Annual Report of the MALAYSIAN PSORIASIS REGISTRY 2007-2013

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Ministry of Health Malaysia

NATIONAL DERMATOLOGY REGISTRY (DermReg)

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- The Dermatological Society of Malaysia
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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

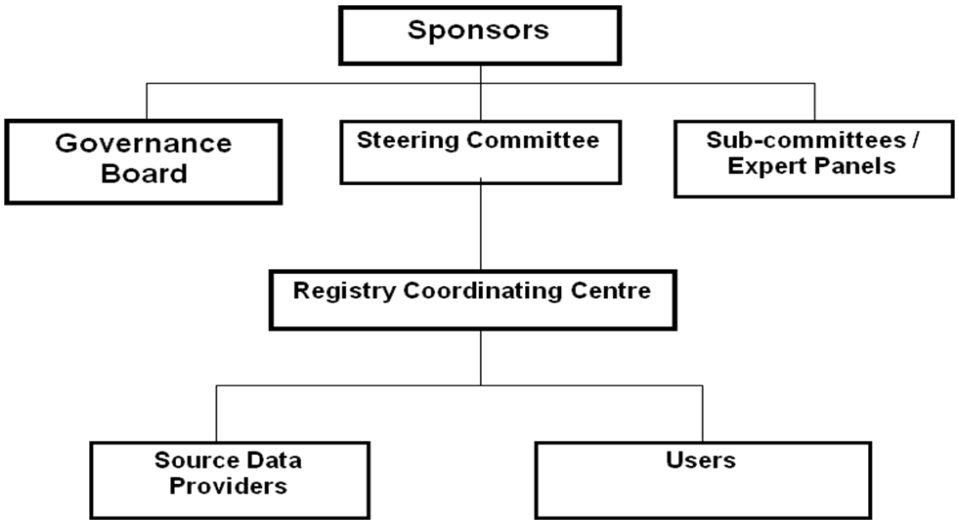
To establish a nationwide systematic prospective collection of data pertaining to skin diseases and dermatological services, in order to study the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities.

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. Clinical Research Centre, Hospital Kuala Lumpur
3. The Dermatological Society of Malaysia
4. Pharma companies – Abbvie, Leo Pharma and Johnson&Johnson 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. Datuk Dr. Roshidah Baba (Chairperson)
   Head of Dermatological Services and Senior Consultant Dermatologist
   Department of Dermatology
   Hospital Melaka

2. Dr. Najeeb Ahmad Mohd Safdar
   President of the Dermatological Society of Malaysia, and
   Consultant Dermatologist
   Hospital Tuanku Jaafar, Seremban
   Negeri Sembilan

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 Chang Choong Chor (2007-Jul 2012) Dr. Azura Mohd Affandi (July 2012 – current)	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

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	Fatimah ‘Afifah Alias

Technical Support Personnel

Epidemiology Officer	Dr. Jamaiyah Haniff Clinical Epidemiology Unit, CRC
Biostatisticians	Ms Tassha Hilda bt Adnan Ms Nurakmal 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. Mani Mala a/p T. Manikam
4.	Hospital Tuanku Fauziah, Perlis	Dr. Sharifah Farihah Syed Abas
5.	Hospital Sultanah Fatimah, Muar	Dr. Siti Khadijah Abdul Wahid
6.	Hospital Tuanku Jaafar, Seremban	Dr. Najeeb Ahmad Mohd Safdar
7.	Hospital Queen Elizabeth, Kota Kinabalu	Dr. Zaigham Mahmood
8.	Hospital Sungai Buloh	Dr. Azahzuddin Hamzah
9.	Hospital Tengku Ampuan Afzan, Kuantan	Dr. Abu Razak Yusof
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. Che Salmi Yusoff
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.	Hospital Universiti Kebangsaan Malaysia	Dr. Mazlin Mohd Baseri
18.	Pusat Perubatan Universiti Malaya	Dr. Wong Su Ming
19.	Hospital Raja Perempuan Zainab II	Dr. Zulrusydi Ismail
20.	Hospital Ampang, Selangor	Dr. Dawn Ambrose
21.	Hospital Selayang, Selangor	Dr. Hazfaneza Abdul Halim
22.	Hospital Putrajaya	Dr Nazatul Shima Abdul Rahim

OFFICIAL WEBSITE OF DermReg

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

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:

1. 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 2013, a total of 9894 patients with psoriasis from 21 dermatology centres (17 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 1.3:1. Ethnic distribution: Malay 49.8%, Chinese 22.5%, Indian 18.1%, other ethnic groups 9.5%. Mean age at notification was 45.3 ± 15.6 years (range 18 - 97 years). Most patients (98.9%) were Malaysian citizens.

In paediatric patients, male-to-female ratio was 0.8:1. Ethnic distribution: Malay 71.3%, Chinese 8.7%, Indian 11.9%, other ethnic groups 7.9%. Mean age at notification was 13.3 ± 3.6 years (range 0 - 17 years). Almost all of the paediatric patients were Malaysian citizens.

Medical History

In adult patients, mean age of onset of psoriasis was 35.2 ± 15.8 years (range 0 – 87 years). Family history of psoriasis was present in 21.4% of the patients. Among those who had positive family history, family members affected were either of their parents in 41.1%, siblings in 36.3% and children in 11.7%.

In the paediatric population, 19.0%, of them had at least one family member with psoriasis. Of these, 34.0% had either of their parents affected with psoriasis.

52.8% adult patients and 40.6% paediatric patients reported one or multiple factors which aggravated their psoriasis. The commonest aggravating factors were stress (67.4% in adult, 57.9% in paediatric), sunlight (33.7% in adult, 43.5% in paediatric) and infection (16.7% in adult, 20.6% in paediatric).

Comorbidities

In adult psoriasis patients aged 18 and above, 31.9% were overweight and 21.7% were obese, 26.1% had hypertension, 18.0% had diabetes mellitus, 17.0% had hyperlidiemia, 5.6% had ischaemic heart disease and 1.5% had previous history of stroke. 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 (28.7 %), followed by bronchial asthma (2.1%).

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 (85.6% and 79.1%, respectively). This was followed by guttate psoriasis (3.8% and 7.3% respectively), erythrodermic psoriasis (1.9% and 0.9% respectively), pustular psoriasis (1.2% and 1.6% respectively) and flexural psoriasis (0.4% and 1.2% respectively). Majority of adult patients (53.2%) had body surface area involvement of 10% or less. The pattern remains the same in child population, i.e. <5% of severity in 33.3%, followed by 5-10% of severity in 28.1% of patients.

Psoriatic arthropathy was reported in 15.1% of adult patients and only 2.0% in paediatric population. The commonest psoriatic arthropathy in adult patients was oligo/monoarthropathy (42.2%) followed by rheumatoid-like symmetrical polyarthropathy (31.1%) and distal hand joints arthropathy (29.2%).

About two-third (60.5%) of adult patients had nail changes associated with psoriasis. Among patients who had nail disease, pitting was commonest (73.7%), followed by onycholysis (49.8%), discoloration (35.6%) and subungual hyperkeratosis (15.7%). Total nail dystrophy was found in 5.0% of patients with nail disease. In paediatric cases, 39.2% of them had nail involvement. Commonest nail involvement in paediatric patients with psoriasis were pitting (89.0%), followed by onycholysis (28.0%).

Treatments received in the past 6 months

Majority of the patients (97.8% in adult and 98.4% in paediatric groups) were on topical treatment. Topical steroid was the commonest prescribed (83.8% in adult and 79.6% in paediatric patients), followed by tar preparations (76.5% in adult and 74.2% in paediatric patients), emollients (73.7% in adult and 66.4% in paediatric patients). 3.6% of adult patients and 1.4% of paediatric patients received phototherapy. Of the patients who had phototherapy, narrowband UVB (NBUVB) was the commonest used (87.1% in adult and 83.3% in paediatric patients). Systemic therapy was given in 20.0% of adult patients and in 7.1% paediatric patients. The most frequently used systemic therapy was methotrexate (70.3% in adult and 57.1% in paediatric ptients), followed by acitretin (20.9% in adult and 30.2% in paediatric patients).

Quality of Life

Measurement of quality of life using Dermatology Life Quality Index (DLQI) or child DLQI (CDLQI) was performed in 5080 adult patients (aged 17 and above) and 311 children/adolescent patients (aged 5 to 16). The mean DLQI score was 8.5 ± 6.5 for adult patients and the mean CDLQI was 7.9 ± 5.6 for children/adolescent patients. 33.1% of adult patients reported DLQI > 10, and 19.9% 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 (39.3% of adult patients and 36.9% 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 2013, a total of 9,894 patients were notified to the registry. The number of notified patients gradually increased throughout the period (**Figure 1.1**). Of the overall population, 8.9% (n=885) patients belong to the age group < 18 years and were categorized as paediatric population, 91.1% (n=9,009) patients belong to the age group ≥ 18 years of age and were categorized as the adult population.

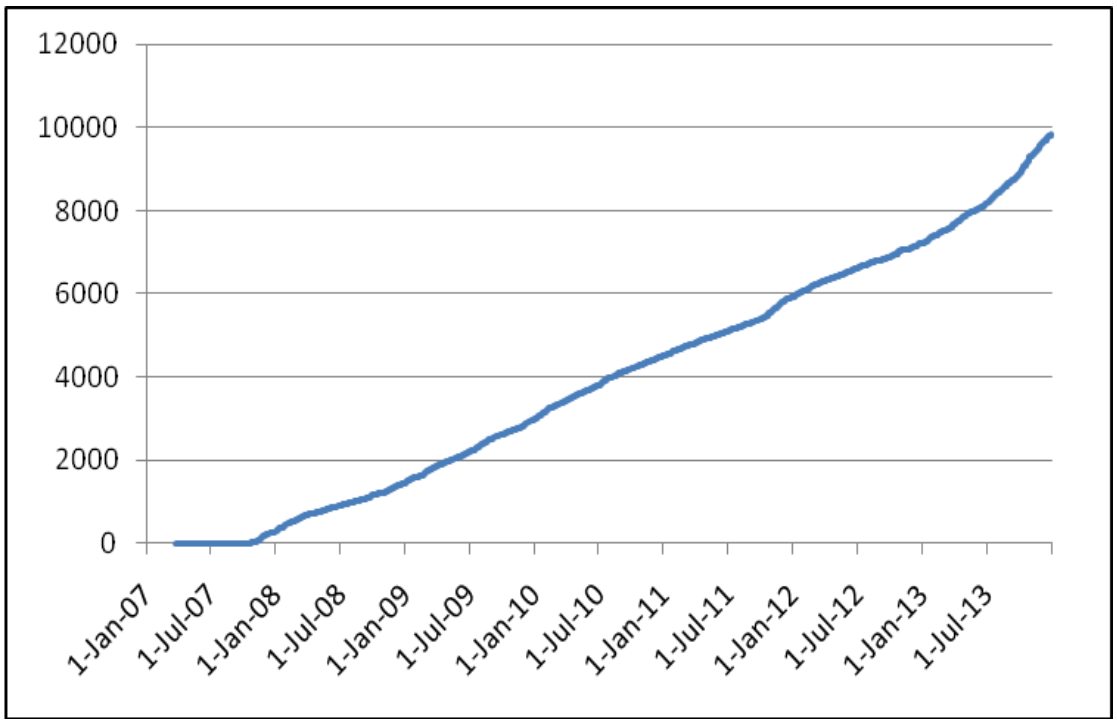


Figure 1.1 Psoriasis patients notified to the MPR

A total of 21 dermatology centres (17 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 Pulau Pinang and Hospital Tengku Ampuan Rahimah, Klang **(Table 1.1).** In the paediatric group, Hospital Kuala Lumpur notified the highest number of paediatric patients. This was followed by Hospital Tengku Ampuan Rahimah, Klang and Hospital Sultanah Bahiyah **(Table 1.2).**

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

No	Centres	No. of adult patients notified							
		2007	2008	2009	2010	2011	2012	2013	Total
1	Hospital Kuala Lumpur	60	200	252	168	85	106	566	1437
2	Hospital Pulau Pinang	20	82	268	144	217	17	158	906
3	Hospital Tengku Ampuan Rahimah	0	67	165	222	111	103	220	888
4	Hospital Melaka	0	0	81	249	202	167	148	847
5	Hospital Queen Elizabeth	19	96	113	133	133	97	128	719
6	Hospital Umum Sarawak	4	139	87	56	46	52	331	715
7	Hospital Raja Permaisuri Bainun	45	49	87	43	106	183	174	687
8	Hospital Sultanah Bahiyah	100	193	79	67	53	84	83	659
9	Hospital Sultanah Aminah	0	35	137	64	62	65	184	547
10	Hospital Tengku Ampuan Afzan	0	40	42	99	86	70	177	514
11	Hospital Sultanah Fatimah	2	36	27	36	53	154	34	342
12	Hospital Tuanku Jaafar	0	49	0	28	60	3	90	230
13	Hospital Tuanku Fauziah	0	23	48	55	44	22	20	212
14	Hospital Raja Perempuan Zainab II	0	0	0	0	9	8	87	104
15	UM Medical Centre	0	0	0	0	32	25	2	59
16	UKM Medical Centre	0	0	0	15	0	24	4	43
17	Prince Court Medical Centre	0	0	6	17	3	1	5	32
18	Hospital Sungai Buloh	5	24	1	0	0	0	0	30
19	Gleneagles Medical Centre	0	12	6	0	0	0	0	18
20	Hospital Ampang	0	0	0	0	4	3	11	18
21	Hospital Selayang	0	0	0	0	0	0	2	2
	Total	**255**	**1045**	**1399**	**1396**	**1306**	**1184**	**2424**	**9009**

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

No	Centres	No. of adult patients notified							
		2007	2008	2009	2010	2011	2012	2013	Total
1	Hospital Kuala Lumpur	10	24	19	11	8	13	21	106
2	Hospital Tengku Ampuan Rahimah	0	10	19	33	16	10	18	106
3	Hospital Sultanah Bahiyah	10	30	15	11	10	9	20	105
4	Hospital Umum Sarawak	1	20	17	10	4	11	21	84
5	Hospital Tengku Ampuan Afzan	0	6	13	14	16	17	17	83
6	Hospital Queen Elizabeth	1	8	17	12	8	9	14	69
7	Hospital Melaka	0	0	7	14	19	12	17	69
8	Hospital Sultanah Aminah	0	2	11	5	4	7	18	47
9	Hospital Sultanah Fatimah	2	8	4	10	8	9	3	44
10	Hospital Pulau Pinang	2	8	14	7	4	0	9	44
11	Hospital Raja Permaisuri Bainun	5	3	11	2	4	12	5	42
12	Hospital Tuanku Fauziah	2	10	4	6	3	2	5	32
13	Hospital Tuanku Jaafar	0	5	0	6	7	0	9	27
14	Hospital Sungai Buloh	3	5	1	0	0	0	0	9
15	Hospital Raja Perempuan Zainab II	0	0	0	0	0	1	7	8
16	Gleneagles Medical Centre	0	4	0	0	0	0	0	4
17	Universiti Malaya Medical Centre	0	0	0	0	2	0	0	2
18	Hospital Selayang	0	0	0	0	0	0	2	2
19	Prince Court Medical Centre	0	0	0	0	0	0	1	1
20	Universiti Kebangsaan Malaysia Medical Centre	0	0	0	1	0	0	0	1
	Total	**36**	**143**	**152**	**142**	**113**	**112**	**187**	**885**

There were a total of 9,894 notifications of patients with psoriasis in the MPR with new cases and follow-up treatment. 6,423 (71.3%) of the adult patients were notified once, and 1,496 (16.6%) were notified more than once (**Table 1.3**). In paediatric population, 722 (81.6%) of the patients were notified once and 112 (18.4%) 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	6423	71.3
Entry and one follow-up notifications	1496	16.6
Entry and 2 follow-up notifications	569	6.3
Entry and 3 follow-up notifications	255	2.8
Entry and 4 follow-up notifications	130	1.4
Entry and 5 follow-up notifications	76	0.8
Entry and 6 follow-up notifications	37	0.4
Entry and 7 follow-up notifications	15	0.2
Entry and 8 follow-up notifications	7	0.1
Entry and 9 follow-up notifications	1	0.0
Total	**9009**	100.0

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

Year	No.	%
Entry notification	722	81.6
Entry and one follow-up notifications	108	12.2
Entry and 2 follow-up notifications	28	3.2
Entry and 3 follow-up notifications	18	2.0
Entry and 4 follow-up notifications	6	0.7
Entry and 5 follow-up notifications	2	0.2
Entry and 6 follow-up notifications	0	0.0
Entry and 7 follow-up notifications	0	0.0
Entry and 8 follow-up notifications	0	0.0
Entry and 9 follow-up notifications	1	0.1
Total	885	100.0

CHAPTER 2

CHARACTERISTICS OF PATIENTS

In adult patients with psoriasis, 98.9% of population was Malaysian. Malays comprised the majority of patients (49.8%), followed by Chinese (22.5%), Indians (18.1%), other ethnic groups (9.5%) and Orang Asli (0.1%) (**Table 2.1**). There were more males than females (57.2% and 42.8% respectively), with a male to female ratio of 1.3:1 (**Figure 2.1**).

The mean age of the adult patients was 45.3 ± 15.6 years with a range from 18 to 97 years. Majority were married (72.9%), 23.7% were single, and the rest, either divorced or widowed (**Table 2.1**).

Almost all paediatric patients with psoriasis were Malaysian. Of the data analyzed, 71.3% paediatric patients were Malays followed by Indian in 11.9%, Chinese in 8.7% and 8.1% belonging to other ethnic groups (**Table 2.2**). Majority or 505 patients of paediatric patients were females (57.1%), while 379 were males (42.9%), giving a male-to-female ratio of 0.8:1 (**Figure 2.2**).

The mean age of the paediatric population was 13.3 ± 3.6 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	8881	98.9	884	100
	Non Malaysian	96	1.1	1	0.0
Ethnic distribution	Malay	4483	49.8	631	71.3
	Chinese	2025	22.5	77	8.7
	Indian	1628	18.1	105	11.9
	Orang Asli	11	0.1	2	0.2
	Others	859	9.5	70	7.9
Gender	Male	5152	57.2	379	42.9
	Female	3857	42.8	505	57.1
Marital status	Single	2067	23.7	879	99.9
	Married	6372	72.9	1	0.1
	Divorced	90	1.0	0	0.0
	Widowed	162	1.9	0	0.0
Age at notification (years)	Mean ± SD (Range)	45.3 ± 15.6 (18 - 97)		13.3 ± 3.6 (0-17)	

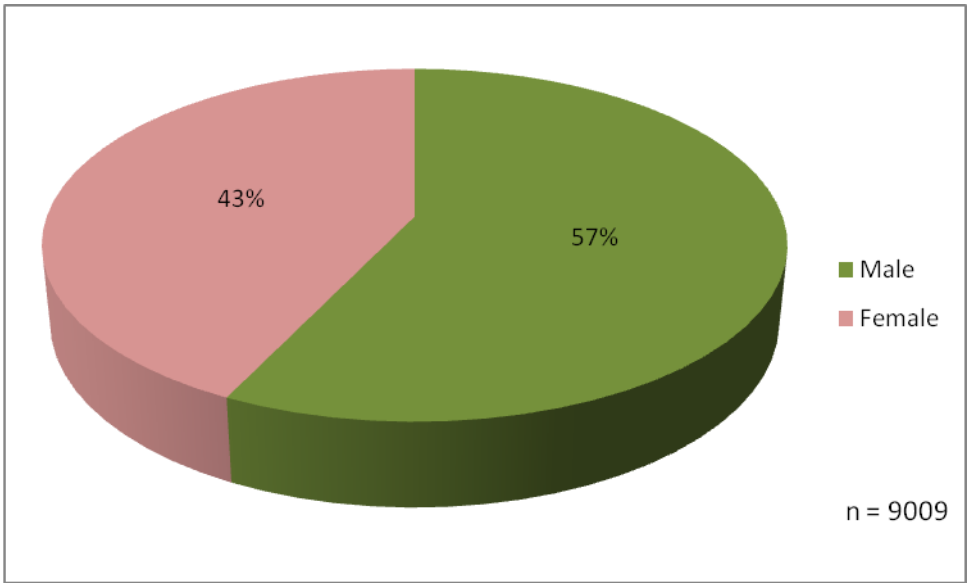


Figure 2.1 Gender distribution of adult patients with psoriasis

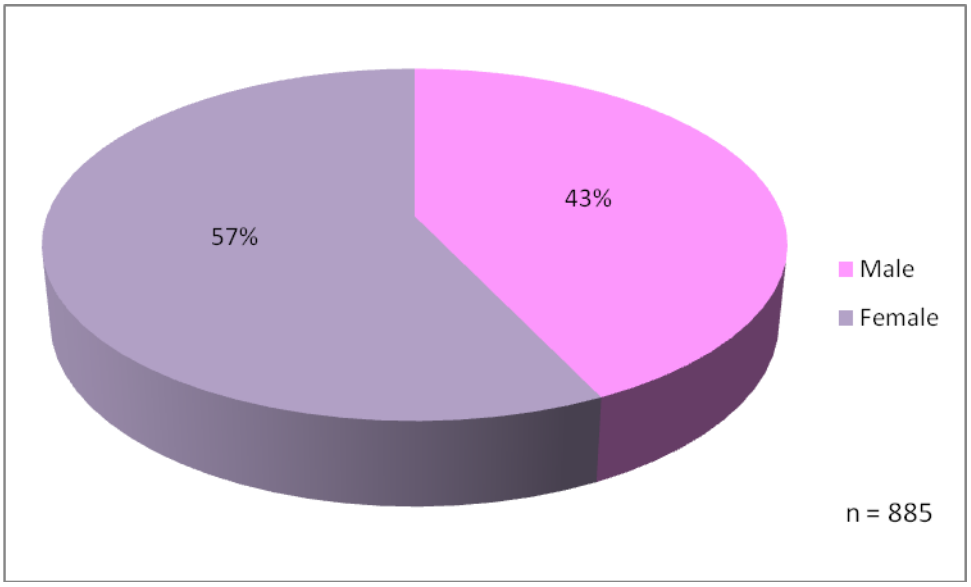


Figure 2.2 Gender distribution of paediatric patients with psoriasis

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 35.2 ± 15.8 years with a wide range from 0 to 87 years. The mean age of onset was 10.0 ± 4.4 years in the paediatric population (0-17). In the adult population, the mean age at which psoriasis was first diagnosed was 37.4 ± 15.7 years. In the paediatric category, the mean age at which psoriasis was first diagnosed was 11.3 ± 4.2 years **(Table 3.1, Table 3.2).**

Looking at the age of onset of psoriasis in adult patients, 2023 patients had the onset of psoriasis between 21-30 years old, followed by 1800 patients between 31-40 years old, and 1539 between 41-50 years old **(Figure 3.1).**

In the paediatric group, 348 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	8840	35.2	34	15.8	0	87
Age of diagnosis	8800	37.4	36	15.7	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	871	10.0	11	4.4	0	17
Age of diagnosis	868	11.3	12	4.2	0	17

Figure 3.1 Age of onset of adult patients with psoriasis

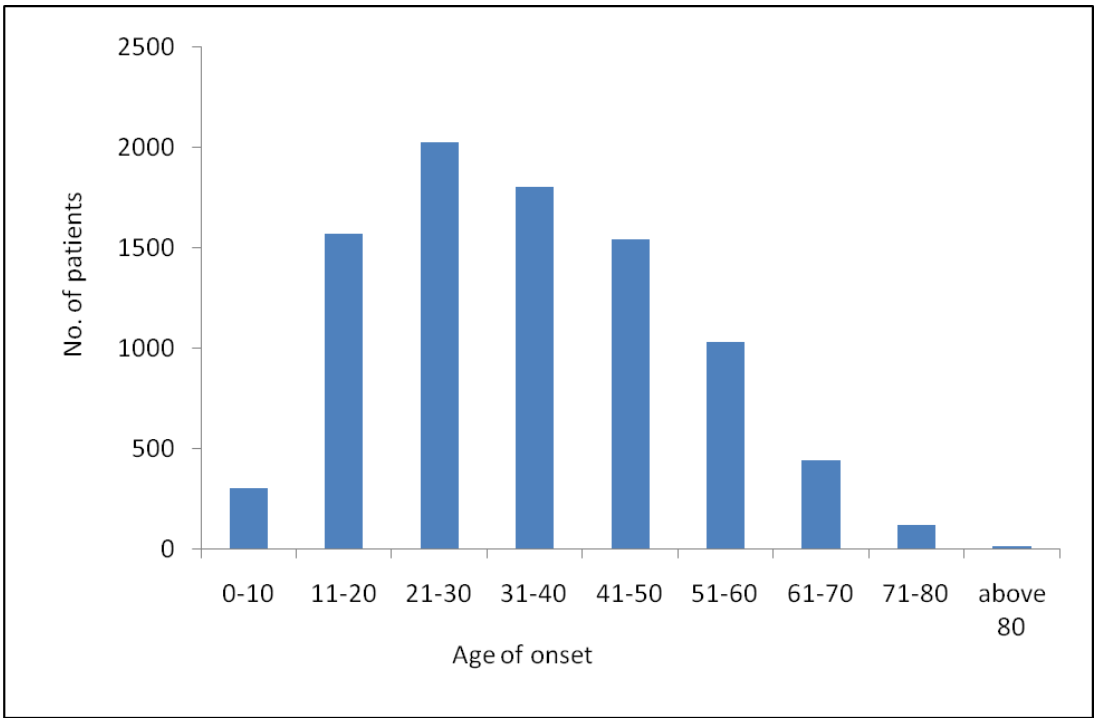
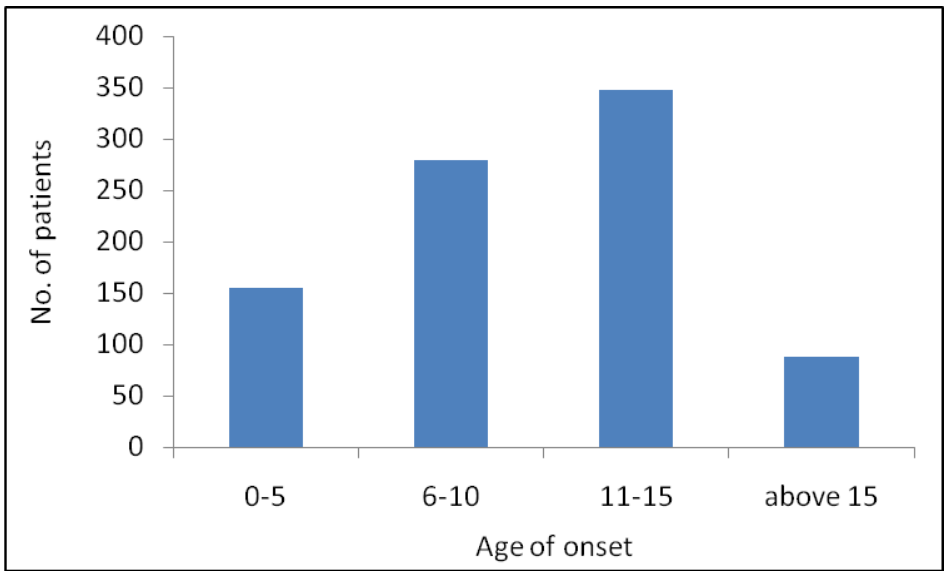


Figure 3.2 Age of onset of paediatric patients with psoriasis



Family History

Psoriasis is a skin disorder with a polygenic mode of inheritance. In our registry, about one-fifth (21.4%) 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 36.3% and children in 11.7% **(Table 3.4, Figure 3.3)**.

In the paediatric patients with psoriasis, 168 or 19.0% of them had at least one family member with psoriasis (**Table 3.3**). Of these, 34.0% 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	1, 932	21.4	168	19.0
No	6, 950	77.1	710	80.2
Not available	127	1.4	7	0.8
Total	**9, 009**	**100**	**885**	**100**

Table 3.4 Family members with psoriasis in adult and paediatric patients

Family member (one or multiple)	Adult		Paediatric	
	n	%	n	%
Father	504	26.1	29	17.3
Mother	290	15.0	28	16.7
Sibling(s)	702	36.3	38	22.6
Children	227	11.7	1	0.6
Others	472	24.4	80	47.6

Figure 3.3 Distribution of family members with psoriasis in adult patients

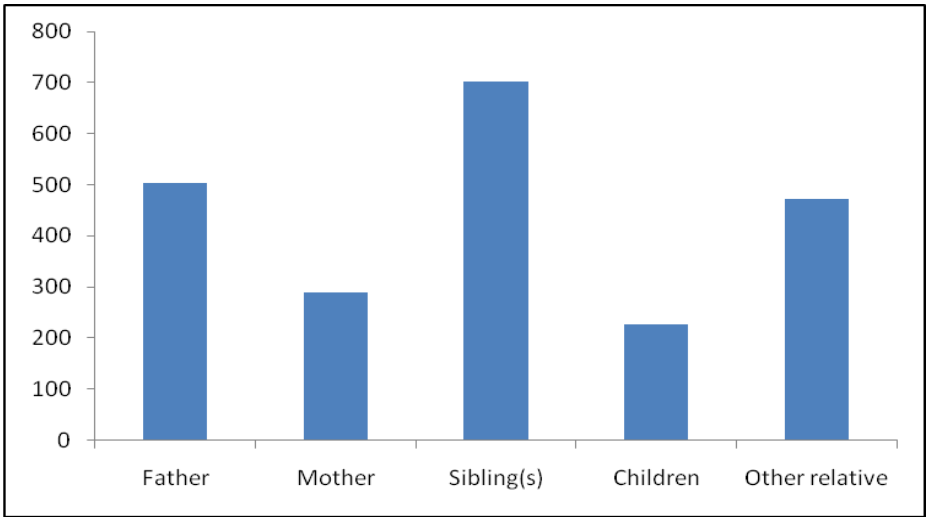
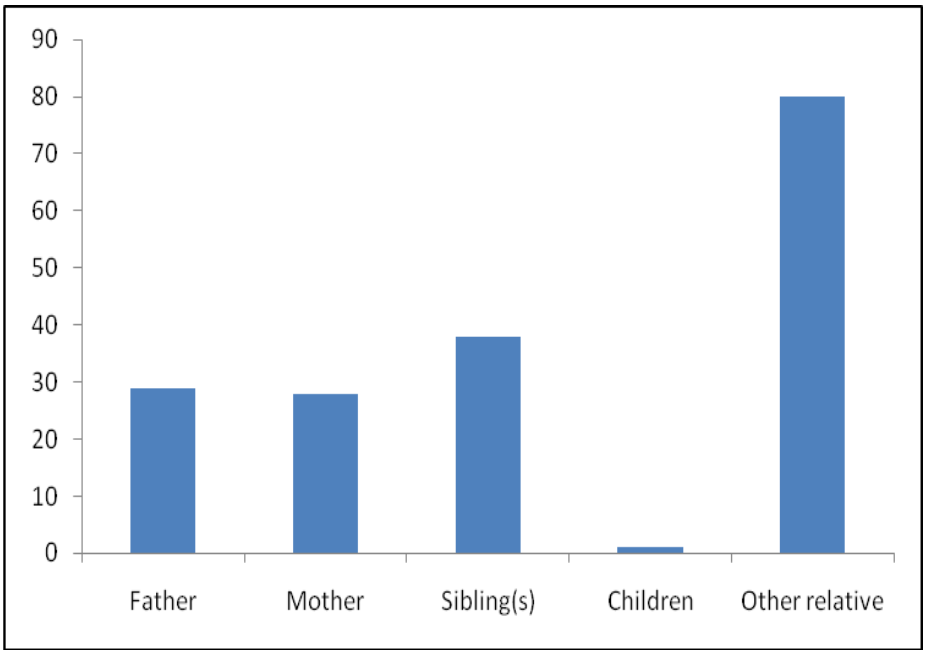


Figure 3.4 Distribution of family members with psoriasis in paediatric patients



Aggravating factors of psoriasis

More than half (52.8%) of adult patients with psoriasis reported one or multiple factors which worsened their psoriasis (**Table 3.5**). Stress was the commonest aggravating factor (67.4%), followed by sunlight (33.7%) and infection (16.7%). Other identified aggravating factors included trauma (7.5%), smoking (7.4%), drugs (5.0%), alcohol (3.3%), pregnancy (3.1%) and topical treatment (1.5%) (**Table 3.6**).

40.6% 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 (57.9%), sunburn (43.5%) and infection (20.6%) (**Table 3.7**).

Analyzing the subgroup of patients who reported infection as an aggravating factor, upper respiratory tract infection (11.9% in adult; 16.2% in paedatric) appeared to be the commonest infective trigger (**Table 3.7**). Common medications found to aggravate psoriasis were withdrawal of systemic steroids (30.4%), beta blocker (24.6%), traditional medication/ homeopathy (9.8%), non-steroidal anti-inflammatory drugs (9.8%), antibiotics (9.8%%) and traditional/homeopathy (9.0%) (**Table 3.8**).

Table 3.5 Aggravating factors of psoriasis in adult and paediatric patients

Characteristics	Adult		Pediatric	
	n	%	n	%
Yes	4754	52.8	359	40.6
No	4036	44.8	514	58.1
Not available	219	2.4	12	1.4
Total	**9009**	**100**	**885**	**100**

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

	Adult		Pediatric	
Aggravating factors (one or multiple)	**n**	**%**	**n**	**%**
Stress	3204	67.4	208	57.9
Sunlight	1601	33.7	156	43.5
Infection	796	16.7	74	20.6
Trauma	355	7.5	30	8.4
Smoking	352	7.4	6	1.7
Drugs	236	5.0	4	1.1
Alcohol	157	3.3	0	0.0
Pregnancy	145	3.1	0	0.0
Topical treatment	71	1.5	3	0.8

Table 3.7 Infections which aggravated psoriasis in adult patients

	Adult		Paediatric	
Infection	**n**	**%**	**n**	**%**
Upper respiratory tract infection	95	11.9	12	16.2
Fever / febrile illness	47	5.9	2	2.7
HIV	5	0.6	0	0.0
Viral infection	5	0.6	1	1.4
Chickenpox	4	0.5	2	2.7
Dengue fever	3	0.4	0	0.0
Skin infection	3	0.4	0	0.0
Chikugunya	1	0.1	0	0.0

Table 3.8 Drugs which aggravated psoriasis in adult and paediatric patients

	Adult		Paediatric	
Drug	**n**	**%**	**n**	**%**
Systemic steroids (withdrawal)	38	30.4	0	0.0
Beta-blocker	30	24.6	0	0.0
Antibiotic	12	9.8	0	0.0
NSAIDs /analgesia	12	9.8	1	33.3
Traditional/ Homeopathy	11	9.0	1	33.3
Antimalarial drug	3	2.5	0	0.0
Oral contraceptive pill	3	2.5	0	0.0
Topical tar preparation	2	1.6	0	0.0
ACE inhibitor	2	1.6	0	0.0
Sodium valporate	1	0.8	0	0.0
Daivobet	1	0.8	1	33.3
“Gamat” (Sea cucumber extract)	1	0.8	0	0.0
Other analgesia	3	2.5	0	0.0
Others	3	2.5	0	0.0
Not available	81			

Disease Burden in the last 6 months:

Analysis of daily activities among adult psoriasis patients showed that 86.9% of them could perform their routine activities regularly. 9.0% of the population reportedly had to take off from work/school from anywhere between 1- 90 days due to psoriasis **(Table 3.9).** 76.3% of adult patients with psoriasis visited the clinic between 1-5 times in the past 6 months **(Table 3.9).** 2.6% of adult patients were hospitalized at least once in the last 6 months, and majority (93.2%) did not require any hospitalization **(Table 3.10).**

Analysis of daily activities among paediatric psoriasis patients showed that, 89.4% of them could perform their routine activities regularly. 7.5% of the population reportedly had to take off from work/school from anywhere between 1- 120 days due to psoriasis **(Table 3.11).** 77.2% of paediatric patients with psoriasis visited the clinic between 1-5 times in the past 6 months **(Table 3.11).** Only 1.3% of paediatric patients were hospitalized at least once in the last 6 months, and the majority (95.6%) 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

	Number of days off from work/school due to psoriasis		Number of clinic visits due to psoriasis	
	n	**%**	**n**	**%**
0	7832	86.9	1258	14.0
1-5	576	6.4	6872	76.3
6-10	105	1.7	409	4.5
>10	79	0.9	100	1.1

Table 3.10 Number of hospital admissions in adult patients with psoriasis

Number of hospital admissions due to psoriasis	n	%
0	8395	93.2
1-3	210	2.3
>3	23	0.3

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

	Number of days off to work/school due to psoriasis		Number of clinic visits due to psoriasis	
	n	**%**	**n**	**%**
0	791	89.4	130	14.7
1-5	43	4.9	683	77.2
6-10	10	1.1	39	4.4
>10	13	1.5	6	0.7

Table 3.12 Number of hospital admissions in paediatric patients with psoriasis

Number of hospital admissions due to psoriasis	n	%
0	846	95.6
1-3	11	1.2
>3	1	0.1

Smoking

Data on smoking status was only available for 3296 (33.3%) of patients. This was because the smoking status data was not collected in the earlier version of the Case Report Form. A total of 403 (7.0%) adult patients with psoriasis were current smokers, while in paediatric population, it was 10 (1.1%) (**Table 3.13**).

Table 3.13 Cigarette smoking in adult and paediatric patients with psoriasis

	Adult		Paediatric	
Cigarette smoking	**n**	**%**	**n**	**%**
Never smoked	2011	22.3	241	27.2
Ex-smoker	403	4.5	1	0.1
Current smoker	630	7.0	10	1.1

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, 31.9% were overweight and 21.7% were obese, 26.1% had hypertension, 18.0% had diabetes mellitus, 17.0% had hyperlipidaemia, 5.6% had ischaemic heart disease and 1.5% 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 (28.7 %), followed by bronchial asthma (2.1%), Down syndrome (0.7%), diabetes mellitus (0.5%), hyperlipidaemia (0.3%), hypertension (0.3%) and congenital heart disease (0.2%). 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 comorbidities in adult patients with psoriasis

Co-morbidity	n	%
Obesity*	1956	21.7
Overweight*	2875	31.9
Hypertension	2352	26.1
Diabetes mellitus	1619	18.0
Hyperlipidaemia	1594	17.7
Ischaemic heart disease	504	5.6
Stroke	138	1.5

* 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≥85th centile)	254	28.7
Bronchial asthma	19	2.1
Down syndrome	6	0.7
Diabetes mellitus	4	0.5
Hyperlipidaemia	3	0.3
Hypertension	3	0.3
Congenital heart disease	2	0.2
Stroke	1	0.1
Thalassemia	1	0.1
Atrial defect	1	0.1
Obstructive sleep apnoea	1	0.1
Brain tumor	1	0.1
Epilepsy	1	0.1

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

Co-morbidities	Arthritis Absent (n=8220)		Arthritis Present (n=1365)		Simple Logistic Regression[a]		
	n	%	n	%	Crude OR	(95% CI)	P-value
Diabetes Mellitus	1239	15.1	292	21.4	1.53	(1.33, 1.76)	<0.001
Hypertension	1796	21.8	445	32.6	1.72	(1.52, 1.95)	<0.001
Hyperlipidaemia	1160	14.1	326	23.9	1.90	(1.65, 2.19)	<0.001
BMI ≥ 30 (obesity WHO)	1659	20.2	333	24.4	1.29	(1.12, 1.47)	<0.001
Ischaemic heart disease	407	5.0	81	5.9	1.21	(0.94, 1.54)	0.136
Cerebrovascular disease	116	1.4	15	1.1	0.8	(0.45, 1.33)	0.347

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 85.6% of patients, followed by guttate psoriasis in 3.8% of patients and erythrodermic psoriasis in 1.9% of the patients. Similarly, in paediatric patients, plaque psoriasis accounted for 79.1% of patients, followed by guttate psoriasis in 7.3% of patients and pustular psoriasis in 1.6% 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, 26.6% of our patients had <5% BSA affected and 26.6% of our patients had 5-10% of BSA affected. Severe psoriasis with >10% BSA affected occurred in 17.0% adult patients, while 1.7% had erythrodermic psoriasis, i.e. >90% BSA involved. In paediatric patients population, 33.3% had <5% BSA involvement, 28.1% had 5-10% BSA involvement, 10.8% had 10-90% BSA and 0.5% were erythrodermic (**Table 5.2**).

Table 5.1 Type of psoriasis in adult and paediatric patients

BMI	Adult		Paediatric	
	n	%	n	%
Plaque	7710	85.6	700	79.1
Guttate	345	3.8	65	7.3
Pustular	107	1.2	14	1.6
Erythrodermic	175	1.9	8	0.9
Flexural/inverse	38	0.4	11	1.2
Palmoplantar non-pustular	22	0.2	2	0.2
Others	160	1.8	51	5.8
Not available	452	5.0	34	3.8
Total	**9009**	**100**	**885**	**100**

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

Body surface area involved	Adult		Paediatric	
	n	%	n	%
<5%	2399	26.6	295	33.3
5 - 10%	2400	26.6	249	28.1
>10% to 90%	1533	17.0	96	10.8
>90%	156	1.7	4	0.5
Not available	2521	28.0	241	27.2
Total	**9009**	**100**	**885**	**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 (37.0%), trunk (32.8%) and upper limbs (29.1%) (**Table 5.3**). Whereas in paediatric patients, moderate and severe lesions were seen mainly on the scalp region (35.5%), followed by the trunk (24.8%) **(Table 5.4).**

Almost half of the adult (48.0%) and paediatric (46.7%) 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 Severity of body parts affected in adult patients with psoriasis

Body part	Clinical score									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	1801	20.0	4551	50.5	1978	22.0	406	4.5	273	3.0
Face & neck	4324	48.0	3599	39.9	652	7.2	74	0.8	360	4.0
Trunk	2210	24.5	3518	39.0	2579	28.6	378	4.2	324	3.6
Upper limbs	1965	21.8	4107	45.6	2312	25.7	309	3.4	316	3.5
Lower limbs	1572	17.4	3790	42.1	2825	31.4	503	5.6	319	3.5

Table 5.4 Severity of body parts affected in paediatric patients with psoriasis

Body part	Clinical score									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	147	16.6	397	44.9	250	28.2	65	7.3	26	2.9
Face & neck	413	46.7	366	41.4	61	6.9	7	0.8	38	4.3
Trunk	270	30.5	363	41.0	194	21.9	26	2.9	32	3.6
Upper limbs	297	33.6	385	43.5	145	16.4	21	2.4	37	4.2
Lower limbs	298	33.7	357	40.3	173	19.5	22	2.5	35	4.0

Majority of adult patients with psoriasis had nail involvement (60.5%) (**Table 5.5**). Among patients who had psoriatic nail disease, most of them had pitting of the nails (73.7%). Other common features were onycholysis (49.8%), discoloration (35.6%) and subungual hyperkeratosis (15.7%). Total nail dystrophy was found in 5.0% of patients with nail involvement (**Table 5.6**).

There were 347 (39.2%) paediatric patients with nail involvement (**Table 5.5**). Most of them had pitting (89.0%), followed by onycholysis (28.0%), discoloration (14.4%), subungual hyperkeratosis (3.7%) and total nail dystrophy (1.7%) (**Table 5.6**).

Joint disease related to psoriasis was reported in 15.1% of the adult patients, while only 2.0% paediatric patients had joint involvement (**Table 5.7**). 266 adult patients had test for Rheumatic factor. Of these, only 1.3% was positive (**Table 5.8**).

In adult patients, the commonest type of psoriatic arthropathy was oligo-/monoarthropathy (42.2%). This was followed by rheumatoid-like symmetrical polyarthropathy (31.1%), distal hand joints arthropathy (29.2%), spondylitis/sacroilitis (8.9%) and arthritis mutilans (2.9%) (**Table 5.9**). Morning stiffness of > 30 minutes was reported in 30.8% of adult and 16.7% of paediatric patients. Enthesopathy was reported in 11.4% of adult patients and 5.6% of paediatric patients.

Table 5.5 Nail involvement in adult and paediatric patients with psoriasis

	Adult		Paediatric	
Nail involvement	**n**	**%**	**n**	**%**
Yes	5449	60.5	347	39.2
No	3394	37.7	526	59.4
NA	166	1.8	12	1.4
Total	**9009**	**100**	**885**	**100**

Table 5.6 Nail features in adult and paediatric patients with psoriasis

	Adult		Paediatric	
Nail features	**n**	**%**	**n**	**%**
Pitting	4016	73.7	309	89.0
Onycholysis	2712	49.8	97	28.0
Discoloration	1942	35.6	50	14.4
Subungual hyperkeratosis	856	15.7	13	3.7
Total nail dystrophy	273	5.0	6	1.7

Table 5.7 Joint disease in adult and paediatric patients with psoriasis

	Adult		Paediatric	
Joint disease	**n**	**%**	**n**	**%**
Yes	1364	15.1	18	2.0
No	7464	82.9	848	95.8
Not available	181	2.0	19	2.1
Total	**9009**	**100**	**885**	**100**

Table 5.8 Rheumatoid factor in adult and paediatric patients with psoriasis

	Adult		Paediatric	
Rheumatoid factor	**n**	**%**	**n**	**%**
Positive	18	1.3	2	11.1
Negative	248	18.2	15	83.3

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

	Adult		Paediatric	
Type of joint disease (one or multiple)	**n**	**%**	**n**	**%**
Oligo-/Monoarthropathy	575	42.2	9	50.0
Symmetrical polyarthropathy (Rheumatoid like)	424	31.1	3	16.7
Distal hand joints arthropathy	398	29.2	7	38.9
Spondylitis / Sacroiliitis	121	8.9	0	0.0
Arthritis mutilans	39	2.9	0	0.0

Most of the patients with psoriatic arthropathy experienced joint pain at time of presentation, both in adults (78.1%) and paediatric (88.9%) patients. Joint swelling was present in 33.1% adults and 11.1% of paediatric patients, while joint deformity occurred in 23.4% of adult patients and 16.7% of paediatric patients (**Table 5.10**, **Table 5.11**). The commonest type of joint deformity was swan neck deformity (17.2%). This was followed by fixed flexion deformity (10.3%), Boutonniere deformity (6.6%), distal hand joint deformity (4.4%), subluxation (2.8%), arthritis mutilans (1.6%), proximal interphalangeal joint deformity (1.3%), rheumatoid arthritis-like (0.9%) and bamboo spine (0.9%) (**Table 5.12**).

Table 5.10 Symptoms of psoriatic arthritis in adult patients with psoriasis

	Yes		No		Not available	
Symptoms	**n**	**%**	**n**	**%**	**n**	**%**
Pain	1065	78.1	219	16.1	80	5.9
Swelling	452	33.1	824	60.4	88	6.5
Deformity	319	23.4	952	69.8	93	6.8

Table 5.11 Symptoms of psoriatic arthritis in paediatric patients with psoriasis

	Yes		No		Not available	
Symptoms	**n**	**%**	**n**	**%**	**n**	**%**
Pain	16	88.9	1	5.6	1	5.6
Swelling	2	11.1	14	77.8	2	11.1
Deformity	3	16.7	13	72.2	2	11.1

Table 5.12 Type of joint deformities in adult patients with psoriasis

Type of joint deformity	n	%
Swan neck deformity	55	17.2
Fixed flexion	33	10.3
Boutonniere deformity	21	6.6
Distal hand joint deformity	14	4.4
Subluxation	9	2.8
Arthritis mutilans	5	1.6
Proximal interphalangeal joint deformity	4	1.3
Bamboo spine	3	0.9
Rheumatoid arthritis-like	3	0.9
Others	45	14.1

By using multiple logistic regressions, 8 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), female gender, Indian ethnicity, BMI ≥ 30, patients with erythrodermic psoriasis, presence of nail involvement and DLQI > 10 (**Table 5.13**).

Table 5.13 Factors associated with psoriatic arthritis in adult patients

Variable	Absent (n=8220)		Present (n=1365)		Multiple Logistic Regression[a]		
	n	%	n	%	Adj. OR	(95% CI)	P-value
Age:							
<18 years	814	9.9	18	1.3	1.00	-	-
18-40 years	3101	37.7	412	30.2	2.67	(0.64, 11.20)	0.180
41-60 years	2984	36.3	727	53.3	6.00	(1.43, 25.19)	0.014
>60 years	1321	16.1	208	15.2	5.11	(1.19, 21.92)	0.028
Age of onset:							
≤40 years (Type 1)	5432	66.1	923	67.6	1.49	(0.68, 0.96)	0.0152
>40 years (Type 2)	2658	32.3	420	30.8	1.00	-	-
Duration of disease:							
≤5 years	4062	49.4	427	31.3	-	-	-
>5 years	4028	49.0	916	67.1	-	-	-
Gender:							
Male	4695	57.1	678	49.7	1.00	-	-
Female	3525	42.9	687	50.3	1.73	(1.44, 2.09)	<0.001
Ethnicity:							
Indian	1384	16.8	299	21.9	1.45	(1.15, 1.82)	0.002
Non-Indian	6833	83.1	1066	78.1	1.00	-	-

Obesity group (WHO):	6129	74.6	956	70.0	-	-	-
BMI <30	1659	20.2	333	24.4	-	-	-
BMI ≥30							
Type of psoriasis:							
Erythrodermic	130	1.6	59	4.3	1.75	(1.09, 2.82)	0.002
Non-erythrodermic	7792	94.8	1240	90.8	1.00	-	-
Body surface area:							
≤10%	4614	56.1	700	51.3	1.00	-	-
>10%	1424	17.3	349	25.6	1.35	(1.09, 1.67)	0.006
Total skin score:							
<10	7551	91.9	1197	87.7	-	-	-
≥10	571	6.9	146	10.7	-	-	-
Nail involvement:							
Yes	4680	56.9	1044	76.5	2.40	(1.92, 3.00)	<0.001
No	3489	42.4	303	22.2	1.00	-	-
DLQI:							
≤10	2571	31.3	434	31.8	1.00	-	-
>10	1194	14.5	318	23.3	1.55	(1.27, 1.89)	<0.001

*Result was based on available information.
Adj. OR = Adjusted odds ratio.
[a] Forward LR was applied.

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 (97.8%) (**Table 6.1**). In 74.2% of the patients, topical monotherapy was the only treatment given. The most commonly used topical medication was topical steroids (83.8%). This was followed by topical tar preparation (76.5%), emollients (73.7%), keratolytics (55.8%) vitamin D analogue such as calcipotriol (23.2%) and calcipotriol with betamethasone dipropionate 6.6%. Dithranol was less favoured and used in 2.5% of patients only (**Table 6.2**).

In the paediatric patients, 98.4% of patients received topical therapy **(Table 6.1)**. The most common type of topical therapy was topical steroids (79.6%), followed by tar preparation (74.2%) and emollient (66.4%) **(Table 6.2).**

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

	Adult		Paediatric	
Topical therapy	**n**	**%**	**n**	**%**
Yes	8814	97.8	871	98.4
No	2	0.0	0	0.0
Not available	193	2.1	14	1.6
Total	9009	100	677	100

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

	Adult		Paediatric	
Topical therapy	**n**	**%**	**n**	**%**
Topical steroids	7384	83.8	693	79.6
Tar preparation	6746	76.5	646	74.2
Emollient	6497	73.7	578	66.4
Keratolytics	4920	55.8	424	48.7
Calcipotriol	2045	23.2	159	18.3
Calcipotriol with betamethasone dipropionate	583	6.6	43	4.9
Dithranol (anthralin)	221	2.5	26	3.0
Others	216	2.5	22	2.5

In the last six months prior to notification, 3.6% of adult patients and 1.4% of paediatric patients received phototherapy (**Table 6.3**).

Most of adult patients (87.1%) and paediatric patients (83.3%) were given narrowband UVB (NB-UVB) while 7.4% of adult patients with psoriasis were given broadband UVB (BB-UVB). Less popular modalities in adult patients were oral PUVA (4.3%), topical PUVA (2.2%), bath PUVA (0.9%) and excimer laser (0.3%). 16.7% of paediatric patients were given topical PUVA (**Table 6.4**).

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

	Adult		Paediatric	
Phototherapy	**n**	**%**	**n**	**%**
Yes	325	3.6	12	1.4
No	8275	91.9	842	95.1
Not available	409	4.5	31	3.5
Total	**9009**	**100**	**885**	**100**

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

	Adult		Paediatric	
Types of Phototherapy	**n**	**%**	**n**	**%**
Narrowband UVB	283	87.1	10	83.3
Broadband UVB	24	7.4	0	0.0
Oral PUVA	14	4.3	0	0.0
Topical PUVA	7	2.2	2	16.7
Bath PUVA	3	0.9	0	0.0
Excimer laser	1	0.3	0	0.0
Others	3	0.9	0	0.0

Systemic therapy was used in 20.0% of adult patients and only 7.1% in paediatric patients with psoriasis (**Table 6.5**).

In adult patients, the commonest systemic agents used were methotrexate (70.3%), followed by acitretin (20.9%) and sulphasalazine (5.6%). 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 (57.1%). This was followed by acitretin in 30.2% of patients **(Table 6.6).**

A total of 38 adult patients received biologic treatment. The biologic therapy most frequently used was adalimumab (10 patients), followed by ustekinumab and etanercept (5 patients each), efalizumab (4 patients) and infliximab (3 patients). The name of the biologic agent was not specified in 11 patients.

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

	Adult		Paediatric	
Systemic therapy	**n**	**%**	**n**	**%**
Yes	1803	20.0	63	7.1
No	6937	77.0	796	89.9
Not available	269	3.0	26	2.9
Total	7362	100	885	100

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

	Adult		Paediatric	
Types of systemic therapy	**n**	**%**	**n**	**%**
Methotrexate	1267	70.3	36	57.1
Acitretin	377	20.9	19	30.2
Sulphasalazine	101	5.6	1	1.6
Cyclosporin	77	4.3	1	1.6
Hydroxyurea	17	0.9	0	3.2
Biologics	38	2.1	0	0.0
Systemic corticosteroids	99	5.5	5	7.9
Others	64	3.5	2	3.2

CHAPTER 7

QUALITY OF LIFE

There were a total of 5080 adult patients (aged 17 and above) and 311 paediatric patients 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 7.9 ± 5.6.

The responses for each question of the DLQI and CDLQI were tabulated in **Table 7.1** and **7.2** respectively. 1683 (33.1%) of adult patients reported DLQI > 10, indicating severe quality of life impairment due to psoriasis or its treatment. There were 279 adults (5.5%) who had a DLQI > 20 indicating extremely large effect on their quality of life by psoriasis. Nevertheless, 13.5% 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. 39.3% 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 63.2% of the adult patients did not have or only have a little effect in this aspect.

In the paediatric group, 19.9% 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 14 patients (4.5%) 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". 36.9% 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 84.3% 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?	921 (10.6)	2396 (27.6)	4412 (50.8)	956 (11.0)	0 (0.0)
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	1350 (15.6)	2143 (24.7)	3124 (36.0)	2052 (23.7)	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?	786 (9.0)	1609 (18.5)	2895 (33.3)	3141 (36.1)	262 (3.0)
4	Over the last week, how much has your skin influenced the clothes you wear?	681 (7.8)	1640 (18.9)	2895 (33.3)	3210 (37.0)	260 (3.0)
5	Over the last week, how much has your skin affected any social or leisure activities?	808 (9.3)	1640 (18.9)	2895 (33.3)	3210 (37.0)	260 (3.0)
6	Over the last week, how much has your skin made it difficult for you to do any sport?	819 (9.5)	1492 (17.3)	2397 (27.7)	2621 (30.3)	1317 (15.2)
7	Over the last week, has your skin prevented you from working or studying?	0 (0.0)	643 (11.1)	1894 (32.7)	3258 (56.2)	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?	417 (4.8)	1030 (11.9)	2635 (30.4)	4214 (48.6)	376 (4.3)
9	Over the last week, how much has your skin caused sexual difficulties?	282 (3.3)	493 (5.7)	1507 (17.5)	4132 (48.0)	2194 (25.5)
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?	544 (6.3)	1345 (15.5)	3062 (35.3)	3283 (37.8)	445 (5.1)

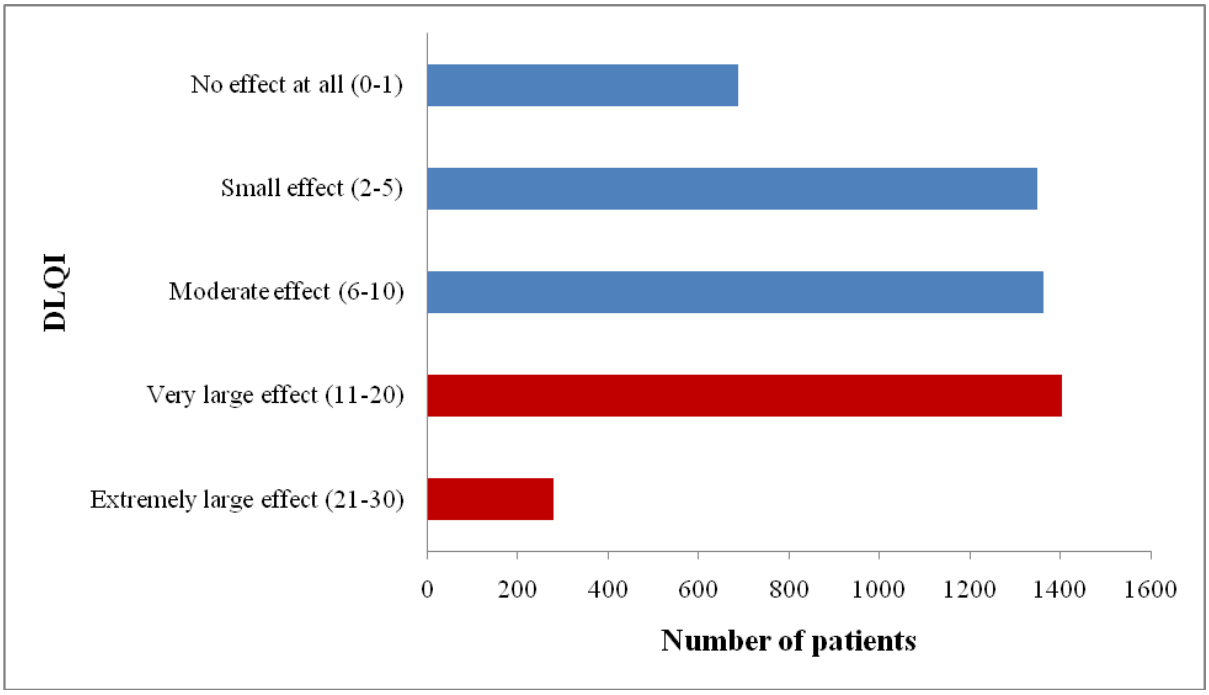


Figure 7.1 Quality of life in adult patients with psoriasis

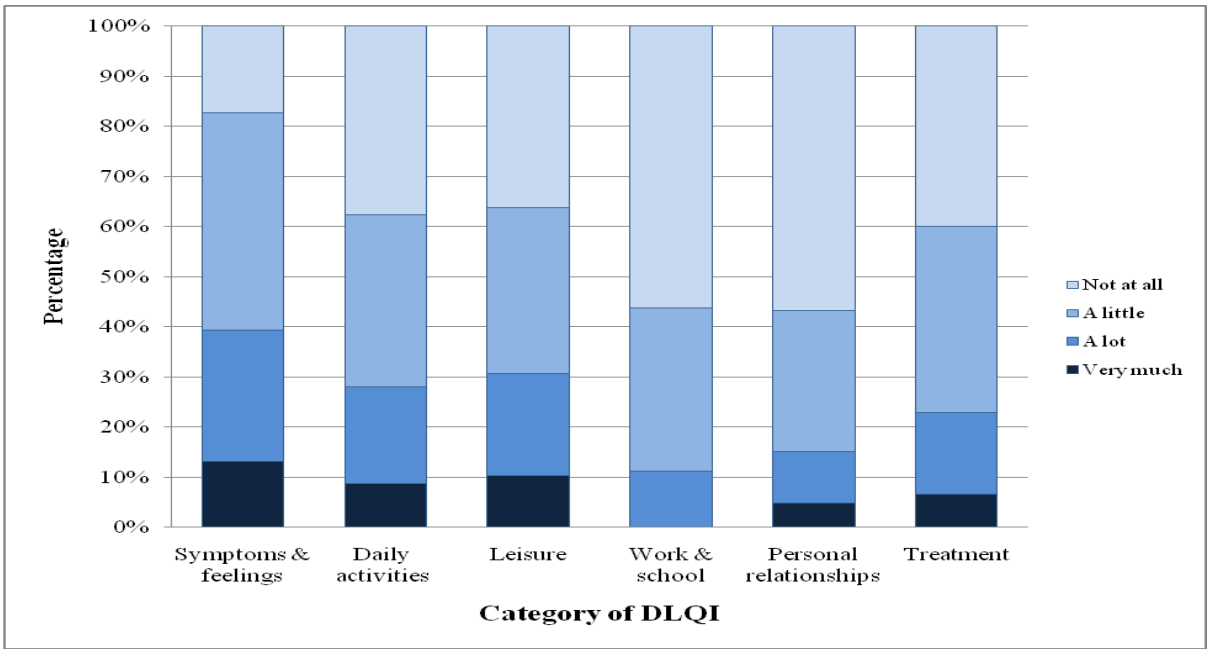


Figure 7.2 Quality of life impairment in adults psoriasis patients based on category of DLQI

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?	50 (8.9)	164 (29.1)	296 (52.5)	54 (9.6)	
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	84 (14.9)	144 (25.6)	221 (39.3)	113 (20.1)	
3	Over the last week, how much has your skin affected your friendships?	21 (3.8)	76 (13.6)	166 (29.7)	296 (53.0)	
4	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	25 (4.3)	100 (7.3)	194 (33.5)	260 (44.9)	
5	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	31 (5.5)	93 (16.6)	196 (35.0)	240 (42.9)	
6	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	38 (6.8)	86 (15.4)	153 (27.3)	283 (50.5)	
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?	21 (3.8)	73 (13.1)	179 (32.1)	284 (51.0)	
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?	25 (4.5)	54 (9.6)	142 (25.4)	339 (60.5)	
9	Over the last week, how much has your sleep been affected by your skin problem?	31 (5.8)	71 (13.3)	173 (32.5)	257 (48.3)	
10	Over the last week, how much of a problem has the treatment for your skin been?	27 (4.8)	80 (14.3)	192 (34.4)	259 (46.4)	

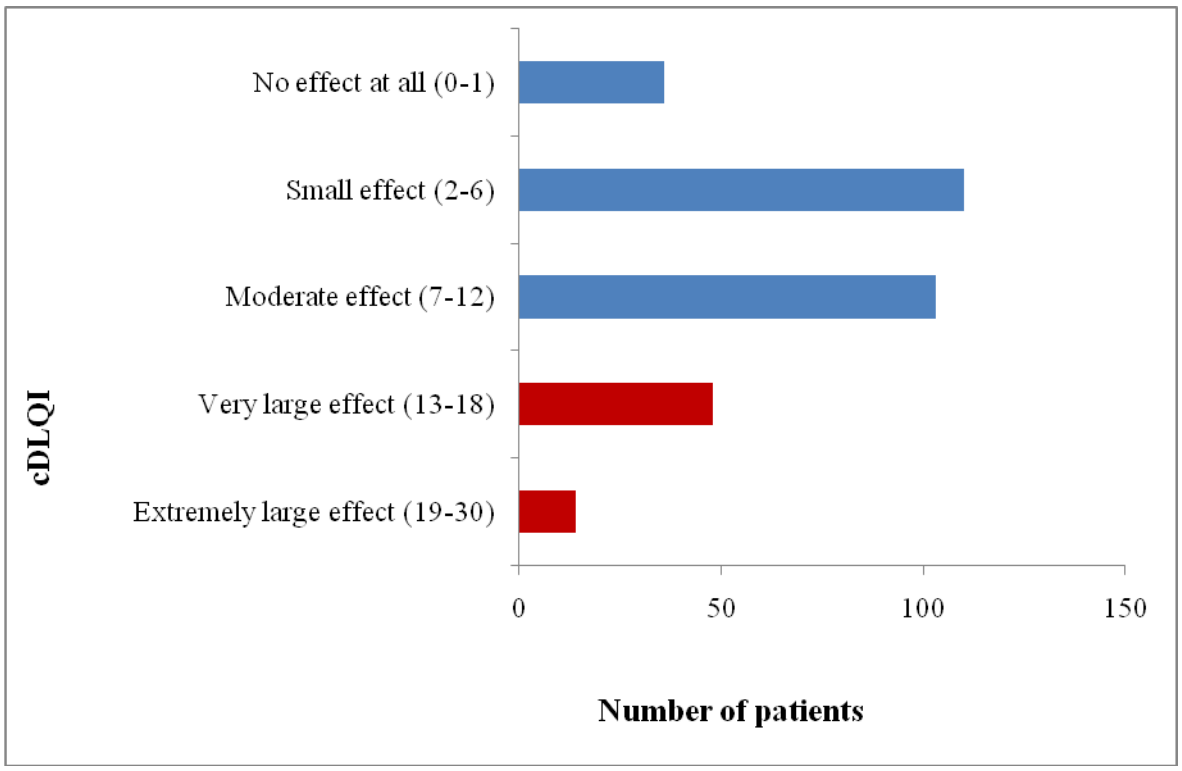


Figure 7.3 Quality of life in paediatric patients with psoriasis

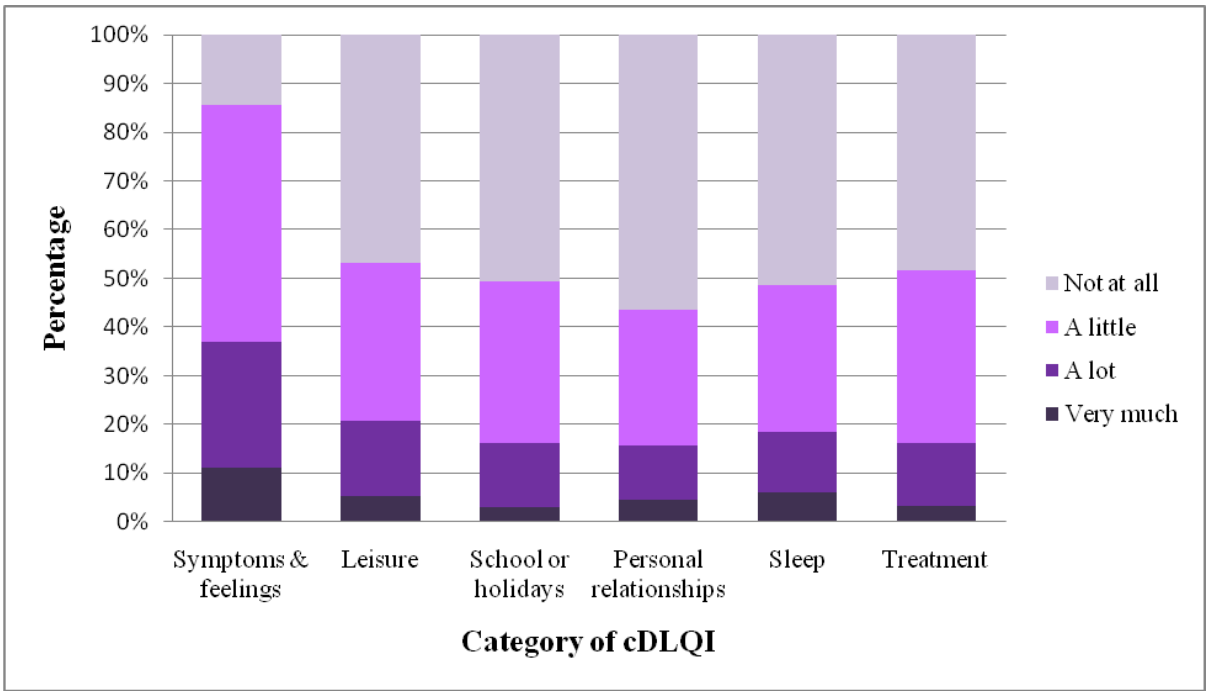


Figure 7.4 Quality of life impairment in paediatric patients with psoriasis based on category of DLQI

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

Parameters	Arthritis Absent (n=8220)		Arthritis Present (n=1365)		Simple Logistic Regression[a]		
	n	%	n	%	Crude OR	(95% CI)	P-value
DLQI, median (IQR)	7	9	9	11	1.04	(1.03, 1.06)	<0.001
≤10	2571	31.3	434	31.8	1.00	-	-
>10	1194	14.5	318	23.3	1.58	(1.34, 1.85)	
***No. of clinic visit**, median (IQR)	2	2	2	2	1.03	(1.01, 1.04)	<0.001
0 time	1230	15.0	132	9.7	1.00	-	-
1-2 times	4577	55.7	749	54.9	1.53	(1.25, 1.85)	<0.001
3-10 times	2060	25.1	427	31.3	1.93	(1.57, 2.38)	<0.001
11-48 times	92	1.1	16	1.2	1.62	(0.93, 2.84)	0.91
***No. of days off work**, median (IQR)	0	0	0	0	1.03	(1.02, 1.04)	<0.001
0 day	7345	89.4	1139	83.4	1.00	-	-
1-3 days	395	4.8	90	6.6	1.47	(1.16, 1.86)	0.001
4-10 days	129	1.6	56	4.1	2.80	(2.03, 3.85)	<0.001
11-90 days	58	0.7	32	2.3	3.56	(2.30, 5.50)	<0.001
***No. of hospital admissions**, median (IQR)	0	0	0	0	1.20	(1.16, 1.86)	0.001
0 time	7788	94.7	1265	92.7	1.00	-	-
1-2 times	145	1.8	54	4.0	2.29	(1.67, 1.35)	0.003
3-15 times	20	0.2	7	0.5	2.16	(0.91, 5.11)	0.081

*Over a 6-month period.
IQR = 25^{th} – 75^{th} 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 2,745 follow-up data were available from 9,894 patients notified to the MPR. From a total of 9,009 adult patients with psoriasis registered in MPR, follow-up data were obtained in 2,576 patients. In paediatric cases, follow-up data were obtained in 169 patients. The mean duration of follow-up was 28.8 ± 20.1 months, with the longest duration of 75 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 1587 patients were evaluated for change in the extent of lesions. Of these patients, 384 patients (24.2%) had improvement by at least one scale, among which 75 (4.7%) had improvement by two scales, and 6 patients improved from BSA>90% to BSA<2%. No improvement was found in 814 patients (51.3%), and 308 patients (19.4%) 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. 192 patients (7.7%) had the most marked improvement in skin scores by 75% or more, and 387 patients (15.6%) had improvement by 50-75%, while 442 patients (17.8%) had 25-50% improvement. 237 patients (9.6%) had modest improvement of less than 25%. No improvement of skin scores were detected in 449 patients (18.1%). Skin scores worsened in 664 patients (31.2%) (**Figure 8.2**).

Joint Pain

From a total of 156 patients who reported to have joint pain, 70 patients (44.9%) had improvement in joint pain as measured by the visual analogue scale. Of these patients, 32 patients (10.9%) had improvement of between 50% and 75%, 5 patients (3.2%) had improvement of more than 75%, 32 patients (20.5%) had improvement of between 25% and 50%, and 16 patients (10.3%) had improvement of less than 25%. There was no improvement of joint pain in 35 patients (22.4%), while joint pain worsened in 51 patients (33.0%) (**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	282	11.0
7 to 12 months	467	18.1
13 to 18 months	343	13.3
19 to 24 months	269	10.4
25 to 30 months	213	8.3
31 to 36	181	7.0
>36	821	31.9
	2204	**100.0**

Mean duration of follow-up: 28.8 ± 20.1 months (range 0 – 75 months)

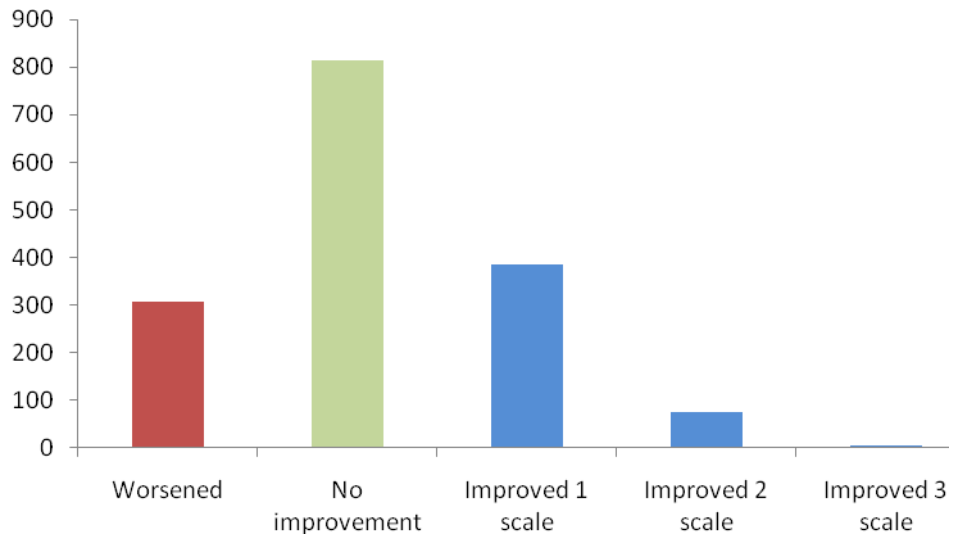


Figure 8.1 Improvement in the extent of skin lesions

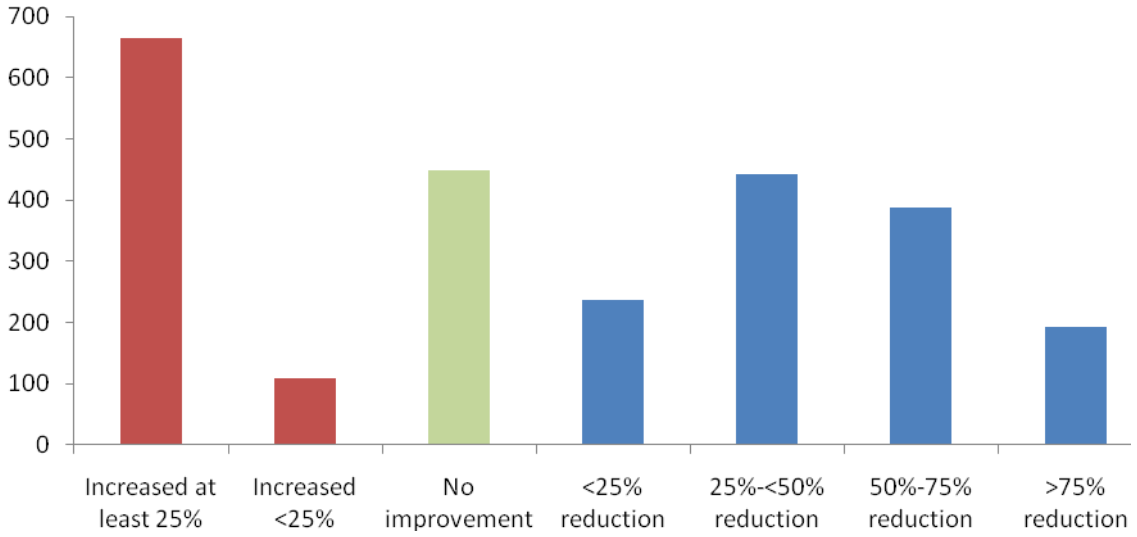


Figure 8.2 Improvement in the total clinical skin scores

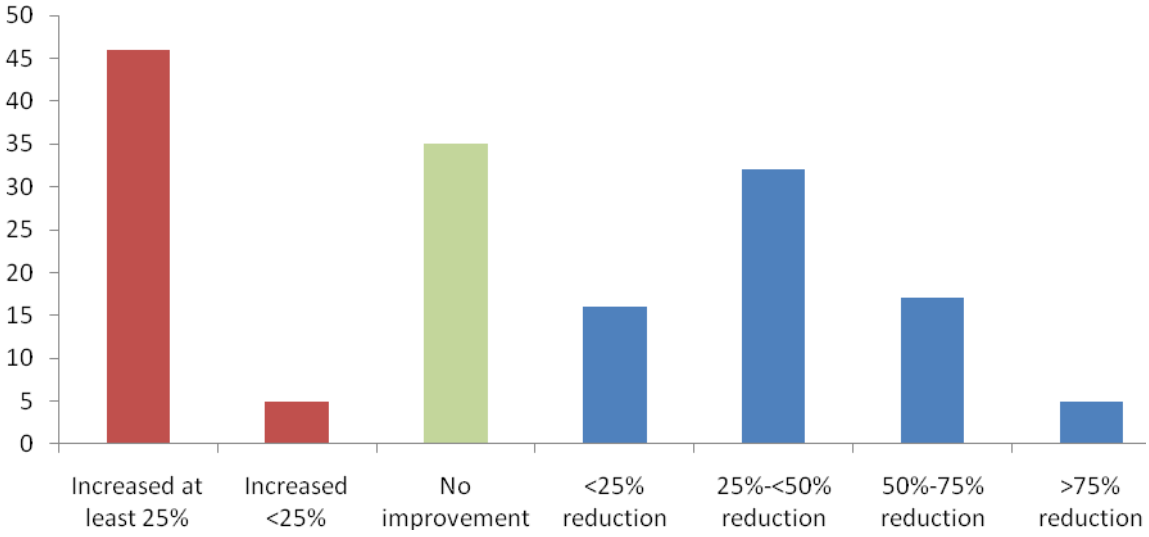


Figure 8.3 Improvement in joint pain

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 1,645 adult patients were evaluated for change in quality of life by DLQI. Of these patients, 406 patients (24.7%) had significant improvement with a reduction of DLQI score by at least 5, whereas 284 patients (17.3%) had significant worsening with an increase in DLQI score by at least 5 (**Figure 8.4**).

A total of 42 patients aged below 17 were evaluated for change in quality of life by DLQI. Of these patients, 11 patients (26.2%) had a significant improvement of Child DLQI score by at least 5, while 4 patients (9.5%) worsened (**Figure 8.4**).

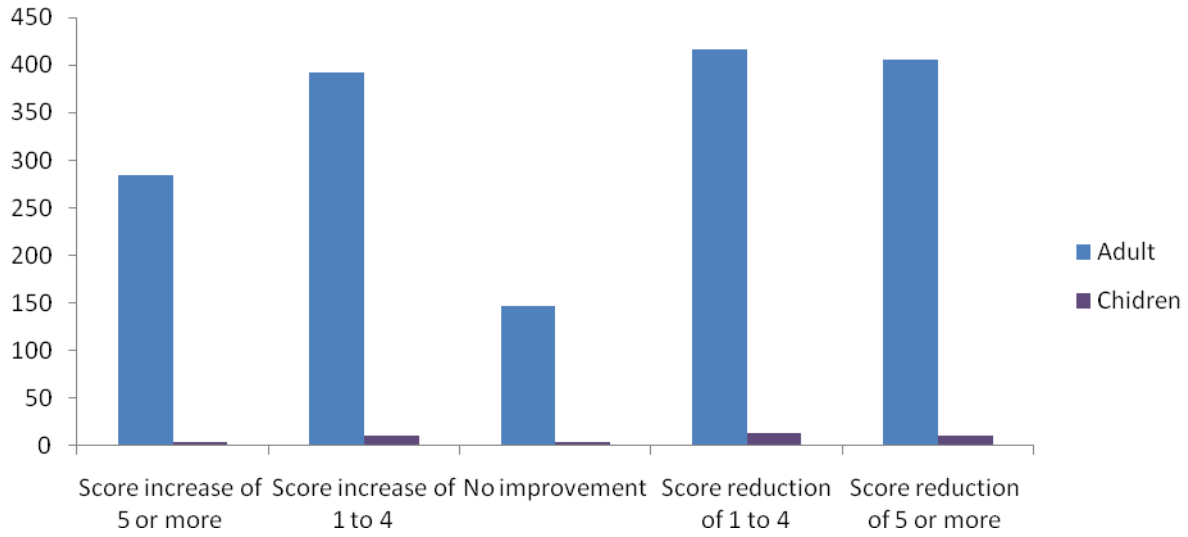


Figure 8.4 Improvement in DLQI and CDLQI

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 2013 were cross-checked against the National Death Registry. Patients certified dead were identified and the causes of death according to the death certificate were analysed. 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 co-morbidities. Missing data were not included in the analysis. Enter method was applied. Multi-collinearity 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 9,775 adult patients (18 and above) were notified to the registry between July 2007 and December 2013, of which 419 deaths (4.3% of patients in the registry) were identified (313 males, 106 females). The mean age at demise was 60.2 ± 13.4 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) 2.70, 95% Confidence Interval (95%CI) 1.75, 4.18; age >60 years OR 7.46, 95%CI 4.62, 12.02), male gender (OR 1.72, 95%CI 1.33, 2.22), severe psoriasis with body surface area (BSA) >10% (OR 1.52, 95%CI 1.19, 1.96) and presence of at least one cardiovascular comorbidity (OR 1.67, 95% CI 1.30, 2.14) **(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 1.32, 95%CI 1.00, 1.75, p=0.049) while there was no significant association between systemic treatment and mortality.

Out of 419 deaths, 301 cases (71.8%) had reported causes of death **(Table 8.4)** in which the most common cause of death was infection (n=102, 33.9%), followed by cardiovascular causes (n=101, 33.6%) and malignancy (n=48, 15.9%). For the remaining 118 cases (28.2%), 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 47 patients, 43 had pneumonia (91.5% of lung infections) while four patients (8.5%) had tuberculosis. Four patients with central nervous system infections, of which three (75.0%) had meningitis or meningoencephalitis while one (25.0%) had a cerebellar abscess. Further analysis showed there were no significant associations between systemic therapy and mortalities due to infections, malignancies or cardiovascular disease while there was no significant association between severity and cardiovascular causes of mortality **(Table 8.6)**.

Table 8.2 Cardiovascular risk factors in patients with psoriasis

Variables	Patient alive (n=9356)		Patient died (n=419)		Logistic Regression		
	n	(%)	n	(%)	Crude OR	(95% CI)	P-value[a]
Hypertension	2103	22.5	179	42.7	2.59	(2.12, 3.17)	<0.001
Diabetes Mellitus	1406	15.0	150	35.8	3.14	(2.55, 3.87)	<0.001
Dyslipidaemia	1406	15.0	108	25.8	1.97	(1.57, 2.47)	<0.001
Ischaemic heart disease	426	4.6	67	16.0	3.98	(3.01, 5.25)	<0.001
Cerebrovascular disease	107	1.1	25	6.0	5.47	(3.50, 8.56)	<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 patients with psoriasis

Variables	Patient alive (n=9356)		Patient died (n=419)		Multiple Logistic Regression[a]		
	n	(%)	n	(%)	Adj. OR	(95% CI)	P-value
1. Age:							
18-40 years	3538	37.8	46	11.0	1.00	-	-
41-60 years	3621	38.7	168	40.1	2.70	(1.75, 4.18)	<0.001
>60 years	1349	14.4	205	48.9	7.46	(4.62, 12.02)	<0.001
Missing	848	9.1	0	0.0	-	-	-
2. Age of onset:							
≤ 40 years (Type 1)	6317	67.5	145	34.6	1.00	-	-
> 40 years (Type 2)	2856	30.5	268	64.0	1.32	(1.00, 1.75)	0.049
Missing	183	2.0	6	1.4	-	-	-
3. Gender:							
Male	5162	55.2	313	74.7	1.72	(1.33, 2.22)	<0.001
Female	4194	44.8	106	25.3	1.00	-	-
4. BSA involved							
≤ 10%	5118	54.7	234	55.8	1.00	-	-
> 10%	1696	18.1	103	24.6	1.52	(1.19, 1.96)	0.001
Missing	2542	27.2	82	19.6	-	-	-
5. Systemic therapy							
Yes	1698	18.1	102	24.3			NS
No	7375	78.8	311	74.2			
Missing	283	3.0	6	1.4			
6. Co-morbidity:							
At least one	2905	31.0	251	59.9	1.67	(1.30, 2.14)	<0.001
None	6330	67.7	163	38.9	1.00	-	-
Missing	121	1.3	5	1.2	-	-	-

*Result was based on available information
Adj. OR = Adjusted odds ratio
[a] Enter method was applied
Multicollinearity was checked and not found
Hosmer-Lemeshow test (p=0.845), classification table (overall correctly classified percentage=94.8%) and area under the ROC curve (76.7%) were applied to check the model fitness

Table 8.4 Reported causes of mortality among patients with psoriasis

Cause of mortality	Number of patients, n (%)
Infection	102 (33.9%)
Cardiovascular	101 (33.6%)
Malignancy	48 (15.9%)
Trauma	20 (6.6%)
Gastrointestinal	18 (6.0%)
Renal	6 (2.0%)
Lung	6 (2.0%)
Total	301 (100.0%)

Table 8.5 Types of infections and malignancy related deaths

Types	Number, n	%
(I) Infection		
Lung	47	46.08
Unspecified site	27	26.47
Others	11	10.78
Human Immunodeficiency Virus (HIV)-related	5	4.90
Urinary tract	4	3.92
Gastrointestinal	4	3.92
Central nervous system	4	3.92
Total	102	100
(II) Malignancy		
Gastrointestinal	12	25.00
Lung	9	18.75
Breast	6	12.50
Lymphoma and leukaemia	5	10.42
Upper aerodigestive tract	3	6.25
Others	7	14.58
Unknown	6	12.50
Total	48	100

Table 8.6 Systemic therapy, severity of psoriasis and causes of mortality

Systemic therapy	Infection n (%)	Other causes of death n (%)	χ^2 statistic (df)	P value[a]
Yes	29 (37.2)	49 (62.8)	0.546	0.460
No	71 (32.6)	147 (67.4)	(1)	
Systemic therapy	**Malignancy n (%)**	**Other causes of death n (%)**	**χ^2 statistic (df)**	**P value[a]**
Yes	12 (15.4)	66 (84.6)	0.003	0.958
No	33(15.1)	185 (84.9)	(1)	
Systemic therapy	**Cardiovascular disease n (%)**	**Other causes of death n (%)**	**χ^2 statistic (df)**	**P value[a]**
Yes	23 (29.5)	55 (70.5)	1.012	0.314
No	78 (35.8)	140 (64.2)	(1)	
Severity	**Cardiovascular disease n (%)**	**Other causes of death n (%)**	**χ^2 statistic (df)**	**P value[a]**
Yes	24 (30.0)	56 (70.0)	1.686	0.194
No	62 (38.5)	99(61.5)	(1)	

*Result was based on available information
[a]Chi-squared test

APPENDIX

APPENDIX A: CASE REPORT FORM

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

CONFIDENTIAL
For Office Use only:
ID: /
Centre

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

Doctor's Name :	
Name of Institution :	

SECTION 1: DEMOGRAPHIC DETAILS

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

SECTION 2 : MEDICAL HISTORY

1. # Age when psoriasis started : ☐☐☐
2. # Age when psoriasis diagnosed : ☐☐☐
3. # Family member(s) with psoriasis : ◯ No ◯ Yes → *(if YES, please tick ONE or MULTIPLE)* ☐ Father ☐ Sibling(s) ☐ Other relative, specify ____ ☐ Mother ☐ Children
4. Aggravating factors : ◯ No ◯ Yes → *(if YES, please tick ONE or MULTIPLE of the following)* ☐ Infection : ____ ☐ Drugs : ____ ☐ Topical Rx : ____ ☐ Trauma ☐ Stress ☐ Sunburn ☐ Hypocalcaemia ☐ Pregnancy ☐ Smoking ☐ Alcohol ☐ Others, specify: ____
5. Disease burden in the last 6 months :
   a) No.of clinic visits due to psoriasis : ☐☐ *(enter 0 if none)*
   b) No. of days off work / school due to psoriasis : ☐☐ *(enter 0 if none)* ☐ Not applicable
   c) No. of hospital admissions due to psoriasis : ☐☐ *(enter 0 if none)*
6. Other diseases :

a) Ischaemic heart disease :	◯ Yes	◯ No	◯ Unknown
b) Cerebrovascular disease (stroke) :	◯ Yes	◯ No	◯ Unknown
c) Diabetes mellitus :	◯ Yes	◯ No	◯ Unknown
d) Hypertension :	◯ Yes	◯ No	◯ Unknown
e) Hyperlipidaemia :	◯ Yes	◯ No	◯ Unknown
f) Other diseases, specify : (e.g. HIV infection, tuberculosis, lymphoma, etc.)	◯ Yes	◯ No	◯ Unknown

7. Cigarette smoking : ◯ Never smoked ◯ Ex-smoker ◯ Current smoker → ☐☐ cigarettes per day

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

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

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

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

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

SECTION 3: CLINICAL EXAMINATION

1. (a) Height : ___ (cm) (b) Weight: ___ (kg)

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

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

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

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

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

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

SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS

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

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

3. Systemic therapy : ○ No ○ Yes
a) Methotrexate ○ No ○ Yes
b) Acitretin ○ No ○ Yes
c) Sulphasalazine ○ No ○ Yes
d) Cyclosporin ○ No ○ Yes
e) Hydroxyurea ○ No ○ Yes
f) Biologics, specify ○ No ○ Yes
g) Systemic corticosteroids ○ No ○ Yes
h) Others, specify ○ No ○ Yes

SECTION 5: QUALITY OF LIFE

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

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

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

NATIONAL DERMATOLOGY REGISTRY (DermReg)
Malaysian Psoriasis Registry
Dermatology Life Quality Index (DLQI)
(For Adults of Age 17 and Above)

CONFIDENTIAL
For Office Use only:
ID: /
Centre

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

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

DLQI Score ☐ *Auto calculated*

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

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

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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: /
Centre

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

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

DLQI Score: (Auto calculated)

Sepanjang Minggu Lalu .... *OVER THE LAST WEEK* 过去一星期中	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 ? *Over the last week, how itchy, "scratchy",sore or painful has your skin been?* 你皮肤发痒、搔抓、破皮或疼痛的程度是如何？	◯	◯	◯	◯
2) Setakat manakah anda berasa malu, segan, susah hati atau sedih disebabkan oleh kulit anda? *Over the last week, how embarrassed or self conscious, upset or sad have you been because of your skin?* 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？	◯	◯	◯	◯
3) Setakat manakah kulit anda mempengaruhi persahabatan anda? *Over the last week, how much has your skin affected your friendships?* 皮肤问题对你和朋友交往的影响是如何？	◯	◯	◯	◯
4) Setakat manakah anda menukar atau memakai pakaian atau kasut kerana kulit anda? *Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?* 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？	◯	◯	◯	◯
5) Setakat manakah masalah kulit anda mempengaruhi anda untuk keluar, bermain atau melakukan hobi anda? *Over the last week, how much has your skin trouble affected going out,playing , or doing hobbies?* 皮肤的问题对你外出、玩耍、或从事休闲嗜好的影响是如何？	◯	◯	◯	◯
6) Setakat manakah anda menjauhi diri daripada berenang atau melakukan sukan lain disebabkan oleh masalah kulit anda? *Over the last week, how much have you avoided swimming or other sports because of your skin trouble?* 你因为皮肤的问题而避免游泳或其他运动的影响程度是如何？	◯	◯	◯	◯
7).Pada minggu yang lalu, *Last week,* 过去一星期 Pada hari persekolahan, setakat manakah kulit anda mempengaruhi kerja sekolah anda? *If school time: Over the last week, how much did your skin problem affect your school work?* 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?* *If holiday time: Over the last week, has your skin problem interfered with your enjoyment of the holiday?* 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？	◯	◯	◯	◯
8) Setakat manakah orang menggelar anda dengan nama yang tidak baik, mengejek, menanya soalan-soalan atau menjauhi diri disebabkan oleh kulit anda? *Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?* 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？	◯	◯	◯	◯
9) Setakat manakah masa tidur anda diganggu kerana masalah kulit? *Over the last week, how much has your sleep been affected by your skin problem?* 你因皮肤的问题而影响到睡眠的程度是如何？	◯	◯	◯	◯
10) Setakat manakah rawatan kulit anda menjadi suatu masalah? *Over the last week, how much of a problem has the treatment for your skin been?* 针对皮肤所进行的治疗对你产生的困扰程度是如何？	◯	◯	◯	◯

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

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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.

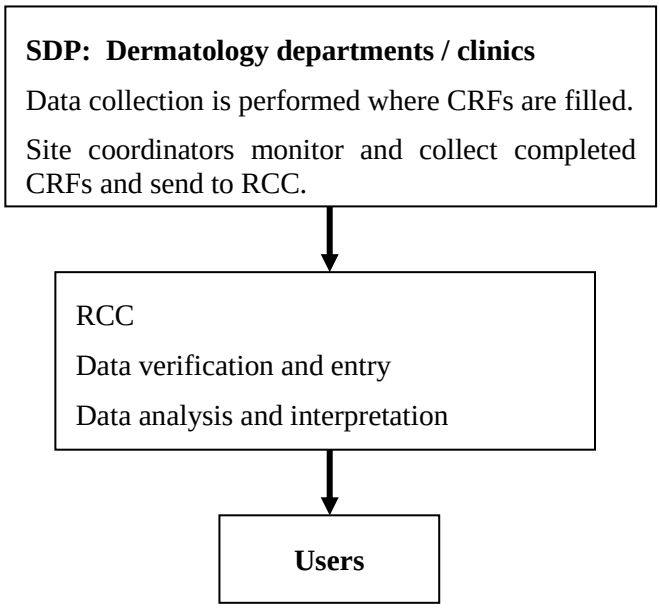
Registry ICT Infrastructure and Data Centre

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.

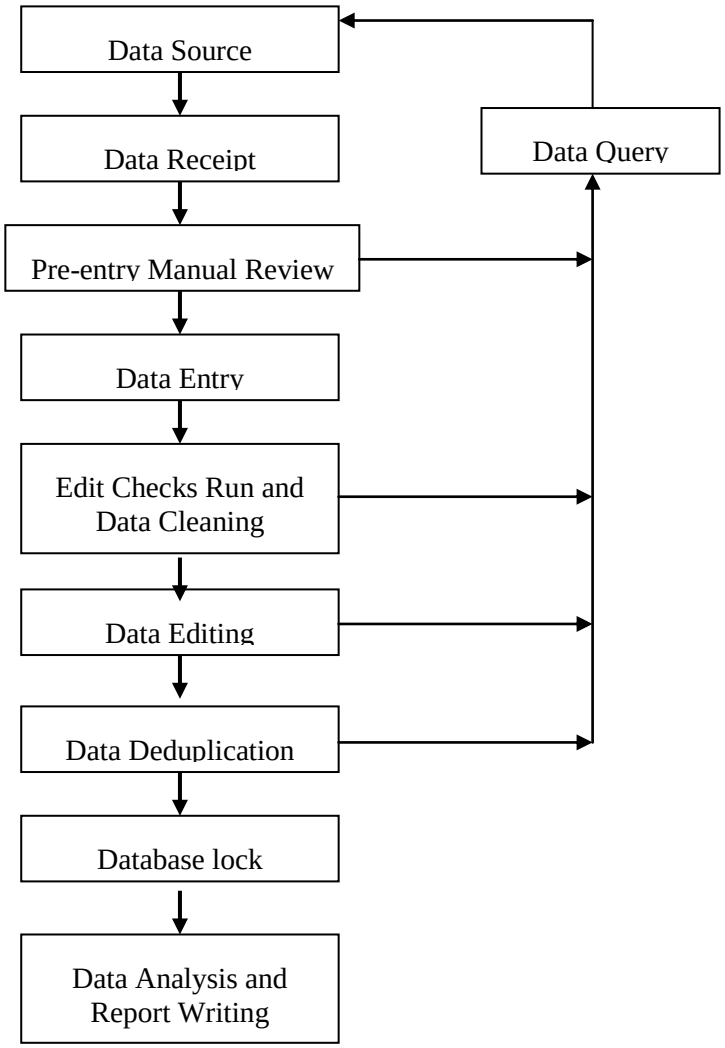
Data Flow Process

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 2013**

   There were 9,894 patients in the dataset. The analysis set was use for the analysis in Chapter 1, 2, 3, 4, 5 and 6, which comprises of 291 cases in year 2007, 1,188 cases in year 2008, 1,551 cases in year 2009, 1,538 cases in year 2010, 1,419 in year 2011, 1, 296 in year 2012 and 2, 611 in year 2013. The cases include first notification and up to five follow-up notifications.

2. **Patient outcome between 2007 and 2013**

   There were 2,745 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 issue 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 METHODS

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 presenteation 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

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