

## **The spasticity-related quality of life tool (SQoL-6D)** **Version 4, 8.7.2014**

### **Developed with input from the SQoL-6D Advisory Group:**

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## **Background:**

The Spasticity-related Quality of Life instrument (SQOL-6D) was developed to fulfil the need for a health-related quality of life measure that would be sensitive to the disease burden and changes following focal treatment for ULS and that could in future be used in economic evaluation of treatments for ULS. It was developed on the basis of previous research led by King's College London over a decade or more, including extensive analysis of goals and other outcomes from several large international studies. The initial draft was then further refined through consensus by members of the advisory board set up to develop the SQOL-6D.

Six main goal areas have now consistently emerged from several studies (2-4) evaluating treatment for ULS. These are:

1. Reduction of pain and discomfort
2. Control of spasms and other involuntary movements
3. Maintaining the range of upper limb movements
4. Passive function: ease of caring for the affected limb;
5. Active function – using the affected limb in activities
6. Mobility/ balance.

The Upper Limb Spasticity Index (ULSI) incorporates the GASEous (GAS evaluation of upper limb spasticity) tool alongside a targeted set of standardised measures that are selected from a limited set to according to the individual's priority goals for treatment. The SQOL-6D was designed to complement the ULSI and GASEous, by providing a systematic assessment of subjects' experience on the main impacts of ULS, and specifically in relation to the individual's priority goals for treatment.

The six dimensions (items) of the SQOL-6D were designed to map on to the same six main goal areas identified from our previous research and so to capture the direct experience and concerns that were most relevant to subjects suffering from ULS.

- Each dimension is assessed using a five-level scale ranging from 0 to 4, with higher scores meaning worse condition (e.g. greater pain, greater difficulty with caring for the affected limb...).
- The Total SQOL-6D score is computed as a linear transformation of the mean of the six dimensions scores to have the Total score ranging from 0 to 100, with the direction of scoring inverted, so that a higher score indicates a better quality of life, in line with other instruments.

Although the SQOL-6D is designed around the common goal areas for treatment of ULS as described above, each individual patient would usually only have goals for treatment in one to two areas. While the whole SQOL-6D tool provides an overall picture of spasticity-related health status, when evaluating response to treatment only the dimensions relevant to the identified treatment goals are expected to change. As a responsive measure of spasticity-related quality of life, the SQOL is designed to be applied in clinical practice in a similarly targeted manner to the ULSI, recording those dimensions that relate to the chosen goal areas.

An initial psychometric evaluation has been undertaken in a national, multicentre, prospective, longitudinal study conducted at eight sites in the United Kingdom (UK) which demonstrates acceptable reliability, validity and responsiveness to clinical change of the SQOL-6D Total score (in preparation for publication). Further evaluation is now underway.

## **Instructions for patients**

**Spasticity** is a condition in which certain muscles are continuously contracted.

- The resulting stiffness and tightness of muscles may affect your ability to move one or more of your limbs.
- Sometimes spasticity is so severe that it gets in the way of daily activities, sleep patterns, and caregiving.

**Common unwanted effects of spasticity are:**

- Pain
- Spasms or involuntary movements
- Contracture and deformity
- Decreased ability to use the arm/hand in active movements, such as reaching for, grasping, holding and releasing objects
- Difficulties with caring for the arm and hand (eg keeping it clean and dressed),
- Reduced balance and mobility

**The SQoL-6D** is a brief questionnaire in six domains, designed to assess quality of life in relation to spasticity that affects the upper limb, which includes the arm, shoulder or hand.

**Please answer the following questions about how you have felt in the last 7 days, in relation to symptoms related to spasticity in your affected upper limb(s)**

# The spasticity-related quality of life tool (SQOL-6D) (anchored)

Within the last 7 days:

## 1. Pain / discomfort:

To what extent have you experienced pain or discomfort due to spasticity in your arm, shoulder or hand that interferes with activities or sleep?

*(eg stiffness or a cramp-like sensation in the muscles, the joints being pulled into uncomfortable positions, or the finger-nails digging into the palm, that can sometimes interfere with activities or sleep)*

- |                          |  |
|--------------------------|--|
| <input type="checkbox"/> | I have no pain or discomfort in my affected upper limb(s)  |
| <input type="checkbox"/> | I have mild pain or discomfort in my affected upper limb(s)<br>which does not interfere with my activities or sleep                |
| <input type="checkbox"/> | I have moderate pain or discomfort in my affected upper limb(s),<br>which only occasionally interferes with my activities or sleep |
| <input type="checkbox"/> | I have severe pain or discomfort in my affected upper limb(s)<br>which sometimes interferes with my activities or sleep            |
| <input type="checkbox"/> | I have extremely severe pain or discomfort in my affected upper limb(s)<br>which frequently interferes with my activities or sleep |

## 2. Involuntary movements or spasms:

To what extent have you experienced involuntary movements or spasms in your arm shoulder or hand that interfere with normal activities?

*(eg movements or abnormal limb postures that you can't control such as sudden spasms; or the arm pulling up or the hand clenching into a fist when you use another part of your body, which may affect normal activities such as your ability to move around)*

- |                          |   |
|--------------------------|---|
| <input type="checkbox"/> | I have not experienced any involuntary movements or spasms in my affected upper limb(s)   |
| <input type="checkbox"/> | I have mild involuntary movements or spasms in my affected upper limb(s)<br>which do not interfere with normal activities               |
| <input type="checkbox"/> | I have moderate involuntary movements or spasms in my affected upper limb(s)<br>which interfere minimally with normal activities        |
| <input type="checkbox"/> | I have severe involuntary movements or spasms in my affected upper limb(s)<br>which interfere significantly with normal activities      |
| <input type="checkbox"/> | I have extremely severe involuntary movements or spasms in my affected upper limb(s)<br>which interfere severely with normal activities |

## 3. Restricted range of movement:

To what extent has spasticity restricted the range of movement in the joints of your arm, shoulder or hand?

*(eg inability to straighten or bend the limb fully due to shortening of muscles or stiffness in joints)*

- |                          |  |
|--------------------------|--|
| <input type="checkbox"/> | I have no restriction of movement in my affected upper limb(s)   |
| <input type="checkbox"/> | I have mild restriction in range of movement in my affected upper limb(s)<br>but I am able to stretch my joints out fully with assistance  |
| <input type="checkbox"/> | I have moderate restriction in range of movement in my affected upper limb(s)<br>or restriction affecting just a few joints                |
| <input type="checkbox"/> | I have severe restriction in range of movement in my affected upper limb(s)<br>or restriction affecting many of my joints                  |
| <input type="checkbox"/> | I have extremely severe restriction in range of movement in my affected upper limb(s)<br>so that I can barely move my affected limb at all |

#### 4. Caring for the affected limb

To what extent has spasticity limited the ability (of or your carer) to care for your arm shoulder or hand?

(Eg to keep the palm or armpit clean and odour-free, to cut the finger-nails or dress the limb (eg getting the arm through a sleeve or the hand in a glove))?

<input type="checkbox"/>	I have no problems with caring for my affected upper limb(s)
<input type="checkbox"/>	I have mild problems caring for my affected upper limb(s) for example it takes some extra time or effort to care for my limb
<input type="checkbox"/>	I have moderate problems caring for my affected upper limb(s) for example it takes me a long time or I need help from someone else to care for the limb
<input type="checkbox"/>	I have severe problems caring for my affected upper limb(s) for example despite assistance my limb is sometimes smelly or left undressed
<input type="checkbox"/>	I am unable to care for my affected limb(s) and am unable to keep my limb clean and dressed

#### 5. Using the affected limb

To what extent has spasticity limited active use of your arm shoulder or hand?

(Eg reaching for, grasping, holding and releasing objects or fine finger movements)

<input type="checkbox"/>	I have no problems using my affected limb(s)
<input type="checkbox"/>	I have slight problems using my affected limb(s), which limit tasks requiring a high level of dexterity
<input type="checkbox"/>	I have moderate problems using my affected limb(s), but am able to use it actively in some tasks
<input type="checkbox"/>	I have severe problems using my affected limb(s), but am able to use it as a 'prop' to hold or steady an object
<input type="checkbox"/>	I am unable to use my affected limb(s) for any useful purpose

#### 6. Mobility / Balance:

To what extent have involuntary movements or tightness of your arm, shoulder or hand interfered with your mobility or balance?

<input type="checkbox"/>	I have no problems with mobility or balance
<input type="checkbox"/>	I have mild problems with mobility or balance, but I can get around independently
<input type="checkbox"/>	I have moderate problems with mobility or balance, which limit my ability to get round independently outdoors
<input type="checkbox"/>	I have severe problems with mobility or balance, which limit my ability to get around independently, outdoors and indoors
<input type="checkbox"/>	I have extremely severe problems with mobility or balance, and need help from another person to get around