Ministry of Health Malaysia

NATIONAL DERMATOLOGY REGISTRY
(DermReg)

The Tenth Report of the MALAYSIAN PSORIASIS REGISTRY 2007 - 2018

Authors:

Suganthy Robinson
Tang Min Moon
Kwan Zhenli
Voo Sook Yee @ Michelle
Rajalingam Ramalingam
Suganthi Thevarajah

Editors:

Wee Ai Leen
Latha Selvarajah
Adawiyah Jamil
Tan Wooi Chiang

Ministry of Health Malaysia

NATIONAL DERMATOLOGY REGISTRY (DermReg)

The Tenth Report of the MALAYSIAN PSORIASIS REGISTRY

2007 - 2018

Authors:

Suganthy Robinson
Tang Min Moon
Kwan Zhenli
Voo Sook Yee @ Michelle
Rajalingam Ramalingam
Suganthi Thevarajah

Editors:

Wee Ai Leen
Latha Selvarajah
Adawiyah Jamil
Tan Wooi Chiang

Published by:
Malaysian Psoriasis Registry, Malaysia

Publication date: 1 December 2020

Contact:
Malaysian Psoriasis Registry (MPR)
Department of Dermatology
Hospital Kuala Lumpur
Jalan Pahang
50586 Kuala Lumpur

Tel: 03-2615 5225 / 03-2615 5555 Ext 5225
Fax: 03-2698 5927
Email: dermreg.acrm@gmail.com
Website: http://www.dermatology.org.my/DermReg/index.htm

Suggested citation
The suggested citation for this report is as follows:
Robinson S, Tang MM, Ramalingam R, Voo SY, Kwan Z, Thevarajah S. The Tenth Report of the Malaysian Psoriasis Registry 2007-2018, Kuala Lumpur, Malaysia 2020.

Electronic version
The electronic version of this report can be downloaded at
http://www.dermatology.org.my/DermReg/publications.html

ISSN 2289-1005

ACKNOWLEDGMENT

We would like to thank the Director General of Health, Malaysia for permission to publish this report.

The Malaysian Psoriasis Registry would like to express its appreciation to everyone who has helped in making this report possible.

We would also like to thank the following for their contribution and support:

- All the doctors, allied health personnel and clerical staff from the participating centres
- The Ministry of Health, Malaysia
- The Dermatological Society of Malaysia
- Clinical Research Centre, Hospital Kuala Lumpur
- All pharmaceutical companies who have provided financial assistance
    - Leo Pharma (Malaysia) - 2010, 2011, 2013, 2014
    - Abbot Malaysia – 2011
    - Janssen (Malaysia) - 2011, 2015 – 2017
    - Abbvie - 2013 – 2016
    - Novartis Malaysia - 2017

CONTENTS

LIST OF TABLES

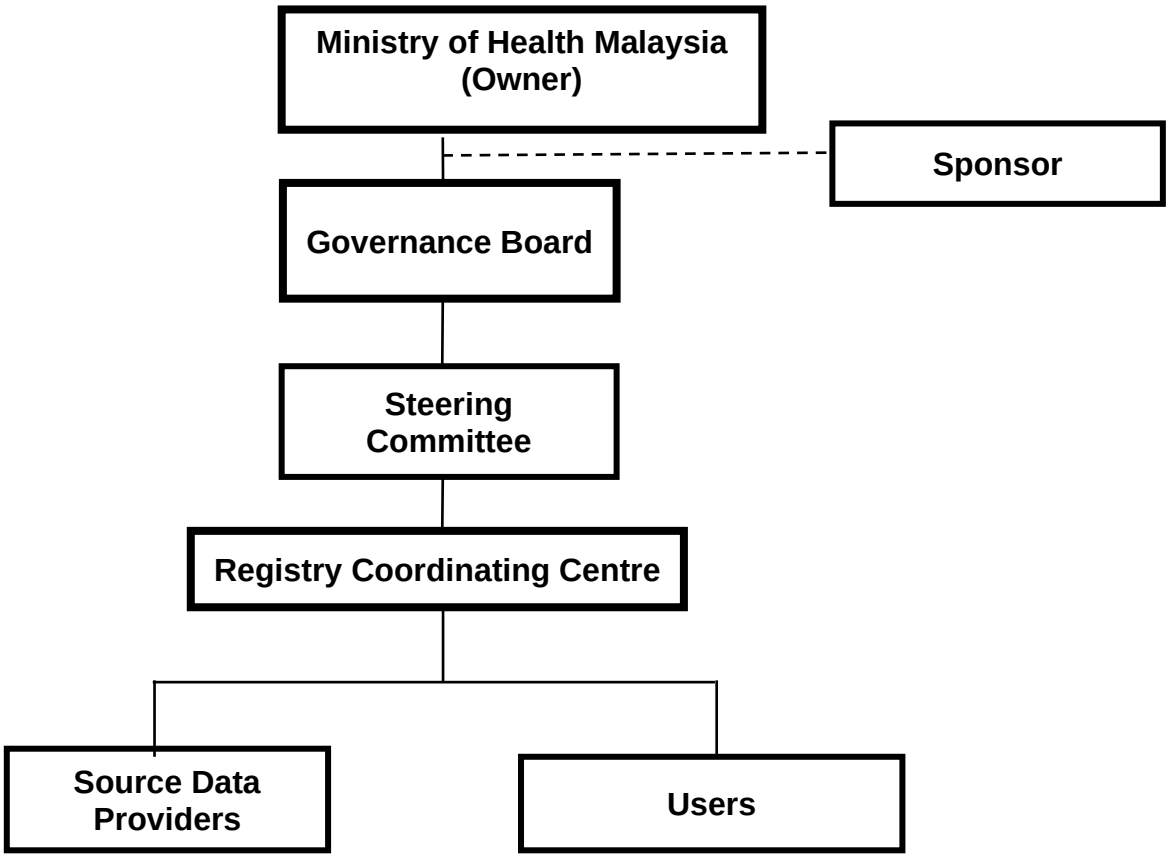
LIST OF FIGURES

ABBREVIATIONS

ACE	Angiotensin-converting enzyme
BB-UVB	Broad-band 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
NA	Not available
NBUVB	Narrow-band ultraviolet B
NSSC	Northern Skin Specialist Clinic
NHMS	National Health and Morbidity Survey
NSAIDs	Nonsteroidal anti-inflammatory drugs
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 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

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

- to ensure that 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. Chan Lee Chin
   President of the Dermatological Society of Malaysia, and
   Consultant Dermatologist
   Northern Skin Specialist Clinic (NSSC)
   Bayan Lepas, Pulau Pinang

3. Dr. Goh Pik Pin
   Director of the Clinical Research Centre Network
   Ministry of Health

STEERING COMMITTEE

Steering Committee for Malaysian Psoriasis Registry (MPR)

No.	Name	Institution
1.	Dr. Suganthy Robinson	Hospital Kuala Lumpur
2.	Dr. Kwan Zhenli	Universiti of Malaya Medical Centre
3.	Dr. Rajalingam Ramalingam	Hospital Tengku Ampuan Afzan, Kuantan
4.	Dr. Wee Ai Leen	Hospital Tunku Azizah
5.	Dr. Voo Sook Yee @ Michelle	Hospital Queen Elizabeth, Kota Kinabalu
6.	Dr. Tang Min Moon	Hospital Kuala Lumpur
7.	Dr. Latha Selvarajah	Hospital Sultan Ismail
8.	Dr. Dawn Angelia Ambrose	Hospital Ampang
9.	Dr. Tan Wooi Chiang	Hospital Pulau Pinang
10.	Associate Professor Adawiyah Jamil	Hospital Canselor Tuanku Muhriz UKM

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	Cik Zalita binti Yaacob
Biostatistician	Ms Nurakmal bt Baharum CRC
Database Administrator	Dr. Muhammad Hafizuddin bin Hamdan Senior Assistant Director 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 Malaysian Psoriasis Registry (MPR) 2007-2018

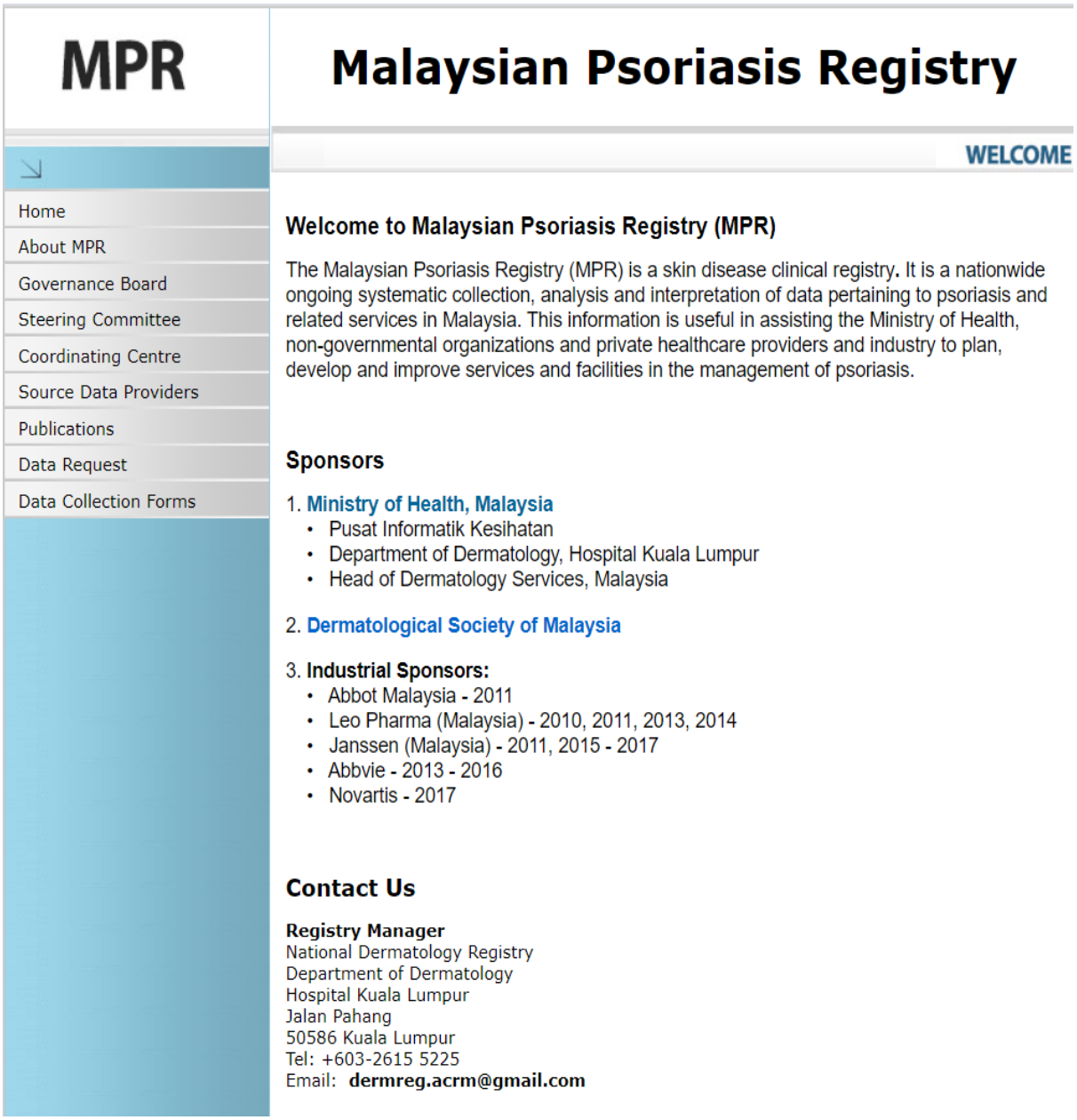
No.	Source Data Provider	Investigator
1.	Hospital Kuala Lumpur	Dr. Suganthy Robinson
2.	Hospital Pulau Pinang	Dr. Tan Wooi Chiang
3.	Hospital Sultanah Bahiyah, Alor Setar	Dr. Yeoh Chin Aun
4.	Hospital Tuanku Fauziah, Perlis	Dr. Hassanin Husseyne Hilmi
5.	Hospital Sultanah Fatimah, Muar	Dr. Evelyn Yap Wen Yee
6.	Hospital Tuanku Jaafar, Seremban	Dr. Najeeb Ahmad Mohd Safdar
7.	Hospital Queen Elizabeth, Kota Kinabalu	Dr. Voo Sook Yee @ Michelle
8.	Hospital Sungai Buloh	Dr. Norli Marwyne Mohd Noor
9.	Hospital Tengku Ampuan Afzan, Kuantan	Dr. Rajalingam Ramalingam
10.	Hospital Permaisuri Bainun, Ipoh	Dr. Tang Jyh Jong
11.	Hospital Umum Sarawak, Kuching	Dr. Pubalan Muniandy
12.	Hospital Tengku Ampuan Rahimah, Klang	Dr. Ng Ting Guan
13.	Hospital Melaka	Dr. Preamala Gunabalasingam
14.	Prince Court Medical Centre	Dr. Gangaram Hemandas
15.	Gleneagles Kuala Lumpur	Dr. Chang Choong Chor
16.	Hospital Sultanah Aminah, Johor Bahru	Dr. Tey Kwee Eng
17.	UKM Medical Centre	Dr. Norazirah Md Nor
18.	UM Medical Centre	Dr. Kwan Zhenli
19.	Hospital Raja Perempuan Zainab II	Dr. Wan Noor Hasbee Wan Abdullah
20.	Hospital Ampang, Selangor	Dr. Dawn Ambrose
21.	Hospital Selayang, Selangor	Dr. Benji Teoh Tze Yuen
22.	Hospital Putrajaya	Dr. Nazatul Shima Abdul Rahim
23.	Hospital Serdang	Dr. Low Dyoie
24.	Hospital Sultan Ismail, Johor Bahru	Dr. Latha Selvarajah
25.	Hospital Sultan Haji Ahmad Shah, Temerloh	Dr. Rajalingam Ramalingam

26.	Hospital Jerantut	Dr. Rajalingam Ramalingam
27.	Hospital Jengka	Dr. Rajalingam Ramalingam
28.	Hospital Sultanah Zahirah, Kuala Terengganu	Dr. Nor Azura Mohamad
29.	Hospital Duchess of Kent, Sandakan	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

UM = Universiti Malaya
UKM = Universiti Kebangsaan Malaysia

OFFICIAL WEBSITE OF MPR

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



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 a significant physical, psycho-social and economic impact on the patient. Being incurable, it may lead to poor patient compliance 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, ongoing systematic collection of data pertaining to patients who have psoriasis. The main reason for setting up a psoriasis registry is to have more 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, its severity, aggravating factors, associated joint and nail disease and the various types of therapies commonly 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 revised under the guidance of CRC and with the financial support from MOH, a new CRF was introduced. A new 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 MPR 2007-2008 was published the following year.

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 and clinical examination findings
- Quality of life assessment i.e. Dermatology Life Quality Index (DLQI)
- 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 any other diseases

Inclusion criteria:

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

Exclusion criteria:

Patients whose diagnosis is in doubt are excluded.

EXECUTIVE SUMMARY

Stock and Flow

During the period from October 2007 to December 2018, a total of 21,735 patients with psoriasis from 30 dermatology centres (26 government hospitals, 2 private centres and 2 university hospitals) were registered.

Demographic Characteristics

In adult patients, the male-to-female ratio was 1.3:1. Ethnic distribution is as follows: Malay 53.1%, Chinese 20.4%, Indian 17.1%, and other ethnic groups 9.4%. Mean age at notification was 44.42 ± 15.77 years (range 18 - 92 years). Most patients (99.1%) were Malaysian citizens.

In paediatric patients, the male-to-female ratio was 1:1.3. Ethnic distribution is as follows: Malay 72.0%, Chinese 7.0%, Indian 11.9%, and other ethnic groups 9.1%. Mean age at notification was 13.14 ± 3.66 years (range 0.2 - 18 years). Most patients (99.8%) were Malaysian citizens.

Psoriasis History

In adult patients, the mean age of onset for psoriasis was 35.36 ± 16.13 years (range 1 – 88 years). Family history of psoriasis was present in 22.9% of the patients. Among those who had a positive family history, 41.1% had either parent affected, 34.4% had siblings with psoriasis and 10.2% had children with psoriasis.

In the paediatric population, the mean age of onset for psoriasis was 10.58±4.23 years (range 1-18). At least one family member was affected with psoriasis in 23.4%. Of these, 38.3% had either parent affected with psoriasis.

Both populations (52.4% of adults and 39.3% of paediatric patients) reported one or multiple factors which aggravated their psoriasis. The common aggravating factors were stress (34.0% in adults, 22.7% in paediatric patients), excessive sun exposure (16.8% in adults, 16.6% in paediatric patients) and infection (6.7% in adults, 6.6% in paediatric patients).

Comorbidities

Among the adult psoriasis patients, 58.3% were obese, 15.6% were overweight, 25.9% had hypertension, 18% had hyperlipidaemia, 17.3% had diabetes mellitus, 5.3% had ischaemic heart disease and 1.6% had suffered a prior stroke. In those aged 18 years and below with psoriasis, the most prevalent comorbidity was obesity (23.1%), followed by bronchial asthma (2.1%).

Clinical Presentation

The most common clinical type of psoriasis in adult and paediatric patients was plaque psoriasis (93.1% and 89.8%, respectively). This was followed by guttate psoriasis (3.3% and 7.4% respectively), erythrodermic psoriasis (2% and 0.5% respectively), flexural/inverse psoriasis (0.5% and 0.8% respectively) and palmoplantar non-pustular (0.4% and 0.5% respectively). In the adult group, 75.4% had a body surface area (BSA) involvement of 10% or less. The pattern is the same in the paediatric population, i.e 55.5% had <5% BSA affected and 27.8% of the patients had 5-10% BSA involvement.

Psoriatic arthropathy was reported in 14% of the adult patients and 2.5% of the paediatric population. The most common type of psoriatic arthropathy in adult patients was oligo/monoarthropathy (48.1%) followed by distal hand joint arthropathy (31.5%) and rheumatoid-like symmetrical polyarthropathy (28.6%).

About two-thirds (58.1%) of the adult patients had nail changes associated with psoriasis. Among the patients who had nail disease, pitting was the most frequent (71.9%), followed by onycholysis (47.5%), discolouration (30.8%) and subungual hyperkeratosis (14.1%). Total nail dystrophy was found in 5% of the patients with nail disease. In the paediatric group, 36.4% had nail involvement with pitting most frequently encountered (87%) followed by onycholysis (25.9%).

Treatment received in the past 6 months

The majority of patients (95.1% of adults and 92.5% of paediatric patients) were on topical treatment. Topical corticosteroids were the most frequently prescribed topical (88% of adults and 84.6% of paediatric patients), followed by emollients (76.6% of adults and 70.6% of paediatric patients), and tar preparations (69.5% of adults and 66.4% of the paediatric group). Phototherapy was administered to 2.8% of the adult patients and 0.7% of the paediatric patients. Majority of the patients received narrowband UVB (NBUVB) (92.4% of adults and 83.3% of paediatric patients). Systemic therapy was given to 14.4% of adult patients and 5.2% of paediatric patients. The most frequently used systemic therapy was methotrexate (81.6% of adults and 58.4% of paediatric patients), followed by acitretin (20% of adults and 36% of paediatric patients).

Biological therapy was used in 136 adult patients (0.7%) with psoriasis but none in the paediatric group. The most commonly prescribed biologics were adalimumab followed by ustekinumab, both contributing to 70% of the total biologics used.

Quality of Life

Measurement of quality of life using the Dermatology Life Quality Index (DLQI) or Children's DLQI (CDLQI) was performed in 19,755 patients aged 17 years and above and 1329 patients aged 4-16 years respectively. The mean DLQI score was 9.62 ± 6.75 and the mean CDLQI was 9.05 ± 5.95.

A DLQI of more than 10 was reported by 40.3% of patients, and 26.8% of the patients reported a CDLQI of more than 12, indicating 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 and CDLQI assessments (43.4% and 43.2% of patients respectively scored 2 points or more per question in this domain).

Outcomes

Outcomes of treatment were measured based on the change of percentage of body surface area involvement and DLQI scores at 6 months post treatment. The extent of psoriasis lesions was assessed in terms of percentage of body surface area involvement categorised into 4 scales, i.e. <5%, 5%-10%, >10%-90%, and >90% (erythrodermic) pre and post treatment. Of 4,027 patients, 973 patients (24.2%) had improvement by at least one scale, among which 234 (5.8%) had improvement by two scales, and 9 patients (0.2%) improved from BSA>90% to BSA<5%. No change was found in 2,342 patients (58.2%), of which 1337 (33.2%) maintained a BSA of <5% pre and post follow up, while 712 patients (17.7%) had worsening by at least one scale.

A total of 6,827 patients were evaluated for change in quality of life using the DLQI pre and post treatment. Of these patients, 1,582 patients (23.2%) had significant improvement with a reduction of the DLQI score by at least 5, whereas 1,050 patients (15.4%) had significant worsening with an increase in the DLQI score by at least 5. A total of 190 patients were evaluated with the CDLQI. Of these patients, 53 patients (27.9%) had a significant improvement in their CDLQI score by at least 5, while 28 patients (14.7%) worsened by a score of 5 and above.

CHAPTER 1

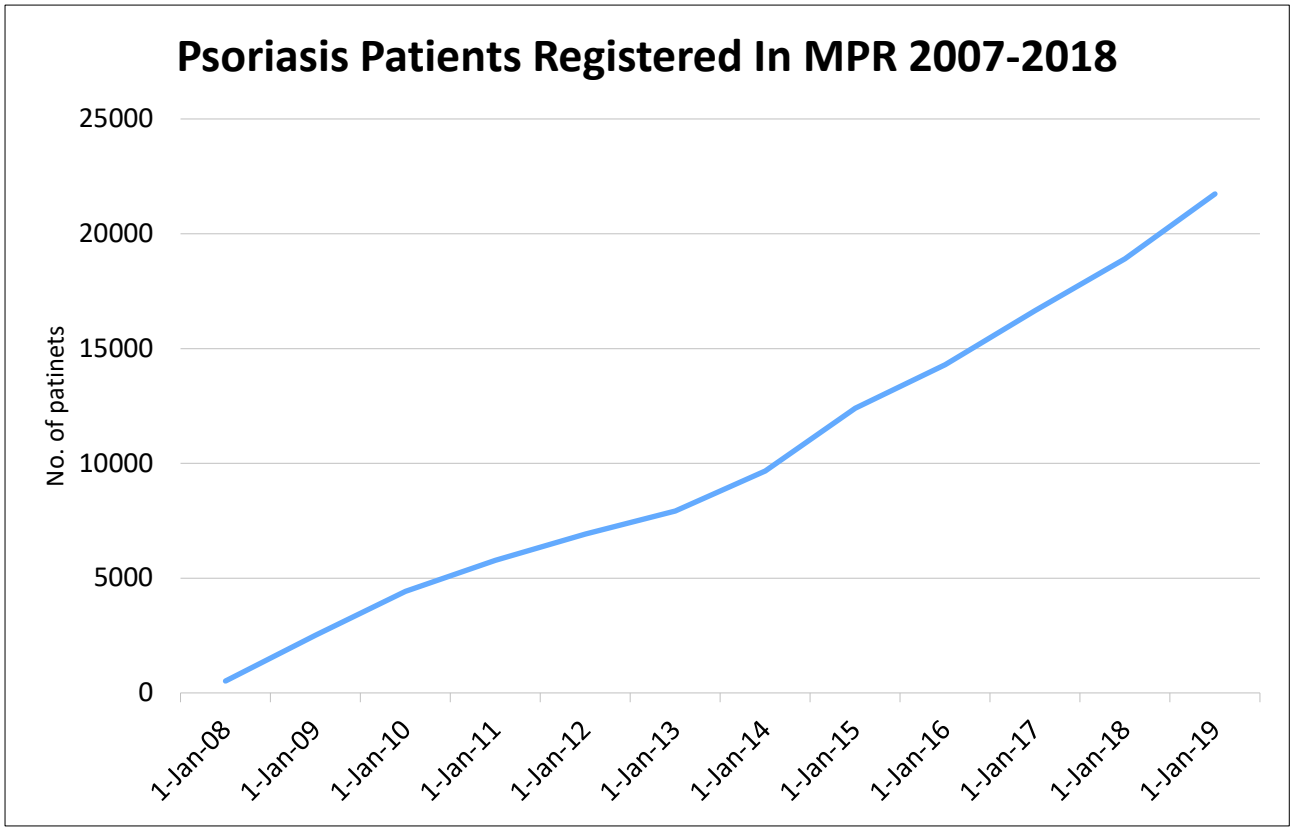
STOCK AND FLOW

Chapter 1

Stock and Flow

Dr Suganthy Robinson

From October 2007 to December 2018, a total of 21,735 patients were registered to the registry (**Figure 1.1**). Of these, 8.3% (n=1,811) belonged to the paediatric age group (≤ 18 years old) and 91.7% (n=19,924) belonged to the adult group (> 18 years old).



n = 21,735

Figure 1.1 No. of psoriasis patients notified to the Malaysian Psoriasis Registry 2007-2018

A total of 30 dermatology centres (26 government hospitals, 2 private centres and 2 university hospitals) contributed to the MPR. The number of patients notified for the adult and paediatric groups are shown in **Table 1.1** and **Table 1.2**.

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

No	Reporting Centre	No. of patients												Total
		2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	
1	Hospital Kuala Lumpur	72	194	204	132	66	79	308	492	501	481	120	101	2750
2	Hospital Queen Elizabeth	23	104	107	91	104	76	111	163	317	375	198	140	1809
3	HTAR	-	78	169	140	88	75	100	257	266	217	100	173	1663
4	Hospital Pulau Pinang	38	132	269	106	107	9	108	95	262	187	39	48	1400
5	Hospital Sultanah Bahiyah	94	177	77	60	48	76	79	344	104	124	147	154	1484
6	Hospital Melaka	-	-	130	268	150	126	121	90	57	120	83	83	1228
7	Hospital Umum Sarawak	13	179	92	46	33	51	110	150	147	215	75	58	1169
8	HRPB	60	55	104	39	73	115	90	165	148	184	71	78	1182
9	Hospital Sultanah Aminah	-	34	135	63	62	65	182	284	7	59	146	219	1256
10	HTAA	1	57	55	75	70	48	98	104	62	293	91	111	1065
11	Hospital Sultanah Fatimah	10	62	35	47	45	66	12	72	74	112	70	55	660
12	Hospital Tuanku Jaafar	-	52	-	30	53	3	83	74	84	128	90	113	710
13	Hospital Selayang	-	-	-	-	-	-	1	206	106	153	17	103	585
14	Hospital Serdang	-	-	-	-	-	-	-	-	-	315	102	23	440
15	Hospital Tuanku Fauziah	-	35	37	42	23	16	6	10	61	67	15	35	347
16	Hospital Putrajaya	-	-	-	-	-	-	-	72	69	77	100	70	388
17	Hospital Ampang	-	-	-	-	3	3	10	87	55	0	23	17	198
18	HRPZ II	-	-	-	-	9	8	86	17	14	24	144	117	419
19	Hospital Sultan Ismail	-	-	-	-	-	-	-	-	-	146	189	124	459
20	UM Medical Centre	-	-	-	-	32	23	2	-	-	2	1	5	65
21	UKM Medical Centre	-	-	-	15	0	21	4	1	-	-	-	-	41
22	Prince Court Medical Centre	-	-	6	17	3	2	2	2	4	-	-	-	36
23	Hospital Sungai Buloh	4	23	1	-	-	-	-	2	-	-	101	38	169
24	Gleneagles Medical Centre	-	10	6	-	-	-	-	-	-	-	-	-	16
25	HoSHAS	-	-	-	-	-	-	-	-	-	-	36	1	37
26	Hospital Jerantut	-	-	-	-	-	-	-	-	-	-	26	-	26
27	Hospital Jengka	-	-	-	-	-	-	-	-	-	-	-	1	1
28	Hospital Sultanah Zahirah	-	-	-	-	-	-	-	-	-	-	-	319	319
29	Hospital Duchess of Kent	-	-	-	-	-	-	-	-	-	-	-	1	1
30	Hospital Kuala Lipis	-	-	-	-	-	-	-	-	-	-	-	1	1
	Total	**315**	**1192**	**1427**	**1171**	**969**	**862**	**1513**	**2687**	**2338**	**3279**	**1984**	**2187**	**19924**

n = 19,924

HTAR Hospital Tengku Ampuan Rahimah, Hospital Raja Permaisuri Bainun HRPB, Hospital Raja Perempuan Zainab II HRPZ II, Hospital Tengku Ampuan Afzan HTAA, UM Universiti Malaya, UKM Universiti Kebangsaan Malaysia, HoSHAS Hospital Sultan Haji Ahmad Shah

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

No	Reporting Centre	No. of patients												Total
		2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	
1	Hospital Sultanah Bahiyah	11	30	11	11	9	9	20	21	16	10	24	16	188
2	Hospital Kuala Lumpur	9	23	14	8	8	10	13	12	22	28	12	12	171
3	HTAR	-	9	18	26	13	7	12	23	18	7	12	22	167
4	Hospital Umum Sarawak	2	26	8	5	4	8	10	15	12	31	13	11	145
5	Hospital Queen Elizabeth	1	10	13	10	6	7	11	13	25	18	20	16	150
6	HTAA	-	7	12	10	16	11	13	6	10	25	14	18	142
7	Hospital Melaka	-	-	7	13	19	11	14	8	8	9	6	9	104
8	Hospital Sultanah Aminah	-	2	8	5	4	7	18	27	1	8	27	36	143
9	Hospital Pulau Pinang	1	12	10	4	2	0	8	8	13	6	4	2	70
10	Hospital Tuanku Jaafar	-	5	0	6	8	0	8	2	10	17	11	15	82
11	Hospital Sultanah Fatimah	3	8	2	6	4	7	2	4	5	14	9	9	73
12	HRPB	4	3	8	2	2	11	5	10	4	4	3	5	61
13	Hospital Tuanku Fauziah	3	9	4	5	3	3	2	1	1	4	2	3	40
14	Hospital Selayang	-	-	-	-	-	-	-	13	5	10	4	5	37
15	Hospital Serdang	-	-	-	-	-	-	-	-	-	18	13	3	34
16	Hospital Ampang	-	-	-	-	-	-	2	8	5	0	3	2	20
17	HRPZ II	-	-	-	-	-	-	7	5	1	1	17	11	42
18	Hospital Sultan Ismail	-	-	-	-	-	-	-	-	-	13	16	19	48
19	Hospital Sungai Buloh	3	5	0	2	0	0	0	0	0	0	6	9	25
20	Hospital Putrajaya	-	-	-	-	-	-	-	2	0	5	12	9	28
21	Gleneagles Medical Centre	-	4	-	-	-	-	-	-	-	-	-	-	4
22	UM Medical Centre	-	-	-	-	2	0	0	0	0	0	0	0	2
23	UKM Medical Centre	-	-	-	1	0	0	0	0	0	0	0	0	1
24	Prince Court Medical Centre	-	-	-	-	-	-	1	0	0	0	0	0	1
25	Hospital Sultanah Zahirah	-	-	-	-	-	-	-	-	-	-	-	29	29
26	HoSHAS	-	-	-	-	-	-	-	-	-	-	4	0	4
	TOTAL	**37**	**153**	**115**	**114**	**100**	**91**	**146**	**178**	**156**	**228**	**232**	**261**	**1811**

n = 1,811

HTAR Hospital Tengku Ampuan Rahimah, Hospital Raja Permaisuri Bainun HRPB, Hospital Raja Perempuan Zainab II HRPZ II, Hospital Tengku Ampuan Afzan HTAA, UM Universiti Malaya, UKM Universiti Kebangsaan Malaysia, HoSHAS Hospital Sultan Haji Ahmad Shah

A total of 40,628 notifications of new patients with psoriasis and follow-up treatment were received from October 2007 till December 2018. Of these, 37,450 (92.2%) notifications were from adult patients and the remaining 3,178 (7.8%) notifications were from paediatric patients. From the total number of adult patients, 12,615 (63.31%) were notified only once and 7,309 (36.69%) had one or more follow-up notifications (**Table 1.3**). For the paediatric population, 1,226 (67.7%) of the patients were notified only once and 585 (32.3%) of them had one or more follow-up notifications **(Table 1.4).**

Table 1.3 Number of notifications for adult patients with psoriasis

No. of notifications	No. of patients	%
Entry notification	12615	63.31
Entry and 1 follow-up notification	3314	16.63
Entry and 2 follow-up notifications	1602	8.04
Entry and 3 follow-up notifications	940	4.72
Entry and 4 follow-up notifications	533	2.67
Entry and 5 follow-up notifications	348	1.75
Entry and 6 follow-up notifications	206	1.03
Entry and 7 follow-up notifications	138	0.69
Entry and 8 follow-up notifications	89	0.45
Entry and 9 follow-up notifications	63	0.32
Entry and 10 follow-up notifications	34	0.17
Entry and 11 follow-up notifications	24	0.12
Entry and 12 follow-up notifications	9	0.05
Entry and 13 follow-up notifications	4	0.02
Entry and 14 follow-up notifications	4	0.02
Entry and 15 follow-up notifications	1	0.01
Total	**19924**	**100.0**

n = 19,924

Table 1.4 Number of notifications for paediatric patients with psoriasis

No. of notifications	No. of patients	%
Entry notification	1226	67.7
Entry and 1 follow-up notification	284	15.68
Entry and 2 follow-up notifications	132	7.29
Entry and 3 follow-up notifications	60	3.31
Entry and 4 follow-up notifications	38	2.1
Entry and 5 follow-up notifications	24	1.32
Entry and 6 follow-up notifications	21	1.16
Entry and 7 follow-up notifications	4	0.22
Entry and 8 follow-up notifications	6	0.33
Entry and 9 follow-up notifications	3	0.16
Entry and 10 follow-up notifications	9	0.5
Entry and 11 follow-up notifications	2	0.11
Entry and 12 follow-up notifications	1	0.06
Entry and 13 follow-up notifications	0	0
Entry and 14 follow-up notifications	1	0.06
Total	**1811**	**100.0**

n = 1,811

CHAPTER 2

DEMOGRAPHIC CHARACTERISTICS

Chapter 2

Demographic Characteristics

Dr Voo Sook Yee @ Michelle

A total of 21,735 patients with psoriasis were notified to the Malaysian Psoriasis Registry between January 2007 to December 2018. Ninety one percent (19,924) of the population comprised of adults (age > 18 years) while the remaining 1,811 patients (9%) belonged to the paediatric group (age ≤ 18). Malaysians made up 99.1% (21,546). The majority of the Malaysians were Malays (54.6%) followed by Chinese (19.3%), Indians (16.6%), indigenous group of Sabah (6.6%) indigenous group of Sarawak (1.9%), Orang Asli (0.1%) and others (0.9%) (Figure 2.1). Among the non-Malaysians, the most common nationality was Indonesian (27.1%) (Figure 2.2).There were 12,058 males and 9,677 females with a ratio of 1.25:1 (Figure 2.3). There were more males in the adult group (11,287 males, 8,637 females) while the paediatric group had more females (771 males, 1040 females).

The mean age of all patients at the first notification was 41.81 years ± 17.43 with the youngest aged 2 months and the oldest aged 92. Among the paediatric group, the mean age was 13.14 years ± 3.66 (0.2 – 18) and the mean age for the adult group was 44.42 years ± 15.77 (18 - 92). Two thirds (66.3%) of the patients were married whereas around one third were single (31.0%). Approximately one third (30.9%, 3,984 patients) of the patients were smokers, of which the majority (63.6%, 2,535 patients) were current smokers (Table 2.1).

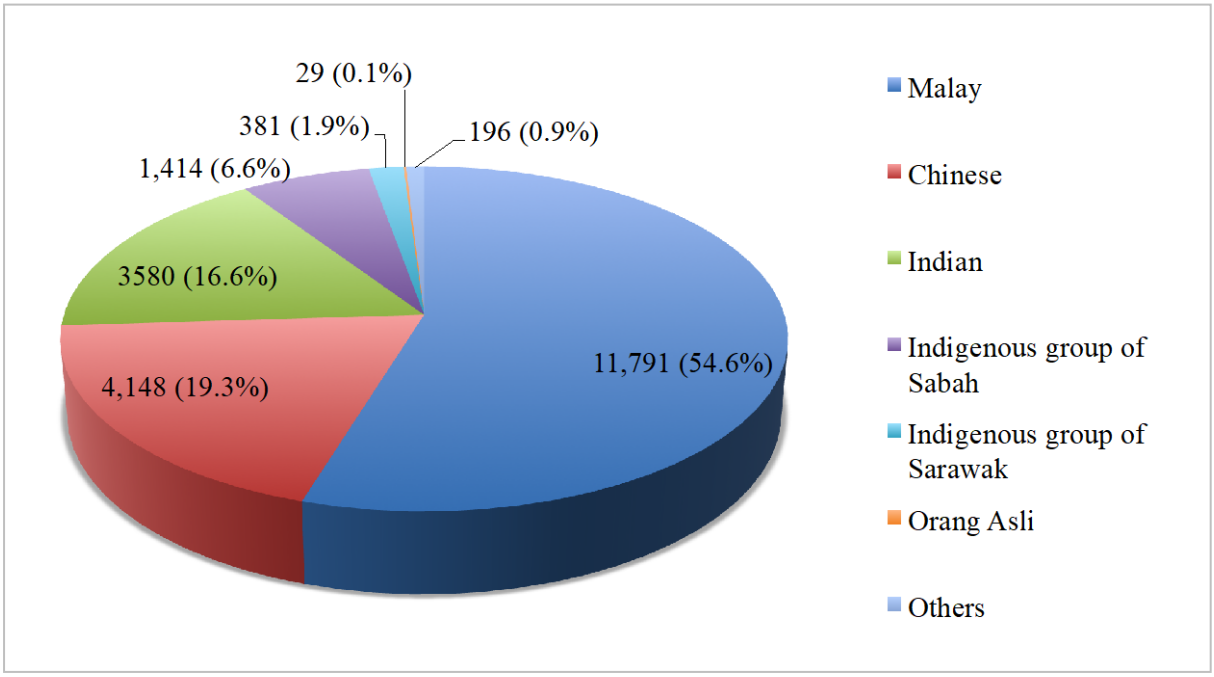


Figure 2.1: Ethnic distribution of Malaysian patients with psoriasis (n=21,539)

Table 2.1: Demographic Characteristics of the Adult and Paediatric group

Characteristics		Adults		Paediatrics	
		n	%	n	%
Nationality (n=21.734)	Malaysian	19739	99.1	1807	99.8
	Non-Malaysian	184	0.9	4	0.2
Gender (n=21,735)	Male	11287	56.7	771	42.6
	Female	8637	43.3	1040	57.4
Ethnicity (n=21,539)	Malay	10490	53.1	1301	72.0
	Chinese	4021	20.4	127	7.0
	Indians	3365	17.1	215	11.9
	Indigenous group of Sabah	1308	6.6	106	5.9
	Indigenous group of Sarawak	346	1.8	35	1.9
	Orang Asli	25	0.1	4	0.2
	Others	177	0.9	19	1.1
Marital status (n=21,060)	Single	4750	24.7	1785	99.5
	Married	13951	72.4	9	0.5
	Divorced	211	1.1	-	-
	Widow	279	1.4	-	-
	Widower	75	0.4	-	-
Cigarette smoking (n=12,892)	Ex-smoker	1,443	12.3	6	0.5
	Current smoker	2,494	21.1	41	3.7
	Never smoked	7,838	66.6	1,070	95.8

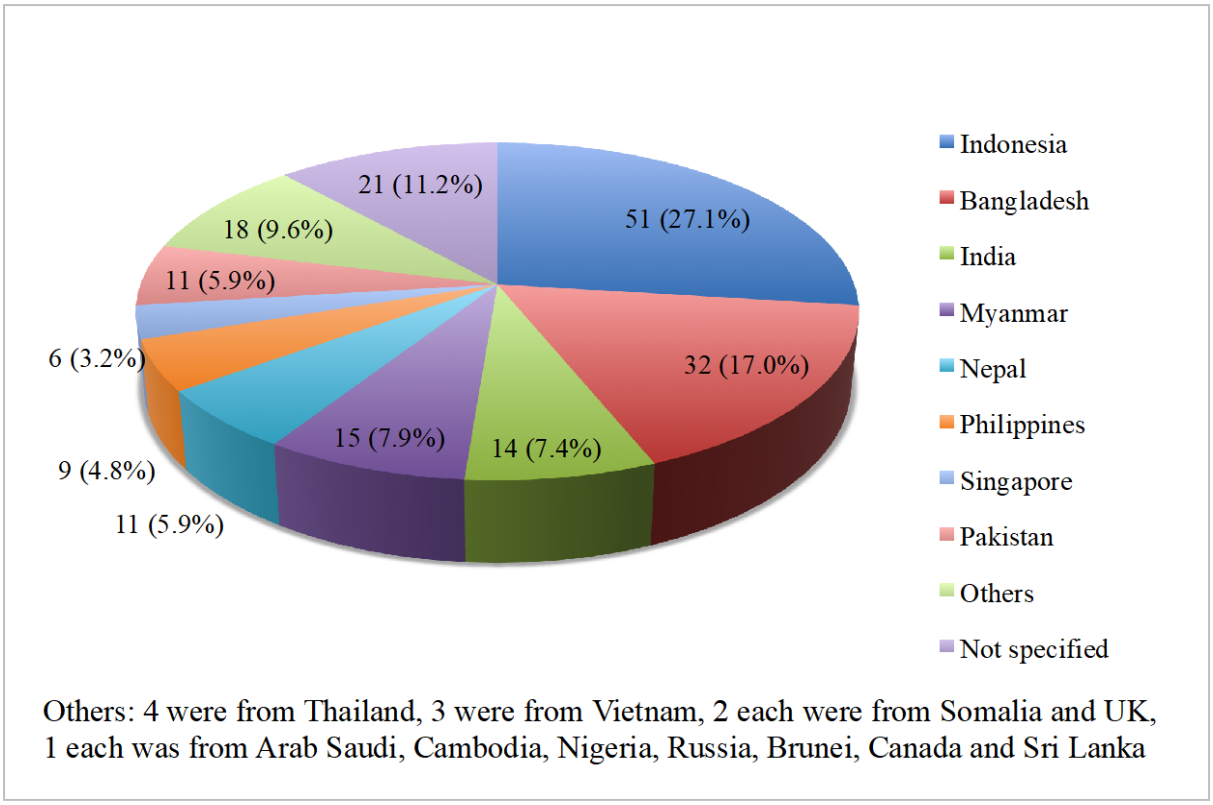


Figure 2.2: Nationality of non-Malaysians with psoriasis (n=188)

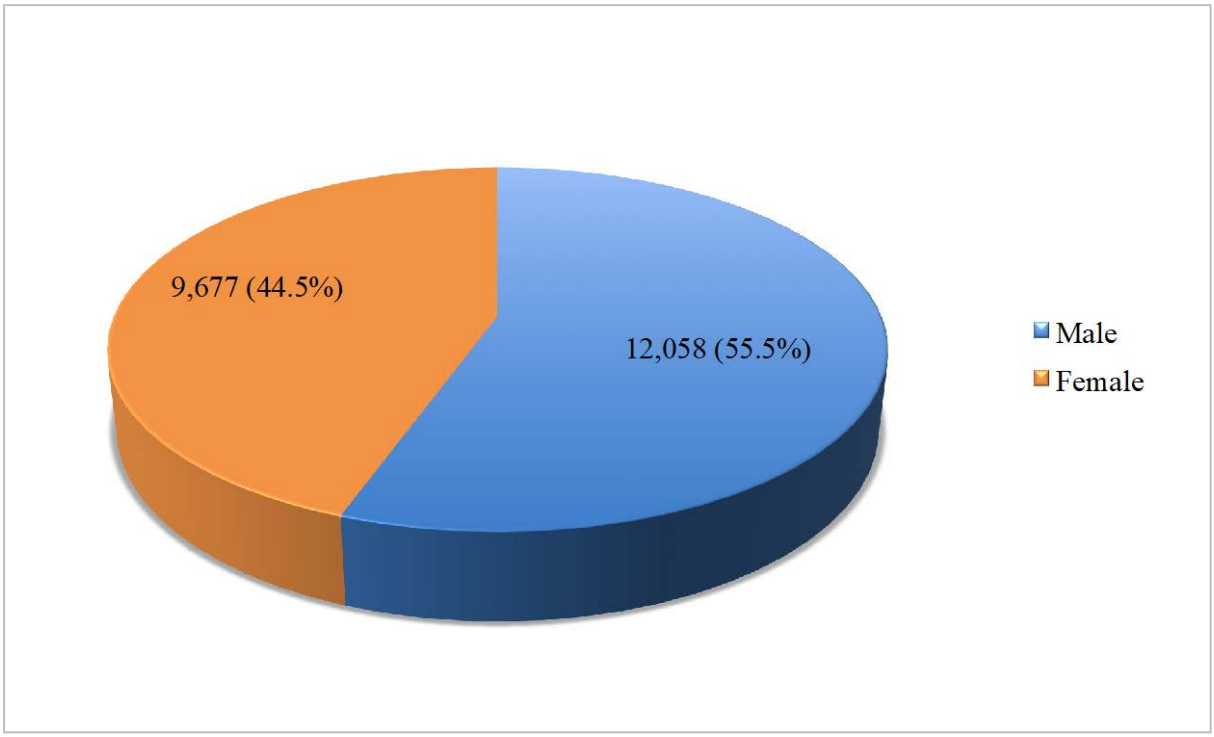


Figure 2.3: Gender distribution of patients with psoriasis (n=21,735)

CHAPTER 3

PSORIASIS HISTORY

Chapter 3

Psoriasis History

Dr Voo Sook Yee @ Michelle

Onset and diagnosis

The mean age of onset of psoriasis in the paediatric group was 10.58± 4.23 (range 1-18) while the mean age of onset in the adult group was 35.36±16.13 years (range 1-88). The majority had their onset of psoriasis during the ages of > 10-15 years (44.0%) and > 20-30 years (23.5%) in the paediatric group and adult group respectively (Figure 3.1 and 3.2).

Table 3.1: Age of onset and diagnosis among the paediatric group

Age (in years)	Mean	SD	Range
Age of onset	10.58	4.23	1-18
Age of diagnosis	11.72	4.03	1-18

Table 3.2: Age of onset and diagnosis among the adult group

Age (in years)	Mean	SD	Range
Age of onset	35.36	16.13	1-88
Age of diagnosis	37.77	15.98	1-92

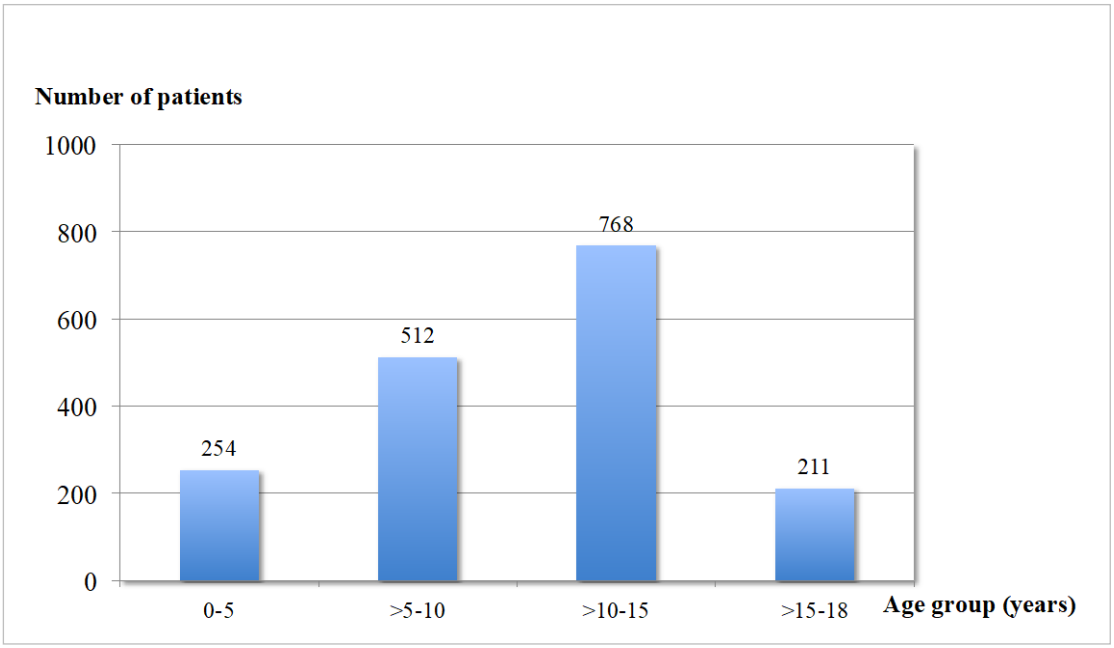


Figure 3.1: Age of psoriasis onset according to age group among the paediatric patients (n=1,745)

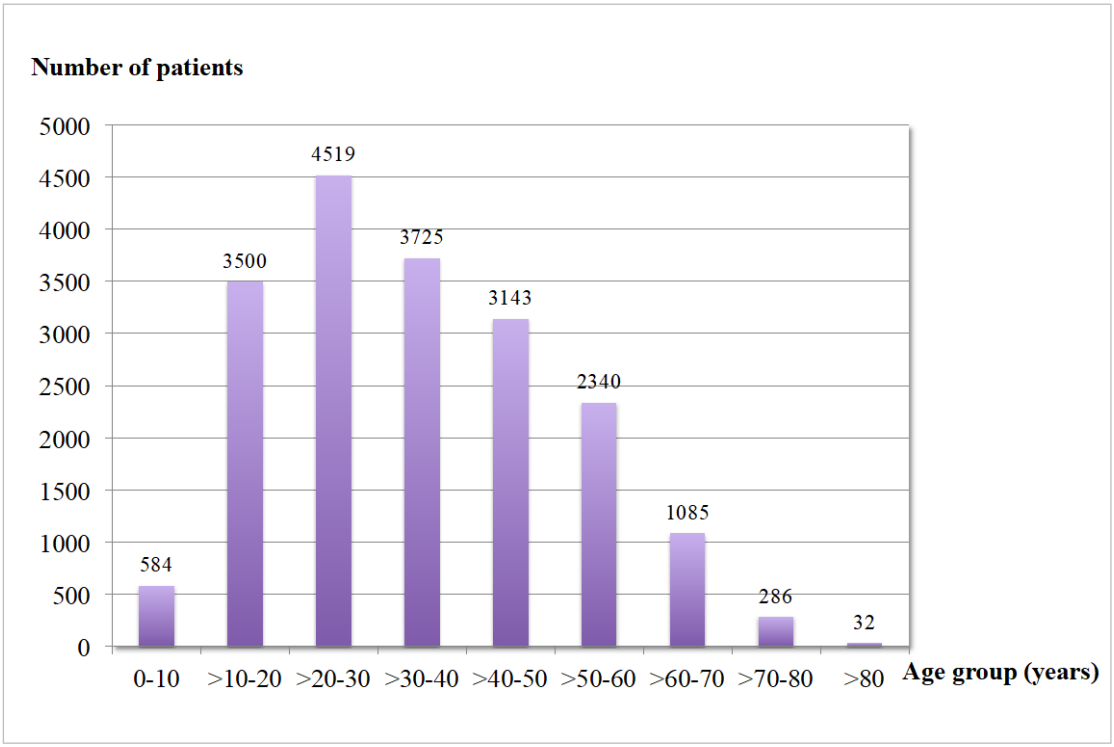


Figure 3.2: Age of psoriasis onset according to age group among the adult patients (n=19,214)

Family history

Of the 21,154 patients, 22.9% (4,857 patients) had positive family history of psoriasis. Of these, 83.7% (4,063 patients) had at least one affected first-degree relative. Approximately 40% (1,986 patients) had an affected father or mother and 33.4% (1,626 patients) had at least an affected sibling. Among the adult patients with family history of psoriasis, 10.2% (451 patients) had at least an affected child (Table 3.3).

Table 3.3: Family history of psoriasis among the psoriasis patients (n=4,857)

	Adult group (n=4442)		Paediatric group (n=415)	
	n	%	n	%
Father	1170	26.3	92	22.2
Mother	657	14.8	67	16.1
Sibling(s)	1532	34.4	94	22.7
Children	451	10.2	0	0
Others	1135	25.6	184	44.3

A patient may have more than one affected family member

Aggravating factors

More than half (52.4%) of the patients' psoriasis was aggravated by various triggers, with stress being the most frequent trigger in both the adult and paediatric groups (34% and 22.7% respectively), followed by excessive sun exposure and infection (Table 3.4). In both age groups, the most common infection implicated was upper respiratory tract infection. This was followed by human immunodeficiency virus (HIV) and varicella zoster infection in adults, whereas for the paediatric group the second most frequently reported infectious trigger was varicella zoster infection followed by gastroenteritis and dengue (Table 3.5). The most frequently implicated drug for aggravating psoriasis were β-blockers followed by corticosteroids and supplements/traditional medications (Table 3.6).

Table 3.4: Aggravating factors for psoriasis

	Adult group (n=19,289)		Paediatric group (n=1,760)	
	n	%	n	%
Stress	6561	34.0	388	22.7
Excessive sun exposure	3235	16.8	283	16.6
Infection	1283	6.7	113	6.6
Smoking	784	4.1	12	0.7
Physical trauma	654	3.4	58	3.4
Drugs	444	2.3	11	0.6
Pregnancy	311	1.6	1	0.05
Alcohol	307	1.6	1	0.05
Topical	110	0.6	6	0.4
Hypocalcaemia	3	0.01	0	0
Others	783	4.1	51	3.0
None	9188	47.6	1068	62.6

A patient may have one or more aggravating factors

Table 3.5: Types of infection as aggravating factors for psoriasis

	Adult group (n=1,283)		Paediatric group(n=113)	
	n	%	n	%
URTI	188	14.7	20	17.7
HIV	105	8.2	0	0
Varicella zoster	10	0.8	5	4.4
Dengue	10	0.8	1	0.9
Cellulitis	4	0.3	0	0
UTI	3	0.2	0	0
Chikungunya	2	0.1	0	0
Pneumonia	1	0.08	0	0
Tuberculosis	1	0.08	0	0
Hepatitis C	1	0.08	0	0
Syphilis	1	0.08	0	0
Gastroenteritis	0	0	1	0.9
Not specified	957	74.5	86	76.1

URTI Upper respiratory tract infection, HIV Human immunodeficiency virus, UTI Urinary tract infection

Table 3.6: Drugs as aggravating factors for psoriasis

	Adult (n=444)		Paediatric (n=11)	
	n	%	n	%
B-blockers	75	16.9	0	0
Systemic corticosteroids	68	15.3	2	18.2
Supplements/other traditional medications	41	9.2	2	18.2
Antibiotics	30	6.8	0	0
NSAIDs	22	5.0	1	9.1
Hormonal treatment/OCP	8	1.8	0	0
ACE-I	7	1.6	0	0
TCM	6	1.4	0	0
Antimalarials	3	0.7	0	0
Ayurvedic treatment	3	0.7	0	0
Chemotherapy	2	0.5	0	0
Statin	2	0.5	0	0
Acitretin	1	0.2	0	0
Anti-tuberculosis	1	0.2	0	0
OHAs	1	0.2	0	0
HAART	1	0.2	0	0
Insulin	1	0.2	0	0
ARB	1	0.2	0	0
CCB	1	0.2	0	0
Tamoxifen	1	0.2	0	0
Others	3	0.7	0	0
Not specified	165	37.2	6	54.5

NSAIDs Non-steroidal anti-inflammatory drugs, OCP Oral contraceptive pill, OHAs Oral hypoglycemic agents, ACE-I Angiotensin converting enzyme inhibitor, HAART Highly active antiretroviral therapy, ARB Angiotensin receptor blocker, CCB Calcium channel blocker

Disease burden in the previous 6 months

Nearly 70% of the patients had clinic visits between 1 – 5 times while 0.5% and 0.9% of the paediatric group and adult group respectively had more than 10 clinic visits due to psoriasis (Table 3.7).

Seven percent (1,401 patients) missed at least one day of school or work owing to psoriasis. Of these, 15.6% (218 patients) missed more than 10 days of school or work (Table 3.8). Notably, more patients with BSA involvement > 10% (3.4%) missed more than 10 days of school or work compared to 0.4% patients who had BSA involvement of ≤ 10% (Table 3.9). Five hundred and two patients (2.5%) had at least one day of hospital admission due to psoriasis (Table 3.10)

Table 3.7: Number of clinic visit(s) within a 6 month period (n=20,333)

No of clinic visit(s)	Adult (n=18,622)		Paediatric (n=1,711)	
	n	%	n	%
0	4751	25.5	440	25.7
1-5	12954	69.6	1198	70.0
6-10	752	4.0	64	37.4
>10	165	0.9	9	0.5

Table 3.8: Number of day(s) of missed school or work within a 6 month period (n=20,151)

No of day(s)	Adult (n=18,448)		Paediatric (n=1,703)	
	n	%	n	%
0	17194	93.2	1556	91.4
1-5	874	4.7	102	6.0
6-10	186	1.0	21	1.2
>10	194	1.1	24	1.4

Table 3.9: Number of day(s) of missed school or work according to severity of psoriasis within a 6 month period (n=15,618)

No of day(s)	Body Surface Area (BSA) involvement		
	≤10%	**>10-90%**	**>90%**
0	11,258	2965	311
1-5	522	189	32
6-10	74	68	23
>10	49	90	37

Table 3.10: Number of day(s) of hospital admission within a 6 month period (n=20,265)

No of day(s)	Adult (n=18,559)		Paediatric (n=1,706)	
	n	%	n	%
0	18094	97.5	1669	97.8
1-3	426	2.3	36	2.1
3	39	0.2	1	0.06

CHAPTER 4

COMORBIDITIES

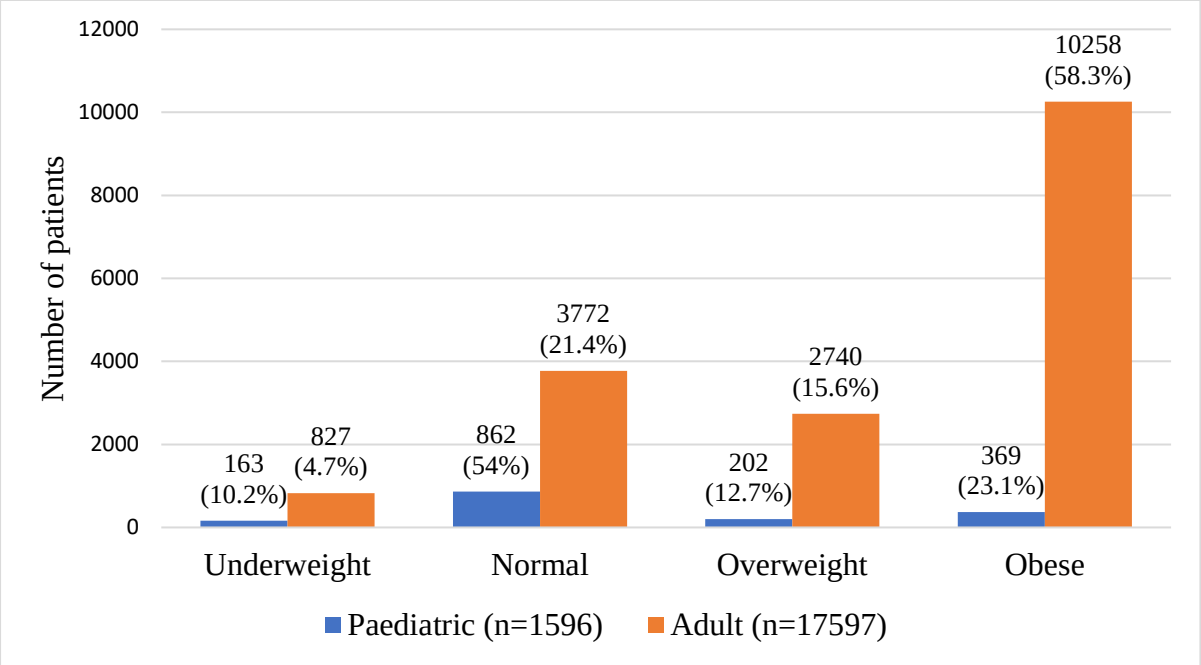
Chapter 4

Comorbidities

Dr Kwan Zhenli

Patients with psoriasis often present with several other concomitant diseases, particularly metabolic comorbidities. As the spectrum of disease differs among age groups, a comparison between adult and paediatric patients was performed.

Majority of the adult patients with psoriasis were in the obese category while the proportion of paediatric patients in the overweight and obese categories were much lower (**Figure 4.1**).



* BMI classification for adult Asians as stated in the World Health Organization. Regional Office for the Western Pacific. (2000). The Asia-Pacific perspective: redefining obesity and its treatment. Sydney: Health Communications Australia
* BMI classification for the paediatric population as defined by Centers for Disease Control and Prevention (CDC) guidelines for ages 2-18

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

The most prevalent comorbidity among adults with psoriasis was obesity (58.3%), followed by hypertension (25.9%), hyperlipidaemia (18.0%), diabetes mellitus (17.3%), ischaemic heart disease (5.3%) and stroke (1.6%) (**Table 4.1**).

Table 4.1 Prevalence of comorbidities in adult patients with psoriasis

Comorbidity	Adult	
	n	%
Obesity (n=17597)	10258	58.3
Hypertension (n=19212)	4982	25.9
Hyperlipidaemia (n=18993)	3410	18.0
Diabetes mellitus (n=19183)	3322	17.3
Ischaemic heart disease (n=19168)	1010	5.3
Stroke (n=19159)	307	1.6

Similarly, 23.1% of paediatric patients were obese and 12.7% were overweight with lower prevalence of other metabolic comorbidities in this age group, namely diabetes mellitus (0.4%), hypertension (0.2%) and hyperlipidaemia (0.1%) (**Table 4.2**). Other comorbidities among children include bronchial asthma (2.1%), Down syndrome (1.0%), congenital heart disease (0.5%), allergic rhinitis (0.3%), blood disorders (0.3%), hypertension (0.2%), kidney disorders (0.2%), epilepsy (0.2%) and systemic lupus erythematosus (0.2%) while other conditions were even less common (**Table 4.2**).

Table 4.2 Prevalence of comorbidities in paediatric patients with psoriasis

Comorbidity	Paediatric	
	n	%
Obesity (n=1596)	369	23.1
Bronchial asthma (n=1811)	38	2.1
Down syndrome (n=1811)	18	1.0
Congenital heart disease (n=1811)	9	0.5
Diabetes mellitus (n=1746)	7	0.4
Allergic rhinitis (n=1811)	5	0.3
Blood disorders (n=1811)	5	0.3
Hypertension (n=1747)	4	0.2
Kidney disorders (n=1811)	4	0.2
Epilepsy (n=1811)	3	0.2
Systemic lupus erythematosus (n=1811)	3	0.2
Hyperlipidaemia (n=1732)	2	0.1
Hypothyroidism (n=1811)	2	0.1
Schizophrenia (n=1811)	1	0.1
Attention deficit hyperactivity disorder (ADHD) (n=1811)	1	0.1
Atopic eczema (n=1811)	1	0.1
Obstructive sleep apnoea (n=1811)	1	0.1
Brain tumour (n=1811)	1	0.1
Biliary atresia (n=1811)	1	0.1
Chronic rheumatic heart disease (n=1747)	1	0.1
Others (n=1811)	4	0.2

CHAPTER 5

CLINICAL PRESENTATION

Chapter 5

Clinical Presentation

Dr Rajalingam Ramalingam

Plaque psoriasis was the most common type of psoriasis in both the adult and paediatric populations. In adult patients, plaque psoriasis accounted for 93.1%, followed by guttate psoriasis 3.3% and erythrodermic psoriasis 2.0%. In paediatric patients, plaque psoriasis accounted for 89.8%, followed by guttate psoriasis 7.4% and flexural/inverse psoriasis 0.8%. Other types of psoriasis which include nail and scalp psoriasis were less common **(Table 5.1).**

Table 5.1 Type of psoriasis in adult and paediatric patients

Type of psoriasis	Adult		Paediatric	
	n	%	n	%
Plaque	17480	93.1	1515	89.8
Guttate	614	3.3	124	7.4
Erythrodermic	382	2.0	8	0.5
Flexural/inverse	90	0.5	14	0.8
Palmoplantar non-pustular	79	0.4	8	0.5
Generalised Pustular	81	0.4	11	0.6
Localised Pustular	52	0.3	4	0.2
Nail	6	0.03	2	0.1
Total	**18784**	**100**	**1686**	**100**

The majority of patients had mild to moderate body surface area involvement, characterized by BSA involvement of <10%. Among the adult patients, 43.8% had <5% BSA involvement, 31.6% had 5-10% BSA involvement, 21.8% had 10-90% BSA involvement while the remaining 2.8% had >90% BSA involvement (erythrodermic). In the paediatric population, 55.5% had <5% BSA involvement, 27.8% had 5-10% BSA involvement, 15.9% had >10% to 90% BSA involvement, and 0.7% were erythrodermic (**Table 5.2**).

Table 5.2 Body surface area involvement in adult and paediatric patients with psoriasis

Body surface area involved	Adult		Paediatric	
	n	%	n	%
<5%	6671	43.8	752	55.5
5 - 10%	4815	31.6	377	27.8
>10%	3310	21.8	216	15.9
Erythrodermic (>90%)	419	2.8	10	0.7
Total	**15215**	**100**	**1355**	**100**

A vast majority of the adult (81.0%) and paediatric (84.5%) psoriatic patients had scalp involvement while more than half of the adult (51.4%) and paediatric (52.2%) psoriatic patients had face and/or neck involvement (**Table 5.3**, **Table 5.4**).

Table 5.3 Scalp, face and neck involvement in adult patients with psoriasis

Scalp, Face & Neck Involvement	Scalp		Face/Neck	
	n	%	n	%
Yes	15316	81.0	9625	51.4
No	3605	19.0	9094	48.6
Total	18921	100	18719	100

Table 5.4 Scalp, face and neck involvement in paediatric patients with psoriasis

Scalp, Face & Neck Involvement	Scalp		Face/Neck	
	n	%	n	%
Yes	1455	84.5	884	52.2
No	266	15.5	809	47.8
Total	1721	100	1693	100

The majority of the adult patients with psoriasis had nail involvement (58.1%) (**Table 5.5**). Among patients who had psoriatic nail disease, most of them had pitting (71.9%). Other common features were onycholysis (47.5%), discoloration (30.8%) and subungual hyperkeratosis (14.1%). Total nail dystrophy was found in 5.0% of patients with nail involvement.

There were 637 (36.4%) paediatric patients with nail involvement (**Table 5.5**). Most of them had pitting (87.0%), followed by onycholysis (25.9%), discolouration (12.6%), subungual hyperkeratosis (5.2%) and total nail dystrophy (3.1%).

Table 5.5 Nail involvement and nail features in adult and paediatric patients with psoriasis

		Adult		Paediatric	
Nail involvement		**n**	**%**	**n**	**%**
Yes		11239	58.1	637	36.4
No		8112	41.9	1114	63.6
	Total	**19351**	**100**	**1751**	**100**
Nail features		**n**	**%**	**n**	**%**
Pitting		8085	71.9	554	87.0
Onycholysis		5343	47.5	165	25.9
Discoloration		3463	30.8	80	12.6
Subungual hyperkeratosis		1581	14.1	33	5.2
Total nail dystrophy		566	5.0	20	3.1
	Total	**11239**	**100**	**637**	**100**

Psoriatic arthropathy was reported in 14.0% of the adult patients, while only 2.5% of the paediatric patients had joint disease (**Table 5.6**).

Table 5.6 Joint disease and type of joint disease in adult and paediatric patients with psoriasis

		Adult		Paediatric	
Joint disease		**n**	**%**	**n**	**%**
Yes		2712	14.0	44	2.5
No		16617	86.0	1707	97.5
	Total	**19329**	**100**	**1751**	**100**
Type of joint disease (one or multiple)		**n**	**%**	**n**	**%**
Oligo-/Monoarthropathy		1305	48.1	15	34.1
Distal hand joints arthropathy		854	31.5	9	20.4
Symmetrical polyarthropathy (Rheumatoid like)		775	28.6	5	11.5
Spondylitis / Sacroiliitis		225	8.3	2	4.5
Arthritis mutilans		87	3.2	0	0
	Total	**2712**	**100**	**44**	**0**

In adult patients, the most common type of psoriatic arthropathy was oligo-/monoarthropathy (48.1%). This was followed by distal hand joints arthropathy (31.5%), rheumatoid-like symmetrical polyarthropathy (28.6%), spondylitis/sacroiliitis (8.3%) and arthritis mutilans (3.2%). Morning stiffness of > 30 minutes was reported in 32.6% of adults and 15.9% of paediatric patients. Enthesopathy was reported in 13.9% of adult patients and 9.1% of paediatric patients.

Both adult (79.5%) and paediatric (73.0%) populations with psoriatic arthropathy experienced joint pain at the time of presentation. Joint swelling was present in 35.5% of adults and 11.1%

of paediatric patients, while joint deformity occurred in 23.2% of adult patients and 8.3% of paediatric patients (**Table 5.7**, **Table 5.8**).

Table 5.7 Symptoms of psoriatic arthritis in adult patients

	Pain		Swelling		Deformity	
	n	**%**	**n**	**%**	**n**	**%**
Yes	2013	79.5	899	35.5	584	23.2
No	520	20.5	1630	64.4	1928	76.8
Total	**2533**	**100**	**2529**	**100**	**2512**	**100**

Table 5.8 Symptoms of psoriatic arthritis in paediatric patients

	Pain		Swelling		Deformity	
	n	**%**	**n**	**%**	**n**	**%**
Yes	27	73.0	4	11.1	3	8.3
No	10	27.0	32	88.9	33	91.7
Total	**37**	**100**	**36**	**100**	**36**	**100**

CHAPTER 6

TREATMENT

Chapter 6

Treatment

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 95% of the adults and 92.5% of the paediatric patients used some form of topical medication for psoriasis. As shown in Table 6.1, the most commonly 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 1.7% of the patients. Calcineurin inhibitors were used in 0.04% of the patients.

Table 6.1 Topical therapy in paediatric and adult patients with psoriasis

	Paediatric* n=1734	**Adult#** n=19,175	**Total n=20,909**
Topical therapy	1604 (92.5%)	18,234 (95.1%)	19,838 (94.9%)
Type of topical therapy			
Tar preparations	1065 (66.4%)	12,664 (69.5%)	13,729 (69.2%)
Topical corticosteroids	1357 (84.6%)	16,048 (88.0%)	17,405 (87.7%)
Vitamin D analogues	197 (12.3%)	3095 (17.0%)	3292 (16.6%)
Keratolytics eg salicylic acid	742 (46.3%)	9678 (53.1%)	10,420 (52.5%)
Calcipotriol with Betamethasone Dipropionate	136 (8.5%)	2085 (11.4%)	2221 (11.2%)
Emollient	1132 (70.6%)	13,972 (76.6%)	15,104 (76.1%)
Dithranol (anthralin)	33 (2.1%)	301 (1.7%)	334 (1.7%)
Calcineurin inhibitors	3 (0.2%)	5 (0.03%)	8 (0.04%)

* missing data – 77; # missing data – 749

Phototherapy was prescribed to 12 children (0.7%) and 527 adults (2.8%) with psoriasis. Narrowband UVB (NBUVB) was the preferred mode of phototherapy and it was used in nearly 92% of the patients who underwent phototherapy (Table 6.2). None of the paediatric patients received oral or bath PUVA.

Table 6.2 Phototherapy in paediatric and adult patients with psoriasis

	Paediatric^ n=1705	**Adult[§]** n=18,872	**Total n=20,577**
Phototherapy	12 (0.7%)	527 (2.8%)	539 (2.6%)
Type of phototherapy			
BBUVB	1 (8.3%)	20 (3.8%)	21 (3.9%)
NBUVB	10 (83.3%)	487 (92.4%)	497 (92.2%)
Oral PUVA	0	17 (3.2%)	17 (3.2%)
Topical PUVA	1 (8.3%)	5 (0.95%)	6 (1.1%)
Bath PUVA	0	4 (0.76%)	4 (0.7%)

^missing data – 106, [§]missing data – 1052; BBUVB – broadband ultraviolet B, NBUVB- narrowband ultraviolet B, PUVA-psoralen + ultraviolet A

Systemic therapy was used in 14.4% of adult patients and only 5.2% of paediatric patients with psoriasis (Table 6.3). The most common systemic agent prescribed was methotrexate in both age group of patients, followed by acitretin. Systemic corticosteroids were used in 6.2% of the patients, mainly for plaque psoriasis (78.4%), erythrodermic psoriasis (8.1%), guttate psoriasis (3.8%), localized pustular psoriasis (2.7%), generalized pustular psoriasis (2.2%) and others. Other systemic agents such as cyclosporin, hydroxyurea and dapsone were used less frequently. None of the paediatric patients were prescribed hydroxyurea or dapsone. Sulfasalazine was prescribed in one child and 4% of the adults to treat psoriatic arthropathy.

Table 6.3 Systemic therapy in paediatric and adult patients with psoriasis

	Paediatric[¥] n= 1713	**Adult[€]** n= 19,067	**Total n=20,780**
Systemic therapy	89 (5.2%)	2748 (14.4%)	2837 (13.7%)
Type of systemic therapy			
Methotrexate	52 (58.4%)	2241 (81.6%)	2293 (80.8%)
Hydroxyurea	0	23 (0.8%)	23 (0.8%)
Acitretin	32 (36.0%)	549 (20%)	581 (20.5%)
Systemic corticosteroids	12 (13.5%)	173 (6.3%)	185 (6.5%)
Cyclosporin	2 (2.2%)	142 (5.2%)	144 (5.1%)
Dapsone	0	3 (0.1%)	3 (0.1%)
Sulfasalazine	1 (1.1%)	110 (4.0%)	111 (3.9)

[¥]missing data-98, [€]missing data-857

Biological therapy was used in 136 adult patients (0.7%) with psoriasis but none in the paediatric group. The most frequently prescribed biologics were adalimumab followed by ustekinumab as shown in Table 6.4, both contributing to 70% of the total biologics used.

Table 6.4 Biological therapy used in 136 adults with psoriasis

Type of biologics	**Adult** n= 136 (%)
Infliximab	5 (3.7)
Etanercept	15 (11.0)
Adalimumab	50 (36.8)
Ustekinumab	46 (33.8)
Golimumab	1 (0.7)
Efalizumab	4 (2.9)
Secukinumab	14 (10.3)
Certolizumab pegol	1 (0.7)

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 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 quality of life.[2]

Out of 21,735 patients who were registered to the MPR, a total of 19,755 adult patients (aged more than 18) and 1329 paediatric patients completed the quality of life questionnaires, namely Dermatology Life Quality Index (DLQI) and Child Dermatology Life Quality Index (CDLQI).

The mean DLQI for adult psoriasis patients was 9.62 ± 6.75, and the mean CDLQI for paediatric patients was 9.05 ± 5.95. 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 7960 (40.3%) adult patients, indicating significant impairment of QoL due to psoriasis or its treatment. There were 1544 adults (7.8%) who had a DLQI > 20 indicating an extremely large effect on their quality of life by psoriasis. Nevertheless, 10.0% of adult patients reported no effect at all on their quality of life (**Figure 7.1**). As shown in **Figure 7.2**, "symptoms and feelings" was the DLQI domain that most affected the adult group with 43.4% 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 relationships" in which 83.1% of the adult patients were affected "a little" or "not at all".

In the paediatric group, 26.8% of patients reported a CDLQI of more than 12 indicating a very large or extremely large effect on their quality of life (**Figure 7.3**). There were 103 patients (7.8%) who had a CDLQI of more than 18, reflecting an extremely large effect on the quality of life. On the other hand, 8.2% of the paediatric patients reported no effect at all on their quality of life. For the paediatric patients, the CDLQI domain most affected was "symptoms and feelings", in which 43.2% reported that psoriasis affected them 'very much' or 'a lot'. The aspect of life least affected by psoriasis was "personal relationship" in which 83.1% of the children were not affected at all or affected only a little (**Figure 7.4**). These results were similar to that of the adult patients.

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	*Over the last week, how itchy, sore, painful, or stinging has your skin been?*	19788	2391 (12.1%)	6120 (30.9%)	9447 (47.7%)	1830 (9.3%)
	Over the last week, how embarrassed or self-conscious have you been because of your skin?	19697	3382 (17.2%)	5251 (26.7%)	6866 (34.8%)	4198 (21.3%)
Daily activities	*Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?*	19234	1949 (10.1%)	4127 (21.5%)	6629 (34.5%)	6529 (33.9%)
	Over the last week, how much has your skin influenced the clothes you wear?	19158	1734 (9.1%)	3974 (20.7%)	6713 (35.0%)	6737 (35.2%)
Leisure	*Over the last week, how much has your skin affected any social or leisure activities?*	19201	1960 (10.2%)	4251 (22.1%)	6443 (33.6%)	6547 (34.1%)
	Over the last week, how much has your skin made it difficult for you to do any sport?	17408	2076 (11.9%)	3876 (22.3%)	5561 (31.9%)	5895 (33.9%)
Work and school	*Over the last week, has your skin prevented you from working or studying?*	15687	1443 (9.2%)	1707 (10.9%)	4282 (27.3%)	8255 (52.6%)
Personal relationship	*Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?*	18921	1050 (5.5%)	2660 (14.1%)	6110 (32.3%)	9101 (48.1%)
	Over the last week, how much has your skin caused sexual difficulties?	14902	667 (4.5%)	1326 (8.9%)	3496 (23.5%)	9413 (63.1%)
Treatment	*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?*	18694	1460 (7.8%)	3329 (17.8%)	6585 (35.2%)	7320 (39.2%)

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 7.2 Responses for Children's Dermatology Life Quality Index in paediatric patients with psoriasis (age 4 to 16 years)

Section	Questions	n	Number of responses (%)			
			Very much	A lot	A little	Not at all/ Not relevant
Symptoms & feelings	*Over the last week, how itchy, "scratchy", sore, painful, or stinging has your skin been?*	1362	129 (9.5%)	464 (34%)	651 (47.8%)	118 (8.7%)
	Over the last week, how embarrassed or self-conscious have you been because of your skin?	1356	237 (17.5%)	345 (25.4%)	534 (39.4%)	240 (17.7%)
Leisure	*Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?*	1343	66 (4.9%)	268 (20%)	492 (36.6%)	517 (38.5%)
	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	1345	93 (6.9%)	257 (19.1%)	452 (33.6%)	543 (40.4%)
	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	1343	101 (7.5%)	205 (15.3%)	403 (30%)	634 (47.2%)
School or holidays	*If school time: Over the last week, how much did your skin problem affect your school work?* *Or* *If holiday time: Over the last week, has your skin problem interfered with your enjoyment of the holiday?*	1332	76 (5.7%)	213 (16.0%)	454 (34.1%)	589 (44.2%)
Personal relationship	*Over the last week, how much has your skin affected your friendships?*	1358	67 (4.9%)	182 (13.4%)	455 (33.5%)	654 (48.2%)
	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?	1341	57 (4.2%)	151 (11.3%)	400 (29.8%)	733 (54.7%)
Sleep	*Over the last week, how much has your sleep been affected by your skin problem?*	1263	67 (5.3%)	175 (13.8%)	439 (34.8%)	582 (46.1%)
Treatment	*Over the last week, how much of a problem has the treatment for your skin been?*	1338	57 (4.3%)	229 (17.1%)	478 (35.7%)	574 (42.9%)

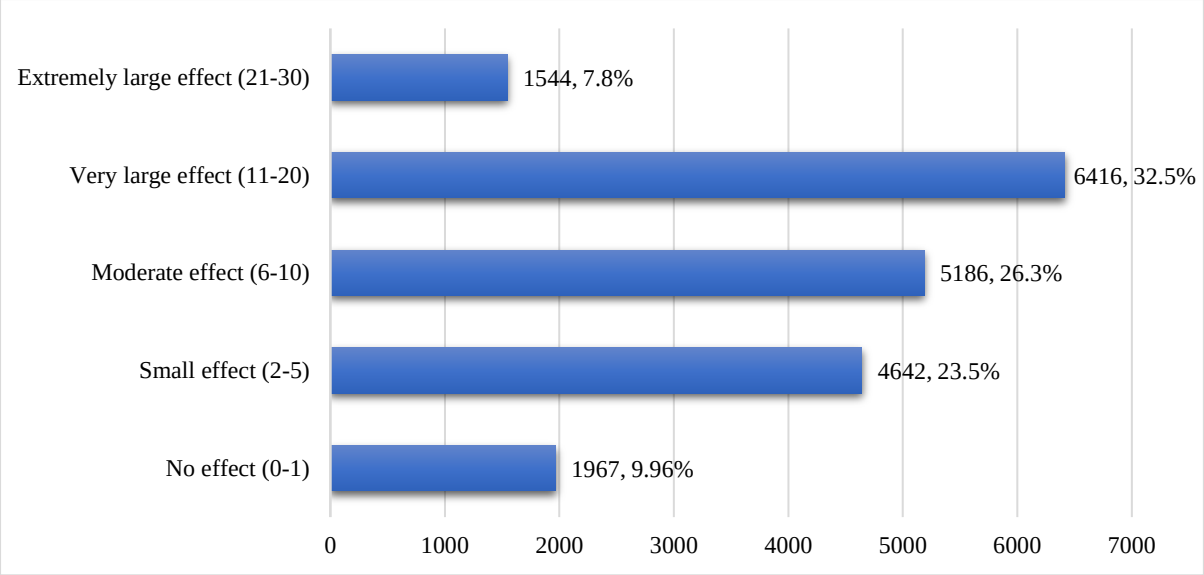
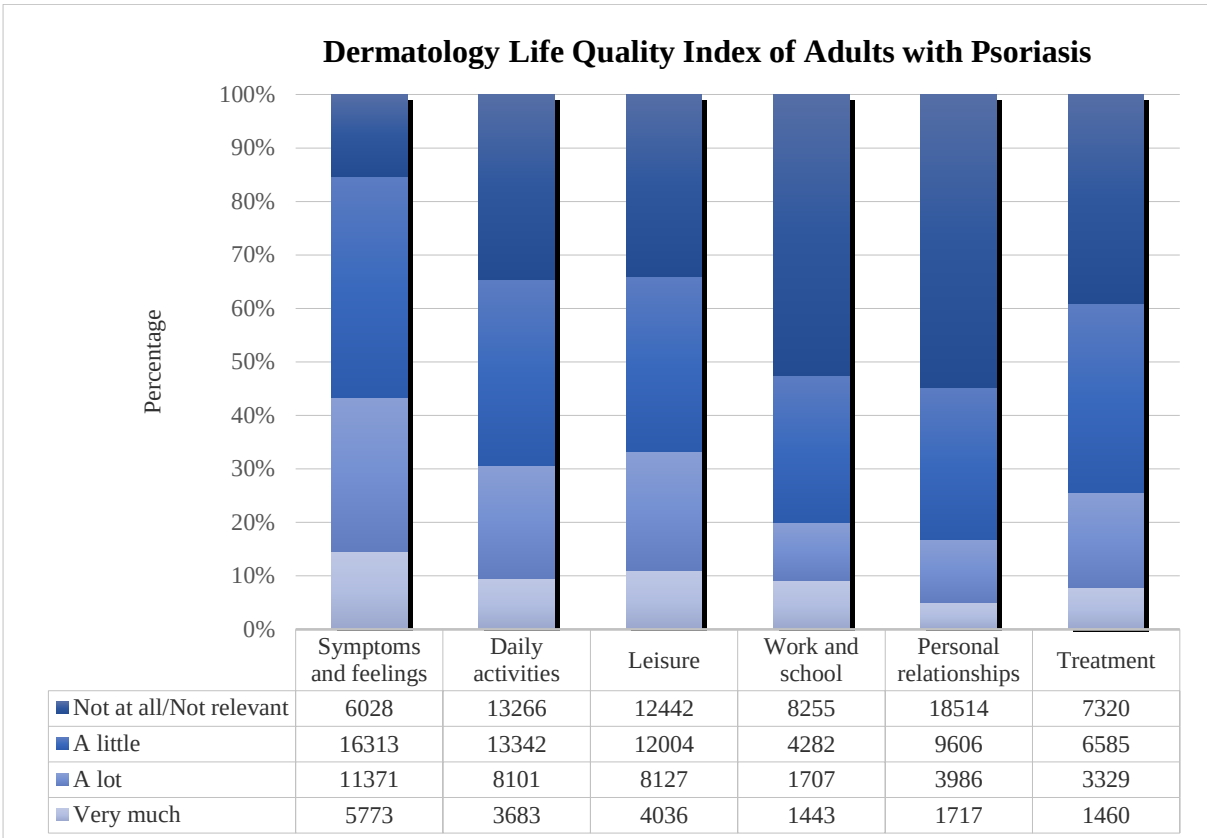


Figure 7.1 Dermatology Life Quality Index scores for Adults with Psoriasis (n=19,755)



	Symptoms and feelings	Daily activities	Leisure	Work and school	Personal relationships	Treatment
Not at all/Not relevant	6028	13266	12442	8255	18514	7320
A little	16313	13342	12004	4282	9606	6585
A lot	11371	8101	8127	1707	3986	3329
Very much	5773	3683	4036	1443	1717	1460

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

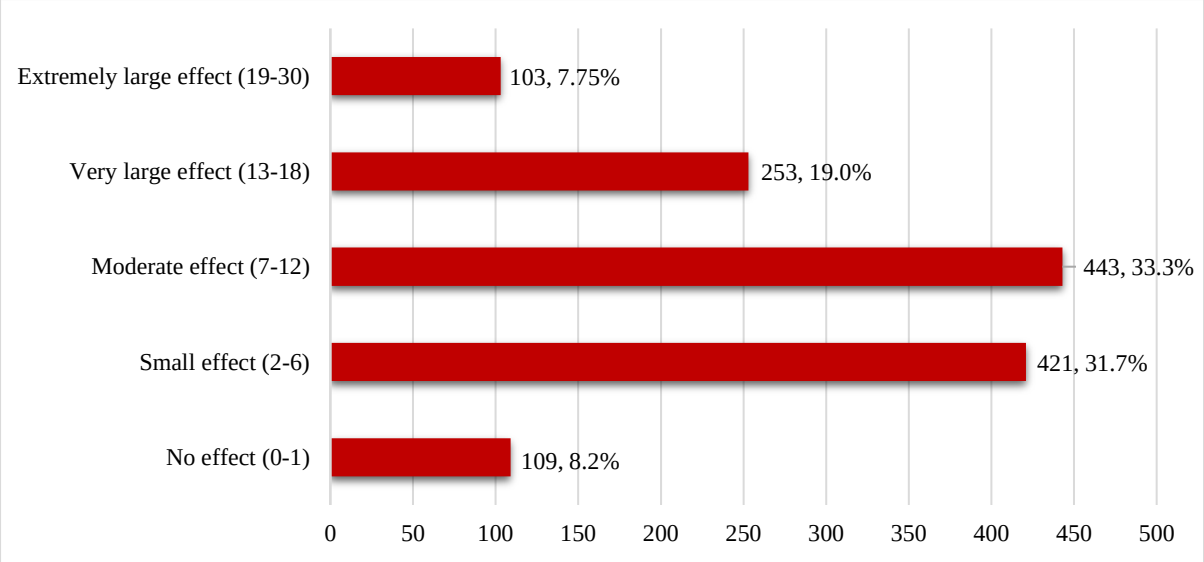
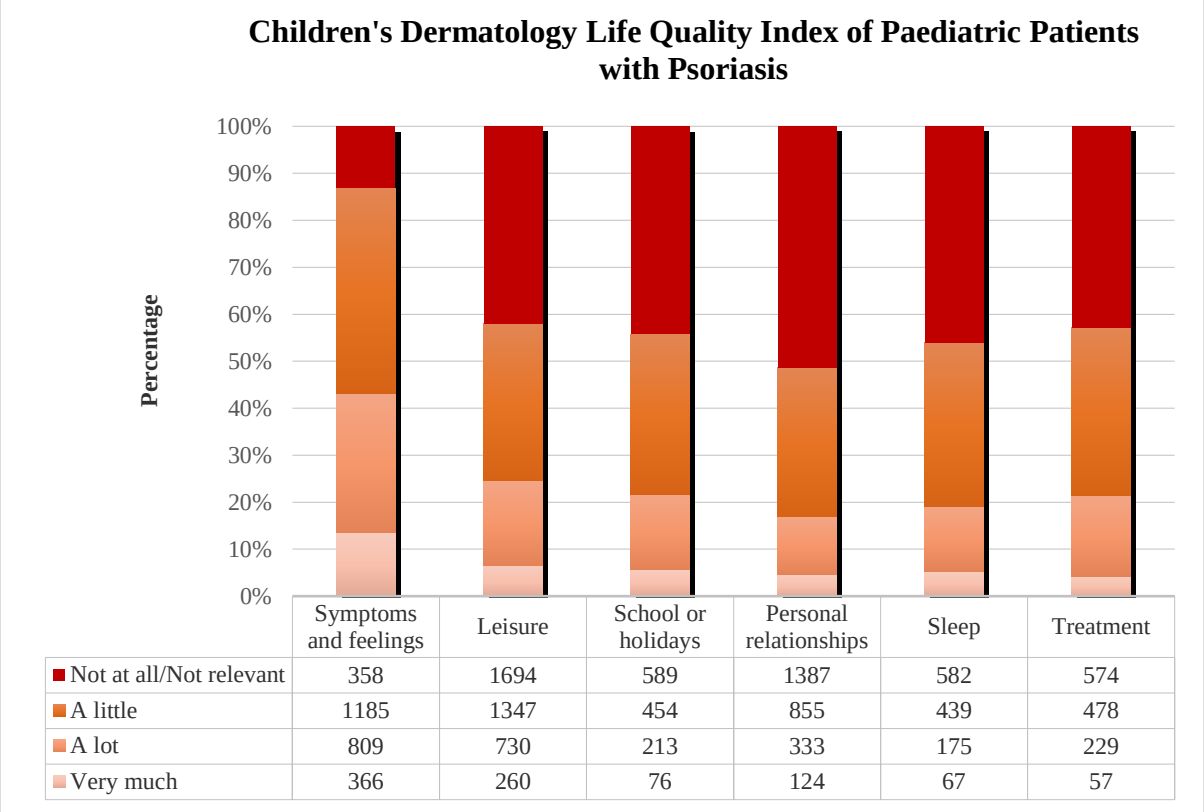


Figure 7.3 Children's Dermatology Life Quality Index Scores for Paediatric Patients with Psoriasis (n=1329)



	Symptoms and feelings	Leisure	School or holidays	Personal relationships	Sleep	Treatment
Not at all/Not relevant	358	1694	589	1387	582	574
A little	1185	1347	454	855	439	478
A lot	809	730	213	333	175	229
Very much	366	260	76	124	67	57

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

CHAPTER 8

OUTCOMES

Chapter 8

Outcomes

Dr Kwan Zhenli & Dr Suganthy Robinson

Treatment outcomes were analysed after at least 3 months of follow-up from the initial visit. As of June 2016, only patients on phototherapy, systemic and biological treatments were required to submit follow-up data every 6 months.

Disease severity was assessed in terms of extent of lesions using the percentage of body surface area (BSA) involvement, and quality of life was monitored with the Dermatology Life Quality Index (DLQI) or Children's Dermatology Life Quality Index (CDLQI).

A total of 7,501 follow-up data were available from 21,735 patients notified to the MPR between 2007 and 2018. From a total of 19,924 adult patients with psoriasis registered in the MPR, follow-up data were obtained from 7,080 patients. For paediatric cases, follow-up data were obtained from 421 patients from a total of 1811 patients. The mean duration of follow-up was 18.5 ± 20.43 months, with the longest duration of 129.7 months (**Table 8.1**). For adult patients, mean duration of follow-up was 18.1 ± 19.96 months while the corresponding duration for paediatric patients was 24.3 ± 26.48 months.

Disease severity

The extent of psoriasis lesions was assessed in terms of percentage of body surface area involvement categorised into 4 scales, i.e. <5%, 5%-10%, >10%-90%, and >90% (erythrodermic). A total of 4,027 patients were evaluated for change in the extent of lesions. Of these patients, 973 patients (24.2%) had improvement by at least one scale, among which 234 (5.8%) had improvement by two scales, and 9 patients (0.2%) improved from BSA>90% to BSA<5%. No change was found in 2,342 patients (58.2%), of which 1337 (33.2%) maintained a BSA of <5 % pre and post follow up, while 712 patients (17.7%) had worsening by at least one scale. Change in severity in terms of proportions was similar when comparing between the adult and paediatric populations (**Table 8.2**).

Table 8.1 Duration of follow-up for adult and paediatric patients with psoriasis from 2007 to 2018

Duration of follow-up	Adult n (%)	Paediatric n (%)	Total n (%)
0 to 6 months	898 (12.7)	47 (11.2)	945 (12.6)
>6 to 12 months	3259 (46.0)	162 (38.5)	3421 (45.6)
>12 to 18 months	959 (13.5)	61 (14.5)	1020 (13.6)
>18 to 24 months	548 (7.7)	28 (6.7)	576 (7.7)
>24 to 30 months	339 (4.8)	19 (4.5)	358 (4.8)
>30 to 36 months	198 (2.8)	14 (3.3)	212 (2.8)
>36 months	879 (12.4)	90 (21.4)	969 (12.9)
Total	**7080 (100)**	**421 (100)**	**7501 (100)**

Table 8.2 Change in severity of disease based on body surface area for adult and paediatric patients with psoriasis

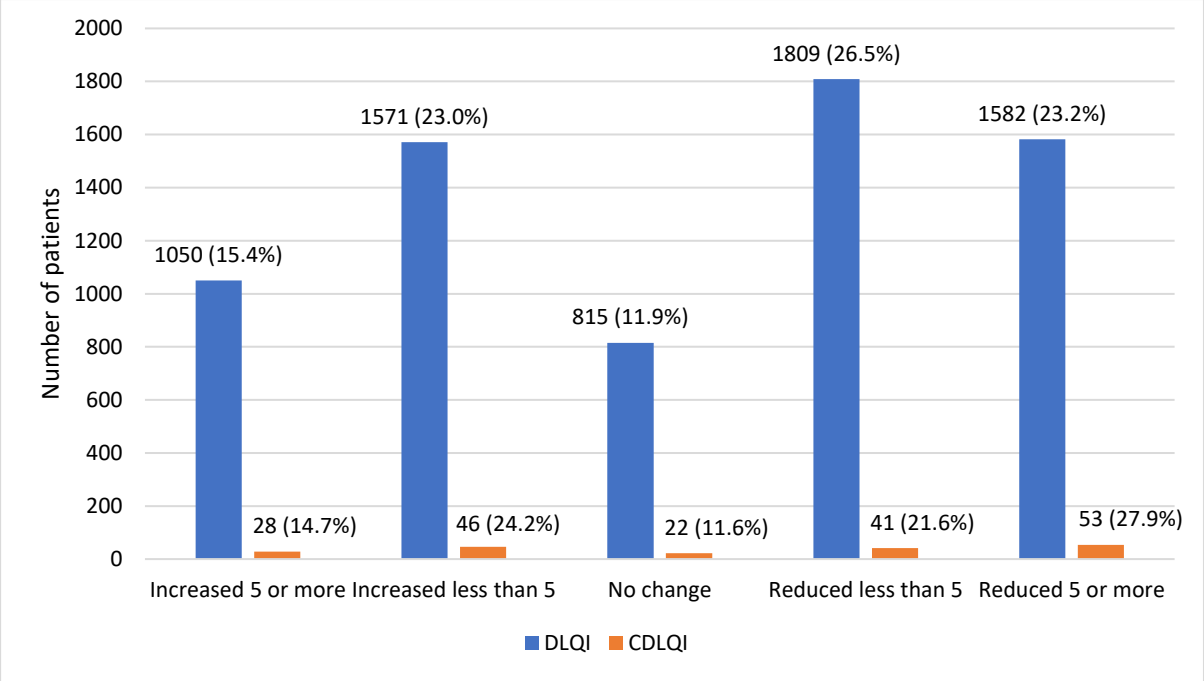
Change in BSA	Adult patients, n (%)	Paediatric patients, n (%)
Worsened	672 (17.7)	40 (17.9)
No change	2214 (58.2)	128 (57.4)
Improved 1 scale	686 (18.0)	44 (19.7)
Improved 2 scales	223 (5.9)	11 (4.9)
Improved 3 scales	9 (0.2)	0 (0.0)

BSA: body surface area

Change in Quality of Life

A total of 6,827 patients were evaluated for change in quality of life using the DLQI. Of these patients, 1,582 patients (23.2%) had significant improvement with a reduction of the DLQI score by at least 5, whereas 1,050 patients (15.4%) had significant worsening with an increase in the DLQI score by at least 5 (**Figure 8.1**).

For patients aged 4 to 16 years, a total of 190 patients were evaluated for change in quality of life. Of these patients, 53 patients (27.9%) had a significant improvement of their CDLQI score by at least 5, while 28 patients (14.7%) worsened by a score of 5 and above (**Figure 8.1**).



DLQI: Dermatology Life Quality Index; CDLQI: Children's Dermatology Life Quality Index

Figure 8.1 Change in quality-of-life parameters at follow-up for adult and paediatric patients with psoriasis

APPENDIX A: CASE REPORT FORM

NATIONAL DERMATOLOGY REGISTRY (DermReg)
Malaysian Psoriasis Registry
Case Report Form

CONFIDENTIAL
For Office Use only:
ID: ____ / ____
Centre ____

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

Doctor's Name :	
Name of Institution :	

SECTION 1: DEMOGRAPHIC DETAILS

1. Patient visit date : (dd/mm/yyyy)	__/__/____
2. Type of visit :	◯ New Case ◯ Follow-Up
3. Name of patient :	
4. NRIC :	MyKad/ MyKid: ____-____-____ Old IC: ____
	Other ID document No: ____
	Specify document type (if others): ◯ Registration number ◯ Mother's I/C ◯ Work Permit ◯ Clinic RN ◯ Passport ◯ Father's I/C ◯ Driver's Licence ◯ Police ID Card ◯ Birth Certificate ◯ Armed Force ID ◯ Hospital RN ◯ Others
5. Address : #	Town / City: ____ State : ____
6. Contact # number :	Homephone: ____-____ H/P: ____-____
7. Gender : #	◯ Male ◯ Female
8. Date of birth : # (dd/mm/yyyy)	__/__/____ ☐ Estimated/ presumed year (If the exact date is not known, please enter 01/07/yyyy & check the estimated/presumed year box)
9. Ethnic group : #	◯ Malay ◯ Chinese ◯ Indian ◯ Orang Asli ◯ Others, specify : ____
10. Nationality : #	◯ Malaysian ◯ Non-Malaysian, specify ____
11. Marital status : #	◯ Single ◯ Married ◯ Divorced ◯ Widow ◯ Widower

SECTION 2 : MEDICAL HISTORY

1. Age when # psoriasis started :	____
2. Age when # psoriasis diagnosed :	____
3. Family # member(s) with psoriasis :	◯ No ◯ Yes → (if YES, please tick ONE or MULTIPLE) ☐ Father ☐ Sibling(s) ☐ Other relative, specify ____ ☐ Mother ☐ Children
4. Aggravating factors :	◯ No ◯ Yes → (if YES, please tick ONE or MULTIPLE of the following) ☐ Infection : ____ ☐ Drugs : ____ ☐ Topical Rx : ____ ☐ Trauma ☐ Stress ☐ Sunburn ☐ Hypocalcaemia ☐ Pregnancy ☐ Smoking ☐ Alcohol ☐ Others, specify: ____
5. Disease burden in the last 6 months :	a) No.of clinic visits due to psoriasis : ____ (enter 0 if none)
	b) No. of days off work / school due to psoriasis : ____ (enter 0 if none) ☐ Not applicable
	c) No. of hospital admissions due to psoriasis : ____ (enter 0 if none)
6. Other diseases :	a) Ischaemic heart disease : ◯ Yes ◯ No ◯ Unknown
	b) Cerebrovascular disease (stroke) : ◯ Yes ◯ No ◯ Unknown
	c) Diabetes mellitus : ◯ Yes ◯ No ◯ Unknown
	d) Hypertension : ◯ Yes ◯ No ◯ Unknown
	e) Hyperlipidaemia : ◯ Yes ◯ No ◯ Unknown
	f) Other diseases, specify : (e.g. HIV infection, tuberculosis, lymphoma, etc.) ◯ Yes ◯ No ◯ Unknown → ____
7. Cigarette smoking :	◯ Never smoked ◯ Ex-smoker ◯ Current smoker → ____ cigarettes per day

Items marked # above need not be entered if the patient has been previously notified to the registry

Version 2.4 Last updated 07/12/2011 *page 1 of 4*

NATIONAL DERMATOLOGY REGISTRY (DermReg)
Malaysian Psoriasis Registry
Case Report Form

CONFIDENTIAL
For Office Use only:
ID: ____ / ____
Centre ____

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 : ___ (cm) (b) Weight: ___ (kg)

2. Type of psoriasis : *(Please select ONE predominant type)*
◯ Plaque ◯ Guttate ◯ Erythrodermic ◯ Flexural / Inverse ◯ Others,specify: ____
◯ Generalised pustular ◯ Localised Pustular ◯ Palmoplantar non-pustular

3. Severity : Body surface area involved : ◯ <5% ◯ 5 - 10% ◯ > 10% ◯ Erythrodermic (>90%)

Body part	Grade of severity
Scalp	◯ 0 ◯ 1 ◯ 2 ◯ 3
Face & Neck	◯ 0 ◯ 1 ◯ 2 ◯ 3
Trunk	◯ 0 ◯ 1 ◯ 2 ◯ 3
Upper Limbs	◯ 0 ◯ 1 ◯ 2 ◯ 3
Lower Limbs	◯ 0 ◯ 1 ◯ 2 ◯ 3

Key for grading
Grade 0 : Skin normal or hypo-/hyperpigmented patch only.
Grade 1 : Mild erythema,fine scales, thin plaque, with or without central clearing.
Grade 2 : Moderate erythema or scaling, moderately thick plaque.
Grade 3 : Severe erythema or scaling, very thick plaque

4. Nail involvement : ◯ No ◯ Yes → *(if YES, please tick ONE or MULTIPLE)*
☐ Pitting ☐ Discoloration ☐ Total nail dystrophy
☐ Onycholysis ☐ Subungual hyperkeratosis

5. Joint disease : ◯ No ◯ Yes

a) Rheumatoid factor		◯ Negative ◯ Positive ◯ Not Available	
b) Morning stiffness > 30 minutes			◯ No ◯ Yes
c) Enthesopathy / Dactylitis			◯ No ◯ Yes
d) Type :-	1. Oligo-/ Monoarthropathy		◯ No ◯ Yes
	2. Distal hand joints arthropathy		◯ No ◯ Yes
	3. Symmetrical polyarthropathy (Rheumatoid-like)		◯ No ◯ Yes
	4. Spondylitis / Sacroiliitis		◯ No ◯ Yes
	5. Arthritis mutilans		◯ No ◯ Yes
e) Severity:-	1. Pain	◯ No ◯ Yes →	Pain Score (1-10) : ___
	2. Swelling	◯ No ◯ Yes	
	3. Deformity	◯ No ◯ Yes →	Please Specify : ____

SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS

1. Topical therapy :

a) Tar preparation	◯ No	◯ Yes	e) Topical steroids (other than face / flexures)	◯ No ◯ Yes
b) Vitamin D analogues e.g calcipotriol	◯ No	◯ Yes	f) Keratolytics e.g. salicylic acid	◯ No ◯ Yes
c) Calcipotriol with betamethasone dipropionate	◯ No	◯ Yes	g) Emollient	◯ No ◯ Yes
d) Dithranol (anthralin)	◯ No	◯ Yes	h) Others, specify	◯ No ◯ Yes →

2. Phototherapy : ◯ No ◯ Yes → *(if YES, please tick ONE or MULTIPLE)*
☐ BB-UVB ☐ Oral PUVA ☐ Topical PUVA ☐ Others,specify
☐ NB-UVB ☐ Bath PUVA ☐ Excimer laser .....

3. Systemic therapy : ◯ No ◯ Yes

a) Methotrexate	◯ No	◯ Yes	f) Biologics, specify	◯ No ◯ Yes →
b) Acitretin	◯ No	◯ Yes		
c) Sulphasalazine	◯ No	◯ Yes	g) Systemic corticosteroids	◯ No ◯ Yes
d) Cyclosporin	◯ No	◯ Yes	h) Others, specify	◯ No ◯ Yes →
e) Hydroxyurea	◯ No	◯ Yes		

SECTION 5: QUALITY OF LIFE

1. Quality of Life : Please instruct and assist patient in completing the attached DLQI form

***Note : Please ensure that all sections of this form have been completed.*
Kindly submit to :
Malaysian Psoriasis Registry, Department of Dermatology, Hospital Kuala Lumpur, Jalan Pahang, 50586 Kuala Lumpur

Version 2.4 Last updated 07/12/2011 *page 2 of 4*

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: /
Centre

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

Objektif kaji selidik adalah untuk memahami setakat manakah masalah kulit anda mempengaruhi kehidupan anda SEPANJANG MINGGU LALU.
The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK.
这份问卷的目的是衡量上周内您的皮肤问题对您的生活造成了多大的影响.
Sila tandakan satu kotak (√) untuk setiap soalan / *Please tick "√" one box for each question* 请在每个问题后选择一项打 " √ ".

DLQI Score ☐ *Auto calculated*

Sepanjang Minggu Lalu .... *OVER THE LAST WEEK* 上周内,	Sangat Banyak *Very much* 非常多	Banyak *A lot* 许多	Sedikit *A little* 一点	Tidak Langsung *Not at all* 完全没有	Tidak Berkenaan *Not Relevant* 无关
1) Setakat manakah kulit anda berasa gatal atau sakit ? *Over the last week, how itchy, sore, painful or stinging has your skin been?* 您的皮肤感到痒、触痛、疼痛、刺痛了吗 ?	◯	◯	◯	◯	
2) Setakat manakah anda berasa malu atau segan, disebabkan oleh kulit anda? *Over the last week, how embarrassed or self conscious have you been because of your skin?* 由于您的皮肤问题，您感到尴尬或自卑吗?	◯	◯	◯	◯	
3) Setakat manakah kulit anda menganggu anda daripada pergi membeli belah atau menjaga rumah atau berkebun ? *Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?* 因为皮肤问题，对您购物、做家务、整理庭院影响程度如何?	◯	◯	◯	◯	◯
4 Setakat manakah kulit anda mempengaruhi pakaian yang anda pakai? *Over the last week, how much has your skin influenced the clothes you wear?* 皮肤问题对您穿衣服影响程度如何?	◯	◯	◯	◯	◯
5) Setakat manakah kulit anda mengganggu aktiviti - aktiviti sosial atau masa lapang anda ? *Over the last week, how much has your skin affected any social or leisure activities?* 皮肤问题对您的社交或休闲生活有多大的影响?	◯	◯	◯	◯	◯
6) Setakat manakah keadaan kulit anda menyebabkan anda tidak selesa bersukan? *Over the last week, how much has your skin made it difficult for you to do any sport?* 皮肤问题对您运动有多大妨碍?	◯	◯	◯	◯	◯
7) Adakah kulit anda menyebabkan anda tidak bekerja atau belajar? *Over the last week, has your skin prevented you from working or studying?* 皮肤问题是否让您无法上班或学习? ☐ Ya *Yes* 是 ☐ Tidak *No* 不是 ☐ Tidak Berkenaan *Not Relevant* 无关 — "Jika "tidak", setakat manakah kulit anda menjadi masalah semasa kerja atau belajar? *If "No", over the last week how much has your skin been a problem at work or studying?* 如果选择 "不是"，那么上周内您的皮肤问题对工作或 学习有多大影响呢?		◯	◯	◯	
8) Setakat manakah kulit anda menimbulkan masalah dengan teman,rakan baik 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 ?* 皮肤问题妨碍了您和爱人、亲密的朋友、亲戚间的交往了 吗?	◯	◯	◯	◯	◯
9) Setakat manakah kulit anda menyebabkan sebarang masalah hubungan seks ? *Over the last week, how much has your skin caused sexual difficulties?* 皮肤问题给您的性生活造成了多大影响?	◯	◯	◯	◯	◯
10) Setakat manakah rawatan kulit anda menimbulkan masalah seperti mengotori rumah anda atau mengambil masa anda? *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?* 由于治疗您皮肤的毛病，给您造成了多少麻烦，如把家 里弄得一团糟或占用了您很多时间?	◯	◯	◯	◯	◯

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih
Please check you have answered EVERY question. Thank you.
请您检查您是否已回答所有问题. 谢谢合作

Version 2.4 Last updated 07/12/2011 *page 3 of 4*

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:	/
Centre	

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.*
请你在每一条问题的其中一个空格画"✓"

DLQI Score [ ] 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**? *Over the last week, how **itchy, "scratchy", sore or painful** has your skin been?* 在过去一星期中，你的皮肤瘙痒、灼热或疼痛的程度如何？	◉	◉	◉	◉
2) Sepanjang seminggu yang lalu, setakat manakah anda berasa **malu** atau **sedar diri**, **susah hati** atau **sedih** disebabkan oleh kulit anda? *Over the last week, how **embarrassed or self conscious, upset or sad** have you been Because of your skin?* 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?	◉	◉	◉	◉
3) Sepanjang seminggu yang lalu, setakat manakah kulit anda memberikan kesan terhadap **persahabatan** anda? *Over the last week, how much has your skin affected your **friendships**?* 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？	◉	◉	◉	◉
4) Sepanjang seminggu yang lalu, setakat manakah anda telah menukar atau memakai **pakaian/kasut** yang **berbeza** atau **khas** disebabkan oleh kulit anda? *Over the last week, how much have you changed or worn **different or special clothes/shoes because of your skin**?* 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？	◉	◉	◉	◉
5) Sepanjang seminggu yang lalu, setakat manakah masalah kulit anda memberikan kesan apabila anda mahu **keluar rumah**, **bermain** atau **melakukan hobi**? *Over the last week, how much has your skin trouble affected **going out, playing, or doing hobbies**?* 在过去一星期中，皮肤问题对你外出、玩耍、或享受兴趣爱好的影响如何？	◉	◉	◉	◉
6) Sepanjang seminggu yang lalu, setakat manakah anda telah mengelakkan diri daripada **berenang** atau **melakukan sukan lain** disebabkan oleh masalah kulit anda? *Over the last week, how much have you avoided **swimming or other sports** because of your skin trouble?* 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？	◉	◉	◉	◉
7) Minggu lepas, adakah semasa **waktu persekolahan** *Last week, **was it school time?*** 在过去一星期中上课期间? **Jika waktu persekolahan:** Sepanjang seminggu yang lalu, setakat manakah kulit anda memberikan kesan kepada **kerja sekolah** anda. *If school time: Over the last week, how much did your skin problem affect your **school work**?* 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？ ☐ Menghalang persekolahan Prevented school 不准上学 ☐ Sangat *Very much* 非常严重 ☐ Agak banyak *Quite a lot* 严重 ☐ Sedikit sahaja *Only a little* 少许 ☐ 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？ **Jika waktu cuti:** Sepanjang seminggu yang lalu, setakat manakah masalah kulit anda mengganggu keseronokan **bercuti**? *If holiday time: How much over the last week, has your skin problem interfered with your enjoyment of the **holiday**?* 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？	◉	◉	◉	◉
8) Sepanjang seminggu yang lalu, berapa banyak masalah yang anda alami disebabkan oleh kulit anda dengan kerenah orang **memanggil anda dengan panggilan yang menyakitkan hati, mengusik, membuli, menanya soalan atau menjauhkan diri anda?** *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**?* 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？	◉	◉	◉	◉
9) Sepanjang seminggu yang lalu, setakat manakah **tidur** anda terjejas oleh masalah kulit anda? *Over the last week, how much has your **sleep been affected by your skin problem**?* 在过去一星期中，皮肤问题对你睡眠的影响程度如何？	◉	◉	◉	◉
10) Sepanjang seminggu yang lalu, setakat manakah **rawatan** untuk kulit anda mendatangkan masalah? *Over the last week, how much of a problem has the treatment for your skin been?* 在过去一星期中，皮肤治疗对你产生的困扰程度如何？	◉	◉	◉	◉

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:
Instructions: Where check boxes ❑ are provided, check (✓)one or more boxes. Where radio buttons ⊙ are provides, check (✓) one button only	Centre

Doctors' name	
Name of institution	

DEMOGRAPHIC DETAILS	
1. Visit date (dd/mm/yyyy)	☐☐/☐☐/☐☐☐☐
2. Name of patient	
3. NRIC	MyKad/ MyKid: ☐☐☐☐☐☐-☐☐-☐☐☐☐ Old IC: ☐☐☐☐☐☐☐☐☐☐ Other ID document No: ☐☐☐☐☐☐☐☐☐☐ Specify document type (if others): ⊙ Registration number ⊙ Mother's I/C ⊙ Work Permit ⊙ Clinic RN ⊙ Passport ⊙ Father's I/C ⊙ Driver's Licence ⊙ Police ID Card ⊙ Birth Certificate ⊙ Armed Force ID ⊙ Hospital RN ⊙ Others

SECTION 1 : MEDICAL HISTORY		
1. Any history of tuberculosis?	⊙ No ⊙ Yes If yes, please specify:	
	Date of diagnosis (dd/mm/yyyy)	☐☐/☐☐/☐☐☐☐
	Type of tuberculosis	⊙ Latent tuberculosis ⊙ Pulmonary tuberculosis ⊙ Extrapulmonary tuberculosis Specify organ involved:_____
	Completed anti-TB treatment?	⊙ No ⊙ Yes
2. Any history of cancer?	⊙ No ⊙ Yes, specify _____	
3. Any history of neurological disease?	⊙ No ⊙ Yes, specify _____	
4. Any history of liver disease?	⊙ No ⊙ Yes, specify _____	
5. Any history of cardiovascular disease?	⊙ No ⊙ Yes, specify _____	
6. Previous systemic treatment?	⊙ No ⊙ Yes If yes, please specify:	

Systemic agent	**Reasons for stopping**
❑ Phototherapy	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Oral methotrexate	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Parenteral methotrexate	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Acitretin	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Sulphasalazine	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Cyclosporin	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Hydroxyurea	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Systemic corticosteroids	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Biologic therapy, specify _____	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify)
❑ Other systemic agent, specify _____	❑Poor response ❑Intolerance ❑Adverse effects ❑Others (specify) _____

SECTION 2 : PRE-TREATMENT 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	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%
Upper limbs	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%
Trunk	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%
Lower limbs	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ 0 ⊙ 1 ⊙ 2 ⊙ 3 ⊙ 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%

SECTION 3 : INVESTIGATIONS	
1. Mantoux test	_____ mm ❑ Not done because of _____
2. Interferon-γ release assay	⊙ Negative ⊙ Positive ⊙ Not available
3. Chest X-ray	⊙ Normal ⊙ Abnormal ⊙ Not available If abnormal, specify findings _____
4. Hepatitis B status	⊙ Negative ⊙ Positive ⊙ Not available
5. Hepatitis C status	⊙ Negative ⊙ Positive ⊙ Not available
6. HIV status	⊙ Negative ⊙ Positive ⊙ Not available

SECTION 4 : INDICATION FOR BIOLOGIC TREATMENT		
Indication for biologic treatment	❑	Phototherapy and standard systemic therapy are contraindicated
	❑	Intolerant to phototherapy and standard systemic therapy
	❑	Failed phototherapy and standard systemic therapy
	❑	Other indication, specify _____

SECTION 5 : CURRENT BIOLOGIC TREATMENT	
1. Biologic agent	⊙ Infliximab IV ⊙ Etanercept SC ⊙ Adalimumab SC ⊙ Ustekinumab SC ⊙ Others, specify _____
2. Date start (dd/mm/yyyy)	☐☐/☐☐/☐☐☐☐
3. Dose	

SECTION 6 : CONCOMITANT SYSTEMIC TREATMENT	
1. Concomitant systemic treatment / phototherapy	⊙ No ⊙ Yes, specify _____

NATIONAL DERMATOLOGY REGISTRY (DermReg) **Malaysian Psoriasis Registry** **Biologic Treatment Follow Up Form**	*CONFIDENTIAL* For official use only: ID:
Instructions: Where check boxes ❑ are provided, check (✓)one or more boxes. Where radio buttons ⊙ are provides, check (✓) one button only	Centre

Doctors' name	
Name of institution	

DEMOGRAPHIC DETAILS

1. Visit date (dd/mm/yyyy)	☐☐/☐☐/☐☐☐☐
2. Name of patient	
3. NRIC	MyKad/ MyKid: ☐☐☐☐☐☐-☐☐-☐☐☐☐ Old IC: ☐☐☐☐☐☐☐☐☐ Other ID document No: ☐☐☐☐☐☐☐☐☐☐☐☐ Specify document type (if others): ⊙ Registration number ⊙ Mother's I/C ⊙ Work Permit ⊙ Clinic RN ⊙ Passport ⊙ Father's I/C ⊙ Driver's Licence ⊙ Police ID Card ⊙ Birth Certificate ⊙ Armed Force ID ⊙ Hospital RN ⊙ Others

SECTION 1 : 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	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%
Upper limbs	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%
Trunk	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%
Lower limbs	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ ⊙ ⊙ ⊙ ⊙ 0 1 2 3 4	⊙ None ⊙ 50 – 69% ⊙ 1 - 9% ⊙ 70 – 89% ⊙ 10 - 29% ⊙ 90 – 100% ⊙ 30 – 49%

SECTION 2 : ADVERSE EVENT(S) DURING BIOLOGIC TREATMENT

Adverse event(s)	**Date onset (dd/mm/yyyy)**
❑ Tuberculosis reactivation	☐☐/☐☐/☐☐☐☐
❑ Septicaemia	☐☐/☐☐/☐☐☐☐
❑ Lymphoma	☐☐/☐☐/☐☐☐☐
❑ Cancer other than lymphoma	☐☐/☐☐/☐☐☐☐
❑ Worsening of psoriasis	☐☐/☐☐/☐☐☐☐
❑ _____	☐☐/☐☐/☐☐☐☐
❑ _____	☐☐/☐☐/☐☐☐☐

SECTION 3 : BIOLOGIC DOSES RECEIVED	
Total number of biologic doses received since initial dose	☐☐☐

SECTION 4 : CHANGE/CESSATION OF BIOLOGIC TREATMENT	
1. Date of change/cessation (dd/mm/yyyy)	☐☐/☐☐/☐☐☐☐
2. Change/cessation of biologic treatment	⊙ Change to another biologic ⊙ Change to another systemic agent. Specify _____ ⊙ Withhold biologic treatment
If changed to another biologic agent, please specify	⊙ Infliximab IV ⊙ Etanercept SC ⊙ Adalimumab SC ⊙ Ustekinumab SC ⊙ Others, specify _____
If changed to another systemic agent, please specify	❑ Phototherapy ❑ Oral methotrexate ❑ Parenteral methotrexate ❑ Acitretin ❑ Sulphasalazine ❑ Cyclosporin ❑ Hydroxyurea ❑ Systemic corticosteroids ❑ Other systemic agent, specify _____

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 six months on follow-up visits for patients receiving phototherapy, systemic and biologic therapy.

A carefully designed 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.

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, systemic and biologic treatment to record the progress of the patient. For patients initiated on biologic treatment, an additional Biologic Treatment Initiation Form is to be filled and the Biologic Treatment Follow Up Form is to be 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 monthly intervals to the users.

Participation of the SDP is entirely voluntary.

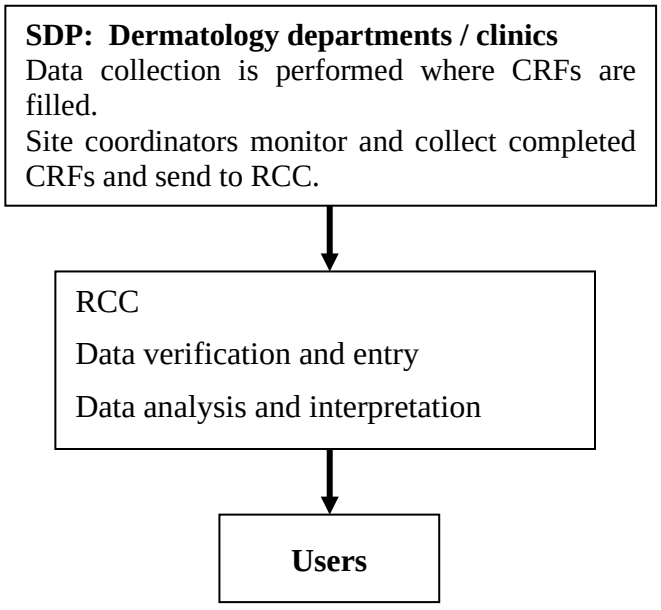
Registry ICT Infrastructure and Data Centre

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

The network infrastructure consists of the network layout, placement of relevant hardware equipment, the general flow of data across the network, as well as the network services required for a functional and secure MPR network infrastructure. MPR servers are located at a data centre in Cyberjaya to provide quality assured data hosting services and state-of-the-art physical and logical security features. The physical security features implemented include fire suppression system, access card and biometrics authentication to gain physical access to the data centre, uninterrupted power supply, and backup devices. Logical security features implemented include firewall, antivirus, automated patching, encryption, traffic monitoring and intrusion detection system.

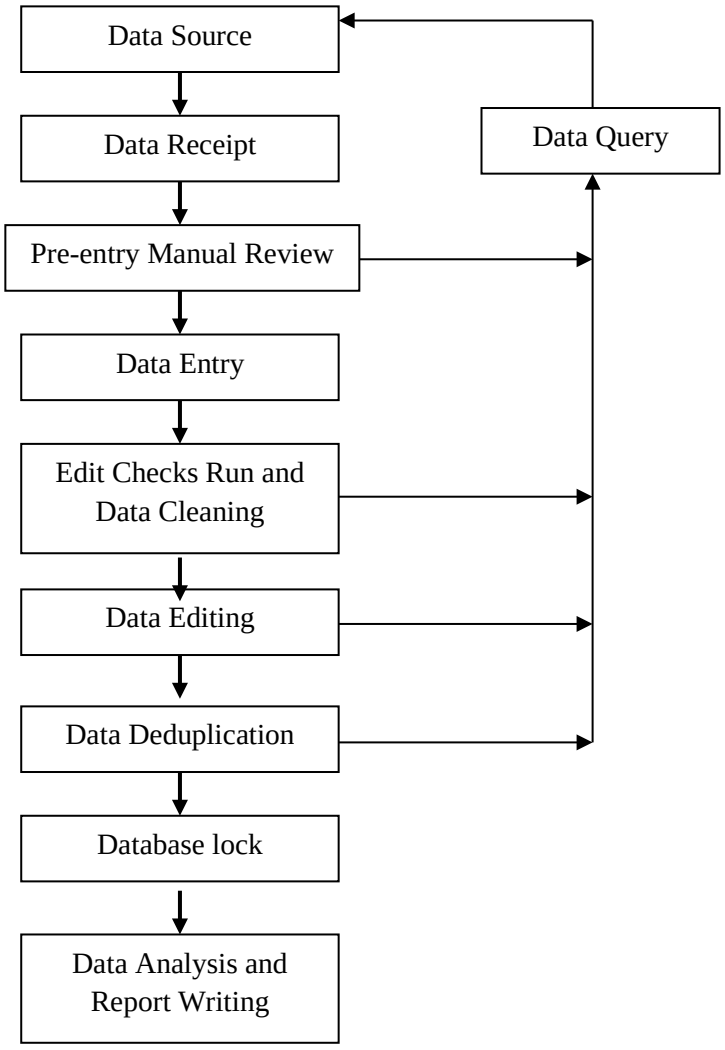
Data Flow Process

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 DermReg Web Application (eDermReg).

Data security features in eDermReg 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 also as the registry's overall data report.

Edit checks run and Data cleaning

Edit checks were 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 IC and deriving gender from the IC. Checking inconsistent data is also done, for example IC 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, fax, 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 2007 and 2018**

There were 21,735 patients in the dataset. This analysis set was used for the analysis in Chapters 1, 2, 3, 4, 5 and 6, which comprised of 352 cases in year 2007, 1,345 cases in year 2008, 1,542 cases in year 2009, 1,285 cases in year 2010, 1,069 cases in year 2011, 953 cases in 2012, 1,659 cases in 2013, 2,865 cases in 2014, 2,494 cases in 2015, 3,507 cases in 2016, 1840 cases in 2017 and 2824 cases in 2018. The cases included first notification and up to fifteen follow-up notifications.

2. **Patient's Quality of life between 2007 and 2018**

For Chapter 7, 21,084 cases were included in the analysis.

3. **Patient outcome between 2007 and 2018**

There were 7,501 cases considered 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 the missing data were issued to the Principal Investigator to be clarified. Traceable missing information was then incorporated into the dataset but for untraceable data, it was 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 range were reported. For standardization of the output tables, the values of percentages and descriptive summary were limited to two decimal points 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 graphically 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 graphically using 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 and vertical bar charts.

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, joint disease and involvement of special sites such as scalp, face and nails. Data were presented using tables.

Treatment

Chapter 6 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, which was the Dermatology Life Quality Index (DLQI) and Children's Dermatology Life Quality Index (CDLQI). 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 and DLQI/CDLQI score were graphically presented using tables and vertical bar charts.

STATISTICAL SOFTWARE

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

APPENDIX D: PARTICIPATING CENTRE DIRECTORY

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: -
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: Prema Dharshini Vicknesvaran
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. Nithiya Visayaragawan
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: Mohd Khairul bin Othman
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: Dr. Khor Yek Huan

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. Loh Ken Chen Site- coordinator: Dr. Azlida Che Man
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. Hassanin Hussaini Hilmi Mohd Khalid Site- coordinator: Wan Suhardi Wan Abdul Rahman Siti Zulaiha Binti Che Hat
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: Ampong Anggarak
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: Mus Azlina Mustafa
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. Gurcharan Jit Singh

Sarawak General Hospital Dermatology Department, Hospital Umum Sarawak, Jln Tun Ahmad Zaidi Adruce, 93586 Kuching, Sarawak. Tel: 082-27 6666 Ext 5117 Fax: 082-242751	Investigator: Dr. Pubalan Muniandy Site- coordinator: Maurice Medan
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. Norasma Roslan, Dr. Balachandran Manoharan
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. Tey Kwee Eng Site- coordinator: Izuddin Aizat Abd Aziz
Gleneagles Kuala Lumpur Suite 602 Gleneagles Hospital 282 & 286 Jalan Ampang 50540 Kuala Lumpur. Tel: 03-42516233 Fax: 03-42516239	Investigator: Dr. Chang Choong Chor Site- coordinator: -
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: Nor Salwa Abdullah Sani
Prince Court Medical Centre Prince Court Medical Centre, 39, Jalan Kia Peng, 50450 Kuala Lumpur. Tel: 03- 26100000 Ext 2955 Fax: 03-2160 0010	Investigator: Dr. Gangaram Hemandas Belani Site- coordinator: -

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
Universiti Kebangsaan Malaysia Medical Centre Dermatology Department, UKM Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Kuala Lumpur. Tel: 03-9145 6075 Fax: 03-9145 6640	Investigator: Dr. Norazirah Md Nor Site- coordinator: -
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: Muhammad Al-Amin Mat Zin
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. Benji Teoh Tze Yuen Site- coordinator:
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: -

Hospital Serdang Dermatology Department, Hospital Serdang, Jalan Puchong, 43000 Kajang, Selangor Darul Ehsan. Tel: 03-8947 5555 Fax: 03-8947 5050	Investigator: Dr. Low Dyoi-E Site- coordinator: -
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. Dawn Ambrose Site- coordinator: - Mohd Lutfi Mohamad Mortadza
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 Site- coordinator: -
Hospital Jerantut Dermatology Department, Hospital Jerantut, 27000 Jerantut, Pahang Darul Makmur. Tel: 09-266 3333/4 Fax: 09-266 1462	Investigator: Dr. Rajalingam Ramalingam Site- coordinator: -
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 Site- coordinator:

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 Fax: 07-356 5034 / 5088	Investigator: Dr. Latha Selvarajah Site- coordinator: - Muhamad Ahmad Fauzi
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: - Azalawati Muhamed
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 Site- coordinator:
Hospital Lahad Datu Peti Surat 60065, 91110 Lahad Datu, Sabah. Tel: 089-895 111 Fax: 088-884 670	Investigator: Dr. Voo Sook Yee @ Michelle Site- coordinator:
Hospital Tawau Peti Surat 67, 91007 Tawau, Sabah. Tel: 089-773 533 Fax: 089-773 317	Investigator: Dr. Voo Sook Yee @ Michelle Site- coordinator:
Hospital Kuala Lipis 27200 Kuala Lipis, Pahang. Tel: 09-3123333 / 3123332 Fax: 09-3121787	Investigator: Dr. Rajalingam Ramalingam Site- coordinator: