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Ministry of Health Malaysia

**NATIONAL DERMATOLOGY REGISTRY
(DermReg)**

ANNUAL REPORT 2007-2015

Malaysian Psoriasis Registry

Editors:

**Azura Mohd Affandi
Nooraishah Ngah Saaya
Asmah Johar**

With contribution from:
**Nurakmal Baharum
Abdul Muneer Abdul Hamid**



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**Annual Report of the
MALAYSIAN PSORIASIS REGISTRY**

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- The Dermatological Society of Malaysia
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- College of Physicians, Academy of Medicine Malaysia
- Altus Solutions Sdn Bhd

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ABBREVIATIONS

BB-UVB	Broad-band ultraviolet B
BMI	Body mass index
BSA	Body surface area
CDLQI	Child 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
HLA	Human leukocyte antigen
IQR	Interquartile range
MOH	Ministry of Health
MPR	Malaysian Psoriasis Registry
NA	Not available
NBUVB	Narrow-band ultraviolet B
NHMS	National Health and Morbidity Survey
PI	Principal Investigator
PUVA	Psoralen and ultraviolet A
QoL	Quality of life
RCC	Registry Coordinating Centre
SC	Site Coordinator
SD	Standard deviation
SDP	Sources data providers

ABOUT DermReg

Introduction

DermReg is an ongoing systematic collection, analysis and interpretation of data pertaining to dermatological diseases and services in Malaysia. It is a nationwide project which aims to integrate all dermatological patient registries and databases developed in Malaysia. These registries are essential in the planning, implementation and evaluation of clinical and health services as well as research in dermatology

Objectives of DermReg

General Objective

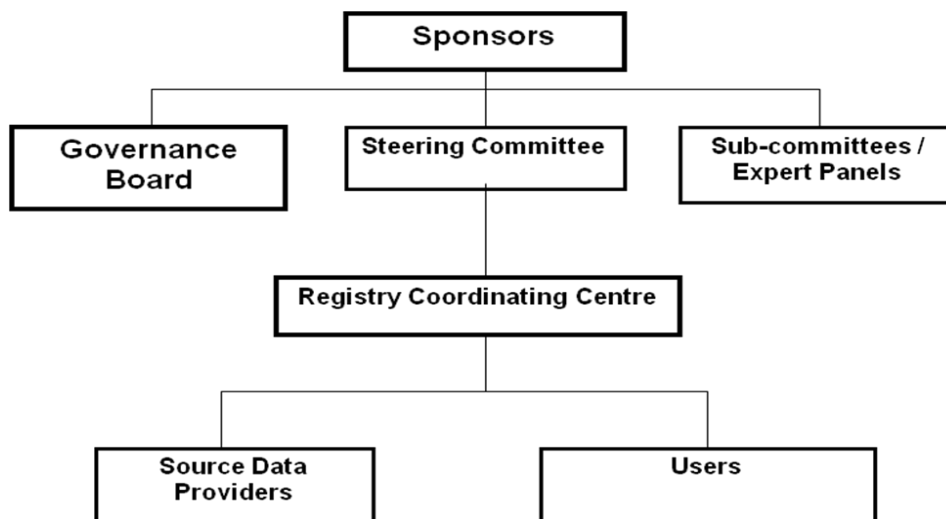
To establish a nationwide systematic prospective collection of data pertaining to skin diseases and dermatological services, in order to study the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities.

Specific Objectives:

1. Determine the socio-demographic profile of patients with skin diseases
2. Determine the burden of skin diseases in the population
3. Describe the natural history of skin diseases
4. Identify the potential causal and risk factors of skin diseases
5. Describe the clinical manifestation of skin diseases
6. Describe the effect of skin diseases on the quality of life
7. Determine the efficacy and cost effectiveness of treatment of skin diseases
8. Monitor the safety and adverse effects of products and services used in the treatment of skin diseases
9. Evaluate accessibility and quality of health services related to skin diseases
10. Stimulate and facilitate basic, clinical and epidemiological research on skin diseases

ORGANISATION OF DermReg

The organizational structure of DermReg consists of sponsors, Governance Board, Steering Committee, Sub-committees or Expert Panels, Registry Coordinating Centre, Source Data Providers (SDP) and users.



SPONSORS

The DermReg is sponsored by:

1. Ministry of Health, Malaysia
2. The Dermatological Society of Malaysia
3. Pharma companies – Abbvie, Janssen Malaysia and Novartis Malaysia

GOVERNANCE BOARD

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

- to ensure that the DermReg stay focused on its objectives
- to ensure its continuing relevance and justification

1. Datin Dr Asmah Johar (Chairperson)

Head of Dermatological Services and Senior Consultant Dermatologist
Department of Dermatology
Hospital Kuala Lumpur

2. Dr. Agnes Heng

President of the Dermatological Society of Malaysia, and
Consultant Dermatologist
Ipoh, Perak

3. Dr. Steven Chow Kim Weng

President of the College of Physicians, Academy of Medicine Malaysia, and
Senior Consultant Dermatologist
The Skin Centre, Kuala Lumpur

4. 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. Azura Mohd Affandi (MPR Chairman)	Hospital Kuala Lumpur
2.	Dr. Choon Siew Eng	Hospital Sultanah Aminah, Johor Bahru
3.	Dr. Pubalan Muniandy	Hospital Umum Sarawak
4.	Dr. Tang Jyh Jong	Hospital Permaisuri Bainun, Ipoh
5.	Dr. Chan Lee Chin	Hospital Pulau Pinang
6.	Dr. Najeeb Ahmad Mohd Safdar	Hospital Tuanku Jaafar, Seremban
7.	Dr. Steven Chow Kim Weng	The Skin Clinic, Kuala Lumpur
8.	Dr. Mohd Noh Idris	Klinik Kulit Md Noh, Kuala Lumpur
9.	Dr. Rohna Ridzwan	Hospital Selayang
10.	Dr. Dawn Angelia Ambrose	Hospital Ampang

REGISTRY COORDINATING CENTRE

The **DermReg 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 Mrs Nooraishah Ngah Saaya

Technical Support Personnel

Epidemiology Officer -

Biostatisticians Ms Nurakmal bt Baharum
CRC

Database Administrator Ms Lim Jie Ying
Altus Solutions Sdn Bhd

SOURCE DATA PROVIDERS (SDP)

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

Source Data Providers for Malaysian Psoriasis Registry (MPR)

No.	Source Data Provider	Investigator
1.	Hospital Kuala Lumpur	Dr. Azura Mohd Affandi
2.	Hospital Pulau Pinang	Dr. Chan Lee Chin
3.	Hospital Sultanah Bahiyah, Alor Setar	Dr. Tan Wooi Chiang
4.	Hospital Tuanku Fauziah, Perlis	Dr Hassanin Husseyne Hilmi
5.	Hospital Sultanah Fatimah, Muar	Dr. Noreen Md Arus
6.	Hospital Tuanku Jaafar, Seremban	Dr. Najeeb Ahmad Mohd Safdar
7.	Hospital Queen Elizabeth, Kota Kinabalu	Dr. Zaigham Mahmood
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. Peamala Gunabalasingam
14.	Prince Court Medical Centre	Dr. Gangaram Hemandas
15.	Gleneagles Intan Medical Centre	Dr. Chang Choong Chor
16.	Hospital Sultanah Aminah, Johor Bahru	Dr. Choon Siew Eng
17.	Pusat Perubatan UKM	Dr. Norazirah Md Nor
18.	Pusat Perubatan UM	Dr. Sean Yong Shin Shen
19.	Hospital Raja Perempuan Zainab II	Dr. Zulrusydi Ismail
20.	Hospital Ampang, Selangor	Dr. Dawn Ambrose

21.	Hospital Selayang, Selangor	Dr. Norli Marwyne Mohammed Noor
22.	Hospital Putrajaya	Dr. Nazatul Shima Abdul Rahim
23.	Hospital Serdang (March 2015)	Dr. Tee Shwu Hoon
24.	Hospital Sultan Ismail, Johor Bahru (Sept 2016)	Dr. Latha Selvarajah
25.	Hospital Sultan Haji Ahmad Shah, Temerloh (May 2017)	Dr. Rajalingam Ramalingam
26.	Hospital Jerantut (May 2017)	Dr. Rajalingam Ramalingam
27.	Hospital Jengka (May 2017)	Dr. Rajalingam Ramalingam
28.	Hospital Sultanah Zahirah, Kuala Terengganu (Sept 2017)	Dr. Nor Azura Mohamad

OFFICIAL WEBSITE OF DermReg

<http://www.acrm.org.my/dermreg/>



About DermReg

Organisation

Governance Board

Steering Committee

Registry Coordinating Centre

Source Data Providers (SDP)

Publications

News & Events

Data Request

Links

eDermReg (MPR, Skin Biopsy)

eCUSUM



Welcome to National Dermatology Registry (DermReg)

National Dermatology Registry (DermReg) is an ongoing systematic collection, analysis and interpretation of data pertaining to skin diseases and related services in Malaysia. This will enable us to know the the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities. This information is useful in assisting the Ministry of Health, non-governmental organizations, private healthcare providers and industry in planning, development and continuous improvement of services and facilities in the prevention and control of skin diseases.

DermReg is a nationwide project which aims to integrate all dermatological patient registries and databases developed in Malaysia.

Registries under **DermReg** include:

1. **Malaysian Psoriasis Registry (MPR)**
2. **Diagnostic Skin Biopsy Registry (DSBR)** - ceased operation on 15 July 2012
3. **Malaysian Leprosy Registry (MLR)**

Sponsors

1. Ministry of Health, Malaysia
 - Clinical Research Centre
 - Department of Dermatology, Hospital Kuala Lumpur
 - Head of Dermatology Services, Malaysia
2. Dermatological Society of Malaysia
3. Faculty of Medicine, College of Physicians, Academy of Medicine Malaysia
4. Industrial Sponsors:
 - Abbot Malaysia
 - Leo Pharma (Malaysia)
 - Janssen-Cilag, a division of Johnson & Johnson (Malaysia) Pvt Ltd

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ABOUT MALAYSIAN PSORIASIS REGISTRY (MPR)

Introduction

Psoriasis is a common skin disease, characterized by inflamed scaly patches and plaques. It runs a chronic relapsing course with variable degree of severity, and causes significant physical, psychosocial and economic impact on the patient. Being incurable, it may lead to poor patient compliance especially in 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 the demographic data, types of psoriasis, its severity, aggravating factors, any associated joint and nail involvement 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 the 17th May 1998. This registry consists of information on patients with psoriasis in Malaysia and is under the umbrella of the National Dermatology Registry (DermReg). A case report form 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, MPR was extensively revised under the guidance of CRC and with the financial support from MOH. A new case report form was introduced and a new centralised electronic database with web application was established to facilitate multi-centre data collection. 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 in the following year.

Objectives

The MPR has the following objectives:

- Primary objective:
 - To obtain more accurate data on various aspects of psoriasis in Malaysia.
- Secondary objectives:
 1. To determine the socio-demographic profiles of patients with psoriasis.
 2. To determine the disease burden attributed to psoriasis.
 3. To provide information for planning of medical services, facilities, manpower 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 measure 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 2015, a total of 14,516 patients with psoriasis from 23 dermatology centres (19 government hospitals, 2 private centres and 2 university hospitals) were notified to the registry.

Demographic Characteristics of Patients

In adult patients, male-to-female ratio was 1.4:1. Ethnic distribution: Malay 50.0%, Chinese 21.8%, Indian 18.0%, other ethnic groups 10.3%. Mean age at notification was 45.60 ± 15.94 years (range 18 - 97 years). Most patients (99.0%) were Malaysian citizens.

In paediatric patients, male-to-female ratio was 0.7:1. Ethnic distribution: Malay 69.0%, Chinese 8.0%, Indian 13.2%, other ethnic groups 9.8%. Mean age at notification was 13.04 ± 3.64 years (range 0 - 17 years). Most patients (99.8%) were Malaysian citizens.

Medical History

In adult patients, mean age of onset of psoriasis was 35.02 ± 16.07 years (range 0 – 87 years). In the paediatric group, the mean age of onset was 10.03 ± 4.37 years (range 0-17 years).

Family history of psoriasis was present in 23.1% of adult patients with psoriasis. Among those who had positive family history, family members affected were either of their parents in 41.1%, siblings in 36.4% and children in 11.5%. In the child population, 21.1%, of them had at least one family member with psoriasis. Of these, 35.6% had either of their parents affected with psoriasis.

52.4% adult patients and 40.5% paediatric patients reported one or multiple factors which aggravated their psoriasis. The commonest aggravating factors were stress (66.4% in adult, 55.8% in paediatric), sunlight (33.3% in adult, 43.5% in paediatric) and infection (13.7% in adult, 18.4% in paediatric).

Comorbidities

In adult psoriasis patients aged 18 and above, 33.8% were overweight and 24.3% were obese, 27.2% had hypertension, 18.9% had hyperlipidaemia, 18.4% had diabetes mellitus, 5.8% had ischaemic heart disease and 1.6% had previous history of stroke. In children and adolescents aged below 18 years with psoriasis, the most prevalent co morbidity was overweight or obesity i.e. BMI at or above 85th centile (28.1 %), followed by bronchial asthma (2.3%).

Compared to patients without arthritis, patients with psoriatic arthritis were found to have increased co-morbidities such as diabetes mellitus, hypertension, hyperlipidaemia and obesity.

Clinical Presentation

The commonest clinical type of psoriasis in adult and paediatric patients was plaque psoriasis (85.4% and 79.2%, respectively). This was followed by guttate psoriasis (3.2% and 7.2% respectively), erythrodermic psoriasis (1.7% and 0.8% respectively), pustular psoriasis (1.1% and 1.5% respectively) and flexural psoriasis (0.4% and 0.8% respectively). In adult patients, 50.9% had body surface area involvement of 10% or less. The pattern remains the same in child population, i.e. <5% of severity in 36.0%, followed by 5-10% of severity in 22.5% of patients.

Psoriatic arthropathy was reported in 13.7% of adult patients and only 1.6% in paediatric population. The commonest psoriatic arthropathy in adult patients was oligo/monoarthropathy (39.0%) followed by distal hand joints arthropathy (31.2%) and rheumatoid-like symmetrical polyarthropathy (30.3%).

About two-third (58.2%) of adult patients had nail changes associated with psoriasis. Among patients who had nail disease, pitting was commonest (73.2%), followed by onycholysis (48.2%), discoloration (31.4%) and subungual hyperkeratosis (13.5%). Total nail dystrophy was found in 4.6% of patients with nail disease. In paediatric cases, 36.1% of them had nail involvement. Distribution of nail features in paediatric psoriasis patients with nail involvement reported that pitting was the commonest (89.3%) followed by onycholysis (26.0%).

Treatments received in the past 6 months

Majority of the patients (94.9% in adult, 93.2% in paediatric) were on topical treatment. Topical steroid was the commonest prescribed (83.0% in adult, 75.5% in paediatric), followed by tar preparations (70.2% in adult and 66.9% in paediatric), emollients (73.8% in adult and 63.8% in paediatric) patients. 3.2% of adult patients and 1.5% of paediatric patients received phototherapy. Of the patients who had phototherapy, narrowband UVB (NBUVB) was the commonest used (86.5% in adult, 81.3 in paediatric). Systemic therapy was given in 18.8% of adult patients and in 5.4% paediatric patients. The most frequently used systemic therapy was methotrexate (73.0% in adult, 52.6% in paediatric), followed by acitretin (18.3% in adult, 35.1% in paediatric).

Quality of Life

Measurement of quality of life using Dermatology Life Quality Index (DLQI) or child DLQI (CDLQI) was performed in 7,208 adult patients (aged 17 and above) and 395 children/adolescent patients (aged 5 to 16). The mean DLQI score was 8.5 ± 6.5 for adult patients and the mean CDLQI was 7.8 ± 5.5 for children/adolescent patients.

32.9% of adult patients reported DLQI > 10, and 20.0% of paediatric patients reported a CDLQI of more than 12, indicating severe quality of life impairment due to psoriasis or its treatment. Symptoms and feelings was the DLQI domain most affected by both adult and paediatric patients (38.8% of adult patients and 39.5% of paediatric patients were affected very much or a lot in this domain).

CHAPTER 1

STOCK AND FLOW

During the period from October 2007 to December 2015, a total of 14,516 patients were notified to the registry. The number of notified patients gradually increased throughout the period (**Figure 1.1**). Of the overall population, 7.3% (n=1,065) patients belong to the age group < 18 years and were categorized as paediatric population, 92.7% (n=13,451) patients belong to the age group \geq 18 years of age and were categorized as the adult population.

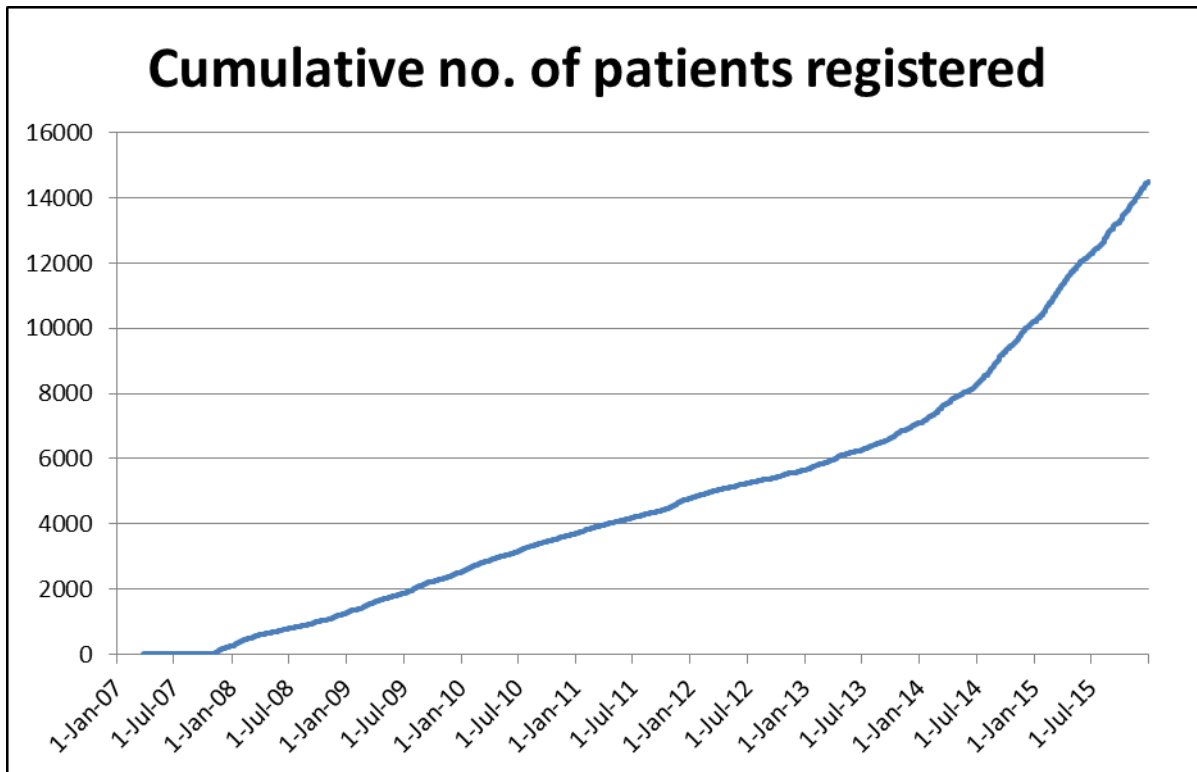


Figure 1.1 Psoriasis patients notified to the MPR

A total of 23 dermatology centres (19 government hospitals, 2 private centres and 2 university hospitals) participated in the MPR. In the adult category, Hospital Kuala Lumpur notified the highest number of patients. This was followed by Hospital Tengku Ampuan Rahimah, Klang and Hospital Pulau Pinang (**Table 1.1**). In the paediatric group, Hospital Sultanah Bahiyah notified the highest number of paediatric patients. This was followed by Hospital Tengku Ampuan Rahimah, Klang and Hospital Kuala Lumpur (**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	
1	Hospital Kuala Lumpur	47	153	167	116	60	62	205	514	914	2238
2	Hospital Tengku Ampuan Rahimah	0	58	132	122	80	62	70	259	499	1282
3	Hospital Pulau Pinang	18	71	214	105	127	10	92	73	504	1214
4	Hospital Queen Elizabeth	18	89	102	101	99	69	100	174	444	1196
5	Hospital Sultanah Bahiyah	86	179	74	63	49	76	79	274	90	970
6	Hospital Melaka	0	0	78	226	178	144	130	123	87	966
7	Hospital Umum Sarawak	3	111	63	40	28	36	66	177	416	940
8	Hospital Raja Permaisuri Bainun	42	39	69	35	62	98	71	210	313	939
9	Hospital Sultanah Aminah	0	33	134	64	62	64	183	284	6	830
10	Hospital Tengku Ampuan Afzan	0	36	36	77	66	51	103	150	146	665
11	Hospital Sultanah Fatimah	2	34	24	24	30	60	10	111	179	474
12	Hospital Tuanku Jaafar	0	47	0	26	56	2	82	83	94	390
13	Hospital Selayang	0	0	0	0	0	0	1	212	129	342
14	Hospital Tuanku Fauziah	0	19	35	43	32	10	8	12	98	257
15	Hospital Ampang	0	0	0	0	1	3	9	86	62	161
16	Hospital Putrajaya	0	0	0	0	0	0	0	82	76	158
17	Hospital Raja Perempuan Zainab II	0	0	0	0	9	8	86	17	14	134
18	Hospital Serdang	0	0	0	0	0	0	0	97	13	110
19	UM Medical Centre	0	0	0	0	32	25	2	0	0	59
20	UKM Medical Centre	0	0	0	15	0	21	4	1	0	41
21	Prince Court Medical Centre	0	0	6	17	3	1	4	3	4	38
22	Hospital Sungai Buloh	4	24	1	0	0	0	0	1	0	30
23	Gleneagles Medical Centre	0	11	6	0	0	0	0	0	0	17
Total		2227	2912	3144	3084	2985	2814	3318	4957	6103	13451

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	
1	Hospital Sultanah Bahiyah	9	27	13	13	9	9	18	18	16	132
2	Hospital Tengku Ampuan Rahimah	0	8	16	26	8	7	7	18	34	124
3	Hospital Kuala Lumpur	7	16	14	7	5	9	11	14	28	111
4	Hospital Queen Elizabeth	1	7	12	11	6	6	10	10	35	98
5	Hospital Tengku Ampuan Afzan	0	4	7	11	14	13	12	10	15	86
6	Hospital Umum Sarawak	1	13	11	6	2	6	6	14	24	83
7	Hospital Melaka	0	0	6	11	18	12	16	8	9	80
8	Hospital Sultanah Aminah	0	2	10	5	4	7	18	27	1	74
9	Hospital Pulau Pinang	0	7	11	4	4	0	7	6	18	57
10	Hospital Raja Permaisuri Bainun	3	3	9	2	3	10	3	9	6	48
11	Hospital Tuanku Jaafar	0	5	0	6	7	0	9	2	11	40
12	Hospital Sultanah Fatimah	2	6	0	3	6	4	1	8	6	36
13	Hospital Tuanku Fauziah	1	8	4	5	2	2	3	2	1	28
14	Hospital Selayang	0	0	0	0	0	0	0	14	5	19
15	Hospital Ampang	0	0	0	0	0	0	2	7	6	15
16	Hospital Raja Perempuan Zainab II	0	0	0	0	0	0	7	5	1	13
17	Hospital Sungai Buloh	3	5	0	0	0	0	0	0	0	8
18	Gleneagles Medical Centre	0	4	0	0	0	0	0	0	0	4
19	Hospital Serdang	0	0	0	0	0	0	0	3	0	3
20	Hospital Putrajaya	0	0	0	0	0	0	0	2	0	2
21	UM Medical Centre	0	0	0	0	2	0	0	0	0	2
22	Prince Court Medical Centre	0	0	0	0	0	0	1	0	0	1
23	UKM Medical Centre	0	0	0	1	0	0	0	0	0	1
Total		27	115	113	111	90	85	131	177	216	1065

There were a total of 14,516 notifications of patients with psoriasis in the MPR with new cases and follow-up treatment. 8,756 (65.1%) of the adult patients were notified once, and 4,695 (34.9%) were notified more than once (**Table 1.3**). In paediatric population, 852 (80.0%) of the patients were notified once and 213 (20.0%) of them had more than one notifications (**Table 1.4**).

Table 1.3 **Distribution of adult patients with psoriasis according to the number of notifications**

Year	No.	%
Entry notification	8756	65.1
Entry and one follow-up notifications	2326	17.3
Entry and 2 follow-up notifications	1102	8.2
Entry and 3 follow-up notifications	566	4.2
Entry and 4 follow-up notifications	305	2.3
Entry and 5 follow-up notifications	195	1.4
Entry and 6 follow-up notifications	97	0.7
Entry and 8 follow-up notifications	57	0.4
Entry and 9 follow-up notifications	28	0.2
Entry and 10 follow-up notifications	11	0.1
Entry and 11 follow-up notifications	5	0.0
Entry and 12 follow-up notifications	3	0.0
Total	13451	100.0

Table 1.4 **Distribution of paediatric patients with psoriasis according to the number of notifications**

Year	No.	%
Entry notification	852	80.0
Entry and one follow-up notifications	121	11.4
Entry and 2 follow-up notifications	51	4.8
Entry and 3 follow-up notifications	27	2.5
Entry and 4 follow-up notifications	9	0.8
Entry and 5 follow-up notifications	4	0.4
Entry and 6 follow-up notifications	0	0.0
Entry and 8 follow-up notifications	0	0.0
Entry and 9 follow-up notifications	0	0.0
Entry and 10 follow-up notifications	1	0.1
Total	1065	100.0

CHAPTER 2

CHARACTERISTICS OF PATIENTS

In adult patients with psoriasis, 92.7% of population was Malaysian. Malays comprised the majority of patients (50.0%), followed by Chinese (21.8%), Indians (18.0%), other ethnic groups (10.2%) and Orang Asli (0.1%) (**Table 2.1**). There were more males than females (56.7% and 43.3% respectively), with a male to female ratio of 1.4:1 (**Figure 2.1**).

The mean age of the adult patients was 45.60 ± 15.94 years with a range from 18 to 97 years. The majority were married (69.5%). 23.5% patients were single, and the rest, either divorced or widowed (**Table 2.1**).

Most paediatric patients (99.8%) with psoriasis were Malaysian. Of the data analyzed, 69.0% paediatric patients were Malays followed by Indian in 13.2%, Chinese in 8.0% and 9.8% belonging to other ethnic groups (**Table 2.2**). Majority or 616 patients of paediatric patients were females (57.8%), while 449 were males (42.2%) (**Figure 2.2**).

The mean age of the paediatric population was 13.04 ± 3.64 years (0-17 years) (**Table 2.2**).

Table 2.1 Demographics of adult and paediatric patients with psoriasis

Patient characteristics		Adult		Paediatric	
		n	%	n	%
Nationality	Malaysian	13246	99.0	1062	99.8
	Non Malaysian	138	1.0	2	0.2
Ethnic distribution	Malay	6720	50.0	735	69.0
	Chinese	2928	21.8	85	8.0
	Indian	2420	18.0	141	13.2
	Orang Asli	14	0.1	3	0.3
	Others	1366	10.2	101	9.5
Gender	Male	7633	56.7	449	42.2
	Female	5818	43.3	616	57.8
Marital status	Single	3160	23.5	-	-
	Married	9348	69.5	-	-
	Divorced	135	1.0	-	-
	Widowed	283	2.1	-	-
	NA	525	3.9	-	-
Age at notification (years)	Mean \pm SD	45.60 ± 15.34		13.04 ± 3.64	
	(Range)	(18 - 97)		(0-17)	

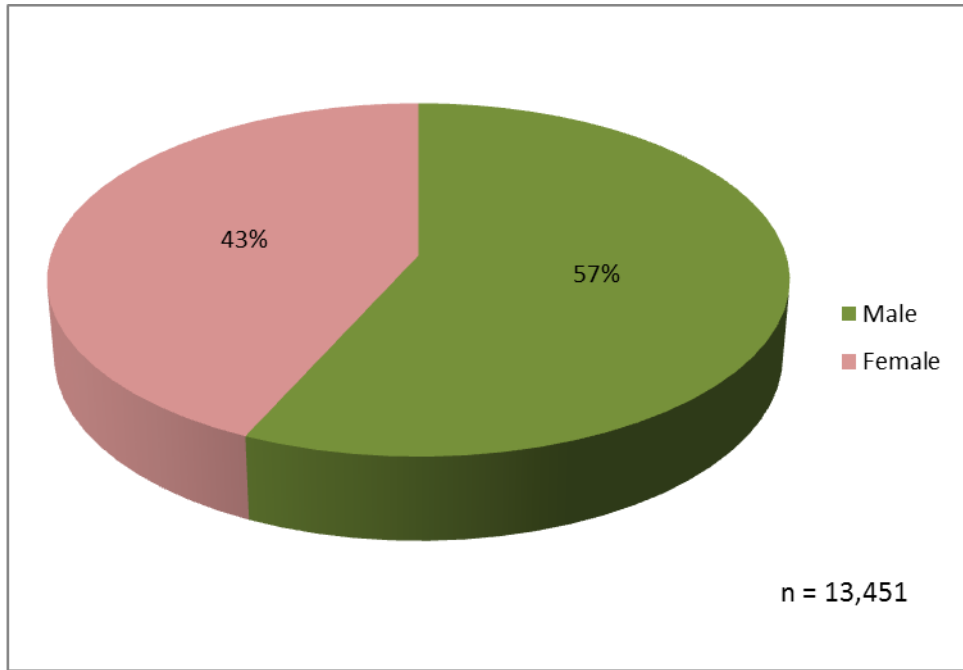


Figure 2.1 Gender distribution of adult patients with psoriasis

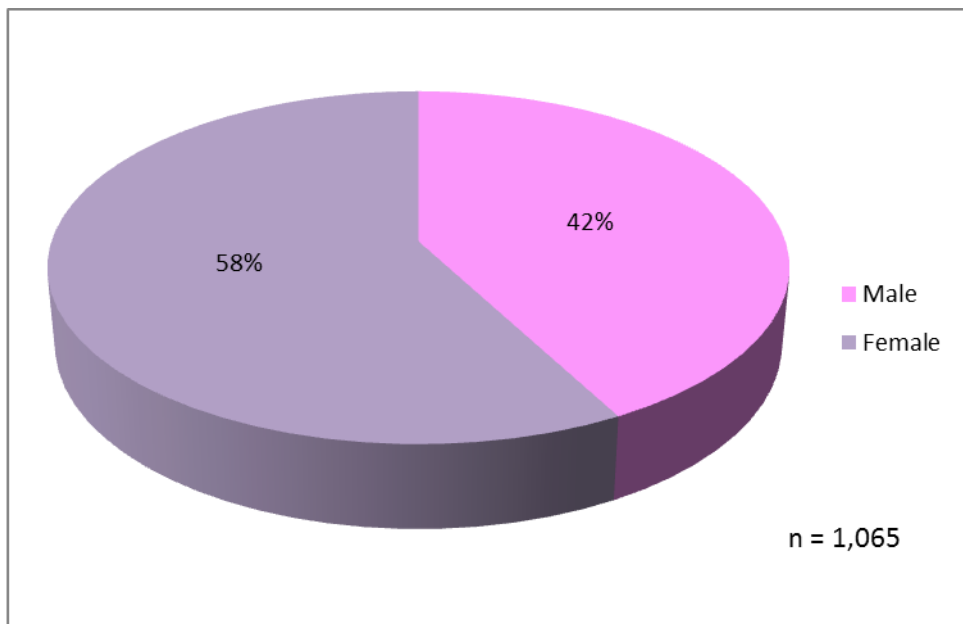


Figure 2.2 Gender distribution of paediatric patients with psoriasis

CHAPTER 3

MEDICAL HISTORY

Onset of Psoriasis

Psoriasis may first appear at any age. The mean age of onset in our cohort for adult patients was 35.02 ± 16.07 years with a wide range from 0 to 87 years. The mean age of onset was 10.03 ± 4.37 years in the paediatric population (0-17). In the adult population, the mean age at which psoriasis was first diagnosed was 37.41 ± 15.92 years. In the paediatric category, the mean age at which psoriasis was first diagnosed was 11.28 ± 4.17 years (**Table 3.1, Table 3.2**).

Looking at the age of onset of psoriasis in adult patients, 2,930 patients had the onset of psoriasis between 21-30 years old, followed by 2,591 patients between 31-40 years old, and 2,228 between 41-50 years old (**Figure 3.1**).

In the paediatric group, 420 of patients had onset of psoriasis between 11-15 years old (**Figure 3.2**).

Table 3.1 Age of onset and age of diagnosis in adult patients with psoriasis

Age	n	Mean	Median	Std Dev	Min	Max
Age of onset	13065	35.02	33	16.07	0	87
Age of diagnosis	13005	37.41	36	15.92	0	92

Table 3.2 Age of onset and age of diagnosis in paediatric patients with psoriasis

Age	n	Mean	Median	Std Dev	Min	Max
Age of onset	1040	10.03	11	4.37	0	17
Age of diagnosis	1035	11.28	12	4.17	0	17

Figure 3.1 Age of onset of adult patients with psoriasis

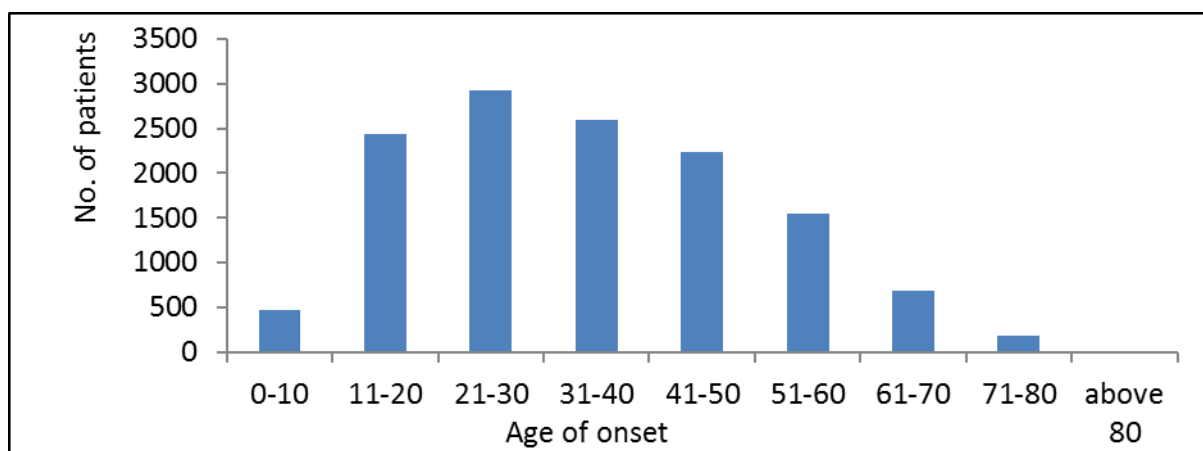
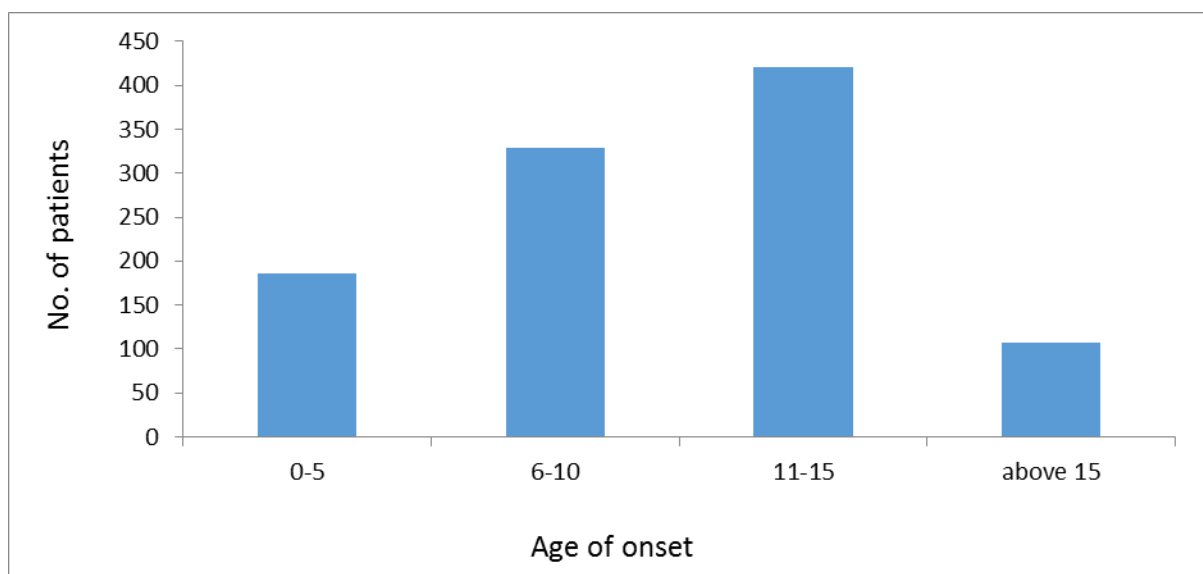


Figure 3.2 Age of onset of paediatric patients with psoriasis



Family History

Psoriasis is a skin disorder with a polygenic mode of inheritance. In our registry, about one-fifth (23.5%) of adult patients had at least one family member with psoriasis (**Table 3.3**). Of those with a positive family history, 41.1% had either of their parents affected. Siblings were affected in 36.4% and children in 11.5% (**Table 3.4, Figure 3.3**).

In the paediatric patients with psoriasis, 225 or 21.4% of them had at least one family member with psoriasis (**Table 3.3**). Of these, 35.6% had either parents affected with psoriasis. (**Table 3.4, Figure 3.4**)

Table 3.3 Positive family history of psoriasis in adult and paediatric patients

Characteristics	Adult		Paediatric	
	n	%	n	%
Yes	3104	23.1	225	21.1
No	10111	75.2	830	77.9
Not available	236	1.8	10	0.9
Total	13451	100	1065	100

Table 3.4 Family members with psoriasis in adult and paediatric patients

Family member (one or multiple)	Adult		Paediatric	
	n	%	n	%
Father	808	26.0	46	20.4
Mother	468	15.1	34	15.1
Sibling(s)	1130	36.4	53	23.6
Children	356	11.5	0	0.0
Others	783	25.2	101	44.9

Figure 3.3 Distribution of family members with psoriasis in adult patients

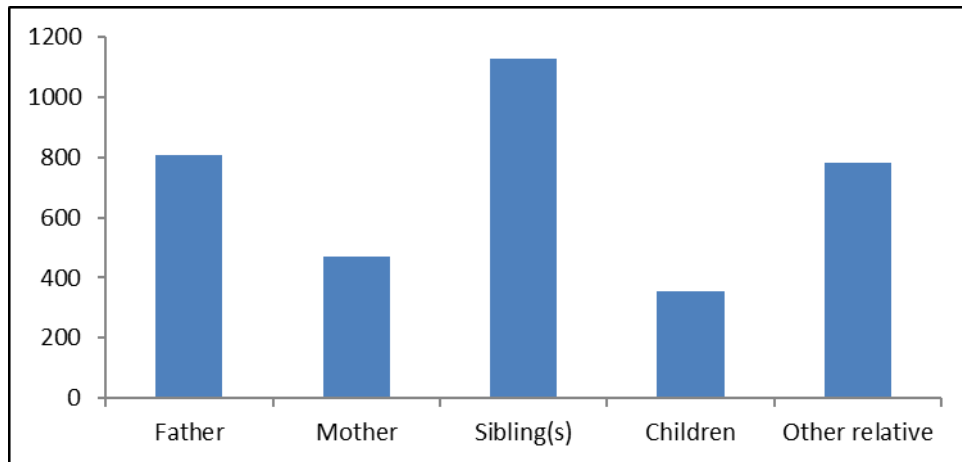
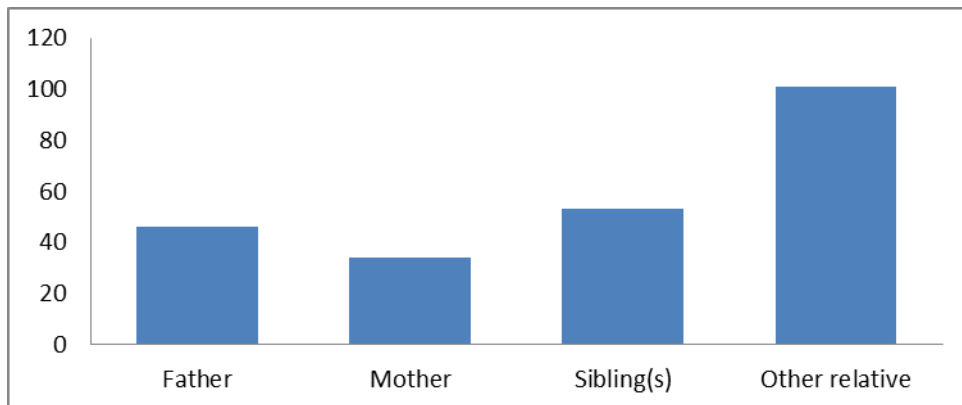


Figure 3.4 Distribution of family members with psoriasis in paediatric patients



Aggravating factors of psoriasis

More than half (52.4%) of adult patients with psoriasis reported one or multiple factors which worsened their psoriasis (**Table 3.5**). Stress was the commonest aggravating factor (66.4%), followed by sunlight (33.3%) and infection (13.7%). Other identified aggravating factors included smoking (8.0%), trauma (6.1%), drugs (4.1%), alcohol (3.3%), pregnancy (2.8%) and topical treatment (1.0%) (**Table 3.6**).

40.5% of paediatric patients, reported at least one factor that aggravated their psoriasis (**Table 3.5**). The most common aggravating factors reported in paediatric patients were stress (55.8%), sunburn (43.5%) and infection (18.4%) (**Table 3.7**).

Analyzing the subgroup of patients who reported infection as an aggravating factor, upper respiratory tract infection appeared to be the commonest infective trigger (12.6% in adult; 9.0% in paediatric patients) (**Table 3.7**). Common medications found to aggravate psoriasis were beta blocker (29.4%), withdrawal of systemic steroids (13.3%), traditional medication/homeopathy (10.8%), antibiotics (6.8%), non-steroidal anti-inflammatory drugs (6.5%), and ACE inhibitor (2.2%) (**Table 3.8**).

Table 3.5 Aggravating factors of psoriasis in adult and paediatric patients

Characteristics	Adult		Paediatric	
	n	%	n	%
Yes	6801	50.6	425	39.9
No	6188	46.0	624	58.6
Not available	462	3.4	16	1.5
Total	13451	100	1065	100

Table 3.6 Proportion of aggravating factors for psoriasis in adult and paediatric patients

Aggravating factors (one or multiple)	Adult		Paediatric	
	n	%	n	%
Stress	4519	66.4	237	55.8
Sunlight	2268	33.3	185	43.5
Infection	934	13.7	78	18.4
Smoking	546	8.0	8	1.9
Trauma	413	6.1	33	7.8
Drugs	279	4.1	4	0.9
Alcohol	225	3.3	0	0.0
Pregnancy	189	2.8	0	0.0
Topical treatment	67	1.0	5	1.2

Table 3.7 Infections which aggravated psoriasis in adult patients

Infection	Adult		Paediatric	
	n	%	n	%
Upper respiratory tract infection	118	12.6	7	9.0
Fever / febrile illness	55	5.9	3	3.8
Skin infection	14	1.5	0	0.0
Viral infection	11	1.2	0	0.0
Dengue fever	9	1.0	2	2.6
Chickenpox	9	1.0	3	3.8
HIV	3	0.3	1	1.3
Hepatitis C	2	0.2	0	0.0
Pneumonia	2	0.2	0	0.0
Chikugunya	2	0.2	0	0.0

Table 3.8 Drugs which aggravated psoriasis in adult and paediatric patients

Drug	Adult		Paediatric	
	n	%	n	%
Beta-blocker	82	29.4	1	25.0
Systemic steroids (withdrawal)	37	13.3	1	25.0
Traditional/ Homeopathy	30	10.8	2	50.0
Antibiotic	19	6.8	2	50.0
NSAIDs /analgesia	18	6.5	1	25.0
Other anti-hypertensive	6	2.2	0	0.0
ACE inhibitor	5	1.8	0	0.0
Oral contraceptive pill	4	1.4	0	0.0
Topical tar preparation	2	0.7	0	0.0
Daivobet	2	0.7	1	25.0
Statins	2	0.7	1	25.0
Sodium valporate	1	0.4	0	0.0
Biologic	1	0.4	0	0.0
HAART	1	0.4	0	0.0
Antimalarial drug	1	0.4	0	0.0
Anti-platelet	1	0.4	0	0.0
Oral hypoglycaemic agents	1	0.4	0	0.0
Others	14	3.4	0	0.0

Disease Burden in the last 6 months:

Analysis of daily activities among adult psoriasis patients showed that 92.9% of them could perform their routine activities regularly. 7.1% of the population reportedly had to take off from work/school from anywhere between 1- 90 days due to psoriasis (**Table 3.9**). 74.7% of adult patients with psoriasis visited the clinic between 1-5 times in the past 6 months (**Table 3.9**). 2.4% of adult patients were hospitalized at least once in the last 6 months, and the majority (97.6%) did not require any hospitalization (**Table 3.10**).

Analysis of daily activities among paediatric psoriasis patients showed that, 91.4% of them could perform their routine activities regularly. 8.6% of the population reportedly had to take off from work/school from anywhere between 1- 120 days due to psoriasis (**Table 3.11**). 76.1% of paediatric patients with psoriasis visited the clinic between 1-5 times in the past 6 months (**Table 3.11**). Only 2.2% of paediatric patients were hospitalized at least once in the last 6 months, and the majority (95.9%) did not require any hospitalization (**Table 3.12**).

Table 3.9 Number of days off from work/school and clinic visits in adult patients with psoriasis in the last 6 months

	Number of days off from work/school due to psoriasis		Number of clinic visits due to psoriasis	
	n	%	n	%
0	11407	92.9	2588	20.8
1-5	650	5.3	9309	74.7
6-10	120	1.0	461	3.7
>10	94	0.9	106	0.9

Table 3.10 Number of hospital admissions in adult patients with psoriasis in the last 6 months

Number of hospital admissions due to psoriasis	n	%
0	12128	97.6
1-3	273	2.2
>3	30	0.2

Table 3.11 Number of days off from work/school and clinic visits in paediatric patients with psoriasis in the last 6 months

	Number of days off to work/school due to psoriasis		Number of clinic visits due to psoriasis	
	n	%	n	%
0	920	91.4	197	19.5
1-5	57	5.7	770	76.1
6-10	13	1.3	40	4.0
>10	17	1.7	5	0.5

Table 3.12 Number of hospital admissions in paediatric patients with psoriasis in the last 6 months

Number of hospital admissions due to psoriasis	n	%
0	993	95.9
1-3	23	2.2
>3	19	1.8

Smoking

Data on smoking status was only available for 8,339 (57.4%) of patients. This was because the smoking status data was not collected in the earlier version of the Case Report Form. A total of 1,569 (20.1%) adult patients with psoriasis were current smokers, while in paediatric population, it was 14 (2.6%) (**Table 3.13**).

Table 3.13 Cigarette smoking in adult and paediatric patients with psoriasis

Cigarette smoking	Adult		Paediatric	
	n	%	n	%
Never smoked	5194	66.5	514	96.8
Ex-smoker	1045	13.4	3	0.6
Current smoker	1569	20.1	14	2.6
Not available	5643	-	534	-
Total	13451	100	1065	100

CHAPTER 4

COMORBIDITIES

Patients with psoriasis were found to have a number of other concomitant diseases. As the spectrum of diseases differs among age groups, adult and paediatric patients were analysed separately.

In adult psoriasis patients aged 18 and above, 33.8% were overweight and 24.3% were obese, 27.2% had hypertension, 18.9% had hyperlipidaemia, 18.4% had diabetes mellitus, 5.8% had ischaemic heart disease and 1.6% had previous history of stroke (**Table 4.1**).

In children and adolescents aged below 18 years with psoriasis, the most prevalent comorbidity was overweight or obesity i.e. BMI at or above 85th centile (28.1 %), followed by bronchial asthma (2.3%), down syndrome (0.7%), kidney disorder (0.5%), thyroid disorder (0.5%) and blood disorder (0.4%). Other comorbid conditions were much less common (**Table 4.2**).

Compared to patients without arthritis, patients with psoriatic arthritis were found to have increased co-morbidities such as diabetes mellitus, hypertension, hyperlipidaemia and obesity ($p < 0.001$) (**Table 4.3**).

Table 4.1 Prevalence of co morbidities in adult patients with psoriasis

Co-morbidity	n	%
Overweight*	4099	33.8
Obesity*	2938	24.3
Hypertension	3659	27.2
Hyperlipidaemia	2546	18.9
Diabetes mellitus	2474	18.4
Ischaemic heart disease	778	5.8
Stroke	209	1.6

* BMI classification for adult Asians as stated in the Clinical Practice Guidelines on Management of Obesity 2004, Ministry of Health, Malaysia.

Table 4.2 Prevalence of comorbidities in paediatric patients with psoriasis

Comorbidity	N	%
Overweight or obesity (BMI \geq 85 th centile)	272	28.1
Bronchial asthma / Allergic Rhinitis	25	2.3
Down syndrome	7	0.7
Kidney Disorder	5	0.5
Thyroid	5	0.5
Blood Disorder	4	0.4
HIV	3	0.3
Nephrotic Syndrome / Liver Disorder	3	0.3
Schizophrenia	3	0.3
Congenital heart Disease	2	0.2
Hypertension	1	0.1
Others	3	0.3

Table 4.3 Co-morbidities associated with psoriatic arthritis in adult patients

Co-morbidities	Arthritis Present (n=1,847)		Arthritis Absent (n=11,395)		Simple Logistic Regression*		
	n	%	n	%	Crude OR	(95% CI)	P-value
Diabetes Mellitus	392	21.2	2038	17.9	1.25	1.11, 1.41	<0.001
Hypertension	611	33.1	2984	26.2	1.40	1.26, 1.56	<0.001
Hyperlipidaemia	464	25.1	2039	17.9	1.56	1.39, 1.75	<0.001
Ischaemic heart disease	111	6.0	656	5.8	1.05	0.86, 1.30	0.619
Cerebrovascular disease	24	1.3	184	1.6	0.81	0.53, 1.24	0.324
BMI \geq 30 (obesity WHO)	457	24.7	2387	21.0	1.26	1.12, 1.42	<0.001

*Result was based on available information

CHAPTER 5

CLINICAL PRESENTATION

Plaque psoriasis was the commonest type of psoriasis in both adult and paediatric population. In adult patients, plaque psoriasis accounted for 85.4% of patients, followed by guttate psoriasis in 3.2% of patients and erythrodermic in 1.7% of the patients. Similarly, in paediatric patients, plaque psoriasis accounted for 79.2% of patients, followed by guttate psoriasis in 7.2% of patients and flexural/inverse psoriasis in 0.8% of the patients. Other types of psoriasis were less common (**Table 5.1**).

Majority of our patients had mild to moderate body surface area involvement. In adult patients, 18.7% of our psoriatic patients had <5% and 5-10% of BSA affected, while 32.2% had 5-10% of BSA affected. Severe psoriasis with >10% BSA affected occurred in 17.1% adult patients, while 1.5% had erythrodermic psoriasis, i.e. >90% BSA involved. In paediatric patients population, 36.0% had <5% BSA involvement, 22.5% had 5-10% BSA involvement, 10.9% had 10-90% BSA and 0.6% were erythrodermic (**Table 5.2**).

Table 5.1 Distribution of psoriasis patients according to the type of psoriasis in adult and pediatric patients

BMI	Adult		Pediatric	
	n	%	n	%
Plaque	11493	85.4	843	79.2
Guttate	431	3.2	77	7.2
Pustular	145	1.1	16	1.5
Erythrodermic	234	1.7	9	0.8
Flexural/inverse	52	0.4	9	0.8
Palmoplantar non-pustular	43	0.3	2	0.2
Others	191	1.4	51	4.8
Not available	426	6.4	58	5.4
Total	13451	100	1065	100

Table 5.2 Distribution of percentage of body surface area affected in adult paediatric patients with psoriasis

Body surface area involved	Adult		Paediatric	
	n	%	n	%
<5%	2521	18.7	383	36.0
5 - 10%	4332	32.2	240	22.5
>10%	2301	17.1	116	10.9
Erythrodermic (>90%)	198	1.5	6	0.6
Not available	4099	30.5	320	30.0
Total	13451	100	1065	100

A composite clinical scoring system was used to evaluate the severity of psoriatic lesions in five body regions. A score of 0 to 3 was given for each body region according to the degree of erythema, thickness and scaliness of the skin lesions. The total clinical score may range from 0 to 15. Analysis on severity of lesion of adult patients with psoriasis noted that most of the moderate to severe lesions (score 2 and 3) were located on the lower limbs (34.4%), trunk (30.5%) and upper limbs (27.0%) (**Table 5.3**). Whereas in paediatric patients, moderate and severe lesions were seen mainly on the scalp region (33.2%), followed by the trunk (25.5%) (**Table 5.4**).

Almost half of the adult (49.4%) and paediatric (48.1%) psoriatic patients did not have any lesion on the face and neck. If present, lesions on face and neck were generally less severe (score 1 or 2) (**Table 5.3, Table 5.4**).

Table 5.3 Distribution of severity of body part affected in adult patients with psoriasis

Body part	Clinical score									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	2789	20.8	6768	50.4	2789	20.8	536	4.0	544	4.1
Face & neck	6620	49.4	5207	38.8	875	6.5	93	0.7	609	4.5
Trunk	3470	25.9	5255	39.2	3560	26.5	531	4.0	597	4.5
Upper limbs	3064	22.8	6144	45.8	3210	23.9	410	3.1	592	4.4
Lower limbs	2478	18.5	5727	42.7	3950	29.4	665	5.0	604	4.5

Table 5.4 Distribution of severity of body part affected in paediatric patients with psoriasis

Body part	Clinical score									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	166	15.6	504	47.3	275	25.8	79	7.4	41	3.8
Face & neck	512	48.1	408	38.3	86	8.1	8	0.8	51	4.8
Trunk	361	33.9	388	36.4	242	22.7	30	2.8	44	4.1
Upper limbs	388	36.4	422	39.6	179	16.8	26	2.4	50	4.5
Lower limbs	379	35.6	408	38.3	204	19.2	26	2.4	48	4.5

Majority of adult patients with psoriasis had nail involvement (58.2%) (**Table 5.5**). Among patients who had psoriatic nail disease, most of them had pitting (73.2%). Other common features were onycholysis (48.2%), discoloration (31.4%) and subungual hyperkeratosis (13.5%). Total nail dystrophy was found in 4.6% of patients with nail involvement (**Table 5.6**).

There were 384 (36.1%) paediatric patients with nail involvement (**Table 5.5**). Most of them had pitting (89.3%), followed by onycholysis (26.0%), discoloration (11.5%) and subungual hyperkeratosis (3.9%) and total nail dystrophy (2.3%) (**Table 5.6**).

Joint disease related to psoriasis was reported in 13.7% of the adult patients, while only 1.6% paediatric patients had joint involvement (**Table 5.7**). 355 adult patients had test for Rheumatic factor. Of these, only 2.1% was positive (**Table 5.8**).

In adult patients, the commonest type of psoriatic arthropathy was oligo-/monoarthropathy (39.0%). This was followed by distal hand joints arthropathy (31.2%), rheumatoid-like symmetrical polyarthropathy (30.3%), spondylitis/sacroilitis (8.0%) and arthritis mutilans (3.0%) (**Table 5.9**). Morning stiffness of > 30 minutes was reported in 31.2% of adult and 11.8% of paediatric patients. Enthesopathy was reported in 14.2% of adult patients and 5.9% of paediatric patients.

Table 5.5 Distribution of nail involvement in adult and paediatric patients with psoriasis

Nail involvement	Adult		Paediatric	
	n	%	n	%
Yes	7824	58.2	384	36.1
No	5259	39.1	657	61.7
NA	368	2.7	24	2.3
Total	13451	100	1065	100

Table 5.6 Distribution of nail features in adult and paediatric patients with psoriasis

Nail features	Adult		Paediatric	
	n	%	n	%
Pitting	5730	73.2	343	89.3
Onycholysis	3772	48.2	100	26.0
Discoloration	2457	31.4	44	11.5
Subungual hyperkeratosis	1054	13.5	15	3.9
Total nail dystrophy	361	4.6	9	2.3

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

Joint disease	Adult		Paediatric	
	n	%	n	%
Yes	1842	13.7	17	1.6
No	11225	83.5	1018	95.6
Not available	384	2.9	24	2.8
Total	13451	100	1065	100

Table 5.8 Rheumatoid factor in adult and paediatric patients with psoriasis

Rheumatoid factor	Adult		Paediatric	
	n	%	n	%
Positive	39	2.1	0	0.0
Negative	316	17.2	1	5.9

Table 5.9 Distribution of type of joint disease in adult and paediatric patients with psoriasis

Type of joint disease (one or multiple)	Adult		Paediatric	
	n	%	n	%
Oligo-/Monoarthropathy	719	39.0	9	52.9
Distal hand joints arthropathy	574	31.2	5	29.4
Symmetrical polyarthropathy (Rheumatoid like)	559	30.3	3	17.6
Spondylitis / Sacroiliitis	148	8.0	1	5.9
Arthritis mutilans	55	3.0	0	0.0

Most of the patients with psoriatic arthropathy experienced joint pain at time of presentation both in adult (76.6%) and paediatric (70.6%) patients. Joint swelling was present in 31.5% adults and 27.3% of paediatric patients, while joint deformity occurred in 23.8% of adult patients and 11.8% of paediatric patients (**Table 5.10, Table 5.11**). The commonest type of joint deformity was swan neck deformity (19.3%). This was followed by fixed flexion deformity (13.5%), boutonniere deformity (6.3%), proximal interphalangeal joint deformity (5.6%), Distal hand joint deformity (3.7%), rheumatoid arthritis-like (2.6%), arthritis mutilans (2.1%), bamboo spine (1.9%), subluxation (1.6%) and dactylitis (0.7%) (**Table 5.12**).

Table 5.10 Symptoms of psoriatic arthritis in adult patients with psoriasis

Symptoms	Yes		No		Not available	
	n	%	n	%	n	%
Pain	1411	76.6	349	18.9	22	1.1
Swelling	580	31.5	1175	63.8	19	1.0
Deformity	429	23.3	1312	71.2	26	1.4

Table 5.11 Symptoms of psoriatic arthritis in paediatric patients with psoriasis

Symptoms	Yes		No		Not available	
	n	%	n	%	n	%
Pain	12	70.6	3	17.6	1	5.9
Swelling	2	11.8	13	76.5	1	5.9
Deformity	3	17.6	12	70.6	1	5.9

Table 5.12 Distribution of type of joint deformities in adult patients with psoriasis

Type of joint deformity	n	%
Swan neck deformity	83	19.3
Fixed flexion	58	13.5
Boutonniere deformity	27	6.3
Proximal interphalangeal joint deformity	24	5.6
Distal hand joint deformity	16	3.7
Rheumatoid arthritis-like	11	2.6
Arthritis mutilans	9	2.1
Bamboo spine	8	1.9
Subluxation	7	1.6
Dactylitis	3	0.7
Others	51	11.9

By using multiple logistic regressions, 10 factors were found to be significantly associated with psoriatic arthritis in adults patients ($p < 0.05$). These were older patients (age > 40 years), younger age of onset (<40 years), longer duration of disease (>5 years), female gender, Indian ethnicity, BMI ≥ 30 , body surface area (BSA) >10, total skin score > 10, presence of nail involvement and DLQI > 10 (**Table 5.13**).

Table 5.13 Factors associated with psoriatic arthritis in adult patients

Variable	Arthritis Present (n=1,847)		Arthritis Absent (n=11,395)		Multiple Logistic Regression ^a		
	n	%	n	%	Adj. OR	(95% CI)	P-value
Age:							<0.001
17-40 years	585	31.7	4777	41.9		1.00 (ref.)	
41-60 years	949	51.4	4382	38.5	1.69	1.36, 2.11	<0.001
>60 years	313	17.0	2236	19.6	1.51	1.11, 2.06	0.010
Age of onset:							
≤40 years (Type 1)	1218	65.9	7206	63.2	1.27	1.01, 1.60	0.041
>40 years (Type 2)	582	31.5	3978	34.9		1.00 (ref.)	
Duration of disease:							
≤5 years	515	27.9	4808	42.2		1.00 (ref.)	
>5 years	1285	69.6	6376	56.0	1.47	1.19, 1.81	<0.001
Gender:							
Male	892	48.3	6587	57.8		1.00 (ref.)	
Female	955	51.7	4808	42.2	1.73	1.46, 2.06	<0.001
Ethnicity:							
Indian	427	23.1	1940	17.0	1.64	1.34, 2.01	<0.001
Non-Indian	1420	76.9	9452	83.0		1.00 (ref.)	
Obesity group (WHO):							
BMI <30	1225	66.3	8072	70.8		1.00 (ref.)	
BMI ≥ 30	457	24.7	2,387	21.0	1.22	1.01, 1.48	0.044

Type of psoriasis:							
Erythrodermic	48	2.6	181	1.6			NS
Non-erythrodermic	1700	92.0	10668	93.6			
Body surface area:							
≤10%	913	49.4	6200	54.4		1.00 (ref.)	
>10%	427	23.1	1844	16.2	1.31	1.07, 1.60	0.009
Total skin score:							
<10	1624	87.9	10516	92.3		1.00 (ref.)	
≥10	181	9.8	688	6.0	1.70	1.23, 2.35	0.001
Nail involvement:							
Absence	455	24.6	4871	42.8		1.00 (ref.)	
Presence	1356	73.4	6468	56.8	2.22	1.83, 2.70	<0.001
DLQI:							
≤10	670	36.3	4068	35.7		1.00 (ref.)	
>10	395	21.4	1900	16.7	1.28	1.06, 1.53	0.009

(Total N=14,516, but missing joint disease category of 414 cases)

*Result was based on available information.

Adj. OR = Adjusted odds ratio; ref. = Reference; NS = Not significant

^a Forward LR was applied.

Multicollinearity was checked and not found.

Hosmer-Lemeshow test ($P=0.298$), classification table (overall correctly classified percentage=85.2%) and area under the ROC curve (67.2%) were applied to check the model fitness.

CHAPTER 6

TREATMENTS

Types of treatment received by the patients for psoriasis in the last six months were analysed.

Most adult patients with psoriasis used some form of topical medications for psoriasis (94.9%) (**Table 6.1**). In 70.2% of the patients, topical monotherapy was the only treatment given. The most commonly used topical medication was topical steroids (83.0%). This was followed by topical tar preparation (70.2%), emollients (73.8%), keratolytics (52.5%) and vitamin D analogue such as calcipotriol (13.3%) and calcipotriol with betamethasone dipropionate (12.9%). Dithranol was less favoured and used in 1.8% of patients only (**Table 6.2**).

In the paediatric patients, 93.2% of patients received topical therapy (**Table 6.1**). The most common type of topical therapy was topical steroids (75.5%), followed by tar preparation (66.9%) and emollient (63.8%) (**Table 6.2**).

Table 6.1 Use of topical therapy in adult and paediatric patients with psoriasis

Topical therapy	Adult		Paediatric	
	n	%	n	%
Yes	12766	94.9	993	93.2
No	215	1.6	32	3.0
Not available	470	3.05	40	3.8
Total	13451	100	1065	100

Table 6.2 Types of topical therapy used in adult and paediatric patients with psoriasis

Topical therapy	Adult		Paediatric	
	n	%	n	%
Topical steroids	11169	83.0	804	75.5
Tar preparation	9437	70.2	712	66.9
Emollient	9929	73.8	680	63.8
Keratolytics	7057	52.5	478	44.9
Vitamin D analogues	2339	13.1	159	14.9
Calcipotriol with betamethasone dipropionate	1734	12.9	96	9.0
Dithranol (anthralin)	242	1.8	29	2.7
Others	209	1.6	23	2.2

In the last six months prior to notification, 3.2% of adult patients and 1.5% of paediatric patients received phototherapy (**Table 6.3**).

Most of adult patients (86.5%) and paediatric patients (81.3%) were given narrowband UVB (NB-UVB) while 5.0% of adult patients with psoriasis were given broadband UVB (BB-UVB). Less popular modalities in adult patients were oral PUVA (2.7%), topical PUVA (2.3%), bath PUVA (2.5%) and excimer laser (0.2%). 12.5% of paediatric patients were given topical PUVA (**Table 6.4**).

Table 6.3 Use of phototherapy in adult and paediatric patients with psoriasis

Phototherapy	Adult		Paediatric	
	n	%	n	%
Yes	437	3.2	15	1.5
No	12325	91.6	992	93.1
Not available	689	5.1	57	5.4
Total	13451	100	1065	100

Table 6.4 Types of phototherapy in adult and paediatric patients with psoriasis

Types of Phototherapy	Adult		Paediatric	
	n	%	n	%
Narrowband UVB	378	86.5	13	81.3
Broadband UVB	22	5.0	1	6.3
Oral PUVA	12	2.7	0	0.0
Bath PUVA	11	2.5	1	6.3
Topical PUVA	10	2.3	2	12.5
Excimer laser	1	0.2	0	0.0
Others	13	3.0	2	12.5

Systemic therapy was used in 18.8% of adult patients and only 5.4% in paediatric patients with psoriasis (**Table 6.5**).

In adult patients, the commonest systemic agents used were methotrexate (73.0%), followed by acitretin (18.3%) and sulphasalazine (5.8%). Other systemic agents such as cyclosporin, hydroxyurea and biologics were used less frequently in adult patients with psoriasis (**Table 6.6**).

In paediatric patients, similarly to adult patients, methotrexate was the commonest systemic agent used (52.6%). This was followed by acitretin in 35.1% of patients (**Table 6.6**).

A total of 82 adult patients was reported to receive biologic treatment. The biologic therapy most frequently used was adalimumab (33 patients), followed by ustekinumab (28 patients), etanercept (17 patients), infliximab (10 patients), efalizumab (4 patients) and golimumab (3 patients). The name of the biologic agent was not specified in 10 patients. Some patients had more than one biologic agent given.

Table 6.5 Use of systemic therapy in adult and paediatric patients with psoriasis

Systemic therapy	Adult		Paediatric	
	n	%	n	%
Yes	2530	18.8	57	5.4
No	10350	76.9	952	89.4
Not available	571	4.2	56	5.3
Total	13451	100	1065	100

Table 6.6 Types of systemic therapy in adult and paediatric patients with psoriasis

Types of systemic therapy	Adult		Paediatric	
	n	%	n	%
Methotrexate	1848	73.0	30	52.6
Acitretin	463	18.3	20	35.1
Sulphasalazine	147	5.8	1	1.8
Cyclosporin	106	4.2	1	1.8
Hydroxyurea	16	0.6	0	0.0
Biologics	77	3.0	0	0.0
Systemic corticosteroids	100	4.0	6	1.5
Others	68	2.7	2	3.5

CHAPTER 7

QUALITY OF LIFE

There were a total of 7,208 adult patients (aged 17 and above) and 395 paediatric patients (aged 5 to 16) who 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 8.5 ± 6.5 , and the mean CDLQI for paediatric patients was 7.8 ± 5.5 .

The responses for each question of the DLQI and CDLQI were tabulated in **Table 7.1** and **7.2** respectively. 2,329 (32.9%) of adult patients reported DLQI > 10, indicating severe quality of life impairment due to psoriasis or its treatment. There were 421 adults (5.8%) who had a DLQI > 20 indicating extremely large effect on their quality of life by psoriasis. Nevertheless, 13.3% 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 category most affected by psoriasis in adult patients. 38.8% of patients were affected very much or a lot by the itch and pain as well as embarrassment due to psoriasis. The aspect of life least affected by psoriasis was “personal relationship” in which 72.2% of the adult patients did not have or only have a little effect in this aspect.

In the paediatric group, 20.0% of patients reported a CDLQI of more than 12 indicating very large or extremely large effect on quality of life (**Figure 7.3**). There were 16 patients (4.1%) who had CDLQI of more than 19, reflecting extremely large effect of quality of life. On the other hand, 11.6% paediatric patients reported no effect at all on their quality of life.

In paediatric patients, the category of CDLQI most affected was “symptoms and feelings”. 39.5% of paediatric reported that psoriasis affected very much or a lot in the symptoms and feelings domain. The aspect of life least affected by psoriasis was “personal relationship” in which 86.1% of the children did not have or only have a little effect (**Figure 7.4**). These results are similar to that of the adult patients.

Patients with psoriatic arthritis were also noted to have poorer quality of life, with a DLQI > 10. They also have more clinic visits, more days off work and more hospital admissions (**Table 7.3**).

Table 7.1 Responses for DLQI in adult patients with psoriasis (age 17 and above)

No.	DLQI Question	n (%)				
		Very much	A lot	A little	Not at all	Not relevant
1	Over the last week, how itchy, sore, painful, or stinging has your skin been?	1356 (10.3)	3701 (28.0)	6790 (51.4)	1358 (10.3)	0 (0.0)
2	Over the last week, how embarrassed or self-conscious have you been because of your skin?	1995 (15.1)	3175 (24.1)	4841 (36.7)	3170 (24.0)	0.0 (0.0)
3	Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?	1148 (8.7)	2498 (18.9)	4557 (34.5)	4613 (34.9)	396 (3.0)
4	Over the last week, how much has your skin influenced the clothes you wear?	1043 (7.9)	2429 (18.4)	4606 (34.9)	4720 (35.7)	408 (3.1)
5	Over the last week, how much has your skin affected any social or leisure activities?	1193 (9.0)	2587 (19.6)	4403 (33.3)	4646 (35.2)	379 (2.9)
6	Over the last week, how much has your skin made it difficult for you to do any sport?	1236 (9.4)	2337 (17.8)	3820 (29.1)	4133 (31.4)	1623 (12.3)
7	Over the last week, has your skin prevented you from working or studying?	989 (11.1)	2908 (32.9)	5029 (56.3)	0 (0.0)	0 (0.0)
8	Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?	633 (4.8)	1627 (12.3)	4010 (30.4)	6365 (48.3)	554 (4.2)
9	Over the last week, how much has your skin caused sexual difficulties?	414 (3.2)	788 (6.0)	2256 (17.2)	6337 (48.4)	3305 (25.2)
10	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?	831 (6.3)	2063 (15.6)	4505 (34.1)	5124 (38.8)	676 (5.1)

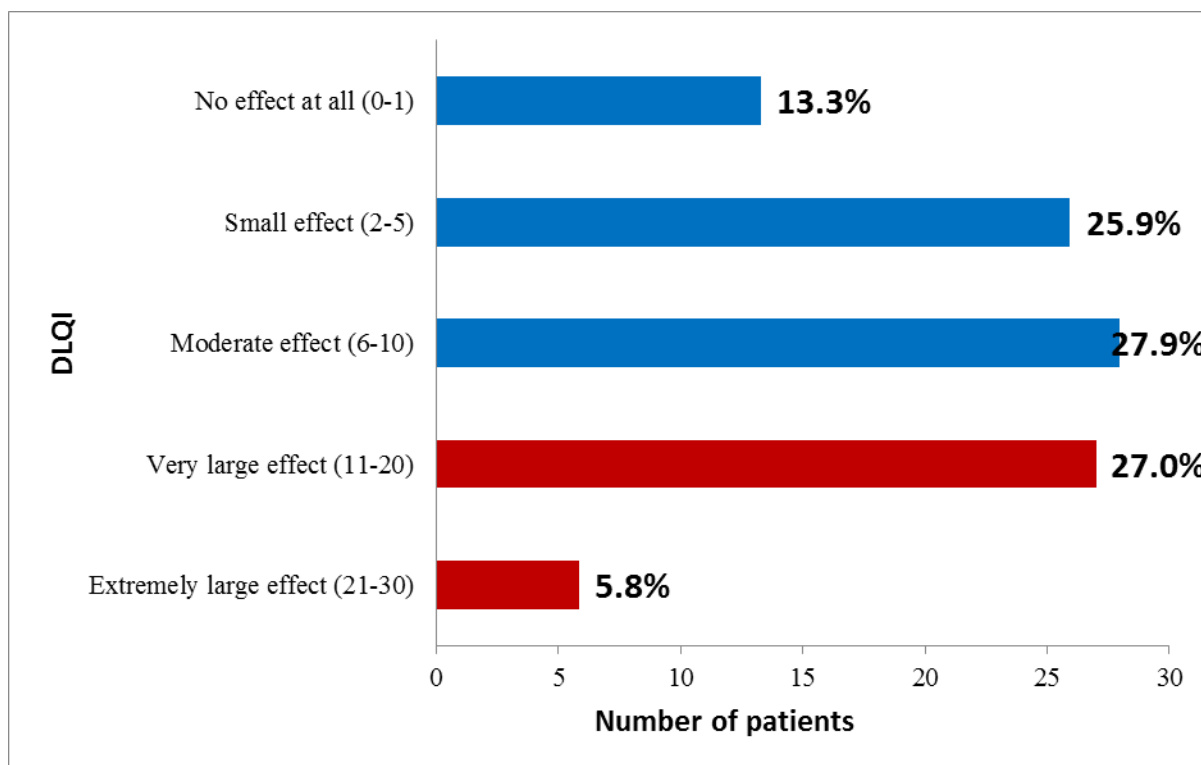


Figure 7.1 Quality of life in adult patients with psoriasis

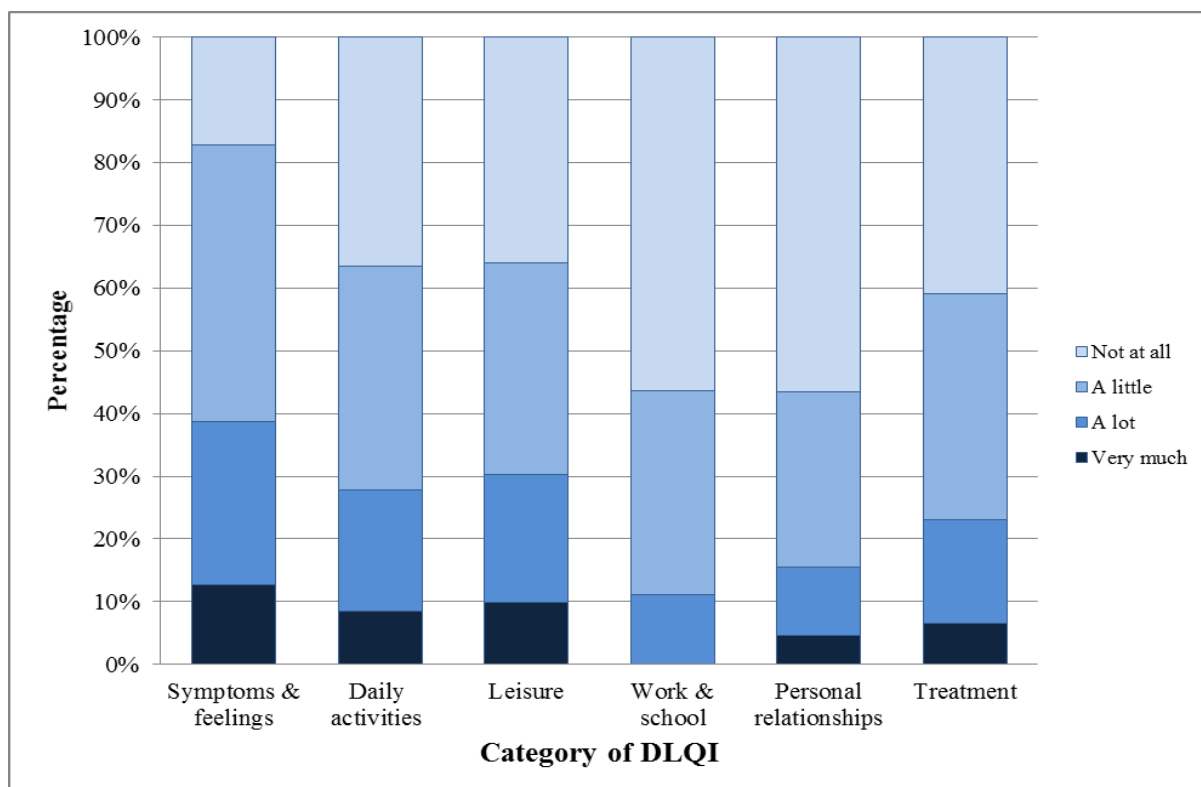


Figure 7.2 Quality of life impairment in adults psoriasis patients based on category of DLQI

Table 7.2 Responses for CDLQI in paediatric psoriasis patients (aged 5 to 16)

No.	CDLQI Question	n (%)				
		Very much	A lot	A little	Not at all	Not relevant
1	Over the last week, how itchy, “scratchy”, sore, painful, or stinging has your skin been?	67 (8.1)	257 (31.1)	427 (51.6)	76 (9.2)	
2	Over the last week, how embarrassed or self-conscious have you been because of your skin?	133 (16.2)	194 (23.6)	331 (40.2)	165 (20.0)	
3	Over the last week, how much has your skin affected your friendships?	32 (3.9)	111 (13.6)	254 (31.2)	417 (51.2)	
4	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	39 (4.8)	116 (18.2)	238 (35.4)	265 (41.6)	
5	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	53 (6.5)	125 (15.4)	234 (28.9)	399 (42.9)	
6	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	59 (7.2)	125 (15.3)	234 (28.6)	399 (48.8)	
7	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?	37 (4.6)	109 (13.5)	277 (34.2)	386 (47.7)	
8	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?	36 (4.4)	80 (9.9)	215 (26.5)	481 (59.2)	
9	Over the last week, how much has your sleep been affected by your skin problem?	43 (5.7)	98 (12.9)	258 (34.1)	358 (47.3)	
10	Over the last week, how much of a problem has the treatment for your skin been?	34 (4.2)	122 (15.1)	286 (35.4)	367 (45.4)	

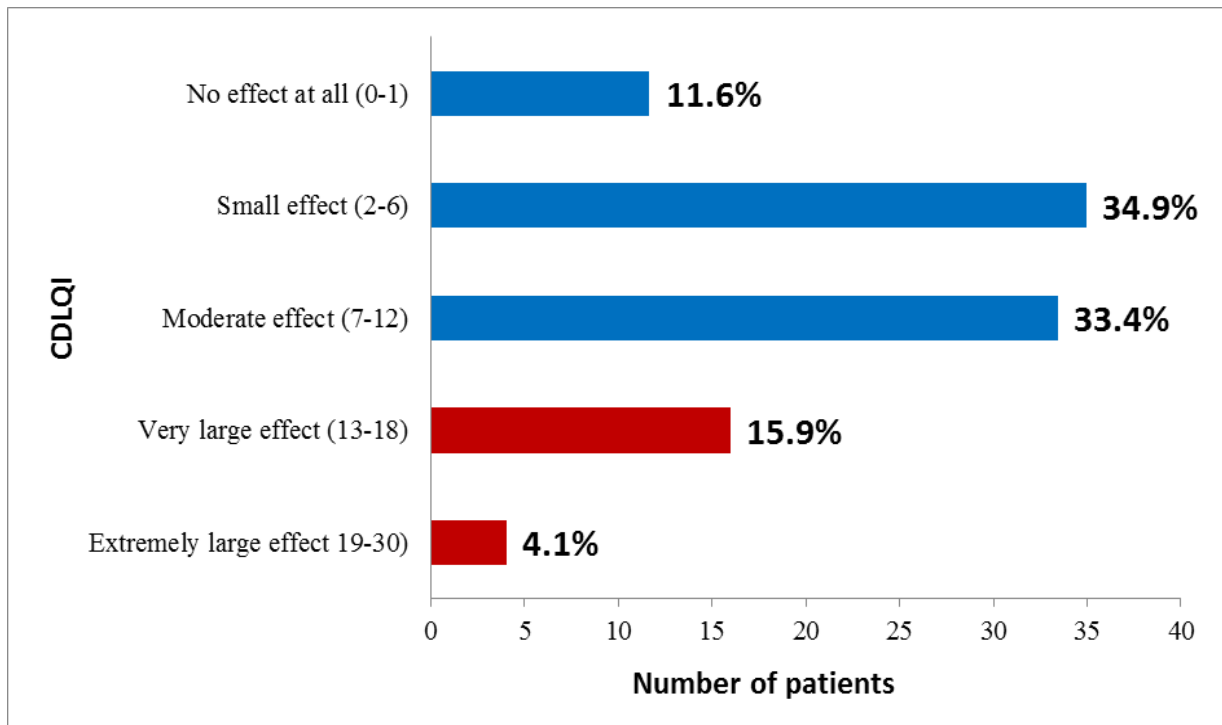


Figure 7.3 Quality of life in paediatric patients with psoriasis

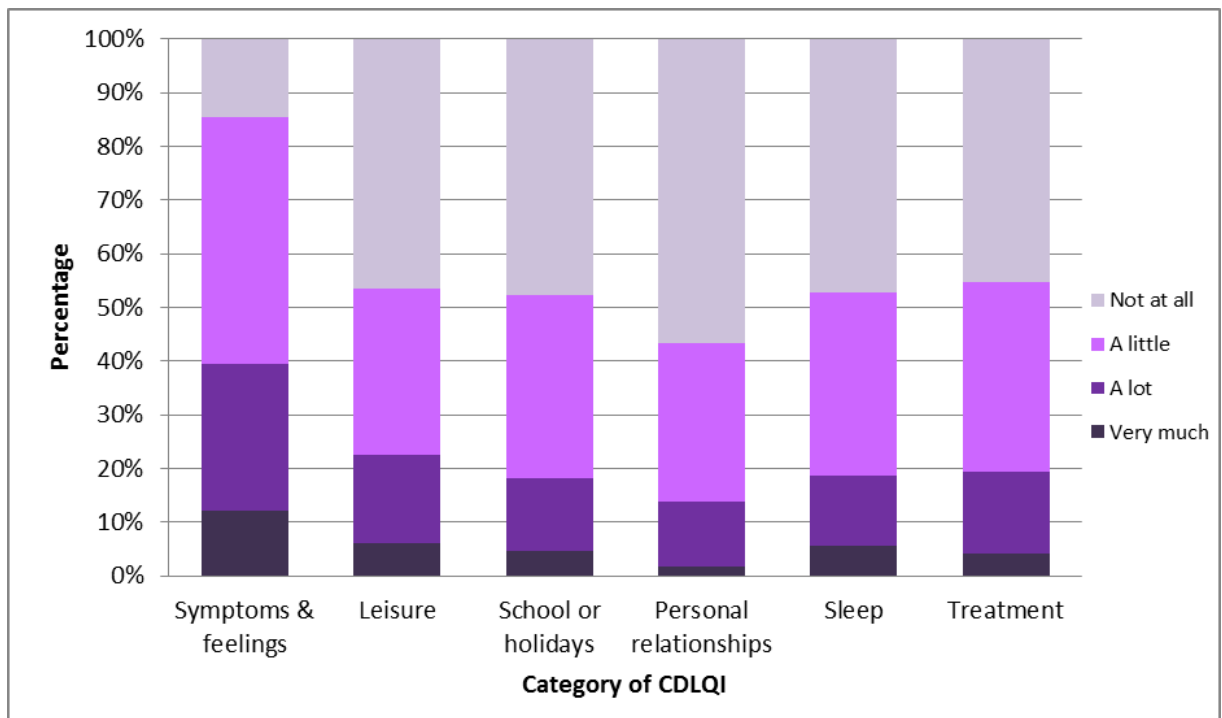


Figure 7.4 Quality of life impairment in paediatric patients with psoriasis based on category of DLQI

Table 7.3 Quality of life and productivity parameters observed in adult patients with psoriatic arthritis

Parameters	Arthritis Present (n=1,847)		Arthritis Absent (n=11,395)		Simple Logistic Regression**		
	n	%	n	%	Crude OR	(95% CI)	P-value
DLQI, mean (SD)	8.5 (6.49)						
≤10	670	36.3	4068	35.7		1.00 (ref.)	
>10	395	21.4	1900	16.7	1.26	1.10, 1.45	0.001
No. of clinic visit*, median (IQR)	2.0 (1.0)						<0.001
0 time	321	17.4	2240	19.7		1.00 (ref.)	
1-2 times	959	51.9	6169	54.1	1.09	0.95, 1.24	0.238
3-10 times	428	23.2	2202	19.3	1.36	1.16, 1.59	<0.001
11-48 times	22	1.2	79	0.7	1.94	1.19, 3.16	0.007
No. of days off work*, median (IQR)	0.0 (0.0)						<0.001
0 day	1502	81.3	9877	86.7		1.00 (ref.)	
1-3 days	107	5.8	457	4.0	1.54	1.24, 1.91	<0.001
4-10 days	55	3.0	149	1.3	2.43	1.77, 3.32	<0.001
11-90 days	38	2.1	67	0.6	3.73	2.50, 5.57	<0.001
No. of hospital admissions*, median (IQR)	0.0 (0.0)						<0.001
0 time	1645	89.1	10453	91.7		1.00 (ref.)	
1-2 times	69	3.7	188	1.7	2.33	1.76, 3.09	<0.001
3-15 times	14	0.8	24	0.2	3.71	1.91, 7.18	<0.001

*Over a 6-month period.

IQR = 75th – 25th percentile.

**Result was based on available information.

CHAPTER 8

OUTCOMES

In this registry, follow-up data were collected approximately every 6 months. Outcomes of patients were assessed by measuring the change in several clinical parameters between the last follow-up visit and the visit at registration. Severity of psoriasis skin lesions were assessed in terms of the extent of lesions, i.e. percentage of body surface area involvement, and lesional characteristics via clinical skin scoring method for each of the five body regions. Other clinical parameters monitored include severity of joint pain on a visual analogue score (0-10), and quality of life using Dermatology Life Quality Index (DLQI).

A total of 4,968 follow-up data were available from 14,516 patients notified to the MPR. From a total of 13,451 adult patients with psoriasis registered in MPR, follow-up data were obtained in 4,695 patients. In paediatric cases, follow-up data were obtained in 213 patients. The mean duration of follow-up was 39.4 ± 28.35 months, with the longest duration of 99 months (**Table 8.1**).

Extent of Psoriasis Lesions

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 2,865 patients were evaluated for change in the extent of lesions. Of these patients, 590 patients (25.0%) had improvement by at least one scale, among which 196 (6.8%) had improvement by two scales, and 15 patients improved from BSA>90% to BSA<2%. No improvement was found in 1,421 patients (49.6%), and 518 patients (18.1%) had worsening by at least one scale (**Figure 8.1**).

Clinical Skin Scores

Clinical skin scores measures the thickness, erythema and scaliness of the psoriasis lesions in each of the five body regions. A score of 0 to 3 is given for each body region. Total Clinical Skin Score is the total of the scores in all five body regions. 358 patients (7.6%) had the most marked improvement in skin scores by 75% or more, and 764 patients (16.2%) had improvement by 50-75%, while 793 patients (16.8%) had 25-50% improvement. 444 patients (9.4%) had modest improvement of less than 25%. No improvement of skin scores were detected in 809 patients (17.1%). Skin scores worsened in 1,560 patients (33.0%) (**Figure 8.2**).

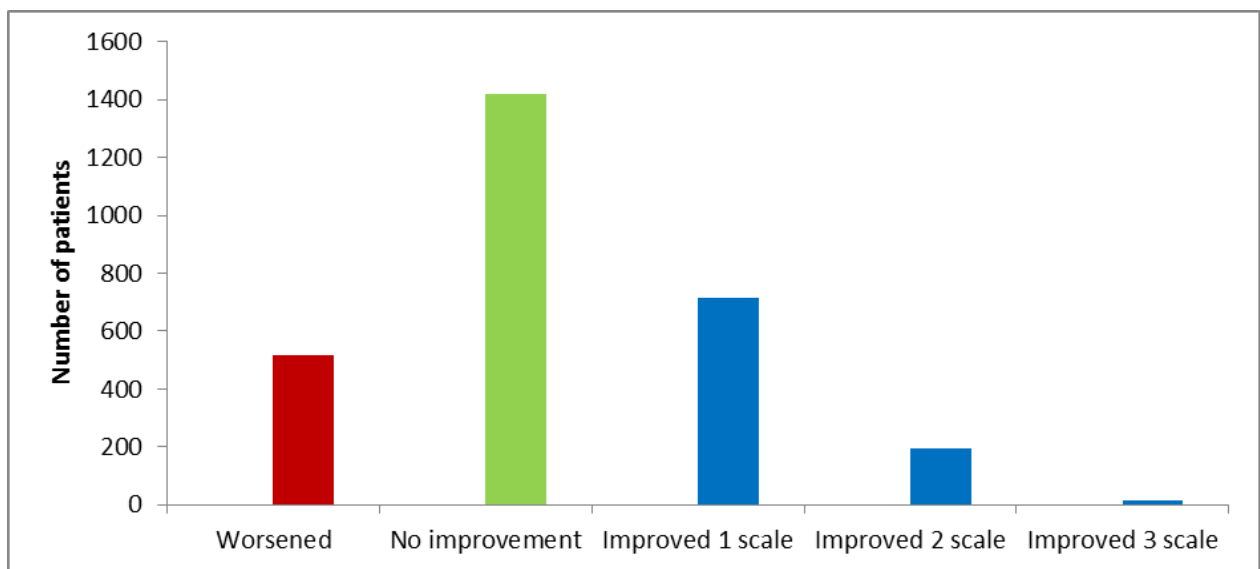
Joint Pain

From a total of 204 patients who reported to have joint pain, 87 patients (42.6%) had improvement in joint pain as measured by the visual analogue scale. Of these patients, 26 patients (12.7%) had improvement of between 50% and 75%, 13 patients (6.4%) had improvement of more than 75%, 36 patients (17.6%) had improvement of between 25% and 50%, and 12 patients (5.9%) had improvement of less than 25%. There was no improvement of joint pain in 456 patients (22.5%), while joint pain worsened in 71 patients (34.8%) (**Figure 8.3**).

Table 8.1 Distribution of psoriasis patients according to the duration of follow-up

Duration of follow-up	n	%
0 to 6 months	420	8.5
7 to 12 months	710	14.3
13 to 18 months	571	11.5
19 to 24 months	440	8.9
25 to 30 months	331	6.7
31 to 36	273	5.5
>36	2223	44.8
	4968	100.0

Mean duration of follow-up: 39.4 ± 28.35 months (range 0 – 99 months)

**Figure 8.1** Improvement in the extent of skin lesions

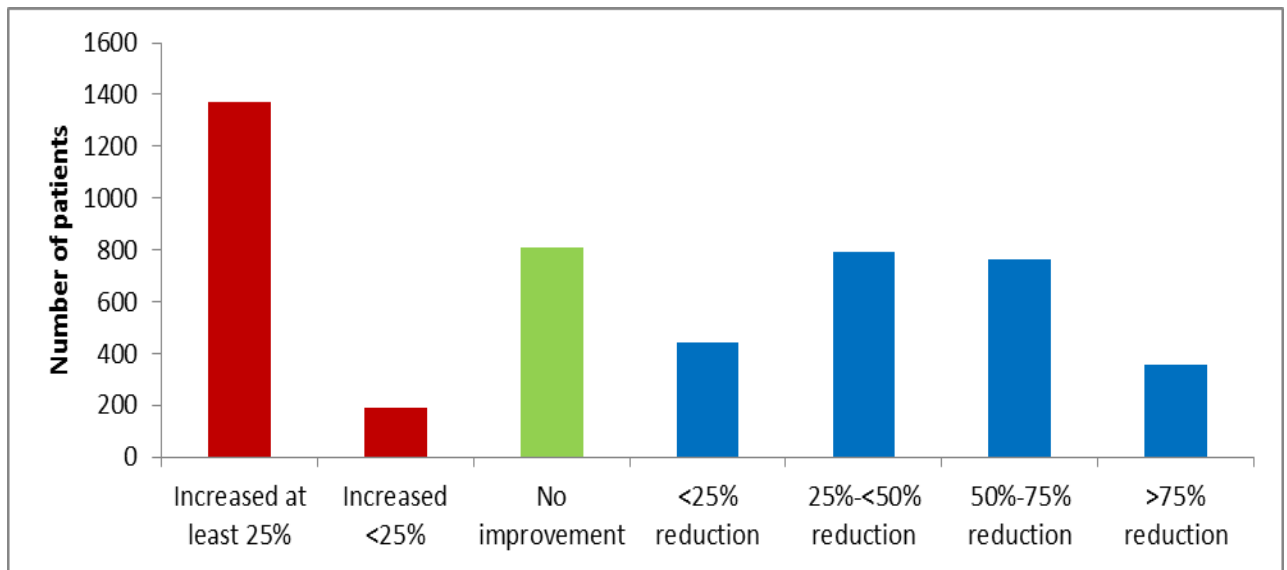


Figure 8.2 Improvement in the total clinical skin scores

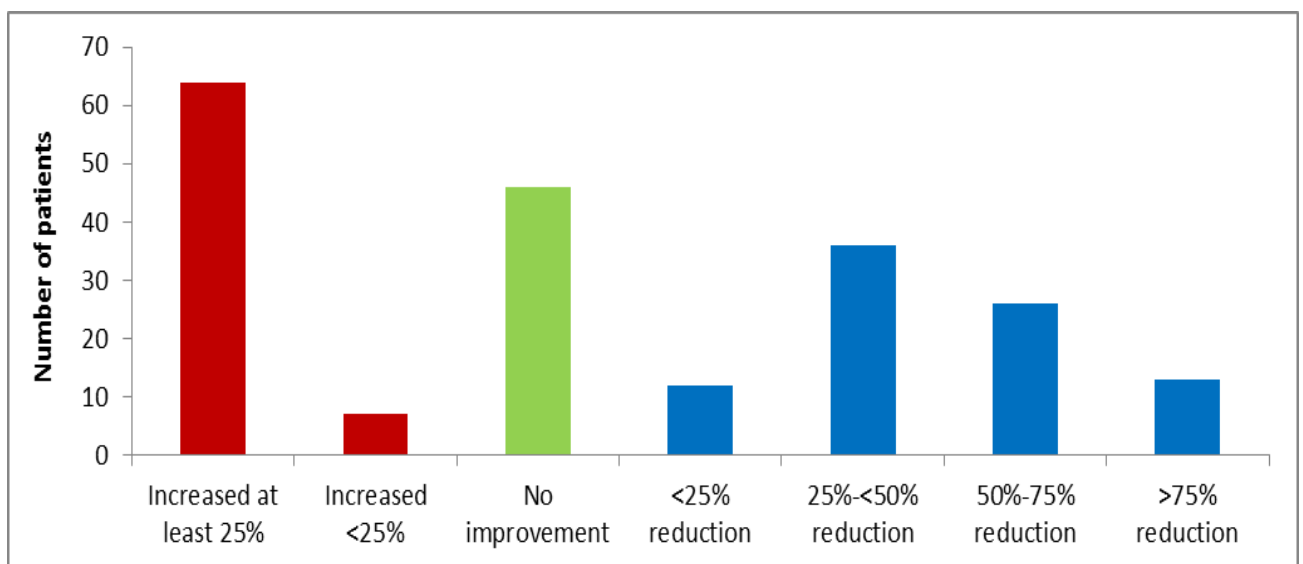


Figure 8.3 Improvement in joint pain

Change in Quality of Life

In adult patients aged 17 years and above, we noted an overall improvement in the quality of life. A total of 2,122 adult patients were evaluated for change in quality of life by DLQI. Of these patients, 545 patients (25.7%) had significant improvement with a reduction of DLQI score by at least 5, whereas 357 patients (16.8%) had significant worsening with an increase in DLQI score by at least 5 (**Figure 8.4**).

A total of 46 patients aged below 17 were evaluated for change in quality of life by DLQI. Of these patients, 11 patients (23.9%) had a significant improvement of Child DLQI score by at least 5, while 4 patients (8.7%) worsened (**Figure 8.4**).

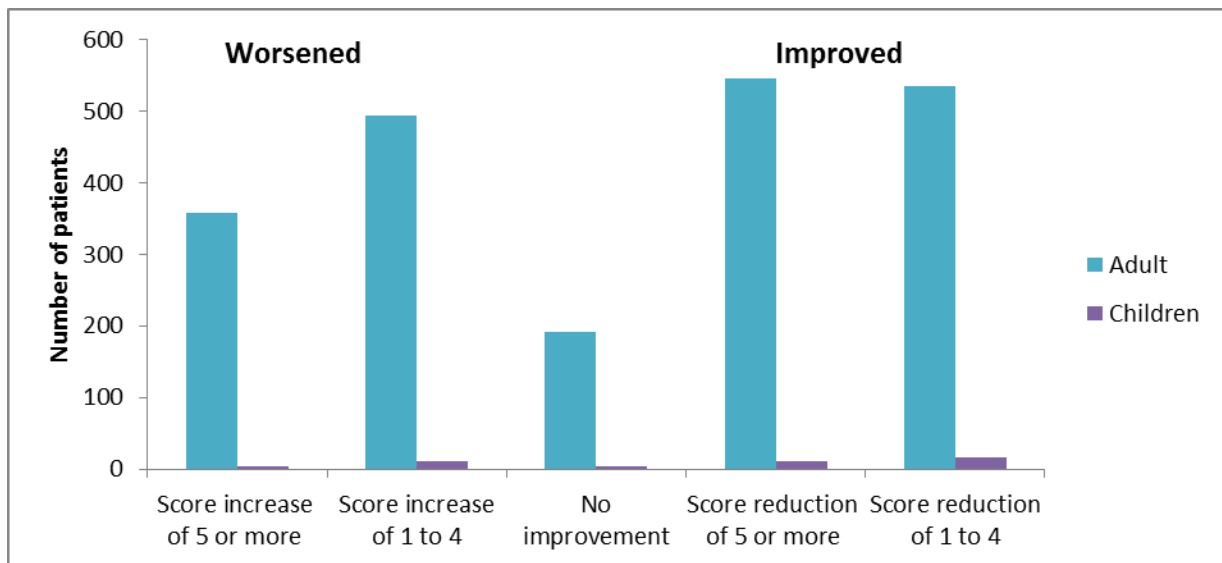


Figure 8.4 Improvement in DLQI and CDLQI

Mortality in Psoriasis

We performed a further sub-analysis to determine the causes of mortality in patients with psoriasis. All adult psoriasis patients aged 18 and above notified to the Malaysian Psoriasis Registry between July 2007 and December 2015 were cross-checked against the National Death Registry. Patients certified dead were identified and the causes of death according to the death certificate were analyzed. Simple logistic regression was performed to determine the role of cardiovascular risk factors affecting mortality while multivariate analysis using multiple logistic regression was performed to determine possible predictive factors of mortality such as age, age of onset (whether above the age of 40 years or not), gender, Body Surface Area (BSA) involvement, the use of systemic therapy and the presence of comorbidities. Missing data were not included in the analysis. Enter method was applied. Multicollinearity was checked to ensure the correlation between predictive factors were not found. Pearson Chi-squared test was used to determine whether the use of systemic therapy was associated with infections, malignancies and cardiovascular diseases causing death as well as whether the severity of disease was associated with cardiovascular causes of mortality.

A total of 13,451 adult patients (18 and above) were notified to the registry between July 2007 and December 2015, of which 702 deaths (4.95% of patients in the registry) were identified (523 males, 179 females). The mean age at demise was 59.7 ± 13.72 years.

Hypertension, diabetes mellitus, dyslipidaemia, ischaemic heart disease and cerebrovascular disease were risk factors that were significantly associated with overall mortality among psoriasis patients ($p < 0.001$) (**Table 8.2**). Four factors emerged as predictive factors of higher mortality in adult patients with psoriasis, namely age >40 years (age 41-60 years old Odds Ratio (OR) 3.11, 95% Confidence Interval (95% CI) 2.17, 4.45; age >60 years OR 7.26, 95% CI 4.93, 10.70), male gender (OR 1.91, 95% CI 1.56, 2.35), severe psoriasis with body surface area (BSA) $>10\%$ (OR 1.81, 95% CI 1.48, 2.21) and presence of at least one cardiovascular comorbidity (OR 1.86, 95% CI 1.50, 2.30) (**Table 8.3**). Age of onset of psoriasis (whether 40 years old and below or more than 40 years old) had a weak association with mortality (OR 1.37, 95% CI 1.10, 1.71, $p=0.005$) while there was no significant association between systemic treatment and mortality.

Out of 705 deaths, 540 cases (76.6%) had reported causes of death (**Table 8.4**) in which the most common cause of death was cardiovascular causes ($n=179$, 33.1%), followed by infection ($n=175$, 32.4%), and malignancy ($n=75$, 13.9%). For the remaining 165 cases (23.4%), the medical causes of death could not be determined as the death certification had been done by police who had listed 'death due to natural causes'. The types of infections and malignancies among the patients who died are listed in **Table 8.5**. For lung infections, out of 70 patients, 62 had pneumonia (88.6% of lung infections) while eight patients (11.4%) had tuberculosis. Five patients with central nervous system infections, of which five (83.3%) had meningitis or meningoencephalitis while one (16.7%) had a cerebellar abscess.

Table 8.2 Cardiovascular risk factors in patients with psoriasis

Variables	Patient died ($n=702$)		Patient alive ($n=12,930$)		Simple Logistic Regression		
	<i>n</i>	(%)	<i>n</i>	(%)	Crude OR	(95% CI)	P-value ^a
Diabetes Mellitus	261	37.2	2215	17.1	2.82	2.41, 3.32	<0.001
Hypertension	320	45.6	3341	25.8	2.39	2.05, 2.79	<0.001
Hyperlipidaemia	194	27.6	2354	18.2	1.72	1.45, 2.05	<0.001
Ischaemic heart disease	107	15.2	673	5.2	3.23	2.59, 4.02	<0.001
Cerebrovascular disease	30	4.3	181	1.4	3.11	2.10, 4.62	<0.001

*Result was based on available information. Percentage (%) was calculated based on number of cases over total number for each group (alive or dead).

^a Wald statistic.

Table 8.3 Predictive factors of higher mortality in adult patients with psoriasis

Variables	Patient died (n=702)		Patient alive (n=12,930)		Multiple Logistic Regression ^a		
	n	(%)	n	(%)	Adj. OR	(95% CI)	P-value
1. Age:							<0.001
17-40 years	69	9.8	5458	42.2		1.00 (ref.)	
41-60 years	289	41.2	5195	40.2	3.11	2.17, 4.45	<0.001
>60 years	344	49.0	2277	17.6	7.26	4.93, 10.70	<0.001
2. Age of onset:							
≤ 40 years (Type 1)	245	34.9	8375	64.8		1.00 (ref.)	
> 40 years (Type 2)	448	63.8	4206	32.5	1.37	1.10, 1.71	0.005
3. Gender:							
Male	523	74.5	7186	55.6	1.91	1.56, 2.35	<0.001
Female	179	25.5	5744	44.4		1.00 (ref.)	
4. BSA involved							
≤ 10%	362	51.6	6792	52.5		1.00 (ref.)	
> 10%	173	24.6	2129	16.5	1.81	1.48, 2.21	<0.001
5. Systemic therapy							
Yes	154	21.9	2388	18.5			NS
No	533	75.9	9978	77.2			
6. Co-morbidity:							
At least one	489	69.7	5229	40.4	1.86	1.50, 2.30	<0.001
None	208	29.6	7367	57.0		1.00 (ref.)	

*Result was based on available information

Adj. OR = Adjusted odds ratio; ref. = Reference; NS = Not significant

a Backward LR was applied

Multicollinearity was checked and not found

Hosmer-Lemeshow test ($P=0.377$), classification table (overall correctly classified percentage=94.2%) and area under the ROC curve (77.5%) were applied to check the model fitness

Table 8.4 Reported cause of mortality among patients with psoriasis

Cause of mortality	Number of patients, n	%
Cardiovascular	179	33.1
Infection	175	32.4
Malignancy	75	13.9
Trauma	31	5.7
Lung	25	4.6
Liver	19	3.5
Gastrointestinal	13	2.4
Suicide	8	1.5
Renal	7	1.3
Others	8	1.5
Total	540	100

Table 8.5 Types of infections and malignancy related deaths

Types	Number, n	%
Infection		
Lung	70	49.0
Sepsis	31	21.7
Gastrointestinal	18	12.6
Urinary Tract	12	8.4
Human Immunodeficiency Virus (HIV)-related	6	4.2
Central Nervous System	6	4.2
Total	143	100
Malignancy		
Gastrointestinal	20	26.7
Liver	15	20.0
Upper Aerodigestive Tract	9	12.0
Lung	9	12.0
Breast	8	10.7
Lymphoma and Leukaemia	8	10.7
Others	6	8.0
Total	75	100

APPENDIX A: CASE REPORT FORM

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Case Report Form		CONFIDENTIAL
		For Office Use only: ID: <input style="width: 50px;" type="text"/> / <input style="width: 50px;" type="text"/>
		Centre: <input style="width: 100%;" type="text"/>
<i>Instruction: Where check boxes <input checked="" type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="checkbox"/> are provided, check (✓) one button only.</i>		
Doctor's Name :		<input style="width: 100%;" type="text"/>
Name of Institution :		<input style="width: 100%;" type="text"/>
SECTION 1: DEMOGRAPHIC DETAILS		
1. Patient visit date : (dd/mm/yyyy)	<input style="width: 20px;" type="text"/> / <input style="width: 20px;" type="text"/> / <input style="width: 40px;" type="text"/>	2. Type of visit : <input type="radio"/> New Case <input type="radio"/> Follow-Up
3. Name of patient :	<input style="width: 100%;" type="text"/>	
4. NRIC :	MyKad/ MyKd: <input style="width: 100%;" type="text"/> - <input style="width: 20px;" type="text"/> - <input style="width: 20px;" type="text"/> Old IC: <input style="width: 100%;" type="text"/>	
	Other ID document No: <input style="width: 100%;" type="text"/>	
	Specify document type (if others): <input type="radio"/> Registration number <input type="radio"/> Mother's I/C <input type="radio"/> Work Permit <input type="radio"/> Clinic RN <input type="radio"/> Passport <input type="radio"/> Father's I/C <input type="radio"/> Driver's Licence <input type="radio"/> Police ID Card <input type="radio"/> Birth Certificate <input type="radio"/> Armed Force ID <input type="radio"/> Hospital RN <input type="radio"/> Others	
5. Address : #	Town / City: <input style="width: 100%;" type="text"/> State: <input style="width: 100%;" type="text"/>	
6. Contact # number :	Homephone: <input style="width: 100%;" type="text"/> - <input style="width: 20px;" type="text"/> - <input style="width: 20px;" type="text"/> HP: <input style="width: 100%;" type="text"/> - <input style="width: 20px;" type="text"/> - <input style="width: 20px;" type="text"/>	
7. Gender :	<input type="radio"/> Male <input type="radio"/> Female	
8. Date of birth : # (dd/mm/yyyy)	<input style="width: 20px;" type="text"/> / <input style="width: 20px;" type="text"/> / <input style="width: 40px;" type="text"/> <input type="checkbox"/> Estimated/ presumed year <small>If the exact date is not known, please enter 01/07/yyyy & check the estimated/presumed year box</small>	
9. Ethnic group :	<input type="radio"/> Malay <input type="radio"/> Chinese <input type="radio"/> Indian <input type="radio"/> Orang Asli <input type="radio"/> Others, specify : _____	
10. Nationality :	<input type="radio"/> Malaysian <input type="radio"/> Non-Malaysian, specify _____	
11. Marital status :	<input type="radio"/> Single <input type="radio"/> Married <input type="radio"/> Divorced <input type="radio"/> Widow <input type="radio"/> Widower	
SECTION 2 : MEDICAL HISTORY		
1. Age when # psoriasis started :	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>	
2. Age when # psoriasis diagnosed :	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>	
3. Family member(s) # with psoriasis :	<input type="radio"/> No <input type="radio"/> Yes → <small>(if YES, please tick ONE or MULTIPLE)</small> <input type="checkbox"/> Father <input type="checkbox"/> Sibling(s) <input type="checkbox"/> Other relative, specify _____ <input type="checkbox"/> Mother <input type="checkbox"/> Children	
4. Aggravating factors :	<input type="radio"/> No <input type="radio"/> Yes → <small>(if YES, please tick ONE or MULTIPLE of the following)</small> <input type="checkbox"/> Infection : _____ <input type="checkbox"/> Drugs : _____ <input type="checkbox"/> Topical Rx : _____ <input type="checkbox"/> Trauma <input type="checkbox"/> Stress <input type="checkbox"/> Sunburn <input type="checkbox"/> Hypocalcaemia <input type="checkbox"/> Pregnancy <input type="checkbox"/> Smoking <input type="checkbox"/> Alcohol <input type="checkbox"/> Others, specify: _____	
5. Disease burden in the last 6 months :	a) No. of clinic visits due to psoriasis :	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (enter 0 if none)
	b) No. of days off work/ school due to psoriasis :	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (enter 0 if none) <input type="checkbox"/> Not applicable
	c) No. of hospital admissions due to psoriasis :	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (enter 0 if none)
6. Other diseases :	a) Ischaemic heart disease :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	b) Cerebrovascular disease (stroke) :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	c) Diabetes mellitus :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	d) Hypertension :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	e) Hyperlipidaemia :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	f) Other diseases, specify : (e.g. HIV infection, tuberculosis, lymphoma, etc.)	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown <input style="width: 100%;" type="text"/>
7. Cigarette smoking :	<input type="radio"/> Never smoked <input type="radio"/> Ex-smoker <input type="radio"/> Current smoker → <input style="width: 20px;" type="text"/> 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
Instruction: Where check boxes <input checked="" type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="checkbox"/> are provided, check (✓) one button only.	For Office Use only: ID: <input style="width: 40px;" type="text"/> / <input style="width: 40px;" type="text"/> Centre: <input style="width: 100%;" type="text"/>

SECTION 3: CLINICAL EXAMINATION																																									
1. (a) Height : <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (cm)	(b) Weight: <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (kg)																																								
2. Type of psoriasis : <small>(Please select ONE predominant type)</small> <input type="checkbox"/> Plaque <input type="checkbox"/> Guttate <input type="checkbox"/> Erythrodermic <input type="checkbox"/> Flexural / Inverse <input type="checkbox"/> Others,specify: <input type="checkbox"/> Generalised pustular <input type="checkbox"/> Localised Pustular <input type="checkbox"/> Palmoplantar non-pustular																																									
3. Severity : Body surface area involved : <input type="checkbox"/> <5% <input type="checkbox"/> 5 - 10% <input type="checkbox"/> > 10% <input type="checkbox"/> Erythrodermic (>90%)																																									
<table border="1" style="width: 100%; border-collapse: collapse; font-size: 0.8em;"> <thead> <tr> <th style="width: 30%;">Body part</th> <th colspan="4">Grade of severity</th> </tr> </thead> <tbody> <tr> <td>Scalp</td> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 2</td> <td><input type="checkbox"/> 3</td> </tr> <tr> <td>Face & Neck</td> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 2</td> <td><input type="checkbox"/> 3</td> </tr> <tr> <td>Trunk</td> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 2</td> <td><input type="checkbox"/> 3</td> </tr> <tr> <td>Upper Limbs</td> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 2</td> <td><input type="checkbox"/> 3</td> </tr> <tr> <td>Lower Limbs</td> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 2</td> <td><input type="checkbox"/> 3</td> </tr> </tbody> </table>	Body part	Grade of severity				Scalp	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Face & Neck	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Trunk	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Upper Limbs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Lower Limbs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<table border="1" style="width: 100%; border-collapse: collapse; font-size: 0.8em;"> <tr> <td colspan="2">Key for grading.</td> </tr> <tr> <td colspan="2">Grade 0 : Skin normal or hypo-/hyperpigmented patch only.</td> </tr> <tr> <td colspan="2">Grade 1 : Mild erythema, fine scales, thin plaque, with or without central clearing.</td> </tr> <tr> <td colspan="2">Grade 2 : Moderate erythema or scaling, moderately thick plaque.</td> </tr> <tr> <td colspan="2">Grade 3 : Severe erythema or scaling, very thick plaque</td> </tr> </table>	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	
Body part	Grade of severity																																								
Scalp	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3																																					
Face & Neck	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3																																					
Trunk	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3																																					
Upper Limbs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3																																					
Lower Limbs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3																																					
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Grade 2 : Moderate erythema or scaling, moderately thick plaque.																																									
Grade 3 : Severe erythema or scaling, very thick plaque																																									
4. Nail involvement : <input type="checkbox"/> No <input type="checkbox"/> Yes → <input type="checkbox"/> Pitting <input type="checkbox"/> Discoloration <input type="checkbox"/> Total nail dystrophy <small>(if YES, please tick ONE or MULTIPLE)</small> <input type="checkbox"/> Onycholysis <input type="checkbox"/> Subungual hyperkeratosis																																									
5. Joint disease : <input type="checkbox"/> No <input type="checkbox"/> Yes →																																									
a) Rheumatoid factor <input type="checkbox"/> Negative <input type="checkbox"/> Positive <input type="checkbox"/> Not Available																																									
b) Morning stiffness > 30 minutes <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
c) Enthesopathy / Dactylitis <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
d) Type :-																																									
1. Oligo-/ Monoarthropathy <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
2. Distal hand joints arthropathy <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
3. Symmetrical polyarthropathy (Rheumatoid-like) <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
4. Spondylitis / Sacroiliitis <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
5. Arthritis mutilans <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
e) Severity:-																																									
1. Pain <input type="checkbox"/> No <input type="checkbox"/> Yes → Pain Score (1-10) : <input style="width: 20px;" type="text"/>																																									
2. Swelling <input type="checkbox"/> No <input type="checkbox"/> Yes																																									
3. Deformity <input type="checkbox"/> No <input type="checkbox"/> Yes → Please Specify : _____																																									

SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS	
1. Topical therapy :	a) Tar preparation <input type="checkbox"/> No <input type="checkbox"/> Yes e) Topical steroids (other than face / flexures) <input type="checkbox"/> No <input type="checkbox"/> Yes b) Vitamin D analogues e.g calcipotriol <input type="checkbox"/> No <input type="checkbox"/> Yes f) Keratolytics e.g. salicylic acid <input type="checkbox"/> No <input type="checkbox"/> Yes c) Calcipotriol with betamethasone dipropionate <input type="checkbox"/> No <input type="checkbox"/> Yes g) Emollient <input type="checkbox"/> No <input type="checkbox"/> Yes d) Dithranol (anthralin) <input type="checkbox"/> No <input type="checkbox"/> Yes h) Others, specify <input type="checkbox"/> No <input type="checkbox"/> Yes →
2. Phototherapy : <input type="checkbox"/> No <input type="checkbox"/> Yes → <input type="checkbox"/> BB-UVB <input type="checkbox"/> Oral PUVA <input type="checkbox"/> Topical PUVA <input type="checkbox"/> Others,specify <small>(if YES, please tick ONE or MULTIPLE)</small> <input type="checkbox"/> NB-UVB <input type="checkbox"/> Bath PUVA <input type="checkbox"/> Excimer laser	
3. Systemic therapy : <input type="checkbox"/> No <input type="checkbox"/> Yes →	
a) Methotrexate <input type="checkbox"/> No <input type="checkbox"/> Yes f) Biologics, specify <input type="checkbox"/> No <input type="checkbox"/> Yes →	
b) Acitretin <input type="checkbox"/> No <input type="checkbox"/> Yes	
c) Sulphasalazine <input type="checkbox"/> No <input type="checkbox"/> Yes g) Systemic corticosteroids <input type="checkbox"/> No <input type="checkbox"/> Yes	
d) Cyclosporin <input type="checkbox"/> No <input type="checkbox"/> Yes h) Others, specify <input type="checkbox"/> No <input type="checkbox"/> Yes →	
e) Hydroxyurea <input type="checkbox"/> No <input type="checkbox"/> 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*

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Dermatology Life Quality Index (DLQI) (For Adults of Age 17 and Above)	CONFIDENTIAL For Office Use only: ID: <input style="width: 50px;" type="text"/> / <input style="width: 50px;" type="text"/> Centre: <input style="width: 100px;" type="text"/>
--	--

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

Objektif kajian 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	<input type="text"/>	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 ? <i>Over the last week, how itchy, sore, painful or stinging has your skin been?</i> 您的皮肤感到痒、酸痛、疼痛、刺痛了吗？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Setakat manakah anda berasa malu atau segan, disebabkan oleh kulit anda? <i>Over the last week, how embarrassed or self conscious have you been because of your skin?</i> 由于您的皮肤问题，您感到尴尬或自卑吗？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Setakat manakah kulit anda mengganggu anda daripada pergi membeli belah atau menjaga rumah atau berkebun ? <i>Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?</i> 因为皮肤问题，对您购物、做家务、整理庭院影响程度如何？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Setakat manakah kulit anda mempengaruhi pakaian yang anda pakai? <i>Over the last week, how much has your skin influenced the clothes you wear?</i> 皮肤问题对您穿衣服影响程度如何？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) Setakat manakah kulit anda mengganggu aktiviti - aktiviti sosial atau masa lapang anda ? <i>Over the last week, how much has your skin affected any social or leisure activities?</i> 皮肤问题对您的社交或休闲生活有多大的影响？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) Setakat manakah keadaan kulit anda menyebabkan anda tidak selesa bersukan? <i>Over the last week, how much has your skin made it difficult for you to do any sport?</i> 皮肤问题对您运动有多大妨碍？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) Adakah kulit anda menyebabkan anda tidak bekerja atau belajar? <i>Over the last week, has your skin prevented you from working or studying?</i> 皮肤问题是否让您无法上班或学习？ <input type="checkbox"/> Ya/Yes 是 <input type="checkbox"/> Tidak/No 不是 <input type="checkbox"/> Tidak Berkenaan /Not Relevant 无关 <div style="border: 1px dashed black; padding: 5px; margin-top: 5px;"> *Jika "tidak", setakat manakah kulit anda menjadi masalah semasa kerja atau belajar? <i>If "No", over the last week how much has your skin been a problem at work or studying?</i> 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？ </div>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8) Setakat manakah kulit anda menimbulkan masalah dengan teman, rakan baik atau saudara mara anda? <i>Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?</i> 皮肤问题妨碍了您和爱人、亲密的朋友、亲戚间的交往了吗？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) Setakat manakah kulit anda menyebabkan sebarang masalah hubungan seks? <i>Over the last week, how much has your skin caused sexual difficulties?</i> 皮肤问题给您的性生活造成了多大影响？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Setakat manakah rawatan kulit anda menimbulkan masalah seperti mengotori rumah anda atau mengambil masa anda? <i>Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy or by taking up time?</i> 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？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih

Please check you have answered EVERY question. Thank you.

请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

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NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Children's Dermatology Life Quality Index (DLQI) (For age 5 to 16)	CONFIDENTIAL	
	For Office Use only:	
	ID:	<input type="text"/>
		Centre: <input type="text"/>

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

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 "✓"

Sepanjang Minggu Lalu OVER THE LAST WEEK 过去一星期中	DLQI Score:			
	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
1) Setakat manakah kulit anda berasa gatal atau sakit ? <i>Over the last week, how itchy, "scratchy", sore or painful has your skin been?</i> 你皮肤发痒、搔抓、破皮或疼痛的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Setakat manakah anda berasa malu, segan, susah hati atau sedih disebabkan oleh kulit anda? <i>Over the last week, how embarrassed or self conscious, upset or sad have you been because of your skin?</i> 你因为自己皮肤问题而感到难为情或害羞、苦恼或难过的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Setakat manakah kulit anda mempengaruhi persahabatan anda? <i>Over the last week, how much has your skin affected your friendships?</i> 皮肤问题对你和朋友交往的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Setakat manakah anda menukar atau memakai pakaian atau kasut kerana kulit anda? <i>Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?</i> 你因为皮肤问题而改变穿著不同或特定衣鞋的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) Setakat manakah masalah kulit anda mempengaruhi anda untuk keluar, bermain atau melakukan hobi anda? <i>Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?</i> 皮肤的问题对你外出、玩耍、或从事休闲嗜好影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) Setakat manakah anda menjauhi diri daripada berenang atau melakukan sukan lain disebabkan oleh masalah kulit anda? <i>Over the last week, how much have you avoided swimming or other sports because of your skin trouble?</i> 你因为皮肤的问题而避免游泳或其他运动的影响程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) Pada minggu yang lalu, Last week, 过去一星期 Pada hari persekolahan, setakat manakah kulit anda mempengaruhi kerja sekolah anda? <i>If school time: Over the last week, how much did your skin problem affect your school work?</i> 如果是上课时间, 皮肤问题影响你学校功课的程度是如何? ATAU OR 或 Pada hari cuti, setakat manakah kulit anda mengganggu anda menikmati cuti? <i>If holiday time: Over the last week, has your skin problem interfered with your enjoyment of the holiday?</i> 如果是放假期间, 皮肤问题干扰到你享受假期的兴致是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8) Setakat manakah orang memanggil anda dengan nama yang tidak baik, mengejek, menanya soalan-soalan atau menjauhi diri disebabkan oleh kulit anda? <i>Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?</i> 因为皮肤的问题使得别人骂你、嘲笑你、欺负你、问你问题或躲避你, 这种困扰程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) Setakat manakah masa tidur anda diganggu kerana masalah kulit? <i>Over the last week, how much has your sleep been affected by your skin problem?</i> 你因皮肤的问题而影响睡眠的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Setakat manakah rawatan kulit anda menjadi suatu masalah? <i>Over the last week, how much of a problem has the treatment for your skin been?</i> 针对皮肤所进行的治疗对你产生的困扰程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih

Please check you have answered EVERY question. Thank you.

请您检查您是否已回答所有问题。谢谢合作

APPENDIX B: DATA MANAGEMENT

The National Dermatology Registry (DermReg) 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 SQL Server due to the high volume of data accumulated throughout the years.

Data Sources

SDPs of DermReg 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 monthly on follow-up visits.

A carefully designed Case Report Form (CRF) is employed in the data collection. This is a double-sided single-sheet CRF which consists of a clinical data form and a multilingual Dermatology Life Quality Index (DLQI) form in both adult and children versions. The clinical data form is to be completed by the doctor in-charge while the DLQI form is to be completed by the patient (parent or guardian for young patient) with guidance from trained staff if necessary. Adult DLQI form should be used for patients above 16 years old, while Children DLQI for patients aged 5 to 16. It is not required to fill the DLQI form for patients below 5 years of age.

One set of CRF is to be completed for each new patient during consultation at the first visit to the participating centre. A new set of CRF is to be completed for the same patient every 6 monthly to record the progress of the patient. The CRFs are used as part of the clinical records.

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 data are analysed, interpreted and presented in regular reports to be disseminated to the users.

Participation of SDP is entirely voluntary.

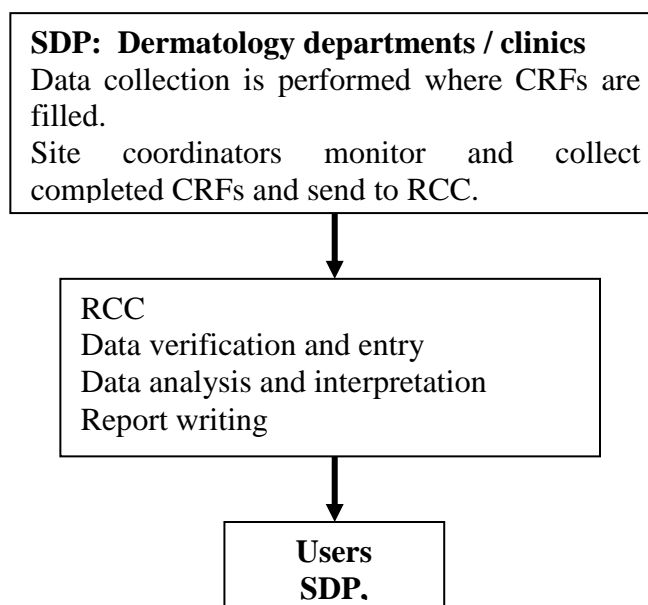
Registry ICT Infrastructure and Data Centre

The operations of the DermReg 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 DermReg network infrastructure. DermReg servers are located in a data centre in Cyberjaya in order to provide DermReg with quality assured data hosting services and state-of-the-art physical and logical security features without having to invest in costly data centre setup internally. 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.

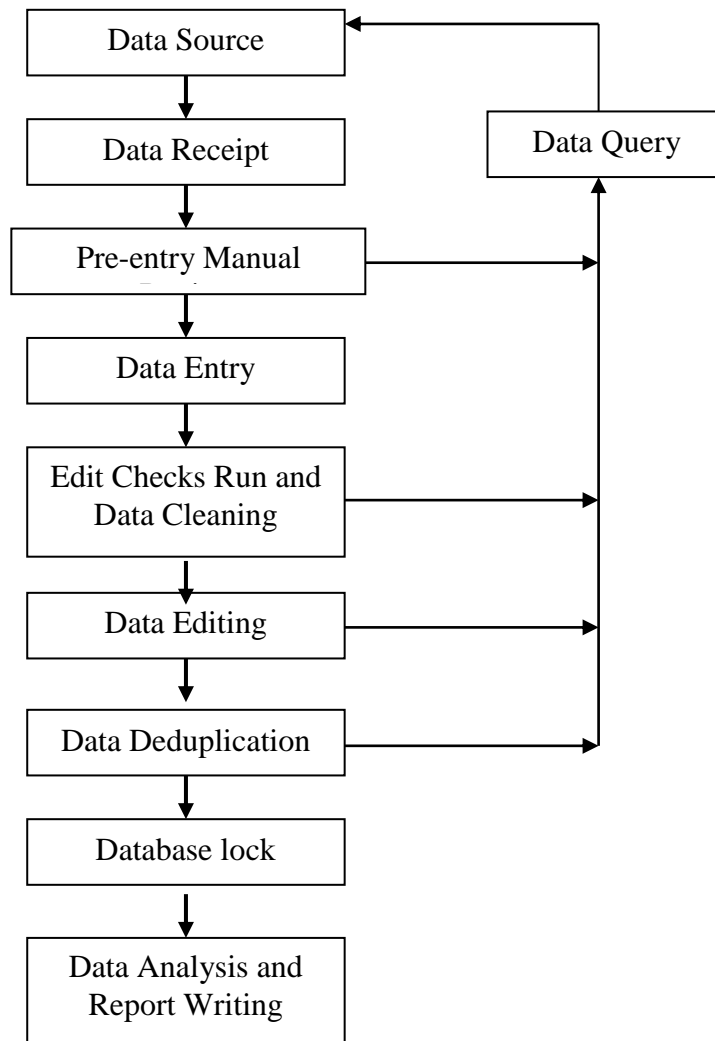
Data Flow Process

Data are collected by doctors in 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 error with deduplication. Data queries that are resolved are then updated to the database.

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



SDP Data Reporting, Data Correction and Submission Tracking

Data submitted by SDP are entered into electronic case report form (eCRF) via DermReg Web Application (eDermReg).

There are a number of data security features that are designed into eDermReg such as 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 patient exist in the entire registry. This step is done to avoid duplicate records. For patients that exist in the database, SDP only needs to add a new notification with basic patient particulars pre-filled based on existing patient 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 value entered is not within the specific range, user is prompted for the correct value.

Real time reports are also provided in the web application. The aggregated data reports are presented in the form of tables and graphs manner. These aggregated data reports are typically presented in two manners, one as the centre's own data report and another as registry's overall data report.

Edit checks run and Data cleaning

Edit check was performed periodically by the registry manager to identify missing compulsory data, out of range values, inconsistency data, invalid values and error with de-duplication. Data cleaning is then performed based on the results of edit checks. Data update and data checking of the dataset is performed when there is a query of certain fields when necessary. It could be due to request by user, correction of data based on checking from data query in 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 IC, deriving gender from IC and name and inferring race from name. Checking inconsistency of the data also done, for example IC and name shows female but gender is 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 producers 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 RCC is highly sensitive and has to be kept strictly confidential with access only to authorized individual working in the RCC. Strict data protection procedure will need to be put in place, following standard disease registration practice, 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) accompanied with a Data Release Application Form and signed Data Release Agreement Form. These requests need prior approval by the Governance Board before data can be released.

APPENDIX C: STATISTICAL METHODS

ANALYSIS SET

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

1. Patient notification between 2007 and 2015

There were 14,516 patients in the dataset. The analysis set was used for the analysis in Chapter 1, 2, 3, 4, 5 and 6, which comprises of 247 cases in year 2007, 1,019 cases in year 2008, 1,254 cases in year 2009, 1,858 cases in year 2010, 1,064 cases in year 2011, 887 cases in 2012, 1,436 cases in 2013, 3,120 cases in 2014 and 4,304 cases in 2015. The cases include first notification and up to five follow-up notifications.

2. Patient outcome between 2007 and 2012

There were 4,968 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 on the missing data were issued to Project Manager to clarify the status of the information. Trackable missing information was then incorporated into the dataset but for untrackable and tolerable missing data were included in the analysis and defined as missing.

STATISTICAL METHOD

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

Stock and Flow

Chapter 1 explained the registry for the distribution of centres reported and distribution of patients according to number of notifications.

Characteristics of Patients

Chapter 2 explained the socio-demographic profiles such as gender, ethnicity, nationality and marital status. Descriptive summary was done for age at visit.

Medical History

Chapter 3 emphasized on the distribution of aggravating factors of psoriasis patients. Crosstabulations were concentrated on the comparison of family members with psoriasis against age of onset.

Comorbidities

Chapter 4 emphasized on the combination of distribution and descriptive summaries of age of onset, several demographic profiles and comorbidities. Figures were presented graphically using bar and stacked bar charts.

Clinical Presentation

Chapter 5 concentrated on the descriptive summaries of pain score. The distribution of psoriasis patients were further analysed on types of psoriasis, body surface area, severity, nail involvement, joint disease, rheumatoid factor, symptoms of psoriatic arthritis and types of joint disease. Crosstabulations performed with several combinations involving age of onset, types of psoriasis, demographic profiles, severities and disease involvements. The graphical presentation were pie chart, bar and stacked bar chart.

Treatment

Chapter 6 presented the distribution of patients with topical therapy, phototherapy, types of phototherapy and systematic therapy. The graphical presentation were in pie chart, bar and stacked bar chart.

Quality of Life

Chapter 7 solely concentrated on a specific intention, which was on Dermatology Life Quality Index (DLQI). The distribution and crosstabulation figures were presented graphically using bar, stacked bar and line charts.

Outcomes

Chapter 8 explained on the distribution and descriptive summary of the outcome variables. The improvement of lesion extent, skin score, joint score and DLQI score were graphically presented using bar charts.

STATISTICAL SOFTWARE

SPSS 18.0

APPENDIX D: PARTICIPATING CENTRE DIRECTORY

<p>Hospital Kuala Lumpur</p> <p>Department of Dermatology Hospital Kuala Lumpur Jalan Pahang, 50586 Kuala Lumpur, Wilayah Persekutuan Kuala Lumpur. Tel: .03-2615 1540 Fax: 03-2698 5927</p>	<p>Investigator: Dr Azura Mohd Affandi</p> <p>Site- coordinator: -</p>
<p>Hospital Sungai Buloh</p> <p>Dermatology Unit Hospital Sungai Buloh, Jalan Hospital, 47000 Sungai Buloh, Selangor Darul Ehsan. Tel: 03-6145 4333 Ext 1286 Fax: 03-6145 4222</p>	<p>Investigator: Dr. Norli Marwyne bt Mohd Noor</p> <p>Site- coordinator: Prima Dharshini</p>
<p>Hospital Tuanku Ja'afar, Seremban</p> <p>Dermatology Department, Hospital Tuanku Ja'afar, Jalan Rasah 70300 Seremban, Negeri Sembilan. Tel: 06-760 4157 Fax: 06-762 5771</p>	<p>Investigator: Dr. Najeeb Ahmad Mohd Safdar</p> <p>Site- coordinator: Dr.Prakash A/L Balasubramaniam</p>
<p>Hospital Sultanah Fatimah, Muar</p> <p>Dermatology Department, Hospital Pakar Sultanah Fatimah, Jalan Salleh, 84000 Muar, Johor Darul Takzim. Tel: 06-952 1901 Fax: 06-952 6003</p>	<p>Investigator: Dr. Noreen Md Arus</p> <p>Site- coordinator: Mohd Khairul bin Othman</p>
<p>Hospital Pulau Pinang</p> <p>Dermatology Department, Hospital Pulau Pinang, Jalan Residensi, 10990 Pulau Pinang, Tel: 04-222 5250 Ext 5246 Fax: 04-228 1737</p>	<p>Investigator: Dr Chan Lee Chin</p> <p>Site- coordinator: Dr Yeoh Chin Aun</p>

<p>Hospital Sultanah Bahiyah, Alor Setar</p> <p>Dermatology Department, Hospital Sultanah Bahiyah, Lebuhraya Darul Aman, 05100 Alor Setar, Kedah Tel: 04-740 6233 Fax: 04-735 0232</p>	<p>Investigator: Dr Tan Wooi Chiang</p> <p>Site- coordinator: Dr Azlida Che Man</p>
<p>Hospital Tuanku Fauziah, Kangar</p> <p>Dermatology Department, Hospital Tuanku Fauziah, Jalan Kolam,01000 Kangar, Perlis Indera Kayangan. Tel: 04-973 8000 Fax: 04-976 7237</p>	<p>Investigator: Dr Sharifah Fariah Syed Abas, Dr. Hassanin Hussaini Hilmi bin Mohd Khalid</p> <p>Site- coordinator: Wan Suhardi bin Wan Abdul Rahman</p>
<p>Hospital Queen Elizabeth, Kota Kinabalu</p> <p>Dermatology Department, Hospital Queen Elizabeth, Karung Berkunci no 2029 , 88586 Kota Kinabalu, Sabah. Tel: 088-517555 Fax: 088-211999</p>	<p>Investigator: Dr Zaigham Mahmood Dr Mervin George Matthew</p> <p>Site- coordinator: Ampong Anggarak</p>
<p>Hospital Tengku Ampuan Afzan, Kuantan</p> <p>Dermatology Department, Hospital Tengku Ampuan Afzan, Jalan Tanah Putih, 25100 Kuantan, Pahang Darul Makmur. Tel: 09-513 3333 Fax: 09-514 2712</p>	<p>Investigator: Dr Rajalingam Ramalingam</p> <p>Site- coordinator: Mazliza binti Mamat</p>
<p>Hospital Raja Permaisuri Bainun, Ipoh</p> <p>Dermatology Department, Jabatan Dermatologi, Hospital Ipoh, Jalan Hospital 30990 Ipoh, Perak Darul Ridzuan. Tel: 05-208 5072 Fax: 05-253 1541</p>	<p>Investigator: Dr. Tang Jyh Jong</p> <p>Site- coordinator: Dr. Gurcharan Jit Singh</p>

<p>Sarawak General Hospital</p> <p>Dermatology Department, Hospital Umum Sarawak, Jln Tun Ahmad Zaidi Adruce, 93586 Kuching, Sarawak. Tel: 082-27 6666 Ext 5117 Fax: 082-242751</p>	<p>Investigator: Dr Pubalan Muniandy</p> <p>Site- coordinator: Dr Ling Hee Ninh</p>
<p>Hospital Tengku Ampuan Rahimah, Klang</p> <p>Dermatology Department, Hospital Tengku Ampuan Rahimah, 41200 Klang, Selangor Darul Ehsan. Tel: 03-3375 7000 Ext 6266 Fax: 03-3374 9557</p>	<p>Investigator: Dr. Ng Ting Guan</p> <p>Site-coordinator: Dr Norasma bt Roslan, Dr Balachandran a/l Manoharan</p>
<p>Hospital Sultanah Aminah, Johor Bahru</p> <p>Jabatan Dermatologi, Hospital Sultanah Aminah Johor Bahru, Jalan Abu Bakar, 80100 Johor Bahru, Johor Darul Takzim Tel: 07-223 1806 Fax: 07-224 2694</p>	<p>Investigator: Dr Choon Siew Eng</p> <p>Site- coordinator: Hasnal Azahare</p>
<p>Gleneagles Intan Medical Centre</p> <p>Hope Skin and Laser Centre, Gleneagles Intan Medical Centre, 282 & 286 Jalan Ampang, 50450 Kuala Lumpur. Tel: 03-4251 6233 Fax: 03-4257 9233</p>	<p>Investigator: Dr. Chang Choong Chor</p> <p>Site- coordinator: -</p>
<p>Hospital Melaka</p> <p>Dermatology Department, Hospital Melaka, Jalan Mufti Hj. Khalil, 75400 Melaka. Tel: 06-289 2690 Fax: 06-284 1590</p>	<p>Investigator: Dr Peamala Gunabalasingam</p> <p>Site- coordinator: Dr Koot Chiew Teen, Dr. Nor Afalailah Mohd Aris</p>
<p>Prince Court Medical Centre</p> <p>Prince Court Medical Centre, 39, Jalan Kia Peng, 50450 Kuala Lumpur. Tel: 03- 26100000 Ext 2955 Fax: 03-2160 0010</p>	<p>Investigator: Dr. Gangaram Hemandas Belani</p> <p>Site- coordinator: -</p>

Appendix D: Participating Centre Directory

<p>Universiti Malaya Medical Centre</p> <p>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</p>	<p>Investigator: Dr. Sean Yong Shin Shen</p> <p>Site- coordinator: Dr. Kwan Zhen Li</p>
<p>Universiti Kebangsaan Malaysia Medical Centre</p> <p>Dermatology Department, UKM Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Kuala Lumpur. Tel: 03-9145 6075 03-9145 6640</p>	<p>Investigator: Dr. Norazirah Md Nor</p> <p>Site- coordinator: -</p>
<p>Hospital Raja Perempuan Zainab II, Kota Bharu</p> <p>Dermatology Department, Hospital Raja Perempuan Zainab II, 15586 Kota Bharu, Kelantan Darul Naim. Tel: 09-7452000 Ext 2384 Fax: 09-7486951</p>	<p>Investigator: Dr. Zulrusydi bin Ismail</p> <p>Site- coordinator: Muhd. Al-Amin Mat Zin</p>
<p>Hospital Selayang</p> <p>Dermatology Department, Hospital Selayang, Lebuh Raya Selayang-kepong, 68100 Batu Caves, Selangor Darul Ehsan. Tel: 03-61263333 Fax: 03-6137 7097</p>	<p>Investigator: Dr. Benji Teoh Tze Yuen</p> <p>Site- coordinator:</p>
<p>Hospital Putrajaya</p> <p>Dermatology Department, Hospital Putrajaya, Ground Floor, Precinct 7, 62250 Putrajaya. Tel: 03- 8312 4200 Ext 4371 Fax: 03-8888 0137</p>	<p>Investigator: Dr. Nazatul Shima bt Abdul Rahim</p> <p>Site- coordinator: -</p>

Appendix D: Participating Centre Directory

<p>Hospital Ampang</p> <p>Dermatology Department, Hospital Ampang, Jalan Mewah Utara, Pandan Mewah, 68000 Ampang, Selangor Darul Ehsan. Tel: 03-4289 6000 Ext 6526 Fax: 03-4295 4666</p>	<p>Investigator: Dr. Angelia Dawn Ambrose</p> <p>Site- coordinator:</p>
<p>Hospital Serdang</p> <p>Dermatology Department, Hospital Serdang, Jalan Puchong, 43000 Kajang, Selangor Darul Ehsan. Tel: 03-8947 5555 03- 8947 5050</p>	<p>Investigator: Dr. Tee Shwu Hoon</p> <p>Site- coordinator: -</p>
<p>Hospital Sultan Ismail, Johor Bahru</p> <p>Dermatology Department, Hospital Sultan Ismail, Jalan Persiaran Mutiara Emas Utama, Taman Mount Austin, 81100 Johor Bahru, Johor Darul Takzim, Tel: 07-356 5000 Ext 2213 Fax: -</p>	<p>Investigator: Dr. Latha Selvarajah</p> <p>Site- coordinator: Muhamad bin Ahmad Pauzi Muhamad</p>
<p>Hospital Sultan Haji Ahmad Shah, Temerloh</p> <p>Dermatology Department, Hospital Sultan Haji Ahmad Shah, Jalan Maran, 28000 Temerloh, Pahang Darul Makmur. Tel: 09-295 5333 Fax: 09-297 2468</p>	<p>Investigator: Dr. Rajalingam Ramalingam</p> <p>Site- coordinator:</p>
<p>Hospital Jerantut</p> <p>Dermatology Department, Hospital Jerantut, 27000 Jerantut, Pahang Darul Makmur. Tel: 09-266 3333 Fax: 09-266 1462</p>	<p>Investigator: Dr. Rajalingam Ramalingam</p> <p>Site- coordinator: -</p>

Appendix D: Participating Centre Directory

<p>Hospital Jengka</p> <p>Dermatology Department, Hospital Jengka, Bandar Jengka Maran, 26400 Bandar Tun Razak, Pahang Darul Makmur. Tel: 09-466 2333 Fax: 09-466 3215</p>	<p>Investigator: Dr. Rajalingam Ramalingam</p> <p>Site- coordinator:</p>
<p>Hospital Sultanah Zahirah, Kuala Terengganu</p> <p>Dermatology Department, Hospital Sultanah Zahirah, Jalan Sultan Mahmud, 20400 Kuala Terengganu, Terengganu Darul Iman. Tel: 09-621 2121 Fax: 09-622 1820</p>	<p>Investigator: Dr. Nor Azura Mohamad</p> <p>Site- coordinator: -</p>