

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 PAIN BASIC DATA SET

DATA COLLECTION FORM – Version 2.0

Date of data collection: YYYY/MM/DD

PAINDT

Table #1

Have you had any pain during the last seven days including today:

No Yes

PAIN7D

If yes:

Please note that the time period during the last week applies to all pain interference questions.

In general, how much has pain interfered with your day-to-day activities in the last week?

No interference 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Extreme interference

PNDAYACT

In general, how much has pain interfered with your overall mood in the last week?

No interference 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Extreme interference

PNMOOD

In general, how much has pain interfered with your ability to get a good night's sleep?

No interference 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Extreme interference

PNSLEEP

How many different pain problems do you have?

1; 2; 3; 4; ≥ 5

PNPROBNO

Please describe your three worst pain problems:

Worst pain problem:

PNPROB

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain Intensity and duration of pain Treatment of pain
Head PNHEADR PNHEADM PNHEADL				Type of pain (check one): Nociceptive <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other Neuropathic <input type="checkbox"/> At-level SCI <input type="checkbox"/> Below-level SCI <input type="checkbox"/> Other <input type="checkbox"/> Other <input type="checkbox"/> Unknown Intensity and duration of pain: Average pain intensity in the last week: 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10 PNINTNST Date of onset: YYYY/MM/DD PNONSTDT Are you using or receiving any <u>treatment</u> for your pain problem: <input type="checkbox"/> No <input type="checkbox"/> Yes PNTX
Neck/shoulders throat PNTHROAR PNTHROAM PNTHROAL neck PNNECKR PNNECKM PNNECKL shoulder PNSHOULR PNSHOULM PNSHOULL				
Arms/hands upper arm PNUPARMR PNUPARMM PNUPARML elbow PNELBOWR PNELBOWM PNELBOWL forearm PNFRARMR PNFRARMM PNFRARML wrist PNWRISTR PNWRISTM PNWRISTL hand/fingers PNHANDR PNHANDM PNHANDL				
Frontal torso/genitals chest PNCHESTR PNCHESTM PNCHESTL abdomen PNABDOMR PNABDOMM PNABDOML pelvis/genitalia PNPELVSR PNPELVSM PNPELVSL				
Back upper back PNUPBCKR PNUPBCKM PNUPBCKL lower back PNLWBCKR PNLWBCKM PNLWBCKL				
Buttocks/hips buttocks PNBUTTOR PNBUTTOL hip PNHIPR PNHIPL anus PNANUSM				
Upper leg/thigh PNUPLEGR PNUPLEGL				
Lower legs/feet knee PNKNEER PNKNEEL shin PNSHINR PNSHINL calf PNCALFR PNCALFL ankle PNANKLER PNANKLEL foot/toes PNFOOTR PNFOOTL				

Second worst pain problem:

Same as page 2

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain Intensity and duration of pain Treatment of pain	
Head				Type of pain (check one): Nociceptive <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other Neuropathic <input type="checkbox"/> At-level SCI <input type="checkbox"/> Below-level SCI <input type="checkbox"/> Other <input type="checkbox"/> Other <input type="checkbox"/> Unknown	
Neck/shoulders throat neck shoulder					
Arms/hands upper arm elbow forearm wrist hand/fingers					
Frontal torso/genitals chest abdomen pelvis/genitalia					
Back upper back lower back					
Buttocks/hips buttocks hip anus					
Upper leg/thigh					
Lower legs/feet knee shin calf ankle foot/toes					
					Intensity and duration of pain: Average pain intensity in the last week: 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10
					Date of onset: YYYY/MM/DD
				Are you using or receiving any <u>treatment</u> for your pain problem: <input type="checkbox"/> No <input type="checkbox"/> Yes	

Same as page 15

Third worst pain problem:

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain Intensity and duration of pain Treatment of pain
Head				Type of pain (check one): Nociceptive <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other Neuropathic <input type="checkbox"/> At-level SCI <input type="checkbox"/> Below-level SCI <input type="checkbox"/> Other <input type="checkbox"/> Other <input type="checkbox"/> Unknown Intensity and duration of pain: Average pain intensity in the last week: 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10 Date of onset: YYYY/MM/DD Are you using or receiving any <u>treatment</u> for your pain problem: <input type="checkbox"/> No <input type="checkbox"/> Yes
Neck/shoulders				
throat				
neck				
shoulder				
Arms/hands				
upper arm				
elbow				
forearm				
wrist				
hand/fingers				
Frontal torso/genitals				
chest				
abdomen				
pelvis/genitalia				
Back				
upper back				
lower back				
Buttocks/hips				
buttocks				
hip				
anus				
Upper leg/thigh				
Lower legs/feet				
knee				
shin				
calf				
ankle				
foot/toes				

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 Table #1				
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Have you had any pain during the last seven days including today:	If yes: In general, how much has pain interfered with your day-to-day activities in the last week?	If yes: In general, how much has pain interfered with your overall mood in the last week?	If yes: In general, how much has pain interfered with your ability to get a good night's sleep?	How many different pain problems do you have?
						0 No interference; 1; 2; 3; 4 ; 5; 6; 7; 8; 9; 10 Extreme interference;	0 No interference; 1; 2; 3; 4 ; 5; 6; 7; 8; 9; 10 Extreme interference;	0 No interference; 1; 2; 3; 4 ; 5; 6; 7; 8; 9; 10 Extreme interference;	1; 2; 3; 4; 5 or more
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst	No; Yes				
8 Character Variable Table #	SITE 1,2	SUBJECT 1,2	PAINDT 1,2	PNPROB 2	PAIN7D 1	PNDAYACT 1	PNMOOD 1	PNSLEEP 1	PNPROBNO 1
Comments/Suggested Revisions	Key	Key	Key	Key					

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 Table #2					
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Head - Right	Pain locations/sites Head - Midline	Pain locations/sites Head - Left	Pain locations/sites Throat - Right	Pain locations/sites Throat - Midline	Pain locations/sites Throat - Left
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst						
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNHEADR	PNHEADM	PNHEADL	PNTHROAR	PNTHROAM	PNTHROAL
Table #	1,2	1,2	1,2	2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key						

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Contd.					
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Neck - Right	Pain locations/sites Neck - Midline	Pain locations/sites Neck - Left	Pain locations/sites Shoulder - Right	Pain locations/sites Shoulder - Left	Pain locations/sites Upper arm - Right
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst						
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNNECKR	PNNECKM	PNNECKL	PNSHOULR	PNSHOULL	PNUPARMR
Table #	1,2	1,2	1,2	2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key						

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Contd.					
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Upper arm - Left	Pain locations/sites Elbow - Right	Pain locations/sites Elbow - Left	Pain locations/sites Forearm - Right	Pain locations/sites Forearm - Left	Pain locations/sites Wrist - Right
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst						
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNUPARML	PNELBOWR	PNELBOWL	PNFRARMR	PNFRARML	PNWRISTR
Table #	1,2	1,2	1,2	2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key						

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Contd.				
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Wrist - Left	Pain locations/sites Hand/fingers - Right	Pain locations/sites Hand/fingers - Left	Pain locations/sites Chest - Right	Pain locations/sites Chest - Midline
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst					
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNWRISTL	PNHANDR	PNHANDL	PNCHESTR	PNCHESTM
Table #	1,2	1,2	1,2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key					

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Contd.					
Data Element	Site	Subject	Date of data collection	Please describe your <u>three worst pain problems</u> :	Pain locations/sites Chest - Left	Pain locations/sites Abdomen - Right	Pain locations/sites Abdomen - Midline	Pain locations/sites Abdomen - Left	Pain locations/sites Pelvis/genitalia - Right	Pain locations/sites Pelvis/genitalia - Midline
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst						
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNCHESTL	PNABDOMR	PNABDOMM	PNABDOML	PNPELVSR	PNPELVSM
Table #	1,2	1,2	1,2	2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key						

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Contd.					
Data Element	Site	Subject	Date of data collection	Please describe your <u>three worst pain problems</u> :	Pain locations/sites Pelvis/genitalia - Left	Pain locations/sites Upper back - Right	Pain locations/sites Upper back - Midline	Pain locations/sites Upper back - Left	Pain locations/sites Lower back - Right	Pain locations/sites Lower back - Midline
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst						
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNPELVSL	PNUPBCKR	PNUPBCKM	PNUPBCKL	PNLWBCKR	PNLWBCKM
Table #	1,2	1,2	1,2	2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key						

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Contd.					
Data Element	Site	Subject	Date of data collection	Please describe your <u>three worst pain problems</u> :	Pain locations/sites Lower back - Left	Pain locations/sites Buttocks - Right	Pain locations/sites Buttocks - Left	Pain locations/sites Hip - Right	Pain locations/sites Hip - Left	Pain locations/sites Anus
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst						
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNLWBCKL	PNBUTTOR	PNBUTTOL	PNHIPR	PNHIPL	PNANUSM
Table #	1,2	1,2	1,2	2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key						

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Cont.				
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Upper legs/thighs - Right	Pain locations/sites Upper legs/ thighs - Left	Pain locations/sites Knee - Right	Pain locations/sites Knee - Left	Pain locations/sites Shin - Right
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst					
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNUPLEGR	PNUPLEGL	PNKNEER	PNKNEEL	PNSHINR
Table #	1,2	1,2	1,2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key					

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Cont.				
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Shin - Left	Pain locations/sites Calf - Right	Pain locations/sites Calf - Left	Pain locations/sites Ankle - Right	Pain locations/sites Ankle - Left
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst					
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNSHINL	PNCALFR	PNCALFL	PNANKLER	PNANKLEL
Table #	1,2	1,2	1,2	2	2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key					

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Cont.		
Data Element	Site	Subject	Date of data collection	Please describe your <u>three</u> worst pain problems:	Pain locations/sites Foot/toes - Right	Pain locations/sites Foot/toes - Left	Pain Type
				Worst; Second Worst; Third Worst			Nociceptive-Musculoskeletal; Nociceptive-Visceral; Nociceptive-Other; Neuropathic-At-level SCI; Neuropathic- Below-level SCI; Neuropathic-Other; Other pain type (not nociceptive or neuropathic) Unknown
Format/ Codes			YYYY/MM/DD				
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNFOOTR	PNFOOTL	PNTYP
Table #	1,2	1,2	1,2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key			

Proposed 8 Character Variables:					PAIN BASIC DATA SET VERSION 2.0 TABLE #2, Cont.		
Data Element	Site	Subject	Date of data collection	Please describe your <u>three worst pain problems</u> :	Average pain intensity in the last week:	Date of onset:	Are you using or receiving any <u>treatment</u> for your pain problem:
					0 no pain; 1; 2; 3; 4 ; 5; 6; 7; 8; 9; 10 pain as bad as you can imagine;		
Format/ Codes			YYYY/MM/DD	Worst; Second Worst; Third Worst		YYYY/MM/DD	No; Yes
8 Character Variable	SITE	SUBJECT	PAINDT	PNPROB	PNINTNST	PNONSTDT	PNTX
Table #	1,2	1,2	1,2	2	2	2	2
Comments/Suggested Revisions	Key	Key	Key	Key			