

## FINAL REPORT

*This report details the analysis of demographic, self-care and clinical data of people referred to specialist diabetes services, collected over approximately one month. The results build on those from the inaugural ANDIAB2 pilot data collection in 2005 and have comparisons to ANDIAB 2009 data where relevant.*

The report was prepared on behalf of the NADC by A/Prof Jeff Flack, Diabetes Centre Bankstown-Lidcombe Hospital and Prof Stephen Colagiuri, Boden Institute of Obesity, Nutrition and Exercise, The University of Sydney.

The following Background and Aims formed the basis of the ANDIAB2 2005 Pilot, and represent the format under which that Pilot and ANDIAB2 2010 were conducted.

### **1. Background:**

In Australia, diabetes remains a serious health problem associated with significant morbidity from long-term complications, with associated increased mortality. Diabetes Education is a major component in assisting individuals to self manage their diabetes, however measurement of patient practices and the effects of care delivered in Diabetes Centres have not been widely canvassed.

Diabetes data collection is essential for monitoring the quality of diabetes care, and in Australia there have been two national diabetes data collections undertaken:

➤ *The NDDP data collection*

Data collected on people with diabetes attending primary care physicians. This has been assessed twice, in 1999-2000 and 2002-2003.

➤ *The ANDIAB data collection*

Clinical data collected on people with diabetes attending specialist diabetes services. Commenced in 1998 and has been performed on 7 occasions. This has a strong 'medical' driven focus targeting physical examination findings, laboratory data and health outcomes.

The National Association of Diabetes Centres [NADC] conducts ANDIAB, a national audit, collating, analysing and reporting of diabetes specialist services. Data pooling, analysis and reporting are managed at the Diabetes Centre Bankstown-Lidcombe Hospital under the directorship of Jeff Flack, who also chairs the National Diabetes Data Working Group [NDDWG].

The ANDIAB data collection utilises the NDOQRIN dataset, now known as the Diabetes (clinical) data set in the National Health Data Dictionary [Version12]. This dataset, overseen by the NDDWG, has since been enhanced, and is now online as part of the AIHW – Metadata Online Registry ['METeOR'] as the Diabetes (clinical) Data Set Specification at – [see AIHW website]<sup>5</sup>: <http://meteor.aihw.gov.au/content/index.phtml/itemId/304865>

The NADC has long desired to establish an Audit Program to be run in alternate years to ANDIAB which would be more Patient / Education focused using these data for quality improvement in order to guide activities and practice changes to improve outcomes.

### **Aims:**

To conduct a Quality Assurance Activity in Diabetes Centres with a focus on Patient Practices and Diabetes Centre Care and Education Outcomes, in order to identify deficits to assist in formulating clinical practice strategies to improve diabetes care.

To specifically explore the differences in results between Centres, and provide data to assist them to develop and implement strategies to target areas of need or deficit, in order to improve diabetes care.

## **2. The Approach:**

*The following sections 2.1-2.4 represent the approach to the process:*

### **2.1 Format of ANDIAB2**

#### 2.1.1 Recruitment of Centres

All Diabetes Centres members of NADC were invited to participate.

#### 2.1.2 Data Items to be Collected

A sub-committee selected data items to be collected – based on experience in ANDIAB 2005. Items *considered* for collection in ANDIAB2 would include *but not be restricted to*:

- Basic Demographic Data – Age, Sex, Diabetes Type, Duration and Therapy ...;
- Patient Self-care Practices
  - Carrying Identification? / Carrying Hypoglycaemia Rx [if relevant]? / DVA patient ? ...;
- Medication Use – Adherence
  - Possibly including assessment of the use of Alternative and Natural Therapies;
- Quality Of Life assessment – [patient self administer – Centre record Score]
  - ? the SF 36
  - ? a simpler and validated tool – eg EuroQol EQ-5D, Centre for Health Economics, University of York, York - used in ANDIAB2 2005
  - ? Diabetes Distress Scale – validated 2 screening question, 17 item questionnaire with total score and 4 sub-scale score interpretations
- Hypoglycaemia Awareness [if relevant];
- Lipohypertrophy Presence [if relevant];
- Smoking;
- Exercise – ?Type, Amount, Frequency;
- Allied Health ‘Usage’ – ?number / frequency of visits,
  - including – educator, dietitian, podiatrist, psychologist, social worker, ?other;
- Depression / Mood [utilizing the Brief Case Find for Depression [BCD] tool © 1993 Monash Univ. Dept of Psychological Medicine. [*This was first used in ANDIAB 2002 and also in ANDIAB2 2005*].

#### 2.1.3. Review of Project

Following the data collection phase of the Project, a questionnaire will be designed and administered seeking feedback on the data items and the process in general. A second questionnaire will be designed and administered seeking feedback on Diabetes Centre views of the reports received. The responses to these questionnaires will guide the Final Report and recommendations for future collections, which are proposed to be run second yearly in the alternate years to ANDIAB.

### **2.2 How the project can improve the care of patients with diabetes**

The results of ANDIAB2 will be expected to provide an indication of the patient care practices and the process of care found amongst participating Centres throughout Australia. There will likely be wide variation in these findings which may inform areas of practice or knowledge deficit amongst patients, or the need for service development or topic revision regarding the specific examples found. For instance – there may be poor carriage of hypoglycaemia therapy that needs to be reinforced or a significant degree of knowledge deficit identified that warrants increased attention by a particular Centre. Sharing this information in a Final Pooled Report should assist in identifying processes that could be adopted to improve education and clinical care which [once implemented] should result in improved outcomes for people attending those Centres.

## 2.3 How efficiency of ANDIAB2 will be assessed

This will be assessed in 2 ways:

- the participation rate in ANDIAB2 itself;
- the assessment of responses to the questionnaires.

## 2.4 Ethics Approval

This is a quality audit exercise utilising de-identified patient data from de-identified sites transmitted through a ‘trusted third party’ [the NADC Secretariat]. There is no disclosure of individual patient data. The usual ethics approval for the ANDIAB data collection will apply, which is, that each site determine how to address this within their individual setting.

### **3. Methodology Undertaken:**

The NADC Board was approached in late 2009 and a sub-committee was nominated and formed to meet by Teleconference and formulate the data set, ie the data items to be collected. Members were Jeff Flack [Chair], Gil Cremer, Trisha Dunning, Gloria Kilmartin and Pamela Jones.

Any data items selected would use current, agreed, preferably national definitions [if in existence], or original NDOW [National Diabetes Outcomes Workshop], (now METeOR<sup>5</sup>) Dataset definitions. Any data item collected would need to be able to provide relevant information for the Centre about its patients with a view to instituting change for identified ‘problems’. These data items and their definitions would be widely discussed and consensus reached where necessary before implementation. The ANDIAB2 2005 dataset was placed on the ADEA Website and feedback sought, and incorporated where possible. This was not done for ANDIAB2 2010.

A separate version of the ANDIAB Database was created and converted to accept the data items to be collected, and Teleform© Software was utilised to create a scannable form for use in data collection [*See Appendix 1*]. Definitions for each data field were agreed and provided to participants [*See Appendix 2*].

The NADC Secretariat coordinated the project, which was conducted in a ‘double blind’ fashion. Diabetes Centres were invited to complete the one-page data collection form during the months of April, May (or June) 2010. Centres who wished to participate, responded to a formal invitation distributed by the NADC Secretariat to all Diabetes Centre members of the NADC across Australia. All subsequent contact and correspondence with participants was conducted through the Secretariat.

The Secretariat allocated a unique code to each Diabetes Centre using the predetermined ANDIAB proforma, and holds the only copy of the code. Centres who had participated in ANDIAB previously used the code already allocated to them. The Central Data Analysis Site generated .pdf electronic ‘Master Copies’ of forms uniquely numbered for each Centre, and sent them to the NADC Secretariat where a copy was forwarded to each participating Centre with printing instructions. Using de-identified data via this methodology, it is not possible for the Benchmarking Centre – Central Analysis Site to identify individual Centres or patients.

Every effort was made to ensure data completeness and correctness. As in ANDIAB, specific ‘Validation Reports’ were generated for each Centre requesting missing data and correction of questionable or potentially invalid data [*See Appendix 2 for data definitions & validation rules*]. Specific items that were altered if not done so by sites were:

- o ‘Management Method’ not Insulin, but ‘Insulin Since’ not null - (Removed Insulin Since);
- o Not ‘Current Smoker’ but ‘Tried to Stop Smoking’ Yes - (Tried to Stop Smoking made Null);
- o ‘Know who to contact’ not Yes - ‘Have Telephone Number’ Yes (Telephone No. made Null).

Data analyses addressed the process and outcome findings for all data fields, to enable Centres to compare and benchmark their practice findings against other participating Centres. An Individual Site Report was generated for each Centre, providing them with comparison data for their Centre versus all other Centres. These included:

- o Process assessment:
  - Missing Data [presented in both tabular and graphical formats];
- o Outcome measurements such as:
  - Frequency Counts Data, Mean Descriptive Results and Outcome Data [where relevant].

In addition, since most of the Data Fields collected in 2005 were again collected in 2010, *in part to ensure the ability for some comparison*, sites that participated then have data from that initiative as well as their 2010 data included in their Individual Site Report. There are three two-year comparative reports, covering the two ANDIAB2 collections of 2005 and 2010:

- o A 2005 and 2010 *Demographic Data* Report;
- o A 2005 and 2010 *Missing Data Analysis* Report;
- o A 2005 and 2010 *Frequency Counts* Report.

Overall, the feedback provided to participants was designed to enable them to identify areas where their services and patient outcomes are good, and equally, areas that may require attention. The potential benefit to persons with diabetes is an assessment of their individual status, as well as an assessment of the local services provided.

The pooled data analysis in this Final Report provides a ‘snapshot’ of the status of patient practices and Diabetes Centre services – as detailed below.

### 3.1 Project Milestones

The major Project Milestones are summarised in **Figure 1[a]** where superscript numbers reference **Figure 1[b]** Project components.

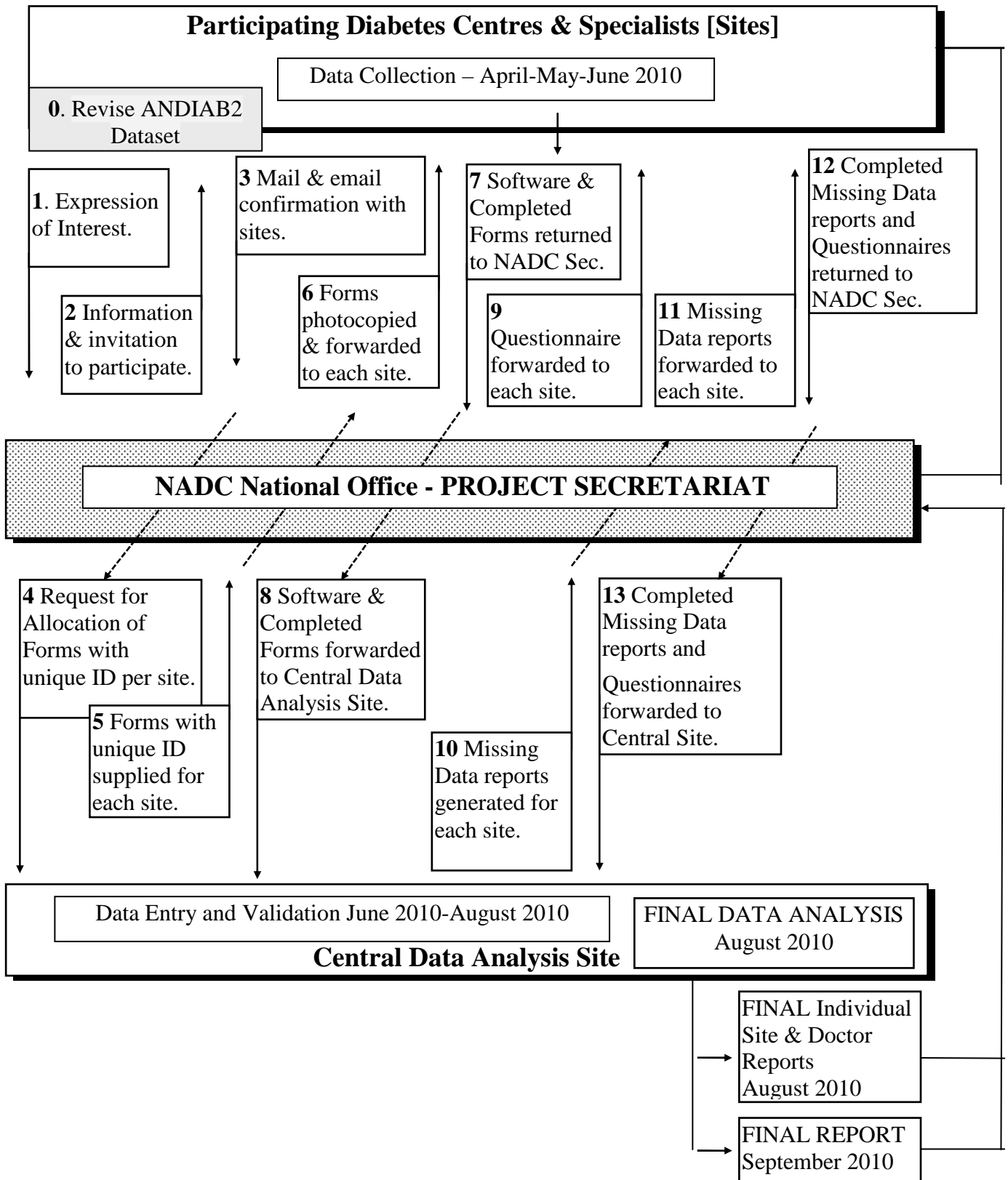
**Figure 1[a] – ANDIAB2 Project Milestones\***

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Initial call for expressions of interest, <u>December 2009-January 2010</u><sup>1</sup>;</li> <li>• Formal invitations received, collation of site acceptances <u>January 2010 - February 2010</u><sup>2</sup>;</li> <li>• Allocation of site codes, <u>March 2010</u><sup>3, 4</sup>;</li> <li>• Generation and distribution of Data Collection Forms, <u>April 2010</u><sup>5, 6</sup>;</li> <li>• Data collection, <u>April-May-June 2010</u><sup>7, 8</sup>;</li> <li>• Study assessment: Post Data Collection Questionnaire<sup>9, 12</sup>;</li> <li>• Data received from ANDIAB Software sites <u>June 2010 - July 2010</u><sup>8</sup>;</li> <li>• Data entry and validation <u>June 2010 – August 2010</u>;</li> <li>• Validation reports forwarded to sites <u>June 2010 - July 2010</u><sup>10, 11</sup>;</li> <li>• Integration of returned missing data <u>July 2010 - August 2010</u><sup>12, 13</sup>;</li> <li>• Final Data Analysis <u>August 2010</u>;</li> <li>• Final Site/Doctor Data Analysis Reports forwarded to sites <u>August 2010</u>;</li> <li>• Final Pooled Data Report <u>September 2010</u>;</li> </ul> |
|---|

\* See also Figure 1[b]

**Figure 1[b]**

**NADC-ANDIAB2  
Australian National Diabetes Information Audit & Benchmarking  
National Clinical Data Collection Project**



### 3.2 Participants Sites

The following NADC member Diabetes Centres participated in ANDIAB2 2010 [Table 1].

<b>Table 1</b>	<b>Participating Centres</b>	<b>State</b>
	The Canberra Hospital – Diabetes Centre	ACT
	ACTION Diabetes	NSW
	Bankstown-Lidcombe Hospital – Diabetes Centre	NSW
	Blacktown Hospital-Diabetes Centre	NSW
	Grafton Community Health-The Clarence Diabetes Centre	NSW
	Liverpool Hospital Diabetes Centre	NSW
	Macarthur Diabetes Service	NSW
	Mt Druitt Hospital-Diabetes Centre	NSW
	St Vincent’s Hospital Sydney – Diabetes Centre	NSW
	Westmead Hospital – Diabetes Centre	NSW
	Greater Newcastle Cluster Diabetes Service	NSW
	Gold Coast Hospital – Diabetes Centre	QLD
	Ipswich Diabetes Service	QLD
	Logan Beaudesert Health Service District	QLD
	Mater Hospital-Diabetes Centre	QLD
	Princess Alexandra Hospital – Dept of Diabetes	QLD
	Sunshine Coast Diabetes Centre	QLD
	Launceston General Hospital – Diabetes Centre	TAS
	Royal Hobart Hospital – Diabetes Centre	TAS
	Barwon Health – Geelong Hospital – Diabetes Centre	VIC
	Dandenong Hospital	VIC
	Goulburn Valley Health – Goulburn Valley Base Hospital	VIC
	Goulburn Valley Health – outreach clinics	VIC
	St John of God Hospital Bendigo	VIC
	St Vincent’s Hospital-Melbourne	VIC
	The Alfred – Department of Endocrinology & Diabetes	VIC
	Park Diabetes Service – Rockingham Hospital	WA

### 3.3 Questionnaires

As in ANDIAB 2009, questionnaires were developed, distributed and replies collated and reported on the assessment of participant responses to aspects of the project. In ANDIAB2 2010, no sites provided data from established databases, with paper form collection used by all of the participants. Participating sites were asked to complete Questionnaire [1] in June/July/August, - [at completion of the data collection phase], to assess the project overall. Questionnaire [2], to assess the Individual Site Report that they receive, were forwarded in August with their Site Report. [See 4.11 & Table 16 Page 17].

[See Appendix 4 for Copies of Questionnaires used in 2010].

## 4. Findings / Results:

### 4.1 Introduction

Thirty five NADC member Diabetes Centres responded to an ‘Expression of Interest’ and twenty seven [27] NADC member Diabetes Centres participated and provided data on **2131** individuals [median 76 per Centre; mean 79 per Centre; range: (8–220)]. In all Tables - figures ‘excluding missing’ represent the % of all responses received [ie after excluding missing data].

[See Appendix 5 for Frequency Counts Data];

[See Appendix 6 for Data Tables & Graphs - Mean Descriptive Data].

## 4.2 Demographic Data

**Table 2** lists the Demographic Characteristics of these individuals. By way of comparison, details are provided from the 2009 ANDIAB Data Collation for Age [years], Sex [%male], Duration [years], Diabetes Type and Therapy, Initial Visit status and Pregnancy.

As can be seen, ANDIAB2 2010 had **3.7%** GDM individuals {representing 19.3% of females aged 15-55} contributing to the slight increase % female compared with ANDIAB 2009. Mean Age and Diabetes Duration were similar [3.2 years less and 0.6 years more respectively], distribution of Diabetes Types was similar [more GDM already noted], and as regards Therapy, this was similar compared to ANDIAB 2009. For a significant percentage of these individuals, this was an Initial Visit - **25.6%** [versus 13.2% ANDIAB 2009].

Compared to 2005, individuals were slightly younger, with higher % male, longer duration, more with Type 1 diabetes and far less on Diet, and far more on Insulin or Insulin & Tablets.

**Table 2 Demographic Data**

Category	2005 - n = 1405	Excluding Missing	2010 - n = 2131	Excluding Missing	ANDIAB 2009 - n = 6029
Age[Years]	55.9 ± 16.4		53.6 ± 17.6		56.8 ± 17.3
Sex [%] - Male	44.7%	45.5%	50.4%	50.7%	52.0%
DM Duration [Years]	8.5 ± 9.6		11.5 ± 10.8		10.9 ± 9.7
Diabetes Type					
Unstated	0.1%		0.2%		2.6%
Type 1	15.6%		27.5%		21.8%
Type 2	76.3%		67.3%		72.5%
GDM	6.0%		3.7%		2.1%
Other	1.4%		0.7%		0.8%
Treatment					
Unstated	0.6%		0.4%		5.0%
Nil	0.3%		0.2%		0.1%
Diet Only	19.7%		8.5%		6.2%
Tablets	35.9%		25.2%		28.7%
Insulin	26.1%		38.9%		34.4%
Insulin & Tablets	17.4%		26.7%		25.6%
Initial Visit	23.8%	24.2%	25.6%	25.7%	13.2%
DVA Patient	1.5%	1.7%	1.9%	2.1%	Not Collected
Interpreter Required	5.4%	6.2%	3.5%	4.0%	Not Collected
Pregnant (99)	28.3%	29.7%	19.3%	20.0%	9.6%

\* Only Adults data [ANDIAB 2009]

\*\* Only female patients aged 15-55

## 4.3 Lifestyle Issues Data

**Table 3** lists Lifestyle Issues data. Overall **13.3%** of Yes/No respondents were current smokers, and **73.5%** {76.2% of Yes/No respondents} reported they had 'Tried to Stop Smoking'.

Adequacy of Physical Activity [with only **44.0%** adjudged as 'sufficient'] was ascertained using the following definition [*See Appendix 2 for all data definitions*].

**Physical Activity** Does the patient undertake sufficient Physical Activity?  
Record as **Sufficient / Insufficient / Sedentary**

\***Sufficient** physical activity for health benefit for a usual 7-day period is calculated by - summing the total minutes of walking, moderate and/or vigorous physical activity. Vigorous physical activity is weighted by a factor of two to account for its greater intensity. **Total minutes for health benefit need to be equal to or more than 150 minutes per week.**

\***Insufficient** physical activity for health benefit is where the sum of the total minutes of walking, moderate and/or vigorous physical activity for a usual 7-day period is **less than 150 minutes but more than 0 minutes.**

\***Sedentary** is where there has been **no** moderate and/or vigorous physical activity during a usual 7-day period.

*The National Physical Activity Guidelines* for Australians describes **Moderate-intensity physical activity** as causing a slight but noticeable, increase in breathing and heart rate and suggests that the person should be able to comfortably talk but not sing. **Vigorous physical activity** is described as activity, which causes the person to 'huff and puff', and where talking in a full sentence between breaths is difficult.

**Table 3 Lifestyle Issues**

Category	2005 - n		2005 - %	2005 Exc Missing	2010 - n		2010 - %	2010 Exc Missing
	Smoker - Current	275		19.6%	187.1%	275		12.9%
Smoker - Past	Not Collected				777		36.5%	37.5%
Smoker - Never	Not Collected				1021		47.9%	49.3%
Smoker tried to stop*	202		73.5%		202		73.5%	76.2%
Physical Activity - Sufficient	937		66.7%	67.4%	937		44.0%	45.8%
Physical Activity - Insufficient	787		56.0%	56.6%	787		36.9%	38.4%
Physical Activity - Sedentary	324		23.1%	23.3%	324		15.2%	15.8%
Vaccination Flu	1279		91.0%	91.4%	1279		60.0%	63.4%
Vaccination Pneumococcal	439		31.2%	31.6%	439		20.6%	31.6%

\*only patients who are current smokers

Further analysis of reported Vaccinations indicated **60.0%** have had a Flu Vaccination and **20.6%** have had a Pneumococcal Vaccination.

**Tables 4a & 4b**, indicate that the percentage of the Age Groups having Flu Vaccination increased from **34.7-41.9%** under 40, to **55.3%** aged 40-59 and **75.3%** over age 60.

For Pneumococcal Vaccination, numbers were smaller and the relative age group population figures were highest for 60+, and substantially lower for 40-59 years and younger.

**Table 4[a] Vaccination - Influenza past 12 months by Age Group**

Age Group	Influenza	2005 - n=	2005 - % of Age Group	2010 - n=	2010 - % of Age Group
<20	Yes	6	24.0%	35	34.7%
20-39	Yes	50	21.0%	171	41.9%
40-59	Yes	193	40.5%	396	55.3%
60+	Yes	470	74.5%	672	75.3%

**Table 4[b] Vaccination - Pneumococcal past 12 months by Age Group**

Age Group	Pneumococcal	2005 - n=	2005 - % of Age Group	2010 - n=	2010 - % of Age Group
<20	Yes	2	8.0%	8	7.9%
20-39	Yes	10	4.2%	36	8.8%
40-59	Yes	35	7.3%	100	14.0%
60+	Yes	181	28.7%	293	32.8%

Looking at these data by Diabetes Type, [Tables 4c & 4d], **50.3%** of Type 1 and **65.4%** of Type 2 individuals had a Flu Vaccination with a Mean age of 41.2 and 63.7 years respectively.

For Pneumococcal Vaccination, figures were **11.6%** and **25.0%** at Mean ages of 44.0 and 66.9 years for Type 1 and Type 2 respectively.

**Table 4[c] Vaccination – Influenza by Diabetes Type**

DM Type	Influenza	2005			2010		
		n =	% who responded	Mean ± SD Age	n =	% who responded	Mean ± SD Age
Type 1	Yes	98	44.7%	46.2 ± 17.6	295	50.3%	41.2 ± 16.8
Type 2	Yes	624	58.2%	65.3 ± 11.1	939	65.4%	63.7 ± 11.6

**Table 4[d] Vaccination - Pneumococcal by Diabetes Type**

DM Type	Pneumococcal	2005			2010		
		n =	% who responded	Mean ± SD Age	n =	% who responded	Mean ± SD Age
Type 1	Yes	24	11.0%	44.9 ± 19.9	68	11.6%	44.0 ± 17.4
Type 2	Yes	205	19.1%	69.1 ± 9.9	359	25.0%	66.9 ± 10.7



#### 4.4 Self-care Data

Several areas of diabetes patient self-care behaviour were assessed [Table 5]. Areas addressed included whether the individual was carrying identification indicating that they had diabetes - only **65.4%**; only **60.4%** of those on insulin or sulphonylureas carried hypoglycaemia therapy; and only **60.8%** [**80.0%** of Type 1 individuals] had told the traffic authority they had diabetes [**64.6%** of those on therapy other than diet].

One deficit of the latter assessment in 2005 was that we did NOT have a NOT APPLICABLE option to account for those who did not drive! This was rectified in 2010.

Notwithstanding the latter caveat, the 2005 pilot identified three important areas of patient self-care that were assessed as being deficient; ie *Carrying Identification*; *Carrying Hypoglycemia Therapy*; and *Informing the Traffic Authority*. **There has been little improvement since.**

**Table 5 Self-care**

Category	2005 n = 1405				2010 n = 2131			
	n	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total
Carrying Identification	865	61.6%	62.5%	1405	1394	65.4%	66.8%	2131
Carrying Hypo Therapy *	559	58.7%	59.1%	953	1074	60.4%	63.0%	1779
Traffic Authority Told **	564	40.1%	44.5%	1405	1026	60.8%	68.8%	1688
Hypo Aware ***	723	82.3%	84.0%	879	1377	79.5%	83.0%	1733
Contact - Know Who To	1266	90.1%	92.1%	1405	1956	91.8%	94.0%	2131
Contact - Phone No ****	1210	95.6%	95.7%	1266	1883	96.3%	96.6%	1956

\* only patients on insulin/sulphonylurea

\*\* in 2010 only [not 2005] this represents the percent of 'Drivers' who have not told the Traffic Authority [i.e. excludes non-drivers]

\*\*\* only patients on insulin/sulphonylurea and a hypo in last 6/12

\*\*\*\* only patients who know who to contact

Overall, amongst patients on insulin or sulphonylureas [and who had had a hypoglycaemic episode in the last 6 months], **79.5%** were adjudged to be Hypo Aware [based upon the definition "In last 6 months has the patient always recognised [and self treated] their hypos"]. [See Appendix 2 for all data definitions].

Individuals were asked whether they knew who to contact "for medical/health advice about their diabetes? [Health Professional or DA]" and of those who did [**91.8%** of all individuals], **over 96%** had a Contact Phone Number in order to do so.

#### 4.5 Assessment Data

**Table 6** lists the assessment data for Lipohypertrophy, Lipoatrophy or Both. Looking at the figures *excluding* the 10 individuals who were on insulin marked 'not relevant', [where we are uncertain what 'not relevant' means (-it should mean not on insulin)], there was a reported **13.8%** Lipohypertrophy, **1.8%** Lipoatrophy and of these, **1.5%** with both.

**Table 6 Assessment**

Category	Excluding Not Relevant				Insulin Rx **				Excluding Not Relevant				Insulin Rx **			
	2005 n = 1405								2010 n = 2131							
	n	%	% (Exc Missing)	Total	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total	%	% (Exc Missing)	Total		
Lipohypertrophy *	88	13.0%	14.3%	677	12.8%	15.1%	687	208	13.8%	13.9%	1497	13.8%	15.5%	1506		
Lipoatrophy *	22	3.3%	3.6%	670	3.2%	3.8%	680	27	1.8%	1.8%	1496	1.8%	2.1%	1504		
Both Lipohypertrophy and Lipoatrophy*	20	3.0%	3.0%	677	2.9%	3.4%	680	23	1.5%	1.5%	1497	1.5%	1.7%	1507		

\*only patients on insulin

\*\* includes 10 marked not relevant in 2005 and includes 9 marked not relevant in 2010

#### 4.6 Medication Use Data

Individuals were asked several questions in regards to Medication Use [Table 7]. Of note **92.8%** claimed to always take “all of their medicines as prescribed by their doctor” [therefore **7.2%** admitted to NOT do so], and whilst **27.8%** admitted to the use of Complimentary Medicines [*“herbal/homeopathic/essential oil/vitamin or mineral supplement OR dietary supplement”*], over 80% [**82.5%**] of these stated that they HAD informed their Doctor of this fact.

**Table 7 Medication use**

Category	2005 n = 1405				2010 n = 2131			
	n	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total
Take Medicines	1231	87.6%	87.9%	1401	1878	92.8%	89.9%	2090
CMI# Leaflets Given	680	48.4%	50.4%	1349	1161	54.5%	57.2%	2031
Complementary Rx Used	326	23.2%	23.6%	1381	592	27.8%	28.7%	2060
Complementary Rx Told Dr *	240	74.1%	73.6%	326	484	82.5%	81.8%	592

#CMI=Consumer Medicines Information \*only patients on complementary Rx

#### 4.7 Brief Case-find for Depression [BCD] / Psychiatric Treatment Data

In 2002, four questions were added to ANDIAB. These can be used to calculate whether depression is ‘likely’ / ‘unlikely’ on the basis that a Yes to either or both of the first two questions ([a] or [b]) AND a Yes to either or both of the second two questions ([c] or [d]), makes ‘depression likely’.

[BCD© 1993 Monash University Department of Psychological Medicine: used with permission].

The questions [*relating to the last two weeks*] are :

- [a] Have you been having restless or disturbed nights? Yes/No
- [b] Have you been feeling unhappy or depressed? Yes/No
- [c] Have you felt unable to overcome your difficulties? Yes/No
- [d] Have you been dissatisfied with the way you have been doing things? Yes/No

**Table 8** shows the % Yes ‘depression likely’ of the total patient population, with results in the next column being the % of those who responded Yes or No to the questions. Overall a BCD calculation could be made for **90.4%** of individuals [*compared with 99.6 % of individuals in ANDIAB2 2005*].

As can be seen from the Table, the reported Likely Depression was **25.6%** (versus 26.0% in ANDIAB2 2005).

**Table 8 BCD Depression**

Category	2005 n = 1405				2010 n = 2131			
	n	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total
Likely Depression Yes	365	26.0%	26.1%	1400	545	25.6%	28.3%	1926
BCD calculated for		99.6%				90.4%		

Additional information was sought regarding whether individuals have/have had Current or Previous Psychiatric Treatment/Counselling. Overall these data were **89.7%** complete [*compared with 99.4% complete in ANDIAB2 2005*] and the results shown in **Table 9** are the % Yes of the total patient population, with results also for the % of those who responded Yes or No [ie excluding missing data]. The data shown in the Table indicate that the reported Current and Previous Psychiatric Treatment were **6.4%** and **19.2%** respectively, very similar to what was reported in ANDIAB2 2005 (6.5% and 16.6% respectively).

**Table 9 Psychiatric Treatment**

Category	2005 n = 1405				2010 n = 2131			
	n	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total
Current Yes	92	6.5%	6.6%	1396	137	6.4%	7.2%	1908
Previous Yes	233	16.6%	16.7%	1396	409	19.2%	21.4%	1909
Completed for		99.4%				89.7%		

These data were supplemented by asking “*Is the patient taking antidepressant medication (not prescribed for peripheral neuropathy)?*” and the results [Table 10], show findings similar to those reported in ANDIAB2 2005 with **15.4%** of all patients reportedly on Antidepressants – the overwhelming majority being those with Likely [versus Unlikely] Depression as per the BCD **30.8%** versus **9.1%** respectively.

**Table 10 On Antidepressant**

Category	2005 n = 1405				2010 n = 2131			
	n	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total
Depression (BCD) likely	96	26.3%	26.3%	365	168	30.8%	31.1%	545
Depression (BCD) unlikely	74	7.1%	7.2%	1035	126	9.1%	9.2%	1381
Total on Antidepressant	170	12.1%	12.2%	1400	296	15.4%	15.5%	1917
Completed for				99.6%				90.0%

#### 4.8 Health Professional Attendance Data

Information was sought about Health Professional [HP] Attendance in the last 12 months, and the findings are summarized in Table 11 [again with results in an adjacent column being the % of those who responded Yes or No]. Relatively few had seen a Psychologist, Social Worker or Exercise Physiologist, with almost **70%** having seen a Specialist and/or a Diabetes Educator, and just over half had seen a Dietitian and / or a Podiatrist. Looking more closely at ‘Attended Ophthalmologist or Optometrist’, 30.6% had seen both, 26.7% an Optometrist only and 18.7% an Ophthalmologist only. Thus **76.0%** had seen either an Ophthalmologist or Optometrist or both [data not shown in Table].

**Table 11 HP attendance**

Category	2005 n = 1405				2010 n = 2131			
	n	%	% (Exc Missing)	Total	n	%	% (Exc Missing)	Total
Attended Diabetes Specialist	883	62.8%	63.4%	1393	1452	68.1%	69.9%	2077
Attended Dentist	Not Collected in 2005				929	43.6%	45.2%	2056
Attended Dietitian	688	49.0%	49.4%	1393	1052	49.4%	51.1%	2059
Attended Educator	968	68.9%	69.5%	1392	1442	67.7%	69.6%	2071
Attended Exercise Physiologist	Not Collected in 2005				118	5.5%	5.8%	2051
Attended Ophthalmologist	Not Collected in 2005				1050	49.3%	50.9%	2061
Attended Optometrist	Not Collected in 2005				1220	57.3%	59.2%	2061
Attended Podiatrist	574	40.9%	41.1%	1398	1023	48.0%	49.2%	2079
Attended Psychologist	107	7.6%	7.7%	1395	206	9.7%	10.0%	2059
Attended Social Worker	95	6.8%	6.9%	1385	140	6.6%	6.9%	2039
Attended 0 (excluding Specialist)	241	17.2%		1405	90	4.2%		2131
Attended 1 (excluding Specialist)	312	22.2%			191	9.0%		
Attended 2 (excluding Specialist)	509	36.2%			387	18.2%		
Attended 3 (excluding Specialist)	276	19.6%			467	21.9%		
Attended 4 (excluding Specialist)	61	4.3%			435	20.4%		
Attended 5 (excluding Specialist)	6	0.4%			346	16.2%		
Attended 6 (excluding Specialist)	N/A	N/A			169	7.9%		
Attended 7 (excluding Specialist)	N/A	N/A			39	1.8%		
Attended 8 (excluding Specialist)	N/A	N/A			6	0.3%		
Attended 9 (excluding Specialist)	N/A	N/A			1	0.05%		

#### 4.9 Quality of Life EQ-5D Assessment Data

An attempt was made to assess patient's Quality of Life and their perceived Self-Assessed Own Health State Rating, based on the EQ-5D instrument developed by the EuroQol Group © 2004 [with permission]. Individuals were asked to rate their own health status on a 0% [poor {or worst imaginable health state}] to 100% [excellent {or best imaginable health state}] scale, as was done in ANDIAB2 2005. *Diabetes Centre staff then transcribed the results to the scannable form for that individual.*

The Diabetes Distress Scale [DDS]<sup>6</sup> was chosen to assess diabetes-related emotional distress. It is a validated 2 screening question, 17 item questionnaire. The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress, these being: Emotional Burden; Physician-related Distress; Regimen-related Distress; Interpersonal Distress. **A mean item score of 3 or higher (moderate distress) is considered as a level of distress worthy of clinical attention.**

Sites were given the following instructions re the DDS and 3 options for scoring:

- If EITHER Screening Question in 'A' is scored **3 or above** the patient should complete the additional DDS 17 item questionnaire and **computed** score results should be entered in 'B' on the Data Field Definitions Form in the **Quality of Life Assessment** section.

##### HOW TO SCORE THE 17 Item DDS Questionnaire

**There are 3 Options:**

[1] Manually calculate the 5 required items using the SCORE SHEET PROVIDED;

[2] Utilise the DDS Calculator Tool provided. This is an application that you can save to your desktop, double click on the icon, and enter the 17 Individual Scores, then press the 'Calculate' button;

[3] Log onto the Diabetes Centre Website [Bankstown-Lidcombe Hospital]  
<http://www.sswahs.nsw.gov.au/bankstown/diabetes/>  
 Click on **Diabetes Distress Scale** on the left;  
 Enter the 17 Individual Scores, then press the 'Calculate' button.

##### NOTE

[a] You should **ONLY CALCULATE THE TOTAL DDS SCORE** if 14 or more questions have been answered [and the Calculators [2]&[3] above will only work], when 14 or more answers are entered.

[b] You should **NOT CALCULATE ANY OF THE OTHER 4 ITEMS** if more than one item in that section has not been answered [and the Calculators [2]&[3] above will NOT work for the individual items when 2 or more items are missing].

Once DDS Scores had been calculated, *Diabetes Centre staff then transcribed the results to the scannable form for that individual.*

Regarding [2] & [3] above we developed, tested and implemented a DDS Calculator to automate the scoring of the DDS and its sub scales in ANDIAB2. This was submitted and accepted as a Poster presentation at the ADEA ASM, see Figure 2 Page 21.

**[See Appendix 3 for the Self-Assessment of Health Status Form, the full DDS17 Questionnaire and the DDS Scoring Sheet ].**

Assessments of 'Own Health Status' were collated and are reported by: Diabetes Type and Age Group; with DiabCo\$t<sup>7</sup> data provided [with permission] for comparison; and for Type 2 diabetes by diabetes management method. Diabetes Distress Scale scores are presented as Screening, Total and Sub scale scores by Diabetes Type and by aspects of Screening Question responses. The findings are summarised in **Tables 12, 12[a]-[d], 13, 14, and 14[a]-[b]** on Pages 13-15.

Firstly, as shown in **Table 12**, individuals rated their 'Own Health Status' as a mean  $\pm$  SD of **63.1  $\pm$  20.5%** [on the 0 to 100% scale], with reasonably similar findings irrespective of Diabetes Type {65.6% T1 DM : 62.0% T2 DM : 64.0% GDM [n= 508, 1266 and 43 respectively]}. **These results were all lower than those reported in ANDIAB2 2005.**

**Table 12 EQ-5D Own Health Rating**

Category	2005 n = 1405		2010 n = 2131	
	Mean $\pm$ SD	n	Mean $\pm$ SD	n
Own Health Rating - All	69.7 $\pm$ 21.3	1367	63.1 $\pm$ 20.5	1849
Own Health Rating - Type 1	71.0 $\pm$ 21.5	208	65.6 $\pm$ 19.2	508
Own Health Rating - Type 2	69.6 $\pm$ 20.7	1046	62.0 $\pm$ 21.1	1273
Own Health Rating - GDM	69.2 $\pm$ 28.8	84	64.0 $\pm$ 17.8	43

'Own Health Status' assessments were analysed by Diabetes Type and Age Group - **Table 12[a]**.

**Table 12[a] EQ-5D Own Health Rating by Age Group and Diabetes Type**

Age	2005 n = 1405						2010 n = 2131					
	All		Type 1		Type 2		All		Type 1		Type 2	
	Mean $\pm$ SD	n	Mean $\pm$ SD	n	Mean $\pm$ SD	n	Mean $\pm$ SD	n	Mean $\pm$ SD	n	Mean $\pm$ SD	n
5-15	84.7 $\pm$ 17.4	7	84.7 $\pm$ 17.4	7	$\pm$	0	78.4 $\pm$ 19.8	21	78.4 $\pm$ 19.8	28	$\pm$	0
16-35	72.8 $\pm$ 21.8	193	75.4 $\pm$ 17.0	99	67.8 $\pm$ 23.0	33	64.8 $\pm$ 19.7	321	65.8 $\pm$ 19.1	272	58.4 $\pm$ 23.9	40
36-50	64.6 $\pm$ 23.5	245	61.7 $\pm$ 23.2	55	65.8 $\pm$ 22.4	172	60.5 $\pm$ 20.0	353	62.5 $\pm$ 19.4	145	59.0 $\pm$ 20.5	237
51-65	67.9 $\pm$ 21.0	489	67.3 $\pm$ 25.1	37	68.0 $\pm$ 20.8	454	61.8 $\pm$ 20.6	639	67.5 $\pm$ 17.9	112	60.9 $\pm$ 20.9	606
66+	73.2 $\pm$ 19.0	401	80.4 $\pm$ 17.2	12	73.0 $\pm$ 19.1	392	64.6 $\pm$ 21.1	502	62.7 $\pm$ 19.8	26	64.6 $\pm$ 21.2	542

DiabCoSt<sup>7</sup> are data provided for comparison - **Table 12[b]**. The DiabCoSt visual analogue scale was 0-1 [ours 0-100], thus a DiabCoSt score of 0.76 equates to 76% on our assessment scales.

**These results were all lower than those reported in DiabCoSt.**

**Table 12[b] DiabCoSt Own Health Rating by Age Group and Diabetes Type**


 Overall Quality of Life by Age Group

Age	Quality of Life Score		
	General Population *	DiabCoSt Type 1	DiabCoSt Type 2
5-15	-	0.84	-
16-35	0.92	0.76	-
36-50	0.88	0.77	0.83
51-65	0.84	0.74	0.80
66+	0.79	0.70	0.78

\* Hawthorne et al, 2001<sup>o</sup>

Also presented *for interest* are the DiabCoSt data for Type 1 diabetes by complication status (for which we do NOT have comparative results) - **Table 12[c]**.

**Table 12[c] DiabCoSt Own Health Rating Type 1 DM by Complications**

	No complications	Microvascular complications	Macrovascular complications	Both
<b>EQ-5D scores</b>				
Number of respondents evaluable	1727	249	16	83
Index Mean (SD)	0.90 (0.17)	0.73 (0.28)	0.68 (0.40)	0.65 (0.36)

Assessment of 'Own Health Status' are reported for Type 2 diabetes by diabetes management method - **Table 12[d]. These results were all lower than those reported in ANDIAB2 2005.**

**Table 12[d] EQ-5D Own Health Rating Type 2 DM by Management Method**

Diabetes Management Method	2005 n = 1405		2010 n = 2131	
	Type 2		Type 2	
	Mean ± SD	n	Mean ± SD	n
Diet Only	74.4 ± 20.8	194	66.4 ± 23.2	121
Tablets	70.0 ± 18.9	500	63.5 ± 21.0	534
Insulin	68.3 ± 22.0	131	57.7 ± 20.5	230
Insulin and Tablets	65.2 ± 22.6	239	61.2 ± 20.8	541
Nil	±	0	60.0 ± 14.1	3

Diabetes Distress Scale [DDS] scores are presented as Screening, Total and Sub scale scores by Diabetes Type and by aspects of Screening Question responses - **Tables 13, 14 and 14[a]**.

**Table 13 DDS Screening Question Mean Scores by Diabetes Type**

Category	2005 n = 1405		2010 n = 2131		
	Mean ± SD	n	Mean ± SD	n	n ≥ 3
Screening Scale Q1 - All	Not collected in 2005		2.2 ± 1.3	1874	628
Screening Scale Q1 - Type 1	Not collected in 2005		2.3 ± 1.2	512	193
Screening Scale Q1 - Type 2	Not collected in 2005		2.1 ± 1.3	1287	410
Screening Scale Q1 - GDM	Not collected in 2005		2.0 ± 1.1	49	16
Screening Scale Q2 - All	Not collected in 2005		2.3 ± 1.4	1873	625
Screening Scale Q2 - Type 1	Not collected in 2005		2.4 ± 1.3	511	201
Screening Scale Q2 - Type 2	Not collected in 2005		2.2 ± 1.4	1287	407
Screening Scale Q2 - GDM	Not collected in 2005		1.8 ± 1.0	49	9
					%
					33.5%
					37.7%
					31.9%
					32.7%
					33.4%
					39.3%
					31.6%
					18.4%

**Table 14 DDS Question Mean Total & Sub-scale Scores by Diabetes Type**

Category	2005 n = 1405		2010 n = 2131	
	Mean ± SD / %	n	Mean ± SD / %	n
DDS 17 Questionnaire Done			50.4%	1073
Total DDS Score - All			2.0 ± 0.9	1060
Total DDS Score - Type 1			2.0 ± 0.7	334
Total DDS Score - Type 2			2.0 ± 0.9	681
Total DDS Score - GDM			1.4 ± 0.5	29
Emotional Burden - All			2.4 ± 1.2	1061
Emotional Burden - Type 1			2.4 ± 1.1	335
Emotional Burden - Type 2			2.4 ± 1.2	681
Emotional Burden - GDM			1.7 ± 0.8	29
Physician-related Distress - All			1.5 ± 0.9	1060
Physician-related Distress - Type 1			1.4 ± 0.7	334
Physician-related Distress - Type 2			1.6 ± 1.0	681
Physician-related Distress - GDM			1.1 ± 0.4	29
Regimen-related Distress - All			2.2 ± 1.1	1061
Regimen-related Distress - Type 1			2.3 ± 1.0	335
Regimen-related Distress - Type 2			2.2 ± 1.2	681
Regimen-related Distress - GDM			1.6 ± 0.8	29
Interpersonal Distress - All			1.8 ± 1.1	1059
Interpersonal Distress - Type 1			1.7 ± 0.9	335
Interpersonal Distress - Type 2			1.8 ± 1.2	679
Interpersonal Distress - GDM			1.3 ± 0.6	29

Regarding aspects of Screening Question responses - **Tables 14[a]**, almost 40% of DDS 17 Questionnaires were undertaken in individuals who 'screened negative' [ie both Screening questions < 3].

A number [n=183], representing 22.3% of those who screened positive, did NOT have a DDS 17 Questionnaire administered.

Those where Individual DDS Scores were  $\geq 3$  were far more likely seen where the one or both Screening questions were scored  $\geq 3$  n= 397 versus n= 44 for Screening questions scored < 3. This was explored further in **Table 14[b]** for individuals 17 years and older.

**Table 14[a] DDS 17 Questionnaire Data by Screening Question Score**

Category	2005 n = 1405		2010 n = 2131	
	%	n	%	n
DDS 17 Questionnaire Done	Not Collected		49.8%	1061
Screening questions $\geq 3$ and DDS 17 Questionnaire Done	Not Collected		60.1%	638
Screening questions < 3 and DDS 17 Questionnaire Done	Not Collected		39.4%	418
Screening questions both Null and DDS 17 Questionnaire Done	Not Collected		0.5%	5
Screening questions $\geq 3$ and DDS 17 Questionnaire <b>NOT</b> Done	Not Collected		22.3%	183
Individual DDS Scores $\geq 3$ where Screening questions $\geq 3$	Not Collected		48.4%	397
Individual DDS Scores $\geq 3$ where both Screening questions < 3	Not Collected		4.2%	44

We also assessed DDS Data for those  $\geq 17$  years old [n=1030 of the 1061 total received]. Of these, there were 60.8% [n=626] where *one or both* DDS Screening questions was  $\geq 3$  and 39.2% [n=404] where the DDS Screening Questions were both <3 *but the 17 item Questionnaire was done anyway*. This seems to have been a function of how some sites administered the overall survey – perhaps giving 'everything' to the patient to complete.

NOTE: Age  $\geq 17$  years old was chosen *arbitrarily* to exclude younger individuals where a parent or guardian may have completed or assisted in completion of the DDS Questionnaire

We sought to compare the outcomes based on the 2 Screening Question findings. We found few individuals would be 'missed' if NOT screened on the basis of both Screening Questions being <3 – **Table 14[b]**. In **Table 14[c]**, data for the 626 are assessed by Age Groups.

**Table 14[b] DDS Sub-scale Scores  $\geq 3$  by Screening Questions  $\geq 3$  versus <3**

	Total	Interpersonal	Regimen	Physician	Emotional
626 Screening Questions 1 or 2 Score $\geq 3$	135	148	228	77	273
404 Screening Questions BOTH Score < 3	3	19	7	15	11

**Table 14[c] DDS Sub-scale Scores  $\geq 3$  by Screening Question  $\geq 3$  by Age Group**

Age Group (years)	n=	Total [%]	Interpersonal	Regimen	Physician	Emotional
17 - 35	127	13 [10.2]	49	48	7	17
36 - 50	137	39 [28.5]	75	61	19	37
51 - 65	243	66 [27.1]	110	90	40	75
66 +	119	17 [14.3]	39	29	11	19

#### 4.10 Missing Data

With regard to Missing Data, **Table 15** Page 17 provides details of the relatively *minimal* ‘Missing Data’ from ANDIAB2.

The Missing Data items are listed in increasing frequency. Overall Missing Data ranged from [n=5] **0.4%** [Have Contact Number for Advice] to [n=451] **21.2 %** [HbA1c], however **53.7% of the data items were less than 5% missing** {[0-1] 13.0% | [1-2] 3.7% | [2-3] 18.5% | [3-4] 14.8%} | [4-5] 3.7%}], **24.1%** were missing from 5-10% of records and **22.2%** were missing from 10.3-22.5% of records.

This is in contrast to ANDIAB2 2005, where there was less missing data:

**85.5% of the data items were less than 5% missing** {[0-1] 36.4% | [1-2] 23.6% | [2-3] 18.2% | [3-4.5] 7.3%}], **9.1%** were missing from 5-10% of records and **5.5%** {just three fields} were missing from 11-27.6% of records.

This is in *stark* contrast to ANDIAB 2009 [N=8563] however, where only **20.0% of the data items were less than 20% missing**. Further analysis of ANDIAB data showed:

*Whilst some data items were almost 100% collected, overall Missing Data ranged from [n=25] 0.4% [Date of Birth] to [n=6007] 70.2% [BP-Thiazides], thence [n=5848] 68.3 % [Attended Optometrist] and 67.4% [BP-Other]. There were 20.0% of the data items less than 20% missing* {[0-5] 7.0% / [5-10] 1.7% / [10-15] 3.5% / [15-20] 7.8%}], *23.5% were missing from 20-40% of records and 56.5% were missing from >40% of records [Table 24]<sup>2</sup>.*

Whilst much of the ANDIAB 2009 missing data relate to Fields such as Eye Data, which may not be readily available to the Clinician, there would appear no doubt that the ANDIAB2 completeness of data collection is a testament to the diligence of those who participated [including the individuals themselves in completing the EQ-5D and DDS components].

[See Appendix 7 for all missing data graphs].

Sites were given an opportunity to supply any missing data and to validate questionable data. **Table 15[a]** shows the Missing ‘Vital’ Data items obtained by requesting their provision from sites – with substantial improvements, (except ‘Insulin Since’ - only 39.3% obtained). As can be seen from the Table below, this process reduced the missing data in six of the seven elements sought, by two thirds - to over 90% {67.6-90.7%}.

It was only necessary in a few instances to review data items that were not possible (as indicated on Page 3) [eg ‘Management Method’ not Insulin, but ‘Insulin Since’ not null - in which case the ‘Insulin Since’ date was removed and considered missing in the pooled database, prior to final data analysis].

There was one duplicate data sheet provided – and the extra one was removed.

**Table 15[a] Missing Data Obtained from Sites**

Data Item	Initially Missing		Still Missing		Obtained
	n =	[%]	n =	[%]	
Date of Birth	28	1.3%	7	0.3%	75.0%
Sex	74	3.5%	9	0.4%	87.8%
Initial Visit	75	3.5%	7	0.3%	90.7%
Diagnosis Year	37	1.7%	12	0.6%	67.6%
Diabetes Type	52	2.4%	5	0.2%	90.4%
Diabetes Therapy	82	3.8%	8	0.4%	90.2%
Insulin Since	56	2.6%	34	1.6%	39.3%



**Table 15 Missing Data**

'Field (Condition)'	'n 2005'	% 2005'	'n 2010'	'% 2010'
Complementary Therapy - Told Dr or Educator of use ( Only Patients who are on Complementary Therapy )	2	0.6	5	0.8
Tried to stop smoking ( Current Smokers Only )	13	8.8	6	2.2
Advice - Have contact number of Diabetes Care contact ( Only Patients who know who to contact )	2	0.2	7	0.4
Date Of Birth	34	2.4	10	0.5
Initial Visit	25	1.8	12	0.6
Year of diagnosis	16	1.1	14	0.7
Type of Diabetes	2	0.1	16	0.8
Management method	9	0.6	18	0.8
DDS 17 Questionnaire Done		0	21	2.6
Sex of Individual	26	1.9	27	1.3
Insulin start year (Only patients using Insulin)	20	3.3	32	2.3
Take Medicines as prescribed?	4	0.3	41	1.9
Carrying Identification	22	1.6	44	2.1
Advice - Know who to contact for Diabetes Care?	30	2.1	50	2.3
Attended Podiatrist	7	0.5	52	2.4
Attended Diabetes Specialist	12	0.9	54	2.5
Smoker: currently	28	2	59	2.8
Smoking Status		0	59	2.8
Attended Diabetes Educator	13	0.9	60	2.8
Attended Optometrist		0	70	3.3
Complementary Therapy or dietary supplement used	24	1.7	71	3.3
Attended Psychologist	10	0.7	72	3.4
Attended Dietitian	12	0.9	72	3.4
Hypoglycemia Awareness (Not on Sulphonylurea / Insulin or no hypo in 6/12)	18	1.3	73	3.4
Attended Dentist		0	75	3.5
Carrying Hypoglycaemic Rx (Not on Sulphonylurea or Insulin)	7	0.5	75	3.5
Attended Exercise Physiologist		0	80	3.8
Attended Social Worker	20	1.4	92	4.3
Given Consumer Medicines Information?	56	4	100	4.7
Vaccination - Flu in past 12 months	6	0.4	115	5.4
LipoHypertrophy Present	62	4.4	119	5.6
Vaccination- Pneumococcal in past 12 months	14	1	130	6.1
LipoAtrophy Present	54	3.8	148	6.9
Indigenous - ATSI	134	9.5	156	7.3
NDSS Member		0	157	7.4
DVA Patient	155	11	178	8.4
DDS - Regimen-related Burden		0	183	22.3
DDS - Emotional Burden		0	183	22.3
DDS - Physician-related Burden		0	184	22.4
DDS - Total DDS Score		0	184	22.4
DDS - Interpersonal Distress		0	185	22.5
Pregnant: Currently	70	5	201	9.4
BCD - Brief case-find for depression (Calculated)		0	205	9.6
BCD - Feeling unhappy or depressed	5	0.4	208	9.8
BCD - Had restless or disturbed nights	7	0.5	210	9.9
BCD - Felt unable to overcome difficulties	6	0.4	212	9.9
On antidepressants		0	214	10
BCD - Dissatisfied with their way of doing things	9	0.6	219	10.3
Psychiatric treatment/counselling - previous	9	0.6	222	10.4
Psychiatric treatment/counselling - current	9	0.6	223	10.5
DDS - Screening Scale Q1		0	257	12.1
DDS - Screening Scale Q2		0	258	12.1
QOL - Own Health State Rating (0-100)	38	2.7	282	13.2
Glycated Haemoglobin		0	451	21.2

#### 4.11 Questionnaire Results:

Two Questionnaires were distributed as in ANDIAB 2009 [*See Appendix 4*]:

- Questionnaire 1 relates to the data collection process,  
[This was sent to each Site after their data had been received];
- Questionnaire 2 relates to comments on the Individual Site Reports,  
[This was sent to each Site with their Report – *however insufficient responses have been received at the time of preparation of this report to be included*].

**Table 16** details the results of assessment of the Questionnaire 1 Lickert Scale responses from participants to the specific questions related to the data collection project. This is a 1 to 5 scale {1[Poor]-5[Good]} 3=Midpoint, and data are presented as Mean  $\pm$  (SD).

Clearly ‘Time to complete the Form’ and ‘Ease of completion’ are concerns for most (rating 2.1 and 3.1 respectively), but pleasingly all other aspects of the Project were rated relatively highly (3.4 – 4.1) amongst the 19 responses received.

In addition, the free text responses to questions and to other items will all be reviewed individually, and utilised to refine the data collection instrument and reporting process, and will thus assist in running future data collections and providing appropriate feedback to participants.

**Table 16 Questionnaire 1 Responses**

Questionnaire 1 [Re Data Collection Process] - Lickert Scale {1[Poor]-5[Good]} 3=Midpoint [ n = 19 ]	Mean $\pm$ (SD)
Information Package/Letters	3.6 + 1.1
Data Definitions Form	3.7 + 1.1
Format (layout of data items)	3.4 + 1.1
Ease of completion	3.1 + 0.9
Time to complete the Form	2.2 + 1.1
Diabetes Distress Scale Calculator	4.1 + 1.3

## 5. DISCUSSION :

### *General Comments*

In 2010 – ANDIAB2 collected and benchmarked data that were more Education Centre and Patient Self-care focused than the more ‘Medically’ focused ANDIAB. Twenty seven NADC member Diabetes Centres participated. Data were provided for assessment on 2131 individuals [with similar demographic findings to those in ANDIAB 2009 [4.2 & Table 2 Page 7] – although there were some differences with [for instance] one quarter initial visit patients (25.6% versus 13.2% ANDIAB 2009) and 3.7% (versus 2.1%) having GDM.

### *Missing Data*

There were minimal missing data [4.10 Page 17 & Table 15 Page 18]. In ANDIAB2 53.7% of the data items were less than 5% missing. Whilst this is not as impressive as was ANDIAB2 2005 [85.5%], it is still far superior to ANDIAB 2009, where only 20.0% of the data items were less than 20% missing. Whilst much of the ANDIAB 2009 missing data relate to Fields such as Eye Data, which may not be readily available to the Clinician, there would appear no doubt that the ANDIAB2 completeness of data collection is a testament to the diligence of those who participated [including the individuals themselves in completing the EQ-5D and DDS components]. Sites were given an opportunity to supply any missing data and to validate questionable data. Table 15[a] Page 17 shows the Missing ‘Vital’ Data items obtained by requesting their provision from sites – with quite substantial improvements noted.

### *Limitations of ANDIAB2*

#### High numbers of Initial Visit Individuals

There were a quarter on the patients [25.6%] for whom this was an initial visit and the possibility exists that the reduced prevalence findings for many of the items assessed may in some part be related to no [or minimal] previous diabetes education [or possibly no recent educational contact for individuals with longer diabetes duration] – even though overall 67.7% of individuals reported having seen a Diabetes Educator within the last 12 months. To assess this we looked at duration of diabetes, initial visit data and whether individuals had seen a Diabetes Educator in the last 12 months - **Table 17[a]** {complete data available for 2051 of the 2131 individuals [96.2%]}. Overall two thirds or more of the individuals had seen an Educator [DE] in the last 12 months *irrespective of duration* [decreasing slightly with increasing duration]. As regards the recently diagnosed, where analysis shows this represented 17.0% of individuals, that for 46.8% of them this was an initial visit, and that only half [50.3%] had already seen an Educator. However this represents only 4.0% of the total number of individuals who may have had no or minimal education. Of those with longer diabetes duration – half or more initial visit individuals {48.4% only for 2-5 years duration} and 71.3 to 77.7% of non-initial visit individuals - had seen an Educator in the last 12 months. It is thus more likely that the reduced prevalence findings for the self-care items assessed, are true ‘deficiencies’ in self-care and less likely due to no or minimal education, or to education undertaken some time ago.

**Table 17[a] 2010 Duration - Initial Visit - Seen by Educator last 12 Months**

Duration	2010 n	2010%	2010 DE last 12mth	2010 Initial Visit = Yes	2010 DE last 12mth	2010 Initial Visit = No	2010 DE last 12mths
<1	348	16.9%	71.3%	46.8%	50.3%	53.2%	89.7%
1-2	84	4.1%	72.6%	27.4%	65.2%	72.6%	75.4%
2-5	212	10.3%	68.9%	30.2%	48.4%	69.8%	77.7%
5-10	411	20.0%	69.3%	23.6%	58.8%	76.4%	72.6%
10+	1001	48.7%	69.2%	16.5%	58.8%	83.5%	71.3%

The same analysis in ANDIAB2 2005 is presented in **Table 17[b]**, with very similar findings.

**Table 17[b] 2005 Duration - Initial Visit - Seen by Educator last 12 Months**

Duration	2005 n	2005%	2005 DE last 12mth	2005 Initial Visit = Yes	2005 DE last 12mth	2005 Initial Visit = No	2005 DE last 12mths
<1	388	28.7%	78.1%	41.0%	51.6%	59.0%	96.5%
1-2	64	4.7%	70.3%	20.3%	69.2%	79.7%	70.6%
2-5	162	12.0%	66.7%	19.1%	41.9%	80.9%	72.5%
5-10	281	20.8%	67.3%	16.4%	54.3%	83.6%	69.8%
10+	458	33.9%	64.6%	16.2%	50.0%	83.8%	67.4%

A similar analysis to that in **Table 17[a]** is presented in **Table 17[c]**, showing data re ‘seen by Dietitian in the last 12 months’. The patterns are similar across duration categories, although fewer individuals had seen a Dietitian compared with a Diabetes Educator.

**Table 17[c] 2010 Duration - Initial Visit - Seen by Dietitian last 12 Months**

Duration	2010 n	2010%	2010 Dietitian last 12mth	2010 Initial Visit = Yes	2010 Dietitian last 12mth	2010 Initial Visit = No	2010 Dietitian last 12mths
<1	348	17.0%	62.6%	47.1%	42.7%	52.9%	80.4%
1-2	84	4.1%	59.5%	27.4%	47.8%	72.6%	63.9%
2-5	210	10.3%	46.2%	30.0%	38.1%	70.0%	49.7%
5-10	409	20.0%	51.6%	23.7%	43.3%	76.3%	54.2%
10+	993	48.6%	47.1%	16.4%	45.4%	83.6%	47.5%

#### Some sites provided data on small numbers of individuals

This fact is always of concern regarding the reliability of the data provided being representative of the individuals seen at a particular Diabetes Centre. The Mean and Median number of individual forms provided by sites in ANDIAB2 [76 and 79 respectively (range 8-220)] suggests a reasonable spread – and indeed 9 sites had 100 or more forms. Eight had less than 50 however - with six of these less than 40. Notwithstanding this, the pooled data are similar in demographic characteristics to the last ANDIAB collection in 2009 as noted above [Page 7 and Table 2]. It is therefore *not* considered that small ‘non-representative’ numbers have adversely affected interpretation of the pooled data as reported here.

#### ***Strengths of ANDIAB2***

##### Geographical spread; significant patient numbers

A total of twenty seven sites participated from across the country, but predominantly from the east coast: [NSW 10; VIC 7; QLD 6; TAS 2; WA 1; ACT 1]. De-identified data were provided from 2131 individuals.

##### Data completeness and correctness

‘Validation Reports’ generated for each Centre requesting missing data and correction of questionable or potentially invalid data were addressed and returned by all but one of the twenty seven sites. This means that sites have done their utmost to ensure data completeness and correctness, enhancing the reliability of the findings.

#### ***Presentation of the Data***

The following Abstract [**Figure 2**] was submitted and accepted as a Poster Presentation at the 2010 ADS/ADEA Annual Scientific Meeting and was published in the Proceedings: Australian Diabetes Educators Association Meeting, Sydney, Sept 2010; Abstract 513, page 224.

Further presentations of the results are planned in 2011.

**Figure 2****DEVELOPMENT AND IMPLEMENTATION OF A DIABETES DISTRESS SCALE CALCULATOR: FREE-STANDING AND WEB BASED COMPUTER APPLICATIONS**

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**Background:** The Diabetes Distress Scale [DDS] is a validated 17-item questionnaire, yielding four reliable subscales targeting different areas of potential diabetes-specific distress to help clinicians and patients identify areas where interventions might be helpful: emotional burden; physician-related distress; regimen-related distress; and interpersonal distress.<sup>1</sup> The Australian National Diabetes Information Audit and Benchmarking<sup>2</sup> [ANDIAB2] initiative is an audit of patient characteristics, self-care practices, quality of life and outcomes. The DDS instrument was chosen to assess individuals in specialist diabetes services in ANDIAB2, to be undertaken in April/May 2010.

**Aim:** To develop, test and implement a DDS Calculator to automate the scoring of the DDS and its subscales in ANDIAB2.

**Methods:** Utilising an advanced Flash™ creation tool, we developed an executable program that provides a total and four-subscale scores, with the option to graph the output. Various rules were implemented: Total-Score calculations do not proceed if fewer than 14 responses are provided; Subscale calculations do not proceed if more than one item response in that subscale is missing. On-screen pop-up messages explain this to the user if invoked. Multiple test scenarios were developed to ensure outputs were correct.

**Results:** A free-standing Shockwave Flash-based executable application for Windows XP© was developed which performed correctly in all test scenarios, and was distributed to ANDIAB2 participants, and a web-based version loaded onto our Diabetes Centre website.<sup>2</sup> Value-added components include on-screen explanatory notes, hyperlinks to relevant publications, ability to see results on-screen in graphical format, and ability to print the computed results and/or the graph.

**Conclusions:** We believe that this easy to use application will assist clinicians utilising the DDS to calculate the relevant scores and display them in a format suitable for feedback of results to individuals with diabetes. If opinion from ANDIAB2 participants is favourable, we intend to offer this application for wider distribution.

1. Development of the Diabetes Distress Scale. Assessing psychosocial distress in diabetes. Polonsky WH, Fisher L, Earles J, Dudl RJ, Lees J, Mullan J, Jackson RA (2005). : *Diabetes Care*, 28, 626-631.

2. <http://www.sswahs.nsw.gov.au/bankstown/diabetes/>

**Acknowledgement:** ANDIAB2 2010 was funded by the Commonwealth Department of Health and Ageing. Presented on behalf of the National Association of Diabetes Centres [NADC].

## **6. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS:**

**In summary**, ANDIAB2 has built on the successful, well-established ANDIAB initiative. ANDIAB2 collected and benchmarked data that were more Education Centre and Patient Self-care focused than the more ‘Medically’ focused ANDIAB and fulfilled the long held NADC desire to have an alternate year collection of this nature. We believe that ANDIAB2 has been successful on several fronts:

- There were very little missing data compared with ANDIAB 2009 and whilst much of the ANDIAB 2009 missing data relate to Fields such as Eye Data which may not be available to the Clinician, there would appear no doubt that the ANDIAB2 completeness of data collection is a testament to the diligence of those who participated [including the individuals themselves in completing the DDS component];
- Each site received an individual report benchmarking their findings against others from which they can identify areas of service or patient self-care that may be deficient, and for which changes or educational strategies may need to be instituted;
- Some general observations [and potential points for intervention] on the findings listed above include:
  - It is noteworthy that of the 12.9% current smokers – over 73% claimed to have tried to cease (and they may be amenable to further attempts to assist them to quit);
  - Physical Activity was adjudged as ‘sufficient’ in only 44.0%;
  - Over 7% admitted to NOT taking all of their prescribed medications;
  - Many [82.5%], *but not all*, of the 27.8% who admitted to the Use of Complimentary Medicines, stated that they had informed their Doctor of this fact;
  - Overall the pilot also identified several areas of patient self-care as deficient, and where strategies could be developed to target and address these areas: [*Carrying Identification : Carrying Hypo Therapy : Informing Traffic Authority*].

We believe that the similarity in the findings to those reported in ANDIAB2 2005 suggest that this is providing an accurate ‘snapshot’ of education and self-care practices in individuals attending Specialist Diabetes Centres

**We conclude**, that ANDIAB2 has been successful and forms the basis by which Diabetes Centre Care Delivery and Patient Self-care practices can be assessed and monitored. Diligence is recommended in assessing areas such as those highlighted in this Report, which should assist in identifying important aspects of self-care about which to educate / re-educate individuals so that they could potentially improve their health and well-being.

**We recommend**, that this format and these data items could be utilised for an ongoing quality audit activity in Diabetes Centres fulfilling the NADC desire to establish an Audit Program to be run in alternate years to ANDIAB which is more Patient / Education focused.

It is strongly recommended that NADC consider an Educational Initiative of Local and/or National strategies to attempt to address some of the deficiencies noted in this report, specifically *Carrying Identification : Carrying Hypo Therapy : Informing Traffic Authority*.

## **7. ACKNOWLEDGEMENTS:**

ANDIAB2 2010 was funded by the Commonwealth Department of Health and Ageing.

Systems Analysis, Systems Implementation and Computer Programming built on previous work and were undertaken by Mr Brian Sandiforth and A/Prof Jeff Flack.

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3. Pilot NADC ANDIAB patient Review Project 2004 [Follow-Up Data 2000 to 2003]. J R Flack and S Colagiuri on behalf of the National Association of Diabetes Centres. Final Report, June 2004.
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