



# A study protocol to develop the domains of an observational well-being scale (WEBS) for non-verbal children and young people with cerebral palsy from using the Innowalk.



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## Introduction and Background

Cerebral palsy (CP) is a group of permanent disorders of the development of movement and posture often accompanied by disturbances of communication, cognition and behaviour. For those with more severe physical disabilities, their ability to participate in physical activities is limited, which includes those with walking limitations. It is known that adults with CP are prone to early development of chronic diseases such as cardiovascular disease and diabetes. Increasing physical activity levels improves well-being across the general population, including children without disabilities. Whether this is so for those children who have mobility limitations and cannot communicate their feelings is currently unknown. It is also unknown whether and how their well-being and quality of life can be influenced.

**Well-being** in this context refers to how children with CP are able to indicate they are enjoying life in their environments- 'thriving or surviving' which directly impacts upon their perceived quality of life. The National Institute for Health and Care Excellence (2017) guidelines for the management of CP included recommendations to use validated measures to monitor their mental health and well-being, however available questionnaires are problematic for those who cannot communicate verbally or have a learning disability and experience epilepsy, fatigue or pain. Additionally, Mpundu-Kaambwa et al (2018) did not find a valid and reliable measure of well-being for those with complex disabilities. However, a recent development by Oliver et al (2020), the Be-Well checklist for children with profound disabilities, has informed this study. Other existing well-being measures will be reviewed in a co-productive way with children and their parents(research advisory group), to develop the domains for this new observational well-being scale for children with CP.

**Figure 1 Innowalk, Made for movement, 2021**



The **Innowalk**, a robotic device (Figure 1), is a dynamic standing frame which has recently been reported to demonstrate an improvement in quality of life (Lauruschkus et al 2022). Prior to this device becoming available for use, there is no suitable alternative that can passively generate motion for non-ambulant children. The Innowalk is reported to have benefits for respiratory, circulation, skin integrity, light physical activity, gastrointestinal function, stretching of muscles and joints, mental function (linked to well-being) and bone mineral density (Verschuren et al 2016). These physical health outcomes are linked to well-being but this has not been explored with these non ambulant children.

## Methods

This research will use a case study design and will observe ten children using the Innowalk, as part of their physiotherapy, as one context for them to indicate their well-being. Data collection will be piloted with 2 children (by observations of indicative well-being behaviours) and parents (by diary entries of any well-being effects and an online interview). These findings will be reviewed and the items re-considered in consultation with the research advisory group. Data collection will be carried out with a further 8 children.

The potential measurement scale developed will be analysed by Mr Tim Pickles. Ethical approval has been sought to commence data collection in August 2022. Mr Ted Shiress has advised on the participation leaflets for 3-11 years old and 12-18 year olds.

## PICO

**Problem:** The lack of a valid and reliable measurement scale for the well-being of children and young people with complex CP .

**Interest:** Developing and testing a new scale by observing the well-being of non-ambulant and non-verbal children and young people with CP when using the Innowalk.

**Context:** Special School setting for children and young people with CP and other complex disabilities who use the Innowalk in physiotherapy.

**Outcome:** The domains established will enable the content validity to be evaluated in larger funded study to test the psychometric properties of the WEBS.

## References:

- Lauruschkus, K et al 2022 Dynamic Standing Exercise in a Novel Assistive Device Compared with Standard Care for Children with Cerebral Palsy Who Are Non-Ambulant, with Regard to Quality of Life and Cost-Effectiveness. *Disabilities* 2022, 2,73–85. <https://doi.org/10.3390/disabilities2010006>
- Made for Movement, 2021 <https://www.madeformovement.com/innowalk> [Accessed 1.12.21]
- Mpundu-Kaambwa, C. et al. 2018. A review of preference-based measures for the assessment of QoL in children and adolescents with CP. *Quality of Life Research* 27(7), pp. 1781-1799.
- National Institute for Health and Care Excellence (NICE). 2017. CP in under 25's assessment and management. NG62. Department of Health. [Accessed 02.12.21]
- Oliver, C, et al 2020, 'The behaviour and wellbeing of children and adults with severe intellectual disability and complex needs: the Be-Well checklist for carers and professionals', *Paediatrics and Child Health*.
- Verschuren et al 2016 Exercise and physical activity recommendations for people with CP. *Developmental Medicine & Child Neurology*, 58(8), pp.798-808.