



Ministry of Health Malaysia

**NATIONAL DERMATOLOGY REGISTRY  
(DermReg)**

**The First Annual Report of the  
MALAYSIAN PSORIASIS REGISTRY  
2007 - 2008**

Editors:

**Chang Choong Chor  
Noor Addillah Shueef  
Asmah Johar  
Roshidah Baba**

With contributions from:

**Wong Su Ming, Tan Wooi Chiang, Mazlin Mohd Baseri, Tang Jyh Jong,  
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Steven Chow Kim Weng**

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*Contact:*

National Dermatology Registry  
Department of Dermatology  
Hospital Kuala Lumpur  
Jalan Pahang  
50586 Kuala Lumpur

Tel: 03-2615 5225 / 03-2615 5555 Ext 5225

Fax: 03-2698 5927

Email: [dermreg@acrm.org.my](mailto:dermreg@acrm.org.my)

Website: [www.acrm.org.my/dermreg/](http://www.acrm.org.my/dermreg/)

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## FOREWORD

On behalf of the Governance Board, I am most honored & privileged to write a foreword for the First Annual Report of the Malaysian Psoriasis Registry. It is a great achievement and important landmark for dermatologists in the country. The Malaysian Psoriasis Registry is the first registry under the National Dermatology Registry. I can still recall the First Malaysian Psoriasis Symposium which was held in IJN on the 17 May 1998 to discuss the development and implementation of the Psoriasis Registry. I would like to acknowledge my sincere thanks to the subcommittee that was involved in producing the subsequent final psoriasis questionnaire then, namely, Puan Sri Datuk Dr. Suraiya H. Hussein, Dato Dr. SK Ratti, Dr. Steven Chow Kim Weng, Dr. Gangaram Hemandas, Dr. Roshidah Baba, Dr. Allan Yee Kim Chye and Dr. Gan Ain Tian. Since then a number of revisions were made to the psoriasis questionnaire and I would like to acknowledge my sincere thanks to Dr. Chang Choong Chor for his help.

The main aim of the National Dermatology Registry is the 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. The DermReg is a nationwide project which aims to integrate all dermatological patient registries and databases developed in Malaysia.

On behalf of the Governance Board of the DermReg, I would like to express my sincere thanks to all involved in the successful implementation of these Registries which include, the Ministry of Health, Malaysia, the Clinical Research Center of the MOH, Malaysia, Head of Dermatological Services, Malaysia, the Dermatological Society of Malaysia, the Faculty of Medicine, College of Physicians, Academy of Malaysia, members of the Steering Committee, the Source Data Providers without whom the registries would not succeed and would like to encourage them to continue with their good work.

Thank you.

Dr. Gangaram Hemandas FRCP

Chairman

Governance Board of the National Dermatology Registry

## **PREFACE**

This First Annual Report of the Malaysian Psoriasis Registry is a major milestone in a nationwide effort to collect essential data for psoriasis in Malaysia. Patient registry is an observational cohort study which is able to provide data on patients in “real life”, as opposed to strictly regulated study environment created under most interventional trials. The pioneer effort in establishing a national database in psoriasis was started in 1998 by a group of dermatologists who conducted a pilot study in a number of public and private dermatologic centres from 2000 to 2005. The results were published in the Malaysian Journal of Dermatology in 2005. With financial and technical support from the Ministry of Health via the Clinical Research Centre (CRC), the registry was revised and officially named the Malaysian Psoriasis Registry. Since October 2007, a centralized electronic database with web application was established to facilitate data capture from various centres in the country.

Since the inception of the newly revised registry, 14 dermatology centres have participated as source data providers of the registry. Most of these centres are dermatology clinics in secondary or tertiary public hospitals, while two are private dermatology clinics. In order to ensure that only genuine psoriasis cases are included in the registry, decision has been made to include only psoriasis cases who are diagnosed by dermatologists or under the supervision of dermatologists.

We would like to express our sincere gratitude to the CRC network of the Ministry of Health, Malaysia, the Dermatological Society of Malaysia, and all investigators, site coordinators, doctors, allied health personnel and research officers for their support and hard work, without which this registry would not have been successful.

We are looking forward to better participation from dermatologists in the private sector as well as universities. We sincerely hope that the information generated from this registry would benefit the users.

Thank you.

Dr. Chang Choong Chor  
Principal Investigator  
Malaysian Psoriasis Registry

## **ACKNOWLEDGMENTS**

First of all, we wish to thank the Director General of Health, Malaysia for permission to publish this report.

The National Dermatology Registry would like to give its appreciation to everyone who has helped make this report possible.

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

- All the doctors, allied health personnel and clerical staff in the participating centres
- The Ministry of Health, Malaysia
- Dermatological Society of Malaysia
- Faculty of Medicine, College of Physicians, Academy of Medicine Malaysia
- Datamed Clinical Computing Services Sdn Bhd

## 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
NB-UVB	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 to the planning, implementation and evaluation of clinical and health services as well as research in dermatology

## Objectives of DermReg

### General Objective

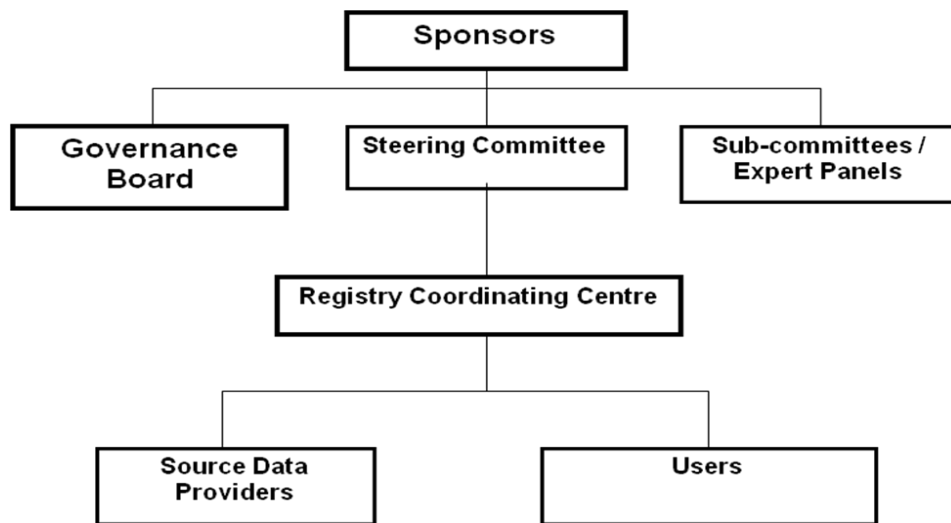
To establish a nationwide systematic prospective collection of data pertaining to skin diseases and dermatological services, in order to study the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities.

### 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
  - a. Clinical Research Centre, Hospital Kuala Lumpur
  - b. Department of Dermatology, Hospital Kuala Lumpur
  - c. Head of Dermatology Services, Malaysia
2. The Dermatological Society of Malaysia
3. Faculty of Medicine, College of Physicians, Academy of Medicine 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. Dr. Gangaram Hemandas Belani (Chairperson)  
Senior Consultant Dermatologist  
Prince Court Medical Centre
2. Dr. Roshidah Baba  
Head of Dermatological Services and Senior Consultant Dermatologist  
Department of Dermatology  
Hospital Kuala Lumpur
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. Mardziah Alias  
President of the Dermatological Society of Malaysia, and  
Senior Consultant Paediatrician and Dermatologist  
Damansara Specialist Hospital
5. Dr. Lim Teck Onn  
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 (Chairman)	Hospital Kuala Lumpur
2.	Dr. Choon Siew Eng	Hospital Sultanah Aminah, Johor Bahru
3.	Dr. Pubalan Muniandy	Hospital Umum Sarawak
4.	Dr. Agnes Heng Yoke Hui	Hospital Raja Permaisuri Bainun, Ipoh
5.	Dr. Chan Lee Chin	Hospital Pulau Pinang
6.	Dr. Koh Chuan Keng	Universiti Malaya Medical Centre
7.	Dr. Allan Yee Kim Chye	Hope Skin & Laser Centre, Gleneagles Intan Medical Centre
8.	Dr. Steven Chow Kim Weng	The Skin Clinic, Kuala Lumpur
9	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**                      Cik Noor Addillah bt Shueef

### **Technical Support Personnel**

**Epidemiology Officer**                Dr. Jamaiyah Haniff  
Clinical Epidemiology Unit,  
CRC

**Biostatisticians**                      Encik Mohd Adam Bujang,  
Ms Premaa A/P Supramaniam  
CRC

**Clinical Data Manager**                Ms Teo Jau Shya  
ClinResearch Sdn Bhd

**Database Administrator**              Ms Lim Jie Ying  
Datamed Clinical Computing Services 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. Chang Choong Chor
2.	Hospital Pulau Pinang	Dr. Chan Lee Chin
3.	Hospital Sultanah Bahiyah, Alor Setar	Dr. M. Balakrishnan
4.	Hospital Tuanku Fauziah, Perlis	Dr. M. Umaselvam
5.	Hospital Sultanah Fatimah, Muar	Dr. Kader Mohamad
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. Ong Cheng Leng
10.	Hospital Raja Permaisuri Bainun, Ipoh	Dr. Agnes Heng Yoke Hui
11.	Hospital Umum Sarawak, Kuching	Dr. Pubalan Muniandy
12.	Hospital Tengku Ampuan Rahimah, Klang	Datin Dr. Saraswathy Devi Sinniah
13.	Hope Skin & Laser Centre, Gleneagles Intan Medical Centre	Dr. Allan Yee Kim Chye
14.	Hospital Sultanah Aminah, Johor Bahru	Dr. Choon Siew Eng

# OFFICIAL WEBSITE OF DermReg

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

Friday, July 30, 2010

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**NATIONAL DERMATOLOGY REGISTRY**  
*Malaysia*

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## 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)**
3. **Malaysian Leprosy Registry (MLR)** - coming soon

### 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

### Contact Us

Registry Manager  
National Dermatology Registry  
Department of Dermatology  
Hospital Kuala Lumpur  
Jalan Pahang  
50586 Kuala Lumpur  
Tel:  **03-2615 5225**   
Email: [mpr@acrm.org.my](mailto:mpr@acrm.org.my)

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# ABOUT 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 should also help in research work and more importantly in improving the overall management of the patients.

## 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:**

1. Patients whose diagnosis is in doubt are excluded.

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# EXECUTIVE SUMMARY

## Stock and Flow

During the period from October 2007 to December 2008, a total of 2,499 patients with psoriasis from 14 dermatology centres (13 government and 1 private) were notified to the registry.

## Demographic Characteristics of Patients

Male-to-female ratio was 1.27:1. Ethnic distribution: Malay 49.9%, Chinese 25.3%, Indian 14.6%, other ethnic groups 10.1%. Mean age at notification was  $43.1 \pm 17.3$  years (range 3 - 91 years). Most patients (99.3%) were Malaysian citizens.

## Medical History

Mean age of onset of psoriasis was  $33.3 \pm 16.6$  years (range 1 – 81 years). Family history of psoriasis was present in 18.9% 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: 21.7% vs 13.6%. Among those who had positive family history, family members affected were either of their parents in 36.4%, siblings in 28.5% and children in 10.4%.

55.5% of the patients reported one or multiple factors which aggravated their psoriasis. The commonest aggravating factors were stress (66.7%), sunlight (37.2%) and infection (19.7%).

## Comorbidities

In adult psoriasis patients aged 18 and above, the common comorbidities were obesity 33.0%, overweight 32.9%, hypertension 25.2%, diabetes mellitus 17.1%, dyslipidaemia 16.6%, and ischaemic heart disease 5.5%. In patients aged below 18, the commonest comorbidity was overweight or obesity (28.5%) followed by bronchial asthma (3.4%).

## Clinical Presentation

The commonest clinical type of psoriasis was plaque psoriasis (83.7%). This was followed by guttate psoriasis (4.8%), erythrodermic psoriasis (3.4%), pustular psoriasis (1.2%) and flexural psoriasis (0.6%). The majority of patients (64.2%) had body surface area involvement of 10% or less.

Psoriatic arthropathy was reported in 16.1% of patients. The commonest clinical pattern was oligo-/monoarthropathy (45.6%) followed by rheumatoid-like symmetrical polyarthropathy (33.2%) and distal hand joints arthropathy (27.9%).

About two-third (63.7%) of patients had nail changes related to psoriasis. Among patients who had nail disease, common nail changes were pitting (73.0%), onycholysis (51.6%), discoloration (40.0%) and subungual hyperkeratosis (17.3%). Total nail dystrophy occurred in 6.3% of patients with nail disease.

## Treatments received in the past 6 months

All patients used topical treatment. The most popular mode of topical treatment was tar preparation (78.9%), followed by topical steroids (78.5%) and emollients (77.2%). Phototherapy was used in 4.3% of patients. Narrowband UVB (NB-UVB) was the commonest mode of phototherapy used (73.5%). Systemic therapy was given in 20.9% of

patients. The most frequently used systemic therapy was methotrexate (15.6%), followed by acitretin (4.4%), and sulphasalazine (1.5%), systemic steroids (1.4%), cyclosporin (1.2%), biologics (0.5%) and hydroxyurea (0.3%).

### **Quality of Life**

Measurement of quality of life using Dermatology Life Quality Index (DLQI) or Child DLQI (CDLQI) was performed in 2,244 adult patients (aged 17 and above) and 180 children/adolescent patients (aged 5 to 16). The mean DLQI score was  $8.3 \pm 6.5$  for adult patients and the mean CDLQI was  $7.5 \pm 5.6$  for children/adolescent patients.



# INTRODUCTION

Psoriasis is a common skin disease characterised 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 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 should also help in research work and more importantly in improving the overall management of the patients.

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. Preliminary work on the MPR started in the year 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 clinical research 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.

The registry has been operating under minimal budget and limited resources mainly on voluntary basis. Although we aim for support from all states and both public and private centres, the main contribution came from only a small number of centres. By revising the registry, we now hope to improve on the implementation of the registry, and to put it up electronically in order to improve the coverage and facilitate data collection. A permanent secretariat with dedicated staffing would tremendously facilitate these activities.



# **CHAPTER 1**

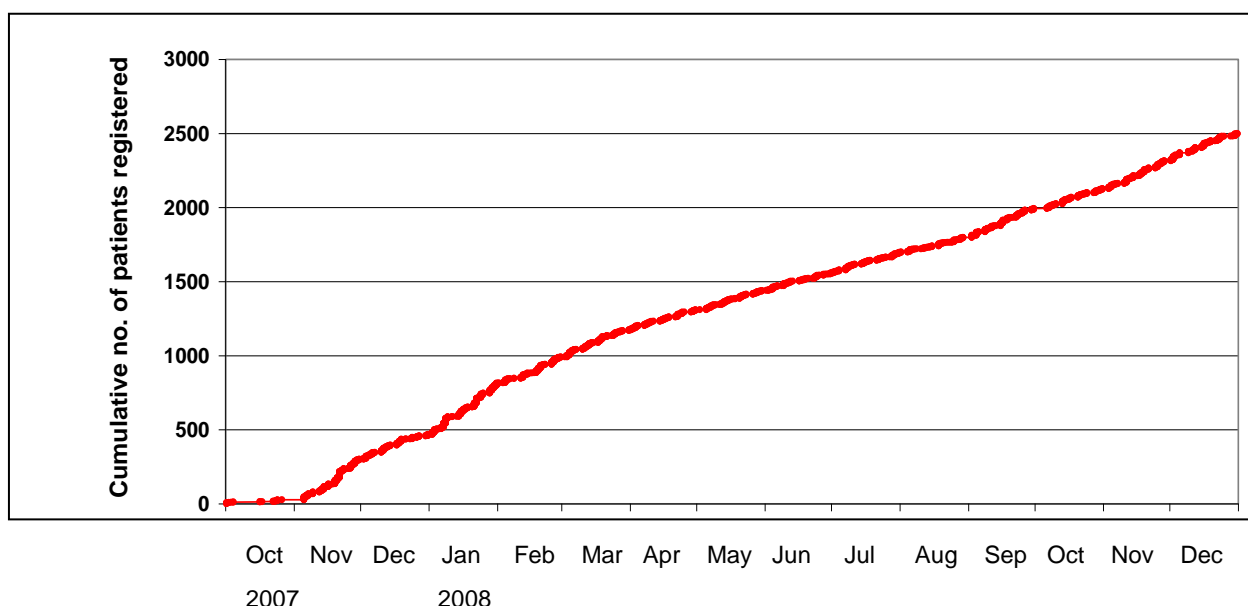
## **STOCK AND FLOW**

**Chang Choong Chor**  
**Gangaram Hemandas**

During the period from October 2007 to December 2008, a total of 2,499 patients were notified to the registry. Despite an initial lag phase, there was an abrupt increase in the number of patients notified in November 2007, possibly due to increase in interest in the registry as well as the inclusion of existing patients under follow-up in the participating centres. Since then, the number of notified patients steadily increased throughout the period (**Figure 1.1**).

A total of 14 dermatology centres participated in the MPR. Ten centres joined the registry as source data provider in year 2007, while another three centres joined in 2008. All except one centre were secondary or tertiary centres in government hospitals. A private dermatologist in Gleneagles Intan Medical Centre, Kuala Lumpur was the only private centre which contributed to the registry. Department of Dermatology, Hospital Kuala Lumpur notified the highest number of patients. This was followed by Hospital Umum Sarawak and Hospital Sultanah Bahiyah, Alor Setar (**Table 1.1**).

The majority of the patients (87.9%) were notified once. A second notification during subsequent follow-up visit was also received in 303 (12.1%) patients. Out of these patients, 298 (11.9%) had one follow-up notification and only five had two follow-up notifications (**Table 1.2**).



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

**Table 1.1 Number of psoriasis patients notified in each participating centre**

No.	Centre	2007	2008	Total
1.	Hospital Kuala Lumpur	125	325	450
2.	Hospital Umum Sarawak	14	427	441
3.	Hospital Sultanah Bahiyah, Alor Setar	114	225	339
4.	Hospital Pulau Pinang	65	249	314
5.	Hospital Sultanah Fatimah, Muar	21	161	182
6.	Hospital Raja Permaisuri Bainun, Ipoh	89	83	172
7.	Hospital Tengku Ampuan Afzan, Kuantan	2	162	164
8.	Hospital Queen Elizabeth, Kota Kinabalu	24	137	161
9.	Hospital Tengku Ampuan Rahimah, Klang	0	90	90
10.	Hospital Tuanku Fauziah, Kangar	5	71	76
11.	Hospital Sungai Buloh	9	29	38
12.	Hospital Sultanah Aminah, Johor Bahru	0	38	38
13.	Hospital Tuanku Ja'afar, Seremban	0	19	19
14.	Gleneagles Intan Medical Centre, Kuala Lumpur	0	15	15
	Total	468	2,031	2,499

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

<b>Year</b>	<b>N</b>	<b>%</b>
Entry notification	2,196	87.9
Entry and one follow-up notification	298	11.9
Entry and two follow-up notifications	5	0.2
Total	2,499	100.0

## **CHAPTER 2**

# **CHARACTERISTICS OF PATIENTS**

**Wong Su Ming**  
**Steven Chow Kim Weng**

## Chapter 2: Characteristics of Patients

There were more males than females (56% and 44% respectively), with a male to female ratio of 1.27:1. Malays comprised the majority of 49.9%, followed by Chinese 25.3%, Indians 14.6%, Orang Asli 0.1% and other ethnic groups 10.1%.

The mean age at presentation to the clinic was  $43.1 \pm 17.3$  years with a range from 3 to 91 years. The majority were married (68.6%), 27.7% were single, and the rest, either divorced or widowed. (**Table 2.1**)

**Table 2.1: Patient demographics**

Patient characteristics		No.	%
Gender	Male	1400	56.0
	Female	1099	44.0
Ethnic distribution	Malay	1247	49.9
	Chinese	633	25.3
	Indian	365	14.6
	Orang Asli	3	0.1
	Others	249	10.0
	NA	2	0.1
Nationality	Malaysian	2481	99.3
	Non Malaysian	18	0.7
Marital status	Single	693	27.7
	Married	1714	68.6
	Divorced	41	1.6
	Widowed	26	1.1
	NA	25	1.0
Age at notification (years)	Mean $\pm$ SD (Range)	$43.1 \pm 17.3$ (3 - 91)	



## **CHAPTER 3**

# **MEDICAL HISTORY**

**Tan Wooi Chiang**  
**Chan Lee Chin**

### **Onset of Psoriasis**

Psoriasis may first appear at any age. In the MPR, 65.7% of patients had first symptoms of psoriasis by the age of 40. The mean age of onset in our cohort was  $33.3 \pm 16.6$  years with a wide range from 1 to 81 years. (**Figure 3.1**) The mean interval between onset (as reported by patient) and diagnosis (first diagnosed by physician) was  $2.26 \pm 4.7$  years.

### **Family History**

Psoriasis is a skin disorder with a polygenic mode of inheritance. In our registry, about one-fifth (18.9%) of patients had at least one family member with psoriasis. (**Table 3.1**) Of those with a positive family history, 36.4% had either of their parents affected. Siblings were affected in 28.5% and children in 10.4%. (**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: 21.7% vs 13.6% (**Table 3.1**).

### **Aggravating factors of psoriasis**

The majority of patients (55.5%) reported one or multiple factors which worsen their psoriasis control. Stress was the commonest aggravating factor (66.7%), followed by sunlight (37.2%) and infection (19.7%). Other identified aggravating factors included trauma (9.9%), drugs (7.6%), smoking (5.0%), alcohol (4.6%), pregnancy (3.6%) and topical treatment (2.0%) (**Table 3.3**).

Analysing the subgroup of patients who reported infection as an aggravating factor, upper respiratory tract infection (20.1%) appeared to be the commonest infective trigger. (**Table 3.4**) Common medications found to aggravate psoriasis were beta blockers (30.5%), withdrawal of systemic steroids (15.2%), antibiotics (7.6%), and non-steroidal anti-inflammatory drugs (6.7%). (**Table 3.5**)

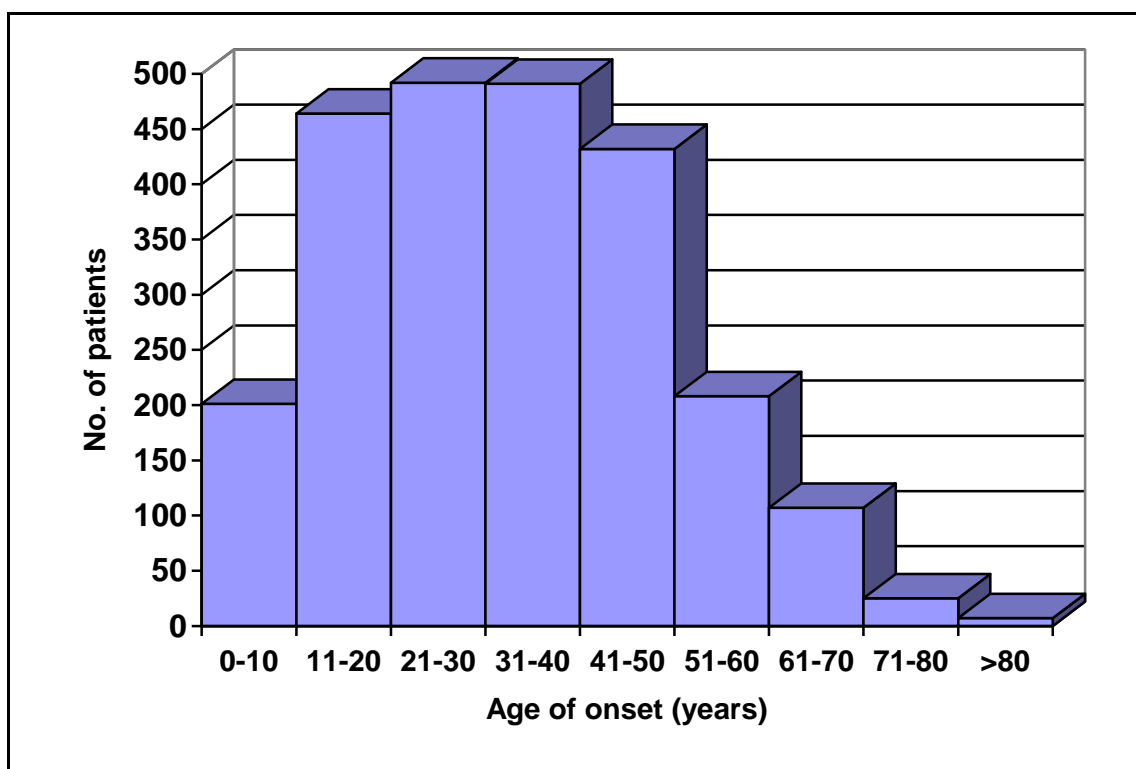


Figure 3.1 Distribution of age of onset

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	471	18.9	357	21.6	114	13.5
	No	2011	80.5	1285	77.7	726	85.9
	NA	17	0.7	12	0.7	5	0.6

Table 3.2 Family members with psoriasis

Family member (one or multiple)	No.	%
Father	119	22.0
Mother	78	14.4
Sibling(s)	154	28.5
Children	56	10.4
Others	134	24.8

**Table 3.3 Aggravating factors of psoriasis**

Aggravating factors (one or multiple)	No.	%
Stress	926	66.7
Sunlight	516	37.2
Infection	274	19.7
Trauma	138	9.9
Drugs	105	7.6
Smoking	70	5.0
Alcohol	64	4.6
Pregnancy	50	3.6
Topical treatment	28	2.0

**Table 3.4 Infections which aggravated psoriasis**

Infection	No.	%
Upper respiratory tract infection	55	20.1
Fever / febrile illness	6	2.2
HIV	4	1.5
Flu	3	1.1
Dengue fever	2	0.7
Viral fever	1	0.4
Pneumonia	1	0.4
Chickenpox	1	0.4
Boil	1	0.4

**Table 3.5 Drugs which aggravated psoriasis**

Drug	No.	%
Beta-blocker	32	30.5
Systemic steroids (withdrawal)	16	15.2
Antibiotic	8	7.6
NSAIDs/ analgesics	7	6.7
Traditional medications	5	4.8
Antimalarial drug	1	1.0
Sodium valporate	1	1.0
'Diane'	1	1.0
Antihistamine	1	1.0
Glucosamine	1	1.0
Homeopathy	1	1.0
Gamat (sea cucumber)	1	1.0



## **CHAPTER 4**

# **COMORBIDITIES**

**Mazlin Mohd Baseri**  
**Gangaram Hemandas**

Patients with psoriasis were found to have a number of other concomitant diseases. Some of them had been associated with psoriasis in other studies, while others were coincidental. 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, obesity was the most prevalent comorbidity affecting 33.0% of the subject population, followed by overweight (32.9%), hypertension (25.2%), diabetes mellitus (17.1%), dyslipidaemia (16.6%), ischaemic heart disease (5.5%) and cerebrovascular disease (1.4%). (**Table 4.1**)

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

Comorbidity	No.	%
Obesity	746 <sup>#</sup> (469*)	33.0 <sup>#</sup> (20.7*)
Overweight	745 <sup>#</sup> (752*)	32.9 <sup>#</sup> (33.2*)
Hypertension	570	25.2
Diabetes mellitus	387	17.1
Dyslipidaemia	375	16.6
Ischaemic heart disease	125	5.5
Cerebrovascular disease	31	1.4

<sup>#</sup> 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



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 (28.5%), followed by bronchial asthma (3.4%). Other comorbid conditions were much less common. (**Table 4.2**)

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

Comorbidity	No.	%
Overweight or obesity (BMI $\geq$ 85 <sup>th</sup> centile)	66	28.5
Bronchial asthma	8	3.4
Down syndrome	1	0.4
Epilepsy	1	0.4
Thalassemia	1	0.4
Atrial septal defect	1	0.4
Patent ductus arteriosus	1	0.4



## **CHAPTER 5**

# **CLINICAL PRESENTATION**

**Tang Jyh Jong**  
**Mohd Noh Idris**

Plaque psoriasis was the commonest type of psoriasis (83.7%). This was followed by guttate psoriasis (4.8%) and erythrodermic psoriasis (3.4%). Pustular and flexural/inverse psoriasis were much less common, constituting 1.2% and 0.6% respectively (**Table 5.1**)

Majority of our patients had mild to moderate body surface area involvement. 33.9% of our psoriatic patients had <2% BSA affected, while 30.3% had 2-10% of BSA affected. Severe psoriasis with >10% BSA affected occurred in 14.6% patients, while 2.8% 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 severe lesion (score 3) located on lower limb (28.7%) , scalp (26.4%) and trunk (23.6%). Almost one third of our psoriatic patients (36%) did not have any lesion on the face and neck. Lesions on face and neck were generally less severe (score 1 or 2). (**Table 5.3**)

The majority (63.7%) patients with psoriasis had nail involvement (**Table 5.4**). Among patients who had psoriatic nail disease, most of them had pitting (73%). Other common features were onycholysis (51.6%), discoloration (39.9%) and subungual hyperkeratosis (17.3%). Total nail dystrophy was found in 6.3 % of patients with nail involvement. (**Table 5.5**)

Joint disease related to psoriasis was reported in 16.1% of the patients. (**Table 5.6**) Rheumatoid factor was positive in 1.5% of patients with arthropathy (8.7% of patients with results available). (**Table 5.7**) The commonest clinical pattern of psoriatic arthropathy was oligo-/monoarthropathy (45.6%). This was followed by rheumatoid-like symmetrical polyarthropathy (34.3%) and distal hand joints arthropathy (26.9%). The most severe form of arthropathy, i.e. arthritis mutilans occurred in 4.2% of patients. (**Table 5.8**)

Most of the patients with psoriatic arthropathy experienced joint pain at time of presentation (84.8%) (**Table 5.9**) Joint swelling was present in 35.2%, while joint deformity occurred in 25.4%. (**Table 5.9**) The commonest types of joint deformities were Boutonniere (15.7%) and swan neck deformity (15.7%), followed by bamboo spine (4.9%), distal hand joint deformities (3.9%) and arthritis mutilans (2.0%). (**Table 5.10**)

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

Type of psoriasis	No.	%
Plaque	2092	83.7
Guttate	119	4.8
Pustular	30	1.2
Erythrodermic	86	3.4
Flexural/Inverse	15	0.6
Others	101	4.0
NA	56	2.3

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

% Body surface area affected	No.	%
<2%	757	30.3
2 - 10%	848	33.9
>10% to 90%	365	14.6
>90%	69	2.8
NA	460	18.4

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

Body part	Clinical score									
	0		1		2		3		NA	
	N	%	N	%	N	%	N	%	N	%
Scalp	490	14.2	1325	23.2	552	20.1	114	26.4	18	20.7
Face & neck	1244	36.0	1030	18.1	175	6.4	17	3.9	33	39.0
Trunk	660	19.1	997	17.5	710	25.8	102	23.6	34	46.2
Upper limbs	588	17.0	1230	21.6	572	20.8	75	17.4	34	46.2
Lower limbs	477	13.8	1124	19.7	742	27.0	124	28.7	32	47.8

**Table 5.4 Distribution of nail involvement in psoriasis patients**

Nail involvement	No.	%
Yes	1592	63.7
No	901	36.1
NA	6	0.2

**Table 5.5 Distribution of nail features in patients with nail involvement**

Nail features	No.	%
Pitting	1162	73.0
Onycholysis	822	51.6
Discoloration	635	39.9
Subungual hyperkeratosis	276	17.3
Total nail dystrophy	101	6.3

**Table 5.6 Distribution of joint disease in psoriasis patients**

Joint disease	No.	%
Yes	401	16.1
No	2,078	83.2
NA	20	0.8

**Table 5.7 Distribution of rheumatoid factor in psoriasis patients with joint disease**

Rheumatoid factor	No.	%
Positive	6	1.5
Negative	63	15.7
NA	332	82.8

**Table 5.8 Distribution of types of joint disease**

Type of joint disease (one or multiple)	No.	%
Oligo/Monoarthropathy	183	45.6
Proximal hand joints arthropathy	133	33.2
Morning stiffness > 30 mins	112	27.9
Distal hand joints arthropathy	104	25.9
Spondylitis	54	13.5
Enthesopathy	40	10.0
Arthritis mutilans	16	4.0

**Table 5.9 Symptoms of psoriatic arthritis**

	Status	No.	%
Joint pain	Yes	340	84.8
	No	49	12.2
	NA	12	3.0
Joint swelling	Yes	141	35.2
	No	256	63.8
	NA	4	1.0
Joint deformity	Yes	102	25.4
	No	291	72.6
	NA	8	2.0

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

Type of joint deformity	No.	%
Boutonniere deformity	16	15.7
Swan neck deformity	16	15.7
Bamboo spine	5	4.9
Distal hand joint deformity	4	3.9
Arthritis mutilans	2	2.0
Others	15	14.7
Unspecified	50	49.0





## **CHAPTER 6**

# **TREATMENTS**

**Chong Yew Thong**

**Choon Siew Eng**

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

All patients used some form of topical medications for psoriasis. Majority of the patients were treated with topical tar preparation (78.9%). Topical steroids were used in areas other than face and flexures in 78.5%. Other topical medications used were topical emollients (77.2%), keratolytics (54.7%), vitamin D analogue such as calcipotriol (22.6%) and dithranol (0.9%). (**Table 6.1**)

4.3% of patients had received phototherapy in the past (**Table 6.2**). Most of these patients (67.3%) were given narrowband UVB (NB-UVB) while 12.1% were given broadband UVB (BB-UVB). Less popular modalities were oral PUVA (6.5%), topical PUVA (2.8%) and bath PUVA (0.9%) (**Table 6.3**).

At least one systemic therapy was given in 20.8% of patients. (**Table 6.4**) Methotrexate, being the commonest systemic therapy, was used in 15.6%. This was followed by acitretin (4.4%), sulphasalazine (1.5%), systemic corticosteroids (1.4%), cyclosporine (1.2%), biologics (0.5%) and hydroxyurea (0.3%). (**Table 6.5**)

**Table 6.1 Use of topical medications in psoriasis patients.**

Topical therapy (one or multiple)	No.	%
Tar preparation	1972	78.9
Topical steroids (other than face and flexures)	1961	78.5
Emollient	1928	77.2
Keratolytics	1368	54.7
Vitamin D analogues	564	22.6
Dithranol (anthralin)	23	0.9
Others	52	2.1

**Table 6.2 Use of phototherapy in psoriasis patients**

Phototherapy	No.	%
Yes	107	4.3
No	2355	94.2
NA	37	1.5

**Table 6.3 Distribution of types of phototherapy**

Type of phototherapy (one or multiple)	No.	%
NB-UVB	72	67.3
BB-UVB	13	12.1
Oral PUVA	7	6.5
Topical PUVA	3	2.8
Bath PUVA	1	0.9
Others	2	1.9

**Table 6.4 Use of systemic therapy in psoriasis patients**

Systemic therapy	No.	%
Yes	521	20.8
No	1978	79.1
Total	2499	100.0

**Table 6.5 Distribution of types of systemic therapy in psoriasis patients**

Type of systemic therapy (one or multiple)	No.	%
Methotrexate	389	15.6
Acitretin	110	4.4
Sulphasalazine	37	1.5
Systemic corticosteroids	35	1.4
Cyclosporin	29	1.2
Biologics	13	0.5
Hydroxyurea	7	0.3
Others	36	1.4

## **CHAPTER 7**

### **QUALITY OF LIFE**

**Tang Min Moon**  
**Agnes Heng Yoke Hui**

There were a total of 2,244 adult patients (aged 17 and above) and 180 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  $8.3 \pm 6.5$ , and the mean CDLQI for child/adolescent patients was  $7.5 \pm 5.6$ .

The responses for each question of the DLQI and CDLQI were tabulated in **Table 7.1 and 7.2** respectively. Seven hundred and twenty eight adult patients (32.4%) reported a DLQI of more than 10, which indicated severe quality of life impairment due to psoriasis or its treatment (**Figure 7.1**). There were 124 adults (5.5%) who had a DLQI of more than 21 indicating extremely large effect on their quality of life by psoriasis. Nevertheless, 14.5% of adult patients reported no effect at all on their quality of life.

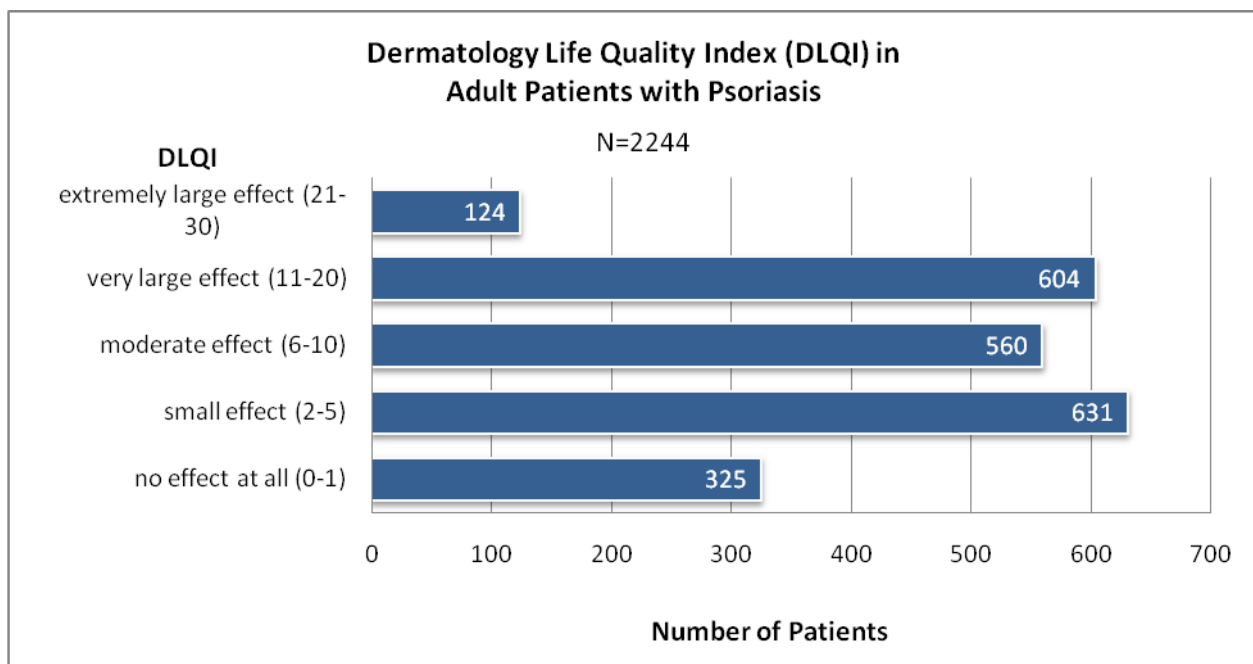
As shown in **Figure 7.2**, higher proportions of adult patients (10.9%) were very much affected by the symptoms of itch and pain due to psoriasis, and they felt very much embarrassed because of psoriasis. The aspect of life least affected by psoriasis was personal relationship in which 89.6% of the adult patients did not have or only have a little effect in this aspect.

In children/adolescents group, 28.3% of patients reported a CDLQI of more than 10 indicating very large or extremely large effect on QoL (**Figure 7.3**). There were four patients (2.2%) who had CDLQI of more than 21, reflecting extremely large effect of QoL. On the other hand, 16.1% child/adolescent patients had no effect at all on QoL.

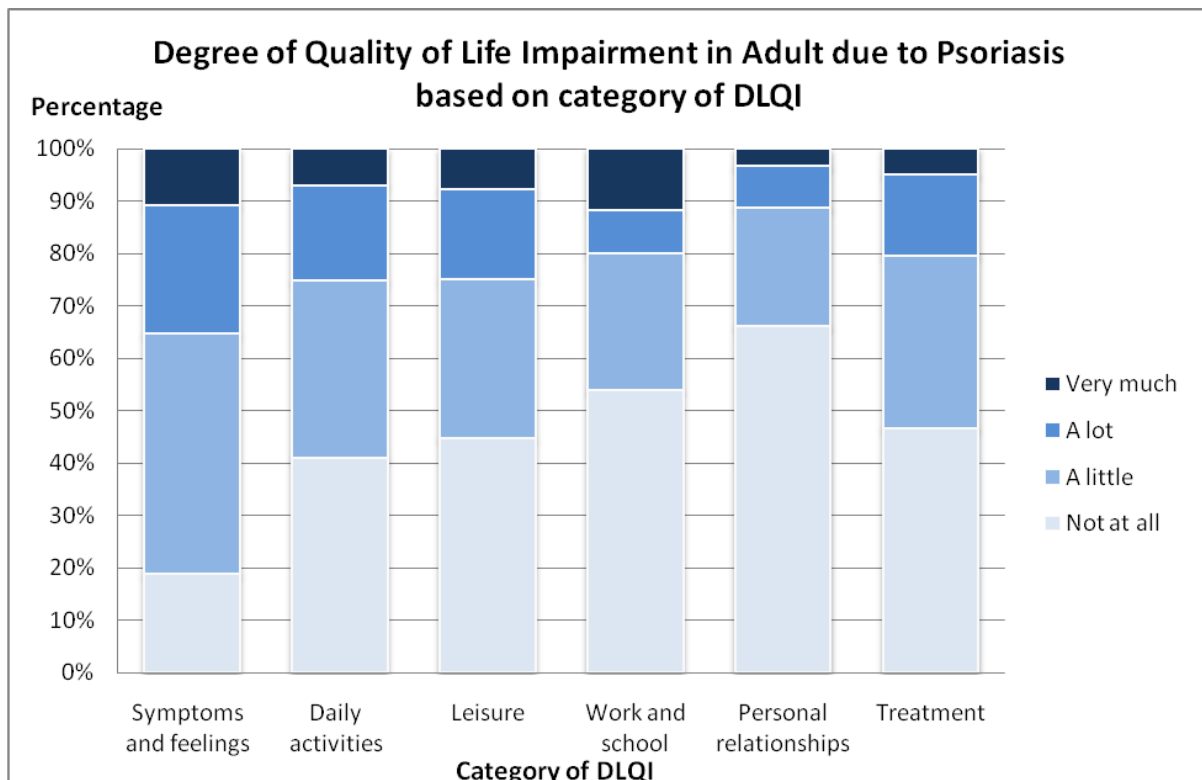
In child/adolescent patients, the category of CDLQI most affected was the symptoms and feeling (11.1%) and aspect of life least affected by psoriasis was personal relationship in which 83.9% of the children did not have or only have a little effect (**Figure 7.4**). These results are similar to that of the adult patients.

**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?	204 (9.0)	549 (24.3)	1218 (53.8)	293 (12.9)	-
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	297 (13.2)	542 (24.9)	819 (36.3)	601 (26.6)	-
3	Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?	153 (6.8)	400 (17.7)	715 (31.6)	919 (40.7)	73 (3.2)
4	Over the last week, how much has your skin influenced the clothes you wear?	151 (6.7)	391 (17.3)	755 (32.1)	895 (39.6)	68 (3.0)
5	Over the last week, how much has your skin affected any social or leisure activities?	161 (7.1)	389 (17.2)	725 (32.1)	920 (40.7)	65 (2.9)
6	Over the last week, how much has your skin made it difficult for you to do any sport?	171 (7.9)	362 (16.1)	570 (25.3)	782 (34.7)	363 (16.1)
7	Over the last week, has your skin prevented you from working or studying?	153 (7.2)	138 (6.5)	414 (19.4)	1044 (48.9)	387 (18.1)
8	Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?	93 (4.1)	223 (9.9)	587 (26.0)	1266 (56.1)	89 (3.9)
9	Over the last week, how much has your skin caused sexual difficulties?	56 (2.5)	101 (4.5)	340 (15.2)	1220 (54.4)	527 (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?	105 (4.7)	312 (13.9)	648 (28.9)	1058 (47.2)	120 (5.3)



**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?	13 (7.0)	55 (29.7)	98 (53.0)	19 (10.3)	-
2	Over the last week, how embarrassed or self conscious have you been because of your skin?	29 (15.7)	38 (20.5)	84 (45.4)	34 (18.4)	-
3	Over the last week, how much has your skin affected your friendships?	9 (4.9)	19 (10.3)	71 (38.4)	86 (46.5)	-
4	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	9 (4.9)	27 (14.7)	62 (33.7)	86 (46.7)	-
5	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	6 (3.3)	33 (17.9)	60 (33.6)	85 (46.2)	-
6	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	12 (6.5)	23 (12.4)	55 (29.7)	95 (51.4)	-
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?	7 (3.8)	26 (14.1)	62 (33.5)	90 (48.7)	-
8	Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?	10 (5.5)	22 (12.0)	46 (25.1)	105 (57.4)	-
9	Over the last week, how much has your sleep been affected by your skin problem?	11 (6.2)	23 (12.9)	52 (29.2)	92 (51.7)	-
10	Over the last week, how much of a problem has the treatment for your skin been?	9 (4.9)	27 (14.7)	59 (32.1)	89 (48.4)	-

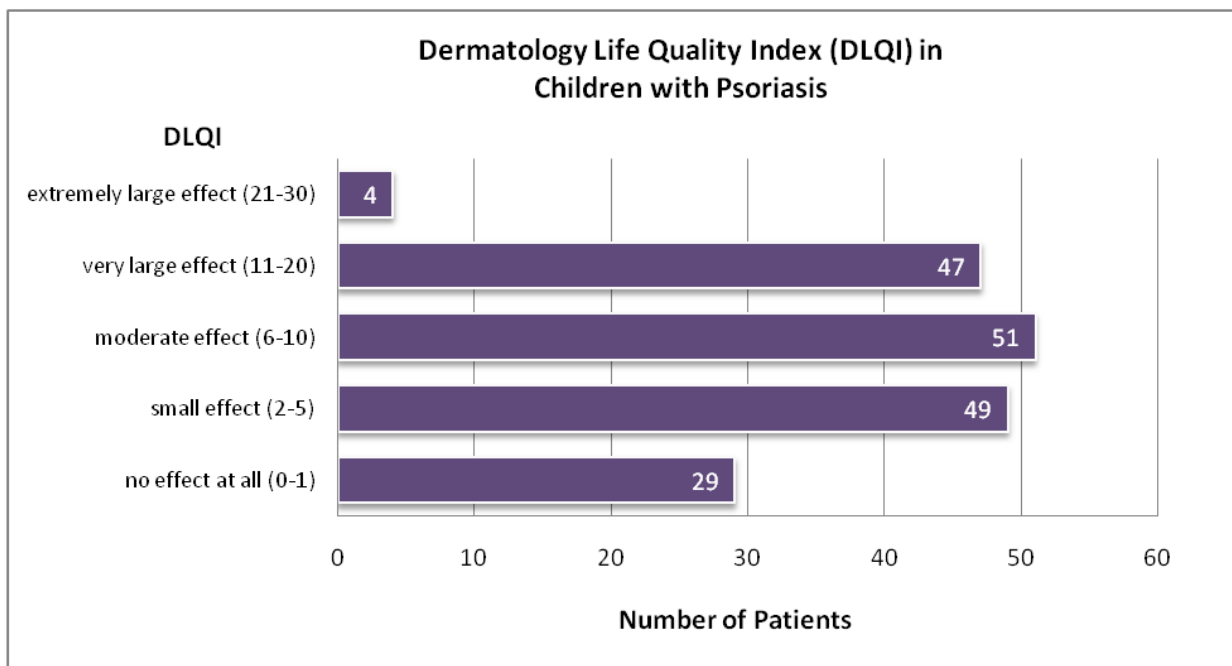


Figure 7.3 Quality of life in children/adolescents with psoriasis.

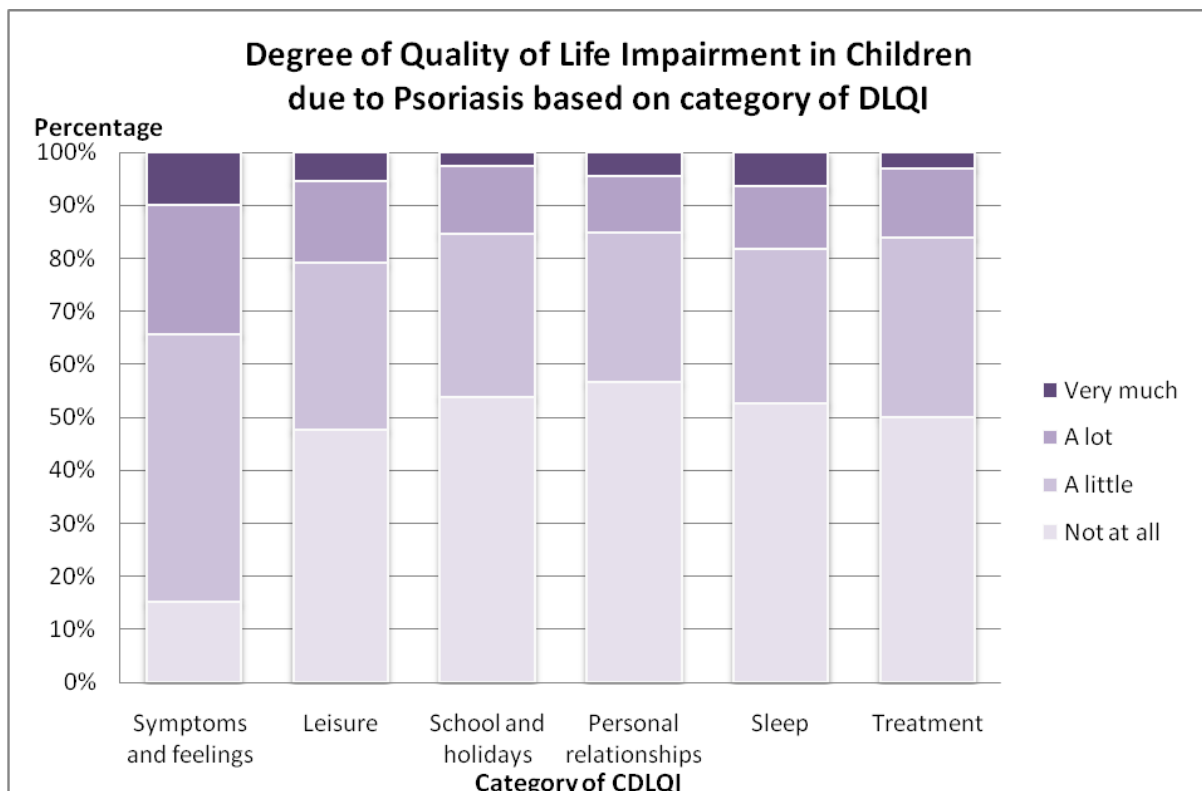


Figure 7.4 QoL impairment in child/adolescent psoriasis patients based on category of DLQI

## **CHAPTER 8**

## **OUTCOMES**

**Felix Yap Boon Bin**

**Pubalan Muniandy**

In this registry, follow-up data are to be collected every 6 months. Outcome of patients is 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 are assessed in terms of the extent of lesions, i.e. percentage of body surface area involvement, and lesional characteristics via a 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 2,499 psoriasis patients registered in MPR, follow-up data were obtained in 303 patients. The duration of follow-up was up to 6 months in 84 patients (27.7%), between 6 to 12 months in 209 patients (69.0%), and between 12 to 18 months in 10 patients (3.3%) (**Table 8.1**).

### **Extent of Psoriasis Lesions**

The extent of psoriasis lesions is 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 201 patients were evaluated for change in the extent of lesions. Of these patients, 56 patients (27.9%) had improvement by at least one scale, among which 14 (7%) had improvement by two scales. 114 patients (56.7%) had no improvement, and 31 patients (15.4%) had worsening by at least one scale (**Figure 8.1**). The subgroup of patients who attended follow-up between 6 to 12 months had the highest proportion of improvement in extent of lesions, i.e. 40/137 (29.2%). As shown in the survival curve **Figure 8.2**, only about 30% of patients had achieved two-scale improvement in the extent of skin lesions at 12 months of follow-up.

### **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. The overall mean total clinical skin score at baseline was  $10.23 \pm 2.51$ , and the mean score at follow-up was  $9.57 \pm 2.40$ . This gave an overall improvement in clinical skin score of  $0.65 \pm 2.57$ . The improvement in mean score was similar in all subgroups of patients with different intervals of follow-up. This relatively small degree of improvement is not surprising in view of the highly dynamic nature of the course of illness in psoriasis due to the potential influence by various aggravating factors.

Nine patients (3.1%) had improvement in skin scores by 25-50%, whereas 128 patients (44.4%) had modest improvement of less than 25%. None of them had improvement of more than 50%. No improvement of skin scores were detected in 77 patients (26.7%). Skin scores worsened in 74 patients (25.7%) (**Figure 8.3**).

There were about 70% of patients who achieved an improvement of skin score by at least 10% in the first 12 months of follow up as shown in the survival curve in **Figure 8.4**.

### Joint Pain

From a total of 35 patients who reported to have joint pain, 14 patients (40%) had improvement in joint pain as measured by the visual analogue scale. Of these patients, 5 patients (14.3%) had improvement of between 25% and 50%, and 9 patients (25.7%) had improvement of less than 25%. There was no improvement of joint pain in 11 patients (31.4%), while joint pain worsened in 10 patients (28.6%) (**Figure 8.5**). The overall mean reduction in the visual analogue scale for joint pain was  $0.37 \pm 1.73$ . From the survival curve in **Figure 8.6**, approximately 25% of patients achieved at least 10% reduction of joint pain after a follow-up period of 10 months.

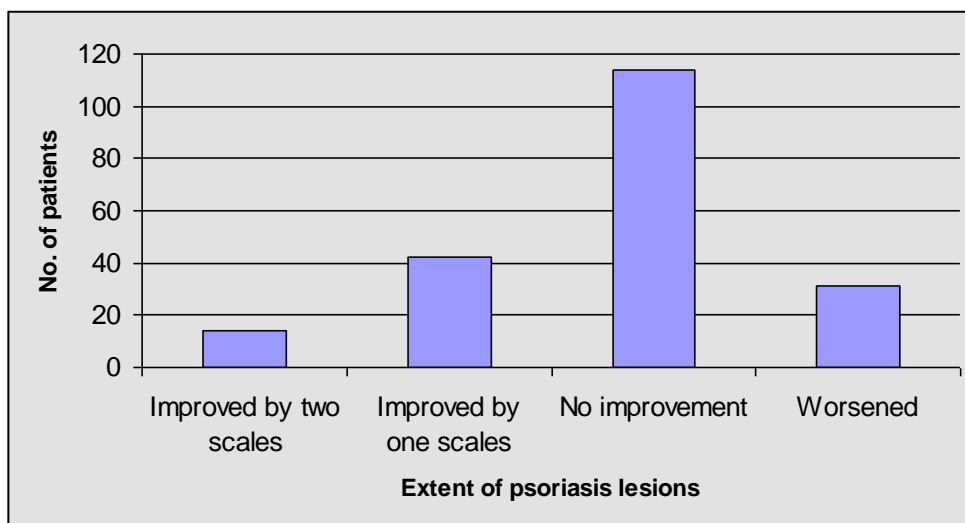
### Change in Quality of Life

In adult patients aged 17 years and above, we noted an overall improvement in the quality of life. A total of 237 adult patients were evaluated for change in quality of life by DLQI. A mean DLQI score reduction of  $1.71 \pm 5.75$  was noted in the first 6 months,  $1.27 \pm 5.61$  in 6 to 12 months, and  $1.38 \pm 5.01$  in 12 to 18 months follow-up periods. (**Table 8.2**) Fifty five patients (23.2%) had significant improvement in their DLQI score by at least 5, whereas 22 patients (9.3%) had significant worsening. (**Figure 8.7**)

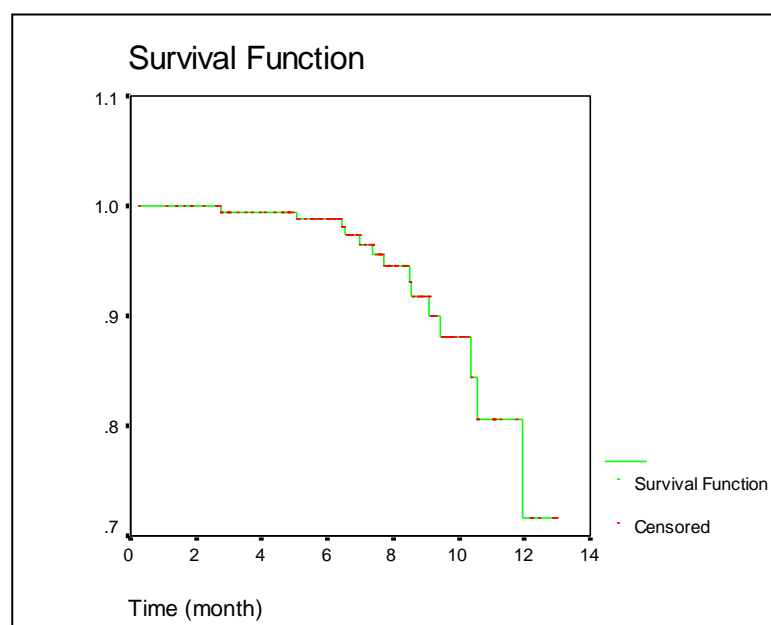
Improvement in the quality of life was also noted in 12 psoriasis patients aged less than 16 years. Mean reduction of Child DLQI was  $3.20 \pm 1.92$  in the first 6 months, and  $1.71 \pm 5.59$  in the 6 to 12 months follow-up interval. (**Table 8.2**) Three patients (25%) had a significant improvement of Child DLQI score by at least 5, while one patient worsened. This improvement was achieved within the first 7 months of follow-up as seen in the survival curve in **Figure 8.8**.

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

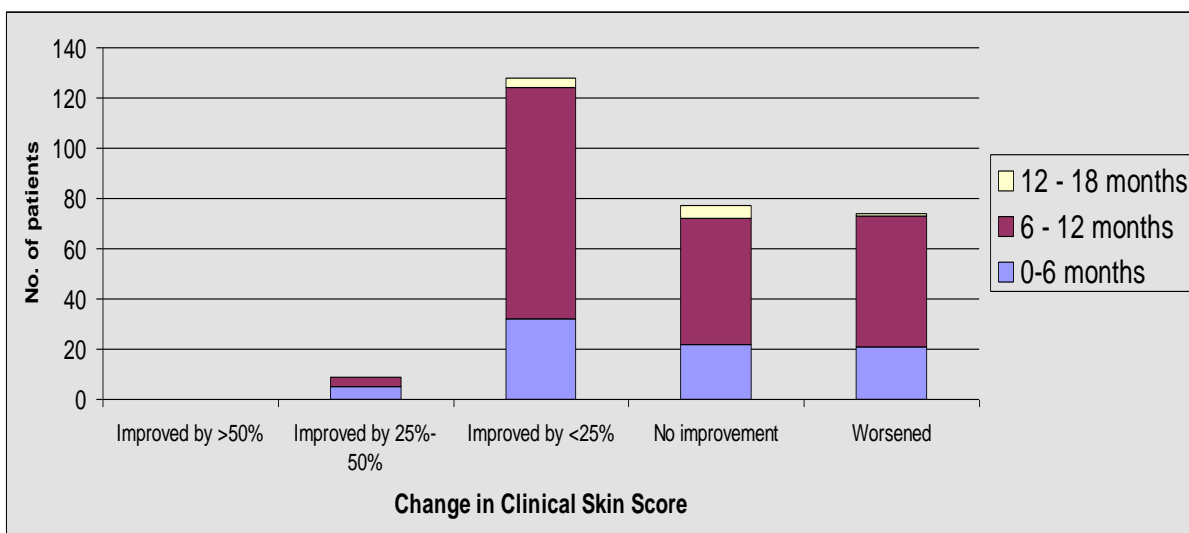
<b>Duration of follow-up</b>	<b>No.</b>	<b>%</b>
0 to 6 months	84	27.7
6 to 12 months	209	69.0
12 to 18 months	10	3.3
Total	303	100.0



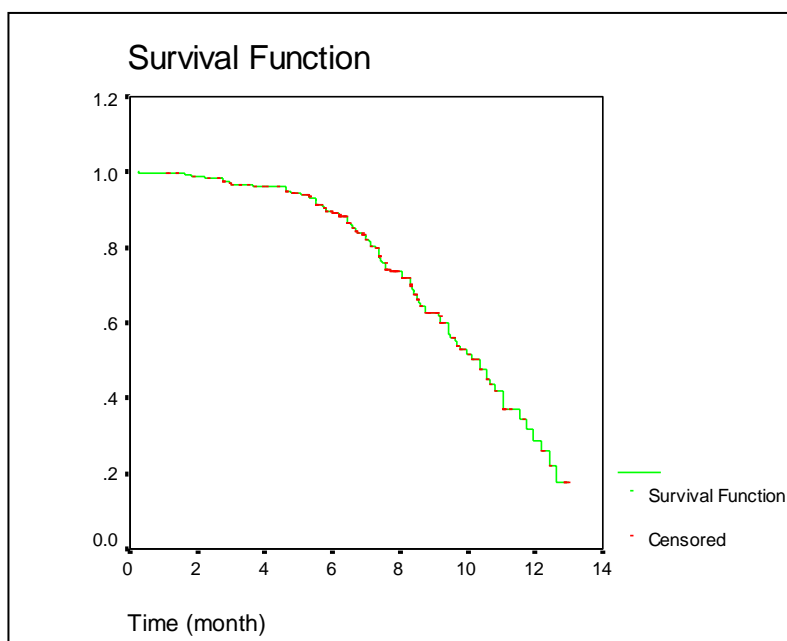
**Figure 8.1: Improvement in the extent of skin lesions**



**Figure 8.2: Survival curve for improvement of lesion extent by at least two scales.**

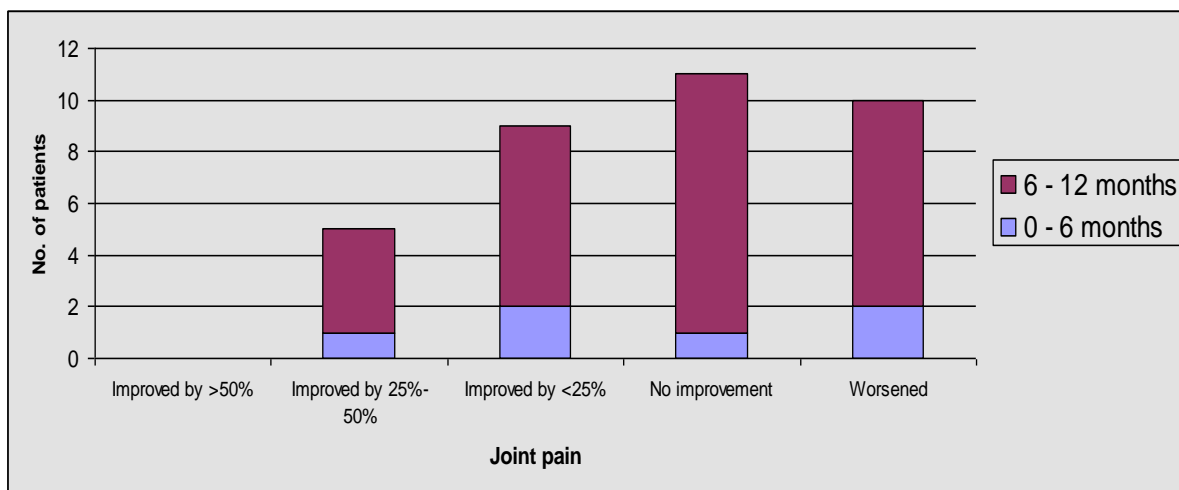


**Figure 8.3: Improvement in Clinical Skin Score.**

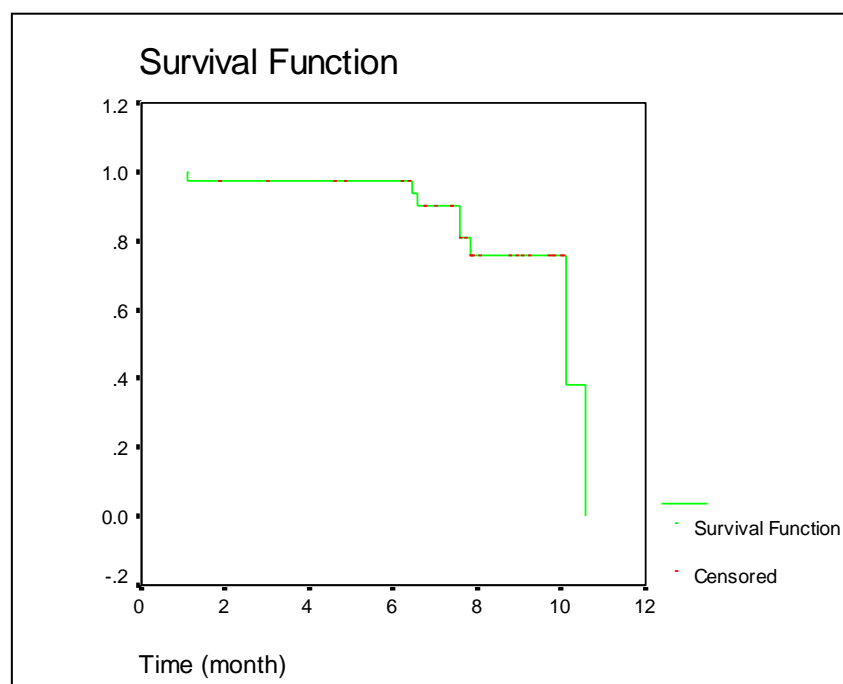


**Figure 8.4: Survival curve for the improvement of skin score by at least 10%.**





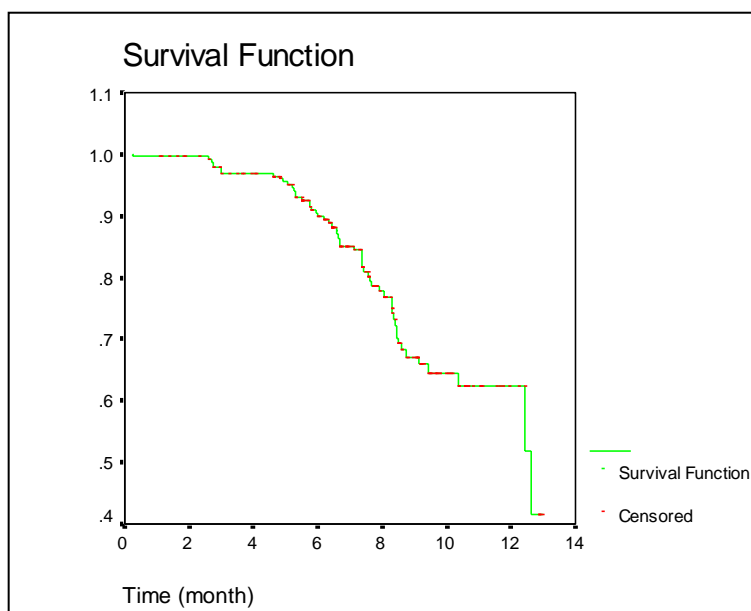
**Figure 8.5: Improvement in joint pain measured by visual analogue scale.**



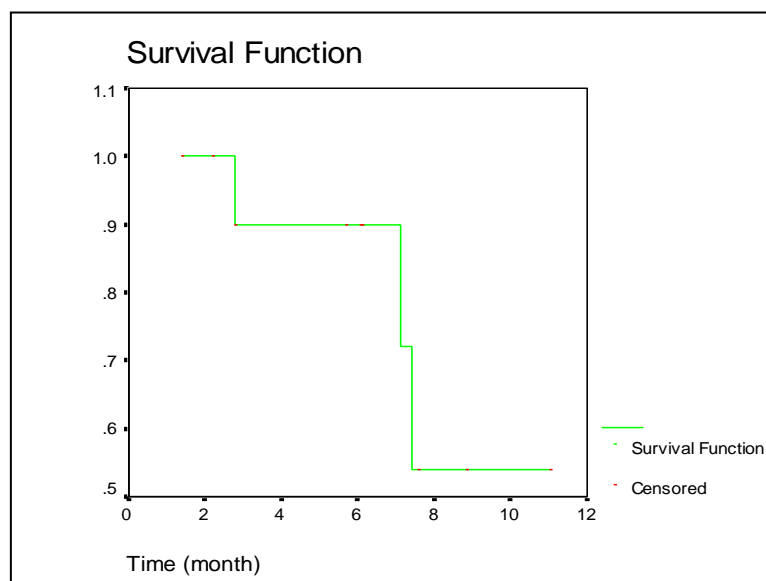
**Figure 8.6: Survival curve for improvement of joint pain by a reduction of at least 10% in visual analogue scale.**

**Table 8.2: Change in DLQI and CDLQI scores in psoriasis patients**

	0 – 6 months		6 – 12 months		12 – 18months	
	N	Mean	N	Mean	N	Mean
Change in DLQI (Adults)	72	-1.71±5.75	157	-1.27±5.61	8	-1.38±5.01
Change in CDLQI (Children/adolescents)	5	-3.20±1.92	7	-1.71±5.59	0	-



**Figure 8.7: Survival curve for improvement in DLQI score of at least 5 in adult psoriasis patients.**



**Figure 8.8: Survival curve for improvement of Child DLQI score by at least 5 in psoriasis patients aged 16 and below.**



**APPENDIX A: CASE REPORT FORM**

<b>Malaysian Psoriasis Registry Case Report Form</b>	<b>CONFIDENTIAL</b> For Office Use only: ID: <input style="width: 40px; height: 20px;" type="text"/> / <input style="width: 40px; height: 20px;" type="text"/> Centre: <input style="width: 100%; height: 20px;" 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.

Doctor's Name :	<input style="width: 100%;" type="text"/>
Name of Institution :	<input style="width: 100%;" type="text"/>

**SECTION 1: DEMOGRAPHIC DETAILS**

1. Patient visit date : (dd/mm/yyyy)	<input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/>	2. Type of visit :	<input type="radio"/> New Case <input type="radio"/> Follow-Up
3. Name of patient :	<input style="width: 100%;" type="text"/>		
4. NRIC :	MyKad/ MyKid: <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> Old ID: <input style="width: 20px; height: 20px;" type="text"/>		
	Other ID document No: <input style="width: 100%;" type="text"/> Specify document type (if others): <input type="radio"/> Registration number <input type="radio"/> Mother's IC <input type="radio"/> Work Permit <input type="radio"/> Clinic RN <input type="radio"/> Passport <input type="radio"/> Father's IC <input type="radio"/> Driver's Licence <input type="radio"/> Police ID Card <input type="radio"/> Birth Certificate <input type="radio"/> Armed Force ID <input type="radio"/> Hospital RN <input type="radio"/> Others		
5. Address : #	Town / City: <input style="width: 100%;" type="text"/> State: <input style="width: 100%;" type="text"/>		
6. Contact number : #	Homephone: <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> HP: <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/>		
7. Gender : #	<input type="radio"/> Male <input type="radio"/> Female	8. Date of birth : #	<input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/>
9. Ethnic group : #	<input type="radio"/> Malay <input type="radio"/> Chinese <input type="radio"/> Indian <input type="radio"/> Orang Asli <input type="radio"/> Others, specify : .....		
10. Nationality : #	<input type="radio"/> Malaysian <input type="radio"/> Non-Malaysian, specify .....		
11. Marital status : #	<input type="radio"/> Single <input type="radio"/> Married <input type="radio"/> Divorced <input type="radio"/> Widow <input type="radio"/> Widower		

**SECTION 2 : MEDICAL HISTORY**

1. Age when psoriasis started : #	<input style="width: 20px; height: 20px;" type="text"/>	2. Age when psoriasis diagnosed : #	<input style="width: 20px; height: 20px;" type="text"/>
3. Family member(s) with psoriasis : #	<input type="radio"/> No <input type="radio"/> Yes → (if YES, please tick ONE or MULTIPLE) <input type="checkbox"/> Father <input type="checkbox"/> Sibling(s) <input type="checkbox"/> Other relative, specify ..... <input type="checkbox"/> Mother <input type="checkbox"/> Children		
4. Aggravating factors : #	<input type="radio"/> No <input type="radio"/> Yes → (if YES, please tick ONE or MULTIPLE of the following) <input type="checkbox"/> Infection : ..... <input type="checkbox"/> Drugs : ..... <input type="checkbox"/> Topical Rx : ..... <input type="checkbox"/> Trauma <input type="checkbox"/> Stress <input type="checkbox"/> Sunlight <input type="checkbox"/> Hypocalcaemia <input type="checkbox"/> Pregnancy <input type="checkbox"/> Smoking <input type="checkbox"/> Alcohol		
5. Disease burden in the last 6 months :	a) No. of clinic visits due to psoriasis :	<input style="width: 20px; height: 20px;" type="text"/>	(enter 0 if none)
	b) No. of days off work due to psoriasis :	<input style="width: 20px; height: 20px;" type="text"/>	(enter 0 if none)
	c) No. of hospital admissions due to psoriasis :	<input style="width: 20px; height: 20px;" type="text"/>	(enter 0 if none)
6. Other diseases :	a) Ischaemic heart disease :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	e) Hyperlipidaemia : <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	b) Cerebrovascular disease (stroke) :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	f) Other diseases, specify : <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	c) Diabetes mellitus :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	↓ <input style="width: 100%; height: 20px;" type="text"/>
	d) Hypertension :	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	

\* Note : Items marked # above need not be entered during follow-up visits.

<b>Malaysian Psoriasis Registry Case Report Form</b>	<b>CONFIDENTIAL</b>
For Office Use only: ID: <input style="width: 100px;" type="text"/>	
Centre: <input style="width: 100px;" type="text"/>	

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

**SECTION 3: CLINICAL EXAMINATION**

1. (a) Height :	<input style="width: 30px;" type="text"/> <input style="width: 30px;" type="text"/> (cm)	(b) Weight:	<input style="width: 30px;" type="text"/> (kg)																														
2. Pregnant : <i>(for female)</i>	<input type="radio"/> No <input type="radio"/> Yes → Period of gestation : <input style="width: 30px;" type="text"/> weeks																																
3. Type of psoriasis :	<input type="radio"/> Plaque <input type="radio"/> Guttate <input type="radio"/> Pustular <input type="radio"/> Erythrodermic <input type="radio"/> Flexural / Inverse <input type="radio"/> Others,specify: <small>( Please select ONE predominant type)</small>																																
4. Severity :	Body surface area involved : <input type="radio"/> <2% <input type="radio"/> 2 - 10% <input type="radio"/> > 10% <input type="radio"/> Erythrodermic (>90%)																																
	<table border="1" style="width: 100%; border-collapse: collapse; font-size: x-small;"> <tr> <th style="width: 30%;">Body part</th> <th colspan="4">Grade of severity</th> </tr> <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 &amp; 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> </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	<p><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</p>	
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																													
5. 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																																
6. 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) Type :-																																
	1. Morning stiffness > 30 minutes	<input type="radio"/> No <input type="radio"/> Yes																															
	2. Enthesopathy	<input type="radio"/> No <input type="radio"/> Yes																															
	3. Oligo-/ Monoarthropathy	<input type="radio"/> No <input type="radio"/> Yes																															
	4. Distal hand joints arthropathy	<input type="radio"/> No <input type="radio"/> Yes																															
	5. Proximal hand joints arthropathy (rheumatoid- like)	<input type="radio"/> No <input type="radio"/> Yes																															
	6. Spondylitis / Sacroiliitis	<input type="radio"/> No <input type="radio"/> Yes																															
	7. Arthritis mutilans	<input type="radio"/> No <input type="radio"/> Yes																															
	c) Severity:-																																
	1. Pain	<input type="radio"/> No <input type="radio"/> Yes → Pain Score (1-10) : <input style="width: 30px;" type="text"/>																															
	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**

1. Topical therapy :	a) Tar preparation <input type="radio"/> No <input type="radio"/> Yes	e) Keratolytics e.g. salicylic acid <input type="radio"/> No <input type="radio"/> Yes	
	b) Vitamin D analogues e.g calcipotriol <input type="radio"/> No <input type="radio"/> Yes	f) Emollient <input type="radio"/> No <input type="radio"/> Yes	
	c) Dithranol (anthralin) <input type="radio"/> No <input type="radio"/> Yes	g) Others, specify	<input type="radio"/> No <input type="radio"/> Yes ↓
	d) Topical steroids (other than face / flexures) <input type="radio"/> No <input type="radio"/> Yes	<div style="border: 1px dashed black; height: 20px;"></div>	
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 :	a) Methotrexate <input type="radio"/> No <input type="radio"/> Yes	f) Biologics, specify <input type="radio"/> No <input type="radio"/> Yes ↓	
	b) Acitretin <input type="radio"/> No <input type="radio"/> Yes	<div style="border: 1px dashed black; height: 20px;"></div>	
	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	h) Others, specify <input type="radio"/> No <input type="radio"/> Yes ↓	
	e) Hydroxyurea <input type="radio"/> No <input type="radio"/> Yes	<div style="border: 1px dashed black; height: 20px;"></div>	

**SECTION 5: QUALITY OF LIFE**

1. Quality of Life :	Please instruct and assist patient in completing the attached DLQI form
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**\*\*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>Malaysian Psoriasis Registry</b> <b>Dermatology Life Quality Index (DLQI)</b> <b>(For Adults of Age Above 16)</b>	<b>CONFIDENTIAL</b> For Office Use only: ID: <input type="text"/> / <input type="text"/> Centre: <input type="text"/>
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*Instrucción: Where check boxes [✓] are provided, check (✓) one or more boxes. Where radio buttons [●] are provided, check (✓) one button only.*

Objektif laci 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	DLQI Score	Auto calculated
						<input type="text"/>	<input type="checkbox"/>
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 <input type="checkbox"/> Tidak No 不是 <input type="checkbox"/> Tidak Berkenaan Not Relevant 无关 *Jika "tidak", setakat manakah kulit anda menjadi masalah semasa kerja atau belajar? If "No", over the last week, how much has your skin been a problem at work or studying? 如果选择 "不是",那么上周内您的皮肤问题对工作或学习有多大影响呢?	<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? 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

<b>Malaysian Psoriasis Registry</b> <b>Children's Dermatology Life Quality Index (DLQI)</b> <b>(For age 5 to 16)</b>	<b>CONFIDENTIAL</b> 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 "✓"

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	DLQI Score: <input style="width: 40px;" type="text"/> Auto calculated
1) Setakat manakah kulit anda berasa gatal atau sakit? <i>Over the last week, how itchy, "scratchy", sore or painful has your skin been?</i> 你皮肤发痒、搔抓、破皮或疼痛的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2) Setakat manakah anda berasa malu, segan, susah hati atau sedih disebabkan oleh kulit anda? <i>Over the last week, how embarrassed or self conscious, upset or sad have you been because of your skin?</i> 你因为自己皮肤问题而感到难为情或害羞、苦恼或难过的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
3) Setakat manakah kulit anda mempengaruhi persahabatan anda? <i>Over the last week, how much has your skin affected your friendships?</i> 皮肤问题对你和朋友交往的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
4) Setakat manakah anda menukar atau memakai pakaian atau kasut kerana kulit anda? <i>Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?</i> 你因为皮肤问题而改变穿著不同或特定衣鞋的影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
5) Setakat manakah masalah kulit anda mempengaruhi anda untuk keluar, bermain atau melakukan hobi anda? <i>Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?</i> 皮肤的问题对你外出、玩耍、或从事休闲嗜好影响是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
6) Setakat manakah anda menjauhi diri daripada berenang atau melakukan sukan lain disebabkan oleh masalah kulit anda? <i>Over the last week, how much have you avoided swimming or other sports because of your skin trouble?</i> 你因为皮肤的问题而避免游泳或其他运动的影响程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
7) Pada minggu yang lalu, <i>Last week, 过去一星期</i> Pada hari persekolahan, setakat manakah kulit anda mempengaruhi kerja sekolah anda? <i>If school time: Over the last week, how much did your skin problem affect your school work?</i> 如果是上课时间, 皮肤问题影响你学校功课的程度是如何? ATAU OR 或 Pada hari cuti, setakat manakah kulit anda mengganggu anda menikmati cuti? <i>If holiday time: Over the last week, has your skin problem interfered with your enjoyment of the holiday?</i> 如果是放假期间, 皮肤问题干扰到你享受假期的兴致是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8) Setakat manakah orang memanggil anda dengan nama yang tidak baik, mengejek, menanya soalan-soalan atau menjauhi diri disebabkan oleh kulit anda? <i>Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?</i> 因为皮肤的问题使得别人骂你、嘲笑你、欺负你、问你问题或躲避你, 这种困扰程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
9) Setakat manakah masa tidur anda diganggu kerana masalah kulit? <i>Over the last week, how much has your sleep been affected by your skin problem?</i> 你因皮肤的问题而影响睡眠的程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
10) Setakat manakah rawatan kulit anda menjadi suatu masalah? <i>Over the last week, how much of a problem has the treatment for your skin been?</i> 针对皮肤所进行的治疗对你产生的困扰程度是如何?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

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



## **APPENDIX B: DATA MANAGEMENT**

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

### **Data Sources**

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

### **Data Collection**

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

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

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

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

Participation of SDP is entirely voluntary.

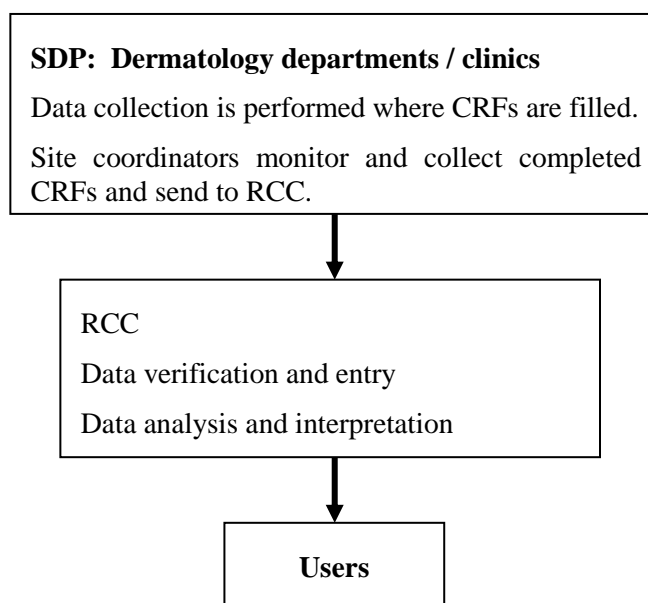
### Registry ICT Infrastructure and Data Centre

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

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

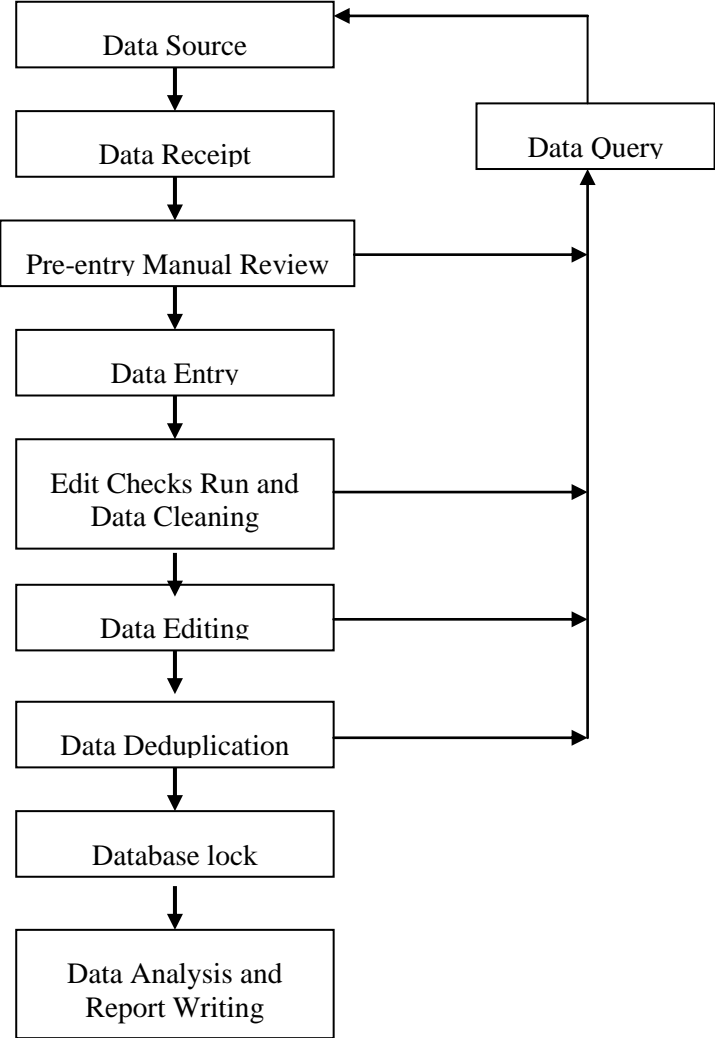
### Data Flow Process

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



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

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



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

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

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

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

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

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

### **Edit checks run and Data cleaning**

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

### **Legal Aspects and Confidentiality**

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

### **Data release policy**

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



## **APPENDIX C: STATISTICAL METHODS**

### **ANALYSIS SET**

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

1. **Patient notification between 2007 and 2008**

There were 2499 patients in the dataset. The analysis set was used for the analysis in Chapter 1, 2, 3, 4, 5 and 6, which comprises of 468 cases in year 2007 and 2031 cases in year 2008. The cases include first notification, second follow-up and third follow-up.

2. **Patient outcome between 2007 and 2008**

There were 303 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, descriptive summary and crosstabulations of the outcome variables. Bar and stacked bar charts were used to represent the distribution figures. The emphasis of the improvement of lesion extent, skin score, joint score and DLQI score were graphically presented using survival function curve.

## **STATISTICAL SOFTWARE**

Stata version 9.0 and SPSS 14.0



**APPENDIX D: PARTICIPATING CENTRE DIRECTORY**

<p><b>Hospital Kuala Lumpur</b> Department of Dermatology Hospital Kuala Lumpur Jalan Pahang 50586 Kuala Lumpur. Tel: 03-26155255 Fax: 03-26985927</p>	<p>Investigator: Dr Chang Choong Chor  Site- coordinator: -</p>
<p><b>Hospital Pulau Pinang</b> Dermatology Department, Hospital Pulau Pinang, Jalan Residensi, 10990 Pulau Pinang, Tel: 04-2293333 Fax: 04-2281737</p>	<p>Investigator: Dr Chan Lee Chin  Site- coordinator: Dr Tan Wooi Chiang</p>
<p><b>Hospital Sultanah Bahiyah, Alor Setar</b> Dermatology Department, Hospital Sultanah Bahiyah, Lebuhraya Darul Aman, 05100 Alor Setar, Kedah Tel: 04-7002295 Fax: 04-7323770</p>	<p>Investigator: Dr M. Balakrishnan  Site- coordinator: Dr Azlida Che Man</p>
<p><b>Hospital Tuanku Fauziah, Kangar</b> Dermatology Department, Hospital Tuanku Fauziah, Jalan Kolam,01000 Kangar, Perlis. Tel: 04-9763333 Fax: 04-9768239</p>	<p>Investigator: Dr M. Umaselvam  Site- coordinator: Dr Sharifah Fariah Syed Abas</p>
<p><b>Hospital Sultanah Fatimah, Muar</b> Dermatology Department, Hospital Pakar Sultanah Fatimah, Jalan Salleh, 84000 Muar, Johor. Tel: 06-9521901 Fax: 06-2810560</p>	<p>Investigator: Dr. Hj. Kader b Mohamed  Site- coordinator: Dr. Siti Khadijah Abdul Wahid</p>
<p><b>Hospital Tuanku Ja'afar, Seremban</b> Dermatology Department, Hospital Tuanku Ja`afar, Jalan Rasah 70300 Seremban, Negeri Sembilan. Tel: 06-7623333 Fax: 06-7625771</p>	<p>Investigator: Dr. Najeeb Ahmad Mohd Safdar  Site- coordinator: Dr.Prakash A/L Balasubramaniam</p>

Appendix D: Participating Centre Directory

<p><b>Hospital Queen Elizabeth, Kota Kinabalu</b> Dermatology Department, Hospital Queen Elizabeth, Karung Berkunci no 2029 , 88586 Kota Kinabalu, Sabah. Tel: 088-206316 Fax: 088-252823</p>	<p>Investigator: Dr Zaigham Mahmood  Site- coordinator: Dr Mervin George</p>
<p><b>Hospital Sungai Buloh</b> Dermatology Unit Hospital Sungai Buloh, Jalan Hospital, 47000 Sungai Buloh, Selangor Darul Ehsan. Tel: 03-61454333 Fax: 03-61454222</p>	<p>Investigator: Dr. Azahzuddin b Hamzah  Site- coordinator: Pn Rohayu Johar</p>
<p><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</p>	<p>Investigator: Dato' Dr Ong Cheng Leng  Site- coordinator: Pn Latipah Hj Othman</p>
<p><b>Hospital Raja Permaisuri Bainun, Ipoh</b> Dermatology Department, Jabatan Dermatologi, Hospital Ipoh, Jalan Hospital 30990 Ipoh, Perak. Tel: 05-2533333 Fax: 05-2531541</p>	<p>Investigator: Dr Agnes Heng Yoke Hui  Site- coordinator: Dr Tang Jyh Jong</p>
<p><b>Sarawak General Hospital</b> Dermatology Department, Hospital Umum Sarawak, Jln Tun Ahmad Zaidi Adruce, 93586 Kuching, Sarawak. Tel: 082-257555 Fax: 082-240767</p>	<p>Investigator: Dr Pubalan Muniandy  Site- coordinator: Dr Felix Yap Boon Bin</p>

<p><b>Hospital Tengku Ampuan Rahimah, Klang</b> Dermatology Department, Hospital Tengku Ampuan Rahimah, 41200 Klang, Selangor. Tel: 03-33723333 Fax: 03-3729089</p>	<p>Investigator: Datin Dr Saraswathy Devi Sinniah</p> <p>Site-coordinator: Dr Norasma bt Roslan</p>
<p><b>Hospital Sultanah Aminah, Johor Bahru</b> Jabatan Dermatologi, Hospital Sultanah Aminah Johor Bahru, Jalan Abu Bakar, 80100, Johor Bahru, Johor Tel: 07-2226920 Fax: 07-2242694</p>	<p>Investigator: Dr Choon Siew Eng</p> <p>Site- coordinator: Dr Tey Kwee Eng</p>
<p><b>Gleneagles Intan Medical Centre</b> Hope Skin and Laser Centre, Gleneagles Intan Medical Centre, 282 &amp; 286 Jalan Ampang, 50450 Kuala Lumpur. Tel: 03-42578112 Fax: 03-42576112</p>	<p>Investigator: Dr. Allan Yee Kim Chye</p> <p>Site- coordinator: -</p>