a sibling (678, 33.6%), followed by other non-first-degree relatives (540, 26.8%), father (510, 25.3%) and mother (330, 16.4%). There were 179 (8.9%) adult patients who had a child affected with psoriasis. Non-first-degree relatives were the most affected family members among paediatric patients (59, 42.5%), followed by father (39, 28.1%) and siblings (34, 24.5%). The frequencies of each first-degree relative and other relatives affected by psoriasis are detailed in **Table 3.2**.

Table 3.2 Family history of psoriasis

Family member with psoriasis	Adult patients n=2016 n (%)	Paediatric patients n=139 n (%)
Father	510 (25.30)	39 (28.06)
Mother	330 (16.37)	25 (17.99)
Sibling(s)	678 (33.63)	34 (24.46)
Children	179 (8.88)	0 (0.00)
Others	540 (26.79)	59 (42.45)

**a patient may have more than one family member with psoriasis*

Psoriasis aggravating factors

Psoriasis may be aggravated by various factors. About half of the adult patients, 4,401/8,187 (53.8%) and a third of the paediatric patients, 213/547 (38.9%) reported at least one aggravating factor as shown in **Table 3.3**. Stress (2943, 66.9%), excessive sun exposure (126, 28.8 %) and infection (445, 10.1%) were the three most common aggravating factors in adults. The findings observed in paediatric patients were similar, with stress (109, 51.2%), excessive sun exposure (81, 38.0%) and infection (26, 12.2%) reported as the most common factors.

Upper respiratory tract infection was the most common infection that aggravated psoriasis in both adult and paediatric patients (**Table 3.4**). COVID-19 infection was the second most common infection (25, 14.1%) identified among the adults. About a third of infections, however, were classified as ‘not specified’ in (35, 19.8%) adults.

COVID-19 vaccine (66, 31.1%), corticosteroids (24, 11.3%), supplements and other traditional medications (12, 5.7%) were the agents most implicated in aggravating psoriasis in adult patients. Corticosteroids (5, 50%) and COVID-19 vaccine (3, 30.0%) were the only agents identified in children. (**Table 3.5**).

Table 3.3 Factors aggravating psoriasis in adult and paediatric patients.

Aggravating Factor	Adult patients n=4401 n (%)	Paediatric patients n=213 n (%)
Stress	2943 (66.87)	109 (51.17)
Excessive sun exposure	1269 (28.83)	81 (38.03)
Infection	445 (10.11)	26 (12.21)
Drugs	212 (4.82)	10 (4.69)
Trauma	210 (4.77)	17 (7.98)
Topical treatment	9 (0.24)	0 (0.00)
Hypocalcemia	2 (0.05)	0 (0.00)
Pregnancy	147 (3.34)	0 (0.00)
Smoking	259 (5.89)	0 (0.00)
Alcohol	93 (2.11)	0 (0.00)
Others	418 (9.50)	27 (12.68)

* a patient may have more than one aggravating factor

Table 3.4. Types of infections identified to aggravate psoriasis

Type of Infection	Adult patients n=177 n (%)	Paediatric patients n=10 n (%)
URTI	97 (54.80)	7 (70.00)
COVID-19	25 (14.12)	1 (10.00)
Cellulitis/abscess	4 (2.26)	1 (10.00)
Dengue	3 (1.69)	0 (0.00)
Otitis	3 (1.69)	0 (0.00)
HIV	2 (1.13)	0 (0.00)
Pneumonia	2 (1.13)	0 (0.00)
UTI	2 (1.13)	0 (0.00)
Superficial fungal infection	2 (1.13)	0 (0.00)
TB	1 (0.56)	0 (0.00)
Leptospirosis	1 (0.56)	0 (0.00)
Not specified	35 (19.77)	1 (10.00)

*a patient may have more than one type of infection

URTI - upper respiratory tract infection, HIV - human immunodeficiency virus, UTI - urinary tract infection, TB - tuberculosis

Table 3.5 Drugs identified that aggravate psoriasis

Type of drug	Adult patients n=212 n (%)	Paediatric patients n=10 n (%)
COVID19 vaccine	66 (31.13)	3 (30.00)
Corticosteroids	24 (11.32)	5 (50.00)
Supplements and other traditional medication	12 (5.66)	0 (0.00)
Antibiotics	10 (4.72)	0 (0.00)
β blockers	10 (4.72)	0 (0.00)
NSAIDS	6 (2.83)	0 (0.00)
Chemotherapy	4 (1.89)	0 (0.00)
TCM	4 (1.89)	0 (0.00)
OCP/Hormonal injections	3 (1.42)	0 (0.00)
Methamphetamine	3 (1.42)	0 (0.00)
Insulin	1 (0.47)	0 (0.00)
Calcium channel blocker	1 (0.47)	0 (0.00)
Others	3 (1.42)	0 (0.00)
Not specified	3 (1.42)	2 (20.00)

*a patient may have more than 1 drug as an aggravating factor

NSAIDS - non-steroidal antiinflammatory drugs, OCP - oral contraceptive pill, TCM- traditional and complementary medicine

Outpatient visits, hospital admissions and days off work/school

Most adults (5,343, 65.3%) had 1-5 outpatient visits within a 6-month period, 2,491 (30.4%) did not have any visits at all, a small percentage (275, 3.4%) had 6-10 visits, while 77 (0.9%) patients had more than 10 visits. One hundred and ninety (2.3%) were admitted once or up to 3 times and 11 (0.1%) were admitted more than 3 times. About 314 (4.1%) patients required 1-5 days off work/school, 68 (0.9%) required 6-10 days and 79 (1.0%) required more than 10 days.

In paediatric patients, 357 (65.3%) visited outpatient clinics 1-5 times, 19 (3.5%) 6-10 times and 4 (0.7%) >10 times. About 167 (30.5%) did not visit outpatient clinics at all. Only 14 (2.6%) were admitted 1-3 times, 1 (0.2%) had more than 3 admissions while 532 (97.3%) did not require admission. One to 5 days off school were reported by 18 (3.4%), 12 (2.3%) reported 6-10 days and 9 (1.7%) reported >10 days. Most children (488, 92.6%) did not have any days off school.

Outpatient visits, hospital admissions and days off work/school within a 6-month period for both adult and paediatric patients are summarized in **Table 3.6** below.

Table 3.6 Outpatient visits, hospital admissions and days off work/school within a 6-month period

Event	Adult patients n (%)	Paediatric patients n (%)
Outpatient visit	n=8186	n=547
0	2491 (30.43)	167 (30.53)
1-5	5343 (65.27)	357 (65.27)
6-10	275 (3.36)	19 (3.47)
>10	77 (0.94)	4 (0.73)
Hospital admission	n=8186	n=547
0	7985 (97.54)	532 (97.26)
1-3	190 (2.32)	14 (2.56)
>3	11 (0.13)	1 (0.18)
Days off work/school	n=7615	n=527
0	7154 (93.95)	488 (92.60)
1-5	314 (4.12)	18 (3.42)
6-10	68 (0.89)	12 (2.28)
>10	79 (1.03)	9 (1.71)

CHAPTER 4

COMORBIDITIES

Chapter 4

Comorbidities*Dr Latha Selvarajah*

Psoriasis is associated with multiple comorbidities. A total of 3,419 patients (39.2%) had at least one comorbidity. These comorbidities were mainly seen among the adult patients as compared to the paediatric age group (41.7% vs 2.2%). The common comorbidities among adults were cardiometabolic diseases such as obesity, hypertension, diabetes mellitus, hyperlipidaemia, ischaemic heart disease, cerebrovascular accident and fatty liver. Other comorbidities included depression, inflammatory bowel disease and malignancy. A small proportion of adult patients, 0.7%, had concurrent HIV/AIDS.

Among the cardiometabolic diseases in adults, obesity was the most common comorbidity seen. Most adult patients (62.9%) were overweight/obese with a BMI of ≥ 25 kg/m², while most of the paediatric patients (69.1%) had a BMI of < 25 kg/m² (**Figure 4.1**). The mean BMI for adults was 27.7 ± 6.4 kg/m², while for the paediatric group it was 22.4 ± 7.1 kg/m².

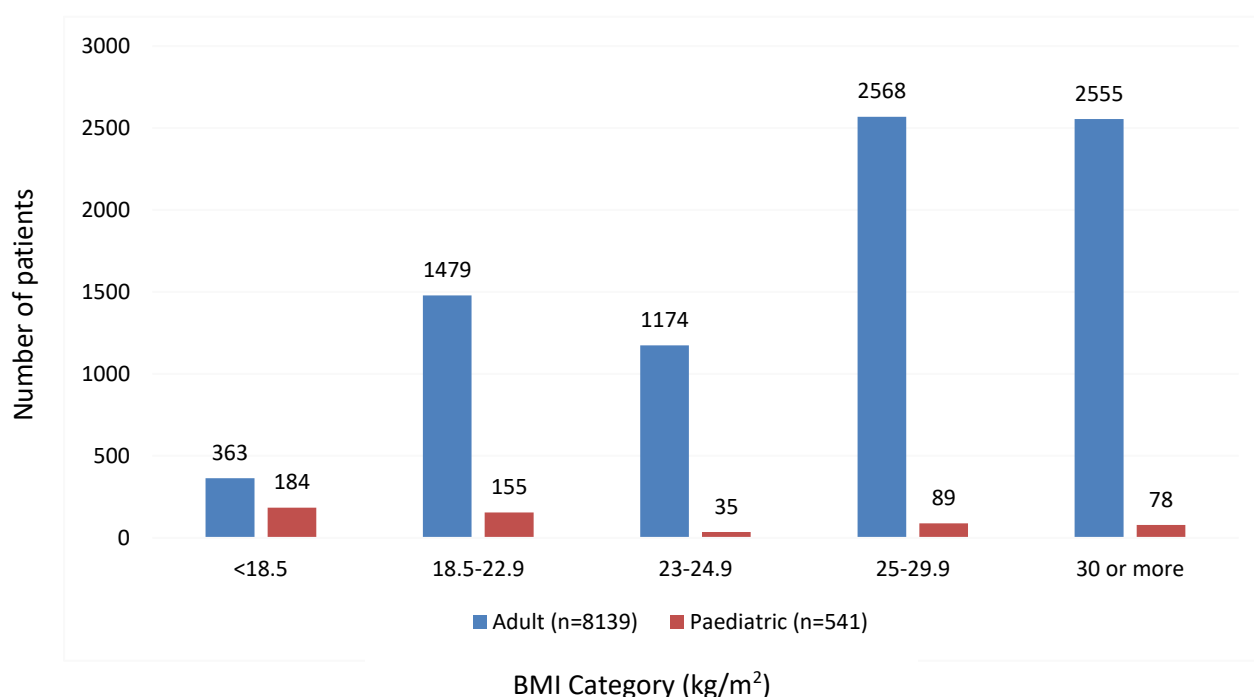


Figure 4.1: Distribution of adult and paediatric patients with psoriasis according to their body mass index (BMI) categories

As for the other cardiometabolic diseases in adults, hypertension was the most prevalent disease (28.5%), followed by hyperlipidaemia (22.7%), diabetes mellitus (19.2%), ischaemic heart disease (4.9%), fatty liver (3.4%) and cerebrovascular accident (1.6%) (**Table 4.1**)

A small proportion of adult patients had concurrent malignancy (100 patients, 1.2%). The most common malignancy seen was breast carcinoma (26 patients, 26.0%). The prevalence of comorbidities among adult patients with psoriasis is shown in **Table 4.1**.

Most paediatric psoriasis patients had no associated comorbidities (**Table 4.2**). The commonest comorbidity encountered among paediatric patients was obesity (14.4%). There were 2 patients who had concurrent malignancy, ie lymphoma.

Table 4.1: Prevalence of comorbidities among adult patients with psoriasis

Comorbidity	Adult	
	n	%
Obesity (n=8139)	2555	31.4
Hypertension (n=8187)	2334	28.5
Hyperlipidaemia (n=8187)	1857	22.7
Diabetes mellitus (n=8187)	1574	19.2
Ischaemic heart disease (n=8187)	398	4.9
Fatty liver (n=8186)	280	3.4
Cerebrovascular accident (n=8187)	135	1.6
Depression (n=8187)	105	1.3
Malignancy (n=8165)	100	1.2
HIV/AIDS (n=8187)	56	0.7
Inflammatory bowel disease (n=8187)	6	0.07

Table 4.2: Prevalence of comorbidities among paediatric patients with psoriasis

Comorbidity	Paediatric	
	n	%
Obesity (n=541)	78	14.4
Hypertension (n=547)	6	1.1
Hyperlipidaemia (n=547)	3	0.5
Diabetes mellitus (n=547)	4	0.7
Depression (n=547)	1	0.2
Malignancy (n=546)	2	0.4

CHAPTER 5

CLINICAL PRESENTATION

Chapter 5

Clinical Presentation
Dr Rajalingam Ramalingam

A total of 8,813 patients with psoriasis were registered between 2020 and 2022, out of which adults made up 93.6%. Plaque psoriasis was the most common type of psoriasis in both the adult and paediatric populations. In adult patients, plaque psoriasis accounted for 94.4%, followed by erythrodermic psoriasis 1.7% and guttate psoriasis 1.6%. In paediatric patients, plaque psoriasis accounted for 90.0%, followed by guttate psoriasis 3.5% and both erythrodermic and generalized pustular psoriasis 2.6% each. (**Table 5.1**).

Table 5.1 Type of psoriasis in adult and paediatric patients

Type of psoriasis	Adult		Paediatric	
	n	%	n	%
Plaque	7710	94.4	493	90.0
Erythrodermic	142	1.7	14	2.6
Guttate	132	1.6	19	3.5
Generalized pustular	127	1.6	14	2.6
Flexural/Inverse	27	0.3	4	0.7
Localized pustular	25	0.3	2	0.4
Palmoplantar non-pustular	14	0.2	2	0.4
Total	8168	100	548	100

Itch was experienced by 77.5% of adults and 76.8% of children, while pain was experienced by only 14.0% of adults and 11.3% of children. (**Table 5.2, Table 5.3**).

Table 5.2 Itch in adult and paediatric patients with psoriasis

Itch	Adult		Paediatric	
	n	%	n	%
Yes	6189	77.5	408	76.8
No	1795	22.5	123	23.2
Total	7984	100	531	100

Table 5.3 Pain in adult and paediatric patients with psoriasis

Pain	Adult		Paediatric	
	n	%	n	%
Yes	1099	14.0	59	11.3
No	6748	86.0	462	88.7
Total	7847	100	521	100

The mean body surface area (BSA) involvement in adult patients was 12.2 ± 17.9 (minimum 0%, maximum 100%), while the mean BSA involvement in paediatric patients was 11.6 ± 19.6 (minimum 0%, maximum 100%). Most of the adult and paediatric patients had a BSA involvement of 0 – 10% (74.2% and 79.7% respectively) (Table 5.4).

Table 5.4 Body surface area involvement in adult and paediatric patients with psoriasis

Body surface area involved	Adult		Paediatric	
	n	%	n	%
0 – 10%	5962	74.2	428	79.7
11 – 20%	938	11.7	35	6.5
21 – 30%	368	4.6	25	4.6
31 – 40%	187	2.3	10	1.9
41 – 50%	177	2.2	9	1.7
51 – 60%	97	1.2	8	1.5
61 – 70%	99	1.2	0	0
71 – 80%	98	1.2	7	1.3
81 – 90%	76	0.9	10	1.9
91 – 100%	33	0.4	5	0.9
Total	8035	100	537	100

The mean psoriasis area and severity index (PASI) score in adult patients was 6.5 ± 8.3 (minimum 0, maximum 72), while the mean PASI score in paediatric patients was 6.6 ± 9.8 (minimum 0, maximum 72). Most of the adult and paediatric patients had a PASI score of 0 – 5 (63.1% and 67.2% respectively) (Table 5.5).

Table 5.5 PASI scores in adult and paediatric patients with psoriasis

PASI score	Adult		Paediatric	
	n	%	n	%
0 – 5	4183	63.1	303	67.2
5.1 – 10	1275	19.3	70	15.5
>10	1167	17.6	78	17.3
Total	6625	100	451	100

Most of the adult patients with psoriasis had nail involvement (57.7%) (**Table 5.6**). Among adult patients who had psoriatic nail disease, most of them had pitting (69.9%). Other common features were onycholysis (49.3%), discoloration (16.3%) and subungual hyperkeratosis (12.4%). Total nail dystrophy was found in 5.8% of adult patients with nail involvement. There were 232 (42.3%) paediatric patients with nail involvement (**Table 5.6**). Most of them had pitting (83.2%), followed by onycholysis (29.3%), discoloration (10.3%), subungual hyperkeratosis (8.6%) and total nail dystrophy (3.4%).

Table 5.6 Nail involvement and nail features in adult and paediatric patients with psoriasis

Nail involvement	Adult		Paediatric	
	n	%	n	%
Yes	4723	57.7	232	42.3
No	3459	42.3	316	57.7
Total	8182	100	548	100
Nail features	n	%	n	%
Pitting	3301	69.9	193	83.2
Onycholysis	2329	49.3	68	29.3
Discoloration	770	16.3	24	10.3
Subungual hyperkeratosis	588	12.4	20	8.6
Total nail dystrophy	274	5.8	8	3.4

Psoriatic arthropathy was reported in 18.8% of the adult patients, while only 2.7% of the paediatric patients had joint disease (**Table 5.7**).

Table 5.7 Joint disease and type of joint disease in adult and paediatric patients with psoriasis

Joint disease	Adult		Paediatric	
	n	%	n	%
Yes	1538	18.8	15	2.7
No	6644	81.2	533	97.3
Total	8182	100	548	100
<hr/>				
Under care of rheumatologist	954	62.0	6	40.0
Symptomatic	1188	77.2	15	100
Enthesitis/dactylitis	265	17.2	3	20.0
Deformity	239	15.5	0	0
<hr/>				
Symptoms				
Morning stiffness	684	57.6	5	33.3
Joint pain	1065	89.6	15	100
Swelling	153	12.9	2	13.3
<hr/>				
Type of joint disease (one or multiple)				
Oligo-/Monoarthropathy	468	30.4	7	46.7
Distal hand joints arthropathy	493	32.1	3	20.0
Symmetrical polyarthropathy (Rheumatoid like)	441	28.7	3	20.0
Spondylitis / Sacroiliitis	147	9.6	0	0
Arthritis mutilans	29	1.9	0	0

In adult patients, the most common type of psoriatic arthropathy was distal hand joint arthropathy (32.1%). This was followed by oligo-/monoarthropathy (30.4%), rheumatoid-like symmetrical polyarthropathy (28.7%), spondylitis/sacroiliitis (9.6%) and arthritis mutilans (1.9%). In paediatric patients, the most common type of psoriatic arthropathy was oligo-/monoarthropathy (46.7%), followed by distal hand joint arthropathy (20.0%) and rheumatoid-like symmetrical polyarthropathy (20.0%). (**Table 5.7**).

Among adult patients with joint disease, 62.0% were under the care of a rheumatologist, while 77.2% were symptomatic. Among the paediatric patients, 40.0% were under the care of a rheumatologist, while all were symptomatic. Enthesitis/dactylitis was found in 17.2% of adults and 20.0% of children, while joint deformity was found in 15.5% of adult patients but none in children. Among those suffering from symptomatic joint disease, joint pain was the commonest symptom among adults (89.6%) and children (100%), followed by morning stiffness (57.6% of adults, 33.3% of children) and joint swelling (12.9% of adults, 13.3% of children). (**Table 5.7**).

Approximately a third of adult patients and 26.9% of paediatric patients with psoriasis had involvement of special sites (face, genital, scalp, tongue, eye). (**Table 5.8**).

Table 5.8 Special sites involvement in adult and paediatric patients with psoriasis

Special sites involvement	Adult		Paediatric	
	n	%	n	%
Yes	2732	33.8	147	26.9
No	5356	66.2	399	73.1
Total	8088	100	546	100
Face				
Yes	2236	27.8	173	31.4
No	5814	72.2	378	68.6
Total	8050	100	551	100
Genital				
Yes	361	4.5	50	9.2
No	7624	95.5	496	90.8
Total	7985	100	546	100
Scalp				
Yes	4776	58.8	348	62.3
No	3342	41.2	211	37.7
Total	8118	100	559	100
Tongue				
Yes	3	0.04	1	0.2
No	7981	99.96	544	99.8
Total	7984	100	545	100
Eye				
Yes	38	0.5	10	1.8
No	7949	99.5	535	98.2
Total	7987	100	545	100

CHAPTER 6A

TREATMENT:

Topical, Phototherapy & Systemic

Chapter 6A

Treatment: Topical, Phototherapy & Systemic*Dr Tang Min Moon*

Analysis of the data showed that the treatment received by the patients in the last 6 months comprised of topical therapy, phototherapy, systemic treatment and biologics. About 89.3% of the adults and 84.2% of the paediatric patients used some form of topical medication for psoriasis. As shown in Table 6.1a, the most used topical medication for both paediatric and adult groups was topical corticosteroids. This was followed by emollients, tar preparations, keratolytics, vitamin D analogues such as calcipotriol and calcipotriol/betamethasone dipropionate fixed-dose combination. Dithranol was less favoured and used in about 1.1% of the patients. Calcineurin inhibitors were used in 2.4% of the patients.

Table 6.1a Topical therapy in adult and paediatric patients with psoriasis

	Paediatric* n=549 (%)	Adult# n=8177 (%)	Total n=8726 (%)
Topical therapy	462 (84.2)	7300 (89.3)	7762 (89.0)
<i>Type of topical therapy</i>			
Tar preparations	257 (55.6)	4604 (63.1)	4861 (62.6)
Topical corticosteroids	420 (90.9)	6831 (93.6)	7251 (93.4)
Vitamin D analogues	40 (8.7)	660 (9.0)	700 (9.0)
Keratolytics eg salicylic acid	169 (36.6)	3740 (51.2)	3909 (50.4)
Calcipotriol with Betamethasone Dipropionate	86 (18.6)	2446 (33.5)	2532 (32.6)
Emollient	361 (78.1)	6130 (84.0)	6491 (83.6)
Calcineurin inhibitors	26 (5.6)	163 (2.2)	189 (2.4)
Dithranol (anthralin)	8 (1.7)	76 (1.0)	84 (1.1)

* missing data –12; # missing data – 75

Phototherapy was prescribed to 9 children (1.6%) and 235 adults (2.9%) with psoriasis. Narrowband UVB (NBUVB) was the preferred mode of phototherapy and it was used in all the 9 children and in 88% of the adults who underwent phototherapy (**Table 6.2a**). Phototherapy was indicated but was not given for another 4,851 patients. Of these, 1,513 patients did not receive phototherapy for the reasons mentioned in **Table 6.3a**.

Table 6.2a Phototherapy in adult and paediatric patients with psoriasis

	Paediatric [^] n=550 (%)	Adult [§] n=8178 (%)	Total n=8728 (%)
Phototherapy	9 (1.6)	235 (2.9)	244 (2.8)
<i>Type of phototherapy</i>			
BBUVB	0 (0)	9 (3.8)	9 (3.7)
NBUVB	9 (100)	206 (87.7)	215 (88.1)
Oral PUVA	0 (0)	1 (0.4)	1 (0.4)
Topical PUVA	0 (0)	1 (0.4)	1 (0.4)
Bath PUVA	0 (0)	1 (0.4)	1 (0.4)
Excimer laser	0 (0)	0 (0)	0 (0)

[^]missing data – 11, [§]missing data – 74; BBUVB – broadband ultraviolet B, NBUVB- narrowband ultraviolet B, PUVA- psoralen + ultraviolet A

Table 6.3a Reasons for phototherapy not being used in 1513 patients who were indicated

Reason	Paediatric n=65 (%)	Adult n=1448 (%)	Total n=1513 (%)
Patient refusal	16 (24.6)	535 (36.9)	551 (36.4)
Adverse events	0 (0)	17 (1.2)	17 (1.1)
Contraindicated	3 (4.6)	29 (2.0)	32 (2.1)
Poor response or failure	3 (4.6)	103 (7.1)	106 (7.0)
Others*	43 (66.2)	765 (52.8)	808 (53.4)

*include logistic issue, machine not available, machine breakdown etc

A patient may have more than one reason

Systemic therapy was used in 32.1% of adult patients and 13.5% of paediatric patients with psoriasis (**Table 6.4a**). The most common systemic agent prescribed was methotrexate in both age groups of patients, followed by acitretin. Systemic corticosteroids were used in 15 patients with 26.7% of them having psoriatic arthropathy and 20% of them having either erythrodermic psoriasis, generalized pustular psoriasis or localized pustular psoriasis. Sulfasalazine was only prescribed to adults (4.3%) to treat psoriatic arthropathy. Systemic therapy was indicated but was not used for another 3,344 patients. Of these, 812 patients were not given systemic therapy for the reasons mentioned in **Table 6.5a**.

Table 6.4a Systemic therapy in adult and paediatric patients with psoriasis

	Paediatric [¥] n= 549 (%)	Adult [€] n= 8177 (%)	Total n= 8726 (%)
Systemic therapy	74 (13.5)	2624 (32.1)	2698 (30.9)
<i>Type of systemic therapy</i>			
Methotrexate	43 (58.1)	1938 (73.9)	1981 (73.4)
Acitretin	31 (41.9)	614 (23.4)	645 (23.9)
Systemic corticosteroids	0 (0)	15 (0.6)	15 (0.6)
Cyclosporine	4 (5.4)	174 (6.6)	178 (6.6)
Sulfasalazine	0 (0)	112 (4.3)	112 (4.2)

[¥]missing data- 12, [€]missing data- 75

Table 6.5a Reasons for systemic therapy not being used in 812 patients who were indicated

Reason	Paediatric n= 50 (%)	Adult n= 762 (%)	Total n=812 (%)
Patient refusal	9 (18.0)	226 (29.7)	235 (28.9)
Adverse events	0 (0)	31 (4.1)	31 (3.8)
Contraindicated	0 (0)	32 (4.2)	32 (3.9)
Poor response or failure	0 (0)	8 (1.0)	8 (1.0)
Others*	41 (82.0)	469 (61.5)	510 (62.8)

**Include logistic issue, lost to follow up, option not offered to the patients etc.*

A patient may have more than one reason

CHAPTER 6B

TREATMENT: Biologic Therapy

Chapter 6B

Treatment: Biologic Therapy*Dr Loo Chai Har*

The MPR registered 8,813 individuals with psoriasis from 2020 to 2022, including 8,252 adults and 561 children. A total of 386 patients (4.4%) were treated with biological agents. Of these, 377 (97.7%) were adults while 9 (2.3%) were paediatric patients. The mean age of adult patients on biologic therapy was 43.4±13.6 years (18.3 - 83.1 years old) while the mean age of paediatric patients was 14.5 ±3.4 years (8.4-17.2 years old). **Table 6.1b** shows the types of biological agents used. The most common agent prescribed was secukinumab (54.9%), followed by ustekinumab (25.1%) and adalimumab (6.5%).

Table 6.1b Biologic therapy in adult and paediatric patients with psoriasis

Biological agents	Adult, n (%)	Paediatric, n (%)	Total, n (%)
Secukinumab	204 (54.1)	8 (88.9)	212 (54.9)
Ustekinumab	96 (25.5)	1 (11.1)	97 (25.1)
Adalimumab	25 (6.6)	0	25 (6.5)
Guselkumab	23 (6.1)	0	23 (6.0)
Risankizumab	16 (4.2)	0	16 (4.1)
Ixekizumab	13 (3.5)	0	13 (3.4)
Total	377	9	386 (100)

Comorbidities among patients on biologic treatment

Liver disease (54, 14.3%) was the most common comorbidity among patients on biologic treatment with fatty liver being the commonest cause. This was followed by history of tuberculosis (24, 6.4%) (**Table 6.2b**). Only one child was diagnosed with latent tuberculosis (TB).

Previous systemic treatment prior to current biologic therapy

Among those on biologic treatment, 330 adults (89.2%) and 8 children (88.9%) had received prior conventional systemic treatment and biologic therapy. Methotrexate was the most often prescribed medication for both age groups, with 245 (74.2%) and 7 (87.5%) adult and paediatric patients, respectively. This was followed by acitretin (123 adults; 4 children) and ciclosporin (112 adults; 6 children). Phototherapy was prescribed to 120 (36.4%) adult patients with psoriasis while only 3 (37.5%) children received it. (**Figure 6.1b**) Sixty-one (18.5%) adult patients had previous exposure to biological agents. The most used biological agent was ustekinumab (24, 39.3%), followed by adalimumab (17, 27.9%) and secukinumab (15, 24.6%). Only one child (12.5%) had received adalimumab prior to current biological use.

Table 6.2b Comorbidities among patients receiving biologic therapy

	Adult (n=377) n (%)	Paediatric (n=9) n (%)
History of Tb	24 (6.4%)	1 (11.1%)
- Latent Tb	19 (79.2%)	1 (11.1%)
- Extrapulmonary Tb	3 (12.5%) (2 pleural Tb, 1 spine Tb)	0
- Pulmonary Tb	2 (8.3%)	0
History of cancer	7 (1.9%)	0
- Breast cancer	2 (28.6%)	0
- Germ Cell Tumour	1 (14.3%)	0
- Thyroid papillary carcinoma	1 (14.3%)	0
- Vocal cord carcinoma	1 (14.3%)	0
- Lymphoma	1 (14.3%)	0
- Skin		0
History of liver disease	54 (14.3%)	0
- Fatty liver	38 (70.4%)	0
- Hepatitis B	5 (9.3%)	0
- Hepatitis C	2 (3.7%)	0
- Liver cirrhosis	4 (7.4%)	0
- NAFLD	1 (1.9%)	0
- Methotrexate induced liver injury	3 (5.6%)	0
- Transaminitis secondary to acitretin	1 (1.9%)	0
History of neurological disease	2 (0.5%) (1 traumatic PID and 1 TIA)	0
History of cardiovascular disease	14* (3.7%)	0
- Ischaemic heart disease	9 (64.3%)	0
- Non-valvular atrial fibrillation	1 (7.1%)	0

*Missing data – 4; Tb-tuberculosis, PID-pelvic inflammatory disease, TIA-transient ischaemic attack

Reasons of stopping previous systemic treatment

Prior systemic treatments were discontinued for a variety of reasons, including inadequate response, treatment intolerance, or acquired adverse effects. The patients' inadequate response to the medication remained the most frequent cause. Of the patients receiving biological therapy, 17 patients had additional reasons for stopping their treatment, including financial restrictions (n=9), secondary failure (n = 2), worsening of psoriatic arthritis (n = 1) and

treatment default (n = 1). One child discontinued adalimumab due to poor response (**Table 6.3b**).

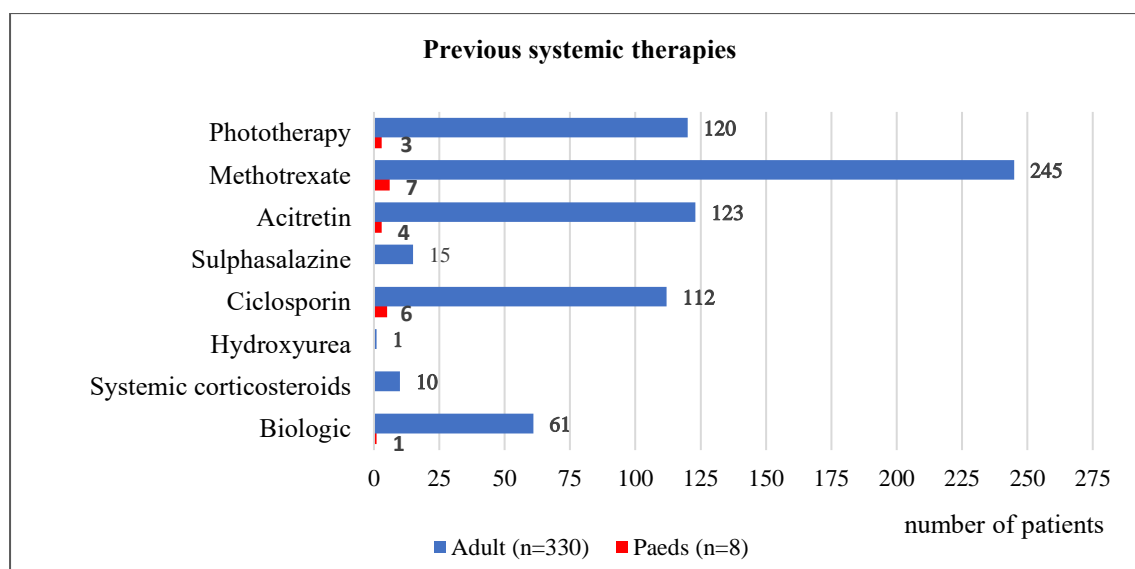


Figure 6.1b: Previous systemic therapies in patients receiving biologic treatment

Table 6.3b: Reasons for stopping previous treatment in patients with psoriasis on biologic therapy

		Poor response n (%)	Intolerance n (%)	Adverse effect n (%)
Adult	Phototherapy, n=120	91 (75.8)	18 (15.0)	5 (4.2)
	Methotrexate, n=245	189 (77.1)	31 (12.7)	55 (22.4)
	Acitretin, n=123	105 (85.4)	10 (8.1)	20 (16.3)
	Ciclosporin, n=112	80 (71.4)	7 (6.3)	22 (19.6)
	Sulfasalazine, n=13	9 (69.2)	1 (7.7)	2 (15.4)
	Other biologics, n=61	37 (60.7)	0	4 (6.6)
Paediatric	Phototherapy, n=3	2 (66.7)	1 (33.3)	0
	Methotrexate, n=7	6 (85.7)	1 (14.3)	0
	Acitretin, n=4	3 (75.0)	1 (25.0)	0
	Ciclosporin, n=6	5 (83.3)	0	1 (16.7)

Concomitant systemic treatment

Concomitant systemic treatment was prescribed to 111 (29.8%) patients (105 adults; 6 children). None of the patients had concomitant phototherapy. Methotrexate was the most common concomitant agent used in 69 (65.7%) adults and 5 (83.3%) children. This was followed by acitretin (18, 17.1% adults; 1 child, 16.7%) and ciclosporin (13, 12.4% adults).

Three adult patients were on sulfasalazine while 2 on leflunomide. No concomitant systemic corticosteroid was used.

Indications for biologic treatment

Nearly 80% of adult patients and 88.9% of children failed phototherapy and standard systemic therapy before commencing biological treatment. Fifty-one (13.5%) adult patients had intolerance to phototherapy and standard systemic therapy while 15 (4.0%) patients were contraindicated for phototherapy or standard systemic treatment. (**Table 6.4b**)

Table 6.4b: Indications for biologic treatment

Indication	Adult (n=377) n (%)	Paediatric (n=9) n (%)
Phototherapy and standard systemic therapy are contraindicated, n (%)	15 (4.0)	0
Intolerant to phototherapy and standard systemic therapy, n (%)	51 (13.5)	0
Failed phototherapy and standard systemic therapy, n (%)	300 (79.6)	8 (88.9)
Others, n (%)	11 (2.9)	1 (11.1)
• Primary failure to biologic	1	0
• Secondary failure to biologic	2	0
• Refused conventional systemic treatment/phototherapy	3	0
• Special site involvement	2	0
• Not specified	3	1

Screening tests prior to biologic therapy initiation

Table 6.5b shows the pre-screening investigations done prior to biological therapy initiation. Mantoux testing was carried out in 235 patients (60.9%) of which 11 (4.8%) were positive. Whereas interferon gamma release assay (IGRA) was done for 95 patients which yielded positive results for nine (2.3%) patients. Nine (2.3%) patients had abnormal chest X-ray results. Among the paediatric group, only one child had a Mantoux test reading of 15mm or higher. Two adults tested HIV positive.

Source of funding

More than half of the paediatric patients received funding from the Jabatan Perkhidmatan Awam (JPA), 1 (11.1%) from government hospital funding and 1 (11.1%) received free

samples for biologic therapy. In contrast, one-third of adult patients (31.3%) received financial assistance from JPA, 58 (15.4%) from government hospital funding, 41(10.9%) from Tabung Bantuan Perubatan (TBP), 41 (10.9%) from free samples and 33 (8.7%) were self-funded as shown in **Figure 6.2b**.

Table 6.5b Screening tests prior to biologic therapy initiation

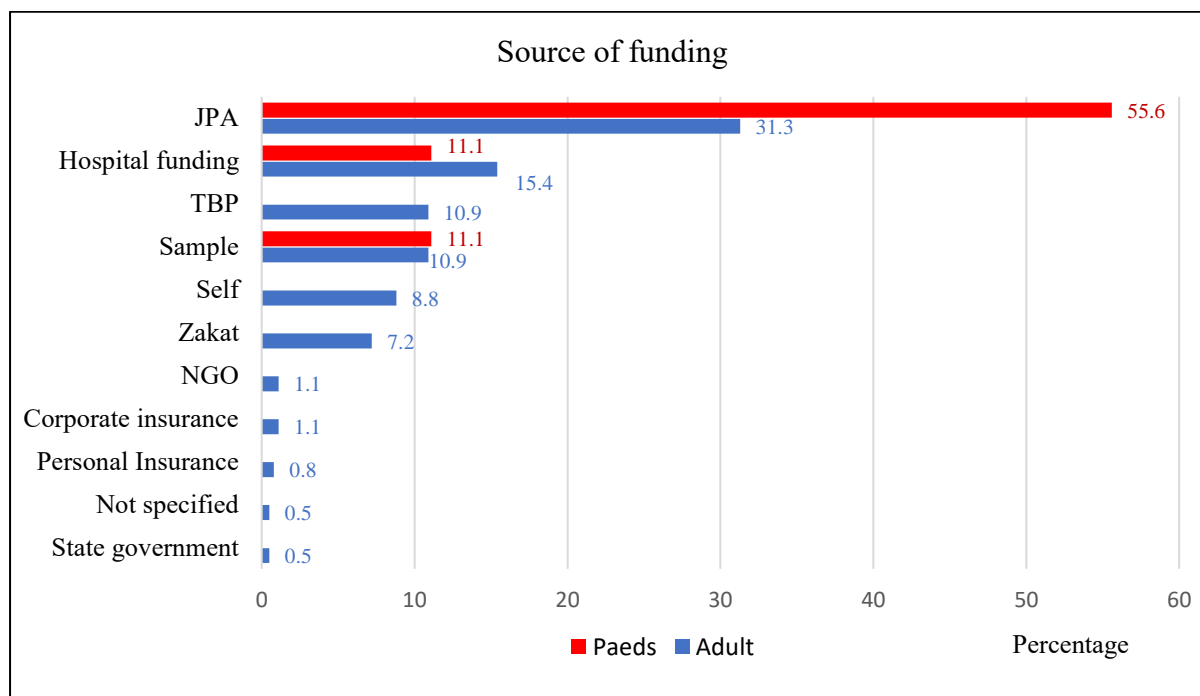
	Adult n (%)	Paediatric n (%)	Total n (%)
*Mantoux reading, n (%)			
0-4 mm	190 (59.1)	4 (44.5)	194 (58.8)
5-9 mm	14 (4.4)	1 (11.1)	15 (4.6)
10-14 mm	14 (4.4)	0	14 (4.2)
15mm or more	11 (3.4)	1 (11.1)	12 (3.6)
Not done	92 (28.7)	3 (33.3)	95 (28.8)
~Interferon Gamma Release Assay, (IGRA) n (%)			
Indeterminate	1 (0.3)	0	1 (0.3)
Negative	82 (24.9)	3 (37.5)	85 (25.2)
Positive	9 (2.7)	0	9 (2.7)
Not available	237 (72.1)	5 (62.5)	242 (71.8)
¹ Chest X-ray, n (%)			
Abnormal	9 (2.6)	0	9 (2.6)
Normal	299 (87.5)	8 (88.9)	307 (87.5)
Not available	34 (9.9)	1 (11.1)	35 (9.9)
[#] Hepatitis B, n (%)			
Positive	8 ^{††} (2.3)	0	8 (2.2)
Negative	329 (94.0)	7 (77.8)	336 (93.6)
Not available	13 (3.7)	2 (22.2)	15 (4.2)
[‡] Hepatitis C, n (%)			
Positive	3 (0.9)	0	3 (0.9)
Negative	335 (95.2)	7 (77.8)	342 (94.7)
Not available	14 (3.9)	2 (22.2)	16 (4.4)
[‡] HIV, n (%)			
Positive	2 (0.5)	0	2 (0.6)
Negative	334 (95.2)	6 (66.7)	340 (94.4)
Not available	15 (4.3)	3 (33.3)	18 (5)

Missing data: *55 adults; ~48 adults and 1 paediatric; ¹35 adults; [#]27 adults; [‡]25 adults; [‡]26 adults. ^{††}Of the 8 positive, 2 are HBsAg positive and 6 are HBcAb positive

Adverse events

Of the 386 patients on biologic treatment, only 293 patients had follow-up data at 3 months (291 adults and 2 children). Of these, none of the paediatric patients experienced adverse effects

(Table 6.7b). The most common adverse events encountered in adults were worsening of psoriasis after initiation of biological treatment (10, 3.4%) followed by upper respiratory tract infection (2, 0.7%) and cellulitis (2, 0.7%). None of the patients experienced any major adverse cardiac event (MACE), skin cancer, or injection site reaction.



adult- 44 missing data; paediatric group- 2 missing data

JPA- Jabatan Perkhidmatan Awam; TBP- Tabung Bantuan Perubatan; NGO- Non-government organisation

Figure 6.2b: Source of funding for biologic treatment

Modification to biologic therapy

At three months, there were modifications to the biologic therapy (discontinuation, dosage, or switching to another agent) among adult patients as shown in Table 6.7b. The main reasons for modification were primary failure (6, 30%), secondary loss of efficacy (5, 25%), financial restrictions (4, 20%), sample stock availability (3, 15%) and adverse events (2, 10%).

Table 6.6b Adverse events to biologic therapy for adult and paediatric patients

	Adults (n=291)	Paeds (n=2)
Skin cancer	0	0
Infection		
• Tuberculosis reactivation	0	0
• Candidiasis	1	0
• Herpes simplex	0	0
• URTI	2	0
• Pneumonia	0	0
• Cellulitis	2	0
• Folliculitis	0	0
• Other infections	4	0
UTI	1	0
Dermatophytosis	1	0
COVID-19	1	0
Molluscum contagiosum	1	0
Worsening of psoriasis	10	0
Neuropsychiatry disorders		
• Demyelinating disease	0	0
• Epilepsy	0	0
• Psychiatric disorder	1 (adjustment disorder)	0
Autoimmune disease	1 (bullous pemphigoid)	0
Injection site reaction	0	0
MACE	0	0
others		
• Lichenoid dermatitis	1	0
• Transaminitis	1	0

URTI- upper respiratory tract infection, UTI-urinary tract infection, COVID-19-coronavirus disease, MACE-major adverse cardiovascular event

A patient may have more than 1 adverse event.

Table 6.7b Modification in biologic treatment at 3 months

Modification in biological treatment at 3 months	Number of patients
Change in current biologic dosage	1 (ustekinumab)
Change to another biological agent	10
Change to another systemic agent	2 (1 acitretin, 1 ciclosporin)
Withhold biologic treatment	4 (3 secukinumab, 1 adalimumab)
Change in biologic treatment interval	3 (2 ustekinumab, 1 guselkumab)
Total	20

CHAPTER 7

QUALITY OF LIFE

Chapter 7

Quality of Life*Dr Tang Min Moon*

The Dermatology Life Quality Index (DLQI) is an adult self-reported quality of life (QoL) questionnaire specific to dermatology. Each question is scored from 0 to 3 (0 indicates ‘not at all’, 3 indicates ‘very much’), and are summed up to obtain the total score.¹ Total scores ranged from 0 (no impairment) to 30 (maximum impairment). A DLQI score of more than 10 (i.e. 11-30) implies a very large or extremely large effect on the patient’s quality of life.¹ If two or more questions are left unanswered the questionnaire is not scored.

The Children’s Dermatology Life Quality Index (CDLQI) is designed to measure the impact of any skin disease on the lives of children.² The questionnaires are self-explanatory and can be simply handed to the patient who is asked to fill them in with the help of the child’s parent or guardian, as necessary.² A CDLQI score of more than 12 (i.e. 13-30) implies a very large or extremely large effect on the patient’s QoL.²

Of the 8,813 patients who were registered to the MPR, 8,296 (of 8,341 patients aged 17 and above) and 407 (of 472 patients aged less than 17 years) completed the QoL questionnaires, namely Dermatology Life Quality Index (DLQI) and Child Dermatology Life Quality Index (CDLQI) respectively. For those who had had QoL assessment done more than once, the latest assessment was used for analysis.

The mean DLQI for adult psoriasis patients was 8.9 ± 7.0 , and the mean CDLQI for paediatric patients was 7.9 ± 6.0 . The responses for each question of the DLQI and CDLQI are tabulated in **Table 7.1** and **7.2** respectively. A DLQI of more than 10 was reported in 2,978 (35.9%) adult patients, indicating significant impairment of QoL due to psoriasis or its treatment. There were 611 adults (7.4%) who had a DLQI > 20 indicating an extremely large effect on their QoL by psoriasis. Nevertheless, 14.9% of adult patients reported no effect at all on their QoL (**Figure 7.1**). As shown in **Figure 7.2**, “symptoms and feelings” was the DLQI domain that most affected the adult group with 38.9% affected “very much” or “a lot” by itch and pain as well as embarrassment due to psoriasis. The domain that least affected them was “personal relationship” in which 87.2% of the adult patients were affected “a little” or “not at all”.

In the paediatric group, 21.8% of patients reported a CDLQI of more than 12 indicating a very large or extremely large effect on their QoL (**Figure 7.3**). There were 27 patients (6.6%) who had a CDLQI of more than 19, reflecting an extremely large effect on the QoL. On the other hand, 14.5% of the paediatric patients reported no effect at all on their QoL. For the paediatric patients, the CDLQI domain most affected was “symptoms and feelings”, in which 36.9% reported that psoriasis affected them ‘very much’ or ‘a lot’. The aspect of life least affected by psoriasis was “personal relationship” in which 85.7% of the children were not affected at all or affected only a little (**Figure 7.4**). These results were similar to that in the adult patients.

¹ Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)—a simple practical measure for routine clinical use. *Clin Exp Dermatol.* 1994;19(3):210-6.

² Lewis-Jones MS, Finlay AY. The Children's Dermatology Life Quality Index (CDLQI): initial validation and practical use. *Br J Dermatol.* 1995;132(6):942-949

Table 7.1 Responses for Dermatology Life Quality Index in patients with psoriasis (age 17 years and above)

Section	Questions	n	Number of responses (%)				
			Very much	A lot	A little	Not at all	Not relevant
Symptoms & feelings	<i>Over the last week, how itchy, sore, painful, or stinging has your skin been?</i>	8296	1028 (12.4%)	2357 (28.4%)	3872 (46.7%)	1039 (12.5%)	
	<i>Over the last week, how embarrassed or self-conscious have you been because of your skin?</i>	8296	1190 (14.3%)	1876 (22.6%)	2835 (34.2%)	2395 (28.9%)	
Daily activities	<i>Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?</i>	8296	759 (9.1%)	1620 (19.5%)	2763 (33.3%)	2916 (35.1%)	238 (2.9%)
	<i>Over the last week, how much has your skin influenced the clothes you wear?</i>	8296	757 (9.1%)	1602 (19.3%)	2732 (32.9%)	2934 (35.4%)	271 (3.3%)
Leisure	<i>Over the last week, how much has your skin affected any social or leisure activities?</i>	8296	726 (8.8%)	1512 (18.2%)	2590 (31.2%)	3151 (38.0%)	317 (3.8%)
	<i>Over the last week, how much has your skin made it difficult for you to do any sport?</i>	8296	657 (7.9%)	1308 (15.8%)	2289 (27.6%)	3327 (40.1%)	715 (8.6%)
Work and school	<i>Over the last week, has your skin prevented you from working or studying?</i>	8296	541 (6.5%)			6888 (83.0%)	867 (10.5%)
	<i>If "No", over the last week how much has your skin been a problem at work or studying?</i>	6827		1013 (14.8%)	1887 (27.6%)	3927 (57.5%)	
Personal relationship	<i>Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?</i>	8296	416 (5.0%)	946 (11.4%)	2347 (28.3%)	4008 (48.3%)	579 (7.0%)
	<i>Over the last week, how much has your skin caused sexual difficulties?</i>	8296	253 (3.0%)	513 (6.2%)	1380 (16.6%)	4000 (48.2%)	2150 (25.9%)
Treatment	<i>Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy or by taking up time?</i>	8296	575 (6.9%)	1118 (13.5%)	2517 (30.3%)	3444 (41.5%)	642 (7.7%)

Table 7.2 Responses for Children’s Dermatology Life Quality Index in psoriasis patients (aged 4 to 16 years)

Section	Questions	n	Number of responses (%)			
			Very much	A lot	A little	Not at all
Symptoms & feelings	<i>Over the last week, how itchy, “scratchy”, sore, painful, or stinging has your skin been?</i>	407	41 (10.1%)	122 (30%)	186 (45.7%)	58 (14.3%)
	<i>Over the last week, how embarrassed or self-conscious, upset or sad have you been because of your skin?</i>	407	54 (13.3%)	84 (20.6%)	140 (34.4%)	129 (31.7%)
Leisure	<i>Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?</i>	407	19 (4.7%)	67 (16.5%)	123 (30.2%)	198 (48.6%)
	<i>Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?</i>	407	25 (6.1%)	66 (16.2%)	142 (34.9%)	174 (42.8%)
	<i>Over the last week, how much have you avoided swimming or other sports because of your skin trouble?</i>	407	25 (6.1%)	45 (11.1%)	104 (25.6%)	233 (57.2%)
School or holidays	<i>If school time: Over the last week, how much did your skin problem affect your school work? Or If holiday time: How much over the last week, has your skin problem interfered with your enjoyment of the holiday?</i>	407	20 (4.9%)	51 (12.5%)	116 (28.5%)	220 (54.1%)
Personal relationship	<i>Over the last week, how much has your skin affected your friendships?</i>	407	12 (2.9%)	59 (14.5%)	96 (23.6%)	240 (59.0%)
	<i>Over the last week, much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?</i>	407	14 (3.4%)	31 (7.6%)	90 (22.1%)	272 (66.8%)
Sleep	<i>Over the last week, how much has your sleep been affected by your skin problem?</i>	407	16 (3.9%)	53 (13.0%)	119 (29.2%)	219 (53.8%)
Treatment	<i>Over the last week, how much of a problem has the treatment for your skin been?</i>	407	15 (3.7%)	46 (11.3%)	131 (32.2%)	215 (52.8%)

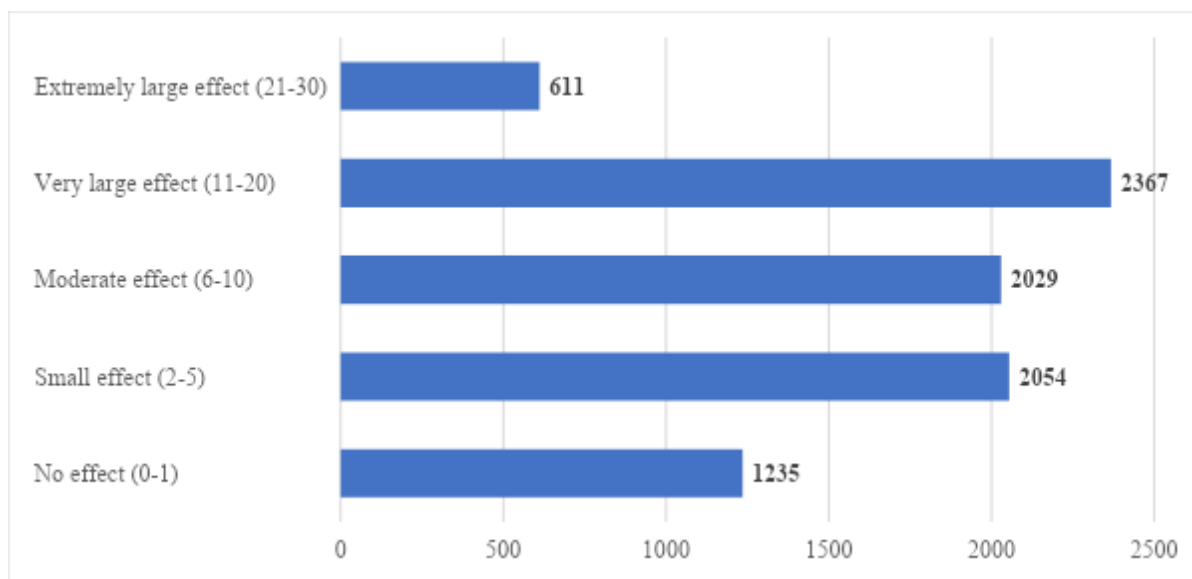


Figure 7.1 Dermatology Life Quality Index scores for psoriasis patients aged 17 years and above (n=8,296)

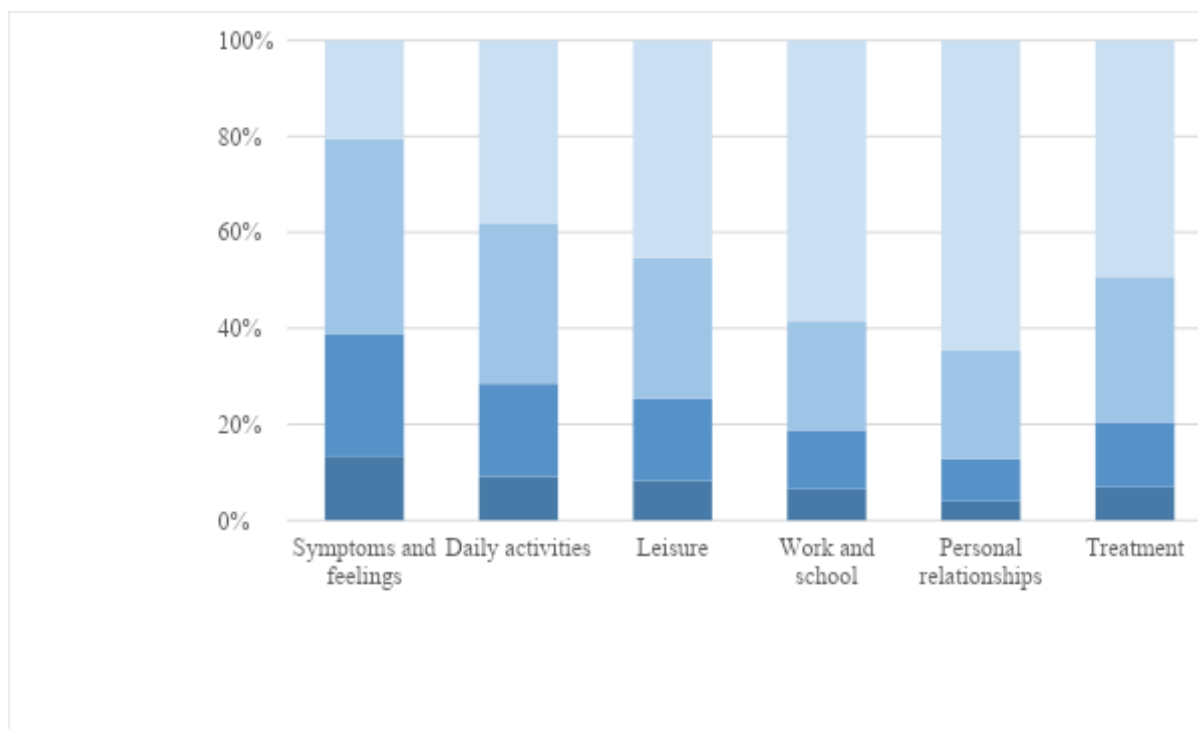


Figure 7.2 Quality of life impairment in psoriasis patients based on the categories of Dermatology Life Quality Index

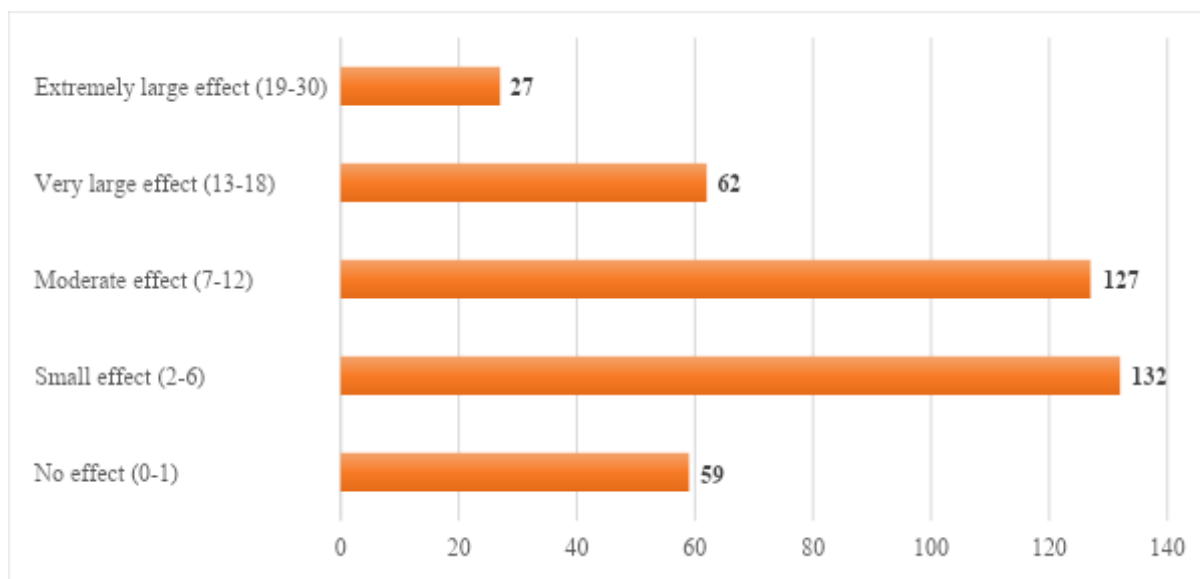


Figure 7.3 Children's Dermatology Life Quality Index Scores for psoriasis patients aged 4-16 years (n=407)

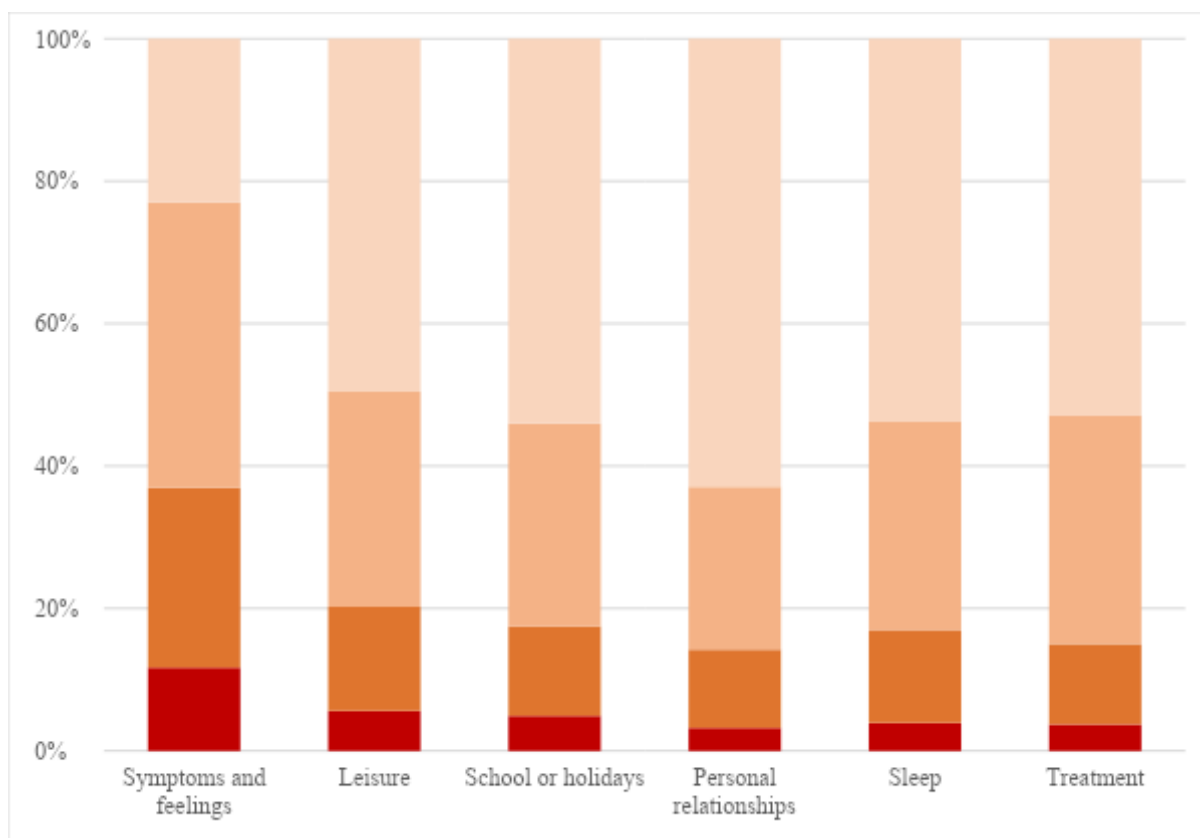


Figure 7.4 Quality of life impairment in psoriasis patients based on the categories of Children's Dermatology Life Quality Index

CHAPTER 8

OUTCOMES

Chapter 8

Outcomes*Assoc Prof Dr Kwan Zhenli*

Treatment outcomes were assessed based on the extent and characteristics of skin lesions using the percentage of body surface area (BSA) involvement and the Psoriasis Area and Severity Index (PASI), as well as quality of life using the Dermatology Life Quality Index (DLQI) for patients aged ≥ 17 years. Treatment outcome for PASI was defined as improvement in PASI of 75% (PASI 75) and 90% (PASI 90) while treatment outcome for BSA involvement was defined as improvement in BSA of 75% (BSA 75) and 90% (BSA 90) from baseline at 6 and 12 months. In terms of quality of life, a good response to treatment was classified as a reduction of at least 5 points in the DLQI score and outcomes were assessed at 6 and 12 months. Treatment outcomes were assessed for each of the therapy categories, i.e. phototherapy, systemic treatment, biologic agents, phototherapy with concomitant systemic therapy and biologic with concomitant systemic treatment.

From a total of 8,813 patients notified to the registry between 2020 to 2022, 1,318 patients had follow-up data (1,286 adults and 32 children). The median duration of follow-up was 14.5 months for adults (interquartile range, IQR = 13.6) and 14.7 months for children (IQR = 13.1). The follow-up duration is as reported in **Table 8.1**. In terms of treatment outcomes, 1,205 patients had follow-up data at 6 months. From these 1,205 patients, 25 patients had two different types of treatment and each course of treatment was considered separately for outcome analysis (total n=1,230 with 1,201 adults and 29 paediatric patients).

Table 8.1 Duration of follow-up for adult and paediatric patients

	Adults n (%)	Paediatric n (%)	Total n (%)
0-6 months	109 (8.5)	3 (9.4)	112 (8.5)
>6 to 12 months	390 (30.3)	9 (28.1)	399 (30.3)
>12 to 18 months	291 (22.6)	9 (28.1)	300 (22.8)
>18 to 24 months	239 (18.6)	4 (12.5)	243 (18.4)
>24 to 30 months	170 (13.2)	4 (12.5)	174 (13.2)
>30 to 36 months	87 (6.8)	3 (9.4)	90 (6.8)
Total	1286 (100.0)	32 (100.0)	1318 (100.0)

Outcomes in adult patients based on PASI and BSA

The median PASI for adults had reduced from a baseline of 4.5 (IQR = 2.4, 11.7) to 3.0 (IQR = 1.8, 6.1) at 6 months and remained stable at 3.0 (IQR = 1.8, 6.0) at 12 months of follow-up for all types of treatment (**Table 8.2**). Similarly, the median BSA in adults improved from 8.0 (IQR = 3.0, 20.0) at baseline to 5.0 (IQR = 2.0, 12.0) at 6 months and was stable at 5.0 (IQR =

2.0, 10.0) at 12 months for all types of treatment (**Table 8.3**). The top category in terms of improvement for both median PASI and BSA was biologic agents with PASI improving from 14.2 (IQR = 5.6, 24.0) at baseline to 2.0 (IQR = 0.9, 5.5) at 6 months and 2.5 (IQR = 1.0, 5.0) at 12 months, and BSA improving from 33.5 (IQR = 10.0, 68.8) to 2.5 (IQR = 1.0, 9.3) at 6 months and 3.0 (IQR = 1.0, 10.0) at 12 months.

Table 8.2 Median PASI scores for adult and paediatric patients at baseline, 6- and 12-months' follow-up

Types of treatment	Median PASI (IQR)					
	Adult			Paediatric		
	Baseline	At 6 months	At 12 months	Baseline	At 6 months	At 12 months
All patients	4.50 (2.40, 11.70) n=975	3.00 (1.80, 6.05) n=646	3.00 (1.80, 6.00) n=774	8.10 (2.90, 17.10) n=23	6.05 (2.33, 9.68) n=19	5.20 (1.65, 8.23) n=18
Phototherapy	7.40 (3.90, 14.70) n=19	3.00 (2.03, 11.80) n=10	3.60 (2.70, 6.80) n=13	-	-	-
Systemic treatment	3.60 (2.20, 7.68) n=700	3.20 (2.10, 6.00) n=466	3.00 (1.80, 5.70) n=556	5.00 (2.75, 15.80) n=20	6.80 (3.03, 10.43) n=16	4.25 (1.50, 7.28) n=14
Biologic agents	14.20 (5.60, 24.00) n=67	2.00 (0.93, 5.53) n=44	2.50 (1.00, 5.00) n=51	14.80 (n=1)	-	6.00 (n=1)
Phototherapy with concomitant systemic therapy	5.95 (3.00, 15.20) n=40	5.80 (1.80, 8.50) n=20	5.25 (3.03, 9.13) n=36	-	-	-
Biologic with concomitant systemic treatment	8.30 (3.00, 18.90) n=149	3.00 (1.00, 5.63) n=106	3.00 (1.20, 8.40) n=118	27.90 (17.10, -) n=2	0.95 (0.90, -) n=2	11.40 (n=1)

PASI: Psoriasis Area and Severity Index; IQR: interquartile range

Overall, at 6 months' follow-up, 23.2% of adult patients had achieved PASI 75 responses and 11.8% had achieved PASI 90 responses (**Table 8.4**). For BSA involvement, 22.3% achieved BSA 75 and 12.1% achieved BSA 90 responses. At 12 months' follow-up for all patients, 19.7% had PASI 75 responses and 9.0% had PASI 90 responses while 21.8% had BSA 75 responses and 13.5% had BSA 90 responses. Improvement was most marked in patients treated with biologic agents followed by the biologic with concomitant systemic treatment category.

Table 8.3 Median BSA involvement for adult and paediatric patients at baseline, 6- and 12-months' follow-up

Types of treatment	Median BSA (IQR)					
	Adult			Paediatric		
	Baseline	At 6 months	At 12 months	Baseline	At 6 months	At 12 months
All patients	8.00 (3.00, 20.00) n=1175	5.00 (2.00, 12.00) n=712	5.00 (2.00, 10.00) n=855	10.00 (5.00, 37.50) n=29	5.50 (3.00, 30.00) n=20	10.00 (1.00, 20.00) n=23
Phototherapy	15.00 (9.00, 30.00) n=25	5.00 (2.00, 25.00) n=13	5.00 (2.50, 10.00) n=17	25.00 (n=1)	-	10.00 (n=1)
Systemic treatment	7.00 (3.00, 20.00) n=892	5.00 (2.00, 12.00) n=554	5.00 (2.00, 10.00) n=651	10.00 (5.00, 20.00) n=24	8.00 (3.75, 30.00) n=18	8.00 (1.00, 17.00) n=19
Biologic agents	33.50 (10.00, 68.75) n=52	2.50 (1.00, 9.25) n=26	3.00 (1.00, 10.00) n=42	45.00 (n=1)	-	18.00 (n=1)
Phototherapy with concomitant systemic therapy	13.00 (8.00, 20.00) n=51	8.00 (5.00, 20.00) n=28	9.0 (5.00, 20.00) n=42	60.0 (n=1)	-	50.0 (n=1)
Biologic with concomitant systemic treatment	9.00 (3.00, 30.00) n=155	3.00 (1.00, 15.00) n=91	5.00 (1.00, 15.00) n=103	50.0 (20.0, -) n=2	1.00 (1.00, 1.00) n=2	40.00 (n=1)

BSA: body surface area; IQR: interquartile range

Outcome in paediatric patients based on PASI and BSA

For all paediatric patients, the median PASI at baseline was 8.1 (IQR = 2.9, 17.1) which improved to 6.1 (IQR = 2.3, 9.7) at 6 months and 5.2 (IQR = 1.7, 8.2) at 12 months of follow-up (**Table 8.2**) while the median BSA at baseline was 10.0 (IQR = 5.0, 37.5) which improved to 5.5 (IQR = 3.0, 30.0) at 6 months but subsequently increased again to 10.0 (IQR=1.0, 20.0) at 12 months (**Table 8.3**).

PASI 75 and PASI 90 responses were achieved by 29.4% and 11.8% of paediatric patients respectively at 6 months, and 26.7% and 0.0% respectively at 12 months while BSA 75 and BSA 90 responses were achieved by 25.0% and 20.0% respectively at 6 months, and 21.7% and 8.7% respectively at 12 months for all types of treatment (**Table 8.5**). For paediatric patients treated with systemic treatment, 20.0% achieved PASI 75 and 16.7% achieved BSA 75 at 6 months, improving to 30.8% and 26.3% respectively at 12 months (**Table 8.5**).

Table 8.4 Proportion of adult patients achieving PASI 75, PASI 90, BSA 75 and BSA 90 at 6- and 12-months' follow-up

	At 6 months, n (%)				At 12 months, n (%)			
	PASI 75	PASI 90	BSA 75	BSA 90	PASI 75	PASI 90	BSA 75	BSA 90
All patients	135 (23.2) n=583	69 (11.8) n=583	155 (22.3) n=696	84 (12.1) n=696	132 (19.7) n=670	60 (9.0) n=670	181 (21.8) n=831	112 (13.5) n=831
Phototherapy	1 (10.0) n=10	0 (0.0) n=10	4 (30.8) n=13	3 (23.1) n=13	2 (15.4) n=13	1 (7.7) n=13	4 (23.5) n=17	2 (11.8) n=17
Systemic treatment	58 (14.1) n=411	18 (4.4) n=411	101 (18.6) n=544	45 (8.3) n=544	63 (13.5) n=468	23 (4.9) n=468	125 (19.6) n=639	74 (11.6) n=639
Biologic agents	30 (68.2) n=44	22 (50.0) n=44	17 (68.0) n=25	11 (44.0) n=25	28 (56.0) n=50	16 (32.0) n=50	20 (55.6) n=36	17 (47.2) n=36
Phototherapy with concomitant systemic therapy	2 (11.1) n=18	0 (0.0) n=18	3 (10.7) n=28	1 (3.6) n=28	4 (12.9) n=31	1 (3.2) n=31	7 (16.7) n=42	1 (2.4) n=42
Biologic with concomitant systemic treatment	44 (44.0) n=100	29 (29.0) n=100	30 (34.9) n=86	24 (27.9) n=86	35 (32.4) n=108	19 (17.6) n=108	25 (25.8) n=97	18 (18.6) n=97

PASI: Psoriasis Area and Severity Index; BSA: body surface area

Outcome based on DLQI

The median DLQI at baseline was 6.0 and this improved to 4.0 at 6 months of follow-up, remaining stable at 12 months for all patients. In terms of median scores, patients on biologics reported the best overall improvement (**Table 8.6**).

In terms of categories, 23.0% of patients had achieved good response to treatment (as defined as a reduction of at least 5 points in the DLQI score) at 6 months and 20.4% had achieved the same endpoint at 12 months (**Tables 8.7 and 8.8**). At 6 months, patients on phototherapy with concomitant systemic therapy reported the highest proportion of patients achieving a good response (37.0%) followed by patients on biologic agents (32.0%) and phototherapy alone (30.8%) (**Table 8.7**). At 12 months' follow-up, the category with the greatest proportion of patients achieving good response was biologic agents (35.9%) followed by biologics with concomitant systemic treatment (24.5%) (**Table 8.8**).

Table 8.5 Proportion of paediatric patients achieving PASI 75, PASI 90, BSA 75 and BSA 90 at 6- and 12-months' follow-up

	At 6 months, n (%)				At 12 months, n (%)			
	PASI 75	PASI 90	BSA 75	BSA 90	PASI 75	PASI 90	BSA 75	BSA 90
All paediatric patients	5 (29.4) n=17	2 (11.8) n=17	5 (25.0) n=20	4 (20.0) n=20	4 (26.7) n=15	0 (0.0) n=15	5 (21.7) n=23	2 (8.7) n=23
Phototherapy	-	-	-	-	-	-	0 (0.0) n=1	0 (0.0) n=1
Systemic treatment	3 (20.0) n=15	0 (0.0) n=15	3 (16.7) n=18	2 (11.1) n=18	4 (30.8) n=13	0 (0.0) n=13	5 (26.3) n=19	2 (10.5) n=19
Biologic agents	-	-	-	-	0 (0.0) n=1	0 (0.0) n=1	0 (0.0) n=1	0 (0.0) n=1
Phototherapy with concomitant systemic therapy	-	-	-	-	-	-	0 (0.0) n=1	0 (0.0) n=1
Biologic with concomitant systemic treatment	2 (100.0) n=2	2 (100.0) n=2	2 (100.0) n=2	2 (100.0) n=2	0 (0.0) n=1	0 (0.0) n=1	0 (0.0) n=1	0 (0.0) n=1

PASI: Psoriasis Area and Severity Index; BSA: body surface area

Table 8.6 Median DLQI scores at baseline, 6- and 12-months' follow-up

	Median DLQI (IQR)		
	Baseline	At 6 months	At 12 months
All patients	6.00 (2.00, 11.00) n=1190	4.00 (1.00, 10.00) n=718	4.00 (1.00, 10.00) n=858
Phototherapy	11.00 (8.50, 14.50) n=25	7.00 (4.50, 13.00) n=13	10.0 (4.00, 14.50) n=17
Systemic treatment	5.00 (2.00, 11.00) n=902	5.00 (1.00, 10.00) n=561	4.00 (1.00, 9.00) n=654
Biologic agents	7.00 (3.00, 13.00) n=55	2.00 (0.00, 6.50) n=25	3.50 (0.00, 11.00) n=42
Phototherapy with concomitant systemic therapy	9.00 (3.25, 14.50) n=52	4.00 (1.00, 11.00) n=27	7.50 (1.00, 13.25) n=42
Biologic with concomitant systemic treatment	6.00 (1.25, 13.00) n=156	2.00 (1.00, 7.75) n=92	4.00 (1.00, 10.00) n=103

DLQI: Dermatology Life Quality Index, IQR: interquartile range

Table 8.7 Treatment outcome based on quality of life using DLQI at 6 months' follow-up

DLQI score	Phototherapy, n (%)	Systemic treatment, n (%)	Biologic agents, n (%)	Phototherapy with concomitant systemic therapy, n (%)	Biologic with concomitant systemic therapy, n (%)	Overall, n (%)
Reduced ≥ 5	4 (30.8)	115 (20.6)	8 (32.0)	10 (37.0)	28 (30.4)	165 (23.0)
Reduced < 5	3 (23.1)	173 (30.9)	10 (40.0)	8 (29.6)	20 (21.7)	214 (29.9)
Static	2 (15.4)	82 (14.7)	3 (12.0)	4 (14.8)	21 (22.8)	112 (15.6)
Increased < 5	2 (15.4)	114 (20.4)	4 (16.0)	3 (11.1)	16 (17.4)	139 (19.4)
Increased ≥ 5	2 (15.4)	75 (13.4)	0 (0.0)	2 (7.4)	7 (7.6)	86 (12.0)
Total	13 (100.0)	559 (100.0)	25 (100.0)	27 (100.0)	92 (100.0)	716 (100.0)

DLQI: Dermatology Life Quality Index

Table 8.8 Treatment outcome based on quality of life using DLQI at 12 months' follow-up

DLQI score	Phototherapy, n (%)	Systemic treatment, n (%)	Biologic agents, n (%)	Phototherapy with concomitant systemic therapy, n (%)	Biologic with concomitant systemic therapy, n (%)	Overall, n (%)
Reduced ≥ 5	3 (17.6)	123 (18.9)	14 (35.9)	9 (21.4)	25 (24.5)	174 (20.4)
Reduced < 5	8 (47.1)	199 (30.6)	14 (35.9)	9 (21.4)	29 (28.4)	259 (30.4)
Static	1 (5.9)	97 (14.9)	2 (5.1)	7 (16.7)	22 (21.6)	129 (15.2)
Increased < 5	3 (17.6)	149 (22.9)	2 (5.1)	11 (26.2)	14 (13.7)	179 (21.0)
Increased ≥ 5	2 (11.8)	83 (12.7)	7 (17.9)	6 (14.3)	12 (11.8)	110 (12.9)
Total	17 (100.0)	651 (100.0)	39 (100.0)	42 (100.0)	102 (100.0)	851 (100.0)

DLQI: Dermatology Life Quality Index

Outcome based on CDLQI

There were only 16 patients who had follow up data for CDLQI at 6 months and 12 months and therefore analysis was not performed

APPENDIX A: CASE REPORT FORM

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Case Report Form	CONFIDENTIAL
	For Office Use only:
	ID: <input style="width: 100px;" type="text"/>
	Centre: <input style="width: 100px;" type="text"/>

Instruction: Where check boxes are provided, check (✓) one or more boxes. Where radio buttons are provided, check (✓) one button only.

Doctor's Name :	<input style="width: 100%;" type="text"/>
Name of Institution :	<input style="width: 100%;" type="text"/>

SECTION 1 : DEMOGRAPHIC DETAILS

1. Patient visit date: (dd/mm/yyyy)	<input type="text"/> / <input type="text"/> / <input type="text"/>	2. Type of visit:	<input type="radio"/> New Case <input type="radio"/> Follow-Up
3. Name of patient:	<input style="width: 100%;" type="text"/>		
4. NRIC:	MyKad/MyKid: <input type="text"/> - <input type="text"/> - <input type="text"/>	Old IC: <input type="text"/>	
	Other ID document No : <input type="text"/>	Specify type of ID :	
# 5. Address:	Town / City: <input style="width: 100%;" type="text"/>	State: <input style="width: 100%;" type="text"/>	
# 6. Contact Number:	Home: <input type="text"/> - <input type="text"/>	H/P: <input type="text"/> - <input type="text"/>	
# 7. Gender:	<input type="radio"/> Male <input type="radio"/> Female		
# 8. Date of birth: (dd/mm/yyyy)	<input type="text"/> / <input type="text"/> / <input type="text"/>	<input type="checkbox"/> Estimated/presumed year	If the exact date is not known, please enter 01/07/yyyy & check the estimated / presumed year box.
# 9. Ethnic group:	<input type="radio"/> Malay <input type="radio"/> Orang Asli Semenanjung <input type="radio"/> Kadazan <input type="radio"/> Melanau <input type="radio"/> Bidayuh <input type="radio"/> Chinese <input type="radio"/> Bajau <input type="radio"/> Murut <input type="radio"/> Kedayan <input type="radio"/> Other Bumiputera Sarawak <input type="radio"/> Indian <input type="radio"/> Dusun <input type="radio"/> Other Bumiputera Sabah <input type="radio"/> Iban <input type="radio"/> Others		
# 10. Nationality:	<input type="radio"/> Malaysian <input type="radio"/> Non-Malaysian, specify:		
# 11. Marital status:	<input type="radio"/> Single <input type="radio"/> Married <input type="radio"/> Divorced <input type="radio"/> Widowed		
# 12. Occupation:	<input type="radio"/> Agriculture & Fisheries <input type="radio"/> Legal <input type="radio"/> Oil & Gas <input type="radio"/> Transportation <input type="radio"/> Art & Talent <input type="radio"/> Manufacturing <input type="radio"/> Service <input type="radio"/> Building & Construction <input type="radio"/> Education <input type="radio"/> Information Technology <input type="radio"/> Mining <input type="radio"/> Telecommunication <input type="radio"/> Medical & Health <input type="radio"/> Others		
# 13. Monthly income:	<input type="radio"/> No Income <input type="radio"/> RM 500 – RM 1000 <input type="radio"/> RM 1501 – RM 3000 <input type="radio"/> RM 5001 – RM 10000 <input type="radio"/> > RM 15000 <input type="radio"/> < RM 500 <input type="radio"/> RM 1001 – RM 1500 <input type="radio"/> RM 3001 – RM 5000 <input type="radio"/> RM 10001 – RM 15000		

SECTION 2 : MEDICAL HISTORY

1. Age when # psoriasis started:	<input type="text"/>	2. Age when psoriasis # diagnosed:	<input type="text"/>
3. Family member(s) # with psoriasis:	<input type="radio"/> No <input type="radio"/> Yes → <input type="checkbox"/> Father <input type="checkbox"/> Sibling(s) <input type="checkbox"/> Other relative, specify: (if YES, please tick ONE or MULTIPLE) <input type="checkbox"/> Mother <input type="checkbox"/> Children		
4. Aggravating factors:	<input type="radio"/> No <input type="radio"/> Yes → <input type="checkbox"/> Infection : <input type="checkbox"/> Stress <input type="checkbox"/> Alcohol <input type="checkbox"/> Drugs : <input type="checkbox"/> Sunburn <input type="checkbox"/> Pregnancy <input type="checkbox"/> Topical Rx : <input type="checkbox"/> Hypocalcaemia <input type="checkbox"/> Trauma <input type="checkbox"/> Other, specify: <input type="checkbox"/> Smoking		
5. Disease burden in the last 6 months:	a) No. of clinic visits due to psoriasis :	<input type="text"/>	(enter 0 if none)
	b) No. of days off work / school due to psoriasis :	<input type="text"/>	(enter 0 if none) <input type="checkbox"/> Not applicable
	c) No. of hospital admissions due to psoriasis :	<input type="text"/>	(enter 0 if none)
6. Comorbidities:	a) Ischaemic heart disease :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	b) Cerebrovascular disease (stroke) :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	c) Diabetes mellitus :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	d) Hypertension :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	e) Hyperlipidaemia :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	f) Depression :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	g) Fatty Liver (NAFLD) :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	h) HIV / AIDS :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
	i) Inflammatory bowel disease (if YES, please tick ONE) →	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
		<input type="radio"/> Ulcerative colitis <input type="radio"/> Crohn's disease	<input type="text"/>
	j) Malignancy, specify :	<input type="radio"/> Yes <input type="radio"/> No	Age at diagnosis <input type="text"/>
		→ <input style="width: 100%;" type="text"/>	
7. Pregnancy:	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> Not Applicable		
8. Cigarette smoking:	<input type="radio"/> Never smoked <input type="radio"/> Ex-smoker <input type="radio"/> Current smoker → <input type="text"/> cigarettes per day		
9. Substance use:	<input type="radio"/> No <input type="radio"/> Yes → <input type="checkbox"/> Alcohol <input type="checkbox"/> Illicit drugs, specify: (if YES, please tick ONE or MULTIPLE) <input type="checkbox"/> Vape		

Items marked # above need not be entered if the patient has been previously notified to the registry
 Version 3.0 Last updated 01/10/2019

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Case Report Form	CONFIDENTIAL For Office Use only: ID: <input style="width: 50px;" type="text"/> / <input style="width: 50px;" type="text"/> Centre: <input style="width: 100px;" type="text"/>
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Instruction: Where check boxes are provided, check (✓) one or more boxes. Where radio buttons are provided, check (✓) one button only.

SECTION 3 : CLINICAL EXAMINATION

1. a) Height:	<input style="width: 20px;" type="text"/>	(cm)	b) Weight:	<input style="width: 20px;" type="text"/>	(kg)	c) Waist circumference:	<input style="width: 20px;" type="text"/>	<input style="width: 20px;" type="text"/>	(cm)	
2. Symptoms	a) Itch <input type="radio"/> Yes <input type="radio"/> No		b) Pain <input type="radio"/> Yes <input type="radio"/> No							
3. Type of Psoriasis:	(Please select ONE predominant type) <input type="radio"/> Plaque <input type="radio"/> Guttate <input type="radio"/> Erythrodermic <input type="radio"/> Flexural / Inverse <input type="radio"/> Generalised pustular <input type="radio"/> Localised pustular <input checked="" type="radio"/> Palmoplantar pustulosis <input type="radio"/> Palmoplantar non-pustular <input type="radio"/> Acrodermatitis of Hallopeau									
4. Severity:	a) Body surface area involved: <input style="width: 20px;" type="text"/> (%)									
	b) PASI evaluation:									
	Body region	Plaque characteristic 0 = None, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Very severe						Percentage involvement of each body region		
		Erythema	Thickness	Scaling						
	Head	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4				<input type="radio"/> None <input type="radio"/> 1-9% <input type="radio"/> 10-29% <input type="radio"/> 30-49% <input type="radio"/> 50-69% <input type="radio"/> 70-89% <input type="radio"/> 90-100%		
Upper limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4				<input type="radio"/> None <input type="radio"/> 1-9% <input type="radio"/> 10-29% <input type="radio"/> 30-49% <input type="radio"/> 50-69% <input type="radio"/> 70-89% <input type="radio"/> 90-100%			
Trunk	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4				<input type="radio"/> None <input type="radio"/> 1-9% <input type="radio"/> 10-29% <input type="radio"/> 30-49% <input type="radio"/> 50-69% <input type="radio"/> 70-89% <input type="radio"/> 90-100%			
Lower limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4				<input type="radio"/> None <input type="radio"/> 1-9% <input type="radio"/> 10-29% <input type="radio"/> 30-49% <input type="radio"/> 50-69% <input type="radio"/> 70-89% <input type="radio"/> 90-100%			
5. Nail involvement:	<input type="radio"/> No <input checked="" type="radio"/> Yes <input type="checkbox"/> Pitting <input type="checkbox"/> Subungual hyperkeratosis <input type="checkbox"/> Discolouration (if YES, please tick ONE or MULTIPLE) <input type="checkbox"/> Onycholysis <input type="checkbox"/> Total nail dystrophy									
6. Joint Disease:	<input type="radio"/> No <input checked="" type="radio"/> Yes									
	a) Under care of rheumatologist: <input type="radio"/> No <input checked="" type="radio"/> Yes									
	b) Symptomatic:	<input type="radio"/> No <input checked="" type="radio"/> Yes		Morning stiffness			<input type="radio"/> No <input checked="" type="radio"/> Yes			
				Pain			<input type="radio"/> No <input checked="" type="radio"/> Yes			
				Swelling			<input type="radio"/> No <input checked="" type="radio"/> Yes			
	c) Enthesitis / Dactylitis <input type="radio"/> No <input checked="" type="radio"/> Yes									
	d) Type:-	1. Oligo- / Monoarthropathy						<input type="radio"/> No <input checked="" type="radio"/> Yes		
2. Distal hand joints arthropathy						<input type="radio"/> No <input checked="" type="radio"/> Yes				
3. Symmetrical polyarthropathy (Rheumatoid-like)						<input type="radio"/> No <input checked="" type="radio"/> Yes				
4. Spondylitis / Sacroiliitis						<input type="radio"/> No <input checked="" type="radio"/> Yes				
5. Arthritis mutilans						<input type="radio"/> No <input checked="" type="radio"/> Yes				
e) Deformity: <input type="radio"/> No <input checked="" type="radio"/> Yes, specify:										
7. Special sites:	<input type="radio"/> Face <input type="radio"/> Genital <input type="radio"/> Scalp <input type="radio"/> Tongue <input type="radio"/> Eye, specify: <input type="radio"/> No									

SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS

1. Topical therapy:	a) Tar preparation		<input type="radio"/> No <input checked="" type="radio"/> Yes	e) Topical steroid		<input type="radio"/> No <input checked="" type="radio"/> Yes
	b) Vitamin D analogue e.g calcipotriol		<input type="radio"/> No <input checked="" type="radio"/> Yes	f) Keratolytic e.g salicylic acid		<input type="radio"/> No <input checked="" type="radio"/> Yes
	c) Topical calcineurin inhibitor		<input type="radio"/> No <input checked="" type="radio"/> Yes	g) Calcipotriol with betamethasone dipropionate		<input type="radio"/> No <input checked="" type="radio"/> Yes
	d) Dithranol (anthralin)		<input type="radio"/> No <input checked="" type="radio"/> Yes	h) Emollient		<input type="radio"/> No <input checked="" type="radio"/> Yes
2. Phototherapy	<input type="radio"/> No <input checked="" type="radio"/> Yes <input type="checkbox"/> Refused <input type="checkbox"/> Not indicated <input type="checkbox"/> Adverse effect <input type="checkbox"/> Contraindicated <input type="checkbox"/> Failure <input type="checkbox"/> Others, specify: (if YES, please tick ONE or MULTIPLE) <input type="checkbox"/> BB-UVB <input type="checkbox"/> Oral PUVA <input type="checkbox"/> Topical PUVA <input type="checkbox"/> Others, specify :- <input type="checkbox"/> NB-UVB <input type="checkbox"/> Bath PUVA <input type="checkbox"/> Excimer laser					
	<input type="radio"/> No <input checked="" type="radio"/> Yes <input type="checkbox"/> Refused <input type="checkbox"/> Not indicated <input type="checkbox"/> Adverse effect <input type="checkbox"/> Contraindicated <input type="checkbox"/> Failure <input type="checkbox"/> Others, specify:					
3. Systemic therapy:	a) Oral Methotrexate		<input type="radio"/> No <input checked="" type="radio"/> Yes	f) Biologics, specify		<input type="radio"/> No <input checked="" type="radio"/> Yes
	b) Parenteral Methotrexate		<input type="radio"/> No <input checked="" type="radio"/> Yes			
	c) Acitretin		<input type="radio"/> No <input checked="" type="radio"/> Yes			
	d) Sulphasalazine		<input type="radio"/> No <input checked="" type="radio"/> Yes			
	e) Cyclosporine		<input type="radio"/> No <input checked="" type="radio"/> Yes	g) Systemic corticosteroids		<input type="radio"/> No <input checked="" type="radio"/> Yes

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NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Dermatology Life Quality Index (DLQI) (For Adults of Age 17 and Above)	CONFIDENTIAL
	For Office Use only:
	ID: <input type="text"/>
	Centre: <input type="text"/>

Instruction: Where check boxes are provided, check (✓) one or more boxes. Where radio buttons are provided, check (✓) one button only.

SECTION 5 : QUALITY OF LIFE

1. Quality of Life

Please instruct and assist patient in completing the attached DLQI form

Matlamat soal selidik ini ialah untuk mengukur sejauh manakah masalah kulit anda telah menjejaskan hidup anda SEPANJANG MINGGU LEPAS.

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK.

本问卷旨在测量您的皮肤问题在过去一周里有多么影响您的生活。

Sila tandakan "✓" pada satu kotak bagi setiap soalan / Please tick "✓" one box for each question.

每一道问题，请勾选"✓"一个格子。

Sepanjang Minggu Lepas ... OVER THE LAST WEEK ... 在过去一周...	Sangat Banyak Very much 非常多的	Banyak A lot 相当多的	Sedikit A little 有点	Tiada sama sekali Not at all 完全没有	Tidak Berkaitan Not Relevant 不相关	DLQI Score <input type="text"/>	Auto calculated
1) Sepanjang minggu lepas, sejauh manakah rasa gatal, pedih, sakit atau mencucuk yang dialami pada kulit anda? Over the last week, how itchy, sore, painful or stinging has your skin been? 在过去一周，您的皮肤有多么痒、疼痛、刺痛或触碰时有多么痛？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
2) Sepanjang minggu lepas, sejauh manakah anda berasa malu disebabkan kulit anda? Over the last week, how embarrassed or self conscious have you been because of your skin? 在过去一周，您的皮肤多么令您觉得尴尬或不自在？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
3) Sepanjang minggu lepas, sejauh manakah keadaan kulit anda mengganggu anda membeli-belah atau semasa menguruskan rumah atau taman anda? Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden? 在过去一周，您的皮肤有多么干扰您出去购物或打理家务或花园？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
4) Sepanjang minggu lepas, sejauh manakah keadaan kulit anda mempengaruhi pakaian yang anda pakai? Over the last week, how much has your skin influenced the clothes you wear? 在过去一周，您的皮肤有多么影响您的穿着？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
5) Sepanjang minggu lepas, sejauh manakah keadaan kulit anda menjejaskan sebarang aktiviti sosial atau riadah anda? Over the last week, how much has your skin affected any social or leisure activities? 在过去一周，您的皮肤有多么影响任何社交或休闲活动？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
6) Sepanjang minggu lepas, sejauh manakah keadaan kulit anda menyukarkan anda untuk melakukan sebarang aktiviti sukan? Over the last week, how much has your skin made it difficult for you to do any sport? 在过去一周，您的皮肤有多么令您难以进行任何体育活动？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
7) Sepanjang minggu lepas, adakah keadaan kulit anda menghalang anda daripada bekerja atau belajar? Over the last week, has your skin prevented you from working or studying? 在过去一周，您的皮肤有阻止到您的工作或学业吗？ <input type="checkbox"/> Ya Yes 有 <input type="checkbox"/> Tidak No 没有 <input type="checkbox"/> Tidak Berkaitan Not Relevant 不相关 * Jika "Tidak", sepanjang minggu lepas, sejauh manakah keadaan kulit anda menjadi masalah semasa bekerja atau belajar? If "No", over the last week how much has your skin been a problem at work or studying? 如果"没有"，在过去一周，您的皮肤对您的工作或学业造成多大的问题？		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
8) Sepanjang minggu lepas, sejauh manakah keadaan kulit anda menimbulkan masalah dengan pasangan anda, atau mana-mana kawan rapat atau saudara-mara anda? Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives? 在过去一周，您的皮肤对您的伴侣或至亲好友造成多大的问题？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
9) Sepanjang minggu lepas, sejauh manakah keadaan kulit anda menyebabkan sebarang masalah seksual? Over the last week, how much has your skin caused any sexual difficulties? 在过去一周，您的皮肤给您带来多少性生活上的困扰？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
10) Sepanjang minggu lepas, sejauh manakah masalah berlaku disebabkan oleh rawatan untuk kulit anda, misalnya menyebabkan rumah anda bersepah dan kotor atau mengambil masa yang banyak? Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time? 在过去一周，您皮肤的治疗给您带来多少麻烦，例如导致您的家居凌乱或霸占您的时间？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih.
Please check you have answered EVERY question. Thank you.
请确保您已回答每一道问题。谢谢。

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Children's Dermatology Life Quality Index (DLQI) (For Age 4 to 16)	CONFIDENTIAL	
	For Office Use only:	
	ID:	<input type="text"/>
	Centre:	<input type="text"/>

Instruction: Where check boxes are provided, check (✓) one or more boxes. Where radio buttons are provided, check (✓) one button only.

Matlamat soal selidik ini adalah untuk mengukur setakat manakah masalah kulit anda telah memberikan kesan kepada anda SEPANJANG SEMINGGU YANG LALU. The aim of this questionnaire is to measure how much your skin problem has affected you OVER THE LAST WEEK. 此问卷调查的目的是度量在过去一个星期里面, 你的皮肤问题对你的生活影响有多大。

Sila tandakan "✓" satu kotak bagi setiap soalan. / Please tick "✓" one box for each question. 请在每一条问题的其中一个空格画"✓"	DLQI Score <input type="text"/>				Auto calculated
Sepanjang seminggu yang Lalu ... OVER THE LAST WEEK 一个星期里面	Sangat Very much 非常严重	Agak Banyak A lot 严重	Sedikit sahaja A little 少许	Tidak sama sekali Not at all 无	
1) Sepanjang seminggu yang lalu, setakat manakah kulit anda berasa gatal, "perlu digaru", pedih atau sakit? <i>Over the last week, how itchy, "scratchy", sore or painful has your skin been?</i> 在过去一星期中, 你的皮肤瘙痒、灼热或疼痛的程度如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2) Sepanjang seminggu yang lalu, setakat manakah anda berasa malu atau sedar diri, susah hati atau sedih disebabkan oleh kulit anda? <i>Over the last week, how embarrassed or self conscious, upset or sad have you been Because of your skin?</i> 在过去一星期中, 你因为自己的皮肤问题而感到难为情或不自在、苦恼或忧伤的程度如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
3) Sepanjang seminggu yang lalu, setakat manakah kulit anda memberikan kesan terhadap persahabatan anda? <i>Over the last week, how much has your skin affected your friendships?</i> 在过去一星期中, 皮肤问题对你和朋友交往的影响程度如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
4) Sepanjang seminggu yang lalu, setakat manakah anda telah menukar atau memakai pakaian/kasut yang berbeza atau khas disebabkan oleh kulit anda? <i>Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?</i> 在过去一星期中, 你因为皮肤问题而改穿不同或特殊衣/鞋的影响如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
5) Sepanjang seminggu yang lalu, setakat manakah masalah kulit anda memberikan kesan apabila anda mahu keluar rumah, bermain atau melakukan hobi? <i>Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?</i> 在过去一星期中, 皮肤问题对你外出、玩耍、或享受兴趣爱好影响如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
6) Sepanjang seminggu yang lalu, setakat manakah anda telah mengelakkan diri daripada berenang atau melakukan sukan lain disebabkan oleh masalah kulit anda? <i>Over the last week, how much have you avoided swimming or other sports because of your skin trouble?</i> 在过去一星期中, 你因为皮肤的问题而避免游泳或其他运动的影响程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
7) Minggu lepas, adakah semasa waktu persekolahan <i>Last week, was it school time? 在过去一星期中上课期间?</i> <div style="border: 1px solid black; padding: 2px;">Jika waktu persekolahan: Sepanjang seminggu yang lalu, setakat manakah kulit anda memberikan kesan kepada kerja sekolah anda. <i>If school time: Over the last week, how much did your skin problem affect your school work?</i> 在过去一星期中上课期间: 皮肤问题影响你学校功课的程度是如何?</div> <input type="checkbox"/> Menghalang persekolahan Prevented school 不准上学 <input type="checkbox"/> Sangat Very much 非常严重 <input type="checkbox"/> Agak banyak Quite a lot 严重 <input type="checkbox"/> Sedikit sahaja Only a little 少许 <input type="checkbox"/> Tidak sama sekali Not at all 无 ATAU OR 或 Adakah semasa waktu cuti? was it holiday time? 是否是放假期间? <div style="border: 1px solid black; padding: 2px;">Jika waktu cuti: Sepanjang seminggu yang lalu, setakat manakah masalah kulit anda mengganggu keseronokan bercuti? <i>If holiday time: How much over the last week, has your skin problem interfered with your enjoyment of the holiday?</i> 在过去一星期中的放假期间: 皮肤问题干扰你享受假期的程度如何?</div>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8) Sepanjang seminggu yang lalu, berapa banyak masalah yang anda alami disebabkan oleh kulit anda dengan kerehan orang memanggil anda dengan panggilan yang menyakitkan hati, mengusik, membuli, menanya soalan atau menjauhkan diri anda? <i>Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?</i> 在过去一星期中, 因为皮肤的问题, 他人骂你、嘲笑你、欺负你、问你问题或躲避你, 这种困扰的程度如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
9) Sepanjang seminggu yang lalu, setakat manakah tidur anda terjejas oleh masalah kulit anda? <i>Over the last week, how much has your sleep been affected by your skin problem?</i> 在过去一星期中, 皮肤问题对你睡眠的影响程度如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
10) Sepanjang seminggu yang lalu, setakat manakah rawatan untuk kulit anda mendatangkan masalah? <i>Over the last week, how much of a problem has the treatment for your skin been?</i> 在过去一星期中, 皮肤治疗对你产生的困扰程度如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Sila pastikan bahawa anda telah menjawab SETIAP soalan. Terima kasih.
Please check you have answered EVERY question. Thank you.

请检查你是否已经回答了所有问题。谢谢你的合作!

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Biologic Treatment Initiation Form	CONFIDENTIAL For official use only: ID: _____ Centre _____
Instructions: Where check boxes <input type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="radio"/> are provided, check (✓) one button only	

Doctors' name	
Name of institution	

SECTION 1: DEMOGRAPHIC DETAILS	
1. Visit date (dd/mm/yyyy)	<input style="width: 10%;" type="text"/> / <input style="width: 10%;" type="text"/> / <input style="width: 10%;" type="text"/>
2. Name of patient	
3. NRIC	MyKad/MyKid: <input style="width: 10%;" type="text"/> - <input style="width: 10%;" type="text"/> - <input style="width: 10%;" type="text"/> Old IC: <input style="width: 10%;" type="text"/>
	Other ID document No : <input style="width: 30%;" type="text"/> Specify type of ID : _____

SECTION 2 : MEDICAL HISTORY																							
1. History of tuberculosis	<input type="radio"/> No <input type="radio"/> Yes If yes, please specify: Date of diagnosis (dd/mm/yyyy) <input style="width: 10%;" type="text"/> / <input style="width: 10%;" type="text"/> / <input style="width: 10%;" type="text"/> Type of tuberculosis <input type="radio"/> Latent tuberculosis <input type="radio"/> Pulmonary tuberculosis <input type="radio"/> Extrapulmonary tuberculosis Specify organ involved: _____ Completed anti-TB treatment? <input type="radio"/> No <input type="radio"/> Yes																						
2. History of cancer	<input type="radio"/> No <input type="radio"/> Yes, specify _____																						
3. History of neurological disease	<input type="radio"/> No <input type="radio"/> Yes, specify _____																						
4. History of liver disease	<input type="radio"/> No <input type="radio"/> Yes, specify _____																						
5. History of cardiovascular disease	<input type="radio"/> No <input type="radio"/> Yes, specify _____																						
6. Previous systemic treatment	<input type="radio"/> No <input type="radio"/> Yes If yes, please specify: <table border="1" style="width:100%; border-collapse: collapse; font-size: x-small;"> <thead> <tr> <th style="width: 50%;">Systemic agent</th> <th style="width: 50%;">Reasons for stopping</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> Phototherapy</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Oral methotrexate</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Parenteral methotrexate</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Acitretin</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Sulphasalazine</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Cyclosporin</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Hydroxyurea</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Systemic corticosteroids</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Biologic therapy, specify _____</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> <tr> <td><input type="checkbox"/> Other systemic agent, specify _____</td> <td> <input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____ </td> </tr> </tbody> </table>	Systemic agent	Reasons for stopping	<input type="checkbox"/> Phototherapy	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Oral methotrexate	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Parenteral methotrexate	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Acitretin	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Sulphasalazine	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Cyclosporin	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Hydroxyurea	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Systemic corticosteroids	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Biologic therapy, specify _____	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____	<input type="checkbox"/> Other systemic agent, specify _____	<input type="checkbox"/> Poor response <input type="checkbox"/> Intolerance <input type="checkbox"/> Adverse effects <input type="checkbox"/> Others (specify) _____
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SECTION 3 : CLINICAL EXAMINATION																												
a) Weight: <input style="width: 10%;" type="text"/> <input style="width: 10%;" type="text"/> kg	b) Blood pressure: <input style="width: 10%;" type="text"/> / <input style="width: 10%;" type="text"/> mmHg																											
c) PRE-TREATMENT PASI EVALUATION																												
Body region	<table border="1" style="width:100%; border-collapse: collapse; font-size: x-small;"> <thead> <tr> <th colspan="3" style="text-align: center;">Plaque characteristic</th> <th rowspan="2" style="text-align: center;">Percentage involvement of each body region</th> </tr> <tr> <th colspan="3" style="text-align: center;"><i>0 = None, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Very severe</i></th> </tr> <tr> <th style="text-align: center;">Erythema</th> <th style="text-align: center;">Thickness</th> <th style="text-align: center;">Scaling</th> <th></th> </tr> </thead> <tbody> <tr> <td style="text-align: center;"> <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 </td> <td style="text-align: center;"> <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 </td> <td style="text-align: center;"> <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 </td> <td style="text-align: center;"> <input type="radio"/> None <input type="radio"/> 50 – 69% <input type="radio"/> 1 - 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Version 2.0 Last updated 01/10/2019

SECTION 4 : INVESTIGATIONS			
1. Mantoux test	_____ mm <input type="checkbox"/> Not done because _____		
2. Laboratory values (within last 6 months)		Result	Date
	Haemoglobin (g/DL):		
	White cell count (x10 ⁹ /L):		
	Platelet (x10 ⁹ /L):		
	Urea (mmol/L):		
	Creatinine (umol/L):		
	Aspartate Aminotransferase (AST) (U/L):		
Alanine transaminase (ALT) (U/L):			
3. Interferon-γ release assay	<input type="radio"/> Negative <input type="radio"/> Positive <input type="radio"/> Not available		
4. Chest X-ray	<input type="radio"/> Normal <input type="radio"/> Abnormal <input type="radio"/> Not available If abnormal, specify findings _____		
5. Hepatitis B status	<input type="radio"/> Negative <input type="radio"/> Positive <input type="radio"/> Not available (If positive, please tick ONE or MULTIPLE) <input type="checkbox"/> HBsAg <input type="checkbox"/> HBcAb <input type="checkbox"/> HBeAg <input type="checkbox"/> anti-HBe		
6. Hepatitis C status	<input type="radio"/> Negative <input type="radio"/> Positive <input type="radio"/> Not available		
7. HIV status	<input type="radio"/> Negative <input type="radio"/> Positive <input type="radio"/> Not available		

SECTION 5 : BIOLOGIC TREATMENT	
a) Indication for biologic treatment	<input type="checkbox"/> Phototherapy and standard systemic therapy are contraindicated <input type="checkbox"/> Intolerant to phototherapy and standard systemic therapy <input type="checkbox"/> Failed phototherapy and standard systemic therapy <input type="checkbox"/> Other indication, specify _____
b) Source of funding	<input type="checkbox"/> Self <input type="checkbox"/> Personal insurance <input type="checkbox"/> Sample <input type="checkbox"/> Zakat <input type="checkbox"/> Tabung Bantuan Perubatan (TBP) <input type="checkbox"/> Jabatan Perkhidmatan Awam (JPA) <input type="checkbox"/> Corporate insurance <input type="checkbox"/> Others, specify _____

SECTION 6 : CURRENT BIOLOGIC TREATMENT	
1. Biologic agent	<input type="radio"/> Infliximab <input type="radio"/> Secukinumab <input type="radio"/> Guselkumab <input type="radio"/> Adalimumab <input type="radio"/> Ixekizumab <input type="radio"/> Risankizumab <input type="radio"/> Etanercept <input type="radio"/> Others, specify _____ <input type="radio"/> Ustekinumab
2. Date start (dd/mm/yyyy)	<input type="text"/> / <input type="text"/> / <input type="text"/>
3. Dose	

SECTION 7 : CONCOMITANT SYSTEMIC TREATMENT	
1. Concomitant systemic treatment / phototherapy	<input type="radio"/> No <input type="radio"/> Yes, <input type="checkbox"/> Phototherapy <input type="checkbox"/> Oral methotrexate <input type="checkbox"/> Parenteral methotrexate <input type="checkbox"/> Acitretin <input type="checkbox"/> Sulphasalazine <input type="checkbox"/> Cyclosporin <input type="checkbox"/> Hydroxyurea <input type="checkbox"/> Systemic corticosteroids <input type="checkbox"/> Others, specify _____

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Biologic Treatment Follow Up Form <i>Instructions: Where check boxes <input type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="radio"/> are provided, check (✓) one button only</i>	CONFIDENTIAL
	For official use only: ID:
	Centre

Doctors' name	
Name of institution	

SECTION 1: DEMOGRAPHIC DETAILS	
1. Visit date (dd/mm/yyyy)	<input type="text"/> / <input type="text"/> / <input type="text"/>
2. Name of patient	
3. NRIC	MyKad/MyKid: <input type="text"/> - <input type="text"/> - <input type="text"/> Old IC: <input type="text"/>
	Other ID document No : <input type="text"/> Specify type of ID :

SECTION 2 : CLINICAL EXAMINATION					
a) Weight:	<input type="text"/> kg	b) Blood pressure:	<input type="text"/> / <input type="text"/> mmHg		
c) POST- TREATMENT PASI EVALUATION					
Body region	Plaque characteristic <i>0 = None, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Very severe</i>			Percentage involvement of each body region	
	Erythema	Thickness	Scaling		
Head	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> None <input type="radio"/> 1 - 9% <input type="radio"/> 10 - 29% <input type="radio"/> 30 - 49%	<input type="radio"/> 50 - 69% <input type="radio"/> 70 - 89% <input type="radio"/> 90 - 100%
Upper limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> None <input type="radio"/> 1 - 9% <input type="radio"/> 10 - 29% <input type="radio"/> 30 - 49%	<input type="radio"/> 50 - 69% <input type="radio"/> 70 - 89% <input type="radio"/> 90 - 100%
Trunk	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> None <input type="radio"/> 1 - 9% <input type="radio"/> 10 - 29% <input type="radio"/> 30 - 49%	<input type="radio"/> 50 - 69% <input type="radio"/> 70 - 89% <input type="radio"/> 90 - 100%
Lower limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="radio"/> None <input type="radio"/> 1 - 9% <input type="radio"/> 10 - 29% <input type="radio"/> 30 - 49%	<input type="radio"/> 50 - 69% <input type="radio"/> 70 - 89% <input type="radio"/> 90 - 100%

SECTION 3 : BIOLOGIC DOSES RECEIVED		
Name of biologic agent	Date of injection	Self-administered
		<input type="radio"/> No <input type="radio"/> Yes
		<input type="radio"/> No <input type="radio"/> Yes
		<input type="radio"/> No <input type="radio"/> Yes
		<input type="radio"/> No <input type="radio"/> Yes

SECTION 4 : ADVERSE EVENT(S) DURING BIOLOGIC TREATMENT		
Adverse event(s)		Date of onset (dd/mm/yyyy)
a) Cancer		
<input type="checkbox"/> Skin cancer	<input type="radio"/> No <input type="radio"/> Yes, specify	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Other cancers	<input type="radio"/> No <input type="radio"/> Yes, specify	<input type="text"/> / <input type="text"/> / <input type="text"/>
b) Infection		
<input type="checkbox"/> Tuberculosis reactivation	<input type="radio"/> No <input type="radio"/> Yes, specify location	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Candida If yes, is it recurrent?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Yes	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Herpes simplex If yes, is it recurrent?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Yes	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Upper respiratory tract infection	<input type="radio"/> No <input type="radio"/> Yes	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Pneumonia	<input type="radio"/> No <input type="radio"/> Yes	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Cellulitis	<input type="radio"/> No <input type="radio"/> Yes	<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Folliculitis	<input type="radio"/> No <input type="radio"/> Yes	<input type="text"/> / <input type="text"/> / <input type="text"/>

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<input type="checkbox"/> Others	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
<input type="checkbox"/> Others	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
<input type="checkbox"/> Others	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
c) Worsening of psoriasis	<input type="radio"/> No <input type="radio"/> Yes	□□□/□□□/□□□□□
d) Neuropsychiatry disorders		
<input type="checkbox"/> Demyelinating disease	<input type="radio"/> No <input type="radio"/> Yes	□□□/□□□/□□□□□
<input type="checkbox"/> Epilepsy	<input type="radio"/> No <input type="radio"/> Yes	□□□/□□□/□□□□□
<input type="checkbox"/> Psychiatric disorder	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
<input type="checkbox"/> Others	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
e) Autoimmune disease	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
f) Injection site reaction	<input type="radio"/> No <input type="radio"/> Yes	□□□/□□□/□□□□□
g) Major adverse cardiovascular event (MACE)	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□
h) Others	<input type="radio"/> No <input type="radio"/> Yes, specify	□□□/□□□/□□□□□

SECTION 5 : CHANGE/CESSATION OF BIOLOGIC TREATMENT	
1. Date of change/cessation (dd/mm/yyyy)	□□□/□□□/□□□□□
2. Change/cessation of biologic treatment	<input type="radio"/> Change in current biologic dosage <input type="radio"/> Change to another biologic <input type="radio"/> Change to another systemic agent. Specify _____ <input type="radio"/> Withhold biologic treatment <input type="radio"/> Change in biologic treatment interval. Specify _____
a) If changed to another biologic agent, please specify	<input type="radio"/> Infliximab <input type="radio"/> Secukinumab <input type="radio"/> Risankizumab <input type="radio"/> Adalimumab <input type="radio"/> Ixekizumab <input type="radio"/> Guselkumab <input type="radio"/> Etanercept <input type="radio"/> Others, specify _____ <input type="radio"/> Ustekinumab
b) If changed to another systemic agent, please specify	<input type="checkbox"/> Phototherapy <input type="checkbox"/> Cyclosporin <input type="checkbox"/> Oral methotrexate <input type="checkbox"/> Hydroxyurea <input type="checkbox"/> Parenteral methotrexate <input type="checkbox"/> Systemic corticosteroids <input type="checkbox"/> Acitretin <input type="checkbox"/> Other systemic agent, specify _____ <input type="checkbox"/> Sulphasalazine
c) Reason for change/cessation	<input type="checkbox"/> Financial reasons <input type="checkbox"/> Patient's decision <input type="checkbox"/> Adverse event <input type="checkbox"/> Almost or clear of lesions <input type="checkbox"/> Primary lack of efficacy <input type="checkbox"/> Clinical trial participation <input type="checkbox"/> Secondary loss of efficacy <input type="checkbox"/> Others, specify _____

SECTION 6 : CONCOMITANT SYSTEMIC TREATMENT	
1. Concomitant systemic treatment / phototherapy	<input type="radio"/> No <input type="radio"/> Yes, <input type="checkbox"/> Phototherapy <input type="checkbox"/> Oral methotrexate <input type="checkbox"/> Parenteral methotrexate <input type="checkbox"/> Acitretin <input type="checkbox"/> Sulphasalazine <input type="checkbox"/> Cyclosporin <input type="checkbox"/> Hydroxyurea <input type="checkbox"/> Systemic corticosteroids <input type="checkbox"/> Others, specify _____

SECTION 7 : INVESTIGATIONS			
1. Laboratory values (within last 6 months)		Result	Date
	Haemoglobin (g/DL):		
	White cell count (x10 ⁹ /L):		
	Platelet (x10 ⁹ /L):		
	Urea (mmol/L):		
	Creatinine (umol/L):		
	Aspartate Aminotransferase (AST) (U/L):		
Alanine transaminase (ALT) (U/L):			

APPENDIX B: DATA MANAGEMENT

The MPR maintains a database that includes patient's demographic data, medical history, comorbidities, clinical presentation, treatments received in the past 6 months and quality of life. Data is stored in a SQL Server due to the high volume of data accumulated throughout the years.

Data Sources

SDPs of MPR comprise of dermatology centres or clinics with dermatologists who participate in the registry throughout Malaysia.

Data Collection

The study involves collection of data on the patient's first visit to the participating centre and thereafter every three months on follow-up visits for patients receiving biologic therapy and every 6 months for patients on phototherapy or systemic treatment.

A Case Report Form (CRF) is employed for the data collection. This is a double-sided single-sheet CRF which consists of a clinical data form and multilingual Dermatology Life Quality Index (DLQI) and Children's Dermatology Life Quality Index (CDLQI) forms. The clinical data form is to be completed by the doctor in-charge while the DLQI/CDLQI forms are to be completed by the patient (parent or guardian for young patients) with guidance from a trained staff if necessary. The DLQI form is used for patients 17 years old and above, whilst the CDLQI for patients aged 4 to 16 years.

The CRF is to be completed for each new patient during consultation at the first visit to the participating centre. A new CRF is to be completed for the same patient every 6 months at follow up visits for those treated with phototherapy and/or systemic treatment to record the progress of the patient. For patients initiated on biologic treatment, an additional Biologic Treatment Initiation Form is filled and the Biologic Treatment Follow Up Form is filled at follow up visits every 3 months.

The CRF is to be completed in duplicate. The participating centre retains the duplicate copy in the patient's medical record, while the original copy is to be sent within 2 weeks to the RCC where the data is analysed, interpreted and presented as reports at intervals to the users.

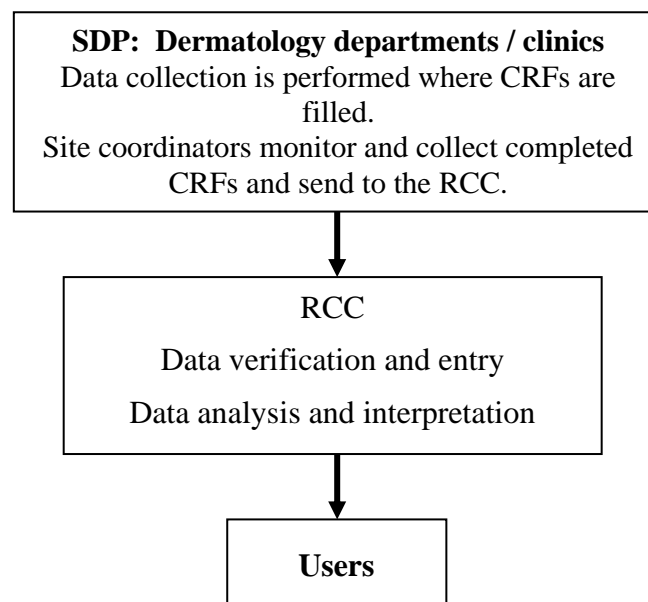
Participation of the SDP is entirely voluntary.

Registry ICT Infrastructure and Data Centre

The operations of the MPR are supported by an extensive ICT infrastructure to ensure operational efficiency and effectiveness under MyHDW.

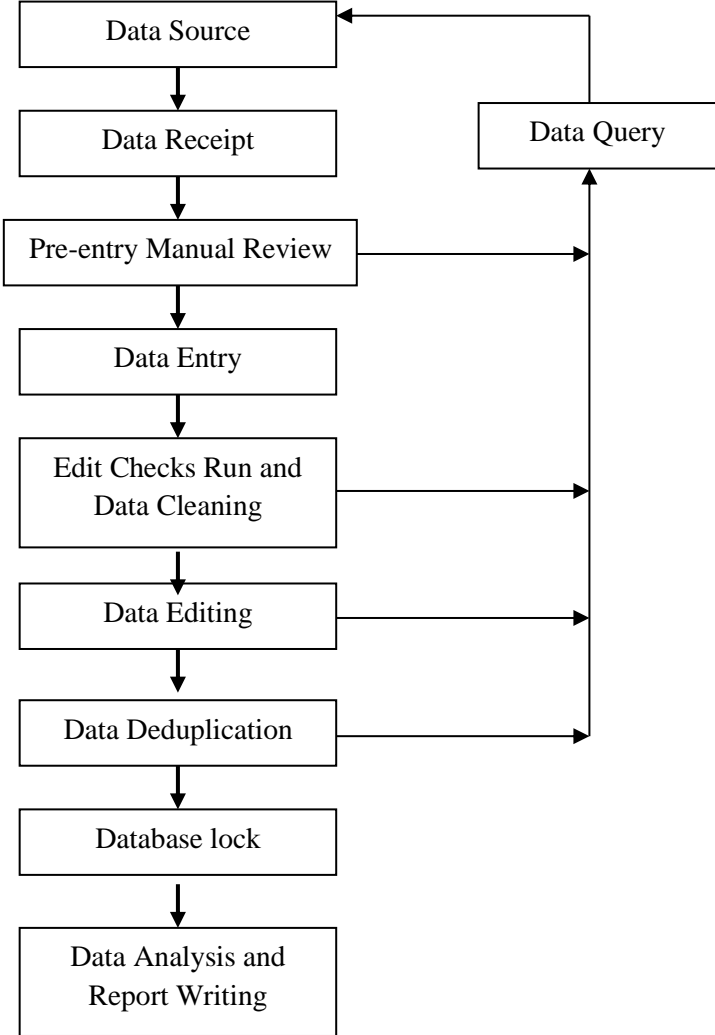
Data Flow Process

Data are collected by the doctors at the dermatology departments or clinics. Completed CRFs are then sent to the RCC.



Data received by the RCC are manually reviewed and checked for completeness and error. Data without apparent problems are entered into the registry database. Edit checks are performed periodically to identify potential data errors, such as missing data, non-allowed values, out of range numeric values, inconsistent data and duplication errors. Data queries that are resolved are then updated in the database.

To ensure complete enumeration and validity of data, a series of tasks as shown in the figure below are in place.



SDP Data Reporting, Data Correction and Submission Tracking

Data submitted by the SDP are entered into the electronic case report form (eCRF) via the DermReg Web Application known as Aplikasi Registri Pesakit (ARP) DermReg.

Data security features in ARP DermReg include web owner authentication, two-level user authentication, access control, data encryption, session management to automatically log off the application, audit trail and data backup and disaster recovery plan.

Prior to registering a patient record, a verification process is done by using the search functionality to search if a patient has been registered in the registry. This step is done to avoid duplicate records. For patients who have an existing record in the database, the SDP needs to add a new notification with the patient's details pre-filled based on the existing information in the database.

There are a few built-in functionalities at the data entry page that serve to improve data quality. One such function is auto calculation which reduces errors in human calculation. There is also inconsistency check functionality that disables certain fields if these fields are answered in a certain manner. When a value entered is not within the specific range, the user is prompted for the correct value.

Real time reports are also provided in the web application. The aggregated data reports are presented in tables and graphs. These aggregated data reports are typically presented as the centre's own data report and as the registry's overall data report.

Edit checks run and Data cleaning

Edit checks are performed periodically by the registry manager to identify missing compulsory data, out of range values, inconsistent data and errors with duplication. Data cleaning is then performed based on the results of the edit checks. Data update and checking of the dataset is performed when there is a query of certain fields. This is done when there is a request by a user, correction of data based on the data query in the eCRF or after receiving results from preliminary data analysis. During data standardization, missing data are handled based on derivation from existing data. For example, deriving age from the MyKad and deriving gender from the MyKad. Checking inconsistent data is also done, for example MyKad and name signifies female but gender is recorded as male. Data de-duplication is also performed to identify duplicate records in the database that might have been missed by the SDP.

Legal Aspects and Confidentiality

Data transfer from source data providers is entirely voluntary. There is no legal provision to compel any individual or institution to report or transfer its data to the RCC. The data transferred to the RCC is highly sensitive and must be kept strictly confidential with access only to the authorized individual working at the RCC. Strict data protection procedures are in place with standard disease registration practices, and in compliance with applicable regulatory guidelines.

Data release policy

One of the primary objectives of the registry is to make data available to the physicians, policy makers and researchers. The registry would appreciate that users acknowledge the registry for the use of the data. Any request for data that requires a computer run must be made in writing (by email, or registered mail) together with the Data Release Application Form and signed Data Release Agreement Form. These requests need prior approval of the Governance Board before such data can be released.

APPENDIX C: STATISTICAL METHODS

ANALYSIS SET

This refers to the set of cases included in the analysis. Three analysis sets were defined:

1. Patient notification between 2020 and 2022

There were 8,813 patients in the dataset. This analysis set was used for the analysis in Chapters 1, 2, 3, 4, 5, 6a and 6b, which comprised of 2,760 cases in year 2020, 3,206 cases in year 2021 and 2,847 cases in 2022.

2. Patient's Quality of life between 2020 and 2022

For Chapter 7, 8,703 cases were included in the analysis.

3. Patient outcome between 2020 and 2022

There were 1,318 cases for the outcome analysis in Chapter 8.

DATA MANAGEMENT

Data Cleaning

The data from the MPR database were subjected to extensive checking prior to definitive analysis. Errors found or queries raised were checked against the database and/or CRF and corrections were made immediately.

Missing Data

Details of missing data were issued to the Principal Investigator to be clarified. Traceable missing information was then incorporated into the dataset. Untraceable data were included in the analysis and defined as missing.

STATISTICAL METHOD

Descriptive analysis was done to present frequencies and percentages of distribution whereas bar and pie charts were used to present the figures. For continuous data, the mean, standard deviation, minimum, maximum, median and interquartile ranges were reported. For standardization of the output tables, the values of percentages and descriptive summary were limited to one decimal point only. The summaries of data presentation by chapter are described as below:

Stock and Flow

Chapter 1 described the contributing centres and number of notifications received. Data were presented using tables and line charts.

Demographic Characteristics

Chapter 2 demonstrated the socio-demographic profiles such as gender, ethnicity, nationality and marital status. Descriptive summary was done for age at visit. Data were presented with tables and pie charts.

Medical History

Chapter 3 depicted the age of onset for psoriasis versus the age of diagnosis, family history of psoriasis, the aggravating factors for psoriasis and disease burden. Data were presented using tables.

Comorbidities

Chapter 4 reported the comorbidities. Tables and bar charts were used to represent the data.

Clinical Presentation

Chapter 5 elucidated the types of psoriasis, disease severity in terms of body surface involvement, PASI, joint disease and involvement of special sites such as scalp, face, genitalia, eyes, tongue and nails. Data were presented using tables.

Treatment

Chapter 6a and 6b presented the various treatment modalities which included topical therapy, phototherapy, systemic and biologic therapy. Tables were used to depict the data.

Quality of Life

Chapter 7 solely concentrated on a specific intention, namely assessment of quality of life using the Dermatology Life Quality Index (DLQI) and Children's Dermatology Life Quality Index (CDLQI) as appropriate. The data were presented graphically using tables, horizontal bar charts and stacked bar charts.

Outcomes

Chapter 8 detailed the descriptive summary of the outcome variables. The improvement of lesion extent (BSA and PASI) and DLQI/CDLQI scores were presented using tables.

STATISTICAL SOFTWARE

IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.

APPENDIX D: PARTICIPATING CENTRE DIRECTORY

1.	Hospital Kuala Lumpur Department of Dermatology Hospital Kuala Lumpur Jalan Pahang, 50586 Kuala Lumpur, Wilayah Persekutuan Kuala Lumpur. Tel: 03-2615 1539 Fax: 03-2698 5927	Investigator: Dr. Suganthy Robinson Site- coordinator: Dr Muhammad Jaya Aiman jaya.aiman@moh.gov.my
2.	Hospital Sungai Buloh Dermatology Unit Hospital Sungai Buloh, Jalan Hospital, 47000 Sungai Buloh, Selangor Darul Ehsan. Tel: 03-6145 4333 Ext 1286 Fax: 03-6145 4222	Investigator: Dr. Norli Marwyne Mohd Noor Site- coordinator: PPP Haifaa Izzah binti Abdul Ghani PPPHaifaa@gmail.com
3.	Hospital Tuanku Ja'afar, Seremban Dermatology Department, Hospital Tuanku Ja'afar, Jalan Rasah, 70300 Seremban, Negeri Sembilan. Tel: 06-760 4157 Fax: 06-762 5771	Investigator: Dr. Preamala Gunabalasingam Site- coordinator: Dr. Nurfarah Nadia Bt Mohd Farid nurfarahnadia@moh.gov.my
4.	Hospital Sultanah Fatimah, Muar Dermatology Department, Hospital Pakar Sultanah Fatimah, Jalan Salleh, 84000 Muar, Johor Darul Takzim. Tel: 06-952 1901 Ext 187 Fax: 06-952 6003	Investigator: Dr. Evelyn Yap Wen Yee Site- coordinator: PPP Fiqah Bin Mohd Nadzri
5.	Hospital Pulau Pinang Dermatology Department, Hospital Pulau Pinang, Jalan Residensi, 10990 Pulau Pinang, Tel: 04-222 5250 Ext 5246 Fax: 04-228 1737	Investigator: Dr. Tan Wooi Chiang Site- coordinator: PPP Mohd Safwan Bin Mat Junoh safwan.26@moh.gov.my

6.	Hospital Sultanah Bahiyah, Alor Setar Dermatology Department, Hospital Sultanah Bahiyah, Lebuhraya Darul Aman, 05100 Alor Setar, Kedah Tel: 04-740 6233 Fax: 04-735 0232	Investigator: Dr. Wong Siu Bee Site- coordinator: Dr Edwin Jude Gunasegaran
7.	Hospital Tuanku Fauziah, Kangar Dermatology Department, Hospital Tuanku Fauziah, Jalan Kolam, 01000 Kangar, Perlis Indera Kayangan. Tel: 04-973 8000 Fax: 04-976 7237	Investigator: Dr. Khoo Voon Ling Site- coordinator: MA Izza Wandee bin Zainal izzawandee@moh.gov.my
8.	Hospital Queen Elizabeth, Kota Kinabalu Dermatology Department, Hospital Queen Elizabeth, Karung Berkunci no 2029 , 88586 Kota Kinabalu, Sabah. Tel: 088-517555 Fax: 088-211999	Investigator: Dr. Voo Sook Yee @ Michelle Site- coordinator: SN Ampong Anggarak
9.	Hospital Tengku Ampuan Afzan, Kuantan Dermatology Department, Hospital Tengku Ampuan Afzan, Jalan Tanah Putih, 25100 Kuantan, Pahang Darul Makmur. Tel: 09-513 3333 Fax: 09-514 2712	Investigator: Dr. Rajalingam Ramalingam Site- coordinator: Herdawati binti Zainal Watie140284@gmail.com
10.	Hospital Raja Permaisuri Bainun, Ipoh Dermatology Department, Jabatan Dermatologi, Hospital Ipoh, Jalan Hospital 30990 Ipoh, Perak Darul Ridzuan. Tel: 05-208 5072 Fax: 05-253 1541	Investigator: Dr. Tang Jyh Jong Site- coordinator: Dr Ang Tick Sheng

11.	Hospital Umum Sarawak, Kuching Dermatology Department, Hospital Umum Sarawak, Jln Tun Ahmad Zaidi Aduce, 93586 Kuching, Sarawak. Tel: 082-27 6666 Ext 5117 Fax: 082-242751	Investigator: Dr. Tang Min Moon Site- coordinator: Ahmad Irwan bin Hamlin Irwan_hamlin@yahoo.com
12.	Hospital Tengku Ampuan Rahimah, Klang Dermatology Department, Hospital Tengku Ampuan Rahimah, 41200 Klang, Selangor Darul Ehsan. Tel: 03-3375 7000 Ext 6266 Fax: 03-3374 9557	Investigator: Dr. Ng Ting Guan Site-coordinator: Dr R. Parvathy R. M. Ramanathan drparvathy@moh.gov.my
13.	Hospital Sultanah Aminah, Johor Bahru Jabatan Dermatologi, Hospital Sultanah Aminah, Jalan Abu Bakar, 80100 Johor Bahru, Johor Darul Takzim Tel: 07-223 1806 Fax: 07-224 2694	Investigator: Dr. Wong Kit Wan Site- coordinator: PPP Izuddin Aizat Abd Aziz Izzuddinaizat7@gmail.com
14.	Hospital Tunku Azizah Department of Paediatrics Hospital Kuala Lumpur Jalan Pahang, 50586 Kuala Lumpur, Wilayah Persekutuan Kuala Lumpur.	Investigator: Dr Sabeera Begum
15.	Hospital Melaka Dermatology Department, Hospital Melaka, Jalan Mufti Hj. Khalil, 75400 Melaka. Tel: 06-289 2690 Fax: 06-284 1590	Investigator: Dr. Lee Choon Sian Site- coordinator: Dr. Fellicesa Ang angelisalice@gmail.com
16.	Hospital Sibul, Sarawak Dermatology Department, Hospital Sibul, Batu 5 ½ Jalan Oya Lama 96000 Sibul Sarawak Tel : 084-343333	Investigator: Dr. Teoh Hock Gin Site Coordinator: PPP Shahrulnizam bin Ibrahim shahrulnizam.ibrahim@moh.gov.my

17.	University of Malaya Medical Centre Division of Dermatology, Department of Medicine, University of Malaya Medical Centre, Faculty of Medicine, University of Malaya, 59100 Kuala Lumpur. Tel: 03-7949 2429 Fax: 03-7956 2253	Investigator: Dr. Kwan Zhenli Site- coordinator: Dr. Yong Shin Shen emyong5@hotmail.com
18.	Hospital Canselor Tuanku Muhriz UKM Dermatology Department, UKM Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Kuala Lumpur. Tel: 03-9145 6075 Fax: 03-9145 6640	Investigator: AP Dr. Adawiyah Jamil
19.	Hospital Raja Perempuan Zainab II, Kota Bharu Dermatology Department, Hospital Raja Perempuan Zainab II, 15586 Kota Bharu, Kelantan Darul Naim. Tel: 09-7452000 Ext 2384 Fax: 09-7486951	Investigator: Dr. Wan Noor Hasbee Wan Abdullah Site- coordinator: PPP Muhammad Al-Amin Bin Mat Zin al_amin@moh.gov.my
20.	Hospital Selayang Dermatology Department, Hospital Selayang, Lebuh Raya Selayang-kepong, 68100 Batu Caves, Selangor Darul Ehsan. Tel: 03-6126 3333 Fax: 03-6137 7097	Investigator: Dr. Teeba Raja Site- coordinator: PPP Nurul Faryana Bt Deraman
21.	Hospital Putrajaya Dermatology Department, Hospital Putrajaya, Ground Floor, Precinct 7, 62250 Putrajaya Tel: 03- 8312 4200 Ext 4371 Fax: 03-8888 0137	Investigator: Dr. Nazatul Shima Abdul Rahim Site- coordinator: SN Norlita binti Mohamad

22.	Hospital Serdang Dermatology Department, Hospital Serdang, Jalan Puchong, 43000 Kajang, Selangor Darul Ehsan. Tel: 03-8947 5555 Fax: 03-8947 5050	Investigator: Dr. Lee Sut Enn Site- coordinator: SN Nadila binti Mohammed Nor
23.	Hospital Ampang Dermatology Department, Hospital Ampang, Jalan Mewah Utara, Pandan Mewah, 68000 Ampang, Selangor Darul Ehsan. Tel: 03-4289 6000 Fax: 03-4295 4666	Investigator: Dr. Kwan Jing Wern Site- coordinator: PPP Evy Debra binti Lee Fui Kong
24.	Hospital Sultan Haji Ahmad Shah, Temerloh Dermatology Department, Hospital Sultan Haji Ahmad Shah, Jalan Maran, 28000 Temerloh, Pahang Darul Makmur. Tel: 09-295 5333 Fax: 09-297 2468	Investigator: Dr. Rajalingam Ramalingam
25.	Hospital Jerantut Dermatology Department, Hospital Jerantut, 27000 Jerantut, Pahang Darul Makmur. Tel: 09-266 3333/4 Fax: 09-266 1462	Investigator: Dr. Rajalingam Ramalingam
26.	Hospital Jengka Dermatology Department, Hospital Jengka, Bandar Jengka Maran, 26400 Bandar Tun Razak, Pahang Darul Makmur. Tel: 09-466 2333 Fax: 09-466 3215	Investigator: Dr. Rajalingam Ramalingam

27.	Hospital Sultan Ismail, Johor Bahru Dermatology Department, Hospital Sultan Ismail, Jalan Persiaran Mutiara Emas Utama, Taman Mount Austin, 81100 Johor Bahru, Johor Darul Takzim Tel: 07- 356 5000	Investigator: Dr. Latha Selvarajah Site- coordinator: - SN Muhamad Ahmad Fauzi Muhamad_789@yahoo.com
28.	Hospital Sultanah Zahirah, Kuala Terengganu Dermatology Department, Hospital Sultanah Zahirah, Jalan Sultan Mahmud, 20400 Kuala Terengganu, Terengganu Darul Iman. Tel: 09-621 2121 Fax: 09-622 1820	Investigator: Dr. Norazura Mohamad Site- coordinator: - Dr Judhaimah Mardhiah Binti Mat Tari judhaimah@moh.gov.my
29.	Hospital Duchess of Kent, Sandakan KM3.2 Jalan Utara, 90000 Sandakan, Sabah. Tel: 089-248 600 Fax: 089-213 607	Investigator: Dr. Voo Sook Yee @ Michelle
30.	Hospital Lahad Datu Peti Surat 60065, 91110 Lahad Datu, Sabah. Tel: 089-895 111 Fax: 088-884 670	Investigator: Dr. Voo Sook Yee @ Michelle
31.	Hospital Tawau Peti Surat 67, 91007 Tawau, Sabah. Tel: 089-773 533 Fax: 089-773 317	Investigator: Dr. Voo Sook Yee @ Michelle
32.	Hospital Kuala Lipis 27200 Kuala Lipis, Pahang. Tel: 09-3123333 / 3123332 Fax: 09-3121787	Investigator: Dr. Rajalingam Ramalingam

33.	Hospital Sultan Abdul Halim 225, Bandar Amanjaya, 08000 Sungai Petani, Kedah Tel: 04-445 7333	Investigator: Dr. Loo Chai Har
34.	Hospital Taiping Dermatology Department, Hospital Taiping Jalan Taming Sari, 34000 Taiping, Perak	Investigator: Dr. Lee Hock Leng Site Coordinator: JM Nadzirah binti Md Zain
35.	KPJ Pahang Specialist Hospital Jalan Tanjung Lumpur, 26060 Kuantan, Pahang	Investigator: Dr. Rajalingam Ramalingam
36.	Hospital Muadzam Shah 26700 Muadzam Shah Pahang	Investigator: Dr. Abdul Rahman Bin Che Abdul Rahim
37.	Hospital Rompin Jalan Kg Kolam Kuala Rompin 26800 Rompin Pahang	Investigator: Dr. Abdul Rahman Bin Che Abdul Rahim
38.	Hospital Miri Jalan Cahaya 98000 Miri Sarawak	Investigator: Dr. Tang Min Moon
39.	Gleneagles Hospital Kota Kinabalu Riverson@Sembulan, Block A-1, Lorong Riverson@Sembulan, Off Coastal Highway, 88100 Kota Kinabalu, Sabah	Investigator: Dr. Voo Sook Yee @ Michelle