Self-Concept of Children with Cerebral Palsy

Submitted by

Sau Kuan Cheong

A thesis submitted in total fulfilment of the requirements for the degree of

Doctor of Philosophy

School of Psychology

Faculty of Health Sciences

Australian Catholic University

22nd November 2017

Graduate Research
Australian Catholic University
PO Box 968
North Sydney NSW 2059

Statement of Authorship and Sources

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma. No parts of this thesis have been submitted towards the award of any other degree or diploma in any other tertiary institution. No other person's work has been used without due acknowledgement in the main text of the thesis. All research procedures reported in the thesis received the approval of the relevant Ethics/Safety Committees (where required). As per the university thesis guidelines, a statement of contribution of others for the manuscripts relevant to this thesis is included in Appendix B.

Name: Sau Kuan Cheong

Date: 22nd November 2017

Signed:

Acknowledgements

Throughout my PhD journey, every step has unfolded new discoveries that would not have been successful without the support of many people. I am grateful for every person who has guided and supported me through every step of my journey.

I would like to express my sincere gratitude to my supervisory team, Dr Cathryne Lang, Dr Leanne Johnston, and Professor Sheryl Hemphill for their guidance and support. I would also like to thank Dr Kate Witteveen and Dr Grace Choy who has provided constructive feedback during their short period with the supervisory team. Each of my supervisors has contributed valuable knowledge and expertise that guided me at different stages of my candidature. I would like to thank the anonymous examiners for their comments on my thesis.

I greatly appreciate the Cerebral Palsy League for supporting my research program. I would like to acknowledge Robin Smedley for assisting with various administrative tasks. I would particularly like to credit Julie Crawford and her team from the Communication Board Service for creating many of the visual components for my studies and the illustrations for the *myTREEHOUSE Self-Concept Assessment – Game Version*.

My PhD journey would not have been achievable without the encouragement of my husband, Hsien-Jin, to whom I am eternally grateful. I would like to thank my parents and extended family for their emotional support. My acknowledgement also goes to all my peers at the School of Psychology, especially Poh Wan, Soo Imm, Deb, Atholl, Kay, Annie, and Gabby for their continuous encouragement and reminders to persist until the end of this journey.

Table of Contents

List of Tables in the Thesis

List of Tables in Manuscripts

Chapter 6 (Study 1 – Systematic Review)

Chapter 7 (Study 2 – Delphi Consensus Survey)

Chapter 9 (Study 3 – Psychometric Testing)

Chapter 10 (Study 4 – Self-Concept of Children with Cerebral Palsy)

Chapter 11 (Study 5 – Self-Concept and Quality of Life of Children with Cerebral Palsy)

List of Figures in the Thesis

List of Figures in Manuscripts

Chapter 6 (Study 1 – Systematic Review)

Chapter 7 (Study 2 – Delphi Consensus Survey)

Chapter 10 (Study 4 – Self-Concept of Children with Cerebral Palsy)

List of Abbreviations

ACPR	Australian Cerebral Palsy Register
BYSI	Beck Youth Self-Concept Inventory
CAPE	Children's Assessment of Participation and Enjoyment
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CP	Cerebral palsy
CP QOL-Child	Cerebral Palsy Quality of Life Questionnaire for Children
CT	Computerised tomography
FCCS	Functional Communication Classification System
GMFCS	Gross Motor Function Classification System
GMFCS-E&R	Gross Motor Function Classification System – Extended and Revised
ICF	International Classification of Functioning, Disability and Health
IRT	Item response theory
MACS	Manual Ability Classification System
MRI	Magnetic resonance imaging
myTREEHOUSE	myTREEHOUSE Self-Concept Assessment
NHMRC	National Health and Medical Research Council
PAC	Preferences for Activities of Children
PedsQL	Pediatric Quality of Life Inventory
Piers-Harris	Piers-Harris Self-Concept Scale
PSI-6	Physical Self Inventory-6

PSPCSA	Pictorial Scale of Perceived Competence and Social Acceptance for Young Children
PSPP	The Physical Self-Perception Profile
Purdue	Purdue Self-Concept Scale for Preschool Children
QoL	Quality of life
RSE	Rosenberg Self-Esteem Scale
SDQ-I	Self-Description Questionnaire-I
SPPA	Self-Perception Profile for Adolescent
SPPC	Self-Perception Profile for Children
TD	Typically developing
VCI	Verbal Comprehension Index
VSS	Viking Speech Scale
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life
WISC-IV	Wechsler Intelligence Scale for Children 4th Edition

List of Statistical Symbols and Abbreviations

α	Alpha
ANOVA	Analysis of variance
d	Measure of effect
df	Degree of freedom
F	F-value, F test statistic value
H	H-value, H test statistic value
HSD	Honestly significant difference
ICC	Intraclass correlation coefficient
M	Mean
Mdn	Median
n	Number of participants
p	Probability value
r	r-value, test statistic value for Person product-moment correlation coefficient
r_s	r-value, test statistic value for Spearman’s correlation coefficient
SD	Standard deviation
t	t-value, test statistic value
U	U-value, U test statistic value
Z	Z-value

Published Works by the Author Incorporated into the Thesis

Paper Incorporated as Study 1 in Chapter 6

Cheong, S. K., & Johnston, L. M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities, 34,* 3566-3575. Retrived from http://dx.doi.org/10.1016/j.ridd.2013.07.023

Paper Incorporated as Study 2 in Chapter 7

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016). What constitutes self-concept for children with CP? A Delphi consensus survey. *Journal of Developmental and Physical Disabilities*, *28*(2), 333-346. doi: 10.1007/s10882-015-9471-z

Paper Incorporated as Study 3 in Chapter 9

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2017). myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy. *Developmental Medicine & Child Neurology, 59*(6), 655-660. doi: 10.1111/dmcn.13392

Published Abstracts

Cheong, S. K., & Johnston, L. M. (2012). Systematic review of self-concept measures for primary school aged children with cerebral palsy [Abstracts of the 6th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine]. *Developmental Medicine and Child Neurology, 54,* 43.

Cheong, S. K., Lang, C. P., & Johnston, L. M. (2014). What denotes self-concept for preadolescent children with cerebral palsy? A Delphi survey [Abstracts of the 7th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine]. *Developmental Medicine and Child Neurology, 56*, 23.

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016). myTREEHOUSE Self-Concept Instrument: Preliminary psychometric validation [Abstracts of the 8th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine]. *Developmental Medicine and Child Neurology*, *58*, 48.

List of Presentations by the Author Relevant to the Thesis

Conference Paper Presentations

Cheong, S. K., & Johnston, L. M. (2012, March). *Systematic review of self-concept measures for primary school aged children with cerebral palsy*. Paper session presented at the 6th Biennial Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Australasian Academy of Cerebral Palsy and Developmental Medicine, Brisbane, Australia.

Cheong, S. K., & Johnston, L. M. (2012, October). *Systematic review of self-concept measures for primary school aged children with cerebral palsy*. Paper session presented at the International Cerebral Palsy Conference, Pisa, Italy.

Cheong, S. K., Lang, C. P., & Johnston, L. M. (2014, March). *What denotes self-concept for pre-adolescent children with cerebral palsy? A Delphi survey*. Paper session presented at the 7th Biennial Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Australasian Academy of Cerebral Palsy and Developmental Medicine, Hunter Valley, Australia.

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2014, October). *What denotes self-concept for pre-adolescent children with cerebral palsy? A Delphi survey*. Paper session presented at the 49th Annual Conference of the Australian Psychological Society, Australian Psychological Society, Hobart, Australia.

Cheong, S. K., Lang, C. P., & Johnston, L. M. (2016, March). *myTREEHOUSE self-concept instrument: Preliminary psychometric validation*. Paper session presented at the 8th Biennial Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Australasian Academy of Cerebral Palsy and Developmental Medicine, Adelaide, Australia.

Conference Posters Presentation

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2015, September). ‘myTREEHOUSE’: *Face and content validity of a newly developed self-concept instrument for children with cerebral palsy*. Poster session presented at the 50th Annual Conference of the Australian Psychological Society, Australian Psychological Society, Gold Coast, Australia.

Accepted Conference Paper Presentations

Cheong, S. K., Lang, C. P., & Johnston, L. M. (2018, March 21-24). *What do children with cerebral palsy think about themselves? Self-concept measured using the CP-specific myTREEHOUSE Self-Concept Assessment*. Accepted for paper session at the 9th Biennial Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Australasian Academy of Cerebral Palsy and Developmental Medicine, Auckland, New Zealand.

Cheong, S. K., Lang, C. P., & Johnston, L. M. (2018, March 21-24). *Self-concept and quality of life of children with cerebral palsy: Relationships found using population specific measures*. Accepted for paper session at the 9th Biennial Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Australasian Academy of Cerebral Palsy and Developmental Medicine, Auckland, New Zealand.

Abstract

Self-concept is the perception that individuals have of themselves across different aspects of life such as academic performance or appearance. The *Self-Concept Feedback Loop* proposed for this research program conceptualised self-concept as developing through an interactive and iterative process involving social experiences and the cognitive processes of individuals. Through this process, individuals evaluate their behaviour or attributes against their internal standards. Subsequently, this evaluation influences their self-concept. In the general population, low self-concept has been linked to a range of negative outcomes, including poor academic achievement, and behaviour and mental health problems. However, research into the self-concept of children with cerebral palsy (CP) is rare. The motor and accompanying impairments associated with CP limit participation opportunities for children with CP, creating a unique social experience for these children that are likely to differ from typically developing (TD) children. Given this unique social experience, children with CP may perceive their self-concept differently from TD children as well as be at potential risk for low self-concept. The overall aim of this research program was to examine the self-concept of children with CP after identifying or developing a CP-specific self-concept instrument suitable for this purpose.

In Study 1, a systematic review was undertaken to identify self-concept instruments suitable for children with CP. Five studies that measured the self-concept of preadolescent children with CP that had population-specific psychometric data were identified. Examination of the psychometric properties of the instruments utilised in those studies identified no CP-specific self-concept instruments, whilst existing instruments developed for TD children did not have strong psychometric support for their use with children with CP.

In Study 2, a three-round Delphi consensus survey was conducted to identify self-concept domains relevant to children with CP. Three groups were recruited: professionals working with children with CP (n=21), caregivers of children with CP (n=18), and children with CP (n=12, 7 boys). Findings demonstrated that children with CP generally conceptualise self-concept using similar domains to TD children. However, several CP-specific domains were identified. Based on these findings, it was determined that the construction of a population-specific instrument which incorporates CP-specific domains was necessary in order to provide a comprehensive evaluation of self-concept for children with CP.

The *myTREEHOUSE Self-Concept Assessment* (*myTREEHOUSE*) was developed using classical test theory based on the rational-empirical approach. Self-concept is measured by the child's appraisal of their performance for 26 items across eight domains. The child's appraisal is rated from three perspectives: *Personal*, *Social*, and *Perceived*. In addition, children also complete an *Importance Rating*. The discrepancy between the *Importance Rating* and the *Personal Performance Perspective* for each item is summed to achieve a *Personal Concern Score* which indicates the presence and severity of self-concept concerns.

In Study 3, the validity and reliability of *myTREEHOUSE* was examined. Support for face and content validity was ascertained through semi-structured interviews with seven experts. *myTREEHOUSE* demonstrated strong internal consistency assessed with 50 children with CP (29 boys). Moderate test-retest reliability was demonstrated with a subset of 35 children (20 boys).

Study 4 explored the profile of self-concept using *myTREEHOUSE* for 50 children with CP (29 boys) in relation to age, gender, and motor, communication, and cognitive function. Children with CP in this cohort reported high self-concept. Findings also demonstrated that self-concept was not associated with age, gender, motor function, or communication function. Cognitive function was found to be associated with the self-concept domains of *Social Skills* and *Learning Skills*.

Study 5 investigated the relationship between self-concept and quality of life measured using two population-specific instruments; *myTREEHOUSE* for self-concept and *CP QOL-Child* for quality of life. Higher self-concept was associated with higher quality of life in this cohort of 25 children with CP (13 boys). The relationships between self-concept with child-reported quality of life were stronger than proxy-reported quality of life.

Through this research program, it was ascertained that existing self-concept instruments are not suitable for children with CP, given their weak psychometric data and the absence of CP-specific domains. In response, the *myTREEHOUSE Self-Concept Assessment* was developed and preliminary validation undertaken. Findings from this research program present the first self-concept profile of children with CP and provide a deeper understanding about how these children perceive their self-concept and quality of life.

Chapter 1. Overview

1.1. Introduction

Self-concept is an individual's perception of him/herself (Shavelson, Hubner, & Stanton, 1976). This perception includes characteristics or attributes that an individual uses to define themselves in various aspects of life. Self-concept is a complicated construct to define, and a universal definition has not been formulated. The elements of self-concept are discussed in Chapter 2.

Drawing upon the existing theories of self-concept, it was proposed that self-concept develops and influences behaviour through a feedback loop (see Figure 1.1). Gathering evidence from pioneer researchers in self-concept including James (1890/1950), Mead (1934), and C. H. Cooley (1902/1964) as well as contemporary researchers like Harter (2012a), it was proposed that the development of self-concept is dependent on the interaction between socialisation experiences and cognitive processes. Self-concept influences individuals' behaviour during social experiences (Hattie, 1992). Individuals then cognitively analyse their social experiences to provide information which, in turn, shapes their self-concept (Harter, 2012a). For example, when children receive positive responses from others during their first attempt at reading, they analyse this response and believe that they have capably performed the reading task. This positive perception of their own reading capability builds their self-concept, which in turn encourages another attempt at reading.

Self-concept development is driven by internal standards – personal ideals for specific behaviours or attributes – which act as a guideline for behaviours. Shavelson et al. (1976) have postulated that information gathered from social experiences is used to adjust existing standards or form new standards. New standards are formed when the individual experiences their first encounter with a specific behaviour; for example, at early stages of schooling the ability to spell is a benchmark for school achievement. Subsequently, these standards are adjusted as required to enhance earlier behaviours, for example, at later stages of schooling passing all subjects may be a new benchmark for school achievement. Over time, these standards guide the development of self-concept, creating a lens that influences the way that people view their environment and themselves. This basic framework (see Figure 1.1) demonstrates this process of self-concept development.

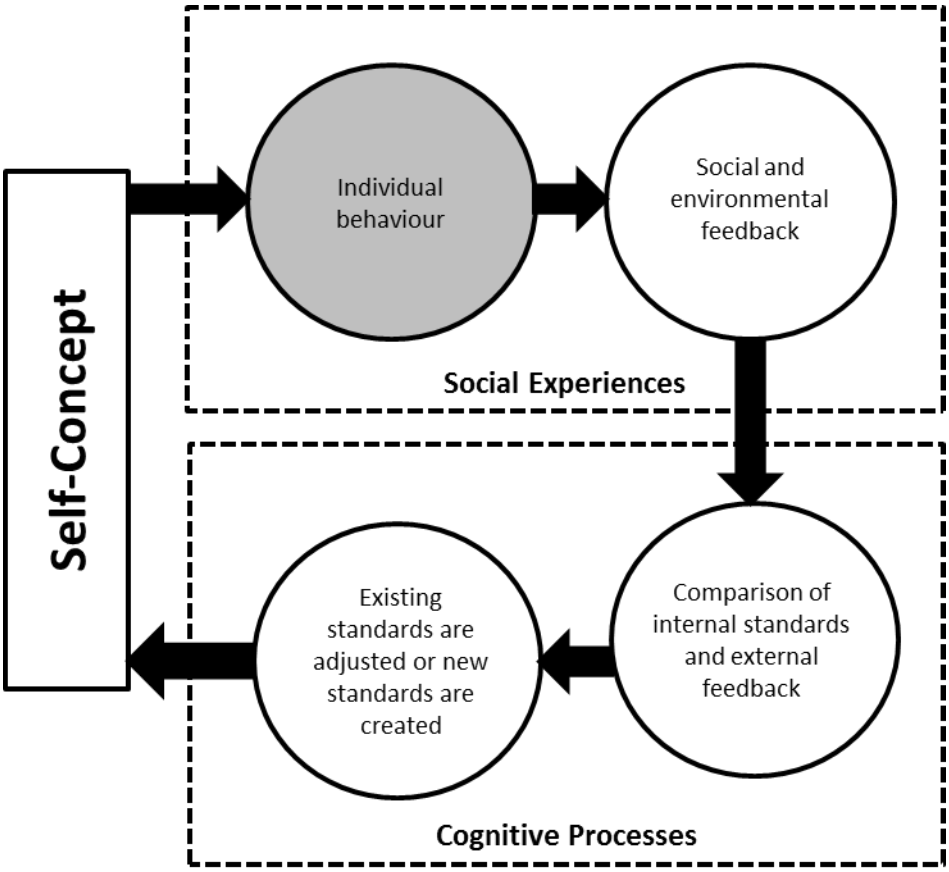


Figure 1.1 A basic self-concept framework

Various authors have reported that self-concept serves multiple functions in people’s lives, including (i) *direction* for behaviours, (ii) *motivation* to engage in behaviour, and (iii) as a *protective factor*. First, individuals use the standards created during the process of self-concept development to chart the *direction* of behaviour. Self-concept acts as a heuristic or mental short cut to prompt appropriate behaviours in social situations. It also acts as a guide for desired behaviours that shape the ideal self. Harter (2012a) proposed that self-concept establishes the standards and guidelines that people use to generate and interpret behaviours during social experiences. Subsequently, people adjust their behaviour and/or standards to maintain a coherent picture of themselves relative to their environment; essentially shaping the ideal person they aspire to be within their environment. Campbell (1990) found that people with vague standards often have poor self-concept and they struggle to create a coherent picture of themselves compared to people with strong self-concept.

The second function proposed is that self-concept provides *motivation* for people to engage in tasks. People with strong self-concept are motivated by success and persist despite difficulties; however, people with poor self-concept are motivated to escape failure and they tend to avoid difficult situations, except where success is guaranteed (Baumeister, Tice, & Hutton, 1989; Buss, 2012). Furthermore, Setterlund and Niedenthal (1993) found that the social decisions made by people with strong self-concept are motivated by standards that create a coherent picture of themselves within their environment. However, social decisions made by those with poor self-concept are often disorganised and are inconsistent with their standards. For example, a child who has a strong self-concept about his/her reading ability is more likely to volunteer for a reading task when he/she desires to engage in the activity. He/she is not easily swayed by decisions of others within his/her environment. Thus, self-concept gives people the *motivation* to engage in behaviours that are consistent with their *direction* for becoming the person they aspire to be.

The final function proposed is that strong self-concept acts as a *protective factor* against stressful situations. Drawing on Terror Management theory, Greenberg et al. (1992) investigated the relationship between self-concept and anxiety. In their experiments, Greenberg et al. exposed participants to threatening environments such as exposure to a graphic video depicting a death-related scene or the threat of painful electric shock. They found that people with strong self-concept were less likely to experience anxiety when exposed to stressful situations. Therefore, they postulate that self-concept acts as a buffer against anxiety and enables individuals to engage in necessary protective behaviours.

Furthermore, self-concept also acts as a *protective factor* in social environments. In their Sociometer theory, Leary, Tambor, Terdal, and Downs (1995) argue that people seek to gain social acceptance and to minimize the possibility of social rejection by projecting a favourable image of themselves. Social acceptance produced as a result of presenting socially favourable attributes and/or successful inclusion in a desired social group in turn strengthens self-concept. However, if social rejection is experienced, this can lead to lower self-concept. The influence of the positive and negative social experiences on self-concept is consistent with the basic self-concept framework. Thus, self-concept performs as a *protective factor* in stressful or social situations by *motivating* the individual to engage in proactive behaviours.

This research program focuses on the self-concept of children with cerebral palsy (CP). CP is defined as "…a group of permanent disorders of the development of movement and posture, causing activity limitations …often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour…" (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2006, p. 9). Independently and collectively, these impairments can significantly limit children's capacity for activity and restrict participation in their environment, creating a unique social experience for children with CP that is likely to differ from typically developing (TD) children. Given this unique social experience, children with CP may perceive their self-concept differently from TD children. Despite the potential for the impairments experienced by children with CP to present barriers to the development of self-concept, there is surprisingly little research that has investigated the self-concept of children with CP.

Living with a lifelong condition like CP, self-concept may be an important construct for these children's development. Self-concept can act as a *protective factor* against prolonged stressors as children with CP learn to cope with their disability and manage the challenges of treatment and therapy. Moreover, self-concept can be the *motivator* in challenging situations, in light of the activity limitations and restrictions in participation that many of these children experience. In the general population, self-concept has been extensively studied; poor self-concept has been associated with poor academic achievement (Trautwein, Lüdtke, Köller, & Baumert, 2006), behaviour (Donnellan, Trzesniewski, Robins, Moffitt, & Caspi, 2005), and mental health problems (Emler, 2002); but there is little knowledge about the impact of poor self-concept for children with CP. Given the likely importance of self-concept for children with CP, the volume of research in this area is not adequate.

Research into the self-concept of children with CP emerged about three decades ago. A large number of these studies were designed to compare the self-concept of children with CP with that of their TD peers (Harvey & Greenway, 1984; Russo, Goodwin, et al., 2008; Shields, Loy, Murdoch, Taylor, & Dodd, 2007; Soyupek, Aktepe, Savas, & Askin, 2010; Teplin, Howard, & O'Connor, 1981; Ziebell, Imms, Froude, McCoy, & Galea, 2009) or with normative data from TD children provided by the creators of the individual self-concept instruments (Adamson, 2003; Manuel, Balkrishnan, Camacho, Smith, & Koman, 2003; Schuengel et al., 2006; Sherrill, Hinson, Gench, Kennedy, & Low, 1990). Although most studies found that children with CP reported lower self-concept than TD children (Harvey & Greenway, 1984; Manuel et al., 2003; Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007; Soyupek et al., 2010; Ziebell et al., 2009), some studies reported conflicting findings (Adamson, 2003; Teplin et al., 1981). Variety in the sample characteristics and methodological approaches, in particular, differences in the self-concept instruments used, has prevented firm conclusions being drawn about the self-concept of children with CP.

Some researchers have focussed on potential personal and environmental factors that could influence the self-concept of children with CP including CP-related impairments (Manuel et al., 2003; Russo, Atkins, Haan, & Crotty, 2009; Russo, Miller, Haan, Cameron, & Crotty, 2008; Scholtes, Vermeer, & Meek, 2002; Schuengel et al., 2006; Soyupek et al., 2010; Ziebell et al., 2009), activity participation (King, Law, Petrenchik, & Hurley, 2013; King et al., 2010; Shikako-Thomas et al., 2013), behavioural problems (Nadeau & Tessier, 2011; Schuengel et al., 2006), and quality of life (Russo, Goodwin, et al., 2008; Soyupek et al., 2010). With few studies investigating the contribution of each personal or environmental factor to self-concept for children with CP, it is difficult to draw useful conclusions that permit a comprehensive understanding of self-concept for the population. A detailed critique of the studies involving children with CP are presented in Chapter 4. Research into the self-concept of children with CP is essential to broaden our understanding of self-concept for this population and to provide stronger evidence to support the inclusion of psychological constructs such as self-concept in routine assessment and intervention planning for children with CP.

Self-concept and quality of life have overlapping features that contributes to an individual's overall wellbeing. These overlaps have led researchers to postulate a potential relationship between these constructs. Studies involving TD children show that higher self-concept correlates with higher quality of life (Marriage & Cummins, 2004). Self-concept and quality of life jointly act as a protective factor against mental health problems and suicidal ideation and/or behaviours in TD children (Valois, Zullig, Huebner, & Drane, 2004). Consequently, quality of life has been recommended as a longitudinal outcome measure for individuals with disabilities (Huebner, 2004), but self-concept is not often assessed and monitored for this population. Research involving children with CP shows that disability severity adversely affects quality of life (Shelly et al., 2008; Vargus-Adams, 2005) but few studies have considered the contribution of self-concept in influencing quality of life for this population. Only two studies involving children with CP investigated both constructs and indicated that self-concept may predict quality of life (Russo, Goodwin, et al., 2008; Soyupek et al., 2010). It may seem reasonable to assume that the relationship between self-concept and quality of life would hold for children with CP because this relationship has been established in adults and TD children. However, with only two relevant studies involving children with CP, this relationship cannot yet be considered an established finding for the CP population. Stronger evidence is required to support the inclusion of self-concept alongside quality of life in creating a comprehensive assessment of overall wellbeing for children with CP.

One of the major barriers to effective self-concept research and management for children with CP is the lack of instruments specifically designed and psychometrically tested for this population. Most self-concept studies involving children with CP have used instruments designed and validated for TD children. It is commonly accepted that the physical, emotional, and social development of children with CP differ from TD children (Dodd, Imms, & Taylor, 2010; Rosenbaum & Rosenbloom, 2012). It is thus unlikely that children with CP could perceive themselves in similar ways to TD children. Llewellyn and Chung (1997) and von der Luft, DeBoer, Harman, Koenig, and Nixon-Cave (2008) indicate that self-concept instruments designed for TD children are unlikely to fully reflect the self-concept construct for children with CP. Moreover, Wright, Boschen, and Jutai (2005) and McGibbon, Benda, Duncan, and Silkwood-Sherer (2009) observed that the methods of administration and item presentation of non-population-specific self-concept instruments are not always suitable for children with CP due the physical and/or communication impairments experienced by these children. To provide an accurate evaluation of self-concept, it is critical to identify a population-specific instrument that incorporates CP-specific domains that reflect the self-concept of children with CP. The instrument also needs to accommodate the needs of these children so that it is accessible. If an instrument cannot be found that fulfils these criteria, then it may be necessary to develop an instrument that is appropriate for children with CP.

1.2. Aim of Research Program

The overall aim of this research program was to identify or develop a CP-specific self-concept instrument, to use this instrument to explore the profile of self-concept, and to investigate factors that are associated with self-concept for children with CP who are aged 8-12. To achieve the aims of this research program, five studies were performed and these are presented in three thesis sections: (i) review of existing literature, (ii) instrument development, and (iii) investigation of the self-concept of children with CP. The objectives of Sections 1 and 2 were to identify and – if necessary – design a population-specific self-concept instrument for children with CP. The final section consisted of two objectives. The first was to use the instrument to explore the self-concept profile for children with CP aged 8-12 in relation to (i) age, (ii) gender, (iii) motor function (gross and fine motor), and (iv) communication and cognitive function. The second objective was to investigate the relationship between self-concept and quality of life in children with CP who have the ability to self-report these constructs. The decision tree below (see Figure 1.2) was developed to guide the direction of this research program. The green arrows in Figure 1.2 illustrate the direction taken for this research program based on the findings of each study.

1.3. Overall Flow of Chapters

This thesis is presented in 12 chapters. Following the Introduction (Chapter 1), Chapters 2-4 form the background to the thesis. In Chapter 2, self-concept is introduced as the main topic for this research program. An overview of self-concept theory and the instruments available for measuring the self-concept of children are included in this chapter. In Chapter 3, the target population of this research program – children with CP – is described, with a brief overview of CP that highlights the characteristics of children with CP that are relevant for the measurement of self-concept. The focus of Chapter 4 is to review literature about what is currently known about the self-concept of children with CP. Literature concerning the relationship between self-concept and quality of life is also reviewed in Chapter 4. Following these background chapters, Chapter 5 describes the general methods employed for each study (Studies 1-5). Following this discussion of methodology, studies that were conducted within this research program according to the decision tree in Figure 1.2 are reported: Chapter 6 (Study 1), Chapter 7 (Study 2), Chapter 9 (Study 3), Chapter 10 (Study 4), and Chapter 11 (Study 5). Each study is formatted as a published or submitted journal manuscript. Chapter 8, in response to the findings of Studies 1 and 2, details the newly-developed instrument. The focus of Chapter 12 is to discuss and summarise the main findings, the clinical and theoretical implications, the strengths and limitations of this research program, and provide recommendations for future clinical and research directions.

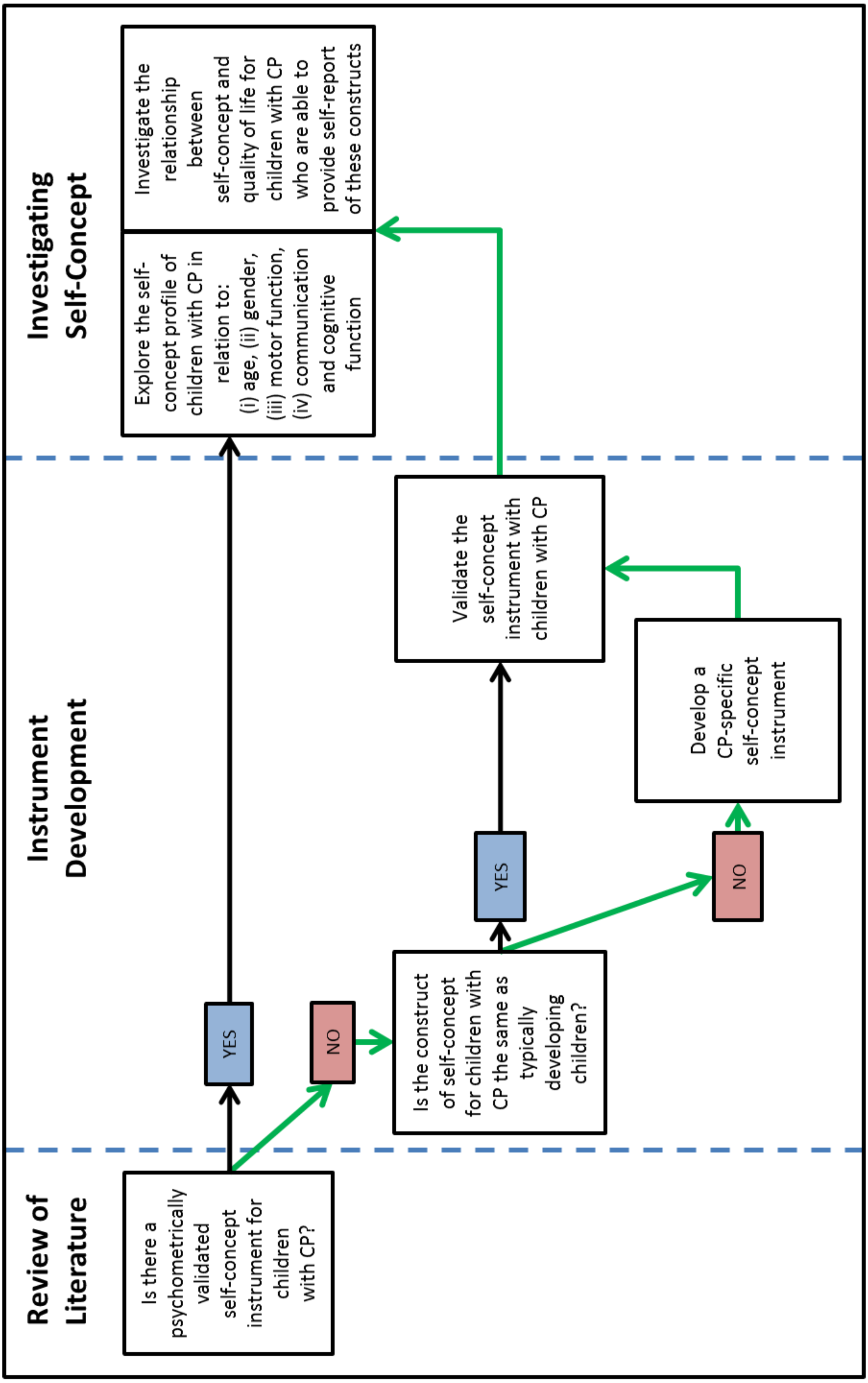


Figure 1.2 Decision tree for this research program

Chapter 2. Overview of Self-Concept

"Who am I?" is a common question when attempting to describe oneself. When responding to this question, most individuals recognise that there are many different answers, which describe the varying dimensions of the self. For example, some people may describe their occupation, family role, favourite sport, political opinion, or they may describe themselves based on physical characteristics such as age, sex, height, or weight. When individuals describe themselves, they reveal their understanding of their unique personal attributes and traits, and essentially describe their perception of themselves – otherwise known as their self-concept. A review of self-concept in terms of (i) current definitions, (ii) developmental constructs, (iii) theoretical model, and (iv) instruments available for measuring self-concept for children is provided in this chapter.

2.1. Defining Self-Concept

Over the past century, researchers have attempted to study self-concept by focusing on factors such as origin (e.g., Where does self-concept come from?), developmental stages (e.g., When do people begin to develop self-concept?), measurement (e.g., How can the existence of self-concept be measured?), and its impact (e.g., How does self-concept influence an individual?). This curiosity has extended across various fields of psychology, particularly social, personality and developmental psychology.

After more than a century of research, a universally-accepted definition and associated terminology for self-concept have still not been formulated. Over 60 related variants have been used to describe the specific areas of self-concept (Byrne, 1996; Wells & Marwell, 1976). Since authors have used terminology that reflects their particular clinical backgrounds and theoretical frameworks, multiple terms are used to describe the same construct, and a single term may be used to describe different constructs. This thesis attempts to clearly define the scope of its research program by reviewing how key researchers have understood self-concept over the past century. A framework of conceptualising self-concept for this research program will be outlined at the end of this section.

2.1.1. William James – the 'I-Self' and the 'Me-Self'. The first scientific analysis of the *study of self* was initiated by William James (1890/1950). James proposed two fundamental components of the self. He first proposed the *I-self* which he described as the subject or the knower, and the second was the *Me-self* which he described as the object or the known. The concepts of *I-self* and *Me-self* are commonly used as the basis for defining the self, whereby the self can only exist when there is an "I" as a subject reference which has the capacity to consider an object which is "Me" (Oyserman, Elmore, & Smith, 2012). Only then can an individual effectively perceive and evaluate the self.

James (1890/1950) further explained that the evaluation of self is a ratio of pretension (i.e., one's aspiration) to success (i.e., one's accomplishment). For example, if an individual has a high pretension to be a runner but cannot run very well because of a physical impairment, then this will have a devastating impact on his/her evaluation of self. On the other hand, if an individual does not have the pretension to be a runner but possesses the natural ability to run at a competitive speed, then winning a running competition does not necessarily provide a noticeable positive impact on his/her evaluation of self. This is especially true when the individual has other aspirations in life that surpass the achievements attained from running competitions.

Both pretension and success jointly influence self-concept. Pretension is the internal standards or goals developed and maintained by individuals. Success is the interpretation of the accomplishments achieved by individuals when they engage in particular social experiences. The balance between pretension and success shapes the self-concept of individuals. Individual success is apparent because it is the outcome of individual behaviour; however, pretension is a thought and must be verbally communicated by the individual to be apparent to others. Many self-concept instruments measure success but very few instruments measure pretension because of its internalised nature. To provide a comprehensive interpretation of cognitive processes relevant to self-concept, *both* pretension and success should be included in self-concept assessments.

The work of James (1890/1950) enabled the *study of self* and presented the first scientific understanding of the self. Although his contribution to the *study of self* was significant, it focuses solely on internal processes and did not explain the role of the social environment in the development of self-concept.

2.1.2. Charles Horton Cooley and George Mead – the social self. In the early 1900s, C. H. Cooley (1902/1964) and Mead (1934) extended the *study of self* through a symbolic interactionist perspective. They described the self as a social construct that interacts with the environment by using symbolic tools – such as language – for communication. In contrast to James (1890/1950), symbolic interactionists suggest that the self is not confined internally, within the person (i.e., *I-Self* and *Me-Self*) and to be assessed using cognitive processes alone (i.e., pretension and success); rather, the self develops and evolves in response to interactions with individuals and events in the environment.

C. H. Cooley (1902/1964) described people as social beings; thus, their behaviours, while guided by internal cognitive processes as suggested by James (1890/1950), are also guided by the "social mirror". Cooley proposed a theory of the *looking-glass self*, where the image of the self is cast onto a social mirror. This social mirror reflects the individual’s behaviour and the responses of others toward that behaviour.

Mead (1934) spanned the gap between the theories of James (1890/1950) and C. H. Cooley (1902/1964) in his understanding of the *study of self*. Mead adopted James’ theory of the *I-self* and the *Me-self*. Similar to Cooley’s concept of the *looking-glass self* was Mead’s acknowledgement that the self is a social construct and, thus, the *Me-self* becomes the object partly by taking account the reactions of others. However, Mead added that language is an essential platform for the *I-self* to evaluate the *Me-self*. Thus, he proposed that, without the intellectual capacity for language, the evaluation of the self will not develop. This notion was further expanded by a number of researchers (see Section 2.2.1).

James (1890/1950), C. H. Cooley (1902/1964) and Mead (1934) pioneered the *study of self* by establishing the core components relevant for evaluating the self. Drawing upon these three key theorists, self-concept can be seen as a construct that influences an individual’s behaviour during social experiences. Cognitively, the outcomes of these experiences are analysed and interpreted to adjust existing standards or create new standards, thus, shaping the individual’s self-concept. This process is illustrated in the basic self-concept framework (see Section 1.1, Figure 1.1). However, shortly after the period of James, C. H. Cooley, and Mead, psychology was heavily influenced by behaviourism, which focused solely on observable behaviours and disregarded unobservable mental constructs such as desires, beliefs, or self-concept. It was not until the mid-twentieth century that researchers realised that human behaviour could not be explained exclusively through observable phenomena. This triggered a renewed interest in mental constructs, including self-concept.

2.1.3. Morris Rosenberg – attitude of the self. Rosenberg (1965) adopted the earlier theories of James (1890/1950) but interpreted the *study of self* as a study of the *attitude of the self*, whereby “attitude” was proposed to mean the opinion and beliefs of people towards an object; in this case, the object is the self. From a social psychology perspective, Rosenberg’s research focussed on studies of social factors that determine the *attitude of the self*. Rosenberg used the term *self-esteem* to represent positive or negative *attitudes of the self*. For example, positive self-esteem is reflected in statements like “On the whole, I am satisfied with myself” or “I feel that I have a number of good qualities”. Negative self-esteem is reflected in statements like “I certainly feel useless at times” or “All in all, I am inclined to feel that I am a failure” (Rosenberg, 1965, p. 17-18). Rosenberg was one of the first researchers to propose that self-esteem can be assessed using a standardised questionnaire, similar to methods of assessing attitudes towards other constructs.

Self-esteem as suggested by Rosenberg (1965) only partially represented the basic self-concept framework (see Figure 1.1). Self-esteem influences people’s behaviour and the analysis or interpretation of the resultant social experiences in turn influence the attitude towards the self. Although Rosenberg’s theory explains the interconnection between socialisation experiences and cognitive processes, the theory does not explain the processes of a feedback loop. For example, James (1890/1950) theory that pretension and success create an individual’s standards which are used to develop self-concept were not incorporated in Rosenberg’s theory. In essence, self-esteem is an evaluation of the *attitude of the self* but is not the developmental process that shapes an individual’s self-concept.

2.1.4. Richard Shavelson, Judith Hubner, and George Stanton – self-concept. Shavelson et al. (1976) were the first researchers to define the term *self-*

concept using a systematic process. Their study proposed and validated seven features which are considered important to the construct of self-concept. These seven features are listed in Table 2.1 and discussed in the following paragraphs.

Table 2.1 Seven features of self-concept proposed by Shavelson, Hubner, and Stanton (1976)

Feature	**Description**
1. Organised	Experiences are categorised and organised to form meaning. The categories are often influenced by culture.
2. Multifaceted	Self-concept presents itself in multiple facets. The facets are reflective of the categories adopted in Feature 1 – Organised.
3. Hierarchical	Self-concept is layered in an ascending hierarchy with general self-concept at the apex.
4. Stable	Self-concept becomes more stable as the hierarchy is ascended.
5. Developmental	Self-concept is connected to developmental stages. Cognitive maturity and experience enhance the complexity of self-concept.
6. Evaluative	Self-concept is evaluative; comparing the self to personal, relative, or perceived standards.
7. Differentiable	Self-concept may be correlated to other constructs but should be differentiable.

Source: Shavelson et al. (1976)

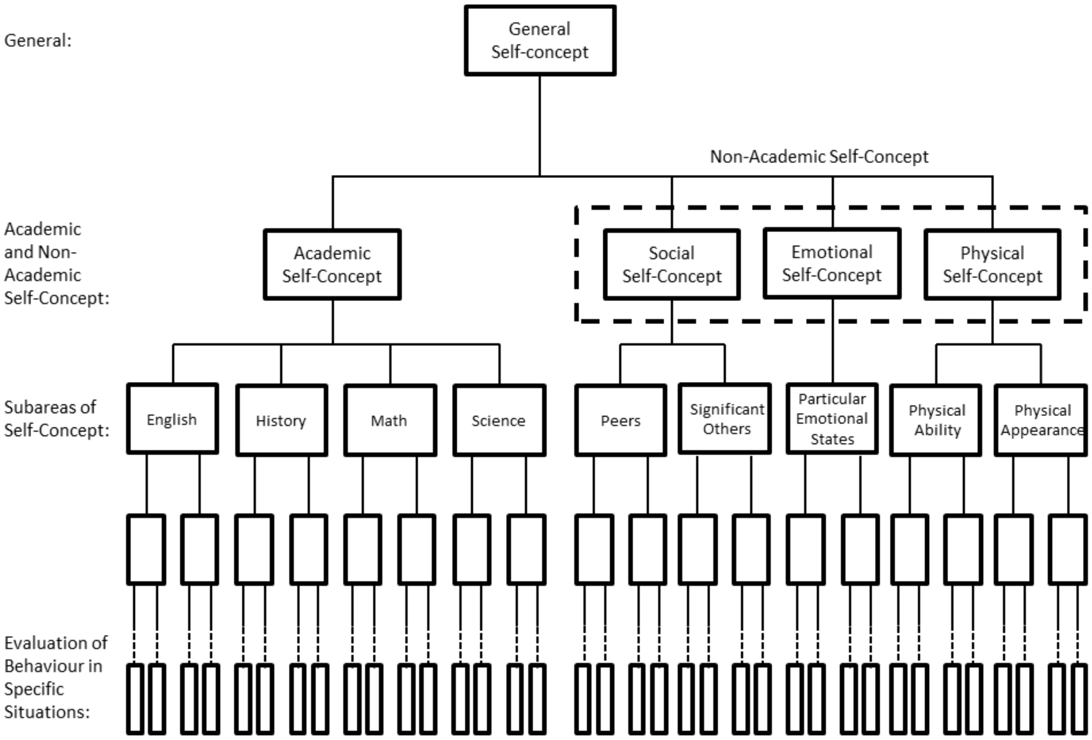
2.1.4.1. Feature 1: Organised. Shavelson et al. (1976) proposed that the construct of self-concept is *organised* from a set of attributes or characteristics that are grouped into broad meaningful categories. These categories are developed from an individual’s interpretation of their experiences. For individuals, these categories are internally congruent. This feature suggests that people draw meaning from their experiences and that these meaningful experiences become the basis of internal standards which are the foundation of the individual’s ideals, that is, their preferred attributes. These attributes shape self-concept and in turn guide, mediate and regulate behaviours (Hattie, 1992). For example, “I am good at learning things” begins with an engagement in tasks that involve learning; subsequently, the positive or favourable outcomes received from successful engagement establish the belief that one is good at learning things. This feature essentially describes the cognitive processes that occur in the basic self-concept framework (see Figure 1.1).

The feature of being organised, is consistent with historical views (C. H. Cooley, 1902/1964; James, 1890/1950; Mead, 1934; Rosenberg, 1965) and has been adopted by current researchers (Harter, 1982, 2012a; Hattie, 1992; Marsh & Shavelson, 1985). This feature supports the notion that the development of self-concept requires a combination of social experiences and cognitive processes to generate a set of personal standards which shape the individual’s character which represents domains within the self.

2.1.4.2. Feature 2: Multifaceted. The concept of a *multifaceted* or multidimensional self was first proposed by Mead (1934). He proposed that people divide the self into different “selves”, presenting a specific “self” when interacting with different individuals. In contrast, the first feature of the self as organised, proposed by Shavelson et al. (1976), suggests that these selves are organised into broad meaningful categories rather than in the context of different people. This multifaceted feature can be observed in people’s behaviour during different social experiences. For example, when an individual meets his/her friends from the running team, athletic attributes may be more salient in his/her behaviour because it is relevant to the activity. Similarly, when the same individual meets his/her study group at school, intellectual attributes become more important during those interactions.

2.1.4.3. Feature 3: Hierarchical. Shavelson et al. (1976) first proposed a *hierarchical* structure for self-concept, which was later adopted by Marsh and Shavelson (1985) and Hattie (1992). This hierarchical model argues that self-concept is organised in multiple layers with individual experiences at the base of that hierarchy.

These individual experiences are grouped into categories to form meaningful domains that create additive layers. The additive layers form the *General Self-Concept* at the apex of the hierarchy which represents the overall perception of self (see Figure 2.1). For example, the "ability to run fast" is a behavioural feature categorised under the self-concept subarea of *Physical Ability*, which contributes to the *Physical Self-Concept*. The *Physical Self-Concept* is in turn part of the *Non-Academic Self-Concept* which itself contributes to the *General Self-Concept* at the apex of the hierarchy. Although the hierarchical model has been adopted by several researchers, others have identified concerns with this structure.

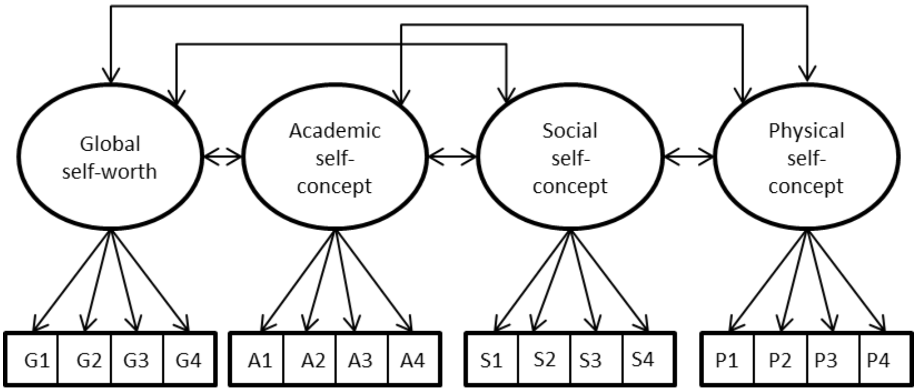


Source: Shavelson et al. (1976) p. 413

Figure 2.1 *Hierarchical Model* of self-concept proposed by Shavelson, Hubner, and Stanton (1976)

Harter (1982) raised concerns about the additive nature of the postulated hierarchical structure of self-concept. Researchers continue to debate the best mechanism to measure the overall perception of the self. Measuring an overall perception of the self by summing scores from domains is a mathematical solution that allows researchers or clinicians to derive a general image of the self. However, this summative approach is subject to the relative weightings and scores of domains included in these assessments, and does not necessary represent the individual's overall perception of self. It does not acknowledge that an individual's overall self-concept may be disproportionately influenced by one or a few domain(s) that influence a large part of their life, or that the individual might consider especially important.

In response to these concerns, Harter (1982) proposed a *Correlated-Factor Model* where self-concept comprises multiple correlated domains (see Figure 2.2). One of these domains is *Global Self-Worth*, which is a separate holistic evaluation by the individual of their life experiences. This overall perception of self reflects the implicit weighting of domains which are more important to that particular individual, rather than the simple summation of scores from all domains. This supports the ration of pretension to success proposed by James (1890/1950), which suggested that domains invested with stronger pretension will impact self-concept to a greater extent than other domains. Thus, presenting an independent domain, such as *Global Self-Worth*, to assess an individual's overall perception of the self is likely to provide a more accurate evaluation.



Source: Adapted from Byrne (1996)

Figure 2.2 *Correlated-Factor Model* of self-concept proposed by Harter

2.1.4.4. Feature 4: Stable. The feature of stability is operationalised differently by various researchers. Shavelson et al. (1976) proposed that self-concept becomes increasingly more stable as the hierarchy is ascended, implying that individual experiences at the base are the least stable but that *General Self-Concept* at the apex of the hierarchy is more stable. On the other hand, Harter (1982, 1999, 2012a) relates stability to developmental stages, suggesting that self-concept becomes more stable with cognitive maturity. Both of these perspectives can co-exist. Harter (1982, 1999, 2012a) argues that younger children focus on individual experiences – depicted at the base of the hierarchy as described by Shavelson et al. (1976) – because their ability for abstraction has not yet developed. As children age, cognitive development permits for abstract thinking and they begin to group information into meaningful categories, progressing toward the apex of the hierarchy. As this occurs, children focus more on abstract categories rather than reacting to individual experiences; therefore, they display greater stability in self-concept as their cognition matures (Harter, 1982, 1999, 2012a). Thus, while younger children tend to react to immediate experiences to derive self-concept, older children learn to collate information from multiple similar experiences before deriving their self-concept relating to a specific aspect of life. Self-concept is viewed as a stable construct, in the sense that it does not change on a daily basis; rather, self-concept evolves over time with increases in social experience and cognitive maturity.

2.1.4.5. Feature 5: Developmental. This feature highlights self-concept as constructed and evolving on the basis of one's increasing cognitive sophistication in the interpretation of iterative social experiences. When a child develops cognitively, the interpretation of social experiences becomes more sophisticated, prompting complex formation of abstract categories. Thus, it is not surprising that the complexity of the self-concept structure is heavily related to developmental stages (Cole et al., 2001; Marsh, Craven, & Debus, 1998). Furthermore, an increased variety of social experiences influences the saliency of self-concept domains across developmental stages (Harter, 2012a). Thus, self-concept evolves as the individual matures, and this development influences the salient self-concept domains to surface at different stages of life.

2.1.4.6. Feature 6: Evaluative. Shavelson et al. (1976) proposed that individuals evaluate their performance against three internal standards: (i) personal standards, which reflect one's personal ideals for specific behaviours, (ii) relative standards, which reflect one's ability to demonstrate benchmarked behaviours based on peers behaviours, and (iii) perceived standards, which reflect one's ability based on the opinions of significant others. This *evaluative* feature represents the cognitive processes of the basic self-concept framework (see Figure 1.1) which analyse and interpret social experiences that are later used to adjust existing standards or create new standards.

Personal standards are people's internal benchmarks or ideals for specific behaviours. James (1890/1950) describes personal standards as pretensions and proposed that people activate behaviours that strengthen or confirm their pretension.

Thus, during the process of self-concept evaluation, people evaluate their behaviour against personal standards. Living a social existence, people’s behaviours are also influenced by those around them (C. H. Cooley, 1902/1964; Mead, 1934) and the behaviours of others are grouped to form relative and perceived standards (Shavelson et al., 1976). Relative and perceived standards guide people’s behaviour in conforming to their society and to gain the acceptance of peers and the acknowledgement of significant others. People are driven to be a part of their society and so they adopt their relative and perceived standards into their personal standards (Shavelson et al., 1976). Thus, personal standards reflect the individual’s internal reference of self-concept after taking into consideration both relative and perceived standards.

This *evaluative* feature proposed by Shavelson et al. (1976) is widely accepted by contemporary researchers including Rosenberg (1965), Marsh and Shavelson (1985), Harter (1982, 1999, 2012b) and Hattie (1992) as a core component of self-concept. Andrews (1991) also acknowledged a similar feature of self-concept in his work with adults with depression using the self-confirmation approach. While the self-confirmation approach proposed by Andrews describes a similar evaluative process, the approach does not describe other features of self-concept proposed by Shavelson et al.. In essence, the *Evaluative* feature is an essential component in the maintenance of the basic self-concept framework.

2.1.4.7. Feature 7: Differentiable. This last feature proposes that self-concept is differentiable from other constructs. Although many constructs may be theoretically related to self-concept – such as motivation, self-efficacy, or quality of life – self-concept should be clearly differentiated from these constructs, making self-concept a unique construct (Shavelson et al., 1976).

2.1.5. Conceptualising self-concept for this research program. Early research into the *study of self* helped to operationalise self-concept by identifying the three fundamental components: the *I-self*, the *Me-self*, and the *looking-glass self* (C. H. Cooley, 1902/1964; James, 1890/1950; Mead, 1934). Shavelson et al. (1976) integrated these components as well as identifying other necessary features in their description of what today is known as self-concept. Upon reviewing the development of the construct of self-concept, a working definition was adopted for this research program: *self-concept is described as an individual's perception of a set of attributes or characteristics that represents them as a person*. The features of self-concept that are key considerations for this thesis are:

1. *Interactive and Iterative* – Self-concept is developed as a result of the interaction between cognitive processes and social experiences via a self-concept framework.
2. *Multidimensional* – Self-concept comprises multiple domains that are salient to the target population. One of these domains is an independent domain to assess overall perception of the self.
3. *Evaluative* – Self-concept is evaluated as part of the cognitive processes within the self-concept framework. Personal, relative, and perceived standards are engaged in the process of evaluation. Salient domains receive greater attention than less salient domains.

These features are incorporated to expand the basic self-concept framework (see Figure 1.1) introduced in Chapter 1 to conceptualise the *Self-Concept Feedback Loop* (see Figure 2.3) proposed for this research program.

Figure 2.3 illustrates the *Self-Concept Feedback Loop* proposed for this research program. Self-concept is multidimensional, containing a number of self-concept domains. An individual’s behaviour in social experiences is influenced by their self-concept in relevant domains. During these social experiences and in response to their own behaviour, individuals may observe the reactions and behaviour of others – both towards themselves and through vicarious learning opportunities – and learn environmental cues. Individuals engage with this information cognitively and make comparisons between this external feedback and their internal standards, judging their behaviour against personal, relative and perceived standards. This interpretative process is used to adjust existing standards or create new standards. Relative and perceived standards are often absorbed to form personal standards. Lastly, the adjusted or new standards influence changes in self-concept, altering the relevant domain lens that an individual uses to view their environment and themselves. This thesis is written in reference to and understanding of self-concept based upon this working definition and the three features.

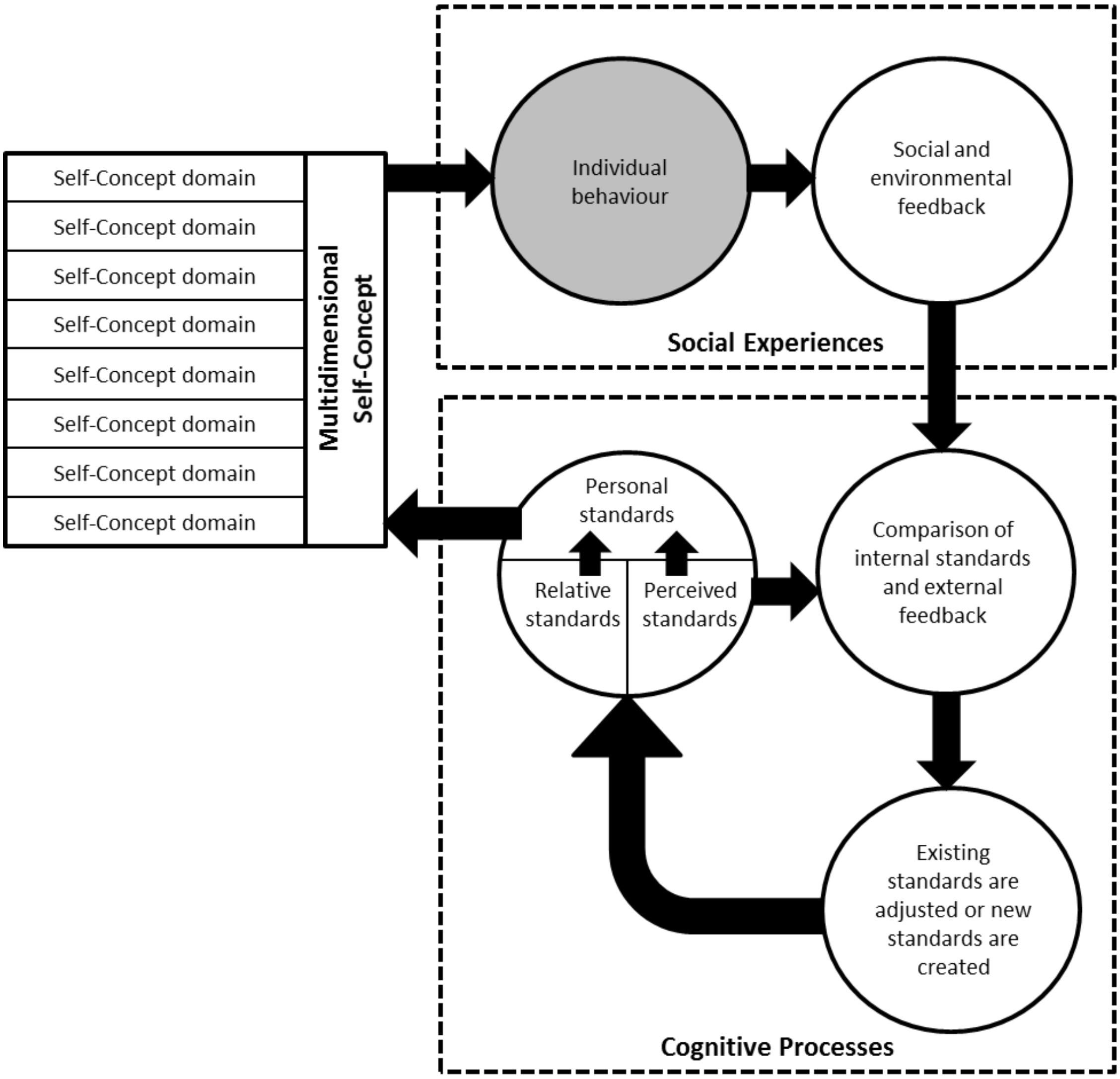


Figure 2.3 The *Self-Concept Feedback Loop* proposed for this research program

2.2. Developmental Constructs of Self-Concept Occurring during Childhood

To effectively assess self-concept, it is necessary to understand the developmental constructs of self-concept. Pioneer researchers believed that self-concept is not innate (C. H. Cooley, 1902/1964; Mead, 1934) and later researchers confirmed that self-concept is the result of developmental processes (Lewis & Brooks-Gunn, 1979). A review of literature identified six cognitive stages that children attain prior to mastering the ability to conceptualise and evaluate self-concept as illustrated in the *Self-Concept Feedback Loop* (see Figure 2.3). Briefly described, the awareness of the self emerges over the first two years of life due to children’s interaction with their environment (Lewis & Brooks-Gunn, 1979). The awareness of the self includes (i) bodily awareness, (ii) self-recognition, and (iii) language development – specifically, the use of personal pronouns. Self-concept begins to develop when an awareness of the self is achieved. Between three and eight years of age, children develop cognitive skills that facilitate the development of self-concept (Damon & Hart, 1982; Eder, 1990; Harter, 2012a) including (iv) abstract thinking, (v) social comparison, and (vi) a theory of mind. All these stages are cognitive processes crucial to activating and maintaining the *Self-Concept Feedback Loop*. These stages are described below, concluding with the identification of the target age group for this research program.

2.2.1. Awareness of self. The awareness of the self begins with *bodily awareness* when children develop the ability to differentiate between ‘me’ (i.e., their physical body) and ‘not me’ (i.e., things in the environment that are not part of their body; Lewis & Brooks-Gunn, 1979). Children learn to interact with their environment when they realise that they have control over their body (e.g., they move their hands and legs purposefully) and that their actions can evince reactions from their environment (e.g., kick the mobile and mobile moves; Bullock & Lutkenhaus, 1990). Bodily awareness is attained when children are able to see themselves as independent objects that are separate from things around them.

Following the achievement of bodily awareness, children develop *self-recognition*, first demonstrated by being able to identify oneself in a mirror and, later, in pictures (Bullock & Lutkenhaus, 1990; Lewis & Brooks-Gunn, 1979). The onset of self-recognition is related to cognitive maturity because this feature is less prevalent in children younger than two years of age (Ramsay & Lewis, 1998); in animal research it is only present in higher primate species (Anderson & Gallup, 2015). Self-recognition is an important developmental stage because the self truly begins to develop when children can cognitively recognise themselves as an entity which they can control to make changes to their environment.

One of the most important facilitators of an awareness of the self is the development of language skills (Mead, 1934). The *use of personal pronouns* indicates that children can identify themselves and distinguish themselves from others (Lewis & Ramsay, 2004) in both verbal and non-verbal communication (e.g., sign language; Koester & Forest, 1998). Children with severe communication impairments, such as autism, who do not use personal pronouns, fail to demonstrate self-recognition (Spiker & Ricks, 1984).

In summary, bodily awareness, self-recognition, and the use of personal pronouns play a key role in the emergence of the self. Children use the language skills developed in the first two years of life to interact with their environment in order to collect, analyse and interpret the outcomes of social experiences. This information then forms the unique attributes that represent the self, independent of others. These unique attributes comprise the individual's self-concept. The subsequent stages of cognitive development facilitate the activation and maintenance of the *Self-Concept Feedback Loop*.

2.2.2. Cognitive skills that facilitate self-concept development. *Abstract thinking*, *social comparison*, and *theory of mind* are three important cognitive skills that facilitate self-concept development. First, *abstract thinking* is necessary for children to organise attributes into meaningful categories that forms multidimensional structure of self-concept domains. Abstract thinking develops over multiple phases during childhood and, at each phase; children gain a still stronger grasp of abstract concepts.

Evidence of abstract thinking emerges at about age five. While children younger than this demonstrate the ability to group similar information into categories, their self-concept domains focus mainly on concrete and observable attributes related to their physical body (e.g., “I have black hair”), activities (e.g., “I can catch a ball”), or possessions (e.g., “I have a bike”) which are used to describe themselves (Damon & Hart, 1982; Eder, 1990). From ages 5-7, children move beyond these superficial categories to form clusters of abstract concepts which represent their competencies (Damon & Hart, 1982; Eder, 1990; Harter, 2012a). For example, competency for playing with balls may include the ability to catch, throw, and bounce a ball.

By approximately age eight, children achieve sufficiently complex abstract thinking to enable them to construct a multidimensional structure of self-concept as illustrated in the *Self-Concept Feedback Loop*. Children create broader competency domains by combining several relevant attributes (Brinthaupt & Lipka, 1985). For example, experiences of running, high jump, and long jump may be combined to construct their profile of an athletic self-concept domain.

The foundations of self-concept domains are developed during preadolescence (between ages 8-12; Harter, 2012a; Marsh, 1990), and thereafter, self-concept continues to be shaped by social experiences across their lifespan. However, Montemayor and Eisen (1977) caution that the development of self-concept is not an additive process of combining earlier simple concepts to later abstract concepts; rather a careful selection of relevant aspects are integrated and other less important aspects are discarded to create a complex picture that reflects their current self. Due to cognitive maturity and changes in social experiences, self-concept domains may emerge at different life stages that are distinctive of preadolescence (ages 8-12 years), adolescence (ages 13-17 years), and adulthood (18 years and older; Harter, 2012a; Marsh, 1990). These are dependent on social and cultural influences (Hattie, 1992). For example, *Job Competence* or *Romantic Appeal* self-concept domains only become relevant to individuals during adolescence and adulthood.

Given that the capacity for abstract thinking is central to the development of self-concept, the complexity required to activate and maintain the self-concept loop is not evident until approximately eight years of age (Harter, 2012a; Marsh, 1990). Thus, self-concept can be effectively measured from that age onwards.

Second, *social comparison* is a cognitive skill necessary to facilitate self-concept development. Self-concept evaluation requires children to assess their behaviour against personal, relative and perceived standards. An evaluation against personal standards is possible once children acquire the ability to conceive the self around ages 2-3 years (Harter, 2012a; Montemayor & Eisen, 1977). The capacity to recognise and evaluate self-concept against relative standards then emerges around age eight, once children can use social comparison skills to gauge their behaviour or performance against peers (R. Butler, 1998; Damon & Hart, 1982). Social comparison can be conducted using direct observation or inferences drawn from the opinions of others. Inference is a cognitive developmental stage involving the *theory of mind*.

The theory of mind –the awareness and beliefs about one’s own mental activities or thoughts – is an essential cognitive component that is necessary for self-concept development (Eisbach, 2004). Between ages 6-8, children’s theory of mind extends to a more elaborate and refined stage in which children understand that each person’s mind is separate and that thoughts in their mind are private (Damon & Hart, 1982). This cognitive development explains the increased prevalence of pretension and success proposed by James (1890/1950) for children at this age. Children freely form pretensions or wishes about what or who they want to be which shape their personal standards; and they engage in behaviours that drive them to achieve these personal standards. However, given that people are social beings, personal standards are often influenced by social standards (e.g., peers and significant others) and the social environment (e.g., cultural values, social economic status; C. H. Cooley, 1902/1964; Hattie, 1992). Children master the skill of assuming roles around ages 6-8, which allows them to collect information about their behaviour from different sources that include personal opinion, observation of peers, and inferring the opinions of others (Miller, Hardin, & Montgomery, 2003; Selman & Byrne, 1974). Following that, children can internalise the opinions of others (i.e., relative and perceived standards) using those opinions as guides to adjust existing personal standards or create new personal standards (Damon & Hart, 1982). Thus, by about age eight, children have the cognitive ability to engage in self-concept evaluation using personal, relative and perceived standards.

2.3. Target Age Group for This Research Program

The preadolescence stage, ages 8-12, was specifically chosen as a focus for this research program because this is the earliest possible stage where children demonstrate skills that enable them to conceptualise self-concept as described in the working definition for this research program. By 8-years-old, children’s cognitive and social abilities are adequate for a more sophisticated perspective of self-concept with greater accuracy than younger children. Cognitively, they are able to grasp abstract concepts which enable them to categorise information to form multiple domains, creating the multidimensional feature of self-concept. Furthermore, by preadolescence, children gain the ability to evaluate self-concept using all three standards: personal, relative, and perceived standards. Jointly, these cognitive processes allow preadolescent children to successfully activate the *Self-Concept Feedback Loop* (see Figure 2.3).

In addition, developmental studies indicate that preadolescent children may report lower self-concept than older age groups (Cole et al., 2001; Harter, 2012a; Marsh, 1989). Self-concept constructed during preadolescence is the foundation for later developmental stages; thus, this stage is a crucial monitoring period to ensure that preadolescent children have a strong foundation. A strong foundation in early years is important because self-concept not only acts as a *protective factor* from environmental stressors but is also a key element to *motivate* individuals to engage in social experiences that are consistent with their *direction* of their ideal self.

In summary, the preadolescence stage was chosen for this research program because, by this stage, children are able to effectively perceive and evaluate self-concept as stipulated in the working definition. A better understanding of the self-concept of preadolescent children can assist in establishing a strong foundation for self-concept as the child enters adolescence. In the next section, the common self-concept models and measurements available for this target age group are discussed.

2.4. Self-Concept Models and Measurements

Self-concept models reflect ideas of self-concept which vary across authors. Thus, like the definition of self-concept, there is no universally accepted model of self-concept. Five common models that utilise the multidimensional approach are the: *Independent-Factor Model, Compensatory Model, Taxonomic Model, Hierarchical Model,* and *Correlated-Factor Model*. Table 2.2 summarises these five common models by their key features and provides examples of instruments suitable for preadolescent children. A critique of each of the five models with reference to their suitability for the current research program is provided in the following paragraphs.

Table 2.2 Summary of common self-concept models that use a multidimensional approach

Models	**Features**	**Example of instruments for preadolescent children**
Independent-Factor	Independent dimensions Provides independent domain scores	Affective Perception Inventory
Compensatory	Domains with bipolar relations	None identified
Taxonomic	Domains with multiple levels	Tennessee Self-Concept Scale Multidimensional Self Concept Scale
Hierarchical	Domains arranged in a hierarchy Provides domain scores and *General Self-Concept* score	Self-Description Questionnaire I
Correlated-Factor	Correlated domains Provides domain scores	Self-Perception Profile for Children

Both the *Independent-Factor Model* and the *Compensatory Model* have only limited psychometric testing to confirm their structure and, therefore, they remain as theoretical frameworks only. The Independent-Factor Model was proposed by Soares and Soares in the development of their self-concept instrument, the Affective Perception Inventory (Soares & Soares, 1980, 1981). The authors suggested that self-concept consists of multiple independent domains where each domain functions in isolation and does not correlate with other domains. The Compensatory Model proposed by Marx and Winne (1980) describes a hierarchical structure of domains with bipolar relations for each domain. The authors suggest that self-concept consists of compensatory domains that act as internalised balancers of overall performance. To date, however, these papers are the only evidence for these models and nothing further supports the continued use of these models. Thus, their weak empirical support makes them unsuitable for adoption for the current research program.

The *Hierarchical Model* is not consistent with the working definition adopted for this research program. Validated by Marsh and Shavelson (1985), the Hierarchical Model views self-concept in a hierarchical structure with *General Self-Concept* at the apex. The hierarchy is divided into domains (e.g., *Academic Self-Concept, Non-Academic Self-Concept*), subdomains (e.g., *Mathematics, Physical Abilities*), and, lastly, specific behaviours (e.g., “Work in mathematics is easy for me”, “I can run fast”). In the Hierarchical Model, the *General Self-Concept* is the summation of all domains. The Self-Description Questionnaire-I (Marsh, 1992) is an example of an instrument developed from this model. Since the summation of domain scores into a *General Self-Concept* score is at odds with the working definition of self-concept adopted for this research program, the Hierarchical Model was not considered appropriate.

For the purpose of this research program, elements from two separate models were adopted and merged to create a new model that reflects the working definition of self-concept outlined earlier. First, elements from the *Correlated-Factor Model* were adopted because it was developed with a similar ideology as the working definition for this research program. The Correlated-Factor Model views all domains, specific self-concept and *Global Self-Worth* to be on an equal level and expected each self-concept domain to correlate (Byrne, 1996). *Global Self-Worth* is considered an independent domain rather than a summation of other domains, which assesses an overall perception of the self (Harter, 1982). The Self-Perception Profile for Children (Harter, 1985) is an example of an instrument applying the Correlated-Factor Model.

Second, elements from the *Taxonomic Model* were adopted because the unique feature of multi-levels assessment is on top of the multidimensional approach of self-concept evaluation (Byrne, 1996). The Tennessee Self-Concept Scale (Fitts, 1965) and the Multidimensional Self Concept Scale (Bracken, 1992) are examples of instruments that employ this model. The multi-levels assessment captures evaluation of self-concept with greater sophistication. In combination, both models provide the platform to enable the evaluation of self-concept which can encompass all the elements of the working definition for this research program.

The Correlated-Factor Model supports the *Multidimensional* feature whereby self-concept considers multiple domains alongside an independent domain to assess the overall perception of the self. Furthermore, this model provides the flexibility for investigating and including salient domains identified for the target population. The inclusion of the Taxonomic Model provides the platform to include the *Evaluative* and the *Interactive and Iterative* features proposed in the working definition of self-concept. According to the *Evaluative* feature, the evaluation of self-concept using the *Self-Concept Feedback Loop* – based on the *Interactive and Iterative* features – engages personal and social (i.e., relative and perceived) standards. Just as social experiences shape the individual's social standards, these social standards influence the individual's personal standards. The interaction between personal and social standards is not distinctly differentiated in existing self-concept instruments for preadolescent children. Applying the multi-level component allows the assessment from the perspectives of personal and social standards to be differentiated.

Furthermore, the *Evaluative* feature also stipulates that self-concept evaluation varies between individuals depending on the importance of specific domains for the individual. By incorporating an importance rating as a separate level, this model can tease out significant factors that influence self-concept for individual children. Thus, isolating the perspectives of personal and social standards as well as the inclusion of an importance rating can broaden the understanding of this construct and eventually provide an advantage for clinicians when formulating interventions for individual clients. The structure of the new model is described in the next section.

2.5. A New Self-Concept Model Proposed for this Research Program

Elements from two separate models, the Correlated-Factor Model and the Taxonomic Model, were adopted and combined to reflect the conceptualisation of self-concept for this research program (see section 2.1.5). A new model was proposed using a 2×2 matrix model to evaluate the salient domains of self-concept (see Figure 2.4).

The 2×2 matrix model targets self-concept assessment from two perspectives across two evaluation aspects (see Figure 2.4). The *Perspective* component consists of two perspectives: (i) *Personal* – an evaluation based on personal standards, and (ii) *Social* – an evaluation based on social standards. The *Evaluation* component also consists of two aspects: (i) *Performance* – the performance of a specific self-concept domain evaluated by reflecting on success or failure in reference to personal and relative standards, and (ii) *Value* – the importance of a specific self-concept domain evaluated by the individual.

The *Performance* and *Value* evaluations are an interpretation of James' (1890/1950) theory of pretension and success. *Performance* represents success evaluated in comparison to personal standards (i.e., comparing current achievement to past achievement) and relative standards (i.e., comparing personal achievement to the achievements of others, usually peers). *Value* represents pretension viewed from personal desires (i.e., personal desire to succeed) and perceived desires (i.e., the individual's perception of the desires of significant others towards their performance). By combining these components, the matrix model delivers four quadrants – *Personal-Performance* (Quadrant A), *Social-Performance* (Quadrant B), *Personal-Value* (Quadrant C), and *Social-Value* (Quadrant D) – as illustrated in Figure 2.5. These quadrants are described in greater detail in the following paragraphs.

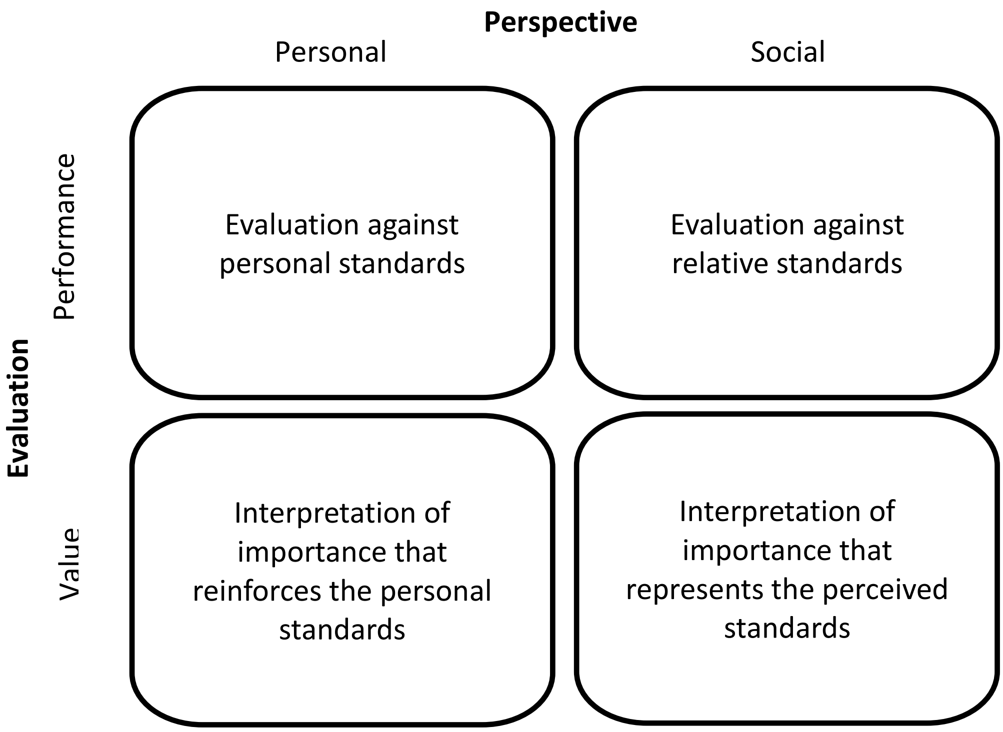


Figure 2.4 Development of the new matrix model of self-concept for this research program

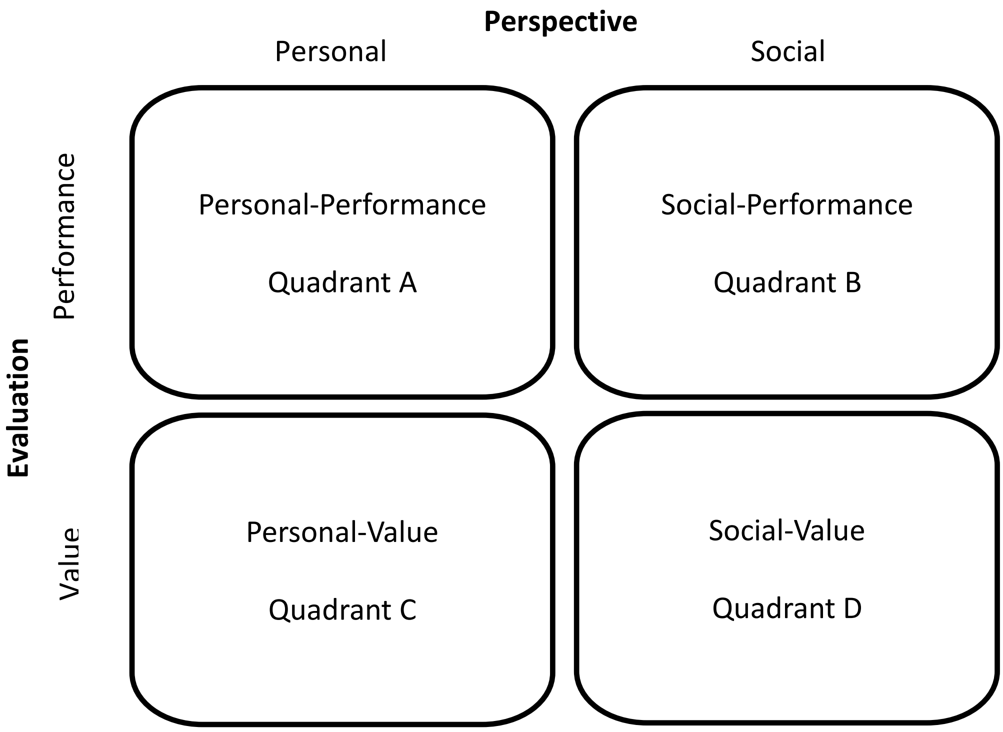


Figure 2.5 Self-concept matrix model proposed for this research program

Personal-Performance and *Social-Performance* (Quadrants A and B) are the key *Evaluative* features of self-concept that maintain the *Self-Concept Feedback Loop*. *Personal-Performance* focuses on the individual's evaluation of their own ability, achievement, limitations, or failures from the perspective of their personal standards. However, *Social-Performance* utilises social comparison as an evaluative tool to appraise one's performance against that of others. Individuals compare themselves to others who are performing similar tasks to determine the success or failure of their behaviour. Both quadrants are similar to Rosenberg's (1965) theory of self-esteem which evaluates an individual's *attitude of the self*. These are the most common features in existing self-concept instruments. Currently, the *Personal* and *Social Perspectives* have not yet been differentiated distinctly in the existing instruments. Thus, this model offers new information for research and clinical practice.

Personal-Value (Quadrant C) is an evaluation of the importance or significance that an individual places on a specific self-concept domain. As James (1890/1950) proposed – and as supported by Harter (2012a) – the greater the importance placed on a domain, the greater the impact of success or failure for that domain on self-concept. For example, an individual who has no aspiration to excel at mathematics will not think badly of themselves if he/she achieves poorly in mathematical tasks. In this case, encouragement to improve in this area is unlikely to significantly increase his/her motivation to engage in related tasks because it is not important to him/her. On the other hand, an individual who aspires to attain a mathematics award at school may think badly of him/herself in response to an even minor mistake on a mathematical task. In this case, comments on his/her failure may cause significant deterioration of self-concept. However, encouragement will likely provide hope for possible success in the future; leading to a higher motivation to strive for success in mathematical-related tasks. Assessing *Personal-Value* can provide insight into children's aspirations in life that motivate them to engage in tasks related to a specific self-concept domain.

Like *Personal-Value*, *Social-Value* (Quadrant D) is an evaluation of importance or significance; however, *Social-Value* is based on the perception or standards set by significant others – otherwise known as perceived standards. Although perceived standards are part of the self-concept *Evaluative* self-concept feature, they are rarely assessed because they are viewed as an internalised process that adopts the opinions of others to adjust personal standards. Since humans are social beings, the way that individuals view themselves – like C. H. Cooley (1902/1964) describes the *looking-glass self* – is guided not only by internal markers but also by social reactions (i.e., the "social mirror"). The social mirror is unique for each individual and depends on the environment and the values or beliefs of their social context (C. H. Cooley, 1902/1964; Hattie, 1992). Thus, *Social-Value* identifies an individual's social mirror, in order to assist the understanding of perceived standards. For preadolescent children, perceived standards are often obtained from significant authority figures, such as parents or teachers, and are absorbed as personal standards or desires. If an individual perceives that a domain is highly valued by people significant to them, then that individual may be more willing to strive for success in that domain and absorb the perceived value as a personal desire. This is observable in preadolescent children because they are still dependent on their caregivers, such as their parents at home or their teachers at school. This relationship with caregivers gradually shifts as the child reaches adolescence because people who are significant to them begin to include peers or interest groups (Harter, 2012a). *Social-Value* represents the individual's view of the expectations that significant others have of him/herself which indirectly affects their self-concept.

The new self-concept model, mapped across the 2×2 matrix model, provides a comprehensive evaluation framework for assessing self-concept that targets the salient domains for the population in focus. Moreover, this self-concept evaluation takes into consideration *Importance Rating* and discerns the contribution of *Personal* and *Social* standards to self-concept.

2.6. Summary

The working definition for this research program stipulates that self-concept has three features including (i) *Interactive and Iterative* which represents the *Self-Concept Feedback Loop*, (ii) *Multidimensional*, comprising domains that are relevant to the target population, and (iii) *Evaluative*, which evaluates self-concept from personal, relative, and perceived standards. The proposed self-concept model incorporates elements from the Correlated-Factor Model within the Taxonomic Model using a 2×2 matrix to encompass all three features of self-concept that have been conceptualised for this research program.

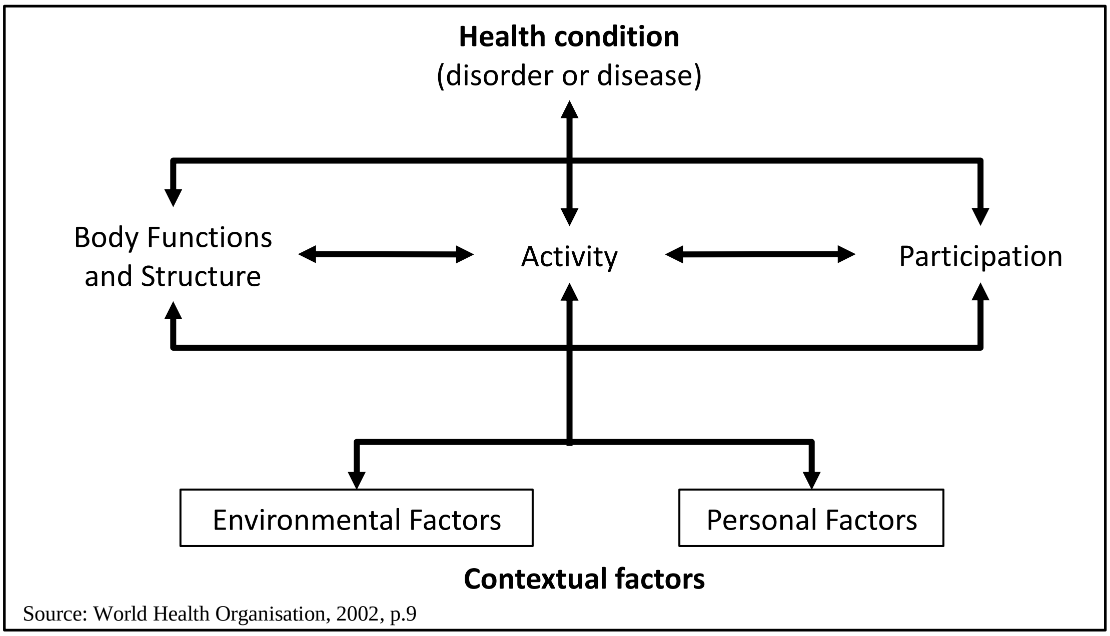
Chapter 3. Overview of Disability and Cerebral Palsy

This chapter offers a brief overview of disability before providing information about CP including a definition, prevalence data, and the clinical characteristics of individuals with CP. The construct of self-concept in the context of children with CP is also discussed.

3.1. Disability

There is no universally accepted definition of disability. Developments in the definition parallel the growth of scientific knowledge and evolving cultural perspectives (Odom, Horner, Snell, & Blacher, 2007). World Health Organisation (WHO) describes disability as "… the umbrella term for impairments, activity limitations, and participation restrictions …" (WHO, 2011, p. 4). WHO conceptualises disability using the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2002; 2016).

The ICF framework is a biopsychosocial model where disability and functioning are regarded as an outcome of the interaction between the *Health Condition* (e.g., diseases, disorders, or injuries) and *Contextual Factors* which include *Environment* and *Personal Factors* (World Health Organisation, 2002, 2016; see Figure 3.1). The ICF framework classifies human functioning at three levels to comprise functioning of the body or body part, the whole person, and the person in a social context. Disability implies a dysfunction at one of these levels: (i) impairment to *Body Functions* (i.e., physiological functions of body system) or *Body Structures* (i.e., anatomical parts of the body), (ii) *Activity Limitations*, or difficulties in executing activities, and (iii) *Participation Restrictions*, which are problems with involvement in life situations (WHO, 2002, 2016). The following sections will focus on children with CP within this framework of disability.



Source: World Health Organisation, 2002, p.9

Figure 3.1 The International Classification of Functioning, Disability and Health Framework recommended by the World Health Organisation (2002)

3.2. Cerebral Palsy

CP was chosen as the focus of this research program because the activity limitations and participation restrictions experienced by children as a result of CP may lead to self-concept concerns. As one of the most commonly diagnosed neurodevelopmental conditions in childhood (Krigger, 2006), the psychosocial needs of these children are important to consider. In this section, the definition of CP, its prevalence, and the characteristics of children with CP are detailed.

3.2.1. Definition. The internationally accepted definition of CP established through a consensus survey indicates that:

> Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are

> attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems (Rosenbaum et al., 2006, pp.9).

According to the directional arrow in the ICF framework (see Figure 3.1), the motor dysfunction, activity limitations, and participation restrictions experienced by children with CP influence one another, affecting the interaction between the child's disability and contextual factors. In combination, the impairments experienced by children with CP may interfere with their self-concept development as described in the *Self-Concept Feedback Loop* (see Section 2.1.5, Figure 2.3). However, as the primary feature of CP is the physical disability, psychological functions are often neglected in both research and clinical practice. This research program aims to address this gap in literature.

3.2.2. Prevalence. The prevalence rate of CP has been consistently recorded at about 2 to 2.5 per 1000 children in Western countries over the past 40 years (Rosenbaum & Rosenbloom, 2012), including Australia (ACPR Group, 2013). Published prevalence rates in Asian and African countries are rare, possibly due to the lack of research and inconsistent birth record keeping in some countries. Like other countries, CP is more prevalent in Australian males, who account for 57.3% of those with CP compared to the national population's average male birth rate of 51% (ACPR Group, 2013).

Being a permanent and non-progressive condition, individuals with CP will require suitable services to meet their physical, social, and psychological needs throughout their lives. This continuous demand for services justifies the need to extend research into all areas of physical, social, and psychological functioning. Further research into the psychological needs of individuals with CP has the potential to inform better treatment selection for these individuals.

3.2.3. Characteristics of individuals with cerebral palsy. Individuals with CP present with a wide range of CP-related characteristics. Classification systems are necessary to differentiate these characteristics to promote better understanding and effective management of the difficulties experienced by individuals with CP (Rosenbaum et al., 2006). The characteristics of individuals with CP are classified into four major dimensions, listed in Table 3.1 and described in the following paragraphs.

Table 3.1 Components of CP classification as recommended by Rosenbaum et al. (2006)

Dimensions	**Description**
1. Motor abnormalities	
A. Nature and typology of the motor disorder	The observed tonal abnormalities assessed on examination and the diagnosed movement disorders.
B. Functional motor abilities	The extent to which the individual is limited in his/her motor function.
2. Accompanying impairments	The presence and absence of later-developing musculoskeletal problems and/or accompanying non-motor neurodevelopmental or sensory problems, and the extent to which these impairments interact.
3. Anatomical and neuro-imaging findings	
A. Anatomic distribution	The parts of the body affected by motor impairments or limitations.
B. Neuro-imaging findings	The neuroanatomic findings on computerised tomography (CT) or magnetic resonance imaging (MRI) imaging.
4. Causation and timing	Assessment of clearly identifiable cause and the presumed time frame during which the injury occurred, if known.

Source: Adapted from Rosenbaum et al. (2006) p.12

3.2.3.1. Motor abnormalities. *Motor abnormalities* are divided into two parts: (a) the nature and typology of the motor disorder, and (b) functional motor abilities. The first, *nature and typology of the motor disorder*, describes the assessment of abnormal muscle tone and identifies the type of motor disorder. There are four types of motor disorder. These are presented in their order of prevalence: (i) spasticity – resistance to movement either increases with speed or changes with varying direction of joint movement (86.5%); (ii) dyskinesia – involuntary, uncontrolled and recurring movements which are further divided into dystonia and choreoathetosis (5.9%); (iii) ataxia – inaccurate muscular coordination in movement (5.3%), and (iv) hypotonicity – reduced ability to activate movement due to low muscle tone (2.2%; ACPR Group, 2013; Rosenbaum et al., 2006; Sanger et al., 2003). Most individuals with CP are grouped within one of these groups but, in cases where a predominant feature is not observed, a mixed motor type group is described (Imms & Dodd, 2010; Rosenbaum et al., 2006).

The second aspect, *functional motor abilities*, ascertains the extent of the motor impairments, and the potential impact of activity limitations and participation restrictions to motor function. Rosenbaum et al. (2006) recommend that functional consequences should be classified using standardised functional classification systems for individuals with CP. Two of the recommended functional classification systems are the Gross Motor Function Classification System – Extended and Revised (GMFCS-E&R) and the Manual Ability Classification System (MACS).

3.2.3.1.1. Gross Motor Function Classification System – Extended and Revised. The GMFCS-E&R is a CP-specific, 5-level classification system used to describe the self-initiated gross motor movement of children with CP from birth to 18 years, for tasks such as sitting, standing, transfers and mobility (Palisano, Rosenbaum, Bartlett, & Livingston, 2007; Palisano et al., 1997). It classifies children according to functional abilities or limitations, including the use of mobility devices, and the quality of movement. General guidelines for each age bracket (ages 0-2, 2-4, 4-6, 6-12, and 12-18 years) are provided to describe motor ability levels as well as distinctions between levels. Classification ranges from Level I, where a child can walk without limitations, to Level V, where a child needs to be transported in a manual wheelchair. Children from Levels II to V require assistance for mobility, ranging from utilising assistive devices to aid with balance on uneven terrain such as sticks or crutches, to self-propelled or powered wheelchair.

3.2.3.1.2. Manual Ability Classification System. The MACS is a 5-level classification system designed to categorise the ability of children with CP to handle items in daily activities (Eliasson et al., 2006). The MACS ranges from Level I, where the child handles objects easily without assistance, to Level V, where the child cannot handle any object, and requires total assistance from others. Children from Levels II to V require assistance or adapted objects and surroundings to handle objects for performing manual tasks.

In summary, the *motor abnormality* dimension provides an indication of the type of motor disorder experienced by the individual as well as the degree of impairment caused by the motor disorder. Individuals with CP present with varying types and different degrees of impairment. This wide range of presentations suggests that children with CP are likely to experience their world differently from both TD children and in comparison with other children with CP. This differing experience may lead to a unique perception of self-concept for a child with CP compared to other children, with or without disability.

3.2.3.2. Accompanying impairments. Although motor impairment is the primary feature of CP, many individuals with CP experience other impairments such as secondary musculoskeletal problems and/or non-motor neurodevelopmental or sensory problems such as seizures, intellectual impairment, speech or communication impairment, hearing or visual impairments, attentional problems, and behavioural problems. These *accompanying impairments* can, and often do, affect individual capacity to perform daily living activities, which impedes social and emotional development to a greater extent than motor impairment (Rosenbaum et al., 2006). According to the ACPR, at age five, 30.7% of children with CP have epilepsy, 57.2% have intellectual impairment, 59.1% have speech impairment, 41.3% have visual impairment, and 10.5% have hearing impairment (ACPR Group, 2013). This high prevalence of accompanying impairments must be taken into account when assessing the impact of the condition on the social and emotion development of children with CP.

Like the functional motor abilities described above, an independent functional classification system is available to classify speech or communication impairment for children with CP. The Functional Communication Classification System (FCCS) is a 5-level classification system designed to classify the observable expressive communication of children with CP (Barty & Caynes, 2009; Caynes, Burmester, Barty, & Johnston, 2014). The FCCS ranges from Level I where a child has minimal to no difficulties communicating when compared to TD children to Level V, where a child is unable to communicate intentionally. Children from Levels II to V may require assistance to communicate or may utilise augmentative and alternative communication systems. Although not available when this research program was developed, the Viking Speech Scale (VSS; Pennington et al., 2013; Virella et al., 2016) is a 4-level scale that can now classify the motor speech of children with CP aged 5-18.

While psychometric evidence for cognitive assessment is not available for children with CP, Yin Foo, Guppy, and Johnston (2013) recommend a suite of cognitive assessments standardised for TD children, that could be used for subgroups of children with CP. These subgroups take into consideration the characteristics of CP, including *motor abnormalities, accompanying impairments*, and *anatomical distribution*. Internationally accepted functional classification systems specifically for children with CP are not available for the other areas of *accompanying impairments* identified in the classification of CP recommended by Rosenbaum et al. (2006).

In view of the high prevalence of accompanying impairments that have been observed for children with CP, it may be concluded that these impairments are as much a part of the life of children with CP as is their motor impairment. Similarly to the motor disorder, accompanying impairments may also influence how children with CP experience their surroundings. Their unique experiences in turn, may influence the development of their self-concept. Therefore, it is important to consider both the motor disorders and the accompanying impairments when considering the impact of CP on self-concept.

3.2.3.3. Anatomical and neuro-imaging findings. This dimension is also divided into two parts: *anatomical distribution* and *neuro-imaging findings*. Although the *neuro-imaging findings* are beyond the scope of this research program, these have the potential to predict the location, extent and timing of the brain injury, and therefore, can be indicative of *anatomical distribution* – the parts of the body that are impacted by the motor disorder (Rosenbaum et al., 2006). *Anatomical distribution* can also be ascertained through clinical assessment when neuro-imaging findings are not available. Rosenbaum et al. (2006) recommend that all body regions should be described independently regarding the type and extent of impairment. Despite the common use descriptors, such as hemiplegia, diplegia, and quadriplegia in clinical practice, the use of these terms as the sole descriptor of *anatomic distribution* is not recommended because these do not provide a complete description of all the bodily regions (Rosenbaum & Rosenbloom, 2012). According to the ACPR, hemiplegia – impairment in the arm and leg on the same side of the body (38.8%) – and diplegia – bilateral motor impairment of the legs, with minor limitations involving the arms in some cases (37.5%) – are the two most common presentations, followed by quadriplegia – impairments in both arms and legs, and trunk and facial muscles (20.9%; ACPR Group, 2013).

In combination, the three dimensions demonstrate the complexity of a CP presentation and further emphasize the range of abilities amongst individuals with CP. *Motor abnormalities*, *accompanying impairments*, and *anatomical distribution* are likely to influence the manner in which children approach their surroundings and, in turn, impact their self-concept. For example, a child with significant gross motor impairment may not be able to access all the play equipment in a conventional playground like their able-bodied peers or siblings. Activity limitations and participation restrictions experienced by this child is likely to impact their self-concept negatively, especially if the child values social inclusion with their peers or siblings in the playground. On the other hand, another child may have mild physical impairment but significant oral-motor impairment, and while the child has better access to the play equipment, the child may have difficulties participating in conversations with other children. Similarly, this may impact their self-concept negatively if they feel socially excluded because of their oral-motor difficulties during conversations. Thus, the different impairments experienced by each child with CP may impact the child's self-concept differently to other children with CP.

In view of the wide range of impairments experienced by children with CP, the evaluation of *Personal-Value* – the importance of a specific self-concept domain in reference to personal standards – becomes an integral part of assessing self-concept. The personal pretension elicited from *Personal-Value* can help explain an individual's evaluation of their *Personal-Performance* – success or failure in reference to personal standards – and *Social-Performance* – success or failure in reference to relative standards (see Section 2.5, Figure 2.4). Such comprehensive self-concept evaluation can assist clinicians in understanding an individual's pretension and the need for success in specific self-concept domains.

3.2.3.4. Causation and timing. CP is the result of brain injury in the prenatal period or in the first two years of life. For children with CP in Australia, 94.4% of brain injuries occurred during the prenatal or perinatal periods, which is the duration from pregnancy through to the first 28 complete days after birth (ACPR Group, 2013). The most common causes of brain injury during these periods include infection, complications during delivery, accidental injuries and other life-threatening events such as complications from surgery, life-threatening medical conditions, or accidents that caused brain trauma (Reddihough & Collins, 2003). Although *causation and timing* is crucial information for categorising the presentation of individuals with CP, it is not directly applicable to the scope of the current research program.

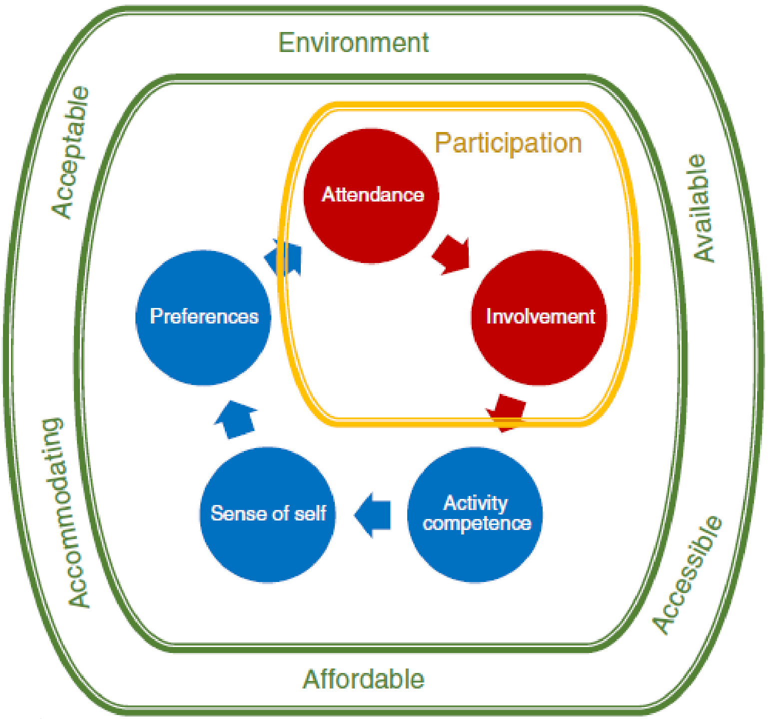
3.2.4. Summary. Individuals with CP present with a wide range of characteristics and, thus, standardised classifications are necessary to provide clarity in both research and clinical practice. Rosenbaum et al. (2006) classified CP using four major dimensions: *motor abnormalities*, *accompanying impairments*, *anatomical and neuro-imaging findings*, and *causation and timing*. Except for *causation and timing*, all dimensions have the potential to influence the development of self-concept. Given the wide range of impairments experienced by children with CP, it is likely that they engage with their environment differently from other children, with or without disability, leading to a unique perception of their self-concept.

3.3. Self-concept in the Context of Children with Cerebral Palsy

The construct of self-concept of children with CP is discussed in this section including the construct of self-concept within the ICF framework (see Section 3.3.1), and the relationship between self-concept and the characteristics of CP (see Section 3.3.2).

3.3.1. Self-concept in the ICF framework. Analysis of the ICF framework to understand self-concept reveals that, although the ICF framework includes domains and items with significant detail for *Body Functions and Structures*, there is significantly less detail for psychological functions. Psychological functions are referred to in the ICF *Body Functions – b1 Chapter 1 Mental Functioning* within the *Global Mental Functions* subsections of *b126 Temperament and Personality Functions* (e.g., extraversion, agreeableness, conscientiousness, psychic stability, openness, optimism, confidence, trustworthiness) and *b130 Energy and Drive Functions* (e.g., energy level, motivation, impulse control). Other psychological functions appear in the *Specific Mental Functions* subsections for mental or cognitive functioning (e.g., *b140 Attention*, *b144 Memory*, *b1640 Abstraction*, *b1521 Regulation of Emotion*; World Health Organisation, 2016). There is no specific subsection for the core psychological construct of self-concept, which presents a major limitation for international awareness and understanding of this important psychological construct. Consequently, the assessment and intervention for addressing self-concept concerns is rare in research and clinical practice for individuals with CP.

Imms et al. (2015) identified the importance of self-concept in their effort to clarify the processes underlying the construct of *Participation* within the ICF framework. In the *Participation Model* proposed by Imms et al. (2015), self-concept, which is termed the *Sense of Self*, plays a significant role in maintaining the relationship between the participation and participation-related constructs (see Figure 3.2). Greater *Sense of Self* increases an individual's confidence when selecting and participating in activities, and, by doing so, increases their *Preference* for the activity. *Preference* leads to the desire for *Attendance* (if the activity is available, accessible, and affordable for the individual) and *Involvement* (if the activity has been adapted to take into account limits and restrictions for the individual and is considered to be an acceptable activity to the individual and his/her community) in the selected activity. *Attendance* and *Involvement* represents *Participation*. Having activities that can be adapted for individuals help reduce their barriers for *Participation*. *Participation* then increases *Activity Competence* which, in turn, influences the individual's *Sense of Self*. For example, a child who has swimming skills but has low self-concept and lacks confidence in his/her abilities is unlikely to choose to attend and be involved in future swimming opportunities, even when these are presented. On the other hand, a child who, despite having only elementary swimming abilities, has high self-concept and is confident in his/her skill may be more likely to engage in swimming. Over time, this participation may increase their swimming competence and in turn strengthen their self-concept. Therefore, building a strong self-concept can enhance participation for children with disabilities like CP.



Source: Imms el al. (2015) p.36

Figure 3.2 A model of participation and participation-related constructs proposed by Imms et al. (2015)

This Participation Model shows consistency with the *Self-Concept Feedback Loop* (see Figure 2.3) where self-concept influences an individual's behaviour in social experiences (i.e., reflected as *Preference* and *Participation*). The outcome of these social experiences – the result of participating in an activity – is cognitively analysed and interpreted based on personal, relative, and perceived standards, which in turn influence self-concept. Favourable outcomes increase preference for, and participation in, these activities. Over time, participation increases competence which is reflected in the adjustment of personal standards, eventually influencing self-concept.

Currently, the ICF framework does not fully embrace psychological constructs such as self-concept, but findings from recent studies about *Participation*, a construct within the ICF framework, show that self-concept plays an important role in encouraging and maintaining participation. Given the current knowledge about the link between self-concept and participation for individuals with disability, it is valuable to re-examine how impairments experienced by children with CP, as defined by Rosenbaum et al. (2006), impact the self-concept of these children.

3.3.2. Relationship between self-concept and characteristics of cerebral palsy. Since CP presentations are wide ranging, Rosenbaum et al. (2006) proposed four dimensions to classify these characteristics to allow for better understanding and clinical management of individuals with CP. These dimensions give a sense of the extent of variability in the characteristics of individuals with CP. In the following paragraphs, the manner in which *motor abnormalities*, *accompanying impairments*, and *anatomic distribution* influence self-concept is discussed.

Figure 3.3 shows that *motor abnormalities*, *anatomical distribution* and *accompanying impairments* may impact individual's behaviour during social experiences. Individuals with CP may have an image of how they would like to behave based on personal, relative, and perceived standards but, when they engage in an activity, limitations caused by their impairment do not allow them to behave in the manner they desire. For example, children with oral-motor impairment may not be able to verbalise their thoughts as they wish due to their oral-motor abilities. This inability to achieve their intention may be interpreted as a personal failure. When they compare their performance to personal, relative, and perceived standards, their failure would emphasize their inability to achieve these standards which, in turn, impacts their self-concept evaluation.

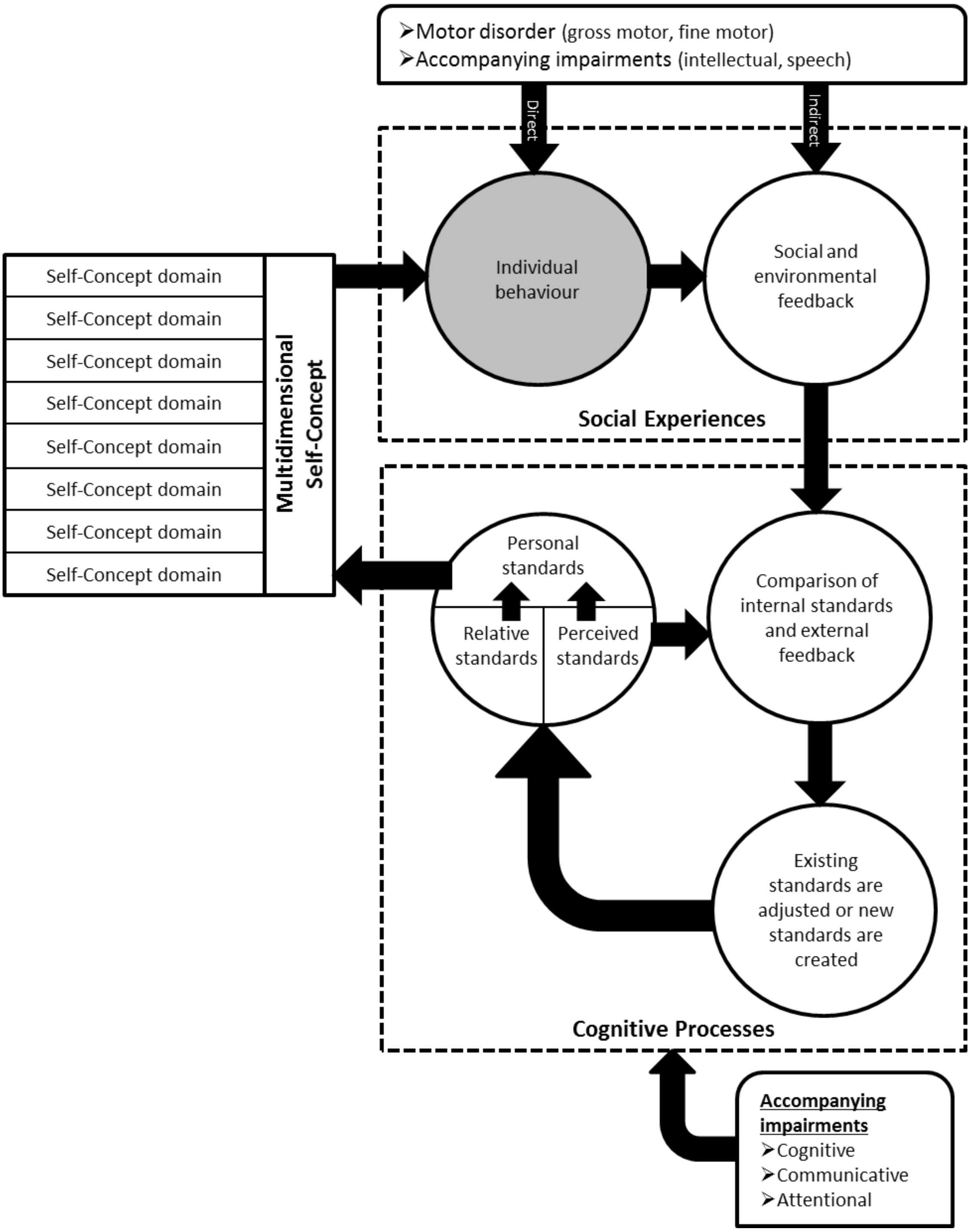


Figure 3.3 The *Self-Concept Feedback Loop* proposed for this research program, taking into consideration the impact of characteristics of CP

Furthermore, these aspects of CP also influence the reactions of others towards the individual. Children with oral-motor impairment may expect others to communicate with them in a manner similar to their peers; however, due to their oral-motor impairments, people who are not familiar with them may underestimate their capacity and “talk down” to them. This may initially trigger frustration but, over time, this pattern of response will likely impact their sense of worth and, in turn, affect their self-concept. As per the *Self-Concept Feedback Loop*, both of these social experiences will influence the individual’s self-concept.

Figure 3.3 shows that *accompanying impairments* such as communication, cognitive, and attentional difficulties may interfere with the *Self-Concept Feedback Loop*. In early research of the *study of self*, Mead (1934) proposed that language and cognition development are key factor in self-concept development. In view of the many children with CP that presents with impairments related to speech or communication as well as cognitive function, it is important to recognise that these impairments may interfere with their capacity to effectively maintain the *Self-Concept Feedback Loop*. Measurements of both communication and cognitive functions, which are required for self-concept evaluation, are necessary components for inclusion in self-concept studies involving children with CP (Llewellyn & Chung, 1997; von der Luft, DeBoer, et al., 2008).

In summary, the characteristics of CP play a major role in influencing the individual’s interaction with their social environment. *Activity Limitations* and *Participation Restrictions* caused by impairments to *Body Functions and Structures* may impact the *Self-Concept Feedback Loop* for children with CP. Despite the potential impact of CP on children’s self-concept and the inherent importance of self-concept, there is surprisingly little research that has investigated the self-concept of children with CP; this research program aims to fill this gap in the literature.

3.4. Summary

CP is a permanent and non-progressive condition that presents with impairment in *Body Functions and Structures* which leads to *Activity Limitations* and *Participation Restrictions*. However, given the limited representation of psychological needs in current disability frameworks, issues related to psychological functions for individuals with CP are often neglected in both research and clinical practice. The characteristics of CP can impact the *Self-Concept Feedback Loop* in many ways; it is, thus, simplistic to assume that the self-concept of children with CP is similar to that of TD children. Despite the impact of CP on self-concept, little research has been conducted in this area. Hence, the focus of this research program is the self-concept of children with CP. The next chapter will review literature around self-concept for this population.

Chapter 4. Literature Review of Self-Concept in Children with Cerebral Palsy

Despite extensive research with TD children, little self-concept research has been conducted with children with physical disabilities, especially children with CP. Due to the nature of CP as primarily a motor disorder, psychological functions, like self-concept, are often overlooked in the CP population. Nonetheless, a detailed examination of CP characteristics reveals that they may play a role in influencing the *Self-Concept Feedback Loop* (see Figure 3.3). In this chapter, self-concept studies involving preadolescent children with CP are reviewed. Several factors act to hamper the synthesis of this literature; these are articulated first to provide a framework for the interpretation of previous studies.

4.1. Barriers in the Synthesis of Self-Concept Studies Involving Children with Cerebral Palsy

The existing literature about self-concept for children with CP is affected by three factors that hampered the synthesis of this literature: (i) utilisation of different self-concept instruments, (ii) utilisation of non-population-specific self-concept instruments, and (iii) inclusion of samples of widely different age ranges. These concerns are discussed in the following paragraphs.

First, self-concept studies involving children with CP have utilised 14 different self-concept instruments, despite the small volume of these studies. As indicated in Chapter 2, the development of self-concept instruments is based on differing understandings of self-concept, and each instrument proposes a set of customised self-concept domains. Table 4.1 lists the 15 instruments and the customised self-concept domains. This variety in domains makes comparing of study outcomes challenging.

Table 4.1 Self-concept instruments that have been used in research with children with cerebral palsy and customised self-concept domains for each instrument

	BYSI	**I think I am**	**Piers-Harris**		**Purdue**	**PSPP**	**RSE***	**SDQ-I***	**PSPCSA**		**SPPA**	**SPPC**			**PSI-6**
			1st Ed.	**2nd Ed.**					**Original**	**Dutch***		**Original***	**Dutch***	**AUS***	
Global Score															
Global Self-Concept	●		●	●	●	●	●	●							●
Global Self-Worth											●	●	●	●	
Global Physical Self-Worth						●									●
Physical															
Athletic						●					●	●	●	●	●
Overall Motor Skills						●		●	●	●			●		●
Fine Motor														●	
Gross Motor														●	
Strength Competence						●									●
Intellectual															
Intellectual/ Scholastic			●	●					●	●	●	●	●	●	
Reading								●							
Mathematics								●							
General School								●							
Job Competence											●				
Social															
Social Acceptance			●	●					●	●	●	●	●	●	
Peer Relations		●						●							
Parent Relations		●						●	●	●					
Close Friends											●				
Romantic Appeal											●				
Personal Attributes															
Physical Appearance		●	●	●		●		●			●	●	●		●
Talents and Gifts		●													
Psychological															
Happiness and Satisfaction			●	●											
Psychological Health		●													
Freedom from Anxiety			●	●											
Behaviour			●	●							●	●			

Note: *Psychometric data for preadolescent children with CP is available; BYSI: Beck Youth Self-Concept Inventory (Beck, Beck, Jolly, & Steer, 2005); Piers-Harris: Piers-Harris Self-Concept Scale (Piers & Harris, 1969), Piers-Harris Self-Concept Scale 2nd Edition (Piers, Harris, & Herzberg, 2002); Purdue: Purdue Self-Concept Scale for Preschool Children (Cicirelli as cited in Teplin et al., 1981); PSPP: The Physical Self-Perception Profile (Fox & Corbin, 1989); RSE: Rosenberg Self-Esteem Scale (Rosenberg, 1965); SDQ-I: Self-Description Questionnaire-I (Marsh, 1992); PSPCSA: Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike, 1984); Dutch: PSPCSA Dutch modified version translated into English (Scholtes et al., 2002); SPPA: Self-Perception Profile for Adolescent (Harter, 2012b); SPPC: Self-Perception Profile for Children; Original: SPPC (Harter, 1985); Dutch: SPPC Dutch modified version (Komdeur, Schuur, Wijnroks, & Vermeer, 2001); AUS: SPPC Australian modified version (Ziebell, 2007); PSI-6: Physical Self Inventory 6 (Ninot, Fortes, & Delighnieres, 2001)

Second, most of these self-concept instruments were designed for TD children, with only a few reporting psychometric data for children with CP. Of the 15 self-concept instruments identified, only six reported psychometric information for children with CP (see Table 4.1). Given that the impairments experienced by children with CP are likely to influence their self-concept, utilisation of non-population-specific self-concept instruments is not recommended (Llewellyn & Chung, 1997; von der Luft, DeBoer, et al., 2008). It is not yet known if domains designed for TD children will encompass all aspects of self-concept for children with CP. Thus, study outcomes using non-population-specific instruments may not provide a comprehensive understanding of the self-concept of children with CP.

Third, the studies in this literature review include samples of widely different age ranges. Despite selectively extracting studies that involved preadolescent children with CP (8-12 years), the compilation of studies involved samples ranging from 3-20 years. Some studies do not take age and cognitive capacity into account in the assessment of self-concept. Since self-concept evolves over a person’s lifespan as a result of cognitive maturity and increased variety in social experiences (Cole et al., 2001; Harter, 2012a; Marsh, 1989; Shavelson et al., 1976), the differences in the perception of self-concept across that lifespan need to be taken into consideration when comparing outcomes of studies which include a widely different age range.

Overall, a synthesis of self-concept studies is difficult because of the barriers imposed by instrument and sample selection. The available self-concept studies for children with CP are reviewed in the following sections. Given that a large proportion of these studies focused on comparing the self-concept of children with CP to TD children, these studies are first discussed. Following that, studies that investigated factors associated with self-concept are discussed. Where possible, the review of studies in the following sections only includes analysis of preadolescent children aged 8-12 years.

4.2. Self-Concept in Children with Cerebral Palsy Compared to Typically Developing Children

In an attempt to understand the self-concept of children with CP, studies comparing children with CP to their TD peers have gained attention in the past three decades. Six controlled trials, three descriptive studies, and one longitudinal study have been identified (see Table 4.2). Two meta-analyses and one systematic review have also investigated studies which compared the self-concept of children with CP to TD children. The systematic review included six studies but reported inconclusive findings (Shields, Murdoch, Loy, Dodd, & Taylor, 2006) and thus, the relevant studies identified for this published review were extracted and included in discussion throughout this section. Both the meta-analyses included children with various health conditions (Ferro & Boyle, 2013b; Miyahara & Piek, 2006) and thus, only studies that were relevant to children with CP were extracted and included for discussion in this section.

Overall, findings from these studies reveal that children with CP report lower self-concept in selected domains compared to TD children. The findings will be discussed in the following paragraphs by domains (see Table 4.1 for details of the domains assessed by each self-concept instrument) to allow for more effective comparison.

Table 4.2 Studies comparing the self-concept between children with cerebral palsy and typically developing children

Author(s)	Instrument	Study design	Children with CP		TD children control group		Significant differences in self-concept; children with CP report
			n	Age (years) Mean; Range	*n*	Age (years) Mean; Range	
Adamson (2003)	I think I am	Descriptive study	7	15; 12-17	Normative data		Higher self-concept in most domains compared to normative data
Harvey and Greenway (1984)	Piers-Harris Children's Self-Concept Scale	Controlled trial[a]	19	Not stated; Total mixed sample range: 9-11	18	10.3; 7-15	Lower *Global Self-Concept*
Manuel et al. (2003)	Rosenberg Self-Esteem Scale	Descriptive study	50	13; 9-18	Normative data		Lower *Global Self-Concept* for 30% of participants
Russo, Goodwin, et al. (2008)	Self-Perception Profile for Children	Controlled trial[b]	3-7 years (*n*=31) 8-16 years (*n*=55)	9.4; 3-16	3-7 years (*n*=31) 8-16 years (*n*=55)	9.5; 3-16	Lower domain scores for: • *Athletic* • *Scholastic* • *Physical Appearance*
Schuengel et al. (2006)	Self-Perception Profile for Children – Dutch Version	Longitudinal study	80	11.2; 9-13	Normative data		Lower domain scores for: • *Athletic*
Sherrill et al. (1990)	Self-Perception Profile for Adolescent	Descriptive study	52	13.9; Total mixed sample range: 9-18	Normative data		Lower domain scores for: • *Close Friend* • *Job Competence*
Shields et al. (2007)	Self-Perception Profile for Children	Controlled trial[b]	47	11.7; 8-16	47	11.7; 8-16	Lower domain scores for: • *Athletic* • *Scholastic* • *Social Acceptance*
Soyupek et al. (2010)	Piers-Harris Children's Self-Concept Scale	Controlled trial[b]	40	11.9; 9-18	46	12.6; 9-18	Lower *Global Self-Concept*
Teplin et al. (1981)	Purdue Self-Concept Scale for Preschool Children	Controlled trial[c]	15	5.9; 4-8	15	5.9; 4-8	No significant differences in self-concept domains
Ziebell et al. (2009)	Self-Perception Profile for Children – Australian Version	Controlled trial[b]	8	9.3; 7-11	8	9.5; 7-11	Lower domain scores for: • *Global Self-Worth* • *Fine Motor Competence*

Note: In controlled trial studies, children with CP were paired with TD children controlled group using the following matched criteria: [a]matched for inclusion criteria; [b]matched for age and gender; [c]matched for age, gender, ethnicity, intelligence, and socio-economic status

4.2.1. Global score. Only *Global Self-Concept* and *Global Self-Worth* are relevant to studies included in this section.

4.2.1.1. Global Self-Concept. Two studies assessed the *Global Self-Concept* of children with CP in comparison with TD children. While Soyupek et al. (2010) reported lower self-concept for children with CP and some evidence of gender differences, Teplin et al. (1981) found no statistically significant difference between groups.

Soyupek et al. (2010) used the Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1969). Although this instrument has six domain scores in addition to the *Global Self-Concept*, which represents a summation of all domains (see Table 4.1), Soyupek et al. (2010) only used the *Global Self-Concept* domain for comparison. It was argued earlier that a summative value of domain scores is a mathematical solution to provide a general image of the self but does not always provide an accurate impression of self-concept (see Section 2.1.4.3) which may influence the interpretation of findings from this study. Soyupek et al. (2010) found that children with CP reported lower *Global Self-Concept* compared to matched-pair TD peers. There was no gender effect for children with CP, indicating that both boys and girls with CP may be experiencing features of low self-concept.

Teplin et al. (1981) used the Purdue Self-Concept Scale for Preschool Children. While they found a similar trend of lower self-concept reported by children with CP, the differences were not statistically significant. This study included 15 children aged 4-8 without indication of the number of children falling in the 8-year-old category. Thus, the findings for preadolescent children cannot be isolated. Conclusions are difficult to make due to the limited volume of studies reporting *Global Self-Concept*.

4.2.1.2. Global Self-Worth. Six studies assessed children's *Global Self-Worth* (Manuel et al., 2003; Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007; Ziebell et al., 2009). The *Global Self-Worth* domain is present in the variations of Harter's Self-Perception scales and the Rosenberg Self-Esteem Scale (Rosenberg, 1965). Harter (2012a) cautioned that self-concept is not cumulative and that the summation of domain scores do not represent overall self-concept. While Harter's instruments present a *Global Self-Worth* domain which represents an individual's overall sense of worth alongside other self-concept domains, Rosenberg's instrument consists of only the *Global Self-Worth* domain.

Two out of the six studies reported that children with CP scored lower for *Global Self-Worth* compared with TD children (Manuel et al., 2003; Ziebell et al., 2009). Ziebell et al. (2009) used a variation of Harter's Self-Perception scales modified for children with CP. However, given the small sample size of this one study (*n*=8) and compared to the four other studies using a variation of Harter's Self-Perception scales, this finding needs to be interpreted with care. On the other hand, Manuel et al. (2003) used the Rosenberg Self-Esteem Scale (Rosenberg, 1965) and found that 30% of children with CP report lower self-concept compared to TD normative data. They also indicate that girls with CP report a lower self-concept score compared to boys with CP.

Since global scores only represent an overall view of self-concept, an analysis of outcomes using domain scores may present more comprehensive evidence of the self-concept of children with CP. In the following sections, findings are discussed according to self-concept domains.

4.2.2. Physical self-concept. Studies included in this section utilised instruments that included the physical self-concept domains of *Athletic, Overall Motor Skills, Fine Motor*, and *Gross Motor*. The *Athletic* domain is discussed in an independent section while the *Overall Motor Skills*, *Fine Motor*, and *Gross Motor* domains are discussed together due to the high similarity between the items.

4.2.2.1. Athletic domain. Five studies assessed children's athletic self-concept (Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007; Ziebell et al., 2009). All five studies utilised one of the variations of the Harter Self-Perception scales. Three studies reported lower *Athletic* domain scores for children with CP compared to matched-pair TD children (Russo, Goodwin, et al., 2008; Shields et al., 2007) or TD normative data (Schuengel et al., 2006). The lower *Athletic* domain reported by children with CP is unsurprising since the *Athletic* domain within these instruments focuses primarily on achievement in sporting activities (e.g., performance in a variety of sporting activities, performance in new sporting activities, participation in sporting activities).

For children with CP, a high focus on sporting activities can impact their self-concept evaluation in several ways. First, functional motor abilities (e.g., GMFCS-E&R and MACS levels) and accompanying impairments (e.g., visual impairment, attentional problems) can lead to activity limitations and participation restrictions in sporting activities for children with CP. Naturally, participation restrictions affect the child's competence and in turn influence their self-concept (see Figures 3.2 and 3.3).

Second, achievement in sporting activities for children with CP in mainstream schools, who are likely to be at GMFCS-E&R Levels I-III, might be especially challenging. Children with CP will probably be expected to engage in activities designed for TD children but many will struggle to compete due to activity limitations and participation restrictions. If activities are not accessible or accommodating for children with CP, they are unlikely to attempt or succeed in tasks, which may lead to lower *Athletic* self-concept domain.

Third, children with CP in mainstream schools most likely have TD children as their peers and, thus, their relative standards will naturally be built on comparison with these peers. Such unrealistically high relative standards indirectly influence personal standards and, eventually, affect their self-concept (see Figure 3.3). If children with CP develop the pretension (based on personal, relative, and perceived standards) to perform in sporting activities like their peers but does not succeed, their self-concept will be negatively impacted. Thus, the lower *Athletic* domain may be attributed to activity limitations and participation restrictions, in addition to unrealistically high standards based on TD peers.

Two studies did not report differences in the *Athletic* domain between children with CP and TD children (Sherrill et al., 1990; Ziebell et al., 2009). Ziebell et al. (2009) included participants with GMFCS levels representative of children with CP who attend mainstream school (GMFCS Levels I=3; II=3; III=2); however, due to small sample size, participant selection may have influenced the findings. Although Sherrill et al. (1990) included a larger sample, the Self-Perception Profile for Adolescent (Harter, 2012b) was used and the means for this instrument are not representative of preadolescent children who were included in the study.

In summary, it is highly likely that the *Athletic* domain for children with CP is different to age-matched cohorts. Since most items within the *Athletic* domain focus on sporting activities, children with CP who experience activity limitations and participation restrictions are unlikely to perform at a similar athletic standard compared to TD children. Their inability to achieve at the same level as TD children may explain their lower *Athletic* self-concept ratings.

***4.2.2.2.* Other motor domains.** Two studies assessed children’s *Overall Motor, Fine Motor*, and *Gross Motor* domains (Schuengel et al., 2006; Ziebell et al., 2009); however only Ziebell et al. (2009) compared the children with CP with TD children for these domains. They used the Australian-modified Self-Perception Profile for Children, modified for children with CP (Ziebell, 2007), which includes two motor competence domains: (a) *Fine Motor,* which assesses skills related to handwriting and handling small items, and (b) *Gross Motor*, which assesses skills related to outdoor play, participation in games, walking or using other forms of transport. They found that children with CP have lower *Fine Motor Competence* domain scores compared to matched-pair TD peers. However, as previous, their small sample size (*n*=8) means that these findings should only be considered preliminary.

4.2.3. Intellectual self-concept. Intellectual self-concept includes domains relevant to school (e.g., *Scholastic*, *Reading*, *Mathematics,* and *General School*)[1]. Six studies assessed children's *Scholastic* domain using different instruments (Harvey & Greenway, 1984; Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007; Ziebell et al., 2009). Four of these six studies found no difference in the *Scholastic* domain between groups. Of the two studies which reported lower *Scholastic* domain scores for children with CP compared to matched-pair TD children (Russo, Goodwin, et al., 2008; Shields et al., 2007), Russo, Goodwin, et al. (2008) indicated that 20% of their sample with CP had below average intellectual ability. This suggests that perception of intellectual ability and actual ability were both lower for the children with CP, but their actual ability was lower as indicated by their intellectual ability being only true for 20% of the sample.

Intellectual impairment is present in more than 50% of children with CP (ACPR Group, 2013) which may influence their capacity to participate in school-related tasks. In addition to intellectual impairment, other accompanying impairments (e.g., speech, hearing, and visual impairment, attentional and behavioural problems) can also affect a child's participation in these tasks. Together, these accompanying impairments may

---

[1] For older adolescents and adults, the *Job Competence* domain also falls under intellectual self-concept.

influence the child's *Scholastic* domain due to poor participation and low competencies in school-related tasks. This is especially true for children with CP in mainstream schools due to the competitive nature of peers and school settings that focus on academic performance.

Overall, there is inconclusive evidence regarding the impact of intellectual self-concept for children with CP. In view of the high prevalence of intellectual impairment and learning difficulties for children with CP, information about cognitive function gathered using standardised assessments is necessary for each participant. Information about cognitive function is vital when interpreting children's rating of their *Scholastic* self-concept.

4.2.4. Social self-concept Table 4.1 reveals that, across self-concept instruments, social self-concept has been evaluated using different domains. Since most studies utilised different instruments, several domains will be discussed including *Social Acceptance* (Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007; Ziebell et al., 2009); *Peer Relations* (Adamson, 2003), and *Parent Relations* (Adamson, 2003)[2].

Five studies investigated *Social Acceptance* but only Shields et al. (2007) found that girls with CP report lower *Social Acceptance* domain scores compared to TD girls. This difference was not observed between boys with CP and TD boys. Although preliminary, this finding may indicate that girls with CP experience greater impact in the *Social Acceptance* domain. However, with limited studies that present gender comparisons, no conclusive recommendations can be achieved.

Very little is known about *Peer Relations* and *Parent Relations* domains for preadolescent children with CP because only one case study exists (Adamson, 2003).

---

[2] For older adolescents and adults, the *Close Friends* and *Romantic Appeal* domains also fall under social self-concept

This 12-year-old child's *Peer Relations* domain score was similar to the normative mean score and his *Parent Relations* domain score was slightly higher than the normative mean score. Other participants in Adamson's (2003) study sample were beyond the preadolescence age range.

In conclusion, there seems to be little difference in social self-concept for children with CP compared to TD children. While there is some evidence that gender may influence social self-concept, there are limited studies which included gender comparison.

4.2.5. Personal attributes. As listed in Table 4.1, self-concept in relation to personal attributes is represented by two domains: *Physical Appearance* and *Talents and Gifts*. No differences in the *Physical Appearance* domain were observed between children with CP and TD children in all six studies that assessed this domain (Adamson, 2003; Harvey & Greenway, 1984; Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007). Again, very little is known about the *Talents and Gifts* domain, being only included in a single case study (Adamson, 2003). This 12-year-old child's *Talents and Gifts* domain score was slightly lower than the normative mean score. In summary, there is little evidence to suggest differences in self-concept in terms of personal attributes between children with CP and TD children.

4.2.6. Psychological self-concept. Four domains are categorised under the psychological self-concept (see Table 4.1): *Behaviour, Psychological Health, Freedom from Anxiety,* and *Happiness and Satisfaction*. Using a variant of the Harter Self-Perception scales, four studies assessed children's *Behaviour* domain (Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007). No differences were observed between children with CP and TD children across all studies. The *Psychological Health* domain was only evaluated by Adamson (2003), who reported a slightly above normative mean score for the single preadolescent child in the sample.

Using the Piers-Harris Children’s Self-Concept Scale (Piers & Harris, 1969), Harvey and Greenway (1984) found that children with CP report lower scores on *Happiness and Satisfaction*, *Freedom from Anxiety*, and *Behaviour* domains compared to matched-pair TD children. Their findings differed from those of the five studies above that had used a variation of the Harter Self-Perception scales (Russo, Goodwin, et al., 2008; Schuengel et al., 2006; Sherrill et al., 1990; Shields et al., 2007). This difference could be partially explained by the utilisation of different instruments. More importantly, Harvey and Greenway (1984) conducted their study about 20 years earlier than most other studies included in this literature review. In the intervening two decades, the social perception of children with disabilities, including CP, has altered with the emergence of the ICF framework (WHO, 2016). This framework has helped lift some of the negative connotations associated with individuals with disability. A change in social perception can influence children’s perception of themselves because self-concept is culturally biased (Hattie, 1992). This shift in perspective over time may partially explain the contrasting findings. More recent studies of psychological self-concept have found that children with CP do not appear to view themselves differently from TD children.

4.2.7. Conclusion and recommendation. Although a limited number of studies have compared the self-concept of children with CP and TD children, they do furnish some evidence to suggest that children with CP report lower self-concept in some but not all self-concept domains. Of all the self-concept domains, the *Athletic* domain provided the strongest evidence that children with CP rated lower compared with TD children. However, all recent studies reported no differences in the *Physical*

Appearance and *Behaviour* domains between children with CP and TD children. Other domains returned inconsistent findings, with most studies indicating no differences between the groups, although few studies showed lower ratings for children with CP.

It needs to be emphasised that self-concept is influenced by the perceived importance of the specific self-concept domain. Domains with higher importance have greater impact on self-concept (James, 1890/1950). For example, if athletic achievement is deemed to be very important for the child, performance outcomes in this area will have greater impact on self-concept compared to performance in those areas rated of lesser importance. Therefore, self-concept domain scores alone do not provide an accurate reflection of the child’s perception of the self. A possible solution is to include *Personal-Value* – the importance of a specific self-concept domain in reference to personal standards – in the evaluation of self-concept. Although this option is available in the Self-Perception Profile for Children (Harter, 1985), only Ziebell et al. (2009) reported importance scores by domain. They found discrepancies in importance ratings between children with CP and TD children, demonstrating that children with CP and TD children do not value the same self-concept domains. Thus, to provide a comprehensive analysis that equally reflects the self-concept of children with CP and TD children, it is recommended that the *Importance Rating* be considered in self-concept evaluation.

Furthermore, there is insufficient evidence to determine the true impact of self-concept for children with CP when most of the studies utilised instruments designed and/or validated for TD children. Due to the impairments experienced by children with CP, they may perceive themselves and their environment differently to TD children, thus creating unique characteristics of self-concept that are not present in TD children. Consequently, continued use of non-population-specific instruments will inadvertently miss CP-specific self-concept domains that are deemed important for children with CP. Further investigation to identify self-concept domains that are relevant to children with CP is crucial.

Despite the complications of interpreting findings from these studies, lower self-concept scores for children with CP indicate clinical concerns. Longitudinal data shows that preadolescent TD children tend to report lower self-concept compared to older age groups (Cole et al., 2001; Harter, 2012a; Marsh et al., 1998). If children with CP are reporting lower self-concept than their TD peers, it may suggest that the self-concept of preadolescent children with CP is affected more. Given that self-concept development at preadolescence is the foundation of later developmental stages, prioritising self-concept research for preadolescent children with CP can assist with monitoring as well as with intervention planning.

4.3. Factors Associated with Self-Concept for Children with Cerebral Palsy

The ICF framework regards disability (i.e., impairment of *Body Functions and Structures*, *Activity Limitations*, *Participation Restrictions*) as an outcome of the interaction between the *Health Condition* (e.g., CP) and *Contextual Factors* (i.e., *Environmental* and *Personal Factors*; World Health Organisation, 2002, 2016; see Figure 3.1). Many studies acknowledge the ICF framework by investigating the relationship between self-concept and factors stipulated in the ICF framework for children with CP. Other psychological factors were also included in some of these studies due to the relationship between self-concept and other psychological variables (Huebner, 2004; Shavelson et al., 1976; Terry & Huebner, 1995). These studies are summarised in Table 4.3 and reviewed in the following sections.

Table 4.3 Studies investigating factors associated with self-concept for children with cerebral palsy

Author(s)	Instrument(s)	*N*	Age (years) Mean and Range	Significant predictors of self-concept
King et al. (2010)	Self-Perception Profile for Children Self-Perception Profile for Adolescent	Between-subjects: Social participators (*n*=41)* Broad participators (*n*=140)* Low participators (*n*=122)* Recreational participators (*n*=124)*	10.4 6-15	Low participator reports lower self-concept domains for: • *Athletic* • *Social Acceptance*
King et al. (2013)	Self-Perception Profile for Children Self-Perception Profile for Adolescent	Children with physical disabilities (*n*=427)* TD children (*n*=354)	Not stated 6-14	Participation factors associated with lower self-concept domains: • Lower enjoyment • Lesser intensity of active physical activities
Manuel et al. (2003)	Rosenberg Self-Esteem Scale	50	13 9-18	Factors associated with lower self-concept domains: • Female • Lower functional ability • Higher perception of impact of disability
Nadeau and Tessier (2011)	Self-Perception Profile for Children	Victimised[3] CP (*n*=17) Non-victimised CP (*n*=41) Victimised TD (*n*=10) Non-victimised TD (*n*=46)	Mean age: Victimised CP=10.6 Non-victimised CP=10.5 Victimised TD=10.2 Non-victimised TD=10.3 Total mixed sample range: 9-12	Victimised CP group reported lower self-concept domains for: • *Social Acceptance* • *Global Self-Worth* Compared to TD group, the CP group reported lower self-concept domain for: • *Athletic*
Russo et al. (2009)	Pictorial Scale of Perceived Competence and Social Acceptance for Young Children Self-Perception Profile for Children	Between-subjects: Orthosis (*n*=60) No orthosis (*n*=47) Assistive technology (*n*=49) No assistive technology (*n*=58)	8.9 3-16	The orthosis and assistive technology group report lower self-concept domain for: • *Global Self-Worth*
Russo, Goodwin, et al. (2008)	Pictorial Scale of Perceived Competence and Social Acceptance for Young Children Self-Perception Profile for Children	Children with CP (*n*=86) TD children (*n*=86)	Mean age: Children with CP=9.4 TD children=9.5 Total mixed sample range: 3-16	Factors associated with lower self-concept: • Lower quality of life

---

[3] Nadeau and Tessier (2011) used the Peer Nomination Inventory (Perry, Kusel, & Perry, 1988) to assess children's victimisation levels and children were classified according to their victimisation score. The authors of the Peer Nomination Inventory employed in this study defined victimisation as "serving as the victim of peer aggression" (Perry et al., 1988, p.808).

Author	Instrument(s)	*N*	Age (years) Mean and Range	Significant findings for self-concept
Russo, Miller, et al. (2008)	Pictorial Scale of Perceived Competence and Social Acceptance for Young Children Self-Perception Profile for Children	Between-subjects: Children reporting pain (*n*=51) Children without pain (*n*=56)	Mean age: Children reporting pain =9.52 Children without pain =8.42 Total mixed sample range: 3-16	Children experiencing pain report lower self-concept domains for: • *Scholastic* • *Behaviour*
Scholtes et al. (2002)	Pictorial Scale of Perceived Competence and Social Acceptance for Young Children, Dutch modified version translated into English	Children with CP aged 4-6 years (*n*=15) Children with CP aged 7-9 years (*n*=17)	Not stated 4-9	Factors associated with lower self-concept: • Greater degree of disability
Schuengel et al. (2006)	Self-Perception Profile for Children, Dutch modified version	80	11.2 9-13	Factors associated with lower self-concept: • Higher GMFCS levels • Higher internalising problems • Lower aggression
Shikako-Thomas et al. (2013)	Self-Perception Profile for Adolescent	187	15.4 12-19	Lower self-concept is associated with lower participation in: • Active physical activities • Skills based activities • Leisure activities
Soyupek et al. (2010)	Piers-Harris Self-Concept Scale	Children with CP (*n*=40) TD children (*n*=46)	Mean age: Children with CP=11.9 TD children=12.6 Total mixed sample range: 9-18	Factors associated with lower self-concept: • Lower quality of life • Presence of incontinence • Higher GMFCS levels
Ziebell et al. (2009)	Self-Perception Profile for Children, Australian modified version	Children with CP (*n*=8) TD children (*n*=8)	Mean age: Children with CP=9.3 TD children=9.5 Total mixed sample range: 7-11	Factors associated with lower self-concept: • Lower physical performance

Note: * Number of participants with CP was not specified

4.3.1. Impairment levels. With the introduction of the ICF framework (see Section 3.1, Figure 3.1), researchers tend to align their studies with components of the ICF (WHO, 2002, 2016). In self-concept studies involving children with CP, functional motor abilities and participation are the two most common variables included.

4.3.1.1. Functional motor abilities. Being the primary feature of CP, motor impairment is often hypothesised to have a negative effect on the self-concept of children with CP. However, the findings from five studies returned inconclusive results (Manuel et al., 2003; Scholtes et al., 2002; Schuengel et al., 2006; Soyupek et al., 2010; Ziebell et al., 2009). While four studies found a relationship between motor impairment and lower self-concept (Manuel et al., 2003; Scholtes et al., 2002; Schuengel et al., 2006; Ziebell et al., 2009), the fifth study did not observe any relationship between these variables (Soyupek et al., 2010).

Utilisation of different instruments resulted in analyses using dissimilar domains. Schuengel et al. (2006) and Ziebell et al. (2009) reported domain scores that utilised a modified version of the Self-Perception Profile for Children adapted for children with CP. They found that motor impairment is only correlated with selective domains (e.g., *Motor Competence, Fine Motor Competence,* and *Athletic Competence*). Using a modified Pictorial Scale of Perceived Competence and Social Acceptance for Young Children, Scholtes et al. (2002) found that disability severity was associated with children's report of their *Physical Competence*. Higher physical competence was reported by children with hemiplegia and diplegia compared to children with quadriplegia. On the other hand, Soyupek et al. (2010) utilised the Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1969) and, reporting only the *Global Self-Concept* domain, found that there was not a correlation between self-concept and motor impairment. This means that motor impairment may have affected the self-concept of children with CP in domains related to motor functioning (e.g., *Motor Competence, Fine Motor Competence, Athletic Competence,* and *Physical Competence*) but not a summative overall score that assesses self-concept.

4.3.1.2. Participation. With increased emphasis on encouraging participation, particularly for children with disabilities, a growth of studies that focus on participation was observed. However, only three studies that investigated participation for children with disabilities (samples inclusive of children with CP) included self-concept as a variable (King et al., 2013; King et al., 2010; Shikako-Thomas et al., 2013). Consistent with the Participation Model proposed by (Imms et al., 2015), all studies reported associations between higher self-concept and greater participation. Moreover, the *Athletic* self-concept domain was positively correlated with enjoyment and intensity of physical activities (King et al., 2013; Shikako-Thomas et al., 2013) while the *Physical Appearance* self-concept domain was positively correlated with engagement in skill-based activities (Shikako-Thomas et al., 2013). King et al. (2010) explored different participation groups including social participators, broad participators, low participators, and recreational participators. They found that low participators – children with low enjoyment and weak preference – as measured by the Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC; King et al., 2004), reported lower *Athletic* and *Social Acceptance* self-concept domains compared with other participators.

However, all three studies have limitations that concern the synthesis of this literature. The studies by King et al. (2013) and King et al. (2010) included children with a number of different disabilities which did not report the number of participants diagnosed with CP. On the other hand, while Shikako-Thomas et al. (2013) included only children with CP, the target age range was 12-19 years and the number of participants within the preadolescent age range (i.e., aged 12 years) was not specified. These limitations leave a gap in research that is needs strengthening in order to understanding the link between self-concept and participation for preadolescent children with CP.

4.3.1.3. Summary. It could be concluded from the evidence of the studies presented above that higher self-concept domains are associated lower impairment levels and greater participation. These findings further strengthen the Participation Model introduced by Imms et al. (2015; see Section 3.3.1). Impairments experienced by children with CP lead to activity limitations and participation restrictions; subsequently, these limits and restrictions impact upon activity competence and, in turn, influence self-concept.

4.3.2. Contextual factors. According to the ICF framework, contextual factors are divided into *Environmental Factors* (e.g., social attitudes, architectural characteristics, legal and social structure) and *Personal Factors* (e.g., gender, age, education, factors that influence how disability is experienced by the individual; WHO, 2002, 2016). Studies involving children with CP have only explored the relationship between self-concept and *Personal Factors*.

In separate studies using the Self-Perception Profile for Children (Harter, 1985), Russo and colleagues investigated the relationship between self-concept and experience of pain symptoms (Russo, Miller, et al., 2008) as well as the use of orthosis and assistive technology (Russo et al., 2009). Children with CP who reported higher levels of CP-related pain report lower *Scholastic* and *Behaviour* self-concept domains compared to children who do not experience pain (Russo, Miller, et al., 2008). Children with CP who use orthosis and assistive technology report a lower *Global Self-Worth* domain compared with children who do not use these devices (Russo et al., 2009). Both pain and the use of devices related to CP have a negative impact on self-concept for children with CP. In contrast, Soyupek et al. (2010) found no relationship between self-concept and pain, communication device usage, and wheelchair usage. Additionally, they found no relationship between self-concept and age, gender, type of CP, or visual problems. Soyupek et al. (2010) instead found moderate correlations between self-concept and school type, presence of incontinence, and quality of life. Regression analysis demonstrated that these factors accounted for 33% of the *Global Self-Concept* domain measured by the Piers-Harris Self-Concept Scale (Piers & Harris, 1969); with quality of life being the strongest predictor. Lastly, Manuel et al. (2003) found that a higher *Global Self-Concept* domain measured by the Rosenberg Self-Esteem Scale (Rosenberg, 1965) is associated with lower perceived impact of disability reported by the sample of children.

Evidence indicates that the self-concept of children with CP is affected by a variety of *Personal Factors*. Although such factors are often seen as secondary variables in research, they are recommended inclusions in self-concept studies involving children with CP (von der Luft, DeBoer, et al., 2008). Due to the limited volume of studies that investigate individual *Personal Factors*, an expansion of research in this area will be valuable for children with CP.

4.3.3. Psychological factors. Behavioural problems and quality of life are the only two psychological factors that have been included in self-concept studies of children with CP. These studies are discussed in the following sections.

4.3.3.1. Behavioural problems. Behavioural problems can be divided into internalising and externalising behaviours. Internalising behaviours are behaviours that are directed inwards (e.g., anxiety, depression, somatic complaints), and externalising behaviours are inappropriate behaviours directed towards others (e.g., aggression, arguing, fighting). In TD children, externalising behaviour problems are linked to lower self-concept (Donnellan et al., 2005). Only two studies involving children with CP examined behavioural problems (Nadeau & Tessier, 2011; Schuengel et al., 2006). Higher symptoms of internalising behaviour are associated with lower self-concept in five self-concept domains including *Athletic*, *Social Acceptance*, *Physical Appearance*, *Scholastic*, and *Global Self-Worth* (Schuengel et al., 2006). On the other hand, higher symptoms of externalising behaviour, specifically aggression, are related to higher *Physical Appearance*, *Motor Competence*, and *Global Self-Worth* self-concept domains (Nadeau & Tessier, 2011; Schuengel et al., 2006).

Accompanying impairments can interfere with the individual's capacity to effectively maintain the *Self-Concept Feedback Loop* (see Figure 3.3). Regarding this, Nadeau and Tessier (2011) explain that the relationship observed between aggression and self-concept could be a result of poor social coding. Given that behavioural problems are identified as one of the accompanying impairments to CP and are prevalent in 25% of children with CP (ACPR Group, 2013; Rosenbaum et al., 2006), this area warrants further investigation.

4.3.3.2. Quality of life. Quality of life is defined as an individual's perception of their position in life with regard to their personal standards, expectations, goals, and concerns (WHO, 1997). In the last few decades, quality of life has been acknowledged as a recommended outcome measure for individuals with disabilities, such as CP, to assist with health promotion strategies (Huebner, 2004). Self-concept, like quality of life, is also shaped by personal standards that influence the individual's expectation of their environment and their behavioural goals (see Section 2.1.5, Figure 2.3). The similarities between self-concept and quality of life have led researchers to postulate that higher self-concept is related to higher quality of life (Huebner, 2004; Terry & Huebner, 1995); however very few studies have investigated this relationship for children with CP.

Only two studies have examined the relationship between self-concept and quality of life for children with CP (Russo, Goodwin, et al., 2008; Soyupek et al., 2010). The findings of both studies indicate a fair to moderate correlation. Quality of life accounts for 33% to 42% of variance in self-concept. This demonstrates the importance of quality of life for self-concept. Regression analysis by Soyupek et al. (2010) indicates that quality of life is the strongest predictor, alongside type of school and presence of incontinence, which cumulatively account for 33% of self-concept. Using quality of life as the outcome variable in another regression analysis, Soyupek et al. (2010) found that self-concept independently accounted for 29% of the variance. In other words, self-concept alone could explain more than a quarter of the variance in quality of life for this participant group, highlighting the significant contribution of self-concept to the perception of overall wellbeing.

A major drawback in both studies is the utilisation of generic quality of life and self-concept instruments that have limited validation for children with CP. While both studies employed the Pediatric Quality of Life Inventory (PedsQL) Version 4.0 (Varni, Seid, & Kurtin, 2001) to measure quality of life, self-concept was measured using the Self-Perception Profile for Children (Harter, 1985) or the Piers-Harris Self-Concept Scale for Children (Piers & Harris, 1969). The PedsQL is a generic measure of health-related quality of life, which is only a subset of quality of life (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). Waters et al. (2005) caution that quality of life assessment needs to include both health and non-health domains to effectively measure satisfaction of life. To counter the limitations of using generic quality of life instruments, Waters et al. developed a CP-specific quality of life instrument called the *Quality of Life Questionnaire for Children* (*CP QOL-Child*) however; this assessment is not yet widely used.

Both studies provide evidence that self-concept is highly probable to be related to quality of life but the use of non-population-specific instruments to measure self-concept and quality of life could affect these findings. To address the limitations of past studies and to extend the investigation of relationship between self-concept and quality of life, further research using population-specific instruments is warranted.

4.3.3.3. Conclusion. Although the quantity of studies investigating the relationship between self-concept and psychological factors is small, the outcomes of these studies are still indicative. They suggest that psychological factors such as behavioural problems and quality of life are likely to be related to self-concept. Since most studies employed generic instruments, it is highly recommended that future studies use population-specific and validated instruments to ensure the accurate collection of data.

4.4. Research Direction

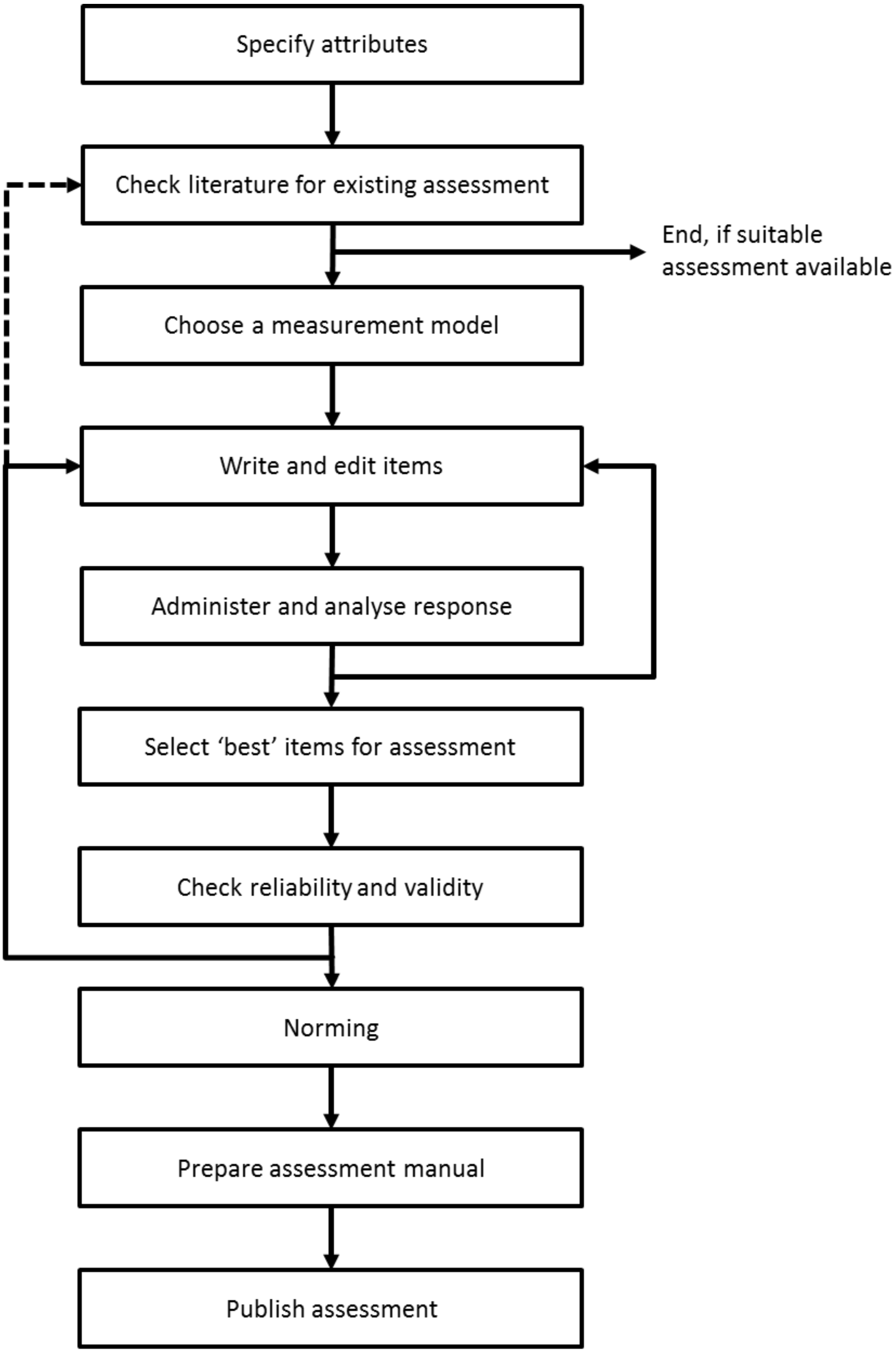
This literature review demonstrates that self-concept research for children with CP is limited in volume and scope, which justifies the need for more targeted studies. A major limitation of existing studies lies in the utilisation of self-concept instruments that are not designed and/or validated for children with CP; thus, the interpretation of findings may be misleading. Further investigation is required to address issues around self-concept instruments for children with CP. Therefore, while there is a need to extend the investigation of self-concept in children with CP, a more pressing need is to address the lack of an instrument specifically designed and validated for this population. To address these gaps in literature, a decision tree (see Section 1.2, Figure 1.2) was developed for this research program which divided studies into three sections: (i) review of existing literature, (ii) instrument development, and (iii) investigation of the self-concept of children with CP.

Chapter 5. Methodology and Design

The overall aim of this research program was to identify or develop a CP-specific self-concept instrument and to use this instrument to explore the profile of self-concept and investigate factors that are associated with self-concept for children with CP. Five studies were conducted to achieve this aim. The results of each study determined the direction of the subsequent study, as outlined in the decision tree in Chapter 1 (see Section 1.2, Figure 1.2). Ethical approval for all studies was obtained from the National Health and Medical Research Council (NHMRC) registered Human Research Ethics Committees of the Cerebral Palsy League (EC00417) and supported by the Australian Catholic University (EC00205; see Appendix C). In this chapter, the instrument development process and general methods employed for each study are described. Although much of the information in this chapter mirrors the manuscripts presented later in the thesis, this chapter is written in accordance with the university's thesis regulations.

5.1. Instrument Development Process

Given that the primary aim of this research program is to identify or develop a CP-specific self-concept instrument, a structured instrument development process was adopted. A rational-empirical approach was used to capitalise on existing theoretical knowledge. A guideline for best practice in test construction using the rational-empirical approach is outlined in Figure 5.1 (Shum, O'Gorman, Myors, & Creed, 2013). In the following sections, the development of the new population-specific self-concept instrument – the *myTREEHOUSE Self-Concept Assessment* – is discussed, based on this guideline.



Source: Adapted from Shum et al. (2013) p. 122

Figure 5.1 Best practice guideline for instrument construction using the rational-empirical approach applied to this research program

Instrument development begins with clear identification and definition of the target construct. Self-concept was identified as the target construct because the literature review (Chapter 4) highlighted the need to extend self-concept research for children with CP. However, the absence of a population-specific and validated self-concept instrument is a major barrier that must to be addressed. The conceptualisation of self-concept – based on the *Interaction and Iterative* feature described in Section 2.1.5 – is an interaction between cognitive processes and social experiences which create the *Self-Concept Feedback Loop* (see Figure 2.3). This *Self-Concept Feedback Loop* also contains the *Multidimensional* feature – self-concept encompassing multiple domains salient to the target population – and the *Evaluative* feature – self-concept evaluated based on personal, relative, and perceived standards (see Section 2.1.5). Given that the characteristics of CP play a major role in influencing children's interaction with their social environment, activity limitation and participation restrictions caused by CP is likely to impact the child's *Self-Concept Feedback Loop* (see Figure 3.3). After deciding to focus on self-concept for children with CP, the first study in this research program was designed as a systematic review (see Study 1, Chapter 6) to identify self-concept instruments with published psychometric evidence for children with CP.

5.2. Systematic Review (Study 1)

Study 1 involved a systematic review of self-concept instruments for which psychometric data for preadolescent children with CP was available. A systematic review of instrument properties is advisable to identify the best instrument for a specific purpose (Mokkink et al., 2009). This process allows for a critical appraisal and comparison of the content and psychometric properties of the available instruments. The process of critical appraisal consists of five steps: (1) reporting descriptive information (e.g., target population, number of studies, or instruments), (2) appraising the quality of the studies included, (3) appraising their methodological qualities, (4) appraising the findings of individual studies, and (5) synthesising Steps 3 and 4 to arrive at an overall recommendation about the suitability of the instruments. This five step process is consistent with established systematic review protocols. An overview of the methodology for Study 1 is provided in the following sections (also see the published manuscript in Chapter 6).

5.2.1. Search strategy and quality assessment. Databases were selected if they included articles relevant to the field of medical, allied health, and psychology or if they published studies of self-concept and CP. Six electronic databases were searched, including PubMed, MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, PsycARTICLES and Web of Science.

Articles identified in the systematic search underwent quality assessment using two guidelines: the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) and the CanChild Outcome Measure Rating Form. COSMIN is designed as a checklist of standards to evaluate the methodological quality of studies that investigate measurement properties for health-related, patient-reported outcome measures (Mokkink, Terwee, Patrick, et al., 2010). The COSMIN checklist contains 12 boxes (Mokkink, Terwee, Knol, et al., 2010), detailed in Table 5.1. Ten boxes (boxes A-J) assess measurement properties and are scored using a 4-point scale with ratings of excellent (3 points), good (2 points), fair (1 point), and poor (0 point; Terwee et al., 2012). The Item Response Theory (IRT) and the Generalisability boxes are designed as checklists and are not scored.

Table 5.1 Quality criteria for measurement properties of health-related, patient-reported outcome measures according to the COSMIN checklist

Criteria	**Description**
Box A Internal consistency	Interpreted as (1) correlation between the items are reflective of a model, and (2) all items forms a unidimensional scale.
Box B Reliability	Includes test-retest reliability, interrater reliability and intrarater reliability.
Box C Measurement error	Measures error analyses information from study error (e.g., missing item, sample size, administration).
Box D Content validity	Assesses (1) relevance: evaluates relevance for construct, population and purpose of the instrument; and (2) comprehensiveness: evaluated by the coverage of items, description of domains and theoretical grounding of the instrument.
Box E Structural validity	Assesses the extent to which the instrument measures the construct it hypothesised to measure.
Box F Hypotheses testing	Includes the expected direction and magnitude of correlation or differences based on the measured construct(s).
Box G Cross-cultural validity	Evaluates cross-cultural issues related to the use of the instrument (e.g., translation information, testing of cultural appropriateness of the instrument).
Box H Criterion validity	Assesses the goal standard of instruments.
Box I Responsiveness	Evaluates the instrument’s ability to detect change over time.
Box J Interpretability	Evaluates the scoring information of the instrument that allows for interpretability of the scores (e.g., means, standard deviation, ceiling score).
IRT box	General requirements for studies that applied the IRT method.
Generalisability box	Information about generalisability of the results obtained.

Adapted from Mokkink, Terwee, Knol, et al. (2010)

The CanChild Outcome Measure Rating Form facilitates a rating of the characteristics and clinical utility of each instrument on the basis of instrument focus, clinical utility, scale construction and standardisation (Canchild Centre for Childhood Disability Research, 2004a, 2004b). Characteristics and clinical utility are classified using a rating of excellent, adequate, or poor (CanChild Centre for Childhood Disability Research, 2004b).

5.2.2. Procedure. The process of the systematic review began with the development of a search strategy and determination of inclusion and/or exclusion criteria, before proceeding to data extraction and data analysis. The details of the procedure are provided in the published manuscript, reproduced in Chapter 6.

5.2.3. Data extraction and analysis. Article selection and data extraction were conducted by the author and, independently, by a member of the supervisory team. A conservative approach was adopted to avoid inadvertently discarding a relevant article. For example, when insufficient details were available from the title and abstract to confirm exclusion, the full text article was sourced.

Findings from the systematic review indicated that (1) there was no self-concept instrument designed specifically for children with CP, and (2) instruments that are used with children with CP lack psychometric support for use with this population. Although the findings from the systematic review indicate that currently, no CP-specific self-concept instrument is available, there is insufficient evidence to support the use of self-concept instruments designed for TD children with children with CP. There is a need to investigate if the construct of self-concept for children with CP is the same as for TD children. Variations in the construct of self-concept for these populations would justify the need for a population-specific instrument.

5.3. Delphi Consensus Survey (Study 2)

Study 2 involved a Delphi consensus survey conducted to identify self-concept items and domains that are relevant to children with CP. A brief overview of the Delphi consensus survey is provided in the following section, which is also reported in the published manuscript (see Chapter 7).

A Delphi consensus survey uses multiple iterations to attain a consensus of opinions about a specific topic (Hsu & Sandford, 2007; Keeney, Hasson, & McKenna, 2011). This technique was chosen because it is known to offset the shortcomings of other conventional means of pooling opinions by allowing independent anonymous administration. A Delphi consensus survey can assist in ensuring that the opinions of each participant are expressed and are not suppressed by manipulation or through the coercion of authority figures (Hsu & Sandford, 2007). This is especially important in this research program because multiple groups of participants (e.g., professionals, caregivers, and children) were included. Furthermore, this process allows independent contact with each participant which is particularly useful to encourage child participants to express their opinions. However, a drawback of this technique is a low response rate because the process is time consuming and strenuous (Hsu & Sandford, 2007).

For this study, a 3-round Delphi consensus survey was conducted to first identify construct (domains) and content (items) that have been used in instruments developed for TD children as well as items identified by the sample population. Second, the Delphi consensus survey provided an opportunity to reduce these items by consensus vote to generate a minimum set of items that reflect the self-concept of children with CP.

5.3.1. Participants. Purposive sampling was used to recruit participants with expertise in understanding children with CP. Three groups of participants were recruited: a professional group, a parent group, and a child group. The professional group consisted of allied health professionals with experience in clinical practice and/or research involving children with CP. The parent group consisted of parents or caregivers of children with CP aged 8-12 years. The child group included children who: (1) had a diagnosis of CP and (2) were aged 8-12 years, in addition to having (3) adequate cognitive function and (4) communication skills to provide a report of self-concept (with an FCCS level between I-III; Barty & Caynes, 2009; Caynes et al., 2014).

5.3.2. Measures. Participants completed a demographic questionnaire in addition to questionnaires for Delphi Rounds I, II, and III according to their participant groups.

5.3.2.1. Demographic questionnaire. The demographic questionnaire for the professional group included information about gender, occupation, number of years in their profession, number of years experience with children with CP, and usage of self-concept instruments. The demographic questionnaire for the parent group included information about the participants' gender and caregiving role (e.g., father, mother, foster carer). The demographic questionnaire and functional classification systems for the child group were completed using proxy-report. The parent group also completed the demographic questionnaire and functional classification systems reporting information about their child with CP. In families with more than one child with CP, caregivers were requested to select and focus on one child aged 8-12 years when providing information. The demographic questionnaire included information about the child's date of birth, age, gender, and diagnosis. In addition to the demographic questionnaire, three functional classification systems were included to measure the child's gross motor function, manual ability, and functional communication. Each functional classification system is described below.

5.3.2.1.1. Gross Motor Function Classification System – Extended and Revised. The GMFCS-E&R is a population-specific classification system used to describe self-initiated movement in children with CP from birth to 18 years (Palisano et al., 2007; Palisano et al., 1997). Information about the GMFCS-E&R was included in Section 3.2.3.1.1. The GMFCS-E&R has demonstrated a good inter-rater reliability between clinicians of kappa coefficient of 0.75 for children aged 2-12 years (Palisano et al., 1997) and clinician-parent consensus on classifications were 97.8% (Bartlett, Galuppi, Palisano, & McCoy, 2015).

5.3.2.1.2. Manual Ability Classification System. The MACS is designed to classify the ability of children with CP to handle items in daily activities (Eliasson et al., 2006). Information about the MACS was included in Section 3.2.3.1.2. The MACS has excellent inter-rater reliability using the Intraclass Correlation Coefficient (ICC) between therapists (ICC=0.97) and between parents and therapists (ICC=0.96).

5.3.2.1.3. Functional Communication Classification System. The FCCS is designed to classify the functional communication of children with CP (Barty & Caynes, 2009; Caynes et al., 2014). Information about the FCCS was included in Section 3.2.3.2. The FCCS has excellent inter-rater reliability between speech pathologists and other therapists (ICC=0.92) and high internal consistency (Cronbach's α=0.97). The demographic questionnaires for each participant group in Study 2 are presented in Appendix D.

5.3.2.2. Delphi consensus survey questionnaire for professional and parent groups. Separate questionnaires were provided for each round of the Delphi consensus survey. Round I consisted of open-ended questions to generate unprompted items that reflect the construct and content of self-concept for the target population. Rounds II and III employed questionnaires that required participants to rate the relevance of items reflecting self-concept for preadolescent children with CP. Professional and parent group questionnaires for each Delphi round are presented in Appendix D.

5.3.2.3. Delphi consensus survey questionnaire for child group. For the child participants, a set of guided questions was used in a face-to-face structured interview for Round I, whereas child-friendly questionnaires were available for Rounds II and III. To prevent children inadvertently rating themselves in Rounds II and III, the questionnaires asked children to rate each item as evaluating an imaginary friend with CP. The structured interview for Round I and the child questionnaires for Rounds II and III are presented in Appendix D.

For some younger children and those with mild intellectual impairment or learning disabilities, the child-friendly questionnaire was too complex. Thus, a board game called "*myTREEHOUSE*" was designed as an alternative administration method. The board game displayed a tree with five ramps leading from the ground up to a treehouse. Each ramp represents progressively higher ratings. Item presented to the child were verbally paired with a $3cm^2$ pictorial card. The child responded by placing the pictorial card on one of the five ramps which indicated their rating levels. The items presented and the rating scales in the board game were identical to the child questionnaires. The *myTREEHOUSE* board game is presented in Appendix D.

5.3.3. Procedure. The professional group was recruited through a state-wide community rehabilitation service. Potential participants were sent an introductory email which included information about the study and a personalised SurveyMonkey link to the consent form and Round I of the Delphi protocol. Interested participants proceeded to the personalised link provided. The parent and child groups were recruited using a mail out. Fliers with brief information about the study and an expression of interest reply slip (see Appendix D) were sent to potential families living in the Brisbane region (located in eastern Australia). Families were contacted by telephone after two weeks to enquire about their interest in participating. The number of attempts to contact each family was restricted to three to reduce potential participant stress.

All participants provided their consent prior to participation (see Appendix D). Parents of the participating children provided their consent prior to obtaining verbal or written assent from their child. Professional and parent participants freely accessed the materials at their convenience and each round could be completed in 30-45 minutes. Appointments with child participants lasted about 45-90 minutes, depending on the ability and attention span of the child. Each Delphi round was conducted approximately one month apart from the last.

It is essential to begin a Delphi consensus survey with a comprehensive pool of data to allow for effective data reduction in following rounds. Therefore, Delphi Round I included a systematic literature search and participant-generated items. The systematic literature search was performed to identify self-concept instruments commonly used for preadolescent children with CP and TD children in order to provide an optimum selection of items. Items from identified instruments were extracted, cross matched to reduce duplication, and then combined with participant-generated items to form the initial pool of data that was used for item reduction in Rounds II and III (see Figure 5.2).

In Rounds II and III, professional and parent participants completed their respective questionnaires, either using paper-and-pencil or web-based questionnaire. During the face-to-face appointments, child participants either completed a paper-and-pencil questionnaire or *myTREEHOUSE* board game, depending on their intellectual capacity and preference. Rounds II and III involved a progressive consensus process to identify items that reflected the self-concept of preadolescent children with CP. In Round II, items achieving positive consensus were removed and banked. Items receiving negative consensus were removed and excluded. The remaining items that did not achieve consensus were re-submitted in Round III. In Round III, professional and parent participants were provided with a list of the banked and excluded items, as well as the Round II median response from their group for each remaining item. Items reaching consensus on Rounds II or III for at least two groups were included in the final item list.

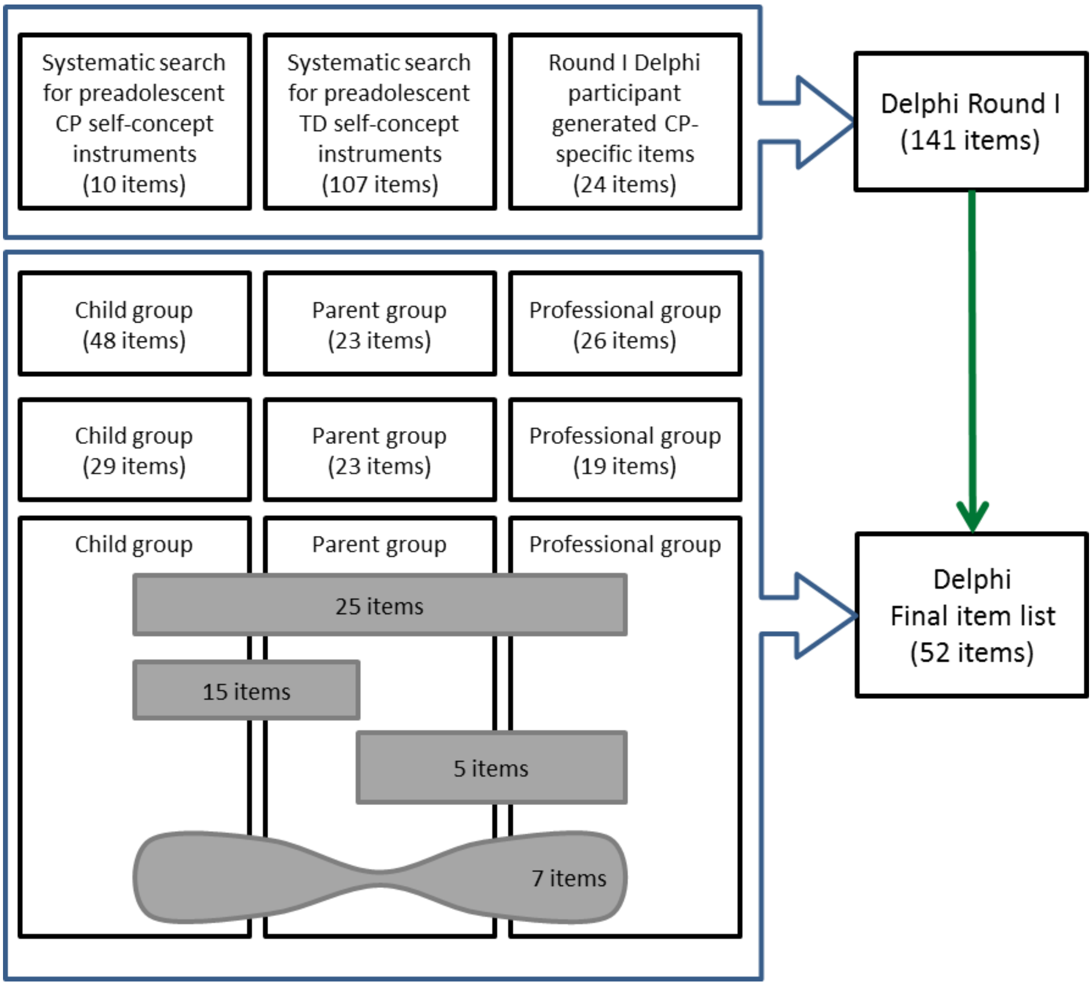


Figure 5.2 Results of item generation and reduction for the Delphi consensus survey (Study 2)

5.3.4. Data collation. The consensus cut-off point for professional and parent groups was set at 75%, with responses combined at each extremity (i.e., very/extremely important or slightly/not important). This process was chosen because most responses fell between these extremes, which allowed for efficient inclusion or exclusion of items. For the child group, a cut-off point of 75% consensus was also used. However, because children were more likely to select extreme responses, the cut-off included only the end points on the scale (i.e., extremely important or not important). Items that achieved consensus were collated and compared across groups to identify items that were the same across all groups.

The findings from this Delphi consensus survey (Study 2) indicate that 80% of items that achieved consensus were similar to existing items in instruments designed for TD children. Given that the remaining 20% of items that achieved consensus were CP-specific items and do not present in existing instruments, it can be inferred that a population-specific self-concept instrument is necessary. Findings from this Delphi consensus survey guided the development of the new self-concept instrument for children with CP, called the *myTREEHOUSE Self-Concept Assessment*.

5.4. Instrument Development Models

Upon deciding to create a new instrument, *classical test theory* was adopted for this research program because it is feasible and suitable for the target construct. Classical test theory is structured on the assumption of a general linear model which guides instrument construction using correlation analysis, linear analysis and factor analysis (Kline, 2000; Rust & Golombok, 2009; Shum et al., 2013). Although IRT is empirically superior to classical test theory, the analyses require large numbers of participants, as well as a high level of technical expertise and interpretation (Shum et al., 2013), beyond the scope of this research program.

The first step in constructing the *myTREEHOUSE Self-Concept Assessment* was writing, then editing, the initial set of items (see Figure 5.1). Writing items for the *myTREEHOUSE Self-Concept Assessment* involved input from relevant groups to ensure that the construct of self-concept was adequately represented and that the items were presented in an appropriate manner for children with CP. Item content was drawn from the findings of the Delphi consensus survey (see Study 2, Chapter 7). This drew on items and domains that were rated as relevant and important in reflecting self-concept for children with CP by professionals who are familiar with the target construct and population, caregivers of children with CP, and preadolescent children with CP. Items for the *myTREEHOUSE Self-Concept Assessment* and the 2×2 matrix model were refined using feedback from a panel of experts (Study 3a – Face and content validity, Chapter 9). The 26-item *myTREEHOUSE Self-Concept Assessment* was written to reflect the three *Performance Perspectives* and the *Importance Rating* (see Chapter 8). This version of the *myTREEHOUSE Self-Concept Assessment* was subjected to reliability testing to assist with further item selection (see Study 3, Chapter 9). The process of item writing and editing is depicted in Figure 5.3.

5.5. Constructing the *myTREEHOUSE Self-Concept Assessment*

The findings from the Delphi consensus survey (Study 2) were used to construct the items for the *myTREEHOUSE Self-Concept Assessment.* Items from the final item list were streamlined to reduce duplication and were themed into domains. New items were written, where necessary, to create a set of comprehensive domains that reflected the self-concept of children with CP (see Figure 5.3).

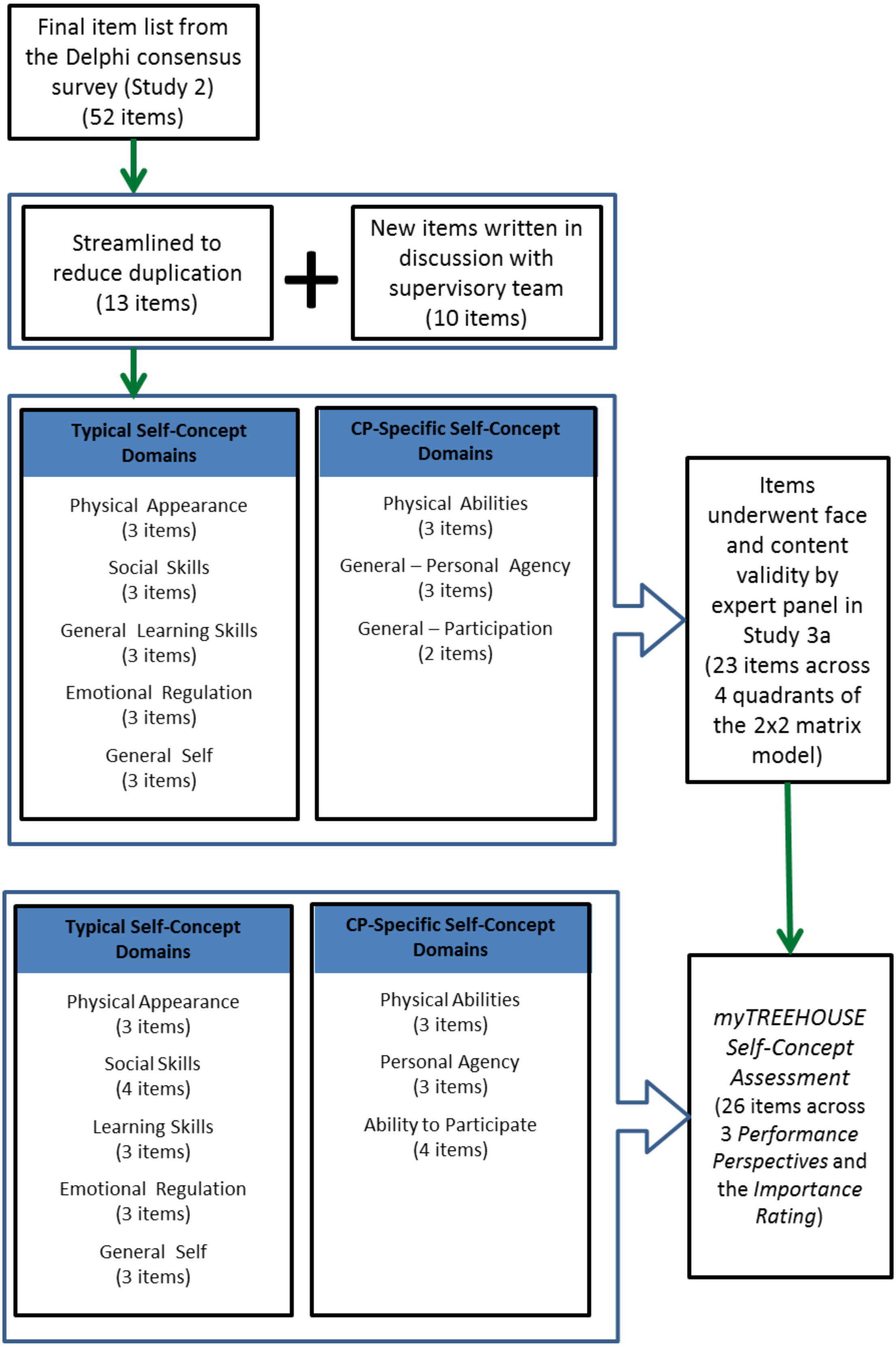


Figure 5.3 Process of item writing and editing for the *myTREEHOUSE Self-Concept Assessment*

The instrument's administration structure adopted the dual administration method used in the Delphi consensus survey (Study 2) because of its success with child participants. The dual administration methods included (i) a *Questionnaire Version*, and (ii) a *Game Version* – for younger children, children with mild intellectual impairment, or significant oral-motor or visual impairments. The instrument was named the *myTREEHOUSE Self-Concept Assessment* after its unique board game administration method. Details of the *myTREEHOUSE Self-Concept Assessment* are provided in Chapter 8. The draft instrument was examined by Study 3 for further item writing and editing before it was administered to the target population.

5.6. Psychometric Testing (Study 3a)

The aim of Study 3 was to explore the psychometric properties of the draft instrument. Psychometric testing involved two phases. The first was Study 3a, face and content validity using a structured interview with an expert panel. The second was Study 3b, which was reliability testing to assess internal consistency and test-retest reliability. The face and content validity checks were conducted to further support item writing and editing with the input of experienced test users. An overview of the methods employed in Study 3a is provided in this section. Details of the study are also included in the published manuscript in Chapter 9.

5.6.1. Participants. Purposive sampling was used to recruit a panel of expert reviewers. Experts were recruited as reviewers if they were (i) psychologists or allied health professionals who have experience working with individuals with CP, and (ii) are trained or experienced in using self-concept instruments. Participants in the Delphi consensus survey (Study 2) were excluded to minimise bias due to previous exposure to item development and to avoid participant burden. The final stage of the face validity and clinical utility evaluation was conducted by a senior speech pathologist who reviewed the language of the draft instrument.

5.6.2. Materials. Each reviewer was guided through a set of slides that prompted specific discussion areas including (i) the *overall assessment structure*, (ii) the *content of assessment items*, (iii) the *language and phrasing of items*, and (iv) the *usefulness of the instrument* (see Appendix E). Structured questions were presented to each reviewer to prompt similar discussion points. Beginning with the *overall assessment structure*, slides included information about the development of the proposed instrument by explaining the findings from the systematic review (Study 1) and the Delphi consensus survey (Study 2). Each reviewer was subsequently, presented with the new matrix model and the hypothesised domains for the new instrument. The dual administration method – the *Questionnaire Version* and the *Game Version* – was also presented. Then, discussion of the *content of assessment items* and *language and phrasing of item* areas were presented together. Reviewers were guided through each item to evaluate the relevance of items for assessing self-concept and the accurate categorisation of items for the hypothesised domains. The reviewers also had the opportunity to comment on sentence structure as well as the phrasing of items in order to assess their suitability for the target population. Finally, reviewers were asked to reflect on the instrument as a whole to comment on the *usefulness of the instrument*.

5.6.3. Procedure. Experts who fulfilled the inclusion criteria were sent an introductory email containing an information letter, followed by a telephone call to confirm their interest in participating. Upon obtaining consent to participate as a reviewer, they were presented with a copy of the draft instrument to assess the instrument for its suitability for evaluating the self-concept of preadolescent children with CP. The reviewers were contacted two weeks after providing consent (see

Appendix E) for an interview to gather their evaluation of the instrument. Using a slide presentation, a structure interview of 60 to 90 minutes was conducted using a face-to-face interview, Skype, or telephone depending on the preference of the reviewer. Each interview was voice recorded and transcribed. After taking into consideration the suggested changes by the reviewers, the senior speech pathologist reviewed the instrument.

5.6.4. Data collation. The responses from each reviewer were collated according to the structured slides. Comments were combined across all the reviewers to identify common themes. Any recommendations by the majority of the reviewers resulted in a change to the instrument. Comments made by a minority group of reviewers were considered on a case-by-case basis in discussion with the research supervisory team. After applying all recommended changes, the instrument was prepared for administration with children with CP to obtain preliminary data. The aim of Study 3b was to obtain preliminary psychometric testing.

5.7. Psychometric Testing (Study 3b), Self-Concept Profile (Study 4), and Self-Concept and Quality of Life (Study 5)

Although Studies 3b, 4, and 5 are detailed together because data collection for these studies was conducted concurrently, these studies are presented in three separate manuscripts in Chapters 9-11. In Study 3b the internal consistency and test-retest reliability of the *myTREEHOUSE Self-Concept Assessment* was assessed. The aim of Study 4 was to investigate the self-concept profile of children with CP in relation to (i) age, (ii) gender, (iii) motor function (gross and fine motor), and (iv) communication and cognitive function. The aim of Study 5 was to explore the relationship between self-concept and quality of life in children with CP who are able to provide self-report of these constructs.

5.7.1. Design. Study 3b was designed as a reliability study. Two methods were used to determine the reliability coefficient of the *myTREEHOUSE Self-Concept Assessment*: (i) internal consistency and (ii) product moment reliability – assessed using the test-retest reliability method. Studies 4 and 5 were cross-sectional studies.

5.7.2. Participants. Participants were recruited, as with the Delphi consensus survey (Study 2), through a state-wide community rehabilitation service. Children were eligible to participate if they fulfilled the following inclusion criteria: (1) a diagnosis of CP, (2) aged 8-12 years, (3) cognitive function within the normal range according to the Wechsler Intelligence Scale for Children 4th edition (WISC-IV; Wechsler, 2003a) with a Verbal Comprehension Index (VCI) of 70 and above, and (4) functional communication skills within the normal range – FCCS Levels I-III.

Participants of the Delphi consensus survey (Study 2) who fulfilled the inclusion criteria were also invited to participate in this next study phase. Recruitment from this previous sample of child participants was deemed appropriate on the basis of two aspects. First, the Delphi consensus survey for children was presented in a manner that did not require the children to evaluate their own self-concept, which differs from the myTREEHOUSE Self-Concept Assessment. Second, there was a 12-month lapse between conclusion of the Delphi consensus survey (Study 2) and the commencement of the Psychometric Testing (Study 3b), Self-Concept Profile (Study 4), and Self-Concept and Quality of Life (Study 5). It was anticipated that this 12-month gap was sufficient to minimise interference across the data collection. Eight out of the 12 children who participated in the Delphi consensus survey (Study 2) fulfilled the inclusion criteria for the next study phase (Study 3b, 4, and 5). These eight children were invited to participate in the next study phase but only six children accepted the invitation.

5.7.3. Instruments. A number of standardised measures were used. The demographic questionnaire and the *myTREEHOUSE Self-Concept Assessment* used in Studies 3b, 4, and 5 are presented in Appendix F.

5.7.3.1. Participant characteristics. Participant characteristics were obtained through proxy-report using the demographic questionnaire and functional classification systems. The demographic questionnaire included information about the child's date of birth, age, gender, school type, and diagnosis. Three functional classification systems were utilised including GMFCS-E&R, MACS, and FCCS (see Sections 5.3.2.1.1, 5.3.2.1.2, and 5.3.2.1.3 for details of these functional classification systems).

5.7.3.2. myTREEHOUSE Self-Concept Assessment. The *myTREEHOUSE Self-Concept Assessment* was used to assess self-concept. Details of the instrument, including structure, administration, and scoring, are described in Chapter 8.

5.7.3.3. myTREEHOUSE Self-Concept Assessment evaluation questionnaire. A structured interview was conducted to assess face validity and clinical utility of the *Game Version* of the *myTREEHOUSE Self-Concept Assessment* from test respondents. The interview focused on four main areas – the board, ramp, picture cards, and accompanying chart – to seek information about the overall look and helpfulness of the *Game Version*.

5.7.3.4. Wechsler Intelligence Scale for Children – Fourth Edition. The WISC-IV is an individually administered intelligence test, suitable for children aged from 6 to 16 years and 11 months (Wechsler, 2003b). Cognitive function is estimated using five composite scores. However, for the purpose of these studies, only the VCI composite score was obtained, consisting of three subtests: Similarities, Vocabulary, and Comprehension. Administration methods and scoring were conducted in reference to the WISC-IV Australian Standardised edition (Wechsler, 2003a). Reliability of the

VCI, according to the Australian Standardised edition, is excellent, with a reliability coefficient of 0.94 and stability coefficient of 0.89.

5.7.3.5. Quality of Life Questionnaire for Children – Child Report Questionnaire. The *CP QOL-Child – Child Report Questionnaire* consists of 53 items to measure quality of life for children with CP aged 9-12 (Waters et al., 2013). It measures five areas: *Social Wellbeing and Acceptance*, *Participation and Physical Health*, *Feelings about Functioning*, *Emotional Wellbeing and Self-Esteem*, and *Pain and Impact of Disability*. Higher scores represent higher quality of life on all subscales except for the *Pain and Impact of Disability* subscale where lower scores indicate higher quality of life. *CP QOL-Child – Child Report Questionnaire* has strong internal consistency (Cronbach's α=0.80-0.90) across subscales (Waters et al., 2007).

5.7.3.6. Quality of Life Questionnaire for Children – Primary Caregiver Questionnaire. The *CP QOL-Child – Primary Caregiver Questionnaire* consists of 65 items that measure quality of life for children with CP aged 4-12 using proxy-report by a primary caregiver (Waters et al., 2013). The *Primary Caregiver Questionnaire* measures all five subscales as presented in the *Child Report Questionnaire*, in addition to *Access to Services*, and *Family Health* subscales. Higher scores represent higher quality of life on all subscales except for the *Pain and Impact of Disability* subscale where lower scores indicate higher quality of life. The *CP QOL-Child – Primary Caregiver Questionnaire* has strong internal consistency (Cronbach's α=0.74-0.92) and good test-retest reliability (ICC=0.76-0.89) across subscales (Waters et al., 2007). Fair to moderate correlations are reported between the *Primary Caregiver Questionnaire* and the *Child Report Questionnaire* (r=0.52-0.77) across subscales (Waters et al., 2007).

5.7.4. Procedure. Similarly to the Delphi consensus survey (Study 2), participants were recruited using flier mail outs. Fliers with brief information about the study and an expression of interest reply slip (see Appendix F) were sent to potential participants. Fliers were mailed to families living in major coastal towns in the state of Queensland, Australia. Within two to three weeks of the mail out, families were contacted by telephone to enquire about their interest in participating. As with the earlier study, only three contact attempts were made with each family to reduce potential participant stress.

Caregivers provided consent for their child to participate in the study. The consent process was explained to each participating child and they were encouraged to complete an assent form or provide verbal assent. Both consent and assent forms (see Appendix F) were completed prior to participation. Two appointments were conducted approximately two to four weeks apart. Each appointment lasted about 45-60 minutes depending on the ability and attention span of the child.

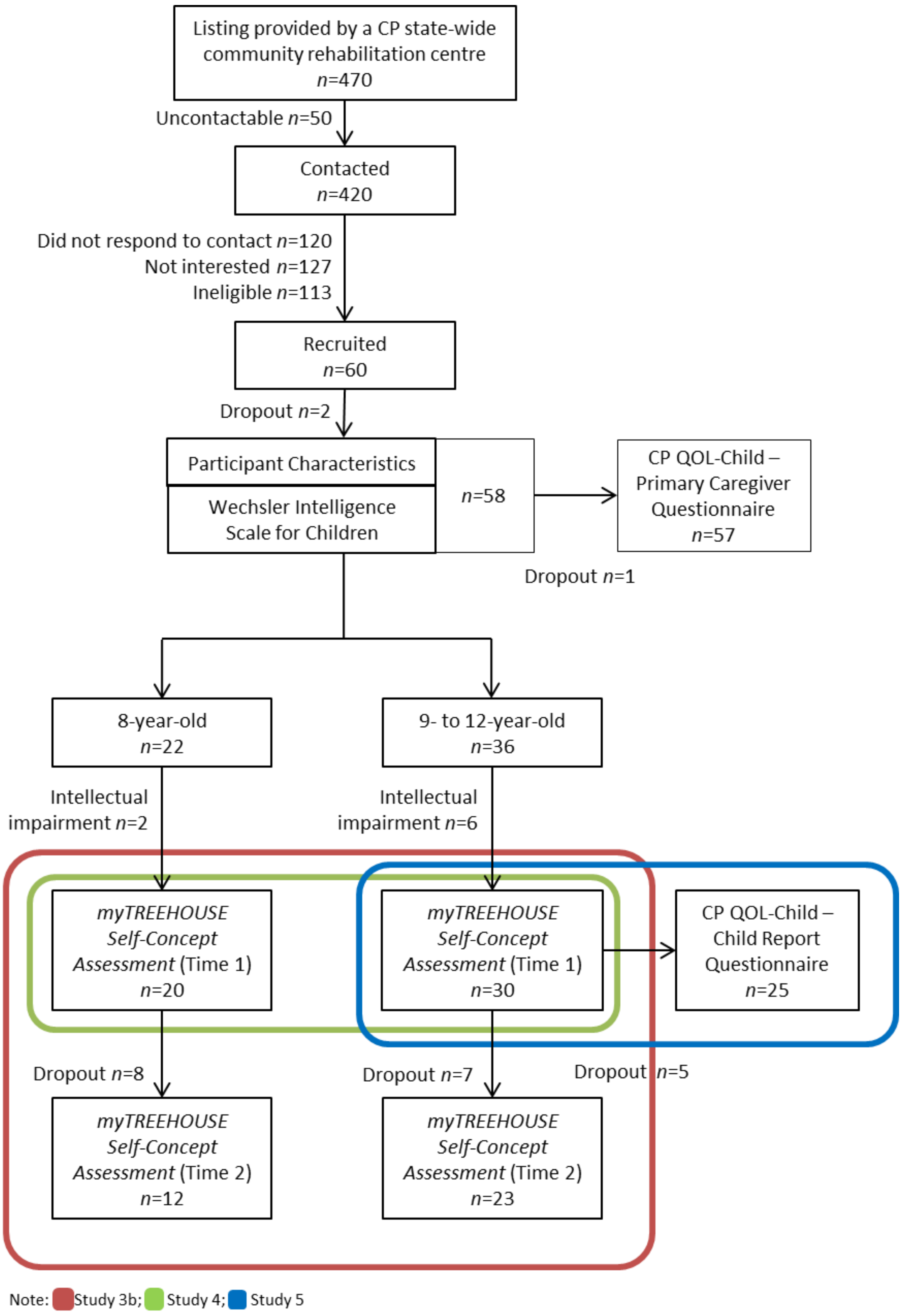


Figure 5.4 Participant recruitment and involvement for Studies 3b, 4, and 5

The caregivers of each participating child completed the demographic questionnaire for functional classification systems at the first appointment, and the *CP QOL-Child Primary Caregiver Questionnaire* at the second appointment. During the first appointment, child participants completed the WISC-IV VCI subtests to ascertain their level of cognitive functioning, and then they continued with the *myTREEHOUSE Self-Concept Assessment*. During the second appointment, they completed the *myTREEHOUSE Self-Concept Assessment*, a structured interview to evaluate the *myTREEHOUSE Self-Concept Assessment – Game Version* (only for participants who selected to use the *Game Version*), and the *CP QOL-Child – Child Report Questionnaire* (only for participants aged 9-12 years). Figure 5.4 illustrates participant recruitment and involvement for Studies 3b, 4, and 5.

5.7.5. Statistical analysis. The following statistical analyses were undertaken to address the aims of Studies 3b, 4, and 5.

5.7.5.1. Psychometric testing (Study 3b). Psychometric evaluation for the *myTREEHOUSE Self-Concept Assessment* included face validity, test-retest reliability, and internal consistency. Descriptive statistics collated the responses from the structured interview to evaluate the *myTREEHOUSE Self-Concept Assessment – Game Version* to provide evidence of face validity for this alternative administration method. Test-retest reliability was calculated using the ICC. The ICC(3,1) was chosen to accurately analyse repeated measures for consistency of the instrument (Portney & Watkins, 2009). Cronbach’s alpha was used to calculate internal consistency.

5.7.5.2. Self-concept profile (Study 4). Descriptive statistics were used to summarise the demographic information and self-concept profile using the *myTREEHOUSE Self-Concept Assessment*. Pearson product moment correlation coefficients were used to investigate the correlations between self-concept domains and age. Independent sample t-tests were used to compare self-concept domains between gender. Lastly, one-way ANOVAs were used to compare the self-concept domains of children at different levels of functional abilities (i.e., GMFCS-E&R, MACS, FCCS, and WISC-IV VCI).

5.7.5.3. Self-concept and quality of life (Study 5). Descriptive statistics were used to summarise demographic information. Paired sample t-tests were used to compare the quality of life subscales between child-report and proxy-report. Pearson product moment correlation coefficients were used to investigate correlations between self-concept domains and quality of life subscales.

5.8. Chapter Summary

The *myTREEHOUSE Self-Concept Assessment* was designed after an extensive process of gathering opinions – from children with CP, their caregivers, and professionals who work with children with CP – to identify the specific self-concept characteristics unique to preadolescent children with CP. The draft instrument underwent several iterations prior to psychometric testing to ensure that the instrument could be readily understood in view of the broad range of impairment types and severity experienced by children with CP. In summary, the development of this instrument was systematically examined to ensure its suitability for children with CP. Each study is described in the following chapters, presented as manuscripts either published or intended for submission to selected journals.

Chapter 6. Systematic Review

6.1. Introduction

The literature reviewed in Chapter 4 presented several self-concept instruments that have been modified and/or validated for children with CP. There was no evidence that a CP-specific self-concept instrument existed. Mokkink et al. (2009) recommend a systematic review in order to identify and select the best instrument for a specific purpose. Following their recommendation, a systematic review was conducted to identify and select the most psychometrically sound self-concept instrument for children with CP. This systematic review is described in the following published manuscript as per the reference below:

Cheong, S. K., & Johnston, L. M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities, 34*, 3566-3575. Retrived from http://dx.doi.org/10.1016/j.ridd.2013.07.023

Systematic review of self-concept measures for primary school aged children with cerebral palsy

Authors: Sau Kuan Cheong[1] and Leanne M Johnston[2,3]

[1]School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, AUSTRALIA. E-mail: sscheo006@myacu.edu.au

[2]Cerebral Palsy League, 55 Oxlade Drive, Brisbane, Queensland 4005, AUSTRALIA. E-mail: ljohnston@cplqld.org.au

[3]School of Health & Rehabilitation Sciences, The University of Queensland, AUSTRALIA.

Correspondence to Sau Kuan Cheong, School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, Australia. E-mail: sscheo006@myacu.edu.au. Phone number: +61430272666

Article history:
Received 20 May 2013
Received in revised from 12 July 2013
Accepted 15 July 2013

Research in Developmental Disabilities, 34, 3566-3575

Abstract

This study involved a systematic review aimed to identify self-concept measures that provided published psychometrics for primary school aged children (8-12 years) with cerebral palsy (CP). Six electronic databases (PubMed, MEDLINE, CINAHL, PsycINFO, PsycARTICLES and Web of Science) were searched to identify assessments that (1) measured self-concept; (2) in children aged 8-12 years; (3) with CP; (4) with psychometrics available. The Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) checklist was used to evaluate psychometric properties and the CanChild Outcome Measure Rating Form was used to evaluate clinical utility. Search yielded 271 papers, of which five met inclusion criteria. These papers reported five measures of self-concept with psychometric properties for the target population: the Rosenberg Self-Esteem Index, Self-Description Questionnaire-I, Self-Perception Profile for Children (original) and two separate modifications of the Self-Perception Profile for Children. Currently, no self-concept measures published in English had sufficient psychometric data for children with CP. The Self-Description Questionnaire-I and the Self-Perception Profile for Children were promising options. Further research is required (a) to determine self-concept construct components important for children with CP and (b) to examine the relative strength, validity, reliability and clinical utility of self-concept measures for the target population.

Keywords:

- Self-concept measures
- Cerebral palsy
- Primary school aged children

Research in Developmental Disabilities, 34, 3566-3575

1. Introduction

Cerebral palsy (CP) is the most commonly reported physical disability in childhood with a prevalence of 2 per 1000 live births (ACPR Group, 2009). It is a permanent, non-progressive disorder of the development of movement and posture (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2006). Current treatments for children with CP are commonly aimed at increase functioning, improving capability and maintaining health targeting on mobility, cognitive development, social interaction and independence (Krigger, 2006). In the last two decades, research had begun to address participation and quality of life (Cooley & Committee on Children With Disabilities, 2004; Imms, 2008; Imms, Reilly, Carlin, & Dodd, 2009; Voorman et al., 2006). This was in line with the introduction of the International Classification of Functioning, Disability and Health in 2001 which focused on four main areas; body functions, body structures, activities and participation, and environmental factors (World Health Organisation, 2011). However, little research has been carried out to investigate other aspects of well-being in children with CP. Self-concept is well researched in the general population but lacking amongst the CP population. Self-concept is important in promoting social functioning and independence leading to higher quality of life (Russo et al., 2008; Soyupek, Aktepe, Savas, & Askin, 2010).

Self-concept, broadly defined as an individual’s perception of oneself, is a multi-dimensional construct arising from characteristics such as scholastic/cognitive competence, physical competence and appearance, behavioural competence, social acceptance, and gender and cultural identity (Marsh & Shavelson, 1985). Past studies have linked low self-concept with poor academic achievement (Trautwein, Lüdtke, Köller, & Baumert, 2006), behaviour problems (Donnellan, Trzesniewski, Robins, Moffitt, & Caspi, 2005), and mental health problems (Emler, 2002). A systematic review of studies in self-concept of children (4-18 years) with CP compared to typically developing children consolidated six articles but found inconclusive results (Shields, Murdoch, Loy, Dodd, & Taylor, 2006). Other studies not included in the systematic review also revealed inconsistent findings. Some studies showed lowered self-concept amongst children with CP compared to typically developing children (Shields, Loy, Murdoch, Taylor, & Dodd, 2007; Ziebell, Imms, Froude, McCoy, & Galea, 2009). On the other hand, there were also studies which showed similar levels of self-concept between children with CP and their typically developing peers (Manuel, Balkrishnan, Camacho, Smith, & Koman, 2003; Schuengel et al., 2006). Most studies focused on comparing children with CP to typically developing children but there is limited research about self-concept development, difficulties or interventions in this population. A major barrier to research in self-concept of children with CP may be due to a lack of measures with suitable psychometric data and clinical utility for children with CP. Researchers had highlighted the importance of using a well validated instrument for its target population when conducting research on self-concept (Llewellyn & Chung, 1997; von der Luft, DeBoer, Harman, Koenig, & Nixon-Cave, 2008).

To enhance future research in self-concept of children with CP there is a need to identify accurate measures for this target population. Therefore, the aim of this systematic review was to identify self-concept instruments that provided published psychometrics for primary school aged children (8-12 years) with CP.

2. Method

2.1 Search Strategy

Articles were retrieved from a systematic search of six electronic databases (PubMed, MEDLINE, CINAHL, PsycINFO, PsycARTICLES and Web of Science) from the earliest possible date (1966 – February 2013). The search strategy included keywords for population (“cerebral palsy” AND “children”) AND construct of interest (“self-concept” OR “self-esteem” OR “self-perception”). To identify all possible assessments and psychometric information, secondary searching included: reference lists of identified articles, citation tracking of included articles, and electronic searches of included test titles and authors’ names.

2.2 Inclusion/Exclusion Criteria

Articles were included if they: (i) involve children with CP; (ii) aged 8-12 years; (iii) reported original data from administration of a self-concept measure with psychometric data available for children with CP; (iv) in English language; (v) in a full text manuscript. A younger limit of eight years was selected because children younger than eight have been deemed to be less capable of making a subjective judgement about self-worth (Harter & Pike, 1984). A higher limit of 12 years was selected, narrowing the focus to pre-adolescence (Marsh, 1990), because research has showed more concerns regarding self-concept in this group (Soyupek et al., 2010). Articles were excluded if they (i) did not include the target population; (ii) were opinions or reviews without original data; (iii) reported a self-concept measure without psychometric data; (iv) were not published in English; (v) or were only conference abstracts or letters.

2.3 Data Extraction and Analysis

Both authors reviewed all articles from the initial search independently. Articles were excluded as able based on title and abstract. Then, if required the full text article was sourced. Decision of inclusion and exclusion was made in consensus between both authors. Full texts of all included articles were sourced to extract data for quality assessment. Psychometric properties evaluated included validity and reliability. Validity is a judgement of how well the instrument measures what it purports to measure, described as content validity, criterion-related validity and/or construct validity (Cohen

& Swerdlik, 2010). The authors further explained reliability as a measure of instrument consistency reported using a reliability coefficient calculated from test-retest reliability, alternate-forms reliability, split-half reliability or inter-scorer reliability.

Psychometric quality of each self-concept instrument was evaluated using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist. The COSMIN checklist assesses the methodological quality of studies using twelve boxes (Mokkink, Terwee, Knol, et al., 2010; Mokkink, Terwee, Patrick, et al., 2010) assessing different aspects. Ten boxes assessing measurement properties scored using a 4-point scale (Terwee et al., 2012) to provide concrete comparison between studies. The statistical strength of each reported psychometric information was rated as good (+), intermediate (0), poor (-) or unknown (?) (Terwee et al., 2007). The methodological strengths of studies reporting psychometric properties were rated as strong (3 points), moderate (2 points), and limited (1 point) which were tabulated across all aspects of evaluation to obtain an overall psychometric rating score ranging from 0 to 24 points (Terwee et al., 2012).

Measure characteristics and clinical utility of each measure was evaluated using the CanChild Outcome Measure Rating Form (e.g., measure focus, clinical utility, scale construction and standardisation). The form enabled classification of clinical utility of instruments using a rating of excellent, adequate or poor (CanChild Centre for Childhood Disability Research, 2004).

3. Results

The initial search yielded 271 articles. From the initial search, 15 articles were excluded as they were inaccessible (no hard copy, electronic copy or full article available). A further 230 articles from the search were excluded due to their content: 96 articles did not include children with CP; 13 articles did not met the specified age group (8-12 years); 97 articles did not employ a self-concept instrument as a measure; and 24 did not include original data collection (review articles). Full texts of the 26 remaining articles were retrieved. Of these 21 were excluded as they did not report instruments with psychometric data for children with CP. The final count included five articles (Dodd, Taylor, & Graham, 2004; Manuel et al., 2003; Schuengel et al., 2006; von der Luft, Harman, Koenig, Nixon-Cave, & Gaughan, 2008; Ziebell et al., 2009) that reported original data using self-concept instruments with psychometric properties for children with CP aged 8 to 12 years. All five articles employed different self-concept instruments: the Rosenberg Self-Esteem Index (RSE; Rosenberg, 1965), Self-Description Questionnaire-I (SDQ-I; Marsh, 1992), Self Perception Profile for Children-original (SPPC-original; Harter, 1985), and two separate modifications of the SPPC (Schuengel et al., 2006; Ziebell et al., 2009). Figure 1 illustrated the search process and outcome of the systematic review. Table 1 describes each instrument employed in the articles.

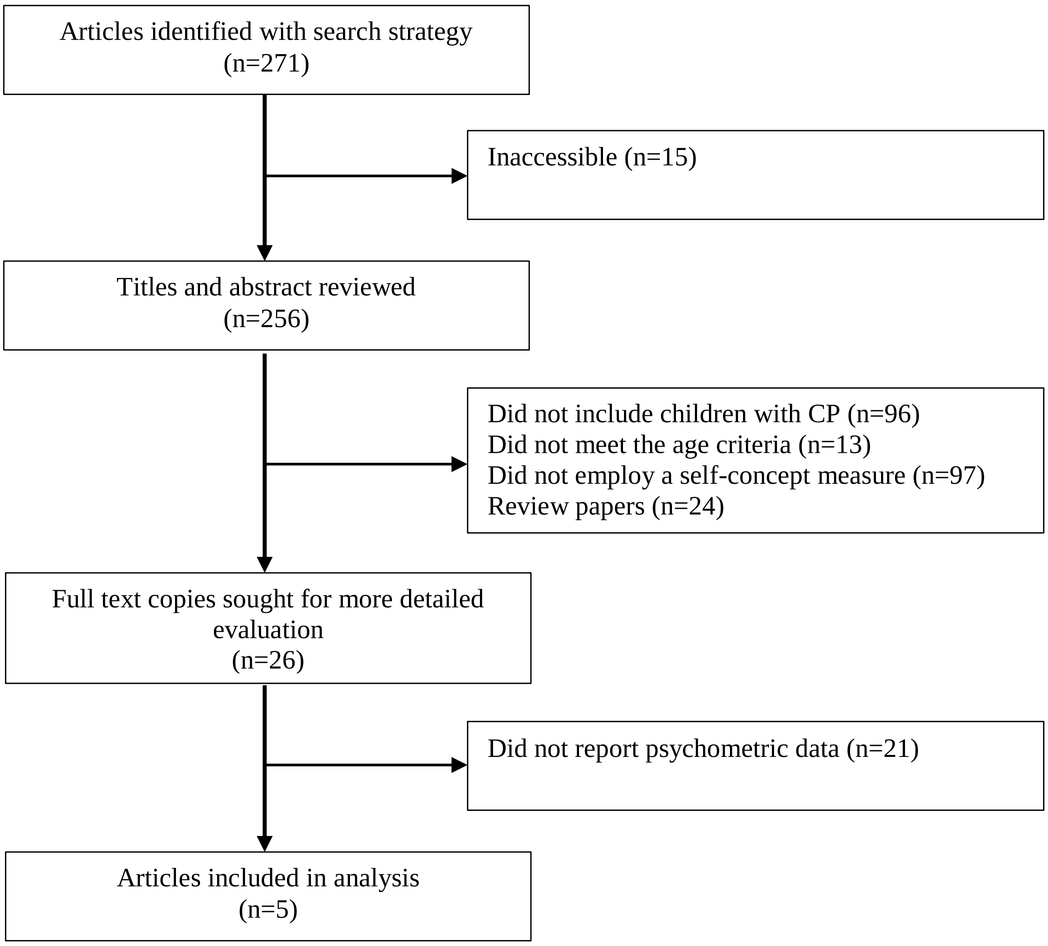


Figure 1: Search processes performed to identify measures of self-concept for children with CP aged 8-12 years.

The RSE (Rosenberg, 1965), SDQ-I (Marsh, 1992) and SPPC-original (Harter, 1985) were self-concept instruments developed for typically developing children and each have published psychometric properties for this group. The two remaining articles reported two separate modified versions of SPPC (Schuengel et al., 2006; Ziebell et al., 2009) specifically designed for children with CP.

Four of the five articles included were research studies that used a self-concept instrument (Dodd et al., 2004; Manuel et al., 2003; Schuengel et al., 2006; Ziebell et al., 2009). Part of the research methodoloy in these studies included either an examination of internal consistency (Manuel et al., 2003; Schuengel et al., 2006), test-retest reliability (Dodd et al., 2004) or content validity (Ziebell et al., 2009) for the research population. Only one article was published as a cross-validation study aimed at evaluating the psychometric properties (i.e, internal consistency and construct validity) of the SDQ-I that included 104 children with CP (von der Luft, Harman, et al., 2008).

The Australian modified-SPPC by Ziebell and her colleagues (2009) was modified from the original SPPC for use in research with children with CP. This modified version removed the ‘physical appearance’ and ‘behavioural conduct’ constructs from the original and replaced these with two self-developed constructs of ‘gross motor competence’ and ‘fine motor competence’ (Ziebell, 2006). The Dutch modified-SPPC by Schuengel and his colleagues (2006) was adapted from a Dutch translation of the SPPC (Komdeur, Schuur, Wijnroks & Vermeer, 2001).

Table 1: Characteristics of self-concept instruments

Measure	Age range	Attributes	Administration method
RSE (Rosenberg, 1965)	Not specified	*Unidimensional* General self-esteem	Participants respond to 10 items by rating each item on a 4-point likert scale (Strongly agree, Agree, Disagree and Strongly disagree).
SDQ-I (Marsh, 1992)	8 – 12 years	*Multidimensional* Physical appearance Physical abilities Parent relations Peer relations General school Reading Mathematics General self	Participants respond to 76 items by rating each item on a 5-point likert scale (False, Mostly false, Sometimes false sometimes true, Mostly true, True).
SPPC (Harter, 1985)	8 – 12 years	*Multidimensional* Scholastic competence Social acceptance Athletic competence Physical appearance Behavioural conduct Global self-worth	Participants respond to 36 items by first deciding which of two options about a particular topic best describes them, then rating the intensity of that choice as “sort of true” or “really true”.
Dutch modified-SPPC (Schuengel et al., 2006)	Not specified	*Multidimensional* Scholastic competence Social acceptance Athletic competence Physical appearance Global self-worth Motor competence	Participants respond to 38 items by first deciding which of two options about a particular topic best describes them, then rating the intensity of that choice as “sort of true” or “really true”.
Australian modified-SPPC (Ziebell, 2006)	Not specified	*Multidimensional* Scholastic competence Social acceptance Athletic competence Global self-worth Gross motor competence Fine motor competence	Participants respond to 36 items by first deciding which of two options about a particular topic best describes them, then rating the intensity of that choice as “sort of true” or “really true”.

RSE, Rosenberg Self-Esteem Index; SDQ-I, Self-Description Questionnaire-I; SPPC, Self Perception Profile for Children.

Reliability and internal consistency of each assessment was extracted and rated according to the COSMIN checklist (refer to Table 2). Three assessments (Manuel et al., 2003; Schuengel et al., 2006; von der Luft, Harman, et al., 2008) reported internal consistency and only one article (Dodd et al., 2004) reported test-retest reliability for the CP population. RSE achieved a cronbach’s alpha of 0.84 for the total score but no factor analysis was performed (Manuel et al., 2003) and thus an intermediate score was given using the COSMIN checklist. The SDQ-I obtained an intermediate score on the COSMIN checklist with reported cronbach’s alpha for each subscale ranging from 0.76-0.94 but factor analysis performed did not include sufficient participants per item (von der Luft, Harman, et al., 2008). However, the Dutch modified-SPPC was rated as poor on the COSMIN checklist because one of its factors reported cronbach’s alpha below 0.70 and factor analysis was not performed (Schuengel et al., 2006). Lastly test-retest reliability was tested on the SPPC-original and reported intraclass correlation coefficient (ICC) ranging from 0.56-0.80 on individual subscales (Dodd et al., 2004). Unfortunately a poor score was given for both methodological and statistical evaluation based the COSMIN checklist due to small sample size and one of the factors reported ICC below 0.70. The small sample of 17 children could not provide sufficient information for generalisation to the broader CP population.

Table 2: Reliability and internal consistency of self-concept instruments for children with CP

Measure	COSMIN overall psychometric rating (Range from 0 to 24 points)	Internal Consistency (Cronbach's Alpha)	Test-Retest Reliability
RSE (Rosenberg, 1965)	1	Limited (one fair study) (0)[18] *n*=50 children aged 9-18y with CP. Cronbach's alpha reliability= 0.84	Nil
SDQ-I (Marsh, 1992)	2	Limited (one fair study) (0)[30] *n*=104 children aged 9-16y with CP. Cronbach's alphas for each dimension: Physical appearance 0.85, Physical abilities 0.76, Parent relations 0.80, Peer relations 0.84, General school 0.89, Reading 0.90, Mathematics 0.94, General self 0.79	Nil
SPPC (Harter, 1985)	1	Nil	Limited (one poor study) (-)[31] *n*=17 children aged 8-16y with CP. Intraclass Correlation Coefficient (ICC) for each dimension: Scholastic competence 0.80, Social acceptance 0.56, Athletic competence 0.82, Physical appearance 0.76, Behaviour conduct 0.80, Global self-worth 0.76
Dutch modified-SPPC (Schuengel et al., 2006)	1	Limited (one fair study) (-)[19] *n*=80 children aged 9-13y with CP. Cronbach's alphas for each dimension ranges from 0.75 – 0.76 except for athletic competence 0.63	Nil
Australian modified-SPPC (Ziebell, 2006)	1	Nil	Nil

Methodological quality rated as limited, moderate, or strong. Statistical strength identified in brackets as + good; 0 intermediate; - poor; ? unknown. RSE, Rosenberg Self-Esteem Index; SDQ-I, Self-Description Questionnaire-I; SPPC, Self Perception Profile for Children.

Validity of each assessment was extracted and rated according to the COSMIN checklist (refer to Table 3). Only two assessments (von der Luft, Harman, et al., 2008; Ziebell et al., 2009) reported validity information. The SDQ-I reported construct validity investigated using scree plot, principal factor analysis and structural equation modelling revealing seven factors, similar to normative data with a model fit of 1.25 (von der Luft, Harman, et al., 2008). The SDQ-I was given a good score on the COSMIN checklist. However the Australian modified-SPPC obtained a poor score on the COSMIN checklist for content validity. Content validity on the instrument was provided by eight professionals (six occupational and two physical therapists) independent to the research who evaluated importance of individual subtests for children with disabilities but no indication of suitability of the entire measure for the target population (Ziebell, 2006).

Clinical utility assessment was conducted for each of the instrument using the CanChild Outcome Measure Rating Form (refer to Table 4). The RSE (Rosenberg, 1965), SDQ-I (Marsh, 1992) and SPPC-original (Harter, 1985) obtained an ‘adequate’ rating. However, both the Australian (Ziebell, 2006) and Dutch (Schuengel et al, 2006) modified-SPPC instruments was rated as ‘poor’ due to limited published information on clinical utility, in particular methodology (e.g., manual and norms unavailable, poor instruction clarity, no indication of examiner qualification and cost).

Table 3: Validity of self-concept instruments for children with CP

Measure	Content validity	Construct Validity	Criterion Validity
RSE (Rosenberg, 1965)	Nil	Nil	Nil
SDQ-I (Marsh, 1992)	Nil	Limited (one fair study) (+)[30] *n*=104 children aged 9-16y with CP. Scree plot indicated eight substantive factors. Principle Factor Analyses showed seven factors (general self is not included as an independent factor). Confirmatory Factor Analyses reported X^2 254 df 203, Model fit of 1.25	Nil
SPPC (Harter, 1985)	Nil	Nil	Nil
Dutch modified-SPPC (Schuengel et al., 2006)	Nil	Nil	Nil
Australian modified-SPPC (Ziebell, 2006)	Limited (one poor study) (-)[17,36] *n*=8 children aged 7-11y with CP. Not specifically for children with CP. Eight expert panels (six occupational and two physical therapists) independent from the study considered the measure's applicability for children with disability.	Nil	Nil

Methodological quality rated as limited, moderate, or strong. Statistical strength identified in brackets as + good; 0 intermediate; - poor; ? unknown. RSE, Rosenberg Self-Esteem Index; SDQ-I, Self-Description Questionnaire-I; SPPC, Self Perception Profile for Children.

Table 4: Clinical utility as measured by the CanChild Outcome Measures Rating Form

Measures	Overall Utility	Focus	Clinical Utility	Scale Construction	Standardisation
RSE (Rosenberg, 1965)	*Adequate*	*ICF:* Body functions Activities and participation *Attributes:* Single *Purpose:* Discriminative Evaluative *Informant:* Client *Population measure designed for:* Not specified	*Instruction Clarity:* Excellent *Format:* Self-completed No physical invasion No special equipment *Duration:* 2 – 3 minutes Easy administration, scoring and interpretation *Examiner qualification:* Not addressed *Cost:* Downloadable without cost	*Item Selection:* Adequate, included most relevant characteristics of attribute *Weighting:* Not weighted *Level:* Ordinal with Likert scaling 10 items without subscales	*Manual:* Adequate *Availability of norms:* For typically developing children
SDQ-I (Marsh, 1992)	*Adequate*	*ICF:* Body functions Activities and participation *Attributes:* Multiple *Purpose:* Discriminative Evaluative *Informant:* Client *Population measure designed for:* TDC aged 8-12 years	*Instruction Clarity:* Excellent *Format:* Self-completed No physical invasion No special equipment *Duration:* 15 – 20 minutes Easy administration, scoring and interpretation *Examiner qualification:* Not addressed *Cost:* Downloadable without cost	*Item Selection:* Adequate, included most relevant characteristics of attribute *Weighting:* Not weighted *Level:* Ordinal with Likert scaling 76 items with eight subscales	*Manual:* Excellent *Availability of norms:* For typically developing children

Measures	Overall Utility	Focus	Clinical Utility	Scale Construction	Standardisation
SPPC (Harter, 1985)	*Adequate*	*ICF:* Body functions Activities and participation *Attributes:* Multiple *Purpose:* Discriminative Evaluative *Informant:* Client and teachers *Population measure designed for:* TDC aged 8 – 12 years	*Instruction Clarity:* Excellent *Format:* Self-completed or teacher rated No physical invasion No special equipment *Duration:* 15 – 20 minutes Easy administration, scoring and interpretation *Examiner qualification:* Not addressed *Cost:* Purchase through author	*Item Selection:* Adequate, included most relevant characteristics of attribute *Weighting:* Not weighted *Level:* Ordinal Structured alternative format 36 items with six subscales	*Manual:* Excellent *Availability of norms:* For typically developing children
Dutch modified-SPPC (Schuengel et al., 2006)	*Poor*	*ICF:* Body functions Activities and participation *Attributes:* Multiple *Purpose:* Discriminative Evaluative *Informant:* Client *Population measure designed for:* Not indicated	*Instruction Clarity:* Not available *Format:* Self-completed No physical invasion No special equipment *Duration:* Duration not indicated Easy administration, scoring and interpretation *Examiner qualification:* Not addressed *Cost:* Not indicated	*Item Selection:* Adequate, included most relevant characteristics of attribute *Weighting:* Not weighted *Level:* Ordinal Structured alternative format 38 items with six subscales	*Manual:* Not available *Availability of norms:* Not indicated

Measures	Overall Utility	Focus	Clinical Utility	Scale Construction	Standardisation
Australian modified-SPPC (Ziebell, 2006)	*Poor*	*ICF:* Body functions Activities and participation *Attributes:* Multiple *Purpose:* Discriminative Evaluative *Informant:* Client and parents *Population measure designed for:* Not indicated	*Instruction Clarity:* Not available *Format:* Self-completed or parent rated No physical invasion No special equipment *Duration:* Duration not indicated Easy administration, scoring and interpretation *Examiner qualification:* Not addressed *Cost:* Not indicated	*Item Selection:* Adequate, included most relevant characteristics of attribute *Weighting:* Not weighted *Level:* Ordinal Structured alternative format 36 items with six subscales	*Manual:* Not available *Availability of norms:* Not indicated

Discriminative assessment – used to distinguish between individuals based on dimension of interest; evaluative assessment – used to measure change in an individual. RSE, Rosenberg Self-Esteem Index; SDQ-I, Self-Description Questionnaire-I; SPPC, Self Perception Profile for Children.

4. Discussion

Development of self-concept amongst children is an important area of focus because self-concept can affect the well-being of an individual. Self-concept of typically developing children is well researched but research is lacking for the CP population especially children with CP. One of the major limitations to research in this area is the lack of well validated measures for this population. The aim of this systematic review was to identify self-concept instruments that have appropriate psychometric properties and clinical utility for children with CP aged between 8-12 years. The systematic review found five articles (Dodd et al., 2004; Manuel et al., 2003; Schuengel et al., 2006; von der Luft, Harman, et al., 2008; Ziebell et al., 2009) reporting psychometric properties for children with CP aged 8-12 years.

Two measures were identified that had been developed for children with CP. Both were modified versions of the SPPC, one in English based on the original SPPC and one in Dutch based on the Dutch translated SPPC. Unfortunately neither of the modified-SPPC measures (Schuengel et al., 2006; Ziebell, 2006) revealed sufficiently strong psychometric properties or clinical utility for use with children with CP. The Australian modified-SPPC (Ziebell, 2006) only reported content validity evaluating subscale relevance to children with disability. The Dutch modified-SPPC (Schuengel et al., 2006) reported acceptable internal consistency. Thus, while strong in intent, they should be used with caution at this time until further reliability and validity research is completed.

The RSE was primarily limited by its construct as a unidimensional scale across the age span, a format which is not supported because this may lead to under-representation of self-concept (Butler & Gasson, 2005). Further, the RSE was originally designed to tap the perspective of adolescent (Rosenberg, 1965) and thus its constructs may not be suitable for pre-adolescent children. Thus, the RSE should be used with caution for the pre-adolescent age group.

The SDQ-I and the SPPC revealed most promising results for use with children with CP. The SDQ-I cross validation for children with CP (von der Luft, Harman, et al., 2008) yielded strong psychometric properties but it is not without flaws. The participants' mean age was 12 year 3 months with a standard deviation of 2 years 5 months thus indicating that a significant proportion of the participants were above the recommended testing age (8-12 years) of the instrument. This would greatly impact the psychometric evidence reported by the article. However, on a positive note, the SDQ-I had previously reported to be suitable for preadolescents with mild intellectual disabilities (Marsh, Tracey, & Craven, 2006). Others, including von der Luft, Harman and his colleagues (2008) supported the use of SDQ-I to assess self-concept in children with CP, but recommended as we do, that more detailed psychometric and clinical utility evaluation of the instrument be performed. Until this occurs, results are again to be considered with caution.

The SPPC is the most commonly used self-concept research instrument for typically developing children. However, in investigating self-concept measures for children with physical disabilities, researchers found that the SPPC has areas of focus that have particular weakness for children with physical disability (i.e., sports, social and academic) (Llewellyn & Chung, 1997). This does not mean that children with disabilities necessarily view themselves poorly in these dimensions, but their life experiences in these areas may be more limited compared to typically developing children, essentially re-weighting other more unique goals, aims and values. Furthermore, the SPPC was developed on the basis of social comparison (Llewellyn & Chung, 1997). This concept may vary from individual child depending on their environment. For example, children with disabilities may view themselves differently when placed in different school placement (i.e, mainstream school vs special school) (Harvey & Greenway, 1984). So, despite the SPPC being one of the most commonly used measure for typically developing children, caution is warranted without specific research in the CP population to ensure that its constructs and psychometric properties are appropriate.

Many past researchers have used self-concept instruments developed for typically developing children, but whether these measures provide an accurate representation of the self-perception of children with CP is questionable. Several factors could potentially impact the evaluation of self-concept for children with CP. Firstly, the ability to view the self and provide an evaluation of self-concept is dependent on an individual's cognitive maturity (Marsh & Shavelson, 1985). In view of that, many self-concept instruments are age dependent. Forty-five percent of children with CP have intellectual disability of varying severity (ACPR Group, 2009) and thus chronological age may not be reflective of cognitive maturity, jeopardising the validity of the measure. In these instances, assessment of self-concept using age-based instruments may not provide an accurate reflection of the child due to intellectual disability (von der Luft, DeBoer, et al., 2008).

Secondly, many children with CP have significant motor disabilities and often may have other impairments such as speech, hearing, vision and intellectual impairment as well as epilepsy (ACPR Group, 2009). Earlier studies investigating self-concept of children with CP in comparison to typically developing children found inconsistent findings (Harvey & Greenway, 1984; Russo et al., 2008; Shields et al., 2007; Ziebell et al., 2009). It is unclear if disabilities due to CP impacted the development or expression of self-concept for these children. von der Luft, DeBoer, et al. (2008) highlights that this is a crucial factor when investigating self-concept amongst the CP population. They further urged the importance of obtaining standardised instruments that will reflect the self-concept of these individuals taking into consideration of their disabilities.

Lastly, communication difficulties presents in more than half of the children with CP in addition to motor difficulties (ACPR Group, 2009). Most of the current assessments of self-concept were paper and pencil assessment which is a major barrier to self-reporting for children with concomitant communication and motor difficulties. Creating an instrument that could accommodate these disabilities could increase the psychometric properties and clinical utility of the instrument for children with CP. This may include instruments that consist of pictorial or symbolised items as well as an alternate administrations method to paper and pencil.

A limitation of this systematic review was limiting searches to articles published in English, which may have omitted literature published in other languages.

5. Conclusion

Multiple researchers had highlighted the urgency to obtain a self-concept instrument that is sensitive to the unique characteristics of children with CP. Further research is proposed to identify self-concept construct components important to children with CP, forming the basis of an appropriate instrument to assess self-concept for the target population. A detailed investigation of psychometric properties and clinical utility would ensure its appropriateness for children with CP.

References

ACPR Group. (2009). *Report of the Australian Cerebral Palsy Register, Birth Years 1993-2003*. Australia: Australian Cerebral Palsy Register.

Butler, R.J., & Gasson, S.L. (2005). Self esteem/self concept scales for children and adolescents: A review. *Child and Adolescent Mental Health, 10*(4), 190-201.

CanChild Centre for Childhood Disability Research. (2004). Outcome measures rating form guidelines. Retrieved 17 July 2012, from http://www.canchild.ca/en/canchildresources/resources/measguid.pdf

Cohen, R.J., & Swerdlik, M.E. (2010). *Psychological testing and assessment: An introduction to tests and measurement* (7th ed.). New York, USA: McGraw-Hill.

Cooley, W.C, & Committee on Children With Disabilities. (2004). Providing a primary care medical home for children and youth with cerebral palsy. *Pediatrics, 114*(4), 1106-1113.

Dodd, K.J., Taylor, N.F., & Graham, K.H. (2004). Strength training can have unexpected effects on the self-concept of children with cerebral palsy. *Pediatric Physical Therapy, 16*(2), 99-105.

Donnellan, M.B., Trzesniewski, K.H., Robins, R.W., Moffitt, T.E., & Caspi, A. (2005). Low self-esteem is related to aggression, antisocial behaviour, and delinquency. *Psychological Science, 16*, 328-335.

Emler, N. (2002). The costs and causes of low self-esteem. *Youth Studies Australia, 21*(3), 45-48.

Harter, S. (1985). *Manual for the Self-Perception Profile for Children*. United States of America: University of Denver.

Harter, S., & Pike, R. (1984). The pictorial scale of Perceived Competence and Social Accetance for Young Children. *Child Development, 55*, 1969-1982.

Harvey, D.H.P., & Greenway, A.P. (1984). The self-concept of physically handicapped children and their non-handicapped siblings: An empirical investigation. *Journal of Child Psychology and Psychiatry, 25*(2), 273-284.

Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation, 30*(24), 1867-1884.

Imms, C., Reilly, S., Carlin, J., & Dodd, K.J. (2009). Characteristics influencing participation of Australian children with cerebral palsy. *Disability and Rehabilitation, 31*(26), 2204-2215.

Komdeur, S.J, Schuur, R., Wijnroks, L., & Vermeer, A. (2001). De CompetentieBelevingsSchaal voor kinderen met cerebrale parese [The self-perception profile for children with cerebral palsy]. *Tijdschrift voor Orthopedagogiek, 40,* 579-594.

Krigger, K.W. (2006). Cerebral palsy: An overview. *American Family Physician, 73*(1), 91-100.

Llewellyn, A., & Chung, M.C. (1997). The self-esteem of children with physical disabilities - Problems and dilemmas of research. *Journal of Developmental and Physical Disabilities, 9*(3), 265-275.

Manuel, J.C., Balkrishnan, R., Camacho, F., Smith, B.P., & Koman, L.A. (2003). Factors associated with self-esteem in pre-adolescents and adolescents with cerebral palsy. *Journal of Adolescent Health, 32*, 456-458.

Marsh, H.W. (1990). A multidimensional, hierarchical model of self-concept: Theoretical and empirical justification. *Educational Psychology Review, 2*(2), 77-172.

Marsh, H.W. (1992). *Self-Description Questionnaire-I Manual*. Australia: University of Western Sydney.

Marsh, H.W., & Shavelson, R. (1985). Self-concept: Its multifaceted hierarchical structure. *Educational Psychologist, 20*(3), 107-123.

Marsh, H.W., Tracey, D.K., & Craven, R.G. (2006). Multidimensional self-concept structure for preadolescents with mild intellectual disabilities: A hybrid multigroup - MIMC approach to factorial invariance and latent mean differences. *Educational and Psychological Measurement*, *66*(5), 795-818.

Mokkink, L.B., Terwee, C.B., Knol, D.K., Stratford, P.W., Alonso, J., Patrick, D.L., . . . de Vet, H.C.W. (2010). The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: A clarification of its content. *BMC Medical Research Methodology, 10*(22).

Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Stratford, P.W., Knol, D.K., . . . de Vet, H.C.W. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: An international Delphi study. *Quality of Life Research, 19*, 539-549.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2006). A report: The definition and classification of cerebral palsy April 2006. *Definition and Classification of CP,* 8-14.

Rosenberg, M. (1965). *Society and the adolescent self-image*. United States of America: Princeton University Press.

Russo, R.N., Goodwin, E.J., Miller, M.D., Haan, E.A., Connell, T.M., & Crotty, M. (2008). Self-esteem, self-concept, and quality of life in children with hemiplegic cerebral palsy. *The Journal of Pediatrics, 153,* 473-477.

Schuengel, C., Voorman, J., Stolk, J., Dallmeijer, A., Vermeer, A., & Becher, J.. (2006). Self-worth, perceived competence, and behaviour problems in children with cerebral palsy. *Disability and Rehabilitation, 28*(20), 1251-1258.

Shields, N., Loy, Y., Murdoch, A., Taylor, N.F., & Dodd, K.J. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine & Child Neurology, 49*, 350-354.

Shields, N., Murdoch, A., Loy, Y., Dodd, K.J., & Taylor, N.F. (2006). A systematic review of the self-concept of children with cerebral palsy compared with children without disability. *Developmental Medicine & Child Neurology, 48*, 151-157.

Soyupek, F., Aktepe, E., Savas, S., & Askin, A. (2010). Do the self-concept and quality of life decrease in CP patients? Focussing on the predictors of self-concept and quality of life. *Disability and Rehabilitation, 32*(13), 1109-1115.

Terwee, C.B., Bot, S.D.M., de Boer, M.R., van der Windt, D.A.W.M., Knol, D.L., Dekker, J., . . . De Vet, H.C.W. (2007). Quality criteria were proposed for measurement properties of health status quesstionnaires. *Journal of Clinical Epidemiology, 60*, 34-42.

Terwee, C.B., Mokkink, L.B., Knol, D.K., Ostelo, R.W.J.G., Bouter, L.M., & de Vet, H.C. W. (2012). Rating the methodological quality in systematic reviews of studies on measurement properties: A scoring system for the COSMIN checklist. *Quality of Life Research, 21*, 651-657.

Trautwein, U., Lüdtke, O., Köller, O., & Baumert, J.J. (2006). Self-esteem, academic self-concept, and achievement: How the learning environment moderates the dynamics of self-concept. *Journal of Personality and Social Psychology, 90*(2), 334-349.

von der Luft, G., DeBoer, B.V., Harman, L.B., Koenig, K.P., & Nixon-Cave, K. (2008). Improving the quality of studies on self-concept in children with cerebral palsy. *Journal of Developmental and Physical Disabilities, 20*, 581-594.

von der Luft, G., Harman, L.B., Koenig, K.P., Nixon-Cave, K., & Gaughan, J.P. (2008). Cross validation of a self-concept tool for use with children with cerebral palsy. *Journal of Developmental and Physical Disabilities, 20*, 561-572.

Voorman, J.M., Dallmeijer, A.J., Schuengel, C., Knol, D.K., Lankhorst, G.J., & Becher, J.G. (2006). Activities and participation of 9- to 13-year-old children with cerebral palsy. *Clinical Rehabilitation, 20*, 937-948.

World Health Organisation (WHO). (2011). International classification of functioning, disability and Health (ICF). Retrieved 7 November 2011, from http://www.who.int/classifications/icf/en/

Ziebell, M. (2006). *The relationship between physical performance and self-perception in children with spastic diplegic cerebral palsy*. School of Occupational Therapy. La Trobe University. Victoria, Australia.

Ziebell, M., Imms, C., Froude, E.H., McCoy, A., & Galea, M. (2009). The relationship between physical performance and self-perception in children with and without cerebral palsy. *Australian Occupational Therapy Journal, 56*, 24-32.

6.2. Interpretation and Direction

This was the first systematic review of self-concept instruments for children with CP, identifying psychometric data published for this population with the aim of identifying the most suitable instrument. A systematic review of instrument properties is the gold standard for the identification and selection of an instrument (Mokkink et al., 2009). The findings from this systematic review indicate that a CP-specific self-concept instrument is not available and existing self-concept instruments designed for TD children do not have strong psychometric properties for preadolescent children with CP. Despite the absence of a suitable self-concept instrument, the findings from this systematic review are still valuable because it is the only study to identify all existing self-concept instruments that have been validated for children with CP in some way. These findings could guide future researchers in instrument selection when they intend to use self-concept instruments designed for TD children. This is most relevant in comparative studies involving children with CP and TD children.

Following the decision tree for this research program presented in Chapter 1 (see Figure 1.2), as a psychometrically validated instrument was not found, the next course of action was to determine whether the construct of self-concept held by children with CP is similar to that of TD children. This step recognises that the characteristics of children with CP may influence the child’s experience with their environment leading to a unique sense of their surroundings. These differences may influence the perception of self for a child with CP. The aim of the next study was to investigate self-concept domains and items that are relevant to children with CP.

Chapter 7. Delphi Consensus Survey

7.1. Introduction

It was evident from the systematic review (Study 1, see Chapter 6) that a self-concept instrument designed specifically for children with CP had not yet been developed. In addition, there is a lack of well-validated instruments available for use with this population. As children with CP are likely to experience their environment differently from TD children in some aspects of life, it is important to identify self-concept items and domains that are relevant and important to children with CP. The next phase of this research program was to identify the items and domains that constitute self-concept specifically for children with CP aged 8-12 years. The Delphi consensus survey is described in the following published manuscript as per the reference below:

Cheong, S.K., Lang, C.P., Hemphill, S.A., & Johnston, L.M. (2016). What constitutes self-concept for children with CP? A Delphi consensus survey. *Journal of Developmental and Physical Disabilities*, *28*(2), 333-346. doi: 10.1007/s10882-015-9471-z

What constitutes self-concept for children with CP? A Delphi consensus survey

Authors: Sau Kuan Cheong[1], Cathryne P Lang[2], and Leanne M Johnston[3]

[1]School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, AUSTRALIA. E-mail: saukuan.cheong@myacu.edu.au

[2]School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, AUSTRALIA. E-mail: cathryne.lang@acu.edu.au

[3]The University of Queensland, School of Health and Rehabilitation Sciences, St Lucia Queensland 4072, AUSTRALIA. E-mail: l.johnston1@uq.edu.au

Correspondence to Sau Kuan Cheong, School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, Australia. E-mail: saukuan.cheong@myacu.edu.au. Phone number:

Journal of Developmental and Physical Disability, 28(2), 333-346

Abstract

This study aimed to identify constructs (factors) and content (items) that constitutes self-concept for children with cerebral palsy (CP). Three participant groups were recruited for a three-round Delphi survey: 12 children with CP aged 8-12 years, 18 caregivers, and 21 professionals working with this population. Delphi Round I involved item generation and literature review. In Round II, participants used a five-point scale to rate the importance of factors/items collated from (a) existing self-concept measures identified from literature review and (b) additional factors/items raised in Round I. To increase understanding for children, the rating process was incorporated into a game-based format called “myTREEHOUSE” where ramps leading up to the tree house represented progressively higher ratings. Each item was presented by the researcher verbally (short standard phrase) and visually (Pictorial Communication Symbols card). Factors and items reaching 75% consensus within each group were removed and those not reaching consensus were repeated in Round III. Consensus on factors and items reaching consensus after Rounds II and III was examined within and between groups. A total of 117 items were identified by the review and 24 from Delphi Round I, totalling 141 items. After Delphi Rounds II and III, 52 items achieved consensus from two or more participant groups. While many areas of self-concept recognised as important for children with CP were similar to typically developing children, several additional CP-specific elements were identified through the Delphi survey.

Keywords: Self-concept, Assessment, Delphi survey, Cerebral palsy, Children

Journal of Developmental and Physical Disability, 28(2), 333-346

What constitutes self-concept for children with CP? A Delphi consensus survey

The introduction of the International Classification of Functioning, Disability and Health (World Health Organisation, 2011) has encouraged clinicians to place greater focus on managing non-physical aspects of functioning, including psychological, social, and environmental factors for children with cerebral palsy (CP). This paper addresses the psychological aspect of self-concept, which is broadly defined as an individual’s perception of the self (Marsh & Shavelson, 1985). The paper focuses on children aged 8-12 years, since children in this age group may be at greater risk of self-concept problems (Marsh, 1990), and they also have the capacity to describe their own competencies and to compare themselves with others (Harter, 2006).

Self-concept is a well-researched attribute with typically developing (TD) children, and research has shown that, for TD children, poor self-concept is linked with poor academic achievement (Trautwein, Lüdtke, Köller, & Baumert, 2006), behaviour problems (Donnellan, Trzesniewski, Robins, Moffitt, & Caspi, 2005), and mental health problems (Emler, 2002), making self-concept an important indicator of psychological functioning. Amongst children with CP, self-concept has been proposed as an important factor in promoting social functioning, independence and a higher quality of life (Russo et al., 2008). Self-concept is generally lower in children with physical disability (Miyahara & Piek, 2006) and chronic illness (Ferro & Boyle, 2013a, 2013b). Studies of self-concept of children with CP (Dodd, Taylor, & Graham, 2004; Russo et al., 2008; Shields, Loy, Murdoch, Taylor, & Dodd, 2007) have shown differences in their self-concept compared to TD children; however, most of these studies employed instruments designed for TD children. A recent systematic review reported that while some authors have modified instruments originally designed for TD children in an attempt to better suit children with CP, comprehensive psychometric validation has not been undertaken

Journal of Developmental and Physical Disability, 28(2), 333-346

for this population (Cheong & Johnston, 2013). Also, in each case, instruments for TD children have been *adapted* rather than developed for children with CP, which may have resulted in important CP-specific aspects of self-concept being inadvertently missed.

Several authors propose that self-concept instruments developed for TD children may not provide an accurate reflection of self-concept of children with physical disabilities (Llewellyn & Chung, 1997; von der Luft, DeBoer, Harman, Koenig, & Nixon-Cave, 2008). For example, while most self-concept instruments include physical aptitude, particularly sports performance, they often fail to evaluate the relative contribution of physical independence or participation which may be more significant for children with limited motor function. Further, phenomenological research shows that the life experiences of children with physical disabilities are qualitatively different (Llewellyn & Chung, 1997), which may also result in a significantly different profile of self-concept elements that are important for children with CP compared to TD children.

In this study, we aimed to identify elements that constitute self-concept specifically for children aged 8-12 years with CP. To obtain the most comprehensive picture, a consensus was sought from the perspectives of three groups: (i) children aged 8-12 years with CP themselves, (ii) their parents/caregivers, and (iii) health care professionals with experience working with children with CP.

Method

The objectives of this study were to (i) identify constructs (factors) and content (items) that have been used in instruments developed for TD children, and/or (ii) suggested by children with CP, their parents or practicing professionals; and (iii) to reduce these items by consensus vote to generate a minimum set of items that reflect self-concept of children with CP. Ethical approval was obtained from the National Health and Medical Research Council (NHMRC) registered Human Research Ethics

Committees of the Cerebral Palsy League (EC00417) and the Australian Catholic University (EC00205).

Participants

Purposive sampling was used to recruit three groups of participants with expertise in understanding children with CP – allied health professionals working with children with CP, parents or caregivers of preadolescent children with CP, and preadolescent children with CP themselves. All participants were recruited from a state-wide community rehabilitation service. Parent and professional participants provided written consent prior to participation. Participating children provided written or verbal assent in addition to their parents providing consent.

Allied health professionals with experience in clinical practice and/or research involving children with CP were eligible to participate. Twenty-one professionals were recruited including: six occupational therapists, six social workers, four physiotherapists, four speech pathologists and one psychologist. Three professional participants were not retained at Delphi Round II and a further three participants were not retained at Round III resulting in a final sample of 15 professionals. High attrition rates in Delphi surveys are not uncommon as the nature of the survey is time consuming and demanding with the inclusion of multiple rounds. The characteristics of the professional participants, including gender, profession, professional experience, and experience with the CP population are presented in Table 1.

Parents of children aged between 8-12 years with CP were eligible to participate. The parent group included 17 parents (16 mothers) and one caregiver. One parent participant was not retained at Delphi Round II, resulting in a total of 17 parents completing the study. The characteristics of the parent participants including gender, family role, gender and age of child with CP, as well as classification of their child with

CP comprising of Gross Motor Function Classification System – Expanded and Revised (GMFCS-E&R; Palisano, Rosenbaum, Bartlett, & Livingston, 2007; Palisano et al., 1997), Manual Abilities Classification System (MACS; Eliasson et al., 2006), and Functional Communication Classification System (FCCS; Barty & Caynes, 2009) are presented in Table 1.

Children were eligible for participation if they (i) had a diagnosis of CP, (ii) were aged between 8-12 years, (iii) had adequate cognitive function, and (iv) had adequate functional communication skills according to the FCCS – meaning that the child could express their own views independently (FCCS Level I-III). Thirteen children were recruited. One child was excluded due to an inability to comprehend the Delphi study instructions resulting in a final group of 12 children (mean age 10 years 3 months, SD 1 year 3 months). Characteristics of the child participants including gender, age, GMFCS-E&R (Palisano et al., 2007; Palisano et al., 1997), MACS (Eliasson et al., 2006), and FCCS (Barty & Caynes, 2009) are presented in Table 1. In this study, all children communicated independently using spoken language and no children were users of augmented or alternative communication devices. During open-ended questioning, additional prompts and time were provided to children as required to ensure they could understand each question and could respond appropriately.

Table 1 Participant characteristics

	N (%)
Characteristics of Professional Participants	
Gender	
Male	4 (19.0)
Female	17 (81.0)
Profession	
Occupational therapist	6 (28.5)
Physiotherapist	4 (19.0)
Psychologist	1 (5.0)
Social worker	4 (19.0)
Speech pathologist	6 (28.5)
Professional experience	
<5years	6 (28.5)
5-10years	5 (24.0)
>10years	10 (47.5)
CP experience	
<5years	10 (47.5)
5-10years	6 (28.5)
>10years	5 (24.0)
Characteristics of Parent Participants	
Gender	
Male	2 (11.0)
Female	16 (89.0)
Family role	
Mother	16 (89.0)
Father	1 (5.5)
Caregiver	1 (5.5)
Gender of child with CP	
Male	9 (50)
Female	9 (50)
Age of child with CP	
8-year-old	3 (16.5)
9-year-old	6 (33.5)
10-year-old	3 (16.5)
11-year-old	3 (16.5)
12-year-old	3 (16.5)
Gross Motor Function Classification System – Expanded and Revised of child with CP	
Level I	7 (38.5)
Level II	5 (28.0)
Level III	5 (28.0)
Level IV	0 (0.0)
Level V	1 (5.5)

Table 1 (continued)

	N (%)
Manual Ability Classification System of child with CP	
Level I	3 (16.5)
Level II	11 (61.5)
Level III	2 (11.0)
Level IV	1 (5.5)
Level V	1 (5.5)
Functional Communication Classification System of child with CP	
Level I	12 (66.5)
Level II	4 (22.5)
Level III	1 (5.5)
Level IV	0 (0.0)
Level V	1 (5.5)
Characteristics of Child Participants	
Gender	
Male	7 (58.0)
Female	5 (42.0)
Age	
8-year-old	0 (0.0)
9-year-old	5 (42.0)
10-year-old	2 (16.5)
11-year-old	2 (16.5)
12-year-old	3 (25.0)
Gross Motor Function Classification System – Expanded and Revised	
Level I	6 (50.0)
Level II	3 (25.0)
Level III	3 (25.0)
Level IV	0 (0.0)
Level V	0 (0.0)
Manual Ability Classification System	
Level I	2 (16.5)
Level II	8 (66.5)
Level III	1 (8.5)
Level IV	1 (8.5)
Level V	0 (0.0)
Functional Communication Classification System	
Level I	8 (66.5)
Level II	3 (25.0)
Level III	1 (8.5)
Level IV	0 (0.0)
Level V	0 (0.0)

Procedure

Items that reflected the self-concept of preadolescent children with CP were identified and prioritised using a Delphi consensus survey method. This method utilises content experts to review and develop items via group consensus through multiple iterations (Hsu & Sandford, 2007). The main advantage of the Delphi survey over less structured methods (e.g., focus groups or round-table discussions) is that the dominating views of a single or few individuals can be minimised. The Delphi survey included three rounds, each approximately one month apart.

In Round I, professionals and parents each completed a hardcopy or web-based questionnaire. Children participated via face-to-face interviews with the first author. Professionals and parents answered three and children answered nine open-ended questions to generate unprompted factors or items that each group believed reflected self-concept for the target population, as seen in Table 2. In addition, a systematic search of published literature was performed to identify items in self-concept instruments currently used for preadolescent children. All items proposed by participants and those identified from the literature review were combined, duplicates were removed, and then items were collated into themes in preparation for item reduction in Rounds II and III. To enable participants to evaluate the importance of each item to the construct of self-concept, rather than a perception of themselves or their child specifically, each item was checked, and if necessary, re-worded to a statement without pronouns. Where appropriate, items were positively worded.

Table 2 Open-ended questions presented to participants in Delphi Round I by participant group

Professional and Parent Participants

1. How would you define self-concept of children with cerebral palsy aged between 8 to 12 years?
2. In your opinion, what dimensions/ areas would be included in an evaluation of self-concept of children with cerebral palsy aged between 8 to 12 years?
3. In your opinion, what are some important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years?

Child Participants

1. What things do you like about yourself?
2. Is there anything that you do not like about yourself?
3. What do you think that other people like about you?
4. Do you think there is anything that other people do not like about you?
5. What things do you think that you are good at?
6. What things do you think you are not so good at?
7. What things do other people say you are good at?
    a. What do your parents say?
    b. What do your brothers/sisters say? (optional)
    c. What do your friends say?
    d. What do your teachers say?
    e. What do other children with cerebral palsy say? (optional)
8. Are there any things that other people say you are not so good at?
    a. What do your parents say?
    b. What do your brothers/sisters say? (optional)
    c. What do your friends say?
    d. What do your teachers say?
    e. What do other children with cerebral palsy say? (optional)
9. What is the best thing about you?

Delphi Rounds II and III involved participants rating the importance of each identified item for ‘reflecting self-concept of preadolescent children with CP’. To achieve optimal engagement and response completion by the three groups, age-appropriate rating procedures were developed. Professionals and parents completed questionnaires using a 5-point rating scale (not important, slightly important, average importance, very important, and extremely important). Pilot trials showed that this procedure was too difficult for younger children. Therefore, a board game called myTREEHOUSE was created by the authors to assist children with understanding the process of hierarchy ratings and for maintaining attention. The game was structured around a game board (42cm x 59cm) that displayed a tree with ramps leading from the ground up to a tree house. Each ramp represented progressively higher ratings on the 5-point scale. The researcher then presented each item verbally (short standard phrase) and visually (using a 3cm x 3cm, Boardmaker Pictorial Communication Symbols card). Each child was asked to rate the importance of each item by positioning the corresponding card on one of the ramps of the game board. To avoid children inadvertently rating themselves, they were asked to rate how important each item would be for evaluating an imaginary friend who was just like them. The imaginary friend was depicted on a card and placed in the tree house. In discussion with parents of the participating child and based upon the assessment of the researcher, children with adequate reading and comprehension abilities were provided the option to either complete the Delphi Rounds II and III using the myTREEHOUSE board game or a conventional paper and pencil questionnaire. All questions and response options were similar for the two administration methods for child participants. Of the 12 children participating in the study, only one opted for the paper and pencil questionnaire, with most preferring to interact using the game format.

Delphi Rounds II and III involved a sequential consensus process for item reduction and selection until a minimum set of items was identified to address relevant self-concept domains. The consensus cut-off point for professionals and parents was set at 75%, with responses combined at each extremity (i.e., very/extremely important, or slightly/not important). This process was chosen because most responses fell within either end of the scale, which allowed for efficient identification of accepted and rejected items. For children with CP, a cut-off point of 75% consensus was also used.

However, as children were more likely to select extreme responses, the cut-off included only the end points on the scale (i.e., extremely important or not important). This narrower cut-off was required to isolate items that were truly deemed to be important for this population. If adult cut-offs were applied, almost three quarters (73%) of the total items would have passed through making discrimination of important items challenging.

In Delphi Round II, items achieving positive consensus for each participant group were removed and placed in the *accepted items* list, items receiving negative consensus were removed and placed in the *rejected items* list. The *remaining items* were then re-presented in Round III. To assist with reaching consensus in Round III, professional and parent participants were provided with a list of the accepted and rejected items, as well as the Round II median response within their group for each remaining item. Children played the myTREEHOUSE game in the standard manner or completed the paper and pencil questionnaire. Items reaching consensus in Rounds II or III for at least two groups were included in the final item list.

Results

Round I identified 141 possible self-concept items. Of these, 117 items were identified from five self-concept instruments used with TD preadolescent children. These included the Self-Perception Profile for Children (Harter, 1982), Self-Description Questionnaire-I (Marsh, 1992), Pier-Harris Self-Concept Scale (Piers, Harris, & Herzberg, 2002), Self-Esteem Inventory (Coopersmith, 1967), and Rosenberg Self-Esteem Scale (Rosenberg, 1965). All items from the five instruments were collated according to currently reported self-concept domains, and then duplicates were removed to yield the 117 individual items. Round I of the Delphi survey then identified 24 additional items deemed as important for children with CP, but not previously presented in self-concept instruments developed for TD children, as seen in Table 3. This yielded a total of 141 items at the end of Round I.

Table 3 New items proposed by participants in Delphi Round I

Items	Professionals	Parents	Children
School/Academic related items			
Good at spelling			✓
Good at writing			✓
Good at science			✓
Good at using the computer			✓
Enjoy being at school	✓		
Enjoy drawing			✓
Disability related items			
Being different because they have a disability[+]		✓	✓
Good at using the part of their body that has CP[+]		✓	✓
Eating is easy for them			✓
Being a good eater			✓
Being able to talk to others easily[+]			✓
Having other people understand what they say[+]			✓
Personal agency items			
Playing with other kids without help from adults[+]		✓	
Keep trying even when it is hard[+]			✓
Being quick at getting themselves ready	✓		
Behaviour and personal characteristics items			
Being responsible for what they do	✓		
Being responsible for actions of others	✓		
Helping their friends[+]			✓
Good at helping their family[+]			✓
Personal characteristics items			
Being a kind person[+]			✓
Being a fun person			✓
Being funny			✓
Being polite[+]			✓
Being neat	✓		

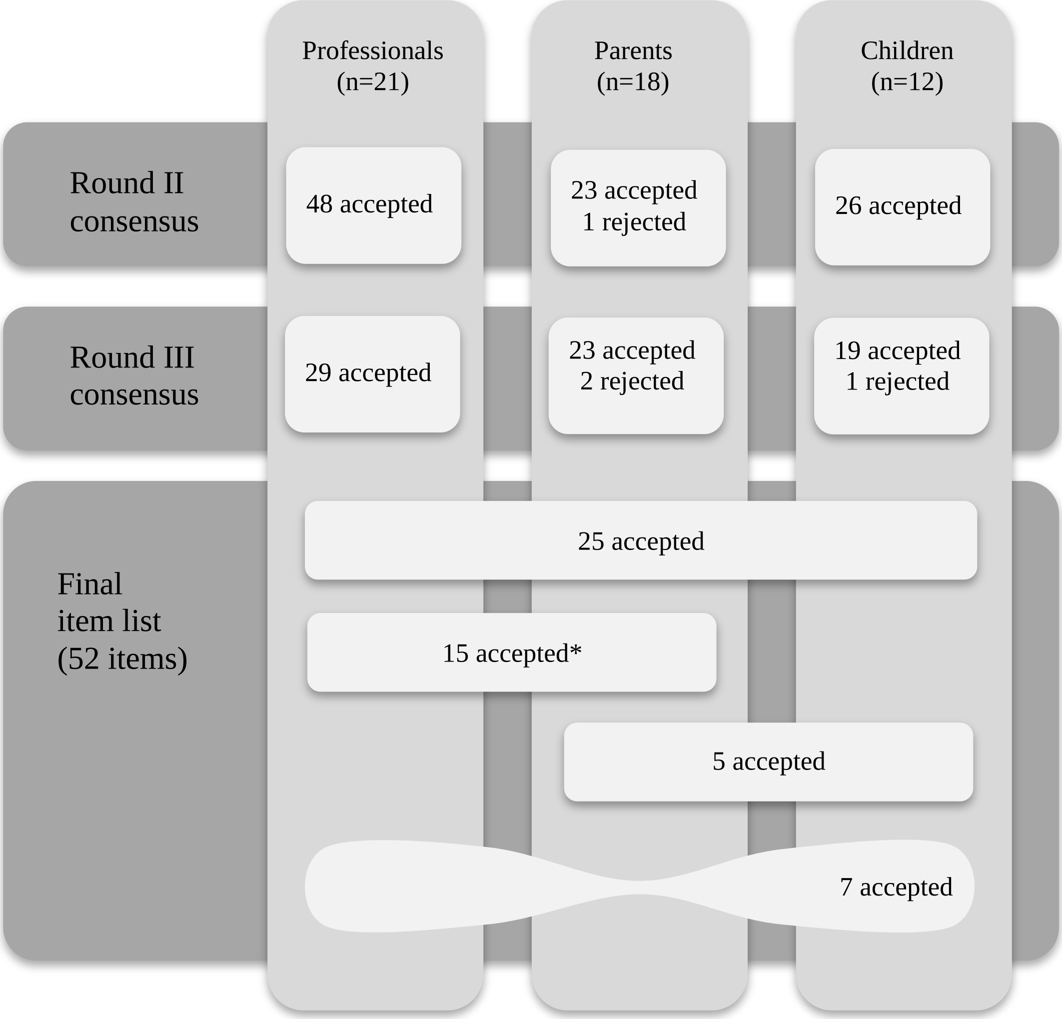
Note: [+]These items achieved consensus at the end of the Delphi consensus process and was included in the final item list

Round II presented the items to each group and commenced the process to establish within-group consensus for each item. To maintain engagement, children responded to a reduced item pool of 97 items which was created by the authors by combining similar items (as previous pilot trials indicated that a survey with 141 items was too lengthy). In Round II, professionals agreed on 48 accepted items; parents agreed on 23 accepted items and one rejected item (‘*giving up easily’*); and children agreed on 26 accepted items.

Round III re-presented the remaining items – those not reaching consensus – for each group. From these, professionals agreed on a further 29 accepted items; parents agreed on a further 23 accepted items and two rejected items (‘*being shy’* and *‘worrying a lot’*); and children agreed on a further 19 accepted items and one rejected item (*‘crying easily’*). Figure 1 presented a summary of the final accepted and rejected items at the end of Round III.

The final accepted item list comprised 52 items that reached consensus for at least two groups: 25 items from all three groups and 27 items from two groups. Of the 52 items that reached consensus, ten items (19%) were new CP-specific items, generated by participants of this study during Delphi Round I, that have not appeared in existing self-concept instruments developed for TD children (Table 3).

The accepted item lists showed a heavy emphasis on personal characteristics and behaviour, for example: ‘*being a good person*’, ‘*liking them self*’, ‘*being happy the way they have been*’, ‘*having a good behaviour in school*’, ‘*do not fight*’, ‘*helping their friends*’, or ‘*doing good things*’. Although a common feature of self-concept scales for TD children, academic or school related performance carried little weight. However, being someone who participates at school was rated as highly important, for example: ‘*completing school work on their own*’, ‘*being able to participate in class*’, and ‘*having others think they have good ideas*’. Social competence was considered highly important, for example: ‘*fitting in with other kids*’, ‘*being asked to join in games*’, ‘*playing with others kids without help from adults*’ or ‘*having kind friends*’. Aspects of their disability also featured, for example: ‘*being different because they have a disability*’, ‘*wishing they were different*’, ‘*being good at using the parts of their body that have CP*’, ‘*being able to talk to others easily*’, and ‘*having other people understand what they say*’. Personal agency was considered highly important, for example: ‘*keeps trying even when* *things are hard*', '*doing their best*', '*being able to look after themself*', or '*making their own decisions*'. Finally, items that reflected their personal value within the parent-child relationship were also valued, for example: '*having parents who understand them*', '*having parents who are proud of what they do*', '*having parents who pays attention to them at home*'. A copy of the final scale can be obtained on request from the corresponding author.



* Seven of these items were not presented to the child group.

Figure 1 Flowchart of Delphi Rounds II and III consensus outcomes within and between groups

Discussion

This study identified and prioritised constructs (factors) and content (items) that constitutes self-concept of preadolescent children with CP using a Delphi consensus survey. These items were specifically determined by preadolescents with CP, their parents and practicing professionals.

This study showed that many factors and items important in the self-concept of children with CP were similar to TD children, with over 80% of items prioritised in the Delphi process identified from instruments originally developed for TD children. Items accepted by participant consensus tended to reflect a child’s ability to achieve general personal or social performance (e.g., schoolwork, making friends), whereas items that did not achieve consensus tended to emphasise more specific or higher level performance (e.g., sports skills, maths skills). This appeared to emphasise that, for children with CP, participation and general competency in everyday environments may play a stronger role in overall self-concept, than the need to achieve high level skills. Further, these items also provided children with a wide variety of functional levels at which to perceive their own strengths. For example, “being good at schoolwork” was able to be reflected regardless of the specific nature of the schoolwork performed (e.g., self-care, maths, communication).

This study also highlighted areas where self-concept of children with CP may be different compared to TD children, with approximately 20% of items being derived from participant suggestions and not instruments for TD children. New participant-generated items reinforced the value placed on participation, and highlighted the importance of interpersonal skills and resilience. New items captured the ability and willingness of children with CP to participate at the child’s own level (e.g., playing with other children without help) and the child’s ability or willingness to persist or try alternate strategies when participation is difficult (e.g., I always try my best). Furthermore, there were also items that highlighted their concerns related to specific areas of disability (e.g., being able to talk to others easily, having others understand what they say, good at using the part of my body that has CP) and an overall perception of their disability (e.g., being different because they have a disability).

So, while there may be overlap between self-concept elements important for children with CP and TD children, our findings suggested that instruments designed for TD children may not fully encapsulate self-concept for children with CP. This supports the recommendations of other authors who have urged greater psychometric testing of instruments designed for TD children before utilising these for the assessment of self-concept of children with physical disability (Llewellyn & Chung, 1997), particularly CP (Cheong & Johnston, 2013; von der Luft et al., 2008). However, to best reflect the self-concept of this population a CP-specific instrument should be considered.

Furthermore, through this study an age-appropriate game-based format was developed to improve clinical administration of rating scales with children with CP called the myTREEHOUSE board game. Given that children with CP often present with multiple difficulties in addition to their physical disability, such as speech impairment, intellectual impairment, vision impairment, and hearing impairment (Australian Cerebral Palsy Register Group, 2013), utilising this method provided an appropriate way to administer rating scales to these children. The visual presentation assisted with understanding of the rating scales especially for younger children and children with learning difficulties. In addition, the board also assisted with children with vision impairments who find written questionnaires daunting and difficult. Children with a physical disability, especially in the upper body, find written questionnaires cumbersome. Most importantly, this administration method was interesting and did not resemble school work, as a questionnaire would; it helped maintain attention; and increased willingness to participate. This administration method should be considered in future administration of rating scales with this population.

One of the strengths of this study is that it incorporated child and proxy perspectives when determining the most important factors and items contributing to the self-concept of preadolescent children with CP. Most other Delphi studies in the field of CP to date have not included the perspectives of the child with CP. However, as self-concept is an internal construct and while behaviour can provide some indication of self-concept, child-report is not equivalent to proxy-report (Rajmil, Lopez, Lopez-Aguila, & Alonso, 2013), and so relying solely on behavioural observations can limit or misrepresent understanding of self-concept. For this reason, we enabled children with CP to provide direct input, ensuring a ‘lived-experience’ was incorporated. Parent contributions ensured that a developmental perspective across multiple environments was considered. Finally, professionals contributed a combined understanding of self-concept as a construct with a population-wide view of factors that might contribute for children with different types of CP. Nonetheless, it is acknowledged that the ratio between groups was unequal with a greater number of adult participants. Very few papers have documented children with CP in Delphi studies (Vargus-Adams & Martin, 2009, 2010) and most have a greater ratio of adult to child participants.

Conclusion

This study presented elements of self-concept that were important for preadolescent children with CP, collected from the perspectives of children with CP, their parents and professionals working with children with CP. While many areas of self-concept important for children with CP were similar to TD children, several additional CP-specific factors and items were identified through the Delphi survey which have not appeared in other instruments developed for TD children. Continued use of self-concept instruments – developed for TD children – for children with CP will cause these CP-specific elements to be inadvertently missed, resulting in a misinterpretation of the child’s self-concept. When assessing the self-concept of children with CP, these elements need to be taken into consideration if assessment is conducted using an instrument developed for TD children. However, the findings in this study would strongly recommend the development of a CP-specific self-concept instrument to ensure an accurate interpretation of self-concept for this population.

Acknowledgements

We would like to thank the Cerebral Palsy League, Brisbane, Australia, for in-kind support for this study and all of the professionals, parents/caregivers and children who participated.

Compliance with Ethical Standards

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the instutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

Informed consent was obtained from all individual particiapnts included in the study.

Conflict of Interest

The authors declare that they have no conflict of interest.

Reference

Australian Cerebral Palsy Register (ACPR) Group. (2013). *Australian Cerebral Palsy Register report 2013*. Australia: Australian Cerebral Palsy Register.

Barty, E. & Caynes, K. (2009). *Development of the Functional Communication Classification System*. Paper presented at the Proceedings of the 3rd International Cerebral Palsy Conference, Sydney, Australia.

Cheong, S.K. & Johnston, L.M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities, 34*, 3566-3575.

Coopersmith, S. (1967). *The antecedents of self-esteem*. California: Consulting Psychologists Press.

Dodd, K.J., Taylor, N.F., & Graham, H.K. (2004). Strength training can have unexpected effects on the self-concept of children with cerebral palsy. *Pediatric Physical Therapy, 16*(2), 99-105.

Donnellan, M.B., Trzesniewski, K.H., Robins, R.W., Moffitt, T.E., & Caspi, A. (2005). Low self-esteem is related to aggression, antisocial behaviour, and delinquency. *Psychological Science, 16*, 328-335. doi: 10.1111/j.0956-7976.2005.01535.x

Eliasson, A-C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A-M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48*(7), 549-554.

Emler, N. (2002). The costs and causes of low self-esteem. *Youth Studies Australia, 21*(3), 45-48.

Ferro, M.A., & Boyle, M.H. (2013a). Longitudinal invariance of measurement and structure of global self-concept: A population-based study examining trajectories among adolescents with and without chronic illness. *Journal of Pediatric Psychology, 38*(4), 425-437. doi: 10.1093/jpepsy/jss112

Ferro, M.A., & Boyle, M.H. (2013b). Self-concept among youth with a chronic illness: A meta-analytic review. *Health Psychology, 32*(8), 839-848.

Harter, S. (1982). The Perceived Competence Scale for Children *Child Development, 53*, 87-97.

Harter, S. (2006). The self. In N. Eisenberg (Ed.). *Handbook of child psychology* (6ed., Vols.3) (pp.505-570). New Jersey: John Wiley.

Hsu, C-C., & Sandford, B.A. (2007). The Delphi technique: Making sense of consensus. *Practical Assessment, Research and Evaluation, 12*(10), 1-8.

Llewellyn, A., & Chung, M.C. (1997). The self-esteem of children with physical disabilities - Problems and dilemmas of research. *Journal of Developmental and Physical Disabilities, 9*(3), 265-275.

Marsh, H.W. (1990). A multidimensional, hierarchical model of self-concept: Theoretical and empirical justification. *Educational Psychology Review, 2*(2), 77-172.

Marsh, H.W. (1992). *Self-Description Questionnaire-I Manual*. Australia: University of Western Sydney.

Marsh, H.W, & Shavelson, R. (1985). Self-concept: Its multifaceted hierarchical structure. *Educational Psychologist, 20*(3), 107-123.

Mcintyre, S., Novak, I., & Cusick, A. (2009). Consensus research priorioties for cerebral palsy: A Delphi survey of consumer, researchers, and clinicians. *Developmental Medicine & Child Neurology, 52,* 270-275. doi: 10.1111/j.1469-8749.2009.03358.x

Miyahara, M., & Piek, J. (2006). Self-esteem of children and adolescents with physical disabilities: Quantitative evidence from meta-analysis. *Journal of Developmental and Physical Disabilities, 18*(3), 219-234. doi: 10.1007/s10882-006-9014-8

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2007). GMFCS - E & R Gross Motor Function Classification System Expanded and Revised. Retrieved 26 November 2014, 2014, from http://motorgrowth.canchild.ca/en/gmfcs/resources/gmfcs-er.pdf

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology, 39,* 214-223.

Piers, E.V., Harris, D.B., & Herzberg, D.S. (2002). *Piers-Harris Children's Self-Concept Scale II*. United States of America: Western Psychological Services.

Rajmil, L., Lopez, A.R., Lopez-Aguila, S., & Alonso, J. (2013). Parent-child agreement on health-related quality of life (HRQOL): A longitudinal study. *Health and Quality of Life Outcomes, 11*, 101.

Rosenberg, M. (1965). *Society and the adolescent self-image*. United States of America: Princeton University Press.

Russo, R.N., Goodwin, E.J., Miller, M.D., Haan, E.A., Connell, T.M., & Crotty, M. (2008). Self-esteem, self-concept, and quality of life in children with hemiplegic cerebral palsy. *The Journal of Pediatrics, 153,* 473-477. doi: 10.1016/j.jpeds.2008.05.040

Shields, N., Loy, Y., Murdoch, A., Taylor, N.F., & Dodd, K.J. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine & Child Neurology, 49,* 350-354.

Trautwein, U., Lüdtke, O., Köller, O., & Baumert, J.J. (2006). Self-esteem, academic self-concept, and achievement: How the learning environment moderates the dynamics of self-concept. *Journal of Personality and Social Psychology, 90*(2), 334-349.

Vargus-Adams, J.N. & Martin, L. (2009). Measuring what matters in cerebral palsy: A breath of important domains and outcome measures. *Achives of Physical Medicine and Rehabilitation, 90,* 2089-2095. doi:10.1016/j.apmr.2009.06.018

Vargus-Adams, J.N. & Martin, L. (2010). Domains of importance for parents, medical professionals and youth with cerebral palsy considering treatment outcomes. *Child: Care, Health and Development, 37*(2), 276-281. doi: 10.1111/j.1365-2214.2010.01121.x

von der Luft, G., DeBoer, B.V., Harman, L.B., Koenig, K.P., & Nixon-Cave, K. (2008). Improving the quality of studies on self-concept in children with cerebral palsy. *Journal of Developmental and Physical Disabilities, 20,* 581-594. doi: 10.1007/s10882-008-9117-5

World Health Organisation (WHO). (2011). *International classification of functioning, disability and Health (ICF)*. Retrieved 7 November 2011, from http://www.who.int/classifications/icf/en/

7.2. Interpretation and Direction

This is one of the few Delphi consensus surveys to include children with CP in addition to input from caregivers and professionals who work with these children. For many internalised psychological constructs, like self-concept or quality of life, proxy-report is not always consistent with child-report (Dunn, Shields, Taylor, & Dodd, 2007, 2009; Rajmil et al., 2013), further supporting the importance of including children’s opinions. Although the findings indicate that children with CP share many self-concept items and domains with TD children, some unique domains were evident. The presence of these domains strongly emphasise that continued use of generic self-concept instruments is likely to compromise the accuracy of self-concept evaluation for children with CP. This is especially important in clinical settings when clinicians rely on the accuracy of instruments to assist in formulation to aid intervention decisions for their clients. Hence, the development of a CP-specific self-concept instrument was strongly recommended.

Based on the decision tree for this research program presented in Chapter 1 (see Figure 1.2), as children with CP present with a different self-concept construct compared with TD children, it was considered appropriate and necessary to develop a new CP-specific self-concept instrument using the model described in Chapter 2 and incorporating the findings from the Delphi consensus survey (Study 2).

Chapter 8. myTREEHOUSE Self-Concept Assessment

8.1. Introduction

Results of the first two studies (systematic review – Study 1 and Delphi consensus survey – Study 2) indicated that the development of a CP-specific self-concept instrument was required for preadolescent children with CP. A new self-concept instrument, called the *myTREEHOUSE Self-Concept Assessment* (*myTREEHOUSE*), was developed. This instrument and its theoretical structure are described below.

8.2. Structure

The new self-concept model described in Chapter 2 incorporates the Correlated-Factor Model within a Taxonomic Model using a 2×2 matrix structure. The matrix consisted of four quadrants that allowed self-concept to be assessed across two aspects of *Evaluations* – *Performance* and *Value* – from two *Perspectives* – *Personal* and *Social* (see Figure 8.1). In order to operationalise the model within an instrument, two crucial steps were taken. First, items that were deemed relevant and important in reflecting self-concept for children with CP – following the findings from the Delphi consensus survey (Study 2) – were grouped to form meaningful categories. Additional items were also written in consultation with the supervisory team to provide a more comprehensive category when required. These categories, referred to as *domains*, represent the *Multidimensional* feature used to conceptualise self-concept for this research program. Second, each item was expanded into four questions/statements to represent the *Evaluative* feature based on the 2×2 matrix model. An example of an item is illustrated in Figure 8.1.

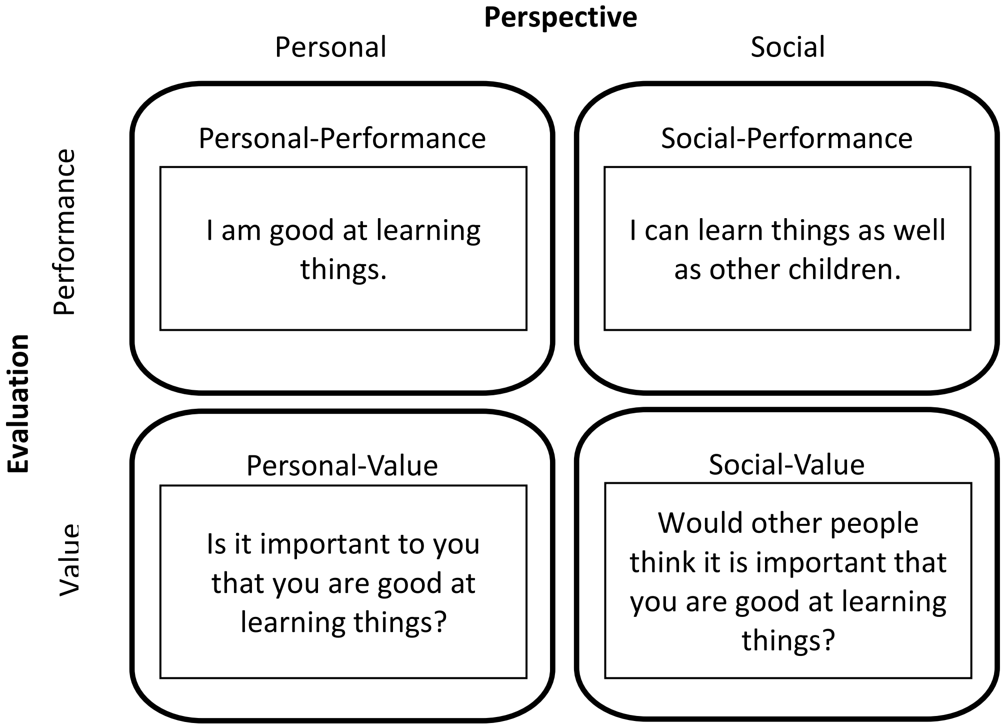


Figure 8.1 Sample of an item proposed in the *myTREEHOUSE Self-Concept Assessment* presented within the 2×2 matrix model

During the development of the instrument, the *Social-Value* quadrant posed the greatest difficulty. For this quadrant, children are required to assess the level of importance placed upon an area of performance rated from the perspective of “other people” – in this case, referring to significant people in their lives such as their caregivers or teachers. To respond to a *Social-Value* question, children require two simultaneously skills: (i) perspective taking skills, and (ii) the ability to grasp the abstract concept of “importance”. According to Selman and Byrne (1974), perspective taking skills at age eight is a transitional phase between the first stage – recognition that people can have differing perspectives – to the second stage – understanding that these differing perspectives are a result of the individual’s unique values or purpose. This transition is a trigger for children to reflect on their own behaviour from the perspectives of others. Moreover, Harter (2012a), observes that the age of eight is also a significant cognitive development stage where children move beyond concrete thinking as they gain a stronger grasp of abstract concepts.

Given the developmental transition for children at the age of eight – which is the lower age limit for *myTREEHOUSE* – in addition to the high rate of intellectual impairment in children with CP, a majority of the expert panel involved in the psychometric testing (Study 3a, see Chapter 9) commented that the *Social-Value* quadrant was too challenging for the target population. To take into consideration the expert feedback and development theory, the *Social-Value* questions were amended and renamed *Perceived Performance*, with questions that sought the child's evaluation of their performance against perceived standards. This will only require the perspective taking skill without requiring children to infer importance ratings from the perspective of others, as previously required. With this change, the model had evolved; now comprising three *Performance Perspectives* and an *Importance Rating* (see Figure 8.2).

The three *Performance Perspectives* and the *Importance Rating* are assessed across eight domains. The domains were derived from themes generated from the findings of the Delphi consensus survey (Study 2). In addition to participant generated items, the Delphi consensus survey collated items from seven instruments, including five commonly used instruments designed for preadolescent TD children: (i) Self-Perception Profile for Children (Harter, 1982); (ii) Self-Description Questionnaire-I (Marsh, 1992); (iii) Piers-Harris Self-Concept Scale (Piers et al., 2002); (iv) Self-Esteem Inventory (Coopersmith, 1967); and (v) Rosenberg Self-Esteem Scale (Rosenberg, 1965); and two modified instruments for children with CP: (vi) Self-Perception Profile for Children – Australian version (Ziebell, 2007), and (vii) Self-Perception Profile for Children – Dutch version (Komdeur et al., 2001). Items from these seven instruments were cross-checked to remove duplicates and reworded into consistent phrases for the Delphi consensus survey. Items achieving consensus in the Delphi survey were extracted and worded suitably for inclusion in *myTREEHOUSE.* Additional items or domains were supplemented, upon discussion with the research supervisory team, if they were deemed relevant and important in reflecting the self-concept of preadolescent children.

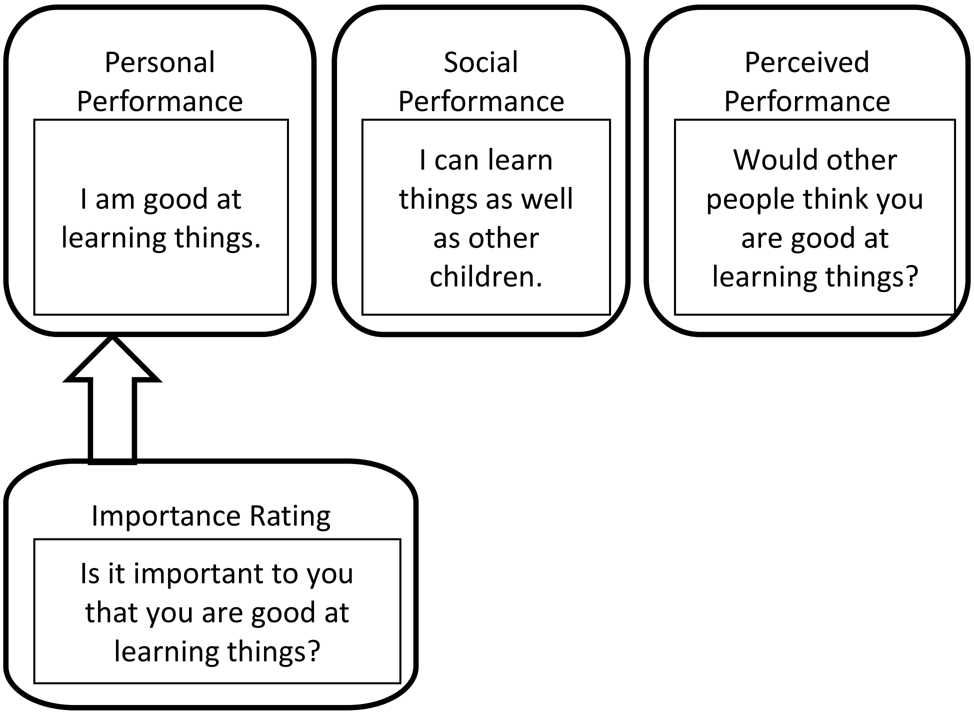


Figure 8.2 Sample of an item proposed in the *myTREEHOUSE Self-Concept Assessment* using the three *Performance Perspectives* and the *Importance Rating*

The five domains identified were (i) *Social Skills*, (ii) *Physical Appearance*, (iii) *Learning Skills*, (iv) *Emotional Regulation*, and (v) *General Self*. The three new domains derived from participant generated items were (i) *Physical Abilities*, (ii) *Personal Agency*, and (iii) *Ability to Participate*.

8.3. Assessment Items

The assessment consists of 26 items divided into eight domains. Each item is linked to the three *Performance Perspectives* where children appraise their performance. In addition, each item also includes a question to seek the child's *Importance Rating* for the item. Items are administered in a pseudo-randomised manner to avoid any order effect across domains. Participants responded using a four-point rating scale.

8.4. Administration

myTREEHOUSE has two administration methods; a *Questionnaire Version* and a *Game Version*. It is recommended that either version is completed by the child out of the presence of significant others, like caregivers, teachers, or peers, to minimise the risk of socially desirable responding. Each administration method is described in the following paragraphs.

8.4.1. Questionnaire Version. The questionnaire is printed on A4-sized paper. Items are presented in individual tables. A short phrase that represents the item is printed on the top row and subsequent rows present the question, beginning with evaluation of items from the *Personal Performance Perspective*, followed by the *Importance Rating,* and then the evaluation of items from the *Social* and *Perceived Performance Perspectives*.

The response columns for each corresponding question/statement were coded from dark green – representing the highest level of agreement – to dark red – representing the highest level of disagreement. With a four-point rating scale children were first encouraged to consider if they agree or disagree with the question/statement before rating the strength agreement. Observations from the Delphi consensus survey (Study 2), where a similar rating system was used, indicated that child participants exhibited a sense of being overwhelmed with a 5-point rating scale. This was especially evident with younger children and children with low verbal ability. The questionnaire is presented with an accompanying 3cm^2 pictorial card that was also used in the *Game Version*.

8.4.2. Game Version. The *Game Version* is structured around the board game adapted from the Delphi consensus survey (Study 2, see Chapter 7). The board game (42cm×59cm) has a picture of a treehouse which “belongs” to the child. A set of portrait cards is available so that for the child can choose a card that represents himself/ herself. This card is placed in the treehouse to signify ownership of the treehouse for the duration of the assessment. The treehouse is accessed by a ramp with four levels leading up from the ground – each level of the ramp represents a progressively more positive rating. Unlike the board game used in the Delphi consensus survey (Study 2), in *myTREEHOUSE*, the number of ramps was reduced from five to four levels to reflect the response options. The upper two ramps are accompanied by “thumbs-up” images to help children orient their responses with high agreement. The lower two ramps have “thumbs-down” images to help children orient their responses with low agreement. A 3cm^2 pictorial card was developed to reflect each item; there is a total of 26 cards. Items are verbally presented to the child, accompanied by the pictorial card. The child rates each item by placing the pictorial card on the ramp of choice.

In addition to the treehouse, the board game also included an accompanying chart that corresponds with the ramp. The chart depicts four response items: “really yes” illustrated with two green ticks; “sort of yes” illustrated with one green ticks; “sort of no” illustrated with one red cross; and “really no” illustrated with two red crosses. Although the accompanying chart was initially designed to reflect the responses for the *Perceived Performance Perspective* and the *Importance Rating* questions, it was observed during assessment that children used the treehouse ramps and the accompanying chart interchangeably. A scoring sheet was created to assist with score recording during administration. The assessment begins with standardised instructions:

> Look at this tree. It has a treehouse inside it. This will be your treehouse for today. It has a ramp that lets you go into the treehouse. Let's pick a picture that looks like you [place several child portrait pictures that resemble the child for him/her to select]. Now…let's go up into the treehouse [move the child's selected portrait from the bottom ramp to the treehouse]. I have a few cards here with different things. If you think the item is "a lot like you" or "describes you the most", place it on the top ramp going into the treehouse [point to the highest ramp]. An item that is "not like you at all" can stay on the bottom ramp [point to the bottom ramp]. The closer they are to the treehouse, the better they describe you [run your finger from the bottom of the ramp to the top]. Sometimes I may ask you a question. You may point to your answers on this chart with "really yes", "sort of yes", "sort of no", or "really no" [point to the accompanying response chart]. Remember, there are no right or wrong answers; it is just what you think of yourself. Are you ready?

As the Game Version involves greater interaction with the child compared to the Questionnaire Version, it is crucial that the myTREEHOUSE items are presented in a neutral tone to minimise potential influence that may result in socially desirable response from the child. Materials for the *Game Version* are presented in Appendix F.

8.5. Scoring

Items are scored using a 4-point rating scale, ranging from 1-4. The response options for the evaluation of an item from the *Personal Performance Perspective* (e.g., “I am good at learning things”) and *Social Performance Perspective* (e.g., “I can learn things as well as other children”) are “a lot like me” (4 points), “a bit like me” (3 points), “not really like me” (2 points), and “not like me at all” (1 point). The response options for the evaluation of an item from the *Perceived Performance Perspective* (e.g., “Would other people think you are good at learning things?”) and the *Importance Rating* (e.g., “Is it important to you that you are good at learning things?”) are “really yes” (4 points), “sort of yes” (3 points), “sort of no” (2 points), and “really no” (1 point).

myTREEHOUSE produces two types of scores; the domain scores rated from the *Personal, Social, and Perceived Performance Perspectives* as well as the *Personal Concern Score*. The domain scores rated from the *Personal, Social,* and *Perceived Performance Perspectives* are the summation of scores for each domain within the specific *Performance Perspectives*. In all domains, scores range from 3-12 points – 8 points and above indicate a high score – except the *Social Skills* and *Ability to Participate* domains, which have score ranges of 4-16 points – 11 points and above indicate a high score. Higher scores represent higher domain specific self-concept.

Domain scores rated from the three specific *Performance Perspectives* are unique to *myTREEHOUSE*. Isolating these *Performance Perspectives* allow researchers and clinicians to individually observe the contribution of each perspective to the child’s self-concept. As demonstrated in the *Self-Concept Feedback Loop* (see Section 2.1.5, Figure 2.3), social and perceived standards are absorbed to adjust existing or create new personal standards. If intervention to strengthen self-concept focuses solely on building personal resilience, it may not be sufficient if the child is exposed to negative feedback which sets their social and perceived standards. This negative feedback can be the result of a harsh or negligent parenting style, bullying, unsupportive teachers, and so forth. In these cases, intervention needs to address the core of these factors before focusing on building the child's resilience. Thus, isolating the three *Performance Perspectives* enables clinicians to target relevant areas for intervention and provides researchers the opportunity to investigate the impact of environmental factors on children's self-concept rated from different perspectives.

The *Personal Concern Score* is calculated by first subtracting the *Personal Performance Perspective* score from the *Importance Rating* at the item level. The *Personal Performance Perspective* scores were used because this perspective represents the child's internal reference of self-concept. Negative scores are assigned a value of zero so that those scores did not cancel the effect of other positive scores. The subtracted score is then summed to obtain the *Personal Concern Score*; higher scores indicate greater concerns with a possible range of 0-78. For example, an item rated with a high *Importance Rating* ("really yes"=4 points) but low domain score rated from the *Personal Performance Perspective* ("not like me at all"=1 point) will obtain a high *Personal Concern Score* (3 points). On the other hand, an item rated with a low *Importance Rating* ("really no"=1 point) but high domain score rated from the *Personal Performance Perspective* ("a lot like me"=4 points) will obtain a negative *Personal Concern Score* (-3 points) and thus, will be assigned a value of zero.

Personal Concern Scores are categorised into three levels: *Low Concern* (0-7 points), *Suspected Concern* (8-12 points), and *Definite Concern* (over 13 points). The score that determines *Definite Concern* levels was assigned on the assumption that, if the child indicated concerns over half the items (13 items×1 *Concern Score* = 13 points), it is likely that self-concept concerns are affecting a large part of their daily experiences, given the broad-based nature of *myTREEHOUSE* domains. A *Definite Concern* level can also signify extreme concerns in five or more self-concept areas (5 items×3 *Concern Score* = 15 points). After data collection for the psychometric study (Study 3, see Chapter 9), an examination of existing data verified the estimated levels. A subsample of participations who fell within the *Low*, *Suspected*, and *Definite Concern* levels matched observational data and proxy-report of self-concept concerns collected during participation.

The *Personal Concern Score* is another unique feature offered by *myTREEHOUSE* to identify self-concept concerns in children. This score is calculated from the child's *Personal Performance Perspective* – reflecting the child's success/failure based on personal standard – and *Importance Rating* – reflecting the child's pretension for the need to succeed. It is, thus, consistent with James' (1890/1950) notion of the relationship between pretension and success in the judgement of one's self-concept.

There has been inconclusive debate about the usefulness of importance ratings and discrepancy scores similar to the *Personal Concern Score*. Most researchers concluded that an importance rating by itself is not a reflection of competence or self-concept (Byrne, 2002; Marsh, 1986). However, some researchers argue that using an importance rating to calculate a discrepancy score can provide useful clinical information to interpret a high or low self-concept score (Harter, 2006; Harter, Whitesell, & Junkin, 1998). Harter et al. (1998) demonstrated that children with high self-concept are better able to discount the importance of weaker domains to preserve their self-concept whereas, children with low self-concept found it difficult to discount the importance of areas of personal weakness.

Thus, for myTREEHOUSE, the *Importance Rating* is not viewed as an independent marker of self-concept; rather the *Importance Rating* is used to obtain the *Personal Concern Score* which provides an indication of possible self-concept problems. The *Personal Concern Score* reflects self-concept concerns from the child's perspective. This is an important consideration because self-concept is an internal construct and, thus, the child's perspective should be the focal point of evaluation. This three-level *Personal Concern Score* can function as an indicator to signify to clinicians the severity of self-concept concerns and the urgency of intervention. myTREEHOUSE includes an *Importance Rating* at the item level; hence, providing specific information about the source of self-concept concerns reported by the child.

8.6. Conclusion

myTREEHOUSE was designed to respond to a gap in literature that indicated the need for a population-specific self-concept instrument for children with CP. Findings from the Delphi consensus survey (Study 2) highlighted unique features that reflect self-concept for children with CP that are not represented in existing instruments designed for TD children. Before utilising *myTREEHOUSE*, the next logical step was to investigate the psychometric properties of this instrument. Psychometric testing was conducted in Study 3 (see Chapter 9).

Chapter 9. Psychometric Testing

9.1. Introduction

Following the development of the *myTREEHOUSE Self-Concept Assessment*, psychometric testing was conducted to investigate the validity and reliability of the new instrument. Psychometric testing involved two phases: (1) Study 3a – Face and content validity, using structured interviews with an expert panel; and (2) Study 3b – Reliability testing to assess internal consistency and test-retest reliability. Although conducted with separate samples, these studies are reported in a single manuscript. It is acknowledged that some of the content in this manuscript and the preceding chapter overlap where the theoretical framework and details of the instrument are described. However, the preceding chapter offered the opportunity to provide fuller details of the instrument in a manner that was not possible in the following manuscript. Psychometric testing of *myTREEHOUSE* is described in the following published manuscript as per the reference below:

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2017). myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy. *Developmental Medicine & Child Neurology*, *59*(6), 655-660. doi: 10.1111/dmcn.13392

myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy

Authors: Cheong SK[1], Lang CP[1], Hemphill SA[2], and Johnston LM[3]

[1]School of Psychology, Australian Catholic University, Queensland, AUSTRALIA

[2]School of Psychology & Learning Sciences Institute Australia, Australian Catholic University, Victoria, AUSTRALIA

[3]School of Health and Rehabilitation Sciences, The University of Queensland, Queensland, AUSTRALIA

Correspondence to Sau Kuan Cheong, School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, Australia.

E-mail: saukuan.cheong@myacu.edu.au

This article is commented on by Causgrove Dunn on page 573 of this issue.

Publication data:

Accepted for publication 13th December 2016

Published online 19th January 2017

Abbreviation:

WISC-IV	Wechsler Intelligence Scale for Children – Fourth Edition

Developmental Medicine & Child Neurology, 59(6), 655-660

Abstract

AIM: To evaluate the preliminary validity and reliability of the myTREEHOUSE Self-Concept Assessment for children with cerebral palsy (CP) aged 8-12 years.

METHOD: The myTREEHOUSE Self-Concept Assessment includes 26 items divided into eight domains, assessed across three Performance Perspectives (Personal, Social, and Perceived) and an additional Importance Rating. Face and content validity was assessed by semi-structured interviews with seven expert professionals regarding the assessment construct, content and clinical utility. Reliability was assessed with 50 children aged 8-12 years with CP (29 males; mean age 10 years 2 months; GMFCS I=35, II=8, III=5, IV=1; mean WISC-IV=104) whose data was used to calculate internal consistency of the scale, and a subset of 35 children (20 males; mean age 10 years 5 months; GMFCS I=26, II=4, III=4, IV=1; mean WISC-IV=103) who participated in test-retest reliability within 14-28 days.

RESULTS: Face and content validity was supported by positive expert feedback, with only minor adjustments suggested to clarify the wording of some items. Following these amendments, strong internal consistency (Cronbach's α=0.84-0.91) and moderate to good test-retest reliability (ICC=0.64-0.75) was found for each component.

INTERPRETATION: The myTREEHOUSE Self-Concept Assessment is a valid and reliable assessment of self-concept for children with CP aged 8-12 years.

Developmental Medicine & Child Neurology, 59(6), 655-660

What this paper adds:

- myTREEHOUSE is population-specific assessment which offers a unique evaluation of self-concept
- myTREEHOUSE is valid and reliable for children with cerebral palsy

Developmental Medicine & Child Neurology, 59(6), 655-660

myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy

According to a number of systematic reviews or meta-analyses, children with a physical disability or chronic illness have lower self-concept than typically developing (TD) children; including children with cerebral palsy (CP),[1] developmental coordination disorder,[2] asthma, diabetes, epilepsy, and juvenile arthritis.[3] However concerns have been raised over the meaning of these findings, since all have used self-concept assessments designed for TD children. Our systematic review[4] and others[5,6] have indicated that using self-concept assessments designed for TD children is unsuitable for children with disabilities. In addition, these assessments may present children with constructs that do not reflect their differing life experiences or omit other important constructs. In support of this, our Delphi consensus survey[7] showed that while clinicians/researchers, parents, and children with CP agreed that some items from commonly used self-concept assessments for TD children were appropriate for children with CP, they also proposed several additional items critical for reflecting self-concept of children with CP. CP-specific measures are internationally supported for accurate assessment of quality of life,[8] gross motor,[9] and upper limb performance.[10] We therefore propose this approach as a mechanism to improve self-concept assessment for children with CP.

In response to this challenge, we designed a new CP-specific self-concept assessment, called the '*myTREEHOUSE Self-Concept Assessment*' (myTREEHOUSE). myTREEHOUSE is based on the developmental theories of 'self' which propose that self-concept development is dependent on the interaction between socialisation experiences and cognitive processes.[11,12] In the paediatric context, Harter[11] proposed that cognitive development impacts two areas of self-development. Firstly, ‘differentiation’ involved the ability to compare one’s performance between the real and ideal self. Secondly, ‘integration’ involved the ability to conceptualise one’s overall self-worth based on various performance areas. (It is important to differentiate self-concept from self-esteem. Although still debated, self-esteem is commonly defined as the evaluation of self. [13]) In contrast, self-concept is the (evolving) product of this evaluation. Applying the developmental theory of ‘self’, we developed myTREEHOUSE to provide a child-reported evaluation of self-concept across three Performance Perspectives: (1) *Personal* – children’s evaluation of their performance against their own personal standards, (2) *Social* – children’s evaluation of their performance against the performance of their peers, and (3) *Perceived* – children’s perception of how significant others like parents or teachers might evaluate their performance.

myTREEHOUSE then assesses each Performance Perspective across eight domains, including five domains from assessments for TD children[13] that have been employed for children with CP,[4] and three additional CP-specific domains derived from our Delphi consensus survey.[7] The domains identified from existing assessments that were supported by Delphi survey participants are: *Physical Appearance*, *Learning Abilities*, *Social Skills*, *Emotional Regulation*, and *General Self*. The new CP-specific domains are: *Physical Abilities*, *Personal Agency*, and *Ability to Participate*.

In addition to evaluating performance, myTREEHOUSE also asks children to provide an *Importance Rating* – where children rate the importance they place on each item. Items viewed as more important are rated higher.[11] Using the *Importance Rating,* a *Personal Concern Score* is derived, which highlights the difference between each child’s *Personal Performance Score* and their *Importance Rating*, and flags key items or domains that are adversely impacting the child’s self-concept. Self-report on constructs of self-concept is considered effective from the age of 8,[11] which is the lower limit we recommend for using myTREEHOUSE.

This paper provides a preliminary psychometric analysis of the myTREEHOUSE Self-concept Assessment for children with CP aged 8-12 years. Objectives were to evaluate its (1) Validity – including face and content validity, and (2) Reliability – including internal consistency and test-retest reliability.

METHOD

Ethical approval was obtained from the National Health & Medical Research Council (NHMRC) registered Human Research Ethics Committees of the Cerebral Palsy League (EC00417) and the Australian Catholic University (EC00205).

Administration of the myTREEHOUSE Self-Concept Assessment

myTREEHOUSE includes 26 items divided into eight domains. Each item is linked to three statements or questions, that enable the child to rate their performance across the three Performance Perspectives, for example: (i) *Personal* – 'I am good at learning things', (ii) *Social* – 'I can learn things as well as other children', and (iii) *Perceived* – 'Would other people think you are good at learning things?' (Table I). An additional question for each item seeks the child's *Importance Rating* for the item – 'Is it important to you that you are good at learning things?'

Table I Final items and hypothesised domains for the myTREEHOUSE Self-Concept Assessment after considering recommendations from the expert panel and speech pathologist through the Validation Evaluation phase

Domains	Items	Question / Statement format	Order of questions present
Physical Abilities	Gross motor ability	I am good at moving around	2
	Fine motor ability	I can do things well with my hands	10
	Oral motor ability	I can speak clearly	18
Physical Appearance	Appearance of my whole body	I have a good looking body	5
	Appearance of my facial features	I have a nice looking face	13
	Appearance when I move	I look good when I move around	21
Learning Abilities	Learning ability	I am good at learning things	4
	Memory ability	I am good at remembering things	12
	Problem solving ability	I am good at working things out	20
Social Skills	Interacting with others	I get along with people	1
	Making new friends	I can make new friends easily	9
	Keeping friends	I can keep friends	17
	Communicating with others	I am good at telling people what I want	25
Emotional Regulation	Behaviour management	I am well behaved	6
	Emotional reactivity	I do not get too upset about things	14
	Emotional regulation	I know how to make myself feel better when I am upset	22
Personal Agency	Trying my best	I always try my best	3
	Setting my own goals	I can achieve what I want	11
	Making my own decisions	I am able to make my own decision	19
Ability to participate	Participation in outdoor activities	I am good at doing things outside	8
	Participation in indoor activities	I am good at doing things inside	16
	Participation in self-care activities	I can look after myself well	24
	Participation in school activities	I do well at school work	26
General Self	Desire to change myself	There is not many things I would change about myself	7
	Being a good person	I am a good person	15
	Liking myself	I am happy with myself	23

Developmental Medicine & Child Neurology, 59(6), 655-660

Two administration methods are available: a *Questionnaire Version* suitable for older children, and a *Game Version* suitable for children with lower reading skills. For both methods, presented items are identical. The Game Version is structured around a game board depicting a picture of a treehouse which ‘belongs’ to the child (i.e., myTREEHOUSE). The treehouse is reached by a universally accessible ramp with four levels leading up from the ground – each level of the ramp represents a progressively more positive rating. The upper two ramps are accompanied by pictures of ‘thumbs up’ to help children orient their responses with high agreement. The lower two ramps have pictures of ‘thumbs down’ to orient towards low agreement. Items are presented verbally, accompanied by a 3cm^2 picture card. The child rates each question by placing the picture card on the ramp of choice.

Each item is scored using a 4-point rating scale. The response options for statements in the *Personal* and *Social Performance Perspectives* are: ‘a lot like me’(4 points), ‘a bit like me’(3 points), ‘not really like me’(2 points), and ‘not like me at all’(1 point). The response options for questions in the *Perceived Performance Perspective* and the *Importance Rating* are: ‘really yes’(4 points), ‘sort of yes’(3 points), ‘sort of no’(2 points), and ‘really no’(1 point).

myTREEHOUSE produces two types of scores; the *Performance Perspective Scores* and a *Personal Concern Score*. The *Performance Perspective Scores* are a summation of scores within each of the Performance Perspectives. Higher scores indicate higher self-concept from that perspective, with a possible score range of 26 to 104 for each perspective. The *Personal Concern Score* is calculated by first subtracting the *Personal Performance Perspective Score* from the *Importance Rating* at the item level. Negative scores are assigned a value of zero to avoid cancelling the effect of other positive scores. The subtracted scores are then summed to obtain the *Personal Concern*

Score; with a possible score range of 0 to 78. Higher scores indicate greater concerns; for example, an item rated with high *Importance Rating* (‘really yes’=4 points) but low *Personal Performance Perspective Score* (‘not like me at all’=1 point) will obtain a high *Personal Concern Score* (3 points).

Validity Evaluation phase

This study phase aimed to test the face and content validity of myTREEHOUSE. These evaluations included the relevance of the items to assess self-concept and representativeness of the items for children with CP.

Participants

Purposive sampling was used to recruit an expert reference panel for validity checking who were: (1) psychologists or other allied health professionals working for Australian CP service organisations or universities, (2) with training or experience in measuring self-concept, (3) with children with CP. In addition, a senior speech pathologist, experienced with children with CP, was recruited to evaluate the language presented in the draft assessment.

Procedure

Semi-structured interviews were conducted by the first author (SKC) with each expert, either face-to-face, via skype, or teleconference. During the 60-minute interview, participants were guided through a set of PowerPoint slides that described the assessment and prompted evaluation of: (i) assessment constructs, (ii) item content, (iii) language and phrasing of items, and (iv) clinical utility of the assessment. At the end of the interview, a summary of responses was checked with the participant. Each interview was voice recorded and transcribed by the first author (SKC) to enable later analysis. Responses were collated and content analysis performed to identify common themes.

Changes recommended by the majority of experts resulted in a change to the assessment. In addition, changes suggested by a minority were considered on a case-by-case basis by the authors. Finally, the speech pathologist reviewed the appropriateness of the language level with respect to the expected level and range of language comprehension in the target population.

Results of the Validity Evaluation phase

Six psychologists and one paediatric physiotherapist participated. A good spread of experience and recent clinical training was obtained. Three participants had over 10 years experience, one reported between 5-10 years experience, and three had less than 5 years experience. Participants responded positively to the overall proposed assessment and strongly supported the dual administration method. Some suggestions were made to improve sentence structure and presentation of individual items to increase ease of understanding. Feedback from the speech pathologist was used to increase readability. Recommendations for new items and changes to existing items are reported in Appendix S1. After implementation of these changes, a final assessment was produced (Table I).

Reliability Evaluation phase

This study phase aimed to assess the internal consistency and test-retest reliability of myTREEHOUSE.

Participants

Participants were recruited from a state-wide community rehabilitation service in Queensland, Australia. Letters were sent to all children who (1) had a diagnosis of CP, and (2) were aged between 8-12 years. Children with parental consent to participate, were then screened for inclusion criteria of (3) cognitive function, determined as a

Verbal Comprehension Index (VCI) of 70 or above on the Wechsler Intelligence Scale for Children – 4th edition (WISC-IV),[14] and (4) functional communication skills, determined as Level I-III on the Functional Communication Classification System (FCCS).[15]

Measures

In addition to myTREEHOUSE, the following measures were included. Parents completed a questionnaire about their child's demographic characteristics and CP classifications, including their Gross Motor Function Classification System-Extended and Revised (GMFCS-E&R) Level,[16] Manual Ability Classification System (MACS) Level,[17] and FCCS Level.[15]

The WISC-IV[14] assesses intelligence for children aged 6 to 16 years 11 months using five composite scores that represent intellectual functioning with scores ranging from 40 to 160. In this study, screening was performed with the VCI, following the recommendations of Yin Foo et al.[18] in order to eliminate the negative impact of poor fine motor performance for children with CP. The VCI has a reliability coefficient of 0.94 and stability coefficient of 0.89.[14]

Procedure

An information sheet and an expression of interest reply slip was mailed to eligible families, and a follow up phone call was provided two weeks later. Prior to participation, written consent was gained from caregivers and assent was gained from children (either verbally or in writing).

At first administration, caregivers completed the demographic questionnaire while their child completed myTREEHOUSE and WISC-IV assessments with the first author (SKC). For myTREEHOUSE, children with sufficient reading ability were provided with the option of completing the Questionnaire Version or playing the Game

Version; otherwise the Game Version was presented. The retest for myTREEHOUSE was conducted 14-28 days after first administration (mean 18 days; SD 3.94 days). As the Game Version was novel, participants who utilised this version were asked to provide their opinion about the suitability of this administration method.

Statistical analysis

Data were analysed using SPSS (version 22). Internal consistency was calculated using Cronbach's alpha. A moderate Cronbach's alpha of between 0.70-0.90 was taken to indicate strong internal consistency.[19] Test-retest reliability was calculated using intraclass correlation coefficients (ICC). Each ICC(3,1) was employed according to the following reliability indicators: 0.90 and higher as excellent, 0.75-0.90 as good, and below 0.75 as poor to moderate reliability.[19] Pearson product moment correlation coefficients were used to examine inter-component correlations. Significance levels were set at $p<0.05$.

Results of the Reliability Evaluation phase

Participants and administration methods

471 families were contacted with 58 families agreeing to participate; however, on further assessment, eight children did not fulfil the inclusion criteria for communication and/or cognitive functioning. Out of the 50 remaining participants (mean age 10 years 2 months, mean WISC-IV=104), 35 participants (mean age 10 years 5 months, mean WISC-IV=103) agreed to complete the retest measure. There were no significant differences in age, gender, GMFCS-E&R, MACS, FCCS, and WISC-IV between the total sample and the retest sample. Participant characteristics are presented in Table SI. Of the total sample, 37 children used the Game Version of which 24 participated in the retest measure.

Reliability

All Performance Perspectives showed strong internal consistency: *Personal* (α=0.87), *Social* (α=0.91), and *Perceived* (α=0.89) (Table II). Strong correlations were found between Performance Perspectives (*r*=0.78-0.85) and as predicted, the *Personal Concern Score* was negatively correlated with all *Performance Perspective Scores* (*r*=-0.51 to -0.76) (Table III).

All Performance Perspectives showed moderate to good test-retest reliability: *Personal* (ICC=0.71), *Social* (ICC=0.75), and *Perceived* (ICC=0.70) (Table II). The *Importance Rating* showed lower reliability (ICC=0.64) (Table II).

The wide range of scores on all Performance Perspectives demonstrates that myTREEHOUSE has the potential for discriminant validity (Table II).

Participant feedback on the Game Version

19 Game Version participants provided feedback on this administration method. Children provided favourable comments, for example: *[the board game is]* "*…more fun than homework…";* and *"it was easy and kind of fun".* They found the treehouse and the ramps helpful when making their evaluations. Children liked the picture cards, but thought they could be slightly enlarged.

Table II Internal consistency (*n*=50) and test-retest reliability (*n*=35) of the myTREEHOUSE Self-Concept Assessment for children with cerebral palsy aged 8-12 years

Components	Mean (SD) *n*=50	Sample Score Range (Min-Max) *n*=50	Cronbach's alpha *n*=50	ICC (95% CI) *n*=35
Overall Scale	-^	-^	0.96	-^
Personal Performance Perspective	84.72 (11.83)	46-98	0.87	0.71 (0.50-0.84)
Social Performance Perspective	80.30 (14.10)	39-104	0.91	0.75 (0.56-0.86)
Perceived Performance Perspective	83.82 (12.12)	45-104	0.89	0.70 (0.49-0.84)
Importance Rating	86.64 (10.81)	49-103	0.84	0.64 (0.39-0.80)

Note: ^This assessment does not yield total scores. Only component scores are available.

Table III Correlation coefficient between the Personal, Social, and Perceived Performance Perspectives and the Personal Concern Score with 95% confidence intervals

	Personal Performance Perspective	Social Performance Perspective	Perceived Performance Perspective	Personal Concern Score
Personal Performance Perspective	1			
Social Performance Perspective	*r*=0.85 (*p*=0.001) CI=0.74 to 0.91	1		
Perceived Performance Perspective	*r*=0.78 (*p*=0.001) CI=0.64 to 0.87	*r*=0.82 (*p*=0.001) CI=0.70 to 0.89	1	
Personal Concern Score	*r*=-0.76 (*p*=0.001) CI=-0.86 to -0.61	*r*=-0.54 (*p*=0.001) CI=-0.71 to -0.30	*r*=-0.51 (*p*=0.001) CI=-0.69 to -0.27	1

DISCUSSION

This is the first study reporting on the development of the myTREEHOUSE Self-Concept Assessment for children with CP aged 8-12 years, which measures self-concept using three Performance Perspectives and an *Importance Rating* over eight domains. Prior to this study, self-concept assessments developed for TD children were used for children with CP; however, those assessments did not fully capture the self-concept of children with CP. myTREEHOUSE was developed in response to the need for population specific self-concept assessments for children with physical disability,[6] like CP,[7] and the lack of well validated assessments for this population.[4,5]

myTREEHOUSE showed strong internal consistency across Performance Perspectives, with values comparable to existing self-concept measures validated for TD children[20-22] or for children with CP, such as the Self-Description Questionnaire-I (Cronbach's α=0.76-0.94).[23] Values were also comparable to those reported for other CP-specific measures of psychological constructs, such as the CP Quality of Life Questionnaire for Children (Cronbach's α=0.80-0.90).[8]

myTREEHOUSE showed moderate to good test-retest reliability. This finding is comparable to other CP-specific measures of psychological constructs, such as the CP Quality of Life Questionnaire for Children (ICC=0.76-0.89).[8] Test-retest reliability is a recommended inclusion in psychometric testing[13] but has not been consistently reported in evaluations of other self-concept assessments.[4,5] The current findings indicate that the myTREEHOUSE self-concept constructs are fairly stable and can be reliably assessed over time.

Impairments caused by CP may limit a child's access to their environment, resulting in a different life experience compared to TD children. myTREEHOUSE was constructed to include several CP-specific areas identified as important contributors[7] under the domain names of *Physical Abilities*, *Personal Agency*, and *Ability to Participate*. Their inclusion provides a more comprehensive evaluation of self-concept for children with CP.

myTREEHOUSE has the unique ability to provide clinicians with a measure of self-concept from three Performance Perspectives (i.e., *Personal, Social,* and *Perceived*). *Personal* and *Social Performance Perspectives* are common features in most self-concept assessments for TD children[13] but they are not evaluated as individual components, making it difficult to ascertain their relative contribution. Measuring these components separately, myTREEHOUSE allows clinicians to assess the relative weight of these perspectives to assist with determining appropriate intervention programs to target the core difficulties for children with low self-concept.

Moreover, myTREEHOUSE has introduced a new evaluative perspective, the *Perceived Performance Perspective*, which evaluates a child's perspective of how others might view their performance. To date, this perspective has not been evaluated as an independent construct in self-concept instruments. Unlike their TD peers, children with CP are consistently exposed to evaluation by clinicians and caregivers, often being commented upon in their presence, about their proficiency related to various areas of impairment. This reality for children with CP makes the *Perceived Performance Perspective* more important for their sense of self. By preadolescence, children have mastered the 'role-taking' skill (i.e., being able to step into another's shoes),[24] which enables them to take in the judgement of others and incorporate this knowledge into their evaluation of self-concept.[11, 12] Thus, the myTREEHOUSE *Perceived Performance Perspective* can provide clinicians with an insight into the best approach for discussing treatment progress in order to protect or promote each child's self-concept.

Furthermore, myTREEHOUSE also incorporates a *Personal Concern Score* that provides clinicians with the ability to identify domains of particular concern to the child. Harter[22] introduced a similar scoring format in the Self-Perception Profile for Children and stressed its significance in interpreting self-concept,[11] but this type of rating has not been included in other self-concept assessments used with children with CP.[4] The myTREEHOUSE *Personal Concern Score* allows clinicians to target specific domains that are negatively impacting a child's overall self-concept.

Lastly, myTREEHOUSE includes two administration methods to facilitate the participation of children with a wide range of abilities – a Questionnaire Version and a pictorial Game Version. Stone and Lemanek[25] emphasized the importance of designing self-report assessments for children to suit their capacity (e.g., attention span, reading and writing skills) and maintaining their interest using pictorial cues. Our Game Version, which uses not only pictorial cues but is presented in a game format, received favourable responses from both allied health professionals in the expert reference group and children with CP who participated in this study. Children indicated that they enjoyed the interactive nature of the game with the ramps making rating scales easy to comprehend.

This study introduces preliminary psychometrics for myTREEHOUSE. Sample size in this study was modest due to strict inclusion criteria for functional communication and cognitive ability which resulted in a reduction in eligible participants. However, these criteria are important to ensure that participants have the language and cognitive ability to perceive the self and to engage in self-concept evaluation.[5] Further investigation with a larger sample would allow for evaluation of construct validity using factor analysis to confirm the domains.

CONCLUSION

The new myTREEHOUSE Self-Concept Assessment is a unique, population specific assessment that is valid and reliable for assessing self-concept of children with CP. It provides comprehensive evaluation across eight domains and three different Performance Perspectives. *Domains* include items from instruments for TD children, as well as new CP-specific items. Finally, myTREEHOUSE is one of the first self-concept instruments to provide a *Personal Concern Score* which can be used to identify domains of particular concern for each child.

Acknowledgements

We would like to thank the Cerebral Palsy League (Brisbane, Australia) for their in-kind support and acknowledge the faculty grant awarded by the Australian Catholic University in support of this study. We would also like to express our appreciation to all of the professionals, parents/caregivers and children who participated. The authors have stated that they had no interests which might be perceived as posing a conflict or bias.

Supporting information

The following additional material may be found online:

Appendix S1: Appendix S1 Changes to the original items and hypothesised domains for the myTREEHOUSE Self-Concept Assessment after considering recommendations from the expert panel and speech pathologist through the Validity Evaluation phase

Table SI: Participant characteristics for the Reliability Evaluation phase

References

1. Shields N, Murdoch A, Loy Y, Dodd KJ, Taylor NF. A systematic review of the self-concept of children with cerebral palsy compared with children without disability. Developmental Medicine & Child Neurology. 2006;48:151-7.
2. Miyahara M, Piek J. Self-esteem of children and adolescents with physical disabilities: Quantitative evidence from meta-analysis. Journal of Developmental and Physical Disabilities. 2006;18(3):219-34.
3. Ferro MA, Boyle MH. Self-concept among youth with a chronic illness: A meta-analytic review. Health Psychology. 2013;32(8):839-48.
4. Cheong SK, Johnston LM. Systematic review of self-concept measures for primary school aged children with cerebral palsy. Research in Developmental Disabilities. 2013;34:3566-75.
5. von der Luft G, DeBoer BV, Harman LB, Koenig KP, Nixon-Cave K. Improving the quality of studies on self-concept in children with cerebral palsy. Journal of Developmental and Physical Disabilities. 2008;20:581-94.
6. Llewellyn A, Chung MC. The self-esteem of children with physical disabilities - Problems and dilemmas of research. Journal of Developmental and Physical Disabilities. 1997;9(3):265-75.
7. Cheong SK, Lang CP, Hemphill SA, Johnston LM. What constitutes self-concept for children with CP? A Delphi consensus survey. Journal of Developmental and Physical Disabilities. 2016;28(2):333-46. Epub 9 Jan 2016.
8. Waters E, Davis E, Mackinnon A, Boyd R, Graham HK, Lo SK, et al. Psychometric properties of the quality of life questionnaire for children with CP. Developmental Medicine & Child Neurology. 2007;49:49-55.

9. Palisano R, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, et al. Validation of a model of gross motor function for children with cerebral palsy. Physical Therapy. 2000;80(10):974-85.

10. Krumlinde-Sundholm L, Holmefur M, Kottorp A, Eliasson A-C. The Assisting Hand Assessment: current evidence of validity, reliability, and responsiveness to change. Developmental Medicine & Child Neurology. 2007;49:259-64.

11. Harter S. The construction of the self: Developmental and sociocultural foundations. 2nd Ed ed. New York: The Guiford Press; 2012.

12. Cooley CH. Human nature and the social order. New York: Schocken Books; 1902/1964.

13. Byrne BM. Measuring self-concept across the life span: Issues and instruments. Washington: American Psychological Association; 1996.

14. Wechsler D. Wechsler Intelligence Scale for Children - Fourth Edition: Administration and scoring manual, Australian adaptation. New South Wales, Australia: Harcourt Assessment; 2003.

15. Caynes K, Burmester D, Barty E, Johnston LM. Concurrent validity of the functional communication classification system for cerebral palsy with the CELF-4 Pragmatic Profile. Developmental Medicine & Child Neurology. 2014;56:45-6.

16. Palisano R, Rosenbaum P, Bartlett D, Livingston M. GMFCS - E & R Gross Motor Function Classification System Expanded and Revised Canada: CanChild Centre for Childhood Disability Research; 2007 [cited 2014 26 November 2014]. Available from: http://motorgrowth.canchild.ca/en/gmfcs/resources/gmfcs-er.pdf.

17. Eliasson A-C, Krumlinde-Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall A-M, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. Developmental Medicine & Child Neurology. 2006;48(7):549-54.
18. Yin Foo R, Guppy M, Johnston LM. Intelligence assessments for children with cerebral palsy: A systematic review. Developmental Medicine & Child Neurology. 2013.
19. Portney LG, Watkins MP. Foundations of clinical research: Applications to practice. 3rd Ed ed. New Jersey: Pearson Education Inc.; 2009.
20. Piers EV, Harris DB, Herzberg DS. Piers-Harris Children's Self-Concept Scale II. United States of America: Western Psychological Services; 2002.
21. Marsh HW. Self-Description Questionnaire-I Manual. Australia: University of Western Sydney; 1992.
22. Harter S. Manual for the Self-Perception Profile for Children. United States of America: University of Denver; 1985.
23. von der Luft G, Harman LB, Koenig KP, Nixon-Cave K, Gaughan JP. Cross validation of a self-concept tool for use with children with cerebral palsy. Journal of Developmental and Physical Disabilities. 2008;20:561-72.
24. Selman RL, Byrne DF. A structural-developmental analysis of levels of role taking in midle childhood. Child Development. 1974;45:803-6.
25. Stone WL, Lemanek KL. Developmental issues in children's self-reports. In: La Greca AM, editor. Through the eyes of the child: Obtaining self-reports from children and adolescents. Miami: Allyn and Bacon; 1990. p. 18-56.

Appendix S1 Changes to the original items and hypothesised domains for the myTREEHOUSE Self-Concept Assessment after considering recommendations from the expert panel and speech pathologist through the Validity Evaluation phase

Domains	Items	Original question / statement format prior to Validation Evaluation stage	Final question / statement format after considering recommendation from the expert panel and speech pathologist through the Validation Evaluation stage
Physical Abilities	Gross motor ability	I am good at doing things with my body	I am good at moving around#
	Fine motor ability	I am good at doing things with my hands	I can do things well with my hands#
	Communication	I am good at getting my message across	N/A^
	Oral motor ability	N/A*	I can speak clearly
Physical Appearance	Appearance of my whole body	I have a good looking body	I have a good looking body
	Appearance of my facial features	I have a nice looking face	I have a nice looking face
	Appearance when I move	I look good when I move around	I look good when I move around
Learning Abilities	Learning ability	I am good at learning things	I am good at learning things
	Memory ability	I am good at remembering things	I am good at remembering things
	Problem solving ability	I am good at figuring things out	I am good at working things out#
Social Skills	Interacting with others	I get along with other people easily	I get along with people#
	Making new friends	I make friends easily	I can make new friends easily#
	Keeping friends	I am good at keeping friends	I can keep friends#
	Communicating with others	N/A*	I am good at telling people what I want
Emotional Regulation	Behaviour management	I am well behaved	I am well behaved
	Emotional reactivity	I do not get upset easily	I do not get too upset about things#
	Perceptiveness	I am good at understanding other people's feelings	N/A^
	Emotional regulation	N/A*	I know how to make myself feel better when I am upset
Personal Agency	Trying my best	I try to do my best at everything	I always try my best#
	Setting my own goals	I can achieve (do) what I want to do	I can achieve what I want#
	Making my own decisions	I am able to make my own decision	I am able to make my own decision
Ability to participate	Participation in outdoor activities	N/A*	I am good at doing things outside
	Participation in indoor activities	N/A*	I am good at doing things inside
	Participation in self-care activities	I can do everyday things on my own	I can look after myself well#
	Participation in school activities	I am good at school work	I do well at school work#
General Self	Desire to change myself	Is there anything you would like to change about yourself?	There is not many things I would change about myself#
	Being a good person	I am a good person	I am a good person
	Liking myself	I think a lot of things about me are good	I am happy with myself#

Note: *New items recommended by the expert panel in Validation Evaluation; ^Original items removed upon the recommendation of the expert panel from the Validation Evaluation stage; #Changes to statement recommended by the expert panel or speech pathologist from the Validation Evaluation stage.

Table SI Participant characteristics for the Reliability Evaluation phase

Variable	*Total sample* *n* (%)	*Subset sample for test-retest* *n (%)*
Total *n*	50	35
Gender		
Male	29 (58%)	20 (57%)
Female	21 (42%)	15 (43%)
Age		
8-year-old	20 (40%)	12 (34%)
9-year-old	4 (8%)	2 (6%)
10-year-old	6 (12%)	5 (14%)
11-year-old	10 (20%)	8 (23%)
12-year-old	10 (20%)	8 (23%)
GMFCS-E&R		
Level I	36 (72%)	26 (75%)
Level II	8 (16%)	4 (11%)
Level III	5 (10%)	4 (11%)
Level IV	1 (2%)	1 (3%)
Level V	0 (0%)	0 (0%)
MACS		
Level I	15 (30%)	9 (26%)
Level II	25 (50%)	17 (48%)
Level III	8 (16%)	7 (20%)
Level IV	2 (4%)	2 (6%)
Level V	0 (0%)	0 (0%)
FCCS		
Level I	33 (66%)	22 (63%)
Level II	6 (12%)	4 (11%)
Level III	11 (22%)	9 (26%)
Level IV	0 (0%)	0 (0%)
Level V	0 (0%)	0 (0%)
WISC-IV (VCI)		
Borderline	4 (8%)	4 (11%)
Low Average	6 (12%)	4 (11%)
Average	22 (44%)	15 (43%)
High Average	7 (14%)	5 (15%)
Superior	8 (16%)	6 (17%)
Very Superior	3 (6%)	1 (3%)

9.2. Interpretation and Direction

Psychometric testing (Studies 3a and 3b) revealed that *myTREEHOUSE* is a valid and reliable instrument to measure the self-concept for children with CP. *myTREEHOUSE* provides a comprehensive evaluation across eight domains from three *Performance Perspectives*. Critically, the instrument includes an *Importance Rating* as a core element that represents the meaning that a child attaches to their performance. This meaning is central to the development of a child's self-concept. At this stage, *myTREEHOUSE* is appropriate for use for research purposes, and more extensive reliability and validity testing is recommended before the instrument is utilised in a clinical setting. Although beyond the scope of this research program, normative data and a manual are advisable when the instrument is intended to be used for clinical decision making. At this point, based on the decision tree for this research program presented in the overview chapter (Chapter 1, see Figure 1.2), when a psychometrically validated self-concept instrument was available, the instrument should be used to explore the self-concept profiles for children with CP aged 8-12 years and to investigate the relationship between self-concept and quality of life for children with CP who are able to provide self-report these constructs. Studies 4 and 5 were conducted to achieve these aims, respectively. Each study is described in the subsequent two chapters.

Chapter 10. Self-Concept of Children with Cerebral Palsy

10.1. Introduction

Using the newly developed population-specific instrument –*myTREEHOUSE Self-Concept Assessment* – Study 4 aims to explore the self-concept profile of children with CP aged 8-12 years in relation to: (i) age, (ii) gender, (iii) motor function (gross and fine motor), and (iv) communication and cognitive function. Study 4 is described in the following manuscript, which is currently under revision, and being considered for publication by the peer reviewed journal, Research in Developmental Disabilities.

Self-concept of children with cerebral palsy measured using the population-specific myTREEHOUSE Self-Concept Assessment

Authors: Sau Kuan Cheong[1], Cathryne P Lang[2], and Leanne M Johnston[3]

[1]School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, AUSTRALIA. E-mail: saukuan.cheong@myacu.edu.au

[2]School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, AUSTRALIA. E-mail: cathryne.lang@acu.edu.au

[3]The University of Queensland, School of Health and Rehabilitation Sciences, St Lucia Queensland 4072, AUSTRALIA. E-mail: l.johnston1@uq.edu.au

Correspondence to Sau Kuan Cheong, School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, Australia. E-mail: saukuan.cheong@myacu.edu.au. Phone number:

What this paper adds?

This is the first study to investigate the self-concept of children with cerebral palsy (CP) using a population-specific assessment – the myTREEHOUSE Self-Concept Assessment. While the findings revealed that self-concept of children with CP is not impacted by age, gender, motor, and communication function, self-concept is impacted by cognitive function. This study offers preliminary insights into how children with CP perceive themselves.

Abstract

Self-concept is an individual's perception of him/herself. Research into the self-concept of children with cerebral palsy (CP) has been sparse due to the lack of a population-specific self-concept instrument. Using the new myTREEHOUSE Self-Concept Assessment for CP, this study investigated the self-concept of children with CP in relation to age, gender, motor, communication and cognitive function. Children with CP aged 8-12 years (*n*=50; 29 males; mean 10 years 2 months; GMFCS-E&R I=36, II=8, III=5, IV=1) completed myTREEHOUSE and a standardised intelligence measure. Most children reported positive self-concept from all three myTREEHOUSE *Performance Perspectives* and over half (60%) fell within the *Low* range for the *Personal Concern Score.* Self-concept was not associated with age, gender, motor function, or communication function. However, for cognitive function, associations were observed for *Social Skills* (Below Average>Average cognitive function; Cohen's *d*=1.07) and *Learning Skills* (Above Average>Average cognitive function; Cohen's *d*=0.95) domains when rated from a *Personal Performance Perspective*. As the first study of the self-concept of children with CP using a CP-specific assessment, this study offers important insights into what children with CP think about themselves. Generally, the self-concept of children with CP was sound. Future research on environmental facilitators and barriers to robust self-concept development is recommended.

Keywords:

Cerebral palsy, children, self-concept, assessment, cognitive function, social skills, learning

1. INTRODUCTION

The primary motor disorder and accompanying impairments experienced by children with cerebral palsy (CP) can lead to atypical life experiences compared to typically developing (TD) children. Atypical experiences across a range of environments over time may lead to a different conceptualisation of self-concept for children with CP (Cheong, Lang, Hemphill, & Johnston, 2016), where self-concept is considered an individual's perception of him/herself across various aspects of one's life such as social relationships, physical appearance, or academic performance (Harter, 2012; Shavelson, Hubner, & Stanton, 1976). Despite this, research into the self-concept of children with CP is sparse compared to the volume of studies on the physical functioning of this population.

A barrier to self-concept research for children with CP has been the lack of well-validated population-specific assessments (von der Luft, DeBoer, Harman, Koenig, & Nixon-Cave, 2008), and the overuse of assessments developed for TD children (Cheong & Johnston, 2013). This situation has changed recently with the development of the population-specific *myTREEHOUSE Self-Concept Assessment* (myTREEHOUSE; Cheong, Lang, Hemphill, & Johnston, 2017). This assessment provides a child-reported evaluation of self-concept from three *Performance Perspectives*: (i) Personal – an evaluation of performance against one's personal standards; (ii) Social – an evaluation of performance against the performance of peers; and (iii) Perceived – one's perception of how significant others might evaluate their performance. Each *Performance Perspective* is assessed across eight domains which were determined via a Delphi process: *Social Skills*, *Physical Abilities*, *Physical Appearance*, *Ability to Participate*, *Learning Skills*, *Personal Agency*, *Emotional Regulation*, and *General Self*. The purpose of this study was to use myTREEHOUSE to establish a self-concept profile of children with CP, focusing on self-concept domains rated from the *Personal Performance Perspective* and the *Personal Concern Score*.

It is known that self-concept develops as a result of the interaction between cognitive processes and social experiences. Based on existing literature, we postulate that an individual’s self-concept develops through a *Self-Concept Feedback Loop* (Figure 1). First, the individual needs to be exposed to socialisation experiences, during which one’s behaviour is influenced by one’s current perspectives across relevant self-concept domains (Harter, 2012). Next, the outcomes of these social experiences are evaluated against one’s current personal standards (i.e., personal ‘ideals’ for specific behaviours), social standards (i.e., benchmarked behaviours based on peers’ behaviours), and perceived standards (i.e., benchmarked behaviours based on the opinions of significant others; Shavelson et al., 1976). Finally, this analysis may lead the individual to adjust existing or create new personal standards, which in turn shape the individual’s self-concept and future behaviours (Cooley, 1902/1964).

Insert Figure 1: The *Self-Concept Feedback Loop* for children with cerebral palsy

The degree to which having CP impacts the self-concept of children is not yet known. It can be postulated that impairments associated with CP can directly and indirectly impact children’s behaviour during social experiences (Figure 1). For example, children with gross motor impairment may be limited in joining physically demanding games or impairments associated with CP can impact the manner in which other people in the child’s environment respond to the child.

The extent to which motor impairment impacts the self-concept of children with CP is unknown. Two separate studies found that better motor function was related to higher self-concept measured using two different modified versions of the Self-Perception Profile for Children (SPPC, Schuengel et al., 2006; Ziebell, Imms, Froude, McCoy, & Galea, 2009). However, while Schuengel et al. (2006) reported that gross motor function was related to the SPPC *Motor Competence* domain, Ziebell et al. (2009) found it was instead related to the *Athletic Competence* and *Global Self-Worth* domains. In contrast, Soyupek, Aktepe, Savas, and Askin (2010) reported no relationship between motor function and self-concept measured via the Piers-Harris Children's Self-Concept Scale, likely due to the use of the more general *Global Self-Concept* score instead of specific domain scores. These studies provide some evidence that gross motor dysfunction may be associated with certain aspects of lower self-concept; however, further research is required to confirm which specific self-concept domains.

Other CP characteristics such as fine motor, communication, or cognitive function are rarely included when investigating the self-concept of children with CP. Ziebell et al. (2009) found that children with better fine motor function reported higher self-concept on the SPPC *Fine Motor* domain. However, due to the small sample size (*n*=8), further investigation is warranted to fully understand population-based profiles. No studies have examined the relationship between communication or cognitive function and self-concept in children with CP. This is surprising given that the self-concept feedback loop emphasises communication during social experiences; and cognitive function during and after these experiences to evaluate self-concept (Cooley, 1902/1964; Harter, 2012). Further research is required to understand how these common impairments (speech/ communication 59% and cognition 39-57%; Australian Cerebral Palsy Register, 2013; Surman et al., 2006) impact the self-concept of children with CP.

It is not known what impact age has on self-concept of children with CP. In TD children, self-concept does not change on a daily basis; rather, the evolution of self-concept is expected over the lifespan in response to maturity and social experiences (Cole et al., 2001; Harter, 2012; Marsh, 1989). Only Soyupek et al. (2010) studied age as a potential variable influencing self-concept in 40 children with CP. This study showed no relationship between age and the Piers-Harris *Global Self-Concept* score. Further research is required to extend this preliminary finding, particularly on specific self-concept domain using a population-specific measure.

Gender differences have been shown to influence self-concept evaluation in TD children (Cole et al., 2001; Marsh, 1989) but inconsistent findings have been reported for children with CP. Manuel, Balkrishnan, Camacho, Smith, and Koman (2003) found that boys with CP have higher self-concept than girls using the Rosenberg Self-Esteem Scale (Rosenberg, 1965). In contrast, Soyupek et al. (2010) found no gender differences using the Piers-Harris. Further research is required to evaluate domain-specific nuances according to gender.

In summary, the evaluation of the self-concept of children with CP is limited in volume and scope, and all studies to date have utilised self-concept instruments designed and adapted for TD children. The aim of this study was to extend the study of self-concept in children with CP using the CP-specific myTREEHOUSE Self-Concept Assessment (Cheong et al., 2017). The specific research questions were to study the self-concept of children with CP in relation to: (i) age, (ii) gender, (iii) motor function (gross and fine motor), and (iv) communication and cognitive function.

2. METHOD

A cross-sectional study was performed with children with CP aged 8-12 years. Ethical approval was obtained from National Health & Medical Research Council registered Human Research Ethics Committees of the Cerebral Palsy League (EC00417) and the Australian Catholic University (EC00205).

2.1 Participants

Children were eligible to participate if they: (1) had diagnosis of CP, (2) were aged between 8-12 years, (3) had cognitive function of 70 or higher according to the Wechsler Intelligence Scale for Children 4th edition (WISC-IV; Wechsler, 2003) Verbal Comprehension Index (VCI), and (4) a functional communication level between I to III according to the Functional Communication Classification System (FCCS; Caynes, Burmester, Barty, & Johnston, 2014). Eligible children were identified from the Queensland CP Register and the client database of the state-wide community rehabilitation service for children with CP in Queensland, Australia (*n*=470). Recruitment was conducted from June 2014 to August 2015. At that time, the service provided care to over 90% of the children with CP in the target age range in the state.

2.2 Measures

2.2.1 Caregiver questionnaire

The caregiver questionnaire included questions on demographic information (age, gender, and school placement type) and three functional classifications as described below.

The Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R) is a 5-point system used to classify gross motor function of children with CP up to 18 years (Palisano, Rosenbaum, Bartlett, & Livingston, 2007). The

GMFCS-E&R ranges from Level I for children who walk independently with minimal limitation, to Level V, where the child is either transported in a manual wheelchair or uses a powered wheelchair with seating and control adaptations.

The Manual Ability Classification System (MACS) is a 5-point system used to classify manual abilities of children with CP aged 4-18 years (Eliasson et al., 2006). The classification ranges from Level I, where children are able to handle objects easily and successfully, to Level V, where children have a severe limitation in manual abilities and are unable to handle objects.

The FCCS is a 5-point system used to classify communication skills of children with CP aged 4-18 years (Caynes et al., 2014). The classification ranges from Level I, where children are able to communicate with minimal or no difficulties, to Level V, where children display unintentional communication using movement and behaviour.

2.2.2 Wechsler Intelligence Scale for Children (Fourth Edition)

The WISC-IV is an individually administered instrument for assessing the intelligence of children aged 6-16 years (Wechsler, 2003). Administration and scoring was completed as per the WISC-IV Australian Standardised edition (Wechsler, 2003). The VCI has excellent reliability coefficient of 0.94 and stability coefficient of 0.89 (Wechsler, 2003). The VCI is recommended for use with children with CP as a screener for verbal intelligence (Yin Foo, Guppy, & Johnston, 2013).

2.2.3 myTREEHOUSE Self-Concept Assessment

myTREEHOUSE measures the self-concept of children with CP aged 8-12 years. myTREEHOUSE has strong internal consistency (Cronbach’s α=0.84-0.91) and moderate to good test-retest reliability (ICC=0.64-0.75) across components (Cheong et al., 2017).

Two administration methods are available; a *Questionnaire Version* and a *Game Version* (Cheong et al., 2017). In both versions, children appraise their performance using a 4-point scale for 26 items from three *Performance Perspectives*: *Personal, Social,* and *Perceived*. In each *Performance Perspective*, items are divided into eight domains: (i) *Social Skills* – 4 items, (ii) *Physical Abilities* – 3 items, (iii) *Physical Appearance* – 3 items, (iv) *Ability to Participate* – 4 items, (v) *Learning Skills* – 3 items, (vi) *Personal Agency* – 3 items, (vii) *Emotional Regulation* – 3 items, and (viii) *General Self* – 3 items. A score of at least 8 points indicates high self-concept on each domain, except in *Social Skills* and *Ability to Participate* domains, which have four items and so at least 11 points indicates high self-concept.

After appraising their performance, children provide an *Importance Rating* for each item using a 4-point scale ranging from 1 = low importance to 4 = high importance (Cheong et al., 2017). The difference between the *Importance Rating* and the *Personal Performance Perspective* score for each item is calculated and summed to achieve a *Personal Concern Score*. *Low Concern* is indicated by a score below 8 points, which reflects mild concerns for less than one-third of items. *Suspected Concern* is indicated by a score of 8-12 points, which reflects mild concerns reported for at least one-third of items, or strong concerns reported for a few items. *Definite Concern* is indicated by a score over 12 points, which reflects mild concerns reported for half or more of the items, or strong concerns reported for a few items.

2.3 Procedure

Eligible families were mailed an invitation with brief information about the study and an expression of interest reply slip. A follow-up phone call was provided two weeks later. Prior to participation, caregivers provided written consent and children provided written or verbal assent. Caregivers completed the caregiver questionnaire. Children completed the VCI and then myTREEHOUSE with the first author. The assessment was conducted in a quiet room with no distractions at the child's home, or their local therapy centre, whichever was the most convenient to the family.

2.4 Statistical analysis

Data were analysed using IBM SPSS Statistical Package (version 22). Descriptive analyses were used to summarise demographic information and myTREEHOUSE *Performance Perspective* scores, *Importance Ratings* and *Personal Concern Score*. Pearson product moment correlation coefficients were used to investigate the relationships between self-concept and age with correlational strengths indicated as good≥0.75, moderate=0.50-0.74, fair=0.26-0.49, and poor≤0.25 (Portney & Watkins, 2009). Independent sample t-tests were used to compare self-concept between genders. One-way ANOVAs were used to compare self-concept scores between children with different functional abilities (i.e., GMFCS-E&R, MACS, FCCS, and WISC-IV VCI). For the purpose of these ANOVA analyses, the GMFCS-E&R and MACS Levels III and IV were combined because the small sample of Level IV GMFCS-E&R (n=1) and MACS (n=2) did not allow for comparison between levels. WISC-IV VCI scores were categorised into three levels, Below Average (score≤89), Average (score 90-109), and Above Average (score≥110). Effect sizes were calculated using Cohen's d and were rated as large≥0.8, medium=0.7-0.3, and small≤0.2 (Portney & Watkins, 2009). Significance levels were set at p<0.05.

3. RESULTS

Study invitations were sent to 470 families and 60 families agreed to participate, of which eight children were excluded due to low cognitive functioning (WISC-IV VCI<70) and two families withdrew. The final cohort included 50 children (mean 10 years 2 months; standard deviation 1 year 9 months; Table 1). Of the 50 children, 13 children utilised the myTREEHOUSE *Questionnaire Version* and the remaining 37 children chose the *Game Version*.

Insert Table 1: Participant characteristics

3.1 Distribution of myTREEHOUSE scores

Most children reported high domain scores for all three *Performance Perspectives* (Table 2). From the *Personal Performance Perspective*, the proportion of children reporting high self-concept ranged from 74% (*n*=37) to 94% (*n*=47) across domains. From the *Social Performance Perspective*, the proportion of children reporting high self-concept ranged from 66% (*n*=33) to 88% (*n*=44) across domains. Lastly, from the *Perceived Performance Perspective*, the proportion of children reporting high self-concept ranged from 66% (*n*=33) to 94% (*n*=47) across domains.

The proportion of children reporting high *Importance Ratings* ranged from 58% (*n*=29) to 98% (*n*=49) across domains (Table 2). The group mean for the *Personal Concern Score* was 7.1 (SD=6.43), with a range of 0-30. Most children reported scores in the *Low Concern* range (*n*=30, 60%); however, 22% of children reported scores within the *Suspected Concern* range (*n*=11) and 18% of children reported scores within the *Definite Concern* range (*n*=9).

The subsequent analyses that assess the relation between self-concept and age, gender, motor, communication, and cognitive functions focus on *Personal Performance Perspective* scores and *Personal Concern Score* only. The *Personal Performance Perspective* scores were the focus because this perspective best represents the child’s internal frame of reference for their self-concept. The *Personal Concern Score* was included in the analyses because it provides an indication of self-concept problems.

Insert Table 2: Distribution of the myTREEHOUSE Self-Concept Assessment domain scores when rated by children with cerebral palsy from the *Personal Performance*, *Social Performance*, and *Perceived Performance Perspectives* as well as the children's *Importance Ratings* according to domains

3.2 Self-concept in relation to age and gender

Age showed no relationship with *Personal Performance Perspective* domain scores (r=-0.16 to 0.25; all p>0.05) or the *Personal Concern Score* (r=0.25; p>0.05). Similarly, gender showed no relationship with *Personal Performance Perspective* domain scores (t=-0.34 to 1.74; all p>0.05), or the *Personal Concern Score* (t=-1.24; p>0.05).

3.3 Self-concept in relation to motor function

None of the *Personal Performance Perspective* domain scores, nor *Personal Concern Score* showed any relationship with gross motor (GMFCS-E&R) or fine motor (MACS) function (Table 3).

Insert Table 3: Self-concept domains as rated from the *Personal Performance Perspective* and *Personal Concern Score* compared across functional classifications (df=2,47)

3.4 Self-concept in relation to communication and cognitive function

No relationships were found between self-concept and communication function (FCCS) (Table 3). However, cognitive function (WISC-IV VCI) was found to be associated with self-concept in the *Social Skills* (F(2,47)=3.70, p=0.03) and *Learning Skills* (F(2,47)=5.26, p=0.01) domains when rated from the *Personal Performance Perspective*. Post-hoc tests (Tukey HSD) confirmed that children with Above Average cognitive functioning reported higher *Learning Skills* scores when compared to children with Average cognitive functioning (Cohen's *d*=0.95). Conversely, children with Below Average cognitive functioning reported higher *Social Skills* scores when compared to children with Average cognitive functioning (Cohen's *d*=1.07).

4. DISCUSSION

This study is the first to employ the population-specific myTREEHOUSE Self-Concept Assessment to investigate the self-concept of children with CP in relation to age, gender, motor, communication, and cognitive function. In this cohort, self-concept showed no relationship with age, gender, motor or communication function. In contrast, relationships were observed between self-concept and cognitive function.

This study offers some initial insights into what children with CP think about themselves. Children from this cohort reported mostly high self-concept across the three *Performance Perspectives*. The lowest mean self-concept score within each *Performance Perspective* was reported for *Physical Appearance*, with 34% of children reporting low self-concept from *Social* and *Perceived Performance Perspectives*, and 16% reporting low self-concept from the *Personal Performance Perspective*. *Physical Appearance* was also associated with a high importance score for over half the sample (*n*=58), emphasising that parents and clinicians need to be sensitive to *Physical*

Appearance as a potential problem for physical or psychological intervention. With regard to *Learning Skills*, 26% of the children reported low scores for *Personal* and *Social Performance Perspectives* despite 90% reporting high scores for *Perceived Performance Perspective*. This means that children in this cohort have poor perception of their own learning abilities based on personal standards and peer comparison despite receiving positive feedback from significant others. The low *Personal Performance Perspective* is worrying especially when most children (98%) rated this domain as having high importance.

In terms of the *Personal Concern Score*, more than half the sample did not reported self-concept problems; however, 18% scored within the *Definite Concern* range. Children falling within the *Definite Concern* range were not differentiable by demographic characteristics or functional abilities, suggesting that this is not a systematic problem according to condition severity. This suggests that physical impairments alone do not determine self-concept and highlights the need to investigate a broader range of possible *Personal* and *Environmental* contributors across the *International Classification of Functioning, Disability and Health* (ICF; World Health Organisation, 2002).

Age was not related to any *Personal Performance Perspective* domain scores nor on the *Personal Concern Score*, which is consistent with the previous study involving children with CP (Soyupek et al., 2010). In TD children, differences in self-concept are observable over larger age periods (e.g., from preadolescence to adolescence to adulthood) due to maturity and exposure to new social experiences (Cole et al., 2001; Marsh, 1989). Similar changes to self-concept may exist for children with CP and this requires further longitudinal research.

Gender demonstrated no impact on *Personal Performance Perspective* domain scores or on the *Personal Concern Score*. This finding is similar to previous studies involving children with CP (Soyupek et al., 2010) but differed from studies with TD children (Cole et al., 2001; Marsh, 1989). Harter (2012) and Marsh (1989) postulate that gender differences in self-concept are a result of gender stereotyping. In myTREEHOUSE, several domains focused on CP-specific elements including *Personal Agency*, and *Ability to Participate*, reflect daily living skills which are not necessarily gender specific. Furthermore, the domains focus on broader performance areas. For example, the *Learning Skills* domain included learning, memory, and problem solving, rather than specific academic subjects. Similarly, the *Physical Abilities* domain included gross, fine, and oral motor functions rather than particular sport or athletic achievements. The broad-based performance areas introduced by myTREEHOUSE provide a holistic view of these performance areas and allow children to generate individualised behaviours that mitigate gender suggestive behaviours unintentionally generated by some instruments.

Except for cognitive function, no other functional classifications were associated with self-concept in our cohort. It was reassuring that all three CP-specific functional classifications (GMFCS-E&R, MACS, or FCCS) were not associated with self-concept, which implies that typical impairments experienced by children with CP do not independently determine self-concept. This is supported by Chong, Mackey, Broadbent, and Stott (2012) who suggested that even though children with CP may be dissatisfied with parts of their life affected by their disability, they often find alternative ways to achieve fulfilment in life. With this in mind, clinicians are encouraged to assist parents to identify a child’s functional strengths, and focus on the child’s interests and goals to boost their self-concept. This reinforces how positive social experiences within families and communities can play a crucial role in improving children's self-concept (Figure 1).

The relationship between self-concept and cognitive function revealed unexpected findings. Results showed that children with Below Average cognitive functioning reported significantly higher scores for *Social Skills* compared to children with Average cognitive functioning. A similar trend was observed in previous studies and it was postulated that children with lower cognitive functioning are more likely to misinterpret social context and have low awareness of social cues (Nadeau & Tessier, 2011; Schuengel et al., 2006); this may indicate that children with Below Average cognitive functioning overestimate their abilities in this area. Our results also showed that children with Above Average cognitive functioning report significantly higher scores for *Learning Skills* compared to children with Average cognitive functioning. We speculate that children with Above Average cognitive functioning are able to accurately predict their abilities and thus, hold higher self-concept in this domain.

A few limitations are of note. First, this study involved a relatively small sample size (*n*=50); however, it is the first and only study of self-concept of children with CP to date using a CP-specific assessment instruments and internationally accepted functional classifications. The utilisation of standardised population-specific assessments for self-concept and functional classifications was recommended for the optimal management of children with CP (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2006). Second, it is acknowledged that the majority of participants in this study had a GMFCS-E&R Level I-III, which may have produced a sample more physically able to adapt to life's demands. Future research would benefit by including a larger sample and a greater proportion of children with non-ambulant CP, which is more reflective of the population of individuals with CP in Australia (Australian Cerebral Palsy Register Group, 2013).

Research to further explore the three *Performance Perspectives* and the potential environmental contributors to self-concept can provide a foundation for clinicians to tailor interventions to address the needs of children with self-concept problems. For example, recent research on the quality of life of children with CP found this was significantly predicted by environmental factors such as family coping and caregiver stress (Chen, Tseng, Shieh, Lu, & Huang, 2014). Other environmental factors contributing to self-concept might include the type of school setting, accessibility of the home and school environment, capacity for inclusion in community activities and funding for support services. Extending self-concept research in this direction may provide greater understanding of children's perspective of themselves within their natural environments.

5. CONCLUSION

In conclusion, this is the first study to use a population-specific assessment to examine the self-concept of children with CP in relation to age, gender, motor, communication and cognitive function. As such, it offers preliminary insights into what children with CP think about themselves. This presents a potential to influence the direction in the clinical avenue to include the perspective of children in assessment and treatment.

Acknowledgement

We would like to thank the Cerebral Palsy League (Brisbane, Australia) for their in-kind support and the Australian Catholic University for providing a faculty grant to support this study. We would also like to express our appreciation to all the families who participated.

Funding Sources

Apart from the faculty grant provided by the Australian Catholic University as part of a post-graduate student support scheme, this research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors.

Reference

Australian Cerebral Palsy Register Group. (2013). Australian Cerebral Palsy Register report 2013. Australia: Australian Cerebral Palsy Register.

Caynes, K., Burmester, D., Barty, E., & Johnston, L. M. (2014). Concurrent validity of the functional communication classification system for cerebral palsy with the CELF-4 Pragmatic Profile. *Developmental Medicine & Child Neurology, 56*, 45-46.

Chen, K.-L., Tseng, M.-H., Shieh, J.-Y., Lu, L., & Huang, C.-Y. (2014). Determinants of quality of life in children with cerebral palsy: A comprehensive biopsychosocial approach. *Research in Developmental Disabilities, 35*, 520-528.

Cheong, S. K., & Johnston, L. M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities, 34*, 3566-3575.

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016). What constitutes self-concept for children with CP? A Delphi consensus survey. *Journal of Developmental and Physical Disabilities, 28*(2), 333-346. doi: 10.1007/s10882-015-9471-z

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2017). myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy. *Developmental Medicine & Child Neurology, 59*(6), 655-660. doi: 10.1111/dmcn.13392

Chong, J., Mackey, A. H., Broadbent, E., & Stott, N. S. (2012). Children's perceptions of their cerebral palsy and their impact on life satisfaction. *Disability and Rehabilitation, 34*(24), 2053-2060. doi: 10.3109/09638288.2012.669021

Cole, D. A., Maxwell, S. E., Martin, J. M., Peeke, L. G., Seroczyniski, A. D., Tram, J. M., . . . Maschman, T. (2001). The development of multiple domains in child and adolescent self-concept: A cohort sequential longitudinal design. *Child Development, 72*(6), 1723-1746.

Cooley, C. H. (1902/1964). *Human nature and the social order*. New York: Schocken Books.

Eliasson, A.-C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.-M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48*(7), 549-554.

Harter, S. (2012). *The construction of the self: Developmental and sociocultural foundations* (2nd Ed ed.). New York: The Guiford Press.

Manuel, J. C., Balkrishnan, R., Camacho, F., Smith, B. P., & Koman, L. A. (2003). Factors associated with self-esteem in pre-adolescents and adolescents with cerebral palsy. *Journal of Adolescent Health, 32*, 456-458. doi: 10.1016/S1054-139X(03)00050-8

Marsh, H. W. (1989). Age and sex effects in multiple dimensions of self-concept: Preadolescence to early adulthood. *Journal of Educational Psychology, 81*(3), 417-430.

Nadeau, L., & Tessier, R. (2011). Self-concept in children with cerebral palsy: Is there something in the wind? *Disability and Rehabilitation, 33*(10), 830-834. doi: 10.3109/09638288.2010.513421

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2007). GMFCS - E & R Gross Motor Function Classification System Expanded and Revised. Retrieved 26 November 2014, 2014, from https://www.canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (3rd Ed ed.). Upper Saddle River, New Jersey: Pearson Education Inc.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2006). A report: The definition and classification of cerebral palsy April 2006. *Definition and Classification of CP,* 8-14.

Rosenberg, M. (1965). *Society and the adolescent self-image*. United States of America: Princeton University Press.

Schuengel, C., Voorman, J., Stolk, J., Dallmeijer, A., Vermeer, A., & Becher, J. (2006). Self-worth, perceived competence, and behaviour problems in children with cerebral palsy. *Disability and Rehabilitation, 28*(20), 1251-1258. doi: 10.1080/09638280600554652

Shavelson, R. J., Hubner, J. J., & Stanton, G. C. (1976). Self-concept: Validation of construct interpertations. *Review of Educational Research, 46*(3), 407-441.

Soyupek, F., Aktepe, E., Savas, S., & Askin, A. (2010). Do the self-concept and quality of life decrease in CP patients? Focussing on the predictors of self-concept and quality of life. *Disability and Rehabilitation, 32*(13), 1109-1115. doi: 10.3109/09638280903391120

Surman, G., Bonellie, S., Chalmers, J., Colver, A., Dolk, H., Hemming, K., . . . Platt, M. J. (2006). UKCP: A collaborative network of cerebral palsy registers in the United Kingdom. *Journal of Public Health, 28*(2), 148-156. doi: 10.1093/pubmed/fdi087

von der Luft, G., DeBoer, B. V., Harman, L. B., Koenig, K. P., & Nixon-Cave, K. (2008). Improving the quality of studies on self-concept in children with cerebral palsy. *Journal of Developmental and Physical Disabilities, 20*, 581-594. doi: 10.1007/s10882-008-9117-5

Wechsler, D. (2003). *Wechsler Intelligence Scale for Children - Fourth Edition: Administration and scoring manual, Australian adaptation*. Sydney, New South Wales, Australia: Harcourt Assessment.

World Health Organisation. (2002). *Towards a common language for functioning, disability and health: ICF*. Geneva: World Health Organisation.

Yin Foo, R., Guppy, M., & Johnston, L. M. (2013). Intelligence assessments for children with cerebral palsy: A systematic review. *Developmental Medicine & Child Neurology*. doi: 10.1111/dmcn.12157

Ziebell, M., Imms, C., Froude, E. H., McCoy, A., & Galea, M. (2009). The relationship between physical performance and self-perception in children with and without cerebral palsy. *Australian Occupational Therapy Journal, 56*, 24-32. doi: 10.1111/j.1440-1630.2008.00775.x

Figures Captions

Figure 1: The *Self-Concept Feedback Loop* for children with cerebral palsy

Tables Captions

Table 1: Participant characteristics

Table 2: Distribution of the myTREEHOUSE Self-Concept Assessment domain scores when rated by children with cerebral palsy from the *Personal Performance*, *Social Performance*, and *Perceived Performance Perspectives* as well as the children's *Importance Ratings* according to domains

Table 3: Self-concept domains as rated from the *Personal Performance Perspective* and *Personal Concern Score* compared across functional classifications (df=2,47)

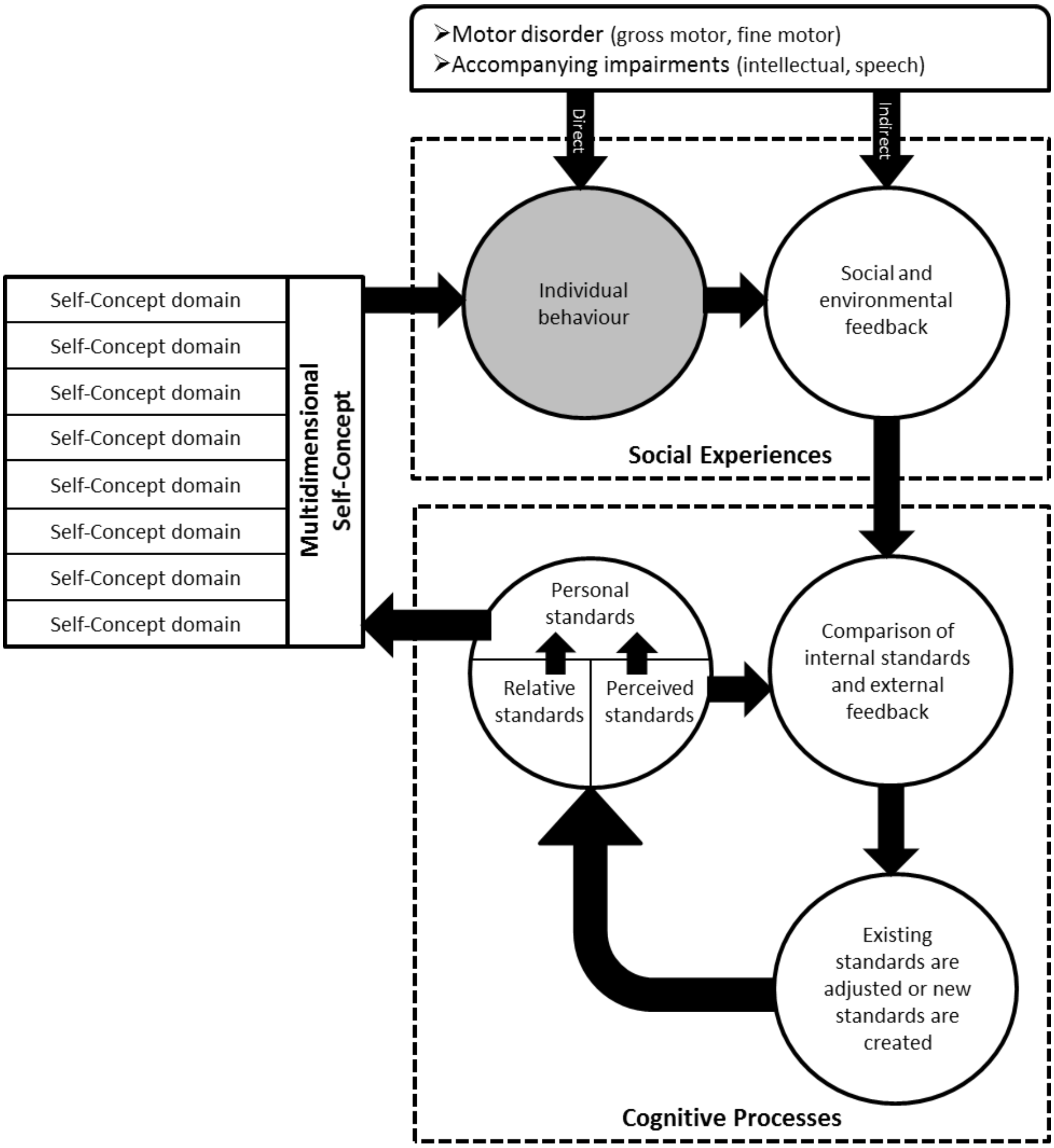


Figure 1: The *Self-Concept Feedback Loop* for children with cerebral palsy

Table 1: Participant characteristics

Characteristics	*N*=50 (%)
Gender	
Male	29 (58%)
Female	21 (42%)
Age	
8-year-old	20 (40%)
9-year-old	4 (8%)
10-year-old	6 (12%)
11-year-old	10 (20%)
12-year-old	10 (20%)
School types	
Mainstream	8 (16%)
Mainstream with learning support	38 (76%)
Special school	2 (4%)
Home school	2 (4%)
GMFCS – E&R	
Level I	36 (72%)
Level II	8 (16%)
Level III	5 (10%)
Level IV	1 (2%)
Level V	0 (0%)
MACS	
Level I	15 (30%)
Level II	25 (50%)
Level III	8 (16%)
Level IV	2 (4%)
Level V	0 (0%)
FCCS	
Level I	33 (66%)
Level II	6 (12%)
Level III	11 (22%)
Level IV	0 (0%)
Level V	0 (0%)
WISC-IV – VCI	
Below Average (70-89)	10 (20%)
Average (90-109)	22 (44%)
Above Average (110-160)	18 (36%)

Note: GMFCS-E&R: Gross Motor Function Classification System – Extended and Revised; MACS: Manual Ability Classification System; FCCS: Functional Communication Classification System; WISC-IV – VCI: Wechsler Intelligence Scale for Children – Fourth Edition, Verbal Comprehension Index

Table 2: Distribution of the myTREEHOUSE Self-Concept Assessment domain scores when rated by children with cerebral palsy from the *Personal Performance*, *Social Performance*, and *Perceived Performance Perspectives* as well as the children's *Importance Ratings* according to domains

Self-concept domains	Possible test scores (Min-Max)	Study Sample											
		Personal Performance Perspective			*Social Performance Perspective*			*Perceived Performance Perspective*			*Importance Rating*		
		Mean (SD)	Range (Min-Max)	Low/high *n* (%)	Mean (SD)	Range (Min-Max)	Low/high *n* (%)	Mean (SD)	Range (Min-Max)	Low/high *n* (%)	Mean (SD)	Range (Min-Max)	Low/high *n* (%)
Social Skills	4-16	13.2 (2.64)	6-16	7 (14)/ 43 (86)	12.8 (2.68)	6-16	10 (20)/ 40 (80)	13.1 (2.65)	7-16	9 (18)/ 41 (82)	13.31 (2.84)	4-16	7 (14)/ 43 (86)
Physical Abilities	3-12	9.9 (1.74)	3-12	3 (6)/ 47 (94)	8.9 (2.02)	4-12	12 (24)/ 38 (76)	9.5 (1.88)	5-12	6 (12)/ 44 (88)	10.4 (1.42)	5-12	2 (4)/ 48 (96)
Physical Appearance	3-12	9.3 (2.20)	3-12	8 (16)/ 42 (84)	8.3 (2.62)	3-12	17 (34)/ 33 (66)	8.6 (2.50)	3-12	17 (34)/ 33 (66)	8.1 (2.98)	3-12	21 (42)/ 29 (58)
Ability to Participate	4-16	13.3 (2.41)	7-16	8 (16)/ 42 (84)	12.7 (2.60)	5-16	10 (20)/ 40 (80)	13.6 (2.13)	6-16	5 (10)/ 45 (90)	13.8 (2.28)	6-16	5 (10)/ 45 (90)
Learning Skills	3-12	9.0 (2.18)	3-12	13 (26)/ 37 (74)	8.9 (2.37)	3-12	13 (26)/ 37 (74)	9.8 (1.78)	4-12	5 (10)/ 45 (90)	10.6 (1.41)	7-12	1 (2)/ 49 (98)
Personal Agency	3-12	10.4 (1.69)	6-12	3 (6)/ 47 (94)	10.0 (1.73)	5-12	6 (12)/ 44 (88)	10.4 (1.57)	6-12	3 (6)/ 47 (94)	10.8 (1.44)	6-12	3 (6)/ 47 (94)
Emotional Regulation	3-12	9.5 (1.76)	5-12	7 (14)/ 43 (86)	9.5 (1.81)	5-12	8 (16)/ 42 (84)	9.8 (1.87)	4-12	6 (12)/ 44 (88)	10.1 (1.63)	7-12	4 (8)/ 46 (92)
General Self	3-12	10.1 (1.88)	4-12	4 (8)/ 46 (92)	9.3 (2.25)	4-12	9 (18)/ 41 (82)	9.1 (2.05)	3-12	8 (16)/ 42 (84)	9.5 (1.94)	5-12	7 (14)/ 43 (86)

Table 3: Self-concept domains as rated from the *Personal Performance Perspective* and *Personal Concern Score* compared across functional abilities (*df*=2,47)

Variables	Possible test scores (Min-Max)	Mean scores by classification levels (SD)			*F*	*p*
GMFCS-E&R		I (*n*=36)	II (*n*=8)	III (*n*=5) IV (n=1)^{a}		
Personal Performance Domains						
Social Skills	4-16	13.2 (2.46)	13.3 (2.82)	13.3 (3.88)	0.01	0.99
Physical Abilities	3-12	10.1 (1.70)	9.9 (1.89)	9.0 (1.79)	1.05	0.36
Physical Appearance	3-12	9.4 (2.10)	9.1 (2.36)	8.5 (2.81)	0.45	0.64
Ability to Participate	4-16	13.3 (2.48)	14.0 (1.20)	13.0 (3.35)	0.37	0.69
Learning Skills	3-12	8.9 (2.10)	9.0 (2.51)	9.7 (2.50)	0.34	0.71
Personal Agency	3-12	10.2 (1.70)	11.3 (0.89)	10.5 (2.26)	1.39	0.26
Emotional Regulation	3-12	9.4 (1.75)	9.9 (1.96)	9.3 (1.86)	0.22	0.80
General Self	3-12	10.2 (1.69)	10.0 (1.93)	9.5 (2.95)	0.38	0.68
Concern Score	0-78	7.1 (6.56)	6.5 (6.39)	7.8 (6.74)	0.07	0.93
MACS		I (*n*=15)	II (*n*=25)	III (*n*=8) IV (*n*=2)^{b}		
Personal Performance Domains						
Social Skills	4-16	13.3 (2.69)	13.3 (2.46)	13.0 (3.27)	0.04	0.96
Physical Abilities	3-12	9.9 (2.26)	10.2 (1.37)	9.5 (1.78)	0.52	0.60
Physical Appearance	3-12	9.2 (2.31)	9.2 (2.03)	9.4 (2.67)	0.03	0.97
Ability to Participate	4-16	13.5 (2.75)	13.2 (2.01)	13.5 (2.99)	0.13	0.87
Learning Skills	3-12	8.7 (2.52)	9.2 (1.91)	8.9 (2.47)	0.18	0.83
Personal Agency	3-12	10.0 (2.10)	10.5 (1.29)	10.7 (1.95)	0.59	0.56
Emotional Regulation	3-12	9.9 (1.25)	9.3 (1.99)	9.5 (1.90)	0.51	0.60
General Self	3-12	9.7 (1.72)	10.3 (1.73)	10.2 (2.49)	0.58	0.57
Concern Score	0-78	6.8 (6.25)	7.2 (7.00)	7.1 (5.80)	0.02	0.98
FCCS		I (*n*=33)	II (*n*=6)	III (*n*=11)		
Personal Performance Domains						
Social Skills	4-16	13.7 (1.88)	11.8 (2.64)	12.6 (4.15)	1.60	0.21
Physical Abilities	3-12	10.3 (1.21)	9.8 (1.94)	8.9 (2.59)	2.85	0.07
Physical Appearance	3-12	9.6 (1.64)	8.7 (3.14)	8.5 (2.98)	1.46	0.24
Ability to Participate	4-16	13.6 (1.92)	12.7 (2.94)	13.0 (3.44)	0.49	0.62
Learning Skills	3-12	9.4 (1.79)	8.0 (2.00)	8.2 (3.03)	2.12	0.13
Personal Agency	3-12	10.5 (1.52)	10.7 (1.21)	9.8 (2.32)	0.79	0.46
Emotional Regulation	3-12	9.6 (1.73)	9.3 (2.25)	9.4 (1.75)	0.09	0.92
General Self	3-12	10.1 (1.86)	10.2 (1.72)	10.1 (2.17)	0.04	0.99
Concern Score	0-78	6.8 (6.23)	7.8 (7.25)	7.6 (7.16)	0.11	0.90

Variables	Possible test scores (Min-Max)	Mean scores by classification levels (SD)			*F*	*p*
WISC-IV VCI		Below Average[c] (*n*=10)	Average[d] (*n*=22)	Above Average[e] (*n*=18)		
Personal Performance Domains						
Social Skills	4-16	14.9 (1.66)	12.3 (2.98)	13.4 (2.23)	3.70*	0.03
Physical Abilities	3-12	10.4 (1.51)	9.7 (2.21)	10.0 (1.14)	0.59	0.56
Physical Appearance	3-12	10.2 (1.40)	8.7 (2.81)	9.4 (1.50)	1.63	0.21
Ability to Participate	4-16	13.6 (2.63)	13.1 (2.72)	13.6 (1.95)	0.29	0.75
Learning Skills	3-12	9.5 (1.43)	8.0 (2.42)	9.9 (1.70)	5.26**	0.01
Personal Agency	3-12	10.2 (1.87)	10.3 (1.86)	10.6 (1.42)	0.16	0.85
Emotional Regulation	3-12	9.8 (1.62)	9.1 (1.69)	9.8 (1.92)	1.06	0.35
General Self	3-12	10.4 (1.43)	9.9 (1.97)	10.2 (2.04)	0.25	0.78
Concern Score	0-78	5.9 (5.38)	8.4 (6.27)	6.1 (7.15)	0.86	0.43

Note: GMFCS-E&R: Gross Motor Function Classification System – Extended and Revised; MACS: Manual Ability Classification System; FCCS: Functional Communication Classification System; WISC-IV VCI: Wechsler Intelligence Scale for Children – Fourth Edition, Verbal Comprehension Index; [a]GMFCS-E&R Levels III and IV combined; [b]MACS Levels III and IV combined; [c]WISC-IV VCI $\leq$89; [d]WISC-IV VCI=90-109; [e]WISC-IV VCI $\geq$110; *Below Average > Average; Cohen’s *d*=1.07; **Above Average > Average; Cohen’s *d*=0.95

Highlights

- Self-concept of children with CP is not impacted by age and gender
- Self-concept of children with CP is not impacted by motor or communication function
- Children with high cognitive function reported higher *Learning Skills* self-concept

10.2. Conclusion

This is the first study to provide a profile of self-concept for children with CP using a CP-specific self-concept assessment. Children with CP in this cohort reported overall positive self-concept from each *Performance Perspective* across domains. Children reporting discord between their *Personal Performance* and their related *Importance Rating* at a magnitude that fell within the *Definite Concern* level could not be discerned from personal characteristics like age, gender, and functional ability. In contrast to previous studies, this study showed no relationship between self-concept and age, gender, or CP-related functional abilities (i.e., GMFCS-E&R, MACS, and FCCS); however a relationship between self-concept and cognitive function (i.e., WISC-IV VCI) was observed. For caregivers of children with CP, it may be comforting to know that the level of impairment experienced by their child does not necessarily influence the child’s self-concept. In clinical practice, self-concept promotion needs to be advocated to all children with CP irrespective of age, gender, or CP-related functional classification.

Chapter 11. Self-Concept and Quality of Life of Children with Cerebral Palsy

11.1. Introduction

The literature presented in Chapter 4 showed that while self-concept and quality of life have been independently studied for children with CP, very few studies have investigated the relationship between these two constructs. Moreover, the previous studies that have investigated this relationship have employed non-population-specific instruments to measure these constructs. With the development of a population-specific self-concept instrument as a result of this research program, the final study aims to investigate the relationship between self-concept and quality of life in children with CP who are able to provide a self-report for these constructs. Both constructs are measured using population-specific instruments, including *myTREEHOUSE* to measure self-concept and *CP QOL-Child* to measure quality of life. Study 5 is described in the following manuscript, which is formatted according to the submission guidelines for the peer reviewed journal, Developmental Medicine and Child Neurology.

Assessing the self-concept and quality of life of children with cerebral palsy using population-specific measures

Authors: Cheong, Sau Kuan[1], Lang, Cathryne P[1], and Johnston, Leanne M[2]

[1]School of Psychology, Australian Catholic University, Queensland, AUSTRALIA

[2] The University of Queensland, School of Health and Rehabilitation Sciences, Queensland, AUSTRALIA

Correspondence to Sau Kuan Cheong, School of Psychology, Australian Catholic University, 1100 Nudgee Road, Banyo, Queensland 4014, Australia.
E-mail: saukuan.cheong@myacu.edu.au

Acknowledgement

We would like to thank the Cerebral Palsy League (Brisbane, Australia) for their in-kind support and the Australian Catholic University for providing a faculty grant to support this study. We would also like to express our appreciation to all the families who participated.

Abstract

AIM: To examine the potential relationship between self-concept and quality of life (QoL) for children with cerebral palsy (CP) using population-specific measures.

METHODS: Participants were children with CP aged 9-12 years (*n*=25, 13 males, Mean 11 years 5 months, GMFCS-E&R I=17, II=6, III=2). Children completed the CP-specific *myTREEHOUSE Self-Concept Assessment*. Parents and children completed the CP-specific *Quality of Life Questionnaire for Children*.

RESULTS: Scores across child-reported self-concept domains indicated positive self-concept. Mean child-reported QoL subscale scores were mostly higher than proxy-reported QoL. Child-reported scores on most self-concept domains showed moderate-good correlations with most child-reported QoL subscales. *Social Skills*, *Physical Abilities*, and *Physical Appearance* self-concept domains showed the strongest positive relationships with child-reported QoL subscales. In contrast, proxy-reported QoL showed only fair positive correlations with some child-reported self-concept domains. The contrasting findings may be explained by discrepancies in child-reported versus proxy-reported QoL.

CONCLUSIONS: This is the first study to utilise population-specific assessments to measure self-concept and QoL for children with CP. Results showed children with CP self-report a generally positive self-concept, which is linked to a generally positive QoL.

What this paper adds:

- First study to use CP-specific assessments
- Children with CP report generally positive self-concept
- Self-concept of children with CP is positively related to QoL
- Child-reported and proxy-reported QoL varies

Keywords: Self-concept, cerebral palsy, quality of life, children

Shorten form of the title: Self-concept and Quality of Life

Assessing the self-concept and quality of life of children with cerebral palsy using population-specific measures

Self-concept is an individual's perception of him/herself.[1] As described in our *Self-Concept Feedback Loop*,[2] self-concept is developed through the iterative process of (i) social environment participation, (ii) receiving and evaluating social feedback, and (iii) adjusting personal standards through cognitive processes. Thus, self-concept can be considered the lens through which an individual views him/herself that influences behaviour in social environments. In contrast, quality of life (QoL) is an individual's perception of their "position in life" with regard to their personal standards, expectations, goals, and concerns.[3] Both self-concept and QoL are shaped by personal standards, which are an individual's personal ideals for specific behaviours that influence the individual's expectations of their environment and their behavioural goals. In view of the similarities between self-concept and QoL, researchers have postulated that higher self-concept may be associated with higher QoL.[4] However, at this time, self-concept[5] and QoL[6, 7] have mostly been studied independently for children with CP, and the potential relationship between these constructs is not clear.

Two studies have investigated the relationship between self-concept and QoL for children with CP[8, 9]. Russo et al. [8] used the Self-Perception Profile for Children (SPPC) to measure self-concept and the Pediatric Quality of Life Inventory (PedsQL) to measure QoL in 86 children with hemiplegia aged 3-16 years (mean age 9.4 years). Study results showed that higher self-concept was moderately correlated with higher QoL (r=0.63, p<0.001). In the second study, Soyupek et al. [9] again used the PedsQL to measure QoL, alongside the Piers-Harris Children's Self-Concept Scale to measure the self-concept of 40 children with all types of CP aged 9-18 years (mean age 11.9 years). In this study only a fair relationship was shown between self-concept and QoL (r=0.44,

$p<0.01$). Although in the same direction, it is not clear whether the different strength of findings is due to differences in the self-concept measures used, different age ranges of the samples, different CP motor types, or other study specific factors. The use of non-population-specific assessments in both studies suggests further research with CP-specific instruments may be needed to fully explore how self-concept and QoL are related, given the differences in the lifestyle and environment of a child with CP compared to their typically developing peers.

Researchers have argued for the use of population-specific assessments for both self-concept and QoL to provide a comprehensive evaluation for children with CP.[10, 11] Until recently, a CP-specific self-concept assessment was unavailable and therefore, researchers have utilised instruments designed for typically developing children despite limited psychometric information for their use with children with CP.[12] A newly developed population-specific self-concept assessment for preadolescent children with CP, called the *myTREEHOUSE Self-Concept Assessment* (*myTREEHOUSE*), allows for CP-specific self-concept domains to be captured.[13] This can now be administered in conjunction with the well-known CP-specific *Quality of Life Questionnaire for Children* (*CP QOL-Child*).[10]

As the relationship between self-concept and QoL has not yet been explored using population-specific measures for children with CP, this study aimed to investigate this relationship using *myTREEHOUSE* and *CP QOL-Child*. We hypothesised that higher *myTREEHOUSE* domain scores when rated from the *Personal Performance Perspective* would be related to higher *CP QOL-Child* subscale scores with the exception of the *Pain and Impact of Disability* subscale, where the inverse is expected. Similarly, we hypothesised that lower *myTREEHOUSE Personal Concern Score* would be related to higher *CP QOL-Child* subscale scores with the exception of the *Pain and Impact of Disability* subscale, where the inverse is again expected.

METHOD

A cross-sectional study of self-concept and QoL was conducted with preadolescent children with CP. Ethical approval was obtained from National Health & Medical Research Council (NHMRC) registered Human Research Ethics Committees of the Cerebral Palsy League (EC00417) and the Australian Catholic University (EC00205).

Participants

Recruitment of participants was conducted through a state-wide community rehabilitation service in Queensland, Australia. Children were eligible to participate if they: (1) had diagnosis of CP, (2) were aged between 9-12 years, (3) did not have intellectual impairment (as indicated by a score of ≥70 on the Verbal Comprehension Index [VCI] of the Wechsler Intelligence Scale for Children 4th edition [WISC-IV][14]), and (4) demonstrated functional communication adequate to respond to study questionnaires (as indicated by Levels I, II or III on the Functional Communication Classification System [FCCS][15]).

Measures

Caregivers completed a child demographic questionnaire and the *CP QOL-Child Primary Caregiver Questionnaire*. Children completed the WISC-IV VCI, the *myTREEHOUSE* and the *CP QOL-Child Child Report Questionnaire*.

Demographic Questionnaire

The child demographic questionnaire was used to gather data on age (in years and months), gender, and three functional classifications for the child with CP, as described below.

Functional Classifications

The Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R) is a 5-level system designed to classify gross motor abilities of children with CP up to 18 years.[16] The levels range from Level I for children who can walk independently with minimal limitations, to Level V, where children have significant mobility limitations that require transport in a manual wheelchair or a powered wheelchair with seating and control adaptations.

The Manual Ability Classification System (MACS) is a 5-level system used to classify fine motor function of children with CP aged 4-18 years.[17] The levels range from Level I, where children are able to independently handle objects easily and successfully, to Level V, where children demonstrate severe limitations in manual abilities and are unable to handle objects.

The FCCS is a 5-level system used to measure observable functional communication of children with CP aged 4-18 years.[15] The levels range from Level I, where children are able to communicate independently with few or no difficulties, to Level V, where children have significant communication difficulties and others usually interpret this communication from the child’s movement and behaviour.

Cognitive Function

The Verbal Comprehension Index (VCI) of the Wechsler Intelligence Scale for Children – Fourth 4th Edition (WISC-IV) is a standardised assessment of verbal cognitive function for children aged 6-16 years.[14] Administration and scoring was completed according to the WISC-IV Australian Standardised edition.[14] The VCI in the Australian Standardised edition has a reliability coefficient of 0.94 and stability coefficient of 0.89. The WISC-IV was recommended for use with children with CP in the systematic review by Foo et al. [18]

Self-Concept

The *myTREEHOUSE Self-Concept Assessment* was designed to measure multidimensional self-concept for children with CP aged 8-12 years.[13] The instrument has two administration methods: a *Questionnaire Version* and a *Game Version*.[13] Self-concept is measured by the child's appraisal of their performance using a 4-point scale for 26-items across eight domains including *Social Skills*, *Physical Appearance*, *Learning Skills*, *Physical Abilities*, *Ability to Participate*, *Emotional Regulation*, *Personal Agency,* and *General Self*. Each domain is rated from three *Performance Perspectives*: *Personal, Social,* and *Perceived Performance*. For the purpose of this study, only the *Personal Performance Perspective* is reported because this perspective represents the child's internal reference of self-concept and so has the greatest theoretical alignment with self-reported QoL. Higher domain scores rated from the *Personal Performance Perspective* indicate higher self-concept. In the six domains that include three items, a high score is indicated by at least 8 points. In the two domains that include four items, i.e., *Social Skills* and *Ability to Participate,* 11 points or more indicates a high score.

In addition to appraising their performance, children also complete an *Importance Rating* using a 4-point scale ranging from 1 (low importance) to 4 (high importance).[13] The discrepancy between the *Importance Score* and the domain score rated from the *Personal Performance Perspective* for each item is then calculated and summed to achieve a *Personal Concern Score*. A higher *Personal Concern Score* indicates the child considers he/she is performing poorly in a domain on which he/she places high value ($\leq$7 points=*Low Concern*, 8-12 points=*Suspected Concerns*, and $\geq$13 points=*Definite Concerns*). The *Personal Performance Perspective* and *Importance Rating* has strong internal consistency (Cronbach's α=0.87, 0.84) and moderate test-retest reliability calculated using Intraclass Correlation Coefficient (ICC=0.71, 0.64).[13]

Quality of Life

The *CP QOL-Child* was used to measure multidimensional QoL. The *CP QOL-Child* includes two versions – a *Child Report Questionnaire* for children with CP aged 9-12 years and a *Primary Caregiver Questionnaire* for caregivers of children with CP aged 4-12 years.[19]

The *Child Report Questionnaire* is a child self-report tool that includes 53 items across five subscales, including: *Social Wellbeing and Acceptance, Feelings about Functioning, Participation and Physical Health, Emotional Wellbeing and Self-Esteem,* and *Pain and Impact of Disability*. Children respond using a 9-point rating scale with the exception of one question which is presented on a 5-point rating scale (i.e., 'Do you worry about who will take care of you in the future?'). Higher subscale scores represent a higher QoL, except for the *Pain and Impact of Disability* subscale where lower scores indicate a higher QoL. The *Child Report Questionnaire* has strong internal consistency across subscales (Cronbach's α=0.80-0.90).[10] In the current study, internal consistency was excellent across subscales, similar to the original data (Cronbach's α=0.83-0.93), with the exception of the *Pain and Impact of Disability* subscale, which showed moderate internal consistency (Cronbach's α=0.68) compared to a strong internal consistency in the original data (Cronbach's α=0.80).

The *Primary Caregiver Questionnaire* includes 65 items across seven subscales, including the five subscales from the *Child Report Questionnaire* plus two additional subscales to measure the caregivers' *Access to Services* for their child and overall *Family Health*. Response rating scales and scoring are identical to the *Child Report Questionnaire*. Also similar to the *Child Report Questionnaire*, higher subscale scores indicate higher QoL except for the *Pain and Impact of Disability* subscale where higher scores indicate a lower QoL. The *Primary Caregiver Questionnaire* has strong internal consistency (Cronbach's α=0.74-0.92), good test-retest reliability (ICC=0.76-0.89), and moderate correlations with the *Child Report Questionnaire* for the five corresponding subscales (r=0.52-0.77).[10] In our current study, the internal consistency fell within the same strength categories as the original data for all subscales (Cronbach's α=0.65-0.93).

Procedure

Eligible families were mailed a flier with brief information about the study and an expression of interest reply slip. A phone call was provided two weeks later to respond to questions and organise an appointment for interested families. Prior to participation, caregivers were required to provide written consent and children provided written or verbal assent. Caregivers completed the demographic questionnaire and the *CP QOL-Child Primary Caregiver Questionnaire*. Children completed the WISC-IV VCI with the first author (SKC) and if they met the inclusion criteria for cognitive function, they then continued with *myTREEHOUSE* and *CP QOL-Child Child Report Questionnaire*.

Statistical analysis

Data was analysed using SPSS (version 22). Descriptive analyses were used to summarise demographic information and scores for self-concept and QoL subscales. Assumption testing revealed that the data was not normally distributed, hence nonparametric tests were used. Wilcoxon Signed-Rank test were used to compare scores on the subscales that were in common between the *CP QOL-Child Child Report Questionnaire* and *Primary Caregiver Questionnaire*. Spearman's correlation coefficients were used to investigate the relationships between *myTREEHOUSE* domain scores rated from the *Personal Performance Perspective* and *Personal Concern Score*, with *CP QOL-Child* subscales. The strength of correlation coefficient relationships were rated according to the criteria proposed by Portney et al. [20] as: good ≥0.75, moderate = 0.50-0.74, fair = 0.26-0.49, and poor ≤0.25. A significance level of $p<0.05$ was used for all analyses.

RESULTS

Study invitations were sent to 400 eligible families in the recruitment area and 31 families agreed to participate. From these, six children did not meet the cognitive function inclusion criteria (VCI<70), leaving a final total of 25 participants aged 9-12 years (mean 11 years 5 months; standard deviation 1 year 2 months; GMFCS-E&R I-III; MACS I-IV; FCCS I-II; Table I). There was an equal distribution of children utilising the myTREEHOUSE *Questionnaire Version* (n=12) and the *Game Version* (n=13).

Distribution of *myTREEHOUSE Self-Concept Assessment* scores

Most children reported high self-concept scores across *myTREEHOUSE* domains when rated from the *Personal Performance Perspective* (Table II). For the *myTREEHOUSE Personal Concern Score,* most children scored within the *Low* (*n*=13, 52%) or *Suspected* (*n*=8, 32%) range. However, 16% of children scored within the *Definite Personal Concern* range (*n*=4). The total sample mean was 7.8 (SD=6.85).

Distribution of *CP QOL-Child* scores

Distribution of subscale scores for both the *Child Report Questionnaire* and the *Primary Caregiver Questionnaire* were indicative of overall positive QoL across the subscales (Table III). Compared to proxy-reported QoL from the primary caregiver, children reported significantly higher scores for two subscales: *Feelings about Functioning* (Z=-2.06, p=0.04) and *Participation and Physical Health* (Z=-2.25, p=0.02; Table III).

Relationship between Child-Reported Self-Concept and Child-Reported QoL

Most *myTREEHOUSE* domain scores rated from the *Personal Performance Perspective* were correlated with *CP QOL-Child Child Report Questionnaire* subscale scores in the predicted direction (Table IV). Moderate to fair positive correlations were shown between *myTREEHOUSE* domains across most *CP QOL-Child* subscales, except for *myTREEHOUSE General Skills* domain reporting no significant relationships.

The *myTREEHOUSE Personal Concern Score* showed a moderate negative correlation with all *CP QOL Child* subscales (r_s=-0.48- -0.57, all p<0.05) with the predicted exception of the *Pain and Impact of Disability* subscale which demonstrated a moderate inverse correlation (r_s=0.52, p<0.01).

Relationship between Child-Reported Self-Concept and Proxy-Reported QoL

Correlations between proxy-reported QoL and child-reported self-concept were weaker than those between child-reported QoL and self-concept (Table IV). Moderate correlations were seen for *myTREEHOUSE Emotional Regulation* and *General Self* domains with *CP QOL-Child* subscales of *Social Wellbeing and Acceptance* (r_s=0.42, p<0.05, and 0.52, p<0.01 respectively), and *Emotional Wellbeing and Self-Esteem* (r_s=0.47, p<0.05, and 0.59, p<0.01 respectively). A positive fair correlation between *myTREEHOUSE General Self* domain and *CP QOL-Child Participation and Physical Health* and *Feelings about Functioning* subscale was also observed (r_s=0.48, p<0.05, and 0.56, p<0.01 respectively). Fair correlations were seen for the *myTREEHOUSE Social Skills* domain with the *CP QOL-Child* subscales of *Social Wellbeing and Acceptance* (r_s=0.40, p<0.05). Fair correlations were reported between the *CP QOL-Child Participation and Physical Health* subscale and the *myTREEHOUSE Physical Appearance* (r_s=0.49, p<0.05). Fair correlations were also reported between the *CP QOL-Child Access to Service* subscale and the *myTREEHOUSE Ability to Participate* (r_s=0.42, p<0.05). The proxy-reported *CP QOL-Child Pain and Impact of Disability* and *Family Health* subscale was not significantly correlated with any *myTREEHOUSE* domains. The *myTREEHOUSE Personal Concern Score* was not significantly correlated to any *CP QOL-Child* subscales.

DISCUSSION

This study was the first to examine the relationship between self-concept and QoL using CP-specific assessments for preadolescent children with CP. As hypothesized, self-concept was positively correlated with the majority of QoL domains for this group of children. Our results show that the strength of the relationship between self-concept domains and QoL subscales varies according to domain and whether the QoL respondent is the child or caregiver. Consistent with previous studies that have utilised non-population-specific assessments for children with CP,[8, 9] we found many aspects of self-concept and QoL were associated; however the strength of these associations tended to be stronger than reported in previous research, perhaps due to the use of CP-specific assessments in this study. These findings deepen our understanding about how children with CP think about themselves with regards to self-concept and QoL. This knowledge can be used by clinicians to more accurately tailor support for children with CP and their families.

Most of the self-concept domains were correlated with child-reported QoL subscales for children in our cohort. The *myTREEHOUSE* domains of *Social Skills*, *Physical Abilities*, and *Physical Appearance* reported the strongest associations across all the *CP QOL-Child* subscales. This demonstrates that the child's perception of their performance in these three areas of self-concept is closely related to his/her evaluation of his/her position in life. Furthermore, a higher *Personal Concern Score* was consistently correlated with lower QoL across all *CP QOL-Child* subscales reported by the children. This shows that children who are experiencing difficulties with their 'perception of self' are also likely to be dissatisfied with their 'position in life'. These data highlight the need for further research on the assessment and management of self-concept concerns in children with CP in order to influence their QoL. Although it is not a standard practice in current clinical settings, findings from this study showed that a psychologist is a fundamental inclusion in a multidisciplinary team for the management of children with CP. Given the broad based nature of the self-concept domains, it is recommended that psychologists monitor the self-concept of children with CP on a regular basis because self-concept concerns can interfere with everyday functioning and social experiences. In typically developing children, lower self-concept is associated with behaviour[21] and mental health problems[22]. Thus, regular monitoring beginning from preadolescence for children with CP is recommended. Children presenting with *Suspected* or *Definite Personal Concern Score* on *myTREEHOUSE* should be provided with opportunities for psychological intervention.

Our findings demonstrate that higher *myTREEHOUSE* domain scores rated from the *Personal Performance Perspective* were only weakly associated with lower *CP QOL-Child Pain and Impact of Disability* subscale scores, which is low compared to the relationships with other *CP QOL-Child* subscales. The *CP QOL-Child Pain and Impact of Disability* subscale assesses two elements: (i) pain – the amount of pain and the level of discomfort experienced, and (ii) impact of disability – the resulting amount of disruption to daily living. Previous studies with children with CP have demonstrated that while experiences of pain are related to lower self-concept,[23] the severity of impairment as a result of CP is not related to self-concept.[2] These studies may explain the weak relationship between the *myTREEHOUSE* domains with the *CP QOL-Child Pain and Impact of Disability* subscale. Furthermore, Chong et al. [24] indicated that children with CP find alternative ways to meet their needs despite possible dissatisfaction with parts of their life that are affected by their disability. However, these weak correlations could also be a result of instrument construction. Psychometric data for original *CP QOL-Child* study, as well as from our sample show that the pain subscale has the weakest internal consistency values, much lower compared to other *CP QOL-Child* subscales, indicating that the items of this subscale tend not to be answered in a consistent manner by children with CP.

Our findings show that child-reported QoL was higher than proxy-reported QoL which is consistent with previous studies using the *CP QOL-Child*[10] as well as other health-related QoL instruments.[25] These inconsistencies in ratings between child- and proxy-report highlight the varying perceptions of children with CP and their caregivers in internal constructs like QoL and possibly self-concept. This is not surprising given that internal constructs rely on non-observable processes. Varni et al. [25] recommends that children's perception of their QoL should be utilised instead of proxy-report, especially for children who have the capacity for self-report. Given that a proxy (e.g., caregivers or clinicians) does not have access to the children's internal processes that generate the child's internal constructs like self-concept or QoL, it is highly unlikely that proxy-report will equate to the child's report. Thus, findings from this study further stress the importance of obtaining the child's report for internal constructs and the child's report should be prioritised over a proxy's report.

Although this study was limited by its relatively small sample size, it remains the first study to investigate both self-concept and QoL using population-specific assessments. Future investigation with a larger sample will allow for a regression model to include self-concept and QoL as well as other biopsychosocial factors to provide a holistic understanding of the factors that may interfere with self-concept development for children with CP.

CONCLUSION

This is the first study to use population-specific assessments to examine the relationship between self-concept and QoL. These findings stress the need to include self-concept assessment and intervention alongside QoL for children with CP. To achieve this, psychological services should be offered within multidisciplinary intervention programmes for children with CP and their families. Furthermore, the findings from this study also highlight the importance of obtaining the child’s report for internal constructs like self-concept and QoL.

References

1. Shavelson RJ, Hubner JJ, Stanton GC. Self-concept: Validation of construct interpertations. Review of Educational Research. 1976;46(3):407-41.
2. Cheong SK, Lang CP, Hemphill SA, Johnston LM. Self-concept of children with cerebral palsy measured using the CP-specific myTREEHOUSE Self-Concept Assessment. 2016, unpublished
3. World Health Organisation (WHO). WHOQOL Measuring Quality of Life: World Health Organization; 1997. Available from: http://www.who.int/mental_health/media/68.pdf.
4. Huebner ES. Research on assessment of life satisfaction of children and adolescents. Social Indicators Research. 2004;66:3-33.
5. Ferro MA, Boyle MH. Self-concept among youth with a chronic illness: A meta-analytic review. Health Psychology. 2013;32(8):839-48.
6. Dickinson HO, Parkinson KN, Ravens-Sieberer U, Schirripa G, Thyen U, Arnaud C, et al. Self-reported quality of life of 8-12-year-old children with cerebral palsy: A cross-sectional European study. Lancet. 2007;369:2171-8.
7. Shelly A, Davis E, Waters E, Mackinnon A, Reddihough D, Boyd R, et al. The relationship between quality of life and functioning for children with cerebral palsy. Developmental Medicine & Child Neurology. 2008;50:199-203.
8. Russo R, Goodwin EJ, Miller MD, Haan EA, Connell TM, Crotty M. Self-esteem, self-concept, and quality of life in children with hemiplegic cerebral palsy. The Journal of Pediatrics. 2008;153:473-7.
9. Soyupek F, Aktepe E, Savas S, Askin A. Do the self-concept and quality of life decrease in CP patients? Focussing on the predictors of self-concept and quality of life. Disability and Rehabilitation. 2010;32(13):1109-15.

10. Waters E, Davis E, Mackinnon A, Boyd R, Graham HK, Lo SK, et al. Psychometric properties of the quality of life questionnaire for children with CP. Developmental Medicine & Child Neurology. 2007;49:49-55.

11. Cheong SK, Lang CP, Hemphill SA, Johnston LM. What constitutes self-concept for children with CP? A Delphi consensus survey. Journal of Developmental and Physical Disabilities. 2016;28(2):333-46. Epub 9 Jan 2016.

12. Cheong SK, Johnston LM. Systematic review of self-concept measures for primary school aged children with cerebral palsy. Research in Developmental Disabilities. 2013;34:3566-75.

13. Cheong SK, Lang CP, Hemphill SA, Johnston LM, editors. myTREEHOUSE self-concept instrument: Preliminary psychometric validation. the Australasian Academy of Cerebral Palsy and Developmental Medicine 8th Biennial Scientific Conference; 2016; Adelaide, Australia.

14. Wechsler D. Wechsler Intelligence Scale for Children - Fourth Edition: Administration and scoring manual, Australian adaptation. New South Wales, Australia: Harcourt Assessment; 2003.

15. Caynes K, Burmester D, Barty E, Johnston LM. Concurrent validity of the functional communication classification system for cerebral palsy with the CELF-4 Pragmatic Profile. Developmental Medicine & Child Neurology. 2014;56:45-6.

16. Palisano R, Rosenbaum P, Bartlett D, Livingston M. GMFCS - E & R Gross Motor Function Classification System Expanded and Revised Canada: CanChild Centre for Childhood Disability Research; 2007 [cited 2014 26 November 2014]. Available from: http://motorgrowth.canchild.ca/en/gmfcs/resources/gmfcs-er.pdf.

17. Eliasson A-C, Krumlinde-Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall A-M, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. Developmental Medicine & Child Neurology. 2006;48(7):549-54.
18. Foo RY, Guppy M, Johnston LM. Intelligence assessments for children with cerebral palsy: A systematic review. Developmental Medicine & Child Neurology. 2013.
19. Waters E, Davis E, Boyd R, Reddihough D, Graham HK, Mackinnon A, et al. Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) manual. Melbourne: University of Melbourne; 2013.
20. Portney LG, Watkins MP. Foundations of clinical research: Applications to practice. 3rd Ed ed. New Jersey: Pearson Education Inc.; 2009.
21. Donnellan MB, Trzesniewski KH, Robins RW, Moffitt TE, Caspi A. Low self-esteem is related to aggression, antisocial behaviour, and delinquency. Psychological Science. 2005;16:328-35.
22. Emler N. The costs and causes of low self-esteem. Youth Studies Australia. 2002;21(3):45-8.
23. Russo R, Miller MD, Haan EA, Cameron ID, Crotty M. Pain characteristics and their association with quality of life and self-concept in children with hemiplegic cerebral palsy identified from a population register. Clinical Journal of Pain. 2008;24(4):335-42.
24. Chong J, Mackey AH, Broadbent E, Stott NS. Children's perceptions of their cerebral palsy and their impact on life satisfaction. Disability and Rehabilitation. 2012;34(24):2053-60.

25. Varni JW, Burwinkle TM, Sherman SA, Hanna K, Berrin SJ, Malcarne VL, et al. Health-related quality of life of children and adolescents with cerebral palsy: Hearing the voices of the children. Developmental Medicine & Child Neurology. 2005;47:592-7.

Tables Legend

Table I Participant characteristics

Table II Distribution of *myTREEHOUSE* domain scores rated from *Personal Performance Perspective* for this sample

Table III *CP QOL-Child* distribution and Wilcoxon Signed-Rank analyses for matched pair comparison between *Child Report Questionnaire* and *Primary Caregiver Questionnaire*

Table IV Spearman’s correlations coefficient between the *myTREEHOUSE* domain scores and the *CP QOL-Child* subscale scores

Table I: Participant characteristics

Characteristics	*N*=25 (%)
Gender	
Male	13 (52%)
Female	12 (48%)
Age	
9-year-old	3 (12%)
10-year-old	4 (16%)
11-year-old	9 (36%)
12-year-old	9 (36%)
GMFCS – E&R	
Level I	17 (68%)
Level II	6 (24%)
Level III	2 (8%)
Level IV	0 (0%)
Level V	0 (0%)
MACS	
Level I	6 (24%)
Level II	15 (60%)
Level III	2 (8%)
Level IV	2 (8%)
Level V	0 (0%)
FCCS	
Level I	17 (68%)
Level II	4 (16%)
Level III	4 (16%)
Level IV	0 (0%)
Level V	0 (0%)

Note: GMFCS-E&R: Gross Motor Function Classification System – Extended and Revised; MACS: Manual Ability Classification System; FCCS: Functional Communication Classification System

Table II: Distribution of *myTREEHOUSE* domain scores rated from *Personal Performance Perspective* for this sample

Self-concept domains	Possible test range (Min-Max)	Study sample		
		Mean (SD)	Range (Min-Max)	Low/high self-concept *n* (%)
Social Skills	4-16	13.1 (2.75)	7-16	1 (4%)/ 24 (96%)
Physical Appearance	3-12	9.2 (2.45)	3-12	5 (20%)/ 20 (80%)
Physical Abilities	3-12	10.0 (1.54)	7-12	2 (8%)/ 24 (92%)
Learning Skills	3-12	9.1 (2.04)	5-12	6 (24%)/ 19 (76%)
Ability to Participate	4-16	13.6 (2.14)	7-16	1 (4%)/ 24 (96%)
Emotional Regulation	3-12	9.5 (1.78)	5-12	4 (16%)/ 21 (84%)
Personal Agency	3-12	10.7 (1.68)	6-12	1 (4%)/ 24 (96%)
General Self	3-12	10.1 (1.61)	6-12	1 (4%)/ 24 (96%)

Table III: *CP QOL-Child* distribution and Wilcoxon Signed-Rank analyses for matched pair comparison between *Child Report Questionnaire* and *Primary Caregiver Questionnaire*

CP QOL-Child Subscales	Median		*Z*	*p*
	Child Report (*n*=25)	Primary Caregiver (*n*=25)		
Social Wellbeing and Acceptance	85.4	79.2	-0.07	0.94
Feelings about Functioning	83.0	71.9	-2.06	0.04
Participation and Physical Health	83.0	65.9	-2.25	0.02
Emotional Wellbeing and Self-esteem	87.5	81.3	-0.84	0.40
Pain and Impact of Disability	31.3	40.63	-0.20	0.84

Table IV: Spearman's correlations coefficient between the *myTREEHOUSE* domain scores and the *CP QOL-Child* subscale scores

Variables	*myTREEHOUSE Self-Concept Assessment* (r_s; *p*-value)								
	Domain scores rated from the *Personal Performance Perspective*								*Personal Concern Score*
	Social Skills	Physical Appearance	Learning Skills	Physical Abilities	Ability to Participate	Emotional Regulation	Personal Agency	General Self	
Child Report Questionnaire									
Social Wellbeing and Acceptance	0.74 *p*<0.001	0.46 *p*=0.02	0.51 *p*=0.009	0.63 *p*=0.001	0.52 *p*=0.008	0.42 *p*=0.04	0.39 *p*=0.054	0.17 *p*=0.41	-0.48 *p*=0.02
Feelings about Functioning	0.58 *p*=0.002	0.51 *p*<0.001	0.33 *p*=0.10	0.67 *p*<0.001	0.53 *p*=0.007	0.36 *p*=0.07	0.38 *p*=0.06	0.26 *p*=0.22	-0.57 *p*=0.003
Participation and Physical Health	0.66 *p*<0.001	0.58 *p*=0.002	0.47 *p*=0.02	0.71 *p*<0.001	0.43 *p*=0.03	0.55 *p*=0.004	0.41 *p*=0.04	0.36 *p*=0.08	-0.54 *p*=0.005
Emotional Wellbeing and Self-Esteem	0.76 *p*<0.001	0.52 *p*=0.008	0.62 *p*=0.001	0.62 *p*=0.001	0.57 *p*=0.003	0.37 *p*=0.07	0.43 *p*=0.03	0.14 *p*=0.49	-0.53 *p*=0.007
Pain and Impact of Disability	-0.31 *p*=0.13	-0.33 *p*=0.11	-0.35 *p*=0.09	-0.31 *p*=0.13	-0.36 *p*=0.07	-0.49 *p*=0.01	-0.40 *p*=0.05	-0.09 *p*=0.68	0.52 *p*=0.008
Primary Caregiver Questionnaire									
Social Wellbeing and Acceptance	0.40 *p*=0.05	0.24 *p*=0.24	0.24 *p*=0.24	0.02 *p*=0.95	0.20 *p*=0.34	0.42 *p*=0.03	0.38 *p*=0.06	0.52 *p*=0.007	-0.14 *p*=0.51
Feelings about Functioning	0.20 *p*=0.34	0.27 *p*=0.19	0.06 *p*=0.72	-0.03 *p*=0.87	0.23 *p*=0.27	0.19 *p*=0.36	0.29 *p*=0.16	0.48 *p*=0.02	-0.24 *p*=0.25
Participation and Physical Health	0.28 *p*=0.18	0.49 *p*=0.01	0.05 *p*=0.81	0.01 *p*=0.95	0.29 *p*=0.16	0.47 *p*=0.02	0.39 *p*=0.06	0.59 *p*=0.002	-0.37 *p*=0.07
Emotional Wellbeing and Self-Esteem	0.18 *p*=0.39	0.35 *p*=0.09	0.05 *p*=0.82	-0.05 *p*=0.82	0.21 *p*=0.31	0.31 *p*=0.14	0.31 *p*=0.13	0.56 *p*=0.004	-0.16 *p*=0.44
Pain and Impact of Disability	-0.02 *p*=0.92	-0.06 *p*=0.79	-0.21 *p*=0.31	-0.05 *p*=0.82	-0.36 *p*=0.08	-0.12 *p*=0.56	-0.14 *p*=0.51	0.01 *p*=0.98	0.19 *p*=0.35
Access to Services	0.33 *p*=0.11	0.32 *p*=0.12	0.32 *p*=0.12	0.17 *p*=0.41	0.42 *p*=0.04	0.33 *p*=0.11	0.32 *p*=0.12	0.08 *p*=0.72	-0.24 *p*=0.25
Family Health	0.32 *p*=0.13	0.34 *p*=0.10	0.29 *p*=0.16	-0.09 *p*=0.69	0.09 *p*=0.66	0.32 *p*=0.12	0.15 *p*=0.49	0.16 *p*=0.46	-0.15 *p*=0.47

Note: ■ *r*≥0.75; ▩ *r*=0.50-0.74; ▨ *r*=0.26-0.49

11.2. Conclusion

This is the first study to examine the relationship between self-concept and quality of life in a sample of children with CP aged 9-12 years, using CP-specific instruments. Children in this sample reported overall positive self-concept and quality of life. The findings from this study demonstrate that higher self-concept is associated with higher quality of life. The link between self-concept and quality of life demonstrated in this study indicates that children who are experiencing difficulties with their “perception of self” are also likely to be dissatisfied with their “position in life”. It is recommended that the assessment of self-concept to be included in standard practice for the management of children with CP alongside quality of life. In addition, children presenting with high self-concept concerns should be provided with opportunities for psychological intervention. Findings from this study also demonstrated inconsistent reporting of children’s quality of life between child-report and proxy-report. This further stresses the importance of obtaining and prioritising child-report during assessment as well as intervention planning. In view of the importance of psychological constructs, like self-concept, in the development of children with CP, it is recommended that psychologists be included in a multidisciplinary management team for children with CP.

Chapter 12. Overall Discussion

The main outcome of this research program has been the development of a new population-specific self-concept instrument for children with CP, called the *myTREEHOUSE Self-Concept Assessment*. This comprehensive population-specific self-concept instrument incorporates self-concept domains that are relevant and important to children with CP. *myTREEHOUSE* was used to explore the self-concept profile of preadolescent children with CP and to investigate factors that might be associated with self-concept for this group of children. In this chapter, the main findings from this research program, theoretical and clinical implications of the findings, study limitations, and recommendations for future research are presented.

12.1. Summary of Main Findings

The findings from each study are summarised and discussed in the following three sections: (i) review of existing literature (Study1); (ii) instrument development (Studies 2 and 3); and (iii) investigation of the self-concept of children with CP (Studies 4 and 5, see Figure 1.2).

12.1.1. Review of existing literature. A thorough review of the literature was conducted with reference to the rational-empirical approach for instrument construction (see Section 5.1, Figure 5.1) to determine if a suitable instrument was available for children with CP. Using a systematic review, the findings of Study 1 revealed five potential instruments that had psychometric data available for children with CP; however, a thorough analysis of this data using the COSMIN checklist (Mokkink, Terwee, Knol, et al., 2010) and the CanChild Outcome Measure Rating Form (Canchild Centre for Childhood Disability Research, 2004a) indicated that none of the instruments had sufficient psychometric data to recommend their use with children with CP.

Additionally, none of the instruments were designed using a “ground up” approach to specifically capture the needs of children with CP specifically.

While some instruments had been adapted with CP-specific modifications, it was not clear if these modifications sufficiently reflected the self-concept of children with CP. For example, with the Australian-modified version of the Self-Perception Profile for Children, only content validity was reported based on eight children with CP (Ziebell, 2007). Llewellyn and Chung (1997) suggest that children with physical disabilities, such as children with CP, may perceive themselves and their environment differently from TD children, leading to a unique sense of self-concept. Thus, continued use of instruments designed for TD children may inadvertently miss important aspects of self-concept for children with CP, or overemphasise aspects that may not be important to children with CP. Following the systematic review, it was evident that a suitable population-specific self-concept instrument was not available.

12.1.2. Instrument development. The first component of instrument development sought to clarify whether the construct of self-concept for children with CP is the same as TD children and, therefore, whether a population-specific self-concept instrument was needed. Study 2 sought empirical evidence to identify self-concept items and domains that were relevant to children with CP by using a 3-round Delphi consensus survey. The study’s participants included professionals familiar with children with CP, caregivers of children with CP, and children with CP themselves. The study’s results showed that over 80% of items prioritised in the Delphi process were similar to those included in instruments for use with TD children. However, several unique items were identified as important by the participant groups that were not evident in existing instruments developed for TD children. It was proposed that the inclusion of these additional CP-specific items could improve the evaluation of self-concept for children with CP. Given the number of additional items unique to children with CP, it was determined that adapting an instrument designed for TD children would not be sufficient to accurately measure the self-concept of children with CP, and thus a CP-specific self-concept instrument was required.

To this end, a population-specific self-concept instrument called the *myTREEHOUSE Self-Concept Assessment* was developed. Item development for this instrument began with items that were deemed relevant and important in representing the self-concept of children with CP aged 8-12 years through the Delphi consensus survey. These items included those that were identified in measures for TD children, and CP-specific items drawn from a participant-generated set. New items were also developed in discussion with the supervisory team. The new suite of items was themed to form a series of meaningful domains. Shared items with TD children were grouped into five domains including *Social Skills, Learning Skills, Physical Appearance, Emotional Regulation*, and *General Self*. New CP-specific domains were created including *Physical Abilities, Personal Agency,* and *Ability to Participate*. The final *myTREEHOUSE* instrument included 26 items divided into these eight domains. Self-concept is measured by the child's appraisal of their performance for each item from three *Performance Perspectives*: *Personal, Social,* and *Perceived*. Each item also includes an *Importance Rating* which is the child's rating of how important the item is to him/her. In addition to the *Performance Perspective* domain scores, *myTREEHOUSE* produces the *Personal Concern Score* which can be obtained by totalling the difference between the *Importance Rating* and the *Personal Performance Perspective* score for each item.

After the development of *myTREEHOUSE*, an evaluation of its validity and reliability was undertaken in Study 3. Face and content validity testing included the ratings of an expert panel in order to assess construct and content validity as well as clinical utility. Face and content validity were supported by the expert panel. The expert panel made suggestions to clarify the wording of some items which led to changes to the instrument structure (see Section 8.2, Figures 8.1 and 8.2). Following these amendments, *myTREEHOUSE* displayed strong internal consistency (Cronbach's α=0.84-0.91) and moderate to good test-retest reliability (ICC=0.70-0.75) across *Performance Perspectives*. Based on these preliminary psychometric analyses, *myTREEHOUSE* is valid and reliable for the assessment of self-concept in children with CP aged 8-12 years and thus suitable for research with this population. However, further psychometric testing is recommended prior to the utilisation of *myTREEHOUSE* clinically.

12.1.3. Investigation of the self-concept of children with cerebral palsy.

Following preliminary validation of *myTREEHOUSE,* the instrument was utilised in Studies 4 and 5 to investigate the self-concept of children with CP. First, in Study 4, a profile of self-concept for children with CP was presented in relation to age, gender, and motor, communication, and cognitive function. Most children reported overall positive self-concept as demonstrated by high self-concept domain scores rated from the *Personal, Social,* and *Perceived Performance Perspectives*. Self-concept was not found to be associated with age or gender nor with gross motor, fine motor, or communication functions. However, self-concept domain scores rated from the *Personal Performance Perspective* did vary for children with different cognitive functioning in the *Social Skills* and *Learning Skills* domains. These findings were positive, indicating that most primary and accompanying impairments experienced by children with CP are not direct determinants of their self-concept. The only exception was cognitive function, which appeared to influence some aspects of self-concept in this sample.

The final study investigated the relationship between self-concept and quality of life for children with CP. The innovative element of this study was that it was the first study to use two CP-specific instruments: the newly developed *myTREEHOUSE* and the existing *CP QOL-Child* with children with CP and their caregivers. According to the child-report, higher *myTREEHOUSE* domain scores from the *Personal Performance Perspective* were associated with higher *CP QOL-Child* subscale scores. Moreover, a higher *Personal Concern Score* for children in this study was associated with lower quality of life across all *CP QOL-Child* subscales. Consistent with previous studies, results from this study also found that child-reported quality of life across most *CP QOL-Child* subscales was higher than proxy-reports.

12.1.4. Summary. Overall the aims of this research program were achieved. The most notable outcome of this research program was the development and validation of *myTREEHOUSE*, the only population-specific self-concept instrument for children with CP aged 8-12 years. This instrument obtained the first self-concept profile for children with CP which takes into consideration essential elements of self-concept for this population. Furthermore, by using two population-specific instruments, the findings in the final study strengthen the evidence for the positive relationship between self-concept and quality of life for children with CP.

12.2. A New Self-Concept Instrument

The details of the newly developed *myTREEHOUSE* instrument for children with CP have been described extensively in Chapter 8. However, *myTREEHOUSE* includes several unique features that do not exist in most self-concept instruments that are worthy of additional consideration.

First, *myTREEHOUSE* is based on a new framework for conceptualising self-concept – the *Self-Concept Feedback Loop* – proposed for this thesis. This was designed to extend the original ideas of self-concept that were informed by the works of James (1890/1950), C. H. Cooley (1902/1964), and Mead (1934) along with the more contemporary theories of Shavelson et al. (1976) and Harter (1982; see Section 2.1.5, Figure 2.3). Furthermore, this framework includes the potential impact of disabilities such as CP on self-concept development (see Section 3.3.2, Figure 3.3). Incorporating the multidimensional feature of the *Self-Concept Feedback Loop, myTREEHOUSE* includes self-concept domains specific to children with CP that were identified through a consensus survey.

Second, *myTREEHOUSE* evaluates self-concept from three *Performance Perspectives – Personal, Social,* and *Perceived*. Most existing self-concept instruments do not examine *Performance Perspectives* independently, rather combining the perspectives loosely. Isolating the *Performance Perspectives* allows clinicians to identify the children's perception of the specific aspect(s) of their lives that impact their self-concept and subsequently streamline intervention to target this specific aspect(s). Furthermore, *myTREEHOUSE* is the first instrument to include the *Perceived Performance Perspective*, in addition to the two conventional perspectives; the *Personal* and *Social Performance Perspectives*. For children with a disability like CP, the *Perceived Performance Perspective* is likely to play a significant role in their life. As children master the skill of perspective taking around the ages of 6-8 (Selman & Byrne, 1974), they absorb the judgements of others and incorporate this knowledge in their evaluation of self-concept (C. H. Cooley, 1902/1964; Damon & Hart, 1982; Harter, 2006; Shavelson et al., 1976). From the time of the initial CP diagnosis, children are routinely scrutinised by clinicians and caregiver/s in relation to their proficiency across many areas of performance. Comments about their abilities are often made in their presence and this has a high potential to impact on their self-concept. The reality of constant judgement highlights the critical need to examine the *Perceived Performance Perspective* for children with CP, which may be less critical for many TD children. This feature of *myTREEHOUSE* enables users to evaluate the impact of the child's perceptive of others' judgements on the overall self-concept of these children.

Third, *myTREEHOUSE* produces a *Personal Concern Score* that highlights the potential severity of the self-concept concerns experienced by an individual child. The *Personal Concern Score* is calculated as the sum of the difference between the *Importance Rating* and the *Personal Performance Perspective* score for each item. The *Personal Concern Score* is consistent with James's (1890/1950) argument that self-concept is a balance between pretension – reflected in the *Importance Rating* – and success – reflected in the *Personal Performance Perspective*. Dissonance between pretension and success may lead to self-concept concerns. The notion of an importance rating was first introduced in the Self-Perception Profile for Children (Harter, 1985) but, because the importance rating is measured in a supplementary form in this instrument, it is not often reported. In contrast, *myTREEHOUSE* completes the *Importance Rating* for all items, in conjunction with the evaluation component.

Evaluation of self-concept which uses the three *Performance Perspectives* in addition to the *Personal Concern Score* provides an individualised profile of self-concept for each child. Given that the impairments experienced by children with CP vary between individuals, a certain level of individuality in assessment is necessary to assist clinicians to identify the specific needs of a child. O'Mara, Marsh, Craven, and Debus (2006) recommend that self-concept interventions are most effective when they target specific difficulties. *myTREEHOUSE* allows the identification of potential self-concept concerns in specific domains that are the sources of the child's concerns.

A final unique feature of *myTREEHOUSE* is the inclusion of alternative administration methods – a *Questionnaire Version* and a *Game Version* – which are suited for children who have different levels of motor and/or communication impairments. The use of such methods allows many more children to self-report without needing their caregivers for translation and/or interpretation. The *Questionnaire Version* is suitable for children with good motor and reading skills who can respond using a paper-and-pencil questionnaire. The *Game Version* caters to children who may be slightly younger, or who experience motor, visual, cognitive, communication, or learning difficulties. Presenting the instrument in a game format using pictorial cues streamlines administration time and engages children who may not be able to complete a 104-item questionnaire. The dual administration options of *myTREEHOUSE* thus accommodate children with CP with a wide range of abilities. These features are consistent with the recommendations proposed by Stone and Lemanek (1990) for effective assessment with children.

Overall, *myTREEHOUSE* uses a new framework to conceptualise and evaluate self-concept for preadolescent children with CP, which includes population-specific domains evaluated from multiple perspectives. From a clinical perspective, *myTREEHOUSE* can be potentially used as a screening instrument that detects self-concept concerns using the *Personal Concern Score*. These unique features of *myTREEHOUSE* offer the potential of a comprehensive assessment of self-reported self-concept for children with CP aged 8-12 years.

12.3. Theoretical Implications

As a result of this research program, a new framework to conceptualise self-concept was developed, termed the *Self-Concept Feedback Loop*. A basic self-concept framework, described in Chapter 1 (see Section 1.1, Figure 1.1), was derived from evidence gathered from existing self-concept theories. This basic framework was refined in Chapter 2 to incorporate the *Multidimensional* and *Evaluative* features of self-concept for this research program (see Section 2.1.5, Figure 2.3). This framework also accommodates the impact of CP-related impairments on the self-concept of children in this population (see Section 3.3.2, Figure 3.3).

It was proposed earlier in this research program that impairments experienced by children with CP may influence their self-concept (see section 3.3.2, Figure 3.3); however, findings from Study 4 indicated that the severity of the impairments experienced by children with CP may not be linearly related with self-concept. This means that improving CP-related functioning alone is unlikely to effectively address self-concept concerns. Rather, impairments experienced by children with CP may produce a different range and intensity of environmental participation, resulting in an indirect influence on their self-concept. Thus, children's self-concept is not just impacted by themselves but also by their environment.

According to Imms et al. (2015), an encouraging environment is likely to engender participation; participation increases competence which fosters stronger self-concept (see Section 3.3.1, Figure 3.2). While the current suite of available interventions for children with CP emphasise addressing physical impairments, the findings of this research program suggest that this form of intervention alone may be insufficient to address self-concept concerns. Instead, a holistic intervention is necessary, one which focuses on multiple personal, family, and environmental aspects to foster healthy development of self-concept.

This framework for conceptualising self-concept has potential application to a wider population, including children with other disabilities and, possibly, even TD children. When applying this framework to other groups, it is crucial to consider the relevant personal and environmental characteristics that are experienced by these children that may likely influence the *Self-Concept Feedback Loop*.

12.4. Clinical Implications

This thesis has produced two key clinical recommendations. First, whenever possible, the self-report of the children should be prioritised when information about self-concept is gathered. Second, in order to obtain self-report from children with a disability such as CP, instruments need to be designed to be both child- and disability-friendly.

The importance of child self-reporting has been recommended by previous researchers (Dunn et al., 2007, 2009; Huebner, Brantley, Nagle, & Valois, 2002; Rajmil et al., 2013; Varni et al., 2005) and findings from this research program are consistent with these recommendations. The findings from the Delphi consensus survey in Study 2 demonstrated that while there was much overlap between the participant groups, child participants provided suggestions for distinctive areas of self-concept that were later acknowledged to be important by participants during the consensus process. Furthermore, when assessing the quality of life for children with CP in Study 5, children reported higher quality of life in several areas compared to proxy-report. These findings strongly suggest that children’s perception of their self-concept and quality of life differed from the proxy’s perception of their experience. Child-reporting in the assessment of internal constructs is essential because the conceptualisation of these constructs is developed from thought processes that are inaccessible to others (Damon & Hart, 1982; see Section 2.2).

To enable self-reporting, instruments should be child-friendly and, in the case of instruments designed for children with a disability, disability-friendly. Self-reporting from children with CP is only possible if instruments can be accessed and can accommodate the physical and communication impairments experienced by these children. Direct access to the instrument is particularly important in measures of self-concept because the physical presence of others, especially significant others, may influence the child's ratings in an effort to present socially desirable responses (Blascovich & Tomaka, 1991). Having used non-population-specific self-concept instruments for children with CP in research, Wright et al. (2005) and McGibbon et al. (2009) observed that the administration methods and item presentation in these instruments were not always accessible and suitable for this population. This highlights the value of the dual administration method offered by *myTREEHOUSE* – the *Questionnaire Version* and the *Game Version* – which provides a greater number of children with varying ability level the opportunity to report on their self-concept.

Although the focus of this research program is children with CP, clinical implications inferred from the findings can potentially be applied to other disability groups. Thus, to facilitate assessment using children's self-reporting and to mitigate the impact of impression management, instruments need to be designed to be child- and disability-friendly. This will allow for independent access by children, taking into consideration their impairments.

12.5. Strengths and Limitations of the Research Program

The strengths and limitations for each study have been addressed in the corresponding chapters; however, a number of aspects are worthy of further consideration. The first strength is the use of the Delphi consensus survey in Study 2. This study is one of the few Delphi studies to have included child participants. Given the nature of self-concept as an internal construct, the inclusion of children's perspectives was vital and strengthens the findings of this study and the subsequent development of *myTREEHOUSE*. Only a few prior Delphi studies have included individuals with CP as part of the expert panel (Batavia & Hammer, 1990; McIntyre et al., 2010; Vargus-Adams & Martin, 2009, 2010). Of those, only the studies by Vargus-Adams and Martin (2009, 2010) have included children with CP.

The second strength is the use of face-to-face contact with child participants for data collection. Face-to-face contact was used for all studies that involved child participants. This method of data collection was chosen over other forms of contact (e.g., telephone, video conference) to reduce the potential influence of a caregiver's presence on the child's ratings (Blascovich & Tomaka, 1991). Data collection was always conducted with a caregiver on-site, but without a caregiver present in the testing area to potentially influence the child's responses. When a child participant requested the presence of their caregiver, caregivers were asked to present a neutral facial expression throughout the session to minimise any influence on the child's responses.

A final strength of this research program is the use of test-retest reliability as part of the psychometric testing. Findings from the systematic review (Study 1) revealed that test-retest reliability is rarely reported for children with CP on self-concept measures. To date, only Dodd et al. (2004) provided test-retest reliability data while other studies mainly reported internal consistency (Manuel et al., 2003; Schuengel et al., 2006; von der Luft, Harman, et al., 2008). The current psychometric testing, which included both internal consistency and test-retest reliability, provides stronger reliability testing of *myTREEHOUSE* than has been calculated for previous self-concept measures for children with CP.

An overall limitation of this research program was sample size and distribution, which consequently limited the statistical robustness of some studies and the generalisability of study findings to the greater CP population. Two factors that contributed to the small sample sizes across studies were the use of strict inclusion and exclusion criteria for child participants and the use of repeat assessments.

First, the use of strict inclusion and exclusion criteria for child participants restricted the number of ***potential*** participants. This involved the exclusion of children with severe cognitive impairment and the inclusion of children with independent functional communication. Both criteria were necessary to ensure that participants possessed the cognitive and language capacity to "perceive the self" and engage in valid self-concept evaluation (von der Luft, DeBoer, et al., 2008). Despite the importance of these criteria for self-concept research for children with CP, very few studies provide information regarding these criteria. Of the few studies that utilised cognitive and/or communication exclusion/inclusion criteria, some studies reported using standardised measures (Manuel et al., 2003; Russo, Goodwin, et al., 2008; Russo, Miller, et al., 2008) while others used proxy-reporting (Shields et al., 2007; Soyupek et al., 2010). Therefore, screening for inclusion and exclusion criteria using standardised assessments (in this case, the WISC-IV VCI to ascertain cognitive function and the FCCS to categorise functional communication) protected the integrity of these studies' samples. Although cognitive and communication impairments are common in children with CP, resulting in reduced numbers of eligible participants, the importance of these criteria outweighed the disadvantages and thus, both criteria were retained.

Second, many families found it difficult to commit to the necessary face-to-face repeat assessments. Repeated measures methodology was a shared feature of the Delphi consensus survey (Study 2) and the test-retest reliability (Study 3). Preadolescent children with CP are often involved in multiple health treatments, including allied health therapy (e.g., speech therapy, occupational therapy, and physiotherapy) and follow-up surgery, in addition to school-related commitments. These commitments saturated their weekly schedules. Therefore, a commitment to multiple face-to-face appointments within a restricted time period for research purposes was difficult for some families. Furthermore, geographical distance also restricted the participation of families living in remote areas. Queensland has a relatively large area compared to most other states in Australia. Recruitment was extended to families in most major cities along the coast from the south to far north Queensland. Thus, families who juggle multiple commitments or who are living in remote areas may have found participation in research too impractical for their family.

The robustness of statistical analyses for several studies may have been limited by the small samples. First, given the small sample of 50 children with CP, only preliminary psychometric analyses were conducted in Study 3. Although initially planned, factor analyses to confirm the *myTREEHOUSE* domains could not be conducted. Second, assumption testing revealed that the data in Studies 4 and 5 was not normally distributed. Although the assumption of normality was not intact for the Study 4 sample, parametric tests were used because the sample size was above 50 for each comparison and parametric tests are robust at N>30 (Field, 2005). Nonetheless, nonparametric statistical analyses were also performed for Study 4 and a detailed investigation of both analysis types revealed similar findings (see Appendix G). For Study 5, where the sample size was smaller, statistical analyses were restricted to nonparametric tests.

The second limitation is the distribution of the samples. Analysis of the distribution of motor severity within each sample demonstrated that children with GMFCS Levels IV and V were underrepresented in comparison to population statistics for individuals with CP in Australia (Australian Cerebral Palsy Register Group, 2013). Therefore, the findings from this research program may not be generalisable to children with CP with severe motor impairments. Given the strict exclusion criteria for individuals with cognitive and communication impairment, children with CP with severe motor impairment were naturally excluded because severe motor impairment is often present with more severe accompanying impairments (i.e., communication and cognitive impairments).

Overall, despite having personally contacted over 400 families, recruiting child participants was the most challenging aspect of the research program, resulting in a modest sample size for several studies. Regardless, a clear strength of the research program was the inclusion of child participants in the development phase of the instrument. Despite the challenges of recruitment, this research program offers stronger psychometric testing of *myTREEHOUSE* than is seen in most instrument-development studies involving children with CP. The overall sample was sufficient to achieve the aims of this research program and protect the integrity of the methodology employed for each study.

12.6. Future Directions

This research program introduced a new framework to conceptualise self-concept and developed *myTREEHOUSE* based on the *Self-Concept Feedback Loop*. Being the first CP-specific self-concept instrument provides an opportunity to investigate the self-concept of children with CP with greater accuracy. Despite the achievements of this research program, there are two areas of research that urgently require attention. These are further development of the CP-specific self-concept instrument and the extension of self-concept research with the CP population.

Extending the psychometric analysis of *myTREEHOUSE* is the most crucial aspect of this research program requiring expansion. Due to the modest sample size, only preliminary psychometric data was obtained. Future investigation with a larger sample will allow for the evaluation of construct validity using factor analysis to confirm the proposed domains. Furthermore, it will also be valuable to widen the coverage of research to include children with varying ranges of *Personal Concern Score* to provide a greater breadth of normative data.

The development of appropriate self-concept instruments is necessary for other age groups. Since CP is a lifelong condition, the impact of CP-related impairments is not present only during childhood but is experienced throughout life. Continued assessment beyond preadolescence is vital. Self-concept issues can occur at any point of life as individuals interact with their environment (Harter, 2012a). For example, transitional periods in life (e.g., transition between primary and high school, or from school to work) and traumatic events (e.g., death of a significant person, major medical decisions) are crucial developmental events that may trigger self-concept concerns. The availability of suitable instruments across the lifespan would allow clinicians to capture concerns that are appropriate for specific life stages. A youth version, for example, may incorporate domains important in the transition from school to post-school environments. Given the permanent nature of CP, social experiences for individuals with CP are likely to always differ from TD individuals. Therefore, the assessment of self-concept using instruments developed for TD populations seems inappropriate, regardless of the age of the individual with CP. Likewise, it is not advisable to adopt the current instrument for older children because salient self-concept domains and characteristics that are relevant to the individual change concurrent with developmental stages and increased social experiences (Harter, 2012a; Shavelson et al., 1976). However, using this research program as a guide, researchers could utilise a Delphi consensus survey to identify the CP-specific self-concept domains that are relevant to adolescents and adults. The findings of such future research would allow for the development of a CP-specific instrument for older populations.

The development of *myTREEHOUSE* highlighted the importance of using a “ground up” approach that includes the opinion of the instrument’s target users (Terwee et al., 2007) – in this case, children with CP – especially for measuring internal constructs, such as self-concept. The Delphi consensus survey conducted in Study 2 provided children with the opportunity to express their opinion independently of authority figures, such as caregivers, teachers, or clinicians. This produced insight into the elements of self-concept for this target population. This approach can be the basis for instrument development with other disability populations. The Delphi consensus survey that was utilised in this research program, or other qualitative methodologies, could be applied to identify features unique to the target construct, taking into account characteristics of individuals with a specific disability.

Our knowledge about self-concept for children with CP can be extended by exploring other factors that contribute to self-concept for children with CP. This can be done using a comprehensive ICF biopsychosocial approach (WHO, 2002). A quality of life study using a biopsychosocial approach by Chen et al. (2014) found that contextual factors such as family impact, family coping patterns, and caregiver parenting stress, play a significant role in predicting quality of life. This is in addition to health-related matters. A study of the relationship between self-concept and *Personal* and *Environmental Contextual Factors* using the ICF framework may guide interventions by clinicians in order to target relevant and specific areas that promote self-concept for children with CP.

Overall, these recommendations for future research can strengthen the psychometric properties of *myTREEHOUSE* and eventually extend the use of this instrument beyond research-related purposes. The availability of this instrument in clinical settings can enhance the assessment of self-concept and promote early identification of self-concept concerns for children with CP. Increased knowledge about self-concept for individuals with CP can assist with the amelioration of self-concept concerns as well as identifying interventions to promote stronger self-concept.

12.7. Conclusion

The most notable outcome of this research program is the development of the first population-specific self-concept instrument for children with CP aged 8-12 years – the *myTREEHOUSE Self-Concept Assessment*. Using *myTREEHOUSE,* the first profile of the self-concept of preadolescent children with CP was presented. Furthermore, using two population-specific instruments – *myTREEHOUSE* and *CP QOL-Child* – the final study provided a deeper understanding about how children with CP perceive their self-concept and quality of life.

This research program has highlighted several key elements regarding self-concept and assessment involving children with disability. Through this research program, a new conceptual framework for self-concept development has been proposed in the *Self-Concept Feedback Loop*, which takes into account the impairments experienced by children with CP. The *Self-Concept Feedback Loop* has provided a way of understanding the integration of the processes involved in the development of self-concept. This framework has also been used to underpin the development of *myTREEHOUSE*. In addition, findings from several studies have highlighted the importance of child-reporting in the assessment of internal constructs, such as self-concept. In order to obtain child-reporting of self-concept for children with CP, *myTREEHOUSE* has been designed to be child- and disability-friendly for these children. For now, this instrument provides the most comprehensive evaluation of self-concept for children with CP aged 8-12 years.

References

Adamson, L. (2003). Brief-report - Self-image, adolescence, and disability. *American Journal of Occupational Therapy, 57,* 578-581.

Anderson, J. R., & Gallup, G. G. (2015). Mirror self-recognition: A review and critique of attempts to promote and engineer self-recognition in primates. *Primates, 56*, 317-326.

Andrews, J. D. (1991). Integrative psychotherapy of depression: A self-confirmation approach. *Psychotherapy, 28*(2), 232-250.

Australian Cerebral Palsy Register [ACPR] Group. (2009). *Report of the Australian Cerebral Palsy Register, Birth Years 1993-2003*. Australia: Australian Cerebral Palsy Register.

Australian Cerebral Palsy Register Group. (2013). Australian Cerebral Palsy Register report 2013. Australia: Australian Cerebral Palsy Register.

Bartlett, D. J., Galuppi, B., Palisano, R. J., & McCoy, S. W. (2015). Consensus classifications of gross motor, manual ability, and communication function classification systems between therapists and parents of children with cerebral palsy. *Developmental Medicine & Child Neurology, Letter to the Editor*, 98-99. doi: 10.1111/dmcn.12933

Barty, E., & Caynes, K. (2009). *Development of the Functional Communication Classification System*. Paper presented at the Proceedings of the 3rd International Cerebral Palsy Conference, Sydney, Australia.

Batavia, A. I., & Hammer, G. S. (1990). Toward the development of consumer-based criteria for the evaluation of assistive devices. *Journal of Rehabilitation Research, 27*(4), 425-436.

Baumeister, R. F., Tice, D. M., & Hutton, D. G. (1989). Self-presentational motivations and personality differences in self-esteem. *Journal of Personality, 57*(3), 547-579.

Beck, J. S., Beck, A. T., Jolly, J. B., & Steer, R. A. (2005). *Beck Youth Inventories* (2nd ed.). Texas: Harcourt Assessment, Inc.

Blascovich, J., & Tomaka, J. (1991). Measures of self-esteem. In J. P. Robinson, P. R. Shaver & L. S. Wrightsman (Eds.), *Measures of personality and social psychological attitudes* (Vol. Volume I of meausres of social psychological attitudes, pp. 115-160). California: Academic Press.

Bracken, B. A. (1992). *Multidimensional Self Concept Scale*. Texas: PRO-ED.

Brinthaupt, T. M., & Lipka, R. P. (1985). Developmental differences in self-concept and self-esteem among kindergarten through twelfth grade students. *Child Study Journal, 15*(3), 207-220.

Bullock, M., & Lutkenhaus, P. (1990). Who am I? Self-understanding in toddlers. *Merrill-Palmer Quarterly, 36*(2), 217-238.

Buss, A. H. (2012). *Pathways to individuality: Evolution and development of personality traits*. Washington: American Psychological Association.

Butler, R. (1998). Age trends in the use of social and temporal comparison for self-evaluation: Examination of a novel developmental hypothesis. *Child Development, 69*(4), 1054-1073.

Butler, R. J., & Gasson, S. L. (2005). Self esteem/self concept scales for children and adolescents: A review. *Child and Adolescent Mental Health, 10*(4), 190-201. doi: 10.1111/j.1475-3588.2005.00368.x

Byrne, B. M. (1996). *Measuring self-concept across the life span: Issues and instruments*. Washington: American Psychological Association.

Byrne, B. M. (2002). Validating the measurement and structure of self-concept: Snapshots of past, present, and future research. *American Psychologist*, 897-909.

Campbell, J. (1990). Self-esteem and clarity of the self-concept. *Journal of Personality and Social Psychology, 59*(3), 538-549.

Canchild Centre for Childhood Disability Research. (2004a). Outcome measures rating form. Retrieved 17 July 2012, from https://www.canchild.ca/system/tenon/assets/attachments/000/000/372/original/measrate.pdf

CanChild Centre for Childhood Disability Research. (2004b). Outcome measures rating form guidelines. Retrieved 17 July 2012, from https://www.canchild.ca/system/tenon/assets/attachments/000/000/371/original/measguid.pdf

Caynes, K., Burmester, D., Barty, E., & Johnston, L. M. (2014). Concurrent validity of the functional communication classification system for cerebral palsy with the CELF-4 Pragmatic Profile. *Developmental Medicine & Child Neurology, 56*, 45-46.

Chen, K.-L., Tseng, M.-H., Shieh, J.-Y., Lu, L., & Huang, C.-Y. (2014). Determinants of quality of life in children with cerebral palsy: A comprehensive biopsychosocial approach. *Research in Developmental Disabilities, 35*, 520-528.

Cheong, S. K., & Johnston, L. M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities, 34,* 3566-3575.

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016a). *myTREEHOUSE self-concept instrument: Preliminary psychometric validation.* Paper presented at the the Australasian Academy of Cerebral Palsy and

Developmental Medicine 8th Biennial Scientific Conference, Adelaide, Australia.

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016b). *Self-concept of children with cerebral palsy measured using the CP-specific myTREEHOUSE Self-Concept Assessment: An exploratory study*. Manuscript submitted for publication.

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016c). What constitutes self-concept for children with CP? A Delphi consensus survey. *Journal of Developmental and Physical Disabilities, 28*(2), 333-346. doi: 10.1007/s10882-015-9471-z

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2017). myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy. *Developmental Medicine & Child Neurology, 59*(6), 655-660. doi: 10.1111/dmcn.13392

Chong, J., Mackey, A. H., Broadbent, E., & Stott, N. S. (2012). Children's perceptions of their cerebral palsy and their impact on life satisfaction. *Disability and Rehabilitation, 34*(24), 2053-2060. doi: 10.3109/09638288.2012.669021

Cohen, R. J., & Swerdlik, M. E. (2010). *Psychological testing and assessment: An introduction to tests and measurement* (7th ed.). New York, USA: McGraw-Hill.

Cole, D. A., Maxwell, S. E., Martin, J. M., Peeke, L. G., Seroczyniski, A. D., Tram, J. M., . . . Maschman, T. (2001). The development of multiple domains in child and adolescent self-concept: A cohort sequential longitudinal design. *Child Development, 72*(6), 1723-1746.

Cooley, C. H. (1902/1964). *Human nature and the social order*. New York: Schocken Books.

Cooley, W. C., & Committee on Children With Disabilities. (2004). Providing a primary care medical home for children and youth with cerebral palsy. *Pediatrics, 114*(4), 1106-1113. doi: 10.1542/peds.2004-1409

Coopersmith, S. (1967). *The antecedents of self-esteem*. California: Consulting Psychologists Press.

Damon, W., & Hart, D. (1982). The development of self-understanding from infancy through adolescence. *Child Development, 53,* 841-864.

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

Dodd, K. J., Imms, C., & Taylor, N. F. (2010). *Physiotherapy and occupational therapy for people with cerebral palsy: A problem-based approach to assessment and management*. London: Mac Keith Press.

Dodd, K. J., Taylor, N. F., & Graham, H. K. (2004). Strength training can have unexpected effects on the self-concept of children with cerebral palsy. *Pediatric Physical Therapy, 16*(2), 99-105.

Donnellan, M. B., Trzesniewski, K. H., Robins, R. W., Moffitt, T. E., & Caspi, A. (2005). Low self-esteem is related to aggression, antisocial behaviour, and delinquency. *Psychological Science, 16,* 328-335. doi: 10.1111/j.0956-7976.2005.01535.x

Dunn, N., Shields, N., Taylor, N. F., & Dodd, K. J. (2007). A systematic review of the self-concept of children with cerebral palsy and perceptions of parents and teachers. *Physical & Occupational Therapy in Paediatrics, 27*(3), 55-71. doi: 10.1300/J006v27n03_05

Dunn, N., Shields, N., Taylor, N. F., & Dodd, K. J. (2009). Comparing the self concept of children with cerebral palsy to the perceptions of their parents. *Disability and Rehabilitation, 31*(5), 387-393. doi: 10.1080/13682820802052125

Eder, R. A. (1990). Uncovering young children's psychological selves: Individual and developmental differences. *Child Development, 61*, 849-863.

Eisbach, A. D. (2004). Children's developing awareness of diversity in people's trains of thought. *Child Development, 75*, 1694-1707.

Eliasson, A.-C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.-M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48*(7), 549-554.

Emler, N. (2002). The costs and causes of low self-esteem. *Youth Studies Australia, 21*(3), 45-48.

Ferro, M. A., & Boyle, M. H. (2013a). Longitudinal invariance of measurement and structure of global self-concept: A population-based study examining trajectories among adolescents with and without chronic illness. *Journal of Pediatric Psychology, 38*(4), 425-437. doi: 10.1093/jpepsy/jss112

Ferro, M. A., & Boyle, M. H. (2013b). Self-concept among youth with a chronic illness: A meta-analytic review. *Health Psychology, 32*(8), 839-848.

Field, A. (2005). *Discovering statistics using SPSS* (2nd ed.). London: Sage Publications.

Fitts, W. H. (1965). *Tennessee Self Concept Scale*. Tennessee: Counselor Recordings and Tests.

Fox, K. R., & Corbin, C. B. (1989). The Physical Self-Perception Profile: Development and preliminary validation. *Journal of Sport & Exercise Psychology, 11*, 408-430.

Greenberg, J., Solomon, S., Pyszczynski, T., Rosenblatt, A., Burling, J., Lyon, D., . . . Pinel, E. (1992). Why do people need self-esteem? Converging evidence that self-esteem serves as anxiety-buffering function. *Journal of Personality and Social Psychology, 63*(6), 913-922.

Harter, S. (1982). The perceived competence scale for children *Child Development, 53*, 87-97.

Harter, S. (1985). *Manual for the Self-Perception Profile for Children*. United States of America: University of Denver.

Harter, S. (1999). *The construction of the self: A developmental perspective*. London: Guilford Press.

Harter, S. (2006). The self. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology* (6 ed., Vol. 3, pp. 505-570). New Jersey: John Wiley.

Harter, S. (2012a). *The construction of the self: Developmental and sociocultural foundations* (2nd Ed ed.). New York: The Guiford Press.

Harter, S. (2012b). *Self-Perception Profile for Adolescents: Manual and Questionnaires*. Denver, Collorado: University of Denver.

Harter, S., & Pike, R. (1984). The pictorial scale of Perceived Competence and Social Acceptance for Young Children. *Child Development, 55*, 1969-1982.

Harter, S., Whitesell, N. R., & Junkin, L. J. (1998). Similarities and differences in domain-specific and global self-evaluations of learning-disabled, behaviourally disordered, and normally achieving adolescents. *American Educational Research Journal, 35*(4), 653-680.

Harvey, D. H. P., & Greenway, A. P. (1984). The self-concept of physically handicapped children and their non-handicapped siblings: An empirical investigation. *Journal of Child Psychology and Psychiatry, 25*(2), 273-284.

Hattie, J. (1992). *Self-concept*. Hillsdale, N.J.: Lawrence Erlbaum Associates.

Hsu, C.-C., & Sandford, B. A. (2007). The Delphi technique: Making sense of consensus. *Practical Assessment, Research and Evaluation, 12*(10), 1-8.

Huebner, E. S. (2004). Research on assessment of life satisfaction of children and adolescents. *Social Indicators Research, 66*, 3-33.

Huebner, E. S., Brantley, A., Nagle, R. J., & Valois, R. F. (2002). Correspondence between parent and adolescent ratings of life satisfaction for adolescents with and without mental disabilities. *Journal of Psychoeducational Assessment, 20,* 20-29.

Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation, 30*(24), 1867-1884. doi: 10.1080/09638280701673542

Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2015). 'Participation': A systematic review of language, definitions,a nd constructs used in intervention research with children with disabilities. *Developmental Medicine & Child Neurology, 58*, 29-38. doi: 10.1111/dmcn.12932

Imms, C., & Dodd, K. J. (2010). What is cerebral palsy? In K. J. Dodd, C. Imms & N. F. Taylor (Eds.), *Physiotherapy and occupational therapy for people with cerebral palsy* (pp. 7-30). London: Mac Keith Press.

Imms, C., Reilly, S., Carlin, J., & Dodd, K. J. (2008). Diversity of participation in children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*, 363-369. doi: 10.1111/j.1469-8749.2008.02051.x

Imms, C., Reilly, S., Carlin, J., & Dodd, K. J. (2009). Characteristics influencing participation of Australian children with cerebral palsy. *Disability and Rehabilitation, 31*(26), 2204-2215.

James, W. (1890/1950). *The principles of psychology*. New York: Dover Publications.

Keeney, S., Hasson, F., & McKenna, H. (2011). *The Delphi technique in nursing and health research*. United Kingdom: Wiley-Blackwell.

King, G., Law, M., Kings, S., Hurley, P., Rosenbaum, P., Hanna, S., . . . Young, N. (2004). *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)*. San Antonio, TX, USA: Harcourt Assessment.

King, G., Law, M., Petrenchik, T., & Hurley, P. (2013). Psychosocial determinants of out of school activity participation for children with and without physical disabilities. *Physical & Occupational Therapy in Paediatrics, 33*(4), 384-404. doi: 10.3109/01942638.2013.791915

King, G., Petrenchik, T., DeWit, D., McDougall, J., Hurley, P., & Law, M. (2010). Out-of-school time activity participation profiles of children with physical disabilities: A cluster analysis. *Child: Care, Health & Development, 36*(5), 726-741. doi: 10.1111/j.1365-2214.2010.01089.x

Kline, P. (2000). *Handbook of psychological testing* (2nd Edition ed.). New York: Routledge.

Koester, L. S., & Forest, D. S. (1998). Self-recognition responses among deaf and hearing 18-month-old infants. *Infant Behaviour and Development, 21,* 505. doi: 10.1016/S0163-6383(98)91718-0

Komdeur, S. J., Schuur, R., Wijnroks, L., & Vermeer, A. (2001). De CompetentieBelevingsSchaal voor kinderen met cerebrale parese [The self-perception profile for children with cerebral palsy]. *Tijdschrift voor Orthopedagogiek, 40,* 579-594.

Krigger, K. W. (2006). Cerebral palsy: An overview. *American Family Physician, 73*(1), 91-100.

Krumlinde-Sundholm, L., Holmefur, M., Kottorp, A., & Eliasson, A.-C. (2007). The Assisting Hand Assessment: current evidence of validity, reliability, and responsiveness to change. *Developmental Medicine & Child Neurology, 49*, 259-264.

Leary, M. R., Tambor, E. S., Terdal, S. K., & Downs, D. L. (1995). Self-esteem as an interpersonal monitor: The sociometer hypothesis. *Journal of Personality and Social Psychology*, *68*(3), 518-530.

Lewis, M., & Brooks-Gunn, J. (1979). *Social cognition and the acquisition of self*. New York: Plenum Press.

Lewis, M., & Ramsay, D. S. (2004). Development of self-recognition, personal pronoun use, and pretend play during the 2nd year. *Child Development*, *75*(6), 1821-1831.

Llewellyn, A., & Chung, M. C. (1997). The self-esteem of children with physical disabilities - Problems and dilemmas of research. *Journal of Developmental and Physical Disabilities*, *9*(3), 265-275.

Manuel, J. C., Balkrishnan, R., Camacho, F., Smith, B. P., & Koman, L. A. (2003). Factors associated with self-esteem in pre-adolescents and adolescents with cerebral palsy. *Journal of Adolescent Health, 32*, 456-458. doi: 10.1016/S1054-139X(03)00050-8

Marriage, K., & Cummins, R. A. (2004). Subjective quality of life and self-esteem in children: The role of primary and secondary control in coping with everyday stress. *Social Indicators Research, 66*, 107-122.

Marsh, H. W. (1986). Global self-esteem: Its relation to specific facets of self-concept and their importance. *Journal of Personality and Social Psychology, 51*(6), 1224-1236.

Marsh, H. W. (1989). Age and sex effects in multiple dimensions of self-concept: Preadolescence to early adulthood. *Journal of Educational Psychology, 81*(3), 417-430.

Marsh, H. W. (1990). A multidimensional, hierarchical model of self-concept: Theoretical and empirical justification. *Educational Psychology Review, 2*(2), 77-172.

Marsh, H. W. (1992). *Self-Description Questionnaire-I Manual*. Sydney, New South Wales, Australia: University of Western Sydney.

Marsh, H. W., Craven, R. G., & Debus, R. L. (1998). Structure, stability, and development of young children's self-concepts: A multicohort-multioccasion study. *Child Development, 69*(4), 1030-1053.

Marsh, H. W., & Shavelson, R. (1985). Self-concept: Its multifaceted hierarchical structure. *Educational Psychologist, 20*(3), 107-123.

Marsh, H. W., Tracey, D. K., & Craven, R. G. (2006). Multidimensional self-concept structure for preadolescents with mild intellectual disabilities: A hybrid multigroup - MIMC approach to factorial invariance and latent mean differences. *Educational and Psychological Measurement, 66*(5), 795-818. doi: 10.1177/0013164405285910

Marx, R., & Winne, P. H. (1980). Self-concept validation research: Some current complexities. *Measurement and Evaluation in Guidance, 13*(2), 72-82.

McGibbon, N. H., Benda, W., Duncan, B. R., & Silkwood-Sherer, D. (2009). Immediate and long-term effects of hippotherapy on symmetry of adductor muscle activity and functional ability in children with spastic cerebral palsy. *Archieves of Phsysiological Medicine and Rehabilitation, 90*, 966-974. doi: doi:10.1016/j.apmr.2009.01.011

McIntyre, S., Novak, I., & Cusick, A. (2010). Consensus research priorities for cerebral palsy: A Delphi survey of consumers, researchers, and clinicians. *Developmental Medicine & Child Neurology, 52*, 270-275. doi: 10.1111/j.1469-8749.2009.03358.x

Mead, G. H. (1934). *Mind, self, and society: From the standpoint of a social behaviourist*. Chicago: The University of Chicago Press.

Miller, S. A., Hardin, C. A., & Montgomery, D. E. (2003). Young children's understanding of the conditions for knowledge acquisition. *Journal of Cognition and Development, 4*, 325-356.

Miyahara, M., & Piek, J. (2006). Self-esteem of children and adolescents with physical disabilities: Quantitative evidence from meta-analysis. *Journal of Developmental and Physical Disabilities, 18*(3), 219-234. doi: 10.1007/s10882-006-9014-8

Mokkink, L. B., Terwee, C. B., Knol, D. K., Stratford, P. W., Alonso, J., Patrick, D. L., . . . de Vet, H. C. W. (2010). The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: A clarification of its content. *BMC Medical Research Methodology, 10*(22).

Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. K., . . . de Vet, H. C. W. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: An international Delphi study. *Quality of Life Research, 19*, 539-549. doi: 10.1007/s11136-101-9606-8

Mokkink, L. B., Terwee, C. B., Stratford, P. W., Alonso, J., Patrick, D. L., Riphagen, I., . . . De Vet, H. C. W. (2009). Evaluation of the methodological quality of systematic reviews of health status measurement instruments. *Quality of Life Research, 18*, 313-333. doi: 10.1007/s11136-009-9451-9

Montemayor, R., & Eisen, M. (1977). The development of self-conceptions from childhood to adolescence. *Developmental Psychology, 13*(4), 314-319.

Nadeau, L., & Tessier, R. (2011). Self-concept in children with cerebral palsy: Is there something in the wind? *Disability and Rehabilitation, 33*(10), 830-834. doi: 10.3109/09638288.2010.513421

Ninot, G., Fortes, M., & Delighnieres, D. (2001). A psychometric tool for the assessment of the dynamics of the physical self. *European Journal of Applied Psychology, 51*, 201-216.

O'Mara, A. J., Marsh, H. W., Craven, R. G., & Debus, R. L. (2006). Do self-concept interventions make a difference? A synergistic blend of construct validation and meta-analysis. *Educational Psychologist, 41*(3), 181-206.

Odom, S. L., Horner, R. H., Snell, M. E., & Blacher, J. (2007). The construct of developmental disabilities. In S. L. Odom, R. H. Horner, M. E. Snell & J.

Blacher (Eds.), *Handbook of developmental disabilities* (pp. 3-14). New York: The Guilford Press.

Oyserman, D., Elmore, K., & Smith, G. (2012). Self, self-concept, and identity. In M. R. Leary & J. P. Tangney (Eds.), *Handbook of self and identity* (2nd Ed ed., pp. 69-104). New York: The Guiford Press.

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

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2007). GMFCS - E & R Gross Motor Function Classification System Expanded and Revised. Retrieved 26 November 2014, 2014, from https://www.canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology, 39*, 214-223.

Pennington, L., Virella, D., Mjøen, T., Andrada, M. d. G., Murray, J., Colver, A., . . . de la Cruz, J. (2013). Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. *Research in Developmental Disabilities, 34*, 3202-3210.

Perry, D. G., Kusel, S. J., & Perry, L. C. (1988). Victims of peer aggression. *Developmental Psychology, 24*(6), 807-814.

Piers, E. V., & Harris, D. B. (1969). *The Piers-Harris Children's Self-Concept Scale*. Los Angeles, California: Western Psychological Services.

Piers, E. V., Harris, D. B., & Herzberg, D. S. (2002). *Piers-Harris Children's Self-Concept Scale II*. Los Angeles, California: Western Psychological Services.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (3rd Ed ed.). Upper Saddle River, New Jersey: Pearson Education Inc.

Rajmil, L., Lopez, A. R., Lopez-Aguila, S., & Alonso, J. (2013). Parent-child agreement on health-related quality of life (HRQOL): a longitudinal study. *Health and Quality of Life Outcomes*, *11*(101).

Ramsay, D. S., & Lewis, M. (1998). The onset of self-recognition and the emergence of self-awareness. *Infant Behaviour and Development, 21*, 637. doi: 10.1016/S0163-6383(98)91850-1

Reddihough, D. S., & Collins, K. J. (2003). The epidemiology and causes of cerebral palsy. *Australian Journal of Physiotherapy, 49*, 7-12.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2006). A report: The definition and classification of cerebral palsy April 2006. *Definition and Classification of CP,* 8-14.

Rosenbaum, P., & Rosenbloom, L. (2012). *Cerebral palsy: From diagnosis to adult life*. London: Mac Keith Press.

Rosenberg, M. (1965). *Society and the adolescent self-image*. United States of America: Princeton University Press.

Russo, R., Atkins, R., Haan, E., & Crotty, M. (2009). Upper limb orthoses and assistive technology utillization in children with hemiplegic cerebralpalsy recruited from a population register. *Developmental Neurorehabilitation, 12*(2), 92-99. doi: 10.1080/17518420902783223

Russo, R., Goodwin, E. J., Miller, M. D., Haan, E. A., Connell, T. M., & Crotty, M. (2008). Self-esteem, self-concept, and quality of life in children with hemiplegic cerebral palsy. *The Journal of Pediatrics, 153,* 473-477. doi: 10.1016/j.jpeds.2008.05.040

Russo, R., Miller, M. D., Haan, E. A., Cameron, I. D., & Crotty, M. (2008). Pain characteristics and their association with quality of life and self-concept in children with hemiplegic cerebral palsy identified from a population register. *Clinical Journal of Pain, 24*(4), 335-342.

Rust, J., & Golombok, S. (2009). *Modern Psychometrics: The science of psychological assessment* (3rd ed.). East Sussex: Routledge.

Sanger, T. D., Delgado, M. R., Gaebler-Spira, D., Hallett, M., Mink, J. W., & Taskforce on Childhood Motor Disorders. (2003). Classification and definition of disorders causing hypertonia in childhood. *Pediatrics, 111*(1), e89-e97.

Scholtes, V., Vermeer, A., & Meek, G. (2002). Measuring perceived competence and social acceptance in children with cerebral palsy. *European Journal of Special Needs Education, 17*(1), 77-87. doi: 10.1080/08856250110099042

Schuengel, C., Voorman, J., Stolk, J., Dallmeijer, A., Vermeer, A., & Becher, J. (2006). Self-worth, perceived competence, and behaviour problems in children with cerebral palsy. *Disability and Rehabilitation, 28*(20), 1251-1258. doi: 10.1080/09638280600554652

Selman, R. L., & Byrne, D. F. (1974). A structural-developmental analysis of levels of role taking in midle childhood. *Child Development, 45,* 803-806.

Setterlund, M. B., & Niedenthal, P. M. (1993). "Who am I? Why am I here?" Self-esteem, self-clarity, and prototype matching. *Journal of Personality and Social Psychology, 65*(4), 769-780.

Shavelson, R. J., Hubner, J. J., & Stanton, G. C. (1976). Self-concept: Validation of construct interpertations. *Review of Educational Research, 46*(3), 407-441.

Shelly, A., Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., . . . Graham, H. K. (2008). The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*, 199-203. doi: 10.1111/j.1469-8749.2008.02031.x

Sherrill, C., Hinson, M., Gench, B., Kennedy, S. O., & Low, L. (1990). Self-concepts of disabled youth atheletes. *Perceptual and Motor Skills, 70*, 1093-1098.

Shields, N., Loy, Y., Murdoch, A., Taylor, N. F., & Dodd, K. J. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine & Child Neurology, 49*, 350-354.

Shields, N., Murdoch, A., Loy, Y., Dodd, K. J., & Taylor, N. F. (2006). A systematic review of the self-concept of children with cerebral palsy compared with children without disability. *Developmental Medicine & Child Neurology, 48*, 151-157.

Shikako-Thomas, K., Shevell, M., Schmitz, N., Lach, L., Law, M., Poulin, C., . . . The QUALA Group. (2013). Determinants of participation in leisure activities among adolescents with cerebral palsy. *Research in Developmental Disabilities, 34*, 2621-2634.

Shum, D., O'Gorman, J., Myors, B., & Creed, P. (2013). *Psychological testing and assessment* (2nd Edition ed.). Victoria, Australia: Oxford University Press.

Soares, L. M., & Soares, A. T. (1980). *Nomological research in self-perceptions: Implications for construct validity in multitrait-multimethod matrix design*. Paper presented at the Annual Meeting of the Eastern Psychological Association, Hartford, CT. http://eric.ed.gov/?id=ED193311

Soares, L. M., & Soares, A. T. (1981). *Convergent and discriminat validation of self-perceptions*. Paper presented at the 65th Annual Meeting of the American Educational Research Association, Los Angeles, CA. http://eric.ed.gov/?id=ED201646

Soyupek, F., Aktepe, E., Savas, S., & Askin, A. (2010). Do the self-concept and quality of life decrease in CP patients? Focussing on the predictors of self-concept and quality of life. *Disability and Rehabilitation, 32*(13), 1109-1115. doi: 10.3109/09638280903391120

Spiker, D., & Ricks, M. (1984). Visual self-recognition in autistic children: Developmental relationships. *Child Development, 55*, 214-225.

Stone, W. L., & Lemanek, K. L. (1990). Developmental issues in children's self-reports. In A. M. La Greca (Ed.), *Through the eyes of the child: Obtaining self-reports from children and adolescents* (pp. 18-56). Miami: Allyn and Bacon.

Surman, G., Bonellie, S., Chalmers, J., Colver, A., Dolk, H., Hemming, K., . . . Platt, M. J. (2006). UKCP: A collaborative network of cerebral palsy registers in the United Kingdom. *Journal of Public Health, 28*(2), 148-156. doi: 10.1093/pubmed/fdi087

Teplin, S. W., Howard, J. A., & O'Connor, M. J. (1981). Self-concept of young children with cerebral palsy. *Developmental Medicine & Child Neurology, 23*, 730-738.

Terry, T., & Huebner, E. S. (1995). The relationship between self-concept and life satisfaction in children. *Social Indicators Research, 35*, 39-52.

Terwee, C. B., Bot, S. D., de Boer, M. R., van der Windt, D. A., Knol, D. L., Dekker, J., . . . De Vet, H. C. W. (2007). Quality criteria were proposed for measurement properties of health status quesstionnaires. *Journal of Clinical Epidemiology, 60*, 34-42. doi: 10.1016/j.jclinepi.2006.03.012

Terwee, C. B., Mokkink, L. B., Knol, D. K., Ostelo, R. W. J. G., Bouter, L. M., & de Vet, H. C. W. (2012). Rating the methodological quality in systematic reviews of studies on measurement properties: A scoring system for the COSMIN checklist. *Quality of Life Research, 21,* 651-657. doi: 10.1007/s11136-011-9960-1

Trautwein, U., Lüdtke, O., Köller, O., & Baumert, J. J. (2006). Self-esteem, academic self-concept, and achievement: How the learning environment moderates the dynamics of self-concept. *Journal of Personality and Social Psychology, 90*(2), 334-349.

Valois, R. F., Zullig, K. J., Huebner, E. S., & Drane, J. W. (2004). Life satisfaction and suicide among high school adolescents. *Social Indicators Research, 66*, 81-105.

Vargus-Adams, J. (2005). Health-related quality of life in childhood cerebral palsy. *Archieves of Phsysiological Medicine and Rehabilitation, 86,* 940-945.

Vargus-Adams, J., & Martin, L. K. (2009). Measuring what matters in cerebral palsy: A breadth of important domains and outcome measures. *Archieves of Physiological Medicine and Rehabilitation, 90*. doi: 10.1016/j.apmr.2009.06.018

Vargus-Adams, J., & Martin, L. K. (2010). Domains of importance for parents, medical professionals and youth with cerberal palsy considering treatment outcomes. *Child: Care, Health & Development, 37*(2), 276-281. doi: 10.1111/j.1365-2214.2010.01121.x

Varni, J. W., Burwinkle, T. M., Sherman, S. A., Hanna, K., Berrin, S. J., Malcarne, V. L., & Chambers, H. G. (2005). Health-related quality of life of children and adolescents with cerebral palsy: Hearing the voices of the children. *Developmental Medicine & Child Neurology, 47,* 592-597.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL^{TM} 4.0: Reliability and validity of the Pediatric Quality of Life Inventory^{TM} Version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*(8), 800-812.

Virella, D., Pennington, L., Andersen, G., Andrada, M. d. G., Greitane, A., Himmelmann, K., . . . On behalf of Surveillance of Cerebral Palsy in Europe Network. (2016). Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy. *Developmental Medicine & Child Neurology, 58*, 285-291. doi: 10.1111/dmcn.12866

von der Luft, G., DeBoer, B. V., Harman, L. B., Koenig, K. P., & Nixon-Cave, K. (2008). Improving the quality of studies on self-concept in children with cerebral palsy. *Journal of Developmental and Physical Disabilities, 20*, 581-594. doi: 10.1007/s10882-008-9117-5

von der Luft, G., Harman, L. B., Koenig, K. P., Nixon-Cave, K., & Gaughan, J. P. (2008). Cross validation of a self-concept tool for use with children with cerebral palsy. *Journal of Developmental and Physical Disabilities, 20*, 561-572. doi: 10.1007/s10882-008-9119-3

Voorman, J. M., Dallmeijer, A. J., Schuengel, C., Knol, D. K., Lankhorst, G. J., & Becher, J. G. (2006). Activities and participation of 9- to 13-year-old children with cerebral palsy. *Clinical Rehabilitation, 20*, 937-948.

Waters, E., Davis, E., Boyd, R., Reddihough, D., Graham, H. K., Mackinnon, A., . . . Ravens-Sieberer, U. (2013). *Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) manual*. Melbourne: University of Melbourne.

Waters, E., Davis, E., Mackinnon, A., Boyd, R., Graham, H. K., Lo, S. K., . . . Reddihough, D. (2007). Psychometric properties of the quality of life questionnaire for children with CP. *Developmental Medicine & Child Neurology, 49*, 49-55. doi: 10.1017/S0012162207000126

Waters, E., Maher, E., Salmon, L., Reddihough, D., & Boyd, R. (2005). Development of a condition-specific measure of quality of life for children with cerebral palsy: Empirical thematic data reported by parents and children. *Child: Care, Health & Development, 31*(2), 127-135.

Wechsler, D. (2003a). *Wechsler Intelligence Scale for Children - Fourth Edition: Administration and scoring manual, Australian adaptation*. Sydney, New South Wales, Australia: Harcourt Assessment.

Wechsler, D. (2003b). *Wechsler Intelligence Scale for Children - Fourth Edition: Technical and interpretive manual*. Sydney, New South Wales, Australia: Harcourt Assessment.

Wells, L. E., & Marwell, G. (1976). *Self-esteem: Its conceptualisation and measurement*. Beverly Hills: Sage Publications.

World Health Organisation. (2002). *Towards a common language for functioning, disability and health: ICF*. Geneva: World Health Organisation.

World Health Organisation. (2016). International classification of functioning, disability and Health (ICF). Retrieved 9 March 2016, from http://www.who.int/classifications/icf/en/

World Health Organisation [WHO]. (1997). *WHOQOL Measuring Quality of Life* Retrieved from http://www.who.int/mental_health/media/68.pdf

World Health Organisation [WHO]. (2011). *World report on disability*. Malta: World Health Organisation (WHO).

Wright, F. V., Boschen, K., & Jutai, J. (2005). Exploring the comparative responsiveness of a core set of outcome measures in a school-based conductive education programme. *Child: Care, Health & Development, 31*(3), 291-302.

Yin Foo, R., Guppy, M., & Johnston, L. M. (2013). Intelligence assessments for children with cerebral palsy: A systematic review. *Developmental Medicine & Child Neurology*. doi: 10.1111/dmcn.12157

Ziebell, M. (2007). *The relationship between physical performance and self-perception in children with spastic diplegia cerebral palsy.* (Master of Occupational Therapy), La Trobe University, Australia.

Ziebell, M., Imms, C., Froude, E. H., McCoy, A., & Galea, M. (2009). The relationship between physical performance and self-perception in children with and without cerebral palsy. *Australian Occupational Therapy Journal, 56*, 24-32. doi: 10.1111/j.1440-1630.2008.00775.x

Research Portfolio Appendices

Appendix A Publication Status

Study 1: Systematic Review (Chapter 6)

Status: Published

Cheong, S. K., & Johnston, L. M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities, 34*, 3566-3575. Retrived from http://dx.doi.org/10.1016/j.ridd.2013.07.023

Study 2: Delphi Consensus Survey (Chapter 7)

Status: Published

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016). What constitutes self-concept for children with CP? A Delphi consensus survey. *Journal of Developmental and Physical Disabilities*, *28*(2), 333-346. doi: 10.1007/s10882-015-9471-z

Study 3: Psychometric Testing (Chapter 9)

Status: Published

Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2017). myTREEHOUSE Self-Concept Assessment: Preliminary psychometric analysis of a new self-concept assessment for children with cerebral palsy. *Developmental Medicine & Child Neurology, 59*(6), 655-660. doi: 10.1111/dmcn.13392

Study 4: Self-concept of Children with Cerebral Palsy (Chapter 10)

Status: Manuscript under revision for consideration for publication in the peer reviewed journal *Research in Developmental Disabilities*

Study 5: Self-concept and Quality of Life of Children with Cerebral Palsy (Chapter 11)

Status: Manuscript prepared for submission

Appendix B Statement of Contribution of Others

I acknowledge that my contribution to the above papers is 54 percent.

Name: Sau Kuan Cheong

Date: 22nd November 2017

Signed:

I acknowledge that my contribution to the above papers is 14 percent.

Name: Cathryne Lang

Date: 22nd November 2017

Signed:

I acknowledge that my contribution to the above papers is 4 percent.

Name: Sheryl Hemphill

Date:

Signed: *Professor Sheryl Hemphill is currently on extended sick leave.*

I acknowledge that my contribution to the above papers is 28 percent.

Name: Leanne Johnston

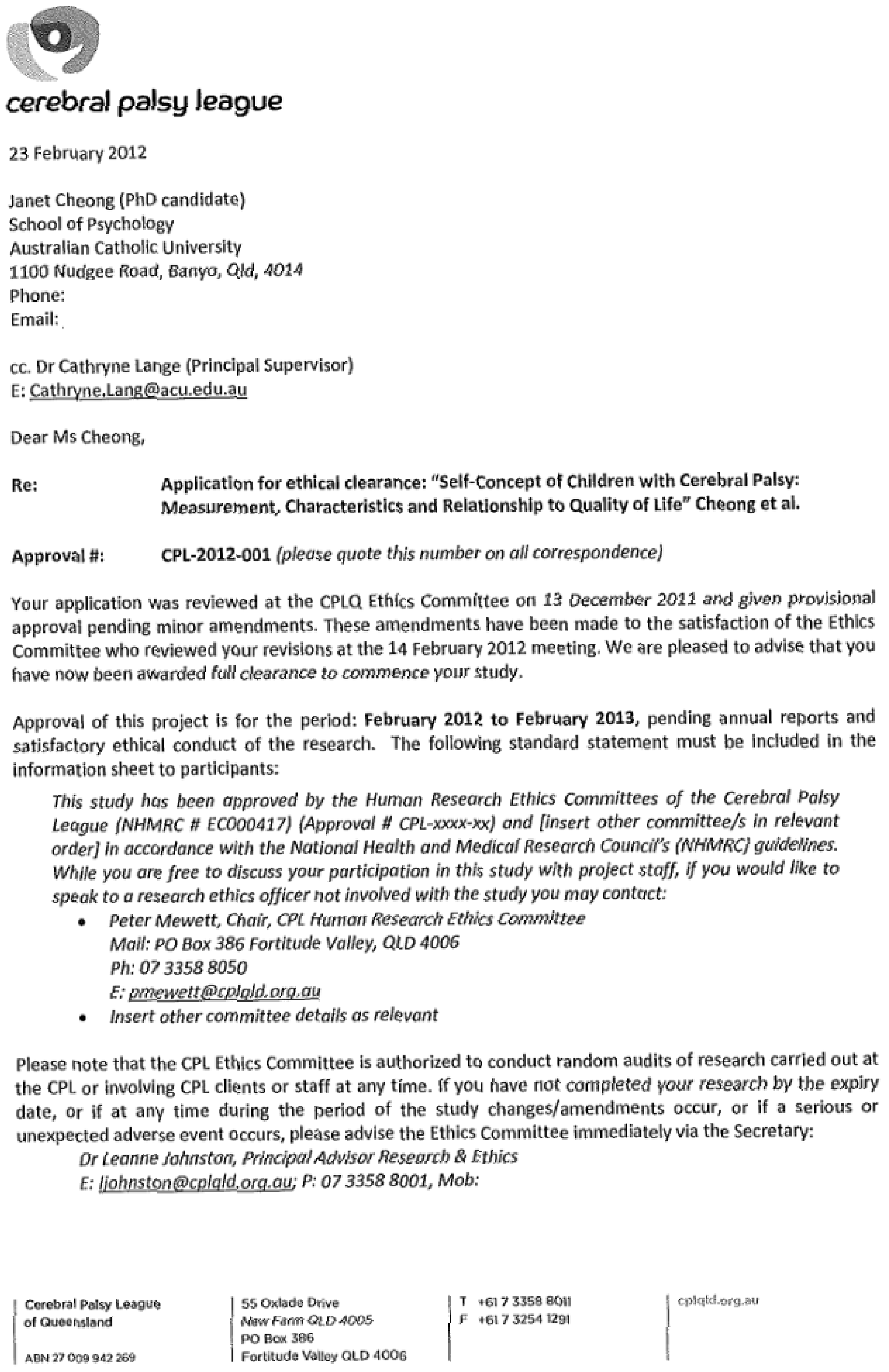
Date: 22nd November 2017

Signed: L Johnston

Appendix C Ethics Documentation

Appendix C includes ethics documentation for the research program. Following are the page reference for the individual items:

Ethics Approval



cerebral palsy league

23 February 2012

Janet Cheong (PhD candidate)
School of Psychology
Australian Catholic University
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email:

cc. Dr Cathryne Lange (Principal Supervisor)
E: Cathryne.Lang@acu.edu.au

Dear Ms Cheong,

Re: **Application for ethical clearance: "Self-Concept of Children with Cerebral Palsy: Measurement, Characteristics and Relationship to Quality of Life" Cheong et al.**

Approval #: **CPL-2012-001** *(please quote this number on all correspondence)*

Your application was reviewed at the CPLQ Ethics Committee on *13 December 2011 and given provisional* approval pending minor amendments. These amendments have been made to the satisfaction of the Ethics Committee who reviewed your revisions at the 14 February 2012 meeting. We are pleased to advise that you have now been awarded *full clearance to commence* your study.

Approval of this project is for the period: **February 2012 to February 2013**, pending annual reports and satisfactory ethical conduct of the research. The following standard statement must be included in the information sheet to participants:

> *This study has been approved by the Human Research Ethics Committees of the Cerebral Palsy League (NHMRC # EC000417) (Approval # CPL-xxxx-xx) and [insert other committee/s in relevant order] in accordance with the National Health and Medical Research Council's (NHMRC) guidelines. While you are free to discuss your participation in this study with project staff, if you would like to speak to a research ethics officer not involved with the study you may contact:*
>
> - *Peter Mewett, Chair, CPL Human Research Ethics Committee*
>   *Mail: PO Box 386 Fortitude Valley, QLD 4006*
>   *Ph: 07 3358 8050*
>   *E: pmewett@cplqld.org.au*
> - *Insert other committee details as relevant*

Please note that the CPL Ethics Committee is authorized to conduct random audits of research carried out at the CPL or involving CPL clients or staff at any time. If you have not completed your research by the expiry date, or if at any time during the period of the study changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise the Ethics Committee immediately via the Secretary:
Dr Leanne Johnston, Principal Advisor Research & Ethics
E: ljohnston@cplqld.org.au; P: 07 3358 8001, Mob:

Cerebral Palsy League
of Queensland
ABN 27 009 942 269
55 Oxlade Drive
New Farm QLD 4005
PO Box 386
Fortitude Valley QLD 4006
T +61 7 3358 8011
F +61 7 3254 1291
cplqld.org.au

If you have any questions regarding the above, please do not hesitate to contact the committee secretary, Dr Leanne Johnston who will refer to me as appropriate. The CPL welcomes this research and wishes you well with the study.

Yours Sincerely,

Peter Mewett
Chair, CPL Human Research Ethics Committee

cc: Dr Leanne Johnston, Chair Research Development Committee

IMPLEMENTING YOUR RESEARCH - INFORMATION SHEET

It is advised that the Ethics Committee have approved your request for ethical clearance.

What Happens Now?

1. **Ethical Guidelines**
   When performing research with CPL clients, staff or services, your work must be in accordance with the following:
   - **National Statement on Ethical Conduct in Human Research:**
     http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf
   - **Australian Code for the Responsible Conduct of Research**
     http://www.nhmrc.gov.au/publications/synopses/r39syn.htm
   - **Cerebral Palsy League's Code of Conduct**
   - **Various and relevant professional Codes of Conduct**
   - **Queensland Health Management Research Policy:**
     http://www.health.qld.gov.au/epic/documents/ethics/research_policy.pdf
   - **Declaration of Helsinki:**
     http://www.health.qld.gov.au/ethics/Documents/24938_policy.pdf
   - **Guidelines under Section 95 of the Privacy Act 1995 and Guidelines approved under Section 95A of the Privacy Act 1995**
     http://www.comlaw.gov.au/ComLaw/Legislation/ActCompilation1.nsf/0/B471AB909A18D172CA25725C0083858A/$file/Privacy1988_WD02HYP.pdf

2. **We will require an annual research progress report** (or sooner if the project is completed under a year)
   - The Ethics Committee will send you a report template in January/February which will be due in by March 31 of the year. In accordance with National Statement 5.5.3, this must include progress to date or outcome in the case of research completed before March 31.
   - Regular progress reports may also be required by the CPL Research Development Committee and/or the CPL service area in which your study is being conducted.

3. **Clinical Trials Register**
   In accordance with the National Statement (3.3.12), before beginning the clinical phase of the research trials, researchers should register those clinical trials in a publicly accessible domain. Copies of registration should be forwarded to the Chair of the CPL HREC.
   Clinical Trials Register: www.ctc.usyd.edu.au/trials/registry/registry.htm

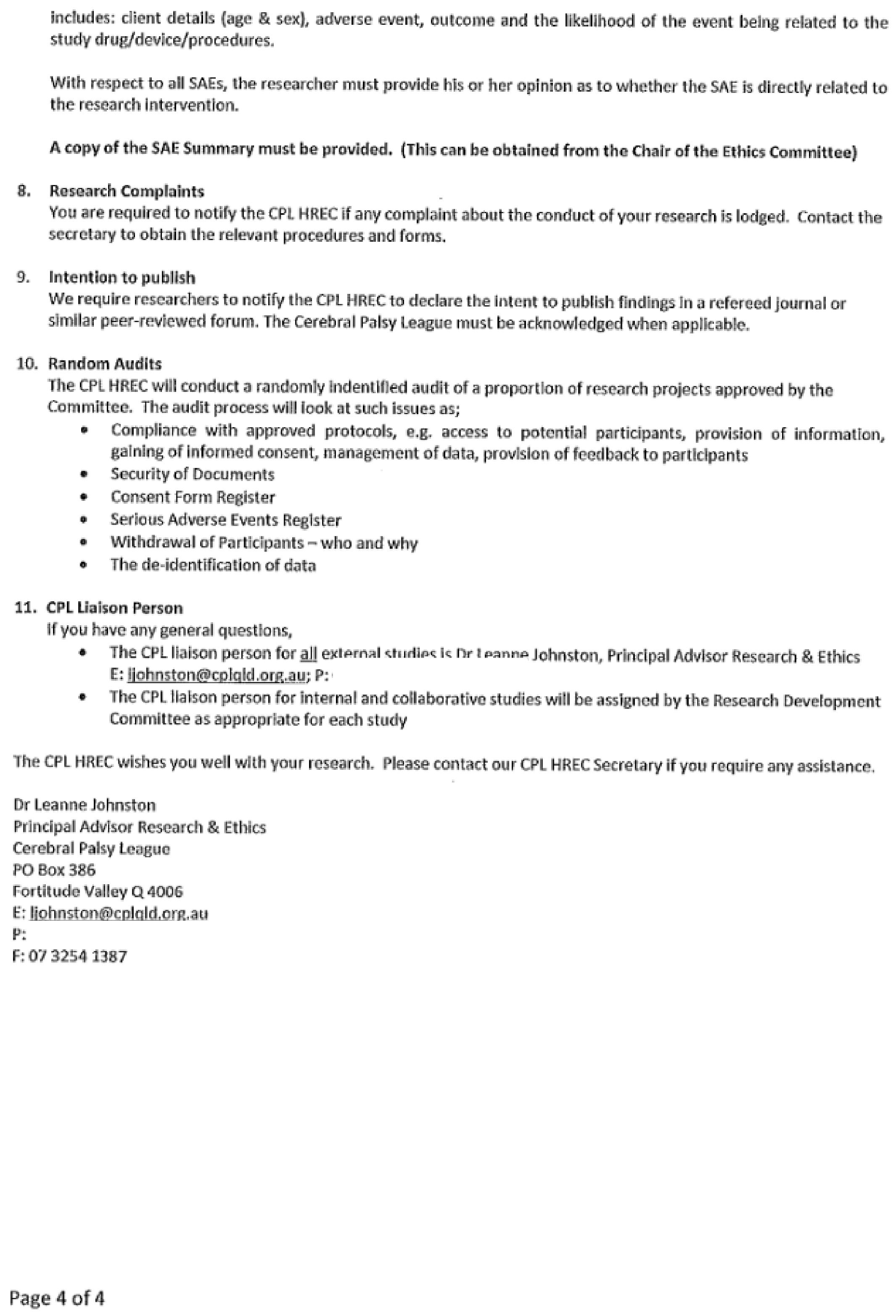
4. **Changes to Protocol**
   If any changes are required for your study that involve CPL clients, services, staff or host CPL ethics clearance, including changes to nominated investigators, please contact the CPL Ethics Committee to request an Amendment Form. This form is to be completed and submitted to the CPL Ethics Committee for review and approval prior to implementing any changes.

5. **Project does not proceed**
   If the project does not proceed, the Committee must be informed as soon as possible.

6. **Unexpected Adverse event**
   The Chair of the CPL HREC must be informed immediately of any potential or realised problem with bioethical implications, if such occurs during the conduct of the research project.

7. **Serious adverse event**
   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 Chair of the CPL HREC within 72 hours and reported to the sponsor (if applicable) within the stipulated timeframe. This contact will generate a Serious Adverse Event Form for you completion and submission to the Ethics Committee.

   Serious Adverse Event Reports that are generated off-site during multi-centre trials are required to the submitted to the Chair of the CPL HREC. A summary of the SAE reports is to accompany the submission. Information required



includes: client details (age & sex), adverse event, outcome and the likelihood of the event being related to the study drug/device/procedures.

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 Chair of the Ethics Committee)

8. **Research Complaints**
   You are required to notify the CPL HREC if any complaint about the conduct of your research is lodged. Contact the secretary to obtain the relevant procedures and forms.

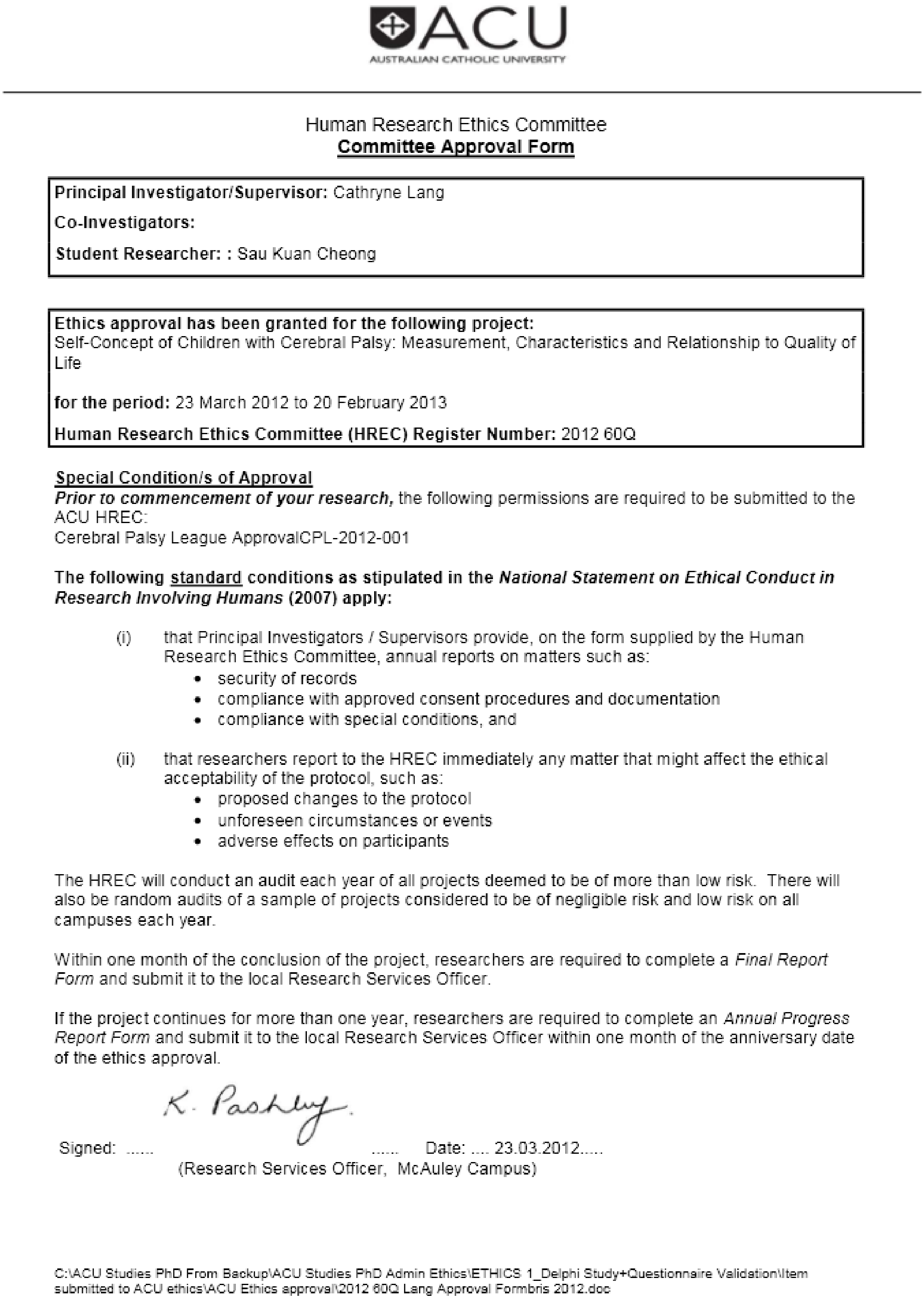
9. **Intention to publish**
   We require researchers to notify the CPL HREC to declare the intent to publish findings in a refereed journal or similar peer-reviewed forum. The Cerebral Palsy League must be acknowledged when applicable.

10. **Random Audits**
    The CPL HREC will conduct a randomly indentified audit of a proportion of research projects approved by the Committee. The audit process will look at such issues as;
    - Compliance with approved protocols, e.g. access to potential participants, provision of information, gaining of informed consent, management of data, provision of feedback to participants
    - Security of Documents
    - Consent Form Register
    - Serious Adverse Events Register
    - Withdrawal of Participants – who and why
    - The de-identification of data

11. **CPL Liaison Person**
    If you have any general questions,
    - The CPL liaison person for all external studies is Dr Leanne Johnston, Principal Advisor Research & Ethics E: ljohnston@cplqld.org.au; P:
    - The CPL liaison person for internal and collaborative studies will be assigned by the Research Development Committee as appropriate for each study

The CPL HREC wishes you well with your research. Please contact our CPL HREC Secretary if you require any assistance.

Dr Leanne Johnston
Principal Advisor Research & Ethics
Cerebral Palsy League
PO Box 386
Fortitude Valley Q 4006
E: ljohnston@cplqld.org.au
P:
F: 07 3254 1387



AUSTRALIAN CATHOLIC UNIVERSITY

Human Research Ethics Committee

Committee Approval Form

Principal Investigator/Supervisor: Cathryne Lang

Co-Investigators:

Student Researcher: : Sau Kuan Cheong

Ethics approval has been granted for the following project:
Self-Concept of Children with Cerebral Palsy: Measurement, Characteristics and Relationship to Quality of Life

for the period: 23 March 2012 to 20 February 2013

Human Research Ethics Committee (HREC) Register Number: 2012 60Q

Special Condition/s of Approval
Prior to commencement of your research, the following permissions are required to be submitted to the ACU HREC:
Cerebral Palsy League ApprovalCPL-2012-001

The following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (2007) apply:

(i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
  - security of records
  - compliance with approved consent procedures and documentation
  - compliance with special conditions, and

(ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
  - proposed changes to the protocol
  - unforeseen circumstances or events
  - adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than low risk. There will also be random audits of a sample of projects considered to be of negligible risk and low risk on all campuses each year.

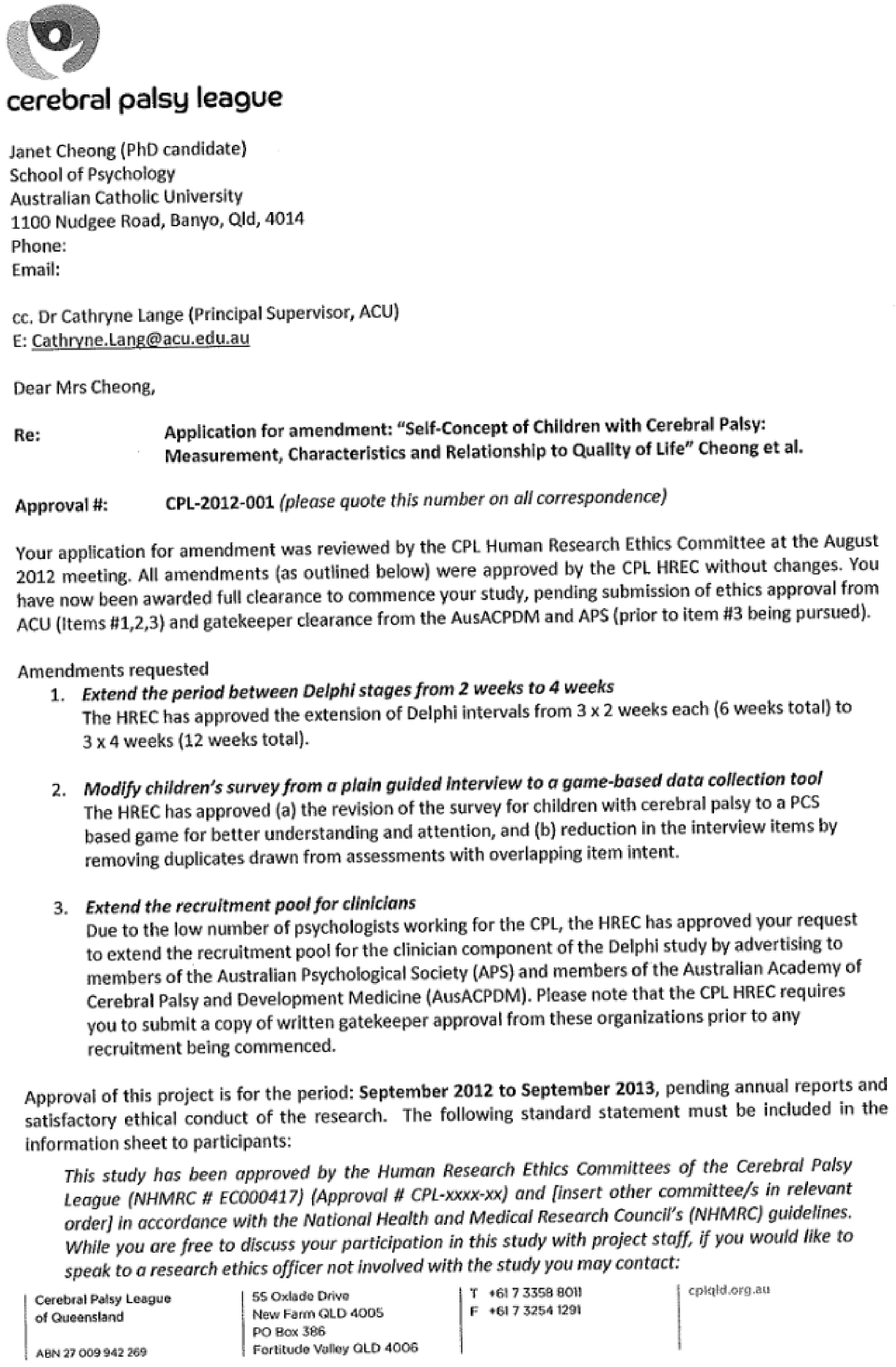
Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

Signed: ...... K. Pashley ...... Date: .... 23.03.2012.....
(Research Services Officer, McAuley Campus)

C:\ACU Studies PhD From Backup\ACU Studies PhD Admin Ethics\ETHICS 1_Delphi Study+Questionnaire Validation\Item submitted to ACU ethics\ACU Ethics approval\2012 60Q Lang Approval Formbris 2012.doc

Ethics Approval – Amendment 1



cerebral palsy league

Janet Cheong (PhD candidate)
School of Psychology
Australian Catholic University
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email:

cc. Dr Cathryne Lange (Principal Supervisor, ACU)
E: Cathryne.Lang@acu.edu.au

Dear Mrs Cheong,

Re: **Application for amendment: "Self-Concept of Children with Cerebral Palsy: Measurement, Characteristics and Relationship to Quality of Life" Cheong et al.**

Approval #: **CPL-2012-001** *(please quote this number on all correspondence)*

Your application for amendment was reviewed by the CPL Human Research Ethics Committee at the August 2012 meeting. All amendments (as outlined below) were approved by the CPL HREC without changes. You have now been awarded full clearance to commence your study, pending submission of ethics approval from ACU (Items #1,2,3) and gatekeeper clearance from the AusACPDM and APS (prior to item #3 being pursued).

Amendments requested

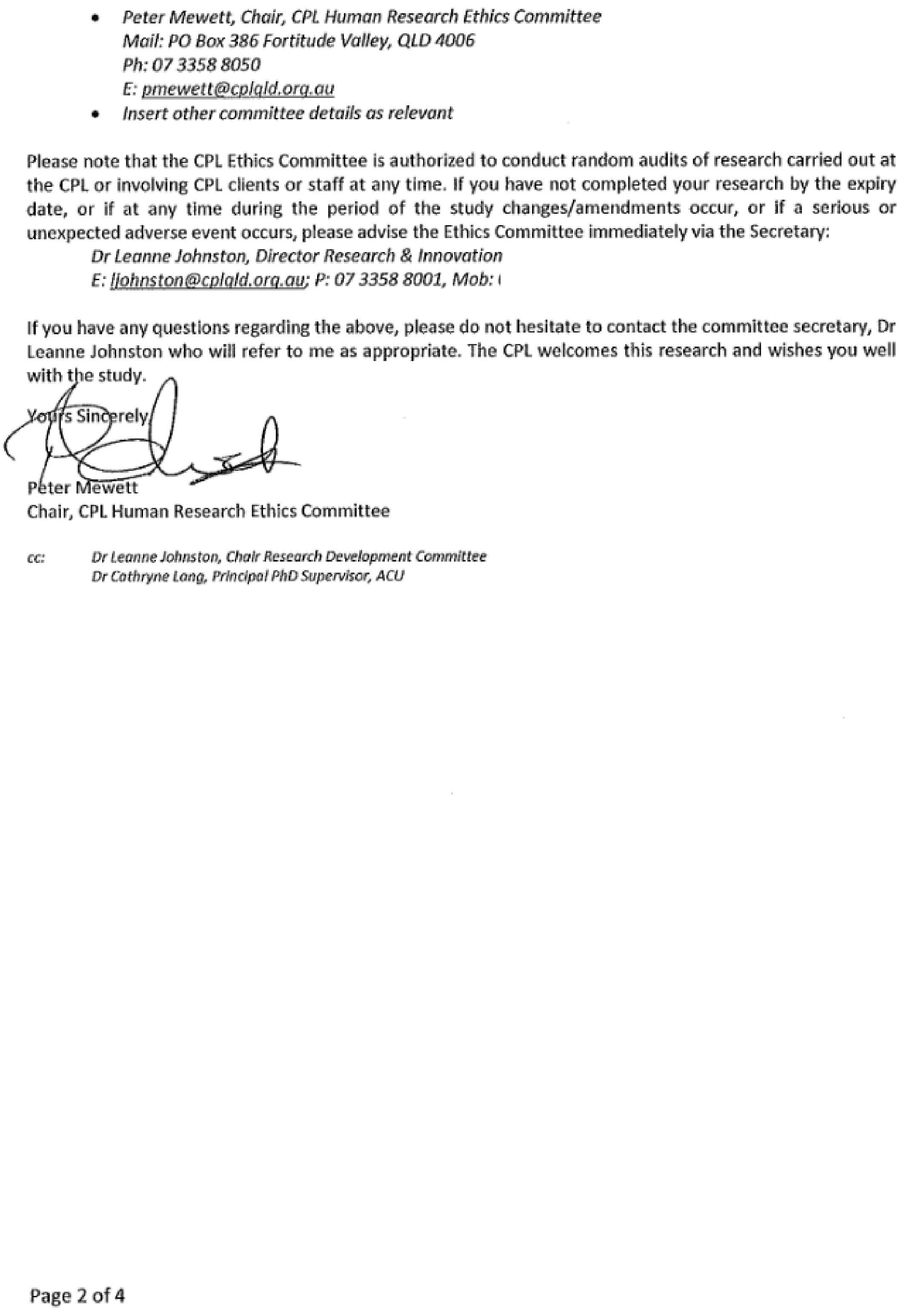
1. ***Extend the period between Delphi stages from 2 weeks to 4 weeks***
   The HREC has approved the extension of Delphi intervals from 3 x 2 weeks each (6 weeks total) to 3 x 4 weeks (12 weeks total).

2. ***Modify children's survey from a plain guided interview to a game-based data collection tool***
   The HREC has approved (a) the revision of the survey for children with cerebral palsy to a PCS based game for better understanding and attention, and (b) reduction in the interview items by removing duplicates drawn from assessments with overlapping item intent.

3. ***Extend the recruitment pool for clinicians***
   Due to the low number of psychologists working for the CPL, the HREC has approved your request to extend the recruitment pool for the clinician component of the Delphi study by advertising to members of the Australian Psychological Society (APS) and members of the Australian Academy of Cerebral Palsy and Development Medicine (AusACPDM). Please note that the CPL HREC requires you to submit a copy of written gatekeeper approval from these organizations prior to any recruitment being commenced.

Approval of this project is for the period: **September 2012 to September 2013**, pending annual reports and satisfactory ethical conduct of the research. The following standard statement must be included in the information sheet to participants:

> *This study has been approved by the Human Research Ethics Committees of the Cerebral Palsy League (NHMRC # EC00417) (Approval # CPL-xxxx-xx) and [insert other committee/s in relevant order] in accordance with the National Health and Medical Research Council's (NHMRC) guidelines. While you are free to discuss your participation in this study with project staff, if you would like to speak to a research ethics officer not involved with the study you may contact:*



- *Peter Mewett, Chair, CPL Human Research Ethics Committee*
  Mail: PO Box 386 Fortitude Valley, QLD 4006
  Ph: 07 3358 8050
  E: pmewett@cplqld.org.au
- *Insert other committee details as relevant*

Please note that the CPL Ethics Committee is authorized to conduct random audits of research carried out at the CPL or involving CPL clients or staff at any time. If you have not completed your research by the expiry date, or if at any time during the period of the study changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise the Ethics Committee immediately via the Secretary:

Dr Leanne Johnston, Director Research & Innovation
E: ljohnston@cplqld.org.au; P: 07 3358 8001, Mob:

If you have any questions regarding the above, please do not hesitate to contact the committee secretary, Dr Leanne Johnston who will refer to me as appropriate. The CPL welcomes this research and wishes you well with the study.

Yours Sincerely,

Peter Mewett
Chair, CPL Human Research Ethics Committee

cc: *Dr Leanne Johnston, Chair Research Development Committee*
Dr Cathryne Long, Principal PhD Supervisor, ACU

Page 2 of 4

IMPLEMENTING YOUR RESEARCH - INFORMATION SHEET

It is advised that the Ethics Committee have approved your request for ethical clearance.

What Happens Now?

1. **Ethical Guidelines**
   When performing research with CPL clients, staff or services, your work must be in accordance with the following:
   - **National Statement on Ethical Conduct in Human Research:**
     http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf
   - **Australian Code for the Responsible Conduct of Research**
     http://www.nhmrc.gov.au/publications/synopses/r39syn.htm
   - **Cerebral Palsy League's Code of Conduct**
   - **Various and relevant professional Codes of Conduct**
   - **Queensland Health Management Research Policy:**
     http://www.health.qld.gov.au/epic/documents/ethics/research_policy.pdf
   - **Declaration of Helsinki:**
     http://www.health.qld.gov.au/ethics/Documents/24938_policy.pdf
   - **Guidelines under Section 95 of the Privacy Act 1995 and Guidelines approved under Section 95A of the Privacy Act 1995**
     http://www.comlaw.gov.au/ComLaw/Legislation/ActCompilation1.nsf/0/B471AB909A18D172CA25725C0083858A/$file/Privacy1988_WD02HYP.pdf

2. **We will require an annual research progress report** (or sooner if the project is completed under a year)
   - The Ethics Committee will send you a report template in January/February which will be due in by March 31 of the year. In accordance with National Statement 5.5.3, this must include progress to date or outcome in the case of research completed before March 31.
   - Regular progress reports may also be required by the CPL Research Development Committee and/or the CPL service area in which your study is being conducted.

3. **Clinical Trials Register**
   In accordance with the National Statement (3.3.12), before beginning the clinical phase of the research trials, researchers should register those clinical trials in a publicly accessible domain. Copies of registration should be forwarded to the Chair of the CPL HREC.
   Clinical Trials Register: www.ctc.usyd.edu.au/trials/registry/registry.htm

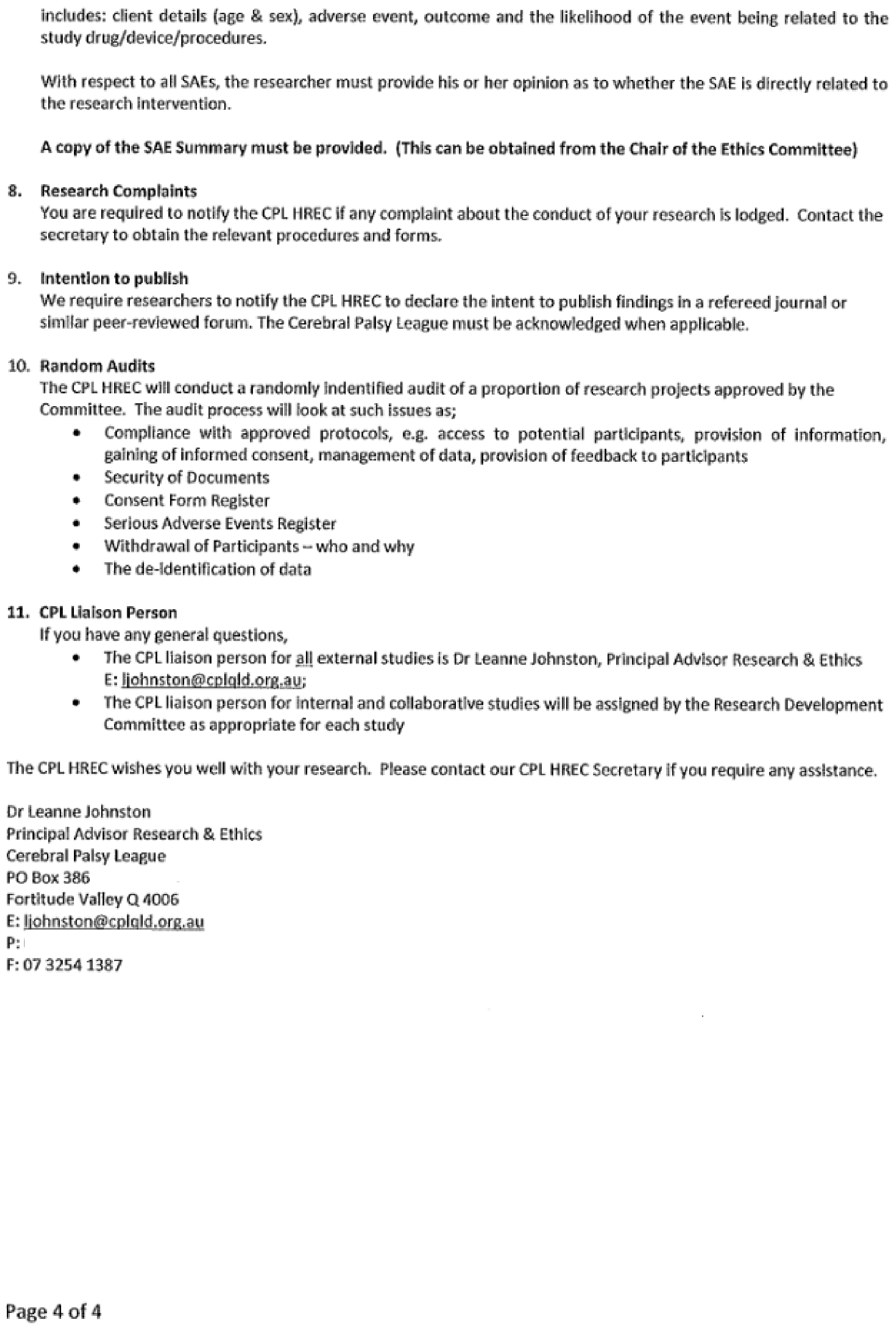
4. **Changes to Protocol**
   If any changes are required for your study that involve CPL clients, services, staff or host CPL ethics clearance, including changes to nominated investigators, please contact the CPL Ethics Committee to request an Amendment Form. This form is to be completed and submitted to the CPL Ethics Committee for review and approval prior to implementing any changes.

5. **Project does not proceed**
   If the project does not proceed, the Committee must be informed as soon as possible.

6. **Unexpected Adverse event**
   The Chair of the CPL HREC must be informed immediately of any potential or realised problem with bioethical implications, if such occurs during the conduct of the research project.

7. **Serious adverse event**
   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 Chair of the CPL HREC within 72 hours and reported to the sponsor (if applicable) within the stipulated timeframe. This contact will generate a Serious Adverse Event Form for you completion and submission to the Ethics Committee.

   Serious Adverse Event Reports that are generated off-site during multi-centre trials are required to the submitted to the Chair of the CPL HREC. A summary of the SAE reports is to accompany the submission. Information required



includes: client details (age & sex), adverse event, outcome and the likelihood of the event being related to the study drug/device/procedures.

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 Chair of the Ethics Committee)

8. **Research Complaints**
   You are required to notify the CPL HREC if any complaint about the conduct of your research is lodged. Contact the secretary to obtain the relevant procedures and forms.

9. **Intention to publish**
   We require researchers to notify the CPL HREC to declare the intent to publish findings in a refereed journal or similar peer-reviewed forum. The Cerebral Palsy League must be acknowledged when applicable.

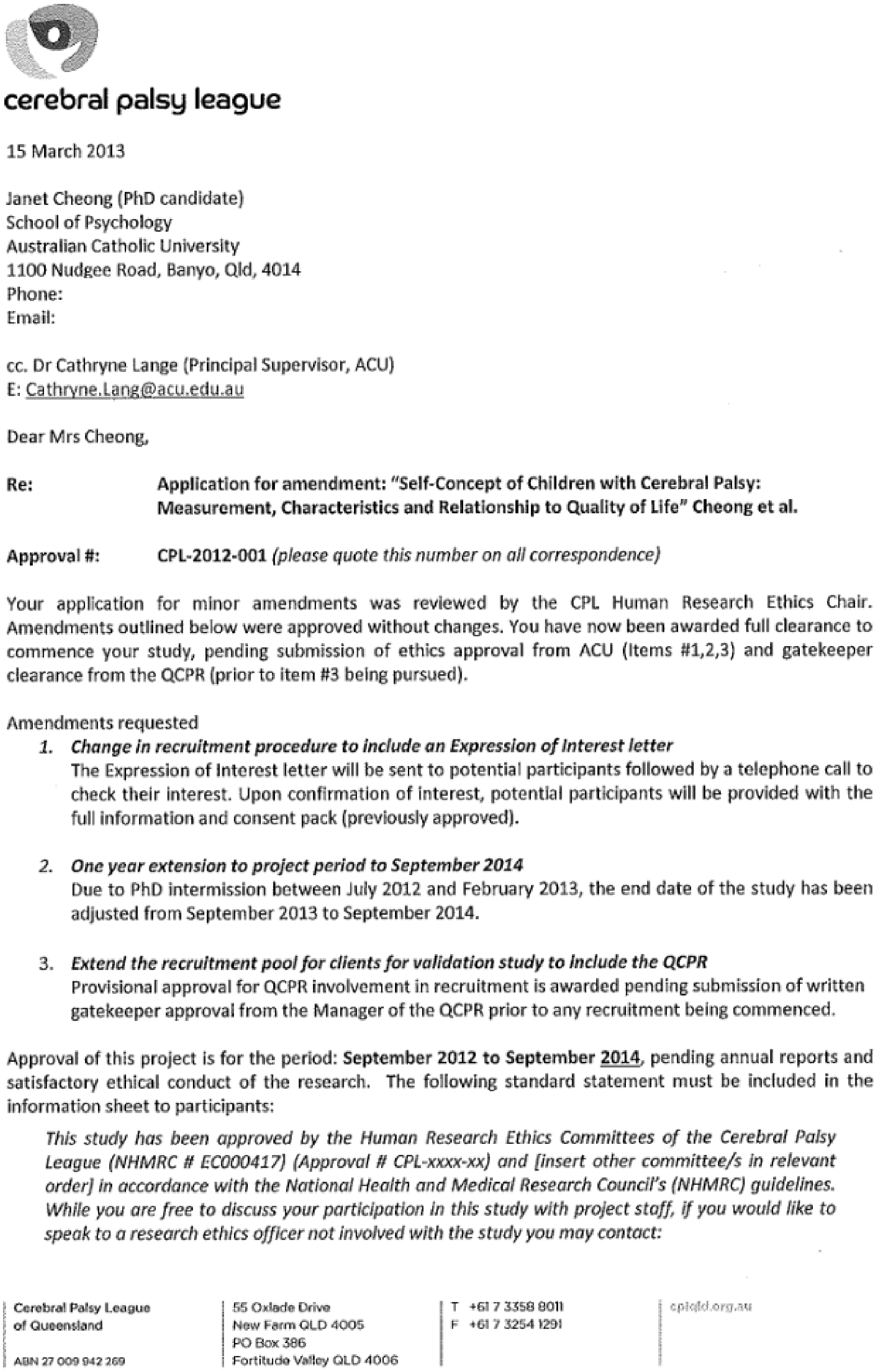
10. **Random Audits**
    The CPL HREC will conduct a randomly indentified audit of a proportion of research projects approved by the Committee. The audit process will look at such issues as;
    - Compliance with approved protocols, e.g. access to potential participants, provision of information, gaining of informed consent, management of data, provision of feedback to participants
    - Security of Documents
    - Consent Form Register
    - Serious Adverse Events Register
    - Withdrawal of Participants – who and why
    - The de-identification of data

11. **CPL Liaison Person**
    If you have any general questions,
    - The CPL liaison person for <u>all</u> external studies is Dr Leanne Johnston, Principal Advisor Research & Ethics
      E: ljohnston@cplqld.org.au;
    - The CPL liaison person for internal and collaborative studies will be assigned by the Research Development Committee as appropriate for each study

The CPL HREC wishes you well with your research. Please contact our CPL HREC Secretary if you require any assistance.

Dr Leanne Johnston
Principal Advisor Research & Ethics
Cerebral Palsy League
PO Box 386
Fortitude Valley Q 4006
E: ljohnston@cplqld.org.au
P:
F: 07 3254 1387

Ethics Approval – Amendment 2



cerebral palsy league

15 March 2013

Janet Cheong (PhD candidate)
School of Psychology
Australian Catholic University
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email:

cc. Dr Cathryne Lange (Principal Supervisor, ACU)
E: Cathryne.Lang@acu.edu.au

Dear Mrs Cheong,

Re: **Application for amendment: "Self-Concept of Children with Cerebral Palsy: Measurement, Characteristics and Relationship to Quality of Life" Cheong et al.**

Approval #: **CPL-2012-001** *(please quote this number on all correspondence)*

Your application for minor amendments was reviewed by the CPL Human Research Ethics Chair. Amendments outlined below were approved without changes. You have now been awarded full clearance to commence your study, pending submission of ethics approval from ACU (Items #1,2,3) and gatekeeper clearance from the QCPR (prior to item #3 being pursued).

Amendments requested

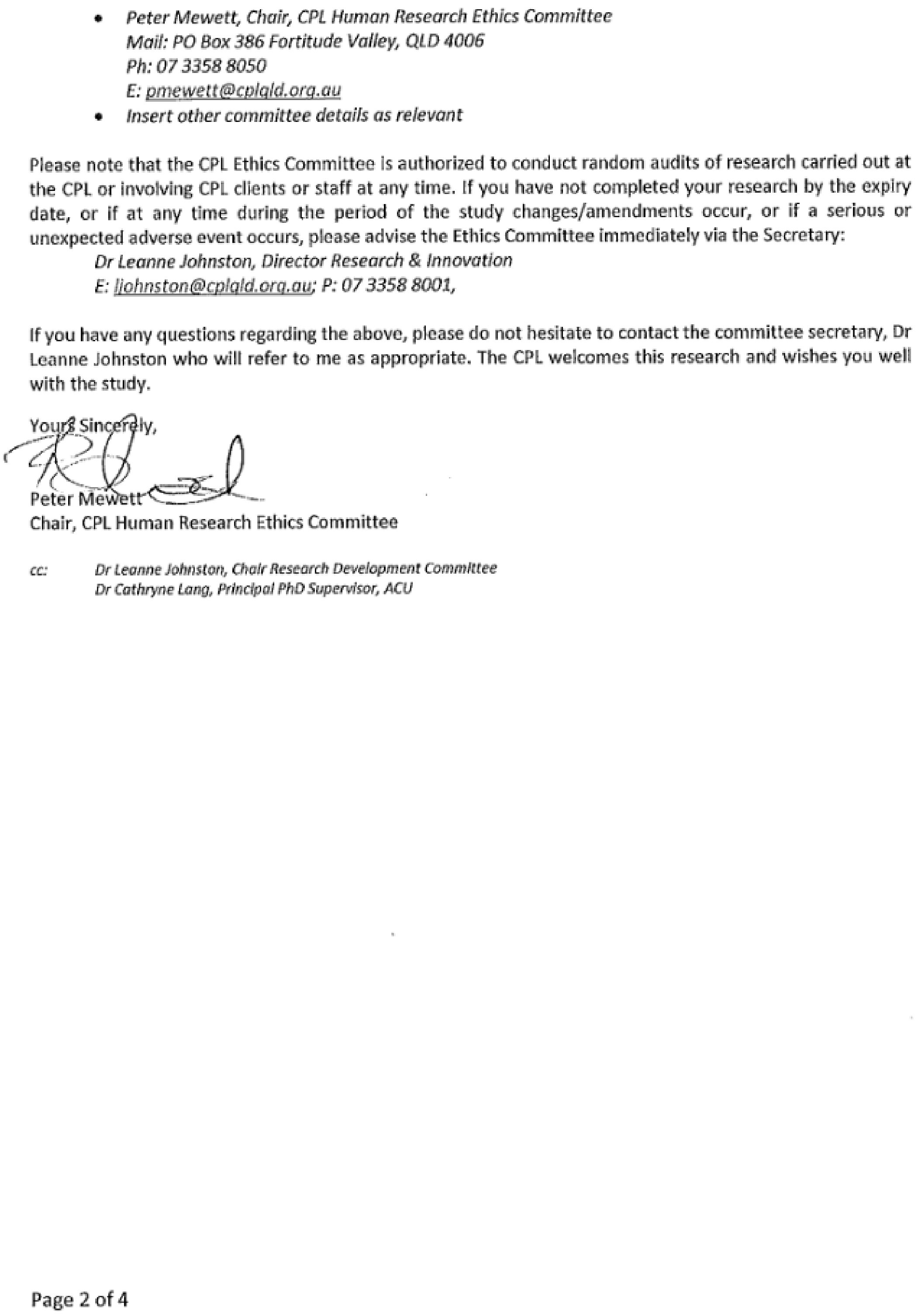
1. ***Change in recruitment procedure to include an Expression of Interest letter***
   The Expression of Interest letter will be sent to potential participants followed by a telephone call to check their interest. Upon confirmation of interest, potential participants will be provided with the full information and consent pack (previously approved).

2. ***One year extension to project period to September 2014***
   Due to PhD intermission between July 2012 and February 2013, the end date of the study has been adjusted from September 2013 to September 2014.

3. ***Extend the recruitment pool for clients for validation study to include the QCPR***
   Provisional approval for QCPR involvement in recruitment is awarded pending submission of written gatekeeper approval from the Manager of the QCPR prior to any recruitment being commenced.

Approval of this project is for the period: **September 2012 to September 2014**, pending annual reports and satisfactory ethical conduct of the research. The following standard statement must be included in the information sheet to participants:

> *This study has been approved by the Human Research Ethics Committees of the Cerebral Palsy League (NHMRC # EC000417) (Approval # CPL-xxxx-xx) and [insert other committee/s in relevant order] in accordance with the National Health and Medical Research Council's (NHMRC) guidelines. While you are free to discuss your participation in this study with project staff, if you would like to speak to a research ethics officer not involved with the study you may contact:*



- *Peter Mewett, Chair, CPL Human Research Ethics Committee*
  Mail: PO Box 386 Fortitude Valley, QLD 4006
  Ph: 07 3358 8050
  E: pmewett@cplqld.org.au
- *Insert other committee details as relevant*

Please note that the CPL Ethics Committee is authorized to conduct random audits of research carried out at the CPL or involving CPL clients or staff at any time. If you have not completed your research by the expiry date, or if at any time during the period of the study changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise the Ethics Committee immediately via the Secretary:

Dr Leanne Johnston, Director Research & Innovation
E: ljohnston@cplqld.org.au; P: 07 3358 8001,

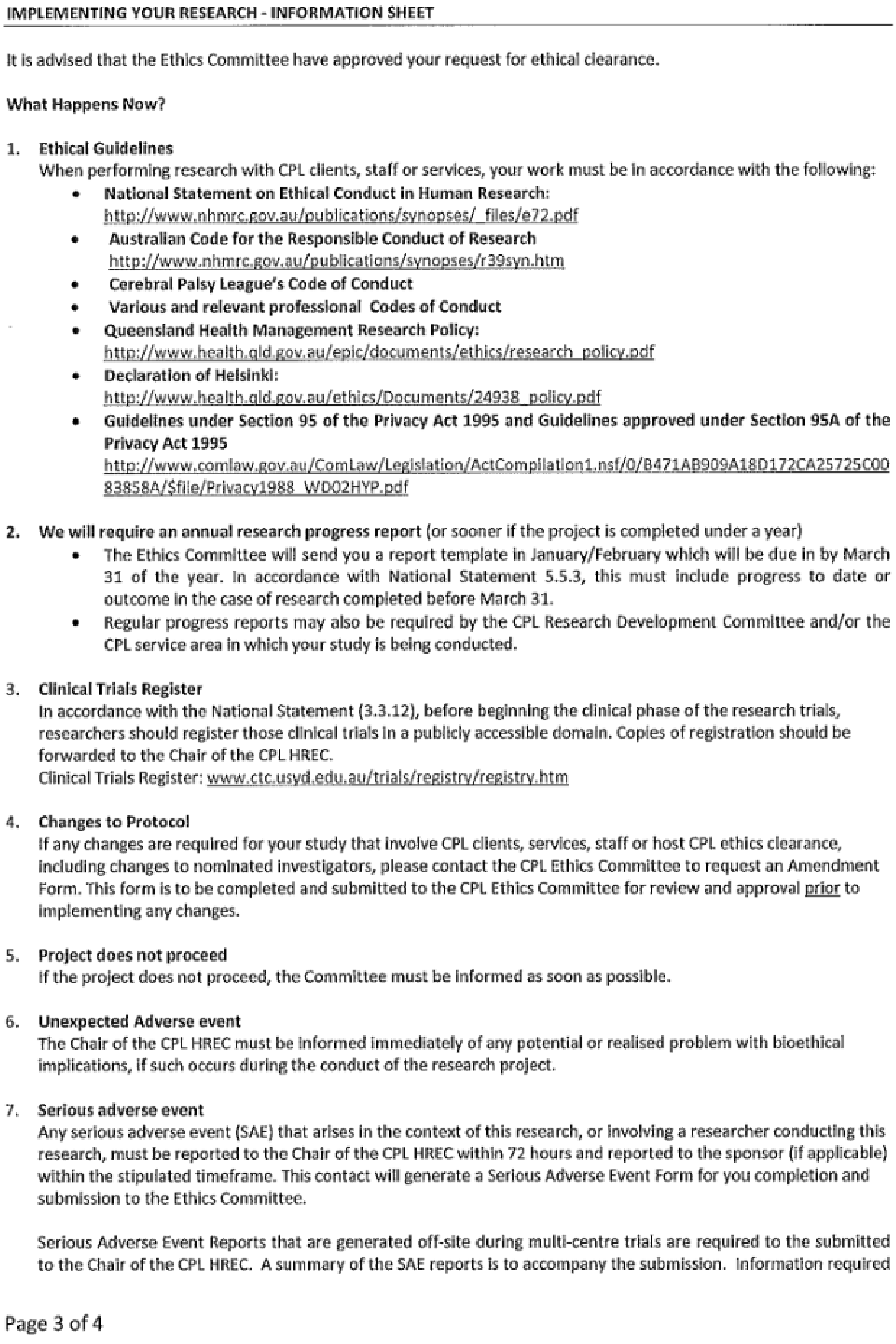
If you have any questions regarding the above, please do not hesitate to contact the committee secretary, Dr Leanne Johnston who will refer to me as appropriate. The CPL welcomes this research and wishes you well with the study.

Yours Sincerely,

Peter Mewett
Chair, CPL Human Research Ethics Committee

cc: *Dr Leanne Johnston, Chair Research Development Committee*
Dr Cathryne Lang, Principal PhD Supervisor, ACU

Page 2 of 4



IMPLEMENTING YOUR RESEARCH - INFORMATION SHEET

It is advised that the Ethics Committee have approved your request for ethical clearance.

What Happens Now?

1. **Ethical Guidelines**
   When performing research with CPL clients, staff or services, your work must be in accordance with the following:
   - **National Statement on Ethical Conduct in Human Research:** http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf
   - **Australian Code for the Responsible Conduct of Research** http://www.nhmrc.gov.au/publications/synopses/r39syn.htm
   - **Cerebral Palsy League's Code of Conduct**
   - **Various and relevant professional Codes of Conduct**
   - **Queensland Health Management Research Policy:** http://www.health.qld.gov.au/epic/documents/ethics/research_policy.pdf
   - **Declaration of Helsinki:** http://www.health.qld.gov.au/ethics/Documents/24938_policy.pdf
   - **Guidelines under Section 95 of the Privacy Act 1995 and Guidelines approved under Section 95A of the Privacy Act 1995** http://www.comlaw.gov.au/ComLaw/Legislation/ActCompilation1.nsf/0/B471AB909A18D172CA25725C0083858A/$file/Privacy1988_WD02HYP.pdf

2. **We will require an annual research progress report** (or sooner if the project is completed under a year)
   - The Ethics Committee will send you a report template in January/February which will be due in by March 31 of the year. In accordance with National Statement 5.5.3, this must include progress to date or outcome in the case of research completed before March 31.
   - Regular progress reports may also be required by the CPL Research Development Committee and/or the CPL service area in which your study is being conducted.

3. **Clinical Trials Register**
   In accordance with the National Statement (3.3.12), before beginning the clinical phase of the research trials, researchers should register those clinical trials in a publicly accessible domain. Copies of registration should be forwarded to the Chair of the CPL HREC.
   Clinical Trials Register: www.ctc.usyd.edu.au/trials/registry/registry.htm

4. **Changes to Protocol**
   If any changes are required for your study that involve CPL clients, services, staff or host CPL ethics clearance, including changes to nominated investigators, please contact the CPL Ethics Committee to request an Amendment Form. This form is to be completed and submitted to the CPL Ethics Committee for review and approval prior to implementing any changes.

5. **Project does not proceed**
   If the project does not proceed, the Committee must be informed as soon as possible.

6. **Unexpected Adverse event**
   The Chair of the CPL HREC must be informed immediately of any potential or realised problem with bioethical implications, if such occurs during the conduct of the research project.

7. **Serious adverse event**
   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 Chair of the CPL HREC within 72 hours and reported to the sponsor (if applicable) within the stipulated timeframe. This contact will generate a Serious Adverse Event Form for you completion and submission to the Ethics Committee.

   Serious Adverse Event Reports that are generated off-site during multi-centre trials are required to the submitted to the Chair of the CPL HREC. A summary of the SAE reports is to accompany the submission. Information required

includes: client details (age & sex), adverse event, outcome and the likelihood of the event being related to the study drug/device/procedures.

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 Chair of the Ethics Committee)

8. **Research Complaints**
You are required to notify the CPL HREC if any complaint about the conduct of your research is lodged. Contact the secretary to obtain the relevant procedures and forms.

9. **Intention to publish**
We require researchers to notify the CPL HREC to declare the intent to publish findings in a refereed journal or similar peer-reviewed forum. The Cerebral Palsy League must be acknowledged when applicable.

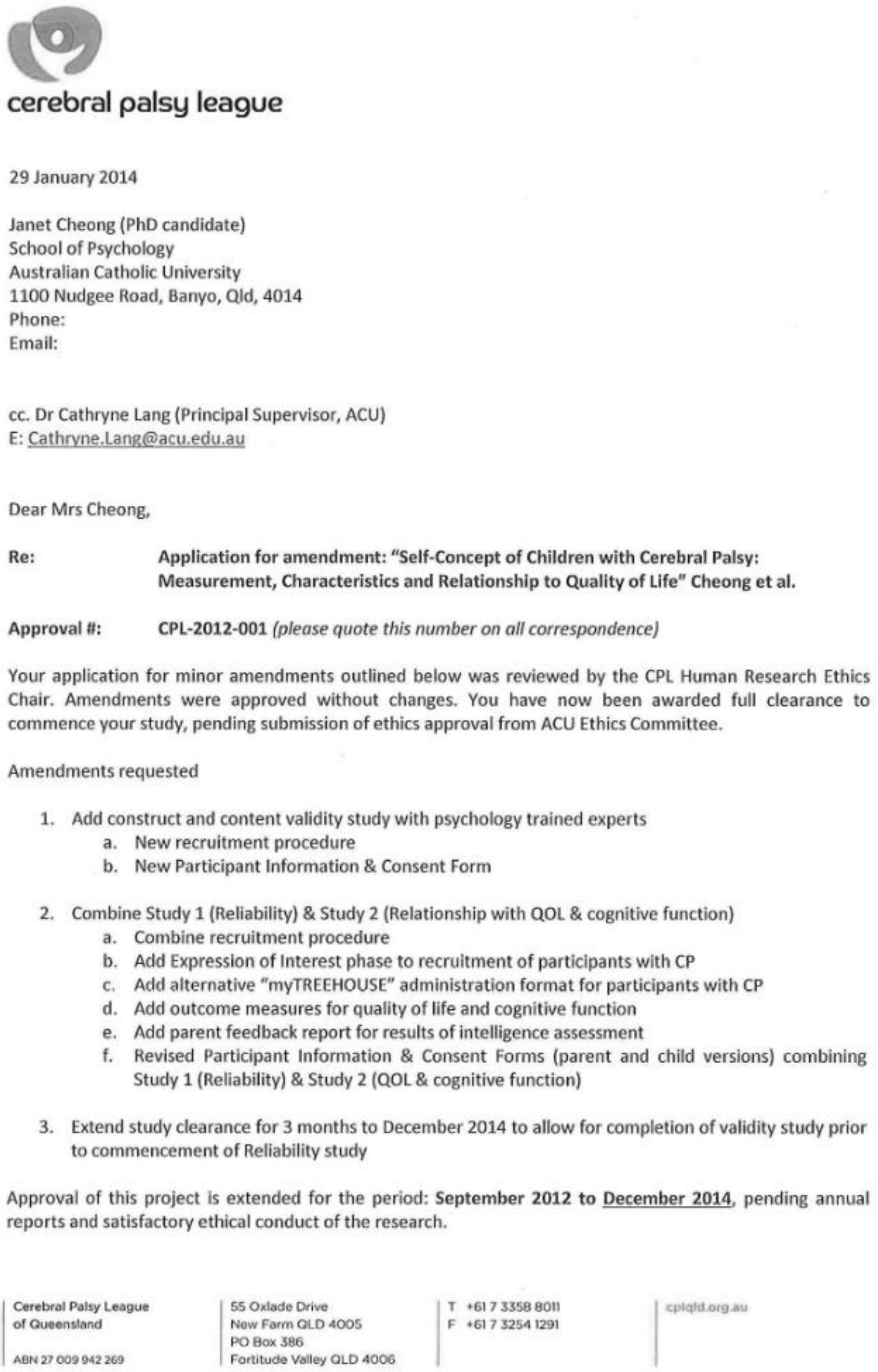
10. **Random Audits**
The CPL HREC will conduct a randomly indentified audit of a proportion of research projects approved by the Committee. The audit process will look at such issues as;
    - Compliance with approved protocols, e.g. access to potential participants, provision of information, gaining of informed consent, management of data, provision of feedback to participants
    - Security of Documents
    - Consent Form Register
    - Serious Adverse Events Register
    - Withdrawal of Participants – who and why
    - The de-identification of data

11. **CPL Liaison Person**
If you have any general questions,
    - The CPL liaison person for <u>all</u> external studies is Dr Leanne Johnston, Principal Advisor Research & Ethics E: ljohnston@cplqld.org.au;
    - The CPL liaison person for internal and collaborative studies will be assigned by the Research Development Committee as appropriate for each study

The CPL HREC wishes you well with your research. Please contact our CPL HREC Secretary if you require any assistance.

Dr Leanne Johnston
Principal Advisor Research & Ethics
Cerebral Palsy League
PO Box 386
Fortitude Valley Q 4006
E: ljohnston@cplqld.org.au
P:
F: 07 3254 1387

Ethics Approval – Amendment 3



cerebral palsy league

29 January 2014

Janet Cheong (PhD candidate)
School of Psychology
Australian Catholic University
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email:

cc. Dr Cathryne Lang (Principal Supervisor, ACU)
E: Cathryne.Lang@acu.edu.au

Dear Mrs Cheong,

Re: **Application for amendment: "Self-Concept of Children with Cerebral Palsy: Measurement, Characteristics and Relationship to Quality of Life" Cheong et al.**

Approval #: **CPL-2012-001** *(please quote this number on all correspondence)*

Your application for minor amendments outlined below was reviewed by the CPL Human Research Ethics Chair. Amendments were approved without changes. You have now been awarded full clearance to commence your study, pending submission of ethics approval from ACU Ethics Committee.

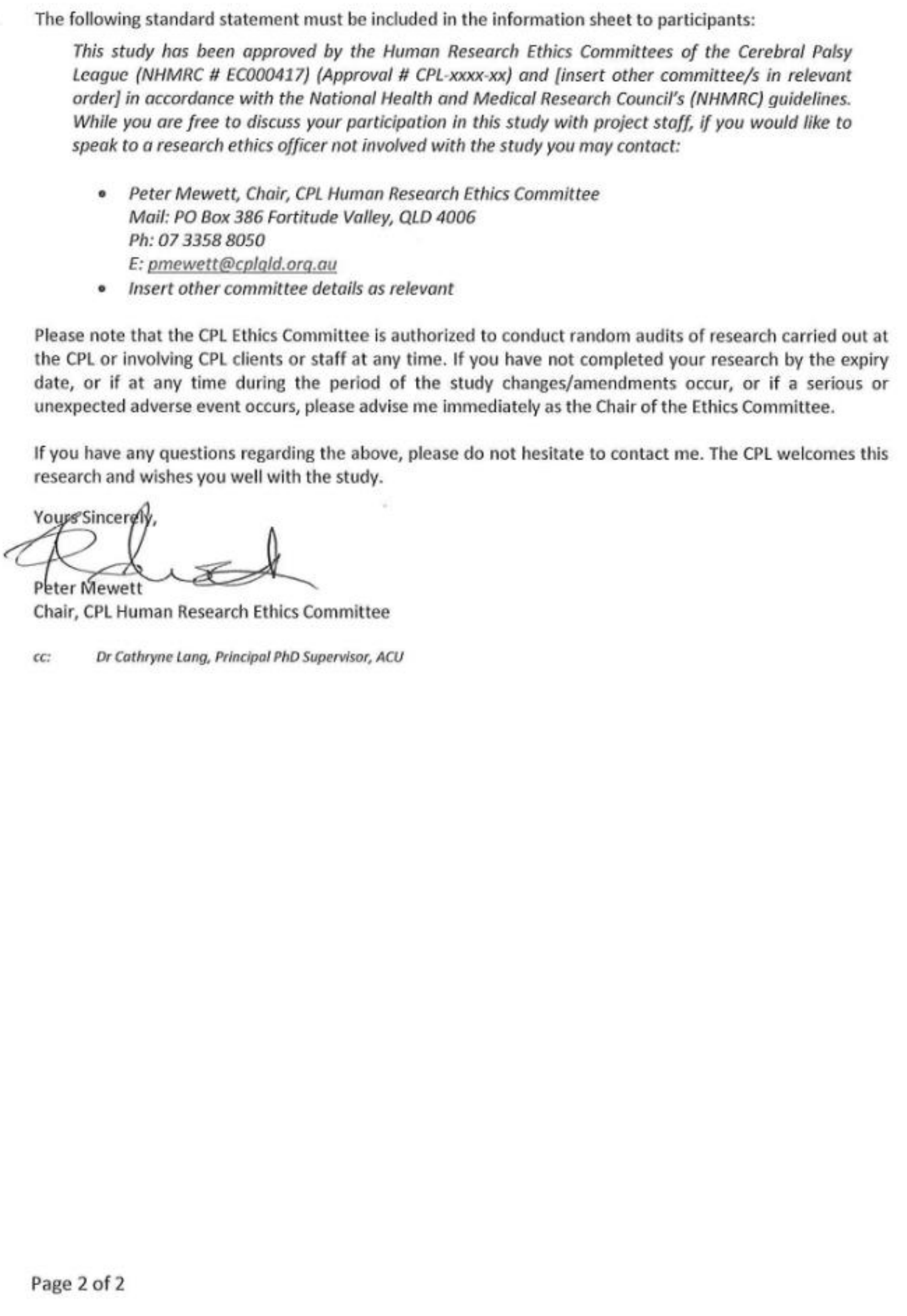
Amendments requested

1. Add construct and content validity study with psychology trained experts
    a. New recruitment procedure
    b. New Participant Information & Consent Form

2. Combine Study 1 (Reliability) & Study 2 (Relationship with QOL & cognitive function)
    a. Combine recruitment procedure
    b. Add Expression of Interest phase to recruitment of participants with CP
    c. Add alternative "myTREEHOUSE" administration format for participants with CP
    d. Add outcome measures for quality of life and cognitive function
    e. Add parent feedback report for results of intelligence assessment
    f. Revised Participant Information & Consent Forms (parent and child versions) combining Study 1 (Reliability) & Study 2 (QOL & cognitive function)

3. Extend study clearance for 3 months to December 2014 to allow for completion of validity study prior to commencement of Reliability study

Approval of this project is extended for the period: **September 2012 to December 2014**, pending annual reports and satisfactory ethical conduct of the research.



The following standard statement must be included in the information sheet to participants:

> *This study has been approved by the Human Research Ethics Committees of the Cerebral Palsy League (NHMRC # EC000417) (Approval # CPL-xxxx-xx) and [insert other committee/s in relevant order] in accordance with the National Health and Medical Research Council's (NHMRC) guidelines. While you are free to discuss your participation in this study with project staff, if you would like to speak to a research ethics officer not involved with the study you may contact:*
>
> - *Peter Mewett, Chair, CPL Human Research Ethics Committee*
>   *Mail: PO Box 386 Fortitude Valley, QLD 4006*
>   *Ph: 07 3358 8050*
>   *E: pmewett@cplqld.org.au*
> - *Insert other committee details as relevant*

Please note that the CPL Ethics Committee is authorized to conduct random audits of research carried out at the CPL or involving CPL clients or staff at any time. If you have not completed your research by the expiry date, or if at any time during the period of the study changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise me immediately as the Chair of the Ethics Committee.

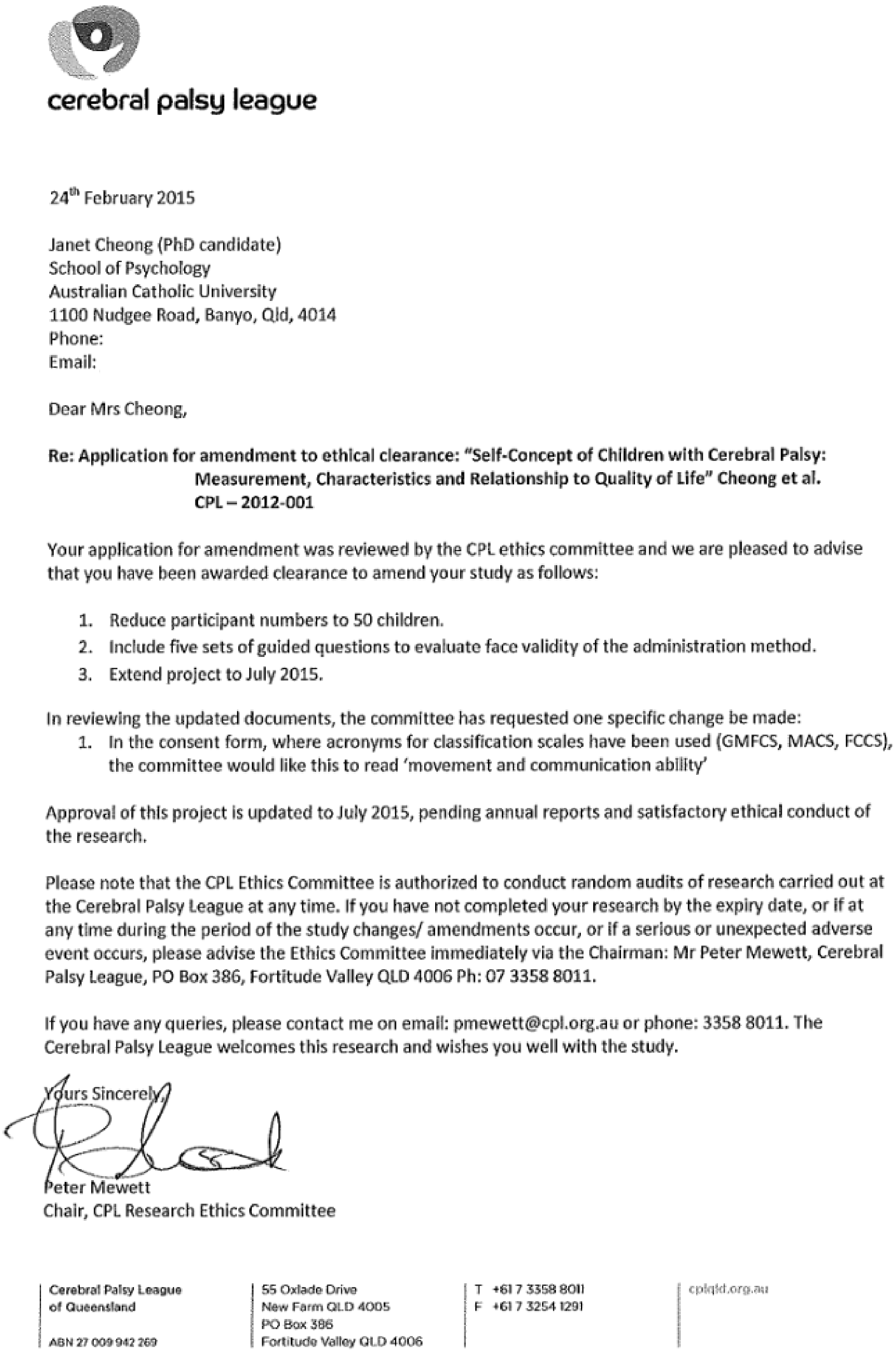
If you have any questions regarding the above, please do not hesitate to contact me. The CPL welcomes this research and wishes you well with the study.

Yours Sincerely,

Peter Mewett
Chair, CPL Human Research Ethics Committee

cc: *Dr Cathryne Lang, Principal PhD Supervisor, ACU*

Ethics Approval – Amendment 4



cerebral palsy league

24th February 2015

Janet Cheong (PhD candidate)
School of Psychology
Australian Catholic University
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email:

Dear Mrs Cheong,

Re: Application for amendment to ethical clearance: "Self-Concept of Children with Cerebral Palsy: Measurement, Characteristics and Relationship to Quality of Life" Cheong et al.
CPL – 2012-001

Your application for amendment was reviewed by the CPL ethics committee and we are pleased to advise that you have been awarded clearance to amend your study as follows:

1. Reduce participant numbers to 50 children.
2. Include five sets of guided questions to evaluate face validity of the administration method.
3. Extend project to July 2015.

In reviewing the updated documents, the committee has requested one specific change be made:

1. In the consent form, where acronyms for classification scales have been used (GMFCS, MACS, FCCS), the committee would like this to read 'movement and communication ability'

Approval of this project is updated to July 2015, pending annual reports and satisfactory ethical conduct of the research.

Please note that the CPL Ethics Committee is authorized to conduct random audits of research carried out at the Cerebral Palsy League at any time. If you have not completed your research by the expiry date, or if at any time during the period of the study changes/ amendments occur, or if a serious or unexpected adverse event occurs, please advise the Ethics Committee immediately via the Chairman: Mr Peter Mewett, Cerebral Palsy League, PO Box 386, Fortitude Valley QLD 4006 Ph: 07 3358 8011.

If you have any queries, please contact me on email: pmewett@cpl.org.au or phone: 3358 8011. The Cerebral Palsy League welcomes this research and wishes you well with the study.

Yours Sincerely,

Peter Mewett
Chair, CPL Research Ethics Committee

Cerebral Palsy League
of Queensland

ABN 27 009 942 269

55 Oxlade Drive
New Farm QLD 4005
PO Box 386
Fortitude Valley QLD 4006

T +61 7 3358 8011
F +61 7 3254 1291

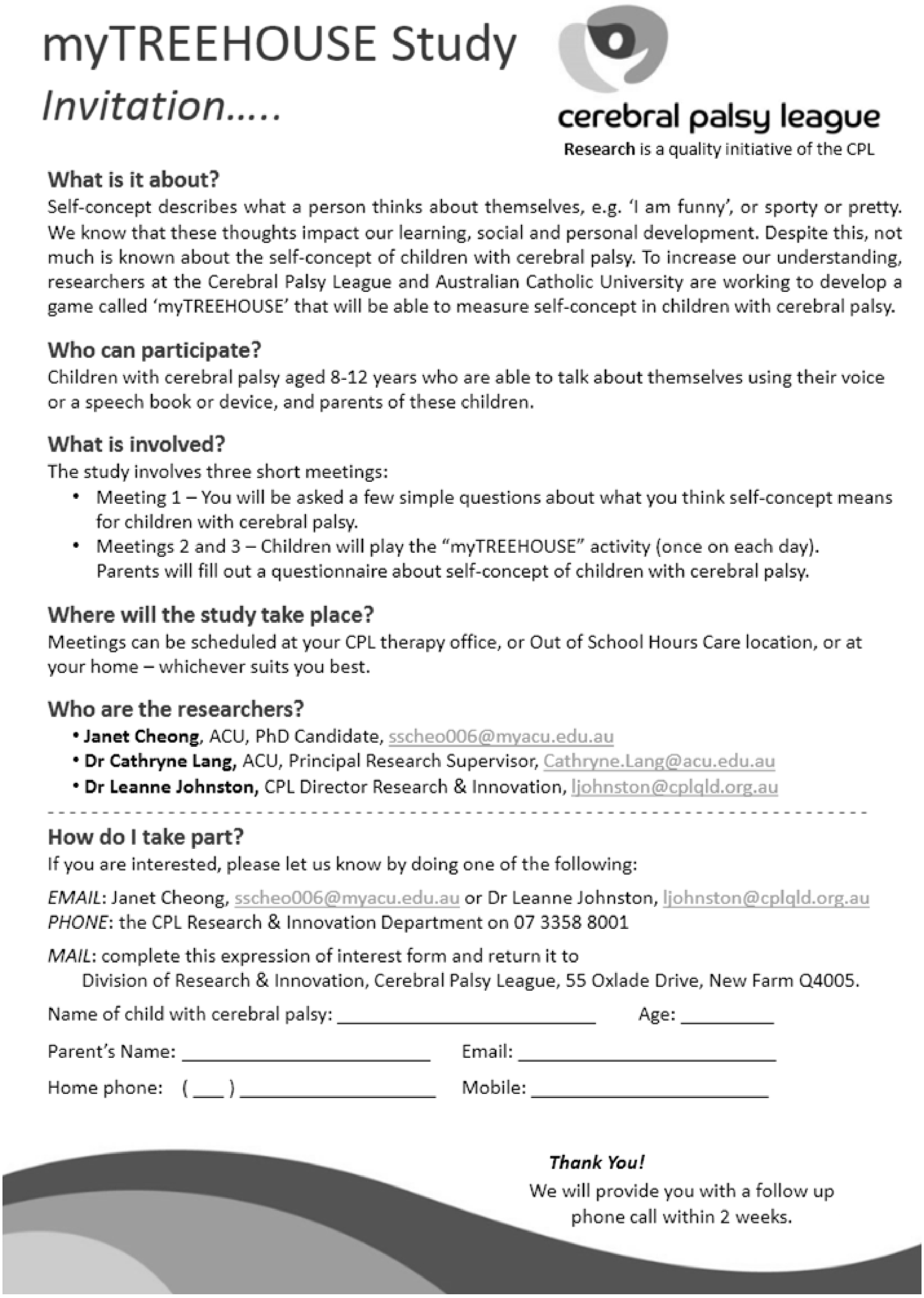
cplqld.org.au

Appendix D Delphi Consensus Survey (Study 2) Materials

Appendix D includes the materials utilised for the Delphi consensus survey (Study 2).

Following are the page reference for the individual items:

Study 2: Mailout Flier



myTREEHOUSE Study

Invitation…..

cerebral palsy league

Research is a quality initiative of the CPL

What is it about?

Self-concept describes what a person thinks about themselves, e.g. 'I am funny', or sporty or pretty. We know that these thoughts impact our learning, social and personal development. Despite this, not much is known about the self-concept of children with cerebral palsy. To increase our understanding, researchers at the Cerebral Palsy League and Australian Catholic University are working to develop a game called 'myTREEHOUSE' that will be able to measure self-concept in children with cerebral palsy.

Who can participate?

Children with cerebral palsy aged 8-12 years who are able to talk about themselves using their voice or a speech book or device, and parents of these children.

What is involved?

The study involves three short meetings:

- Meeting 1 – You will be asked a few simple questions about what you think self-concept means for children with cerebral palsy.
- Meetings 2 and 3 – Children will play the "myTREEHOUSE" activity (once on each day). Parents will fill out a questionnaire about self-concept of children with cerebral palsy.

Where will the study take place?

Meetings can be scheduled at your CPL therapy office, or Out of School Hours Care location, or at your home – whichever suits you best.

Who are the researchers?

- **Janet Cheong**, ACU, PhD Candidate, sscheo006@myacu.edu.au
- **Dr Cathryne Lang,** ACU, Principal Research Supervisor, Cathryne.Lang@acu.edu.au
- **Dr Leanne Johnston,** CPL Director Research & Innovation, ljohnston@cplqld.org.au

- -

How do I take part?

If you are interested, please let us know by doing one of the following:

EMAIL: Janet Cheong, sscheo006@myacu.edu.au or Dr Leanne Johnston, ljohnston@cplqld.org.au
PHONE: the CPL Research & Innovation Department on 07 3358 8001

MAIL: complete this expression of interest form and return it to
Division of Research & Innovation, Cerebral Palsy League, 55 Oxlade Drive, New Farm Q4005.

Name of child with cerebral palsy: ______________________ Age: ________

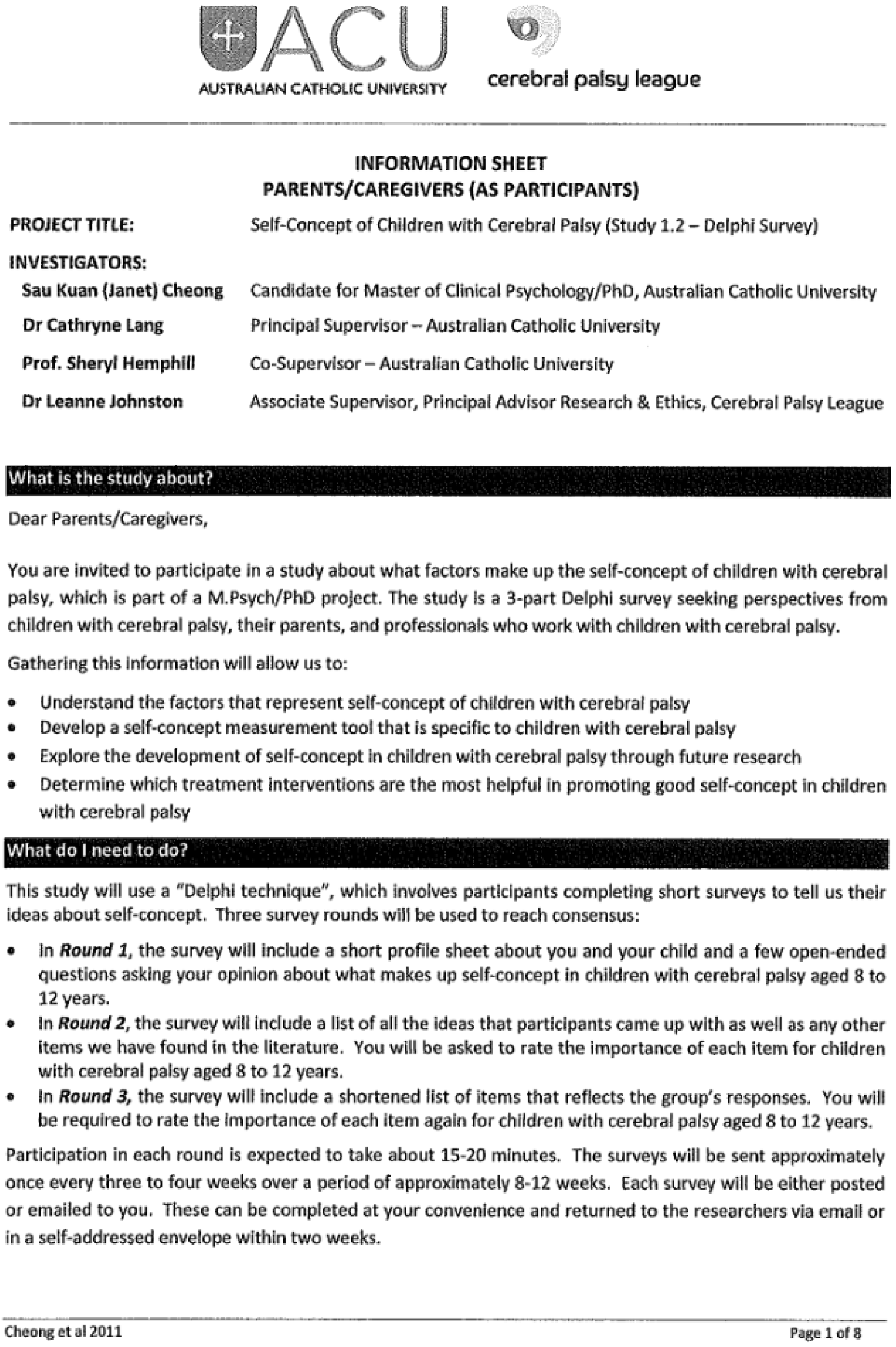
Parent's Name: ______________________ Email: ______________________

Home phone: (___) __________________ Mobile: ______________________

Thank You!

We will provide you with a follow up
phone call within 2 weeks.

Study 2: Parent Information Letter



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

INFORMATION SHEET
PARENTS/CAREGIVERS (AS PARTICIPANTS)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Study 1.2 – Delphi Survey)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

What is the study about?

Dear Parents/Caregivers,

You are invited to participate in a study about what factors make up the self-concept of children with cerebral palsy, which is part of a M.Psych/PhD project. The study is a 3-part Delphi survey seeking perspectives from children with cerebral palsy, their parents, and professionals who work with children with cerebral palsy.

Gathering this information will allow us to:

- Understand the factors that represent self-concept of children with cerebral palsy
- Develop a self-concept measurement tool that is specific to children with cerebral palsy
- Explore the development of self-concept in children with cerebral palsy through future research
- Determine which treatment interventions are the most helpful in promoting good self-concept in children with cerebral palsy

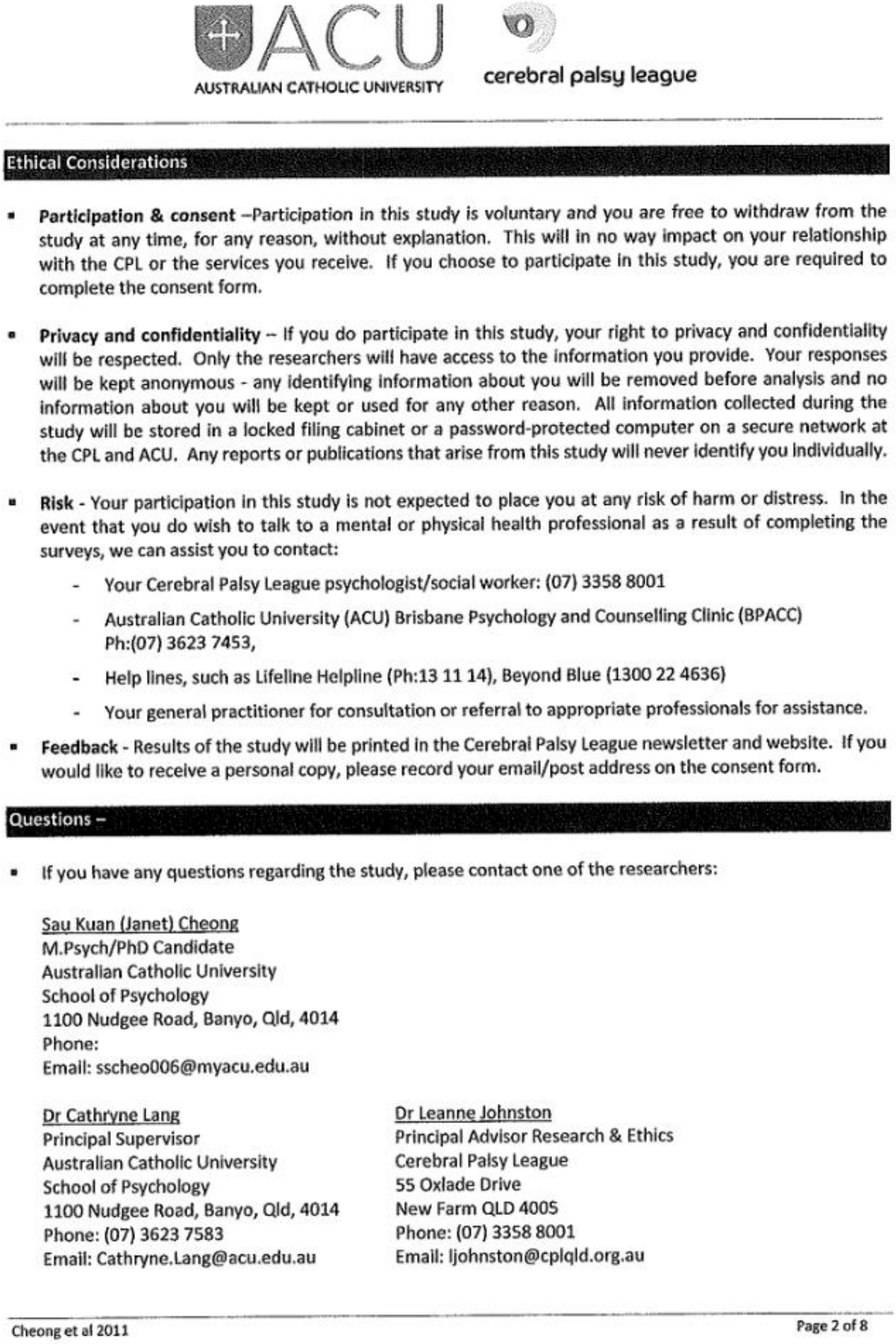
What do I need to do?

This study will use a "Delphi technique", which involves participants completing short surveys to tell us their ideas about self-concept. Three survey rounds will be used to reach consensus:

- In ***Round 1***, the survey will include a short profile sheet about you and your child and a few open-ended questions asking your opinion about what makes up self-concept in children with cerebral palsy aged 8 to 12 years.
- In ***Round 2***, the survey will include a list of all the ideas that participants came up with as well as any other items we have found in the literature. You will be asked to rate the importance of each item for children with cerebral palsy aged 8 to 12 years.
- In ***Round 3,*** the survey will include a shortened list of items that reflects the group's responses. You will be required to rate the importance of each item again for children with cerebral palsy aged 8 to 12 years.

Participation in each round is expected to take about 15-20 minutes. The surveys will be sent approximately once every three to four weeks over a period of approximately 8-12 weeks. Each survey will be either posted or emailed to you. These can be completed at your convenience and returned to the researchers via email or in a self-addressed envelope within two weeks.

Cheong et al 2011 Page 1 of 8



ACU
AUSTRALIAN CATHOLIC UNIVERSITY
cerebral palsy league

Ethical Considerations

- **Participation & consent** –Participation in this study is voluntary and you are free to withdraw from the study at any time, for any reason, without explanation. This will in no way impact on your relationship with the CPL or the services you receive. If you choose to participate in this study, you are required to complete the consent form.
- **Privacy and confidentiality** – If you do participate in this study, your right to privacy and confidentiality will be respected. Only the researchers will have access to the information you provide. Your responses will be kept anonymous - any identifying information about you will be removed before analysis and no information about you will be kept or used for any other reason. All information collected during the study will be stored in a locked filing cabinet or a password-protected computer on a secure network at the CPL and ACU. Any reports or publications that arise from this study will never identify you individually.
- **Risk** - Your participation in this study is not expected to place you at any risk of harm or distress. In the event that you do wish to talk to a mental or physical health professional as a result of completing the surveys, we can assist you to contact:
    - Your Cerebral Palsy League psychologist/social worker: (07) 3358 8001
    - Australian Catholic University (ACU) Brisbane Psychology and Counselling Clinic (BPACC) Ph:(07) 3623 7453,
    - Help lines, such as Lifeline Helpline (Ph:13 11 14), Beyond Blue (1300 22 4636)
    - Your general practitioner for consultation or referral to appropriate professionals for assistance.
- **Feedback** - Results of the study will be printed in the Cerebral Palsy League newsletter and website. If you would like to receive a personal copy, please record your email/post address on the consent form.

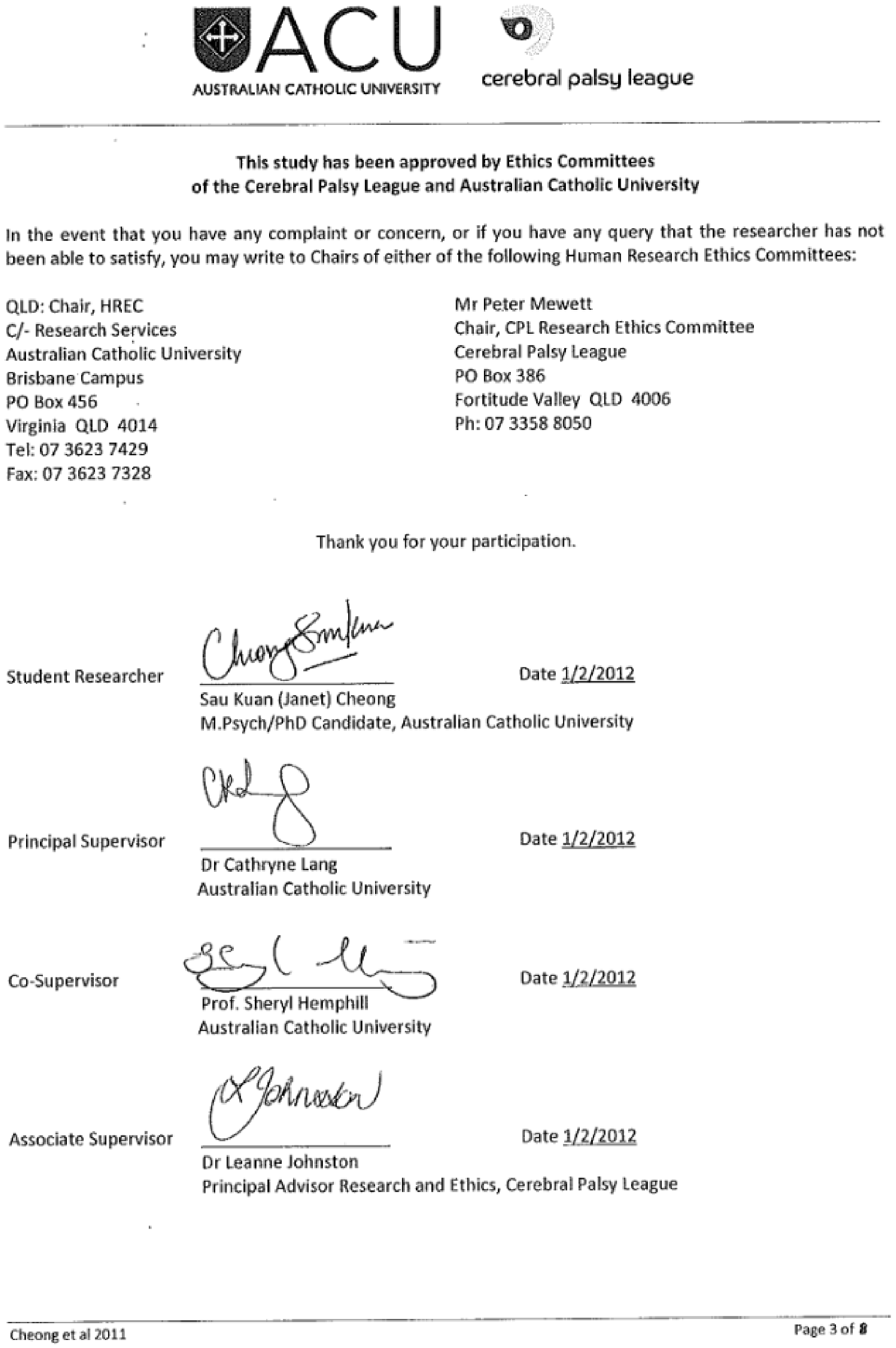
Questions –

- If you have any questions regarding the study, please contact one of the researchers:

Sau Kuan (Janet) Cheong
M.Psych/PhD Candidate
Australian Catholic University
School of Psychology
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email: sscheo006@myacu.edu.au

Dr Cathryne Lang
Principal Supervisor
Australian Catholic University
School of Psychology
1100 Nudgee Road, Banyo, Qld, 4014
Phone: (07) 3623 7583
Email: Cathryne.Lang@acu.edu.au

Dr Leanne Johnston
Principal Advisor Research & Ethics
Cerebral Palsy League
55 Oxlade Drive
New Farm QLD 4005
Phone: (07) 3358 8001
Email: ljohnston@cplqld.org.au



AUSTRALIAN CATHOLIC UNIVERSITY
cerebral palsy league

This study has been approved by Ethics Committees of the Cerebral Palsy League and Australian Catholic University

In the event that you have any complaint or concern, or if you have any query that the researcher has not been able to satisfy, you may write to Chairs of either of the following Human Research Ethics Committees:

QLD: Chair, HREC
C/- Research Services
Australian Catholic University
Brisbane Campus
PO Box 456
Virginia QLD 4014
Tel: 07 3623 7429
Fax: 07 3623 7328

Mr Peter Mewett
Chair, CPL Research Ethics Committee
Cerebral Palsy League
PO Box 386
Fortitude Valley QLD 4006
Ph: 07 3358 8050

Thank you for your participation.

Student Researcher ______ Date 1/2/2012
Sau Kuan (Janet) Cheong
M.Psych/PhD Candidate, Australian Catholic University

Principal Supervisor ______ Date 1/2/2012
Dr Cathryne Lang
Australian Catholic University

Co-Supervisor ______ Date 1/2/2012
Prof. Sheryl Hemphill
Australian Catholic University

Associate Supervisor ______ Date 1/2/2012
Dr Leanne Johnston
Principal Advisor Research and Ethics, Cerebral Palsy League

This page is deliberately left blank

Please turn to the next page

AUSTRALIAN CATHOLIC UNIVERSITY
cerebral palsy league

CONSENT FORM (COPY FOR PARTICIPANT TO KEEP)
PARENT/CAREGIVER (AS A PARTICIPANT)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Study 1.2 – Delphi Survey)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

1. I, ______________________________ agree to take part in the research project titled:
(PLEASE PRINT YOUR NAME)

Self-Concept of Children with Cerebral Palsy

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me has been fully explained to my satisfaction by the investigators.

3. The details of the research procedures for me has been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I understand that the procedures to be undertaken in the project are as follows:
   - **Round 1: Provide demographic information and complete a questionnaire about self-concept in children with cerebral palsy**
   - **Round 2: Complete a questionnaire about self-concept in children with cerebral palsy**
   - **Round 3: Complete a questionnaire about self-concept in children with cerebral palsy**

5. I understand that the purpose of this research is to gain information that will improve the quality of services for children with cerebral palsy and my involvement may not be of any direct benefit to me/my child.

6. I have been informed that the results of research involving me will not be published so as to reveal my identity and that my privacy will be maintained at all times.

7. I understand that I am free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My questionnaire data to be used for the current study

Potential future use of my information
☐ Copies of my questionnaire data to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___/___/___
(Participant)

Telephone: ____________________________

Email: ________________________________

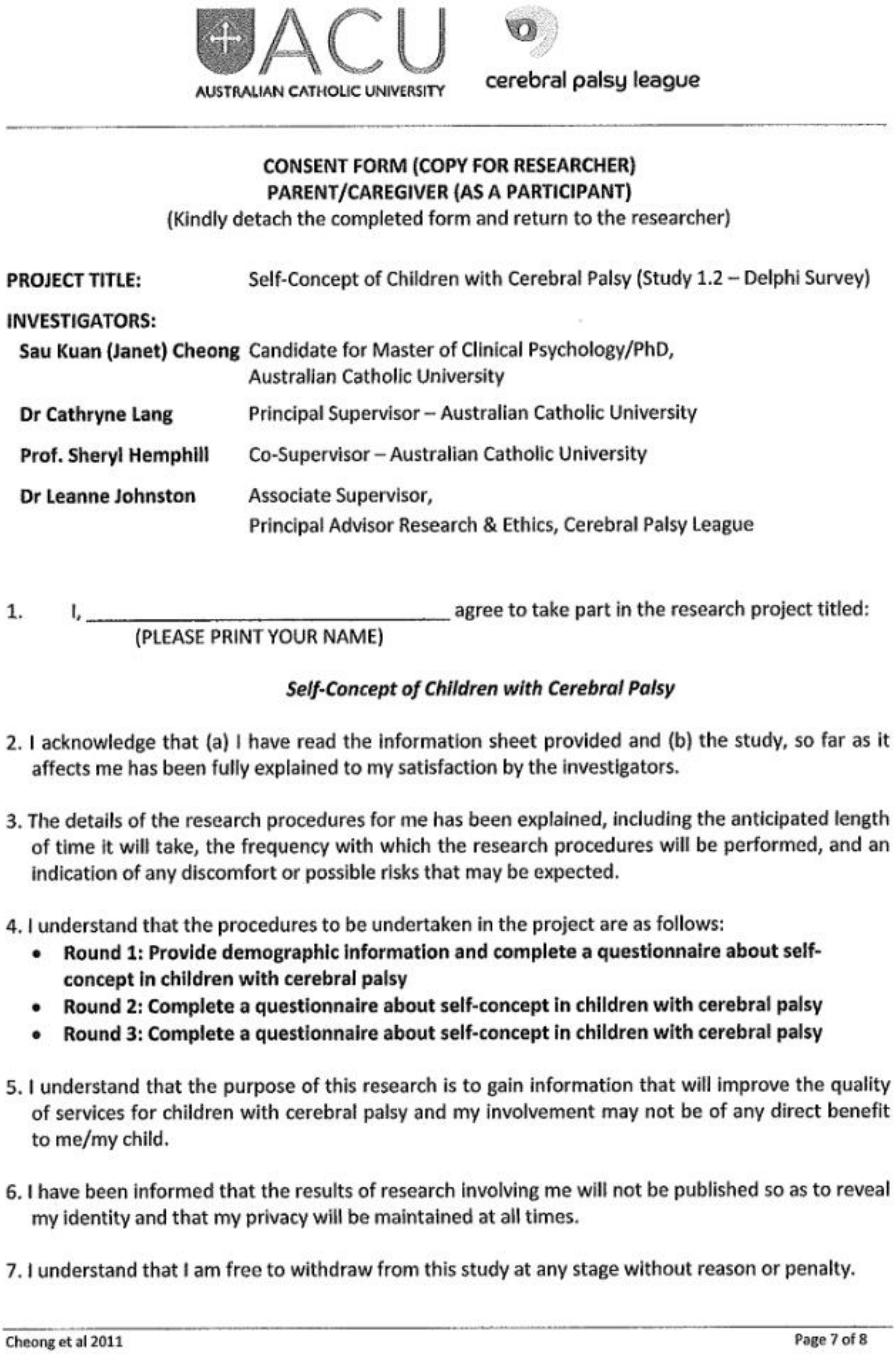
Postal address: ____

I would like to receive a copy of the study results
☐ No ☐ Yes, by email ☐ Yes, by post

Signed: ______________________________ Date: ___/___/___
(Witness)

Signed: ______________________________ Date: ___/___/___
(Investigator)

Footnote ** According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*



ACU
AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CONSENT FORM (COPY FOR RESEARCHER)
PARENT/CAREGIVER (AS A PARTICIPANT)

(Kindly detach the completed form and return to the researcher)

PROJECT TITLE: Self-Concept of Children with Cerebral Palsy (Study 1.2 – Delphi Survey)

INVESTIGATORS:

Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

1. I, ________________________________ agree to take part in the research project titled:
(PLEASE PRINT YOUR NAME)

Self-Concept of Children with Cerebral Palsy

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me has been fully explained to my satisfaction by the investigators.

3. The details of the research procedures for me has been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I understand that the procedures to be undertaken in the project are as follows:
   - **Round 1: Provide demographic information and complete a questionnaire about self-concept in children with cerebral palsy**
   - **Round 2: Complete a questionnaire about self-concept in children with cerebral palsy**
   - **Round 3: Complete a questionnaire about self-concept in children with cerebral palsy**

5. I understand that the purpose of this research is to gain information that will improve the quality of services for children with cerebral palsy and my involvement may not be of any direct benefit to me/my child.

6. I have been informed that the results of research involving me will not be published so as to reveal my identity and that my privacy will be maintained at all times.

7. I understand that I am free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My questionnaire data to be used for the current study

Potential future use of my child's information
☐ Copies of my questionnaire data to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___/___/___
(Participant)

Telephone: ____________________________

Email: ________________________________

Postal address: ____

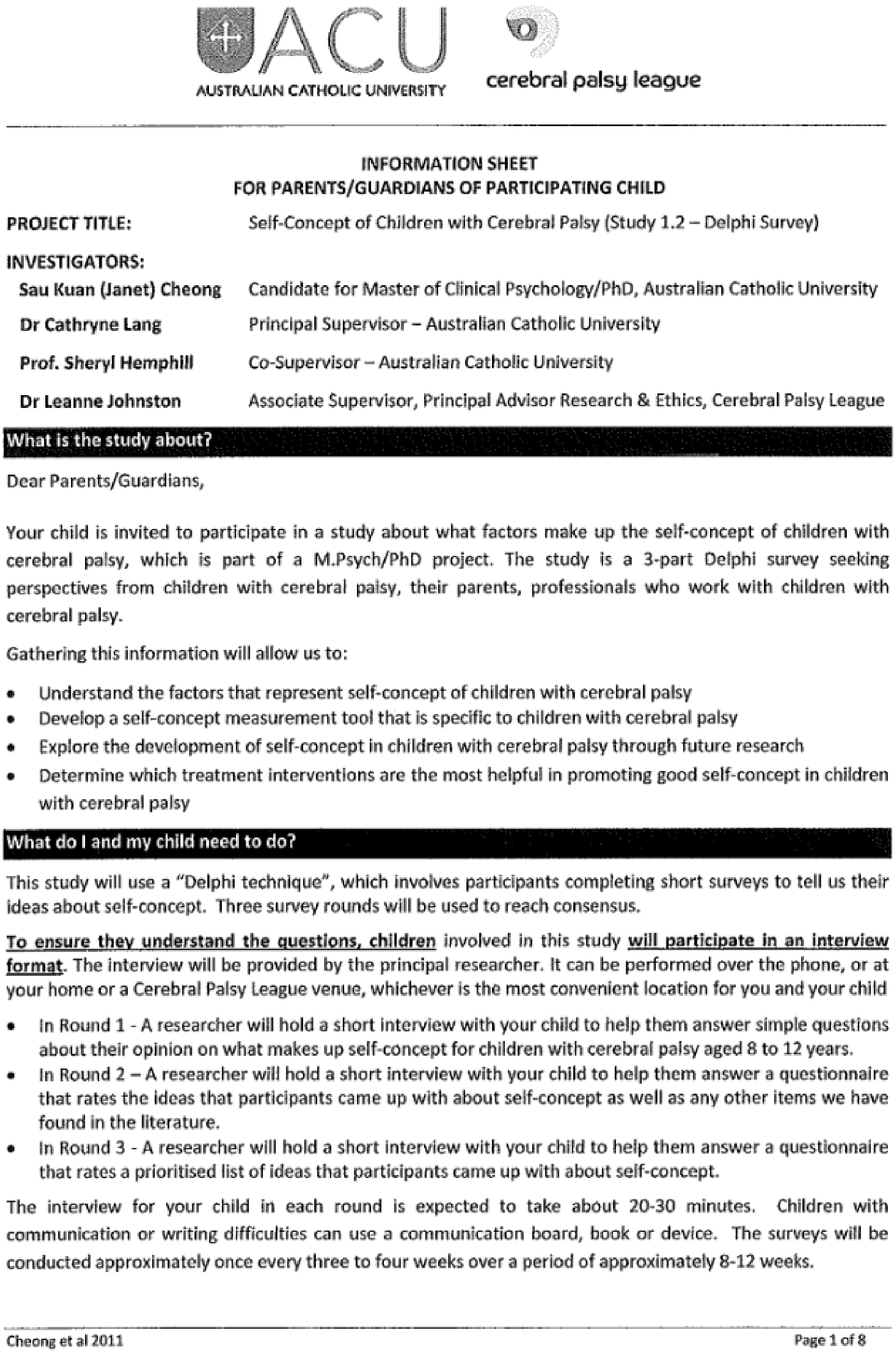
I would like to receive a copy of the study results
☐ No ☐ Yes, by email ☐ Yes, by post

Signed: ______________________________ Date: ___/___/___
(Witness)

Signed: ______________________________ Date: ___/___/___
(Investigator)

Footnote ** According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*

Study 2: Child Information Letter



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

INFORMATION SHEET
FOR PARENTS/GUARDIANS OF PARTICIPATING CHILD

PROJECT TITLE: Self-Concept of Children with Cerebral Palsy (Study 1.2 – Delphi Survey)

INVESTIGATORS:

Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

What is the study about?

Dear Parents/Guardians,

Your child is invited to participate in a study about what factors make up the self-concept of children with cerebral palsy, which is part of a M.Psych/PhD project. The study is a 3-part Delphi survey seeking perspectives from children with cerebral palsy, their parents, professionals who work with children with cerebral palsy.

Gathering this information will allow us to:

- Understand the factors that represent self-concept of children with cerebral palsy
- Develop a self-concept measurement tool that is specific to children with cerebral palsy
- Explore the development of self-concept in children with cerebral palsy through future research
- Determine which treatment interventions are the most helpful in promoting good self-concept in children with cerebral palsy

What do I and my child need to do?

This study will use a "Delphi technique", which involves participants completing short surveys to tell us their ideas about self-concept. Three survey rounds will be used to reach consensus.

To ensure they understand the questions, children involved in this study **will participate in an interview format**. The interview will be provided by the principal researcher. It can be performed over the phone, or at your home or a Cerebral Palsy League venue, whichever is the most convenient location for you and your child

- In Round 1 - A researcher will hold a short interview with your child to help them answer simple questions about their opinion on what makes up self-concept for children with cerebral palsy aged 8 to 12 years.
- In Round 2 – A researcher will hold a short interview with your child to help them answer a questionnaire that rates the ideas that participants came up with about self-concept as well as any other items we have found in the literature.
- In Round 3 - A researcher will hold a short interview with your child to help them answer a questionnaire that rates a prioritised list of ideas that participants came up with about self-concept.

The interview for your child in each round is expected to take about 20-30 minutes. Children with communication or writing difficulties can use a communication board, book or device. The surveys will be conducted approximately once every three to four weeks over a period of approximately 8-12 weeks.

Cheong et al 2011 Page 1 of 8

Ethical Considerations

- **Participation & consent** – Participation in this study is voluntary and your child is free to withdraw from the study at any time, for any reason, without explanation. This will in no way impact on your child's relationship with the CPL, or the services that you/your child receive. If you choose to allow your child to participate in this study, you are required to complete the consent form. Your child will need to complete an assent form.
- **Privacy and confidentiality** – If your child does participate in this study, their right to privacy and confidentiality will be respected. Only the researchers will have access to the information you or your child provide. Your child's responses will be kept anonymous - any identifying information about your child will be removed before analysis and no information about your child will be kept or used for any reason without your consent. All information collected during the study will be stored in a locked filing cabinet or a password-protected computer on a secure network at the CPL and ACU. Any reports or publications that arise from this study will never identify your child individually.
- **Risk** - Participation in this study is not expected to place your child at any risk of harm or distress. In the event that they might wish to talk to a mental or physical health professional as a result of completing the surveys, we can assist you to contact:
    - Your Cerebral Palsy League psychologist/social worker: (07) 3358 8001,
    - Australian Catholic University (ACU) Brisbane Psychology and Counselling Clinic (BPACC) Ph: (07) 3623 7453,
    - Help lines, such as Lifeline Helpline (Ph:13 11 14), Beyond Blue (1300 22 4636), Kids Help Line (1800 55 1800)
    - Your general practitioner for consultation or referral to appropriate professionals for assistance.
- **Feedback** - Results of the study will be printed in the Cerebral Palsy League newsletter and website. If your child would like to receive a personal copy, please record your address on the consent form.

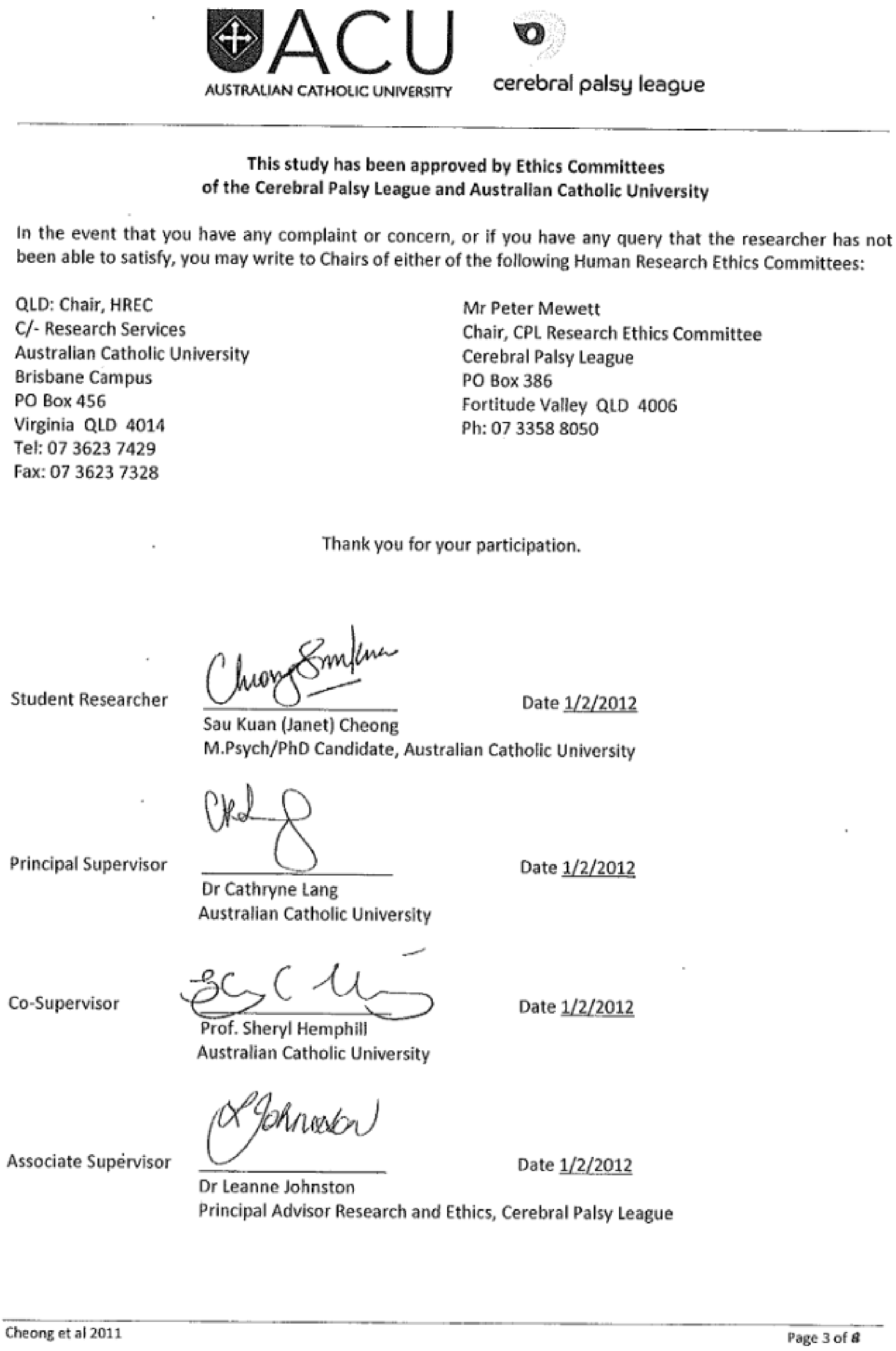
Questions –

- If you have any questions regarding the study, please contact one of the researchers:

Sau Kuan (Janet) Cheong
M.Psych/PhD Candidate
Australian Catholic University
School of Psychology
1100 Nudgee Road, Banyo, Qld, 4014
Phone:
Email: sscheo006@myacu.edu.au

Dr Cathryne Lang
Principal Supervisor
Australian Catholic University
School of Psychology
1100 Nudgee Road, Banyo, Qld, 4014
Phone: (07) 3623 7583
Email: Cathryne.Lang@acu.edu.au

Dr Leanne Johnston
Principal Advisor Research & Ethics
Cerebral Palsy League
55 Oxlade Drive
New Farm QLD 4005
Phone: (07) 3358 8001
Email: ljohnston@cplqld.org.au



ACU
AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

This study has been approved by Ethics Committees of the Cerebral Palsy League and Australian Catholic University

In the event that you have any complaint or concern, or if you have any query that the researcher has not been able to satisfy, you may write to Chairs of either of the following Human Research Ethics Committees:

QLD: Chair, HREC
C/- Research Services
Australian Catholic University
Brisbane Campus
PO Box 456
Virginia QLD 4014
Tel: 07 3623 7429
Fax: 07 3623 7328

Mr Peter Mewett
Chair, CPL Research Ethics Committee
Cerebral Palsy League
PO Box 386
Fortitude Valley QLD 4006
Ph: 07 3358 8050

Thank you for your participation.

Student Researcher
Sau Kuan (Janet) Cheong
M.Psych/PhD Candidate, Australian Catholic University
Date 1/2/2012

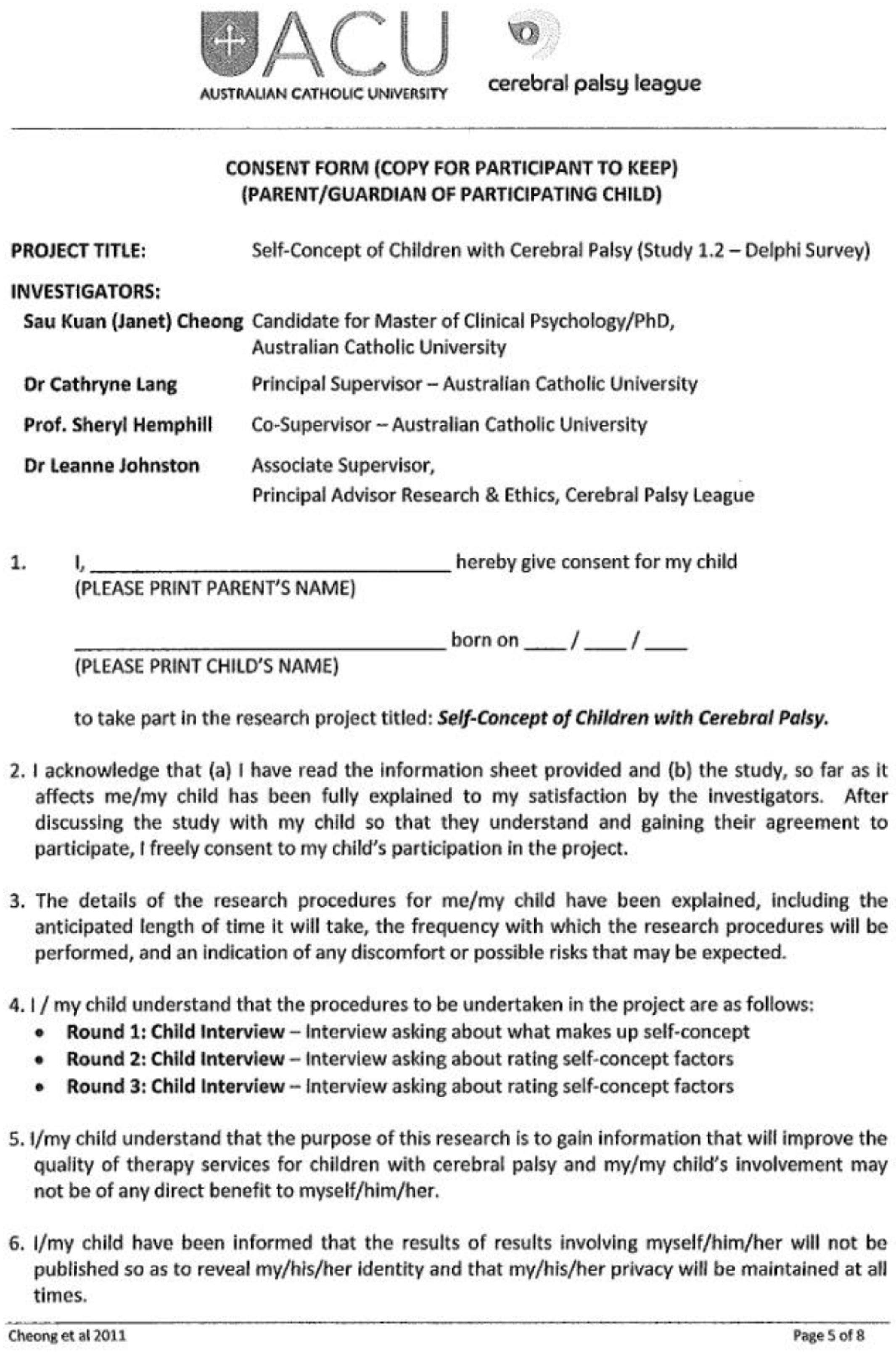
Principal Supervisor
Dr Cathryne Lang
Australian Catholic University
Date 1/2/2012

Co-Supervisor
Prof. Sheryl Hemphill
Australian Catholic University
Date 1/2/2012

Associate Supervisor
Dr Leanne Johnston
Principal Advisor Research and Ethics, Cerebral Palsy League
Date 1/2/2012

This page is deliberately left blank

Please turn to the next page



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CONSENT FORM (COPY FOR PARTICIPANT TO KEEP)
(PARENT/GUARDIAN OF PARTICIPATING CHILD)

PROJECT TITLE: Self-Concept of Children with Cerebral Palsy (Study 1.2 – Delphi Survey)

INVESTIGATORS:

Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

1. I, ______________________________ hereby give consent for my child
(PLEASE PRINT PARENT'S NAME)

______________________________ born on ____/____/____
(PLEASE PRINT CHILD'S NAME)

to take part in the research project titled: ***Self-Concept of Children with Cerebral Palsy.***

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me/my child has been fully explained to my satisfaction by the investigators. After discussing the study with my child so that they understand and gaining their agreement to participate, I freely consent to my child's participation in the project.

3. The details of the research procedures for me/my child have been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I / my child understand that the procedures to be undertaken in the project are as follows:
   - **Round 1: Child Interview** – Interview asking about what makes up self-concept
   - **Round 2: Child Interview** – Interview asking about rating self-concept factors
   - **Round 3: Child Interview** – Interview asking about rating self-concept factors

5. I/my child understand that the purpose of this research is to gain information that will improve the quality of therapy services for children with cerebral palsy and my/my child's involvement may not be of any direct benefit to myself/him/her.

6. I/my child have been informed that the results of results involving myself/him/her will not be published so as to reveal my/his/her identity and that my/his/her privacy will be maintained at all times.

7. I/my child understand that I/my child is free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My child to participate in a structured interview
☐ My/my child's interview (questionnaire) data to be used for the current study

Potential future use of my child's information
☐ Copies of my/my child's questionnaire to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___/___/___
(parent/guardian)

Telephone: ____________________________

Email: ________________________________

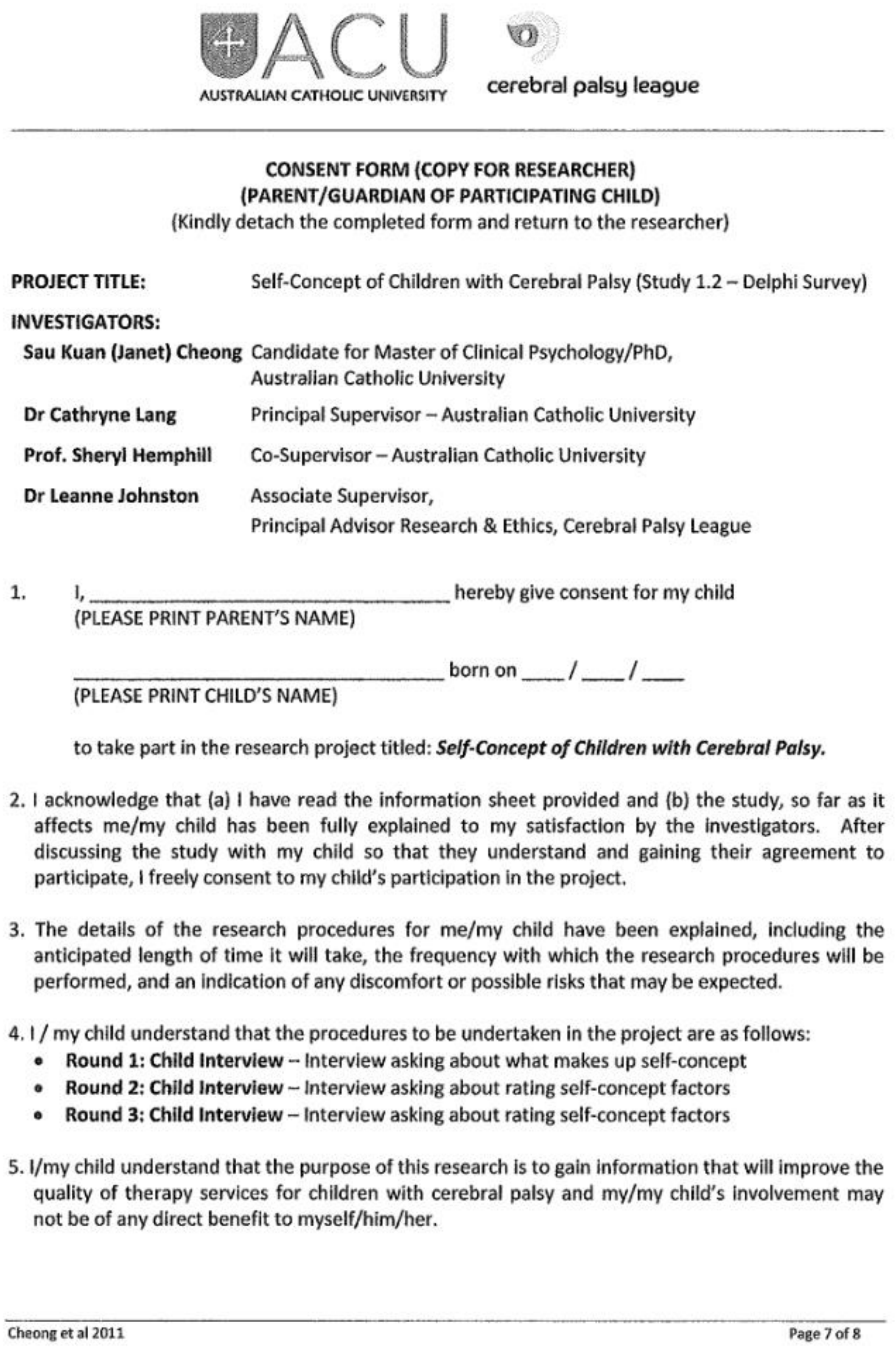
Postal address: ____

I would like to receive a copy of the study results
☐ No ☐ Yes, by email ☐ Yes, by post

Signed: ______________________________ Date: ___/___/___
(Witness)

Signed: ______________________________ Date: ___/___/___
(Investigator)

Footnote ** According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CONSENT FORM (COPY FOR RESEARCHER)
(PARENT/GUARDIAN OF PARTICIPATING CHILD)
(Kindly detach the completed form and return to the researcher)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Study 1.2 – Delphi Survey)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

1. I, ________________________________ hereby give consent for my child
(PLEASE PRINT PARENT'S NAME)

________________________________ born on ____ / ____ / ____
(PLEASE PRINT CHILD'S NAME)

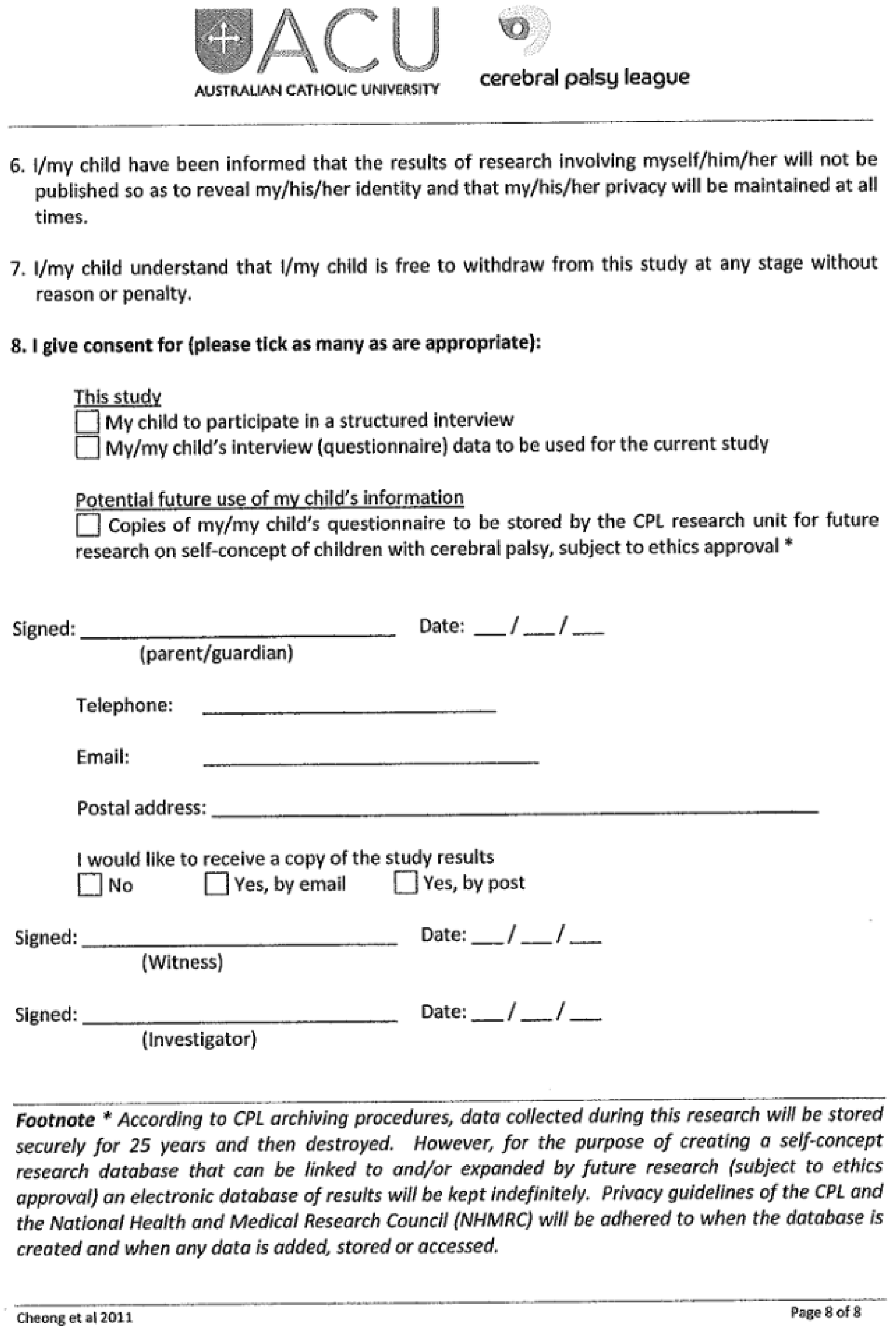
to take part in the research project titled: ***Self-Concept of Children with Cerebral Palsy.***

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me/my child has been fully explained to my satisfaction by the investigators. After discussing the study with my child so that they understand and gaining their agreement to participate, I freely consent to my child's participation in the project.

3. The details of the research procedures for me/my child have been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I / my child understand that the procedures to be undertaken in the project are as follows:
   - **Round 1: Child Interview** – Interview asking about what makes up self-concept
   - **Round 2: Child Interview** – Interview asking about rating self-concept factors
   - **Round 3: Child Interview** – Interview asking about rating self-concept factors

5. I/my child understand that the purpose of this research is to gain information that will improve the quality of therapy services for children with cerebral palsy and my/my child's involvement may not be of any direct benefit to myself/him/her.



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

---

6. I/my child have been informed that the results of research involving myself/him/her will not be published so as to reveal my/his/her identity and that my/his/her privacy will be maintained at all times.

7. I/my child understand that I/my child is free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My child to participate in a structured interview
☐ My/my child's interview (questionnaire) data to be used for the current study

Potential future use of my child's information
☐ Copies of my/my child's questionnaire to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___/___/___
(parent/guardian)

Telephone: ____________________________

Email: ________________________________

Postal address: ____

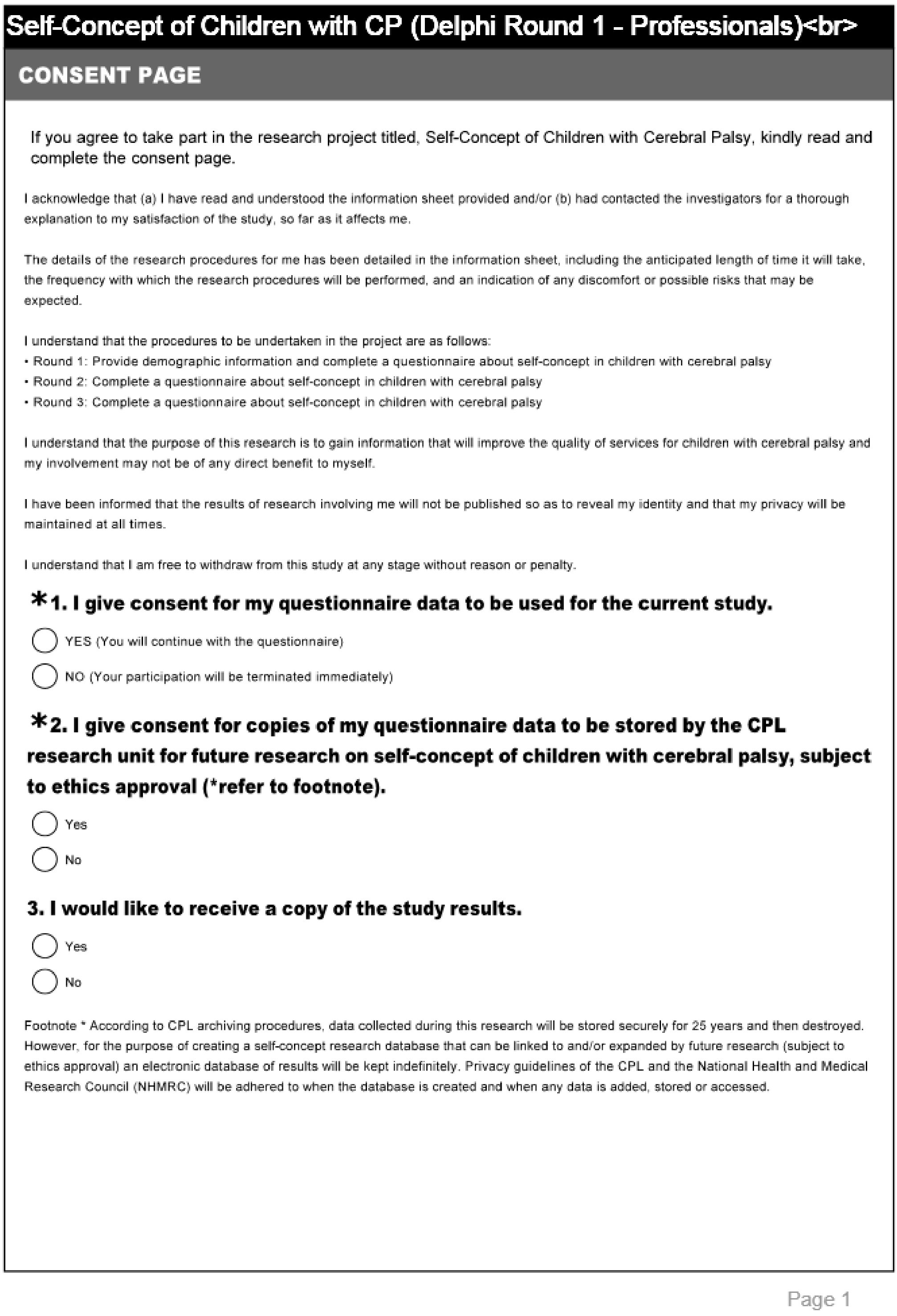
I would like to receive a copy of the study results
☐ No ☐ Yes, by email ☐ Yes, by post

Signed: ______________________________ Date: ___/___/___
(Witness)

Signed: ______________________________ Date: ___/___/___
(Investigator)

Footnote ** According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*

Study 2: Professional group questionnaire – Delphi Round I



Self-Concept of Children with CP (Delphi Round 1 - Professionals)

CONSENT PAGE

If you agree to take part in the research project titled, Self-Concept of Children with Cerebral Palsy, kindly read and complete the consent page.

I acknowledge that (a) I have read and understood the information sheet provided and/or (b) had contacted the investigators for a thorough explanation to my satisfaction of the study, so far as it affects me.

The details of the research procedures for me has been detailed in the information sheet, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

I understand that the procedures to be undertaken in the project are as follows:
- Round 1: Provide demographic information and complete a questionnaire about self-concept in children with cerebral palsy
- Round 2: Complete a questionnaire about self-concept in children with cerebral palsy
- Round 3: Complete a questionnaire about self-concept in children with cerebral palsy

I understand that the purpose of this research is to gain information that will improve the quality of services for children with cerebral palsy and my involvement may not be of any direct benefit to myself.

I have been informed that the results of research involving me will not be published so as to reveal my identity and that my privacy will be maintained at all times.

I understand that I am free to withdraw from this study at any stage without reason or penalty.

***1. I give consent for my questionnaire data to be used for the current study.**

○ YES (You will continue with the questionnaire)

○ NO (Your participation will be terminated immediately)

***2. I give consent for copies of my questionnaire data to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval (*refer to footnote).**

○ Yes

○ No

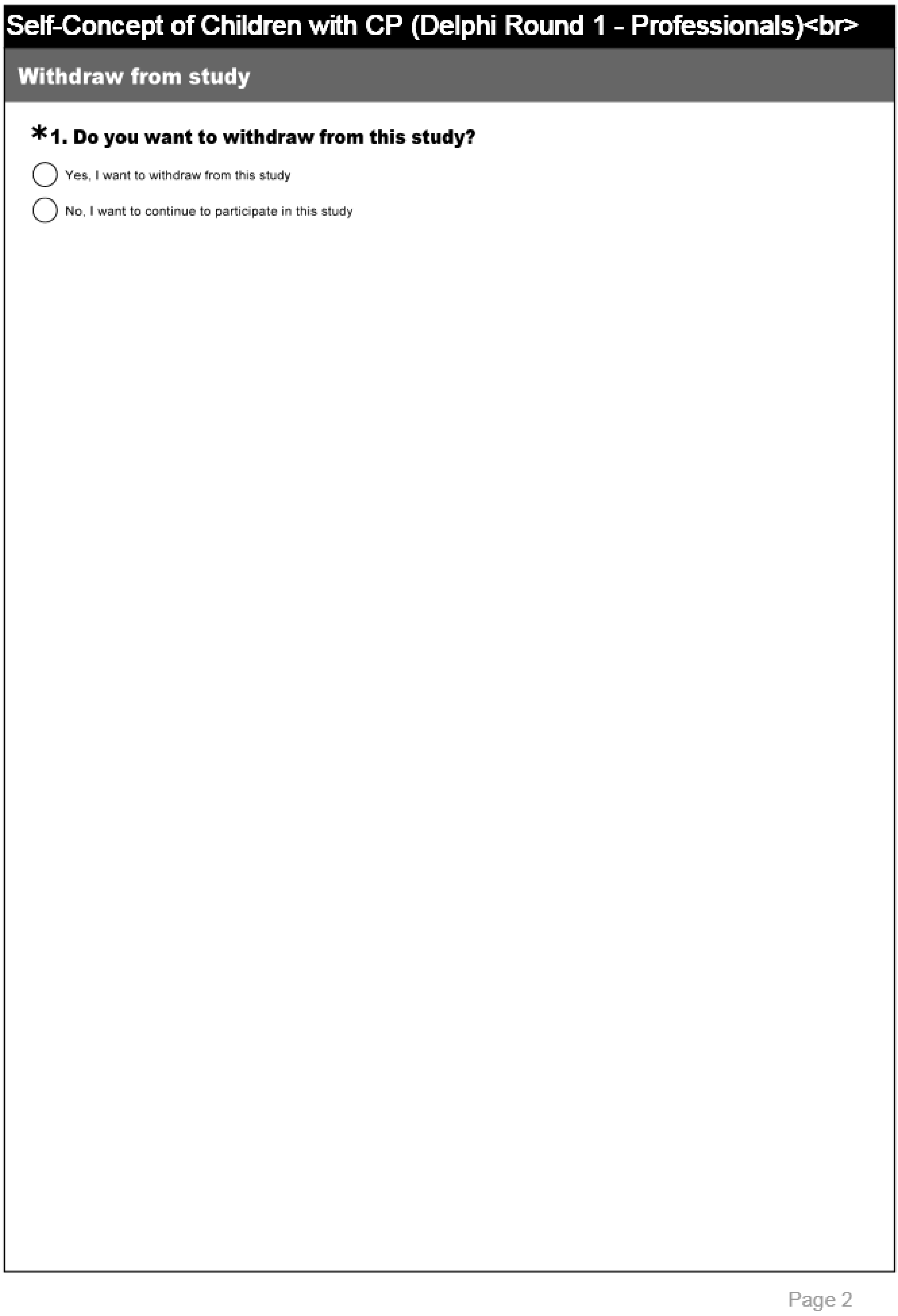
3. I would like to receive a copy of the study results.

○ Yes

○ No

Footnote * According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.

Page 1



Self-Concept of Children with CP (Delphi Round 1 - Professionals)

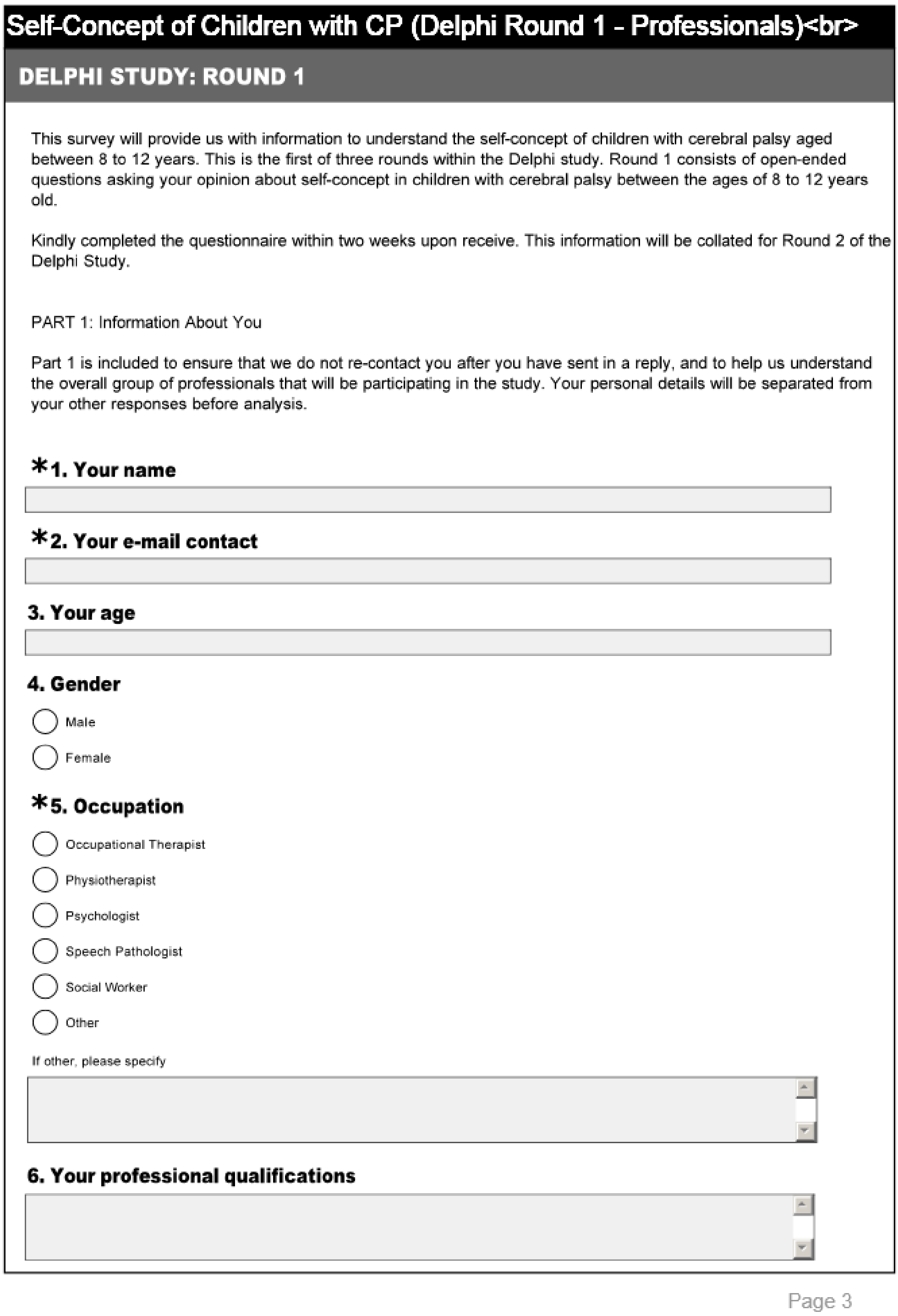
Withdraw from study

***1. Do you want to withdraw from this study?**

○ Yes, I want to withdraw from this study

○ No, I want to continue to participate in this study

Page 2



Self-Concept of Children with CP (Delphi Round 1 - Professionals)

DELPHI STUDY: ROUND 1

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is the first of three rounds within the Delphi study. Round 1 consists of open-ended questions asking your opinion about self-concept in children with cerebral palsy between the ages of 8 to 12 years old.

Kindly completed the questionnaire within two weeks upon receive. This information will be collated for Round 2 of the Delphi Study.

PART 1: Information About You

Part 1 is included to ensure that we do not re-contact you after you have sent in a reply, and to help us understand the overall group of professionals that will be participating in the study. Your personal details will be separated from your other responses before analysis.

***1. Your name**

***2. Your e-mail contact**

3. Your age

4. Gender

○ Male
○ Female

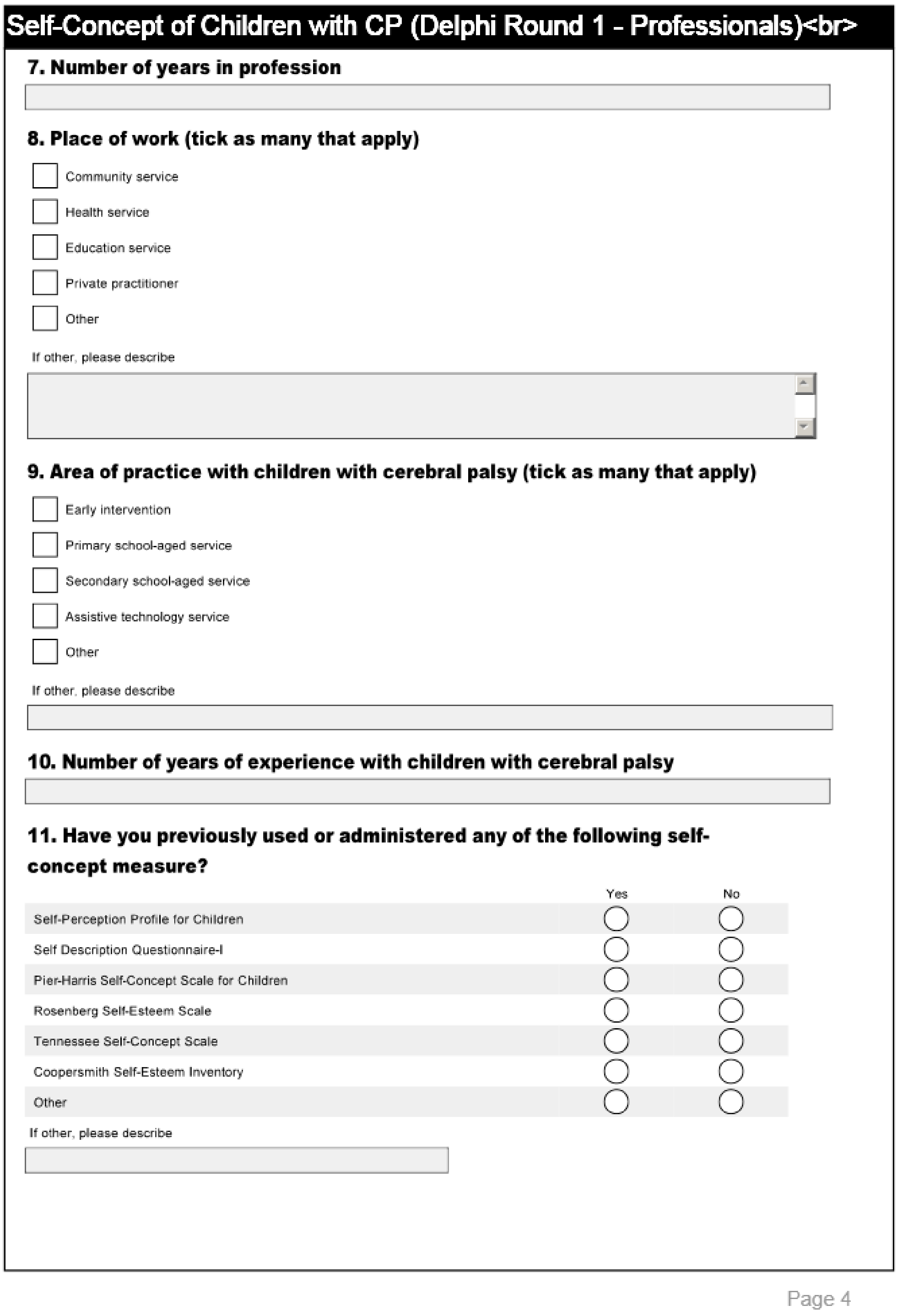
***5. Occupation**

○ Occupational Therapist
○ Physiotherapist
○ Psychologist
○ Speech Pathologist
○ Social Worker
○ Other

If other, please specify

6. Your professional qualifications

Page 3



Self-Concept of Children with CP (Delphi Round 1 - Professionals)

7. Number of years in profession

8. Place of work (tick as many that apply)

☐ Community service
☐ Health service
☐ Education service
☐ Private practitioner
☐ Other

If other, please describe

9. Area of practice with children with cerebral palsy (tick as many that apply)

☐ Early intervention
☐ Primary school-aged service
☐ Secondary school-aged service
☐ Assistive technology service
☐ Other

If other, please describe

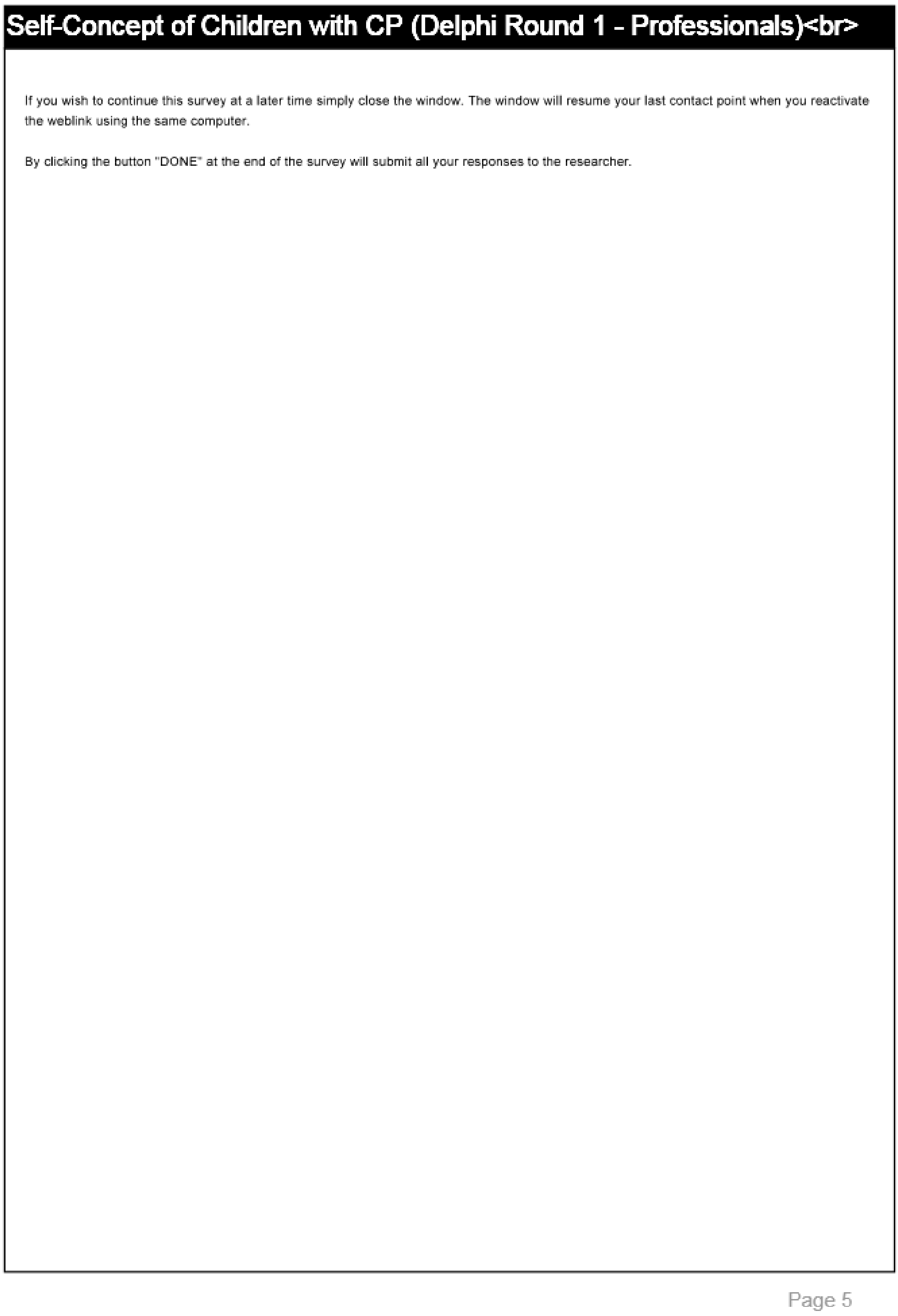
10. Number of years of experience with children with cerebral palsy

11. Have you previously used or administered any of the following self-concept measure?

	Yes	No
Self-Perception Profile for Children	○	○
Self Description Questionnaire-I	○	○
Pier-Harris Self-Concept Scale for Children	○	○
Rosenberg Self-Esteem Scale	○	○
Tennessee Self-Concept Scale	○	○
Coopersmith Self-Esteem Inventory	○	○
Other	○	○

If other, please describe

Page 4

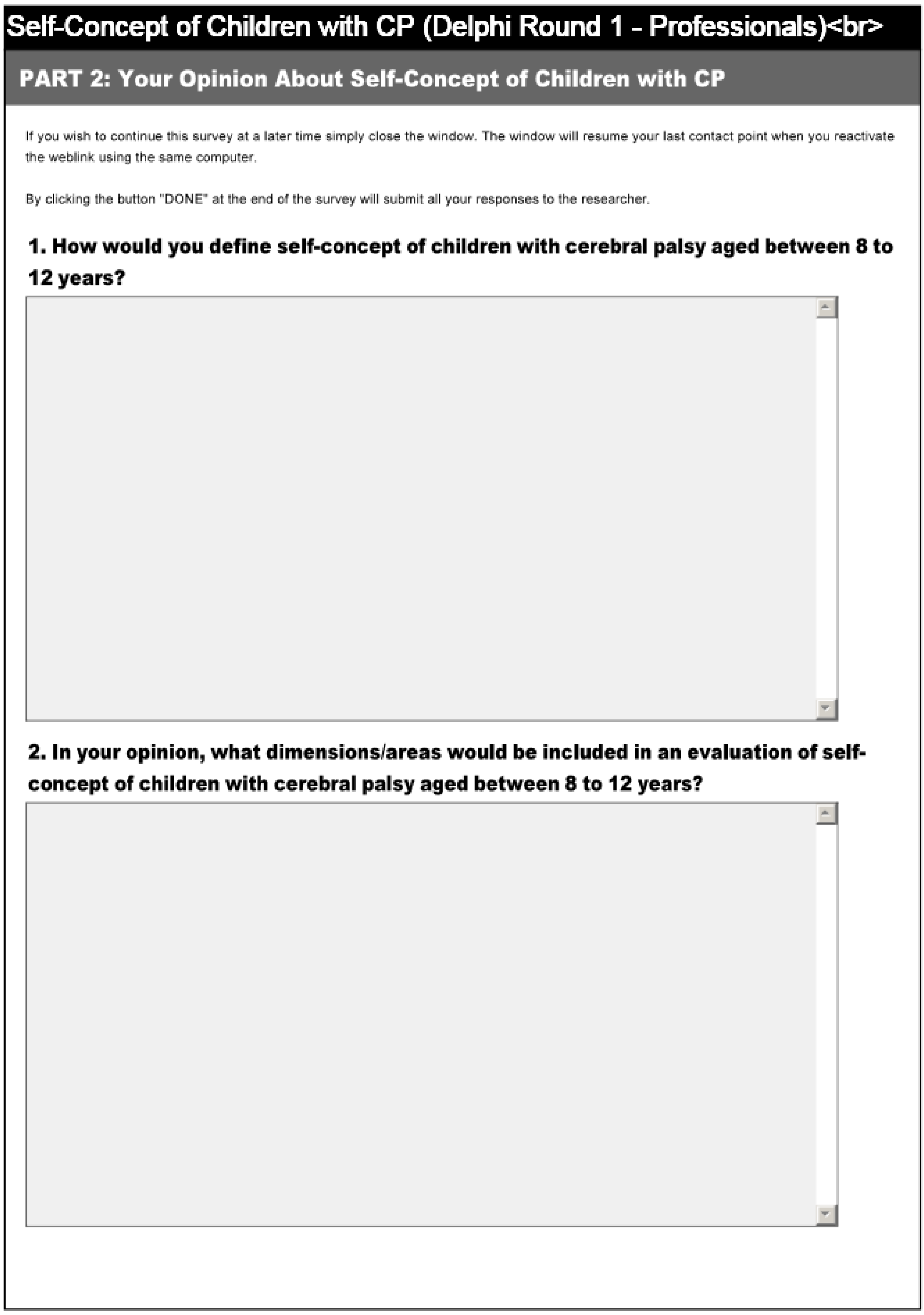


Self-Concept of Children with CP (Delphi Round 1 - Professionals)

If you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

By clicking the button "DONE" at the end of the survey will submit all your responses to the researcher.

Page 5



Self-Concept of Children with CP (Delphi Round 1 - Professionals)

PART 2: Your Opinion About Self-Concept of Children with CP

If you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

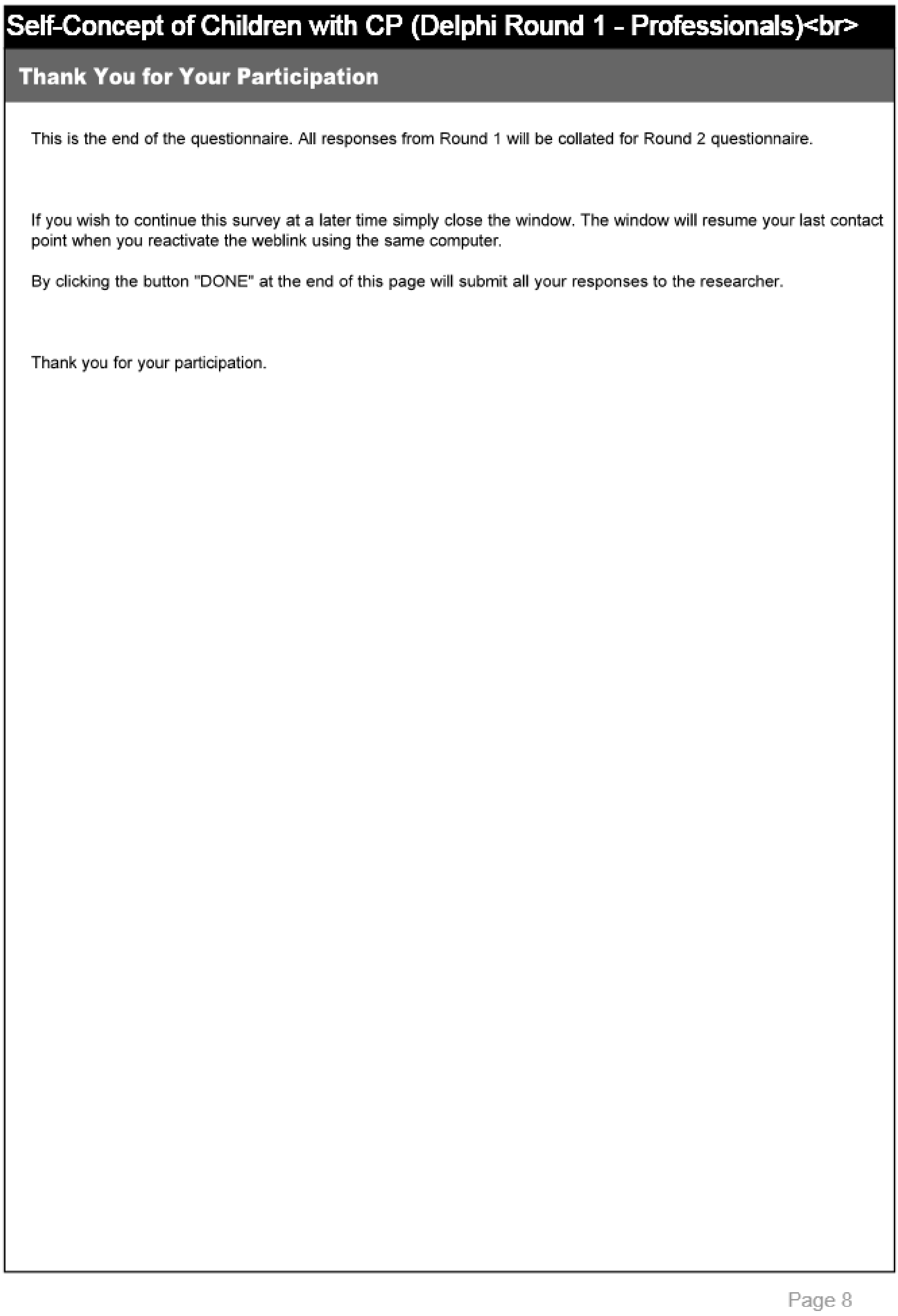
By clicking the button "DONE" at the end of the survey will submit all your responses to the researcher.

1. How would you define self-concept of children with cerebral palsy aged between 8 to 12 years?

2. In your opinion, what dimensions/areas would be included in an evaluation of self-concept of children with cerebral palsy aged between 8 to 12 years?

**Self-Concept of Children with CP (Delphi Round 1 - Professionals)
**

3. In your opinion, what are some important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years?



Self-Concept of Children with CP (Delphi Round 1 - Professionals)

Thank You for Your Participation

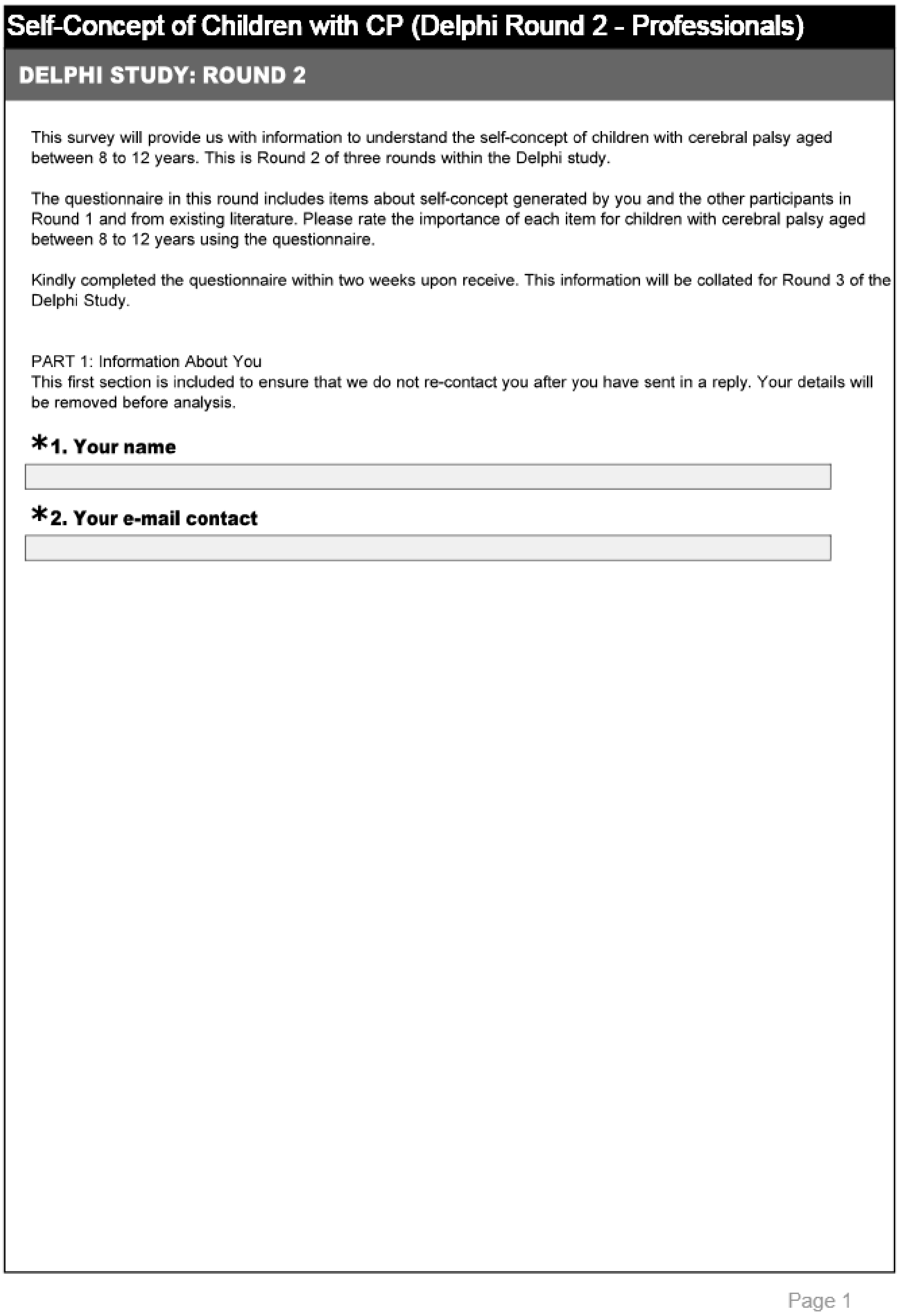
This is the end of the questionnaire. All responses from Round 1 will be collated for Round 2 questionnaire.

If you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

By clicking the button "DONE" at the end of this page will submit all your responses to the researcher.

Thank you for your participation.

Study 2: Professional group questionnaire – Delphi Round II



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

DELPHI STUDY: ROUND 2

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is Round 2 of three rounds within the Delphi study.

The questionnaire in this round includes items about self-concept generated by you and the other participants in Round 1 and from existing literature. Please rate the importance of each item for children with cerebral palsy aged between 8 to 12 years using the questionnaire.

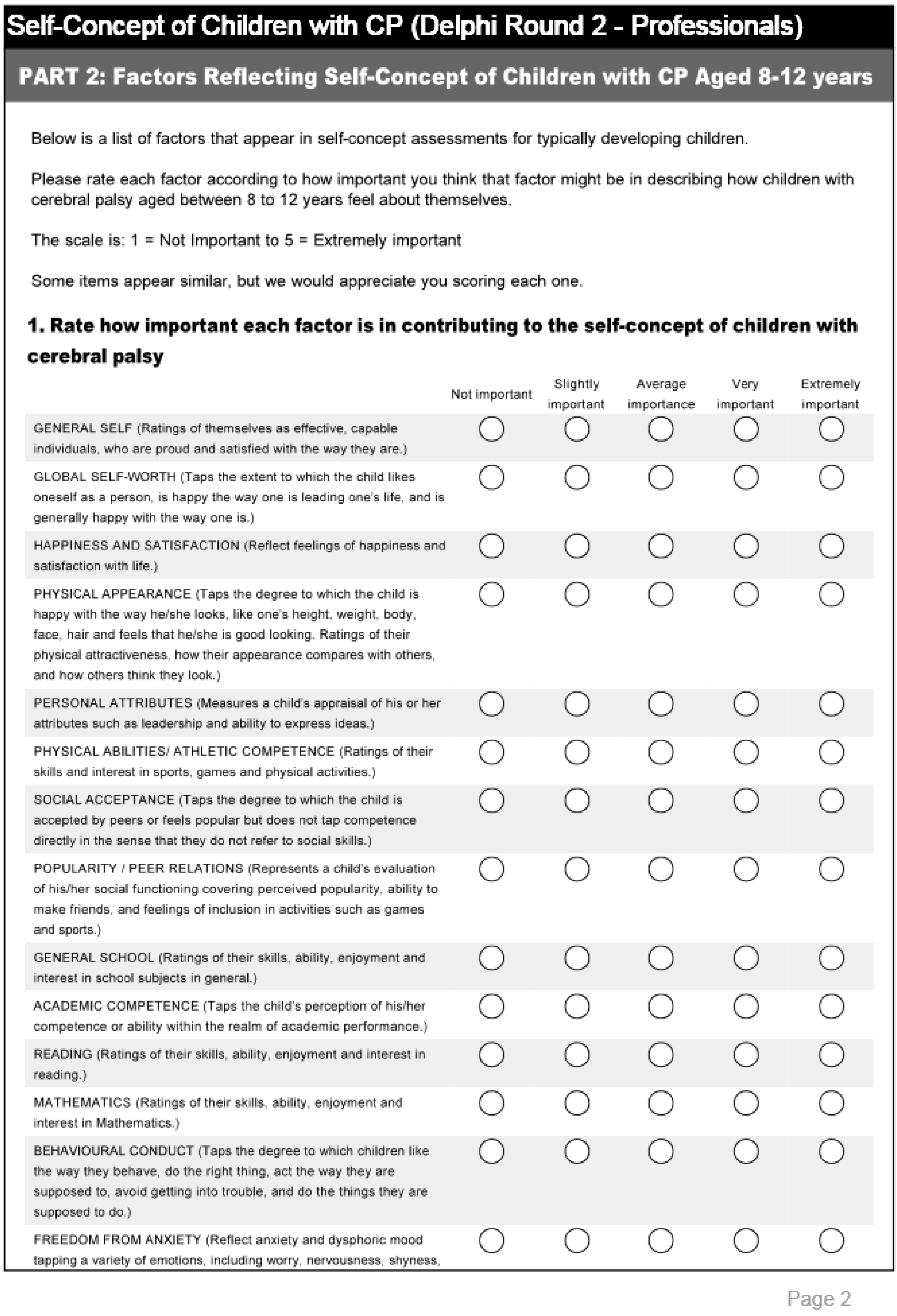
Kindly completed the questionnaire within two weeks upon receive. This information will be collated for Round 3 of the Delphi Study.

PART 1: Information About You
This first section is included to ensure that we do not re-contact you after you have sent in a reply. Your details will be removed before analysis.

***1. Your name**

***2. Your e-mail contact**

Page 1



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

PART 2: Factors Reflecting Self-Concept of Children with CP Aged 8-12 years

Below is a list of factors that appear in self-concept assessments for typically developing children.

Please rate each factor according to how important you think that factor might be in describing how children with cerebral palsy aged between 8 to 12 years feel about themselves.

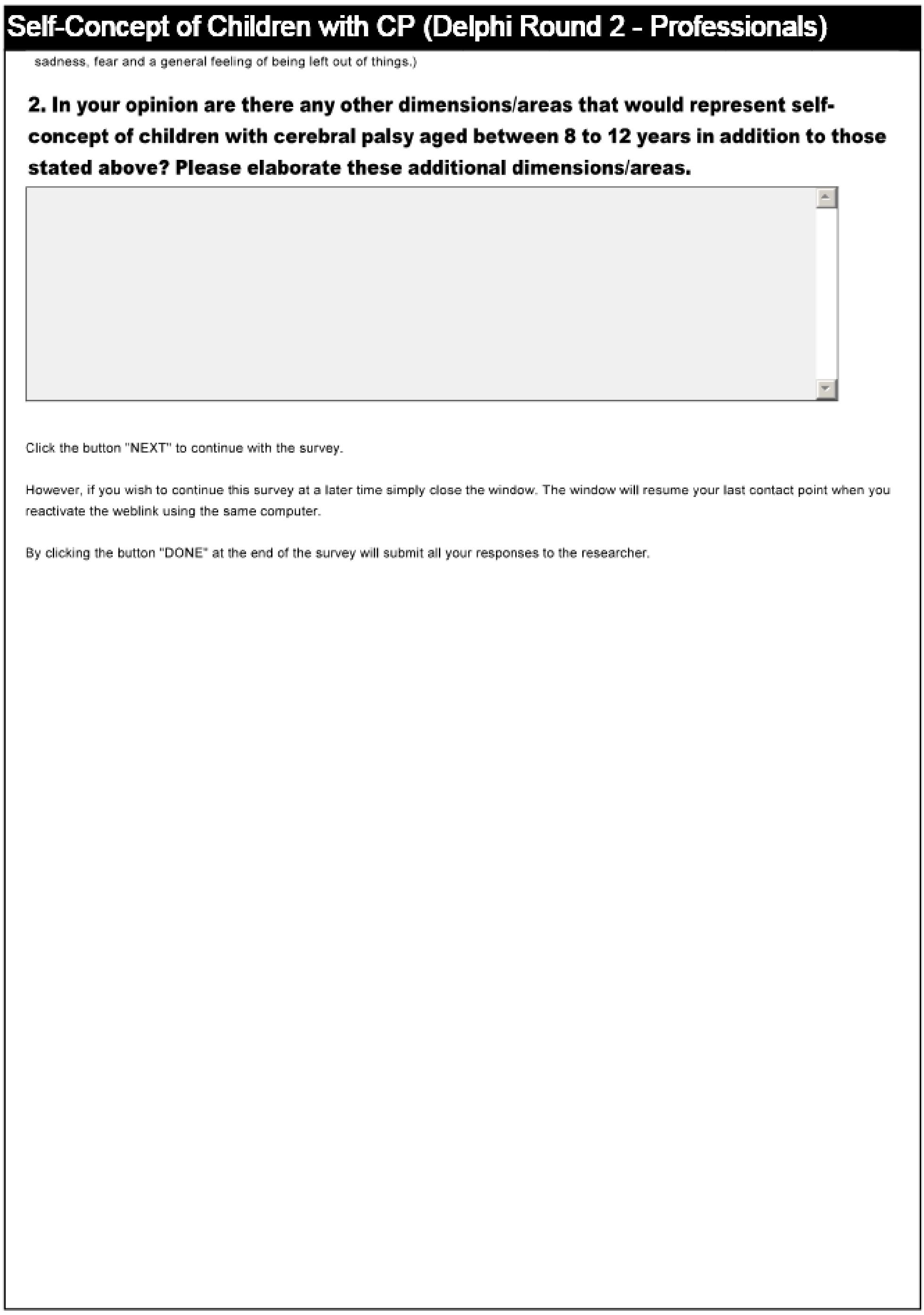
The scale is: 1 = Not Important to 5 = Extremely important

Some items appear similar, but we would appreciate you scoring each one.

1. Rate how important each factor is in contributing to the self-concept of children with cerebral palsy

	Not important	Slightly important	Average importance	Very important	Extremely important
GENERAL SELF (Ratings of themselves as effective, capable individuals, who are proud and satisfied with the way they are.)	○	○	○	○	○
GLOBAL SELF-WORTH (Taps the extent to which the child likes oneself as a person, is happy the way one is leading one's life, and is generally happy with the way one is.)	○	○	○	○	○
HAPPINESS AND SATISFACTION (Reflect feelings of happiness and satisfaction with life.)	○	○	○	○	○
PHYSICAL APPEARANCE (Taps the degree to which the child is happy with the way he/she looks, like one's height, weight, body, face, hair and feels that he/she is good looking. Ratings of their physical attractiveness, how their appearance compares with others, and how others think they look.)	○	○	○	○	○
PERSONAL ATTRIBUTES (Measures a child's appraisal of his or her attributes such as leadership and ability to express ideas.)	○	○	○	○	○
PHYSICAL ABILITIES/ ATHLETIC COMPETENCE (Ratings of their skills and interest in sports, games and physical activities.)	○	○	○	○	○
SOCIAL ACCEPTANCE (Taps the degree to which the child is accepted by peers or feels popular but does not tap competence directly in the sense that they do not refer to social skills.)	○	○	○	○	○
POPULARITY / PEER RELATIONS (Represents a child's evaluation of his/her social functioning covering perceived popularity, ability to make friends, and feelings of inclusion in activities such as games and sports.)	○	○	○	○	○
GENERAL SCHOOL (Ratings of their skills, ability, enjoyment and interest in school subjects in general.)	○	○	○	○	○
ACADEMIC COMPETENCE (Taps the child's perception of his/her competence or ability within the realm of academic performance.)	○	○	○	○	○
READING (Ratings of their skills, ability, enjoyment and interest in reading.)	○	○	○	○	○
MATHEMATICS (Ratings of their skills, ability, enjoyment and interest in Mathematics.)	○	○	○	○	○
BEHAVIOURAL CONDUCT (Taps the degree to which children like the way they behave, do the right thing, act the way they are supposed to, avoid getting into trouble, and do the things they are supposed to do.)	○	○	○	○	○
FREEDOM FROM ANXIETY (Reflect anxiety and dysphoric mood tapping a variety of emotions, including worry, nervousness, shyness,	○	○	○	○	○

Page 2



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

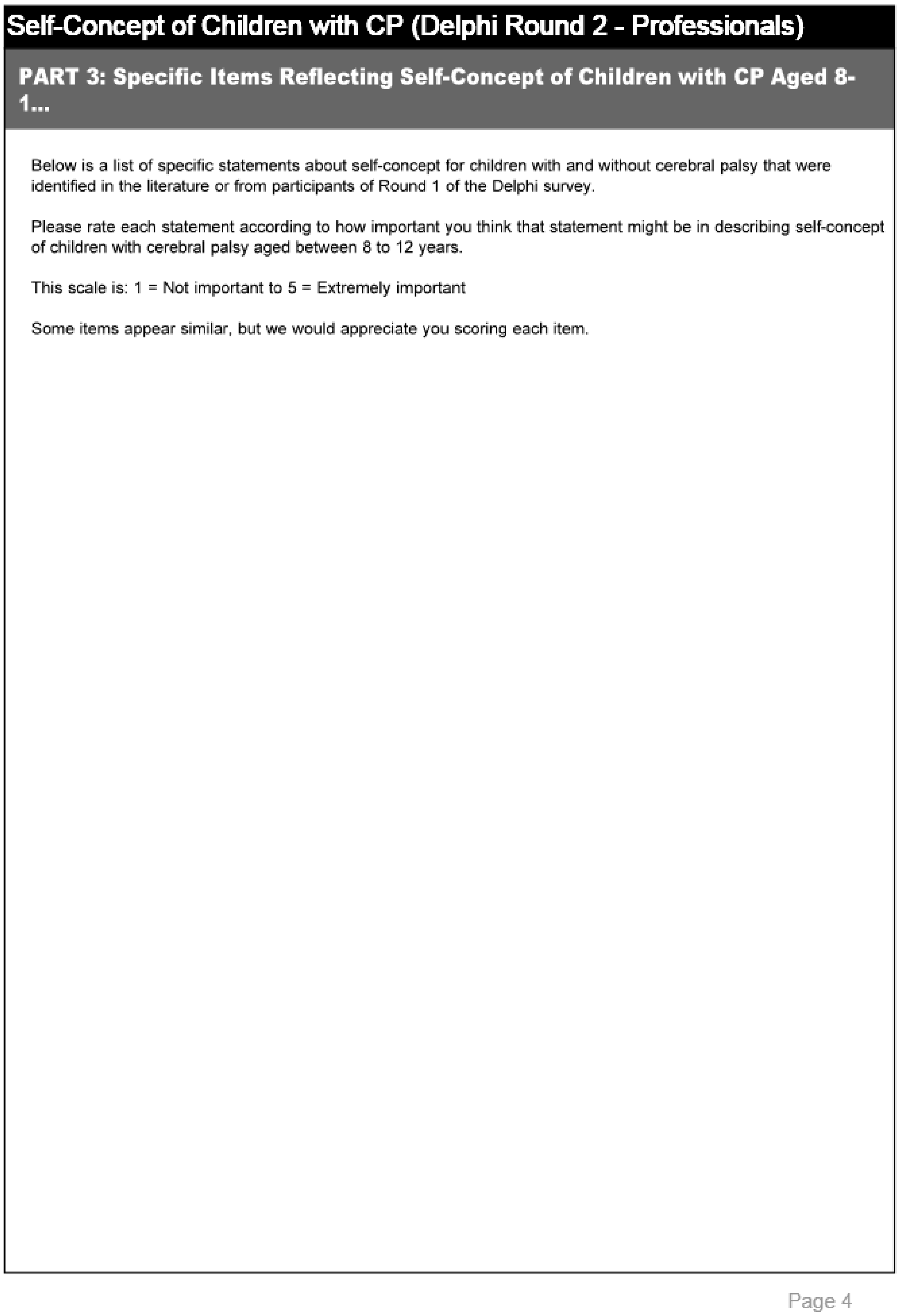
sadness, fear and a general feeling of being left out of things.)

2. In your opinion are there any other dimensions/areas that would represent self-concept of children with cerebral palsy aged between 8 to 12 years in addition to those stated above? Please elaborate these additional dimensions/areas.

Click the button "NEXT" to continue with the survey.

However, if you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

By clicking the button "DONE" at the end of the survey will submit all your responses to the researcher.



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

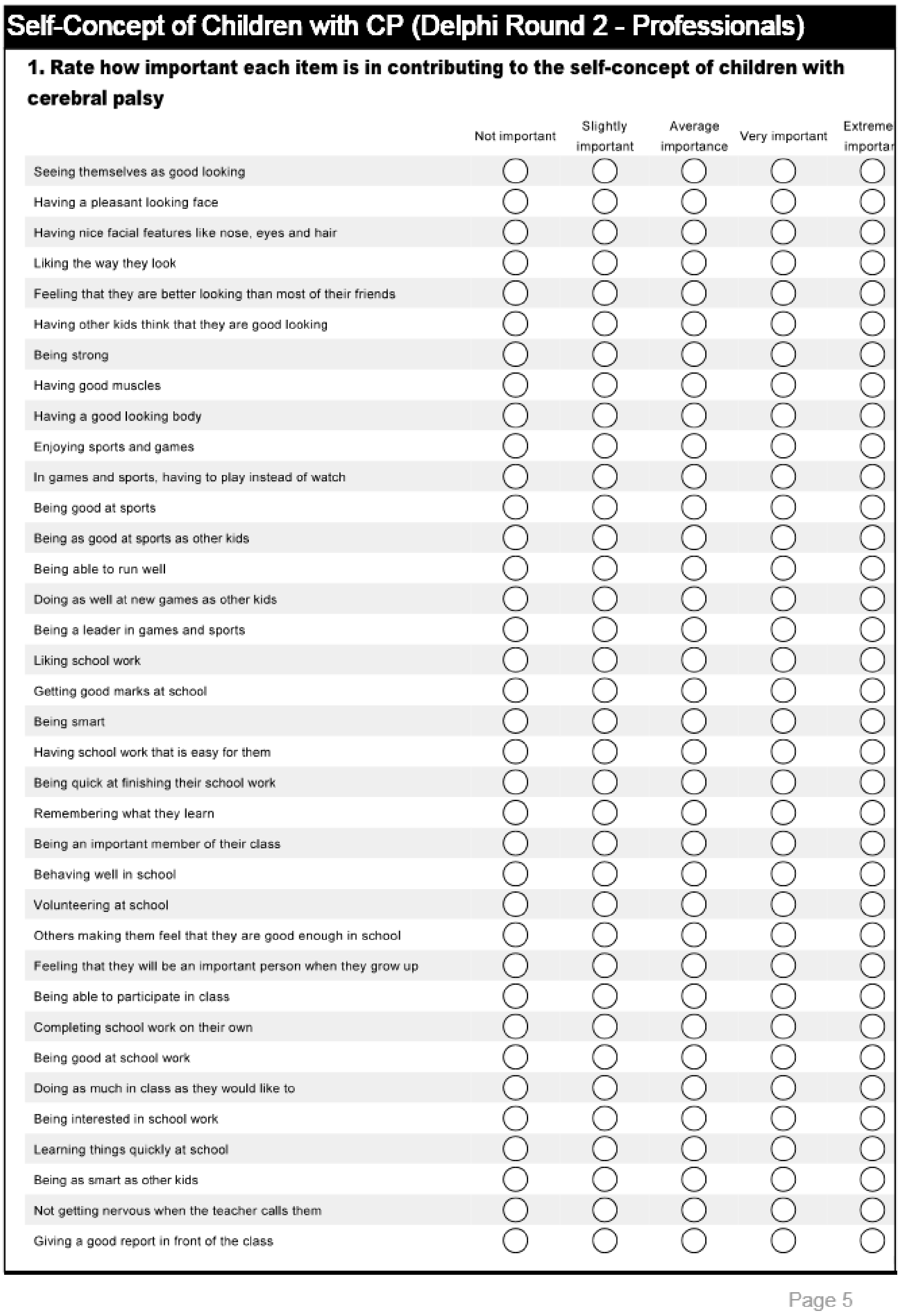
PART 3: Specific Items Reflecting Self-Concept of Children with CP Aged 8-1...

Below is a list of specific statements about self-concept for children with and without cerebral palsy that were identified in the literature or from participants of Round 1 of the Delphi survey.

Please rate each statement according to how important you think that statement might be in describing self-concept of children with cerebral palsy aged between 8 to 12 years.

This scale is: 1 = Not important to 5 = Extremely important

Some items appear similar, but we would appreciate you scoring each item.



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

1. Rate how important each item is in contributing to the self-concept of children with cerebral palsy

	Not important	Slightly important	Average importance	Very important	Extreme importa
Seeing themselves as good looking	○	○	○	○	○
Having a pleasant looking face	○	○	○	○	○
Having nice facial features like nose, eyes and hair	○	○	○	○	○
Liking the way they look	○	○	○	○	○
Feeling that they are better looking than most of their friends	○	○	○	○	○
Having other kids think that they are good looking	○	○	○	○	○
Being strong	○	○	○	○	○
Having good muscles	○	○	○	○	○
Having a good looking body	○	○	○	○	○
Enjoying sports and games	○	○	○	○	○
In games and sports, having to play instead of watch	○	○	○	○	○
Being good at sports	○	○	○	○	○
Being as good at sports as other kids	○	○	○	○	○
Being able to run well	○	○	○	○	○
Doing as well at new games as other kids	○	○	○	○	○
Being a leader in games and sports	○	○	○	○	○
Liking school work	○	○	○	○	○
Getting good marks at school	○	○	○	○	○
Being smart	○	○	○	○	○
Having school work that is easy for them	○	○	○	○	○
Being quick at finishing their school work	○	○	○	○	○
Remembering what they learn	○	○	○	○	○
Being an important member of their class	○	○	○	○	○
Behaving well in school	○	○	○	○	○
Volunteering at school	○	○	○	○	○
Others making them feel that they are good enough in school	○	○	○	○	○
Feeling that they will be an important person when they grow up	○	○	○	○	○
Being able to participate in class	○	○	○	○	○
Completing school work on their own	○	○	○	○	○
Being good at school work	○	○	○	○	○
Doing as much in class as they would like to	○	○	○	○	○
Being interested in school work	○	○	○	○	○
Learning things quickly at school	○	○	○	○	○
Being as smart as other kids	○	○	○	○	○
Not getting nervous when the teacher calls them	○	○	○	○	○
Giving a good report in front of the class	○	○	○	○	○

Page 5

Self-Concept of Children with CP (Delphi Round 2 - Professionals)

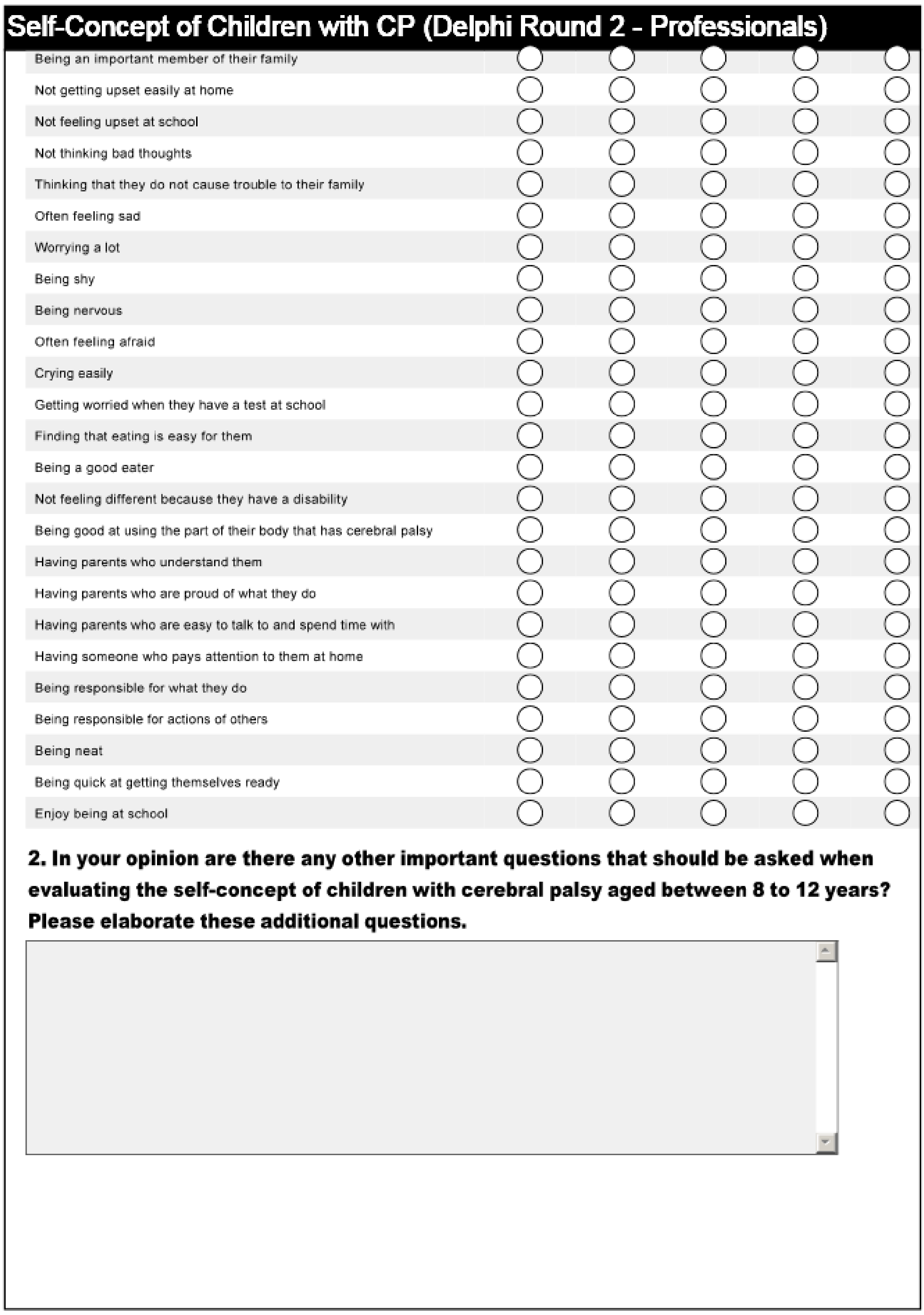
Liking Mathematics	○	○	○	○	○
Being good in Mathematics	○	○	○	○	○
Feeling that Mathematics is easy for them	○	○	○	○	○
Learning Mathematics quickly	○	○	○	○	○
Liking reading	○	○	○	○	○
Being good at reading	○	○	○	○	○
Feeling that reading is easy for them	○	○	○	○	○
Being interested in reading	○	○	○	○	○
Learning reading quickly	○	○	○	○	○
Enjoy drawing	○	○	○	○	○
Being good at spelling	○	○	○	○	○
Being good at writing	○	○	○	○	○
Being good at science	○	○	○	○	○
Being good at using the computer	○	○	○	○	○
Thinking that they are a good person	○	○	○	○	○
Being a happy person	○	○	○	○	○
Feeling useful	○	○	○	○	○
Being lucky	○	○	○	○	○
Taking a positive attitude towards themselves	○	○	○	○	○
Understanding themselves	○	○	○	○	○
Being proud of themselves	○	○	○	○	○
Liking the way they are	○	○	○	○	○
Being satisfied with themselves	○	○	○	○	○
Other people think that they are a good person	○	○	○	○	○
Not wanting to change themselves	○	○	○	○	○
Being a kind person	○	○	○	○	○
Being funny	○	○	○	○	○
Being polite	○	○	○	○	○
Being a fun person	○	○	○	○	○
Not feeling like a failure	○	○	○	○	○
Thinking that a lot of things about them are good	○	○	○	○	○
Being as good as most other people	○	○	○	○	○
Do not give up easily	○	○	○	○	○
Not wishing they were different	○	○	○	○	○
Having respect for themselves	○	○	○	○	○
Feeling that it is not tough being them	○	○	○	○	○
Feeling that things usually do not bother them	○	○	○	○	○
Not feeling different from other people	○	○	○	○	○
Doing the best work that they can	○	○	○	○	○
Trying even when it is hard	○	○	○	○	○

Page 6

Self-Concept of Children with CP (Delphi Round 2 - Professionals)

Doing lots of important things	○	○	○	○	○
Being able to take care of themselves	○	○	○	○	○
Liking the way they do things	○	○	○	○	○
Getting used to new things quickly	○	○	○	○	○
Being able to make their own decision and sticking to it	○	○	○	○	○
Doing things as well as most other people	○	○	○	○	○
Saying what they want to say	○	○	○	○	○
Being able to talk to others easily	○	○	○	○	○
Having other people understand what they say	○	○	○	○	○
Thinking that when they do something, they do it well	○	○	○	○	○
Do not give in easily	○	○	○	○	○
Doing things right	○	○	○	○	○
Having lots of friends	○	○	○	○	○
Feeling that they can be depended on	○	○	○	○	○
Being easily liked	○	○	○	○	○
Having more friends than most other kids	○	○	○	○	○
Having friends who do not make fun of them	○	○	○	○	○
Not being picked on by other kids	○	○	○	○	○
Having friends who think they have good ideas	○	○	○	○	○
Not feeling left out of things	○	○	○	○	○
Being popular with kids of their own age	○	○	○	○	○
Being popular with girls	○	○	○	○	○
Being popular with boys	○	○	○	○	○
Getting along with other kids easily	○	○	○	○	○
Playing with other kids without help from adults	○	○	○	○	○
Helping their friends	○	○	○	○	○
Making friends easily	○	○	○	○	○
Having most other kids like them	○	○	○	○	○
Being among the first few to be chosen for games and sports	○	○	○	○	○
Enjoying being with other people	○	○	○	○	○
Having friends who like their ideas	○	○	○	○	○
Behaving well at home	○	○	○	○	○
Doing many good things	○	○	○	○	○
Doing the right thing	○	○	○	○	○
Don't get into trouble	○	○	○	○	○
Don't get into fights	○	○	○	○	○
Being good to other people	○	○	○	○	○
Thinking that when something goes wrong, it is not usually their fault	○	○	○	○	○
Liking the way they behave	○	○	○	○	○
Being good at helping their family	○	○	○	○	○

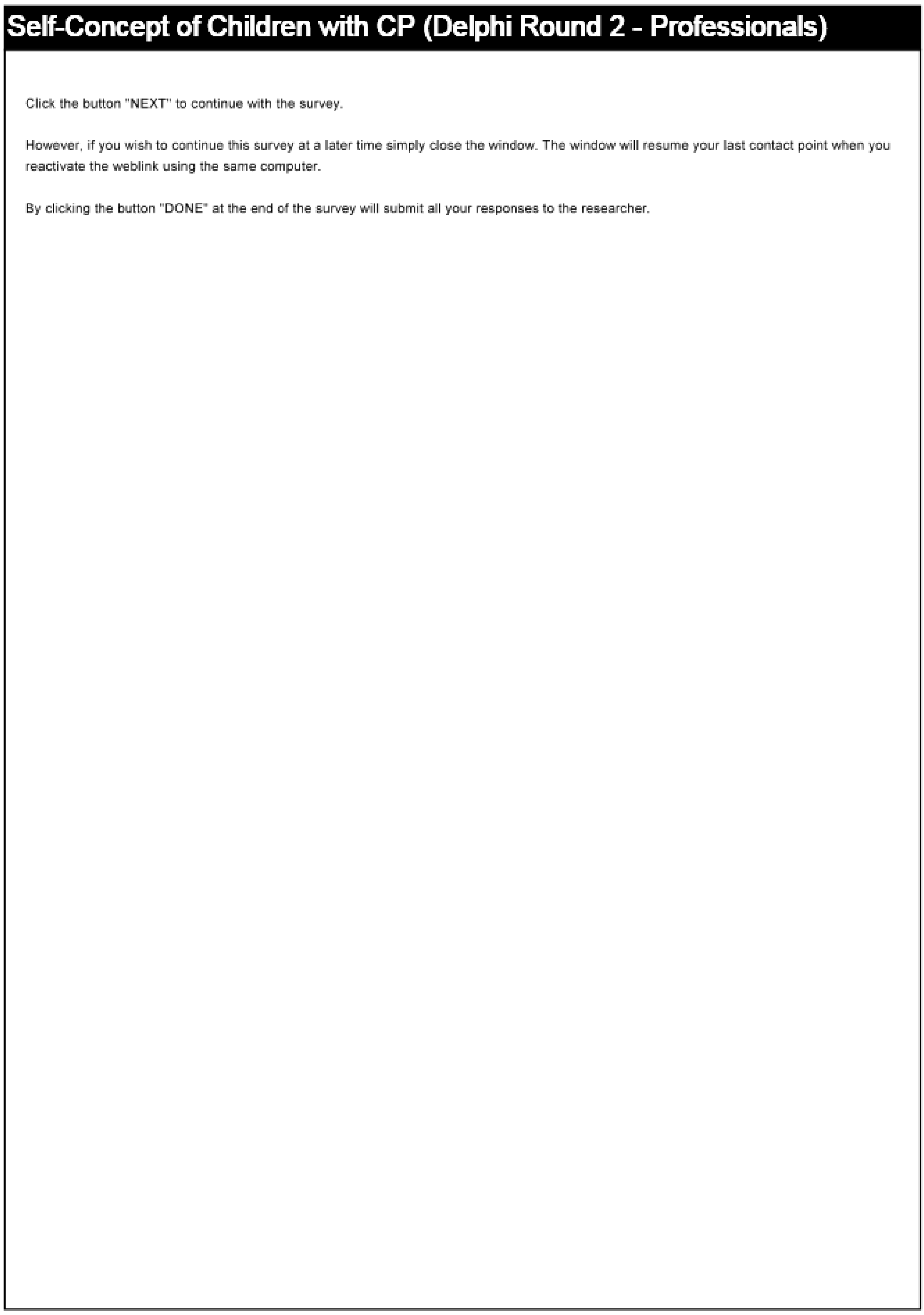
Page 7



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

Being an important member of their family	○	○	○	○	○
Not getting upset easily at home	○	○	○	○	○
Not feeling upset at school	○	○	○	○	○
Not thinking bad thoughts	○	○	○	○	○
Thinking that they do not cause trouble to their family	○	○	○	○	○
Often feeling sad	○	○	○	○	○
Worrying a lot	○	○	○	○	○
Being shy	○	○	○	○	○
Being nervous	○	○	○	○	○
Often feeling afraid	○	○	○	○	○
Crying easily	○	○	○	○	○
Getting worried when they have a test at school	○	○	○	○	○
Finding that eating is easy for them	○	○	○	○	○
Being a good eater	○	○	○	○	○
Not feeling different because they have a disability	○	○	○	○	○
Being good at using the part of their body that has cerebral palsy	○	○	○	○	○
Having parents who understand them	○	○	○	○	○
Having parents who are proud of what they do	○	○	○	○	○
Having parents who are easy to talk to and spend time with	○	○	○	○	○
Having someone who pays attention to them at home	○	○	○	○	○
Being responsible for what they do	○	○	○	○	○
Being responsible for actions of others	○	○	○	○	○
Being neat	○	○	○	○	○
Being quick at getting themselves ready	○	○	○	○	○
Enjoy being at school	○	○	○	○	○

2. In your opinion are there any other important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years? Please elaborate these additional questions.

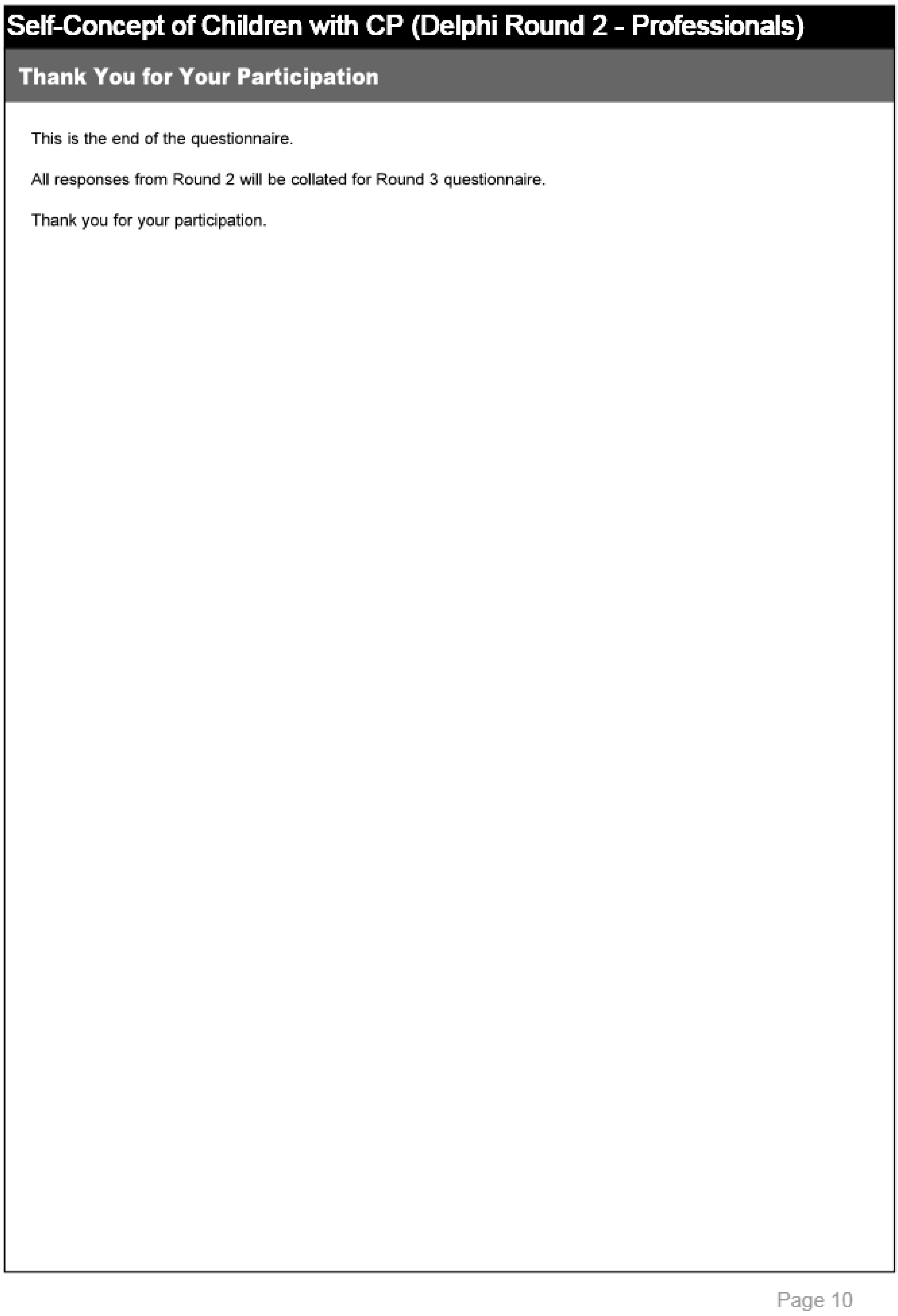


Self-Concept of Children with CP (Delphi Round 2 - Professionals)

Click the button "NEXT" to continue with the survey.

However, if you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

By clicking the button "DONE" at the end of the survey will submit all your responses to the researcher.



Self-Concept of Children with CP (Delphi Round 2 - Professionals)

Thank You for Your Participation

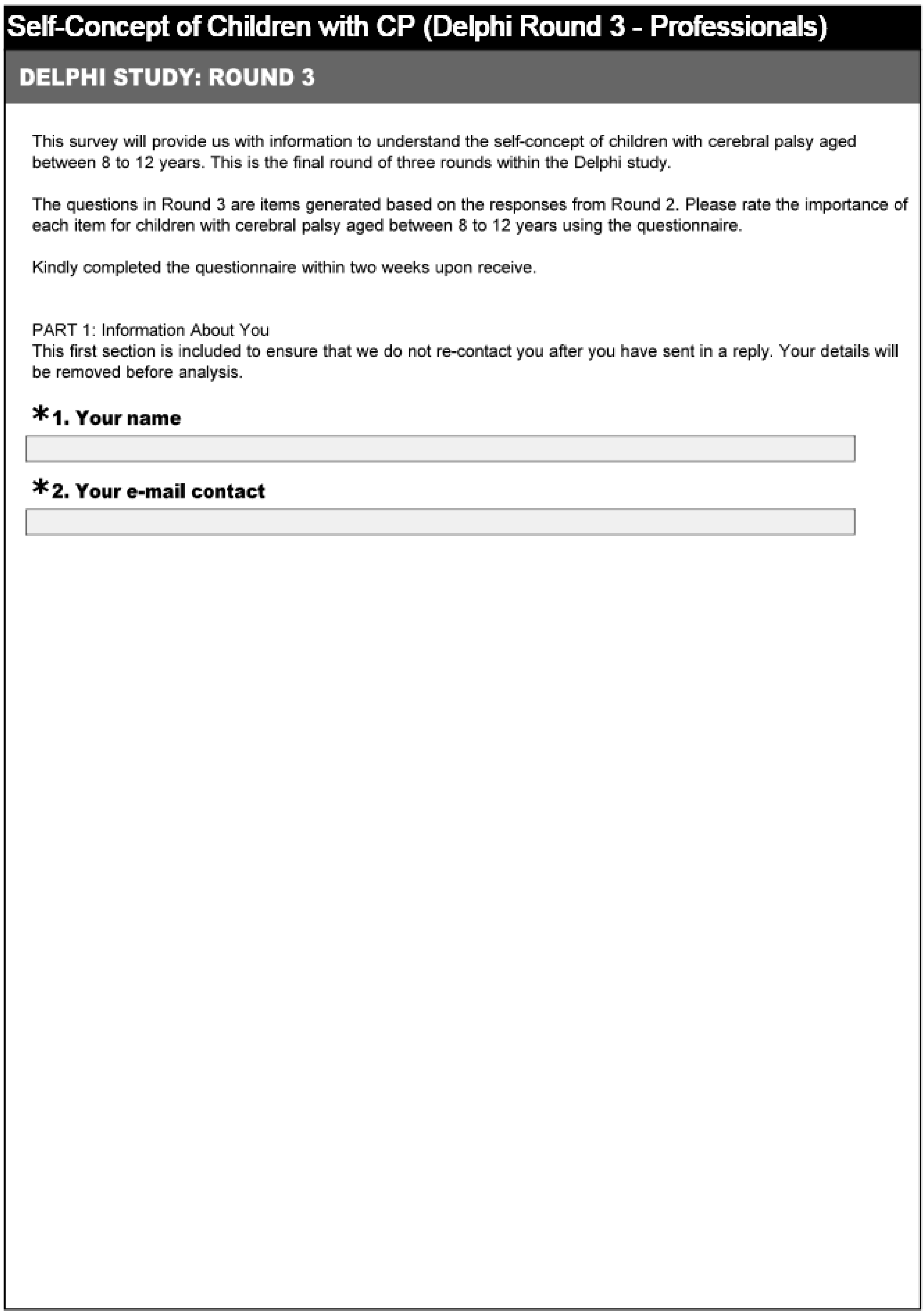
This is the end of the questionnaire.

All responses from Round 2 will be collated for Round 3 questionnaire.

Thank you for your participation.

Page 10

Study 2: Professional group questionnaire – Delphi Round III



Self-Concept of Children with CP (Delphi Round 3 - Professionals)

DELPHI STUDY: ROUND 3

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is the final round of three rounds within the Delphi study.

The questions in Round 3 are items generated based on the responses from Round 2. Please rate the importance of each item for children with cerebral palsy aged between 8 to 12 years using the questionnaire.

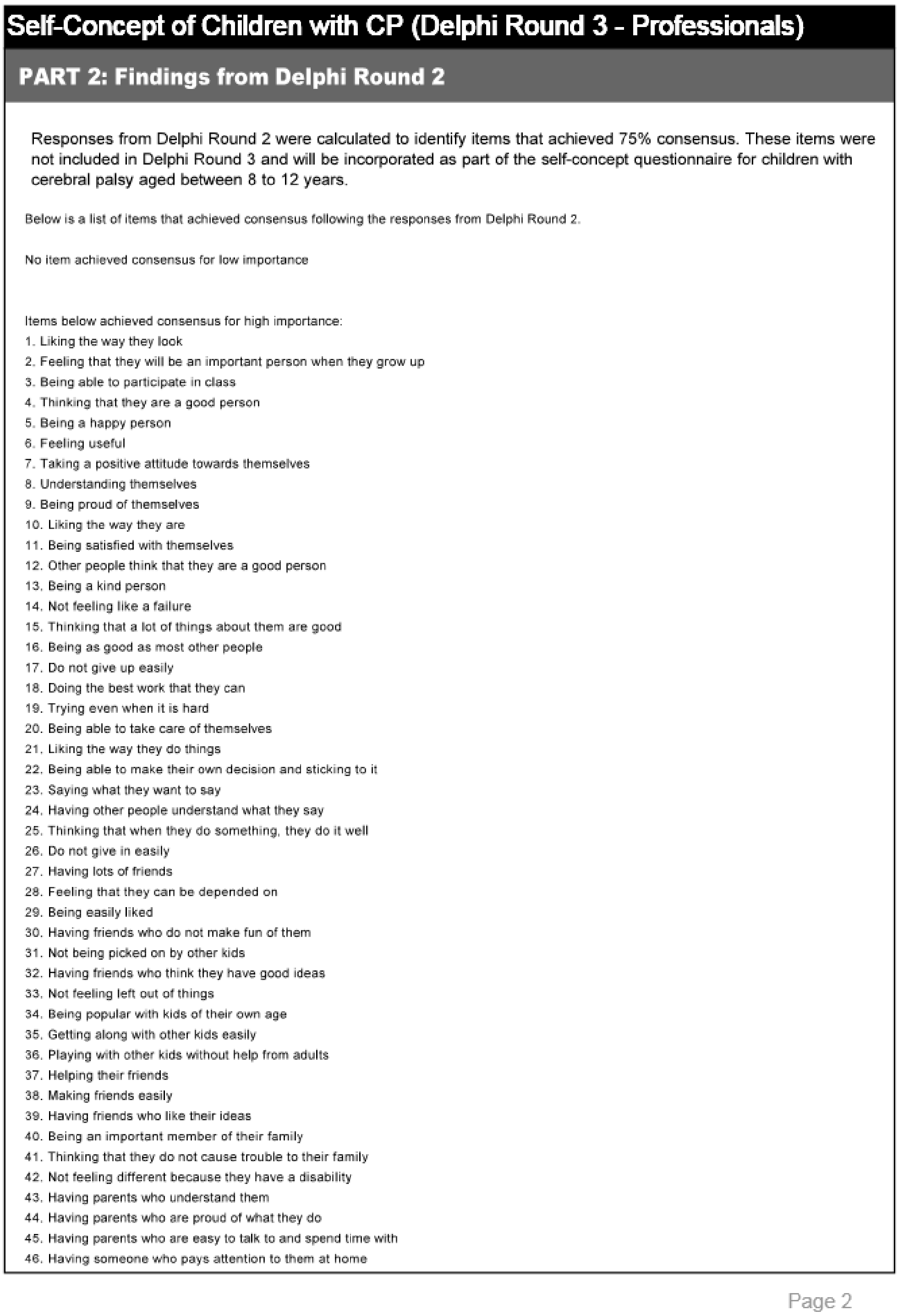
Kindly completed the questionnaire within two weeks upon receive.

PART 1: Information About You
This first section is included to ensure that we do not re-contact you after you have sent in a reply. Your details will be removed before analysis.

***1. Your name**

***2. Your e-mail contact**

Page 1



Self-Concept of Children with CP (Delphi Round 3 - Professionals)

PART 2: Findings from Delphi Round 2

Responses from Delphi Round 2 were calculated to identify items that achieved 75% consensus. These items were not included in Delphi Round 3 and will be incorporated as part of the self-concept questionnaire for children with cerebral palsy aged between 8 to 12 years.

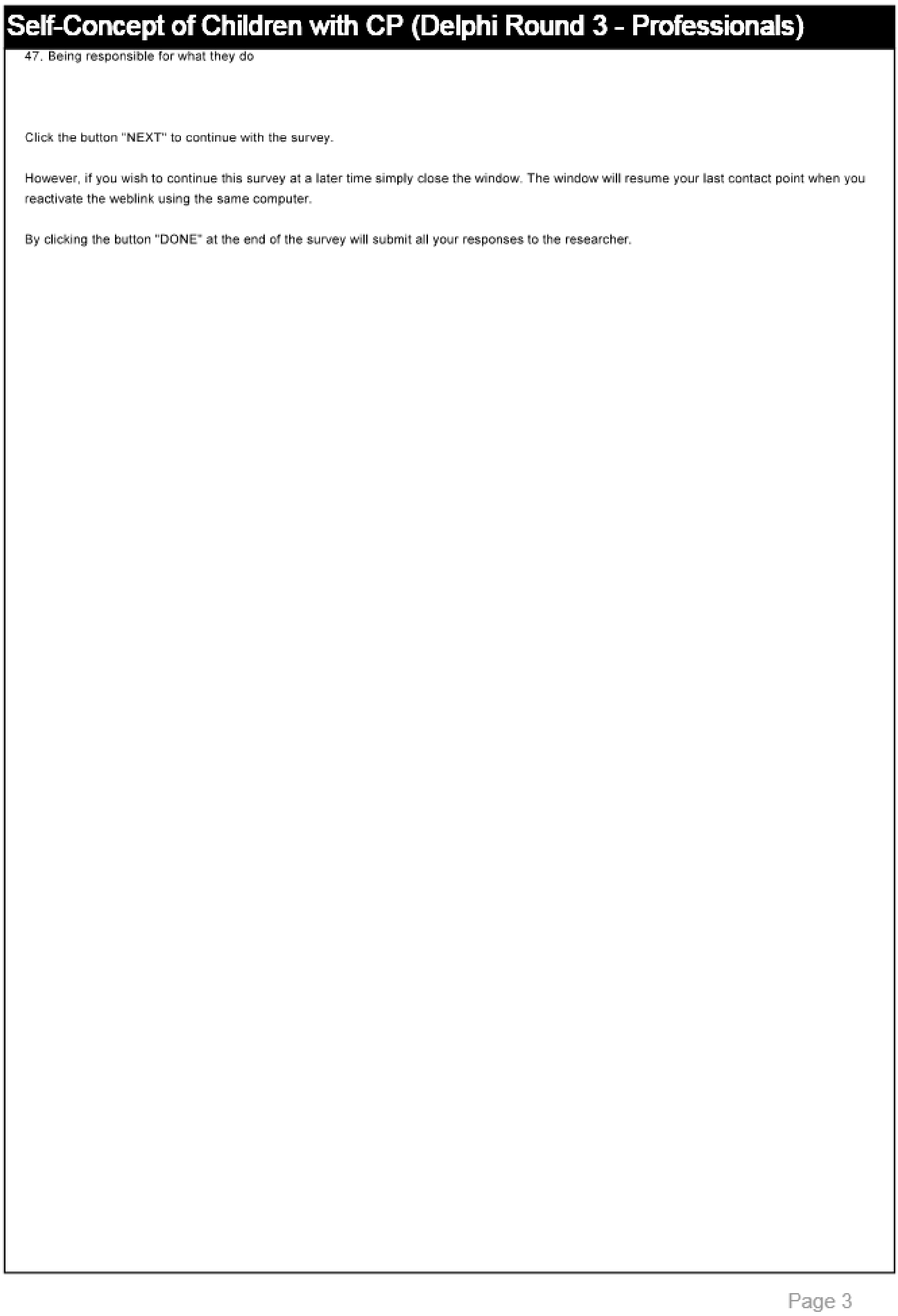
Below is a list of items that achieved consensus following the responses from Delphi Round 2.

No item achieved consensus for low importance

Items below achieved consensus for high importance:

1. Liking the way they look
2. Feeling that they will be an important person when they grow up
3. Being able to participate in class
4. Thinking that they are a good person
5. Being a happy person
6. Feeling useful
7. Taking a positive attitude towards themselves
8. Understanding themselves
9. Being proud of themselves
10. Liking the way they are
11. Being satisfied with themselves
12. Other people think that they are a good person
13. Being a kind person
14. Not feeling like a failure
15. Thinking that a lot of things about them are good
16. Being as good as most other people
17. Do not give up easily
18. Doing the best work that they can
19. Trying even when it is hard
20. Being able to take care of themselves
21. Liking the way they do things
22. Being able to make their own decision and sticking to it
23. Saying what they want to say
24. Having other people understand what they say
25. Thinking that when they do something, they do it well
26. Do not give in easily
27. Having lots of friends
28. Feeling that they can be depended on
29. Being easily liked
30. Having friends who do not make fun of them
31. Not being picked on by other kids
32. Having friends who think they have good ideas
33. Not feeling left out of things
34. Being popular with kids of their own age
35. Getting along with other kids easily
36. Playing with other kids without help from adults
37. Helping their friends
38. Making friends easily
39. Having friends who like their ideas
40. Being an important member of their family
41. Thinking that they do not cause trouble to their family
42. Not feeling different because they have a disability
43. Having parents who understand them
44. Having parents who are proud of what they do
45. Having parents who are easy to talk to and spend time with
46. Having someone who pays attention to them at home

Page 2



Self-Concept of Children with CP (Delphi Round 3 - Professionals)

47. Being responsible for what they do

Click the button "NEXT" to continue with the survey.

However, if you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

By clicking the button "DONE" at the end of the survey will submit all your responses to the researcher.

Self-Concept of Children with CP (Delphi Round 3 - Professionals)

PART 3: Specific Items Reflecting Self-Concept of Children with CP Aged 8-1...

Below is a list of self-concept items (specific questions to be asked) that were:
a) identified from self-concept scales for typically developing children, and then prioritised for children with cerebral palsy by participants in Round 2 of this Delphi survey
b) suggested as missing / additional items relevant for children with cerebral palsy from participants in Round 2 of this Delphi survey

Please rate each statement according to how important you think that statement might be in describing self-concept of children with cerebral palsy aged between 8 to 12 years. Some items appear similar, but we would appreciate you scoring each item.

This scale is: 1 = Not important to 5 = Extremely important

Responses from Round 2 were analysed and median responses from participants were indicated in brackets beside every item.

Page 4

Self-Concept of Children with CP (Delphi Round 3 - Professionals)

1. Rate how important each item is in contributing to the self-concept of children with cerebral palsy

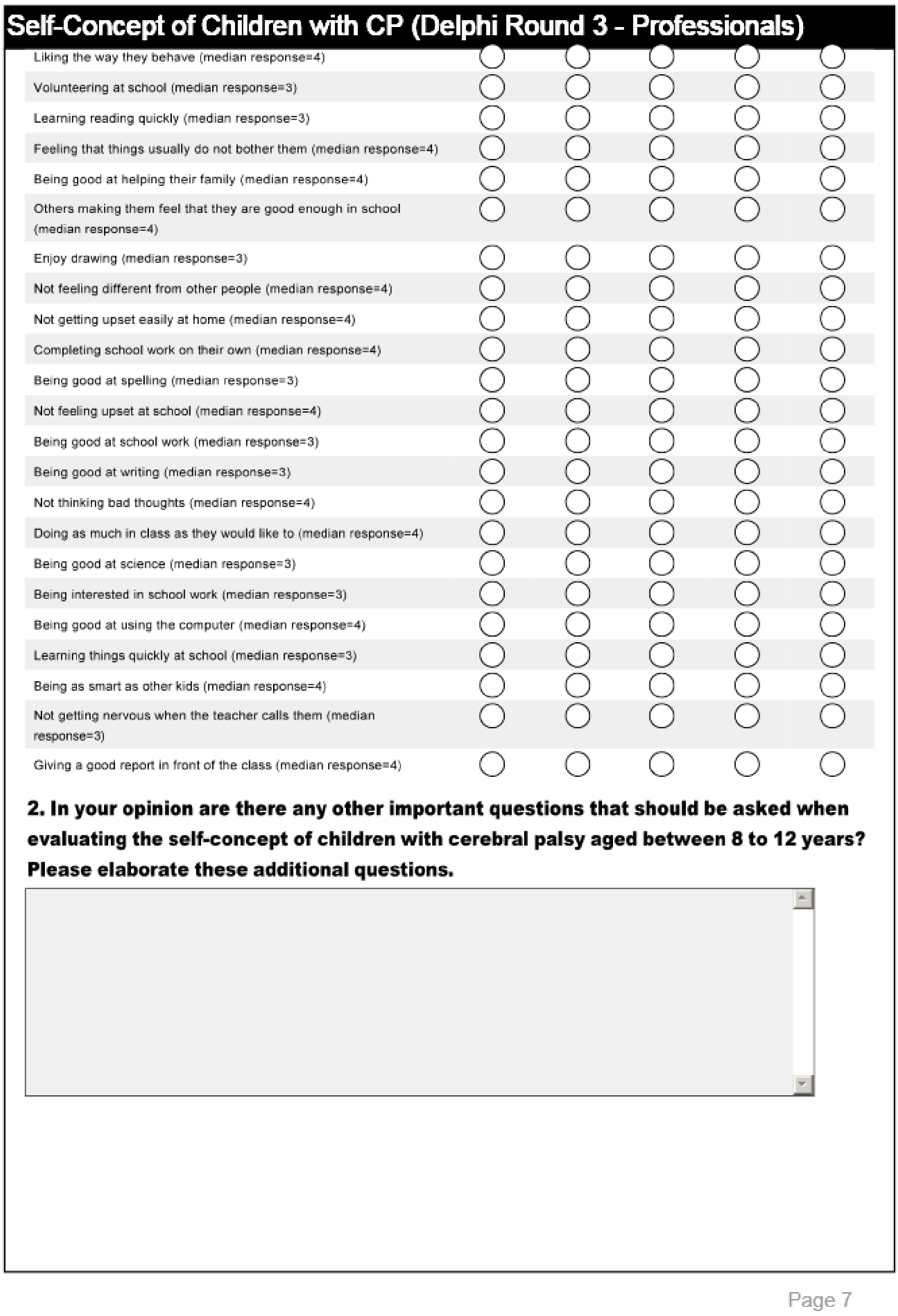
	Not important (1)	Slightly important (2)	Average importance (3)	Very important (4)	Extremely important (5)
Seeing themselves as good looking (median response=3)	○	○	○	○	○
Enjoying sports and games (median response=4)	○	○	○	○	○
Liking school work (median response=3)	○	○	○	○	○
Liking Mathematics (median response=3)	○	○	○	○	○
Being lucky (median response=3)	○	○	○	○	○
Doing lots of important things (median response=4)	○	○	○	○	○
Having more friends than most other kids (median response=3)	○	○	○	○	○
Behaving well at home (median response=4)	○	○	○	○	○
Often feeling sad (median response=4)	○	○	○	○	○
Finding that eating is easy for them (median response=3)	○	○	○	○	○
Having a pleasant looking face (median response=3)	○	○	○	○	○
In games and sports, having to play instead of watch (median response=4)	○	○	○	○	○
Getting good marks at school (median response=3)	○	○	○	○	○
Being good in Mathematics (median response=3)	○	○	○	○	○
Not wanting to change themselves (median response=4)	○	○	○	○	○
Getting used to new things quickly (median response=3)	○	○	○	○	○
Being popular with girls (median response=4)	○	○	○	○	○
Doing many good things (median response=3)	○	○	○	○	○
Worrying a lot (median response=4)	○	○	○	○	○
Being a good eater (median response=3)	○	○	○	○	○
Having nice facial features like nose, eyes and hair (median response=3)	○	○	○	○	○
Being good at sports (median response=3)	○	○	○	○	○
Being smart (median response=3)	○	○	○	○	○
Feeling that Mathematics is easy for them (median response=3)	○	○	○	○	○
Being funny (median response=4)	○	○	○	○	○
Doing things as well as most other people (median response=4)	○	○	○	○	○
Being popular with boys (median response=4)	○	○	○	○	○
Doing the right thing (median response=4)	○	○	○	○	○
Being shy (median response=3)	○	○	○	○	○
Being good at using the part of their body that has cerebral palsy (median response=4)	○	○	○	○	○
Feeling that they are better looking than most of their friends (median response=3)	○	○	○	○	○
Being as good at sports as other kids (median response=4)	○	○	○	○	○
Having school work that is easy for them (median response=3)	○	○	○	○	○

Page 5

Self-Concept of Children with CP (Delphi Round 3 - Professionals)

Learning Mathematics quickly (median response=3)	○	○	○	○	○
Being polite (median response=4)	○	○	○	○	○
Being able to talk to others easily (median response=4)	○	○	○	○	○
Having most other kids like them (median response=4)	○	○	○	○	○
Don't get into trouble (median response=4)	○	○	○	○	○
Being nervous (median response=4)	○	○	○	○	○
Being responsible for actions of others (median response=3)	○	○	○	○	○
Having other kids think that they are good looking (median response=3)	○	○	○	○	○
Being able to run well (median response=3)	○	○	○	○	○
Being quick at finishing their school work (median response=3)	○	○	○	○	○
Liking reading (median response=3)	○	○	○	○	○
Being a fun person (median response=4)	○	○	○	○	○
Doing things right (median response=4)	○	○	○	○	○
Being among the first few to be chosen for games and sports (median response=4)	○	○	○	○	○
Don't get into fights (median response=4)	○	○	○	○	○
Often feeling afraid (median response=4)	○	○	○	○	○
Being neat (median response=3)	○	○	○	○	○
Being strong (median response=3)	○	○	○	○	○
Doing as well at new games as other kids (median response=4)	○	○	○	○	○
Remembering what they learn (median response=3)	○	○	○	○	○
Being good at reading (median response=3)	○	○	○	○	○
Not wishing they were different (median response=4)	○	○	○	○	○
Enjoying being with other people (median response=4)	○	○	○	○	○
Being good to other people (median response=4)	○	○	○	○	○
Crying easily (median response=4)	○	○	○	○	○
Being quick at getting myself ready (median response=3)	○	○	○	○	○
Having good muscles (median response=3)	○	○	○	○	○
Being a leader in games and sports (median response=3)	○	○	○	○	○
Being an important member of their class (median response=4)	○	○	○	○	○
Feeling that reading is easy for them (median response=3)	○	○	○	○	○
Having respect for themselves (median response=4)	○	○	○	○	○
Thinking that when something goes wrong, it is not usually their fault (median response=4)	○	○	○	○	○
Getting worried when they have a test at school (median response=4)	○	○	○	○	○
Enjoy being at school (median response=4)	○	○	○	○	○
Having a good looking body (median response=3)	○	○	○	○	○
Behaving well in school (median response=3)	○	○	○	○	○
Being interested in reading (median response=3)	○	○	○	○	○
Feeling that it is not tough being them (median response=4)	○	○	○	○	○

Page 6

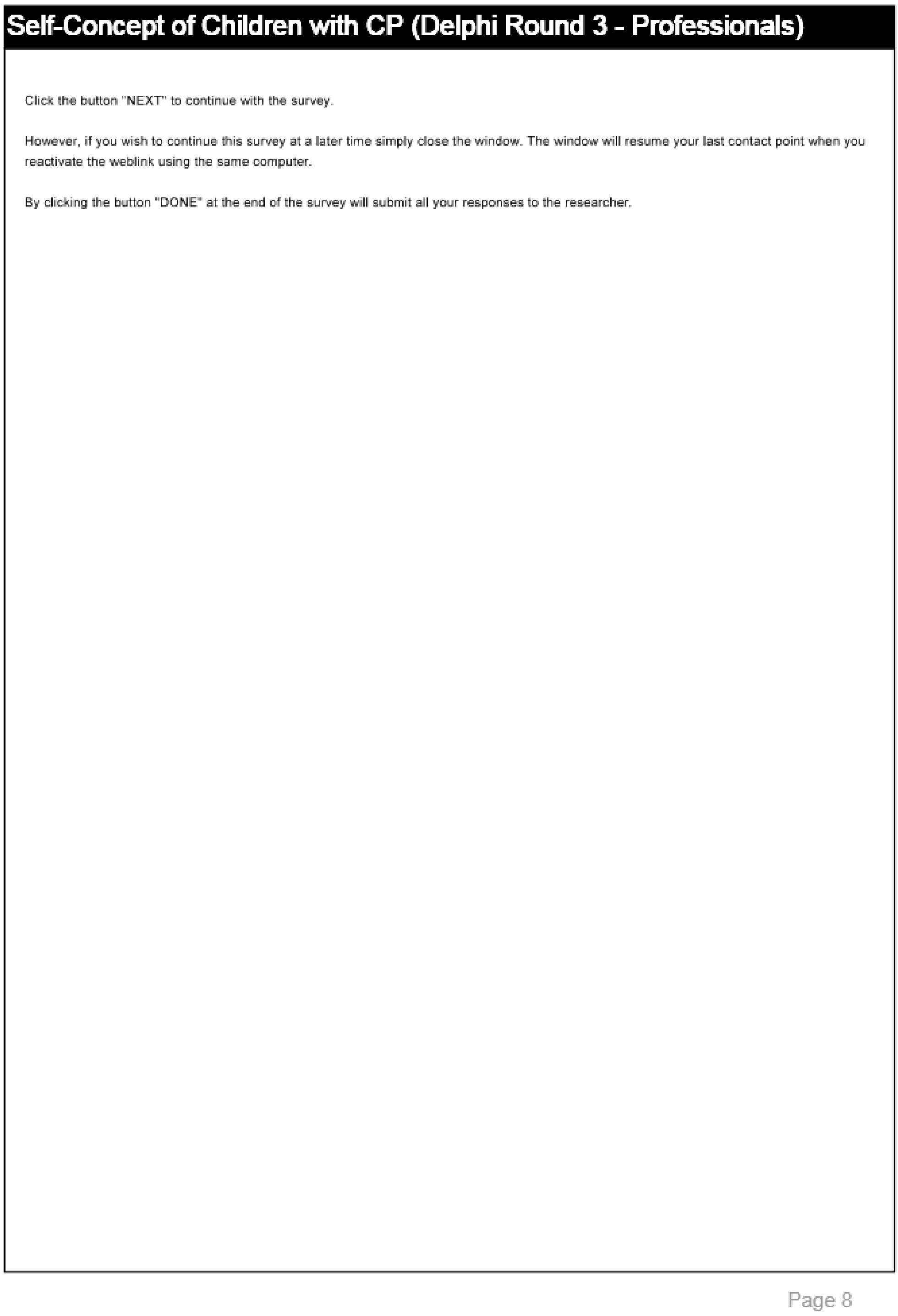


Self-Concept of Children with CP (Delphi Round 3 - Professionals)

Liking the way they behave (median response=4)	○	○	○	○	○
Volunteering at school (median response=3)	○	○	○	○	○
Learning reading quickly (median response=3)	○	○	○	○	○
Feeling that things usually do not bother them (median response=4)	○	○	○	○	○
Being good at helping their family (median response=4)	○	○	○	○	○
Others making them feel that they are good enough in school (median response=4)	○	○	○	○	○
Enjoy drawing (median response=3)	○	○	○	○	○
Not feeling different from other people (median response=4)	○	○	○	○	○
Not getting upset easily at home (median response=4)	○	○	○	○	○
Completing school work on their own (median response=4)	○	○	○	○	○
Being good at spelling (median response=3)	○	○	○	○	○
Not feeling upset at school (median response=4)	○	○	○	○	○
Being good at school work (median response=3)	○	○	○	○	○
Being good at writing (median response=3)	○	○	○	○	○
Not thinking bad thoughts (median response=4)	○	○	○	○	○
Doing as much in class as they would like to (median response=4)	○	○	○	○	○
Being good at science (median response=3)	○	○	○	○	○
Being interested in school work (median response=3)	○	○	○	○	○
Being good at using the computer (median response=4)	○	○	○	○	○
Learning things quickly at school (median response=3)	○	○	○	○	○
Being as smart as other kids (median response=4)	○	○	○	○	○
Not getting nervous when the teacher calls them (median response=3)	○	○	○	○	○
Giving a good report in front of the class (median response=4)	○	○	○	○	○

2. In your opinion are there any other important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years? Please elaborate these additional questions.

Page 7



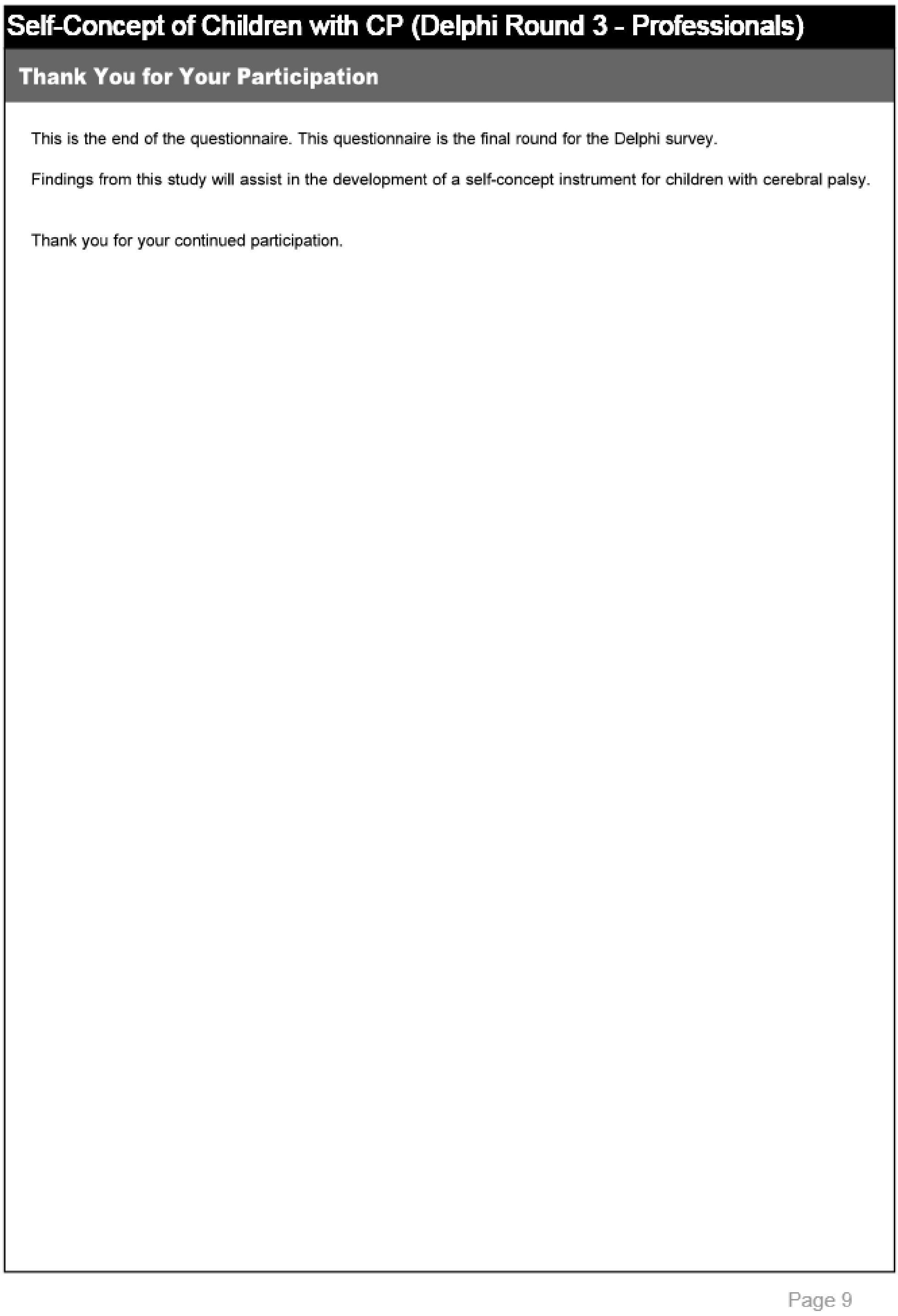
Self-Concept of Children with CP (Delphi Round 3 - Professionals)

Click the button "NEXT" to continue with the survey.

However, if you wish to continue this survey at a later time simply close the window. The window will resume your last contact point when you reactivate the weblink using the same computer.

By clicking the button "DONE" at the end of the survey will submit all your responses to the researcher.

Page 8



Self-Concept of Children with CP (Delphi Round 3 - Professionals)

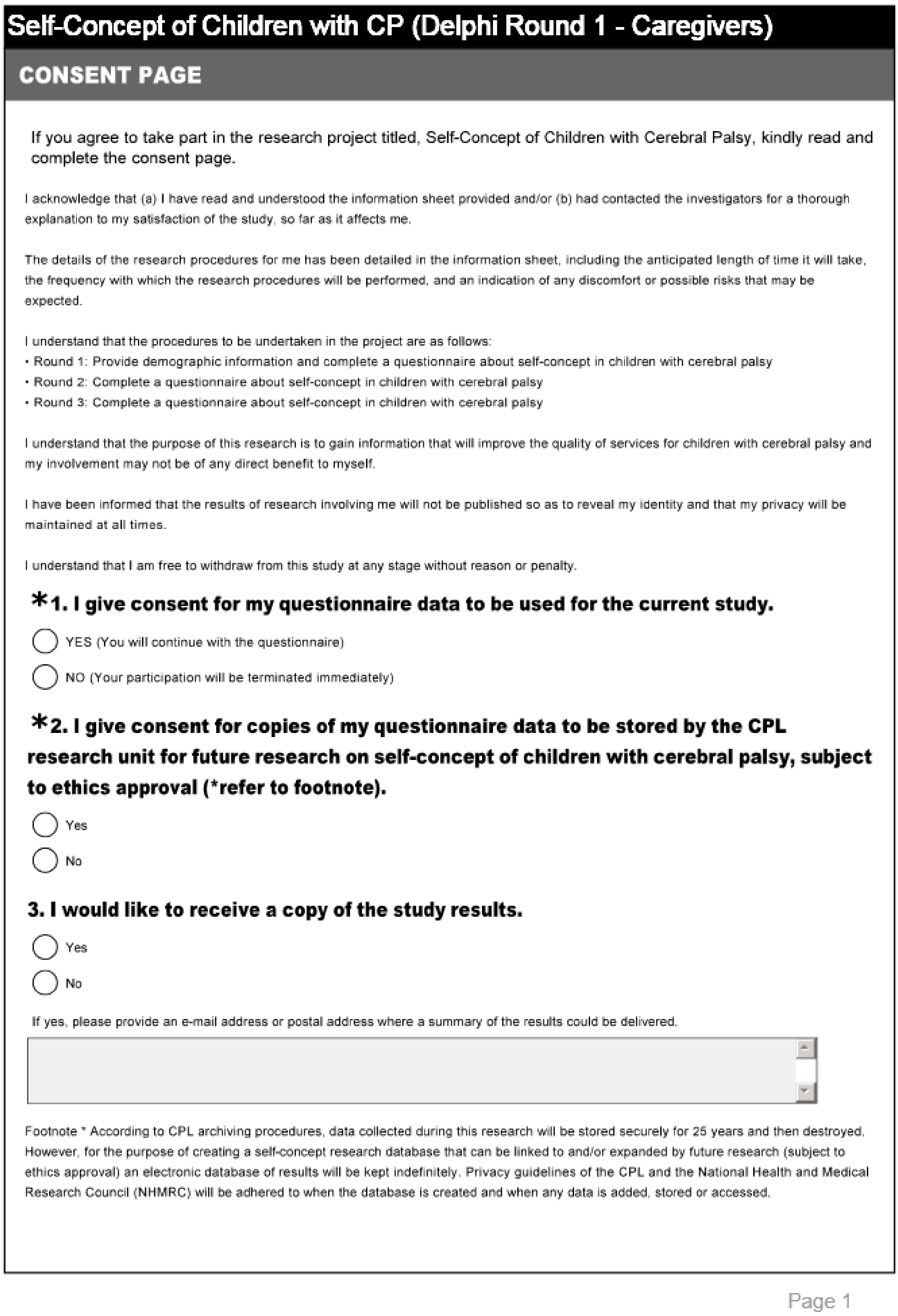
Thank You for Your Participation

This is the end of the questionnaire. This questionnaire is the final round for the Delphi survey.

Findings from this study will assist in the development of a self-concept instrument for children with cerebral palsy.

Thank you for your continued participation.

Study 2: Parent group questionnaire – Delphi Round I



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

CONSENT PAGE

If you agree to take part in the research project titled, Self-Concept of Children with Cerebral Palsy, kindly read and complete the consent page.

I acknowledge that (a) I have read and understood the information sheet provided and/or (b) had contacted the investigators for a thorough explanation to my satisfaction of the study, so far as it affects me.

The details of the research procedures for me has been detailed in the information sheet, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

I understand that the procedures to be undertaken in the project are as follows:
- Round 1: Provide demographic information and complete a questionnaire about self-concept in children with cerebral palsy
- Round 2: Complete a questionnaire about self-concept in children with cerebral palsy
- Round 3: Complete a questionnaire about self-concept in children with cerebral palsy

I understand that the purpose of this research is to gain information that will improve the quality of services for children with cerebral palsy and my involvement may not be of any direct benefit to myself.

I have been informed that the results of research involving me will not be published so as to reveal my identity and that my privacy will be maintained at all times.

I understand that I am free to withdraw from this study at any stage without reason or penalty.

***1. I give consent for my questionnaire data to be used for the current study.**

○ YES (You will continue with the questionnaire)

○ NO (Your participation will be terminated immediately)

***2. I give consent for copies of my questionnaire data to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval (*refer to footnote).**

○ Yes

○ No

3. I would like to receive a copy of the study results.

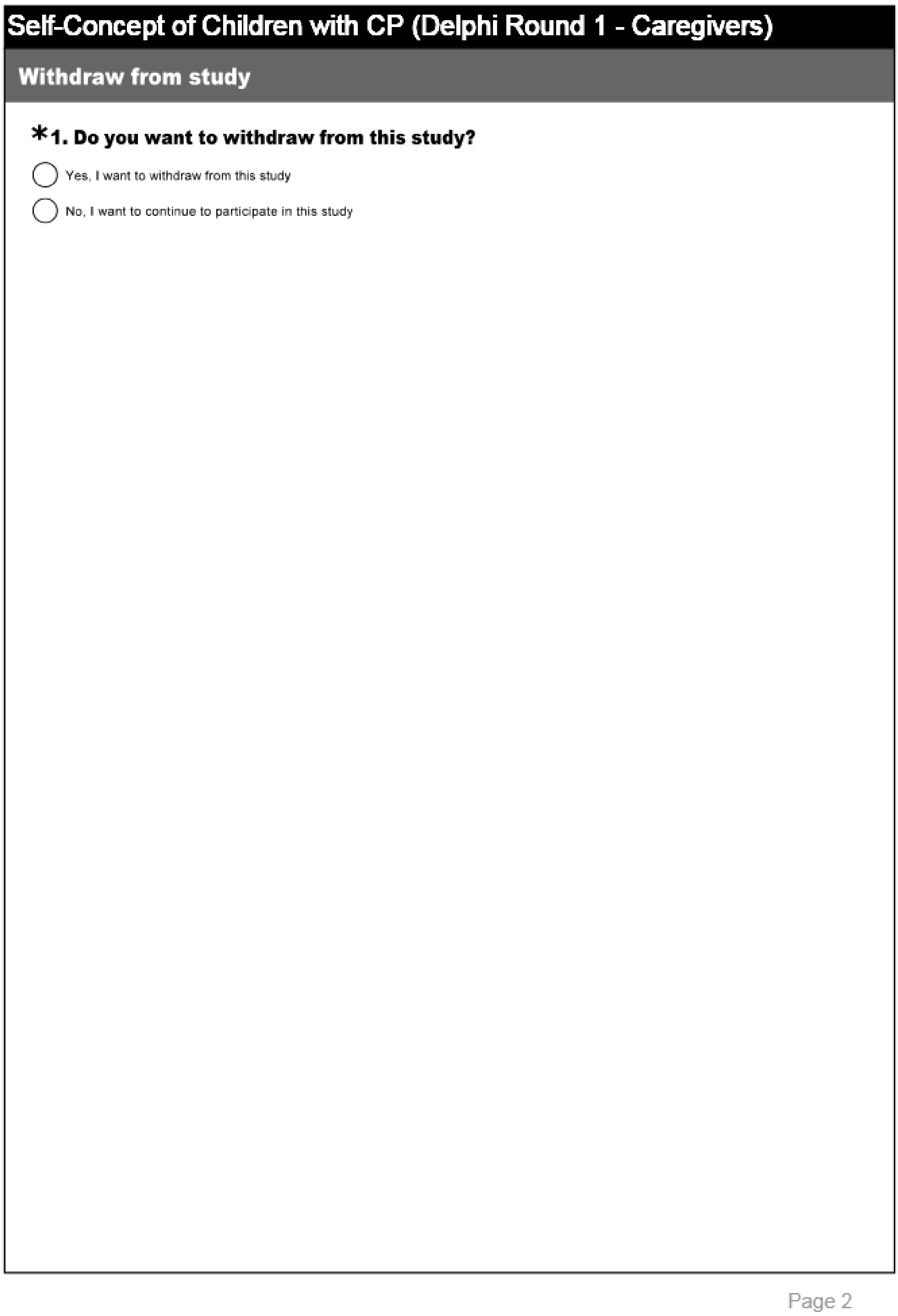
○ Yes

○ No

If yes, please provide an e-mail address or postal address where a summary of the results could be delivered.

Footnote * According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.

Page 1



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

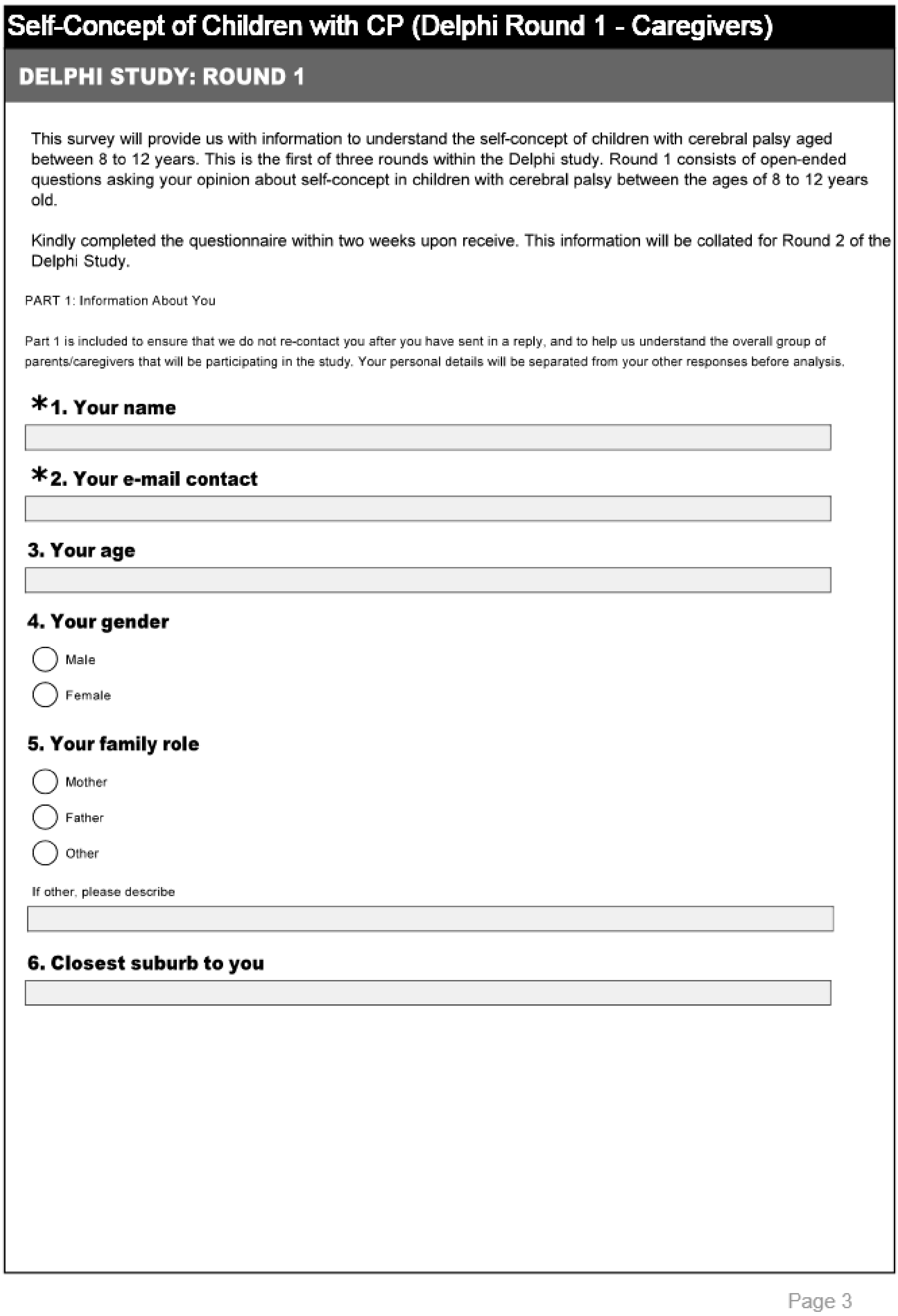
Withdraw from study

***1. Do you want to withdraw from this study?**

○ Yes, I want to withdraw from this study

○ No, I want to continue to participate in this study

Page 2



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

DELPHI STUDY: ROUND 1

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is the first of three rounds within the Delphi study. Round 1 consists of open-ended questions asking your opinion about self-concept in children with cerebral palsy between the ages of 8 to 12 years old.

Kindly completed the questionnaire within two weeks upon receive. This information will be collated for Round 2 of the Delphi Study.

PART 1: Information About You

Part 1 is included to ensure that we do not re-contact you after you have sent in a reply, and to help us understand the overall group of parents/caregivers that will be participating in the study. Your personal details will be separated from your other responses before analysis.

***1. Your name**

***2. Your e-mail contact**

3. Your age

4. Your gender

○ Male

○ Female

5. Your family role

○ Mother

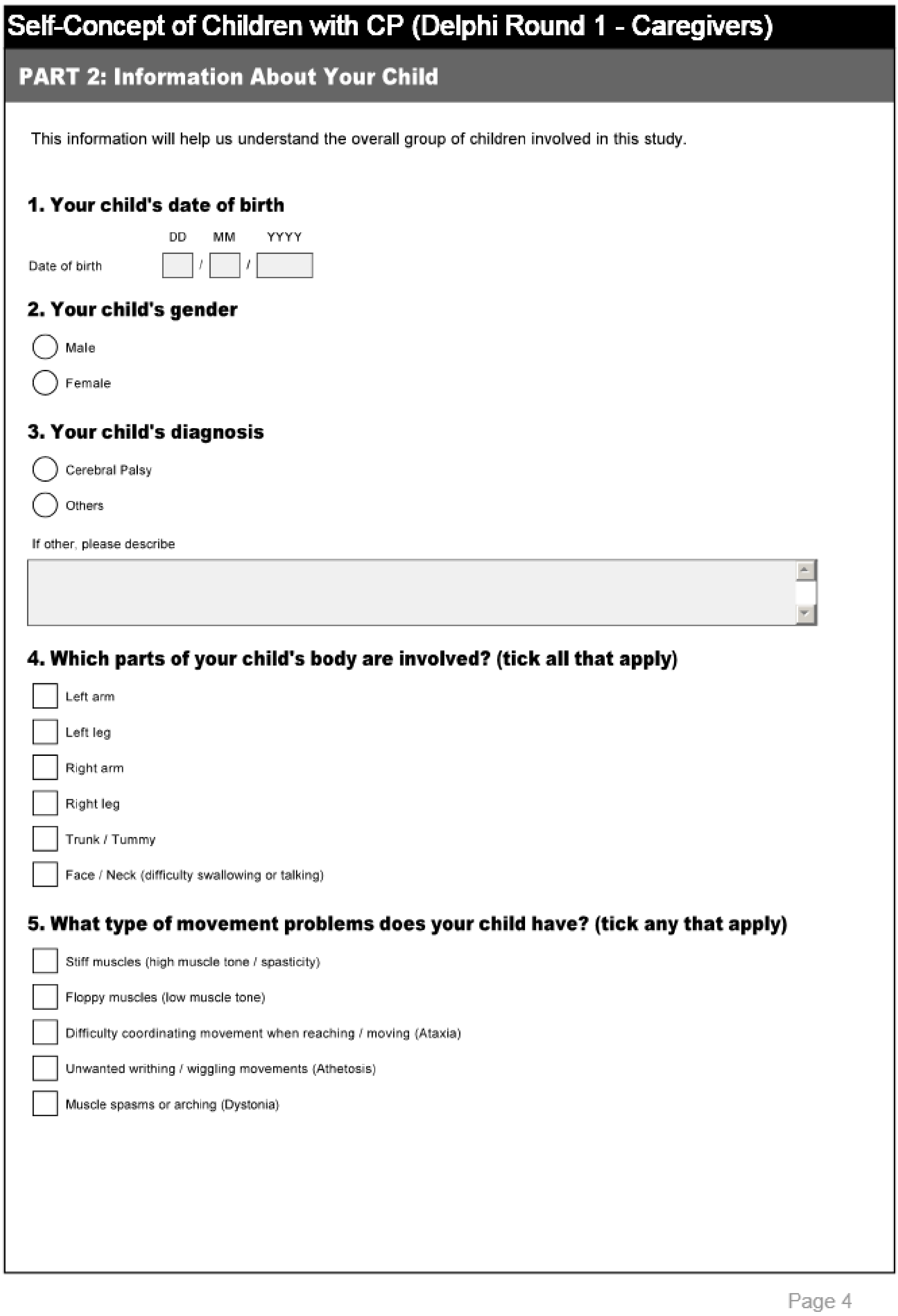
○ Father

○ Other

If other, please describe

6. Closest suburb to you

Page 3



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

PART 2: Information About Your Child

This information will help us understand the overall group of children involved in this study.

1. Your child's date of birth

Date of birth DD / MM / YYYY

2. Your child's gender

○ Male
○ Female

3. Your child's diagnosis

○ Cerebral Palsy
○ Others

If other, please describe

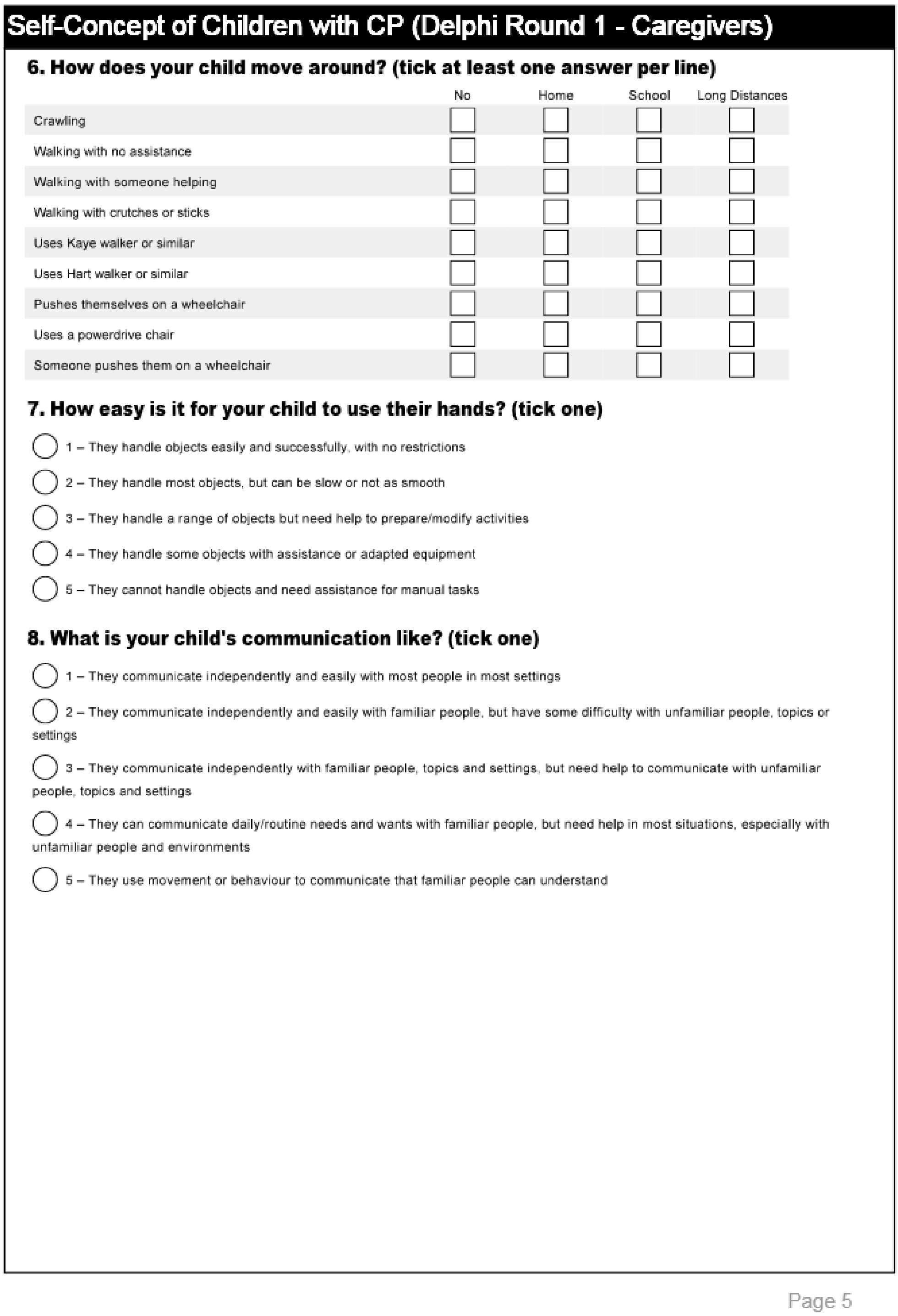
4. Which parts of your child's body are involved? (tick all that apply)

☐ Left arm
☐ Left leg
☐ Right arm
☐ Right leg
☐ Trunk / Tummy
☐ Face / Neck (difficulty swallowing or talking)

5. What type of movement problems does your child have? (tick any that apply)

☐ Stiff muscles (high muscle tone / spasticity)
☐ Floppy muscles (low muscle tone)
☐ Difficulty coordinating movement when reaching / moving (Ataxia)
☐ Unwanted writhing / wiggling movements (Athetosis)
☐ Muscle spasms or arching (Dystonia)

Page 4



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

6. How does your child move around? (tick at least one answer per line)

	No	Home	School	Long Distances
Crawling	☐	☐	☐	☐
Walking with no assistance	☐	☐	☐	☐
Walking with someone helping	☐	☐	☐	☐
Walking with crutches or sticks	☐	☐	☐	☐
Uses Kaye walker or similar	☐	☐	☐	☐
Uses Hart walker or similar	☐	☐	☐	☐
Pushes themselves on a wheelchair	☐	☐	☐	☐
Uses a powerdrive chair	☐	☐	☐	☐
Someone pushes them on a wheelchair	☐	☐	☐	☐

7. How easy is it for your child to use their hands? (tick one)

○ 1 – They handle objects easily and successfully, with no restrictions

○ 2 – They handle most objects, but can be slow or not as smooth

○ 3 – They handle a range of objects but need help to prepare/modify activities

○ 4 – They handle some objects with assistance or adapted equipment

○ 5 – They cannot handle objects and need assistance for manual tasks

8. What is your child's communication like? (tick one)

○ 1 – They communicate independently and easily with most people in most settings

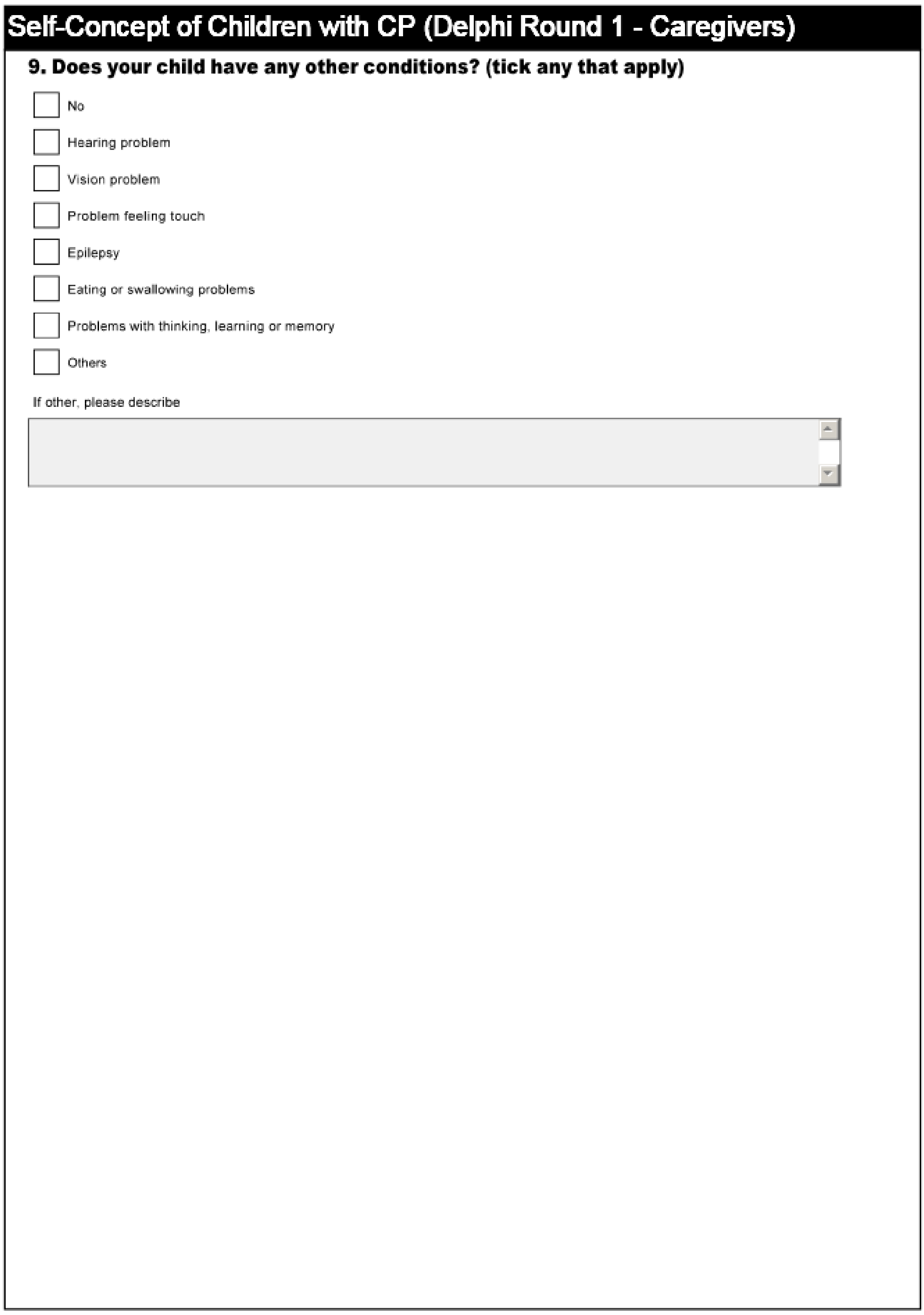
○ 2 – They communicate independently and easily with familiar people, but have some difficulty with unfamiliar people, topics or settings

○ 3 – They communicate independently with familiar people, topics and settings, but need help to communicate with unfamiliar people, topics and settings

○ 4 – They can communicate daily/routine needs and wants with familiar people, but need help in most situations, especially with unfamiliar people and environments

○ 5 – They use movement or behaviour to communicate that familiar people can understand

Page 5

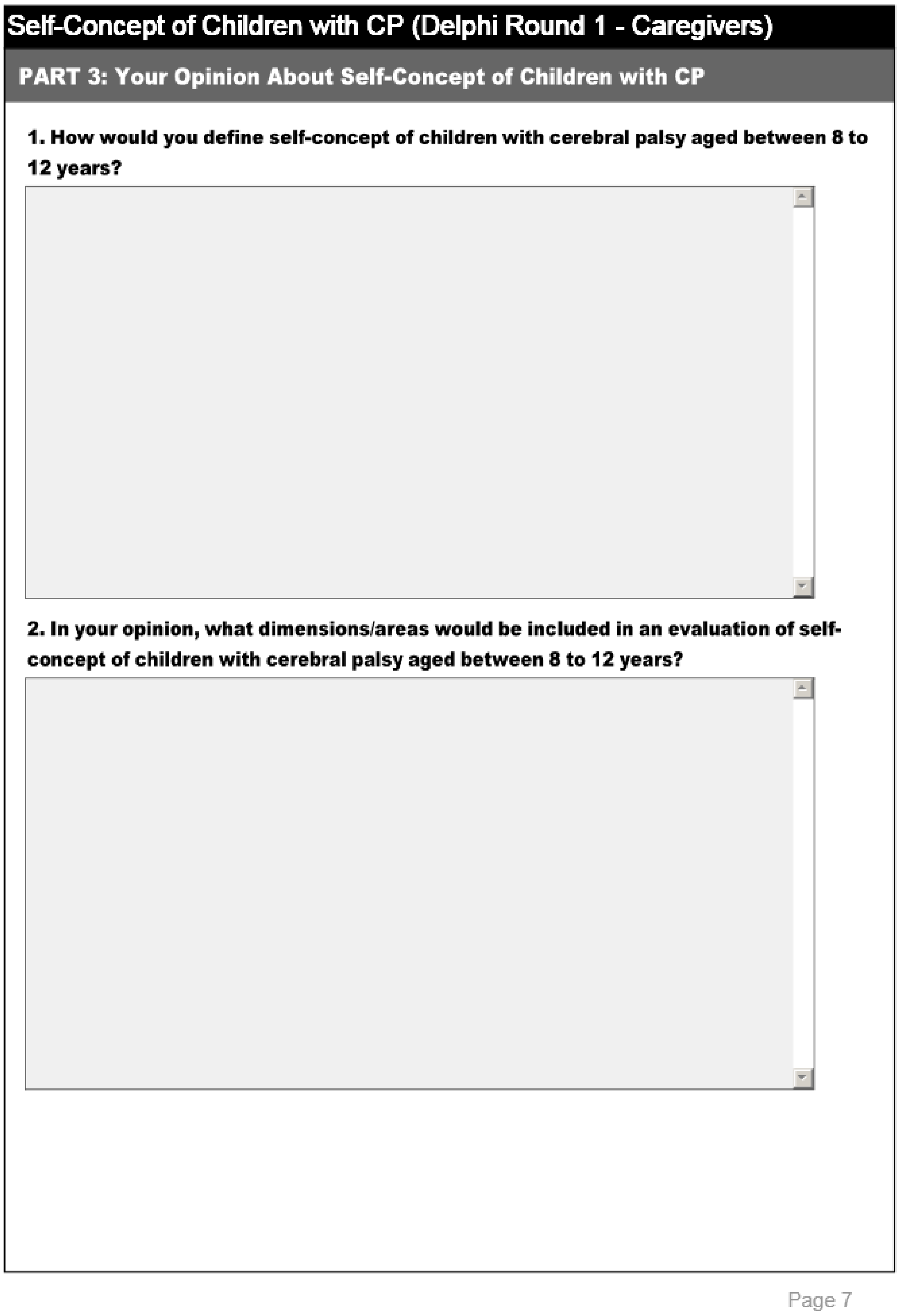


Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

9. Does your child have any other conditions? (tick any that apply)

- ☐ No
- ☐ Hearing problem
- ☐ Vision problem
- ☐ Problem feeling touch
- ☐ Epilepsy
- ☐ Eating or swallowing problems
- ☐ Problems with thinking, learning or memory
- ☐ Others

If other, please describe



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

PART 3: Your Opinion About Self-Concept of Children with CP

1. How would you define self-concept of children with cerebral palsy aged between 8 to 12 years?

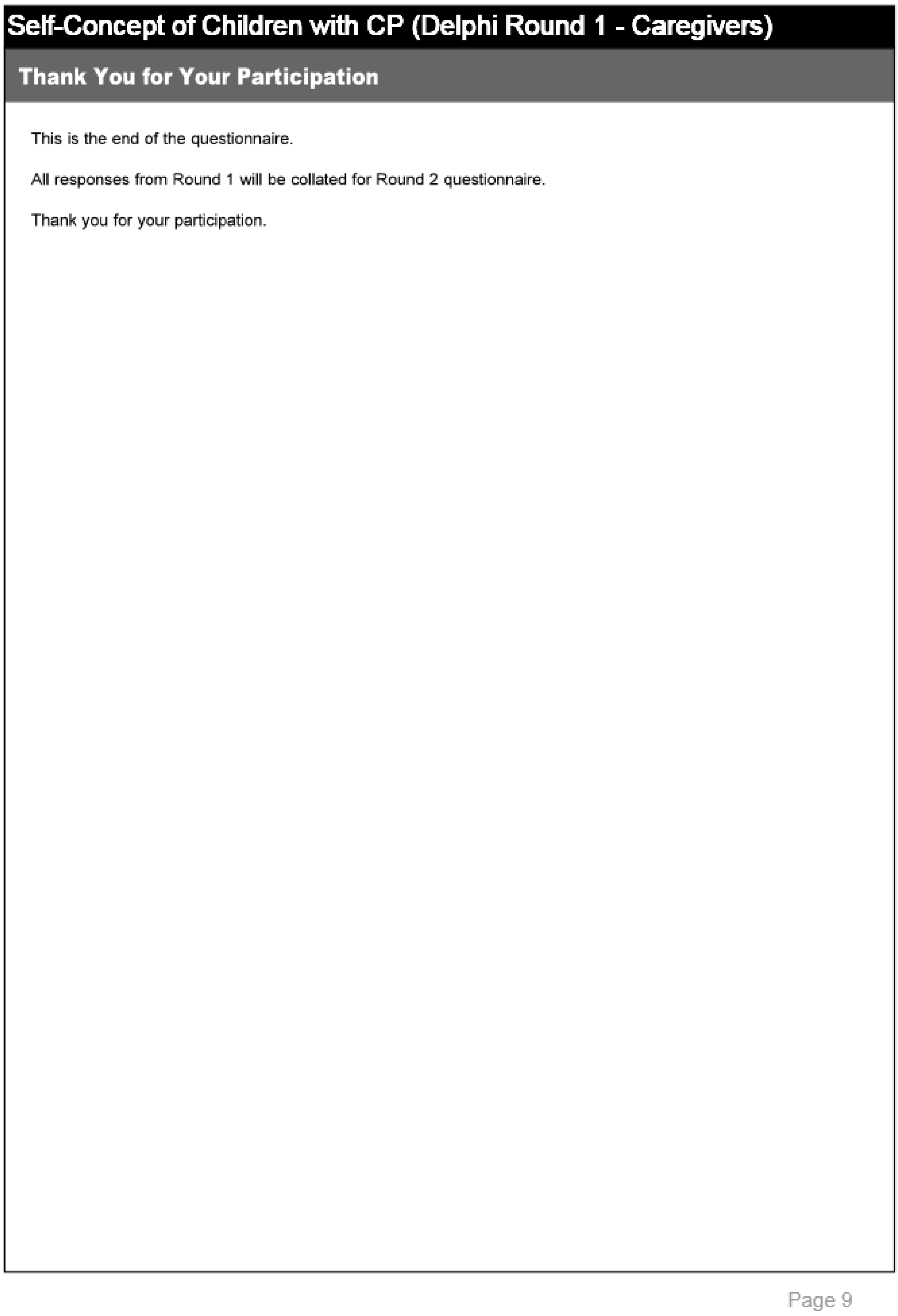
2. In your opinion, what dimensions/areas would be included in an evaluation of self-concept of children with cerebral palsy aged between 8 to 12 years?

Page 7

Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

3. In your opinion, what are some important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years?

Page 8



Self-Concept of Children with CP (Delphi Round 1 - Caregivers)

Thank You for Your Participation

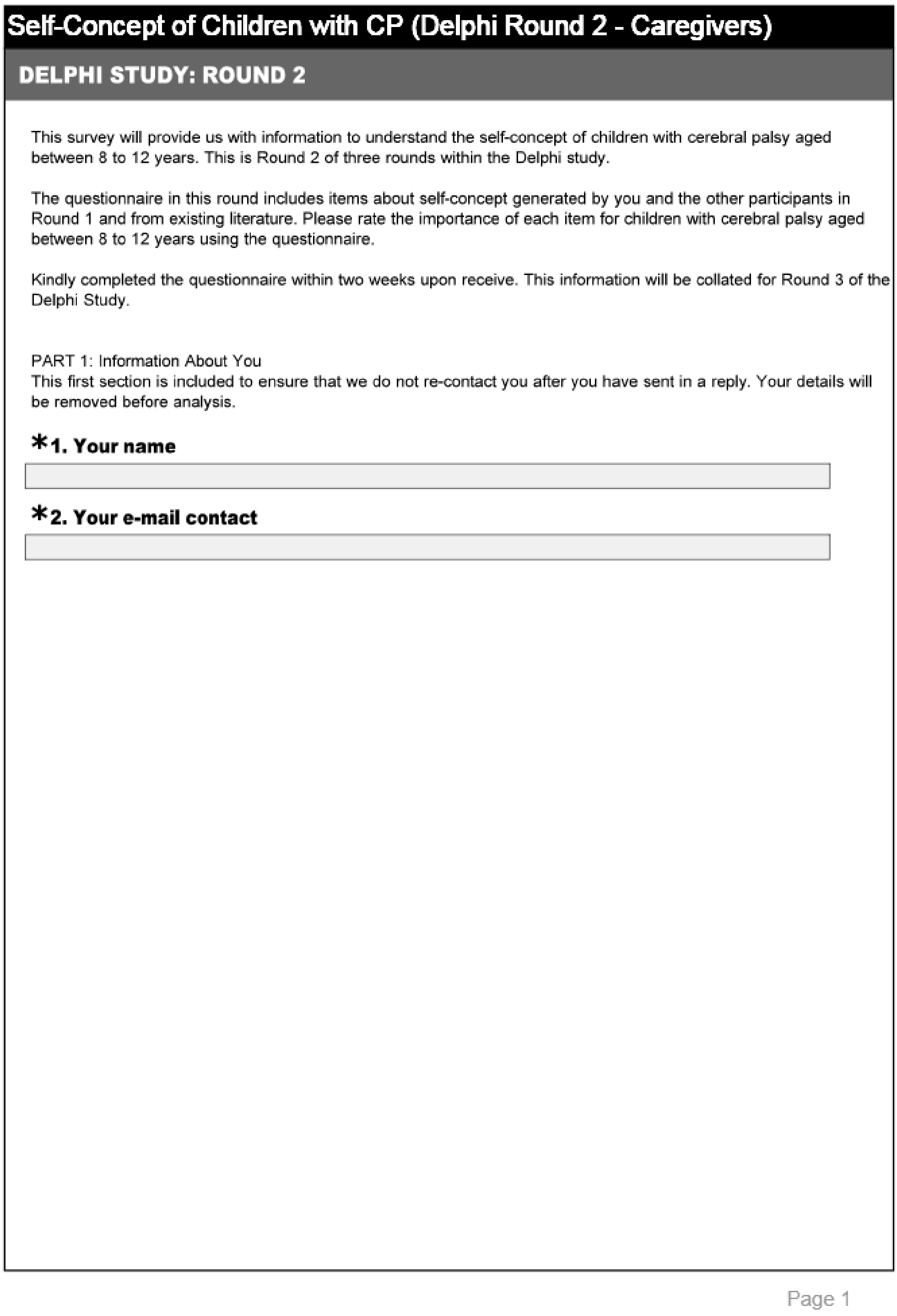
This is the end of the questionnaire.

All responses from Round 1 will be collated for Round 2 questionnaire.

Thank you for your participation.

Page 9

Study 2: Parent group questionnaire – Delphi Round II



Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

DELPHI STUDY: ROUND 2

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is Round 2 of three rounds within the Delphi study.

The questionnaire in this round includes items about self-concept generated by you and the other participants in Round 1 and from existing literature. Please rate the importance of each item for children with cerebral palsy aged between 8 to 12 years using the questionnaire.

Kindly completed the questionnaire within two weeks upon receive. This information will be collated for Round 3 of the Delphi Study.

PART 1: Information About You
This first section is included to ensure that we do not re-contact you after you have sent in a reply. Your details will be removed before analysis.

***1. Your name**

***2. Your e-mail contact**

Page 1

Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

PART 2: Factors Reflecting Self-Concept of Children with CP Aged 8-12 years

Below is a list of factors that appear in self-concept assessments for typically developing children.

Please rate each factor according to how important you think that factor might be in describing how children with cerebral palsy aged between 8 to 12 years feel about themselves.

The scale is: 1 = Not Important to 5 = Extremely important

Some items appear similar, but we would appreciate you scoring each one.

1. Rate how important each factor is in contributing to the self-concept of children with cerebral palsy

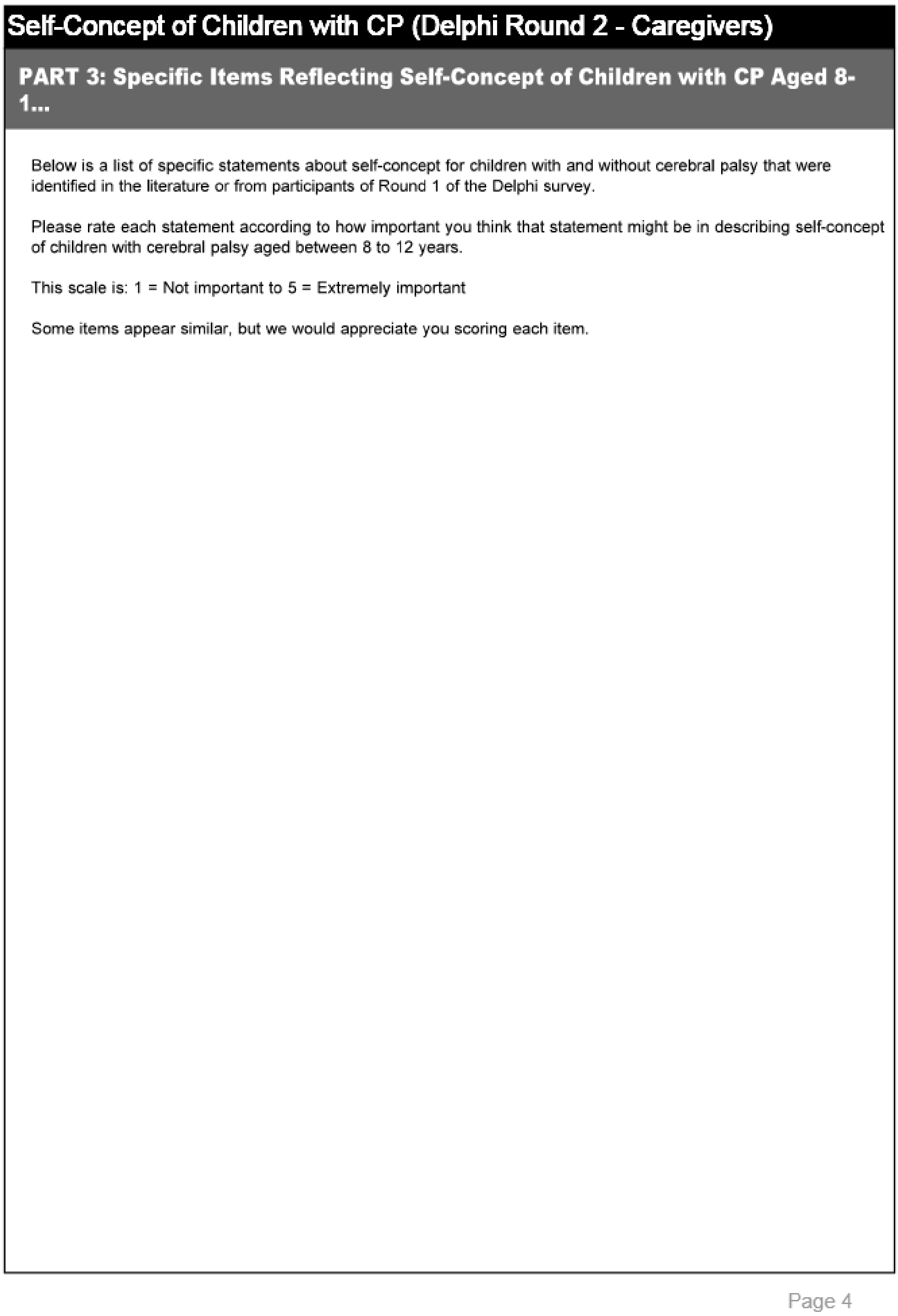
	Not important	Slightly important	Average importance	Very important	Extremely important
GENERAL SELF (Ratings of themselves as effective, capable individuals, who are proud and satisfied with the way they are.)	○	○	○	○	○
GLOBAL SELF-WORTH (Taps the extent to which the child likes oneself as a person, is happy the way one is leading one's life, and is generally happy with the way one is.)	○	○	○	○	○
HAPPINESS AND SATISFACTION (Reflect feelings of happiness and satisfaction with life.)	○	○	○	○	○
PHYSICAL APPEARANCE (Taps the degree to which the child is happy with the way he/she looks, like one's height, weight, body, face, hair and feels that he/she is good looking. Ratings of their physical attractiveness, how their appearance compares with others, and how others think they look.)	○	○	○	○	○
PERSONAL ATTRIBUTES (Measures a child's appraisal of his or her attributes such as leadership and ability to express ideas.)	○	○	○	○	○
PHYSICAL ABILITIES/ ATHLETIC COMPETENCE (Ratings of their skills and interest in sports, games and physical activities.)	○	○	○	○	○
SOCIAL ACCEPTANCE (Taps the degree to which the child is accepted by peers or feels popular but does not tap competence directly in the sense that they do not refer to social skills.)	○	○	○	○	○
POPULARITY / PEER RELATIONS (Represents a child's evaluation of his/her social functioning covering perceived popularity, ability to make friends, and feelings of inclusion in activities such as games and sports.)	○	○	○	○	○
GENERAL SCHOOL (Ratings of their skills, ability, enjoyment and interest in school subjects in general.)	○	○	○	○	○
ACADEMIC COMPETENCE (Taps the child's perception of his/her competence or ability within the realm of academic performance.)	○	○	○	○	○
READING (Ratings of their skills, ability, enjoyment and interest in reading.)	○	○	○	○	○
MATHEMATICS (Ratings of their skills, ability, enjoyment and interest in Mathematics.)	○	○	○	○	○
BEHAVIOURAL CONDUCT (Taps the degree to which children like the way they behave, do the right thing, act the way they are supposed to, avoid getting into trouble, and do the things they are supposed to do.)	○	○	○	○	○
FREEDOM FROM ANXIETY (Reflect anxiety and dysphoric mood tapping a variety of emotions, including worry, nervousness, shyness,	○	○	○	○	○

Page 2

Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

sadness, fear and a general feeling of being left out of things.)

2. In your opinion are there any other dimensions/areas that would represent self-concept of children with cerebral palsy aged between 8 to 12 years in addition to those stated above? Please elaborate these additional dimensions/areas.



Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

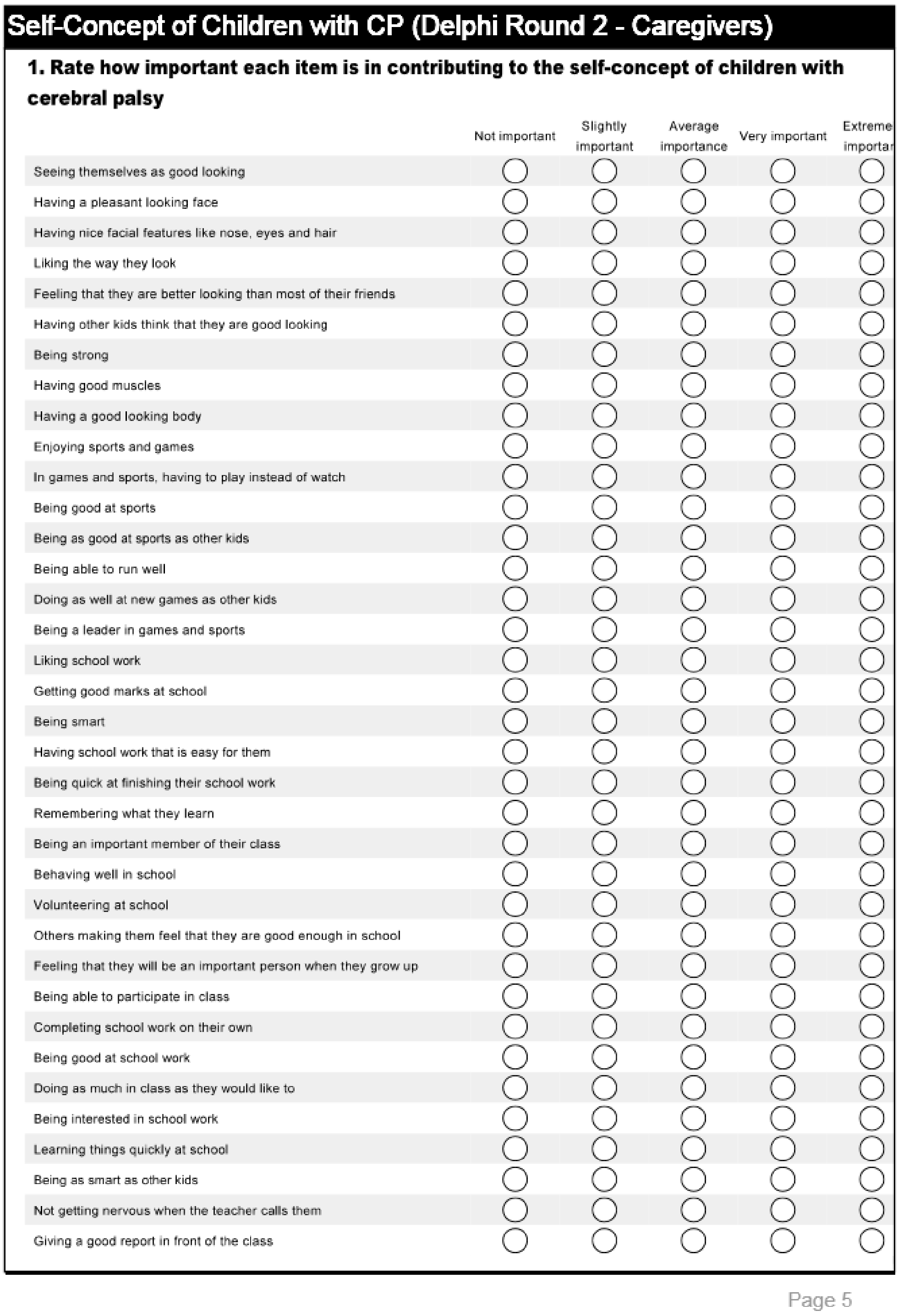
PART 3: Specific Items Reflecting Self-Concept of Children with CP Aged 8-1...

Below is a list of specific statements about self-concept for children with and without cerebral palsy that were identified in the literature or from participants of Round 1 of the Delphi survey.

Please rate each statement according to how important you think that statement might be in describing self-concept of children with cerebral palsy aged between 8 to 12 years.

This scale is: 1 = Not important to 5 = Extremely important

Some items appear similar, but we would appreciate you scoring each item.



Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

1. Rate how important each item is in contributing to the self-concept of children with cerebral palsy

	Not important	Slightly important	Average importance	Very important	Extreme importar
Seeing themselves as good looking	○	○	○	○	○
Having a pleasant looking face	○	○	○	○	○
Having nice facial features like nose, eyes and hair	○	○	○	○	○
Liking the way they look	○	○	○	○	○
Feeling that they are better looking than most of their friends	○	○	○	○	○
Having other kids think that they are good looking	○	○	○	○	○
Being strong	○	○	○	○	○
Having good muscles	○	○	○	○	○
Having a good looking body	○	○	○	○	○
Enjoying sports and games	○	○	○	○	○
In games and sports, having to play instead of watch	○	○	○	○	○
Being good at sports	○	○	○	○	○
Being as good at sports as other kids	○	○	○	○	○
Being able to run well	○	○	○	○	○
Doing as well at new games as other kids	○	○	○	○	○
Being a leader in games and sports	○	○	○	○	○
Liking school work	○	○	○	○	○
Getting good marks at school	○	○	○	○	○
Being smart	○	○	○	○	○
Having school work that is easy for them	○	○	○	○	○
Being quick at finishing their school work	○	○	○	○	○
Remembering what they learn	○	○	○	○	○
Being an important member of their class	○	○	○	○	○
Behaving well in school	○	○	○	○	○
Volunteering at school	○	○	○	○	○
Others making them feel that they are good enough in school	○	○	○	○	○
Feeling that they will be an important person when they grow up	○	○	○	○	○
Being able to participate in class	○	○	○	○	○
Completing school work on their own	○	○	○	○	○
Being good at school work	○	○	○	○	○
Doing as much in class as they would like to	○	○	○	○	○
Being interested in school work	○	○	○	○	○
Learning things quickly at school	○	○	○	○	○
Being as smart as other kids	○	○	○	○	○
Not getting nervous when the teacher calls them	○	○	○	○	○
Giving a good report in front of the class	○	○	○	○	○

Page 5

Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

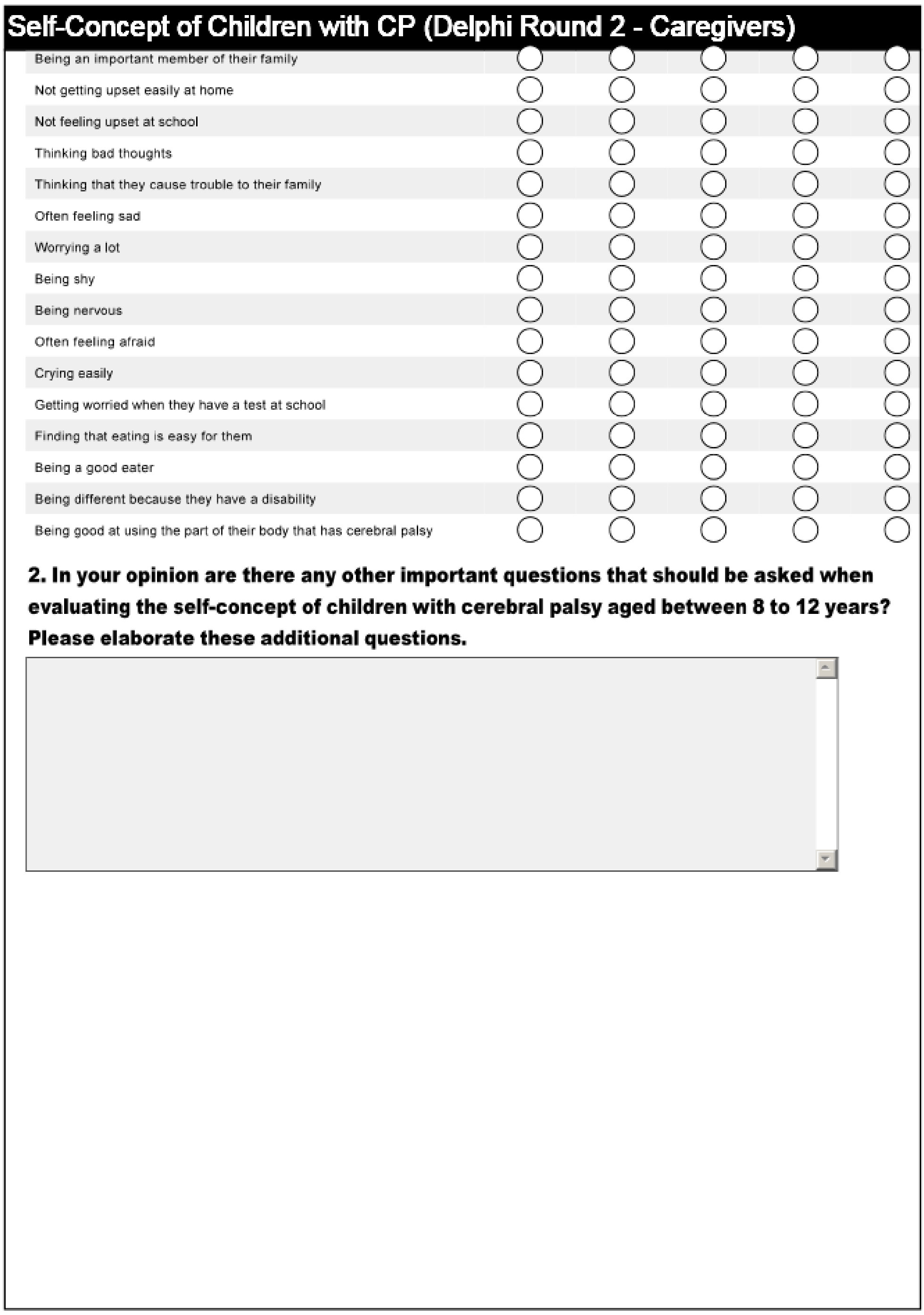
Liking Mathematics	○	○	○	○	○
Being good in Mathematics	○	○	○	○	○
Feeling that Mathematics is easy for them	○	○	○	○	○
Learning Mathematics quickly	○	○	○	○	○
Liking reading	○	○	○	○	○
Being good at reading	○	○	○	○	○
Feeling that reading is easy for them	○	○	○	○	○
Being interested in reading	○	○	○	○	○
Learning reading quickly	○	○	○	○	○
Enjoy drawing	○	○	○	○	○
Being good at spelling	○	○	○	○	○
Being good at writing	○	○	○	○	○
Being good at science	○	○	○	○	○
Being good at using the computer	○	○	○	○	○
Thinking that they are a good person	○	○	○	○	○
Being a happy person	○	○	○	○	○
Feeling useful	○	○	○	○	○
Being lucky	○	○	○	○	○
Taking a positive attitude towards themselves	○	○	○	○	○
Understanding themselves	○	○	○	○	○
Being proud of themselves	○	○	○	○	○
Liking the way they are	○	○	○	○	○
Being satisfied with themselves	○	○	○	○	○
Other people think that they are a good person	○	○	○	○	○
Wanting to change themselves	○	○	○	○	○
Being a kind person	○	○	○	○	○
Being funny	○	○	○	○	○
Being polite	○	○	○	○	○
Being a fun person	○	○	○	○	○
Not feeling like a failure	○	○	○	○	○
Thinking that a lot of things about them are good	○	○	○	○	○
Being as good as most other people	○	○	○	○	○
Giving up easily	○	○	○	○	○
Wishing they were different	○	○	○	○	○
Wishing they could have more respect for themselves	○	○	○	○	○
Feeling that it is tough being them	○	○	○	○	○
Feeling that things usually do not bother them	○	○	○	○	○
Being different from other people	○	○	○	○	○
Doing the best work that they can	○	○	○	○	○
Trying even when it is hard	○	○	○	○	○

Page 6

Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

Doing lots of important things	○	○	○	○	○
Being able to take care of themselves	○	○	○	○	○
Liking the way they do things	○	○	○	○	○
Getting used to new things quickly	○	○	○	○	○
Being able to make their own decision and sticking to it	○	○	○	○	○
Doing things as well as most other people	○	○	○	○	○
Saying what they want to say	○	○	○	○	○
Being able to talk to others easily	○	○	○	○	○
Having other people understand what they say	○	○	○	○	○
Thinking that when they do something, they do it well	○	○	○	○	○
Giving in very easily	○	○	○	○	○
Doing things right	○	○	○	○	○
Having lots of friends	○	○	○	○	○
Feeling that they can be depended on	○	○	○	○	○
Being easily liked	○	○	○	○	○
Having more friends than most other kids	○	○	○	○	○
Having friends who do not make fun of them	○	○	○	○	○
Not being picked on by other kids	○	○	○	○	○
Having friends who think they have good ideas	○	○	○	○	○
Not feeling left out of things	○	○	○	○	○
Being popular with kids of their own age	○	○	○	○	○
Being popular with girls	○	○	○	○	○
Being popular with boys	○	○	○	○	○
Getting along with other kids easily	○	○	○	○	○
Playing with other kids without help from adults	○	○	○	○	○
Helping their friends	○	○	○	○	○
Making friends easily	○	○	○	○	○
Having most other kids like them	○	○	○	○	○
Being among the first few to be chosen for games and sports	○	○	○	○	○
Enjoying being with other people	○	○	○	○	○
Having friends who like their ideas	○	○	○	○	○
Behaving well at home	○	○	○	○	○
Doing many good things	○	○	○	○	○
Doing the right thing	○	○	○	○	○
Don't get into trouble	○	○	○	○	○
Don't get into fights	○	○	○	○	○
Being good to other people	○	○	○	○	○
Thinking that when something goes wrong, it is usually their fault	○	○	○	○	○
Liking the way they behave	○	○	○	○	○
Being good at helping their family	○	○	○	○	○

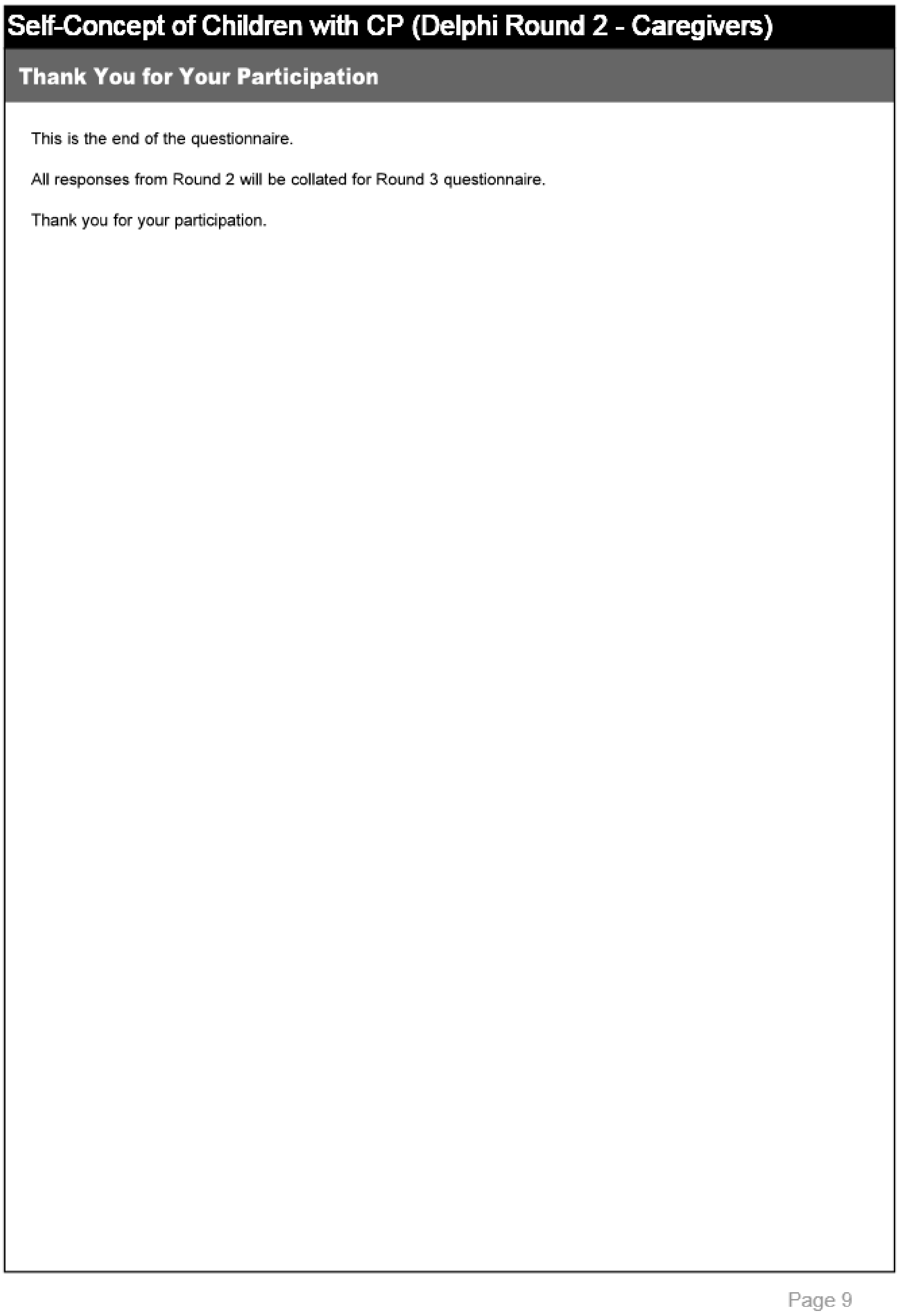
Page 7



Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

Being an important member of their family	○	○	○	○	○
Not getting upset easily at home	○	○	○	○	○
Not feeling upset at school	○	○	○	○	○
Thinking bad thoughts	○	○	○	○	○
Thinking that they cause trouble to their family	○	○	○	○	○
Often feeling sad	○	○	○	○	○
Worrying a lot	○	○	○	○	○
Being shy	○	○	○	○	○
Being nervous	○	○	○	○	○
Often feeling afraid	○	○	○	○	○
Crying easily	○	○	○	○	○
Getting worried when they have a test at school	○	○	○	○	○
Finding that eating is easy for them	○	○	○	○	○
Being a good eater	○	○	○	○	○
Being different because they have a disability	○	○	○	○	○
Being good at using the part of their body that has cerebral palsy	○	○	○	○	○

2. In your opinion are there any other important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years? Please elaborate these additional questions.



Self-Concept of Children with CP (Delphi Round 2 - Caregivers)

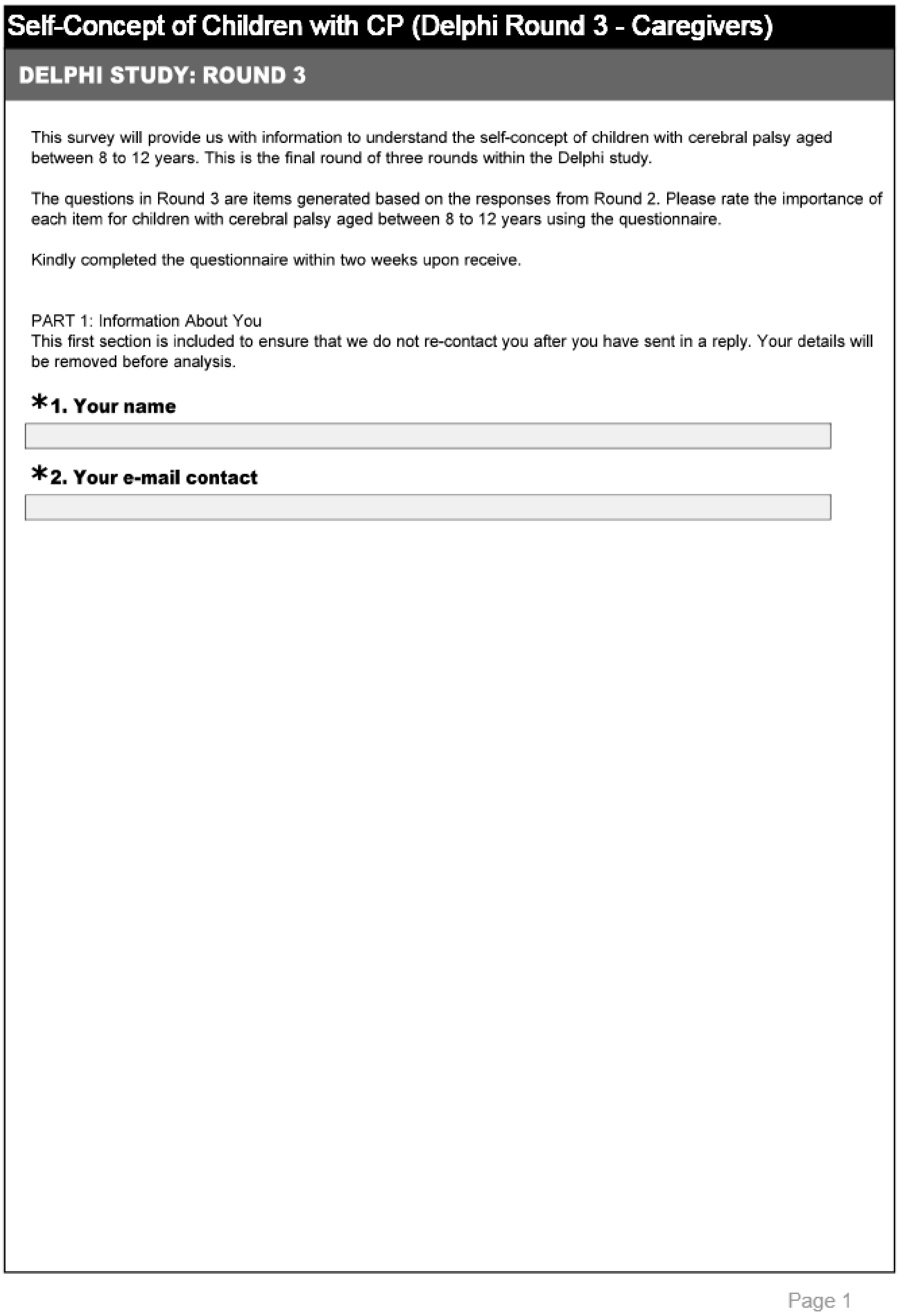
Thank You for Your Participation

This is the end of the questionnaire.

All responses from Round 2 will be collated for Round 3 questionnaire.

Thank you for your participation.

Study 2: Parent group questionnaire – Delphi Round III



Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

DELPHI STUDY: ROUND 3

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is the final round of three rounds within the Delphi study.

The questions in Round 3 are items generated based on the responses from Round 2. Please rate the importance of each item for children with cerebral palsy aged between 8 to 12 years using the questionnaire.

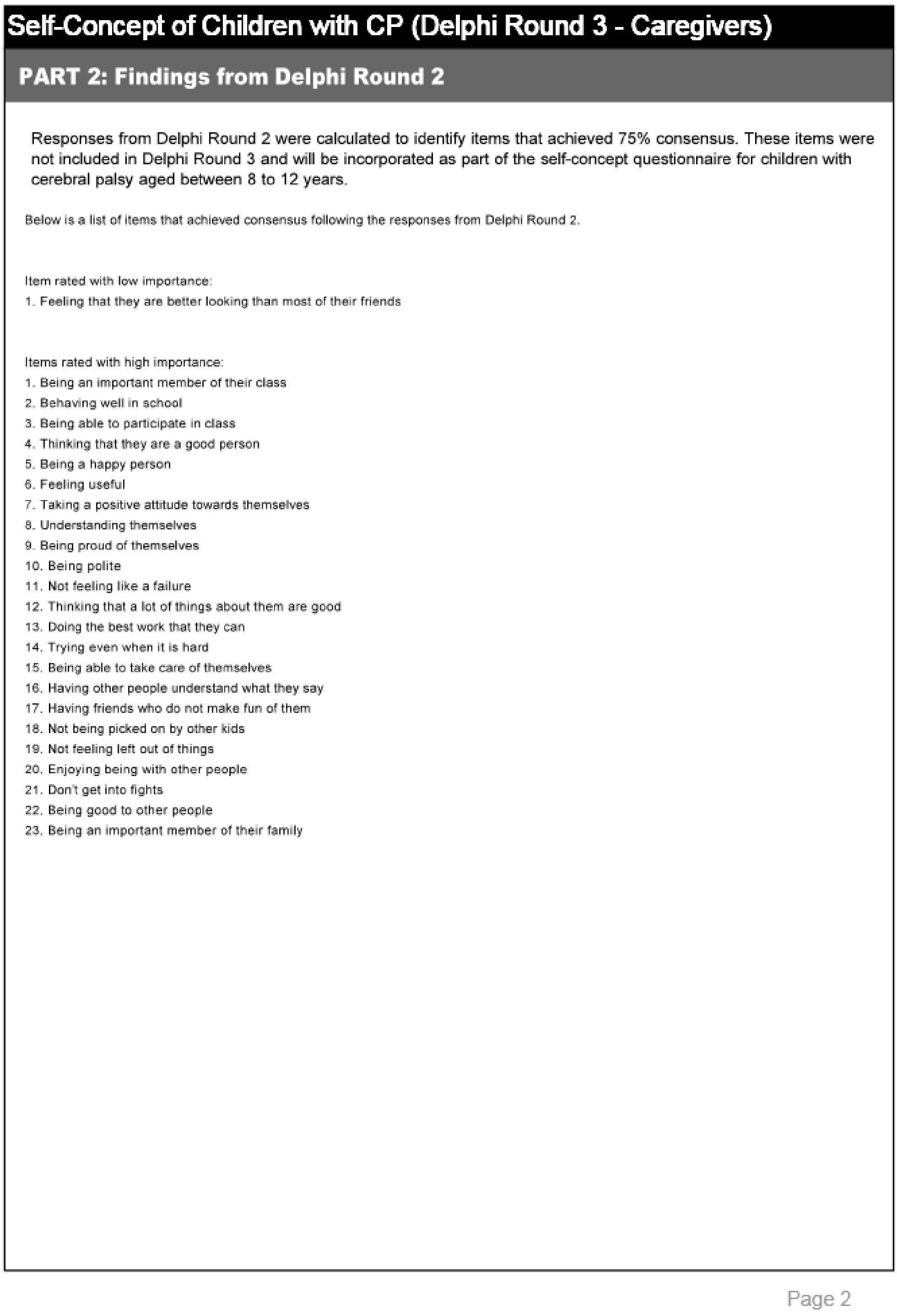
Kindly completed the questionnaire within two weeks upon receive.

PART 1: Information About You
This first section is included to ensure that we do not re-contact you after you have sent in a reply. Your details will be removed before analysis.

***1. Your name**

***2. Your e-mail contact**

Page 1



Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

PART 2: Findings from Delphi Round 2

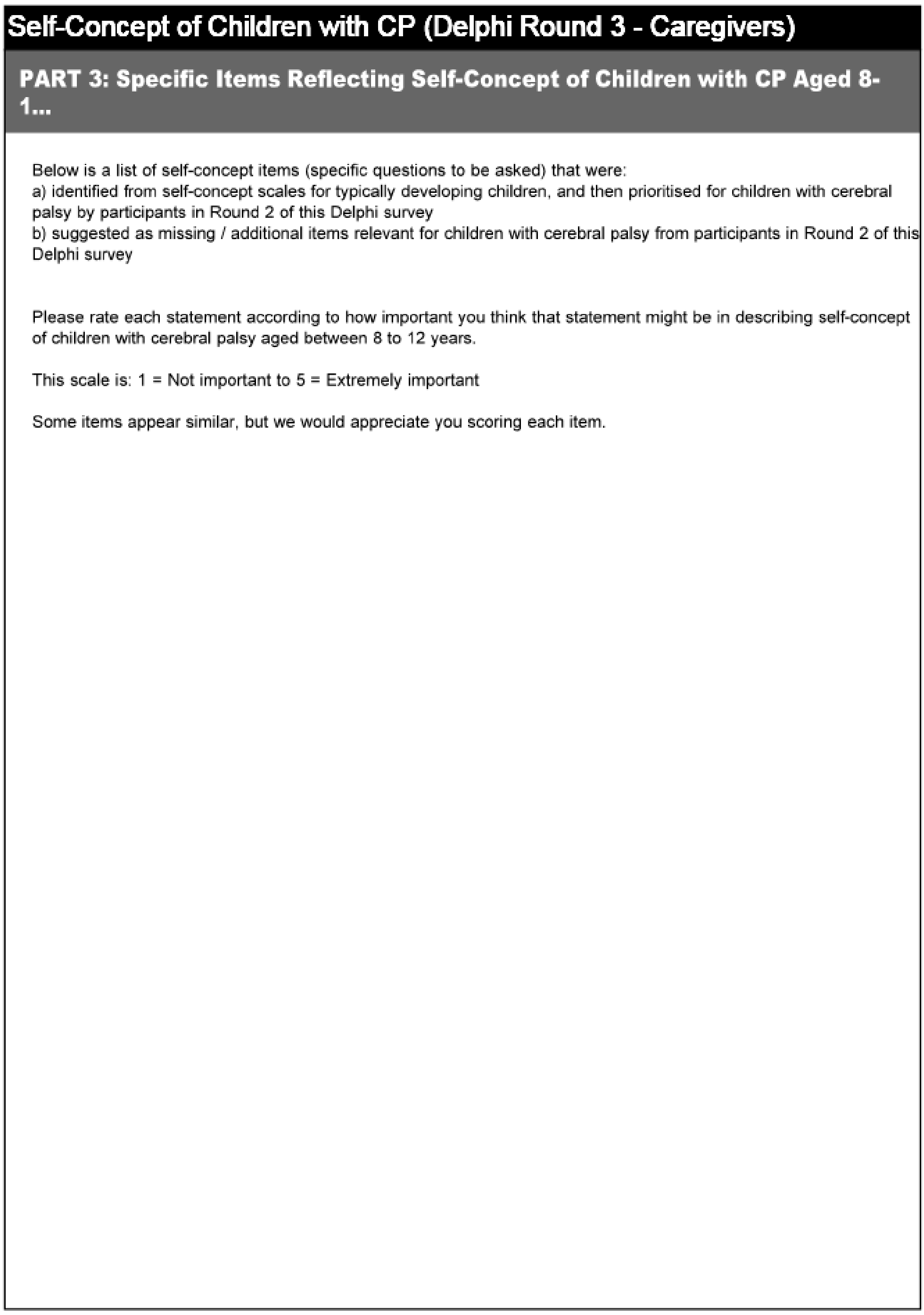
Responses from Delphi Round 2 were calculated to identify items that achieved 75% consensus. These items were not included in Delphi Round 3 and will be incorporated as part of the self-concept questionnaire for children with cerebral palsy aged between 8 to 12 years.

Below is a list of items that achieved consensus following the responses from Delphi Round 2.

Item rated with low importance:
1. Feeling that they are better looking than most of their friends

Items rated with high importance:
1. Being an important member of their class
2. Behaving well in school
3. Being able to participate in class
4. Thinking that they are a good person
5. Being a happy person
6. Feeling useful
7. Taking a positive attitude towards themselves
8. Understanding themselves
9. Being proud of themselves
10. Being polite
11. Not feeling like a failure
12. Thinking that a lot of things about them are good
13. Doing the best work that they can
14. Trying even when it is hard
15. Being able to take care of themselves
16. Having other people understand what they say
17. Having friends who do not make fun of them
18. Not being picked on by other kids
19. Not feeling left out of things
20. Enjoying being with other people
21. Don't get into fights
22. Being good to other people
23. Being an important member of their family

Page 2



Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

PART 3: Specific Items Reflecting Self-Concept of Children with CP Aged 8-1...

Below is a list of self-concept items (specific questions to be asked) that were:
a) identified from self-concept scales for typically developing children, and then prioritised for children with cerebral palsy by participants in Round 2 of this Delphi survey
b) suggested as missing / additional items relevant for children with cerebral palsy from participants in Round 2 of this Delphi survey

Please rate each statement according to how important you think that statement might be in describing self-concept of children with cerebral palsy aged between 8 to 12 years.

This scale is: 1 = Not important to 5 = Extremely important

Some items appear similar, but we would appreciate you scoring each item.

Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

1. Rate how important each item is in contributing to the self-concept of children with cerebral palsy

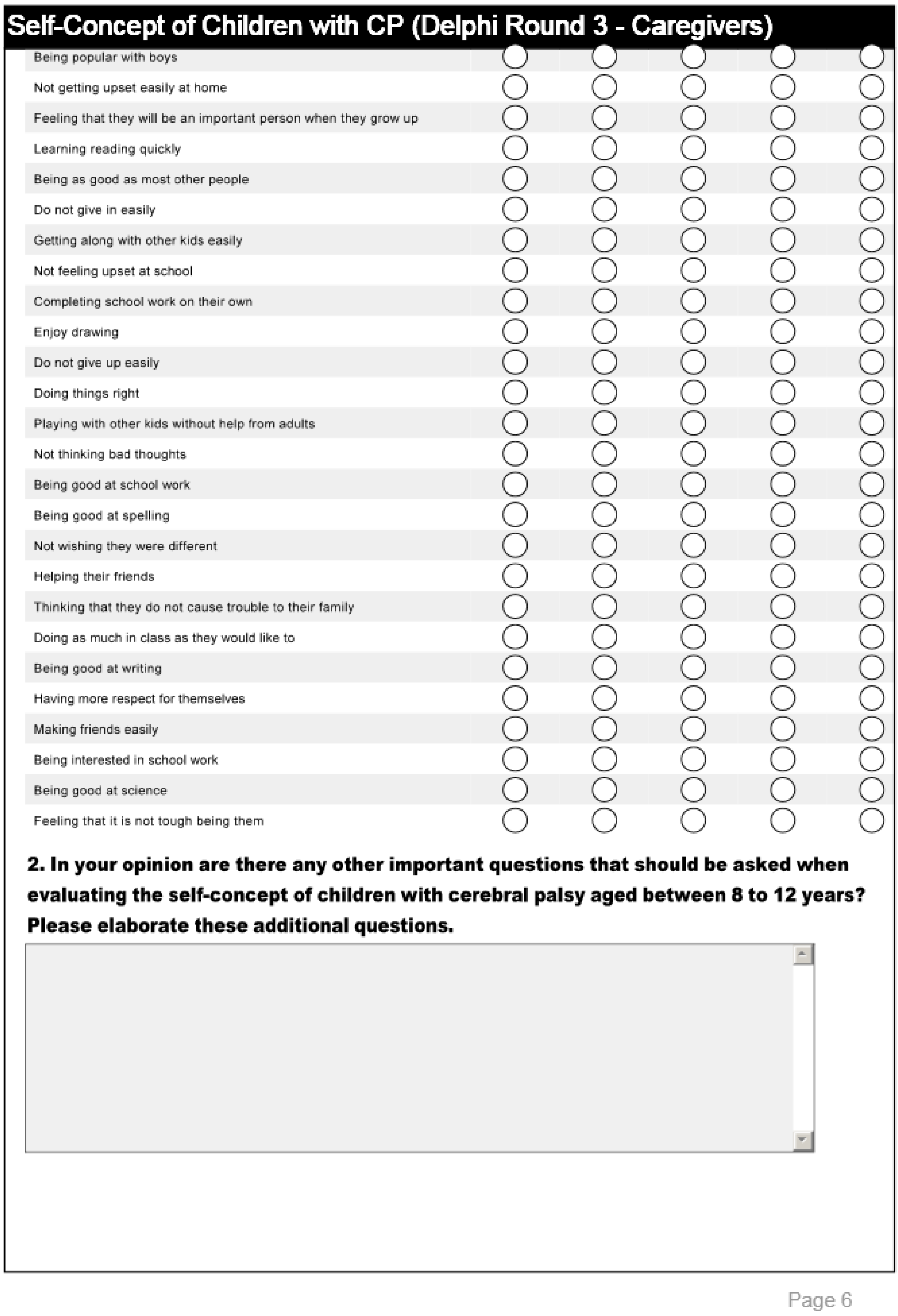
	Not important	Slightly important	Average importance	Very important	Extreme importar
Seeing themselves as good looking	○	○	○	○	○
Enjoying sports and games	○	○	○	○	○
Liking school work	○	○	○	○	○
Liking Mathematics	○	○	○	○	○
Being lucky	○	○	○	○	○
Doing lots of important things	○	○	○	○	○
Having lots of friends	○	○	○	○	○
Behaving well at home	○	○	○	○	○
Often feeling sad	○	○	○	○	○
Finding that eating is easy for them	○	○	○	○	○
Having parents who understand them	○	○	○	○	○
Having a pleasant looking face	○	○	○	○	○
In games and sports, having to play instead of watch	○	○	○	○	○
Getting good marks at school	○	○	○	○	○
Being good in Mathematics	○	○	○	○	○
Liking the way they are	○	○	○	○	○
Liking the way they do things	○	○	○	○	○
Feeling that they can be depended on	○	○	○	○	○
Doing many good things	○	○	○	○	○
Worrying a lot	○	○	○	○	○
Being a good eater	○	○	○	○	○
Having nice facial features like nose, eyes and hair	○	○	○	○	○
Having parents who are proud of what they do	○	○	○	○	○
Being good at sports	○	○	○	○	○
Being smart	○	○	○	○	○
Feeling that Mathematics is easy for them	○	○	○	○	○
Being satisfied with themselves	○	○	○	○	○
Getting used to new things quickly	○	○	○	○	○
Being easily liked	○	○	○	○	○
Doing the right thing	○	○	○	○	○
Being shy	○	○	○	○	○
Not feeling different because they have a disability	○	○	○	○	○
Having parents who are easy to talk to or spend time with	○	○	○	○	○
Liking the way they look	○	○	○	○	○
Being as good at sports as other kids	○	○	○	○	○
Having school work that is easy for them	○	○	○	○	○

Page 4

Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

Learning Mathematics quickly	○	○	○	○	○
Other people think that they are a good person	○	○	○	○	○
Being able to make their own decision and sticking to it	○	○	○	○	○
Having more friends than most other kids	○	○	○	○	○
Don't get into trouble	○	○	○	○	○
Being nervous	○	○	○	○	○
Being good at using the part of their body that has cerebral palsy	○	○	○	○	○
Having someone who pays attention to them at home	○	○	○	○	○
Having other kids think that they are good looking	○	○	○	○	○
Being able to run well	○	○	○	○	○
Being quick at finishing their school work	○	○	○	○	○
Liking reading	○	○	○	○	○
Not wanting to change themselves	○	○	○	○	○
Doing things as well as most other people	○	○	○	○	○
Having friends who think they have good ideas	○	○	○	○	○
Thinking that, when something goes wrong, it is usually not their fault	○	○	○	○	○
Often feeling afraid	○	○	○	○	○
Being strong	○	○	○	○	○
Doing as well at new games as other kids	○	○	○	○	○
Remembering what they learn	○	○	○	○	○
Being good at reading	○	○	○	○	○
Being a kind person	○	○	○	○	○
Saying what they want to say	○	○	○	○	○
Being popular with kids of their own age	○	○	○	○	○
Liking the way they behave	○	○	○	○	○
Crying easily	○	○	○	○	○
Having good muscles	○	○	○	○	○
Being a leader in games and sports	○	○	○	○	○
Volunteering at school	○	○	○	○	○
Feeling that reading is easy for them	○	○	○	○	○
Being funny	○	○	○	○	○
Being able to talk to others easily	○	○	○	○	○
Being popular with girls	○	○	○	○	○
Being good at helping their family	○	○	○	○	○
Getting worried when they have a test at school	○	○	○	○	○
Having a good looking body	○	○	○	○	○
Others making them feel that they are good enough in school	○	○	○	○	○
Being interested in reading	○	○	○	○	○
Being a fun person	○	○	○	○	○
Thinking that when they do something, they do it well	○	○	○	○	○

Page 5

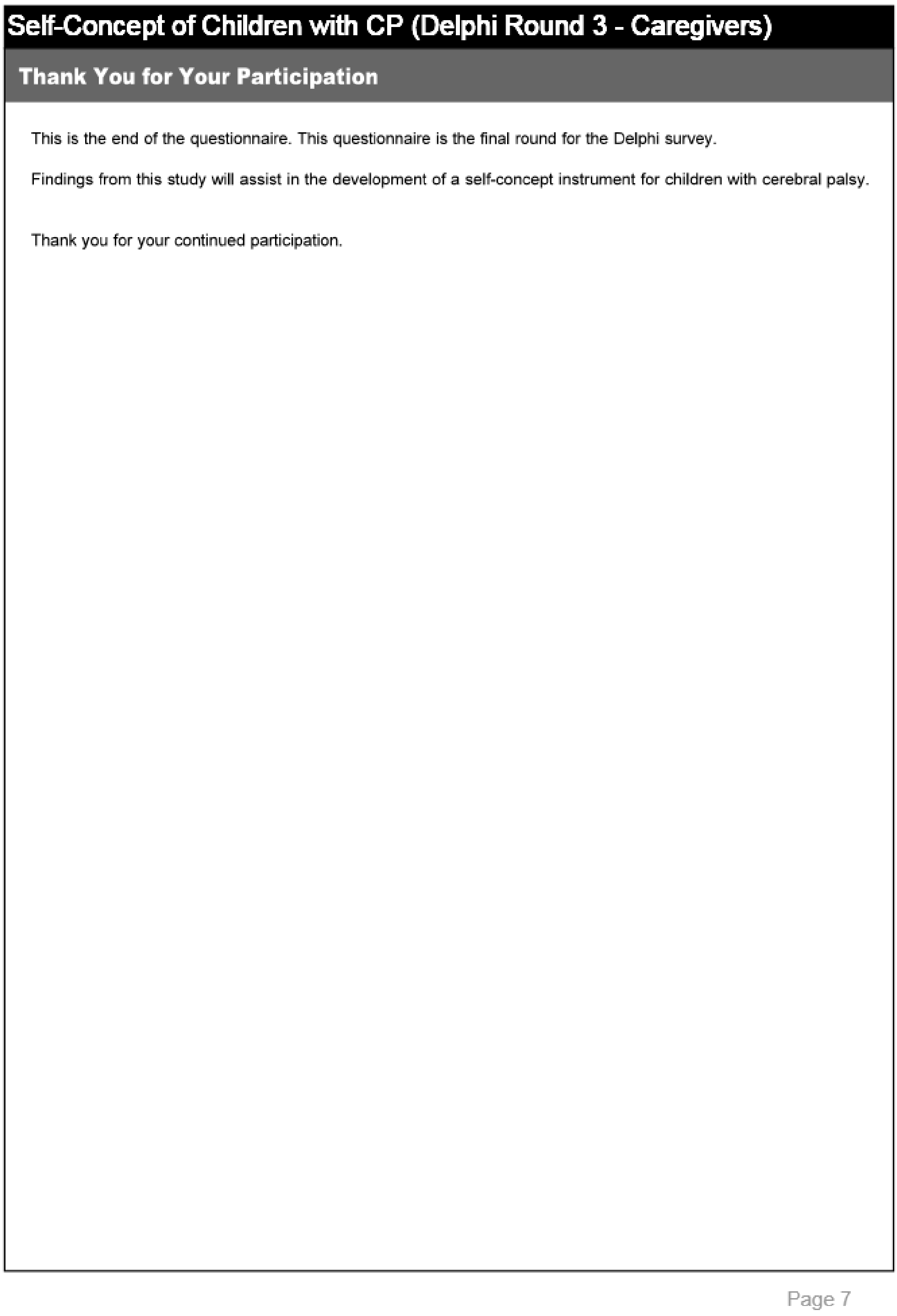


Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

Being popular with boys	○	○	○	○	○
Not getting upset easily at home	○	○	○	○	○
Feeling that they will be an important person when they grow up	○	○	○	○	○
Learning reading quickly	○	○	○	○	○
Being as good as most other people	○	○	○	○	○
Do not give in easily	○	○	○	○	○
Getting along with other kids easily	○	○	○	○	○
Not feeling upset at school	○	○	○	○	○
Completing school work on their own	○	○	○	○	○
Enjoy drawing	○	○	○	○	○
Do not give up easily	○	○	○	○	○
Doing things right	○	○	○	○	○
Playing with other kids without help from adults	○	○	○	○	○
Not thinking bad thoughts	○	○	○	○	○
Being good at school work	○	○	○	○	○
Being good at spelling	○	○	○	○	○
Not wishing they were different	○	○	○	○	○
Helping their friends	○	○	○	○	○
Thinking that they do not cause trouble to their family	○	○	○	○	○
Doing as much in class as they would like to	○	○	○	○	○
Being good at writing	○	○	○	○	○
Having more respect for themselves	○	○	○	○	○
Making friends easily	○	○	○	○	○
Being interested in school work	○	○	○	○	○
Being good at science	○	○	○	○	○
Feeling that it is not tough being them	○	○	○	○	○

2. In your opinion are there any other important questions that should be asked when evaluating the self-concept of children with cerebral palsy aged between 8 to 12 years? Please elaborate these additional questions.

Page 6



Self-Concept of Children with CP (Delphi Round 3 - Caregivers)

Thank You for Your Participation

This is the end of the questionnaire. This questionnaire is the final round for the Delphi survey.

Findings from this study will assist in the development of a self-concept instrument for children with cerebral palsy.

Thank you for your continued participation.

Study 2: Child group questionnaire – Delphi Round I

SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY
DELPHI STUDY: ROUND 1
Child - Structured Interview

To be read out by the investigator:

This interview will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years. This is the first of three rounds within the Delphi study. Round 1 is an interview. I am going to ask you about your opinion about self-concept in children with cerebral palsy aged between 8 to 12 years old.

PART 1: INFORMATION ABOUT YOU

First I am going to ask you some questions about you. Your details will be removed before analysis.

1. **Your details** **Name:** ____________________________

   Date of birth: ___ / ___ / ___

   Age: ______ years ____ months

   Gender: male ☐ female ☐

2. **Your diagnosis** ☐ **Cerebral Palsy → type: __________________**

   ☐ **Other condition → type: __________________**

------This section will be removed from your answers we ask from the next page--------

PART 2: YOUR OPINION ABOUT SELF-CONCEPT OF CHILDREN WITH CERBRAL PALSY AGED BETWEEN 8 TO 12 YEARS

1a. What things do you **like** about yourself?

1b. Is there anything that you **do not like** about yourself?

2a. What do you think that **other people like about you**?

2b. Do you think there is anything that **other people don’t like about you**?

3a. What things do you think that you are **good at**?

3b. What things do you think you are **not so good at**?

4. What things do **other people say you are good at**?

    4a. What do your parents say?

    4b. What do your brothers/sisters say? (optional)

    4c. What do your friends in school say?

    4d. What do your teachers in school say?

    4e. What do other children with cerebral palsy say? (optional)

5. Are there any things that **other people say you are not so good at**?

    5a. What do your parents say?

    5b. What do your siblings say? (optional)

    5c. What do your friends in school say?

    5d. What do your teachers in school say?

    5e. What do other children with cerebral palsy say? (optional)

6. What is the best thing about you?

Thank you for your participation.

Study 2: Child group questionnaire – Delphi Round II

SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY
DELPHI STUDY: ROUND 2
Child Questionnaire

This survey will provide us with information to understand how children with cerebral palsy aged between 8 to 12 years think about themselves – their self-concept.

This is Round 2 of three rounds within the Delphi study.

The questionnaire in this round includes items about self-concept that
- were thought up by children, parents, therapists and doctors in Round 1
- or we found them in science books and papers

PART 1: INFORMATION ABOUT YOU

I need your name so that I know you have completed this interview. Your detail will be removed before analysis.

1. **Your detail** **Name:** ____

----------------This section will be removed from your answers on the next page---------------------

This page is deliberately left unmarked

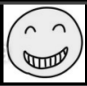
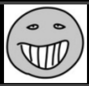
Please turn to the next page

PART 2: SPECIFIC ITEMS REFLECTING SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY AGED BETWEEN 8 TO 12 YEARS

Imagine you have a magic wand and you can create a friend. What are some important things you want to give your friend? Below is a list of things you could give your friend.

Rate each item according to ***how important you think they might be***.

The scale is: 1 = Not important (Trash it) to 5 = Extremely important (Must keep)

Item/Statement	**Rate how important**				
	1 **Not important**	**2** **Slightly important**	**3** **Average importance**	**4** **Very important**	**5** **Extremely important**
					
Good looking	Trash it	A bit	Average	A lot	Must keep
Nice face	Trash it	A bit	Average	A lot	Must keep
Nice nose, eyes and hair	Trash it	A bit	Average	A lot	Must keep
Like their looks	Trash it	A bit	Average	A lot	Must keep
Better looking than others	Trash it	A bit	Average	A lot	Must keep
Others think they are good looking	Trash it	A bit	Average	A lot	Must keep
Strong	Trash it	A bit	Average	A lot	Must keep
Good muscles	Trash it	A bit	Average	A lot	Must keep
Like sports	Trash it	A bit	Average	A lot	Must keep
Play sports	Trash it	A bit	Average	A lot	Must keep
Good at sports	Trash it	A bit	Average	A lot	Must keep
As good as others in sports	Trash it	A bit	Average	A lot	Must keep
Good runner	Trash it	A bit	Average	A lot	Must keep
Like school work	Trash it	A bit	Average	A lot	Must keep
Good marks	Trash it	A bit	Average	A lot	Must keep
Smart	Trash it	A bit	Average	A lot	Must keep
School work is easy for them	Trash it	A bit	Average	A lot	Must keep
Quick at finishing school work	Trash it	A bit	Average	A lot	Must keep
Remember what they learn	Trash it	A bit	Average	A lot	Must keep
An important person in class	Trash it	A bit	Average	A lot	Must keep
Having good behaviour in school	Trash it	A bit	Average	A lot	Must keep
Volunteering for special jobs in school	Trash it	A bit	Average	A lot	Must keep
Others think they are good enough in school	Trash it	A bit	Average	A lot	Must keep

Item/Statement	Rate how important				
	1 Not important	2 Slightly important	3 Average importance	4 Very important	5 Extremely important
Thinking that they will be an important person when they grow up	Trash it	A bit	Average	A lot	Must keep
Being able to participate in class	Trash it	A bit	Average	A lot	Must keep
Completing school work on their own	Trash it	A bit	Average	A lot	Must keep
Like math	Trash it	A bit	Average	A lot	Must keep
Good at math	Trash it	A bit	Average	A lot	Must keep
Math is easy for them	Trash it	A bit	Average	A lot	Must keep
Like reading	Trash it	A bit	Average	A lot	Must keep
Good at reading	Trash it	A bit	Average	A lot	Must keep
Reading is easy for them	Trash it	A bit	Average	A lot	Must keep
Enjoy drawing	Trash it	A bit	Average	A lot	Must keep
Good at spelling	Trash it	A bit	Average	A lot	Must keep
Good at writing	Trash it	A bit	Average	A lot	Must keep
Good at science	Trash it	A bit	Average	A lot	Must keep
Good at using the computer	Trash it	A bit	Average	A lot	Must keep
Good person	Trash it	A bit	Average	A lot	Must keep
Happy person	Trash it	A bit	Average	A lot	Must keep
Useful person	Trash it	A bit	Average	A lot	Must keep
Lucky person	Trash it	A bit	Average	A lot	Must keep
Able to look on the bright side	Trash it	A bit	Average	A lot	Must keep
Understanding themselves	Trash it	A bit	Average	A lot	Must keep
Proud of themselves	Trash it	A bit	Average	A lot	Must keep
Like themselves	Trash it	A bit	Average	A lot	Must keep
Being happy the way they have been	Trash it	A bit	Average	A lot	Must keep
Others think they are a good person	Trash it	A bit	Average	A lot	Must keep
Want to change themselves	Trash it	A bit	Average	A lot	Must keep
Being a kind person	Trash it	A bit	Average	A lot	Must keep
Being funny	Trash it	A bit	Average	A lot	Must keep
Being polite	Trash it	A bit	Average	A lot	Must keep
Being a fun person	Trash it	A bit	Average	A lot	Must keep

Item/Statement	Rate how important				
	1 Not important	2 Slightly important	3 Average importance	4 Very important	5 Extremely important
	🗑	😟	🙂	😊	😁
Doing their best	Trash it	A bit	Average	A lot	Must keep
Keep trying even when things are hard	Trash it	A bit	Average	A lot	Must keep
Doing important things	Trash it	A bit	Average	A lot	Must keep
Able to look after themselves	Trash it	A bit	Average	A lot	Must keep
Happy with the way they do things	Trash it	A bit	Average	A lot	Must keep
Getting used to new things quickly	Trash it	A bit	Average	A lot	Must keep
Making their own decision and stick to it	Trash it	A bit	Average	A lot	Must keep
Doing as good as other people	Trash it	A bit	Average	A lot	Must keep
Say what they want to say	Trash it	A bit	Average	A lot	Must keep
Being able to talk to others easily	Trash it	A bit	Average	A lot	Must keep
Having other people understand what they say	Trash it	A bit	Average	A lot	Must keep
Having lots of friends	Trash it	A bit	Average	A lot	Must keep
Being a reliable person	Trash it	A bit	Average	A lot	Must keep
Other kids like them	Trash it	A bit	Average	A lot	Must keep
Having more friends than other kids	Trash it	A bit	Average	A lot	Must keep
Having kind friends	Trash it	A bit	Average	A lot	Must keep
Other kids in school are kind to them	Trash it	A bit	Average	A lot	Must keep
Others think they have good ideas	Trash it	A bit	Average	A lot	Must keep
Being asked to join in games	Trash it	A bit	Average	A lot	Must keep
Popular among kids of the same age	Trash it	A bit	Average	A lot	Must keep
Popular among girls	Trash it	A bit	Average	A lot	Must keep
Popular among boys	Trash it	A bit	Average	A lot	Must keep
Fit in with other kids	Trash it	A bit	Average	A lot	Must keep
Playing with other kids without help from adults	Trash it	A bit	Average	A lot	Must keep
Helping their friends	Trash it	A bit	Average	A lot	Must keep
Well behaved at home	Trash it	A bit	Average	A lot	Must keep

Item/Statement	Rate how important				
	1 Not important	2 Slightly important	3 Average importance	4 Very important	5 Extremely important
	🗑	😕	🙂	😀	😁
Do good things	Trash it	A bit	Average	A lot	Must keep
Do the right thing	Trash it	A bit	Average	A lot	Must keep
Don't get into trouble	Trash it	A bit	Average	A lot	Must keep
Don't fight	Trash it	A bit	Average	A lot	Must keep
Being good to others	Trash it	A bit	Average	A lot	Must keep
Knowing that bad things are not their fault	Trash it	A bit	Average	A lot	Must keep
Liking the way they behave	Trash it	A bit	Average	A lot	Must keep
Good at helping their family	Trash it	A bit	Average	A lot	Must keep
An important family member	Trash it	A bit	Average	A lot	Must keep
Eating is easy for them	Trash it	A bit	Average	A lot	Must keep
Being a good eater	Trash it	A bit	Average	A lot	Must keep
Being different because they have a disability	Trash it	A bit	Average	A lot	Must keep
Good at using the part of their body that has cerebral palsy	Trash it	A bit	Average	A lot	Must keep
Being sad	Trash it	A bit	Average	A lot	Must keep
Being worried	Trash it	A bit	Average	A lot	Must keep
Being shy	Trash it	A bit	Average	A lot	Must keep
Being nervous	Trash it	A bit	Average	A lot	Must keep
Being afraid	Trash it	A bit	Average	A lot	Must keep
Cry easily	Trash it	A bit	Average	A lot	Must keep

Thank you for your participation.

Study 2: Child group questionnaire – Delphi Round III

SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY
DELPHI STUDY: ROUND 3
Child Questionnaire

This survey will provide us with information to understand how children with cerebral palsy aged between 8 to 12 years think about themselves – their self-concept.

This is the final round of three rounds within the Delphi study. The questions in Round 3 are items generated based on the responses from Round 2.

The questionnaire in this round includes items about self-concept that

- were thought up by children, parents, therapists and doctors in Round 1 and 2
- or we found them in science books and papers

PART 1: INFORMATION ABOUT YOU

I need your name so that I know you have completed this interview. Your detail will be removed before analysis.

1. **Your detail** **Name:** ____

----------------This section will be removed from your answers on the next page---------------------

This page is deliberately left unmarked

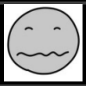
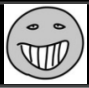
Please turn to the next page

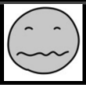
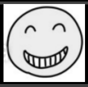
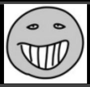
PART 2: SPECIFIC ITEMS REFLECTING SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY AGED BETWEEN 8 TO 12 YEARS

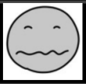
Imagine you have a magic wand and you can create a friend. What are some important things you want to give your friend? Below is a list of things you could give your friend.

Rate each item according to ***how important you think they might be***.

The scale is: 1 = Not important (Trash it) to 5 = Extremely important (Must keep)

Item/Statement	**Rate how important**				
	1 Not important	**2 Slightly important**	**3 Average importance**	**4 Very important**	**5 Extremely important**
					
Good looking	Trash it	A bit	Average	A lot	Must keep
Like sports	Trash it	A bit	Average	A lot	Must keep
Like school work	Trash it	A bit	Average	A lot	Must keep
Like Math	Trash it	A bit	Average	A lot	Must keep
Useful person	Trash it	A bit	Average	A lot	Must keep
Keep trying even when things are hard	Trash it	A bit	Average	A lot	Must keep
Having lots of friends	Trash it	A bit	Average	A lot	Must keep
Knowing that bad things are not their fault	Trash it	A bit	Average	A lot	Must keep
Being a good eater	Trash it	A bit	Average	A lot	Must keep
Having parents who understand them	Trash it	A bit	Average	A lot	Must keep
Nice face	Trash it	A bit	Average	A lot	Must keep
Play sports	Trash it	A bit	Average	A lot	Must keep
Good marks	Trash it	A bit	Average	A lot	Must keep
Good at Math	Trash it	A bit	Average	A lot	Must keep
Lucky person	Trash it	A bit	Average	A lot	Must keep
Doing important things	Trash it	A bit	Average	A lot	Must keep
Being a reliable person	Trash it	A bit	Average	A lot	Must keep
Good at helping their family	Trash it	A bit	Average	A lot	Must keep
Not feeling different because they have a disability	Trash it	A bit	Average	A lot	Must keep
Having parents who are proud of what they do	Trash it	A bit	Average	A lot	Must keep

Item/Statement	Rate how important				
	1 Not important	2 Slightly important	3 Average importance	4 Very important	5 Extremely important
					
Nice nose, eyes and hair	Trash it	A bit	Average	A lot	Must keep
Good at sports	Trash it	A bit	Average	A lot	Must keep
Smart	Trash it	A bit	Average	A lot	Must keep
Math is easy for them	Trash it	A bit	Average	A lot	Must keep
Able to look on the bright side	Trash it	A bit	Average	A lot	Must keep
Happy with the way they do things	Trash it	A bit	Average	A lot	Must keep
Other kids like them	Trash it	A bit	Average	A lot	Must keep
An important family member	Trash it	A bit	Average	A lot	Must keep
Having parents who are easy to talk to or spend time with	Trash it	A bit	Average	A lot	Must keep
Like their looks	Trash it	A bit	Average	A lot	Must keep
As good as others in sports	Trash it	A bit	Average	A lot	Must keep
School work is easy for them	Trash it	A bit	Average	A lot	Must keep
Good at reading	Trash it	A bit	Average	A lot	Must keep
Understanding themselves	Trash it	A bit	Average	A lot	Must keep
Getting used to new things quickly	Trash it	A bit	Average	A lot	Must keep
Having more friends than most other kids	Trash it	A bit	Average	A lot	Must keep
Having someone who pays attention to them at home	Trash it	A bit	Average	A lot	Must keep
Better looking than others	Trash it	A bit	Average	A lot	Must keep
Good runner	Trash it	A bit	Average	A lot	Must keep
Quick at finishing school work	Trash it	A bit	Average	A lot	Must keep
Reading is easy for them	Trash it	A bit	Average	A lot	Must keep
Like themselves	Trash it	A bit	Average	A lot	Must keep
Doing as good as other people	Trash it	A bit	Average	A lot	Must keep
Others think they have good ideas	Trash it	A bit	Average	A lot	Must keep
Others think they are good looking	Trash it	A bit	Average	A lot	Must keep
Remembering what they learn	Trash it	A bit	Average	A lot	Must keep

Item/Statement	**Rate how important**				
	1 Not important	**2 Slightly important**	**3 Average importance**	**4 Very important**	**5 Extremely important**
					
Enjoy drawing	Trash it	A bit	Average	A lot	Must keep
Others think they are a good person	Trash it	A bit	Average	A lot	Must keep
Say what they want to say	Trash it	A bit	Average	A lot	Must keep
Popular among kids of the same age	Trash it	A bit	Average	A lot	Must keep
Strong	Trash it	A bit	Average	A lot	Must keep
An important person in class	Trash it	A bit	Average	A lot	Must keep
Good at spelling	Trash it	A bit	Average	A lot	Must keep
Not wanting to change themselves	Trash it	A bit	Average	A lot	Must keep
Having other people understand what they say	Trash it	A bit	Average	A lot	Must keep
Being popular with boys	Trash it	A bit	Average	A lot	Must keep
Good muscles	Trash it	A bit	Average	A lot	Must keep
Volunteering for special jobs in school	Trash it	A bit	Average	A lot	Must keep
Good at science	Trash it	A bit	Average	A lot	Must keep
Being funny	Trash it	A bit	Average	A lot	Must keep
Fit in with other kids	Trash it	A bit	Average	A lot	Must keep
Others think they are good enough in school	Trash it	A bit	Average	A lot	Must keep
Good at using the computer	Trash it	A bit	Average	A lot	Must keep
Being polite	Trash it	A bit	Average	A lot	Must keep
Playing with other kids without help from adults	Trash it	A bit	Average	A lot	Must keep
Thinking that they will be an important person when they grow up	Trash it	A bit	Average	A lot	Must keep
Being a fun person	Trash it	A bit	Average	A lot	Must keep
Being able to participate in class	Trash it	A bit	Average	A lot	Must keep
Being sad	Trash it	A bit	Average	A lot	Must keep

Item/Statement	Rate how important				
	1 Not important	2 Slightly important	3 Average importance	4 Very important	5 Extremely important
	🗑	😟	🙂	😁	😆
Being worried	Trash it	A bit	Average	A lot	Must keep
Being shy	Trash it	A bit	Average	A lot	Must keep
Being nervous	Trash it	A bit	Average	A lot	Must keep
Being afraid	Trash it	A bit	Average	A lot	Must keep
Cry easily	Trash it	A bit	Average	A lot	Must keep

Imagine that you went to show the wizard master your creation. The wizard master is very pleased with your creation but make your creation come to life, you have to give your magic friend four of these. Which will you give your friend?

Being sad	**Being worried**	**Being shy**	**Being nervous**	**Being afraid**	**Cry easily**

😆 MUST KEEP	
😁 A LOT	
🙂 AVERAGE	
😟 A BIT	
🗑 TRASH IT	
🗑 TRASH IT	

Thank you for your participation.

Study 2: Child group myTREEHOUSE board game scoring sheet – Delphi Round II

myTREEHOUSE: Delphi study Round 2 (children)

Imagine that this is your Tree House. You can invite your friends into your tree house. The walkway here is how you get into the tree house (point to the path from bottom to the top). Imagine you have a magic wand and you can create a friend. What are the important things you want to give your friend? We will place the most important things along the tree house and the things that we do not want we place it on the ground. Some things are not so important but would be good to have, we can place them along the walkway. Let’s look at the first item….

Physical appearance (body)	
	Good looking
	Nice face
	Nice nose, eyes and hair
	Like their looks
	Better looking than others
	Others think they are good looking
	Strong
	Good muscles
Physical abilities (sports)	
	Like sports
	Play sports
	Good at sports
	As good as others in sports
	Good runner
School	
	Like school work
	Good marks
	Smart
	School work is easy for them
	Quick at finishing school work
	Remember what they learn
	An important person in class
	Having good behaviour in school
	Volunteering for special jobs in school
	Others think they are good enough in school
	Thinking that they will be an important person when they grow up
	Being able to participate in class
	Completing school work on their own
Mathematics (Math)	
	Like math
	Good at math
	Math is easy for them

Reading	
	Like reading
	Good at reading
	Reading is easy for them
	Enjoy drawing
	Good at spelling
	Good at writing
	Good at science
	Good at using the computer
Self	
	Good person
	Happy person
	Useful person
	Lucky person
	Able to look on the bright side
	Understanding themselves
	Proud of themselves
	Like themselves
	Being happy the way they have been
	Others think they are a good person
	Want to change themselves (-)
	Being a kind person
	Being funny
	Being polite
	Being a fun person
Doing things	
	Doing their best
	Keep trying even when things are hard
	Doing important things
	Able to look after themselves
	Happy with the way they do things
	Getting used to new things quickly
	Making their own decision and stick to it
	Doing as good as other people

	Say what they want to say
	Being able to talk to others easily
	Having other people understand what they say
Peer (Friends)	
	Having lots of friends
	Being a reliable person
	Other kids like them
	Having more friends than other kids
	Having kind friends
	Other kids in school are kind to them
	Others think they have good ideas
	Being asked to join in games
	Popular among kids of the same age
	Popular among girls
	Popular among boys
	Fit in with other kids
	Playing with other kids without help from adults
	Helping their friends

Behaviour	
	Well behaved at home
	Do good things
	Do the right thing
	Don't get into trouble
	Don't fight
	Being good to others
	Knowing that bad things are not their fault
	Liking the way they behave
	Good at helping their family
	An important family member
CP	
	Eating is easy for them
	Being a good eater
	Being different because they have a disability
	Good at using the part of their body that has cerebral palsy

Imagine that you went to show the wizard master your creation. The wizard master is very pleased with your creation but to make your creation come to life, you have to give your magic friend four of these. Which will you give your friend?

Emotion	
	Being sad
	Being worried
	Being shy
	Being nervous
	Being afraid
	Cry easily

Study 2: Child group myTREEHOUSE board game scoring sheet – Delphi Round III

myTREEHOUSE: Delphi study Round 3 (children)

Imagine that this is your Tree House. You can invite your friends into your tree house. The walkway here is how you get into the tree house (point to the path from bottom to the top). Imagine you have a magic wand and you can create a friend. What are the important things you want to give your friend? We will place the most important things along the tree house and the things that we do not want we place it on the ground. Some things are not so important but would be good to have, we can place them along the walkway. Let’s look at the first item….

	Good looking
	Like sports
	Like school work
	Like Math
	Useful person
	Keep trying even when things are hard
	Having lots of friends
	Knowing that bad things are not their fault
	Being a good eater
	Having parents who understand them
	Nice face
	Play sports
	Good marks
	Good at Math
	Lucky person
	Doing important things
	Being a reliable person
	Good at helping their family
	Not feeling different because they have a disability
	Having parents who are proud of what they do
	Nice nose, eyes and hair
	Good at sports
	Smart
	Math is easy for them
	Able to look on the bright side
	Happy with the way they do things
	Other kids like them
	An important family member
	Having parents who are easy to talk to or spend time with
	Like their looks
	As good as others in sports
	School work is easy for them
	Good at reading
	Understanding themselves
	Getting used to new things quickly

	Having more friends than most other kids
	Having someone who pays attention to them at home
	Better looking than others
	Good runner
	Quick at finishing school work
	Reading is easy for them
	Like themselves
	Doing as good as other people
	Others think they have good ideas
	Others think they are good looking
	Remembering what they learn
	Enjoy drawing
	Others think they are a good person
	Say what they want to say
	Popular among kids of the same age
	Strong
	An important person in class
	Good at spelling
	Not wanting to change themselves
	Having other people understand what they say
	Being popular with boys
	Good muscles
	Volunteering for special jobs in school
	Good at science
	Being funny
	Fit in with other kids
	Others think they are good enough in school
	Good at using the computer
	Being polite
	Playing with other kids without help from adults
	Thinking that they will be an important person when they grow up
	Being a fun person
	Being able to participate in class

Imagine that you went to show the wizard master your creation. The wizard master is very pleased with your creation but to make your creation come to life, you have to give your magic friend four of these. Which will you give your friend?

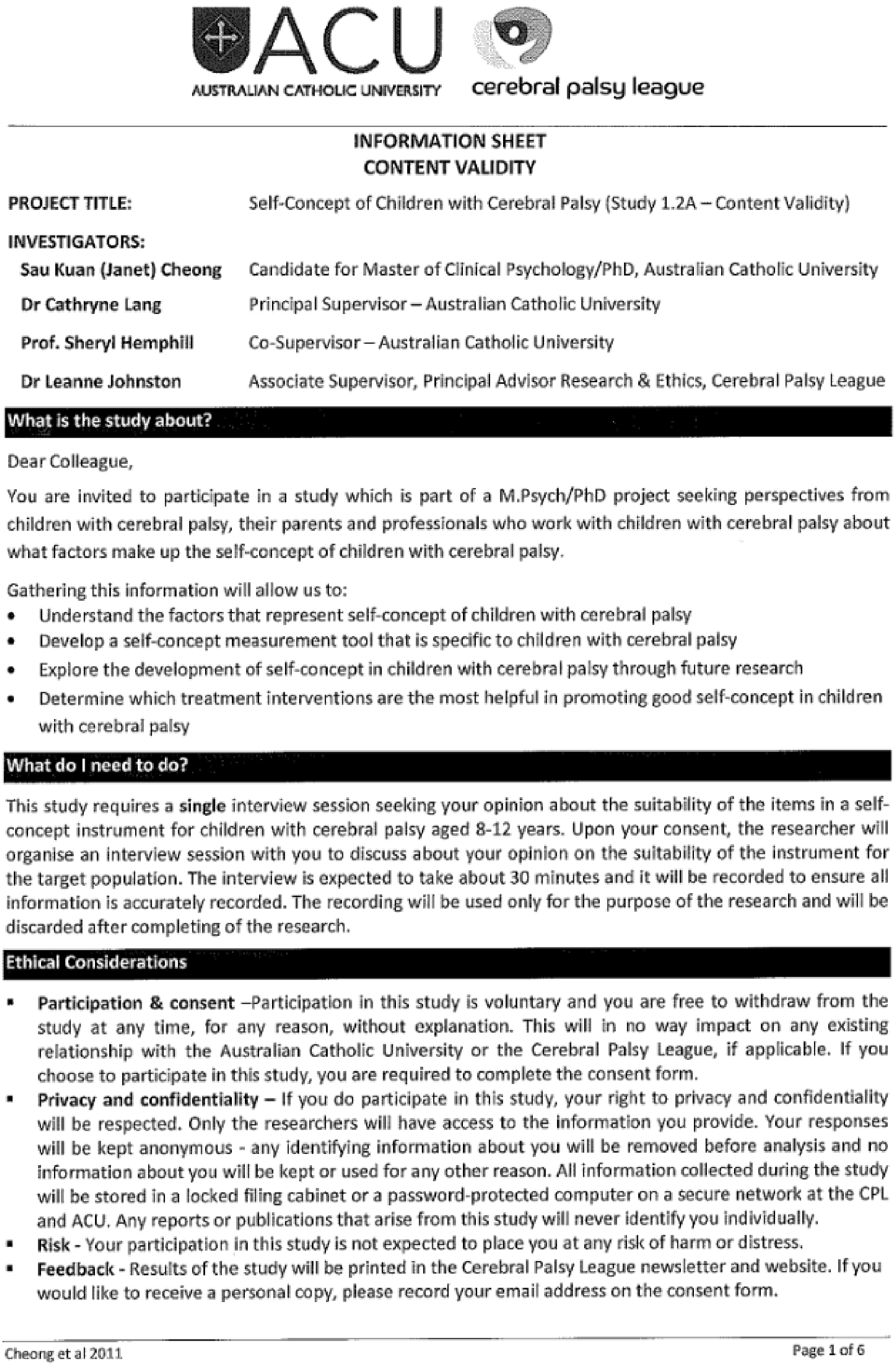
	Being sad
	Being worried
	Being shy
	Being nervous
	Being afraid
	Cry easily

Study 2: myTREEHOUSE board game administration

Appendix E Psychometric Testing (Study 3a) Materials

Appendix E includes the materials utilised for the psychometric testing (Study 3a) materials. Following are the page reference for the individual items:

Study 3a: Information Letter



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

INFORMATION SHEET
CONTENT VALIDITY

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Study 1.2A – Content Validity)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

What is the study about?

Dear Colleague,

You are invited to participate in a study which is part of a M.Psych/PhD project seeking perspectives from children with cerebral palsy, their parents and professionals who work with children with cerebral palsy about what factors make up the self-concept of children with cerebral palsy.

Gathering this information will allow us to:

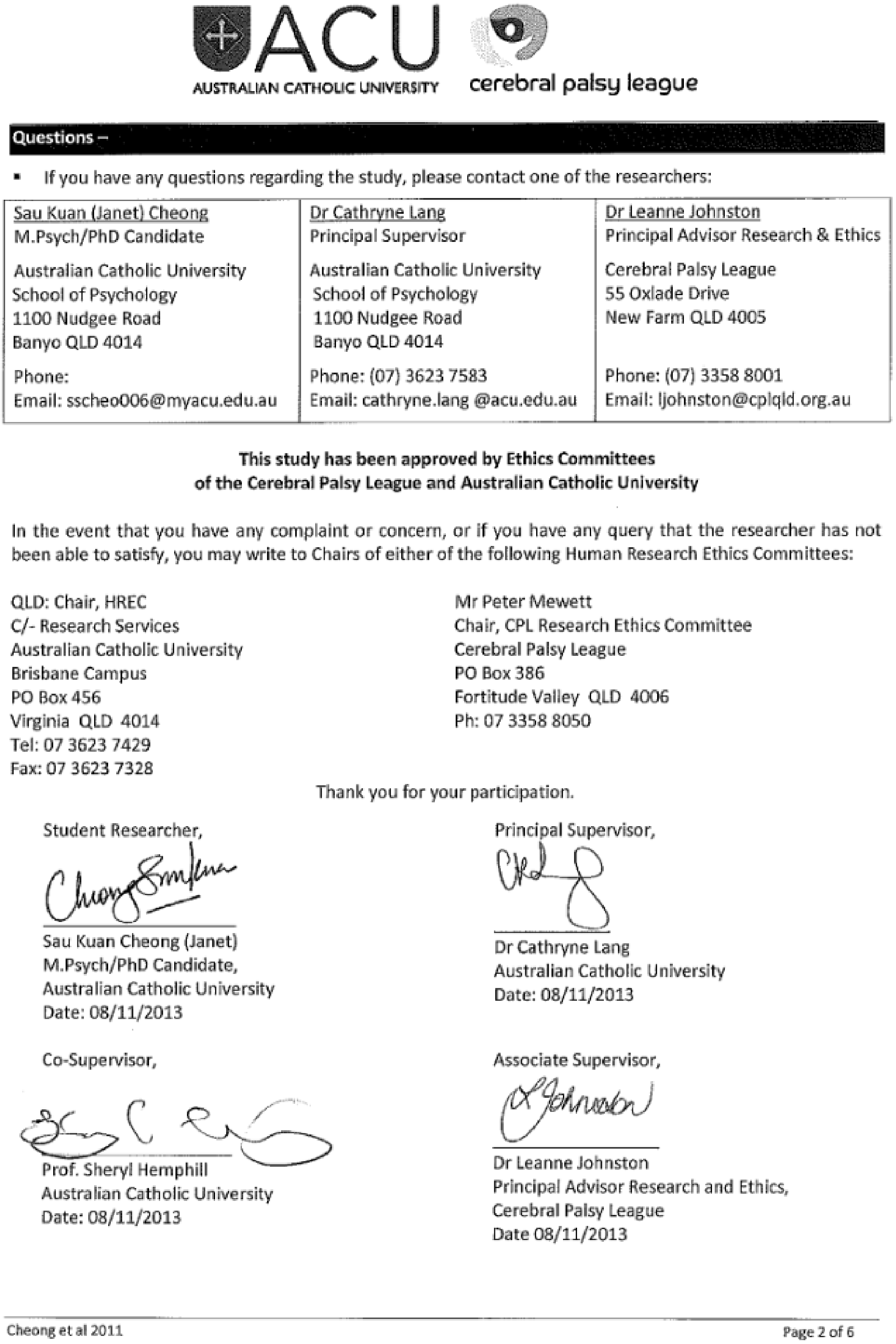
- Understand the factors that represent self-concept of children with cerebral palsy
- Develop a self-concept measurement tool that is specific to children with cerebral palsy
- Explore the development of self-concept in children with cerebral palsy through future research
- Determine which treatment interventions are the most helpful in promoting good self-concept in children with cerebral palsy

What do I need to do?

This study requires a **single** interview session seeking your opinion about the suitability of the items in a self-concept instrument for children with cerebral palsy aged 8-12 years. Upon your consent, the researcher will organise an interview session with you to discuss about your opinion on the suitability of the instrument for the target population. The interview is expected to take about 30 minutes and it will be recorded to ensure all information is accurately recorded. The recording will be used only for the purpose of the research and will be discarded after completing of the research.

Ethical Considerations

- **Participation & consent** –Participation in this study is voluntary and you are free to withdraw from the study at any time, for any reason, without explanation. This will in no way impact on any existing relationship with the Australian Catholic University or the Cerebral Palsy League, if applicable. If you choose to participate in this study, you are required to complete the consent form.
- **Privacy and confidentiality –** If you do participate in this study, your right to privacy and confidentiality will be respected. Only the researchers will have access to the information you provide. Your responses will be kept anonymous - any identifying information about you will be removed before analysis and no information about you will be kept or used for any other reason. All information collected during the study will be stored in a locked filing cabinet or a password-protected computer on a secure network at the CPL and ACU. Any reports or publications that arise from this study will never identify you individually.
- **Risk -** Your participation in this study is not expected to place you at any risk of harm or distress.
- **Feedback -** Results of the study will be printed in the Cerebral Palsy League newsletter and website. If you would like to receive a personal copy, please record your email address on the consent form.



AUSTRALIAN CATHOLIC UNIVERSITY   cerebral palsy league

Questions –

- If you have any questions regarding the study, please contact one of the researchers:

Sau Kuan (Janet) Cheong	Dr Cathryne Lang	Dr Leanne Johnston
M.Psych/PhD Candidate	Principal Supervisor	Principal Advisor Research & Ethics
Australian Catholic University School of Psychology 1100 Nudgee Road Banyo QLD 4014	Australian Catholic University School of Psychology 1100 Nudgee Road Banyo QLD 4014	Cerebral Palsy League 55 Oxlade Drive New Farm QLD 4005
Phone: Email: sscheo006@myacu.edu.au	Phone: (07) 3623 7583 Email: cathryne.lang @acu.edu.au	Phone: (07) 3358 8001 Email: ljohnston@cplqld.org.au

This study has been approved by Ethics Committees
of the Cerebral Palsy League and Australian Catholic University

In the event that you have any complaint or concern, or if you have any query that the researcher has not been able to satisfy, you may write to Chairs of either of the following Human Research Ethics Committees:

QLD: Chair, HREC
C/- Research Services
Australian Catholic University
Brisbane Campus
PO Box 456
Virginia QLD 4014
Tel: 07 3623 7429
Fax: 07 3623 7328

Mr Peter Mewett
Chair, CPL Research Ethics Committee
Cerebral Palsy League
PO Box 386
Fortitude Valley QLD 4006
Ph: 07 3358 8050

Thank you for your participation.

Student Researcher,

Sau Kuan Cheong (Janet)
M.Psych/PhD Candidate,
Australian Catholic University
Date: 08/11/2013

Principal Supervisor,

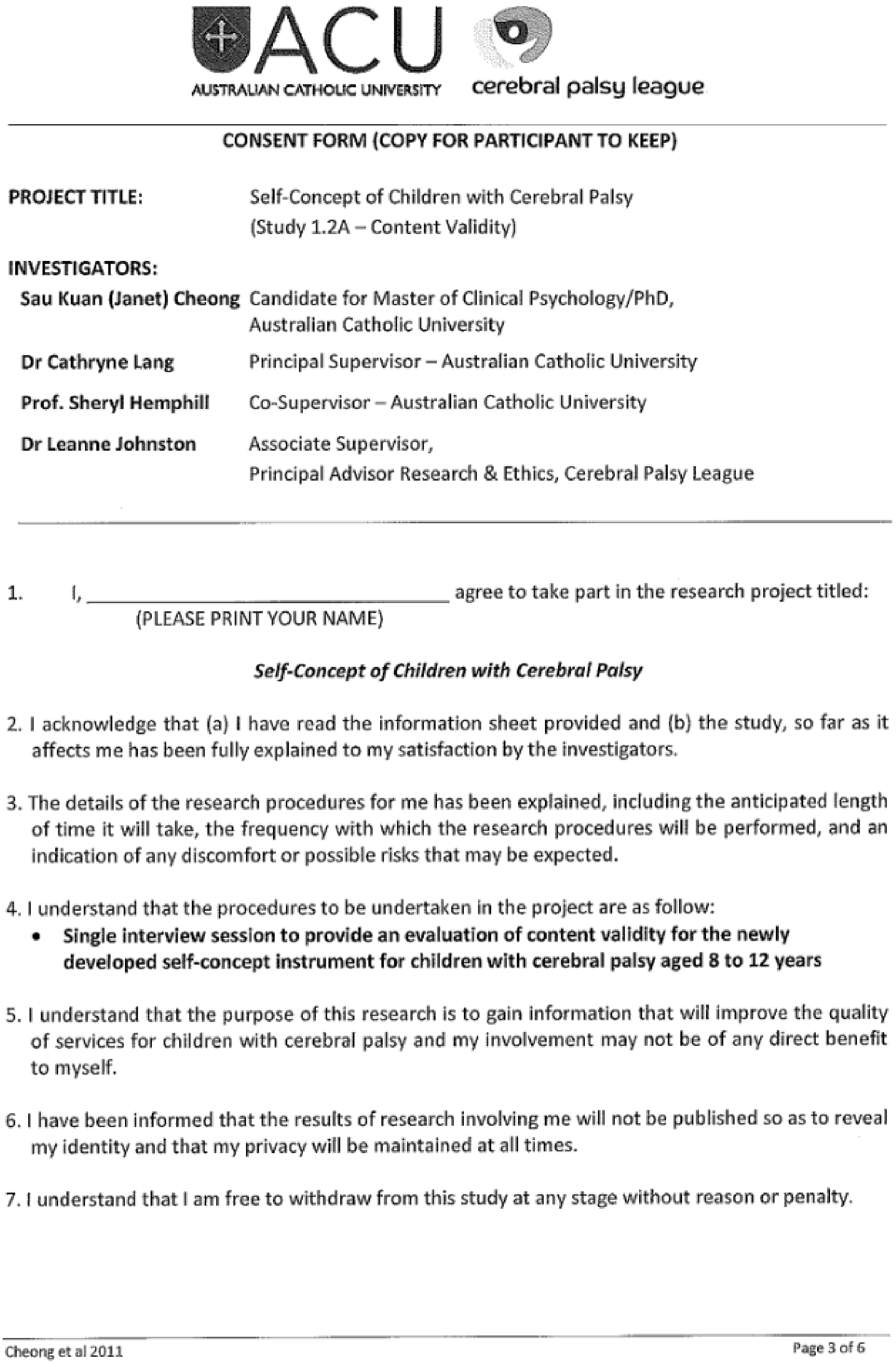
Dr Cathryne Lang
Australian Catholic University
Date: 08/11/2013

Co-Supervisor,

Prof. Sheryl Hemphill
Australian Catholic University
Date: 08/11/2013

Associate Supervisor,

Dr Leanne Johnston
Principal Advisor Research and Ethics,
Cerebral Palsy League
Date 08/11/2013



ACU
AUSTRALIAN CATHOLIC UNIVERSITY
cerebral palsy league

CONSENT FORM (COPY FOR PARTICIPANT TO KEEP)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Study 1.2A – Content Validity)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

1. I, ________________________________ agree to take part in the research project titled:
(PLEASE PRINT YOUR NAME)

Self-Concept of Children with Cerebral Palsy

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me has been fully explained to my satisfaction by the investigators.

3. The details of the research procedures for me has been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I understand that the procedures to be undertaken in the project are as follow:
   - **Single interview session to provide an evaluation of content validity for the newly developed self-concept instrument for children with cerebral palsy aged 8 to 12 years**

5. I understand that the purpose of this research is to gain information that will improve the quality of services for children with cerebral palsy and my involvement may not be of any direct benefit to myself.

6. I have been informed that the results of research involving me will not be published so as to reveal my identity and that my privacy will be maintained at all times.

7. I understand that I am free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My questionnaire data to be used for the current study

Potential future use of my information
☐ Copies of my questionnaire data to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___ / ___ / ___
(Participant)

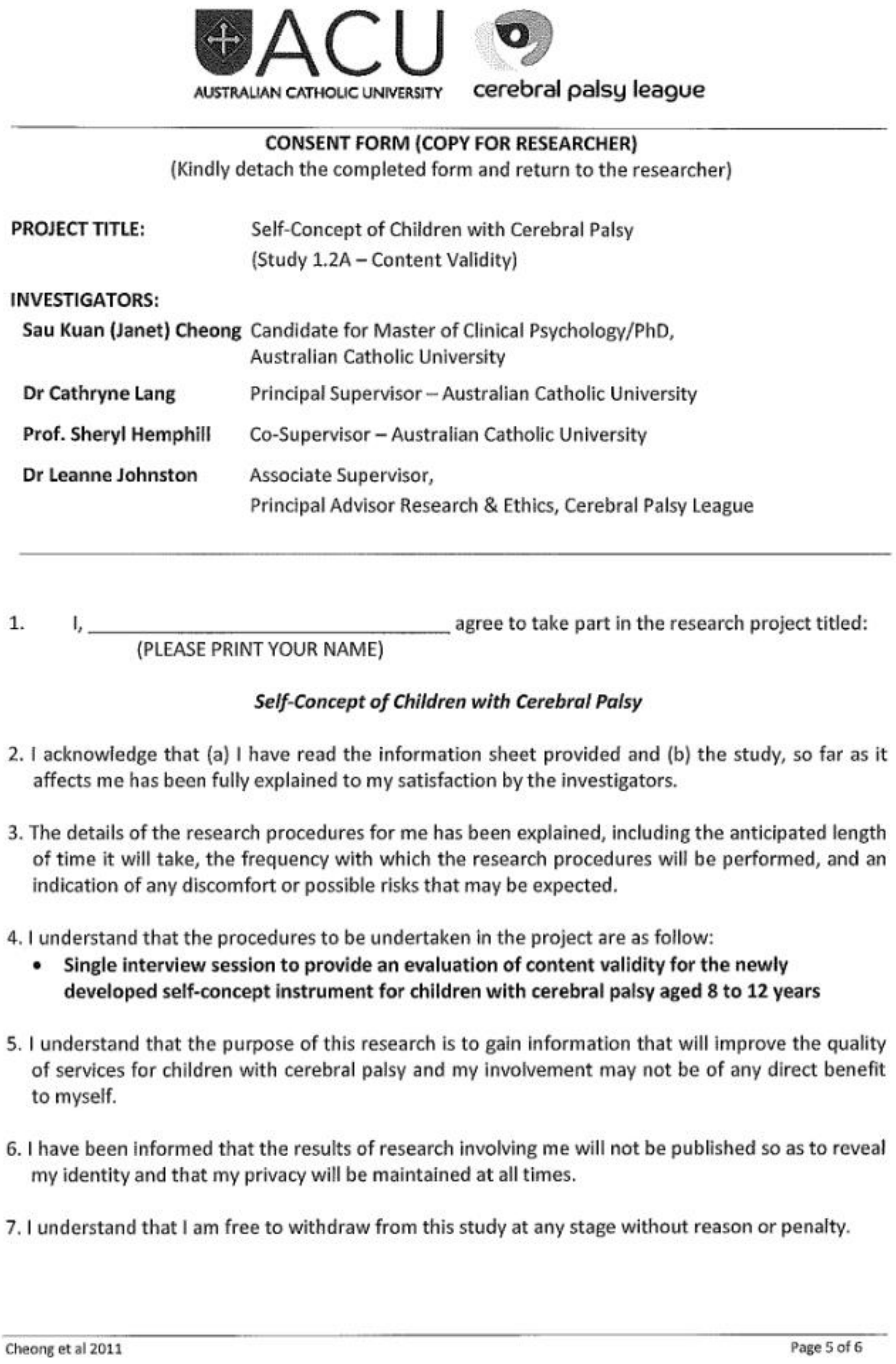
Telephone: ____________________________

Email: ________________________________

I would like to receive a copy of the study results
☐ No ☐ Yes, by email

Signed: ______________________________ Date: ___ / ___ / ___
(Investigator)

Footnote ** According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*



AUSTRALIAN CATHOLIC UNIVERSITY cerebral palsy league

CONSENT FORM (COPY FOR RESEARCHER)

(Kindly detach the completed form and return to the researcher)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Study 1.2A – Content Validity)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Prof. Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor, Principal Advisor Research & Ethics, Cerebral Palsy League

1. I, ______________________________ agree to take part in the research project titled:
(PLEASE PRINT YOUR NAME)

Self-Concept of Children with Cerebral Palsy

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me has been fully explained to my satisfaction by the investigators.

3. The details of the research procedures for me has been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I understand that the procedures to be undertaken in the project are as follow:
   - **Single interview session to provide an evaluation of content validity for the newly developed self-concept instrument for children with cerebral palsy aged 8 to 12 years**

5. I understand that the purpose of this research is to gain information that will improve the quality of services for children with cerebral palsy and my involvement may not be of any direct benefit to myself.

6. I have been informed that the results of research involving me will not be published so as to reveal my identity and that my privacy will be maintained at all times.

7. I understand that I am free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My questionnaire data to be used for the current study

Potential future use of my information
☐ Copies of my questionnaire data to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ________________________ Date: ___/___/___
(Participant)

Telephone: ____________________

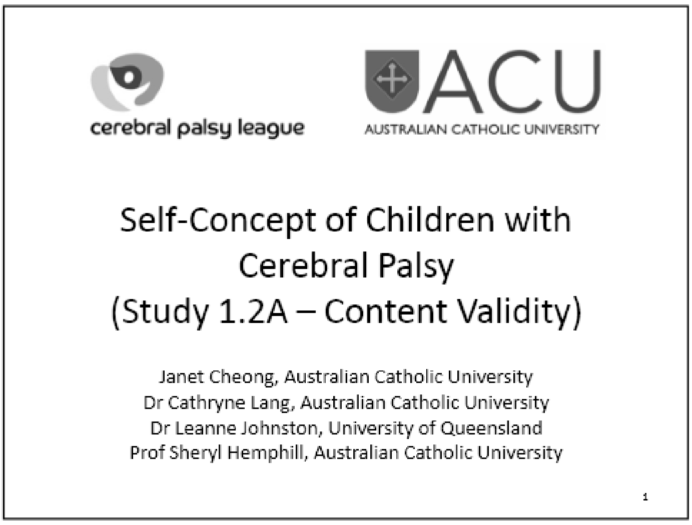
Email: ____________________

I would like to receive a copy of the study results
☐ No ☐ Yes, by email

Signed: ________________________ Date: ___/___/___
(Investigator)

Footnote * *According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*

Study 3a: PowerPoint Presentation Slides

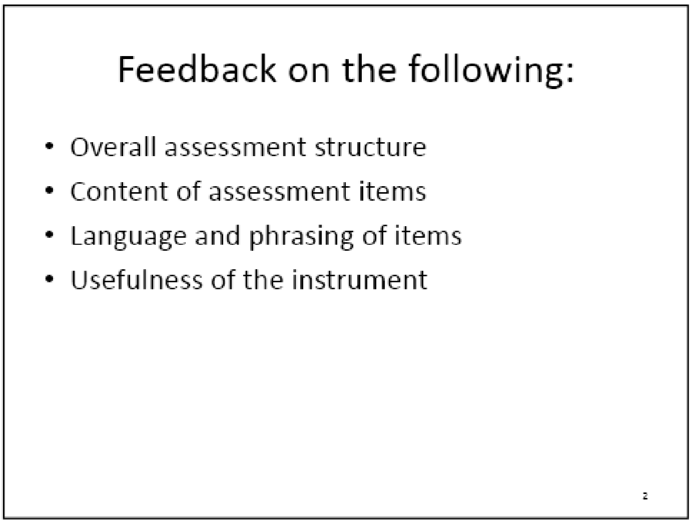


cerebral palsy league

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

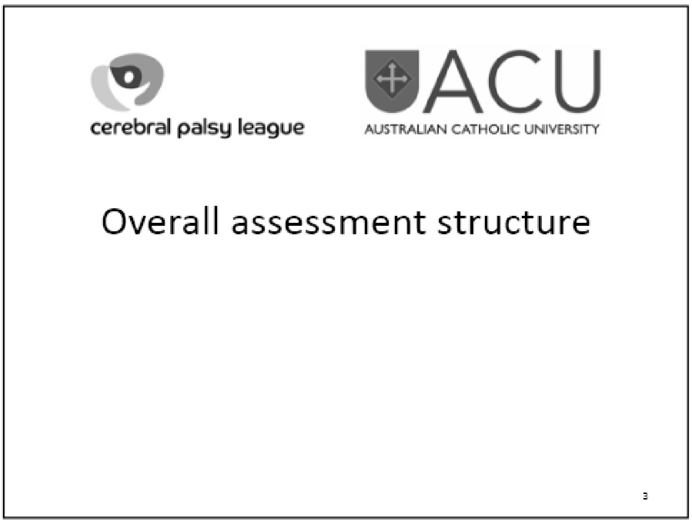
Self-Concept of Children with Cerebral Palsy (Study 1.2A – Content Validity)

Janet Cheong, Australian Catholic University
Dr Cathryne Lang, Australian Catholic University
Dr Leanne Johnston, University of Queensland
Prof Sheryl Hemphill, Australian Catholic University



Feedback on the following:

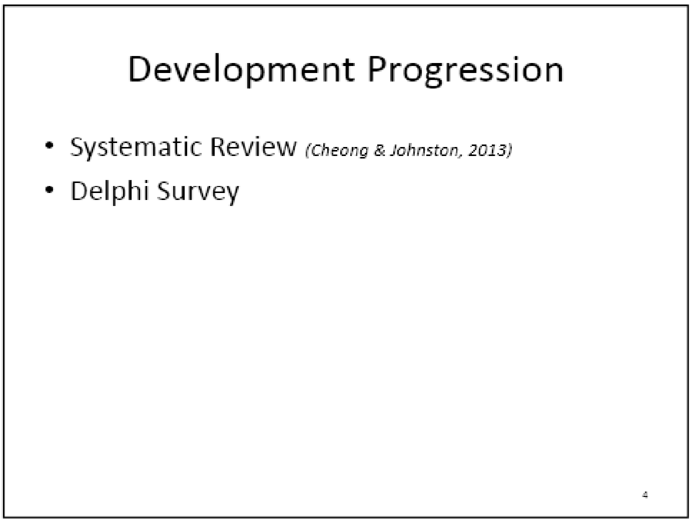
- Overall assessment structure
- Content of assessment items
- Language and phrasing of items
- Usefulness of the instrument



cerebral palsy league

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

Overall assessment structure



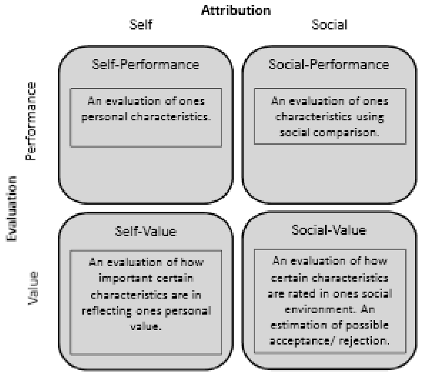
Development Progression

- Systematic Review *(Cheong & Johnston, 2013)*
- Delphi Survey

Factors

- Physical Appearance
- Physical Abilities
- General Learning Skills
- Social Skills
- Emotional Regulation
- General Self

Domains



Attribution

Self

Social

Evaluation

Performance

Value

Self-Performance

An evaluation of ones personal characteristics.

Social-Performance

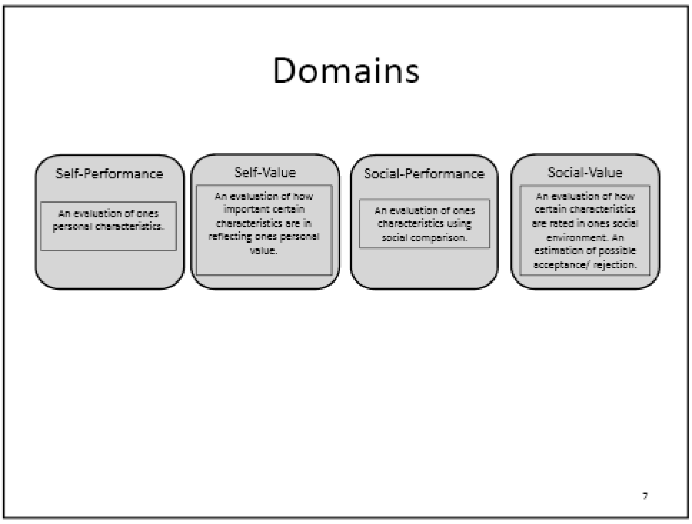
An evaluation of ones characteristics using social comparison.

Self-Value

An evaluation of how important certain characteristics are in reflecting ones personal value.

Social-Value

An evaluation of how certain characteristics are rated in ones social environment. An estimation of possible acceptance/ rejection.



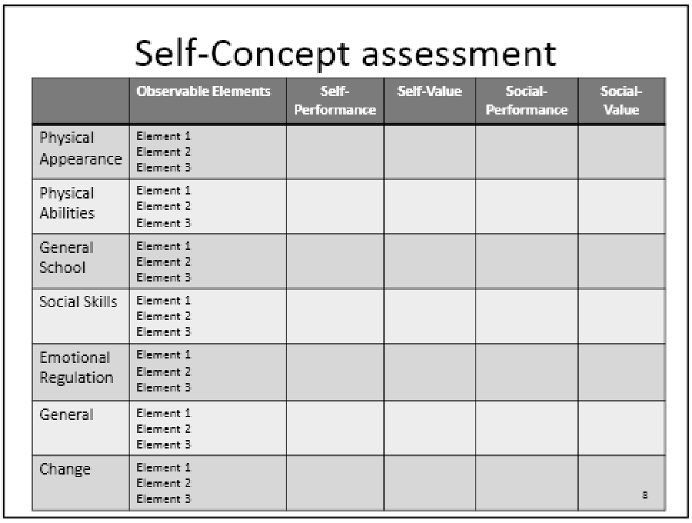
Domains

Self-Performance
An evaluation of ones personal characteristics.

Self-Value
An evaluation of how important certain characteristics are in reflecting ones personal value.

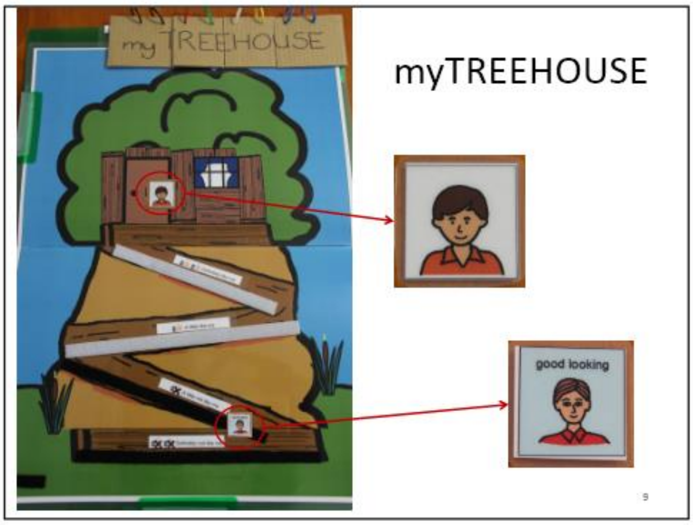
Social-Performance
An evaluation of ones characteristics using social comparison.

Social-Value
An evaluation of how certain characteristics are rated in ones social environment. An estimation of possible acceptance/ rejection.



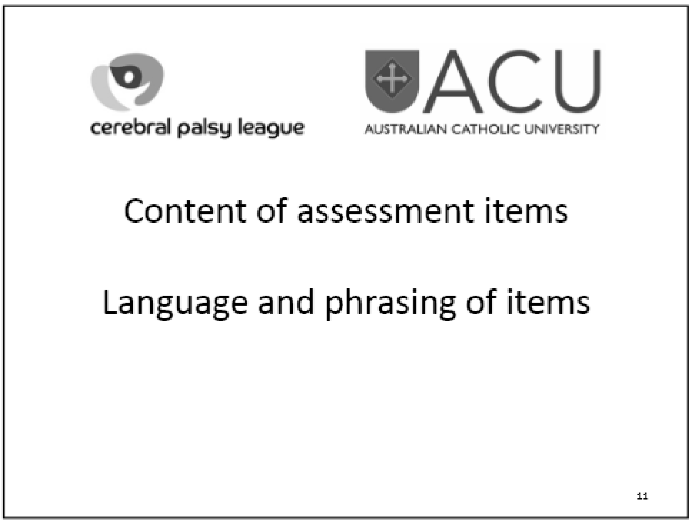
Self-Concept assessment

	Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Physical Appearance	Element 1 Element 2 Element 3				
Physical Abilities	Element 1 Element 2 Element 3				
General School	Element 1 Element 2 Element 3				
Social Skills	Element 1 Element 2 Element 3				
Emotional Regulation	Element 1 Element 2 Element 3				
General	Element 1 Element 2 Element 3				
Change	Element 1 Element 2 Element 3				



myTREEHOUSE

myTREEHOUSE

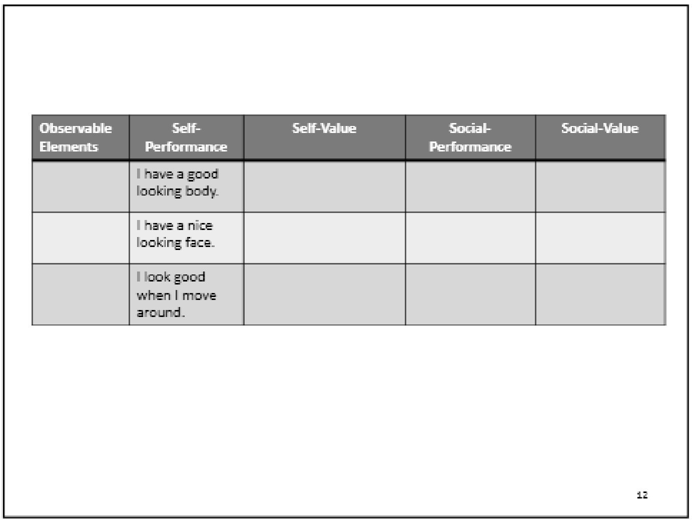


cerebral palsy league

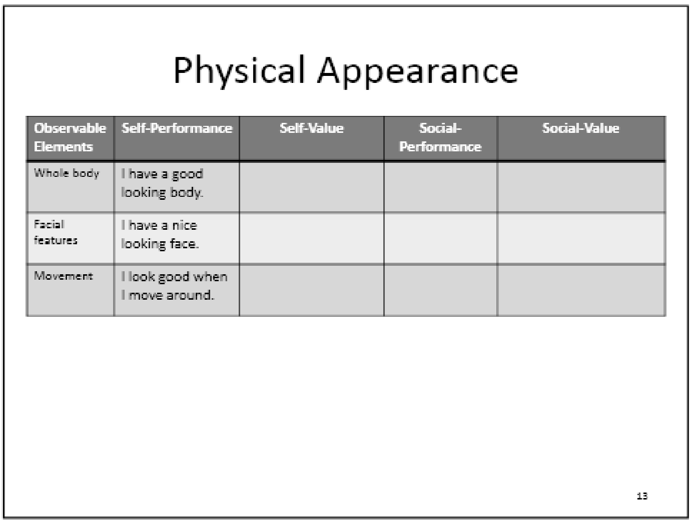
ACU
AUSTRALIAN CATHOLIC UNIVERSITY

Content of assessment items

Language and phrasing of items

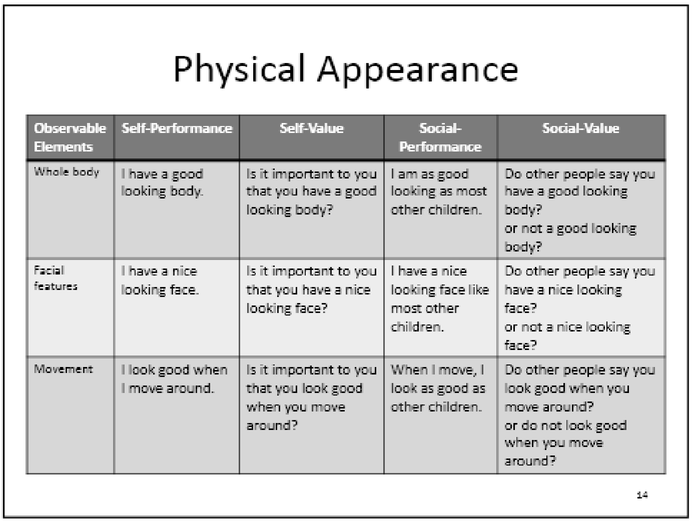


Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
	I have a good looking body.			
	I have a nice looking face.			
	I look good when I move around.			



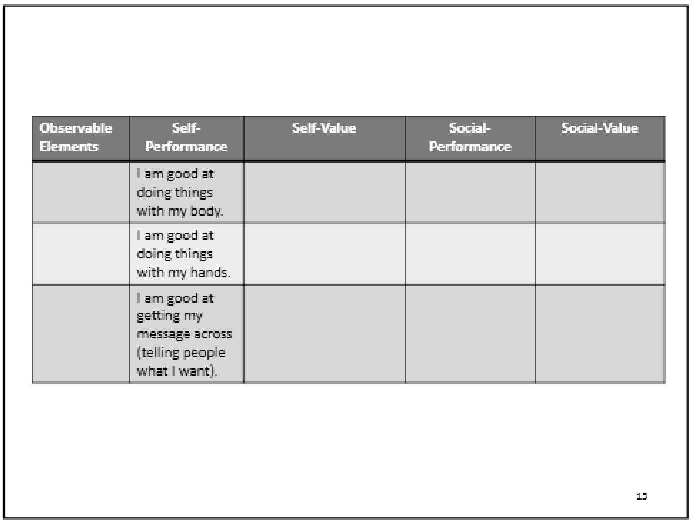
Physical Appearance

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Whole body	I have a good looking body.			
Facial features	I have a nice looking face.			
Movement	I look good when I move around.			

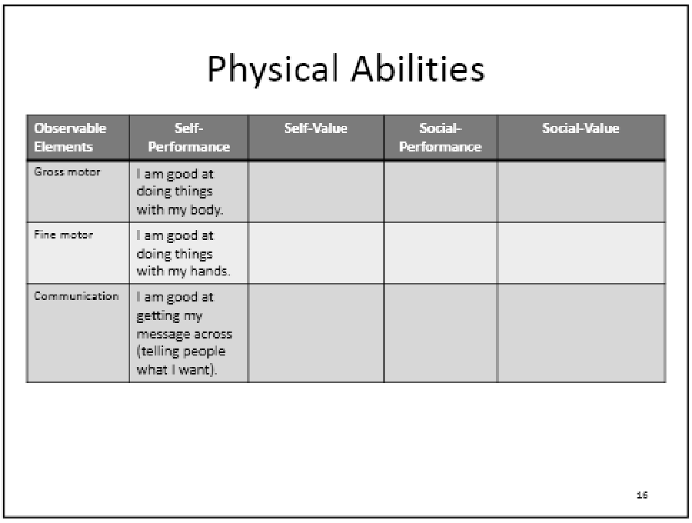


Physical Appearance

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Whole body	I have a good looking body.	Is it important to you that you have a good looking body?	I am as good looking as most other children.	Do other people say you have a good looking body? or not a good looking body?
Facial features	I have a nice looking face.	Is it important to you that you have a nice looking face?	I have a nice looking face like most other children.	Do other people say you have a nice looking face? or not a nice looking face?
Movement	I look good when I move around.	Is it important to you that you look good when you move around?	When I move, I look as good as other children.	Do other people say you look good when you move around? or do not look good when you move around?

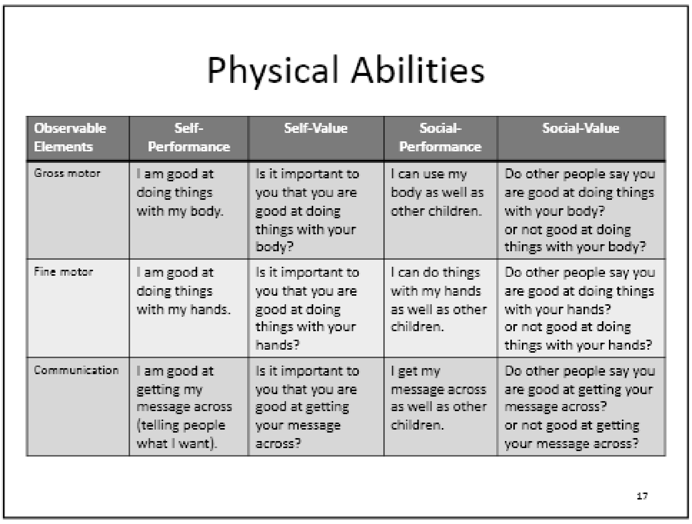


Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
	I am good at doing things with my body.			
	I am good at doing things with my hands.			
	I am good at getting my message across (telling people what I want).			



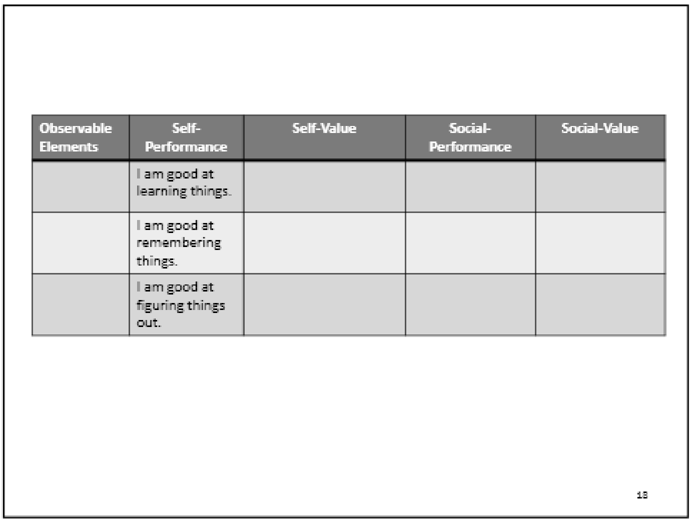
Physical Abilities

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Gross motor	I am good at doing things with my body.			
Fine motor	I am good at doing things with my hands.			
Communication	I am good at getting my message across (telling people what I want).			

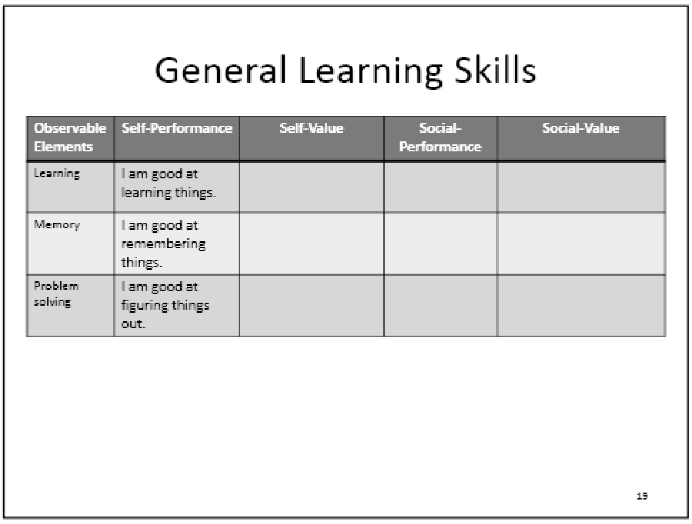


Physical Abilities

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Gross motor	I am good at doing things with my body.	Is it important to you that you are good at doing things with your body?	I can use my body as well as other children.	Do other people say you are good at doing things with your body? or not good at doing things with your body?
Fine motor	I am good at doing things with my hands.	Is it important to you that you are good at doing things with your hands?	I can do things with my hands as well as other children.	Do other people say you are good at doing things with your hands? or not good at doing things with your hands?
Communication	I am good at getting my message across (telling people what I want).	Is it important to you that you are good at getting your message across?	I get my message across as well as other children.	Do other people say you are good at getting your message across? or not good at getting your message across?

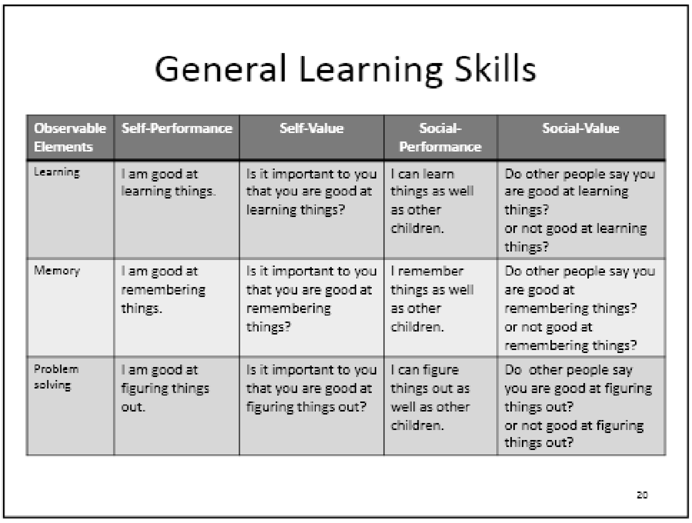


Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
	I am good at learning things.			
	I am good at remembering things.			
	I am good at figuring things out.			



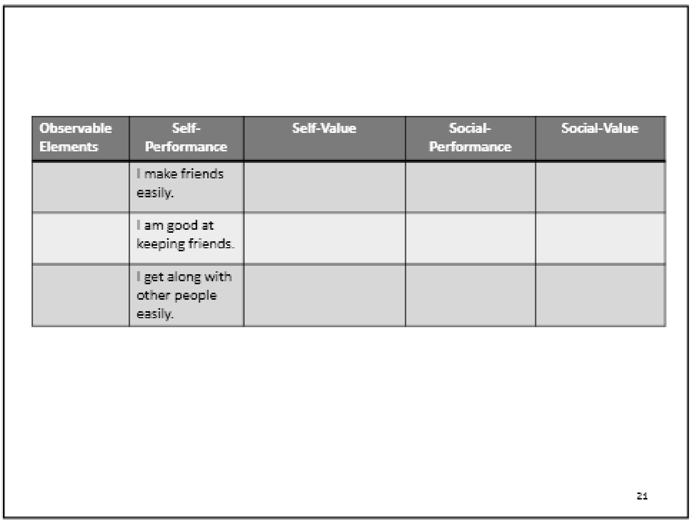
General Learning Skills

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Learning	I am good at learning things.			
Memory	I am good at remembering things.			
Problem solving	I am good at figuring things out.			

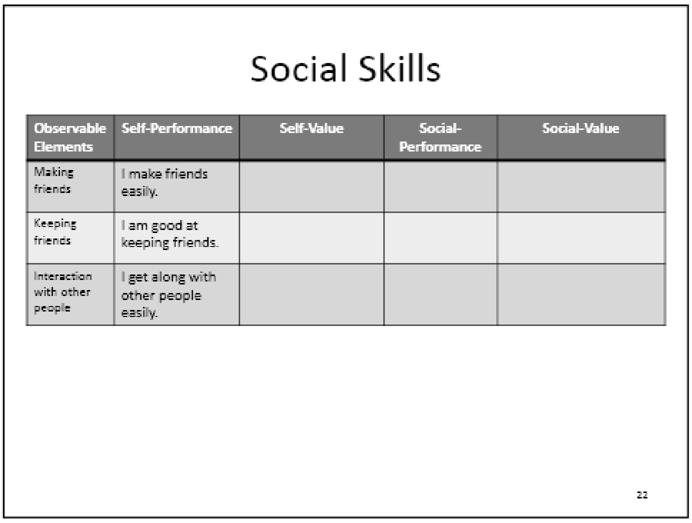


General Learning Skills

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Learning	I am good at learning things.	Is it important to you that you are good at learning things?	I can learn things as well as other children.	Do other people say you are good at learning things? or not good at learning things?
Memory	I am good at remembering things.	Is it important to you that you are good at remembering things?	I remember things as well as other children.	Do other people say you are good at remembering things? or not good at remembering things?
Problem solving	I am good at figuring things out.	Is it important to you that you are good at figuring things out?	I can figure things out as well as other children.	Do other people say you are good at figuring things out? or not good at figuring things out?

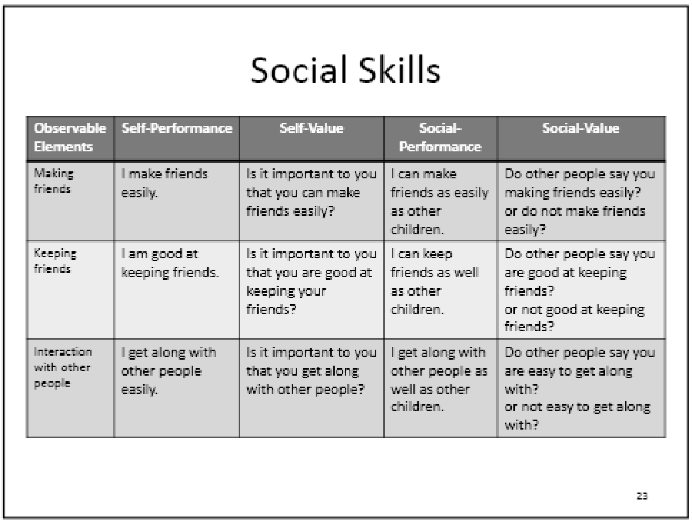


Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
	I make friends easily.			
	I am good at keeping friends.			
	I get along with other people easily.			



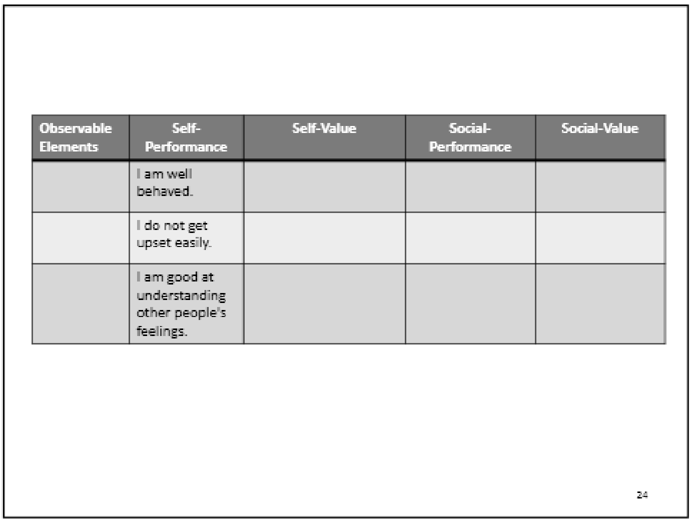
Social Skills

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Making friends	I make friends easily.			
Keeping friends	I am good at keeping friends.			
Interaction with other people	I get along with other people easily.			

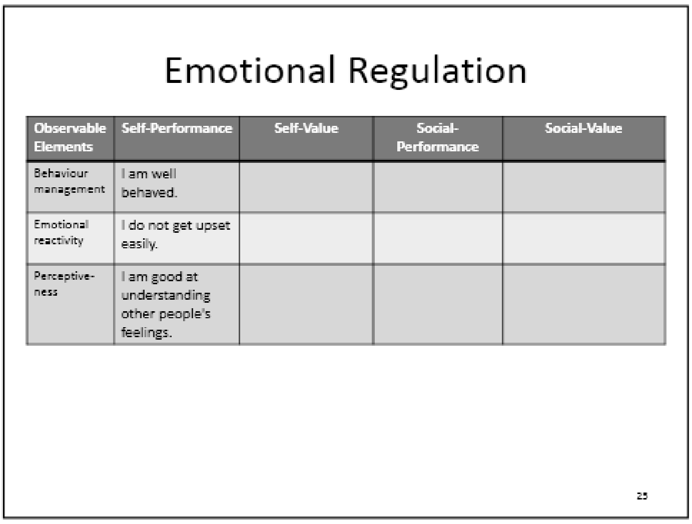


Social Skills

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Making friends	I make friends easily.	Is it important to you that you can make friends easily?	I can make friends as easily as other children.	Do other people say you making friends easily? or do not make friends easily?
Keeping friends	I am good at keeping friends.	Is it important to you that you are good at keeping your friends?	I can keep friends as well as other children.	Do other people say you are good at keeping friends? or not good at keeping friends?
Interaction with other people	I get along with other people easily.	Is it important to you that you get along with other people?	I get along with other people as well as other children.	Do other people say you are easy to get along with? or not easy to get along with?

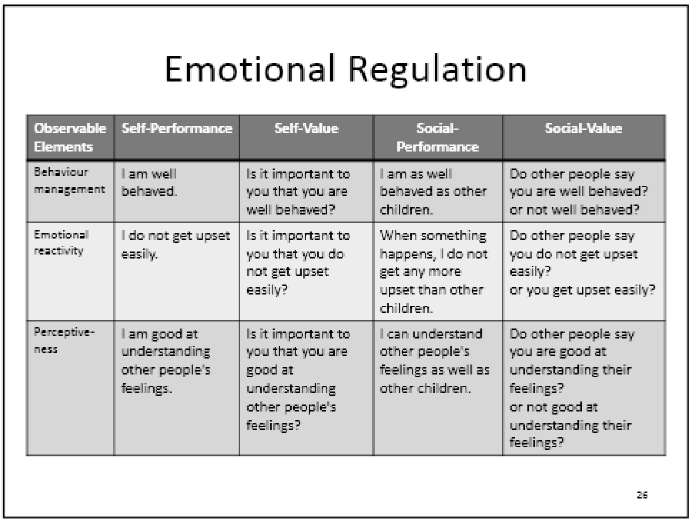


Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
	I am well behaved.			
	I do not get upset easily.			
	I am good at understanding other people's feelings.			



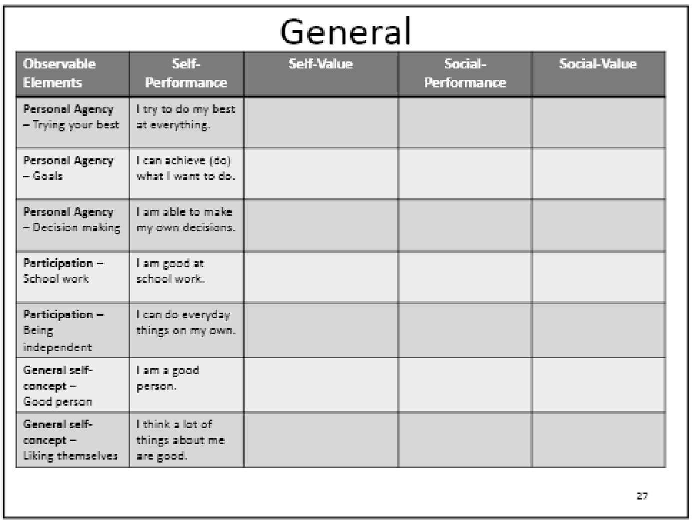
Emotional Regulation

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Behaviour management	I am well behaved.			
Emotional reactivity	I do not get upset easily.			
Perceptive-ness	I am good at understanding other people's feelings.			



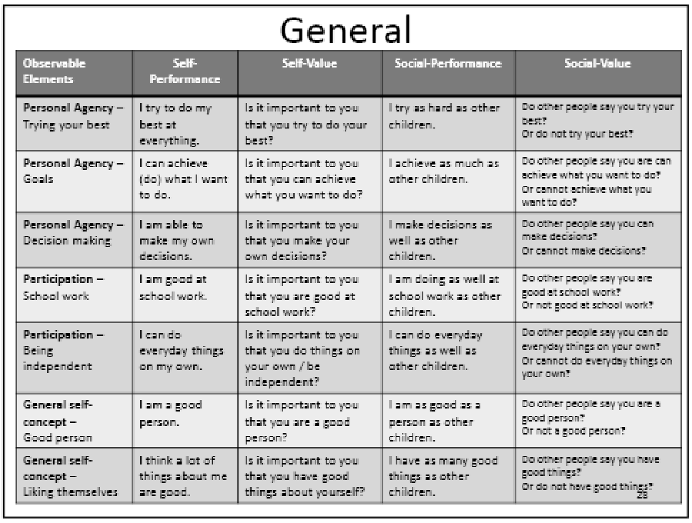
Emotional Regulation

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Behaviour management	I am well behaved.	Is it important to you that you are well behaved?	I am as well behaved as other children.	Do other people say you are well behaved? or not well behaved?
Emotional reactivity	I do not get upset easily.	Is it important to you that you do not get upset easily?	When something happens, I do not get any more upset than other children.	Do other people say you do not get upset easily? or you get upset easily?
Perceptive-ness	I am good at understanding other people's feelings.	Is it important to you that you are good at understanding other people's feelings?	I can understand other people's feelings as well as other children.	Do other people say you are good at understanding their feelings? or not good at understanding their feelings?



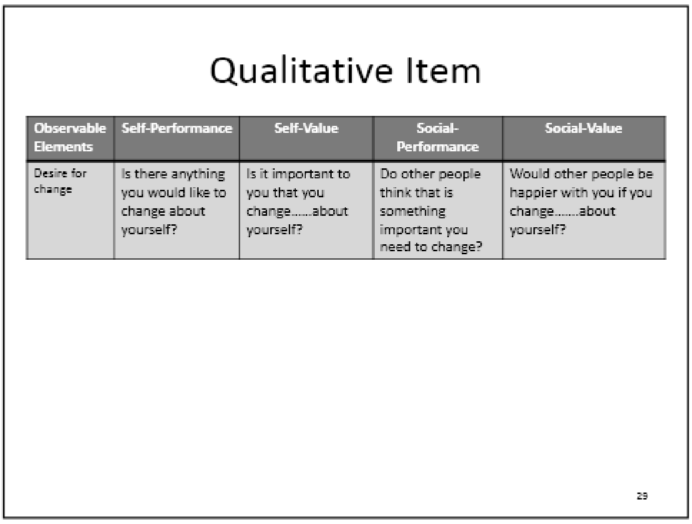
General

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Personal Agency – Trying your best	I try to do my best at everything.			
Personal Agency – Goals	I can achieve (do) what I want to do.			
Personal Agency – Decision making	I am able to make my own decisions.			
Participation – School work	I am good at school work.			
Participation – Being independent	I can do everyday things on my own.			
General self-concept – Good person	I am a good person.			
General self-concept – Liking themselves	I think a lot of things about me are good.			



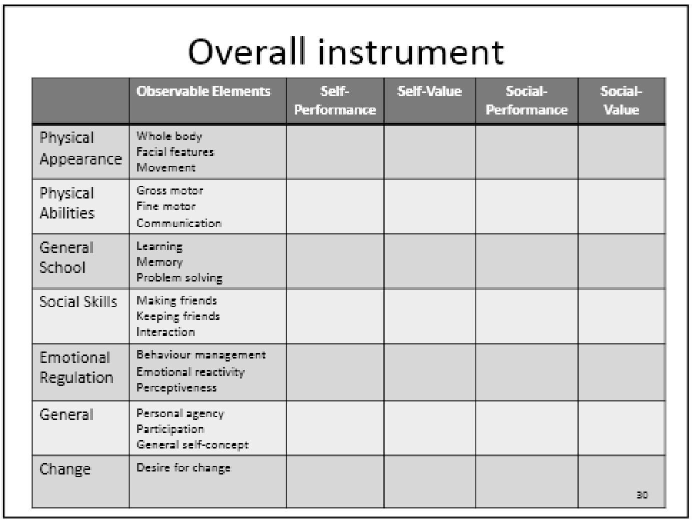
General

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Personal Agency – Trying your best	I try to do my best at everything.	Is it important to you that you try to do your best?	I try as hard as other children.	Do other people say you try your best? Or do not try your best?
Personal Agency – Goals	I can achieve (do) what I want to do.	Is it important to you that you can achieve what you want to do?	I achieve as much as other children.	Do other people say you are can achieve what you want to do? Or cannot achieve what you want to do?
Personal Agency – Decision making	I am able to make my own decisions.	Is it important to you that you make your own decisions?	I make decisions as well as other children.	Do other people say you can make decisions? Or cannot make decisions?
Participation – School work	I am good at school work.	Is it important to you that you are good at school work?	I am doing as well at school work as other children.	Do other people say you are good at school work? Or not good at school work?
Participation – Being independent	I can do everyday things on my own.	Is it important to you that you do things on your own / be independent?	I can do everyday things as well as other children.	Do other people say you can do everyday things on your own? Or cannot do everyday things on your own?
General self-concept – Good person	I am a good person.	Is it important to you that you are a good person?	I am as good as a person as other children.	Do other people say you are a good person? Or not a good person?
General self-concept – Liking themselves	I think a lot of things about me are good.	Is it important to you that you have good things about yourself?	I have as many good things as other children.	Do other people say you have good things? Or do not have good things?



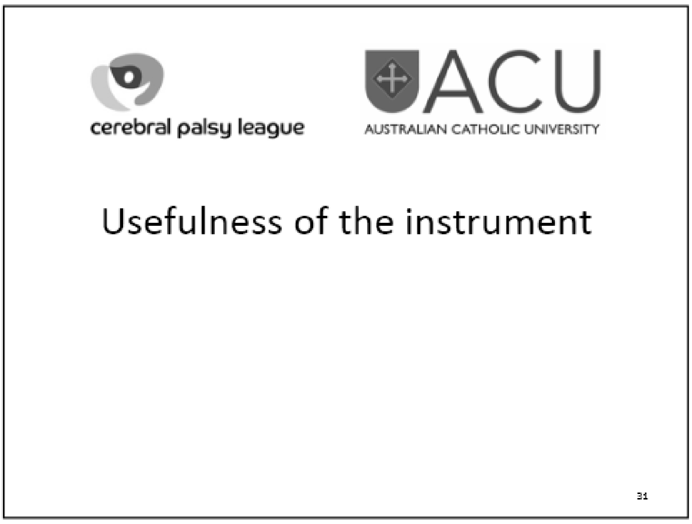
Qualitative Item

Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Desire for change	Is there anything you would like to change about yourself?	Is it important to you that you change……about yourself?	Do other people think that is something important you need to change?	Would other people be happier with you if you change…….about yourself?



Overall instrument

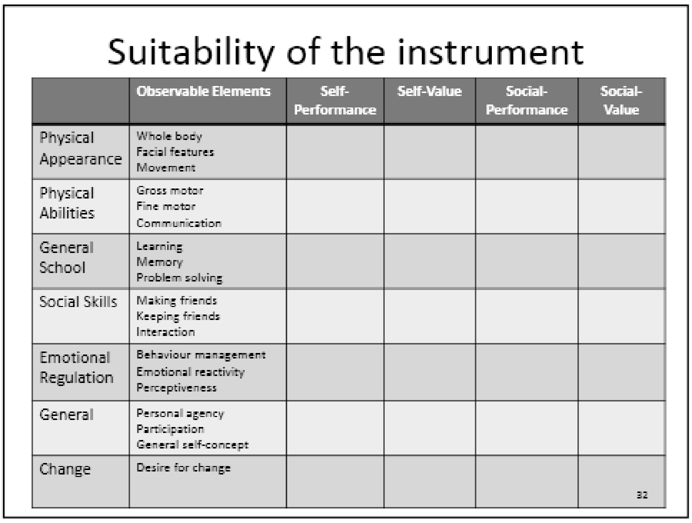
	Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Physical Appearance	Whole body Facial features Movement				
Physical Abilities	Gross motor Fine motor Communication				
General School	Learning Memory Problem solving				
Social Skills	Making friends Keeping friends Interaction				
Emotional Regulation	Behaviour management Emotional reactivity Perceptiveness				
General	Personal agency Participation General self-concept				
Change	Desire for change				



cerebral palsy league

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

Usefulness of the instrument



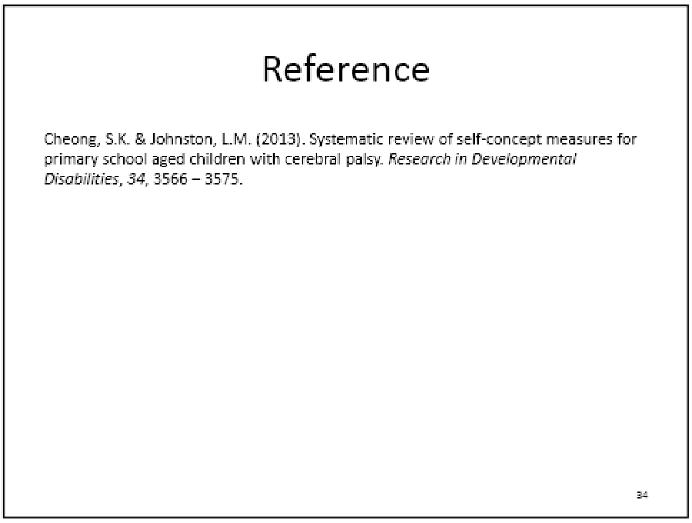
Suitability of the instrument

	Observable Elements	Self-Performance	Self-Value	Social-Performance	Social-Value
Physical Appearance	Whole body Facial features Movement				
Physical Abilities	Gross motor Fine motor Communication				
General School	Learning Memory Problem solving				
Social Skills	Making friends Keeping friends Interaction				
Emotional Regulation	Behaviour management Emotional reactivity Perceptiveness				
General	Personal agency Participation General self-concept				
Change	Desire for change				

cerebral palsy league

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

Thank you very much for your participation



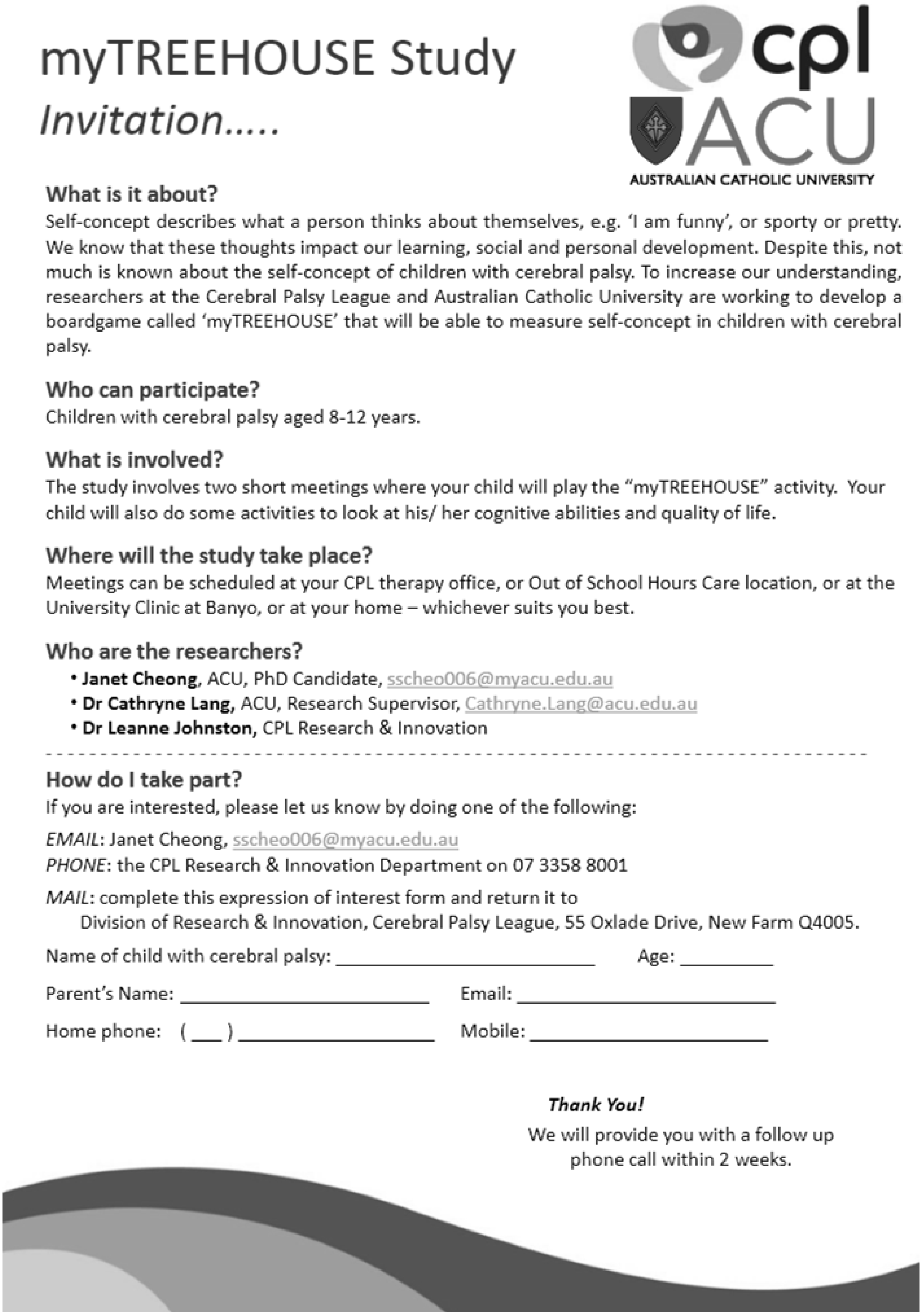
Reference

Cheong, S.K. & Johnston, L.M. (2013). Systematic review of self-concept measures for primary school aged children with cerebral palsy. *Research in Developmental Disabilities*, *34*, 3566 – 3575.

Appendix F Materials for Studies 3b, 4, and 5: Psychometric Testing (Study 3b), Self-Concept of Children with Cerebral Palsy (Study 4), and Self-Concept and Quality of Life for Children with Cerebral Palsy (Study 5)

Appendix F includes the materials utilised for the psychometric testing (Study 3b), the self-concept of children with CP study (Study 4), and the self-concept and quality of life for children with CP study (Study 5). Following are the page reference for the individual items:

Study 3b, 4, and 5: Mailout Flier



myTREEHOUSE Study

Invitation…..

cpl

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

What is it about?

Self-concept describes what a person thinks about themselves, e.g. 'I am funny', or sporty or pretty. We know that these thoughts impact our learning, social and personal development. Despite this, not much is known about the self-concept of children with cerebral palsy. To increase our understanding, researchers at the Cerebral Palsy League and Australian Catholic University are working to develop a boardgame called 'myTREEHOUSE' that will be able to measure self-concept in children with cerebral palsy.

Who can participate?

Children with cerebral palsy aged 8-12 years.

What is involved?

The study involves two short meetings where your child will play the "myTREEHOUSE" activity. Your child will also do some activities to look at his/ her cognitive abilities and quality of life.

Where will the study take place?

Meetings can be scheduled at your CPL therapy office, or Out of School Hours Care location, or at the University Clinic at Banyo, or at your home – whichever suits you best.

Who are the researchers?

- **Janet Cheong**, ACU, PhD Candidate, sscheo006@myacu.edu.au
- **Dr Cathryne Lang,** ACU, Research Supervisor, Cathryne.Lang@acu.edu.au
- **Dr Leanne Johnston,** CPL Research & Innovation

- -

How do I take part?

If you are interested, please let us know by doing one of the following:

EMAIL: Janet Cheong, sscheo006@myacu.edu.au
PHONE: the CPL Research & Innovation Department on 07 3358 8001

MAIL: complete this expression of interest form and return it to
Division of Research & Innovation, Cerebral Palsy League, 55 Oxlade Drive, New Farm Q4005.

Name of child with cerebral palsy: ___________________________ Age: _________

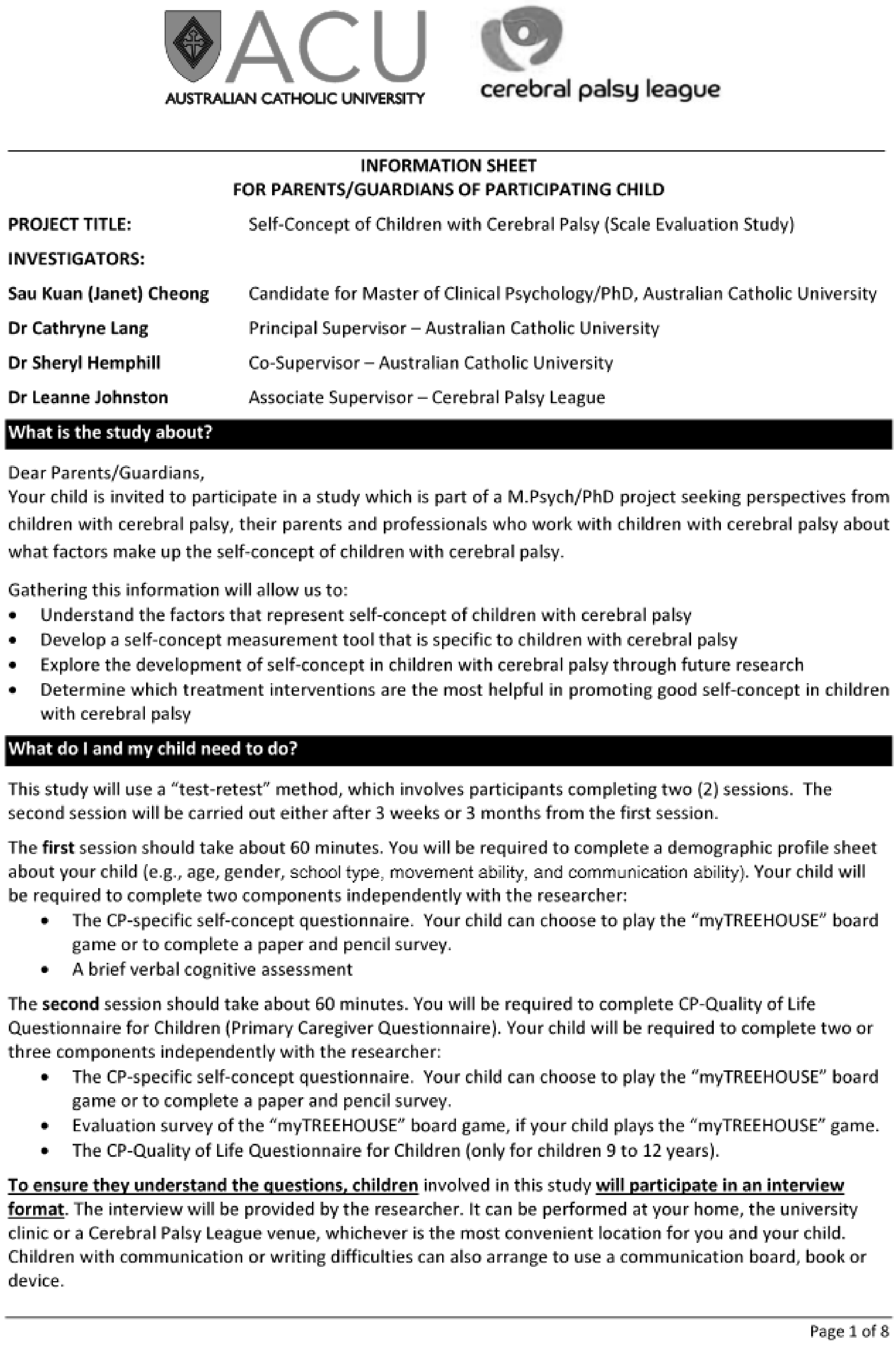
Parent's Name: __________________________ Email: ___________________________

Home phone: (___) ____________________ Mobile: _________________________

Thank You!

We will provide you with a follow up
phone call within 2 weeks.

Study 3b, 4, and 5: Parent Information Letter and Consent Form



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

INFORMATION SHEET
FOR PARENTS/GUARDIANS OF PARTICIPATING CHILD

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Scale Evaluation Study)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Dr Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor – Cerebral Palsy League

What is the study about?

Dear Parents/Guardians,
Your child is invited to participate in a study which is part of a M.Psych/PhD project seeking perspectives from children with cerebral palsy, their parents and professionals who work with children with cerebral palsy about what factors make up the self-concept of children with cerebral palsy.

Gathering this information will allow us to:
- Understand the factors that represent self-concept of children with cerebral palsy
- Develop a self-concept measurement tool that is specific to children with cerebral palsy
- Explore the development of self-concept in children with cerebral palsy through future research
- Determine which treatment interventions are the most helpful in promoting good self-concept in children with cerebral palsy

What do I and my child need to do?

This study will use a "test-retest" method, which involves participants completing two (2) sessions. The second session will be carried out either after 3 weeks or 3 months from the first session.

The **first** session should take about 60 minutes. You will be required to complete a demographic profile sheet about your child (e.g., age, gender, school type, movement ability, and communication ability). Your child will be required to complete two components independently with the researcher:
- The CP-specific self-concept questionnaire. Your child can choose to play the "myTREEHOUSE" board game or to complete a paper and pencil survey.
- A brief verbal cognitive assessment

The **second** session should take about 60 minutes. You will be required to complete CP-Quality of Life Questionnaire for Children (Primary Caregiver Questionnaire). Your child will be required to complete two or three components independently with the researcher:
- The CP-specific self-concept questionnaire. Your child can choose to play the "myTREEHOUSE" board game or to complete a paper and pencil survey.
- Evaluation survey of the "myTREEHOUSE" board game, if your child plays the "myTREEHOUSE" game.
- The CP-Quality of Life Questionnaire for Children (only for children 9 to 12 years).

To ensure they understand the questions, children involved in this study **will participate in an interview format**. The interview will be provided by the researcher. It can be performed at your home, the university clinic or a Cerebral Palsy League venue, whichever is the most convenient location for you and your child. Children with communication or writing difficulties can also arrange to use a communication board, book or device.

Ethical Considerations

- **Participation & consent** – Participation in this study is voluntary and your child is free to withdraw from the study at any time, for any reason, without explanation. This will in no way impact on your child's relationship with the CPL, or the services that you/your child receive. If you choose to allow your child to participate in this study, you are required to complete the consent form. Your child will need to complete an assent form.
- **Privacy and confidentiality** – If your child does participate in this study, their right to privacy and confidentiality will be respected. Only the researchers will have access to the information you or your child provide. Your child's responses will be kept anonymous - any identifying information about your child will be removed before analysis and no information about your child will be kept or used for any reason without your consent. All information collected during the study will be stored in a locked filing cabinet or a password-protected computer on a secure network at the CPL and ACU. Any reports or publications that arise from this study will never identify your child individually.
- **Risk** – Participation in this study is not expected to place your child at any risk of harm or distress. In the event that they might wish to talk to a mental or physical health professional as a result of completing the questionnaire, we can assist you to contact:
  - Your Cerebral Palsy League psychologist/social worker: (07) 3358 8001,
  - Australian Catholic University (ACU) Brisbane Psychology and Counselling Clinic (BPACC) Ph:(07) 3623 7453,
  - Help lines, such as Lifeline Helpline (Ph:13 11 14), Beyond Blue (1300 22 4636), Kids Help Line (1800 55 1800)
  - Your general practitioner for consultation or referral to appropriate professionals for assistance.
- **Feedback** – Results of the study will be printed in the Cerebral Palsy League newsletter and website. If you would like to receive a personal copy, please record your address on the consent form.

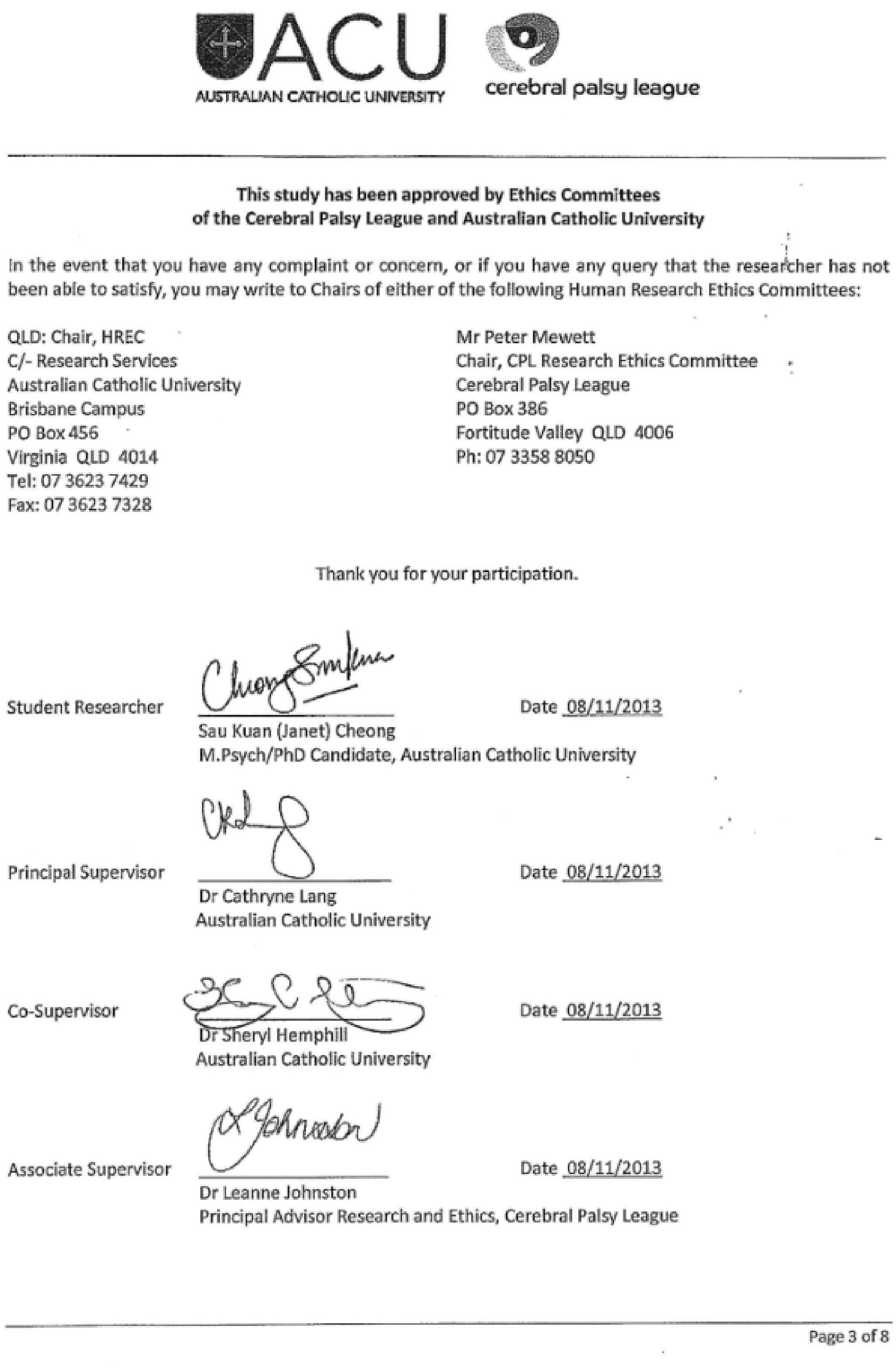
Questions –

- If you have any questions regarding the study, please contact one of the researchers:

<u>Sau Kuan (Janet) Cheong</u>
M.Psych/PhD Candidate
Australian Catholic University
School of Psychology
1100 Nudgee Road, Banyo QLD, 4014
Phone:
Email: sscheo006@myacu.edu.au

<u>Dr Cathryne Lang</u>
Principal Supervisor
Australian Catholic University
School of Psychology
1100 Nudgee Road, Banyo QLD, 4014
Phone: (07) 3623 7583
Email: cathryne.lang @acu.edu.au

<u>Dr Leanne Johnston</u>
Associate Supervisor
Cerebral Palsy League
55 Oxlade Drive
New Farm QLD 4005
Phone: (07) 3358 8001 (via Robyn Smedley)
Email: ljohnston1@uq.edu.au



ACU
AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

This study has been approved by Ethics Committees
of the Cerebral Palsy League and Australian Catholic University

In the event that you have any complaint or concern, or if you have any query that the researcher has not been able to satisfy, you may write to Chairs of either of the following Human Research Ethics Committees:

QLD: Chair, HREC
C/- Research Services
Australian Catholic University
Brisbane Campus
PO Box 456
Virginia QLD 4014
Tel: 07 3623 7429
Fax: 07 3623 7328

Mr Peter Mewett
Chair, CPL Research Ethics Committee
Cerebral Palsy League
PO Box 386
Fortitude Valley QLD 4006
Ph: 07 3358 8050

Thank you for your participation.

Student Researcher
Sau Kuan (Janet) Cheong
M.Psych/PhD Candidate, Australian Catholic University
Date 08/11/2013

Principal Supervisor
Dr Cathryne Lang
Australian Catholic University
Date 08/11/2013

Co-Supervisor
Dr Sheryl Hemphill
Australian Catholic University
Date 08/11/2013

Associate Supervisor
Dr Leanne Johnston
Principal Advisor Research and Ethics, Cerebral Palsy League
Date 08/11/2013

This page is deliberately left unmarked

Please turn to the next page

AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CONSENT FORM (COPY FOR PARTICIPANT TO KEEP)
(PARENT/GUARDIAN OF PARTICIPATING CHILD)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Scale Evaluation Study)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Dr Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor – Cerebral Palsy League

1. I, ___________________________________ hereby give consent for my child
(PLEASE PRINT PARENT'S NAME)

___________________________________ born on ____ / ____ / ____
(PLEASE PRINT CHILD'S NAME)

to take part in the research project titled: ***Self-Concept of Children with Cerebral Palsy.***

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me/my child has been fully explained to my satisfaction by the investigators. After discussing the study with my child so that they understand and gaining their agreement to participate, I freely consent to my child's participation in the project.

3. The details of the research procedures for me/my child have been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.

4. I / my child understand that the procedures to be undertaken in the project are as follows:
   - **Session 1: Parent Questionnaire** – Provide demographic profile about my child (e.g. age, gender, school type, GMFCS, MACS and FCCS); **Child Questionnaire** – Completing the CP-specific self-concept questionnaire and a brief verbal cognitive assessment.
   - **Session 2: Parent Questionnaire** – CP-Quality of Life Questionnaire for Children (Primary Caregiver Questionnaire); **Child Questionnaire** – Completing the CP-specific self-concept questionnaire, evaluation survey and the CP-Quality of Life Questionnaire for Children

5. I/my child understand that the purpose of this research is to gain information that will improve the quality of therapy services for children with cerebral palsy and my/my child's involvement may not be of any direct benefit to myself/him/her.
6. I/my child have been informed that the results of research involving myself/him/her will not be published so as to reveal my/his/her identity and that my/his/her privacy will be maintained at all times.
7. I/my child understand that I/my child is free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My/my child's questionnaire data to be used for the current study

Potential future use of my child's information
☐ Copies of my/my child's questionnaire to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___ / ___ / ___
(parent/guardian)

Telephone: ____________________________

Email: ________________________________

Postal address: ____

I would like to receive a copy of the study results
☐ No ☐ Yes, by email ☐ Yes, by post

Signed: ______________________________ Date: ___ / ___ / ___
(Investigator)

Footnote ** According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*

AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CONSENT FORM (COPY FOR RESEARCHER)
(PARENT/GUARDIAN OF PARTICIPATING CHILD)

(Kindly detach the completed form and return to the researcher)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Scale Evaluation Study)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Dr Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor – Cerebral Palsy League

1. I, ___________________________________ hereby give consent for my child
(PLEASE PRINT PARENT'S NAME)

___________________________________ born on ____ / ____ / ____
(PLEASE PRINT CHILD'S NAME)

to take part in the research project titled: ***Self-Concept of Children with Cerebral Palsy.***

2. I acknowledge that (a) I have read the information sheet provided and (b) the study, so far as it affects me/my child has been fully explained to my satisfaction by the investigators. After discussing the study with my child so that they understand and gaining their agreement to participate, I freely consent to my child's participation in the project.
3. The details of the research procedures for me/my child have been explained, including the anticipated length of time it will take, the frequency with which the research procedures will be performed, and an indication of any discomfort or possible risks that may be expected.
4. I / my child understand that the procedures to be undertaken in the project are as follows:
   - **Session 1: Parent Questionnaire** – Provide demographic profile about my child (e.g. age, gender, school type, GMFCS, MACS and FCCS); **Child Questionnaire** – Completing the CP-specific self-concept questionnaire and a brief verbal cognitive assessment.
   - **Session 2: Parent Questionnaire –** CP-Quality of Life Questionnaire for Children (Primary Caregiver Questionnaire); **Child Questionnaire** – Completing the CP-specific self-concept questionnaire, evaluation survey and the CP-Quality of Life Questionnaire for Children
5. I/my child understand that the purpose of this research is to gain information that will improve the quality of therapy services for children with cerebral palsy and my/my child's involvement may not be of any direct benefit to myself/him/her.

6. I/my child have been informed that the results of research involving myself/him/her will not be published so as to reveal my/his/her identity and that my/his/her privacy will be maintained at all times.
7. I/my child understand that I/my child is free to withdraw from this study at any stage without reason or penalty.

8. I give consent for (please tick as many as are appropriate):

This study
☐ My/my child's questionnaire data to be used for the current study

Potential future use of my child's information
☐ Copies of my/my child's questionnaire to be stored by the CPL research unit for future research on self-concept of children with cerebral palsy, subject to ethics approval *

Signed: ______________________________ Date: ___ / ___ / ___
(parent/guardian)

Telephone: ____________________________

Email: ________________________________

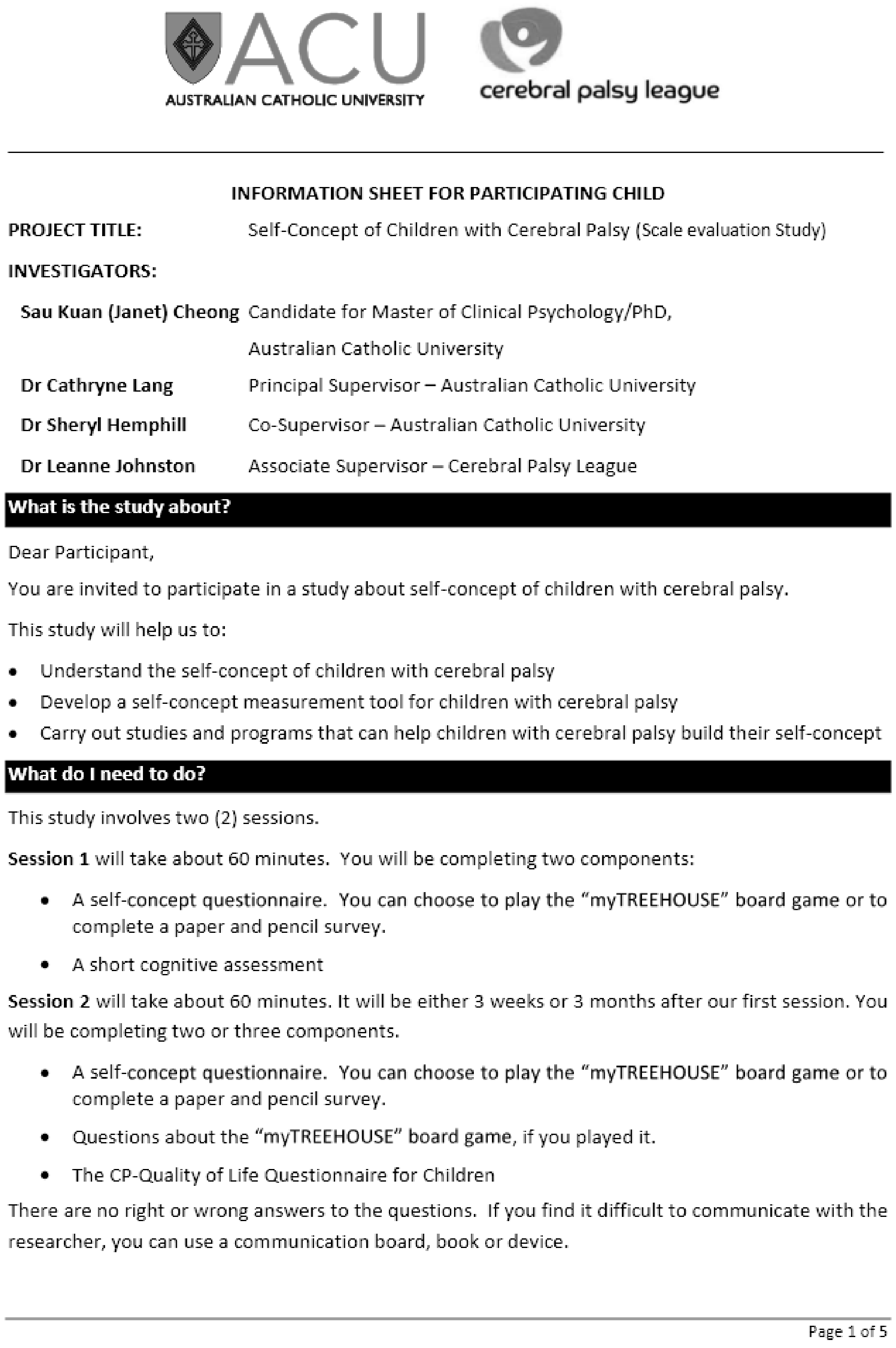
Postal address: ____

I would like to receive a copy of the study results
☐ No ☐ Yes, by email ☐ Yes, by post

Signed: ______________________________ Date: ___ / ___ / ___
(Investigator)

***Footnote** * According to CPL archiving procedures, data collected during this research will be stored securely for 25 years and then destroyed. However, for the purpose of creating a self-concept research database that can be linked to and/or expanded by future research (subject to ethics approval) an electronic database of results will be kept indefinitely. Privacy guidelines of the CPL and the National Health and Medical Research Council (NHMRC) will be adhered to when the database is created and when any data is added, stored or accessed.*

Study 3b, 4, and 5: Child Information Letter and Assent Form



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

INFORMATION SHEET FOR PARTICIPATING CHILD

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Scale evaluation Study)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Dr Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor – Cerebral Palsy League

What is the study about?

Dear Participant,

You are invited to participate in a study about self-concept of children with cerebral palsy.

This study will help us to:

- Understand the self-concept of children with cerebral palsy
- Develop a self-concept measurement tool for children with cerebral palsy
- Carry out studies and programs that can help children with cerebral palsy build their self-concept

What do I need to do?

This study involves two (2) sessions.

Session 1 will take about 60 minutes. You will be completing two components:

- A self-concept questionnaire. You can choose to play the “myTREEHOUSE” board game or to complete a paper and pencil survey.
- A short cognitive assessment

Session 2 will take about 60 minutes. It will be either 3 weeks or 3 months after our first session. You will be completing two or three components.

- A self-concept questionnaire. You can choose to play the “myTREEHOUSE” board game or to complete a paper and pencil survey.
- Questions about the “myTREEHOUSE” board game, if you played it.
- The CP-Quality of Life Questionnaire for Children

There are no right or wrong answers to the questions. If you find it difficult to communicate with the researcher, you can use a communication board, book or device.

Ethical Considerations

- You can decide whether or not you want to participate in this study. If you decide to participate, you are free to stop at any time, for any reason.
- Everything you say to the researcher is confidential and will not be told to anyone else. Your name or any personal information will not be used so other people will not know your responses.
- Participating in this study will not harm/hurt you. If you feel unhappy after the surveys, tell your parents/guardians. They can talk to the researcher or the ethics committee.

Questions –

- If you have any questions please ask your parents/guardians to help you contact me or one of the researchers:

  Sau Kuan (Janet) Cheong
  M.Psych/PhD Candidate
  Australian Catholic University
  Email: sscheo006@myacu.edu.au

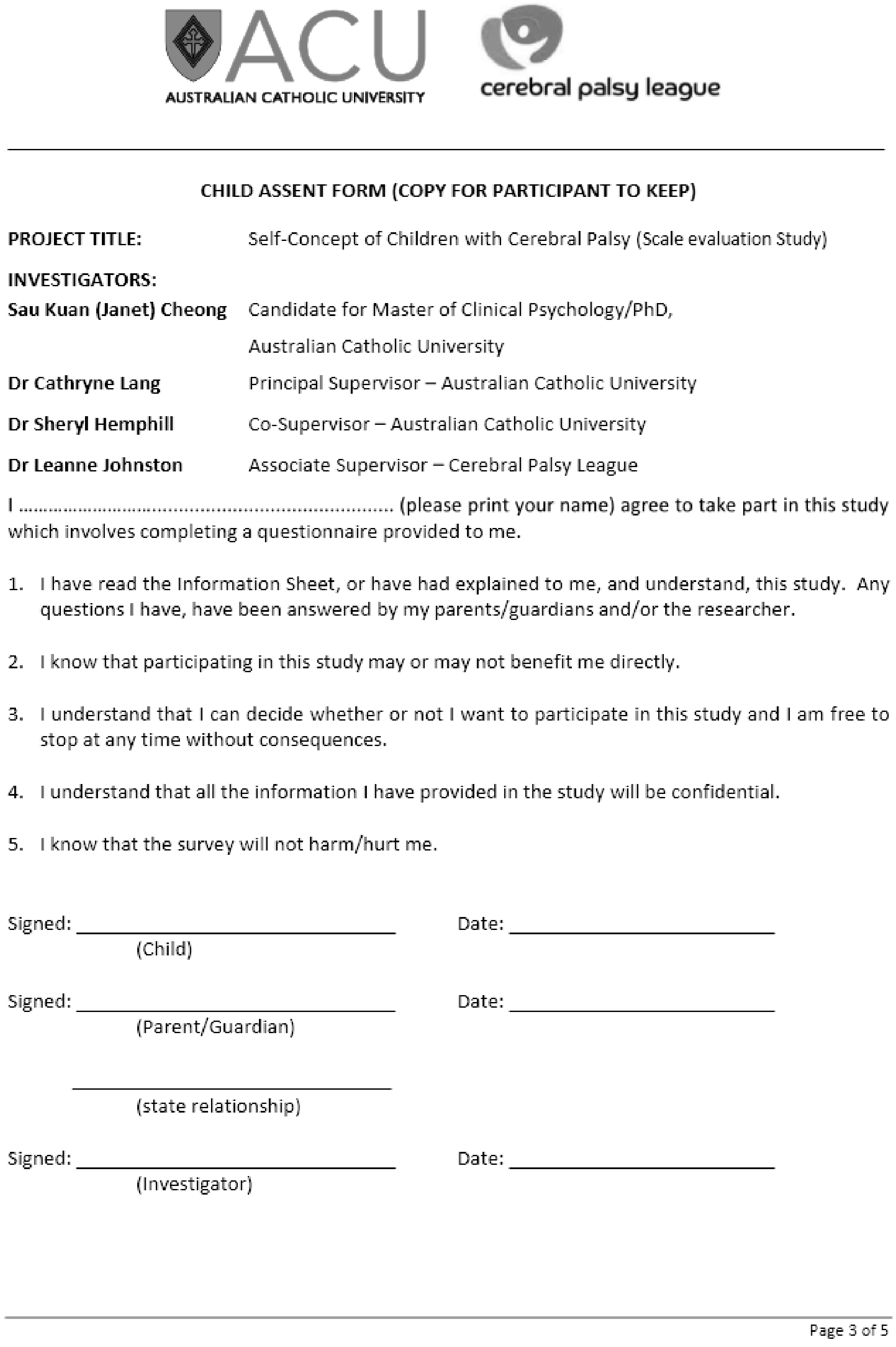
Thank you for your participation.

Student Researcher ______________ Date 08/11/2013
Sau Kuan (Janet) Cheong
M.Psych/PhD Candidate, Australian Catholic University

Principal Supervisor ______________ Date 08/11/2013
Dr Cathryne Lang
Australian Catholic University

Co-Supervisor ______________ Date 08/11/2013
Dr Sheryl Hemphill
Australian Catholic University

Associate Supervisor ______________ Date 08/11/2013
Dr Leanne Johnston
Principal Advisor Research and Ethics, Cerebral Palsy League



AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CHILD ASSENT FORM (COPY FOR PARTICIPANT TO KEEP)

PROJECT TITLE: Self-Concept of Children with Cerebral Palsy (Scale evaluation Study)

INVESTIGATORS:

Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Dr Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor – Cerebral Palsy League

I ……………………………………………………………… (please print your name) agree to take part in this study which involves completing a questionnaire provided to me.

1. I have read the Information Sheet, or have had explained to me, and understand, this study. Any questions I have, have been answered by my parents/guardians and/or the researcher.
2. I know that participating in this study may or may not benefit me directly.
3. I understand that I can decide whether or not I want to participate in this study and I am free to stop at any time without consequences.
4. I understand that all the information I have provided in the study will be confidential.
5. I know that the survey will not harm/hurt me.

Signed: ______________________________ Date: ________________________
(Child)

Signed: ______________________________ Date: ________________________
(Parent/Guardian)

____
(state relationship)

Signed: ______________________________ Date: ________________________
(Investigator)

This page is deliberately left unmarked

Please turn to the next page

AUSTRALIAN CATHOLIC UNIVERSITY

cerebral palsy league

CHILD ASSENT FORM (COPY FOR RESEARCHER)

PROJECT TITLE:	Self-Concept of Children with Cerebral Palsy (Scale evaluation Study)
INVESTIGATORS:	
Sau Kuan (Janet) Cheong	Candidate for Master of Clinical Psychology/PhD, Australian Catholic University
Dr Cathryne Lang	Principal Supervisor – Australian Catholic University
Dr Sheryl Hemphill	Co-Supervisor – Australian Catholic University
Dr Leanne Johnston	Associate Supervisor – Cerebral Palsy League

I ……………………………………………………………… (please print your name) agree to take part in this study which involves completing a questionnaire provided to me.

1. I have read the Information Sheet, or have had explained to me, and understand, this study. Any questions I have, have been answered by my parents/guardians and/or the researcher.
2. I know that participating in this study may or may not benefit me directly.
3. I understand that I can decide whether or not I want to participate in this study and I am free to stop at any time without consequences.
4. I understand that all the information I have provided in the study will be confidential.
5. I know that the survey will not harm/hurt me.

Signed: ______________________________ Date: ________________________
(Child)

Signed: ______________________________ Date: ________________________
(Parent/Guardian)

____
(state relationship)

Signed: ______________________________ Date: ________________________
(Investigator)

Study 3b, 4, and 5: Demographic Questionnaire

SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY
Scale Evaluation Study
Parent/Caregiver Questionnaire

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years.

This first page is included to ensure that we do not re-contact you after you have sent in a reply, and to help us understand the overall group of children that will be participating in the study. Details about your name and your child's name will be removed before analysis.

PART 1: INFORMATION ABOUT YOU & YOUR CHILD

1. **Your details** **Name:** ________________________________

   Age: ________ years

   Family role: Mother ☐ Father ☐

   Other ☐ ______________________

   Closest suburb: __________________________

2. **Your child's details** **Name:** ________________________________

------This section will be removed from your answers we ask from the next page-------

This page is deliberately left unmarked

Please turn to the next page

PART 2: INFORMATION ABOUT YOUR CHILD

Your child’s condition

a. **Date of birth:** ___ / ___ / ___

b. **Age:** ______ years ____ months

c. **Gender:** ☐ male ☐ female

d. **Diagnosis:** ☐ Cerebral Palsy→ type: ___________________

☐ Other→ type: __________________________

e. **Which parts of their body are involved?** *(tick all that apply)*

☐ Left arm ☐ Right arm

☐ Left leg ☐ Right leg

☐ Trunk / Tummy ☐ Face / Neck (difficulty swallowing or talking)

f. **What type of movement problems do they have?** *(tick any that apply)*

☐ Stiff muscles (high muscle tone / spasticity)

☐ Floppy muscles (low muscle tone)

☐ Difficulty coordinating movement when reaching / moving (Ataxia)

☐ Unwanted writhing / wiggling movements (Athetosis)

☐ Muscle spasms or arching (Dystonia)

g. **How do they move around?**	**N/A**	**Home**	**School**	**Long distance**
Crawling	☐	☐	☐	☐
Walking- with no assistance	☐	☐	☐	☐
- someone helps	☐	☐	☐	☐
- with crutches or sticks	☐	☐	☐	☐
Walker - Kaye walker or similar	☐	☐	☐	☐
- Hart walker or similar	☐	☐	☐	☐
Wheelchair - can push self	☐	☐	☐	☐
- powerdrive chair	☐	☐	☐	☐
- someone else pushes	☐	☐	☐	☐

h. **How easy is it for them to use their <u>hands</u>?** *(tick <u>one</u>)*

☐ 1 – They handle objects easily and successfully, with no restrictions

☐ 2 – They handle most objects, but can be slow or not as smooth

☐ 3 – They handle a range of objects but need help to prepare/modify activities

☐ 4 – They handle some objects with assistance or adapted equipment

☐ 5 – They cannot handle objects and need assistance for manual tasks

i. **What is their <u>communication</u> like?** *(tick <u>one</u>)*

☐ 1 – They communicate independently and easily with most people in most settings

☐ 2 – They communicate independently and easily with familiar people, but have some difficulty with unfamiliar people, topics or settings

☐ 3 – They communicate independently with familiar people, topics and settings, but need help to communicate with unfamiliar people, topics and settings.

☐ 4 – They can communicate daily/routine needs and wants with familiar people, but need help in most situations, especially with unfamiliar people and environments.

☐ 5 – They use movement or behaviour to communicate that familiar people can understand

j. Does your child have intellectual impairment?

☐ No

☐ Yes

If Yes, please indicate the level of impairment ☐ Mild

☐ Moderate

☐ Severe

k. What type of school does your child attend?

☐ Mainstream school **without** any learning support

☐ Mainstream school **with** learning support

☐ Special school

☐ Other: ___________________________________

l. **Do they have any other conditions?** *(tick <u>any that apply</u>)*

☐ Hearing problem

☐ Epilepsy

☐ Vision problem

☐ Eating or swallowing problems

☐ Problem feeling touch

☐ Problems with thinking, learning or memory

☐ No

☐ Other: ___________________________________

Thank you for your participation.

Study 3b, 4, and 5: ***myTREEHOUSE Self-Concept Assessment – Questionnaire Version***

SELF-CONCEPT OF CHILDREN WITH CEREBRAL PALSY
Scale Evaluation Study
Child Questionnaire

This survey will provide us with information to understand the self-concept of children with cerebral palsy aged between 8 to 12 years.

This first page is included to ensure that we do not re-contact you after your participation, and to help us understand the overall group of children that will be participating in the study. Details about your name will be removed before analysis.

PART 1: INFORMATION ABOUT YOU

1. **Your detail** **Name: ____**

   Date of birth: ___/___/_____

   Age: _______ years ______ months

   Gender: ☐ Male ☐ Female

2. **Your diagnosis ☐ Cerebral Palsy Type:_________________________**

   ☐ Other condition Type:_______________________

-----------This section will be removed from your answers on the next page--------------

This page is deliberately left unmarked

Please turn to the next page

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

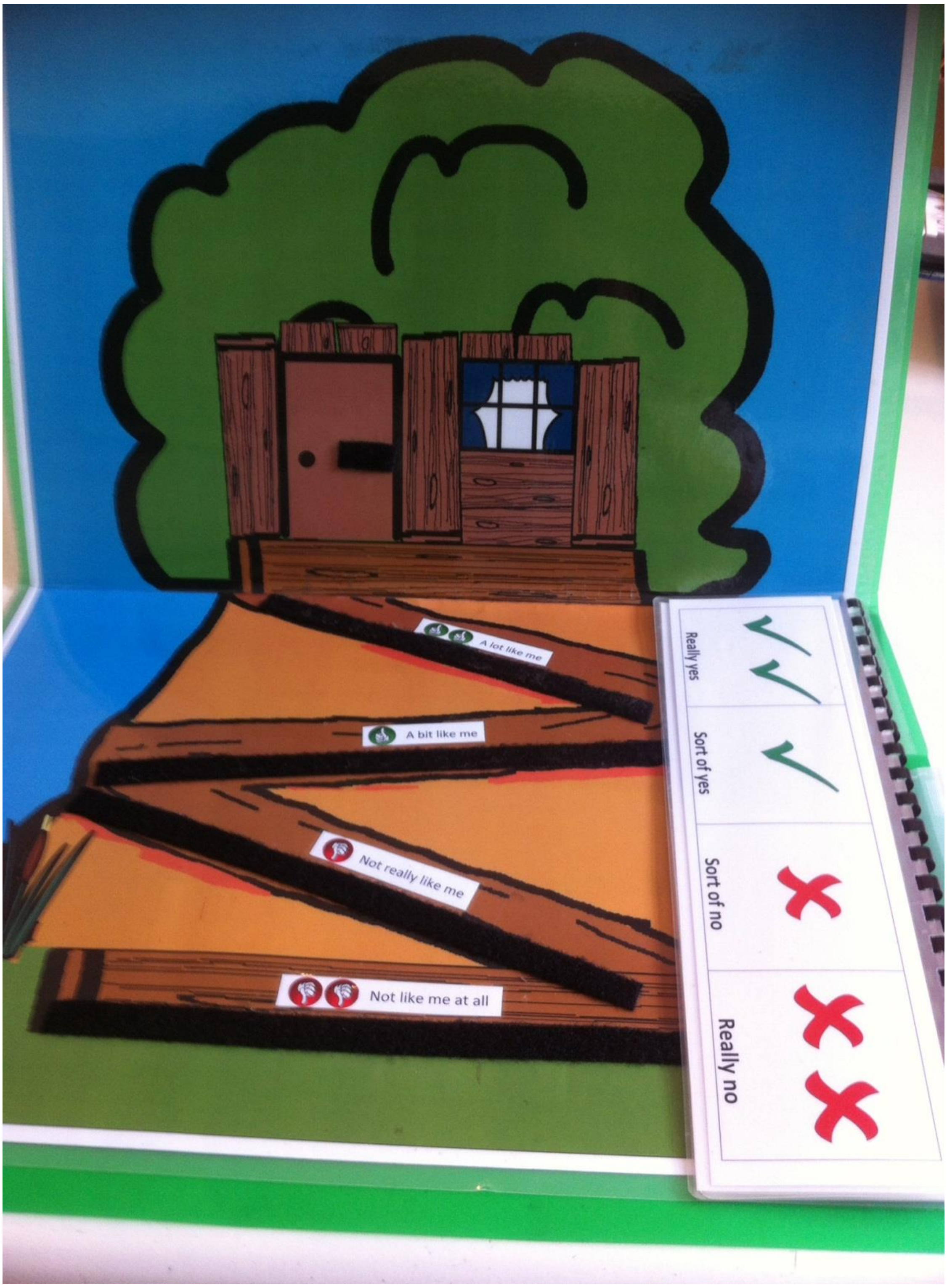
This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

Study 3b, 4, and 5: *myTREEHOUSE Self-Concept Assessment – Game Version*

board game



Study 3b, 4, and 5: *myTREEHOUSE Self-Concept Assessment – Game Version* Scoring Sheet

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

This section has been removed to protect the intellectual property of the instrument created by the author. The instrument can be obtained by directly contacting the author.

Study 3b, 4, and 5: *myTREEHOUSE Self-Concept Assessment – Game Version* Evaluation Sheet

BOARD		PICTURE CARDS	
Overall look	Too boring / Just right / Too busy	Was it helpful?	Not helpful / Sort of / Very helpful
Colour	Not enough / Just right / Too much Not helpful / Sort of / Very helpful	Pictures	Too small / Just right / Too big Not helpful / Sort of / Very helpful
		Words	Too small / Just right / Too big Not helpful / Sort of / Very helpful
Would you change anything on the board? What?		Would you change anything on the cards? What?	
RAMP		FLIPCHART	☐ I did not use the flipchart
Was it helpful?	Not helpful / Sort of / Very helpful	Was it helpful?	Not helpful / Sort of / Very helpful
Thumb picture	Too small / Just right / Too big Not helpful / Sort of / Very helpful	Picture	Too small / Just right / Too big Not helpful / Sort of / Very helpful
Words	Too small / Just right / Too big Not helpful / Sort of / Very helpful	Words	Too small / Just right / Too big Not helpful / Sort of / Very helpful
Would you change anything on the ramp? What?		Would you change anything on the flipchart? What?	

Did you enjoy the myTREEHOUSE? ☹ 😐 ☺
What did you like the most?
What did you least like?

Appendix G Supplementary Statistical Analyses for Study 4

Appendix G includes the results of the statistical analyses for Study 4 using non-parametric tests.

Self-concept in relation to age

Age showed no relationship with *Personal Performance Perspective* domain scores (r_s=-0.16 to 0.13; all p>0.05) or the *Personal Concern Score* (r_s=0.27; p>0.05) using the Spearman's rho analyses (Table G1).

Table G1 Spearman's rho analyses results for relationship between age and self-concept domains as rated from *the Personal Performance Perspective* and *Personal Concern Score*

Factors	*Personal Performance Perspective*								*Personal Concern Score*
	Social Skills	Physical Abilities	Physical Appearance	Ability to Participate	Learning Skills	Personal Agency	Emotional Regulation	General Self	
Age									
r_s	-.07	-.11	-.12	.02	-.04	.13	-.16	-.09	.27
p	.64	.47	.42	.89	.77	.36	.27	.53	.06

Self-concept in relation to gender

Mann-Whitney U tests showed no significant difference between boys (*Mdn* = 9.0 to 14.0) and girls (*Mdn* = 9.0 to 15.0) with CP across *Personal Performance Perspective* domain scores (*U*=232.50 to 303.50; all *p*>0.05; Table G2). The Mann-Whitney U test also revealed non-significant findings for *Personal Concern Score* (Boys *Mdn* = 4.0; Girls *Mdn* = 9.0; *U*=264.50; *p*=0.430).

Table G2 Mann-Whitney U test results for gender comparison of self-concept domains as rated from the *Personal Performance Perspective* and *Personal Concern Score*

Factors	Mean Rank		Mann-Whitney U	Z score	*p* value
	Male (*N*=29)	Female (*N*=21)			
Personal Performance Domains					
Social Skills	25.47	25.55	303.50	-.020	.984
Physical Abilities	27.09	23.31	258.50	-.922	.357
Physical Appearance	26.53	24.07	274.50	-.599	.549
Ability to Participate	25.88	24.98	293.50	-.219	.827
Learning Skills	25.05	26.12	291.50	-.261	.794
Personal Agency	27.90	22.19	235.00	-1.408	.159
Emotional Regulation	27.98	22.07	232.50	-1.435	.151
General Self	25.86	25.00	294.00	-.211	.833
Personal Concern Score	24.12	27.40	264.50	-.789	.430

Self-concept in relation to motor function

None of the *Personal Performance Perspective* domain scores, nor *Personal Concern Score* showed significant difference between gross motor (GMFCS-E&R) or fine motor (MACS) function (Table G3).

Self-concept in relation to communication and cognitive function

No relationships were found between self-concept and communication function (FCCS; Table G3). However, cognitive function (WISC-IV VCI) was found to be associated with self-concept in the *Social Skills* (*H*(2)=7.52, *p*=0.02) and *Learning Skills* (*H*(2)=8.97, *p*=0.01) domains when rated from the *Personal Performance Perspective*. A follow up testing using Mann-Whitney U tests confirmed that children with Below Average cognitive functioning (*Mdn* = 15.5) reported higher *Social Skills* scores when compared to children with Average cognitive functioning (*Mdn* = 13.0; *U*=44.500; *p*=0.007). Conversely, children with Above Average cognitive functioning (*Mdn* = 10.0) reported higher *Learning Skills* scores when compared to children with Average cognitive functioning (*Mdn* = 9.0; *U*=94.000; *p*=0.004)

Table G3 Kruskal-Wallis test results for self-concept domains as rated from the *Personal Performance Perspective* and *Personal Concern Score* compared across functional classifications.

Factors	Mean Rank			Chi-square	*p* value
GMFCS-E&R	I (*n*=36)	II (*n*=8)	III (*n*=5) IV (n=1)[a]		
Personal Performance Domains					
Social Skills	24.71	25.88	29.75	0.637	.727
Physical Abilities	27.19	24.69	16.42	2.953	.228
Physical Appearance	26.39	24.56	21.42	0.658	.720
Ability to Participate	25.21	27.13	25.08	0.122	.941
Learning Skills	24.39	26.06	31.42	1.259	.533
Personal Agency	23.56	32.38	28.00	2.757	.252
Emotional Regulation	25.10	28.69	23.67	0.519	.771
General Self	26.00	24.31	24.08	0.159	.923
Concern Score	25.57	23.94	27.17	0.172	.918
MACS	I (*n*=15)	II (*n*=25)	III (*n*=8) IV (*n*=2)[b]		
Personal Performance Domains					
Social Skills	25.40	25.42	25.85	0.007	.996
Physical Abilities	26.6	26.66	20.95	1.266	.531
Physical Appearance	25.23	24.94	27.30	0.201	.905
Ability to Participate	28.07	22.90	28.15	1.633	.442
Learning Skills	24.27	26.16	25.70	0.167	.920
Personal Agency	23.60	25.00	29.60	1.142	.565
Emotional Regulation	28.03	244.08	25.25	0.713	.700
General Self	21.00	27.08	28.30	2.193	.334
Concern Score	25.07	25.26	26.75	0.094	.954

Factors	Mean Rank			Chi-square	*p* value
FCCS	I (*n*=33)	II (*n*=6)	III (*n*=11)		
Personal Performance Domains					
Social Skills	26.56	17.17	26.86	2.288	.319
Physical Abilities	27.83	24.33	19.14	3.098	.212
Physical Appearance	26.98	23.83	21.95	1.105	.575
Ability to Participate	25.77	22.33	26.41	0.346	.841
Learning Skills	28.06	17.75	22.05	3.468	.177
Personal Agency	26.18	26.50	22.91	0.476	.788
Emotional Regulation	26.30	24.00	23.91	0.303	.859
General Self	25.23	25.00	26.59	0.084	.959
Concern Score	25.20	26.50	25.86	0.050	.975
WISC-IV VCI	Below Average[c] (*n*=10)	Average[d] (*n*=22)	Above Average[e] (*n*=18)		
Personal Performance Domains					
Social Skills	35.85	20.80	25.50	7.516	.023*
Physical Abilities	28.95	24.64	24.64	0.728	.695
Physical Appearance	31.10	23.80	24.47	1.925	.382
Ability to Participate	27.85	24.39	25.56	0.399	.819
Learning Skills	26.80	19.09	32.61	8.968	.011**
Personal Agency	24.55	25.52	26.00	0.068	.967
Emotional Regulation	27.30	21.95	28.83	2.462	.292
General Self	27.00	24.11	26.36	0.385	.825
Concern Score	23.05	29.36	22.14	2.802	.246

Note: GMFCS-E&R: Gross Motor Function Classification System – Extended and Revised; MACS: Manual Ability Classification System; FCCS: Functional Communication Classification System; WISC-IV VCI: Wechsler Intelligence Scale for Children – Fourth Edition, Verbal Comprehension Index; [a]GMFCS-E&R Levels III and IV combined; [b]MACS Levels III and IV combined; [c]WISC-IV VCI ≤89; [d]WISC-IV VCI=90-109; [e]WISC-IV VCI ≥110; *Below Average > Average; Mann-Whitney *U*=44.500; *p*=0.007; **Above Average > Average; Mann-Whitney *U*=94.000*;* *p*=0.004