

**NATIONAL DERMATOLOGY REGISTRY
(DermReg)**

**Annual Report of the
MALAYSIAN PSORIASIS REGISTRY
2007-2010**

Editors:
**Azura Mohd Affandi
Fatimah `Afifah Alias
Asmah Johar
Roshidah Baba**

With contribution from:
**Chang Choong Chor
Tan Wooi Chiang
Noor Addillah Shueef
Tasha Hilda Adnan**



Ministry of Health Malaysia

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- The Dermatological Society of Malaysia
- Clinical Research Centre (CRC), Ministry of Health, Malaysia
- College of Physicians, Academy of Medicine Malaysia
- Altus Solutions Sdn Bhd

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ABBREVIATIONS

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

ABOUT DermReg

Introduction

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

Objectives of DermReg

General Objective

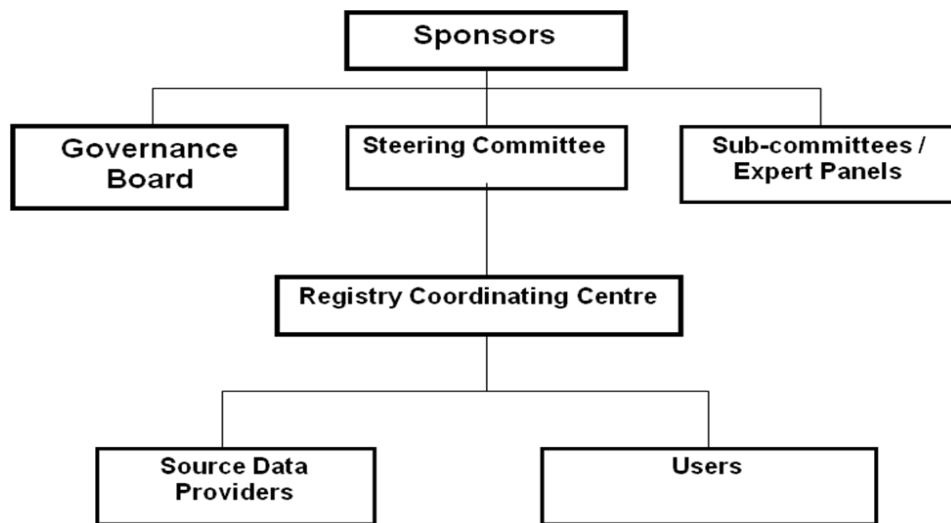
To establish a nationwide systematic prospective collection of data pertaining to skin diseases and dermatological services, in order to study the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities.

Specific Objectives:

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

ORGANISATION OF DermReg

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



SPONSORS

The DermReg is sponsored by:

1. Ministry of Health, Malaysia
2. Clinical Research Centre, Hospital Kuala Lumpur
3. The Dermatological Society of Malaysia
4. Pharma companies – Abbott Malaysia, Leo Pharma Malaysia 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. Koh Chuan Keng
President of the Dermatological Society of Malaysia, and
Consultant Dermatologist
Koh Skin Specialist Clinic
3. Dr. Steven Chow Kim Weng
President of the College of Physicians, Academy of Medicine Malaysia, and
Senior Consultant Dermatologist
The Skin Centre, Kuala Lumpur
4. Dr. Goh Pik Pin
Director of the Clinical Research Centre Network
Ministry of Health

STEERING COMMITTEE

Steering Committee for Malaysian Psoriasis Registry (MPR)

No.	Name	Institution
1.	Dr Chang Choong Chor (2007-Jul 2012) Dr. Azura Mohd Affandi (July 2012 – current)	Hospital Kuala Lumpur
2.	Dr. Choon Siew Eng	Hospital Sultanah Aminah, Johor Bahru
3.	Dr. Pubalan Muniandy	Hospital Umum Sarawak
4.	Dr. Tang Jyh Jong	Hospital Permaisuri Bainun, Ipoh
5.	Dr. Chan Lee Chin	Hospital Pulau Pinang
6.	Dr. Najeeb Ahmad Mohd Safdar	Hospital Tuanku Jaafar, Seremban
7.	Dr. Steven Chow Kim Weng	The Skin Clinic, Kuala Lumpur
8.	Dr. Mohd Noh Idris	Klinik Kulit Md Noh, Kuala Lumpur

REGISTRY COORDINATING CENTRE

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

Registry Manager Fatimah ‘Afifah Alias

Technical Support Personnel

Epidemiology Officer Dr. Jamaiyah Haniff
Clinical Epidemiology Unit,
CRC

Biostatisticians Ms Premaa A/P Supramaniam
Ms Tassha Hilda bt Adnan
CRC

Clinical Data Manager Ms Teo Jau Shya
ClinResearch Sdn Bhd

Database Administrator Ms Lim Jie Ying
Altus Solutions Sdn Bhd

SOURCE DATA PROVIDERS (SDP)

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

Source Data Providers for Malaysian Psoriasis Registry (MPR)

No.	Source Data Provider	Investigator
1.	Hospital Kuala Lumpur	Dr. Azura Mohd Affandi
2.	Hospital Pulau Pinang	Dr. Chan Lee Chin
3.	Hospital Sultanah Bahiyah, Alor Setar	Dr. Mani Mala a/p T. Manikam
4.	Hospital Tuanku Fauziah, Perlis	Dr. Sharifah Fariah 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

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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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 17th May 1998. This registry consists of information on patients with psoriasis in Malaysia and is under the umbrella of the National Dermatology Registry (DermReg). A case report form was developed and data collection started as a pilot project in March 2000. A preliminary report of the registry (March 2000 to July 2005) was published in the Malaysian Journal of Dermatology in the August 2005 issue.

In 2007, MPR was extensively revised under the guidance of CRC and with the financial support from MOH. A new case report form was introduced and a new centralised electronic database with web application was established to facilitate multi-centre data collection. Preliminary report of the newly revised MPR was published in the Medical Journal of Malaysia in September 2008. The First Annual Report of MPR 2007-2008 was published in the following year.

Objectives

The MPR has the following objectives:

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

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

Scope of MPR

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

The MPR collects:

- Demographic data
- Clinical data including patients' history and clinical examination findings
- Quality of life measure i.e. Dermatology Life Quality Index (DLQI)
- Modalities of treatment used

Outcomes of interest include:

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

Inclusion criteria:

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

Exclusion criteria:

Patients whose diagnosis is in doubt are excluded.

EXECUTIVE SUMMARY

Stock and Flow

During the period from October 2007 to December 2010, a total of 5,824 patients with psoriasis from 19 dermatology centres (14 governments, 2 private centres and 1 university hospital) were notified to the registry.

Demographic Characteristics of Patients

Male-to-female ratio was 1.3:1. Ethnic distribution: Malay 49.3%, Chinese 23.3%, Indian 18.2%, other ethnic groups 9.0%. Mean age at notification was 43 ± 17.22 years (range 0 - 97 years). Most patients (99.0%) were Malaysian citizens.

Medical History

Mean age of onset of psoriasis was 33.43 ± 16.6 years (range 0 – 85 years). Family history of psoriasis was present in 19.9% 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: 22.8% vs 13.8%. Among those who had positive family history, family members affected were either of their parents in 41.4%, siblings in 35.4% and children in 11.0%.

49.2% of the patients reported one or multiple factors which aggravated their psoriasis. The commonest aggravating factors were stress (66.5%), sunlight (35.0%) and infection (18.4%).

Comorbidities

In adult psoriasis patients aged 18 and above, the common comorbidities were overweight 34.3%, obesity 22.4%, hypertension 24.8%, diabetes mellitus 17.7%, hyperlipidaemia 15.7%, and ischaemic heart disease 5.6%. In patients aged below 18, the commonest comorbidity was bronchial asthma (2.1%) followed by diabetes mellitus (0.6%).

Clinical Presentation

The commonest clinical type of psoriasis was plaque psoriasis (88.4%). This was followed by guttate psoriasis (4.6%), erythrodermic psoriasis (2.3%), pustular psoriasis (1.6%) and flexural psoriasis (0.5%). The majority of patients (77.2%) had body surface area involvement of 10% or less.

Psoriatic arthropathy was reported in 15.5% of patients. The commonest psoriatic arthropathy was oligo/monoarthropathy (42.7%) followed by rheumatoid-like symmetrical polyarthropathy (34.5%) and distal hand joints arthropathy (29.0%). Spondylitis/sacroilitis accounted for only 9.6% of cases and arthritis mutilans in 3.4% of patients.

About two-third (60.7%) of patients had nail changes associated with psoriasis. Among patients who had nail disease, pitting was commonest (70.5%), followed by onycholysis (50.9%), discoloration (35.5%) and subungual hyperkeratosis (14.7%). Total nail dystrophy was found in 6.2% of patients with nail disease.

Treatments received in the past 6 months

Majority of the patients (70.9%) were on topical treatment only. Topical steroid was the commonest prescribed (84.7%), followed by tar preparations in 81.1% and emollients in 74.4% of patients. 3.8% of patients received phototherapy. Of the patients who had phototherapy, narrowband UVB (NBUVB) was the commonest used (72.2%). Oral psoralen and ultraviolet A (PUVA) was used in 4.5% of patients only. Systemic therapy was given in 21.8% of patients. The most frequently used systemic therapy was methotrexate (60.3%), followed by acitretin (18.6%), systemic corticosteroids (5.6%), sulphasalazine (5.1%), cyclosporine (3.5%), biologics (1.6%) and hydroxyurea (1.2%).

Quality of Life

Measurement of quality of life using Dermatology Life Quality Index (DLQI) or Child DLQI (CDLQI) was performed in 4,005 adult patients (aged 17 and above) and 236 children/adolescent patients (aged 5 to 16). The mean DLQI score was 8.5 ± 6.4 for adult patients and the mean CDLQI was 7.4 ± 5.5 for children/adolescent patients.

CHAPTER 1

STOCK AND FLOW

Chapter 1: Stock and Flow

During the period from October 2007 to December 2010, a total of 5,824 patients were notified to the registry. The number of notified patients gradually increased throughout the period (**Figure 1.1**).

A total of 17 dermatology centres (14 government, 2 private centres and 1 university hospital) participated in the MPR. Department of Dermatology, 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**).

The majority of the patients (72.4%) were notified once. A second notification during subsequent follow-up visit was also received in 1608 (27.6%) patients. Out of these patients, 1052 (18.1%) had one follow-up notification, 353 (6.1%) had two follow-up notifications, and 203 (3.5%) had more than two follow-up notifications (**Table 1.2**).

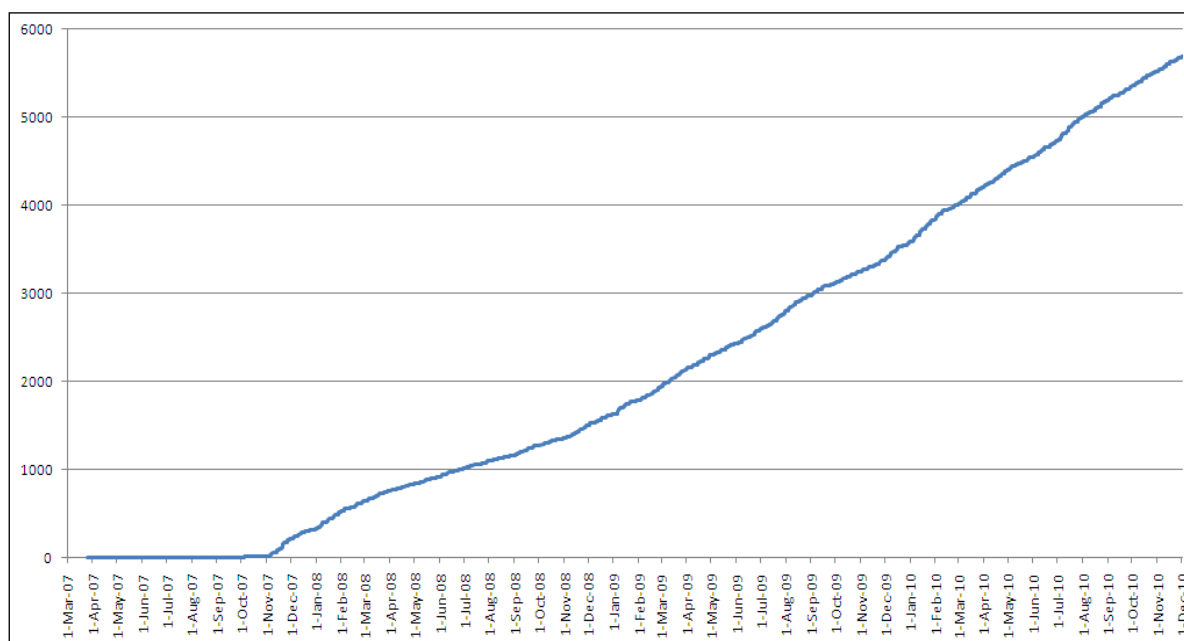


Figure 1.1 Psoriasis patients notified to the MPR

Table 1.1 Number of psoriasis patients notified from each participating centre

	No. of patients notified				Total
	2007	2008	2009	2010	
Hospital Kuala Lumpur	85	269	352	242	948
Hospital Pulau Pinang	23	100	351	245	719
Hospital Tengku Ampuan Rahimah, Klang	0	85	200	314	599
Hospital Umum Sarawak, Kuching	6	210	190	163	569
Hospital Melaka	0	0	125	410	535
Hospital Sultanah Bahiyah, Alor Setar	111	223	97	78	509
Hospital Queen Elizabeth, Kota Kinabalu	21	109	135	148	413
Hospital Raja Permaisuri Bainun, Ipoh	68	63	178	75	384
Hospital Tengku Ampuan Afzan, Kuantan	0	52	61	168	281
Hospital Sultanah Fatimah, Muar	4	54	45	169	272
Hospital Sultanah Aminah, Johor Bahru	0	38	150	69	257
Hospital Tuanku Fauziah, Kangar	2	35	59	82	178
Hospital Tuanku Jaafar, Seremban	0	18	0	39	57
Prince Court Medical Centre	0	0	6	18	54
Hospital Sungai Buloh	9	29	2	0	40
Gleneagles Medical Centre	0	16	6	0	22
UKMMC	0	0	0	17	17
Total	329	1301	1957	2237	5824

Table 1.2 **Distribution of psoriasis patients according to the number of notifications**

Year	No.	%
Entry notification	4,216	72.4
Entry and one follow-up notifications	1,052	18.1
Entry and 2 follow-up notifications	353	6.1
Entry and 3 follow-up notifications	135	2.3
Entry and 4 follow-up notifications	59	1.0
Entry and 5 follow-up notifications	9	0.2
Total	5824	100.0

CHAPTER 2

CHARACTERISTICS OF PATIENTS

There were more males than females (56.6% and 43.4% respectively), with a male to female ratio of 1.30:1. Malays comprised the majority of patients (49.3%), followed by Chinese (23.3) Indians (18.2%), other ethnic groups (9.0%) and Orang Asli (0.1%).

The mean age at presentation to the clinic was 43.0 ± 17.2 years with a range from 0 to 97 years. The majority were married (67.6%), 27.9% were single, and the rest, either divorced or widowed (**Table 2.1**).

Table 2.1 Patient demographics

Patient characteristics		No.	%
Gender	Male	3,297	56.6
	Female	2,527	43.4
Ethnic distribution	Malay	2,872	49.3
	Chinese	1,358	23.3
	Indian	1,062	18.2
	Orang Asli	8	0.1
	Others	524	9.0
	Nationality	Malaysian	5,766
	Non Malaysian	58	1.0
Marital status	Single	1,623	27.9
	Married	3,939	67.6
	Divorced	46	0.8
	Widowed	119	2.1
	NA	97	1.6
Age at notification (years)	Mean \pm SD (Range)	43.0 ± 17.2 (0 - 97)	

CHAPTER 3

MEDICAL HISTORY

Onset of Psoriasis

Psoriasis may first appear at any age. In the MPR, 66.4% of patients had first symptoms of psoriasis by the age of 40. The mean age of onset in our cohort was 33.4 ± 16.6 years with a wide range from 0 to 87 years (**Figure 3.1**). The mean interval between onset (as reported by patient) and diagnosis (first diagnosed by physician) was 2.08 ± 4.4 years.

Family History

Psoriasis is a skin disorder with a polygenic mode of inheritance. In our registry, about one-fifth (19.9%) of patients had at least one family member who has psoriasis (**Table 3.1**). Of those with a positive family history, 41.4% had either of their parents affected. Siblings were affected in 35.4% and children in 11.0% (**Table 3.2**). More patients with positive family history were observed among those with a younger onset of disease (aged 40 and below) compared to those with later onset of disease: 22.8% vs 13.8% (**Table 3.1**).

Aggravating factors of psoriasis

49.2% of patients reported one or multiple factors which worsened their psoriasis. Stress was the commonest aggravating factor (66.5%), followed by sunlight (35.0%) and infection (18.4%). Other identified aggravating factors included trauma (6.9%), drugs (5.7%), smoking (5.3%), alcohol (3.7%), pregnancy (2.7%) and topical treatment (1.5%) (**Table 3.3**).

Analyzing the subgroup of patients who reported infection as an aggravating factor, upper respiratory tract infection (41.2%) appeared to be the commonest infective trigger (**Table 3.4**). Common medications found to aggravate psoriasis were traditional medication/homeopathy (11.2%), beta blocker (10.3%), withdrawal of systemic steroids (8.6%), non-steroidal anti-inflammatory drugs (7.8%) and antibiotics (6.9%) (**Table 3.5**).

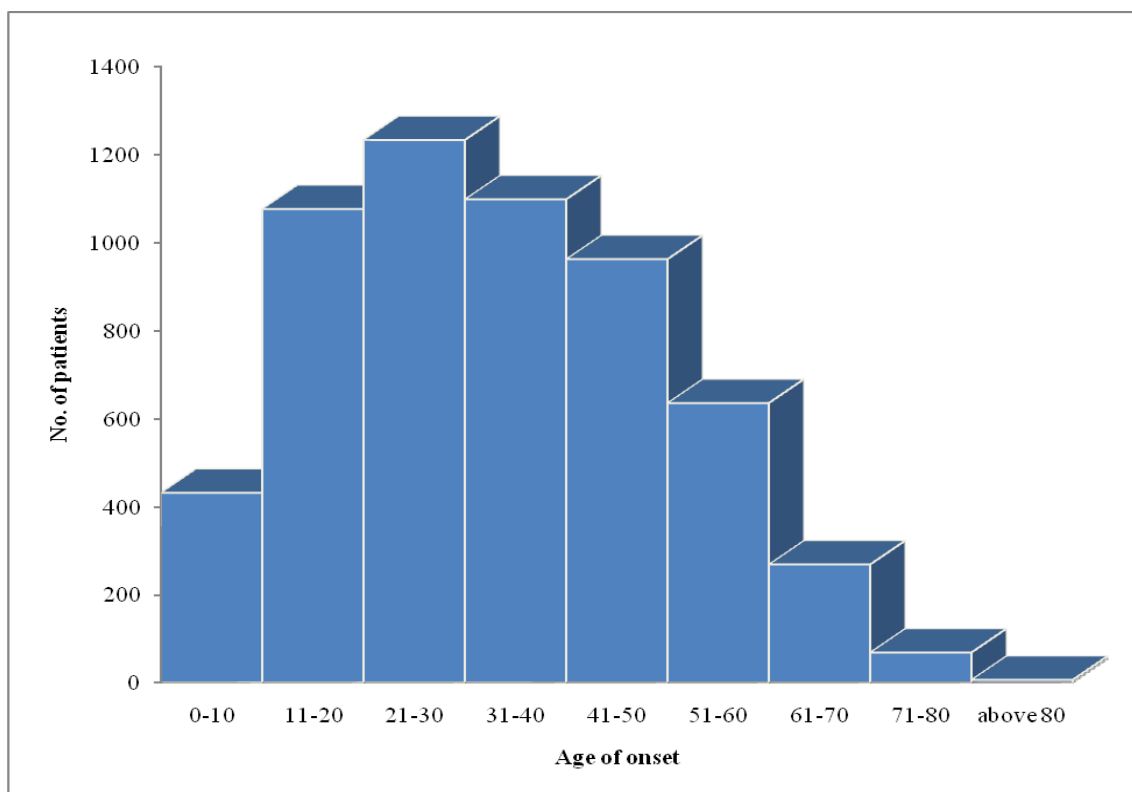


Figure 3.1 Distribution of age of onset

Table 3.1 Positive family history of psoriasis and its relationship with age of onset

		Overall		Age of onset of psoriasis			
		No.	%	40 & below		Above 40	
				N	%	N	%
Family members with psoriasis	Yes	1,149	19.7	873	22.8	267	13.8
	No	4,623	79.4	2,940	76.7	1,660	85.8
	NA	52	0.9	19	0.5	8	0.4

Table 3.2 Family members with psoriasis

Family member (one or multiple)	No.	%
Father	301	26.2
Mother	175	15.2
Sibling(s)	407	35.4
Children	126	11.0
Others	290	25.2

Table 3.3 Aggravating factors of psoriasis

Aggravating factors (one or multiple)	No.	%
Stress	1,876	66.5
Sunlight	986	35.0
Infection	519	18.4
Trauma	194	6.9
Drugs	160	5.7
Smoking	149	5.3
Alcohol	105	3.7
Pregnancy	76	2.7
Topical treatment	41	1.5

Table 3.4 Infections which aggravated psoriasis

Infection	No.	%
Upper respiratory tract infection	73	41.2
Fever / febrile illness	17	9.6
HIV	3	1.7
Chickenpox	3	1.7
Viral infection	2	1.1
Dengue fever	1	0.6
Chikugunya	1	0.6
Boil	1	0.6
Not specified	76	42.9

Table 3.5 **Drugs which aggravated psoriasis**

Drug	N	%
Traditional/ Homeopathy	13	11.2
Beta-blocker	12	10.3
Systemic steroids (withdrawal)	10	8.6
NSAIDs / analgesics	9	7.8
Antibiotic	8	6.9
Antimalarial drug	3	2.6
Oral contraceptive pill	2	1.7
Topical tar preparation	1	0.9
Sodium valporate	1	0.9
ACE inhibitor	1	0.9
Daivobet	1	0.9
“Gamat” (Sea cucumber extract)	1	0.9
Others	6	5.2
Unknown	2	1.7

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 children/adolescent patients were analysed separately.

In adult psoriasis patients aged 18 and above, 34.4% were overweight and 22.5% were obese. 24.8% patients had hypertension, 17.7% had diabetes mellitus, 15.7% had dyslipidaemia, 5.6% had ischaemic heart disease and 1.5% had previous history of stroke (**Table 4.1**).

In children and adolescents aged below 18 years with psoriasis, the most prevalent comorbidity was overweight or obesity i.e. BMI at or above 85th centile (29.3 %), followed by bronchial asthma (2.1%) and diabetes mellitus (0.6%). 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 (BMI \geq 30) (**Table 4.3**).

Table 4.1 Prevalence of comorbidities in adult psoriasis patients aged 18 and above

Co-morbidity	No.	%
Overweight	1,995 [#] (1,739 [*])	34.3 [#] (34.3 [*])
Obesity	1,834 [#] (1,135 [*])	31.5 [#] (22.5 [*])
Hypertension	1,325	24.8
Diabetes mellitus	946	17.7
Dyslipidaemia	839	15.7
Ischaemic heart disease	298	5.6
Stroke	81	1.5

[#] according to BMI classification for adult Asians as stated in the Clinical Practice Guidelines on Management of Obesity 2004, Ministry of Health, Malaysia

^{*} according to the WHO International Classification of BMI

Table 4.2 Prevalence of comorbidities in psoriasis patients aged below 18 years

Comorbidity	N	%
Overweight or obesity (BMI \geq 85 th centile)	138	29.3
Bronchial asthma	10	2.1
Diabetes mellitus	3	0.6
Hypertension	1	0.2
Hyperlipidaemia	1	0.2
Down syndrome	2	0.4
Epilepsy	1	0.2
Thalassemia	0	0.0
Atrial defect	1	0.2
Congenital heart disease	2	0.4
Obstructive sleep apnoea	1	0.2

Table 4.3 Co-morbidities associated with psoriatic arthritis patients

Co-morbidities	Arthritis Absent (n=4847)		Arthritis Present (n=886)		Simple Logistic Regression ^a		
	n	%	n	%	Crude OR	(95% CI)	P-value
Diabetes Mellitus	754	15.7	182	20.8	1.41	(1.18, 1.69)	<0.001
Hypertension	1022	21.2	279	31.8	1.73	(1.48, 2.02)	<0.001
Hyperlipidaemia	634	13.3	188	21.6	1.81	(1.51, 2.17)	<0.001
Ischaemic heart disease	239	5.0	56	6.4	1.30	(0.96, 1.76)	0.085
Cerebrovascular disease	66	1.4	14	1.6	1.16	(0.65, 2.08)	0.616
BMI \geq 30 (obesity WHO)	880	19.1	216	25.5	1.46	(1.23, 1.73)	<0.001

*Result was based on available information

CHAPTER 5

CLINICAL PRESENTATION

Plaque psoriasis was the commonest type of psoriasis (88.4%). This was followed by guttate psoriasis (4.5%) and erythrodermic psoriasis (2.2%). Pustular and flexural/inverse psoriasis were much less common, constituting 1.6% and 0.5% respectively (**Table 5.1**).

Majority of our patients had mild to moderate body surface area involvement. 36.0% of our psoriatic patients had <2% BSA affected, while 41.2% had 2-10% of BSA affected. Severe psoriasis with >10% BSA affected occurred in 21.2% patients, while 2.2% had erythrodermic psoriasis, i.e. >90% BSA involved (**Table 5.2**).

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 noted that most of the moderate to severe lesions (score 2 and 3) located on lower limb (35.4%), trunk (31.8%) and upper limb (28.0%). Half of our psoriatic patients (49.9%) 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**).

Majority of patients with psoriasis had nail involvement (59.9%) (**Table 5.4**). Among patients who had psoriatic nail disease, most of them had pitting (70.5%). Other common features were onycholysis (50.9%), discoloration (35.5%) and subungual hyperkeratosis (14.7%). Total nail dystrophy was found in 6.2% of patients with nail involvement (**Table 5.5**).

Joint disease related to psoriasis was reported in 15.2% of the patients (**Table 5.6**). Rheumatoid factor was detected in 11.3% of patients with arthropathy who were tested (**Table 5.7**). The commonest clinical pattern of psoriatic arthropathy was oligo-/monoarthropathy (42.7%). This was followed by rheumatoid-like symmetrical polyarthropathy (34.5%), distal hand joints arthropathy (29.0%), spondylitis (9.6%) and arthritis mutilans (3.4%). Morning stiffness was observed in 29.1% and enthesopathy in 7.9% (**Table 5.8**).

Most of the patients with psoriatic arthropathy experienced joint pain at time of presentation (81.9%) (**Table 5.9**). Joint swelling was present in 31.8%, while joint deformity occurred in 21.4% (**Table 5.9**). The commonest types of joint deformity was swan neck deformity (20.0%). This was followed by Boutonniere deformity (12.6%), distal hand joint deformity (6.8%), fixed flexion deformity (6.8%), proximal interphalangeal joint deformity (4.2%) and bamboo spine (2.1%). Rheumatoid arthritis-like and arthritis mutilans were observed in only 1.1% of patients (**Table 5.10**).

By using multiple logistic regressions, 9 factors were found to be associated with psoriatic arthritis. These were age (>18 years), 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 5.11**).

Table 5.1 Distribution of psoriasis patients according to the type of psoriasis

Type of psoriasis	No.	%
Plaque	5,032	86.4
Guttate	261	4.5
Erythrodermic	131	2.2
Pustular	93	1.6
Flexural/Inverse	28	0.5
Palmoplantar non-pustular	7	0.1
Others	143	2.5
NA	129	2.2

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

% Body surface area affected (N=3565)	No.	%
<2%	1,666	36.0
2 - 10%	1,910	41.2
>10% to 90%	983	21.2
>90%	104	2.2

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

Body part	Clinical score									
	0		1		2		3		NA	
	No.	%	No.	%	No.	%	No.	%	No.	%
Scalp	1,191	20.4	2,976	51.1	1,272	21.8	269	4.6	117	2.0
Face & neck	2,909	49.9	2,278	39.1	407	7.0	60	1.0	171	2.9
Trunk	1,509	25.9	2,313	39.7	1,607	27.6	247	4.2	149	2.6
Upper limbs	1,353	23.2	2,691	46.2	1,436	24.7	195	3.3	150	2.6
Lower limbs	1,101	18.9	2,511	43.1	1,785	30.6	280	4.8	148	2.5

Table 5.4 Distribution of nail involvement in psoriasis patients.

Nail involvement	No.	%
Yes	3,491	59.9
No	2,258	38.8
NA	75	1.3

Table 5.5 Distribution of nail features in patients with nail involvement

Nail features	No.	%
Pitting	2,461	70.5
Onycholysis	1,776	50.9
Discoloration	1,238	35.5
Subungual hyperkeratosis	513	14.7
Total nail dystrophy	215	6.2

Table 5.6 Distribution of joint disease in psoriasis patients

Joint disease	No.	%
Yes	886	15.2
No	4,847	83.2
NA	91	1.6

Table 5.7 Rheumatoid factor results in psoriasis patients with joint disease

Rheumatoid factor	No.	%
Positive	16	11.3
Negative	126	88.7
NA	658	

Table 5.8 Distribution of types of joint disease

Type of joint disease (one or multiple)	No.	%
Oligo-/monoarthropathy	378	42.7
Symmetrical polyarthropathy (rheumatoid-like)	306	34.5
Morning stiffness > 30 mins	258	29.1
Distal hand joints arthropathy	257	29.0
Spondylitis	85	9.6
Enthesopathy	70	7.9
Arthritis mutilans	30	3.4

Table 5.9 Symptoms of psoriatic arthritis

	Status	No.	%
Pain	Yes	726	81.9
	No	112	12.6
	NA	48	5.4
Joint swelling	Yes	282	31.8
	No	558	63.0
	NA	46	5.2
Joint deformity	Yes	190	21.4
	No	648	73.1
	NA	48	5.4

Table 5.10 Distribution of type of joint deformities in patients with joint disease

Type of joint deformity	No.	%
Swan neck deformity	38	20
Boutonniere deformity	24	12.6
Distal hand joint deformity	13	6.8
Fixed flexion	13	6.8
Proximal interphalangeal joint deformity	8	4.2
Bamboo spine	4	2.1
Rheumatoid arthritis-like	2	1.1
Arthritis mutilans	2	1.1
Others	9	4.7
Unspecified	19	10.0

Table 5.11 Factors associated with psoriatic arthritis

Variable	Absent (n=4847)		Present (n=886)		Multiple Logistic Regression ^a		
	n	%	n	%	Adj. OR	(95% CI)	P- value
Age:							
<18 years	457	9.4	8	0.9	1.00	-	
18-40 years	1745	36.0	254	28.7	8.91	(2.80, 28.32)	<0.001
41-60 years	1843	38.0	500	56.4	16.70	(5.27, 52.90)	<0.001
>60 years	802	16.5	124	14.0	11.57	(3.59, 37.35)	<0.001
Age of onset:							
≤40 years (Type 1)	3187	66.2	596	67.7			NS
>40 years (Type 2)	1629	33.8	284	32.3			
Duration of disease:							
≤5 years	2281	47.4	259	29.4	1.00	-	
>5 years	2535	52.6	621	70.6	1.62	(1.32, 1.99)	<0.001
Gender:							
Male	2801	57.8	442	49.9	1.00	-	
Female	2046	42.2	444	50.1	1.62	(1.33, 1.97)	<0.001
Ethnicity:							
Indian	852	17.6	195	22.0	1.32	(1.05, 1.67)	0.019
Non-Indian	3995	82.4	691	78.0	1.00	-	
Obesity group (WHO):							
BMI <30	3738	80.9	630	74.5	1.00	-	
BMI ≥30	880	19.1	216	25.5	1.33	(1.07, 1.66)	0.011
Type of psoriasis:							
Erythrodermic	92	1.9	35	4.1	1.72	(1.06, 2.79)	0.027
Non-erythrodermic	4665	98.1	828	95.9	1.00	-	
Body surface area:							
≤10%	3049	78.3	499	68.5			NS
>10%	843	21.7	229	31.5			
Total skin score:							
<10	4362	93.4	763	89.6	1.00	-	
≥10	310	6.6	89	10.4	1.63	(1.17, 2.26)	0.004
Nail involvement:							
Absence	2044	42.4	190	21.9	1.00	-	
Presence	2774	57.6	676	78.1	1.99	(1.60, 2.47)	<0.001

DLQI:	2659	67.4	421	56.4	1.00	-		
≤10	1289	32.6	325	43.6	1.55	(1.27, 1.90)	<0.001	
>10								

(Total N=5824, but missing joint disease category of 91 cases)

*Result was based on available information.

Adj. OR = Adjusted odds ratio.

^a Forward LR was applied.

Multicollinearity was checked and not found.

Hosmer-Lemeshow test (p=0.723), classification table (overall correctly classified percentage=84.5%) and area under the ROC curve (70.1%) were applied to check the model fitness.

CHAPTER 6

TREATMENTS

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

Most patients (96.5%) used some form of topical medications for psoriasis (**Table 6.1**). In 70.9% of the patients, topical monotherapy was the only treatment given. The most commonly used topical medication was topical steroids (84.7%). This was followed by topical tar preparation (81.1%), emollients (74.4%), keratolytics (53.9%) and vitamin D analogue such as calcipotriol (24.8%). Dithranol was less favoured and used in 1.9% of patients only (**Table 6.2**).

In the last six months prior to notification, 3.8% of patients received phototherapy (**Table 6.3**). Most of these patients (72.2%) were given narrowband UVB (NB-UVB) while 9.4% were given broadband UVB (BB-UVB). Less popular modalities were oral PUVA (4.5%), topical PUVA (1.3%) and bath PUVA (0.4%) (**Table 6.4**).

Systemic therapy was used in 21.8% of patients (**Table 6.5**). Methotrexate, being the commonest systemic therapy, was used in 60.3%. This was followed by acitretin (18.6%), systemic corticosteroids (5.6%), sulphasalazine (5.1%), cyclosporine (3.5%), biologics (1.6%) and hydroxyurea (1.2%) (**Table 6.6**). 20 patients received biologic treatment. The biologic therapy most frequently used was etanercept (6 patients), followed by adalimumab (4 patients), efalizumab (4 patients), and infliximab (2 patients). The name of the biologic agent was not specified in 4 patients.

Table 6.1 Use of topical therapy in psoriasis patients

Topical therapy	No.	%
Yes	5,621	96.5
No	203	3.5
Total	5,824	100.0

Table 6.2 Distribution of types of topical therapy

Topical therapy (one or multiple)	No.	%
Topical steroids (other than face and flexures)	4,762	84.7
Tar preparation	4,556	81.1
Emollient	4,182	74.4
Keratolytics	3,028	53.9
Vitamin D analogues	1,395	24.8
Dithranol (anthralin)	104	1.9
Others	119	2.1

Table 6.3 Use of phototherapy in psoriasis patients

Phototherapy	No.	%
Yes	223	3.8
No	5,366	92.1
NA	235	4.0
		99.9

Table 6.4 Distribution of types of phototherapy

Type of phototherapy (one or multiple)	No.	%
Narrowband UVB	161	72.2
Broadband UVB	21	9.4
Oral PUVA	10	4.5
Topical PUVA	3	1.3
Bath PUVA	1	0.4
Others	2	0.9

Table 6.5 Use of systemic therapy in psoriasis patients

Systemic therapy	No.	%
Yes	1,271	21.8
No	4,553	78.2
Total	5,824	100.0

Table 6.6 Distribution of types of systemic therapy in psoriasis patients

Type of systemic therapy (one or multiple)	No.	%
Methotrexate	766	60.3
Acitretin	237	18.6
Sulphasalazine	65	5.1
Cyclosporin	44	3.5
Hydroxyurea	15	1.2
Biologics	20	1.6
Systemic corticosteroids	71	5.6
Others	53	4.2

CHAPTER 7

QUALITY OF LIFE

There were a total of 4,005 adult patients (aged 17 and above) and 236 child/adolescent patients who completed the quality of life questionnaires, namely Dermatology Life Quality Index (DLQI) and Child Dermatology Life Quality Index (CDLQI).

The mean DLQI for adult psoriasis patients was 8.5 ± 6.4 , and the mean CDLQI for child/adolescent patients was 7.4 ± 5.5 .

The responses for each question of the DLQI and CDLQI were tabulated in **Table 7.1** and **7.2** respectively. 1,304 adult patients (32.6%) reported a DLQI of more than 10 indicating severe quality of life impairment due to psoriasis or its treatment (**Figure 7.1**). There were 221 adults (5.5%) who had a DLQI of more than 21 indicating extremely large effect on their quality of life by psoriasis. Nevertheless, 12.8% of adult patients reported no effect at all on their quality of life.

As shown in **Figure 7.2**, “systems and feelings” was the DLQI category most affected by psoriasis in adult patients. 36.3% 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 86.3% of the adult patients did not have or only have a little effect in this aspect.

In children/adolescents group, 17.3% of patients reported a CDLQI of more than 12 indicating very large or extremely large effect on QoL (**Figure 7.3**). There were 10 patients (4.2%) who had CDLQI of more than 19, reflecting extremely large effect of QoL. On the other hand, 13.1% child/adolescent patients reported no effect at all on their QoL.

In child/adolescent patients, the category of CDLQI most affected was “symptoms and feelings”. 36.9% of children/adolescents reported that psoriasis affected very much or a lot in the symptoms and feelings domain. The aspect of life least affected by psoriasis was “personal relationship” in which 84.3% of the children did not have or only have a little effect (**Figure 7.4**). These results are similar to that of the adult patients.

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

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

No.	DLQI Question	No. (%)				
		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?	488 (9.2)	1,331 (25.1)	2,894 (54.6)	587 (11.1)	-
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	727 (13.8)	1,297 (24.6)	1,998 (37.8)	1,257 (23.8)	-
3	Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?	415 (7.8)	948 (17.9)	1,842 (34.7)	1,924 (36.3)	175 (3.3)
4	Over the last week, how much has your skin influenced the clothes you wear?	348 (6.6)	977 (18.6)	1,875 (35.7)	1,889 (35.9)	170 (3.2)
5	Over the last week, how much has your skin affected any social or leisure activities?	443 (8.4)	979 (18.5)	1,775 (33.5)	1,924 (36.3)	175 (3.3)
6	Over the last week, how much has your skin made it difficult for you to do any sport?	446 (8.5)	860 (16.3)	1,514 (28.7)	1,761 (33.4)	687 (13.0)
7	Over the last week, has your skin prevented you from working or studying?	482 (10.4)	324 (7.0)	1,115 (24.1)	1,944 (42.0)	764 (16.5)
8	Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?	222 (4.2)	574 (10.9)	1,623 (30.7)	2,642 (50.0)	228 (4.3)
9	Over the last week, how much has your skin caused sexual difficulties?	158 (3.0)	288 (5.5)	886 (16.9)	2,676 (51.1)	1,229 (23.5)
10	Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy or by taking up time?	295 (5.6)	826 (15.6)	1,859 (35.1)	2,048 (38.7)	268 (5.1)

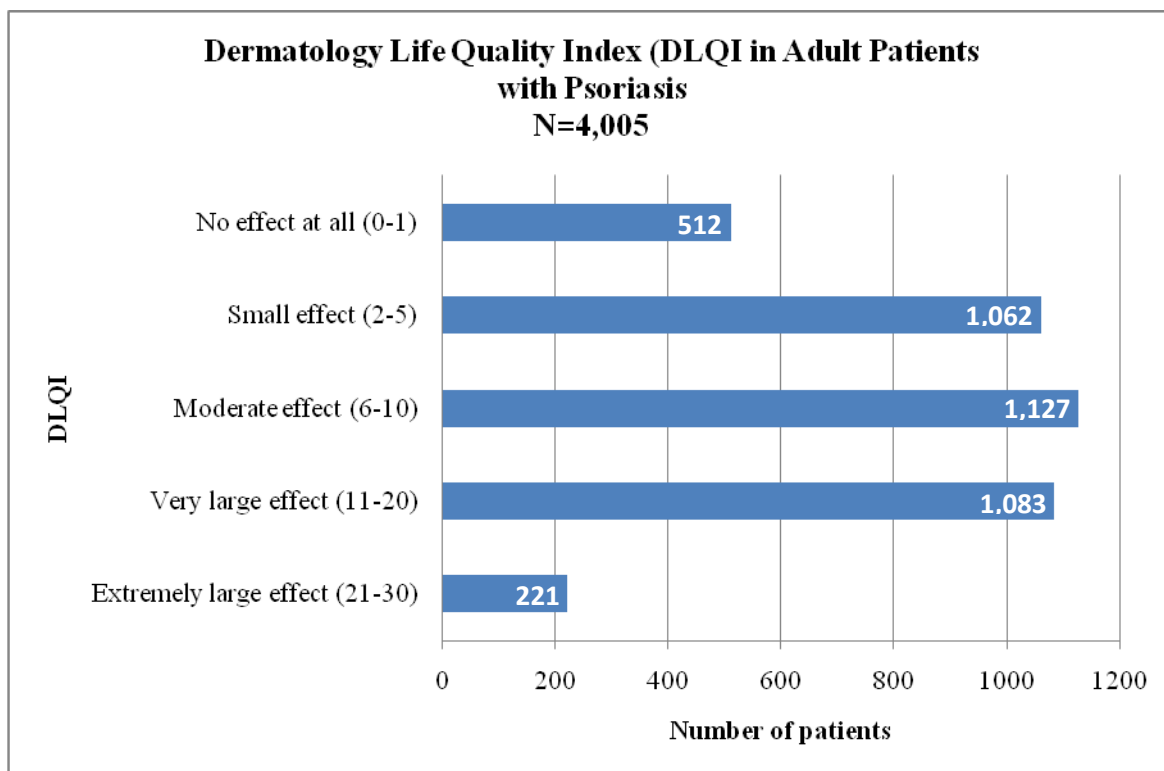


Figure 7.1 Quality of life in adult patients with psoriasis

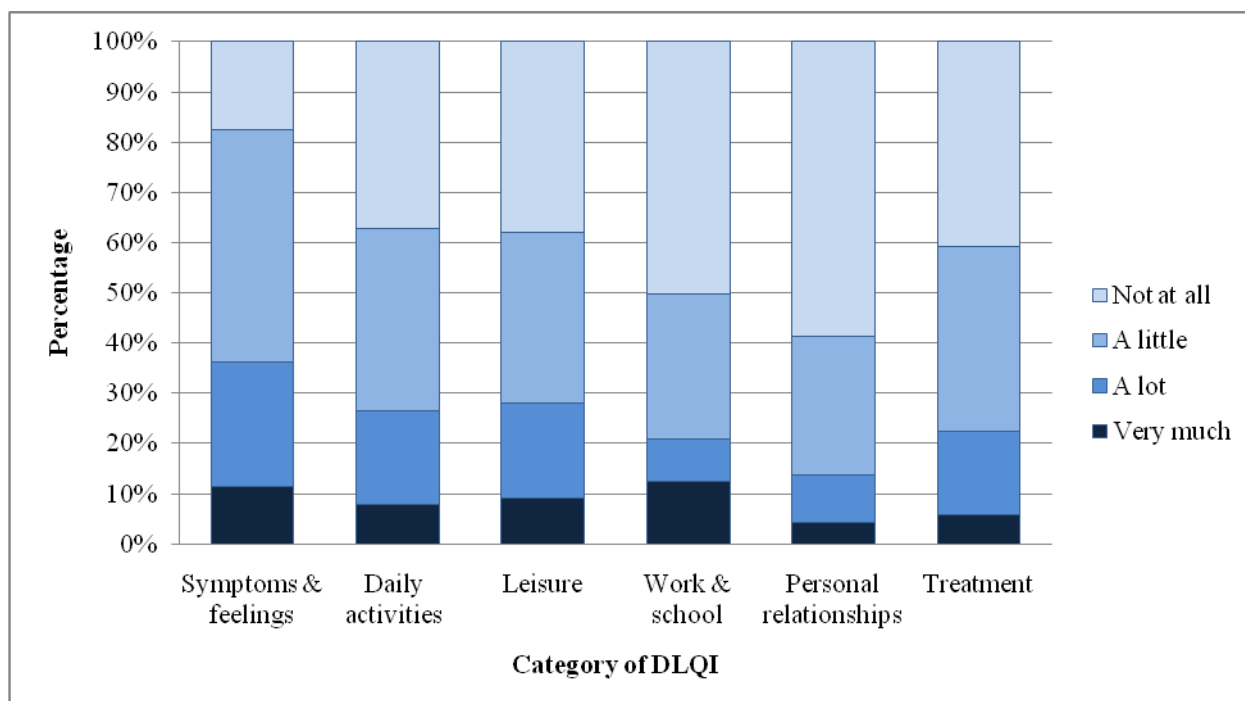


Figure 7.2 QoL impairment in adults psoriasis patients based on category of DLQI

Table 7.2 Responses for CDLQI in child/adolescent psoriasis patients (aged 5 to 16)

No.	CDLQI Question	No. (%)				
		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?	23 (7.3)	86 (27.1)	181 (57.1)	27 (8.5)	-
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	48 (15.1)	77 (24.3)	127 (40.1)	65 (20.5)	-
3	Over the last week, how much has your skin affected your friendships?	14 (4.4)	41 (12.9)	96 (30.3)	166 (52.4)	-
4	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	15 (4.7)	49 (15.5)	111 (35.1)	141 (44.6)	-
5	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	14 (4.4)	53 (16.7)	107 (33.8)	143 (45.1)	-
6	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	22 (6.9)	44 (13.9)	90 (28.4)	161 (50.8)	-
7	If school time: Over the last week, how much did your skin problem affect your school work? Or If holiday time: Over the last week, has your skin problem interfered with your enjoyment of the holiday?	9 (2.9)	42 (13.4)	104 (33.1)	159 (50.6)	-
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?	15 (4.8)	29 (9.2)	80 (25.4)	191 (60.6)	-
9	Over the last week, how much has your sleep been affected by your skin problem?	18 (6.0)	37 (12.4)	90 (30.2)	153 (51.3)	-
10	Over the last week, how much of a problem has the treatment for your skin been?	10 (3.2)	41 (13.1)	111 (35.4)	152 (48.4)	-

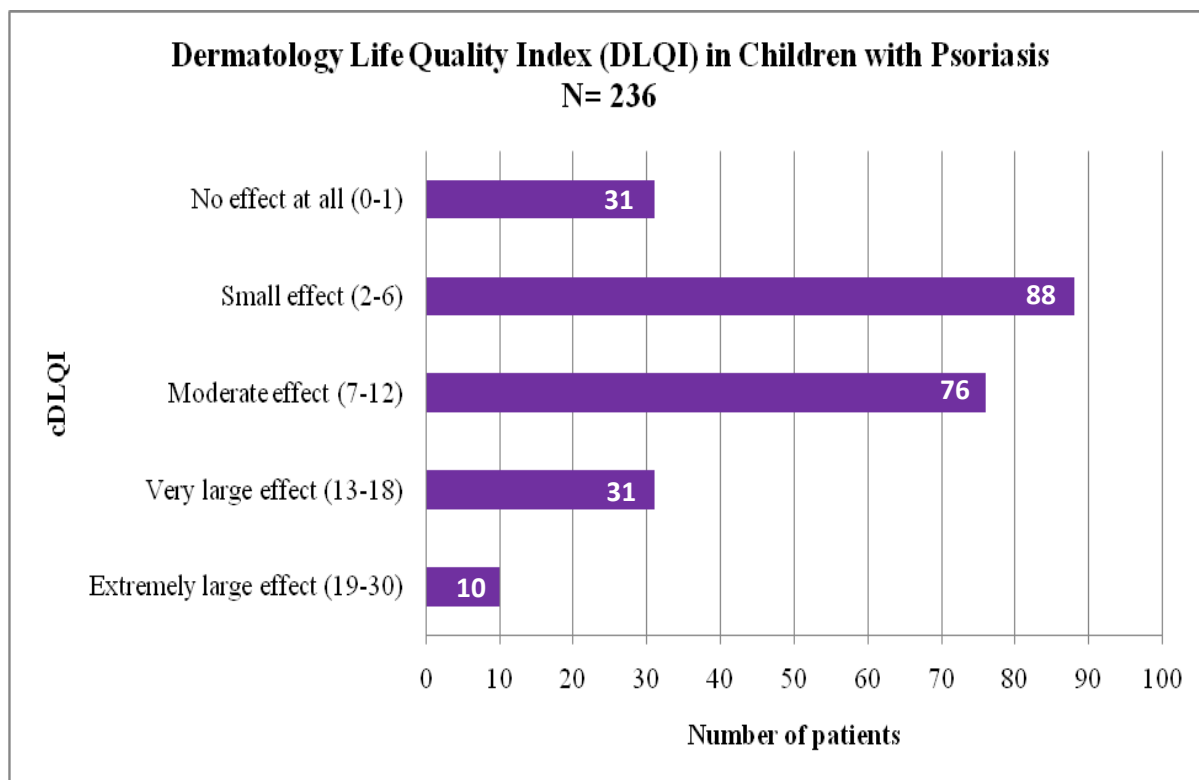


Figure 7.3 Quality of life in children/adolescents with psoriasis.

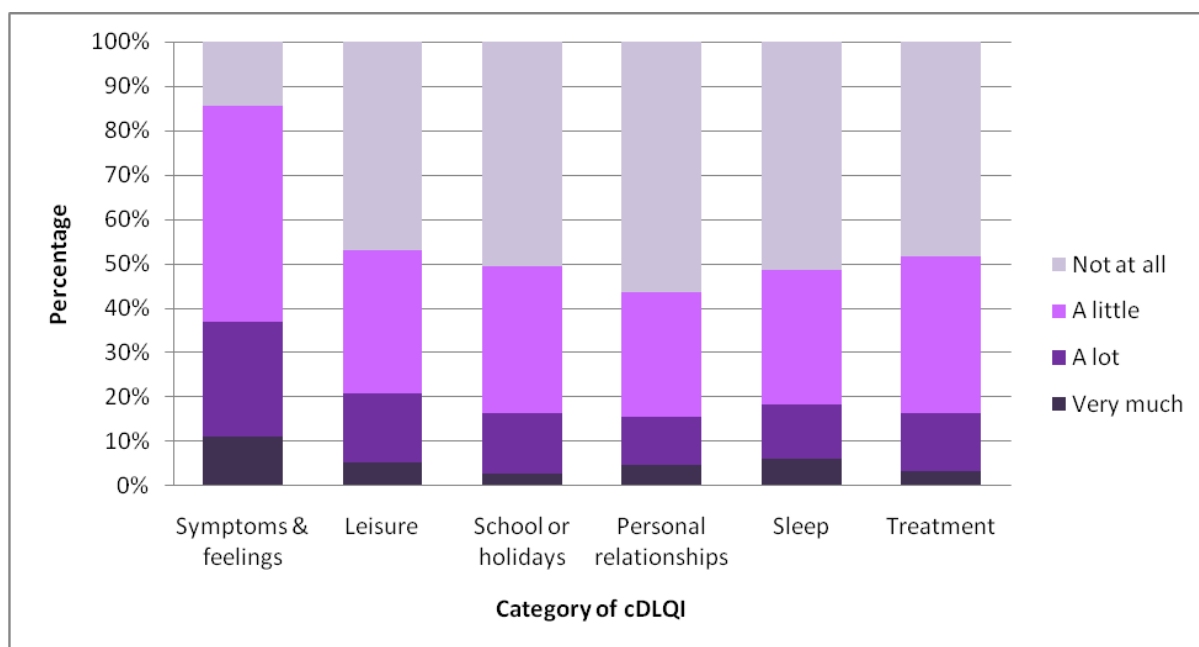


Figure 7.4 QoL impairment in child/adolescent psoriasis patients based on category of DLQI

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

Parameters	Absent (n=4847)		Present (n=886)		Simple Logistic Regression ^a		
	n	%	n	%	Crude OR	(95% CI)	P-value
DLQI, median (IQR)							
≤10	3738	80.9	630	74.5	1.00	-	
>10	880	19.1	216	25.5	1.59	(1.36, 1.87)	<0.001
*No. of clinic visit, median (IQR)							
0 time	725	15.3	84	9.8	1.00	-	
1-2 times	2720	57.3	483	56.6	1.53	(1.20, 1.96)	0.001
3-10 times	1253	26.4	277	32.5	1.91	(1.47, 2.48)	<0.001
11-48 times	48	1.0	9	1.1	1.62	(0.77, 3.42)	0.207
*No. of days off work, median (IQR)							
0 day	4419	93.3	754	88.2	1.00	-	
1-3 days	219	4.6	49	5.7	1.31	(1.20, 1.96)	0.096
4-10 days	76	1.6	28	3.3	2.16	(1.39, 3.35)	0.001
11-90 days	23	0.5	24	2.8	6.12	(3.43, 10.89)	<0.001
*No. of hospital admissions, median (IQR)							
0 time	4660	98.4	815	95.0	1.00	-	
1-2 times	64	1.4	37	4.3	3.31	(2.19, 4.99)	<0.001
3-15 times	10	0.2	6	0.7	3.43	(1.24, 9.47)	0.017

*Over a 6-month period.

IQR = 25th – 75th 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).

From a total of 5,824 psoriasis patients registered in MPR, follow-up data were obtained in 1,602 patients. The mean duration of follow-up was 15.5 ± 8.4 months, with the longest duration of 36 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. <2%, 2%-10%, 10%-90%, and >90% (erythrodermic). A total of 1140 patients were evaluated for change in the extent of lesions. Of these patients, 281 patients (24.6%) had improvement by at least one scale, among which 44 (3.9%) had improvement by two scales, and 2 patients improved from BSA>90% to BSA<2%. No improvement was found in 628 patients (55.1%), and 185 patients (16.2%) 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. 113 patients (7.2%) had the most marked improvement in skin scores by 75% or more, and 271 patients (17.4%) had improvement by 50-75%, while 288 patients (18.4%) had 25-50% improvement. 147 patients (9.4%) had modest improvement of less than 25%. No improvement of skin scores were detected in 329 patients (21.1%). Skin scores worsened in 413 patients (26.5%) (**Figure 8.2**).

Joint Pain

From a total of 106 patients who reported to have joint pain, 53 patients (50%) had improvement in joint pain as measured by the visual analogue scale. Of these patients, 16 patients (15.1%) had improvement of between 50% and 75%, 3 patients (15.1%) had improvement of more than 75%, 22 patients (20.8%) had improvement of between 25% and 50%, and 12 patients (11.3%) had improvement of less than 25%. There was no improvement of joint pain in 26 patients (24.5%), while joint pain worsened in 27 patients (25.5%) (**Figure 8.3**).

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 1,440 adult patients were evaluated for change in quality of life by DLQI. Of these patients, 304 patients (21.1%) had significant improvement with a reduction of DLQI score by at least 5, whereas 209 patients (14.5%) had significant worsening with an increase in DLQI score by at least 5 (**Figure 8.4**).

A total of 55 patients aged below 17 were evaluated for change in quality of life by DLQI. Of these patients, 13 patients (23.6%) had a significant improvement of Child DLQI score by at least 5, while four patients (7.3%) worsened (**Figure 8.4**).

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 2010 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 213 deaths (166 males, 47 females) were identified among the 5,352 adult patients notified to the registry (Figure 8.5). The mean age at death was 60.8 ± 14.4 years. The leading cause of death was cardiovascular disease (24.4%). Other major causes of death were infections (23.9%) and malignancy (11.7%). In patients with malignancy, 10.8% were due to solid organ malignancy, and 0.9% were due to haematological malignancy (**Figure 8.6**).

The cardiovascular risk factors in patients with psoriasis were analysed. In patients who died, 46.5% had hypertension, 37.6% were diabetic, 29.1% patients had hyperlipidaemia, 19.7% 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**).

More than one-third (43.2%) of the deceased patients had severe psoriasis with body surface area involvement (BSA) of $>10\%$, and majority of the patients (79.3%) were on systemic treatment for psoriasis (**Figure 8.8**).

Significantly higher mortality rates were found in male gender (OR 2.11, 95%CI 1.46-3.06), severe psoriasis with BSA $>10\%$ (OR 1.75, 95%CI 1.24-2.47), patients who had systemic therapy (OR 2.24, 95%CI 1.54-3.27) and those with at least one co-morbidity (OR 2.04, 95%CI 1.43-2.92) (**Table 8.2**)

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

Duration of follow-up	No.	%
0 to 6 months	272	17
7 to 12 months	470	29.3
13 to 18 months	360	22.5
19 to 24 months	239	14.9
25 to 30 months	172	10.7
31 to 36	84	5.2
>36	5	0.3
	1602	100.0

Mean duration of follow-up: 15.5 ± 8.4 months (range 0 – 36 months)

Table 8.2 Predictive factors of higher mortality in patients with psoriasis

Predictive factors of higher mortality	Mortality rates	Odds Ratio (95% CI)*
Male gender	5.34% vs 2.10%	2.11 (1.46 – 3.06)
Body surface area involved >10%	5.33% vs 3.71%	1.75 (1.24 – 2.47)
Systemic therapy needed	5.22% vs 2.17%	2.24 (1.54 – 3.27)
Co-morbidity (at least one)	6.72% vs 2.11%	2.04 (1.43 – 2.92)

*Multiple logistic regression analysis

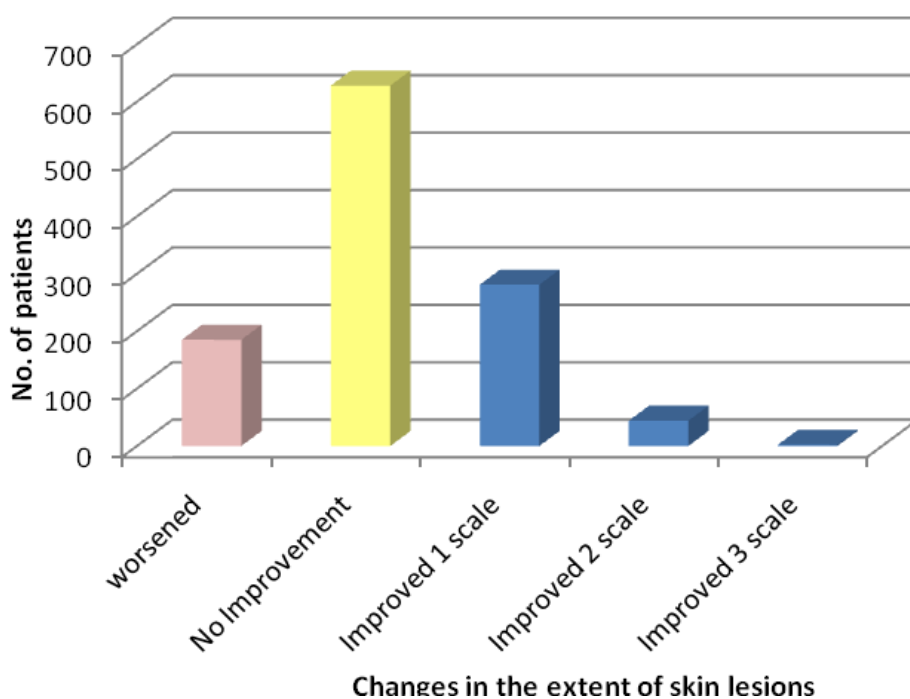


Figure 8.1 Improvement in the extent of skin lesions

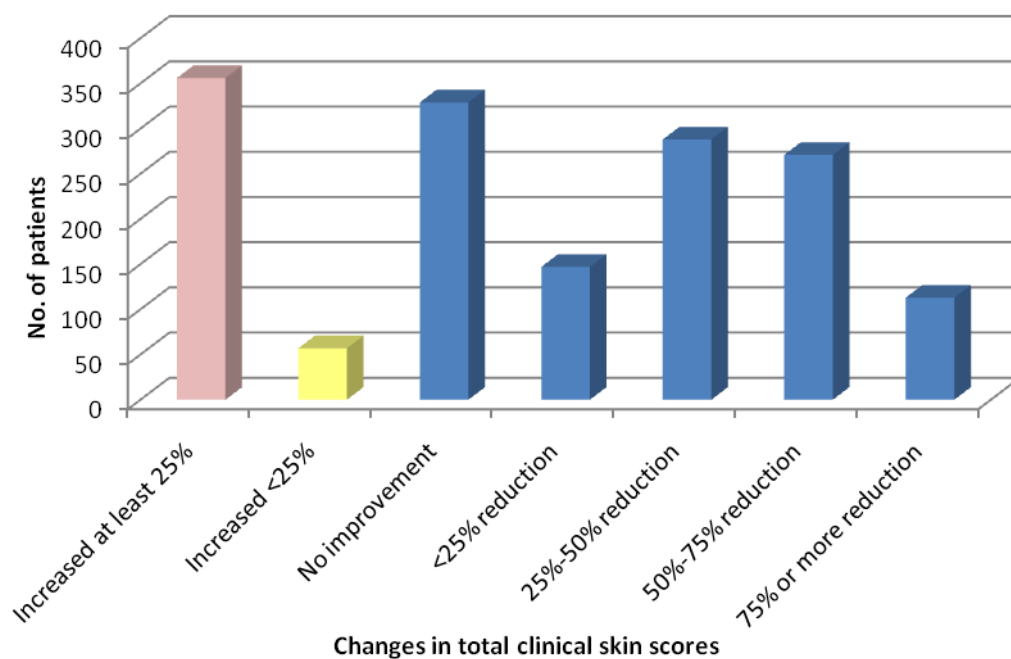


Figure 8.2 Improvement in the total clinical skin scores

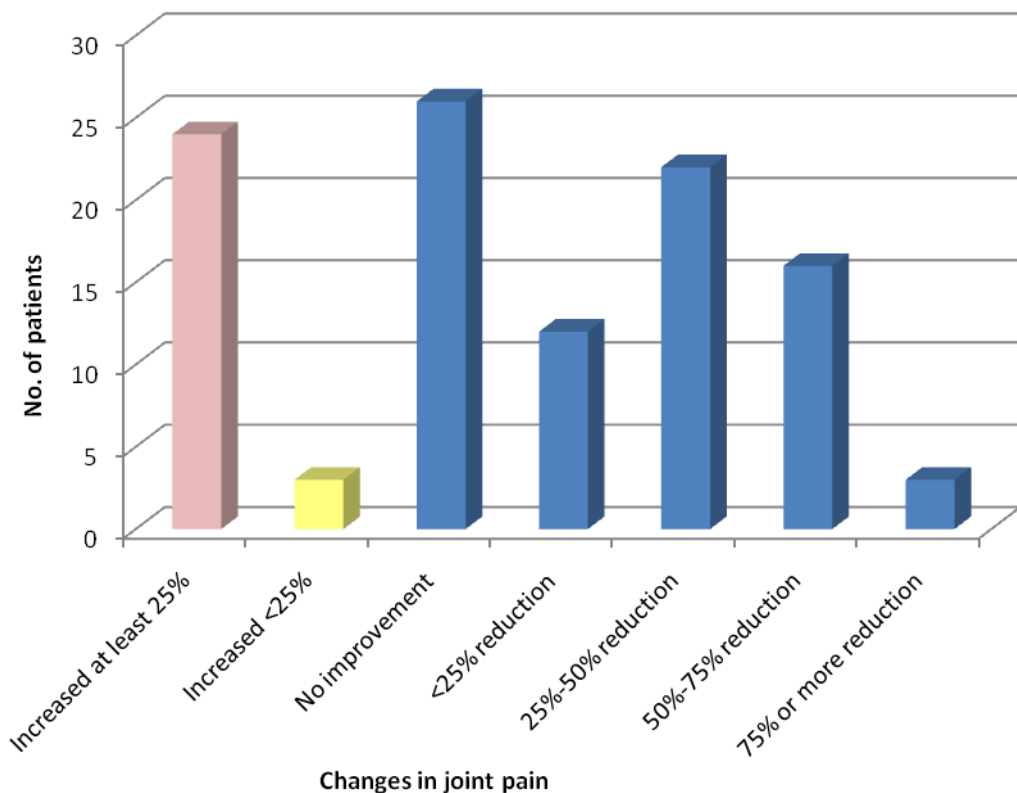


Figure 8.3 Improvement in joint pain

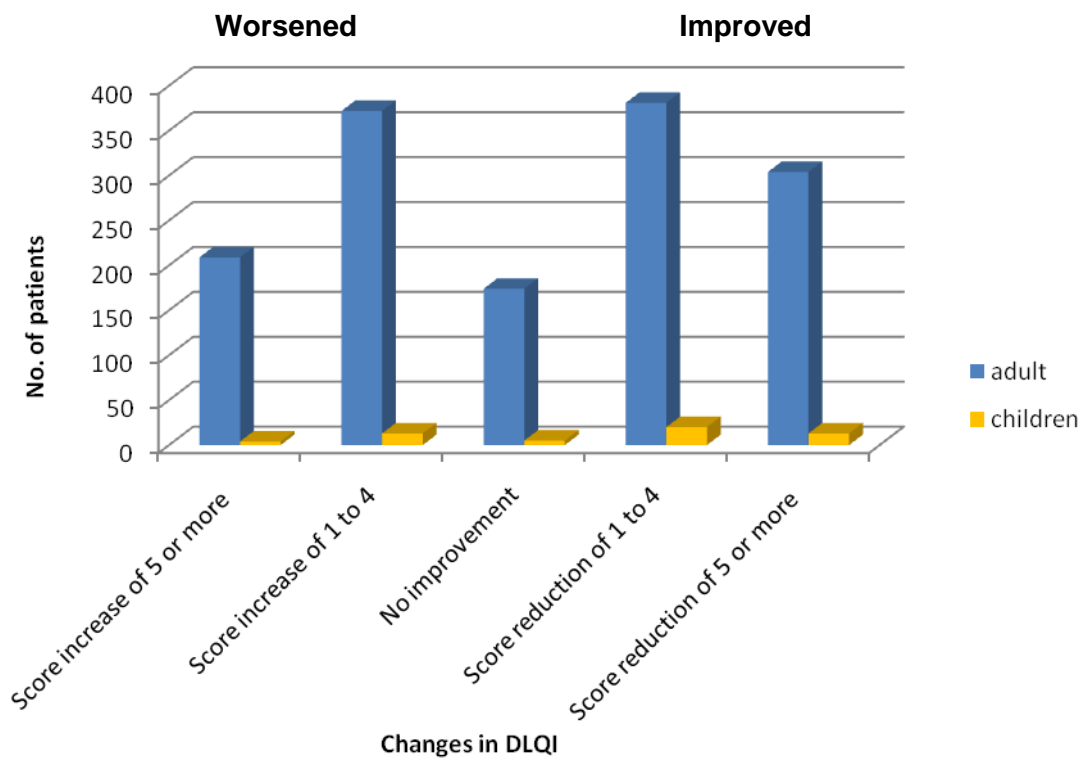


Figure 8.4 Improvement in DLQI and CDLQI

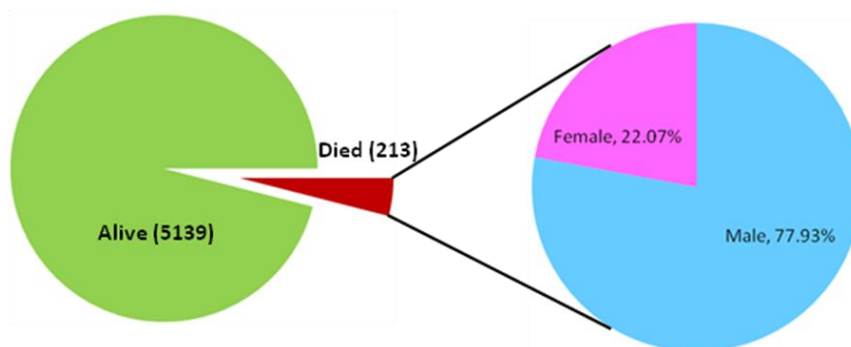


Figure 8.5 Mortality rate and gender distribution

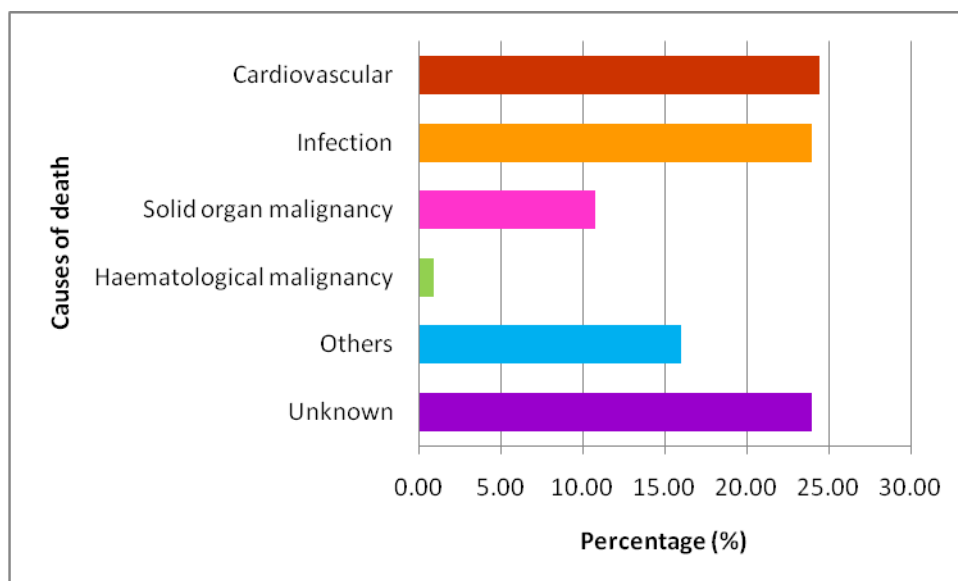


Figure 8.6 Causes of death

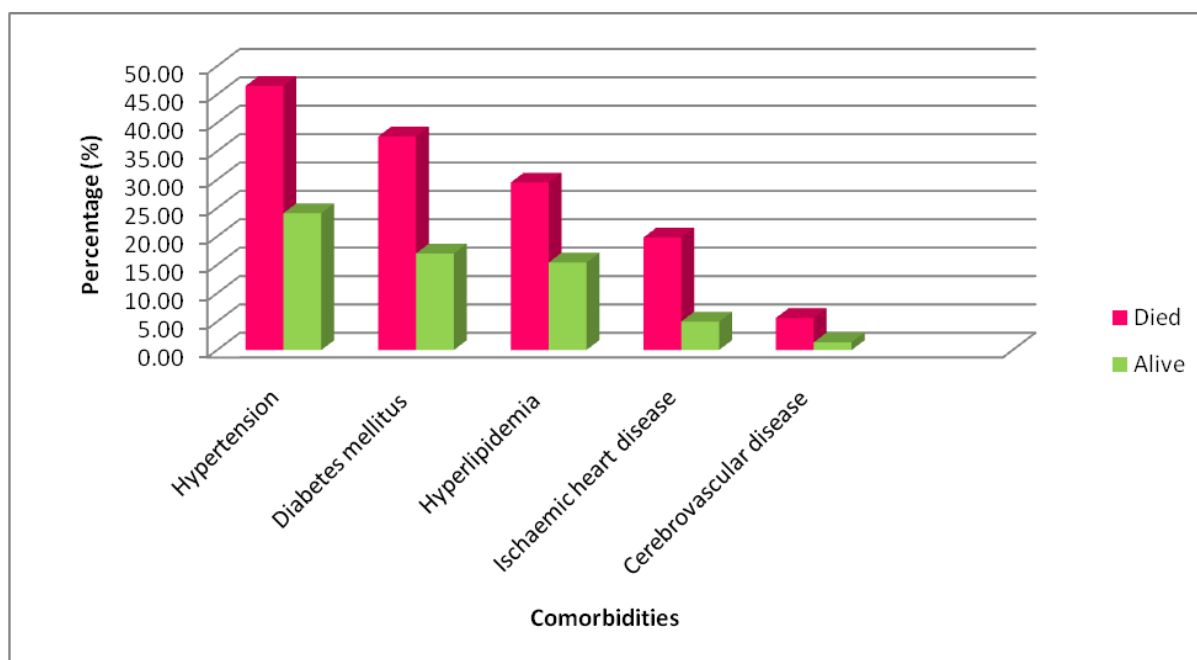


Figure 8.7 Cardiovascular risk factors in patients with psoriasis

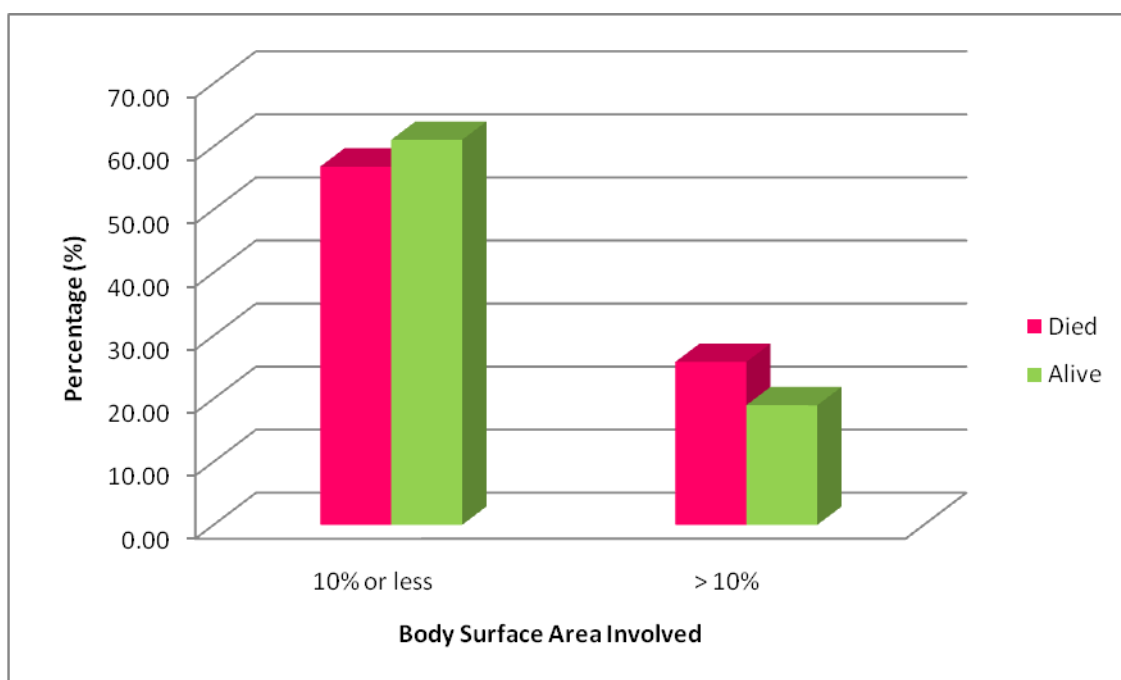


Figure 8.8 Severity of psoriasis based on the body surface area involvement

NATIONAL DERMATOLOGY REGISTRY (DermReg)		CONFIDENTIAL																														
Malaysian Psoriasis Registry		For Office Use only:																														
Case Report Form		ID: <input style="width: 50px;" type="text"/> / <input style="width: 50px;" type="text"/>																														
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: <input style="width: 100px;" type="text"/>																														
SECTION 3: CLINICAL EXAMINATION																																
1. (a) Height :	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (cm)	(b) Weight: <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (kg)																														
2. Type of psoriasis :	<small>(Please select ONE predominant type)</small> <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 colspan="4">Grade of severity</th> </tr> </thead> <tbody> <tr> <td>Scalp</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 3</td> </tr> <tr> <td>Face & Neck</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 3</td> </tr> <tr> <td>Trunk</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 3</td> </tr> <tr> <td>Upper Limbs</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 3</td> </tr> <tr> <td>Lower Limbs</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 2</td> <td><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	Key for grading. Grade 0 : Skin normal or hypo-/hyperpigmented patch only. Grade 1 : Mild erythema, fine scales, thin plaque, with or without central clearing. Grade 2 : Moderate erythema or scaling, moderately thick plaque. Grade 3 : Severe erythema or scaling, very thick plaque
Body part	Grade of severity																															
Scalp	<input type="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																												
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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 <small>(if YES, please tick ONE or MULTIPLE)</small> <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: 30%;">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>		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																				
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5. Arthritis mutilans	<input type="radio"/> No <input type="radio"/> Yes																															
	e) Severity:- <table style="width: 100%;"> <tr> <td style="width: 30%;">1. Pain</td> <td><input type="radio"/> No <input type="radio"/> Yes →</td> <td>Pain Score (1-10) : <input style="width: 20px;" type="text"/></td> </tr> <tr> <td>2. Swelling</td> <td><input type="radio"/> No <input type="radio"/> Yes</td> <td></td> </tr> <tr> <td>3. Deformity</td> <td><input type="radio"/> No <input type="radio"/> Yes →</td> <td>Please Specify : _____</td> </tr> </table>		1. Pain	<input type="radio"/> No <input type="radio"/> Yes →	Pain Score (1-10) : <input style="width: 20px;" type="text"/>	2. Swelling	<input type="radio"/> No <input type="radio"/> Yes		3. Deformity	<input type="radio"/> No <input type="radio"/> Yes →	Please Specify : _____																					
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2. Swelling	<input type="radio"/> No <input type="radio"/> Yes																															
3. Deformity	<input type="radio"/> No <input type="radio"/> Yes →	Please Specify : _____																														
SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS																																
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	<input type="radio"/> No <input type="radio"/> Yes → <input style="width: 100px;" type="text"/>																												
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 _____ <small>(if YES, please tick ONE or MULTIPLE)</small> <input type="checkbox"/> NB-UVB <input type="checkbox"/> Bath PUVA <input type="checkbox"/> Excimer laser																															
3. Systemic therapy :	<input type="radio"/> No <input type="radio"/> Yes →																															
	a) Methotrexate	<input type="radio"/> No <input type="radio"/> Yes	f) Biologics, specify	<input type="radio"/> No <input type="radio"/> Yes → <input style="width: 100px;" type="text"/>																												
	b) Acitretin	<input type="radio"/> No <input type="radio"/> Yes	g) Systemic corticosteroids	<input type="radio"/> No <input type="radio"/> Yes																												
	c) Sulphasalazine	<input type="radio"/> No <input type="radio"/> Yes	h) Others, specify	<input type="radio"/> No <input type="radio"/> Yes → <input style="width: 100px;" type="text"/>																												
	d) Cyclosporin	<input type="radio"/> No <input type="radio"/> Yes																														
	e) Hydroxyurea	<input type="radio"/> No <input type="radio"/> Yes																														
SECTION 5: QUALITY OF LIFE																																
1. Quality of Life :	Please instruct and assist patient in completing the attached DLQI form																															

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

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Dermatology Life Quality Index (DLQI) (For Adults of Age 17 and Above)	CONFIDENTIAL For Office Use only: ID: <input style="width: 50px;" type="text"/> / <input style="width: 50px;" type="text"/> Centre: <input style="width: 100px;" type="text"/>
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Instruction: Where check boxes are provided, check (✓) one or more boxes. Where radio buttons are provided, check (✓) one button only.

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

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

这份问卷的目的是衡量上周内您的皮肤问题对您的生活造成了多大的影响。

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

DLQI Score <input style="width: 30px;" type="text"/>	Auto calculated
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Sepanjang Minggu Lalu OVER THE LAST WEEK 上周内,	Sangat Banyak Very much 非常多	Banyak A lot 许多	Sedikit A little 一点	Tidak Langsung Not at all 完全没有	Tidak Berkenaan Not Relevant 无关
1) Setakat manakah kulit anda berasa gatal atau sakit ? <i>Over the last week, how itchy, sore, painful or stinging has your skin been?</i> 您的皮肤感到痒、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? <i>Over the last week, how embarrassed or self conscious have you been because of your skin?</i> 由于您的皮肤问题, 您感到尴尬或自卑吗？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Setakat manakah kulit anda mengganggu anda daripada pergi membeli belah atau menjaga rumah atau berkebun ? <i>Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?</i> 因为皮肤问题, 对您购物、做家务、整理庭院影响程度如何？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Setakat manakah kulit anda mempengaruhi pakaian yang anda pakai ? <i>Over the last week, how much has your skin influenced the clothes you wear?</i> 皮肤问题对您穿衣服影响程度如何？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) Setakat manakah kulit anda mengganggu aktiviti - aktiviti sosial atau masa lapang anda ? <i>Over the last week, how much has your skin affected any social or leisure activities?</i> 皮肤问题对您的社交或休闲生活有多大的影响？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) Setakat manakah keadaan kulit anda menyebabkan anda tidak selesa bersukan? <i>Over the last week, how much has your skin made it difficult for you to do any sport?</i> 皮肤问题对您运动有多大妨碍？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) Adakah kulit anda menyebabkan anda tidak bekerja atau belajar? <i>Over the last week, has your skin prevented you from working or studying?</i> 皮肤问题是让您无法上班或学习？ <input type="checkbox"/> Ya/Yes 是 <input type="checkbox"/> Tidak/No 不是 <input type="checkbox"/> Tidak Berkenaan Not Relevant 无关 <div style="border: 1px dashed black; padding: 5px; margin-top: 5px;"> *Jika "tidak", setakat manakah kulit anda menjadi masalah semasa kerja atau belajar? <i>If "No", over the last week how much has your skin been a problem at work or studying?</i> 如果选择“不是”, 那么上周内您的皮肤问题对工作或学习有多大影响呢? </div>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8) Setakat manakah kulit anda menimbulkan masalah dengan teman, rakan baik atau saudara mara anda? <i>Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?</i> 皮肤问题妨碍了您和爱人、亲密的朋友、亲戚间的交往了吗？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) Setakat manakah kulit anda menyebabkan sebarang masalah hubungan seks ? <i>Over the last week, how much has your skin caused sexual difficulties?</i> 皮肤问题给您的性生活造成了多大影响？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Setakat manakah rawatan kulit anda merimbulkan masalah seperti mengotori rumah anda atau mengambil masa anda? <i>Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy or by taking up time?</i> 由于治疗您皮肤的毛病, 给您造成了多少麻烦, 如把家里弄得一团糟或占用了您很多时间？	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih

Please check you have answered EVERY question. Thank you.

请您检查您是否已回答所有问题。谢谢合作

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Children's Dermatology Life Quality Index (DLQI) (For age 5 to 16)				CONFIDENTIAL
<i>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.</i>				For Office Use only: ID: <input style="width: 50px;" type="text"/> / <input style="width: 50px;" type="text"/> Centre: <input style="width: 100px;" 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 style="width: 50px;" type="text"/> <small>Auto calculated</small>
Sepanjang Minggu Lalu OVER THE LAST WEEK 过去一星期中	Sangat Banyak Very much 非常多	Banyak A lot 许多	Sedikit A little 一点	Tidak Langsung Not at all 完全没有
1) Setakat manakah kulit anda berasa gatal atau sakit ? <i>Over the last week, how itchy, "scratchy", sore or painful has your skin been?</i> 你皮肤发痒、搔抓、破皮或疼痛的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Setakat manakah anda berasa malu, segan, susah hati atau sedih disebabkan oleh kulit anda? <i>Over the last week, how embarrassed or self conscious, upset or sad have you been because of your skin?</i> 你因为自己皮肤问题而感到难为情或害羞、苦恼或难过的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Setakat manakah kulit anda mempengaruhi persahabatan anda? <i>Over the last week, how much has your skin affected your friendships?</i> 皮肤问题对你和朋友交往的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Setakat manakah anda menukar atau memakai pakaian atau kasut kerana kulit anda? <i>Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?</i> 你因为皮肤问题而改变穿著不同或特定衣鞋的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) Setakat manakah masalah kulit anda mempengaruhi anda untuk keluar, bermain atau melakukan hobi anda? <i>Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?</i> 皮肤的问题对你外出、玩耍、或从事休闲嗜好的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) Setakat manakah anda menjauhi diri daripada berenang atau melakukan sukan lain disebabkan oleh masalah kulit anda? <i>Over the last week, how much have you avoided swimming or other sports because of your skin trouble?</i> 你因为皮肤的问题而避免游泳或其他运动的影响程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) Pada minggu yang lalu, Last week, 过去一星期 Pada hari persekolahan, setakat manakah kulit anda mempengaruhi kerja sekolah anda? <i>If school time: Over the last week, how much did your skin problem affect your school work?</i> 如果是上课时间, 皮肤问题影响你学校功课的程度是如何? ATAU OR 或 Pada hari cuti, setakat manakah kulit anda mengganggu anda menikmati cuti? <i>If holiday time: Over the last week, has your skin problem interfered with your enjoyment of the holiday?</i> 如果是放假期间, 皮肤问题干扰到你享受假期的兴致是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8) Setakat manakah orang memanggil anda dengan nama yang tidak baik, mengejek, menanya soalan-soalan atau menjauhi diri disebabkan oleh kulit anda? <i>Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?</i> 因为皮肤的问题使得别人骂你、嘲笑你、欺负你、问你问题或躲避你, 这种困扰程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) Setakat manakah masa tidur anda diganggu kerana masalah kulit? <i>Over the last week, how much has your sleep been affected by your skin problem?</i> 你因皮肤的问题而影响睡眠的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Setakat manakah rawatan kulit anda menjadi suatu masalah? <i>Over the last week, how much of a problem has the treatment for your skin been?</i> 针对皮肤所进行的治疗对你产生的困扰程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih. Please check you have answered EVERY question. Thank you. 请您检查您是否已回答所有问题。谢谢合作				

APPENDIX B: DATA MANAGEMENT

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

Data Sources

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

Data Collection

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

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

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

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

Participation of SDP is entirely voluntary.

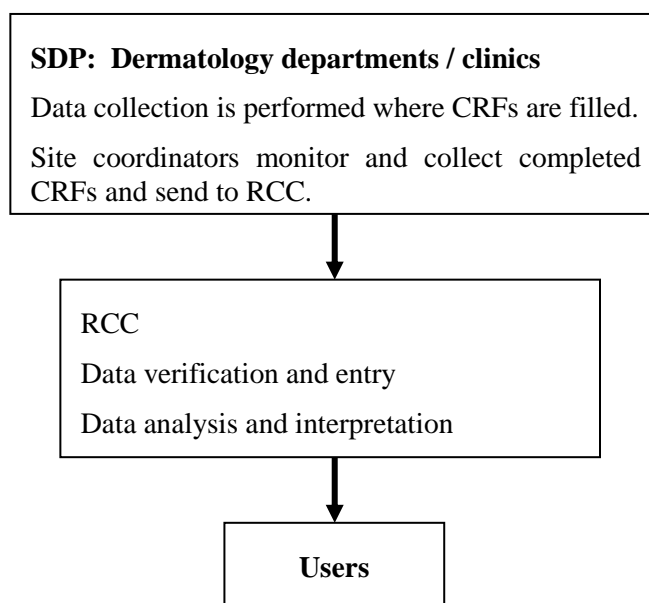
Registry ICT Infrastructure and Data Centre

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

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

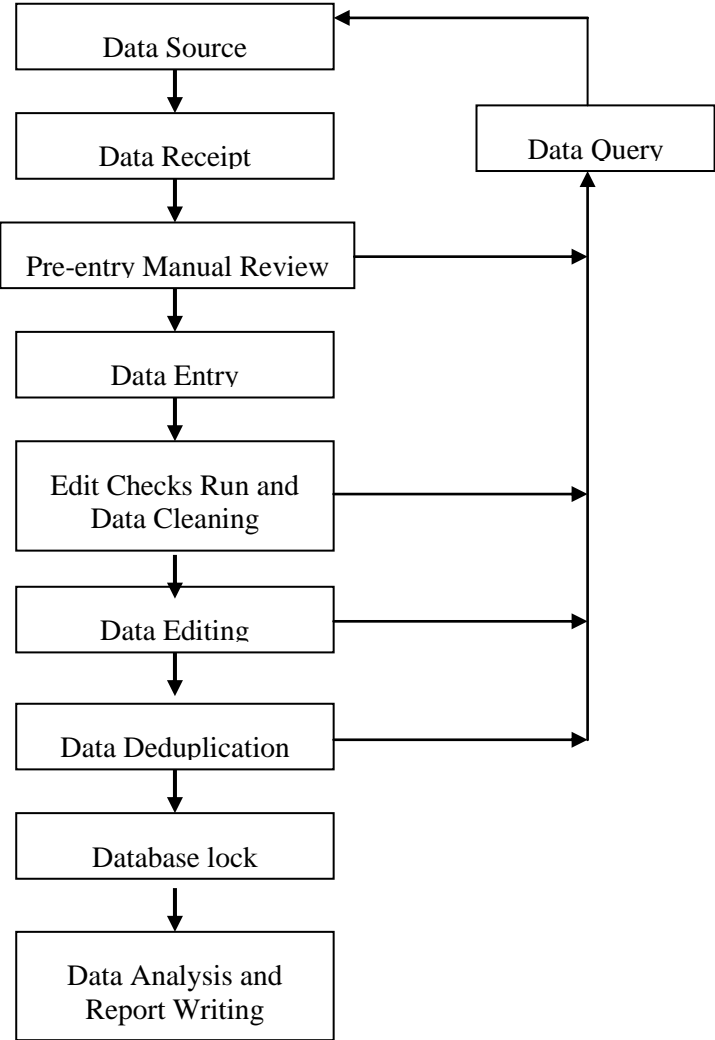
Data Flow Process

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



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

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



SDP Data Reporting, Data Correction and Submission Tracking

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

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

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

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

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

Edit checks run and Data cleaning

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

Legal Aspects and Confidentiality

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

Data release policy

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

Appendix B: Data Management

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 2010**

There were 5,824 patients in the dataset. The analysis set was used for the analysis in Chapter 1, 2, 3, 4, 5 and 6, which comprises of 329 cases in year 2007, 1,301 cases in year 2008, 1,957 cases in year 2009 and 2,237 in year 2010. The cases include first notification and up to five follow-up notifications.

2. **Patient outcome between 2007 and 2010**

There were 1602 cases considered for the outcome analysis in Chapter 8.

DATA MANAGEMENT

Data Cleaning

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

Missing Data

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

STATISTICAL METHOD

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

Stock and Flow

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

Characteristics of Patients

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

Medical History

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

Comorbidities

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

Clinical Presentation

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

Treatment

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

Quality of Life

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

Outcomes

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

STATISTICAL SOFTWARE

SPSS 18.0

APPENDIX D: PARTICIPATING CENTRE DIRECTORY

<p>Hospital Kuala Lumpur Department of Dermatology Hospital Kuala Lumpur Jalan Pahang 50586 Kuala Lumpur. Tel: 03-2615 1540 Fax: 03-26985927</p>	<p>Investigator: Dr Azura Mohd Affandi Site- coordinator: -</p>
<p>Hospital Sungai Buloh Dermatology Unit Hospital Sungai Buloh, Jalan Hospital, 47000 Sungai Buloh, Selangor Darul Ehsan. Tel: 03-61454333 Ext 1286 Fax: 03-61454222</p>	<p>Investigator: Dr. Azahzuddin b Hamzah Site- coordinator: Prima Dharshini</p>
<p>Hospital Tuanku Ja'afar, Seremban Dermatology Department, Hospital Tuanku Ja`afar, Jalan Rasah 70300 Seremban, Negeri Sembilan. Tel: 06-760 4157 Fax: 06-7625771</p>	<p>Investigator: Dr. Najeeb Ahmad Mohd Safdar Site- coordinator: Dr.Prakash A/L Balasubramaniam</p>
<p>Hospital Sultanah Fatimah, Muar Dermatology Department, Hospital Pakar Sultanah Fatimah, Jalan Salleh, 84000 Muar, Johor. Tel: 06-9521901 Fax: 06-9526003</p>	<p>Investigator: Dr. Siti Khadijah Abdul Wahid Site- coordinator: Mohd Khairul bin Othman</p>
<p>Hospital Pulau Pinang Dermatology Department, Hospital Pulau Pinang, Jalan Residensi, 10990 Pulau Pinang, Tel: 04-222 5250 Ext 5246 Fax: 04-2281737</p>	<p>Investigator: Dr Chan Lee Chin Site- coordinator: Dr Yeoh Chin Aun</p>

<p>Hospital Sultanah Bahiyah, Alor Setar</p> <p>Dermatology Department, Hospital Sultanah Bahiyah, Lebuhraya Darul Aman, 05100 Alor Setar, Kedah Tel: 04-740 6233 Fax: 04-7350232</p>	<p>Investigator: Dr Mani Mala a/p T. Manikam</p> <p>Site- coordinator: Dr Azlida Che Man</p>
<p>Hospital Tuanku Fauziah, Kangar</p> <p>Dermatology Department, Hospital Tuanku Fauziah, Jalan Kolam,01000 Kangar, Perlis. Tel: 04-973 8000 Fax: 04-9767237</p>	<p>Investigator: Dr Sharifah Fariah Syed Abas, Dr. Hassanin Hussaini Hilmi bin Mohd Khalid</p> <p>Site- coordinator: Wan Suhardi bin Wan Abdul Rahman</p>
<p>Hospital Queen Elizabeth, Kota Kinabalu</p> <p>Dermatology Department, Hospital Queen Elizabeth, Karung Berkunci no 2029 , 88586 Kota Kinabalu, Sabah. Tel: 088-517555 Fax: 088-211999</p>	<p>Investigator: Dr Zaigham Mahmood Dr Mervin George Matthew</p> <p>Site- coordinator: Ampong Anggarak</p>
<p>Hospital Tengku Ampuan Afzan, Kuantan</p> <p>Dermatology Department, Hospital Tengku Ampuan Afzan, Jalan Tanah Putih, 25100 Kuantan, Pahang. Tel: 09-5133333 Fax: 09-5142712</p>	<p>Investigator: Dr Abu Razak Yusof</p> <p>Site- coordinator: Mazliza binti Mamat</p>
<p>Hospital Raja Permaisuri Bainun, Ipoh</p> <p>Dermatology Department, Jabatan Dermatologi, Hospital Ipoh, Jalan Hospital 30990 Ipoh, Perak. Tel: 05-208 5072 Fax: 05-2531541</p>	<p>Investigator: Dr. Tang Jyh Jong</p> <p>Site- coordinator: Dr. Gurcharan Jit Singh</p>

Appendix D: Participating Centre Directory

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

<p>Universiti Malaya Medical Centre</p> <p>Department of Medicine, University of Malaya Medical Centre, Faculty of Medicine, University of Malaya, 59100 Kuala Lumpur. Tel: 03-79492429 Fax: 03-7956 2253</p>	<p>Investigator: Dr. Wong Su Ming</p> <p>Site- coordinator: Dr. Kwan Zhen Li</p>
<p>Universiti Kebangsaan Malaysia Medical Centre</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>Hospital Raja Perempuan Zainab II, Kota Bharu</p> <p>Dermatology Department, Hospital Raja Perempuan Zainab II, 15586 Kota Bharu, Kelantan Darul Naim Tel: 09-7452000 Ext 2384 Fax: 09-7486951</p>	<p>Investigator: Dr. Zulrusydi bin Ismail</p> <p>Site- coordinator: Muhd. Al-Amin Mat Zin</p>