MASTER'S THESIS

Study programme

May 2019

Children with cerebral palsy and preferred functional mobility methods

A population-based cross-sectional study

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Arbeidet med masteroppgaven har vært en veldig lang og krevende prosess, men en spennende en. Jeg har lært utrolig mye om det å skrive oppgave med dette omfanget, og ikke minst innsatsen som ligger bak. Jeg har lært mye om meg selv i måter å jobbe på, men viktigst av alt har jeg lært mye om tematikken i oppgaven. Ettersom jeg ikke har mye klinisk erfaring da det kommer til barn med cerebral parese, vil dette absolutt være nyttig informasjon for min fremtidige jobbhverdag.

Midt i oppstarten av oppgaven ble jeg konfrontert med en hendelse som gjorde at oppgaven måtte vike i ett års tid. Det har vært en veldig anstrengende tid, men jeg hadde ikke klart det uten hjelp fra min dyktige veileder Sigird Østensjø. Det skal nå bli ekstra deilig å komme i mål etter hva som føles som en lang evighet med arbeid.

Jeg vil gjerne takke foreldrene som samtykker til å registrere informasjon om deres barn med CP i de to registrene CPOP og CPRN. Uten dere hadde det ikke vært mulig for meg å utforske disse spennende spørsmålene relatert til barn med CP og funksjonell forflytning. Jeg håper at mitt arbeid vil komme barn med cerebral parese til gode.

For at dette arbeidet i det hele tatt skulle være mulig vil jeg gjerne takke mine to foreldre som har vært enorme støttespillere i tunge tider, samt nære venner som alltid har heiet på meg. En stor takk må rettes til Sigrid Østensjø, som har vært så uendelig tålmodig med meg og gitt meg konstruktiv tilbakemelding. Dine innspill har vært motiverende og til uvurderlig hjelp,

Takk også til Fysiofondet for økonomisk støtte.

Sara Oslo, mai 2019

Abstract

Background: Cerebral palsy is a complex disorder that can cause several impairments affecting the children's mobility. Previous studies have mostly investigated specific interventions or gross motor capability of children, but very few studies have explored the children's preferred mobility methods in their daily environments.
Aim: The aim of this study was to describe the preferred mobility methods in a population of children with CP, in relation to age, CP characteristics, and CP related motor impairments.
Method and material: The study includes population-based longitudinal data from one consent-based registry, the national motor follow-up program for children with CP (CPOP), but is designed as a cross-sectional study. The research participants consist of 773 children whom all were 4 years or older. Data were collected from 01.01.2002-31-12.2017.
Results: There were statistically significant associations between functional mobility scale (FMS), subtype of CP, severity of CP (GMFCS), spasticity and joint mobility restrictions. No significant associations were found for FMS and age. The majority of children had a low severity of CP and walked independently across home, school and community environments. Amongst the children with a higher level of CP, an increase in wheelchair use was seen. There were a tendency of fewer children walking independently and more using a wheelchair compared from the home to communal environments. Almost all of the children with high severity of CP had bilateral spasticity, whereas unilateral spasticity encountered for most of the more self-mobilising children.
Conclusion: The majority of children walked independently across their home, school and communal environments. The largest proportion of children walking independently had GMFCS level I, whereas the largest proportion of wheelchair users had GMFCS level IV and V. There was a positive correspondence between the functional mobility scale and GMFCS levels, as well as that neither spasticity nor joint mobility restrictions were hallmarks in terms of preventing children from walking independently across 5, 50 and 500-meter distances.
Keywords: cerebral palsy, children, functional mobility scale

Key abbreviations

CP	Cerebral Parese
CPOP	Cerebral parese oppfølgnignsprogram
CPUP	Uppföljningprogram för cerebral parese
CPRN	Cerebral parese retionalt medisinsk kvalitetsgregister
FMS	Functioal Mobility Scale
GMFCS	Gross Motor Function Classification System
ICF	International Classification and Functioning
MAS	Modified Ashworth Scale
PROM	Passive range of motion
SCPE	Surveillance of cerebral palsy in Europe
WHO	World Health Organization

1. Introduction

Cerebral Palsy (CP) is the most common motor disability in childhood (Himmelmann & Panteliadis, 2018). The prevalence of cerebral palsy (CP) is about 2.4 per 1000 live births in Norway, meaning that approximately 120-150 of Norwegian children are born with, or develop CP every year (Andersen, 2018). CP is an umbrella term covering a group of non-progressive motor impairment syndromes, causing activity limitations that are attributed to disturbances that occurred in the developing foetal or infant brain (Rosenbaum et al., 2007). Most children are diagnosed around the time they turn two years old when motor skills, or lack thereof become more visible (Andersen, 2018). These motor disorders are often accompanied by disturbances of sensation, cognition and communicational problems (Rosenbaum et al., 2007), which consequently leads CP to be a complex disorder that can require a multidisciplinary approach throughout life.

In Norway, children with CP are offered a systematic follow-up through a national medical quality register (CPRN), and the associated motor follow-up program (CPOP). CPOP was established from the corresponding follow-up program in Sweden (CPUP). The purpose of the CPRN and CPOP is to increase knowledge about CP, predict and follow known medical and motor complications, as well as improve treatment quality. It is estimated that around 90% of the children with CP in Norway are registered in CPRN and CPOP (Andersen et al., 2017)

In CPOP, the child's motor function is monitored yearly or every second year until turned 18 years old based on age and severity of CP. The CPOP protocol consists of several classifications and measurement tools to monitor the children's motor impairments, motor skills and mobility in contexts of daily life (Andersen et al., 2017). Thus, the CPOP presents a unique opportunity for research on mobility among children with CP in Norway, which is the theme of the present study.

The interest regarding gait abilities in children with CP is clearly visible in research, where many studies have investigated gait deviations and the effect of specific interventions on walking capacity (Booth et al., 2018; Eek, Tranberg, Zügner, Alkema, & Beckung, 2008; Novak et al., 2013; Rajagopal et al., 2018; Smania et al., 2011; Valentin-Gudiol et al., 2013; Woollacott & Shumway-Cook, 2005). Previously, outcomes of interventions for children with

CP was measured almost exclusively in clinical settings (Calderon-Gonzalez, Calderon-Sepulveda, Rincon-Reyes, Garcia-Ramirez, & Mino-Arango, 1994; McLaughlin et al., 1998; Palmer et al., 1988; Steinbok, Reiner, Beauchamp, Armstrong, & Cochrane, 1997; Tieman et al., 2004), however these measurements under standardized conditions indicated only the capability of what the children could do, and did not account for the environmental factors that could influence walking performance of everyday settings (Young, Williams, Yoshida, Bombardier, & Wright, 1996). Although this research is of important knowledge, it does not enlighten the fact that how an individual chooses to move in his or her everyday environment, which is related to the individuals own decision of mobility, may in fact differ from the individual is able to do (Tieman et al., 2004).

So far, only one study has assessed preferred mobility methods in a total population of children with CP (Rodby-Bousquet & Hägglund, 2012). Using data from the CPUP, Rodby-Bousquet et al. described the most frequent mobility methods for different distances and environments, and the children's walking performance related to age, CP subtype and level of gross motor function. They found that the children's walking performance was related to CP subtype and the severity of limitations in gross motor function. They also found that overall walking performance increased up to 7 years of age (Rodby-Bousquet & Hägglund, 2012). By using data from CPOP, it is possible to attempt to replicate some of the findings in the Swedish study, and to expand on previous research by including more factors that might be associated with the mobility performance of children with CP. Knowledge as such is of importance of health care planning as well as for prediction of future mobility methods in young children with CP.

1.1 Purpose and aims

The overall purpose of this study is to describe the preferred mobility methods in a population of Norwegian children with CP in relation to age, CP characteristics and CP related motor impairments. The study will expand previous research based on CPRN and CPOP data, and thus contribute to the ongoing work for making the follow-up programs for children with CP more evidence-based.

In order to achieve the purpose of this study, the more specific aims are to:

1. Describe which mobility methods children with cerebral palsy use most frequently for different distances and environments.

2. Examine the association between preferred mobility methods and age, CP subtype and gross motor function.
3. Examine the association between preferred mobility methods and lower extremity spasticity and joint mobility restrictions.

1.2 Build-up of master thesis

This master thesis consists of six chapters. The introduction chapter (chapter 1) is followed by a description of theoretical backgrounds and research related to the overarching themes of the study (chapter 2). Chapter three explains the methods used in the handling of the data and the analysis of the data material. Chapter four presents the results, with tables and descriptions of the findings related to the research questions. In chapter five the results are presented, followed by a discussion of the method section, and lastly the results are discussed. The study finishes in chapter six with a conclusion and suggestions for future research. At the very end of the thesis there are appendixes relevant to the study as well as the literature list.

2. Theory

The theory chapter begins with a presentation of the International Classification of Functioning, Disability and Health (ICF) as a framework for describing and organizing information on functioning and disability (World Health Organization, 2001). The ICF provides a standard language and a conceptual basis for the definition and measurement of health and disability. It will be used to organize the description of the phenomena included in the study and previous research. The chapter finishes with a presentation of Cerebral Palsy Motor Follow-up Programme (CPOP) and some of their previous findings related to this study.

2.1 International Classification of Functioning

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains. It is the World Health Organization's (WHO) framework for measuring health and disability at both individual and population levels. The ICF was developed through a collaborative international approach with the aim of developing a single generic classification for assessing health status and disability across different cultures and settings. The ICF conceptualises functioning as a dynamic interaction between a person's health condition, environmental and personal factors. Functioning and disability are understood as umbrella terms symbolising the positive and the negative aspects of functioning from a biological, individual and social perspective. Notably it should be clear that the ICF is not associated with specific health problems or diseases, but it describes the associated dimensions of functioning at the body, persons and social levels (World Health Organization, 2001, 2013).

The ICF model can be used for population-based statistics and the information gathered can for instance indicate which areas of the social environment are most disabling for people experiencing functional difficulties (World Health Organization, 2013), which is relevant to the context of this study; children with CP and their preferred mobility methods across different environments. In an attempt to cover the development perspective of health and functional disability, WHO approved a child and youth version of the ICF in 2007 (IFC-CY) (World Health Organization, 2007). However, the original, child and youth version have now been merged into one version (World Health Organization, 2019).

The ICF organises information in two parts. The first one is functioning and disability, and is organized as three components: body functions and body structures, activity and participation. The second part is contextual factors which entails environmental factors and personal factors (see figure 1).

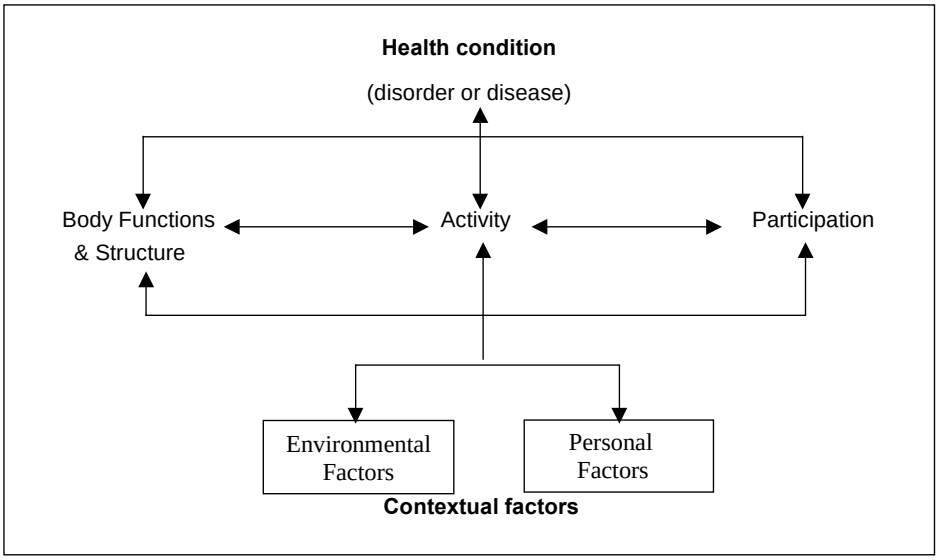

Figure 1, Overview over the components included in the ICF model (World Health Organization, 2001)

Body Functions are the physiological functions of body systems, whereas Body Structures are the anatomical parts of the body such as an organ, limbs and their components. Activity is the execution of a task or action by an individual. The model distinguishes between two perspectives of activities: what a child does in his/her daily environment (performance) and what a child can do in a controlled environment (capacity). Participation is the involvement in a life situation (World Health Organization, 2001).

Disability is an umbrella term for impairments, activity limitations and participation restrictions. Impairments are the problems in the body function and structure such as significant deviant loss. Activity limitations are the difficulties an individual may have executing activities. Participation restrictions are problems an individual may experience in involvement in life situations.

Contextual Factors covers environmental and personal factors. Environmental Factors are the physical, social and attitudinal environment in which people live and conduct their lives.

These are either barriers to, or facilitators of the persons functioning. Personal factors are aspects such as age and gender (World Health Organization, 2001).

2.1.1 Health Condition, Cerebral Palsy

Cerebral Palsy (CP) is the most frequent cause of severe motor disability in children, and makes a heavy demand on families, social services and on the children themselves (SCPE, 2000). In fact, children with CP are the largest diagnostic group treated in paediatric rehabilitation (Odding, Roebroeck, & Stam, 2006). The prevalence is about 2.4 per 1000 live births according to a network called Surveillance of Cerebral Palsy in Europe (SCPE) (Odding et al., 2006; SCPE, 2000). In Norway these estimates are similar (Andersen et al., 2018). There is a larger occurrence of CP amongst boys than girls (57% vs 43%) (Andersen et al., 2018).

Cerebral Palsy is an umbrella term covering a group of non-progressive, motor impairment syndromes arising in the early stages of development either before, during or after birth (Andersen et al., 2017; Himmelmann & Panteliadis, 2018; Rosenbaum et al., 2007). These children have damage to the central control system of the brain, and CP is permanent. The damage is commonly resulting in activity limitations due to disturbances in motor control, with associated delay in the onset of walking and gait deviations (Bell, Õunpuu, DeLuca, & Romness, 2002). CP is a complex disorder, and is often accompanied by disturbances of sensation, cognition, perception, communication, and behaviour such as epilepsy (Rosenbaum et al., 2007). Although the brain lesion is static, progressive musculoskeletal impairment is seen in most children, meaning the consequent symptoms varies, and may change over time (Andersen et al., 2017). Secondary musculoskeletal problems such as muscle/tendon contractures, bony torsion, hip displacement and spinal deformity can contribute to functional deterioration. Many of these problems develop throughout life, and are related to physical growth, muscle spasticity and weakness, aging, and other factors (Rosenbaum et al., 2007; Wright & Wallman, 2012). The motor disorders are classified as either spastic (uni- or bilateral), dyskinetic or ataxic, although spasticity is often the dominant disorder (Himmelmann & Panteliadis, 2018; Rethlefsen, Ryan, & Kay, 2010).

Gross motor development in children is commonly described as the achievement of motor milestones such as sitting unsupported, crawling and walking. A child with CP will be recognised by delay of gross motor development and the presence of abnormal movement and

posture patterns (Beckung, Carlsson, Carlsdotter, & Uvebrant, 2007; Woollacott & Burtner, 1996). A population-based study (Himmelmann, Beckung, Hagberg, & Uvebrant, 2006) reported about half of the children to have mainly motor function affected, whereas the rest additionally had accompanying major impairments adding to the disability which in turn affected several areas of activity and participation (Beckung et al., 2007).

2.1.2 Body Functions and Structures

Classification of CP subtype

Since CP is a heterogenous health condition, the *subtype of CP* is important to know because it gives necessary information about the clinical consequences of the damaged brain for children with CP. CP is classified according to the disturbances in muscle tone, and the dominant lesion of the affection, which refer to body functions in the ICF. All children in the CPOP will be classified with subtype of CP. Based on recommendation from the SCPE, the concluding subtype of CP should be set at around five years of age (Andersen et al., 2018; SCPE, 2000).

SCPE divides CP into three groupings based on the predominant neuromotor abnormality; spastic (unilateral or bilateral), dyskinetic or ataxic type (SCPE, 2000). The type of abnormal muscle tone or involuntary movement disorder observed is usually assumed to be related to the underlying pathophysiology of the disorder, and may also reflect etiologic circumstances, but could have mixed presentations of the subtypes of CP. Despite this, CP is classified by the dominant type of tone or movement abnormality (Rosenbaum et al., 2007).

Spastic CP is characterized by stiffness in the musculature, and is divided into unilateral type and bilateral type. Unilateral type is characterized by spasticity in one arm or leg at the same side of the body, whereas bilateral type is when arms and legs on each side of the body is affected. Dyskinetic CP is characterized by involuntary movements and often a changing muscle tone. Ataxic CP is characterized by coordination difficulties (SCPE, 2000).
The National Medical Quality Register (CPRN) presents a yearly report together with the Cerebral Palsy Motor Follow-up Program (CPOP) (Andersen et al., 2018). In 2016 they found that the proportion of children with spastic bilateral CP decreased, whereas there were an increase in the number of children with spastic unilateral CP (Andersen et al., 2018).
According to the yearly report from CPRN and CPOP in 2017, 43% of the children with CP

have spastic unilateral CP, 45% spastic bilateral CP, 6% dyskinetic CP and 4% ataxic CP (Andersen et al., 2018).

Motor impairments

The study collects information on two motor impairments, spasticity and joint mobility restrictions, which both are included in the CPOP assessments.

Spasticity is a primary cause of physical activity limitation for children with CP (Jeffries, Fiss, McCoy, & Bartlett, 2016). It is defined as the resistance to passive stretch while a person is attempting to maintain a relaxed state of muscle activity (Himmelmann & Panteliadis, 2018). An abnormally increased resistance to an externally imposed movement around a joint is called hypertonia. Spasticity may be described as a form of muscle hypertonia in which there is a speed-dependent resistance to passive movement due to heightened stretch reflexes (Rice, 2018). Hypertonia manifests with an increase in the resistance at higher speeds of movement, and may be measured by several methods (Himmelmann & Panteliadis, 2018). The Modified Ashworth Scale (MAS) is the most used method in clinical practice and research to measure resistance to passive movement (Bohannon & Smith, 1987; Himmelmann & Panteliadis, 2018; Tilton, 2004).

In children with CP, spasticity is a primary motor impairment. Population-based studies have shown that spasticity increases in the children till four years of age, after which there is a steady decline in muscle tone (Hägglund & Wagner, 2008). Spasticity is found to be a contributor to restrictions in joint mobility in children with CP (Dayanidhi & Lieber, 2018).

Joint Mobility Restrictions, often caused by the shortening of muscles and stiffening of joints (contractures) is considered a secondary musculoskeletal problem as a result from the primary deficits related to CP. Secondary musculoskeletal problems (muscle contractures and bone deformities) are added progressively with time to the clinical image of children with CP, in response to the primary deficits and produce further motor dysfunction (Himmelmann & Panteliadis, 2018)

Examination of the range of motions (ROM) can give information whether the muscle contracture is dynamic or static. Measurement of passive range of motion (PROM) gives an indication of the muscle length at rest (static muscle length) which is different from the

dynamic muscle length, which is identified by measuring the point of resistance to a rapid velocity stretch-catch. Dynamic contracture completely disappears under anaesthesia, whereas the static contracture remains, showing that the differentiation between these two types of contractures is best performed as the child is under anaesthesia (Himmelmann & Panteliadis, 2018). The joint range of motion is often measured by goniometry, and there are several clinical tests that can be performed in order to differentiate between static and dynamic contracture (Himmelmann & Panteliadis, 2018).

2.1.3 Activity

Classification of the gross motor function

According to the definition of CP, the brain damage is often leading to activity limitations. The heterogeneity of the motor condition tells that there is also a need to classify levels of motor related activity limitations, in addition to the classification of subtype of CP based on impairment in body functions. In the CPOP all children are classified with the Gross Motor Classification System (GMFCS) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). The GMFCS is a tool to understand the gross motor function limitations and expectations for further development in children with CP. The GMFCS is widely used as an indicator of the severity of CP (Palisano, Rosenbaum, Bartlett, & Livingston, 2007; Rutz, Thomason, Willoughby, & Graham, 2018).

The GMFCS is a five-level classification system (see figure 2), which has the focus on determining which level best represents the child's or youth's present abilities and limitations in gross motor functions. Emphasis is on usual performance (what a child does) in their home, school or community settings, rather than what they are capable of doing at their best (capacity). The classification is based on self-imitated movement, with emphasis on sitting, transfers and mobility performance (Palisano et al., 2007).

The distinctions between the five levels are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches and canes) or wheeled mobility, and to a much lesser extent, quality of movement. The GMFCS recognizes that the manifestations of gross motor function are dependent on age. For each level, separate descriptions are provided in several age bands: before 2nd birthday, between 2nd and 4th birthday, between 4th and 6th birthday, between 6th-12th birthday and lastly between 12th and 18th birthday (Palisano et al., 2007). (See Appendix 5).

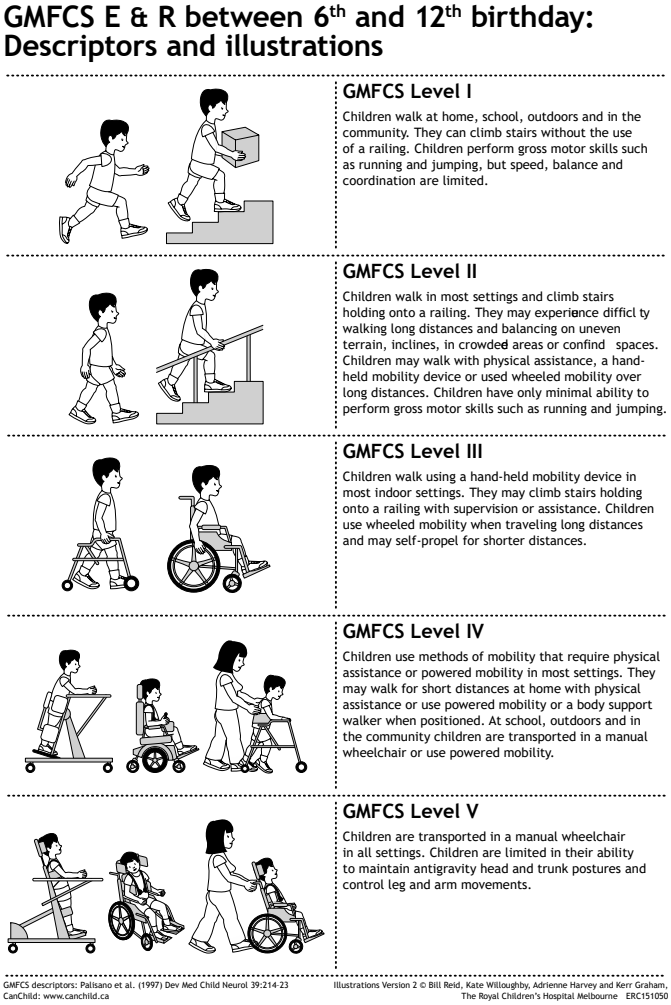

Figure 2, Illustration and description of GMFCS between 6th and 12th birthday (CanChild, 2019).

The title for each of the five levels is the method of mobility that is most characteristic after 6 years of age. Children at level I is expected to walk without restrictions, but may have some limitations in more advanced gross motor skills. Children at level II is expected to be able to walk without assistive devices, however have limitations in walking outdoors and in the community. Children at level III walks with assistive devices but have limitations in walking outdoors and in the community, and will most likely need a wheelchair for outdoor activity. Children at level IV have limitations in self-mobility. They are often able to sit (with support) but will need manual transportation or in an electric wheelchair, especially around the community. Lastly, the children at level V have severely limited abilities of self-mobility, even with the use of assistive technology (Palisano et al., 2007). These children also have serious limitations in relation to head- and trunk control, and often need extensive

technological adjustments and physical help (Palisano et al., 2007; Rosenbaum et al., 2007; Rosenbaum et al., 2002).

The GMFCS has strong predictive values in areas of musculoskeletal management, such as the prediction of the risk of hip displacement and the shape of the proximal femur (Robin et al., 2008; Rutz et al., 2018; Soo et al., 2006). The GMFCS is also a strong predictor of the success or failure of interventions for hip displacement such as injection of the adductor muscles, adductor release surgery and bony reconstructive surgery (Graham et al., 2008; Rutz et al., 2018; Shore et al., 2012; Shore et al., 2015; Willoughby, Ang, Thomason, & Graham, 2012). Notably, sometimes the children's GMFCS levels change (Rutz et al., 2018). As the children can be classified before two years of age, it is recommended that they are re-classified with every examination they undergo in the CPOP (Andersen et al., 2018). The GMFCS classification underlines how the children should be followed up with x-rays of the hips and with different interventions, as the risk of secondary complications can be very different between the different GMFCS levels (Andersen et al., 2018). After a major intervention, such as a single-event multilevel surgery, a small number of children might move up a GMFCS level (Rutz et al., 2018). However, this is uncommon and should not be expected in more than 5-10% of children (Rutz, Gaston, Camathias, & Brunner, 2012). Deterioration in GMFCS level is more common (Rutz et al., 2018).

Mobility performance

Mobility performance involves moving from one place to another in everyday environments. It encompasses body movements such as walking and using equipment (walkers/wheelchairs) and to move around (World Health Organization, 2001).

Children with CP have damage to the central control system of the brain, commonly resulting in abnormal motor control, and gait limitations (Bell et al., 2002). Consequently children with CP often start to walk later than non-disabled children, and with a slower speed and higher energy cost (Rodby-Bousquet & Hägglund, 2012). Tracking the development of mobility performance in children with CP, such as walking, is important for the clinicians, families and children. There can be changes in preferred mobility methods when the child gets older or has surgical or non-surgical interventions, and these changes are of great importance to the surrounding care-team of the child, as well as for the child's further development.

There are different tools available for clinicians in order to track the activity of children with CP (Imms & Gibson, 2018), one of them being the Functional Mobility Scale (FMS). The FMS was designed as a measure of ambulatory performance in children with CP across three different distances (see Appendix 3); 5-meters (representing moving at home), 50-meters (moving around at school) and lastly 500-meters (moving around the community) (Rethlefsen et al., 2010). The children are rated from 1-6 where 1 represents the use of wheelchair and 6 represents independent walking. The ratings are equal for all three distances (Graham, Harvey, Rodda, Nattrass, & Pirpiris, 2004; Palisano et al., 2003) Currently, the FMS is the only existing measure that accounts for the fact that children might use different assistive devices to move various distances, and may demonstrate different ambulatory for different environments. Although intended as an outcome measure, the FMS is also a useful tool as a means of classifying ambulatory performance (Rethlefsen et al., 2010).

The FMS measure functional mobility in children, considering the range of assistive devices a child might use. The scale can be used to classify children's functional mobility, document changes over time for the same child, and to show changes after interventions. The assessment is not a direct observation, but based on questions from the clinician to the child or parent. The FMS clearly states that it is a performance measure which rates what the child actually does at this point in time, and not what they can or are able to do (Graham et al., 2004; Palisano et al., 2003).

2.1.4 Participation and Environmental Factors

Participation and Environmental factors from the ICF are two elements that can be of great importance for the life of children with CP. Participation, which is an underlying section of 'functioning and disability' is about the child's involvement in life situations (Rethlefsen et al., 2010), whereas environmental factors are part of the contextual factors in the ICF, and is defined as the physical, social and attitudinal conditions that are present in an individual's life (World Health Organization, 2001).

Participation

Children with CP do not have the same prerequisite as non-disabled children when it comes everyday aspects such as participation. Compared with young people with CP, non-disabled children had higher participation in home, extracurricular and community activities. The participation amongst the children with CP was highest in GMFCS level I and lowest in

GMFCS levels IV and V (Bode, 2018; Orlin et al., 2010). In children and adolescents with CP, developmental trajectories of mobility performance depend on the level of gross motor function (Vos et al., 2013), whereas the trajectories of daily activities mainly relate to intellectual ability. Adults with CP without mental handicaps are generally able to master the daily activities, the mobility and the communication by themselves, however, 70% of young adults with CP have reported experiencing problems in their daily lives (Bode, 2018; Nieuwenhuijsen et al., 2009). Nonetheless, children with CP seem to have a fairly similar quality of life as compared to their healthy peers (Bode, 2018; Dickinson et al., 2007), however this is not the same as health-related quality of life, which are measures of self-perceived health status (Karimi & Brazier, 2016; Moons, 2004).

A cohort study found that there was a clear relation between the severity of CP and the health-related quality of life (HRQOL). The three domains that had notably lower HRQOL scores all reflected mobility and motor skills, showing the severity related to physical functioning issues (Vargus-Adams, 2005). Another study about participation in leisure activities in children with CP, found involvement to be lower in skill-based and active physical activities, as well as community-based activities. Cognitive and behavioural difficulties, activity limitations and parental stress showed to be obstacles for participation (Majnemer et al., 2008). Additionally, evidence suggest that children with a variety of disabilities have fewer social engagements than their peers, and are involved in fewer activities and that these activities tend to be home based and less physically active (Imms & Adair, 2017; Spittle & Morgan, 2018).

An exploratory analysis (Kerr, McDowell, & McDonough, 2007) found that children with CP that share level of impairment, do not necessarily have the same participation abilities. Due to difficulties in functional abilities and social backgrounds, the relationship between motor function and participation restriction may not be as straight forward as previously anticipated (Kerr et al., 2007).

Environment

According to the ICF, environmental factors include for example family support and assistance, as well as peer acceptance which are social and attitudinal environmental factors that may influence the mobility methods used by children with CP (Palisano et al., 2003; World Health Organization, 2001).

It is established in research that independent mobility is important for activity, participation, self-sufficiency, reducing the dependence on caregivers and the environment (Palisano, Kang, et al., 2009; Palisano et al., 2003; Tefft, Guerette, & Furumasu, 1999). A study enlightening the consequences of this found children with CP to have fewer mutual friendships, exhibit fewer sociable/leadership behaviours, and they were more isolated and victimised by their peers than classmates without a disability, and this already at the age of 10 (Bode, 2018; Nadeau & Tessier, 2006).

As children with CP often start to walk later than non-disabled children (Rodby-Bousquet & Hägglund, 2012) it is important that physical and social features of the environment are considered when establishing goals and planning interventions to improve mobility (Østensjø, Carlberg, & Vøllestad, 2003). Low declining levels of confidence in walking is likely to be associated with reduced physical activity, reduced community walking and perhaps avoidance of challenging activities (Morgan & McGinley, 2014). It has been shown that the mobility performance of children with CP vary across the environmental settings at home, at school and around the community (Harvey, Baker, et al., 2010; Palisano et al., 2003; Tieman et al., 2004).

As the daily lives of children with CP include a variety of environmental settings, decisions on interventions to improve mobility have traditionally been based on examinations performed in clinical settings (Palisano et al., 2003). Nonetheless, a study (Østensjø et al., 2003) investigating the effect of environmental settings on mobility methods of children with CP found that children were less dependent on adult assistance for mobility at school, and more dependent on adult assistance for mobility outdoors or in the community. Age was not a contributing factor however to the mobility method of environmental settings. However, there are still only a few studies that have investigated what impact environmental factors can have on children with CP in relation to their preferred mobility method (Palisano, Hanna, Rosenbaum, & Tieman, 2010; Palisano et al., 2003; Tieman et al., 2004; Østensjø et al., 2003).

2.2 Treatment interventions

Early intervention for infants and children with CP aims to improve brain connections during key periods of brain development, rather than waiting for an impairment to occur once altered brain connections have developed. Early intervention focuses on coaching parents to use play

to train motor, cognitive, language and behaviour skills (Spittle & Morgan, 2018). As the inability move independently can have a significant negative impact on cognitive, perceptual and/or motor development (Tatlow, 1980; Verburg, 1987; Zubek, Aftanas, Kovach, Wilgosh, & Winocur, 1963), it is necessary to manage and influence the ability for self-mobility for children with CP.

Effective interventions to improve motor activities in older children with CP tend to be goal oriented, involving practice of functional tasks that are meaningful to the child and family, delivered in a natural environment and repeated at sufficient intensity (Novak et al., 2013; Spittle & Morgan, 2018). Interventions such as goal-oriented training or functional training have shown to produce improvements in gross motor function and performance of daily activities in young children and toddlers with CP (Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Law et al., 2011; Spittle & Morgan, 2018; Østensjø et al., 2003)

Although, as spasticity is the largest subcategory in the subtypes of CP, and 70-90% of children with CP have spasticity either unilaterally or bilaterally (Braun et al., 2016; Himmelmann & Panteliadis, 2018), it is not unexpected that a lot of the treatment interventions are aimed at reducing spasticity in children with CP. Spasticity reducing treatment can be given orally, intramuscular, intrathecally, through selective dorsal rhizotomy, orthopaedic surgery and multilevel surgery (Solheim, 2018).

From a more functional perspective, therapy for children with CP ought to aim at enabling the children to master important tasks and participate in day-to-day activities (Østensjø et al., 2003). Physiotherapy, like occupational therapy, completes a number of important tasks and specific goals in the treatment of children with CP, such as promoting sensorimotor development, improvement of abnormal posture and movement control in all activities, prevention of deformities, finding the best possible position when standing, sitting and lying, advice in the adaption of orthotics and assistive technology, and support for the patient and family to cope with the demands of everyday life (Karch & Heinemann, 2018). However, there is little knowledge regarding the long-term effects of interventions related to daily use and how the children's preferred mobility methods evolve over time.

2.3 Walking performance with an environmental focus

Regarding previous research on mobility methods for children with CP, there is only one study that has explored how children choose to ambulate across the different environmental distances related to the FMS scale, based on three different distances: 5, 50 and 500 meters (representing at home, school and around the community).

Rodby-Bousquet et al (Rodby-Bousquet & Hägglund, 2012) did a cross-sectional study in a population of children with CP in Sweden. In total there were 562 children aged 3-18 years old. The aim of their study was to describe the most frequent mobility method in a total population of children with CP and examined the associations between walking performance and GMFCS level, CP subtype and age. Some of their findings were that 63% of the children walked without aids at home, 60% at school and 57% in the community setting. Most children at GMFCS level I and II walked all distances independently but with more difficulties on uneven surfaces and longer distances for those at GMFCS level II, and walking aids were most frequently used by children at GMFCS level III. The overall functional mobility increased with age at all three distances (home, school and around the community), and the walking performance without aids increased from preschool children up to 7 years of age. The walking performance increased too with GMFCS level, and they found a high correlation between FMS and GMFCS, indicating that GMFCS is a good predictor for walking performance (Rodby-Bousquet & Hägglund, 2012).

Environmental factors such as equipment and other modifications seek to enhance the child's functioning in daily life (Østensjø et al., 2003), and the severity of motor impairments can be the most important factor affecting the need and use of technical aids in children with neurological disorders (Korpela, Seppänen, & Koivikko, 1992). It is therefore important that these factors are in focus when determining the treatment interventions for children with CP aimed at self-mobility in the children's daily environment.

2.4 The CPOP Protocol

Children with CP in Norway are offered a systematic follow-up through a national medical quality register (CPRN) and the associated motor follow-up program (CPOP). CPRN was established through an initiative from a group of researchers and clinicians at NTNU (Norwegian University of Science and Technology), Medical Birth Registry (Folkehelseinstituttet) and the hospital in Vestfold. Previously there were no existing national

overview over prevalence and severity of children with CP in Norway and the knowledge concerning causes and risk factors were still limited. Between 2003-2006 a pilot study was conducted and concluded that it was realistic to manoeuvre a national registry for cerebral palsy in Norway. In 2006 CPRN was approved by the social- and health directorate as a national medical quality register (Andersen et al., 2017).

Since 1994, a corresponding follow-up program existed in Sweden (CPUP), and the CPUP had shown that after ten years it was possible to prevent several of the known complications around CP. On the basis of this, the Norwegian version CPOP began as a three-year project in 2006 and was established as a national motoric follow-up program in 2009. The purpose of the CPOP is to increase knowledge about CP, predict and follow known medical and motor complications, as well as improve treatment quality. Both CPRN and CPOP take part in evaluating the priority of health-related services offered to children with CP in Norway (Andersen et al., 2017).

The CPOP protocol consists of several measurement tools to monitor the children's motoric skills and abilities, and data from these registries have previously been used in research (Andersen et al., 2017; Andersen et al., 2018)

CPRN & CPOP yearly rapport findings

CPRN and CPOP yearly come out with rapports regarding the Norwegian children in the registry with CP. As they are being monitored and tested/re-tested yearly or every second year depending on their age, this is a good basis for relevant data. The following information is collected from the 2017 rapport (Andersen et al., 2018):

CP subtype was missing for 10% of the children at the initial registration, but the percentage decreased to 1% by the time the children were five years old. A decrease was shown in the CP subtype bilateral, however an increase was shown in the CP subtype unilateral.

GMFCS measures showed that of the registry (n=1415) born between 2002-2017, over half had GMFCS level I (52%). 17%, 7% and 9% had GMFCS level II, III and IV respectively. 13% were classified as GMFCS level V, and two percent were not classified.

Spasticity reducing treatment was given to 90% of the children with spasticity as a motor deficit. This was in order to reduce pain or adjustments of joints, and by the time the children were around 5-6 years of age, 50% had botulinum toxin injections (BoNT), and 16% had orthopaedic surgeries. By 15-17 years of age this percentage increased to 58% and 64% respectively, which in turn means that a large proportion of children would have been hospitalized, most likely in pain, and have missed out on school and social events.

Joint mobility was shown to decrease with increasing age. Reduced hip abduction occurred most for children with GMFCS level III, and these children also presented the most alarming results (pathological values) in terms of joint mobility restrictions when tested. The children at GMFCS level III children walked with aids and struggled holding themselves upright, and spasticity, reduced muscle strength and increasing weight often lead to bent knees which also increased with age (Andersen et al., 2018).

3. Method

In this chapter there will be a presentation of this study's design, the population and the data material. Further on the analysis of the data will be explained. The chapter finishes with discussing the ethical aspects of importance to this study.

3.1 Design

This study is designed as a population based cross-sectional study based on data from the CPOP.

A Population-based and cross-sectional study such as this can provide a snapshot of the mobility methods in different environments in a Norwegian population of children with CP. The benefit of a cross-sectional study is that it allows comparisons of many different variables at the same time and to explore different relationships. In this study, the relationship between the children's preferred mobility performance at different distances, selected child and CP characteristics, and motor impairments is explored.

3.2 Population of the study

The population was children with clinical signs of cerebral palsy registered in the CPOP follow-up program in the South Eastern Norway Regional Health Authority between 01.01.2006 to 31.12.2017 (n=823). The reason for only including the South Eastern Health Region was that the CPOP started as regional registry in this area in 2006, and first became a national registry in 2010. The South Eastern Norway Regional Health Authority cover about 60% of the Norwegian population of children with CP (Andersen et al., 2018)

In order to be eligible for the study, the children had to be registered in CPOP at the earliest when the child had turned four years old. The age criteria were necessary because the children's mobility performance was not systematically assessed in the CPOP before four years of age, due to the validity of the measurement scale. Children without any measurement of mobility performance registered in the CPOP also had to be excluded. Thus, a total of 773 children were included in the study. The inclusion process is illustrated in figure 3.

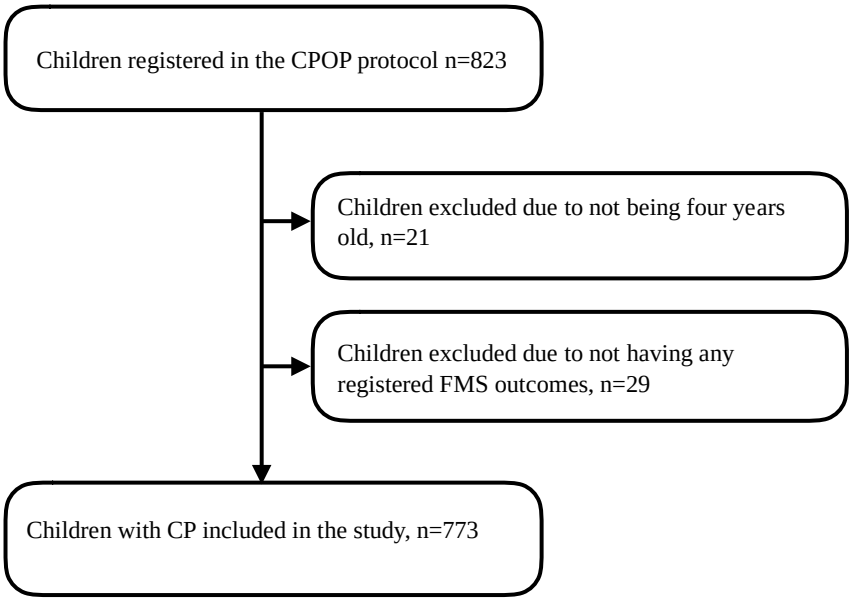

Figure 3, Inclusion process

3.3 Data material

This study used anonymous data from the physiotherapy protocol in in the CPOP (Appendix 1). The data comprises information about the characteristics of the children and their subtype of CP, gross motor function, mobility performance, spasticity measures and joint status of their lower limbs. In CPOP, the information is collected yearly or every second year. The last registered information in the CPOP constituted the data material for this cross-sectional study. Most of the children (85%) had their latest registration in 2016 or 2017 (see Table 3.1)

Table 3.1 Last year of registration in CPOP, n=733

Year of latest registration	Number of children, n (%)
2007	1 (0.1)
2008	1 (0.1)
2010	2 (0.3)
2011	4 (0.5)
2012	3 (0.4)
2013	17 (2.2)
2014	23 (3.0)
2015	72 (9.3)
2016	216 (27.9)

3.3.1 Data collected from the CPOP protocol

The data comprises information about characteristics of the children, the children's CP and CP related motor impairments. The characteristics are age, gender, subtype of CP and level of gross motor function. The included motor functions are measures of mobility performance, and of spasticity and joint status of the lower limbs. The collected information and its relation to the ICF components are illustrated in figure 4.

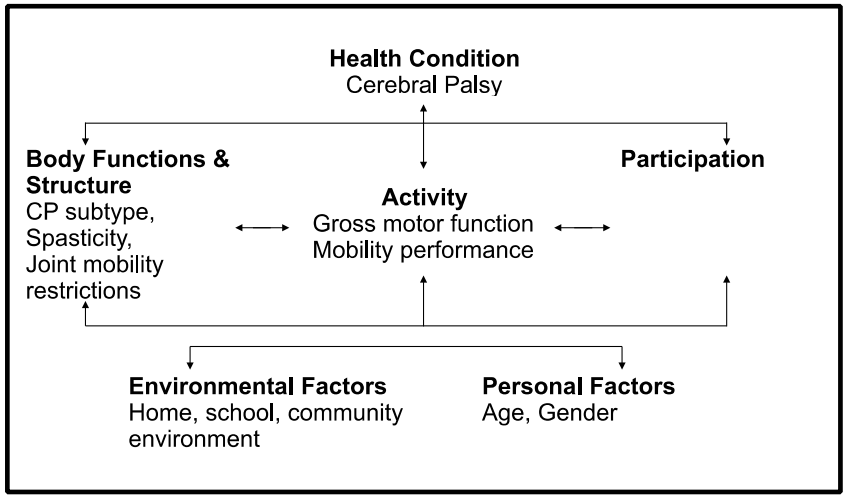

Figure 4, Overview of ICF components related to this study in light of the ICF model

Characteristics of the children

Characteristic of the children in this study is age and gender.

Age (ICF personal factor) was collected from the CPOP protocol. The children's date of birth and the date of their last registration in the CPOP was converted into months and compared in order to determine the child's exact age at the time of their last registration. To analyse the data the children were divided into four different age groups, 4-6 years old (48-83 months), 7-9 years old (84-119 months), 10-12 years old (120-155 months), and lastly 13-15 years old (156-191 months) based on a pervious study (Rodby-Bousquet & Hägglund, 2012), and in order to have a fairly even distribution of children in each group.

Characteristics of CP

The characteristic of CP that were included in this study are subtype of CP and gross motor function.

Subtype of CP (ICF Body Functions) is classified in relation to Surveillance of Cerebral Palsy in Europe (SCPE) (SCPE, 2000), which classifies subtypes of CP into spastic unilateral, spastic bilateral, dyskinetic and ataxic CP, based on disturbances in muscle tone (spastic, dyskinetic, ataxic) and the involved body side(s), unilateral or bilateral.

Gross motor function (ICF Activity) is classified according to the five levels of the Gross Motor Classification System (GMFCS) (Rosenbaum, Palisano, Bartlett, Galuppi, & Russell, 2008), as described in chapter 2, page 15-17. Evidence supports the validity and reliability of the GMFCS (Imms & Gibson, 2018; Morris, Galuppi, & Rosenbaum, 2004; Palisano et al., 2000; Wood & Rosenbaum, 2000), its stability over time (Palisano, Cameron, Rosenbaum, Walter, & Russell, 2006; Wood & Rosenbaum, 2000), its clinical utility (Gray, Ng, & Bartlett, 2010; Morris & Bartlett, 2004) and its prognostic ability (Rosenbaum et al., 2002).

Measures of motor functions

The motor functions which are a part of this study are mobility performance (ICF Activity), and spasticity measures and measures of joint mobility restrictions in the lower limbs (ICF Body Functions & Structures).

Mobility performance (ICF Activity) is measured using the Functional Mobility Scale (FMS) (Graham et al., 2004). This is an assessment tool that focuses on the children's walking performance and not their walking capacity. FMS measures the child's preferred mobility method across three different distances; 5-meter (representing moving at home), 50-meter (moving at school) and 500-meters (moving around the community). The FMS was developed as a performance measure (see chapter 2.3.1, page 18), giving ratings of the assistance required by children with CP for mobility in the included settings. The ratings range from 6 to 1, where 6 represents independent walking on all surfaces, and 1 wheeled mobility. In the FMS, there are two additional ratings (C & N). The scale is described in table 3.2 and is available in more detail in Appendix 3. The FMS has demonstrated to be a reliable tool for functional mobility over time (Harvey, Morris, Graham, Wolfe, & Baker, 2010)

Table 3.2 Functional Mobility Scale (FMS)

Rating	Description
6	*Independent on all surfaces* Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs etc. and in a crowded environment.
5	*Independent on level surfaces* Does not use walking aids or need help from another person. Requires a rail for stairs.
4	*Uses sticks (one or two)* Without help from another person.
3	*Uses crutches* Without help from another person.
2	*Uses a walker or frame* Without help from another person.
1	*Uses wheelchair* May stand for transfers, may do some stepping supported by another person or using a walker/frame.
C	*Crawling* Child crawls for mobility at home (5m).
N	*Does not apply* Child does not complete the distance (500m)

(Graham et al., 2004)

As it is not always practical or feasible for clinicians and researchers to observe and assess children in their own environments, parent-reports or self-reports are relied on in order to evaluate performance (Harvey, Baker, et al., 2010). Nonetheless, there can be questions raised whether parent-reports really represent the accurate information on the performance of the child. This, however was refuted according to a study by Harvey et al (Harvey, Baker, et al., 2010) which found that there was a substantial agreement between the FMS scores using parent reports and direct observation of mobility of children in their usual environments (Harvey, Baker, et al., 2010, showing that the reports from the parents are accurate enough to be trusted in the use of the FMS. Studies of the reliability and responsiveness has demonstrated that thee FMS is a reliable tool for assessing mobility performance in children with CP over time (Harvey, Morris, et al., 2010).

Spasticity (ICF Body Functions) is measured with the "Modified Ashworth Scale" (MAS) (Bohannon & Smith, 1987). The MAS measures resistance during passive soft-tissue stretching, using a 5-point scale. It is used in clinical practice as a simple measure of

increased muscle tone. Included in this study was measures of the hip adductors, knee flexors, and plantar flexors in the most affected leg. The child's positioning for the assessments is described in the CPOP manual (Appendix 4, CPOP manual page 5) for the physiotherapy protocol. The MAS scale is described in table 3.3.

Table 3.3 Modified Ashworth Scale (MAS)

Score	Description
0	Normal tone, no increase in tone.
1	Slight increase in muscle tone, manifested by a catch and release or minimal resistance at the end of the range of motion (ROM) where the affected part(s) is moved in flexion or extension.
1+	Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM.
2	More marked increase in muscle tone throughout most of the ROM, but affected part(s) easily moved.
3	Considerable increase in muscle tone, passive movement difficult.
4	Affected part(s) rigid in flexion or extension.

(Bohannon & Smith, 1987); CPOP manual, 2015)

MAS has proven to be a reliable tool in adults (Pandyan et al., 1999), yet somewhat lower intra- and inter reliability have been reported for the usage of MAS for children with CP . Thus, a child's MAS score has to be interpreted with great caution (Bauch & Steinberg, 2005; Mutlu, Livanelioglu, & Gunel, 2008).

Joint mobility (ICF Body Functions & Structures) was measured as passive range of motion (PROM) in the most affected leg, using a goniometer. This study included measures of hip abduction, popliteal angle, and ankle dorsiflexion (with extended knee) in the most affected leg. The PROM was measured according to the procedure described in the CPOP manual for the physiotherapy protocol (Appendix 4, CPOP manual page 6). In CPOP, the joint measurements are categorized into three groups (normal, control/treatment, pathological) with associated alarming-values (green, yellow, red) in relation to GMFCS levels (I-III and IV-V). The alarming-values for GMFCS levels I-III were determined based on the child's ability to dorsiflex the foot in the stand- and swing phase during gait. For GMFCS levels IV-V the values were determined based on sufficient movement in the hip, knee and ankle joint in order

to get a good standing position (Appendix 4, CPOP manual page 9). An overview over groups and the alarming values, in relation to GMFCS levels are presented in table 3.4.

Table 3.4 Alarming-values for passive range of motion in relation to GMFCS levels

GMFCS level I-III	**Pathological value**	**Control/treatment**	**Normal value**
Hip abduction	≤ 30	31-39	≥ 40
Popliteal angle	≥ 50	41-49	≤ 40
Dorsiflexion with extended knee	≤ 0	1-9	≥ 10
GMFCS level IV-V			
Hip abduction	≤ 20	21-29	≥ 30
Popliteal angle	≥ 60	51-59	≤ 50
Dorsiflexion with extended knee	≤ -10	-9 - -1	≥ 0

(CPOP manual, page 9, Appendix 4)

Regular measurement of ROM are recommended in the follow-up for children with spastic diplegic CP (Mutlu, Livanelioglu, & Gunel, 2007). Regarding the reliability of goniometric measurements for children with CP, errors of measurements are estimated to be approximately ±10° (Fosang, Galea, McCoy, Reddihough, & Story, 2003; McDowell, Hewitt, Nurse, Weston, & Baker, 2000). This there is need for caution when reporting and evaluating on changes in PROM.

3.4 Analysis

The data have been analysed with the statistical program IBM SPSS version 25.
Firstly, the data were thoroughly reviewed. As age was converted into age-intervals, all data were categorical. Descriptive statistics were conducted for relevant variables. In order to assess associations between mobility performance, child and CP characteristics and motor impairments, Chi-Square test was used. Chi-Square test is a non-parametric test commonly used for exploring the relationships between two categorical variables. Each of these variables can have two or more categories. The test is based on a crosstabulation table. The lowest expected frequency of any cell should be 5 or more. With expected values less than 5, Fisher's Exact test is a way to test the association between two categorical variables. The level of significance was set to $p<0.05$. (Pallant, 2016)

3.4.1 Collapsed data

In order to complete the association analysis and explore the results, CP subtypes, GMFCS, FMS, MAS and PROM were collapsed.

The subtypes of CP were collapsed into two groups, *unilateral* or *bilateral CP*, based on if one or two sides of the body were affected. In addition to children with bilateral spastic CP, bilateral CP included the dyskinetic and ataxic type, since children with these two types of CP also have a bilateral affection.

GMFCS was analysed with its represented categories ranging from level I-V in all analysis but one. For the 500-meter distance for FMS, GMFCS could not be processed and was therefore collapsed (see table 3.5). A literature review from 2018 showed that GMFCS was frequently collapsed into two or three groups in 38 of 118 studies (Towns, Rosenbaum, Palisano, & Wright, 2018).

Table 3.5 Collapsed categories for GMFCS

	GMFCS Level
1. Walking without limitations	I
2. Walking with some limitations or aids	II-III
3. Serious limitations in self-mobility or using a wheelchair	IV-V

FMS scores were collapsed into three groups, based on the level of aid required for mobility as described in table 3.6. The scores representing crawling (C) were excluded from the collapse of FMS and was not part of the association analysis.

Table 3.6. Collapsed categories for FMS

	FMS Score
1. Independent walking	6/5
2. Walking with some limitations or aids	4/3/2
3. Using a wheelchair	1

MAS for spasticity were collapsed into two groups described in table 3.7, because there were too few reports in the moderate/severe spasticity category. The group *no/light* included MAS

scores 0, 1 and 1+, while the *moderate/severe* spasticity group included MAS scores 2, 3 and 4.

Table 3.7 Collapsed categories for spasticity

	MAS-score
No/light spasticity	0/1/1+
Moderate/severe spasticity	2/3/4

Joint mobility (PROM) was also collapsed into two groups as described in table 3.8, because over 68% of the scores were in the '*normal values*' category.

Table 3.8 Collapsed categories for passive range of motion (PROM)

	CPOP-protocol
Normal PROM	Normal values
Limited PROM	Control/treatment /Pathological

3.5 Ethical Considerations

This master thesis project is based on anonymous data from CPOP. CPOP have a licence from the General Data Protection Regulation (GDRP) (2012 05/01484-4/EOL) and is a consent-based registry that include research. The licence is limited to 31.12.2030 (Oslo Universitetssykehus, 2019).

The study has been approved by the Regional Ethics Research Committee (registration number: 2017/2137). Access to specific data from CPOP to use in this study has been sought (Appendix 2). The data was made available for the study after the approval from REK was final. All data will be deleted after the master thesis has been passed, and at the latest 31.12.2019.

The data has been collected as part of CPOP. This study will therefore not involve an extra burden for neither the children nor their parents. The mission of CPOP is to contribute to an increased understanding of CP in the ongoing work of giving knowledge-based and equal treatment to children with CP in Norway (Andersen et al., 2017).

4. Results

The result chapter begins with presenting the descriptive characteristics of the participants. Onwards, the occurrence of the most used methods of mobility methods (FMS) in relation to the children's everyday environment is shown on 5-, 50- and 500-meter distance. Further on, functional mobility methods in different distances and environments related to age, CP subtype and gross motor limitations (GMFCS level) is presented. Lastly the analysis of the relationship between mobility methods (FMS) in the three distances and spasticity and joint range of motion (PROM) in the lower limbs is presented. The result chapter aims to answer the three research questions which are: 1) Which mobility methods children with CP use most frequently for 5-meter (home environment), 50-meter (school environment) and 500-meter (communal environment)? 2) What is the relationship between mobility methods at 5, 50 and 500 meters and age, CP subtype and severity of CP (GMFCS levels)? And lastly, 3) What is the relationship between mobility methods at 5, 50 and 500 meters and lower extremity spasticity and joint mobility restrictions?

4.1 Characteristics of the children

The population group in this study consisted of 773 children with CP registered in the CPOP protocol from 2006 until 2017. Table 4.1 describes the characteristics of the 773 children, showing their gender, age, CP-subtype and severity of gross motor limitations (GMFCS level).

Table 4.1 Characteristic of the children and the children's CP, n=773

n=733	
Gender, n (%)	
Male	438 (56.7)
Female	335 (43.3)
Age groups (years), n (%)	
4-6	182 (23.5)
7-9	208 (26.9)
10-12	256 (33.2)
13-15	127 (16.4)
CP-subtype, n (%)	
Spastic unilateral	336 (43.5)
Spastic bilateral	343 (44.4)

Dyskinetic	55 (7.1)
Ataxic	31 (4.0)
Not classified	8 (1.0)
GMFCS level, n (%)	
Level I	432 (55.9)
Level II	127 (16.4)
Level III	47 (6.1)
Level IV	72 (9.3)
Level V	95 (12.3)

GMFCS: Gross motor classification system

Table 4.1 shows that out of the 773 children that participated in this study, just over 50 percent were male (56.7%). The age ranged from 4 years old to 15 years old. With exception of the group with the oldest children (13-15 years) whom encompassed 16.4% of the children, there was a fairly even distribution of the age of the participating children. Onwards, the table shows that most children had spastic unilateral (43.5%) or spastic bilateral CP (44.4%), thus 87.9% of the sample group had a spastic form of CP. Regarding the severity of CP, 55.9% of the children were to the group with least limitations in gross motor function (GMFCS level I). Least of the children were classified at GMFCS level III and IV, 6.1% and 9.3%, respectively.

4.2 Mobility methods in different environments

Information regarding the children's preferred mobility at 5-meter (home), 50-meter (School) and 500-meter (community) is presented in table 4.2.

Table 4.2 Preferred mobility method (FMS) across 5, 50 and 500 meters, n=733

FMS, n=773	**5 m (home)**, n (%)	**50 m (school)**, n (%)	**500 m (community)**, n (%)
6	435 (56.3)	417 (53.9)	387 (50.1)
5	131 (16.9)	136 (17.6)	125 (16.2)
4	4 (0.5)	2 (0.3)	1 (0.1)
3	2 (0.3)	1 (0.1)	2 (0.3)
2	31 (4.0)	31 (4.0)	11 (1.4)
1	145 (18.8)	179 (23.2)	234 (30.3)
C	22 (2.8)	4 (0.5)	1 (0.1)
N			4 (0.5)
Missing	3 (0.4)	3 (0.4)	8 (1.0)

FMS 6: independent walking on all surfaces, FMS 5: independent walking on level surfaces, FMS 4: walking uses sticks (one or two), FMS 3: walking uses crutches, FMS 2: walking uses a walker or frame, FMS 1: uses wheelchair, FMS C: crawling, FMS N: does not apply.

Table 4.2 shows that at the shortest distance, 5-meter, representing mobility at home, 56.3% of the children walked independently on all surfaces (FMS score 6). The number of children moving independently on all surfaces (FMS 6) decreased as the distance became longer, from 56.3 % at the 5-meter distance to 50.1% at the 500-meter distance, representing mobility in the community. The proportion of children whom walked independently on level surfaces only (FMS score 5), did not vary much between the three distances. These children did not need any walking aid or help from another person, but may have required a rail for walking stairs.

In contrast to the high number of children whom walked independently or used a wheelchair, very few children walked across the distances using aids (FMS score, 4, 3 and 2). There were in total 4.8% of children whom used sticks, crutches or a walker to move at home, 4.4% at school, and a somewhat lower proportion (1.8%) used walking aids to move around the community. 2.8% of the children used crawling as a preferred mobility method at the 5-meter distance, but this number decreased drastically as the distance increased.

The proportion of children using a wheelchair (FMS score 1) increased as the distance got longer, just opposite to what was seen for the children walking independently (FMS score 6). In the home environment, 18.8% of the children used a wheelchair, at school, this was the case for 23.2%, and as many as 30.3% used a wheelchair to move around in the community.

4.3 Mobility methods related to age, CP subtype and severity of CP (GMFCS)

The following tables (4.3, 4.4 and 4.5), shows the children's preferred mobility methods for different distances (5, 50 and 500-meters) in relation to age, CP-subtype and gross motor function (GMFCS level).

Table 4.3 Preferred mobility methods at 5-meter (home) related to age, CP-subtype, and GMFCS level

	Independent walking FMS score 6-5	Walking with aids FMS score 4-2	Uses wheelchair FMS score 1	Sig[1]
Age groups (years), n=748 (%)				p=0.328
4-6	136 (24.0)	10 (27.0)	25 (17.2)	
7-9	160 (28.3)	7 (18.9)	36 (24.8)	
10-12	179 (31.6)	13 (35.2)	58 (40.1)	
13-15	91 (16.1)	7 (18.9)	26 (17.9)	
CP-subtype, n=740 (%)				p<0.000*
Unilateral	334 (59.7)	2 (5.4)	0 (0)	
Bilateral[+]	225 (40.3)	35 (94.6)	144 (100)	
GMFCS levels, n=748 (%)				p<0.000*
Level I	430 (76.0)	0 (0.0)	2 (1.4)	
Level II	124 (21.9)	2 (5.4)	0 (0.0)	
Level III	9 (1.6)	32 (86.5)	1 (0.7)	
Level IV	3 (0.5)	3 (8.1)	49 (33.8)	
Level V	0 (0.0)	0 (0.0)	93 (64.1)	

[1]Analysed with chi-square test or Fisher's Exact test
*Significant value with p<0.05
[+]Includes the CP-subtypes dyskinetic and ataxic

Table 4.3 shows that there was no significant relationship between the preferred mobility method and the children's age. Of the children whom walked independently in their home environment (FMS 6-5), most of them (31.6%) were between 10-12 years old. Notably most of the children whom walked at home with aids (FMS 4-2) and used a wheelchair (FMS 1) were also between 10-12 years old. In total there were a fewer number of children who used walking aids at home, in comparison to the larger number of children walking independently or using a wheelchair, however most children walked independently at home.

In contrast to age, both CP characteristics; CP-subtype and severity of CP (GMFCS level) were significantly related to preferred mobility method. Regarding subtypes, more children with unilateral CP (59.7%) walked independently compared to children with bilateral CP (40.3%). Moreover, the table shows that almost all children at GMFCS level I and II walked independently in their home environments, whereas most children at level III walked with aids (86.5%). Regarding using a wheelchair at home, the majority of these children had GMFCS level IV and V, with 33.8% and 64.1%, respectively.

Table 4.4 Preferred mobility methods at 50-meter (school) related to age, CP subtype and GMFCS level

50 meters	Independent walking FMS score 6-5	Walking with aids FMS score 4-2	Uses wheelchair FMS score 1	Sig[1]
Age groups (years), n=755 (%)				p=0.433
4-6	134 (24.2)	6 (17.6)	39 (21.8)	
7-9	158 (28.6)	8 (23.5)	41 (22.9)	
10-12	174 (31.5)	12 (35.4)	69 (38.5)	
13-15	87 (15.7)	8 (23.5)	30 (16.8)	
CP-subtype, n=758 (%)				p<0.000*
Unilateral	333 (60.9)	1 (3.0)	2 (1.1)	
Bilateral[+]	214 (39.1)	32 (97.0)	176 (98.9)	
GMFCS levels, n=766 **(%)**				p<0.000*
Level I	430 (77.8)	0 (0.0)	2 (1.1)	
Level II	118 (21.3)	6 (17.6)	1 (0.6)	
Level III	5 (0.9)	26 (76.6)	15 (8.3)	
Level IV	0 (0.0)	1 (2.9)	68 (38.0)	
Level V	0 (0.0)	1 (2.9)	93 (52.0)	

[1]Analysed with chi-square test or Fisher's Exact test
*Significant value p<0.05
[+]Includes the CP-subtypes dyskinetic and ataxic

The relationship between age, CP-subtype and GMFCS level and preferred mobility methods for 50-meter (school environment) was similar as for the 5-meter distance. No significant relationship was found in relation to age, however significant relationships were found for both CP-subtype and GMFCS level. The proportion of children walking independently (FMS 5-6) was a little lower in all age groups, whereas the use of wheelchair (FMS 1) was somewhat higher, compared to the 5-meter distance. Regarding GMFCS levels, there was small trend of fewer children classified at level II and III walking independently, and an increase in use of wheelchair, particularly among children at level IV, from 33.8% to 38.0%. Amongst the usage of wheelchair for school environments, just over half, 52% were classified as GMFCS level V.

Table 4.5 Preferred mobility methods at 500-meter (community) related to age, CP subtype and GMFCS level

	Independent walking	Walking with aids	Uses wheelchair	Sig[1]
Age group (years), n=760 (%)				p=0.787
4-6	126 (24.7)	3 (21.4)	50 (21.4)	
7-9	143 (27.9)	5 (35.7)	58 (24.8)	
10-12	163 (31.8)	4 (28.6)	85 (36.3)	
13-15	80 (15.6)	2 (14.3)	41 (17.5)	
CP-subtype, n=752 (%)				p<0.000*
Unilateral	322 (63.6)	2 (14.3)	9 (3.9)	
Bilateral[+]	184 (36.4)	12 (85.7)	223 (96.1)	
GMFCS levels, n=760 (%)				P<0.000*
Level I	422 (82.4)	0 (0.0)	7 (3.0)	
Level II & III	90 (17.6)	14 (100)	67 (28.6)	
Level IV & V	0 (0.0)	0 (0.0)	160 (68.4)	

[1]Analysed with chi-square test or Fisher's Exact test
*Significant value p<0.05
[+]Includes the CP-subtypes dyskinetic and ataxic

For the 500-meter distance, The GMFCS levels had to be collapsed into three groups (level I, level II-III, level IV-V) in order to complete the analyses for the distance, differentiating between walking without limitations, (level I) walking with limitations/aids (level II-III) and having serious limitations in self-mobility or using a wheelchair (level IV & V). Of the children walking with aids, all of them had GMFCS level II or III.

The associations between age, CP-subtype and GMFCS level and preferred mobility methods for 50-meter (representing school environment) was the same as for the 5-meter and 50-meter distances. No significant relationship was found between FMS distances and age, but significant relationships were seen for CP-subtype and GMFCS levels in all distances (5, 50 and 500-meters). Comparing the 5-meter distance (home environment) to 50-meter distance (school environment) somewhat fewer children were walking independently (FMS 6-5) in all age groups. This trend continued at the 500-meter distance (community environments). Regarding the use of wheelchair (FMS 1), there was an opposite trend, where more children in all age groups seemed to use a wheelchair as their preferred mobility method as the distance became greater. Children aged 10-12 were the largest group of wheelchairs (FMS 1)

users in all three distances.

4.4 Mobility methods related to spasticity and joint mobility restrictions

Table 4.6, 4.7 and 4.8 show the relationships between preferred mobility performance (FMS scores) at 5-meter (home), 50-meter (school) and 500-meter (community) and spasticity and joint restrictions in the most affected hip, knee and ankle. Spasticity was measured using the Modified Ashworth scale and the joint mobility restrictions were measured using a goniometer giving a result of passive range of motion (PROM).

Table 4.6 Relationship between spasticity, joint mobility restrictions and preferred mobility method at 5-meter distance (home environments)

5 meters	Independent walking FMS score 6-5	Walking with aids FMS score 4-2	Uses wheelchair FMS score 1	Sig[1]
Spasticity, n (%)				
Hip adductors (n=648)				p<0.000*
No/light	478 (98.0)	26 (78.8)	83 (65.4)	
Moderate/severe	10 (2.0)	7 (21.2)	44 (34.6)	
Knee flexors (n=672)				p<0.000*
No/light	453 (89.3)	22 (66.7)	52 (39.4)	
Moderate/severe	54 (10.7)	11 (33.3)	80 (60.6)	
Plantar flexors (n=715)				p=0.006*
No/light	362 (65.9)	19 (55.9)	68 (51.5)	
Moderate/severe	187 (34.1)	15 (44.1)	64 (48.5)	
Joint Mobility, n (%)				
Hip abduction (n=704)				p<0.000*
Normal PROM	394 (74.1)	13 (37.1)	75 (54.7)	
Limited PROM	138 (25.9)	22 (62.9)	62 (45.3)	
Popliteal angle (n=752)				p<0.000*
Normal PROM	404 (73.5)	16 (44.4)	78 (56.1)	
Limited PROM	146 (26.5)	20 (55.6)	61 (43.9)	
Ankle dorsiflexion (n=729)				p<0.000*
Normal PROM	395 (70.5)	24 (66.7)	119 (89.5)	
Limited PROM	165 (29.5)	12 (33.3)	14 (10.5)	

[1]Analysed with chi-square test or Fisher's Exact test
*Significant value p<0.05

There were statistically significant findings between FMS 5-meter distance and spasticity for the hips, knees and ankles, as well for the joint mobility of the same regions. 98% of the children with no/light spasticity in the most affected hip walked independently (FMS 6-5), whereas 34.6% of the children with moderate/severe spasticity used a wheelchair (FMS 1) at home. For the children using walking aids at home (FMS 4-2) most of them had no/light spasticity in their most affected hip (78.8%) and knee (66.7%).

Over 65% of the children with no/light spasticity in their most affected hip, knee or ankle walked independently (FMS 6-5) at home. For the children with no/light or moderate/severe spasticity in their plantar flexors (ankle), the majority walked independently (FMS 6-5) at home without aids. Moderate/severe spasticity in the knee and ankle seemed to be larger triggers for wheelchair use at home, than for spasticity in the hip. The majority of children with either limited or normal PROM findings in their hips, knees and ankles walked independently (FMS 6-5) at home. The largest proportion of children using a wheelchair (FMS 1) at home were the ones with normal PROM findings in the ankle (89.5%).

Overall the table (4.6) shows that most children walked independently (FMS 6-5) at home non-related to severity of spasticity or PROM. Hip spasticity and ankle PROM appeared to be the largest contributors for walking with aids and using a wheelchair for mobility at home.

Table 4.7 presents the relationship between preferred mobility methods (FMS) at 50 meters (representing at school), lower extremity spasticity and joint mobility restrictions. There were statistically significant findings between FMS and spasticity in the hips and knees and ankles at the 50-meter distance. There was also a significant relationship between FMS and joint mobility restrictions in the same three regions: hips, knees and ankles at the 50-meter distance.

Table 4.7 Relationship between spasticity, joint mobility restrictions and preferred mobility method at 50-meters (school environments)

50 meters	Independent walking FMS score 6-5	Walking with aids FMS score 4-2	Uses wheelchair FMS score 1	Sig[1]
Spasticity, n (%)				
Hip adductors (n=663)				p<0.000*
No/light	469 (98.1)	25 (86.2)	104 (66.7)	

Moderate/severe	9 (1.9)	4 (13.8)	52 (33.3)	
Knee flexors (n=687)				p<0.000*
No/light	446 (89.7)	19 (65.5)	70 (43.5)	
Moderate/severe	51 (10.3)	10 (34.5)	91 (56.5)	
Plantar flexion (n=731)				p=0.036*
No/light	354 (65.9)	19 (59.4)	89 (54.9)	
Moderate/severe	183 (34.1)	13 (40.6)	73 (45.1)	
Joint Mobility, n (%)				
Hip abduction (n=721)				p<0.000*
Normal PROM	390 (75.1)	12 (36.4)	93 (55.0)	
Limited PROM	129 (24.9)	21 (63.6)	76 (45.0)	
Popliteal angle (n=743)				p<0.000*
Normal PROM	399 (74.3)	12 (35.3)	96 (55.8)	
Limited PROM	138 (25.7)	22 (64.7)	76 (44.2)	
Ankle dorsiflexion (n=744)				p<0.000*
Normal PROM	388 (70.8)	23 (69.7)	142 (87.1)	
Limited PROM	160 (29.2)	10 (30.3)	21 (12.9)	

[1]Analysed with chi-square test or Fisher's Exact test
*Significant value p<0.05

Around school environmental (50-meters) areas, most children walking independently (FMS 6-5) had no/light spasticity in their hips and knees. Similar to the home environment (5-meters), over 65% of children non-related to joint area of spasticity walked independently (FMS 6-5) around their school environments. Most children with moderate/severe spasticity in their hips and knees used a wheelchair (FMS 1) across the 50-meter distance, however for the children with the same severity of spasticity in the ankle, more children walked independently (FMS 6-5) than that used a wheelchair (FMS 1).

The table (4.7) shows that there were more children with limited PROM in their hip and knee that walked with aids across the 50-meter distance, compared to children with PROM in the ankle. For the children with limited PROM non-related to joint area, the majority walked independently (FMS 6-5). Wheelchair usage was largest for the children with limited PROM in their ankle.

In comparison to the 5-meter distance, non-related to severity of spasticity or PROM, a small trend can be seen as the number of children walking independently (FMS 6-5) and walking with aids (FMS 4-2) decreased, and the number of children using a wheelchair (FMS 1) slightly increased.

Table 4.8 presents the relationship between preferred mobility method (FMS) at 500-meter distance (representing around the community), lower extremity spasticity and joint mobility restrictions. There was found significantly statistical findings between FMS at 500 meters and spasticity results for hips, knees and ankles. The same was found for joint mobility restrictions at the same joint areas.

Table 4.8 Relationship between spasticity, joint mobility restrictions and preferred mobility method at 500-meters (communal environment)

500 meters	Independent walking FMS score 6-5	Walking with aids FMS score 4-2	Uses wheelchair FMS score 1	Sig[1]
Spasticity, n (%)				
Hip adductors (n=658)				p<0.000*
No/light	438 (98.9)	9 (75.0)	147 (72.4)	
Moderate/severe	5 (1.1)	3 (25.0)	56 (27.6)	
Knee flexors (n=638)				p<0.000*
No/light	417 (90.3)	8 (66.7)	107 (51.2)	
Moderate/severe	45 (9.7)	4 (33.3)	102 (48.8)	
Plantar flexion (n=725)				p=0.004*
No/light	333 (66.7)	10 (71.4)	114 (53.8)	
Moderate/severe	166 (33.3)	4 (28.6)	98 (46.2)	
Joint Mobility, n (%)				
Hip abduction (n=718)				p<0.000*
Normal PROM	363 (75.3)	7 (50.0)	124 (55.9)	
Limited PROM	119 (24.7)	7 (50.0)	98 (44.1)	
Popliteal angle (n=737)				p<0.000*
Normal PROM	376 (75.7)	8 (57.1)	122 (54.0)	
Limited PROM	121 (24.3)	6 (42.9)	104 (46.0)	
Ankle dorsiflexion (n=739)				p=0.002*
Normal PROM	359 (70.7)	10 (71.4)	180 (82.9)	

Limited PROM	149 (29.3)	4 (28.6)	37 (17.1)

[1]Analysed with chi-square test or Fisher's Exact test
*Significant value $p<0.05$

Looking at the results from the relationship between FMS and spasticity and joint mobility restrictions from 5- (table 4.6) to 500 meters (table 4.8), a larger trend is visible regarding the decrease in number of children walking independently (FMS 6-5) and increase of children using a wheelchair (FMS 1) as their preferred mobility method.

Still, children with no/light spasticity in their hip represent the highest number of children walking independently (FMS 6-5). Most children with moderate/severe spasticity in their hip or knee ambulated the 500-meter distance with a wheelchair, whereas children with moderate/severe spasticity in the ankle walked independently (FMS 6-5).

There were a higher number of children walking independently (FMS 6-5) with limited PROM in all joint areas (hip, knee & ankle) than the number of children using walking aids or wheelchairs across their communal areas. The largest proportion of children using a wheelchair (FMS 1) for the 500-meter distance were the children with normal PROM in the ankle, followed by no/light spasticity in the hip.

Overall, the table (4.8) shows that with exception of moderate/severe spasticity in the hip and knee, most children still walk independently (FMS 6-5) across the 500-meter distance. Related to severity of spasticity and PROM, (moderate/severe) knee spasticity and (limited PROM) joint restriction in the knee appears to be the largest contributors for wheelchair (FMS 1) as preferred mobility method around the community.

5. Discussion

The purpose of this study has been to provide information about the preferred mobility methods for children with CP across different environmental settings from a cross-sectional perspective.

5.1 Main findings

The mobility methods most frequently used for children with CP for home, school and around communal environments were quite similar for all three distances (5, 50 and 500 meters). Generally over half (50%) of the children walked independently (FMS 6) across all distances. The second most frequent preferred mobility method was to use a wheelchair (FMS 1). This ranged from 18.8% (5-meter distance), to 23.2% (50-meter distance) and lastly to 30.3% (500-meter distance). The third most frequently mobility method was independent walking on level surfaces (FMS 5), which steadily encountered for around 16-17% of the children across all three distances (5, 50, 500-meter).

There were no statistically significant findings amongst FMS 5-meter, 50-meter, 500-meter and age groups. However, statistically significant findings ($p<0.005$) were seen in all distances (5, 50, 500-meter), and CP subtype, and GMFCS levels. The majority of children walked independently (FMS 6-5) at home, at school and around the community non-related to age, subtype of CP or GMFCS level. The largest proportion of children using a wheelchair (FMS 1) was at the 500-meter distance (community environment), where 89 children more than in comparison to the home environment (5-meter) had this as preferred mobility method. Children aged 10-12 used wheelchair (FMS 1) as their preferred mobility method the most, in comparison to the other age groups. The number of children walking with handheld-devices (FMS 4-2) across the three distances (5, 50, 500-meter) decreased as the distance became greater. Around 60% of the children walking independently (FMS 6-5) had unilateral spasticity, whereas 96-100% of the children whom used a wheelchair (FMS 1) were diagnosed with bilateral spasticity. Almost all (97.9%) of the children walking independently (FMS 6-5) at home (5-meter) had GMFCS level I and II, and a similar percentage was found for children using a wheelchair for the same distance, where 97.9% had GMFCS level IV and V. This fluctuated little for at school environment (50-meter), where 99.1% of the children walking independently (FMS 6-5) had GMFCS level I and II, and 90% using a wheelchair had GMFCS level IV and V. A small shift was seen for the communal environment (500-

meter), where 28% of the children using a wheelchair had GMFCS level II and III, and 68.4% had GMFCS level IV and V.

There were statistically significant findings ($p<0.005$) between mobility performance at 5, 50, and 500-meter distances and lower extremity spasticity, and joint mobility restrictions.

Regarding the home environment (5-meter), most children walked independently (FMS 6-5) non-related to severity of spasticity or PROM. Of the children walking independently (FMS 6-5) with spasticity in their most affected hip, only 2% had moderate/severe spasticity. The percentage of children with moderate/severe spasticity in the hip increased to 21.1% when walking with aids (FMS 4-2), and 34.6% when using a wheelchair (FMS 1) at home. 60.6% of children with moderate/severe spasticity in their most affected knee used a wheelchair (FMS 1), and just under 50% of children with moderate/severe spasticity in their ankle as well chose wheelchair (FMS 1) as preferred mobility method across the 5-meter distance. For children with limited PROM in the hip, 25.9% walked independently (FMS 6-5) at home, and 45.3% used a wheelchair (FMS 1) in comparison to the children with normal PROM. The largest proportion of children using a wheelchair (FMS 1) at home was seen for the children with normal PROM in their ankle (119 children).

About the school environment (50-meter), most children here also walked independently (FMS 6-5) non-related to severity of spasticity or PROM. There were at no point more than 34 children that used walking aids (FMS 4-2) across the school environment, and in relation to the total population group of the study, that only encountered for 4.5%. The largest proportion of children using a wheelchair (FMS 1) in regards to joint mobility, were also the children with normal PROM in their ankle (142 children).

For the community environment (500-meter), relatively similar results were shown. The majority of children walked independently (FMS 6-5) non-related to severity of spasticity or PROM. In regards to moderate/severe spasticity, there were a larger proportion of children using a wheelchair (FMS 1) with hip and knee related findings across all distances (5, 50 500-meters) in contrast to children with moderate/severe spasticity in the ankle, where the larger proportion walked independently (FMS 6-5). Notably, amongst the lower extremity spasticity and joint mobility restrictions, there were a declining tendency in the number of children choosing independent walking (FMS 6-5) and an increase in the use of wheelchair (FMS 1) as

the distance became larger.

5.2 Discussion of methods

This study is population based and has a cross-sectional design. Data were collected from one consent-based registry, CPOP. Strengths and weaknesses regarding the method section of this study as well as decisions that could have influenced the reliability and validity of the study will be highlighted and discussed in the following section.

Of the 823 children that initially were eligible to participate in the study, 50 were excluded because they were either too young (under 4 years of age) or did not have any registered outcome measures in the functional mobility scale (FMS). That left 773 children that became the population group of this study.

It is a strength that information about the excluded children were available, showing that they did not differ from the participating children in regards to age and gender. This is important as the population group of this study potentially represents larger proportions of the children with CP in Norway. It was, however statistically significant findings amongst CP subtype and severity (GMFCS-level) of CP. The study has a larger proportion of children with bilateral CP and low severity (GMFCS level I) of CP, in addition to having a lesser proportion of children with moderate/severe (GMFCS level III) level of CP. Such differences may affect the external validity and generalisability of the results. Based on this, analysis have been done for the whole population group, as well as in collapsed groupings based on subtype of CP and GMFCS-level.

This study has a relatively large sample size (n=773), which is positive in terms of the possible generalisability of the results. However, in order to complete the analysis appropriate for the study design, several groups had to be merged to meet the criteria of the association analysis. CP subtype, GMFCS levels, FMS, spasticity (MAS) and passive range of motion (PROM) were collapsed into smaller groups.

For CP subtypes, over 80% of the children had either unilateral CP or bilateral CP. In total, only 12.1% of the children were either dyskinetic, ataxic, or were not classified. Because dyskinetic children (7.1%) or ataxic children (4%) also have a bilateral affection, these subtypes were merged with bilateral spasticity. This prevented a skew distribution of data,

and the two groups ‘unilateral spasticity’ and ‘bilateral spasticity’ were used for further associational analysis.

For most of the analysis, GMFCS was kept with its original levels ranging from I-V giving the possibility to explore the results within the different levels. However, GMFCS had to be collapsed for the association analysis of the preferred walking method across the 500-meter distance. GMFCS was then collapsed into three groups based on severity of CP (level I, level II-III and level IV-V). Children with GMFCS level I could be seen as their own group, as it was expected that these children were able to walk without any limitations inside and outside at the age of four. Notably 55.9% of the children were classified as GMFCS level I. Children at GMFCS level II-III at the same age was expected to use a handheld device during walking. Children at GMFCS level III could need adult assistance when walking in contrast to children at level II. Children at level IV-V constituted a separate group as they were not able to walk without any handheld device. What separated level IV and V was that GMFCS level IV could move independently over short distances indoors, whereas children at level V had severely limited abilities of self-mobility (Palisano et al., 2007). Collapsing the GMFCS levels created a somewhat uneven distribution between the three categories; walking without limitations (55.9%), walking with some limitations or aids (22.5%) and serious limitations in self-mobility or using a wheelchair (21.6%). Collapsing variables can affect the results (Svensson, Hjartåker, & Laake, 2007), although GMFCS levels frequently have been collapsed in previous studies (Towns et al., 2018). Nonetheless, evidence supports the validity and reliability of the GMFCS (Imms & Gibson, 2018; Morris et al., 2004; Palisano et al., 2000).

Functional mobility scale (FMS) was firstly presented with its full range of scores (6-1, C & N) across all three distances (5, 50 and 500-meters) for a thorough overview over the most used mobility methods for children with CP. Onwards in the association analysis, the FMS was collapsed in three groups. Independent walking (FMS score 6-5), walking with some limitations (FMS 4-2) and using a wheelchair (FMS 1). Scores such as C (crawling) and N (does not apply) were not included in the association analysis of the functional mobility scale. As the FMS measured the children’s preferred mobility method across three distances (5, 50 and 500-meters) three different distributions were presented. Over 65% of the children walked independently (FMS 6-5) across all distances, whereas much lower percentages were seen in the remaining scores. No more than 4.8% walked with some limitations (FMS 4-2) and no more than 30.3% and used a wheelchair (FMS 1) across the three distances. Even

though an uneven distribution was seen across the scores (FMS 6-1), dividing the group with the highest proportion of children; 'independent walking' (FMS 6-5) was not logical as both FMS 6 and 5 represented independent walking, in contrast to the remaining scores that required handheld walking aid or a wheelchair. Again, collapsing variables can affect the results (Svensson et al., 2007), though similar groupings were found in a comparable study (Rodby-Bousquet & Hägglund, 2012). Although based on parent-reports, the FMS has been found to be a reliable tool for assessing mobility performance in children with CP over time (Harvey, Morris, et al., 2010). And a substantial agreement has been found between the FMS scores using parent reports and direct observation of mobility in children in their usual environments (Harvey, Baker, et al., 2010). A weakness in the FMS however, is that it will only allow the reporter (parent or health-care professional) to choose one method of mobility, although children might have more than one approach in terms preferred mobility at home, school and around the communal environment (Harvey, Baker, et al., 2010; Tieman et al., 2004; Østensjø et al., 2003) and this is not given any attention in the functional mobility scale.

Regarding spasticity measured with Modified Ashworth Scale (MAS) it can be seen as a strength that the five grades of resistance to passive movement were collapsed into two (no/light and moderate/severe spasticity) groups. That is because the scale previously has not shown satisfactory reliability (Numanoglu & Günel, 2012) for children with CP. In addition, there were too few reports within MAS scores 2, 3 and 4, which in turn made up the 'moderate/severe' spasticity group. Collapsing these groups prevented uneven distributions of data. The same goes for PROM, where there also were advantages in collapsing the most alarming values (pathological, control/treatment) as over half of the reports were in the 'normal value' category. By collapsing the three categories into two 'normal PROM' (normal values) and 'limited PROM' (pathological & control/treatment values), a more even distribution was seen. As errors of measurements using a goniometric measure has been estimated to be approximately ±10°, the reliability also here not satisfactory (Fosang et al., 2003; McDowell et al., 2000).

Children in the CPOP were registered between 2006-2017, meaning they were between 4-15 years old. There was a fairly even distribution of children in all the age-groups. Most children were between 10-12 (33.2%) years old and 13-15 (16.4%) years old the last time they were registered in protocol. Because children in CPOP are followed and measured yearly or every second year, CPOP have over time accumulated large amounts of data regarding children with

CP in Norway. It is a strength for this study that the children in the registry are measured regularly which in turn means that the study can base itself on a large amount of rapports.

The information collected from the CPOP were anonymous longitudinal data, collected from 2006-2017. Given the opportunity to use already existing data made it possible to track the previous results listed for subtypes of CP, GMFCS classifications, FMS measurements, spasticity and joint mobility restrictions in children with CP, presenting a thorough overview of the population group. However, the collected data came from different areas of Norway, and most likely from different health-care professionals. Even though trained in how to use the CPOP protocol, the possibility of own interpretations should be established as a possible limitation related to the data in this study. Onwards, since the FMS is based on parent-reports which have been found to be a reliable tool for assessing mobility performance in children with CP (Harvey, Morris, et al., 2010), it should be notated that other researchers have found that parents tend to overestimate functioning abilities for children with CP (Keith & Markie, 1969). Notably, the same study also found significant differences in ratings amongst paediatricians, physiotherapists, occupational therapists, parents and nursery school teachers. This should be considered as both parents and health-care professional's own interpretations may have affected the results in CPOP.

The design of this study was cross-sectional, which is a type of observational study design. A cross-sectional study enables measurements between outcomes measures and participants at the same time. However, since it is a 1-time measurement of exposure and outcome, it is difficult to derive casual relationships from cross-sectional analysis. Nonetheless, it allows for the exploration of associations between exposure and the outcomes in the design (Setia, 2016). In other words, a cross-sectional design is suitable for providing a snapshot of the most used mobility methods in different environments for children with CP, but it cannot provide information regarding possible causes of results. Although this is a limitation, a strength in the study is the large population group (n=733). The data from CPOP used in this study were from the South Eastern Norway Region Health Authority, providing data only from the South-East part of Norway. 29 of the 823 children did not have any listed outcome measures, giving a small dropout of 3.6%. In 2017, according to the yearly rapport from CPOP, there were in total 1428 children with CP in Norway (Andersen et al., 2018), which in turn means that the population group for this study constitutes 54% (773/1428 x 100) of the total population of children with CP in Norway. This raises the question whether results from this

study can be generalized as this study presents information for over half of the total population of children with CP in Norway. Though, the results only account for children between 4-15 years of age, and does not say anything about older children with CP. For future research, it is a disadvantage that the data in this study were anonymous which makes it impossible to retrace.

5.3 Discussion of results

In this study, children with CP and their preferred mobility methods across different environmental settings have been presented in light of the international classification of functioning (ICF) model (World Health Organization, 2001). This was in order to enlighten the associated dimensions of functioning at the body, persons and social levels which the ICF model helps describe (World Health Organization, 2001, 2013). This chapter will continue to follow the components from the ICF model, discussing the relevant findings in light of the Body Functions and Structures, Activity, Participation, Environmental and Personal factors, which are the most relevant to this study.

5.3.1 Body Functions and Structures

The information gathered regarding Body functions and Structures for this population group of children with CP, were subtype of CP, spasticity and joint mobility restrictions.

Subtype of CP is classified in relation to Surveillance of Cerebral Palsy in Europe (SCPE) (SCPE, 2000), which classifies the subtypes of CP into spastic unilateral, spastic bilateral, dyskinetic and ataxic CP based on disturbances in muscle tone, and the involved side(s) of the body. The majority of the children in this study were diagnosed with either unilateral (43.5%), or bilateral (44.4%) spasticity. Few children were diagnosed with dyskinetic or ataxic subtype of CP, and 8 children were not classified. According to the CPOP rapport form 2017 (Andersen et al., 2018), the main focus in the international community of CP research is early intervention. It is desirable that children in need of interventions to be identified as early as possible, for both the children and their parent's sake. According to the SCPE, the concluding subtype of CP should be set around five years of age (Andersen et al., 2018; SCPE, 2000), however in light of early interventions, it is positive that the average age of diagnosis of CP for children registered in the CPRN were at 25 months (Andersen et al., 2018). Knowing the subtype of CP is necessary because it gives information about the clinical consequences of the

damaged brain for children with CP (SCPE, 2000). Motor findings suggestive of CP can improve or disappear at later age; thus, it can be expected that some children given a CP diagnosis at an early age will not fulfil the criteria later (Himmelmann & Panteliadis, 2018). Although motor incoordination is a hallmark of the CP diagnosis, no studies have examined motor coordination development in children with CP (Jeffries et al., 2016).
Some different percentages exist in literature, but around 70-90% of children with CP have either unilateral or bilateral spasticity as their diagnosed subtype (Braun et al., 2016; Himmelmann & Panteliadis, 2018), which corresponds with the children in this study, where 87.9% were diagnosed with either unilateral or bilateral spasticity.

It has been shown that walking ability is strongly associated with CP subtype (Beckung, Hagberg, Uldall, & Cans, 2008), although walking ability might mean walking outdoors in everyday life, being able to walk a few meters or able to only walk indoors (Blair, Cans, & Sellier, 2018). Given that bilateral spasticity affects both sides of the body, it more likely that these children have bigger challenges when it comes to mobilising in general. The results of this study could perhaps relate to that, as around 60% of children with unilateral spasticity walked independently (FMS 6) at home (5 meter), at school (50 meter) and around the community (500 meter). Of the children using wheelchair at home, 100% had bilateral spasticity. 98.9% with bilateral spasticity used a wheelchair at school, and 96.1% used a wheelchair around the community. Some children with moderately severe bilateral spasticity may achieve independent walking at the age of 7-8 years, an age where the peak motor performance occurs in children with CP. Notably some children also lose their walking ability as they grow (Himmelmann & Panteliadis, 2018)

Spasticity is one of the main causes of physical limitation for children with CP (Jeffries et al., 2016) and is considered a primary impairment because it is a direct result of the injury or disturbance that occurred in the developing brain. Children with CP have fixed deformities at birth, but with time, and despite nonoperative management, the majority of children develop a complex mixture of spasticity, weakness, impaired selective motor control, contractures of muscle tendon-units, bony torsion and joint-subluxations, especially in the hip and midfoot (Rutz et al., 2018; Scrutton, 1984). Population-based studies have shown that spasticity increases in the children till four years of age, after which there is a steady decline in muscle tone (Hägglund & Wagner, 2008). As spasticity can have such an impact on these children's physical abilities, it is not surprising that a lot of the treatment interventions are aimed at this.

Specific treatments are given either orally, intramuscular, intrathecally, through selective dorsal rhizotomy, orthopaedic surgery and multilevel surgery (Solheim, 2018).

For children with bilateral spastic CP, whom are non-ambulatory and require orthopaedic intervention, the most frequent deformities are dislocation of the hip and spinal deformity such as scoliosis. Knee and ankle problems of children with milder bilateral spastic CP are treated in similar ways (Himmelmann & Panteliadis, 2018). For children with unilateral spastic CP, it is rare for the child to start walking during the first years of life. Independent ambulation begins around the 18th to 20th month of life and in severe cases, even later (Himmelmann & Panteliadis, 2018). Which in turn is a reminder on the importance of early interventions. From the 2017 rapport from CPOP (Andersen et al., 2018), 45% of the children in the registry received intramuscular injections (botulinum toxin /BoNT) between 1-12 times from 2006-2017. Most of the children had GMFCS level III-IV, and the injections were mostly put in the calf, hamstrings and hip flexors. It is estimated that by the time the children are 5-6 years of age 50% have had BoNT injections, and by 15-17 years of age this encounters for 58% of the children (Andersen et al., 2018). A systematic review of interventions for children with CP, found that intramuscular injections such as BoNT was shown to be effective (Novak et al., 2013).

It is not known whether children in this study were given spasticity reducing treatment, however, based on the information from the yearly rapport from CPOP (Andersen et al., 2018) it is likely that around 50% of the children have had BoNT injections, and around 16% have had orthopaedic surgery before the age of 6. The successful choice of treatment (BoNT orthopaedic surgery) could support the large proportion (over 65%) of children with no/light spasticity to walk independently (FMS 6-5) at home (5 meter), at school (50-meter) and around the community (500-meter). Notably, given that hip dislocations are one of most frequent deformities (Himmelmann & Panteliadis, 2018) for children with CP, this could enlighten why around 30% of the children with moderate/severe spasticity in their most affected hip used a wheelchair (FMS 1) across home (5 meter), school (50 meter) and community (500 meter) environment.

Joint mobility restriction is a secondary impairment which defines problems that occur over time, often as a result of primary impairments (spasticity) (Jeffries et al., 2016). It is often caused by the shortening of muscles and stiffening of joints (Himmelmann & Panteliadis,

2018). Secondary impairments are potentially preventable and with right intervention may improve the motor and participation outcomes of young children with CP (Jeffries et al., 2016). Postural stability typically continues to develop over the first 6 years of life, and this development is slower for children with CP (McCoy et al., 2014; Westcott & Burtner, 2004). Even though primary impairments are more obvious, lower extremity range of motion changes have been noticed in children that are typically developing. However, these differences are generally very minor, representing less than 5° to 8° from 18 months to 5 years of age (Orlin & Lowes, 2012). A study by Jeffries et al. found that children with CP, even at preschool age with GMFCS level I, as young as 18-30 months old, presented secondary impairments such as restricted range of motion (Jeffries et al., 2016).

The CPOP rapport from 2017 (Andersen et al., 2018) showed that there was an increase in the children with the most alarming values (pathological value) as they grew older. Reduced ability to abduct the hip occurred mostly with for children at GMFCS level III. Regarding the knee joint, most pathological values were seen for children at GMFCS level III. These children walk with handheld devices and might struggle holding themselves in an upright position (Palisano et al., 2007). Spasticity, reduced muscle strength and increasing weight often lead to bent hips and knees with increasing age. Concerning the ankle joint, the highest occurrence of reduced dorsal flexion was seen in walking children at GMFCS level II and III. These children presented a tiptoe-walking pattern, which could be the result of spasticity in the calf, however most children presented a stable ankle mobility. The stable ankle mobility could be explained by the usage of ankle-foot-orthosis. These orthosis give the children a persistent stretch in the calf whilst weightbearing, and they are often used in combination with BoNT injections in order to reduce spasticity (Andersen et al., 2018).

It could be expected that children with CP receiving treatment for their primary impairments will in addition be treating their secondary impairments. However, the elimination of spasticity based on selective spinal surgeries does not in itself prevent contracture development (Tedroff, Löwing, Jacobson, & Åström, 2011). Similar results can be seen in children undergoing injections (BoNT) for local reduction of spasticity. After initially displaying short-term gains, the long-term follow up (1-3 years later) showed a decline in range of motion (Tedroff, Granath, Forssberg, & Haglund-Akerlind, 2009). These studies suggest that development of contractures is not simply caused by the presence of spasticity, and one does not exclude the other. Nonetheless, similar to spasticity, it is not known whether

the children in this study were in fact given any kind of spasticity reducing or joint mobility increasing treatment, although this can possibly be anticipated as most of the children with either limited PROM or normal PROM walked independently across their home (5 meter), school (5 meter) and communal (500 meter) environment. Spasticity reducing treatment or not, the majority of the children with CP in this study nevertheless walked independently across home, school and environmental distances.

5.3.2 Activity and Participation

The information gathered regarding Activity and Participation for this population group of children with CP, were gross motor function and mobility performance.

There are several differences between the GMFCS and the FMS, even though both measure mobility performance based on gross motor function. Firstly, GMFCS is a classification system ranging from level I-V, organising the severity of CP. Whereas, the FMS ranges from 6-1 (plus crawling and 'does not apply'), displaying the children's preferred mobility method across three distances (home, school and community environment). The FMS additionally connects of the environmental factors to the scores, whereas the GMFCS goes more into depth regarding the need for assistance in certain situations. Nevertheless, 55.9% of children in this study had the lowest severity of CP (GMFCS level I), and between 50.1%-56.3% of the children walked independently (FMS 6) across all distances (5, 50 and 500 meter). Onwards, the percentage of children with higher severity of CP (GMFCS III, IV and V) appeared to be similar for the proportion of children using a wheelchair (FMS 1) as their preferred mobility method, which is what could be expected based on the GMFCS. Rodby-Bousquet et al. (Rodby-Bousquet & Hägglund, 2012) did a cross-sectional study based on data from the CPUP (Swedish version of CPOP), and found high correlations (0.907-1) between GMFCS and FMS. Although correlations as such cannot be confirmed in this study, it should be noted that a tendency was seen in the relationship between children's GMFCS levels and FMS results.

The greatest increase in gross motor development in children with CP occurs between 1 ½ years to 5 years of age (Jeffries et al., 2016). In this study, 24% of the children aged 4-6 walked independently (FMS 6) at home, at school and around the communal environment. Although there was a fairly even distribution of children in all age groups, it should be noted that around 1/5 of the children, all aged 4-6 years old, preferred to walk independently across

the three distances. This could perchance support the increase of gross motor development occurring till the children are 5 years old, as it would have been less likely that these children preferred independent walking if their gross motor development was either decreasing or delayed.

Rodby-Bousquet et al. (Rodby-Bousquet & Hägglund, 2012) found walking performance (FMS) to increase with GMFCS level, similar to findings in this study. They also found walking performance to increase up to 7 years of age. Most of the children walking independently (FMS 6) in this study, were children aged 10-12 and 7-9 years old. The group with the fewest children walking independently were aged 13-15 years old. Rodby-Bousquet et al. found a small increase in children walking independently at age 18, indicating that walking performance did not necessarily stop peaking at 7 years of age. This was interestingly not too dissimilar from this study. Firstly, although no child was older than 15 years of age in this study, and the age group 13-15 years old had the smallest portion of participants across the age groups, this age group had the fewest wheelchair users over all distances. Notably however, they also had the fewest independent walkers.

This raises the question to what could be possible causes to why some children walk independently and some use a wheelchair, considering that age group 13-15 had the lowest portion of wheelchair users but the age group below, 10-12 had the highest (across all distances). The natural progression of walking in children with CP over a 2-4 year period without surgical interventions, can lead to a gradual reduction in permissible joint execution, and a crouch gait pattern (Bell et al., 2002; Johnson, Damiano, & Abel, 1997). Furthermore, gait deterioration is a change in gait impairments in children with CP that result in either a decrease in functional capacity (what the child is able to do) for walking, or higher energy cost of walking (Ross & Engsberg, 2007). It is established that children with CP often start to walk later than non-disabled children, with a slower speed and higher energy cost (Furukawa, Nii, Iwatsuki, Nishiyama, & Uchida, 1998). There is a strong correlation between the energy cost of walking and the degree of motor impairment (Johnston, Moore, Quinn, & Smith, 2004; Raja, Joseph, Benjamin, Minocha, & Rana, 2007). Walking is one of the most important functions, and during all the physiotherapy applied in childhood, the greatest hope for the family and child is to ambulate independently (Bottos, Feliciangeli, Sciuto, Gericke, & Vianello, 2001). However, adults with CP, especially those with poor gait function who required the use of aids during childhood (GMFCS level III), are more likely to report

deterioration in their walking ability over time and may stop walking entirely (Bottos et al., 2001).

5.3.3 Environmental and Personal Factors

The information gathered regarding Environmental and Personal factors for this population group of children with CP, were home- school and community environment, as well as age and gender.

The knowledge regarding how mobility methods and the adult need for assistance vary across different environmental settings for children with CP is limited (Palisano et al., 2003). A study by Palisano et al. found that the interaction between age and setting was not statistically significant, indicating that the effect of environmental settings on mobility method did not vary based on age (Palisano et al., 2003). This corresponds with the results of this study, where there also were no statistically significant findings between environments and age of the children with CP. Safety and efficiency are important factors when choosing mobility method for different distances (Palisano, Shimmell, et al., 2009). This may explain why wheelchairs were more frequently used than walking aids, and walkers more frequently than sticks. Rodby-Bousquet et al. (Rodby-Bousquet & Hägglund, 2012) found the same results in their study of children with CP and functional mobility.

Environmental factors such as equipment, seek to enhance the child's functioning in daily life (Østensjø et al., 2003). Most of the children at GMFCS level III (walking with handheld mobility device) had FMS 4-2 (walking with aids) as their preferred mobility method. This could possibly confirm that the severity of motor impairment is the most important factor affecting the need and use for technical aids (Korpela et al., 1992)

6. Conclusion

The purpose of this study has been to provide knowledge about children with cerebral palsy, and their preferred mobility methods across different environments. The study shows that the majority of children walk independently across their home, school and communal environments. The largest proportion of children walking independently had GMFCS level I, whereas the largest proportion of wheelchair users had GMFCS level IV and V. Overall, the study shows that there was a somewhat positive correspondence between the functional mobility scale and GMFCS level, as well as that neither spasticity nor joint mobility restrictions were hallmarks in terms of preventing children from walking independently across 5, 50 and 500-meter distances. However, the possible causes of such high numbers of children walking independently is not known.

There was found statistically significance for subtype of CP, GMFCS level and FMS 5 meter, however not for age. Most children aged 4-6 and 7-9 that walked independently at home. The majority of these children had unilateral spasticity, and had GMFCS level I or II. The majority of children using a wheelchair at home were between 10-12 years old.

Similar results were seen at the 50-meter distance, representing at school. Statistically significant findings were seen here as well, with exception of age. Most children using walking aids were between 10-12 years old, had bilateral spasticity and had GMFCS level III. The majority of children walking independently at school were also between 10-12 years old.

Most children between 10-12 years old walked independently around the community. The majority of these had unilateral spasticity and GMFCS level I. Most children using a wheelchair across the 500-meter distance was also aged 10-12. The majority of these children had bilateral spasticity and GMFCS level IV and V.

Non-related to joint localization or severity of spasticity or joint mobility restrictions, the majority of children walked independently across all distances. There were statistically significant associations found between FMS, severity of CP, GMFCS, spasticity and joint mobility restrictions in the lower extremities for Norwegian children with CP.

6.1 Future research

Through this study it has become apparent that the majority of children with CP in Norway are able to move independent without assistance at home, at school and around the community. Very few studies have previously investigated the FMS scale in relation to children with CP. This suggests that future research should be aimed at obtaining more knowledge of functional mobility for children with CP, and how it can change over time. Future studies should also focus on the specific treatment interventions given, in order to draw parallels from clinical practice to everyday functioning.

7. References

Andersen, G. (2018). Hva er CP? Retrieved from http://www.cp.no/om-cerebral-parese/hva-er-cp/

Andersen, G., Julsen Hollung, S., Vik, T., Jahnsen, R., Elkjær, S., & Myklebust, G. (2017). *CPRN og CPOP Årsrapport for 2016* Retrieved from www.oslo-universitetssykehus.no

Andersen, G., Julsen Hollung, S., Vik, T., Jahnsen, R., Myklebust, G., Elkjær, S., & Klevberg, G. (2018). *CPRN og CPOP Årsrapport for 2017*. Retrieved from www.oslo-universitetssykehus.no

Bauch, F., & Steinberg, H. (2005). A Review: The validity and reliability of the Modified Ashworth Scale as a measurement tool for the evaluation of spasticity and its applicability to children with cerebral palsy European School of Physiotherapy. In *Class of 2005*.

Beckung, E., Carlsson, G., Carlsdotter, S., & Uvebrant, P. (2007). The natural history of gross motor development in children with cerebral palsy aged 1 to 15 years. *Developmental Medicine & Child Neurology*, *49*(10), 751-756.

Beckung, E., Hagberg, G., Uldall, P., & Cans, C. (2008). Probability of walking in children with cerebral palsy in Europe. *Pediatrics*, *121*(1), e187-e192.

Bell, K. J., Õunpuu, S., DeLuca, P. A., & Romness, M. J. (2002). Natural progression of gait in children with cerebral palsy. *Journal of Pediatric Orthopaedics*, *22*(5), 677-682.

Blair, E., Cans, C., & Sellier, E. (2018). Epidemiology of the Cerebral Palsies. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 18-28): Springer.

Bode, H. (2018). Long-Term Prognosis. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 327-334): Springer.

Bohannon, R. W., & Smith, M. B. (1987). Interrater reliability of a modified Ashworth scale of muscle spasticity. *Physical therapy*, *67*(2), 206-207.

Booth, A. T., Buizer, A. I., Meyns, P., Oude Lansink, I. L., Steenbrink, F., & van der Krogt, M. M. (2018). The efficacy of functional gait training in children and young adults with cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, *60*(9), 866-883.

Bottos, M., Feliciangeli, A., Sciuto, L., Gericke, C., & Vianello, A. (2001). Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental medicine and child neurology*, *43*(8), 516-528.

Braun, K. V. N., Doernberg, N., Schieve, L., Christensen, D., Goodman, A., & Yeargin-Allsopp, M. (2016). Birth prevalence of cerebral palsy: a population-based study. *Pediatrics*, *137*(1), 1.

Calderon-Gonzalez, R., Calderon-Sepulveda, R., Rincon-Reyes, M., Garcia-Ramirez, J., & Mino-Arango, E. (1994). Botulinum toxin A in management of cerebral palsy. *Pediatric Neurology*, *10*(4), 284-288.

CanChild. (2019). Gross Motor Function Classification System, Expanded and Revised (GMFCS E&R). *GMFCS E&R between 6th-12th and 12th to 18th Descriptors and Illustrations.* Retrieved from https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r

Dayanidhi, S., & Lieber, R. L. (2018). Muscle Biology of Contractures in Children with Cerebral Palsy. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 143-153): Springer.

Dickinson, H. O., Parkinson, K. N., Ravens-Sieberer, U., Schirripa, G., Thyen, U., Arnaud, C., . . . Michelsen, S. I. (2007). Self-reported quality of life of 8–12-year-old children with cerebral palsy: a cross-sectional European study. *The Lancet, 369*(9580), 2171-2178.

Eek, M. N., Tranberg, R., Zügner, R., Alkema, K., & Beckung, E. (2008). Muscle strength training to improve gait function in children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(10), 759-764.

Fosang, A. L., Galea, M. P., McCoy, A. T., Reddihough, D. S., & Story, I. (2003). Measures of muscle and joint performance in the lower limb of children with cerebral palsy. *Developmental medicine and child neurology, 45*(10), 664-670.

Furukawa, A., Nii, E., Iwatsuki, H., Nishiyama, M., & Uchida, A. (1998). Factors of influence on the walking ability of children with spastic cerebral palsy. *Journal of Physical Therapy Science, 10*(1), 1-5.

Graham, H. K., Boyd, R., Carlin, J. B., Dobson, F., Lowe, K., Nattrass, G., . . . Reddihough, D. (2008). Does Botulinum Toxin A Combined with Bracing Prevent Hip Displacement in Children with Cerebral Palsy and "Hips at Risk"? A Randomized, Controlled Trial. *J Bone Joint Surg Am, 90*(1), 23-33.

Graham, H. K., Harvey, A., Rodda, J., Nattrass, G. R., & Pirpiris, M. (2004). The functional mobility scale (FMS). *Journal of Pediatric Orthopaedics, 24*(5), 514-520.

Gray, L., Ng, H., & Bartlett, D. (2010). The gross motor function classification system: an update on impact and clinical utility. *Pediatric Physical Therapy, 22*(3), 315-320.

Harvey, A. R., Baker, R., Morris, M. E., Hough, J., Hughes, M., & Graham, H. K. (2010). Does parent report measure performance? A study of the construct validity of the Functional Mobility Scale. *Developmental Medicine & Child Neurology, 52*(2), 181-185.

Harvey, A. R., Morris, M. E., Graham, H. K., Wolfe, R., & Baker, R. (2010). Reliability of the functional mobility scale for children with cerebral palsy. *Physical & occupational therapy in pediatrics, 30*(2), 139-149.

Himmelmann, K., Beckung, E., Hagberg, G., & Uvebrant, P. (2006). Gross and fine motor function and accompanying impairments in cerebral palsy. *Developmental medicine and child neurology, 48*(6), 417-423.

Himmelmann, K., & Panteliadis, C. P. (2018). Clinical Characteristics. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Thrid ed., pp. 75-87): Springer.

Hägglund, G., & Wagner, P. (2008). Development of spasticity with age in a total population of children with cerebral palsy. *BMC musculoskeletal disorders, 9*(1), 150.

Imms, C., & Adair, B. (2017). Participation trajectories: impact of school transitions on children and adolescents with cerebral palsy. *Developmental Medicine & Child Neurology, 59*(2), 174-182.

Imms, C., & Gibson, N. (2018). An Overview of Evidence-Based Occupational and Physiohterapy for Children with Cerebral Palsy. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 165-192): Springer.

Jeffries, L., Fiss, A., McCoy, S. W., & Bartlett, D. J. (2016). Description of primary and secondary impairments in young children with cerebral palsy. *Pediatric Physical Therapy, 28*(1), 7-14.

Johnson, D. C., Damiano, D. L., & Abel, M. F. (1997). The evolution of gait in childhood and adolescent cerebral palsy. *Journal of Pediatric Orthopaedics, 17*(3), 392-396.

Johnston, T. E., Moore, S. E., Quinn, L. T., & Smith, B. T. (2004). Energy cost of walking in children with cerebral palsy: relation to the Gross Motor Function Classification System. *Developmental medicine and child neurology, 46*(1), 34-38.

Karch, D., & Heinemann, K. (2018). Physiotherapeutic Interventions: Bobath, Vojta, and Motor Learning Approaches. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 155-164): Springer.

Karimi, M., & Brazier, J. (2016). Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics, 34*(7), 645-649.

Keith, R. A., & Markie, G. S. (1969). Parental and professional assessment of functioning in cerebral palsy. *Developmental Medicine & Child Neurology, 11*(6), 735-742.

Kerr, C., McDowell, B., & McDonough, S. (2007). The relationship between gross motor function and participation restriction in children with cerebral palsy: an exploratory analysis. *Child: care, health and development, 33*(1), 22-27.

Ketelaar, M., Vermeer, A., Hart, H. t., van Petegem-van Beek, E., & Helders, P. J. (2001). Effects of a functional therapy program on motor abilities of children with cerebral palsy. *Physical therapy, 81*(9), 1534-1545.

Korpela, R., Seppänen, R. L., & Koivikko, M. (1992). Technical aids for daily activities: a regional survey of 204 disabled children. *Developmental Medicine & Child Neurology, 34*(11), 985-998.

Law, M. C., Darrah, J., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., . . . Galuppi, B. (2011). Focus on function: a cluster, randomized controlled trial comparing child-versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine & Child Neurology, 53*(7), 621-629.

Majnemer, A., Shevell, M., Law, M., Birnbaum, R., Chilingaryan, G., Rosenbaum, P., & Poulin, C. (2008). Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(10), 751-758.

McCoy, S. W., Bartlett, D. J., Yocum, A., Jeffries, L., Fiss, A. L., Chiarello, L., & Palisano, R. J. (2014). Development and validity of the early clinical assessment of balance for young children with cerebral palsy. *Developmental neurorehabilitation, 17*(6), 375-383.

McDowell, B. C., Hewitt, V., Nurse, A., Weston, T., & Baker, R. (2000). The variability of goniometric measurements in ambulatory children with spastic cerebral palsy. *Gait & posture, 12*(2), 114-121.

McLaughlin, J. F., Bjornson, K. F., Astley, S. J., Graubert, C., Hays, R. M., Roberts, T. S., . . . Temkin, N. (1998). Selective dorsal rhizotomy: efficacy and safety in an investigator-masked randomized clinical trial. *Developmental Medicine & Child Neurology, 40*(4), 220-232.

Moons, P. (2004). Why call it health-related quality of life when you mean perceived health status? *European Journal of Cardiovascular Nursing, 3*(4), 275-277.

Morgan, P., & McGinley, J. (2014). Gait function and decline in adults with cerebral palsy: a systematic review. *Disability and rehabilitation*, *36*(1), 1-9.

Morris, C., & Bartlett, D. (2004). Gross motor function classification system: impact and utility. *Developmental medicine and child neurology*, *46*(1), 60-65.

Morris, C., Galuppi, B. E., & Rosenbaum, P. L. (2004). Reliability of family report for the gross motor function classification system. *Developmental medicine and child neurology*, *46*(7), 455-460.

Mutlu, A., Livanelioglu, A., & Gunel, M. K. (2007). Reliability of goniometric measurements in children with spastic cerebral palsy. *Medical science monitor*, *13*(7), CR323-CR329.

Mutlu, A., Livanelioglu, A., & Gunel, M. K. (2008). Reliability of Ashworth and Modified Ashworth scales in children with spastic cerebral palsy. *BMC musculoskeletal disorders*, *9*(1), 44.

Nadeau, L., & Tessier, R. (2006). Social adjustment of children with cerebral palsy in mainstream classes: Peer perception. *Developmental medicine and child neurology*, *48*(5), 331-336.

Nieuwenhuijsen, C., Donkervoort, M., Nieuwstraten, W., Stam, H. J., Roebroeck, M. E., & Netherlands, T. R. G. S. W. (2009). Experienced problems of young adults with cerebral palsy: targets for rehabilitation care. *Archives of physical medicine and rehabilitation*, *90*(11), 1891-1897.

Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., . . . Goldsmith, S. (2013). A systematic review of interventions for children with cerebral palsy: state of the evidence. *Developmental Medicine & Child Neurology*, *55*(10), 885-910.

Numanoglu, A., & Günel, M. K. (2012). Intraobserver reliability of modified Ashworth scale and modified Tardieu scale in the assessment of spasticity in children with cerebral palsy. *Acta Orthop Traumatol Turc*, *46*(3), 196-200.

Odding, E., Roebroeck, M. E., & Stam, H. J. (2006). The epidemiology of cerebral palsy: incidence, impairments and risk factors. *Disability and rehabilitation*, *28*(4), 183-191.

Orlin, M. N., & Lowes, L. P. (2012). *Musculoskeletal system: structure, function, and evaluation.* Paper presented at the Meeting the Physical Therapy Needs of Children.

Orlin, M. N., Palisano, R. J., Chiarello, L. A., Kang, L.-J., Polansky, M., Almasri, N., & Maggs, J. (2010). Participation in home, extracurricular, and community activities among children and young people with cerebral palsy. *Developmental Medicine & Child Neurology*, *52*(2), 160-166.

Oslo Universitetssykehus. (2019). Cerebral Parese Oppfølgningsprogram, samtykke og vedtekter. Retrieved from https://oslo-universitetssykehus.no/avdelinger/barne-og-ungdomsklinikken/barneavdeling-for-nevrofag/cpop-cerebral-parese-oppfolgingsprogram#samtykke-og-vedtekter

Palisano, R. J., Cameron, D., Rosenbaum, P. L., Walter, S. D., & Russell, D. (2006). Stability of the gross motor function classification system. *Developmental medicine and child neurology*, *48*(6), 424-428.

Palisano, R. J., Hanna, S. E., Rosenbaum, P. L., Russell, D. J., Walter, S. D., Wood, E. P., . . . Galuppi, B. E. (2000). Validation of a model of gross motor function for children with cerebral palsy. *Physical therapy*, *80*(10), 974-985.

Palisano, R. J., Hanna, S. E., Rosenbaum, P. L., & Tieman, B. (2010). Probability of walking, wheeled mobility, and assisted mobility in children and adolescents with cerebral palsy. *Developmental Medicine & Child Neurology*, *52*(1), 66-71.

Palisano, R. J., Kang, L.-J., Chiarello, L. A., Orlin, M., Oeffinger, D., & Maggs, J. (2009). Social and community participation of children and youth with cerebral palsy is associated with age and gross motor function classification. *Physical therapy*, *89*(12), 1304-1314.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2007). Gross Motor Function Classification System–Expanded and Revised. CanChild Centre for Childhood Disability Research, McMaster University. *Institute for Applied Health Sciences McMaster University, Hamilton, Ontario*, b15.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology*, *50*(10), 744-750.

Palisano, R. J., Shimmell, L. J., Stewart, D., Lawless, J. J., Rosenbaum, P. L., & Russell, D. J. (2009). Mobility experiences of adolescents with cerebral palsy. *Physical & occupational therapy in pediatrics*, *29*(2), 133-153.

Palisano, R. J., Tieman, B. L., Walter, S. D., Bartlett, D. J., Rosenbaum, P. L., Russell, D., & Hanna, S. E. (2003). Effect of environmental setting on mobility methods of children with cerebral palsy. *Developmental medicine and child neurology*, *45*(2), 113-120.

Pallant, J. (2016). SPSS, Survival Manual, A Step by Step Guide to Data Analysis using IBM SPSS, 6th. In (6th ed.): Philadelphia, PA, USA: Mcgraw-Hill Higher Education, Open University Press.

Palmer, F. B., Shapiro, B. K., Wachtel, R. C., Allen, M. C., Hiller, J. E., Harryman, S. E., . . . Capute, A. J. (1988). The effects of physical therapy on cerebral palsy. *New England Journal of Medicine*, *318*(13), 803-808.

Pandyan, A., Johnson, G., Price, C., Curless, R., Barnes, M., & Rodgers, H. (1999). A review of the properties and limitations of the Ashworth and modified Ashworth Scales as measures of spasticity. *Clinical rehabilitation*, *13*(5), 373-383.

Raja, K., Joseph, B., Benjamin, S., Minocha, V., & Rana, B. (2007). Physiological cost index in cerebral palsy: its role in evaluating the efficiency of ambulation. *Journal of Pediatric Orthopaedics*, *27*(2), 130-136.

Rajagopal, A., Kidziński, Ł., McGlaughlin, A. S., Hicks, J. L., Delp, S. L., & Schwartz, M. H. (2018). Estimating the effect size of surgery to improve walking in children with cerebral palsy from retrospective observational clinical data. *Scientific reports*, *8*(1), 16344.

Rethlefsen, S. A., Ryan, D. D., & Kay, R. M. (2010). Classification systems in cerebral palsy. *Orthopedic Clinics*, *41*(4), 457-467.

Rice, J. (2018). Oral Medication Use i Cerebral Palsy. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Mulitidisciplinary Approach* (Third ed., pp. 259-267): Springer.

Robin, J., Graham, H. K., Selber, P., Dobson, F., Smith, K., & Baker, R. (2008). Proximal femoral geometry in cerebral palsy: a population-based cross-sectional study. *The Journal of bone and joint surgery. British volume*, *90*(10), 1372-1379.

Rodby-Bousquet, E., & Hägglund, G. (2012). Better walking performance in older children with cerebral palsy. *Clinical Orthopaedics and Related Research®, 470*(5), 1286-1293.

Rosenbaum, P. L., Palisano, R. J., Bartlett, D. J., Galuppi, B. E., & Russell, D. J. (2008). Development of the gross motor function classification system for cerebral palsy. *Developmental Medicine & Child Neurology, 50*(4), 249-253.

Rosenbaum, P. L., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., . . . Jacobsson, B. (2007). A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl, 109*(suppl 109), 8-14.

Rosenbaum, P. L., Walter, S. D., Hanna, S. E., Palisano, R. J., Russell, D. J., Raina, P., . . . Galuppi, B. E. (2002). Prognosis for gross motor function in cerebral palsy: creation of motor development curves. *Jama, 288*(11), 1357-1363.

Ross, S. A., & Engsberg, J. R. (2007). Relationships between spasticity, strength, gait, and the GMFM-66 in persons with spastic diplegia cerebral palsy. *Archives of physical medicine and rehabilitation, 88*(9), 1114-1120.

Rutz, E., Gaston, M. S., Camathias, C., & Brunner, R. (2012). Distal femoral osteotomy using the LCP pediatric condylar 90-degree plate in patients with neuromuscular disorders. *Journal of Pediatric Orthopaedics, 32*(3), 295-300.

Rutz, E., Thomason, P., Willoughby, K., & Graham, H. K. (2018). Integrated Management in Cerebral Palsy: Musculoskeletal Surgery and Rehabilitation in Ambulatory Patients. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 229-251): Springer.

SCPE. (2000). Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine & Child Neurology, 42*(12), 816-824.

Scrutton, D. (1984). *Management of the motor disorders of children with cerebral palsy*: Cambridge University Press.

Setia, M. S. (2016). Methodology series module 3: Cross-sectional studies. *Indian journal of dermatology, 61*(3), 261.

Shore, B. J., Yu, X., Desai, S., Selber, P., Wolfe, R., & Graham, H. K. (2012). Adductor surgery to prevent hip displacement in children with cerebral palsy: the predictive role of the Gross Motor Function Classification System. *J Bone Joint Surg Am, 94*(4), 326-334.

Shore, B. J., Zurakowski, D., Dufreny, C., Powell, D., Matheney, T. H., & Snyder, B. D. (2015). Proximal femoral varus derotation osteotomy in children with cerebral palsy: the effect of age, gross motor function classification system level, and surgeon volume on surgical success. *J Bone Joint Surg Am, 97*(24), 2024-2031.

Smania, N., Bonetti, P., Gandolfi, M., Cosentino, A., Waldner, A., Hesse, S., . . . Munari, D. (2011). Improved gait after repetitive locomotor training in children with cerebral palsy. *American journal of physical medicine & rehabilitation, 90*(2), 137-149.

Solheim, S. O. (2018). Spastisitetsbehandling. Retrieved from https://www.cp.no/om-cerebral-parese/behandling/

Soo, B., Howard, J. J., Boyd, R. N., Reid, S. M., Lanigan, A., Wolfe, R., . . . Graham, H. K. (2006). Hip displacement in cerebral palsy: a population based study of incidence in relation to motor type, topographical distribution and gross motor function. *J Bone Joint Surg Am, 88*(1), 121-129.

Spittle, A. J., & Morgan, C. (2018). Early Intervention for Children with Cerebral Palsy. In C. P. Panteliadis (Ed.), *Cerebral Palsy, A Multidisciplinary Approach* (Third ed., pp. 193-200): Springer.

Steinbok, P., Reiner, A. M., Beauchamp, R., Armstrong, R. W., & Cochrane, D. D. (1997). A randomized clinical trial to compare selective posterior rhizotomy plus physiotherapy with physiotherapy alone in children with spastic diplegic cerebral palsy. *Developmental Medicine & Child Neurology, 39*(3), 178-184.

Svensson, E., Hjartåker, A., & Laake, P. (2007). Hva skal måles og hvordan. *Epidemiologiske og kliniske forskningsmetoder. Gyldendal Akademisk, Gyldendal Norsk Forlag AS*, 45-65.

Tatlow, A. (1980). Towards a comprehensive motor education in the treatment of cerebral palsy. *Physiotherapy, 66*(10), 332.

Tedroff, K., Granath, F., Forssberg, H., & Haglund-Akerlind, Y. (2009). Long-term effects of botulinum toxin A in children with cerebral palsy. *Developmental Medicine & Child Neurology, 51*(2), 120-127.

Tedroff, K., Löwing, K., Jacobson, D. N., & Åström, E. (2011). Does loss of spasticity matter? A 10-year follow-up after selective dorsal rhizotomy in cerebral palsy. *Developmental Medicine & Child Neurology, 53*(8), 724-729.

Tefft, D., Guerette, P., & Furumasu, J. (1999). Cognitive predictors of young children's readiness for powered mobility. *Developmental medicine and child neurology, 41*(10), 665-670.

Tieman, B. L., Palisano, R. J., Gracely, E. J., Rosenbaum, P. L., Chiarello, L. A., & O'neil, M. E. (2004). Changes in mobility of children with cerebral palsy over time and across environmental settings. *Physical & occupational therapy in pediatrics, 24*(1-2), 109-128.

Tilton, A. H. (2004). *Management of spasticity in children with cerebral palsy.* Paper presented at the Seminars in Pediatric neurology.

Towns, M., Rosenbaum, P., Palisano, R., & Wright, F. V. (2018). Should the Gross Motor Function Classification System be used for children who do not have cerebral palsy? *Developmental Medicine & Child Neurology, 60*(2), 147-154.

Valentin-Gudiol, M., Bagur-Calafat, C., Girabent-Farrés, M., Hadders-Algra, M., Mattern-Baxter, K., & Angulo-Barroso, R. (2013). Treadmill interventions with partial body weight support in children under six years of age at risk of neuromotor delay: a report of a Cochrane systematic review and meta-analysis. *Eur J Phys Rehabil Med, 49*(1), 67-91.

Vargus-Adams, J. (2005). Health-related quality of life in childhood cerebral palsy. *Archives of physical medicine and rehabilitation, 86*(5), 940-945.

Verburg, G. (1987). *Predictors of successful powered mobility control.* Paper presented at the Childhood Powered Mobility: Developmental, Technical and Clinical Perspectives. Proceedings of the RESNA 1st NW Regional Conference, Seattle, WA. Washington, DC: RESNA Press. p.

Vos, R. C., Becher, J. G., Ketelaar, M., Smits, D.-W., Voorman, J. M., Tan, S. S., . . . Dallmeijer, A. J. (2013). Developmental trajectories of daily activities in children and adolescents with cerebral palsy. *Pediatrics, 132*(4), e915-e923.

Westcott, S. L., & Burtner, P. (2004). Postural control in children: implications for pediatric practice. *Physical & occupational therapy in pediatrics, 24*(1-2), 5-55.

Willoughby, K., Ang, S. G., Thomason, P., & Graham, H. K. (2012). The impact of botulinum toxin A and abduction bracing on long-term hip development in children with cerebral palsy. *Developmental Medicine & Child Neurology, 54*(8), 743-747.

Wood, E., & Rosenbaum, P. (2000). The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. *Developmental medicine and child neurology, 42*(5), 292-296.

Woollacott, M. H., & Burtner, P. (1996). Neural and musculoskeletal contributions to the development of stance balance control in typical children and in children with cerebral palsy. *Acta Paediatrica, 85*, 58-62.

Woollacott, M. H., & Shumway-Cook, A. (2005). Postural dysfunction during standing and walking in children with cerebral palsy: what are the underlying problems and what new therapies might improve balance? *Neural plasticity, 12*(2-3), 211-219.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*: World Health Organization.

World Health Organization. (2007). International classification of functioning, disability and health: children & youth version: ICF-CY. Retrieved from https://apps.who.int/iris/handle/10665/43737.

World Health Organization. (2013). *How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment*: Geneva: WHO.

World Health Organization. (2019, 02.03.2018). International Classification of Functioning, Disabilty and Health (ICF). Retrieved from https://www.who.int/classifications/icf/en/

Wright, M., & Wallman, L. (2012). *Physical Therapy for Children, Chapter 18; Cerebral Palsy, page 557* (Fourth ed.): Elsevier Saunders.

Young, N. L., Williams, J. I., Yoshida, K. K., Bombardier, C., & Wright, J. G. (1996). The context of measuring disability: does it matter whether capability or performance is measured? *Journal of clinical epidemiology, 49*(10), 1097-1101.

Zubek, J. P., Aftanas, M., Kovach, K., Wilgosh, L., & Winocur, G. (1963). Effect of severe immobilization of the body on intellectual and perceptual processes. *Canadian Journal of Psychology/Revue canadienne de psychologie, 17*(1), 118.

Østensjø, S., Carlberg, E. B., & Vøllestad, N. K. (2003). Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. *Developmental medicine and child neurology, 45*(9), 603-612.

Appendix

1. CPOP protocol
2. REK Approval
3. Functional Mobility Scale (FMS)
4. CPOP manual for physiotherapists
5. GMFCS E&R between 12th and 18th birthday: Descriptors and Illustrations

1. CPOP-protocol

Oppfølgingsprogram for barn med cerebral parese
Fysioterapiprotokoll
010615.

Personnummer:	Dato undersøkelse:	Dato siste rtg:
Etternavn:		Fornavn:
Navn/tlf fysioterapeut i habiliteringstjenesten:		
Navn/tlf fysioterapeut i 1.linje:		

SCPE DIAGNOSE

Spastisk	Unilateral	Hemiplegi, hø	☐
		Hemiplegi, ve	☐
	Bilateral	Diplegi	☐
		Kvadriplegi	☐
Dyskinetisk		Choreoathetose	☐
		Dystoni	☐
Ataktisk			☐
Ikke klassifiserbar CP			☐

GMFCS **I** ☐ **II** ☐ **III** ☐ **IV** ☐ **V** ☐ Ikke klassifisert ☐

GMFM
Dato utført:

GMFM 66
Total poengsum: _____
Nedre konfidensintervall _____ Øvre konfidensintervall _____
Percentil _____

GMFM 88

A	B	C	D	E	Total
_____	_____	_____	_____	_____%	_____%

FMS The Functional Mobility Scale 5 m ☐ 50 m ☐ 500 m ☐

Rullestol innendørs (velg et alternativ)

Bruker manuell rullestol	Bruker ikke ☐	Blir kjørt ☐	Kjører selv ☐
Bruker elektrisk rullestol	Bruker ikke ☐	Blir kjørt ☐	Kjører selv ☐

Rullestol utendørs

Bruker manuell rullestol	Bruker ikke ☐	Blir kjørt ☐	Kjører selv ☐
Bruker elektrisk rullestol	Bruker ikke ☐	Blir kjørt ☐	Kjører selv ☐

Ståfunksjon

Bruker ståhjelpemiddel? Ja ☐ Nei ☐

Dager pr uke 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 ☐

Antall timer pr dag <1 ☐ 1-2 ☐ 3-4 ☐ > 4 ☐

Type ståhjelpemiddel

Ståstativ ☐ Ståskall ☐ Stårullestol ☐ NF-Walker ☐

Ortoser

Bruker barnet ortoser? Ja ☐ Nei ☐

		Antall timer			**Hensikt med ortosen**			**Har ortosen effekt?**	
Type		**≤2**	**3-6**	**≥7**	ROM	Funksjon	Stabilitet	Ja	Nei
FO	☐	☐	☐	☐	☐	☐	☐	☐	☐
AFO	☐	☐	☐	☐	☐	☐	☐	☐	☐
KAFO	☐	☐	☐	☐	☐	☐	☐	☐	☐
KO	☐	☐	☐	☐	☐	☐	☐	☐	☐
HO	☐	☐	☐	☐	☐	☐	☐	☐	☐

Rygg

Skolioseoperert Ja ☐ Nei ☐

Vurdert i stående ☐ sittende på benk ☐ liggende ☐

Har barnet skoliose Ja ☐ Nei ☐

Skoliose

Thorakal	høyrekonkveks ☐	venstrekonveks ☐
Thorakolumbal	høyrekonkveks ☐	venstrekonveks ☐
Lumbal	høyrekonkveks ☐	venstrekonveks ☐

Skoliosen er korrigerbar ☐ ikke korrigerbar/rigid ☐

Skoliosen er lett ☐ moderat ☐ uttalt ☐

Truncus-ortose

Bruker barnet truncus-ortose? Ja ☐ Nei ☐

Hensikt med truncus-ortosen

Stabiliserende ☐ Korrigerende ☐

Har truncus-ortosen ønsket effekt? Ja ☐ Nei ☐

Bruker truncus-ortosen antall timer pr døgn:

≤2 ☐ 3-6 ☐ ≥7 ☐

Spastisitet etter "Modified Ashwort" skala

Kryssing ved gange/aktivitet ingen ☐ lett ☐ uttalt ☐
Kryssing i hvile ingen ☐ lett ☐ uttalt ☐

Fotklonus **Høyre** Ja ☐ Nei ☐ **Venstre** Ja ☐ Nei ☐

Vurdering av spastisitet

	Høyre						**Venstre**					
	0	**1**	**1+**	**2**	**3**	**4**	**0**	**1**	**1+**	**2**	**3**	**4**
Hoftefleksorer	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hofteekstensorer	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hofteadduktorer	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Knefleksorer	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kneekstensorer	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Plantarfleksorer	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Leddstatus

Hofte	Høyre	Venstre
Abduksjon	_____ o	_____ o
Ekstensjon i mageleie	_____ o	_____ o
Fleksjon	_____ o	_____ o
Innadrotasjon	_____ o	_____ o
Utadrotasjon	_____ o	_____ o
Duncan Ely	_____ o	_____ o
Kne		
Poplitealvinkel	_____ o	_____ o
Ekstensjon	_____ o	_____ o
Ankel		
Dorsalfleksjon med flektert kne	_____ o	_____ o
Dorsalfleksjon med ekstendert kne	_____ o	_____ o

Ankel / fot

	Høyre			**Venstre**		
Belastet hel er	Normal	Varus	Valgus	Normal	Varus	Valgus
	☐	☐	☐	☐	☐	☐

Fraktur - har barnet hatt fraktur siden forrige vurdering?

Ja ☐ Nei ☐

Smerte - opplever barnet selv eller foreldrene at barnet har smerter?
Ja ☐ Nei ☐
Hvis ja, hvor?
Hode/nakke ☐ Rygg ☐ Armer, hender ☐ Hofter ☐ Knær ☐ Føtter ☐
Tenner ☐ Mage ☐ Trykk ☐ Hudsår ☐ Annet ☐

Fysioterapi

Har barnet fått fysioterapeutiske tiltak i tillegg til CPOP-vurderingen siden forrige vurdering?

Ja ☐ Nei ☐

Hvis ja, hvor ofte?

<1 g/mnd ☐ 1-3 g/mnd ☐

1-2 g/uken ☐ 3-5 g/uken ☐ >5 g/uken ☐

Hvor ofte har fysioterapeuten vært tilstede?

<1 g/mnd ☐ 1-3 g/mnd ☐

1-2 g/uken ☐ 3-5 g/uken ☐ >5 g/uken ☐

Har barnet deltatt i intensive treningsprogram siden forrige vurdering?

Ja ☐ Nei ☐

Treningsperiodens lengde 2-6 uker ☐ 7-12 uker ☐ > 12 uker ☐

Treningen er utført 3-5g/ uken ☐ daglig ☐

Er det formulert mål for fysioterapeutiske tiltak? Ja ☐ Nei ☐

Kroppsfunksjoner og kroppsstrukturer

Har barnet fått fysioterapeutiske tiltak for å fremme og påvirke bevegelsesrelaterte funksjoner og strukturer siden forrige vurdering siden forrige vurdering?

	Ja	Nei
Muskelstyrke	☐	☐
Muskeltonus	☐	☐
Leddbevegelse	☐	☐
Postural kontroll	☐	☐
Kondisjon	☐	☐
Kroppsoppfatning	☐	☐
Respirasjon	☐	☐
Smerte	☐	☐

Opprettholde stilling- Endre posisjon- Forflytning

Har barnet siden forrige vurdering trent for å

	Ja	Nei
Opprettholde stilling (sittende, knestående, stående)	☐	☐
Endre posisjon (fra liggende til sittende til stående)	☐	☐
Forflytning (rulle, krype, forflytning med/uten hjmidler)	☐	☐

Fysisk aktivitet

Har barnet deltatt i organisert fysisk aktivitet/kroppsøving i barnehage/skole siden forrige vurdering?

Ja ☐ Nei ☐

Hvis ja, hvor ofte?

<1 g/uken ☐ 1-2 g/uken ☐ 3-5 g/uken ☐

Har barnet deltatt i fysiske fritidsaktiviteter siden forrige vurdering?

Ja ☐ Nei ☐

Hvis ja, hvor ofte?

<1 g/uken ☐ 1-2 g/uken ☐ 3-5 g/uken ☐

Hvilke fysiske fritidsaktiviteter?

Basseng ☐	Riding ☐	Fotball ☐	Dans ☐	Styrketrening ☐	Gym ☐	
Kj. hockey ☐	Skøyter ☐	Basket ☐	Boccia ☐	Bueskyting ☐	Ski ☐	
Sykling ☐	Annet ☐					

Deltar ikke i fysiske fritidsaktiviteter pga?

Tilbud finnes ikke ☐	Manglende tilrettelegging ☐	Orker ikke ☐
Manglende assistanse ☐	Manglende interesse ☐	

Operasjoner og spastisitetsreduserende behandling

Har barnet siden forrige vurdering gjennomgått

Ortopedisk operasjon Ja ☐ Nei ☐ Dato:

Type operasjon: Bløtdelsoperasjon:	H	V	Benet kirurgi:	H	Ve
Psoastenotomi	☐	☐	Acetabulumosteotomi	☐	☐
Adductortenotomi	☐	☐	Variserende femurosteotomi	☐	☐
Rectus femoris transposisjon	☐	☐	Rotasjonsosteotomi femur	☐	☐
Hamstringstenotomi	☐	☐	Ekstenderende distal femurosteotomi	☐	☐
Patellar Tendon Advancement	☐	☐	Benet kirurgi i foten	☐	☐
Gastrocnemiusforlengelse	☐	☐	Annet	☐	☐
Akillesseneforlengelse	☐	☐			
Bløtdelskirurgi i foten	☐	☐	Skolioseopr	☐	

Botulinum toxin injeksjon (BoNT-A) Ja ☐ Nei ☐ Dato:

I hvilke muskelgrupper:

Psoas	☐
Adductorer	☐
Hamstrings	☐
Rectus femoris	☐
Gastrocnemius	☐
Soleus	☐
Tibialis posterior	☐

Intrathecal Baclofenpumpe (ITB) Ja ☐ Nei ☐ Dato:

Selektiv dorsal rithzotomi (SDR) Ja ☐ Nei ☐ Dato:

Røntgen av Hofter

Personnummer:	Dato hofte rtg:	
Etternavn:	Fornavn:	
Navn på ortoped /lege som har vurdert røntgen bildet		
Acetabularindeks AI	Hø	Ve
Migrasjonsprosent MP	Hø	Ve

Kommentar

1. Normale måleverdier. Anbefaler videre rtg kontroller iht CPOP ☐
2. Normale, stabile måleverdier. Anbefaler at screening avsluttes. Nytt rtg bilde av bekken front tas ved eventuell klinisk mistanke/indikasjon ☐
3. Patologiske verdier. Anbefaler at barnet vurderes snarlig av barneortoped mht operasjon ☐
4. Patologiske verdier, barnet er søkt til operasjon. ☐
5. Patologiske verdier, men foreldre ønsker ikke operasjon ☐
6. Patologiske verdier, men ikke indikasjon for operasjon ☐
7. Annet.. ☐

Rtg av Rygg

Dato rygg rtg:		Navn på ortoped /lege som har vurdert røntgen bildet	
	Cobbvinkel	Høyrekonveks	Venstrekonveks
Thoracal skoliose		☐	☐
Thoracolumbal skoliose		☐	☐
Lumbal skoliose		☐	☐

2. REK Approval

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Mariann Glenna Davidsen	22845526	19.12.2017	2017/2137 REK sør-øst B
			Deres dato:	Deres referanse:
			31.10.2017	

Vår referanse må oppgis ved alle henvendelser

Sigrid Østensjø
Høgskolen i Oslo og Akershus

2017/2137 Barn med cerebral parese og funksjonell forflytning

Forskningsansvarlig: Høgskolen i Oslo og Akershus
Prosjektleder: Sigrid Østensjø

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 29.11.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektleders prosjektbeskrivelse
«Bedring eller bevaring av gangfunksjon er et sentralt mål for barn med CP og deres familier. Studien vil fremskaffe kunnskap om endringer i funksjonell gange hos barn med CP gjennom førskole- og grunnskolealder sett i relasjon til motoriske funksjonsforstyrrelser og grovmotorisk kapasitet. Den vil også gi kunnskap om langsiktige effekter av intervensjoner som har som mål å bedre funksjonelle ferdigheter. Studien er populasjonsbasert og inkluderer alle barn med CP født mellom 01.01.2009 og 01.01.2013. Den har et longitudinelt design og gjør bruk av anonymiserte data fra det nasjonale motoriske oppfølgingsprogrammet for barn med CP (CPOP). Forskningsspørsmålene omfatter hvordan funksjonell gange endrer seg over tid, hvordan endringer i funksjonell gange kan knyttes til endringer i spastisitet, leddbevegelighet og grunnleggende grovmotoriske ferdigheter, samt effekter av ortopedisk kirurgi og intensivert trening på funksjonell gange. Spørsmålene besvares med bruk av statistiske analyser.»

Komiteens vurdering
Dette er en masteroppgave hvor formålet er å få kunnskap om de langsiktige effektene av intervensjoner hvorpå målet å bedre funksjonelle ferdigheter. Det legges opp til å innhente følgende opplysninger fra Cerebral Parese Registeret (CPRN/CPOP):
- alder
- kjønn
- type cerebral parese og alvorlighetsgrad
- funksjonell mobilitet
- bruk av rullestol
- spastisitet
- leddstatus
- fysioterapi
- intensiv motorisk trening
- ortopedisk kirurgi og spastisitetsreduserende behandling

Besøksadresse: Gullhaugveien 1-3, 0484 Oslo
Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/
All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff

Forskningsdeltakere
Antall forskningsdeltakere anslåes til å være omlag 600, og inkluderer alle barn som er registrert i CPOP fra det ble et nasjonalt register, 01.01. 2009 og frem til 01.01.2013.

Deltakelse vil også inkludere barn under 12 år.

Samtykke
Det foreligger allerede et samtykkeskriv i forbindelse med CPRN registeret som vil være dekkende for formålet i dette prosjektet.

Komiteen har ingen innvendinger til at prosjektet gjennomføres slik det nå foreligger.

Vedtak
Komiteen godkjenner prosjektet i henhold til helseforskningsloven § 9 og § 33.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden.

Tillatelsen gjelder til 31.12.2019. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.12.2024. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder «*Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren*».

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK sør-øst på eget skjema, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK sør-øst dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst B. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Komiteens avgjørelse var enstemmig.

Med vennlig hilsen

Ragnhild Emblem
professor, dr. med.
leder REK sør-øst B

Mariann Glenna Davidsen
rådgiver

Kopi til:
- *Dekan Gro Jamtvedt, Høgskolen i Oslo og Akershus ved øverste administrative ledelse*

Examples

a) A child who walks independently at home on all surfaces but uses crutches in the school playground and a wheelchair for long family walks or school outings would be scored as:

6 3 1

b) A child who uses crutches indoors at home, a walker in the playground at school and a wheelchair to go to the shopping centre would be scored as:

3 2 1

c) A child who walks independently on all surfaces at home including steps without a rail but at school and for longer distances tend to lose balance on uneven ground or in crowds would be scored as:

6 5 5

d) A child who uses a walker at home and in physiotherapy but in all other settings uses a wheelchair would be scored as:

2 1 1

e) A child who walks independently without assistive devices at home on level ground only and uses two single point sticks at school in the classroom and the playground and a walker for longer distances would be scored as:

5 4 2

References

1) Graham H.K., Harvey A., Rodda J., Nattrass G.R., Pirpiris M. (2004). The Functional Mobility Scale (FMS). JPO 24(5): 514–520.

2) Palisano R.J., Tieman B.L., Walter S.D., Bartlett D.J., Rosenbaum P.L., Russell D., Hanna S.E. (2003). Effect of environmental setting on mobility methods of children with cerebral palsy. Dev. Med. Child Neurol. 45: 113–120.

For further information or more copies please contact:
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phone: +61 3 9345 5354

www.rch.org.au/gait

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ERC: 061076

FMS

The Functional Mobility Scale

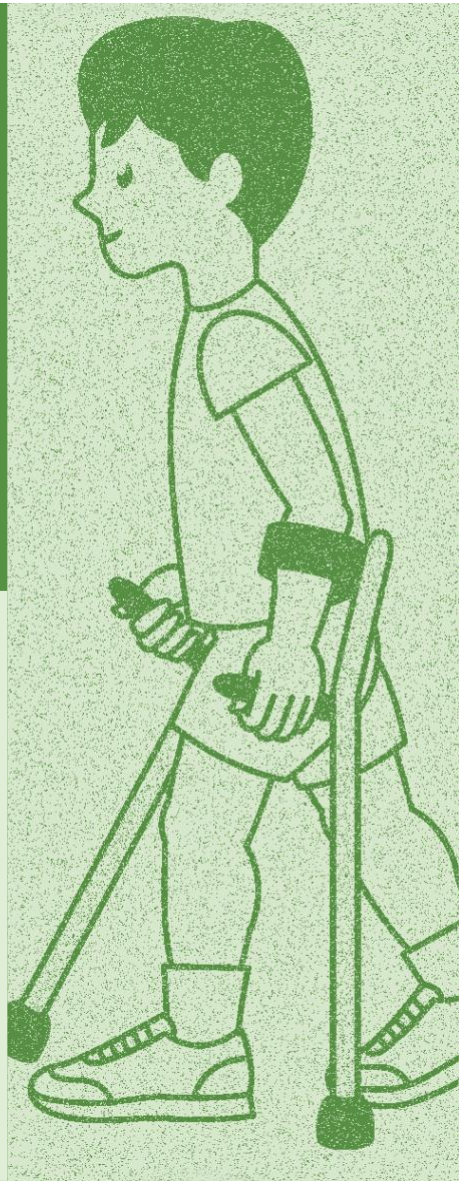
(version 2)

For children with cerebral palsy aged 4–18 years

Developed by the
Hugh Williamson Gait Laboratory
The Royal Children's Hospital
Melbourne, Australia

Part of the Gait CCRE

www.rch.org.au/gait



Introduction

The Functional Mobility Scale (FMS) has been constructed to classify functional mobility in children, taking into account the range of assistive devices a child might use.

The scale can be used to classify children's functional mobility, document change over time in the same child and to document change seen following interventions, for example orthopaedic surgery or selective dorsal rhizotomy.

The FMS rates walking ability at three specific distances, 5, 50 and 500 metres, (or 5, 50, 500 yards). This represents the child's mobility in the home, at school and in the community setting. It therefore accounts for different assistive devices used by the same child in different environments.

Assessment is by the clinician on the basis of questions asked of the child/parent (not direct observation). The walking ability of the child is rated at each of the three distances according to the need for assistive devices such as crutches, walkers or wheelchair. Orthotics which are regularly used should be included for the rating.

The FMS is a **performance** measure. It is important to rate what the child **actually does** at this point in time, not what they **can do** or **used to be able to do**.

Developed by the Hugh Williamson Gait Laboratory, The Royal Children's Hospital, Melbourne, Australia. Part of the Gait CCRE.

www.rch.org.au/gait

Rating **6**

Independent on all surfaces:

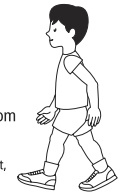
Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs etc. and in a crowded environment.

Rating **5**

Independent on level surfaces:

Does not use walking aids or need help from another person.* Requires a rail for stairs.

*If uses furniture, walls, fences, shop fronts for support, please use 4 as the appropriate description.



Rating **4**

Uses sticks (one or two):

Without help from another person.

Walking distance	Rating: select the number (from 1–6) which best describes current function
5 metres (yards)	
50 metres (yards)	
500 metres (yards)	

Rating **3**

Uses crutches:

Without help from another person.

Rating **2**

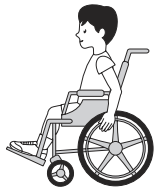
Uses a walker or frame:

Without help from another person.

Rating **1**

Uses wheelchair:

May stand for transfers, may do some stepping supported by another person or using a walker/frame.



Rating **C**

Crawling:

Child crawls for mobility at home (5m).

Rating **N**

N = does not apply:

For example child does not complete the distance (500 m).

Questions

To obtain answers that reflect performance, the manner in which the questions are asked of the child/parent is important. The questions we use to obtain the appropriate responses are:

1. How does your child move around for short distances in the house? (5m)
2. How does your child move around in and between classes at school? (50m)
3. How does your child move around for long distances such as at the shopping centre? (500m)

The distances are a guide. It is the environment that is most relevant.

Qualifiers

The difference between 1–4 is self-explanatory, however the difference between 5 and 6 is less clear.

5 metres: children who require a rail for stairs would be rated as 5 and children who do not require a rail or help would be rated as 6.

50 metres: children who can walk on all surfaces including uneven surfaces and steps, particularly at school are rated as 6 and children that require help on these surfaces but can walk on level surfaces without help are rated as 5.

500 metres: children who can walk on all surfaces including rough ground, curbs, steps and in crowded environments in the community without help are rated as 6 and children who walk long distances only on level surfaces and have difficulty walking in crowds are rated as 5.

4. CPOP manual for physiotherapists

Cerebral parese Oppfølgingsprogram

MANUAL
for
Fysioterapiprotokoll
01.06.15

Samtykke
Informer foresatte om CPOP og gi dem informasjonsskriv med samtykkeerklæring.
Foresatte må gi samtykke til at opplysningene skal lagres i CPOP databasen.
CPOP har felles samtykkeerklæring med CPRN som kan lastes ned fra
www.oslo-universitetssykehus.no/cpop

Diagnose
Diagnosen settes av lege i Habiliteringstjenesten. Cerebral Parese klassifiseres etter SCPE,
Cans C. (2000) Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers.
Dev Med Child Neurol. 42: 816-824, oversatt til norsk av Andersen G, Haagaas I og Syse J, 2003.

GMFCS E&R

Klassifiser etter "Grovmotorisk funksjon - klassifikasjonssystem for cerebral parese". Før du klassifiserer, les introduksjonen og brukerveiledningen.
Ref; Gross Motor Function Classification System for Cerebral Palsy, Palisano et al, Dev. Med &Child Neurol 1997. GMFCS E&R 2007.
GMFCS E&R, GMFCS beskrivelse og illustrasjoner samt GMFCS spørreskjema kan lastes ned fra www.oslo-universitetssykehus.no/cpop

GMFM

Gross Motor Function Measure-66 anbefales å utføres årlig. Testark for GMFM 66, GMFM 66 B&C og GMFM 66&88 kan lastes ned fra www.oslo-universitetssykehus.no/cpop
Ref; Gross Motor Function Measure (GMFM-66 & GMFM-88) User'Manual 2nd Edition. Russell D, Rosenbaum P, Wright W, Avery L. McKeith Press 2013

FMS kan lastes ned fra www.oslo-universitetssykehus.no/cpop
The Functional Mobility Scale (versjon 2 for barn og unge med CP fra 4-18 år)
Velg en av følgende alternativ som best beskriver barnets nåværende funksjonelle forflytning på alle tre distanser; **5 meter** i hjemmet, **50 meter** på skolen, **500 meter** i nærmiljøet.

6: Går selvstendig på all slags underlag. Bruker ikke ganghjelpemidler eller trenger hjelp fra annen person under gange på all slags underlag, inkludert ujevnt underlag, skråninger o.s.v. og i omgivelser med mange mennesker.
5: Går selvstendig på jevnt underlag. Bruker ikke ganghjelpemidler eller trenger hjelp fra en annen person*. Trenger rekkverk i trapper.
*Hvis det blir brukt møbler, vegger, gjerder eller butikkvinduer til støtte, bruk 4 som er korrekt beskrivelse.
4: Bruker stokker (en eller to). Uten hjelp fra en annen person.
3: Bruker krykker. Uten hjelp fra en annen person.
2: Bruker fremover- eller bakovervendt rollator. Uten hjelp fra en annen person.
1: Bruker rullestol. Kan muligens stå ved overflytting og kanskje ta noen skritt med støtte fra en annen person eller bruk av fremover- eller bakovervendt rollator. (bæres, kjøres i vogn eller rullestol, kjører rullestol selv eller går med NF-Walker)
C = Krabber; Barnet krabber ved forflytning hjemme (5meter). Kan gjelde i barnehaven (50 m) for små barn, men C anvendes aldri ute i lokalsamfunnet (500 m).
N = Kan ikke anvendes; For eksempel: Barnet fullfører ikke gangdistansen (500 m) N benyttes bare for distansen 500 m/nærmiljøet. Benyttes når barnet for eksempel aldri er med til et kjøpesenter p.g.a. nedsatt allmenntilstand.

Ref; The Functional Mobility Scale, Pirpiris, Graham et. al, J. Of Pediatric Orthoped. 2004 sep.-oct.; 24(5):514-20
Harvey A. Graham HK, Baker R, Wolfe R. The Functional Mobility Scale: responsiveness to change. Abstract DMCN Suppl no 106, vol 48 September 2006

FMS; eksempler på skåring etter CPUP

A. Et barn som går selvstendig på all slags underlag hjemme, men bruker krykker på skolen og rullestol på lengre turer med familien eller på skoleturer.
Skår: 6-3-1

B. Et barn som bruker krykker hjemme, rullator på skolen og rullestol på kjøpesenteret.
Skår: 3-2-1

C. Et barn som går selvstendig på all slags underlag hjemme inklusiv i trapper uten rekkverk, men har lett for å miste balansen på skolen samt på lengre avstander på ujevnt underlag og i store folkemengder.
Skår: 6-5-5

D. Et barn som bruker rullator hjemme og hos fysioterapeuten, men rullestol i alle andre omgivelser.
Skår:2-1-1

E. Et barn som går selvstendig uten hjelpemiddel hjemme på jevnt underlag og bruker to stokker i klasserommet og skolegården, samt rullator ved lengre strekninger.
Skår: 5-4-2

F. Et barn som går selvstendig hjemme og på skolen (hvis det hadde vært trapper hadde barnet trengt rekkverk, men det er ikke trapper), men støtter seg til rekkverk på et kjøpesenter.
Skår: 6-6-5

G. Et barn som går med to firpunkt-stokker hjemme, går med rullator i barnehaven og sitter i vogn på utflukter.
Skår: 3-2-1

H. Et barn som bæres hjemme, kjøres i rullestol på skolen og kjøres i vogn i lokalmiljøet.
Skår 1-1-1

I. Et barn som går hjemme med mye støtte av en voksen, kjører el rullestol på skolen og kjøres i manuell rullestol på utflukter.
Skår: 1-1-1

J. Et barn som rompeaker hjemme og i barnehagen, men kjøres i vogn utendørs.
Skår: C-C-1

K. Et barn som går i gåstol hjemme, bruker rullestol på skolen, men er aldri ute i lokalmiljøet p.g.a. nedsatt almentilstand.
Skår: 1-1-N

Ortoser; Definisjoner;

Innlegg (FO) i sko – alle typer individuelt tilpassede innlegg som går nedenfor fotens malleoler uavhengig av materiale.

Ankel -Fot-Ortose (AFO) – alle ortoser som proksimalt avsluttes mellom malleoler og knehase og distalt inkluderer foten. Det skilles ikke mellom ortoser med og uten ledd. Faste, "dynamiske" eller leddede ortoser inkluderes for eksempel DAFO.

Kne-Ankel-Fot-Ortose (KAFO) – alle typer ortoser som avsluttes over kneleddet t.o.m. trochanter major og distalt inkluderer foten. Det skilles ikke mellom ortoser med og uten ledd.

Kne-Ortose (KO) – alle ortoser som proksimalt avsluttes over kneleddet t.o.m. trochanter major og strekker seg distalt til malleolen.

Hofte-Abduksjons-Ortose (HO) – ortoser som har til hensikt å abdusere hoftene som f. eks. SWASH- ortose og som ikke går lenger ned enn til lårene.

FO AFO AFO KAFO KAFO KO HO Ståskall

Rygg

Viser til "Ryggoppfølging for barn med cerebral parese" som kan lastes ned fra www.oslo-universitetssykehus.no/cpop

Angi om barnet er skolioseoperert. Hvis ja, er vurderingen ikke aktuell. Fysioterapeut skal undersøke barnet klinisk for å avgjøre om barnet bør henvises til røntgen. Vurderingen utføres hvis mulig i stående med korreksjon av eventuell benlengdeforskjell, alternativ utgangstilling er sittende på benk med korreksjon av eventuell bekkensenkning.

Graden av skoliose (lett, moderat eller uttalt) er en grov inndeling av skoliosens størrelse og avgjør om det skal tas røntgen skoliosebilde. CPUP har følgende definisjoner;

Lett skoliose: Skoliose som sees ved fremoverbøying med rett bekken.

Moderat skoliose: Skoliose som er tydelig både ved fremoverbøying og ved oppreist stilling

Uttalt skoliose: Skoliose som krever sidestøtte for å opprettholde rett stilling i sittende eller stående

Når du skal vurdere om skoliosen er korrigerbar eller ikke korrigerbar/ rigid, undersøk barnet i mageleie evntuelt sittende på benk og rett opp barnets rygg ved å støtte rundt thorax med dine hender.

Truncus-ortose- alle typer truncusortoser / korsett som er individuelt tilpasset.

Manual for røntgen av hofte kan lastes ned fra www.oslo-universitetssykehus.no/cpop

- Røntgenscreening for å forebygge hofteluksasjon ved cerebral parese
- Måling av Migrasjonsprosent (MP) og Acetabular index (AI) for CPOP

Spastisitet "Modified Ashworth"-skala

Ref; Bohannon & Smith, 1987, "Interrater reliability of a modified Ashworth scale of muscle spasticity", Physical Therap;, 67(2): 206-207.

0: Ingen økning av muskeltonus.
1: Lett økning av muskeltonus; viser seg som "catch and release" eller som minimal motstand i slutten av bevegelsesbanen når affisert ekstremitet beveges i fleksjon eller ekstensjon.
1+: Lett økning av muskeltonus; viser seg som "catch" fulgt av minimal motstand gjennom resten av bevegelsesbanen (mindre enn halve).
2: Mer markert økning av muskeltonus gjennom mesteparten av bevegelsesbanen, men affisert ekstremitet kan lett beveges.
3: Betydelig økning av muskeltonus; passiv bevegelse er vanskelig.
4: Affisert ekstremitet er rigid i fleksjon eller ekstensjon.

Utgangsstilling ved vurdering av spastisitet:

Hoftefleksorer; Ryggleie, før benet i fleksjon-ekstensjon, kjenn etter tonus når hoften ekstenderes

Hofteekstensorer; Ryggleie, før benet i ekstensjon-fleksjon, kjenn etter tonus når hoften flekteres

Adduktorer; Ryggleie med ekstenderte knær og hofter. Før benet i adduksjon- abduksjon og kjenn etter tonus når benet føres i abduksjon.

Knefleksorer; Ryggleie med 90° hoftefleksjon. Før benet i fleksjon-ekstensjon og kjenn etter tonus når kneet ekstenderes

Kneekstensore Ryggleie med 90° hoftefleksjon. Før benet i fleksjon-ekstensjon og kjenn etter tonus når kneet flekteres.

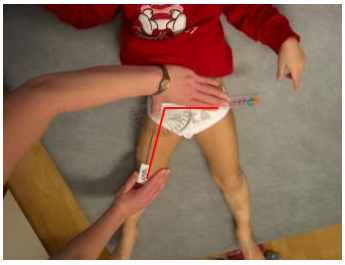
Plantarfleksorer; Ryggleie med ekstendert hofte og kne. Før foten i plantar-dorsalfleksjon og kjenn etter tonus når foten dorsalflekteres.

Leddstatus;

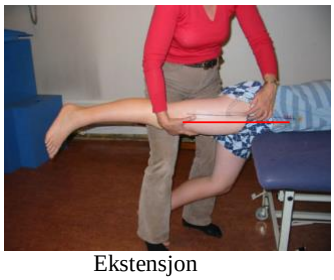
Passive leddutslag måles med vinkelmål (goniometer) av to personer.
Ref; American Academy of Orthopaedic Surgeons 1988, ISBN 0443002703
Tall i parentes er oppgitt som normalverdier for 4 års alder etter Sutherland 1988.

Hofte

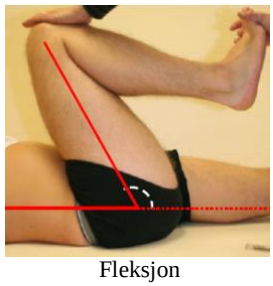
Bevegelse	Utgangsstilling	Fast vinkelben	Bevegelig vinkelben
Abduksjon, (50º)	Ryggleie med ekstensjon i hofte og kne	Goniometerledd over SIAS (spina iliaca superior anterior) på aktuell side, fast vinkelben følger tenkt linje mellom begge SIAS	Langs femur mot midten av patella
Ekstensjon (10º) Evnt manglende ekstensjon til horisontal-leiet angis med minus	Mageleie med bena utenfor benken	Goniometerledd over trochanter major, fast vinkelben følger truncus	Langs tenkt linje mellom trochanter major og laterale epikondyl på femur
Fleksjon (110º-120º)	Ryggleie, fikser bekkenet ved å ekstendere motsatt ben. Flekter i kne og hofte	Goniometerledd over trochanter major, fast vinkelben følger truncus paralelt med columna	Langs femur



Abduksjon



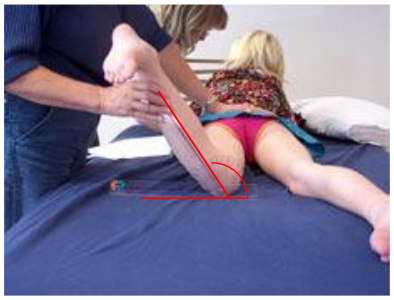
Ekstensjon



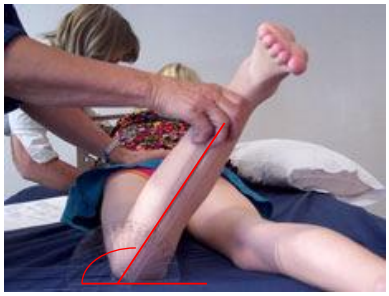
Fleksjon

Hofte forts.

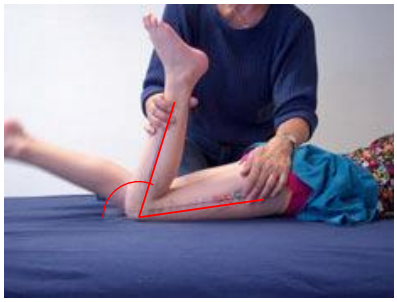
Bevegelse	Utgangsstilling	Fast vinkelben	Bevegelig vinkelben
Innadrotasjon (50º)	Mageleie med ekstendert hofte, kne i 90° fleksjon, stabiliser bekkenet for å hindre bekkenrotasjon	Fast vinkelben langs underlaget	Vinkelben følger tibia aksen mot 2. tå
Utadrotasjon (45º)	Som ovenfor	Som ovenfor	Som ovenfor
Duncan Ely. Teste lengden av rectus femoris. Flekter kneet og angi knevinkel mellom underlag og skinnlegg når bekkenet heves.	Mageleie med ekstenderte hofter, fikser bekkenet.	Goniometerledd over lateralel kneledd, fast vinkelben følger femur mot trochanter major	Holdes parallelt med tibias fremkant mot laterale malleol



Innadrotasjon



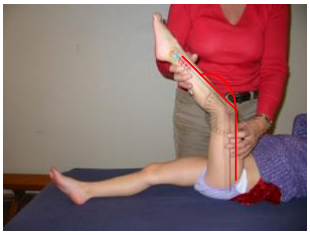
Utadrotasjon



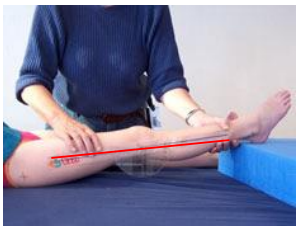
Duncan Ely

Kne

Bevegelse	Utgangsstilling	Fast vinkelben	Bevegelig vinkelben
Poplitealvinkel angi manglende ekstensjon	Ryggleie med 90° hoftefleksjon i aktuelt ben, fikser motsatt ben i ekstendert stilling	Goniometerledd over laterale kneledd, fast vinkelben langs femur mot trochanter major	Holdes parallelt med tibias fremkant mot laterale malleol
Ekstensjon (10°)	Ryggleie med ekstendert hofte og kne	Som ovenfor	Som ovenfor



Popliteal

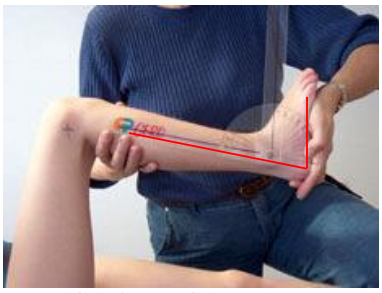


Ekstensjon

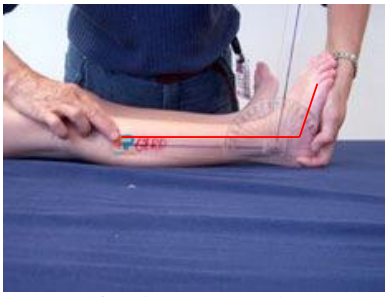
Ankel

Bevegelse	Utgangsstilling	Fast vinkelben	Bevegelig vinkelben
***Dorsalfleksjon m/flektert kne**	Ryggleie med fleksjon i hofte og kne	Goniometerledd over laterale malleol, fast vinkelben parallelt med tibias fremkant	Følger laterale fotrand, 5. metatarsal
***Dorsalfleksjon m/ekstendert kne** (15°)	Ryggleie med ekstendert kne	Som ovenfor	Som ovenfor

*Stabiliser det subtalare leddet ved å fiksere calcaneus for å forhindre valgus/varus stilling.
90° i ankelledd=0°. Dorsalfleksjon mindre enn 0° angis med minus.



Dorsalfleksjon m/ flektert kne



Dorsalfleksjon m/ ekstendert kne

Alarmverdier for passive bevegelsesutslag

Alarmverdiene er bestemt ut fra at barna skal ha mulighet til å dorsalflektere i stand- og svingfasen under gange på GMFCS nivå I-III, og tilstrekkelig bevegelsesutslag i hofte-, kne- og ankelledd for å få en god stående stilling på GMFCS nivå IV-V.

GMFCS I-III	**Patologisk**	**Kontroll/ tiltak**	**Normalverdi**
Hofte abduksjon	**≤ 30**	**31- 39**	**≥ 40**
Hofte ekstensjon	**< 0**		**≥ 0**
Hofte fleksjon	**≤ 100**	**101 - 109**	**≥ 110**
Hofte utadrotasjon	**≤ 30**	**31- 39**	**≥ 40**
Hofte innadrotasjon	**≤ 30**	**31- 39**	**≥ 40**
Duncan Ely/lengden av RF	**≤100**	**101-119**	**≥ 120**
Poplitealvinkel	**≥ 50**	**41- 49**	**≤ 40**
Kne ekstensjon	**≤ -10**	**- 9 til -1**	**≥ 0**
Dorsalfleksjon med flex kne	**≤ 10**	**11- 19**	**≥ 20**
Dorsalfleksjon med ex kne	**≤ 0**	**1- 9**	**≥ 10**
GMFCS IV-V	**Patologisk**	**Kontroll/ tiltak**	**Normalverdi**
Hofte abduksjon	**≤ 20**	**21- 29**	**≥ 30**
Hofte ekstensjon	**< -10**	**- 9 til -1**	**≥ 0**
Hofte fleksjon	**≤ 90**	**91 - 109**	**≥ 110**
Hofte utadrotasjon	**≤ 30**	**31- 39**	**≥ 40**
Hofte innadrotasjon	**≤ 30**	**31- 39**	**≥ 40**
Duncan Ely / lengden av RF	**≤ 90**	**91-109**	**≥ 110**
Poplitealvinkel	**≥ 60**	**51- 59**	**≤ 50**
Kne ekstensjon	**≤ - 20**	**-19 til -11**	**≥ -10**
Dorsalfleksjon med flex kne	**≤ 0**	**1- 9**	**≥ 10**
Dorsalfleksjonmed ex kne	**≤ -10**	**- 9 til -1**	**≥ 0**

Fysioterapi

Hensikten med dette avsnittet er å få en oversikt over om barnet/ungdommen har fått fysioterapi/ fysioterapeutiske tiltak utover CPOP vurderingen siden forrige undersøkelse.
Med fysioterapeutiske tiltak menes veiledning og tiltak som har til hensikt å forebygge, undersøke og/eller behandle funksjonsforstyrrelser som begrenser eller kommer til å begrense motorisk funksjon. Tiltakene kan være individuelle, i gruppe, i basseng eller lignende.
Hvis ja, hvor ofte har det vanligvis skjedd? Hvor ofte har fysioterapeuten vært tilstede?

Videre spørres det om barnet har deltatt i intensive treningsprogram siden forrige vurdering? Intensive treningsprogram kan for eks. være PIH, BIP, PITH, PETØ, Beitostølen Helsesportsenter, private institutt og lignende, Doman.
Dernest spørres det om det er formulert mål for de fysioterapeutiske tiltakene.

Kroppsfunksjoner og kroppsstrukturer
Aktivitet/deltagelse – opprettholde kroppsstilling, endre posisjon, forflytning
Her spørres det om barnet siden forrige vurdering har fått fysioterapi som har til hensikt å fremme og påvirke bevegelsesrelaterte funksjoner og strukturer samt trene ferdigheter for å fremme aktivitet og deltagelse.
Begrepene fra WHO er anvendt; klassifikasjon av helserelatert funksjonsevne og –begrensninger, International Classification of Functioning, Disability and Health (ICF).
ICF-komponentene **kroppsfunksjoner og strukturer** henviser til:
Kapittel 7; Nerve-, muskel-, skjelett- og bevegelsesrelaterte funksjoner. Dette kapittel handler om bevegelsessystemets funksjoner, funksjoner i ledd, skjelett, reflekser og muskulatur.
Kapittel 4; Kretsløps-, blod-, immun- og respirasjonsfunksjoner.
Kapittel 2; Sansefunksjoner (som henger sammen med kroppsstilling, balanse og bevegelse) og smerte.

Tilsvarende utvalg av ICF-komponentene **Aktivitet/deltagelse** omtales i Kapittel 4; Mobilitet. Dette kapittel handler om å endre og opprettholde kroppsstilling, bære, flytte og håndtere gjenstander, gå og bevege seg omkring og bevege seg omkring med transportmidler.

Ref; International Classification of Functioning, Disability and Health (ICF). WHO 2001

Fysisk aktivitet
Det er positivt forhold mellom fysisk aktivitet og helse/livskvalitet. Hensikten med dette avsnittet er å få en oversikt om barnet siden forrige vurdering har:

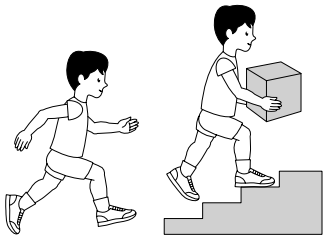
- deltatt i **organisert** fysisk aktivitet/kroppsøving i barnehage og skole og hvor ofte?
- deltatt i fysiske **fritids**aktiviteter?
- hvor ofte og hvilke fysiske **fritids**aktiviteter?

Med fysisk aktivitet menes all fysisk aktivitet / kroppsbevegelse som en følge av at skjelettmuskulaturen trekkes sammen og som fører til økt energiforbruk og økt puls.

Ref; Jahnsen R, Villien L, Aamodt G, Stanghelle JK, Holm I. Physiotherapy and physical activity - experiences of adults with cerebral palsy - with implications for children. Advances in Physiotherapy 2003; 5(1): 21-32

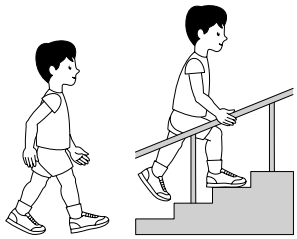
5. GMFCS E&R between 6th and 12th, and 12th and 18th birthday: Descriptors and Illustrations, retrieved from CanChild website: https://www.canchild.ca/system/tenon/assets/attachments/000/002/114/original/GMFCS_English_Illustrations_V2.pdf. (CanChild, 2019)

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations



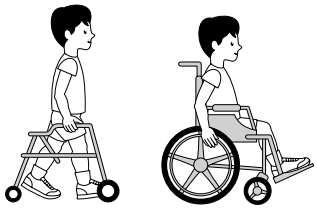
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



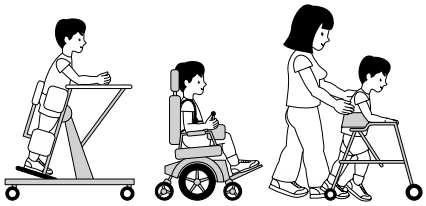
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



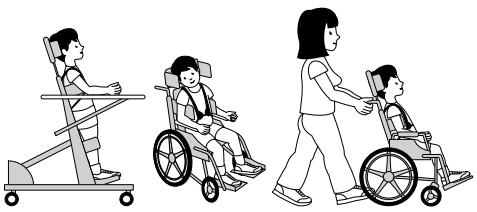
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



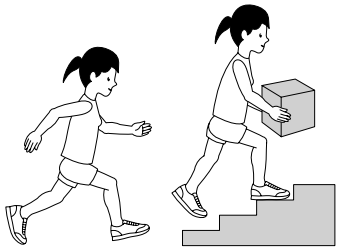
GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

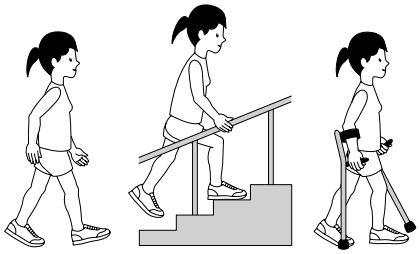
Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham, The Royal Children's Hospital Melbourne ERC151050

GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations



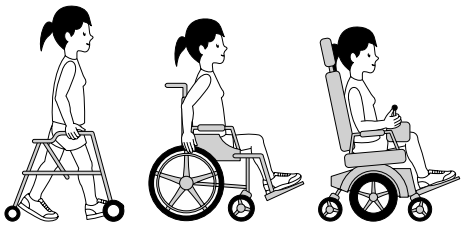
GMFCS Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.



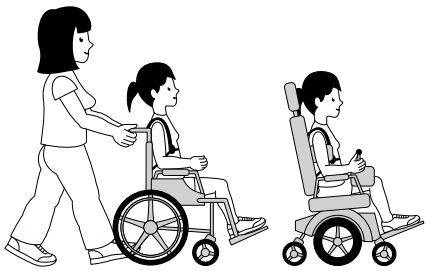
GMFCS Level II

Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.



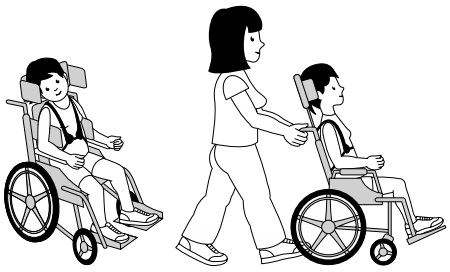
GMFCS Level III

Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.



GMFCS Level IV

Youth use wheeled mobility in most settings. Physical assistance of 1–2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.



GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

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