

## Standardized Minimum Dataset

Up to date: 03.07.2024



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.

E-Mail:      sascha.tittel@uni-ulm.de

FAX:      0049 731 50 25309

Phone:      0049 731 50 25353

## 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 2022)

Item	Request
Name of centre	
Location of centre	
Address 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 2022)

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

	Eating disorder (F50) ....	<b>Please do not insert patient's demographics!</b>
<b>Celiac disease</b>	yes/no	Celiac disease is diagnosed according to current guidelines
<b>Presentation at onset</b>	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.
<b>HbA1c on diagnosis</b>	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 2022)

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	

<b>Screening for celiac disease</b>	screening performed yes/no	In case you cannot provide results
<b>Number of injections per day</b>	number of injection time points per day	
<b>Type of treatment</b>	pump yes/no	
<b>Daily insulin dose</b>	units per day	1 decimal
<b>Daily basal insulin</b>	units per day	1 decimal
<b>Daily prandial insulin</b>	units per day	1 decimal
<b>Number of SMBG/day</b>	average daily number of SMBG measurements	
<b>Sensor use</b>	yes/no or FGM or CGM	
<b>Type of basal insulin</b>	only NPH, only analog, both	analog/normal
<b>Type of prandial insulin</b>	only NI, only analog, both	analog/normal
<b>Oral antidiabetics</b>	generic name of drug	
<b>Injectable (non-insulin) antidiabetic</b>	yes/no	
<b>Severe hypoglycemia</b>	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.
<b>DKA leading to hospitalization</b>	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).
<b>Nephropathy</b>	spontaneous urine: numeric value of albuminuria OR nephropathy yes/no OR normal/pathologic	

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

<b>Or alternatively:</b>		
<b>Range of external HbA1c in healthy subjects</b>		

**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:**

**Andreas Hungele**                      **andreas.hungele@uni-ulm.de**

**Ramona Ranz**                        **ramona.ranz@uni-ulm.de**

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

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

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

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