Ευρωπαϊκές συνεργασίες και ειδικά κέντρα στα πλαίσια στα πλαίσια της αντιμετώπισης του Διαβήτη

(European collaborations and reference centers for the treatment of diabetes)

Ανδριανή Βαζαίου
Διευθύντρια ΕΣΥ
Επιστημονικά Υπεύθυνη Διαβητολογικού Κέντρου
Α' Παιδιατρική Κλινική
Νοσοκομείο Παίδων Π&Α Κυριακού

3ης Συνάντησης του Ελληνικού Οικοσυστήματος Ηλεκτρονικής Υγείας
Ξενοδοχείο Τιτάνια 1.10.2014

Type 1 Diabetes

- T1D is a chronic disease due to the destruction of islet beta cells in the pancreas with the consequence of lack of insulin production
- T1D is accompanied by considerable morbidity and mortality
- Increase of T1D incidence over the last years

T2D

- Increase in incidence of T2D all over the world
- T2D is no longer an adult's disease
- T2D is related to increase of obesity
- Different etiology of T1D

Diabetes mellitus is a significant economic burden

- Current cost for diabetes accounts for 10% of the total health cost and is estimated to rise to 17% for 2035/2036.
- Complications related to the disease account for a substantial proportion of the direct health costs.
- In the UK: T1D: £1 bn for direct costs and £ 0.9 bn for indirect costs for 2010-11
- In the UK 28.8 bn for Type 2 diabetes and £ 13bn for indirect costs
- As prevalence of the disease increases, the cost of treating complications will grow if current care regimes are maintained.

Hex N et al Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. Diabet Med 2012 Jul;29(7):855-62.

Treatment of T1D is complex and difficult

- Insulin therapy and glycemic control
- Exercise
- Healthy Diet
- Psychological support
- Education

Hyper and hypoglycemia cause CNS changes acute or chronic

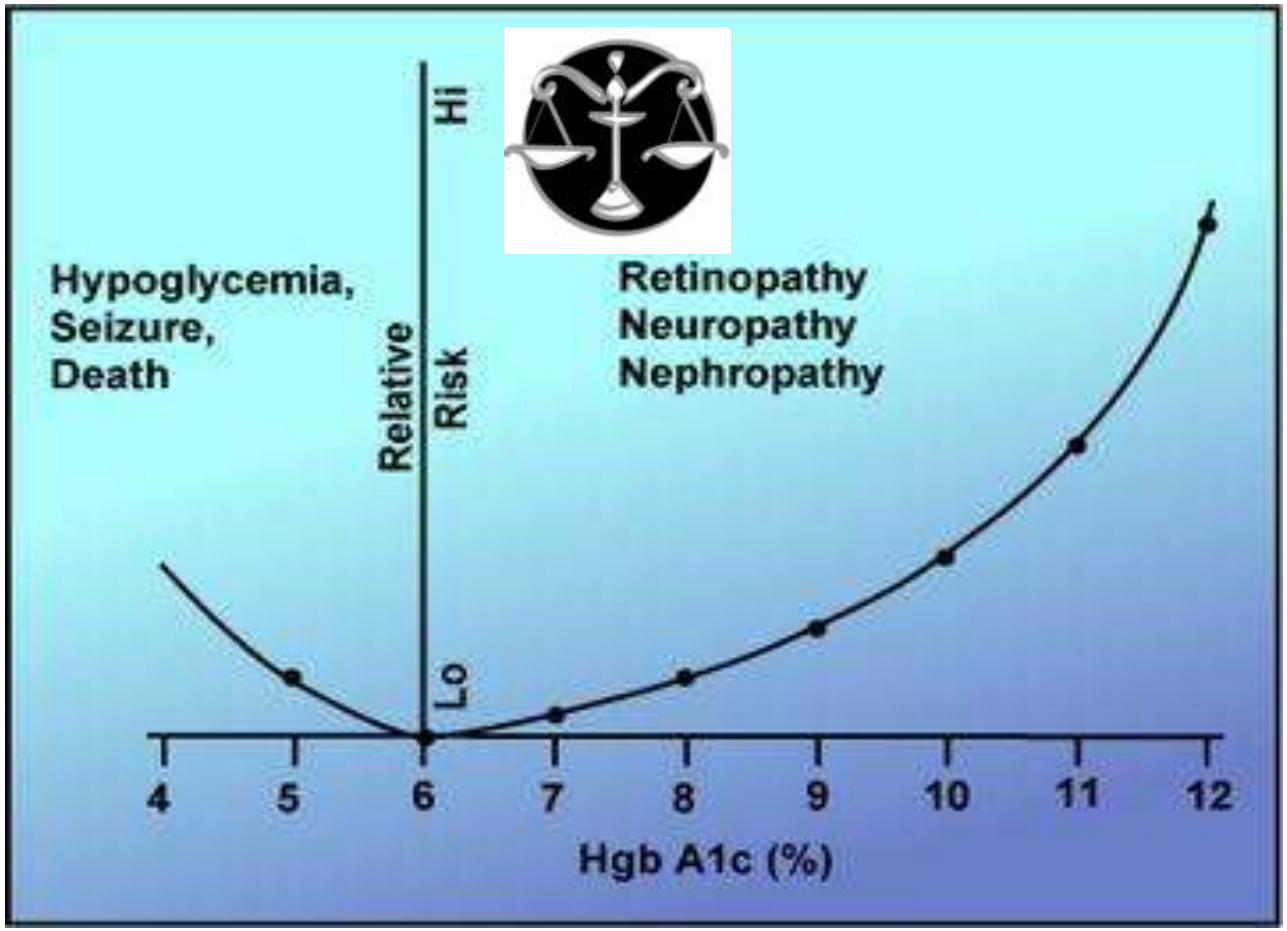
Strudwick SK et al.J Pediatr 2005: 147: 680–685

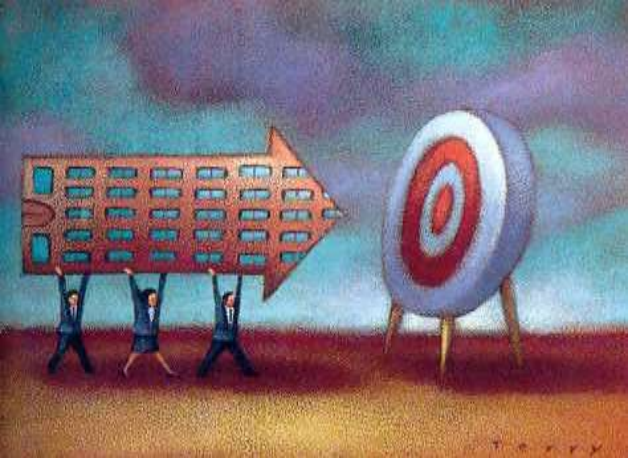
Jacobson AM, et al. N Engl J Med 2007: 356: 1842–1852.

Schoenle EJ, et al Diabetologia 2002: 45: 108–114

Perantie DC et al., Diabetes Care 2007: 30: 2331–2337

Balance between hypoglycemia and hyperglycemia (Treat-to-target)





Treatment targets

- Longevity
- Good quality of life

Joslin Awards
50 years with T1D with no complications (2500 participants)

Treatment for T2D

- Change in life style
- Reduction of weight –treatment of obesity

  : Very hard task
- Oral antidiabetic medication
- GLP-1
- Insulin

Treatment of children with T1D demands highly qualified health care professionals

Team

- Doctors
- Nurses
- Dieticians
- Psychologists
- Social workers

Heterogeneity across European countries in health care systems

Danne[1], Z. Šumník[2], Veeze[3], C. de Beaufort[4], J.-J. Robert[5], G. Forsander[6], E. Pańkowska[7], J. Allgrove[8], S. Waldron[9], V. Serban[10], A. Gerasimidi-Vazeou[11], K. Lange[12], O. Kordonouri[1], L. Pinelli[13], J.-F. Raposo[14], L. Madacsy[15], A.-M. Felton[16], I. Rurik[17], B. Aschemeier[1],

[1]Kinderkrankenhaus auf der Bult, Hannover, Germany, [2]University Hospital Motol, Department of Paediatrics, Prague, Czech Republic, [3]Stichting Diabeter, Rotterdam, Netherlands, [4]DCCP- Clinique pédiatrique de Luxembourg, Luxembourg, Luxembourg, [5]Hopital des Enfants-Malades, Department Diabete de l´enfant, Paris, France, [6]Sahlgrenska University Hospital, Gothenburg, Sweden, [7]The Medical University of Warsaw, Department of Pediatric Diabetology , Neonatology and Birth Defects, Warsaw, Poland, [8]Royal London Hospital, Whitechapel, Barts and the London NHS Trust, London, United Kingdom, [9]Dorset County Hospital,, Dietetic Department, Dorset, United Kingdom, [10]Clinical Medical Center "Cristian Serban" For The Evaluation And Rehabilitation Of Children And Adolescents Buzias, Buzias, Romania, [11]Panagioti and Aglalia Kyriakou Children´s Hospital, Department of Pediatrics and Diabetes Center, Athens, Greece, [12]Hannover Medical School Medical School, Department of Medical Psychology, Hannover, Germany, [13]University of Verona, Pediatric Diabetes Unit, Verona, Italy, [14]Associação Protectora dos Diabéticos de Portugal, Lisboa, Portugal, [15]International Diabetes Federation Diabetes European Region, Budapest, Hungary, [16]Federation of European Nurses in Diabetes, London, United Kingdom, [17]Primary Care Diabetes Europe, Budapest, Hungary

Better control in Paediatric and adolescent diabetes: working of create Centres of Reference

- EU Funding: Public Health Agency (PHEA) regarding: Health information (HI 2007)
- Exchange of information and experience regarding the best practice
- Aim of the SWEET study: Creation of centers of reference for T1D for children and adolescents in Europe with the target of improvement of secondary prevention, diagnosis and glycemic control in T1D and T2D

ISPAD
International Society for Pediatric and Adolescent Diabetes

International Diabetes Federation
European Region

FEND
Federation of European Nurses in Diabetes

PCDE
primary care diabetes europe

Bayer HealthCare
Diabetes Care

Medtronic
Alleviating Pain · Restoring Health · Extending Life

dexcom

Johnson & Johnson
DIABETES INSTITUTE, LLC

Roche

novo nordisk

Lilly
Answers That Matter.

“Better control in paediatric and adolescent diabetes in the EU: working to create centres of reference (SWEET)”

Work package 3 draft report: Recommendations for the proper for age education for children and adolescents with T1D across Europe

Funded from the European Union in the framework of the Public Health Programme.

SWEET website www.sweet-project.eu

“Better control in paediatric and adolescent diabetes in the EU: working to create centres of reference (SWEET)”

Work package 4 draft report:
Recommendations for the best programs on education for health care professionals

Funded from the European Union in the framework of the Public Health Programme.

SWEET website www.sweet-project.eu

“Better control in paediatric and adolescent diabetes in the EU: working to create centres of reference (SWEET)”

Work package 5 :
Collection of educational tools for the creation of the best toolbox for education of children and their parents on diabetes

SWEET
PEDIATRIC DIABETES
WORKING TO CREATE CENTRES OF REFERENCE

Funded from the European Union in the framework of the Public Health Program.

SWEET website www.sweet-project.eu

SWEET STUDY

1. Criteria for Centers of Reference for pediatric diabetes--a European perspective.
Danne T, Lion S, Madaczy L, Veeze H, Raposo F, Rurik I, Aschemeier B, Kordonouri O; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:62-75.
2. A pediatric diabetes toolbox for creating centres of reference.
Lange K, Klotmann S, Saßmann H, Aschemeier B, Wintergerst E, Gerhardsson P, Kordonouri O, Szypowska A, Danne T; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:49-61.
3. Technical solution for data collection, data safety and data privacy legislation: experiences from the SWEET study.
Forsander G, Pellinat M, Volk M, Muller M, Pinelli L, Magnen A, Danne T, Aschemeier B, de Beaufort C; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:39-48.
4. Good practice recommendations on paediatric training programmes for health care professionals in the EU.
Waldron S, Rurik I, Madacsy L, Donnasson-Eudes S, Rosu M, Skovlund SE, Pankowska E, Allgrove J; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:29-38.
5. Recommendations for age-appropriate education of children and adolescents with diabetes and their parents in the European Union.
Martin D, Lange K, Sima A, Kownatka D, Skovlund S, Danne T, Robert JJ; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:20-8..
6. Harmonize care to optimize outcome in children and adolescents with diabetes mellitus: treatment recommendations in Europe.
de Beaufort C, **Vazeou A**, Sumnik Z, Cinek O, Hanas R, Danne T, Aschemeier B, Forsander G; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:15-9.
7. Heterogeneity in the systems of pediatric diabetes care across the European Union.
Cinek O, Sumník Z, de Beaufort C, Rurik I, **Vazeou A**, Madácsy L, Papo NL, Danne T; SWEET group.
Pediatr Diabetes. 2012 Sep;13 Suppl 16:5-14.
8. SWEET--where are we heading with international type 1 diabetes registries?
Danne T, Aschemeier B, Perfetti R; SWEET group. Pediatr Diabetes. 2012 Sep;13 Suppl 16:1-4.

European Registry SWEET

- Common Database
- SWEET is a registry of large(>150 pediatric patients) diabetes centers (www.sweet-project.eu)
- Data in participating centers were directly extracted from 2006 ongoing from local electronic health records.
- The SWEET on line platform hosts currently 27 centers from 19 countries under one unified anonymized diabetes database

Centers of reference

- >150 children and adolescents <18 years
- Electronic database
- Quality circle with the data
- Employs a pediatrician with diabetes expertise and a nurse with pediatric diabetes expertise
- Knowledge and skills of a dietician, psychologist, social worker are present
- Follows the ISPAD guidelines
- Includes at least one ISPAD member
- Fulfills national requirements for specialist education
- Has outpatient diabetes services with confirmed in-patient access
- Audit every 5 years

Αριθμός ασθενών 12,085

SWEET-Certification
Selected year 2013

Centre-ID	Location	Centre	Number of patients
10161	DE	Kinderkrankenhaus Auf der Bult	527
10212	UK	Barts and the London NHS Trust	420
10213	PT	APDP - Portuguese Diabetes Association	671
10214	HU	Semmelweis University Budapest	17
10215	NL	Diabeter Clinic	810
10216	SE	The Queen Silvia Children's Hospital	442
10217	CZ	University Hospital Motol Prague	498
10218	IT	Universita di Verona - Cattedra di Pediatria Prev	368
10219	PL	Medical University of Warsaw - Department of Paedi	773
10221	RO	Centrul medical Clinic de evaluare si recuperare p	81
10222	LU	Centre Hospitalier de Luxembourg	173
10223	GR	Panagioti and Aglaia Kyriakou Children's Hospital	212
10224	PL	Instytut Matki i Dziecka	72
10225	FR	Hopital Necker Enfants Malades	186
10289	HR	Klinički bolnički centar Zagreb	185
10292	DK	Herlev University Hospital	352
10313	PT	Pediatric Hospital of Coimbra	170
10314	PT	Hospital Dona Estefania	122
10318	CZ	Third Faculty of Medicine, Department of Children	167
10322	TR	Ege University Faculty of Medicine	16
10329	SI	University Children's Hospital, Ljubljana	325
10335	BE	University Hospital Leuven (UZ Leuven)	228
10341	IT	G. Salesi Hospital, Ancona	182
10342	IT	Meyer Children Hospital, Firenze	443

Requirements
- >= 150 patients documented per year
- at least one HbA1c-measurement
- diabetes since documented
- year of date of birth >= 1995
- date of birth documented
- biological sex documented

ISPAD recommendations for HbA1c <7.5%

HbA1c

- Indicator of glycemic control (mean blood glucose levels of the last trimester
- Correlation with complications

HbA1c - Όλα τα κέντρα

Metabolic outcome: T1DM, *HbA1c-RAW*
All centres

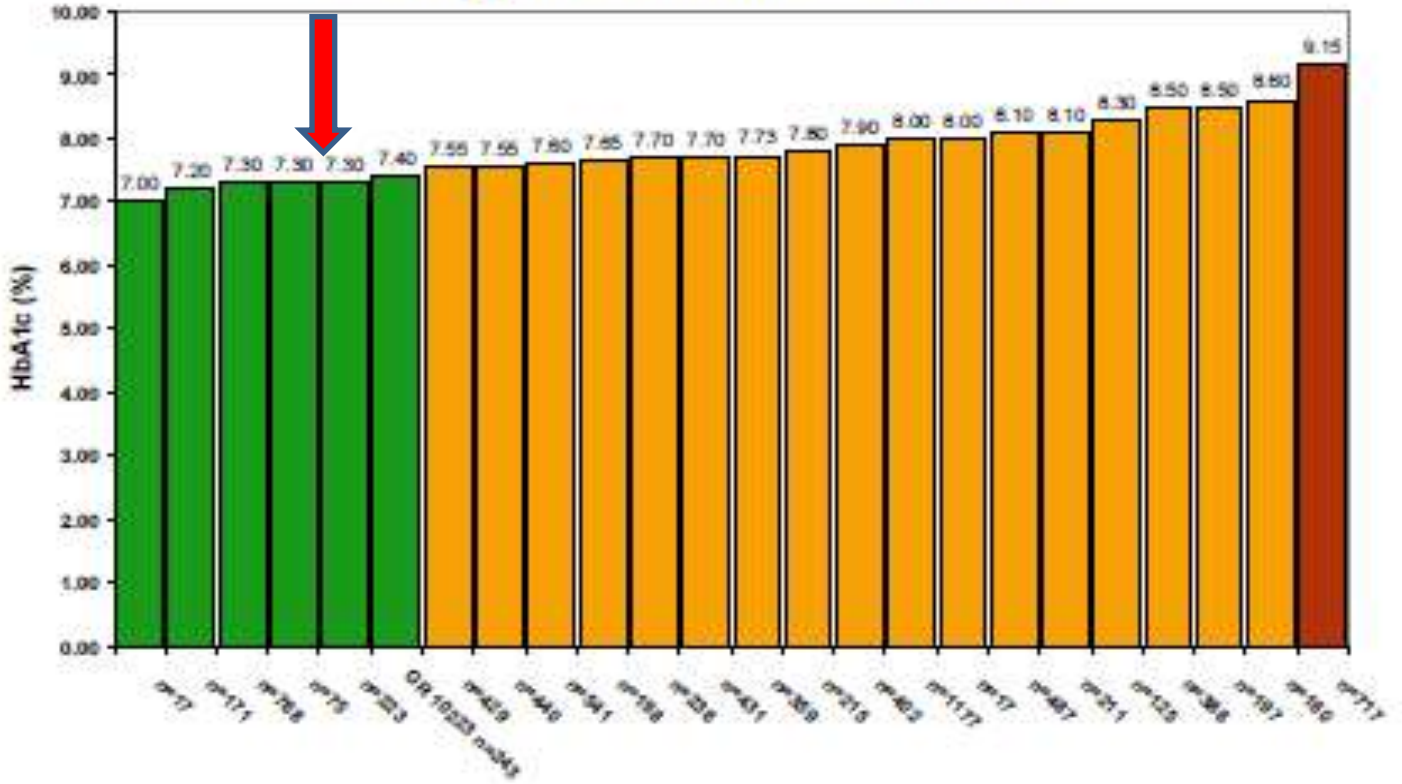
Selected period 01/01/2013 - 31/12/2013

	Number of patients	Mean of all values	Median of all values	Mean of patient's median	Median of patient's median	Mean of patient's last value	Median of patient's last value
all patients	8,288	8.19	7.90	8.12	7.87	8.08	7.80
< 1 year duration	597	7.33	7.10	7.54	7.30	7.20	7.00
> 1 year duration	7,408	8.23	8.00	8.12	7.90	8.12	7.90
age 0 - <6	615	7.92	7.73	7.93	7.73	7.83	7.70
age 6 - <12	2,447	7.85	7.70	7.81	7.65	7.77	7.64
age 12 - <18	3,929	8.42	8.10	8.26	8.00	8.24	8.00
age >=18	1,293	8.32	8.00	8.34	7.90	8.32	7.90
age 0 - <18	6,991	8.18	7.90	8.08	7.85	8.04	7.80

- If **diabetes duration < 1 year** only values after month 3 were taken into account
- *HbA1c-RAW*:
  HbA1c-values WITHOUT ANY STANDARDIZATION: In particular this view is useful regarding your own values. You can easily compare them with your own local statistics
- **Mean and mean of all values:** all HbA1c values were taken into account
- **Mean and median of patient's median:** first the median of every chosen patient is calculated, then the mean and the median of the these values. Every patient is analysed only with 1 median.
- **Mean and median of the patient's last value:** Only the patient's last value of the chosen interval is analysed

HbA1c

HbA1c: *raw data*, median of patient´s median, T1DM, all ages



Greece

Metabolic outcome: T1DM, *HbA1c-RAW*
Centre: GR-10223

Longitudinal analysis, median of patient's median

Year	Number of patients	all patients	< 1 year duration	> 1 year duration	age 0 - <6	age 6 - <12	age 12 - <18	age >=18	age 0 - <18
2014	50	7.80	6.80	7.90	7.20	7.25	7.90	7.80	7.80
2013	244	7.43	7.38	7.40	7.50	7.30	7.47	7.45	7.40
2012	367	7.45	7.00	7.45	7.35	7.30	7.53	7.25	7.50
2011	364	7.50	7.10	7.50	7.20	7.40	7.70	7.20	7.50
2010	199	7.50	7.50	7.50	7.50	7.60	7.50	7.30	7.50
2009	94	7.60	7.63	7.55	6.80	7.70	7.30	7.80	7.45
2008	32	7.20	7.30	7.00	6.70	7.15	7.00	7.20	7.10

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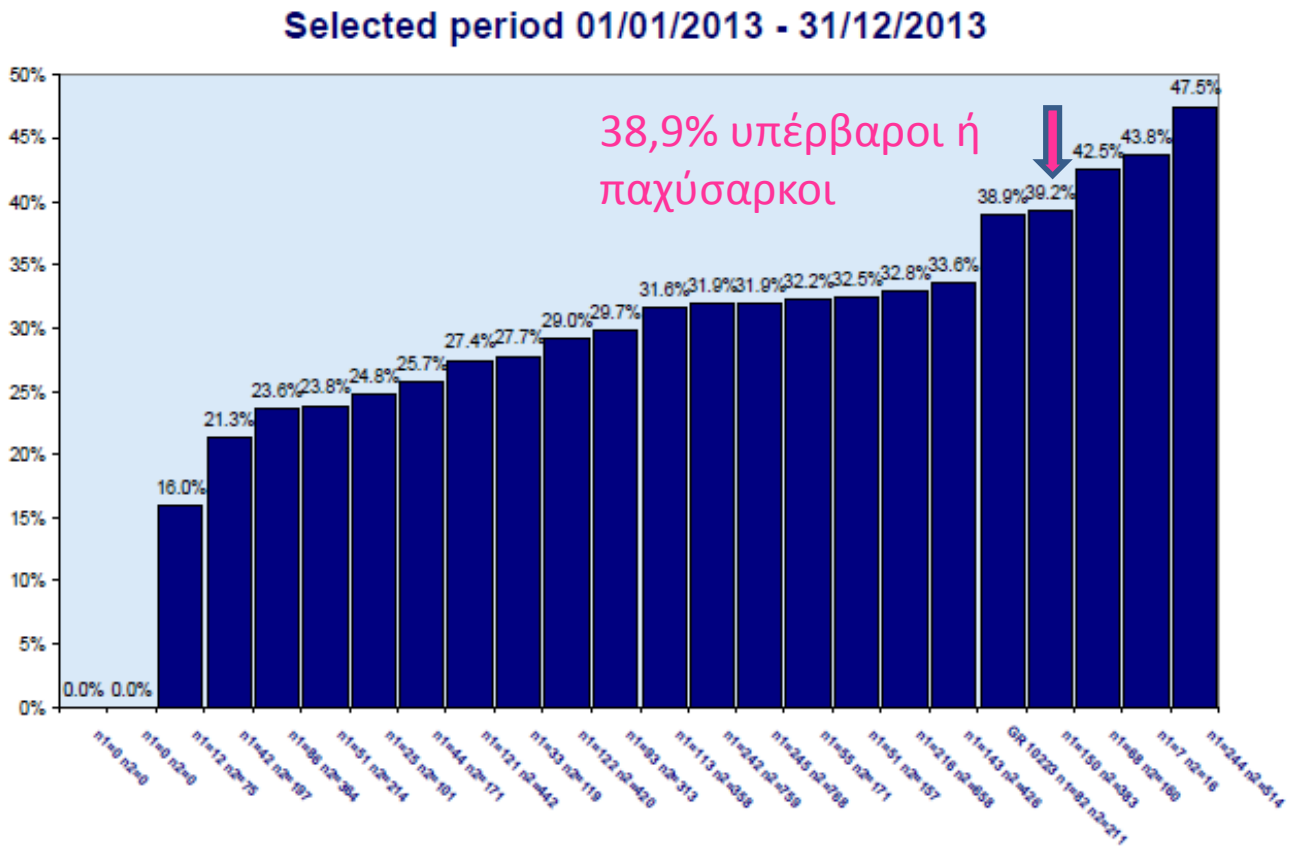
BMI: percentage of patients with BMI>85p, T1DM, patients 0-18y, WHO 2007 reference



SWEET
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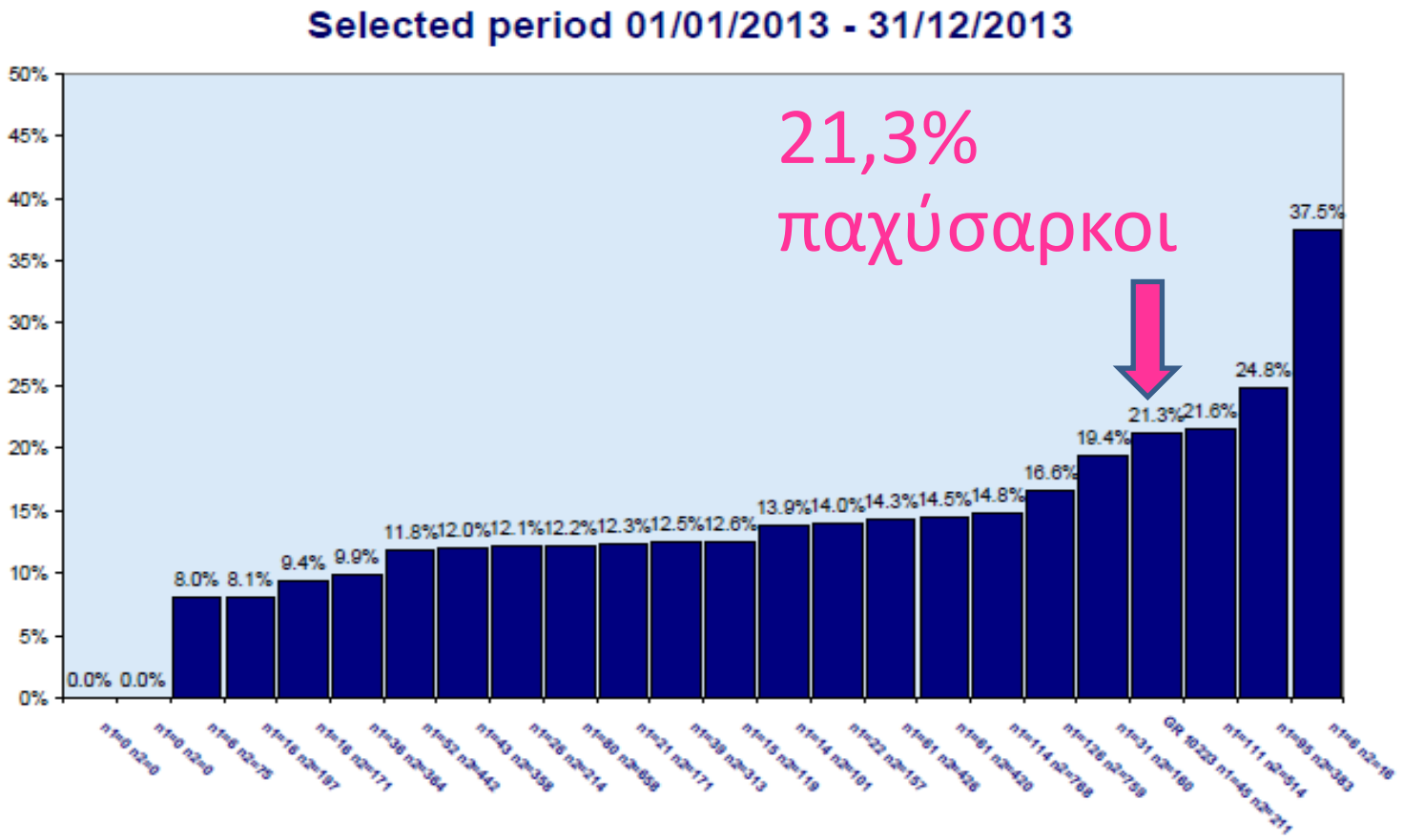
WORKING TO CREATE CENTRES OF REFERENCE

BMI: percentage of patients with BMI>95p, T1DM, patients 0-18y, WHO 2007 reference



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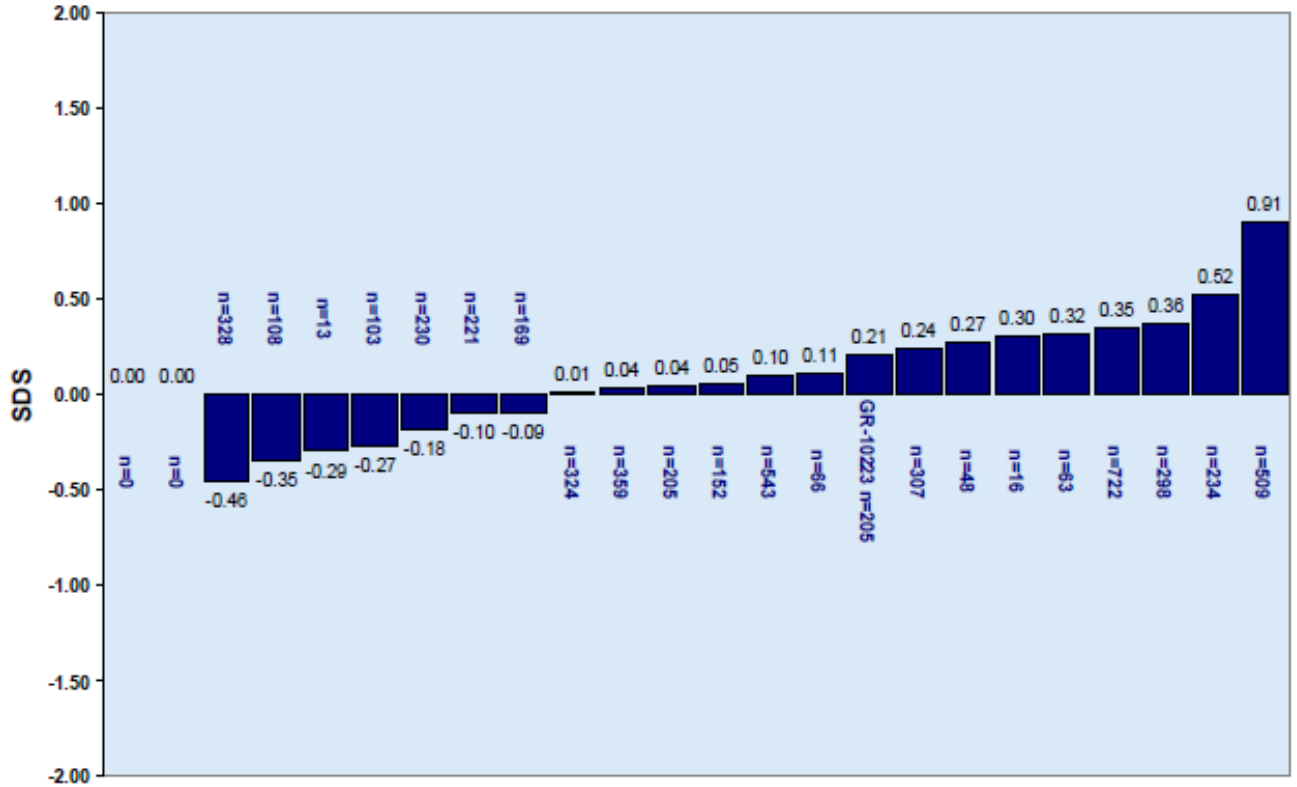
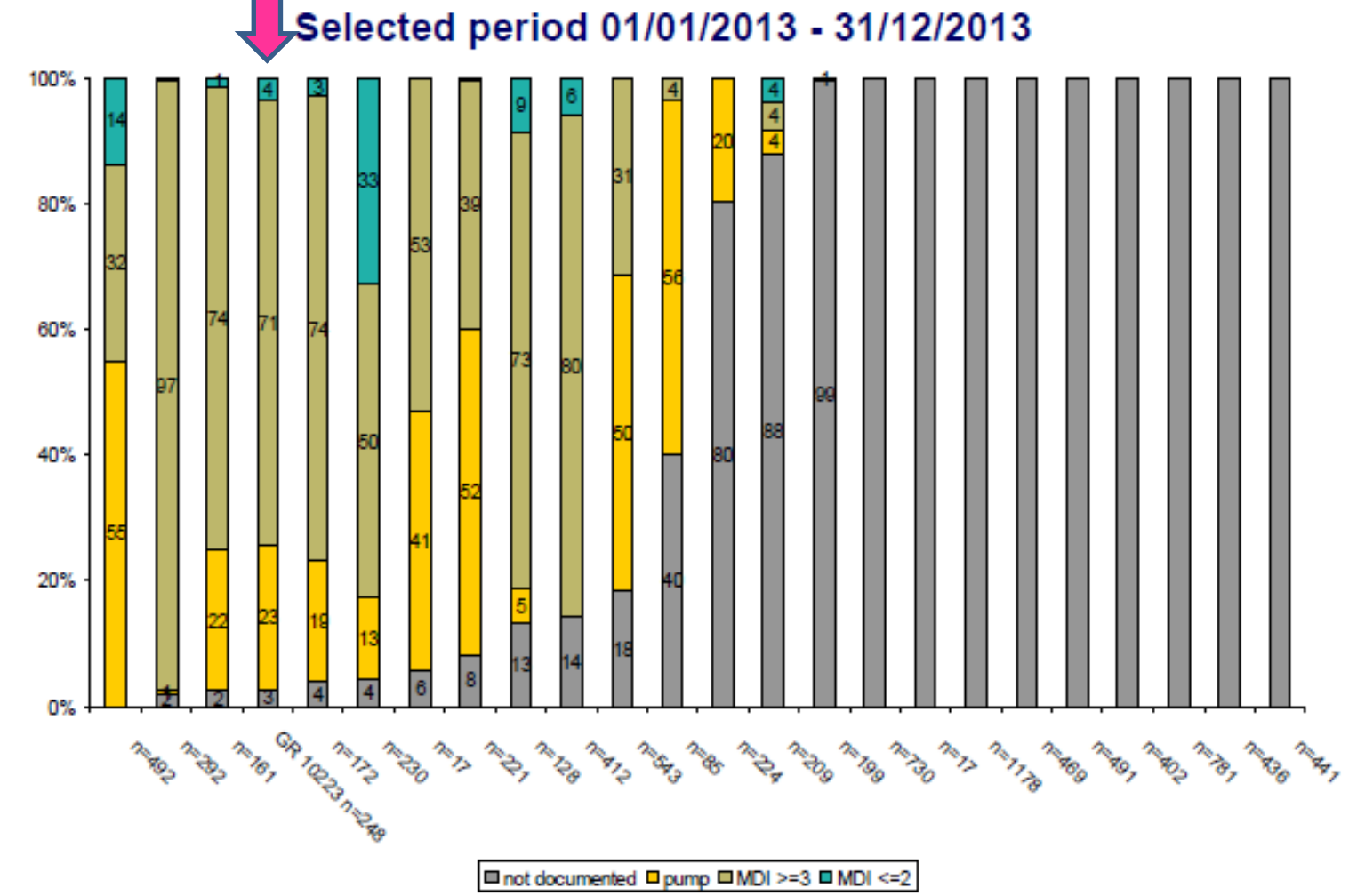
Systolic blood pressure expressed in SDS, T1DM, patients 0-18y

Selected period 01/01/2013 - 31/12/2013



Insulin treatment, T1DM

22% PUMP
71% MDI
4% 2 INJECTIONS



Έλεγχος για επιπλοκές

Completeness of monitoring: T1DM, screening
Centre: GR-10223

Year	Number of all Patients	Screening for nephropathy *percentage and number of patients*	Screening for hyperlipidaemia *percentage and number of patients*	Screening for celiac disease *percentage and number of patients*	Screening for thyroid disease *percentage and number of patients*	Screening for retinopathy *percentage and number of patients*
2014	77	5.0% (2/40)	7.7% (3/39)	1.3% (1/77)	9.1% (7/77)	0.0% (0/40)
2013	248	18.6% (26/140)	47.8% (65/136)	6.9% (17/248)	48.0% (119/248)	8.6% (12/140)
2012	377	1.3% (3/234)	56.7% (131/231)	2.7% (10/377)	57.6% (217/377)	1.7% (4/234)
2011	370	0.9% (2/224)	42.2% (92/218)	0.5% (2/370)	44.3% (164/370)	1.3% (3/224)
2010	202	10.9% (13/119)	57.4% (62/108)	0.5% (1/202)	58.4% (118/202)	18.5% (22/119)
2009	97	0.0% (0/56)	41.8% (23/55)	0.0% (0/97)	43.3% (42/97)	10.7% (6/56)
2008	33	15.0% (3/20)	27.3% (6/22)	0.0% (0/33)	36.4% (12/33)	5.0% (1/20)
2007	25	0.0% (0/17)	18.8% (3/16)	0.0% (0/25)	12.0% (3/25)	0.0% (0/17)
2006	10	12.5% (1/8)	12.5% (1/8)	0.0% (0/10)	20.0% (2/10)	0.0% (0/8)

High quality of care

- Diabetes is a chronic disease where a high quality of care has a proven impact on the prognosis of the individual patient in terms of life expectancy and quality of life
- High quality of care has an impact on society in terms of medical costs , insurance expenditures and working capacity of patients

- DCCT J Pediatt 1994 125:177-88
- Milton et al Diabet Med 2006 23:821-29

High quality data

- High quality of care is possible by prospective measurement of the target achievement by the single diabetes unit
- The guidelines to follow should be based on evidence, relying on solid data from a high number of patients who are treated according to a well defined policy and updated according to the results
- SWEET Project may serve as an excellent reference model for children suffering from any type of chronic disease

Ελληνική Διαβητολογική Εταιρεία

ISPAD
International Society for Pediatric and Adolescent Diabetes

SWEET
PEDIATRIC DIABETES

International Diabetes Federation Europe

CERTIFICATE

The Center of A' Department of Pediatrics
"P&A Kyriakou Childrens's Hospital"
24 Messogion Avenue Goudi
11527 Athens, Greece

has fulfilled the criteria to qualify as

CENTRE OF REFERENCE FOR PEDIATRIC DIABETES

2011 / 2012

Hannover, Germany, 15th Aug 2011

Dr. Lynda Fisher
ISPAD President

Prof. Dr. Thomas Danne
SWEET e.V., Chairman

Joao Manuel Valente Nabais
IDF Europe, President Elect

Criteria for a Centre of Reference for Pediatric Diabetes

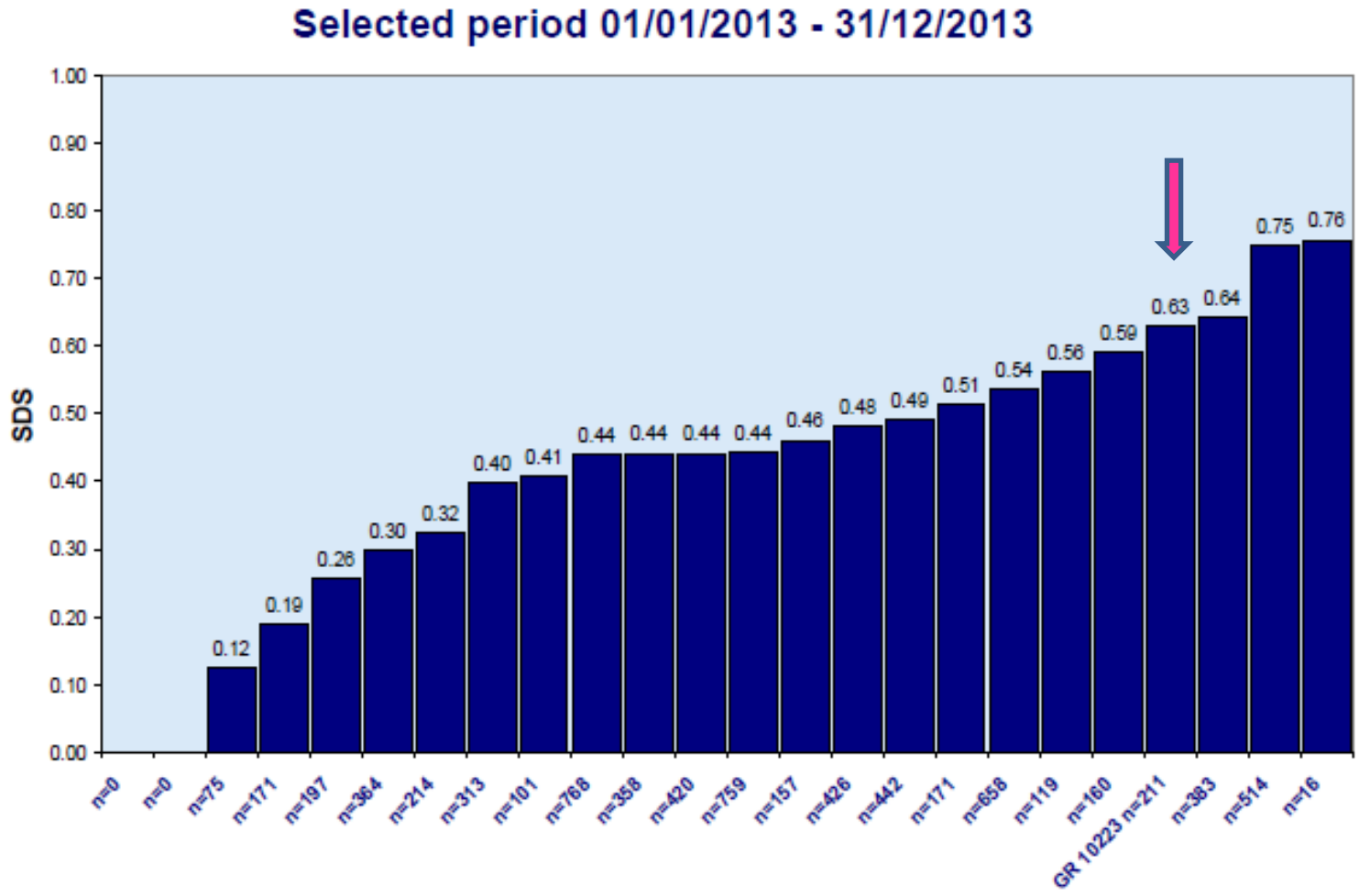
- Sufficient activity and capacity to provide relevant services, at a sustained level of quality
- Capacity to provide expert advice, diagnosis or confirmation of diagnosis, to produce and adhere to good practice guidelines and to implement outcome measures and quality control
- Multidisciplinary approach
- High level of expertise and experience, as documented through publications, grants, or honorific positions, teaching and training activities
- Strong contribution to research
- Involvement in epidemiological surveillance such as registries
- Close links and collaboration with other expert national and international centres, and capacity to network
- Close links and collaboration with patient associations where they exist
- Appropriate arrangements for patient referrals from other EU countries
- Appropriate capacities for diagnosing, following up and managing patients with evidence of good outcome

Conclusions

- Treatment of diabetes in children is complex
- The presence of centers of reference with quality control system improve health care
- Electronic database is essential for estimation of indicators for reduction of health care cost

BMI SDS

BMI-SDS: T1DM, patients 0-18y, WHO 2007 reference



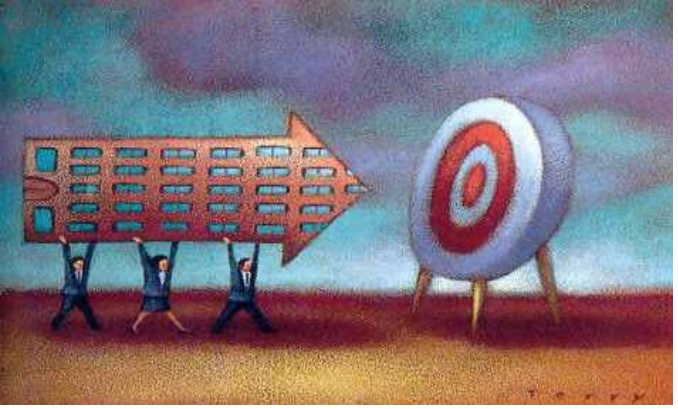
SWEET-Benchmarking
GR-10223

Data-analysis based on
SWEETBASE-Datapool
01/01/2006 - 27/03/2014

focused on:
01/01/2013 - 31/12/2013

created 01/04/2014

On behalf of SWEET
Michael Witsch, LU



Treatment targets

- **Normal to near normal glucose levels**
  - **Reduction of frequency of acute complications (hypoglycemia, ketoacidosis)**
  - **Avoidance of weight increase**
  - **Prevention or delay of chronic complications (nephropathy, retinopathy, neuropathy, macroangiopathy)**