ULSI

Upper Limb Spasticity Index

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Introduction

Outcome measurement in the context of upper limb spasticity management poses a number of challenges:

1) **Diversity of presentation** - Patients present different patterns of spasticity
2) **Goal diversity** – patients and their families have different priorities, and different goals for treatment.
3) **Outcome diversity** – a range of outcome measurement tools are therefore required to capture the diverse benefits of treatment.

That said, research to date has demonstrated some commonality in goal areas. The purpose of the Upper Limb Spasticity Index is to provide a brief battery of assessment measures that cover the range of diversity described above, but which capture the essential benefits to the patients/ families who live with spasticity.

Goal Attainment Scaling has been used since the 1960s as a person-centred method to capture the achievement of individual goals for treatment across a range of life experience [1]. It has been widely used in rehabilitation and is shown to be a sensitive outcome measures for recording gains in upper limb spasticity. However, a number of concerns have been expressed about using GAS as a primary outcome:

- As originally described, it is time-consuming to apply in routine practice, and clinicians are frequently confusing by the 5-point numerical goal rating system
- The validity of GAS has been questioned with respect to the subjective nature of goal prediction
- It is an evaluation of the achievement of intention, rather than outcome per se. Therefore it does not replace standardized measurement tools

Nevertheless, it represents a useful assessment of whether the treatment was successful overall in achieving its intended goals.

The GAS Evaluation of Outcome in Upper Limb Spasticity (GASeous) tool

The GAS-eous tool has been developed to address some of the criticisms of GAS as a tool for measurement of outcome in the treatment of upper limb spasticity.

- It is a structured goal setting tool centred on the 6 common goal areas for treatment, which are mapped onto the WHO ICF [2].
- It includes standardised measures as the reference point for goal achievement
- It used the GAS-light method of recording goal attainment, which is based on verbal descriptors that align with clinical decision-making.

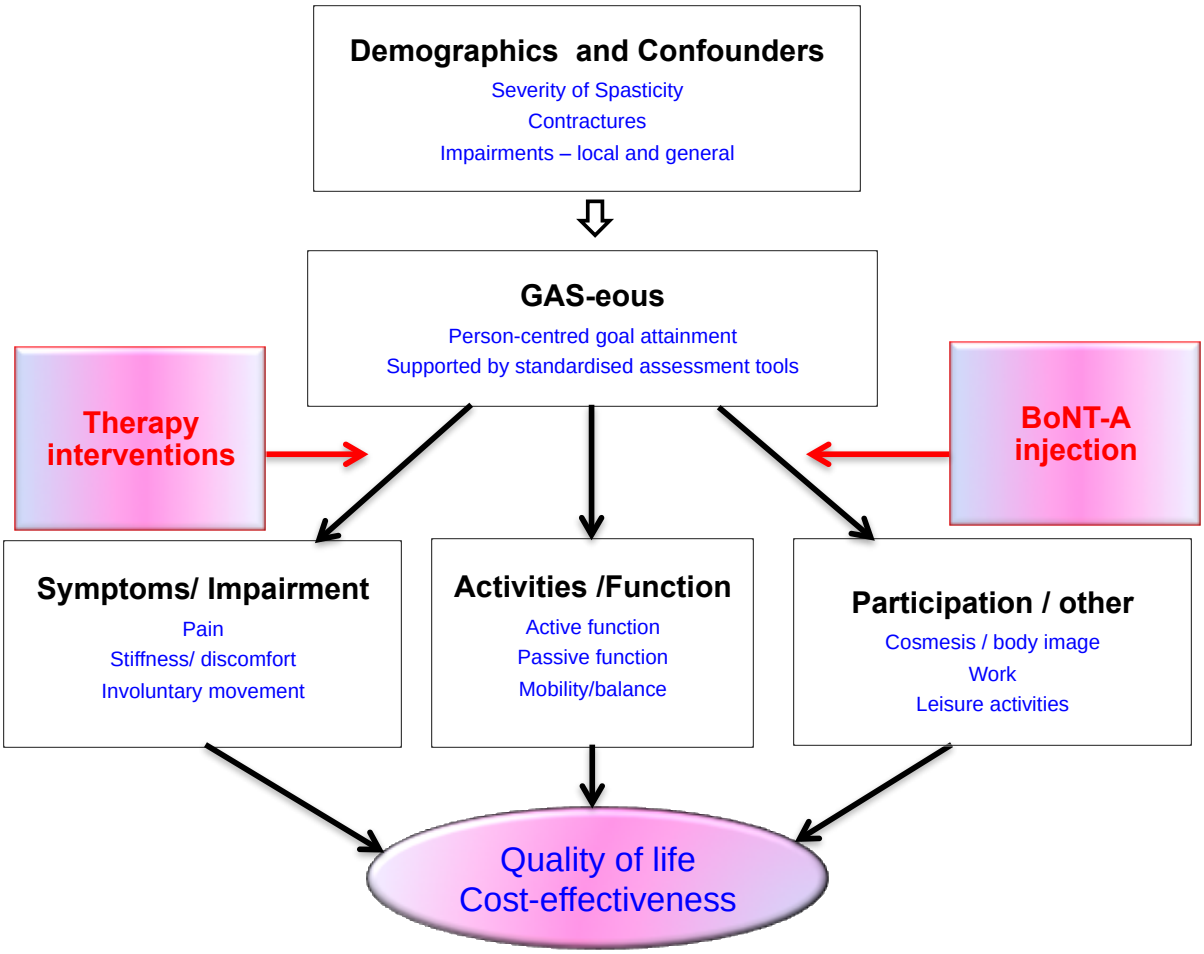
The goals areas were identified from secondary analysis of goal statements from four large international studies [3-7], representing a diverse selection of patient populations ranging from profoundly disabled patients in residential care, to a mixed acute and post-acute neurorehabilitation population [3, 4, 8] to an ambulant out-patient group with chronic post stroke spasticity [5, 6].

Although the emphasis of goals set and achieved varied between these populations, all goals mapped consistently onto 6 key goal areas in two principal ICF domains as shown in Table 1:

Table 1

Principal ICF Domains	Key goal areas
Domain 1: Symptoms and impairment:	1. Pain/discomfort / stiffness (ICF: b280, b780, b134) 2. Involuntary movements (ICF: b760, b765) 3. Impairment (prevention of contractures) ((ICF b710, b735)
Domain 2: Activities and function	4. Passive function (caring for the affected limb), (d520) 5. Active function (using the affected limb in some motor task) (d430, d440, d445) 6. Mobility(d415, d450)
Other	▪ Cosmesis (improving body image) ▪ Facilitation of therapy

OVERVIEW: The Upper Limb Spasticity Index (ULSI)



SUMMARY of ULSI

*The **Upper Limb Spasticity Index** is a standard battery of assessments, which includes both patient-reported and clinician-rated elements **– ultimately reflecting Quality of life related to UL spasticity**.*

The ULSI has 3 main components as summarized below and detailed in Table 2:

1. **Severity of presentation and confounders to recovery**, including
   - Demographics
   - Distribution and severity of spasticity and soft tissue contractures
   - Severity of impairment
     - Local to upper limb (eg, motor control, sensory loss, neglect)
     - General – Cognitive, behavioural, communicative, mood
2. **Individual goal attainment scaling**
     - GAS-eous –SMART goal setting supported by targeted standard measures according to goal areas
     - Patient satisfaction with and engagement in goal setting
3. **A limited set of standardised measures**

Table 2 Components of the ULSI

ULSI	**Rated by Clinician**	**Rated by Patient / carer**
A. Severity and confounders (History & Examination)	• Demographics	
	• Distribution of spasticity • Severity of spasticity (MAS) • Severity of impairment (NIS) • Soft tissue contractures (loss of range)	
B. Goals for treatment	• GAS-eous tool – SMART goals negotiated between patient and team • with associated measurement parameters within each chosen goal area	
C. Standardised measures – conducted as routine on all patients		
Symptoms		Pain rating/10 (NGRS or SPIN) [9]
Involuntary movements	Associated Reaction Rating Scale [10]	
Function – passive and active		Arm Activity Scale (ArmA) [11] - passive and active function Ease of caring for limb (NGRS)
Mobility	Functional Ambulation Category [12] 10m walk (speed)	
Global benefits	Global benefit scale (-2 to +2)	ArmA Impact [11] Global benefit scale (-2 to +2)

MAS = Modified Ashworth Scale; NIS = Neurological Impairment Scale. NGRS = Numbered Graphic Rating Scale SPIN = Scale of Pain Intensity

DEMOGRAPHICS and severity indicators

These data are collected by clinicians, and is largely the same as the data that were previously included in the electronic Case Report Form (e-CRF) for ULIS-II.

This section of the ULSI records:

- **Basic demographic characteristics** to define the population,
- **Distribution and severity of the spasticity** – spasticity is a focal condition which may affect the whole upper limb - or just the proximal or distal part of it. Its severity and distribution will affect the types of goals for treatment
- **Factors which may confound outcome from treatment** including
    - dominance,
    - impairments within the affected limb,
    - general impairments which may limit the individual's ability to engage successfully in rehabilitation and achievement of their set goals

Table 3: Summary of demographics and severity indicators

Demographics **(Section A1)**	▪ Age / Gender / Diagnostic category ▪ Duration – time since onset ▪ Dominance of the affected upper limb ▪ Care - who cares for the limb ?
Spasticity **(Section A1)**	▪ Distribution and severity of spasticity – by joint ○ Modified Ashworth Scale (MAS)
Impairment **(Section A2)**	Adapted Neurological Impairment Scale (NIS): ▪ Local to upper limb ○ Motor control (0-3) ▪ Proximal: arm raise- reach ▪ Distal: hand function ○ Sensation (0-3) ○ Neglect (0-3) ▪ General ○ Cognitive/Communication /Behavioral /Mood ▪ Soft tissue contractures – by joint ○ % loss of range (0-3)

The GAS-eous, with examples of tools to assist with SMART goal setting is given in the supporting appendices. Tools include the Numbered Graphic Rating Scale (NGRS) and the SPIN (a simple visual analogue score for pain designed for patients who are unable to use the NGRS of verbal 10-point rating scale/10, due cognitive or communicative problems.

The other standardised tools are also detailed in the supporting appendices.

Supporting Appendices

Details of the Upper Limb Spasticity Index Tools

Section	Tool
A1	Demographics, Spasticity
A2	Neurological Impairment Scale – adapted for Upper Limb Spasticiity
B1	The GAS-eous tool
C1	NGRS and SPIN
C2	Associated Reaction Rating Scale (ARRS)
C3	Arm Activity Scale (ArmA)
C4	Functional Ambulation Categories (FACs)
C5	Patient satisfaction with goal setting process
C6	Patient engagement in goal setting
C7	Global assessment of benefits

Section A1: Demographics

Age	Age in years						
Gender	Male / female						
Diagnosis	Neurological condition giving rise to spasticity: ❒ Acquired brain injury (stroke, trauma, other) ❒ Spinal cord injury ❒ Progressive neurological condition ❒ Congenital - e.g. CP						
Aetiology	❒ Trauma ❒ Vascular (infarct or haemorrhage) ❒ Hypoxic ❒ Inflammatory / infective ❒ Tumour ❒ Degenerative						
Duration	Time since onset of spasticity or injury (months)						
Dominance	Is the affected upper limb ❒ Dominant side (i.e. Right arm in a right handed person) ❒ Non-dominant						
Care	Who cares for the upper limb (e.g. washing, dressing, hygiene) ❒ The patient themselves ❒ A carer ❒ Both together						
Spasticity	Modified Ashworth Scale (MAS)	**Circle 1**					
	Shoulder	0	1	+1	2	3	4
	Elbow	0	1	+1	2	3	4
	Wrist	0	1	+1	2	3	4
	Fingers	0	1	+1	2	3	4
	Thumb	0	1	+1	2	3	4

Section A2: Impairment

NEUROLOGICAL IMPAIRMENT SCALE (NIS) ADAPTED FOR UPPER LIMB SPASTICITY OUTCOME EVALUATION

CATEGORY OF IMPAIRMENT

	Types			
☐ **Motor impairment in affected upper limb**	☐ b730 - Muscle power			
	☐ b760 - Control of voluntary movement			
	Select one severity grade			
	Severity		**Descriptor**	
	Right	**Left**		**Definition of severity category**
a) Motor proximal upper limb	0	0	Normal	Normal - raises arm above horizontal, normal power
Ability to move arm away from body in order to place the affected hand in a functional position	1	1	Mild	Mild loss of proximal motor function affecting higher motor control only
☐ Arm raising/reaching d445	2	2	Significant	Significant loss of proximal motor function but some useful movement
	3	3	Total	Useless - flickers or no active movement
b) Motor distal upper limb	0	0	Normal	Normal hand function
Use of affected hand to manipulate large and small objects	1	1	Mild	Mild loss eg difficulty with fine motor control for manipulating small objects
☐ Hand function (d440)	2	2	Significant	Significant loss, but some useful movement eg grasping / stabilising larger objects
	3	3	Total	Useless - flickers or no active movement
☐ **Sensation in affected upper limb**	0	0	Normal	Normal sensation
☐ Somatic (eg touch) b265	1	1	Mild	Mild or patchy loss - minimal interference with sensory function
☐ Proprioception b260	2	2	Significant	Partial sensory loss with significant impact on ability to feel the limb and where it is
☐ Dysaesthesia b279	3	3	Total	Complete / near-complete less of sensation (all modalities) in one or more limbs
	U	U	Untestable	

GENERALISED IMPAIRMENTS THAT MAY AFFECT FUNCTIONAL OUTCOME

☐ **Communication (Speech and Language)**	**Severity**	**Descriptor**	**Definition of severity category**
Communication affects functional outcome if pt unable to understand instructions	0	Normal	Normal communication
in therapy - comprehension more important than expression in this respect	1	Mild	Mild deficit affecting high level communication only - eg understands complex instructions
☐ Expressive b1671	2	Significant	Significant communication difficulties - unable to understand complex instructions
☐ Receptive b1670	3	Total	Severe deficit - effectively unable to communicate, or only at a very basic level
☐ Dysarthria b320	U	Untestable	
☐ Cognitive speech b1670			

☐ **Cognitive function**	**Severity**	**Descriptor**	**Definition of severity category**
Cognition affects functional outcome if pt unable to attend to or remember therapy	0	Normal	Normal cognitive function
sessions or carry over instructions from one session to another	1	Mild	Mild deficit affecting higher level cognitive function only
☐ Consciousness b110	2	Significant	Significant deficit impacting on carryover and engagement in rehabilitation
☐ Orientation b114	3	Total	Severe cognitive deficit effectively preventing carryover and active engagement in rehabilitation
☐ Memory b144	U	Untestable	
☐ Attention b140			
☐ Initiation b147			
☐ Executive function b164 (e.g. insight, planning, flexible thought)			

OTHER IMPAIRMENTS OF SUFFICIENT SEVERITY TO IMPACT ON FUNCTIONAL USE OR LIMB OR ENGAGEMENT IN TREATMENT AND REHABILITATION

☐ **Cortical function**	**Definition**
☐ Neglect of upper limb b180	Reduced awareness of affected upper limb
☐ Visuoperceptual function b156	Reduced ability to perceive objects in space, which impacts on functional use
☐ Dyspraxia	Reduced ability to carry out learned complex movements
☐ **Emotional / behavioral**	**Definition**
☐ Mood /emotional function b152	Mood disturbance eg depression, anxiety or emotional lability impacting on activities
☐ Behavioral problems d720	Eg physical / verbal aggression impacting on interpersonal interaction with treating team
☐ Pain b280	Pain (in the limb itself or elsewhere - eg headache) which limits activities
☐ Fatigue b740	Physical fatigue, de-conditioning or loss of stamina

☐ **Mobility of joints b710 (soft tissue or joint restriction)** *Underlying contracture or restricted range of movement non spastic component of joint restriction*	**Severity**		**Descriptor**	**Definition of severity category**
	Right	**Left**		
☐ Shoulder	0	0	None	No soft-tissue / joint restriction
	1	1	Mild	Mild restriction (less than 1/4 range affected)
	2	2	Significant	Significant restriction limiting range, but still some useful movement
	3	3	Total	Severe restriction of range (3/4 or more limitation)
☐ Elbow	0	0	None	No soft-tissue / joint restriction
	1	1	Mild	Mild restriction (less than 1/4 range affected)
	2	2	Significant	Significant restriction limiting range, but still some useful movement
	3	3	Total	Severe restriction of range (3/4 or more limitation)
☐ Wrist	0	0	None	No soft-tissue / joint restriction
	1	1	Mild	Mild restriction (less than 1/4 range affected)
	2	2	Significant	Significant restriction limiting range, but still some useful movement
	3	3	Total	Severe restriction of range (3/4 or more limitation)
☐ Hand	0	0	None	No soft-tissue / joint restriction
	1	1	Mild	Mild restriction (less than 1/4 range affected)
	2	2	Significant	Significant restriction limiting range, but still some useful movement
	3	3	Total	Severe restriction of range (3/4 or more limitation)

Section B1: GAS-eous Tool: GAS– Evaluation of Outcome for Upper-limb Spasticity

Important: *Select only those goal areas that are relevant*

Domain 1: Impairment / symptoms				**Measurement / goal rating**		
Goal Area	**Set Goal?**	**Sub-categories**	**Goal parameter** (suggestions provided)	**Baseline**	**Goal**	**Achieved**
Pain /discomfort (b280, b780, b134) Including stiffness	❒ 1° ❒ 2°	❒ Pain (b280) ❒ Stiffness (b780) ❒ Sleep disturbance (b134)	Level of pain / /stiffness / sleep disturbance Eg rated /10 or on graphic rating scale* Score 0-10 in whole numbers (see Appendix 1)	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more
Involuntary movements (b760, b765) Eg spasms or flexed posturing of arm when walking)	❒ 1° ❒ 2°	❒ Associated reactions ❒ Spasms ❒ Posturing / dystonia	Carry angle of elbow/height of hand up torso Spasm frequency (no. per day or night) Resting angle – degrees or % joint range	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more
Range of movement / prevention of contractures (b710, b735)	❒ 1° ❒ 2°	❒ Contracture prevention ❒ Passive ROM ❒ Active ROM ❒ Splint tolerance	Joint angles or anatomical distances eg - Goniometry - % normal joint range (25, 50, 75%) - finger-tips to palm Splint tolerance – time per day	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more
Cosmesis Perception of body image **Facilitation of therapy**	❒ 1° ❒ 2°	❒ Aesthetic appearance ❒ Body image ❒ Facilitating therapy	Satisfaction with appearance / body image eg rated /10 or on graphic rating scale Interference with therapy (Team rating/10)	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more

* We recommend using a visual analogue scale with numbers (technically called a Numeric graphic rating Scale (NGRS)) to optimize patient report – see appendix 1

Domain 2: Activities / Function				**Measurement / goal rating**		
Goal Area	**Set Goal?**	**Sub-categories**	**Goal parameter** (suggestions provided)	**Baseline**	**Goal**	**Achieved**
Passive function (d520) **Caring for the affected limb** whether care is done by someone else or by the person him/herself.	❒ 1° ❒ 2°	❒ Hygiene – hand ❒ Hygiene – axilla / elbow ❒ Nails ❒ Dressing the limb ❒ Positioning the limb ❒ Splint application/removal	Ease of care - eg rated /10 or on NGRS Time taken to achieve functional task	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some function ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more
Active function (d430, d440, d445) **Using the affected limb** in some active task involving motor movement /dexterity	❒ 1° ❒ 2°	❒ Reaching (d445) ❒ Grasp/release/grip (d445) ❒ Holding/bimanual function (d445) ❒ Manipulating objects (d445) ❒ Dexterity / fine motor (d440) ❒ Lifting / carrying (d430)	Able to manage motor task eg - holding and using the object - lifting cup to mouth etc Improved control / dexterity eg - rating/10, or NGRS etc - improved speed	Measurement	Measurement	Measurement
Ideally, goals should also have a clear functional purpose	❒ 1° ❒ 2°	❒ Eating /drinking (d550, d560) ❒ Personal ADL (d510, d520, d540) ❒ Extended ADL (d630, d640) ❒ Typing / writing (d345, d360) ❒ Hobbies /recreation (d920) ❒ Work (d850)	Achievement of functional task	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some function ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more
Mobility (d415, d450) Improved mobility – transfers / standing / walking due to better balance, etc	❒ 1° ❒ 2°	❒ Ease of transfers (d420) ❒ Balance (d415) ❒ Gait quality (b770) ❒ Speed / efficiency ❒ Type of walking ai used	Gait parameters – speed, distance Ability to climb stairs Falling / tripping frequency Safety / confidence /fatigue (NGRS) Video rating of gait quality	Measurement	Measurement	Measurement
Goal statement	*Write SMART goal statement here*			Baseline ❒ Some function ❒ Bad as could be	❒ Partially ❒ Same ❒ Worse	❒ As expected ❒ A little more ❒ A lot more

Example of a GAS-eous Record:

Patient: Ivor Payne. Age 46. Post stroke spasticity in his right upper limb causing severe pain and restriction of his right shoulder – **3 goals**

Domain 1: Impairment / symptoms					**Measurement / goal rating**	
Goal Area	**Set Goal?**	**Sub-categories**	**Goal parameter** (suggestions provided)	**Baseline**	**Goal**	**Achieved**
Pain /discomfort (b280) Including stiffness	❒ **1°**	❒ **Pain** ❒ Stiffness ❒ Sleep disturbance	Pain rating – numbered graphic NGRS	8	4-5	3
Goal statement	*To reduce resting pain in right shoulder from 8/10 to 4-5/10 at 3 months post injection*			Baseline GAS **-1**	**A little more**	
Range of movement / prevention of contractures (b710, b735)	❒ **2°**	❒ Contracture prevention ❒ **Passive ROM** ❒ Active ROM	Angle of passive shoulder abduction with scapula stabilised	30°	75°	60°
Goal statement	*To be able to abduct arm passively to 75° in order to facilitate cleaning under the axilla at 3 months post injection*			Baseline GAS **-1**	**Partially**	

Domain 2: Activities / Function					**Measurement / goal rating**	
Goal Area	**Set Goal?**	**Sub-categories**	**Goal parameter** (suggestions provided)	**Baseline**	**Goal**	**Achieved**
Passive function (d520) Ease of caring for the affected limb whether care is done by someone else or by the person him/herself	❒ **2°**	❒ Hygiene – hand ❒ **Hygiene – axilla / elbow** ❒ Nails ❒ Dressing the limb ❒ Positioning the limb ❒ Splint application	Ease of cleaning right armpit - rated out of 10 by carer.	3	6	6
Goal statement	*To make it easier to clean under axilla – carer rating of ease of care to improve from 3/10 to 6/10 at 3 months post injection*			Baseline GAS **-1**	**As expected**	

Baseline GAS T score: **36.7**	Achieved GAS T score: **53.3**

Section C1: NGRS and SPIN screen

The NGRS Screen. 1

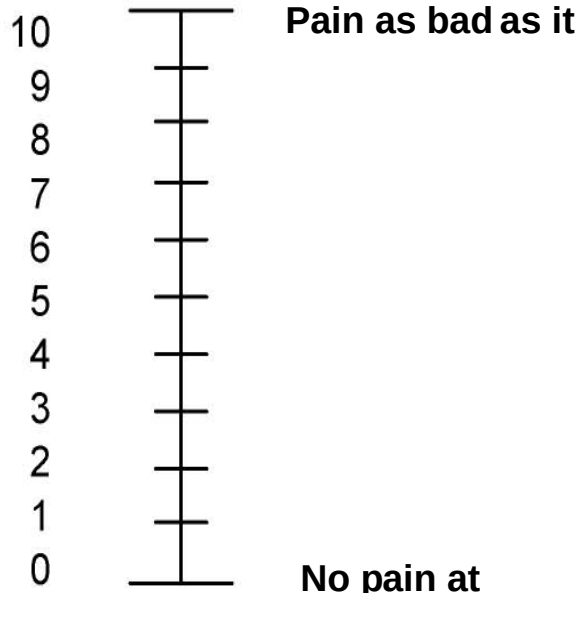
1. The scale below is a measure of pain.

The top LEVEL (Marked 10) indicates pain as bad as it could be

The bottom LEVEL (0) indicates no pain at all

Which number best describes the pain that you feel?

The Numeric Graphic Rating Scale (NGRS)



2. To the administrator:

In your opinion, does the patient understand this scale?

Comments:

- ☐ **Yes**
- ☐ **No**
- ☐ **Not sure**

3. Which scale would they prefer to use to assess their pain next time?

- ☐ **The SPIN**
- ☐ **The NGRS**
- ☐ **Either**

The SPIN Screen. 1

1. Do you have pain anywhere?

☐ **Yes**

☒ **No**

If yes, where?.....

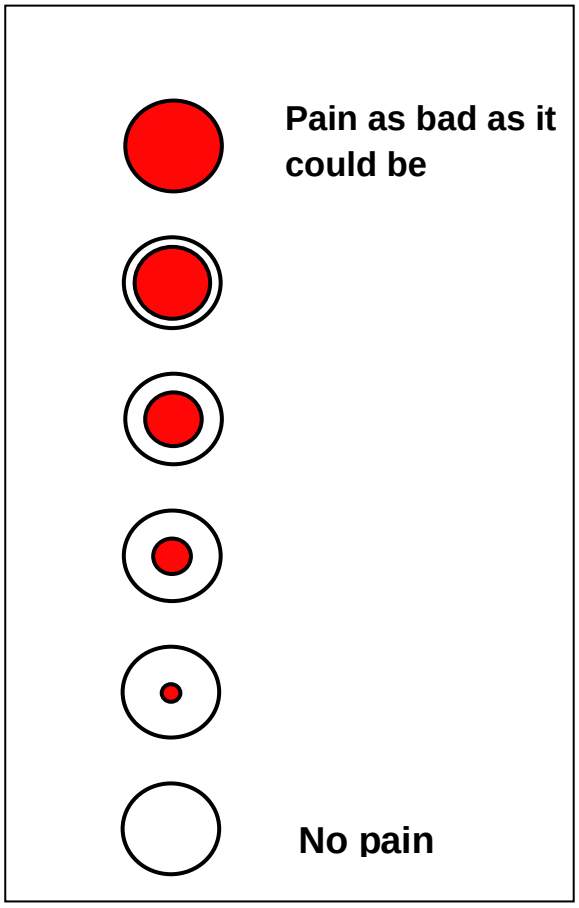
NB if >1 site, complete separate sheet for both

2. The scale below is a measure of pain.

The top red circle indicates pain as bad as it could be

The bottom clear circle indicates no pain at all

Which circle best describes the pain that you feel?



3. To the administrator:

In your opinion, does the patient understand this scale?

Comments:

Section C2: Associated Reaction Rating Scale (ARRS)

A	Excursion and duration of associated reaction
0	No involuntary movement/excursion of the limb
1	Excursion of the limb occurs on effort and disappears when effort ceases
2	Excursion of the limb occurs on effort, May be variable through the task and remains present for some time after the task has been completed. Residual posturing may be evident
3	Static 'stereotypical posturing'. Limb reaction remains essentially present and unchanging throughout task.
B	**Number of joints in the affected upper limb involved in associated reaction**
0	No involuntary movement of joints during task
1	Limb reaction confined to 1–2 joints
2	Limb reaction involves 3–4 joints
3	All joints of the limb involved and/or trunk.
C	**Release of associated reaction**
0	No limb reaction. Release not required
1	Initial position is regained through the subject's conscious control or with the assistance of gravity alone
2	Subject needs to use unaffected hand in order to return affected limb towards starting position
3	Subject needs to use unaffected hand in order to return affected limb towards starting position, but limb immediately returns to stereotypical posture when handling ceases. Or limb is unable to be released
D	**Effect of upper limb associated reaction on functional task (sit-to-stand, stand to sit).**
0	No limb reaction. Task unaffected.
1	Limb reaction present but does not interfere with task
2	Obvious interference with task, but able to complete task
3	Significantly affects ability to complete task *or* task not completed.

MODAL SCORE = …… 0 = None, 1 = Mild, 2 = Moderate, 3 = Severe

Most frequently occurring.

If scores are equally distributed between 2 levels, score the higher (most severe).

TOTAL SCORE = …….

(sum all sections above)

Note whether the subject uses arm support during sit-to-stand Y/ N (circle).

ARRS – scoring guidelines

1) Score each section A–D.

2) Chose one rating only from 0 to 3.

3) If you cannot decide between two levels, score the highest (most severe).

4) If the performance of the patient varies between tasks or during a single task score the worst performance.

5) If severity varies between joints of the upper limb, score the worst, most affected joint.

6) If using their unaffected limb to return the affected limb to its starting position provokes further associated reaction, score the worst situation observed during the test.

Clarifications

1) Arm swing of the affected limb during tasks such as sit-to-stand is not considered to be an involuntary movement or a limb reaction.

2) Number of joints.

> Joints in this instance are said to be hand, wrist, elbow and shoulder. Each is taken to represent one joint.

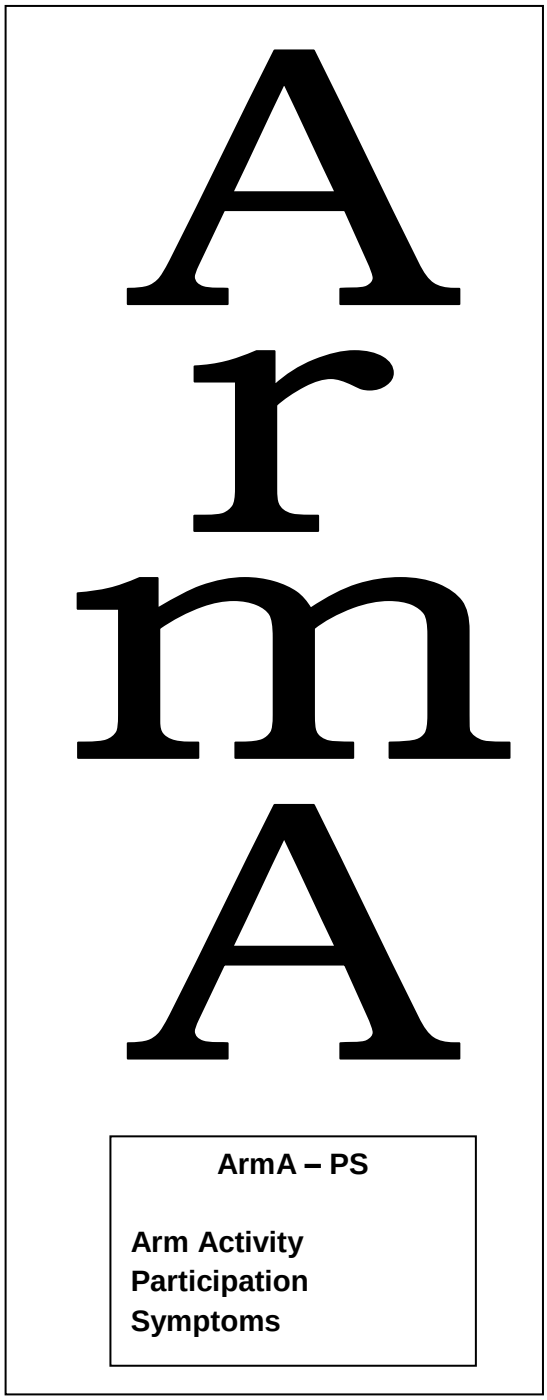
3) Section D: Score 3 'Task not completed'.

> This refers to a subject, who can attempt a task independently, but does not complete it. For example, in sit-to-stand they initiate the task but fail to achieve full standing.

Section C3: Arm Activity Measure (ArmA)

Details:

Surname…….. ……Forename(s)…….. Date of completion……../……../……



Arm Activity Measure

Please indicate (cross) who completed this questionnaire.

☐ Completed by yourself alone (patients)
☐ Completed by your carer (a family member ☐ or paid carer ☐ or another person ☐
☐ Completed by yourself with the assistance of another person (not your carer)

Please indicate (cross) who 'cares' for your affected arm (see the ArmA items for examples of tasks – page 4, section B).

☐ Yourself
☐ Your carer (a family member ☐ or paid carer ☐)
☐ Yourself and your carer together (a family member ☐ or paid carer ☐) together
☐ Yourself and another person, not your carer ☐

This section of the questionnaire asks for general information about you

Guidance for completion of the ArmA:

Section A asks about 'caring' for your affected arm either yourself with your unaffected arm or by a carer or a combination of both of these. This section does not ask about using your affected arm to complete any of the tasks.

Section B asks what you can do with your affected arm or using both arms.

For each of the activities listed, please indicate (circle):

1. The amount of difficulty that you or your carer experience in doing the task, based on your activity over the last 7 days. Please estimate if you do the task but have not done so in the last 7 days (e.g. for cutting finger nails).

2. If the task is never done, but this has nothing to do with your arm or is never done with your affected arm, score 0 = No difficulty.

Section C asks what general difficulties you are having related to your arm which impact on your life.

Section D asks symptoms that relate to your arm.
For these questions you will need to score the extent to which each item bothers you in your life based on the last 7 days.

If you are unable to complete the questionnaire independently, you may:

- Receive assistance from a carer or professional to act as scribe
- Receive assistance from a carer or professional to facilitate understanding and completion question by question.
- A carer may complete the questionnaire on your behalf based on difficulty in performance of the tasks.

In each column, please CIRCLE the amount of difficulty that you or your carer have experienced in doing the activity, over the last 7 days.

Arm function	Difficulty 0 = no difficulty 1 = mild 2 = moderate 3 = severe difficulty 4 = Unable to do activity

Section A Caring for your affected arm (not using it in tasks or activities)

1. Cleaning the palm of the hand	**0**	**1**	**2**	**3**	**4**
2. Cutting finger nails	**0**	**1**	**2**	**3**	**4**
3. Cleaning the armpit	**0**	**1**	**2**	**3**	**4**
4. Cleaning the elbow crease	**0**	**1**	**2**	**3**	**4**
5. Positioning arm on a cushion or support in sitting (If never done circle 0)	**0**	**1**	**2**	**3**	**4**
6. Putting arm through a garment sleeve	**0**	**1**	**2**	**3**	**4**
7. Putting on a glove (If never done circle 0)	**0**	**1**	**2**	**3**	**4**
8. Putting on a splint (If never done circle 0)	**0**	**1**	**2**	**3**	**4**

Section B Independently completing tasks or activities using your affected arm

1. Difficulty with balance when walking due to your arm	**0**	**1**	**2**	**3**	**4**
2. Hold an object still while using unaffected hand	**0**	**1**	**2**	**3**	**4**
3. Open (affected hand) a previously opened jar	**0**	**1**	**2**	**3**	**4**
4. Pick up a glass, bottle, or can	**0**	**1**	**2**	**3**	**4**
5. Drink from a cup or mug	**0**	**1**	**2**	**3**	**4**
6. Brush your teeth	**0**	**1**	**2**	**3**	**4**
7. Tuck in your shirt	**0**	**1**	**2**	**3**	**4**
8. Write on paper	**0**	**1**	**2**	**3**	**4**
9. Eat with a knife and fork	**0**	**1**	**2**	**3**	**4**
10. Dial a number on home phone	**0**	**1**	**2**	**3**	**4**
11. Do up buttons on clothing	**0**	**1**	**2**	**3**	**4**
12. Comb or brush your hair	**0**	**1**	**2**	**3**	**4**
13. Use a key to unlock the door	**0**	**1**	**2**	**3**	**4**

Section C Impact on your life

In <u>each column</u>, please <u>CIRCLE</u> how much you were bothered by the item over the <u>last 7 days</u>.

	Impact of your arm on wider participation	'Bother' 0 = not at all 1 = A little 2 = moderately 3 = Quite a bit 4 = Extremely				
1.	To what extent has your affected arm, shoulder or hand bothered you in your normal activities with family, friends, neighbours or groups?	**0**	**1**	**2**	**3**	**4**
2.	To what extent has your affected arm, shoulder or hand bothered you in your work or other regular activities (e.g. hobbies)?	**0**	**1**	**2**	**3**	**4**

Section D Symptoms (impairments)

In <u>each column</u>, please <u>CIRCLE</u> how severe the symptom was over the <u>last 7 days</u>.

	Symptoms	Symptom severity 0 = none 1 = Mild 2 = moderate 3 = Severe 4 = Extreme				
1.	Arm, shoulder or hand pain at rest	**0**	**1**	**2**	**3**	**4**
2.	Arm, shoulder or hand pain when you performed a specific activity	**0**	**1**	**2**	**3**	**4**
3.	Arm, shoulder or hand pain at night	**0**	**1**	**2**	**3**	**4**
4.	Lack of feeling in your arm, shoulder or hand	**0**	**1**	**2**	**3**	**4**
5.	Weakness in your arm, shoulder or hand	**0**	**1**	**2**	**3**	**4**
6.	Stiffness in your arm, shoulder or hand	**0**	**1**	**2**	**3**	**4**

Total Scores

Section A ☐

Section B ☐

Section C ☐

Section D ☐

Totalling section A, B, C and D separately produces a total score for each sub-scale of the measure.

The sub-scales should not be combined.

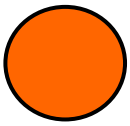
Section C4: Functional Ambulation Category

Score	Descriptor
0	Patient cannot walk, or needs help from 2 or more persons
1	Patients needs firm continuous support from 1 person who helps carrying weight and with balance
2	Patient needs continuous or intermittent support of one person to help with balance and coordination.
3	Patient requires verbal supervision or stand-by help from one person without physical contact
4	Patient can walk independently on level ground, but requires help on stairs, slopes or uneven surfaces
5	Patient can walk independently anywhere

Section C5: Goals: Patient Satisfaction

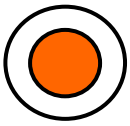
Patient satisfaction with the goal setting process

(as judged by patient / family)

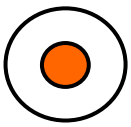


Excellent
My goals matched all my key priorities for rehab
And were entirely my own choice

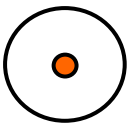
Very good
My goals matched my main priorities for rehab
And I was pretty happy with my agreed goal-set



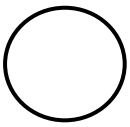
Good
My goals met most of my priorities for rehab
And I agreed with most of them



Moderate
My goals met some of my priorities for rehab
And I agreed with some of them



Poor
My goals were largely irrelevant to me
And I disagreed with most of them



None
My goals were completely irrelevant
And I did not agree with any of them
Or
What goals???

This is a scale to record the patient's satisfaction with goal setting.
It takes into account a number of factors related to goals:

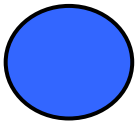
- How well the goals **matched their priorities** for rehab
- The extent to which they **agreed** with the goals
- The extent of **choice in goal areas**
- The extent to which they felt **involved with / in charge** of the goal setting process

The simple scale below does not attempt to tease these out.
If the patient is at different level with respect to these factors – e.g. they have a wide choice of goals but did not agree with any of them, **score to the lower**!

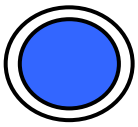
Section C6: Goals: Patient engagement in goal setting

Patient level of engagement in goal setting

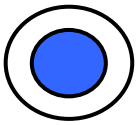
(as judged by team)



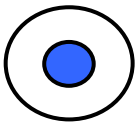
Excellent engagement
Fully independent in goal monitoring
And setting their own goals



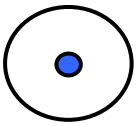
Very good engagement,
Patient takes most of responsibility for
monitoring and re-setting goals



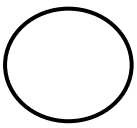
Good engagement,
But requires active support
Patient and team take 50/50 responsibility



Moderate engagement,
Patient engages to some degree, but team takes most of
responsibility (>50%) for monitoring and re-setting goals



Minimal engagement,
Patient indicates general goal area, but
Cannot engage in goal setting to any meaningful level



Unable
Cannot engage in goal setting at any level

This is a scale to record the level of engagement of a patient in their own goal setting.
It takes into account a number of factors related to goal-setting behaviour:

- Their **cognitive ability** to be aware of themselves, their situation and their environment
- Their **communicative ability** to articulate their priorities and frame those in specific goals
- Their **adjustment to limitations** and level of **realistic expectation** for the future.
- Their **behavioural approach to rehabilitation**, including self-monitoring, motivation and ability to organize themselves

The simple scale below does not attempt to tease these out.
If the patient is at different level with respect to these factors – e.g. they have the cognitive ability to understand, but cannot/ will not accept the concept of goal negotiation, **score to the lower**!

Section C7: Global Assessment of benefit

Patient rating	Global assessment of benefit following the BoNT-A treatment cycle	Clinicians rating
+2	Much better	+2
+1	A bit better	+1
0	The same	0
-1	Worse	-1
-2	Much worse	-2

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