

Bengkel Aplikasi Web Bagi Diabetes Registry Malaysia Diabetes in Children & Adolescents Registry (DiCARE) http://www/acrm.org.my/dicare

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Epidemiology of T1DM - 1

- More than half of T1DM : diagnosed in < 15 yrs old.
- In most western countries, it accounts for >90% of childhood & adolescent DM.
- Epidemiological incidence studies define the "onset of T1DM" by the date of the 1st insulin injection (variable time between the onset of symptoms & diagnosis).
- Incidence : varies greatly between different countries,
 within countries & between different ethnic population :
 0.1 37.4 per 100,000.
- In Japan : 1.5-2.0 per 100,000 (low).
 A slowly progressive T1DM is common.



Epidemiology of T1DM - 2

- Gender differences in incidence is found in some, but not all populations.
- A well-documented rise in the incidence has been noted in many countries.
- Seasonal variation : peak in the winter months.
- There is no recognizable pattern of inheritance despite familial aggregation.
- TIDM is 2-3x more common in the offspring of diabetic men (3.6-8.5%) compared with diabetic women (1.3-3.6%).



Annual incidence rate of T1DM (58 countries), 0-14 yr age group from the IDF Atlas 1990-1999. *Diabetic Medical 2006 : 23 : 857-866.*

45



Incidence / Prevalence of T2DM

- A recent ↑ in the incidence of T2DM in children & adolescents, parallel that of obesity.
- It's increasingly more common in 6-11 yrs old & adolescents 12-19 yrs old.
- USA : 4/100,000 children & adolescents have T2DM.
- The prevalence of obesity (6-19 yo), jumped from 4% (1963) to 15% (2000).
- 10-30 fold ↑ of T2DM over the past 10 15 years.
- It accounts for 8 45% of new onset paediatric diabetes in USA.
- 80% in Japan, 70% among Native Americans.
- Diagnoses of T2DM are now 4x as common as T1DM in Japan & China.







DiCARE : Introduction

- It is a MOH supported service / registry to collect information about DM among children & adolescents in Malaysia.
- The information can be used :
 - to estimate the incidence of DM & types.
 - to evaluate its risk factors & treatment.
- It is useful to assist MOH, NGO, private providers & industries in planning & evaluation → diabetes prevention & control.





Objectives

1) To determine the number & the time trend of DM in the children & adolescent in Malaysia.

- 2) To determine the socio-economic profiles of these patients to better identify the high risk group in our Malaysian population.
- 3) To determine the number, evaluate & monitor the outcomes of intervention in terms of metabolic control & complications.
- 4) To stimulate & facilitate research using this database.





Methodology

Source Data Providers

- 1. All paediatricians & physician in Malaysia beginning with those currently working in the government sector and later on extending it to those beyond (private and armed forces) for data on DM in the country.
- 2. Jabatan Pendaftaran Negara (JPN) for data on all-cause mortality in the country.



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Methodology

Patient Population

- 1. < 20 years old (from May 2009 : <18 yrs old)
- 2. Satisfy the definition of diabetes mellitus
- 3. Seen in any participating sites

DiCARE Reporting

- 1. e-DiCARE web application
- 2. Relevant data from the patients' medical record will be collected and transcribed onto online Case Report Format (CRF)







CRF – Notification : Old form

DIABETES IN CHILDREN & ADOLESCENT REGISTRY (DICARE) NOTIFICATION FORM

Instruction: Please complete the following form for the disbetic patient age below 29 years old (r. 29). Tak (t) (1) one only where 🕜 bax is provided. Tak (1) one or more where applicable where 📃 bax is provided. 198

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Diabetes in Children and Adolescent Registry



CRF - Notification

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Page 1 of 2





CRF-Annual Census

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Diabetes in Children and Adolescent Registry



CRF - Annual Census

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DiCARE Website



PRESENTATION GOVERNANCE BOARD

EXPERT PANEL

REGISTRY UNIT

REGISTRATION

PUBLICATIONS

LINKS

GALLERY

eDiCARE

Visitor number:

001011

since 29/8/2006

FAQ

2

CENTRES DIRECTORY

DICARE Diabetes in Children and

Adolescents Registry

Welcome to Diabetes in Children and Adolescents Registry """ DiCARE

The Diabetes in Children and Adolescents Registry (DiCARE) is a MOH supported service to collect information about diabetes mellitus. The information can be used to estimate the incidence of diabetes disease according to the types, to evaluate its risk factors and treatment in the country. Such information is useful for assisting the MOH, non-governmental organizations, private providers and industry in planning and evaluation, leading to diabetes disease prevention and control.

JOIN DICARE!

The Diabetes in Children and Adolescents Registry (DiCARE) needs you!

Ideally all paediatricians and physician in this country who have anything to do with diabetes mellitus ought to participate in the DiCARE.

All that is required of you is to report diabetes mellitus data to the DiCARE, and this is simple (see below).

We urge you to do your bit for your community, and help DiCARE obtain the information so crucial to diabetes disease prevention and control.

Click here to find out all the benefits of being a participant of the DiCARE

Register online to be a participant of the DiCARE

Diabetes Disease Reporting

Diabetes Disease Reporting Made Simple • Online data collection

SPONSORS

Department of Paediatrics & Adult Medicine, MOH Clinical Research Centre, HKL Hospital Universiti Kebangsaan Malaysia University Malaya Medical Centre

E.

O CONTACT US

Manager, Diabetes in Children and Adolescents Registry (DiCARE) 1st Floor, MMA House 124, Jalan Pahang 50286 Kuala Lumpur Malaysia

Tel: 03 - 4044 3060 / 4044 3070 Fax: 03 - 4044 0613 Email: dicare@acrm.org.my Website: http://www.acrm.org.my/dicare

🥝 Internet







e-DiCARE Web Application





Participating SDPs

- 1) H. Kuala Lumpur
- 2) H. Putrajaya
- 2) HUKM
- 3) PPUM
- 4) H. Kluang
- 5) HUSM

- 7) H. Umum Sarawak
- 8) H. Saratok
- 9) H. Teluk Intan
- 10) H. Kuala Terengganu
- 11) H. Pulau Pinang
- 12) H. Kuala Pilah





FINDINGS (as of 1st June 2007)







Table 1 : Age Distribution

	Ν	Mean (SD)	Median	Min	Max
Current Age	219	12.51 (4.26)	13.33	1.08	19.75



> Table 2 : State of Residence

State of Residence	Frequency (%)
Johor Darul Takzim	15 (6.4)
Kedah Darul Aman	2 (0.9)
Kelantan Darul Naim	5 (2.1)
Melaka	3 (1.2)
Negeri Sembilan	6 (2.6)
Pahang Darul Makmur	5 (2.1)
Perak Darul Ridzuan	8 (3.4)
Perlis Indera Kayangan	0 (0.0)
Pulau Pinang	2 (0.9)
Sabah	0 (0.0)
Sarawak	7 (3.0)
Selangor Darul Ehsan	56 (23.8)
Terengganu	19 (8.1)
Wilayah Persekutuan	86 (36.6)
Not available / Missing	12 (5.1) / 9 (3.8)
Total	235 (100)





Chart 2: Sex Distribution



Total = 235 cases

Missing = 3(1.3%)





Table 3 : Parent's Education Level

Education	Fath	ner	Мо	ther
Primary	13	(5.5)	11	(4.7)
Secondary	100	(42.6)	57	(24.3)
Fertiary	43	(18.3)	17	(7.2)
Nil	1	(0.4)	3	(1.3)
Not known	38	(16.2)	29	(12.3)
Aissing	40	(17.0)	118	(50.2)
Fotal	235	(100)	235	(100)





Table 4 : Duration of Diabetes

	No.	Mean (SD)	Median
			(min, max)
Age at	195	8.31 (4.13)	9.17
diagnosis			(0.17, 18.5)
Duration of Diabetes	195	4.32 (3.55)	3.33 (0.08, 16.08)

Missing Data : 24 cases





Table 5 : Distribution of Ethnicity

Ethnicity	Father	Mother	Child		
	No. (%)	No. (%)	No. (%)		
Malay	104 (44.3)	103 (43.8)	105 (44.7)		
Chinese	73 (31.1)	76 (32.3)	75 (31.9)		
Indian	46 (19.6)	46 (19.6)	43 (18.3)		
Orang Asli	0 (0.0)	0 (0.0)	0 (0.0)		
Bumi Sabah	0 (0.0)	0 (0.0)	0 (0.0)		
Bumi Sarawak	3 (1.3)	3 (1.3)	3 (1.3)		
Other M'sian	3 (1.3)	4 (1.7)	4 (1.7)		
Non - M'sian	3 (1.3)	1 (0.4)	1 (0.4)		
Not known	0 (0.0)	0 (0.0)	0 (0.0)		
Missing	3 (1.3)	2 (0.9)	4 (1.7)		
Total	235 (100)	235 (100)	235 (100)		



Chart 4 : Type of Diabetes



Total = 235 cases

Missing = 16(6.8%)





Table 6: Anthropometry& Clinical Examination at Diagnosis

Measurement	At	Diagnosis	
	No.	Mean (SD)	Median (min, max)
Height	120	128.46 (26.17)	134.00 (46.00, 173.50)
Weight (kg)	145	33.20 (20.90)	29.00 (2.30, 120.00)
BMI	120	19.27 (7.59)	16.31 (9.98, 46.06)





Table 7: Anthropometry& Clinical Examination at Notification

Measurement	At	Diagnosis	
	No.	Mean (SD)	Median
			(min, max)
Height	139	143.57 (19.75)	147.00
			(73.40, 173.00)
Weight (kg)	142	44.59 (19.42)	42.50
			(9.60, 117.70)
BMI	135	20.62 (6.10)	19.00
			(12.05, 48.07)
Systolic BP	145	107.74 (12.87)	110.00
			(70.00, 143.00)
Diastolic BP	145	65.91 (11.57)	66.00
			(43.00, 121.00)





Table 8: Basis Diagnosis of Diabetes-1

Basis of Diagnosis	Clinical Presentation	No (%)
INCIDENTAL		8 (3.4)
CLINICAL		94 (40.0)
	DKA	36 (38.3)
	Obesity	8 (8.5)
	Acanthosis nigricans	7 (7.4)
	Pruritis (genitalia)	3 (3.2)
	Recurrent abscess	1 (1.1)
	Weight loss	61 (64.9)
	Hyperosmolar symptoms (polyuria, polydipsia, secondary enuresis)	72 (76.6)
	Missing	1 (1.1)





Table 8: Basis Diagnosis of Diabetes-2

Basis of Diagnosis	Investigation	No (%)
BIOCHEMISTRY		12 (5.1)
	RBS (>11.1 mmol/L)	94 (40.0)
	FBS (>7.0 mmol/L)	36 (38.3)
	OGTT (2HPP >11.1 mmol/L)	8 (8.5)
	Insulin autoantibodies	7 (7.4)
	C-peptide / Insulin level	3 (3.2)
	Ketonuria	1 (1.1)
	Ketonaemia (>0.5 mmol/L)	61 (64.9)
	HCO3 (<15 mmol/L)	72 (76.6)
	Missing	0 (0.0)
MISSING		121 (51.5)











Diabetes in Children and Adolescents Registry (DiCARE)

Progress Report

(as at 1st June 2007)



Cases Reported by SDPs

SDP	No.	%
H. Putrajaya	18	7.2
H. Kuala Lumpur	9	3.6
HUKM	90	36.0
PPUM	91	36.4
H. Kluang	5	2.0
HUSM	8	3.2
H. Kuala Terengganu	14	5.6
H. Umum Sarawak	5	2.0
H. Saratok	1	0.4
H. Teluk Intan	6	2.4
H. Pulau Pinang	1	0.4
H. Kuala Pilah	2	0.8
TOTAL	250	100



Annual Census (AC) at 31.12.2006

Year: 2006 No. of Notification : 188 No. of AC reported : 117 Overdue in AC reporting: 71



DiCARE		Problems Faced by SDPs : Data Entry		
Diabetes in Children and Adolescent Registry	No Problems Solutions			
	1.	Delay in data entry because of not enough staff	To pay nurses per cases entered to motivate them. To hire RA to perform data entry. Training for staff – in house training / national level.	
	2.	Lack of training	Training by site coordinator at SDP level. Site visits by registry manager to every SDP.	
	3.	Role of each person involved in SDP (circulated at the initiation meeting)	Specific role & responsibility of each person in DiCARE clearly stated (authorization form)	



Problems Faced by SDPs : Data Entry

2	No	Problems	Solutions
1	4.	Incompleteness of CRF	Site coordinator to look into the completeness of CRF before data entry. Mandatory fill of CRF since June 2007.
	5.	Annual census reporting not being practised	Site coordinator to ensure all the annual census is reported.



DiCARE	Problems by SDPs : Communication		
	No	Problems	Solutions
Adolescent Registry	1.	Message does not reach the SDPs	a) To have a newsletter to share the current news of DiCARE with all users.
			b) To form a DiCARE e.mail group.
	2.	Documentation of problems	 a) To come up with Problem Assessment Form where the SDP who has problems will fill it → DiCARE office. b) To produce standard progress report by defined duration.
	3.	Technical committee meeting	 a) To have a meeting every 2 months b) Suggesting a mode of communication via teleconference. c) Face to face meeting only when required.



Problems by SDPs : System

No	Problems	Solutions
1.	System error / bug problems	a) To contact Helpdesk at 03-40443060 / 3070 (Ms Tee / Akma / Zaiti) or 03-40440615 (Ms Lim Jie Ying)
		 b) To report using Enhancement of Error / Bug Form weekly or monthly.





Problems by SDPs : Report

No	Problems	Solutions
1.	No list of real time reports available.	Committee to decide on the list of real time report to be available online.







DiCARE Study Group

No	Names	Centres
1.	Dr. Fuziah Md. Zain	Hospital Putrajaya
2.	Dr. Zanariah Hussein	Hospital Putrajaya
3.	Dr. Janet Hong Yeow Hua	Hospital Putrajaya
4.	Prof Fatimah Harun	UMMC
5.	Prof Rokiah Pendek	UMMC
6.	Prof Wu Loo Ling	HUKM
7.	Dr. Ng Sheau Fang	HUKM
8.	Dr. Nor Azlin Kamal	HUKM
9.	PM Rahmah Rasat	HUKM
10.	PM Rokiah Mohd Yusof	UPM
11.	Dr. Jamaiyah Haniff	CRC, HKL
12.	Ms. Geeta Appannah	CRC, HKL





Join Us Today...

DICARE REGISTRATION FORM

What about Confidentiality?

Current legislation allows doctors to release their patients' data to persons demonstrating a need, which is essential to public health and safety. The DiCARE meets this requirement.

The DiCARE has also developed strict policies and procedures to maintain confidentiality of data collection as well as its disclosure.

Wouldn't You Want to Report to the DiCARE?

For the DiCARE to succeed, ideally all doctors who deal with diabetic patients ought to report to the DiCARE. We urge you to contribute to your community by helping DiCARE to obtain the information so crucial in promoting effective diabetes prevention and control.

For further information, the DiCARE is also published electronically on website at:

http://www.acrm.ora.mv/dicare

We look forward to the continued support and collaboration from all parties that will enable the Diabetes in Children and Adolescents Registry (DiCARE) to develop and contribute significantly to the control of diabetes mellitus in this country.



Postal Code: _	City/Town:	and the
State:	1	
Tel:	()	
Fax:	()	
Handphone:	()	
EMail		

Please mail or fax to:

Manager, Diabetes in Children and Adolescents Registry 1st Floor, MMA House, 124 Jalan Pahang, 53000 Kuala Lumpur, Malaysia Tel: 03-40443060 / 03-40443070 Fax: 03-40443080 Website: http://www.acrm.org.my/dicare Email: dicare@acrm.org.my

DIABETES IN CHILDREN AND ADOLESCENTS REGISTRY (DiCARE)



Sponsored by:

Departments of Paediatrics & Adult Medicine, MOH

Clinical Research Centre, HKL Hospital Universiti Kebangsaan Malaysia Universiti Malaya Medical Centre

CRC MB14.4_20070515





Benefits When You Participate in DiCARE

- Access to database & therefore study the trend of diabetes in children & adolescents.
- Online data query & statistics of your own institution data versus the country data anytime, anywhere.
- Online comparison of your institution data versus the country data anytime, anywhere.
- Data security & privacy are in compliance with regulatory requirement.
- Invitation to all functions organized by DiCARE.
- Acknowledgement in all publications of DiCARE.
- Complementary personal copy of all DiCARE publications.
- Free listing in the DiCARE's website.
- Tap into a network of like-minded people from diverse professional disciplines & backgrounds.



Progress Report since start of DiCARE December 2008



Cases Reported by SDP

SDPs	2006	2007	2008
1001	18 (9.2)	0	7 (6.4)
1002	7 (3.6)	7 (6.6)	1 (0.9)
1003	73 (36.5) 32 (33.9)	36 (33.1)
1004	87 (43.5) 6 (6.4)	0
1005	2 (1.0)	3(3.2)	0
1006	0	8 (8.5)	0
1007	0	13 (13.8)	0
1008	2 (1.0)	9 (9.5)	0
1009	0	1 (1.1)	0
1010	0	3 (3.2)	6 (5.5)
1011	0	1 (1.1)	6 (5.5)
1012	1 (0.5)	1 (1.1)	8 (7.4)
1013	0	1 (1.1)	38 (34.9)
1014	5 (2.5)	2 (2.1)	1 (0.9)
1015	0	4 (4.2)	5 (4.6)
1016	0	2 (2.1)	0
1017	0	1(1.1)	0
Total	195	94	108



Diabetes in Children and Adolescent Registry





Project Activities

➤ 16 –17 July 2008

: Report write-up

- 26 September 2008
 - : Centre Survey Study discussion

16 -17 October 2008

- : Report write-up
- : Revise on the Case Report Form → will use the new version CRF to collect data in 2009

26 November 2008

- : Centre Survey Study discussion
- : Finalize on the report writing
- : 2009 planning





Achievements

September 2008

 Medical Journal of Malaysia (MJM), Vol.63, Supplement C, September 2008

> 20- 22 October 2008

- Create 2008
- Poster presentation

14 November 2008

 Presentation of DiCARE data at World Diabetes Day, Malacca





Achievements

> December 2008 Registry report





Future Planning

- To invite more sites to join DiCARE.
- To provide more user trainings for the sites / SDPs.
- To present in scientific conferences.
- To recruit a Research Assistant
- To promote DiCARE (MPA, MMA)
- To form a SDP e.mailing group





- Please visit the DiCARE website.
- Please begin to report to DiCARE
- We need to know our Malaysian statistics.
- How bad / well are we doing?
- Planning for diabetes care in the young for better healthcare in 2020.

Thank you

