



# **Annual Report of the MALAYSIAN PSORIASIS REGISTRY 2007-2012**

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Ministry of Health Malaysia

**NATIONAL DERMATOLOGY REGISTRY  
(DermReg)**

**Annual Report of the  
MALAYSIAN PSORIASIS REGISTRY**

**2007 - 2012**

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- The Dermatological Society of Malaysia
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- Altus Solutions Sdn Bhd

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# ABBREVIATIONS

BB-UVB	Broad-band ultraviolet B
BMI	Body mass index
BSA	Body surface area
CDLQI	Child Dermatology Life Quality Index
CRC	Clinical Research Centre
CRF	Case report form
DermReg	National Dermatology Registry
DLQI	Dermatology Life Quality Index
eCRF	Electronic case report form
eDermReg	DermReg web application
HLA	Human leukocyte antigen
IQR	Interquartile range
MOH	Ministry of Health
MPR	Malaysian Psoriasis Registry
NA	Not available
NBUVB	Narrow-band ultraviolet B
NHMS	National Health and Morbidity Survey
PI	Principal Investigator
PUVA	Psoralen and ultraviolet A
QoL	Quality of life
RCC	Registry Coordinating Centre
SC	Site Coordinator
SD	Standard deviation
SDP	Sources data providers

# **ABOUT DermReg**

## **Introduction**

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

## **Objectives of DermReg**

### **General Objective**

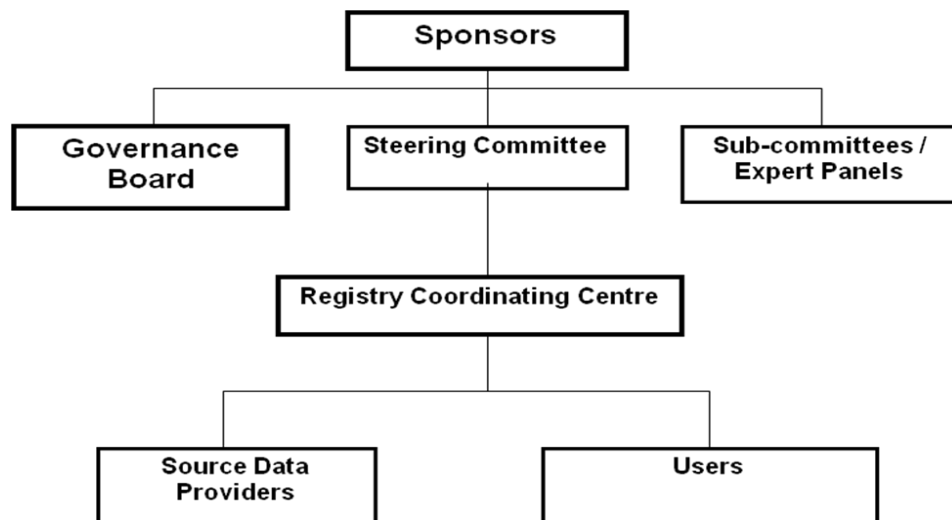
To establish a nationwide systematic prospective collection of data pertaining to skin diseases and dermatological services, in order to study the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities.

### **Specific Objectives:**

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

# ORGANISATION OF DermReg

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



## SPONSORS

The DermReg is sponsored by:

1. Ministry of Health, Malaysia
2. Clinical Research Centre, Hospital Kuala Lumpur
3. The Dermatological Society of Malaysia
4. Pharma companies – Abbvie, Leo Pharma and Janssen 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.

<b>Registry Manager</b>	Fatimah ‘Afifah Alias
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### **Technical Support Personnel**

<b>Epidemiology Officer</b>	Dr. Jamaiah Haniff Clinical Epidemiology Unit, CRC
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<b>Biostatisticians</b>	Ms Tassha Hilda bt Adnan CRC
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<b>Database Administrator</b>	Ms Lim Jie Ying Altus Solutions Sdn Bhd
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## 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 Fariyah 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

# OFFICIAL WEBSITE OF DermReg

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

Friday, October 12, 2012

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**NATIONAL DERMATOLOGY REGISTRY**  
*Malaysia*



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- Publications
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- Data Request
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- eDermReg (MPR, Skin Biopsy)
- eCUSUM



## Welcome to National Dermatology Registry (DermReg)

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

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

Registries under **DermReg** include:

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

### Sponsors

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

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# ABOUT MALAYSIAN PSORIASIS REGISTRY (MPR)

## Introduction

Psoriasis is a common skin disease, characterized by inflamed scaly patches and plaques. It runs a chronic relapsing course with variable degree of severity, and causes significant physical, psychosocial and economic impact on the patient. Being incurable, it may lead to poor patient compliance especially in treatment which will further compromise the overall management of the disease.

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

Preliminary work on the MPR started in 1998 by a group of dermatologists, which culminated in the First Malaysian Psoriasis Symposium on the 17<sup>th</sup> 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 2012, a total of 8,039 patients with psoriasis from 19 dermatology centres (15 government hospitals, 2 private centres and 2 university hospitals) were notified to the registry.

## Demographic Characteristics of Patients

In adult patients, male-to-female ratio was 1.4:1. Ethnic distribution: Malay 49.3%, Chinese 22.8%, Indian 18.2%, other ethnic groups 9.6%. Mean age at notification was  $45 \pm 15.51$  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 70.6%, Chinese 8.9%, Indian 12.3%, other ethnic groups 8.1%. Mean age at notification was  $13 \pm 3.7$  years (range 0 - 17 years). All of the paediatric patients were Malaysian citizens.

## Medical History

In adult patients, mean age of onset of psoriasis was  $35.32 \pm 15.7$  years (range 18 – 85 years). Family history of psoriasis was present in 20.6% of the patients. Positive family history was more common among patients with younger onset (aged 40 and below) compared to those with later onset of disease: 15.5% vs 5.1%. Among those who had positive family history, family members affected were either of their parents in 42.0%, siblings in 36.9% and children in 11.8%.

In the child population, 19.0%, of them had at least one family member with psoriasis. Of these, 34.9% had either of their parents affected with psoriasis.

51.8% adult patients and 38.1% paediatric patients reported one or multiple factors which aggravated their psoriasis. The commonest aggravating factors were stress (67.0% in adult, 57.0% in paediatric), sunlight (34.0% in adult, 45.0% in paediatric) and infection (16.7% in adult, 20.5% in paediatric).

## Comorbidities

In adult psoriasis patients aged 18 and above, 34.6% were overweight and 34.5% were obese, 25.6% had hypertension, 17.6% had diabetes mellitus, 17.0% had hyperlipidemia, 5.6% had ischaemic heart disease and 1.6% had previous history of stroke. In children and adolescents aged below 18 years with psoriasis, the most prevalent comorbidity was overweight or obesity i.e. BMI at or above 85<sup>th</sup> centile (27.0 %), followed by bronchial asthma (2.2%).

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

## Clinical Presentation

The commonest clinical type of psoriasis in adult and paediatric patients was plaque psoriasis (87.2% and 79.7%, respectively). This was followed by guttate psoriasis (4.3% and 7.4% respectively), erythrodermic psoriasis (2.0% and 1.2% respectively), pustular psoriasis (1.3% and 1.6% respectively) and flexural psoriasis (0.4% and 1.2% respectively). The majority of adult patients (56.8%) had body surface area involvement of 10% or less. The pattern remains the same in child population, i.e. <5% of severity in 30.28%, followed by 5-10% of severity in 34.27% of patients.

Psoriatic arthropathy was reported in 15.7% of adult patients and only 2.2% in paediatric population. The commonest psoriatic arthropathy in adult patients was oligo/monoarthropathy (44.3%) followed by rheumatoid-like symmetrical polyarthropathy (32.4%) and distal hand joints arthropathy (29.3%).

About two-third (60.6%) of adult patients had nail changes associated with psoriasis. Among patients who had nail disease, pitting was commonest (73.1%), followed by onycholysis (51.6%), discoloration (37.8%) and subungual hyperkeratosis (15.6%). Total nail dystrophy was found in 5.4% of patients with nail disease. In paediatric cases, 61% of them had no nail involvement. Distribution of nail features in paediatric psoriasis patients with nail involvement reported that pitting was the commonest (89.92%) followed by onycholysis (29.1%).

## Treatments received in the past 6 months

Majority of the patients (95.5% in adult, 95.1% in paediatric) were on topical treatment. Topical steroid was the commonest prescribed (85.7% in adult, 81.4% in paediatric), followed by tar preparations in 80.6% (adult) and 78.7% in paediatric, emollients in 74.7% (adult) and 51.6% (paediatric) patients. 3.6% of adult patients and 1.2% of paediatric patients received phototherapy. Of the patients who had phototherapy, narrowband UVB (NBUVB) was the commonest used (85.6% in adult, 87.5 in paediatric). Systemic therapy was given in 19.6% of adult patients and in 5.3% paediatric patients. The most frequently used systemic therapy was methotrexate (69.5% in adult, 50 in paediatric), followed by acitretin (19.0% in adult, 27.8% in paediatric).

## Quality of Life

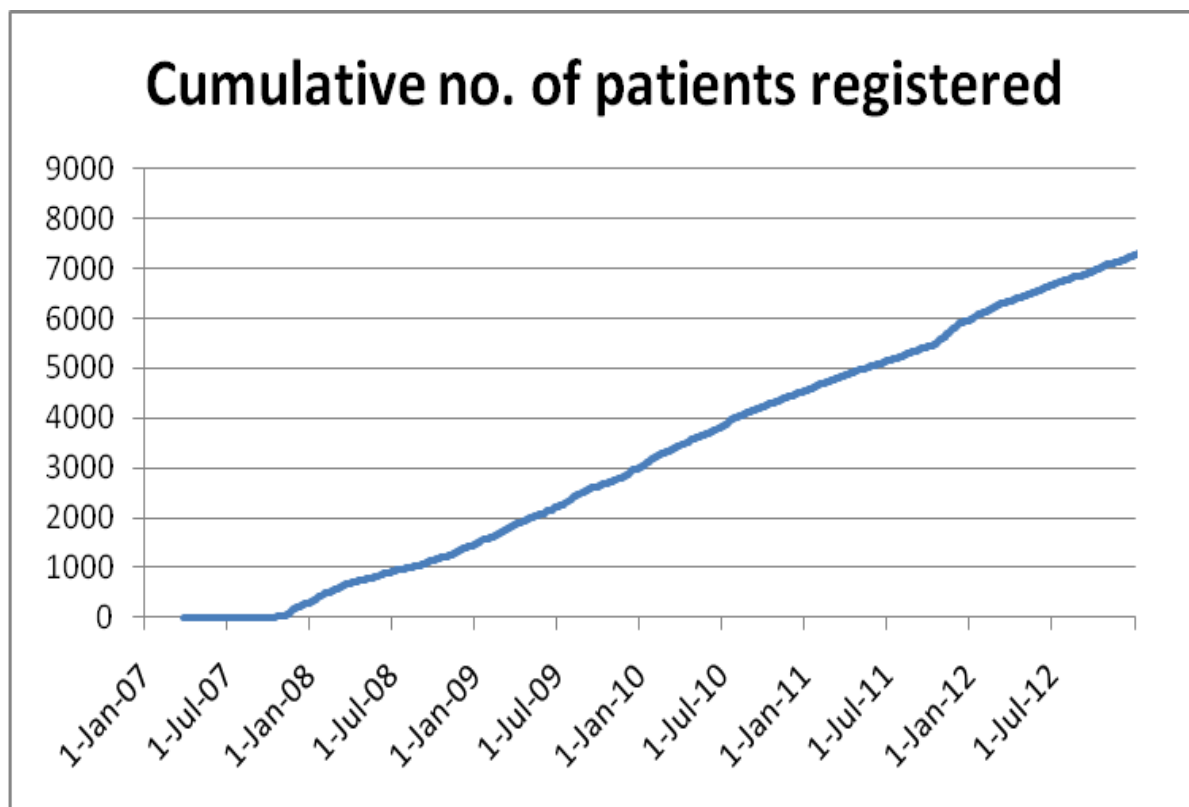
Measurement of quality of life using Dermatology Life Quality Index (DLQI) or child DLQI (CDLQI) was performed in 4,348 adult patients (aged 17 and above) and 260 children/adolescent patients (aged 5 to 16). The mean DLQI score was  $8.4 \pm 6.4$  for adult patients and the mean CDLQI was  $7.7 \pm 5.5$  for children/adolescent patients.

In the adult population, 80.9% of patients reported that psoriasis had small (26.4%), moderate (27.5%) and large effect (26.9%) on their personal life. Only, 5.4% of patients reported that psoriasis had extremely large effect on their personal life.

# **CHAPTER 1**

## **STOCK AND FLOW**

During the period from October 2007 to December 2012, a total of 8,039 patients were notified to the registry. The number of notified patients gradually increased throughout the period (**Figure 1.1**). Of the overall population, 8.42% (n=677) patients belong to the age group < 18 years and were categorized as paediatric population, 81.58% (n=7362) patients belong to the age group  $\geq 18$  years of age and were categorized as the adult population.



**Figure 1.1 Psoriasis patients notified to the MPR**

A total of 19 dermatology centres (15 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 Tengku Ampuan Rahimah, Klang notified the highest number of paediatric patients. This was followed by Hospital Sultanah Bahiyah and Hospital Kuala Lumpur. (**Table 1.2**).

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

No		No. of adult patients notified						
		2007	2008	2009	2010	2011	2012	Total
1	Hospital Kuala Lumpur	71	236	312	215	107	150	1091
2	Hospital Pulau Pinang	20	84	275	147	224	19	769
3	Hospital Tengku Ampuan Rahimah	0	72	179	265	121	117	754
4	Hospital Melaka	0	0	85	260	204	174	723
5	Hospital Umum Sarawak	5	169	123	88	96	150	631
6	Hospital Raja Permaisuri Bainun	49	51	101	51	131	212	595
7	Hospital Queen Elizabeth	19	96	113	133	133	97	591
8	Hospital Sultanah Bahiyah	100	193	79	67	53	84	576
9	Hospital Tengku Ampuan Afzan	0	44	42	116	109	86	397
10	Hospital Sultanah Aminah	0	36	137	64	62	64	363
11	Hospital Sultanah Fatimah	2	36	27	36	60	175	336
12	Hospital Tuanku Fauziah	0	24	50	57	47	21	199
13	Hospital Tuanku Jaafar	0	53	0	32	61	3	149
14	UM Medical Centre	0	0	0	0	32	25	57
15	UKM Medical Centre	0	0	0	15	0	24	39
16	Hospital Sungai Buloh	5	24	1	0	0	0	30
17	Prince Court Medical Centre	0	0	6	17	3	1	27
18	Gleneagles Medical Centre	0	12	6	0	0	0	18
19	Hospital Raja Perempuan Zainab II	0	0	0	0	9	8	17
Total		271	1130	1536	1563	1452	1410	7362



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

No		No. of paediatric patients notified						
		2007	2008	2009	2010	2011	2012	Total
1	Hospital Tengku Ampuan Rahimah	0	10	18	34	17	10	89
2	Hospital Sultanah Bahiyah	9	30	15	11	10	9	84
3	Hospital Kuala Lumpur	10	21	17	11	9	13	81
4	Hospital Tengku Ampuan Afzan	0	4	10	14	20	17	65
5	Hospital Umum Sarawak	1	15	12	9	7	17	61
6	Hospital Queen Elizabeth	1	8	17	12	8	9	55
7	Hospital Melaka	0	0	6	14	19	13	52
8	Hospital Raja Permaisuri Bainun	4	3	11	2	5	12	37
9	Hospital Pulau Pinang	0	8	13	6	4	0	31
10	Hospital Sultanah Fatimah	2	6	0	3	7	12	30
11	Hospital Sultanah Aminah	0	2	10	5	4	7	28
12	Hospital Tuanku Fauziah	1	8	4	7	5	3	28
13	Hospital Tuanku Jaafar	0	5	0	6	8	0	19
14	Hospital Sungai Buloh	3	5	1	0	0	0	9
15	Gleneagles Medical Centre	0	4	0	0	0	0	4
16	UM Medical Centre	0	0	0	0	2	0	2
17	UKM Medical Centre	0	0	0	1	0	0	1
18	Hospital Raja Perempuan Zainab II	0	0	0	0	0	1	1
19	Prince Court Medical Centre	0	0	0	0	0	0	0
Total		31	129	134	135	125	123	677

There were a total of 8, 039 notifications of patients with psoriasis in the MPR with new cases and follow-up treatment. 5,270 (71.6%) of the adult patients were notified once, and 2,092 (28.4%) were notified more than once. (**Table 1.3**). In paediatric population, 565 (83.5%) of the patients were notified once and 112 (16.5%) 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**

<b>Year</b>	<b>No.</b>	<b>%</b>
Entry notification	5,270	71.6
Entry and one follow-up notifications	1,227	16.7
Entry and 2 follow-up notifications	468	6.4
Entry and 3 follow-up notifications	200	2.7
Entry and 4 follow-up notifications	106	1.4
Entry and 5 follow-up notifications	51	0.7
Entry and 6 follow-up notifications	27	0.4
Entry and 7 follow-up notifications	9	0.1
Entry and 8 follow-up notifications	4	0.1
<b>Total</b>	<b>7362</b>	<b>100.0</b>

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

<b>Year</b>	<b>No.</b>	<b>%</b>
Entry notification	565	83.5
Entry and one follow-up notifications	73	10.8
Entry and 2 follow-up notifications	20	3.0
Entry and 3 follow-up notifications	13	1.9
Entry and 4 follow-up notifications	4	0.6
Entry and 5 follow-up notifications	1	0.1
Entry and 6 follow-up notifications	1	0.1
<b>Total</b>	<b>677</b>	<b>100.0</b>

## **CHAPTER 2**

### **CHARACTERISTICS OF PATIENTS**

In adult patients with psoriasis, 98.94% of population was Malaysian. Malays comprised the majority of patients (49.3%), followed by Chinese (22.8), Indians (18.2%), other ethnic groups (9.6%) and Orang Asli (0.1%) (**Table 2.1**). There were more males than females (57.6% and 42.4% respectively), with a male to female ratio of 1.4:1 (**Figure 2.1**).

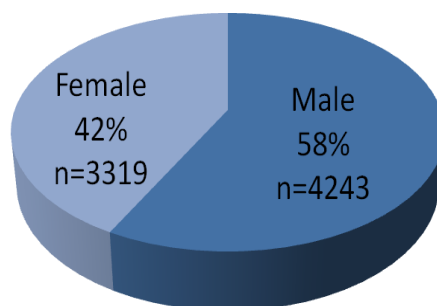
The mean age of the adult patients was  $45.3 \pm 15.5$  years with a range from 18 to 97 years. The majority were married (72.3), 22.5% were single, and the rest, either divorced or widowed (**Table 2.1**).

All paediatric patients with psoriasis were Malaysian. Of the data analyzed, 70.6% paediatric patients were Malays followed by Indian in 12.3%, Chinese in 8.9% and 8.1% belonging to other ethnic groups (**Table 2.2**). Majority or 385 patients of paediatric patients were females (56.87%), while 292 were males (43.13%) (**Figure 2.2**).

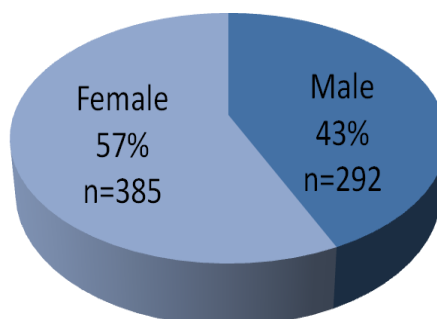
The mean age of the paediatric population was  $13.0 \pm 3.7$  years (0-17 years) (**Table 2.2**).

**Table 2.1 Demographics of adult and paediatric patients with psoriasis**

Patient characteristics		Adult		Paediatric	
		n	%	n	%
Nationality	Malaysian	5,766	98.9	677	100.0
	Non Malaysian	78	1.1	0	0.0
Ethnic distribution	Malay	3,627	49.3	478	70.6
	Chinese	1,678	22.8	83	12.3
	Indian	1,342	18.2	60	8.9
	Orang Asli	10	0.1	1	0.2
	Others	704	9.6	55	8.1
Gender	Male	4,243	57.6	292	43.1
	Female	3,119	42.3	385	56.9
Marital status	Single	1,657	22.5	-	-
	Married	5,326	72.3	-	-
	Divorced	65	0.9	-	-
	Widowed	32	0.4	-	-
	NA	157	2.1	-	-
Age at notification (years)	Mean $\pm$ SD	$45.3 \pm 15.5$		$13.0 \pm 3.7$	
	(Range)	(18 - 97)		(0-17)	



**Figure 2.1** Gender distribution of adult patients with psoriasis



**Figure 2.2** Gender distribution of paediatric patients with psoriasis

## **CHAPTER 3**

### **MEDICAL HISTORY**

### Onset of Psoriasis

Psoriasis may first appear at any age. The mean age of onset in our cohort for adult patients was  $35.3 \pm 15.7$  years with a wide range from 18 to 87 years. The mean age of onset was  $9.8 \pm 4.4$  years in the paediatric population (0-17). In the adult population, the mean age at which psoriasis was first diagnosed was  $37.54 \pm 15.5$  years. In the paediatric category, the mean age at which psoriasis was first diagnosed was  $11.15 \pm 4.3$  years (**Table 3.1, Table 3.2**).

Looking at the age of onset of psoriasis in adult patients, 1667 patients had the onset of psoriasis between 21-30 years old, followed by 1504 patients between 31-40 years old, and 1297 between 41-50 years old (**Figure 3.1**).

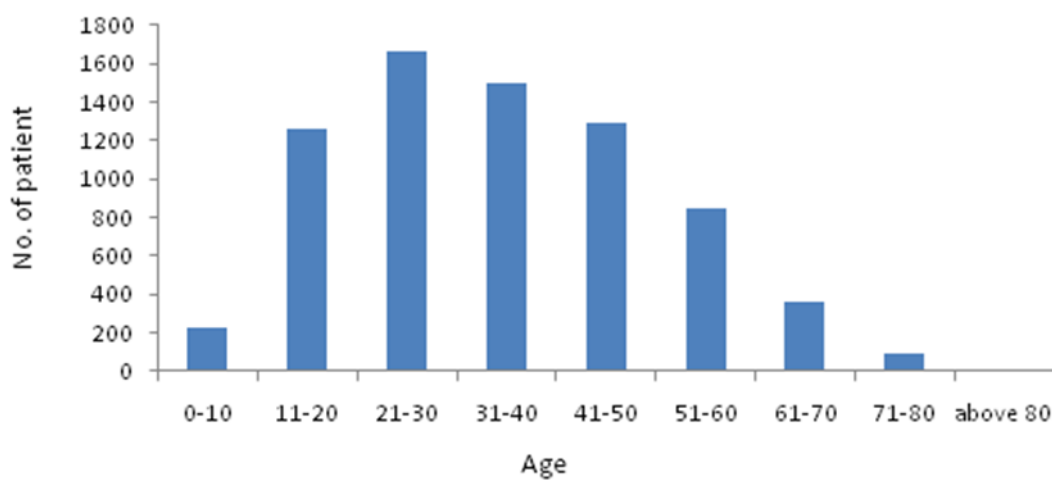
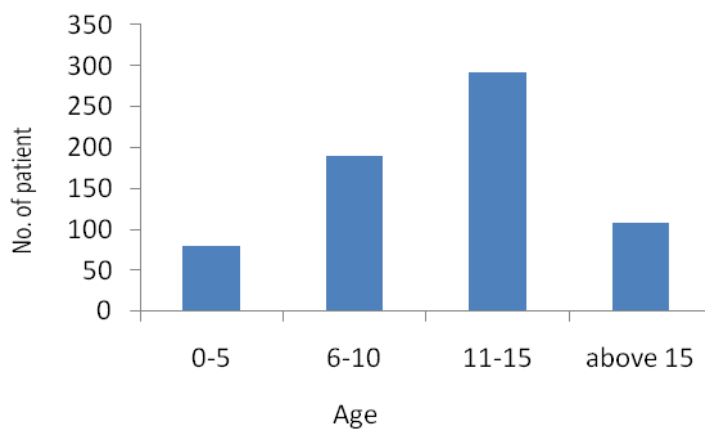
In the paediatric group, 291 of patients had onset of psoriasis between 11-15 years old (**Figure 3.2**).

**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	7272	35.3	34	15.7	0	85
Age of diagnosis	7254	37.5	36	15.5	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	668	9.8	10	4.4	0	17
Age of diagnosis	667	11.2	12	4.3	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 (20.6%) of adult patients had at least one family member with psoriasis (**Table 3.3**). Of those with a positive family history, 42.0% had either of their parents affected. Siblings were affected in 36.9% and children in 11.8% (**Table 3.4, Figure 3.3**).

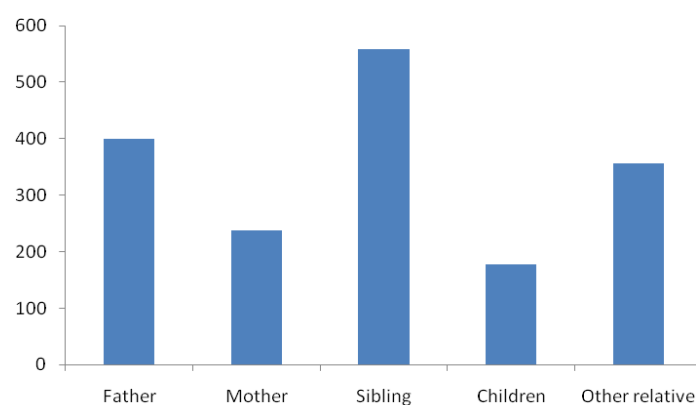
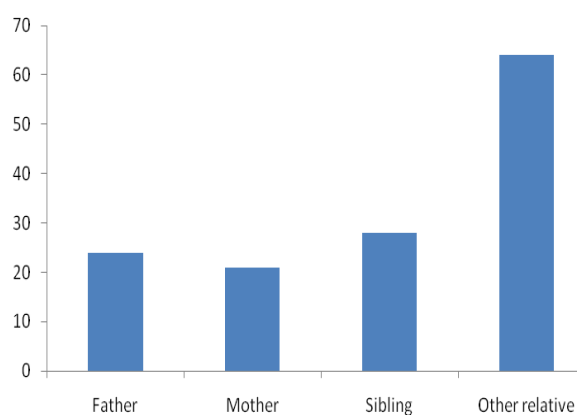
In the paediatric patients with psoriasis, 129 or 19.1% of them had at least one family member with psoriasis (**Table 3.3**). Of these, 34.9% had either parents affected with psoriasis. (**Table 3.4, Figure 3.4**)

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

Characteristics	Adult		Paediatric	
	n	%	n	%
Yes	1, 515	20.6	129	19.1
No	5, 780	78.5	543	80.2
Not available	67	0.9	5	0.7
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

**Table 3.4 Family members with psoriasis in adult and paediatric patients**

Family member (one or multiple)	Adult		Paediatric	
	n	%	n	%
Father	400	26.4	24	18.6
Mother	237	15.6	21	16.3
Sibling(s)	559	36.9	28	21.7
Children	178	11.8	0	0
Others	356	23.5	64	49.6

**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 (51.8%) of adult patients with psoriasis reported one or multiple factors which worsened their psoriasis (**Table 3.5**). Stress was the commonest aggravating factor (67.0%), followed by sunlight (34.0%) and infection (16.7%). Other identified aggravating factors included trauma (7.5%), smoking (7.0%), drugs (5.3%), alcohol (3.6%), pregnancy (3.1%) and topical treatment (1.7%) (**Table 3.6**).

38.1% 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 (56.98%), sunburn (44.96%) and infection (20.54%) (**Table 3.7**).

Analyzing the subgroup of patients who reported infection as an aggravating factor, upper respiratory tract infection (64.0% in adult; 66.7% in paediatric) 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		Paediatric	
	n	%	n	%
Yes	3811	51.8	258	38.1
No	3436	46.7	414	61.2
Not available	115	1.6	5	0.7
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

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

Aggravating factors (one or multiple)	Adult		Paediatric	
	n	%	n	%
Stress	2555	67.0	147	57.0
Sunlight	1294	34.0	116	45.0
Infection	635	16.7	53	20.5
Trauma	287	7.5	24	9.3
Drugs	203	5.3	3	1.2
Smoking	267	7.0	3	1.2
Alcohol	138	3.6	0	0.0
Pregnancy	117	3.1	0	0.0
Topical treatment	64	1.7	2	0.8

**Table 3.7 Infections which aggravated psoriasis in adult patients**

<b>Infection</b>	<b>Adult</b>		<b>Paediatric</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Upper respiratory tract infection	80	64.0	8	66.7
Fever / febrile illness	23	18.4	1	8.3
Sore throat	5	4.0	0	0.0
Chickenpox	4	3.2	3	25.0
HIV	4	3.2	0	0.0
Viral infection	4	3.2	0	0.0
Dengue fever	2	1.6	0	0.0
Chikugunya	1	0.8	0	0.0
Boil	1	0.8	0	0.0
Hepatitis C	1	0.8	0	0.0
Not available	510		41	

**Table 3.8 Drugs which aggravated psoriasis in adult and paediatric patients**

<b>Drug</b>	<b>Adult</b>		<b>Paediatric</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
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 87.8% of them could perform their routine activities regularly. 12.2% of the population reportedly had to take off from work/school from anywhere between 1- 90 days due to psoriasis (**Table 3.9**). 76.2% of adult patients with psoriasis visited the clinic between 1-5 times in the past 6 months (**Table 3.9**). 5.4% of adult patients were hospitalized at least once in the last 6 months, and the majority (94.7%) did not require any hospitalization (**Table 3.10**).

Analysis of daily activities among paediatric psoriasis patients showed that, 91.1% of them could perform their routine activities regularly. 8.9% of the population reportedly had to take off from work/school from anywhere between 1- 90 days due to psoriasis (**Table 3.11**). 76.8% of paediatric patients with psoriasis visited the clinic between 1-5 times in the past 6 months (**Table 3.11**). Only 1% of paediatric patients were hospitalized at least once in the last 6 months, and the majority (96.3%) 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	6461	87.8	1072	14.6
1-5	488	6.6	5608	76.2
6-10	96	1.3	376	5.1
>10	317	4.3	306	4.2
Total	7362	100	7362	100

**Table 3.10 Number of hospital admissions in adult patients with psoriasis**

Number of hospital admissions due to psoriasis	n	%
0	6969	94.7
1-3	158	2.2
>3	235	3.2
Total	7362	100

**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	617	91.1	102	15.1
1-5	31	4.6	520	76.8
6-10	6	0.9	32	4.7
>10	23	3.4	23	3.4
Total	677	100	677	100

**Table 3.12** Number of hospital admissions in paediatric patients with psoriasis

Number of hospital admissions due to psoriasis	n	%
0	652	96.3
1-3	7	1.0
>3	18	2.7
Total	677	100

### Smoking

Data on smoking status was only available for 1225 (15.2%) of patients. This was because the smoking status data was not collected in the earlier version of the Case Report Form. A total of 237 (21.1%) adult patients with psoriasis were current smokers, while in paediatric population, it was 5 (4.9%) (**Table 3.13**).

**Table 3.13** Cigarette smoking in adult and paediatric patients with psoriasis

Cigarette smoking	Adult		Paediatric	
	n	%	n	%
Never smoked	732	65.2	95	93.1
Ex-smoker	154	13.7	2	2.0
Current smoker	237	21.1	5	4.9
Not available	6239	-	575	-
Total	7362	100	677	100

## **CHAPTER 4**

## **COMORBIDITIES**

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

In adult psoriasis patients aged 18 and above, 34.6% were overweight and 34.5% were obese, 25.6% had hypertension, 17.6% had diabetes mellitus, 17.0% had hyperlipidemia, 5.6% had ischaemic heart disease and 1.6% had previous history of stroke (**Table 4.1**).

In children and adolescents aged below 18 years with psoriasis, the most prevalent comorbidity was overweight or obesity i.e. BMI at or above 85<sup>th</sup> centile (27.0 %), followed by bronchial asthma (2.2%) and diabetes mellitus (0.3%), hyperlipidaemia (0.3%), Down syndrome (0.3%) and congenital heart disease (0.3%). 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*	2544	34.6
Overweight*	2541	34.5
Hypertension	1, 886	25.6
Diabetes mellitus	1, 299	17.6
Hyperlipidaemia	1, 254	17.0
Ischaemic heart disease	413	5.6
Stroke	114	1.6

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



**Table 4.2** Prevalence of comorbidities in paediatric patients with psoriasis

Comorbidity	N	%
Overweight or obesity (BMI $\geq$ 85 <sup>th</sup> centile)	183	27.0
Bronchial asthma	15	2.2
Diabetes mellitus	2	0.3
Hyperlipidaemia	2	0.3
Down syndrome	2	0.3
Congenital heart disease	2	0.3
Hypertension	1	0.1
Thalassemia	1	0.1
Atrial defect	1	0.1
Obstructive sleep apnoea	1	0.1

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

Co-morbidities	Arthritis Absent (n=6089)		Arthritis Present (n=1156)		Simple Logistic Regression <sup>a</sup>		
	n	%	n	%	Crude OR	(95% CI)	P-value
Diabetes Mellitus	1036	17.0	244	21.1	1.30	(1.12, 1.53)	0.0009
Hypertension	1473	24.2	383	33.1	1.54	(1.35, 1.77)	<0.001
Hyperlipidaemia	938	15.4	293	25.4	1.87	(1.61, 2.17)	<0.001
BMI $\geq$ 30 (obesity WHO)	4843	20.5	294	25.4	1.33	(1.15, 1.54)	0.0002
Ischaemic heart disease	334	5.5	76	6.6	1.21	(0.93, 1.56)	0.1487
Cerebrovascular disease	98	1.6	15	1.3	0.8	(0.46, 1.38)	0.4249

## **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 87.2% of patients, followed by guttate psoriasis in 4.3% of patients and pustular psoriasis in 1.3% of the patients. Similarly, in paediatric patients, plaque psoriasis accounted for 79.6% of patients, followed by guttate psoriasis in 7.4% 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, 26.7% of our psoriatic patients had <5% BSA affected, while 30.2% had 5-10% of BSA affected. Severe psoriasis with >10% BSA affected occurred in 17.7% adult patients, while 1.8% had erythrodermic psoriasis, i.e. >90% BSA involved. In paediatric patients population, 34.3% had <5% BSA involvement, 30.3% had 5-10% BSA involvement, 11.7% had 10-90% BSA and 0.6% were erythrodermic (**Table 5.2**).

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

BMI	Adult		Pediatric	
	n	%	n	%
Plaque	6417	87.2	539	79.6
Guttate	315	4.3	50	7.4
Pustular	94	1.3	11	1.6
Erythrodermic	145	2.0	8	1.2
Flexural/inverse	31	0.4	8	1.2
Palmoplantar non-pustular	12	0.2	2	0.3
Others	139	1.9	44	6.5
Not available	209	2.8	15	2.2
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

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

Body surface area involved	Adult		Paediatric	
	n	%	n	%
<5%	1962	26.7	232	34.3
5 - 10%	2220	30.2	205	30.3
>10% to 90%	1300	17.7	79	11.7
>90%	130	1.8	4	0.6
Not available	1750	23.8	157	23.2
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

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 (35.4%), trunk (33.2%) and upper limbs (29.4%). (**Table 5.3**). Whereas in paediatric patients, moderate and severe lesions were seen mainly on the scalp region (36.5% ), followed by the trunk (24.2% ) (**Table 5.4**).

Almost half of the adult (49.3%) and paediatric (47.3%) psoriatic patients did not have any lesion on the face and neck. If present, lesions on face and neck were generally less severe (score 1 or 2) (**Table 5.3, Table 5.4**).

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

Body part	Clinical score									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	1504	20.4	3724	50.6	1642	22.3	320	4.4	172	2.3
Face & neck	3631	49.3	2914	39.6	508	6.9	65	0.9	244	3.3
Trunk	1861	25.3	2840	38.6	2112	28.7	330	4.5	219	3.0
Upper limbs	1651	22.4	3336	45.3	1913	26.0	249	3.4	213	2.9
Lower limbs	1324	18.0	3065	41.6	2372	32.2	392	5.3	209	2.8

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

Body part	Clinical score									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	110	16.3	306	45.2	195	28.8	52	7.7	14	2.1
Face & neck	320	47.3	282	41.7	44	6.5	7	1.0	24	3.6
Trunk	213	31.5	282	41.7	141	20.8	23	3.4	18	2.7
Upper limbs	246	36.3	277	40.9	116	17.1	15	2.2	23	3.4
Lower limbs	242	35.8	271	40.0	123	18.2	19	2.8	22	3.3

Majority of adult patients with psoriasis had nail involvement (60.6%) (**Table 5.5**). Among patients who had psoriatic nail disease, most of them had pitting (73.1%). Other common features were onycholysis (51.6%), discoloration (37.8%) and subungual hyperkeratosis (15.6%). Total nail dystrophy was found in 5.4% of patients with nail involvement (**Table 5.6**).

There were 258 (38.1%) paediatric patients with nail involvement (**Table 5.5**). Most of them had pitting (89.9%), followed by onycholysis (29.1%), discoloration (15.1%) and subungual hyperkeratosis (3.5%) and total nail dystrophy (1.9%) (**Table 5.6**).

Joint disease related to psoriasis was reported in 15.7% of the adult patients, while only 2.2% paediatric patients had joint involvement (**Table 5.7**). 229 adult patients had test for Rheumatic factor. Of these, only 1.6% was positive (**Table 5.8**).

In adult patients, the commonest type of psoriatic arthropathy was oligo-/monoarthropathy (44.0%). This was followed by rheumatoid-like symmetrical polyarthropathy (32.4%), distal hand joints arthropathy (29.3%), spondylitis/sacroilitis (9.1%) and arthritis mutilans (3.2%) (**Table 5.9**). Morning stiffness of > 30 minutes was reported in 30.3% of adult and 13.3% of paediatric patients. Enthesopathy was reported in 10.2% of adult patients.

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

Nail involvement	Adult		Paediatric	
	n	%	n	%
Yes	4462	60.6	258	38.1
No	2802	38.1	413	61.0
NA	98	1.3	6	0.9
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

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

Nail features	Adult		Paediatric	
	n	%	n	%
Pitting	3261	73.1	232	89.9
Onycholysis	2300	51.6	75	29.1
Discoloration	1686	37.8	39	15.1
Subungual hyperkeratosis	698	15.6	9	3.5
Total nail dystrophy	240	5.4	5	1.9

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

Joint disease	Adult		Paediatric	
	n	%	n	%
Yes	1156	15.7	15	2.2
No	6089	82.7	653	96.5
Not available	117	1.6	9	1.3
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

**Table 5.8 Rheumatoid factor in adult and paediatric patients with psoriasis**

<b>Rheumatoid factor</b>	<b>Adult</b>	
	<b>n</b>	<b>%</b>
Positive	19	1.6
Negative	210	18.2

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

<b>Type of joint disease (one or multiple)</b>	<b>Adult</b>		<b>Paediatric</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Oligo-/Monoarthropathy	509	44.0	6	40.0
Symmetrical polyarthropathy (Rheumatoid like)	375	32.4	3	20.0
Distal hand joints arthropathy	339	29.3	4	26.7
Spondylitis / Sacroiliitis	105	9.1	0	0.0
Arthritis mutilans	37	3.2	0	0.0

Most of the patients with psoriatic arthropathy experienced joint pain at time of presentation both in adult (80.6%) and pediatric (93.3%). Joint swelling was present in 34.4% adults and 6.7% of paediatric patients, while joint deformity occurred in 23.3% of adult patients and 6.7% of paediatric patients (**Table 5.10**, **Table 5.11**). The commonest type of joint deformity was swan neck deformity (27.6%). This was followed by Boutonniere deformity (15.3%), fixed flexion deformity (14.1%), distal hand joint deformity (8.6%), subluxation (4.3%), arthritis mutilans (3.1%), proximal interphalangeal joint deformity (2.5%) and bamboo spine (2.5%). Rheumatoid arthritis-like were observed in only 0.6% of patients (**Table 5.12**).

**Table 5.10 Symptoms of psoriatic arthritis in adult patients with psoriasis**

<b>Symptoms</b>	<b>Yes</b>		<b>No</b>		<b>Not available</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Pain	932	80.6	171	14.8	53	4.6
Swelling	398	34.4	698	60.4	60	5.2
Deformity	269	23.3	824	71.3	63	5.5

**Table 5.11 Symptoms of psoriatic arthritis in paediatric patients with psoriasis**

<b>Symptoms</b>	<b>Yes</b>		<b>No</b>		<b>Not available</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Pain	14	93.3	0	0.0	1	6.7
Swelling	1	6.7	12	80.0	2	13.3
Deformity	1	6.7	12	80.0	2	13.3

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

Type of joint deformity	n	%
Swan neck deformity	45	27.6
Boutonniere deformity	25	15.3
Fixed flexion	23	14.1
Distal hand joint deformity	14	8.6
Subluxation	7	4.3
Arthritis mutilans	5	3.1
Proximal interphalangeal joint deformity	4	2.5
Bamboo spine	4	2.5
Rheumatoid arthritis-like	1	0.6
Others	35	21.5

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

**Table 5.13** Factors associated with psoriatic arthritis in adult patients

Variable	Absent (n=6089)		Present (n=1156)		Multiple Logistic Regression <sup>a</sup>		
	n	%	n	%	Adj. OR	(95% CI)	P- value
<b>Age:</b>							
<18 years							
18-40 years	2408	39.6	337	29.2	-		
41-60 years	2470	40.6	638	55.2	2.04	(1.72, 2.42)	<0.001
>60 years	1211	19.9	181	15.7	1.36	(1.07, 1.73)	0.0123
<b>Age of onset:</b>							
$\leq 40$ years (Type 1)	3878	63.7	785	67.9	0.807	(0.68, 0.96)	0.0152
>40 years (Type 2)	2211	36.3	371	32.1			
<b>Duration of disease:</b>							
$\leq 5$ years	2497	41.0	292	25.3	0.9		
>5 years	3592	59.0	864	74.7		(1.37, 1.87)	<0.001
<b>Gender:</b>							
Male	3593	59.0	586	50.7	-		
Female	2496	41.0	570	49.3	1.633	(1.43, 1.87)	<0.001
<b>Ethnicity:</b>							
Indian	1077	17.7	247	21.4	1.337	(1.14, 1.57)	
Non-Indian	5012	82.3	909	78.6	-		0.0005

<b>Obesity group (WHO):</b>								
BMI <30	4843	79.5	862	74.6	-			
BMI ≥30	1246	20.5	294	25.4	1.262	(1.08, 1.47)	0.0029	
<b>Type of psoriasis:</b>								
Erythrodermic	100	1.6	41	3.6	1.632	(1.10, 2.41)	0.0143	
Non-erythrodermic	5844	96.0	1077	93.2	-			
<b>Body surface area:</b>								
≤10%	3545	58.2	603	52.2	0.804	(0.67, 0.96)	0.0167	
>10%	1111	18.3	298	25.8				
<b>Total skin score:</b>								
<10	2876	47.2	478	41.4	-			
≥10	3213	52.8	678	58.7	1.048	(0.91, 1.21)	0.5307	
<b>Nail involvement:</b>								
Yes	3523	57.9	885	76.6	2.33	(1.99, 2.73)	<0.001	
No	2624	41.5	252	21.8				
								<0.001
<b>DLQI:</b>								
≤10	2523	41.4	438	37.9				
>10	1119	18.4	289	25.0	1.452	(1.24, 1.70)	<0.001	

\*Result was based on available information.

Adj. OR = Adjusted odds ratio.

<sup>a</sup> 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 (95.5%) (**Table 6.1**). In 76.8% of the patients, topical monotherapy was the only treatment given. The most commonly used topical medication was topical steroids (85.7%). This was followed by topical tar preparation (80.6%), emollients (74.7%), keratolytics (55.4%) and vitamin D analogue such as calcipotriol (25.9%). Calcipotriol with betamethasone dipropionate and dithranol were less favoured and used in 2.6% of patients only (**Table 6.2**).

In the paediatric population, 95.1% of patients received topical therapy (**Table 6.1**). The most common type of topical therapy was topical steroids (81.4%), followed by tar preparation (78.7%) and emollient (64.86%) (**Table 6.2**).

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

Topical therapy	Adult		Paediatric	
	n	%	n	%
Yes	7030	95.5	644	95.1
No	238	3.2	28	4.2
Not available	94	1.3	5	0.7
Total	7362	100	677	100

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

Topical therapy	Adult		Paediatric	
	n	%	n	%
Topical steroids	6026	85.7	524	81.4
Tar preparation	5664	80.6	507	78.7
Emollient	5251	74.7	437	67.9
Keratolytics	3892	55.4	332	51.6
Calcipotriol	1823	25.9	124	19.3
Calcipotriol with betamethasone dipropionate	183	2.6	20	3.1
Dithranol (anthralin)	182	2.6	12	1.9
Others	177	2.5	19	3.0

In the last six months prior to notification, 3.8% of adult patients and 1.2% of paediatric patients received phototherapy (**Table 6.3**).

Most of adult patients (85.6%) and paediatric patients (87.5%) were given narrowband UVB (NB-UVB) while 9.4% of adult patients with psoriasis were given broadband UVB (BB-UVB). Less popular modalities in adult patients were oral PUVA (4.6%), topical PUVA (0.8%) and bath PUVA (0.4%). 12.5% of paediatric patients were given topical PUVA (**Table 6.4**).

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

Phototherapy	Adult		Paediatric	
	n	%	n	%
Yes	263	3.6	8	1.2
No	6781	92.1	650	96.0
Not available	318	4.3	19	2.8
<b>Total</b>	<b>7362</b>	<b>100</b>	<b>677</b>	<b>100</b>

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

Types of Phototherapy	Adult		Paediatric	
	n	%	n	%
Narrowband UVB	225	85.6	7	87.5
Broadband UVB	27	10.3	0	0.0
Oral PUVA	12	4.6	0	0.0
Topical PUVA	2	0.8	1	12.5
Bath PUVA	1	0.4	0	0.0
Others	3	1.1	0	0.0

Systemic therapy was used in 19.6% of adult patients and only 5.3% in paediatric patients with psoriasis (**Table 6.5**).

In adult patients, the commonest systemic agents used was methotrexate (69.5%), followed by acitretin (19.0%) and sulphasalazine (6.6%). 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 (50%). This was followed by acitretin in 27.8% of patients (**Table 6.6**).

A total of 23 adult patients received biologic treatment. The biologic therapy most frequently used was etanercept and adalimumab (5 patients each), followed by ustekinumab and efalizumab (4 patients each) and infliximab (2 patients). The name of the biologic agent was not specified in 3 patients.

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

<b>Systemic therapy</b>	<b>Adult</b>		<b>Paediatric</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Yes	1442	19.6	36	5.3
No	5747	78.1	628	92.8
Not available	173	2.3	13	1.9
Total	7362	100	677	100

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

<b>Types of systemic therapy</b>	<b>Adult</b>		<b>Paediatric</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Methotrexate	1002	69.5	18	50.0
Acitretin	274	19.0	10	27.8
Sulphasalazine	95	6.6	0	0.0
Cyclosporin	65	4.5	0	0.0
Hydroxyurea	18	1.3	0	0.0
Biologics	23	1.9	0	0.0
Systemic corticosteroids	92	6.4	3	8.3
Others	68	4.7	2	5.6

## **CHAPTER 7**

### **QUALITY OF LIFE**

There were a total of 4,484 adult patients (aged 17 and above) and 260 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  $8.4 \pm 6.4$ , and the mean CDLQI for paediatric patients was  $7.7 \pm 5.5$ .

The responses for each question of the DLQI and CDLQI were tabulated in **Table 7.1** and **7.2** respectively. 1,455 adult patients (32.5%) reported a DLQI of more than 10 indicating severe quality of life impairment due to psoriasis or its treatment. There were 240 adults (5.4%) who had a DLQI of more than 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. 38.3% 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 73.2% of the adult patients did not have or only have a little effect in this aspect.

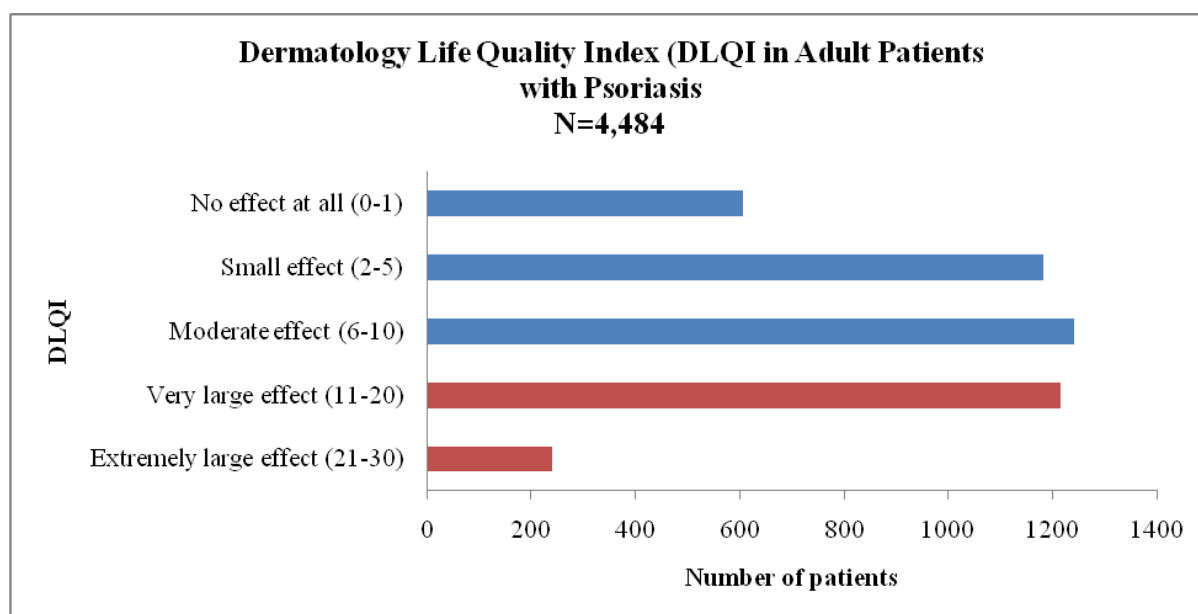
In the paediatric group, 18.4% of patients reported a CDLQI of more than 12 indicating very large or extremely large effect on QoL (**Figure 7.3**). There were 12 patients (4.6%) who had CDLQI of more than 19, reflecting extremely large effect of QoL. On the other hand, 11.9% paediatric patients reported no effect at all on their QoL.

In paediatric patients, the category of CDLQI most affected was “symptoms and feelings”. 39.0% 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 84.0% 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.

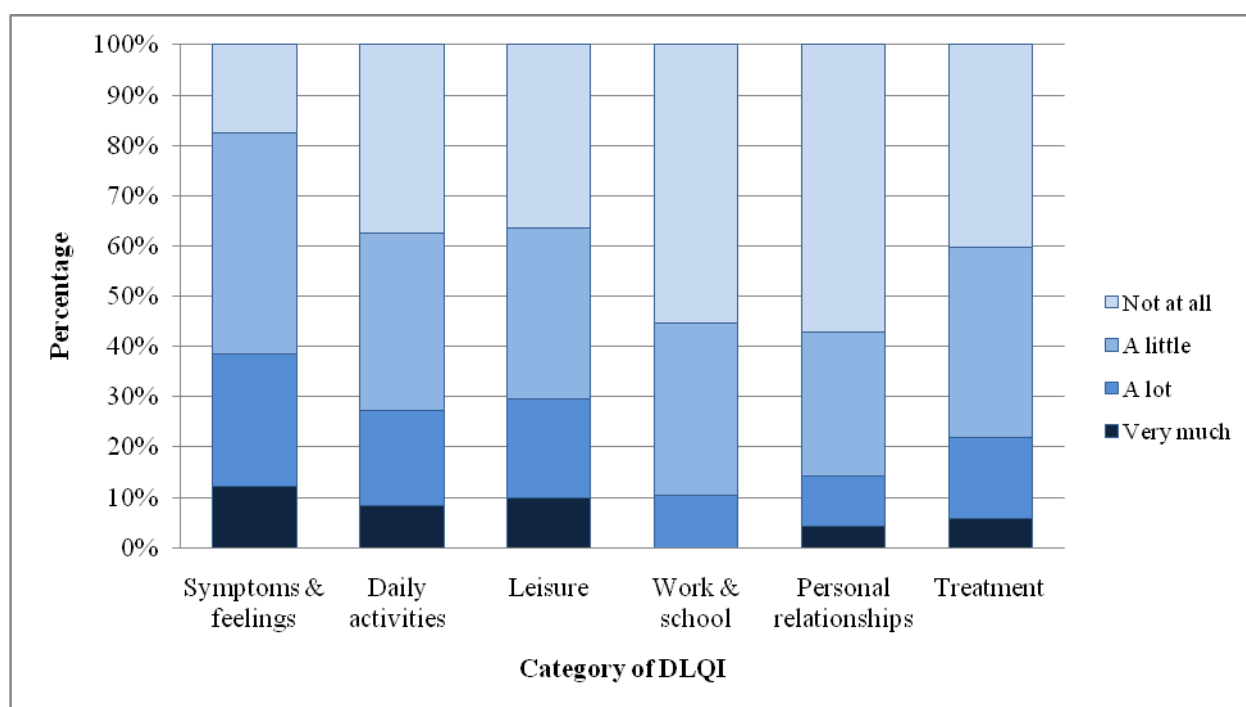
Patients with psoriatic arthritis were also noted to have poorer quality of life, with a DLQI > 10. They also have more clinic visits, more days off work and more hospital admissions (**Table 7.3**).

**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?	678 (9.2)	1958 (26.6)	3690 (50.1)	787 (10.7)	0 (0.0)
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	1049 (14.3)	1753 (23.8)	2575 (35.0)	1714 (23.3)	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?	596 (8.1)	1299 (17.6)	2397 (32.6)	2593 (35.2)	231 (3.1)
4	Over the last week, how much has your skin influenced the clothes you wear?	536 (7.3)	1321 (17.9)	2451 (33.3)	2582 (35.1)	219 (3.0)
5	Over the last week, how much has your skin affected any social or leisure activities?	639 (8.7)	1356 (18.4)	2359 (32.0)	2527 (34.3)	226 (3.1)
6	Over the last week, how much has your skin made it difficult for you to do any sport?	632 (8.6)	1187 (16.1)	2007 (27.3)	2169 (29.5)	1075 (14.6)
7	Over the last week, has your skin prevented you from working or studying?	0 (0.0)	478 (6.5)	1600 (21.7)	2592 (35.2)	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?	306 (4.2)	823 (11.2)	2227 (30.3)	3427 (46.6)	312 (4.2)
9	Over the last week, how much has your skin caused sexual difficulties?	223 (3.0)	376 (5.1)	1218 (16.5)	3469 (47.1)	1751 (23.8)
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?	398 (5.4)	1077 (14.6)	2546 (34.6)	2696 (36.6)	384 (5.2)



**Figure 7.1** Quality of life in adult patients with psoriasis

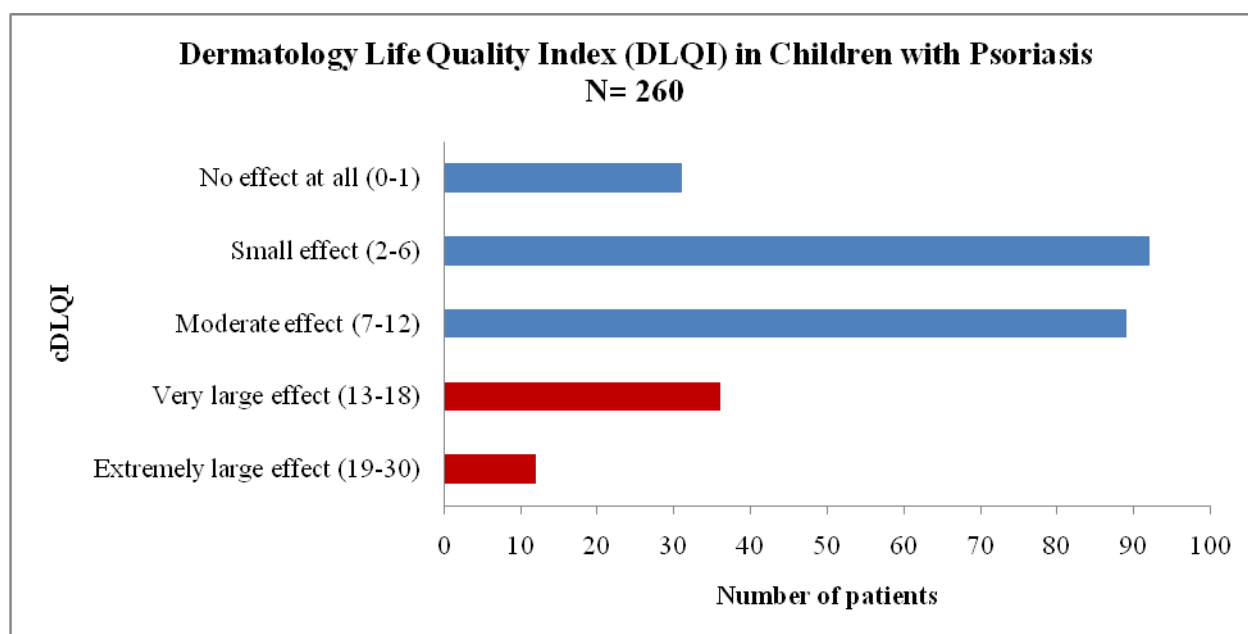


**Figure 7.2** QoL impairment in adults psoriasis patients based on category of DLQI

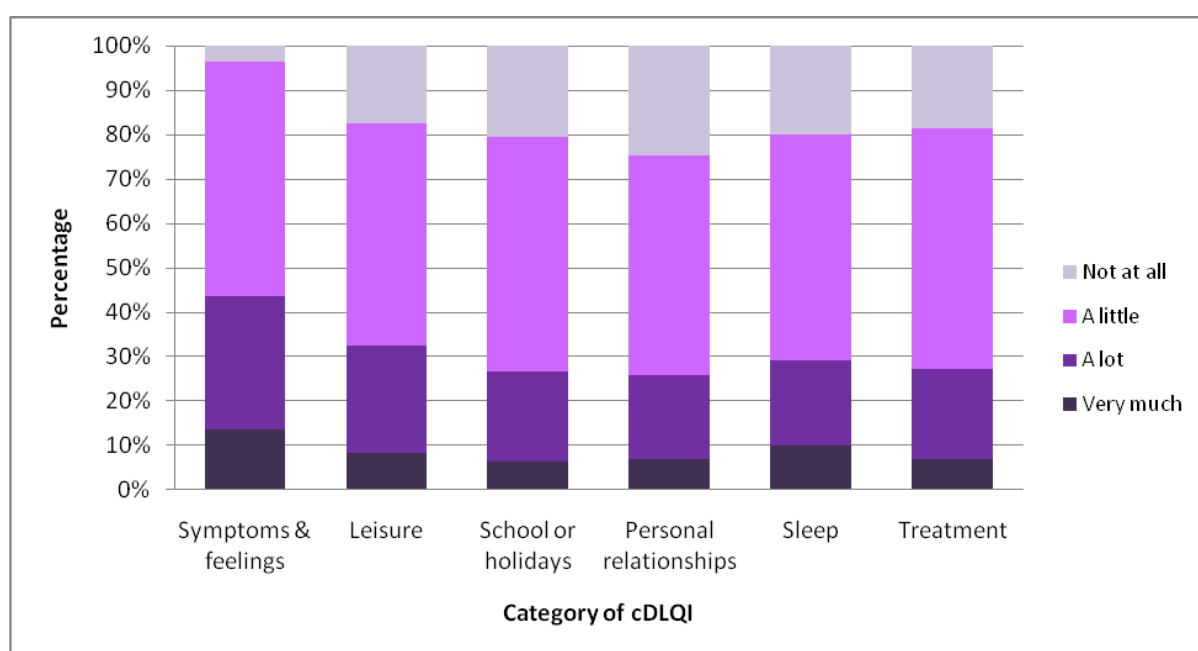


**Table 7.2 Responses for CDLQI in paediatric psoriasis patients (aged 5 to 16)**

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?	41 (6.1)	133 (19.7)	247 (36.5)	37 (5.5)	
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	70 (10.3)	116 (17.1)	187 (27.6)	84 (12.4)	
3	Over the last week, how much has your skin affected your friendships?	19 (2.8)	58 (8.6)	145 (21.4)	233 (34.4)	
4	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	20 (3.0)	78 (11.5)	162 (23.9)	195 (28.8)	
5	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	23 (3.4)	27 (11.4)	162 (23.9)	194 (28.7)	
6	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	32 (4.7)	65 (9.6)	127 (18.8)	231 (34.1)	
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?	18 (2.7)	57 (8.4)	150 (22.2)	226 (33.4)	
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?	18 (2.7)	41 (6.1)	117 (17.3)	279 (41.2)	
9	Over the last week, how much has your sleep been affected by your skin problem?	28 (4.1)	54 (8.0)	142 (21.0)	210 (31.0)	
10	Over the last week, how much of a problem has the treatment for your skin been?	20 (3.0)	80 (8.9)	159 (23.5)	213 (31.5)	



**Figure 7.3** Quality of life in paediatric patients with psoriasis



**Figure 7.4** QoL impairment in paediatric patients with psoriasis based on category of DLQI

**Table 7.3 QOL and productivity parameters observed in adult patients with psoriatic arthritis**

Parameters	Arthritis Absent (n=6089)		Arthritis Present (n=1156)		Simple Logistic Regression <sup>a</sup>		
	n	%	n	%	Crude OR	(95% CI)	P-value
<b>DLQI, median (IQR)</b>							
≤10	2523	41.4	438	37.9	-	-	-
>10	1119	18.4	289	25.0	1.40	(1.20, 1.62)	<0.001
<b>*No. of clinic visit, median (IQR)</b>							
0 time	1099	18.1	137	11.9	-	-	-
1-2 times	3331	54.7	635	54.9	1.52	(1.24, 1.85)	<0.001
3-10 times	1583	26.0	368	31.8	1.64	(1.33, 2.04)	<0.001
11-48 times	73	1.2	16	1.4	1.03	(0.56, 1.92)	0.919
<b>*No. of days off work, median (IQR)</b>							
0 day	5616	92.2	980	84.8	-	-	-
1-3 days	326	5.4	95	8.2	1.50	(1.18, 1.91)	0.001
4-10 days	109	1.8	48	4.2	2.09	(1.46, 3.00)	<0.001
11-90 days	35	0.6	33	2.9	4.43	(2.65, 7.43)	<0.001
<b>*No. of hospital admissions, median (IQR)</b>							
0 time	5970	98.1	1104	95.5	-	-	-
1-2 times	101	1.7	44	3.8	1.54	(1.04, 2.28)	0.030
3-15 times	15	0.3	8	0.7	2.42	(1.00, 5.85)	0.049

\*Over a 6-month period.

IQR = 25<sup>th</sup> – 75<sup>th</sup> 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 2,204 follow-up data were available from 8,039 patients notified to the MPR. From a total of 7,362 adult patients with psoriasis registered in MPR, follow-up data were obtained in 2,092 patients. In paediatric cases, follow-up data were obtained in 112 patients. The mean duration of follow-up was  $22.6 \pm 14.9$  months, with the longest duration of 65 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 1486 patients were evaluated for change in the extent of lesions. Of these patients, 363 patients (24.4%) had improvement by at least one scale, among which 63 (4.2%) had improvement by two scales, and 5 patients improved from BSA>90% to BSA<2%. No improvement was found in 773 patients (0.5%), and 282 patients (19.0%) 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. 170 patients (8.2%) had the most marked improvement in skin scores by 75% or more, and 360 patients (17.5%) had improvement by 50-75%, while 366 patients (17.7%) had 25-50% improvement. 180 patients (8.7%) had modest improvement of less than 25%. No improvement of skin scores were detected in 388 patients (18.8%). Skin scores worsened in 599 patients (29.0%) (**Figure 8.2**).

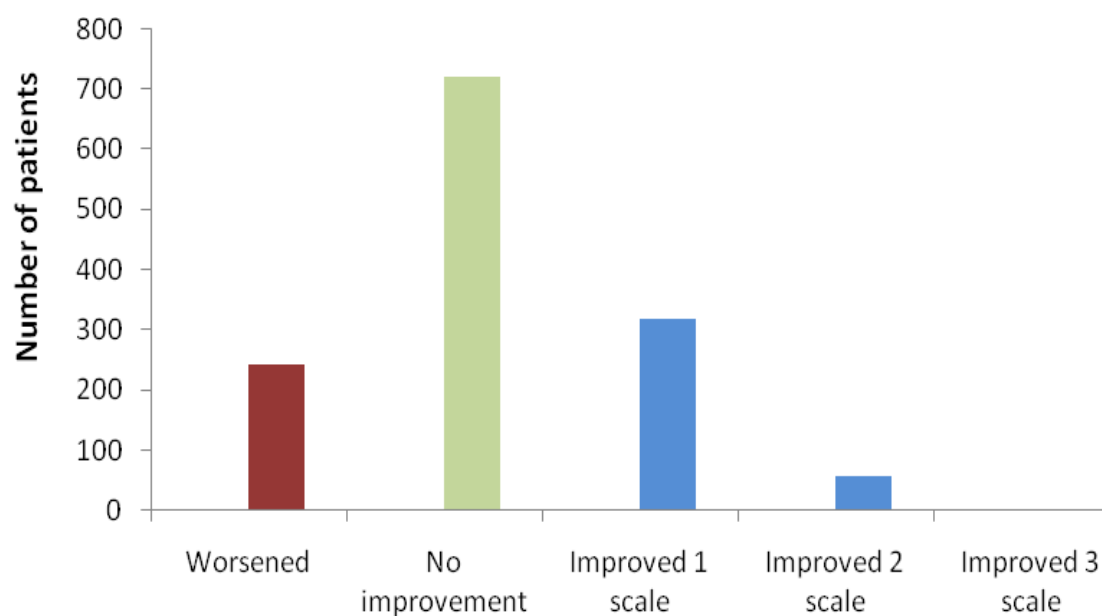
### Joint Pain

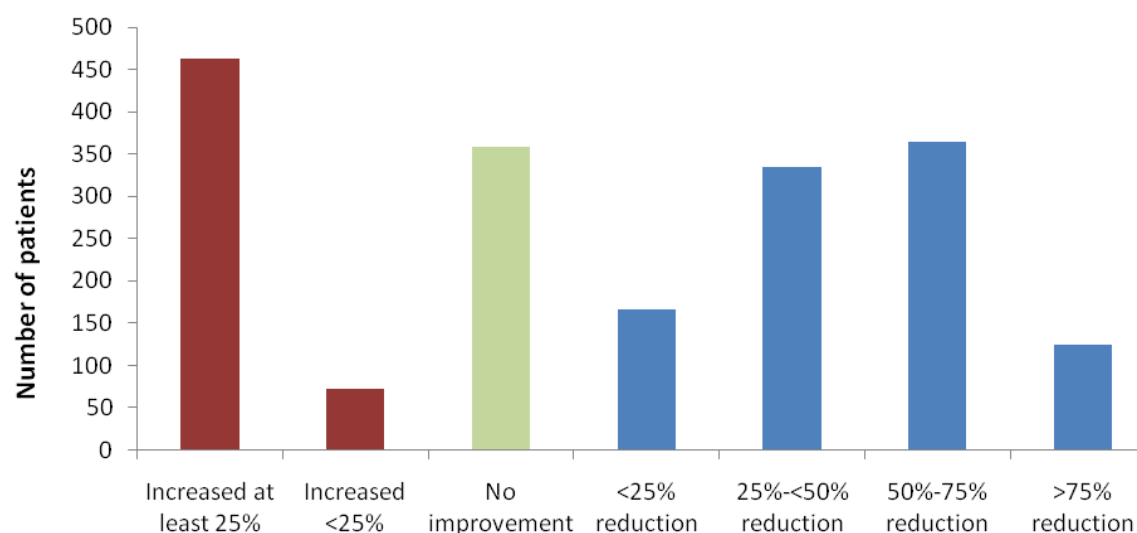
From a total of 133 patients who reported to have joint pain, 60 patients (45.1%) had improvement in joint pain as measured by the visual analogue scale. Of these patients, 17 patients (12.8%) had improvement of between 50% and 75%, 4 patients (3.0%) had improvement of more than 75%, 25 patients (18.8%) had improvement of between 25% and 50%, and 14 patients (10.5%) had improvement of less than 25%. There was no improvement of joint pain in 34 patients (24.6%), while joint pain worsened in 39 patients (29.2%) (**Figure 8.3**).

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

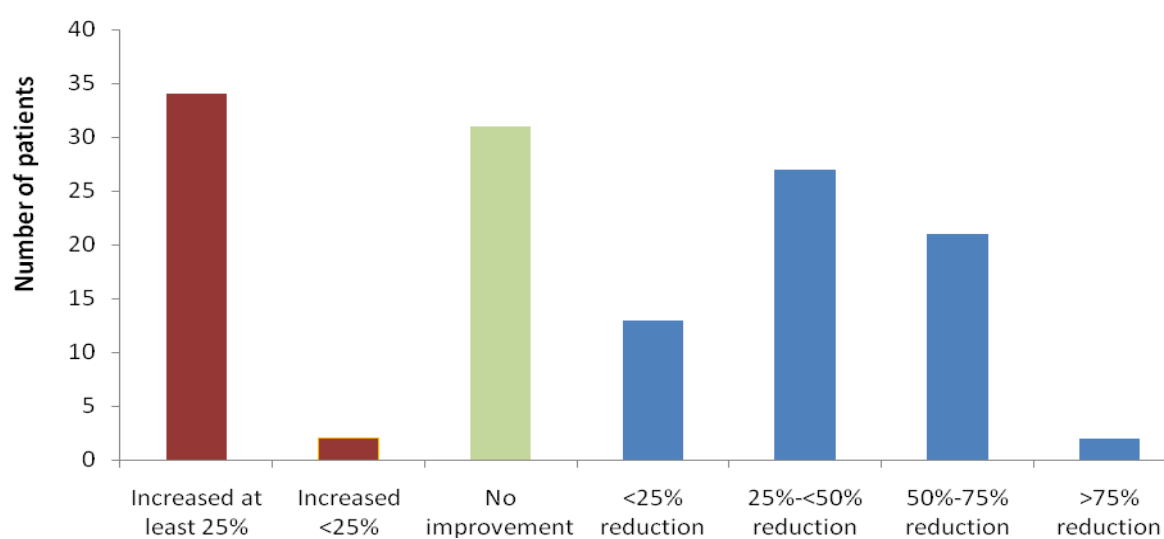
<b>Duration of follow-up</b>	<b>n</b>	<b>%</b>
0 to 6 months	289	13.1
7 to 12 months	462	21.0
13 to 18 months	367	16.7
19 to 24 months	269	12.2
25 to 30 months	222	10.1
31 to 36	184	8.3
>36	411	18.6
	<b>2204</b>	<b>100.0</b>

Mean duration of follow-up:  $22.6 \pm 14.9$  months (range 0 – 65 months)

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



**Figure 8.2 Improvement in the total clinical skin scores**

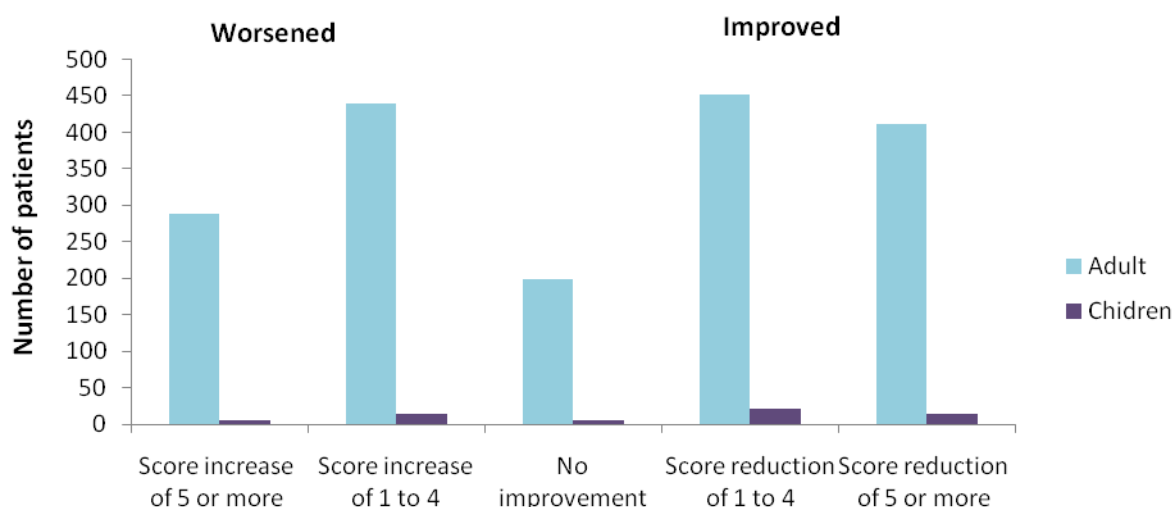


**Figure 8.3 Improvement in joint pain**

### 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 1,501 adult patients were evaluated for change in quality of life by DLQI. Of these patients, 368 patients (24.5%) had significant improvement with a reduction of DLQI score by at least 5, whereas 238 patients (15.9%) had significant worsening with an increase in DLQI score by at least 5 (**Figure 8.4**).

A total of 36 patients aged below 17 were evaluated for change in quality of life by DLQI. Of these patients, 4 patients (11.1%) had a significant improvement of Child DLQI score by at least 5, while 4 patients (11.1%) worsened (**Figure 8.4**).



**Figure 8.4 Improvement in DLQI and CDLQI**

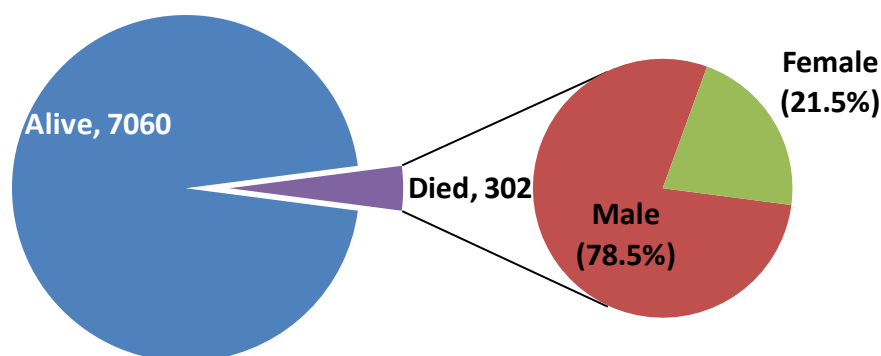
### Mortality in Psoriasis

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 January 2007 and December 2012 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. Increased risk of mortality associated with co-morbidities was checked using Fisher's exact test. Multivariate analysis using multiple logistic regression were conducted on potential factors associated with higher risk of mortality.

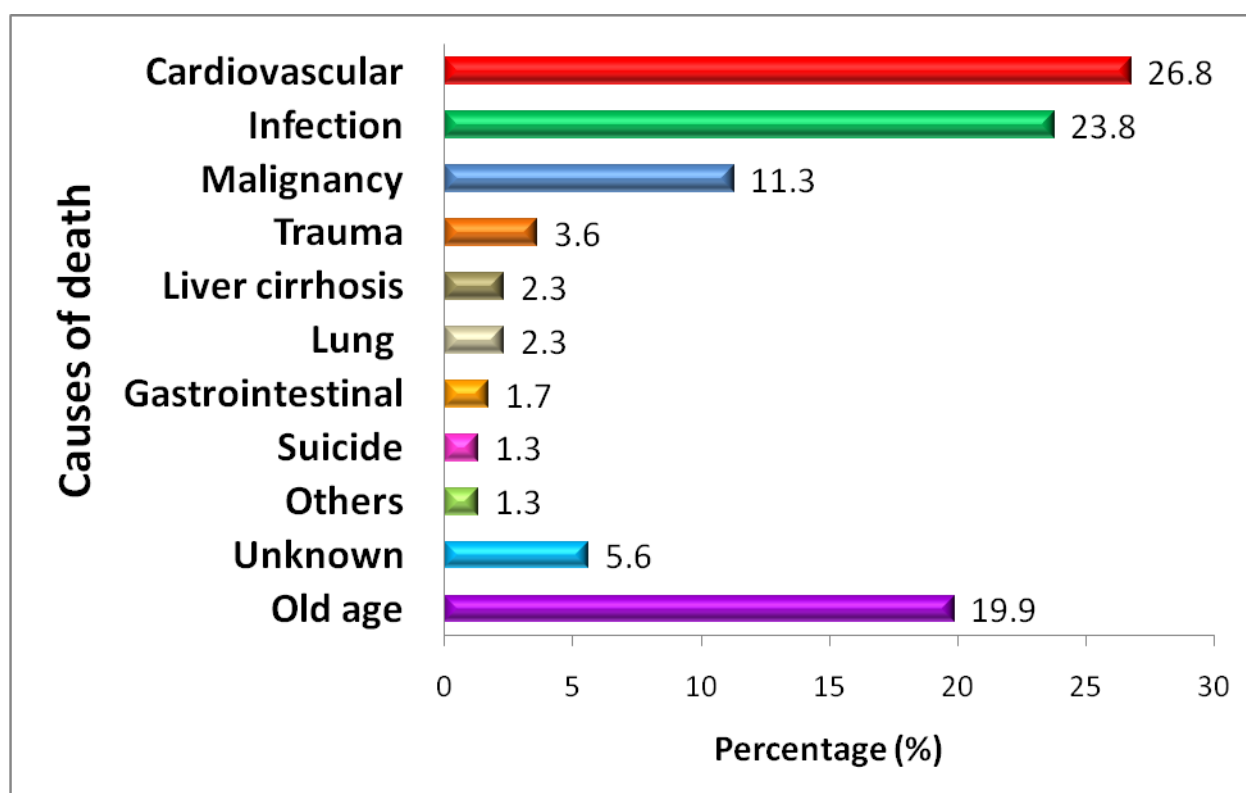
A total of 302 deaths (237 males, 65 females) were identified among the 7,362 adult patients notified to the registry (**Figure 8.5**). 78.5% of the patients who had died were male, and 21.5% were female (**Table 8.2**). The mean age at death was  $60.2 \pm 13.4$  years. The leading causes of death were cardiovascular disease (26.8%) and infections (23.8%). Malignancy (solid organ and haematological) accounted for 11.3% of cases. (**Figure 8.6**).



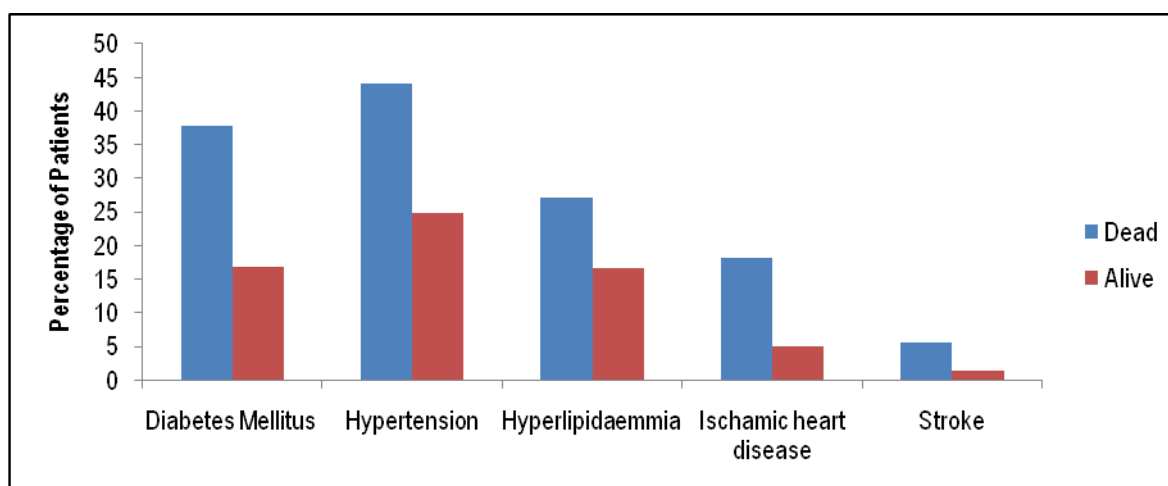
The cardiovascular risk factors in patients with psoriasis were analysed. In patients who died, 44.0% had hypertension, 37.8% were diabetic, 27.2% patients had hyperlipidaemia, 18.2% had ischaemic heart disease and 5.6% had history of cerebrovascular disease. These were compared with the patients who are alive, and the results were statistically significant ( $p < 0.01$ , Fisher's exact test) (**Figure 8.7**).



**Figure 8.5** Percentage of mortality and gender distribution in adult patients with psoriasis



**Figure 8.6** Causes of death in adults patients with psoriasis



**Figure 8.7 Cardiovascular risk factors in patients with psoriasis**

After adjusting for confounding factors, 4 variables emerged as significant predictive factors of higher mortality in adult patients with psoriasis, namely older age (>40 years) (OR 2.87), older age of onset (>40 years) (OR 1.83), male gender (OR 2.33) and more severe disease (BSA >10%) (OR 1.54) (**Table 8.3**)

**Table 8.2 Predictive factors of higher mortality in adult patients with psoriasis**

Variable	Alive (n=7060)		Died (n=302)		Multiple Logistic Regression <sup>a</sup>		
	n	%	n	%	Crude OR	(95% CI)	P-value
<b>Age:</b>							
18-40 years	2761	39.1	27	8.9	-	-	-
41-60 years	3036	43.0	129	42.7	2.87	(1.80, 4.56)	<0.001
>60 years	1263	17.9	146	48.3	6.92	(4.22, 11.37)	<0.001
<b>Age of onset:</b>							
≤40 years (Type 1)	4648	65.8	101	33.4	-	-	-
>40 years (Type 2)	2412	34.2	201	66.6	1.83	(1.35, 2.48)	<0.001
<b>Duration of disease:</b>							
≤5 years	2734	38.7	108	35.8	-	-	-
>5 years	4326	61.3	194	64.2	1.05	(0.80, 1.37)	0.736
<b>Gender:</b>							
Male	4006	56.7	237	78.5	2.33	(1.75, 3.10)	<0.001
Female	3054	43.3	65	21.5	-	-	-

<b>Ethnicity:</b>							
Indian	1280	18.1	62	20.5	1.17	(0.87, 1.58)	0.297
Non-Indian	5780	81.9	240	79.5	-	-	-
<b>Body surface area:</b>							
≤10%	4010	56.8	172	57.0	-	-	-
>10%	1352	19.2	78	25.8	1.54	(1.16, 2.06)	0.003
<b>Systemic therapy:</b>							
1367	1367	19.4	75	24.8	1.23	(0.92, 1.65)	0.163
5521	5521	78.2	226	74.8	-	-	-
<b>Comorbidities:</b>							
Yes	5543	78.5	256	84.8	1.15	(0.83, 1.60)	0.400
No	1517	21.5	46	15.2	-	-	-
<b>Joint disease:</b>							
Yes	1107	15.7	49	16.2	1.07	(0.76, 1.50)	0.697
No	5839	82.7	250	82.8	-	-	-

## APPENDIX A: CASE REPORT FORM

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Case Report Form		CONFIDENTIAL
Instruction: Where check boxes <input checked="" type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="radio"/> are provided, check (✓) one button only.		For Office Use only: ID: <span style="border: 1px solid black; display: inline-block; width: 50px; height: 15px;"></span> / <span style="border: 1px solid black; display: inline-block; width: 50px; height: 15px;"></span> Centre: <span style="border: 1px solid black; display: inline-block; width: 100px; height: 15px;"></span>
<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;">                 Doctor's Name : <span style="border: 1px solid black; display: inline-block; width: 150px; height: 15px;"></span>                  Name of Institution : <span style="border: 1px solid black; display: inline-block; width: 150px; height: 15px;"></span> </div> <div style="width: 50%;"></div> </div>		
<b>SECTION 1: DEMOGRAPHIC DETAILS</b>		
1. Patient visit date : (dd/mm/yyyy)	<div style="border: 1px solid black; display: inline-block; width: 20px; height: 15px;"></div> / <div style="border: 1px solid black; display: inline-block; width: 20px; height: 15px;"></div> / <div style="border: 1px solid black; display: inline-block; width: 40px; height: 15px;"></div>	

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

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NATIONAL DERMATOLOGY REGISTRY (DermReg)				CONFIDENTIAL																	
Malaysian Psoriasis Registry				For Office Use only:																	
Case Report Form				ID: <span style="border: 1px solid black; display: inline-block; width: 100px; height: 20px;"></span>																	
Instruction: Where check boxes <input checked="" type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="radio"/> are provided, check (✓) one button only.				Centre: <span style="border: 1px solid black; display: inline-block; width: 150px; height: 20px;"></span>																	
<b>SECTION 3: CLINICAL EXAMINATION</b>																					
1. (a) Height :		<div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div> <div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div> (cm)		(b) Weight: <div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div> <div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div> (kg)																	
2. Type of psoriasis :		( Please select ONE predominant type )																			
		<input type="radio"/> Plaque <input type="radio"/> Guttate <input type="radio"/> Erythrodermic <input type="radio"/> Flexural / Inverse <input type="radio"/> Others, specify: _____ <input type="radio"/> Generalised pustular <input type="radio"/> Localised Pustular <input type="radio"/> Palmoplantar non-pustular																			
3. Severity :		Body surface area involved : <input type="radio"/> <5% <input type="radio"/> 5 - 10% <input type="radio"/> > 10% <input type="radio"/> Erythrodermic (>90%)																			
		<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th>Body part</th> <th>Grade of severity</th> </tr> </thead> <tbody> <tr> <td>Scalp</td> <td><input type="radio"/> 0    <input type="radio"/> 1    <input type="radio"/> 2    <input type="radio"/> 3</td> </tr> <tr> <td>Face &amp; Neck</td> <td><input type="radio"/> 0    <input type="radio"/> 1    <input type="radio"/> 2    <input type="radio"/> 3</td> </tr> <tr> <td>Trunk</td> <td><input type="radio"/> 0    <input type="radio"/> 1    <input type="radio"/> 2    <input type="radio"/> 3</td> </tr> <tr> <td>Upper Limbs</td> <td><input type="radio"/> 0    <input type="radio"/> 1    <input type="radio"/> 2    <input type="radio"/> 3</td> </tr> <tr> <td>Lower Limbs</td> <td><input type="radio"/> 0    <input type="radio"/> 1    <input type="radio"/> 2    <input type="radio"/> 3</td> </tr> </tbody> </table>		Body part	Grade of severity	Scalp	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	Face & Neck	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	Trunk	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	Upper Limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	Lower Limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	<b>Key for grading.</b> Grade 0 : Skin normal or hypo-/hyperpigmented patch only. Grade 1 : Mild erythema, fine scales, thin plaque, with or without central clearing. Grade 2 : Moderate erythema or scaling, moderately thick plaque. Grade 3 : Severe erythema or scaling, very thick plaque					
Body part	Grade of severity																				
Scalp	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3																				
Face & Neck	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3																				
Trunk	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3																				
Upper Limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3																				
Lower Limbs	<input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3																				
4. Nail involvement :		<input type="radio"/> No <input type="radio"/> Yes → <input type="checkbox"/> Pitting <input type="checkbox"/> Discoloration <input type="checkbox"/> Total nail dystrophy (if YES, please tick ONE or MULTIPLE ) <input type="checkbox"/> Onycholysis <input type="checkbox"/> Subungual hyperkeratosis																			
5. Joint disease :		<input type="radio"/> No <input type="radio"/> Yes →																			
		a) Rheumatoid factor <input type="radio"/> Negative <input type="radio"/> Positive <input type="radio"/> Not Available b) Morning stiffness > 30 minutes <input type="radio"/> No <input type="radio"/> Yes c) Enthesopathy / Dactylitis <input type="radio"/> No <input type="radio"/> Yes d) Type :- <table style="width: 100%;"> <tr> <td style="width: 50%;">1. Oligo-/ Monoarthropathy</td> <td><input type="radio"/> No    <input type="radio"/> Yes</td> </tr> <tr> <td>2. Distal hand joints arthropathy</td> <td><input type="radio"/> No    <input type="radio"/> Yes</td> </tr> <tr> <td>3. Symmetrical polyarthropathy (Rheumatoid-like)</td> <td><input type="radio"/> No    <input type="radio"/> Yes</td> </tr> <tr> <td>4. Spondylitis / Sacroiliitis</td> <td><input type="radio"/> No    <input type="radio"/> Yes</td> </tr> <tr> <td>5. Arthritis mutilans</td> <td><input type="radio"/> No    <input type="radio"/> Yes</td> </tr> </table> e) Severity:- <table style="width: 100%;"> <tr> <td style="width: 50%;">1. Pain</td> <td><input type="radio"/> No    <input type="radio"/> Yes → Pain Score (1-10) : <div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div></td> </tr> <tr> <td>2. Swelling</td> <td><input type="radio"/> No    <input type="radio"/> Yes</td> </tr> <tr> <td>3. Deformity</td> <td><input type="radio"/> No    <input type="radio"/> Yes → Please Specify : _____</td> </tr> </table>				1. Oligo-/ Monoarthropathy	<input type="radio"/> No <input type="radio"/> Yes	2. Distal hand joints arthropathy	<input type="radio"/> No <input type="radio"/> Yes	3. Symmetrical polyarthropathy (Rheumatoid-like)	<input type="radio"/> No <input type="radio"/> Yes	4. Spondylitis / Sacroiliitis	<input type="radio"/> No <input type="radio"/> Yes	5. Arthritis mutilans	<input type="radio"/> No <input type="radio"/> Yes	1. Pain	<input type="radio"/> No <input type="radio"/> Yes → Pain Score (1-10) : <div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div>	2. Swelling	<input type="radio"/> No <input type="radio"/> Yes	3. Deformity	<input type="radio"/> No <input type="radio"/> Yes → Please Specify : _____
1. Oligo-/ Monoarthropathy	<input type="radio"/> No <input type="radio"/> Yes																				
2. Distal hand joints arthropathy	<input type="radio"/> No <input type="radio"/> Yes																				
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4. Spondylitis / Sacroiliitis	<input type="radio"/> No <input type="radio"/> Yes																				
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1. Pain	<input type="radio"/> No <input type="radio"/> Yes → Pain Score (1-10) : <div style="border: 1px solid black; width: 40px; height: 20px; display: inline-block;"></div>																				
2. Swelling	<input type="radio"/> No <input type="radio"/> Yes																				
3. Deformity	<input type="radio"/> No <input type="radio"/> Yes → Please Specify : _____																				
<b>SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS</b>																					
1. Topical therapy :		a) Tar preparation <input type="radio"/> No <input type="radio"/> Yes    e) Topical steroids (other than face / flexures) <input type="radio"/> No <input type="radio"/> Yes b) Vitamin D analogues e.g. calcipotriol <input type="radio"/> No <input type="radio"/> Yes    f) Keratolytics e.g. salicylic acid <input type="radio"/> No <input type="radio"/> Yes c) Calcipotriol with betamethasone dipropionate <input type="radio"/> No <input type="radio"/> Yes    g) Emollient <input type="radio"/> No <input type="radio"/> Yes d) Dithranol (anthralin) <input type="radio"/> No <input type="radio"/> Yes    h) Others, specify _____																			
2. Phototherapy :		<input type="radio"/> No <input type="radio"/> Yes → <input type="checkbox"/> BB-UVB <input type="checkbox"/> Oral PUVA <input type="checkbox"/> Topical PUVA <input type="checkbox"/> Others, specify _____ (if YES, please tick ONE or MULTIPLE ) <input type="checkbox"/> NB-UVB <input type="checkbox"/> Bath PUVA <input type="checkbox"/> Excimer laser																			
3. Systemic therapy :		<input type="radio"/> No <input type="radio"/> Yes → <table style="width: 100%;"> <tr> <td style="width: 50%;">a) Methotrexate    <input type="radio"/> No    <input type="radio"/> Yes</td> <td style="width: 50%;">f) Biologics, specify _____</td> </tr> <tr> <td>b) Acitretin    <input type="radio"/> No    <input type="radio"/> Yes</td> <td></td> </tr> <tr> <td>c) Sulphasalazine    <input type="radio"/> No    <input type="radio"/> Yes</td> <td>g) Systemic corticosteroids    <input type="radio"/> No    <input type="radio"/> Yes</td> </tr> <tr> <td>d) Cyclosporin    <input type="radio"/> No    <input type="radio"/> Yes</td> <td></td> </tr> <tr> <td>e) Hydroxyurea    <input type="radio"/> No    <input type="radio"/> Yes</td> <td>h) Others, specify _____</td> </tr> </table>				a) Methotrexate <input type="radio"/> No <input type="radio"/> Yes	f) Biologics, specify _____	b) Acitretin <input type="radio"/> No <input type="radio"/> Yes		c) Sulphasalazine <input type="radio"/> No <input type="radio"/> Yes	g) Systemic corticosteroids <input type="radio"/> No <input type="radio"/> Yes	d) Cyclosporin <input type="radio"/> No <input type="radio"/> Yes		e) Hydroxyurea <input type="radio"/> No <input type="radio"/> Yes	h) Others, specify _____						
a) Methotrexate <input type="radio"/> No <input type="radio"/> Yes	f) Biologics, specify _____																				
b) Acitretin <input type="radio"/> No <input type="radio"/> Yes																					
c) Sulphasalazine <input type="radio"/> No <input type="radio"/> Yes	g) Systemic corticosteroids <input type="radio"/> No <input type="radio"/> Yes																				
d) Cyclosporin <input type="radio"/> No <input type="radio"/> Yes																					
e) Hydroxyurea <input type="radio"/> No <input type="radio"/> Yes	h) Others, specify _____																				
<b>SECTION 5: QUALITY OF LIFE</b>																					
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

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

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

Objektif kaji selidik adalah untuk memahami setakat manakah masalah kulit anda mempengaruhi kehidupan anda SEPANJANG MINGGU LALU.

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

这份问卷的目的是衡量上周内您的皮肤问题对您的生活造成了多大的影响。

Sila tandakan satu kotak (✓) untuk setiap soalan / Please tick "✓" one box for each question 请在每个问题后选择一项打 "✓".

Sepanjang Minggu Lalu .... OVER THE LAST WEEK 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Setakat manakah anda berasa malu atau segan, disebabkan oleh kulit anda? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Setakat manakah kulit anda mengganggu anda daripada pergi membeli belah atau menjaga rumah atau berkebun? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Setakat manakah kulit anda mempengaruhi pakaian yang anda pakai? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) Setakat manakah kulit anda mengganggu aktiviti - aktiviti sosial atau masa lapang anda? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) Setakat manakah keadaan kulit anda menyebabkan anda tidak selesa bersukan? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) Adakah kulit anda menyebabkan anda tidak bekerja atau belajar? 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?  <input type="checkbox"/> Ya/Yes 是 <input type="checkbox"/> Tidak/No 不是 <input type="checkbox"/> Tidak Berkenaan/Not Relevant 无关 <div style="border: 1px dashed black; padding: 5px; margin-top: 5px;">           "Jika "tidak", setakat manakah kulit anda menjadi masalah semasa kerja atau belajar?            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?         </div>					
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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) Setakat manakah kulit anda menyebabkan sebarang masalah hubungan seks? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Setakat manakah rawatan kulit anda menimbulkan masalah seperti mengotori rumah anda atau mengambil masa anda? 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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih

Please check you have answered EVERY question. Thank you.

请您检查您是否已回答所有问题。谢谢合作

Version 2.4 Last updated 07/12/2011

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NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Children's Dermatology Life Quality Index (DLQI) (For age 5 to 16)		CONFIDENTIAL	
Instruction: Where check boxes <input type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="radio"/> are provided, check (✓) one button only.		For Office Use only: ID: <input type="text"/> / <input type="text"/> Centre: <input type="text"/>	
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: <input type="text"/> 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
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?		<input type="radio"/>	<input type="radio"/>
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?		<input type="radio"/>	<input type="radio"/>
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?		<input type="radio"/>	<input type="radio"/>
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?		<input type="radio"/>	<input type="radio"/>
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、或从事休闲嗜好影响是如何?		<input type="radio"/>	<input type="radio"/>
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?		<input type="radio"/>	<input type="radio"/>
7) Pada minggu yang lalu, Last week, 过去一星期 Pada hari persekolahan, setakat manakah kulit anda mempengaruhi kerja sekolah anda? 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 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?		<input type="radio"/>	<input type="radio"/>
8) Setakat manakah orang memanggil anda dengan nama yang tidak baik, mengejek, menanya soalan-soalan atau menjauhi diri disebabkan oleh kulit anda? 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?		<input type="radio"/>	<input type="radio"/>
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睡眠的程度是如何?		<input type="radio"/>	<input type="radio"/>
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?		<input type="radio"/>	<input type="radio"/>
Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih Please check you have answered EVERY question. Thank you. 请您检查您是否已回答所有问题。谢谢合作			

## **APPENDIX B: DATA MANAGEMENT**

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

### **Data Sources**

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

### **Data Collection**

The study involves collection of data on the patient's first visit to the participating centre and thereafter every six monthly on follow-up visits.

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

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

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

Participation of SDP is entirely voluntary.



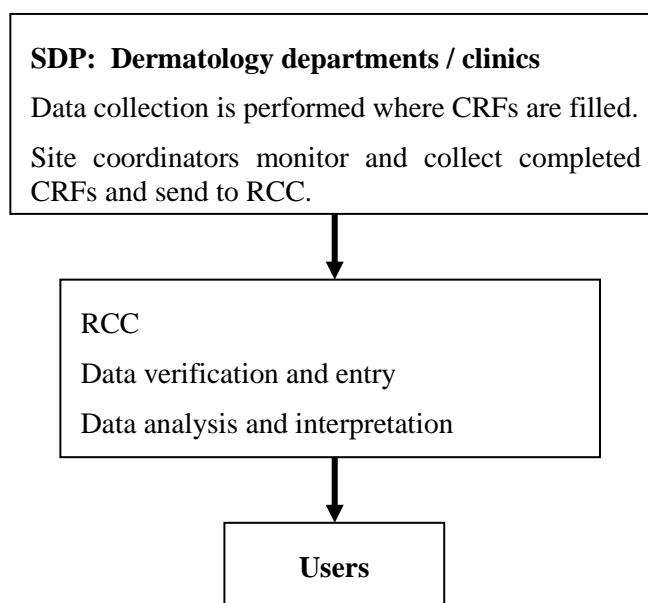
### Registry ICT Infrastructure and Data Centre

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

The network infrastructure consists of the network layout, placement of relevant hardware equipment, the general flow of data across the network, as well as the network services required for a functional and secure DermReg network infrastructure. DermReg servers are located in a data centre in Cyberjaya in order to provide DermReg with quality assured data hosting services and state-of-the-art physical and logical security features without having to invest in costly data centre setup internally. The physical security features implemented include fire suppression system, access card and biometrics authentication to gain physical access to the data centre, uninterrupted power supply, and backup devices. Logical security features implemented include firewall, antivirus, automated patching, encryption, traffic monitoring and intrusion detection system.

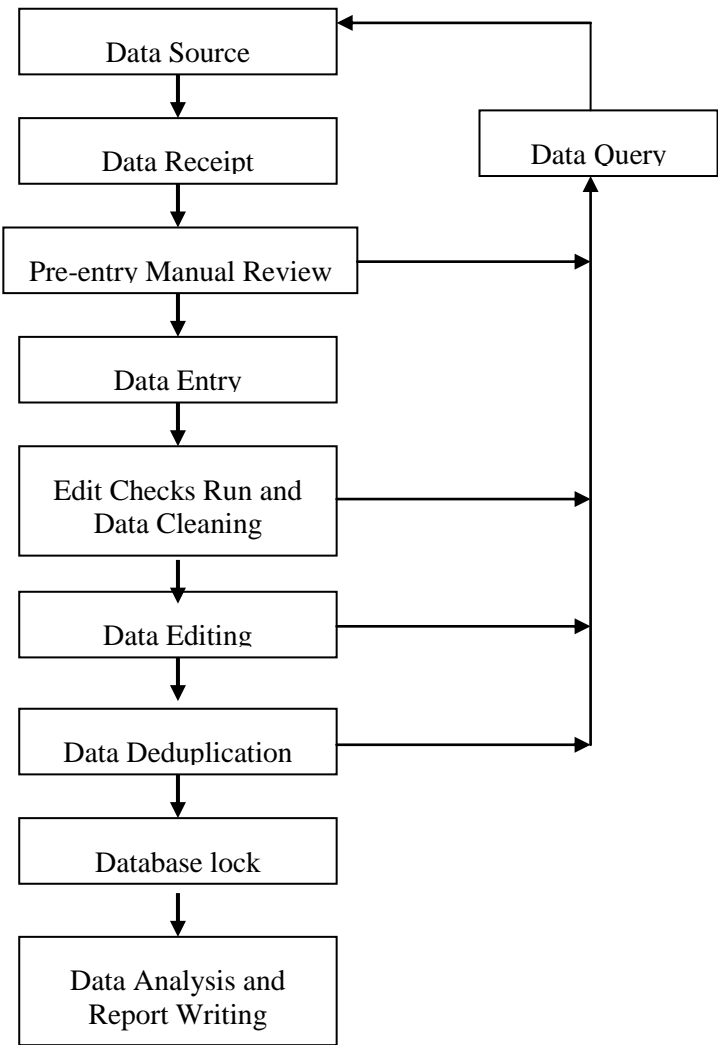
### Data Flow Process

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



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

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



### **SDP Data Reporting, Data Correction and Submission Tracking**

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

There are a number of data security features that are designed into eDermReg such as web owner authentication, two-level user authentication, access control, data encryption, session management to automatically log off the application, audit trail and data backup and disaster recovery plan.

Prior to registering a patient record, a verification process is done by using the search functionality to search if patient exist in the entire registry. This step is done to avoid duplicate records. For patients that exist in the database, SDP only needs to add a new notification with basic patient particulars pre-filled based on existing patient information in the database.

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

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

**Edit checks run and Data cleaning**

Edit check was performed periodically by the registry manager to identify missing compulsory data, out of range values, inconsistency data, invalid values and error with de-duplication. Data cleaning is then performed based on the results of edit checks. Data update and data checking of the dataset is performed when there is a query of certain fields when necessary. It could be due to request by user, correction of data based on checking from data query in eCRF or after receiving results from preliminary data analysis. During data standardization, missing data are handled based on derivation from existing data. For example, deriving age from IC, deriving gender from IC and name and inferring race from name. Checking inconsistency of the data also done, for example IC and name shows female but gender is male. Data de-duplication is also performed to identify duplicate records in the database that might have been missed by the SDP.

**Legal Aspects and Confidentiality**

Data transfer from source data producers is entirely voluntary. There is no legal provision to compel any individual or institution to report or transfer its data to the RCC. The data transferred to RCC is highly sensitive and has to be kept strictly confidential with access only to authorized individual working in the RCC. Strict data protection procedure will need to be put in place, following standard disease registration practice, and in compliance with applicable regulatory guidelines.

**Data release policy**

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

## **APPENDIX C: STATISTICAL METHODS**

### **ANALYSIS SET**

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

**1. Patient notification between 2007 and 2012**

There were 8, 039 patients in the dataset. The analysis set was use for the analysis in Chapter 1, 2, 3, 4, 5 and 6, which comprises of 302 cases in year 2007, 1,259 cases in year 2008, 1,670 cases in year 2009, 1,698 cases in year 2010, 1,577 in year 2011 and 1, 533. The cases include first notification and up to five follow-up notifications.

**2. Patient outcome between 2007 and 2012**

There were 2204 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 METHOD

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

### Stock and Flow

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

### Characteristics of Patients

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

### Medical History

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

### Comorbidities

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

### Clinical Presentation

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

### **Treatment**

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

### **Quality of Life**

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

### **Outcomes**

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

## **STATISTICAL SOFTWARE**

SPSS 18.0

**APPENDIX D: PARTICIPATING CENTRE DIRECTORY**

<b>Hospital Kuala Lumpur</b> Department of Dermatology Hospital Kuala Lumpur Jalan Pahang 50586 Kuala Lumpur. Tel: 03-26151540 Fax: 03-26985927	Investigator: Dr Azura Mohd Affandi  Site- coordinator: -
<b>Hospital Sungai Buloh</b> Dermatology Unit Hospital Sungai Buloh, Jalan Hospital, 47000 Sungai Buloh, Selangor Darul Ehsan. Tel: 03-61454333 Ext 1286 Fax: 03-61454222	Investigator: Dr. Azahzuddin b Hamzah  Site- coordinator: Prima Dharshini
<b>Hospital Tuanku Ja'afar, Seremban</b> Dermatology Department, Hospital Tuanku Ja'afar, Jalan Rasah 70300 Seremban, Negeri Sembilan. Tel: 06-760 4157 Fax: 06-7625771	Investigator: Dr. Najeeb Ahmad Mohd Safdar  Site- coordinator: Dr.Prakash A/L Balasubramaniam
<b>Hospital Sultanah Fatimah, Muar</b> Dermatology Department, Hospital Pakar Sultanah Fatimah, Jalan Salleh, 84000 Muar, Johor. Tel: 06-9521901 Fax: 06-9526003	Investigator: Dr. Siti Khadijah Abdul Wahid  Site- coordinator: Mohd Khairul bin Othman
<b>Hospital Pulau Pinang</b> Dermatology Department, Hospital Pulau Pinang, Jalan Residensi, 10990 Pulau Pinang, Tel: 04-222 5250 Ext 5246 Fax: 04-2281737	Investigator: Dr Chan Lee Chin  Site- coordinator: Dr Yeoh Chin Aun



<b>Hospital Sultanah Bahiyah, Alor Setar</b>  Dermatology Department, Hospital Sultanah Bahiyah, Lebuhraya Darul Aman, 05100 Alor Setar, Kedah Tel: 04-740 6233 Fax: 04-7350232	Investigator: Dr Mani Mala a/p T. Manikam  Site- coordinator: Dr Azlida Che Man
<b>Hospital Tuanku Fauziah, Kangar</b>  Dermatology Department, Hospital Tuanku Fauziah, Jalan Kolam,01000 Kangar, Perlis. Tel: 04-973 8000 Fax: 04-9767237	Investigator: Dr Sharifah Fariah Syed Abas, Dr. Hassanin Hussaini Hilmi bin Mohd Khalid  Site- coordinator: Wan Suhardi bin Wan Abdul Rahman
<b>Hospital Queen Elizabeth, Kota Kinabalu</b>  Dermatology Department, Hospital Queen Elizabeth, Karung Berkunci no 209 , 88586 Kota Kinabalu, Sabah. Tel: 088-517555 Fax: 088-211999	Investigator: Dr Zaigham Mahmood Dr Mervin George Matthew  Site- coordinator: Ampong Anggarak
<b>Hospital Tengku Ampuan Afzan, Kuantan</b>  Dermatology Department, Hospital Tengku Ampuan Afzan, Jalan Tanah Putih, 25100 Kuantan, Pahang. Tel: 09-5133333 Fax: 09-5142712	Investigator: Dr Abu Razak Yusof  Site- coordinator: Mazliza binti Mamat
<b>Hospital Raja Permaisuri Bainun, Ipoh</b>  Dermatology Department, Jabatan Dermatologi, Hospital Ipoh, Jalan Hospital 30990 Ipoh, Perak. Tel: 05-208 5072 Fax: 05-2531541	Investigator: Dr. Tang Jyh Jong  Site- coordinator: Dr. Gurcharan Jit Singh

<b>Sarawak General Hospital</b>  Dermatology Department, Hospital Umum Sarawak, Jln Tun Ahmad Zaidi Adruce, 93586 Kuching, Sarawak. Tel: 082-27 6666 Ext 5117 Fax: 082-242751	Investigator: Dr Pubalan Muniandy  Site- coordinator: Dr Ling Hee Ninh
<b>Hospital Tengku Ampuan Rahimah, Klang</b>  Dermatology Department, Hospital Tengku Ampuan Rahimah, 41200 Klang, Selangor. Tel: 03-3375 7000 Ext 6266 Fax: 03-3374 9557	Investigator: Dr. Ng Ting Guan  Site-coordinator: Dr Norasma bt Roslan, Dr Balachandran a/l Manoharan
<b>Hospital Sultanah Aminah, Johor Bahru</b>  Jabatan Dermatologi, Hospital Sultanah Aminah Johor Bahru, Jalan Abu Bakar, 80100, Johor Bahru, Johor Tel: 07-223 1806 Fax: 07-2242694	Investigator: Dr Choon Siew Eng  Site- coordinator: Hasnal Azahare
<b>Gleneagles Intan Medical Centre</b>  Hope Skin and Laser Centre, Gleneagles Intan Medical Centre, 282 & 286 Jalan Ampang, 50450 Kuala Lumpur. Tel: 03-4251 6233 Fax: 03-4257 9233	Investigator: Dr. Chang Choong Chor  Site- coordinator: -
<b>Hospital Melaka</b>  Dermatology Department, Hospital Melaka, Jalan Mufti Hj. Khalil, 75400 Melaka. Tel: 06-2892690 Fax: 06-2841590	Investigator: Dr Che Salmi Yusoff  Site- coordinator: Dr Koot Chiew Teen, Dr. Nor Afalailah Mohd Aris

<p><b>Prince Court Medical Centre</b></p> <p>Prince Court Medical Centre, 39, Jalan Kia Peng, 50450 Kuala Lumpur. Tel: 03- 26100000 Ext 2955 Fax: 03-2160 0010</p>	<p>Investigator: Dr. Gangaram Hemandas Belani</p> <p>Site- coordinator: -</p>
<p><b>Universiti Malaya Medical Centre</b></p> <p>Department of Medicine, University of Malaya Medical Centre, Faculty of Medicine, University of Malaya, 59100 Kuala Lumpur. Tel: 03-79492429 Fax: 03-7956 2253</p>	<p>Investigator: Dr. Wong Su Ming</p> <p>Site- coordinator: Dr. Kwan Zhen Li</p>
<p><b>Universiti Kebangsaan Malaysia Medical Centre</b></p> <p>Dermatology Department, Universiti Kebangsaan Malaysia Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Kuala Lumpur Tel: 03-9145 6075 03-9145 6640</p>	<p>Investigator: Dr. Mazlin Mohd Baseri</p> <p>Site- coordinator: -</p>
<p><b>Hospital Raja Perempuan Zainab II, Kota Bharu</b></p> <p>Dermatology Department, Hospital Raja Perempuan Zainab II, 15586 Kota Bharu, Kelantan Darul Naim Tel: 09-7452000 Ext 2384 Fax: 09-7486951</p>	<p>Investigator: Dr. Zulrusydi bin Ismail</p> <p>Site- coordinator: Muhd. Al-Amin Mat Zin</p>