Efficacy of a web-based therapy program on occupational performance in children and adolescents with unilateral cerebral palsy

Sarah James

B. Occupational Therapy (Hons I)

A thesis submitted for the degree of Doctor of Philosophy at The University of Queensland in 2015
School of Medicine
Abstract

Background
Cerebral palsy (CP) is a group of non-progressive disorders of movement and posture resulting from disturbances to the developing central nervous system. Unilateral CP (UCP), or congenital hemiplegia, is the most prevalent subtype and is characterised by motor impairments lateralised to one side of the body. Due to the motor and associated impairments, individuals with UCP often experience difficulties in occupational performance. Activities of daily living (ADL) are necessary to support participation in occupational roles and enhancing ADL performance is a high priority for children with UCP and their caregivers. Current clinical practice affords children with UCP time-limited therapy, and for this reason interactive computer play has emerged as a feasible, child-active alternative to face-to-face therapy. Evidence to date however is limited to pilot studies and further studies with greater methodological rigour are required.

Aim
This doctoral program aimed to investigate the effectiveness of a novel, web-based therapy program, “Move it to improve it” (Mitii™), on improving occupational performance in children and adolescents with UCP. The primary objective was to evaluate the effectiveness of Mitii™ compared to standard care on enhancing ADL motor and processing skills, perceived occupational performance, upper limb function and visual perception. Secondary objectives were to (i) systematically review the psychometric properties of ADL measures for school aged children with CP; (ii) establish the reproducibility of the Assessment of Motor and Process Skills (AMPS) in children and adolescents with UCP; (iii) investigate relationships between ADL motor and processing skills, unimanual capacity, bimanual performance and visual perception; and (iv) understand engagement in Mitii™ from the perspective of children and their caregivers.

Methods
A matched-pairs waitlist control randomised controlled trial was conducted between April 2012 and March 2014 in Brisbane, Australia to investigate the effectiveness of Mitii™ compared to standard care over 20 weeks in children aged 8-18 years with UCP. Participants (n=102) were matched in pairs and randomised to intervention (Mitii™) or waitlist control (standard care). Mitii™ incorporates upper limb, cognitive, visual perception and physical activities and is delivered in the home environment via an internet-connected computer. Virtual therapists create individualised programs and modify modules weekly to provide incremental challenge. Outcomes were assessed at baseline
and post-intervention (20 weeks). Primary outcomes were ADL motor and processing skills (AMPS), bimanual performance (Assisting Hand Assessment; AHA), unimanual speed and dexterity (Jebsen Taylor Test of Hand Function; JTTHF) and unimanual capacity (Melbourne Assessment of Unilateral Upper Limb Function; MUUL). Secondary outcomes were perceived occupational performance (Canadian Occupational Performance Model; COPM) and visual perception (Test of Visual Perceptual Skills (non-motor) 3rd edition; TVPS-3).

Results
A systematic review identified the AMPS as the best available measure of ADL performance for school-aged children with CP, however the test-retest reliability had not been established in this population. A reproducibility study of the AMPS found high test-retest reliability for children with UCP (AMPS motor scale ICC=0.93; AMPS process scale ICC=0.86). Analysis of cross-sectional data revealed that 57% of variance in AMPS motor scale scores were explained by bimanual performance and unimanual capacity of the dominant upper limb. Visual sequential memory, visual closure and dominant upper limb capacity together explained 35% of the variance in AMPS process scale scores.

In the RCT, participants in the intervention group completed on average 32.4 hours of Mitii™ (range 3.7-74.7 hours). After 20 weeks, AMPS motor scale scores were 0.28 logits higher in the intervention group than in the control group after adjusting for baseline scores, (95%CI=0.17, 0.39; p=<0.001) and 0.30 logits higher on the AMPS process scale (95%CI=0.19, 0.41; p=<0.001). The Mitii™ group demonstrated statistically significantly higher scores on the JTTHF dominant upper limb, COPM performance and satisfaction scales and TVPS-3 compared to the control group. These differences did not exceed levels of clinical significance. There was no significant difference between groups on the AHA or MUUL, while there was a trend towards an improvement on the JTTHF impaired upper limb (p=0.058).

A qualitative study identified key themes relating to client, intervention and service provider characteristics that influenced engagement in the Mitii™ program. The novelty of the program captured children’s interest initially however motivation declined over time. Caregivers desired programs to be ‘finely tuned’ to address individual needs and strong family support was necessary to facilitate engagement. Individual strategies

Conclusion
In an appropriately powered RCT, Mitii™ led to significant improvements in ADL motor and processing skills, perceived occupational performance and visual perception in children with UCP. Increased speed and dexterity of the dominant upper limb following Mitii™ may
reflect improvements in motor planning abilities. Mitii™ offers a web-based multimodal therapy that has potential to increase the therapy dose received by children with UCP and supplement face-to-face therapy. Clinical implementation of Mitii™ will require therapists to consider children’s physical and cognitive abilities, interests, individual goals and available family support to identify suitable participants for this mode of therapy delivery.
Declaration by Author

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Robert Ware
Robert Ware (continued)
- Critically reviewed manuscript (20%)
- Advised on statistical analysis (100%)
- Performed statistical analysis (20%)

Roslyn Boyd
- Critically reviewed manuscript (40%)


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<td>Gillian King</td>
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Contributions by others to the thesis

Principal supervisor: Roslyn Boyd

Associate supervisor: Jenny Ziviani

Conception and design of project: Roslyn Boyd, Jenny Ziviani, Lynne McKinlay, Stephen Rose, Ross Cunnington, Leanne Sakzewski, Anthony Smith, Koa Wittingham and Robert Ware were chief investigators on the initial program grant for “EBrain” which was funded by the Smart Futures Coinvestment Funds from the Queensland State Government. This program grant included the Mitii™ RCT for children with unilateral CP and an RCT of Mitii™ compared to standard care in children and adolescents with acquired brain injury. The chief investigators conceptualised the study design and selected primary and secondary outcome measures.

Conduct of project: Sarah James (candidate, occupational therapist), Louise Mitchell (physiotherapist) and Dr. Harriet Bodimeade (neuropsychologist) conducted a pilot study with typically developing children prior to commencement of the RCT. Melinda Lewis (occupational therapist) was responsible for study coordination and recruitment of participants. Naomi Westwood assisted with booking participant travel and accommodation. Sarah James, Louise Mitchell, Stephanie Ross (neuropsychologist) and Dr. Carly Mayberry (clinical psychologist and neuropsychologist) delivered the Mitii™ intervention of the RCT.

Technical support: The Mitii™ program was provided by the Helene Elsass Centre, Denmark and technical support was provided by Mitii™ Development A/S throughout the study. Ellen Gaudry, Chloe Noble and Joanne Bowden (occupational therapists) were blinded scorers for occupational therapy clinical assessments. Clare Vacha (graphic designer) designed study flyers, rewards charts and certificates.

Statement of parts of the thesis submitted to qualify for the award of another degree

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<tr>
<td>AACPDM</td>
<td>American Academy of Cerebral Palsy and Developmental Medicine</td>
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<td>AusACPDM</td>
<td>Australasian Academy of Cerebral Palsy and Developmental Medicine</td>
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<td>AHA</td>
<td>Assisting Hand Assessment</td>
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<td>AMPS</td>
<td>Assessment of Motor and Process Skills</td>
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<td>BoNT-A</td>
<td>Botulinum Neurotoxin Type-A</td>
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<td>CI</td>
<td>Confidence interval</td>
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<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
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<td>GMFCS</td>
<td>Gross Motor Function Classification System</td>
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<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>JTTHF</td>
<td>Jebsen Taylor Test of Hand Function</td>
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<td>MACS</td>
<td>Manual Ability Classification System</td>
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<td>Mitii™</td>
<td>Move it to improve it™</td>
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<td>MUUL</td>
<td>Melbourne Assessment of Unilateral Upper Limb Function</td>
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<td>RCT</td>
<td>Randomised controlled trial</td>
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<td>TVPS-3</td>
<td>Test of Visual Perceptual Skills (non-motor) 3rd edition</td>
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<td>UCP</td>
<td>Unilateral cerebral palsy</td>
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Chapter 1: Introduction, thesis plan and aims

1.1 Introduction

Cerebral palsy (CP) describes a group of non-progressive disorders of movement and posture, resulting from disturbances to the developing central nervous system. Motor impairments are often accompanied by seizure disorders, secondary musculoskeletal problems, and disturbances in sensation, perception, cognition and communication. Cerebral palsy is the most common physical disability in childhood with a prevalence of 0.2% worldwide. Risk factors for CP include low birthweight, intrauterine infections and multiple gestations.

Cerebral palsy is classified according to three main characteristics: motor type; topographical distribution; and severity of the motor disorder. The most common motor type is spasticity with a prevalence of approximately 80% of children with CP. Individuals with spasticity have muscle hypertonia with resistance to passive stretch and often increased deep tendon reflexes and muscle weakness. Cerebral palsy also presents as hypotonia (low muscle tone), dyskinesia (involuntary writhing movements most noticeable upon active movement), and more rarely ataxia (interruption of muscle control with unsteady movements or tremor).

The most common topographical distribution in children born at term is unilateral CP (UCP) or congenital hemiplegia, which is characterised by motor impairment lateralised to one side of the body. The upper limb is typically more involved than the lower limb and males are more likely to be impacted than females. Depending on severity of impairment, improving upper limb function and associated impairments to support participation in daily activities can require a lifetime of ongoing therapy, interventions and adaptive equipment.

Severity of CP is classified according to the Manual Ability Classification Scale (MACS) and the Gross Motor Function Classification System (GMFCS). The MACS describes how well children use their hands in daily activities on a five level scale from Level I (handles objects easily and successfully) to Level V (severely limited ability to perform simple actions) (see Table 1-1). This classification is designed to reflect the child’s typical performance in manual tasks when using one or both hands rather than each hand separately. The GMFCS classifies self-initiated movement and ranges from Level I (walks without limitations) through to Level V (restricted voluntary control of movement).
GMFCS and MACS are highly correlated (r=0.79) and both are valid and reliable tools for individuals with CP.\(^{(5)}\)

Table 1-1 The Manual Ability Classification System (MACS) \(^{(5)}\)

| Level I: Handles objects easily and successfully. | At most limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities. |
| Level II: Handles most objects but with somewhat reduced quality and/or speed of achievement. | Certain activities may be avoided or be achieved with some difficulty; alternative ways or performance might be used but manual abilities do not usually restrict independence in daily activities. |
| Level III: Handles objects with difficulty; needs help to prepare and/or modify activities. | The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted. |
| Level IV: Handles a limited selection of easily managed objects in adapted situations. | Performs parts of activities with effort and limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity. |
| Level V: Does not handle objects and has severely limited ability to perform even simple actions. | Requires total assistance. |

1.1.1 Occupational performance in children with UCP

Occupational performance is “the ability to perceive, desire, recall, plan and carry out roles, routines, tasks and sub-tasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/or external environment”.\(^{(7)}\)

Various conceptual models have been developed to guide the understanding of occupational performance and these models form the basis of occupational therapy (OT) practice. The Person-Environment-Occupation (PEO) Model is widely used and the intersect of Person (P), Environment (E) and Occupation (O) is proposed to describe occupational performance. \(^{(8)}\)

The tasks required for self-maintenance and self-care are termed activities of daily living (ADL).\(^{(9)}\) These tasks are fundamental in supporting participation across school, home and
community environments. Tasks are classified as either personal ADL tasks, which are oriented towards self-care (e.g. grooming, bathing); or instrumental ADL tasks, which are oriented towards sustaining independence and require a higher level of physical and cognitive competency than personal ADL (e.g. preparing meals, taking care of pets). Younger children perform predominantly personal ADL while adolescents engage in an increasing number of instrumental ADL tasks.

The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) provides a framework for measuring health and disability at the individual and population level. The ICF describes three components in which disability can arise: Body Structures and Functions, Activities, Participation and Contextual Factors. Activities of daily living are conceptualised under the broad “Activities and Participation”, rather than distinctly one domain or the other as they are specific tasks that enable participation. The ICF framework is used to understand and describe the impact of CP and allow for the categorization of outcome measures.

Figure 1-1 International Classification of Functioning, Disability and Health (ICF) model

![Image of ICF model]

Activities of daily living can be evaluated through measures of performance, capability or capacity. Performance describes what a person actually does in his/her daily environment, capacity describes what a person can do in a standardised environment, and capability describes what an individual can do in his/her daily environment. Measures of performance are the most relevant can do in his/her daily environment. A barrier to utilizing measures of performance is the need for home visits, and measures of capability or capacity may often be more clinically feasible.
The motor and associated difficulties of CP can make engaging in ADL a challenging experience. Individuals with UCP often aspire to be independent with ADL and their ability to perform these tasks is a high priority for caregivers.\(^{(13)}\) Many children with mild to moderate UCP do achieve independence in ADL but at a later age than typically developing children.\(^{(14)}\) Despite the importance of ADL in supporting participation across various environments, limited research has investigated ADL skills in this population.\(^{(15)}\) Impaired upper limb function is reported to be the main factor contributing to difficulties in ADL for children with UCP.\(^{(16)}\) At the body structures and function level, impairments in the hemiplegic upper limb can arise in muscle tone (primarily spasticity), strength, passive range of movement and sensation. At the activity level, quality of movement, dexterity, movement speed and spontaneous use of the upper limb can be impaired. Children with UCP are reported to have limited improvement in spontaneous hand use after 7 years.\(^{(16)}\) As children with UCP age, the impact of the positive and negative features of the central nervous system damage (e.g. hypertonicity and limited movement patterns) can have an increasing effect on their ability to move freely.\(^{(17)}\)

Research investigating relationships between manual ability and ADL have shown that the MACS explained 66% of variance in self-care functional skill scale on the Pediatric Evaluation of Disability Inventory (PEDI),\(^{(18)}\) and showed strong correlations with the PEDI self-care caregiver assistance scale \(r=0.72.\)\(^{(19)}\) Similarly, Arnould and colleagues investigated manual ability (i.e. capacity to manage activities including ADL) in children with CP and found 66% of variance in scores was explained by hand skills.\(^{(20)}\) Many conventional upper limb therapy approaches assume that enhanced upper limb function will improve manual ability and ADL performance.\(^{(20)}\) These findings indicate that one third of variance in self-care and manual ability is not explain by upper limb function, so other factors must also be considered.

Activities of daily living involve planning and carrying out a sequence of actions, and the ability to perform tasks is not based solely on the ability to physically execute an activity.\(^{(21)}\) Limited research has investigated the ADL processing skills in children with UCP. Processing skills relate to the ability to select and use tools, carry out steps and modify performance.\(^{(22)}\) Van Zelst and colleagues investigated ADL motor and processing skills in the home environment in children with UCP \(n=54\) using the Assessment of Motor and Process Skills (AMPS).\(^{(15)}\) This study found that children with UCP had motor and processing skills below that of age-matched normative data. Vos and colleagues described the developmental trajectories of daily activities for children and adolescents with CP using the Vineland Adaptive Behavior Scale, by GMFCS level.
Individuals with CP without intellectual disability reached levels close to typically developing individuals, with significant differences only between participants classified as GMFCS 1 and GMFCS level IV. (Figure 1-2-i) Children with CP with intellectual disability had significantly lower developmental trajectories of ADL performance. (Figure 1-2-ii) These trajectories show the importance of the cognitive, or processing aspects of ADL ability.

**Figure 1-2 Developmental trajectory models of ADL by GMFCS level for individuals with CP: (i) without intellectual disability; and (ii) with intellectual disability**

In comparison to typically developing children, individuals with UCP are reported to have significantly impaired visual perception. The impact of visual perceptual ability on ADL skills has not been examined in this population to date. A study examining visual perception and ADL in children with developmental disabilities found the Motor Free Visual Perception Test (MVPT-3) total score, visual memory and visual closure were significantly related with Functional Independence Measure for Children (WeeFIM) total score, and
visual discrimination was significantly related to the WeeFIM self-care domain.\(^{(24)}\) These findings may reflect that ADL require skills to store and retrieve information to complete steps in a logical order and to identify tools that may be partially in view, within a crowded spaces or among similar objects.

1.1.2 Interventions for occupational performance in UCP

Evidence for intervention approaches for children with UCP are categorised into three domains: (i) health and secondary prevention (interventions to manage health, comorbidities and prevent or lessen the natural history of CP); (ii) compensatory and environmental (environmental and task modifications) and (iii) child-active rehabilitation (therapy involving active engagement of child).\(^{(25)}\) (Figure 1-3) To enhance self-care ability, current research supports six effective or “green light” motor-learning based therapy approaches, including bimanual training, constraint-induced movement therapy (CIMT), context-focused therapy, goal-directed training, occupational therapy following intramuscular Botulinum Neurotoxin Type-A (BoNT-A) upper limb injections and home programs.\(^{(26)}\)

Figure 1-3 Effective interventions for individuals with unilateral cerebral palsy\(^{(25)}\)

(Reproduced with permission from SAGE Journals: Novak I. Evidence-Based Diagnosis, Health Care, and Rehabilitation for Children With Cerebral Palsy. J Child Neurol. 2014:29(8);1152)
Child-active rehabilitation approaches for children with UCP typically involve task specific training to stimulate motor learning. Motor learning is the co-adaptation of the neural systems and structural anatomy associated with practice or experience. Learning is reflected in changes in the pattern of interconnections in the sensory and motor systems involved in learning a specific task, particularly the effectiveness of neural connections. The Cognitive Orientation to Daily Occupational Performance (CO-OP) is an individualised intervention developed by occupational therapists that can assist with task-specific learning. A metacognitive global problem solving approach, Goal-Plan-Do-Check, facilitates children to work towards goals through discovering, trialling and evaluating individual strategies.

Therapy approaches can be considered either top-down or bottom-up. Therapy which begins by focusing on the child’s occupation is considered a top-down approach and includes therapy such as goal-directed training and bimanual training. Assessment and treatment of deficits in motor and cognitive skills that are considered prerequisites for successful ADL performance are considered bottom-up approaches. A bottom-up approach assumes that the acquisition of such skills will ultimately result in enhanced
performance in ADL.\(^{(30)}\) The top-down and bottom-up approaches both present inherent benefits and challenges.

A challenge of both approaches is achieving access adequate therapy dose (i.e. amount of therapy). While evidence regarding therapy dose remains inconclusive, research suggests that up to 60 hours may be required to achieve optimal changes in function.\(^{(31)}\) Children with UCP in Australia currently receive only consultative or time-limited therapy post pharmacological intervention. Accessing therapy is particularly challenging for those families who reside in rural areas and alternate approaches to therapy are required.

### 1.1.3 Interactive computer play: An alternative therapy approach for UCP

Therapy delivered via interactive computer play is emerging as a promising, child-active alternative to face-to-face therapy for individuals with UCP.\(^{(25)}\) (Figure 1-4) Interactive computer play is an umbrella term defined as “any kind of computer game or virtual reality technology where the individual can interact and play with virtual objects in a computer generated environment”.\(^{(32)}\) This term incorporates both two dimensional computer games and virtual reality technologies, which engage users in environments that appear and feel similar to real world experiences.\(^{(32)}\)

A review of interactive computer play for individuals with CP reported a moderate level of evidence for improved gross motor outcomes yet inconclusive evidence for upper limb function.\(^{(33)}\) Of ten studies that assessed upper limb function, four reported statistically significant functional improvements as measured by the Canadian Occupational Performance Measure (COPM) (n=18)\(^{(34)}\), Melbourne Assessment of Unilateral Upper Limb Function (MUUL) (n=9)\(^{(35)}\), AMPS (n=9)\(^{(36)}\) and Bruinink-Oseretsky Performance Test of Motor Proficiency (BOTMP) (n=32)\(^{(37)}\). There was significant variation in the ICP systems utilised in the studies, ranging from customised systems including robot assisted rehabilitation to commercially available systems. The small sample sizes of these studies however mean they are underpowered to appropriately investigate significant changes in function.

A meta-analysis examining the effect of virtual reality technologies in children with CP found a strong effect on upper limb function (d=1.00, 95% confidence interval (CI) 0.45, 1.56) when comparing pre and post-intervention.\(^{(38)}\) Analysis of outcome variables by ICF domains found a large effect on participation (d=1.92, 95% CI=1.198, 2.66), a small effect on activity (d=0.46, 95% CI=-0.08, 1.16) and a medium effect on body structure and function measures (d=0.70, 95% CI=0.10, 1.30). Young children were identified as the best responders and engineer-built virtual reality systems had a greater effect than
commercially available systems. Delivery in the home or laboratory rather than a clinic setting was recommended. The 18 articles in this meta-analysis again had small sample sizes and poor to fair methodology quality.\(^{(38)}\)

A small number of the pilot studies have investigated the effect of interactive computer play on visual perception. Bilde and colleagues found significant improvements in visual perception as measured by the Test of Visual Perceptual Skills (TVPS-3) following a web-based therapy program (pre-intervention= 88.3±5.4, post-intervention=95.7±5.9, p<0.001).\(^{(36)}\) A case study of a 13 year adolescent with spastic diplegia (GMFCS level III) reported that the Nintendo Wii\(^{™}\) improved visual perceptual skills as measured by the TVPS-3.\(^{(39)}\) While these results provide promising preliminary evidence for the use of interactive computer play for children and adolescents with CP to improve visual perception, larger studies are required.

Interactive computer play systems are considered therapy ‘tools’ and this label emphasises that clinician input is necessary to integrate the system into practice.\(^{(40)}\) A disadvantage of implementing commercially available systems (e.g. the Nintendo Wii\(^{™}\)) is the inability to individualise the activities. Conversely, the expense of complex interactive computer play systems is a barrier to implementation in the home environment and consequently they are typically delivered in clinical settings. An advantage of interactive computer play is the ability for families to access therapy without having to attend a clinical appointment. To achieve the best possible outcomes, interactive computer play should involve an engineer-built system delivered in the home environment.\(^{(38)}\) To be feasible however, the system needs to be inexpensive while allowing tailored therapy delivery that can become progressively challenging as the child’s skills improve.

A scoping review by Levac and colleagues defined a number of active ingredients for interactive computer play for children with neuromotor impairments.\(^{(41)}\) The key areas identified in regards to the system were: (i) opportunities for practice with increased duration, intensity and/or frequency of practice; (ii) task specificity; (iii) flexibility to individualise treatment parameters; (iv) visual and/or auditory feedback about results; (v) social play equalization for children with CP.\(^{(41)}\) The beneficial effects on the user were: (i) neuroplasticity; (ii) problem-solving opportunities through task-driven training; and (iii) motivation to participate.\(^{(41)}\) Finally, it was identified that the presence of a support person (parent and/or therapist) may have contributed to positive outcomes.\(^{(41)}\)

A novel web-based therapy program, “Move it to improve it” (Mitii™) was recently developed which allows therapists to create and modify individualised programs.\(^{(42)}\) Mitii™ is a multimodal program that is delivered in the home environment and comprises upper
limb, cognitive, visual perceptual and physical activities. The aim of Mitii™ is to increase neural circuits as a basis for task-specific learning. Mitii™ is based on neuroplasticity principles and therefore the training is designed to be intensive, incrementally challenging, motivating and require individuals to pay close attention to the tasks.\(^{(43)}\)

The Mitii™ system operates from a cloud server-based system using Adobe® Flash® technology and is accessed via an internet connected computer. The Mitii™ system detects and tracks bodily movements via a web-camera using green tracking bands worn on the hands, knee or head. Occupational therapists, physiotherapists and neuropsychologists collaboratively devise programs based on the child’s baseline assessment scores, selecting from 14 training modules to devise a program that includes approximately 60% upper limb, cognitive and visual perceptual activities, and 40% gross motor activities. Mitii™ is ideally completed for 20-30 minutes, six days per week for 20 weeks providing a maximum potential dose of 60 hours.

Therapists remotely monitor children’s program and adjust modules weekly by increasing speed, accuracy, repetitions and/or task complexity. The protocol for adjusting difficulty levels is to increase a parameter of the module when a child consistently achieves 80-90% of correct responses over the week. This protocol ensures consistency in adjustments made to programs by the virtual therapists. The levels within the individual games ranged from very easy to difficult. The most difficult level in terms of visual perceptual/cognition is often challenging for adults, and the repetitions can be increased as required for physical activities to limit a possible ceiling effect.

A pilot pre-post study of Mitii™ was conducted in a cohort of children with UCP (n=9) and found promising results, with statistically significant improvements in ADL motor and processing skills, visual perception and functional strength.\(^{(36)}\) Following this pilot study, an adequately powered RCT is required to determine the efficacy of Mitii™ in comparison to standard care for children and adolescents with UCP.

### 1.2 Thesis Outline

As interactive computer play is a novel therapy approach, evidence to date is limited to pilot studies. The efficacy of Mitii™ on occupational performance, upper limb function and visual perception for children and adolescents with UCP in comparison to standard care is unknown. An adequately powered RCT provides the highest level of evidence to investigate the efficacy of Mitii™ compared to standard care and is the focus of this doctoral program. The primary objective of this thesis is supported by four secondary objectives.
Primary Objective

To investigate the efficacy Mitii™ in comparison to standard care on improving occupational performance, upper limb function and visual perception in 8-18 year olds with UCP immediately post-intervention in a waitlist-control RCT.

Secondary Objectives

1. To systematically review the psychometric properties and clinical utility of ADL measures for school aged children with CP.
2. To examine the reproducibility of the AMPS in children and adolescents with UCP.
3. To investigate relationships between ADL motor and processing skills, unimanual capacity, bimanual performance and visual perception.
4. To understand engagement in the Mitii™ program from the perspectives of children and their caregivers.

1.3 Aims and Hypotheses

**Primary Objective:** To investigate the efficacy Mitii™ in comparison to standard care on improving occupational performance, upper limb function and visual perception in 8-18 year olds with UCP immediately post-intervention in a waitlist-control RCT.

**Hypothesis:** The primary hypothesis is that Mitii™ will improve ADL motor and processing skills and upper limb function to a greater extent than standard care. The secondary hypothesis is that Mitii™ will enhance perceived occupational performance and visual perception.

**Rationale:** A pilot study of nine children with UCP completed the Mitii™ program for 20 weeks and following the intervention showed significantly improvements in their ADL motor skills (1.49±0.37 to 1.84±0.37; p<0.001), ADL process skills (0.87±0.40 to 1.29±0.38; p<0.05) and visual perception (88.3±5.4 to 95.7±5.9, p<0.001).(36) An adequately powered RCT is required to determine the efficacy of Mitii™ compared to standard care in children and adolescents with UCP.

**Methods:** A matched-pairs waitlist control RCT will be conducted to investigate the effectiveness of Mitii™ compared to standard care over 20 weeks in children with UCP. Participants will be matched in pairs based on age, gender and MACS level and randomised to either Mitii™ intervention or waitlist control. Participants in the Mitii™ group will complete an individualised Mitii™ program in their home environment, ideally for 20-30
minutes for 20 weeks. Virtual therapists will modify their program weekly to provide incremental challenge and remain in regular contact to encourage engagement in the program. Outcome measures will be assessed at baseline (T0) and post-intervention at 20 weeks (T1). Primary outcome measures are: (i) AMPS for ADL motor and processing skills; (ii) Assisting Hand Assessment (AHA) for bimanual performance; (iii) Jebsen-Taylor Test of Hand Function (JTTHF) for unimanual speed and dexterity; and (iv) MUUL for unimanual capacity of the impaired upper limb. Secondary outcome measures are the COPM for perceived occupational performance and TVPS-3 (non-motor) for visual perception.

The primary object is supported by the following four secondary objectives.

1.3.2 Secondary Objective 1: To systematically review the psychometric properties and clinical utility of ADL measures for school aged children with CP.

Hypothesis: Evidence of validity, reliability and clinical utility of ADL measures will not be specific to this population and will vary in methodological quality.

Rationale: Previous systematic reviews of outcome measures in CP have focused on upper limb activity and participation, yet none to date have reviewed measures of ADL exclusively. The importance of ADL in enabling involvement in all life situations warrants a distinct review of ADL measures.

Methods: Five electronic databases will be searched to systematically identify available ADL measures with published psychometric data for school aged children with CP. Measures will be included if at least 60% of items address ADL in the full assessment or in a domain that can be administered and scored independently. A modified CanChild Outcome Rating Form will be used to report the validity, reliability, responsiveness and clinical utility of measures.

1.3.3 Secondary Objective 2: To examine the reproducibility of the AMPS in children and adolescents with UCP.

Hypothesis: The AMPS will demonstrate good-excellent test-retest reliability for both the motor and process scales when administered in a clinical setting.

Rationale: The AMPS has demonstrated excellent test-retest reliability in adult populations however there is no evidence of test-retest reliability in children and youth with UCP. It is important for the test-retest reliability to be examined to determine the stability
of the AMPS in children with UCP in order to attribute changes in scores to real changes in performance or capacity.

**Methods:** Thirty participants from the Mitii™ study who are scheduled to attend assessments over a two day period will be invited participate in this study. Children will carry out two AMPS tasks on day one and day two following standardised AMPS administration procedures. Participants will complete the same two tasks each day.

**1.3.4 Objective 3:** To examine the relationships between ADL motor and processing skills, unimanual capacity, bimanual performance and visual perception

**Hypothesis:** There will be moderate-strong relationships between ADL motor skills and upper limb function measures, and a moderate relationship between ADL processing skills and visual perception.

**Rationale:** Previous research has demonstrated relationships between self-care ability and manual ability in children with CP.\(^{14,19,20}\) No studies to date however have examined the relationships between both ADL motor and processing skills through use of the AMPS, and measures of upper limb function and visual perception in this population group.

**Methods:** Data for this study will be drawn from baseline measures from the RCT (Primary Objective) \((n=102)\). Relationships between variables will be investigated with multivariable analyses using Software Package for Social Sciences (SPSS) v.22.

**1.3.5 Objective 4:** To understand engagement in the Mitii™ program from the perspectives of children and their caregivers.

**Hypothesis 1:** Key factors influencing the experiences of children in the Mitii™ program will be the length of the program, competing interests and technical issues. Caregivers will value the convenience of a home-based intervention however may observe their child’s motivation to engage in Mitii™ to decline over the 20 week period.

**Rationale:** As ICP is a relatively novel therapeutic modality, there is limited evidence regarding issues surrounding engagement for children with UCP. It is important to capture the experiences of both children and caregivers to evaluate the feasibility, challenges and perceived benefits of delivering therapy via ICP systems in the home environment.

**Methods:** Ten child-caregivers dyads will be purposively sampled from the Mitii™ cohort. Participants will be selected to reflect a range of circumstances including their level of engagement in Mitii™, age and area of residence. Data will be gathered using semi-structured interviews conducted by a study investigator unknown to the participant and caregiver.
1.4 Format of Thesis

This thesis is presented as a series of six papers published in or submitted to international peer-review journals. Chapter 2 is a systematic review of ADL measures for children and adolescents with CP addressing Secondary Objective 1. The study protocol is presented in Chapter 3, outlining the background information and overall design of the RCT. Chapter 4 presents results of a reproducibility study of the AMPS, addressing Secondary Objective 2. A cross-sectional evaluation examining relationships between ADL motor and process skills, upper limb function and visual perception is presented in Chapter 5 (Secondary Objective 3). Outcomes of the RCT are presented in Chapter 6, addressing the Primary Objective of this thesis. The experiences of children and their caregivers in the Mitii™ program follows in Chapter 7 and address Secondary Objective 4. Finally, Chapter 8 links results from all studies within this thesis, discusses the implications of results on clinical practice and outlines limitations and future directions for this emerging field of research.
Chapter 2: Systematic review of activities of daily living measures for children and adolescents with cerebral palsy

2.1 Introduction to Chapter 2

The published paper entitled, “A systematic review of activities of daily living measures for children and adolescents with cerebral palsy” comprises Chapter 2. This paper outlines and discusses the results of a systematic review examining measures of ADL for children and adolescents aged 5-18 years with CP. Various measures are utilised to capture ADL ability in children with CP, however no systematic reviews have previously examined the psychometric properties and clinical utility of available ADL measures. This study was carried out to identify suitable measures to evaluate ADL in this population and to inform the choice of measure to evaluate ADL in the RCT. This systematic review critically discusses the purpose, content, validity, reliability and clinical utility of available ADL measures for children and adolescents with CP.

2.2 Paper 1: A systematic review of activities of daily living measures for children aged 5-18 years with cerebral palsy

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This paper was presented as a free paper at the 25th Occupational Therapy Australia National Conference, 24-26th July 2013, Adelaide, SA; the Queensland Paediatric Rehabilitation Service Conference, 22nd-23rd August 2013, Brisbane, QLD; and the 7th Biennial Conference of the Australiasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM), 11-14th March 2014, Hunter Valley, Australia. This paper received the award for the Best Scientific Poster at the 2014 AusACPDM conference.
A systematic review of activities of daily living measures for children and adolescents with cerebral palsy

SARAH JAMES | JENNY ZIVIANI | ROSLYN BOYD

Queensland Cerebral Palsy and Rehabilitation Research Centre, The University of Queensland, Royal Children's Hospital, Brisbane, Qld; Children's Allied Health Research, Queensland Health and School of Health and Rehabilitation Sciences, The University of Queensland, St Lucia, Qld, Australia.

Correspondence to Sarah James at Queensland Cerebral Palsy and Rehabilitation Research Centre, The University of Queensland, Level 7, Block 6, Royal Brisbane and Women's Hospital, Herston Rd, Herston, Qld, 4029, Australia. E-mail: s.james2@uq.edu.au

AIM This study aimed to systematically review the psychometric properties and clinical utility of measures of activities of daily living (ADL) for children with cerebral palsy (CP) aged 5 to 18 years.

METHOD Five electronic databases were searched to identify available ADL measures with published psychometric data for school-aged children with CP. Measures were included if at least 60% of the items addressed ADL in the full assessment or in an independent domain. A modified CanChild Outcome Rating Form was used to report the validity, reliability, responsiveness, and clinical utility of the measures.

RESULTS Twenty-six measures were identified and eight met inclusion criteria. The Pediatric Evaluation of Disability Inventory (PEDI) had the strongest psychometric properties but was limited by its age range. The Assessment of Motor and Process Skills (AMPS) was the most comprehensive evaluation of underlying motor and cognitive abilities yet further psychometric testing is required for children with CP.

INTERPRETATION The PEDI should be used to measure ADL capability in elementary school aged children. The AMPS is the best measure to evaluate ADL performance or capacity and is suitable for all ages. Future research should examine the reliability of the AMPS to determine its stability in children and adolescents with CP.

The focus of assessment and treatment of children with cerebral palsy (CP) has changed in response to the introduction of the International Classification of Functioning, Disability and Health (ICF).1 The ICF has evolved since its inception and today comprises four components: (1) body structures; (2) body functions; (3) activities and participation; and (4) environmental factors.2 The conceptualisation of disability in the ICF highlights its biopsychosocial nature and emphasises the need to support individuals to achieve optimal capacity and participation in all aspects of life.3 Broadening intervention goals to address all areas of functioning necessitates the identification of outcome measures that capture each aspect.4

Cerebral palsy is defined as ‘a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances which occurred in the developing fetal or infant brain’.5 Activities of daily living (ADL) are tasks that are fundamental to supporting participation across school, home and community environments. ADL are conceptualised in the ‘Activities and Participation’ domain of the ICF and defined as life tasks required for self-care and self-maintenance such as grooming, bathing, eating, and doing chores.6 These tasks are classified as either (1) personal ADL tasks, which are oriented towards self-care (e.g. grooming, bathing); or (2) instrumental ADL tasks, which are oriented towards sustaining independence and require a higher level of physical and cognitive competency than personal ADL (e.g. preparing meals, taking care of pets).7 Personal ADL are more commonly performed by younger children, while adolescents also engage in an increasing number of instrumental ADL tasks.

Because of their motor and associated difficulties, children and adolescents with CP often fall below the typical developmental trajectory. These children are also likely to experience difficulty with ADL and their performance of these tasks is a high priority for parents.8 It is necessary, therefore, for therapists to assess ADL with rigorous outcome measures to facilitate intervention planning and document outcomes. Outcome measures that are validated for children with CP should be used because the movement disorders and the disturbances of sensation, perception, cognition and communication that are associated with CP8
will influence ADL performance. The nature of the predominant movement disorder of CP (i.e. spasticity) will affect children’s ADL performance differently compared with other developmental disabilities such as autism or Down syndrome.

ADL can be measured by assessing an individual’s performance, capacity or capability. Performance describes what a person actually performs in his or her daily environment, capacity describes what a person can do in a standardised, controlled environment, and capability describes what an individual can do in his or her daily environment. Measures of performance are the most relevant for children as they capture everyday typical function.

Previous systematic reviews on relevant outcome measures in CP have focused on upper limb activity, visual perception and habitual physical activity. While systematic reviews of activity and functional motor abilities and participation in children with CP have incorporated measures with ADL domains, none to date has reviewed measures of ADL exclusively. The importance of ADL in enabling involvement in all life situations warrants a distinct review of ADL measures. This systematic review aimed to (1) identify the available measurement tools of ADL used to assess children and adolescents with CP; and (2) review the validity, reliability, responsiveness, and clinical utility of these measures.

**METHOD**

**Search strategy**

A systematic search was performed by the first author (SJ) of five electronic bibliographic databases including PubMed, EMBASE, CINAHL, PsycINFO® and the Cochrane Library, from their respective inception dates to May 2013. Databases were searched using the text words (child* OR kid* OR adolescent* OR youth* OR teen* OR minor* OR pediatric* OR juvenile*) AND (cerebral palsy OR hemiplegia OR monoplegia OR quadriplegia OR diplegia OR tetraplegia) AND (assessment* OR measure* OR outcome* OR instrument* OR evaluation* OR tool* OR test*) AND (‘activity of daily living’ OR ‘activities of daily living’ OR ‘daily care’ OR ‘self-care’) and corresponding Medical Subject Headings (MeSH) terms. Identified measures were used as terms for a further search of the five electronic databases. Targeted hand searching was employed to minimise the chance of missing important studies by scanning reference lists of key papers.

**Inclusion/exclusion criteria**

For an assessment to be included in the review, it had to meet the following a priori inclusion criteria: (1) measure performance, capacity or capability of ADL; (2) consist of at least 60% ADL items in the full assessment or in a domain that can be administered and scored independently; (3) have published validity and reliability data for children aged 5 to 18 years with CP; and (4) be available for use. Assessment tools were excluded if they were (1) not published in English, because of a lack of translation services; (2) primarily assessed body structures or function, health-related quality of life or health status; or (3) individualised goal setting tools. Measures used for goal setting for children with CP (e.g. the Canadian Occupational Performance Measure and the Goal Attainment Scaling) do not consistently assess ADL and have been appraised in a previous review of participation measures.

Studies were included in the review if they were (1) primary investigations of a tool that fulfilled the above criteria, (2) full papers published in a peer-reviewed journal, (3) testing the clinimetric properties of the measurement tool, and (4) evaluating a sample with children and adolescents with CP. Studies were excluded if they examined associations between tools without focusing on particular aspects of clinimetric testing or validated a measurement tool in a language other than English.

**Data extraction and quality assessment**

Titles and abstracts of all retrieved references from the initial search yield were screened independently by two authors (SJ, JZ) and conflicting views were discussed to reach consensus. The full text of selected papers, assessment manuals and score sheets were retrieved for analysis of included measures. All authors collaboratively discussed the content of measures to determine ADL items based upon the definition: ‘typical life tasks required for self-care and self-maintenance’.

A modified CanChild Outcome Measures Rating Form was used to extract descriptive information and rate the validity, reliability, responsiveness, and clinical utility of measurement tools (see Appendix S1, online supporting information). This proforma incorporates the ICF framework and has been utilised in previous reviews of outcome measures for this population.

Descriptive information was extracted for each measure to determine the focus of the measure (linked to ICF categories), respondent(s), target population, evaluation context and scale construction.

Reliability is the degree to which an item, scale or assessment measures consistently with variations in examiner, time of administration, environment or population. Internal consistency, intrerrater reliability, intrarater reliability and test–retest reliability were considered in this review. The CanChild Outcome Measures Rating Form describes reliability intraclass correlation coefficients of 0.8 or above as ‘excellent’, 0.6 to 0.79 as ‘adequate’ and less than 0.6 as ‘poor’. Kappa statistics of 0.41 to 0.6 were considered ‘moderate’, 0.61 to 0.8 ‘substantial’, and 0.81 to 1.00 ‘almost perfect’. Validity is the extent to which an assessment measures what it purports to measure. This review evaluated the content, construct and criterion validity of included measures. Responsiveness is the ability of

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**What this paper adds**

- Eight measures of ADL are appropriate for school-aged children with CP.
- The PEDI is the best measure of ADL capability but is only suitable for elementary school aged children.
- The AMPS is the best evaluation of ADL performance or capacity for children and adolescents with CP of all ages.
an instrument to detect change over time in the construct to be measured. The minimal clinically important difference (MCID) is the smallest difference in score that would mandate a change in patient management and is a frequently reported index of responsiveness. The MCID has been reported where possible for measures in this review; however, as there is no standard on how to calculate MCID, these indices must be interpreted with caution. Clinical utility was rated according to the assessment format, administration time, feasibility (ease of administration, scoring and interpretability) and cost of manual and score sheets. Assessor training, space and material requirements, and the ability of the measure to identify problem areas for intervention, were also considered.

RESULTS
Twenty-six measures were identified by the search strategy and eight met the predefined inclusion criteria. Selected measures were the ABILHAND-Kids, Assessment of Motor and Process Skills (AMPS), Children’s Hand-use Experience Questionnaire (CHEQ), Klein-Bell Activities of Daily Living (ADL) scale, Functional Independence Measure for Children (WeeFIM), Pediatric Evaluation of Disability Inventory (PEDI), School Function Assessment (SFA), and Vineland Adaptive Behavior Scales Motor and Process Skills (AMPS). The content of each measure is summarised in Table II. The majority of assessments measured capability and were administered via proxy report. The AMPS and Klein-Bell ADL scale were observational evaluations that measured ADL performance (or capacity if administered in a clinical setting), while the VABS and WeeFIM had the option for administration via observational evaluation. The age ranges varied for the assessments. The upper limits of the PEDI and WeeFIM were 7 years 6 months and 8 years respectively, but both were appropriate for older children with functional disabilities, and the SFA extended to 12 years.

Characteristics of included assessments
The characteristics of included assessments are summarised in Table I. The majority of assessments measured capability and were administered via proxy report. The AMPS and Klein-Bell ADL scale were observational evaluations that measured ADL performance (or capacity if administered in a clinical setting), while the VABS and WeeFIM had the option for administration via observational evaluation. The age ranges varied for the assessments. The upper limits of the PEDI and WeeFIM were 7 years 6 months and 8 years respectively, but both were appropriate for older children with functional disabilities, and the SFA extended to 12 years.

Content
The content of each measure is summarised in Table II. The ABILHAND-Kids, AMPS, CHEQ, and Klein-Bell ADL scale were entirely ADL assessments while the PEDI, SFA, VABS and WeeFIM had ADL domains that could be administered and scored independently. Specific examples of the ADL skill items addressed in each assessment are provided. The items were predominantly personal ADL tasks and comparable across the measures yet considerable differences exist in the number of items and scoring criteria.

Validity
Table III summarises evidence for validity of each measure. Content validity was supported for all measures by expert opinion and also by pilot work for most measures. It was further supported by principal component analysis for the CHEQ, VABS, and WeeFIM. The ABILHAND-Kids, AMPS, CHEQ and PEDI utilised Rasch modelling in test development. There was evidence of construct validity for all eight measures. The PEDI had the strongest evidence with adequate to excellent levels of construct validity reported between the PEDI and six measures. There was an adequate level of evidence of criterion validity for the PEDI and WeeFIM, and the SFA and VABS Classroom Edition.

Reliability and responsiveness
Evidence for reliability and responsiveness of each measure is summarised in Table IV. Internal consistencies were reported for all measures except the Klein–Bell ADL Scale. The ABILHAND-Kids, Klein–Bell ADL Scale, and the ADL domains of the PEDI, SFA and WeeFIM had high test–retest reliability. Interrater reliability was high for the Klein–Bell ADL Scale and the ADL domains of the PEDI and WeeFIM. Test–retest and interrater reliability were only reported for the VABS and AMPS in the standardisation sample and adult populations, respectively, and not reported, to date, for the CHEQ. Minimal clinically important differences are reported only for the AMPS (0.3 logit on ADL motor and process ability measures), PEDI (11 points on 0–100 scale) and WeeFIM (3.1 for medium effect size and 5.0 for large effect size) with good responsiveness detected for the AMPS and PEDI. Ceiling effects were found in the WeeFIM among children with diplegia and hemiplegia.

Clinical utility
Clinical utility is summarised in Table V. Administration time varied considerably across the measures and within measures depending on the number of domains administered and the tasks chosen (AMPS). The shortest assessments were the ABILHAND-Kids and CHEQ, both requiring approximately 20 minutes for administration and scoring. The assessment with the greatest administration burden was the Klein–Bell ADL Scale (60–180 minutes for full administration plus 15 minutes scoring time). The only measure that required formal assessor training was the AMPS. The ABILHAND-Kids, AMPS and PEDI had Rasch analysis software available for computing scores and generating reports. Details on the scoring and interpretability are reported in Table IV.

DISCUSSION
This systematic review of ADL measures for children and adolescents aged 5 to 18 years with CP identified eight appropriate outcome measures. The ability to perform ADL is a high priority for children and adolescents with CP and their parents. It is essential that ADL measures are...
included in routine clinical practice and as outcome measures in research in this population. As a number of measures are available to therapists, selection of an appropriate ADL tool involves careful consideration of the measure’s purpose and content, psychometric properties, and clinical utility.

The content within each ADL measure consisted predominantly of personal ADL tasks, which are the basic tasks required for self-care. The AMPS also contained a wide range of instrumental ADL tasks which allows children and adolescents with mild to moderate CP to be evaluated performing tasks that are sufficiently challenging. The CHEQ was designed specifically for children with unilateral hand dysfunction and all 29 ADL items in this measure require the use of both hands. This differs from the ABILHAND-Kids in which three-quarters of the items can be performed with one hand. The PEDI covers a broad range of tasks with 73 items in the Self Care domain while the WeeFIM has a limited data set of only 6 items. The VABS and SFA are not specific ADL measures but contain domains with personal ADL items that are performed in a school environment. The Klein–Bell ADL Scale has 170 items that are task components (e.g. putting right toe into right shoe) of tasks (putting on shoes) and over 80% of tasks are ADL.

Validation work of the included assessments has mostly been carried out on large cohorts including children with CP. It is important to note that while the AMPS was validated on over 148 000 individuals with an assortment of diagnoses (including CP), less than 10% of this standardisation sample was below 16 years. The validity of the AMPS has been confirmed in typically developing children demonstrating acceptable goodness-of-fit to the AMPS motor and process scales. While the AMPS is a

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**Figure 1:** Included and excluded studies of activities of daily living measures for 5 to 18 year olds with cerebral palsy.
psychometrically sound measure, further validation work with children with CP would strengthen its application in this population. The ABILHAND-Kids and CHEQ have been validated on children with CP and children with unilateral hand dysfunction, respectively. These tools are valuable for therapists as they have been tailored specifically to address the challenges experienced by children with CP. Evidence of validity for the Klein–Bell Scale for children with CP is limited to a study of discriminative validity and further validation work is required on the new version of the CHEQ with the condensed 1 to 4 scale. Once the validity of the CHEQ is strengthened, it has the potential to be a useful tool for children and adolescents up to 18 years. The PEDI has the strongest evidence of construct validity and has high criterion validity with the WeeFIM in the Self-Care domain; its use as a measure of ADL capability is recommended.

The reported psychometric properties of reliability varied across the measures and further studies of reliability are required for the AMPS, CHEQ, Klein–Bell ADL Scale, and VABS. Studies of reliability to date on the AMPS are limited to adult populations and on the VABS to the standardisation sample. The recently developed CHEQ requires evidence of test–retest reliability to determine its stability as an outcome measure. Evidence of interrater and test–retest reliability of the Klein–Bell ADL Scale was weak because of the very small sample size of the study \((n = 5)\) and results must be interpreted with caution. The PEDI, SFA, and WeeFIM had excellent reliability overall (Table IV). The ABILHAND-Kids had excellent test–retest reliability and is a promising new tool for both clinicians and researchers. The strong psychometric properties of the PEDI have led to its extensive use as an outcome measure in research. Evidence of responsiveness was limited despite all measures in this systematic review, except the VABS, being evaluative tools. Responsiveness is a necessary requirement to measure change over time yet there is no consensus regarding the best method to determine responsiveness. While the MCID is a valuable index to detect change, there is currently no agreed method of calculating MCID and it is not considered a stable concept. Minimal clinically important differences have been reported for the AMPS, PEDI and WeeFIM, which provide clinicians with a guide to interpreting individual and group changes on these measures. Although the PEDI is responsive to meaningful clinical change, the dichotomous response format does not allow for minor changes within items to be recorded. The Klein–Bell ADL Scale is not sensitive to change over time. A ceiling effect was detected in the WeeFIM in children with diplegia and hemiplegia. This limits the use of the WeeFIM with children with mild CP who, despite being independent with ADL, may still experience challenges with some task components.

A key factor when considering the clinical utility of a measure is its administrative burden. The Klein–Bell ADL...
<table>
<thead>
<tr>
<th>Measure</th>
<th>Domains (subdomains)</th>
<th>Scoring</th>
<th>ADL item examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABILHAND-Kids</td>
<td>N/A</td>
<td>Overall score 21 manual ability items rated on a 3-level scale (0 = impossible, 1 = difficult, 2 = easy)</td>
<td>Opening a jar of jam, Washing the upper-body, Sharpening a pencil, Filling a glass with water, Zipping-up a jacket</td>
</tr>
<tr>
<td>AMPS</td>
<td>ADL motor skills ADL process skills</td>
<td>Overall score 16 motor and 20 process skills rated on a 4-point ordinal scale for a minimum of two tasks</td>
<td>Putting on shoes and socks, Setting a table, Upper body dressing, Jam sandwich, Toast and instant coffee/tea, Pulling up tracksuit trousers, Butter a slice of soft bread, Pick money out of purse, Screw cap off bottle, Tie shoelaces</td>
</tr>
<tr>
<td>CHEQ</td>
<td>Independence Affected hand usage Grasp efficacy Time taken Feeling bothered</td>
<td>Overall score 29 bimanual activities rated for independence (yes/no) Affected hand use (not used/as support/with grip) and grasp, time and feeling bothered (4-point ordinal scale) rated for activities performed independently</td>
<td>Domain scores</td>
</tr>
<tr>
<td>Klein–Bell ADL</td>
<td>Dressing Bathing/hygiene Elimination Functional mobility Eating Emergency communication Self-care Mobility Social function Part 1: Functional Skill Scale Part 2: Caregiver Assistance Scale Part 3: Modifications Scale</td>
<td>Overall score (82.35% ADL) 170 items scored with a tick (capable) or 0 (incapable) or N/A Items weighted 1, 2 or 3 Domain scores</td>
<td>Shoes: R toe into R shoe, R heel into R shoe, L toe into L shoe, L heel into L shoe, Fasten R shoe, Fasten L shoe, Uses a fork well, Thoroughly brushes teeth, Washes hands thoroughly, Puts on T-shirt, Puts shoes on correct feet</td>
</tr>
<tr>
<td>SFA</td>
<td>Part 1: Participation (1 domain)</td>
<td>Eating and drinking Hygiene Clothing management Personal care awareness Participation: 6 items rated on a 6-point scale Task supports: 21 possible items rated on two 4-point scale for assistance and adaptations (1 = extensive to 4 = none) Activity performance: 304 items rated on a 4-point scale (1 = does not perform to 4 = consistently performs) Domain scores</td>
<td>Drinks from a cup/glass, Washes hands, Zips and unzips, Puts shoes/boots on, Wipes self after toileting</td>
</tr>
<tr>
<td>VABS and VABS-</td>
<td>Communication (receptive, expressive, written) Daily living skills (personal, domestic, community) Socialisation (interpersonal, play and leisure, coping skills) Motor skills (gross, fine)</td>
<td>Daily living skills Each item rated 0 (never), 1 (sometimes), 2 (usually) or (don’t know) Identify basal and ceilings Raw score equals sum of responses plus number of items before basal × 2 Domain and subdomain scores</td>
<td>Feeds self with spoon without spilling, Brushes teeth, Buttons large buttons in front, Wears appropriate clothing, Takes medicine as directed</td>
</tr>
<tr>
<td>WeeFIM</td>
<td>Self-care (eating, grooming, bathing, dressing – upper, dressing – lower, toileting) Sphincter control (bladder management, bowel management) Transfers (chair, toilet, tub/shower) Locomotion (mode/stairs) Communication (comprehension/expression) Social cognition (social interaction/ problem solving/memory)</td>
<td>Self-care 18 subdomains rated on a 7-point ordinal scale (1 = total assistance to 7 = independence) Domain scores</td>
<td>Eating Grooming Bathing Dressing – upper Dressing – lower Toileting</td>
</tr>
<tr>
<td>Measure*</td>
<td>Content</td>
<td>Construct (convergent/divergent)</td>
<td>Criterion</td>
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<tr>
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<tr>
<td><strong>ABILHAND-Kids</strong></td>
<td>Adapted from adult version; review by 27 experts; pilot work (n = 113, 6-15 y, children with CP and their parents) Rasch model</td>
<td>Significant relationship with school education program, type of CP and GMFCS</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>AMPS</strong></td>
<td>Extensive literature review; filming and observation of wide range of ADL tasks Rasch model</td>
<td>Moderate correlations between AMPS-M and COPM-P r = 0.67, and AMPS-P and COPM-S r = 0.64 (n = 33, 3-15 y, DCD/CP/ASD/other)</td>
<td>No equivalent assessment method Moderate correlation between AMPS and FI r = 0.62 (persons with dementia)</td>
</tr>
<tr>
<td><strong>CHEQ</strong></td>
<td>Literature review; expert opinion; interviews with families (children with CP, ULRD or OBPP) Rasch model; item reliability 0.82-0.90</td>
<td>Activities relevant to children, bimanual and able to be performed independently (n = 86, 6-18 y, CP/ULRD/OBPP)</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Klein-Bell ADL Scale</strong></td>
<td>Empirical analysis of ADL tasks and components; point values for each item reviewed by 10 experts</td>
<td>Significantly different between children with CP and children without disabilities, regression analysis p &lt; 0.001</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>PEDI</strong></td>
<td>Literature review; field testing (children with developmental disabilities); panel of 31 experts; normative sample (n = 412, 6 mo-7 y); clinical sample of children with disabilities including CP (n = 120, 1 y-10 y 6 mo) Rasch model</td>
<td>PEDI Self-care (FSS) and PDMS Fine Motor r = 0.66-0.95; PDMS Gross Motor r = 0.24-0.94; PODCI Transfers and Mobility r = 0.81; PODCI Upper Extremity r = 0.85, CHQ Physical Function r = 0.86; GMFCS r = 0.84; MACS r = 0.82</td>
<td>PEDI and WeeFIM: r &gt; 0.88 for self-care, transportation/locomotion and communication/social function</td>
</tr>
<tr>
<td><strong>SFA</strong></td>
<td>Panel of 30 experts and 40 service providers Factor analysis identified two moderately correlated factors: physical and cognitive/behavioural (0.60 and 0.51 on two samples) 15 of 18 scales were unidimensional (Personal Care Awareness failed to meet criteria)</td>
<td>Significant difference between children with CP, LD and without disabilities; correct classification of children with LD and autism, less accurate for TBI</td>
<td>Strongly correlated with VABS Classroom Ed. r = 0.56-0.72</td>
</tr>
<tr>
<td><strong>VABS</strong></td>
<td>Literature review; initial pool of 2000 items in developmentally sequenced clusters; field testing; national item tryout; national standardisation Principal component analysis confirmed organisation of subdomains into respective domains</td>
<td>Significant difference between children with CP and children with LD and without disabilities; moderate correlations between VABS DLS and Capacity Profile domains; adj r = 0.85 (n = 94, 12-16 y, CP)</td>
<td>Moderate to strong correlations between VABS DLS and Capacity Profile domains; adj r = 0.85 (n = 94, 12-16 y, CP)</td>
</tr>
<tr>
<td><strong>WeeFIM</strong></td>
<td>Adapted from adult Functional Independence Measure (FIM); review by 8 interdisciplinary experts Principal Component Analysis identified two distinct dimensions: motor and cognitive</td>
<td>Direct relationship between WeeFIM Self-Care domain and GMFCS level</td>
<td>WeeFIM and PEDI: r &gt; 0.88 for self-care, transportation/locomotion and communication/social function</td>
</tr>
</tbody>
</table>

*See Table I for definitions of measures. ADL, activities of daily living; AMPS-M/P, Assessment of Motor and Process Skills – Motor Skills/Process Skills; ASD, autism spectrum disorder; CAS, Caregiver Assistance Scales; CHQ, Child Health Questionnaire; CP, cerebral palsy; COPM, Canadian Occupational Performance Measure (P-Performance, S-Satisfaction); DCD, developmental co-ordination disorder; DLS, Daily Living Skills; FSS, Functional Skills Scales; GMFCS, Gross Motor Function Classification System; KGM, known groups method; LD, learning disability; MACS, Manual Ability Classification System; MUUL, Melbourne Assessment of Unilateral Upper Limb Function; N/A, not available; OBPP, obstetric brachial plexus palsy; OTs, occupational therapists; ULRD, upper limb reduction deficiency; PDMS-V, PediaSource Developmental Motor Scales, 2nd edition visual-motor integration subscale; PODCI, Pediatric Outcomes Data Collection Instrument; SIB, Scales of Independent Behavior; TBI, traumatic brain injury.
<table>
<thead>
<tr>
<th>Measure*</th>
<th>Internal consistency</th>
<th>Interrater</th>
<th>Intrarater</th>
<th>Test-retest</th>
<th>Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABILHAND-Kids</td>
<td>$r = 0.94$ (person separation reliability; $n = 113$, 6–15 y, CP)$^{20}$</td>
<td>N/A</td>
<td>N/A</td>
<td>$r = 0.91$ (N = 36, 6–15 y, CP)$^{20}$</td>
<td>MCID not established: Change in two children after 3–4 wk virtual reality intervention (N = 4, 3–14 y, unilateral CP)$^{25}$</td>
</tr>
<tr>
<td>AMPS</td>
<td>Separation reliability: AMPS-M: $r = 0.92$, (n = 148158, 3–130 y, various diagnoses including CP and well)$^{21}$</td>
<td>Misfitting ratings (6 raters) $-2.5%$ (n = 10, 22–38 y, well)$^{60}$</td>
<td>AMPS-P: $r = 0.93$ (n = 20, 24–35 y, well)$^{61}$</td>
<td>AMPS-M: $r = 0.9-0.91$; AMPS-P: $r = 0.87-0.90$ (adult populations, various diagnoses)$^{21}$</td>
<td>MCID = 0.3 logit on ADL motor and process ability measures$^{21}$ Change in children with developmental disabilities after client-centred OT, unilateral CP after botulinum toxin type-A injections and OT/standard OT, and unilateral CP after home-based online training$^{27}$</td>
</tr>
<tr>
<td>CHEQ</td>
<td>Separation reliability: Scales $r = 0.90-0.94$ (n = 86, 6–18 y, CP/ULRD/OBPP)$^{22}$</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>MCID not established: Change in four children after 3–4 wk virtual reality intervention compared to two children in ABILHAND-Kids (N = 4, 3–14 y, unilateral CP)$^{29}$</td>
</tr>
<tr>
<td>Klein–Bell ADL Scale</td>
<td>Three pairs of OTs and three pairs of RNs achieved 92% agreement on 20 adult patients$^{38}$</td>
<td>ICC 0.99 (n = 5, 6–18 y, CP)$^{38}$</td>
<td>N/A</td>
<td>ICC 0.98 (n = 5, 1.5–6 y, CP)$^{38}$</td>
<td>MCID not established: Change after 9-mo period: $p = 0.8$ Parental ratings (same, worse, better ADL function) compared to change in functional rating over 9 mo: $x = 77.7%$</td>
</tr>
<tr>
<td>PEDI</td>
<td>PEDI: $x = 0.98-0.99$ SC $x = 0.98$ (n = 115, 3–10 y, CP)$^{47}$</td>
<td>PEDI: ICC 0.15–0.95 SC (FSS) and (CAS): ICC 0.84 (n = 17, 1–7 y, CP/DD/other)$^{32}$</td>
<td>N/A</td>
<td>PEDI: ICC 0.67–1.0 SC (FSS): ICC 0.98; (CAS): ICC 0.92 (n = 23, 1–7 y, CP/DD/other)$^{32}$</td>
<td>MCID = approx. 11 points (0–100 scale)$^{36}$ Responsive over time$^{63,64}$ and sensitive to change after SDR$^{56}$, CIMT$^{34}$, and botulinum toxin type-A injections: SC domain$^{66}$ and FSS$^{67}$</td>
</tr>
<tr>
<td>SFA</td>
<td>SFA scales: $x = 0.92-0.98$ Eating and drinking, hygiene and clothing management: $x = 0.97$ (n = 363, 5–13 y, various diagnoses including CP)$^{26}$</td>
<td>Teachers versus OT: Participation: ICC 0.70 Task supports: ICC 0.68 Activity performance: ICC 0.73$^{55}$</td>
<td>N/A</td>
<td>SFA scales: ICC 0.80–0.99 Eating and drinking: ICC 0.93 Hygiene: ICC 0.98 Clothing management: ICC 0.98 (n = 29, 5–13 y, various diagnoses including CP)$^{26}$</td>
<td>MCID not established: Change in participation and task support domains ($p \leq 0.1$), not in travel/maintaining position (n = 16, 6–13 y, CP/DD/speech disorder)$^{68}$</td>
</tr>
<tr>
<td>VABS</td>
<td>Split-half reliability (Guilford formula): Adaptive behaviour composite: 0.89–0.98; DLS: 0.83–0.92 (n = 3000, standardisation sample)$^{27}$</td>
<td>Domains ICC: 0.93–0.99; DLS: $r = 0.72$ Adaptive behaviour composite ICC: 0.98; $r = 0.74$ (n = 160, 6 mo–18 y 11 mo, standardisation sample)$^{27}$</td>
<td>N/A</td>
<td>Domains ICC: 0.95–0.99 Adaptive behaviour composite ICC: 0.99 (n = 160, 6 mo–18 y 11 mo, standardisation sample)$^{27}$</td>
<td>MCID not established VABS Classroom Edition: Change in communication and motor skills domains ($p &lt; 0.1$) (n = 16, 6–13 y, CP/DD/speech disorder)$^{68}$</td>
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</table>
Table IV: Continued

<table>
<thead>
<tr>
<th>Measure*</th>
<th>Internal consistency</th>
<th>Interrater</th>
<th>Intrarater</th>
<th>Test–retest</th>
<th>Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>WeeFIM Motor $\alpha = 0.91$</td>
<td></td>
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<tr>
<td>WeeFIM Process $\alpha = 0.98$</td>
<td>Total WeeFIM: ICC 0.73–0.98; WeeFIM Self-care ICC: 0.86</td>
<td>NA</td>
<td>Total WeeFIM ICC 0.98; Self-care ICC 0.92–0.97</td>
<td>SC of WeeFIM SC = 3.1 (medium ES) and 5.0 (large ES)</td>
<td></td>
</tr>
<tr>
<td>(n = 134, 6 mo–16 y, CP)</td>
<td>(n = 205, 1–7 y, developmental disabilities)</td>
<td></td>
<td></td>
<td>Responsive over 1-y period: Total WeeFIM RCI = 2.82, $p &lt; 0.00$; SC RCI = 2.64, $p &lt; 0.00$ (n = 205, 1–7 y, developmental disabilities)</td>
<td>Ceiling effect in children with diplegia and hemiplegia undergoing surgery</td>
</tr>
<tr>
<td></td>
<td>Subscales ICC 0.94–0.99, total score ICC 0.98–0.99 (n = 67, 1–6 y, developmental disabilities)</td>
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</tbody>
</table>

*See Table I for definitions of measures. ADL, activities of daily living; AMPS-M/P, Assessment of Motor and Process Skills – Motor Skills/Process Skills; CAS, Caregiver Assistance Scales; CIMT, constraint-induced movement therapy; CP, cerebral palsy; DCD, developmental coordination disorder; ES, effect size; FSS, Functional Skills Scales; ICC, intraclass correlation; MCID, minimal clinically important difference; N/A, not available; OBPP, obstetric brachial plexus palsy; OT, occupational therapy; OTs, occupational therapists; RCI, reliability change index; SC, Self-Care; SDR, selective dorsal rhizotomy; SRM, standardised response mean; ULRD, upper limb reduction deficiency; VABS-DLS, Vineland Adaptive Behavior Scales – Daily Living Skills.

Scale requires 60 to 180 minutes for administration which significantly reduces its clinical utility. The ABILHAND-Kids was the quickest assessment to administer and score, taking only 5 to 10 minutes for administration. The AMPS was the only assessment that required specific assessor training. The length of this training process (a 5-day course plus additional scoring) reflects the complexity of the scoring but the time commitment is an initial consideration for therapists. The available space and materials will also influence the choice of this measure. Observational assessments require either a home visit, which is typically not feasible in routine clinical practice, or the use of appropriate facilities (e.g. kitchen area) and all necessary items and consumables.

The only measure that evaluates underlying motor and cognitive deficits in task performance is the AMPS. The AMPS scoring software generates various summary reports, which aids therapists considerably in identifying problem areas and planning intervention. Software is also available for the ABILHAND-Kids, which increases therapist efficiency with electronic scoring and report generation. Preliminary studies of the computerised adaptive test of the PEDI (PEDI-CAT) report adequate concurrent validity, item-specific reliability and score distributions in a sample of children with neurodevelopmental disabilities including CP. The potential of PEDI-CAT is enhanced with an extended age range up to 20 years. The PEDI and WeeFIM have upper age limits of 7 years 6 months and 8 years, respectively, although both can be used with older children with developmental delay. The adult Functional Independence Measure (FIM), from which the WeeFIM was adapted, is reported to be a reliable measure for adolescents with diplegia and quadriplegia.

Overall, the PEDI is the best measure to evaluate ADL capability in elementary school aged children. The PEDI has strong psychometric properties and broad item content within the Self-Care domain. Limitations of the PEDI are the age range and dichotomous response format, which may limit its ability to detect minor functional changes on items. For adolescents with CP, use of the ABILHAND-Kids (<15 years) is recommended to measure ADL capability because of its clinical utility and specificity to children with CP. Available measures of ADL capability for adolescents up to 18 years are the CHEQ, VABS and FIM; however, there are some caveats to be considered by therapists. The new version of the CHEQ requires further validation work, the VABS is a discriminative measure (and therefore not suitable to evaluate change) and evidence of the psychometric properties of the FIM is limited in this population group.

The AMPS is the best measure to evaluate ADL performance or capacity for children and adolescents of all ages. The AMPS is a useful tool to link ADL ability with underlying motor and process difficulties and children typically enjoy and engage willingly in this assessment. The AMPS should ideally be conducted in the home environment (as a measure of performance) but can be used as a measure of capacity in the clinical setting. Process skills differ slightly between home and clinical environments so therapists must familiarise the child to the clinical setting before carrying out AMPS tasks.

There are some limitations to this review. Articles not published in English were excluded and so some relevant articles may have been missed. The strict 60% item inclusion criteria excluded a number of measures which included ADL items such as the Pediatric Outcomes Data Collection Instrument and the Capacity Profile. The authors deemed that assessments with less than 60% of ADL items were not a true reflection of ADL ability.
**CONCLUSION**

This systematic review identified eight suitable ADL measures for school aged children with CP. The PEDI is the best measure of ADL capability for elementary school aged children with robust psychometric properties and a broad range of personal ADL items. For adolescents with CP, the CHEQ, VABS and FIM are promising measures of ADL capability but therapists should take into consideration the limitations of these assessments before implementing them in practice or research. The AMPS is the best tool to evaluate ADL task performance or capacity in children and adolescents regardless of age. There is extensive evidence of its psychometric properties in adults but further work is required to strengthen its reliability in this population. Activities of daily living play a central role in supporting participation and health professionals must incorporate ADL measures into clinical practice and research with a judiciously chosen assessment tool.

**ACKNOWLEDGEMENTS**

SJ is supported by an Australian Federal Government Australian Postgraduate Award (APA) and Queensland Government Smart Futures PhD Scholarship. RB is supported by an NHMRC...
Career Development Award Fellowship 1037220 and the University of Queensland.

SUPPORTING INFORMATION
Additional Supporting Information may be found in the online version of this article:

REFERENCES

Appendix S1: Adapted CanChild Outcomes Measure Rating Form for the review of activities of daily living measures for children aged 5–18 years with cerebral palsy.

Appendix S2: Excluded measures of activities of daily living for school-aged children with cerebral palsy.

ADL Measures for CP. Sarah James et al. 11
2.3 Summary and Conclusions

This systematic review identified eight ADL measures that have reported psychometric properties and are available for use with children and adolescents with CP. The main findings from this systematic review are:

- The AMPS is the best available measure to evaluate ADL performance or capacity in children and adolescents with UCP. The AMPS was validated on a large sample and AMPS motor and process scale items have shown adequate goodness-of-fit in typically developing children.
- The PEDI is recommended to measure ADL capacity however is limited by the upper age limit of 7.5 years (and older with developmental disabilities).
- The majority of available assessments are measures of capability and are administered via proxy report. The AMPS and Klein-Bell ADL scale are observational evaluations that measure ADL performance (or capacity if administered in a clinical setting). Observational evaluation allows for therapist assessment of ADL skills without relying on proxy report.
- The ADL tasks within the assessments are predominantly personal ADL, which are the most relevant for younger children. The AMPS also contains a wide range of instrumental ADL, which allows children and adolescents with mild to moderate CP to carry out more challenging tasks.
- The AMPS is the most appropriate assessment to measure ADL in the RCT, as it has high clinical utility and evaluates both the motor and processing components of ADL. The test-retest reliability however should be established in this population in order to attribute potential changes in score following the intervention to real changes in ADL capacity.
Chapter 3: Study protocol

3.1 Introduction to Chapter 3

Chapter 3 consists of the study protocol entitled, “Move it to improve it (Mitii™): study protocol of a RCT of a novel web-based multimodal training program for children and adolescents with cerebral palsy”. This paper describes the research aims and methods for the overall Mitii™ study, of which this doctoral program comprises evaluation of the occupational therapy outcome measures.

3.2 Paper 2: Move it to improve it (Mitii™): study protocol of a randomised controlled trial of a novel web-based multimodal training program for children and adolescents with cerebral palsy

This protocol paper was published in BMJ Open in March, 2013.

Move it to improve it (Mitii): study protocol of a randomised controlled trial of a novel web-based multimodal training program for children and adolescents with cerebral palsy

Roslyn N Boyd,1,2 Louise E Mitchell,1,2 Sarah T James,1,2 Jenny Ziviani,2,3 Leanne Sakzewski,1,2 Anthony Smith,4 Stephen Rose,5 Ross Cunnington,5,7 Koa Whittingham,1,7 Robert S Ware,8,9 Tracey A Comans,10 Paul A Scuffham10

ABSTRACT

Introduction: Persons with cerebral palsy require a lifetime of costly and resource intensive interventions which are often limited by equity of access. With increasing burden being placed on health systems, new methods to deliver intensive rehabilitation therapies are needed. Move it to improve it (Mitii) is an internet-based multimodal programme comprising upper-limb and cognitive training with physical activity. It can be accessed in the client’s home at their convenience. The proposed study aims to test the efficacy of Mitii in improving upper-limb function and motor planning. Additionally, this study hopes to further our understanding of the central neurovascular mechanisms underlying the proposed changes and determine the cost effectiveness of Mitii.

Methods and analysis: Children with congenital hemiplegia will be recruited to participate in this waitlist control, matched pairs, single-blind randomised trial. Children be matched at baseline and randomly allocated to receive 20 weeks of 30 min of daily Mitii training immediately, or waitlisted for 20 weeks before receiving the same Mitii training (potential total dose=70 h). Outcomes will be assessed at 20 weeks after the start of Mitii, and retention effects tested at 40 weeks. The primary outcomes will be the Assessment of Motor and Process Skills (AMPS), the Assisting Hand Assessment (AHA) and unimanual upper-limb capacity using the Jebsen-Taylor Test of Hand Function (JTTHF). Advanced brain imaging will assess use-dependent neuroplasticity. Measures of body structure and functions, activity, participation and quality of life will be used to assess Mitii efficacy across all domains of the International Classification of Functioning, Disability and Health framework.

Ethics and dissemination: This project has received Ethics Approval from the Medical Ethics Committee of The University of Queensland (2011000608) and the Royal Children’s Hospital Brisbane (HREC/11/QRCH/35). Findings will be disseminated widely through conference presentations, seminars and peer-reviewed scientific journals.

Trial registration: ACTRN12611001174976

ARTICLE SUMMARY

Article focus

- The main aim of this proposed study was to determine if 20 weeks of intensive move it to improve it (Mitii) training can improve upper-limb (UL) activity (unimanual and bimanual), occupational performance and cognitive skills in children and adolescents with CP compared with standard care.

- The secondary aim is to further our understanding of the central neurovascular mechanisms underlying changes in UL function, motor planning and executive function (using functional MRI and transcranial magnetic stimulation to measure central activation in the parts of the brain controlling movement).

- It is hypothesised that Mitii will be more effective than Usual Care (occupational therapists/physiotherapists) for children with congenital hemiplegia (aged 8–18 years) to improve activity (unimanual capacity and bimanual performance) by a mean difference of five points on the Assisting Hand Assessment and 10% decrease in time on the Jethson-Taylor Test of Hand Function and motor and process skills (Assessment of Motor and Process Skills) will improve by 0.5 logit scores following Mitii intervention.

BACKGROUND

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitations, which are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, cognition, perception, behaviour and/or seizure disorders and by secondary...
Musculoskeletal problems.\textsuperscript{1} In Australia, around 600–700 infants are born with CP each year, making it the most common physical disability in childhood.\textsuperscript{2} There remains no cure for CP; meaning that an infant born with this condition will require a lifetime of investigations, interventions and equipment. In 2007, CP was estimated to cost AUD$43,431 per person with CP per annum.\textsuperscript{3} CP is not only a costly but burdensome condition, impacting the individual, his/her family and society more generally. These impacts highlight the need to optimise health, function and fitness of individuals with CP to reduce costs associated with the condition.

Several intensive therapy approaches delivered by a therapist directly to the child with CP are currently offered to improve upper limb (UL) function. A systematic review and meta-analysis of all non-surgical UL interventions found some evidence to support these intensive training approaches (eg, modified-Constrained Induced Movement Therapy (mCIMT) and bimanual training (BIM)) to improve the amount of use (effect size (ES) =1.54) and efficiency of movement (ES=0.44) of the impaired arm and new repertoires of hand skills (ES=1.22). Our group recently completed a single blind randomised controlled trial of a web-based program for cerebral palsy (Mitii: randomised controlled trial of a web-based program for cerebral palsy). The results suggest that a minimum of 60 h in a block of training is required to drive neuroplasticity, which has implications for the current dose and intensity of standard training regimens for children with unilateral CP. These findings support the need for training to be intensive, repetitious and incrementally challenging in order to drive neuroplasticity.

The challenge is that while both interventions are effective they are costly and require 60 h of direct rehabilitation provided by specialist trained occupational therapists (OTs) and/or physiotherapists (PTs). Implementing direct intensive interventions in specialist settings also potentially limits access to children who live in major metropolitan centres. The reality is that current clinical practice affords children with unilateral CP only consultative or time-limited therapy following pharmacological intervention (1–12 h/year). Limited available health resources mean the amount of therapy may be insufficient to drive neuroplastic changes necessary for functional improvements to occur. Alternatives for intensive rehabilitation programmes are required. Internet-delivered programs and ‘active’ video games are emerging as a popular modality for paediatric interventions. These systems have the potential to deliver novel, engaging and intensive therapies to children in both metropolitan and more isolated areas where services are limited, in a potentially cost effective manner.

‘Active’ video games not only have the potential to deliver UL interventions, but also to use otherwise sedentary screen time to promote physical activity. Children today, particularly those with motor disabilities which limit participation in sports or exercise, spend increased time in sedentary screen-based leisure activities, such as watching television or playing sedentary video games. This displaces more active behaviours which in part contributes to obesity and other adverse health outcomes.\textsuperscript{4} It is known that children and adolescents with CP are less physically active than their typically developing peers\textsuperscript{5,6} or compared with children with other physical disabilities, such as spina bifida or head injuries.\textsuperscript{11} This is an important health promotion consideration as patterns of physical activity acquired during childhood are more likely to be maintained into adult life, providing the foundation for healthy lifestyle choices.\textsuperscript{12} Additionally, for school-aged children with CP, interventions including intramuscular botulinum toxin type-A, casting and surgery usually followed by a limited amount of therapy are common at this age. Success of these interventions should be assessed against all dimensions of the International Classification of Functioning, Disability and Health (ICF),\textsuperscript{13} including their impact on physical activity capacity and performance, as well as participation.
Activities of daily living (ADL; ie, life tasks required for self-care and self-maintenance) are fundamental in supporting participation across school, home and community environments. Children and adolescents with unilateral CP often experience difficulties with ADL due to their motor and associated difficulties. Performance of ADL is a high priority for parents/guardians. Therapy targeting ADL for children with unilateral CP often involves task-specific training to stimulate motor learning. Alternatively, therapy may address deficits in motor and cognitive skills that are considered prerequisites for successful performance of ADL. Rehabilitation that involves a combination of UL, gross motor, cognitive and visual perceptual training is likely to improve performance of ADL. Enhanced-ADL ability may increase independence for children and adolescents and reduce the burden of care for parents/guardians.

Underpinning participation in many daily tasks are executive functions. This describes an umbrella term for functions such as planning, working memory, inhibition, mental flexibility, as well as the initiation and monitoring of action. Children with mild CP have demonstrated impairments with executive function in multiple domains. Therapies that not only target improvement in physical impairments but also components of executive function have the potential to improve a child’s performance and participation in more complex activities, including academic school performance.

An effective web-based multimodal training that enhances cognitive and motor abilities using multidisciplinary virtual trainers may be a cost effective means of delivering therapy and facilitate translation of skills into home and community environments. This has significant implications for equity of access for children in diverse geographical locations. Move it to improve it (Mitii) is an internet-based multimodal training program comprising UL and cognitive training within the context of meaningful physical activity. Mitii detects bodily movements generated by a child using a green tracking band worn on the hand, head or knee. These movements are tracked by a web camera attached to an internet-connected computer. Mitii requires no specialist or costly equipment and can be delivered in the client’s home. PTs, OTs and psychologists act as virtual trainers remotely accessing the program to set up a series of ‘games’ via the program’s ‘cockpit’. These are graded regularly to deliver an incrementally challenging and individualised programme.

The feasibility of delivering Mitii has been confirmed in a pilot study of nine children achieving on average 35 min of training daily for 20 weeks (total dose 70 h). Compliance was high, with an average of 85% of children meeting or exceeding this dose. In a prepost performance measure (COPM) performance and satisfaction; 6. Occupational performance (Canadian occupational performance measure (COPM) performance and satisfaction); 7. Functioning and participation domains of quality of life (CP-QOL-Child or CP-QOL-Teen); 8. Functional abilities in self-care and daily activities (mobility questionnaire-28 (MobQues28)); 9. Physical activity capacity immediately following Mitii training (Functional strength: repeated sit to stand, half-kneel to stand and step up tests; and 6 min walk test (6MWT)); 10. Physical activity performance (ActiGraph) and greater compliance with the national physical activity recommendations;
Mitii: randomised controlled trial of a web-based program for cerebral palsy

11. Mitii will be more cost-effective compared with Usual Care as shown by resource use and effectiveness based on function (AMPS) and quality of life (CP-QOL).

Ethics
Full ethical approval has been obtained from the Medical Ethics Committee of The University of Queensland (2011000608) and the Royal Children’s Hospital Brisbane (HREC/11/QRCH/35). Written and informed consent will be obtained from parents or guardian and all participants over 12 years of age, by study coordinators and personnel, upon entering the trial before matching and randomisation. The proposed Mitii clinical trial has been registered with the Australian and New Zealand Clinical Trials registration: ACTRN12611001174976.

Study sample and recruitment
Children and youth with spastic-type congenital hemiplegia aged 8–18 years will be recruited across Queensland and New South Wales, Australia. Potential study participants will be identified through a population-based research database, which currently comprises over 1600 children with CP at the Queensland Cerebral Palsy and Rehabilitation Research Centre (QCPRRC), the Queensland Cerebral Palsy Register (QCPR), Queensland CP Health Service and advertising to OTs, PTs and Paediatricians at the Royal Children’s Hospital, Brisbane and in the community. The recruitment process will target both publicly funded services and private practitioners with the expectation that the sample will be representative of children with congenital hemiplegia.

Inclusion and exclusion criteria
Children with mild to moderate congenital hemiplegia will be recruited, who are: (1) Gross Motor Function Classification (GMFCS) I or II\(^{25}\); Manual Abilities Classification scale (MACS) I, II, III\(^{23}\); (2) aged 8–18 years with sufficient cooperation and cognitive understanding to perform the tasks and (3) able to access the internet at home (phone line or internet access). Children will be excluded if they have (1) received UL or lower-limb surgery in the previous 6 months; (2) unstable epilepsy (ie, frequent seizures not controlled by medication) or (3) a respiratory, cardiovascular or other medical condition that would prevent them participating safely in the Mitii training. Diagnosis of CP will be confirmed by a paediatrician or clinician and in accordance with published recommendations.\(^{25}\)

Sample size
Sample size calculation is based on the primary hypothesis comparison between the functional effects of Mitii compared with standard care at 20 weeks on the AMPS. This study examines a continuous response variable from matched waitlist control and immediate-intervention participants with one waitlist control per immediate-intervention participant. In a previous study of Mitii the response within each group was normally distributed with SD 0.58 on the AMPS.\(^{20}\) To detect a clinically significant difference (0.5 units or greater) between groups with 80% power and a=0.05, 44 children are required in each group. Allowing for 10% attrition, the sample size will be 98 participants. To assist in achieving this sample size, participants will be offered reimbursement of travel expenses and flexible appointment times and locations.

For hypothesis two, based on our previous randomised trial using 3T fMRI we see activation in the representative cortex for motor studies with good signal-to-noise ratio. Participant numbers will allow for some loss of information due to participant refusal (10%) and scans where motion is a confounder (10%). With 40 participants in an analysis of baseline to week 20 changes on fMRI, this study will have 80% power to detect a difference between groups of 0.65 SD. If the supplementary motor area (SMA) is considered, given coefficient of variation (CV) for control participants performing motor tasks (CV of 11% in PM1 and 35% in SMA),\(^{26}\) and activation signal of 1.5%, we are able to detect differences in % activation levels over time as small as 0.47.

Design
The efficacy of Mitii will be tested using a waitlist control assessor masked randomised controlled trial (RCT) conducted according to CONSORT guidelines (see figure 1). Participants will be consented to the study and then matched in pairs. All participants of the study will receive Mitii training. Within the pair, each participant will be randomised to either:

1. Immediate intervention group
   Families return home with Mitii equipment and begin training immediately; or

2. Waitlist delayed intervention (control) group
   Families continue care as usual for 20 weeks and then return to Brisbane for 1-day reassessment then receive the same intervention as the immediate intervention group.

Children will not be provided with any concomitant treatments, such as arm splinting, casting or UL intramuscular botulinum toxin type-A injections during the baseline to 20-week intervention period. Participants who have received intramuscular botulinum toxin type-A in the UL the previous 2 months will have assessments and interventions postponed until after their standard follow-up has been completed (usually 6–8 weeks post-injection). All concurrent therapies provided by local services duration, frequency and content will be recorded by questionnaire at 20-week follow-up.

Randomisation
Children will be matched in pairs according to age (within 12-month age bands), gender and level of functional ability based on MACS level, at screening. A matched pairs design is the design of choice as it minimises the likelihood of group differences at baseline that
has often been present in rehabilitation studies.\textsuperscript{27, 28} Once matching has been achieved, children will be randomly allocated within pairs (one member of each pair to be randomly allocated to each group) from sealed envelopes opened by non-study personnel. The randomisation process will involve randomly allocating a number
Mitii: randomised controlled trial of a web-based program for cerebral palsy

‘1’ or ‘2’ to each member of the pair. As each pair is entered, they will be allocated the next consecutive envelope, which will be opened by the non-study personnel who will read and record the treatment allocation from the paper inside the envelope. Treatment allocation will be recorded on a piece of folded paper inside each envelope, in random order (either 1:Waitlist 2: Immediate; or 1:Immediate 2:Waitlist, with the sequence being computer generated). Study personnel will be informed of group allocation; however, participants and their parents/guardians will not be informed of their group allocation until after their baseline assessments.

Blinding
Functional MRI and TMS data will be qualitatively analysed by neurologists masked to group allocation. Paediatric neurologists with fMRI training will independently rate scan quality (0–5), region of activation, change over time and patterns of reorganisation. Data on the AHA and Melbourne assessment of unilateral UL function (MUUL) will be rated from video recordings analysed by assessors masked to group allocation and assessment time point.

Adverse events
Any minor and major event associated with the training model will be screened at 20 weeks by open-ended questions.

Study procedure
Children will attend the Queensland Cerebral Palsy and Rehabilitation Research Centre in Brisbane for 1 day for baseline assessments. Participants in the immediate intervention group will spend an additional day for Mitii training and then return home with Mitii equipment and start the training immediately. The delayed intervention (Waitlist control) group will continue care as usual for 20 weeks and then return to Brisbane for 1-day reassessment and then receive the Mitii training and equipment. For each participant, data will be collected at baseline (T1). For the Immediate intervention group, follow-up assessments will be conducted postintervention at 20 weeks postrandomisation (T2), and then retention (40-week post-randomisation, T3). For the Waitlist group, an additional baseline assessment will be conducted at 20 weeks postrandomisation (T2), and then postintervention at 20 weeks after commencing the Mitii training (40 weeks postrandomisation, T3). Retention of effects will be collected in the Waitlist group by an additional assessment at 60 weeks postrandomisation (T4; see figure 1).

Mitii intervention
Mitii is delivered in the participant’s home through an internet-connected computer with a web camera using a cloud server-based interactive training system employing Adobe Flash technology. The system has been developed through collaboration between The Helene Elsass Centre and the Ministry of Research under the name Mitii (Move it to improve it; Mitii developments, Charlottenlund, Denmark).

A child is initially assessed by a multidisciplinary team (PT, OT and psychologist) to ascertain fine and gross motor skills and cognitive abilities. A deidentified alias account is created for the child in Mitii and therapists develop an individually tailored group of tasks/games available in the program. The child then logs onto Mitii (through internet access) and completes the activities in his/her own home or local environment. Activities include gross motor control (eg, unilateral and bilateral UL movement, sit-to-stand, balance) as well as cognitive tasks (eg, matching, ordering, moving and tracking objects; see table 1). The combination of UL and lower-limb gross motor, cognitive and visual perceptual training is designed to have a multimodal effect by training multiple networks which then enhances performance in each area. It consists of a number of training modules or ‘games’ in which the child has to analyse visual information, solve a cognitive problem (ie, mathematical question or similar) and respond with a motor act (ie, bend to pick up needle and pop the balloon with the right answer). The participant interacts with the system through movement of a green tracking band worn on the hands or head. The computer program identifies the movements of the child from video images sampled from a simple web camera attached to the computer.

Mitii training
Participants log into the Mitii website and access their individualised training programmes at their convenience, enabling training to be completed at any time. The specific content and progression of the programme will be decided from a weekly evaluation of participants’ performance. The different modules will be combined uniquely according to the specific cognitive and motor abilities of each child. The level of difficulty can be adjusted by increasing the difficulty of the perceptual (eg, increasingly complex forms have to be correctly identified), cognitive (eg, increasingly difficult mathematical questions) or motor challenges (eg, child has to do more repetitions or work with higher load). This is completed by therapists (PT, OT and psychologists) who are in weekly email contact with the participants and their families. This has the effect that the participants and their parents have a private ‘virtual’ coach who oversees their training.

A series of individual tasks or games will be combined in a sequence to make a daily programme of 30-min duration. Mitii should be completed in, at least, 30 min daily for 6 days/week for 20 weeks to provide sufficient training intensity (providing a total dose of 60 h). Tasks can be divided into those training gross-motor or physical activity (eg, repetitive sit-to-stand exercises) or those
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<tr>
<th>Task</th>
<th>Task description</th>
<th>Action</th>
<th>Parameters adjusted</th>
<th>Domains trained</th>
<th>Results displayed</th>
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<tbody>
<tr>
<td>Memory</td>
<td>Memorise a sequence of images</td>
<td>Look at number of images. Images disappear and client must memories them in order which they were shown. Displays sample of images and uses upper limb movement to recreate sequence</td>
<td>Number of images displayed</td>
<td>Upper limb movement</td>
<td>% Correct</td>
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<td>Number of images in sequence</td>
<td>Memory/cognition</td>
<td>Time spent on exercise</td>
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<td>Length of time displayed</td>
<td>Visual perception</td>
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<td>Complexity of images</td>
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<td>Position of images</td>
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<td>Number of repetitions</td>
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<td>Complexity of images</td>
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<tr>
<td>Brick</td>
<td>Ability to recognise the outline of a picture</td>
<td>Sequence of images displayed, one of which matches shape. Client uses upper limb to drag corresponding image to shape</td>
<td>Number of images</td>
<td>Upper limb movement</td>
<td>% Correct</td>
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<td>Rotation of figures</td>
<td>Memory/cognition</td>
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<td>Position of images</td>
<td>Visual perception</td>
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<td>Complexity of images</td>
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<tr>
<td>Figure builder</td>
<td>Ability to construct a complete image from smaller pieces</td>
<td>An image is in the middle of screen. Small pieces of this and other images are falling down either side. Use upper limb to reach and drag corresponding piece to recreate image from bottom to top</td>
<td>Number of images</td>
<td>Upper limb movement</td>
<td>Number of pieces missed</td>
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<td>Number of pieces</td>
<td>Memory/cognition</td>
<td>Time spent on exercise</td>
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<td>Interval between pieces</td>
<td>Visual perception</td>
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<td>Speed of falling pieces</td>
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<td>Number of repetitions</td>
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<td>Complexity of images</td>
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<td>Figure ground</td>
<td>Ability to pick out a figure from an unorganised background</td>
<td>Large background image presented. Use upper limb to pick up small brick and drag to corresponding place in image</td>
<td>Time held over correct place</td>
<td>Upper limb movement</td>
<td>Time spent on exercise</td>
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<td></td>
<td>Ability to perceive spatial orientation of a figure</td>
<td>Use upper limb to touch the image in the sequence which differs. (eg, Pear, Apple, Orange, Car. The car is different.)</td>
<td>Precision of placement</td>
<td>Visual perception</td>
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<td>Number of repetitions</td>
<td>Complexity of background</td>
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<td>Interval between images</td>
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<td>Time held over correct image</td>
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<td>Complexity of images</td>
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<tr>
<td>Spatial relation</td>
<td>Ability to perceive spatial orientation of a figure</td>
<td>Use upper limb to touch the image in the sequence which differs. (eg, Pear, Apple, Orange, Car. The car is different.)</td>
<td>Time held over correct image</td>
<td>Upper limb movement</td>
<td>% Correct</td>
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<td>Number of repetitions</td>
<td>Visual perception</td>
<td>Time spent on exercise</td>
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<td>Complexity of images</td>
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<tr>
<td>Visual closure</td>
<td>Ability to recognise an incomplete figure</td>
<td>Series of incomplete images displayed, and complete single image. Use upper limb to drag incomplete image to complete image. Correct image is one that if complete, would be identical to the presented complete image</td>
<td>Number of images</td>
<td>Upper limb movement</td>
<td>% Correct</td>
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<td>Position of images</td>
<td>Memory/cognition</td>
<td>Time spent on exercise</td>
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<td>Internal between images</td>
<td>Visual perception</td>
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<td>Time held over correct image</td>
<td>Repetitions</td>
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<td>Complexity of images</td>
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<tr>
<th>Task</th>
<th>Task description</th>
<th>Action</th>
<th>Parameters adjusted</th>
<th>Domains trained</th>
<th>Results displayed</th>
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<tbody>
<tr>
<td>Balloon mathematics</td>
<td>Ability to complete mathematical calculations</td>
<td>Equation and a number of answer options are presented in balloons. Use upper limb to drag pin and pop balloon with correct answer</td>
<td>Complexity of equation, Number of terms in equation, Size of number in equation, Time held over correct balloon, Time equation displayed, Time answer displayed, Position of balloons, Position of pin, Number of repetitions</td>
<td>Upper limb movement, Memory/cognition, Visual perception</td>
<td>% Correct, Time spent on exercise</td>
</tr>
<tr>
<td>Combination (two-hand exercise)</td>
<td>Ability to coordinated both upper limbs</td>
<td>Series of images presented on both sides. Use both hands to drag two matching items into a circle in the centre of the screen</td>
<td>Number of images presented, Number of matching pairs, Location of goal circle, Size of goal circle, Time held on correct image, Time held in goal circle, Number of repetitions, Time bomb, Complexity of images</td>
<td>Bimanual upper limb coordination, Memory/cognition, Visual Perception</td>
<td>% Correct, Time spent on exercise</td>
</tr>
<tr>
<td>Flight simulator</td>
<td>Ability to balance against series of lateral displacements</td>
<td>Use band on head to steer the plane against a series of lateral wind gust disturbances</td>
<td>Airplane speed, Wind direction, Time of wind gust, Strength of wind gust, Exercise duration</td>
<td>Balance</td>
<td>Time spent on exercise, Balance distribution</td>
</tr>
<tr>
<td>Follow</td>
<td>Ability to control gross motor movements and activate larger muscle groups</td>
<td>Use band on head to steer an object around screen</td>
<td>Route of object, Speed of object movement, Amplitude of object movement, Size of object, Number of repetitions</td>
<td>Lower limb strength, Balance</td>
<td>% Correct route, Time spent on exercise</td>
</tr>
<tr>
<td>Get up/get down</td>
<td>Activate larger muscle groups to increase intensity and pulse rate</td>
<td>Use band on head to steer object from top to bottom of screen while doing gross motor movement (eg, Sit to stand, Squat to stand, Lunge to stand, Step on/off block)</td>
<td>Location of object, Number of repetitions, Time bomb</td>
<td>Lower limb strength, Balance, Time challenge</td>
<td>Time spent on exercise, Time per repetition</td>
</tr>
<tr>
<td>Follow the leader</td>
<td>Follow a sequence of movements</td>
<td>Video sequence uploaded and client follows visualising themselves and the video in a split screen view</td>
<td>Video created by therapist therefore can modify</td>
<td>Lower limb strength, Balance</td>
<td>Time spent on exercise, Balance</td>
</tr>
</tbody>
</table>

Continued
combining cognitive or visual perception and an UL task (eg, moving the UL to solve a mathematic equation). To ensure each participant receives a similar training programme, all sequences will comprise approximately 60% cognitive-UL and 40% gross-motor training tasks individualised to the child’s abilities. Step blocks and balance foam can be added as the child progresses to add additional challenge to the tasks.

**Participant and data management**

The percentage of eligible participants successfully recruited, and number of eligible participants who choose not to participate will be recorded. Participant retention will be recorded throughout the trial period. All data will be analysed by intention to treat, whereby a participant’s assessment from the last available time-point is carried forward in the event of withdrawal or loss to follow-up. Treatment dose is automatically recorded by the Mitii program and will be monitored by the therapists. Strategies to manage engagement in the programme will be discussed with the participant and parent/guardian during their initial Mitii training. All participants will receive a Mitii rewards chart which segments the 20-week programme into four 5-week blocks and allows small rewards to be decided in advance for completing each stage. Other strategies such as parent/guardian involvement, feedback, positive reinforcement and incorporating Mitii into the family routine will also be discussed. Therapists will contact participants via email, telephone and Skype to troubleshoot any technical problems and to support engagement.

**Classification measures**

**Classification of the brain lesion**

Brain lesion will be classified using a qualitative and quantitative structural MRI classification system. The classification system is based on the presumed timing and nature of the insult that resulted in CP including both genetic and non-genetic aetiologies such as cortical malformations and hypoxic ischaemic injury and a quantitative system to grade the location, extent and severity of the brain lesions with an asymmetry index.

**Gross motor function classification system**

The gross motor function classification system (GMFCS) classifies the child’s ability to carry out self-initiated movements related to sitting and walking across five levels. The GMFCS has strong construct validity with the Gross Motor Function Measure (r=0.91) and good inter-observer reliability between professionals and between professionals and parents. In this sample of children with hemiplegia, all children will be GMFCS level I (walks without limitations) and II (walks with limitations).

**Manual abilities classification system**

MACS classifies the child’s ability to handle objects in daily activities on one of five levels. MACS has reported construct validity, and excellent inter-rater reliability.
(Intraclass Correlation Coefficient (ICC)=0.97 between therapists and ICC=0.96 between therapists and parents). All children in the sample will be MACS level I (able to handle objects easily and successfully), level II (able to handle most objects but with somewhat reduced quality and/or speed of achievement so that alternate ways of performance might be used) or level III (handles objects with difficulty; needs help to prepare and/or modify activities).

Anthropometric data
Height will be measured to the nearest 0.5 cm while the child is standing with the back against a wall.

Wechsler Intelligence Scale for Children—fourth edition short form
The seven subtest short-form version of the Wechsler Intelligence Scale for Children fourth edition (WISC-IV) will be used to measure intellectual functioning across four indices: verbal comprehension index (VCI), perceptual reasoning index (PRI), Working Memory Index (WMI) and processing speed index (PSI). An overall short form, full-scale intellectual functioning score will be calculated from the index scores. The VCI consists of the Vocabulary and Similarities subtests, the PRI is comprised from Block Design and Matrix Reasoning subtests, the WMI is derived from the Digit Span subtest and the PSI from the Coding and Symbol Search subtests. In the Vocabulary subtest, children will name pictures or provide definitions of words (eg, ‘what is a hat’). For Similarities, children will describe how two words that are common objects or represent common concepts are similar (eg, ‘in what ways are a cat and a mouse alike’). In Block Design, children will reproduce a set of red-and-white blocks either modelled or printed, two-dimension geometric patterns, within a specified time limit. Matrix Reasoning will involve the child being shown an array of pictures with one missing square and they will need to select the picture that fits the array from five options. In Digit Span, children will repeat a string of verbally presented numbers in both a forward and backward direction. Finally, in Symbol Search, children will visually scan a search group of symbols and indicate whether or not a target symbol is in the search group and in Coding, children will transcribe a digit code. Both the Symbol Search and the Coding tasks need to be rapidly completed within 2 min. Index scores will be converted into scaled scores in accordance with normative data based on the child’s age and gender (mean=100, SD=15). All index scores of the WISV-IV SF have shown moderate to high levels of internal consistency (α=0.87–0.96) and are equivalent to those documented for the full WISV-IV, with the exception of the WMI which is marginally lower than its full-length equivalent.

Neurovascular measures
Neurovascular outcomes will be collected at baseline and 20 weeks.

Whole-brain fMRI studies
Functional imaging at 3T on a Siemens MAGNETOM Trio MR scanner will be conducted on the research-dedicated scanner at the Centre for Advanced Imaging at the University of Queensland. The 3T scanner provides approximately twice the signal-to-noise ratio compared with conventional 1.5T scanners which will reduce the time in the scanner and improve the resolution of data collected. Published methods will be utilised for conducting serial fMRI studies preparing in a mock MRI scanner and the motor paradigm will consist of a 2-condition block design (wrist extension compared with rest), visually cued via instructions projected on a screen, timed with an auditory cue for the rate of movement at 2 Hz. The task and rest periods are 30 s with the activation cycle repeated four times.

Children with sufficient comprehension will also complete a complex motor task as an additional task in the scanner. This task is timing versus sequencing task performed in a block design (two runs of 6 min each), where the participant alternates between a block of single index-finger button-pressing and a block of random sequences of three-finger button-presses. For the sequence task, visual cues of ‘123, 321, 213’ numbers denote a random sequencing of pushing three buttons with their index, third and fourth fingers on buttons with their dominant hand. This complex task is designed to differentiate activation in the primary motor cortex and different aspects of the basal ganglia circuit.

The rationale behind the simple and complex movement is based on previous studies that showed these movements are able to induce activation of the motor cortex and basal ganglia circuits. Notably increased complexity of finger movements increases activation of the basal ganglia circuit, and thus provides an ideal model to utilise fMRI to locate function specific regions of the cortex associated with finger movements.

An additional 5 min of resting-state fMRI will also be collected for analysis of functional connectivity (FC). Tasks performed prior to resting-state fMRI can influence FC. The movements performed in the scanner will be rated for speed, range of motion, ability to isolate and the presence of mirror movements in the contralateral hand, Functional MRI will be acquired using a BOLD acquisition sequence (gradient-recalled-echo, echo-planar imaging (EPI), repetition time=3.0 s, Echo Time (TE)=60 ms, Flip angle=85°, Slice thickness=3 mm, FOV=216 mm, 44 slices, 72×72 matrix yielding an in-plane resolution of 3.0 mm×3.0 mm). A single set of T2-weighted anatomical, FLAIR and three-dimensional T1 volumes will also be collected. Functional MRI image processing, analysis and visualisation will be performed using iBrain software and SPM software (Welcome Department of Imaging Neuroscience, London, UK). Detailed information about preprocessing and postprocessing of the fMRI has been published. The same processing and established analysis of data will be utilised for this proposed Mitii project. In addition, temporal...
autocorrelation will be modelled using a white noise and autoregressive AR(1) model within SPM. Motion correction parameters will be included as covariates.\(^{39}\) Due to heterogeneity in lesion location and size across participants, group analysis of intraparticipant change in activation will be using region of interest with iBrain software.\(^{38}\)

**Diffusion imaging and structural connectivity**

Diffusion-weighted images will be acquired using a twice-refocussed single-shot EPI sequence (64 directions, b value 3000 s/mm\(^2\), 60 contiguous slices with 2.5 mm thickness covering the whole brain, in-plane resolution 2.35×2.35 mm, acquisition time approximately 10 min). White matter tractography will be performed with MRtrix using probabilistic tractography, with fibre orientations obtained using constrained spherical deconvolution, taking into account the presence of crossing fibres.\(^{40}\) \(^{41}\) An automated technique has been developed to generate whole brain tractograms, from which individual white matter pathways (eg, motor and sensory) can be extracted for statistical analysis.\(^{42}\)

To improve our understanding of cortical plasticity post-training, cortical reorganisation will be investigated using a combined fMRI-structural connectivity analysis strategy. In this approach, regions of corticomotor activation derived from the fMRI analysis (generated posttherapy) will be used as target masks for extracting white matter motor pathways. This will enable the identification of all corticomotor networks exhibiting plasticity as a result of the motor training paradigms. Plasticity within these neural circuits will be measured by comparing apparent fibre density,\(^{43}\) a quantitative measure of the organisation of WM fibres, derived over the entire pathway. This strategy enables both an anatomical view of cortical reorganisation and quantitative measures of altered connectivity induced by therapy. We also propose to measure plasticity based on an analysis of structural connectivity. In this approach, connectivity matrices will be generated based on parcellation of cortical and subcortical using Freesurfer image analysis suite (http://surfer.nmr.mgh.harvard.edu) and the whole brain tractograms, as outlined above. Hit-testing every streamline with every cortical parcellation will generate the connectivity matrices. Diffusivity indices (Fractional Anisotropy (FA) and Mean Diffusivity (MD)), quantitative markers of the integrity of white matter, will be encoded within the connectome to enable assessment of motor task generated reorganisation.\(^{44}\) \(^{45}\) Network-based statistics\(^{46}\) will be performed between the FA and MD connectomes for the control (CP without intervention) and intervention groups to identify statistically significant cortical networks that are associated with neural reorganisation.

**Transmagnetic stimulation (TMS)**

Transmagnetic stimulation (TMS) (MAGSTIM 200) will be performed on all participants in both groups at baseline then at 20–22 weeks postintervention. The baseline study will be conducted following fMRI to prevent contamination of fMRI findings by TMS. A figure of eight TMS coil is used to stimulate the brain and surface EMG electrodes are used to record motor evoked potentials (MEPs) from the target muscles, right and left abductor pollicis brevis (APB). TMS will be performed at the same time of day to reduce variability. MEPS will be recorded on a Synergy EMG machine using band-pass filtering 10 Hz–5 kHz, sweep speed 100 m and gain 100 V/div. Auditory EMG feedback will be given to ensure voluntary relaxation of the target muscles during stimulation.

The experimental session will record the following parameters:

**Motor threshold**

Stimulation will start at 30% of maximum output and increase in 5% increments until the MEP is established. Only 1% changes in intensity will then be used to calculate the threshold value. Motor threshold (MT) is defined as the lowest level of stimulus intensity which produced an MEP in the target muscle of peak-to-peak amplitude >100 µV on 50% or more of 10 trials.\(^{47}\)

**MEP recruitment curves**

The maximum compound muscle action potential (CMAP) amplitude of the resting APB will be determined by supramaximal stimulation of the median nerve at the wrist. For each participant, the average of the CMAP amplitudes obtained after three stimuli will be calculated defined as 100%.\(^{48}\) MEPS obtained by single-pulse TMS using different randomised stimulus intensities of 110%, 120%, 130% and 140% MT will be expressed as a percentage of the CMAP in order to obtain recruitment curves.\(^{49}\) An average of 10 peak-to-peak MEPS recorded for each stimulus intensity will be calculated.

For MTs and recruitment curve measurements, the stimulus will be delivered to the contralateral cerebral hemisphere using the appropriate direction of coil current flow (anticlockwise for left cortical stimulation and clockwise for right cortical stimulation). This will be performed using a flat circular 9 cm diameter magnetic coil (14 cm external diameter) connected to a Magstim stimulator (Magstim, Whitland, Dyfed, UK). The centre of the coil will be positioned over the vertex and held in a plane tangential to it. The coil will be held in place by a support stand, and its position will be checked regularly through each experiment.

**Ipsilateral motor pathways**

This will be performed using a figure-of-eight-shaped coil (outer diameter of each loop 70 mm) connected to a Magstim stimulator (Magstim, Whitland, Dyfed, UK). The coil will be placed tangentially over the ipsilateral hand motor cortex with the handle pointing back and laterally 45° away from the midline at the optimal site for the activation of the APB. This is thought to be the best position for activating the pyramidal cells transsynaptically and
preferentially elicits late I-waves. The direction of current induced in the brain will be anterior to posterior.

**Primary outcome measures**

**Assessment of motor and process skills**

AMPS is a standardised, criterion-referenced, observational assessment of the motor abilities of people 2 years of age and older. An OT evaluates the quality of a person’s ADL task performance at the level of activity and participation in a culturally relevant manner. For the assessment, the patient selects a minimum of two daily activities (eg, dressing, eating and food preparation) from 116 task options, for which the quality of activity is scored on the degree of exertion, efficacy, confidence and independence in 16 ADL motor and 20 ADL processing skills. The child is also given ratings for overall functioning levels. The performance of children in each of the motor and processing skills is scored from 1 to 4 (1=deficient performance that impeded the action progression and yielded unacceptable outcomes, through to 4=competent performance that supported the action progression and yielded good outcomes). These raw scores are entered into the AMPS computer-scoring software, and converted through many-faceted Rasch analyses into linear ADL motor and ADL process ability measures, ranging from 4 to –3 for motor skills and 3 to –4 for processing skills. Test–retest reliability of the AMPS is high for both motor (r=0.9) and process (r=0.87) skill scales in an adult population. This measure is also very sensitive to change, as it evaluates the smallest possible units of ADL task performance and involves 116 task options which vary in challenge.

**Assisting hand assessment**

Bimanual performance will be assessed using the AHA. This is a Rasch analysed measure of the effectiveness with which a child with a unilateral impairment makes use of his/her impaired hand in bimanual tasks. The test consists of 22 items that are videotaped and each scored on a four-point rating scale, yielding a range of scores between 22 and 88. Scaled scores are calculated by transforming the total raw score to a percentage and range from 25 to 100. Rasch analysis allows conversion of these ordinal scores into logits (log odds probability units) which are equal interval measures. Inter-rater and intrarater reliability is high for summed scores (ICC=0.98 and 0.99, respectively). There are three versions of the AHA; small kids (18 months to 5 years), school kids (6–12 years) and an adolescent version is under development (>13 years). Test–retest reliability is high for small kids (ICC=0.99) and school kids (ICC=0.98) and reliability between the two forms (small kids vs school kids) is also high (ICC=0.99). The AHA is responsive to change due to UL intervention. Investigation of reliability yielded a smallest detectible difference of 3.89 raw scores for the small kids and 3.65 raw scores for the school kids version. The AHA requires standardised training and certification of raters. The AHA will be scored by certified raters who will be masked to group allocation and order of assessment.

**Jebesen-Taylor test of hand function**

Activity limitations will be measured for unimanual capacity using the JTTHF. The JTTHF evaluates speed and dexterity in six timed tasks with an individual score for each UL. The tasks are of varying complexity and use everyday items to assess grasp and release abilities. The original test designed and validated in adults and typically developing children will be modified with omission of the writing activity and by reducing the maximum allowable time of each task to 2 min to both minimise frustration and allow comparison with similar studies in children with congenital hemiplegia. JTTHF has been shown to be responsive to change due to an intervention; however, there are some difficulties with stability of test–retest performance in the unimpaired limb. There is high inter-rater reliability (ICC=0.82–1.0) for each subtest and test–test reliability with five patients and two raters (r=0.84–0.85) in an aging adult population. JTTHF has demonstrated good responsiveness to detect change due to interventions that improve UL speed and manipulation.

Secondary outcomes will assess Mitii against all dimensions of the ICF:

**Body structure and function domain**

**Executive functioning**

EF will be assessed across four domains: attentional control, information processing, cognitive flexibility and attentional control in accordance with Anderson’s paediatric model of EF. A neuropsychological test battery will be utilised to assess these domains comprising of subtests from the Delis-Kaplan Executive Function System (D-KEFS) and the WISC-IV. Behavioural manifestations of EF in daily life will also be assessed using the Behaviour Rating Inventory of Executive Function (BRIEF). All scores will be converted into scaled scores according to normative data based on the child’s age and gender.

**Colour-word interference test (from the D-KEFS)**

The Inhibition condition from the Colour-Word Interference Test will be used to measure attentional control. Children will be required to name the ink colour that colour words are printed in across five rows (eg, say ‘red’ for the word ‘blue’ printed in red ink). The total time (seconds) taken to complete the task will be the primary outcome measure, with longer time indicative of poorer attentional control. Raw scores will be converted into scaled scores (mean=10, SD=3). Excellent test–retest reliability has been shown for the Colour-Word Interference Test (r=0.90).

**Trail making test (from the D-KEFS)**

The Number Sequencing condition from the Trail Making Test will be used to measure attentional control and the
Number-Letter Switching condition will be used to measure cognitive flexibility. In Number Sequencing, children will connect numbers printed on an A3 sheet in numerical order from 1 to 16, while in Number-Letter Switching, children will be required to switch back and forth between connecting numbers from 1 to 16 in numerical order and letters from A to P in alphabetical order, also printed on an A3 sheet (eg, ‘1-a-2-b-3-c’). The total time (seconds) taken to complete each task will be recorded, with a longer time indicating greater difficulty with attention control or cognitive flexibility. Raw scores will be converted into scaled scores (mean=10, SD=3). Adequate test–retest reliability for Number Sequencing (r=0.77) and Number-Letter Switching (r=0.20–0.55) has been documented.\(^6\)

**Tower test (from the D-KEFS)**
The Tower Test will be used to measure goal setting. Children will move five disks across three pegs to build a target tower as illustrated in a picture within a specified time limit. They will be instructed to use the least number of possible moves to complete the tower; they can only move one disk at a time and they must not place a larger disk on top of a smaller disk. The total achievement score, which is based on the total number of moves needed to build the tower, and the total number of rule violations will be used to measure goal setting abilities. The lower the achievement score and the higher the rule violations score indicate greater goal setting difficulties. Raw scores will be converted into scaled scores (mean=10, SD=3). The Tower Test has a moderate to high level of internal consistency (\(\alpha=0.43–0.84\)) and adequate test–retest reliability (r=0.51).\(^6\)

**Digit span (from the WISC-IV)**
Digit Span Backwards is a verbal WMI task that requires children to temporarily store and manipulate information and will be used as a measure of cognitive flexibility. A string of numbers will be given orally to the children increasing from two digits to eight, and they have to repeat the number string in the reverse order (eg, if ‘3–7–2’ the child should say ‘2–7–3’). A score of one is given to each string repeated correctly in the reverse order with a lower overall score indicating poorer cognitive flexibility. Raw scores will be converted into scaled scores (mean=10, SD=3). Digit Span Backwards has been shown to have a good internal consistency (\(\alpha=0.80\)) and adequate test–retest reliability (r=0.74).\(^6\)

**Coding (from the WISC-IV)**
Coding will be used as a measure of information processing. Children will have to copy simple geometric shapes that are paired with numbers within 2 min. The overall number of correctly copied geometric shapes will be calculated, with a lower number indicating poorer information processing. Raw scores will be converted into scaled scores (mean=10, SD=3). Good internal consistency (\(\alpha=0.82\)) and test–retest reliability (r=0.81) for Coding has been shown.\(^6\)

**Symbol search (from the WISC-IV)**
Information processing will also be assessed using Symbol Search. Children will visually scan for target symbols in groups of five symbols and indicate whether the target symbol is in the group or not by placing a line through the word ‘yes’ or ‘no’. Children will be told to work as fast as they can in 2 min. The total number of correctly identified symbols minus the total number of incorrectly identified symbols will be calculated, with lower scores indicating poorer information processing. Raw scores will be converted into scaled scores (mean=10, SD=3). Symbol search has been documented to have an adequate internal consistency (\(\alpha=0.79\)) and a high level of test–retest reliability (r=0.80).\(^6\)

**Behaviour Rating Inventory of Executive Function**
In addition to cognitive measures of EF, behavioural manifestations of executive functions in daily life will be measured using the BRIEF, an 85-item parent-rated questionnaire. Parents rate items (eg, ‘does not think before doing’) on a three-point scale ranging from 1 (never) to 3 (often). Two index scores will be obtained from the BRIEF: (1) the behavioural regulation index (BRI), which is derived from four subscales: initiate, WMI, plan, organisation of materials and monitor and (2) the metacognition index (MCI), which is derived from three subscales: inhibit, shift and emotional control. The BRI and MCI will then be combined to form an overall global executive composite score (GEC). Raw scores will be converted into T scores (mean=50, SD=10), with higher T scores indicating a greater level of executive dysfunction. A T score of 65 and above, which is 1.5 SDs above the mean, will be used as the cut-off for abnormal elevations across all scales.\(^6\) The BRIEF has been found to be ecologically valid measure of EF and has been shown to have good internal consistency (\(\alpha=0.80–0.98\)) and high test–retest reliability on the BRI (r=0.92), MCI (r=0.88) and the GEC (r=0.86).\(^6\)

**Test of visual perceptual skills**
The Test of visual perceptual skills-3 (TVPS-3) consists of seven subscales: visual discrimination, visual memory, visual spatial relationships, form constancy, visual sequential memory, figure-ground and visual closure.\(^6\) Performance will be determined by the number of correct answers in each test (maximum 16 in each of seven tests). Performance will be scaled according to normative data and converted into a percentage score for the age group. The TVPS-3 is a reliable and valid measure of visual perception in persons aged 4–18 years.\(^6\)

**Melbourne assessment of unilateral upper limb function**
MUUL measures both UL impairment and quality of UL function.\(^6\) It is designed for children aged 5–15 years with CP and consists of 16 criterion-referenced items measuring aspects of reach, grasp, release and manipulation. The maximum possible raw score is 122, with raw scores being computed into percentage scores.
Inter-rater and intrarater reliability for the MUUL is very high for total test scores (ICC=0.95 and 0.97, respectively) and moderate to high for individual items (ICC=0.69–0.91). The MUUL also has good internal consistency (α=0.96). Construct and content validity for the MUUL was established during test development.

Lower-limb functional strength

Mitii will focus on training functional strength therefore assessment of Repetition Maximum during functional exercise will be used to assess strength. Functional strength will be tested according to the protocol outline by Verschuren et al.

Lateral step-up

This is the number of step up repetitions onto a bench during 30 s. This is tested with the stool height adjusted to the GMFCS level (I, II=15–20 cm stool). The child stands with the leg being tested on the stool and the non-testing leg on the floor, with feet parallel and shoulder width apart. The child then extends the test leg (on the stool) to within 10° of full knee extension, so that the non-test leg is off the ground, then lowers the foot back down to the floor until either the toes or heel touches. This is considered one full cycle. The child should maintain dorsiflexion of the non-test foot and a horizontal pelvis throughout by keeping hands on hips throughout the test. This is repeated and the cycle completed within 30 s is recorded starting with the right leg for all children. This is then repeated for the left leg.

Sit-to-stand

This tests the number of sit-to-stand repetitions that can be achieved within 30 s, with sit-stand-sit considered a full cycle. The seated position is reached when the knees and hips are in 90° flexion. Full standing is considered within 15° full extensions of the hips and legs. The sit-to-stand must be achieved with arms free and without any support from the chair or the child’s body.

Half kneel-to-stand

This is the number of repetitions of half kneel-to-stand that can be completed in 30 s. The child is in half-kneeling position on a mat, with the buttocks clear of the lower leg and/or the kneeling position on a mat, with the buttocks clear of that can be completed in 30 s. The child is in half-kneel-to-stand left. Children will be instructed to perform as many repetitions as possible in 30 s and will be verbally encouraged.

Acceptable intertester reliability has been demonstrated for functional strength testing in 25 children with CP (ICC=0.91; CV=12.1–22.7%). Reliability for the tests were strong (lateral step up ICC=0.94; Sit-to-stand ICC=0.91; Half knee-to-stand ICC=0.93–0.96). Mean repetitions for the lateral step up were 13.2 (SD=10.5; SE of measurement (SEM)=2.4 reps; CV=17.8%) for the left side, and 12.6 (SD=10.4; SEM=2.6 reps; CV=22.7%) for the right side. Mean number of repetitions for the sit-to-stand was 14.4 (SD=5.0; SEM=2.6 reps; CV=22.7%). Half knee-to-stand was less, with an average of 7.5 reps (SD=5.5; SEM=1.1 reps; CV=28.6%) for the left side and 6.0 (SD=5.3; SEM=1.4 reps; CV=39.9%) for the right side.

Six-minute walk test

The 6MWT is a simple, submaximal clinical exercise test which measures the distance walked (6MWD) under controlled conditions over 6 min. The 6MWT has been found to be reliable in independently ambulant adolescents with CP. In this population, test-retest reliability was excellent (ICC=0.98). Percentile curves for the 6MWT have been created, though these were from 1445 typically developing Chinese children aged 7–16 years. No reference curves for children and adolescents with CP exist. While children with CP may exhibit lower 6MWD compared with typically developing children due to muscle spasticity, aberrant gait patterns and functional restrictions, GMFCS Levels I and II are able to walk with little to no restrictions therefore one could expect similar test results to a typically developing child. The 6MWT will be performed using standardised verbal encouragement asking the children to walk as fast as possible along a flat, straight, 10 m corridor with cones marking the turn-around at each end as per Maher et al.

Passive range of motion

UL and lower-limb passive range of motion for the unimpaired and impaired side will be assessed by occupational and PTs at baseline.

Activity domain

Habitual physical activity

Habitual physical activity (HPA) will be measured using ActiGraph GT3X+ tri-axial accelerometer (Pensacola, Florida, USA). This detects accelerations of a magnitude and frequency with raw acceleration data, proportional to the amount of HPA done by an individual. ActiGraph units will be fitted during assessment and worn during waking hours for 4 days. After 4 days it will be returned by registered post for data extraction and analysis. An activity diary will be coupled with an ActiGraph to detect and log accelerations of human movement. Data will be considered for analysis where accelerations are recorded for >4 h/day. Analysis will convert counts to activity
intensity using Evenson cut points to allow comparison to the national physical activity guidelines. The ActiGraph will also be set up to detect step counts.

The ActiGraph is a valid instrument to detect HPA in children and adolescents with CP. The ActiGraph accelerometer is strongly correlated to direct observation during structured activity and free play, and more accurate than heart rate. It has also demonstrated excellent classification accuracy, and Evenson cut points were found to be the most accurate for adolescents with CP.

In typically developing children, the reliability of accelerometers has been shown to increase with increased recording days (ICC: 0.45 for 1 days to 0.9 for 8 days). Seasonal variation has been demonstrated with less activity being performed in the winter months (ICC=0.54). Age has also been found to influence reliability, with typically developing primary school aged children participating in more moderate to vigorous physical activity on weekends and exhibiting less day-to-day variability in activity, requiring only 4–5 days monitoring, in contrast to adolescents who exercise less on weekends and require 8 or 9 days of monitoring. Acceptable reliability has been found with 4 days of monitoring (r=0.75–0.78). However, there is no evidence that documents the reliability of the ActiGraph in children with CP. Children in the present study will be fitted with an ActiGraph accelerometer to collect 4 days of free living activity after the assessments and training days. Additionally, further work on the reliability of the ActiGraph in children and adolescents with CP will be conducted. Participants will rest for a 5 min period and then conduct selected light, moderate and vigorous assessment tasks, interspersed with 5 min rest periods in a standardised manner while wearing an ActiGraph monitor and concurrently measuring heart rate and classifying the activity using direct observation. All participants will have the option to undergo this assessment during the assessment and the Mitii training 2-day visit.

Mobility questionnaire

The MobQues measures mobility of children with CP by assessing amount of difficulty the children have in executing mobility activities. It addresses mobility limitations a child experiences in daily life and covers a range of severity levels. The MobQues focuses on 47 mobility activities, from which the MobQues47 and the MobQues28 scores can be calculated by scoring 47 or 28 mobility activities, respectively. Response options of the MobQues are: impossible without help (score 0), very difficult (score 1), somewhat difficult (score 2), slightly difficult (score 3), not difficult at all (score 4). Total scores are calculated by adding all item scores (range 0–4) divided by the maximum possible score and multiplied by 100 to obtain scores on a scale of 0–100 (with a low score representing severe limitations in mobility): MobQues47=(Σ item/188)·100; MobQues28=(Σ item/112)·100. For research purposes, the shorter version (MobQues28) is recommended due to better measurement properties, whereas the MobQues47 can be used for clinical applications. Content validity of the instrument has been demonstrated as 46 of the 47 test questions relate to ‘mobility’ according to the definitions of the ICF. Construct validity was demonstrated as MobQues scores decreased with increasing GMFCS level (p<0.001). In a subgroup of 162 children, MobQues score was positively correlated to GMFCS level (p<0.001). It has also been demonstrated to be a reliable instrument. For the strong inter-rater reliability was found for the MobQues47 (ICC=0.92) and MobQues28 (ICC=0.87). The SEM was 7.8 and 8.9, respectively. As expected, the intrarater reliability was higher for both MobQues versions (ICC=0.96–0.99; SEM=3.5–4.9). The English version has not yet been cross-validated therefore the results demonstrated may differ slightly to that in an English speaking population. Data sharing has been arranged with the MobQues authors to enable cross cultural validation of this tool. To allow this the MobQues47 clinical version will be used at baseline to obtain a full dataset, and then the MobQues28 will be collected at subsequent assessments. The MobQues28 will be extracted from the baseline assessment to allow comparison across time points.

Participation domain

Canadian occupational performance measure

Individualised goals will be measured using the COPM to evaluate self-perception of occupational performance over time. COPM will be administered by one OT with the child/adolescent and parent. COPM is a standardised individualised, client-centred measure that evaluates client’s self-perception of occupational performance. Clients identify areas of difficulty in everyday occupational performance and rate their performance and satisfaction for each problem on a scale of 1–10. An average score for performance and satisfaction is calculated. The COPM was designed for all ages and disability groups. There is good evidence of construct, content and criterion validity. The retest reliability of the performance and satisfaction scores on the COPM is high (ICC=0.76–0.89). The COPM has demonstrated responsiveness to change in paediatric clinical trials, and a two-point change on COPM performance has been reported as being clinically significant.

Assessment of life habits

The LIFE-H is designed for children aged 5–13 years and measures life habits in home, school and neighbourhood environments. It is a questionnaire completed by the parent/caregiver about the child. The child version is based on an adult version. The longer version consists of 197 items divided into 12 categories and includes regular activities (eg, eating meals, communication and mobility) and social roles. A weighted score ranging from 0 to 10 is generated for each category and overall total.
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Evidence of construct validity and criterion validity, with strong correlations between the LIFE-H and PEDI and Functional Independence Measure for Children (WeeFIM), are established. Adequate to excellent internal consistency (α=0.73–0.90 for categories, 0.97 for daily activities and 0.90 for social roles), intrarater (ICC=0.83–0.95 for daily activities), inter-rater (ICC=0.8–0.91 for daily activities and ICC=0.65–0.9 for social roles) and test–retest reliability (ICC=0.73 for total score) have also been established. Four categories will be evaluated in this study including nutrition (eg, mealtime activities), personal care (eg, dressing), education and recreation. These areas were considered to reflect many of the identified difficulties confronted by children with congenital hemiplegia that might be amenable to the intervention programme.

Participation and environment measure for children and youth

Participation and environment measure for children and youth (PEM-CY) is a newly developed, parent-report measure for children aged 5–17 years that examines participation and environment across three settings: home, school and community. No interview is required for administration with parents completing the assessment either online or using a paper based form, which supports its use in this large-scale study. The PEM-CY examines the extent to which youth participate in important activities within the home, school and community environments and the extent to which particular features of these environments are perceived to support or challenge the youth’s participation. Evidence of the psychometric properties of this new instrument are limited to date, however data from a sample of 576 youth showed internal consistency was moderate to good (α=0.59) across the scales. Test–retest reliability was moderate-to-good (ICC=0.58) across a 1-week to 4-week period using the online version of the assessment. The PEM-CY will be collected at baseline.

Strengths and Difficulties Questionnaire

The SDQ will be used to measure parents’ perceptions of prosocial and difficult behaviours in their child. The SDQ has a total of 33 items. The first 25 items are divided into five scales and assess the frequency of emotional symptoms, conduct problems, inattention/hyperactivity, peer problems and prosocial behaviour (eg, ‘considerate of other people’s feelings’). These items are rated upon reflection of the last 6 months on a three-point scale, from zero (not true) to two (certainly true). A total score for each scale (0–10) and an overall total difficulty score (0–40) will be calculated, with higher scores indicating more distress on all scales except prosocial behaviour. A clinical cut-off of ≥17 will be utilised on the total difficulties score. The total score on the five scales and the overall total difficulties score will be utilised as measures of the child’s psychological functioning. Moderate to high internal consistency (α=0.73–0.82) and test–retest reliability (r=0.77–0.85) has been shown on the overall total difficulties score.

Cerebral palsy quality of life

QOL will be measured using a condition specific measure, either the cerebral palsy QOL (CPQOL)-Child parent report, or for children 9 years or age or older, the CPQOL-Teen. Results of factor analysis demonstrated that the CPQOL measures seven broad domains of QOL: social well-being and acceptance, functioning, participation, physical health, emotional well-being, access to services, pain, impact of disability and family health. The psychometric properties of the CPQOL-Child are excellent, with strong internal consistency (α=0.74–0.92 for parent-proxy report; α=0.80–0.90 for child self-report). Test–retest is adequate (ICC=0.76–0.89) and it is moderately correlated with generic QOL and health (r=0.30–0.51). The CPQOL-Teen, for adolescents aged 13–18 years has strong psychometric properties, with strong internal consistency (α=0.81–0.95 for the primary caregiver report; α=0.84–0.96 for the adolescent self-report) and strong test–retest reliability for adolescents (ICC=0.84–0.87) and for primary caregivers (ICC=0.72–0.92). In terms of validity, all domains of the CPQOL-Teen parent report (r=0.40–0.46) and adolescent report (r=0.58–0.68) were correlated with a generic QOL instrument.

Environmental and personal factors

A study questionnaire was developed to capture demographic information that has been shown in the literature to influence a child’s participation. These include family ethnicity, household income, parental education and employment, family structure and supports and family interests. This will be collected at baseline assessments then any changes will be measured at subsequent assessments. A measure of social advantage/disadvantage will be derived from postcode of residence using the Index of Relative Socio-economic Advantage/Disadvantage from the Australian Bureau of Statistics. Deciles will be reported on a continuum with lower scores reflecting greater socioeconomic disadvantage and higher scores reflecting socioeconomic advantage.

Economic analysis

An economic analysis will be conducted to synthesise health outcomes and costs to both families and health systems. Costs will be obtained for healthcare use (measured through self/proxy reports) and measured directly for the intervention (including the number and duration of visits by the intervention team). Standard costs will be assigned to the resource use (eg, medical care, allied health visits and diagnostic/investigational services will be assigned a cost according to a fee schedule and medications will be priced based on their description, dosage regimens and whether or not they are listed on the Pharmaceutical Benefits Schedule). Outcomes will be measured as change in QOL from baseline to end of
intervention based on the CPQOL. The base case model timeframe will be 20 weeks consistent with the trial follow-up and all costs and outcomes will be extrapolated for at least 10 years, with an annual discount rate of 5% applied to both costs and outcomes, to estimate future expected costs and benefits. Sensitivity analyses will be undertaken around key parameters to assess the effect on results from varying these parameters. These can then be compared with other healthcare interventions and value for money judgments made by policy-makers. An incremental cost-effectiveness ratio (ie, \( \frac{\text{cost}_{\text{Mitii}} - \text{cost}_{\text{usual care}}}{\text{outcome}_{\text{Mitii}} - \text{outcome}_{\text{usual care}}} \)) will be calculated.

**Statistical analysis**

Analysis will follow standard principles for RCTs, using two-group comparisons on all participants on an intention-to-treat basis. External and internal validity of results will be checked using baseline and general descriptive information available for all eligible families; comparing the characteristics of families who completed the study with those who enrolled in the study but did not complete, and those who did not enrol. Data from each outcome measure will be summarised for each treatment group and descriptive statistics (frequencies, means, medians, 95% CIs) calculated depending on data distribution. The primary comparison immediately postintervention (20 weeks) will be the AMPS and AHA scores. Outcomes between treatment groups will be compared at follow-up using generalised estimating equations (GEEs), with time (0, 20 and 40 weeks) and study group (Mitii, usual care), as well as a time by group interaction as covariates. We will use the Gaussian family, identity link and an exchangeable correlation structure. Secondary analyses will compare the outcomes between groups for participation (domains of LIFE-H and QOL (domains of CP-QOL). For dichotomous outcomes we will compare outcomes between-group outcomes using GEEs with the logistic family and logit link. For continuous variables we shall compare using the Gaussian family and identity link (possibly after transformation, depending on the distribution). The magnitude of BOLD changes between groups will be determined using iBrain: ROI will be delineated for each individual primary motor cortex (PM1), SMA and ipsilateral motor cortex (PMlipsi) and active voxels in those regions will be counted. These data will be compared for each region over time using GEEs. In participants where mirror movements did not occur, lateralisation between ipsilateral and contralateral PM1 will be assessed to determine the incidence and magnitude of brain reorganisation. For TMS data changes in mean MT to TMS from ipsilateral and contralateral hemispheres will be analysed in each group at each F/U. The probability of ipsilateral projections appearing as a result of each treatment paradigm will also be analysed. Statistical significance will be at \( p < 0.05 \) with adjustment for multiple comparisons, and all analyses will be intention to treat. Sensitivity analyses using imputation techniques will investigate whether the effect estimates are biased as a consequence of non-ignorable missing data.

**DISCUSSION**

Current models of rehabilitation for children with CP are costly, limited by inequity of access and often not provided at sufficient intensity to drive neuroplasticity to improve outcomes. An effective web-based multimodal training that enhances motor and cognitive abilities using virtual trainers is likely to be a cost effective means of delivering therapy. It is also likely to lead to better translation of skills into the community as participants are responsible for their own training in the home environment. This study has the potential to establish a new cost-effective evidence-based therapy accessible equally by urban, rural and remote children and their families. Should our hypotheses be correct, Mitii has the potential to revolutionise delivery of intensive rehabilitation to children and adolescents with CP.

**Author affiliations**

1. School of Medicine, Queensland Cerebral Palsy and Rehabilitation Research Centre, The University of Queensland, Brisbane, Queensland, Australia
2. Children’s Allied Health Research, Children’s Health Queensland, Brisbane, Queensland, Australia
3. School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Queensland, Australia
4. Centre for Online Health, University of Queensland, Brisbane, Queensland, Australia
5. CSIRO, ICT—Australian e-Health Research Centre, Royal Brisbane and Women’s Hospital Centre for Clinical Research, The University of Queensland, Brisbane, Queensland, Australia
6. Queensland Brain Institute, The University of Queensland, Brisbane, Queensland, Australia
7. School of Psychology, The University of Queensland, Brisbane, Queensland, Australia
8. Queensland Children’s Medical Research Institute, The University of Queensland, Brisbane, Queensland, Australia
9. School of Population Health, The University of Queensland, Brisbane, Queensland, Australia
10. Griffith Health Institute and School of Medicine, Griffith University, Brisbane, Queensland, Australia

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**Contributors** RNB, JZ, LS, AS and SR are the chief investigators (CIs) who designed and established this research study. The content of the therapy programme Mitii was developed by the Helene Elsass Centre then adapted and modified in English for the Australian study. LEM drafted the first version of this manuscript. All authors have contributed to the writing of the manuscript and have critically reviewed and approved the final version. RNB, JZ and LEM were responsible for ethics applications and reporting. SR, RC and RNB were responsible for the design, implementation, data collection, analysis of the Advanced Brain Imaging studies. RNB, JZ, LS, KW, LEM and STJ will take lead roles on data management and preparation of publications on the clinical outcomes of the study and RNB, SR, RC will take lead roles on the neuroscience publications from the study. TAC and PAS will lead the economic evaluation and associated publications. KW advised on EF assessments and will advise on their interpretation. QCPRRC is responsible for the Mitii training.
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for the coordination, delivery, ethics, outcomes and study publication. The CI’s overseas scientific conduct of the trial.

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**Competing interests** None.

**Patient consent** Obtained.

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**Provenance and peer review** Not commissioned; internally peer reviewed.

**Data sharing statement** All data from this study will be submitted to peer review journals. LEM and STJ will use the data from this study to contribute to their PhD thesis.

**REFERENCES**


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3.3 Summary

This study protocol describes the aims and methods of a waitlist-control RCT designed to investigate the efficacy of Mitii™ compared to standard care on measures across all domains of the ICF. This doctoral program comprises the occupational therapy outcome measures and key points from the study protocol related to this thesis include:

- Mitii™ is a web-based therapy program comprising upper limb, cognitive, visual perception and physical activities that is delivered in the home environment for a 20 week period. Mitii™ is based on the principles of neuroplasticity and the aim of the program is to increase neural circuits as a basis for task specific learning.
- The feasibility of delivering Mitii™ has been confirmed in a pilot study of 9 children with UCP. An adequately powered RCT will provide the highest level of evidence to determine if Mitii™ is effective for children and adolescents with UCP.
- The outcome measures investigated within this doctoral thesis are the AMPS, AHA, JTTHF, MUUL, COPM and TVPS-3 (non-motor). The primary end point is post-intervention at 20 weeks, and differences between groups will be examined through linear regression in SPSS.
- Methods relating to secondary objectives are outlined within respective chapters in this thesis.
Chapter 4: Reproducibility of the Assessment of Motor and Process Skills in children with unilateral cerebral palsy

4.1 Introduction

Chapter 4 comprises of a paper entitled, “Test-retest reproducibility of the Assessment of Motor and Process Skills in children and adolescents with unilateral cerebral palsy”. The AMPS is a standardised, observational evaluation designed to be used by occupational therapists to evaluate the quality of an individual’s performance in ADL. The AMPS was identified through the systematic review (Chapter 2) as the most appropriate, available measure of ADL performance or capacity for children and adolescents with CP. The AMPS has strong content validity and has been standardised on over 150,000 persons internationally, however the test-retest reliability of the AMPS however is limited to adult population (ADL motor scale, r=0.90; ADL process scale, r=0.87). This study therefore aimed to investigate the test-retest reliability of the AMPS in children and adolescents with UCP.


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Title: Test-retest reproducibility of the Assessment of Motor and Process Skills in children with unilateral cerebral palsy

Sarah James B Occ Thy (Hons), PhD Scholar¹
Professor Jenny Ziviani PhD, MEd, BA, B App Sc (OT)²
Robert S Ware PhD, B Sc (Hons)⁴
Professor Roslyn N Boyd PhD, MSc (Physio), B App Sc B Sc, Pgrad (Biomech)¹

¹ Queensland Cerebral Palsy and Rehabilitation Research Centre, The University of Queensland, Royal Children’s Hospital, Brisbane, QLD, Australia
² Children's Allied Health Research, Queensland Health and School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia
⁴ School of Population Health & Queensland Children’s Medical Research Institute, The University of Queensland, Brisbane, QLD, Australia

Corresponding Author
Sarah James
Queensland Cerebral Palsy and Rehabilitation Research Centre
The University of Queensland
Level 7, Block 6, Royal Brisbane and Women’s Hospital
Herston Rd, Herston, Queensland, 4029
Email: s.james2@uq.edu.au
Fax: +61 7 3365 5538

Declaration of Interest
The authors report no declarations of interest.

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Abstract

Aim: To examine test-retest reproducibility of the Assessment of Motor and Process Skills (AMPS) in children aged 8-16 years with unilateral cerebral palsy (UCP).

Methods: Thirty children with mild to moderate UCP (mean age=11y7m, SD 2y4m; males=18; Manual Ability Classification System level I=10, II=20; Gross Motor Function Classification System level I=9, II=21) enrolled in a large randomized controlled trial were recruited via consecutive series sampling. Children carried out two AMPS tasks over two consecutive days according to standardized AMPS administration procedures. The standard error of measurement (SEM), smallest detectable change (SDC), 95% limits of agreement using the Bland-Altman method, and intraclass correlation coefficients (ICC; 2,1) were calculated.

Results: The SDC was 0.23 logits for the AMPS motor scale and 0.30 logits for the AMPS process scale. Test-retest reliability was excellent for both the AMPS motor scale (ICC=0.93) and the AMPS process scale (ICC=0.86). Intra-rater reliability (n=10) was excellent for AMPS motor scale (ICC=0.96) and AMPS process scale (ICC=0.98).

Conclusions: The AMPS can be used by therapists with 8-16 year old children with UCP as an outcome measure with changes in scores reflecting real changes in performance or capacity.

Keywords: Cerebral palsy, congenital hemiplegia, children, adolescents, activities of daily living, reproducibility
Children and adolescents with unilateral cerebral palsy (CP), also known as congenital hemiplegia, experience motor and associated difficulties that can make engaging in activities of daily living (ADL) a challenging experience. The ability to carry out ADL affords individuals independence in their daily routine and supports participation in school, home and community environments. Activities of daily living are often a high priority for both children with UCP and their caregivers (Cusick et al., 2006). Enhanced ADL ability may increase children’s level of independence and also reduce the burden of care for parents.

Activities of daily living (ADL) are defined as the life tasks required for self-care and self-maintenance (Christiansen and Baum, 1991). An individual’s ADL ability can be evaluated using measures of performance, capacity or capability. Performance describes what a person does in their daily environment, capacity describes what a person can do in a standardized and controlled environment and capability describes what an individual can do in their daily environment (Holsbeeke et al., 2009).

Measures of performance are recommended as they capture typical every day function (Gilmore et al., 2010). In rehabilitation settings however, opportunities for home visits are often limited and measures of capacity or capability may be more clinically feasible.

A systematic review of ADL measures for children with CP identified the Pediatric Evaluation of Disability Inventory (PEDI) as the best measure of ADL capability and the Assessment of Motor and Process Skills (AMPS) as the best available measure of ADL performance or capacity (James et al., 2014). The AMPS is a standardized, observational evaluation of the quality of performance in ADL in a task-relevant environment (Fisher and Jones, 2012). The AMPS can be used with individuals three years of age and older with any diagnosis and it is free from cultural bias. The AMPS has not been widely used in research with children and adolescents to date, however the usefulness of this measure has been recognized. A cross sectional study utilizing the AMPS in children with UCP reported that strengths of the measure are the opportunity for tasks to be performed in a familiar environment and the ability to tailor the assessment to individual preferences while maintaining an appropriate level of challenge (Van Zelst et al., 2006).

The AMPS has strong content validity and has been standardized on over 148,000 persons internationally however less than 10% of this sample were children below 16 years (Fisher and Jones, 2012). Typically developing children have demonstrated
acceptable goodness-of-fit to the AMPS motor skill and process skill scales (90% AMPS motor; 95% AMPS process) which support its use for school-aged children (Poulson, 1996). Investigation of the psychometric properties of the AMPS specifically in children and adolescents with CP may support future use of this measure in this population.

Reproducibility is an umbrella term for the concepts of agreement and reliability (de Vet et al., 2006). Agreement parameters assess how close the scores are of repeated measurements by estimating the measurement error on the actual scale of measurement, and are important for clinical interpretation (de Vet et al., 2006). Reliability parameters relate the measurement error to the variability between study participants and reflect how well a measurement differentiates individuals (de Vet et al., 2006). Test-retest reliability is the stability of measurements across two different time points when administered by the same person under the same conditions. The intraclass correlation (ICC) is the preferred statistical method to examine test-retest reliability as it accounts for both random and systematic differences in test scores (Rankin and Stokes, 1998), with values greater than 0.75 typically considered to represent excellent reliability (Lexel and Downhnam, 2005).

Two studies to date, of which one is unpublished, have investigated the test-retest reliability of the AMPS and results support high reliability in adult populations (AMPS motor r=0.90-0.91; AMPS process r=0.87-0.90) (Fisher and Jones, 2012; Rockwood et al., 1996). Reliability parameters are highly dependent upon the variation in the population sample and can only be generalized to similar samples. The test-retest reliability of the AMPS in children and adolescents with UCP has not yet been reported. The aim of this study therefore is to investigate the test-retest reproducibility of scores on the AMPS in children aged 8-16 years with mild to moderate UCP.

**Methods**

Full ethical approval for this study was granted by the Medical Ethics Committee of the Royal Children’s Hospital (HREC/11/QRCH/35) and The University of Queensland (2011000608). Written and informed consent was obtained from parents/caregivers and participants over 12 years of age, and verbal assent from younger children.

**Participants**
Thirty children aged 8-16 years with UCP enrolled in a large randomized controlled trial of an online rehabilitation program were recruited via consecutive series sampling (Boyd et al., 2013). If participants declined to participate in this sub-study, there was no effect on their treatment in the overall study. Potentially eligible families were identified through the Queensland Cerebral Palsy and Rehabilitation Research Centre database, the Queensland Cerebral Palsy Register (QCPRRC), Queensland CP Health Service and the Cerebral Palsy Alliance (CPA) in Sydney, Australia.

Participants met the following criteria: (a) diagnosis of UCP (b) aged between 8-16 years (c) Manual Ability Classification System (MACS) level I-III and Gross Motor Function Classification System (GMFCS) level I or II and (d) sufficient cognitive understanding and cooperation to complete the online program. Children were excluded if they had: (a) unstable epilepsy, (b) undergone surgery in the previous six months or (c) a respiratory, cardiovascular or any other medical condition that would prevent them from safely participating in the larger randomized controlled trial (Boyd et al., 2013).

**The Assessment of Motor and Process Skills**

The AMPS was carried out according to standardized procedures. Administration begins with an occupational therapist conducting an interview to obtain information about what daily tasks are of most concern to the participant. The occupational therapist then shortlists the most relevant three to five AMPS tasks from 116 possible and the participant selects a minimum of two tasks. Examples of AMPS tasks relevant to children and adolescents with UCP include putting on socks and shoes and preparing a bowl of cereal and beverage (further examples in Table 1). For each task chosen, participants are scored on 16 ADL motor and 20 ADL processing performance skills (Table 2). Performance skills are defined as the “universal, goal directed ADL motor and ADL process actions that are compiled to enact ADL task performance” (Fisher and Jones, 2012, pp. 2-5). Motor skills relate to an individual’s ability to move him/herself or task objects, and process skills reflect an individual’s ability to select and use tools, logically carry out steps and modify his/her performance. The performance of each skill is scored on a 4-point scale from 1 (deficient performance) through to 4 (competent performance).

The AMPS computer-scoring software uses a many-faceted Rasch model (Linacre, 1993) to convert raw scores into linear ADL motor and ADL process ability measures.
(-3 to 4 logits for ADL motor skills, -4 to 3 logits for ADL processing skills). The many-faceted Rasch model considers four facets: (i) ADL skill item difficulty; (ii) ADL task challenge; (iii) rater severity; and (iv) person ADL ability measure. A change of 0.30 logits on both the AMPS motor scale and AMPS process scale is considered clinically significant. (Fisher and Jones, 2012)

Procedure
The test-retest interval was set at 24 hours. A short interval decreases the chance for a change in health status but increases the possibility of a learning effect (Allen and Yen, 1979). As the AMPS tasks chosen are familiar to the client, learning effect was considered negligible. The short retest interval allowed children to participate in this sub-study without the burden of an additional appointment. The assessments were carried out in a clinical setting as a measure of ADL capacity. It was not feasible to conduct home visits within this large inter-state research trial. The kitchen area in the facility was well equipped with a variety of tools and materials to replicate a home environment. There were a variety of logical and illogical items, tools and equipment so that the participants had to choose those appropriate for the task. The facility had a separate bathroom where personal ADL tasks could be performed. The setting was free from distractions during the assessment.

On day one, an AMPS calibrated occupational therapist conducted the AMPS interview and the participant chose two tasks. The occupational therapist thoroughly explained the task requirements and discussed with the participant the items they intended to use for the assessment. The participant was familiarized to the location of items and had the opportunity to practice interacting with electrical appliances. The child then carried out the two chosen tasks and their assessment was video recorded. The same procedure was followed on the consecutive day with the child carrying out the same two tasks. All AMPS evaluations were scored from video recordings by one AMPS calibrated occupational therapist who administered the assessments. To reduce potential bias, the therapist scored day one assessments close to the day of the test, and scored the day two assessments after a minimum two-week period without viewing day one scores.

Statistical Analysis
Raw scores were entered into the AMPS scoring software (version 9.0) to compute linear ADL motor and ADL process ability measures (logits). Agreement parameters
assessed were: (i) standard error of measurement (SEM) using SD x √1-ICC; (ii) smallest detectable change (SDC) using SEM x 1.96 x √2; and (iii) 95% limits of agreement using the Bland-Altman method (Mean_{diff} ± 1.96 x SD_{diff}). Test-retest reliability was assessed using intraclass correlation coefficients (ICCs) for agreement (2,1). To establish intra-rater reliability, ten assessments were randomly selected by non-study personnel and rescored by the AMPS scorer after a minimum two-week period. Intra-rater reliability was assessed using ICCs. All data analyses were performed using Statistical Package for the Social Sciences (version 22.0).

Results
Participant demographics are reported in Table 3. The most common AMPS tasks chosen were: (i) making a bowl of cereal and a cup of juice; and (ii) making a jam sandwich (task descriptions in Table 1). Test-retest reproducibility data are presented in Table 4. The SDC was 0.23 for the AMPS motor scale and 0.30 for the AMPS process scale. The test-retest reliability was excellent for both scales (AMPS motor scale ICC (2,1)=0.93; AMPS process scale ICC (2,1)=0.86). Intra-rater reliability (n=10) was excellent for the AMPS motor scale (ICC (2,1)=0.96; 95% CI 0.84-0.99) and AMPS process scale (ICC (2,1) =0.98; 95% CI 0.86-0.99). Bland-Altman plots showed high levels of agreement for both the AMPS motor scale (Figure 1) and the AMPS process scale (Figure 2).

Discussion
This study demonstrated excellent test-retest reproducibility of the AMPS in 8-16 year old children with UCP, supporting the use of the AMPS to evaluate ADL motor and processing skills in this population. Changes in scores of 0.23 logits on the AMPS motor skill scale and 0.30 logits on the AMPS process skill scale should detect change in ability beyond measurement error. These estimates suggest that the previously reported minimal important clinical difference of 0.30 logits on both the AMPS motor and process scales is relevant for children aged 8-16 years with UCP. Results of this study are consistent with results of the two previous studies (one unpublished) of the AMPS test-retest reliability in adult populations (Fisher and Jones, 2012; Rockwood et al., 1996). Differences exist however in methodology between the current study and previous studies, which utilized Pearson’s correlation coefficients (r) rather than ICCs (Rankin and Stokes, 1998). The excellent ICC values reported in this study are supported by the narrow 95% limits of agreement.
for the AMPS motor scale (-0.28 to 0.30) and AMPS process scale (-0.42 to 0.25). The Bland-Altman plots (Figures 1 and 2) show a high degree of agreement.

The AMPS process ability measure fluctuated slightly more than the AMPS motor ability measure. The mean AMPS process ability measure improved marginally on the second day, from 1.21 to 1.29 logits. Although every effort was made to familiarize the participant on the first day, the children may have been more familiar with the environment on the second day. The participants may also have been aware of their processing skill errors from the previous day. For example, if the child required verbal cueing to initiate the step of serving the sandwich onto the table on day one, he/she may have been mindful of this on the second day and carried out this step without requiring a cue.

The high test-retest reproducibility results support the use of the AMPS in a clinical setting. Task performance in the clinical setting however cannot always be generalized to the home environment. Evidence shows that between clinic and home settings, motor skills are 95% consistent and processing skills are 75% consistent (Darragh et al., 1998; Nygard et al., 1994; Park et al., 1994). Therapists must bear this in mind if they intend to assess between clinic and home environments. It is emphasized that when conducting an AMPS evaluation in the clinical setting, the therapist must make every effort to ensure the environment approximates that in which the individual usually carries out the task.

The limited use of the AMPS as an outcome measure in research studies with children and adolescents with CP may be partially due to the time commitment and financial cost of the AMPS training course. To become a calibrated rater, therapists are required to attend a five day course and complete ten further AMPS assessments. Research using the AMPS with children with UCP has suggested that deficits in processing skills may be more important than previously recognized in their ability to carry out ADL tasks (Van Zelst et al., 2006). These findings highlight the importance of evaluating both the motor and cognitive components of ADL ability and the value of the AMPS in assessing both domains.

There are some potential limitations to this study. There may have been greater potential for variation in scores if the assessments were scored live as opposed to from video recording. The kitchen area did not have an oven or stove and this eliminated a number of AMPS task options, particularly for adolescents. There were a small number of adolescents with mild CP who could have been challenged further
if such appliances had been available. All participants completed the same tasks on both days. An advantage of the AMPS is that the same tasks do not have to be completed when evaluating change, so it would be interesting to compare the test-retest reproducibility of the AMPS when different tasks are chosen. The characteristics of the participants in this study mean the results cannot be generalized to children with more severe CP or other developmental disabilities. Given the excellent test-retest reproducibility of the AMPS found in this study, use of the AMPS is recommended in clinical settings and as an outcome measure in research. The AMPS allows occupational therapists to identify the motor and processing skills that impact most on the individual’s task performance. In a clinical setting, these identified skills can help to build a conceptual model of the person’s overall ADL ability that considers person, environment, task, society and cultural factors. Therapists are then able to consider the most appropriate intervention options to enhance children’s ability to carry out meaningful daily tasks.

**Conclusion**

This study examined the test-retest reproducibility of the AMPS in 8-16 year old children with UCP. Our findings showed excellent test-retest agreement and reliability for both the AMPS motor ability scale and the AMPS process ability scale. Therapists can attribute changes in score greater than 0.23 logits on the AMPS motor and 0.30 logits on the AMPS process scale to real changes in ADL motor and/or ADL processing abilities. The AMPS can confidently be used by therapists to evaluate ADL ability in 8-16 year old children with UCP in both clinical and research settings.
References
Table 1: Examples of Assessment of Motor and Process Skills Motor and Process Skill tasks suitable for children with unilateral cerebral palsy (22)

<table>
<thead>
<tr>
<th>Description of Task</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Putting on socks and shoes - fastened or tied</strong></td>
</tr>
<tr>
<td>- Put on pair of below knee socks, and pair of shoes that require fastening,</td>
</tr>
<tr>
<td>placed 2 to 3 metres away</td>
</tr>
<tr>
<td><strong>Cold cereal and beverage</strong></td>
</tr>
<tr>
<td>- Prepare one bowl of dry cereal with milk or cream</td>
</tr>
<tr>
<td>- Pour glass, cup, or mug of prepared beverage</td>
</tr>
<tr>
<td>- Serve in appropriate dishes</td>
</tr>
<tr>
<td>- Clean up</td>
</tr>
<tr>
<td><strong>Toast and instant coffee; tea; instant soup; or hot chocolate</strong></td>
</tr>
<tr>
<td>- Prepare two slices toast (presliced bread, one spread, no oven grill)</td>
</tr>
<tr>
<td>- Prepare hot instant beverage (heat water or milk)</td>
</tr>
<tr>
<td>- Serve in appropriate dishes</td>
</tr>
<tr>
<td>- Clean up</td>
</tr>
<tr>
<td><strong>Jam sandwich</strong></td>
</tr>
<tr>
<td>- Prepare one jam sandwich with two slices of presliced bread (not toasted)</td>
</tr>
<tr>
<td>- Cut sandwich in half</td>
</tr>
<tr>
<td>- Serve on plate</td>
</tr>
<tr>
<td>- Clean up</td>
</tr>
<tr>
<td><strong>Setting a table for one or two persons</strong></td>
</tr>
<tr>
<td>- Set one or two place settings at a counter or table, with placemat, plate,</td>
</tr>
<tr>
<td>cup or glass, knife, fork, spoon, and napkin</td>
</tr>
<tr>
<td>- Put away unneeded items</td>
</tr>
</tbody>
</table>
Table 2: Examples and logit difficulty levels for Assessment of Motor and Process Skills Motor and Process Skill items (22)

<table>
<thead>
<tr>
<th>Easier items</th>
<th>ADL motor scale item</th>
<th>Difficulty level (logits)</th>
<th>ADL process scale item</th>
<th>Difficulty level (logits)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endures</td>
<td>0.6</td>
<td>Chooses</td>
<td>0.7</td>
<td></td>
</tr>
<tr>
<td>Transports</td>
<td>0.2</td>
<td>Inquires</td>
<td>0.3</td>
<td></td>
</tr>
<tr>
<td>Reaches</td>
<td>0.1</td>
<td>Handles</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>Coordinates</td>
<td>-0.2</td>
<td>Initiates</td>
<td>-0.2</td>
<td></td>
</tr>
<tr>
<td>Positions</td>
<td>-0.8</td>
<td>Notices/Responds</td>
<td>-0.6</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: ADL, Activities of daily living
Table 3: Study participant demographics (n=30)

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD (range)</td>
<td>11y7m ± 2y4m (8-16y)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 (60%)</td>
</tr>
<tr>
<td>Female</td>
<td>12 (40%)</td>
</tr>
<tr>
<td>Intellectual ability</td>
<td></td>
</tr>
<tr>
<td>FSIQ, mean ± SD (range)</td>
<td>85.43 ± 17.48 (45-109)</td>
</tr>
<tr>
<td>MACS distribution, n (%)</td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>10 (33.3%)</td>
</tr>
<tr>
<td>Level II</td>
<td>20 (66.7%)</td>
</tr>
<tr>
<td>Level III</td>
<td>0</td>
</tr>
<tr>
<td>GMFCS, n (%)</td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>9 (30%)</td>
</tr>
<tr>
<td>Level II</td>
<td>21 (70%)</td>
</tr>
</tbody>
</table>

Abbreviations: SD, standard deviation; MACS, Manual Ability Classification System; GMFCS, Gross Motor Function Classification System; FSIQ, Full Scale Intelligence Quotient

NB. FSIQ ranges: <80 (below average); 80-89 (low average); 90-109 (average)
Table 4: Assessment of Motor and Process Skills test-retest reproducibility in children with unilateral cerebral palsy (n= 30)

<table>
<thead>
<tr>
<th></th>
<th>AMPS motor scale</th>
<th>AMPS process scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test mean ± SD (range)</td>
<td>1.22 ± 0.4 (0.59-2.03)</td>
<td>1.20 ± 0.37 (0.53-2.03)</td>
</tr>
<tr>
<td>Retest mean ± SD (range)</td>
<td>1.21 ± 0.38 (0.59-1.76)</td>
<td>1.29 ± 0.35 (0.72-1.94)</td>
</tr>
<tr>
<td>SEM</td>
<td>0.10</td>
<td>0.13</td>
</tr>
<tr>
<td>SDC</td>
<td>0.23</td>
<td>0.30</td>
</tr>
<tr>
<td>ICC (2,1) (95% CI)</td>
<td>0.93 (0.86-0.97)</td>
<td>0.86 (0.65-0.94)</td>
</tr>
<tr>
<td>Mean difference</td>
<td>0.01</td>
<td>-0.09</td>
</tr>
<tr>
<td>95% limits of agreement</td>
<td>-0.28-0.30</td>
<td>-0.42-0.25</td>
</tr>
</tbody>
</table>

Abbreviations: AMPS, Assessment of Motor and Process Skills; SD, standard deviation; SEM, standard error of measurement; SDC, smallest detectable change; ICC, intraclass correlation coefficient; CI, confidence interval
Figure 1: Test-retest reproducibility of the Assessment of Motor and Process Skills (AMPS) motor scale: Bland-Altman plot
Figure 2: Test-retest reproducibility of the Assessment of Motor and Process Skills (AMPS) process scale: Bland-Altman plot
4.3 Summary and Conclusions

This study found that the AMPS is a reliable measure to evaluate ADL capacity in children and adolescents aged 8-16 years with UCP. Analysis of reliability and agreement parameters indicate the following:

- Changes greater than the identified smallest detectable change (0.23 on the AMPS motor scale; 0.30 on the AMPS process scale) can be attributed to real changes in ADL ability. The standardized minimal clinically important difference of 0.30 logits on both scales is therefore relevant in this population and can be used to identify if the mean difference between the intervention group and control group in this study are clinically significant.

- There is excellent test-retest reliability with intraclass correlation coefficients (ICC) values of 0.93 for the AMPS motor scale and 0.86 for the AMPS process scale.

- The higher reliability on the motor scale compared to the process scale, may reflect that children with UCP have relatively stable motor skills on a day-to-day basis, but vary slightly in the way they carry out steps.

- Agreement was high using the Bland-Altman method, with plots showing neat clustering within the 95% limits of agreement.

- The AMPS is a useful tool to investigate underlying difficulties in ADL ability and it can be used by occupational therapists as a reliable measure in clinical practice and research to evaluate ADL capacity or performance.
Chapter 5: Relationships between activities of daily living, upper limb function and visual perception in children and adolescents with unilateral cerebral palsy

5.1 Introduction

The published paper entitled, “Relationships between activities of daily living, upper limb function and visual perception in children and adolescents with unilateral cerebral palsy” comprises Chapter 5 of this thesis. Significant relationships are reported between self-care ability and measures of manual ability and gross motor function in children with UCP. No studies to date however have investigated relationships of both the motor and processing components of ADL and measures of upper limb function and visual perception in this population. The aim of this study therefore was to examine relationships between ADL motor and processing skills, unimanual capacity, bimanual performance and visual perception in children and adolescents with UCP.

5.2 Paper 4: Relationships between activities of daily living, upper limb function and visual perception in children and adolescents with unilateral cerebral palsy

This paper has been accepted for publication in Developmental Medicine and Child Neurology. Journal impact factor: 3.292 (2015).


This paper was presented as a free paper at the 7th Biennial Conference of the AusACPDM, 11-14th March 2014, Hunter Valley, Australia; a scientific poster at the 68th AACPDM Meeting, 10-13th September 2014, San Diego, USA; and as a free paper at the 25th Occupational Therapy Australia Queensland State Conference, 23-25th October 2014, Noosa, Australia.
Title: Relationships between activities of daily living, upper limb function and visual perception in children and adolescents with unilateral cerebral palsy

Authors
Sarah James B Occ Thy (Hons), PhD Scholar
Professor Jenny Ziviani PhD, MEd, BA, B App Sc (OT)
Robert S Ware PhD, B Sc (Hons)
Professor Roslyn N Boyd PhD, MSc (Physio), B App Sc B Sc, Pgrad (Biomech)

1 Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, The University of Queensland, Royal Children’s Hospital, Brisbane, QLD, Australia
2 Children’s Allied Health Research, Queensland Health, Brisbane, QLD, Australia
3 School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, QLD, Australia
4 School of Population Health, The University of Queensland, Brisbane, QLD, Australia
5 Queensland Children’s Medical Research Institute, The University of Queensland, Brisbane, QLD, Australia

Corresponding Author
Sarah James
Queensland Cerebral Palsy and Rehabilitation Research Centre
The University of Queensland
Level 7, Block 6, Royal Brisbane and Women’s Hospital
Herston, Queensland, Australia 4029
Email: s.james2@uq.edu.au
Fax: +61 7 3365 5538
Abstract

Aim: This study examined relationships between unimanual capacity, bimanual performance and visual perception, and motor and processing skills of activities of daily living (ADL) in children with unilateral cerebral palsy (CP).

Methods: Participants were 101 children (mean age=11.8±2.4 years; 51 males; MACS level I=24, II=76; III=1) with unilateral CP. Measures were: (i) Assessment of Motor and Process Skills (AMPS); (ii) Jebsen-Taylor Test of Hand Function (JTTHF), (iii) Assisting Hand Assessment (AHA); and (iv) Test of Visual Perceptual Skills 3rd edition (TVPS-3). Regression models were constructed with the AMPS motor scale and AMPS process as the dependent variables.

Results: The AHA and JTTHF dominant together explained 57% of the variance in AMPS motor scale scores. TVPS Visual Sequential Memory, TVPS Visual Closure and JTTHF together explained 35% of the variance in AMPS process scale scores.

Conclusion: Bimanual performance and unimanual capacity of the dominant upper limb are significantly associated with ADL motor skills in children with unilateral CP. Processing skills of ADL are related to visual perceptual ability and dominant upper limb unimanual capacity, which may reflect motor planning required to perform daily tasks.

Key Words: cerebral palsy, activities of daily living, upper limb function, visual perception, relationships

What this Study Adds

1. Bimanual performance and unimanual capacity of the dominant upper limb are associated with ADL motor skill ability in children with unilateral CP
2. Visual perception ability, most significantly sequential memory and visual closure, are associated with ADL processing skills
3. There is 65% variance in the current model for ADL processing skills which is not explained by visual perception and dominant upper limb capacity.
A longitudinal perspective is required if young individuals with unilateral CP are to be supported to develop skills that will afford independence in adulthood.\(^{(1)}\) The ability to carry out activities of daily living (ADL) can significantly impact an individual’s level of independence and ADL evaluation should form part of a multi-faceted treatment approach. Knowledge of factors that are associated with ADL ability may allow therapists to target areas of underlying difficulties in these important tasks. Activities of daily living are life tasks required for self-care and self-maintenance and are conceptualized within the broad ‘Activities and Participation’ domain of the International Classification of Functioning, Disability and Health (ICF), incorporating activity limitations at the level of an individual and participation restriction at the level of society. Measures of ADL can evaluate *performance* (what an individual does in a natural environment), *capability* (what an individual can do in a natural environment), or *capacity* (what an individual can do in a controlled environment).\(^{(2)}\) Significant relationships have been reported between self-care ability and manual ability\(^{(3-5)}\) and also gross motor function.\(^{(6-8)}\) Personal ADL (self-care tasks) have shown stronger relationships than domestic ADL (household tasks) with manual ability.\(^{(9)}\) Children with CP are reported to have lower visual perception abilities \(^{(10)}\) compared to typically developing children. Relationships between visual perception and ADL have not been examined in children with unilateral CP but have been in children with developmental disabilities.\(^{(11)}\) A measure that has not yet been widely utilized in studies of children with unilateral CP, but can provide useful insight into the underlying ADL skills is the Assessment of Motor and Process Skills (AMPS). The AMPS is a standardized, observational evaluation of the quality of motor and processing abilities in ADL performance or capability in a task-relevant environment.\(^{(12)}\) The items scored on the AMPS are ADL performance skills (goal directed ADL motor and ADL process actions that together enable ADL task performance)\(^{(12)}\), in contrast to the majority of ADL assessments that are scored on specific personal and/or domestic ADL items. Motor skills are the actions a person performs in order to move him/herself or task objects, and process skills relate to the person’s ability to select and use tools, logically carry out steps and modify his/her performance. This study furthers existing knowledge on ADL in children with unilateral CP by utilizing the AMPS to investigate associations that may explain or contribute to difficulties in ADL. The aim of this study was to examine relationships between ADL
motor and processing skills, unimanual capacity, bimanual performance and visual perception in children and adolescents with unilateral CP. We hypothesized that unimanual capacity and bimanual performance would be significantly related to ADL motor skills, and visual perception would be significantly related to ADL processing skills.

Methods

A cross-sectional study examined baseline data from a large randomized controlled trial (RCT) conducted in Brisbane, Australia between April 2012 and March 2014. Ethical approval was obtained by the Medical Ethics Committee at The University of Queensland (2011000608), the Children’s Health Service Human Research Ethics Committee at the Royal Children’s Hospital Brisbane (HREC/11/QRCH/35) and the Cerebral Palsy Alliance’s HREC (2013-04-01). Written informed consent was obtained from parents and participants over 12 years and verbal assent from younger children.

Participants

One hundred and two participants with spastic type unilateral CP were recruited at a tertiary referral centre in Brisbane, Australia. The sample size from the overall RCT was based on the AMPS. To detect a change of 0.35 logits with 80% power and \( \alpha = 0.05 \) (assuming a standard deviation (SD) of 0.58 logits) 44 participants were required in each group. Allowing for 10% attrition, the recruitment target was 98 participants (49 in each group). Inclusion criteria were: (i) ability to walk unaided (Gross Motor Function Classification System I or II); (ii) ability to handle objects without continuous assistance (MACS I-III); (iii) aged 8-18 years with sufficient co-operation and cognitive understanding to complete a web-based therapy program involving upper limb, gross motor, visual perception and cognitive challenge. Children were excluded if they had (i) received upper-limb or lower-limb surgery in the previous 6 months; (ii) unstable epilepsy (i.e. frequent seizures not controlled by medication), or (iii) a respiratory, cardiovascular or other medical condition that would prevent them participating safely in the therapy program.

Measures

Motor and processing skills of ADL were evaluated using the AMPS. An AMPS calibrated occupational therapist (OT) conducted an interview to gather information about ADL that were of most concern to the participant. The OT then shortlisted
three to five relevant AMPS tasks from 116 options and the participant selected and carried out a minimum of two tasks. The AMPS is scored on the degree of exertion, efficacy, confidence and independence in 16 motor and 20 processing skills. Raw scores are converted into linear ADL motor and ADL process ability measures using a many-faceted Rasch model (-3 to 4 logits for ADL motor skills, -4 to 3 logits for ADL processing skills). The AMPS has strong content validity and excellent test-retest reliability.\(^{12}\) The AMPS was carried out in a naturalistic clinic setting, video recorded and scored from video by a calibrated AMPS rater.

Unimanual capacity was assessed using the Jebsen-Taylor Test of Hand Function (JTTHF).\(^{16}\) The JTTHF evaluates speed and dexterity in six timed tasks of both the dominant and impaired upper limbs. An overall score is calculated for each upper limb with lower scores reflecting greater unimanual capacity. The modified version of the JTTHF was used (writing task omitted and maximum time of 2 minutes per task). The tasks vary in complexity and use everyday items. There is high inter-rater reliability (ICC=0.82-1.00) for each subtest and the modified version has shown responsiveness to change in children with CP.\(^ {17}\)

Bimanual performance was evaluated using the Assisting Hand Assessment (AHA).\(^ {18}\) The AHA assesses how well a child with a unilateral impairment uses his/her impaired hand as an assisting hand in bimanual tasks. The School Kids-AHA was used with children up to 12 years and the Adolescent-AHA, which is in developmental stage, was used with children 13 years and above. Overall raw scores are converted through Rasch analysis into AHA units (0-100 scale). Test-retest reliability of the school kids version is high (ICC=0.99),\(^ {19}\) and reliability is yet to be established between the School Kids-AHA and Adolescent-AHA. Both AHA versions were administered via semi structured board games, video recorded and scored by certified raters.

The Test of Visual Perceptual Skill (non-motor) 3\(^{rd}\) edition (TVPS-3) evaluated visual perception across seven subtests: Visual Discrimination, Visual Memory, Visual Spatial Relationships, Form Constancy, Visual Sequential Memory, Figure-Ground and Visual Closure.\(^ {20}\) Each subscale has a maximum score of 16 with higher scores indicating better visual perception. Raw scores are converted into scaled, standard and percentile scores for interpretation. Basic, sequential and complex visual perception index scores and an overall score is calculated. The TVPS-3 has high
test-retest reliability (r=0.97)\textsuperscript{(20)} and has shown correlations with the Developmental Test of Visual Perception 2\textsuperscript{nd} edition (r=0.62).\textsuperscript{(21)}

**Statistical Analyses**

Descriptive statistics are presented as mean +/- standard deviation (SD) for continuous variables and as frequency (percentage) for categorical variables. We investigated the univariable associations between measures of upper limb function and visual perception with ADL motor and process skills using a linear regression model. Independent variables were: (i) AHA; (ii) JTTHF dominant UL; (iii) JTTHF impaired UL; and (iv) TVPS-3 subscale scores. Dependent variables were: (i) AMPS motor scale; and (ii) AMPS process scale. Next we constructed multivariable models to identify which variables were significantly associated with ADL motor and process skills. The most appropriate multivariable model was identified using the Bayesian information criterion (BIC), which identifies the model with the most explanatory power relative to its complexity.\textsuperscript{(22)} The BIC was calculated for all possible models and the model with the smallest BIC was chosen as the final model, except when two BIC values were very similar (within 1 unit) and when this was the case the most parsimonious model was chosen (see Supplementary Online 1).\textsuperscript{(23)} Bootstrapping was used to obtain confidence intervals for the final models, using 2000 replications. Assumptions of normality, linearity and homoscedasticity were examined using residual scatterplots and pp-plots. Multicollinearity between variables was assessed using tolerance and variance inflation factor coefficients. Data were analysed in Stata (to calculate BIC) and Statistical Package for the Social Sciences (v.22).

**Results**

**Group characteristics**

Of the 102 enrolled participants, 101 completed baseline assessments.

Demographic and clinical characteristics of participants are presented in Table 1. The mean age of participants was 11.8 years (SD 2.4 years) and 51% were males. There were 24 (24%) children classified as MACS level I (handles objects easily and successfully) and 48 (48%) children with left sided hemiplegia.

**ADL motor skills**

In the univariable linear regression models, the strongest associations emerged between the AMPS motor scale and JTTHF impaired (r=0.617; p<0.001), AHA (r=0.609; p<0.001) and JTTHF dominant (r=-0.512, p<0.001). (Table 2) There was a moderate association between the AMPS motor scale and TVPS-3 overall score.
(r=0.408; p<0.001). The most parsimonious model identified using the BIC consisted of the JTTHF dominant and the AHA. The JTTHF dominant and AHA explained 57% of the variation in the AMPS motor scale scores. (Table 3) The AHA made the strongest unique contribution to the model (β=0.018; 95% CI 0.014-0.022; p<0.001).

**ADL process skills**

In the univariable linear regression models, the AMPS process scale was moderately associated with the JTTHF dominant (r=-0.428; p<0.001) and four TVPS-3 subscales: Visual Closure (r=0.475; p<0.001), Visual Sequential Memory (r=0.465; p<0.001), Visual Memory (r=0.412; p<0.001) and Figure-Ground (r=0.400; p<0.001) (Table 2) The most parsimonious model identified using the BIC consisted of TVPS Visual Closure, TVPS Visual Sequential Memory and JTTHF dominant. (Table 3) TVPS Visual Sequential Memory made the strongest unique contribution to the model (β=0.034; 95% CI 0.011, 0.057; p=0.007).

**Discussion**

Our findings indicate that bimanual performance and unimanual capacity of the dominant upper limb are significantly associated with ADL motor skills. Visual perception components are associated with ADL processing skills, along with unimanual capacity of the dominant upper limb which may reflect underlying motor planning ability. Visual sequential memory was most strongly associated with ADL processing ability. Associations found on the AMPS motor scale suggest that bimanual performance and unimanual capacity may impact ADL skills and thus may explain possible difficulties in ADL performance. Our results are consistent with previous studies that have demonstrated relationships between manual ability and measures of ADL capacity. Previous studies have predominantly utilized the MACS as a measure of manual ability, and this study provides further evidence about the association between both bimanual performance and unimanual capacity on ADL motor skills. There is emerging research examining upper limb function for children with unilateral CP with strong evidence for the use of constraint-induced movement therapy and intensive bimanual therapy. What has been studied less is if improved upper limb function translates into improvements in daily life tasks. A number of clinical trials of upper limb interventions have examined ADL capability and measures of participation however few studies have evaluated ADL performance or capacity. Measures of capability and participation are typically administered via parent or child
report with the potential for response bias, while measures of ADL performance (natural environment) or capacity (controlled environment) are administered via observational evaluation by trained therapists. Inclusion of ADL performance or capacity measures is recommended in future clinical trials to determine the impact of interventions on ADL motor and process skills.

It can be speculated that the relationship between the AHA and AMPS motor scale arises from similarity of some items such as grips, manipulation and coordination. While some items are similar given both measures assess motor ability, the assessments investigate different constructs. The AHA is administered in a ‘play’ context to elicit a child’s usual bimanual performance, with focus on the skill of the assisting (or hemiplegic) upper limb. The AMPS involves tasks that are somewhat challenging for children and the motor skills are carried out with the added complexity of the processing components of ADL tasks. The AMPS also includes items not focused on upper limb function, such as body position and walking ability. (12)

The association between ADL processing skills and unimanual capacity of the dominant upper limb may reflect elements of motor planning. Evidence regarding motor planning is sparse, (25) however it has been shown to be impaired compared in children with unilateral CP. (26) To complete tasks in the JTTHF in a timely manner, individuals require proficient planning, sequencing and feedback of movements. Scores on the JTTHF dominant upper limb, in the absence of upper limb impairment, may reflect underlying motor planning abilities. Motor planning skills are also required to successfully carry out ADL tasks, as captured on the AMPS processing scale with items such as organizes, sequences and initiates steps. This association emphasizes the importance of addressing not only movement execution but also motor planning in therapy.

The associations between ADL processing skills and visual perception are also of interest as little research has investigated visual perceptual abilities of children with CP. It is known that individuals with CP have difficulties with visual perception, (10) however limited research has examined how such difficulties manifest in functional tasks. Craje et al investigated the effect of visual information on motor planning in children with unilateral CP and reported that visual information systematically impacted on motor or ‘action planning’. (26) Our results suggest that visual perception abilities are associated with functional task performance in ADL.
The relationships between visual closure, visual sequential memory and the AMPS process scale are consistent with previous research. Significant relationships are reported between the Functional Independence Measure for Children (WeeFIM) and visual memory and visual closure domains of the Motor Free Visual Perception Test 3rd edition in children with developmental disabilities.(11) Our study provides further evidence to support the inclusion of visual processing assessment for children and adolescents with CP, given the potential for visual processing to significantly influence an individual's ability to carry out ADL. Other aspects that may be associated with ADL processing skills could be further explored in future studies, given that there is variance in the current model not explained by visual perception and dominant upper limb capacity. Cognitive and executive functioning skills could be investigated, as limited research has investigated relationships between cognition and ADL in children with CP. A previous study reported that the cognitive scale of the Bayley Infant Development Screening Test-II (BSID-II) was not correlated with the WeeFIM in young children (1-44 months) with CP.(27) It would be useful to explore associations between ADL and cognition in older children and adolescents with CP.

Strengths of this study are the large sample size and complete dataset. The use of the AMPS provided further information than previous cross-sectional studies examining ADL through evaluation of both the motor and processing aspects of ADL ability. A potential limitation of this study is that the AMPS was carried out in a naturalistic clinic setting due to pragmatic reasons of the large inter-state study. Both the home and clinic settings are appropriate environments for administration of the AMPS. The home environment however is considered a measure of everyday typical performance, while the clinic setting will capture capacity.(2) The kitchen area in the clinic setting did not have an oven or stove which eliminated a number of AMPS task options.

**Conclusion**

This cross-sectional study demonstrated that bimanual performance and unimanual capacity of the dominant upper limb are most strongly associated with ADL motor skills in children and adolescents with unilateral CP. Processing skills of ADL tasks are associated with visual sequential memory, visual closure and unimanual capacity of the dominant upper limb. Our results further the existing evidence of the relationship between upper limb function and ADL motor abilities, and provide
evidence that has not previously been reported in this population in relation to processing skills of ADL. This study emphasises the importance of evaluating and understanding both the motor and processing domains of ADL and provides insight into factors which are associated with both domains. Therapists have the ability to assist individuals with unilateral CP to develop skills required for ADL and doing so from an early age may positively influence their independence in daily tasks throughout life.

Acknowledgements

We thank all the children and families who participated in this study. We thank Chloe Noble and Ellen Gaudry (occupational therapists) for their assistance with scoring, and thank the Queensland CP Health Service and the CP Alliance for their assistance with recruitment.

The project from which this data was gathered is supported by a Foundation for Children Grant and Smart Futures Co-Investment Program Grant. SJ is supported by an Australian Postgraduate Award (APA) and Queensland Government Smart Futures PhD Scholarship. RB is supported by a NHMRC Career Development Fellowship (1037220).
Table 1: Study participant demographics (n=101)

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age mean ± SD (range)</td>
<td>11.8 ± 2.4 (8-17y)</td>
</tr>
<tr>
<td>Gender, male (%)</td>
<td>51</td>
</tr>
<tr>
<td>Hemiplegia, left sided (%)</td>
<td>48</td>
</tr>
<tr>
<td>MACS, (%)</td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>24</td>
</tr>
<tr>
<td>Level II</td>
<td>75</td>
</tr>
<tr>
<td>Level III</td>
<td>1</td>
</tr>
<tr>
<td>GMFCS, (%)</td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>45</td>
</tr>
<tr>
<td>Level II</td>
<td>56</td>
</tr>
<tr>
<td>Intellectual ability</td>
<td></td>
</tr>
<tr>
<td>FSIQ &lt; 80 (below average), (%)</td>
<td>11</td>
</tr>
<tr>
<td>Other Diagnoses, (%)</td>
<td></td>
</tr>
<tr>
<td>Learning disorder</td>
<td>23</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>4</td>
</tr>
<tr>
<td>Vision impairment</td>
<td>11</td>
</tr>
<tr>
<td>Attention Deficit/Hyperactivity Disorder</td>
<td>10</td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>4</td>
</tr>
<tr>
<td>AMPS-M, mean logits (SD) (range -3 to 4)</td>
<td>1.09 (0.53)</td>
</tr>
<tr>
<td>AMPS-P, mean logits (SD) (range -4 to 3)</td>
<td>1.11 (0.49)</td>
</tr>
<tr>
<td>AHA, mean units (SD) (range 0-100)</td>
<td>66.3 (16.36)</td>
</tr>
<tr>
<td>JTTHF Dominant, mean (SD) (max 720 sec)</td>
<td>41.55 (16.10)</td>
</tr>
<tr>
<td>JTTHF Impaired, mean (SD) (max 720 sec)</td>
<td>214.14 (189.82)</td>
</tr>
<tr>
<td>TVPS-3 Overall, mean standard score (SD) (range 55-145)</td>
<td>84.78 (16.81)</td>
</tr>
<tr>
<td>TVPS-3 Subtest, mean raw score (SD) (range 0-16)</td>
<td></td>
</tr>
<tr>
<td>Visual Discrimination</td>
<td>7.74 (3.35)</td>
</tr>
<tr>
<td>Visual Memory</td>
<td>9.61 (4.36)</td>
</tr>
<tr>
<td>Visual Spatial Relationships</td>
<td>10.78 (4.36)</td>
</tr>
<tr>
<td>Form Constancy</td>
<td>6.78 (3.84)</td>
</tr>
<tr>
<td>Visual Sequential Memory</td>
<td>8.53 (3.79)</td>
</tr>
<tr>
<td>Figure-Ground</td>
<td>7.84 (4.20)</td>
</tr>
<tr>
<td>Visual Closure</td>
<td>6.55 (4.35)</td>
</tr>
</tbody>
</table>

Abbreviations: SD, standard deviation; MACS, Manual Ability Classification System; GMFCS, Gross Motor Function Classification System; FSIQ, Full Scale Intelligence Quotient; AMPS, Assessment of Motor and Process Skills (M, motor scale; P, process scale); AHA, Assisting Hand Assessment; JTTHF, Jebsen-Taylor Test of Hand Function; sec, seconds; TVPS-3, Test of Visual Perceptual Skills 3rd edition (non-motor)
Table 2: Univariable regression results for Assessment of Motor and Process Skills motor and process scales and measures of upper limb function and visual perception

<table>
<thead>
<tr>
<th></th>
<th>r</th>
<th>β</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AMPS-M</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AHA</td>
<td>0.61</td>
<td>0.02</td>
<td>0.02, 0.03</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>JTTHF Dominant</td>
<td>-0.51</td>
<td>-0.02</td>
<td>-0.02, -0.01</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>JTTHF Impaired</td>
<td>-0.62</td>
<td>-0.002</td>
<td>-0.002, -0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>TVPS-3 Overall</td>
<td>0.41</td>
<td>0.01</td>
<td>0.007, 0.02</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>TVPS-3 Subtest</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual Discrimination</td>
<td>0.31</td>
<td>0.04</td>
<td>0.02, 0.07</td>
<td>0.002</td>
</tr>
<tr>
<td>Visual Memory</td>
<td>0.38</td>
<td>0.05</td>
<td>0.03, 0.08</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Visual Spatial Relations</td>
<td>0.28</td>
<td>0.03</td>
<td>0.01, 0.05</td>
<td>0.004</td>
</tr>
<tr>
<td>Form Constancy</td>
<td>0.25</td>
<td>0.03</td>
<td>0.01, 0.06</td>
<td>0.011</td>
</tr>
<tr>
<td>Visual Sequential Memory</td>
<td>0.39</td>
<td>0.05</td>
<td>0.03, 0.07</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Figure-Ground</td>
<td>0.30</td>
<td>0.04</td>
<td>0.01, 0.06</td>
<td>0.002</td>
</tr>
<tr>
<td>Visual Closure</td>
<td>0.34</td>
<td>0.04</td>
<td>0.02, 0.06</td>
<td>0.001</td>
</tr>
<tr>
<td><strong>AMPS-P</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AHA</td>
<td>0.28</td>
<td>0.01</td>
<td>0.003, 0.01</td>
<td>0.004</td>
</tr>
<tr>
<td>JTTHF Dominant</td>
<td>-0.43</td>
<td>-0.013</td>
<td>-0.02, -0.007</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>JTTHF Impaired</td>
<td>-0.24</td>
<td>-0.001</td>
<td>-0.001, 0.000</td>
<td>0.018</td>
</tr>
<tr>
<td>TVPS-3 Overall</td>
<td>0.38</td>
<td>0.01</td>
<td>0.006, 0.02</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>TVPS-3 Subtest</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual Discrimination</td>
<td>0.29</td>
<td>0.04</td>
<td>0.01, 0.07</td>
<td>0.003</td>
</tr>
<tr>
<td>Visual Memory</td>
<td>0.41</td>
<td>0.06</td>
<td>0.03, 0.08</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Visual Spatial Relations</td>
<td>0.29</td>
<td>0.03</td>
<td>0.01, 0.05</td>
<td>0.003</td>
</tr>
<tr>
<td>Form Constancy</td>
<td>0.32</td>
<td>0.04</td>
<td>0.02, 0.07</td>
<td>0.001</td>
</tr>
<tr>
<td>Visual Sequential Memory</td>
<td>0.47</td>
<td>0.06</td>
<td>0.04, 0.08</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Figure-Ground</td>
<td>0.40</td>
<td>0.05</td>
<td>0.03, 0.07</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Visual Closure</td>
<td>0.48</td>
<td>0.05</td>
<td>0.03, 0.07</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

CI, Confidence Interval; AMPS, Assessment of Motor and Process Skills (M, motor scale; P, process scale); AHA, Assisting Hand Assessment; JTTHF, Jebsen-Taylor Test of Hand Function; TVPS-3, Test of Visual Perceptual Skills 3rd edition (non-motor)
Table 3: Models for Assessment of Motor and Process Skills motor and process scales and measures of upper limb function and visual perception

<table>
<thead>
<tr>
<th>Model</th>
<th>r²</th>
<th>β</th>
<th>BCa 95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMPS-M</td>
<td>0.57</td>
<td>0.02</td>
<td>0.01, 0.02</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>AHA</td>
<td></td>
<td>-0.02</td>
<td>-0.02, -0.006</td>
<td>0.001</td>
</tr>
<tr>
<td>JTTHF Dominant</td>
<td></td>
<td>-0.007</td>
<td>-0.02, -0.001</td>
<td>0.010</td>
</tr>
<tr>
<td>AMPS-P</td>
<td>0.35</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TVPS Visual Closure</td>
<td></td>
<td>0.03</td>
<td>0.01, 0.05</td>
<td>0.009</td>
</tr>
<tr>
<td>TVPS Sequential Memory</td>
<td></td>
<td>0.03</td>
<td>0.01, 0.6</td>
<td>0.007</td>
</tr>
<tr>
<td>JTTHF Dominant</td>
<td></td>
<td>-0.007</td>
<td>-0.02, -0.001</td>
<td>0.010</td>
</tr>
</tbody>
</table>

CI, Confidence Interval; BCa, bias corrected accelerated; AMPS, Assessment of Motor and Process Skills (M, motor scale; P, process scale); AHA, Assisting Hand Assessment; JTTHF, Jebsen-Taylor Test of Hand Function; TVPS-3, Test of Visual Perceptual Skills 3rd edition (non-motor)
**Supplementary Online 1:** Bayesian information criterion values for models for the Assessment of Motor and Process Skills motor and process scales

<table>
<thead>
<tr>
<th>Number of Variables</th>
<th>BIC</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AMPS-M</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>105.77</td>
<td>JTTHF Impaired</td>
</tr>
<tr>
<td>2</td>
<td>81.39</td>
<td>JTTHF Dominant AHA</td>
</tr>
<tr>
<td>3</td>
<td>80.45</td>
<td>JTTHF Dominant AHA TVPS Sequential Memory</td>
</tr>
<tr>
<td>4</td>
<td>90.00</td>
<td>JTTHF Dominant AHA TVPS Sequential Memory JTTHF Impaired</td>
</tr>
<tr>
<td>5</td>
<td>84.76</td>
<td>JTTHF Dominant AHA TVPS Sequential Memory JTTHF Impaired TVPS Visual Closure</td>
</tr>
<tr>
<td><strong>AMPS-P</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>120.70</td>
<td>TVPS Visual Closure</td>
</tr>
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<td>2</td>
<td>114.60</td>
<td>TVPS Visual Closure TVPS Sequential Memory</td>
</tr>
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<td>3</td>
<td>112.90</td>
<td>TVPS Visual Closure TVPS Sequential Memory JTTHF Dominant</td>
</tr>
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<td>4</td>
<td>112.71</td>
<td>TVPS Visual Closure TVPS Sequential Memory JTTHF Dominant TVPS Spatial Relations</td>
</tr>
<tr>
<td>5</td>
<td>114.29</td>
<td>TVPS Visual Closure TVPS Sequential Memory JTTHF Dominant TVPS Spatial Relations AHA</td>
</tr>
</tbody>
</table>

BIC, Bayesian information criterion; AMPS, Assessment of Motor and Process Skills (M, motor scale; P, process scale); JTTHF, Jebsen-Taylor Test of Hand Function; AHA, Assisting Hand Assessment; TVPS-3, Test of Visual Perceptual Skills 3rd edition (non-motor)
References


5.3 Summary and Conclusions

This cross-sectional study examined relationships between ADL motor and processing skills, unimanual capacity, bimanual performance and visual perception in children and adolescents with UCP. The Mitii™ program aims to improve underlying skills considered prerequisite for the successful completion of ADL tasks, and it was therefore of interest to investigate factors that are related to ADL motor and processing skills. The following conclusions can be drawn from this study:

- Bimanual performance and unimanual capacity of the dominant upper limb are most strongly associated with ADL motor skills in children and adolescents with unilateral CP, and together explained 57% of variance in ADL motor skill scores.
- Processing skills of ADL tasks are related to visual sequential memory, visual closure and unimanual capacity of the dominant upper limb, which together explained 35% of variance in ADL processing skill scores.
- The relationship between unimanual capacity of the dominant upper limb and ADL processing skills may reflect underlying motor planning abilities such as planning, sequencing and feedback of movements.
- The relationship between ADL processing skills and visual sequential memory may reflect children’s ability to store and retrieve information to complete ADL steps in a logical, sequential order. The relationship between ADL processing skills and visual closure may reflect skills such as identifying objects on bench tops, in cupboards or drawers when they are only partially in view.
- A direct transfer of skills cannot be assumed between related variables, however this study provides insight into which skills may contribute to capacity in ADL and help us to interpret results from the RCT. Improvements in bimanual performance or unimanual capacity of the dominant upper limb following the Mitii™ intervention may relate to any improvements observed in ADL motor skills. Any improvements observed in visual perception may relate to ADL processing skills following Mitii™, however the unexplained variance in the ADL processing skills model suggests that other factors also contribute to ADL processing skills ability.
Chapter 6: Efficacy of a web-based multimodal therapy on occupational performance for children with unilateral cerebral palsy: A randomised controlled trial

6.1 Introduction

Chapter 6 consists of the paper entitled, “Randomised controlled trial of web-based multimodal therapy for unilateral cerebral palsy to improve occupational performance”. This paper addresses the primary hypothesis of this doctoral program, which was to investigate the efficacy of Mitii™ in comparison to standard care on improving occupational performance, upper limb function and visual perception in 8-18 year olds with UCP immediately post-intervention in a waitlist-control RCT.

6.2 Paper 5: Randomised controlled trial of web-based multimodal therapy for unilateral cerebral palsy to improve occupational performance

This manuscript has been accepted for publication in Developmental Medicine and Child Neurology. Journal impact factor: 3.292 (2015).


This paper was presented as a free paper at the 7th Biennial Conference of the AusACPDM, 11-14th March 2014, Hunter Valley, Australia; 68th AACPDM Meeting, 10-13th September 2014, San Diego, USA; and the 25th Occupational Therapy Australia Queensland State Conference, 23-25th October 2014, Noosa, Australia. This paper received the Gayle G. Arnold award for best paper at the 68th AACPDM Meeting.
Title: Randomised controlled trial of web-based multimodal therapy for unilateral cerebral palsy to improve occupational performance

Authors
Sarah James, BOccThy (Hons)1
Jenny Ziviani PhD, MEd, BA, BAppSc (OT)2,3
Robert S Ware PhD, BSc (Hons)4,5
Roslyn N Boyd PhD, MSc (Physio), BAppSc BSc, Pgrad (Biomech)1

1 Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, The University of Queensland, Royal Children’s Hospital, Brisbane, QLD, Australia; 2 Children's Allied Health Research, Queensland Health, Brisbane, QLD, Australia; 3 School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, QLD, Australia; 4 School of Population Health, The University of Queensland, Brisbane, QLD, Australia; 5 Queensland Children’s Medical Research Institute, The University of Queensland, Brisbane, QLD, Australia

Corresponding Author
Sarah James
Queensland Cerebral Palsy and Rehabilitation Research Centre
The University of Queensland
Level 7 Block 6 Royal Brisbane and Women’s Hospital
Herston Rd, Herston,
Queensland, AUSTRALIA 4029
E-mail: s.james2@uq.edu.au
Phone: +61 7 3646 5361

Clinical Trial Registration
Australian New Zealand Clinical Trials Registration Number (ACTRN)
12611001174976
Abstract

Aim: The study aimed to investigate the effectiveness of a web-based therapy program, “Move it to improve it” (Mitii™) in children with unilateral cerebral palsy (UCP) on occupational performance, upper limb (UL) function and visual perception.

Methods: Participants (n=102) were matched in pairs and randomised to intervention (Mitii™ for 20 weeks; 26 males, mean age=11y8m (2y4m), Manual Ability Classification System (MACS) I=11, II=39, III=1) or control (standard care; 25 males, mean age=11y10m (2y5m), MACS I=13, II=37). Outcomes were the Assessment of Motor and Process Skills (AMPS), Assisting Hand Assessment, Jebsen-Taylor Test of Hand Function (JTTHF), Melbourne Assessment of Unilateral Upper Limb Function, Canadian Occupational Performance Measure (COPM) and Test of Visual Perceptual Skills (TVPS-3).

Results: Participants completed on average 32.4 hours of Mitii™ (range=3.7-74.7 hours). The Mitii™ group demonstrated significantly greater post-intervention scores compared to the control group on the AMPS, JTTHF dominant UL, COPM and TVPS-3. The differences between groups were not clinically significant. There were no differences between groups on measures of impaired UL function.

Interpretation: Mitii™ delivers individualised, web-based therapy at home and has potential to increase therapy dose. Mitii™ can be considered as an option to enhance occupational performance and visual perception for children with UCP.

Key Words: randomised controlled trial, cerebral palsy, hemiplegia, child, adolescent, rehabilitation, interactive computer play, activities of daily living, upper limb, visual perception

What This Study Adds

1. This randomised controlled trial is the first adequately powered study of interactive computer play for UCP.
2. Mitii™ can enhance activities of daily living motor and processing skills, perceived occupational performance and visual perception.
3. There was no effect on measures of impaired UL function following the Mitii™ program.
Cerebral palsy (CP) is the most common physical disability in childhood with an estimated prevalence of 0.2% worldwide.\(^{(1)}\) Individuals with unilateral CP (UCP) experience difficulties with upper limb (UL) function which can impact independence in activities of daily living (ADL) and participation in life situations.\(^{(2)}\) Depending on severity of impairment, improving UL function can require ongoing therapy, interventions and adaptive equipment. Although high intensity therapy is required to optimise neuroplasticity, children and adolescents with CP typically receive only limited therapy services.\(^{(3)}\)

Therapy delivered via interactive computer play (ICP) is emerging as a feasible, child-active alternative to standard face-to-face therapy for individuals with CP.\(^{(4)}\) Interactive computer play is an umbrella term defined as “any kind of computer game or virtual reality technology where the individual can interact and play with virtual objects in a computer generated environment”.\(^{(5)}\) This term incorporates both two dimensional computer games and virtual reality technologies, which engage users in environments that appear and feel similar to real world experiences.

A review of ICP for individuals with CP reported a moderate level of evidence for improved gross motor outcomes yet inconclusive evidence for UL motor function.\(^{(6)}\) A meta-analysis examining the effect of specific virtual reality technologies in children with CP found a strong effect on UL function.\(^{(7)}\) Young children were identified as the best responders and engineer-built virtual reality systems had a greater effect compared to commercially available systems.\(^{(7)}\) Delivery in the home or laboratory rather than a clinic setting was recommended.\(^{(7)}\) The associated expense of some engineer-built systems may be a barrier to implementation in the home environment.

Evidence for ICP in this population is limited to pilot studies and further research with larger sample sizes and greater methodological rigour are required. A limitation of commercial systems, such as the Nintendo Wii™,\(^{(8, 9)}\) is the inability for therapists to individualize programs. A recently developed web-based multimodal therapy, “Move it to improve it” (Mitii™), allows therapists to create individualised programs, remotely monitor progress and adjust modules to provide incremental challenge for children to complete in their home environment.

The feasibility of delivering Mitii™ was confirmed in a pilot study of children aged 9-13 years with CP (n=9).\(^{(10)}\) Following 20 weeks of Mitii™ (average dose= 73.6 hours) children made significant gains in ADL motor and processing skills, visual
perception, functional strength and endurance. Mitii™ has also been reported to increase sense of agency in children with CP, which is the ability to perceive oneself as the cause of an action. It is proposed that improved sense of agency may positively impact functional task performance.

The aim of this RCT was to examine the effects of Mitii™ on occupational performance, upper limb (UL) function and visual perception in children with UCP. The primary hypothesis was that Mitii™ would enhance ADL motor and processing skills and reduce UL activity limitations (improve bimanual performance and unimanual capacity) compared to standard care. Secondarily, it was hypothesised that children would have increased attainment in occupational performance goals and visual perceptual skills.

Methods

A matched-pairs waitlist control RCT investigated the effectiveness of Mitii™ compared to standard care over 20 weeks in children with UCP between April 2012 and March 2014. Full ethical approval was obtained by the Medical Ethics Committee at The University of Queensland (2011000608), the Children’s Health Service Human Research Ethics Committee at the Royal Children’s Hospital Brisbane (HREC/11/QRCH/35) and the Cerebral Palsy Alliance’s HREC (2013-04-01). The study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12611001174976). Written informed consent was obtained from parents and participants over 12 years and verbal assent from younger children.

Participants

Children with spastic type UCP were recruited across Queensland and New South Wales, Australia. Inclusion criteria were: (i) Manual Ability Classification System (MACS) level I-III and Gross Motor Function Classification System (GMFCS) level I or II; (ii) aged 8-18 years with sufficient co-operation and cognitive understanding to perform required tasks; and (iii) internet access at home. Children were excluded if they had: (i) received upper-limb or lower-limb surgery in the previous 6 months; (ii) unstable epilepsy, or (iii) a respiratory, cardiovascular or other medical condition that would prevent them participating safely in the Mitii™ program. An experienced occupational therapist recruited participants and confirmed inclusion/exclusion criteria in consultation with relevant medical and allied health professionals when necessary.

Study Design and Procedure
Participants were consented to the study and matched in pairs based on age (within 12 month age bands), gender and MACS level. Participants were randomised in pairs to intervention (Mitii™ for 20 weeks) or waitlist control (standard care for 20 weeks) using a computer-generated list of random numbers placed in concealed envelopes and opened by non-study personnel. This study reports on baseline and 20 week data (collected within two weeks either side of 20 week assessment due date). Data were gathered in a naturalistic clinic setting at The University of Queensland in Brisbane, Australia.

**Intervention**

Mitii™ (Mitii Development A/S, Copenhagen Denmark)(13) is a web-based multimodal therapy program that is delivered in the home environment comprising UL, cognitive, visual perceptual and physical activity training. The program operates from a cloud server-based system using Adobe® Flash® technology and is accessed via an internet connected computer. The Mitii™ system detects and tracks bodily movements via a web-camera using green tracking bands worn on the hands, knee or head. Approximately 6 feet (1.8 metres) of space in front of a computer is required to complete the program. Equipment including laptops, webcams, internet dongles, green tracking bands, step blocks and balance foam was available for loan by participants.

Occupational therapists, physiotherapists and psychologists collaboratively devised individualised programs based on the child’s baseline assessment scores. Therapists selected from 14 training modules to devise a program that included approximately 60% cognitive/visual perceptual activities combined with UL (predominantly the impaired UL), and 40% gross motor activities. Mitii™ was ideally completed for 20-30 minutes, six days per week for 20 weeks providing a maximum potential dose of 60 hours.(10) Therapists remotely monitored the participant’s program and adjusted modules weekly by increasing speed, accuracy, repetitions and/or task complexity.

Regular contact was maintained with participants to provide feedback, technical support and facilitate engagement. Each family’s preferred frequency and mode of contact was obtained and typically involved weekly emails and telephone and/or Skype calls each fortnight. Participants were encouraged to track their progress over the 20 weeks using a rewards chart (Online Supporting Information 1).
Standard care was defined for the purposes of this study as “care as usual” so that participants in the control group were not disadvantaged in any way. Standard care typically involves consultative sessions with medical and allied health professionals. Children were not provided with any concomitant treatments including upper limb therapy, splinting or casting. Details of standard care and adverse events during the intervention period were captured by questionnaire at 20 weeks.

Primary Outcomes
Primary outcome measures were: (i) AMPS; (ii) Assisting Hand Assessment (AHA); (iii) Jebsen-Taylor Test of Hand Function (JTTHF); and (iv) Melbourne Assessment of Unilateral Upper Limb Function (MUUL). The AMPS is a Rasch-analyzed, observational evaluation of ADL motor and processing skills involving participants selecting and carrying out a minimum of two ADL tasks in a naturalistic environment.\(^{(14)}\) The AMPS motor scale assesses body position, obtaining and holding objects, moving self and objects and sustaining performance, and the AMPS process scale assesses applying knowledge, temporal organization, organizing space and objects and adapting performance. Changes greater than 0.30 logits are considered clinically significant on the AMPS motor and process scales.\(^{(14)}\) The AHA is a Rasch-analyzed measure of impaired hand use in bimanual tasks.\(^{(15)}\) The school kids version (≤12 years) and the adolescent board game version (≥13 years), which is in developmental stage, were used. Test-retest reliability of the school kids AHA is high (ICC=0.98) and the smallest detectable difference is 3.65 raw scores.\(^{(16)}\) The JTTHF evaluated upper limb unimanual speed and dexterity.\(^{(17)}\) The modified version was used (writing task omitted and time limit of 2 minutes per task), which has shown responsiveness to change following UL intervention in CP.\(^{(18)}\) The MUUL measures quality of reach, grasp, release and manipulation of the impaired upper limb.\(^{(19)}\) Inter-rater and intra-rater reliability is high (ICC=0.95 and 0.97 respectively).\(^{(20)}\) The AMPS, AHA and MUUL were video recorded for scoring. Scorers of the AHA and MUUL were masked to treatment allocation and time point.

Secondary Outcomes
Secondary outcome measures included: (i) Canadian Occupational Performance Measure (COPM); and (ii) Test of Visual Perceptual Skill (non-motor) 3rd edition (TVPS-3). The COPM evaluates self-perceived occupational performance in five areas identified by child and/or caregivers.\(^{(21)}\) The test-retest reliability of the COPM performance and satisfaction scales is high (ICC=0.76 and 0.89 respectively) and a
2 point change is considered clinically significant.\(^{(21)}\) The TVPS-3 evaluates visual perception across seven domains (Visual Discrimination, Spatial Relations, Visual Memory, Form Constancy, Sequential Memory, Figure Ground Discrimination and Visual Closure).\(^{(22)}\) Each subscale has a maximum score of 16, and scoring involves converting raw scores into scaled, standard and percentile scores. Test-retest reliability of the TVPS-3 overall standard score is high \(r=0.97\) and the smallest detectable change (SDC) is 8.15 points based on standard error of measurement (SEM) of 2.94\(^{(22)}\) and formula SDC=SEM x 1.96 x \(\sqrt{2}\).

**Participant Characteristics**

Intellectual ability was classified by neuropsychologists using the Full Scale Intelligence Quotient from the Wechsler Intelligence Scale for Children.\(^{(23)}\) Geographical location was classified by the Accessibility/Remoteness Index of Australia.\(^{(24)}\) Socio-economic status was measured at the postcode level using the Index of Relative Socio-economic Disadvantage (deciles range 1-10; 1 indicates lowest 10%).\(^{(25)}\) Sensory measures including moving two point discrimination (Disk-criminator®), grip strength (hand held dynamometer) and stereognosis (identifying nine objects with vision occluded) were assessed by an occupational therapist.

**Sample Size**

To detect a change of 0.35 logits on the AMPS with 80% power and \(\alpha=0.05\), and assuming a standard deviation (SD) of 0.58 logits, a sample size of 44 participants in each group was required. Allowing for 10% attrition, the minimum recruitment target was 98 participants (49 participants in each group).

**Statistical Analyses**

Descriptive statistics were used to calculate participant demographic, social and clinical characteristics of participants in the intervention and control groups. Differences between intervention groups were examined using linear regression models, where treatment group (Mitii™/control) and baseline score were entered into the model as main effects. Linear regression assumptions were tested and not violated. Regression results are presented as mean difference and 95% confidence interval. A p-value <0.05 (two-tailed) was defined as being statistically significant and missing data was accommodated by case-wise deletion. Analyses were on an intention-to-treat (ITT) basis using Statistical Package for Social Sciences (SPSS, version 22). Secondary analyses examined the effect of therapy dose on primary
outcome measures using fractional polynomial regression to account for the possible
non-linearity in dose-therapy effect.

Results
During recruitment, 270 individuals were screened and 102 children were
randomised to Mitii™ (n=51) or waitlist control (n=51) (Figure 1). Baseline
demographic, social and clinical characteristics are presented in Table 1. Groups
were similar at baseline.

Intervention
Participants in the intervention group completed an average 32.4 hours of Mitii™
(range 3.7-74.7 hours) (Figure 2). In the control group, seven participants (14%)
saw an OT as part of their standard care during the intervention period (five received
one consultative session). Nine participants (18%) in the Mitii™ group received OT
(seven received one consultative session). One child in the intervention group
received UL BoNT-A injections and was excluded from analyses of impaired UL
outcome measures. One participant in the intervention group had seizures during
the intervention period but parents reported that this was not related to Mitii™.

Primary Outcome Measures
Baseline and 20 week data for Mitii™ and control groups and regression analysis
results of primary outcome measures are presented in Table 2. After 20 weeks, the
AMPS motor scale scored were 0.28 logits higher in the intervention group than in
the control group, after adjusting for baseline scores, (95%CI=0.17, 0.39; p=<0.001)
and 0.30 logits higher on the AMPS process scale (95%CI=0.19, 0.41; p=<0.001).
These differences were close but did not exceed clinical significance. The Mitii™
group demonstrated statistically significantly higher JTTHF scores on the dominant
UL, while there was a trend towards an improvement on the impaired UL (p=0.058).
There was no significant difference between groups on the AHA or MUUL. When
the effect of therapy dose was examined, an increased benefit was observed in the
first 20 hours of therapy for the primary outcome variables, followed by a plateau.

Secondary Outcome Measures
Table 3 presents baseline and 20 week data and regression analysis results for
secondary outcome measures. The Mitii™ group had significantly higher scores on
the COPM performance scale by 1.29 points (95%CI=0.73, 1.85; p=<0.001), COPM
satisfaction scale by 1.45 points (95%CI=0.44, 0.83; p=<0.001) TVPS-3 overall score
by 6.79 points (95%CI=2.80, 10.78, p=0.001) compared to the control group post-
intervention. These differences however were not clinically significant. Analysis of TVPS-3 domain scores revealed significantly higher scores in visual discrimination, spatial relations and figure ground discrimination.

Discussion

In this adequately powered RCT, children with UCP allocated to the Mitii™ intervention achieved greater improvements in ADL motor and processing skills, goal attainment and visual perception compared to the control group. The Mitii™ group showed significant improvements in speed and dexterity of the dominant UL, while the impaired UL trended towards an improvement. The differences between groups were close to the limits of clinical significance. This intensive multimodal training delivered in the home environment offers an option for enhancing occupational performance skills.

The purpose of a multimodal therapy such as Mitii™ is to enhance neural circuits in the brain that establish a basis for specific learning and skill development. When learning new skills, the perceptual, cognitive and motor control components are closely interconnected and Mitii™ is designed to train these multiple networks at the same time. Mitii™ combines gross UL movements requiring accuracy and motor planning with cognitive and/or visual perceptual challenge. To optimise neuroplasticity, the program is designed to be intensive, incrementally challenging, motivating and require individuals to pay close attention to the tasks. Mitii™ does not however target fine motor manipulation, incorporate a substantial amount of bimanual UL activities or involve task-specific training. As such, the hypothesis that Mitii™ would enhance bimanual performance and unimanual capacity of the impaired UL was not confirmed. Current evidence for child-active rehabilitation approaches supports therapy that is goal-directed, task specific and involves high-dose repetition in order to stimulate experience-dependent plasticity.

The Mitii™ program offers an individualised, web-based therapy that can greatly increase the dose of therapy received by children with UCP, and supplement goal based training. Results of this clinical trial largely reflect the nature of the Mitii™ program in that they gained what they trained and are consistent with the neuroplasticity principle, “use it and improve it.” Improvements in the Mitii™ group on both the AMPS motor and process scales reflect increased proficiency in underlying skills that are necessary for successful ADL task performance. Mitii™ allows children to drive their own therapy, providing...
repetitive practice planning and carrying out motor actions, problem solving and giving self-feedback. Children may have enhanced motor planning abilities such as timing of movements, visual-motor integration or self-corrective motions following Mitii™, which transferred into ADL motor and processing skills. Improvements in ADL processing skills were slightly greater than improvements in motor skills, and this may be related to improvements in visual processing skills. Visual processing skills are involved in ADL skills such as searching and locating items in drawers, and organizing workspaces, which are evaluated on the AMPS process scale. Given these findings, Mitii™ may be of particular benefit to children with UCP with processing and/or visual perceptual problems as the program targets these skills in a combination with functional UL activities.

Although it is known that children with CP have difficulties in visual perception which can impact daily functioning, visual perceptual outcomes are not commonly incorporated in intervention studies. The improvements on the TVPS-3 in this study suggest that visual perceptual skills can be enhanced with targeted therapy. The TVPS-3 standard score is age-adjusted and therefore increases in the intervention group can be attributed to the intervention rather than age-related improvements. The greatest improvements were found in visual discrimination, spatial relations and visual closure domains, which can be targeted with Mitii™.

Occupational performance goals were not specifically practised over the intervention period. This differs to traditional client-centred therapy approaches where goal setting would precede specific task practice to improve occupational performance. While our results found on the COPM suggest that Mitii™ may assist in achieving goals, the differences between groups did not reach clinical significance. It is possible that children increased their sense of agency of their impaired UL following Mitii™, which may have led to increased use of the impaired UL in functional tasks. Children may have improved motor, cognitive or visual perceptual skill components which constituted a basis for developing skills related to their individual goals.

Our study found no significant improvements in impaired UL function, however there was a trend towards an improvement in the Mitii™ group in speed and dexterity of the impaired UL (JTTHF). Previous studies of ICP have reported mixed results in UL measures. It is possible that children improved their motor planning abilities and
demonstrated greater improvements in their dominant UL in the absence of underlying motor impairment.

The non-significant findings on the MUUL may be influenced by the high baseline scores, which compromise the extent of possible improvement. Previous studies in this population have reported this impact\(^{(30)}\) suggesting the MUUL is not sensitive to change following intensive UL intervention.\(^{(31)}\) A pilot RCT (n=10) using the Sony PlayStation reported no change in the MUUL\(^{(32)}\), while a robot assisted virtual reality system led to clinically meaningful changes in three of nine children with UCP.\(^{(33)}\)

The lack of change in bimanual performance on the AHA reflects that Mitii™ does not incorporate a substantial amount of bimanual activities nor target grasp and manipulation skills.

Investigations into therapy dose showed considerable variation among participants in their level of engagement in Mitii™ over the 20 week period (Figure 2). Secondary analysis of the dose-therapy effect suggested that the first 20 hours of therapy may be the most important, with an increased benefit observed in this time period for the primary outcome variables. The effect of therapy dose on outcomes is an important consideration for future work. Further investigation is also warranted to determine factors that may contribute to engagement to assist future clinical implementation.

Future research to examine the effect of age or co-morbid diagnoses (e.g. attention deficit hyperactivity disorder) may also assist therapists to select the most appropriate children for this mode of therapy delivery.

Strengths of this study are the rigorous study design and large sample size. Given the novelty of ICP as a therapeutic modality, previous studies have been conducted on relatively small samples and have lacked rigor in methodology. This study had high retention rates and the matched-pairs design minimized baseline differences. A further strength was the availability of resources to loan to families who otherwise would not have been able to participate in Mitii™.

A limitation of this study is that few children reached the maximum target dose of 60 hours. Technical issues may have contributed to the lower than target dose and these aspects are being addressed with further updates of the program. The JTTHF administrator was not masked to treatment allocation, however the therapist was unaware of baseline scores when administering 20 week assessments and assessments were video recorded for data checking. Scoring of the AMPS was not blinded due to limited availability of calibrated therapists. In an effort to reduce
potential bias, the therapist who administered and scored the AMPS rated videos in a random order with codes masking treatment group and time point. The inclusion of children with mild to moderate UCP in this study as the ideal group for Mitii™ limits the generalizability of these results to other populations. While details of standard care were obtained, a limitation is the lack of specific details of any home exercises.

Conclusion
In an appropriately powered RCT, Mitii™ led to significant improvements in ADL motor and processing skills, occupational performance goal attainment and visual processing in children with UCP. Increased speed and dexterity of the dominant UL following Mitii™ may reflect improvements in motor planning abilities. There were no differences between groups on measures of impaired UL function. Mitii™ offers a web-based multimodal therapy that can greatly increase the therapy dose received by children with UCP and is recommended as supplementary rehabilitation to complement goal-directed therapy. Mitii™ has potential to be a beneficial component of the therapy toolbox for children with UCP.

Acknowledgements
We thank all the children and families who participated in this study. We acknowledge the contributions of Melinda Lewis as study coordinator and the Mitii™ study team. We thank Chloe Noble, Ellen Gaudry and Joanne Bowden (occupational therapists) for their assistance with scoring, and Leanne Sakzewski for proofreading. We thank the Queensland CP Health Service and the CP Alliance for their assistance with recruitment.

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References


Table 1. Baseline participant characteristics of the Mitii™ randomised controlled trial

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Intervention Group (n=51)</th>
<th>Control Group (n=50)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, mean (SD)</strong></td>
<td>11y8m (2y4m)</td>
<td>11y10m (2y5m)</td>
</tr>
<tr>
<td><strong>Gender, male (%)</strong></td>
<td>26 (51.0%)</td>
<td>25 (50.0%)</td>
</tr>
<tr>
<td><strong>Hemiplegia, left sided (%)</strong></td>
<td>28 (55.0%)</td>
<td>20 (40.0%)</td>
</tr>
<tr>
<td><strong>MACS, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>11 (21.6%)</td>
<td>13 (26.0%)</td>
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<tr>
<td>Level II</td>
<td>39 (76.5%)</td>
<td>37 (74.0%)</td>
</tr>
<tr>
<td>Level III</td>
<td>1 (2.0%)</td>
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<td><strong>GMFCS, n (%)</strong></td>
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<td></td>
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<tr>
<td>Level I</td>
<td>20 (39.2%)</td>
<td>25 (50.0%)</td>
</tr>
<tr>
<td>Level II</td>
<td>31 (60.8%)</td>
<td>25 (50.0%)</td>
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<tr>
<td><strong>Intellectual ability</strong></td>
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<tr>
<td>FSIQ &lt;80 (below average), n (%)</td>
<td>4 (7.8%)</td>
<td>7 (14.0%)</td>
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<tr>
<td><strong>Other Diagnoses, n (%)</strong></td>
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<tr>
<td>Learning disorder</td>
<td>14 (27.5%)</td>
<td>9 (18.0%)</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>1 (2%)</td>
<td>3 (5.9%)</td>
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<tr>
<td>Vision impairment</td>
<td>5 (9.8%)</td>
<td>6 (12.0%)</td>
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<tr>
<td>ADHD</td>
<td>4 (7.8%)</td>
<td>6 (12.0%)</td>
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<tr>
<td>Autism spectrum disorder</td>
<td>3 (5.9%)</td>
<td>1 (0.02%)</td>
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<td><strong>Sensory measures (impaired UL)</strong></td>
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<tr>
<td>M2PD, median (Q1-Q3)</td>
<td>2 (2.0-3.8)</td>
<td>3 (2-3)</td>
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<td>Grip strength, mean kg (SD)</td>
<td>7.5 (6.9)</td>
<td>8.1 (7.1)</td>
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<tr>
<td>Stereognosis (/9), median (Q1-Q3)</td>
<td>7.5 (3.5-9)</td>
<td>7 (3-9)</td>
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<tr>
<td><strong>Standard OT, n (%)</strong></td>
<td>22 (43.1%)</td>
<td>23 (46.0%)</td>
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<tr>
<td>Once per week</td>
<td>0</td>
<td>1 (2.0%)</td>
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<tr>
<td>Once per month</td>
<td>3 (5.8%)</td>
<td>3 (6.0%)</td>
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<tr>
<td>Once a term</td>
<td>10 (19.6%)</td>
<td>6 (12.0%)</td>
</tr>
<tr>
<td>Once per year</td>
<td>9 (17.6%)</td>
<td>13 (26.0%)</td>
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<tr>
<td><strong>Geographic location, n (%)</strong></td>
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<td></td>
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<tr>
<td>Major Cities</td>
<td>21 (41.2%)</td>
<td>25 (50.0%)</td>
</tr>
<tr>
<td>Inner Regional</td>
<td>13 (25.5%)</td>
<td>14 (28.0%)</td>
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<tr>
<td>Outer Regional</td>
<td>13 (25.5%)</td>
<td>9 (18.0%)</td>
</tr>
<tr>
<td>Remote/Very Remote</td>
<td>4 (7.8%)</td>
<td>2 (4.0%)</td>
</tr>
<tr>
<td><strong>Socio-economic status, mean decile (SD)</strong></td>
<td>6.0 (2.7)</td>
<td>6.5 (2.9)</td>
</tr>
</tbody>
</table>

SD, standard deviation; MACS, Manual Ability Classification System; GMFCS, Gross Motor Function Classification System; FSIQ, Full Scale Intelligence Quotient; ADHD, Attention Deficit/Hyperactivity Disorder; UL, upper limb; M2PD, moving two point discrimination; imp, impaired upper limb; Q1, 25th centile; Q3, 75th centile; Standard OT, occupational therapy services typically received.

N.B Missing values: Sensory measures=5; Geographic location=2.
<table>
<thead>
<tr>
<th>Primary Outcome Measures</th>
<th>Mitii™ Group</th>
<th>Control Group</th>
<th>Mean Difference</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AMPS-M (range -3 to 4)</strong></td>
<td></td>
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<tr>
<td>Baseline, mean logits (SD)</td>
<td>1.06 (0.56)</td>
<td>1.14 (0.50)</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>20 weeks</td>
<td>1.38 (0.44)</td>
<td>1.11 (0.48)</td>
<td>0.28</td>
<td>0.17, 0.39</td>
<td>&lt;0.001</td>
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<tr>
<td><strong>AMPS-P (range -4 to 3)</strong></td>
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</tr>
<tr>
<td>Baseline, mean logits (SD)</td>
<td>1.05 (0.48)</td>
<td>1.15 (0.54)</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>20 weeks</td>
<td>1.39 (0.34)</td>
<td>1.08 (0.53)</td>
<td>0.30</td>
<td>0.19, 0.41</td>
<td>&lt;0.001</td>
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<tr>
<td><strong>JTTHF Impaired UL (max 720 sec)</strong></td>
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</tr>
<tr>
<td>Baseline, mean sec (SD)</td>
<td>201.56 (181.93)</td>
<td>216.24 (187.11)</td>
<td>-22.03</td>
<td>-44.78, 0.72</td>
<td>0.058</td>
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<tr>
<td>20 weeks</td>
<td>173.09 (178.39)</td>
<td>197.18 (171.30)</td>
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<tr>
<td><strong>JTTHF Dominant UL (max 720 sec)</strong></td>
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<tr>
<td>Baseline, mean sec (SD)</td>
<td>40.65 (9.92)</td>
<td>42.48 (20.67)</td>
<td>-4.68</td>
<td>-7.39, -1.98</td>
<td>&lt;0.001</td>
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<td>20 weeks</td>
<td>35.85 (7.14)</td>
<td>43.76 (19.16)</td>
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<tr>
<td><strong>AHA (range 0-100)</strong></td>
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<tr>
<td>Baseline, mean AHA-logits (SD)</td>
<td>66.68 (16.59)</td>
<td>66.06 (16.42)</td>
<td>0.61</td>
<td>-1.46, 3.08</td>
<td>0.478</td>
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<tr>
<td>20 weeks</td>
<td>68.24 (15.32)</td>
<td>67.84 (15.41)</td>
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<td><strong>MUUL (range 0-100)</strong></td>
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<tr>
<td>Baseline, mean (SD)</td>
<td>83.01 (17.96)</td>
<td>81.30 (16.99)</td>
<td>1.71</td>
<td>-4.11, 1.15</td>
<td>0.265</td>
</tr>
<tr>
<td>20 weeks</td>
<td>82.94 (17.92)</td>
<td>80.49 (16.74)</td>
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</table>

SD, standard deviation; CI, confidence interval; AMPS-M, Assessment of Motor and Process Skills – motor scale; AMPS-P, Assessment of Motor and Process Skills – process scale; JTTHF, Jebsen-Taylor Test of Hand Function; UL, upper limb; sec, seconds; AHA, Assisting Hand Assessment; MUUL, Melbourne Assessment of Unilateral Upper Limb Function.
Table 3. Secondary outcome measures: Baseline and 20 week scores for Mitii™/control groups and regression results

<table>
<thead>
<tr>
<th>Secondary Outcomes Measures</th>
<th>Mitii™ Group</th>
<th>Control Group</th>
<th>Mean Difference</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
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<tbody>
<tr>
<td>COPM-P (range 0-10)</td>
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<tr>
<td>Baseline, mean (SD)</td>
<td>4.15 (1.37)</td>
<td>4.22 (1.29)</td>
<td>1.29</td>
<td>0.73, 1.85</td>
<td>&lt;0.001</td>
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<td>20 weeks</td>
<td>6.26 (1.69)</td>
<td>4.98 (1.39)</td>
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<tr>
<td>COPM-S (range 0-10)</td>
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<tr>
<td>Baseline, mean (SD)</td>
<td>4.59 (1.45)</td>
<td>4.58 (1.76)</td>
<td>0.01</td>
<td>0.73, 1.85</td>
<td>&lt;0.001</td>
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<tr>
<td>20 weeks</td>
<td>6.67 (1.92)</td>
<td>5.16 (1.69)</td>
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<tr>
<td>TVPS-3 Overall (range 55-145)</td>
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<tr>
<td>Baseline, mean overall standard (SD)</td>
<td>85.02 (16.07)</td>
<td>84.54 (17.70)</td>
<td>0.48</td>
<td>0.26, 0.72</td>
<td>&lt;0.001</td>
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<td>20 weeks</td>
<td>92.55 (17.60)</td>
<td>83.72 (18.48)</td>
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<td>TVPS-3 Domain Scores (range 0-16)</td>
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<td>Visual Discrimination</td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>7.59 (3.35)</td>
<td>7.90 (3.37)</td>
<td>1.41</td>
<td>0.26, 2.55</td>
<td>0.017</td>
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<td>20 weeks</td>
<td>9.38 (3.51)</td>
<td>8.29 (3.60)</td>
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<td>Visual Memory</td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>9.71 (3.34)</td>
<td>9.52 (3.86)</td>
<td>0.19</td>
<td>-0.29, 2.71</td>
<td>0.113</td>
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<tr>
<td>20 weeks</td>
<td>10.72 (3.70)</td>
<td>9.31 (4.89)</td>
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<td>Spatial Relations</td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>11.10 (4.04)</td>
<td>10.46 (4.68)</td>
<td>0.64</td>
<td>-0.33, 1.59</td>
<td>0.100</td>
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<tr>
<td>20 weeks</td>
<td>12.36 (3.35)</td>
<td>10.33 (4.25)</td>
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<tr>
<td>Form Constancy</td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>7.06 (3.64)</td>
<td>6.50 (4.04)</td>
<td>0.56</td>
<td>-0.10, 1.12</td>
<td>0.071</td>
</tr>
<tr>
<td>20 weeks</td>
<td>8.32 (3.86)</td>
<td>6.69 (4.02)</td>
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<tr>
<td>Sequential Memory</td>
<td></td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>8.28 (3.66)</td>
<td>8.78 (3.94)</td>
<td>0.50</td>
<td>-0.07, 1.07</td>
<td>0.065</td>
</tr>
<tr>
<td>20 weeks</td>
<td>9.92 (3.33)</td>
<td>8.91 (3.85)</td>
<td></td>
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<tr>
<td>Figure Ground Discrimination</td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>7.80 (4.00)</td>
<td>7.88 (4.43)</td>
<td>0.08</td>
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<td>20 weeks</td>
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<td>7.56 (4.37)</td>
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<tr>
<td>Visual Closure</td>
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<tr>
<td>Baseline, mean raw score (SD)</td>
<td>6.65 (4.42)</td>
<td>6.44 (4.31)</td>
<td>0.21</td>
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<td>0.070</td>
</tr>
<tr>
<td>20 weeks</td>
<td>8.40 (4.31)</td>
<td>6.69 (4.87)</td>
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</table>

Figure 1. CONSORT flowchart of participants and assessments through the Mitii™ study
Figure 2. Individual participant dose of Mitii™ therapy over 20 weeks
Online Supporting Information 1. Mitii™ rewards chart (youth version) provided to participants to monitor progress over 20 weeks
6.2 Summary and Conclusions

Chapter 6 presented and discussed findings from the overall RCT investigating the effectiveness of Mitii™ compared to standard care for children and adolescents aged 8-16 years with mild to moderate UCP. Findings from this study are positioned within the context of previous studies of interactive computer play and alternate interventions for enhancing occupational performance in Chapter 8. A summary of findings is as follows:

- Participants in the Mitii™ intervention group completed an average 32.4 hours of Mitii™ over the 20 week period. There was considerable range in the overall therapy dose of participants, ranging from 3.7 hours to 74.7 hours. This variation in therapy dose reflects differing levels of engagement in the program, which may be related to various characteristics of participants and factors associated with the intervention.
- Compared to participants in the waitlist group, who were assigned standard care, participants in the intervention group demonstrated statistically significantly greater improvements in ADL motor and processing skills, speed and dexterity of the dominant upper limb, visual perception and perceived occupational performance. The differences between groups however were not clinically significant.
- There was no significant difference between groups in bimanual performance or unimanual capacity as measured by the MUUL following the Mitii™ intervention.
Chapter 7: Understanding engagement in a web-based therapy delivered in the home environment: Perspectives of children with cerebral palsy and their caregivers

7.1 Introduction

The paper entitled, “Understanding engagement in web-based therapy delivered in the home environment: Perspectives of children with unilateral cerebral palsy and their caregivers” comprises Chapter 7. There was considerable variation in the overall therapy dose achieved by participants in the Mitii™ intervention group over the 20 week period in the RCT. This reflects that there was a range in terms of the participants’ level of engagement. As interactive computer play is a relatively novel therapeutic modality, it is important to understand engagement from the perspectives of children and their caregivers to guide future clinical implementation. Therefore, the aim of this study was to investigate factors which impact engagement in Mitii™ in children with UCP from the view of children and their caregivers.

7.2 Paper 6: Understanding engagement in a web-based therapy program delivered in the home environment: Perspectives of children with cerebral palsy and their caregivers

This paper was submitted to Physical and Occupational Therapy in Paediatrics in January 2015. Journal impact factor: 1.418 (2013)


This paper was presented as a free paper at the 7th Biennial Conference of the AusACPDM, 11-14th March 2014, Hunter Valley, Australia.
Understanding engagement in web-based therapy delivered in the home environment: Perspectives of children with unilateral cerebral palsy and their caregivers

Authors
Sarah James
Jenny Ziviani
Gillian King
Roslyn N Boyd

1 Queensland Cerebral Palsy and Rehabilitation Research Centre, The University of Queensland, Royal Children’s Hospital, Brisbane, Australia
2 Children’s Allied Health Research, Queensland Health and School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia
3 Bloorview Research Institute and University of Toronto, Toronto, Canada

Corresponding Author
Sarah James
Queensland Cerebral Palsy and Rehabilitation Research Centre
The University of Queensland
Level 7, Block 6, Royal Brisbane and Women’s Hospital
Herston Rd, Herston, Queensland, 4029
Email: s.james2@uq.edu.au
Fax: +61 7 3365 5538

Declarations
The authors report no declarations of interests.

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Abstract

Aims: This study aimed to understand engagement of children participating in a web-based therapy program, “Move it to improve it” (Mitii™).

Methods: Participants were ten children with unilateral cerebral palsy (mean age=11 years 4 months; 5 males) and their caregivers. Semi-structured interviews were audio recorded and transcribed verbatim. Transcripts were analysed independently by two researchers using an inductive approach.

Results: Key themes were mapped against three characteristics of engagement: (1) Child/family characteristics comprising (i) children’s interest is captured through novelty and technology; (ii) motivation declines as novelty wears off; (iii) children require ‘finely tuned’ programs; (iv) strong family support facilitates engagement; and (v) children develop confidence and ownership; (2) Intervention characteristics including (i) increased therapy frequency with reduced caregiver involvement; (ii) Mitii™ ‘becomes therapy’ and competes with other interests; (iii) convenience within family routine; (iv) lack of real-time feedback and technical issues; and (v) therapist guidance is essential; (3) Service provider characteristics comprising (i) initial and ongoing therapist input; (ii) family-friendly therapy approach; and (iii) tailored strategies to sustain engagement.

Conclusions: Therapists should be cognisant of factors that may impact on children’s engagement in Mitii™ and similar programs, and devise individual strategies collaboratively with families to support sustained engagement.

Key words: Qualitative, virtual reality, cerebral palsy, children, adolescents, caregivers
Current evidence supports a suite of effective interventions for individuals with unilateral cerebral palsy (UCP) to improve motor activity performance and self-care ability. (Novak et al., 2013) There has been a focus in recent literature on the required ‘dose’ (amount of therapy) to achieve changes in function. (Sakzewski et al., 2010) Many families however have limited access to therapy services, particularly those living in rural areas. For this reason, interactive computer play (ICP) has emerged as a feasible mode of therapy delivery. The umbrella term, ICP, incorporates “any kind of computer game or virtual reality technology where the individual can interact and play with virtual objects in a computer generated environment”. (Sandlund et al., 2009)

A recent review of ICP found a moderate level of evidence for gross motor outcomes yet inconclusive evidence for UL motor function for individuals with CP. (Fehlings et al., 2013) A recent randomised controlled trial (RCT) investigated the effectiveness of a multimodal web-based therapy program, “Move it to improve it” (Mitii™), compared to standard care in children and adolescents with UCP on a broad range of outcome measures. (Boyd et al., 2013) Mitii™ combines upper limb, gross motor, visual perception and cognitive activities in individualised programs that are guided by therapists. The program is accessed on a computer in the home environment and movement is tracked via a webcam (original version used in this RCT) or Microsoft Kinect (current version). Participants aimed to complete 20-30 minutes, six days per week for 20 weeks (maximum potential dose = 60 hours) and could track their progress with a rewards chart. (Figure 1)

In the RCT, the average overall dose of Mitii™ completed by participants over the 20 week period was 32.4 hours, with a range from 3.7 to 74.7 hours. (James et al, in press; Mitchell et al, in submission) Compared to the waitlist group, children in the intervention group achieved statistically significant improvements in activities of daily living motor and processing skills (Assessment of Motor and Process Skills), occupational performance (Canadian Occupational Performance Measure), visual perception (Test of Visual Perceptual Skills 3rd edition) and functional strength. The intervention group showed also statistically significant improvements in upper limb speed and dexterity of their dominant upper limb, and a trend towards an improvement on the impaired upper limb (Jebsen-Taylor Test of Hand Function). The differences between groups were not clinically significant. There were no differences between groups on measures of bimanual performance (James et al, accepted), physical activity participation (Mitchell et al, in submission) or executive function (Ross et al, in submission).

The substantial variation in the overall dose of Mitii™ reflects differing levels of engagement among participants. As ICP is an emerging therapy approach, and one that
differs considerably from standard face-to-face approaches, it is important to understand factors contributing to this variability. Only one previous qualitative study has investigated parents’ perceptions of an ICP system (Eye Toy®: Play 3 for PlayStation 2®; 4 week home-based program). (Sandlund, Dock, et al., 2011) Parents reported that the Eye Toy® facilitated a positive experience of physical activity training and promoted independent practice, however they identified a need for the program to be better tailored to children’s individual rehabilitation needs. (Sandlund, Waterworth, et al., 2011)

Questionnaires and anecdotal reports within pilot studies generally report high levels of enjoyment in children using ICP systems. (Jannink et al., 2008; Sharan et al., 2012) This mode of therapy delivery has been reported to provide motivation, interest and intrigue in therapy for children and adolescents. Participants from the pilot study of Mitii™ reported that the ‘game-like’ nature of the program was initially motivating, although this was difficult to maintain over a long period of time. (Bilde et al., 2011)

Engagement is defined as “a multifaceted state of affective, cognitive and behavioural commitment or investment in the client role over the intervention process”. (King, Currie, et al., 2014) In a recently proposed framework, three factors were advanced as influencing engagement in the therapy process: (i) client characteristics; (ii) intervention characteristics; and (iii) service provider characteristics. (King, Currie, et al., 2014) These factors are believed to influence clients’ perceptions of the intervention, their within-session involvement and behavioural participation over time. The objective of this study is to understand engagement of children participating Mitii™ from the perspectives of children and their caregivers.

Methods
This study was conducted within a large randomised controlled trial that investigated the effectiveness of Mitii™ in children and adolescents with unilateral CP. (Boyd et al., 2013) The trial received full ethical approval by the Medical Ethics Committee at The University of Queensland (2011000608), the Children’s Health Service Human Research Ethics Committee at the Royal Children’s Hospital Brisbane (HREC/11/QRCH/35) and the Cerebral Palsy Alliance’s HREC (2013-04-01). Written informed consent was obtained from caregivers and participants over 12 years and verbal assent from younger children.

Participants
Participants were ten children aged 8-18 years with UCP and their caregivers. Purposive sampling was used to select participants across a broad range in age and level of completed Mitii™, and with various family circumstances reflecting the overall sample.
Inclusion criteria for the Mitii™ study were: (i) Gross Motor Function Classification (GMFCS) I or II; (ii) Manual Abilities Classification Scale (MACS) I-III; (iii) sufficient cooperation and cognition to complete the Mitii™ program. Children were excluded from the study if they had: (i) received upper-limb or lower-limb surgery in the previous 6 months; (ii) unstable epilepsy; (iii) respiratory, cardiovascular or other medical conditions that would prevent them participating safely in the Mitii™ training.

Study Design

This study employed a generic qualitative research design (i.e. one that is not guided by an explicit set of philosophical assumptions), which Caelli et al posit must address four key areas: (i) theoretical positioning of the researcher; (ii) congruence between methodology and methods; (iii) strategies to establish rigor; and (iv) analytic lens through which data is examined. (Caelli et al., 2003)

The theoretical positioning of the researchers in the current study in respect to disciplinary affiliations is as follows: SJ and JZ are occupational therapists, RB is a physiotherapist and GK is a social psychologist with an interest in intervention processes. We were motivated to understand the experiences of children and caregivers in the Mitii™ program through our roles in the overall RCT, where SJ was a PhD student investigating occupational therapy outcomes, and JZ and RB were chief study investigators. No financial or commercial affiliations existed between the researchers and the Mitii™ developers.

Assumptions which informed our investigation were that there would be considerable variation in the experiences of children and their caregivers given the mix of clients and family characteristics.

In planning the study design, we ensured congruence between methodology and methods. Interviews were conducted in a quiet room by an experienced occupational therapist unknown to the participants. A semi-structured interview schedule allowed probing of responses. The length of the interview depended on the detail of the child and/or caregiver’s responses. Seven children and their caregivers were interviewed separately while three children were interviewed with their caregivers and answered questions together as a ‘team’. Interview questions focused on what children liked/disliked about Mitii™, caregiver’s expectations of the program, how Mitii™ compared to other therapy and suggestions for changes (Tables 1 and 2).

[Insert Tables 1 and 2 about here]

To establish rigor, the semi-structured interview format maintained a level of consistency between interviews while providing opportunity for elaboration. A written summary of
findings was provided to participants for review to ensure their views were accurately captured. Rigor in data analysis was carefully considered and is described below.

The analytical lens or the interpretive presuppositions of the researchers was to understand engagement in web-based therapy, in terms of the engagement framework. (King, Currie, et al., 2014) Engagement is a fluctuating state that changes over the course of an intervention and this framework considers within-session involvement in terms of: (i) affective i.e. emotional involvement in the therapy and with therapist; (ii) cognitive i.e. belief in the need for and efficacy of the intervention; and (iii) behavioural i.e. goal setting process, shared decision-making, in-session participation and self-efficacy. (King, Currie, et al., 2014)

Data analysis
Interviews were audio recorded and transcribed verbatim. Transcripts were combined and immersion in data occurred through multiple reading by two researchers (SJ, JZ). (Braun and Clarke, 2006) An inductive approach was used to identify themes using computer software (NVivo, v10.0) and a preliminary coding strategy was developed (SJ). Themes were mapped to the engagement framework (child/family, intervention and service provider characteristics). Minor changes were made to the coding strategy in response to second independent coding through discussion and consensus.

Results
Participant demographics are presented in Table 3. For the purpose of this study primary participants are considered to be the children and adolescents who participated in Mitii™. The mean age of participants was 11 years 4 months and there were five males. Seven children had a left sided hemiplegia and seven children were classified as MACS level I. There were nine female caregivers and one male caregiver. Two caregivers were employed full time and four part-time.

The children and caregivers generally conveyed a positive view of Mitii™ as a therapeutic modality. There was no distinct difference between child and caregiver views. Themes are outlined under relevant engagement characteristics, followed by clinical implementation suggestions from children and caregivers. Table 4 provides an overview of factors drawn from the themes that were considered to either enhance or inhibit engagement.

[Insert Table 3 about here]

Child/Family Characteristics
Themes within this category relate to child and caregiver perceptions of personal characteristics that affect engagement with the intervention, such as motivation,
confidence, skills/resources and their belief in the need for an intervention.

**Children’s interest is captured through novelty and technology**

Children and adolescents were initially interested in the Mitii™ program as it was a novelty and tapped into their interest in technology. The therapy program delivery via a computer was a key factor that contributed to the ‘buy in’. An 11-year-old girl commented that, “I just loved how it was done on a computer… because I’m a technology person”. Caregivers commented that Mitii™ captured the interest of children more than previous therapy. “It appealed to him greatly because it was something that has his interest, he loves computer games and anything related to do that, so I would say that aspect of it is fantastic, especially trying to target children of his age… nothing else has ever had B’s interest like this before”

- K (Mother of 13-year-old boy)

**Motivation declines as novelty wears off**

Interest in participating in the program declined as novelty faded. Children commented that to try and sustain motivation over the 20 week period, they adopted personal strategies such as setting personal goals for Mitii™ modules (e.g. “making less crashes in the UFO game”), scheduling free play computer time after completing Mitii™ or negotiating slightly larger rewards on their Mitii™ rewards chart. Caregivers generally reported providing more encouragement in the later weeks of the program to support children’s ongoing engagement.

“(Her motivation) did change over time… In the beginning it was like, “Oh I love this can I do it forever? I want to do it forever”… about three-quarters of the way in, it was like, “Oh do I have to do it?” So yeah, I did have to nag her to do it.”- H (Mother of a 13-year-old girl)

**Children require ‘finely tuned’ programs**

A caregiver of an 8-year-old boy (GMFCS II; MACS II) stated that the program was well targeted to her child’s needs and she could see the relevance of all the activities to target areas of difficulty. Conversely, another caregiver felt that Mitii™ was too broad as a therapy approach for her child who was impacted mildly by CP (GMFCS I; MACS I). Some caregivers reported that their children’s goals were focused on physical activity, and Mitii™ offered an opportunity to encourage them to work towards these goals in a motivating and relatively independent manner.

**Strong family support facilitates engagement**

In addition to the required physical and cognitive skills to complete the Mitii™ program, children also required strong family support. Children found it helpful to have an adult around to supervise who “knows what they’re doing a little bit” to solve technical issues.
Caregivers reported that younger children required assistance in the early stages of the program. For older children, the role of the adult was often just giving children the “push to go” and do the program. Some caregivers reflected that perhaps they could have been more involved in the program but weren’t sure about what would have been optimal. Conversely, lack of available family support was not conducive to sustained engagement in the program.

“It was always going to be a challenge with our family situation with a young baby and possibly slow internet speed… I guess I feel like it was a bit set up to fail.” - M (Mother of an 11-year-old boy)

**Children develop confidence and ownership**

Children reported that they generally felt confident in their ability “to do Mitii™” after their initial training with therapists. Children commented that while they had most and least favourite modules, the challenge of the modules was appropriate. Caregivers reported that children began to take ownership of Mitii™ over the course of the program. Older children were often able to independently problem solve if they encountered technical issues. The Mitii™ program also allowed children to accommodate it into their daily schedules.

**Intervention Characteristics**

This category includes themes relating to aspects of the Mitii™ program that affected engagement such therapy frequency, home-based setting, technological issues and targeted areas of difficulty.

**Increased therapy frequency with reduced caregiver involvement**

Caregivers and children viewed Mitii™ positively as an intervention approach. A number of caregivers expressed that they highly valued having access to a therapy program in their home environment as they typically received very limited therapy services given their geographical location. Caregivers commented that a benefit of the Mitii™ program was that it was regular and allowed greater frequency of therapy sessions than they had received in the past. Caregivers especially valued not having to take on the role of the therapist in a home program.

“Traditional services are here’s your therapy plan, off you go… you run it with your child, you’re in charge of it and it makes me the person who says you have to do this, and that’s a really hard job as a mum… I don’t want to always take on that role and constantly push, push, push with therapy and also, am I doing it right?... Whereas I find with Mitii™, I don’t have to be in charge of that, all I’ve got to say is, you’ve got to go and do it, but then I’m
Mitii™ ‘becomes therapy’ and competes with other interests

Children did not perceive Mitii™ as therapy initially but rather found the program to be a fun computer game or “a new toy”. Children commented that, “it was good but at the end it was a bit hard to keep going” and “at the start it was really cool and fun… but sometimes it got in the way of me doing other things”. (11-year-old boy) Caregivers expressed the view that the program began to feel like therapy for their child over the 20 week period. “He saw this as fun. He obviously on another level understood that it was part of therapy and it meant he didn’t have to do his normal physio stuff… that was in the beginning and of course, as we went on, not so much… It became therapy” - K (Mother of 13-year-old boy)

Convenience of Mitii™ within family routine

Caregivers appreciated the convenience of having a therapy program that was delivered in the home-environment as opposed to a clinical setting. The home-based nature of the program allowed caregivers to accommodate their own work duties and commitments of other family members. Some caregivers also commented that it was less stressful for their child than attending an appointment to see a therapist. “It was so much better to do something within the home environment… than having to go to an occupational therapy session once a week where I’d have to take my younger boy, get in the car, drive, park, go in, you know give him something to keep him busy while H was doing her thing… then spend the next few days trying to get her to do the exercise… so from a family perspective it fitted in really, really well.” - J (Mother of 11-year-old girl)

Lack of real-time feedback and technical issues

Caregivers reported that a drawback of Mitii™ being delivered remotely was the lack of real-time explanation and feedback. Caregivers acknowledged the potential room for error in the way children were doing the activities without having a therapist physically present. One child commented that they preferred getting the “real thing” with a therapist. Caregivers and children consistently reported technical issues with Mitii™ that interrupted the smooth running of the program, which sometimes caused frustration for the children. While children and caregivers found the instructional videos before each module useful, they had difficulty with the videos loading smoothly and requested more detail. “He needed some level of supervision or a check in with the professionals regularly to keep him doing the things the correct way” - G (Father to an 11-year-old boy)

Guidance by therapists is essential
Caregivers acknowledged that having programs guided by therapists was essential to target the modules at the appropriate level and to focus on specific areas of difficulty. Caregivers commented that the availability of virtual therapists to adjust parameters of modules quickly when required was very beneficial. Support from the virtual therapists was also essential to assist with any technical problems that arose throughout the program. “Having the activities guided would be essential because otherwise it would get too bland or not be focused on what she needs to develop.” - H (Mother of a 13-year-old girl)

Service Provider Characteristics

The third category relates to the service provider’s overall expertise and skills (e.g. providing input and advice), approach to practice (e.g. family-friendly approach) and strategies employed to encourage engagement.

Initial and ongoing therapist input

Caregivers appreciated having the program details explained at the outset so they knew what to expect and how to seek advice from the therapists when required. Children commented that the training they had completed with the therapists before commencing the Mitii™ program gave them the necessary skills to complete the program in their home environment. Caregivers valued the expertise of the virtual therapists to target the activities appropriately and provide incremental challenge in the program for children. The various communication methods employed by therapists, (e.g. email, telephone and Skype) were appreciated by caregivers as they felt that someone was always available to provide assistance.

Family-friendly therapy approach

The caregivers generally perceived Mitii™ to be a family-friendly therapy approach given it was home-based and could be incorporated flexibly around the family routine. While some children and caregivers did Mitii™ at a set time each day, others adjusted the time to accommodate their daily schedules. Caregivers particularly valued not having to travel to therapy as it reduced time demands for both themselves and their child. “On the weekend it was variable, so he had the choice of when he wanted to complete it but through the week it was a pretty set time just wherever it fitted in with our schedule at home” - K (Mother of 13-year-old boy)

Tailored strategies to facilitate engagement

Strategies that were effective to facilitate engagement in the program varied for each family. Younger children commented that the Mitii™ rewards chart was a useful strategy and they were motivated to do Mitii™ straight after school to get a star on the chart. An older participant commented that the best part of Mitii™ was getting benefits out of the
program, rather than receiving extrinsic rewards. Some caregivers expressed that they needed to increase the rewards (which were set individually by families) throughout the program to maintain their child’s motivation in the program. Caregivers reported that the strategies that virtual therapists put in place to assist with technical issues, such as providing equipment and technical support were beneficial. One mother commented that a program such as Mitii™ needed a high level of support from therapists as it was tailored to each child depending on the child’s level of understanding, skills, motivation and support in the home environment.

**Clinical implementation suggestions**

The majority of caregivers and children felt that a 20 minute daily program would have been easier to sustain than a 30 minute program, which sometimes could take longer when complicated by technical delays. Some caregivers thought that three to five times per week would have been more manageable than aiming for six days each week. Caregivers’ suggestions included doing Mitii™ only on weekdays, having a break half way through or capping the program at 15 instead of 20 weeks. Children suggested that having other siblings or friends involved the program may have increased their motivation. It was also suggested by participants that having competitions built into the program or a means to monitor and track progress (e.g. a ‘ladder’ showing their scores over time) may have enhanced their motivation.

**Discussion**

The challenge for caregivers and therapists delivering ICP interventions in the home environment is how to best support children’s engagement. Our findings align with previous research investigating engagement in therapy for children with CP, in that sustaining engagement is a balancing act between enhancers and barriers. (Gilmore et al., 2010) This study identified key themes and summarized factors that either enhanced or inhibited engagement in the Mitii™ program, which may be relevant to alternate home-based ICP interventions.

While the novelty of Mitii™ was a key factor in capturing children’s interest in the program, this wore off over time for many children. The feeling that Mitii™ “became therapy” may reflect the repetitive nature of the program. In Sandlund et al’s study investigating parent perceptions of the Eye Toy®, children’s motivation was reported to decline over a four week period. (Sandlund, Dock, et al., 2011) Our findings revealed that, similarly to the pilot Mitii™ study, (Bilde et al., 2011) sustaining engagement over a longer period was challenging.
Many children were initially motivated by Mitii™ as it was a new technology. In a recent systematic review of motivating interventions for children with CP, eight of nine interventions involved a virtual reality component. (Tatla et al., 2014) While evidence of the effect of these interventions was inconclusive, this review identified the need for a valid and reliable measure of motivation. (Tatla et al., 2014) The inclusion of motivation measures in future ICP studies may help us to understand key issues relating to engagement.

A notable difference between engineer built and commercial systems is the ability to tailor the activities. Caregivers involved in the Eye Toy® intervention reported that the activities were not targeted to their child’s individual needs. (Sandlund, Dock, et al., 2011) In the present study, caregivers valued that Mitii™ was targeted to their child’s specific therapy needs, however some still felt it was ‘too broad’. A design and evaluation study of ICP games for children with CP found that the ability to adjust difficulty settings and target games to focus on specific goals was highly valued by therapists. (Lian Ting et al., 2014) The accessibility and frequency of therapy that was possible with Mitii™ was most valued by families who resided in regional areas and had limited access to therapy. While ICP does not negate the need of task-specific and goal-directed face-to-face therapy, these systems offers an accessible means of therapy for these families. Furthermore, caregivers valued not having to take on the “therapist role” which allowed children to take ownership of their Mitii™ program. Adolescents are required to take on increasing responsibility for their own therapy as they mature and programs such as Mitii™ may support this transition. Although Mitii™ requires less caregiver involvement than task-specific home programs, the need for strong family support was evident. The level of available family support must be considered by therapists when implementing a home-based ICP intervention such as Mitii™, particularly for younger children. Consistent and positive parenting styles have been associated with higher motivation in children with cerebral palsy. (Miller et al., 2014) Caregivers should be supported to engage in such parenting styles by therapists to facilitate engagement in home-based programs.

A disadvantage of Mitii™ is the lack of real-time feedback. In the current program, children receive a generated comment pre-written by the therapists after each activity, but do not receive specific feedback on their performance. Future developments of Mitii™ and other ICP systems may allow feedback on performance if therapists were able to view children in home via a webcam. Additional built-in feedback into each activity to show progress over time or to allow competition between participants were suggested by children and are likely to positively impact on motivation.
A challenge with programs that rely on technology, and in particular on the internet, is the coinciding technical issues. In the RCT of Mitii™ conducted in Australia, a number of families experienced difficulties with the smooth running of the program, largely due to internet connectivity issues given the distance from the server in Denmark. Ongoing updates by the program developers are addressing technical concerns that were encountered during the study.

Mitii™ was regarded by caregivers as a family-friendly therapy approach that could be completed at any time of the day and accommodated within family routines. In comparison to typical therapy services that often require considerable planning around family routines, Mitii™ allowed flexibility and eliminated the need to travel. The flexibility of Mitii™ may be of particular benefit to students in secondary school, who often are involved in extra-curricular activities in addition to their schooling commitments.

Finally, it was apparent that there was not one ideal strategy to support participants’ engagement in the Mitii™ program. Therapists need to be cognisant of the child’s individual needs and preferences when establishing strategies at the outset of the program. Younger children were often motivated by extrinsic rewards, while some older children were motivated intrinsically which may reflect their greater insight into the therapy rationale. Effective communication is important to engage families, and therapist strategies such as understanding the family situation, building a collaborative relationship and ensuring the caregiver’s understanding may facilitate engagement. (King, Desmarais, et al., 2014)

A strength of this study is that the perspectives of both children and caregivers were captured through the interviews. The interviewer was unknown to participants which fostered frank discussion. This study is limited to perspectives from participants and caregivers on the Mitii™ program and results do not reflect all ICP programs. Findings however may be relevant to similar home-based ICP programs.

**Conclusion**

This study identified various child, intervention and service provider characteristics that influenced children’s engagement in Mitii™. Children’s interest was captured through the novelty of the program and the technology, but the novelty wore off over time. Caregivers valued that Mitii™ provided individualised programs, was flexible and allowed children to develop ownership of their therapy, but called for real-time feedback. Key take-home messages are that therapists need to consider the capacity of the family to take on an intensive home-based program and collaboratively devise strategies based on individual preferences to sustain engagement over the course of the program.
References


Table 1. Semi-structured interview schedule for children conducted by experienced occupational therapist

<table>
<thead>
<tr>
<th>Question</th>
<th>Prompts</th>
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<tr>
<td>Can you tell me about being involved in the Mitii™ program?</td>
<td>- Were there any particular games you liked best?</td>
</tr>
<tr>
<td></td>
<td>- Using the step block/foam?</td>
</tr>
<tr>
<td>What did you like best about the Mitii™ program?</td>
<td>- Any particular games you didn’t like?</td>
</tr>
<tr>
<td></td>
<td>- How often you had to do the program?</td>
</tr>
<tr>
<td></td>
<td>- Using the green bands?</td>
</tr>
<tr>
<td>What did you not enjoy about the Mitii™ program?</td>
<td>- IT issues e.g. webcam issues, interference with green bands, glitches in the Mitii program?</td>
</tr>
<tr>
<td></td>
<td>- Other commitments e.g. homework/extracurricular activities?</td>
</tr>
<tr>
<td>Can you tell me about anything that made it hard for you to do the Mitii™ program?</td>
<td>- Personal care tasks?</td>
</tr>
<tr>
<td></td>
<td>- School tasks?</td>
</tr>
<tr>
<td></td>
<td>- Leisure tasks?</td>
</tr>
<tr>
<td>Have you noticed any differences in the way you use your affected arm/leg in daily activities?</td>
<td>- Fitting in with life e.g. missing school days?</td>
</tr>
<tr>
<td></td>
<td>- Enjoyment e.g. more fun/more frustrating?</td>
</tr>
<tr>
<td>How did you find doing your therapy on a computer at home compared to going into the hospital for therapy?</td>
<td>- Length of each training (25-30 minutes)/entire program (20 weeks)?</td>
</tr>
<tr>
<td></td>
<td>- Number of times per week?</td>
</tr>
<tr>
<td></td>
<td>- Would you recommend this program to a friend?</td>
</tr>
<tr>
<td>If you could change some things about the Mitii™ program, what would you change?</td>
<td>- Personal care tasks?</td>
</tr>
<tr>
<td></td>
<td>- School tasks?</td>
</tr>
<tr>
<td></td>
<td>- Leisure tasks?</td>
</tr>
<tr>
<td></td>
<td>- Fitting in with life e.g. missing school days?</td>
</tr>
<tr>
<td></td>
<td>- Enjoyment e.g. more fun/more frustrating?</td>
</tr>
<tr>
<td></td>
<td>- Length of each training (25-30 minutes)/entire program (20 weeks)?</td>
</tr>
<tr>
<td></td>
<td>- Number of times per week?</td>
</tr>
<tr>
<td></td>
<td>- Would you recommend this program to a friend?</td>
</tr>
<tr>
<td>Is there anything else you would like to tell me?</td>
<td></td>
</tr>
</tbody>
</table>

Key: Mitii™, “Move it to improve it”
Table 2. Semi-structured interview schedule for caregivers conducted by experienced occupational therapist

<table>
<thead>
<tr>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you tell me about how you and your child experienced your participation in the Mitii™ program?</td>
<td></td>
</tr>
<tr>
<td>What were the best things about your involvement?</td>
<td>IT issues e.g. webcam issues, interference with green bands, glitches in the Mitii program?</td>
</tr>
<tr>
<td>What were the most difficult things about your involvement?</td>
<td>How did you manage these?</td>
</tr>
<tr>
<td></td>
<td>- Willingness of child to engage?</td>
</tr>
<tr>
<td></td>
<td>- How did you manage this?</td>
</tr>
<tr>
<td></td>
<td>- How did your child react to being involved in Mitii™?</td>
</tr>
<tr>
<td>What were your expectations of being involved in the Mitii™ program?</td>
<td></td>
</tr>
<tr>
<td>How do you think Mitii™ impacted on your child’s ability to participate in their daily life tasks?</td>
<td>- Personal care tasks?</td>
</tr>
<tr>
<td>How do you think Mitii™ impacted on your child’s ability to achieve the goals that you/your child set at the beginning of the program?</td>
<td>- School tasks?</td>
</tr>
<tr>
<td>How did you find this mode of therapy (home based, online) compared to previous types of therapy your child may have received?</td>
<td>- Leisure tasks?</td>
</tr>
<tr>
<td></td>
<td>- Effort required?</td>
</tr>
<tr>
<td></td>
<td>- Child's enjoyment level?</td>
</tr>
<tr>
<td></td>
<td>- Fitting with daily routine e.g. managing other children/time off school?</td>
</tr>
<tr>
<td></td>
<td>- Role of the therapist?</td>
</tr>
<tr>
<td>What things would you change about the Mitii™ intervention?</td>
<td>Length of each training (25-30 minutes)/ entire program (20 weeks)?</td>
</tr>
<tr>
<td></td>
<td>- Number of times per week?</td>
</tr>
<tr>
<td></td>
<td>- Therapist interaction?</td>
</tr>
<tr>
<td></td>
<td>- Do you have any other feedback?</td>
</tr>
</tbody>
</table>

Key: Mitii™, “Move it to improve it”
Table 3. Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sample (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>11y 4m (2y 6m)</td>
</tr>
<tr>
<td>Gender, male n</td>
<td>5</td>
</tr>
<tr>
<td>Side of hemiplegia, left n</td>
<td>7</td>
</tr>
<tr>
<td>MACS, n</td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>3</td>
</tr>
<tr>
<td>Level II</td>
<td>7</td>
</tr>
<tr>
<td>Diagnoses, n</td>
<td></td>
</tr>
<tr>
<td>Learning difficulties</td>
<td>1</td>
</tr>
<tr>
<td>Autism</td>
<td>1</td>
</tr>
<tr>
<td>Attention deficit/hyperactivity disorder</td>
<td>2</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>1</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>Dose of Mitii™, mean hours (range)</td>
<td>32.1 (8.9-74.7)</td>
</tr>
<tr>
<td>Family Household, n</td>
<td></td>
</tr>
<tr>
<td>Original</td>
<td>6</td>
</tr>
<tr>
<td>Step-family</td>
<td>2</td>
</tr>
<tr>
<td>Single-parent</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Parental Employment, n</td>
<td></td>
</tr>
<tr>
<td>Full-time employment</td>
<td>2</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>4</td>
</tr>
<tr>
<td>Full-time parent/home duties</td>
<td>3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1</td>
</tr>
<tr>
<td>Annual Income, n</td>
<td></td>
</tr>
<tr>
<td>&lt;25,000</td>
<td>1</td>
</tr>
<tr>
<td>25,000-50,000</td>
<td>1</td>
</tr>
<tr>
<td>50,000-75,000</td>
<td>1</td>
</tr>
<tr>
<td>&gt;75,000</td>
<td>7</td>
</tr>
<tr>
<td>School, n</td>
<td></td>
</tr>
<tr>
<td>Public Primary School</td>
<td>4</td>
</tr>
<tr>
<td>Public High School</td>
<td>2</td>
</tr>
<tr>
<td>Private Primary</td>
<td>1</td>
</tr>
<tr>
<td>Private Secondary</td>
<td>2</td>
</tr>
<tr>
<td>Home Schooled</td>
<td>1</td>
</tr>
</tbody>
</table>

Key: SD, standard deviation; MACS, Manual Ability Classification System, Mitii™, “Move it to improve it”
Table 4. Factors considered by children and caregivers to enhance or inhibit engagement in the Mitii™ program

<table>
<thead>
<tr>
<th></th>
<th>Enhancers</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child/Family Characteristics</strong></td>
<td>Initial novelty of Mitii™&lt;sup&gt;TM&lt;/sup&gt;</td>
<td>Novelty wears off</td>
</tr>
<tr>
<td></td>
<td>Technology based</td>
<td>Too broad for some children</td>
</tr>
<tr>
<td></td>
<td>Individual needs can be targeted</td>
<td>Lack of family support</td>
</tr>
<tr>
<td></td>
<td>Strong family support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Children’s increasing confidence</td>
<td></td>
</tr>
<tr>
<td><strong>Intervention Characteristics</strong></td>
<td>Alternate to no or limited therapy</td>
<td>Repetitive and it “becomes therapy”</td>
</tr>
<tr>
<td></td>
<td>Increased therapy frequency</td>
<td>Competing interests at home</td>
</tr>
<tr>
<td></td>
<td>Home-based</td>
<td>Lack of real-time feedback</td>
</tr>
<tr>
<td></td>
<td>Flexibility within family routines</td>
<td>No “hands on” therapy</td>
</tr>
<tr>
<td></td>
<td>Therapist guidance</td>
<td>Technical issues</td>
</tr>
<tr>
<td></td>
<td>Tailored to individuals</td>
<td>Duration of program</td>
</tr>
<tr>
<td><strong>Service Provider Characteristics</strong></td>
<td>Therapist support</td>
<td>Lack of other social support</td>
</tr>
<tr>
<td></td>
<td>Family-friendly therapy approach</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tailored strategies</td>
<td></td>
</tr>
</tbody>
</table>

Key: Mitii™, “Move it to improve it”
**Figure 1.** Mitii™ rewards chart provided to participants to track progress (youth version)
7.2.1 Duration of Mitii™: Additional feedback from participants and health professionals

Evidence from neurophysiological models of rehabilitation suggests that a high dose of specific practice is required to induce neuroplasticity and achieve changes in function.\(^{(44)}\) Intervention studies from children with UCP suggest that up to 60 hours of therapy may be required to achieve changes in function,\(^{(31)}\) however other studies have reported clinically meaningful changes with significantly fewer hours of goal-directed therapy. Studies investigating therapy dose in children with CP are limited and there is no definitive optimal level of therapy.

In terms of the Mitii™ program, the overall consensus from participants in the RCT and health care professionals was that the overall duration of the program (20 weeks) was too long for many children to maintain interest in an intensive and repetitive therapy program. Families and health professionals have proposed a number of alternatives to a continuous 20 week program, specifically:

- Reduce the length of the overall Mitii™ program to 15 weeks to help to sustain motivation over a more manageable time period.
  - *Father of 12 year old male*

- Complete Mitii™ only on weekdays to keep weekends as ‘their time’. This may mean that Mitii™ fits within the daily routine around homework during the week but does not become a ‘chore’ on weekends and compete with other interests.
  - *Mother of 15 year old male*

- Include breaks within the 20 week program e.g. completing Mitii™ for three weeks followed by one week break. This structure may help to maintain motivation in the program as children might look forward to participating in the program again after a short break.
  - *Biomedical engineer and interactive computer play game designer*

- Complete Mitii™ to coincide with the school terms and having a break over the school holiday periods, ideally for two school terms to achieve a high therapy dose.
  - *Neuropsychologist involved with delivering Mitii™*
7.3 Summary and Conclusions

This qualitative study identified key factors that impacted on children’s level of engagement in the Mitii™ program. The factors formed themes that were mapped according to an engagement framework and considered as child, intervention or service provider characteristics. Findings from this study may assist therapists when implementing programs such as Mitii™ in a clinical setting. The key findings from this study are as follows:

- The novelty of the Mitii™ program captured interest and contributed to the initial ‘buy in’ to the therapy, however motivation typically declined as the novelty wore off.
- Caregivers desired programs to be ‘finely tuned’ to address individual needs and therapist guidance was considered essential to ensure programs were targeted at an appropriate level of difficulty.
- Mitii™ required less intensive caregiver involvement than alternate home-based therapy programs, however strong family support was required to facilitate engagement.
- Many children developed ownership with a program such as Mitii™, which may support adolescents in their transition period to adulthood as they begin to take increasing control over their own therapy.
- Technical issues caused frustrations for some families and ongoing updates of the Mitii™ program are addressing these issues.
- Mitii™ was generally considered to be a family-friendly therapy approach as it did not require travel and could be fitted in flexibly around family routines.
- Engagement may be enhanced in future programs with the inclusion of social interaction through multi-player settings, a ‘ladder’ to track progress within programs and real-time feedback.
Chapter 8: Discussion

The final chapter of this thesis discusses the major findings from the RCT of Mitii™ and related studies within this doctoral program. Findings will be positioned within published literature on interactive computer play interventions and alternate therapeutic approaches for enhancing occupational performance in children and adolescents with UCP. Study limitations will be discussed and the clinical feasibility of the Mitii™ program will be explored including implementation suggestions. Finally, future research recommendations to further pursue this body of research for children and adolescents with UCP will be outlined.

8.1 Overview of findings

Interactive computer play is a relatively novel therapeutic modality and evidence to date of its efficacy in children with UCP has been limited to pilot studies. Researchers advocate the need for large, rigorous studies to strengthen the evidence base. This doctoral program provides the first evidence of an interactive computer play intervention for children with UCP from an adequately powered RCT. The matched-pairs design of this RCT is considered a methodological gold-standard as it minimises baseline differences between groups. Comprehensive evaluation across ICF domains was completed to capture the effect of the intervention on various aspects of activity and participation. A variety of outcome measures have been used in paediatric clinical trials to measure ADL, yet a detailed comparison of these measures had not yet been carried out for children with CP. A systematic review was therefore initially performed to identify which measure/s had the strongest validity, reliability and clinical utility in this population (Chapter 2). As a result of the systematic review, the AMPS was identified as a suitable measure of ADL performance or capacity, however the reproducibility of the measure had not been investigated in children with UCP. A reproducibility study was therefore carried out with a sample of 30 children from the overall RCT to investigate reliability and agreement parameters of the AMPS, which found excellent test-retest reliability (ADL motor scale ICC=0.93; ADL process scale ICC=0.86) (Chapter 4). A cross-sectional study of baseline measures from the RCT (n=101) explored the relationship between the ADL motor and processing skills, upper limb function and visual perception (Chapter 5). Bimanual performance and unimanual capacity of the dominant upper limb were found to significantly contribute to ADL motor skills, while two visual perception domains (spatial...
relations and visual closure) and unimanual capacity of the dominant upper limb significantly contributed to ADL processing skills.

The RCT investigating the efficacy of Mitii™ identified a statistically significant improvement in ADL motor and processing skills, unimanual speed and dexterity of the unimpaired upper limb, occupational performance and visual perception in the intervention group compared to the control group (standard care) (Chapter 6). The differences between groups did not exceed levels of clinical significance. The average overall therapy dose was 32.4 hours, which was lower than the maximum potential dose (60 hours) and there was significant variation among participants. Issues surrounding engagement were explored through child-caregiver interviews (Chapter 7). This qualitative study provided valuable insight into child, intervention and service provider characteristics that influenced engagement in Mitii™, which may assist in the future clinical implementation of Mitii™ or similar programs in the future.

8.1.1. Hypothesis 1. Evidence of the validity, reliability and clinical utility of existing ADL measures will not be specific to children and adolescents with UCP and will vary in methodological quality.

A systematic review was performed (Chapter 2) to identify available measures of ADL for school-aged children and adolescents with CP, to inform the selection of a measure to capture ADL in the RCT. Eight measures were identified that had been used in this population and had evidence of validity and reliability. These measures were classified as measures of capability, capacity or performance. Performance measures are considered ideal for measuring ADL as they capture what an individual ‘does do’ in their natural environment, as opposed to what they ‘can do’ in their natural environment (capability) or what they do in a controlled environment (capacity). The AMPS was identified as the best available measure of ADL performance or capacity across all age ranges. The AMPS has been validated on large sample and has shown adequate goodness-of-fit in typically developing children. The alternate ADL performance measure that was identified, the Klein-Bell Scale has limited psychometric properties and poor clinical utility with an extensive administration time. The PEDI was identified as the best measure of ADL capability, however its clinical utility was found to be limited by the upper age limit. It is noted that subsequent to the systematic review undertaken in this doctoral program, the PEDI-Computer Adapted Test (PEDI-CAT) became available with an extended age limit, which will expand its use across adolescents and young adults.
Administration of the AMPS in a clinical setting is considered a measure of ADL capacity, whereas administration in the home environment is considered ADL performance. The AMPS has been used previously in an RCT of intramuscular upper limb BoNT-A injections combined with upper limb therapy and has shown responsiveness in children with UCP. It has not been widely used as an outcome measure however and the test-retest reliability had not been established in children and adolescents with UCP.

8.1.2 Hypothesis 2. *The AMPS will demonstrate moderate-excellent test-retest reliability for both the motor and process scales when administered in a clinical setting.*

While the AMPS has previously demonstrated excellent test-retest reliability in adult populations, there was no evidence of test-retest reliability in children and adolescents with UCP. It was important for the test-retest reliability to be examined to determine if the AMPS could provide a stable outcome measure to use with children with UCP and attribute changes in score to real changes in performance or capacity. To investigate the reproducibility of the AMPS, 30 participants from the RCT who attended assessments over a two day period were invited to participate in this study. Children carried out two AMPS tasks on consecutive days following standardised AMPS administration procedures and completing the same two tasks each day. Results found excellent test-retest reliability for both the AMPS motor scale (ICC=0.93) and the AMPS process scale (ICC=0.86). The minimal clinically important difference was 0.23 logits on the AMPS motor scale and 0.30 logits on the AMPS process scale. The reported magnitude of clinically significant change on the AMPS of greater than 0.30 logits is relevant for children and adolescents with UCP.

8.1.3 Hypothesis 3: *There will be moderate-strong relationships between ADL motor skills and upper limb capacity measures and a moderate relationship between the ADL processing scores and visual perception.*

One hundred and one children who attended baseline assessments in the RCT were included in a cross-sectional study to examine the relationships between the ADL motor and processing skills, upper limb function and visual perception. The multivariable model for the AMPS motor scale explained 57% of variance in scores and included bimanual performance and unimanual speed and dexterity of the dominant upper limb. The AMPS process scale multivariable model explained 35% of variance in scores and included two TVPS domains, visual sequential memory and visual closure, and unimanual speed and
dexterity of the dominant upper limb. The relationship between unimanual capacity of the dominant upper limb and ADL processing skills may reflect underlying motor planning abilities, such as planning, sequencing and feedback of movements. The modelling used in this study demonstrates associations, but could not inform the directionality of the relationship. These findings are of interest to the RCT as the program does not include specific ADL task practice, but rather aims to improve underlying skills required for successful ADL task performance. Given the identified relationships, it was of interest to determine if any improvements observed in upper limb speed and dexterity or bimanual performance coincided with improvements in ADL motor skills; or similarly if improvements in unimanual speed and dexterity of the dominant upper limb and visual perception corresponded with improvements in ADL processing skills.

8.1.4 Hypothesis 4: The primary hypothesis is that Mitii™ will improve ADL motor and processing skills and upper limb function to a greater extent than standard care. The secondary hypothesis is that Mitii™ will enhance perceived occupational performance and visual perception.

A matched-pairs RCT was conducted to investigate the effectiveness of Mitii™ compared to standard care for children and adolescents aged 8-16 years with mild to moderate UCP. Participants in the Mitii™ intervention group completed an average 32.4 hours of Mitii™ (range=3.7-74.7 hours) over the 20 week period. Children and adolescents in the intervention group demonstrated significantly greater improvements in ADL motor and processing skills, speed and dexterity of the dominant upper limb, visual perception and perceived occupational performance compared to the control group who were assigned standard care. There was no difference between groups in bimanual performance or unimanual capacity as measured by the MUUL, but there was a trend towards an improvement in the speed and dexterity of the impaired upper limb.

8.1.5 Hypothesis 5. Key factors influencing the experiences of children in the Mitii™ program will be the length of the program, competing interests and technical issues. Caregivers will value the convenience of a home-based intervention however may observe their child’s motivation to engage in Mitii™ to decrease over the 20 week period.

There has been a focus on therapy dose in recent literature for children with UCP to determine the amount of therapy that will drive neuroplasticity and lead to changes in function, with research suggesting that up to 60 hours of therapy is optimal.\(^{31}\) Attaining a
high therapy dose however requires children or adolescents to be engaged in the therapy process. This study involved 10 child-caregiver dyads and aimed to understand engagement in the Mitii™ program from the perspectives of children and their caregivers. Findings revealed a number of key themes relating to child characteristics, intervention characteristics and service provider characteristics influenced engagement in Mitii™. The novelty of the program initially captured children’s interest, however motivation this was reported to decline as the novelty wore off over the 20 week period. Caregivers valued that Mitii™ programs were individualised, was convenient within the family routine and allowed children to take ownership of their own therapy, however they called for real-time feedback. Strong family support was required to facilitate engagement and individual strategies were utilised to sustain motivation.

8.2 Contextualising findings

Results from the RCT provided new evidence for interactive computer play as a therapeutic modality for individuals with UCP. These findings are discussed below in the context of previous studies of interactive computer play and also with alternate therapy approaches for enhancing occupational performance in this population.

8.2.1 Enhancing occupational performance, upper limb function and visual perception through interactive computer play

Prior to the RCT described within this doctoral program, studies investigating interactive computer play for children and adolescents with UCP were limited to feasibility or pilot studies with small sample sizes. A systematic review of interactive computer play studies had reported a moderate level of evidence for gross motor outcomes yet inconclusive evidence for upper limb motor outcomes.(33) While motor capacity outcomes, aimed at the activity level of the ICF, have been frequently investigated in pilot studies of interactive computer play, relatively little research has focused on occupational performance at the activity and participation level of the ICF. Evidence regarding the effect of interactive computer play on visual perception in this population is also limited.

The only study to date that has investigated the effects of interactive computer play on ADL motor and processing skills using the AMPS is the pilot study of Mitii™.(36) The AMPS is a useful measure as it captures both the motor and processing components involved in carrying out daily living tasks. This is in contrast with the majority of measures identified in the systematic review of ADL measures (Chapter 2) that evaluate capability in
specific ADL tasks. The AMPS was identified as the best available measure of performance or capacity in the systematic review, and initial responsiveness to change was reported following the Mitii™ intervention in the pilot study.\(^{(36)}\)

Bilde and colleagues reported an increase in both the AMPS motor and processing skill abilities post-intervention (ADL motor scale: pre=1.49±0.37, post=1.84±0.37, p<0.001; ADL process scale: pre=0.87±0.40, post=1.29±0.38, p < 0.05). Results from this RCT provide further evidence relating to the ADL motor and processing skills following Mitii™ using a more rigorous study design and a significantly larger sample size. Participants in the intervention group achieved statistically significantly greater improvements on both the ADL motor and process scales compared to the control group post-intervention. The aim of the Mitii™ program is to enhance underlying skill components as a basis for specific task practice. Results from the AMPS reflect there was a degree of improvement in underlying motor and processing skill components, with slightly greater improvements found in ADL processing skills.

Two previous studies have evaluated perceived occupational performance following interactive computer play intervention utilising the COPM. In a pilot RCT by Reid and Campbell that investigated the Gesture Xtreme IREX system (8 weekly sessions of approximately 1.5 hours) compared to standard care in children with CP (8-10 years, GMFCS levels I-V), no difference was found between the intervention group (n=19) and control group (n=12) on the COPM.\(^{(46)}\) Both groups showed increased scores on the COPM performance scale and satisfaction scale post-intervention. This differs to results from the Mitii™ RCT, with statistically significant differences found between groups post-intervention on both COPM scales. There are notable differences between Reid and Campbell’s study and the Mitii™ RCT, specifically in terms of the age and GMFCS levels of the samples, delivery environment (laboratory compared to home-based) and the intervention content (random games selected rather than an individualised program).

A similarity between the studies is how the COPM was framed by therapists during the administration to families. In Reid and Campbell’s study, the COPM interview was framed in terms of difficulties in functional activities involving the upper limb to maintain relevance of goals to the predominantly upper limb based intervention. In the current study, the COPM interview was framed in terms of identifying goals that may be achieved with Mitii™, e.g. improving balance when kicking a ball, increasing spontaneous use of the impaired upper limb in ADL or improving attention span when completing homework. It is noted however, that if children and/or parents could only identify goals that were not
directly relevant to the Mitii™ program (e.g. fine motor skill goals), these were still recorded and included in statistical analysis.

This framing of the COPM differs somewhat from how this measure would typically be administered in goal-directed therapy approaches, where children and families identify goals and therapists collaboratively select therapy approaches to work towards the goals. A potential limitation of Mitii™ is that while the programs are individualised to each child, it is not a goal-directed program. In a clinical setting however, when therapists are identifying individual goals with children and adolescents with UCP, they could ascertain which goals could be worked towards using Mitii™ and choose to implement the program when there was a good fit between the child’s goals and Mitii™.

Establishing the relevance of Mitii™ to specific goals requires therapists to break down task components. An example from the current study was a 16-year-old male who identified an important goal of improving his panel beating skills to allow him to successfully complete his school-based apprenticeship. Task analysis of panel beating identified a number of task components including, but not limited to: motor skills (e.g. physical endurance, gross upper limb movements at the shoulder, elbow and wrist, grasp of tools), positioning (e.g. both bimanual and unimanual components, standing and/or crouching positions), perceptual factors (e.g. visual discrimination, figure ground discrimination, spatial relations, hand-eye coordination) and cognitive factors (e.g. memory of steps, problem solving and concentration). It was identified that a number of these task components, such as physical endurance, gross upper limb movements, visual perception and task concentration, could be worked towards with the Mitii™ program. It is recommended that therapists implementing the Mitii™ program ensure that participants have identified relevant goals and it may be helpful to explain the links between task components and activities within Mitii™.

The COPM has also been utilised in a prospective case series study by Weightman et al (n=18; CP; 5-16 years) that investigated the feasibility of delivering a home-based rehabilitation exercise system linked to a computer game.(34) An increase in a median of an overall parent-reported COPM score for competency (pre=4.2, post=6.0) was reported, rather than the standardised reporting of mean scores for both COPM performance and satisfaction scales.(34) Individual variation in the difference between pre-post COPM scores was reported by Weightman et al, as was similarly found in the Mitii™ RCT. Individual variation is inherent within overall group results, and therapists need to be mindful of this when interpreting overall group findings.
A number of pilot studies have investigated the effect of various interactive computer play systems on upper limb function and the evidence remains inconclusive. A direct comparison of upper limb results from interactive computer play is difficult due to the various interventions and outcomes measures that have been utilised. Unimanual capacity has been more frequently investigated to date than bimanual performance. No change in MUUL scores was reported by Jannink et al following a six-week intervention using the Sony PlayStation in conjunction with regular physiotherapy (n=10)\(^{(47)}\) while a statistical significant improvement in the MUUL following an upper limb robotic intervention combined with interactive computer play was identified by Fluet et al (n=9)\(^{(35)}\). These differing results may reflect the more complex upper limb rehabilitation system in Fluet’s study (New Jersey Institute of Technology-Robot Assisted Virtual Rehabilitation) in comparison to the Sony PlayStation\(^{®}\). Improvements in body structure and function measures including reaching kinematics and upper limb range of motion were also reported in Fluet’s study\(^{(35)}\).

Following a four-week Sony PlayStation\(^{®}\) intervention completed daily for 20 minutes (n=14) conducted by Sandlund et al, children demonstrated a statistically significant increase in Movement-ABC 2 total scores, yet no change in the Bruininks-Oseretky Test of Motor Proficiency\(^{(48)}\). No effect on upper limb function as measured by the Quality of Upper Extremity Skills Test (QUEST) was identified by Reid and Campbell following the eight-week Gesture Xtreme IREX intervention\(^{(46)}\). It is interesting that despite no change in the QUEST scores, significant results were found on the COPM which was focused on upper limb goals\(^{(46)}\). The study was powered to detect change on the COPM, so it may be that the study sample was not large enough to detect change on the QUEST. Alternatively, improvement in functional upper limb activities may occur without significant improvements on standardised tests.

The results of the current study found mixed results, with no difference between groups in unimanual capacity assessed with the MUUL and a trend towards an improvement observed in the intervention group in upper limb speed and dexterity on the JTTHF impaired upper limb. Unexpectedly, there was a statistically significant difference between groups on the JTTHF dominant upper limb. Dominant upper limb capacity has not been previously reported in pilot studies and these results suggest that other elements, such as motor planning, which may contribute to upper limb capacity, require consideration and should be investigated in future studies.

An earlier pilot study (n=9) investigated the effect of interactive computer play on bimanual performance found no improvement as measured by the AHA following 20 weeks of
Similarly, the current RCT found no effect of Mitii™ on bimanual performance. The principle that you ‘gain what you train’ appears consistent across studies investigating the effects of interactive computer play on upper limb function in children with UCP. For example, Fluet et al implemented a specific upper limb rehabilitation system and found changes in unimanual capacity and upper limb body structures and function. Results in the current study are reflective of the Mitii™ program, which involves gross upper limb movements and motor planning and limited bimanual activities (two out of fourteen activities).

Evidence suggesting changes in visual perception is limited not only for interactive computer play interventions for individuals with UCP, but more broadly across intervention studies to date in children with UCP. While improvements in visual perception are reported following interactive computer play interventions, evidence is limited to two small studies including a single case study and a pilot study of 9 participants. The quality of evidence for visual perception outcomes is strengthened with findings from the current RCT which had strong methodological rigour. Statistically significant improvements were found between groups post-intervention on the TVPS-3. Analysis by subtest revealed statistically significant improvements in three domains: visual discrimination, spatial relations and visual closure. This subtest analysis differs from Bilde and colleagues, who reported a statistically significant improvement in the figure ground discrimination subtest. Subtest results from the TVPS-3 however must be interpreted with caution, as the reliability of the subtests is variable.

The level of clinical significance has not been reported to date for the TVPS-3, however the smallest detectable change (SDC) has been calculated to be 8.15 points based on smallest error of measurement (SEM) of 2.94 and formula SDC=SEM x 1.96 x \( \sqrt{2} \). The mean difference between groups was close to this limit at 6.79 points. The smallest detectable change however does not necessarily equate to a clinically meaningful change. The way in which a clinically meaningful change in visual perception manifests in functional tasks is difficult to assess and is perhaps why it has not yet been discussed in these terms.

Examining relationships between visual perception and functional outcomes may provide useful information in terms of transfer between skill components and task performance. The cross sectional study in Chapter 4 found that visual perceptual components, most significantly visual sequential memory and visual closure, are associated with processing skills of ADL task performance. Interestingly, visual closure was a domain that improved significantly following Mitii™ and also emerged as significantly associated with ADL
processing skills. Given that children with UCP often have difficulty with visual perception\(^{(23)}\), and visual perception is associated with task performance, programs such as Mitii™ that can specifically target visual perception may be valuable in the therapy toolbox.

### 8.2.2 Engagement in interactive computer play: Child and caregivers’ perceptions

The substantial variation in the therapy dose achieved by participants in the randomised controlled trial reflected differing levels of engagement in the Mitii™ program. It was important to understand factors contributing to this variability to assist in the future clinical implementation of Mitii™ and similar programs. There is paucity in the evidence of qualitative reports of interactive computer play for children and adolescents with UCP. One qualitative study by Sandlund et al investigated parents’ perceptions of using a commercial system, the EyeToy® Play3 for PlayStation2®, in the home environment with their children who had mild-moderate CP.\(^{(50)}\)

In comparison to the Mitii™ intervention in the current RCT, the EyeToy® intervention in Sandlund et al’s study was considerably shorter (20 minutes daily over a four-week period) and differed in that the intervention was a commercially available system.\(^{(50)}\) A potential limitation of Sandlund et al’s study is that children’s perceptions were not captured. The qualitative study conducted within this doctoral program captured the views of both children and their caregivers to gain a broad perspective of involvement in the program. Consideration of our findings in context with results from Sandlund et al’s study provides insight into the experiences of using an individually tailored web-based therapy program in comparison to a commercial system. The themes emerging from Sandlund et al’s study were: (i) facilitate a positive experience of physical activity training; (ii) promote independent physical training; and (iii) call for refinements.\(^{(50)}\) A number of consistent factors emerged that impact engagement, providing important insight for clinicians implementing both engineer-built and commercial interactive computer play interventions. In the current qualitative study, themes relating to child/family characteristics were: (i) children’s interest captured through technology and novelty; (ii) motivation declines as novelty wears off; (iii) children require ‘finely tuned’ programs (iv) strong family support facilitates engagement; and (v) children develop confidence and ownership. These themes relate to the first theme in Sandlund et al’s study, which focused on a positive therapy experience and consisted of two sub-themes: (i) gaming practice promotes motivation; and (ii) physical training becomes a social activity.\(^{(50)}\)
A similarity between the studies is that the game-like design of the intervention being a key factor to promote initial ‘buy-in’ to the therapy program and to maintain motivation over the therapy period. Participants in the Mitii™ study expressed that the games were fun and it didn’t feel like therapy at the beginning of the program, which was likewise reported by caregivers in Sandlund et al’s study.(50) Families in both studies reported a fading interest in the games over time. The parents in Sandlund et al’s study reported that children began to lose interest in the game by the fourth and final week.(50) While some participants in the Mitii™ program lost motivation after a similar time period, other participants sustained motivation for approximately 15 weeks. This variation suggests the importance of taking an individual approach when facilitating engagement for children in interactive computer play interventions.

The social paradigm that emerged in the first theme of Sandlund et al’s study is of interest when comparing commercial games and Mitii™. There are no multi-player settings in the current version of Mitii™, while multi-player settings are typically a feature of commercial systems. Parents of children who were using the EyeToy® reported that parents were often involved in playing the games and also experienced the therapy as fun: “And when the parents play together with the child the parent has fun too. You do not experience it as training because you have done something together.” (50)

The second theme in Sandlund et al’s study, promoting independent training, also relates to child/family characteristics. Caregivers in both studies reported that they typically received very limited rehabilitation services, with families reporting that the majority of their appointments were consults rather than regular therapy services. In Sandlund et al’s study, caregivers reported that the majority of therapy they had received in the past was typically carried out at home with parental supervision.(50) Parents from both studies report that taking on the ‘therapist role’ in the home environment could be frustrating and lead to frequent nagging of their children and a bad conscience if the child was not completing the prescribed therapy.

An advantage of interactive computer play systems is the ability for children to take control and drive their own therapy. While parent support is often required initially to set up the program and to a varying degree throughout the program to assist with motivation or technical issues, interactive computer programs allow a much greater opportunity for autonomy than other home-based therapy programs that rely on parent involvement to structure activities. Parental effort and support may be further reduced in commercial systems that allow siblings or friends to be involved, compared to the Mitii™ program, which is completed independently. Inherent to the Mitii™ program however is guidance by
virtual therapists, who make adjustments to the program without caregivers being required to decide on appropriate activities or increments.

The second grouping of themes in the current qualitative study related to intervention characteristics and included: (i) increased therapy frequency with reduced caregiver involvement, (ii) Mitii™ ‘becomes therapy’ and competes with other interests; (iii) convenience within family routine, (iv) lack of real-time feedback and technical issues; and (v) therapist guidance is essential. These themes are linked closely to themes relating to service provider characteristics, including: (i) initial and ongoing therapist input; (ii) family-friendly therapy approach; and (iii) tailored strategies to sustain engagement.

The final theme in Sandlund et al.’s paper addressed the need for individualisation, which is related to all levels of engagement characteristics. Parents reported that the program may have been more beneficial if it had been tailored to the specific needs of each child (e.g. to use only their hemiplegic upper limb) and if the level of difficulty could be adjusted so that it wasn’t too easy or too difficult.\(^{(50)}\) The Mitii™ program allows individualisation with various modifiable parameters and a number of caregivers involved in the Mitii™ study commented that they felt the program was targeted well to their individual child’s needs. This is an advantage of Mitii™ in comparison to commercial systems, nevertheless one caregiver reported that Mitii™ was too broad as a therapy approach despite the individualised programs.

The comparison between commercial and specific rehabilitation systems, such as Mitii™, raises the discussion of participating in interactive computer play for enjoyment compared to engaging for therapeutic reasons. Given the dominance in the commercial market of large corporations such as Nintendo®, these popular gaming systems are commonly owned and played by children and adolescents for leisure. One avenue of therapist input is making such games accessible for children with UCP and other disabilities, while the focus of this research is on the alternate avenue of engaging children in specific rehabilitation systems for therapeutic value.

Interactive computer games that are designed for rehabilitation purposes by smaller organisations, such as Mitii™, may not be as appealing in terms of game design, selection and graphics to children who are accustomed to commercial systems. Given the relatively early stage of rehabilitation system design, future development of rehabilitation systems will no doubt evolve with more sophisticated graphics and game design. The intensity and repetitiveness that is characteristic to interactive computer play mean that these programs may still ‘become therapy’ over time. We have learned through our qualitative research
that interactive computer play is initially appealing given children's interest in technology, but it can be difficult for children to sustain engagement over time.

To enhance children's motivation in interactive computer play, methods that have been developed in the gaming community to entice participants to increase the number of hours spent on the device could be incorporated within future programs. For example, a limited number of modules could be released at the start of the program with further "teasers" for other games that are released only when a certain number of hours of interaction are completed. Such strategies may assist in sustaining motivation over the duration of the program by reducing the feelings of repetitiveness.

A key element when considering service provider characteristics is how therapists can facilitate engagement through communication. Effective communication is important to engage families in the therapeutic process, and therapist strategies such as understanding the family situation, building a collaborative relationship and ensuring the caregiver's understanding may assist in promoting engagement. The use of clear and concise communication is particularly important with interactive computer play interventions at the outset of the program, when therapists are explaining the therapy rationale and the expectations of the program.

A further consideration for therapists delivering a home-based intervention is the impact of parenting styles. Consistent and positive parenting styles have been associated with higher motivation in children with cerebral palsy. While it is typically out of the scope of occupational therapists to provide formal parenting interventions, it may be beneficial to inform caregivers of the influence of parenting styles on motivation. Alerting caregivers to the way they interact with children in the process of encouraging participation may increase their awareness of how they can foster task persistence.

A number of key messages that can be drawn from our qualitative findings. Firstly, therapists should communicate clearly with families and inform children and adolescents who are participating in Mitii™ at the outset of the program that it differs from commercial systems. Sustaining engagement can be challenging over time, so strategies should be put in place at the outset of the program to facilitate engagement, such as a rewards chart to monitor progress and provide extrinsic motivation. When identifying suitable children for Mitii™, therapists need to consider the child’s interests, goals and available family support.

8.2.3 Comparison of therapy approaches for improving occupational performance

Traditional neurodevelopmental therapy approaches to therapy delivery aimed to promote efficient and automatic movements during functional activities and prevent undesired
movement patterns. Evidence for neurodevelopmental therapy however is weak, and current research supports a number of contemporary motor learning based therapy approaches to improve self-care or motor activities for children with cerebral palsy.\(^{(26)}\) Interventions that are shown to be effective to improve self-care ability or motor activities at the activities and participation level of the ICF include bimanual training, CIMT, context-focused therapy, goal-directed training, occupational therapy following intramuscular BoNT-A upper limb injections and home programs (Figure 1-3).\(^{(26)}\)

Interactive computer play is currently considered a promising child-active intervention for children with UCP to improve self-care and motor activities, with less extensive evidence to date in comparison to current best practice interventions (Figure 1-4).\(^{(26)}\) The theoretical underpinning of interactive computer play, and specifically Mitii™ differs considerably from motor-learning therapy approaches. Mitii™ is based on the principles of neuroplasticity and aims to enhance underlying skills required for daily tasks through part practice, in comparison to motor learning where learning involves specific task practice to stimulate changes in the interconnections in the sensory and motor systems. The emphasis in interactive computer play is on enhancing individual skill components and translating these skills into tasks carried out in natural environment. In contrast, the emphasis in contemporary motor learning approaches is on the interaction between the person, the environment and the task for successful occupational performance.

A significant body of research supports the use of the CO-OP approach to achieve goals relating to ADL and leisure activities in children with motor-based difficulties, predominantly children with developmental coordination disorder.\(^{(29)}\) The CO-OP approach facilitates guided discovery and development of cognitive strategies to promote skill acquisition, generalization and transfer. While the CO-OP approach differs from interactive computer play in that it is a cognitively oriented method of supporting goal-directed activity, the principles of generalisation and transfer may help to understand the mechanisms underlying the small improvements found in ADL motor and processing skills and in perceived occupational performance following the Mitii™ intervention.

The Mitii™ program is multimodal and was designed to replicate the combination of the simultaneous physical and cognitive skills that are required for daily task performance. Repetitive practice of physical skill training combined with cognitive, visual perception and problem solving challenge forms a basis to learn skills to transfer to specific tasks. Results of the RCT suggest that children may have shown some transfer of skills learned from Mitii™ into daily tasks. It is possible that the improvements may have been greater if task-
specific practice had been incorporated in addition to the Mitii™ program, given the strength of the evidence that supports task-specific therapy approaches.\(^{26}\) The outcome measures used in the majority of studies that have investigated the efficacy of motor learning based interventions have aimed at the activity level of the ICF with measures of upper limb function, including both unimanual capacity and bimanual performance. Fewer studies have utilised outcome measures aimed at the participation level or a combination of activity and participation ICF levels. Given that the ultimate goal of occupational therapy is to optimise function in meaningful occupations, measures that capture important areas of daily life function should be used. A number of rigorous RCTs investigating various motor learning approaches have incorporated measures of occupational performance, and the results can be considered in context with the results of the Mitii™ RCT.

The only RCT to date that has utilised the AMPS as an outcome measure in children with CP investigated the effect of intramuscular BoNT-A injections combined with four weekly one hour occupational therapy sessions compared to occupational therapy alone.\(^{45}\) This trial found that both groups made clinically significant improvements following the intervention in their motor and processing skill abilities, however there was no statistical differences between groups at 3 month or 6 month follow up.\(^{45}\) The occupational therapy intervention component in this study involved weight bearing, ball skills, fine motor and bilateral functional training for a total of approximately 3-4 hours.\(^{45}\) These results suggest that improvements in ADL motor and processing abilities can be achieved with a relatively low overall dose of therapy.

Studies investigating bimanual training and CIMT however suggest that 60 hours of therapy may be required to achieve changes in function.\(^{31}\) The reported dose of therapy in the majority of studies to date investigating intensive motor learning based approaches varies between 40 and 120 hours.\(^{31}\) The dose at even the lower end of this range is considerably higher than in the study by Russo et al and indeed higher than what is typically received by children with UCP.\(^{45, 53}\)

While direct comparisons between bimanual therapy and CIMT have shown minimal differences between approaches in terms of upper limb function,\(^{53}\) bimanual training is reported to lead to significantly greater improvement in individual goal attainment.\(^{54}\) These findings may be due to the increased time spent by the bimanual group practicing goals compared to the CIMT group in this study. These results reflect the principle, ‘you gain what you train’, with additional therapy targeting occupational performance goal training leading to enhanced performance and satisfaction with individual goals.
Occupational therapy home programs are shown to be effective in enhancing perceived occupational performance (55) and again the recommended therapy dose again differs to alternate motor learning approaches. An RCT investigating occupational therapy home programs (4 or 8 week duration) found significantly greater COPM Performance and Satisfaction scores compared to children who did not receive a home program. (55) The home programs included therapeutic activities focused on achieving individual goals, in comparison to the Mitii™ intervention that did not involve task-specific practice.

It is suggested that home programs should be prescribed for a minimal duration of 8 weeks, and should be clinically effective if implemented 17.5 times per month, for an average of 16.5 minutes per session (55). This equates to approximately 9.6 hours over an 8-week period, which is somewhat lower than that of participants in the Mitii™ intervention when compared over an equivalent 20 week time period (occupational therapy home programs=24 hours; Mitii™=32.4 hours). Improvements in COPM scores following the OT home program however reached clinical significance after 8 weeks, while the COPM improvements following Mitii™ were close to but did not reach clinical significance. This may reflect the goal-directed nature and environmental context of the occupational therapy home programs in comparison to Mitii™.

While there is significant variation in the therapy dose delivered in studies investigating motor learning approaches, a common feature of these approaches is that they are all 'hands on' approaches, requiring either direct therapist input or parent input in the case of occupational therapy home programs. Many families however have limited access to therapy services, with data from the current RCT showing that a small percentage had access to occupational therapy. While contemporary motor learning approaches are gold-standard for enhancing occupational performance, Mitii™ has the potential to lead to improvements in occupational performance in children with UCP and offers an alternate approach for families who have limited access to therapy services.

Selecting the most appropriate intervention for each child is an individualised process and there is no 'one size fits all' therapy approach to enhance occupational performance. Interventions must reflect each child’s strengths and interests to facilitate motivation and to sustain engagement in the therapy process. The Mitii™ program is likely to be a suitable intervention for children who have relevant goals, a keen interest in technology and a supportive family environment. Mitii™ is particularly suited to families who have limited or no access to therapy services and ideally would be implemented as a supplement to goal-directed task practice.
8.3 Study limitations and generalisability

A potential limitation of the systematic review of ADL measures for children with CP (Chapter 2) is the exclusion of articles not published in English and exclusion of measures with less than 60% of items relating to ADL. Self or parent rated individualised goal setting tools, such as the COPM or the Goal Attainment Scaling (GAS) were also excluded as they do not necessarily focus on ADL. These measures however can be used to identify and measure goals relating to ADL and they have been appraised in a previous systematic review focusing on participation outcomes.\(^{56}\)

The AMPS reproducibility study (Chapter 3) was carried out with children performing the same tasks on each day. The AMPS tasks chosen were somewhat challenging, yet familiar to each child. There however could have been a learning effect on the second day, with the children having the opportunity to reflect on their performance the previous day. Any such learning effect would be considered less of a threat when measuring ADL in comparison to tests of executive functioning for example, where children are required to strategize to solve tasks or remember sequences of numbers. The AMPS was carried out in a clinical setting as a measure of capacity due to pragmatic reasons. Ideally, the AMPS would have been conducted in the home environment as a measure of performance, however travelling for home visits was not feasible given that participants resided across both Queensland and New South Wales. While the clinical setting was set up to similarly to a home environment and the children were familiarised with the layout and use of all items, the setting nonetheless still differs from their typical home environment.

The RCT included children with mild to moderate spastic UCP, with sufficient cognition and cooperation to complete the Mitii™ program. The presence of intellectual impairment or learning disabilities did not preclude participation in the study, and rather it was caregiver discretion following detailed explanation of the study assessment and intervention requirements by study personnel. The presence of other disabilities such as Attention Deficit Hyperactivity Disorder also did not preclude participation, as has done in previous pilot studies.\(^{46}\) The sample was therefore deemed to be a more representative sample of children of children and adolescents with mild to moderate UCP than some previous studies. The inclusion of participants from Queensland, New South Wales and Victoria further supports the generalizability of our results to this population. Our findings however cannot be generalised to children with more severe UCP, those with other distributions of CP (e.g. diplegia) or type of CP (e.g. dystonia). This study excluded
children with acquired hemiplegia (post 28 days after birth), however a separate RCT of Mitii™ is being conducted with acquired brain injury. (Boyd et al, in submission)

The control group in the current study was assigned ‘standard care’, which was continuation of any therapy services they typically received. Children in the intervention group were also able to access their typical services if required as to not restrict their participation in the program. Participants in both groups did not participate in other intensive therapy programs during the intervention period and were excluded if they received intramuscular BoNT-A injections or upper/lower limb surgery. Details of standard care were captured by questionnaire at 20 weeks, with the majority of children accessing very limited therapy services. There was individual variation in the services received by participants, and this could be considered a limitation of the study. While children were matched in pairs based on age, gender and MACS level, it was not ethical to restrict therapy services of some children in order to match participants on the basis of their typical therapy services.

There are a number of considerations in regards to outcome measures utilised in the current study that require discussion. Firstly, use of the COPM in this study differs from clinical use of the COPM where goals would routinely re-evaluated and adapted over time depending on individual progress. The goals were set at baseline and were not adjusted during the intervention period so the measure was delivered in a standardised manner to all participants. Some identified goals however were not always relevant after a 20 week period, for example goals relating to seasonal sporting activities. While there was a statistically significant difference between groups post-intervention, the difference did not reach clinical significance of 2 points. There was indeed individual variation, and future research could further examine the characteristics of children who were the best responders following the intervention. Further research focusing on the COPM to identify which type of goals had the greatest amount of improvement post-intervention, may be useful to inform clinicians about the nature of occupational goals that are most likely to improve following Mitii™ (i.e. self care, productivity or leisure).

There are a number of points to consider when interpreting findings from the measures of unilateral upper limb function used in this study (JTTHF and MUUL). A benefit of using these measures is that they have been previously used in clinical trials involving children with UCP, which allows comparison across studies. While the JTTHF has shown responsiveness to change following intervention in children with UCP, there is no published data on the test-retest reliability of the JTTHF in this population. It has been suggested that the JTTHF may not be stable across testing situations in children with UCP.
and results therefore must be interpreted with some caution. The findings on the JTTHF, with statistically significant improvements on the dominant upper limb and a trend towards an improvement on the impaired upper limb were unexpected. Although the differences between groups did not reach statistical significance for the impaired upper limb, it is possible that the faster times achieved by the intervention group post-intervention may reflect meaningful improvements in their impaired upper limb speed and dexterity. The level of clinical significance has not been reported for the JTTHF and this will be important to establish in future research in order to better interpret findings from this measure. The sensitivity of the MUUL to detect change has been questioned.\(^{(58)}\) A recent study investigated the internal construct and dimensionality of the MUUL with Rasch analysis found unidimensionality was not supported for the overall scale, however revised subscales showed good internal consistency and no differential item functioning for gender or age.\(^{(59)}\) Accordingly, a revised version of the assessment was published, the Melbourne Assessment 2 (MA2) which extends and refines the original version with four elements of upper limb movement quality: movement range, accuracy, dexterity and fluency. Wallen reported in a recent commentary that the MUUL is probably the assessment of choice for unilateral upper limb function and knowledge regarding sensitivity to change following intervention will be gained through use of the MA2 in future research.\(^{(60)}\)

A measure of the ‘amount of use’ of the hemiplegic upper limb in daily activities was not included in this study, and therefore a potentially important finding from this intervention is unknown. The Mitii™ program focuses on upper limb movement and caregivers frequently provided subjective reports of increased spontaneous use of their child’s impaired upper limb in daily activities. The revised version of the Pediatric Motor Activity Log (PMAL-R)\(^{(61)}\) measures the ‘actual use of an impaired upper extremity in everyday life’, which differs from the measures of upper limb function described above that measure motor capacity. Inclusion of this measure would have been valuable, as it is possible that children with mild UCP may increase the use of their impaired upper limb in daily tasks without showing improvements on motor capacity measures in the clinical setting. It is acknowledged that inclusion of additional outcome measures would have increased the assessment burden given the comprehensive range that were included in this study.

A number of characteristics of the intervention in this study require discussion given their likely impact on the overall dose of participants in the intervention group. Many participants encountered technical difficulties with the Mitii™ program, which were found to be largely as a result of the distance between families residing in Australia and the server located in Denmark. Internet speed tests to determine the upload and download
connection bandwidth were carried out and while we able to suggest service providers that may provide better connections, we were unfortunately limited in our ability to fix issues around the internet connectivity. The Mitii™ program developers acknowledge this issue and if the program is to be distributed in Australia, a server would need to be established in closer proximity.

There were a number of issues experienced by families when setting up the Mitii™ program, as the green colour detection meant that any green objects in the background had to be removed, children could not be wearing the colour green and different lighting conditions interfered with the smooth running of the program. The Mitii™ program used in this study was the first generation of the program, which has now been superseded by a second generation that uses the Microsoft Kinect®. It was decided not to transfer to the new system when it became available approximately two-thirds of the way through the study, so that all children received the same intervention.

The second generation of Mitii™ (Kinect®) is undergoing continual development and remains available only for research use at this point in time, but is expected to become commercially available in the future. A benefit of Kinect® system is that tracking of specific body parts, which ensures the hemiplegic upper limb is used when required. The Mitii™ system used within this doctoral program was not able to ensure that the hemiplegic upper limb was used, and parental support was required to monitor participants.

Although the Mitii™ program involves upper limb movement, it does not target fine motor skills. Occupational performance goals of children with mild to moderate UCP often involve fine motor skills and therefore this program was not ideal for achieving such goals. The Mitii™ program was designed to develop underlying neural circuits as a basis for task specific practice, and hence the program would ideally be used in conjunction with goal-directed practices to work towards goals that require fine motor skills. With ongoing advances in technology however, it is possible that future development of the Kinect® or similar technologies will be able to capture smaller body movements, which could be beneficial for children with mild UCP to target isolated finger movements.

A limitation of the Mitii™ program is that the virtual therapists could not watch the participants as they completed their program, meaning that there was room for error in the way the children carried out the activities. As the Mitii™ program used in this study required a webcam to detect the green tracking bands, other applications that could have been used a webcam to watch their performance (e.g. Skype) could not run simultaneously. Therapists were able to watch participants demonstrating exercise from
the program (e.g. step up technique) over Skype video calls. Future development of the program to include video feedback built into the system to provide smooth access to real-time feedback would be greatly beneficial.

8.4 Clinical feasibility and implementation

The clinical feasibility of delivering Mitii™ was initially established in a pilot study with children with UCP conducted at the Helene Elsass Centre in Denmark (n=9). This RCT, with a larger sample of 102 children, has confirmed the feasibility of delivering Mitii™. As the Mitii™ program requires minimal, low-cost equipment; the program can easily be set up in home environment and it is not restricted to use in clinical settings. This is an advantage over many engineer-built systems that are costly and limited to clinical or laboratory settings.

Inherent to Mitii™ is that the programs are created and monitored by therapists, meaning that it would be government and private therapy providers rather than individual families who would purchase the program. While the system is currently limited to research use, if it becomes commercially available the cost of purchasing the system will impact on its uptake by health service providers. Other financial costs for health providers (if they are to loan equipment) or families would be purchase of the Kinect®, step block and balance foam, and the cost of service support by the program developers.

This study has shown that Mitii™ is not a ‘one size fits all’ approach to delivering therapy, with the considerable variation in the overall dose by children in the intervention group. The client’s goals and the relevance of the program to their goals, as well as their home environment situation needs to be considered when selecting which children and adolescents would benefit from the program. A number of clinical implementation suggestions were obtained through discussion with children and caregivers, as well as experienced occupational therapists, physiotherapists, neuropsychologists, life skill coaches and biomedical engineers involved in interactive computer game development both in Australia and abroad. These suggestions, outlined in Chapter 7, provide useful insight for researchers and therapists involved with delivering interactive computer play interventions in the future.

8.4.1 Duration of the Mitii™ program

Feedback from children and their caregivers, from both the qualitative study and anecdotally in the RCT, was relatively consistent in terms of desired length of the daily
session. Many families suggested that 20 minutes would have been easier to sustain rather than 30 minutes, however there were some children who were happy with completing 30 minutes daily. The overall consensus from participants and healthcare professionals was that 20 weeks was too long for many children to sustain engagement. While some children lost motivation relatively early in the intervention, some caregivers found it wasn’t until approximately three-quarters of the way through the program (15 weeks) when their child’s motivation declined.

The length of the daily program did need to be reduced for some younger children who had difficulty concentrating for sustained periods of time. In future clinical implementation, therapists could prescribe two 15 minute sessions per day as an alternative to completing one 30 minute session. Research in physical activity suggests that short bouts of physical activity can have positive health outcomes as the key factor is the accumulation of time.\(^\text{(62)}\)

This principle may apply to the motor components of the Miti™ intervention. Investigations into the effect of therapy dose on outcomes in the RCT suggested a positive effect to approximately 20 hours, after which a plateau was observed. One possible explanation for these findings is that children were more engaged initially in the first 20 hours, compared to the latter stages of the program when children perhaps were just “putting in the time”. These findings may relate to the qualitative findings, in which children reported that the program became repetitive over time and their motivation declined. A key principle of neuroplasticity is that individuals must pay close attention to the task to benefit. As children’s motivation declined, it is possible that their attention to the modules consequently declined.

In the adult stroke literature, a systematic review and meta-analysis investigating the effect of therapy dose on activity outcomes by Cooke et al found some, however limited, support for the hypothesis that higher therapy doses lead to enhanced functional outcomes.\(^\text{(63)}\) A key consideration when investigating and comparing therapy dose is the nature of the interventions. In Cooke et al’s review, the highest therapy doses were task-specific interventions, which may have influenced outcomes.\(^\text{(63)}\) A further consideration is what is realistic in terms of therapist capacity and also children’s motivation to participate over time.

In a clinical setting, determining the target therapy dose will be an individual process. Findings from the current research indicate that 20-30 minutes daily is feasible and many families may prefer to do the program only on weekdays to allow children to have a break over the weekend. An overall dose of approximately 20-30 hours can have a positive
effect on functional outcomes and this could be achieved over a 10 week period, which is approximately the length of a school term.

8.4.2 Conjunction with face-to-face therapy approaches

The Mitii™ program has potential to be implemented in conjunction with other evidence-based therapy approaches for children and adolescents with UCP. For example, the modules that require use of the impaired upper limb could be used within a constraint-induced movement therapy program as a unimanual therapy activity, while the bimanual games could be used to encourage bimanual hand use within a bimanual therapy program. The Mitii™ program could be implemented within group therapy camps that focus on constraint-induced movement therapy, bimanual therapy, or a combination of both approaches. If future development of the Mitii™ program allowed two children to play the program together, this may strengthen its application in group therapy settings. Mitii™ also has potential to be used within post BoNT-A therapy programs for either upper or lower limb therapy, as well as a strengthening program post-surgery with the possibility of including resistance exercise for different activities (e.g. sandbag weights). As an example, if a child had six weekly sessions of post BoNT-A therapy available through a service provider, Mitii™ could be introduced in the initial session and then implemented as a home program. The therapist could follow the child’s progress in the program remotely via the therapist cockpit, and also have the opportunity to watch the child doing the program within follow-up sessions to provide real-time feedback. The child could then continue The Mitii™ program in their home environment after completion of their post BoNT-A therapy block without requiring face-to-face therapy. Mitii™ has potential to be a useful supplement to goal-directed therapy. Results from the RCT suggest that Mitii™ can enhance children’s underlying motor, processing and visual perceptual skills that are required for daily life tasks. As an example, a child who has the goal of being able to prepare a bowl of cereal independently in the morning for breakfast requires the motor skills to perform the task as well as the processing skills to plan and carry out the steps in a sequential order. The Mitii™ program trains gross upper limb movements in conjunction with visual processing abilities such as sequential memory and figure ground discrimination. Strengthening these pathways in the brain may assist the child to carry out these skill components in the task, however a direct transfer of skills from Mitii™ to a specific task however cannot be assumed. The Mitii™ program however does not target fine motor manipulation skills that are required to open containers and lids. These skills could be focused on within goal-directed therapy or context-focused therapy.
within an occupational therapy program, with Mitii™ prescribed as a supplementary home-based program.

### 8.4.3 Application in diverse populations

The current Mitii™ program is ideally suited to children with CP or acquired brain injury, however it could be applied to children with other developmental disabilities. Children with global developmental delay, developmental coordination disorder, autism spectrum disorder or spina bifida may also benefit from this multimodal therapy approach. Mitii™ may also be beneficial as a therapeutic modality for children and adolescents who are overweight as a means of increasing physical activity levels in a motivating manner, with the addition benefit of cognitive and visual perceptual training compared to standard commercially available games.

The Mitii™ program is currently being trialled with adult patients post-stroke, and it has potential to be a suitable mode of therapy to retrain lost function in this population. Mitii™ could be particularly useful in inpatient rehabilitation settings as a means to increase therapy dose without requiring direct therapist contact. The Mitii™ program could provide repetitive upper limb retraining, resistance training with light weights to increase strength, physical activity training, memory and concentration tasks, and also as a means to address visual field deficits for patients post stroke. Factors such as the appropriateness of images in the Mitii™ modules require consideration for use with adults. Engagement in adults is likely to differ from children and adolescents, particularly for patients who have insight into their limitations and an understanding of the therapy rationale. These patients may be more motivated to engage in therapy to improve their function compared to children with UCP who might consider their need for therapy less urgent. Future investigations of Mitii™, or similar programs, in various paediatric and adult population will be of great interest to therapists working in rehabilitation settings.

### 8.5 Future research recommendations

The systematic review in Chapter 2 identified that while the AMPS is best available measure of performance or capacity for children and adolescents with CP, further validation work in this population would strengthen its use. The AMPS was validated on a large sample including children and adolescents with CP, however a relatively small percentage of this sample was under the age of 16 years. The AMPS is a useful tool to evaluate both the motor and processing components of ADL ability, and further validity and
reliability studies in various paediatric populations (e.g. developmental coordination disorder or acquired brain injury) may broaden its use in research and clinical practice. Given the relative novelty of interactive computer play as a mode of therapy delivery, there is scope for a substantial amount of future research. Considering the Mitii™ program specifically, future research could investigate the efficacy of Mitii™ combined with standard occupational therapy in comparison to the Mitii™ program alone. While this research provides evidence to suggest that Mitii™ is superior to standard care in improving occupational performance, there may be a greater effect if Mitii™ was combined with specific goal-directed therapy. A benefit of the Mitii™ program however is that children residing in rural and regional areas can access the program, so to investigate the effect of Mitii™ combined with standard care reintroduces the issue of the availability of therapy services in these areas. This could however be feasible to investigate in a multi-site trial in the future.

A further possibility would be to investigate the effectiveness of Mitii™ in conjunction with a task-specific home program. Research shows that home programmes are effective for children with UCP to improve their motor activity and self-care ability and it would be of interest to effect of Mitii™ as a complement to task-specific home programs. This could potentially be delivered with alternating days of Mitii™ with days focusing on task-specific practice, or a shorter duration of both therapy approaches (e.g. 15 minutes of each) on each weekday. Considering this design of therapy pragmatically and in context with results from the qualitative study, it is apparent that combining Mitii™ with task-specific therapy requires greater input from caregivers and gives caregivers the ‘role of the therapist’. Findings from the qualitative study were that many caregivers valued not having to take on the role of therapist with the Mitii™ program with children often being able to take ownership of their therapy.

Future work to determine the optimal dose of interactive computer play interventions for children will be important. This will be particularly important for adolescents with mild to moderate UCP, who are often involved in extra-curricular activities on top of their schooling commitments and have busy daily schedules. As individuals respond differently to different therapeutic approaches, characteristics of the best responders to Mitii™ could also be investigated to assist therapists to identify the most appropriate children to participate in this intervention.
8.6 Conclusions

This thesis examined the efficacy of Mitii™, a web-based therapy program delivered in the home environment, compared to standard care for children and adolescents with UCP. The main conclusions from this research are summarised:

i. A systematic review of ADL measures for school aged children with CP identified eight suitable measures. The AMPS was recommended to measure performance or capacity, while the PEDI was recommended to measure ADL capacity.

ii. A reproducibility study found that the AMPS demonstrated excellent test-retest reliability with ICC values of 0.93 for the AMPS motor scale and 0.86 for the AMPS process scale. The standardised minimal clinically important difference of 0.3 logits is relevant for children and adolescents with UCP.

iii. A cross sectional study identified that 57% of variation in ADL motor skills was explained by bimanual performance and unimanual capacity of both the dominant upper limb; and 35% of variation in ADL processing skills were explained by visual sequential memory, visual closure and unimanual capacity of the dominant upper limb.

iv. In an RCT, children and adolescents in the Mitii™ intervention group showed statistically significantly greater improvements in ADL motor and processing skills, speed and dexterity of their dominant upper limb, perceived occupational performance and visual perception compared to the control group. The differences did not exceed clinically significant levels.

v. A qualitative study identified key themes that related to child/family, intervention and service provider characteristics. Children’s interest was initially captured with the novelty of the program, however motivation declined over the 20 week period. Caregivers valued that Mitii™ programs were individualised and allowed children to take ownership of their own therapy. Strong family support facilitated engagement and individual strategies were utilised to sustain motivation.

This research provides evidence to further preliminary findings from pilot studies of interactive computer play interventions for children and adolescents with UCP. This RCT is the first adequately powered study of an interactive computer play intervention for
children with UCP and specifically of the Mitii™ program. New data on the selection of ADL measures for this population and the reproducibility of the AMPS was reported. Outcomes that are associated with both ADL motor and processing skills were identified, which may assist therapists to understand factors that contribute to difficulties in ADL performance. Feedback from children and caregivers was captured to understand the key factors that contribute to engagement in the Mitii™ program to assist future clinical implementation.

Overall, this research supports the inclusion of Mitii™ within the therapy toolbox to enable children and adolescents with UCP to improve their occupational performance. Future research may investigate the effects of Mitii™ when combined with face-to-face occupational therapy sessions that focuses on specific goal-directed training, or within group therapy sessions. Clinical implementation of Mitii™ requires therapists to identify suitable participants through consideration of children’s physical and cognitive abilities, interests, individual goals and available family support. Collaboration between therapists and families to devise and implement individualised strategies will support children to sustain engagement in the Mitii™ program.
Chapter 9: References


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Chapter 10: Appendices

10.1 Ethics approvals and trial registration

10.1.1 Royal Children's Hospital approval letter
10.1.2 The University of Queensland approval letter
10.1.3 Cerebral Palsy Alliance approval letter
10.1.4 Australian New Zealand Clinical Trials Registration
Dear Assoc Prof Boyd

HREC Reference number: HREC/11/QRCH/35
Project title: MiTi: A randomised trial of novel web-based upper limb intervention for congenital hemiplegia

Many thanks for your application for the above project for review by the QLD Children’s Health Services (RCH) Human Research Ethics Committee (HREC) at its meeting held on 9th May 2011.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise the proposal meets the requirement of the National Statement on Ethical Conduct in Human Research and the Committee has granted approval for this research project. The documents reviewed and approved include:

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<thead>
<tr>
<th>Document</th>
<th>Version</th>
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<tr>
<td>Master Participant Information Sheet: Parent/Guardian Version</td>
<td>1.0</td>
<td>18 March 2011</td>
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<tr>
<td>Master Participant Information Sheet: Participant (child) version</td>
<td>1.0</td>
<td>18 March 2011</td>
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<tr>
<td>Master Consent Form: Parent/Guardian Version</td>
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<td>Questionnaire: CP-QOL CHILD - CHILD QUESTIONNAIRE</td>
<td>2.0</td>
<td>22 March 2011</td>
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Please note the following conditions of approval:

1. We require an annual progress report (or sooner if the project is completed) concerning the study. This must include progress to date or outcome in the case of completed research. (In accordance with National Statement 5.5.3)

2. HREC approval is valid from 13/05/11 to 13/05/14.

3. In accordance with the National Statement (3.3.12), before beginning the clinical phase of the research, researchers should register clinical trials in a publicly accessible domain.

4. If the project does not proceed, the Committee must be informed as soon as possible. (In accordance with National Statement 5.5.6)

5. The Committee must be informed of any potential or realised problem with bioethical implications, if such occurs during the conduct of the research project.

6. Any serious adverse event (SAE) that arises in the context of this research, or involving a researcher conducting this research, must be reported to the Ethics Committee within 72 hours and reported to the sponsor (if applicable) within the stipulated time frame.

   Serious Adverse Event Reports that are generated off-site may be (a) Serious Unexpected Adverse Reactions or (b) Serious Events which the Research Team believes cannot be related to the research intervention. The Research team must report incidents of (a) during multi-centre trials. Such are required to be submitted to the Chair of the QLD Children’s Health Services District Ethics Committee (RCH) on receipt by the researcher. A summary of the SAE reports is to accompany the submission. Information required includes: patient details (age & sex), adverse event, outcome and the likelihood of the event being related to the study drug/device/procedure.

   With respect to all SAEs, the researcher must provide his or her opinion as to whether the SAE is directly related to the research intervention. A copy of the SAE Summary must be provided. (This can be obtained from the Ethics Officer)

7. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a revised online NEAF (accompanied by all relevant updated documentation and a cover letter from the principal investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study). Hard copies of the revised NEAF, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC coordinator as per standard HREC SOP. Further advice on submitting amendments is available from: [http://www.health.qld.gov.au/epic/documents/ethics/researcher_userguide.pdf](http://www.health.qld.gov.au/epic/documents/ethics/researcher_userguide.pdf)

8. The Ethics Committee will conduct a randomly identified audit of a proportion of research projects approved by the Committee. That audit process will look at such issues as;
   a. Security of Documents
   b. Consent Form Register
   c. Serious Adverse Events Register
   d. Withdrawal of Participants – who and why
   e. The de-identification of data
9. We require researchers to give a declaration of intention to publish their findings in a refereed journal or similar peer-reviewed forum. Your work must be in accordance with the following:

- Guidelines under Section 95 of the Privacy Act 1995 and Guidelines approved under Section 95A of the Privacy Act 1995.

10. Researchers should note, if not QLD Health employees, a Blue Card may be required for contact with children.

11. The Researcher must send the 'Notification of Commencement of Research Protocol' as soon as research begins. Status of the project will remain as 'Not Started' until this form is received.

Should you have any queries about the HREC's consideration of your project please contact Amanda Smith (Co-ordinator) or Professor John Pearn (Chairperson). The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from: http://www.health.qld.gov.au/epic/ethics/reagu_homepage.asp

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the District CEO or Delegale of that site has been obtained.

A copy of this approval must be submitted to the District Executive with a completed Institutional Approval Form for authorisation from the CEO or Delegate to conduct this research within the Children's Health Service District.

This approval is applicable to the following Queensland Health sites:

Royal Children's Hospital, Brisbane
Cairns Base Hospital, Cairns
The Townsville Hospital, Townsville

The HREC wishes you every success in your research.

Yours sincerely,

[Signature]

Professor Alan Isles
Deputy Chair
Queensland Children's Health Services (RCH) Human Research Ethics Committee

cc: Ethics Committee Files
THE UNIVERSITY OF QUEENSLAND
Institutional Approval Form For Experiments On Humans
Including Behavioural Research

Chief Investigator: A/Prof Roslyn Boyd, Prof Jenny Ziviani, Dr David Abbott,
A/Prof Stephen rose, Prof Richard Macdonell, Dr Leanne
Sakzewski, Dr Robert Ware, A/Prof Anthony Smith

Project Title: MiTii: A Randomised Trial Of Novel Web-Based Upper
Limb Intervention For Congenital Hemiplegia

Supervisor: A/Prof Roslyn Boyd, Prof Jenny Ziviani

Co-Investigator(s): Prof Jens Bo Nielsen, Director Peder Esben Bilde, Dr
Radwa Badawy, Dr Koa Whittingham, Ms Kate Hunt, Ms
Louise Mitchell

Department(s): Queensland Cerebral Palsy Rehabilitation and Research
Centre, Royal Children's Hospital, School of Medicine

Project Number: 2011000608

Granting Agency/Degree: NHMRC

Duration: 1st March 2014

Comments:

Expedited review on the basis of approval from the Queensland Children's Health
Services (RCH) HREC, dated 13/05/2011.

Name of responsible Committee:-
Medical Research Ethics Committee

This project complies with the provisions contained in the National Statement on
Ethical Conduct in Human Research and complies with the regulations governing
experimentation on humans.

Name of Ethics Committee representative:-
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

Date: 25-5-25N Signature: ____________________________
Professor Ros Boyd  
Queensland Cerebral Palsy and Rehabilitation Research Centre  
Department of Paediatrics and Child Health  
The University of Queensland  
Herston QLD 4029

April 4th 2013

Dear Prof Boyd

RE: “MiTii: A randomised trial of novel web-based upper limb intervention for congenital hemiplegia.”

Thank you for your application of the above project for consideration by the Cerebral Palsy Alliance's Human Research Ethics Committee (HREC) at its meeting held on 3rd April 2013.

Our HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007).

I am pleased to inform you that your project meets the requirements of the National Statement on Ethical Conduct in Human Research and our Committee has granted approval for this project.

The Committee also provides the following comments for your consideration:

- The Committee notes that Version 4 of the Standard Participant Information Statement and Assent Form is 10 pages long and expressed some concern about this length and expectation that a young person would be able to fully comprehend such a statement.
- Additionally, on page 29 of the NEAF, the Committee noted that not all the columns on table were completed for the participants. It has assumed that this is an oversight and that people with cognitive impairment/intellectual disability or mental illness are the only participants that this project specifically excludes.

Details of the approval are as follows:

Project approval number: 2013-04-01. Please use this number in all subsequent correspondence to the Committee.

Approval period: April 2013 to April 2016
Authorised research personnel:
Principal researchers/investigators
 o Prof Ros Boyd
 o Prof Jenny Ziviani
 o A/Prof Steven Rose
 o Dr Robert Ware
 o Dr Leanne Sakzewski
 o A/Prof Anthony Smith
 o Dr David Abbott
 o Prof Richard MacDonnell
 o Dr Tracy Comans
 o Prof Paul Scuffham

Associate researchers/investigators
 o Prof Jens BoNielsen
 o Dir Peder Esben Bilde
 o Dr Koa Whittingham
 o Ms Sarah James
 o Ms Louise Mitchell
 o Ms Melinda Lewis
 o Ms Rachel Thomas
 o Ms Laura Pareezer
 o Dr Lynne McKinlay
 o Ms Stephanie Ross
 o Mr Henry Tsao

Approved documentation:

Please attach a footer “This study has been approved by the Cerebral Palsy Alliance Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research you may contact the Ethics Committee on (02) 9975 8776 or ethics@cerebralpalsy.org.au” to the information statements and consent forms, labelling this version 1.

Please send a copy of the final updated documents to the Ethics Committee. If you wish to change these in the future please send a copy to the Ethics Committee for review.

The approval of this project is conditional upon your continuing compliance with the National Statement.

Accordingly, it is the responsibility of the principal investigator/s to:
- Provide a summary of your progress on a yearly basis to the committee commencing April 2014. A final report on completion and notification of any publications from this project is also requested. Failure to submit required reports will result in withdrawal of consent for the project to continue.
- Advise the HREC immediately in writing of any serious adverse events occurring during the course of the research.
- Advise the HREC immediately of all unforeseen events that might affect continued ethical acceptability of the project.
- Advise the HREC of any proposed changes to the research protocol, research personnel, information statement or consent form. All proposed amendments
must be addressed in writing to the HREC and must be approved by the HREC before continuation of the project.

- Advise the HREC immediately, providing reasons, if the research is discontinued prior to its completion.
- Request an extension of ethics approval should the project not be completed within the time period specified above.
- Ensure that copies of all signed consent forms are retained and made available to the HREC on request.
- Provide a copy of this letter to any internal/external granting agencies if requested.

The Ethics Committee and Board of Directors wish you well with this important project.

Yours sincerely

Deborah Hoffman, on behalf of

Dr Neroli Best
Chair, Ethics Committee
Cerebral Palsy Alliance Ethics Committee is a NHMRC HREC: EC00402
MiTii: A randomised trial of novel web-based upper limb intervention for congenital hemiplegia

A randomised control trial evaluating the functional, neurological and participation outcomes of the “Move it To improve it” program for children with congenital Hemiplegia

Nil

MiTii

MiTii ("Move it To improve it") is an internet-based multimodal therapy which combines upper-limb training within the context of meaningful physical activity that can be accessed in children's homes. Inherent in this approach is the ability to scaffold visual perception skills and cognitive challenge, both important aspects of activity engagement and participation in a virtual training environment. The program is potentially cost effective as only three centre-based therapists (Physiotherapist, Occupation, etc.).
Therapist, and psychologist) are required to provide initial assessment, goal setting and training for families and participating children. Each therapist then spends 30 minutes each week to remotely modify the individualised program. This current application proposes to test the efficacy of MiTii in a wait list randomised controlled trial. We propose to provide MiTii at an intensity of 30 minutes per day, 6 days/week for 20 weeks (total dose 60 hours). All children will therefore receive the therapy within 10 months of being randomised either to commence MiTii immediately or waitlisted for 20 weeks before receiving the same MiTii therapy as the Immediate invention group. Retention of effects will be tested at 10 months. As current therapy programs are resource intensive and time consuming it is important to determine if gains from MiTii are sustained over a 10 month period as this could offer a cost effective model of care, particularly for rural, remote and isolated children with CP.

**Intervention code:** Rehabilitation

**Comparator / control treatment:**
The delayed intervention or waitlist group will act as a control group. These children will undergo baseline assessment and then be sent home for 20 weeks receiving standard Treatment/Care as Usual. After the 20 weeks, assessments will be repeated and they will then receive the same 20 week MiTii training as the Immediate Intervention group. Standard care is considered Physiotherapy, Occupational Therapy or Psychology that the child would otherwise receive without the intervention, excluding splinting, casting or surgery management. Should children normally received Botox, their inclusion in the study will be delayed until after their Botox and standard follow up care has been completed. Standard care will be assessed using a parent questionnaire which documents the types of therapies and frequency received.

**Control group:** Active

**Primary outcome:** Motor and Process Skills in daily living activities as demonstrated by a 0.5 logit score on the Assessment of Motor and Process Skills (AMPS)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement

**Secondary outcome 1:** Activity limitations (unimanual capacity and bimanual performance) by mean difference of 5 points on the Assisting Hand Assessment (AHA) and 10% decrease in time on the Jebsen-Taylor Test of Hand Function (JTHF)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

**Secondary outcome 2:** Neuroplasticity determined on the Motor Evoked Potential (MEP) curves using Transcranial Magnetic Stimulation (TMS)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40weeks post intervention commencement.

**Secondary outcome 3:** Visual perception (visual discrimination, visual memory and visual sequential memory)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.
Secondary outcome 4: Executive functioning (sustained attention, working memory and cognitive flexibility)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

Secondary outcome 5: Executive functioning in everyday life (measured by the BRIEF)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

Secondary outcome 6: Participation (LIFE-H) by 0.5 weighted score for categories of personal care, nutrition, education and recreation

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

Secondary outcome 7: Occupational performance (COPM performance and satisfaction) by 2 points

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

Secondary outcome 8: Functioning and participation domains of quality of life (CP-QOL-child/CP-QOL-Teen) by 5 points on specified domains

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

Secondary outcome 9: MiTii will be more cost-effective compared with Usual Care as shown by resource use and effectiveness based on function (AMPs) and quality of life (CPQOL)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

Secondary outcome 10: MiTii will increase physical activity capability (measured using the functional strength assessments, walking tests and modified shuttle run test) and performance (measured using a physical activity questionnaire and accelerometers over >3 days)

**Timepoint:** immediately post-intervention (at 20 weeks) and retained at 40 weeks post intervention commencement.

**Key inclusion criteria:**

i. Gross Motor Function Classification (GMFCS) I or II; Manual Abilities (MACs) I, II, III. ii. Sufficient co-operation and cognitive understanding to perform the tasks and access the computer equipment; iii. Are able to attend 3 appointments in Brisbane for initial assessment/training and follow-up assessments. iv. Able to access the internet at home (phone line or internet access). Note; laptops will be loaned for those require them and camera’s provided for all children with the treatment phase.

**Minimum Age:** 8 Years

**Maximum Age:** 18 Years

**Gender:** Both males and females

**Healthy volunteers?** No
Key exclusion criteria:

- i. received upper limb surgery in the last 6mths;
- ii. unstable epilepsy (i.e. not controlled by medication) is a precaution for TMS. Where children have received BoNT-A or upper limb casting in the previous 1 month, inclusion in the study will be delayed until after treatment and standard follow up.

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Describe the procedure for enrolling a subject and allocating the treatment (allocation concealment procedures):

Screening phone call to ensure participant's suitability. Rolling recruitment in blocks of 10-15 children. Matching pairs for age/gender/MACS scores. Once baseline assessments have been completed, children will be randomised within pairs from concealed envelopes opened by non-study personnel. Treatment allocation will be recorded on a piece of folded paper inside each envelope in random order (computer generated). The randomisation process will involve allocating a number "1" or "2" to each member of the pair which will be written on the paper inside the envelope. As each pair is entered, they will be allocated the next consecutive envelope, which will be opened by the non-study personnel who will read and record the treatment allocation from the paper inside the envelope. Study personnel will be informed of group allocation.

Describe the methods used to generate the sequence in which subjects will be randomised (sequence generation):

Randomisation within pairs by computer number generation of 1 or 2 alternatives within the pairs.

Masking / blinding:

Blinded (masking used)

Who is/are masked/blinded:

The people assessing the outcomes
The people analysing the results/data

Assignment:

Parallel

Other design features (specify):

Nil

Type of endpoint(s):

Efficacy

---

**Page 7**

<table>
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</tr>
</thead>
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<tr>
<td>Anticipated or actual date of first participant enrolment:</td>
<td>1/04/2012</td>
</tr>
<tr>
<td>Target sample size:</td>
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</tr>
<tr>
<td>Recruitment status:</td>
<td>Not yet recruiting</td>
</tr>
</tbody>
</table>

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**Page 8**

| Funding source 1:             | Government funding body e.g. Australian Research Council |

Has the study received approval from at least one ethics committee?

No

Ethics Committee name 1: Royal Childrens Hospital and Health Services District
Address: Department of Pediatrics and Child Health
3rd Floor, Foundation Building, Royal Childrens Hospital,
Herston Rd, Herston
QLD 4029
Country: Australia
Date submitted/Date which intend to submit to ethics committee: 26/03/2011

Ethics Committee name 2: University of Queensland
Address: Medical Ethics Committee,
University of Queensland,
Research and Graduate Studies Office,
St Lucia,
QLD 4072
Country: Australia
Date submitted/Date which intend to submit to ethics committee: 26/03/2011
committee:

Countries of recruitment: Australia

Brief summary: This randomized comparison trial will test the efficacy of a novel rehabilitation (MiTii: Move it To improve it) which involves the use of a web-based, intensive and individualized, multimodal therapy program with therapists acting as ‘virtual trainers’, over a 20 week period, and comparing this approach to standard care received in children with congenital hemiplegia.

Trial website: Nil

Presentations / publication list: Nil
10.2 Information statement and consent forms

10.2.1 Parent/guardian information statement and consent form

10.2.2 Participant information statement and consent form
You are invited to participate in a Research Project that is explained below.

Thank you for taking the time to read this Information Statement.
This information statement and consent is 11 pages long. Please make sure you have all the pages.

For people who speak languages other than English:
If you would also like information about the research and the Consent Form in your language, please ask the person explaining this project to you.

What is an Information Statement?
These pages contain a lot of information about a research project we are inviting your child to take part in. Please read this information carefully as it explains clearly and openly what is involved in participating in this project. This information is to help you to decide whether or not you would like your child to take part in the research.

Before you decide to take part or not, you can ask us questions you have about the project. You may want to talk to about the project with your family, friends or one of your child’s therapists.

If you would like your child to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:
- understand what you have read
- had a chance to ask questions and receive satisfactory answers
- consent to your child taking part in the project.
We will give you a copy of the information and consent to keep.

What is the Research Project about?
Hemiplegia is a type of cerebral palsy that involves just one side of the body – impacting on function of the arm and the leg. Many children who have a hemiplegia attend regular school but may have physical and cognitive (eg. thinking, memory, attention, planning) difficulties. This might mean that children with a hemiplegia find it difficult to participate in the things that they would like to do at school, home or in the community. In this study we want to see if a new form of therapy (Mitii – Move it to improve it) is effective at improving some physical, manipulation, coordination & cognitive difficulties in children with Hemiplegia. Mitii is delivered over the internet and uses a web-
cam to pick up movements of your child’s arm, leg or head which allows you to play computer games on the screen. The therapy can be completed at any time at home.

This project has two parts. Part A is the Assessment and treatment component. Part B is the neuroscience component.

In Part A we want to see if Mitii can help children with hemiplegia improve their physical and cognitive skills. We do this by comparing two groups – one who will receive the Mitii training straight away for 20 weeks and one who will continue with normal therapy and receive Mitii after 20 weeks. 98 families will join the study and your child will be allocated randomly to one of two groups. The group that they are in is decided by chance – like a flip of a coin. No one is able to influence which group your child will be in, however they will receive Mitii despite which group they are in.

When doing the Mitii training we would like your child to do it at home every day for 20 weeks – this will mean they get to access up to 60 hours of therapy. The Mitii program is completed at home using the internet and a webcam – if you don’t have these things we can loan them to you. The webcam picks up movements of green bands and your child plays the games by moving their arm, leg or your head. The Mitii therapists back in Brisbane (occupational therapist, physiotherapist and neuropsychologist) will be your child’s ‘virtual trainers’. They will log on and see how you and your child’s going and make sure that the program is just right for them by making it harder or easier. If we can prove that Mitii does help children with hemiplegia it will mean that children who don’t receive a lot of therapy or who live a long way away, will be able to access it at home.

If your child participates in the first part of the study (Part A Assessment and Mitii Training) we will also ask you if you want them to be in the second part (Part B the Neuroscience). In this part we want to find out how their brain actually controls their hand movements and whether this might change after the training. The tests we use are:
(i) Functional Magnetic Resonance Imaging (fMRI) which shows the parts of the brain that are active when you move your hand.
(ii) Transcranial Magnetic Stimulation (TMS) which measures which side of the brain controls each hand.

Both fMRI and TMS are safe to receive as there is no radiation (unlike X rays). In our study we will involve children with a hemiplegia aged 8 to 16 years. We will do the assessments and training at the University of Queensland.

Who are the Researchers?
1. Professor Roslyn Boyd is a Paediatric Physiotherapist. She is the lead investigator of the study and will coordinate the project and supervise the staff conducting the assessments and training in the program.
2. Professor Jenny Ziviani is an Occupational Therapist at the University of Queensland who will be involved in the study design and analysis.
3. Associate Professor Stephen Rose, Dr Jens Bo Nielsen are all experienced neurologists and neuroscience researchers who are involved in the neuroscience part of the study (the brain imaging and measures of brain activity).
4. Dr Robert Ware is a biostatistician from the School of Population Health, University of Queensland who will provide expert opinion on biostatistical analyses.
5. Sarah James (Occupational Therapist), Stephanie Ross (Psychologist), Louise Mitchell (Physiotherapist), Kelly Hentschke (Occupational Therapist) and Adina Piovesana (Psychologist) are therapists conducting research. They will do assessments and run the online treatment programs.
6. Dr Leanne Sakzewski is an Occupational Therapist who will assist with the research process and conduct some of the analysis.
7. Peder Esben Bilde is part of the team in Denmark who devised the Mitii program and will provide expert assistance with the program implementation and technical support.
8. Dr Koa Whittingham is a psychologist who will provide guidance and assistance with measures of Executive Functioning.

9. A/Professor Anthony Smith is the Deputy Director of the Centre for Online Health. He will provide technical assistance for the web-based program delivery.

10. Melinda Lewis is an Occupational Therapist experienced in working with children with CP and is the study clinical co-ordinator.

11. Rachel Thomas (physiotherapist) and Dr Lynne McKinlay work within the Department of Paediatric Rehabilitation. They provide clinical support to the Mitii project.

**Why is my child being asked to be in this research project?**

They are
- between 8 and 16 years old and
- have hemiplegia
- do not have uncontrolled seizures

**What are my child’s alternatives to participating in this project?**

Your child does not have to take part in this project if you do not want them to. If you decide for your child not to participate they will still have access to their normal care and treatment in the Department of Paediatric Rehabilitation at the Royal Children’s Hospital, Brisbane.

You might decide for your child to take part in Part A (the individual assessment and training) but not do Part B (the fMRI and TMS). If you decide you don’t want your child to do Part B it won’t impact on them doing the Mitii assessment and training (part A).

**What do I need to do for my child to be in this research project?**

Before your child is accepted into the study we will call you to do a screening checklist. This will help us work out if this study is one that your child can participate in. This is also a chance for us to answer any questions or concerns that you or your child might have.

**Part A: Assessment Treatment Component**

Once you have consented for your child to participate and they have been accepted into the study, you and your child will need to come to the University of Queensland at St Lucia for 3-4 assessment sessions. Your child will have the opportunity to complete the Mitii training either immediately or after a 20 week wait. They will be randomly allocated to either the IMMEDIATE or the WAITLIST group using the toss of a coin.

All children will be assessed at baseline and then at 20 weeks (straight after the first group finishes training) and 40 weeks after this baseline assessment. If your child is in the WAITLIST group they will come back for one further assessment at 60 weeks.

**What is the Mitii training – “Move it to improve it”?**

- A web-based, intensive and individualized therapy program;
- Completed at home using a webcam and computer;
- Involves a series of interactive, game-like activities that will take approximately 30 minutes to complete each day.
- Uses green band technology to track the movements of the hand/head bands you child wears.
- We ask your child to use the Mitii program each day, over 20 weeks (total of 60 hours training).
- Is Multimodal – uses your child’s physical and thinking skills at the same time.
- Can be made more challenging each week

You and your child will discuss their progress with the research staff on a weekly basis by email, computer skype or phone contact. As this is a new type of treatment we are very interested to find out what you and your child think about it.

All assessments will be completed by an Occupational Therapist, Physiotherapist and/or Neuropsychologist. The following flow chart outlines the assessments you and your child would do:
BASELINE ASSESSMENT:
All children come to UQ for an assessment looking at:
- hand and arm skills
- physical skills and activity levels
- attention, memory and other thinking skills.
- we will also give your child a device called an accelerometer – which is similar to wearing a watch on a belt around their waist. This will measure your child’s physical activity and they will wear it for 4 days
IMMEDIATE GROUP comes for two days so they can do the Mitii training
WAITLIST GROUP comes for one day of assessment.
We will support travel and overnight accommodation for you and your child if you need it.

IMMEDIATE GROUP (48 children)  
Starts 20 weeks of Mitii training.  
If your child trains every day they will get access to up to 60 hours of therapy.

WAITLIST GROUP (48 children)  
Continue with usual therapy for 20 weeks

ASSESSMENT 2 at 20 weeks  
All children come back to UQ for an assessment  
We will do a lot of the same assessments that were done with your child at the first assessment to see if there have been any changes.

WAITLIST GROUP comes for two days so they can do the Mitii training  
IMMEDIATE GROUP comes for one day of assessment.  
We will support travel and overnight accommodation if you need it.

IMMEDIATE GROUP  
Continue with usual therapy for 20 weeks

WAITLIST GROUP  
Starts 20 weeks of Mitii training.  
If your child trains every day you will get access to up to 60 hours of therapy.

ASSESSMENT 3 at 40 weeks  
All children come back to UQ for an assessment  
We will do a lot of the same assessments that were done with your child at the first assessment to see if there have been any changes.  
BOTH GROUPS come for one day of assessment. We will support travel if you need it.

ASSESSMENT 4 at 60 weeks  
WAITLIST GROUP ONLY will come back to UQ for an assessment for one day

Part B: Neuroimaging Component
The Neuroimaging component of the assessment will take 1½ - 2 hours and will occur at the same visits as the functional assessments.

Whole-brain functional MRI studies (fMRI)
MRI stands for Magnetic Resonance Imaging. A MRI scanner is a machine that uses electromagnetic energy (from strong magnets) to take pictures of the inside of the body. MRI is safe and is not the same as ionising radiation, for example, in X-rays.
Functional MRI (or fMRI) measures the change in blood flow that is related to a change in brain activity. This change in brain blood flow is directly related to the hand movements that your child will perform while you are in the MRI scanner.

We will ask your child to lie on a firm bed which moves inside the MRI scanner tunnel. The scanner will take pictures of the brain. It is very important that your child keeps very still during the scanning so that the pictures are not blurry. We will make sure that your child is in a comfortable position so that they can keep still. To help keep your child’s head still we will place
some padding around their head. We will also use some Velcro straps and padding to help them keep their body still. The MRI scanner can be very noisy and we will give your child special earphones to reduce the noise and so that they can hear the radiographer explaining to them what will happen next. A member of the research team can stay with your child at all times and you can wait just outside. You child can talk to the team at any time through a special microphone in the headpiece. For some of the scan your child will be able to watch a favourite movie or DVD of their choice. The test should take approximately 1-1.5 hours to complete, but only 30-45 minutes of this time will be spent inside the MRI scanner.

There are no proven long-term risks related to MRI scans as used in this research project. MRI is considered to be safe when performed at a centre with appropriate procedures. However, the magnetic attraction for some metal objects can pose a safety risk, so it is important that metal objects are not taken into the scanner room.

We will thoroughly examine your child to make sure there is no reason for them not to have the scan. You must tell us if they have had metal, electronic, magnetic or mechanical implants, devices or objects in their body, such as a pacemaker, brain clip, ventricular shunt or metal pins. You must advise in advance if they have had any previous procedures involving surgery or a general anesthetic, so that any devices or objects inside their body can be checked that they are safe for use with the 3T MRI scanner. The magnet used in the research MRI scanner is very strong (called 3 Tesla or 3T), and is twice as strong as the magnet normally used in hospitals. So even if your child has had a clinical MRI previously, it is important that we check all past procedures again to ensure safety for your child in this higher strength MRI scanner. You will be asked to counter-sign an MRI screening form that lists all previous procedures involving surgery or general anesthetic since birth in order for MRI compatibility of devices or objects to be checked.

**Transcranial Magnetic Stimulation (TMS):** is a non-invasive method of measuring how the brain works, which will involve your child sitting very still in a chair. The researcher will place a special metal coil above their head. The coil will send a message to their brain – this is called a stimulus. This will cause a slight twitch in the muscle in your child’s hand. The coil will be measured by a small metal disc on their skin (a small electrode). At the same time as the twitch in their hand, your child might feel the muscles of their scalp tighten. They will also hear a click. This may cause surprise and sometimes people find this uncomfortable. At the start the coil will deliver a very small stimulus. We will try and find the smallest message or stimulus that is needed to make the twitch. This is called the threshold stimulus. Some children may get a slight headache by the end of the procedure. The test will take about an hour. Your child does not need to do anything during the test and again they can choose a video to watch during the test.

**All assessments for Part A and Part B are outlined in the following table:**

<table>
<thead>
<tr>
<th>Assessment Table</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Visit 1:</strong> BASELINE ASSESSMENT</td>
</tr>
<tr>
<td>Assessments you’re your child will take approximately 3-4 hours</td>
</tr>
<tr>
<td><strong>Part A: Clinical Tests:</strong> Assessments your child will do:</td>
</tr>
<tr>
<td>• Upper-limb and lower-limb passive range of motion</td>
</tr>
<tr>
<td>• Sensory Assessments</td>
</tr>
<tr>
<td>• Grip Strength</td>
</tr>
<tr>
<td>• Assisting Hand Assessment (AHA)</td>
</tr>
<tr>
<td>• Assessment of Motor and Process Skills (AMPS)</td>
</tr>
<tr>
<td>• Melbourne Assessment of Unilateral Upper limb Function (MUUL)</td>
</tr>
<tr>
<td>• Jebsen-Taylor Test of Hand Function (JTTHF)</td>
</tr>
<tr>
<td>• Wechsler Intelligence Scale for Children – Version IV (WISC-IV)</td>
</tr>
<tr>
<td>• Executive functioning tests</td>
</tr>
<tr>
<td>• Test of Visual Perception Skills (TVPS)</td>
</tr>
</tbody>
</table>
The questionnaires for you to complete will take between 1-2 hours. They are done while your child is doing the other assessments.

**Questionnaires for you to complete**
- Canadian Occupational Performance Measure (COPM)
- Brief Rating Inventory of Executive Function (BRIEF)
- Assessment of Life Habits – modified questionnaire (LIFE-H)
- Mobility Questionnaire (Mobques47)
- Participation and Environment (PEM-CY)
- Strengths and Difficulties Questionnaire (SDQ)
- Baseline study questionnaire

**Part B: Neuroscience Tests:**
- Functional Magnetic Resonance Imaging (fMRI)
- Transcranial Magnetic Stimulation (TMS)

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**Visit 2**

**20 WEEK FOLLOW-UP ASSESSMENT**

20 weeks after the baseline assessment.

Assessments with your child will take approximately 3-4 hours

The questionnaires for you to complete will take between 1-2 hours. They are done while your child is doing the other assessments.

**Questionnaires for you to complete**
- Canadian Occupational Performance Measure (COPM)
- Brief Rating Inventory of Executive Function (BRIEF)
- Assessment of Life Habits – modified questionnaire (LIFE-H)
- Mobility Questionnaire (Mobques47)
- Participation and Environment (PEM-CY)
- Strengths and Difficulties Questionnaire (SDQ)
- Baseline study questionnaire

**Part A: Assessment and Training Clinical Tests:**
Assessments your child will do:
- Assisting Hand Assessment (AHA)
- Assessment of Motor and Process Skills (AMPS)
- Melbourne Assessment of Unilateral Upper limb Function (MUUL)
- Jebsen-Taylor Test of Hand Function (JTTHF)
- Executive functioning tests
- Test of Visual Perception Skills (TVPS)
- Functional strength testing
- Six-minute walk test
- 4 day Actigraph physical activity recording with written record

**Part B: Neurological Tests:**
- Functional Magnetic Resonance Imaging (fMRI)
- Transcranial Magnetic Stimulation (TMS)

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**Visit 3:**

**40 WEEK FOLLOW-UP**

**Part A: Clinical Tests:**
Assessments your child will do:
### ASSESSMENT

<table>
<thead>
<tr>
<th>40 weeks after the baseline assessment</th>
<th><strong>Assessments with your child will take approximately 3-4 hours</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The questionnaires for you to complete will take between 1-2 hours. They are done while your child is doing the other assessments.</td>
</tr>
</tbody>
</table>

#### Visit 4: 60 WEEK FOLLOW-UP ASSESSMENT

**WAITLIST GROUP ONLY**

<table>
<thead>
<tr>
<th>60 weeks after the baseline assessment</th>
<th><strong>Assessments with your child will take approximately 3-4 hours</strong></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>The questionnaires for you to complete will take between 1-2 hours. They are done while your child is doing the other assessments.</td>
</tr>
</tbody>
</table>

### Descriptions of the Assessment Measures

1) **Range of motion, spasticity (stiffness), sensation and strength of your child’s impaired arm and lower leg.**

2) **Assisting Hand Assessment (AHA)** – a measure of skill in using both hands together. This assessment will be videotaped then scored by an independent rater masked to the group allocation.

3) **The Assessment of Motor and Process Skills (AMPS)** – your child will be asked to complete an activity that they might complete during daily life so that it can be used to...
measure the way they use motor and thinking skills to do daily tasks. The Occupational therapist will measure the quality (by rating the effort, efficiency, safety, and independence of motor and process skill items

4) The Melbourne Assessment of Unilateral Upper limb function (MUUL) - is a videotaped measure of arm and hand skills. It looks at movement quality during tasks which will be videotaped and scored by an occupational therapist.

5) J ebsen-Taylor Test of Hand Function (JTTHF) – is a measure of speed of hand dexterity.

6) The Wechsler Intelligence Scale for Children (WISC-IV) will be used to measure intellectual functioning at baseline to see if it has an impact on your child’s results with Mitii.

7) Executive Functioning will be assessed with a selection of neuropsychological tests: (i) The Colour-Word Interference Test, Trail Making Test and the Tower Test from the Delis-Kaplan Executive Function System (DKEFS) to measure cognitive flexibility and response inhibition; and (ii) Digit Span, Coding and Symbol Search from the (WISC-IV) to measure working memory. Executive Functioning in Everyday Life will be assessed using the parent-report questionnaire the Brief Rating Inventory of Executive Function (BRIEF).

8) Test of Visual Perceptual Skills (TVPS) will be performed on 7 subtests (visuo-spatial relationships, visual discrimination, visual memory, visual sequencing memory, visual closure, visual constancy and visual figure ground).

9) Functional strength testing measures how many repetitions of sit to stand and step ups your child can do in 30 seconds.

10) Six-minute walk test (6MWT) will measure the maximum distance walked over a six minutes.

11) An Activity diary will be used to report on your child’s physical activities. The ActiGraph GT3M triaxial accelerometer will also be used and log accelerations of movement. This will be worn in the centre of your child’s back and will be worn for 4 days pre-intervention and 4 days post-intervention

12) Canadian Occupational Performance Measure (COPM): asks you and your child to identify some things they find difficult in everyday life. You will score how they are going and how satisfied you are with how they do those things. This helps to identify goals and whether or not the Mitii training has helped your child meet these goals.

13) Assessment of Life Habits (LIFE-H) is designed to habits in home, school and community as appropriate. Four categories will be tested: nutrition (mealtimes), personal care (dressing), education and recreation.

14) Mobility Questionnaire (Mobques47) is a questionnaire that measures mobility limitations based on caregiver-reported items.

15) Participation and Environment (PEM-CY) provides important information about how the environment influences participation in the home, school and community.

16) The Strengths and Difficulty Questionnaire (SDQ) will be used to measure your perceptions of prosocial and difficult behaviours in your child.

17) Neuroimaging tests: (i) Whole-brain functional MRI studies (fMRI) is a non-invasive procedure that measures the haemodynamic response (change in blood flow) related to neural activity in the brain. (ii) Transcranial Magnetic Stimulation (TMS) measures which side of the brain controls each hand.

Assessment of Motor and Process Skills (AMPS) test-retest sub-study
If your child is having assessments over a two day period, they will be asked if they are happy to participate in the AMPS test-retest sub-study. This involves completing the same two daily tasks on DAY TWO that they completed on DAY ONE. These tasks are chosen on day one collaboratively with the child and Occupational Therapist and are tasks that the child is familiar with but finds somewhat challenging. The AMPS assessment takes approximately 10-20 minutes per day. The AMPS has shown good test-retest reliability (that is, people typically achieve the same score when they complete the test again in a short time period) in adults, yet there is no evidence of the test-retest reliability in children with CP. It is important to carry out this study to ensure that the AMPS is a reliable test of daily living skills for children with CP. If your child does not want to participate in the retest component of this study, it will not affect their participation or treatment in the overall Mitii study in any way.

Mitii Exit Interviews
Children and their caregivers who are returning for an appointment after finishing their Mitii training will be invited to participate in an exit interview with a Chief Investigator on the project (who you will not have met before at your previous visit/s). These interviews can be done separately or with the child and caregiver together, and will be audio recorded to allow for analysis of the interview content. The interviews will take approximately 10 minutes each, or 20 minutes as a combined child/caregiver interview. The Chief Investigator will ask simple questions for example, (i) How did you find participating in an online program delivered at home? (ii) Did you have any challenges over the 20 weeks? (iii) How does this therapy compare to standard face-to-face therapy? Information gained from these interviews will help us as therapists to understand the benefits and challenges of delivering online therapy. If you or your child does not wish to do an interview, this will not affect your child’s participation in the overall Mitii study in any way.

Is there likely to be a benefit to my child?
All participants will receive the Mitii Program in the study. If your child logs on to the program for 30 minutes a day they will have the opportunity to access around 60 hours of an online, interactive, multimodal therapy program. Based on information from previous studies you might see improvements in their physical skills (strength and endurance), motor processing and task performance, and visual perception skills. With these improvements it might lead to more self-confidence and self-esteem. They might also be able to participate and enjoy more things at school, home and in the community.

Is there likely to be a benefit to other people in the future?
We hope that the results of our project will help other children with hemiplegia and their families in the future. If we find that this type of therapy has better and longer lasting effects on physical and cognitive skills, it may change the way we provide treatment in the future. Better outcomes for physical and cognitive training may improve these children’s ability to participate in activities at home and school.

What are the possible risks and/or side effects?
We do not think that there will be any risks or side effects from completing the Mitii program. If you or your child would like, we can give you information about making sure they have a good balance of sedentary ‘screen time’ with electric media and more ‘active’ leisure activities. (Australian Government’s National Guidelines for Physical Activity for all children)

There is no known health risks associated with the magnetic radiation in MRI scans. MRI is considered a safe procedure when performed at a centre with appropriate guidelines. However, the electromagnetic attraction for some metal objects can pose a safety risk, so it is important that metal objects are not taken into the scanner room. We will thoroughly examine your child to make sure there is no reason for them not to have the scan. You must tell us if your child has metal in their body such as a pacemaker, or metal pins/plates after surgery. The MRI could be mildly inconvenient as your child has to remain very still while in the scanner. The noise during the fMRI test can be loud but we use high-quality headphones to make sure this is comfortable. Keeping still during the fMRI is important, so we will use Velcro strapping to keep your child’s head still - this can be a little uncomfortable after 30-45 minutes of scanning. Your child will receive a practice session in a mock scanner before the real fMRI. At this time they can try lying in a mock scanner and ask any questions. The research team has safely performed over 150 functional MRIs with children with cerebral palsy.

The MRI scans taken are for research purposes. They are not intended to be used like brain scans taken for a full clinical examination. The scans cannot be used to help diagnose, treat or manage a particular condition. A specialist will look at the MRI scans for features relevant to the research project. On rare occasions, the specialist may find an unusual feature that could have a significant risk to a participant’s health. If this happens, we will contact families to talk about the findings. In the unlikely event that we find an unusual feature, it could have consequences for a participant. It may impact on their ability to work in certain professions, or get life or health insurance. However, if we do find an unusual feature, a participant may be able to get treatment that might be of benefit. We cannot guarantee that we will find any/all unusual features. Participants will be notified of these issues when they are considering being in the study.
Transcranial Magnetic Stimulation (TMS) is a safe procedure. We do not anticipate any adverse side effects. Some children may get a slight headache by the end of the procedure. There is an extremely low (0-3.6%) risk of TMS causing a seizure. It should be noted that in all the reports in which seizures have been associated with TMS, it was unclear whether this really was due to TMS or a coincidental finding in patients already having frequent seizures.

What are the possible discomforts and/or inconveniences?
You will have 3-4 visits with your child to the university to do the assessments. We will do our best to make sure that you have a lot of time to plan for these visits. The only inconvenience to you and your family will be the time of the assessments. The assessments will take approximately 5 hours in total (3-4 hours for the clinical assessments, and 1-2 hours for the neurological assessments with a break in between). You will do this with your child on three separate occasions over the 10 months of the study at UQ. Your child can do your Mitii training at home at any time that suits you and your family.

What will be done to make sure the information is confidential?
All results of assessments will be stored without your child’s name on them. A number will be used to identify them. This number will be linked to your child’s name but the linking file will be kept confidential, separate to their data and only made available to the researchers. Data collection sheets recording the assessment scores and the videotapes of the assessments and group program will be stored in a secure filing cabinet and only the researchers will have access to this information. On the video files, your child will be able to be identified and these files will be used for assessment purposes only for this study. These video files would not be used for teaching or promotional material for the project without directly seeking your permission separate to your child participating in this study. These data sheets and video CDs/files will be kept at the RCH in a locked filing cabinet or in a password-protected digital file on a secure server that is only able to be accessed by the researchers until the youngest child in the study turns 21 years of age, and then destroyed. If we give presentations or write about the results of this project, we will not use any names or identifying details.

Will I be informed of the results when the research project is finished?
If at any time you would like information about your child’s results, an appointment will be organised with one of the researchers. A newsletter will also be sent to you about the progress of the study every 6 months. At the end of the study, all families will be sent a summary of the results. The newsletter and final summary will talk about the children as a group and your child will not be identified in person.

You can decide whether or not to give permission for your child to take part in this research project. You can decide whether or not you would like to withdraw your child at any time without explanation.
You can talk to your family or other people about this study. You can ask for any information before you decide if you would like your child to participate. If you would like more information about the study or if you need to contact a study representative in an emergency, the person to contact is:

Name: Professor Roslyn Boyd Sarah James/Stephanie Ross
Role: Chief Investigator Mitii OT/Neuropsychologist
Contact telephone: +61 (7) 3365 5315 +61 (7) 3646 6423
QCPRRC Administration: +61 (7) 3646 5542

What are my rights as a participant?
- I am informed that except where stated above, no information regarding my medical history will be released. This is subject to legal requirements.
- I am informed that the results of any tests involving me will not be published so as to reveal my identity. This is subject to legal requirements.
- The detail of the procedure proposed has also been explained to me. This includes how long it will take, how often the procedure will be performed and whether any discomfort will result.
• It has also been explained that my involvement in the research may not be of any benefit to me. I understand that the purpose of this research project is to improve the quality of medical care in the future.

• I have been asked if I would like to have a family member or a friend with me while the project is explained to me.

• I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (2007).

• I understand that this research project has been approved by the Royal Children’s Hospital Ethics in Human Research Committee on behalf of the Royal Children’s Hospital Board.

• I have received a copy of this document.

Ethics Contact:
The Human Research Ethics Committee of the Royal Children’s Hospital and Health Services District has approved this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or if you wish to make a confidential complaint, please contact:
RCH&HSD Ethics Committee Coordinator
Royal Children’s Hospital and Health Services District
Level 3, RCH Foundation Building,
Royal Children’s Hospital
Herston Road
Herston QLD 4029
Tel: (07) 3636 9167 (Monday to Friday 9am-5pm)
STANDARD PARTICIPANT INFORMATION STATEMENT AND ASSENT FORM

Project Number: Royal Children’s Hospital: HREC/11/QRCH/35
University of Queensland: 2011000608

Title of Project: Mitii – “Move it to improve it”: A Randomised Trial of Novel Internet-based Multimodal Therapy for Children with Congenital Hemiplegia.

Chief Investigators: Professor Roslyn Boyd, Professor Jenny Ziviani, A/Professor Stephen Rose, Dr Robert Ware, Dr Leanne Sakzewski, A/Professor Anthony Smith, Professor Richard MacDonnell, Dr David Abbott, Dr Tracy Comans, Professor Paul Scuffam

Associate Investigators: Louise Mitchell, Sarah James, Prof Jens Bo Neilsen, Peder Esben Bilde, Dr Koa Whittingham, Melinda Lewis, Rachel Thomas, Dr Lynne McKinlay, Stephanie Ross, Naomi Westwood, Julien Savina, Lee Reid, Kelly Hentschke and Adina Piovesana.

You are invited to participate in a Research Project that is explained below.

Thank you for taking the time to read this Information Statement. This information statement and consent is 10 pages long. Please make sure you have all the pages.

For people who speak languages other than English:
If you would also like information about the research and the Consent Form in your language, please ask the person explaining this project to you.

What is an Information Statement?
These pages contain a lot of information about a research project we are inviting you to take part in. Please read this information carefully as it explains clearly and openly what is involved in participating in this project. This information is to help you to decide whether or not you would like to take part in the research.

Before you decide to take part or not, you can ask us questions you have about the project. You may want to talk to about the project with your family, friends or one of your therapists.

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and receive satisfactory answers
- consent to taking part in the project.

We will give you a copy of the information and consent to keep.

What is the Research Project about?
Hemiplegia is a type of cerebral palsy that involves just one side of the body – impacting on function of the arm and the leg. Many children who have a hemiplegia attend regular school but may have physical and cognitive (eg. thinking, memory, attention, planning) difficulties. This might mean that children with a hemiplegia find it difficult to participate in the things that they would like to do at school, home or in the community. In this study we want to see if a new form of therapy (Mitii – Move it to improve it) is effective at improving some physical, manipulation, coordination & cognitive difficulties in children with Hemiplegia. Mitii is delivered over the internet and uses a web-cam to pick up movements of your arm, leg or head which allows you to play computer games on the screen. The therapy can be completed at any time at home.
This project has two parts. Part A is the Assessment and treatment component. Part B is the neuroscience component.

In Part A we want to see if Mitii can help children with hemiplegia improve their physical and cognitive skills. We do this by comparing two groups – one who will receive the Mitii training straight away for 20 weeks and one who will continue with normal therapy and receive Mitii after 20 weeks. 98 families will join the study and you will be allocated randomly to one of two groups. The group that you are in is decided by chance – like a flip of a coin. No one is able to influence which group you will be in, however you will receive Mitii despite which group you are in.

When you are doing the Mitii training we would like you to do it at home every day for 20 weeks – this will mean you get to access up to 60 hours of therapy. The Mitii program is completed at home using the internet and a webcam – if you don’t have these things we can loan them to you. The webcam picks up the movements of green bands and you play the games by moving your arm, leg or your head. The Mitii therapists back in Brisbane (occupational therapist, physiotherapist and neuropsychologist) will be your ‘virtual trainers’. They will log on and see how you are going and make sure that the program is just right for you by making it harder or easier. If we can prove that Mitii does help children with hemiplegia it will mean that children who don’t receive a lot of therapy or who live a long way away, will be able to access it at home.

If you participate in the first part of the study (Part A Assessment and Mitii Training) we will also ask you if you want to be in the second part (Part B the Neuroscience). In this part we want to find out how your brain actually controls your hand movements and whether this might change after the training. The tests we use are:
(i) Functional Magnetic Resonance Imaging (fMRI) which shows the parts of the brain that are active when you move your hand.
(ii) Transcranial Magnetic Stimulation (TMS) which measures which side of the brain controls each hand.

Both fMRI and TMS are safe to receive as there is no radiation (unlike X rays). In our study we will involve children with a hemiplegia aged 8 to 16 years. We will do the assessments and training at the University of Queensland.

Who are the Researchers?
1. Professor Roslyn Boyd is a Paediatric Physiotherapist. She is the lead investigator of the study and will coordinate the project and supervise the staff conducting the assessments and training in the program.
2. Professor Jenny Ziviani is an Occupational Therapist at the University of Queensland who will be involved in the study design and analysis.
3. Associate Professor Stephen Rose, Dr Jens Bo Neilsen are all experienced neurologists and neuroscience researchers who are involved in the neuroscience part of the study (the brain imaging and measures of brain activity).
4. Dr Robert Ware is a biostatistician from the School of Population Health, University of Queensland who will provide expert opinion on biostatistical analyses.
5. Sarah James (Occupational Therapist), Stephanie Ross (Psychologist), Louise Mitchell (Physiotherapist), Kelly Hentschke (Occupational Therapist) and Adina Piovesana (Psychologist) are therapists conducting research. They will do assessments and run the online treatment programs.
6. Dr Leanne Sakzewski is an Occupational Therapist who will assist with the research process and conduct some of the analysis.
7. Peder Esben Bilde is part of the team in Denmark who devised the Mitii program and will provide expert assistance with the program implementation and technical support.
8. Dr Koa Whittingham is a psychologist who will provide guidance and assistance with measures of Executive Functioning.
9. A/Professor Anthony Smith is the Deputy Director of the Centre for Online Health. He will provide technical assistance for the web-based program delivery.
10. Melinda Lewis is an Occupational Therapist experienced in working with children with CP and is the study clinical co-ordinator.
11. Rachel Thomas (physiotherapist) and Dr Lynne McKinlay work within the Department of Paediatric Rehabilitation. They provide clinical support to the Mitii project.

**Why am I being asked to be in this research project?**
You are
- between 8 and 16 years old and
- have hemiplegia
- do not have uncontrolled seizures

**What are my alternatives to participating in this project?**
You do not have to take part in this project if you do not want to. If you decide not to participate you will still have access to your normal care and treatment in the Department of Paediatric Rehabilitation at the Royal Children’s Hospital, Brisbane.

You might decide to take part in Part A (the individual assessment and training) but not do Part B (the fMRI and TMS). If you decide you don’t want to do Part B it won’t impact on you doing the Mitii assessment and training (part A).

**What do I need to do to be in this research project?**
Before you are accepted into the study we will call your parent/guardian to do a screening checklist. This will help us work out if this study is one that you can participate in. This is also a chance for us to answer any questions or concerns that you or your parent/guardian might have.

**Part A: Assessment Treatment Component**
Once you have consented to participate and have been accepted into the study, you and your parent/guardian will need to come to the University of Queensland at St Lucia for 3-4 assessment sessions. You will have the opportunity to complete the Mitii training either immediately or after a 20 week wait. You will be randomly allocated to either the IMMEDIATE or the WAITLIST group using the toss of a coin.

All children will be assessed at baseline and then at 20 weeks (straight after the first group finishes training) and 40 weeks after this baseline assessment. If you are in the WAITLIST group you will come back for one further assessment at 60 weeks.

**What is the Mitii training – “Move it to improve it”?**
- A web-based, intensive and individualized therapy program;
- Completed at home using a webcam and computer;
- Involves a series of interactive, game-like activities that will take approximately 30 minutes to complete each day.
- Uses green band technology to track the movements of the hand/head bands you wear.
- We ask you to use the Mitii program each day, over 20 weeks (total of 60 hours training).
- Is Multimodal – uses your physical and thinking skills at the same time.
- Can be made more challenging each week

You and your family will discuss your progress with the research staff on a weekly basis by email, computer skype or phone contact. As this is a new type of treatment we are very interested to find out what you think about it.

All assessments will be completed by an Occupational Therapist, Physiotherapist and/or Neuropsychologist. The following flow chart outlines the assessments you and your parents would do:

**BASELINE ASSESSMENT:**
All children come to UQ for an assessment looking at:
- hand and arm skills
- physical skills and activity levels
- attention, memory and other thinking skills.
- we will also give you a device called an accelerometer – which is similar to wearing a watch on a belt around your waist. This will measure your physical activity and you will wear it for 4 days

IMMEDIATE GROUP comes for two days so they can do the Mitii training
WAITLIST GROUP comes for one day of assessment.
We will support travel and overnight accommodation if you need it.

IMMEDIATE GROUP (48 children)
Starts 20 weeks of Mitii training.
If you train every day you will get access to up to 60 hours of therapy.

WAITLIST GROUP (48 children)
Continue with usual therapy for 20 weeks

ASSESSMENT 2 at 20 weeks
All children come back to UQ for an assessment
We will do a lot of the same assessments that were done with you at the first assessment to see if there have been any changes.

WAITLIST GROUP comes for two days so they can do the Mitii training
IMMEDIATE GROUP comes for one day of assessment.
We will support travel and overnight accommodation if you need it.

IMMEDIATE GROUP
Continue with usual therapy for 20 weeks

WAITLIST GROUP
Starts 20 weeks of Mitii training.
If you train every day you will get access to up to 60 hours of therapy.

ASSESSMENT 3 at 40 weeks
All children come back to UQ for an assessment
We will do a lot of the same assessments that were done with you at the first assessment to see if there have been any changes.
BOTH GROUPS come for one day of assessment. We will support travel if you need it.

ASSESSMENT 4 at 60 weeks
WAITLIST GROUP ONLY will come back to UQ for an assessment for one day

Part B: Neuroimaging Component
The Neuroimaging component of the assessment will take 1½ - 2 hours and will occur at the same visits as the functional assessments.

Whole-brain functional MRI studies (fMRI)
MRI stands for Magnetic Resonance Imaging. A MRI scanner is a machine that uses electromagnetic energy (from strong magnets) to take pictures of the inside of the body. MRI is safe and is not the same as ionising radiation, for example, in X-rays.
Functional MRI (or fMRI) measures the change in blood flow that is related to a change in brain activity. This change in brain blood flow is directly related to the hand movements that you will perform while you are in the MRI scanner.

We will ask you to lie on a firm bed which moves inside the MRI scanner tunnel. The scanner will take pictures of the brain. It is very important that you keep very still during the scanning so that the pictures are not blurry. We will make sure that you are in a comfortable position so that you can keep still. To help keep your head still we will place some padding around your head. We will also use some Velcro straps and padding to help you keep your body still. The MRI scanner can be very noisy and we can give you special earphones to reduce the noise and so that you can hear the radiographer explaining to you what will happen next. A member of the research team can stay with you at all times and your parent/guardian will be just outside. You can talk to the team at any time through a special microphone in the headpiece. For some of
the scan you will be able to watch a favourite movie or DVD of your choice. The test should take approximately 1-1.5 hours to complete, but only 30-45 minutes of this time will be spent inside the MRI scanner.

There are no proven long-term risks related to MRI scans as used in this research project. MRI is considered to be safe when performed at a centre with appropriate procedures. However, the magnetic attraction for some metal objects can pose a safety risk, so it is important that metal objects are not taken into the scanner room.

We will thoroughly examine you to make sure there is no reason for you not to have the scan. You must tell us if you have metal, electronic, magnetic or mechanical implants, devices or objects in your body, such as a pacemaker, brain clip, ventricular shunt or metal pins. You must advise if you have had any previous procedures involving surgery or a general anesthetic, so that any devices or objects inside your body can be checked that they are safe for use with the 3T MRI scanner. The magnet used in the research MRI scanner is very strong (called 3 Tesla or 3T), and is twice as strong as the magnet normally used in hospitals. So even if you have had a clinical MRI previously, it is important that we check all past procedures again to ensure safety for you in this higher strength MRI scanner.

**Transcranial Magnetic Stimulation (TMS):** is a non-invasive method of measuring how the brain works, which will involve you sitting very still in a chair. The researcher will place a special metal coil above your head. The coil will send a message to your brain – this is called a stimulus. This will cause a slight twitch in the muscle in your hand. The twitch in your muscle will be measured by a small metal disc on your skin (a small electrode). At the same time as the twitch in your hand, you might feel the muscles of your scalp tighten. You will also hear a click. This may cause surprise and sometimes people find this uncomfortable. At the start the coil will deliver a very small stimulus. We will try and find the smallest message or stimulus that is needed to make the twitch. This is called the threshold stimulus. Some children may get a slight headache by the end of the procedure. The test will take about an hour. You do not need to do anything during the test and again you can choose a video to watch during the test.

All assessments for Part A and Part B are outlined in the following table:

<table>
<thead>
<tr>
<th>Assessment Table</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Visit 1: BASELINE ASSESSMENT</strong></td>
</tr>
<tr>
<td>Assessments with you will take approximately 3-4 hours</td>
</tr>
<tr>
<td>The questionnaires for your parents to complete will take between 1-2 hours. They are done while you</td>
</tr>
<tr>
<td><strong>Part A: Clinical Tests:</strong> Assessments you will do:</td>
</tr>
<tr>
<td>- Upper-limb and lower-limb passive range of motion</td>
</tr>
<tr>
<td>- Sensory Assessments</td>
</tr>
<tr>
<td>- Grip Strength</td>
</tr>
<tr>
<td>- Assisting Hand Assessment (AHA)</td>
</tr>
<tr>
<td>- Assessment of Motor and Process Skills (AMPS)</td>
</tr>
<tr>
<td>- Melbourne Assessment of Unilateral Upper limb Function (MUUL)</td>
</tr>
<tr>
<td>- Jebsen-Taylor Test of Hand Function (JTTHF)</td>
</tr>
<tr>
<td>- Wechsler Intelligence Scale for Children – Version IV (WISC-IV)</td>
</tr>
<tr>
<td>- Executive functioning tests</td>
</tr>
<tr>
<td>- Test of Visual Perception Skills (TVPS)</td>
</tr>
<tr>
<td>- Functional strength testing</td>
</tr>
<tr>
<td>- Six-minute walk test</td>
</tr>
<tr>
<td>- 4 day Actigraph physical activity recording with written record</td>
</tr>
<tr>
<td><strong>Questionnaires for your parent/guardian to complete</strong></td>
</tr>
<tr>
<td>- Canadian Occupational Performance Measure (COPM)</td>
</tr>
<tr>
<td>- Brief Rating Inventory of Executive Function (BRIEF)</td>
</tr>
<tr>
<td>- Assessment of Life Habits – modified questionnaire (LIFE-H)</td>
</tr>
</tbody>
</table>
| are doing the other assessments. | Mobility Questionnaire (Mobques47)  
| Participation and Environment (PEM-CY)  
| Strengths and Difficulties Questionnaire (SDQ)  
| Baseline study questionnaire |

**Part B: Neuroscience Tests:**  
- Functional Magnetic Resonance Imaging (fMRI)  
- Transcranial Magnetic Stimulation (TMS)

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**Visit 2**  
**20 WEEK FOLLOW-UP ASSESSMENT**  
20 weeks after the baseline assessment.  
Assessments with you will take approximately 3-4 hours

The questionnaires for your parents to complete will take between 1-2 hours. They are done while you are doing the other assessments.

| WAITLIST MITII GROUP | is waitlisted for 20 weeks and continues usual care at home. They then return for reassessment and training in the Mitii system  
Families allocated to the Immediate Mitii group will receive:  
- Training in the Mitii system  
- Training in the activity log and accelerometer measurements  
They will then receive all equipment required to return home and complete the 20 weeks intervention. |

| Part A: Assessment and Training Clinical Tests: | Assessments you will do:  
- Assisting Hand Assessment (AHA)  
- Assessment of Motor and Process Skills (AMPS)  
- Melbourne Assessment of Unilateral Upper limb Function (MUUL)  
- Jebsen-Taylor Test of Hand Function (JTTHF)  
- Executive functioning tests  
- Test of Visual Perception Skills (TVPS)  
- Functional strength testing  
- Six-minute walk test  
- 4 day Actigraph physical activity recording with written record |

**Questionnaires for your parent/guardian to complete**  
- Canadian Occupational Performance Measure (COPM)  
- Brief Rating Inventory of Executive Function (BRIEF)  
- Assessment of Life Habits – modified questionnaire (LIFE-H)  
- Mobility Questionnaire (Mobques47)  
- Participation and Environment (PEM-CY)  
- Strengths and Difficulties Questionnaire (SDQ)  
- Study Questionnaire

| Part B: Neurological Tests: | Functional Magnetic Resonance Imaging (fMRI)  
| Transcranial Magnetic Stimulation (TMS) |

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**Visit 3:**  
**40 WEEK FOLLOW-UP ASSESSMENT**  
40 weeks after the baseline assessment  
Assessments with you will take approximately 3-4 hours

| Part A: Clinical Tests: | Assessments you will do:  
- Assisting Hand Assessment (AHA)  
- Assessment of Motor and Process Skills (AMPS)  
- Melbourne Assessment of Unilateral Upper limb Function  
- Jebsen-Taylor Test of Hand Function (JTTHF)  
- Executive functioning tests  
- Test of Visual Perception Skills (TVPS)  
- Functional strength testing |
The questionnaires for your parents to complete will take between 1-2 hours. They are done while you are doing the other assessments.

Questionnaires for your parent/guardian to complete
- Canadian Occupational Performance Measure (COPM)
- Brief Rating Inventory of Executive Function (BRIEF)
- Assessment of Life Habits – modified questionnaire (LIFE-H)
- Mobility Questionnaire (Mobques47)
- Participation and Environment (PEM-CY)
- Strengths and Difficulties Questionnaire (SDQ)
- Study questionnaire

Part B: Neurological Tests:
- Functional Magnetic Resonance Imaging (fMRI)

Visit 4:
60 WEEK FOLLOW-UP ASSESSMENT
WAITLIST GROUP ONLY

60 weeks after the baseline assessment

Assessments with you will take approximately 3-4 hours

The questionnaires for your parents to complete will take between 1-2 hours. They are done while you are doing the other assessments.

Questionnaires for your parent/guardian to complete
- Canadian Occupational Performance Measure (COPM)
- Brief Rating Inventory of Executive Function (BRIEF)
- Assessment of Life Habits – modified questionnaire (LIFE-H)
- Mobility Questionnaire (Mobques47)
- Participation and Environment (PEM-CY)
- Strengths and Difficulties Questionnaire (SDQ)
- Study questionnaire

Part A: Clinical Tests:
Assessments your will do:
- Assisting Hand Assessment (AHA)
- Assessment of Motor and Process Skills (AMPS)
- Melbourne Assessment of Unilateral Upper limb Function
- Jebsen-Taylor Test of Hand Function (JTTHF)
- Executive functioning tests
- Test of Visual Perception Skills (TVPS)
- Functional strength testing
- Six-minute walk test
- 4 day Actigraph physical activity recording with written record

Descriptions of the Assessment Measures
1) Range of motion, spasticity (stiffness), sensation and strength of your impaired arm and lower leg.
2) **Assisting Hand Assessment (AHA)** – a measure of your skill in using both hands together. This assessment will be videotaped then scored by an independent rater masked to the group allocation.
3) **The Assessment of Motor and Process Skills (AMPS)** – you will be asked to complete an activity that you might complete during your daily life so that it can be used to measure the way you use your motor and thinking skills to do daily tasks. The Occupational therapist will measure the quality (by rating the effort, efficiency, safety, and independence of motor and process skill items
4) **The Melbourne Assessment of Unilateral Upper limb function (MUUL)** - is a videotaped measure of your arm and hand skills. It looks at movement quality during tasks which will be videotaped and scored by an occupational therapist.
5) **Jebsen-Taylor Test of Hand Function (JTTHF)** – is a measure of speed of hand dexterity.
6) **The Wechsler Intelligence Scale for Children (WISC-IV)** will be used to measure intellectual functioning at baseline to see if it has an impact on your results with Mitii.
7) **Executive Functioning** will be assessed with a selection of neuropsychological tests: (i) The Colour-Word Interference Test, Trail Making Test and the Tower Test from the Delis-Kaplan Executive Function System (DKEFS) to measure cognitive flexibility and response inhibition; and (ii) Digit Span, Coding and Symbol Search from the (WISC-IV) to measure working memory. Executive Functioning in Everyday Life will be assessed using the parent-report questionnaire the **Brief Rating Inventory of Executive Function (BRIEF)**.

8) **Test of Visual Perceptual Skills (TVPS)** will be performed on 7 subtests (visuo-spatial relationships, visual discrimination, visual memory, visual sequencing memory, visual closure, visual constancy and visual figure ground).

9) **Functional strength testing** measures how many repetitions of sit to stand and step ups you can do in 30 seconds.

10) **Six-minute walk test (6MWT)** will measure the maximum distance walked over a six minutes.

11) An **Activity diary** will be used to report on your physical activities. The **ActiGraph GT3M triaxial accelerometer will also be used** and log accelerations of movement. This will be worn in the centre of your back and will be worn for 4 days pre-intervention and 4 days post-intervention.

12) **Canadian Occupational Performance Measure (COPM):** asks you to identify some things you find difficult in everyday life. You will score how you are going and how satisfied you are with how you do those things. This helps to identify goals and whether or not the MiiTi training has helped you meet these goals.

13) **Assessment of Life Habits (LIFE-H)** is designed to habits in home, school and community as appropriate. Four categories will be tested: nutrition (mealtimes), personal care (dressing), education and recreation. Your parent/guardian will complete this.

14) **Mobility Questionnaire (Mobques47)** is a questionnaire that measures mobility limitations based on caregiver-reported items.

15) **Participation and Environment (PEM-CY)** provides important information about how the environment influences participation in the home, school and community.

16) **The Strengths and Difficulty Questionnaire (SDQ)** will be used to measure parent’s perceptions of prosocial and difficult behaviours in their child.

17) **Neuroimaging tests:**
   (i) **Whole-brain functional MRI studies (fMRI)** is a non-invasive procedure that measures the haemodynamic response (change in blood flow) related to neural activity in the brain.
   (ii) **Transcranial Magnetic Stimulation (TMS)** measures which side of the brain controls each hand.

**Assessment of Motor and Process Skills (AMPS) test-retest sub-study**

If you are coming for your assessments over two days, you will be asked if they are happy to participate in the AMPS test-retest sub-study. You would do the same two daily tasks on DAY TWO that they completed on DAY ONE. The tasks are activities like putting on your shoes or making a jam sandwich. This activity would take about 10-20 minutes each day. If you do not want to do this part of this study, it will not affect your participation or treatment in the overall MiiTi study in any way.

**MiiTi Exit Interviews**

After finishing the MiiTi program, you and your parent/guardian may be invited to participate in an interview to talk about the MiiTi program. These interviews can be done by yourself or together with your parent/guardian. The interviews will be audio recorded and take about 10-20 minutes. You will be asked some simple questions for example, (i) What did you like about MiiTi? (ii) What didn’t you like about MiiTi? (iii) How does this therapy compare to going to see a therapist? If you don’t want to do an interview, this will not affect your child’s participation in the overall MiiTi study at all.

**Is there likely to be a benefit to me?**

All participants will receive the MiiTi Program in the study. If you log on to the program for 30 minutes a day you will have the opportunity to access around 60 hours of an online, interactive, multimodal therapy program. Based on information from previous studies you might see improvements in your physical skills (strength and endurance), motor processing and task performance, and visual perception skills. With these improvements it might lead to more self-
confidence and self-esteem. You might also be able to participate and enjoy more things at school, home and in the community.

**Is there likely to be a benefit to other people in the future?**
We hope that the results of our project will help other children with hemiplegia and their families in the future. If we find that this type of therapy has better and longer lasting effects on physical and cognitive skills, it may change the way we provide treatment in the future. Better outcomes for physical and cognitive training may improve these children’s ability to participate in activities at home and school.

**What are the possible risks and/or side effects?**
We do not think that there will be any risks or side effects from completing the Mitii program. If you or your parent/guardian would like, we can give you information about making sure you have a good balance of sedentary ‘screen time’ with electric media and more ‘active’ leisure activities. (Australian Government’s National Guidelines for Physical Activity for all children)

There is no known health risks associated with the magnetic radiation in MRI scans. MRI is considered a safe procedure when performed at a centre with appropriate guidelines. However, the electromagnetic attraction for some metal objects can pose a safety risk, so it is important that metal objects are not taken into the scanner room. We will thoroughly examine you to make sure there is no reason for you not to have the scan. You must tell us if you have metal in your body such as a pacemaker, or metal pins/plates after surgery. The MRI could be mildly inconvenient as you have to remain very still while in the scanner. The noise during fMRI test can be loud but we use high-quality headphones to make sure this is comfortable. Keeping still during the fMRI is important, so we will use Velcro strapping to keep your head still - this can be a little uncomfortable after 30-45 minutes of scanning. You will receive a practice session in a mock scanner before the real fMRI. At this time you can try lying in a mock scanner and ask any questions. The research team has safely performed over 150 functional MRIs with children with cerebral palsy.

The MRI scans taken are for research purposes. They are not intended to be used like brain scans taken for a full clinical examination. The scans cannot be used to help diagnose, treat or manage a particular condition. A specialist will look at the MRI scans for features relevant to the research project. On rare occasions, the specialist may find an unusual feature that could have a significant risk to a participant’s health. If this happens, we will contact families to talk about the findings. In the unlikely event that we find an unusual feature, it could have consequences for a participant. It may impact on their ability to work in certain professions, or get life or health insurance. However, if we do find an unusual feature, a participant may be able to get treatment that might be of benefit. We cannot guarantee that we will find any/all unusual features. Participants will be notified of these issues when they are considering being in the study.

Transcranial Magnetic Stimulation (TMS) is a safe procedure. We do not anticipate any adverse side effects. Some children may get a slight headache by the end of the procedure. There is an extremely low (0-3.6%) risk of TMS causing a seizure. It should be noted that in all the reports in which seizures have been associated with TMS, it was unclear whether this really was due to TMS or a coincidental finding in patients already having frequent seizures.

**What are the possible discomforts and/or inconveniences?**
You will have 3-4 visits to the university to do the assessments. We will do our best to make sure that you have a lot of time to plan for these visits. The only inconvenience to you and your family will be the time of the assessments. The assessments will take approximately 5 hours in total (3-4 hours for the clinical assessments, and 1-2 hours for the neurological assessments with a break in between). You will do this on three separate occasions over the 10 months of the study at UQ. You can do your Mitii training at home at any time that suits you and your family.

**What will be done to make sure the information is confidential?**
All results of assessments will be stored without your name on them. A number will be used to identify them. This number will be linked to your name but the linking file will be kept confidential, separate to your data and only made available to the researchers. Data collection sheets
recording the assessment scores and the videotapes of the assessments and group program will be stored in a secure filing cabinet and only the researchers will have access to this information. On the video files, you will be able to be identified and these files will be used for assessment purposes only for this study. These video files would not be used for teaching or promotional material for the project without directly seeking your permission separate to your participating in this study. These data sheets and video CDs/files will be kept at the RCH in a locked filing cabinet or in a password-protected digital file on a secure server that is only able to be accessed by the researchers until the youngest child in the study turns 21 years of age, and then destroyed. If we give presentations or write about the results of this project, we will not use any names or identifying details.

Will I be informed of the results when the research project is finished?
If at any time you would like information about your results, an appointment will be organised with one of the researchers. A newsletter will also be sent to you about the progress of the study every 6 months. At the end of the study, all families will be sent a summary of the results. The newsletter and final summary will talk about the children as a group and you will not be identified in person.

You can decide whether or not to give permission to take part in this research project. You can decide whether or not you would like to withdraw at any time without explanation.
You can talk to your family or other people about this study. You can ask for any information before you decide if you would like to participate. If you would like more information about the study or if you need to contact a study representative in an emergency, the person to contact is:

Name: Professor Roslyn Boyd Sarah James/Stephanie Ross
Role: Chief Investigator Mitii OT/Neuropsychologist
Contact telephone: +61 (7) 3365 5315 +61 (7) 3646 6423
QCPRRRC Administration: +61 (7) 3646 5542

What are my rights as a participant?
- I am informed that except where stated above, no information regarding my medical history will be released. This is subject to legal requirements.
- I am informed that the results of any tests involving me will not be published so as to reveal my identity. This is subject to legal requirements.
- The detail of the procedure proposed has also been explained to me. This includes how long it will take, how often the procedure will be performed and whether any discomfort will result.
- It has also been explained that my involvement in the research may not be of any benefit to me. I understand that the purpose of this research project is to improve the quality of medical care in the future.
- I have been asked if I would like to have a family member or a friend with me while the project is explained to me.
- I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (2007).
- I understand that this research project has been approved by the Royal Children’s Hospital Ethics in Human Research Committee on behalf of the Royal Children’s Hospital Board.
- I have received a copy of this document.

Ethics Contact:
The Human Research Ethics Committee of the Royal Children’s Hospital and Health Services District has approved this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or if you wish to make a confidential complaint, please contact:
RCH&HSD Ethics Committee Coordinator
Royal Children’s Hospital and Health Services District
Level 3, RCH Foundation Building,
Royal Children’s Hospital, Herston Road
Herston, QLD 4029
Tel: (07) 3636 9167 (Monday to Friday 9am-5pm)
10.3 Recruitment information

10.3.1 Mitii™ Recruitment flyer

10.3.2 Mitii™ parent/guardian recruitment letter

10.3.3 Clinician referral letter
Mitii™ Australia
“Move it to improve it”

We want to evaluate the effectiveness of Mitii, a new home-based therapy program delivered over the internet.

A novel internet-based rehabilitation program for children with congenital hemiplegia

An Occupational Therapist, Physiotherapist and Psychologist act as ‘virtual trainers’ making changes to each child’s individualised Mitii program. We want to see whether using the Mitii program at home, daily for 20 weeks is effective at improving upper-limb function, performance in everyday tasks, participation in home, school and leisure activities, strength and fitness, and higher order thinking tasks known as ‘executive function’. **ALL children who participate will receive 20 weeks access to an individualised Mitii therapy program for free.**

Can you help us?

- We need children aged **8 to 18 years** with mild to moderate Cerebral Palsy impacting on one side of the body
- It is important that children do not have an uncontrolled seizure disorder
- Children should have sufficient cognitive understanding and cooperation to use the computer program
- You would need to commit to 3 visits to Brisbane over 10 months, and 20 weeks of 30 minutes daily Mitii training at home (24hrs/day access)

For more information please call us on: (07) 3636 6423 or (07) 3636 5361 or contact:

<table>
<thead>
<tr>
<th>Name</th>
<th>Email</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof Roslyn Boyd</td>
<td><a href="mailto:r.boyd@uq.edu.au">r.boyd@uq.edu.au</a></td>
<td>(07) 3365 5315</td>
</tr>
<tr>
<td>Prof Jenny Ziviani</td>
<td><a href="mailto:j.ziviani@uq.edu.au">j.ziviani@uq.edu.au</a></td>
<td>(07) 3365 3008</td>
</tr>
<tr>
<td>Louise Mitchell</td>
<td><a href="mailto:louise.mitchell@uq.edu.au">louise.mitchell@uq.edu.au</a></td>
<td></td>
</tr>
<tr>
<td>Sarah James</td>
<td><a href="mailto:s.james2@uq.edu.au">s.james2@uq.edu.au</a></td>
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</table>

Level 7, Block 6, RBWH, Herston QLD 4029 Australia
Ph (07) 3636 5542 • Fax (07) 3636 5538 • Email qcpprc@uq.edu.au

Queensland Government • Medicine • Queensland Cerebral Palsy & Rehabilitation Research Centre
Mitii (Move it to Improve It) Australia:
A Novel Internet-based Therapy Program for Children with Congenital Hemiplegia

The team at QCPRRC are very excited to announce that Mitii, a new and exciting home based and internet delivered therapy program will soon be launched in Australia!

Mitii is a multi-modal training program comprising upper-limb, cognitive and physical activity training. However, Mitii makes this fun by delivering therapy using an interactive computer game, which is controlled by movement of the hands and body. All that is required is a home computer connected to the internet, a web-camera (these can be provided if needed) and some green bands which are worn on the hand or head. A Physiotherapist, Occupational Therapist and a Psychologist act as virtual trainers, remotely accessing the Mitii program regularly to set up and progress an individualised series of games.

Mitii was designed in Denmark by researchers at the Helene Elsass Centre and the University of Copenhagen, in collaboration with worldwide expert in neuroplasticity, Professor Michael Merzenich. Since the development of this program, many children in Denmark have completed their home therapy programs using Mitii with great success.

We are currently recruiting children and adolescents aged between 8 and 18 years with mild to moderate congenital hemiplegia Cerebral Palsy (one side of their body impaired) to participate in this exciting study. As part of this, all participants will receive specialist assessments from the Mitii therapists (including neuropsychological tests of executive function), and an intensive daily therapy program of 30 minutes each day for 20 weeks that will be individualised and tailored to each child’s needs. Children will be in regular contact with their virtual trainers (using Skype and email) to keep them on track and ensure the Mitii program is at the right level.
Children will be randomly assigned to one of two Mitii groups (like the toss of a coin):

1. **Immediate intervention group** – children attend two days in Brisbane for assessment and learning the Mitii program and then complete daily Mitii training for 20 weeks in their own home;  
   OR
2. **Waitlist intervention group** – children attend one day in Brisbane for assessments and return home for 20 weeks, before returning to Brisbane for 2 days of assessments and learning the Mitii program and then complete daily Mitii training for 20 weeks in their own home.

Children and adolescents who receive Botulinum Toxin A (BTXA) injections through the Cerebral Palsy Health Service will be still be able to participate in the study, receiving either Mitii group allocation after their Botulinum Toxin A injections and follow up care. Children and adolescents who would benefit from intensive training and not requiring Botulinum Toxin A injections are also welcome to participate in the study.

All participants would be required to attend 3 assessment visits in Brisbane at the start of the study, and then at 20 weeks (5 months) and 40 weeks (10 months). Depending on group allocation, the 2nd day of Mitii training would be at the start of the study (Immediate intervention group), or at 20 weeks (Waitlist intervention group). Children and adolescents would be expected to participate in 20 weeks of 30 minutes of daily Mitii training; however this would be conducted within your own home and at your own convenience as you would have access to the Mitii program 24hrs a day.

Please find attached a flyer providing you with more information regarding this study. We will be giving you a call in the next few weeks to discuss any questions you may have about the Mitii study.

If you would like further information before this time or wish to discuss your child’s potential participation in this study, please contact Louise, Sarah, Laura or Ros on the email/phone numbers.

Louise Mitchell: louise.mitchell@uq.edu.au or 3646 6423
Sarah James: s.james2@uq.edu.au or 3646 5361
Laura Pareezer: Laura_Pareezer@health.qld.gov.au or 3646 5061
Professor Roslyn Boyd: r.boyd@uq.edu.au or (07) 3345 5315

Thank you,
The Mitii team (Louise Mitchell, Sarah James, Laura Pareezer, Jenny Ziviani, Ros Boyd)
Referral to:
Mitii (Move it to Improve It) Australia:
A Novel Internet-based Therapy Program for
Children with Congenital Hemiplegia

Name of Referrer: ____________________________________________________________

Profession: ___________________________________________________________________

Address: ____________________________________________________________________

Phone No: __________________________ Fax No: ____________________________

Email: ______________________________________________________________________

Child’s Name: _____________________________________________________________

DOB: ________________________ Gender: Male / Female

Parent Name & Relationship: _________________________________________________

Address: ____________________________________________________________________

Phone No: H) ______________________ M) ______________________________________

Hospital Record Number (if applicable): ______________________________________

1. Parent of the child is aware of this referral? Yes
2. Are the family aware of Cerebral Palsy diagnosis? Yes / No
3. Has the child recently had Botulinum Toxin Type-A Injections, serial casting, or surgery of
any kinds? If yes, when and what? Yes / No
   If yes, where and when? _____________________________________________________
4. Child has already had an MRI? Yes / No
   If yes, where and when? _____________________________________________________

Please note that the parent must be aware of this referral under privacy guidelines.
The study flyer can also be provided to parents to enable them to self refer to the study.

Signed: ____________________________ Date: __________________

SEND TO: Mitii Study, Attention: Louise Mitchell
Queensland Cerebral Palsy & Rehabilitation Research Centre
Level 7, Block 6, Royal Brisbane and Women’s Hospital,
Herston QLD 4029 Australia

Or email louise.mitchell@uq.edu.au
Or call on 07 3646 6423
• QCPRRRC Phone: 07 3636 5542 • Facsimile 07 3636 5538 • Email: qcpprc@uq.edu.au.au
10.4 Study Questionnaires

10.4.1 Parent/guardian baseline questionnaire

10.4.2 Participant baseline questionnaire
Introduction

Welcome to the questionnaires for the Mitii study.

You will have been sent a copy of the Information statement. These questionnaires are outlined in detail in this statement. Should you have any questions or concerns, about the overall study or any particular questions, please feel free to contact the Mitii team on 3636 6423.

It will take approximately 40 minutes to complete these questionnaires.

The questionnaires are broken into 4 sections:
* Some questions about your child and your family
* Your child's function and mobility
* Your child's behaviour
* Your child's quality of life.

Each questionnaire will tell us something important about how Mitii could be used to better support parents of children with Cerebral Palsy and help children with Cerebral Palsy.

It is possible to complete these questionnaires in several sittings. Every time you finish a section and click the >> button at the bottom of the screen the information that you have entered so far will be saved. The next time you return to the website you will be prompted for your Study ID again and the program will remember which section you were up to. It is possible to go back to questionnaires that you have already completed using the << button at the bottom of the screen.

By clicking the >> button below, you consent to taking part in this study. By clicking the >> button below, you consent to the off-site storage of all de-identified data. All the information provided in this survey is de-identified, meaning that your responses will be anonymous. The information and results of these surveys is stored off-site on a secure server in the United States of America, in accordance with the Privacy Act and within the University and Queensland Health Ethics Guidelines. Should you have any questions about this please feel free to call the Mitii team on 3636 6423.

Should you NOT consent to participate in the Mitii study, close the browser. However, please note each time you press the >> button to advance the survey, your responses will be saved. If you do NOT consent to participate in the Mitii study, please contact the team on 3636 6423. Thank you.

If you are confused by some of the questions or have any queries, you can contact the study coordinator, Louise Mitchell on phone 3636 6423 or email louise.mitchell@uq.edu.au with any questions.

Information about your child and your family

We will start our questionnaires by asking about your child and your family

Please enter your ID number (sent in the email) eg. 01

Your child's date of birth as day/month/year (eg. 01/01/2001)

Your child's current age in years

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<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
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</table>

Please read the following and mark only one box beside the description that best represents your child's movement abilities. My child...
I: Can walk on their own without using a walking aid, and can go up and down stairs without needing to hold the handrail AND walks whenever they want to go (including uneven surfaces, slopes or in crowds) AND can run and jump although their speed, balance and coordination may be slightly limited

II: Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs often finds it difficult to walk on uneven surfaces, slopes or in crowds

III: Can stand on their own and only walks using a walking aid (such as a walker rollator, crutches, canes etc) AND finds it difficult to climb stairs or walk on uneven surfaces AND may use a wheelchair when traveling for long distances or in crowds

IV: Can sit on their own but does not stand or walk without significant support AND therefore relies mostly on wheelchair at home, school and in the community AND may achieve self-mobility using a powered wheelchair

V: Has difficulty sitting on their own and controlling their head and body posture in most positions AND has difficulty achieving any voluntary control of movement AND needs a specially-adapted supportive chair to sit comfortably AND has to be lifted or hoisted by another person to move

Now please think about your child's ability to handle objects in important daily activities, for example how they pick up toys or objects during play and leisure, how they handle their cutlery during eating and or put their clothes on during dressing tasks.

In which situation is the child independent and to what extent do they need support and adaptation?

Please click which best describes your child's ability to handle objects in important daily activities.

I. Handles objects easily and successfully. At most might have some problems with tasks requiring speed and accuracy. However, these do not restrict the child being able to do these independently.

II. Handles most objects but with reduced quality and/or speed of achievement. Certain activities may be avoided or be achieved with some difficulty. The child may find alternative ways to complete these tasks but this does not normally restrict them being able to carry these out independently.

III. Handles objects with difficulty; needs help from another person to prepare and/or modify the activity. The performance is slow and achieved with limited quality and quantity. Activities are performed independently if they have been set up or adapted.

IV. Handles a limited selection of easily managed objects in adapted situations. Performs part of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

V. Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.
Your child’s sex

- Male
- Female

What hand does your child normally write with?

- Right
- Left

Has your child been diagnosed with any of the following? (please tick all relevant boxes)

- Intellectual Disability
- Learning Difficulties
- Autism Spectrum Disorder (includes Apsergers)
- ADHD
- Vision impairment
- Hearing impairment
- Epilepsy
- Other

What type of school does your child attend?

- Public primary
- Public secondary
- Special school
- Special education classroom at a mainstream school
- Private primary
- Private secondary
- Home schooled
- Other

What grade is your child currently in?

1  2  3  4  5  6  7  8  9  10  11  12

Does your child receive any other assistance for schooling (eg. tutoring)?

Yes, please describe....  No
The next questions about your family. Their are many factors that can impact on a child's participation in home, school and community activities. Some of these relate to families. These answers will help us understand some of these factors. Your responses will in no way be identified.

What is your relationship to this child?
- Mother (biological or adoptive)
- Father (biological or adoptive)
- Step mother
- Step father
- Legal Guardian

What is your current age in years?

Does your child have any siblings.
Yes, please indicate the number of OTHER siblings living in the household

Is English the main language spoken at home?
- Yes
- No

What is your postcode?

What is your current marital status?
- Married
- Separated
- Defacto
- Never married/defacto
- Divorced
- Widow/er

These questions relate to household education and income level, factors thought to influence many health outcomes.

Which best describes the household in which your child is presently living?
- Original family (both biological or adoptive parents present)
○ Step-family (two parents, one being a step-parent)
○ Sole parent family
○ Other

What is your highest level of education?
○ Less than year 10
○ Year 10/11
○ Year 12
○ Trade/apprenticeship
○ TAFE/college certificate
○ University degree

Which best describes your current employment?
○ Full time
○ Part time
○ Full time parent/home duties
○ Unemployed (seeking work)

These questions relate to household education and income level, factors thought to influence many health outcomes.

If you do not have a partner please leave blank.

What is your partner’s highest level of education?
○ Less than year 10
○ Year 10/11
○ Year 12
○ Trade/apprenticeship
○ TAFE/college certificate
○ University degree

Which best describes your partner’s current employment?
If you do not have a partner please leave blank.
○ Full time
○ Part time
○ Full time parent/home duties
○ Unemployed (seeking work)
Which best describes your family's combined annual income?

- <25,000
- 25,000-50,000
- 50,000-75,000
- 75,000+

The next questions relate to the usual therapy services that your child receives.

Have you sought professional assistance from any of the following (please tick all that apply), and then please indicate then how often where indicated.

| Does your child receive services from... | Functional and mobility
<table>
<thead>
<tr>
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<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>How often does your child receive these?</td>
</tr>
<tr>
<td></td>
<td>More than once a week</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>Yes</td>
</tr>
<tr>
<td>Occupational therapist</td>
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<tr>
<td>Psychologist</td>
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<tr>
<td>Orthotist/Prothetist</td>
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<tr>
<td>Pediatrician</td>
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<tr>
<td>Other, please specify</td>
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</tbody>
</table>

**Function and mobility**

This questionnaire is about the daily activities of your child

Please click the box to indicate how much difficulty your child had with each activity during the past week.

Please cross “impossible without help” if your child requires assistance from others with the activity (e.g. parent/carer).

We would like to know how your child normally performs the activity, possibly with the use of aids, e.g. a walker, splints or holding onto the wall.

**Part 1: Indoor activities**

Which of the aids does your child use indoors?

(More than one answer possible)

- splints
- elbow crutches
- four-legged walking stick
- walker
In the last week, how difficult was it for your child to:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not difficult at all</th>
<th>Slightly difficult</th>
<th>Somewhat difficult</th>
<th>Very difficult</th>
<th>Impossible without help</th>
</tr>
</thead>
<tbody>
<tr>
<td>sit down on a bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>turn over in bed</td>
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<td></td>
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<tr>
<td>get out of bed</td>
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<tr>
<td>walk indoors at home</td>
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<tr>
<td>stand still at home</td>
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<tr>
<td>sit down on a chair</td>
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<tr>
<td>sit on a chair</td>
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</tr>
<tr>
<td>get up from a chair</td>
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</tr>
<tr>
<td>walk to and from the toilet</td>
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<tr>
<td>sit down on the toilet</td>
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<tr>
<td>get up from the toilet</td>
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<tr>
<td>walk bare foot</td>
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<tr>
<td>stand still bare foot</td>
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<tr>
<td>bend down to the floor</td>
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<tr>
<td>sit down on the floor</td>
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<tr>
<td>get up off the floor</td>
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<tr>
<td>sit on a stool</td>
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<tr>
<td>get into the shower</td>
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<tr>
<td>stand while taking a shower</td>
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<tr>
<td>get out of the shower</td>
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<tr>
<td>walk up stairs</td>
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<tr>
<td>walk up stairs with something in his/her hands</td>
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<tr>
<td>walk down stairs</td>
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<tr>
<td>walk down stairs with something in his/her hands</td>
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Part 2: Outdoor activities
Which of the aids does your child use outdoors?  
(More than one answer possible)

- splints
- elbow crutches
- four-legged walking stick
- walker
- tricycle
- bicycle (with/without training wheels)
- manual wheelchair
- electric wheelchair
- no aids used
- other...

In the last week, how difficult was it for your child to....

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not difficult at all</th>
<th>Slightly difficult</th>
<th>Somewhat difficult</th>
<th>Very difficult</th>
<th>Impossible without help</th>
</tr>
</thead>
<tbody>
<tr>
<td>walk outdoors</td>
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<tr>
<td>stand still outdoors</td>
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<tr>
<td>walk to and from the car</td>
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<tr>
<td>get into the car</td>
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<tr>
<td>get out of the car</td>
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<tr>
<td>walk on a flat surface</td>
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<tr>
<td>walk on an uneven surface</td>
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<tr>
<td>walk for a quarter on an hour outdoors</td>
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<tr>
<td>walk for half an hour outdoors</td>
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<tr>
<td>walk for an hours outdoors</td>
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<tr>
<td>walk on asphalt (road surface)</td>
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<tr>
<td>walk on grass</td>
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<td>walk on sand</td>
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<td>walk over obstacles such as curbs</td>
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<td>get on a bicycle</td>
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<tr>
<td>ride a bicycle</td>
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<tr>
<td>get off a bicycle</td>
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<tr>
<td>play outdoors</td>
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<tr>
<td>kick a ball</td>
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<tr>
<td>run</td>
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<tr>
<td>run on asphalt</td>
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</tbody>
</table>
run on grass 
run on sand

Thank you for filling in this portion of the questionnaire, you are doing well! Click >> to continue.

Child behaviour

Next, we need to ask about your child's behaviour

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

- No
- Yes, minor difficulties
- Yes, definite difficulties
- Yes, severe difficulties

How long have these difficulties been present?

- Less than a month
- 1-5 months
- 6-12 months
- Over a year

Do the difficulties upset or distress your child?

- Not at all
- Only a little
- Quite a lot
- A great deal

Do the difficulties interfere with your child's everyday life in the following areas?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Only a little</th>
<th>Quite a lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home life</td>
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<tr>
<td>Friendships</td>
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<tr>
<td>Classroom learning</td>
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<tr>
<td>Leisure activities</td>
<td></td>
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</tbody>
</table>

Do the difficulties put a burden on you or the family as a whole?

- Not at all
- Only a little
- Quite a lot
- A great deal

Below are a series of phrases that describe children's behaviour. Please (1) tick the number describing how often the behavior currently occurs with your child (where 1 is "never" and 7 is "always") and (2) tick either "yes" or "no" to indicate whether the behaviour is currently a problem.

Is this a problem
For each item please mark the box for not true, somewhat true or certainly true. Please answer all items as best you can, even if you are not absolutely certain. Give your answers on the basis of your child's behaviour over the last six months.

<table>
<thead>
<tr>
<th>How often does this occur with your child?</th>
<th>1 Never</th>
<th>2 Seldom</th>
<th>3 Seldom</th>
<th>4 Sometimes</th>
<th>5 Often</th>
<th>6 Often</th>
<th>7 Always</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dawdles in getting dressed</td>
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<td>2. Dawdles or lingers at mealtine</td>
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<td>3. Has poor table manners</td>
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<td>4. Refuses to eat food presented</td>
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<td>5. Refuses to do chores when asked</td>
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<td>6. Slow in getting ready for bed</td>
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<td>7. Refuses to go to bed on time</td>
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<td>8. Does not obey house rules on own</td>
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<td>9. Refuses to obey until threatened with punishment</td>
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<td>10. Acts defiant when told to do something</td>
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<td>11. Argues with parents about rules</td>
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<td>12. Gets angry when doesn't get own way</td>
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<td>13. Has temper tantrums</td>
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<td>14. Answers back to adults</td>
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<td>15. Whines</td>
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<td>16. Cries easily</td>
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<td>17. Yells or screams</td>
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<td>18. Hits parents</td>
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</tbody>
</table>

For each item please mark the box for not true, somewhat true or certainly true. Please answer all items as best you can, even if you are not absolutely certain. Give your answers on the basis of your child's behaviour over the last six months.

<table>
<thead>
<tr>
<th></th>
<th>Not true</th>
<th>Somewhat true</th>
<th>Certainly true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Considerate of other people's feelings</td>
<td></td>
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<tr>
<td>2. Restless, overactive, cannot stay still for long</td>
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<tr>
<td>3. Often complains of headaches, stomach-aches or sickness</td>
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<td>4. Shares readily with other children (treats, toys, pencils etc.)</td>
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<tr>
<td>5. Often has temper tantrums or hot</td>
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<td></td>
<td>Not true</td>
<td>Somewhat true</td>
<td>Certainly true</td>
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<td>6. Rather solitary, tends to play alone</td>
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<td>7. Generally obedient, usually does what adults request</td>
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<td>8. Many worries, often seems worried</td>
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<td>9. Helpful if someone is hurt, upset or feeling ill</td>
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<tr>
<td>10. Constantly fidgeting or squirming</td>
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<tr>
<td>11. Has at least one good friend</td>
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<tr>
<td>12. Often fights with other children or bullies them</td>
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<tr>
<td>13. Often unhappy, down-heated or tearful</td>
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<tr>
<td>14. Generally liked by other children</td>
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<tr>
<td>15. Easily distracted, concentration wanders</td>
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<td>16. Nervous or clingy in new situations, easily loses confidence</td>
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<tr>
<td>17. Kind to younger children</td>
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<td>18. Often lies or cheats</td>
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<tr>
<td>19. Picked on or bullied by other children</td>
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<tr>
<td>20. Often volunteers to help others (parents, teachers, other children)</td>
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<tr>
<td>21. Thinks things out before acting</td>
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<tr>
<td>22. Steals from home, school or elsewhere</td>
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<tr>
<td>23. Gets on better with adults than with other children</td>
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<td>24. Many fears, easily scared</td>
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<tr>
<td>25. Sees tasks through to the end, good attention span</td>
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</tbody>
</table>
Thank you for completing this section, you are nearly there - only one more survey to complete.

**Your child's quality of life**

We want to ask about how you think your child FEELS about certain aspects of their life such as family, friends, health and school. Each question begins with "How do you think your child FEELS about...?"

It is important for you to report how you believe your child feels. Sometimes it is difficult to know how your child is feeling. Please try and answer as best as you can.

For each question we want you to check the box with the best number that shows how you think your child FEELS. You can circle any number from 1 (Very unhappy) to 9 (Very happy).

This questionnaire is measuring how your child feels, not what they can do.

How do you think your child feels about....

**Friends and family**

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<tbody>
<tr>
<td>the way they get along with people, generally?</td>
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<td>the way they get along with you?</td>
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<td>the way they get along with brothers and sisters?</td>
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<td>the way they get along with other children at school?</td>
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<td>the way they get along with other children outside of school?</td>
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<td>the way they get along with adults?</td>
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<td>the way they get along with their teachers and/or carers?</td>
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<td>their ability to play on their own?</td>
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<td>their ability to play with friends?</td>
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<td>going out on trips with the family?</td>
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<tr>
<td>How they are accepted by...</td>
<td>5. Neither Happy nor Unhappy</td>
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<td>their family?</td>
<td>1. Very Happy</td>
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<tr>
<td>how they are accepted by other children at preschool or school?</td>
<td>2. Unhappy</td>
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<tr>
<td>(If they attend more than one school, please think about the school where they spend most of their time)</td>
<td>3. Unhappy</td>
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<tr>
<td>how they are accepted by other children outside of school?</td>
<td>4. Unhappy</td>
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<td>how they are accepted by adults?</td>
<td>6. Happy</td>
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<td>how they are accepted by people in general?</td>
<td>7. Happy</td>
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<td>being able to do the things they want to do?</td>
<td>9. Very Happy</td>
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<table>
<thead>
<tr>
<th>Participation</th>
<th>5. Neither Happy nor Unhappy</th>
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<tbody>
<tr>
<td>their ability to participate at school?</td>
<td>1. Very Happy</td>
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<tr>
<td>(If your child attends more than one school, please think about the school where they spend most of their time)</td>
<td>2. Unhappy</td>
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<tr>
<td>their ability to participate in recreational activities?</td>
<td>3. Unhappy</td>
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<tr>
<td>their ability to participate in sporting activities?</td>
<td>4. Unhappy</td>
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<tr>
<td>(This question is asking how your child feels about their ability to participate in sport, not whether they can participate)</td>
<td>6. Happy</td>
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<tr>
<td>their ability to participate in social events outside of school?</td>
<td>7. Happy</td>
</tr>
<tr>
<td>their ability to participate in your community?</td>
<td>9. Very Happy</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Communication</th>
<th>5. Neither Happy nor Unhappy</th>
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<tbody>
<tr>
<td>1. Very Happy</td>
<td>7. Happy</td>
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<tr>
<td>9. Very Happy</td>
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How do you think your child feels about....

Health

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<td>their physical health?</td>
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<td>the way they get around?</td>
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<td>the way they sleep?</td>
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<td>the way they look?</td>
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<td>their ability to keep up academically with their peers?</td>
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<td>their ability to keep up physically with their peers?</td>
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<td>their life in general?</td>
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<td>their future?</td>
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<td>their opportunities in life?</td>
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The next 3 questions are about how you think your child feels about using parts of their body, not whether or not they can use part of their body.

How do you think you child feels about....

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The next 3 questions are asking about how you think your child feels about their ability to complete daily activities, not whether your child can complete the activities.

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<td>their ability to dress themselves?</td>
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<td>their ability to eat or drink independently?</td>
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<td>their ability to use the toilet by themselves?</td>
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<tr>
<th>How do you think your child feels about....</th>
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<tr>
<td>Special equipment</td>
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<tr>
<td>the special equipment they have at home? (eg. special seating, standing frames, wheelchairs, walkers)</td>
</tr>
<tr>
<td>the special equipment they have at their school? (eg. special seating, standing frames, wheelchairs, walkers)</td>
</tr>
<tr>
<td>the special equipment that is available in the community? (eg. special seating, standing frames, wheelchairs, walkers)</td>
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</tbody>
</table>

Pain and bother

The next few questions ask about things that may bother your child

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<tr>
<th>Pain and bother</th>
<th>1. Not at all bothered</th>
<th>2.</th>
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<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9. Very bothered</th>
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</thead>
<tbody>
<tr>
<td>Are they bothered by hospital visits?</td>
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<td>Are they bothered</td>
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https://uqpsych.qualtrics.com/ControlPanel/PopUp.php?PopType=SurveyPrintPreview... 12/04/2012
when they miss school for health reasons?
Are they bothered by being handled by other people?

Does your child worry about who will take care of them in the future?

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
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</table>

Now some final questions about your child:

Is your child concerned about having cerebral palsy?

1. Not at all concerned
2. 3. 4. 5. 6. 7. 8. 9. Very concerned

How much pain do your child have?

1. No pain at all
2. 3. 4. 5. 6. 7. 8. 9. A lot of pain

How does your child feel about the amount of pain they have?

1. Not upset at all
2. 3. 4. 5. 6. 7. 8. 9. Very upset

How much discomfort does your child experience?

1. No discomfort at all
2. 3. 4. 5. 6. 7. 8. 9. A lot of discomfort

How happy is your child?

1. Very Unhappy
2. 3. Unhappy
4. 5. Neither Happy nor Unhappy
6. 7. Happy
8. 9. Very Happy

Now we will ask some final questions about how YOU feel.
How do YOU feel about....

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<tbody>
<tr>
<td>your child's access to treatment?</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<td>your child's access to therapy?</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<td>(for example, physiotherapy, occupational therapy, speech therapy)</td>
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<tr>
<td>your child's access to specialized medical or surgical care?</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>your ability to get advice from a pediatrician?</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>your child's access to community services and facilities? (eg. kindergarten childcare, after-school programs, holiday programs, community based groups such as cubs or brownies)</td>
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<tr>
<td>your child's access to extra help with learning at preschool or school?</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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How do you feel about your access to respite care?

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<tbody>
<tr>
<td>I have never tried to access respite care</td>
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If you receive respite care, how do you feel about....

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<tr>
<td>the amount of respite care you receive?</td>
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<tr>
<td>how easy it is to get respite?</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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How do you feel about....
Parents health

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<td>your physical health?</td>
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<td>your work situation?</td>
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<td>your family’s financial situation?</td>
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<td>how happy are you?</td>
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</table>

How confident are you that you can report how your child feels?

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<tr>
<th></th>
<th>1. Not at all confident</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
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<th>7.</th>
<th>8.</th>
<th>9. Very Confident</th>
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</table>

Thank you so much for your participation in this study. The results from this survey and the assessments we will conduct at your visit will help us to see whether the Mitii training program can help children with Cerebral Palsy.

Should you have any concerns or questions, either about this survey or the Mitii training, please feel free to contact the Mitii study team on 3636 6423.

Thank you once again for your help in this important research study.
We look forward to seeing you soon for your Mitii assessment and training!
Introduction

Welcome to the questionnaires for the Mitii study.

You will have been sent a copy of the Information statement. These questionnaires are outlined in detail in this statement. Should you have any questions or concerns, about the overall study or any particular questionnaires, please feel free to contact the Mitii team on 3636 6423.

It will take approximately 15 minutes to complete these questionnaires.

The questionnaires are broken into 2 sections:
* Some questions about you
* Your quality of life.

Each questionnaire will tell us something important about how Mitii could be used to better support parents of children with Cerebral Palsy and help children with Cerebral Palsy.

It is possible to complete these questionnaires in several sittings. Every time you finish a section and click the >> button at the bottom of the screen the information that you have entered so far will be saved. The next time you return to the website you will be prompted for your Study ID again and the program will remember which section you were up to.

It is possible to go back to questionnaires that you have already completed using the << button at the bottom of the screen.

By clicking the >> button below, you consent to taking part in this study. By clicking the >> button below, you consent to the off-site storage of all de-identified data. All the information provided in this survey is de-identified, meaning that your responses will be anonymous. The information and results of these surveys is stored off-site on a secure server in the United States of America, in accordance with the Privacy Act and within the University and Queensland Health Ethics Guidelines. Should you have any questions about this please feel free to call the Mitii team on 3636 6423.

Should you NOT consent to participate in the Mitii study, close the browser. However, please note each time you press the >> button to advance the survey, your responses will be saved. If you do NOT consent to participate in the Mitii study, please contact the team on 3636 6423. Thank you.

If you are confused by some of the questions or have any queries, you can contact the study coordinator, Louise Mitchell on phone 3636 6423 or email louise.mitchell@uq.edu.au with any questions.

Some questions about you

We will start with asking a couple of questions about you

Please enter your study ID (we have provided this in your email) eg. 01

Please enter you date of birth (as in day/month/year) eg. 01/01/2001
Your age at the moment

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Your gender

- Boy
- Girl

Child quality of life

We want to ask some questions about your life such as your family, your friends, your health and your school. Each question begins with “How do you FEEL about...?”

For each question we want you to click the box with the best number that shows how you FEEL. You can click any response from Very unhappy to Very happy.

This questionnaire is measuring how you feel, not what you can do.

How do you feel about....

Friends and family

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<td>the way you get along with people, generally?</td>
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<td>the way you get along with the person who looks after you?</td>
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<td>the way you get along with your brothers and sisters? (Leave blank if you do not have brothers or sister)</td>
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<td>the way you get along with other children at school? (If you attend more than one school, please think about the school where you spend most of your time).</td>
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<td>the way you get along with other children outside of school?</td>
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<td>the way you get along with adults?</td>
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<td>the way you get along with your teachers and/or carers?</td>
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**How do you feel about....**

**Participation**

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<td>your ability to participate at school?</td>
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<tr>
<td>(If you attend more than one school, please think about the school where you spend most of your time)</td>
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<td>your ability to participate in recreational activities?</td>
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<td>your ability to participate in sporting activities?</td>
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<td>(This question is asking how you feel about your ability to participate in sport, not whether you can participate)</td>
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<td>your ability to participate in social events outside of school?</td>
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<td>your ability to participate in your community?</td>
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**How do you feel about....**

**Communication**

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<td>the way you communicate with people you know well? (using any means of communication)</td>
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the way you communicate with people you don't know well? (using any means of communication)

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<td>the way people communicate with you?</td>
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How do you feel about....

Health

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<td>your physical health?</td>
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<td>the way you get around?</td>
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<td>the way you sleep?</td>
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<td>the way you look?</td>
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<td>your ability to keep up academically with your peers?</td>
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<td>your ability to keep up physically with your peers?</td>
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<td>your life in general?</td>
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<td>yourself?</td>
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<td>your future?</td>
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<td>your opportunities in life?</td>
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The next 3 questions are about how you feel about using parts of your body, not whether or not you can use part of your body.

How do you feel about....

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<td>the way you use your arms?</td>
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<td>the way you use your legs?</td>
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<td>the way you use your hands?</td>
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The next 3 questions are asking about how you feel about your ability to complete daily activities, not whether you can complete the activities.
### How do you feel about....

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<tbody>
<tr>
<td>your ability to dress yourself?</td>
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<td>your ability to eat or drink independently?</td>
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<td>○</td>
</tr>
<tr>
<td>your ability to use the toilet by yourself?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tbody>
</table>

### How do you feel about.....

#### Special equipment

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>the special equipment you have at home? (eg. special seating, standing frames, wheelchairs, walkers)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>the special equipment you have at your school? (eg. special seating, standing frames, wheelchairs, walkers)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>the special equipment that is available in the community? (eg. special seating, standing frames, wheelchairs, walkers)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tbody>
</table>

### Pain and bother

#### The next few questions ask about things that may bother you

<table>
<thead>
<tr>
<th></th>
<th>1. Not at all bothered</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9. Very bothered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you bothered by hospital visits?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Are you bothered when you miss school for health reasons?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Are you bothered by being handled by other people?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

### Do you worry about who will take care of you in the future?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Now some final questions about you:

### Are you concerned about having cerebral palsy?

<table>
<thead>
<tr>
<th>1. Not at all concerned</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9. Very concerned</th>
</tr>
</thead>
</table>

### How much pain do you have?

<table>
<thead>
<tr>
<th>1. No pain at all</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9. A lot of pain</th>
</tr>
</thead>
</table>

### How do you feel about the amount of pain you have?

<table>
<thead>
<tr>
<th>1. Not upset at all</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9. Very upset</th>
</tr>
</thead>
</table>

### How much discomfort do you experience?

<table>
<thead>
<tr>
<th>1. No discomfort at all</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9. A lot of discomfort</th>
</tr>
</thead>
</table>

### How happy are you?

|------------------|----|------------|----|------------------------------|----|----------|----|-------------|

### Did your parents help you complete the questionnaire?

<table>
<thead>
<tr>
<th>No</th>
<th>Yes, a little bit</th>
<th>Yes, quite a bit</th>
<th>Yes, a lot</th>
</tr>
</thead>
</table>

Thank you for helping us with our questions. Well done!

We look forward to seeing you soon for your Mitii assessments and training!
If you have any problems or questions about this survey or anything about Mitii, please talk to a parent or adult, or feel free to call the Mitii study team (Louise and Sarah) on 3636 6423 or email on louise.mitchell@uq.edu.au
10.5 Clinical Measures

10.5.1 Classification and sensory measures
10.5.2 Assessment of Motor and Process Skills
10.5.3 Jebsen-Taylor Test of Hand Function
10.5.4 Assisting Hand Assessment
10.5.5 Melbourne Assessment of Unilateral Upper Limb Function
10.5.6 Canadian Occupational Performance Measure
10.5.7 Test of Visual Perceptual Skills – 3rd ed. (non-motor)
### DEMOGRAPHIC INFORMATION

<table>
<thead>
<tr>
<th>Name</th>
<th>Date of Birth</th>
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<tbody>
<tr>
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</table>

<table>
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<th>Date of Birth</th>
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<tr>
<td>Female</td>
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<table>
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<th>Date of Birth</th>
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<td>Right</td>
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<table>
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<th>Date of Birth</th>
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<table>
<thead>
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<th>Timepoint collected</th>
<th>Date of Birth</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

### CLINICAL CLASSIFICATIONS

#### GMFCS
- I: Walks Without Limitations
- II: Walks with Limitations
- III: Walks Using a Hand-Held Mobility Device
- IV: Self-Mobility with Limitations; May Use Powered Mobility
- V: Transported in a Manual Wheelchair

#### MACS
- Type I: Complete extension of the fingers with the wrist in the neutral position or with less than 20 degrees of flexion.
- Type IIa: Active extension of the wrist with the fingers flexed.
- Type IIb: No active extension of the wrist even with the fingers flexed.
- Type III: No active extension of the fingers even with maximal wrist flexion.

#### ZANCOLLI
- Type I: Complete extension of the fingers with the wrist in the neutral position or with less than 20 degrees of flexion.
- Type IIa: Active extension of the wrist with the fingers flexed.
- Type IIb: No active extension of the wrist even with the fingers flexed.
- Type III: No active extension of the fingers even with maximal wrist flexion.

#### HOUSE
- 0: Does not use
- 1: Poor passive assist
- 2: Fair passive assist
- 3: Good passive assist
- 4: Poor active assist
- 5: Fair active assist
- 6: Good active assist
- 7: Spontaneous use, partial
- 8: Spontaneous use, full

### CLINICAL MEASURES

<table>
<thead>
<tr>
<th>Melbourne Assessment (Total)</th>
<th>Jebson Taylor Hand Function Test (Total)</th>
<th>Assisting Hand Assessment (Raw)</th>
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</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

### SENSORY MEASURES

<table>
<thead>
<tr>
<th>Stereognosis score (1-9)</th>
<th>2-Point discrimination mm</th>
<th>Texture Tactile Perception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Left</td>
<td>Right</td>
<td>Left</td>
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<tr>
<td>Left</td>
<td>Right</td>
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### MIRROR MOVEMENTS

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<tr>
<td>Index</td>
<td>Pron/Sup</td>
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<tr>
<td></td>
<td>Index</td>
</tr>
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### Grip Strength

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# Musculoskeletal Measures

## Upper Limb Musculoskeletal

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<tr>
<th>Muscle group</th>
<th>LEFT</th>
<th>RIGHT</th>
<th>SPASTICITY</th>
</tr>
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<tbody>
<tr>
<td>Shoulder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexion</td>
<td>R1</td>
<td>R2</td>
<td>MAS</td>
</tr>
<tr>
<td>Abduction</td>
<td></td>
<td></td>
<td>ASAS</td>
</tr>
<tr>
<td>Extension</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elbow</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extension</td>
<td>R1</td>
<td>R2</td>
<td>MAS</td>
</tr>
<tr>
<td>Flexion</td>
<td></td>
<td></td>
<td>ASAS</td>
</tr>
<tr>
<td>Supination</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wrist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ext with fingers straight</td>
<td>R1</td>
<td>R2</td>
<td>MAS</td>
</tr>
<tr>
<td>Ext with fingers bent</td>
<td></td>
<td></td>
<td>ASAS</td>
</tr>
<tr>
<td>Thumb</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radial abduction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palmar abduction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fingers</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>MCP Extension</td>
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</tbody>
</table>

## Lower Limb Musculoskeletal

<table>
<thead>
<tr>
<th>Muscle group</th>
<th>LEFT</th>
<th>RIGHT</th>
<th>SPASTICITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hip</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexion/Extension</td>
<td>R1</td>
<td>R2</td>
<td>MAS</td>
</tr>
<tr>
<td>Abduction – Hip 0</td>
<td></td>
<td></td>
<td>ASAS</td>
</tr>
<tr>
<td>Abduction – Hip 90</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rotation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knee</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexion/Extension</td>
<td>R1</td>
<td>R2</td>
<td>MAS</td>
</tr>
<tr>
<td>Popliteal Angle</td>
<td></td>
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<td>ASAS</td>
</tr>
<tr>
<td>Ankle</td>
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<tr>
<td>Dorsiflexion – Kn 0</td>
<td>R1</td>
<td>R2</td>
<td>MAS</td>
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<tr>
<td>Dorsiflexion – Kn 90</td>
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<td>ASAS</td>
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## Sensory Assessments

<table>
<thead>
<tr>
<th>Assessment</th>
<th>LEFT</th>
<th>RIGHT</th>
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</thead>
<tbody>
<tr>
<td>Two Point Discriminator (mm)</td>
<td>Moving, Palmar side distal phalanx. Distance between points in mm, 7/10 trials</td>
<td></td>
</tr>
<tr>
<td>Stereognosis (score out of 9)</td>
<td>Spoon, key, peg, pen/pencil, safety pin/paperclip, coin, button.</td>
<td></td>
</tr>
<tr>
<td>Texture Tactile Perception (3 trials each)</td>
<td>AsTEX perpex board, Rough to smooth</td>
<td></td>
</tr>
<tr>
<td>Mirror Movements</td>
<td>Rapid tapping index on DIP of same hand</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alternating pronation and supination of forearm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Repetitive alternating touching thumb to fingertip thumb to 2nd, 3rd, 4th, 5th.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TOTAL (0- 12)</td>
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AMPS SCORE FORM

**Occupational Therapist:**

**Client:**

**Client ID:** ___________ **Age:**

**Gender:** Male ______ Female ______

**Major Diagnosis:**

**Secondary Diagnosis:**

**Date of Evaluation:**

**Task Observation Number:** 1 __ 2 __ 3 __ 4 __

**Task Number:**

**Task:**

**RATE THE OVERALL QUALITY OF THE PERSON’S PERFORMANCE OF THIS TASK:**

<table>
<thead>
<tr>
<th></th>
<th>No Problem</th>
<th>Inordinate</th>
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<tbody>
<tr>
<td><strong>Increased Effort</strong></td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td><strong>Decreased Efficiency</strong></td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td><strong>Decreased Safety</strong></td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td><strong>Assistance Provided</strong></td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>

**RATE THE PERSON’S OVERALL ABILITY TO LIVE IN THE COMMUNITY.** (Consider everything you know about the person):

- The person can/could live independently
- The person needs/shall have minimal assistance/supervision
- The person needs/shall have moderate to maximal assistance

**ITEM RAW SCORES**

**COMPETENT = 4** **QUESTIONABLE = 3** **INEFFECTIVE = 2** **DEFICIT = 1**

**BODY POSITION**

<table>
<thead>
<tr>
<th></th>
<th>4 3 2 1</th>
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<tbody>
<tr>
<td>Stabilizes</td>
<td></td>
</tr>
<tr>
<td>Aligns</td>
<td></td>
</tr>
<tr>
<td>Positions</td>
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</table>

**OBTAINING AND HOLDING OBJECTS**

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Reaches</td>
<td></td>
</tr>
<tr>
<td>Bends</td>
<td></td>
</tr>
<tr>
<td>Grips</td>
<td></td>
</tr>
<tr>
<td>Manipulates</td>
<td></td>
</tr>
<tr>
<td>Coordinates</td>
<td></td>
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**MOVING SELF AND OBJECTS**

<table>
<thead>
<tr>
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<th>4 3 2 1</th>
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<tbody>
<tr>
<td>Moves</td>
<td></td>
</tr>
<tr>
<td>Lifts</td>
<td></td>
</tr>
<tr>
<td>Walks</td>
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<tr>
<td>Transports</td>
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<tr>
<td>Calibrates</td>
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<td>Flows</td>
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**SUSTAINING PERFORMANCE**

<table>
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<td>Paces</td>
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<tr>
<td>Attends</td>
<td></td>
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<td>Heeds</td>
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**APPLYING KNOWLEDGE**

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<tr>
<td>Chooses</td>
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<tr>
<td>Uses</td>
<td></td>
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<tr>
<td>Handles</td>
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**TEMPORAL ORGANIZATION**

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<tr>
<td>Initiates</td>
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<tr>
<td>Continues</td>
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<tr>
<td>Sequences</td>
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<td>Terminates</td>
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**ORGANIZING SPACE AND OBJECTS**

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<tr>
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<tbody>
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<td>Gathers</td>
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<td>Organizes</td>
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<td>Restores</td>
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<td>Navigates</td>
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**ADAPTING PERFORMANCE**

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<td>Notices/Responds</td>
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<tr>
<td>Adjusts</td>
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</tr>
<tr>
<td>Accommodates</td>
<td></td>
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<tr>
<td>Benefits</td>
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This Score Form may be downloaded from www.ampsintl.com or photocopied for the purpose of creating additional copies.
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<th>Item</th>
<th>Time (seconds)</th>
<th>Comments</th>
</tr>
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<tbody>
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<td>LEFT</td>
<td>RIGHT</td>
</tr>
<tr>
<td>1. Card turning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Small object placement</td>
<td></td>
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<tr>
<td>3. Simulated eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Stacking plastic discs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Grasping, transporting and releasing empty cans</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Grasping, transporting and releasing heavy cans</td>
<td></td>
<td></td>
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<tr>
<td>General Usage items</td>
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<tr>
<td>-----------------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>Approaches objects</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Initiates use</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Chooses AH when closer to objects</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Arm use items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stabilizes by weight or support</td>
</tr>
<tr>
<td>Reaches</td>
</tr>
<tr>
<td>Moves upper arm</td>
</tr>
<tr>
<td>Moves forearm</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Grasp-release items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grasps</td>
</tr>
<tr>
<td>Holds</td>
</tr>
<tr>
<td>Stabilizes by grip</td>
</tr>
<tr>
<td>Readjusts grip</td>
</tr>
<tr>
<td>Varies type of grasp</td>
</tr>
<tr>
<td>Releases</td>
</tr>
<tr>
<td>Puts down</td>
</tr>
</tbody>
</table>
## Fine motor adjustment

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moves fingers</td>
<td></td>
</tr>
<tr>
<td>Calibrates</td>
<td></td>
</tr>
<tr>
<td>Manipulates</td>
<td></td>
</tr>
</tbody>
</table>

## Coordination

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordinates</td>
<td></td>
</tr>
<tr>
<td>Orients objects</td>
<td></td>
</tr>
</tbody>
</table>

## Pace items

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proceeds</td>
<td></td>
</tr>
<tr>
<td>Changes strategies</td>
<td></td>
</tr>
<tr>
<td>Flow in task performance</td>
<td></td>
</tr>
<tr>
<td>Item</td>
<td>Activity</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>Item 1</td>
<td>Reach forwards</td>
</tr>
</tbody>
</table>
Item 9  Manipulation

9.1 Finger dexterity  □ 0  □ 1  □ 2  □ 3  □ 4
9.2 Fluency  □ 0  □ 1  □ 2  □ 3

Item 10  Pointing

10.1 Red square  □ 0  □ 1  □ 2  □ 3  □ 4
10.2 Green square  □ 0  □ 1  □ 2  □ 3  □ 4
10.3 Yellow square  □ 0  □ 1  □ 2  □ 3  □ 4
10.4 Blue square  □ 0  □ 1  □ 2  □ 3  □ 4

Item 11  Reach to brush from forehead to back of neck

11.1 Range of movement  □ 0  □ 1  □ 2  □ 3  □ 4
11.2 Fluency  □ 0  □ 1  □ 2  □ 3

Item 12  Palm to bottom

12.1 Range of movement  □ 0  □ 1  □ 2  □ 3
12.2 Fluency  □ 0  □ 1  □ 2  □ 3

Item 13  Pronation/supination  □ 0  □ 1  □ 2  □ 3  □ 4

Item 14  Hand to hand transfer  □ 0  □ 1  □ 2  □ 3  □ 4

Item 15  Reach to opposite shoulder

15.1 Range of movement  □ 0  □ 1  □ 2  □ 3
15.2 Target accuracy  □ 0  □ 1  □ 2  □ 3
15.3 Fluency  □ 0  □ 1  □ 2  □ 3

Item 16  Hand to mouth down

16.1 Range of movement  □ 0  □ 1  □ 2  □ 3
16.2 Target accuracy  □ 0  □ 1  □ 2  □ 3
16.3 Fluency  □ 0  □ 1  □ 2  □ 3
16.4 Speed  □ 0  □ 1  □ 2

Total raw Score: □ □ □ □ □

% Score: □ □ □ □ □
Canadian Occupational Performance Measure

Child's name: ____________________________

Date: ______/_____/______  Male  Female

Therapist: ____________________________

Timing: Baseline 1

Respondent: Child  Mother  Father  Other

STEP 1A: Self-care

STEP 1B: Productivity

STEP 1C: Leisure

STEP 2: Importance

Subject ID: 27609 245

14/06/2007

Page 1 of 2
STEPS 3 & 4: SCORING - INITIAL ASSESSMENT and REASSESSMENT

1. Performance: [ ]  Satisfaction: [ ]

2. Performance: [ ]  Satisfaction: [ ]

3. Performance: [ ]  Satisfaction: [ ]

4. Performance: [ ]  Satisfaction: [ ]

5. Performance: [ ]  Satisfaction: [ ]

Performance score: [ ] . [ ]

Satisfaction score: [ ] . [ ]
Name:  
Gender:  
Grade:  
School:  
Examiner:  

Reason for Testing:  

Date of Test  
- year  
- month  
- day  

Date of Birth  
- year  
- month  
- day  

Chronological Age  
- year  
- month  
- day*  

*Do not round months up by one if days exceed 15

<table>
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<tr>
<th>Subtests</th>
<th>Raw Score</th>
<th>Scaled Score</th>
<th>Percentile Rank</th>
<th>Index Scores</th>
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<tbody>
<tr>
<td>1. Visual Discrimination (DIS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Visual Memory (MEM)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Spatial Relations (SPA)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Form Constancy (CON)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sequential Memory (SEQ)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Figure Ground (FGR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Visual Closure (CLO)</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Sum of Scaled Scores  
Standard Scores  
Percentile Rank  

<table>
<thead>
<tr>
<th>Overall</th>
<th>Basic Processes</th>
<th>Sequencing</th>
<th>Complex Processes</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>%ile Rank</th>
<th>Scaled Score</th>
<th>SUBTEST SCALED SCORES</th>
<th>INDEX AND OVERALL SCORES</th>
<th>Standard Score</th>
<th>% ile Rank</th>
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<tbody>
<tr>
<td>&gt;99</td>
<td>19</td>
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<td>OVERALL BASIC SEQUEN. COMPLEX</td>
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<tr>
<td>95</td>
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<td>130 98</td>
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<tr>
<td>91</td>
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<td>84</td>
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<tr>
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<td>63</td>
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<tr>
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<tr>
<td>25</td>
<td>9</td>
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<td>16</td>
<td>8</td>
<td>DIS MEM SPA CON SEQ FGR CLO</td>
<td>OVERALL BASIC SEQUEN. COMPLEX</td>
<td>90 25</td>
<td></td>
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<tr>
<td>9</td>
<td>7</td>
<td>DIS MEM SPA CON SEQ FGR CLO</td>
<td>OVERALL BASIC SEQUEN. COMPLEX</td>
<td>85 16</td>
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<td>5</td>
<td>6</td>
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<td>2</td>
<td>5</td>
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<td>OVERALL BASIC SEQUEN. COMPLEX</td>
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<td>OVERALL BASIC SEQUEN. COMPLEX</td>
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<tr>
<td>&lt;1</td>
<td>1</td>
<td>DIS MEM SPA CON SEQ FGR CLO</td>
<td>OVERALL BASIC SEQUEN. COMPLEX</td>
<td>55 &lt;1</td>
<td></td>
</tr>
</tbody>
</table>

Student has known (diagnosed) attention problems?  
Student has known (diagnosed) visual problems?

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10.6 Study Resources

10.6.1 Baseline information pack
10.6.2 20 week information pack
10.6.3 Mitii™ participant manual
10.6.4 Mitii™ rewards chart
10.6.5 Mitii™ certificate
Mitii Study Information Pack for Parents

Thank you for participating in the Mitii study!

The details for your child’s assessments are below. We need your child to participate in several assessments with different therapists. These have been arranged over either one or two days. All children will return again at 20 weeks for further assessment. The last assessments will occur at the 40 week time point. We have provided an approximate time for these assessments below however these will be confirmed closer to the time.

Assessment Dates

Important dates for you to remember:

<table>
<thead>
<tr>
<th>Assessment Dates</th>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRI Scan Time:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re-assessment (20 weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dates:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRI Scan Time:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Final re-assessment and feedback (40 weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dates:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Assessment Locations and Parking

Motor and cognitive assessments will be conducted at the University of Queensland St Lucia Campus, in the Seddon Building (Building Number 82) (see Map 1 attached). A parking voucher has been included for the Multi-story car park on Sir Fred Schonell Drive (see Map 1). The Seddon Building is a short walk from this car park. This building has the Mitii assessment room, an area for parents with magazines, kitchen with a fridge and tea/coffee equipment and amenities.
MRI scans (if your child is having one) will be done in the Gehrmann Laboratories (Building Number 60). If your child is having a MRI scan, please note the MRI Scan Time in the box above - you will need to be at the Gerhmann Laboratory at this time. The Mitii team members can help you to find this building within the university so come to the Seddon Building first.

Assessment Day Program

Three children will typically be completing assessments or Mitii training on each day. On the day of assessment, your child will rotate through various assessments with scheduled breaks throughout the day.

What to Bring

Please ensure your child wears clothes suitable on the day for exercise and socks and sneakers. Please bring with you food (or money to purchase lunch/snacks at various food outlets on the campus) and water. For one of the assessments, your child will be observed performing two typical daily tasks that will be chosen on the day. For this purpose, please also bring the following items with you:

- Hairbrush
- Toothbrush
- Toothpaste
- Face towel
- Face wash (if a particular one is used, face soap can be provided)
- Snack to be eaten with spoon/fork
- Optional - Typical meal that you child could eat for lunch with a knife and fork

Online Questionnaires

You will have been sent an email with links to online questionnaires. Please complete these questionnaires before the day of the initial assessment. Please call any of the Mitii Team if you have any questions about these questionnaires between 8.30am-4.30pm on 07 3636 5361 or 07 3636 6423.
Activity monitors

Your child will be wearing an activity monitor for four days following the initial day of assessment re-assessment. You will be provided with further instructions about these monitors on the day.

Reimbursement of travel costs
Reminder that if you are requesting reimbursement of travel costs that you will need to provide us with ORIGINAL receipts.

Parking vouchers
These have been provided for the number of days you are attending. Please read the instructions on the card and remember to scratch off the dates that you are attending.

Concerns or questions
If you have any concerns or questions on the day of assessment, please contact us on Mitii Mobile: 0417 604 935

Or call us on any other day from 8.30am – 4.30pm at QCPRRC on 07 3636 6423.

Feel free to email us on:

Melinda Lewis (Study Coordinator) m.lewis3@uq.edu.au
Louise Mitchell (Physiotherapist) (louise.mitchell@uq.edu.au); or
Stephanie Ross (Psychologist) (stephanie.ross@uq.edu.au); or
Sarah James (Occupational Therapist) (s.james2@uq.edu.au); or
Carly Mayberry (Psychologist) (c.mayberry@uq.edu.au)

Thank you once again for participating in this study and we look forward to meeting you on the day of assessment!
Drive down Sir Fred Schonnell Drive. Turn Right at the roundabout.

Parking: Multi-Story car park. Multi-level car park 98 A
- Use the orange “One day Parking Permit” supplied.
- Scratch off the appropriate day (Day, Month, Year)
- Display on dashboard

Block 82C Seddon Building:
Come out of the car park onto a path, turn right and walk up the slope towards Chancellors Place and the main university.

Near the Biol. Refectory, veer Right into Slip Rd. We are the first building on your right next to the Vet School.

If you get lost on the day call, the Mitii team on 0417 604 935 for directions.

Map: Parking in Green, assessments in Seddon Building (Building No. 82, Room 314) pink.
Mitii Study Information Pack for Parents

Thank you for participating in the Mitii study!

The details for your child’s assessments are below. We need your child to participate in several assessments with different therapists. These have been arranged over either one or two days.

Assessment Dates

<table>
<thead>
<tr>
<th>Re-assessment (20 weeks)</th>
<th>Time:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dates:</td>
<td></td>
</tr>
</tbody>
</table>

MRI Scan Time:

Assessment Locations and Parking
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What to Bring
Please ensure your child wears clothes suitable on the day for exercise and socks and sneakers. Please bring with you food (or money to purchase lunch/snacks at various food outlets on the campus) and water. For one of the assessments, your child will be observed performing two typical daily tasks that will be chosen on the day. For this purpose, please also bring the following items with you:

- Hairbrush
- Toothbrush, toothpaste
- Face towel
- Face wash (if a particular one is used, face soap can be provided)
Online Questionnaires
You will have been sent an email with links to online questionnaires. Please complete these questionnaires before the day of the initial assessment. Please call any of the Mitii Team if you have any questions about these questionnaires between 8.30am-4.30pm on 07 3636 6423.

Activity monitors
Your child will be wearing an activity monitor for four days following the initial day of assessment re-assessment. You will be provided with further instructions about these monitors on the day.

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Stephanie Ross (Psychologist) stephanie.ross@uq.edu.au; or
Sarah James (Occupational Therapist) s.james2@uq.edu.au

Thank you!
If you get lost on the day call, the Mitii team on 0417 604 935 for directions.

Map: Parking in Green, assessments in Seddon Building (Building No. 82, Room 314) pink.

Drive down Sir Fred Schonell Drive. Turn Right at the roundabout.

Parking: Multi-Story car park.
Multi-level car park 9B A
- Use the orange "One day Parking Permit" supplied.
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Come out of the car park onto a path, turn right and walk up the slope towards Chancellors Place and the main university.

Near the Biol. Refectory, veer Right into Slip Rd. We are the first building on your right next to the Vet School.
Move it to improve it

Participant Training Manual
Thank for participating in this important study testing Mitii.

Chief Investigators:  
Professor Roslyn Boyd  
Professor Jenny Ziviani  
Dr. Leanne Sakzewski  
Dr. Koa Whittington 
Dr. Anthony Smith  
Dr. Ross Cunnington

Researchers:  
Louise Mitchell  
Stephanie Ross  
Sarah James 
Dr. Carly Mayberry  
Melinda Lewis

Should you have any concerns, questions or need to speak to us for any reason, please contact:

Call us on: (07) 3636 5361; Or email:
Louise Mitchell Email: louise.mitchell@uq.edu.au (Mitii Physiotherapist)  
Sarah James Email: s.james2@uq.edu.au (Mitii Occupational Therapist)  
Stephanie Ross Email: stephanie.ross@uq.edu.au (Mitii Neuropsychologist)  
Melinda Lewis Email: m.lewis3@uq.edu.au (Mitii study coordinator)

To contact the chief investigators:
Prof Roslyn Boyd Email: r.boyd@uq.edu.au Phone: (07) 3365 5315  
Prof Jenny Ziviani Email: j.ziviani@uq.edu.au Phone: (07) 3365 3008

For general enquiries please contact QCPRRC Admin Officer: Sabina Scott - Phone: (07) 3636 5542

Mitii was designed in Denmark, Copenhagen by the Helene Elsass Center, The University of Copenhagen and Mitii Development A/S.
Getting Started
Before logging into Mitii you will need the following:

1. **Computer or Laptop that is connected to the internet**
   Ideally plug the computer directly into the internet by connecting the network cable to the computer, otherwise wireless will work – but it might be a little slower to load the programs.

2. **Web-camera connected to computer or laptop.**
   Most laptops will have a camera built into them. If your computer does not have one and you need to use a web-camera, this usually plugs into a USB port and the required programs and/or drivers will automatically install. However you may need to insert a CD and install a program. This will depend on your individual web-camera.

3. **Green sweatbands – one for the head and two for your hands**
   Two sets will be provided by us. If you lose them (or the dog eats them) any bright green object or material will work until we send you out replacements.

4. **A “green-free” zone to train in**
   The Mitii program is very sensitive to green and if the camera can detect green in the background or the paint it will make the training much harder. If you can find a white wall this works best, or you could always pin up a white sheet onto a wall. Be sure to clear away any green objects, paintings or plants from the camera field.

Once you have your Mitii training area set up you will need to log into the program. Connect to the internet and enter the following URL: [http://queensland.mitii.dk](http://queensland.mitii.dk)

Use your username (email address) and password to log into the program.

My Username is: _____________________________

My Password is: _____________________________
When you log in you will come to this screen:

Welcome Mitii

Choose program

Start Week 1

All your new programs will be listed here and old ones will be deleted.

Click on Start to begin loading the program (make sure pop-ups are enabled for this site!)
This may take a little while to load as it’s coming all the way from Denmark!
(A good idea might be to start loading your training program and then go do something, and
it will be ready to go by the time you are finished). This could be up to 5 minutes.

This box may appear

Click Allow

As the program is loading
this screen will appear and
will gradually count to 100%
Mitii Games

There are 14 different Mitii games which the team will select for you based on your needs.

We will go through these in detail on the training day but the table below is provided to remind you of what to do for each game. There are also videos may come up before each game which give instructions.

The background and the pictures may change and the order they come in will be different from the ones shown below however the game remains the same.

<table>
<thead>
<tr>
<th>Name</th>
<th>Green band on your...</th>
<th>Description</th>
<th>Instructions</th>
<th>Sample Screen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory</td>
<td>Hand</td>
<td>Memorise the order of images</td>
<td>Look at a series of pictures. These pictures then disappear and you must memorise them in the order in which they were shown. Hold your hand over picture to select the order.</td>
<td><img src="image1" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Brick</td>
<td>Hand</td>
<td>Match shape to the blank image</td>
<td>There are a series of pictures displayed, one of which matches the blank shape. Uses your hand to drag the matching picture to the blank shape.</td>
<td><img src="image2" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Figure builder</td>
<td>Hand</td>
<td>Construct the picture from smaller pieces falling down the side</td>
<td>The full picture is in the middle of screen. Small pieces of this and other pictures are falling down the side. Reach and drag the piece that matches using your hand to build the picture image from bottom to top.</td>
<td><img src="image3" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Name</td>
<td>Green band on your...</td>
<td>Description</td>
<td>Instructions</td>
<td>Sample Screen</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Figure ground</td>
<td>Hand</td>
<td>Match the small piece of the larger picture</td>
<td>Down the bottom of the screen is a small part of a larger picture. Pick up the part at the bottom with your hand and then drag and hold it where it matches on the big background picture.</td>
<td><img src="image" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Spatial relation</td>
<td>Hand</td>
<td>Pick out which picture does not match</td>
<td>Hold your hand over the picture which does not match (eg. Middle dog has smaller ears)</td>
<td><img src="image" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Visual closure</td>
<td>Hand</td>
<td>Pick out which part-drawn picture matches</td>
<td>A series of part-drawn pictures is shown. Drag the part-drawn picture that matches to the fully drawn picture underneath.</td>
<td><img src="image" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Balloon maths</td>
<td>Hand</td>
<td>Solve the maths problem</td>
<td>A maths question will be shown. Pick up the pin with your hand and drag it to the balloon with the correct answer to solve the maths problem.</td>
<td><img src="image" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Name</td>
<td>Green band on your...</td>
<td>Description</td>
<td>Instructions</td>
<td>Sample Screen</td>
</tr>
<tr>
<td>----------------------</td>
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<td>------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Combo (2-hand exercise)</td>
<td>Both hands</td>
<td>Use both hands to drag the matching pictures into the circle</td>
<td>Find the matching pictures on the side of the screen. Pick up one picture from each side (both hands) and drag into the circle</td>
<td></td>
</tr>
<tr>
<td>Flight simulator</td>
<td>Head</td>
<td>Keep the plane upright!</td>
<td>Put the band on your head and your arms out wide. You need to keep the middle of the plane as upright as possible but the wind will try to blow you off course.</td>
<td></td>
</tr>
<tr>
<td>Follow</td>
<td>Head</td>
<td>Keep the man dry under the umbrella</td>
<td>Put the band on your head and move the umbrella around on the screen so that the man stays dry.</td>
<td></td>
</tr>
<tr>
<td>Follow the leader</td>
<td>Head</td>
<td>Follow the video sequence so that they match</td>
<td>The screen will split into two and a video will play on one side. Follow the leader so that you match the screen!</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Green band on your...</td>
<td>Description</td>
<td>Instructions</td>
<td>Sample Screen</td>
</tr>
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<td>------------------</td>
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<td>--------------------------------------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>UFO</td>
<td>Head</td>
<td>Steer the UFO through the tunnel</td>
<td>Use band on head to steer UFO through a series of tunnels. Squat up and down and make sure it doesn’t hit the walls!</td>
<td><img src="image1" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Move</td>
<td>Both Hands</td>
<td>Blow up the balloon until it pops</td>
<td>Move both hands back and forth to inflate the balloon until it bursts</td>
<td><img src="image2" alt="Sample Screen" /></td>
</tr>
<tr>
<td>Get up/Get down</td>
<td>Head</td>
<td>Let’s get moving! Squat/Jump/Lunge to get the object into the target</td>
<td>Put the band on your head, pick up the object and put it into the target (eg. Cannon blows up the ship!) (We will email you instructions about whether you are to jump, squat, lunge, or use step up etc)</td>
<td><img src="image3" alt="Sample Screen" /></td>
</tr>
</tbody>
</table>

There will be an instruction video before each game to help you learn the games. You can skip over these videos by moving the green band over the Start button. As you become more familiar with Mitii we will remove these videos unless we have specific instructions to give you.

Queensland Cerebral Palsy & Rehabilitation Research Centre
**Challenging you over the whole program**

We will be in contact with you by email (approximately once a week) to let you know when we have changed your program and tell you which games we want you to add a step block or foam to make it harder.

For any game you may be asked to:

- **Lunge (one leg in front of the other)**
- **Sit to stand on and off a chair**

- **Step up onto the step**
- **Squat down and either stand or jump up**

- **Step up sideways onto the step**
- **Or stand on the foam and balance**

**Have fun!**
Study Information and Important dates
I have been allocated to the Immediate / Waitlist group.

My first baseline assessment was: ________________________________

I will be training for 20 weeks from _______________________ to ______________________

My 20 week assessment will be: ________________________________

My final assessment will be: ________________________________

*These are approximate dates. Exact dates and times will be confirmed with you closer to the time.*

If you need help with Mitii or have any questions, contact the Mitii team on **07 3636 4361**

Or email us on:
Louise Mitchell Email: louise.mitchell@uq.edu.au (Mitii Physiotherapist)
Sarah James Email: sarah.james@uqconnect.edu.au (Mitii Occupational Therapist)

Thank you once again for your help in this important study.
Mitii Reward Chart

Make your way through the Mitii Reward Chart to get prizes along the way and special rewards at the end of each 5 week stage!

Practice 20-30 minutes of Mitii each day for one sticker. You will get a prize when you have 6 stickers in a week!

<table>
<thead>
<tr>
<th>Week</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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</thead>
<tbody>
<tr>
<td>6 Prize Time!</td>
<td>Week 1 Prize</td>
<td>Week 2 Prize</td>
<td>Week 3 Prize</td>
<td>Week 4 Prize</td>
<td>Week 5 Prize</td>
<td>Week 6 Prize</td>
<td>Week 7 Prize</td>
<td>Week 8 Prize</td>
<td>Week 9 Prize</td>
<td>Week 10 Prize</td>
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</tr>
</tbody>
</table>

Week

1 2 3 4 5 6 7 8 9 10

6 Prize Time!

Week 11 Prize

Week 12 Prize

Week 13 Prize

Week 14 Prize

Week 15 Prize

Week 16 Prize

Week 17 Prize

Week 18 Prize

Week 19 Prize

Week 20 Prize

WELL DONE!

You have now finished Mitii Stage 1

You have now finished Mitii Stage 2

Half way!

Week

11 12 13 14 15

End of stage reward!

Week 15

WELL DONE!

You have now finished Mitii Stage 3

You have now finished Mitii Stage 4

Week 20

End of stage reward!
Congratulations!

You have completed the Mitii program!

Thank you from Team Mitii for your effort over the 20 weeks.

great work!

well done!

Move it to improve it “Mitii” Australia
10.7 Family feedback

10.7.1 Summary of results for families
Results

Thank you for participating in the Mitii™ study. Without your hard work and effort this study would not have been possible!

We analysed the assessments that you did and we have included a summary of the effects of Mitii™ compared to standard care.

There was a big range in the amount of Mitii™ that participants did over the 20 weeks. The maximum training that one participant did was almost 80 hours!

Quick Summary
Mitii™ improved:
• Activities of daily living skills
• Visual perception
• Goals - e.g. brushing own hair
• Strength – e.g. sit to stands and squats

Mitii™ did not change:
• Executive functioning skills
• Everyday physical activity
• Bimanual performance
Thanks to your help we now know a lot more about physical activity in children and adolescents with cerebral palsy impacting one side of their body.

We conducted a number of studies using data from the activity monitors that you wore (the red box worn around the waist). These devices record acceleration data, so every time you moved it registered the movement and recorded it.

Louise (physiotherapist) was then able to use a computer program to convert the acceleration data into physical activity – such as how many minutes were spent inactive or active; how many steps you took; or if activity was light, moderate or vigorous.

Most of the children in the study wore the activity monitor after each assessment. The data was then pooled together and analysed to look at how much physical activity was happening across the whole group.
This provided us with important information about physical activity in children with cerebral palsy impacting one side of their body. We found that on average:

- The activity monitors that we used are reliable for measuring physical activity (meaning they register and record the same activity between days).
- Only 25% meet the recommended level of physical activity (60 minutes of moderate to vigorous or ‘huffing and puffing’ exercise) on at least one day. On average, children achieved 44 minutes of moderate to vigorous physical activity a day so you were pretty close!
- On a typical day, children took 7,541 steps. It is recommended that adults take 10,000 steps daily and children take over 12,000 steps where able.
- On a typical day (weekday or weekend day), children were inactive for a little over 8½ hours. Physical inactivity has also been found for children who are developing typically, though it appears at first glance that children with CP are more inactive.
- Boys are more physically active than girls; children are more physically active than adolescents; and weekdays are more physically active than weekends. This is what has also been found in typically developing children.
- Children who had more cardiovascular endurance and who participated more in the home and community tended to do more physical activity.
- It is important to remember that while you might actually be really active, this is what data from the whole group told us about physical activity in children with cerebral palsy.
Thanks to your help, we were also able to see what effects Mitii™ had on activities of daily living skills, upper limb skills, visual perception and individuals goals in children with cerebral palsy impacting one side of their body. Overall, from the assessments you did with Sarah (occupational therapist) we found that:

- There was an improvement in the way that you carried out activities of daily living (e.g. making a sandwich or preparing a bowl of cereal). There was an overall improvement in both the physical skills and the thinking skills involved in the tasks.
- The children who did Mitii™ reported higher scores on their goals that you or your caregivers set at your baseline assessment. These goals were often things like being able to do your hair, concentrating in class, or kicking a ball.
- There was an improvement in visual perception, which is the ability of your brain to make sense of what your eyes see. This includes things like being able to identify objects from a background, or remember a sequence of shapes in the correct order. We found that these skills impact on you how you do activities of daily living.
- After Mitii™, there was a slight improvement in how quickly you could do things with your tricky hand and a big improvement in how quickly you can do things with your dominant hand. This maybe tells us that you improved the way you could plan your movements.

Well done on all of your efforts!
Interview Feedback

Some of our participants and their caregivers did some extra work with us by participating in interviews with Jenny, an occupational therapist who supervised the overall project. We did these interviews so that we could understand what were the most important things impacted on how often and how much children and adolescents enjoyed doing the Mitii™ program.

We found a number of things that were common in the feedback that you gave us:

- Many families often didn’t receive any therapy, so Mitii™ offered a way to access therapy at home.
- The Mitii™ program captured the interest of children and adolescents because it was a novelty or “a new toy”!
- Using a computer to do therapy made it seem like a fun game rather than therapy.
- It was a bit hard for some children to keep motivation up over the 20 weeks when it wasn’t new and exciting anymore.
- Some children would have liked to get more feedback from the program about how they were going.
- There were some technical issues that were frustrating which are being addressed in ongoing updates of Mitii™. We thank you again for your understanding with these technical issues!
- Caregivers appreciated that Mitii™ was flexible and it could fit in with other family routines.
- It was important to have strong support from families to help children doing the Mitii™ program at home.