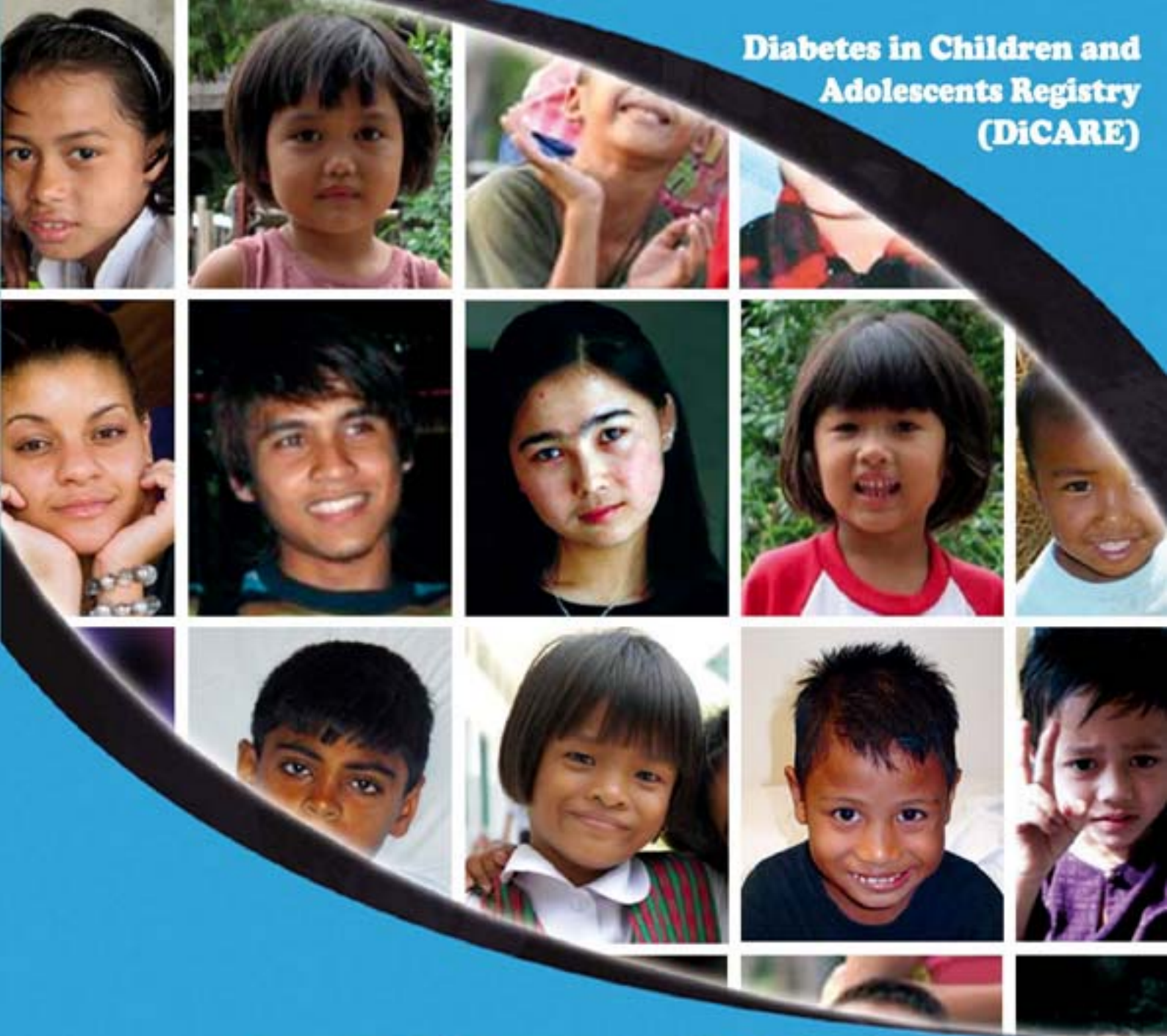


**Diabetes in Children and
Adolescents Registry
(DiCARE)**



Annual Report of Diabetes in Children and Adolescents Registry (2006-2007)

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ANNUAL REPORT OF THE DIABETES IN CHILDREN AND ADOLESCENTS REGISTRY (2006-2007)

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CHAPTER 1

PATIENTS' SOCIO-DEMOGRAPHIC PROFILE

Jamaiyah Haniff

Geeta Appannah

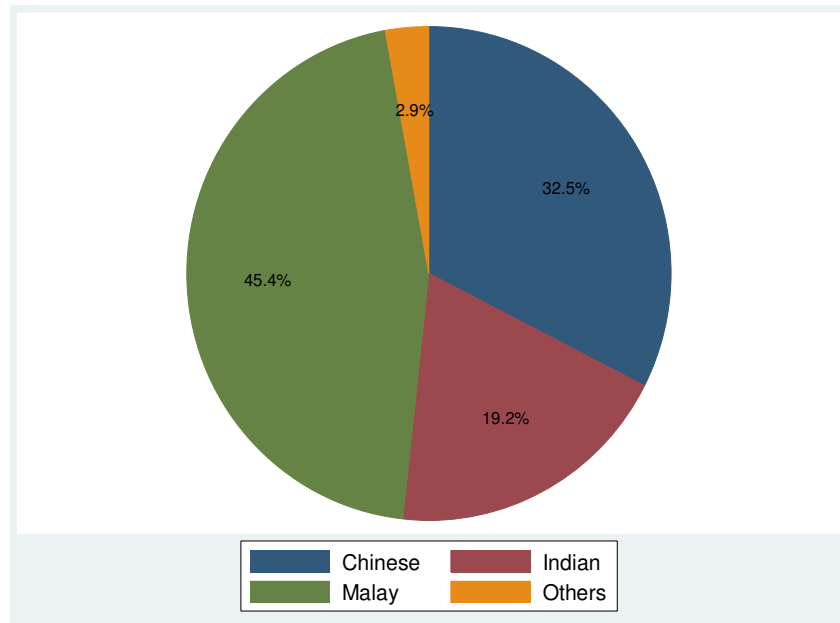
Fuziah Md. Zain

1.0 Socio-demographic profile

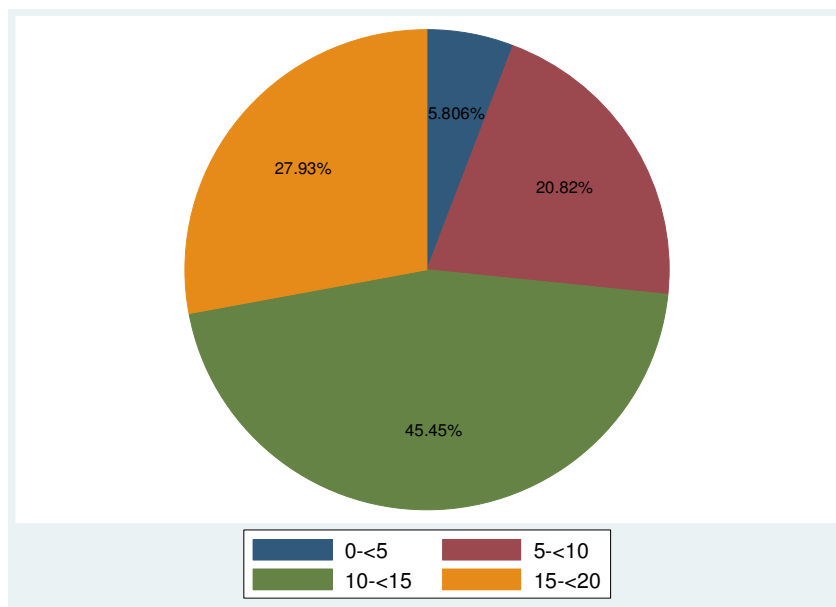
The male to female ratio was 1:1.2, indicating a higher female distribution. In terms of ethnicity 45.4% of patients were Malay, 32.5% Chinese, 19.2% Indian and 2.9% represented the other ethnic groups. The majority (45.4%) of patients were between 10 and less than 15 years of age (*refer to Table 1.0.1, Figure 1.0.1 and Figure 1.0.2*)

**Table 1.0.1 Summary of patient characteristics for patients with diabetes mellitus,
DiCARE 2006-2007**

Socio-demographic characteristics	Total N=240	
	N	%
Gender		
• Male	110	45.8
• Female	130	54.2
Ethnicity		
• Malay	109	45.4
• Chinese	78	32.5
• Indian	46	19.2
• Others	7	2.9
Age Group (years)		
• <5	14	5.8
• 5 - <10	50	20.8
• 10 - <15	109	45.4
• 15 - <20	67	27.9



**Figure 1.0.1 Distribution of patients with diabetes mellitus by ethnicity,
DiCARE 2006-2007**



**Figure 1.0.2 Distribution of patients with diabetes mellitus by age (years),
DiCARE 2006-2007**

1.1 Types of diabetes

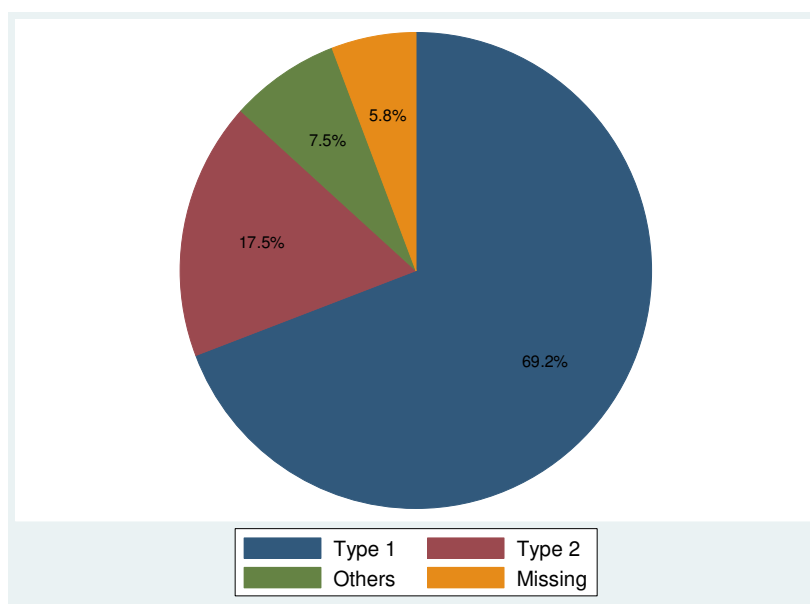
From the cases reported, it was found that majority of patients were type 1 diabetics (69.2%). We do not observe a similar trend with Japan, where there is an increasing number of T2DM among adolescents with 80% of all newly diagnosed cases were T2DM.⁵ Our sample size was however comparatively smaller.

Nevertheless, Malaysia is similar to Singapore and Hong Kong. Type 2 diabetes mellitus is on the rise in Singapore, accounting for approximately 10% of all new cases of childhood diabetes.⁴ According to the Hong Kong Childhood Diabetes Registry, the incidence of T1DM was 1.4 per 100,000 and 0.1 per 100,000 for T2DM. According to the Hong Kong Childhood Diabetes Registry, T2DM accounted for 7% of all identified cases of childhood diabetes in all districts of Hong Kong in 1996.¹¹ In Thailand, the proportion of new cases of T2DM in children in the 0-14 years age group rose from 5% in 1987–1996 to 17.9% in 1997–1999.^{12,13}

**Table 1.1.1 Types of diabetes mellitus in children and adolescents,
DiCARE 2006-2007**

Type of Diabetes (N=240)	Total	
	N	%
Type 1	166	69.2
Type 2	42	17.5
Others*	18	7.5
Not available/indeterminate	14	5.8

**Others = secondary to other diseases i.e thalassaemia, steroid induced (exogenous/ endogenous), post pancreatitis/pancreatectomy*



**Figure 1.1.1 Types of diabetes mellitus in children and adolescents,
DiCARE 2006-2007**

CHAPTER 2

SOCIO-DEMOGRAPHIC PARAMETERS BY TYPES OF DIABETES

Zanariah Hussein

2.1 Type 1 Diabetes Mellitus (T1DM)

2.1.1 Patient characteristics

In this study, T1DM makes up the largest proportion (69.2%) of the reported cases. Among the patients with T1DM, there were more females than males (54.2% vs 45.8%). Epidemiological studies of T1DM have shown inconsistent findings on gender differences in incidence of Type 1 diabetes. In general, a male excess has been found in countries with a high incidence and a female excess in countries with a low incidence of Type 1 diabetes.^{14, 15, 16}

There was a similar proportion of cases of T1DM of Malay and Chinese ethnicity, i.e. 38.6% and 36.7% respectively. About one fifth (21.1%) of T1DM cases were Indians.

In this study there was an increasing incidence of T1DM with age. The highest incidence (42.2%) occurred in the pubertal age group of 10 - < 15 years. The number of cases in the youngest age group of < 5 years was much lower than that in the other older age groups. This pattern has been reported in other studies.¹⁷

The median age at diagnosis in cases of T1DM in this study was 4.0 years with the minimum age of 0.2 and maximum age of 16.8 years.

Table 2.1.1 Characteristics of patients with type 1 diabetes, DiCARE 2006-2007

Socio-demographic characteristics (N=166)	N	%
Gender		
• Male	76	45.8
• Female	90	54.2
Ethnicity		
• Malay	64	38.6
• Chinese	61	36.7
• Indian	35	21.1
• Others	6	3.6
Age group		
• <5	10	6.0
• 5 - <10	42	25.3
• 10 - <15	70	42.2
• 15 - <20	44	26.5

2.1.2 Family history of diabetes

There was a positive family history of diabetes mellitus in 13.3% of the cases of T1DM. In those with a positive family history, the majority had only one parent with diabetes mellitus.

Increased risk has been reported in siblings of T1DM patients.¹⁸ The risk of type 1 rises with an increasing number of affected relatives.¹⁹ It has also been shown that the risk varies, depending on which relatives have diabetes. For type 1 diabetes, several studies have shown that having a father with diabetes is associated with a higher risk than having a mother with diabetes.²⁰

**Table 2.1.2 Patients with T1DM with positive family history of diabetes mellitus,
DiCARE 2006-2007 (N = 166)**

Family history	Yes		No	Unknown
	n=22 (13.3%)	%		
Parents			n=138 (83.1%)	n=6 (3.6%)
• Both parents	0	0		
• 1 parent only (father/mother)	15	68.2		
Sibling				
• 1 or > 1 siblings only	5	22.7		
• Sibling(s) & 1 parent	2	9.1		
• Sibling(s) & both parents	0	0		

2.2 Type 2 Diabetes Mellitus (T2DM)

2.2.1 Patient characteristics

In this study, T2DM makes up 17.5% of the reported cases. Among the patients with T2DM, there were more females than males (57.1% vs 42.9%). Studies in the western population have indicated gender differences in the incidence of childhood T2DM with a higher frequency of cases in females.²¹

The majority of cases of T2DM were Malay (64.3%). A similar proportion of cases were of Chinese and Indian ethnicity, i.e. 19.0% and 16.7% respectively. These figures may not however represent the general population as this was a hospital-based study and the sample size was small. In the recent 3rd National Health and Morbidity Survey 2006 (NHMS III), the prevalence of diabetes among adults (above 18 years) was highest among Indian (19.1%) and similar among the Malay and Chinese, 11.9% and 11.4% respectively.²²

Puberty, a period associated with insulin resistance, plays an important role in the development of type 2 diabetes in children. Most T2DM patients (57.1%) in this study are at pubertal age of 10 to < 15 years. There seemed to be a reduction in the proportion of cases in the above 15 years age group. This may be under representation due to transfer of cases to the adult care and the mobility of patients as a result of job or education. The lowest proportion of cases was in the 5 - <10 year age group and there were no reported cases in the youngest age group of < 5 years.

Median age of diagnosis was 11.4 years with the minimum age of 7.7 and maximum age of 16.8 years. Most studies have reported the peak age at diagnosis for T2DM during the mid-pubertal period, although few cases have been observed in the younger prepubertal age groups.²¹

Table 2.2.1 Characteristics of patients with T2DM, DiCARE 2006-2007

Socio-demographic characteristics (N= 42)	N	%
Gender		
• Male	18	42.9
• Female	24	57.1
Ethnicity		
• Malay	27	64.3
• Chinese	8	19.0
• Indian	7	16.7
• Others	0	0.0
Age group		
• <5	0	0.0
• 5 - <10	2	4.8
• 10 - <15	24	57.1
• 15 - <20	16	38.1

2.2.2 Family history of diabetes

Family history of diabetes is strongly associated with T2DM in children. In previous studies, the frequency of a history of T2DM in a first- or second-degree relative has been reported in the range between 74% and 100%.²¹

The majority of T2DM cases (64.3%) in this study had a positive family history of diabetes mellitus in first degree relatives. All these patients had either one or both parents with diabetes mellitus.

**Table 2.2.2 Patients with T2DM with positive family history of diabetes mellitus,
DiCARE 2006-2007 (N= 42)**

Family history	Yes		No	Unknown
	n=27 (64.3%)	%		
Parents			n=14 (33.3)%	n=1 (2.4)%
• Both parents	4	14.8		
• 1 parent only (father/mother)	20	74.1		
Sibling				
• 1 or > 1 siblings only	0	0		
• Sibling(s) & 1 parent	2	7.4		
• Sibling(s) & both parents	1	3.7		

The classification of diabetes in some patients may not be straight forward because of atypical presentation. At the year-end census, data was available in 78 patients of whom one out of 54 T1DM patients and one out of 18 T2DM had their diagnosis revised.

**Table 2.2.3 Distribution in Reclassification of Diagnosis at Year-end Census 2006
N=78**

Reclassification	Diagnosis	n	%
Yes	From type 1 to Others	1	1.3
	From type 2 to Others	1	1.3
No	Type 1	53	68.6
	Type 2	17	22.1
	Others	6	9.1

CHAPTER 3

CLINICAL CHARACTERISTICS & ANTHROPOMETRICS PARAMETERS BY TYPES OF DIABETES

Fuziah Md Zain

Janet Hong Yeow Hua

3.1 Type 1 Diabetes Mellitus (T1DM)

Of the 240 patients, 166 (69.2%) had type 1 diabetes.

3.1.1 Basis of diagnosis

The basis of diagnosis is known in 162 patients. The clinical presentations at diagnosis include hyperosmolar symptoms (62.8%), diabetic ketoacidosis (DKA) (57.1%) and weight loss (50.0%). The biochemical characteristics at the time of diagnosis include random plasma glucose (RPG) >11.1 mmol/L (89.1%), ketonuria (68.6%) and serum bicarbonate (HCO₃) <15mmol/L (39.4%). Of these patients, only 2.9% had their insulin auto-antibodies measured and 12.4% had their C-peptide/insulin levels tested. This may reflect the unavailability of these tests in most centres. Two patients had the diagnosis made incidentally based only on biochemical findings.

(refer Table 3.1.1, Figure 3.1.1(a) and Figure 3.1.1(b))

Table 3.1.1 The basis of diagnosis for patients with T1DM, DiCARE 2006-2007

Basis of diagnosis, N = 162		Total	
		N	%
Incidental	Asymptomatic	2	1.2
Clinical evaluation (N= 156)	DKA	89	57.1
	Obesity	3	1.9
	Acanthosis nigricans	3	1.9
	Pruritis (genitalia)	2	1.3
	Recurrent abscess	1	0.6
	Weight loss	78	50.0
	Hyperosmolar symptoms (polyuria or polydipsia or secondary enuresis)	98	62.8
	Indeterminate	2	1.3
Biochemical parameters (N= 137)	RPG > 11.1 mmol/L	122	89.1
	FBG > 7.0 mmol/L	27	19.7
	OGTT (2 hours) > 11.1 mmol/L	3	2.2
	Insulin auto-antibodies	4	2.9
	C-peptide/ insulin level	17	12.4
	Ketonuria	94	68.6
	Ketonaemia (>0.5 mmol/L)	14	10.2
HCO ₃ < 15mmol/L	54	39.4	

DKA=diabetic ketoacidosis

HCO₃=serum bicarbonate

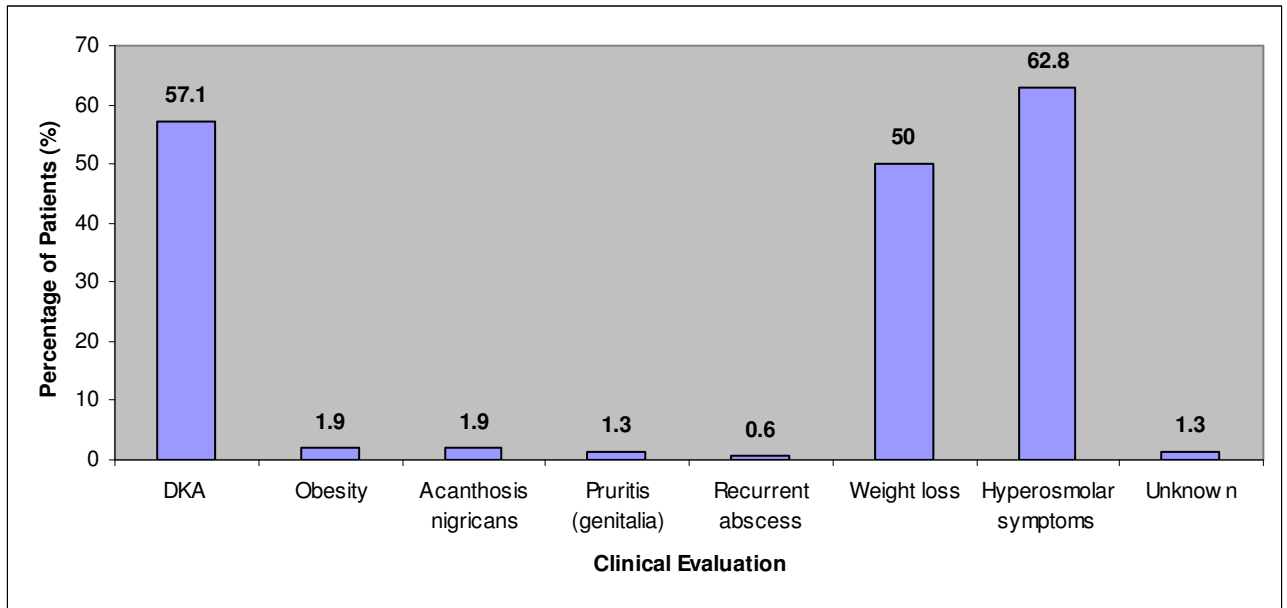


Figure 3.1.1 (a) The basis of diagnosis (Clinical evaluation) of T1DM patients, DiCARE 2006-2007

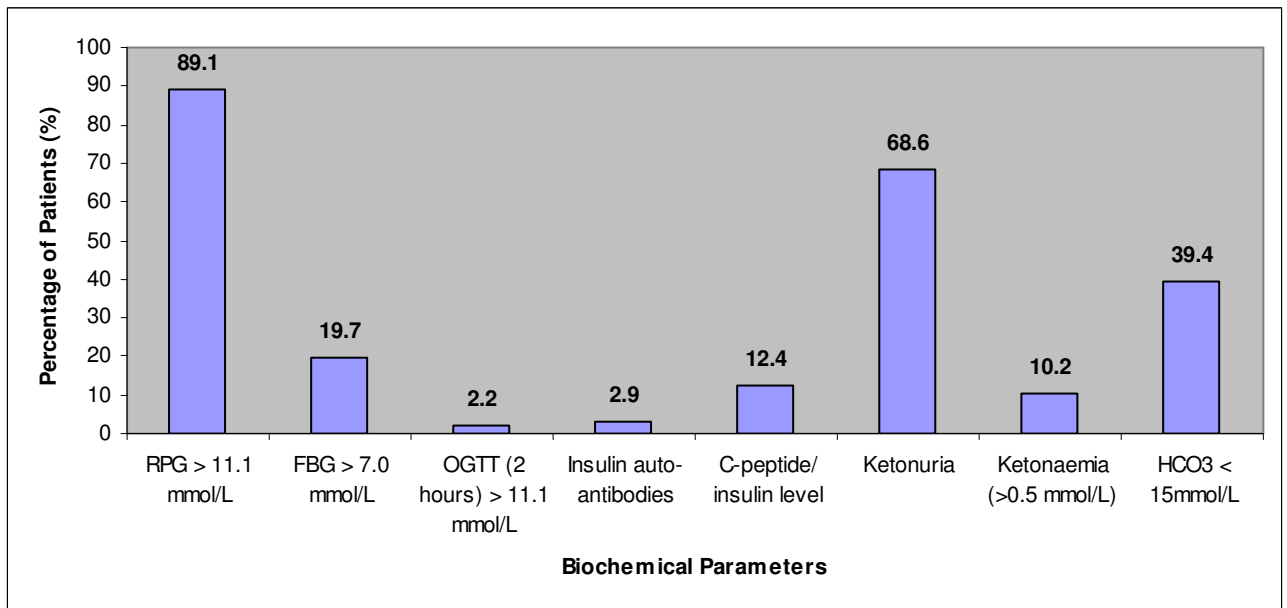


Figure 3.1.1 (b) The basis of diagnosis (Biochemical parameters) of T1DM patients, DiCARE 2006-2007

3.1.2 Blood pressure

Hypertension is defined as blood pressure (systolic and/or diastolic) of more than 95th percentile for age and gender using International Task Force reference tables (1998).

At diagnosis, only 68 of 166 (41.0%) patients had their blood pressures reported. Of these, 6 (8.8%) patients had hypertension, 5 of whom were females aged between 5 and 10 years.

At the year-end annual census, only 4 out of 39 (10.3%) were hypertensive, and there was equal gender distribution. Of these 4 patients with hypertension, 3 were in the 10 to 15 years old group and 1 patient was in the 5 to 10 years age group.

3.1.3 Anthropometry

Sixty-three percent (63.3%) of T1DM patients had their height reported at notification and these were plotted on the NCHS growth curves for children 2-18 years old (See Appendix 4). Of the 58 girls with height reported, only one (1.7%) was tall for her age (>97th percentile), 47 (81.0%) were of normal height (between 3rd and 97th percentile) and 10 (17.2%) were short for their ages (<3rd percentile). Majority of the girls were in the normal height category.

Of the 47 boys with their heights reported, one (2.1%) was tall for his age (>97th percentile), 41 (87.2%) were of normal height (between 3rd and 97th percentile) and 5 (10.6%) were short for their ages (<3rd percentile).

Of all T1DM patients (N=166), only 111 (67%) had their BMI reported.

Of the 64 girls with BMI reported, majority (92.2%) were in the normal weight category, while two (3.1%) were obese, two (3.1%) were overweight and one (1.56%) was underweight. Of the 47 boys with BMI reported, 32 (68.1%) had normal weight, while 4 (8.5%) were obese, 5 (10.6%) were overweight and 6 (12.8%) were underweight.

(refer Table 3.1.2(a) and Table 3.1.2(b))

3.2 Type 2 Diabetes Mellitus (T2DM)

Of the 240 patients, 42 (17.5%) had type 2 diabetes.

3.2.1 The basis of diagnosis

Of 42 T2DM patients in this registry, the basis of diagnosis was reported for 41 of them. The common clinical manifestations were hyperosmolar symptoms (63.9%), obesity (55.6%) and acanthosis nigricans (44.4%). Two (5.6%) presented with DKA, which is uncommon in T2DM patients. The diagnosis was confirmed by biochemical findings [RPG > 11.1 mmol/L (69.7%), FBG > 7.0 mmol/L (48.5%) and OGTT (24.2%)].

(refer Table 3.2.1, Figure 3.2.1(a) and Figure 3.2.1(b))

Table 3.2.1 The basis of diagnosis of patients with T2DM, DiCARE 2006-2007

Basis of diagnosis (N = 41)		Total	
		n	%
Incidental	Asymptomatic	1	2.4
Clinical evaluation N=36	DKA	2	5.6
	Obesity	20	55.6
	Acanthosis nigricans	16	44.4
	Pruritis vulvae	5	13.9
	Recurrent abscess	0	0.0
	Weight loss	8	22.2
	Hyperosmolar symptoms (polyuria or polydipsia or secondary enuresis)	23	63.9
	Unknown	1	2.8
Biochemical parameters N = 33	RPG > 11.1 mmol/L (RBS)	23	69.7
	FBG > 7.0 mmol/L (FBS)	16	48.5
	OGTT	8	24.2
	Insulin auto-antibodies (IAA)	0	0.0
	C-peptide / insulin level	5	15.2
	Ketonuria	4	12.1
	Ketonaemia (>0.5 mmol/L)	1	3.0
	Bicarbonate < 15mmol/L	1	3.0
	Unknown	1	3.0

DKA=diabetes ketoacidosis
RPG=random plasma glucose
RBG=random blood glucose

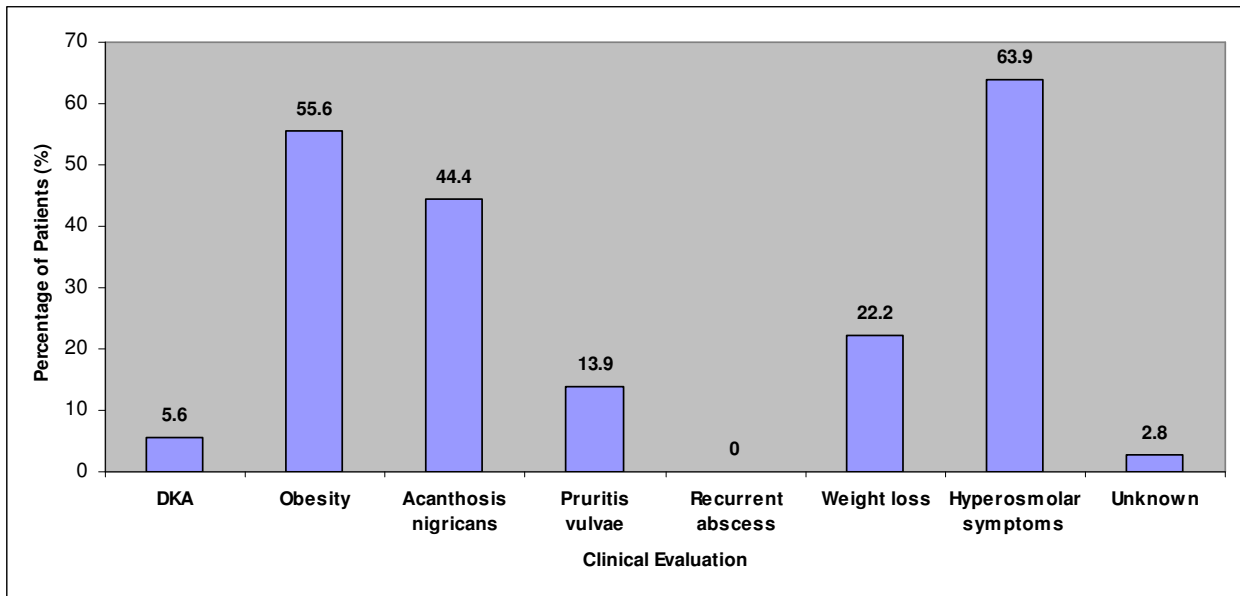


Figure 3.2.1 (a) The basis of diagnosis (Clinical evaluation) of T2DM patients, DiCARE 2006-2007

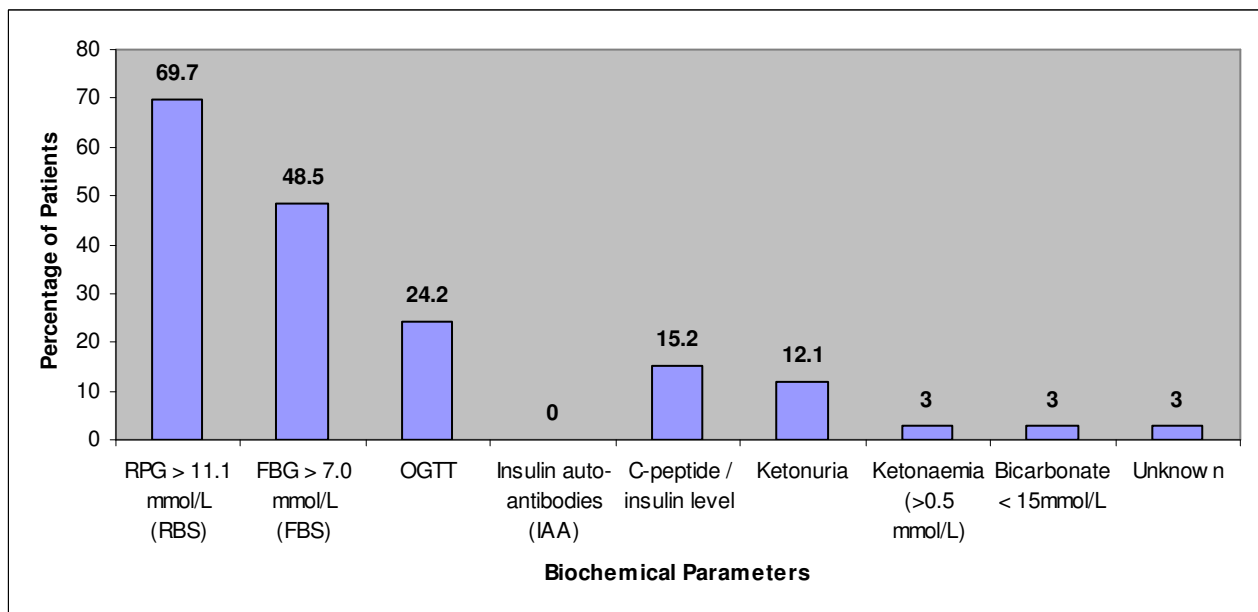


Figure 3.2.1 (b) The basis of diagnosis (Biochemical parameters) of T2DM patients, DiCARE 2006-2007

3.2.2 Blood pressure

At diagnosis, only 30 out of 42 (71.4%) patients had their blood pressures documented. Of these, 10 (33.3%) were found to be hypertensive their age were between 9 to 16 years. Five out of 11 (45.5%) males and five of 19 (26.3%) females were reported to have hypertension. At the year-end annual census, only 4 out of 28 patients (14.3%) with documented blood pressure had hypertension.

**Table 3.2.2 Hypertension at diagnosis (by age) in patients with T2DM,
DiCARE 2006-2007**

Age (years)	Hypertension	
	N	%
<5 (n=0)	0	0.0
5 - <10 (n=2)	1	50.0
10 - <15 (n=20)	8	40.0
15 - <20 (n=8)	1	12.5

3.2.3 Anthropometry

Of the patients with T2DM (N=42), 64.3% had their height and weight recorded, from which their BMIs were calculated.

Patients' heights were plotted on the NCHS growth curves for children aged 2-18 years old (See Appendix 4A). Of the 15 girls with their heights reported, eight (53.3%) were of normal height (between the 3rd and 97th percentile), 2 (13.3%) were tall for their age (>97th percentile), and 5 (33.0%) were short for their ages (<3rd percentile). Of the 12 boys with their heights reported, eight (66.7%) were of normal height (between 3rd and 97th percentile), one (8.3%) was tall for his age (>97th percentile), and three (25.0%) were short for their ages (<3rd percentile).

Of all T2DM patients (N=42), only 27 (64.3%) had data on BMI.

Of the 15 girls with BMI reported, majority was either overweight (4 patients) or obese (6 patients). Five girls were in the normal weight category. None of the girls were underweight. Of the 12 boys with BMI reported, majority was either overweight (4 patients) or obese (7 patients). Only one boy had normal weight.

(refer Figure 3.2.2(a) and Figure 3.2.2(b))

CHAPTER 4

MANAGEMENT DETAILS OF DIABETES MELLITUS

Wu Loo Ling

Rahmah Rasat

4.0 Overall self care practices

4.0.1 Self care practices

The majority of the children with diabetes self-monitor their diabetes control. Eighty percent (80.4%) of them practise blood glucose testing, 1.3% do urine glucose testing and 2.5% reported testing for blood ketone (*refer Table 4.0.1*).

**Table 4.0.1 Self care practices for patients with diabetes mellitus,
DiCARE 2006-2007**

Self care Practices	Distribution of patients	Total	
		N	%
Self Monitoring Blood Glucose (SMBG) testing	Yes	193	80.4
	No	24	10.0
	Missing	23	9.6
Blood ketone testing	Yes	6	2.5
	No	164	68.3
	Missing	70	29.2
Urine glucose testing	Yes	3	1.3
	No	166	69.2
	Missing	71	29.6

4.0.2 Self Monitoring Blood Glucose (SMBG)

Among those who do Self Monitoring Blood Glucose (SMBG) as a self care practice, 79% (N=122) responded to this questionnaire. The frequency of SMBG ranges widely from 0.25 to 40 times a week with mean of 9.2 (7.7) per week and median of 7 per week. This is much below the ideal practice of ≥ 28 times a week. The wide variation in frequency of SMBG may be due to high cost and lack of subsidy for glucose strips in the hospitals or government agencies.

(refer Table 4.0.2).

**Table 4.0.2 Blood glucose testing for patients with diabetes mellitus,
DiCARE 2006-2007**

Self care monitoring	N	Mean	SD	Min	Max	Median	IQR
SMBG testing (no. of times/week)	122	9.2	7.7	0.3	40.0	7.0	9.0

SMBG = Self Monitoring Blood Glucose
IQR=inter quartile range

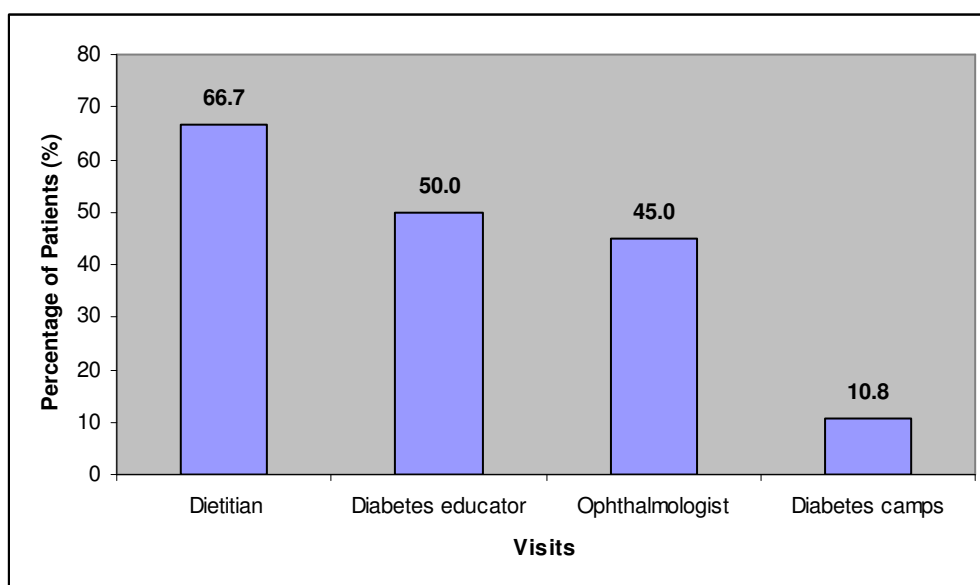
4.0.3 Visits to healthcare professionals over the last 12 months

A substantial proportion of diabetic children reported that they consulted with dietitian (66.7%), diabetes educator (50%), and ophthalmologist (45%) over the past 12 months. Eleven percent (10.8%) reported having participated in the annual diabetes camp over the last 12 months. This data needs to be verified as many centers in Malaysia still lack healthcare professionals and therefore the figures might be an over-estimate.

(refer Table 4.0.3 and Figure 4.0.1).

**Table 4.0.3 Visits to healthcare professionals over the last 12 months,
DiCARE 2006-2007**

Visits	Distribution of patients	N	%
Dietitian	Yes	160	66.7
	No	51	21.3
	Missing	29	12.1
Diabetes educator	Yes	120	50.0
	No	78	32.5
	Missing	42	17.5
Ophthalmologist	Yes	108	45.0
	No	65	27.1
	Missing	67	27.9
Diabetes camps	Yes	26	10.8
	No	129	53.8
	Missing	85	35.4



**Figure 4.0.1 Visits to healthcare professionals over the last 12 months for patients
with diabetes mellitus, DiCARE 2006-2007**

4.0.4 The number of visits to healthcare professionals over the last 12 months

This section had poor response from the patients. The mean frequency of visits to the dietitian, diabetes educators and ophthalmologist was 1.88 ± 1.6 , 2.27 (1.7), 1.96 (1.8) times respectively over the past 12 months. Twenty-four respondents reported that their participation in two diabetes camps over the past 12 months which is very encouraging.

(refer Table 4.0.4).

**Table 4.0.4 Number of visits to healthcare professionals over the last 12 months,
DiCARE 2006-2007**

Number of visits to healthcare professionals	N	Mean	SD	Min	Max	Median	IQR*
Dietitian	78	1.9	1.6	1.0	10.0	1.0	1.0
Diabetes educator	51	2.3	1.7	1.0	10.0	2.0	2.0
Ophthalmologist	69	2.0	1.8	1.0	10.0	1.0	1.0
Diabetes camps	24	2.0	2.1	1.0	10.0	1.0	1.0

*IQR=inter quartile range

4.0.5 Other self care practices

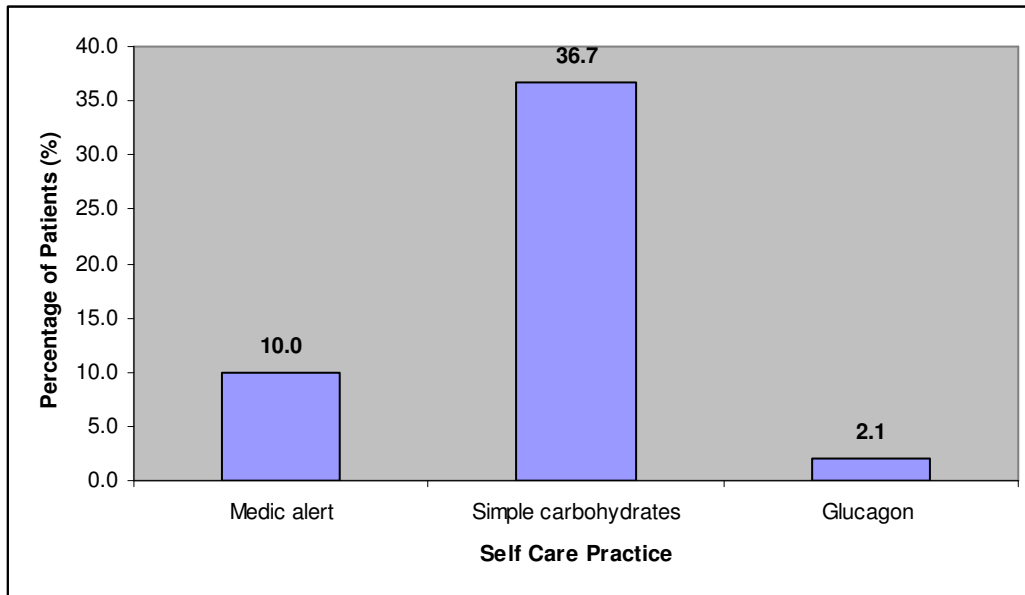
Apart from monitoring of glucose control, patients also carry out self care practices such as carrying a medic alert (10%), ready access to simple carbohydrate (hypo kit) at all times (36.7%) and having standby glucagon at home (2.1%) for emergency use.

(refer Table 4.0.5 and Figure 4.0.2).

**Table 4.0.5 Other self care practices for patients with diabetes mellitus,
DiCARE 2006-2007**

Other self care practice	Distribution of patients	N	%
Carrying medic alert	Yes	24	10.0
	No	130	54.2
	Missing	86	35.8
Carrying simple carbohydrates	Yes	88	36.7
	No	70	29.2
	Missing	82	34.2

Keeping glucagon at home	Yes	5	2.1
	No	155	64.6
	Missing	80	33.3



**Figure 4.0.2 Other self care practices for patients with diabetes mellitus,
DiCARE 2006-2007**

4.0.6 Treatment

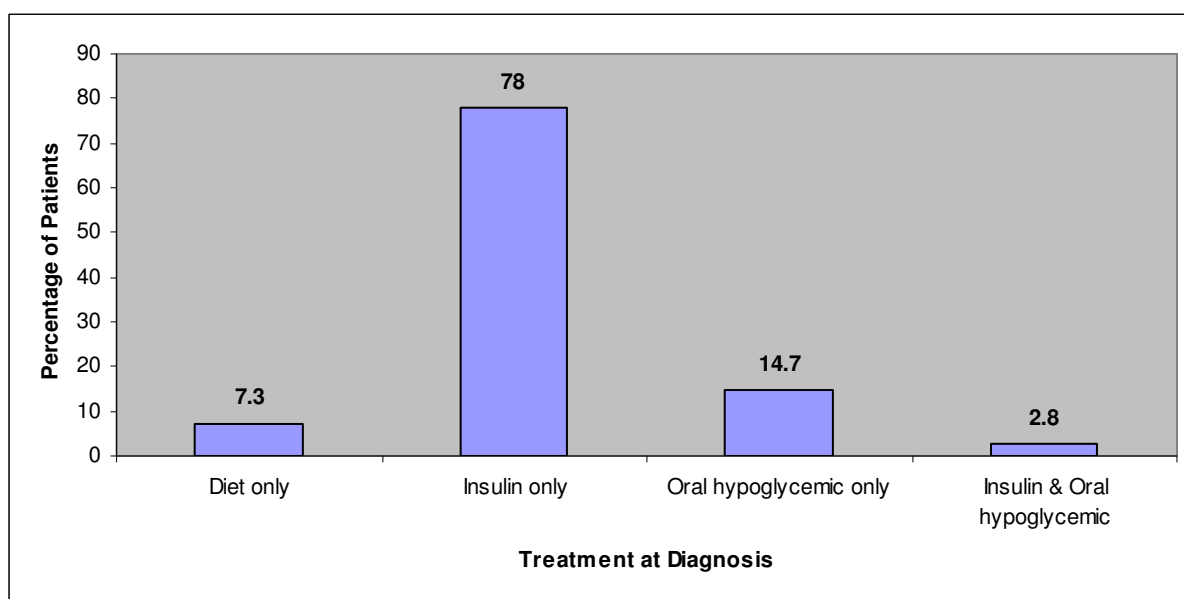
At diagnosis of diabetes, 7.3% of the children were put on dietary control only, 78.0% on insulin only, 14.7% on oral hypoglycemic agent only and 2.8% on a combination of insulin and oral hypoglycemic agent (*refer Table 4.0.6 and Figure 4.0.3*).

At notification, none of the patients were on diet control only, 69.7% on insulin only, 22.9% on oral hypoglycemic agent only and 6.4% on a combination of insulin and oral hypoglycemic agent (*refer Table 4.0.7 and Figure 4.0.4*).

During the year-end annual census 2006-2007 however 4.1% were on diet only, 64.3% on insulin only, 21.4% on oral hypoglycemic agent only and 5.1% on a combination of insulin and hypoglycemic agent (*refer Table 4.0.8 and Figure 4.0.5*).

**Table 4.0.6 Treatments at diagnosis for patients with diabetes mellitus,
DiCARE 2006-2007**

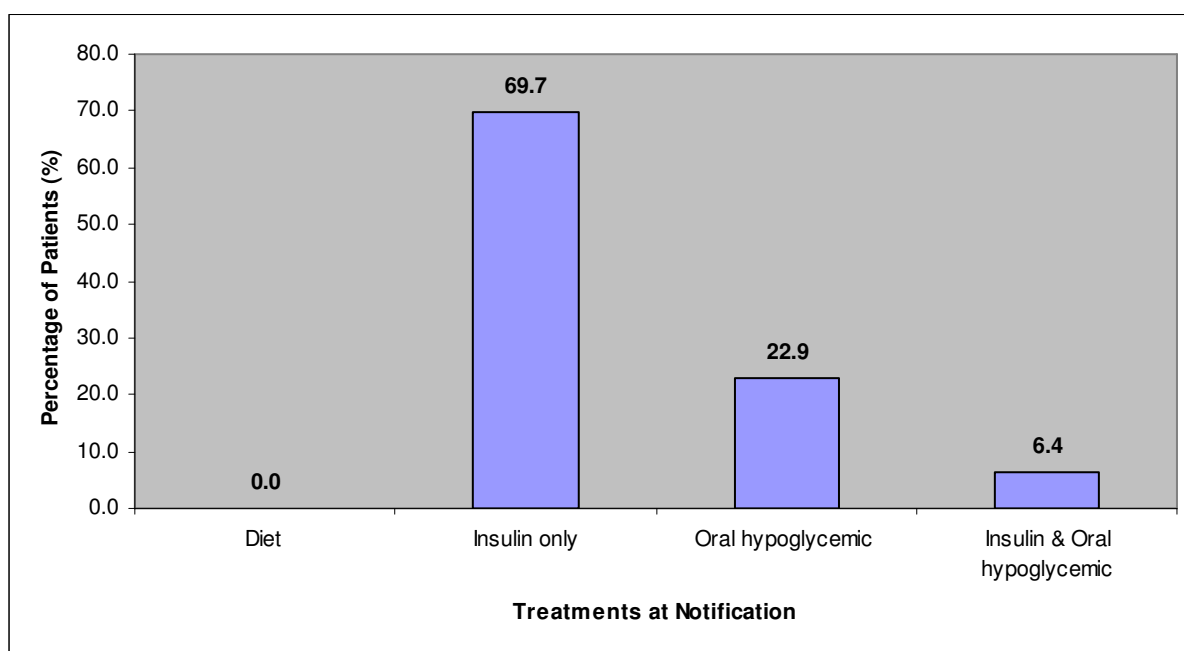
Treatments at diagnosis	Distribution of patients	N	%
Diet only	Yes	8	7.3
	No	101	92.7
Insulin only	Yes	85	78.0
	No	24	22.0
Oral hypoglycemic only	Yes	16	14.7
	No	93	85.3
Insulin & Oral hypoglycemic	Yes	3	2.8
	No	106	97.2



**Figure 4.0.3 Treatments at diagnosis for patients with diabetes mellitus,
DiCARE 2006-2007**

**Table 4.0.7 Treatments at notification for patients with diabetes mellitus,
DiCARE 2006-2007**

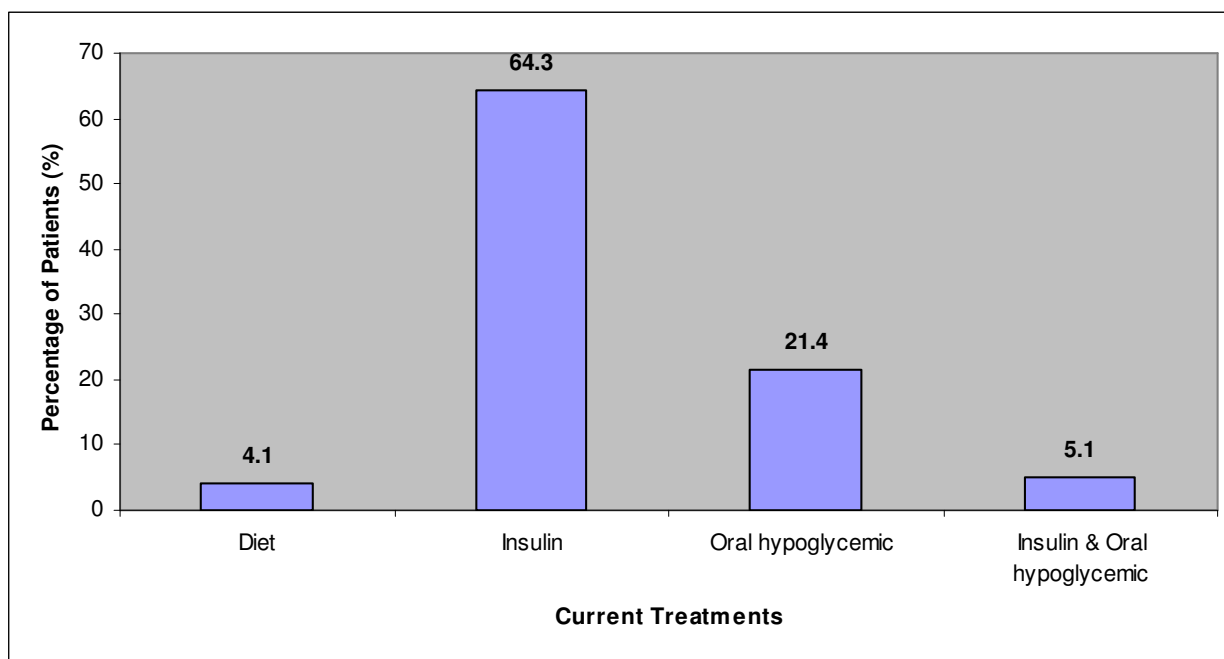
Treatments at notification	Distribution of patients	N	%
Diet only	Yes	0	0.0
	No	109	100.0
Insulin only	Yes	76	69.7
	No	33	30.3
Oral hypoglycemic only	Yes	25	22.9
	No	84	77.1
Insulin & Oral hypoglycemic	Yes	7	6.4
	No	102	93.6



**Figure 4.0.4 Treatments at notification for patients with diabetes mellitus,
DiCARE 2006-2007**

**Table 4.0.8 Current treatments for patients with diabetes mellitus,
DiCARE 2006-2007**

Current treatments	Distribution of patients	N	%
Diet only	Yes	4	4.1
	No	94	95.9
Insulin only	Yes	63	64.3
	No	35	35.7
Oral hypoglycemic only	Yes	21	21.4
	No	77	78.6
Insulin & Oral hypoglycemic	Yes	5	5.1
	No	93	94.9



**Figure 4.0.5 Current treatments for patients with diabetes mellitus,
DiCARE 2006-2007**

4.0.7 Insulin Treatment.

At diagnosis, 47.7% of patients who required insulin were started on a conventional regime with one or two injections daily and 14.7% on intensive regime with three or more injections daily. Data was however unavailable for 37.6% of patients.

(refer Table 4.0.9 and Figure 4.0.6)

At the time of notification, less patients (42.2% vs 47.7%) continued on conventional insulin regime and more patients (21.1% vs 14.7%) were given intensive insulin regime. Data was unavailable for 36.7% of patients.

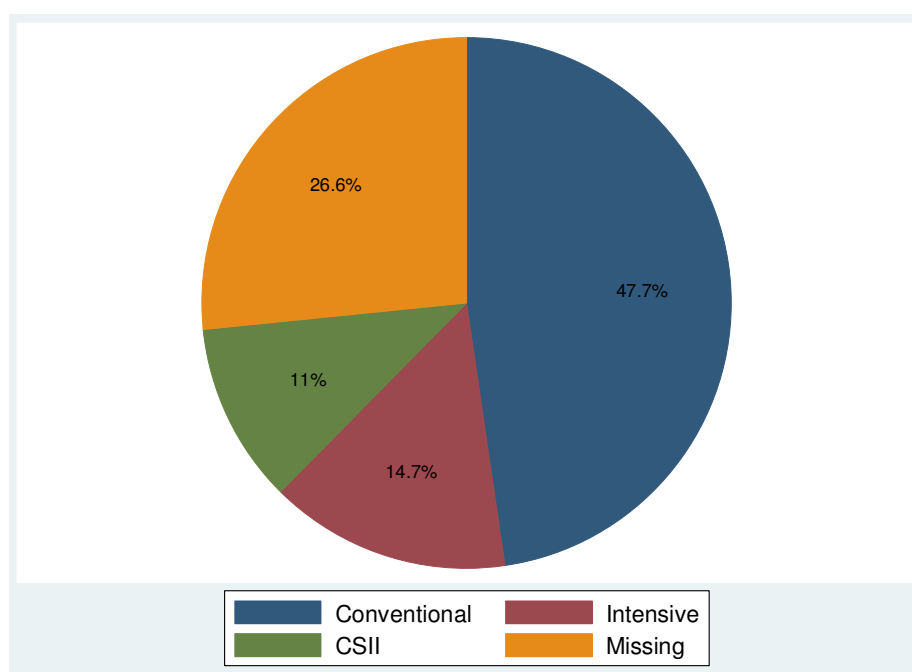
(refer Table 4.0.10 and Figure 4.0.7)

The year-end annual census 2006-2007 however suggest a changing trend towards intensive insulin regimen where only 22.4% of patients remained on conventional regime, but 37.8% were on intensive regime. Data was unavailable for 39.8% of patients.

(refer Table 4.0.11 and Figure 4.0.8)

**Table 4.0.9 Insulin treatments at diagnosis for patients with diabetes mellitus,
DiCARE 2006-2007**

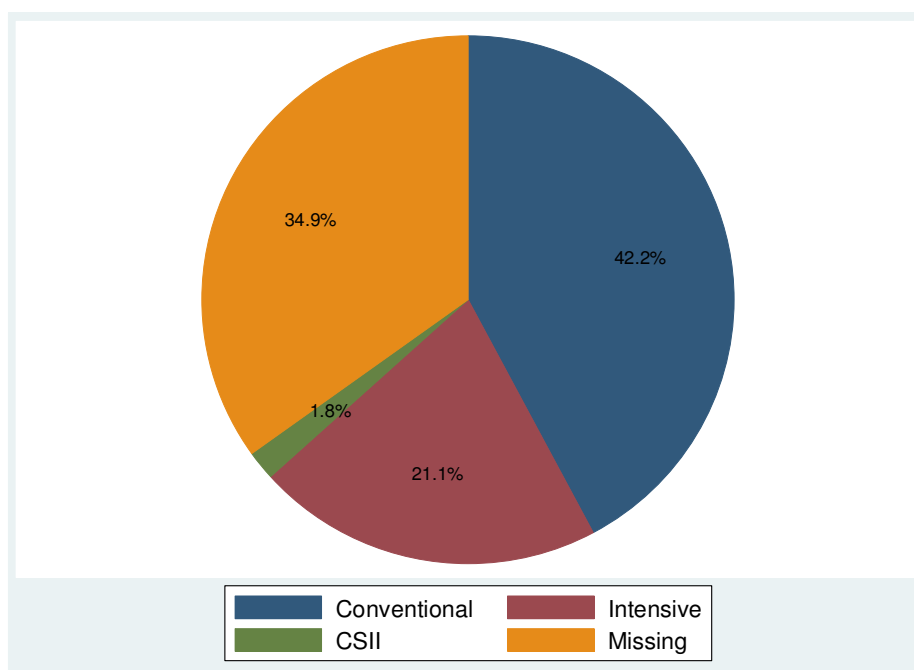
Insulin types	N (109)	%
Conventional	52	47.7
Intensive	16	14.7
Missing	41	37.6



**Figure 4.0.6 Insulin treatments at diagnosis for patients with diabetes mellitus,
DiCARE 2006-2007**

**Table 4.0.10 Insulin treatments at notification for patients with diabetes mellitus,
DiCARE 2006-2007**

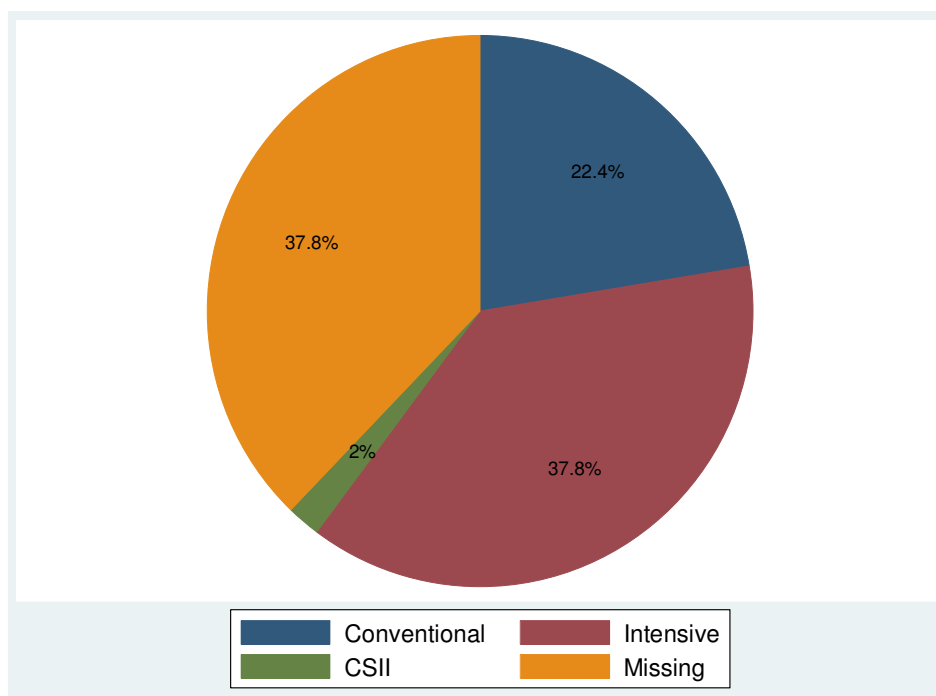
Insulin types	N (109)	%
Conventional	46	42.2
Intensive	23	21.1
Missing	40	36.7



**Figure 4.0.7 Insulin treatments at notification for patients with diabetes mellitus,
DiCARE 2006-2007**

**Table 4.0.11 Current insulin treatments for patients with diabetes mellitus,
DiCARE 2006-2007**

Insulin types	N (98)	%
Conventional	22	22.4
Intensive	37	37.8
Missing	39	39.8



**Figure 4.0.8 Current insulin treatments for patients with diabetes mellitus,
DiCARE 2006-2007**

4.1 Type 1 Diabetes Mellitus (T1DM)

4.1.1 Self care practices

The year-end annual census data 2006-2007 revealed that in T1DM patients, 91.0% practice SMBG and 1.8% do urine glucose test to monitor their diabetes control. In addition, 3.6% also monitor blood ketone at some points (*refer Table 4.1.1*).

**Table 4.1.1 Self-care practices for patients with type 1 diabetes mellitus,
DiCARE 2006-2007**

Self monitoring	Distribution of patients	Total	
		N	%
Blood glucose testing (SMBG)	Yes	151	91.0
	No	10	6.0
	Missing	5	3.0
Blood ketone testing	Yes	6	3.6
	No	109	65.7
	Missing	51	30.7
Urine glucose testing	Yes	3	1.8
	No	111	66.9
	Missing	52	31.3

SMBG = Self Monitoring Blood Glucose

4.1.2 Self Monitoring Blood Glucose (SMBG)

The mean frequency for those who performed SMBG (N=91) was 10.0 (8.0) times per week, ranging from 1 to 40 times per week (*refer Table 4.1.2*).

Table 4.1.2 Frequency of SMBG in T1DM patients, DiCARE 2006-2007

Self-care monitoring	N	Mean	SD	Min	Max	Median	IQR*
SMBG** (no. of times/week)	91	10.0	8.0	1.0	40.0	7.0	9.0

**SMBG = Self Monitoring Blood Glucose

*IQR=inter quartile range

4.1.3 Visits to healthcare professionals over the last 12 months

Over the past 12 months, 70.5% of the T1DM patients reported to have consulted a dietitian, 54.2% with a diabetes educator and 51.8% with an ophthalmologist. In addition, 15.1% reported to have attended a diabetes camp over the same period (*refer Table 4.1.3*).

Table 4.1.3 Visits by T1DM patients to healthcare professionals over the last 12 months, DiCARE 2006-2007

Visits	Distribution of patients	N	%
Dietitian	Yes	117	70.5
	No	35	21.1
	Missing	14	8.4
Diabetes educator	Yes	90	54.2
	No	52	31.3
	Missing	24	14.5
Ophthalmologist	Yes	86	51.8
	No	39	23.5
	Missing	41	24.7
Diabetes camp	Yes	25	15.1
	No	82	49.4
	Missing	59	35.5

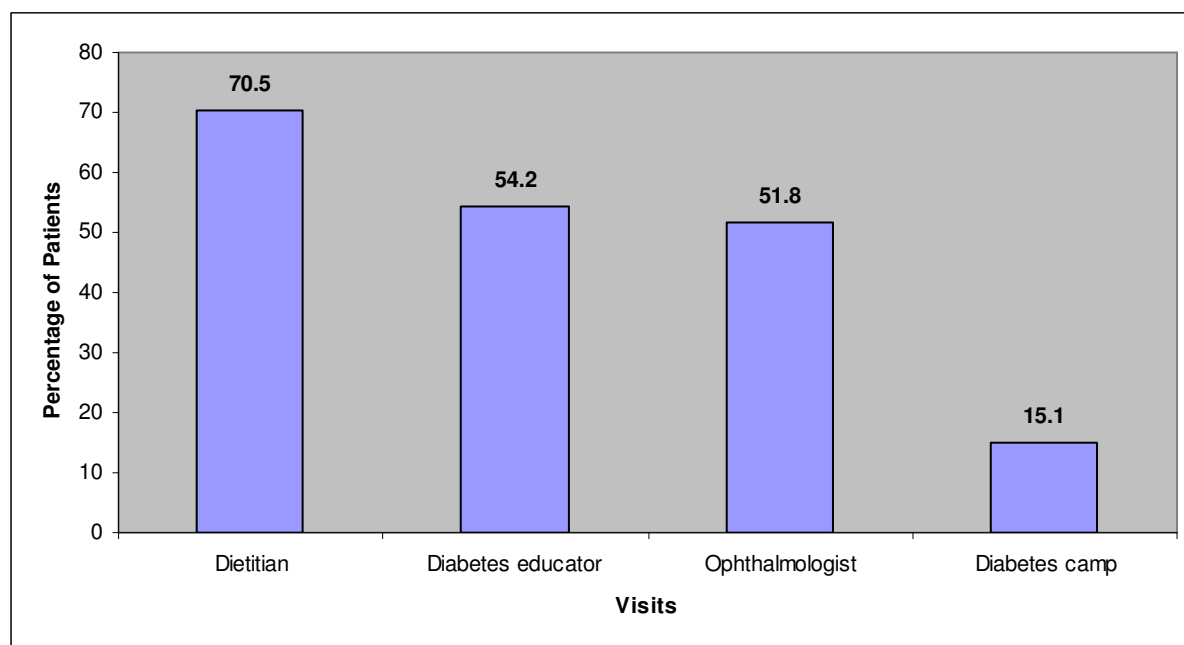


Figure 4.1.1 Visits by T1DM patients to healthcare professionals over the last 12 months, DiCARE 2006-2007

4.1.4 The number of visits to healthcare professionals over the last 12 months

The mean frequencies of visits to the dietitians, diabetic educators and ophthalmologists were reported to be 1.88 (1.8), 2.3 (2.0) and 2.04 (1.8) respectively over the past 12 months. The average number of diabetes camp attended was 2.04 (*refer Table 4.1.4*).

**Table 4.1.4 Number of visits to healthcare professionals over the last 12 months,
DiCARE 2006-2007**

Visits to healthcare professionals	N	Mean	SD	Min	Max	Median	IQR*
Dietitian	58	1.9	1.8	1.0	10.0	1.0	1.0
Diabetes educator	37	2.3	2.0	1.0	10.0	1.0	2.0
Ophthalmologist	52	2.0	1.8	1.0	10.0	1.0	2.0
Diabetes camp	23	2.0	2.1	1.0	10.0	1.0	1.0

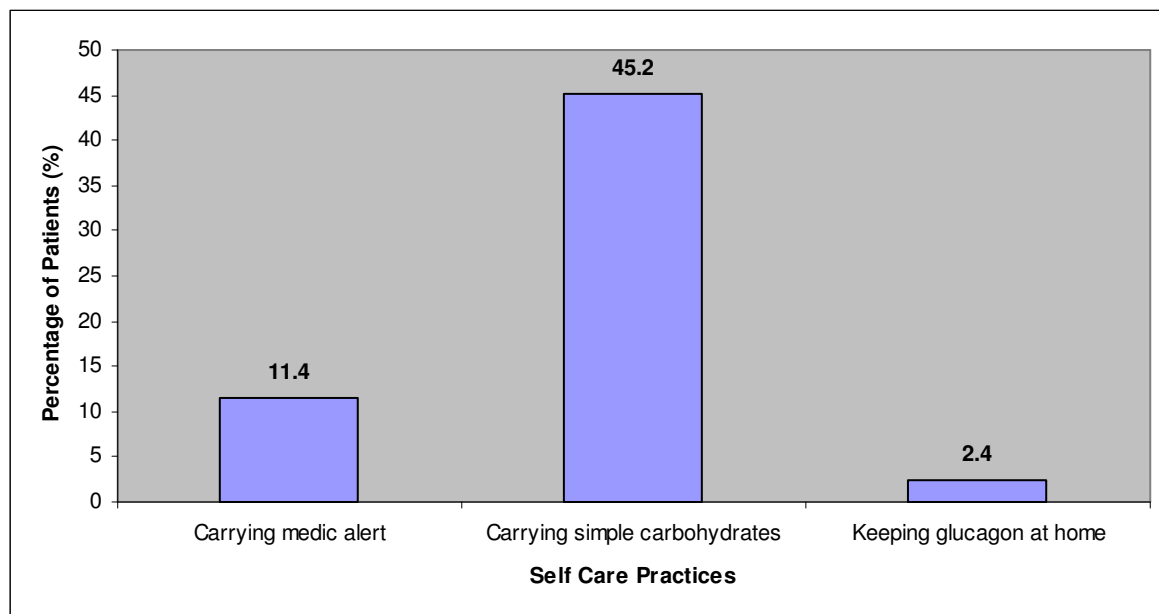
*IQR=inter quartile range

4.1.5 Other self care practices

Other self care practices among the T1DM patients include carrying a medic alert (11.4%), carrying simple carbohydrate (45.2%) and keeping glucagon at home for emergency use (2.4%) (*refer Table 4.1.5 and Figure 4.1.2*).

**Table 4.1.5 Other self care practices among T1DM patients,
DiCARE 2006-2007**

Other self care practices	Distribution of patients	N	%
Carrying medic alert	Yes	19	11.4
	No	86	51.8
	Missing	61	36.7
Carrying simple carbohydrates	Yes	75	45.2
	No	33	19.9
	Missing	58	34.9
Keeping glucagon at home	Yes	4	2.4
	No	106	63.9
	Missing	56	33.7



**Figure 4.1.2 Other self care practices among patients with T1DM,
DiCARE 2006-2007**

4.1.6 Treatment

At diagnosis, 93.1% of the T1DM patients were treated with insulin only. Interestingly 6.9% of the patients were given only dietary advice, 1.4% oral hypoglycemic agent and none of the patients received a combination of insulin and oral hypoglycemic agent.

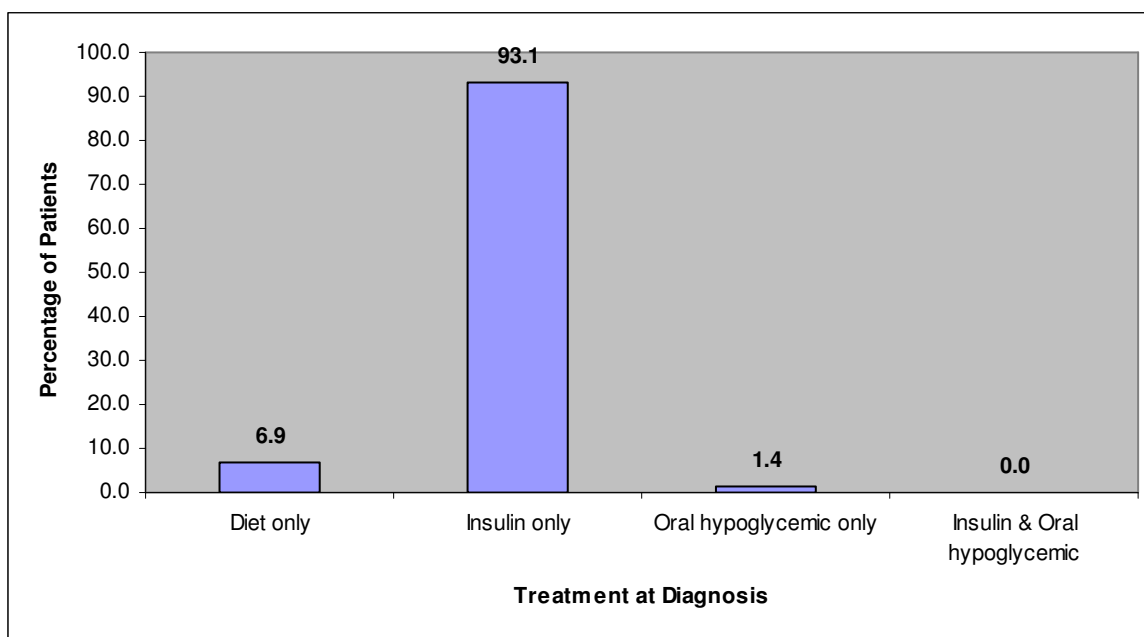
(refer Table 4.1.6 and Figure 4.1.3).

At notification, 90.3% of the T1DM were treated with insulin only, 8.3% oral hypoglycemic agent only and 6.9% a combination of insulin and oral hypoglycemic agent. None of the patients were controlled on diet only *(refer Table 4.1.7 and Figure 4.1.4).*

At year-end annual census, data revealed that none of the T1DM were on dietary control only or combination of insulin and oral hypoglycemic agent. Eighty-three percent (82.5%) of the type 1 diabetics were given insulin and 1.6% received oral hypoglycemic agent without insulin. In view of the poor response at the year-end census however, analysis and interpretation was difficult *(refer Table 4.1.8 and Figure 4.1.5).*

**Table 4.1.6 Treatment at diagnosis for patients with T1DM,
DiCARE 2006-2007**

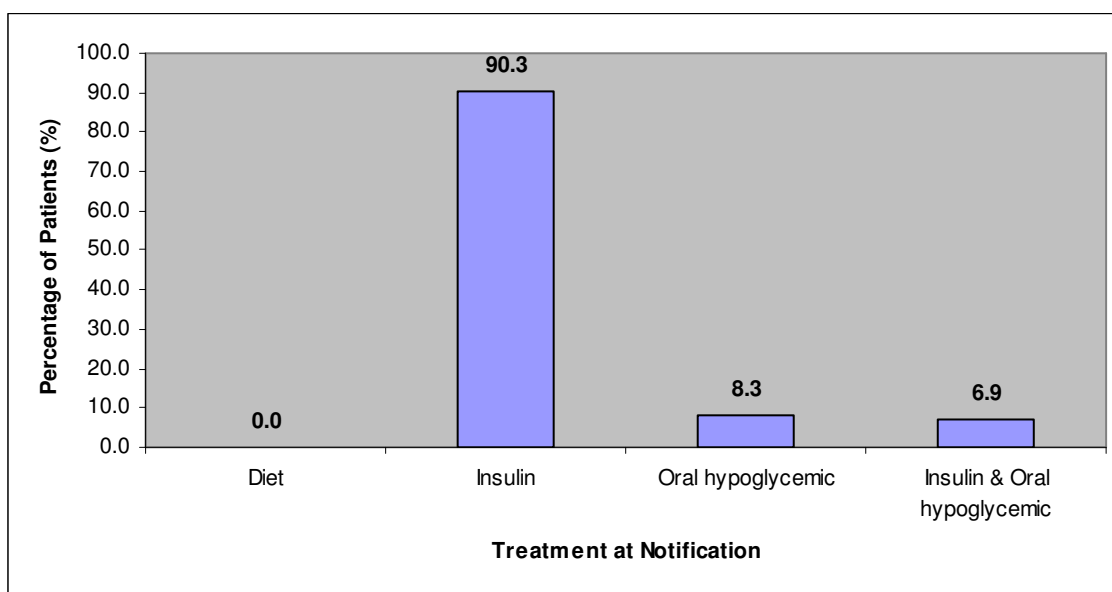
Treatments at diagnosis	Distribution of patients	N	%
Diet only	Yes	5	6.9
	No	67	93.1
Insulin only	Yes	67	93.1
	No	5	6.9
Oral hypoglycemic only	Yes	1	1.4
	No	71	98.6
Insulin & Oral hypoglycemic	Yes	0	0.0
	No	72	100.0



**Figure 4.1.3 Treatment at diagnosis for patients with type 1 diabetes mellitus,
DiCARE 2006-2007**

**Table 4.1.7 Treatments at notification for patients with T1DM,
DiCARE 2006-2007**

Treatments at notification	Distribution of patients	N	%
Diet only	Yes	0	0.0
	No	72	100.0
Insulin only	Yes	65	90.3
	No	7	9.7
Oral hypoglycemic only	Yes	6	8.3
	No	66	91.7
Insulin & Oral hypoglycemic	Yes	5	6.9
	No	67	93.1

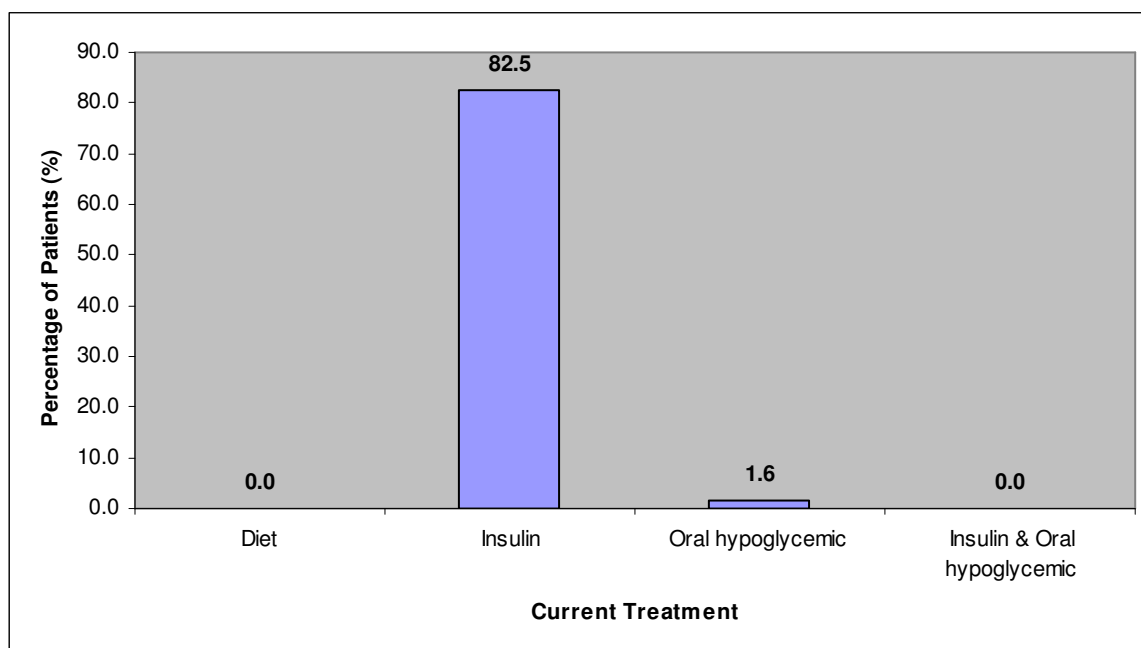


**Figure 4.1.4 Treatment at notification for patients with type 1 diabetes mellitus,
DiCARE 2006-2007**

**Table 4.1.8 Current treatment for patients with T1DM,
DiCARE 2006-2007**

Current treatment	Distribution of patients	N	%
Diet only	Yes	0	0.0
	No	63	100.0
Insulin only	Yes	52	82.5
	No	11	17.5
Oral hypoglycemic only	Yes	1	1.6
	No	62	98.4
Insulin & Oral hypoglycemic	Yes	0	0.0
	No	63	100.0

* Only 185 out of 240 reported annual census; only 53 out of 185 responded to this section



**Figure 4.1.5 Current treatment for patients with type 1 diabetes mellitus,
DiCARE 2006-2007**

4.1.7 Insulin Treatment

At diagnosis, 54.2% of patients who were treated with insulin were prescribed a conventional regime while 19.4% were put in an intensive regime. Information was not available for 26.4% of patients (*refer Table 4.1.9*).

At notification, there were comparatively more patients on the intensive insulin regime compared with at diagnosis (29.2% vs 19.4%). Continuous subcutaneous insulin infusion (CSII) using insulin pump was used in 2.8% of patients at notification. There were no changes in the number of patients for conventional regime.

(refer Table 4.1.10)

At the year-end annual census, the proportion of patients on conventional regime reduced (27.0%) while intensive regime increased (54.0%). CSII using insulin pump is now being used in 1.6% of the patients. There is a general trend toward intensification of insulin therapy even among the children. Intensive insulin regime using basal bolus concept and CSII are now being used on a wider scale to mimic physiological insulin secretion. In view of the poor response at the year-end census however analysis and interpretation was difficult.

(refer Table 4.1.11)

**Table 4.1.9 Insulin treatments at diagnosis for T1DM patients,
DiCARE 2006-2007**

Insulin types	N	%
Conventional	39	54.2
Intensive	14	19.4
Missing	19	26.4

**Table 4.1.10 Insulin treatments at notification for T1DM patients,
DiCARE 2006-2007**

Insulin types	N	%
Conventional	39	54.2
Intensive	21	29.2
Missing	12	16.7

**Table 4.1.11 Current insulin treatments for T1DM patients,
DiCARE 2006-2007**

Insulin types	N	%
Conventional	17	27.0
Intensive	34	54.0
Missing	12	19.0

4.2 Type 2 Diabetes Mellitus (T2DM)

4.2.1 Self care practices

The year-end census data revealed that 52.4% of T2DM patients performed SMBG. None practiced urine glucose or blood ketone testing (*refer Table 4.2.1*).

Table 4.2.1 Self care practices of T2DM patients, DiCARE 2006-2007

Self monitoring	Distribution of patients	Total	
		N	%
Blood glucose testing	Yes	22	52.4
	No	12	28.6
	Missing	8	19.0

4.2.2 Self monitoring blood glucose (SMBG)

Among the T2DM patients who performed SMBG (N=16), the mean frequency of blood glucose monitoring was 4.38 (3.7) times per week. The range however varied widely from 0.25 to 14 times a week (*refer Table 4.2.2*).

Table 4.2.2 SMBG of T2DM patients, DiCARE 2006-2007

Self care monitoring	N	Mean	SD	Min	Max	Median	IQR*
SMBG (no. of times/week)**	16	4.4	3.7	0.3	14.0	4.0	6.1

**SMBG = Self Monitoring Blood Glucose

*IQR=inter quartile range

4.2.3 Visits to healthcare professionals over the last 12 months

Seventy-one percent (70.5%) of T2DM patients reported having consulted dietitian, 54.2% diabetes educator, 51.8% were seen by ophthalmologist and 15.1% had attended a diabetes camp (*refer Table 4.2.3 and Figure 4.2.1*).

Table 4.2.3 Visits by patients with T2DM to healthcare professionals over the last 12 months, DiCARE 2006-2007

Visits to healthcare professionals	Distribution	N	%
Dietitian	Yes	117	70.5
	No	35	21.1
	Missing	14	8.4
Diabetes educator	Yes	90	54.2
	No	52	31.3
	Missing	24	14.5
Ophthalmologist	Yes	86	51.8
	No	39	23.5
	Missing	41	24.7
Diabetes camp	Yes	25	15.1
	No	82	49.4
	Missing	59	35.5

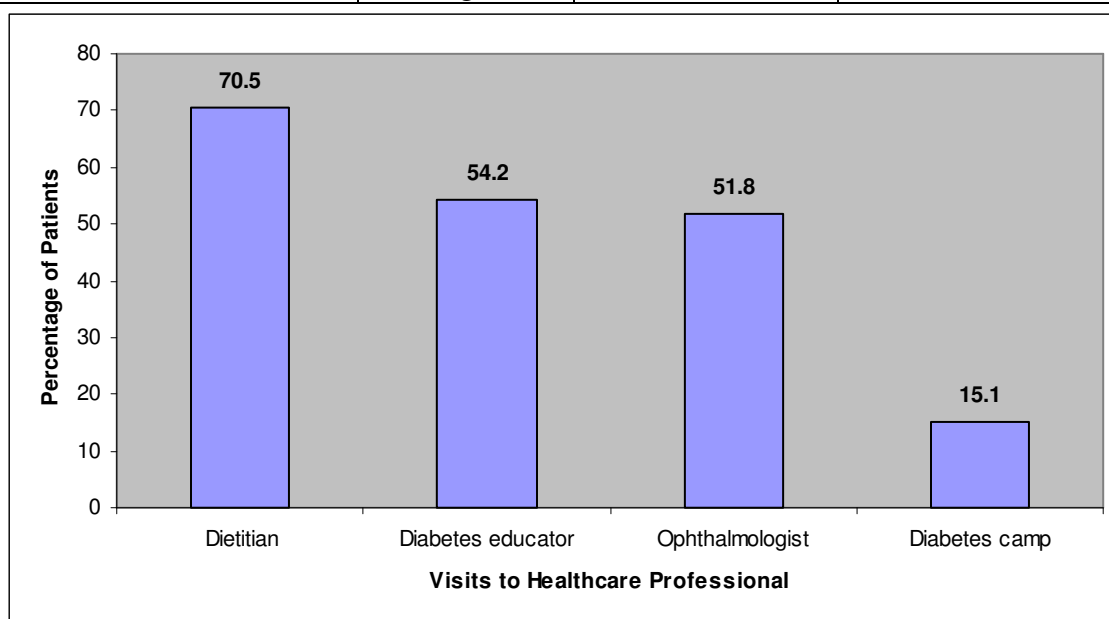


Figure 4.2.1 Visits by patients with T2DM to healthcare professionals over the last 12 months, DiCARE 2006-2007

4.2.4 Number of visits to healthcare professionals

Response for this section was poor. Mean frequencies of visits to the dietitian, diabetes educators and ophthalmologist were 1.92 (1.0), 2.2 (1.0), 1.86 (1.5) times respectively over the past 12 months. One respondent reported participation in diabetes camp once over the past 12 months. Among the respondents, all reported at least one consultation with the dietitian, diabetes educator and ophthalmologist over the past 12 months.

(refer Table 4.2.4)

Table 4.2.4 Number of visits to health professionals over the last 12 months of patients with T2DM, DiCARE 2006-2007

Number of visits to health professionals	N	Mean	SD	Min	Max	Median	IQR*
Dietitian	12	1.9	1.0	1.0	3.0	1.5	2.0
Diabetes educator	10	2.2	1.0	1.0	4.0	2.0	2.0
Ophthalmologist	7	1.9	1.5	1.0	5.0	1.0	1.0
Diabetes camp	1	1.0	-	1.0	1.0	1.0	-

**IQR=inter quartile range*

4.2.5 Other self care practices

Other healthcare practices are less commonly practiced in T2DM than T1DM patients; for example carrying medic alert (4.8% vs 10.0%), carrying simple carbohydrate (14.3% vs 36.7%), standby glucagon at home (0 vs 2.1%) (*refer Table 4.2.5 and Figure 4.2.2*).

Table 4.2.5 Other self care practices of patients with T2DM, DiCARE 2006-2007

Other self care practice	Distribution of patients	N	%
Carrying medic alert	Yes	2	4.8
	No	27	64.3
	Missing	13	31.0
Carrying simple carbohydrate	Yes	6	14.3
	No	24	57.1
	Missing	12	28.6
Keeping glucagon at home	Yes	0	0.0
	No	31	73.8
	Missing	11	26.2

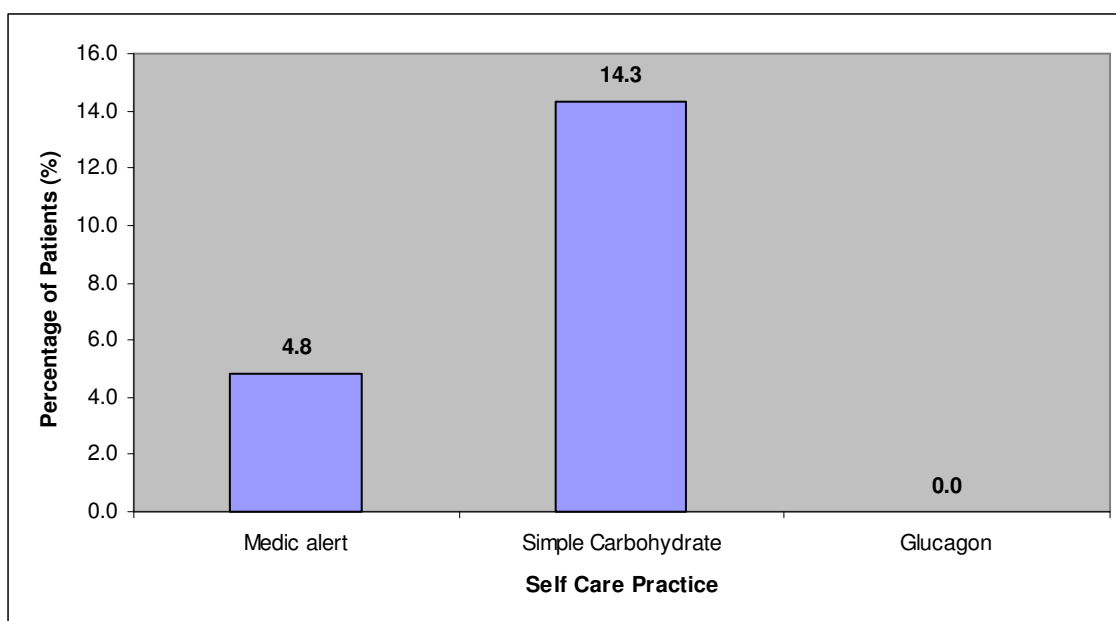


Figure 4.2.2 Other self care practices of patients with T2DM, DiCARE 2006-2007

4.2.6 Treatment

At diagnosis, 10.5% of patients were controlled on diet alone and 68.4% on oral hypoglycemic agents. Despite diagnosis of T2DM, 36.8% of patients were prescribed insulin and 15.8% a combination of insulin and oral hypoglycemic agents.

(refer Table 4.2.6 and Figure 4.2.3)

At notification, 73.3% of T2DM patients were treated with oral hypoglycemic only and 5.3% of patients were on combination therapy of oral hypoglycemic and insulin. Interestingly, despite the diagnosis, 15.8% of the patients were prescribed insulin only. None of the patients was treated with dietary control only.

(refer Table 4.2.7 and Figure 4.2.4)

The year-end annual census suggested that only 60.0% of T2DM patients were on oral hypoglycemic agent whereas 16.0% were on a combination of oral hypoglycemic agent and insulin. Twenty percent were on insulin only and 12.0 % on diet control only.

(refer Table 4.2.8 and Figure 4.2.5)

**Table 4.2.6 Treatment at diagnosis of patients with T2DM,
DiCARE 2006-2007**

Treatment at diagnosis	Distribution of patients	N	%
Diet only	Yes	2	10.5
	No	17	89.5
Insulin only	Yes	7	36.8
	No	12	63.2
Oral hypoglycemic only	Yes	13	68.4
	No	6	31.6
Insulin & Oral hypoglycemic	Yes	3	15.8
	No	16	84.2

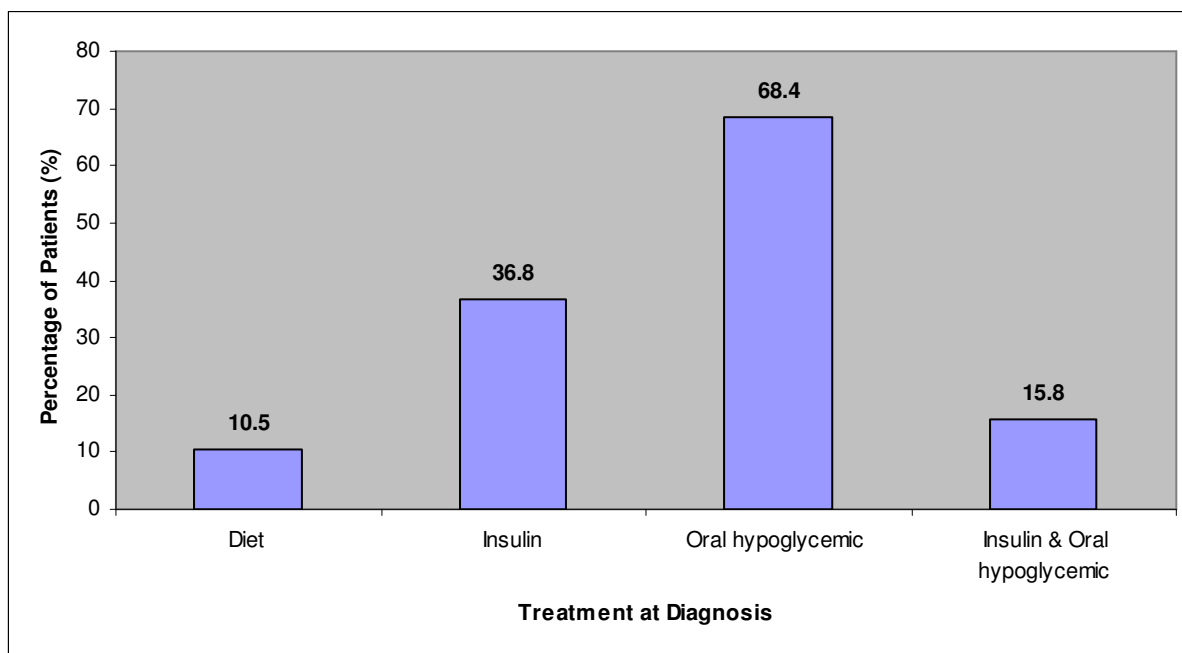


Figure 4.2.3 Treatment at diagnosis of patients with T2DM, DiCARE 2006-2007

**Table 4.2.7 Treatment at notification of patients with T2DM,
DiCARE 2006-2007**

Treatment at notification	Distribution of patients	N	%
Diet only	Yes	0	0.0
	No	19	100.0
Insulin only	Yes	3	15.8
	No	16	84.2
Oral hypoglycemic only	Yes	14	73.7
	No	5	26.3
Insulin & Oral hypoglycemic	Yes	1	5.3
	No	18	94.7

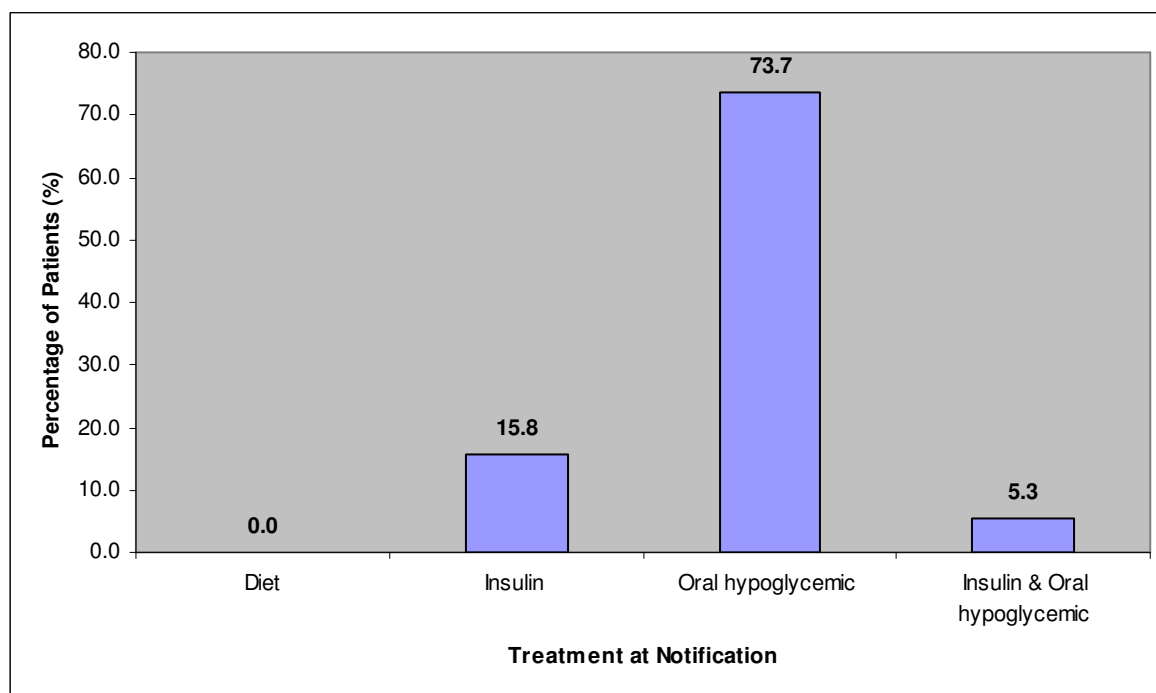
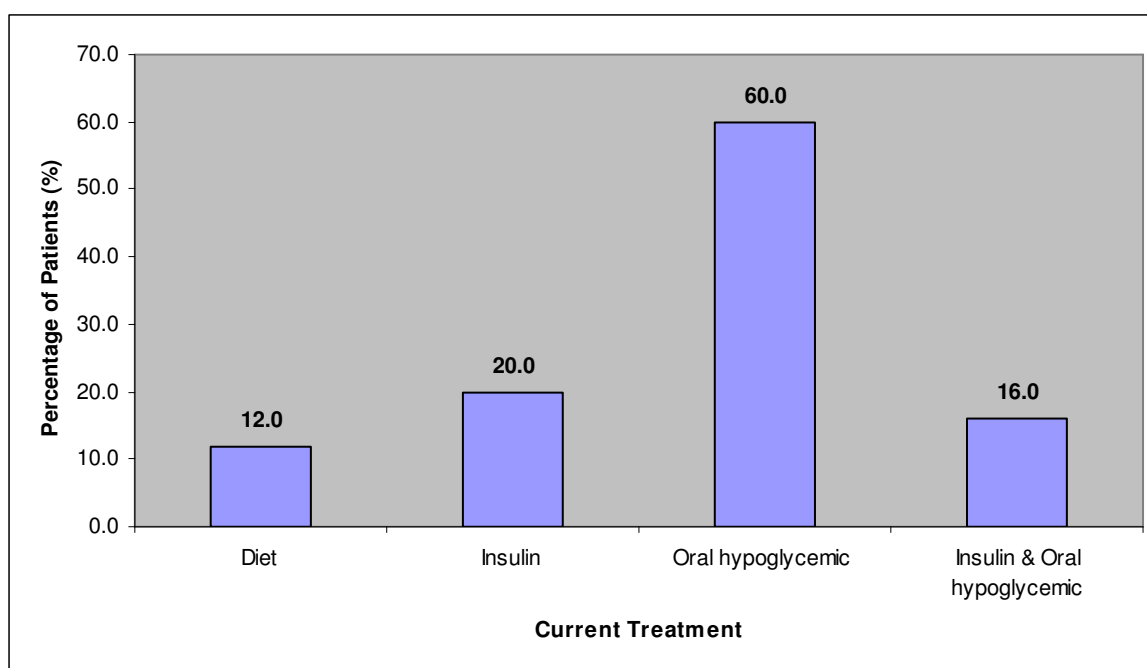


Figure 4.2.4 Treatment at notification of patients with T2DM, DiCARE 2006-2007

**Table 4.2.8 Treatment of patients with T2DM at year-end annual census,
DiCARE 2006-2007**

Current treatment	Distribution of patients	N	%
Diet only	Yes	3	12.0
	No	22	88.0
Insulin only	Yes	5	20.0
	No	20	80.0
Oral hypoglycemic only	Yes	15	60.0
	No	10	40.0
Insulin & Oral hypoglycemic	Yes	4	16.0
	No	21	84.0



**Figure 4.2.5 Treatment of patients with T2DM at year -end annual census,
DiCARE 2006-2007**

4.2.7 Insulin Regime

As this section we had very poor response, we could not make any sensible analysis and reporting.

CHAPTER 5

OUTCOMES

Chan Siew Pheng

Fatimah Harun

5.0 Overall

This chapter describes the outcomes of all patients with diabetes mellitus for the year-ending 2006.

Of the 240 cases in the entire registry for 2006-2007, 185 reports the annual census for the year-ending 2006 were received. Information on outcomes / disposition were available for 98 (53%) of this 185 cases. Of this population with known outcomes, there were no reported deaths, 12 were lost to follow-up, and of the remaining 86, all were alive and 81 were still on active follow-up.

(refer Table 5.0.1 and Figure 5.0.1).

The high proportion of unknown outcomes (47%) was due to the failure to report follow-up data. Due to this inadequate information, the following results may not be a true reflection of the actual outcomes. This underscores the importance of proper reporting and monitoring of data.

(refer Table 5.0.1 and Figure 5.0.1).

**Table 5.0.1 Outcome for patients with diabetes mellitus, DiCARE
as at 31st December 2006**

Outcomes (Total=185)	Known	Unknown
	n=98 (53%)	n=87 (47%)
Still on active follow up (Alive)	80 (81.6)	NA
Transferred to another centre/department	6 (6.1)	
Lost to follow up	12 (12.3)	

* No. Of patients on annual census/notification for 2006

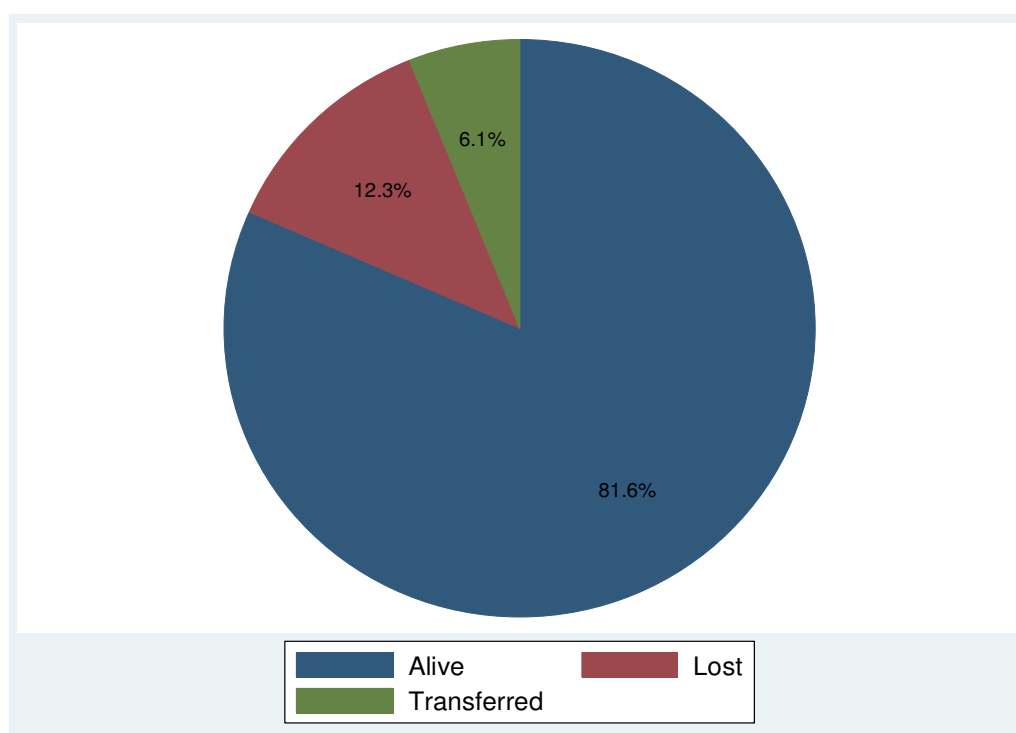


Figure 5.0.1 Overall disposition of patients with diabetes mellitus, DiCARE 2006

There is no apparent ethnic difference seen in those with known outcomes.

(refer Table 5.02 (a))

**Table 5.0.2 (a) Disposition of patients with diabetes mellitus by ethnicity,
DiCARE as at 31st December 2006**

Ethnic	Outcomes	Known (N=98)		Unknown (N=87)
		n	%	
Malay (N=73)	Total	41 (56.2%)		32 (43.8%) NA
		n	%	
	Alive	35	85.4	
	Dead	0	0.0	
	Transferred to another centre/department	0	0.0	
	Lost to follow up	6	14.6	
Chinese (N=66)	Total	41 (47.0%)		32 (53.0%) NA
		n	%	
	Alive	26	83.9	
	Dead	0	0.0	
	Transferred to another centre/department	3	9.7	
	Lost to follow up	2	6.4	
Indian (N=40)	Total	23 (57.5%)		17 (42.5%) NA
		n	%	
	Alive	18	78.3	
	Dead	0	0.0	
	Transferred to another centre/department	2	8.7	
	Lost to follow up	3	13.0	
Others (N=6)	Total	3 (50.0%)		3 (50.0%) NA
		n	%	
	Alive	1	33.3	
	Dead	0	0.0	
	Transferred to another centre/department	1	33.3	
	Lost to follow up	1	33.3	

Follow up appeared to be better in the younger age group (below 5 years). The proportion of patients lost to follow up rose with increasing age (none in 0-<5, 4.5% in 5-<10, 6.7% in 10-<15 and 34.8% in 15-<20 age group) (*refer Table 5.0.2(b)*).

**Table 5.0.2 (b) Disposition of patients with diabetes mellitus by age,
DiCARE at 31st December 2006**

Age group	Outcomes	Known (N=98)		Unknown (N=87)
		N	%	
0-<5 (N=11)	Total	8 (72.7%)		3 (27.3)
		N	%	NA
	Alive	7	87.5	
	Transferred out	1	12.5	
	Lost to follow up	0	0.0	
5-<10 (N=41)	Total	22 (53.7)		19 (46.3)
		N	%	NA
	Alive	21	95.5	
	Transferred out	0	0.0	
	Lost to follow up	1	4.5	
10-<15 (N=85)	Total	45 (52.9)		40 (47.1)
		N	%	NA
	Alive	41	91.1	
	Transferred out	1	2.2	
	Lost to follow up	3	6.7	
15-<20 (N=48)	Total	23 (47.9)		25 (52.1)
		N	%	NA
	Alive	11	47.8	
	Transferred out	4	17.4	
	Lost to follow up	8	34.8	

5.0.1 Hospitalization

Hospitalization status of 82 out of 98 patients was identified with follow up data, of whom 21 (25.6%) required hospitalization for diabetes-related complications. The majority of hospitalizations were for stabilization of diabetes (61.9%), followed by diabetic ketoacidosis (23.8%) (*refer Table 5.0.3 and Figure 5.0.2*).

Table 5.0.3 Proportion of patients requiring diabetes-related hospitalization, DiCARE as at 31st December 2006

Hospitalization N=98	Known N=82	Unknown N=16
Yes	21 (25.6%)	NA
No	61 (74.4%)	

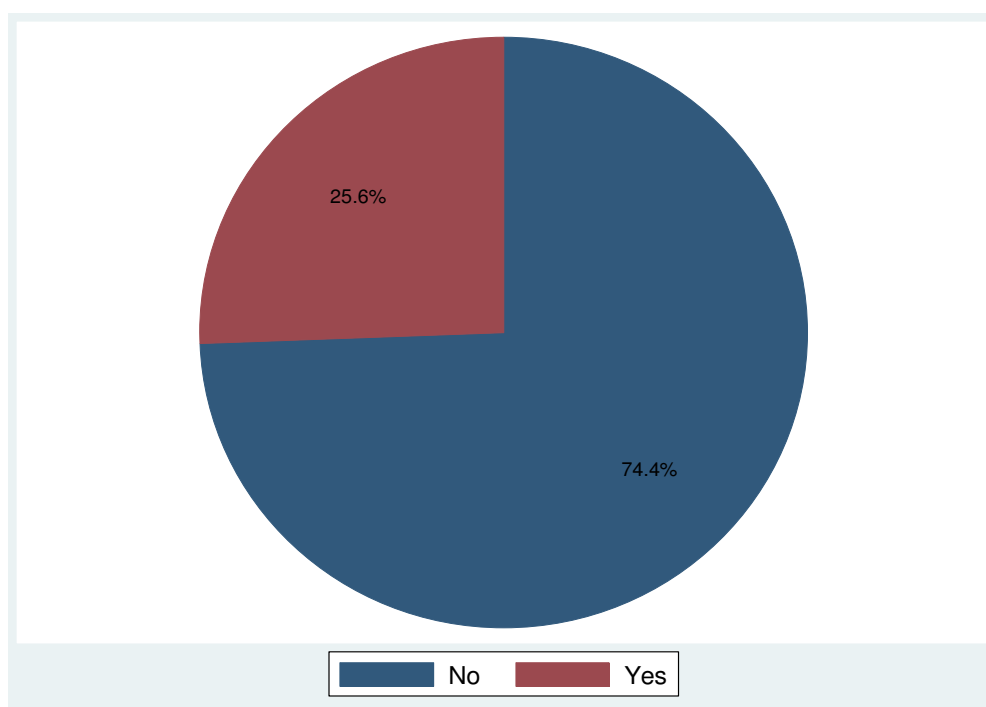


Figure 5.0.2 Diabetes-related hospitalizations in patients with diabetes mellitus, DiCARE 2006

There were no reported cases of severe hypoglycemic episodes requiring hospitalization. Severe hypoglycemic episodes not requiring hospitalization were however not captured. As such, this may be an underestimate of the true incidence of severe hypoglycaemia. (refer Table 5.0.4 and Figure 5.0.3).

Table 5.0.4 Hospitalization by diabetes-related complications, DiCARE as at 31st December 2006

Complication	N = 21	%
DKA	5	22.7
Hypoglycaemia	0	0.0
Infection	1	4.6
Stabilization of DM	13	59.1
Others	3	13.6

**One patient had two complications*

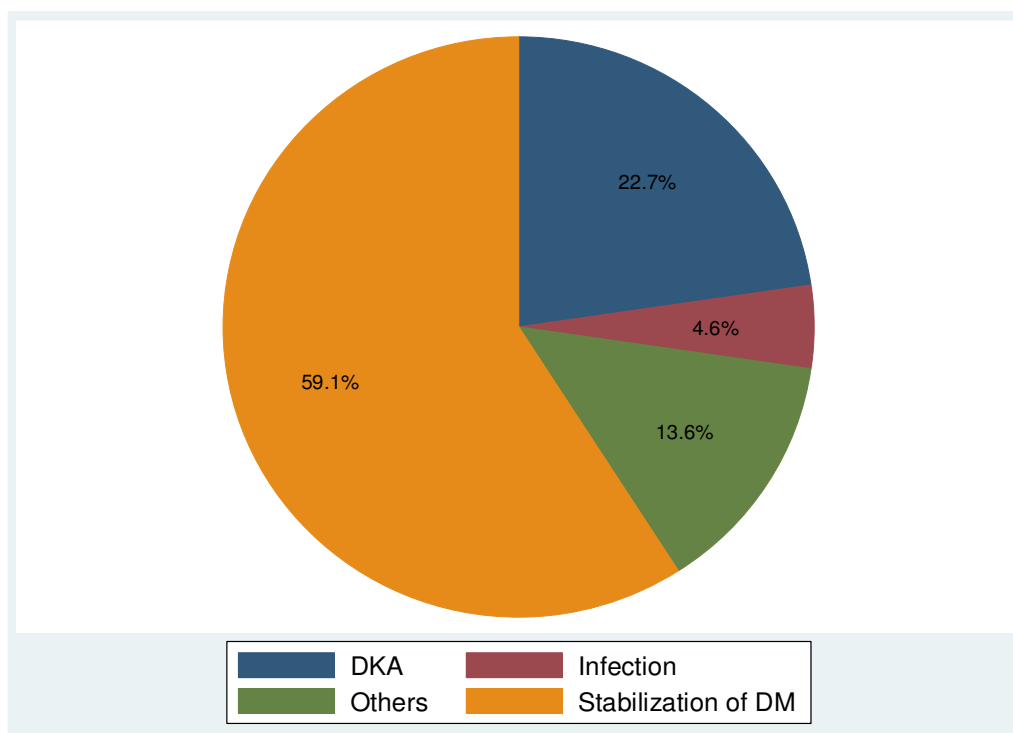


Figure 5.0.3 Causes of diabetes-related hospitalizations in patients with diabetes mellitus, DiCARE as at 31st December 2006

5.0.2 Complications

Of the 98 patients, status regarding complications was available for 82 of them (72.7%).

The most common cause for hospitalization was DKA which occurred in 6.1% (6 out of 98) of the reported cases (*refer Table 5.0.5*).

Eighty-two (81.6%) of the 98 patients were examined for chronic complications. None were reported to have microvascular complications (*refer Table 5.0.5*).

No macrovascular complication events were reported.

Table 5.0.5 Complications in the past one year for patients with diabetes mellitus, DiCARE, as at 31st December 2006

Complications			N	%
Acute	Severe hypoglycemia	Yes	1	1.0
		No	81	82.7
		NA/Indeterminate	16	16.3
	DKA*	Yes	6	6.1
		No	76	77.6
		NA/Indeterminate	16	16.3
Chronic	Neuropathy	Yes	0	0.0
		No	80	81.6
		Not examined	2	2.0
		NA/Indeterminate	16	16.3
	Microalbuminuria	Yes	0	0.0
		No	81	82.7
		Not examined	1	1.0
		NA/Indeterminate	16	16.3
	Nephropathy	Yes	0	0.0
		No	81	82.7
		Not examined	1	1.0
		NA/Indeterminate	16	16.3
	Retinopathy	Yes	0	0.0
		No	81	82.7
		Not Missing examined	1	1.0
		NA/Indeterminate	16	16.3

*DKA= *diabetic ketoacidosis*

5.0.3 Blood pressure

Of the 98 patients with outcome variables in this registry, 62 (63.3%) had their blood pressure reported, of whom 43 were T1DM and 19 were T2DM.

Presence of hypertension was determined by the treating physician. There were 5 (7.5%) patients who were hypertensive, all were girls, of whom 2 (4.7% of total T1DM patients) had T1DM while 3 (15.8% of total T2DM patients) had T2DM.

5.0.4 HbA_{1c} level

The HbA_{1c} is a measure of diabetes control. Data was available for 70 out of the 98 patients with outcome data.

The mean HbA_{1c} in this cohort was 10.0% which is above the target value set by the International Society for Paediatric and Adolescent Diabetes (ISPAD)¹. Only 19.7% of patients had HbA_{1c} measured four or more times a year. This means that 80.3% had less than ideal monitoring frequencies.

Worryingly, 19 (19.4%) of the patients in this registry did not have HbA_{1c} performed in the last one year.

Table 5.0.6 Glycemic control in the past one year for patients with diabetes mellitus, DiCARE as at 31st Dec 2006

Lab test	N	Mean	SD	Min	Max	Median	IQR*
HbA _{1c} (%)							
Overall Mean	79	10.0	2.2	5.2	17.0	9.7	2.9
	N	%					
Not done	19	19.4					
Lab test	N	Mean	SD	Min	Max	Median	IQR
Frequency of test in the last 12 months	71	2.7	1.0	1.0	5.0	3.0	1.0

*IQR=inter quartile range

The majority of reported patients were mainly managed in tertiary centers (*refer Table 5.0.7*).

Table 5.0.7 HbA_{1c} in the past one year for patients with diabetes mellitus by level of healthcare, DiCARE as at 31st December 2006

Level of healthcare	N	Mean	SD	Min	Max	Median
Primary	4	10.8	1.9	8.3	12.6	11.2
Secondary	5	9.6	1.6	7.7	12.1	9.4
Tertiary	70	9.9	2.3	5.2	17.0	9.7

5.0.5 Comorbidities

Frequency of comorbidities were as reported by the SDPs. Ninety (91.8%) of the 98 patients at year-end census were found not to have any comorbidities. Five were obese/ overweight, two had hyperlipidemia and two were hypertensive. Only one patient was receiving anti-hypertensive treatment (*refer Table 5.0.8*).

Table 5.0.8 Comorbidities and medications for patients with diabetes mellitus, DiCARE as at 31st December 2006

Comorbidities	Yes	On medication	No medication	N
Hypertension	2	1	1	2
Dyslipidemia	2	0	2	2
Obesity	5	0	5	5
Without any co-morbidity				90

5.1 Type 1 Diabetes Mellitus (T1DM)

Table 5.1.1 Outcomes for patients with T1DM, DiCARE 2006

Outcomes (Total=130)	Known	Unknown
	n=63 (48.5%)	n=67 (51.5%)
Still on active follow up	53 (84.1%)	NA
Transferred to another centre/department	6 (9.5%)	
Lost to follow up	4 (6.4%)	

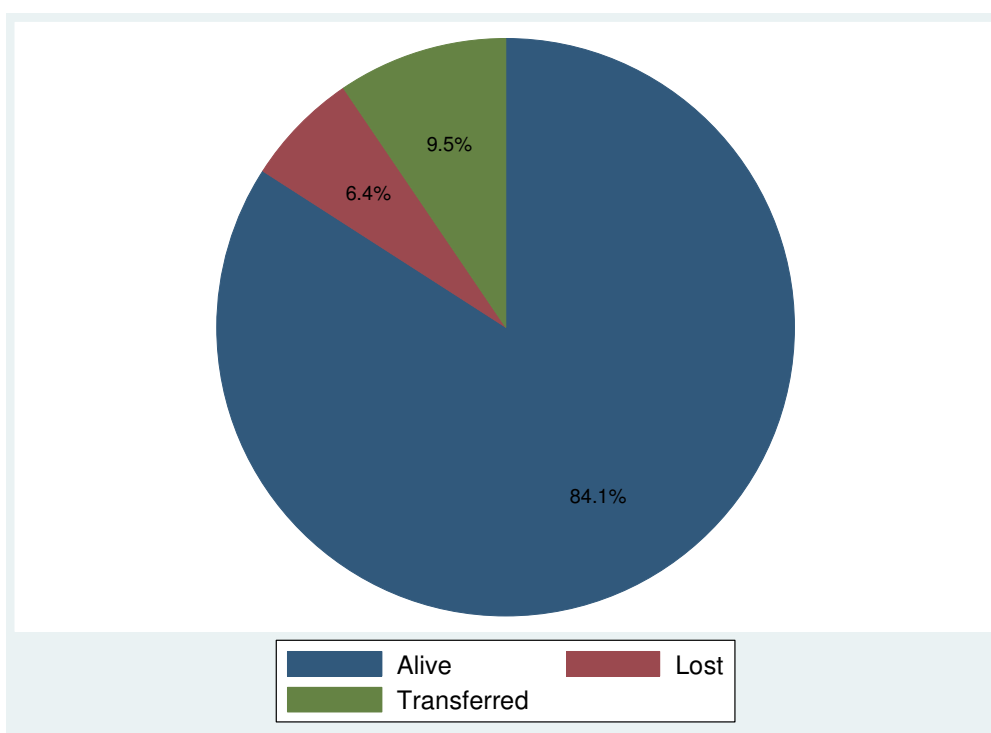


Figure 5.1.1 Outcomes for patients with T1DM, DiCARE 2006

(N=63)

Table 5.1.2 Diabetes-related hospitalization for patients with T1DM, DiCARE 2006

Hospitalization N=63	Known (n=55)	Unknown (n=8)
Yes	15 (27.3%)	NA
No	40 (72.7%)	

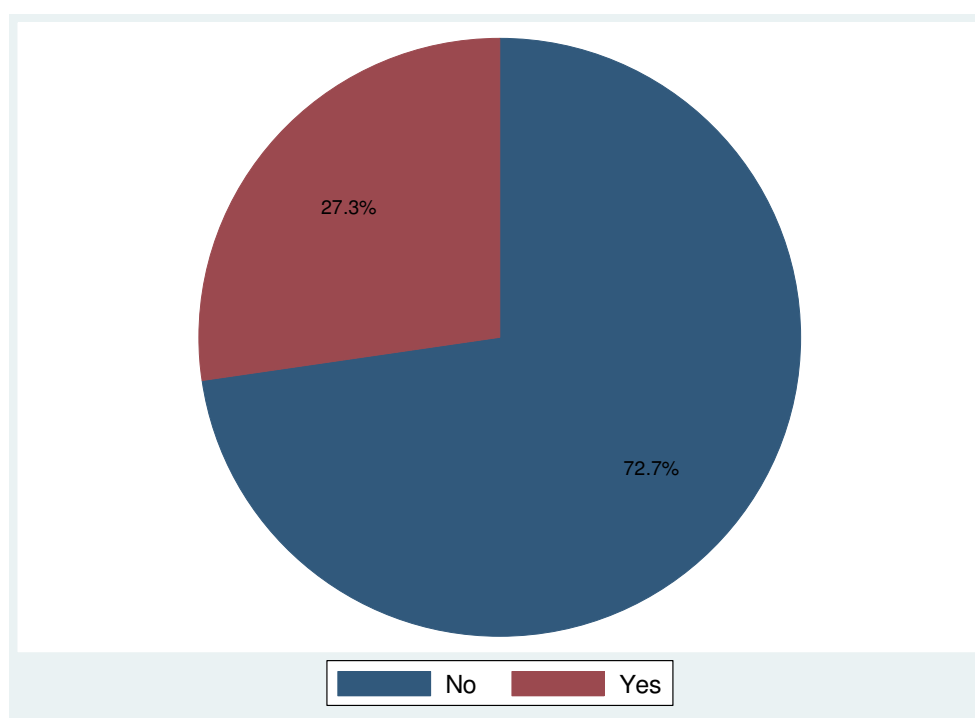


Figure 5.1.2 Diabetes-related hospitalization for patients with T1DM, DiCARE 2006
(N=55)

Thirteen of the 63 patients with T1DM were admitted for hyperglycaemia (DKA/stabilization) (*refer Table 5.1.2 and Figure 5.1.2*).

Data for chronic complications was available in 52 of the patients, none of whom had microvascular complications.

Table 5.1.3 Causes of diabetes-related hospitalizations in T1DM, DiCARE 2006

(N=15)

Causes of Hospitalization	n	%
Hypoglycemia	0	0.0
Diabetes Ketoacidosis (DKA)	5	33.3
Infection	0	0.0
Stabilization of diabetes mellitus	8	53.4
Not known	0	0.0
Others	2	13.3

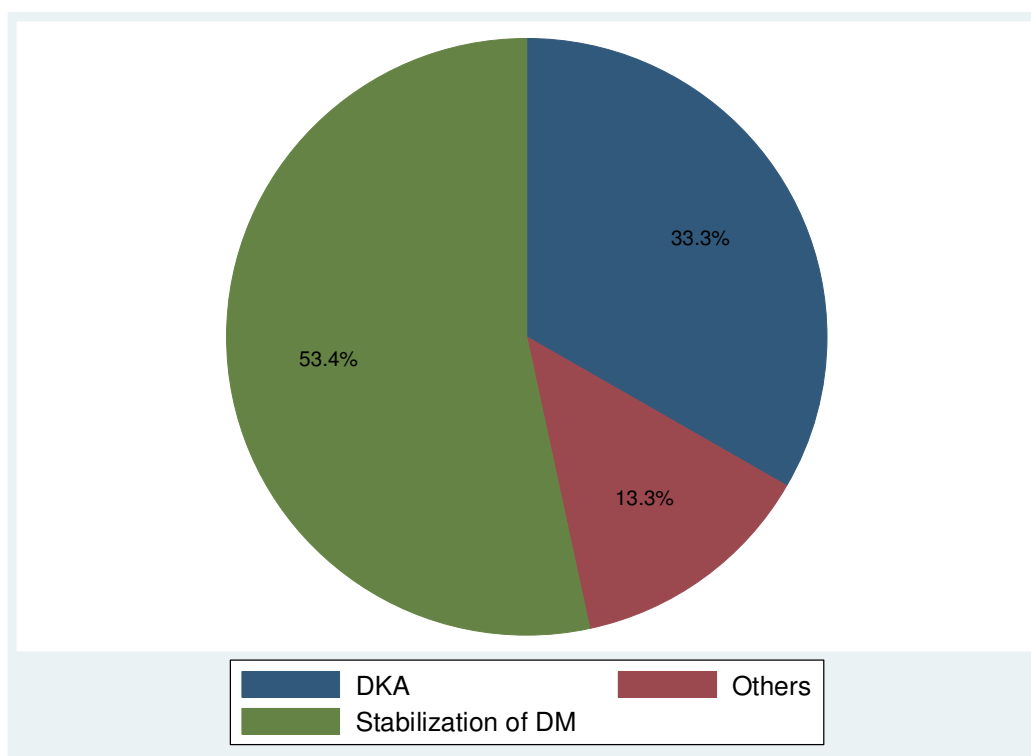


Figure 5.1.3 Causes of diabetes-related hospitalization in T1DM, DiCARE 2006

(N=15)

5.1.1 HbA_{1c} level

Glycemic control was unsatisfactory with the median of 9.5%. Six percent of patients (3 out of 50) achieved target HbA_{1c} less than 7.5% (*refer Table 5.1.4*).

Table 5.1.4 Glycemic control in T1DM, DiCARE 2006

Glycemic control	N	Mean	SD	Min	Max	Median	IQR*
HbA _{1c} (%)	50	9.9	2.0	6.8	17.0	9.5	2.7

* IQR=*inter quartile range*

5.1.2 Comorbidities

Two of the patients were reported to have hypertension of whom one was treated. No other comorbidities were reported.

5.2 Type 2 Diabetes Mellitus (T2DM)

Outcome status was available for 25 out of the 32 T2DM patients. A big proportion of patients (32%, 8 out of 25) had been lost to follow up by the year-end census.

(refer Table 5.2.1(a) and Table 5.2.1(b))

Table 5.2.1(a) Outcomes for patients with T2DM, DiCARE 2006 (N=32)

Outcomes (Total N=32)	Known	Unknown
	n=25 (78.1%)	n=7 (21.9%)

Table 5.2.1(b) Outcomes for patients with T2DM, DiCARE 2006

Outcomes (N=32)	Known n=25
	Still on active follow up
Transferred to another centre/department	0 (0.0%)
Lost to follow up	8 (32.0%)

Data was available in only 17 of the 25 patients. Four (23.5%) required hospitalization. Three patients required admission for stabilization of diabetes. Unlike for T1DM, there was no admission for DKA (0 vs 33.3%)

Data for chronic complications was available in 52 of the patients, none of whom had microvascular complications.

Table 5.2.2 Diabetes-related hospitalization in patients with T2DM, DiCARE 2006

Hospitalization status	Known N=17
Yes	4 (23.5%)
No	13 (76.5%)

**Table 5.2.3 Causes of diabetes-related hospitalization in patients with T2DM,
DiCARE 2006**

Causes of hospitalization	N	%
Hypoglycemia	0	0.0
Diabetes Ketoacidosis (DKA)	0	0.0
Infection	1	20.0
Stabilization of diabetes mellitus	3	60.0
Others	1	20.0

- *One patient had two admissions*

Data for complications was available for 17 of the patients; one patient was reported to have severe hypoglycaemia. No patients had microvascular complications.

(refer Table 5.2.3)

5.2.1 HbA_{1c} level

Glycemic control was unsatisfactory (median of 9.8%). Twenty percent of patients (4 out of 20) achieved target HbA_{1c} of less than 7.5% (*refer Table 5.2.4*).

Table 5.2.4 Glycemic control in T2DM, DiCARE 2006

Glycemic control	N	Mean	SD	Min	Max	Median	IQR*
HbA _{1c} (%)	20	9.7	2.3	5.2	13.4	9.8	2.8

*IQR=*inter quartile range*

5.2.2 Comorbidities

SDP reported that there were two patients with dyslipidemia and three with obesity. Although there were no patients with hypertension the blood pressure recorded in the CRF was above the 95th percentile for age and sex in four patients. None were receiving pharmacologic therapy.

RECOMMENDATION

The first year results of DiCARE have provided us with an insight into diabetes mellitus among the young in Malaysia. However, many hospitals have not participated in the registry, under reporting was a major problem. Therefore, all paediatricians and physicians who manage children and adolescents with diabetes in Malaysia must be encouraged to start reporting their cases to DiCARE. Subsequently, it can be extended to include doctors in the private sectors and armed forces to ensure more cases are registered nationwide.

During the first year of the registry, there was delay in data entry because of staff shortage and lack of training. Therefore more training to the source data providers (SDP) will be planned in the years to come and research officers/assistants will be recruited to assist with the reporting. Furthermore, incomplete Case Report Forms (CRF) caused some missing data at analysis. Hence, the CRF must be revised and simplified to capture only the data that is required in the data analysis. Dedicated doctors and personnel must be identified to coordinate the reporting to ensure accurate and complete information.

There was also communication problems which caused information not to reach the SDP. Some SDP mentioned that the website was not user friendly even though instructions on patient registration were given manually. The problem may be solved by forming a DiCARE email group for better communication. Eventually a newsletter can be created to share latest news on DiCARE; encouraging active participation from all users.

Any problems that may arise in this registry need to be documented. A Problem Assessment Form can be designed where any SDP who encounters problems will fill the form and submit to the DiCARE/ CRC office. A standard progress report can be generated so that SDP can update their progress in a defined duration of time. Technical committee meetings can be held on a regular basis to review and solve any problems encountered. Teleconference can be a mode of communication with face-to-face meeting only when required. Any system problems can be rectified by contacting the CRC staff concerned.

To avoid double or triple online entry of a case, the database must have a mechanism to recognize a “pre-existing patient” or send an alert when a name or MyKid is repeated. A SEARCH method should be made available in order to avoid duplication and an alert message is to be provided on the front page of the application. In addition, there are no real time reports and the committee will decide on the list of real time report to be made available online.

It is hoped that with these recommendations, data collection and reporting to DiCARE will be consolidated in due time. This will enable us to have a better perspective of the real situation of diabetes among the children and adolescents in Malaysia. Hence, measures and strategies can be implemented to upgrade our standard of diabetes care among children and adolescents with diabetes.

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APPENDIX 1:

DATA MANAGEMENT

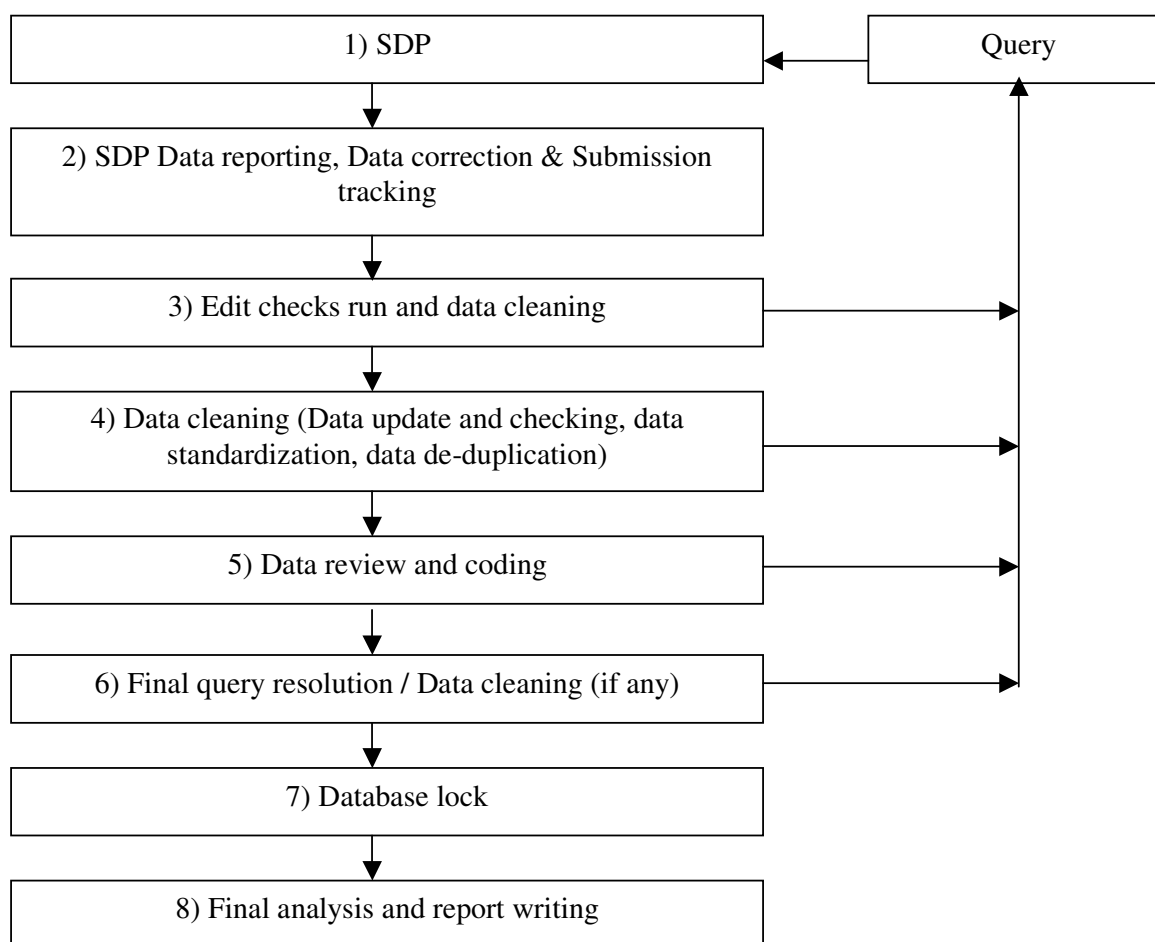
The Diabetes in Children and Adolescent Registry (DiCARE) maintains a database that includes data from notification form and annual census form. Data is stored in SQL Server due to the high volume of data accumulated throughout the years.

Data sources

SDPs or Source Data Providers of DiCARE comprise of hospitals throughout Malaysia.

Data Flow Process

This section describes the data management flow process of the Diabetes in Children and Adolescent Registry.



SDP Data reporting, Data correction and Submission tracking

Data reporting by SDP is done via Web Applications e-Case Report Forms.

There are a number of data security features that are designed into DiCARE web application (eCRF) such as web owner authentication, two-level user authentication (user name and password authentication and a Short Messaging System (SMS) of authorization code to mobile phone authentication), access control, data encryption, session management to automatically log off the application, audit trail and data backup and disaster recovery plan.

SDP submits DiCARE Notification form on ad hoc basis whenever there is a case. SDP also submits annual census data. An alert page containing all overdue submissions for annual census is available to users to ease submissions tracking.

Prior to registering a patient record, a verification process is done by using the search function to find if a patient exist in the entire registry. The application will still detect a duplicate record if the same IC number is keyed in should the step of searching patient is left out. This step is done to avoid duplicate records. For patients that exist in the database, SDP only needs to add a new notification with basic patient particulars pre-filled based on existing patient information in the database.

There are a few in-built functionalities at the data entry page that serve to improve data quality. One such function is auto calculation function to reduce error in human calculation. There is also an inconsistency check function that disables certain fields if these fields are answered in a certain manner. When value entered is out of range, user is prompted for the correct value.

A real time data query page is also available via the web application to enable user to check which non-compulsory data is missing, out of range or inconsistent. A link is provided on the data query page for users to click on to resolve the query for the particular patient.

Real time reports are also provided in the web application. The aggregated data reports are presented in the form of tables and graphs. The aggregated data reports are typically presented in two manners; one as centre's own data aggregated data report and second as registry's overall aggregated data report. This way, the centre is able to compare itself against the overall registry's average.

Data download function is also available in the web application to allow users to download their own centre's data for all the forms entered for their own further analysis. The data are downloadable as Text - tab delimited (.txt) format, Microsoft excel workbook (.xls) and Comma separated value (.csv) format.

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 for preliminary data analysis. During data standardization, missing data are handled based on derivation from existing data. Data de-duplication is also performed to identify duplicate records in the database that might have been missed by the SDP.

Data review and coding

Data coding of free text description was done by data manager. The expert panel comprising of members with expertise and knowledge in the relevant area serves as Quality Control to assess the coding by data manager. They ensure that complex medical data are reviewed and assessed to detect clinical nuances in the data.

Final query resolution / data cleaning / database lock

A final edit check run was performed to ensure that data is clean. All queries were resolved before database is locked to ensure data quality and integrity. Final dataset is subsequently locked and exported to the statistician for analysis.

Data analysis

Please refer to the Statistical Analysis Method section for further details.

Data release policy

One of the primary objectives of the Registry is to make data available to the pediatricians, 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 e-mail, fax, or registered mail) accompanied with a Data Release Application Form and signed Data Release Agreement Form. These requests need prior approval by the Advisory Board before data can be released.

Registry ICT infrastructure and Data centre

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

DiCARE subscribes to co-location service with a high availability and highly secured Internet Data Centre at Cyberjaya in order to provide DiCARE with quality assured Internet Hosting services and state-of-the-art physical and logical security features without having to invest in costly data centre setup internally. Physical security features implemented are of state of the art technology and include anti-static raised flooring, fire protection with smoke and heat alarm warning system, biometric security access, video camera surveillance system, uninterrupted power supply, environmental control, etc.

Other managed security services include patch management of the servers, antivirus signature monitoring and update, firewall traffic monitoring and intrusion detection, security incidence response, data backup service done on a daily, weekly and monthly basis, data recovery simulation to verify that backup works which is done at least once yearly, network security scan and penetration test done on a half-yearly basis, security policy maintenance, maintenance and monitoring of audit trail of user access and etc. Managed system services are also provided such as usage and performance report, operating system maintenance and monitoring, bandwidth monitoring and systems health monitoring.

APPENDIX 2:

ANALYSIS SETS, STATISTICAL METHODS AND DEFINITIONS

ANALYSIS SETS

This refers to the sets of cases whose data are to be included in the analysis. Two analysis sets were defined:

1. Patients notification between 2006 and 2007.

There were 240 patients in this dataset. This analysis set was used for the analysis in Chapter 1, 2, 3 and 4 which include data such as patient's particulars, family history, duration and type of diabetes, anthropometric and clinical examination details and diabetes management.

2. Patients annual census in 2006.

There were 98 patients in this dataset. This analysis set was used for the analysis in Chapter 5 which included data on outcome, hospitalization, complications, anthropometric and examination details, lab result, management, co morbidities/medications and change in classification of diagnosis.

DATA MANAGEMENT

Data cleaning

The data from DiCARE database were subjected to extensive checking prior to definitive analysis. Any error found or queries raised were checked against the database and/or CRF, and correction made thereof.

Missing data

Imputation method was used to overcome missing data but only variables in demographic profiles were eligible to be imputed for example variables such as father's and mother's education. The hot deck imputation method implemented is the Approximate Bayesian Bootstrap Hot deck.

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, median, minimum, maximum, median and inter quartile range were reported.²³ For standardization in output table, the value of percentages and summary descriptive were limited to one decimal point only. The summaries of data presentation by chapter were described as below:

Patient's socio-demographic particulars

Chapter 1 explained the registry for patient's socio-demographic particulars such as gender, ethnicity, age group, parent's education level, types of diabetes mellitus and family history. Other output include the distribution of types of diabetes mellitus, the summary of estimated age of diagnosis in years, estimated duration of diabetes mellitus in years and family history for patients with diabetes mellitus.

Socio-demographic details by types of diabetes mellitus

Chapter 2 present the similar outputs in Chapter 1 and the difference was in the way the tables' were displayed based on type 1 and type 2 diabetes of mellitus. Other than that, this chapter also presented the basis of diagnosis for patients based on overall and different types of diabetes.

Anthropometric examination details

Chapter 3 presented findings of anthropometric examination details such as weight, height and Body Mass Index (BMI). The mean, standard deviation, median, minimum and maximum for weight, height and BMI were produced. The findings also specified results for type 1 and 2 diabetes mellitus.

Management details of diabetes mellitus

Chapter 4 explained the management details of diabetes mellitus such as self care practice, visits to healthcare providers, treatment at diagnosis, notification and current and also insulin treatment. The findings also specified the result for type 1 and 2 diabetes mellitus.

Outcome details of diabetes mellitus

Chapter 5 showed the outcome details of diabetes mellitus including issues related with hospitalization, complication, laboratory test, self care practices, visits to healthcare provider, treatments, comorbidities and classification of type of diabetes mellitus. Cross tabulation was done for outcome based on demographic profile of patients and hospitalization in relation to diabetes mellitus. New variables such overall mean for HbA1C was generated since this registry observed maximum of three HbA1C readings. The denominator was based on the number of readings taken and not by the maximum number of three. Hence, only one reading will represent the HbA1C for each patient. Instead for general findings, this result also specified the outcome for type 1 and 2 diabetes mellitus.

STATISTICAL SOFTWARE

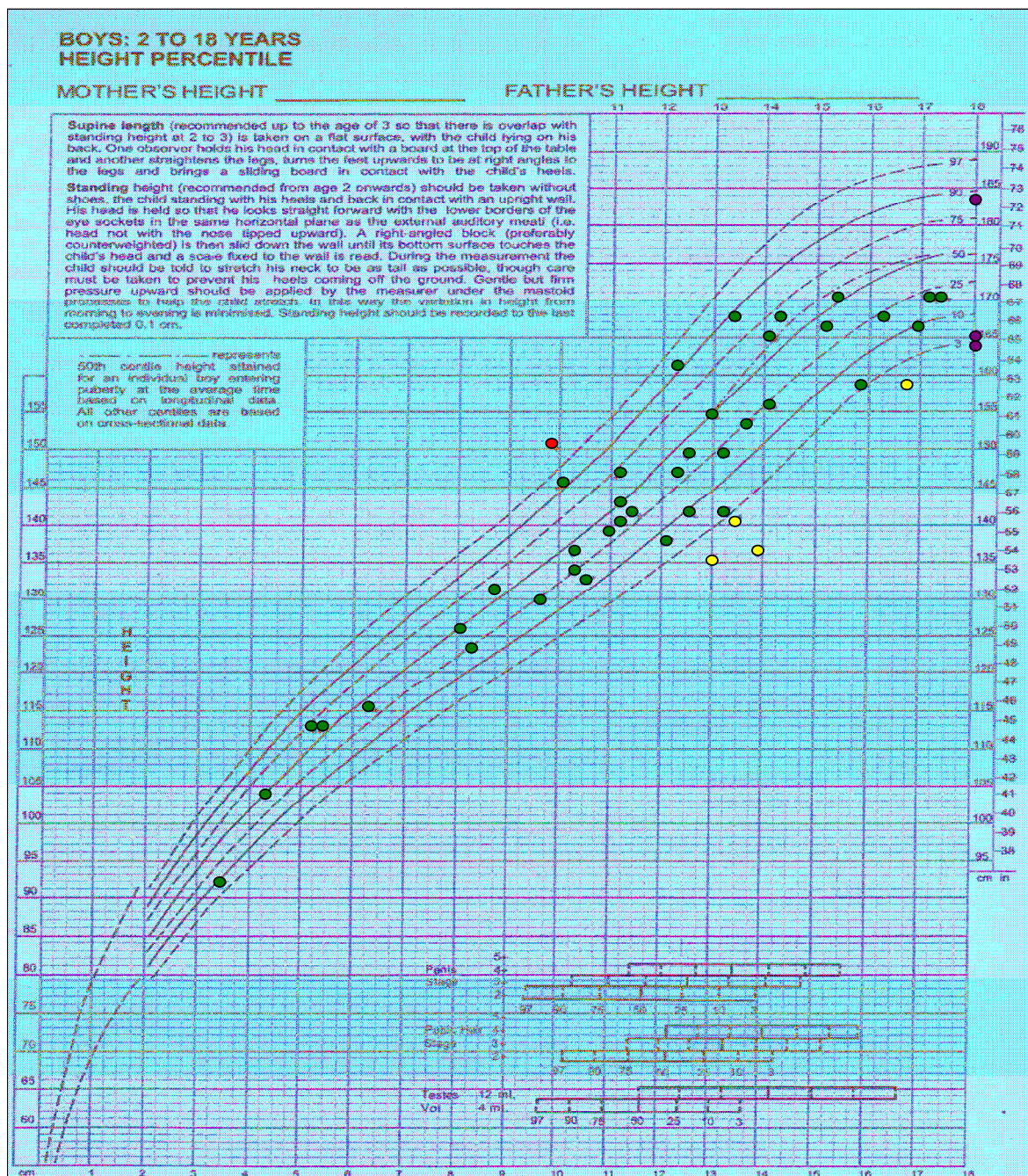
Stata version 9.2 and SPSS 14.0

APPENDIX 3:**ABBREVIATION**

BMI	Body Mass Index
CRC	Clinical Research Centre
CRF	Case Report Form
CSII	Continuous Subcutaneous Insulin Infusion
DiCARE	Diabetes in Children and Adolescent Registry
DKA	Diabetes Ketoacidosis
DM	Diabetes Mellitus
eCRF	electronic Case Report Form
eDiCARE	electronic Diabetes In Children and Adolescent Registry
FBS	Fasting Blood Sugar
HbA1c	Haemoglobin A1c (glycosylated haemoglobin)
HCO ₃	Serum bicarbonate
HKL	Hospital Kuala Lumpur
HPJ	Hospital Putrajaya
HUKM	Hospital Universiti Kebangsaan Malaysia
HUSM	Hospital Universiti Sains Malaysia
IAA	Insulin auto-antibodies
ISPAD	International Society for Paediatric and Adolescent Diabetes
MOH	Ministry of Health
NA	Not available
NCHS	National Centre for Health Statistics
NHMS III	National Health Malaysian Survey III
OGTT	Oral Glucose Tolerance Test
OPT	Optometrist/ ophthalmologist
RBS	Random Blood Sugar
RPG	Random Plasma Glucose
RR	Response Rate
SD	Stabilization of diabetes mellitus
SDPs	Source Data Providers of DiCARE
SMBG	Self Monitoring Blood Glucose
SMS	Short Messaging System
T1DM	Type I Diabetes Mellitus
T2DM	Type II Diabetes Mellitus
UMMC	University Malaya Medical Centre

APPENDIX 4:

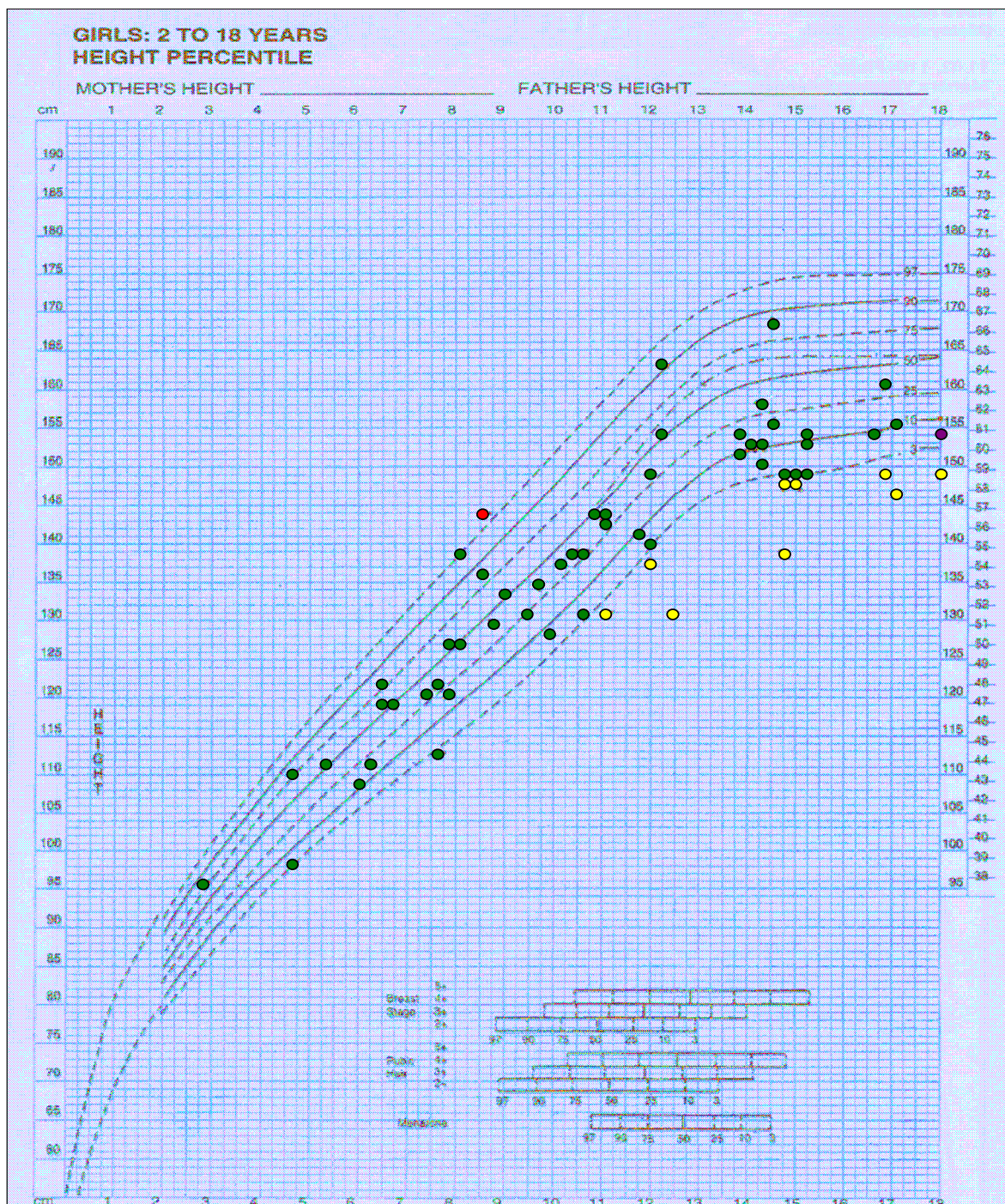
(a) Height percentile chart for patients with T1DM by gender, DiCARE 2006-2007



Note:

- Height <3rd percentile (Short for age)
- Height between 3rd-97th percentile (normal height)
- Height >97th percentile

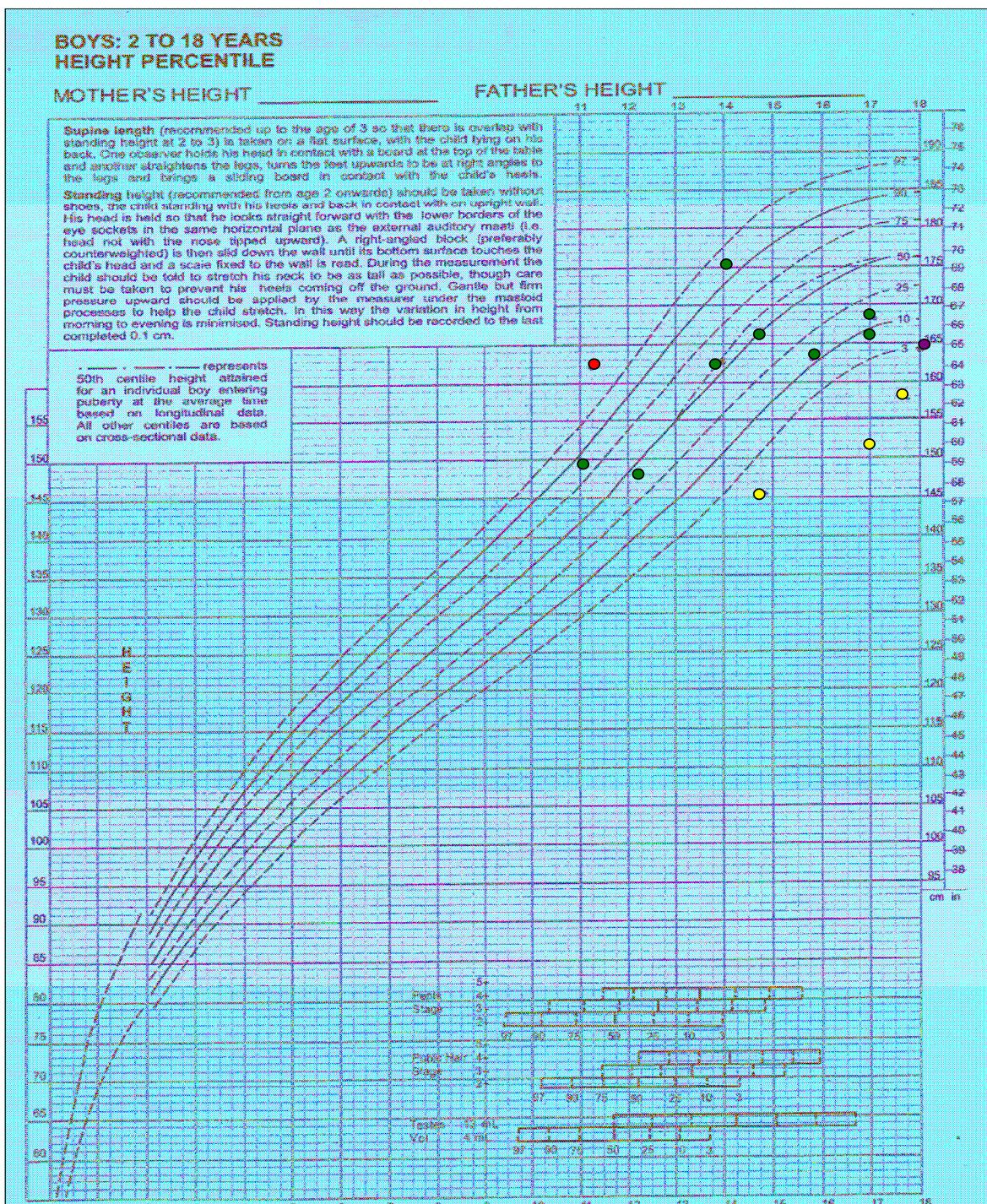
(b) Height percentile chart for patients with T1DM by gender, Malaysia 2006-2007



Note:

- Height <3rd percentile (Short for age)
- Height between 3rd-97th percentile (Normal height)
- Height >97th percentile

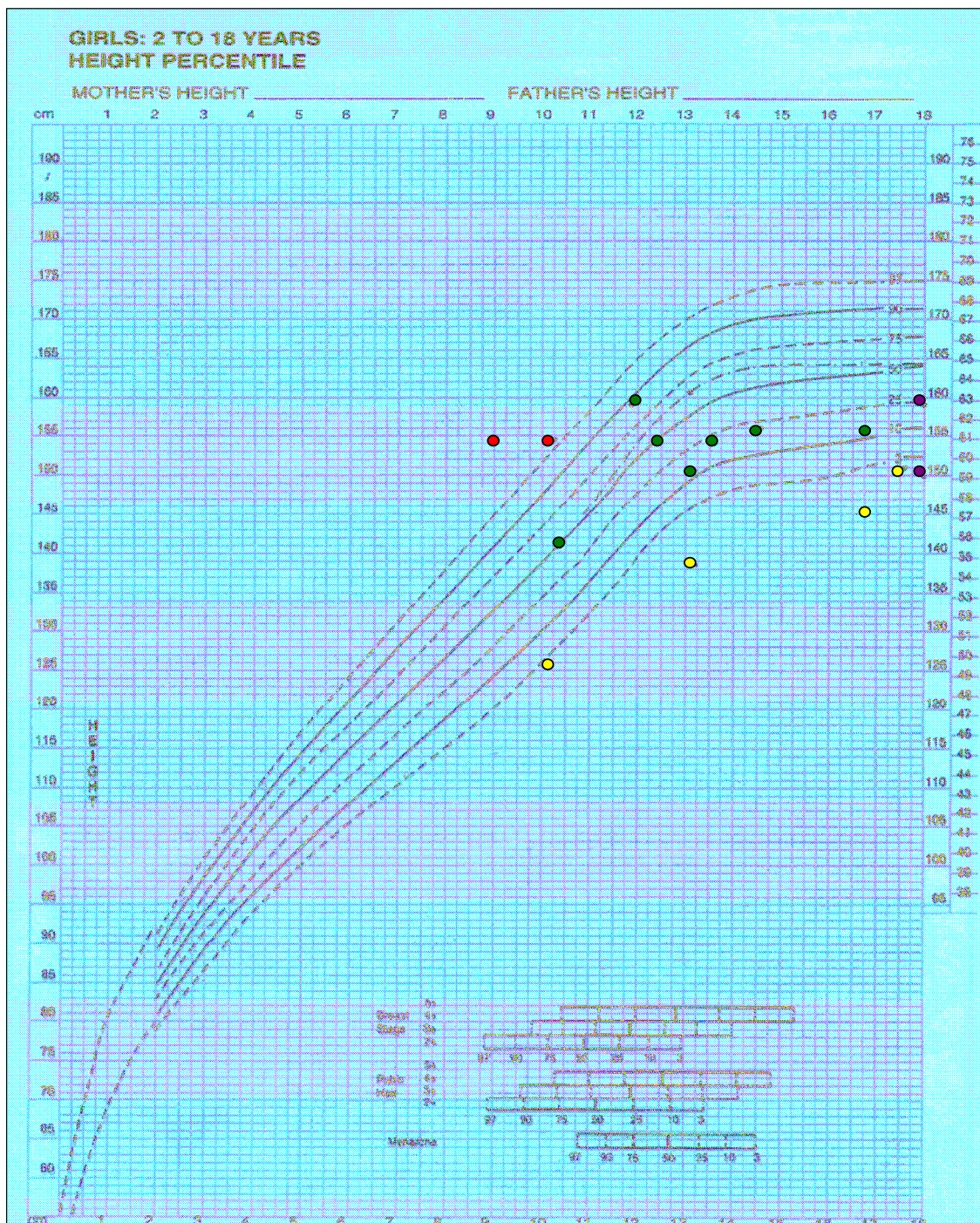
(c) Height percentile chart for patients with T2DM by gender, DiCARE 2006-2007



Note:

- Height <3rd percentile (Short for age)
- Height between 3rd-97th percentile (Normal height)
- Height >97th percentile

(d) Height percentile chart for patients with T2DM by gender, DiCARE 2006-2007



Note:

- Height <3rd percentile (short for age)
- Height between 3rd-7th percentile (normal height)
- Height >97th percentile

APPENDIX 5:

DIRECTORY OF PARTICIPANT CENTRES 2006-2007

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APPENDIX 6:**NOTE OF APPRECIATION**

A heart-felt note of appreciation is extended to everyone who has chipped in from day one until the successful publication of the annual report.

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