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GUIDELINES

Evidence-based position paper on the professional practice of Physical and Rehabilitation Medicine for persons with cerebral palsy

The European PRM position (UEMS PRM section)

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ABSTRACT

Cerebral palsy (CP) is a group of the most common developmental disorders affecting movement and posture of the body, causing activity limitations and participation restrictions. The motor disorders of persons with CP are often accompanied by disturbances of sensation, cognition, communication and perception. The symptoms of CP are very diverse and persons with CP are usually presented with a mixed type of symptoms. The non-progressive disturbances can be attributed to disorders that were developed during pregnancy, birth and/or infant stage. The aim of this study was to improve physicians' professional practice of Physical and Rehabilitation Medicine for persons with cerebral palsy in order to improve their functionality, social and community integration, and to reduce activity limitations and/or participation restrictions. A systematic review of the literature including an 18-year period and consensus procedure by means of a Delphi process was performed and involved the delegates of all European countries represented in the Union of European Medical Specialists Physical and Rehabilitation Medicine (UEMS PRM) Section. As the result of a Consensus Delphi procedure, 74 recommendations are presented together with the systematic literature review. The PRM physician's role for persons with cerebral palsy is to lead and coordinate the multiprofessional team, working in an interdisciplinary way. They should propose and manage the complex but individual PRM program developed in conjunction with other health professionals, medical specialists and importantly in agreement with the patient, their family and care giver. This should be, according to the specific medical diagnosis to improve patients' health, functioning, social and education status, considering all impairments, comorbidities and complications, activity limitations and participation restrictions. This evidence-based position paper is representing the official position of The European Union through the UEMS PRM Section and designates the professional role of PRM physicians in persons with cerebral palsy.

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Introduction

Cerebral palsy (CP) describes a group of permanent disorders of movement and posture causing activity limitations that are attributed to nonprogressive disturbances that occur in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems.[1]

Cerebral palsy (CP) is the most common developmental disorder associated with lifelong motor impairment and disability. It is ubiquitous and it occurs all around the world. In spite of improved obstetrical and perinatal care CP remains with us. As a result of injury to the brain, these children have motor defects which will affect them for their entire lifetime.[2]

The exact prevalence of CP is variable and depends on definitions and case ascertainment. The Surveillance of CP in Europe uses standardized procedure for ascertaining figures for CP for registers and databases.[2-4] There are no official epidemiological data for CP in many countries. The epidemiology of CP has been based on the use of national registers in the UK, Sweden and other Scandinavian countries.[4] The prevalence of cerebral palsy (CP) worldwide varies from 1.2 to 3 per 1000 live births[5-8] and resulting disability varies from mild to total dependence. Life expectancy is reduced, especially for the several affected.[9] Lifetime cost to the healthcare system and to the family and caregivers is high. The extra lifetime costs associated with CP is estimated to be US$ 800,000 per person.[10]

In many children, the cause of CP is unknown. Known risk factors include low birth weight (lower than 2500 grams) and prematurity.[3] Prenatal events are responsible for approximately 75% of all cases of CP and include brain malformations, maternal infections (the TORCH group of organisms — toxoplasmosis, rubeola, cytomegalovirus and herpes simplex virus), vascular events such as middle cerebral artery occlusion, metabolic conditions and toxins.[11] Perinatal causes are responsible for approximately 10-15% of cases and result from problems during labor and delivery such as antepartum hemorrhage or cord prolapse, compromising the fetus.[11] Postnatal causes are responsible for about 10% of cases of CP and include infections (meningitis) and injuries.[12, 13]

Diagnostic improvement including ultrasonography for intraventricular hemorrhage in newborn babies and magnetic resonance imaging of structural lesions have led to greater understanding of etiology of CP and the timing of such lesions and accurate diagnosis and classification, leading to more correct prognosis of potential outcome and complications.[14, 15] Clinicians classify patients to describe the specific problem, to predict prognosis and to guide treatment. Classification is based on the change in muscle tone, anatomical region of involvement and severity of the problem. The predominant types of motor impairment are spastic (diplegia, quadriplegia, hemiplegia), dyskinetic (dystonia, choreoathetosis) and ataxic.[2] Hypotonic type is rare. Mixed forms, containing elements of all types of CP, are most frequent.

The treatment must be complex, timely, continuous and adequately intense according to the age, complications, etc. In practice, interventions for person with CP can be broadly divided into three categories: 1) physical training; 2) medicine and/or surgical intervention; 3) behavioral interventions.[6] The so-called conservative treatment is in the field of competence of physical and rehabilitation medicine (PRM) physicians. It includes different PRM interventions: kinesiotherapy, physical agents, speech and language therapy, neuropsychological interventions, occupational and complementary therapy. The PRM physician and the team must be prepared to anticipate certain acute and chronic problems during the rehabilitation course of the child with CP.[2]

It is very important that PRM physicians ensure timely diagnosis of infants with CP or babies at high risk of CP. They perform regular check-ups of their development and prescribe timely and complex rehabilitation.[16-18] The pediatric PRM physician evaluates the child's overall medical, surgical and therapy options and helps the child and the family to set functional, achievable goals.[2] It is to consider that parents of younger patients showed significantly higher concern score than those of older patients.[19]

The disability model for people with CP is a fundamental professional practice topic for PRM physicians. People with CP have persistent disability and might require long-term rehabilitation. CP rehabilitation is one of the main practice areas of PRM physicians.[2, 4, 5, 16, 20]

PRM is the primary medical specialty that focuses on the improvement of functioning based on the WHO's integrative model of functioning, disability and health, and rehabilitation as its core health strategy. PRM physicians are adequately trained and qualified to organize and manage the comprehensive rehabilitation program for persons with CP within a holistic teamwork approach.[21]

The motor disorders of CP are mostly accompanied by multisystem disturbances such as neurological (perception, sensation, muscle tone, epilepsy), dermatological, di-

gestive (constipation), respiratory, cardiological, psychological (mental retardation, cognition, communication, behavior), urogenital (urinary incontinence, sexual function), and secondary musculoskeletal problems (pain, hip subluxation, kyphoscoliosis, bone demineralization).[2, 4, 5, 18]

PRM physicians are adequately trained and qualified to clinically examine and treat patients with CP and their multisystem impairments.

Clinical evaluation, includes the specific scales and classifications such as International Classification of Functioning, Disability and Health (ICF), International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), Gross Motor Function Measure (GMFM), Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), etc. which are adequately validated and should be used to assess components of functioning during rehabilitation.[20, 22] Generally, standardized outcome assessments evaluate daily living activities (*e.g.*, Barthel Index, Functional Independence Measure [FIM], Timed Up-and-Go Test [TUG], Timed Up-and-Down Stairs Test [TUDS], Safety Trained Supervisor [STS]) and are used as important outcome criteria in the rehabilitation process. Also, other secondary outcome criteria/clinical measures evaluating specific areas (*e.g.*, spasticity, visual ability, grip strength) can be employed. Different sets of determinants may help to set realistic expectations and to create appropriate treatment plans for different domains of daily activities in persons with CP.[21-27] Also, the intellectual assessments are critically important for any rehabilitation program. There is a significant relationship between motor abilities and early social development in preschool children with CP aged between 18 and 30 months.[28] It is to consider that preadolescent children with CP spend less time in moderate and vigorous activity and more time in sedentary behavior than children with typical development. It is associated with overweight, chronic disease and disability. Adaptive seating systems that include trunk and hip support devices may improve postural control outcomes, and may improve activity, self-care, and participation at home among children with severe CP.[29, 30]

Nowadays there is no uniformity among different countries across Europe and in the world in the PRM approach. CP care and rehabilitation processes throughout Europe vary considerably from one country to another and even within countries. Organization and provision of CP inpatient and also outpatient rehabilitation shows variation across countries in contents of therapy, therapy time, and are inadequate in many parts of Europe. Some methods preferred in one country (the Vojta method, therapeutic riding, balneotherapy, acupuncture) are not available, or even forbidden in another country. Social, psychological, and educational support and occupational, and speech and language therapy are limited, or not reachable in many countries. Also, there is not enough scientific evidence and information on many therapeutic methods which are used in complex rehabilitation in persons with CP. For these reasons the Union of European Medical Specialists Physical and Rehabilitation Medicine (UEMS PRM) Section decided to develop one of its evidence-based position papers, representing the official position of the European Union. The aim of the paper is to improve PRM physician's professional practice for patients with CP in order to promote their functioning and enhance their quality of life.

Materials and methods

This paper was developed according to the methodology defined by the Professional Practice Committee of the UEMS PRM Section in the methodology paper by Negrini *et al*.[31] The EBPP comprises two parts:

- a systematic review of the literature including a 19-year period;
- a consensus following a Delphi procedure among UEMS PRM Section delegates.

A comprehensive electronic literature search has been performed in PubMed the 6th of September 2018. Search filters used in methodology were: 1) English language; 2) publication types: Cochrane reviews, systematic reviews, meta-analysis, randomized controlled trials, guidelines; 3) published between 2000/01/01 and 2016/01/31, later extended until 2018/08/31. The string used for the selection has been: "("Cerebral Palsy" [MeSH Terms]) OR ("Little Disease" [MeSH Terms]) OR "Little's Disease" [MeSH Terms] OR "Infantile Cerebral Palsy" [MeSH Terms]) AND ("physical therapy" OR "rehabilitation medicine" OR "physical and rehabilitation medicine" [MeSH Terms]) AND ("disability" OR "disabled persons" [MeSH Terms]) AND ("care" OR "functioning" OR "motor activity" [MeSH Terms] OR "physical activity" [MeSH Terms] OR "quality of life" [MeSH Terms]).

The only criterion for including the studies was the professional relevance for PRM physicians as assessed at least by two of the authors, with the main author resolving conflicts.

The steps of the Delphi process have been changed slightly as from 2020 as shown in Table I.

TABLE I.—*Delphi rounds.*

Delphi round	Participants	Timing	Voting of recommendations
1	Authors	14 days	Accept: 36 Accept with changes: 38 Reject: 12
2	All delegates	14 days	Accept: 47 Accept with changes: 27 Reject: 0
3	All delegates	14 days	Accept: 74 Reject: 0
4	Authors	14 days	A. It must be normally applied: 49 (62.22%) B. It is important, but cannot be applied in all situations: 23 (31.08%) C. Less important, it can be applied on a voluntary basis: 2 (2.70%) D. Very low importance: 0 (0%)
5	All delegates	14 days	Final paper including recommendations Yes: 74 No: 0

Results

Systematic review

The electronic literature search identified 3941 titles. The papers were screened on the titles, duplicates articles and not relevant to PRM practice were excluded and 714 papers were left. We reviewed these articles according to the abstracts to eliminate not relevant to PRM or to CP articles. Overall, 359 articles were left. Finally, we reviewed the full text of the articles to eliminate not relevant to PRM papers and not relevant to CP, leaving 124 articles (Supplementary Digital Material 1: Supplementary Text File 1). They were considered for the preparation of this EBPP with 86 recommendations. The selection process is reported in Supplementary Digital Material 2 (Supplementary Figure 1).

Recommendations were formulated according to the methodology paper[31] as defined by the Professional Practice Committee of the UEMS PRM Section:

- I. overall general recommendations;
- II. recommendations on PRM physician's role in Medical Diagnosis according to ICD;
- III. recommendations on PRM physician's role in PRM diagnosis and assessment according to ICF;
- IV. recommendations on PRM management and process
  - a. project definition (definition of overall aims and strategies of PRM interventions)
  - b. team work (professionals involved and specific modalities of team work)
  - c. PRM interventions
  - d. outcome criteria
  - e. duration and intensity of treatment (overall practical PRM approach)
  - f. follow-up criteria and agenda
  - g. discharge criteria (*e.g.*, when and why to end PRM interventions);
- V. recommendations on future research of PRM professional practice.

Recommendations

The results of the Consensus procedure are reported in Supplementary Digital Material 3 (Supplementary Table I, II).

I. Overall general recommendations

1. The professional role of the PRM physician is to manage and coordinate the multi-professional team, working in an interdisciplinary way, with the goal to create a complementary but individual attitude to persons with all forms of CP in complex treatment and rehabilitation in agreement with the patient and family.[2, 4, 5, 16-18, 32-34] **(SoE: I; SoR: A)**
2. It is recommended that PRM physicians propose a rehabilitation program and lead a well-educated rehabilitation team in both in-patient and out-patient settings and in the community to reduce impairments in functions, activity limitations, participation restrictions, pathologies, comorbidities, and complications associated with CP conditions. All rehabilitation professionals need to work in a coordinated way and regularly communicate their observations to the primary medical coordinator.[2, 4, 16-18, 33, 34] **(SoE: I; SoR: A)**
3. PRM physicians are recommended to ensure timely diagnostics of infants at high risk of CP-related limitations of functioning. They perform regular check-ups of their development and prescribe timely and complex rehabilitation.[16-18, 35] **(SoE: I; SoR: A)**
4. PRM physicians are recommended to be partners in transitioning patients with CP to adult care. Barriers to PRM physicians' engagement with this population appear to be amenable to change. PRM physicians are ideally suited to manage adults with cerebral palsy. CP adults lose functional abilities earlier than able-bodied individuals. It is recommended that PRM physicians are aware of these changes because CP is a lifespan disability. PRM is the most appropriate specialization

to provide disability-related care to adults with CP following their paediatric discharge. Among the most frequently identified barriers to caring for this population have been lack of accessible resources (*i.e*. social work, funded therapy, equipment) and lack of referrals.[4, 17, 18, 20, 36] **(SoE: I; SoR: A)**

5. PRM physicians are recommended to take into account the fact that CP adults require greater knowledge and understanding to enhance decision-making process about their health. Although young adults receive a good level of service up to the age of 18 when they leave Pediatric Services, they often are not transferred to an appropriate multidisciplinary adult neuro-disability service that provides a holistic overview of their disability and addresses all their problems.[4, 17, 18, 20] **(SoE: I; SoR: A)**
6. It is recommended that PRM physicians follow appropriate guidelines and evidence-based interventions when administrating complex rehabilitation to persons with CP.[5, 17, 18, 37] **(SoE: I; SoR: A)**

II. Recommendations on PRM physicians' role in Medical diagnosis according to ICD

7. It is recommended that PRM physicians provide an enhanced clinical and developmental follow-up program as members of multidisciplinary team for children up to 3 years of age (corrected for gestational age) who are at increased risk of developing CP-related limitations of functioning.[17, 18, 35] **(SoE: I; SoR: A)**
8. It is recommended that early diagnosis begins with a medical history and involves using neuroimaging, standardized neurological, and standardized motor assessments that indicate congruent abnormal findings indicative of CP. PRM physicians take into account the fact that patients with CP are in a vulnerable position and invasive diagnostic procedures should be performed only if it is really necessary and should always be connected to a functional evaluation of patients with CP, in order to decrease the probability of deterioration of patient's mental or physical health condition.[4, 5, 35, 37-40] **(SoE: I; SoR: A)**
9. Before 5 months' corrected age, as the most predictive tools for detecting risk are recommended the Prechtl Qualitative Assessment of General Movements, the Hammersmith infant neurological examination (HINE), the Test of Infant Motor Performance (TIMP), Vojta's postural reactions and term-age neonatal magnetic resonance imaging. After 5 months' corrected age, as the most predictive tools for detecting risk are recommended HINE, Developmental Assessment of Young Children and magnetic resonance imaging.[4, 18, 35] **(SoE: I; SoR: A)**
10. It is recommended that PRM physicians use the tests GMFM, GMFCS, MACS, FMS, etc., assessments to evaluate daily living activities (*e.g*., Barthel Index, FIM, TUG, TUDS, STS) and measures evaluating specific areas (*e.g*., spasticity, visual ability) during routine follow-up assessments for children who are at increased risk of developing CP-related limitations of functioning or persons with CP.[4, 5, 17, 23, 25, 41-43] **(SoE: I; SoR: A)**
11. It is recommended that PRM physicians or/with a paediatric neurologist identify infants at high risk of CP-related limitations of functioning in a timely fashion. They evaluate their deviations from regular psychomotor development. They utilize the neuro-kinesiological examination of postural activity, postural reactivity, primitive reflexes, muscular tonus, feeding difficulties and physicians classify different forms of CP. Regular assessment is necessary in order to identify possible changes of these forms.[16-18, 35] **(SoE: I; SoR: A)**
12. It is recommended that PRM physicians observe patients with CP thoroughly and periodically for the early diagnosis and treatment of comorbidities, complications and secondary conditions, *e.g*., pain, fatigue, sleep problems, anxiety, depression, musculoskeletal issues (spinal deformities, contractures, pressure ulcers, osteoporosis), neurological problems (spasticity, epilepsy), infections (urinary, respiratory), neuropathic bladder and bowel dysfunction, gastrointestinal problems (constipation, drooling, gastroesophageal reflux, dysphagia), obesity/malnutrition — cachexia, cardiovascular, respiratory, sensory (ablatio retinae), psychosomatic, sexual issues, etc., which may further affect the primary level of disability or can be increased by their primary disability.[6, 16, 17, 32, 33, 44] **(SoE: I; SoR: A)**
13. It is recommended that PRM physicians refer to a preventive orthopedic examination and imaging investigations (ultrasonography, X-ray, etc.) in the event of suspected dysplasia, subluxation and luxation of coxa. The early identification of hip dysplasia or subluxation and early treatment can substantially improve a child's long-term function, even preventing hip luxation in persons with CP.[13, 38, 39] **(SoE: II; SoR: B)**
14. It is recommended that PRM physicians take into account the fact that gait analysis has positive im-

pact on effective treatment decision and surgical and non-surgical treatments of joint contractures and gait.[13, 38, 39, 45-47] **(SoE: II; SoR: A)**

III. Recommendations on PRM physicians' role in Medical diagnosis according to ICF

15. It is recommended that PRM physicians and the rehabilitation team use the International classification of Functioning, Disability, and Health (ICF) and the International classification of Functioning, Disability, and Health for Children and Youth (ICF CY) as a basic instruments to obtain complete bio-psycho-social information about the CP patient's impairments of body functions and structures, activity limitations, and participation restrictions, as well as personal needs, and to assist managing the rehabilitation process.[4, 22, 24, 32, 37, 41, 48-51] **(SoE: I; SoR: A)**
16. It is recommended that assessment of impairments in body functions, activity limitations and participation restrictions of patients with CP, and environmental factors be performed using standardized methods and valid assessment or outcome measurement instruments connected to the ICF and ICF CY.[32, 43, 48, 52-54] **(SoE: I; SoR: B)**
17. It is recommended that PRM physicians apply brief ICF Core Sets for Cerebral Palsy which are useful tools for research, teaching, and especially for clinical practice to assess and monitor changes in functional status before and after completed rehabilitation process and to organize PRM interventions in complex health conditions such as those of patients with CP.[22, 54] **(SoE: III; SoR: B)**
18. It is recommended that PRM physicians consider that vision impairment is relevant to the functioning of children with CP. However, measurement of vision is most often focused at "body function" levels. Measuring visual abilities in the Activities and Participation domain of the ICF is important in assessing how a child with CP functions in vision-related activities. The lack of psychometrically strong meassures for visual ability is a gap in current clinical practices and research.[23, 49] **(SoE: III; SoR: B)**

IV. Recommendations on PRM management and process

Inclusion criteria (*e.g.*, when and why to prescribe PRM interventions):

19. It is recommended that all patients with CP and infants at high risk of CP should get appropriate individualized PRM interventions as soon as possible and be regularly monitored to identify and manage any decline in functional status and optimally maintain it. The clinical picture in CP ranges from very mild to very severe depending on the extent of the CNS lesion. This wide spectrum of clinical findings makes it difficult to predict prognosis. Predicting prognosis forms the basis of management.[2, 17, 18, 35, 42, 53, 55] **(SoE: I; SoR: A)**
20. It is recommended that PRM physicians prescribe PRM interventions always when necessary for persons with CP in order to decrease or maintain impairments in body structures and functions. This will serve to prevent or manage complications and medicate secondary conditions, with the goal of improving and maintaining functioning properties, such as general activities and participation.[37-40] **(SoE: II; SoR: A)**

IV. a. Project definition (definition of overall aims and strategies of PRM interventions)

21. It is recommended that PRM interventions for the patients with CP be based on a bio- psycho-social model. The overall aims and strategies of PRM interventions are defined by a PRM physician in collaboration with a multi-professional team to optimize and restore impaired body functions and structures, enhance activities and participation, prevent further assumed impairments and complications, and improve or maintain quality of life.[2, 28, 56, 57] **(SoE: III; SoR: A)**
22. It is recommended that PRM physicians lead the rehabilitation team and plan the PRM programs in agreement with the patient, his family, and/or caregivers. Rehabilitation program including PRM intervention is planned on an individualized basis in a patient-centered approach and incorporates proposals of experts from the rehabilitation team.[2, 4, 16, 18] **(SoE: III; SoR: A)**
23. It is recommended that members of the multi-professional rehabilitation team, especially PRM physicians, physical and occupational therapists, should continually adapt their role to parents of young children with CP in need of information, communication and partnership and they should support and facilitate parents in becoming empowered and participating in setting of therapy goals.[2, 58] **(SoE: IV; SoR: A)**
24. It is recommended that PRM interventions are proposed when functional capacity and quality of life are reduced and disabling comorbidities are present. Specific PRM interventions are to be prescribed to improve gross and fine motor function, muscle strength, balance, endurance, and condition, maximizing motor

and cardiorespiratory function. In addition, intervention and prescription are needed to manage when pediatric population presents with swallowing deficits and dysphagia, dental hygiene due to neurological morbidities. In adolescence PRM intervention may include sexual education for patient and family.[6, 32, 33, 37-40] **(SoE: I; SoR: A)**

25. It is recommended that PRM physicians offer instruction on modalities and schedules among sectors, participants, community, and decision makers to fulfil the needs of the person with CP. PRM programs are offered in centers specialized in CP rehabilitation, PRM departments at university or general hospitals, outpatient PRM departments/centers, at home, or in the community, or with the use of information and communication technologies in the form of telerehabilitation. It is recommended that the PRM physicians form a network of experts included in CP care, so they can cooperate as well as share knowledge and expertise.[41, 59-61] **(SoE: III; SoR: B)**

IV. b. Team work (professionals involved and specific modalities of team work

26. It is recommended that the PRM physician is the coordinator of a multi-disciplinary team of physicians (paediatrician, neurologist, orthopaedic surgeon, neurosurgeon, psychiatrist, dermatologist, ophthalmologist, gastroenterologist, cardiologist, etc.), and other health professionals who are essential in the management of persons with CP. The structure of the multiprofessional team may vary at different stages of the rehabilitation process.[2, 5, 16, 18] **(SoE: III; SoR: A)**
27. It is recommended that the PRM physician is the leader of a multi-professional rehabilitation team, consisting also of physiotherapist, occupational therapist, educational therapist, speech and language therapist, orthotist, clinical psychologist, masseur, social care providers, liaison person, community-based worker, nutritionist, rehabilitation engineer, peer counsellor, as well as other health professionals. They participate in the specialized rehabilitation program for patients with CP throughout the whole time of the health care.[2, 4, 16, 43] **(SoE: III; SoR: A)**
28. It is recommended that the multi-professional team working in an interdisciplinary and collaborative way should aim at the patient as well as on his caregivers, family members, and their life priorities, taking into account the patients' preferences. The shared and differing priorities of parents and young people with CP may reflect different roles, perceptions and experiences. The patient and his family should participate according to the suggestions of the physician's team that participate in treatment. The physical, social environment, and attitude toward disabled children influences their participation in everyday activities and social roles.[19, 58, 62-66] **(SoE: III; SoR: A)**

IV. c. PRM interventions

29. PRM physician creates the rehabilitation plan for patients with CP within the ICF framework and aims at a setting with the collaboration of the multi-professional rehabilitation team and the acceptance of the patient and family-caregivers.[2, 4, 16-18] **(SoE: I; SoR: A)**
30. It is recommended that PRM physicians or developmental pediatricians or pediatric neurologists administer screening of newborns in order to identify infants at high risk of CP-related limitations of functioning in a timely fashion, *i.e*. within the first few days and weeks, at three months after birth. They assess anomalies in physiological development in the area of psychomotor development. They perform the following examinations: neuro-kinesiological examinations of postural activity, postural reactivity, primitive reflexology, and muscular tonus.[17, 18, 35, 42] **(SoE: I; SoR: A)**
31. It is recommended in infants at high risk of CP-related limitations of functioning to perform regular monitoring, timely, long-term, and complex rehabilitation, starting after birth, latest within three months after birth. The fundamental element of the rehabilitation is kinesiotherapy based on developmental kinesiology and neurophysiological principles.[16-18, 35] **(SoE: III; SoR: A)**
32. It is recommended that the PRM physician plans a lifelong suitable exercise program for persons with CP which is modified according to the general health status, gross motor functions, neurological and orthopaedic levels, complications, comorbidities, and age.[2, 4, 17, 18] **(SoE: I; SoR: A)**
33. It is recommended the PRM physicians prescribe the most appropriate rehabilitative interventions considering the needs and capabilities of each patient, the findings of Evidence Based Medicine (EBM) and best practice as well as the knowledge and training of therapists, the available resources and their own knowledge and skills.[1, 4, 5, 13, 17, 18, 32, 33, 43, 53, 59, 67-69] **(SoE: II; SoR: A)**
34. It is recommended that, when prescribing rehabilitation interventions, PRM physicians consider that neu-

rodevelopmental techniques (such as Bobath's NDT), the Vojta reflex locomotion (diagnostic and therapeutic system found on the principle of developmental kinesiology), new-born individualized developmental care and assessment program (NIDCAP), auditory tactile visual vestibular stimulation (ATVV), developmental program stimulation (DPI), conductive education, overground and treadmill-based gait training, robotic-assisted gait training, virtual reality training, motion capture systems, biofeedback, suit therapy, resistance training, cycling, rhythmic auditory stimulation, therapeutic riding, and aquatic exercise can be used to improve gross motor functions, especially standing and walking.[4, 16, 32, 45, 47, 68-87] Neurodevelopmental techniques, the Vojta reflex locomotion, constraint-induced movement therapy (conventional or modified), hand-arm bimanual intensive therapy including lower extremity, repetitive, progressively adapted, task-specific and goal-oriented upper and lower-extremity and trunk therapy, robotic assistive therapy, web-based multi modal training, virtual reality rehabilitation, functional training, interventions for sensory impairment and virtual reality, biofeedback, stretching, mobilization, mental practice, animal assisted therapy and mirror therapy should be administered to improve motor control and sensorimotor function of the affected limbs and fine motor function and dexterity for eligible patients with CP. It is to be considered that older children benefit when training of hand skills and ADL is organized as a combination of training sessions and practice within everyday activities.[4, 16, 32, 49, 52, 68-73, 76-79, 81, 83-85, 87-97] **(SoE: II; SoR: A)**

35. It is recommended that strengthening training and fitness, and functional electrical stimulation to wrist, forearm, and shoulder muscles be considered to improve strength and upper limb function. Strengthening training and fitness, and functional electrical stimulation of foot, ankle, calf, and hip muscles should be applied to improve lower limb function, especially for standing and walking. These therapeutic methods are to be considered for CP patients with mild and moderate motor impairment, however, they should not aggravate spasticity and pain.[4, 39, 88, 92, 94, 95, 98, 99] **(SoE: II; SoR: A)**
36. It is recommended that PRM physicians consider that children with CP have a significant chance of developing neuromuscular scoliosis during their early years and adolescence. The behaviour of this scoliosis is closely associated with the severity of the CP disability and unlike idiopathic scoliosis, it continues to progress beyond skeletal maturity. A timely therapeutic intervention is recommended to detect the risk of progression of scoliotic curves and limit the related impairment in function and increased risk of poor health.[2, 100] **(SoE: III; SoR: A)**
37. It is recommended that for CP patients with poor balance and at risk of falling, PRM physicians prescribe balance training interventions (*e.g.*, trunk balance exercises, virtual reality training, force platform biofeedback).[18, 46, 101] **(SoE: I; SoR: B)**
38. It is recommended that PRM physicians consider that the impact of kinesio-taping technique on gross and fine motor function and dynamic activities is more effective than postural and static activities. This intervention as part of a multimodal therapy program can be effective in the rehabilitation of children with CP to improve motor function and dynamic activities especially in the child at higher developmental and motor stages.[75] **(SoE: III; SoR: C)**
39. It is recommended that PRM physicians assess sitting posture and balance in children and youth with CP and it is acceptable with the use of some clinical measures such as Pediatric Reach Test (PRT), Sitting Assessment for Children with Neuromotor Dysfunction (SACND), Segmental Assessment of Trunk Control (SATCo), Trunk Control Measurement Scale (TCMS).[29, 30, 55, 102, 103] **(SoE: II; SoR: B)**
40. It is recommended that speech-language therapists support functional seating for school-age children with CP by communicating with professionals with seating expertise and by invoking recommended guidelines for children with basic and complex seating needs.[104] **(SoE: IV; SoR: B)**
41. It is recommended that PRM physicians consider and apply tele-health interventions and tele-rehabilitation to improve the quality of the health care, especially for patients with CP in distant regions.[18, 60, 105] **(SoE: III; SoR: B)**
42. It is recommended that management of spasticity in persons with CP involves multidisciplinary efforts and starts as early as possible. There are a number of treatments available for combined management of spasticity. Antispastic pattern positioning, use of orthoses for joint position maintaining, elimination of triggering factors (infection, pain, constipation), range of motion exercises, and stretching can be useful to decrease spasticity, maintain joint range of motion, facilitate

function, and prevent contracture.[2, 13, 18, 34, 49, 59, 106-113] **(SoE: I; SoR: A)**

43. It is recommended that PRM physicians in cooperation with neurologist use pharmacological therapy, including targeted botulinum toxin injections into upper and lower limbs muscles and intrathecal drug administration in order to reduce spasticity, prevent contracture, increase range of motion, and improve activities of daily living.[2, 13, 18, 34, 59, 69, 99, 106, 108-117] **(SoE: I; SoR: B)**
44. It is recommended that PRM physicians in collaboration with a pediatric neurologists and neurosurgeons consider selective dorsal rhizotomy (SDR) to improve muscle tone, gross motor function, and performance of ADLs, as well as a decreased need for adjunct orthopedic procedures or botulinum toxin injections. SDR should only be undertaken by units that have a high throughput of patients and have accrued extensive experience with the procedure. It should be considered only if more conservative treatments have been unsuccessful.[2, 13, 18, 34, 59, 106, 108, 109, 115, 117, 118] **(SoE: I; SoR: B)**
45. It is recommended that PRM physicians in collaboration with a paediatric neurologists and neurosurgeons consider deep brain stimulation which can be an effective treatment option for dyskinetic CP.[109, 119] **(SoE: I; SoR: C)**
46. It is recommended that PRM physicians prescribe, on an individual basis, assistive equipment such as a walker or a wheelchair, computer-based technologies or smart homes, and all the technical devices that may increase independence, safety, mobility, and activities in daily life of patients with CP. It is imperative for people with disabilities to make their homes accessible in order to foster self-reliance and have the opportunity to live life as they choose.[17, 27, 43, 51, 66, 92, 115, 120, 121] **(SoE: I; SoR: A)**
47. It is recommended that PRM physicians may consider the convenient physical modalities (*e.g.*, FES, transcranial direct-current stimulation, NMES) and advanced technology (*e.g.*, robotic rehabilitation, exergaming/virtual reality systems) for persons with CP, whenever useful.[45-47, 69, 72, 74, 75, 82, 86, 91, 106, 122] **(SoE: I; SoR: B)**
48. It is recommended that PRM physicians be trained in swallowing assessment (videofluoroscopy, GUSS test) to recognize dysphagia which can lead to aspiration pneumonia, recurrent respiratory problems, dehydration, malnutrition, or other complications. It is recommended that PRM physicians consider that nutrition is extremely important in people with CP, particularly for those with dystonic movements and those with poor bulbar function.[4, 5, 17, 51, 81] **(SoE: II; SoR: B)**
49. It is recommended that PRM physicians create an individualized plan for the management of eating, drinking and swallowing difficulties in persons with CP taking into account the understanding, knowledge and skills of parents, carers and any other people involved in feeding the child/person, and also considering the role of postural management and positioning when eating (trunk and head control), modifying fluid and food textures and flavors, feeding techniques (such as pacing and spoon placement, oral stimulation techniques), strategies for developing oral motor skills, oral hygiene, equipment (such as specialized feeding utensils), optimizing the mealtime environment, etc.[17, 30, 51, 73] **(SoE: I; SoR: A)**
50. It is recommended that enteral feeding in the first place via nasogastric tube should be used for patients with CP who are not able to swallow effectively and safely. The use of percutaneous endoscopic gastrostomy (PEG) feeding is suggested in patients with severe forms of dysphagia lasting more than 3-4 weeks. It is recommended that PRM physicians consider that PEG has nutritional benefits for children and adults with CP and can improve well-being and quality of life for carers. Age-related deterioration in swallowing can be supported using gastrostomy feeding to prevent nutritional compromise.[4, 5, 17, 32, 51] **(SoE: II; SoR: B)**
51. It is recommended that PRM physicians regularly assess children and young people with CP during routine reviews to identify concerns about speech, language and communication, including speech intelligibility and to offer interventions to improve their communication skills and speech intelligibility (*e.g.*, targeting posture, breath control, voice production, articulation, oromotor deficits, language skills, rate of speech, readiness for school, and use of communication systems).[17, 18, 104] **(SoE: I; SoR: B)**
52. It is recommended that PRM physicians consider augmentative and alternative communication systems for patients with CP who need support in understanding and producing speech. These may include pictures, objects, symbols, and speech generating devices. The interventions should be always tailored to their individual needs, taking into account their cognitive, linguistic, motor, hearing and visual abilities. Aids that improve function and inclusion in the community are spectacles, hearing aids, communication devices,

and adaptations to enable use of computers.[17, 60, 72, 104] **(SoE: I; SoR: B)**

53. It is recommended that PRM physicians consider that individuals with CP are predisposed to sleep-disordered breathing (obstructive sleep apnoea), which leads to hypoxia events during sleep, an impairment on mood, behaviour, and neurocognitive function and causes greater damage in their quality of life.[2, 17, 123] **(SoE: I; SoR: B)**
54. It is recommended that PRM physicians consider occupational therapy (OT) for persons with CP to develop the skills necessary for the performance of the activities of daily living (such as feeding, dressing, toileting, bathing and use of adaptive technologies and equipment) and so enhance quality of their life and the lives of their families. Occupational therapy aims to improve hand and upper extremity functions in the child through systematic treatment methods for OT, purposeful activity, and play.[2, 18, 28, 49, 57, 67, 124] **(SoE: I; SoR: A)**
55. It is recommended that PRM physicians consider the vocational rehabilitation to persons with CP in relation to the communication limitation, social integration, and possible working activities still present in order to obtain adequate work.[60, 125] **(SoE: IV; SoR: B)**
56. It is recommended that particular attention be paid to the intellectual level in terms of evaluation of gross motor function. It is recommended to require support for social development in addition to physical interventions, from as early as 18 months.[28, 51, 56, 57] **(SoE: IV; SoR: B)**
57. It is recommended that PRM physicians consider psychosocial interventions for patients with CP with disquiet, sleep disturbance, distress, depressive symptoms, and pain.[51] **(SoE: IV; SoR: B)**
58. It is recommended that PRM physicians consider educational interventions for some persons with CP to improve their independence. For cognitive and neuropsychological impairments, clinicians should work closely with educators to help identify teaching methods that are consistent with deficits. Social determinants of health to be considered are also — family educational and economic status, living area (urban / non-urban) and access to health and social services.[4, 18, 60] **(SoE: IV; SoR: B)**
59. It is recommended that PRM physicians consider complex rehabilitation interventions with frequent participation in leisure activities for children with CP. Such activities should be associated with gross motor function, manual ability, cognitive ability, communicative skills, age, and gender which are the most important variables (*e.g.*, movement ability and social skills at age 2 are most predictive of leisure participation when the child is 6 years old).[64, 126, 127] **(SoE: I; SoR: A)**
60. It is recommended that PRM physicians consider the Active Lifestyle and Sports Participation intervention for adolescents and young adults with CP is offered in an outpatient rehabilitation department. Dance is recommended because it improves functionality and psychosocial adjustment in patients with CP. Future studies should determine the short- and long-term effectiveness of the intervention.[2, 68, 121, 128] **(SoE: I; SoR: B)**
61. It is recommended that PRM physicians offer useful answers to family members and caregivers of persons with CP to support their physical, psychological, and social status. Monitoring of family functioning and identification of factors associated with distress to optimize child and family well-being is necessary.[65] **(SoE: IV; SoR: A)**

IV. d. Outcome criteria

62. It is recommended that PRM physicians determine patient-centered outcome criteria according to the individual clinical situation, in relation to the quality of life, impact of treatments, individual patient's functional impairments, activity limitations, and participation restrictions. For children and some adults with CP family-centered care is an accepted component in achieving maximal independence, especially for patients with cognitive impairment.[18, 54, 129] **(SoE: II; SoR: A)**
63. It is recommended that PRM physicians determine the outcome criteria through the evaluation and goal-setting processes using functional scales which conform to the ICF framework.[22, 24-27, 30, 41, 42, 48-50, 130-135] **(SoE: II; SoR: A)**

IV. e. Duration and intensity of treatment (overall practical PRM approach)

64. It is recommended that PRM physicians, as coordinators of a multi-professional team, define the purposes of treatment plans in compliance with the specific status of the person with CP related to length and intensity of the PRM approach, together with the rehabilitation team, as well as the patient, family, and caregivers.[2, 4, 5, 16-18, 32] **(SoE: I; SoR: A)**

65. It is recommended that patients with CP are regularly monitored by PRM physicians during their lifetime with consideration to potential progression of comorbidities and impairments in body functions, activity limitations, and participation restrictions, and if needed they are prescribed an appropriate complex rehabilitation program.[2, 4, 5, 16-18, 32] **(SoE: I; SoR: A)**
66. When planning an intervention to improve ability of daily living function in CP children, it is recommended that PRM physicians consider that their respiratory muscle strength is correlated positively to their capability levels of daily living self-care and social function.[44] **(SoE: II; SoR: B)**

IV. f. Follow-up criteria and agenda

67. A multidisciplinary follow-up at periodic intervals based on the clinical and functional status of the person with CP and individualized indication of outpatient PRM interventions in different settings are recommended throughout the lifespan of persons with CP with a life-long disability.[2, 4, 5, 16-18, 32, 33] **(SoE: I; SoR: A)**
68. It is recommended that throughout long-term monitoring, management of complications (spasticity, contracture, developmental dysplasia of the hip - DDH, sarcopenia, osteoporosis, low energy fractures, obstipation, pressure ulcers, etc.) is done by the PRM physician and the multi-professional team, working in an interdisciplinary way.[2, 4, 5, 16-18, 32, 33, 59] **(SoE: I; SoR: A)**

IV. g. Discharge criteria (e.g., when and why to end PRM interventions)

69. It is recommended that the patients with CP are followed up by PRM physicians and receive complex rehabilitation throughout their lifespan with regards to the progression of their condition and their consequent inability to undergo some of the PRM interventions.[2, 4, 5, 16-18, 33] **(SoE: I; SoR: A)**

V. Recommendations on future research of PRM professional practice

70. It is recommended that PRM physicians participate in research on PRM professional practice which is focused on effective and comprehensive rehabilitation of physical, behavioral, and cognitive problems caused by CP.[18, 61, 120, 123, 126] **(SoE: I; SoR: A)**
71. It is recommended that research trends focus on integrating technological advances into rehabilitation care for a person with CP. PRM physicians are involved in the future research projects that should be targeting the effectiveness of various innovative interventions, such as new technologies (*e.g*., virtual reality, tele-rehabilitation: intelligent monitoring devices that can monitor motor activities and transmit information bidirectionally between patients and therapists), robotic therapy, deep brain stimulation, transmagnetic cranial stimulation, transcranial direct current stimulation, etc. Specific pharmacological and non-pharmacological approaches to rehabilitation of individuals with CP must also be assessed in rigorously designed clinical trials, *e.g*. what is the clinical and cost effectiveness of exercise therapy, especially neurophysiological principle, casting (*e.g*., for equinus deformity), multilevel soft tissue surgery, botulinum toxin type A, sleep-disordered breathing (obstructive sleep apnea), measuring visual abilities, acupuncture, multimodal interventions (*e.g*. pharmacological therapy plus exercise therapy, brain stimulation plus exercise therapy), provide a clear definition of quality of Life (QoL), and investigate the relationship between symptoms severity with QoL, etc.[6, 46, 61, 99, 106, 116, 120, 122, 123, 136] **(SoE: I; SoR: A)**
72. It is recommended that rehabilitation of neurological health conditions in general, and particularly in CP therapeutics, would capitalize on growing appreciation of brain plasticity throughout the lifespan and the possibility that this feature can be harnessed for therapeutic gains. Advances in neuroscience suggest that the CNS has some plasticity and the potential to reorganize throughout the entire lifespan, rather than merely during a short period of development and that activity-dependent plasticity takes place in the motor cortex. Potential plasticity of the CNS has led to the development successful interventions (*e.g*., constraint-induced movement therapy, bodyweight-supported treadmill training, task-specific exercise) and future research should continue in this direction. Brain plasticity is important to the pathophysiology and treatment of CP throughout a patient's life.[18, 61, 107] **(SoE: I; SoR: A)**
73. It is recommended that PRM physicians participate in research on epidemiology, in the field of possible prevention of various forms of CP, early diagnostics and prognostic factors of CP. PRM physicians are involved also in the future research on the socialization of CP families, physical, psychological, and social questions of caregivers, and interpersonal relationship problems of persons with CP. Future research is required

to clearly establish the factors underlying deficits in social function capability in children with CP and to develop interventions to support social development in this population. These and analogical information could be utilized in better care-management of patients with CP.[28, 33] **(SoE: II; SoR: A)**

74. It is recommended that future research projects in the field of CP rehabilitation support and strengthen evidence-based practice and develop standardized outcome evaluation instruments (*e.g*., computer adaptive testing). ICF compatible evidence-based assessment methods should be implemented. Application of evidence-based methods, will ensure maximum gains in children and adults with CP.[37, 61, 102] **(SoE: I; SoR: A)**

Conclusions

The professional role of PRM physicians in CP throughout the lifespan of persons with life-long disability is to propose and to manage rehabilitation programs in multiprofessional teams, working in an interdisciplinary way in a diversity of settings to maintain or improve the functioning of persons with CP considering all the concurring diseases and pathologies, impairments, activity limitations, and participation restrictions. PRM physicians should focus in CP patients from birth until maturity, especially however, during the early years of life, on minimizing the possibilities of occurrence, in some cases on adjustment and/or maintenance of existing functional, structural physical, mental, cognitive, and social restrictions and changes corresponding and reflecting functional and pathologic-anatomic changes in the CNS. In adults with CP, PRM physicians focus throughout the patient's lifetime on stabilizing his health condition, social state, and ADL. It is recommended that PRM physicians perform screening of newborns and identify infants at high risk of CP. They should monitor them regularly and prescribe complex rehabilitation care.

This EBPP represents the official position of the European Union through the UEMS PRM section and designates the professional role of PRM physicians for persons with CP.

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