

Dites-nous ce dont vous avez besoin .



L'Enquête sur les besoins en
lésion médullaire (LM) et
l'utilisation des services



Rick Hansen Institute
Institut Rick Hansen

Luc Noreau, Ph.D

et

les membres du Réseau sur l'intégration
communautaire (SCISN)

et

le Registre national en lésion médullaire (RHSCIR)

L'étude: Son origine

- SCI- Translational Research Network (RHI)
 - Recherche sur les services en LM (soins aigus, réadaptation, soutien à l'intégration sociale)
 - Identification des domaines qui nécessiteraient un développement et une application de connaissances

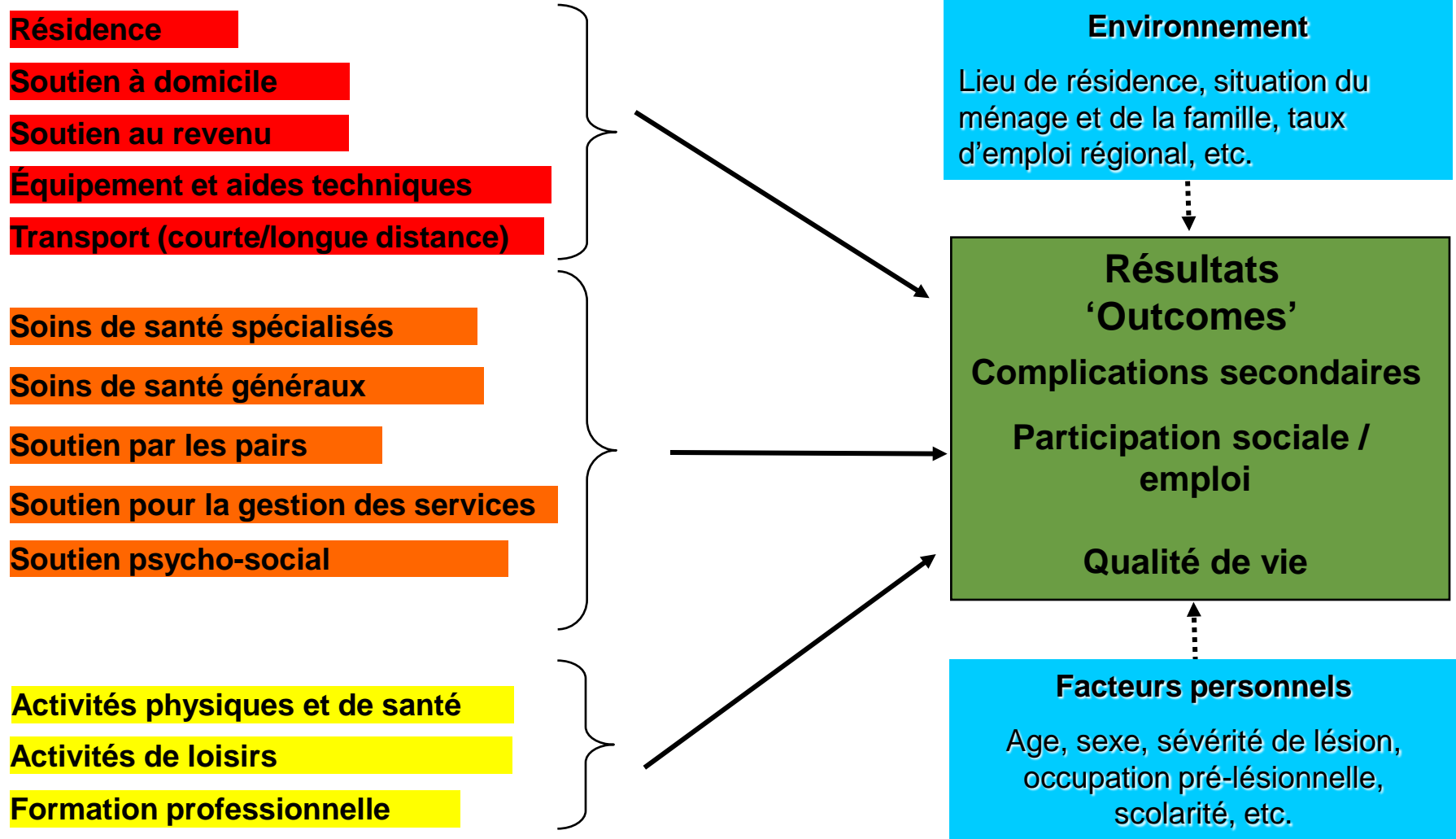
Objectifs généraux de l'enquête

1. Identifier les besoins (comblés / non-comblés) des personnes ayant une LM au Canada et leurs perceptions de l'accès (obstacles) aux services;
2. Décrire le niveau d'intégration sociale (résultats) à partir d'indicateurs existants (déf. secondaires, participation, emploi, Q de V);
3. Identifier les relations potentielles entre les besoins, la perception d'accès (obstacles) aux services et les résultats;
4. Identifier les facteurs personnels (âge, sexe, lésion) ou environnementaux (localisation du domicile, taux d'emploi, type de ménage) pouvant influencer ces relations potentielles;

Les indicateurs de l'étude

- Données démographiques et lésionnels
- Complications secondaires
 - Présence/fréquence, traitement (O/N), impact
- Identification des besoins et obstacles à l'accès aux services
- Participation sociale / emploi
- Utilisation des services de santé
- Qualité de vie

Schématisation de l'étude



Population vs. échantillon

1. Population estimée: 41,000 LM traumatiques
2. Échantillon anticipé: 3,000 participants (trauma et non-trauma) sur le territoire canadien
 - Erreur d'estimation réduite par un échantillon élevée à environ $\pm 2\%$:
 - Exemple:
 - 56% ($\pm 2\%$) des personnes rapportent un besoin non comblé en aide personnelle

Recrutement

- Canada : 10 provinces + territoires
 - Canadian Paraplegic Association (provincial)
 - Site du Registre Rick Hansen (n =13)
- Québec
 - MÉMO-Québec
 - Site RHSCIR (IRDQP/IRGLM)

Mode de passation

- Utilisation du WEB
 - La mise en page permettant une utilisation ‘web’ de l’étude a été développée (anglais / français)
 - Temps de passation (testé): ~ 90 minutes
 - Vérification avec lésion haute
- Pré-test de la version WEB
 - Élimination des erreurs de programmation et ajout d’indication d’erreurs



The Spinal Cord Injury Needs vs. Services Utilization Survey



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INFORMED CONSENT - PLEASE READ CONTENTS WITHIN THIS WINDOW

Survey on Needs and Service Utilization and Outcomes of People with Spinal Cord Injury Online Version

Principal Investigator:

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Co-Investigators:

Dr. Kathryn Boschen, PhD, University of Toronto
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Participant

I indicate my voluntary consent to take part in the Needs Survey.

[Click here to download a pdf copy of the blank consent form for your records.](#)

Continue



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Percentage of survey completed: **6%**

***** You are now beginning Section 3 - 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 SCI spinal cord injury needs and how well they are being met.**

Need 1 (of 15): Accessible Housing

1. After a spinal cord injury, some people need housing that has been specially adapted for better access. Adaptations may include increased door widths, the installation of ramps or bathroom transfer bars, etc.

Since leaving the hospital or rehabilitation centre, have you had such accessible housing needs?

- No
 Yes

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For all other questions or concerns, please contact the Survey Support team at: survey@rickhanseninstitute.org or call 1.877.594.6333

Section 3 - Needs Measure

Need 1 (of 15): Accessible Housing (Continued)

Accessible Housing = Housing which has been specially adapted for better access. Adaptations may include increased door widths, the installation of ramps or bathroom transfer bars, etc.

2. Are your accessible housing needs being met at this time?

- Completely
- To a great extent
- To some extent
- Very little
- Not at all

3. People sometimes get help with their accessible housing needs from friends and family. They might help pay for or do renovations, make arrangements to have the renovations done, or help you obtain existing accessible housing. Since leaving the hospital or rehabilitation centre, have you received help for your accessible housing needs from your friends and family?

- No
- Yes

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Percentage of survey completed: 19%

*** You are now beginning Section 4 - Secondary Complications ***

The following are questions that ask about health problems you may have that occur as a consequence of your spinal cord injury. We will be asking you about a total of 21 such health problems.

1. 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.)

In the past 12 months, have you experienced this problem?

Never

Once a year

A few times a year

A few times a month

A few times a week

Everyday

Don't Know

2. 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.)

In the past 12 months, have you experienced this problem?

Never

Once a year

A few times a year

A few times a month

A few times a week

Everyday

Don't Know

3. Sexual dysfunction (This includes dissatisfaction with sexual functioning. Causes for dissatisfaction can be decreased sensation, changes in body image,



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Percentage of survey completed: 24%

Section 4 - Secondary Complications

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.)

You mentioned that you experienced respiratory infections in the past 12 months. Did you seek, are you receiving some form of treatment for this problem?

- No
- Yes

When you had this problem, to what extent did they limit your activities?

- Not at all
- Very little
- To some extent
- To a great extent
- Completely

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Percentage of survey completed: 30%

*** You are now beginning Section 6 - Community Participation Measure ***

The questions in this section ask about your participation in regular daily activities at home and in your community.

- Daily activities are all the things you normally do that help you lead a productive life. It is not necessary that you do these things every day, but that you do them on a regular basis.
- Participation means **any level** of involvement on your part whether it is physical, verbal (e.g. giving directions to a helper) or both.

Activity 1 (of 26)

Moving from one place to another using transportation. *For example, moving as a driver or passenger, using a bus, a taxi or a car.*

1. Do you participate in this activity?

- Yes - as much as I want.
- Yes - but less than I want.
- No - but I would like to do it.
- No - and I don't want to do it.

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Percentage of survey completed: **96%**

Section 10 - Overall Health Rating

This question is designed to measure your overall health.

1. How do you rate your overall health?

- Very good
- Good
- Fair
- Bad
- Very bad

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Étapes à venir

- Lancement de l'étude: hiver 2011
 - Mise en place du recrutement : janvier 2011
 - Lancement de l'étude : février 2011
 - ** envoi de cartes postales
 - Période de collecte WEB : 4-6 mois
 - Analyse des données: Début été 2011
 - Possibilité d'analyses spécifiques pour le Québec

Utilité d'une telle étude

- Modèle possible de suivi à long-terme:
 - Établissement des besoins de service à la suite du congé de la réadaptation
 - Indications sur les obstacles potentiels à l'accès aux services (selon la région où vit l'utilisateur)
 - Mesure de résultat sur des indicateurs significatifs de l'intégration sociale et les conditions de vie:
 - Apparition de déficiences secondaires
 - Niveau de participation sociale / emploi
 - Qualité de vie