Botulinum Toxin A Upper Limb Paediatric Rehabilitation Clinical Guidance

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*This guidance is produced by the members of The UK & Ireland Upper Limb Specialist Interest Group 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 Specialist Interest Group holds no responsibility for the consequences of use of this guidance which is at the discretion of the individual clinician.

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For more information the can be The UK & Ireland Upper Limb Specialist Interest Group contacted at: BACD Website.

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.

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Introduction

The purpose of this document is to guide the clinical reasoning and processes that accompanies the administration of Botulinum Toxin Type A (BoNT-A) There are a number of pharmaceutical preparation available (in this document referred to as 'Botulinum Toxin A') as an adjunct to evidence-based upper limb (UL) therapy.

Evidence based, goal focused therapy should be provided for children and young people under 19 years with upper limb impairment secondary to upper motor neurone injury. If abnormal posture impacts on goal related task performance, then BoNT-A can be used as an adjunct to therapy, with the aim of reducing muscle overactivity and maximising activity and/or comfort. [1-3]

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

This guidance includes recommendations on:

i. Multi-disciplinary upper limb assessment procedure.
ii. Child/young person (YP) and family centred goal setting.
iii. Recommended time frames for administration of BoNT-A injection and subsequent interventions.
iv. When not to proceed with BoNT-A injections and why.
v. Upper limb intervention type and dosage suggestions.
vi. Evidence informed outcome measures.
vii. Procedure for reviewing children and young people.

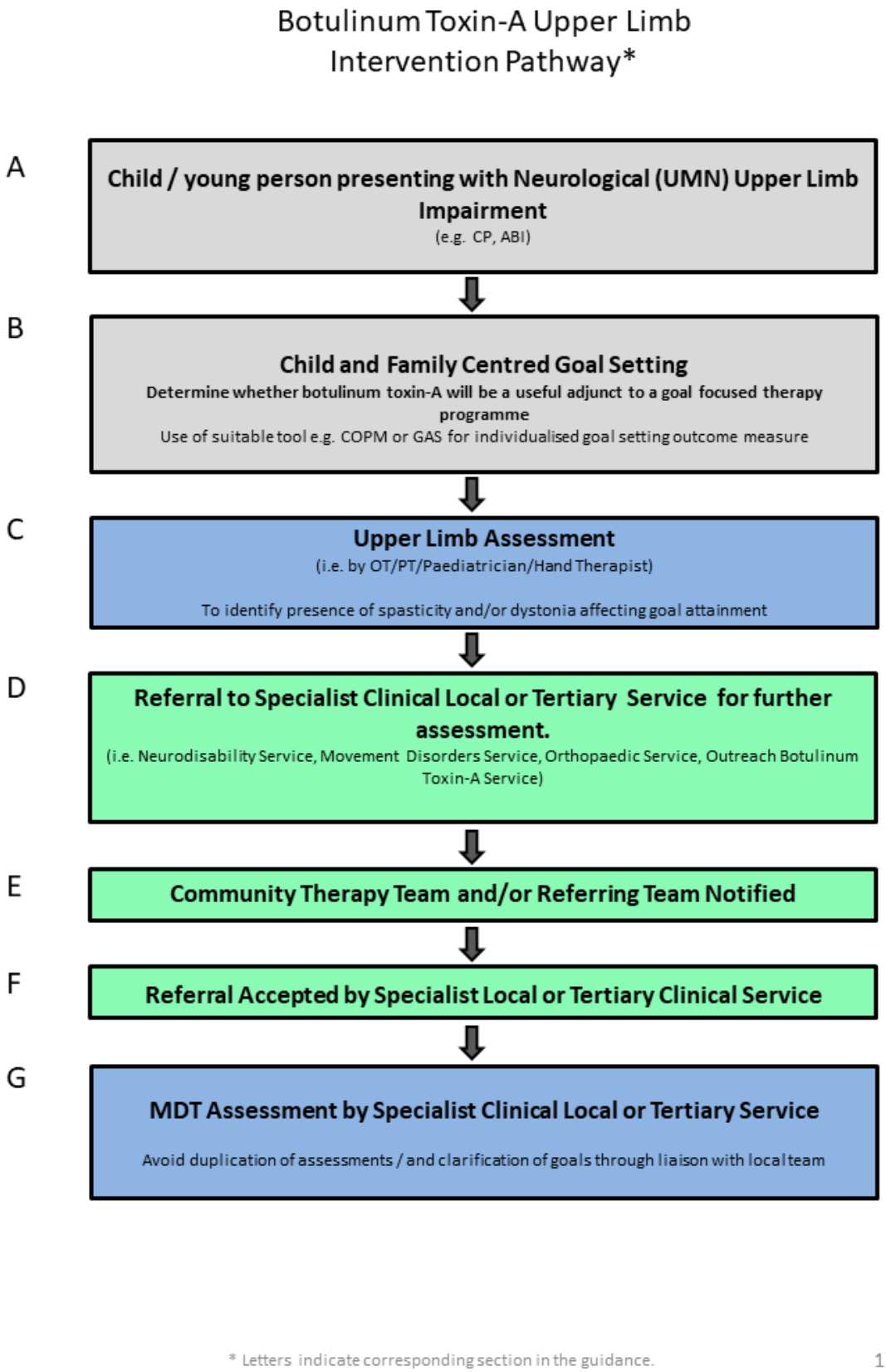
Who is this guidance for?

Healthcare professionals working with children and young people under 19 years with upper limb impairment secondary to upper motor neurone injury.

How to use this guidance

The following guidance is structured 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.
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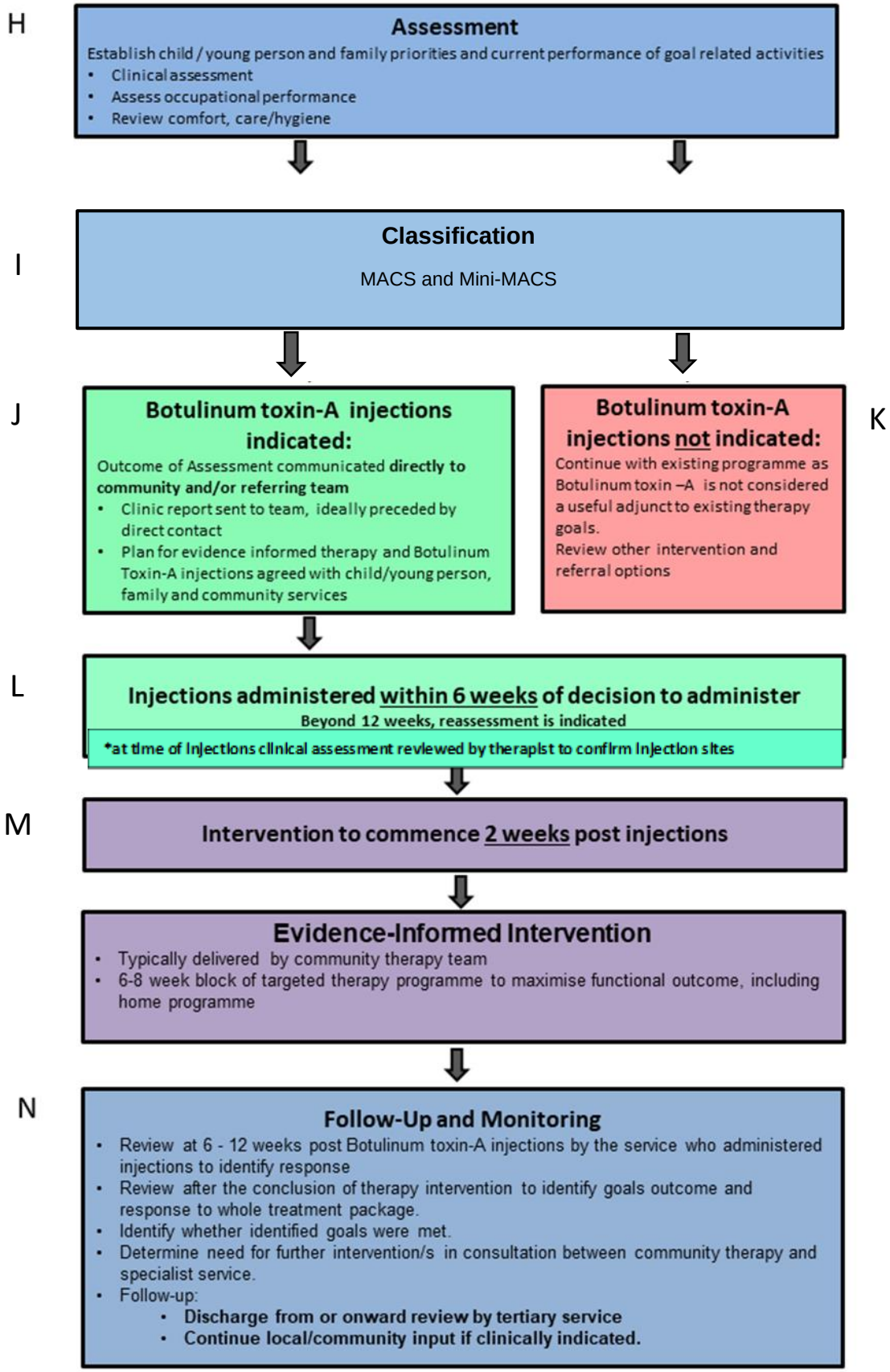


* Letters indicate corresponding section in the guidance.

A. Child/young person presenting with Upper Limb Impairment secondary to Upper Motor Neurone injury

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. BoNT-A is a safe treatment option for the short-term management of focal upper limb muscle overactivity in children under 2 years of age with cerebral palsy (CP) but should always be considered as an adjunct to evidence-based therapy.[65] Sound clinical reasoning is always required.
ii. Upper limb impairment including but not exclusive to children/young people with bilateral 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, Occupational Therapist, Paediatrician, Physiotherapist, School Nurse or other paediatric services (services vary by Health Provider e.g. NHS Trust, Region and Country).
iv. Issues identified as a priority by the child/young person and/or caregivers with regard to neurological upper limb impairment that may be affecting task performance (occupations), 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, for guiding muscle selection, and evaluating outcome. It is important to establish the priorities and motivation of the child/ young person and their family, and whether it is the right time for the family to proceed with injection of BoNT-A.

BoTN-A should only be used when it has been determined that muscle overactivity and/or muscle stiffness is impacting on goal related task performance, hygiene, pain or cosmesis.[5]

How?

Goal Attainment Scaling (GAS)[6] and/or the Canadian Occupational Performance Measure (COPM)[7] are the two most relevant valid and reliable tools that can be used to understand a child/young person's and/or caregiver's priorities [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 BoTN-A alone only affects changes at the level of body functions and structures. However, this change provides a window of opportunity for change at the activity level through goal directed evidence informed, task focused 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 in children with more significant impairment and limited ability to use their upper limbs for purposeful actions.

Who?

Goal setting should be completed with the child/young person and parent/carer by a member of the MDT. Goal setting should ideally be carried out by the community therapy team prior to referral and assessment for BoTN-A intervention. It is important that goal setting is carried out at local level and fed back to the tertiary level service. 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 – led by the therapist who is supporting the child's current goal focused upper limb therapy programme.
This assessment to include: [1-3, 5, 8, 12-14]

Subjective assessment:

i. Explore current priorities and concerns with child/young person and family.
ii. Establish the 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. Discuss child/young person's manual ability with caregiver and classify according to MACS (Manual Ability Classification System), Mini-MACS, BFMF (Bimanual Fine Motor Function) and classify gross motor function using the GMFCS (Gross Motor Function Classification system). These systems are recommended for children/young people with CP.
ii. Discuss the child/young person's goals.
iii. Observe the child/young person's performance of these goal related activities (where possible). Observe the impact of the child's upper limb posture on goal related task performance.
iv. Observe the impact of postural support e.g. supportive seating system, or how they are supported and held on a parent/carer knee on their hand and arm function.
v. Based on the observations during performance of goal related activities, undertake an examination of body functions and structures to identify the presence of spasticity and/or dystonia and identify range of motion (passive/active) which are limiting/impacting function.
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]
vi. Use suitable standardised activity measures.
vii. Use suitable tools to identify muscle activity (see section H).

Outcome:

i. Discuss the roles of local and specialist clinical service teams to child/young person and their family 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 upper limb impairment secondary to upper motor neurone injury. Clinical signs may include spasticity, dystonia, dyskinesia, weakness, rigidity or contracture affecting body functions and structures, activities and participation. For example; hygiene, manual ability, posture, 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 provide advice about possible interventions that may be 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 standardised 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: BoNT-A, oral medication, orthoses, casting, upper limb therapy, and in some cases, referral to plastic surgery, orthopaedics or other specialist movement disorder clinics (e.g. for opinion regarding intrathecal baclofen, selective dorsal rhizotomy, deep brain stimulation).[3, 8, 13, 14, 17, 18]

What to include:

i. Reasons for referral
ii. History
iii. Other investigations
iv. Previous and current interventions
v. Information gained from assessment
vi. Names and contact details of therapists and other key member of the child/young persons team.

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

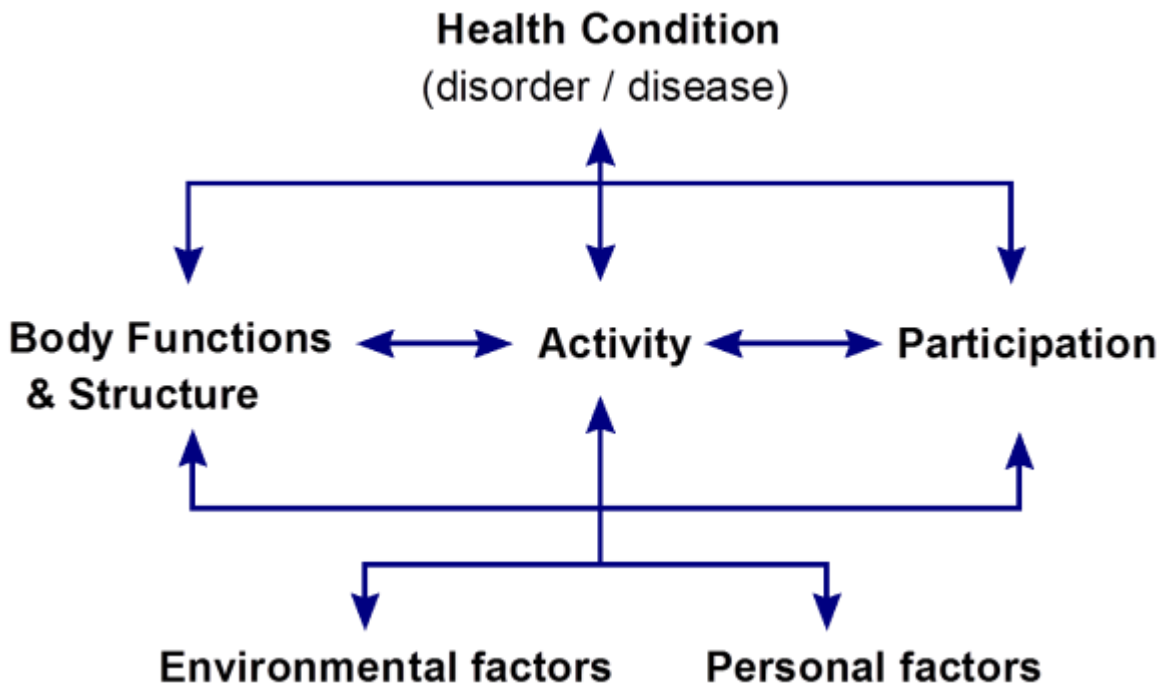
i. Referring team to gain consent from parents/carers or young person as appropriate to liaise with specialist clinical service.
ii. Communicate with local teams, establish communication methods with community therapists e.g. telephone, secure email, letter.
iii. Invite local professionals to clinic 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

National Institute of Clinical Excellence (NICE) guidelines define a multi-disciplinary team as a minimum of an occupational therapist or physiotherapist and a medical professional from neurology or neuro-disability or an 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).

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



H. Assessment

Standardised Assessment tools should be used to:

i. Inform the decision as to whether BoNT-A should be considered as an adjunct to the child/YP's current goal focused UL therapy programme.

ii. Provide a baseline of the child/YP's UL functional ability so that their response to any UL interventions and change over time can 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. See Table 1.

Table 1

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] Observation of the influence of posture and movement on performance of goal-related skill or activity. Video pre and post intervention	**<u>UL Performance Measures</u>** **Hand Assessment for Infants** (HAI)[34]. **Mini Assisting Hand assessment** (Mini AHA) [32] **Assisting Hand Assessment** (AHA)[31]. **Both Hand Assessment** (BOHA) [33] **Shriners Hospital Upper Extremity Evaluation tool** (SHUEE)[36] **Box and Block test**[35] **<u>Patient reported Measures</u>** **Abilhands Kids [37]**

		Children's Hand use Experiences Questionnaire (CHEQ) [38]: **<u>Activities of Daily Living Skills:</u>** **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	

All children and young people should have assessment consisting of:

i. A measure of **activity** to record functional goals.[1,2,5, 11-13,17,19]
ii. Record any limitation in passive range of movement and any resistance felt in muscle tone
iii. Observation of the influence of posture and movement on performance of goal-related skill or activity

I. CLASSIFICATION

Classification measures describe a child/YP's presentation and provide a common language to healthcare professionals thereby facilitating clearer understanding for clinical discussion and written communication. The classification measures listed below describe UL function in broad categories, however, they are not outcome measures, and the classification levels of children/YP are not expected to change through intervention.

Manual Ability Classification Scale (MACS)

All children and young people with a diagnosis of CP should have a Manual Ability Classification System **MACS** classification to establish their manual ability.

Mini-MACS The mini-MACS describes how children aged 1–4 years with CP 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 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 MACS describe how children and young people aged 4–18 years with CP use their hands when handling objects in daily activities. The classification is designed to reflect the child/young person's typical manual performance, not their 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

The recent study by Eliasson *et al.*[73] at the Karolinska Institutet looked at the longitudinal development of hand use in children with unilateral spastic CP from 18 months to 18 years. The paper demonstrated that the use of the effected hand develops mainly during the early per-school period. Bimanual performance was stable from approximately seven years and during adolescence. MACS levels were predictive of the rate and the extent of bimanual performance development. Children in MACS level iii reached their stable performance at the oldest age. Hand motoe training is recommended at early preschool period. The content of training for older children should aim at specific goals and participation.

A lesser used classification system is: Bimanual Fine Motor Function (BFMF)

The Bimanual Fine Motor Function (BFMF) classifies fine motor function in children with cerebral palsy. It classifies fine motor function according to the child's best ability (capacity) to grasp, hold and manipulate objects for each hand separately.

The BFMF describes five levels of fine motor function and covers the entire spectrum of limitations in fine motor function found among children with all cerebral palsy sub-types.

The BFMF version 2.0 is available online, is free to use and can be downloaded as a leaflet. This includes diagrams and descriptions of the fine motor function levels to facilitate the use of this classification system.[60]

This can be found at the following web link:

Bimanual-Fine-Motor-Function-2.0.pdf (europa.eu)

Use of the BFMF may provide complementary information to the MACS regarding fine motor function and actual use of the hands, particularly if used as a classification of fine motor capacity.[61]

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

J. BoNT-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 BoNT- A information leaflet (see Appendix A for an example)
   b. Consideration of psychological support and/or intervention from play specialists
   c. Consideration of analgesia or sedation
   d. BoNT-A plan
   e. Goals for use of BoNT-A
   f. Plan for evidence informed therapy; such as targeted intervention approaches and use of a hand/wrist orthosis, only to be worn through the night.
   g. Consider use of a BoNT-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 BoNT-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 clear goal for injection and service provision or capacity to provide support services, follow-up, and therapy around the time of injection is not available** [2, 5,12]

Muscle Selection

i. Targeted muscles should have focal spasticity and/or dystonia which is either:
   a. limiting goal-related task performance
   b. impeding caregiving
   c. causing pain or deformity[36,37 5, 8, 12-14,]

ii. 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, 62]

iii. For some children and young people BoNT-A has the potential to decrease functional use of their upper limb. Some children utilise their spasticity, even if involuntarily, for functional

benefit. BoNT-A injections in these muscle groups may result in a negative impact on manual function. This may be a contraindication and needs careful observation and consideration based on a child's goal related performance.[1,11,13,36] Caution should also be taken with significant underlying muscle weakness.[16]

iv. Just because a muscle is overactive, or posture is abnormal, this does not mean it should be injected. It is only via carefully observation-based assessment of a child's goal related performance that a decision should be made.

Recommendations for administering BoNT-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. Gain written informed consent by person with parental responsibility/child/young person. Include documentation of potential side effects, planned muscle selection and goal of intervention.[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 (Paediatric Early Warning Signs) pre- and post-injections
ii. Drug sheet or record
iii. Method for muscle localisation
iv. What muscles were injected
v. Unit dose per kg
vi. Dilution
vii. Who carried out the injections
viii. Post injection plan

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

BoNT-A dosage.

Dosage should be determined based on the child/young person's goals, level of muscle overactivity, severity of disability, underlying muscle weakness, previous response to injections and weight.[1,3,5,13, 66, 67, 68]

Localisation

Ultrasound guidance is recommended for accurate localisation for BoNT-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. Local anaesthesia – Anaesthetic cream/cold spray
iii. Local Anaesthesia + Analgesia (Paracetamol)
iv. Local Anaesthesia + Analgesia + Sedation (Nitrous Oxide/ Oral Midazolam)
v. General anaesthesia

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. BoNT- 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.

K. When BoNT-A injections are not indicated

Service to liaise with community team promptly, with appropriate written communication either clinic report or email to explain assessment findings. Primary community based therapist to continue with child/young person's usual upper limb therapy intervention.

L. When BoNT-A injections are indicated, it is recommended that they be administered within 6 weeks of the decision to proceed and therapy initiated within 2 weeks.

Why are timeframes in place?

i. BoNT-A is taken up by the neuromuscular junction within approximately 12 hours, and clinically noticeable reductions in muscle overactivity begin at around 4-7 days (occasionally this can take a bit longer for peak effect) creating a 'window of opportunity' for improving motor and activity performance.[2]
ii. Evidence informed therapy is recommended to commence 2 weeks after BoNT-A has been administered[1]
iii. The effects can last up to 3-4 months.[2,3,13]
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.

M. Evidence informed therapy. BoNT-A should not be used in isolation.

BoNT-A when used in combination with evidence based therapy can reduce upper limb impairments, and improve activity level outcomes and goal achievement in children/young people with upper limb impairment secondary to upper motor neurone injury [3, 17, 45]

BoNT-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 BoNT-A is an adjunct.

[17, 50-53, 56-5]Therapy programmes that are based on **motor learning theory**[51, 63], which target activity performance are recommended to improve upper limb activity and function in populations of children/young people with CP or other neurological conditions.

M**otor learning theory**, considers the interaction between the following subsystems and their impact on goal directed task performance:

- Child/young person
- Task
- Environment

The intervention approach chosen is dependent on:

- Child/young person and family goals
- Physical presentation
- Severity of impairment impacting on function.

Models of therapy: [2,3,12,17,51]

- **mCIMT** (modified Constraint Induced Movement Therapy)
- **bimanual therapy** (BIMT)**,**
- **goal directed therapy,**
- **context based therapy** [70,72]

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 therapy should be developmentally appropriate and achievable[1,3,46-49, 71]

Coaching models can be considered to support engagement and outcomes. (E.g. Occupational performance coaching, solution focused therapy,

Principles of the interventions:

Motor learning theory informs all models of rehabilitation[50, 51, 63]

- Child/young person
- Task
- Environment

Intervention approach is dependent on:

1. Child/young person and family goals
   Physical presentation
   Severity of impairment impacting on function

   Cognition/attention- ability to tolerate an intensive approach
   Family factors- ability to facilitate an intensive intervention block

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

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

Dosage of therapy

Like medication, a recommended amount of therapy should be given if it is to be effective. This is known as therapy dosage.

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].

Table 2. Examples of intervention modality and models/dosage

Modality	**Models/dosage**
• Bimanual therapy • mCIMT • Hybrid (add references?)	Dose of ?intensive practice (8-10 weeks) with a total dosage of 30-40 hours for Bimanual, mCIMT [62] (dependant on child/young person's age and developmental level, baseline, child/young person, caregivers' goals and family's capacity to support programme)[12,45,55,56]
Goal directed therapy	14-25 hours[62]
Context based therapy [70]	Optimal intensity not defined

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

Clinicians are required to keep up to date with evidence-based practice for children with upper motor neurone injury

Therapeutic Activity:

All therapy programs should be led by a qualified therapist to compile the program, monitor progress and modify the programme accordingly. The program must address the child and family's explicit goal(s) and preferences, because motivation is essential to participation.[3, 17, 50]

The child/young person should actively and repetitively practice these goal related actions or tasks in a meaningful and motivating environment. The therapist should support the child during practice using a range of discrete motor learning strategies which may include physical assistance (primarily to show how) and verbal feedback. [72, 3, 50]

For pre-school children who may be engaging in skills-based programs such as mCIMT and bimanual therapy activities should be matched to their specific goals and moderately challenging. Strategies should be used to progressively grade tasks to ensure success. Careful consideration should be given to using strategies that provide opportunities for repetition.

Environment for Therapy:

Upper limb models of therapy can be effective when carried out across a variety of different environments including community settings home and school. The therapy can also be provided on a one to one basis, or in groups.

Home therapy programs are an essential part of all contemporary distributed models of upper limb therapy. They are a pragmatic way to achieve the dosage requirements for skill acquisition and generalisation[17, 51, 52, 56]

Parents, carers, or teaching staff should be active partners in carrying out therapy programs. Therefore, they need to be provided with education and coaching and regularly supported through regular reviews by the local therapy team[15, 17,] Reviews should always be completed by a qualified therapist and may include phone call/virtual video link, clinic visit, and therapy assistant update.

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

For children/YP with very limited hand function and/or significant spasticity and/or deformity BoNT-A may be helpful when used in combination with one or more impairment-based interventions including orthoses, casting, and positioning. These may increase comfort and reduce secondary pain, make caregiving and maintenance of hygiene easier, and reduce skin breakdown[2, 13, 14, 19.]

Use of Wrist Hand Orthoses (WHO):

- NICE guidelines, and international consensus recommend the use of an overnight orthosis to provide prolonged low load stretch to the overactive muscles that has been injected with BoNT-A[1, 3, 54, 59]. Some children do not tolerate night/sleep worn wrist hand orthosis and the therapist may then recommend use at rest e.g. evening, TV viewing or during bedtime story. The important thing is that they are not worn when a child needs to be using their hand.
- Outcomes from a recent study on the longitudinal evidence for WHO provides some evidence to support the use of rigid-WHO to change or prevent further loss of passive range of motion, at the wrist, for children aged 5–15 years with CP over a 12-month period. Minor adverse events are commonly experienced when wearing a splint and should be discussed prior to prescription.[64]
- There is currently limited research supporting the use of upper limb orthoses following Botulinum Toxin A with children/young people with CP. Therefore, clinical decision making should be guided by a clear clinical rationale and consensus-based guidelines [44]
- Regular review of WHO by named therapist or local splinting clinic is necessary to ensure correct position, comfort and compliance to adjust as required to provide optimal stretch.

Serial Casting:

- Serial casting provides a prolonged static low load stretch, which can assist in increasing passive range of movement of the joints targeted. The use of serial casting can be helpful prior to fabrication of a rigid-WHO to achieve an optimal position and tolerance. Serial casting should be started 2-4 weeks after the injections, and changed every 1-4 days.[3,19, 55] It should always be immediately followed by the fabrication of a rigid-WHO to maintain the gains in passive range of motion.

. 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]

- Obtain feedback from local team, child/young person/family, and if appropriate school.
- Assess response to BoNT-A injections.
- Establish child/YP's tolerance of procedure and sedation.
- Record adverse events related to BoNT-A and the procedure.
- Review and observe performance of goal related skill(s) or task(s).
- Determine ongoing therapy and reasonable adjustments (to current programme e.g. intervention, dosage, environment).

* Recognise that 6 weeks is too early to review the therapeutic intervention that the child/young person received.

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 BoNT-A Injections

Decisions regarding re-injection of BoNT-A should include consideration as to whether previous injections were effective. This includes the impact on abnormal posture during goal related task performance, reviewing goal attainment measures, child/young person access and engagement with therapy program.[3, 44, 45, 58]

BoNT-A injections can lead to a temporary detrimental decline in function. It is identified that BoNT-A causes weakness in the targeted muscles. It is therefore important that BoNT-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 deemed to be ineffective:

- Selection of muscle site and dosage.
- Muscle overactivity had no impact on the child's goal related performance. Task performance was impacted by other factors such as planning and motivation.
- Access and engagement of family and child/young person in ongoing therapy program.

The use of BoNT-A should always be carefully considered for each child and young person. The benefits should always outweigh the risks and ongoing use should be minimised to lessen the impact on muscle [11].

Further research is needed to evaluate the long-term risks and effects of BoNT-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:

Botulinum-toxin-for-muscle-spasm.pdf (medicinesforchildren.org.uk)

(Link accessed: 23/01/2023)