

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  
 FUNCTION BASIC DATA SET - FORM (Version 2.0)**

Date performed: YYYY/MM/DD  ENDMETDT  Unknown  TABLES 1, 2 and 3

**Endocrine & metabolic conditions diagnosed before spinal cord lesion** TABLE 1

**(collected once):**

None  Unknown (any endocrine disorder)

Diabetes mellitus  Type 1  Type 2  Unknown

Lipid values, if available, provide the most recent values prior to injury:  Unknown

Date YYYY/MM/DD  Unknown

Total cholesterol (TC) \_\_\_\_\_ mg/dL Triglycerides (TG) \_\_\_\_\_ mg/dL

HDL cholesterol \_\_\_\_\_ mg/dL LDL cholesterol \_\_\_\_\_ mg/dL

(TC, HDL or LDL cholesterol: mmol/L x 39 = mg/dL; TG: mmol/L x 89 = mg/dL)

Lipid disorder Specify diagnosis: \_\_\_\_\_  Unknown

Osteoporosis Method:  DXA  Other (e.g. CT, radiograph)  Unknown

Thyroid disease Specify diagnosis: \_\_\_\_\_  Unknown

Other, specify \_\_\_\_\_

**Endocrine & metabolic conditions diagnosed after the spinal cord lesion** TABLE 2

**within the last year:**

None  Unknown (any endocrine disorder)

Diabetes mellitus  Type 1  Type 2  Unknown

Lipid disorder Specify diagnosis: \_\_\_\_\_  Unknown

Osteoporosis Method:  DXA  Other (e.g. CT, radiograph)  Unknown

Thyroid disease Specify diagnosis: \_\_\_\_\_  Unknown

Adrenal disease Specify diagnosis: \_\_\_\_\_  Unknown

Gonadal disease Specify diagnosis: \_\_\_\_\_  Unknown

Pituitary disease Specify diagnosis: \_\_\_\_\_  Unknown

Other, specify \_\_\_\_\_

**Gonadal status (check appropriate stage):** MGONADST TABLE 3

Male:  Prepubertal  Pubertal  Adult  Unknown

Female:  Prepubertal  Pubertal  Adult  Adult Menopausal  Unknown

Adult Postmenopausal FGONADST  Unknown

**Height (or length) and Weight:**

Height (or length) HEIGHT \_\_\_\_\_ m      Weight WEIGHT \_\_\_\_\_ kg  Unknown

**Fasting serum lipid profile within the last year:**

During anti-lipid therapy:  Yes  No ANTILIPD TRIGLYCR  Unknown

Total cholesterol (TC) TOTLCHOL \_\_\_\_\_ mg/dL      Triglycerides (TG) \_\_\_\_\_ mg/dL

HDL cholesterol HDLCHOL \_\_\_\_\_ mg/dL      LDL cholesterol LDLCHOL \_\_\_\_\_ mg/dL

(TC, HDL or LDL cholesterol: mmol/L x 39 = mg/dL; TG: mmol/L x 89 = mg/dL)

**How often do you have a drink containing alcohol?**

Never       Monthly or less       2-4 times a month       2-3 times a week

4 or more times a week       Unknown ALCOHFRQ

**How often do you have six or more drinks on one occasion?**

Never       Less than monthly       Monthly       Weekly       Daily or almost daily

Unknown ALC6+1OC

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**Proposed 8 Character Variables:**

<b>Data Element</b>	Site	Subject	Date performed	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Diabetes Mellitus and Type	Date of most recent Lipid Profile values prior to injury	Lipid Profile most recent values prior to injury: Total cholesterol	Lipid Profile most recent values prior to injury: Triglycerides	Lipid Profile most recent values prior to injury: HDL cholesterol	Lipid Profile most recent values prior to injury: LDL cholesterol	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Lipid Disorder	Endocrine and Metabolic conditions present before spinal cord lesion- Lipid Disorder, Specify	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Osteoporosis and Diagnosis Method
<b>Format/ Codes</b>			Numeric (yyyymmdd) 9999-99-99 = Unknown	Yes, Type 1; Yes, Type 2; No (Default code); Unknown	Numeric (yyyymmdd) 9999-99-99 = Unknown	____(mg/dL)	____(mg/dL)	____(mg/dL)	____(mg/dL)	Yes; No (Default code); Unknown	Free text	Yes, Dexa; Yes, Other; No (Default code); Unknown
<b>Table</b>	1, 2, and 3	1, 2, and 3	1, 2, and 3	1	1	3	3	3	3	1	1	1
<b>8 Character Variable</b>	SITE	SUBJECT	ENDMETDT	DIABTYHX	LIPDHXDT	TOTCHLHX	TRIGLYHX	HDLCHLHX	LDLCHLHX	LIPDISHX	LIPDHXSP	OSTEOPHX
<b>Comments/ Notes</b>	<b>key</b>	<b>key</b>		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".						If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".

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**Proposed 8 Ch**

<b>Data Element</b>	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Thyroid Disease	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Thyroid Disease, Specify	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Other	Endocrine and Metabolic conditions diagnosed before spinal cord lesion- Other, Specify	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Diabetes Mellitus and Type	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Lipid Disorder	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Lipid Disorder, Specify	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Osteoporosis and Diagnosis Method	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Thyroid Disease	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Thyroid Disease, Specify	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Adrenal Disease
<b>Format/ Codes</b>	Yes; No (Default code); Unknown	Free text	Yes; No (Default code); Unknown	Free text	Yes, Type 1; Yes, Type 2; No (Default code); Unknown	Yes; No (Default code); Unknown	Free text	Yes, Dexa; Yes, Other; No (Default code); Unknown	Yes; No (Default code); Unknown	Free text	Yes; No (Default code); Unknown
<b>Table</b>	1	1	1	1	2	2	2	2	2	2	2
<b>8 Character Variable</b>	THYROIHX	THYRHXSP	OTHENDHX	OTHEHXSP	DIABTYPE	LIPIDDIS	LIPIDDSP	OSTEOPOR	THYROID	THYROISP	ADRENAL
<b>Comments/ Notes</b>	If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".	If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".	If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".

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<b>Data Element</b>	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Adrenal Disease, Specify	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Gonadal Disease	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Gonadal Disease, Specify	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Pituitary Disease	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Pituitary Disease, Specify	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Other	Endocrine and Metabolic conditions diagnosed after spinal cord lesion within the last year- Other, Specify	Male Gonadal Status	Female Gonadal Status	Body mass index: Height	Body mass index: Weight	Fasting Serum Lipid Profile within the last year: During anti-lipid therapy?
<b>Format/ Codes</b>	Free text	Yes; No (Default code); Unknown	Free text	Yes; No (Default code); Unknown	Free text	Yes; No (Default code); Unknown	Free text	Prepubertal; Pubertal; Adult	Prepubertal; Pubertal; Adult; Menopausal; Postmenopausal	____(m)	____(kg)	Yes; No (Default code); Unknown
<b>Table</b>	2	2	2	2	2	2	2	3	3	3	3	3
<b>8 Character Variable</b>	ADRENLSP	GONADAL	GONADLSP	PITUITAR	PITUITSP	OTHENDMT	OTHENDSP	MGONADST	FGONADST	HEIGHT	WEIGHT	ANTILIPD
<b>Comments/ Notes</b>		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		Data element should be checked against Gender. Question should be blank for Females.	Data element should be checked against Gender. Question should be blank for Males.			

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<b>Data Element</b>	Fasting Serum Lipid Profile within the last year: Total cholesterol	Fasting Serum Lipid Profile within the last year: Triglycerides	Fasting Serum Lipid Profile within the last year: HDL cholesterol	Fasting Serum Lipid Profile within the last year: LDL cholesterol	How often do you have a drink containing alcohol?	How often do you have six or more drinks on more than one occasion?
<b>Format/ Codes</b>	____(mg/dL)	____(mg/dL)	____(mg/dL)	____(mg/dL)	Never; Monthly or less; 2-4 times a month; 2-3 times a week; 4 or more times a week; Unknown	Never; Less than monthly; Monthly; Weekly; Daily or almost daily; Unknown
<b>Table</b>	3	3	3	3	3	3
<b>8 Character Variable</b>	TOTLCHOL	TRIGLYCR	HDLCHOL	LDCCHOL	ALCOHFRQ	ALC6+1OC
<b>Comments/ Notes</b>						