A clinical guideline for respiratory assessment for individuals with spinal cord injury.

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TOOLKIT FOR RESPIRATORY ASSESSMENT

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For questions or comments on this guideline, please contact clinical@rickhanseninstitute.org.
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 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 injury, through acute care and 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.

To learn more about RHSCIR, please visit www.rickhanseninstitute.org.
WHY IS THIS INFORMATION IMPORTANT?

Individuals with spinal cord injury (SCI), particularly in tetraplegia, can have severe limitations in their respiratory function. Acutely, this can limit the individual’s ability to begin the healing and rehabilitation process (1). It can also lead to long term secondary complication risks such as decreased ventilation, pneumonia, sleep apnea, fatigue and other issues (1–3). With early diagnosis and treatment, we can determine what treatments are necessary to improve respiratory function and we can help to ensure fewer complications. With a thorough interdisciplinary team evaluation we can also ensure patients go home with the proper equipment to reduce the chances of a readmission for respiratory reasons. The literature shows that the most common cause of death in patients with chronic tetraplegic spinal cord injuries are respiratory complications (2).

Information regarding the incidence and severity of respiratory disease in the SCI population may be used to identify trends and subsequently used for program planning and resource allocation. Additionally, such information can serve as a basis for patient education as part of learning self-management and directing care.

Benefits to Clinicians and Patients

Being informed is a crucial part of an injured person’s recovery process. This information can be used as the basis for patient education, which is part of learning self-management and directing care.

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

➤ Understanding patients’ respiratory status and respiratory care needs.

➤ Assessing cough strength/effectiveness (i.e. ability to clear secretions).

➤ Screening/assessing for sleep disordered breathing (including obstructive sleep apnea, etc.) and need for appropriate therapies.

➤ Optimizing respiratory support, including lung volume recruitment techniques, assisted coughs and ventilatory support.

➤ Ensuring standards of practice are being met to ensure the best possible outcome for the patient.

➤ Monitoring effects of treatment/therapy.

➤ Ensuring the patient understands respiratory status to allow direction of care during their stay and after discharge.

➤ Reducing the risk of secondary complications.

➤ Reducing the risk of readmission after discharge.
Benefits to the Program

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

➤ Analysing staffing levels, determining what type of staff (e.g. RN, LPN, WOCN, OT, PT, research, etc.) are involved, and what the equipment and supply requirements are.

➤ Facilitating larger system planning (e.g. feedback to EHS transport systems) to coordinate and improve service delivery between different points of care.

➤ Creating continuity between health care providers.

➤ Providing comparators to national data and a system of tracking to support requirements for Accreditation Canada SCI Acute and Rehabilitation Standards and Required Organizational Practices.

➤ Reporting metrics to facility administrators to allow correlation of program expenditures (e.g. equipment, regular and overtime staffing requirements, etc.) with the patient population.

➤ Ensuring that discharge locations are prepared to support the patients’ respiratory care needs, which can remove barriers to discharge.

What Happens Once I Collect the Data?

➤ Providing invaluable data to RHSCIR: Once you collect the data, your facility’s Rick Hansen Spinal Cord Injury Registry (RHSCIR) coordinator will abstract this information from the medical record and input the data into a database along with additional data collected in the community through self-report (See Section 10: RHSCIR - ADDITIONAL RESPIRATORY DATA), and other clinical, demographic, socio-demographic, participant flow, and outcomes information. RHSCIR has developed a number of practices to ensure patient confidentiality is maintained and strict privacy policies and procedures are followed.

➤ Providing a baseline for management of SCI across Canada: The de-identified data from your site will be reported back to you on a quarterly basis providing information on your site’s respiratory assessment data, your patients’ use of therapies as well as their respiratory requirements when discharged to community.

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 SCI2 site by visiting www.rickhanseninstitute.org.
To complete collection of data as outlined in this toolkit, the following resources are required:

**Time**

Estimated time required for good clinical practice:
- Spirometry: 20 minutes
- Peak cough flow: 15 minutes
- Overnight oximetry: 50 minutes active clinical time, plus interpretation time 15-20 minutes

**Equipment**

- Spirometry: spirometer or pulmonary function lab
- Peak cough flow and peak expiratory flow: peak flow meter
- Maximal inspiratory and expiratory pressures: respiratory pressure metre
- Overnight oximetry: oximeter with the capacity to record up to 12 hours of data and software program to download and analyze data
Respiratory Clinical Data Collection Form

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

There are two levels of collection. Sites should self-select which measures they are able to complete based on experience and resources.

The **BASIC** dataset, which includes three measures:

- **Vital Capacity**, a measure of the amount of air the patient can expel from the lungs after a maximal inhalation.
- **Unassisted Peak Cough Flow**, a measure of the patient’s ability to cough without help
- **Overnight Oximetry**, one of the tools used to determine whether a patient has sleep disordered breathing, including obstructive sleep apnea (OSA).

And the **ADVANCED** dataset, which includes all the measures below in the RHSCIR data collection form.

What you see here is the respiratory information collected, both by patient interview and chart review by your local RHSCIR coordinator. If you would like help developing a clinical form to put in your chart, please email clinical@rickhanseninstitute.org.

There is not a Clinical Form to insert in your chart here because each site’s workflow is so different.

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6. a) What is your smoking history?
   - □ Current smoker
   - □ Former smoker
   - □ Never smoked (skip to question 13)
   - □ Unknown (skip to question 13)

   b) If a former or current smoker, for how many years did (have) you smoke(d)?
      (please estimate if exact number unknown)

      □ Unknown

   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)

      □ Unknown

11. a) Was Spirometry performed? (You may find only some of the spirometry tests have been performed. If so, please answer [Yes] and enter values available into the table below.)
b) If Yes, enter values from spirometry test performed: (if multiple values obtained during the first test (e.g., RT performed multiple spirometry measurements, enter best values obtained)

<table>
<thead>
<tr>
<th>Test</th>
<th>Value</th>
<th>% Predicted</th>
</tr>
</thead>
<tbody>
<tr>
<td>FVC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FEV1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PEF</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MIP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEP</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Pulmonary complications and conditions diagnosed after the SCI, during the stay:

- None (skip to Data Collection Details)
- Pneumonia: (clinically, i.e., by a medical doctor) with any of clinical (e.g., increased temperature or amount of purulent secretions), radiographic (e.g. infiltrate on chest x-ray), or laboratory (e.g. positive culture & sensitivity (C&S), increased white blood cell count) supporting evidence AND resulting in treatment with antibiotics

Number of episodes of pneumonia treated with antibiotics:

<table>
<thead>
<tr>
<th>Date first pneumonia diagnosis</th>
<th>% Predicted</th>
</tr>
</thead>
<tbody>
<tr>
<td>(date antibiotic treatment started)</td>
<td></td>
</tr>
</tbody>
</table>

- Asthma
- Chronic Obstructive Pulmonary Disease (includes emphysema and chronic bronchitis)
- Venothromboembolic Event (including pulmonary embolus and DVT)
- Obstructive Sleep Apnea

Did the participant receive any treatment?

- Yes
- No (skip to Data Collection Details)
- Unknown (skip to Data Collection Details)

If Yes, specify type of treatment: (check ALL that apply)

- Continuous Positive Airway Pressure (CPAP)
- Bi-Level Positive Airway Pressure (BiPAP®)
- Oral appliance
- Surgery (e.g., Uvulopalatopharyngoplasty, Radiofrequency Ablation (RFA), Nasal Surgery, etc.)
- Other (specify): ________________
- Unknown type

Other Respiratory Conditions (specify): __________________________

Collected only in rehabilitation:

2. a) Was Overnight Oximetry performed?

- Yes
- No (skip to Question 8)

b) Overnight Oximetry Values:

<table>
<thead>
<tr>
<th>Value</th>
<th>% Predicted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean oxygen sat.</td>
<td>Unk</td>
</tr>
<tr>
<td>Mean low oxygen sat.</td>
<td>Unk</td>
</tr>
<tr>
<td>Percentage of time below 90%</td>
<td>Unk</td>
</tr>
</tbody>
</table>

c) Date of Spirometry Test:

<table>
<thead>
<tr>
<th>YYYY</th>
<th>MM</th>
<th>DD</th>
</tr>
</thead>
</table>

Enter as much of the date as is known. If the tests have been performed over multiple days, enter the date of the last test.

3. a) Was Peak Cough Flow measurement performed?

- Yes
- No (skip to Question 10 on page 5)

b) Unassisted peak cough flow (PCF):

<table>
<thead>
<tr>
<th>Litres/minute</th>
</tr>
</thead>
</table>

(c) Date Peak Cough Flow measurement performed:

<table>
<thead>
<tr>
<th>YYYY</th>
<th>MM</th>
<th>DD</th>
</tr>
</thead>
</table>

Enter as much of the date as is known.
Timing of Assessment

**Admission:** Spirometry assessment should be completed within the first 24 hours of the patient being cognitively aware enough to complete them in the acute care setting. In the rehabilitation setting, within seven days of admission is considered standard. Early assessments may be at the bedside, and may not include all values.

**Discharge:** Within seven days of discharge is advisable to ensure proper supports are set up for discharge to the next facility or in the community.

It is advisable to perform some respiratory testing on all patients with SCI where the respiratory muscles have been affected. This would include those with a neurological level of injury of L1 (i.e. any cervical or thoracic injury) or above (4).

**Specific instructions for spirometry and peak cough flow are available under the [resources](#) section on the SCI² website.** While we know that many clinicians are already familiar with these measures, it is a good idea to familiarize yourself with the instructions and differences with the assessment of those with SCI.

Instructions for overnight oximetry are specific to the equipment you use; please consult the manufacturer’s instructions.
**DEFINITIONS**

**Forced expiratory volume in one second (FEV1):** is the volume expired in the first second of the FVC maneuver.

**Forced vital capacity (FVC):** total volume of air that a person can forcibly exhale during a maximal expiratory effort.

**Maximal expiratory pressure (MEP):** maximal expiratory pressure maintained for one second after full inhalation.

**Maximal inspiratory pressure (MIP):** maximal inspiratory pressure maintained for one second after full exhalation.

**Overnight oximetry:** recording taken while the patient is sleeping of their oxygen oximetry.

**Peak cough flow (PCF):** maximal flow rate achieved during a coughing maneuver.

**Peak expiratory flow (PEF):** is the maximal expiratory flow rate achieved during the FVC maneuver.

**Vital capacity (VC):** total volume of air that a person can exhale at a steady rate, and represents the difference between total lung capacity and residual volume.

Questions or comments regarding this guideline?  
Email clinical@rickhanseninstitute.org.
The Institute for Rehabilitation Research and Development, based at The Rehabilitation Centre in Ottawa, has a site with comprehensive respiratory protocols for SCI and neuromuscular diseases, among other resources: www.irrd.ca/education/.

The American Thoracic Society has consensus statements on respiratory assessment available: www.thoracic.org/statements/.


If you are new to pulmonary function testing, there are instructions for all the tests in the registry available on the SCI² site. If you are viewing this document in paper form, ask your RHSCIR Local Site Coordinator for login information.

- Hamilton Health Sciences has a training document about breath stacking and assisted cough for patients and families: [www.hamiltonhealthsciences.ca/documents/Patient%20Education/SCI-KeepingLungsHealthyPORTRAIT.pdf](http://www.hamiltonhealthsciences.ca/documents/Patient%20Education/SCI-KeepingLungsHealthyPORTRAIT.pdf).


Please see the SCI² website for other sites' documentation and policy documents for your reference.


In addition to the clinically collected data outlined in this toolkit, there will also be data collected by RHSCIR from those participants who consent to the community follow-up RHSCIR. This includes subjective information 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 at one year, two years, five years, and then every five years from their date of injury.

**Sociodemographics Plus - continued**

6. a) What is your smoking history:
   - Current smoker
   - Former smoker
   - Never smoked (skip to Question 11)
   - Unknown (skip to Question 11)

   b) If a former or current smoker, for how many years did (have) you smoke(d)? (please estimate if exact number unknown)
   - Years
   - Unknown

   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)
   - ___ Cigarettes
   - ___ Cigars
   - ___ Pipe Bowls
   - Unknown

**From the Spinal Cord Independence Measure III – Self Report**

1. 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

**Health Conditions Questionnaire**

The following are questions that ask about health problems you may have that occur in association with (but not because of) your spinal cord injury. We will be asking you about a total of 17 such health problems. If this is your first community follow-up survey, please only consider the time since you were discharged from your initial inpatient hospital stay (acute care and/or rehab).

Version: 03Dec2013
1. **Chronic Lung Disease** (Chronic Obstructive Pulmonary Disease, emphysema, chronic bronchitis, tuberculosis, etc.)
   a) In the past 12 months, have you had a chronic lung disease? (check ONE)
      - Yes
      - No
      - Don't know
      (If No or Don't know, skip to Question 4)
   b) You mentioned that you had chronic lung disease in the past 12 months. Have you received some form of treatment for this problem? (check ONE)
      - Yes
      - No
      (If No, skip to Question 3a)
   c) Do you take any medicines for your emphysema, chronic bronchitis, or COPD? (check ONE)
      - Yes
      - No
   d) How much has the chronic lung disease limited your activities? (check ONE)
      - Not at all
      - Very little
      - To some extent
      - To a great extent
      - Completely

2. **Sleep Apnea** (A common disorder in which you have one or more pauses in breathing or shallow breaths while you sleep.
The most common type of sleep apnea is obstructive sleep apnea. In this condition, the airway collapses or becomes blocked during sleep. This causes shallow breathing or breathing pauses.)
   a) In the past 12 months, have you had sleep apnea? (check ONE)
      - Yes
      - No
      - Don't know
      (If No or Don't know, skip to Question 5)
   b) You mentioned that you had sleep apnea in the past 12 months. Have you received some form of treatment for this problem? (check ONE)
      - Yes
      - No
   c) How much has sleep apnea limited your activities? (check ONE)
      - Not at all
      - Very little
      - To some extent
      - To a great extent
      - Completely

3. **Asthma** (A chronic (long-term) lung disease that inflames and narrows the airways. Asthma causes recurring periods of wheezing (a whistling sound when you breathe), chest tightness, shortness of breath, and coughing. The coughing often occurs at night or early in the morning.)
   a) In the past 12 months, have you had asthma? (check ONE)
      - Yes
      - No
      - Don't know
      (If No or Don't know, skip to Question 6)
   b) You mentioned that you had asthma in the past 12 months. Have you received some form of treatment for this problem? (check ONE)
      - Yes
      - No
   c) How much has asthma limited your activities? (check ONE)
      - Not at all
      - Very little
      - To some extent
      - To a great extent
      - Completely

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 about a total of 22 such health problems. If this is your first community follow-up survey, please only consider the time since you were discharged from your initial inpatient hospital stay (acute care and/or rehab).

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.)
   a) In the past 12 months, have you experienced respiratory infection(s)? (check ONE)
      - Yes
      - No
      - Don't know
      (If Never or Don't know, skip to Question 18)
   b) You mentioned that you experienced respiratory infection(s) in the past 12 months. Have you received some form of treatment for this problem? (check ONE)
      - Yes
      - No
   c) When you had respiratory infection(s), to what extent did it limit your activities? (check ONE)
      - Not at all
      - Very little
      - To some extent
      - To a great extent
      - Completely

4. **Deep Vein Thrombosis/Pulmonary Embolism (DVT/PE)** (DVT = blood in the veins of the legs or arms that collects and forms into a thick mass (i.e. blood clot); PE = a piece of a blood clot that breaks free, lodges in the lung, and may cause breathing difficulty.)
   a) In the past 12 months, have you experienced DVT/PE? (check ONE)
      - Yes
      - No
      - Don't know
      (If Never or Don't know, proceed to Health Care Utilization Measure Questionnaire)
   b) You mentioned that you experienced DVT/PE in the past 12 months. Have you received some form of treatment for this problem? (check ONE)
      - Yes
      - No
   c) When you had DVT/PE, to what extent did it limit your activities? (check ONE)
      - Not at all
      - Very little
      - To some extent
      - To a great extent
      - Completely