



COMMUNITY QUESTIONNAIRE

Community Follow-Up

INTERVIEW/MAIL

CQ-CFU

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This questionnaire asks your opinion about how your spinal cord injury may be affecting you on a day-to-day basis.

This questionnaire has been written for a large group of people — all who have a spinal cord injury. Certain questions may not apply to your personal situation, but as every injury affects a person differently, all questions are included in this questionnaire. If you come across a question that you think does not apply to you, please answer it the best that you can.

Sociodemographics Plus

1. What is your current relationship status? (check ONE response only)

- ☐ Single
- ☐ Married
- ☐ Divorced
- ☐ Separated
- ☐ Widowed
- ☐ Common Law
- ☐ Unknown

2. What is your current body weight?

Round up to the
nearest whole
number.

☐ lbs

☐ kg

3. a) Currently, are you employed in a paid working setting? (if you are currently employed but on long term disability, please choose 'Yes')

- ☐ Yes
- ☐ No (skip to question 4b on page 2)

Paid Work

b) If Yes, which one of the following best describes your paid work? (check ONE response only)

- ☐ Working → **Full-time or part-time?**
 - ☐ **Full-time** (includes persons who usually worked 30 hours or more per week, at their main or only job)
 - ☐ **Part-time** (includes persons who usually worked less than 30 hours per week, at their main or only job)
- ☐ On-the-job training (paid)
- ☐ Sheltered workshop (e.g., paid work in a modified setting that may include increased supervision, physical assistance, modified tasks, etc.)
- ☐ On long-term disability

Sociodemographics Plus - continued**4. a) What is your paid occupation?**

- ☐ Executive, administrative and managerial (includes self-employment; e.g., managers, department heads, government officers, accountants, financial managers, personnel specialists etc.)
- ☐ Professional specialty (e.g., physician, lawyer, engineer, registered nurse, architect, computer systems analyst etc.)
- ☐ Technicians and related support (e.g., pilot, lab technician, dental hygienist, licensed practical nurse etc.)
- ☐ Sales
- ☐ Administrative support including clerical
- ☐ Private household (e.g., nanny, caregiver, house cleaner, gardener, caretaker etc.)
- ☐ Protective services (e.g., police, firefighter, security guard, etc.)
- ☐ Service, except protective and household (e.g., bartender, concierge, server, hospital orderly, janitor, cook, hair stylist etc.)
- ☐ Farming, forestry and fishing
- ☐ Precision, production, craft and repair (e.g., electrician, carpenter, mechanic, plumber, painter, machinist, baker etc.)
- ☐ Machine operators, assemblers, and inspectors (e.g., welder, typesetter, factory machine operator etc.)
- ☐ Transportation and material moving (e.g., truck driver, bus driver, train conductor, excavators, crane operator etc.)
- ☐ Handlers, equipment cleaners, helpers and labourers (e.g., construction labourer, garbage collector, store shelf-stocker, factory worker etc.)
- ☐ Military occupations
- ☐ Not applicable
- ☐ Unknown

Unpaid Work

b) If No, which one of the following best describes your unpaid work? (check ONE response only. Does not include attendance to medical appointments or therapies)

- ☐ Homemaker
- ☐ On-the-job training (unpaid)
- ☐ Retired
- ☐ Student
- ☐ Unemployed
- ☐ Other (specify): _____ (e.g., volunteer work, etc.)
- ☐ Unknown

Sociodemographics Plus - continued

5. a) Currently, what is your approximate total, annual household income? (annual income of the WHOLE household BEFORE taxes, including subsidies, grants or other supplemental income from any source)

- ☐ Under 10,000
- ☐ 10,000 - 19,999
- ☐ 20,000 - 29,999
- ☐ 30,000 - 39,999
- ☐ 40,000 - 49,999
- ☐ 50,000 - 59,999
- ☐ 60,000 - 69,999
- ☐ 70,000 - 79,999
- ☐ 80,000 - 89,999
- ☐ 90,000 - 99,999
- ☐ 100,000 +
- ☐ Unknown

b) How many people are in your household? _____

6. What, if any, compensation are you receiving as a result of your spinal cord injury? (check ALL that apply)

- ☐ Worker's insurance (e.g., Worker's Compensation Board (WCB) or similar)
- ☐ Other disability insurance (e.g., Federal CPP Disability, Provincial Persons with Disability (PWD), private short or long term disability)
- ☐ Vehicle insurance (government or private)
- ☐ Other insurance (i.e., Employment Insurance, private insurance including payment protection plans, life insurance, accidental death and dismemberment, Veterans Benefits or Veterans Affairs Canada Benefits)
- ☐ Other compensation (specify): _____
- ☐ Unknown compensation type
- ☐ None

Sociodemographics Plus - continued**7. a) What type of setting do you currently live in:**

- ☐ Private residence (includes house, condominium, mobile home, apartment, or houseboat)
- ☐ Assisted living residence (semi-independent housing, a middle option between home support and residential care)
- ☐ Hotel/motel (includes short or long-term living arrangements, single room occupancy, etc.)
- ☐ Homeless (includes cave, car, tent, street, etc.)
- ☐ Other (specify): _____
- ☐ Group living arrangement (includes transitional living facility or any residence shared by non-family members)
- ☐ Nursing home/Long-term care within a hospital setting (includes skilled nursing facilities and institutions providing long-term, custodial, chronic disease care, and extended care)
- ☐ Correctional institute (includes prison, penitentiary, jail, correctional centre, etc.)

b) Indicate who you live with: (choose ALL that apply)

- ☐ Partner/spouse
- ☐ Family member
- ☐ Non-family, unpaid (e.g., roommate)
- ☐ Paid attendant
- ☐ Alone
- ☐ Other (specify): _____
- ☐ Unknown

c) Are you receiving health services at home?

(e.g., homecare/support, home OT, etc.)

- ☐ Yes
- ☐ No
- ☐ Unknown

→ **Skip to Question 8**

8. a) What is your smoking/vaping (nicotine) history: (Check ALL that apply; Note – this does not include marijuana use)

- ☐ Current smoker
- ☐ Former smoker
- ☐ Never smoked (skip to Question 9)
- ☐ Current vaper
- ☐ Former vaper
- ☐ Never vaped (skip to Question 9)
- ☐ Unknown (skip to Question 9)

b) If a former or current smoker/vaper, how many total years have you smoked or vaped? (please estimate if exact number unknown)

_____ Years smoked

☐ Unknown

_____ Years vaped

Sociodemographics Plus - continued

c) If a former or current smoker, on average how many (cigarettes/cigars/pipes) do (did) you smoke on a daily basis? (Note: There are normally 20 cigarettes in a pack. Check

ALL that apply. If less than one per day please enter 0)

_____ Cigarettes

_____ Cigars

_____ Pipe Bowls

☐ Unknown

9. a) How often do you have a drink containing alcohol?

☐ Never (skip to Question 10)

☐ Monthly or less

☐ 2-4 times/ month

☐ 2-3 times/ week

☐ 4 or more times/ week

☐ Unknown

b) How many alcoholic drinks do you have on a typical day when you are drinking?

☐ 1 or 2

☐ 3 or 4

☐ 5 or 6

☐ 7, 8, or 9

☐ 10 or more

☐ Unknown

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

☐ Never

☐ Less than monthly

☐ Monthly

☐ Weekly

☐ Daily or almost daily

☐ Unknown

10. Since your injury, have you used cannabis/marijuana for MEDICAL reasons?

(This includes use for any medical purpose even if not prescribed by a physician) (if this is your first community follow-up survey, please consider the time since you were discharged from your initial inpatient hospital stay [acute care and/or rehab])

☐ Yes

☐ No

☐ Unknown

11. a) Since your injury, have you used prescribed medications, street drugs or cannabis/marijuana for NON-MEDICAL reasons? (if this is your first community follow-up survey, please consider the time since you were discharged from your initial inpatient hospital stay [acute care and/or rehab])

- ☐ Yes
- ☐ No (skip to Pain Questionnaire)
- ☐ Unknown (skip to Pain Questionnaire)

b) If Yes, check ALL that apply:

- ☐ Cocaine
- ☐ Cannabis/marijuana
- ☐ Hallucinogens
- ☐ Heroin
- ☐ Opiates
- ☐ Speed/stimulants
- ☐ Medications prescribed for you
- ☐ Medications prescribed for someone else
- ☐ Other or unknown type

Pain Questionnaire

These questions ask your opinion about any pain you may be experiencing and how it may interfere with your daily living. Also, you will be asked to describe what you do to manage it.

1. a) Are you currently using or receiving any treatment for a pain problem?

- ☐ Yes (e.g., medications, recreational drugs, physical therapies, etc.)
- ☐ No
- ☐ Unknown

b) If Yes, What treatments do you use to manage your pain? (check ALL that apply)

- ☐ Complementary (e.g., biofeedback, acupuncture, hypnosis)
- ☐ Medical and procedural or neuromodulation (e.g., nerve blocks, injections, implanted stimulators, intrathecal pump, TENS)
- ☐ Non-prescription medications (e.g., non prescription pain killers such as Tylenol®)
- ☐ Non-traditional (e.g., naturopathy, homeopathy, herbal remedies)
- ☐ Psychotherapeutic (e.g., psychotherapy, cognitive behavioural therapy, relaxation, stress management, psycho-education, support group)
- ☐ Physical therapies (e.g., physiotherapy, massage, chiropractic)
- ☐ Recreational drugs (e.g., marijuana)
- ☐ Prescription medications (e.g., morphine, codeine)
- ☐ Other (specify): _____
- ☐ Unknown

2. Overall, how satisfied are you with the management of your pain?

0 1 2 3 4 5 6 7 8 9 10 ☐ Unknown

Not at all satisfied

Completely
Satisfied**3. a) Have you had any pain during the last 7 days, including today?**☐ Yes☐ No (skip to SCIM)**b) If YES, in the LAST WEEK:****i. In general, how much has pain interfered with your day to day activities in the last week?**

0 1 2 3 4 5 6 7 8 9 10 ☐ Unknown

No interference

Extreme interference

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

0 1 2 3 4 5 6 7 8 9 10 ☐ Unknown

No interference

Extreme interference

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

0 1 2 3 4 5 6 7 8 9 10 ☐ Unknown

No interference

Extreme interference

4. (if this is your first community follow-up survey, please consider the time since you were discharged from your initial inpatient hospital stay [acute care and/or rehab])**In the past 12 months, have you experienced Neuropathic pain?**

(Pain, that is often ongoing and intense, caused by damage to nerves, that occurs spontaneously or by light touching and is characterized by feelings of burning, shooting, tingling, etc.)


☐ Yes☐ No (skip to SCIM)**5. Location (s) of your neuropathic pain:** check ALL that apply to your neuropathic pain)

- ☐ Head
- ☐ Neck and/or Shoulders
- ☐ Arms and/or Hands
- ☐ Torso (chest, abdomen, pelvis, and/or genitals)

- ☐ Back (upper and/or lower back)
- ☐ Hips, Buttocks, and/or Anus
- ☐ Upper Legs/Thighs
- ☐ Lower Legs or Feet

6. a) Average pain intensity of your neuropathic pain in the past week:

0 1 2 3 4 5 6 7 8 9 10 ☐ Unknown

No pain  Pain as bad as you can imagine

b) You mentioned that you experienced this in the past 12 months. Have you received some form of treatment for the neuropathic pain?

- ☐ Yes
- ☐ No

c) When you had this, did it limit your activities?

- ☐ Yes
- ☐ No

SCIM – Spinal Cord Independence Measure (Version III, Self-report 2013)**This section asks about functioning in activities of daily living.**

For each item, please check the box next to the statement that best reflects **your current situation**. Please read the text carefully and only check one box in each section.

1. Eating and drinking

- ☐ I need artificial feeding or a stomach tube
- ☐ I need total assistance with eating/drinking
- ☐ I need partial assistance with eating/drinking or for putting on/taking off adaptive devices
- ☐ I eat/drink independently, but I need adaptive devices or assistance for cutting food, pouring drinks or opening containers
- ☐ I eat/drink independently without assistance or adaptive devices

2. (a) Washing your upper body and head

*Washing your **upper body and head** includes soaping and drying, and using a water tap.*

- ☐ I need total assistance
- ☐ I need partial assistance
- ☐ I am independent but need adaptive devices or specific equipment (e.g., bars, chair)
- ☐ I am independent and do not need adaptive devices or specific equipment

(b) Washing your lower body

*Washing your **lower body** includes soaping and drying, and using a water tap.*

- ☐ I need total assistance
- ☐ I need partial assistance
- ☐ I am independent but need adaptive devices or specific equipment (e.g., bars, chair)
- ☐ I am independent and do not need adaptive devices or specific equipment

3. (a) Dressing your upper body

*Dressing the **upper body** includes putting on and taking off clothes like t-shirts, blouses, shirts, bras, shawls, or orthoses (e.g., arm splint, neck brace, corset)*

Easy-to-dress clothes are those **without** buttons, zippers, or laces

Difficult-to-dress clothes are those **with** buttons, zippers, or laces

- ☐ I need total assistance
- ☐ I need partial assistance, even with easy-to-dress clothes
- ☐ I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- ☐ I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- ☐ I am completely independent

(b) Dressing your lower body

*Dressing the **lower body** includes putting on and taking off clothes like shorts, trousers, shoes, socks, belts, or orthoses (e.g., leg splint)*

Easy-to-dress clothes are those **without** buttons, zippers, or laces

Difficult-to-dress clothes are those **with** buttons, zippers, or laces

- ☐ I need total assistance
- ☐ I need partial assistance, even with easy-to-dress clothes
- ☐ I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- ☐ I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- ☐ I am completely independent

4. Grooming

Please think about activities such as washing hands and face, brushing teeth, combing hair, shaving, or applying makeup

- ☐ I need total assistance
- ☐ I need partial assistance
- ☐ I am independent with adaptive devices
- ☐ I am independent without adaptive devices

5. Breathing

*Please check **only one box**, depending on whether or not you need a respiratory (tracheal) tube.*

*I **need** a respiratory (tracheal) tube...*

- ☐ as well as permanent or from time to time assisted ventilation
- ☐ as well as extra oxygen and a lot of assistance in coughing or respiratory tube management
- ☐ as well as little assistance in coughing or respiratory tube management

*I **do not** need a respiratory (tracheal) tube...*

- ☐ but I need extra oxygen or a lot of assistance in coughing or a mask (e.g., positive end-expiratory pressure (PEEP)) or assisted ventilation from time to time (e.g., bilevel positive airway pressure (BIPAP))
- ☐ and only little assistance or stimulation for coughing
- ☐ and can breathe and cough independently without any assistance or adaptive device

6. Bladder management

Please think about the way you empty your bladder.

(a) Use of an indwelling catheter

- ☐ Yes → Please go to question 7a
- ☐ No → Please also answer questions 6b and 6c

(b) Intermittent catheterization

- ☐ I need total assistance
- ☐ I do it myself with assistance (self-catheterization)
- ☐ I do it myself without assistance (self-catheterization)
- ☐ I do not use it

(c) Use of external drainage instruments (e.g., condom catheter, diapers, sanitary napkins)

- ☐ I need total assistance for using them
- ☐ I need partial assistance for using them
- ☐ I use them without assistance
- ☐ I am continent with urine and do not use external drainage instruments

7. Bowel management**(a) Do you need assistance with bowel management (e.g., for applying suppositories)?**

- ☐ Yes
- ☐ No

(b) My bowel movements are...

- ☐ irregular or seldom (less than once in 3 days)
- ☐ regular (at least once every 3 days)

(c) Faecal incontinence ('accidents') happens...

- ☐ twice a month or more
- ☐ once a month
- ☐ not at all

8. Using the toilet

Please think about the use of the toilet, cleaning your genital area and hands, putting on and taking off clothes, and the use of sanitary napkins or diapers.

- ☐ I need total assistance
- ☐ I need partial assistance and cannot clean myself
- ☐ I need partial assistance but can clean myself
- ☐ I do not need assistance but I need adaptive devices (e.g., bars) or a special setting (e.g., wheelchair accessible toilet)

☐ I do not need any assistance, adaptive devices or a special setting

9. How many of the following four activities can you perform without assistance or electrical aids

- *turning your upper body in bed*
- *turning your lower body in bed*
- *sitting up in a bed*
- *doing push-ups in wheelchair (with or without adaptive devices)*

- ☐ none, I need assistance in all these activities
- ☐ one
- ☐ two or three
- ☐ all of them

10. Transfers from the bed to the wheelchair

- ☐ I need total assistance
- ☐ I need partial assistance, supervision or adaptive devices (e.g., sliding board)
- ☐ I do not need any assistance or adaptive devices
- ☐ I do not use a wheelchair

11. Transfers from the wheelchair to the toilet/tub

Transferring also includes transfers from the wheelchair or bed to a toilet wheelchair

- ☐ I need total assistance
- ☐ I need partial assistance, supervision or adaptive devices (e.g., grab-bars)
- ☐ I do not need any assistance or adaptive devices
- ☐ I do not use a wheelchair

12. Moving around indoors

*Please check **only one box**, depending on whether or not you usually use a wheelchair or walk to move around indoors.*

I use a wheelchair. To move around, I...

- ☐ need total assistance
- ☐ need an electric wheelchair or partial assistance to operate a manual wheelchair
- ☐ am independent in a manual wheelchair

I walk indoors and I...

- ☐ need supervision while walking (with or without walking aids)

- ☐ walk with a walking frame or crutches, swinging forward with both feet at a time
- ☐ walk with crutches or two canes, setting one foot before the other
- ☐ walk with one cane
- ☐ walk with a leg orthosis(es) only (e.g., leg splint)
- ☐ walk without walking aids

13. Moving around moderate distances (10 to 100 metres)

Please check **only one box**, depending on whether or not you usually use a wheelchair or walk to move around moderate distances (10 to 100 meters).

I use a wheelchair. To move around, I...

- ☐ need total assistance
- ☐ need an electric wheelchair or partial assistance to operate a manual wheelchair
- ☐ am independent in a manual wheelchair

I walk moderate distances and I...

- ☐ need supervision while walking (with or without walking aids)
- ☐ walk with a walking frame or crutches, swinging forward with both feet at a time
- ☐ walk with crutches or two canes, setting one foot before the other
- ☐ walk with one cane
- ☐ walk with a leg orthosis(es) only (e.g., leg splint)
- ☐ walk without walking aids

14. Moving around outdoors for more than 100 metres

Please check **only one box**, depending on whether or not you usually use a wheelchair or walk to move around outdoors for more than 100 metres.

I use a wheelchair. To move around, I...

- ☐ need total assistance
- ☐ need an electric wheelchair or partial assistance to operate a manual wheelchair
- ☐ am independent in a manual wheelchair

I walk more than 100 metres and I...

- ☐ need supervision while walking (with or without walking aids)
- ☐ walk with a walking frame or crutches, swinging forward with both feet at a time
- ☐ walk with crutches or two canes, setting one foot before the other
- ☐ walk with one cane
- ☐ walk with a leg orthosis(es) only (e.g., leg splint)

- ☐ walk without walking aids

15. Going up and down stairs

Please check **only one box**, depending on whether or not you are able to go up and down stairs.

- ☐ I am unable to go up and down stairs

I can go up and down at least 3 steps...

- ☐ but only with assistance or supervision
☐ but only with devices (e.g., handrail, crutch or cane)
☐ without any assistance, supervision or devices

16. Transfers from the wheelchair into the car

Transfers also include putting the wheelchair into and taking it out of the car.

- ☐ I need total assistance
☐ I need partial assistance, supervision or adaptive devices
☐ I do not need any assistance or adaptive devices
☐ I do not use a wheelchair

17. Transfers from the floor to the wheelchair

- ☐ I need assistance
☐ I do not need any assistance
☐ I do not use a wheelchair

Secondary Complications & Health Conditions Questionnaire

If this is your first community follow-up survey, please consider the time since you were discharged from your initial inpatient hospital stay (acute care and/or rehab). You can answer 'Yes' to questions below even if you have had the conditions for a long time.

Secondary Complications & Health Conditions	a) In the past 12 months, have you experienced this? (If No or Don't know, skip to next Question)	b) You mentioned that you experienced this in the past 12 months. Have you received some form of treatment for this problem?	c) When you had this, did it limit your activities?
1. Autonomic dysreflexia	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Light headedness/dizziness	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Respiratory infections	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Pressure Ulcers - New	<p>In the past 12 months (or if this is your first CFU, in the time since you were discharged from the hospital), how many NEW pressure ulcers have you had?</p> <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more <input type="checkbox"/> None <input type="checkbox"/> Don't know <p>Of these NEW pressure ulcers, how many are in a NEW location? (i.e., a location where you have not had a previous pressure ulcer)</p> <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Yes <input type="checkbox"/> No <p>If Yes, were the new ulcers surgically treated?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

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Secondary Complications & Health Conditions	a) In the past 12 months, have you experienced this? (If No or Don't know, skip to next Question)	b) You mentioned that you experienced this in the past 12 months. Have you received some form of treatment for this problem?	c) When you had this, did it limit your activities?
5. Pressure Ulcers - Ongoing	Other than the NEW pressure ulcers described above, how many ONGOING/UNRESOLVED pressure ulcers do you have that were previously existing? <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more <input type="checkbox"/> None <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No If Yes, were the ongoing or unresolved ulcers surgically treated? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
6. Urinary tract infections	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
7. Urinary incontinence	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
8. Fatigue	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
9. Depression/Mood Problems	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
10. Shoulder Problems	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
11. Spasticity	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know Which best describes your muscle spasms <input type="checkbox"/> Induced only by stimulation <input type="checkbox"/> Infrequent spontaneous spasms occurring < 1 per hour <input type="checkbox"/> Spontaneous spasms occurring < 10 per hour <input type="checkbox"/> Spontaneous spasms occurring > 10 per hour <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

Secondary Complications & Health Conditions	a) In the past 12 months, have you experienced this? (If No or Don't know, skip to next Question)	b) You mentioned that you experienced this in the past 12 months. Have you received some form of treatment for this problem?	c) When you had this, did it limit your activities?
12. Joint contractures	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
13. Bone fractures	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
14. Osteoarthritis/degenerative arthritis	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
15. Sexual dysfunction	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
16. Cerebrovascular disease, stroke, trans-ischemia attack (i.e. TIA)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
17. Heart Disease	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
18. Diabetes	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No What type of treatment(s)? (check ALL that apply) <input type="checkbox"/> Diet modification <input type="checkbox"/> Medications taken by mouth <input type="checkbox"/> Insulin injections <input type="checkbox"/> Other (specify): <hr/>	<input type="checkbox"/> Yes <input type="checkbox"/> No

- 1. Autonomic dysreflexia** (Sometimes called hyperreflexia - symptoms of dysreflexia include sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache. It can occur as the body's response to pain where an individual doesn't experience sensation, or from interference in the body's temperature regulating systems.)
- 2. Light headedness/dizziness** (Sometimes called postural hypotension - This involves a strong sensation of light-headedness following a change in position. It is caused by a sudden drop in blood pressure.)
- 3. Respiratory infections** (Also called pneumonia - Short-term lung disease caused by infection that includes inflammation and congestion; followed by clearing. It includes increased secretions, fever, chills, coughing, and difficulty breathing.)
- 4. Pressure Ulcers - New** (Also called skin ulcers, bedsores, and decubitus ulcers - A skin wound often caused by constant pressure against the skin causing reduced blood supply to the area and death of the tissue. These develop as a skin rash or redness and may progress to an infected sore.)
- 5. Pressure Ulcers - Ongoing** (Also called skin ulcers, bedsores, and decubitus ulcers - A skin wound often caused by constant pressure against the skin causing reduced blood supply to the area and death of the tissue. These develop as a skin rash or redness and may progress to an infected sore.)

- 6. Urinary tract infections** (This includes infections such as cystitis and pseudomonas. Symptoms include pain when urinating, a burning sensation throughout the body, blood in the urine and cloudy urine.)
- 7. Urinary incontinence** (Urine leakage, catheter bypassing.)
- 8. Fatigue** (Constantly feeling tired, having low energy, feeling listless.)
- 9. Depression/Mood Problems** (A state of intense sadness that **lasts for more than two weeks**, and has advanced to the point of interfering with daily life - feeling "down", being tired, or feeling irritable for no apparent reason.)
- 10. Shoulder problems** (This includes pain in the shoulder joints and/ or muscles. People who must overuse a particular muscle group, such as shoulder muscles, or who put too much strain on their joints are at risk of developing pain.)
- 11. Spasticity** (Spontaneous and uncontrolled, jerky muscle movements, such as uncontrolled muscle twitch or spasm. Often spasticity increases with infection or some kind of restriction, like a tight shoe or belt.)
- 12. Joint contractures** (Limitation in range of motion caused by a shortening of the soft tissue around a joint, such as an elbow or hip. This occurs when a joint cannot move frequently enough through its range of motion. Pain often accompanies this problem.)
- 13. Bone fractures** (Broken bones.)
- 14. Osteoarthritis/degenerative arthritis** ("Wear and tear" on joints causing pain, swelling, and reduced movement/function of the joint.)
- 15. Sexual dysfunction** (This includes dissatisfaction with sexual functioning. Causes for dissatisfaction can be decreased sensation, changes in body image, difficulty in movement, and problems with bowel or bladder, like infections.)
- 16. Cerebrovascular disease, stroke, trans-ischemia attack (i.e. TIA)** (Permanent or temporary loss or reduction of brain function due to an interruption of blood flow to the brain.)
- 17. Heart Disease** (An umbrella term for a variety of diseases affecting the heart including: heart attack, angina [i.e. chest pain], heart failure, coronary artery disease.)
- 18. Diabetes** (Diabetes is a problem resulting from irregularities in blood sugar levels. Symptoms include frequent urination and excessive thirst. This condition is diagnosed by a physician.)

Health Care Utilization Measure

The following are questions about your contact with the health care system. (if this is your first Community Follow-up survey please consider the time since discharge from your initial in-patient hospital stay [including acute care and/or rehab].)

1. In the past 12 months, have you been a patient, overnight, in a hospital?

- ☐ Yes
☐ No (skip to Question 3)

2. For how many nights in the past 12 months? (if exact number is unknown, please estimate)

3. Number of Emergency Department visits in past 12 months: (if exact number is unknown, please estimate)

4. During the past 12 months, was there ever a time when you felt that you needed health care but didn't receive it?

- ☐ Yes
☐ No (skip to SF-12 on page 20)

5. How many times in the past 12 months did this occur? (if exact number is unknown, please estimate)

6. Thinking of the most recent time, why didn't you receive care? (check ALL that apply)

- ☐ Not available in my area
- ☐ Not available at the time (doctor on holiday, inconvenient hours)
- ☐ Waiting time too long
- ☐ Felt it would be inadequate
- ☐ Cost
- ☐ Too busy
- ☐ Didn't get around to it/Didn't bother
- ☐ Didn't know where to go
- ☐ Transportation problems
- ☐ Language problems
- ☐ Personal or family responsibilities
- ☐ Dislike doctor/afraid
- ☐ Decided not to seek care
- ☐ Facilities inaccessible/inadequate care due to environmental barriers in facility
- ☐ Other (specify): _____

7. Again, thinking of the most recent time, what was the type of care that was needed? (check ALL that apply)

- ☐ Regular check-up
- ☐ Care of an injury (e.g., burns, broken bones, cuts, concussions)
- ☐ Physical health problem (e.g., high blood pressure, pneumonia)
- ☐ Emotional/ mental health problem
- ☐ Other (specify): _____

SF-12v2™ Health Survey**Your Health and Well-Being**

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Climbing <u>several</u> flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) <u>Accomplished less</u> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Were limited in the <u>kind</u> of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) <u>Accomplished less</u> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Did work or other activities <u>less carefully than usual</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. These questions are about how you have feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Have you felt downhearted and depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.?)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing these questions!

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LISAT-11 Questionnaire

Instructions: Here are a number of statements concerning how satisfied you are with different aspects of your life. For each of these statements please circle a number from 1-6, where 1 means very dissatisfying and 6 very satisfying.

	Very dissatisfying	Dissatisfying	Rather dissatisfying	Rather satisfying	Satisfying	Very satisfying
1. My life as a whole is:	1	2	3	4	5	6
2. My vocational situation is:	1	2	3	4	5	6
3. My financial situation is:	1	2	3	4	5	6
4. My leisure situation is:	1	2	3	4	5	6
5. My contact with friends and acquaintances is:	1	2	3	4	5	6
6. My sexual life is:	1	2	3	4	5	6
7. My ability to manage my self-care (dressing, hygiene, transfers, etc.) is:	1	2	3	4	5	6
8. My family life is: <input type="checkbox"/> Have no family	1	2	3	4	5	6
9. My partner relationship is: <input type="checkbox"/> Have no steady partner relationship	1	2	3	4	5	6
10. My physical health is:	1	2	3	4	5	6
11. My psychological health is:	1	2	3	4	5	6

Needs Measure

To live a full life, people with spinal cord injuries (SCI) have disability-related needs that must be met.

We would like to find out more about **your spinal cord injury needs and how well they are being met.**

Are the following needs for services (to support your community living) being met at this time?					
Accessible Housing	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Attendant Care	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Income Support	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Equipment and Technical Aids	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Short Distance Transportation	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Long Distance Transportation	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
SCI-Specialized Health Care	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
General Health Care	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Emotional Counselling	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Case Management	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
SCI Peer Support	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Job Training	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Healthy Living, Recreational & Leisure Programs	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Other: _____	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A
Other: _____	<input type="checkbox"/> To a great extent or completely	<input type="checkbox"/> To some extent	<input type="checkbox"/> Very little	<input type="checkbox"/> Not at all	<input type="checkbox"/> N/A

Please record the date you completed this questionnaire:

				/			/		
YYYY					MM			DD	

Thank you!

Your continued participation in RHSCIR is very important.

People who work in the field of spinal cord injury use the information to provide better care today, and perform research that can lead to a cure tomorrow.