The original working-group consisted of:
Ann-Katrin Karlsson, chair and member of International Spinal Cord Society (ISCoS)
Andrei Krassioukov, chair of the Autonomic Committee under the Standards Committee in ASIA, and for the joint ASIA / ISCoS working group under the International Spinal Cord Injury (SCI) Standards and Data Sets executive committee, member of ISCoS and ASIA
Marca Sipski, member of ISCoS and ASIA
William Donovan, member of ISCoS and ASIA
Christopher Mathias, member of ISCoS
Fin Biering-Sørensen, co-chair of the International SCI Standards and Data Sets executive committee under ISCoS and ASIA, member of ISCoS and ASIA

The changes made from Version 1.0 to Version 1.1 and detailed below were suggested by Floris W.A. van Asbeck and Marcel W.M. Post.

The loss of supraspinal control of the sympathetic nervous system and the loss of sensation may cause severe long lasting morbidity and might be life-threatening according to the effects on skin and thermoregulation.
The reduced ability to regulate body temperature puts the individual with spinal cord injury (SCI) at risk of both hyperthermia and hypothermia. Fever, hyperthermia and even hypothermia may accompany infections both in the acute and chronic phase of SCI, however increased temperature without identified etiologies is also seen1,2. Hyperthermia could be a risk following physical activity as well as during a stay in warm surroundings due to the impaired capacity to reduce body temperature by vasodilatation and sweating3. The individual with SCI and especially with cervical injury is poikilothermic and is at risk of developing hypothermia in low environmental temperature, even though hypothermia may also be seen in normal ambient temperature4. It is known that body temperature differs according to methods of measurement5.

Hypohidrosis is usually seen below the level of lesion, whereas hyperhidrosis could be present above as well as below the level of lesion, and may be a sign of an ongoing pathological process such as syringomyelia, autonomic dysreflexia, dyspepsia or may accompany micturition and defecation. Hyperhidrosis may also be present without any known cause6.

The newly injured as well as those with chronic SCI are at increased risk of developing pressure ulcers7,8. The impaired vasoregulation below level of lesion together with abnormalities in sweating probably contributes and makes the skin more sensitive to pressure. A tendency towards increasing incidence and prevalence of pressure ulcers has been reported9.

In accordance with the aims of the International Spinal Cord Injury Data Sets10 the aim of the Skin and Thermoregulation Function Basic Data Set for Spinal Cord Injury is to standardize the collection and reporting of a minimal amount of information on
these issues in daily practice. Furthermore, the International SCI Skin and Thermoregulation Function Basic Data Set makes it possible to evaluate and compare results from various published studies on skin and thermoregulation function after SCI.

The International SCI Skin and Thermoregulation Function Basic Data Set is applicable to adult individuals with traumatic or non-traumatic supraconal, conal or cauda equina lesions. To ensure that data are collected in a uniform manner each variable and each response category within variables have been specifically defined.

The International SCI Skin and Thermoregulation Function Basic Data Set will mostly be used in connection with the background information within the International SCI Core Data Set11. This specifically applies to the documentation of the level, completeness and time post spinal cord lesions, which play an important role on skin and thermoregulation parameters following injury. The International SCI Skin and Thermoregulation Function Basic Data Set may be used once yearly in chronic SCI individuals.

This document was produced under the umbrella of the American Spinal Injury Association (ASIA) and the International Spinal Cord Society (ISCoS).

**Version changes of the International SCI Skin and Thermoregulation Function Basic Data Set.**

*Version 1.0 to Version 1.1:*

After the dataset was in practical use, challenges regarding the recommendations for measuring the size of the pressure ulcer became clear:

The recommendation “largest diameter, including undermining” was an impracticable measurement since it adds the largest undermining to a certain diameter of the surface. Therefore, it was decided to use the definition for undermining measurement as recommended by the latest update of the Consortium for Spinal Cord Medicine12 (p.32): “[...]. where there is undermining or tunnelling, a measuring tool such as a swab should be inserted into the undermined area or tunnel to indicate its full extent with a visible ruler on top of the skin paralleling that swab located in the undermined or tunnelled area to reflect the exact measurement”. As a consequence the wording is changed to: **Largest undermining**, and the description how to measure this is inserted.

The “smallest opening diameter” had impracticable and confusing wording. Therefore, it was decided to use the definition for width measurement as recommended in the updated Consortium for Spinal Cord Medicine12 (p.31): “Length should be along the longest dimension of the wound and width is the maximum dimension perpendicular to the length axis”. As a consequence, the wording is changed to: **Width** as the maximum dimension perpendicular to the length axis.

In the literature there is a tendency to replace “grades” or “stages” with “categories” because grades and stages suggest that the one follows the other, which is not always the case. The Consortium for Spinal Cord Medicine12 (pp. 7-9) has stated: “Pressure ulcers are described by a category/ staging system based on the extent of anatomical tissue loss.” This is supported by the updated National Pressure Ulcer Advisory Panel (NPUAP)13 (pp. 12-13). As a consequence the word **category** is used instead of “grade” or “stage”.
Acknowledgement:
Coloplast A/S, Denmark has supported the work with the original Data Set with an unconditional grant. We are thankful for comments and suggestions received to the original Version 1.0 from Ralph Marino, Susan Charlifue, Gordana Savic, Inge Eriks Hoogland, Jan Groothuis Marcel Post, Inder Perkash, Eric Weerts, Lawrence Vogel, Floris van Asbeck and and the National Institute of Neurological Disorders and Stroke (NINDS), and the Common Data Elements (CDE) Project Team.
To Version 1.1 we have received comments and suggestions from Susan Charlifue.
INTERNATIONAL SPINAL CORD INJURY DATA SETS
SKIN AND THERMOREgULATION FUNCTION BASIC DATA SET –
COMMENTS – Version 1.1

VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD

COMMENTS: As the collection of data on skin and thermoregulatory functions may be carried out at any time following SCI, the date of data collection is imperative to compute time since the spinal cord lesion and to identify the data collected in relation to other data collected on the same individual at various time points.

VARIABLE NAME: Thermoregulation history after spinal cord lesion within the last three months

DESCRIPTION: This variable documents the thermoregulation history after spinal cord lesion within the last three months

CODES: Hyperthermia
    Non infectious
    Infectious
    Unknown

Hypothermia
    Non infectious
    Infectious
    Unknown

Hyperhidrosis
    Above level of lesion
    Below level of lesion

Hypohydrosis
    Above level of lesion
    Below level of lesion

Other
    None of the above
    Unknown

COMMENTS: Hyperthermia, usually defined as rectal temperature above 38,4°C, as well as hypothermia, defined as rectal temperature below 35°C may be caused by an infection. Hyper and hypothermia may also be caused by non infectious reasons as exercise or by increased or decreased environmental temperature; the individual with spinal cord lesion is prone to be poikilothermic. Hyperhidrosis is defined...
as excessive sweating above or below level of injury in the absence of increased ambient temperature. Hyperhidrosis may be a sign of an ongoing pathological process such as syringomyelia, autonomic dysreflexia, or dyspepsia or may accompany micturition and defecation. Hyperhidrosis may also be present without any known cause. Hypohidrosis is defined as a loss of ability to sweat and is normally seen below the level of injury due to disruption of sympathetic outflow. Hypohidrosis may be total or partial. Other thermoregulatory (for example subjective feeling of coldness) and sudomotor findings may be present and should be specified.

<table>
<thead>
<tr>
<th>VARIABLE NAME:</th>
<th>Time performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESCRIPTION:</td>
<td>This variable documents the time the temperature was measured</td>
</tr>
<tr>
<td>CODES:</td>
<td>HHMM (hours and minutes) Unknown</td>
</tr>
<tr>
<td>COMMENTS:</td>
<td>Temperature is affected by the circadian rhythm. Therefore, the time of evaluation should be reported.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>VARIABLE NAME:</th>
<th>Temperature</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESCRIPTION:</td>
<td>This variable documents the body core temperature investigated rectally, orally, axillary or in the ear.</td>
</tr>
<tr>
<td>CODES:</td>
<td>Method used: Rectal Ear Oral Axilla Unknown</td>
</tr>
<tr>
<td>COMMENTS:</td>
<td>Present body temperature at the day of investigation should be documented. It should be noted that rectal investigation of body core temperature is most reliable.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>VARIABLE NAME:</th>
<th>Any pressure ulcer at present</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESCRIPTION:</td>
<td>This variable documents presence of a pressure ulcer at the time of investigation, the category and location of the ulcer. One diagram with the location and category is to be filled in for each ulcer.</td>
</tr>
</tbody>
</table>
CODES:  
Yes  
No  
Unknown  
If yes: document

Category:
  category I
  category II
  category III
  category IV
  unstageable/unclassified

Location:
  occiput
  ear
  scapula
  elbow
  ribs
  spinous process
  iliac crest
  sacral
  ischial tuberosity
  trochanter
  genitals
  knee
  malleolus
  heel
  foot
  other location

size;
  length - largest opening diameter (mm)
  largest undermining (mm)
  width - max. dimension perpendicular to the length axis(mm)
  largest depth (mm)

COMMENTS: A pressure ulcer could be present at any time post spinal cord injury. This variable documents the presence of pressure ulcer(s) at the time of investigation. An ulcer is usually seen on prominent body structures and caused by pressure on the region. The location of the pressure ulcer should be documented including right/left side of the body when applicable. A pressure ulcer is defined by different categories of skin involvement according to the definitions below\textsuperscript{12,13}

**Category I:** An observable pressure-related alteration of intact skin whose indicators as compared to an adjacent or opposite area on the body may include changes in one or more of the following: skin temperature (warmth or coolness), tissue consistency (firm or boggy feeling), and/or sensation (pain, itching). The ulcer appears as a defined area of persistent redness in lightly pigmented skin, whereas in darker skin tones, the ulcer may appear with persistent red, blue, or purple hues.
Category II: Partial-thickness skin loss involving epidermis, dermis, or both. The ulcer is superficial and presents clinically as an abrasion, blister, or shallow crater.

Category III: Full-thickness skin loss involving damage to or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia. The ulcer presents clinically as a deep crater with or without undermining of adjacent tissue.

Category IV: Full-thickness skin loss with extensive destruction, tissue necrosis, or damage to muscle, bone, or supporting structures (e.g., tendon, joint capsule). Undermining and sinus tracts also may be associated with category IV pressure ulcers. Pressure ulcers do not progress from category I to category II to category III and ultimately to category IV. Rather, they begin deep inside the tissues, close to the bone, and erupt on the surface of the skin. Conversely, healing ulcers do not progress in reverse order of the categories. Muscle tissue is more sensitive than skin to pressure-induced ischemia.

Unstageable/Unclassified: Full thickness tissue loss in which the base of the ulcer is covered by slough (yellow, tan, gray, green or brown) and/or eschar (tan, brown or black) in the wound bed. Until enough slough and/or eschar is removed to expose the base of the wound, the true depth, and therefore category, cannot be determined.

Category I pressure ulcers are not always accurately assessed, especially in people with darkly pigmented skin.

Size: The size of the ulcer may be difficult to measure accurately since the opening may be small whereas there is undermining of the skin below. Therefore we recommend according to the Consortium for Spinal Cord Medicine (p.31) to measure the ‘largest opening diameter’ as the ‘length’ along the longest dimension of the wound and the ‘width’ as the maximum dimension perpendicular to the length axis. The ‘largest undermining’, and ‘largest depth’ should be measured since the size of the ulcer has influence on treatment and time to healing. To determine undermining or tunneling, a measuring tool such as a swab should be inserted into the undermined area or tunnel to indicate its full extent with a visible ruler on top of the skin paralleling that swab located in the undermined or tunnelled area to reflect the exact measurement” (p.32). “The depth of the wound should be measured from the deepest point to the imaginary surface in continuity with the wound edges” (pp.31-32).

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**VARIABLE NAME:** Date of appearance of the ulcer

**DESCRIPTION:** This variable documents the date of appearance of the ulcer.

**CODES:** YYYYMMDD
Unknown
COMMENTS: A pressure ulcer usually presents with a minor alteration to the skin and progresses later. The date of appearance should be the date when the first alteration to the skin was observed. If the date is unknown this should be documented.

VARIABLE NAME: Surgical treatment
DESCRIPTION: This variable documents if the ulcer has been surgically treated.
CODES: Yes
Date for last surgical treatment YYYYMMDD
No
Unknown

COMMENTS: Surgical treatment may include any treatment ranging from small debridement of the surface of the ulcer to rotation flaps. In this context the variable includes major surgical methods such as direct closure, skin grafting, or rotation flaps. Minor debridement is defined as conservative treatment and should not be documented.

VARIABLE NAME: Any other pressure ulcer during the last 12 months. Location should be given for each pressure ulcer.
DESCRIPTION: This variable documents presence of any pressure ulcers during the last 12 months. The location should be given for each pressure ulcer during the last 12 months.
CODES: Yes
No
Unknown
If yes: document location:
- occiput
- ear
- scapula
- elbow
- ribs
- spinous process
- iliac crest
- sacral
- ischial tuberosity
- trochanter
- genitals
- knee
- malleolus
A pressure ulcer could have been present at any time post spinal cord injury. This variable documents the presence and location of any other skin ulcer(s) during the period of the last 12 months only.

**VARIABLE NAME:** Surgical treatment of any other pressure ulcer during the last 12 months

**DESCRIPTION:** This variable documents if the ulcer has been surgically treated.

**CODES:**
- Yes
- Date for last surgical treatment YYYYMMDD
- No
- Unknown

**COMMENTS:** Surgical treatment may include any treatment ranging from small debridement of the surface of the ulcer to rotation flaps. In this context the variable includes major surgical methods such as direct closure, skin grafting, or rotation flaps. Minor debridement is defined as conservative treatment and should not be documented.

**References:**
Date of data collection:  YYYYMMDD  Unknown

Thermoregulation history after spinal cord lesion within the last three months:
- Hyperthermia  Non infectious
  Infectious
  Unknown
- Hypothermia  Non infectious
  Infectious
  Unknown
- Hyperhidrosis  Above lesion
- Hypohidrosis  Above lesion
- Other, specify_____________________
- None of the above
- Unknown

Objective measures:
Time performed: ______________________HHMM  Unknown

Temperature:
Method used: Rectal  Ear  Oral  Axilla  Unknown
Temperature measured: __________°C

Any pressure ulcer at present:  Yes  No  Unknown
If yes, Fill in one diagram for each ulcer, by indicating the ulcer category (I, II, III, IV, U (Unstageable)) at the appropriate location.
<table>
<thead>
<tr>
<th>Location</th>
<th>Right</th>
<th>Mid-line</th>
<th>Left</th>
<th>Length - largest opening diameter (mm)</th>
<th>Width - max. dimension perpendicular to the length axis (mm)</th>
<th>Largest undermining (mm)</th>
<th>Largest depth (mm)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occiput</td>
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<td>Ear</td>
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<td>Scapula</td>
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<td>Elbow</td>
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<td>Ribs</td>
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<tr>
<td>Spinous process</td>
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<td>Iliac crest</td>
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<td>Sacral</td>
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<tr>
<td>Ischial tuberosity</td>
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<tr>
<td>Trochanter</td>
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<td>Genitals</td>
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<td>Knee</td>
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<tr>
<td>Malleolus</td>
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<td>Heel</td>
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<td>Foot</td>
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<tr>
<td>Other location</td>
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</tbody>
</table>

**Date of appearance of the pressure ulcer:** YYYYMMDD  
**Has the ulcer been surgically treated:**  
- Yes  
- No  
- Unknown  
If yes, **date of last surgical intervention:** YYYYMMDD

**Any other pressure ulcer during the last 12 months:**  
- Yes  
- No  
- Unknown  
If yes, Fill in one diagram for each pressure ulcer, with tick of the location:

<table>
<thead>
<tr>
<th>Location</th>
<th>Right</th>
<th>Mid-line</th>
<th>Left</th>
</tr>
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<td>Ear</td>
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<td>Scapula</td>
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<td>Ribs</td>
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<tr>
<td>Spinous process</td>
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<tr>
<td>Iliac crest</td>
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<td>Sacral</td>
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<tr>
<td>Ischial tuberosity</td>
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<td>Knee</td>
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<td>Malleolus</td>
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<td>Foot</td>
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<tr>
<td>Other location</td>
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</tbody>
</table>

**Has the ulcer been surgically treated:**  
- Yes  
- No  
- Unknown  
If yes, **date of last surgical intervention:** YYYYMMDD