Standardized Minimum Dataset

Up to date: 16.08.2021

Export a file with your center data prior to each deadline and upload the data at

https://sweet.zibmt.uni-ulm.de/uploadSweet/

First deadline **31st of January** **Second deadline** **31st of July**

- Please do not send your data by e-mail!
- Center data must be password protected! Please follow the instructions on data safety on the homepage.
  Please send us the password using e-mail, fax, or phone.

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Center level data

Data contains one record data. Data should be transmitted each time.

Blue color: Mandatory items for all centres (emerging countries included)
Red color: Changes/new variables (July 2021)

Item	Request
Name of centre	
Location of centre	
Adress of centre	
Date of profile	Day/month/year (this first profile date must include the earliest date of visit)
Total number of pediatric patients with T1D treated in your center during the previous year	All patients seen at your center during the previous year.
Total number of pediatric patients with T2D treated in your center during the previous year	
Total number of pediatric patients with other forms of diabetes treated in your center during the previous year	
Laboratory method of HbA1c	1 = HPLC, 2 = DCA 2000, 3 = others
Unit for HbA1c	% or mmol/mol
Mean of the HbA1c in healthy subjects	
SD of the HbA1c in healthy subjects	
Or alternatively: **Range of the HbA1c in healthy subjects**	
Unit for urine albumin screening	g/l, mg/l, mg/mol Crea, mg/g Crea, g/24h, µg/min
Start year of Benchmarking reports	Year

Patient level data

Data contains one record for each patient.

Blue color: Mandatory items for all centres (emerging countries included)
Red color: Changes/new variables (July 2021)

Item	Request	Comment
Patient ID	unique patient identifier	Only one ID per patient. Only one patient per ID. ID has to be identical in future data uploads.
Sex	male/female	Biological sex
Year of birth	year	YYYY
Month of birth	month	MM
Date of onset	month and year	If possible also day of onset The dates have to be entered in a consistent format.
Type of diabetes	0, 1, 2, 3, 4	0: Prediabetes 3: Other specific types 4: gestational diabetes
If type of diabetes = "3", other specific type of diabetes or "0" (Prediabetes)	if known, please provide the number of subtype according to ISPAD classification.	For number of the ISPAD classification see table below: "diabetes subtypes"
Specification of diabetes subtype	text explaining diabetes subtype, syndrome, mutation etc.	
Date of death	if patient died, please provide date	
Cause of death	if patient died, please provide cause of death	
Chronic Comorbidity	Depression (F32, F33) AD(H)D (F90) Anxiety disorder (F41) Multiple sclerosis (G35) Juvenile idiopathic arthritis (M08) Eating disorder (F50)	Please provide ICD-10-Code for each confirmed chronic comorbidity (disease under treatment and/or clear diagnosis by physician).

	….	**Please do not insert patient's demographics!**
Celiac disease	yes/no	Celiac disease is diagnosed according to current guidelines
Presentation at onset	1: DKA with coma 2: DKA without coma 3: Ketosis 4: Hyperglycemia 5: By screening	Use the most severe category which applies to the patient. Definition of DKA according to ISPAD guidelines (pH <7.3 or bicarbonate <15 mmol/L). Coma defined as Glasgow coma scale ≤11.
HbA1c on diagnosis	mmol/mol or %	1-2 decimals HbA1c during the first 10 days after diagnosis

Visit level data

Data contains one record for each patient visit (outpatient or inpatient).

Blue color: Mandatory items for all centres (emerging countries included)
Red color: Changes/new variables (July 2021)

Item	Request	Comment
Patient ID	unique patient identifier	Only one ID per patient. Only one patient per ID. ID has to be identical in future data uploads.
Date of visit	day, month, year	The dates have to be entered in a consistent format.
Height	cm	1 decimal
Weight	kilogram	1 decimal
Blood pressure systolic	mmHg	no decimal
Blood pressure diastolic	mmHg	no decimal
HbA1c	mmol/mol or %	1-2 decimals
Cholesterol	mmol, mg/dl, mg/l	0-2 decimal
HDL cholesterol	mmol, mg/dl, mg/l	0-2 decimal
LDL cholesterol	mmol, mg/dl, mg/l	0-2 decimal
Triglyceride	mmol, mg/dl, mg/l	0-2 decimal
TSH	µU/ml, mU/l	1-2 decimal
Free T4	different units possible	1-2 decimal
Thyroid peroxidase antibody	different units possible	1-2 decimal
Antithyroglobulin antibody	different units possible	1-2 decimal
Screening for thyroid disease	screening performed yes/no	In case you cannot provide results for TSH and/or thyroid AB: Screening = yes if either TSH or AB have been checked.
Celiac antibodies	numeric value OR normal/pathological	
Screening for celiac disease	screening performed yes/no	In case you cannot provide

		results
Number of injections per day	number of injection time points per day	
Type of treatment	pump yes/no	
Daily insulin dose	units per day	1 decimal
Daily basal insulin	units per day	1 decimal
Daily prandial insulin	units per day	1 decimal
Number of SMBG/day	average daily number of SMBG measurements	
Sensor use	yes/no or FGM or CGM	
Type of basal insulin	only NPH, only analog, both	analog/normal
Type of prandial insulin	only NI, only analog, both	analog/normal
Oral antidiabetics	generic name of drug	
Injectable (non-insulin) antidiabetic	yes/no	
Severe hypoglycemia	number of events since last data entry, or number of events during last year if no preceding data entry available	Severe hypoglycemia is defined as an event during which a patient requires assistance of another person based on ISPAD guidelines.
DKA leading to hospitalization	number of events since last data entry, or number of events during last year if no preceding data entry	DKA without DKA at diabetes onset Definition of DKA according to ISPAD guidelines (pH <7.3 or bicarbonate <15 mmol/L).
Nephropathy	spontaneous urine: numeric value of albuminuria OR nephropathy yes/no OR normal/pathologic	
Screening for nephropathy	screening performed yes/no	In case you cannot provide

		results
Retinopathy	retinopathy yes/no OR normal/pathologic	
Screening for retinopathy	screening performed yes/no	In case you cannot provide results
Antihypertensive agents	yes/no	
Lipid lowering agents	yes/no	
Thyrostatic agents	yes/no	Treatment for Basedow's disease
Iodine	yes/no	Treatment of iodine deficiency
Thyroid hormone	yes/no	T4, T3 or combination
Closed Loop	1: Low Glucose Suspend 2: Predicted Low Glucose Suspend 3: Medtronic 670G 4: Hybrid closed loop 9: OpenAPS	Sensor driven pump.
Time in Range (TIR)	%	Time spent in the target range between 70 and 180 mg/dl during the last 2 weeks
Time below Range	%	Time spent below 70 mg/dl during the last 2 weeks.
Covid-19 swab	Positive, negative, unknown	
Covid-19 antibody test	Positive, negative, unknown	
Telemedicine consultation	Yes/no	Document everything available during a telemedicine clinic.
HbA1c from external laboratory (% or mmol/mol)		
Mean of the external HbA1c in healthy subjects		
SD of the external HbA1c in healthy subjects		

Or alternatively: **Range of external HbA1c in healthy subjects**		

Further variables mentioned in the ISPAD guidelines for the quality of treatment might be also transmitted for specific research projects agreed by the DPPC committee. The structure and format have to be agreed with the data management team in Ulm.

Glucose profiles

Centers using the DPV software

- Sensor data from various CGM-/FGM-meters can be *imported* into DPV since version 7.35.
- How to contribute sensor data to SWEET using DPV, see https://sweet-project.org/downloads/documentation-sensor-data-to-sweet-dpv-software.pdf

Centers using an individual documentation system

- If you are not using DPV, you can create a *ZIP-file containing all your sensor data*.
- Please use the following convention for naming the individual files:
  "<<*patientid*>>-<<Year>>-<<Month>>*.*<<*file extension*>>" (e.g. "745-2019-07.txt")
  so we can match your sensor data to your patients' data.
- How to contribute sensor data to SWEET using an individual documentation system, see https://sweet-project.org/downloads/documentation-sensor-data-to-sweet-individual-documentation-system.pdf

If you have any question regarding the documentation of sensor data, please do not hesitate to contact the Ulm team:

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Diabetes subtypes and diabetes associated syndromes

List can be used for patients with type-3 diabetes as well as for patients with pre-diabetes (type 0). When coding with other specific type of diabetes please provide more information under “specification for diabetes subtype”.

Up to date: 04.11.2016

Category Number	Diabetes subtype for type 3 diabetes
	A. Genetic defects of β -cell function
1	HNF−1α (MODY3), Chromosome 12
2	Glucokinase (MODY2), Chromosome 7
3	HNF−4α (MODY1), Chromosome 20
4	Insulin promoter factor- (IPF-1; MODY4), Chromosome 13
5	HNF−1β (MODY5), Chromosome 17
6	NeuroD1 (MODY6), Chromosome 2
601	KLF11 (MODY7), Chromosome 2
602	CEL (MODY8), Chromosome 9
603	PAX4 (MODY9), Chromosome 7
7	Mitochondrial DNA mutation
8	KCNJ11 (Kir6.2), Chromosome 11,
801	ABCC8 (SUR1), Chromosome 11,
802	INS gene mutation
803	PLAGL1/HYMAI Imprinting defect on 6q24 (paternal uniparental disomy or hypomethylation defect)
804	GATA6 mutation
810	Permanent Neonatal Diabetes other causes
811	Transient Neonatal Diabetes other causes

812	Permanent Neonatal Diabetes (cause undetermined)
813	Transient Neonatal Diabetes (cause undetermined)
9	Others
	B. Genetic defects in insulin action
10	Type A insulin resistance
101	Alstrom syndrome (ALMS1 gene on chromosome 2p13)
12	Leprechaunism
13	Rabson-Mendenhall syndrome
14	Lipoatrophic diabetes
15	Others
	C. Diseases of the exocrine pancreas
16	Pancreatitis
161	Pancreatic agenesis
17	Trauma / pancreatectomy
18	Neoplasia
19	Cystic fibrosis
20	Haemochromatosis
201	Haemosiderosis (transfusion related)
21	Fibrocalculous pancreatopathy
22	Others
	D. Endocrinopathies
23	Acromegaly
24	Cushing's syndrome
25	Glucagonoma
26	Phaeochromocytoma
27	Hyperthyroidism

28	Somatostatinoma
29	Aldosteronoma
30	Others
	E. Drug- or chemical-induced
31	Vacor
32	Pentamidine
33	Nicotinic acid
34	Glucocorticoids
35	Thyroid hormone
36	Diazoxide
37	β-adrenergic agonists
38	Thiazides
39	Dilantin
40	α -Interferon
401	Post transplantation (excludes patients with CF which should be under CFRD)
403	Atypical anti-psychotic agents
41	Others
	F. Infections
42	Congenital rubella
43	Cytomegalovirus
44	Others
	G. Uncommon forms of immune-mediated diabetes
45	‘‘Stiff-man’’ syndrome
46	Anti-insulin receptor antibodies
48	Polyendocrine autoimmune deficiencies APS I and II
47	Others

	H. Other genetic syndromes sometimes associated with diabetes
49	Trisomy 21 (Down syndrome)
50	Klinefelter syndrome
51	Turner syndrome
52	Wolfram syndrome
53	Friedreich's ataxia
54	Huntington's chorea
55	Laurence-Moon-Biedl syndrome
56	Myotonic dystrophy
57	Porphyria
58	Prader-Willi syndrome
60	Wolcott-Rallison (EIF2AK3 mutation)
61	Rogers syndrome (Thiamine-responsive megaloblastic anemia, TRMA)
59	Others
Category Number	**Diabetes subtype for prediabetes patients (diabetes type 0) only**
1001	T1D autoimmunity (≥ 2 antibodies)
1002	Glucose intolerance
1003	Genetic risk of monogenic diabetes
1004	Genetic risk of Type 1 diabetes (first degree relative with type 1, no or 1 antibody positive, or antibody status unknown)
1005	Past history of glucose intolerance or diabetes
1006	Child born to a mother with gestational diabetes or type 2 diabetes present during pregnancy