Botulinum Toxin A Upper Limb Rehabilitation Clinical Guidance

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*This guidance is produced by the members of the UK & Ireland Upper Limb Rehabilitation Network, a voluntary network of clinicians. This network was created to improve access and standards of practice for children and young people who have rehabilitation needs related to their upper limb function. It is intended to be used as guidance only, and to supplement statutory clinical guidelines that exist in this and related fields of practice. The UK & Ireland Upper Limb Rehabilitation Network holds no responsibility for the consequences of use of this guidance which is at the discretion of the individual clinician.

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This guidance was prepared with the intention of being used freely by clinicians across the United Kingdom and Ireland, and beyond. If you find it useful in setting up, delivering, or evaluating your practice please do let us know.

Thank you to the British Academy of Childhood Disability for hosting access to this guidance.

Table of Contents

Introduction

The purpose of this document is to guide the clinical reasoning and processes that accompanies the administration of Botulinum Toxin Type A (in this document referred to as 'Botulinum Toxin A') as an adjunct to evidence-based upper limb therapy.

Botulinum Toxin A is used as an adjunct to therapy for children and young people under 19 years with upper motor neurone upper limb impairment, with the aim of maximising activity and/or comfort in everyday activities. [1-3]

This guidance supports clinical practice from assessment and considerations to support decision making as to whether use of Botulinum Toxin A injection is appropriate, through to the accompanying evidence-informed upper limb therapy and follow up after Botulinum Toxin A injections.

This guidance includes recommendations on:

i. Multi-disciplinary upper limb assessments
ii. Child/young person and family centred goal setting
iii. Recommended timeframes for administration of Botulinum Toxin A injection and subsequent interventions.
iv. When not to proceed with Botulinum Toxin A injections and why
v. Upper limb intervention type and dosage
vi. Evidence informed outcome measures
vii. Procedures for reviewing children and young people

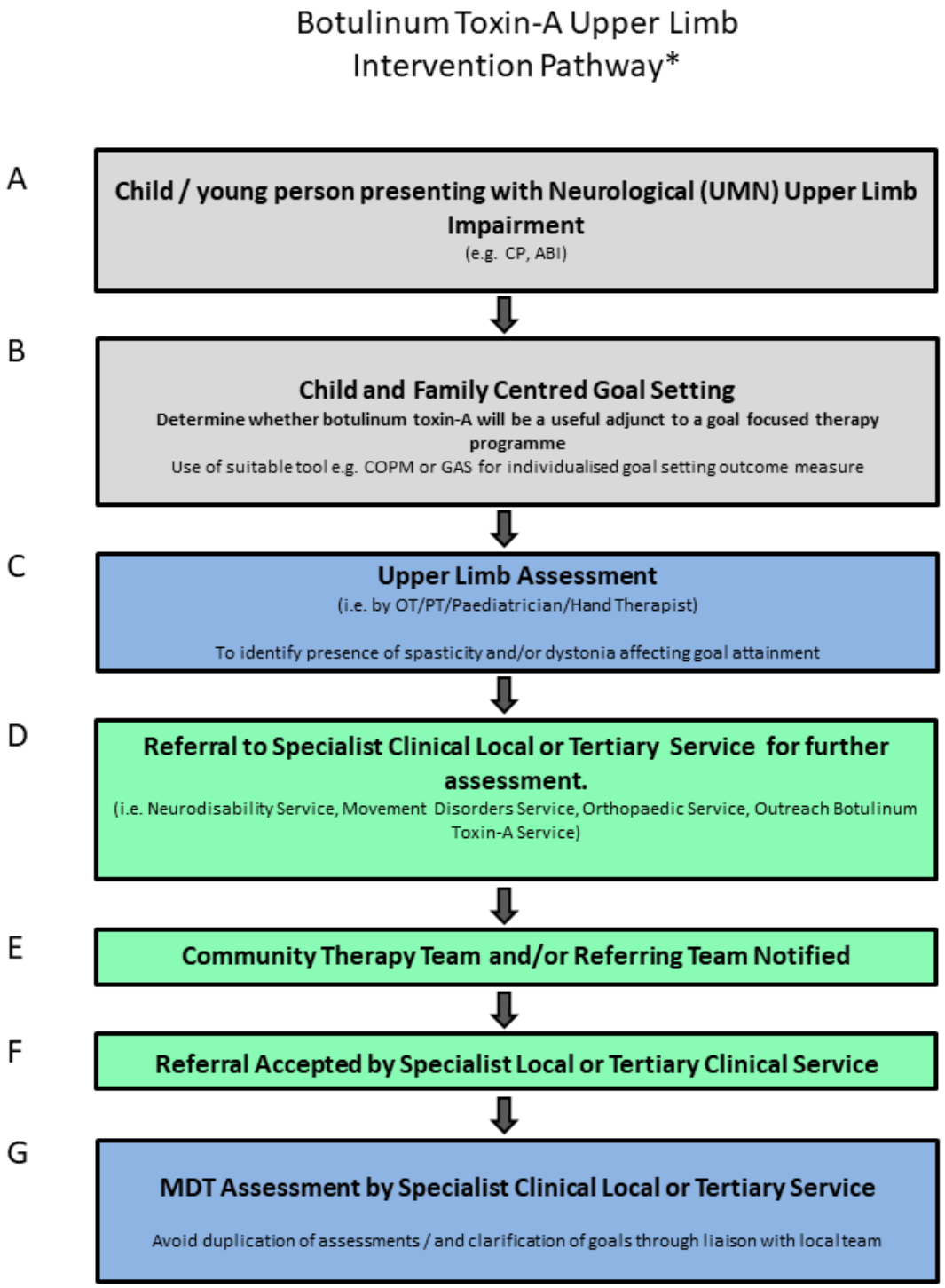
Who is this guidance for?

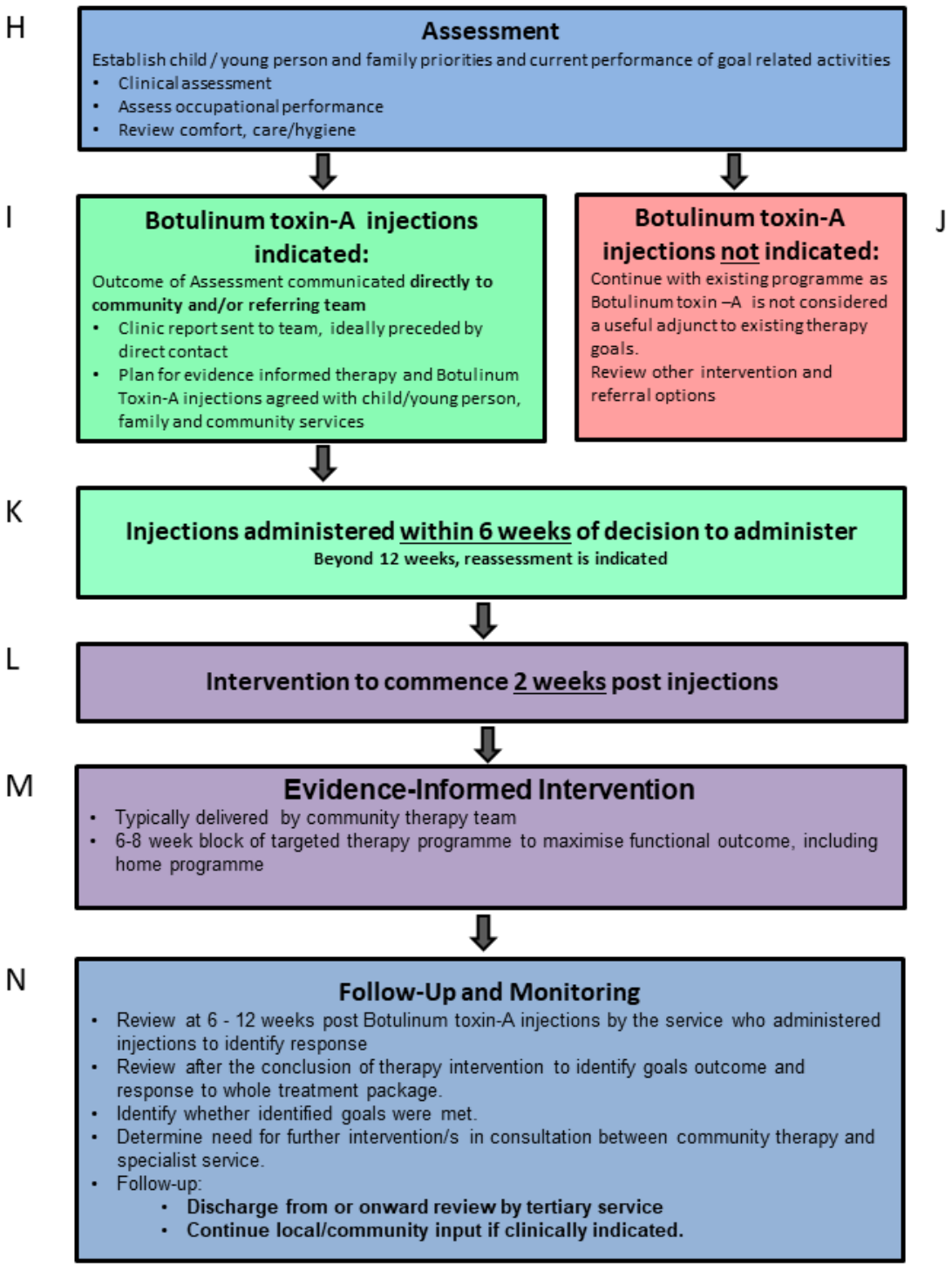
Healthcare professionals working with a paediatric population

How to use this guidance

The following guidance is arranged to follow a recommended pathway (see pages 4-5). The sections in this document (lettered A onwards) correspond to the sections of the pathway.

Figure 1.


Botulinum Toxin-A Upper Limb Intervention Pathway*
A
Child / young person presenting with Neurological (UMN) Upper Limb Impairment
(e.g. CP, ABI)
B
Child and Family Centred Goal Setting
Determine whether botulinum toxin-A will be a useful adjunct to a goal focused therapy programme
Use of suitable tool e.g. COPM or GAS for individualised goal setting outcome measure
C
Upper Limb Assessment
(i.e. by OT/PT/Paediatrician/Hand Therapist)
To identify presence of spasticity and/or dystonia affecting goal attainment
D
Referral to Specialist Clinical Local or Tertiary Service for further assessment.
(i.e. Neurodisability Service, Movement Disorders Service, Orthopaedic Service, Outreach Botulinum Toxin-A Service)
E
Community Therapy Team and/or Referring Team Notified
F
Referral Accepted by Specialist Local or Tertiary Clinical Service
G
MDT Assessment by Specialist Clinical Local or Tertiary Service
Avoid duplication of assessments / and clarification of goals through liaison with local team
* Letters indicate corresponding section in the guidance.
1



* Letters indicate corresponding section in the guidance.

2

A. Child/young person presenting with Upper Motor Neuron (UMN) Upper Limb Impairment

This guidance refers to

i. Children and young people aged from birth to 19 years, although it is acknowledged that this is service dependent. Some services may provide for young people up to 25 years.
ii. UMN Upper Limb Impairment including but not exclusive to children/young people with four limb cerebral palsy (CP), unilateral CP, primary dystonia, acquired brain injury including trauma, stroke, brain tumour, infection, near drowning and other anoxic episodes[4]
iii. Children/young people known to a local Children's Healthcare Team, which may include: GP, Health Visitor, School Nurse, Physiotherapist, Occupational Therapist, Paediatrician, and other paediatric services (services vary by Health Provider e.g. NHS Trust, Region and Country).
iv. Issue identified as a priority by the child/young person and/or caregivers with regard to neurological upper limb impairment that may be affecting function, pain levels, posture or cosmesis.

B. Goal setting

Why?

Specific, measurable, achievable, realistic and timely (SMART) goal setting is key for identifying the child/young person's and/or caregiver's priorities, appropriate therapy approaches determining the need for Botulinum Toxin–A, for guiding muscle selection, and evaluating outcome. It is important to establish the priorities and motivation of the young person and families, and whether it is the right time for the family to proceed with the intervention.

Botulinum Toxin A should only be used when it has been determined that muscle over-activity and/or stiffness is impacting on goal attainment, hygiene, pain or cosmesis.[5]

How?

Goal Attainment Scale (GAS)[6] and/or the Canadian Occupational Performance Measure (COPM)[7] are the two tools most relevant to paediatric goal setting and are commonly used in the literature. [8-10]

It is helpful to use the World Health Organisation International Classification of Functioning Disability and Health (Children and Young Person) (ICF-CY)[11] domains to classify goals. Injection of Botulinum Toxin A alone affects changes at the level of body functions and structures and provides a window of opportunity for change at the activity level through targeted goal setting and evidence informed therapy. The child/young person and caregiver goals will be aimed at the activity levels. See Figure 2.

Goal setting is also relevant to address comfort, ease of care and hygiene priorities.

Who?

Goal setting should be completed by an MDT or treating therapist jointly with the child/young person and parent/carer. Goal setting should ideally be carried out by the community therapy team prior to referral and assessment for Botulinum Toxin A intervention. It is important that goal setting is carried out at local level and fed back to the tertiary level services. If goal setting is completed with the tertiary service professionals, the community team should be included alongside consideration of the child/young person's environmental and personal factors e.g. home / school / nursery / leisure activities.[5]

C. **Community team upper limb assessment -** ideally multidisciplinary (MDT) assessment.

This assessment to include:[1-3,5,8,12-14]

Subjective assessment:

i. Exploration of current priorities and concerns with child/young person and family.
ii. History including antenatal, birth and developmental history.
iii. Identify difficulties in participation and activities of daily living e.g. dressing, feeding, personal care and leisure.
iv. Discuss current orthoses and equipment.
v. Discuss current interventions e.g. medication, therapy, home programmes and what has been successful for the child/young person and family.
vi. Establish if pain is present and use a suitable tool to classify.

Clinical assessment:

i. Observe arm posture at rest and during activity.
ii. Observe use of arms and hands in spontaneous activity and during walking and running.
iii. Observe the effects of postural support on hand and arm function.
iv. Undertake a systematic examination of body functions and structures to identify presence of spasticity and/or dystonia.
Spasticity is defined as the velocity dependent increase to the tonic stretch reflex, which includes brisk tendon jerks and increased resistance when moving a joint quickly.[15]
Dystonia is defined as involuntary muscle contractions which can be sustained or intermittent that cause abnormal postures and twisting and repetitive movements, or both.[15]
v. Use of suitable standardised activity measures.
vi. Use of suitable tools to identify muscle activity (see section H).
vii. Establish child/young person and family centred goals.
viii. Assign MACS (Manual Ability Classification System) and GMFCS (Gross Motor Function Classification system) levels in conjunction with family. These systems are to be used with children/young people with cerebral palsy only.

Outcome:

i. Explain roles of local and specialist clinical service teams and explain referral pathway.
ii. Gain consent for onward referral and to share clinical information with specialist clinical service.

D. Referral to specialist local or tertiary clinical service for further assessment.

Who?

Infants, children and young people (see section A above) with identified upper motor neuron signs present in their upper limb. This may include spasticity/dystonia/dyskinesia/weakness/rigidity or contracture affecting body functions and structures, activities and participation. For example, contractures, hygiene management, bimanual hand function, postural management, activities of daily living, school or leisure activities, accessing communication tools and devices, cosmesis, and pain.[13, 14, 16]

When?

Refer as early as possible, as soon as the above difficulties are identified to enable information and advice to be given to families.[13, 14] At later ages refer if any concerns arise in relation to the above.

Why?

To ensure that children and young people have timely access to a network of care that uses agreed care pathways and has access to a specialist team of healthcare professionals.[2, 3, 5, 8, 12-14]

What?

The specialist clinical local or tertiary level service will offer a holistic assessment and consider which interventions are indicated to support goal attainment. Referral information should include the outcomes of the assessment completed by the local team, in particular highlighting the child / young person's goals, the assessment findings and details of any assessment tools used. Details about the intervention available locally and relevant information about timing of intervention is also of benefit.

Possible interventions offered by the specialist clinical service may include: Botulinum Toxin A, oral medication for tone management, orthoses, casting, intensive upper limb (UL) therapy and onward referral to plastic surgery, orthopaedics or other specialist movement disorder clinics (e.g. for opinions regarding intrathecal baclofren, selective dorsal rhizotomy, deep brain stimulation).[3, 8, 13, 14, 17, 18]

What to include:

i. Reasons for referral
ii. History
iii. Other investigation.
iv. Previous interventions
v. Information gained from assessment
vi. Names and contact details of therapists and other key workers

E. Referral accepted by specialist clinical service

Child and young person allocated assessment appointment according to local procedures.

F. Community and/or referring team notified

i. Referring team to gain consent from parents/carers or young person as appropriate to liaise with specialist clinical service.
ii. Communicate with local teams, establish communication methods with community therapists e.g. telephone, secure email, letter.
iii. Invite local professionals to clinic appointment.
iv. Establish what assessments have been undertaken or planned by the community teams.
v. Establish what intervention is available from the local team and timeframes for this.

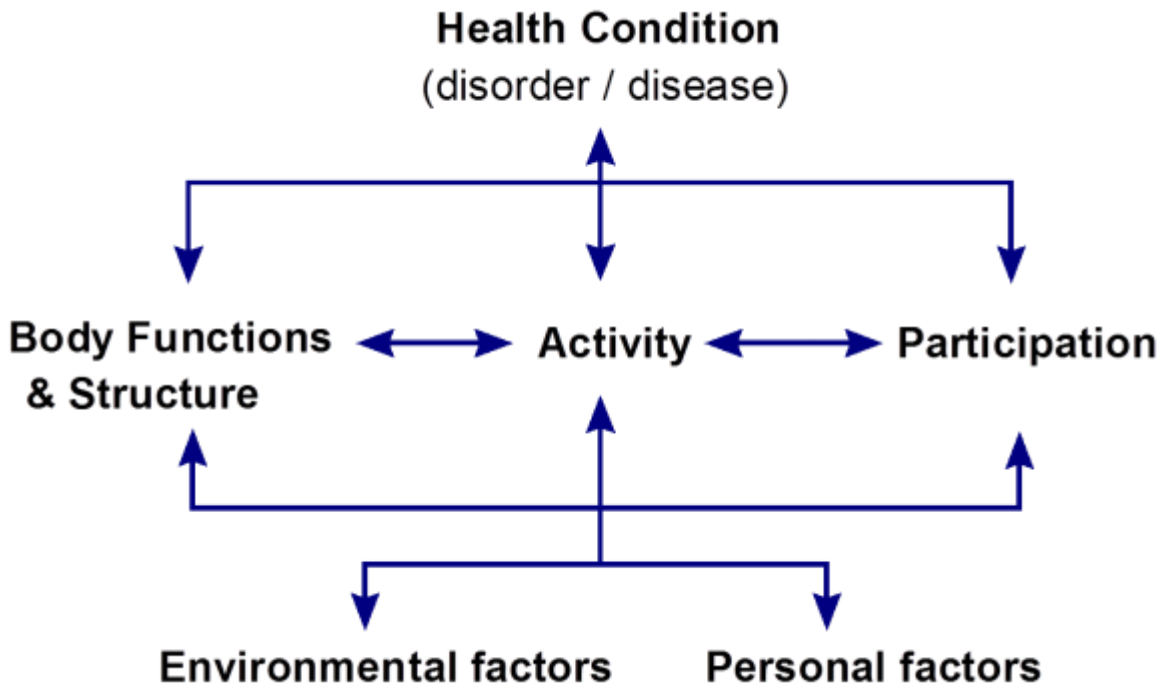
G. MDT assessment by specialist clinical service

NICE guidelines define a multi-disciplinary team as a minimum of an occupational therapist or physiotherapist and a medical professional from neurology or neurodisability, orthopaedic/plastic surgeon.[3, 4]

Assessment should consider all aspects of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) framework.[11,19] The ICF-CY is designed to frame health and wellbeing in domains including functions and structures of the body, activity limitations and participation restrictions manifested in infancy, childhood and adolescence and relevant environmental factors (see Figure 2).

Impairment and activity-level measures assist in providing information for muscle selection, dosage and guiding post-injection therapy.

Figure 2. The International Classification of Functioning Disability and Health Framework



H. Assessment

Standardised Tools should be used to:

i. Inform the decision as to whether the treatment is appropriate.
ii. Provide a baseline against which the response to treatment can be measured. [2, 8, 9]

Standardised assessments:

The selection of the outcome measure depends on the nature of the child's individual goal(s). The tool selected should be valid and reliable to detect change[2]. Assessment tools should be chosen based on appropriate clinical reasoning.
It is important to separate the assessment into:

i. Selection/screening of children and young people for Botulinum Toxin A.
ii. Specialist assessments to identify clinical indicators for Botulinum Toxin A. The tools used are not necessarily mutually exclusive.

All children and young people should have a minimum assessment consisting of:

i. **body structure and function** (active range of motion (AROM)
ii. passive range of motion (PROM) and tone).[,,]
iii. a measure of **activity** to record functional goals as a minimum.[1,2,5, 11-13,17,19]

Assign MACS level

Mini-MACS

All children and young people with a diagnosis of cerebral palsy should have a classification of **mini MACS/MACS** (Manual Ability Classification System).

Mini-MACS is an adaptation of MACS. It described how children aged 1–4 years with cerebral palsy use their hands when handling objects in daily activities The Mini-MACS shows evidence of validity and reliability when used both by parents and by therapists [5.] It is recommended that children's Mini-MACS levels should be reviewed annually because their condition and presentation may change in the early years.

This can be found at the following web link:

http://www.macs.nu/files/Mini-MACS_English_2016.pdf

MACS

The Manual Ability Classification System (MACS) describe how children and young people aged 4–18 years with cerebral palsy use their hands when handling objects in daily activities. The classification is designed to reflect the child/young person's typical manual performance, not the child/young person's maximal capacity. It classifies the collaborative use of both hands together.

The MACS can be found at the following link:

http://www.macs.nu/files/MACS_English_2010.pdf

Examples of additional classification systems

Classification measures can be useful in describing a child's presentation, however they are not outcome measures. Examples include:

i. Modified House Functional Classification System[10]

ii. Volkmann's angle[20]

iii. Zancolli's Classification of Wrist and Finger Deformities[21]

Table 1. Examples of assessment tools

ICF-CY	Assessment Methods At minimum	Suggested Additional Methods
Body structure and function	**Spasticity**: Tardieu scale or modified Tardieu scale (MTS)[22] **Muscle tone:** (modified Ashworth scale (MAS) [23] modified Tardieu scale[22], Hypertonia Assessment Tool (HAT)[24] **Active range of motion (AROM)** in context of activity analysis **Passive range of motion (PROM)**	**Sensation:** two-point discrimination, Semmes-Weinstein monofilament test [25] **Grip and pinch strength**[26] (measured using a dynamometer or pinch gauge) **Visual Analogue Scale (VAS)**[27] **Paediatric Pain Profile**[28] **Electromyography (EMG)** at rest and during stretch may be used in addition to kinematics in some settings, although this is not usual clinical practice at this time.
Activity (execution of a task or action by an individual)	**Individual goal identification**, rating and scaling (Canadian Occupational Performance Measure **(COPM)** [29], Goal Attainment Scaling **(GAS)** [30] and GAS light. [6] Observe functional performance Observation of the influence of posture and movement on performance of goal-related skill or activity. Video pre and post intervention	**Bimanual performance**: **Assisting Hand Assessment** (AHA)[31]. **Mini Assisting Hand assessment** (Mini AHA) [32]. **Both Hand Assessment** (BOHA) [33] **Hand Assessment for Infants** (HAI)[34]. **Box and Block test**[35] **SHUEE:** Shriners Hospital Upper Extremity Evaluation tool[36] **Abilhands Kids** [37] **Perceived performance:**

		Children's Hand use Experiences Questionnaire (CHEQ) [38:] **Activities of Daily Living Skills:** **Paediatric Evaluation of Disability Inventory Computer Adaptive Test** (PEDI-CAT) [39] **Functional Independence Measure for Children**(Wee FIM) [40]
Participation (involvement in a life situation)	**Detailed interview of occupational performance and observation of functional performance** in relation to identified goals (video pre and post outcome) **Canadian Occupational Performance Measure** (COPM)[29]	**The Children's Assessment of Participation and Enjoyment** (CAPE) [41] **Child and Adolescent Scale of Participation** CASP [42] **Participation and Environment Measure for Children and Youth (PEM-CY)** [43]
Environmental and personal factors	Family and young person interview – including school / college, leisure, home environments	

I. Botulinum Toxin A injections indicated

Communication and Information Sharing

i. Best practice is to ensure continuity of service and quality of care through clear communication across the services addressing the client's physical, medical and care needs.[3, 5] This may include (but is not limited to):
    a. Complex Physical Disabilities Team
    b. Botulinum Toxin A clinics
    c. Community teams
    d. Specialist therapy providers
    e. Education centres

ii. Information shared should include (but is not limited to):
    a. Provide child/young person and parents/carers with Botulinum Toxin A information leaflet (see Appendix A for an example)
    b. Botulinum Toxin A plan
    c. Goals for use of Botulinum Toxin A
    d. Plan for evidence informed therapy; such as targeted intervention approaches, splinting, and exercises.
    e. Consider use of a Botulinum Toxin A passport where multiple services are involved for effective information sharing. This is consistent with current best practice when working with children and young people receiving Botulinum Toxin A injections.

iii. Child/young person and/or parents/carers should be informed of the clinical reasoning for Botulinum Toxin A injections, the risks and the procedures (including evidence informed therapy required)[1,3, 5,12]

iv. **Clinicians should not recommend Botulinum Toxin A if there is no service provision or capacity to provide support services, follow-up, and therapy following injection** [2,5,12] .

Muscle Selection

i. Selection of the muscles that are primarily causing the child/young person's functional/care giving difficulty as identified through their goal is essential for a good outcome. [36,37 5, 8, 12-14,

ii. Targeted muscles should have focal, spasticity and/or dystonia which is either:
    a. limiting function
    b. impeding caregiving
    c. causing pain or deformity

iii. Muscles that have fixed contractures without a dynamic element should not be injected. Note that children / young people with MACS levels IV and V may have significant muscle contracture and high levels of stiffness but very little dynamic component.[1, 2, 5]

iv. For some children and young people Botulinum Toxin A has the potential to decrease functional use of their upper limb. Some children utilise their spasticity, even if involuntarily, for functional benefit. Botulinum Toxin A injections in these muscle groups may result in a negative impact on manual function. This may be a contraindication and needs careful consideration.[1,11,13,36] Caution should also be taken with significant underlying muscle weakness.[16]

Recommendations for administering Botulinum Toxin A

Who?

Injections should be carried out by a specialist team trained in the administration of Botulinum Toxin A [2, 3, 12]

How?

Consent:

i. Written informed consent by person with parental responsibility/ child/young person documentation of what, why, side effects and goals.[1-3,5]
ii. Transient adverse events occur in 3-23% of injections and these include pharyngitis, non-specific pain, respiratory tract infection, vomiting, bruising, flu-like illness, seizures and urinary incontinence.[1,12]
iii. Adverse systemic events (including dysphagia, aspiration pneumonia, and generalised weakness) occur in approximately 1-4% of cases, and more predominately in those in GMFCS levels IV or V. [44,45]

Documentation should include:

Child/young person:

i. Observations/PEWS pre- and post-injections
ii. Drug sheet or record
iii. Which muscles were injected
iv. How many sites
v. Unit dose per kg
vi. Who carried out the injections
vii. Post injection plan

United Kingdom Cerebral Palsy guidelines [4] recommend the use of a Botulinum Toxin-A passport when multiple providers are involved in intervention.

Botulinum Toxin A dosing

Dosage should be determined based on the child/young person's goals, level of muscle activity, severity of disability, underlying muscle weakness, previous response to injections and weight.[1,3,5,13]

Localisation

Ultrasound guidance is recommended for accurate localisation for Botulinum Toxin A injection.[1]

Sedation (to be carried out in accordance with local protocol and service guidelines)

Safe sedation for procedure is dependent on child/young person's co-morbidity. All options should be discussed with the family. Available options include:

i. No sedation or analgesia – older children/young people may opt for this
ii. General anaesthesia
iii. Local anaesthesia – Emla/Ametop/Cold spray
iv. Local Anaesthesia + Analgesia (Paracetamol)
v. Local Anaesthesia + Analgesia + Sedation (Nitric Oxide/ Oral Midazolam)

The child/young person should be assessed for suitability for the procedure and sedation by the administering team prior to procedure.

Administration

i. Child/young person should be in a safe setting where regular monitoring of pulse, respiratory rate, blood pressure, oxygen saturation and level of consciousness can be monitored.
ii. Facilities for emergency resuscitation should be available.
iii. Available professionals who are trained in basic life support in paediatrics.
iv. All doses should be prescribed and checked by two health care professionals.
v. Botulinum Toxin A should be administered by a health care professional who has been trained on selection, identification, ultrasound technique and administration of the injections
vi. Use aseptic no touch technique.

J. When Botulinum Toxin A injections are not indicated

Service to liaise with community team promptly, with appropriate written communication to demonstrate assessment findings. Verbal communication should be attempted especially if therapy blocks are already arranged to inform the community team in a timely manner.

K. When Botulinum Toxin A injections are indicated, it is recommended that they be administered within 6 weeks of the decision to proceed.

Why are timeframes in place?

i. Botulinum Toxin A is taken up by the neuromuscular junction within approximately 12 hours, and clinically noticeable reductions in spasticity begin at around 4-7 days (occasionally this can take a bit longer) creating a 'window of opportunity' for improving motor and activity performance.[2]
ii. The effects can last up to 3-4 months.[2,3,13]
iii. Evidence informed therapy is recommended to commence 2 weeks after Botulinum Toxin A has been administered[1]
iv. Timing should be considered in line with child/young person and family's needs. When there is a delay beyond 12 weeks from assessment to administration a reassessment is indicated.
v. Service to liaise with community team promptly, with appropriate written communication to demonstrate assessment findings. Verbal communication should be attempted to allow community service time to organise recommended intervention.

L. Evidence informed therapy to commence within 2 weeks post Botulinum Toxin A injections

M. Evidence informed therapy. Botulinum Toxin A should not be used in isolation.

The use of Botulinum Toxin A in combination with therapy can reduce upper limb impairments, and improve activity level outcomes and goal achievement in children/young people with cerebral palsy who have spastic hemiplegia. [3, 17, 45]

Botulinum Toxin A in isolation is not effective, and injections should always be accompanied by a pre-planned therapy programme [1, 2, 3, 5, 45]

Evidence informed therapy where Botulinum Toxin A may be considered as an adjunct.

Which intervention approach? [17,50-53,56-59]

- Therapy programmes that are based on **motor learning theory**, which target activity performance are recommended to improve upper limb activity and function in populations of children/young people with cerebral palsy or other neurological conditions.
- These programmes include **bimanual therapy, task based goal directed therapy, mCIMT** (modified Constraint Induced Movement Therapy)**, hybrid** (bimanual therapy and mCIMT), **home programmes and occupational therapy programmes**.
- Decisions about therapy approaches should be made based on the child/young person's goals, and the child/young person/family's preferences and resources. The selection of interventions should be developmentally appropriate and achievable[1,3,46-49]
- Coaching models can be considered to support engagement and outcomes. (e.g. Occupational performance coaching, solution focused therapy, CO-OP (cognitive orientation to occupational performance)

Principles of the interventions:

Motor learning theory informs all models of rehabilitation[50, 51]

- Child/young person
- Task
- Environment

Intervention approach is dependent on:

- Child/young person and family goals
- Presenting symptoms
- Severity of impairment ('rehabilitative' approach/ 'compensatory' approach to facilitate success)

Modalities: [2,3,12,17,51]

- Bimanual therapy (BIT)
- mCIMT
- Hybrid – BIT and mCIMT
- Task based goal directed therapy

Currently the evidence base in upper limb rehabilitation indicates that **high intensity** and **repetitive training** is required to induce neuroplasticity, and functional changes in performance [2, 17, 45, 48]

Intervention can be delivered in a number of ways including:

- Home programme with weekly review
- Home programme with weekly session with therapist
- Community clinic/ outpatient setting
- In child / young person's educational setting

Table 2. Examples of intervention modality and intensity

Modality	**Models/dosage**
Intensive intervention • Bimanual therapy (BIT) • mCIMT • Hybrid (BIT and mCIMT) • Task based goal directed therapy	Frequency between 3-8 weeks and dosage varying within this. • Dosage ranging from 15 hours to 30/72 hours (dependant on child/young person's age and developmental level, baseline, child/young person and caregivers' goals)[12, 45,55,56]
Task based goal directed therapy	Optimal intensity unknown
Occupational therapy	Optimal intensity unknown
Strength training	8-10 repetitions of movement at maximum load, three sets of movements with a short rest between sets, 3 × week

A programme that delivers sufficient dosage, and is achievable, should be negotiated with the child/young person and family.[3,29,57]

Clinicians are required to keep updated with evidence for best evidenced modalities, dosage and intervention.

Therapeutic Activity:

The child/young person should actively participate in goal directed tasks, and be given opportunities to learn through both trial and error, and provision of timely feedback (verbal and physical).[3, 50]

Activities should be set at a level that is challenging but realistic and progressively graded so the child/young person is continually challenged, whilst able to achieve success at the task. Opportunities for repetition to be embedded into the activity. The activities need to be selected based on the child/young person's goals and preferences as motivation is essential to participation.[3, 17, 50]

The activity should be set and delivered to allow strengthening in the antagonist muscle group and improvements in motor control, coordination and spontaneous use of the hemiplegic upper limb.[55]

Environmental Factors:

Upper limb rehabilitation interventions can be effective when carried out in a variety of different environments: community setting, including one to one/group intensive intervention, at home or at school.

It is particularly beneficial to undertake therapy activities and interventions in the child/young person's home environment to promote carry over into daily life situations and to achieve the optimal dose.[17, 51,52,56]

Parents, carers, or teaching staff are to be active partners in carrying out the prescribed therapy activities and interventions. In order carry this out they need to be trained, educated, and well supported with weekly reviews by the local therapy team [15, 17,] Review may include phone call/SKYPE, clinic visit, and therapy assistant review.

Interventions to support goals of increasing ease of care, comfort and hygiene

Botulinum Toxin A, in combination with other impairment based interventions e.g. splinting, casting, positioning and active movement can improve ease of care, increase comfort and reduce secondary pain, hygiene issues and skin breakdown.[2, 13, 14, 19]

Splinting and casting:

- NICE guidelines, and international consensus recommend the use of a splint to stretch the muscle that has been temporarily weakened or where the spasticity has been reduced, with the Botulinum Toxin A[1, 3, 54, 59]
- Serial casting can be used to achieve a gradual prolonged stretch, which can be particularly helpful if the underlying passive range of movement in the limb is not sufficient to allow the use of a traditional resting splint. Serial casting should be started 2-4 weeks after the injections, and changed every 1-4 days.[3,19, 55]
- There is currently insufficient research investigating upper limb splinting following Botulinum Toxin A with children/young people with cerebral palsy to make empirically based decisions regarding the use of upper limb splinting therefore consensus based guidelines need to be followed.[44]

N. Follow up and monitoring

Review should be performed by the same healthcare professionals who undertook the baseline assessment.

Review at **6-12 weeks*** [3, 5] - assess the response to Botulinum Toxin A injections.

- Early response to treatment
- Tolerance of procedure and sedation
- Side effects of injections
- Review goal progress
- Obtain feedback from local team, child/young person/family, and if appropriate school
- Determine ongoing therapy and reasonable adjustments (define reasonable adjustments)

* Recognise that 6 weeks is too early to review intervention child/young person received. The review appointment should accommodate any intervention taking place.

Review at 12-26 weeks after injection to inform decisions about further treatment.

- Determine need for further interventions and follow up in consultation between community and hospital team.

Repeat Botulinum Toxin A Injections

Decisions regarding if further Botulinum Toxin A injections are given should include consideration as to whether previous injections were effective by reviewing goal attainment, clinical change, child/young person access and engagement with recommended intervention.[3, 44, 45, 58]

It is important to be aware Botulinum Toxin A injections can lead to a temporary and significantly detrimental decline in function. It is identified that Botulinum Toxin A injections without an intervention programme can lead to weakened muscle. It is important that Botulinum Toxin A is considered as an adjunct to therapy and should only be used when careful assessment has been undertaken.

Careful consideration should be given to the following factors if previous injections were ineffective:

- Selection of muscle site and dosage
- Outcomes and goal attainment
- Access to recommended intervention
- Engagement of family and child/young person in recommended intervention

Reducing over activity in muscle using Botulinum Toxin A is achieved at the cost of muscle atrophy which may not be completely reversible. Further research is required to evaluate long term effects and risk versus benefit of use of Botulinum Toxin A in children and young people[11].

It is important to review each child/young person individually to weigh-up the benefits versus the risks of continued Botulinum Toxin A use. Further research is needed to evaluate the long-term risks and effects of Botulinum Toxin-A injections in children with cerebral palsy.[57]

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Appendix A.

Botulinum Toxin A information sheet for parents/carers
See downloadable leaflet from the Medicines for children (UK) website:
https://www.medicinesforchildren.org.uk/botulinum-toxin-muscle-spasticity-0
(link accessed 22nd October 2019)