

Ministry of Health Malaysia

**NATIONAL DERMATOLOGY REGISTRY
(DermReg)**

The Ninth Annual Report of the MALAYSIAN PSORIASIS REGISTRY 2007-2016

Editors:

Suganthi Robinson

Kwan Zhenli

Rajalingam Ramalingam

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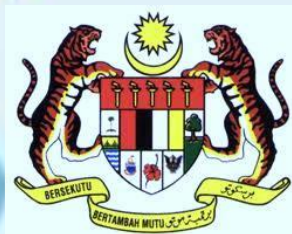
Nooraishah Ngah Saaya

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With contribution from:

Nurakmal Baharum

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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

ACE	Angiotensin-converting enzyme
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
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
IC	Identity card
ICT	Information and communications technology
MOH	Ministry of Health
MPR	Malaysian Psoriasis Registry
NA	Not available
NBUVB	Narrow-band ultraviolet B
NSSC	Northern Skin Specialist Clinic
NHMS	National Health and Morbidity Survey
NSAIDs	Nonsteroidal anti-inflammatory drugs
PI	Principal Investigator
PUVA	Psoralen and ultraviolet A
QoL	Quality of life
RCC	Registry Coordinating Centre
SC	Site Coordinator
SD	Standard deviation
SDP	Source data providers
SPSS	Statistical Package for the Social Sciences
SQL	Structured Query Language
STATA	Statistics and Data
UM	Universiti Malaya
UKM	Universiti Kebangsaan Malaysia

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

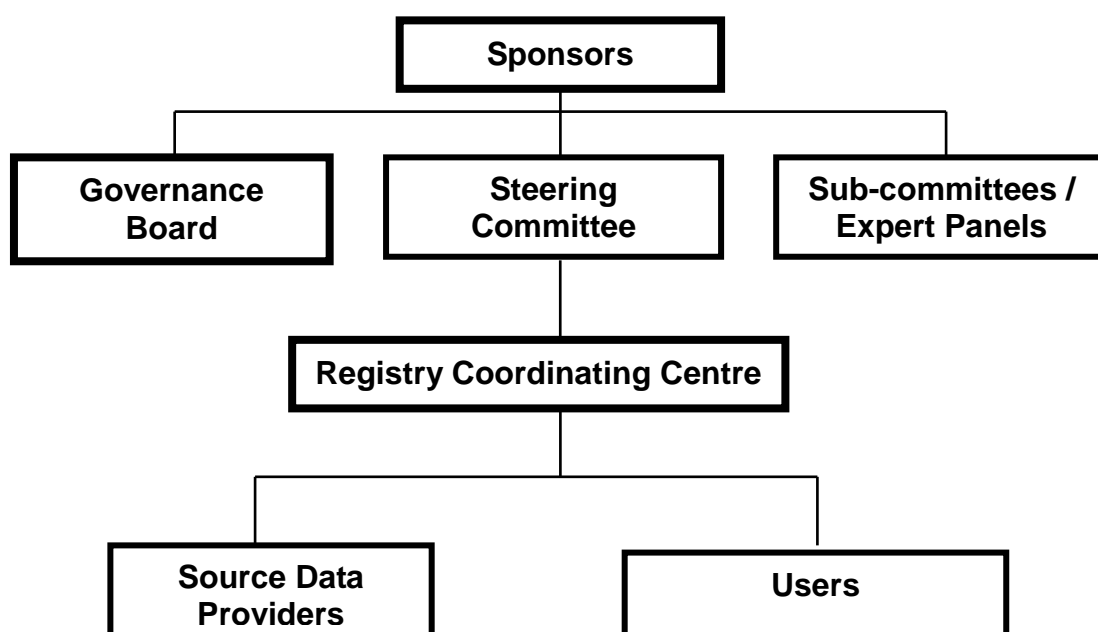
To establish a nationwide systematic prospective collection of data pertaining to skin diseases and dermatological services, in order to study the natural history, outcome and quality of life issues of skin diseases, as well as the effectiveness, safety and accessibility of various treatment modalities.

Specific Objectives:

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

ORGANISATION OF DermReg

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



SPONSORS

The DermReg is sponsored by:

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

GOVERNANCE BOARD

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

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

1. Dr. Suganthi Thevarajah (Chairperson)
National Head of Dermatological Services and Senior Consultant Dermatologist
Department of Dermatology
Hospital Kuala Lumpur
2. Dr. Chan Lee Chin
President of the Dermatological Society of Malaysia, and
Consultant Dermatologist
Northern Skin Specialist Clinic (NSSC)
Bayan Lepas, Pulau Pinang
3. 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. Suganthy Robinson	Hospital Kuala Lumpur
2.	Dr. Kwan Zhenli	Universiti of Malaya Medical Centre
3.	Dr. Rajalingam Ramalingam	Hospital Tengku Ampuan Afzan, Kuantan
4.	Dr. Yeoh Chin Aun	Hospital Sultanah Bahiyah, Alor Setar
5.	Dr. Voo Sook Yee @ Michelle	Hospital Queen Elizabeth, Kota Kinabalu
6.	Dr. Tang Min Moon	Hospital Kuala Lumpur
7.	Dr Felix Yap Boon Bin	Sunway Medical Centre
8.	Dr. Dawn Angelia Ambrose	Hospital Ampang

REGISTRY COORDINATING CENTRE

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

Registry Manager	Mrs Nooraishah Ngah Saaya
Biostatisticians	Ms Nurakmal bt Baharum CRC
Database Administrator	Ms Lim Jie Ying Altus Solutions Sdn Bhd

SOURCE DATA PROVIDERS (SDP)

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

Source Data Providers for Malaysian Psoriasis Registry (MPR)

No.	Source Data Provider	Investigator
1.	Hospital Kuala Lumpur	Dr. Suganthi Robinson
2.	Hospital Pulau Pinang	Dr. Tan Wooi Chiang
3.	Hospital Sultanah Bahiyah, Alor Setar	Dr. Yeoh Chin Aun
4.	Hospital Tuanku Fauziah, Perlis	Dr. Hassanin Husseyne Hilmi
5.	Hospital Sultanah Fatimah, Muar	Dr. Noreen Md Arus
6.	Hospital Tuanku Jaafar, Seremban	Dr. Najeeb Ahmad Mohd Safdar
7.	Hospital Queen Elizabeth, Kota Kinabalu	Dr. Voo Sook Yee @ Michelle
8.	Hospital Sungai Buloh	Dr. Norli Marwyne Mohd Noor
9.	Hospital Tengku Ampuan Afzan, Kuantan	Dr. Rajalingam Ramalingam
10.	Hospital Permaisuri Bainun, Ipoh	Dr. Tang Jyh Jong
11.	Hospital Umum Sarawak, Kuching	Dr. Pubalan Muniandy
12.	Hospital Tengku Ampuan Rahimah, Klang	Dr. Ng Ting Guan
13.	Hospital Melaka	Dr. Preamala Gunabalasingam
14.	Prince Court Medical Centre	Dr. Gangaram Hemandas
15.	Gleneagles Intan Medical Centre	Dr. Chang Choong Chor
16.	Hospital Sultanah Aminah, Johor Bahru	Dr. Tey Kwee Eng
17.	UKM Medical Centre	Dr. Norazirah Md Nor
18.	UM Medical Centre	Dr. Kwan Zhenli
19.	Hospital Raja Perempuan Zainab II	Dr. Wan Noor Hasbee Wan Abdullah
20.	Hospital Ampang, Selangor	Dr. Dawn Ambrose
21.	Hospital Selayang, Selangor	Dr. Benji Teoh Tze Yuen
22.	Hospital Putrajaya	Dr. Nazatul Shima Abdul Rahim
23.	Hospital Serdang (March 2015)	Dr. Moonyza Akmal Bt Ahmad Kamil
24.	Hospital Sultan Ismail, Johor Bahru (September 2016)	Dr. Latha Selvarajah
25.	Hospital Sultan Haji Ahmad Shah, Temerloh (May 2017)	Dr. Rajalingam Ramalingam

26.	Hospital Jerantut (May 2017)	Dr. Rajalingam Ramalingam
27.	Hospital Jengka (May 2017)	Dr. Rajalingam Ramalingam
28.	Hospital Sultanah Zahirah, Kuala Terengganu (September 2017)	Dr. Nor Azura Mohamad
29.	Hospital Duchess of Kent, Sandakan (October 2018)	Dr. Voo Sook Yee @ Michelle
30.	Hospital Tawau (October 2018)	Dr. Voo Sook Yee @ Michelle
31.	Hospital Lahad Datu (October 2018)	Dr. Voo Sook Yee @ Michelle

UM = Universiti Malaya

UKM = Universiti Kebangsaan Malaysia

OFFICIAL WEBSITE OF DermReg

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



About DermReg

Organisation

Governance Board

Steering Committee

Registry Coordinating Centre

Source Data Providers (SDP)

Publications

News & Events

Data Request

Links

eDermReg (MPR, Skin Biopsy)

eCUSUM



Welcome to National Dermatology Registry (DermReg)

National Dermatology Registry (DermReg) is an ongoing systematic collection, analysis and interpretation of data pertaining to skin diseases and related services in Malaysia. This will enable us to know the 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, a common disease, is a chronic, T cell mediated skin disorder characterized by erythematous scaly 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 demographic data, types of psoriasis, its severity, aggravating factors, associated joint and nail disease 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 (CRF) 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 CRF was introduced and a new web-based centralised database 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 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 sociodemographic profiles of patients with psoriasis.
 2. To determine the disease burden attributed to psoriasis.
 3. To provide information for planning of medical services, facilities, human resource 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 2016, a total of 17,071 patients with psoriasis from 24 dermatology centres (20 government hospitals, 2 private centres and 2 university hospitals) were registered.

Demographic Characteristics of Patients

In adult patients, male-to-female ratio was 1.3:1. Ethnic distribution is as follows: Malay 50.4%, Chinese 21.5%, Indian 17.6%, other ethnic groups 10.5%. Mean age at notification was 45.17 ± 15.87 years (range 18 - 97 years). Most patients (98.5%) were Malaysian citizens.

In paediatric patients, male-to-female ratio was 0.7:1. Ethnic distribution is as follows: Malay 69.1%, Chinese 8.0%, Indian 12.7%, other ethnic groups 10.2%. Mean age at notification was 13.06 ± 3.58 years (range 0 - 17 years). Most patients (99.8%) were Malaysian citizens.

Medical History

In adult patients, mean age of onset of psoriasis was 35.21 ± 16.10 years (range 0 – 88 years). Family history of psoriasis was present in 22.6% of the patients. Among those who had positive family history, family members affected were either of their parents in 40.8%, siblings in 35.2% and children in 11.3%.

In the paediatric population, 21.1%, of them had at least one family member with psoriasis. Of these, 35.3% had either of their parents affected with psoriasis.

Both populations (50.2% of adults and 38.2% of paediatric patients) reported one or multiple factors which aggravated their psoriasis. The commonest aggravating factors were stress (65.6% in adults, 54.8% in paediatric patients), sunlight (32.9% in adults, 40.5% in paediatric patients) and infection (13.3% in adults, 18.5% in paediatric patients).

Comorbidities

In adult psoriasis patients, 33.1% were overweight and 23.6% were obese, 26.3% had hypertension, 18.5% had hyperlipidaemia, 17.4% had diabetes mellitus, 5.6% had ischaemic heart disease and 1.6% had previous history of stroke. In children and adolescents aged below 18 years with psoriasis, the most prevalent co morbidity was overweight or obesity i.e. body mass index (BMI) at or above 85th centile (24.0 %), followed by bronchial asthma (2.0%).

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

Clinical Presentation

The commonest clinical type of psoriasis in adult and paediatric patients was plaque psoriasis (86.6% and 82.1%, respectively). This was followed by guttate psoriasis (3.1% and 7.3% respectively), erythrodermic psoriasis (1.8% and 0.7% respectively), flexural/inverse psoriasis (0.4% and 0.9% respectively) and palmoplantar non-pustular (0.4% and 0.4% respectively). In adult patients, (15.6%) had body surface area involvement of 10% or less. The pattern remains the same in child population, i.e. <5% of severity in 17.3%, followed by 5-10% of severity in 33.3% of patients.

Psoriatic arthropathy was reported in 14.1% of adult patients and only 2.4% in paediatric population. The commonest type of psoriatic arthropathy in adult patients was oligo/monoarthropathy (38.9%) followed by distal hand joints arthropathy (30.8%) and rheumatoid-like symmetrical polyarthropathy (29.6%).

About two-thirds (57.7%) of the adult patients had nail changes associated with psoriasis. Among patients who had nail disease, pitting was the commonest (72.5%), followed by onycholysis (48.0%), discolouration (30.9%) and subungual hyperkeratosis (12.9%). Total nail dystrophy was found in 4.9% of patients with nail disease. In the paediatric group, 37.9% of them had nail involvement with pitting being the commonest (88.2%) followed by onycholysis (25.1%).

Treatments received in the past 6 months

Majority of the patients (95.7% in adult, 94.2% in paediatric) were on topical treatment. Topical corticosteroids was the commonest prescribed (82.4% in adult, 77.2% in paediatric), followed by tar preparations in 68.3% (adult) and 64.8% in paediatric, emollients in 72.3% (adult) and 63.7% (paediatric) patients. 2.9% of adult patients and 1.2% of paediatric patients received phototherapy. Of the patients who had phototherapy, narrowband UVB (NBUVB) was the commonest used (93.3% in adult, 81.3 in paediatric). Systemic therapy was given in 17.7% of adult patients and in 5.4% paediatric patients. The most frequently used systemic therapy was methotrexate (72.6% in adult, 52.1% in paediatric), followed by acitretin (18.7% in adult, 35.2% in paediatric).

Quality of Life

Measurement of quality of life using Dermatology Life Quality Index (DLQI) or child DLQI (CDLQI) was performed in 8,905 adult patients (aged 17 and above) and 403 children/adolescent patients (aged 5 to 16). The mean DLQI score was 8.67 ± 6.57 for adult patients and the mean CDLQI was 7.83 ± 5.44 for children/adolescent patients.

A DLQI of more than 10 was reported by 27.2% of the adult patients, and 18.9% of the paediatric patients reported a CDLQI of more than 12, indicating significant impact on quality of life (QoL) due to psoriasis or its treatment. Symptoms and feelings was the DLQI domain most affected by both adult and paediatric patients (40.2% of the adult patients and 40.0% of the paediatric patients scored 2 points or more per question in this domain).

CHAPTER 1

STOCK AND FLOW

During the period from October 2007 to December 2016, a total of 17,071 patients were registered to the registry. The number of notified patients gradually increased throughout the period (**Figure 1.1**). Of the overall population, 7.7% (n=1,318) patients belong to the age group < 18 years and were categorized as paediatric population, 92.3% (n=15,753) patients belong to the age group \geq 18 years of age and were categorized as the adult population.

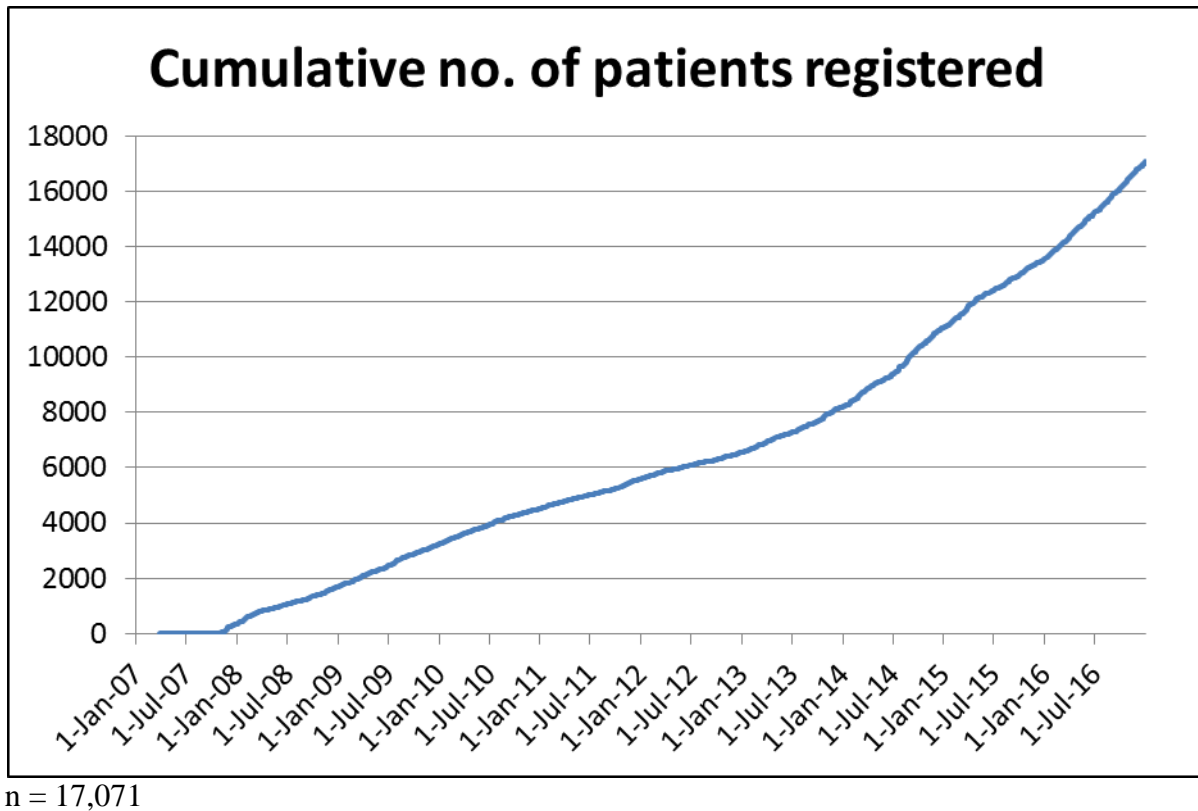


Figure 1.1 Psoriasis patients notified to the Malaysian Psoriasis Registry

A total of 24 dermatology centres (20 government hospitals, 2 private centres and 2 university hospitals) participated in the MPR. In the adult category, Hospital Kuala Lumpur notified the highest number of patients. This was followed by Hospital Queen Elizabeth, Kota Kinabalu and Hospital Tengku Ampuan Rahimah, Klang (**Table 1.1**). In the paediatric group, Hospital Sultanah Bahiyah, Alor Setar notified the highest number of paediatric patients. This was followed by Hospital Kuala Lumpur and Hospital Tengku Ampuan Rahimah, Klang (**Table 1.2**).

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

No	Reporting Centre	No. of patients										Total
		2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	
1	Hospital Kuala Lumpur	72	194	204	132	66	79	308	492	501	481	2529
2	Hospital Queen Elizabeth	23	104	107	91	104	76	111	163	317	375	1471
3	Hospital Tengku Ampuan Rahimah	0	78	169	140	88	75	100	257	266	217	1390
4	Hospital Pulau Pinang	38	132	269	106	107	9	108	95	262	187	1313
5	Hospital Sultanah Bahiyah	94	177	77	60	48	76	79	344	104	124	1183
6	Hospital Melaka	0	0	130	268	150	126	121	90	57	120	1062
7	Hospital Umum Sarawak	13	179	92	46	33	51	110	150	147	215	1036
8	Hospital Raja Permaisuri Bainun	60	55	104	39	73	115	90	165	148	184	1033
9	Hospital Sultanah Aminah	0	34	135	63	62	65	182	284	7	59	891
10	Hospital Tengku Ampuan Afzan	1	57	55	75	70	48	98	104	62	293	863
11	Hospital Sultanah Fatimah	10	62	35	47	45	66	12	72	74	112	535
12	Hospital Tuanku Jaafar	0	52	0	30	53	3	83	74	84	128	507
13	Hospital Selayang	0	0	0	0	0	0	1	206	106	153	466
14	Hospital Serdang	0	0	0	0	0	0	0	0	0	315	315
15	Hospital Tuanku Fauziah	0	35	37	42	23	16	6	10	61	67	297
16	Hospital Putrajaya	0	0	0	0	0	0	0	72	69	77	218
17	Hospital Ampang	0	0	0	0	3	3	10	87	55	0	158
18	Hospital Raja Perempuan Zainab II	0	0	0	0	9	8	86	17	14	24	158
19	Hospital Sultan Ismail	0	0	0	0	0	0	0	0	0	146	146
20	UM Medical Centre	0	0	0	0	32	23	2	0	0	2	59
21	UKM Medical Centre	0	0	0	15	0	21	4	1	0	0	41
22	Prince Court Medical Centre	0	0	6	17	3	2	2	2	4	0	36
23	Hospital Sungai Buloh	4	23	1	0	0	0	0	2	0	0	30
24	Gleneagles Medical Centre	0	10	6	0	0	0	0	0	0	0	16
Total		315	1192	1427	1171	969	862	1513	2687	2338	3279	15753

n = 15,753

UM = Universiti Malaya

UKM = Universiti Kebangsaan Malaysia

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

No	Reporting Centre	No. of patients										Total
		2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	
1	Hospital Sultanah Bahiyah	11	30	11	11	9	9	20	21	16	10	148
2	Hospital Kuala Lumpur	9	23	14	8	8	10	13	12	22	28	147
3	Hospital Tengku Ampuan Rahimah	0	9	18	26	13	7	12	23	18	7	133
4	Hospital Umum Sarawak	2	26	8	5	4	8	10	15	12	31	121
5	Hospital Queen Elizabeth	1	10	13	10	6	7	11	13	25	18	114
6	Hospital Tengku Ampuan Afzan	0	7	12	10	16	11	13	6	10	25	110
7	Hospital Melaka	0	0	7	13	19	11	14	8	8	9	89
8	Hospital Sultanah Aminah	0	2	8	5	4	7	18	27	1	8	80
9	Hospital Pulau Pinang	1	12	10	4	2	0	8	8	13	6	64
10	Hospital Tuanku Jaafar	0	5	0	6	8	0	8	2	10	17	56
11	Hospital Sultanah Fatimah	3	8	2	6	4	7	2	4	5	14	55
12	Hospital Raja Permaisuri Bainun	4	3	8	2	2	11	5	10	4	4	53
13	Hospital Tuanku Fauziah	3	9	4	5	3	3	2	1	1	4	35
14	Hospital Selayang	0	0	0	0	0	0	0	13	5	10	28
15	Hospital Serdang	0	0	0	0	0	0	0	0	0	18	18
16	Hospital Ampang	0	0	0	0	0	0	2	8	5	0	15
17	Hospital Raja Perempuan Zainab II	0	0	0	0	0	0	7	5	1	1	14
18	Hospital Sultan Ismail	0	0	0	0	0	0	0	0	0	13	13
19	Hospital Sungai Buloh	3	5	0	2	0	0	0	0	0	0	10
20	Hospital Putrajaya	0	0	0	0	0	0	0	2	0	5	7
21	Gleneagles Medical Centre	0	4	0	0	0	0	0	0	0	0	4
22	UM Medical Centre	0	0	0	0	2	0	0	0	0	0	2
23	UKM Medical Centre	0	0	0	1	0	0	0	0	0	0	1
24	Prince Court Medical Centre	0	0	0	0	0	0	1	0	0	0	1
TOTAL		37	153	115	114	100	91	146	178	156	228	1318

n = 1,318

UM = Universiti Malaya

UKM = Universiti Kebangsaan Malaysia

There were a total of 17,071 notifications of patients with psoriasis in the MPR with new cases and follow-up treatment. 10,028 (63.7%) of the adult patients were notified once, and 5,725 (36.3%) were notified more than once (**Table 1.3**). In the paediatric population, 1,007 (76.4%) of the patients were notified once and 311 (23.6%) of them had more than one notification (**Table 1.4**).

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

Year	No.	%
Entry notification	10028	63.7
Entry and one follow-up notifications	2622	16.6
Entry and 2 follow-up notifications	1287	8.2
Entry and 3 follow-up notifications	780	5.0
Entry and 4 follow-up notifications	433	2.7
Entry and 5 follow-up notifications	258	1.6
Entry and 6 follow-up notifications	156	1.0
Entry and 8 follow-up notifications	89	0.6
Entry and 9 follow-up notifications	52	0.3
Entry and 10 follow-up notifications	30	0.2
Entry and 11 follow-up notifications	7	0.1
Entry and 12 follow-up notifications	8	0.1
Entry and 13 follow-up notifications	3	0.0
Total	15753	100.0

n = 15,753

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

Year	No.	%
Entry notification	1007	76.4
Entry and one follow-up notifications	200	15.2
Entry and 2 follow-up notifications	59	4.5
Entry and 3 follow-up notifications	32	2.4
Entry and 4 follow-up notifications	13	1.0
Entry and 5 follow-up notifications	7	0.5
Entry and 6 follow-up notifications	0	0.0
Entry and 8 follow-up notifications	0	0.0
Entry and 9 follow-up notifications	0	0.0
Entry and 10 follow-up notifications	0	0.0
Total	1318	100.0

n = 1,318

CHAPTER 2

CHARACTERISTICS OF PATIENTS

In adult patients with psoriasis, 98.5% of the population was Malaysian. Malays comprised the majority (50.4%), followed by Chinese (21.5%), Indians (17.6%), other ethnic groups (10.4%) and Orang Asli (0.1%) (**Table 2.1**). There were more males than females (56.9% and 43.1% respectively), with a male to female ratio of 1.3:1 (**Figure 2.1**).

The mean age of the adult patients was 45.17 ± 15.87 years with a range from 18 to 97 years. The majority were married (70.1%), (23.4%) were single, and the rest, either divorced or widowed (**Table 2.1**).

Most paediatric patients (99.8%) with psoriasis were Malaysian. Of the data analysed, (69.1%) paediatric patients were Malays followed by Indian in (12.7%), Chinese in (8.0%) and (10.2%) belonging to other ethnic groups (**Table 2.2**). Majority or 782 patients of paediatric patients were females (59.3%), while 536 were males (40.7%) (**Figure 2.2**).

The mean age of the paediatric population was 13.06 ± 3.58 years (0-17 years) (**Table 2.2**).

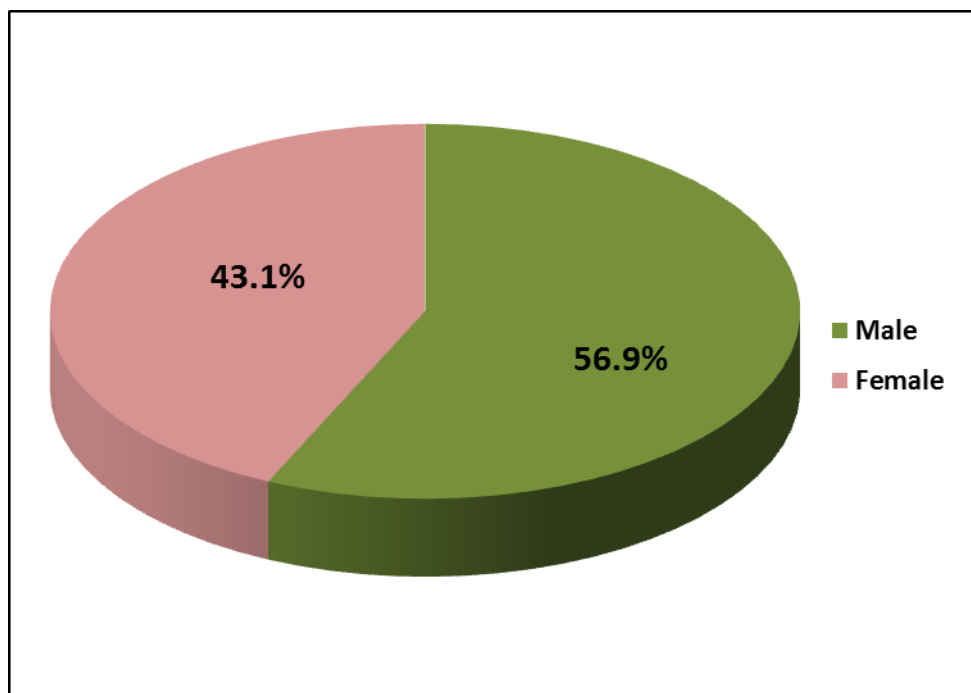
Table 2.1 Demographics of adult and paediatric patients with psoriasis

Patient characteristics		Adult		Paediatric	
		n	%	n	%
Nationality	Malaysian	15512	98.5	1316	99.8
	Non-Malaysian	241	1.5	2	0.2
Ethnic distribution	Malay	7937	50.4	911	69.1
	Chinese	3382	21.5	106	8.0
	Indian	2771	17.6	167	12.7
	Orang Asli	17	0.1	4	0.3
	Others	1646	10.4	130	9.9
Gender	Male	8957	56.9	536	40.7
	Female	6796	43.1	782	59.3
Marital status	Single	3683	23.4	1302	98.8
	Married	11046	70.1	2	0.2
	Divorced	155	1.0	-	-
	Widowed	304	1.9	-	-
	NA	565	3.6	14	1.1
Age at notification (years)	Mean \pm SD	45.17 ± 15.876		13.06 ± 3.58	
	(Range)	(18 - 97)		(0-17)	

n (Adult) = 15,753

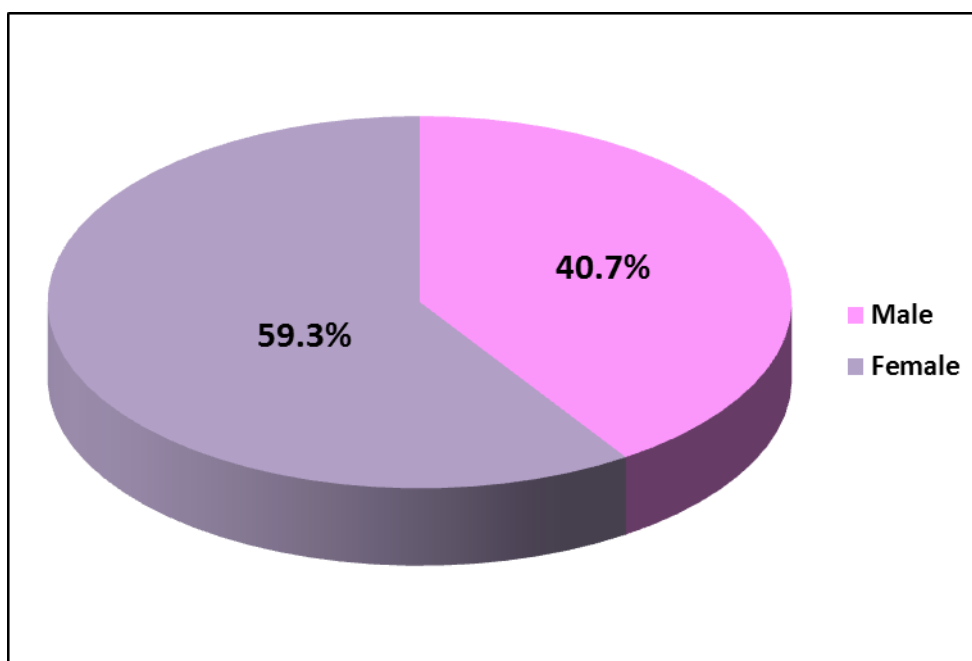
n (Paediatric) = 1,318

SD = Standard deviation



n = 15,753

Figure 2.1 Gender distribution of adult patients with psoriasis



n = 1,318

Figure 2.2 Gender distribution of paediatric patients with psoriasis

CHAPTER 3

MEDICAL HISTORY

Onset of Psoriasis

Psoriasis may first appear at any age. The mean age of onset in our cohort for adult patients was 35.21 ± 16.10 years with a wide range from 0 to 88 years. The mean age of onset was 10.14 ± 4.32 years in the paediatric population (0-17). In the adult population, the mean age at which psoriasis was first diagnosed was 37.56 ± 15.95 years. In the paediatric category, the mean age at which psoriasis was first diagnosed was 11.35 ± 4.13 years (**Table 3.1, Table 3.2**).

Looking at the age of onset of psoriasis in adult patients, 3,502 patients had the onset of psoriasis between 21-30 years old, followed by 2,992 patients between 31-40 years old, and 2,589 between 41-50 years old (**Figure 3.1**).

In the paediatric group, 546 of patients had onset of psoriasis between 11-15 years old (**Figure 3.2**).

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

Age	n	Mean	Median	Std Dev	Min	Max
Age of onset	15300	35.21	33	16.10	0	88
Age of diagnosis	15190	37.56	36	15.95	0	92

n (Age of onset) = 15,300

n (Age of diagnosis) = 15,190

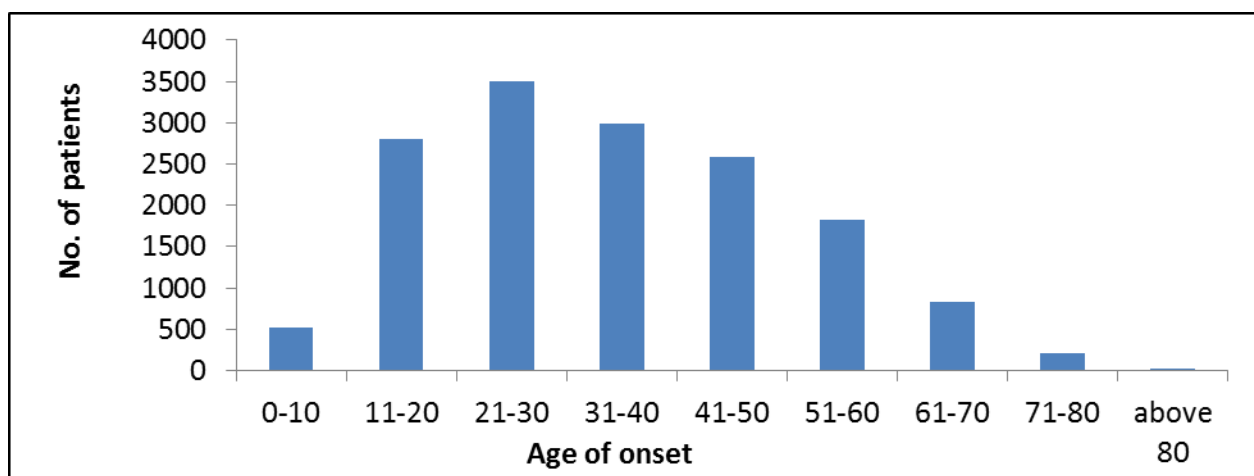
Table 3.2 Age of onset and age of diagnosis in paediatric patients with psoriasis

Age	n	Mean	Median	Std Dev	Min	Max
Age of onset	1283	10.14	11	4.32	0	17
Age of diagnosis	1277	11.35	12	4.13	0	18

n (Age of onset) = 1,283

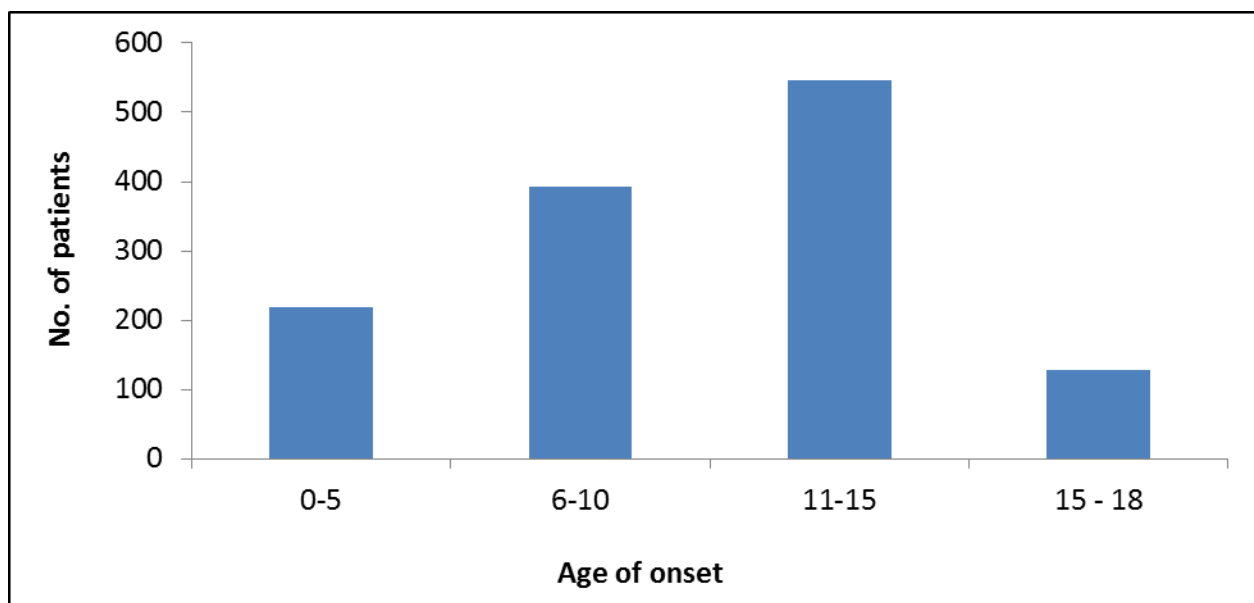
n (Age of diagnosis) = 1,277

Figure 3.1 Age of onset of adult patients with psoriasis



n = 15,300

Figure 3.2 Age of onset of paediatric patients with psoriasis



n = 1,283

Family History

Psoriasis is a skin disorder with a polygenic mode of inheritance. In our registry, about one-fifth (22.6%) of adult patients had at least one family member with psoriasis (**Table 3.3**). Of those with a positive family history, 40.7% had either of their parents affected. Siblings were affected in 35.2% and children in 11.3% (**Table 3.4, Figure 3.3**).

In the paediatric patients with psoriasis, 278 or 21.1% of them had at least one family member with psoriasis (**Table 3.3**). Of these, 35.2% had either parent affected with psoriasis. (**Table 3.4, Figure 3.4**)

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

Characteristics	Adult		Paediatric	
	n	%	n	%
Yes	3557	22.6	278	21.1
No	11858	75.3	1019	77.3
Not available	338	2.1	21	1.6
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

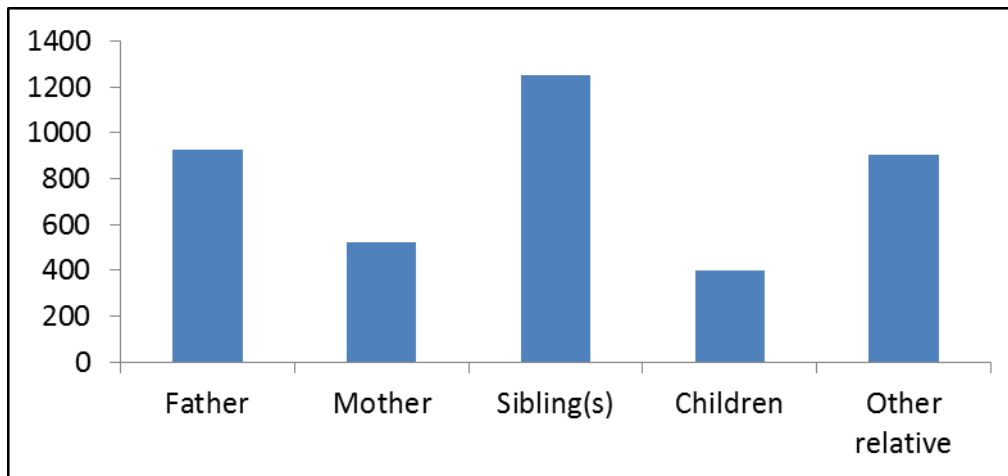
Table 3.4 Family members with psoriasis in adult and paediatric patients

Family member (one or multiple)	Adult		Paediatric	
	n	%	n	%
Father	926	26.0	56	20.1
Mother	524	14.7	42	15.1
Sibling(s)	1253	35.2	68	24.5
Children	401	11.3	0	0.0
Others	904	25.4	125	45.0

n (Adult) = 15,753

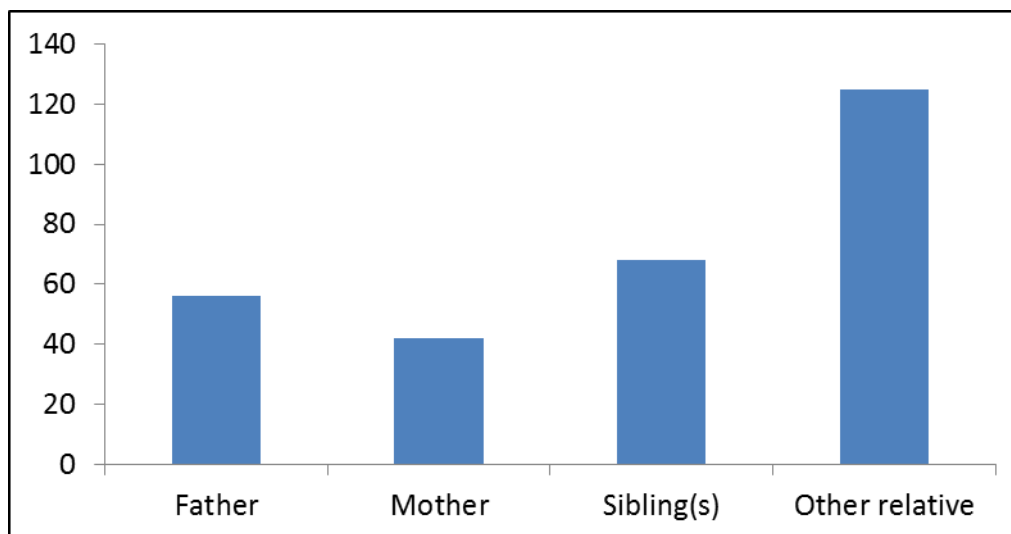
n (Paediatric) = 1,318

Figure 3.3 Distribution of family members with psoriasis in adult patients



n = 4,008

Figure 3.4 Distribution of family members with psoriasis in paediatric patients



n = 291

Aggravating factors of psoriasis

More than half (50.2%) of adult patients with psoriasis reported one or multiple factors which worsened their psoriasis (**Table 3.5**). Stress was the commonest aggravating factor (65.6%), followed by sunlight (32.9%) and infection (13.3%). Other identified aggravating factors included smoking (7.6%), trauma (6.9%), drugs (4.3%), alcohol (3.3%), pregnancy (2.7%) and topical treatment (1.0%) (**Table 3.6**).

Among the paediatric patients, 38.2% reported at least one factor that aggravated their psoriasis (**Table 3.5**). The most common aggravating factors reported in paediatric patients were stress (54.8%), sunlight (40.5%) and infection (18.5%) (**Table 3.7**).

In the subgroup of patients who reported infection as an aggravating factor, upper respiratory tract infection (52.0% in adults; 41.9% in paediatric patients) appeared to be the commonest infective trigger (**Table 3.7**). Common medications found to aggravate psoriasis were beta blockers (35.7% in adults; 14.3% in paediatric patients), withdrawal of systemic steroids (19.0% in adults; 14.3% in paediatric patients), traditional and complementary medicine (TCM) (11.9% in adults; 42.9% in paediatric patients), non-steroidal anti-inflammatory drugs (8.7% in adults; 14.3% in paediatric patients), antibiotics (7.9%) and ACE inhibitors (2.0%) (**Table 3.8**).

Table 3.5 Aggravating factors of psoriasis in adult and paediatric patients

Characteristics	Adult		Paediatric	
	n	%	n	%
Yes	7915	50.2	504	38.2
No	7266	46.1	785	59.6
Not available	572	3.6	29	2.2
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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

Aggravating factors (one or multiple)	Adult		Paediatric	
	n	%	n	%
Stress	5193	65.6	276	54.8
Sunlight	2602	32.9	204	40.5
Infection	1050	13.3	93	18.5
Smoking	605	7.6	10	2.0
Trauma	544	6.9	44	8.7
Drugs	339	4.3	7	1.4
Alcohol	262	3.3	0	0.0
Pregnancy	215	2.7	0	0.0
Topical treatment	76	1.0	5	1.0

n (Adult) = 15,753

n (Paediatric) = 1,318

Table 3.7 Infections which aggravated psoriasis in adult patients

Infection	Adult		Paediatric	
	n	%	n	%
Upper respiratory tract infection	119	52.0	18	41.9
Fever / febrile illness	50	21.9	6	14.0
Skin infection	14	6.1	4	9.3
Viral infection	12	5.2	1	2.3
Dengue fever	11	4.8	11	25.6
Chickenpox	9	3.9	3	7.0
HIV	8	3.5	0	0.0
Hepatitis C	2	0.9	0	0.0
Pneumonia	2	0.9	0	0.0
Chikungunya	2	0.9	0	0.0
Not available	821	-	50	-

n (Adult) = 1,050

n (Paediatric) = 93

HIV = Human Immunodeficiency Virus

Table 3.8 Drugs which aggravated psoriasis in adult and paediatric patients

Drug	Adult		Paediatric	
	n	%	n	%
Beta-blockers	90	35.7	1	14.3
Systemic steroids (withdrawal)	48	19.0	1	14.3
TCM	30	11.9	3	42.9
NSAIDs /analgesics	22	7.9	1	14.3
Antibiotics	20	8.7	0	0.0
Antihypertensives	6	2.4	0	0.0
ACE inhibitors	5	2.0	0	0.0
Oral contraceptive pills	4	1.6	0	0.0
Topical tar preparations	2	0.8	0	0.0
Betamethasone/calcipotriol	2	0.8	1	14.3
Statins	2	0.8	0	0.0
Sodium valproate	1	0.4	0	0.0
Biologics	1	0.4	0	0.0
HAART	1	0.4	0	0.0
Antimalarial drugs	1	0.4	0	0.0
Anti-platelets	1	0.4	0	0.0
Anti-diabetic medication	1	0.4	0	0.0
Others	14	5.6	0	0.0
Not available	87	-	-	-

n (Adult) = 339

n (Paediatric) = 7

TCM = Traditional chinese medicine

NSAIDs = Nonsteroidal anti-inflammatory drugs

ACE = Angiotensin-converting enzyme

HAART = Highly active antiretroviral therapy

Disease Burden in the last 6 months:

With regards to daily activities, 93.3% of the adult psoriasis patients were able to perform their routine daily activities regularly whereas, 6.7% reportedly had to take time off from work or school between 1- 90 days due to psoriasis (**Table 3.9**). Among the adult patients with psoriasis, 73.8% visited the clinic between 1-5 times in the past 6 months (**Table 3.9**). While 2.4% were hospitalised at least once in the last 6 months, the majority (97.6%) did not require any hospitalisation (**Table 3.10**).

Analysis of daily activities among paediatric psoriasis patients showed that 91.4% of them could perform their routine activities regularly. A small proportion, 8.6% had to take off from work/school between 1- 120 days due to psoriasis (**Table 3.11**). Of the paediatric patients with psoriasis, 75.2% visited the clinic between 1-5 times in the past 6 months (**Table 3.11**). Only 2.0% were hospitalised at least once in the last 6 months, and the majority (98.0%) did not require any hospitalisation (**Table 3.12**).

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

	Number of days off from work/school due to psoriasis		Number of clinic visits due to psoriasis	
	n	%	n	%
0	13498	93.3	3141	21.5
1-5	698	4.8	10813	73.8
6-10	147	1.0	551	3.8
>10	130	0.9	128	0.9

n (Number of days off from work/school due to psoriasis) = 14,473

n (Number of clinic visits due to psoriasis) = 14,633

Table 3.10 Number of hospital admissions in adult patients with psoriasis

Number of hospital admissions due to psoriasis	n	%
0	14244	97.6
1-3	313	2.2
>3	36	0.2

n (Number of hospital admissions due to psoriasis) = 14,593

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

	Number of days off to work/school due to psoriasis		Number of clinic visits due to psoriasis	
	n	%	n	%
0	1134	91.4	254	20.4
1-5	71	5.7	936	75.2
6-10	18	1.5	50	4.0
>10	18	1.5	5	0.4

n (Number of days off from work/school due to psoriasis) = 1,241

n (Number of clinic visits due to psoriasis) = 1,245

Table 3.12 Number of hospital admissions in paediatric patients with psoriasis

Number of hospital admissions due to psoriasis	n	%
0	1219	98.0
1-3	24	1.9
>3	1	0.1

n (Number of hospital admissions due to psoriasis) = 1,244

Smoking

Data on smoking habits were only available for 9,730 (57.0%) of patients. This was because the smoking status data was not collected in the earlier version of the CRF. A total of 1,857 (20.5%) adult patients with psoriasis were current smokers, while in the paediatric population, it was 20 (2.9%) (**Table 3.13**).

Table 3.13 Cigarette smoking in adult and paediatric patients with psoriasis

Cigarette smoking	Adult		Paediatric	
	n	%	n	%
Never smoked	6007	66.5	668	96.5
Ex-smoker	1174	13.0	4	0.6
Current smoker	1857	20.5	20	2.9
Not available	6715	-	626	-
Total	15753	100	1318	100

n (Adults) = 15,753

n (Paediatric) = 1,318

CHAPTER 4

COMORBIDITIES

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

In adult psoriasis patients, 33.1% were overweight and 23.6% were obese, 26.3% had hypertension, 18.5% had dyslipidaemia, 17.4% had diabetes mellitus, 5.6% had ischaemic heart disease and 1.6% had previous history of stroke (**Table 4.1**).

In the paediatric group, the most prevalent comorbidity was overweight or obesity i.e. BMI at or above 85th centile (24.0 %), followed by bronchial asthma (2.0%), Down syndrome (0.9%), blood disorder (0.5%), congenital heart disease (0.5%) and kidney disorder (0.3%). Other comorbid conditions were much less common (**Table 4.2**).

Table 4.1 Prevalence of comorbidities in adult patients with psoriasis

Comorbidity	n	%
Overweight*	4726	33.1
Obesity*	3372	23.6
Hypertension	4149	26.3
Hyperlipidaemia	2922	18.5
Diabetes mellitus	2746	17.4
Ischaemic heart disease	886	5.6
Stroke	252	1.6

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

n = 15,753

BMI = Body Mass Index

Table 4.2 Prevalence of comorbidities in paediatric patients with psoriasis

Comorbidity	N	%
Overweight or obesity (BMI \geq 85 th centile)	281	24.0
Bronchial Asthma / Allergic Rhinitis	27	2.0
Down syndrome	12	0.9
Blood Disorder	7	0.5
Congenital heart Disease	6	0.5
Kidney Disorder	4	0.3
Schizophrenia	4	0.3
Obstructive Sleep Apnoea	1	0.1
Brain Tumor	1	0.1
Liver Disease	1	0.1
Others	4	0.3

n = 1,318

BMI = Body Mass Index

CHAPTER 5

CLINICAL PRESENTATION

Plaque psoriasis was the commonest type of psoriasis in both the adult and paediatric populations. In adult patients, plaque psoriasis accounted for 86.6%, followed by guttate psoriasis 3.1% and erythrodermic psoriasis 1.8%. Similarly, in paediatric patients, plaque psoriasis accounted for 82.1%, followed by guttate psoriasis 7.3% and erythrodermic psoriasis 0.7%. Other types of psoriasis which include nail and scalp psoriasis were less common (**Table 5.1**).

Majority of our patients had mild to moderate body surface area involvement. For the adult patients, 17.3% had <5% BSA affected, while 33.3% had 5-10% BSA affected. Patients with >10% BSA involvement were noted in 15.6%, while 1.4% had erythrodermic psoriasis, i.e. >90% BSA involvement. In the paediatric population, 30.8% had <5% BSA involvement, 19.9% had 5-10% BSA involvement, 9.2% had 10-90% BSA and 0.5% were erythrodermic (**Table 5.2**).

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

Type of psoriasis	Adult		Paediatric	
	n	%	n	%
Plaque	13644	86.6	1082	82.1
Guttate	484	3.1	96	7.3
Erythrodermic	284	1.8	9	0.7
Flexural/inverse	66	0.4	12	0.9
Palmoplantar non-pustular	68	0.4	5	0.4
Generalised Pustular	52	0.3	8	0.6
Localised Pustular	32	0.2	1	0.1
Others	7	0.0	2	0.2
Not available	1116	7.1	103	7.8
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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

Body surface area involved	Adult		Paediatric	
	n	%	n	%
<5%	2724	17.3	406	30.8
5 - 10%	5240	33.3	262	19.9
>10%	2451	15.6	121	9.2
Erythrodermic (>90%)	222	1.4	6	0.5
Not available	5116	32.5	523	39.7
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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 scaling of the skin lesions. The total clinical score may range from 0 to 15. Analysis on severity of lesion of adult patients with psoriasis noted that most of the moderate to severe lesions (score 2 and 3) were located on the lower limbs (34.5%), trunk (30.5%) and upper limbs (27.0%) (**Table 5.3**). Whereas in paediatric patients, moderate and severe lesions were seen mainly on the scalp region (35.1%), followed by the trunk (24.3%) (**Table 5.4**).

Almost half of the adult (47.6%) and paediatric (48.3%) psoriatic patients did not have any lesion on the face and neck. If present, lesions on the face and neck were generally less severe (score 1 or 2) (**Table 5.3**, **Table 5.4**).

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

Body part	Score of severity									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	3179	20.2	7745	49.2	3390	21.5	674	4.3	765	4.9
Face & neck	7501	47.6	6155	39.1	1113	7.1	108	0.7	876	5.6
Trunk	3938	25.0	6162	39.1	4225	26.8	584	3.7	844	5.4
Upper limbs	3560	22.6	7109	45.1	3792	24.1	463	2.9	830	5.3
Lower limbs	2871	18.2	6629	42.1	4646	29.5	785	5.0	822	5.2

n = 15,753

NA = Not available

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

Body part	Score of severity									
	0		1		2		3		NA	
	n	%	n	%	n	%	n	%	n	%
Scalp	216	16.4	588	44.6	361	27.4	101	7.7	52	3.9
Face & neck	637	48.3	501	38.0	101	7.7	10	0.8	69	5.2
Trunk	434	35.9	502	38.1	284	21.5	36	2.7	62	4.7
Upper limbs	473	35.9	526	39.9	214	16.2	35	2.7	70	5.3
Lower limbs	460	35.0	503	38.3	251	19.1	36	2.7	64	4.9

n = 1,318

NA = Not available

Majority of adult patients with psoriasis had nail involvement (57.7%) (**Table 5.5**). Among patients who had psoriatic nail disease, most of them had pitting (72.5%). Other common features were onycholysis (48.0%), discoloration (30.9%) and subungual hyperkeratosis (12.9%). Total nail dystrophy was found in 4.9% of patients with nail involvement (**Table 5.6**).

There were 449 (37.9%) paediatric patients with nail involvement (**Table 5.5**). Most of them had pitting (88.2%), followed by onycholysis (25.1%), discolouration (11.6%) and subungual hyperkeratosis (4.6%) and total nail dystrophy (2.8%) (**Table 5.6**).

Psoriatic arthropathy was reported in 14.1% of the adult patients, while only 2.4% paediatric patients had joint disease (**Table 5.7**).

In adult patients, the commonest type of psoriatic arthropathy was oligo-/monoarthropathy (38.9%). This was followed by distal hand joints arthropathy (30.8%), rheumatoid-like symmetrical polyarthropathy (29.6%), spondylitis/sacroiliitis (7.9%) and arthritis mutilans (2.8%) (**Table 5.8**). Morning stiffness of > 30 minutes was reported in 31.7% of adult and 15.6% of paediatric patients. Enthesopathy was reported in 13.1% of adult patients and 6.3% of paediatric patients.

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

Nail involvement	Adult		Paediatric	
	n	%	n	%
Yes	9086	57.7	499	37.9
No	6192	39.3	787	59.7
Not available	475	3.0	32	2.4
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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

Nail features	Adult		Paediatric	
	n	%	n	%
Pitting	6588	72.5	440	88.2
Onycholysis	4361	48.0	125	25.1
Discoloration	2804	30.9	58	11.6
Subungual hyperkeratosis	1174	12.9	23	4.6
Total nail dystrophy	446	4.9	14	2.8

n (Adult) = 15,371

n (Paediatric) = 660

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

Joint disease	Adult		Paediatric	
	n	%	n	%
Yes	2221	14.1	32	2.4
No	13053	82.9	1248	94.7
Not available	479	3.0	38	2.9
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

Table 5.8 Distribution of type of joint disease in adult and paediatric patients with psoriasis

Type of joint disease (one or multiple)	Adult		Paediatric	
	n	%	n	%
Oligo-/Monoarthropathy	865	38.9	10	31.3
Distal hand joints arthropathy	685	30.8	8	25.0
Symmetrical polyarthropathy (Rheumatoid like)	658	29.6	4	12.5
Spondylitis / Sacroiliitis	175	7.9	2	6.3
Arthritis mutilans	63	2.8	0	0.0

n (Adult) = 2,446

n (Paediatric) = 24

Both adult (73.1%) and paediatric (59.4%) populations with psoriatic arthropathy experienced joint pain at the time of presentation. Joint swelling was present in 30.4% of adults and 9.4% of paediatric patients, while joint deformity occurred in 22.8% of adult patients and 9.4% of paediatric patients (**Table 5.9**, **Table 5.10**). The commonest type of joint deformity was swan neck deformity (26.2%). This was followed by fixed flexion deformity (18.4%), boutonniere deformity (8.1%), proximal interphalangeal joint deformity (8.1%), distal hand joint deformity (6.3%), subluxation (4.8%), rheumatoid arthritis-like (4.5%), arthritis mutilans (2.4%), bamboo spine (1.5%) and dactylitis (0.9%) (**Table 5.11**).

Table 5.9 Symptoms of psoriatic arthritis in adult patients with psoriasis

Symptoms	Yes		No		Not available	
	n	%	n	%	n	%
Pain	1623	73.1	460	20.7	41	2.0
Swelling	675	30.4	1403	63.2	33	1.5
Deformity	507	22.8	1558	70.1	41	1.9

n (Yes) = 2,805

n (No) = 3,421

n (Not available) = 115

Table 5.10 Symptoms of psoriatic arthritis in paediatric patients with psoriasis

Symptoms	Yes		No		Not available	
	n	%	n	%	n	%
Pain	19	59.4	9	28.1	1	3.5
Swelling	3	9.4	25	78.1	1	3.5
Deformity	3	9.4	24	75.0	1	3.5

n (Yes) = 25

n (No) = 58

n (Not available) = 3

Table 5.11 Distribution of type of joint deformities in adult patients with psoriasis

Type of joint deformity	n	%
Swan neck deformity	87	26.2
Fixed flexion	61	18.4
Boutonniere deformity	27	8.1
Proximal interphalangeal joint deformity	27	8.1
Distal hand joint deformity	21	6.3
Subluxation	16	4.8
Rheumatoid arthritis-like	15	4.5
Arthritis mutilans	8	2.4
Bamboo spine	5	1.5
Dactylitis	3	0.9
Others	62	18.7
n = 332		

CHAPTER 6

TREATMENT

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

Most adult patients with psoriasis used some form of topical medication for psoriasis (95.7%) (**Table 6.1**). In 71.5% of the patients, topical monotherapy was the only treatment given. The most commonly used topical medication was topical corticosteroids (82.4%). This was followed by emollients (72.3%), tar preparations (68.3%), keratolytics (51.3%) and vitamin D analogue such as calcipotriol (16.6%) and calcipotriol/betamethasone dipropionate fixed-dose combination 11.6%. Dithranol was less favoured and used in only 1.7% of patients (**Table 6.2**).

For paediatric patients, 94.2% received topical therapy (**Table 6.1**). The most common type of topical therapy was topical corticosteroids (77.2%), followed by tar preparation (64.8%) and emollient (63.7%) (**Table 6.2**).

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

Topical therapy	Adult		Paediatric	
	n	%	n	%
Yes	14754	95.7	1218	94.2
No	215	1.6	32	3.0
Not available	470	3.05	40	3.8
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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

Topical therapy	Adult		Paediatric	
	n	%	n	%
Topical corticosteroids	12981	82.4	1017	77.2
Emollients	11396	72.3	840	63.7
Tar preparations	10757	68.3	854	64.8
Keratolytics	8080	51.3	573	43.5
Vitamin D analogues	2610	16.6	180	13.7
Calcipotriol/betamethasone dipropionate fixed-dose combination	1839	11.7	114	8.6
Dithranol (anthralin)	269	1.7	27	2.0
Calineurin inhibitor	8	0.1	2	0.2

n (Adult) = 14,754

n (Paediatric) = 1,218

In the last six months prior to notification, 2.8% of the adult patients and 1.2% of the paediatric patients received phototherapy (**Table 6.3**).

Most of the adult patients (93.3%) and paediatric patients (81.3%) were given narrowband UVB (NB-UVB) while 2.7% of the adult patients received oral PUVA. Less popular modalities in adult patients were topical PUVA (1.6%), bath PUVA (1.1%), broadband UVB (BB-UVB) (1.1%) and excimer laser (0.2%). Of the paediatric patients, 12.5% and 6.3% received topical PUVA and bath PUVA respectively (**Table 6.4**).

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

Phototherapy	Adult		Paediatric	
	n	%	n	%
Yes	448	2.8	16	1.2
No	14472	91.9	1230	93.3
Not available	833	5.3	72	5.5
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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

Types of Phototherapy	Adult		Paediatric	
	n	%	n	%
Narrowband UVB	418	93.3	13	81.3
Oral PUVA	12	2.7	0	0.0
Topical PUVA	7	1.6	2	12.5
Bath PUVA	5	1.1	1	6.3
Broadband UVB	5	1.1	0	0.0
Excimer laser	1	0.2	0	0.0

n (Adult) = 448

n (Paediatric) = 16

UVB = Ultraviolet B

PUVA = Psoralen and ultraviolet A

Systemic therapy was used in 17.7% of adult patients and only 5.4% in paediatric patients with psoriasis (**Table 6.5**).

In adult patients, the commonest systemic agents used were methotrexate (72.6%), followed by acitretin (18.7%) and sulphasalazine (5.8%). Other systemic agents such as cyclosporin, hydroxyurea and biologics were used less frequently in adult patients with psoriasis (**Table 6.6**).

In paediatric patients, similarly to adult patients, methotrexate was the commonest systemic agent used (52.1%). This was followed by acitretin in 35.2% of patients (**Table 6.6**).

A total of 78 adult patients received biologic treatment. The biologic therapy most frequently used was adalimumab (28 patients), followed by ustekinumab (18 patients), etanercept (14 patients), infliximab (9 patients), efalizumab (4 patients), golimumab (3 patients) and secukinumab (2 patients). (Table 6.7).

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

Systemic therapy	Adult		Paediatric	
	n	%	n	%
Yes	2787	17.7	71	5.4
No	12264	77.9	1177	89.3
Not available	702	4.5	70	5.3
Total	15753	100	1318	100

n (Adult) = 15,753

n (Paediatric) = 1,318

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

Types of systemic therapy	Adult		Paediatric	
	n	%	n	%
Methotrexate	2023	72.6	37	52.1
Acitretin	520	18.7	25	35.2
Sulphasalazine	161	5.8	1	1.4
Cyclosporine	117	4.2	1	1.4
Systemic corticosteroids	112	4.0	9	12.7
Biologics	78	2.8	0	0.0
Hydroxyurea	18	0.6	0	0.0
Azathioprine	2	2.8	1	1.4
Dapsone	1	1.4	0	0.0

n (Adult) = 2,787

n (Paediatric) = 71

Table 6.7 Types of biologic in adult patients with psoriasis

Types of biologic	n	%
Adalimumab	28	37.8
Ustekinumab	18	24.0
Etanercept	14	18.7
Infliximab	9	12.0
Efalizumab	4	5.3
Golimumab	3	4.0
Secukinumab	2	2.7

n = 78

CHAPTER 7

QUALITY OF LIFE

A total of 8,905 adult patients (aged 17 and above) and 403 paediatric patients 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 8.67 ± 6.57 , and the mean CDLQI for paediatric patients was 7.83 ± 5.44 .

The responses for each question of the DLQI and CDLQI were tabulated in **Table 7.1** and **7.2** respectively. A DLQI of more than 10 was reported in 2,418 (27.2%) adult patients, indicating significant impairment of QoL due to psoriasis or its treatment. There were 427 adults (4.8%) who had a DLQI > 20 indicating extremely large effect on their quality of life by psoriasis. Nevertheless, 10.7% of adult patients reported no effect at all on their quality of life (**Figure 7.1**).

As shown in **Figure 7.2**, “symptoms and feelings” was the DLQI domain that most affected the adult group with 40.2% affected ‘very much’ or ‘a lot’ by itch and pain as well as embarrassment due to psoriasis. The domain that least affected them was “personal relationships” in which 71.5% of the adult patients were affected ‘a little’ or ‘not at all’.

In the paediatric group, 18.9% of patients reported a CDLQI of more than 12 indicating very large or extremely large effect on quality of life (**Figure 7.3**). There were 17 patients (4.2%) who had CDLQI of more than 19, reflecting extremely large effect of quality of life. On the other hand, 10.4% paediatric patients reported no effect at all on their quality of life.

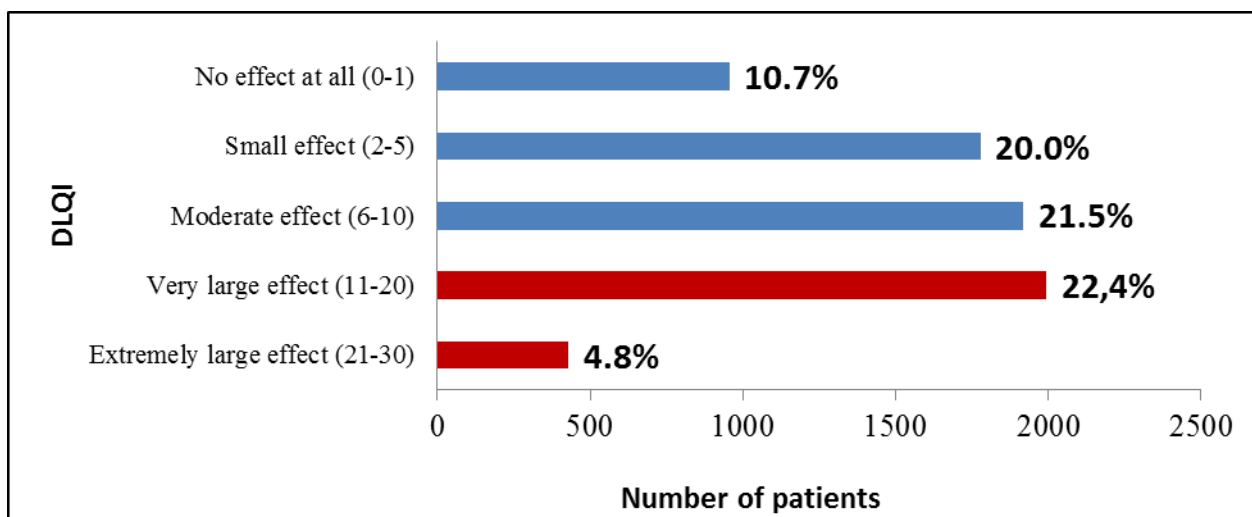
In paediatric patients, the CDLQI domain most affected was “symptoms and feelings”. Forty percent of the paediatric group reported that psoriasis affected very much or a lot in the symptoms and feelings domain. The aspect of life least affected by psoriasis was “personal relationship” in which 86.8% 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 Dermatology Life Quality Index in adult patients with psoriasis (age 17 and above)

No.	DLQI Question	n (%)				
		Very much	A lot	A little	Not at all	Not relevant
1	Over the last week, how itchy, sore, painful, or stinging has your skin been?	1658 (10.7)	4473 (28.9)	7788 (50.3)	1575 (10.2)	0 (0.0)
2	Over the last week, how embarrassed or self-conscious have you been because of your skin?	2446 (15.8)	3869 (25.0)	5499 (35.6)	3635 (23.5)	0.0 (0.0)
3	Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?	1410 (9.1)	3053 (19.7)	5193 (33.5)	5412 (34.9)	436 (2.8)
4	Over the last week, how much has your skin influenced the clothes you wear?	1260 (8.1)	2938 (19.0)	5331 (34.4)	5484 (35.4)	487 (3.1)
5	Over the last week, how much has your skin affected any social or leisure activities?	1449 (9.3)	3146 (20.3)	5053 (32.6)	5386 (34.8)	464 (3.0)
6	Over the last week, how much has your skin made it difficult for you to do any sport?	1520 (9.9)	2860 (18.5)	4371 (28.3)	4772 (30.9)	1901 (12.3)
7	Over the last week, has your skin prevented you from working or studying?	1227 (12.1)	3272 (32.4)	5606 (55.5)	0 (0.0)	0 (0.0)
8	Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?	769 (5.0)	1975 (12.8)	4686 (30.3)	7369 (47.6)	669 (4.3)
9	Over the last week, how much has your skin caused sexual difficulties?	506 (3.3)	968 (6.3)	2647 (17.3)	7309 (47.7)	3898 (25.4)
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?	1075 (6.9)	2482 (16.0)	5189 (33.5)	5915 (38.2)	821 (5.3)

n = 15,753

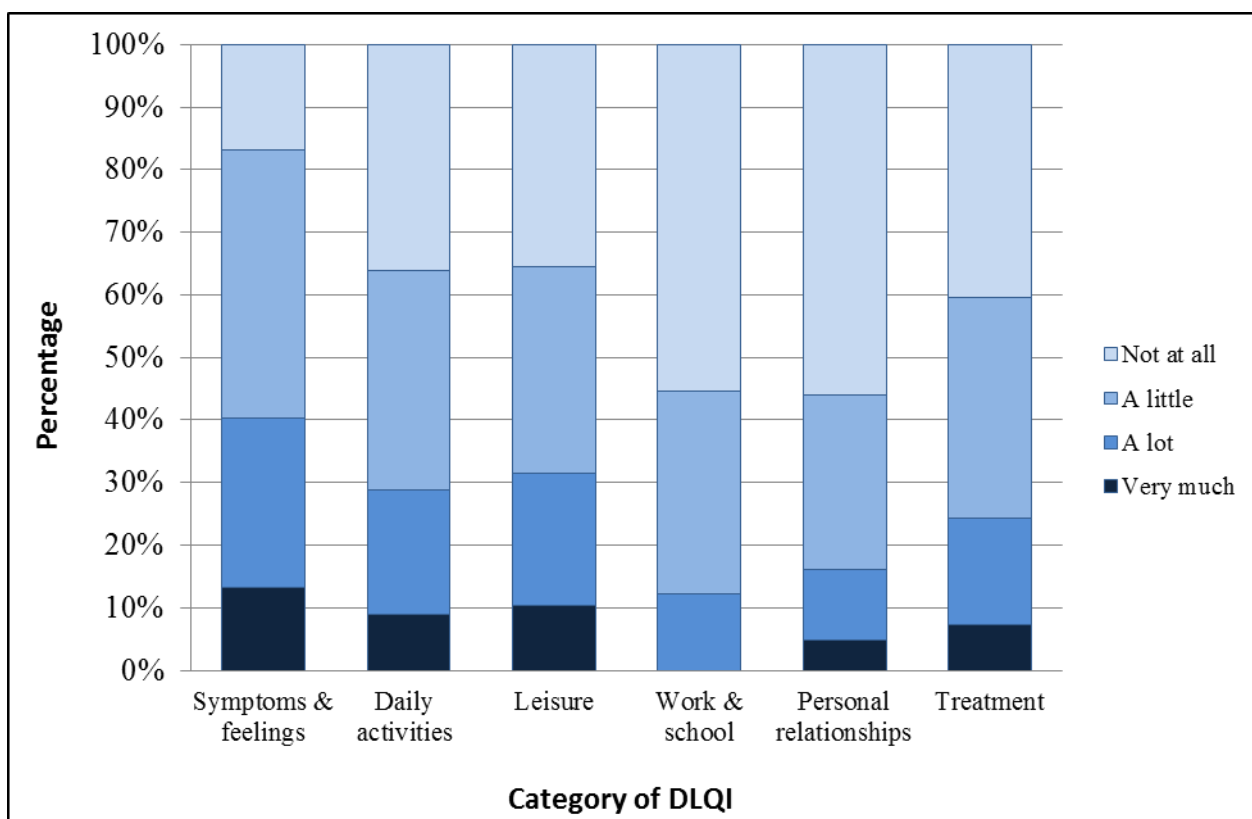
DLQI = Dermatology Life Quality Index



n = 8,905

DLQI = Dermatology Life Quality Index

Figure 7.1 Quality of life in adult patients with psoriasis



n = 15,753

DLQI = Dermatology Life Quality Index

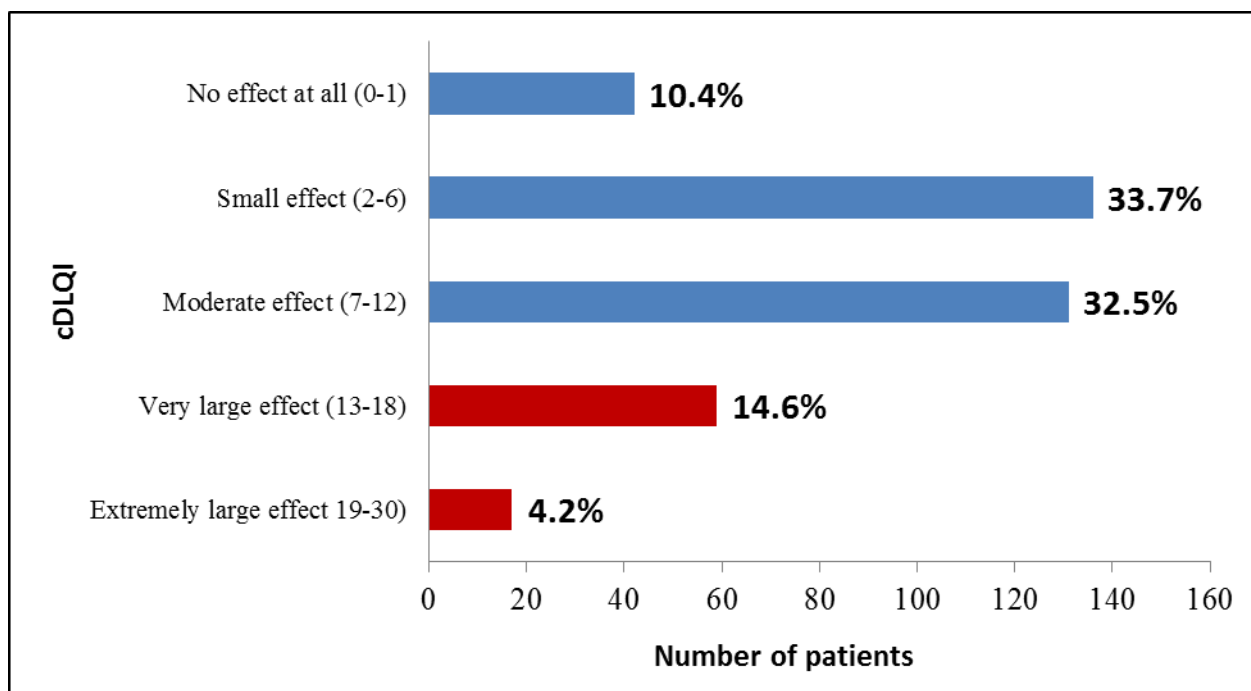
Figure 7.2 Quality of life impairment in adult psoriasis patients based on category of Dermatology Life Quality Index

Table 7.2 Responses for Child Dermatology Life Quality Index in paediatric psoriasis patients (aged 5 to 16)

No.	CDLQI Question	n (%)				
		Very much	A lot	A little	Not at all	Not relevant
1	Over the last week, how itchy, “scratchy”, sore, painful, or stinging has your skin been?	83 (8.9)	294 (31.4)	471 (50.4)	87 (9.3)	
2	Over the last week, how embarrassed or self-conscious have you been because of your skin?	147 (15.8)	223 (23.9)	377 (40.5)	185 (19.8)	
3	Over the last week, how much has your skin affected your friendships?	34 (3.7)	117 (12.7)	291 (31.6)	478 (52.0)	
4	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	34 (3.7)	177 (19.2)	335 (36.3)	377 (40.8)	
5	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies?	58 (6.3)	175 (18.9)	305 (33.0)	387 (41.8)	
6	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	62 (6.7)	143 (15.5)	257 (27.8)	461 (49.9)	
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?	48 (5.2)	131 (14.3)	314 (34.3)	423 (46.2)	
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?	39 (4.2)	91 (9.9)	249 (27.0)	542 (58.8)	
9	Over the last week, how much has your sleep been affected by your skin problem?	49 (5.7)	115 (13.4)	298 (34.7)	396 (46.2)	
10	Over the last week, how much of a problem has the treatment for your skin been?	37 (4.0)	146 (15.9)	327 (35.7)	406 (44.3)	

n = 1,318

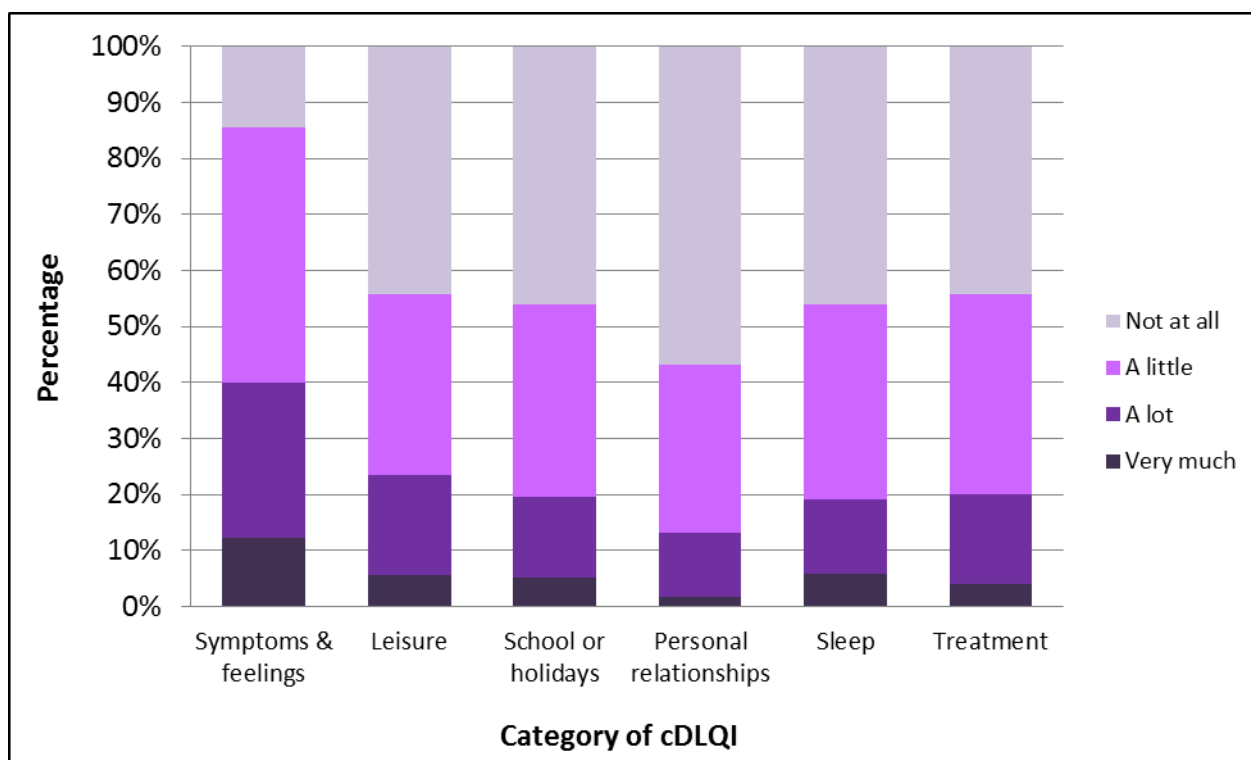
CDLQI = Child Dermatology Life Quality Index



n = 403

CDLQI = Child Dermatology Life Quality Index

Figure 7.3 Quality of life in paediatric patients with psoriasis



n = 1,318

CDLQI = Child Dermatology Life Quality Index

Figure 7.4 Quality of life impairment in paediatric patients with psoriasis based on category of Dermatology Life Quality Index

CHAPTER 8

OUTCOMES

In this registry, follow-up data were collected approximately every 6 months. However as of June 2016, only patients on phototherapy, systemic and biologic treatment were required to submit follow-up data 6 monthly. 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 lesion characteristics via clinical skin scoring method for each of the five body regions. Other clinical parameters monitored include severity of joint pain on a visual analogue score (0-10), and quality of life using Dermatology Life Quality Index (DLQI).

A total of 6,141 follow-up data were available from 17,071 patients notified to the MPR. From a total of 15,753 adult patients with psoriasis registered in MPR, follow-up data were obtained in 5,928 patients. In paediatric cases, follow-up data were obtained in 213 patients. The mean duration of follow-up was 42.3 ± 31.27 months, with the longest duration of 112 months (**Table 8.1**).

Extent of Psoriasis Lesions

The extent of psoriasis lesions was assessed in terms of percentage of body surface area involvement categorised into 4 scales, i.e. <5%, 5%-10%, 10%-90%, and >90% (erythrodermic). A total of 3,260 patients were evaluated for change in the extent of lesions. Of these patients, 792 patients (24.3%) had improvement by at least one scale, among which 231 (7.1%) had improvement by two scales, and 15 patients improved from BSA>90% to BSA<2%. No improvement was found in 1,651 patients (50.6%), and 571 patients (17.5%) had worsening by at least one scale (**Figure 8.1**).

Joint Pain

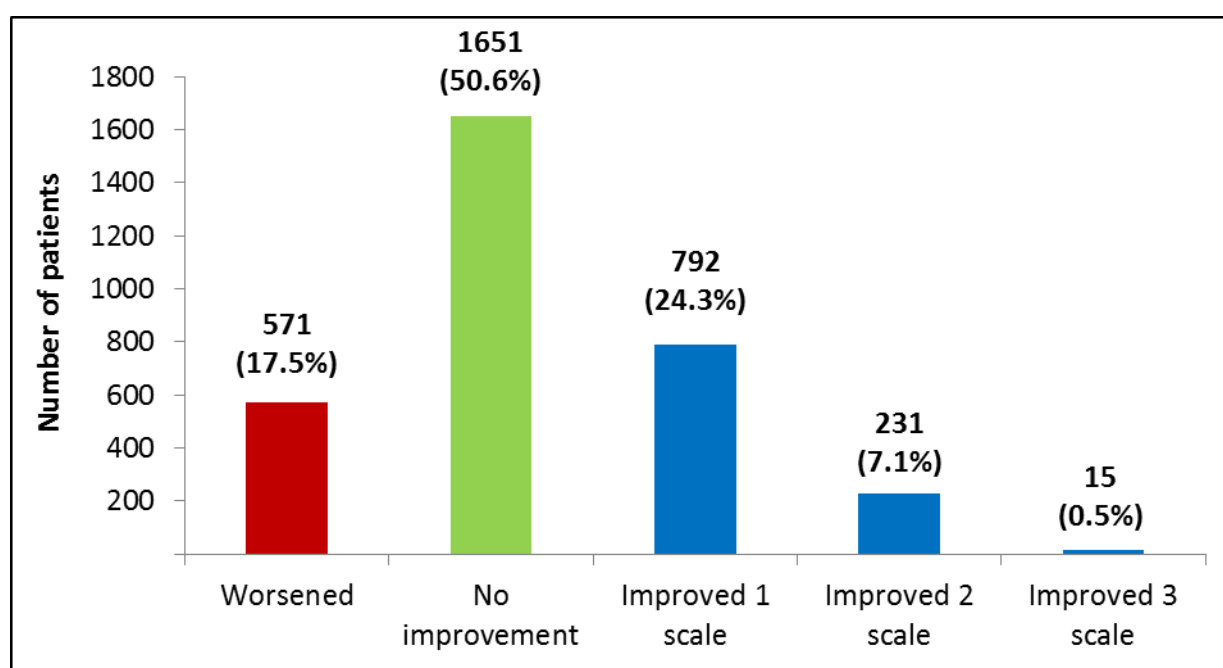
From a total of 231 patients who reported to have joint pain, 73 patients (31.6%) had improvement in joint pain as measured by the visual analogue scale. Of these patients, 37 patients (16.0%) had improvement of between 50% and 75%, 10 patients (4.3%) had improvement of more than 75%, 46 patients (19.9%) had improvement of between 25% and 50%, and 17 patients (7.4%) had improvement of less than 25%. There was no improvement of joint pain in 39 patients (16.9%), while joint pain worsened in 73 patients (31.6%) (**Figure 8.2**).

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

Duration of follow-up	n	%
0 to 6 months	536	8.7
7 to 12 months	763	12.4
13 to 18 months	666	10.9
19 to 24 months	572	9.3
25 to 30 months	427	7.0
31 to 36	348	5.7
>36	2829	46.1
	6141	100.0

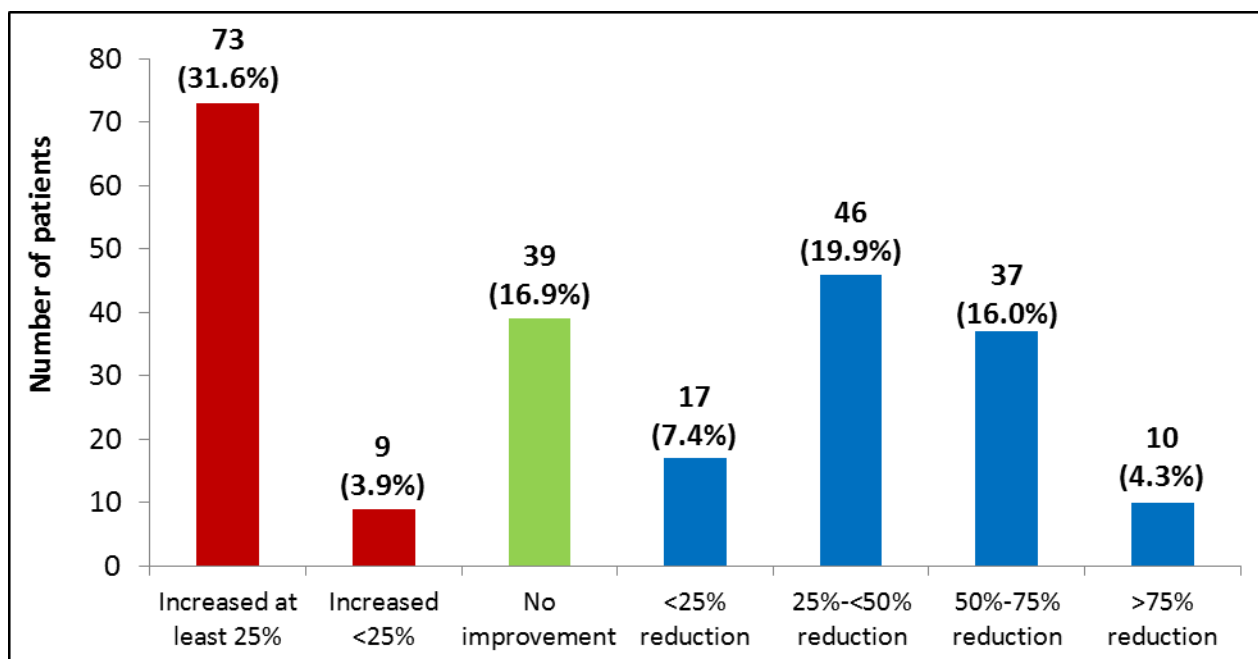
Mean duration of follow-up: 42.3 ± 31.27 months (range 0 – 112 months)

n = 6,141



n= 3,260

Figure 8.1 Improvement in the extent of skin lesions



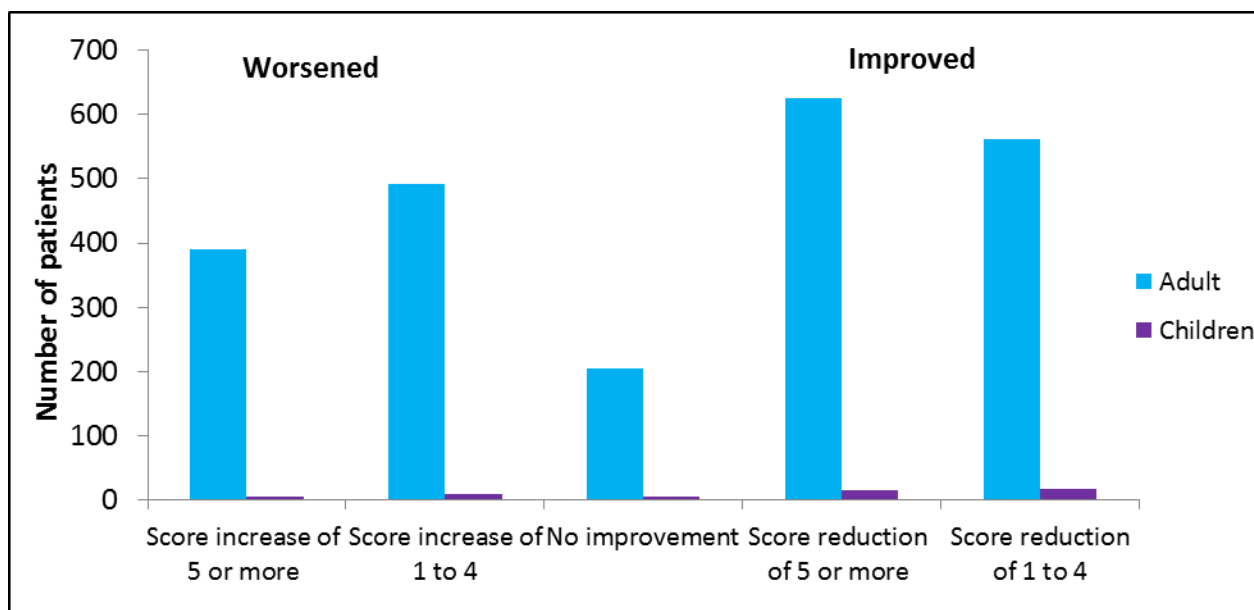
n = 231

Figure 8.2 Improvement in joint pain

Change in Quality of Life

In adult patients aged 17 years and above, we noted an overall improvement in the quality of life. A total of 2,272, out of 5,928 adult patients were evaluated for change in quality of life by DLQI as 3,656 patients did not complete the DLQI questionnaires. Of these patients, 625 patients (27.5%) had significant improvement with a reduction of DLQI score by at least 5, whereas 391 patients (17.2%) had significant worsening with an increase in DLQI score by at least 5 (**Figure 8.3**).

As for the paediatric group, a total of 53 out of 213 paediatric patients aged below 17 were evaluated for change in quality of life by DLQI as 160 patients did not complete the DLQI questionnaires. Of these patients, 15 patients (28.3%) had a significant improvement of Child DLQI score by at least 5, while 5 patients (9.4%) worsened (**Figure 8.3**).



n (Adult) = 2,272

n (Children) = 53

Figure 8.3 Improvement in Dermatology Life Quality Index and Child Dermatology Life Quality Index

Mortality in Psoriasis

We performed a further sub-analysis to determine the causes of mortality in patients with psoriasis. All adult psoriasis patients aged 18 and above notified to the Malaysian Psoriasis Registry between July 2007 and December 2016 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.

A total of 15,753 adult patients (18 and above) were notified to the registry between July 2007 and December 2016, of which 892 deaths (5.66% of patients in the registry) were identified (666 males, 226 females). The mean age at demise was 59.3 ± 13.84 years.

Out of 892 deaths, 776 cases (86.9%) had reported causes of death (**Table 8.4**) in which the most common cause of death was infection causes (n=318, 41.0%), followed by cardiovascular (n=224, 28.9%), and malignancy (n=95, 12.2%). For the remaining 116 cases (13.0%), the medical cause of death could not be determined. The types of infections and malignancies among the patients who died are listed in **Table 8.5**. For lung infections, out of 106 patients, 98 had pneumonia (92.5% of lung infections) while eight patients (7.5%) had tuberculosis. Twelve patients with central nervous system infections, of which five (83.3%) had meningitis or meningoencephalitis while one (16.7%) had a cerebellar abscess.

Table 8.2 Reported cause of mortality among patients with psoriasis

Cause of mortality	Number of patients, n	%
Infection	318	41.0
Cardiovascular	224	28.9
Malignancy	95	12.2
Lung	43	5.5
Trauma	33	4.3
Liver	26	3.4
Gastrointestinal	16	2.1
Suicide	11	1.4
Renal	5	0.6
Others	5	0.6
Total	776	100

n = 776

Table 8.3 Types of infections and malignancy related deaths

Types	Number, n	%
Infection		
Lung	106	48.0
Sepsis	54	24.4
Gastrointestinal	25	11.3
Urinary Tract	16	7.2
Central Nervous System	12	5.4
HIV - related	8	3.6
Total	221	100
Malignancy		
Gastrointestinal	24	27.3
Lung	13	14.8
Liver	12	13.6
Upper Aerodigestive Tract	11	12.5
Lymphoma and Leukaemia	10	11.4
Breast	9	10.2
Others	9	10.2
Total	88	100

n (Infection) = 221

n (Malignancy) = 88

HIV = Human Immunodeficiency Virus

APPENDIX A: CASE REPORT FORM

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

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

NATIONAL DERMATOLOGY REGISTRY (DermReg) Malaysian Psoriasis Registry Case Report Form	CONFIDENTIAL
Instruction: Where check boxes <input checked="" type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="checkbox"/> are provided, check (✓) one button only.	For Office Use only: ID: <input style="width: 40px;" type="text"/> / <input style="width: 40px;" type="text"/> Centre: <input style="width: 100%;" type="text"/>

SECTION 3: CLINICAL EXAMINATION

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

SECTION 4 : TREATMENT RECEIVED IN THE PAST 6 MONTHS

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

SECTION 5: QUALITY OF LIFE

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

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 type="text"/> / <input type="text"/> Centre: <input 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 kajian adalah untuk memahami setakat manakah masalah kulit anda mempengaruhi kehidupan anda SEPANJANG MINGGU LALU.

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

这份问卷的目的是衡量上周内您的皮肤问题对您的生活造成了多大的影响。

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

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

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih

Please check you have answered EVERY question. Thank you.

请您检查您是否已回答所有问题。谢谢合作

Version 2.4 Last updated 07/12/2011

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page 3 of 4

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

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

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

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

这份问卷的目的是衡量上周内您的皮肤问题对您的生活造成了多大的影响。

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

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

Sila semak sama ada SETIAP soalan telah dijawab. Terima kasih

Please check you have answered EVERY question. Thank you.

请您检查您是否已回答所有问题。谢谢合作

APPENDIX B: DATA MANAGEMENT

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

Data Sources

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

Data Collection

The study involves collection of data on the patient's first visit to the participating centre and thereafter every six months 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 the SDP is entirely voluntary.

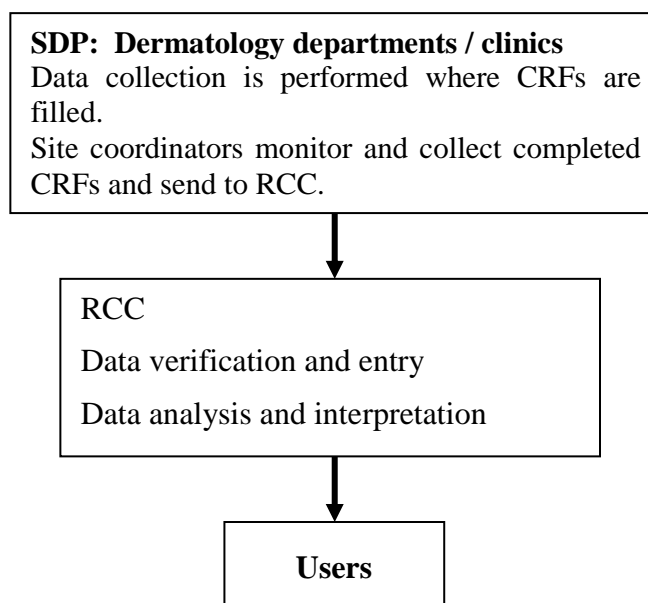
Registry ICT Infrastructure and Data Centre

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 at a data centre in Cyberjaya to provide 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.

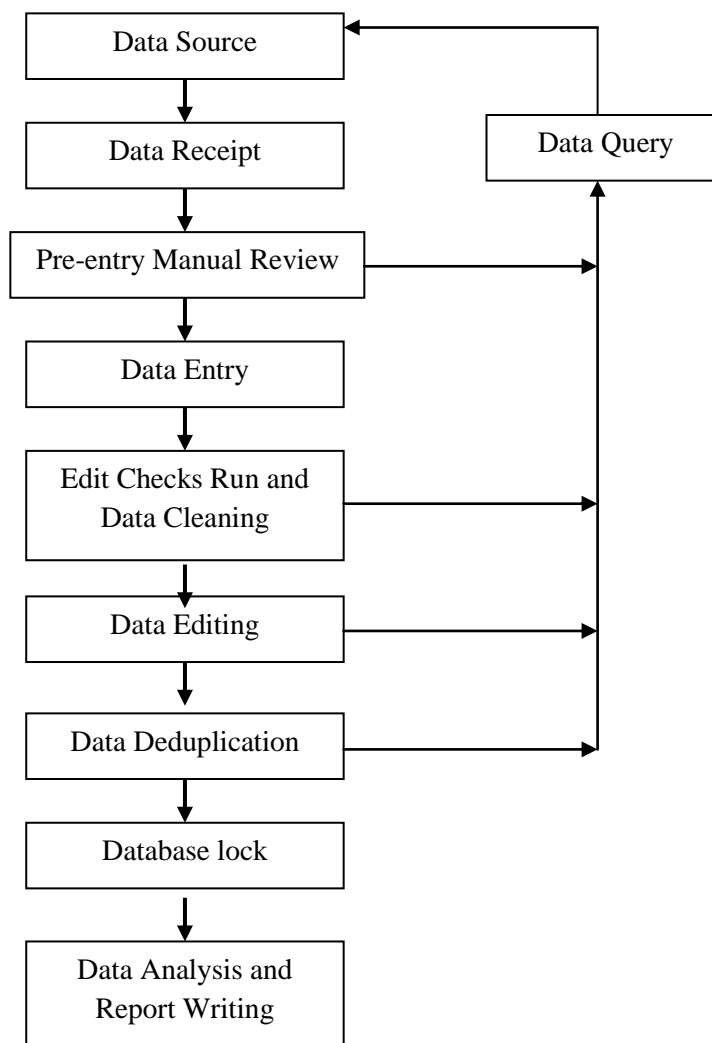
Data Flow Process

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 duplication. 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 must 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 several 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 already in the database, the SDP only needs to add a new notification with the patient's details 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 must 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 2016

There were 17,071 patients in the dataset. The analysis set was used for the analysis in Chapter 1, 2, 3, 4, 5 and 6, which comprises of 352 cases in year 2007, 1,345 cases in year 2008, 1,542 cases in year 2009, 1,285 cases in year 2010, 1,069 cases in year 2011, 953 cases in 2012, 1,659 cases in 2013, 2,865 cases in 2014, 2,494 cases in 2015 and 3,507 cases in 2016. The cases include first notification and up to five follow-up notifications.

2. Patient outcome between 2007 and 2016

There were 6,141 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 of the missing data were issued to the Project Manager to be clarified. Traceable missing information was then incorporated into the dataset but for the untraceable data, it was 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. Figures were presented graphically using tables and line charts.

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. Figures were presented graphically using tables and pie charts.

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. Figures were presented graphically using tables and vertical bar charts.

Comorbidities

Chapter 4 emphasized on the combination of distribution and descriptive summaries of age of onset, several demographic profiles and comorbidities. The distribution figures were presented using tables.

Clinical Presentation

Chapter 5 concentrated on the descriptive summaries of pain score. The distribution of psoriasis patients was 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 distribution figures were presented using tables.

Treatment

Chapter 6 presented the distribution of patients with topical therapy, phototherapy and systemic therapy. The distribution figures were presented using tables.

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 tables, horizontal bar and stacked bar 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 tables and vertical bar charts.

STATISTICAL SOFTWARE

SPSS 22.0

STATA 15.0

APPENDIX D: PARTICIPATING CENTRE DIRECTORY

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<p>Hospital Tuanku Ja'afar, Seremban</p> <p>Dermatology Department, Hospital Tuanku Ja'afar, Jalan Rasah, 70300 Seremban, Negeri Sembilan. Tel: 06-760 4157 Fax: 06-762 5771</p>	<p>Investigator: Dr. Najeeb Ahmad Mohd Safdar</p> <p>Site- coordinator: Dr. Prakash Balasubramaniam</p>
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