

**The physical activity status and patterns in adults with  
Cerebral Palsy - an accelerometry study**

by

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## DECLARATION

I, **Thulfieq Behardien** (student number: BHRTHU001), hereby declare that the work on which this dissertation is based is my original work, except where acknowledgements indicate otherwise. In addition, I declare that, apart from the normal guidance from my supervisors, I have written this thesis myself.

I empower my supervisors to reproduce for the purposes of research either the whole or any portion of the contents in any manner whatsoever.

Signed by candidate

Signature

Date: 10<sup>th</sup> October 2019



## ABBREVIATIONS

ADL	Activity of Daily Living
BMI	Body Mass Index
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification System
HPA	Habitual Physical Activity'
HREC	Human Research Ethics Committee
HQOL	Health-related Quality of Life
ICC	Interclass Correlation Coefficient
ICF	International Classification of Function, Disability and Health
IQR	Interquartile Ranges
LMN	Lower Motor Neurons
MVPA	Moderate to Vigorous Physical Activity
N	Sample size
PA	Physical Activity
SCPE	Surveillance of Cerebral Palsy in Europe
SD	Standard Deviation
SES	Social Economical Status
TD	Typically Developed
UMN	Upper Motor Neurons
WHO	World Health Organization



## **ABSTRACT**

One of the most common causes of physical disability acquired during childhood is cerebral palsy (CP). Due to improvements in medical care over the past decades, almost all children with CP survive into adulthood nowadays. In addition, based on a stable incidence rate and longevity of individuals with CP, currently most persons with CP are adults. Therefore, it is appropriate to draw awareness to focus on rehabilitation in adults with CP.

Due to the nature of their physical disability, adults with CP are at risk to an inactive lifestyle, which can lead to increased health risks. Physical inactivity may be the predisposition to developing a cycle of deconditioning, in which reduced levels of PA (physical activity) may lead to lower levels of physical fitness. Lower levels of physical fitness cause individual's with CP to expend more energy during daily activities such as walking. As a consequence, individuals with CP may experience earlier fatigue, pain or other factors that increase the impact of the disorder on daily functioning. It is therefore important to intervene in this vicious cycle of physical inactivity. This thesis provides an overview of the methods used to record PA and reports on PA levels in adults with CP.

The literature review evidently showed that adults with CP were less physically active compared to TD (typically developed) peers and spent more time in sedentary behaviour compared to TD adults. Various methods have been shown to be available to assess levels of PA, such as questionnaires, pedometers, and more advanced accelerometers that allow for measuring acceleration in three directions (x-y-z axes). Previously, research studies' most commonly used hip-worn devices among adults with CP to assess PA levels, such as the Actigraph that has been used and validated in various populations with and without disabilities. Unfortunately, the Actigraph is not water resistant, which does not allow individuals to continuously wear the device. Alternatively, wrist-worn devices can be used to

assess PA levels, such as the Polar Loop 2, which is convenient to wear and water-resistant. However, no previous research has proven the validity of the Polar Loop 2 to assess PA levels in a cohort with CP. In addition, most studies focused on adults with CP in developed countries, while no studies have been conducted in developing countries.

Therefore, the aim of the second study was to determine differences in PA between adults with CP and TD adults living in South Africa, assessed with the Actigraph and Polar Loop 2 accelerometers. In addition, we aimed to determine the validity of the Polar Loop 2 compared to the Actigraph for different levels of PA. This study showed that adults with CP were less physically active than TD adults, based on findings that the number of steps taken per day were substantially lower, they spent more time being sedentary and less time in low and moderate intensity PA. The Polar Loop 2 showed to be a valid measure for PA in adults with CP and TD adults. Since the Polar Loop 2 is water-resistant and convenient to wear it can be a useful tool to measure PA in clinical practice.

The reduced levels of PA presented in this thesis highlight that adults with CP are at risk of reduced fitness levels and secondary complications during daily life activities. This cycle of deconditioning may progress during ageing in adults with CP. More PA and exercise, at the correct intensity and duration, can break the barrier of this vicious cycle. Regular exercise can have a variety of beneficial effects on the health of adults with CP. For example, it may reduce the incidence of obesity, improve muscle function and muscle strength. Furthermore, exercise can reduce the incidence of chronic health conditions like diabetes, cardiovascular diseases and osteoporosis. In order to avoid health issues at older ages and to prevent inactive lifestyles, it is important to encourage a healthy and active lifestyle during early adulthood to promote physically active when growing older. Regular exercise also positively influences the development of the musculoskeletal system, which may prevent the decline in mobility.

## **LITERATURE REVIEW**



## **BACKGROUND**

It is generally known that low levels of physical activity (PA) are associated with health risk factors and chronic disease.<sup>1</sup> Individuals living with physical disabilities such as *Cerebral Palsy* (CP) are prone to being less physically active than their typically developed (TD) peers. A result of lower PA levels is the predisposition to developing a cycle of deconditioning, in which reduced levels of PA may lead to secondary conditions such as; pain fatigue and/or cardiovascular conditions that could further attenuate this deconditioning cycle. Decreased levels of moderate to vigorous physical activity (MVPA) with increased sedentary behaviour is associated with metabolic syndrome risk factors of cardiovascular disease, type-2-diabetes, dyslipidaemia, obesity and generalized inflammatory markers.<sup>2</sup>

Therefore, investigating the PA status and patterns in adults with CP will be potentially informative for themselves, in addition to clinicians and care-givers when considering health and wellness from a psychological, physical and economical perspective. The aim of this literature review is to provide insight into CP, how to measure PA and the levels of PA reported in adults with CP.

## **CEREBRAL PALSY**

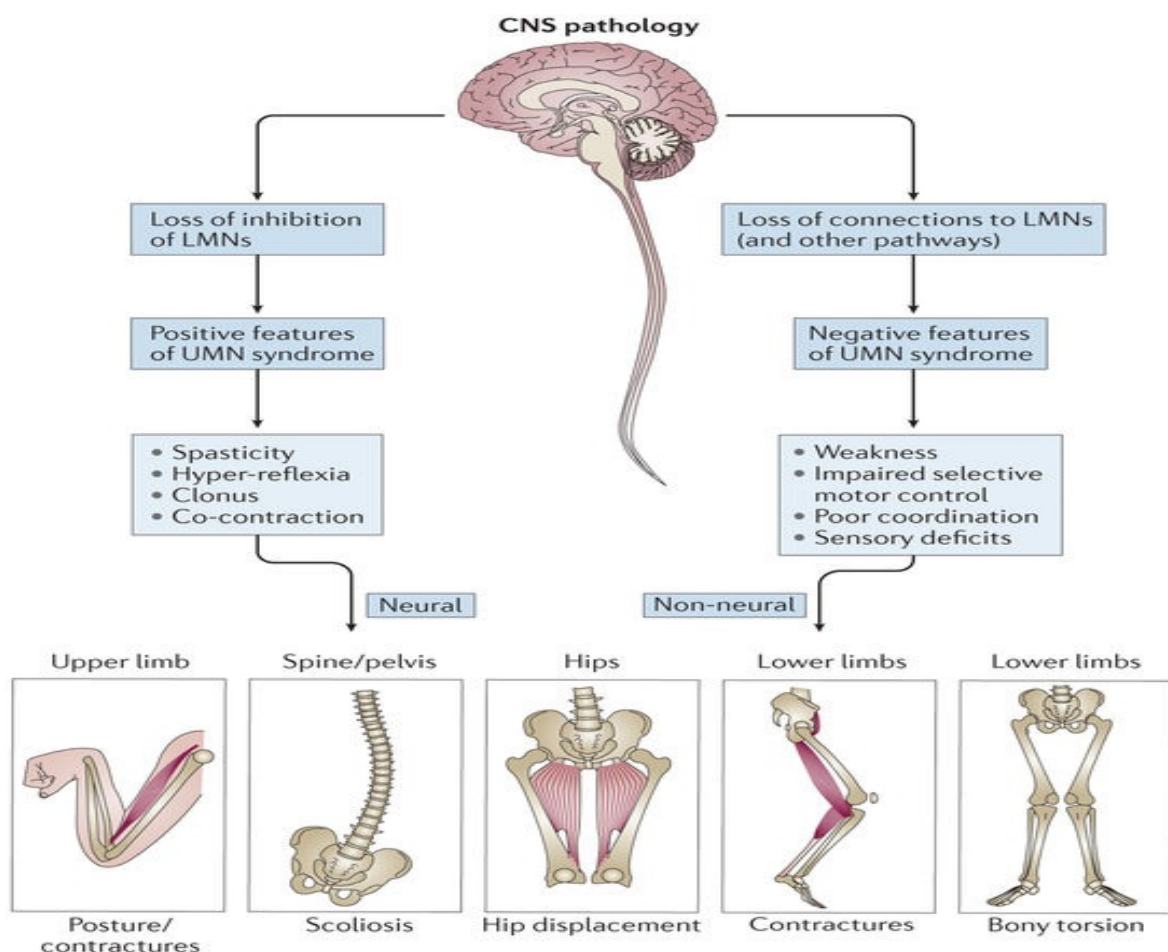
### **Aetiology and epidemiology**

CP is the most common cause of physical disabilities in children.<sup>3-6</sup> It is caused by a neurological disorder that occurs before, during or after delivery which is characterised by a non-progressive nature.<sup>2</sup> As a consequence of this neurological disorder, children with CP often show impairments in; growth, posture, and motor development.<sup>2</sup> CP serves as an umbrella term constituting a spectrum of disorders as a result of the permanent encephalopathy.<sup>5</sup> The outcome of early-onset encephalopathy predisposes neurological deficits including; ‘disturbances in cognition, perception, sensation, communication and behavioural problems’.<sup>6</sup>

The population based prevalence of CP varies amongst registries and historically reports estimates of 1.5 to 2.5 per 1000 live births.<sup>3, 6, 7</sup> South African data however, remain inconclusive with estimates of between 1% and 8% of the population being affected.<sup>8, 9</sup> Irrespective of the prevalence, advancements in neonatal care over the recent decades have

lowered the mortality of premature infants, contributing to a modest increase in its prevalence.<sup>10</sup> Thus with the expected rise in adolescence and adults with CP, compensated strain on the health-care system has prompted the emphasis of management of all markers of activities of daily living (ADL) including participating in adjusted physical activity.<sup>11</sup> These markers of ADL such as mobilization, washing and dressing are affected due to the deteriorating clinical expression of the original neonatal injury, resulting in the inability to control movement and posture while definitively affecting the peripheral joints.

The consequential conditions which present with CP are a maturation of the *upper motor neuron* (UMN) syndrome. (Figure 1) The UMN syndrome is divided into and including the sensory pathology, as the loss of inhibition to the lower motor neurons (LMN) and the motor pathology, as the loss of connection to the LMN's.<sup>10</sup>



**Figure 1:** Dichotomous pathology of the UMN's and LMN's and their physical expression in CP.<sup>6</sup>

## Classification

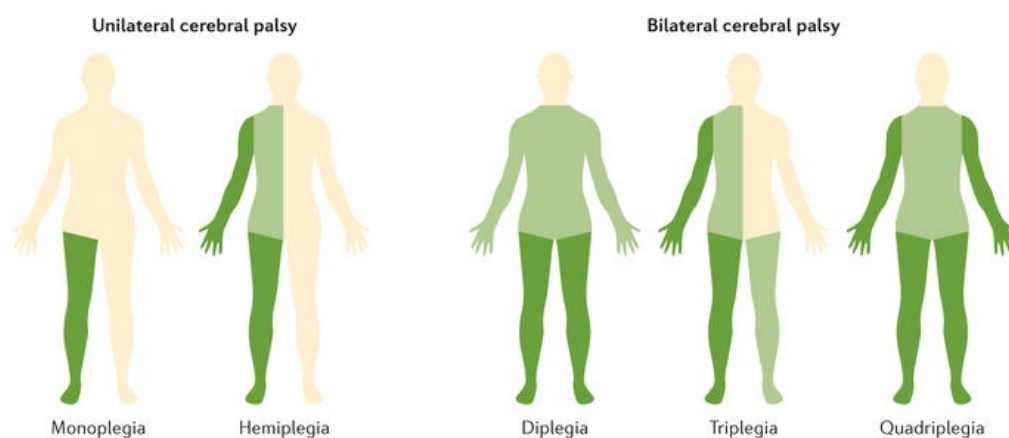
The classification of CP is commonly based on either the 1) *physiological*, 2) *topographical* or 3) *functional* components. Classification is important to determine suitable management for individuals with CP.

### Physiological classification

According to the Surveillance of Cerebral Palsy (SCPE), there are three predominant types based on the physiological classification, Spastic, Dyskinetic (which includes dystonia and choreo-athetoid) and ataxic.<sup>4,6,9</sup> The subtypes are classified by the type of movement impairment and location of the brain lesion. Spastic CP commonly presents with damage to the motor cortex, dyskinetic CP is evident in lesions at the basal ganglia and ataxic CP is consistent with damage at the cerebellum.<sup>14</sup> Cerebral lesions then coincide with damage to the body's peripheral nerves and limbs as part of the UMN syndrome.

### Topographical distribution

The topographical distribution provides a peripheral illustration of the limbs that are most affected by CP (Figure 2). In unilateral CP, one side of the body is affected, while in bilateral CP both sides are affected. Unilateral CP is referred to as monoplegia when one limb is affected (usually the lower extremity), or hemiplegia, when both the upper and lower limbs are affected (usually with the upper limb being more affected).<sup>15</sup> The presentation of bilateral CP can be divided into diplegia, in which both lower limbs are affected, triplegia in which both lower limbs and a single upper limb are affected, quadriplegia, in which all limbs are affected.<sup>15</sup>

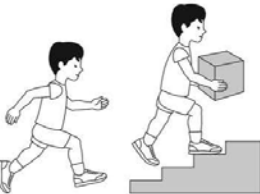

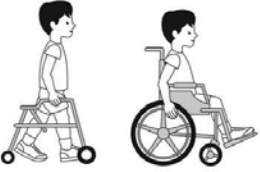




**Figure 2:** Topographical classification of Cerebral Palsy.<sup>16</sup>

## Level of gross-motor function

In addition to the physiological and topographical classifications, the Gross Motor Function Classification System (GMFCS) has widely been accepted as a tool to classify the severity of functional disability of children with CP<sup>16</sup> and has been expanded and revised for the assessment of adults and adolescents with CP (Figure 3).<sup>17,18</sup> Observations seen within the GMFCS are based on the patients' usual performance in the context of the home, school and community setting.

### GMFCS E & R Descriptors and Illustrations for Children between their 6<sup>th</sup> and 12<sup>th</sup> birthday

	<p><b>GMFCS Level I</b></p> <p>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</p>
	<p><b>GMFCS Level II</b></p> <p>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.</p>
	<p><b>GMFCS Level III</b></p> <p>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.</p>
	<p><b>GMFCS Level IV</b></p> <p>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.</p>
	<p><b>GMFCS Level V</b></p> <p>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.</p>

**Figure 3:** Overview of Gross motor function classification system (GMFCS).<sup>16</sup> Image copied from [www.canchild.ca](http://www.canchild.ca)

## **Ageing with Cerebral Palsy**

There is an increase in the survival rate of children with CP into adulthood.<sup>19,20</sup> The increased survival rate creates a compensated strain on the adult health-care system, that has prompted the emphasis of management of all markers of activities of daily living (ADL) including participating in adjusted PA.<sup>4</sup> The long-term effects of reduced PA and increased sedentary time can lead to a greater risk of developing secondary health problems, such as metabolic dysfunction, cardiovascular disease and poor bone density.<sup>13,21–24</sup> The increase in the transition from childhood into adulthood warrants the need for objectively monitored tools to be used to conduct evidence based-rehabilitation, research and practice.

## **PHYSICAL ACTIVITY**

Individuals with CP are prone to develop secondary consequences, which may include but are not limited to pain, stiffness, poor balance and fatigue.<sup>23,25,26</sup> All of these problems may lead to a further reduction in PA levels, which in turn can cause deterioration in physical functioning and a loss of mobility initiating at early adulthood.<sup>3</sup> PA contributes to the prevention of chronic disease,<sup>1,27</sup> depending on its modality, intensity and frequency. It is therefore important to monitor PA levels in adults with CP in order to maintain and/or improve PA levels and provide guidelines that are suitable for populations with physical impairments, such as CP.

### **Definition of physical activity**

PA is defined as any body movement that results in energy expenditure.<sup>1</sup> More specifically the term ‘habitual physical activity’ (HPA) has been used, which refers to the ‘pattern and magnitude of bodily movements during ADL’ and includes domains such sleep, rest, work and leisure.<sup>28</sup> In addition to measuring PA, sedentary behaviour is defined as any waking activity which involves low energy expenditure in a reclined or seated posture.<sup>1,29</sup>

### **Recommendations for physical activity**

The World health organization has recently updated PA guidelines for adults: being active for at least 30 minutes of moderate-to-vigorous intensity PA per day and that sedentary time ought to be minimized as much as possible.<sup>27</sup> Individuals with CP may be a vulnerable population who find it challenging to meet these PA guidelines, because of their limitations in physical functioning.<sup>27,28,30</sup>

### **Methods to obtain physical activity data**

Several methods are available to obtain PA levels in daily life, such as accelerometry and PA questionnaires.<sup>31</sup> The validity and accuracy of questionnaires, as reported by Troaino *et al.* (2015), is questionable as it self-reports the total duration of activity perceived by the individual and does not appropriately quantify activity-related movement.<sup>32</sup> Based on questionnaires, individuals with CP have been previously reported to be less physically active,<sup>33</sup> however the same trend has been seen in TD adults when self-reporting PA.<sup>34</sup> The reliance of self-report for PA is therefore questioned. This highlights the need for monitoring PA using quantitative measurements, like accelerometry, which can help to provide estimated goals for targeted intervention of PA in CP.

### **ACCELEROMETRY**

Accelerometers are wearable devices that are commonly used to objectively quantify, characterize and monitor PA behaviour. Previously, physical activity was recorded by using step counts, however no information could be obtained about intensity or the type of daily PA.<sup>32,35</sup> Nowadays, accelerometers are able to record accelerations in different planes (antero-posterior, medio-lateral and vertical), which allows for accurate outcome measures in individuals' PA and sedentary behaviour in terms of time, intensity and type.<sup>30,35</sup> In general, accelerometers are fairly light and recordings are non-invasive.<sup>28,36</sup>

Accelerometers may be worn around the hip, such as the *Actigraph* or the wrist, which may include the *Polar band*, *Fitbit*, *Smartband*, *Vivofit*. Hip worn devices are among the most commonly used accelerometers. The actigraph has been validated to measure PA in general populations,<sup>37</sup> as well as in individuals with CP.<sup>30</sup> Most of these hip worn devices are not water-resistant; hence it needs to be removed in cases of showering, bathing, swimming or during excessive sweating.<sup>23,38</sup> In addition, emerging research suggests that participants consider wrist worn devices to be less burdensome, which may result in higher levels of compliance.<sup>39</sup> Furthermore wrist worn devices are generally more cost-effective compared to hip worn devices, such as the Actigraph.<sup>35</sup> Therefore a recent shift toward wrist worn activity monitoring is noticeable in the literature.<sup>39,40</sup>

Using device specific software, accelerometers can be used to obtain the time that individuals partake in different levels of intensity, either classifying PA into laying, sitting, standing, walking and running, or sedentary and low, moderate and high intensities. Sedentary

behaviour has become increasingly popular to assess, since previous research has shown that there is reasonable evidence for a causal relationship between sedentary behaviour and all-cause mortality.<sup>41</sup>

### **PHYSICAL ACTIVITY LEVELS IN ADULTS WITH CEREBRAL PALSY**

Table 1 provides an overview of the literature that reports on PA levels in adults with CP, including details regarding the ages, gender, sample size, GMFCS, the period of wear-time and the outcome measures which were evaluated.

Ryan *et al* (2014) showed that adults with CP spent less time in light, moderate and vigorous PA than TD peers.<sup>13</sup> In addition, adults with CP were reported to spend 523min in sedentary behaviour, while TD adults spent about 420min of the day being sedentary. Ryan *et al* (2014) also showed that adults with CP classified in GMFCS level I, spent more time in moderate and vigorous PA compared to levels' II and III, and adults with CP classified in GMFCS level II spent more time being moderately physically active compared to level III.<sup>13</sup> These differences between GMFCS levels may evidently be explained by differences in functional mobility. Interestingly, Ryan *et al* (2014) found no difference in the time adults with CP classified in GMFCS level I spent in low, moderate and vigorous PA compared to TD peers, as well as time spent in sedentary behaviour.<sup>13</sup>

In consistence with the findings of Ryan *et al* (2014), Nieuwenhuijsen *et al* (2010) showed that GMFCS level was a strong predictor of PA levels in adults with bilateral spastic CP,<sup>38</sup> which is in accordance with previous research that included children and adolescents with CP.<sup>42</sup> Claridge *et al* (2015) showed that adults with CP classified in GMFCS levels' III-V spent significantly more time being sedentary than adults with CP classified GMFCS I and II.<sup>30</sup> These findings highlight the importance of the impact that GMFCS level has on mobility and PA.

A cross-sectional study conducted by Van der Slot *et al* (2007) reported that adults with unilateral spastic CP were as physically active as their TD peers.<sup>43</sup> In contrast, Nieuwenhuijsen *et al* (2010) reported that adults with bilateral spastic CP were less physically active than TD peers.<sup>38</sup> This difference between subtypes of spastic CP was confirmed by Ryan *et al* (2014), whom showed that adults with bilateral spastic CP spent more time in sedentary behaviour compared to adults with a unilateral spastic involvement.<sup>13</sup>

The relationship between unilateral/bilateral CP and PA and sedentary behaviour has been illustrated in Ryan *et al* (2014) in which the entire cohort consisted of 60% bilateral CP and 40% unilateral CP, more specifically a greater population of bilateral CP constituted the GMFCS III level (90%) compared the unilateral CP (10%).<sup>13</sup> These findings convey the topographical distribution of CP impairments and its relationship with PA, however this relationship has not been extensively studied in a mixed group of CP, considering the various types of CP (choreoathetoid, ataxic, dystonic) and for PA recommendations for these particular subgroups of CP.

Studies by Nieuwenhuijsen *et al* (2010) and Van der Slot *et al* (2007) reported that individuals with CP did not meet recommended PA guidelines as documented by the World Health Organization (WHO).<sup>38,43</sup> While these guidelines recommend individuals to be physically active for 150min per week, from findings reported by Ryan *et al* (2014) adults with CP are estimated to be physically active for only 46min per week.<sup>13</sup> Ryan *et al* (2014), however, showed that adults with CP classified in GMFCS I were active for a mean of 27min per day in moderate to vigorous activity, resulting in over half of their cohort with GMFCS I meeting the guidelines. While these studies highlight the deficits in PA compared to recommended guidelines, their heterogeneity in distribution do not effectively convey PA measurements across all GMFCS levels.

Nieuwenhuijsen *et al* (2010) suggested that a negative cycle of deconditioning may form as a result of inactivity leading to lower physical fitness levels. Subsequently, these lower fitness levels may then lead to further detriments in function which may lead to further inactivity.<sup>38</sup> In addition, Nieuwenhuijsen *et al* (2010) showed that in their cohort only 39% of adults with CP had one or two periods of continuous activity, with no participants involved in activity greater than 10min and the majority being involved in activity lasting 10-30secs.<sup>38</sup> Thus, being less physically active may be particularly detrimental for adults with CP who show more severe limitations in gross motor function. Furthermore, Nieuwenhuijsen *et al* (2010) highlighted that inactivity and lower fitness levels may 'negatively affect health-related quality of life (HRQOL).'<sup>38</sup>

The increased risk of developing cardiometabolic disease in adults with CP as a result of a negative physical deconditioning cycle may be associated with pain and fatigue.<sup>23,44</sup> Jahnsen *et al* (2004) reported a positive association with the lack of PA and increased pain, of which may result in further physical deterioration. McPhee *et al* (2017) documented a 'significant

negative relationship between MVPA and fatigue' and suggested that PA intensity be targeted for reducing the loss in physical functioning.<sup>23</sup> Russchen *et al* (2014) highlighted the trend in lower fatigue associated with a higher cardiopulmonary fitness.<sup>45</sup> PA may therefore improve the experience of both pain<sup>44</sup> and fatigue<sup>23</sup> which has a direct relationship to an improvement in HRQOL and participation in life situations.<sup>6</sup>

## CONCLUSION

This literature review evidently showed that adults with CP were substantially less physically active compared to TD peers and spent considerably more time in sedentary behaviour. These lower levels of PA may result in a deconditioning cycle that progresses with age. PA levels can be assessed in a variety of ways, with many studies that used hip-worn devices, while wrist-worn devices, such as the Polar Loop 2, may be more convenient to wear and therefore may improve feasibility in clinical practice. In addition, most studies focused on adults with CP in developed countries, while no studies have been conducted in developing countries. Therefore, it would be interesting to investigate the PA levels of adults with CP residing in developing countries like South Africa and to determine the validity of wrist-worn devices, the Polar Loop 2, in a population with CP.

**Table 1.** Overview of literature reporting on physical activity levels in adults with cerebral palsy

Author	Population: Age (years) Gender	Sample size	CP classification (GMFCS)	Accelerometer type	Test period	Main findings
McPhee <i>et al.</i> <sup>23</sup>	Adults: Mean=33.7 (SD12.3) Males=20, Females=21	N=41	I=5 II=9 III=10 IV=10 V=7	Actigraph GTX3 (hip-worn)	A tleast 5 hours on 4 consecutive days	-Negative relationship between MVPA and fatigue -Non-linear relationship between fatigue and GMFCS
Claridge <i>et al.</i> <sup>30</sup>	Adults: Range=18-75 Males= 21, Females=21	N=42	I=5 II=9 III=10 IV=11 V=7	Hip-worn Actigraph GT3X Wrist-worn Actigraph GT3X	-Atleast 5hours p/day -7 consecutive days	-GMFCS III-IV displayed increased sedentary time with less breaks from being sedentary regardless of cut-points used -Hip and wrist accelerometers feasible for population
Russchen <i>et al.</i> <sup>45</sup>	Adults: Mean=20.0 (SD=2.8) Males=27, Females=29	N=56	I=31 II=21 III=4	Vitamore (VM) system (3 recorders placed, at trunk and thighs)	72 hours (randomly selected, consecutive days)	-Decreased levels of PA in young adults -no relationship between fatigue and PA
Ryan <i>et al.</i> <sup>13</sup>	Adults: Mean=36.5 (SD=12.5) Males=22, Females= 19	N=41	I=13 II=18 III=10	RT3 (hip-worn)	7 consecutive days on the right hip	-Adults with CP spend less time in light, moderate and vigorous PA -Inverse relationship between GMFCS, PA and sedentary time -GMFCS I comparable to TD for PA
Nieuwenhuijsen <i>et al.</i> <sup>38</sup>	Adults: Mean=36.4 (SD=5.8) Males=35, Females= 21	N=56	I=13 II=28 III=11 IV=4 V=0	Activity Monitor (AM), hip-worn	48 hours of continuous wear, on random days of week	- Inverse relationship between PA and GMFCS in bilateral spastic CP -Personal and CP-related factors other than GMFCS not related to PA
Van de Slot <i>et al.</i> <sup>43</sup>	Adults: Mean= 28 (SD=3) Males=7, Females=9	N=16	I=16	Activity Monitor (AM), hip-worn	48 hours of continuous wear, on random days of week	-No difference in PA between CP hemiplegia and TD

Abbreviations: CP, cerebral palsy; TD, typically developed; SD, standard deviation; PA, physical activity; MVPA, moderate to vigorous physical activity.

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## **Research Manuscript**



# RESEARCH MANUSCRIPT

## Manuscript based mini-dissertation assignment

The following dissertation is prepared in line with the author guidelines for the following journal:

### Developmental Medicine & Child Neurology (DMCN)

The candidate is required to full-fill all the requirements as requested by the DMCN, which are outlined in the author's instructions (see **Appendix I**).

However, to provide a better insight into the data and improve the readability of the dissertation the **following adaptations to the DMCN author guidelines** were accepted in the dissertation manuscript:

\* details of the authors and ethics committee are not blinded in the manuscript

\* tables and graphs are inserted in the manuscript for readability purposes



# PHYSICAL ACTIVITY IN ADULTS WITH CEREBRAL PALSY; VALIDATION OF POLAR LOOP 2

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**ABSTRACT**

**AIM** To compare the physical activity (PA) status between adults with Cerebral Palsy (CP) and typically developed (TD) adults. In addition, to determine the validity of the Polar Loop 2 capturing PA in comparison to the Actigraph (wGT3X) in adults with CP and TD adults.

**METHODS** Participants wore both the Polar Loop and Actigraph for seven consecutive days. The number of steps and time participants spent sedentary and in low, moderate and high intensity PA's were recorded.

**RESULTS** A total of 46 participants were enrolled, consisted of adults with CP (n=26; median [IQR] = 34.5 [30.5-36.3] years) and TD adults (n=30; median [IQR] = 34.0 [29.8-35.2] years). Adults with CP accumulated less steps, spent more time being sedentary and spent less time in low and moderate PA intensities than TD adults. No difference in high intensity PA was observed between adults with CP and TD adults. Strong correlation was observed between the Polar Loop 2 and Actigraph for the number of steps and across all PA intensity levels.

**INTERPRETATION** Results showed that adults with CP are less physically active than TD adults, except during high intensity PA. In addition, the Polar Loop 2 showed to be a valid tool to measure PA in adults with CP and TD adults. Since the Polar Loop 2 is convenient to wear, it can be useful to measure PA in clinical practice.

## **WHAT THIS PAPER ADDS**

- Adults with cerebral palsy are less physically active than their typically developed peers, except during high intensity physical activity.
- Adults with cerebral palsy do not meet international guidelines for physical activity.
- Polar Loop 2 showed to be valid to measure physical activity in adults with cerebral palsy and typically developed adults.

## INTRODUCTION

Cerebral palsy (CP) is one of the most common causes of physical disability in childhood, with a prevalence of 1.5 to 2.5 per 1000 live births.<sup>1,2</sup> CP is described as a non-progressive lesion of the brain that occurs before, during or after delivery.<sup>3</sup> This cerebral lesion causes impairments which result in problems with movement and posture.<sup>4</sup> Although CP is a non-progressive condition, these primary motor impairments often lead to limitations in gross motor function and daily activities such as personal care and mobility.<sup>5</sup>

As a result of these limitations in daily activities, individuals with CP are prone to being or becoming less physically active, which has been shown to be associated with negative risk factors for obesity and cardio metabolic disease.<sup>6</sup> The guidelines for physical activity (PA), published by the World Health Organization (WHO), document recommendations for adults (18-64years) to be physically active for at least 150min of moderate intensity PA throughout the week, or do at least 75min of vigorous intensity PA throughout the week.<sup>7</sup> Young adults with CP, however, appeared to be less physically active than their typically developed (TD) peers,<sup>8,9</sup> indicative of not meeting PA activity guidelines. In addition, literature has shown that individuals with CP have reduced physical fitness levels.<sup>10,11</sup> The combination of reduced PA and fitness levels can lead to a sedentary lifestyle which may further deteriorate the physical status of those with CP,<sup>8</sup> and furthermore result in fatigue and a decreased health-related quality of life (HRQOL).<sup>12,13</sup> The impact of reduced PA associated with CP may therefore lead to a vicious cycle of deconditioning, and thus it is imperative for these individuals' to be physically active to improve their fitness levels and HRQOL.

In order to identify those individuals who are at risk for inactive lifestyles and secondary complications (obesity, cardio metabolic disease), it is essential to monitor PA. Troaino *et al.* (2015) reported that the validity and accuracy of self-report questionnaires only accounted for the individual's perception of their PA, therefore not appropriately quantifying PA.<sup>14</sup> Similarly, a study

with individuals with CP<sup>15</sup> and TD adults<sup>16</sup>, observed a similar trend when self-reporting PA, using questionnaires. Alternatively, PA can be measured using accelerometry. Accelerometers provide accurate measures of the type, time and intensity of PA and sedentary time,<sup>17,18</sup> and are typically worn around the waist or wrist. The Actigraph is a waist worn accelerometer, that has been used as a golden standard for PA research in TD cohorts and cohorts with CP.<sup>17,19–21</sup> The Actigraph (wGTX +BT) has been validated using double-labelled water as a criterion measure to differentiate between PA intensities in individuals with CP.<sup>19,20,22</sup> The Actigraph (wGTX + BT) is however not water resistant,<sup>13</sup> and is more expensive than wrist worn devices.<sup>18</sup> Alternatively, the Polar Loop 2 is a water resistant, wrist worn accelerometer,<sup>23</sup> which might imply a greater degree of compliance due to its comfort on the wrist and user friendly design when attaining long-term PA measurements. Accordingly, the Polar Loop 2 may be a more suitable instrument for research. However, no previous studies have validated the Polar Loop 2 in adults with CP and TD adults.

Therefore, the aim of this study was to determine differences in PA between adults with CP and TD adults, assessed with the Actigraph and Polar Loop 2 accelerometers. In addition, we aimed to determine the validity of the Polar Loop 2 compared to the Actigraph for different levels of PA.

## **METHODS**

### **Study design**

In this observational comparative study PA was obtained from adults with CP and matched TD adults. This study was approved by the Human Research Ethics Committee at the University of Cape Town, South Africa (HREC 014 2017), and was conducted in accordance with the International Declaration of Helsinki for human participation in research.<sup>1</sup>

### **Participants**

Adults with CP were eligible for inclusion if they had a medical diagnosis of CP and a Gross Motor Function Classification System (GMFCS<sup>25</sup>) level between I and V. The age limit for participants was 40 years and participants had to live within a 100km radius of Cape Town, South Africa. Participants were excluded if they had any neuromuscular or physical disorder unrelated to CP, were unable to effectively comprehend instructions and if they were unable to communicate in English or Afrikaans. TD adults that were recruited, included those that did not have a medical diagnosis of CP or any other neurological disease and adults who designated in a similar radius as adults with CP. TD adults were excluded should they not be able to comprehend instruction pertinent to the research protocol. TD adults were matched for age, gender and socio-economic status (SES).

### **Procedure and data collection**

During the first visit, participants were addressed on the study purpose and testing requirements. After agreeing to participate, they signed the informed consent. Participants' date of birth was noted and height and weight were obtained. The SES was estimated based on housing density, by dividing the number of residents in the house by the number of rooms in the house, excluding the bathroom and kitchen. The SES was categorised into low (score > 1.5), middle (1-1.5) or high (score < 1)

SES.<sup>26</sup>

### **Physical activity**

PA levels were obtained using the hip-worn Actigraph (wGT3X + BT) and wrist-worn Polar Loop 2, which were worn at the same time continuously for seven consecutive days and followed similar instructions regarding the removal and protection of the two accelerometers.

The Actigraph (Actigraph Inc., Pensacola, Florida, USA, mass: 19grams dimensions: 4.6 x 3.3 x 1.5cm; **Figure 1a**) was positioned anteromedially to the non-dominant hip.<sup>17,27,28</sup> Since the Actigraph is not water resistant, participants were asked to remove the Actigraph prior to bathing, showering or swimming, and to wear to it over the clothes in case of excessive sweating. The Actigraph measured the magnitude of movement triaxially, with a sampling frequency of 50Hz. Using ActiLife software, accelerations were digitally filtered to eliminate non-human motion and subsequently a composite vector magnitude was computed from the three axes. In the current study, data was reported as counts per 30 seconds. Cut-off points (Actilife software: Troiano) were used to generate the following outcome measures: total number of daily steps and time (minutes) spent during laying and sitting (defined as sedentary), standing (low intensity), walking (moderate intensity) and running (high intensity). The Actigraph was able to differentiate between different intensities of walking and has excellent classification accuracy for moderate intensity PA.<sup>19,20,22</sup>

The Polar Loop 2 (Polar Electro Ltd., Kempele, Finland: mass: 38grams; dimensions: 1.1 x 1.0; **Figure 1b**) was worn around the non-dominant wrist consecutively. Black tape was placed on the Polar Loop 2 display to prevent feedback to the participant during data collection. Using the PolarFlow software the following outcome measures were extracted: total number of daily steps and time (minutes) spent during, sedentary, low, moderate and high intensities. Related Polar devices have been used in previous research,<sup>27,28</sup> the Polar Loop 2 has not been validated yet.



**Figure 1:** a) Accelerometer Actigraph GT3X



**Figure 1:** b) Accelerometer Polar Loop 2

### Statistical analysis

Descriptive statistics were used to summarize the demographic characteristics of the participants. The Shapiro-Wilk test was used to determine whether the data was normally distributed. Data showed to be non-normally distributed and were therefore presented as median and interquartile ranges (IQR). In addition, differences in the daily step count and time spent sedentary, and in low, moderate and high intensity PA (for the Actigraph and the Polar Loop 2) were investigated using Mann-Whitney U tests.

Interclass correlation coefficient (ICC) was calculated (absolute agreement, two-way random, single measure with 95% confidence agreement) to examine agreement between time periods per day and step counts derived from the Polar Loop 2 and Actigraph. The following classification was used: ICC below 0.50 was considered a poor correlation, 0.50 to 0.75 was considered moderate, 0.75 to 0.90 was considered strong and 0.90 or higher was considered an excellent correlation.<sup>14</sup> Finally, Bland-Altman plots were created to evaluate the mean bias and the limits of agreement between the devices. All statistical analyses will be performed using IBM SPSS (version 25.0; IBM Armonk, NY, USA) with a significance level of  $\alpha \leq 0.05$ .



## RESULTS

### Participants

Twenty-eight adults with CP participated in current study, of which two participants had incomplete data sets and were excluded for further analyses. The twenty-six adults with CP who were included matched with thirty TD adults for gender, age, BMI (Body Mass Index) and SES (**Table 1**). Six adults with CP were classified as GMFCS I (23%), six as GMFCS II (23%), eight as GMFCS III (30%), three as GMFCS IV (12%) and three as GMFCS V (12%). Four adults with CP were diagnosed with spastic hemiplegia (15%), seventeen with spastic diplegia (65%), two with spastic quadriplegia (8%), two with ataxic (8%) and one with athetoid (4%).

**Table 1.** Participants' characteristics of adults with CP (n=26) and TD adults (n=30)

Variable	Adults with CP	TD adults	t/ $\chi$	p
	n (%) / median [IQR]	n (%) / median [IQR]		
Gender, m/f n (%)	10 (38%) / 16 (62%)	10 (33%) / 20 (67%)	0.335	0.563
Age (years)	34.5 [30.5 – 36.3]	34.0 [29.8 – 35.2]	387.5	0.780
BMI ( $kg/m^2$ )	26.6 [22.2 – 35.4]	28.1 [22.9 – 32.9]	396.5	0.892
SES	1.2 [0.8 – 1.7]	1.3 [1.0 – 1.7]	388.0	0.783

Abbreviations: IQR, interquartile range; SES, socio-economic status; BMI, Body Mass Index; and GMFCS, Gross Motor Function Classification System.

### Levels of activity

As a total, 155 valid days were recorded in adults with CP and 187 valid days in TD adults and included in the analyses. The mean number of valid days recorded was 6.0 days per adult with CP and 6.2 days per TD adult.

The total number of steps and the time participants spent in different physical intensity levels

assessed with the Actigraph and Polar Loop 2 are presented in **Table 2**. The number of steps per day in adults with CP was significantly lower than in adults with TD ( $p<0.001$ ). Adults with CP spent more time sedentary ( $p<0.001$ ), while TD adults spent more time in low ( $p<0.001$ ) and moderate ( $p<0.001$ ) intensity. No difference was observed between TD adults and adults with CP in time spent in high intensity.

**Table 2.** Outcomes of accelerometers for adults with CP (n=26) and TD adults (n=30)

Variable	Adults with CP median [IQR]	TD adults median [IQR]	U	p
<b>Actigraph</b>				
Steps (number/day)	3047 [1059 – 6854]	7848 [5863 – 12852]	136.0	<0.001
<b>Intensity (min/day)</b>				
Sedentary time	1208 [1130 – 1311]	1055 [1021 – 1098]	117.0	<0.001
Low intensity	210 [100 – 284]	356 [319 – 399]	83.0	<0.001
Moderate intensity	5 [2 – 30]	22 [9 – 38]	252.0	0.023
High intensity	0 [0 – 1]	0 [0 – 3]	349.5	0.486
<b>Polar Loop 2</b>				
Steps (number/day)	4568 [1444 – 7720]	9318 [8239 – 11717]	158	<0.001
<b>Intensity (min/day)</b>				
Sedentary time	1244 [1121 – 1320]	1050 [991 – 1120]	116	<0.001
Low intensity	162 [99 – 243]	329 [265 – 392]	105	<0.001
Moderate intensity	13 [0 – 29]	24 [16 – 42]	242	0.009
High intensity	0 [0 – 2]	1 [0 – 5]	318.5	0.151

Abbreviations: IQR, interquartile range.

## Agreement between Actigraph and Polar Loop 2

ICC showed excellent agreement for number of steps recorded by the Actigraph and Polar Loop 2 for both adults with CP and TD adults (**Table 3**). In addition, time spent in low, moderate and high intensity showed an excellent agreement for adults with CP, while only high intensity was excellent for TD adults. Time spent sedentary showed a good agreement between the Actigraph and Polar Loop 2 for both adults with CP and TD adults, as well as time spent in low and moderate intensity for TD adults.

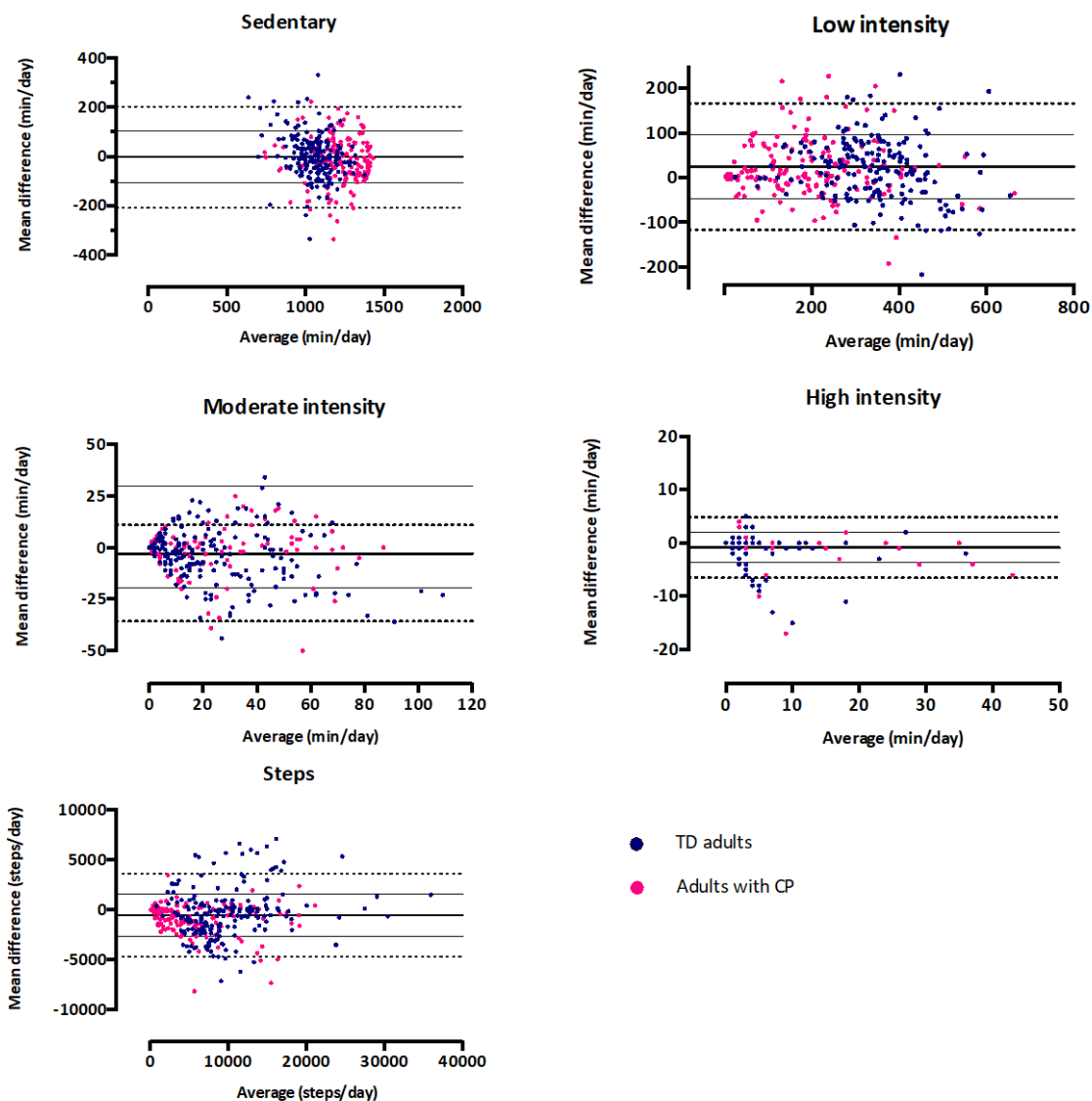
**Table 3.** Intraclass correlation coefficient (ICC) between Actigraph and Polar Loop 2 at different intensity levels for adults with CP and TD adults.

Parameter	Adults with CP	TD adults
	ICC [95%CI]	ICC [95%CI]
Steps	0.95 [0.93 – 0.96]	0.97 [0.94 – 0.98]
Intensity		
Sedentary	0.88 [0.83 – 0.91]	0.83 [0.77 – 0.87]
Low intensity	0.92 [0.88 – 0.95]	0.87 [0.81 – 0.91]
Moderate intensity	0.93 [0.91 – 0.95]	0.82 [0.75 – 0.86]
High intensity	0.96 [0.94 – 0.97]	0.97 [0.96 – 0.98]

Abbreviations: ICC, intraclass correlation coefficient; 95%CI, 95% confidence interval.

Bland-Altman plots presented in **Figure 1** illustrate the agreement between the Actigraph and Polar Loop 2 in estimating steps and time spent on different activity levels. The mean difference (Actigraph – Polar Loop 2) between the numbers of steps recorded was -536, indicating that on average the Polar Loop 2 recorded a lower number of steps. In 79% of the cases the value fell within  $\pm 1.00 \times \text{SD}$  and 93% fell within  $\pm 1.96 \times \text{SD}$ , showing acceptable agreement between the two accelerometers. Similar results were observed for the different levels of intensity, showing

mean differences of -3min for sedentary, 24min for low intensity, -3min for moderate intensity and -1min for high intensity. The highest agreement was observed for the time spent in high intensity, showing that 91% of the cases fell within  $\pm 1.00 \times \text{SD}$  and 96% fell within  $\pm 1.96 \times \text{SD}$ , whereas the lowest agreement was observed for time spent in low intensity, in which 77% of the cases fell within  $\pm 1.00 \times \text{SD}$  and 94% fell within  $\pm 1.96 \times \text{SD}$ .



**Figure 1.** Bland-Altman plots showing mean difference between Actigraph and Polar Loop 2 (thick line),  $\pm 1.00 \times \text{SD}$  (thin lines) and  $\pm 1.96 \times \text{SD}$  (dashed thin lines) for adults with CP and TD adults.

## DISCUSSION

The main finding of this study was that adults with CP were less physically active than TD adults. In addition, the Polar Loop 2 was found to be a valid measure for PA in adults with CP and TD adults. Adults with CP and TD adults included in the study were matched for gender, age, BMI and SES.

According to the results of the current study it was found that adults with CP were less physically active than TD adults, based on the reduced number of steps taken per day, more time spent sedentary and less time spent in low and moderate intensity PA. On average, adults with CP spent 86% of the day being sedentary, whereas TD adults spent 73% of the day sedentary. These relatively long periods of sedentary behaviour of adults with CP can be explained by the limitations that adults with CP have in movement and posture. In this study, a large proportion of adults with CP was dependent on walking aids or a wheelchair (GMFCS III-V), which makes it challenging for these adults to adhere to WHO guidelines given their limitations in physical functioning.<sup>9,17,29</sup>

The current findings are supported by Ryan *et al.* (2014), who found that adults with CP spent more time being sedentary and spent less time in light and moderate PA.<sup>30</sup> The study by Claridge *et al.* (2015) further emphasized that sedentary time was associated with GMFCS levels, indicating that adults with CP classified in GMFCS levels III-V spent more time being sedentary.<sup>17</sup> In contrast, Van de Slot *et al.* (2007) found no differences in PA between adults with CP and TD adults. However, in that study only ambulant adults with CP and spastic hemiplegic adults were included, who showed minor physical impairments and spent on average 2hours and 32min per day in dynamic activities (i.e. walking, cycling, general movements). Unfortunately, the study of van der Slot *et al.* (2007) did not provide information about GMFCS levels.<sup>31</sup> The majority of adults with CP in the current study did show physical impairments, i.e. 54% of adults with CP were classified in GMFCS III-V, which potentially caused the limited time spent in moderate to high intensity

physical activity of adults with CP 9 mins (0-30 mins) compared to TD adults 23 min (9-42 mins). Although adults with CP did not meet the recommended WHO guidelines for physical activity, TD adults included in current study had also failed to meet the guidelines. This is highlighted by the finding that, on average, adults with CP and TD adults did not show any difference in high intensity PA. The limited PA of TD adults could be caused by lower SES compared to previous studies, which were predominantly conducted in developed countries,<sup>30,31</sup> implying a possibly decreased access to established health-care facilities. This is in contrast to the study by Ryan *et al.* (2014), who found that adults with CP, spent 5.2 min per day in high intensity PA.<sup>30</sup> An explanation for the observed differences might be that Ryan *et al.* (2014) included adults with CP who were classified in GMFCS levels I-III, while a heterogeneous cohort of adults with CP classified in GMFCS levels I-V were included in the current study.

The substantially reduced PA levels in adults with CP compared to TD adults highlight the importance that PA should be addressed in rehabilitation or physical therapy. From previous research among younger individuals with CP and adults with CP (unpublished), it is known that energy cost during walking is higher compared to TD peers. Training is therefore beneficial in two-fold – it may increase the individual's maximum functional capacity, thereby reducing the relative load, and it reduces the risk of metabolic diseases, pain and fatigue.

Agreement between the Actigraph and the Polar Loop 2 was presented in this study to investigate the validity of the Polar Loop 2, in both adults with CP and TD adults. The ICC, between the two accelerometers showed that the Polar Loop 2 had a strong correlation with the Actigraph for the number of steps and across all PA intensity levels. Upon closer observation, the strongest correlates between the devices were found for the number of steps and in high intensity PA for both adults with CP and TD adults. In contrast, Leinonen *et al.* (2017), who investigated the validity of a different Polar device (Polar Active), found considerably lower ICC values when comparing it to

outcomes of the Actigraph, ranging from 0.078 for MVPA to 0.309 for sedentary time.<sup>28</sup> The large differences in outcomes could be explained by the different Polar devices, i.e. the Polar Loop 2 versus the Polar Active. In addition, a larger cohort was included in the current study, which may have increased the accuracy.

The ICC results of the current study suggest that the Polar Loop 2 is a valid tool for assessing PA in both adults with CP and TD adults. In addition, Bland-Altman plots showed that the mean difference in the number of steps recorded and the times spent in different PA levels between the Actigraph and Polar Loop 2 is limited. However, the Bland-Altman plots also indicate that there is still a considerable variation between two devices for both adults with CP and TD adults, particularly in the time spent in low intensity PA (**Figure 1**). This finding indicates that in certain cases the Polar loop overestimated and in other cases underestimated the time spent in low intensity PA. The fact that this applies for both adults with CP and TD adults suggests that the variation between the Actigraph and Polar Loop 2 is not caused by the disabilities of adults with CP, for example in case individuals were wheelchair bound. Therefore, although the result of the current study suggests that the Polar Loop 2 is a valid tool for measuring PA in adult with CP and TD adults, it ought to be noted that variations in outcomes exist with the Polar Loop 2. Hence, ascertaining the need for further research with a heterogeneous cohort of adults with CP and a larger sample size in various GMFCS levels.

### **Limitations**

Importantly, the relatively small sample size acts as a limitation. A larger sample size would enable distinguishing between GMFCS levels (e.g. wheelchair bound compared to ambulatory adults with CP), which may have an influence on validity. Therefore, future research could include a large matched sample size inclusive of GMFCS I-V, to confirm validity in subgroups using the Polar Loop 2 in an adult population.

**Conclusion**

In summary, this study showed that adults with CP were less physically active than TD adults, based on findings that the number of steps taken per day were substantially lower, they spent more time being sedentary and less time in low and moderate intensity PA. The Polar Loop 2 showed to be a valid measure for PA in adults with CP and TD adults. The Polar Loop 2 is water-resistant and convenient to wear, thus it can a useful tool to measure PA in clinical practice.

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## **APPENDIX I**

Author guidelines - Developmental Medicine & Child Neurology





## Author Guidelines

### *Developmental Medicine & Child Neurology*

Updated July 2019

All papers should be submitted online at <http://mc.manuscriptcentral.com/dmcn>. Please email the editorial office with any queries about the process ([dmcn@editorialoffice.co.uk](mailto:dmcn@editorialoffice.co.uk)).

Papers published in *Developmental Medicine & Child Neurology* (DMCN) are freely available online from 12 months after publication. Authors who wish to make their papers freely accessible immediately upon publication may use Wiley's pay-to-publish service, **OnlineOpen**. (See 2 Copyright below).

#### **Note to NIH Grantees**

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In order to be eligible for submission to the next REF, DMCN is compliant with the REF Open Access policy which states authors' outputs must be deposited in an institutional or subject repository after an embargo period of 12 months. For further information about the policy, see

[http://www.hefce.ac.uk/media/HEFCE,2014/Content/Pubs/2014/201407/HEFCE2014\\_04\\_07updated%2](http://www.hefce.ac.uk/media/HEFCE,2014/Content/Pubs/2014/201407/HEFCE2014_04_07updated%2)

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## 1. Good publication practice

The journal follows the guidelines of the International Committee of Medical Journal Editors ([www.icmje.org](http://www.icmje.org)) and Wiley's Best Practice Guidelines on Publication Ethics ([www.wiley.com/bw/publicationethics/](http://www.wiley.com/bw/publicationethics/)). In particular, please note the following points.

### a) Authorship

Our criteria for authorship are based on the International Committee of Medical Journal Editors guidelines. More information can be found here: [www.icmje.org](http://www.icmje.org)

Credit for authorship should be based on:

1. substantial contributions to research design, or the acquisition, analysis or interpretation of data;
2. drafting the paper or revising it critically;
3. approval of the submitted and final versions.

The corresponding author must state that all the authors have read the manuscript and agreed to its being submitted for publication. The covering letter should state that all individuals listed as authors meet the appropriate authorship criteria, that nobody who qualifies for authorship has been omitted from the list, that contributors and their funding sources have been properly acknowledged, and that authors and contributors have approved the acknowledgement of their contributions. The covering letter should include a short description of each author's contribution and should state whether he or she had complete access to the study data that support the publication.

Up to ten authors may be included on the title page. When there are more than ten authors, nine may be included on the title page and the tenth slot given to an appropriately named group; the members of this group will be listed in an appendix published online only. The authors listed in the study group will still be recognised as collaborators of the paper in search engines such as PubMed.

Contributors who do not qualify as authors should be listed, and their contribution described, in an acknowledgement section at the end of the article.

### **b) Reporting guidelines:**

For **all** Original Articles, Systematic Reviews, and Meta-analyses, the Editors and Editorial Board require that authors follow the guidelines of the Equator network when reporting research methods and findings (<http://www.equator-network.org/library/>).

We strongly recommend the authors conduct all original research, Systematic Reviews, and Scoping Reviews, based on an appropriate pre-established protocol.

Submissions must be accompanied by the appropriate checklist, fully completed with page numbers where applicable. Please select the most suitable checklist from the following and download the appropriate checklist:

- **Observational studies (i.e. most Original Articles): STROBE guidelines**
- **Systematic Reviews or Meta-analyses: PRISMA checklist** (for all systematic reviews) and **AMSTAR-2 checklist** (for all systematic reviews of interventions)
- **Scoping reviews: PRISMA-ScR**
- **Randomized controlled trials: CONSORT guidelines**
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### **c) Registration of clinical trials, systematic reviews, and scoping reviews**

If publishing the results of a clinical trial or systematic review, please include the clinical trial registration number. All trials should be registered in a publicly accessible database such as [PROSPERO](#), [ClinicalTrials.gov](#), [ICMJE](#),

and [WHO](#). Scoping reviews should be registered in a publicly accessible database such as the Joanna Briggs Institute. [Scoping Reviews in the Joanna Briggs Institute Reviewer's Manual](#).

Please upload a copy of the trial protocol as a supplementary file.

#### d) Duplicate or related submission

Authors should declare that the submitted work and its essential substance have not previously been published and are not being considered for publication elsewhere. Manuscripts must not be submitted simultaneously to another journal. All suspected cases of multiple submissions or redundant publication will be subject to investigation.

If other aspects of the same study were reported previously, are in press, or currently submitted elsewhere, this must be clearly indicated in the Methods section, with full referencing.

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##### Consent

Please indicate in the text that patients or their carers have given informed consent to the research and to publication of the results.

If recognizable photographs or verbal descriptions of an individual are used in an article, written consent from the appropriate person(s) for publication must be submitted to, and kept by, the author. *All* case series and clinical photographs require consent. Names, initials, or any other means of identification should not be shown on any photograph. Please use the Consent Form available from the DMCN submission site (Click [here](#)).

#### f) Disclosures and funding

Disclosures of interest **must** be made during the online submission process for authors and during the review process for referees. During the online submission process, you will need to clarify the involvement of any funder in study design, data collection and analysis, and manuscript preparation. It is mandatory that a DMCN Disclosure Form is completed when your paper is submitted, and your paper will not be sent for review until we have received your form. ALL authors must sign the DMCN Disclosure Form before their paper will be published. The form

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## 3. Presentation and formatting of your paper

### a) Maximum length requirements

Article type	Abstract	"What this paper adds"	Text words	References	Figures/tables	Protocol recommended
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**(excl refs)**

Original article	Structured, 200 words	1 to 5 points	3000	30	4	Recommended
Systematic review	Structured, 200 words	1 to 5 points	— As appropriate —			Required
Scoping review	Structured, 200 words	1 to 5 points	— As appropriate —			Required
Invited review	Unstructured, 150 words	1 to 2 points	3000	30	4	Required
Clinical practice guidelines	Unstructured, 150 words	1 to 5 points	3000	30	4	No
Case series	Unstructured, 150 words	1 to 2 points	1500	15	2	No
Letter to the Editor	None	None	600	5	1	No
Editorial, commentary, opinion	None	None	600	5	0	No

**b) All papers**

**Title page** Include the title of the paper, authors' full names, main appointments and primary affiliations, and word count. Identify the corresponding author and give his or her postal address, and e-mail address.

We encourage corresponding authors to provide an ORCID (Open Researcher and Contributor ID) identifier. ORCID is a registry that provides researchers with a unique digital identifier. Some funding agencies recommend or even require the inclusion of the ORCID in all published articles, and authors should consult their funding agency guidelines for details. Registration is easy and free (for further information, see <http://orcid.org/>).

**Abstract** On the second page of original articles and systematic reviews, provide a full structured abstract of no more than 200 words, with the following headings: Aim; Method, Results, Interpretation. The abstract should use plain language, as it will be available openly—that is, independent of the main paper. The Aim section should focus exclusively on the objective of the paper. Where relevant the Method section should follow Equator guidelines (<http://www.equator-network.org/>), and should include means (SD) or medians and sample size, and sex for study and control groups, definition of clinical characteristics, entry criteria for study, assessments used, duration and frequency of intervention, and timing of outcome assessments. Where relevant Results should follow Equator guidelines and should summarize significant results with statistical values, including negative findings if related to the study hypothesis. Non-significant trends should not be noted in the abstract. In the Interpretation, authors should consider addressing what their findings add to the understanding of the topic.

Non-systematic reviews and case series should have a non-structured abstract without headings of up to 150 words, covering the aims, method, results, and conclusions of the study.

On the abstract page, also provide a shortened form of the title (up to six words) for use as a running footer.

**‘What this paper adds’** All original articles and systematic reviews should have a section ‘What this paper adds’ after the abstract. This should comprise up to five bullet points up to 12 words. Other articles should have one or two similar bullet points.

The bullet points should contain only new results offered by the paper (i.e. not the paper’s design or implications), presented in a direct way. They should be succinct, and preferably they should use plain language because the ‘What this paper adds’ section will be openly accessible (that is, free to view by anyone).

**General** Include tables and figure legends in your main article file, after the references. Submit figures (illustrations) as separate files, as described below. Name all files using the surname of the first author (e.g. Smith.doc, Smith fig1.tif, etc.).

**Common Data Elements** We encourage the authors of papers relating to research on cerebral palsy to use the Common Data Elements suggested by the National Institute of Neurological Disorders and Stroke and American Academy for Cerebral Palsy and Developmental Medicine (<https://onlinelibrary.wiley.com/doi/10.1111/dmcn.13723>).

### c) Original articles

Articles should comprise an introductory section (but not headed ‘Introduction’), followed by ‘Method’ (with optional subheadings, such as ‘Participants’ (rather than ‘Subjects’) and ‘Statistical analysis’), ‘Results’, and ‘Discussion’ sections. The Discussion section should include the limitations of the study. Subheadings should otherwise be kept to a minimum.

Authors are encouraged to submit video material supporting their papers, where appropriate, for publication in the Journal.

Papers longer than 3000 words, such as those reporting randomized controlled trials, may be published at the Editors’ discretion.

Randomized controlled trials should include a short trial protocol as supplementary information.

We encourage the inclusion of a graphical abstract which captures the content of the article for readers at a single glance.

### d) Reviews

We publish three types of review. Please refer to the ‘Reporting guidelines’ section for reporting guidelines and protocol registration.

1. **Systematic review:** a type of research synthesis of quantitative evidence that uses pre-defined, explicit, systematic methods selected to minimize bias and provide reliable findings on which to make decisions. A systematic review answers a precise, pre-stated question based on the PICO/PICOT (Population, Intervention, Comparator, Outcome [and Treatment]) elements. Quality assessment of the evidence both within the review and across the included studies is essential in order to analyse the risks of bias and gauge the degree of confidence that can be had in its conclusions.

We publish three types of review. Please refer to the 'Reporting guidelines' section for reporting guidelines and protocol registration.

A systematic review must be carried out following a pre-established protocol that is registered on a public registry, such as:

- [PRISMA-P](#)

We require the use of an appropriate quality appraisal tool, such as:

- [Critical Appraisal Skills Programme \(CASP\) relevant checklist\(s\)](#).

- [Joanna Briggs Institute \(JBI\) relevant tool\(s\)](#).

- [Grading of Recommendations Assessment, Development and Evaluation \(GRADE\)](#).

Should quality of included articles be felt to be sufficient, then a protocol for defining levels of evidence should be followed, such as:

- [Centre for Evidence-Based Medicine \(CEBM\) levels of evidence](#)

We require the inclusion of a graphical abstract which captures the content of the article for readers at a single glance.

2. **Scoping review:** similar to the systematic review in terms of systematic approach, rigor, and transparency but with a broader, preliminary approach. The goal is to 'scope out' available evidence in emerging clinical areas and the research question is less precise than that of a systematic review. The results of the review are charted to give an overview of the current state of research as well as to identify gaps in the evidence to guide future research. Quality assessment of the evidence is encouraged, in order to most effectively identify gaps in the existing body of evidence. We require the inclusion of an evidence map which visually identifies gaps in knowledge and/or future research needs, capturing the content of the article for readers at a single glance.

For more information authors are advised to read the chapter on Scoping Reviews in the [Joanna Briggs Institute Reviewer's Manual](#).

3. **Review:** a narrative review providing the reader with up-to-date information about the subject in question in a relatively brief format, referring to significant papers but not forming a systematic overview of the literature.

Authors are advised to refer to the paper by [Grant et al: A Typography of Reviews](#) published in *Health Information and Libraries Journal*, 2009, 26:2, before submitting a review paper to DMCN.

### e) Clinical practice guides

Clinical practice guides are developed to assist practitioners with appropriate health care and informed decision making for specific clinical circumstances. If appropriate they should include relevant clues to diagnosis, including differential diagnosis, and management. Photo and video illustrations are welcome. Some of the information can be synthesized in tables and algorithm.

### f) Case series

DMCN accepts a very limited number of case series (not single case reports). These should significantly add to our understanding of a condition or present a novel finding. They should comprise an introductory section as above, followed by the 'Case Report', then a 'Discussion' section.

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Letters are published at the Editors' discretion. They may comment on a published paper, or raise issues that are new to DMCN. In the case of letters commenting on a published paper, usually the author of that paper will be invited to comment on the letter, with both letter and comments being published in the same issue. The editor may suggest the letter is made available online on the Mac Keith Press website, without formal publication, to encourage debate (see <http://www.mackeith.co.uk/journal/letters-to-the-editor/>).

### h) References

The Vancouver style is used, as recommended by the International Committee of Medical Journal Editors. Cite using a superscript number in the text, with a numerical list of references at the end of the paper presented in order of citation. Cite only peer-reviewed, published material. The journal does not recognize abstracts or submitted (as opposed to accepted, or 'forthcoming') papers as proper citations; such material should not be listed with the references but cited only in text, followed by '(personal communication)'.

List all authors unless more than six, in which case list the first three followed by 'et al.', using Index Medicus abbreviations for journal names (see [www.nlm.nih.gov/tsd/serials/lji.html](http://www.nlm.nih.gov/tsd/serials/lji.html)). Order and punctuate bibliographic information as follows, omitting issue month and number unless needed to distinguish issues. For additional citation formats, adapt appropriate examples from the NLM's *Citing Medicine* ([www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=citmed](http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=citmed)).

#### Journal Article

Abrams RA, Tsai AM, Watson B, Jamali A, Lieber RL. Skeletal muscle recovery after tenotomy and 7-day delayed muscle length restoration. *Muscle Nerve* 2003; **23**: 707–14.

Auvin S, Joriot-Chekaf S, Cuvellier JC, Vallée C. Familial alternating hemiplegia of childhood or channelopathy? [letter]. *Dev Med Child Neurol* 2004; **46**: 500.

#### Journal Article, online only

High PC; the Committee on Early Childhood, Adoption, and Dependent Care and Council on School Health. School readiness. *Pediatrics* 2008; **121**: e1008–15.

**Journal Article, e-pub/online early**

Forsyth R, Basu AP. The change we want to see: the promotion of recovery after acquired brain injury. *Dev Med Child Neurol* 2014 Sep 8. doi: 10.1111/dmcn.12575. [Epub ahead of print].

**Book, whole**

Mesibov GB, Kuncle L, Schopler E. Asperger syndrome or high functioning autism? Current issues in autism. New York: Plenum Press, 1998.

**Book, chapter**

Finnegan LP, Kaltenbach K. Neonatal abstinence syndrome. In: Hoekelman RA, Nelson NM, editors. Primary pediatric care. 2nd edition. St. Louis: Mosby Yearbook, Inc., 1992: 1367–78.

For references to online sources, supply the author names, full title, and full URL including the date on which the site was accessed.

**i) Figures and tables**

*Note that the Editors may decide that large figures or tables should be published online-only.*

**Tables, figure legends and short appendices** Set out on separate pages at the end of (and as part of) the main document, after the references.

**Tables and appendices to be published online only** Present as separate files in Microsoft Word or Rich Text format.

**Figures** (e.g. illustrations, charts and photographs) Present electronically as separate files (not in the main text of the article). Guidelines about acceptable file formats and illustration preparation are provided at [authorservices.wiley.com/bauthor/illustration.asp](http://authorservices.wiley.com/bauthor/illustration.asp).

Please label radiographs, CT, or MRI scans with left [L] and right [R], and if appropriate with anterior [A] and posterior [P]. Areas of interest should be marked with an arrow. For EEGs please indicate the gain, timescale, and lead position.

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### **j) Statistical reporting**

The Editors advise reading “Statistical recommendations for papers submitted to *Developmental Medicine & Child Neurology*” (**Rigby AS, Dev Med Child Neurol 2010; 52: 299–304**) for guidelines on appropriate use and reporting of statistical analyses. Authors are recommended to work with a statistician where appropriate.

### **k) Supporting information (supplementary material)**

DMCN publishes online supporting information (including audio and video files, data sets, additional images, and large appendices) that cannot be included in the print version of an article. This material should be relevant to and supportive of the parent article. For guidelines see [authorservices.wiley.com/bauthor/suppmat.asp](http://authorservices.wiley.com/bauthor/suppmat.asp).

Authors are encouraged to submit video material to support their papers (e.g. to demonstrate techniques or methods, or to demonstrate a randomized controlled trial protocol).

## **4. Selection and publication**

### **a) Editorial review**

Submissions are subjected to an editorial discussion about their general suitability for the journal. This may lead to the decision to not accept the paper, or to send for review by at least two independent referees. During the submission process, authors have the opportunity to suggest up to three suitable independent referees (with their contact details), but the choice of referee rests with the Editors. At a later stage in the review process, papers with statistical analyses undergo specific statistical review.

Editors and editorial board members are not involved in editorial processes or decisions about their own work.

Reviewers are asked to disclose potential conflicts of interest when they are invited to review a paper and when they submit their review.

Papers thought to have immediate, clinically important consequences may be considered for fast-track publication. The decision to prioritize remains with the Editors.

### **b) After acceptance**

After acceptance, authors will be able to track the progress of their article through production to publication by registering for Author Services with Wiley. Authors will be sent information about how to register for Author Services once their article has been accepted.

When an accepted paper has been copy-edited and proofed authors will receive a PDF proof. When this has been approved by the authors and the paper is ready for publication, it will normally be posted online in the journal's 'EarlyView' section before allocation to an issue. EarlyView articles are in their final form and are fully published and citable.

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### **c) After publication**

Authors are encouraged to promote their articles, for example, through social media.

If errors affecting the interpretation of data or information are discovered after publication, an erratum will be published in the next available issue of the journal and published online.

## **5. Style points**

**Jargon** Avoid it strenuously. The journal aims to communicate across disciplines, and many of its readers do not have English as their first language, so plain language is preferred. The Editors may clarify and shorten manuscripts accepted for publication as necessary.

**Abbreviations** These should be kept to a minimum and restricted to those that are generally recognised. They must be spelled out in full on first usage in text and again in figure captions and table footnotes. They should be avoided in titles, headings and subheadings.

**Participant details** Give mean (SD) age in years and months (not decimal years) and gender (*n*, not %). Ensure this information is included in the abstract. In the text, indicate where study and comparison groups are from and how participants were selected.





**Measurements** Use SI units, except for blood pressure (mmHg); convert imperial units to metric. Do not use percentages for sample sizes below 50; use the symbol '%' in tables. Show standard deviations as (SD), not  $\pm$ . Abbreviate probability with a lower case italicized *p*, and provide to 3 decimal places when possible.

**Numbers** In general, use numerals, but spell out numbers at the beginning of sentences. Spell out numbers ‘one’ to ‘nine’ if they refer to nouns that are not units of measurement, e.g. ‘The results from four children confirm the findings’. For ages and time periods, use years, months, weeks and days, not decimals (e.g. 5 years 3 months, not 5.25 years).

**Equipment and drugs** Include (in parentheses) the name of the manufacturer, the city, and country of production.

**Terminology** We favour person-first language eg ‘individuals with cerebral palsy’. We no longer use ‘mental retardation’, but rather ‘intellectual disability’ for example. Rather than ‘normal children’ etc, we use ‘typically developing’, ‘population norms’, etc. We also avoid the term ‘race’, which has no scientific basis for divisions into biologically determined groups and is a poor proxy for better defined socio-demographic or genetic categories. Instead, use predefined population categories or ‘ethnic group’.

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## **APPENDIX II**

Ethics approval





**FHS016: Annual Progress Report / Renewal**

<b>HREC office use only (FWA00001637; IRB00001938)</b>			
<b>This serves as notification of annual approval, including any documentation described below.</b>			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30.04.2020
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC	Signature Removed	Date Signed	3/4/2019

Comments to PI from the HREC

**Principal Investigator to complete the following:**

**1. Protocol information**

Date (when submitting this form)	2 April 2019		
HREC REF Number	014 2017	Current Ethics Approval was granted until	30 April 2019
Protocol title	The status and challenges of transition from adolescence into adulthood with Cerebral Palsy living in Cape Town, South Africa		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
If yes, could you please provide the HREC Ref's for all sub-studies? <b>Note:</b> A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Dr Nelleke G. Langerak		
Department / Office Internal Mail Address	<a href="mailto:Nelleke.langerak@uct.ac.za">Nelleke.langerak@uct.ac.za</a>		

1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
--	------------------------------	--



## **APPENDIX III**

Turn it in report



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- 1 Ryan, Jennifer M., Vivion E. Crowley, Owen Hensey, Julie M. Broderick, Ailish McGahey, and John Gormley. "Habitual physical activity and cardiometabolic risk factors in adults with cerebral palsy", *Research in Developmental Disabilities*, 2014.  
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