

# Diabetes Registry Malaysia

Newsletter Issue No:1, August 2009



## Note from the coordinating office:-

ADCM is a place for you to find data about diabetes and its complications, as well as statistical information about the extent and impact of diabetes in Malaysia. The registry was started in May 2008, with its pilot study in Negeri Sembilan. ADCM is growing rapidly with an average of 2000 cases entered into the web application every month. Kudos to these source data producers (SDP) for their support and contributions!

DiCARE first started in 2006 and is continuously growing from day to day. We are already in our fourth year. In this inaugural DiCARE e-Newsletter, we hope to be the source of information and updates for users. Thank you very much for the continuous support and encouragement from participating sites and committee members.

## ANNOUNCEMENTS!

ADCM has completed its 6 months pilot study in Negeri Sembilan and the committees are now working towards publishing its FIRST report.

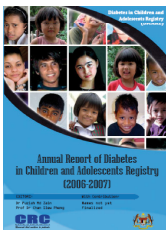
The Diabetes Registry Malaysia (DRM) is a mother registry for diabetes mellitus. An Adult of Diabetes Control and Management (ADCM) and Diabetes in Children and Adolescents Registry (DiCARE) will come under one umbrella.

### Coming Soon!

2006-2007 registry report

### Upcoming Event

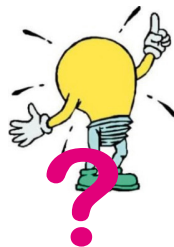
Registry User's Seminar  
27-29 October 2009



## DO YOU NEED HELP? PLEASE CONTACT US!

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Diabetes Registry Malaysia (DRM)  
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## DID YOU KNOW?

1. Diabetes currently affects 246 million people worldwide and is expected to affect 380 million by 2025.
2. Every 10 seconds a person dies from diabetes-related causes.
3. Every 10 seconds two people develop diabetes.
4. Cardiovascular disease is the major cause of death in diabetes, accounting for some 50% of all diabetes fatalities, and much disability.
5. The cost in human suffering and lives is heartbreaking . . .

Source: International Diabetes Federation (IDF), 2009

## Message from the Chairman of Diabetes Registry Malaysia

Diabetes Registry Malaysia (DRM) is a mother registry for diabetes mellitus in Malaysia. Currently, DRM consisted of two registries Diabetes In Children and Adolescents Registry (DRM\_DiCARE) and An Audit of Diabetes Control and Management (DRM\_ADCM).

DRM is a collaborative effort of health clinics and hospitals under the Ministry of Health (MOH), the university hospitals and the Clinical Research Centre, Hospital Kuala Lumpur (CRC, HKL).

Since DRM is an on-going evaluation of the clinical status of diabetes in Malaysia, therefore the amount of data will continue to expand. I would like to share with you the remarkable response from both registries. As to date, a total of ~59,000 patients from 343 centers and ~640 patients from 33 centers were enrolled in ADCM and DiCARE respectively. We foresee the registries to extend their data collection to all health clinics and general hospitals nationwide as well as private and army hospitals.

I would like to convey our sincere appreciation and gratitude for the untiring efforts and invaluable supports from those involved in this registry including the hospital staff.

Here, I would like to motivate all participating members to maintain excellent performance and quality of diabetes database. Participations from other diabetes experts are very much encouraged and welcomed to seize the opportunity as part of DRM family. Welcome to Diabetes Registry Malaysia!!

Hopefully, this effort will be the first step to a more comprehensive, ongoing database which will enable us to improve the quality of diabetes care in Malaysia.

Your comments would be very much appreciated. I will be glad to receive your contributions for this newsletter.



Prof Dr Wan Mohamad  
Wan Bebakar  
(Chairman of DRM)

## REGISTRY COMMITTEE

**Governance Board Chairperson:**  
Prof Wan Mohamed Wan Bebakar

**ADCM Principal Investigator:**

Dr Mastura Ismail

### Members:

- Dr Zanariah Hussein
- Dr Jamaiah Haniff
- Dr G. R. Letchumanan a/k Ramanathan
- Dr Sri Wahyu Taher
- Dr Lee Ping Yein
- Dr Feisul Idzwan Mustapha
- Dr Rozita Zakaria
- Prof Fatimah Harun
- Dr Cheong Ai Theng
- Dr Zaiton Ahmad
- Dr Syed Alwi Syed Abd.Rahman
- Dr Chew Boon How
- Dr Asmah Zainal Abidin

**DiCARE Principal Investigator:**

Dr Fuziah Md Zain

### Members:

- Dr Janet Yeow Hua Hong
- Prof Dr SP Chan
- Dr Soo Thian Lian
- Dr Jamaiah Haniff
- Prof Dr Wu Loo Ling
- Assoc Prof Dr Rahmah Rasat
- Dr Ang Ee Lee
- Dr Vanitha
- Dr Nachal RMN Nachiappan
- Dr Zalwani Zainuddin
- Dr Miza Hiriyanti Zakaria

**Registry Manager:** Ms Tee Chin Kim

**Registry Associates:** Ms Noor Akma Hassim, Ms Norzaiti Ab Majid



# An Audit of Diabetes Control and Management (DRM-ADCM)

## MESSAGE FROM THE PRINCIPAL INVESTIGATOR OF DRM-ADCM



Dr Mastura Ismail  
(Principal Investigator  
of DRM-ADCM)

The adult diabetes registry – An Audit of Diabetes Control and Management (ADCM) – comes under the Diabetes Registry Malaysia (DRM) which is the mother Diabetes registry. Therefore ADCM is now known as the Diabetes Registry Malaysia - An Adult of Diabetes Control and Management (DRM-ADCM).

This MOH - supported service collects information about diabetes mellitus among adults, which can be used to estimate incidences of different

types of diabetes and evaluate its risk factors and treatments in the country. Such information is useful for the MOH, non-governmental organisations, private providers and industry to plan and evaluate diabetes prevention and control.

The Steering Committee first met in October 2007 to plan for the DRM. Data collection using paper CRF and the DRM Registry's eCRF began in May 2008 and preliminary results were presented in several scientific meetings. We would not have achieved our current progress without everyone's dedication – those who contributed data, the secretariat based at CRC HKL led by Ms Tee Chin Kim and the grant from the Ministry of Health

Malaysia. This is only the beginning as we move forward in adding value and sustainability.

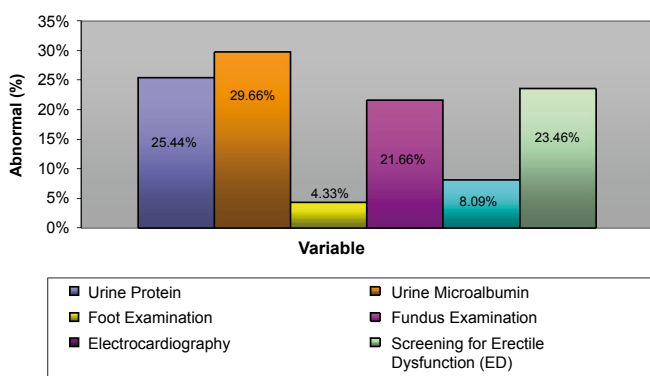
I am proud to note such tremendous response; ~ 45,500 patients up to June 2009! But we still need more centres for it to be truly national data. For already participating centres, data quality needs to be substantially improved. Missing data and incomplete data to be filled up as soon as possible, more doctors in the technical committee, the publications committee, etc. Such improvements add value to the data collected, which would then influence our clinical practice and contribute to the scientific knowledge of diabetes disease regionally and beyond. Our 1st Annual Report of the DRM Registry, which we hope to be ready by year end will feature our preliminary findings.

There are many hurdles – Political, Resources, Motivational and Cognitive but together, through innovation & proactiveness, we can do something for ourselves, for the next generation and for the country.

We have established an Advisory Committee to govern the DRM. The MOH, various professional bodies, and providers of diabetic patients related services) from all sectors will be represented in this committee to ensure that the DRM stays focused on its objectives, and to assure its continuous relevance and justification.

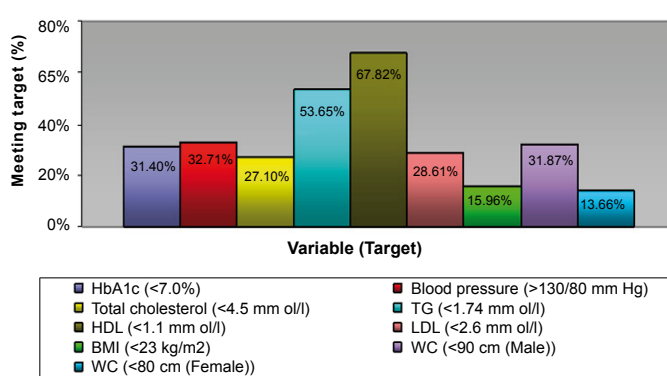
I welcome your comments and contributions for this newsletter.

Distribution of Clinical Information (qualitative) in the target (n=53846)



Note: Unclean data as of 20th July 2009

Distribution of Clinical Variables in target (n=53849)



Note: Unclean data as of 20th July 2009

### Progress of ADCM

Source Data Providers (SDP)	N	%
Perak	1092	2.04
Terengganu	166	0.31
Negeri Sembilan	33765	63.09
Kelantan	557	1.04
Pahang	2139	4.00
Kedah	2617	4.89
PKD Gombak	2613	4.88
Wilayah Persekutuan & Putrajaya	10567	19.75
Total	53516	100



### Events & Activities

SC meeting: 21<sup>st</sup> Jan 2009, 21<sup>st</sup> May 2009

GB meeting: 9<sup>th</sup> April 2009

User training: 24<sup>th</sup> Feb 2009 (Kedah), 5-6<sup>th</sup> March 2009 (Negeri Sembilan), 20<sup>th</sup> March 2009 (Perak), 23<sup>rd</sup> March 2009 (Wilayah Persekutuan), 13<sup>th</sup> April 2009 (Kelantan), 11<sup>th</sup> May 2009 (Pahang)

### Oral presentation:

- Singapore Conference (1st-2<sup>nd</sup> April 2009)
- Diabetes Education conference (23<sup>rd</sup>-25<sup>th</sup> July 2009)

### Booth exhibition:

- National Diabetes Education Conference 2009
- Diabetes Asia 2009



# Diabetes Registry Malaysia - Diabetes in Children and Adolescents (DRM-DiCARE)

## Message from the Principal Investigator of DiCARE

DiCARE, an ongoing real-time register of diabetic patients ≤ 20 years old via online case report forms (e-DiCARE), began in April 2006 as a pilot project involving four hospitals (Putrajaya Hospital, Kuala Lumpur Hospital, PPUKM and PPUM). In August 2009, it became nationwide and 34 hospitals registered under DiCARE. We have produced our first report of 240 patients from April 2006 to December 2007 and published the results in the Medical Journal of Malaysia (Vol 63, Supp C, Sept 2008, P 37-40).



Dr Fuziah Md Zain  
(Principle Investigator  
of DRM-DiCARE)

Since then, more cases were notified. From August 2006 till December 2008, 397 patients from ages 1 to 19 years were notified by 17 centres in Malaysia. After the 2006-2007 annual report writing meeting, the case report form (CRF) was revised and a new version was introduced in May 2009. This new CRF is concise and more user friendly and is hoped to encourage more source data providers (SDP) to be involved in the registry.

With DiCARE, we are beginning to understand about the standard of care and outcome of our children and adolescents with diabetes and hence we are able to identify areas for improvement.

Such information is useful for assisting the MOH, non-governmental organizations, private healthcare providers and industries in planning and evaluation, leading to diabetes prevention and control.

In addition, it will help us to improve standard of care and quality of life of children and adolescents with diabetes and thus reducing health cost of complications, morbidity and mortality. More centres have begun to register in 2008 and we hope to invite and encourage more doctors to be part of our SDPs to notify and report all diabetic cases under their care. For DiCARE to become a success, ideally all doctors who care for diabetic patients should be involved. It is hoped that in future, we will know the incidence and prevalence of diabetes mellitus among children and adolescents in Malaysia. We look forward to your continued support and collaboration to enable DiCARE to develop and contribute significantly to the control of diabetes mellitus in Malaysia.

Fuziah Md. Zain, Janet Hong on behalf of DiCARE study group.

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ppjanet@hpj.gov.my



Would you like to share any tips or information with us?

Send us your suggestions at  
ADCM@acrm.gov.my/ dicare@acrm.gov.my

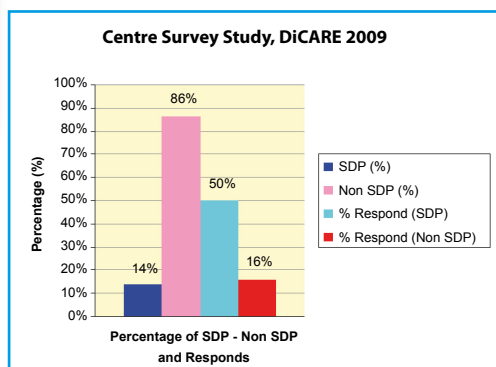
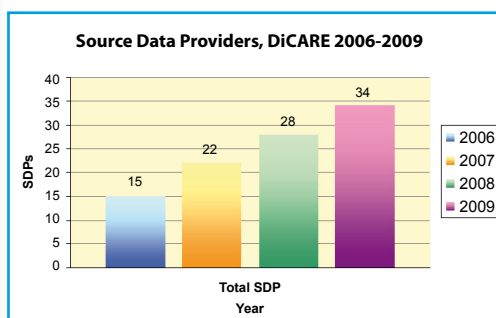
## Progress of DiCARE

### 1. Source Data Providers, DiCARE 2006-2009

2006 (Hospital)	2007 (Hospital)	2008 (Hospital)	2009 (Hospital)
• Ampang	• Kajang	• Duchess of Kent	• Kota Marudu
• Bentong	• Likas	• Jeli	• Kudat
• Kluang	• Raja Permaisuri Bainun	• Pakar Sultanah Fatimah	• Sg Buloh
• Kuala Lumpur	• Sg Bakap	• Sibu	• Sultanah Bahiyah
• Melaka	• Tuanku Ampuan Najihah	• Sipitang	• Tengku Ampuan Rahimah
• Pulau Pinang	• Tuanku Ahmad Shah	• Sultanah Aminah	• Tg Karang
• Putrajaya	• Sultanah Nur Zahirah		
• Saratok	• Teluk Intan		
• Sultan Hj	• Umum		
• Sultanah Nur Zahirah	• Sarawak		
• Teluk Intan	• HUSM		
• Umum	• PPUM		
• Sarawak	• PPUM		
• HUSM			
• PPUM			
• PPUM			

### 2. Involve in Centre Survey Study 2009

Targeting existing and prospective individual Source Data Providers (SDP) of a patient registry. While the Patient registries target individual patients and the outcome of interest, the centre survey will target the healthcare provided by these SDPs to determine the availability and quality of health services to patients which potentially impact patients' health outcomes. It also serves to provide an accurate count of the universe of SDPs for purposes of statistical estimation from available data reported by responding SDPs.



### Events & Activities

**1st Steering Committee Meeting:**  
26<sup>th</sup> March 2009

**Governance Board Meeting:**  
9<sup>th</sup> April 2009

**User Training in HUKM:**  
20<sup>th</sup> May 2009

#### Oral presentation:

Diabetes Education conference  
(23<sup>rd</sup> - 25<sup>th</sup> July 2009)  
Diabetes Asia 2009

#### Booth exhibition:

National Diabetes Education Conference 2009  
Diabetes Asia 2009