



A clinical guideline for the assessment of pain for individuals with spinal cord injury.



#### **TOOLKIT FOR PAIN ASSESSMENT**

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# 01

# **BACKGROUND**

## **About RHSCIR**

The RICK HANSEN SPINAL CORD INJURY REGISTRY (RHSCIR) is a pan-Canadian prospective observational registry located at 31 major Canadian acute care and rehabilitation facilities. Across Canada, RHSCIR is collecting comprehensive SCI data for the purpose of improving spinal cord injury (SCI) care and clinical outcomes. Using standardized research protocols and data collection forms, RHSCIR tracks the experiences and outcomes of people with traumatic SCI during their journey from acute care to rehabilitation to community reintegration. Details about participants' spinal cord injuries including extent of injury and level of paralysis, recovery, and success of various treatments are among the data recorded.

The data collected in RHSCIR contains powerful information that will help track the effectiveness of specific treatments, practices or programs for improving functional outcomes and quality of life after SCI. RHSCIR promotes, encourages and supports the pursuit of excellence in all areas of SCI health care management.

This network of 31 facilities has a new goal of standardizing the basic assessment of pain across facilities in their patients who have sustained a SCI. This minimum amount of standardized pain assessment information is not meant to replace current clinical practice, but is being standardized and will be added to RHSCIR in order to support tracking and reporting of this important information across the facilities. The ultimate goals are to support the use of this important



# 02

# WHY IS THIS INFORMATION IMPORTANT?

The majority of people with a spinal cord injury (SCI) will experience pain during their life time. Pain negatively affects health-related quality of life, social participation and every day function (e.g., sleep, exercise and employment) as well as psychological well-being. Pain is likely to increase over time in 47% of persons with SCI, and decrease in only 7% (1). Given the prevalence and negative effects of pain, it is important to gather information to better understand how to manage it. This information can then be used to identify/develop needed resources (e.g., staffing, intervention programs). In addition, such information can serve as the basis for patient education as part of learning about self-management and directing care.

All the information collected will be added to RHSCIR providing validation and support of evidence-based practice. Much of this information is aligned with the International SCI Pain Basic Data set (Version 2.0), which is an important source of expert-derived recommendations developed by experts in SCI-related pain.

# Benefits to Clinicians and Patients

### Collection and reporting of this data can benefit clinicians and patients by:

- > Provides information on the more common pain types that are most troublesome to patients
- Makes you aware of what to ask for and what to look for in new patients
- Contributes to the discipline by furthering understanding of:
  - Risk factors for worst pain experienced.
  - Average pain severity for worst pain experienced.
  - The most common location of worst pain experienced.
  - Impact of pain on daily functioning.
  - Frequency with which different treatment options are used.
  - · Level of satisfaction with treatment strategies.

Should a patient ask why the information is being collected, it may be useful to respond in a similar manner by highlighting some key points (e.g. "As a patient, members of your health care team will be asking you many different questions about pain at multiple time points after your injury. Since there are a variety of types of pain caused by different things that can occur after a spinal cord injury, these questions are important as they will assist your health care team in determining how best to treat your specific pain.)

As clinicians, you will be collecting pain data from your patients throughout their stay at your facility. Section 3 outlines the minimum amount of pain assessment data recommended to collect (i.e. Clinical Data Collection Forms). Collecting this data consistently on your patients will allow you to objectively track and analyze any changes and help modify, enhance and direct future care and treatment plans. In addition, community follow-up interviews with the patient will be completed by a RHSCIR coordinator or designate.

# Benefits to the Program

In order to optimize the efficiency and outcome of pain management in individuals with SCI on your program, it is important to collect, analyze, and review the pain assessment information in a standardized manner. The collection of this standardized pain assessment data by both clinicians and RHSCIR staff at your facility, will allow you to access the type of data outlined below that will support both program level management and evaluation as well as give you the ability to compare your program with similar programs across Canada.

#### Collection and reporting of this data can benefit your program by:

- Setting staffing levels, determining what type of staff are required (e.g., RN, OT, PT, research) and how many.
- Determining required equipment.
- Larger system planning.
- Providing metrics to support quality improvement initiatives.
- Providing comparisons to national data.
- Reporting metrics to program managers and facility administrators.
- Meeting requirements for the new Accreditation Canada SCI Acute Care and Rehabilitation Standards.
- > Providing insight into understanding and ensuring that inpatient programs are meeting the needs of patients (i.e. patient satisfaction), and setting the stage for life in the community.
- Identifying gaps in the community.

# What Happens Once I Collect the Data?

- > Providing invaluable data to RHSCIR: Once you collect the data, your facility's RHSCIR coordinator will abstract this information and input it along with any other relevant clinical information into the registry database. The national RHSCIR team has developed and implemented a number of practices to ensure patient confidentiality is maintained and strict privacy policies and procedures are adhered to.
- Providing a baseline for management of SCI across Canada: The de-identified data from your facility and other facilities participating from your site will be reported back on a quarterly basis and will provide information on the frequency of pain treatment (worst pain, general pain) including things like treatment type, satisfaction with pain management, pain interference, location, intensity, as well as the frequency, intensity and location of neuropathic pain, etc.

To access your site's data reports, visit Supporting Clinical Initiatives in SCI (SCI2) resource site at http://sci2.rickhanseninstitute.org. Please see your local RHSCIR coordinator, or designated representative, to receive this log in information.

You can also access the SCI<sup>2</sup> site by visiting www.rickhanseninstitute.org.

# 03

# RESOURCE REQUIREMENTS

Please take note of the following instructions to complete the Clinical Data Collection.

- Time
  - Estimated time required: 20 minutes
- S Equipment (if applicable)
  - Clinician Pain Assessment form
  - Pain assessment tool e.g., DN4, LANSS (optional)



# Clinical Data Collection Form

A version of this form you can insert into your chart is available at http://sci2.rickhanseninstitute.org.

Clinical Pain Assessment				ADDRESSOGRAPH						
Please complete this form	within 7 d	lays of ad	mission ar	nd 7 days prior to discharge from	facility.					
☐ Admission Assessment										
☐ Discharge Assessment										
~		. –		u an marriale of the data and in						
1. Date pain assessment of	1. Date pain assessment completed:									
			YYYY	MM DD						
2. Clinician Name/Signatu	ıre:									
3 Is participant receiving	any treat	ment for	nain? (e d	, medications, recreational drugs, phys	ical theranies psychological					
treatment, etc.)	,,		pann (c.g.	, medications, recreational arago, pm,	near arerapies, psychological					
☐ Yes										
□ No										
4. a) Has the participant I	had any n	ain in the	lact 7 day	s including today?						
	iau ally pe	ann nn the	iast / uay	s including today:						
☐ Yes										
□ No										
☐ Unknown										
		lama daa.		simput have2						
b) How many different				· <u> </u>						
		□ 3	□ 4	□ ≥5						
c) For participant's pair	n, please i	indicate w	orst pain	location and characteristics belo						
Pain Location/Sites:	Right	Midline	Left	Type of pain (check ONE only)	Date of Onset (Date this pain problem started)					
Head				Nociceptive	,					
Neck/shoulders				☐ Musculoskeletal	//					
throat				□ Visceral	YYYY/ MM/DD					
neck				□ Other	Enter as much of the date as is					
shoulder				Neuropathic	known.					
Arms/hands				□ At-level						
upper arm				□ Below-level						
elbow				□ Other						
forearm				Other (specify):						
wrist										
hand/fingers										
Frontal torso/genitals				□ Unknown  Which pain assessment tool w	as used?					
Frontal torso/genitals chest										
				Which pain assessment tool w	Symptoms and Signs (LANSS)					
chest				Which pain assessment tool w  □ Leeds Assessment of Neuropathic  □ Douleur Neuropathique en 4	Symptoms and Signs (LANSS) Questions (DN4)					
chest abdomen				Which pain assessment tool w  □ Leeds Assessment of Neuropathic  □ Douleur Neuropathique en 4	Symptoms and Signs (LANSS) Questions (DN4)					
chest abdomen pelvis/genitals				Which pain assessment tool w  Leeds Assessment of Neuropathic  Douleur Neuropathique en 4  Other (specify):	Symptoms and Signs (LANSS) Questions (DN4)					
chest abdomen pelvis/genitals Back				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None	Symptoms and Signs (LANSS) Questions (DN4)					
chest abdomen pelvis/genitals Back upper back				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity:	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals Back upper back lower back Buttocks/hips				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown  Pain Intensity: Average pain intensity in the las 0 No pain 1	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las 0 No pain 1 2	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus  Upper legs/thighs				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las 0 No pain 1 2 3	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus  Upper legs/thighs Lower legs/feet				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las 0 No pain 1 1 2 2 3 3	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus  Upper legs/thighs Lower legs/feet knee				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las 0 No pain 1 1 2 2 3 3 4 4	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus  Upper legs/thighs Lower legs/feet knee shin				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown  Pain Intensity:  Average pain intensity in the las 0 No pain 1 1 2 2 3 3 4 4 5 5	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus  Upper legs/thighs Lower legs/feet knee shin calf				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown  Pain Intensity: Average pain intensity in the las 0 No pain 1 1 2 3 1 4 5 6 6 7	Symptoms and Signs (LANSS)  Questions (DN4)					
chest abdomen pelvis/genitals  Back upper back lower back  Buttocks/hips buttocks hips anus  Upper legs/thighs Lower legs/feet knee shin calf ankle				Which pain assessment tool w Leeds Assessment of Neuropathic Douleur Neuropathique en 4 Other (specify): None Unknown Pain Intensity: Average pain intensity in the las 0 No pain 1 2 3 4 5 6 7 8	Symptoms and Signs (LANSS)  Questions (DN4)					

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# **INSTRUCTIONS**

PLEASE NOTE: This is not meant to replace existing practice at your site, but is the **minimum** amount of information required for a research study or good clinical practice.

# Timing of Assessment

**Admission:** A comprehensive Clinician Pain Assessment should be performed as soon as possible after admission, but within seven days at a minimum. If you are unable to complete the comprehensive assessment within seven days (e.g. the patient is too critically ill, or access is not possible due to surgery, etc.), please complete the pain assessment and data collection form as soon as possible.

**Discharge:** A comprehensive Clinician Pain Assessment should be performed within seven days prior to discharge. Ideally, please complete as close to discharge as possible.

## Step 1: Schedule the Comprehensive Clinician Pain Assessment

- Schedule the comprehensive Clinician Pain Assessment with the patient.
- > Inform the patient of this procedure and obtain verbal consent from the patient.

## Step 2: Collect Supplies

- Clinician Pain Assessment form.
- Pain assessment tool e.g. DN4, LANSS (optional).

Insert the date of assessment and your name on the form.

# Step 3: Review Patient Information

Review available information on the patient e.g. history, chart notes, clinician assessments to obtain background information about the patient and their pain.

## Step 4: Patient Interview

- Ask the patient the following questions, from the Clinical Pain Assessment form:
  - 3. Is the participant receiving any treatment for pain?
  - 4. Has the participant had any pain in the last 7 days including today?
- If the patient identifies the presence of pain, document their worst pain and complete the following sections on the form pertaining only to their worst pain:
  - Pain location/sites
  - Type of pain (nociceptive vs. neuropathic)
  - Date of onset
  - Which pain assessment tool was used (if any)
  - Pain intensity

# **DEFINITIONS OF SPINAL CORD PAIN TYPES**

## **NOCICEPTIVE PAIN TYPES**

Musculoskeletal: refers to pain occurring in a region where there is preserved sensation above, at or below the neurological level of injury and which is believed to be arising from musculoskeletal structures. The presence of this type of pain is suggested by pain descriptors such as dull or aching, pain related to movement, tenderness of musculoskeletal structures on palpation, response to anti-inflammatory or opioid medications and evidence of skeletal pathology on imaging consistent with the pain presentation. Examples include mechanical pain, spinal fractures, muscular injury, shoulder overuse syndromes and muscle spasm.

Visceral: refers to pain usually located in the thorax, abdomen, or pelvis and believed to be generated in visceral structures. The presence of this type of pain is suggested by characteristics such as dull, tender, or cramping and a relationship to visceral pathology or dysfunction (e.g. infection or obstruction). Examples include urinary tract infection, ureteric calculus and bowel impaction. Note: Failure to find evidence of visceral pathology or failure to respond to treatment directed at visceral pathology may indicate the presence of neuropathic pain.

Other: refers to nociceptive pains that may be present but do not fall into the musculoskeletal or visceral categories. Examples include pain associated with ulceration of the skin and headache.

## NEUROPATHIC PAIN TYPES

At-level: refers to neuropathic pain presenting in a segmental pattern. A necessary condition for this to occur is that there is a lesion or disease affecting the spinal cord or nerve roots. At-level neuropathic pain is perceived anywhere within the dermatome of the level of neurological injury and three dermatomes below this level. Atlevel neuropathic pain is often characterized as hot-burning, tingling, pricking, pins and needles, squeezing, cold, electric, or shooting. Sensory changes such as allodynia, hypoalgesia, or hyperalgesia within the pain distribution are often found.

Below-level: refers to neuropathic pain that is present more than three dermatomes below the dermatome of the neurological level of injury; it may be in addition be perceived up to the dermatome representing the neurological level of injury and the three dermatomes just below this. A necessary condition for this to occur is that there is a lesion or disease affecting the spinal cord and that the pain is believed to arise as a result of this damage. Belowlevel pain is often characterized as hot-burning, tingling, pricking, pins and needles, squeezing, cold, electric, or shooting; it usually has a regional distribution. Sensory changes such as allodynia, hypoalgesia, or hyperalgesia may be present.

Other: refers to neuropathic pains that are present above, at or below the neurological level of injury but are not directly related to the SCI. Examples include postherpetic neuralgia, pain associated with diabetic neuropathy, central post stroke pain, and compressive mononeuropathies.

Other pain: refers to pain that occurs when there is no identifiable noxious stimulus nor any detectable inflammation or damage to the nervous system responsible for the pain and the pain is thought to be unrelated to the underlying SCI, both temporally and mechanistically. It is unclear what causes the pain to develop or persist. Examples include Complex Regional Pain Syndrome type I, interstitial cystitis pain, irritable bowel syndrome pain and fibromyalgia.

Note: Source of definitions from the International Spinal Cord Injury Pain Basic Data Set (v2.0)(2).



# TRAINING RESOURCES

# Training Resources

The International SCI Pain Basic Data Set version 2.0 has Training Cases to help you understand the types of pain patients express and how to chart it: http://www.iscos.org.uk/sitefiles/2013%20 06%2011 International%20SCI%20Pain%20Basic%20Data%20Set Version%202%200.pdf.

The National Pain Centre produces the Canadian Guideline for Safe and Effective Use of Opioids for Chronic Non-Cancer Pain. http://nationalpaincentre.mcmaster.ca/opioid/.

Registered Nurses Association of Ontario has the Best Practice Guideline on the Assessment and Management of Pain. http://rnao.ca/bpg/guidelines/assessment-and-management-pain.

The SCIRE project has evidence based guidelines for the assessment and management of pain in spinal cord injury: http://www.scireproject.com/rehabilitation-evidence/pain-management.

Questions or comments regarding this guideline? Email clinical@rickhanseninstitute.org.

# REFERENCES & ADDITIONAL RESOURCES

# References

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# Additional Resources

Pain BC has many resources for health care providers and their patients: http://www.painbc.ca/resources-for-health-care-providers.

Pain resource centre, developed by the Canadian Pain Coalition is available here: http://prc.canadianpaincoalition.ca/en/.

Other resources are available on the SCI<sup>2</sup> site, including examples of assessment and charting forms.

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# OTHER RHSCIR PAIN DATA -NOT COMPLETED BY CLINICIAN

In addition to the clinically collected data outlined in this toolkit, there will be additional patient selfreported data collected by your facility's RHSCIR team as outlined in the following pages. In addition, there will also be data collected by RHSCIR from those participants who consent to the community follow-up in RHSCIR. This includes subjective information on neuropathic pain, pain treatment(s), and pain interference and is collected upon discharge to the community and during subsequent RHSCIR community follow-up interviews (data collection points). This portion of data does not require any clinician time, but is collected by registry personnel and will also be made available to your facility.

These questions are collected by the RHSCIR team when the participant is discharged into the community (i.e. home, extended care, etc.) as well as at one year, two years, five years, and then every five years from their date of injury.

	n Questioi												
	e questions a daily living.								now it ma	y inte	rfere with		
1.						-		_					
		•	urrently using or receiving any treatment for a pain problem?										
		No	Yes (e.g., medications, recreational drugs, physical therapies, psychological treatment, etc.)										
		Unknown											
	b) If Yes, W	/hat treatmo	ents do	you use t	to manag	je your p	ain? (che	ck ALL th	at apply)				
		Compleme	ntary (e.	g., biofee	dback, ac	upuncture	, hypnosi	s)					
			Medical and procedural or neuromodulation (e.g., nerve blocks, injections, implanted stimulators, intrathecal pump, TENS)										
		Non-prescr	Non-prescription medications (e.g., non-prescription pain killers such as Tylenol® )										
		Non-traditi	onal (e.g	g., naturop	pathy, hor	meopathy,	herbal re	emedies)					
			Psychotherapeutic (e.g., psychotherapy, cognitive behavioural therapy, relaxation, stress management, psycho-education, support group)										
		Physical th	Physical therapies (e.g., physiotherapy, massage, chiropractic)										
		Recreation	al drugs	(e.g., mai	rijuana)								
		Prescriptio	n medica	ntions (e.g	., morphi	ne, codein	ie)						
		Other (spe	cify):										
2.	Overall, hov	v satisfied a	re you v	with the r	managen	nent of yo	our pain?	?					
0	1 2	3	4	5	6	7	8	9	10		Unknown		
Not a	at all satisfied								<b>►</b> Comp	oletely	satisfied		
3.	a) Have you	had anv pa	in durin	a the las	t 7 davs.	includin	g todav?						
		Yes		•	, ,		,						
		No (skip to	questio	n 4)									
	b) If YES, in	n the LAST V	VEEK:										
	i) In	general, ho	w much	n has paiı	n interfe	red with	your day	to day a	ctivities	in the	last week?		
0	1 2		4	5	6	7	8	9	10				
No in	nterference—							<b></b>	Extre	eme in	terference		
		n general, h											
0	1 2		4	5	6	7	8	9	10		Unknown		
No in	nterference—							<b></b>	Extre	me in	terference		
	iii) In	general, ho	w much	n has paiı	n interfe	red with	your abil	ity to ge	t a good	night's	s sleep?		
0	1 2	3	4	5	6	7	8	9	10		Unknown		
No in	terference —							<b></b>	Extre	me inte	erference		

4. a) Since your injury, have you experienced neuropathic pain? (Pain that is often ongoing and intense that occurs spontaneously or by light touching and is characterized by feelings of burning, shooting, tingling, etc.)													
			Everyday										
			Few times a	Few times a week									
			Few times a month										
			Few times a	Few times a year									
			Once a year										
			Never (Pain information complete, no other questions answered) Don't know (Pain information complete, no other questions answered)										
b) Location(s) of your neuropathic pain (check ALL that apply):													
			Head										
			Neck and/or	shoulder	S								
			Arms and/or	hands									
			Torso (chest, abdomen, pelvis, and/or genitals)										
			Back (upper and/or lower back)										
			Hips, buttock	Hips, buttocks, and/or anus									
			Upper legs/th	nighs									
			Lower legs or	feet									
	c) Averag	je pa	ain intensity	of your	neurop	athic pai	n in the p	past wee	k:				
	1	2	2	4	-		7	0	0	10	□ Unknown		
0 No pa	1 ain	2	3	4	5	6	7	8	9	10 Pain a	as bad as you can		
NO Pa	alli <u> </u>								<b></b>	imagi			
	d) Have y	ou r	received som	e form	of treat	ment for	the neu	ropathic	pain?				
			Yes										
			No										
			Unknown										
e) When you had neuropathic pain, to what extent did it limit your activities?													
			Not at all										
			Very little										
			To some extent										
			To a great extent										
			Completely										
			Don't know										



### **Rick Hansen Institute**

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