

Note: It is recommended that this Data Set have two additional key variables:
 - SITE (to distinguish the location where the data are recorded) and
 - SUBJECT (to distinguish the patient/study participant)

**INTERNATIONAL SPINAL CORD INJURY ENDOCRINOLOGY AND METABOLISM
 EXTENDED DATA SET (Version 1.0)**

TABLE 1

Carbohydrate Metabolism:

Plasma glucose:

Fasting _____ mmol/L

FASTGLUC

Date: YYYYMMDD

Unknown

2 hours _____ mmol/L

2HRGLUC

CARBMTDT

OGTT diagnostic classification: normal Impaired Glucose Tolerance Diabetes Mellitus

OGTTDIAG

Plasma insulin:

Fasting _____ pmol/L

FASTINS

2 hours _____ pmol/L

2HRINS

Hemoglobin A1c: _____ %

HBA1C

TABLE 2

Calcium & Bone Metabolism:

Date: YYYY/MM/DD Unknown

Plasma/Serum calcium _____ mmol/L

PLSSERCA

CABNMTDT

Plasma ionized calcium _____ mmol/L

PLSIONCA

Urine calcium _____ mmol/24hours

URINECA

Urine calcium/creatinine _____ mmol/mg

UCACREAT

Serum 25-OH D: _____ nmol/L

SE25OHD

Plasma parathyroid hormone (PTH) level: _____ ng/L

PLPTHVL

Plasma/Serum N-telopeptide _____ nmol BCE

PLSERNTP

Urine N-telopeptide _____ nmol BCE/mmol creat

URNNTTP

Plasma/Serum C-telopeptide _____ ng/L

PLSERCTP

Plasma/Serum osteocalcin: _____ µg/L

PSOSTCAL

Plasma/Serum P1NP: _____ µg/L

PLSRP1NP

DEXADT

TABLE 3

Dual energy x-ray absorptiometry:

Date: YYYY/MM/DD

Unknown

If osteoporosis (-2.5 or less SD) is present for persons ≥ 50 years old, place an "X" in the space provided for each skeletal site of interest:

OSTEOHIP

Total Hip _____ Femoral neck _____

Radius _____

OSTEORAD

Bone mineral density for each skeletal site of interest:

OSTEOFNK

Total hip _____ (g/cm²)

BMDTHIP

Femoral neck _____ (g/cm²)

BMDFMNK

Distal femur _____ (g/cm²)

BMDDISFM

Proximal tibia _____ (g/cm²)

BMDPXTIB

Radius _____ (g/cm²)

BMDRADI

If Z-values are below the expected range for age for persons <50 years old, place an "X" in the space provided:

Hip _____ (-2.0 or less SD)

ZVALHIP

Radius _____ (-2.0 or less SD)

ZVALRAD

Prior Thyroid Disease (to be filled in once only): PTHYDZDT TABLE 4

Absent Present Unknown Date: YYYY/MM/DD Unknown

If present, thyroid diagnosis

Hashimoto's disease Date disease diagnosed YYYYMMDD Unknown PHASHIDT

Goiter: Diffuse toxic goiter Diffuse nontoxic goiter Nontoxic multinodular goiter PGOITRDX

Toxic multinodular goiter Date disease diagnosed YYYYMMDD Unknown PGOITRDT

Thyroiditis: Acute thyroiditis Subacute thyroiditis PTHITIDX

Date disease diagnosed YYYYMMDD Unknown PTHITIDT

Thyroid cancer: Papillary cancer Follicular cancer Medullary cancer Anaplastic cancer Other Date disease diagnosed YYYYMMDD Unknown PTHCANDT

Thyroid nodule: Hyperfunctioning thyroid nodule Hypofunctioning thyroid nodule PTHCANDX PTHNODDX

Date disease diagnosed YYYYMMDD Unknown PTHNODDT

Other, specify PTHYDXSP Date disease diagnosed YYYYMMDD Unknown PTHOTHDT

PTHDXOTH

Thyroid Function: THYLABDT TABLE 5

Thyroid function laboratory tests/new diagnosis: Date: YYYY/MM/DD Unkn

Thyroid gland size: Goiter: absent present THYGLSZ

Plasma/Serum thyroid stimulating hormones (TSH) _____ mU/L PLSERT3 PLSERTSH

Plasma/Serum triiodothyronine (T₃) _____ nmol/L SERT3RU

Serum thyroxine (T₄) _____ nmol/L PLSERT4

Serum T₃ resin uptake (T₃RU) _____ PLSERFT4

Plasma/Serum free thyroxine (FT₄) _____ pmol/L THYROIAB

Thyroid antibodies: absent present

New thyroid diagnosis:

Hashimoto's disease HASHIMDX

Goiter: Diffuse toxic goiter Diffuse nontoxic goiter Nontoxic multinodular goiter Toxic multinodular goiter GOITERDX

Thyroiditis: Acute thyroiditis Subacute thyroiditis THITISDX

Thyroid cancer: Papillary cancer Follicular cancer Medullary cancer Anaplastic cancer Other THYCANDX

Thyroid nodule: Hyperfunctioning thyroid nodule Hypofunctioning thyroid nodule THYNODDX

Other, specify THYOTHDX THYRDXSP

Adrenal Function: ADRFXNDT TABLE 6

FSTSECOR Date: YYYY/MM/DD Unknown

06-08 (a.m.) fasting serum cortisol _____ nmol/L

24-hour urine cortisol _____ nmol/24 hours 24HURCOR

Gonadal Function: GNDFXNDT TABLE 7

Date: YYYY/MM/DD Unknown

Men:

Testis normal size small TESTISSZ

Plasma/Serum testosterone _____ nmol/L PLSETSTO

Serum sex hormone binding globulin _____ nmol/L SSEXHOBG

Serum albumin _____ µmol/L SERALBUM

Serum bioactive testosterone _____ pmol/L SEBATSTO

Serum free testosterone _____ pmol/L SEFRTSTO

Women:

Plasma/Serum estradiol _____ pmol/L PLSEESTD

		APTFXNDT	TABLE 8
Anterior Pituitary Function:		Date: YYYY/MM/DD	<input type="checkbox"/> Unknown
Plasma prolactin _____ mmol/L	PLPROLAC		
Plasma leuteinizing hormone (LH) _____ IU/L	PLASMALH		
Plasma follicular stimulating hormone (FSH) _____ IU/L	PLASMFSH		
Plasma insulin-like growth factor-1 (IGF-1) (baseline) _____ kU/L	PLSMIGF1		
<i>Women:</i>	MENSTCYC		
Identify the time of the menstrual cycle (basal, ovulatory surge, postmenopausal) _____			

		PPTFXNDT	TABLE 9
Posterior Pituitary Function:		Date: YYYY/MM/DD	<input type="checkbox"/> Unknown
Plasma copeptin _____ pmol/L	PLCOPEPT		
Fluid deprivation test with DDAVP	<input type="checkbox"/> positive	<input type="checkbox"/> negative	FLUDDAVP

		SYMPNSDT	TABLE 10
Sympathetic Nervous System Function:		Date: YYYY/MM/DD	<input type="checkbox"/> Unknown
Plasma norepinephrine supine _____ nmol/L	PLNEPISU		
Plasma norepinephrine seated/standing _____ nmol/L	PLNEPISS		

		RAAXISDT	TABLE 11
Renin-Aldosterone Axis Function:		Date: YYYY/MM/DD	<input type="checkbox"/> Unknown
Plasma renin supine _____ µg/L/h	PLRENISU		
Plasma renin seated/standing _____ µg/L/h	PLRENISS		
Serum aldosterone supine _____ pmol/L	SRALDSUP		
Serum aldosterone seated/standing _____ pmol/L	SERALDSS		

Conversion factor (CF) x Conventional (C) = System or International Units (SI)

Glucose	0.05551 x mg/dL = mmol/L
Insulin	7.175 x µU/mL = pmol/L
Total Calcium (plasma)	0.2595 x mg/dL = mmol/L
25-Hydroxycholecalciferol (25-OH-D)	2.496 x ng/dL = nmol/L
Thyroxine (T ₄)	12.87 x µg/dL = nmol/L
Triiodothyronine (T ₃)	0.0154 x ng/dL = nmol/L
Free Thyroxine (FT ₄)	12.85 x ng/dL = pmol/L
Cortisol	27.59 x µg/dL = nmol/L
Testosterone	4.467 x ng/mL = nmol/L
Estradiol	3.671 x pg/ml = pmol/L
Creatinine	88.4 x mg/dL = µmol/L
Other conversions:	pg/mL = ng/L
	ng/mL = µg/L
	ng/mL/h = µg/L/h
	µU/mL = mU/L
	mU/mL = U/L
	U/mL = kU/L

Proposed 8 Character Variables:

Data Element	Site	Subject	Carbohydrate Metabolism Date Performed	Carbohydrate Metabolism Plasma glucose Fasting	Carbohydrate Metabolism Plasma Glucose 2 hours	Carbohydrate Metabolism OGTT diagnostic classification	Carbohydrate Metabolism Plasma insulin-Fasting	Carbohydrate Metabolism-Plasma insulin 2 hours	Carbohydrate Metabolism Hemoglobin A1c	Calcium & Bone Metabolism Date Performed	Calcium & Bone Metabolism Plasma /serum calcium	Calcium & Bone Metabolism Plasma ionized calcium	Calcium & Bone Metabolism Urine calcium	Calcium & Bone Metabolism Urine calcium / creatinine	Calcium & Bone Metabolism Serum 25-OH D
Format/Codes			Numeric (yyyymmdd) 9999-99-99 = Unknown	___ (mmol/L) Numeric 9.9 = Unknown	___ (mmol/L) Numeric 9.9 = Unknown	Normal; Impaired glucose tolerance; Diabetes Mellitus	___ (pmol/L) Numeric 999 = Unknown	___ (pmol/L) Numeric 9999 = Unknown	% Numeric Unknown	Numeric (yyyymmdd) 9999-99-99 = Unknown	___ (mmol/L) Numeric 9.9 = Unknown	___ (mmol/L) Numeric 9.9 = Unknown	___ (mmol / 24 hour) Numeric 9.9 = Unknown	___ (mmol/mg) Numeric 9.999 = Unknown	___ (nmol/L) Numeric 999 = Unknown
Table	1 - 11	1 - 11	1	1	1	1	1	1	1	2	2	2	2	2	2
8 Character Variable	SITE	SUBJECT	CARBMTDT	FASTGLUC	2HRGLUC	OGTTDIAG	FASTINS	2HRINS	HBA1C	CABNMTDT	PLSSERCA	PLSIONCA	URINECA	UCACREAT	SE25OHD
Comments/Notes	key	key													

Proposed 8 Ch

Data Element	Calcium & Bone Metabolism Plasma parathyroid hormone (PHT) level	Calcium & Bone Metabolism Plasma/Serum N-telopeptide	Calcium & Bone Metabolism Urine N-telopeptide	Calcium & Bone Metabolism Plasma/Serum C-telopeptide	Calcium & Bone Metabolism Plasma/Serum osteocalcin	Calcium & Bone Metabolism Plasma/Serum P1NP	Dual energy x-ray absorptiometry Date Performed	Dual energy x-ray absorptiometry: If osteoporosis (-2.5 or less SD) is present for person>50 years old, place an "X" in the space provided for each skeletal site of interest	Dual energy x-ray absorptiometry: If osteoporosis (-2.5 or less SD) is present for person>50 years old, place an "X" in the space provided for each skeletal site of interest	Dual energy x-ray absorptiometry: If osteoporosis (-2.5 or less SD) is present for person>50 years old, place an "X" in the space provided for each skeletal site of interest	Dual energy x-ray absorptiometry: Bone mineral density for each skeletal site of interest	Dual energy x-ray absorptiometry: Bone mineral density for each skeletal site of interest	Dual energy x-ray absorptiometry: Bone mineral density for each skeletal site of interest	Dual energy x-ray absorptiometry: Bone mineral density for each skeletal site of interest	Dual energy x-ray absorptiometry: Bone mineral density for each skeletal site of interest	Dual energy x-ray absorptiometry: If Z-score values are below the expected range for persons <50 years old, place an "X" in the space provided	Dual energy x-ray absorptiometry: If Z-score values are below the expected range for persons <50 years old, place an "X" in the space provided
Format/Codes	____(ng/L) Numeric 99 = Unknown	____(nmol/BCE) Numeric 99.9 = Unknown	____(nmol BCE/mmol creat) Numeric 99 = Unknown	____(ng/L) Numeric 9999 = Unknown	____(µg/L) Numeric 99 = Unknown	____(µg/L) Numeric 999 = Unknown	Numeric (yyyymmdd) 9999-99-99 = Unknown	Total Hip	____Femoral neck	____Radius	Total hip____ g/cm ² Numeric	Femoral neck____ g/cm ² Numeric	Distal femur____ g/cm ² Numeric	Proximal tibia____ g/cm ² Numeric	Radius____g/cm ² Numeric	Hip (-2.0 or less SD)____ Numeric	Radius (-2.0 or less SD)____ Numeric
Table	2	2	2	2	2	2	3	3	3	3	3	3	3	3	3	3	
8 Character Variable	PLPHTLVL	PLSERNTP	URNNTPT	PLSERCTP	PSOSTCAL	PLSRP1NP	DEXADT	OSTEOHIP	OSTEOFNK	OSTEORAD	BMDTHIP	BMDFMNK	BMDDISFM	BMDPXTIB	BMDRADI	ZVALHIP	ZVALRAD
Comments/Notes																	

Proposed 8 Ch

Data Element	Prior Thyroid Disease Date Performed	Prior Thyroid Disease	Prior Thyroid Disease If present, thyroid diagnosis: Hashimoto's Disease	Prior Thyroid Disease If present, thyroid diagnosis: Hashimoto's Disease Date Performed	Prior Thyroid Disease If present, thyroid diagnosis: Goiter	Prior Thyroid Disease If present, thyroid diagnosis: Goiter Date Performed	Prior Thyroid Disease If present, thyroid diagnosis: Thyroiditis	Prior Thyroid Disease If present, thyroid diagnosis: Thyroiditis Date Performed	Prior Thyroid Disease If present, thyroid diagnosis: Thyroid Cancer	Prior Thyroid Disease If present, thyroid diagnosis: Thyroid Cancer Date Performed	Prior Thyroid Disease If present, thyroid diagnosis: Thyroid Nodule	Prior Thyroid Disease If present, thyroid diagnosis: Thyroid Nodule Date Performed	Prior Thyroid Disease If present, thyroid diagnosis: Other, specify	Prior Thyroid Disease If present, thyroid diagnosis: specify text	Prior Thyroid Disease If present, thyroid diagnosis: Other, specify Date Performed
Format/Codes	Numeric (yyyymmdd) 9999-99-99 = Unknown	Absent; Present; Unknown	Hashimoto's Disease	Numeric (yyyymmdd) 9999-99-99 = Unknown	Diffuse toxic goiter; Diffuse nontoxic goiter; nontoxic multinodular goiter; Toxic multinodular goiter	Numeric (yyyymmdd) 9999-99-99 = Unknown	Acute thyroiditis; Subacute thyroiditis	Numeric (yyyymmdd) 9999-99-99 = Unknown	Papillary cancer; Follicular cancer; Medullary cancer; Anaplastic cancer; Other	Numeric (yyyymmdd) 9999-99-99 = Unknown	Hyperfunctioning thyroid nodule; Hypofunctioning nodule	Numeric (yyyymmdd) 9999-99-99 = Unknown	Other, specify	Free-text	Numeric (yyyymmdd) 9999-99-99 = Unknown
Table	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
8 Character Variable	PTHYZDT	THYOPRS	PHASHDX	PHASHDT	PGOITRDX	PGOITRDT	PTHITDX	PTHITDT	PTHCANDX	PTHCANDT	PTHNODDX	PTHNODDT	PTHDXOTH	PTHYDXSP	PTHOTHDT
Comments/Notes															

Proposed 8 Ch

Data Element	Thyroid Function laboratory tests/new diagnosis Date Performed	Thyroid Function Thyroid Gland Size: Goiter	Thyroid Function Plasma/Serum thyroid stimulating hormones (TSH)	Thyroid Function Plasma / Serum triiodothyronine (T3)	Thyroid Function Serum thyroxine (T4)	Thyroid Function Serum T3 resin uptake (T3RU)	Thyroid Function Plasma/Serum free thyroxine(FT ₄)	Thyroid Function Thyroid antibodies	Thyroid Function New thyroid diagnosis: Hashimoto's Disease	Thyroid Function New thyroid diagnosis: Goiter	Thyroid Function New thyroid diagnosis: Thyroiditis	Thyroid Function New thyroid diagnosis: Thyroid Cancer	Thyroid Function New thyroid diagnosis: Thyroid Nodule	Thyroid Function New thyroid diagnosis: Other, specify	Thyroid Function New thyroid diagnosis: Other, specify text
Format/Codes	Numeric (yyyymmdd) 9999-99-99 = Unknown	Absent; present	___ (mU/L) Numeric 9.9 = Unknown	___ (nmol/L) Numeric 9.9 = Unknown	___ (nmol/L) Numeric 999 = Unknown	Numeric 9.99 = Unknown	___ (pmol/L) Numeric 99 = Unknown	Absent; Present	Hashimoto's Disease	Diffuse toxic goiter; Diffuse nontoxic goiter; nontoxic multinodular goiter; Toxic multinodular goiter	Acute thyroiditis; Subacute thyroiditis	Papillary cancer; Follicular cancer; Medullary cancer; Anaplastic cancer; Other	Hyperfunctioning thyroid nodule; Hypofunctioning nodule	Other, specify	Free-text
Table	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
8 Character Variable	THYLABDT	THYGLSZ	PLSERTSH	PLSERT3	PLSERT4	SERT3RU	PLSERFT4	THYROIAB	HASHIMDX	GOITERDX	THITISDX	THYCANDX	THYNODDX	THYOTHDX	THYRDXP
Comments/Notes															

Proposed 8 Ch

Data Element	Adrenal Function Date Performed	Adrenal Function 06-08(am) fasting serum cortisol	Adrenal function 24-hour urine cortisol	Gonadal Function Date performed	Gonadal Function men: Testis	Gonadal Function men: Plasma/Serum testosterone	Gonadal Function Men: Serum sex hormone binding globulin	Gonadal Function Men:Serum albumin	Gonadal Function Men: Serum bioactive testosterone	Gonadal Function Men: Serum free testosterone	Gonadal Function Women:Plasma/ Serum estradiol	Anterior Pituitary Function Date Performed	Anterior Pituitary Function Plasma Prolactin	Anterior Pituitary Function Plasma luteinizing hormone (LH)	Anterior Pituitary Function: Plasma follicular stimulating hormone (FSH)	Anterior Pituitary Function: Plasma insulin-like growth factor-1 (IGF-1) (Baseline)	Anterior Pituitary Function Women: Identify the time of menstrual cycle
Format/Codes	Numeric 9999-99-99 = Unknown	___(nmol/L) Numeric 999 = Unknown	___ (nmol/ 24 hours) Numeric 999 = Unknown	Numeric 9999-99-99 = Unknown	Normal size;small	___ (nmol/L) Numeric 99 = Unknown	___ (nmol/L) Numeric 99.9 = Unknown	___ (µmol/L) Numeric 999 = Unknown	___ (pmol/L) Numeric 99999 = Unknown	___ (pmol/L) Numeric 999 = Unknown	___ (pmol/L) Numeric 999 = Unknown	Numeric 9999-99-99 = Unknown	___ mmol/L Numeric 999 = Unknown	___ (IU/L) Numeric 999 = Unknown	___ (IU/L) Numeric 99.9 = Unknown	___ (kU/L) Numeric 9.99 = Unknown	Free text
Table	6	6	6	7	7	7	7	7	7	7	7	8	8	8	8	8	8
8 Character Variable	ADRFXNDT	FSTSECOR	24HURCOR	GNDFXNDT	TESTISSZ	PLSETSTO	SSEXHOBG	SERALBUM	SEBATSTO	SEFRTSTO	PLSEESTD	APTFXNDT	PLPROLAC	PLASMALH	PLSMFSH	PLSMIGF1	MENSTCYC
Comments/Notes																	

Proposed 8 Ch

Data Element	Posterior pituitary Function Date Performed	Posterior pituitary function Plasma copeptin	Posterior pituitary function fluid deprivation test with DDAVP	Sympathetic Nervous System Function Date Performed	Sympathetic Nervous System Function Plasma norepinephrine supine	Sympathetic Nervous System Function Plasma norepinephrine seated/standing	Renin-Aldosterone Axis Function Date Performed	Renin-Aldosterone Axis Function Plasma renin supine	Renin-Aldosterone Axis Function Plasma renin seated/standing	Renin-Aldosterone Axis Function Serum aldosterone supine	Renin-Aldosterone Axis Function Serum aldosterone seated/standing
Format/Codes	Numeric 9999-99-99 = Unknown	____(pmol/L) Numeric 99-99 = Unknown	positive; negative	Numeric 9999-99-99 = Unknown	____(nmol/L) Numeric 9-99 = Unknown	____(nmol/L) Numeric 9-99 = Unknown	Numeric 9999-99-99 = Unknown	____(µg/L/h) Numeric 9-9 = Unknown	____(µg/L/h) Numeric 9-9 = Unknown	____(pmol/L) Numeric 999 = Unknown	____(pmol/L) Numeric 999 = Unknown
Table	9	9	9	10	10	10	11	11	11	11	11
8 Character Variable	PPTFXNDT	PLCOPEPT	FLUDDAVP	SYMPNSDT	PLNEPISU	PLNEPISS	RAAXISDT	PLRENISU	PLRENISS	SRALDSUP	SERALDSS
Comments/Notes											