Development and initial validation of an assessment of visual ability for children with cerebral palsy

Deramore Denver, B.

DEVELOPMENT AND INITIAL VALIDATION OF AN ASSESSMENT OF VISUAL ABILITY FOR CHILDREN WITH CEREBRAL PALSY

Belinda Deramore Denver

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ABSTRACT

BACKGROUND Children with cerebral palsy have a primary motor disorder that may be accompanied by disturbances of sensation or perception that impact their ability to use vision. Many other factors may also influence how a child ‘uses their vision’, yet our understanding of how to optimise outcomes rarely includes a focus on visual abilities. For some children with cerebral palsy, visual ability may be a strength. To maximise a child’s ability to use vision we first need a method to quantify visual ability. This thesis describes the conceptualisation, development, and initial validation of a scale to describe ‘how vision is used’ by children with cerebral palsy.

METHODS Using a multi-phase mixed methods instrument project design, the first step was a systematic review to identify and appraise existing measures. This was followed by a study to map items from existing measures to the International Classification of Functioning, Disability and Health (ICF) framework using standard linking methodology. After confirming the need for a new measurement tool, the second phase of this research involved an international online survey of key stakeholders; the construction of items and a rating scale; and pre-testing with cognitive interviews. The third phase explored the psychometric properties of the tool in initial field testing.

RESULTS The systematic review confirmed a gap in assessment practices for describing ‘how vision is used’. The mapping exercise led to the conceptualisation of visual ability as a measurable construct at the Activity level of the ICF, and observable visual behaviours were identified to describe how vision is used. Findings from the stakeholder survey contributed to evidence of the relevance and comprehensiveness of content, whilst also defining what is not the focus of the measure: child factors (e.g. eye functions), environmental factors (e.g. type of visual information), or performance and participation in vision-related activities (e.g. play). The primary outcome of this research, the Measure of Early Vision Use (MEVU), is a 14-item parent-report questionnaire describing a child’s ability to use vision. Each item is an observable visual behaviour, scored on a 4-point ordinal scale. Psychometric data from field testing (n=100) supports MEVU as a unidimensional scale with good internal consistency, sufficient construct validity, and feasibility as a parent-completed online assessment.

CONCLUSION MEVU is a new instrument to describe the use of basic visual abilities that has potential to support early intervention planning for children with (or at high risk of) cerebral palsy.

DECLARATION OF ORIGINALITY

This is to certify that the content of this thesis is my own work.

This thesis contains no material that has been extracted in whole or in part from a thesis that I have 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 acknowledgment in the main text of this thesis.

All research procedures reported in this thesis received the approval of the relevant Human Research Ethics Committees.

[redacted]

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PUBLICATIONS DURING CANDIDATURE

1.1.1 Peer-reviewed publications included in this thesis

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2021a). Measure of Early Vision Use: Development of a new assessment tool for children with cerebral palsy. *Disability and Rehabilitation*, 1-11. https://doi.org/10.1080/09638288.2021.1890241

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2021b). Measure of early vision use: Initial validation with parents of children with cerebral palsy. *Disability and Rehabilitation*, 1-9. https://doi.org/10.1080/09638288.2021.

Deramore Denver, B., Adolfsson, M., Froude, E., Rosenbaum, P. & Imms, C. (2017). Methods for conceptualising 'visual ability' as a measurable construct in children with cerebral palsy. *BMC Medical Research Methodology, 17,* 46. https://doi.org/10.1186/s12874-017-0316-6

Deramore Denver, B., Froude, E., Rosenbaum, P., Wilkes-Gillan, S., & Imms, C. (2016). Measurement of visual ability in children with cerebral palsy: A systematic review. *Developmental Medicine and Child Neurology, 58,*1016-1029. https://doi.org/10.1111/dmcn.14090

Note. A statement of contributions to these published works of joint authorship is provided in Appendix A.

1.1.2 Invited commentary

Deramore Denver, B. (2019). The validity of early intervention for children with visual impairment. *Developmental Medicine & Child Neurology*, *61*(6), 627-627. https://doi.org/10.1111/dmcn.14090

Note. A copy of this commentary is provided in Appendix B.

1.1.3 Published conference abstracts

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2020). Measure of Early Vision Use (MEVU): A new tool for assessing how vision is used by children with cerebral palsy. *Developmental Medicine & Child Neurology, 62(s2),* 32. https://doi.org/10.1111/dmcn.14469

Goman, H., **Deramore Denver, B** & Froude, E. (2020). Typically developing children aged 0-24 months performance on the Measure of Early Vision Use. *Developmental Medicine & Child Neurology, 62(s2),* 32. https://doi.org/10.1111/dmcn.14469

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2019). Measure of Early Vision Use (MEVU): A new scale to assess visual abilities in children with cerebral palsy. *Australian Occupational Therapy Journal, 66 (s1),* 53. https://doi.org/10.1111/1440-1630.12585

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2018). Three perspectives for understanding how children with cerebral palsy use vision in daily activities. *Developmental Medicine and Child Neurology, 60 (Suppl. 2),* 13. https://doi.org/10.1111/dmcn.13788. (Paper presented at the European Academy of Childhood Disability Conference, Tbilisi, Georgia). 28-31 May

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2018). Visual ability: A relevant construct to measure in children with cerebral palsy. *Developmental Medicine and Child Neurology, 60 (Suppl. 1),* 53-54. https://doi.org/10.1111/dmcn.13069. (Paper presented at the Australasian Academy of Cerebral Palsy & Developmental Medicine Conference, Auckland, New Zealand). 21-24 March

Deramore Denver, B., Froude, E., Rosenbaum, P., Wilkes-Gillan, S., & Imms, C. (2016). A systematic review of functional visual ability measurement in children with cerebral palsy. *Developmental Medicine and Child Neurology, 58,* 9-10. https://doi.org/10.1111/dmcn.13665. (Paper presented at the Australasian Academy of Cerebral Palsy & Developmental Medicine Conference, Adelaide, Australia). 30/3-2/4

Deramore Denver, B., Adolfsson, M., Froude, E., Rosenbaum, P. & Imms, C. (2016). Linking the content of 'functional' visual ability measures in cerebral palsy to the International Classification of Functioning, Disability and Health. *Developmental Medicine and Child Neurology, 58,* 10-11. https://doi.org/10.1111/dmcn.13069. (Paper presented at the Australasian Academy of Cerebral Palsy & Developmental Medicine Conference, Adelaide, Australia).

Deramore Denver, B., Froude, E., Rosenbaum, P. & Imms, C. (2015). Measuring functional visual ability in children with cerebral palsy: A systematic review. Australian Occupational Therapy Journal, 62 (Suppl. 1), 141. https://doi.org/10.1111/1440-1630.12212 (Occupational Therapy Australia, 26th National Conference and Exhibition).

1.1.4 Unpublished conference abstracts

Richard, C. & **Deramore Denver, B.** (2021, August 13-14). *Preventative care for sensory co-morbidities: Hearing and vision.* Early Cerebral Palsy E-Health Summit, New York, NY, USA.

Deramore Denver, B., Froude, E., Rosenbaum, P. & Imms, C. (2020, January 12-15). *Introducing the Measure of Early Vision Use (MEVU) for children with cerebral palsy* [Paper presentation]. South Pacific Educators in Vision Impairment Conference, Adelaide, SA, Australia.

Deramore Denver, B., Froude, E., Rosenbaum, P. & Imms, C. (2019, November 7-8). *A new and complimentary approach to the measurement of vision for children with cerebral palsy.* [Paper presentation]. AAPOS/RANZCO/APSPOS Joint Meeting: An international perspective of Pediatric Ophthalmology and Strabismus, Sydney, NSW, Australia.

Deramore Denver, B. (2019, September 21). *Visual 'ability' in children with cerebral palsy* [Invited presentation]. Community Forum, American Academy for Cerebral Palsy and Developmental Medicine, Anaheim, California, USA.

Deramore Denver, B. (2019, September 19). CVI - Approaches within Australia. In C. Bauer, L. Lawrence, K. Harpster, B. Deramore Denver, E. Ortibus (Panel), *Differences in practice patterns around the world for cerebral visual impairment: finding a common ground* [Symposium]. Combined AACPDM 73rd Annual and IAACD 2nd Triannual Meeting, Anaheim, California, USA.

Deramore Denver, B. (2019, September 21). Visual ability. In K. Harpster, B. Deramore Denver, C. Bauer, F. Tinelli, M. Shusterman, L. Hillier. (Panel). *Vision impairment and visual ability in children with cerebral palsy: a multidisciplinary perspective* [Symposium]. Combined AACPDM 73rd Annual and IAACD 2nd Triannual Meeting, Anaheim, California, USA.

Deramore Denver, B., Froude, E., Rosenbaum, P. & Imms, C. (2018, November 16-17). *How do children with cerebral palsy use vision in everyday activities?* [Paper presentation]. National Paediatrics Symposium – Occupational Therapy Australia, Sydney, NSW, Australia.

Deramore Denver, B. (2016, June 1-4). A systematic review of visual ability measurement in children with cerebral palsy. In G. Baranello, D. Ricci, B. Deramore Denver & L. Haataja (Panel), *The Visual Function Classification System: a new classification system for visual function in children with Cerebral Palsy* [Symposium]. 28th European Academy of Childhood Disability, 5th International Cerebral Palsy Conference, 1st International Alliance of Academies of Childhood Disability, Stockholm, Sweden.

Deramore Denver, B., Froude, E. & Imms, C. (2015). *Evaluating functional visual ability in children with cerebral palsy – current evidence.* [Paper presentation]. South Pacific Educators in Vision Impairment Conference, Melbourne, VIC, Australia.

FORMAT AND STYLE USED IN THESIS

This PhD thesis presents knowledge in nine chapters including content from four published manuscripts. For consistency, all chapters, including the accepted versions of published manuscripts, use the same style and numbering system. Where permission has been granted, the published version of a manuscript is included in the appendices.

Headings, figures and tables use a numbered system, and the appendices are listed alpha-numerically. References for all chapters, including the embedded manuscripts, are presented together in the References section. All referencing, figures and tables utilise the 7th edition American Psychological Association referencing style. Acronyms are provided in full in their first occurrence within each chapter. 'Cerebral palsy' is not abbreviated in this thesis.

The appendices contain figures, tables and other documents that support, but are not essential to dialogue within chapters.

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LIST OF ABBREVIATIONS

AHA	Assisting Hand Assessment
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CTT	Classical Test Theory
CVI	Cortical/cerebral visual impairment
EpCS	Eye-pointing Classification System
FVA	Functional Visual Assessment
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
ICF	International Classification of Functioning, Disability & Health
ICF-CY	International Classification of Functioning, Disability & Health for Children and Youth
IRT	Item Response Theory
MACS	Manual Ability Classification System
MEVU	Measure of Early Vision Use
VFCS	Visual Function Classification System

CHAPTER 1: Introduction

> "The best research starts with two words: 'I wonder'. A sense of curiosity is all that is needed to begin the research process. Observations about a problem become questions, and these questions lead to…research"
> (Houser 2015, as cited in Liamputtong & Schmied, 2017, p. 30).

I wonder whether we are doing enough to maximise and utilise the visual abilities of children with cerebral palsy. I wonder, because I worry that outcomes for children with cerebral palsy and their families may be limited by current approaches to visual assessment and intervention. Can we improve outcomes for children, and their families, by focusing on 'how vision is used' in everyday activities? These thoughts underpin the research reported in this thesis.

The aim of this research was to develop an assessment of visual ability for children with cerebral palsy. This thesis brings together a series of published manuscripts on the creation of a measurement tool for this purpose – the Measure of Early Vision Use (MEVU). MEVU is the primary outcome of this PhD research. In this introductory chapter the personal and theoretical contexts behind this research are introduced. This is followed by an overview of the problem, a statement of the research questions to be answered, and an outline of the chapters, papers and research phases that make up the project.

1.1 THE CONTEXT OF CURIOSITY

Where does my sense of curiosity come from to undertake this research project? It did not come from a drive to embark on a journey to develop a new measurement tool. As DeVellis (2017) notes, the need to quantify a phenomenon must sometimes be addressed before the primary research objective can be tackled. This research project, and the ideas behind it, have developed over many years and will not end with this PhD. The long-term aim is to maximise performance and participation in vision-related activities for children with cerebral palsy.

My sense of curiosity for pursuing questions with a research mind was first ignited within my undergraduate Bachelor of Psychology. This was followed by a second degree, a Bachelor of Applied Science (Occupational Therapy), but it was not until I had several years of clinical experience that my interest and need to answer clinical questions emerged. As an occupational therapist, my curiosity is informed by theoretical models that have focused my attention on performance and participation as an outcome of the dynamic interaction among person characteristics, occupations (activities), and the environmental contexts in which they are situated (Law et al., 1996). Despite the acceptance that an occupational therapist should consider the role vision – a person characteristic – plays in the occupational performance of an individual, over the years I have developed a sense that all professionals working with children with cerebral palsy and their families could be doing more in regard to ‘how vision is used’.

Early in my occupational therapy career I worked within a specialty state-wide early intervention service for families in which there was a child with vision impairment. Many of these children also had additional disabilities or diagnoses such as cerebral palsy. During this time my clinical skills and experience grew, and I developed an interest in the assessment of functional vision skills. I had the opportunity to undertake a Graduate Certificate in Special Education (Vision Impairment), and within these studies I explored existing evidence for interventions relevant to young children with vision impairment. Despite my growing skills and experience, I found myself constrained by the limited research evidence available to guide responses to family questions about assessment, intervention and future outcomes.

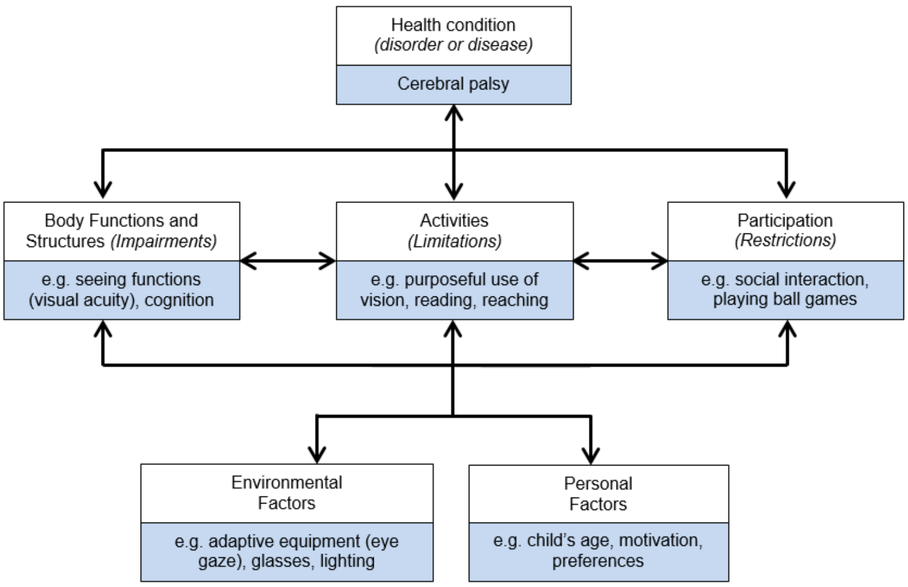
Questions about vision and its relationship to other abilities, performance and participation outcomes continued to develop in my mind after transitioning to a new professional role within a tertiary level Cerebral Palsy Service. This found me working with the population at the centre of this thesis and my insight evolved that visual ability may be a strength, as well as a limitation, for children with cerebral palsy. My role in the field of cerebral palsy practice also exposed me to an evidence-based culture and to multidisciplinary use of the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF) for describing the health and disability of children and youth (World Health Organization, 2001, 2007).

The ICF describes the influence of health conditions (e.g., cerebral palsy) and contextual factors (both personal and environmental) on functioning in the domains of body functions and structures, activities and participation. In this classification, ‘functioning’ is a term encompassing all body functions, activities, and participation, and ‘disability’ is a term that encompasses impairments, activity limitations, and participation restrictions. The ability of an individual to function is seen as a dynamic interaction between elements of these domains and is powerfully influenced by contextual factors, including environmental barriers and facilitators to functioning, and personal factors. Another concept from the ICF is the ability to differentiate between qualifiers of capacity (‘what the child does in a standardised environment’) and performance (‘what the child does in his/her actual environment’) when describing activities and participation (World Health Organization, 2001, 2007).

Figure 1.1, the ICF framework with its bi-directional arrows, illustrates (in blue) some important areas of functioning and disability relevant to an individual with the health condition (diagnosis) of cerebral palsy, including activity level use of vision. The ICF framework provided language and a definition to the problem I was observing in clinical practice.

Figure 1.1

ICF framework: domains, interactions and examples of vision-related outcomes for a child with cerebral palsy



1.2 A PROBLEM

The problem at the centre of this thesis will be summarised by sharing a scenario from clinical practice.

> *A young child receiving early intervention services has a goal to improve play with toys. This child has a diagnosis of cerebral palsy and has been described as having probable cerebral vision impairment. There is no report of anything being wrong with her eyes, but she rarely looks at toys and lacks visual curiosity. Her mother and therapist wonder whether she will learn to look at toys, and they wonder whether improving how she uses vision should be a focus in their therapy, which is currently focused on hand use.*

Within this brief scenario, four elements of the problem at the core of this research are illustrated:

1. A clinical report of visual function (e.g., nothing wrong with eyes) and cerebral vision impairment does not explain visual performance in everyday activities;
2. 'How vision is used' (e.g., rarely looks at toys and lacks visual curiosity) can be described qualitatively;
3. Parents and clinicians have unanswered questions about visual prognosis; and
4. Parents and clinicians want knowledge to inform goal setting and intervention planning.

These elements include both measurement and intervention problems and can be summarised by the following clinical questions: "How does this child use her vision?", "Is it important to consider her vision?", "Will use of vision improve?" and "What can be done to improve vision use?".

Quantifying the phenomenon of 'how vision is used' is central to exploring each element of this problem; the rationale for focusing on measurement in this research (rather than intervention) will be further outlined in Chapter 2. Each of the four problem elements will then be reflected upon in Chapter 9 when the integration of new knowledge into clinical and research practice is discussed. The significance of developing a new measurement tool to address the problem includes:

- A language and a way to describe how any child uses their vision that is relevant to everyone involved with a child;

- Promotion and understanding of the role of vision use or impact that vision impairment (ocular or cerebral) can have on other areas of development, learning and participation; and
- A performance profile and score that may help with goal setting, planning and monitoring therapy.

In the longer term, a valid and reliable assessment tool may also lead to:

- Evidence-based interventions targeted at visual abilities;
- Levels of visual ability guiding the selection of level-specific intervention and management options; and
- Establishment of validity for predictive purposes that assists parents, clinicians, services and policy makers with planning for future intervention and care needs.

1.3 QUESTIONS

The over-arching questions that are the focus of this research project are: How can we describe the visual abilities of children with cerebral palsy? and, can this be quantified in a psychometrically sound manner? After first exploring, in **Chapter 2 – Background and context for research program**, that visual ability is an important construct to measure in children with cerebral palsy, the specific research questions addressed in this thesis are:

i. What is visual ability?
ii. Is there an existing instrument that can be used/modified to measure visual ability in children with cerebral palsy?

Then, in the absence of an existing tool:

iii. How can visual ability be assessed? For which purpose, and which target population?

Subsequently, after developing a new assessment tool:

iv. For which measurement properties is there evidence?

These questions will be addressed within the research studies outlined in Chapters 3 to 8. Through the process of answering these questions, further questions have arisen, and these will be included in discussions of future research in **Chapter 9 – Grand Discussion**.

1.4 RESEARCH

The overall purpose of this PhD program of research is to develop a psychometrically sound and clinically useful measurement tool that quantifies visual ability in children with cerebral palsy. The approach to answering the research questions is a mixed methods multi-phase instrument development design, and this is outlined in more detail in Chapter 4 – Methodology for an instrument design project. In response to the key research questions outlined above, the objectives of this PhD research are:

i. To identify and evaluate existing measurement tools that assess visual ability in children with cerebral palsy;
ii. To define visual ability as a measurable construct;
iii. To develop a new tool to measure visual ability in children with cerebral palsy; and
iv. To evaluate the measurement properties of this new measurement tool.

This PhD answers these research questions and starts here in **Chapter 1 – Introduction** with an overview of the problem and questions that underpin the research process. The thesis includes four published papers that used both quantitative and qualitative methods to address the research objectives. An outline of the chapters and papers, and how they fit together, is portrayed in Figure 1.2.

The next two chapters further introduce the measurement problem of quantifying 'how vision is used' in children with cerebral palsy. **Chapter 2 – Background and context for research program** provides rationale for this program of research by describing the population of children with cerebral palsy, vision and the relationship between vision and functional outcomes. This chapter expands on the definition of visual ability provided in the introduction by reviewing other definitions and approaches to functional vision assessment and confirms the ICF as the framework to be used in this research program. A review of current assessment and intervention practices then leads into the rationale for starting with a review of the available measurement tools, rather than intervention options.

Chapter 3 – Systematic review of measurement tools then presents the results from Study 1, a systematic review of existing tools to measure vision at the activity level of the ICF for children with cerebral palsy. The study methods follow established protocols for conducting a systematic review. Gaps in the measurement of visual ability for children with cerebral palsy are reported, and the need for a clear conceptual definition and framework for measuring visual ability is identified. This paper has been published in *Developmental Medicine & Child Neurology*.

The research undertaken to find a solution to the problem of visual ability measurement is the subject of the remaining chapters starting with **Chapter 4 – Methodology for an instrument design project**. This chapter provides detail and rationale for the multi-phase mixed methods research design for the development of a new measurement tool. This is then followed by chapters outlining the three research phases of conceptualisation, development and initial psychometric evaluation.

Chapter 5 – Conceptualisation of visual ability defines visual ability as a measurable construct, confirms the need for the development of a new measurement tool utilising data from Study 1, and identifies observable visual behaviours that may be developed into items to assess 'how vision is used'. This conceptualisation phase has been published in *BMC Medical Research Methodology* and is included in this chapter as Study 2.

Chapter 6 – Development of Measure of Early Vision Use describes the development phase and contains the manuscript published in *Disability & Rehabilitation* – Study 3. This chapter includes information about item/scale development and refinement, as well as the purpose, target population and format of the tool. The three steps in the development phase included an online survey of key stakeholders, construction of the measure, and cognitive interviews with parents.

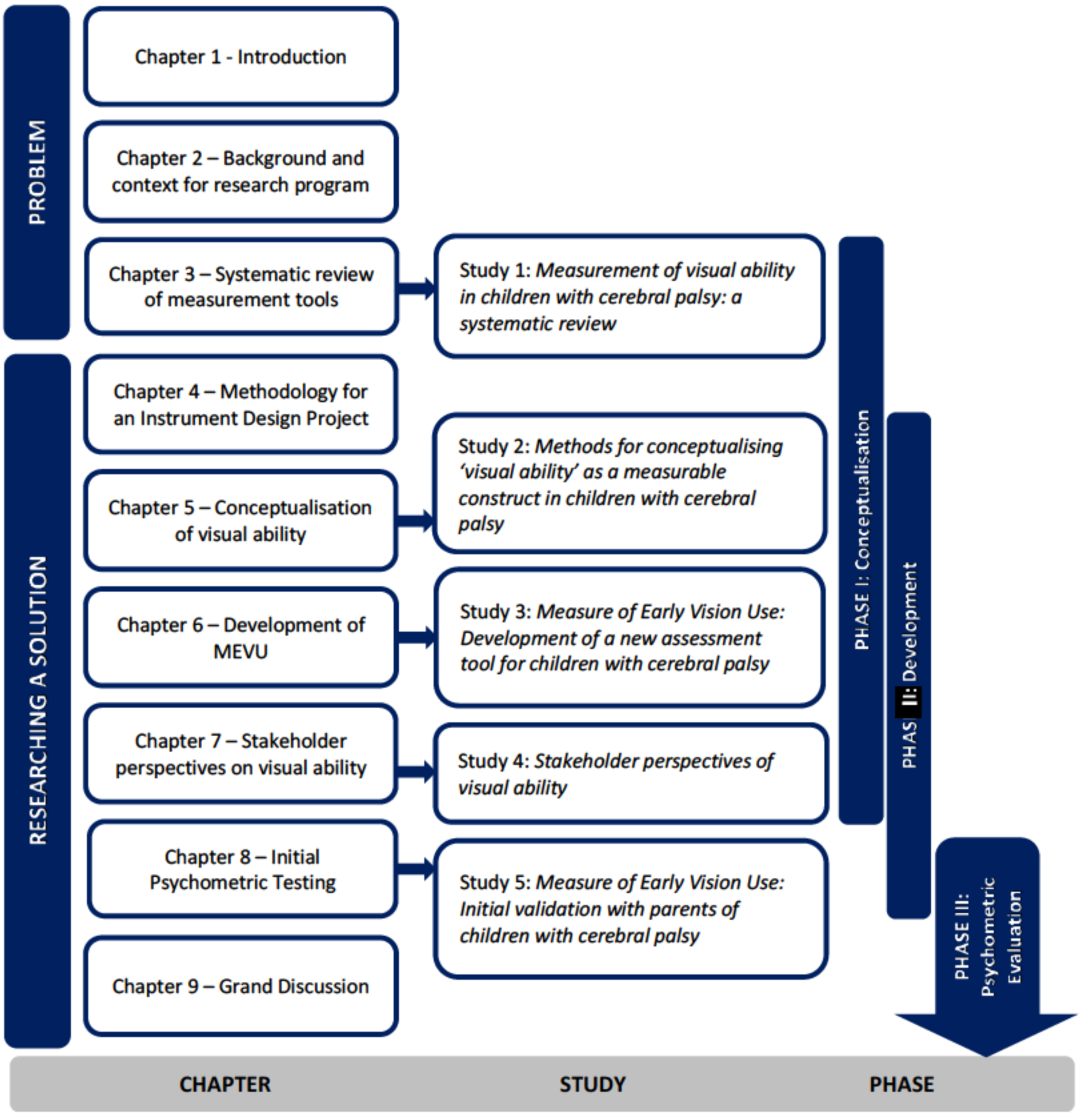
Chapter 7 – Stakeholder perspectives on visual ability describes secondary analysis of qualitative data from the online survey described in Chapter 6. The purpose of this chapter is to explore the complete range of factors reported by stakeholders when asked about visual abilities. The results (Study 4) are important to the conceptualisation of visual ability, development of hypotheses for psychometric testing (construct validation) and the final discussion on implementing MEVU into clinical and research practice.

Chapter 8 – Initial psychometric testing reports the results of the initial field testing with parents of children with cerebral palsy to explore the evidence for measurement properties. This chapter contains the manuscript published in *Disability & Rehabilitation* – Study 5.

The final chapter, **Chapter 9 – Grand Discussion** provides a synthesis of the research findings including limitations. This chapter links results from all studies within this thesis and presents a plan for implementing MEVU as a new measurement tool into clinical and research practice.

Figure 1.2

Structure of thesis



1.5 FUNDING SUPPORT

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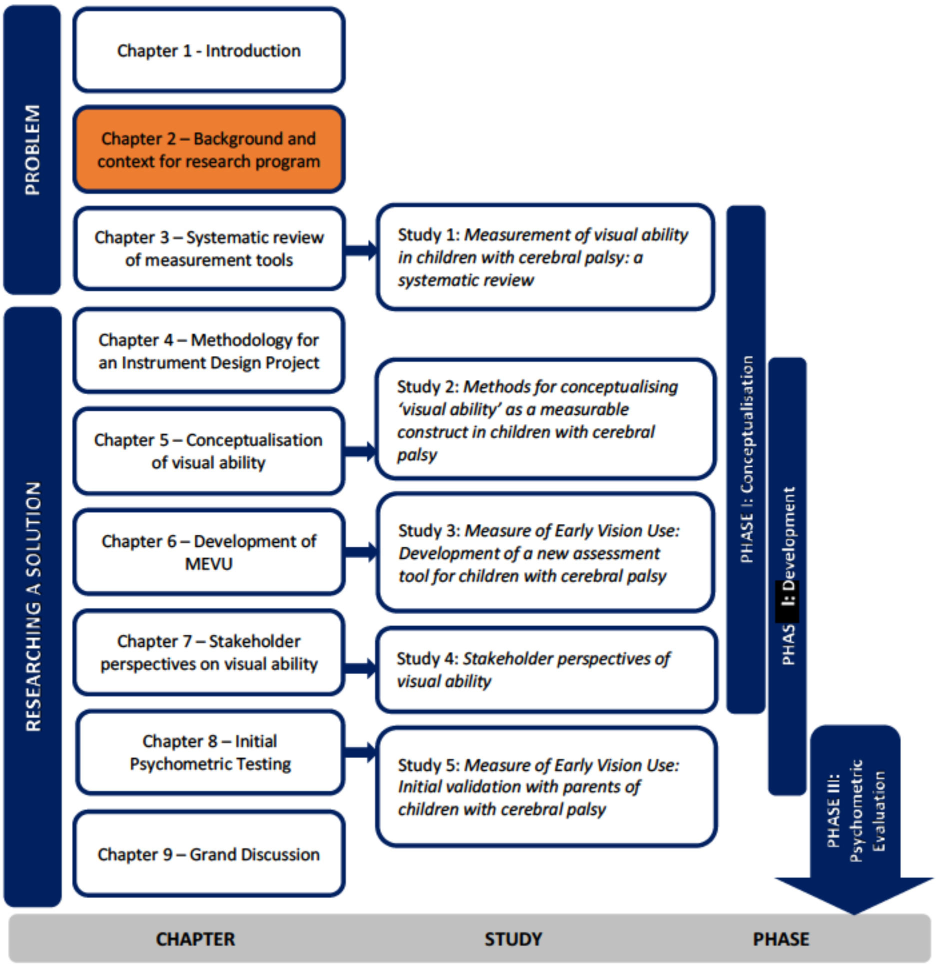
CHAPTER 2: Background and context for research program



2.1 INTRODUCTION TO CHAPTER 2

Chapter 2 provides a background and context for this program of research by describing the population of children with cerebral palsy, vision, and the relationship between vision and functional outcomes for children with cerebral palsy. The chapter also provides a brief summary of current recommendations for the intervention of vision-related problems in children with cerebral palsy, including a discussion of limitations with current intervention approaches. The chapter concludes with a proposal that measurement may be pertinent to addressing vision-related problems for children with cerebral palsy.

2.2 CEREBRAL PALSY

Cerebral palsy is the health condition of the target population in this research. It is a neurodevelopmental condition that begins in early childhood and persists throughout life. Cerebral palsy is the most common physical disability in childhood and its diagnosis is based on a combination of clinical and neurological signs. Whilst the diagnosis of cerebral palsy will always include motor impairment, the most recent definition also specifies that this disorder causes activity limitations, and may include additional impairments, including vision:

> "Cerebral palsy 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., 2007, p. 9).

The definition of cerebral palsy incorporates a heterogenous group of children with a broad range of functioning and health presentations, and whilst the definition states the condition occurs because of a lesion or injury to the brain, the causal pathway is often unclear (Nelson, 2008). Cerebral palsy or "high risk of cerebral palsy" can be accurately predicted before 6-months' corrected age (Novak et al., 2017). The currently reported birth prevalence of cerebral palsy within high-income countries varies between 1.4 and 2.5 cases per 1000 live births, and low-to-middle income countries report higher prevalence rates (Morgan et al., 2021).

In order to describe the differences and similarities between children with cerebral palsy several methods of classification are used. These include the nature and typology of the motor disorder, the functional motor abilities (severity), accompanying impairments, anatomic distribution, and neuro-imaging findings, and causation and timing of the cause or injury (Rosenbaum et al., 2007). In this research, the way cerebral palsy affects a child's movement, and the parts of the body affected, are described for study participants. This includes reference to spasticity, dyskinesia, ataxia and/or hypotonia for the way movement and posture are affected, as well as a description of whether there is a bilateral presentation (e.g., quadriplegia or diplegia) or unilateral (e.g., hemiplegia).

The severity of cerebral palsy is determined by evaluating the functional abilities of the child (or adult). Three classifications that have been used to describe functioning in (as opposed to limitations of) children with cerebral palsy within this research are the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997; Palisano et al., 2008), the Manual Ability Classification System (MACS) (Eliasson et al., 2006), and the Communication Functioning Classification System (CFCS) (Hidecker et al., 2011). Each of these classifications is summarised in Table 2.1. Another classification system, the Eating & Drinking Ability Classification System (Sellers et al., 2014), has less relevance to this research and has not been used. In 2020 the Visual Function Classification System (VFCS) became the latest edition to this collection of classification system (Baranello et al., 2020). The VFCS will be introduced further in Section 2.3.

Table 2.1

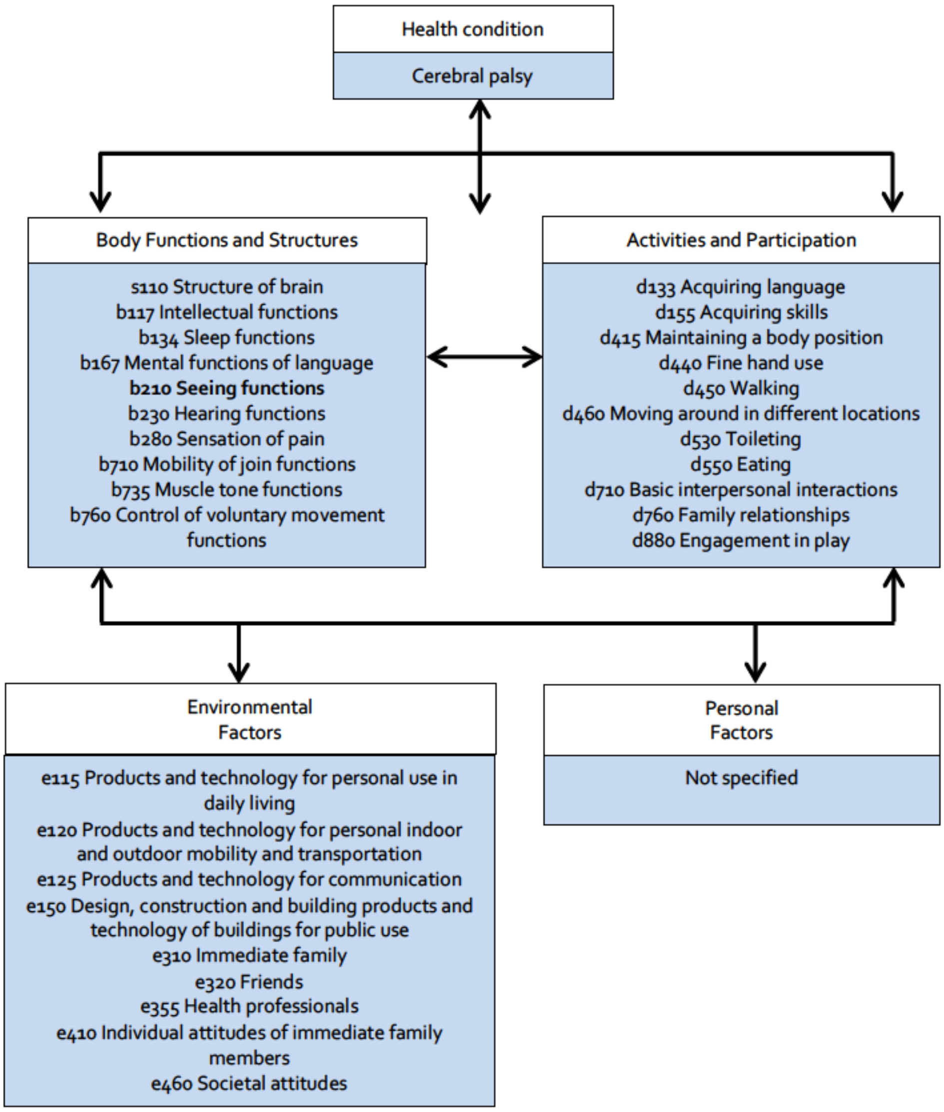
Summary of functional classification systems for children with cerebral palsy (Hidecker et al., 2011)

	GMFCS	MACS	CFCS
Level I	Walks without limitations.	Handles objects easily and successfully.	Sends and receives with familiar and unfamiliar partners effectively.
Level II	Walks with limitations	Handles most objects but with somewhat reduced quality and/or speed of achievement.	Sends and receives with familiar and unfamiliar partners but may need extra time.
Level III	Walks using a hand-held mobility device.	Handles objects with difficulty; needs help to prepare and/or modify activities.	Sends and receives with familiar partners effectively, but not with unfamiliar partners.
Level IV	Self-mobility with limitations; may use powered mobility.	Handles a limited selection of easily managed objects in adapted situations.	Inconsistently sends and/or receives even with familiar partners.
Level V	Transported in a manual wheelchair.	Does not handle objects and has severely limited ability to perform even simple actions.	Seldom effectively sends and receives, even with familiar partners.

The functioning and disability of children with cerebral palsy can also be described by using the ICF framework and core sets. ICF Core Sets are lists of ICF categories that describe the most relevant or important areas of functioning and limitations for a specific population (Schiariti et al., 2015). The ICF categories included in a core set provide a guide for identifying areas of functioning that need to be assessed, with information gathered using validated measurement tools, patient-reported questionnaires, clinical examinations, and/or technical investigations can be used to address the content of the ICF categories. Both comprehensive and brief core sets have recently been developed for children with cerebral palsy (Schiariti et al., 2015). Figure 2.1 illustrates the 31 ICF categories that best represent the functional profile of young children with cerebral palsy (aged 0-6 years) in a brief core set, including b210 Seeing Functions, a Body Function code. Among the 135 ICF categories in the comprehensive core set for all children and youth with cerebral palsy is the ICF code most relevant to the focus of the research project; d110 Watching, a code for Activity level use of vision. The large number of categories in this core set is reflective of the complexity and heterogeneity of the cerebral palsy population.

Figure 2.1

ICF framework & brief core set second level categories applicable to children with cerebral palsy 0-6 years and second-level categories (Schiariti et al., 2015)

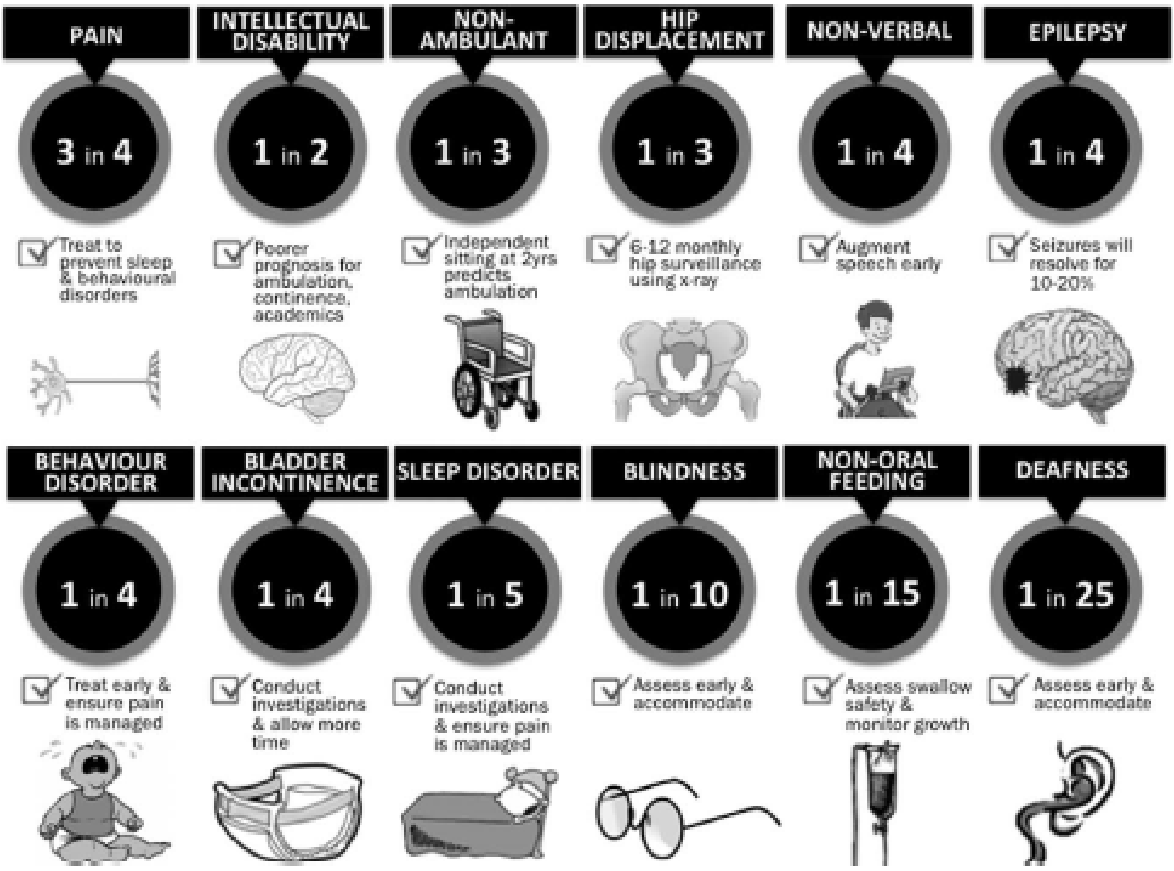


Note. The one vision-related second level category included in the brief core set, *b210* Seeing functions, is bolded.

Children with cerebral palsy may have impairments that impact on their function and quality of life as much, or more than, their motor impairment. A 2012 systematic review and meta-analysis of co-occurring impairments, diseases and functional limitations from cerebral palsy population register evidence reported their findings with summary statements of rates (Novak et al., 2012). This includes the finding that 1 in 10 children with cerebral palsy has a severe vision impairment or is blind. All findings from that review are summarised in Figure 2.2 and included here as a summary of the diverse outcomes for children with cerebral palsy (Novak, 2014).

Figure 2.2

Comorbidities of cerebral palsy and evidence-based management



Note. Reproduced with permission from SAGE Journals: Novak, I. (2014). Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy. *Journal of Child Neurology*, *29*(8), 1141-1156. https://doi.org/10.1177/0883073814535503

2.3 VISION

This section outlines why vision (including visual abilities) is an important problem to address for children with cerebral palsy. Key definitions are introduced including functional vision and the role of the ICF as the conceptual framework for understanding different types of vision. Current assessment practices and the development of vision in typically developing children are also reviewed.

As introduced in the previous section, a systematic review and meta-analysis found that 1 in 10 children with cerebral palsy has a severe vision impairment or is blind, and that 1 in 4 children with cerebral palsy has a vision impairment (Novak et al., 2012). This suggests that impaired vision is a significant problem for many children with cerebral palsy; however, the authors of that systematic review identified a lack of consistency among studies in the recording of information about vision impairments and were consequently not able to include all vision impairment data in their analysis (Novak et al., 2012). In their review, descriptions of other 'visual impairments' included refractive errors, myopia, hypermetropia, astigmatism, and strabismus, in addition to the reporting of children with 'some impairment' or 'functional blindness'. The rates with which children with cerebral palsy have disturbances of vision vary greatly in the literature, and are influenced by factors including the lack of consensus and definitions, by the variable purposes for which data is collected, by the lack of consistency in coding by authors and registries, and by the purposes of studies or data collection (Odding et al., 2006). For example, the Australian Cerebral Palsy Register (ACPR) determines vision status based on clinical or formal assessment before any correction and the definitions are as follows:

> *functional blindness* is defined as a tested visual acuity of 6/60 or worse in the better eye and included those who clinically had light or colour perception, but are unable to use their vision in a functional way; *some visual impairment* described children who, at age 5, require corrective lenses to achieve normal visual acuity; and *no impairment* indicates normal uncorrected visual acuity on formal testing, or visual status that was not clinically questioned (Delacy & Reid, 2016, p.51).

Using these definitions, a recent publication by the ACPR reported that 36% of children in the database had some degree of visual impairment and 6% had functional blindness (Delacy et al., 2016).

The majority of prevalence literature for visual problems relates to a rate of 'vision impairment', which is obtained by measuring visual acuity with best possible refractive correction, and results are categorised from 'mild or no visual impairment' (visual acuity equal to or better than 6/18), to 'blindness' (no light perception, light perception, or visual acuity worse than 3/60) (World Health Organisation, 1992). A definition or measurement of ‘visual impairment’ only describes the eye or visual functions being assessed, and these results, although valuable, do not specifically tell us how a child with cerebral palsy functions in vision-related activities (their ‘visual ability’), particularly in the presence of other impairments (e.g., gross motor limitations or cognition). For this program of research, it is also particularly noteworthy that measures of visual impairments do not provide information on the positive aspects or ‘ability’ levels found in children with cerebral palsy. Some children with cerebral palsy may have a visual impairment that limits performance and restricts participation in daily life, whilst for other children, visual ability may be considered a strength.

Children with cerebral palsy may be diagnosed with visual deficits that are of ocular (eye) or cerebral (brain) origin, or a combination of both. Visual impairments that result from damage to the brain may be referred to as cortical or cerebral visual impairment (CVI), and recognition of vision impairment resulting from damage to the brain is a rapidly growing area of research (Dutton & Bax, 2010). In this research, the focus is not on cerebral/cortical vision impairment, or ocular vision impairment – rather it is about visual ability or ‘how vision is used’. The visual abilities of a child can be impacted by impairments at any point along the primary visual pathway (eye, optic nerves, thalami, optic radiations, and primary visual cortices), in the visual association areas, or the oculomotor system. The visual pathways in the cerebral cortex are commonly described as two distinct but interacting pathways (Milner & Goodale, 2006); the ventral (‘what’) stream and the dorsal (‘where’) stream. Both visual pathways may be impacted in children with cerebral palsy (Philip et al., 2020). The cause of motor impairment may also be the etiological reason for a vision impairment in the child with cerebral palsy (Jacobson et al., 2010). Different types of visual disturbances have been correlated with different sub-types of cerebral palsy, such as the high prevalence of visual cognitive deficits in children diagnosed with periventricular leukomalacia (Jacobson & Dutton, 2000).

In this program of resaerch, the ICF has been used as the conceptual framework to define and understand visual ability. Colebrander (2020) first used the ICF for this purpose in 2003 when he differentiated between two types or perspectives of vision: visual function and functional vision.

Visual functions describe how the eyes and basic visual system work. Measurement of visual function determines a threshold performance in a controlled environment where only visual parameters are measured, for example visual acuity, visual field or contrast sensitivity. Visual function can be assessed in each eye individually, which provides a measure of what a child can see, or how the eyes and visual system functions (Colenbrander, 2010a). Whilst formal and standardised measures of visual acuity provide recordable aspects of visual function, they do not provide a measure of how vision is used in everyday life.

A common approach to measuring visual acuity in children is a technique called ‘Forced Preferential Looking’ where children are observed to see whether they look at a blank screen or one with stripes of differing spatial frequency that have been correlated with the acuity level required to see them as separate lines (Teller et al., 1986). Assessment of visual functions may also include measurement of detection vision (Sonksen et al., 1991). In addition to measuring visual acuity and visual field deficits, an ophthalmological assessment of a child with cerebral palsy may be completed including observations, refractive examination of the eyes, contrast sensitivity, optokinetic nystagmus, stereopsis, oculomotor assessment (including fixation, smooth pursuit, and saccadic movements), visual axis alignment (to detect strabismus), and visual perceptual assessment. There are assessment batteries, such as Ricci’s neonatal assessment of visual functions (Ricci et al., 2008), that provide useful information on various aspects of visual function. A thorough assessment may additionally include neuro-radiological examinations (e.g., brain magnetic resonance imaging), neurophysiological investigations (e.g., visual evoked potentials), clinical history taking and neurological examination, developmental assessment and cognitive assessment (Fazzi et al., 2007). Developmental assessments such as the Griffiths Mental Developmental Scales include sub-sections on visual skills (e.g., eye-hand coordination) (Griffiths, 1970), and there is a range of cognitive assessments, such as the Raven’s Progressive Matrices (Raven et al., 2008), that include sub-sections that measure aspects of visual-skills (e.g., visual-spatial processing and visual-memory).

The presence of developmental and cognitive difficulties in children can make it difficult or impossible to complete traditional measurement of visual function with some children with cerebral palsy (Droste et al., 1991). The lack of motivation and cooperation within a testing environment can add to the challenge. For some children there is a need to provide visual stimulation (warm-up) and favourable environmental conditions to capture the desired best level of ability (Guzzetta et al., 2006). Some children with cerebral palsy have good visual (Hyvärinen & Jacob, 2011) acuity because they have no ‘problem’ with their eyes, but it can be difficult to assess their acuity due to other limited abilities. This has led to the development of behavioural evaluation methods to account for the possibility of good visual acuity in the presence of poor cognitive or verbal skills (Jan et al., 1987).

Functional vision describes how the person functions, and it measures sustainable performance in everyday life environments via an individual's vision-related skills and abilities (Colenbrander, 2003). This concept has also been referred to as 'visual functioning' (Hyvärinen & Jacob, 2011). Functional vision is different to visual functions that describe how the eye and basic visual system work and in this program of research functional vision evolves into a definition of visual ability or 'how vision is used'. Non-visual factors may influence the measurement of functional vision making it multi-dimensional in nature (Szlyk et al., 1990). An example is the way that the cognitive or learning skills of a child may influence their ability to see and recognise their written name. For this reason, it has been recommended that vision be considered and interpreted alongside cognition, attention and the control of manual actions (Atkinson & Braddick, 2012).

Assessments of functional vision, or 'functional visual assessments' (FVA), are typically completed by teachers of people who have visual impairments and by orientation and mobility (O&M) instructors (Corn & Erin, 2010). This type of assessment is usually conducted for a child with an identified visual function disability (i.e., a visual impairment). Whilst the approach to the content and structure of a FVA can vary, the results of a typical functional visual assessment will report on "binocular functional vision, visual acuity, colour vision, contrast sensitivity, visual fields, movement perception, the degree of visual crowding, the accuracy of visual guidance of movement, and recognition" (Dutton, 2011, p.390). The goals of a functional visual assessment are typically to determine the vision available for everyday activities such as communication, education, and movement, and the assessment is defined by its need to guide visual skill interventions or accommodations (e.g., environmental) (Dutton, 2011). They may also be used to evaluate the effectiveness of interventions (Roman-Lantzy, 2007). Whilst the primary focus of the functional visual assessment is on evaluating use of vision in everyday environments and activities, the results of many assessments of functional vision do not include any information about how an individual uses their vision in tasks of everyday life (Jan et al., 1987). Functional activities are used to gather information on 'capacity' of ‘functional vision’ and ‘visual functions’, rather than describing how a child functions in vision-related activities, or uses their vision.

Unlike adults, children with congenital impairments including those with cerebral palsy, are limited in their ability to self-report on their visual disability as this is their only experience (Dutton & Bax, 2010). This influences the way in which visual information is captured, highlighting the need for parents, caregivers and teachers to provide information related to the visual skills and abilities of children. In addition to the FVA commonly used by teachers, many questionnaires have been developed to collect information from parents about the typical functioning of their children (Ferziger et al., 2011; McCulloch et al., 2007). A common reason for asking parents about their children, and one of the challenges reported within the literature on measuring daily visual functioning of children with cerebral visual impairment, is that these children tend to vary their visual performance both during a day, and from one day to another (Dutton, 2011). This variability in functioning is important to incorporate into the response options for new measurement tools. Other suggestions for gathering information on how vision is used within activities include observations made during everyday play situations (Porro et al., 1998); and use of eye-gaze tracking technology (Venker & Kover, 2015).

There is also a range of visual-perceptual tests for children with cerebral palsy including those that consider the child with limited motor abilities (Auld et al., 2011). Often visual perception is assessed on the assumption that the results can be correlated with daily functioning (James et al., 2015; Menken et al., 1987). A proposal for classifying visual perceptual impairment has been published with categories that include handling the complexity of the visual scene (e.g. finding clothes in a drawer), visual guidance of movement (inaccurate reach and grasp), dual tasking (e.g., talking causes bumping into objects whilst walking), recognition (e.g., facial expressions), and orientation (e.g., navigation) (Dutton, 2009); however, these categories are descriptive and do not provide any quantitative measure.

Of particular importance for this area of research is the recently developed visual function classification system (VFCS) (Baranello et al., 2020). The purpose of the VFCS is to classify visual functioning of children with cerebral palsy in everyday life into one of five levels of ability, in a manner similar to the existing classification systems for gross motor, manual abilities and communication function (Rosenbaum et al., 2014). In this classification, visual functioning refers to how the child actively uses vision to see, direct gaze, recognise (watch), interact with the environment and explore it, both in static and dynamic conditions, as expected for the child's age. The VFCS classifies the child's visual ability considering both sensory and motor elements of vision, but it is not intended as an assessment tool. It is also not meant to replace formal assessments of visual function and does not explain the underlying reasons for the level of visual functioning performed by the child. The VFCS is expected to be used by parents and caregivers, and by professionals working with children with cerebral palsy (e.g., health care professionals, school professionals), and is currently undergoing reliability testing.

In relation to the vision of children with cerebral palsy, there is one more important consideration – development of vision. Whilst the infant is born with a complete visual system, even a typically developing child must learn how to see, with the most important development occurring in the first two years (Lenassi et al., 2008). The early milestones of vision development include focusing ability, eye coordination and tracking, depth perception, seeing colour, and object or face perception. Loss of these visual functions, as seen in an adult or older child is very different to impaired development of that same function (Dutton & Bax, 2010). Visual disturbances in children manifest in a visual system that is still developing (Dutton & Jacobson, 2001). The 1981 Nobel Prize winning work of the neurobiologists Hubel and Wiesel with animals demonstrated that proper visual system development requires integration of visual and perceptual experience, and the window of heightened brain plasticity for vision is noted to come earlier than that of motor and language development (Wiesel, 1982). This understanding of plasticity of the brain and visual system suggests that vision should be a high priority in early intervention and lead to research into whether training can enhance visual function (Guzzetta, 2010).

2.4 VISION-RELATED OUTCOMES FOR CHILDREN WITH CEREBRAL PALSY

Following this introduction to the target population and outcome of interest (visual ability), this section contextualises the importance of research on visual abilities in children with cerebral palsy by exploring vision's impact on development and its relationship to functional outcomes. This is followed by a review of the ways in which vision can impact the effectiveness of interventions for a range of functional and developmental domains (through inclusion/exclusion criteria) and using visual strategies within interventions. In this section the term *vision* is broadly used to capture the related constructs of visual (seeing) functions, vision impairment, visual perception, functional vision and visual ability. Where appropriate, further clarification is provided.

2.4.1 Relationships between vision and functional outcomes

This section reviews the growing body of literature reporting relationships between vision and functional outcomes, however, it must be acknowledged that correlations are not causal, and that relationships may co-vary as a function of underlying impairment in children with cerebral palsy.

In general, visual skills play an essential role in development for all children, and the absence of, or limitations in, vision are known to impact children's development and functioning (Cass et al., 1994; Kaul et al., 2016; Stjerna et al., 2015). Visual impairment has been reported as being more important that the severity of motor disability or the extent of lesions on MRI in determining neurodevelopmental scores for infants with periventricular leukomalacia (Cioni et al., 2000). The relationship between vision and development has also been demonstrated by the need to modify developmental assessments for children with vision impairment (Visser et al., 2013).

Motor abilities & motor outcomes

Findings from research in the field of vision impairment and blindness suggest that reduced vision negatively impacts developmental outcomes including very early motor abilities (Prechtl et al., 2001; Tröster & Brambring, 1993). Evidence from developmental literature suggests that typical visual development plays an important role in a child's development and use of motor abilities (Gibson & Schumuckler, 1989). In children with cerebral palsy, for whom movement and posture limitations are core elements of their condition, it is particularly important to consider the relationship between vision and motor outcomes.

Vision impairment, as a comorbidity for children with cerebral palsy, has been included in conceptual models of change in gross motor abilities in children with cerebral palsy (Chiarello et al., 2011); however, the unique contribution of vision as a mediator of change or a prognostic factor is not well understood (Bartlett et al., 2014; Smits et al., 2019; Størvold et al., 2018). In their recent study evaluating the new VFCS, a measure of visual abilities, Baranello and colleagues (2020) reported that a significant moderate positive correlation was found between gross motor (GMFCS) and vision classification in 160 children with cerebral palsy aged 1-19 years. The availability of the VFCS may enable inclusion of visual ability in future analyses of determinants of motor abilities.

Children with cerebral palsy plus poor vision are more likely to have delays in motor development and lower functional skills in mobility (Salavati et al., 2014). Severe vision impairment has been correlated with the inability to walk (Beckung & Hagberg, 2002), and the preservation of vision functions has been described as a predictor of ambulation (Wu et al., 2004). Children with the most impaired motor functioning (e.g., GMFCS Level V) are reported to have the greatest likelihood of severe vision impairment (Delacy et al., 2016; Shevell et al., 2009), which adds to the challenges facing this group of children, as they are the same group who would be likely to find the most benefit from optimising their functional visual abilities as a compensatory strategy for their motor impairments (Cohen & Rein, 1992).

Visual deficits may impact the attainment and performance of motor abilities for children by removing or reducing the visible motivation to move and by limiting the usability of commonly used visual cues (Ryan et al., 2020; Sonksen et al., 1984; Tripathi et al., 2020). Vision provides a reference point for self-position and the position of obstacles within an individual's environment; it also assists with motor functions including balance and can decrease the incidence of falls (Black & Wood, 2005). In adults with cerebral palsy, when there is a change in functional behaviour such as reduced mobility and independence or falling, vision has also been identified as an area requiring investigation (P. Morgan et al., 2016). The visual skills of a child with cerebral palsy (e.g., direction of looking, searching, scanning, detection and recognition) and the speed with which they process visual information have all been reported to have implications for making effective and safe movement decisions, such as when using powered mobility, riding a bicycle, crossing roads and driving (Durkin, 2009; Field & Livingstone, 2018; Lafrance et al., 2017; McGarry et al., 2012; Toovey et al., 2019). Whilst any limitations in a child's visual or perceptual system need to be identified, it is recommended that children with limited vision should not be excluded from the opportunity to achieve mobility via a powered device (Livingstone & Paleg, 2014). However, children with cerebral palsy may have more difficulties utilising visual compensatory strategies (e.g., cane use) than children with vision impairment but no motor impairment (Simpson et al., 2008). Amongst some children with cerebral palsy who have independent mobility there are also reports of difficulties in orientation or 'way finding', and easily getting lost in unfamiliar surroundings (Jacobson et al., 1996; Pavlova et al., 2007).

Just as visual limitations can impact on motor abilities, a child's motor abilities may impact on vision use. For example, postural control influences head or eye position, which can influence the available field of view, thereby the visual experiences in the environment around the child (Franchak, 2020; Harbourne et al., 2014; Lew et al., 2015). Children with less motor ability (e.g., GMFCS Level IV & V) are likely to have less ability and opportunity to use their vision in everyday activities and environments, regardless of level of visual function. For example, a child who does not have head control in the first year of life will have a restricted view of the environment as a direct result of the positions in which they are placed and held (e.g., more supine, and reclined positions). Even typically developing children have been shown to do less looking when the motor cost is higher than the visual reward (Franchak et al., 2018). In some instances, adaptive positioning equipment such as standing frames has been indicated for use with children with cerebral palsy to help them use their vision (Goodwin et al., 2018). On the other hand, assistive devices can present their own barriers; for example, children who use a wheelchair and have difficulty moving their head, or are limited by head restraints, may risk colliding with obstacles they cannot see (Simpson et al., 2008). Some children make use of 'atypical' or 'preferred' head and body postures in order to maximise their visual abilities (Butler et al., 2010). The overall impact of this on trunk control, head movements and posture need to be considered when assessing the child's overall functional profile, as correcting posture may lead to reduced vision. There are also extensive references in the developmental and disability literature that mobility experience such as self-produced locomotion (e.g., walking), and the problem-solving associated with that independent mobility, influences the development of visual-spatial skills (spatial cognition) (Foreman et al., 1990; Kenyon et al., 2017; Kermoian & Campos, 1988; Pritchard-Wiart et al., 2019).

Hand use

The developmental literature has extensive references and discussion on how vision contributes to hand use (Berk, 2012; Pehoski & Henderson, 2006). Vision level has recently been reported to have a significant moderate positive correlation with detection vision in visually impaired children (Smyth et al., 2021), however, the specific relationship between vision and hand use in children with cerebral palsy has received little research attention. Unsurprisingly, given the contribution of vision and visual-motor skills towards hand skills, use of the new classification of children with cerebral palsy with the VFCS (visual ability) recently reported a moderate positive correlation with the MACS (manual ability) (Baranello et al., 2020).

Communication and social interaction

Vision can also be linked to communication, social interaction and socio-emotional development (Vos et al., 2014). The typical responses of children to parents are heavily based on visual cues including nodding, visual glances and referencing, smiling, face recognition, and reaching (Blacher, 1984); in fact, parental observations of poor eye-contact and non-purposeful gaze can be the earliest indications of something being 'not quite right' with a child (Jackel et al., 2010). Helping parents and caregivers to both recognise and make use of their child's vision can facilitate bonding and early communication because interacting with a child who does not look, track or show recognition of returned smiles can present a significant challenge to the shaping of early interactions (Boyle et al., 2005; Chokron et al., 2020; Lantz & Ottosson, 2013).

Specific knowledge of the complex relationship between vision and communication is emerging. Whilst published developmental trajectories for receptive and expressive language communication in children and young adults have not reported on the influence of vision impairment (Vos et al., 2014), other studies have found severe vision impairment to be a predictor of communication ability in young children (Pennington et al., 2020). One longitudinal study examining language development in younger children did not report on the influence of vision, but demographic data reports that all children with CVI in the study were anarthric (unable to talk) at 48-54 months (Hustad et al., 2018). Whilst children with vision impairment in addition to severe motor and language impairments have been recognised as a challenge for clinicians to address communication goals, they are an important group who require specialised support to optimise their outcomes (Smith & Hustad, 2015). The methods used to assess language must be carefully considered, because children with vision impairment may find it difficult to participate in methods of testing such as scanning and discriminating between small line drawings (Watson & Pennington, 2015). The interplay between vision, communication skills and cognition also have implications for social communication outcomes (Hidecker et al., 2018; Mei et al., 2020).

The motor impairment of cerebral palsy can impact communication and social interaction in a child who is unable to coordinate their head and eye movements to be in a position to use vision independently. As a result of motor impairments, some children with cerebral palsy will be unable to finger-point or vocalise during interactions. This creates challenges for communication and parent-child relationships, but children may be able to compensate using directed gaze or 'eye-pointing' (Sargent et al., 2013). Successful communicators have been defined by this ability to use eye gaze and the ability to perceive subtle physical cues and facial expressions (Myrden et al., 2014). The recently published Eye-pointing Classification System (EpCS) provides a method for describing looking behaviours for communication (Clarke et al., 2020). Goossens' (1989) report of a young girl receiving eye-gaze communication training is an example of how an increased use of vision resulted in greater understanding of both a child's visual function and their overall development. Whilst children with limited vision have been identified as having reduced communication capacities (Coleman et al., 2015), the benefits of good visual abilities for enhancing activity performance and participation are being supported by advances in technology including the use of tablet screens with children who can see pictures (Chai et al., 2015) and eye-gaze technology for children with limited motor abilities (Borgestig et al., 2021; Myrden et al., 2014). It has also been noted that barriers to social interactions can arise from the cross-eyed appearance associated with strabismus or other atypical 'seeing behaviours' (Blair et al., 2016; Paysse et al., 2001).

Learning and acquiring skills

Vision enables children to learn by watching or looking, and visual cues are frequently used to support the acquisition of skills. In young children with cerebral palsy, the relationship between looking and problem solving within both cognitive and motor outcomes is being incorporated into new early intervention approaches (Dusing et al., 2020; Harbourne et al., 2021). Visual inattentiveness in infants has also been reported as a predictor of poor long term intellectual and cognitive outcomes (Kivlin et al., 1990). In older children with cerebral palsy, visual abilities have been linked to school performance (Burtner et al., 2006), and this has recently been highlighted as an area requiring greater attention due to the large number of children and adolescents demonstrating impairments on assessments of visual perception (Molloy et al., 2013). Most research related to learning outcomes refers to visual cognitive measures (Critten et al., 2019; Williams et al., 2011).

The ability to use vision for reading is the most commonly asked question in functional vision assessments for adults (Crews et al., 2012). For children with cerebral palsy, reading may be complicated by difficulties with eye accommodation (changing focus), and the ability, or not, of children to hold the book at an appropriate distance from their eyes (Lampe et al., 2014; Pansell et al., 2014). Not considering the relationship between vision and reading can lead to children with reading difficulties being misinterpreted as having reduced cognition. It has also been recognised that vision impacts on cognitive and intelligence testing, and that appropriate tool selection and accommodations must be sought (Morgan et al., 2019; Yin Foo et al., 2013).

Play and leisure

Participation in play and leisure activities is an important outcome for children and families and visual engagement has been reported as a contributor to this outcome. Children with cerebral palsy and significant motor limitations have been reported to utilise their strengths in using vision by "engaging in play through watching" (Graham et al., 2019) where full engagement within play was described without the need for physical participation. Visual regard (looking at the toy) has been included in studies evaluating improvements in play (Clark et al., 2019); and behaviours indicating a lack of engagement (i.e., self-stimulation) may reduce when a child is watching (Tarnowski & Drabman, 1985). Strategies to promote gaze and visual play in young children are reported to include positioning, visual offerings in the environment, and opportunities to develop more sophisticated gaze search (Pierce et al., 2009).

Vision can also support independent leisure activities such as playing online games and look at pictures and videos (Caron & Light, 2017), and eye-gaze-controlled computers have also been reported to facilitate engagement in play and leisure activities (Borgestig et al., 2021). It is important that children with cerebral palsy have access to choices that fit their level of visual abilities, especially in the pursuit of autonomous leisure or play. A child who has impaired visual perception is unlikely to choose, or be successful, in activities that require visual figure ground, spatial relations, or visual discrimination skills (e.g., reading, puzzles, nesting toys, and construction materials) (Blanche, 2008; Ek et al., 2003). Limitations in a child's visual perceptual skills may be compounded by motor abilities that limit experience in playing with these types of toys.

Self-care and sleep

Children with cerebral palsy may be limited in their ability to complete self-care tasks as a result of their motor abilities and their visual abilities (Salavati et al., 2014). For example, a child may not have the ability to discriminate visually within activities, such as finding a required object to complete a task (Elbasan et al., 2011). In their study, Salavati et al. (2014) compared children with cerebral palsy and CVI, to those without CVI, using the Dutch version of the Pediatric Evaluation of Disability Inventory for both self-care function skills and caregiver assistance, and in both instances, children with cerebral palsy and CVI scored significantly lower. This suggests that visual skills are the limiting factor as children were otherwise similar; however, this was a very small sample. In a study with school-aged children and unilateral cerebral palsy, an association has also been found between visual perceptual abilities and the ability to carry out activities of daily living (James et al., 2015).

One area of self-care that illustrates the potential impact of vision is a child's performance and participation in feeding and mealtime routines. Typically, infants will be breast or bottle fed whilst cradled in the arms of a parent. This positioning provides infants with a frequent opportunity to observe the face of their caregiver from an optimal viewing distance (Paul et al., 1996). The absence of visual engagement during feeding can be an early warning sign as shared by one parent of a child with CVI: "I began to record concerns about his development and visual behaviour when I noticed that he did not make eye contact while feeding" (Lueck & Dutton, 2015, p. 639). Children who require alternative positioning, or who receive their nutrition via a feeding tube without being held in the same way, may therefore receive less visual stimulation. Vision has also been identified as a potential contributor to oral phase impairment, where the initial steps in eating include visual orientation to the bolus (food) and recognition of the spoon (Benfer et al., 2014). In research with typically developing children, visual behaviours observable within mealtimes have recently been defined by the Infant Gaze at Mealtime coding scheme that includes the following behaviours: a) watches caregiver activity; b) gazes at caregiver’s face; c) gazes at own or other's drink; d) gazes at own or other's food; e) gazes at item other than food, drink or caregiver; f) exploratory gaze (engaging in intent gazing at feeding utensils, food remnants or other objects while touching or manipulating them); and g) active gaze aversion (actively averting eyes and face from caregiver in response to offer of food) (McNally et al., 2019). All these opportunities to use vision across daily mealtimes may be lost, or at least be different, for the child who is unable to take food through their mouth and needs to be fed through a feeding tube; reported to be in 1 in 15 children with cerebral palsy (Novak et al., 2012). Whilst early self-feeding skills in typically developing children includes both finger feeding and repeated practice using tools such as spoons at each mealtime, this opportunity for visual-motor skill development can be lost for children with upper limb motor impairments. In addition to being repetitive, mealtimes (or more specifically food) can be highly motivating activities. This is significant as both repetition and salience are important to childhood interventions for children based on the principles of neuroplasticity (Kleim & Jones, 2008). Thus, the ability to use and develop visual skills may be further disadvantaged in the child who does not participate in mealtimes. With vision’s involvement in the organisation of sleep-wake rhythm, children with cerebral palsy and limited vision have also been reported to have increased sleep difficulties (Jan et al., 2008; Rosen, 2020).

2.4.2 Interventions and the role of vision

Vision is also likely to have a role as a mediator or moderator within therapies for children with cerebral palsy including motor and cognitive interventions. Evidence-based interventions are not always validated with populations of children with cerebral palsy that include those with impaired vision as children are excluded if they have visual problems that could interfere with participating in testing or the intervention (Gordon et al., 2007) (C. Morgan et al., 2016). The reason for exclusion may be related to the difficulties in finding a validated outcome tool for children with vision impairment (Salavati, Krijnen, et al., 2015; Salavati, Waninge, et al., 2015; Visser et al., 2013). Strategies used within intervention approaches may not be appropriate for children who are not using their vision optimally. For example, review of the *The Baby CIMT Manual* (Eliasson & Sjöstrand, 2015), developed to help therapists start a modified constraint-induced movement therapy (CIMT) programme for infants at risk of developing unilateral cerebral palsy, includes a number of recommendations that highlight the importance of vision within the intervention: “first infants should learn to move their hands towards visual stimuli” (p. 11), “when a toy is held in the hand, some exploration is expected, such as waving within the visual field” (p.12), “it is important that the infant should look at his or her own actions and pay attention to the toys” (p.12), and during sessions “parents should always be in front of the infant for good eye contact” (p.10).

Vision is now receiving more attention within the early intervention research focused on motor and cognitive outcomes – as a focus of intervention or as a skill used to participate in intervention activities. For example, the Sitting Together and Reaching to Play (START-Play) and Supporting Play Exploration and Early Development Intervention (SPEEDI) trials both refer within their intervention protocols to looking and following (Dusing et al., 2020; Harbourne et al., 2018). Whilst the responsiveness of vision to these interventions is not explicitly evaluated in these studies, frequency of looking is one element of evaluation via an assessment of problem-solving (Molinini et al., 2021). Other trials are including visual function as a focus within outcome measures (Benfer et al., 2018).

2.5 VISION-RELATED INTERVENTIONS

Children with a visual impairment are often well connected to specialist visual support services; however, navigating the maze for a child with multiple disabilities (e.g., cerebral palsy and vision impairment) can be more complex. Research in the United Kingdom found that visual difficulties occurring in children with disability are not always actively identified (Sargent, 2014) and it was felt that children with less severe impairments were least likely to receive the support they needed. It was also suggested that whilst children with severe and multiple disabilities are more likely to receive some kind of support, they may not receive specialist vision services (Ackland & Wade, 1995); it has been proposed that this may result from the idea that ‘nothing much can be done to help them’ (Elmenshawy et al., 2010). It has been suggested that the functional limitations of children with cerebral palsy are most often attributed to the more obvious motor skill impairments (Hyvarinen, 2010), so consideration of visual difficulties may be a low priority, with other health issues and therapy goals overshadowing visual concerns. A recent study exploring the perceptions of parents of young children with cerebral palsy reported that vision is a priority, with parents requesting providers offer more discussion on vision (Byrne et al., 2019).

In 2014, when the background to this PhD research was first being developed, there were two publications that provided guidance for managing vision-related problems in children with cerebral palsy. The first was a review article with a recommendation to "assess early and accommodate" for visual comorbidities (Novak, 2014), however, this instruction lacked specificity and an evidence base. The second publication, a scoping review of the literature on how to help children with visual problems and neurodevelopmental disorders, reported that the strongest evidence exists for the provision of spectacles to improve distance or near vision, but also identified many gaps (Williams et al., 2014). That scoping review reported that training programs and environmental modifications may help, but that additional research was required on the type of training and modification, the duration, and the age for training/modifications. Whilst it was also acknowledged in the review that the degree to which improvements in measured visual functions carry over to functional improvements was not clear, the limited outcome measurement options available for clinicians and researchers were noted as a limiting factor.

In 2020 an updated systematic review of interventions to prevent and treat children with cerebral palsy was published (Novak et al., 2020). This review of the best available evidence from 2012-2019 was aggregated with findings from a 2013 review (Novak et al., 2013). The 2020 review resulted in the addition of *vision training* as a newly listed intervention for children with cerebral palsy despite the existence of only very low quality of evidence. Using the best available evidence, the authors determined that benefits outweigh harms and vision is a very important problem to treat – important advice for clinicians seeking guidance on interventions for vision-related problems.

In 2021 an international clinical practice guideline based on systematic reviews for 'Early Intervention for Children Aged 0 to 2 years with or at high risk of cerebral palsy' published further recommendations related to vision (Morgan et al., 2021). In this guideline, three recommendations related to vision fall under the category of 'complication prevention': correction of strabismus, visual training and use of colour contrast cues. Interestingly, interventions 'to improve vision' are categorised by the guideline as complication prevention rather than 'skill development', perhaps placing less emphasis on the potential neuroplastic benefits that could result from improved vision.

Visual training, as included in both the systematic review of interventions (Novak et al., 2020) and the clinical practice guidelines for early intervention (Morgan et al., 2021), was recommended based on just one observational study (Lanners et al., 1999). In their study, Lanners and colleagues provided at least one course of visual rehabilitation to 30 infants including 15 infants with cerebral palsy. The visual training included exposure to black-and-white slides, black light training and multi-sensory stimulation. Following intervention, 20 of the 30 infants had increased attention and spontaneous visual curiosity and required less marked conditions of contrast and light for daily interactions than at baseline. It was, however, noted that six children with the most severe neuromotor damage had no change after treatment. The authors of this study described ‘improve’ as “a greater spontaneous use of residual vision, which, in turn, increases a child’s capacity for communication and interaction with the outside world, and participation in daily life” (p.8). They also acknowledged that “this type of improvement does not necessarily correspond to a measurable improvement at the medical-diagnostic level, as in measurement of visual acuity” (p.8) (Lanners et al., 1999). It is interesting that whilst Lanners and colleagues described the focus of their intervention study as improving the use of a child’s vision, which could be considered an outcome at the Activities and Participation levels of the ICF, vision training has been categorised by Novak and colleagues (2020) in their systematic review as an intervention focused on body structure and function change (specifically, improved vision processing). This suggests that in addition to the need for higher quality visual intervention studies to be undertaken with children with cerebral palsy, a review of outcome measures and their link to the focus of intervention within vision-related research is warranted.

2.6 THE ROLE OF MEASUREMENT IN INTERVENTION RESEARCH

Measurement has an important, indeed essential, role in intervention effectiveness research, as the ability to draw valid inferences from an intervention study is directly related to the choice of outcome measure (Coster, 2013; Rosenbaum et al., 1990). Whilst the psychometric properties of a measurement tool are important, the definition of the dependent variable in the intervention effectiveness study, which involves specifying the goals of the intervention in a measurable way, is also crucial (Whyte & Hart, 2003). It is the outcome measure that is used to determine the effect of the intervention. Implications of using an inadequate measure in intervention research include findings that are not useful or are misleading or underestimated. It is also unethical to use flawed measurement scales as they waste participant time and can present a risk if findings lead to ineffective or inappropriate clinical decisions or interventions (Polit & Yang, 2016).

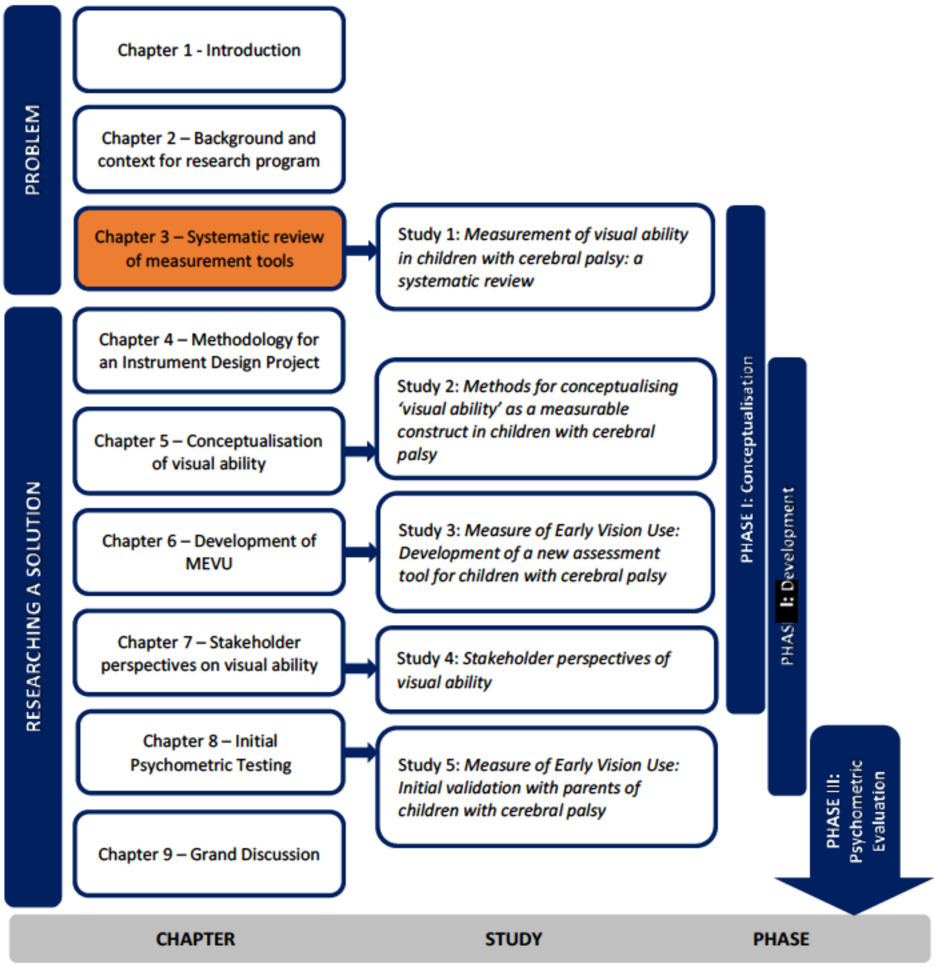
To maximise the usefulness of a chosen measurement tool in intervention research it is important to specify the link between the intervention and the outcome of interest (Coster, 2013). One method for specifying this link between outcome measures and interventions (dependent variables) that has previously been used within cerebral palsy research is use of the ICF framework and linking rules (Cieza et al., 2002; Hoare et al., 2011). Appraisal of the outcome measures used within intervention studies addressing the outcome of interest (visual ability) is therefore an important research direction.

The use of a tool to measure outcomes (i.e., to evaluate) is just one measurement purpose (Kirshner & Guyatt, 1985; Laver Fawcett, 2007). The clinical questions introduced in Chapter 1 suggest that it is relevant and necessary to look for visual ability measures with a range of purposes. “How does this child use her vision?” requires the use of an assessment for descriptive purposes. “Will use of vision improve?” requires the use of predictive tool, and “What can be done to improve vision use?” would need to be investigated using an outcome measure or evaluative tool. Whilst not identified as a need in Chapter 1, there is also a fourth purpose for measurement – to discriminate between individuals or groups (Kirshner & Guyatt, 1985). Because a measurement tool can be developed for one purpose, and then later validated for a different purpose, the identification of visual ability measurement tools for any of the four purposes is an appropriate and important first step for this program of research.

2.7 SUMMARY OF CHAPTER 2

This chapter outlined the key elements of the question behind this research: Can we improve outcomes for children with cerebral palsy, and their families, by focusing on ‘how vision is used’ in everyday activities? In doing so, the rationale and importance of this research has been established. Chapter 2 has also explained the importance of measurement tools within intervention studies and established the need to identify an appropriate measure of visual ability before undertaking research on the effectiveness of interventions to optimise visual ability. This chapter sets up the intention that should an appropriate measurement tool not be found to assess visual ability in children with cerebral palsy, a measurement project will be needed as a pre-requisite to intervention research on how to optimise outcomes for children with cerebral palsy and their families related to visual ability.

CHAPTER 3: Systematic review of measurement tools



3.1 INTRODUCTION TO CHAPTER 3

This chapter addresses the first objective of this thesis: to identify and evaluate existing measures that assess visual ability in children with cerebral palsy. This chapter comprises a systematic review of the literature undertaken to address this objective, followed by an update on recent publications available since 2016, when the review was published.

3.2 STUDY 1: A SYSTEMATIC REVIEW

This manuscript has been accepted and published by MacKeith Press in the journal *Developmental Medicine and Child Neurology*. The published pdf version of this manuscript is available in Appendix C with permission from the publisher.

> Deramore Denver, B., Froude, E., Rosenbaum, P., Wilkes-Gillan, S., & Imms, C. (2016). Measurement of visual ability in children with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*, *58*(10), 1016-1029. https://doi.org/10.1111/dmcn.13139

For reasons of text consistency, some alternations may exist between the published manuscript and the version presented in this chapter. Supplementary figures and tables published online with this manuscript by MacKeith Press are included in this chapter, whilst online appendices are available in Appendix C.

Title

Measurement of visual ability in children with cerebral palsy: A systematic review

Authors

Belinda Deramore Denver[1,2], Elspeth Froude[3], Peter Rosenbaum[1,4], Sarah Wilkes-Gillan[3] & Christine Imms[1]

Affiliations

[1] Faculty of Health Sciences, School of Allied Health, Australian Catholic University, Fitzroy, Vic.; [2] Victorian Paediatric Rehabilitation Service, Monash Children's Hospital, Clayton, Vic.; [3] Faculty of Health Sciences, School of Allied Health, Australian Catholic University, North Sydney, NSW, Australia. [4] Department of Pediatrics and CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada.

Corresponding author

Belinda Deramore Denver, School of Allied Health, Locked Bag 4115, Fitzroy, Victoria 3065, Australia belinda.deramoredenver@myacu.edu.au

Abstract

AIM To identify and evaluate measures of visual ability used with children with cerebral palsy.

METHOD Eight databases were searched for measures of visual ability. Key selection criteria for measures were: use with children with cerebral palsy; focus of visual ability measurement at the Activities and Participation domain of the International Classification of Functioning, Disability and Health (ICF). The Consensus-based Standards for the Selection of Measurement Instruments (COSMIN) Checklist was used to assess psychometric properties.

RESULTS From 6763 papers retrieved, 25 were relevant and 19 measures of visual ability were identified. Only 10 measures were supported with evidence of validity or reliability. No discriminative measure analogous to existing cerebral palsy functional classification systems was found. No outcome measure valid for evaluation of visual abilities of children with cerebral palsy was found.

INTERPRETATION Vision impairment is recognised as relevant to the functioning of children with cerebral palsy; however, measurement of vision is most often focused at 'Body Function' levels, for example visual acuity. Measuring visual abilities in the Activities and Participation domain is important in considering how a child with cerebral

palsy functions in vision-related activities. The lack of psychometrically strong measures for visual ability is a gap in current clinical practices and research.

What this paper adds

- A clear conceptual definition and framework for measuring visual ability is critical in furthering our understanding of the topic.
- No valid evaluative measures of visual ability were identified.
- There is no currently available measure of visual ability for children with cerebral palsy analogous to existing cerebral palsy functional classification systems.

3.2.1 Background

Cerebral palsy is a prevalent physical disability in childhood (ACPR Group, 2013). Its definition has been revised to identify the possibility of secondary impairments relating to vision:

> Cerebral palsy describes a group of permanent dis-orders 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., 2007, p.9).

Impairments additional to the motor disorder contribute to the developmental and performance challenges faced by children with cerebral palsy (Novak et al., 2012), and evidence suggests that disturbances to vision can be especially challenging for children (Cass et al., 1994). There is a growing body of literature reporting the relationship between vision impairments and various aspects of functioning for children with cerebral palsy, including gross motor, communication, cognition, self-care, and daily functioning skills (Coleman et al., 2015; Dutton et al., 2012; Elbasan et al., 2011; James et al., 2015; Salavati et al., 2014; Schenk-Rootlieb et al., 1993; Yin Foo et al., 2013).

Being able to describe the visual abilities of children with cerebral palsy, and targeting interventions to promote visual abilities, are important areas for practice and research, and valid and reliable measurement is required to establish efficacy for interventions targeting visual abilities or 'useful vision'. The 'Classification of Cerebral Palsy' specifies that accompanying impairments, including vision, should be classified as either present or absent, and that if present, the extent to which they interfere with the individual's ability to function or participate in desired activities and roles should be described, but no specific guidelines are provided for this (Rosenbaum et al., 2007). It is recommended that vision be assessed, and measures of visual impairment (corrected vision in each eye) are accepted.

The challenge of terminology when measuring 'vision'

The definition of visual impairment in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (World Health Organisation, 1992) is based on 'best corrected' vision. A level of vision impairment is obtained by measuring visual acuity with best possible refractive correction, and results are categorised from 'mild or no visual impairment' (visual acuity equal to or better than 6/18) to 'blindness' (no light perception, light perception, or visual acuity worse than 3/60). A recent systematic review and meta-analysis of the rates of co-occurring impairments and functional limitations in children with cerebral palsy used this definition in its finding that one in 10 children with cerebral palsy has a severe visual impairment or is blind (Novak et al., 2012). These findings suggest that impaired vision is a significant problem for some children with cerebral palsy; however, the authors of that review identified a lack of consistency among studies in the recording of information about vision impairments, and were consequently not able to include all vision impairment data in their analysis. Other 'visual impairments' included refractive errors, myopia, hypermetropia, astigmatism, and strabismus, in addition to the reporting of children with 'some impairment' or 'functional blindness'.

A definition or measurement of 'visual impairment' only describes the eye or visual functions being assessed, and these results, although valuable, do not specifically tell us how a child with cerebral palsy functions in vision-related activities (their 'visual ability'), particularly in the presence of other comorbidities such as gross motor limitations or cognitive impairments. Children with cerebral palsy may be diagnosed with visual deficits that are of ocular (eye) or cerebral (brain) origin, or a combination of both, and recognition of vision impairment resulting from damage to the brain is a rapidly growing area of research (Dutton & Bax, 2010). Visual impairments that result from damage to the brain may be referred to as cortical, cerebral, or neurological visual impairment. The visual abilities of a child can be impacted by impairments at any point along the primary visual pathway (eye, optic nerves, thalami, optic radiations, and primary visual cortices), in the visual association areas, or the oculomotor system (Dufresne et al., 2014).

Measurement of visual impairments, at the eye or brain level, does not directly provide information on functional limitations in daily life resulting from visual dysfunction, and does not provide information on the 'positive aspects' or 'ability' levels found in children with cerebral palsy. Whereas some children with cerebral palsy may have a visual impairment that limits performance and restricts participation in daily life, for other children visual ability may be considered a strength.

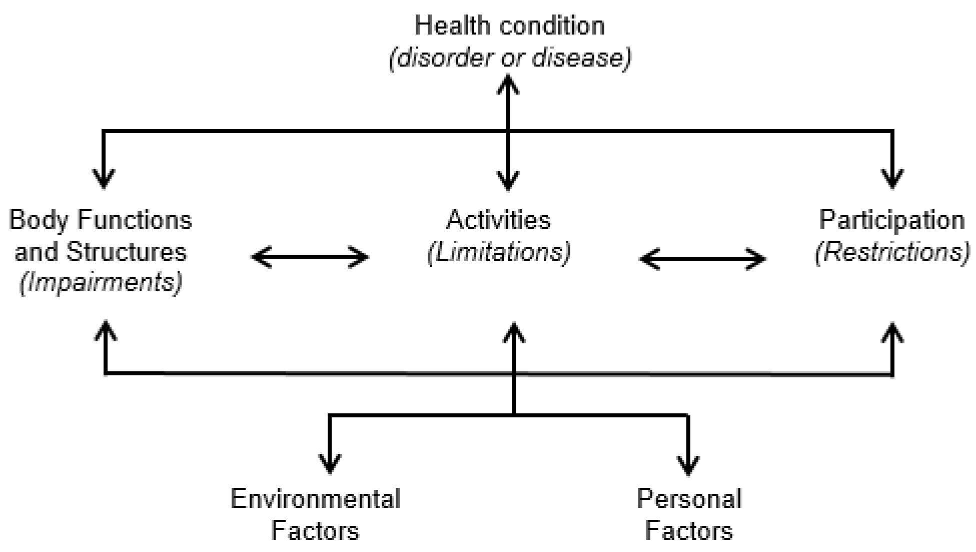
The measurement of visual abilities is complex. Unlike visual acuity, where a count or measure of the finest detectable visual detail can be made, providing direct counts or observations of how vision is used in daily life is less straightforward; the assessor is confronted by parameters in addition to vision. Measurement of visual functioning requires conceptualisation of what constitutes the variable 'visual ability', for inferences to be made from observations (Massof, 2002). The distinction between commonly used terminologies such as 'visual function' and 'functional vision' must be clarified, because the measurement of these apparently similar terms can describe very different aspects of vision-related functioning (Colenbrander, 2003). The absence of clearly defined measurement concepts is likely to lead to errors in measurement, in the interpretation of results, or both (Laver Fawcett, 2007).

A framework to describe the measurement of vision

The International Classification of Functioning, Disability and Health (ICF) was published by the World Health Organisation in 2001 as a framework for measuring health and disability (World Health Organization, 2001) (see Figure 3.1), and this was followed in 2006 by the release of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), designed to record the characteristics specific to the developing child. In this framework, 'functioning' is a term encompassing all body functions, activities, and participation, and 'disability' is a term encompassing impairments, activity limitations, and participation restrictions. The ability of a child to function is seen as a dynamic interaction between elements of these domains and is powerfully influenced by contextual factors, including environmental barriers and facilitators to functioning, and personal factors. The ICF and ICF-CY provide a common language to describe functioning, and can serve as a connecting framework between assessments and interventions (Cieza et al., 2002). The ICF framework is now frequently used in clinical and research practice (Schiariti et al., 2014), and there is a growing body of evidence reporting that impairment-based measures can only provide limited information on functional abilities (Gorter et al., 2004; Hoare et al., 2011).

Figure 3.1

International Classification of Functioning, Disability and Health (ICF)



Note. Reproduced with permission from the World Health Organization

The ICF framework can be used to define and describe the measurement of vision, and has been used by Colenbrander (2010a) to differentiate between two types of vision.

‘Visual functions’ describe how the eye functions, with deficits described as ‘visual impairments’, and these have been aligned with the Body Functions and Structures domain of the ICF. ‘Functional vision’ describes how the child functions in vision-related activities, and this has been aligned with the Activities and Participation domain of the ICF. Functional vision is what the current authors term ‘visual ability’. Although in this non-hierarchical framework no domain is superior to another, and interaction between domains is highlighted, the ICF framework provides a structure for considering where assessments and/or interventions are placed, and it defines the type of information in each domain.

‘Body Functions’ are the ‘physiological functions of body systems (including psychological functions)’, and ‘Body Structures’ are ‘anatomical parts of the body such as organs, limbs and their components’ (World Health Organization, 2001). Vision is most clearly described by the second chapter of the ICF Body Functions and Structures domain. The code b210 ‘Seeing functions’ describes ‘sensory functions relating to sensing the presence of light and sensing the form, size, shape and colour of the visual stimuli’ (World Health Organization, 2007). This includes visual acuity, visual field functions, light sensitivity, colour vision, contrast sensitivity, and the overall quality of the picture. This chapter also includes the functions of structures in and around the eye that facilitate seeing functions, including internal muscles (e.g. accommodation of the lens), external muscles (e.g. muscles to move the eyes for looking in different directions), and the eyelid (e.g. protective reflex). The codes for b210 ‘Seeing functions’ and b2152 ‘Functions of external muscles of the eye’ have recently been included in the ICF Core Set of categories most relevant to children and young people with cerebral palsy (Schiariti et al., 2015).

Vision involves more than seeing with the eyes, however, and another chapter from the ICF Body Functions and Structures domain is critical to how and what children see. The first chapter, b1 ‘Mental functions’, includes codes for orientation, intellect, attention, memory, psychomotor functions, perception (including visual perception and visuospatial perception), and basic and higher-level cognition. These functions are all relevant and necessary to seeing and creating useful vision. Vision may also be impaired by damage to structures related to the eye or structures of the brain.

Performance in vision-related activities is captured by the ICF Activities and Participation domain. Activity is ‘the execution of a task or action by an individual’, and

Participation is ‘involvement in a life situation’ (World Health Organization, 2001). The domain chapters describe tasks, actions, and life situations where vision occurs: d1 ‘Learning and applying knowledge’, d2 ‘General tasks and demands’, d3 ‘Communication’, d4 ‘Mobility’, d5 ‘Self-care’, d6 ‘Domestic life’, d7 ‘Interpersonal interactions and relationships’, d8 ‘Major life areas’ (including education), and d9 ‘Community, social and civic life’.24 There are three codes in the first chapter which are particularly relevant to using vision: d110 ‘Watching’, d160 ‘Focusing attention’, and d161 ‘Directing attention’. An example of the assessment of vision that references the ICF-CY activity areas is the work of Hyvärinen and Jacob (2011), where four core areas of functioning have been identified for assessment: orientation/mobility, communication, activities of daily living, and sustained near vision tasks, such as reading.

Visual abilities can be measured for different types of impairment (i.e. ocular or cerebral visual impairment [CVI]), and the type or reason for the impairment is not the relevant factor. In this sense the measurement of vision can be descriptive of current abilities without the need to explain or interpret what is facilitating or inhibiting functioning. A valid measure of visual abilities will provide information about what a child with cerebral palsy can do in vision-related activities; this is different from information that can be derived from results of measures of the eye/s or visual functions. Activity- and Participation-level measurement is influenced by ‘Body Function’ parameters such as cognition, visual acuity, and muscle tone; ‘Environmental Factors’ such as wearing glasses to aid vision, or the presence and quality of lighting and distractions; and ‘Personal Factors’ such as age and interest in the tasks at hand. This is consistent with the ICF Framework’s depiction of these many factors as constituting a dynamic biopsychosocial model, and a report of visual ability is likely to represent an integrated assessment of ‘functioning’.

Two qualifiers or constructs within the ICF Activities and Participation domain can further assist with interpreting abilities, including vision. ‘Capacity’ describes an individual’s ‘best performance’, and ‘performance’ describes an individual’s ‘usual activity’ (World Health Organization, 2001). A measure of visual ability that describes performance in vision-related activities would be considered to provide the most useful information on daily functioning (Rosenbaum et al., 2014), whereas a measure that describes visual capacity provides valuable information on how a child can perform given optimal environmental conditions. Both forms of assessment were of interest in this review, because interventions are often aimed at reducing the gap between these two related aspects of functioning (Rosenbaum & Stewart, 2004).

Measurement of 'visual ability'

The definition of vision that describes a child's functioning at the Activity and Participation domain of the ICF is the focus of the current review, and what has previously been referred to as 'functional vision' is hereafter defined as 'visual ability'. The importance of visual abilities to the functioning of children with cerebral palsy, and the potential for providing clinical interventions at the Activity and Participation level, together warrant a review of the availability of this type of measure. We have addressed the complexity of defining visual ability for measurement and intervention by applying the ICF framework to this area of practice. The primary objectives of this systematic review were to identify what tools are currently available to classify and/or measure the visual ability of children with cerebral palsy; and to explore, among the identified tools, the evidence for validity and reliability of visual ability measures in children with cerebral palsy. The broader research question of whether interventions can be provided to children with cerebral palsy and their families to improve activity performance (skills and abilities) in vision-related activities, and/or minimise the impact of vision impairment (ocular or cerebral) on daily activities and participation, cannot be answered in the absence of valid and reliable measures. This review is one step towards addressing the visual abilities of children with cerebral palsy for clinicians and researchers focusing on Activity and Participation level interventions.

3.2.2 Method

The methods used in this systematic review were designed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2009). The review protocol was registered online in February 2014 with the International Prospective Register of Systematic Reviews (Registration number CRD 42014006387) and can be accessed online at http://www.crd.york.ac.uk/PROSPERO/prospero.asp.

Eligibility criteria

Populations

The review is focused on the measurement of visual ability in children (aged 0–18y) with cerebral palsy. A measure that has been developed for, or used with, children with a disorder of movement and posture was considered a core requirement in the search for valid and reliable measures of visual abilities for children with cerebral palsy. Studies including children with neurological impairments were eligible for inclusion when participant descriptions were suggestive of cerebral palsy, for example terms such as hemiplegia, hypoxic–ischemic encephalopathy, periventricular leukomalacia or intraventricular haemorrhage, brain injury or impairment in the first 5 years of life, or where there was mention of a motor impairment (e.g. physical disability). There was no limitation placed on what percentage of participants must be children or have an eligible diagnosis.

Studies were excluded when participants were exclusively described by a diagnosis other than cerebral palsy (e.g. Down syndrome) or no participants were younger than 18 years old. The paediatric focus was important because of the variations in the activities and participation of adults compared with children, and because the impairments seen in the adult population are different from those seen in paediatric populations. Studies were also excluded if participants were described as having only ocular or 'low vision' impairment – that is, with no mention or exclusion of children with physical or neurological disabilities.

Measures

Studies were sought that included measures of visual ability. 'Visual ability' was defined as 'how someone performs in vision-related activities', (Colenbrander, 2003) and measures were identified as addressing visual ability when the focus of the vision measurement was at the Activities and Participation domain of the ICF. Any tool designed or described as measuring 'functional vision' was included, and vision-specific subscales of broader tools were included. Tools that assessed components of vision that focused only on the Body Functions and Structures domain of the ICF (e.g. visual acuity, visual perception) are not considered to be measuring visual ability as defined by this review and were excluded. Measures designed for any purpose were eligible for inclusion, that is descriptive, discriminative, evaluative, and predictive measures (Kirshner & Guyatt, 1985). A measure was eligible when assessment resulted in a visual ability category, level, or score. Descriptive records or checklists were excluded, as were single item measures with only two categories (e.g. ‘functional vision’ and ‘no functional vision’). Measurement tools were not excluded on the basis of their psychometric properties.

Publication types

Quantitative interventions, diagnostic, prediction or prognostic studies, aetiological assessments, frequency, instrumentation or psychometric studies were included. Abstracts from conferences and unpublished studies were initially included, and further information sought from the authors. Letters to the editor and commentaries were excluded. Only full papers written in English were included. There was no limit placed on the publication dates of studies; it was anticipated that because of advances in technology, recent studies might have a greater focus on the measurement of Body Function elements of vision compared with the older approaches that relied on observation of performance.

Search

The search strategy was conducted in two steps. Step 1 involved the identification of visual ability measures, and Step 2 searched for evidence of validity and reliability of the identified measures. Searches were conducted in the following databases: Medline, CINAHL, PsycINFO, ERIC, A+ Education, Embase, Scopus, and the Cochrane Library. An example of the search strategy used in MEDLINE and modified for other databases is provided in Appendix C. Additionally, citations from papers and measures meeting the inclusion criteria were tracked through Web of Knowledge, and hand searching of reference lists of retrieved studies was carried out to ensure additional relevant references were identified. The searches were conducted up to April 2015.

Step 1: Three key concepts were used to guide the first search strategy to identify measures of visual ability: (1) measurement (e.g. classification, assessment), (2) cerebral palsy (e.g. hemiplegia, brain injury), and (3) vision (e.g. vision, blindness). Relevant terms and synonyms from the literature and medical subject headings (MeSH terms) and relevant terms from key literature (in title and abstract) were used to guide the search. Search results were limited to children.

Step 2: The names of the tools/measures found during the first search were used in a complementary search that aimed to identify additional papers with evidence of validity and/or reliability. The second search was conducted using the measure or author name as text words, and then combined with MeSH terms and keywords for validity and reliability. A decision was made not to seek psychometric evidence for measures containing visual subscales where these properties could not be interpreted separately from the whole measurement score.

Study selection

The first author screened all identified papers by title, and irrelevant papers were excluded. Two authors (BDD and EF) then independently assessed the titles and abstracts of papers. Papers potentially meeting the inclusion criteria were retrieved in full text and reviewed independently by the same two authors. Consensus on the inclusion or exclusion of papers was reached using additional input through discussions with a third author (CI) when required. Where papers did not provide descriptive information on a tool, further searching was undertaken and/or authors of papers were contacted as required.

Data collection process

A data extraction sheet adapted from the CanChild Outcome Measures Rating Form (Law, 2004) was developed, piloted, and used to summarise information from published papers, manuals, and correspondence with authors. Extracted data included: information on papers reporting use of measures; general information on the tool (e.g. name of measure, authors); the focus of measure (ICF domains); clinical utility of the measure (e.g. instructions, format, time, training, and cost); scale construction; standardisation; reliability; and validity. The purpose of each measurement tool was determined by the review authors by looking at the aim, content, and use of the measure, and by using established definitions. Measures were defined as ‘describing’ details of what and how children function; ‘discriminating’ variations of an issue to identify discrete levels of function; ‘evaluating’ within-person change over time; and/or ‘predicting’ some concurrent or future status (Rosenbaum, 2015). Tools were categorised as measuring visual ability at a ‘performance’ or ‘capacity’ level by analysing their aim and format of administration.

‘Validity’ refers to the accuracy of a measure (Law, 1987). This review evaluated the content and construct validity of included measures. Special consideration was given to the development and content of measures, because in considering measurement of a concept like ‘vision’ it is important first to be sure that the measure is assessing the ‘right’ thing. Because there is no criterion standard for visual ability measurement, in this review whenever ‘criterion’ validity was mentioned as a psychometric property it was rated as ‘construct’ validity, as done previously by De Boer et al. (2004). ‘Reliability’ is the property of measure that shows that it is measuring something in a reproducible and consistent fashion (Law, 2004). Internal consistency, interrater reliability, intrarater reliability, and test-retest reliability were considered in this review. Reliability correlation coefficients were described according to the CanChild Outcome Measures Rating Form (≥0.8 as ‘excellent’, 0.6–0.79 as ‘adequate’, and <0.6 as ‘poor’) (Law, 2004). Responsiveness is the ability of a measure to detect change within an individual over time (Kirshner & Guyatt, 1985).

Quality assessment

The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist was used to evaluate the methodological quality of studies investigating aspects of reliability, validity, responsiveness, and interpretability of identified measures of visual ability (Terwee et al., 2012). Measurement properties were scored on a 4-point rating scale (poor, fair, good, or excellent), and a final rating was determined from the lowest rating of any within the set of items measuring that psychometric property. Pairs of raters including BDD plus one of EF, CI, or SWG completed the quality assessments independently, followed by discussion to reach consensus on a final rating. Consensus was reached for all ratings without involvement of a third author.

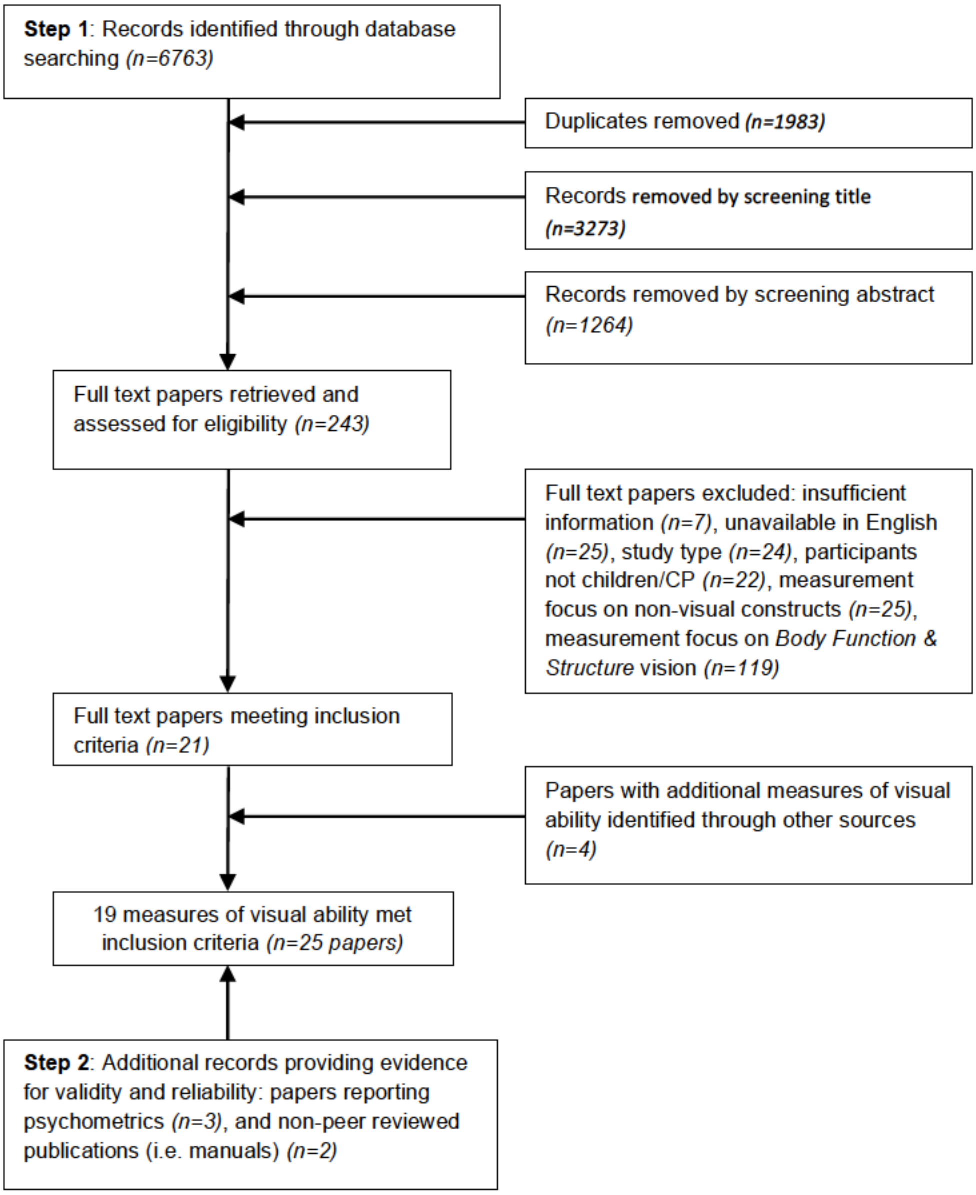
3.2.3 Results

Search results

Search results and study selection processes that led to the identification of nineteen included measures are illustrated in Figure 3.2. Most excluded papers measured vision at the ICF Body Functions and Structures domain – that is, visual acuity, visual field, or visual perception. A list of excluded measures is available on request from the lead author (BDD).

Figure 3.2

Flow diagram describing selection of relevant papers for inclusion in the review



Included measures of visual ability

Table 3.1 summarises the included measures of visual ability. Nine measures focused on visual performance, and were typically questionnaires administered using caregiver report (Alimovic & Mejaski-Bosnjak, 2011; Feeny & Torrance, 1996; Ferziger et al., 2011; McCulloch et al., 2007; Ortibus et al., 2011; Pueyo et al., 2014; Saigal et al., 2005; Sintonen & Richardson, 1994; van Genderen et al., 2012). Nine measures focused on visual capacity, and were mostly administered test items or judgment-based therapist ratings (Atkinson et al., 2002; Bellman & Cash, 1987; Blanksby & Langford, 1993; Erhardt et al., 1988; Hoyt, 2003; Malkowicz et al., 2006; Salati et al., 2001; Stillman, 1974; Wong et al., 2006). One measure addressed both visual performance and visual capacity (Roman-Lantzy, 2007). Although authors did not articulate the purpose of their measure using defined terminology, it was determined by the review authors that included measures had been developed and/or used to describe, discriminate, predict, or evaluate visual ability, and some measures were intended for more than one purpose. The Atkinson Battery for Child Development for Examining Functional Vision (Atkinson et al., 2002) was the most commonly used measure, and the Health Utilities Index – Mark III (Feeny & Torrance, 1996) was the second most common, but most measures were described or used in only a single study. A list of studies using the measures is available in Appendix C.

Table 3.1

Summary of visual ability measures

Measure & Year Published	Aim of measure & Target population	Purpose[a]	Measurement constructs	Administration/ response format	Scores & Interpretation	Focus[b]
ABCDEFV 2002	To assess functional visual capacities in children with a mental age of 0-6 years	Descriptive Predictive	Core vision; Additional tests	Administered items	Pass/fail score for each test based on normative data (*n*=318 typically developing children)[45]; each failed item includes suggestions for further specific assessment or follow-up	Capacity
Alimovic et al 2011	To assess visual attention & visual communication in children with perinatal brain damage	Evaluative	Visual attention; Visual communication	Judgment-based therapist rating[c]	Two scales rating function - visual attention: 'very interested in looking' to 'does not keep attention'; visual communication: 'using vision in communication (looks and response to facial expressions)' to 'does not look at other person at all'	Performance
Callier Azusa Scale 1974	To assess development, including visual development in deaf-	Descriptive	Visual development	Observation; Administered items	Developmental level for visual skills determined by highest level of achievement, where all lower level behaviours	Capacity

	blind and multi-handicapped children				consistently reached; level/score corresponds with a developmental age	
CVI Questionnaire 2011	To screen for cerebral visual impairment in children suspected of CVI	Discriminative Predictive	Visual attitude (fixation, visual field, visual attention, influence of environment); Ventral stream; Dorsal stream; Complex problems; Other senses; Associated characteristics	Parent/caregiver completed questionnaire	CVI characteristics rated as present/not present; sum scores interpreted for CVI prediction	Performance
CVI Range 2007	To assess visual functioning in children with CVI	Descriptive Evaluative	Colour preference; Need for movement; Visual latency; Visual field preferences; Difficulties with visual complexity; Light gazing; Non-purposeful gaze; Difficulty with distance; Atypical visual reflexes; Difficulty with visual novelty; Absence of visually guided reach	Interview administered questionnaire; Observation; Administered items	Two scores: Across CVI (level of functioning across behaviours) and Within-CVI Characteristics (how much each characteristic is interfering with vision, or how much the CVI characteristics has resolved); Summary score from 0 (no functional vision) to 10 (typical or near-typical visual functioning)	Performance & Capacity

EDVA 1998	To measure visual development in subjects of all ages and cognitive levels (e.g. children with developmental disabilities, multiple handicaps, cerebral palsy and/or learning disabilities)	Descriptive Evaluative	Primarily Involuntary Visual Patterns (reflexive): Pupillary Reactions, Doll's Eye Responses, & Eyelid Reflexes; Primarily Voluntary Eye Movements (cognitively directed): Localisation (Visual Approach), Fixation (Visual Grasp), Ocular Pursuit (Visual Manipulation), & Gaze Shift (Visual Release)	Administered items	Skills rated as present, normal and well-integrated; emerging or abnormal; absent; or transitional pattern replaced by more mature pattern; results indicate development level (up to 6 months) for each skill cluster, and indicate gaps in skill sequences, developmentally inappropriate patterns, and specific intervention needs.	Capacity
Functional Visual Questionnaire 2011	To assess daily visual performance in children with cerebral palsy who are difficult to assess (severe motor, cognitive, and communicative limitations)	Descriptive	Basic visual skills; Visual function during interactive play and communication situations	Educator completed questionnaire	Items rated 1 (never) to 5 (often >75%) or N/A	Performance
Hoyt 2003	To functionally evaluate vision in research study (children with PVL or	Evaluative	Visual function	Judgment-based therapist rating[c]	Scale rated from 1 (Light perception only) to 6 (Completely normal vision); improvements in vision	Capacity

	infarction of the visual cortex)				determined by change in level of function score	
HSCS-PS 2005	To assess health status of preschool children (2.5 to 5 years of age), including vision	Descriptive	Vision (ability to see)	Parent/caregiver and/or clinician completed questionnaire	Five levels of ability – 1 (sees normally without glasses e.g. able to see well enough to recognise small objects and familiar people at distance) to 5 (unable to see at all); vision not interpreted independently of other dimensions of health status	Performance
HUI-III 1996	To measure health status and health-related quality of life, including vision, in people older than 5-years in both clinical and general populations	Descriptive	Vision	Parent/caregiver completed questionnaire or self-report version for ≥12-year	Six levels – 1 (able to see well enough to read ordinary newsprint and recognise a friend on the other side of the street, without glasses or contact lenses) to 6 (unable to see at all); vision attribute of health status and health-related quality of life is not interpreted independently of other attributes	Performance

Institutes' Developmental Profile 2006	To evaluate neurological abilities, including visual competency in brain injured populations	Evaluative	Visual competency	Judgment-based therapist rating[c]	Visual competence subscale scored from I (Light reflex) to VII (Reading with total understanding)	Capacity
Low Vision Checklist 1999	To measure visual function in uncooperative patients (children with low vision, neurological deficits, or both)	Descriptive	Light perception; visual exploration; fixation; following; grabbing; grabbing a moving object; deambulation; optokinetic nystagmus	Administered items	Item success scored yes/no; sum of success scores divided by number administered tests; final visual quotient score ranges from 0 (absence of visual behaviour responses) to 1 (presence of visual behavioural responses to all tests)	Capacity
PreViAs 2014	To assess visual behaviour/visual cognitive abilities in infants <24 months	Descriptive	Visual attention; Visual communication; Visual-motor coordination; Visual processing	Parent/caregiver completed questionnaire	Visual behaviours rated yes/no; total score for each domain place child within or outside normal range of visual maturation	Performance
Short CVI Questionnaire 2012	To diagnose CVI in children with good visual acuity suspected to have CVI	Discriminative	Dorsal stream; Ventral stream	Questionnaire[c]	Presence of problems scored no/yes/sometimes; sum score not valid predictor of CVI diagnosis	Performance
SoGS 1987	To screen development,	Descriptive	Function (functional response to visual	Administered items	Achieved skills recorded and summed for total score and	Capacity

	including visual skills in children birth to 5 years		stimuli); Comprehension (interpretation of intact visual function)		plotted against chronological age to produce developmental level; performance two bands below age range is recommended for further investigation	
VAP-CAP 1993	To assess visual functioning (capacity, processing and attention) in children who are visually impaired	Descriptive	Low Vision (visual capacity and basic levels of visual attention - how much the child can see and how visual attention is motivated); Visual Processing (visual perceptual and visual cognitive abilities and the more complex levels of visual attention)	Administered items	Scoring method unclear; range of response options and interpretation described[d]; highlights areas of visual deficit and areas for intervention	Capacity
Visual Skills Inventory 2007	To evaluate visual skills and responses to familiar situations in children with neurological impairment	Descriptive	Visual skills and responses to familiar situations -visual recognition of food and objects; visual guided behaviours with social content	Parent/caregiver completed questionnaire	Questions scored yes/no for visual behaviours; additional scores for some items e.g. distance for vision from 6 feet to less than 1 foot	Performance

Wong et al 2006	To assess functional visual outcome in research study (children aged 18 months to 14.5 years with central or peripheral visual disorder, and lack of clinical visual recovery for at least 12 months)	Evaluative	Functional vision	Judgment-based therapist rating[c]	Scale from 1 (light perception only) to 5 (completely normal vision); study interpreted positive outcomes as improvement of one level	Capacity
15-D 1994	To measure health-related quality of life, including vision, in adults (aged 16 years+)[e]	Descriptive	Vision	Self-administered questionnaire	5 level scale: 1 (I see normally, i.e. I can read newspapers and TV text without difficulty, with or without glasses) to 5 (I cannot see enough to walk about without a guide, i.e. I am almost or completely blind); vision scale not interpreted separately from other health domains	Performance

Note. [a]Purpose of measure (to describe, discriminate, predict or evaluate) determined by review authors based on aim, content and use of the measure. [b]Focus of measure (Performance or Capacity) determined by review authors based on measurement aim and format. [c]Administration format interpreted by review authors from limited information. [d]The Instructional Video and VAP-CAP Kit which were unavailable may provide additional information on scoring and interpretation. [e]16D (for adolescents aged 12-15 years) and 17D (for children aged 8-11 years) were developed based on the original 15D. ABCDEFV, Atkinson Battery for Child Development for Examining Functional Vision; CVI, cerebral or cortical visual impairment; EDVA, Erhardt Developmental Visual Assessment; PVL, periventricular leukomalacia; HSCS-PS, Health Status Classification System – Preschool; HUI-III, Health Utilities Index – Mark III; PreViAs, Preverbal Visual Assessment; SoGS, Schedule of Growing Skills; VAP-CAP, Visual Assessment Procedure – Capacity, Attention, and Processing; 15-D, 15-Dimension Questionnaire

The identified measures used nominal (e.g. yes or no responses in the Preverbal Visual Assessment (Pueyo et al., 2014)) or ordinal levels of measurement. No measure used item weighting to calculate a total score, and the level of difficulty for individual visual ability items has not been established in any measure. The scores from measures were used to describe visual skills and abilities (Ferziger et al., 2011), to establish normal or estimated visual development (Atkinson et al., 2002; Bellman & Cash, 1987; Erhardt et al., 1988; Pueyo et al., 2014; Stillman, 1974), to describe or predict CVI (Ortibus et al., 2011; Roman-Lantzy, 2007; van Genderen et al., 2012), and to make recommendations about follow-up or further assessment and for intervention planning (Alimovic & Mejaski-Bosnjak, 2011; Blanksby & Langford, 1993; Erhardt et al., 1988; Hoyt, 2003; Malkowicz et al., 2006; Roman-Lantzy, 2007; Wong et al., 2006).

Psychometric properties of visual ability measures

Table 3.2 summarises the studies (n=11) that provided evidence about validity and reliability of the included measures. Studies included children with a range of motor and visual impairments (ocular and cerebral). Many of the included studies recruited participants from sites providing services to children known or suspected to have visual impairments, such as from vision clinics (Blanksby & Langford, 1993; Ferziger et al., 2011; García-Ormaechea et al., 2014; McCulloch et al., 2007; Newcomb, 2010; Ortibus et al., 2011; Pueyo et al., 2014; van Genderen et al., 2012).

Table 3.2

Summary of studies reporting data on validity and reliability

Measure	Study	*n*	Motor impairment	Visual impairment	Other participant details	Age	Recruitment	Location
ABCDEFV	Mercuri et al (1999)	29	Cererbal palsy (*n*=10) at 2-year follow-up: hemiplegia (*n*=4), tetraplegia/ severe delay (*n*=6)	Number of abnormal visual tests (in CP participants): one (*n*=1), three (*n*=2), four (*n*=2), five (*n*=1), and six (*n*=4)	nd	5 months + 2 years	Larger study on outcomes in full term infants with brain lesions	UK
CVI Questionnaire	Ortibus et al (2011)	91	Cerebral palsy (*n*=41) including unilateral (*n*=14); bilateral (*n*=26); athetosis (*n*=1); wheelchair users (*n*=6); not self-mobile (*n*=3)	Visual field loss (*n*=8); glasses (*n*=36); fixation problems (*n*=12); attention problems (*n*=23); CVI (*n*=45); low vision (*n*=0), near normal vision (*n*=31)	Mentally delayed (*n*=45)	41 to 204 months (6 years 10 months)	Specialist CVI clinic	Belgium
CVI Range	Newcomb (2010)	104	Other disabilities including cerebral palsy	CVI (*n*=104); other ocular conditions	Other disabilities including DD, ID, health impairment, HI	6 to 144 months (46.5 months)	Multistate CVI mentorship project	USA
EDVA	Erhardt et al (1988)	1	Moderate cerebral palsy (*n*=1)	nd	College student	21 years	nd	USA
Functional Visual Questionnaire	Ferziger et al (2011)	77	Cerebral palsy (GMFCS V, MACS V) (*n*=77) including spastic quadriplegia (*n*=61), athetoid quadriplegia (*n*=5),	CVI (*n*=26); OA (*n*=25); no visual impairment (*n*=26)	All participants: severe to profound ID, unable to communicate verbally or use communication	3 to 20 years (8 years, 3 months)	Rehabilitation centre	Israel

			mixed quadriplegia (*n*=8), hemiplegia (*n*=3)		devices in consistent manner; totally dependent ADLs			
PreViAs	Garcia-Ormaechea et al (2014)	220	Motor disability (*n*=8)	Normal visual maturation (*n*=128), motor disability + normal visual maturation (*n*=2); Abnormal visual maturation (*n*=92), motor disability + abnormal visual maturation (*n*=6)	nd	Birth to 24 months	Vision clinic	Spain
PreViAs	Pueyo et al (2014)	20	nd	nd	nd	Under 24 months	Vision clinic	Spain
		298	No motor impairment	No visual impairment	nd	0.1 month to 23.98 months (39.31 weeks)	Primary health care centres	Spain
Short CVI Questionnaire	van Genderen et al (2010)	53	Mild to moderate cerebral palsy (*n*=20)	CVI (*n*=30) including visual field defects (*n*=16); Ophthalmology assessment (in cerebral palsy participants): significant refractive error (*n*=1), OA (*n*=3), normal (*n*=16)		5 to 16 years (8 years)	Institute for Visually Impaired	Netherlands

SoGS	Bellman & Cash (1987)	20	nd	nd	nd	36 to 60 months	Health district	UK
VAP-CAP	Blanksby & Langford (1993)	193	Normal physical status (*n*=98), mild delay or impairment (*n*=32), moderate delay or impairment (*n*=25), severe delay or impairment (*n*=38)	Visually impaired children. Visual acuity range: light perception to 6/18. Functional vision subjectively classified: profoundly low (*n*=11), low (*n*=8), impaired (*n*=109), CVI (medical diagnosis) (*n*=65).	nd	3 months to 4.5 years	Institute for the Blind	Australia
Visual Skills Inventory	McCulloch et al (2007)	76	Physical disability type: normal (*n*=15), spastic hemiplegia (*n*=9), diplegia (*n*=12). Quadriplegia (*n*=17), dyskinesia (*n*=6), ataxia (*n*=2), other (*n*=15); Physical disability: normal (*n*=10), mild (*n*=20), moderate (*n*=22), severe (*n*=23), unknown (*n*=1)	VI: ocular (retina/lens) (*n*=11), optic nerve (*n*=14), cerebral (posterior pathways/visual field) (*n*=32), cognitive visual dysfunction (*n*=8), nystagmus (*n*=44), strabismus (*n*=57); Blind (*n*=5), light perception or gross form perception (*n*=10), severe (*n*=7), moderate (*n*=12), mild (*n*=16), very mild (*n*=16), no acuity impairment (*n*=9)	Intellectual disability: normal (*n*=13), mild (*n*=9), moderate (*n*=25), severe (*n*=25), unknown (*n*=4)	7 months to 16 years	Vision clinic	UK

Note. [a]Not a peer-reviewed study (reliability study published in manual). SoGS, Schedule of Growing Skills; nd, not documented; VAP-CAP, Visual Assessment Procedure – Capacity, Attention, and Processing; CVI, corticial/cerebral visual impairment; EDVA, Erhardt Developmental Visual Assessment; GMFCS V, Gross Motor Function Classification System (Level V – Lowest level of functioning with child having no means of independent movement and is transported in a wheelchair); MACS V, Manual Ability Classification System (Level V – lowest level of functioning with child not handling objects, and severely limited in ability to perform even simple actions); OA, optic atrophy; ID, intellectual disability; ADLs, activities of daily living; PreViAs, Preverbal Visual Assessment; VI, visual impairment; ABCDEFV, Atkinson Battery for Child Development for Examining Functional Vision; DD, developmental delay; HI, hearing impairment.

Validity and reliability results for the included measures are summarised in Table 3.3. While construction of visual ability measures included comprehensive reviews of the literature and existing measures, combined with clinical experience of authors, there was no reported inclusion of children or primary caregivers in the selection of items for any visual ability measure. The Functional Visual Questionnaire (Ferziger et al., 2011), Visual Assessment Procedure – Capacity, Attention and Processing (Blanksby & Langford, 1993), and Visual Skills Inventory (McCulloch et al., 2007) used factor analysis and principal components analysis to confirm dimensionality; however, these factors were not incorporated into the scoring schema or used to aid interpretability of the measures. Internal consistency, test–retest, or interrater reliability were reported for six measures (Bellman & Cash, 1987; Blanksby & Langford, 1993; Erhardt et al., 1988; Ferziger et al., 2011; García-Ormaechea et al., 2014; Newcomb, 2010; Pueyo et al., 2014). Clinicians in reliability studies for the CVI Range (Roman-Lantzy, 2007) and Erhardt Developmental Visual Assessment (Erhardt et al., 1988) had undergone training programmes in the administration and scoring of the measure, before testing. No measure reported intra-rater reliability, and there were no studies of responsiveness. Although seven intervention studies were identified in the search, and six of these aimed to evaluate change in vision ability, none used an assessment tool with evidence to support validity for evaluative purposes (Alimovic & Mejaski-Bosnjak, 2011; Erhardt, 1987; Luan et al., 2013; Malkowicz et al., 2006; Poland & Doebler, 1980; Wong et al., 2006; Woolfson, 1998).

Table 3.3

Summary of results: Validity and Reliability

Measure	Psychometric properties	Study	Result
ABCDEFV	Validity	Mercuri et al (1999)	VEP, visual fields, fixation shift highly sensitive to negative developmental and neuromotor outcomes; OKN and acuity highly specific to positive developmental and neuromotor outcomes; vision at 5-months correlated with DQ at 2-years on GMDS 0.86 (*n*=29)
CVI Questionnaire	Validity	Ortibus et al (2011)	Discriminates between children with and without a diagnosis of CVI; more sensitive (75-80%) but less specific (60%) in identifying CVI; AUC 0.81 for L94, AUC 0.78 for TVPS-R, AUC 0.84 for VP subtest of VMI (*n*=91)
CVI Range	Reliability	Newcomb (2010)	Excellent internal consistency for total score *α*=0.96 (*n*=104); Excellent test-retest reliability *r*=0.99; *k*=1.0 (*n*=20) after 1-14 days; Excellent inter-rater agreement between two assessors *r*=0.98; *k*=0.83 (*n*=27); Absolute difference in scores 0.31 point difference can change CVI Range placement (e.g. 3.0 is Phase 1 and 3.25 is Phase 2); Agreement between Across- and Within-CVI scoring methods *k*=0.88
EDVA	Validity	Erhardt et al (1988)	Literature review of visual development; pilot phase of use and revisions
	Reliability	Erhardt et al (1988)	Poor inter-rater agreement with test author (*n*=20 raters, 1 subject) entire test ICC 0.53 and 80.9%; (Pupillary reactions ICC 0.022 and 63.4%; Doll's Eye Responses ICC 0.74 and 85.6%; Eyelid Reflexes ICC 0.63 and 86.6%; Localisation ICC 0.67 and 86.3%; Fixation ICC 0.59 and 77.5%; Ocular Pursuit ICC 0.52 and 77.2%; and Gaze Shift ICC 0.57 and 80.1%); Four scoring categories agreement, 82.3% (present, normal and well-intergrated); 68.4% (emerging or abnormal); 71.7% (absent); 90.6% (transitional pattern not present)
Functional Visual Questionnaire	Validity	Ferziger et al (2011)	Exploratory factor analysis identified 2 dimensions (81.12% of variance): task-oriented visual skills (eigenvalue 8.78%) and basic visual skills (eigenvalue 5.83%); Discriminates for children with no visual impairment; does not discriminate between children with CVI and children with OA; does not discriminate/predict visual function in children with CVI; 55% of variance of task oriented visual skills was explained by visual diagnosis, and 33% of variance of basic visual skills were explained by visual diagnosis; basic visual skills subscale correlates with VCS (*r*=0.691; 95% CI 0.504-0.816) and CIB visual performance code (*r*=0.525; 95% CI 0.280-0.706); task-oriented

			visual skills subscale correlates with VCS (r=0.802; 95% CI 0.669-0.885) and CIB visual performance code (r=0.605; 95% CI 0.385-0.760) (n=77)
	Reliability	Ferziger et al (2011)	Excellent internal consistency for factors: α =0.97 Task oriented visual skills; α=0.95 Basic visual skills (n=77); Excellent test-retest ICC=0.98; 95% CI 0.964-0.996 (n=14) after 8 months; Excellent inter-rater agreement by second caregiver ICC=0.87; (95% CI 0.762-0.935) (n=34)
PreViAs	Validity	Pueyo et al (2014)	Literature review, existing measures reviewed, working group with clinical experience domains, and pilot testing (n=20 caregivers)
		Garcia-Ormaechea et al (2014)	Normative outcomes determined for each domain at each age group (n=298); discriminates for infants with abnormal visual maturation; predictive values correlate with test battery of same visual domains/ages AUC ranged from 0.74 to 0.83 (n=220)
	Reliability	Pueyo et al (2014)	Excellent internal consistency for domains: α =0.92 visual attention; α=0.85 visual communication; α=0.92 visual–motor coordination; α=0.94 visual processing (n=298)
		Garcia-Ormaechea et al (2014)	Excellent test-retest reliability r=0.97 visual attention; r=0.94 visual communication; r=0.98 visual motor coordination; r=0.98 visual processing, within 7 days
Short CVI Questionnaire	Validity	van Genderen et al (2010)	Does not discriminate for children with CVI from children with behavioural, learning, attention, motor or coordination problems
SoGS	Validity	Bellman & Cash (1987)	Validity not established separately from other developmental domains
	Reliability	Bellman & Cash (1987)	Excellent agreement for vision subscale R=0.87 (<0.001) (n=20)
VAP-CAP	Validity	Blanksby & Langford (1993)	Existing measures reviewed, items selected for visual component, pilot testing of clinical utility, items with high correlations (>.85) and similar items from principal component analysis and factor analysis removed; principal component factor analysis identified three factors: visual processing ability (variables that require higher-order responses - visual perception, and visual cognition), visual capacity (variables that require the simplest responses with no need for prior experience or understanding e.g such as detection, location, fixation, following, and reaching), and formal visual learning (variables that reflect a degree of formal or educational learning e.g. writing and reading) (n=193)
	Reliability	Blanksby & Langford (1993)	Excellent test-retest correlation 0.97 (0.5-1.0) (n=30) within 14 days; excellent inter-rater agreement 0.99 (0.91-1.0) (n=30)

Visual Skills Inventory	Validity	McCulloch et al (2007)	Exploratory factor analysis identified two factors with a cumulative variance of 70.4%: visual recognition of food and objects (56.4% of variance), and visually guided behaviours with social content and reaction to bright sunlight (14%); sensitivity high for children with moderate or severe vision loss (96% and 94%) but lower specificity for children with normal to mild visual deficits (70% and 81%); responses to most questions in the inventory correlate with level of VA

Note. [a]Not a peer-reviewed study. ABCDEFV, Atkinson Battery for Child Development for Examining Functional Vision; VEP, Visual Evoked Potential; OKN, Optokinetic nystagmus; DQ, Developmental Quotient; GMDS, Griffith's Mental Development Scales; CVI, cortical/cerebral visual impairment; AUC, Area under curve; TVPS-R, Test of Visual-Perceptual Skills, Revised; VP, Visual Perception; VMI, Developmental Test of Visual-Motor Integration; *α*, Cronbach's alpha coefficient; *r*, Pearson's correlation coefficient; *k*, Cohen's kappa coefficient; EDVA, Erhardt Developmental Visual Assessment; ICC, intraclass correlation coefficient; OA, optic atrophy; VCS, Visual Classification Scale; CI, confidence interval; CIB, Coding Interactive Behaviour rating system; PreViAs, Preverbal Visual Assessment; SoGS, Schedule of Growing Skills; *R*, Spearman's rank correlation coefficient; VAP-CAP, Visual Assessment Procedure – Capacity, Attention and Processing; VA, visual acuity.

The visual ability subscales identified from the Health Status Classification System – Preschool (Saigal et al., 2005), Health Utilities Index – Mark III (Feeny & Torrance, 1996), and 15-Dimension Questionnaire (Sintonen & Richardson, 1994) do not allow interpretation of the vision scale separate from the other dimensions of health, and were therefore excluded from the analysis of psychometric information. Five measures had no available evidence for validity or reliability (Alimovic & Mejaski-Bosnjak, 2011; Hoyt, 2003; Malkowicz et al., 2006; Salati et al., 2001; Wong et al., 2006).

The methodological quality of 10 studies reporting psychometric properties was evaluated using the COSMIN (Blanksby, 1998; Blanksby & Langford, 1993; Erhardt et al., 1988; Ferziger et al., 2011; García-Ormaechea et al., 2014; McCulloch et al., 2007; Mercuri et al., 1999; Newcomb, 2010; Ortibus et al., 2011; Pueyo et al., 2014; van Genderen et al., 2012). The results of this analysis can be found in Table 3.4. No studies reported evidence for intra-rater reliability, measurement error, cultural validity, or responsiveness on any measure. The overall quality of studies is primarily limited by small samples and lack of hypotheses to support construct validation. The statistical methods used in all studies were based on classical test theory. No study used an item response theory model to develop or evaluate the measure.

Table 3.4

Quality assessment of psychometric studies according to COSMIN criteria

Measure	Study	Reliability			Validity					Responsiveness
		Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	
ABCDEFV	Mercuri et al 1999	x	x	x	x	x	POOR	x	x	n/a
CVI Questionnaire	Ortibus et al 2011	x	x	x	x	POOR	FAIR	x	x	n/a
CVI Range	Newcomb 2010	POOR	POOR	x	x	x	x	x	x	x
EDVA	Erhardt et al 1988	x	POOR	x	POOR	x	x	x	x	x
Functional Visual Questionnaire	Ferziger et al 2011	POOR	POOR	x	x	POOR	POOR	x	x	n/a
PreViAs	Pueyo et al 2014	POOR		x	GOOD	x	x	x	x	n/a
	Garcia-Ormaechea et al 2014	x	FAIR	x	x	x	FAIR	x	x	n/a

Short CVI Questionnaire	van Genderen et al 2012	x	x	x	x	x	POOR	x	x	n/a
VAP-CAP	Blanksby & Langford 1993	x	FAIR	x	FAIR	FAIR	x	x	x	n/a
Visual Skills Inventory	McCulloch et al 2007	x	x	x	x	POOR	POOR	x	x	n/a

Note. COSMIN, Consensus-based Standards for the selection of health Measurement Instruments; ABCDEFV, Atkinson Battery for Child Development for Examining Functional Vision; x, psychometric property not assessed; EDVA, Erhardt Developmental Visual Assessment; PreViAs, Preverbal Visual Assessment; VAP-CAP, Visual Assessment Procedure – Capacity, Attention and Processing.

3.2.4 Discussion

In this review, we sought measurement systems used to describe, discriminate, predict, or evaluate the visual abilities of children with cerebral palsy, and 19 measures were identified. The need to measure vision at a functional level has been identified previously (Colenbrander, 2010b; Hyvarinen, 2010; Leissner et al., 2014), and this systematic review contributes an important contemporary overview of the field that could be used to inform future developments in alignment with modern approaches to measurement. The findings of this review suggest that visual ability measures are not in common use with children with cerebral palsy and there is little evidence of ongoing validation of existing measures.

For this review the ICF was used as a conceptual framework to define the measurement of visual ability in relation to a child's level of functioning in vision-related activities. This approach measures vision at the Activities and Participation domain, rather than measuring vision according to the Body Functions and Structures domain, where inferences need to be made about levels of functioning in daily activities. Despite the frequent use of the ICF in rehabilitation research since its publication in 2001, only the authors of the Visual Function Questionnaire made reference to this framework.

The review identified some evidence of measures discriminating between levels of visual ability (Ortibus et al., 2011; van Genderen et al., 2012), but there is currently no available measure to discriminate between levels of daily visual functioning analogous to existing functional classification systems for children with cerebral palsy: the Gross Motor Function Classification System (Rosenbaum et al., 2008), Manual Ability Classification System (Eliasson et al., 2006), Communication Function Classification System (Hidecker et al., 2011), and Eating and Drinking Ability Classification System (Sellers et al., 2014). Most available measures of visual ability are descriptive, and there are no measures validated for predictive or evaluative purposes.

Current issues in visual ability measurement

The results of this systematic review highlight a number of problems with the measurement of visual ability. First, a measure should be designed and validated for a specific purpose (Hanna et al., 2005), but most measures included in this review did not clearly state the intended purpose of the 'assessment'. Analysis of the included measures by the review authors suggests that most existing measures are meant to be descriptive tools.

Second, the items selected for a measure are important, and items in a descriptive measure should include all the characteristics that discriminate between individuals (Law, 1987). The absence of children with cerebral palsy, their primary caregivers, and practitioners in the development of included measures makes it difficult to determine whether all domains of visual ability that are meaningful to the target population have been included. Furthermore, vision is a complex construct and it is important, in establishing validity, to determine whether only visual ability is being measured or whether other factors are also making a significant contribution to the assessment of ability (e.g. motor skills, cognition, or attention). Non-visual factors influence performance in vision-related activities, and therefore probably the measurement of visual ability. For example, the cognitive or learning skills of a child may influence their ability to see and recognise letters. Visual ability has been established as a unidimensional construct for measurement in other populations (Lamoureux et al., 2006; Velozo et al., 2013) and therefore it appears theoretically possible to achieve this in a measure suitable for children with cerebral palsy. When determining the measurement construct it is also important not to be influenced by the name of a measure, but instead to look at the content and items (Rosenbaum, 2015). The Atkinson Battery for Child Development for Examining Functional Vision would appear to consist primarily of tests and items measuring vision at the Body Functions domain of the ICF, and although it includes 'Functional Vision' in the battery name, it may not provide the type of information required by a practitioner interested in the direct assessment of daily visual functioning.

The third problem is that some measures included in this review used the common but problematic approach of adding raw nominal or ordinal scores to determine the 'level' of ability, and the relative contribution of each item to the total score was either not considered or not reported (Law, 1987; Wright & Linacre, 1989). This problem has previously been explained by Massof (2002), and an example from the Functional Visual Questionnaire illustrates the issue. Two items from this measure, 'Looks around when entering a room' and 'Responds to facial expressions', have the same ordered response alternatives that range from 'never' to 'often >75%' on a 5-point Likert scale. Although both items load on the same task-orientated visual skills factor, looking around a room is not likely to require the same level of visual ability as recognising and responding to facial expressions. Averaging the scores on items such as these to produce a score would not provide a valid measure of daily visual performance, because the items themselves are not equivalent. In measurement systems such as this, the score estimating a person's visual ability depends on the choice of items. The scoring option of 'not relevant' – or an equivalent option that results in no numerical score – was present in a number of the included measures and provides additional compromise to the measurement score (Ferziger et al., 2011; Salati et al., 2001; Stillman, 1974). The degree to which one can assign any qualitative meaning to quantitative scores is also a major limitation of the visual ability measures in this review.

Finally, measures included in this review with evidence of construct validity relied heavily on correlations with, or discrimination from, Body Functions or impairment-level measures (Ferziger et al., 2011; García-Ormaechea et al., 2014; McCulloch et al., 2007; Mercuri et al., 1999; Ortibus et al., 2011; van Genderen et al., 2012). This was done in the absence of specific hypotheses for evidence of construct validity. The visual acuity and visual perceptual measures commonly used in these validation studies do not measure the same construct as visual ability or functioning in vision-related activities, and while positive correlations could be expected, a priori hypotheses that specify both the direction and the strength of the anticipated relationships need to be developed and tested to support construct validity (Terwee et al., 2012).

Implications for practice and research

The focus of this systematic review should encourage practitioners and researchers to consider the possibility of visual impairments (ocular or cerebral) influencing the activities and participation of children with cerebral palsy. Vision should be considered when gathering information from families, setting goals, and considering the focus for assessment and intervention. The results of this review can be used to guide visual ability measurement in practice and research. Clinical reasoning should include the consideration of purpose, content, and focus of available measures, and tools chosen must have proven validity and reliability for the intended purpose and population.

Based on the results of this review, five tools have some evidence to support their validity and reliability as descriptive performance measures of daily visual functioning

(Ferziger et al., 2011; McCulloch et al., 2007; Ortibus et al., 2011; Pueyo et al., 2014; Roman-Lantzy, 2007). The CVI Range assesses visual functioning in children with CVI, the CVI Questionnaire screens for CVI, the Functional Visual Questionnaire assesses daily visual performance in children with cerebral palsy who are difficult to assess, and the Visual Skills Inventory evaluates visual skills and responses in neurologically impaired children. The Preverbal Visual Assessment assesses visual behaviour and visual cognitive abilities in infants, although there is only limited evidence of construct validity for children with motor impairments. Until psychometric evidence is available to support the use of these measures in clinical practice, questionnaires can be used to guide information-gathering on areas of daily functioning that are commonly limited by visual impairment. A useful finding of this review is the knowledge that measures using questionnaires to gather information from parents result in information about a child's daily performance, while clinician-administered measures provide information on best performance. There are also six tools with some psychometric evidence to support their use as descriptive measures of visual capacity (best performance) (Atkinson et al., 2002; Bellman & Cash, 1987; Blanksby & Langford, 1993; Erhardt et al., 1988; Roman-Lantzy, 2007; Stillman, 1974).

There are currently no valid measures of visual ability for predictive or evaluative purposes. In the absence of valid and reliable evaluative measures, it is impossible to quantify whether interventions are without efficacy or whether we are simply unable to detect clinically important change. The current lack of evidence about interventions to improve the visual abilities of children with cerebral palsy adds urgency to the need for valid and reliable measures of visual abilities (Novak et al., 2013; Williams et al., 2014; Zihl & Dutton, 2015). Until valid and reliable visual ability measures are developed, it is recommended that practitioners consider using individualised goal-based measures such as the Canadian Occupational Performance Measure (Law et al., 2000) or Goal Attainment Scaling (Kiresuk & Sherman, 1968) for the evaluation of interventions related to specific visual ability goals. These outcome measures have established validity, reliability, and are sensitive to change (Sakzewski et al., 2007).

Future directions for research

Several directions for future research have been highlighted by this review. First, further analysis of the conceptual foundations of identified measures is essential, because clinicians and researchers must know whether they are measuring visual ability or some other construct. Linking items from measures to specific chapters and codes of the ICF using Cieza's established linking rules (Cieza et al., 2005) will clarify which content and tools focus at an item level on measuring visual ability. Preliminary analysis of the content of included visual ability measures at a subscale level identifies frequently occurring constructs such as attention, communication and social interactions, visual processing, visual motor coordination, and the role of the environment and other senses (e.g. touch, listening). Further analysis of content may also provide insight into whether vision measured within the context of functional activities is a measure of activity level performance, or whether scoring occurs at the Body Function level (Hoare et al., 2011).

Second, the review results also suggest the need for a classification system to describe 'levels' of visual functioning in children with cerebral palsy analogous to existing functional classification systems, for example the Manual Ability Classification System (Eliasson et al., 2006). Third, future research should seek confirmation from children with cerebral palsy and their families that all characteristics relating to levels of visual functioning, and those that are meaningful, have been identified. Fourth, there is a need for evaluative measures of visual ability for use in intervention studies and clinical practice. Parents and practitioners are likely to have valuable insights on what is functionally important in the daily lives of children with cerebral palsy, and which abilities are likely to change after intervention (Kirshner & Guyatt, 1985). Fifth, the dimensionality of a measure of visual ability needs to be investigated to confirm whether measurement of this construct can be achieved in a single scale. Sixth, a hierarchy for visual abilities should be established using methods such as item response theory, and using interval level measurement. And finally, systems for the qualitative interpretation of scores must also be developed for families, practitioners, and researchers to make use of quantitative scores.

To move this field of research forward, future studies need to consider the spectrum of children diagnosed with cerebral palsy, including age and functional levels. Researchers are encouraged to select and describe participants using the Gross Motor Function Classification System, Manual Ability Classification System, and Communication Function Classification System. Limiting factors for a number of the included measures in this review are the focus on subsets of the cerebral palsy population, or not all measurement items being relevant for all children. Children with cerebral palsy present with a diverse range of functional abilities, including varied levels of motor and cognitive abilities. It is also suggested that –in the future, as a complement to visual diagnoses –measures of visual ability should focus not only on the underlying reasons for impairment (i.e. CVI), but also on levels of visual ability in daily activities. This approach, focusing on ability, has been well established in other functional measurement systems for children with cerebral palsy (Rosenbaum et al., 2014). This review also highlights the importance of good quality psychometric studies. An increasing awareness and use of checklists such as the COSMIN rating system would help in designing and reporting future high-quality studies in support of measurement systems.

Benefits from focusing on the functional impact of visual impairments are likely to include: increased focus on and monitoring of the development of visual abilities; increased analysis of how vision impacts activity performance; and increased focus on visual abilities as facilitators or barriers to participation. Interventions will be developed to target visual abilities, and levels of visual ability may be able to guide the selection of management options. Consistency in terminology will increase the clarity of communication about vision and visual abilities, and enable comparisons across cerebral palsy populations and research studies. Research into other areas of functioning (e.g. manual abilities) will also benefit from the ability to stratify participants by level of visual ability. Establishing the validity of visual ability measurement systems for predictive purposes will also assist services and policy makers with planning for future intervention and care needs.

Limitations

There are some limitations to this review. First, studies not published in English were excluded, so some measures of visual ability may have been missed. Second, this review focused specifically on the identification of measurement in children with cerebral palsy. Although this criterion was established because the primary disability of this population is a movement or posture impairment that is likely to need consideration in item selection, it is acknowledged that measures developed for use with children without physical impairments might also provide valuable information. Future research may include validation studies of other existing measures for children with cerebral palsy (e.g. CVI Inventory (Macintyre-Beon, 2015)). Third, this review has not reported on clinical utility of avail-able measures, focusing instead on measurement properties.

Finally, although inclusion criteria focused this review on the identification of visual measurement at the Activities and Participation level of the ICF, the extent to which the selected measures met this aim requires further assessment, as some included measures appear to contain both Body Function and Activities- and Participation-level items. Body Function items are likely to assess different aspects of visual ability from items related to Activities and Participation. While analysis of visual ability measures at an item level was beyond the scope of this review, further exploration may contribute to our understanding of the visual ability construct in children with cerebral palsy, and provide evidence on the usefulness of existing visual ability measures at an item level.

3.2.5 Conclusion

This systematic review used the ICF framework to define, identify, and evaluate currently available measures of visual ability for children with cerebral palsy. Results show that while visual ability is being measured, there is no consensus on which visual abilities should be measured, nor how, and there is generally a lack of strong psychometric properties. We are currently unable to discriminate the range of visual abilities across the cerebral palsy population, and there is no valid method to evaluate interventions aiming to change visual ability. While measurement in the Body Functions and Structures domain, such as visual acuity tests for measuring eye function, and cognitive test for measuring perception of vision, will continue to be important, it is hoped that the ICF framework can be used by researchers, practitioners, and policy administrators to understand the inadequacy of relying on impairment measures to describe levels of functioning and disability. In the future, vision measurement should occur at both the Body Function and Activity and Participation levels of the ICF.

The results of this review can be used to develop the ways that visual impairment and daily functioning are considered, and to guide future development of valid and reliable visual ability measurement in both new and existing tools. Although not an easy task, appropriately developed and psychometrically sound measures would have tremendous clinical and practical utility for children with cerebral palsy because they would promote understanding of the impact visual impairment (ocular or cerebral) can have on daily functioning and other areas of development, and facilitate the development of future interventions targeted at visual abilities.

3.3 ADDITIONAL STUDIES PUBLISHED SINCE 2016

Since publication of this systematic review in 2016, new guidelines for undertaking a systematic review and evaluating measurement properties have been published, additional measurement tools meeting the inclusion criteria have been published, and some additional studies have been published reporting further use of assessments identified in the original systematic review (Study 1).

In 2017 the COSMIN group published their new guidelines and Risk of Bias form for the assessment of the quality of studies on measurement properties (Mokkink et al., 2017; Prinsen et al., 2018). The quality of measurement property ratings reported in this systematic review may have been different had this new form been available at the time, however the ensuing direction of this doctoral research program would not have been different. The reason is that the research program was influenced by the content of identified measures and questions about the measurement constructs within existing tools, rather than the quality of measurement properties and studies reporting on measures. COSMIN's new guidelines have been used to guide self-evaluation of the design and evaluation of MEVU's measurement properties – see Chapter 8 – Initial Psychometric Testing and Chapter 9 – Grand Discussion. A summary of COSMIN's steps for evaluating a measurement tool are included in Appendix D.

The published systematic review identified 19 measures that met the inclusion criteria as a measure of visual ability for children with cerebral palsy (Deramore Denver et al., 2016), however, the research question "Is there an existing instrument that can be used/modified to measure visual ability in children with cerebral palsy?" could not be definitively answered. Whilst questions remained, the review findings suggested that gaps in the availability of good assessments have since been corroborated by another systematic review that focused on vision assessment more broadly in children with cerebral palsy, or high risk of cerebral palsy, under the age of two (Chorna et al., 2017). That review concluded that vision should be assessed early, and that clinical visual function examinations be used.

The most significant contribution to the field that has been published since 2016 is the 2020 publication of the Visual Function Classification System (VFCS), which provides a tool to discriminate visual abilities across the cerebral palsy population (Baranello et al., 2020). This important addition to the field and the implications for the use of a classification tool alongside MEVU (descriptive assessment), will be further discussed in Chapter 9. A second classification system, the Eye-pointing Classification System (EpCS), was also published in 2020 and meets our definition as a measure of visual ability (Clarke et al., 2020). The EpCS provides a way to classify how non-speaking children with cerebral palsy use looking behaviours functionally for communication. This classification is targeted at a specific group of children with cerebral palsy and does not reduce the need for, or importance of, MEVU.

Since publication of the systematic review, there has also been an increase in publications reporting on the use of eye-gaze or eye-tracking performance (Bekteshi et al., 2020; Harbourne & Berger, 2019; Kooiker et al., 2016; Pratesi et al., 2015). This method of assessing how vision is used in real time may not be suitable for children with impaired vision and there are limitations with its clinical utility (Venker & Kover, 2015). The modified Eye Contact Avoidance Scale has recently been used to describe the visual abilities of children, including those with cerebral palsy (Williams et al., 2021). This scale has a very specific focus; it measures a child's eye contact during social functioning when initiating communication.

Screening and predictive measures for CVI also continue to be developed (Gorrie et al., 2019; Hellgren et al., 2020; McDowell, 2020; Mitry et al., 2016; Moon et al., 2021; Salavati et al., 2017; Tsirka et al., 2020; Vancleef et al., 2020b). As a measure that describes or predicts CVI is different from a measure of visual ability or 'how vision is used', these new tools are a welcome addition to the field, but are not the focus of this research program. Brief review of items and/or questions within these CVI measures also suggests many items may not be appropriate for children with cerebral palsy due to their motor impairment.

Some measurement tools identified in the 2016 systematic review have been used in additional studies and/or had additional measurement properties evaluated since that publication (Black et al., 2019; Lee et al., 2021; Simon-Martinez et al., 2018). This also suggests some growth in the frequency in which vision-related constructs are the focus of research; however, because none of the measures identified in the systematic review were later found to focus on the revised visual ability construct (Deramore Denver et al., 2017), these findings have little impact on the direction of this program of research. One exception is the new scoring system for the revised Flemish CVI Questionnaire (previously the CVI Questionnaire) (Ben Itzhak et al., 2019) which was used in a construct validation study in this research – see Chapter 8.

There continues to be no evidence that a valid measure exists to evaluate improvements in visual ability over time or following intervention. The parent-completed Child Health Conditions Questionnaire is not a specific measure of visual ability, but it does measure the number and impact of impairments in body functions and associated conditions (including seeing) on daily activities, and it has recently been used to report on changes in the impact of health conditions on daily life over time for children with cerebral palsy (Bartlett et al., 2019). A measure, not yet available in English, that has been developed for children with vision impairment to assess daily visual functioning is the Participation and Activities Inventory for Children and Youth (Elsman et al., 2017); it is currently being used to evaluate outcomes in an intervention trial for children at risk of visual processing dysfunction (Kooiker et al., 2020).

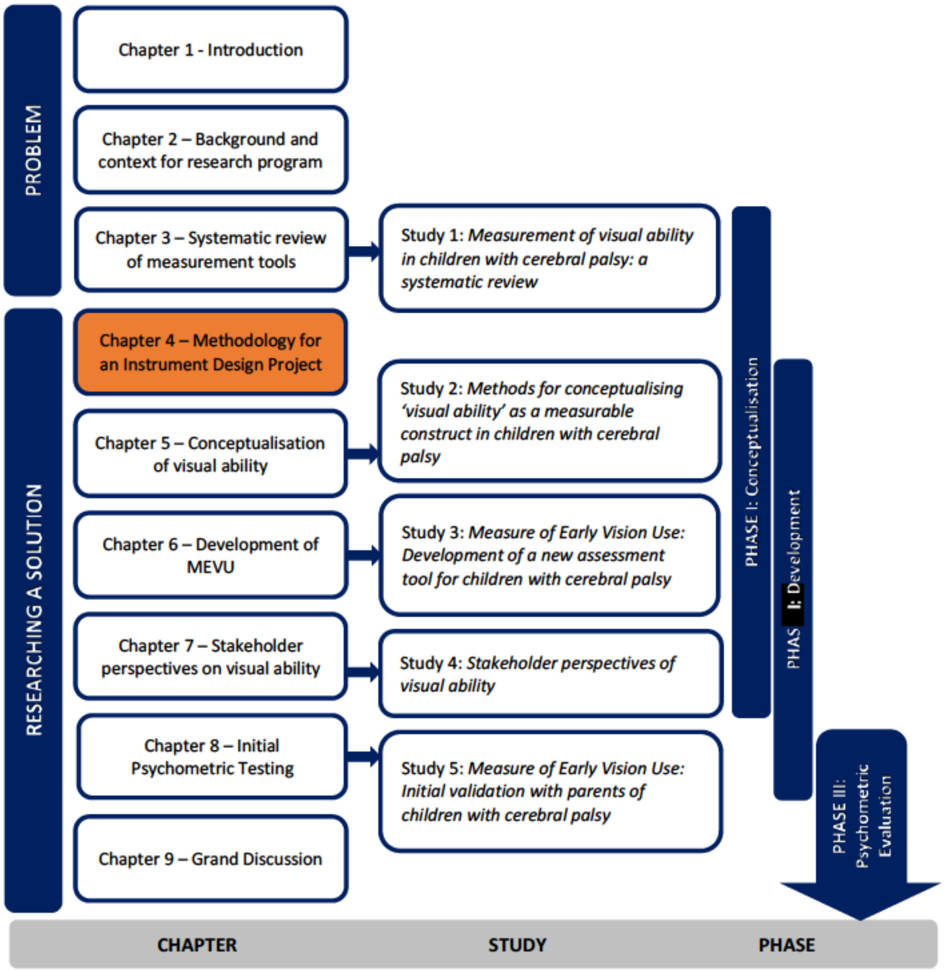
Whilst not meeting the inclusion criteria for a measure of visual ability, there are other measurement tools important to the background of this research program that have recently been used in intervention studies with children with cerebral palsy, or infants at high risk of cerebral palsy: the Near Detection Scale (Benfer et al., 2018; Sonksen et al., 1991), the Ricci assessment protocol (Fontana et al., 2020; Ricci et al., 2008) and Teller acuity cards (Sgandurra et al., 2018; Teller et al., 1986).

3.4 SUMMARY OF CHAPTER 3

Based on the findings of the 2016 systematic review, and the review of more recently published research, there remains a need to analyse the conceptual foundations of identified measures to further understand the assessment of visual ability. Until this is done it will not be possible to determine whether a suitable visual ability measure exists, or whether a new measure needs to be created.

The absence of key stakeholders in the development of existing measures, such as the parents of children with cerebral palsy and professionals who work with these children and families, was also a concern and became a focus in this program of research. The finding that measurement using questionnaires to gather information from parents results in information about a child’s daily performance, while clinician-administered measures provide information on best performance, was also significant and considered in the development of new visual ability assessment tool.

CHAPTER 4: Methodology for an instrument design project



4.1 INTRODUCTION TO CHAPTER 4

Chapter 4 introduces the second part of the thesis: 'Researching a solution' to the measurement problem of visual ability in children with cerebral palsy. The chapter's placement after the systematic review of existing measures of visual ability, occurs because the need to develop a new instrument was not confirmed until Study 2 (Chapter 5). It was only at that point that this research became an instrument design project.

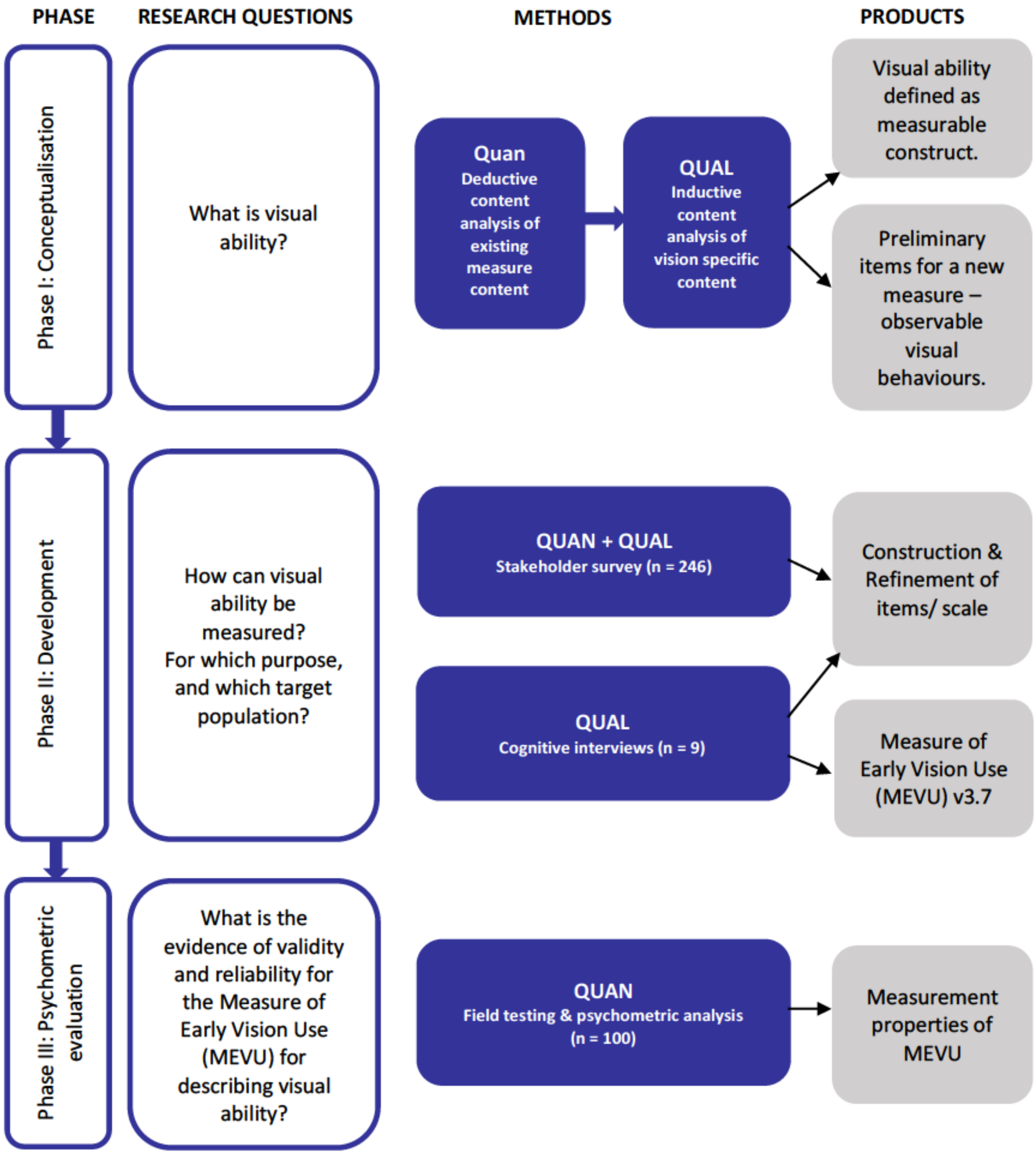
The aim of this chapter is to convey the overall research design of a multi-phase mixed methods instrument design project. The use of multiple phases, including both qualitative and quantitative methods to answer the research questions, would not be clear without this overview. The methods of individual studies, their analyses, and findings, are then reported in Chapters 5-8.

4.2 AN INSTRUMENT DESIGN PROJECT

The primary outcome of this PhD research program is the development of a new measure or *instrument* to collect, and ultimately quantify, data about visual ability: the Measure of Early Vision Use (MEVU). *Instrument design* was introduced by Creswell et al. (2004) to describe a type of mixed methods research project and this label has been adopted in this research. 'Instrument design project' is terminology considered more descriptive of this research process than alternatives (e.g., a scale development project). Creswell and Plano Clark (2018) have recommended that instrument design projects use a procedural diagram to convey the design and highlight the numerous steps required to design a good instrument. These are presented in Figure 4.1.

Figure 4.1

Mixed methods instrument design for the development of the Measure of Early Vision Use



Note. Creswell and Plano Clark's (2018) notation system has been used to describe the mixed method design. Quan and Qual are shorthand notation for quantitative and qualitative strands. The use of capitals (e.g., QUAN) represents priority, a plus sign (+) represents concurrent methods, and an arrow is used to represent sequential methodology.

Methodological consideration has been given to 'how do we make a good instrument' with a range of reference texts on measurement development providing guidance for this instrument design project (DeVellis, 2017; Polit & Yang, 2016; Streiner et al., 2015). Where possible, new guidelines and resources published by the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) initiative have also been utilised in this program of research to ensure important design requirements are incorporated (https://www.cosmin.nl/).

4.3 MULTI-PHASE RESEARCH

Instrument design is complex and time-consuming, yet achievable within a part-time Doctor of Philosophy candidature. It involves multiple steps or phases and is an iterative process. The research described in this thesis involved three distinct yet overlapping stages or *phases*: (i) conceptualisation of the measurable construct, (ii) development of a scale, and (iii) evaluation of the measurement properties of the scale.

4.3.1 Conceptualisation

The first step in researching a solution to the measurement problem in this research was the need for a clear definition and understanding of the concept or construct of interest, that is, *'what'* is to be measured. The importance of this *conceptualisation* phase has been stressed by many authors (de Vet et al., 2011; DeVellis, 2017; MacKenzie, 2003; Polit & Yang, 2016; Straus, 2019), because clear conceptualisation of the construct has implications for creating items that produce meaningful scores and construct validation. DeVellis (2017) refers to this as "Step 1. Determine clearly what it is you want to measure" (p. 105). Most recently, the revised COSMIN guidelines reflect the growing importance placed on conceptualisation through the incorporation of leading questions explicitly about conceptualisation:

> Question 1. Is a clear description provided of the constructed to be measured?
> Question 2. Is the origin of the construct clear: was a theory, conceptual framework of disease model used, or clear rationale provided to define the construct to be measured? (Mokkink, 2017, p.4)

Despite the recognised importance of conceptualisation within an instrument design study, there are few guidelines on 'how' to undertake this phase of research (Onwuegbuzie et al., 2010; Straus, 2019). The conceptualisation phase requires the researcher to become an 'expert' on the construct, and this involves being knowledgeable about theory and research relating to the construct, understanding the availability and limitations of existing instruments, and learning about the construct from key stakeholders (Polit & Yang, 2016). This has been described as the process of moving from theory, frameworks, and clinical experience to a definition of 'what variable should be measured' (Krebs, 1987). Conceptualisation also involves determining which related constructs should be differentiated from the target construct (Polit & Yang, 2016).

The importance of the conceptualisation phase cannot be underestimated. The development and evaluation of the psychometric properties of a measurement tool are dependent on clear conceptualisation of the construct, and the existence of a dedicated phase for conceptualisation. Absence of this phase may result in errors in measurement, in the interpretation of results, or both (Laver Fawcett, 2007). In this instrument design project, the conceptualisation phase is most explicitly presented in Chapter 5; however, Chapter 6 also contributes by confirming 'what' should be measured. The organisational framework presented in Chapter 7 further contributes to the conceptualisation phase by articulating what MEVU is <u>not</u> measuring. Whilst conceptualisation is a key step in this program of research, instrument design projects do not always explicitly identify conceptualisation as a distinct phase, instead incorporating (at best) conceptualisation into the development phase.

4.3.2 Development

The second phase in researching a solution to the measurement problem is determining *'how'* to measure the clearly defined construct of interest – a process also referred to as *operationalisation* (Waltz et al., 2010). Following from the conceptualisation of a measurable construct, the development phase is about *creating* the measurement instrument – which in this research project is the development of MEVU. This phase includes generating items for a scale and making decisions about items, response options and scoring, determining the population of interest, perspective sought, setting of use and format (method) of measurement, pilot testing and refinement before testing psychometrics with a larger population. The development process requires careful consideration of the purpose of the measure and the measurement model. These points will be further explained.

Purpose of measurement

Just as clinicians need to consider the purpose for which they intend to use a measurement tool, researchers need to consider their intended purpose(s) when developing and evaluating a tool. The content, methods, psychometric properties and clinical utility of a measure should all be evaluated against a tools' intended purpose (Laver Fawcett, 2007). The four main purposes of measurement are: descriptive, discriminative, predictive, and evaluative (Laver Fawcett, 2007), and a measurement tool may be developed for one or more purposes. There must however be evidence of validity for each purpose.

In this program of research, the focus was on the development of a descriptive tool that could be used to describe a child's current level of visual ability. Consideration has also been given to the potential future use of MEVU as an evaluative tool by incorporating into the development phase data collection about visual abilities that change. The additional testing that would have been required to gather evidence on MEVU's use as an evaluative tool is beyond this scope of the PhD program of research, so the psychometric phase is focused on MEVU's validity for descriptive purposes.

Measurement model and theory

When developing a measurement tool, it is important to understand the expected relationship between the *construct* and *indicators* (items used to assess the construct) (Avila et al., 2015). These relationships are frequently depicted or described by a measurement model, conceptual models or conceptual frameworks (de Vet et al., 2011; DeVellis, 2017; Waltz et al., 2010). The measurement model demonstrates whether the construct is uni- or multi-dimensional. A full conceptualisation of the construct will lead to conclusions about whether the scale is *reflective* or *formative*. In a reflective model, "all items are a manifestation of the same underlying construct and are expected to be highly correlated and interchangeable" (p. 3), whilst in a formative model "the items together form a construct" (p. 3) (Mokkink et al., 2010). The measurement model and type of scale then inform structural validity and internal consistency analyses, and the measurement theory used to develop and evaluate the scale.

Measurement theory refers to how the scores generated by items on an instrument represent the construct being measured (Edwards & Bagozzi, 2000). The two dominant models of measurement have both influenced this program of research: *Classical Test Theory* (CTT) and *Item Response Theory* (IRT). CTT has traditionally been used in the development of multi-item scales; in CTT the score on a measure is conceptualised as having a 'true score' and an error component, and the aim in development is to minimise error (Polit & Yang, 2016). IRT, a type of modern measurement theory, seeks to develop highly precise measures by focusing on understanding the item characteristics, independent of the people who complete the items (Polit & Yang, 2016). Whilst the principles and assumptions of IRT were considered in the development of MEVU, the large number of participants required for Rasch analysis (a method of IRT analysis) was not possible within this PhD, so CTT was used for all the psychometric evaluation. Decisions made during the conceptualisation and development phases, including the development of a unidimensional scale that reflects the abilities of children with different abilities, make it likely that future analyses can be undertaken using IRT.

In this thesis the development phase is reported in Chapter 7. Examples of early versions of the items and response options are provided in Appendix E, followed by a copy of MEVU 3.7 in Appendix F, the version of MEVU used in the psychometric evaluation phase reported in Chapter 8.

4.3.3 Psychometric Evaluation

The third step in researching a solution to the measurement problem involves evaluating *'how well'* the instrument works. That is, what *psychometric* or *measurement properties* reflect the quality of the measurement tool (Polit & Yang, 2016). Definitions and areas of psychometric evaluation focused on in this PhD are outlined in Table 4.1.

Table 4.1

Definitions of measurement properties (Mokkink et al., 2010)

Measurement property	Definition	Addressed in PhD?
Content validity	The degree to which the content of the instrument is an adequate reflection of the construct to be measured.	Yes
Structural validity	The degree to which the scores of the instrument are an adequate reflection of the dimensionality of the construct to be measured.	Yes
Internal consistency	The degree of the interrelatedness among the items.	Yes
Cross-cultural validity	The degree to which the performance of the items on a translated or culturally adapted instrument are an adequate reflection of the performance of the items of the original version of the instrument.	No
Reliability	The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: for example, using different sets of items from the same instruments (internal consistency), over time (test-retest) by different persons on the same occasion (inter-rater) or by the same persons (i.e., raters or responders) on different occasions (intra-rater).	Yes - internal consistency No – test-retest, inter-rater and intra-rater
Measurement error	The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured.	No
Hypothesis testing (construct validity)	The degree to which the scores of an instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between	Yes

	relevant groups) based on the assumption that the instrument validly measures the construct to be measured.	
Responsiveness	The ability of an instrument to detect change over time in the construct to be measured.	No

The priority given to some measurement properties in this program of research aligns with new recommendations from the COSMIN group that content validity is the most important measurement property to consider before internal structure (structural validity and internal consistency) and then the remaining measurement properties (Prinsen et al., 2018). A focus on validity, rather than reliability, was followed because visual ability is a new construct and it is more important to know whether MEVU does measure visual ability before it is established whether the measurement can be done reliably.

Evaluation of MEVU's psychometric properties is reported in Chapter 8. In undertaking this research, and in reporting, care has been taken to "be humble; no individual study can ever 'establish' or 'prove' the reliability or validity of an instrument" (Streiner & Kottner, 2014, p.1976).

4.4 MIXED METHODS RESEARCH DESIGN

The design of any good research project is determined by the research questions being asked. In this research, both exploratory and explanatory questions support the need for a mix of qualitative and quantitative strategies, or a mixed method approach. The assumption of mixed methods research is that both qualitative and quantitative methods can enhance the research beyond the use of either method by itself, and this use of a combination of methods to answer the research questions most effectively is aligned with a pragmatist approach creating new knowledge (Liamputtong & Schmied, 2017).

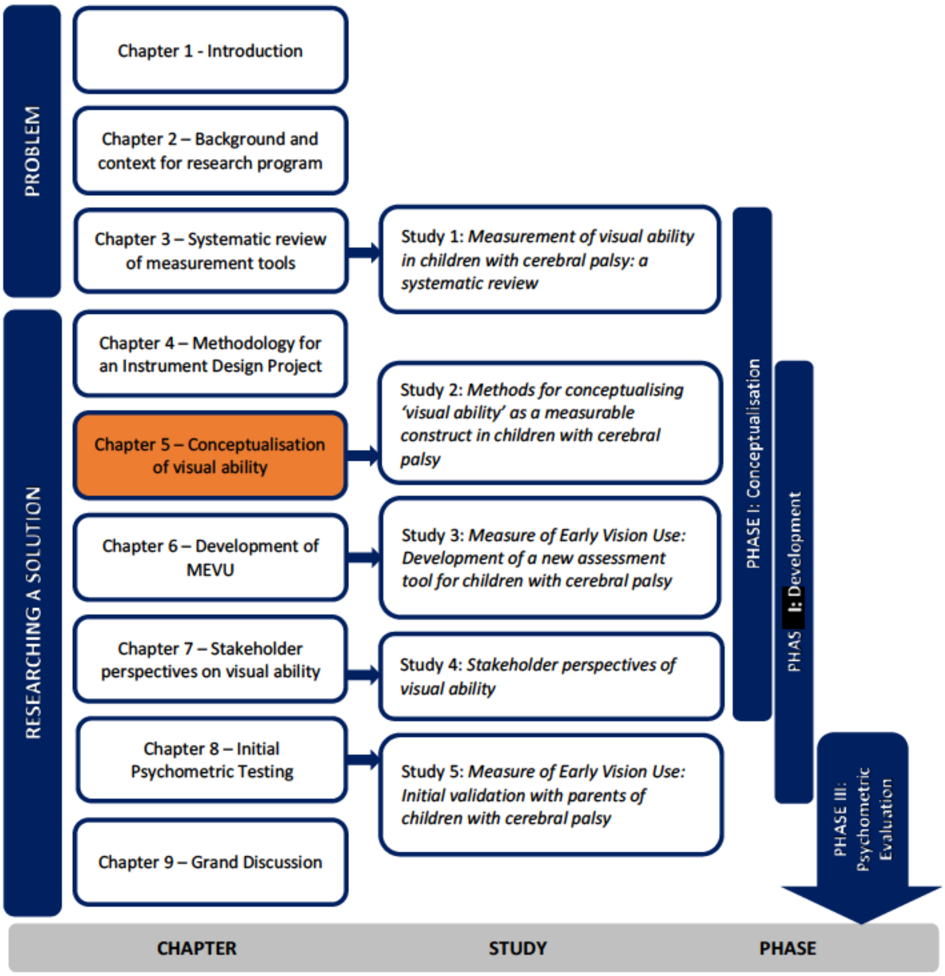
In their textbook on mixed methods research, Creswell and Plano Clark (2018) describe an exploratory sequential design that has the intent of developing and testing an instrument. They describe the use of an initial qualitative phase that informs a second (connecting) quantitative phase where an instrument is developed or modified, before the final quantitative phase of data collection using the instrument. This exploratory sequential design has largely influenced this program of research; however, the overall design of this instrument design project is more reflective of a *multistage mixed methods framework* where multiple stages of data collection include a variety of mixed method studies (Fetters et al., 2013). It is important to note that whilst this research is sequential, this is not the same as the process being linear.

Within mixed method research it is common practice to describe the weighting of the relative importance or priority of each methodology in answering the research questions. Whilst it has been reported that priority is given to quantitative data collection and analysis in the psychometric testing of a new instrument (Creswell et al., 2004), contemporary approaches to instrument design place greater emphasis on qualitative methodologies within conceptualisation and development of content for instruments (Creswell & Plano Clark, 2018; Terwee et al., 2018; Zhou, 2019). This priority is reflected in the title of this research, *Development and initial validation of an assessment of visual ability for children with cerebral palsy*, where validation is preceded by the word 'initial' suggesting that it has less focus than the 'development' process.

4.5 ETHICAL APPROVAL FOR THE RESEARCH PROGRAM

Primary ethical approval was granted for this research program from the Human Research Ethics Committee (HREC) at Australian Catholic University. Three separate applications for ethics approval were necessary as distinct selection, recruitment, informed consent, data collection and data analysis methods, were used for different studies within this program of research. The three approvals received were for the following studies: *Survey on visual abilities in children with cerebral palsy 2016-282E* (Study 3 & 4); *Developing and testing a measure of vision use for children with cerebral palsy 2017-313H* (Study 3); and *Testing the 'Measure of Early Vision Use' 2018-178H* (Study 5). Confirmation of approvals, supporting documents, and secondary approvals for recruitment from other organisations, are provided in the appendices. All studies complied to all ethical requirements and no adverse events were recorded. Ethical approval was not required for Studies 1 and 2 as they used data on measurement tools available in the published literature and did not involve participant data.

CHAPTER 5: Conceptualisation of visual ability



5.1 INTRODUCTION TO CHAPTER 5

Chapter 5 consists of a published manuscript (Study 2) and follows the systematic review (Study 1) presented in Chapter 3, where there remained an unanswered question: is there an existing instrument that can be used or modified to describe visual abilities in children with cerebral palsy? The research reported in Chapter 5 answered this question and addressed the second objective of this thesis: to define visual ability as a measurable construct.

5.2 STUDY 2: CONCEPTUALISING 'VISUAL ABILITY' AS A MEASURABLE CONSTRUCT

This manuscript has been accepted and published in the Open Access journal *BMC Medical Research Methodology*. The published pdf version of this manuscript is available in Appendix G.

> Deramore Denver, B., Adolfsson, M., Froude, E., Rosenbaum, P., & Imms, C. (2017). Methods for conceptualising 'visual ability' as a measurable construct in children with cerebral palsy. *BMC Medical Research Methodology*, *17*(46), 1-13. https://doi.org/10.1186/s12874-017-0316-6

For reasons of text consistency, some alternations may exist between the published manuscript and the version presented in this chapter. Two additional files published online with this manuscript are available in Appendix G.

Title

Methods for conceptualising 'visual ability' as a measurable construct in children with cerebral palsy

Authors

Belinda Deramore Denver[1], Margareta Adolfsson[2], Elspeth Froude[1], Peter Rosenbaum[3], & Christine Imms[4]

Affiliations

[1] Faculty of Health Sciences, School of Allied Health, Australian Catholic University, North Sydney, NSW, Australia; [2] Jönköping University, CHILD, School of Education and Communication, Box 1026, 551 11 Jönköping, Sweden; [3] Department of Pediatrics and CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada; [4] Faculty of Health Sciences, School of Allied Health, Australian Catholic University, Fitzroy, VIC, Australia.

Corresponding author

Belinda Deramore Denver, Australian Catholic University, School of Allied Health, Level 9, 33 Berry Street, North Sydney, NSW 2060, Australia
belinda.deramoredenver@myacu.edu.au

Abstract

BACKGROUND Vision influences functioning and disability of children with cerebral palsy, so there is a growing need for psychometrically robust tools to advance assessment of children's vision abilities in clinical practice and research. Vision is a complex construct, and in the absence of clarity about this construct it is challenging to know whether valid, reliable measures exist. This study reports a method for conceptualising 'visual ability' as a measurable construct.

METHODS Using the items from 19 assessment tools previously identified in a systematic review, this study used a two-phase process: first, deductive content analysis linked items to the International Classification of Functioning, Disability and Health - Child and Youth version (ICF-CY), and second, vision-specific 'Activity'-level items were explored using inductive thematic analysis.

RESULTS The linking and content analysis identified that existing assessment tools are measuring vision across the ICF-CY domains of Body Functions, Activities and Participation, and Environmental and Personal Factors. Items specifically coded to vision at the Activity level were defined as measuring 'how vision is used', and these items form the basis of the conceptualisation that 'visual ability' is measurable as a single construct.

The thematic analysis led to the identification of 3 categories containing 13 themes that reflect a child's observable visual behaviours. Seven abilities reflect how a child uses vision: responds or reacts, initiates, maintains or sustains looking, changes or shifts looking, searches, locates or finds, and follows. Four interactions reflect the contexts in which a child uses their vision to purposefully interact: watches and visually interacts with people and faces, objects, over distance, and with hands. Finally, two themes reflect a child's overall use of vision in daily activities: frequency of use, and efficiency of use.

CONCLUSIONS This study demonstrates an approach to exploring and explaining a complex topic utilising World Health Organisation language and building on existing research. Despite the complexity of vision, the concept of 'how vision is used' can be clearly defined as a measurable construct at the Activity level of the ICF-CY. This study has identified observable visual behaviours that may be developed into items assessing how vision is used in daily activities.

5.2.1 Background

Vision is an important construct to measure in children with cerebral palsy for both health care research and clinical practice. The primary motor disorder of cerebral palsy may be accompanied by additional impairments including vision (Rosenbaum et al., 2007), and there is growing evidence of the relationship between vision and various aspects of functioning (Coleman et al., 2015; Delacy et al., 2016; James et al., 2015; Salavati et al., 2014; Yin Foo et al., 2013). This is not surprising as visual skills play an important role in development for all children, and the absence of, or limitations in, vision are known to impact development and functioning (Cass et al., 1994). Children with cerebral palsy may be diagnosed with visual impairment at the ocular (eye) or cerebral/cortical (brain) level. One recent publication reported a prevalence of 'some visual impairment' in 36% of the population, and 'functional blindness' in 6% (Delacy et al., 2016). Information on the rates of visual impairments (ocular or cerebral) vary greatly in the literature (Novak et al., 2012); however, it is likely that vision impacts outcomes for at least some children with cerebral palsy and their families.

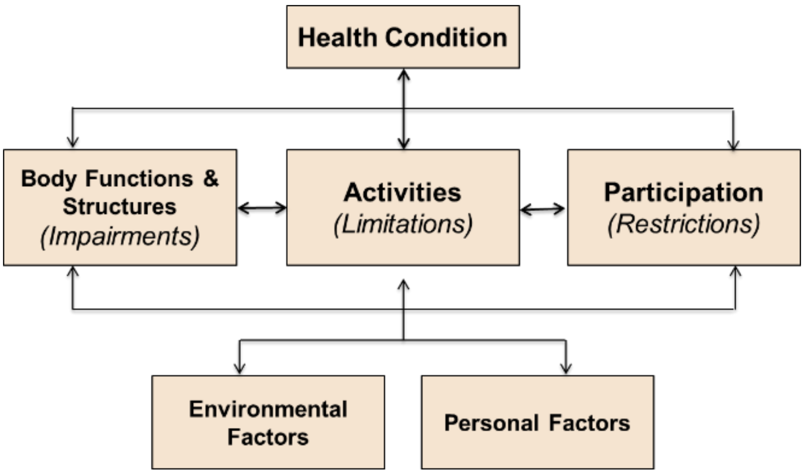
Research in this area is expanding, but there are knowledge gaps and complexities to the assessment and management of vision for children with cerebral palsy (Deramore

Denver et al., 2016; Dutton & Bax, 2010; Williams et al., 2014). Although valid and reliable assessment practices are required to evaluate and establish the effectiveness of interventions, there is currently limited clarity on *what* to measure, *how* to measure, *when* to measure and *who* should be measuring vision-related constructs for children with cerebral palsy. In the absence of clarity about the construct to be measured (i.e., the 'what'), it is challenging to answer the question of whether a measure exists to answer clinical and research questions; this in turn can impact clinical and research outcomes (Streiner et al., 2015). A prerequisite to instrumentation and measurement is to determine what concept(s) is (are) to be measured, and how to translate the concept into measurable phenomena (Waltz et al., 2010). In this paper the phase of defining and understanding the construct to be measured is referred to as *conceptualisation*.

Vision is a complex construct, and its influence can be considered from multiple perspectives. These include how effectively a child's eyes work, how well the child understands and interprets what they see, and how well vision is used in daily activities. The World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) (2001) and the Child and Youth version (ICF-CY) (2007) provide a framework that can be used to consider functioning and disability, including vision, from a dynamic bio-psychosocial perspective. This framework, see Figure 5.1, includes four domains: (1) Body Functions and Structures; (2) Activities and Participation; (3) Personal Factors; and (4) Environmental Factors. The ability of a child to function is the outcome of a dynamic interaction among elements of these domains and contexts (World Health Organization, 2007). Within the ICF-CY, the concept of vision is represented at the Body Function level (*Seeing functions* and *Perceptual functions*) and the Activity level (*'purposeful use of vision'*). These vision-related concepts interact in a process that is influenced by other factors including cognitive skills, motor abilities and aspects of the environment, and together they contribute to an individual's overall level or functioning or disability.

Figure 5.1

Framework of Functioning, Disability and Health (ICF and ICF-CY) (World Health Organization, 2001)



Our recent systematic review on the measurement of visual ability in children with cerebral palsy focused on identifying tools assessing “vision that describes a child’s functioning at the Activity and Participation domain of the ICF-CY” (Deramore Denver et al., 2016, p. 1018). This focus was driven by the need for clinicians to provide interventions at the Activity level, and the need for clinicians and researchers to have psychometrically robust methods to measure the effects of interventions. Measurement at the Activity level – that is, of ‘visual ability’– is required to eliminate the need to make inferences or assumptions about levels of functioning in daily activities from an assessment limited to a Body Function (impairment) level e.g., visual acuity. Inclusion criteria for the systematic review were measures “addressing visual ability when the focus of the vision measurement was at the Activities and Participation domain of the ICF” (Deramore Denver et al., 2016, p. 1019), and the review included any tool designed or described as measuring “functional vision”. The systematic review did not identify an existing psychometrically valid and reliable tool that could be used. Findings also suggested that attributes included in existing assessment tools were conceptually varied and may not be limited to the assessment of how vision is used. From the review it was not possible to make a decision as to whether an existing tool could be modified by researchers (Streiner et al., 2015), or whether a new assessment specific to how a child uses their vision in daily activities was required (Deramore Denver et al., 2016). Thus, the need for an additional conceptual study was identified. The current study expands on the systematic review by analysing the content of identified tools at an item level. Content analysis was beyond the scope and inclusion criteria of the previous systematic review; however, it is critical that a measurement concept be clearly defined and understood before determining what, when and how to measure a phenomenon. The detailed content analysis in this study enables the important step whereby attributes can be identified and established as indicators of how visual ability can be measured (Waltz et al., 2010). This process supports the overall goal of this research program, namely, to identify an approach to the assessment of visual ability or to generate items for the development of a new measure.

The systematic review defined *visual ability* as “how someone performs in vision-related activities” (p. 1019) (Deramore Denver et al., 2016); the aim of the current study was to explore the ways that existing assessment tools conceptualised this as a construct at the Activity level of the ICF-CY. The specific research questions addressed were: (1) What ICF-CY constructs do items in identified assessment tools measure? (2) How can items that specifically assess vision at the Activity level of the ICF-CY be described in terms of what they measure? (3) What observable behaviours indicate levels of visual ability in assessment tools for children with cerebral palsy?

The study was conducted in two parts. Part I identified the *content* of measures in previously identified tools that assess vision at the Activity level of the ICF-CY. Part II identified and analysed the visual ability *themes* in that content. The goal was to identify assessments, or assessment items, to inform the future development of a valid visual ability assessment. This paper reports on the conceptualisation process used in this instrumentation research.

5.2.2 Method

This two-part qualitative study used both descriptive content and thematic content analysis, and the sequential process is illustrated in Figure 5.2. Our earlier systematic review (Deramore Denver et al., 2016) utilised a rigorous process to identify 19 assessment tools containing 266 items that formed the units for analysis in this study. Details of the assessments tools, including purpose, format, psychometric properties and limitations, are described in detail in the systematic review (Deramore Denver et al., 2016). The 19 assessments are variable in their purpose, including screening for CVI (e.g., Ortibus et al., 2011), developmental assessment (e.g., Bellman & Cash, 1987), and assessment of daily visual performance (e.g., Ferziger et al., 2011). All assessments have been developed for, or used with, children (0–18 years) with cerebral palsy or a diagnosis suggestive of cerebral palsy. All 19 assessments are included in this study as the focus was to capture the constructs measured by assessment tools, rather than how well visual ability was measured. The type of content and number of items, scales or questions are provided for all assessments in Table 5.1.

Figure 5.2

Flow diagram describing methodological process and results

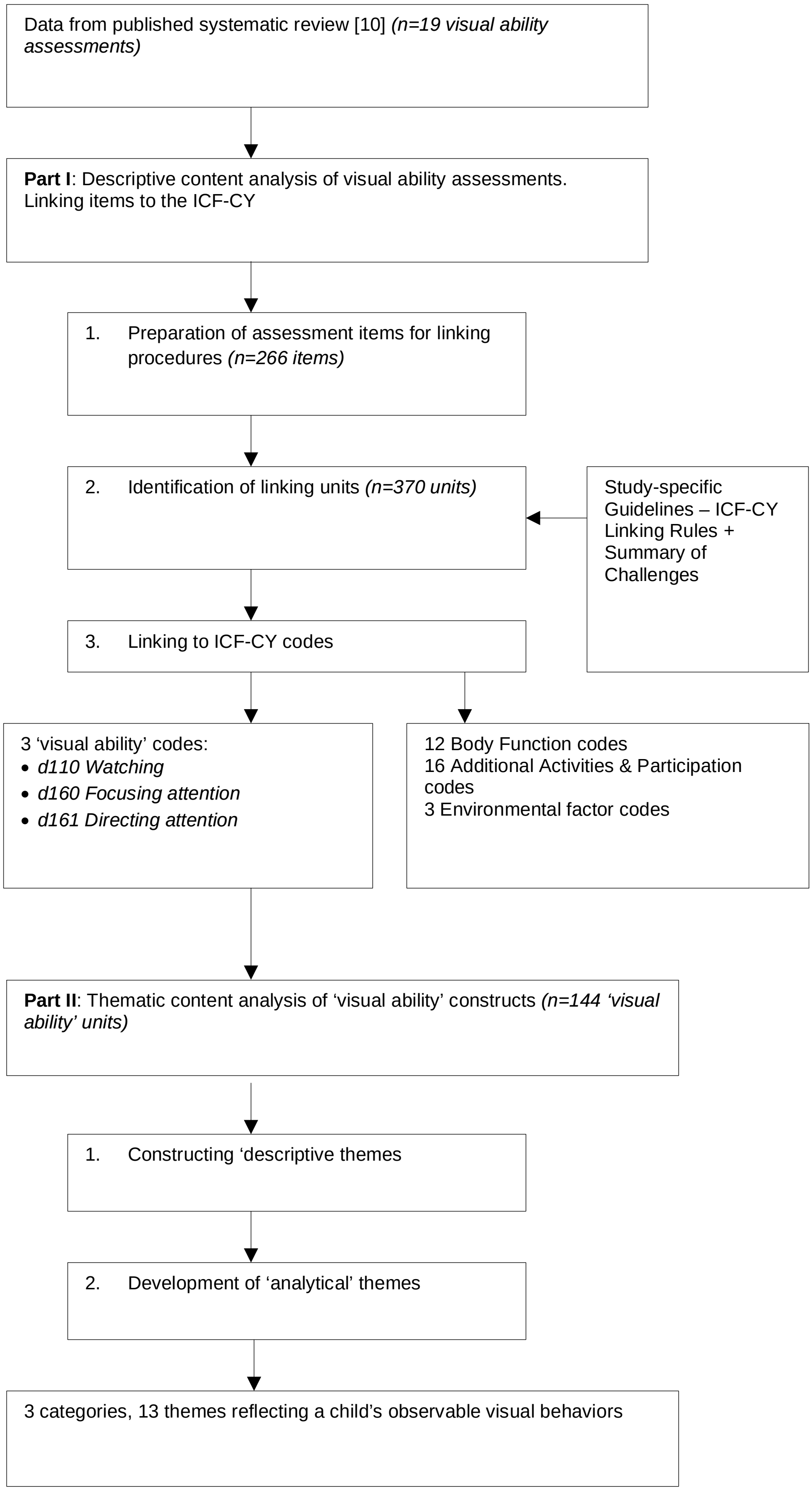


Table 5.1

Summary of included visual ability assessment tools

Assessment tool	Type of content[a]	Items/Scales	Linking units (N)	ICF-CY Codes (N)[b] BF/BS[c]	ACT/ PART[d]	ENV[e]	Other/Not coded[f]	Visual ability constructs[g] N (%)
ABCDEFV	Clinical	22 Tests	28	20	8	0	0	6 (21.4)
Alimovic	Patient oriented	2 Scales	5	0	5	0	0	4 (80)
CAS	Clinical	33 Visual development items	41	14	26	0	1	18 (43.9)
CVI Q	Patient oriented	46 Items	56	11	41	0	6	28 (50)
CVI R	Clinical &	10 Characteristics	12	3	11	0	0	8 (66.7)
	Patient oriented	1 Scale	1	0	1	0	0	1 (100)
EDVA	Clinical	7 Test Items	7	3	4	0	0	4 (57.1)
FVQ	Patient oriented	26 Questions	34	5	30	0	0	23 (67.6)
Hoyt	Patient oriented	1 Scale	2	1	1	0	0	1 (50)
HSCS-PS	Patient oriented	1 Vision Sub-scale	4	2	1	1	0	1 (25)
HUI-III	Patient oriented	1 Vision Sub-scale	5	2	2	1	0	1 (20)
IDP	Patient oriented	Visual competence 1 Scale	7	5	2	0	0	1 (14.3)
LVC	Clinical	8 Tests	10	2	8	0	0	4 (40)
PreViAs	Patient oriented	30 Questions	41	13	27	0	1	12 (29.3)
Short CVI Q	Patient oriented	12 Questions	15	5	10	0	0	4 (26.7)
SoGS	Clinical	22 Visual skill Items	25	13	12	0	0	10 (40)
VAP-CAP	Clinical	19 Items	34	22	12	0	0	10 (29.4)
VSI	Patient oriented	22 Items	35	11	17	3	3	6 (17.1)
Wong	Patient oriented	1 Scale	2	1	1	0	0	1 (50)
15-D	Patient oriented	1 Vision Sub-scale	6	1	3	2	0	1 (16.7)

Note. [a]Type of assessment determines type of information to be linked: patient-oriented measure (self-report, caregiver report or health professional reported) or clinical assessment; [b]Number of domain codes may equal more than the number linking units as some linking units were given two codes; [c]Examples of constructs linked to Body Functions: seeing functions (visual acuity, visual field, and the ability to sense light, form, shape and colour, and eye functions), mental functions (orientation, memory, response time, visual perception and discrimination, visuospatial perception, knowledge and application of knowledge, recognition and object permanence), hearing functions, and neuromuscular functions such as reflexes and eye-hand coordination; [d]Activities and Participation codes are expanded in Table 3; [e]Environmental factors include supports or barriers of adapted products including large print or glasses/contacts, light in the environment, or people providing support; [f]Other includes personal factors such as a child's interest or mood, the use of compensatory strategies, and interventions such as patching; [g] Number of 'visual ability' constructs is total number of linking units coded to the visual ability codes (d110 Watching, d160 Focusing attention, d161 Directing attention) as % of the total linking units. ABCDEFV, Atkinson Battery for Child Development for Examining Functional Vision; CAS, Callier Azusa Scale; CVI Q, CVI Questionnaire; CVI R, CVI Range; EDVA, Erhardt Developmental Visual Assessment; FVQ, Functional Visual Questionnaire; HSCS-PS, Health Status Classification System – Preschool, Vision scale; HUI-III, Health Utilities Index – Mark III, Vision Scale; IDP, Institutes' Developmental Profile – Visual Competence Scale; LVC, Low Vision Checklist; PreViAs, Preverbal Visual Assessment; Short CVI Q, Short CVI Questionnaire; SoGS, Schedule of Growing Skills, Visual skills domain; VAP-CAP, Visual Assessment Procedure – Capacity, Attention, and Processing; VSI, Visual Skills Inventory; 15-D, 15-Dimension Questionnaire, Vision scale.

Part I: process of linking visual ability assessments to the ICF-CY

Part I provided a descriptive content analysis of previously identified visual ability assessment items utilising established methodology for the linking of measurement tools to the ICF-CY. The ICF-CY classification contains categories and codes in two sections. The first part refers to functioning and disability and includes Body Functions (b) and Body Structures (s), and Activities and Participation (d). The second part refers to Contextual Factors and includes Environmental Factors (e) and Personal Factors (World Health Organization, 2007). The classification is an alphanumeric system. The letters b, s, d, and e refer to the category or domain of the classification and are followed by a numeric code that starts with the chapter number (a single digit), followed by the second level (two digits), and the third and fourth levels (one digit each) (World Health Organization, 2007). An example from the Activities and Participation domain is as follows:

d1 Learning and applying knowledge (first or chapter level)
d160 Focusing attention (second level)
d1600 Focusing attention on the human touch, face and voice (third level)

Published *ICF Linking Rules* detail the steps for the process of linking measurement tools to the classification system. These rules include two key stages: 1) identification of 'linking units', and 2) linking the units to ICF-CY codes (Cieza et al., 2002; Cieza et al., 2016; Cieza et al., 2005). Table 5.2 summarises published rules, together with examples specific to this study, and was used by the authors to undertake the process. Linking methodology has previously been used to compare and contrast information from outcome measures for the purpose of clarity about constructs (e.g., upper limb measures for children with cerebral palsy (Hoare et al., 2011)).

Table 5.2

Study specific ICF-CY linking rules

Identification of linking units

i. Determine the type of information to be linked: *patient-oriented measure* (self-report, caregiver report, or health professional reported) or *clinical assessment*.

ii. Identify linking unit(s). The linking unit of a measure answers the question: What is the item about?

The names of measures, the instructions, and subscale titles provide useful information to define the linking units.

e.g. Item 17 from the CVI Questionnaire asks whether the child "Sits right in front of the television". This item needs to be considered in the context of being an item in a measure screening for cerebral visual impairment. The item falls in the section of 'Visual attitude' and the subscale of 'visual attention'. This item is not about 'sitting'.

For Patient-oriented measures:

- Refer to the item as it appears in the questionnaire
- Identify response options of items that contain linking unit(s)

For Clinical assessments:

- Refer to the aim of the clinical assessment
- Consider that the linking unit may change depending on the context in which the clinical assessment is used.

iii. Identify any relationship between concepts: when there are more than two linking units the relationship between the units is also provided**.**

e.g. Item 21 in the Functional Visual Questionnaire asks whether the child "Looks at a toy or object while reaching/moving hand towards it". This item is about looking 'whilst' reaching. The relationship should be recorded.

Linking of linking units to the ICF-CY

a. Select the appropriate code(s) to describe the linking unit:

Is the linking unit an element of Body Functions, Body Structures, Activities and Participation, or Environmental factors?

Which chapter within the selected domain is the most appropriate?

Which category within the selected chapter is the most precise?

b. If the content of an item is not explicitly named in the corresponding ICF-CY category, then the "other specified" is linked. This code allows for coding of functioning that is not included within any of the other specific categories. When an "other specified" code is used, the specification has to be annotated.

c. If the content of an item is insufficient to permit assignment of a more specific category, the "unspecified" is linked. The code has the same meaning as the second- or third-level term immediately above (b), without any additional information.

i.e. Use d199 Learning and applying knowledge, unspecified rather than d1 Learning and applying knowledge

d. If the linking unit is an element of 'Health condition' the code HC is used.

e. If the linking unit is an element of 'Personal factors' it would be considered to have a positive or negative influence on disability and functioning. To determine if a linking unit is a Personal factor ask: Can the linking unit be impaired, restricted or limited? If no, it is a personal factor.

f. If the content of an item is unclear or too general to permit assignment of any category or component, the “nondefinable” (nd) is used. The perspective is documented as General Health (nd-gh), Quality of life (nd-qol), Physical health (nd-ph), Mental health (nd-mh), or Life satisfaction (nd-s).

g. If the linking unit is not a Health condition, Body function/body structure, Activity, Participation, Environmental factor or Personal factor, it is “Not covered” (nc).

The deductive linking process was completed by researchers with good knowledge of the concepts, definitions, and structure of the ICF-CY. The first author (BDD) is an occupational therapist with experience working with children with cerebral palsy and vision impairment, and had acquired relevant knowledge using the eLearning tool developed by the World Health Organisation (World Health Organisation ICF Research Branch, 2015). The second and last authors (MA and CI) are both knowledgeable in the ICF-CY and linking methodology, and all authors have clinical experience with the cerebral palsy population.

The first author initially prepared the data for linking by entering all 266 items from the 19 measures into a linking extraction table. Next, items were analysed independently by two authors (BD and either MA or CI) to identify linking units (‘what the item is about’). Items were analysed for both main and additional concepts; this was done at an item and response level for patient-oriented measures, and by considering the aim in clinical assessments. This process was complex, with most measures containing some items whose meaning was unclear, making it difficult to know what the item was about, and as a result, the identification of linking units and ICF-CY codes was inconsistent between linkers. For example, Item 3 from the Preverbal Visual Assessment (PreViAs) asks “Is he/she able to look towards a sound source?” (Pueyo et al., 2014). Different authors (linkers) considered that this item may be about ‘looking’, ‘turning to look’, ‘hearing a sound’ or ‘sound localisation’. Five iterative rounds of independent linking were subsequently undertaken using a process of constant review, comparison and discussion until consensus was reached.

Consistent consensus-based decisions were made possible when a set of study-specific guidelines was developed from notes on discussions and refined continuously as suggested by other authors (Fayed, Cieza, et al., 2012; Granberg et al., 2014; Klang Ibragimova et al., 2011; van de Ven-Stevens et al., 2015). The guidelines are a summary of ICF Linking Rules (Cieza et al., 2016; Cieza et al., 2005; World Health Organisation ICF Research Branch, 2015) annotated with study-specific examples, in addition to a summary of solutions to commonly occurring challenges specific to this study (available in Appendix G). Throughout the linking process, the guidelines were used to improve the consistency of the approach. Once consensus-based decisions could be reached by the first and second author using the guidelines, the first author completed the linking for all assessments. Units were linked to the most precise code in the ICF-CY, however most results are reported and discussed at the second level.

To present the results, a tabulated descriptive summary is provided for assessment tools including details of the assessment tool and type of information to be linked, number of items and linking units, and the number of linking units for each of the ICF-CY domains. The number of linking units determined to be measuring ‘visual ability’ is presented for each assessment tool, and details of all Activities- and Participation-level codes at a two-level classification are presented to illustrate what constructs are measured by existing assessment tools. Details of the Body Function and Environmental factor codes are available in Appendix G.

Part II: process of establishing ‘visual ability’ themes

Part II included thematic content analysis undertaken in two steps (Thomas & Harden, 2008) to examine the 128 items that linked to specific codes identified in Part I as vision in the Activities and Participation domain. In addition to the ICF-CY code of d110 *Watching*, two additional second-level codes were commonly considered to be about the use of vision: d160 *Focusing attention*, and d161 *Directing attention*; however, care was taken in the analysis of items linked to these codes as they might not be exclusive to vision. The analysis involved (a) constructing ‘descriptive’ themes (e.g., ‘tracking’), followed by (b) the development of ‘analytical’ themes (e.g., ‘follows’). The results of this process were recorded in the same data management and extraction table used in Part I.

To construct descriptive themes, the first author (BDD) immersed herself in the data and sought evidence for (1) verbs describing visual abilities, and (2) indicators, characteristics or specifications of different levels of visual ability. This decision was guided by the overarching aim of the study, namely that the results should inform the development of a new visual ability assessment. It was determined that words describing how vision is used (e.g., verbs) would be essential to the development of an ability measure. Table 5.3 provides four examples of the inductive process of constructing descriptive themes.

Analytical themes were developed by the first author (BDD) from the descriptive themes by grouping similar verbs and indicators into clusters that could be identified using an over-arching label that reflected the 'observable visual behaviour/s'. This stage was influenced by knowledge of the literature, research, and clinical practice in the area. The results were confirmed by the co-authors (EF and CI) independently analysing 15% of the items and discussing themes until consensus was reached. Short descriptions of theme clusters were written and validated by referring back to the items. A final step involved the grouping of similar themes into overarching categories that reflected all themes within the group. The process of developing analytical themes and combining these into categories is also illustrated in Table 5.3.

Table 5.3

Example of process to identify linking units and ICF-CY codes (Part I) and 'visual ability" themes & categories (Part II)

Part I				**Part II**			
				Descriptive theme		**Analytical theme**	
Measure	**Item**	**Linking unit**[a]	**ICF-CY code**[b]	**Descriptive word for visual ability**	**Indicator of visual ability**	**Theme: Observable visual behaviour**	**Category of visual ability behaviour**
CVI Q	Manipulates an object rather than look at it *(Item 40, Other senses domain)*	Use of other senses	**d110 Watching** d1201 Touching[c]	Look	Look at object	Watches and/or visually interacts with objects	Interactions
					Manipulate rather than look (other senses)	Frequency of use of vision in activities	Use of vision
FVQ	Tracks an object/toy *(Item 2)*	Tracking	**d110 Watching**	Tracking	Tracks an object/toy	Follows	Abilities
						Watches and/or visually interacts with objects	Interactions
PreViAs	Is he/she able to look towards a sound source? *(Item 3)*	Looking toward a sound source[d]	**d110 Watching** b2302 Localisation of a sound source	Look	Looks toward sound source	Searches	Abilities
VSI	Does your child reach for a large, bright, silent object? *(Item 17)*	Reaching	d4452 Reaching	n/a			

Note. [a]Linking unit = What is the item about?; [b]Only assessment items which have been linked to an ICF-CY 'visual ability' code of d*110 Watching*, *d160 Focusing attention* or *d161 Directing attention* are included in Part II; [c]This is an example where the exact term in the ICF-CY does not match the construct as described in the measure i.e. linked to *d1201 Touching* and not *d4402 Manipulating*; [d]Example of an item where it was not easy to identify what the item was about e.g. is it about 'Turning to look'?, 'Hearing a sound' or 'Looking'.

The results of Part II are reported using a narrative description of the analytical themes as visual behaviours observable in daily activity performance of children with cerebral palsy. The themes are presented under their categorical headings, along with examples or extracts from items, responses or instructions from visual ability assessment tools that contributed to their development. Examples from a range of assessment tools are utilised to assist with the transparency and trustworthiness of the findings and interpretations. In line with the over-arching goal of establishing a method for assessing the visual ability of children with cerebral palsy, examples that represented the themes were selected from included tools to describe *ability*, rather than what a child *cannot do* (e.g., "…keep looking" rather than "cannot keep looking" CVI Q) (Ortibus et al., 2011).

Decision points throughout both phases of this research were regularly discussed among the authors, ensuring a peer review process aiming to increase the confirmability of the results.

5.2.3 Results

Part I: constructs measured by vision assessments

In total, 266 assessment items, scales or tests were included in the analysis of constructs measured by existing assessment tools, and 370 units were linked to the ICF-CY. Items were linked to constructs across the ICF-CY domains including Body Functions, Activities and Participation, Environmental factors and Personal factors (see Table 5.1). This study found that all 19 previously-identified assessments contained items and linking units that were linked to one of the specific codes identified as 'visual ability' codes (d110 *Watching*, d160 *Focusing attention*, and d161 *Directing attention*) (see Table 5.4), but in addition to measuring vision, an additional 16 second-level codes from the Activity and Participation domain were also identified as constructs within the assessment tools (e.g., d445 *Hand and arm use*, for items about reaching). These findings support the previous decision for inclusion of all 19 assessments in the systematic review, and confirms that these tools include measurement of a variety of constructs. Whilst vision measurement is varied, occurring across the ICF-CY domains, the results suggest that vision measured using specific 'visual ability' items could result in measurement of a single construct, and further analysis was indicated.

Table 5.4

Activity and Participation ICF-CY categories identified in assessment tools

	Assessment tools with visual ability items[a]																			
ICF-CY Activities and Participation Chapters and Two-level classification[b]	**ABCDEFV**	**Alimovic**	**CAS**	**CVI Q**	**CVI R**	**EDVA**	**FVQ**	**Hoyt**	**HSCS-PS**	**HUI-III**	**IDP**	**LVC**	**PreViAs**	**ShCVI Q**	**SoGS**	**VAP-CAP**	**VSI**	**Wong**	**15-D**	**N**
d1 LEARNING AND APPLYING KNOWLEDGE																				
d110 Watching and/or d160 Focusing attention[c,d]	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**19**
d120 Other purposeful sensing[e]				X	X		X										X			4
d130 Copying[f]			X										X							2
d131 Learning through actions with objects[g]	X		X										X							3
d161 Directing attention[h]	**X**	**X**		**X**																**3**
d166 Reading[i]										X	X			X					X	4
d170 Writing[j]													X							1
d2 GENERAL TASKS AND DEMANDS																				
d3 COMMUNICATION																				
d315 Communicating with – receiving – non-verbal messages[k]				X			X						X				X			4
d335 Producing nonverbal messages[l]							X						X		X					3
d350 Conversation[m]		X																		1
d4 MOBILITY																				
d440 Fine hand use[n]	X		X	X	X		X					X	X			X				8
d445 Hand and arm use[o]			X		X		X						X		X	X	X			7
d450 Walking[p]				X								X		X						3
d460 Moving around in different locations[q]												X							X	2
d499 Mobility, unspecified[r]			X	X																2

d5 SELF-CARE																	
d6 DOMESTIC LIFE																	
d7 INTERPERSONAL INTERACTIONS AND RELATIONSHIPS																	
d710 Basic interpersonal interactions[s]	X	X			X						X	X			X		6
d8 MAJOR LIFE AREAS																	
d880 Engagement in play[t]		X									X						2
d9 COMMUNITY, SOCIAL AND CIVIC LIFE																	
d920 Recreation and Leisure[u]		X															1

Notes. [a]Assessment tools identified in systematic review (Deramore Denver et al., 2016); [b]Only two-level classification codes linked to items from visual ability assessment tools are presented in this table; [c]Items linked to codes *d110 Watching* and *d160 Focusing attention* are combined in this presentation due to difficulties in discriminating between the constructs, and the three concepts which represent the concept of 'visual ability' are presented in bold font; Examples of constructs linked to Activities and Participation codes: [d]Focusing on or tracking a toy, [e]Mouthing, touching and smelling, [f]Imitation of facial expression, [g]Relating two or more objects such as block building or posting, [h]Keep looking, [i]Reading crowded text, [j]Scribble with pen on paper, [k]Responds to/understands facial expressions, [l]Smiles or demonstrates visual preference, [m]Starting/sustaining visual communication, [n]Picking up, Grasping or Manipulating object, [o]Reaching for seen object, [p]Walking around and over different surfaces and avoiding obstacles, [q]Moving about +/- guidance, [r]Moves to object, [s]Appropriate use of eye contact and differentiation of familiar people/strangers, [t]Play with objects, and [u]Memory game.

Part II: analysis of 'visual ability' themes

Thirteen analytical themes emerged from the data to describe items that specifically assess vision at the Activity level of the ICF-CY. These 13 themes are clustered into three categories that reflect a child's observable visual behaviours (Table 5.5). The category *Abilities* includes seven themes reflecting how a child uses vision; *Interactions* includes four themes reflecting the contexts in which the child uses their vision to interact purposefully; and *Use of vision* includes two themes reflecting a child's overall use of vision in daily activities. These results provide the conceptualisation of the construct 'visual ability'.

Table 5.5

Categories and related themes reflecting how visual behaviours are described in assessment tools

I. Abilities	II. Interactions	III. Use of vision
1. Responds or reacts 2. Initiates 3. Maintains or sustains looking 4. Changes or shifts looking 5. Searches 6. Locates or finds 7. Follows	8. Watches and visually interacts with people/faces 9. Watches and visually interacts with objects 10. Watches and visual interacts over distances 11. Watches and visually interacts with hands	12. Frequency of use of vision in activities 13. Efficiency of use of vision in activities

Category I: abilities

<u>Responds/reacts</u>: The first theme incorporates the basic visual ability of responding or reacting to visual stimuli and utilises *observations of behaviours that suggest a child is responding, at some level, to visual information*. The theme is derived from items describing a wide range of responses or reactions and includes both purposeful and non-purposeful use of vision, and both passive and active responses.

> …the light perception test is deemed positive if the patient shows some reaction to light, even high-intensity light…by moving his or her head, winking, or making a

defensive or stopping movement (extract from LVC, Test 1 guidelines) (Salati et al., 2001).

Items that contributed to the development of this theme often appeared first in a measurement tool, and it is proposed that responding or reacting is a pre-requisite for other visual abilities i.e., if a child does not respond they will not be able to demonstrate other visual behaviours such as watching, finding, or following. Some items themed to ‘responds or reacts’ were additionally linked to b210 *Seeing functions* in Part I.

<u>Initiates</u>: This theme is about how quickly vision is used; the observable behaviour is *time to respond to visual information in a purposeful way*. Items contributing to this theme include descriptions of prompt or delayed responses.

> Exhibits a delayed response to visual stimuli (FVQ, Question 6) (Ferziger et al., 2011).

<u>Maintains/sustains looking</u>: This theme is about how much or for how long a child keeps looking. The observable behaviour is *the purposeful use of vision for a length of time appropriate to the activity*.

> …keep looking at objects or persons (extract from CVI Q, Item 9) (Ortibus et al., 2011).

Contextual information about type of visual stimuli or the environment where the visual behaviours occur reflects some of the variability in items about a child’s ability to maintain/sustain looking, and these facilitators or barriers also apply to the previous theme of ‘initiates’.

> … brief fixations on movement and reflective materials; Movement continues to be an important factor to initiate visual attention; Movement not required for attention at near…(extract from CVI Characteristic - Need for movement, CVI R) (Roman-Lantzy, 2007).

<u>Changes/shifts looking</u>: This theme addresses whether the child can initiate a purposeful change or shift in looking between objects, people and/or the surrounding environment. The observable behaviour is *the child easily disengaging attention from one stimulus to look at another*.

> …able to move the eyes quickly between two persons or two objects (extract from Question 4, PreViAs) (Pueyo et al., 2014).

> Shifts gaze between targets in near and middle space accurately (extract from 5-month Pattern Component, Gaze Shift - Visual Release, EDVA) (Erhardt et al., 1988).

Items contributing to the theme suggest variations in the ability to shift gaze, and may include use of internal strategies (e.g., blinking to facilitate visual release) and/or the need for physical support to prompt or redirect looking behaviours.

<u>Searches</u>: This theme considers whether the child uses a process of visually searching, scanning and exploring in a purposeful way. Searching may or may not result in 'finding' the desired target – that is themed separately. The observable behaviour *is the self-initiated ability of the child to explore visually by moving their visual attention around the information in the visual environment for a goal-directed purpose*.

> Visually seeks missing object or person (Item 9b, CAS) (Stillman, 1974).

> Looks around when entering a room (Question 25, FVQ) (Ferziger et al., 2011).

By definition, this theme is suggestive of prerequisite skills including initiation, the ability to interact with different stimuli including over distances, sustained looking or attention, and shifting between stimuli.

<u>Locates/finds</u>: The theme 'locates/finds' is about whether and how easily a child uses their vision to locate or find specific information. The observable behaviour is *successfully locating the specified or required visual information*.

> Looks in correct place for fallen toy (Item 78, SoGS) (Bellman & Cash, 1987).

Items that contribute to the development of this theme suggest that the ease with which a child locates or finds specific visual information may be impacted by the environmental context in which the behaviour occurs, including distance, background clutter, colour, low contrast/similar background, in addition to the prerequisite skills described under the 'searches' theme. Success in locating or finding a target are more likely to be observed if a child has good searching abilities.

> …find his teddy bear (or equal) amongst other cuddly animals (extract from Item 33, CVI Q) (Ortibus et al., 2011).

> …Finding parents or friends in a crowd (extract from Question 3, Short CVI Q) (van Genderen et al., 2012).

This theme was predominantly derived from assessment items designed to diagnose or screen for cerebral or cortical visual impairment (CVI), suggesting that locates/finds may contain significantly more cognitive requirements than some other abilities. In addition to items about locating or finding a person or object, this theme also included items about navigation.

> …find his/her way to the classroom, in his house [familiar environments] (extract from Item 26, CVI Q) (Ortibus et al., 2011).

<u>Follows</u>: This theme, and the observable behaviour, concerns *whether and how effectively the child follows or tracks moving targets*. It was derived from items also contributing to other themes, including the types of stimuli that are followed, the distances at which following occurs, and how often a child demonstrates following behaviours. The abilities that are unique to this theme are the direction and extent (e.g., how far) of following behaviours, and the quality of the following with eyes and/or head.

> …Either saccadic (jerky) tracking or smooth pursuit can be accepted but it should be noted which type of eye movement the child makes … For infants over 3 months, tracking should be easily elicited on the first trial in either direction, provided the child is reasonably attentive at the start of each trial (extract from procedure, Item 3, ABCDEFV) (Atkinson et al., 2002).

The content of items contributing to this theme, and the relationship between items in different themes, suggests that following has a number of prerequisite abilities including ‘sustains looking’. There is also a suggestion that ‘shifts looking’, ‘searches’ and ‘finds’ may result in successful performance (‘use of vision’) in the absence of the ability to follow.

Category II: interactions

<u>Watches and interacts visually with people & faces</u>: The first ‘interaction’ theme describes whether the child watches or looks at people and faces; the observable behaviour is *purposeful looking at people and faces within everyday social interactions*.

> …Generally no regard of the human face…Regards familiar faces when voice does not compete… Smiles at/regards familiar and new faces… Typical visual/social responses (extract from CVI Characteristic –Visual Complexity, CVI R) (Roman-Lantzy, 2007).

> Focuses on a face when seated opposite him/her (Question 13, FVQ) (Ferziger et al., 2011).

The importance and relationship of this theme to a child's overall functioning is evident when revisiting the items and codes analysed in Part I of this study where additional related concepts included the variables such as responding to facial expressions and recognising faces.

<u>Watches and interacts visually with objects</u>: This theme explores whether the child looks at objects (e.g., inanimate stimuli such as toys and books) and includes the range of objects with which the child watches or visually interacts. The observable behaviour is *the child's purposeful response to the visual properties of objects*, in a manner which is appropriate to the child's motor capacity and developmental level.

> …reach for a drink bottle when you hold it in front of him/her…become excited but does not reach for the drink bottle (extract from Item 11, VSI) (McCulloch et al., 2007).

> Looks at/focuses on pictures in a book or on a communication board (Item 19, FVQ) (Ferziger et al., 2011).

Limitations in the range of stimuli with which a child interacts visually are suggested by items describing the need for specific characteristics to facilitate looking e.g., sound, light, colour.

> Requires an additional sensory modality (e.g. sound, touch, etc.) to focus on or respond to an object/toy (Question 7, FVQ) (Ferziger et al., 2011).

> …Objects viewed are generally a single colour…(extract from CVI Characteristic – Color Preference, CVI R) (Roman-Lantzy, 2007).

<u>Watches and interacts visually over distances</u>: This theme is about whether the child watches/looks at visual information over a range of distances. The observable behaviours

are *responses indicating that visual in-formation has been experienced*. It is about seeing/using vision to experience information beyond the child's immediate space, and the distance is considered in relation to the child's age.

> Visually attends in near space only … Visual attention extends beyond near space, up to 4 to 6 feet (extract from CVI Characteristic: Difficulty with distance viewing. CVI R) (Roman-Lantzy, 2007).

> Watches movements of people at distances or out of window with interest (Item 79, SoGS) (Bellman & Cash, 1987).

<u>Watches and visually interacts – with hands</u>: The next theme is about whether there is an interaction between the child and the manual actions of his/her hands, or the manual actions done by the hands of another person. The observable behaviour is *whether there is purposeful and effective use of this interaction in everyday activities*. Whilst it is acknowledged that children with cerebral palsy have varying manual abilities, the interaction between vision and manual actions is a strong theme.

> …observe his/her own hands (extract from Question 6, PreViAs) (Pueyo et al., 2014).

> Visually explores the toy whilst you turn it over: The child looks interested in the toy but either because of physical disability or tactile defensiveness can't or won't take the toy, but visually examines the toy as the adult turns it over (extract from response option, Item 5, Low Vision Assessment, VAP-CAP) (Blanksby & Langford, 1993).

> Looks at a toy or object while reaching/moving hand towards it (Item 21, FVQ) (Ferziger et al., 2011).

The identification of relationships between linking units, as recommended in the ICF eLearning Tool (World Health Organisation ICF Research Branch, 2015), contributed significantly to this theme with many of the items contributing to this theme also being linked to another ICF-CY code (e.g., d1201 *Touching* or d440 *Fine hand use*).

Category III: use of vision

Uses vision in activities – Frequency of use: This theme is about observations of *the overall frequency or 'how often' the child uses their visual abilities*. This theme is derived from items describing the consistency and reliability with which visual abilities are used in daily activities.

> …Student functions with more consistent visual response…(extract from scoring, Rating I, Across CVI Characteristics, CVI R) (Roman-Lantzy, 2007).

> Attention is fluctuating from moment to moment and from day to day (Item 10, CVI Q) (Ortibus et al., 2011).

This theme was also developed from items suggesting a low frequency of use of vision by referring to the use of senses other than vision (e.g., listening, mouthing, touch-ing, smelling, or tasting) when vision could be used.

> Manipulates an object rather than look at it (Item 40, CVI Q) (Ortibus et al., 2011).

Uses vision in activities – Efficiency of use: The final theme is about the efficiency with which vision is used in daily functioning. The observable behaviours are *how independently and easily a child has success when performing in vision-related activities*. Items contributing to this theme describe how performance in vision-related activities is affected by limited visual functions, and describe limitations in performance related to the need for assistance, guidance, time or prompting, a reduced level of independence, or difficulty in performance. As such, items contributing to this theme were commonly linked to codes in addition to the visual ability code in Part I, such as b1561 *Visual perception*, b210 *Seeing functions*, and e1251 *Assistive products and technology for communication*.

> …able to see well enough to recognise small objects and familiar people at a distance…Sees objects close to oneself - e.g. at arm's length, but has visual limitations at distance, even with glasses (extract from Vision (ability to see) subscale, HSCS-PS) (Saigal et al., 2005).

5.2.4 Discussion

This paper presents a methodological approach applicable to research conundrums where definition and understanding of a complex issue are required. Our example involves the initial stages in instrumentation research to establish ‘vision use’ as a construct that is measurable in children with motor impairments. By utilising a two-part process this study demonstrates an approach to conceptualise complex constructs and operationalise how a concept will be measured. In this study the WHO’s ICF-CY provided a framework for conceptualising a complex construct utilising terminology that has been endorsed world-wide (World Health Organization, 2007), increasing the transferability of both the methods and findings. The outcome from this work is a conceptualisation of visual ability that is grounded in a common language and builds on, and takes advantage of, the work of previous researchers. It is an approach that other healthcare researchers, clinicians and policy makers are encouraged to consider when clarity is sought regarding complex or unclear constructs.

In the first phase of this study a deductive and explanatory method established ‘visual ability’ within the conceptual framework of the ICF-CY. The process built upon the focus of vision measured at the Activities and Participation level of the ICF-CY previously presented in a systematic review (Deramore Denver et al., 2016), and developed a refined definition of ‘visual ability’ as a construct measurable *within* the Activity level of the ICF-CY as ‘how vision is used’. This finding arose from linking procedures that identified that existing assessment tools measuring visual ability in fact measure a wide range of constructs. This demonstrates the complexity and multidimensionality of ‘vision’ and provides valuable information about the need to define clearly which component(s) of functioning is (are) being measured at any given time. At an item level, existing visual ability assessment tools are measuring constructs across the ICF-CY framework, and these findings support the need for the development of a discrete assessment tool that measures ‘visual ability’.

Whilst the ICF-CY provides a strong framework from which to develop the conceptualisation of visual ability, the process of linking items to the classification in this study was not straightforward. It is proposed that issues identified during linking in this study regarding ‘what an item is about’ likely reflect problems utilising the existing measurement tools in clinical practice and research. If the authors of this paper could not reliably link items, it is reasonable to assume that parents and clinicians may also be unlikely to respond consistently to items, thus potentially impacting both the reliability and validity of measurement. The development of study-specific guidelines was an important step in this study to establish trustworthiness in the findings, and a summary of key challenges encountered during the linking process is provided in Appendix F. This information will be useful to researchers wishing to apply these methods in the future.

It must be recognised that the study results may not reflect the original intent of the authors of included measures. Linking the content of existing tools to the ICF-CY was completed in this study as one step in the methodological process of defining the concept of ‘visual ability’ and its place within the larger conceptual framework. The process of making conceptual distinctions within measurement tools and how this is important for content validity has previously been reported in quality of life research (Fayed, De Camargo, et al., 2012).

In the second phase, the application of an inductive and exploratory method resulted in a description of visual ability using 13 behaviours observable during typical daily activities. These behaviours are not new, but it is proposed that the act of identifying and describing these themes forms the step of item generation for a new assessment tool as this research moves from conceptualisation of visual ability to a measurement development phase. The analytical process and interpretation in this study also suggest the possibility of a hierarchy of visual abilities within the identified behaviours, that is, that careful ordering of the behaviours may reveal how a child functions in vision-related activities. This is a finding which could be explored in future instrumentation work using Item Response Theory (Bond & Fox, 2015).

Whilst the results of this study provide key foundational information for the development of an assessment of visual abilities in children with cerebral palsy, they are not yet operationalised in a measure. The observable behaviours are expected to be of interest to a wide range of researchers and clinicians, however they require further revision, development and validation before they can be considered an ‘assessment’. In their current format the results of this study may only provide guidance to practitioners in relation to their informal observations of visual abilities in children and will likely inform discussion and future research. The previously published systematic review provides a summary of currently available assessment options and recommendations for assessing children with cerebral palsy. However, it is important to note that the assessment tools reviewed in the systematic review do not measure the construct of visual ability as conceptualised in this methods paper.

Because this study used existing measures as the unit of analyses, whether all themes identified within this study are relevant, and whether they represent a comprehensive set of items about vision use, is an empirical question that requires further research. It is imperative that individuals with cerebral palsy, parents and carers, and the professionals who work clinically with the population contribute to future development of the visual ability construct, and the way it is measured (Terwee et al., 2012). It will be important to confirm the relevance of the observable behaviours across the diverse cerebral palsy population including people of different age groups, gross motor, manual and cognitive abilities. It is also likely that the definition of visual ability established in this study could be applicable to a range of health conditions other than cerebral palsy, however further investigation of the validity of this premise would be required.

5.2.5 Conclusion

Despite the complexity of vision, the concept of 'how vision is used' can be clearly defined as a measurable construct within the Activity level of the ICF-CY, so discrete measurement of this construct appears feasible. This construct is labelled 'visual ability', and this study has identified observable visual behaviours that may be developed into items assessing how vision is used in daily activities. The approach used in this study to explain and explore a complex construct may be useful in other health care research. Future research is required to confirm the results of this study and expand the findings through further instrumentation research. It is now planned that a tool be developed and validated to assess the construct of visual ability in children with cerebral palsy, and then used to establish effective interventions to optimise how vision is used.

5.3 SUMMARY OF CHAPTER 5

Chapter 5 confirms, using rigorous linking methodology, that no adequate instrument exists that can be used or modified to describe visual abilities in children with cerebral palsy. This is where the instrument design project begins. Had an existing measurement tool be available and suitable for use, this program of research may have focused on intervention research. Key findings from Study 2 are:

- Existing tools measure multiple constructs across the ICF-CY when assessing visual ability. That is, existing assessments do not provide specific information on how a child with cerebral palsy *uses their vision* in daily activities. These assessments are measuring multiple constructs.

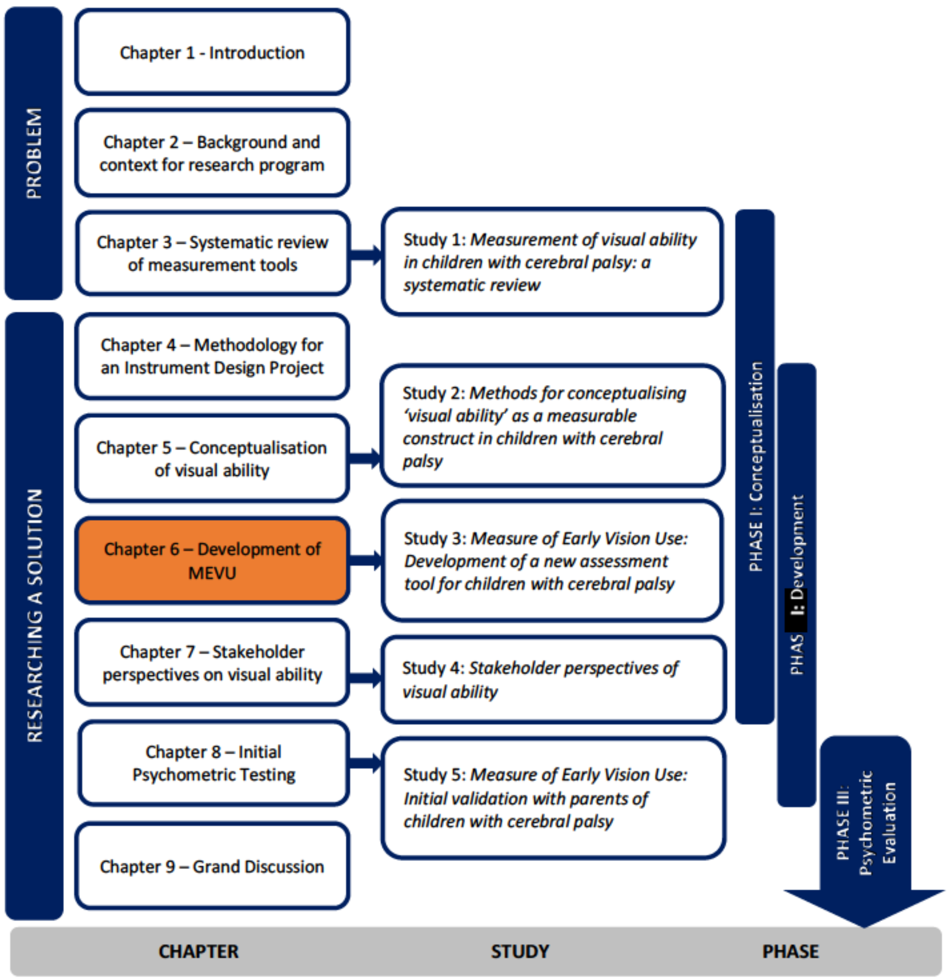
- Linking visual ability assessments was complex. The issues identified during linking in this study, in regard to determining what an item is about, are likely to be problematic in clinical or research practice. If researchers can't reliably link an item, parents and clinicians may also be unlikely to respond reliably to items.

- The ICF Framework can be used to conceptualise visual ability as a construct at the Activities and Participation domain. Items or constructs which link to *d110 Watching*, *d160 Focusing attention*, and *d161 Directing attention* form the basis of a conceptual model on visual ability.

- The construct of visual ability includes 13 observable behaviours or 'characteristics' of visual ability.

The conceptualisation of visual ability as a measurable construct, and the identification of theoretical content for a new measurement tool, needs exploration with key stakeholders (i.e., parents and clinicians) and development into a measurement scale.

CHAPTER 6: Development of Measure of Early Vision Use



6.1 INTRODUCTION TO CHAPTER 6

Chapter 6 addresses the third objective in this program of research: to develop a new tool to measure visual ability in children with cerebral palsy. This chapter is based on findings from Chapters 3 and 5 that highlighted limitations of existing visual ability measurement tools and concluded that there is no existing measurement tool available to measure visual ability as the single construct 'how vision is used'. Chapter 6 comprises the published manuscript describing the development of the Measure of Early Vision Use (MEVU).

6.2 STUDY 3: DEVELOPMENT OF THE MEASURE OF EARLY VISION USE

This manuscript has been accepted and published by Taylor & Francis in the journal *Disability & Rehabilitation*. Permission from the publisher to include the accepted version of this manuscript in this PhD thesis is available in Appendix H.

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For reasons of text consistency with other chapters in this thesis, some alternations may exist between the published manuscript and the version in this chapter.

Title

Measure of Early Vision Use: Development of a new assessment tool for children with cerebral palsy

Authors

Belinda Deramore Denver[a], Elspeth Froude[a], Peter Rosenbaum[b], Christine Imms[c]

Affiliations

[a]Australian Catholic University, North Sydney, NSW, Australia; [b]McMaster University, Hamilton, Ontario, Canada; [c]University of Melbourne, Parkville, VIC, Australia

Corresponding author

Belinda Deramore Denver. Australian Catholic University, 8-20 Napier Street, Level 3, North Sydney NSW, 2060 Australia. belinda.deramoredenver@acu.edu.au

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measurement, vision, cerebral palsy, Measure of Early Vision Use, validity, children

Abstract

PURPOSE To report the development of an assessment tool to describe ‘how vision is used’ for children with cerebral palsy.

METHOD Measurement development consisted of three steps: i) an online survey to explore the relevance and comprehensiveness of visual behaviours identified in a previous conceptualisation study; ii) construction of items and a rating scale for the new measure; and iii) cognitive interviews to explore comprehensibility and refine the measure in preparation for field testing. Survey respondents were 130 parents of children with cerebral palsy, eight adults with cerebral palsy, and 108 clinicians (n=246). Nine parents participated in the interviews.

RESULTS The new tool, the Measure of Early Vision Use, is a 14-item descriptive measure of typical performance of visual behaviours observable in everyday activities, as rated by parent/caregiver observation. Each item is rated on a 4-point ordinal scale.

CONCLUSIONS This new measure is conceptually grounded within the Activity level domain of the International Classification of Functioning, Disability & Health as a measure of a single visual ability construct. The target population is children with cerebral palsy, and using parent report the Measure of Early Vision Use describes both strengths and

limitations in using vision. This study addressed the selection of items and response options for the new scale, and provides evidence to support content relevance, comprehensiveness and comprehensibility from key stakeholders. Further research will explore psychometric properties and clinical utility.

Implications for rehabilitation

- The ability to use vision in daily activities is relevant to the development and learning of all children, so the availability of a method for describing visual abilities has potential for diverse research and clinical purposes.
- The Measure of Early Vision Use is a parent-report tool that provides a criterion-referenced method for quantifying and describing how children use vision in typical daily activities to support intervention planning.
- Clinicians and parents wishing to measure vision use in children with cerebral palsy can be confident about the rigorous methods used to develop this tool, including consultation with key stakeholders.

6.2.1 Background

A vision impairment is one potential associated impairment for children with a diagnosis of cerebral palsy, which by definition is a motor disorder attributed to a non-progressive disturbance that occurred in the developing brain (Rosenbaum et al., 2007). Visual impairments may result from problems with visual acuity, eye motility, or visual cognition, and have important implications for neurodevelopmental outcomes (Cioni et al., 2000). Reported rates of vision impairment are influenced by definitions of vision impairment, measurement methods (e.g. clinical test, observation or report) and focus (e.g. visual acuity or visual activity performance). Rates of severe vision impairment amongst children with cerebral palsy vary from 4-11% (Novak et al., 2012; Sakki et al., 2018; Sellier et al., 2020). Rates of visual cognitive impairments are likely to be much higher (Ego et al., 2015).

Whilst vision is typically assessed using measures of eye or seeing functions, the ability of a child to use vision in everyday activities reflects more than eye functions. Cognitive or processing abilities, motor abilities and other factors within the environment (e.g. lighting and distractions) also contribute. Determining the reason why a child with cerebral palsy has difficulties using their vision can be complex and there is growing clinical and research attention on cerebral/cortical vision impairments in cerebral palsy (Bennett et al., 2020; Kooiker et al., 2020; Salavati et al., 2017). An alternative to focusing on 'why' a child uses their vision as they do is to consider 'how vision is used'. This 'visual ability' is our research focus.

There is a gap in the availability of assessments for describing how children 'use vision' (Deramore Denver et al., 2016). Available tools focus on the measurement of visual (eye) functions or visual capacity (Ricci et al., 2008; Sonksen et al., 1991), or describe/discriminate features of cerebral/cortical visual impairment (Roman-Lantzy, 2007; Tsirka et al., 2020; Vancleef et al., 2020a). There is growth in the availability of eye gaze technology for the purpose of assessing 'abilities' and strengths in using vision; however, the availability and clinical utility of this method are limited (Venker & Kover, 2015). Recently, two classification systems have been developed to categorise levels of vision use, demonstrating growing recognition and importance in this field. The Visual Function Classification System classifies how children with cerebral palsy use visual functions in vision-related activities (Baranello et al., 2020). The Eye-pointing Classification System describes how non-speaking children with bilateral cerebral palsy use looking behaviours functionally for communication (Clarke et al., 2020). Both five-level classification systems discriminate between children with different levels of functional vision, but the availability of an assessment tool to describe and/or evaluate how a child uses vision remains a gap in clinical and research practice. It is proposed that there is a clinical and research need to be able to describe how children with cerebral palsy use vision, both when there are limitations, and for children whose visual abilities are a strength. If a child's ability to use vision across their daily environments could be described and quantified, this may provide a method to answer questions such as: "How well is this child using their vision?", "Will/can their use of vision improve?", and "What can be done to improve vision use?". The question of "Why does my child use vision this way?" is not the focus of this research.

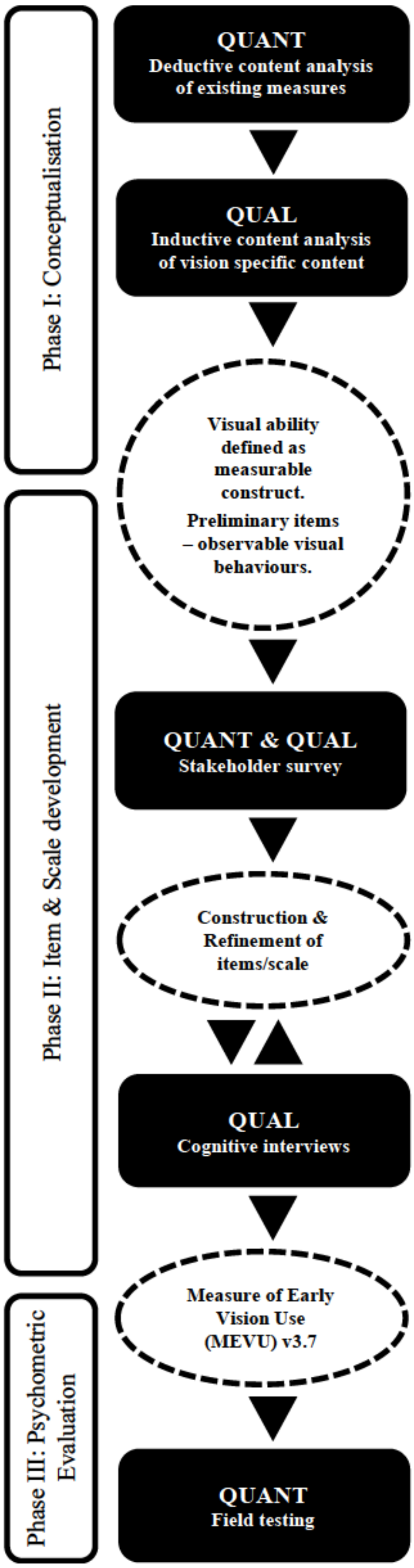
The aim of this paper is to report on the development of a new descriptive measure of how children with cerebral palsy use vision in everyday activities. In line with recommendations that measures be designed and validated for a specific purpose, this paper reports on the extent to which this new tool contains items that describe how vision is used (Kirshner & Guyatt, 1985). This focus on content aligns with recent recommendations that content validity is the most important measurement property, with its absence known to affect all other measurement properties, and that a well-designed development study helps to ensure content validity (Terwee et al., 2018). A descriptive assessment provides detailed information on current functioning that can be used for intervention planning and clinical decision-making (Laver Fawcett, 2007), and therefore requires ‘descriptive items’ (Law, 1987). The potential for this new measure to be used in the future for evaluative purposes is also important, and therefore ‘responsive items’ were also sought. The aim of this paper will be achieved by reporting the development of the Measure of Early Vision Use (MEVU), and exploring its comprehensiveness, relevance, and comprehensibility.

6.2.2 Methods

This research used a mixed methods instrument design approach to develop a new measure (Creswell et al., 2004), and has been completed over three phases: I) Conceptualisation; II) Development; and III) Evaluation of psychometric properties. Figure 6.1 highlights the steps and methods used in this multi-phase project. This paper briefly reviews important findings from the conceptualisation phase (Deramore Denver et al., 2017), and then reports on the second phase: development of the MEVU.

Figure 6.1

Flow diagram outlining the three-phase instrument design process



Note. Quant = Quantitative design, Qual = qualitative design

Phase I: conceptualisation

The first phase of this research has been published and follows from a systematic review that identified and appraised measures of visual ability used with children with cerebral palsy (Deramore Denver et al., 2016). Limitations with existing measures included problems with interpreting scores, a lack of psychometric properties to support their use, and uncertainty about whether measures were describing ‘how vision is used’ as opposed to other related constructs such as eye functions and performance in vision-related activities. Existing measures using a questionnaire format gathered information from parents about their child’s usual daily performance, while clinician-administered measures sought information on best performance.

A second study mapped items from existing measures to the International Classification of Functioning, Disability and Health (Child and Youth) (ICF-CY) framework (World Health Organization, 2007) using linking methodology (Deramore Denver et al., 2017). This step confirmed the need for development of a new measure, as it found items from existing measures tapped vision constructs from across the ICF-CY domains of Body Functions (e.g. visual acuity and visual perception), Activities and Participation (e.g. reaching and mobility, as well as watching), and Environmental and Personal Factors (e.g. prescriptive lenses and motivation, respectively). The mapping process resulted in a definition of visual ability as a measurable construct at the Activity level of the ICF-CY, and 13 observable visual behaviours were identified to describe how vision is used. These visual behaviours are presented in Figure 6.2 as ‘theoretical content’ for the new assessment tool and form the initial stage of item generation. One of the major limitations of this content, however, was that none of the measures from which these behaviours were sourced had included the parents of children with cerebral palsy, or their clinicians, in their design: the perspectives of key stakeholders were missing. This made it difficult to determine whether all meaningful and important visual behaviours had been identified, leading to the next research phase.

Figure 6.2

Development from "theoretical content" in the Conceptualisation Phase through to MEVU items designed and tested in the Development Phase

CONCEPTUALISATION PHASE

"Theoretical content"

Abilities
- Responds or reacts
- Initiates
- Maintains or sustains looking
- Changes or shifts looking
- Searches, scans and explores
- Locates or finds
- Follows

Interactions
- Watches and interacts visually with people/faces
- Watches and interacts visually with objects
- Watches and interacts visually over distances
- Watches and interacts visually with hands

Use of vision
- Frequency of use of vision in activities
- Efficiency of use of vision in activities

DEVELOPMENT PHASE

MEVU v3.0	MEVU v3.7
Reacts	Reacts
Notices & Responds	Responds to details
	Time to respond
Visually attends to objects & toys	Visually attends to toys & objects
Visually attends to faces	Visually attends to people
Visually attends to digital screens	Visually attends to digital screens
Visually attends to pictures	Visually attends to books & pictures
Visually attends to hand actions	Visually attends to what the hands are doing
Searches for & finds	Searches for & finds
Follows	Follows
Looks between people/objects	Shifts looking
	Shares visual attention
Uses vision over distance	Uses vision over distance
Overall use of vision	Overall use of vision

Note. MEVU 3.7 will be used in the third phase of the research project: Evaluation of psychometric properties.

Phase II: development

Ethical approval was granted by the Human Research Ethics Committees at Australian Catholic University (2016-282E & 2017-313H) and Cerebral Palsy Alliance (2017-04-04) for the two studies within this phase of the research project: Stakeholder survey and pre-testing with interviews.

Survey of key stakeholders

Theoretically-derived content identified in the conceptualisation phase was presented to key stakeholders using a customised web-based survey to explore its relevance and comprehensiveness for describing the visual abilities of children with cerebral palsy. The survey was designed following recommendations by Gideon (2012), which utilises a combination of closed- and open-ended questions. This approach enabled participants to provide detailed answers and allowed for maximum variation in answers. The use of an online survey facilitated collection of data from a wider range of participants than is practicable when using other qualitative methods (e.g. focus groups and interviews). Data were collected and managed via the online platform REDCap (Harris et al., 2009), and the survey was distributed to three key stakeholder groups. A secondary objective of the survey was to explore the need, purpose, format and target population for the new assessment tool.

Participants were eligible for inclusion in the online survey if they were (a) a parent or caregiver (hereafter referred to as parents for simplicity) of a child with cerebral palsy, or an infant diagnosed at high risk of cerebral palsy; (b) an adult with a diagnosis of cerebral palsy; or (c) a clinician or professional with at least two years' experience working with children with cerebral palsy and their families, including clinical, educational, research and management roles. Eligibility was not limited by geographical location; however targeted advertising was undertaken mainly through Australian networks, e.g. state-based Cerebral Palsy Registers and the Australasian Academy of Cerebral Palsy & Developmental Medicine. Resources were not available for translation from English or for support to complete the survey. The perspectives of children with cerebral palsy were not sought because they would be limited in their ability to comment on the measurement construct: 'observable' visual behaviours.

Open to participants between April and June 2017, the purpose-built survey had three sections: (i) demographic information; (ii) descriptions and ratings of visual behaviours; and (iii) descriptions of visual behaviours that change, and the usefulness of measuring visual ability. All participants completed the same survey, however the number and type of questions a participant received were dependent on previous answers. The survey was reviewed with both parents and clinicians and refined prior to distribution. Feedback was sought on ease of understanding and survey length, and the functionality of the data collection and management platform was tested.

Visual behaviours were rated for relevance in two ways. Parents rated the observability of visual behaviours in their child, and clinicians and adults with a diagnosis of cerebral palsy rated visual behaviours for importance using a 4-point descriptive scale. This meant that whilst parents rated relevance of visual behaviours to their own child, clinicians and adults with cerebral palsy were rating relevance to the population of children with cerebral palsy more generally. Descriptive statistics were calculated to report the participant sample and the relevance of visual behaviours.

Qualitative data collected from participants (via open-ended questions) were utilised to explore the comprehensiveness of the visual behaviours identified in the preceding conceptualisation phase. Participants were explicitly asked to identify omitted visual behaviours, and, using a directed content analysis approach, the complete data set was explored for behaviours not previously defined (Hsieh & Shannon, 2005). Qualitative responses from surveys were also explored for examples of variations in visual behaviours that could be used to build response options, and support for using observable visual behaviours as a method of measuring vision use in children with cerebral palsy. Qualitative data were analysed and managed within Excel spreadsheets with participant characteristics alongside responses. Rigor was enhanced by the first author completing all data coding and confirming the analysis with the research team. Ongoing triangulation occurred to ensure the fit of items and response options with the conceptualisation of visual ability as a measurable construct at the Activity level of the ICF, a process contributing to review of item relevance and content validity.

MEVU: Constructing the items and rating scale

Operationalisation of visual behaviours from 'theoretical content' into a measurement scale occurred concurrently with survey data analysis and continued until version 3.0 was ready for pre-testing with parents in cognitive interviews (see Figure 6.2). The intention was to create a standardised criterion-referenced tool that could describe and measure (quantify) how children with cerebral palsy use vision within everyday activities, that is, their typical daily performance. Decisions during construction were undertaken by the research team using the available data, clinical experience and measurement expertise. This included determination that the perspective sought by the measure would be performance (what a child 'does do in daily environments'), whilst descriptions of capability (what a child 'can do in daily environments') were built into the response options (Holsbeeke et al., 2009). This format captures parent clarification of visual behaviours, such as "my child can x if y" without the need for exhaustive and potentially restrictive examples. Parents were confirmed as the most appropriate respondents to questions about observable visual behaviours. Young children with cerebral palsy and 'early visual skills' were identified as the key target population. This decision was supported by the research teams' understanding of neuroplasticity research, survey responses from open-ended questions on 'who' and 'when' to assess, and the finding that descriptions of older children included more comments about visual processing and performance in vision-related activities, rather than observable visual behaviours. Special consideration was also given to the need for 'visual ability' to be the focus of items and response options, rather than the construct of motor ability.

Variations in visual ability, including examples of good, limited and poor performance, as well as meaningful indicators of how visual abilities change over time, or how parents would like visual abilities to improve, were used to develop four response options for each item (visual behaviour). An example is provided in Figure 6.3. The rating criteria reflect those used in other ability assessments such as the Assisting Hand Assessment (AHA) (Krumlinde-Sundholm & Eliasson, 2003) and CVI Range (Roman-Lantzy, 2007). Response options within MEVU ask parents for confirmation of the criteria that best describe their child's typical performance over the last week. Consideration was given throughout this process to the utility of the tool being developed, including format, layout, wording, time to complete and whether parents would be able to answer the questions independent of clinician help.

Figure 6.3

Example of 'Item 2. Visually attends to people' from MEVU 3.7, with scoring criteria (response options), general meaning of the scale, and examples of the qualitative data used to build the rating scale

Item	Level of Ability	Score	Response options	General meaning for scale	Example of qualitative data used to build scale for Item 2
2. Visually attends to people How much does your child look at and attend to people?	Ability ↑	4	Sustains visual attention to people, and gives eye-contact to at least some familiar people.	Does do: Child typically demonstrates this ability in everyday activities.	
		3	Sustains visual attention to people, with some limitations. Does not typically give eye contact.	Does do, but limited: Child typically demonstrates this ability in everyday activities, but there are some limitations.	"Poor eye contact" *Survey ID 163 Parent of 3-5 yo GMFCS II*
		2	Can visually attend to people but this is not a frequently seen behaviour. *OR* Looks or glances in their direction, but no sustained looking at people. *OR* Mostly it is hard to tell if he/she is looking or just listening.	Can do, or may do: Child may be capable, but does not typically demonstrate this ability in everyday activities.	"never look directly at anything but would turn his ear towards people and avoided looking a people…he would not look at faces" *Survey ID 338 Parent of 12-17yo GMFCS III* "look out of the sides of her eyes – people think she is not looking when in fact she is" *Survey ID 41 Parent of adult with cerebral palsy GMFCS V*
	↓ No ability	1	Does not look at people.	Does not do: Child does not demonstrate this ability.	"…does not show interest in people…" *Survey ID 203 Parent of 9-month-old infant with cerebral palsy*

Pre-testing with cognitive interviews

Cognitive interviews were undertaken with parents of children with cerebral palsy to explore understandability of the instructions, questions and response options of MEVU, and whether parents can describe their child's level of visual ability by selecting a response from the available options. Cognitive interviewing pays explicit attention to the mental processes that respondents use when answering questions, with the aim of identifying solutions that result in a measure with less chance of systematic errors (Collins, 2003). This step was also used to identify potential sources of measurement error within the question and answer process before testing begins with a larger group of participants. The proposal that MEVU be completed by parents answering questions about their child's visual abilities, independent from the support of a healthcare professional, highlights the importance of this step.

Parents who participated in the survey and provided the research team with contact details (n=55) were invited via email invitation to participate in interviews to explore and test MEVU. Targeted sampling was utilised to gain perspectives from a diverse range of participants (i.e. parents of children of variable age, range of functional levels (using the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997), Manual Ability Classification System (MACS) (Eliasson et al., 2006), and Communication Function Classification System (CFCS) (Hidecker et al., 2011), type of cerebral palsy, and presence or absence of vision impairment). The interview phase started with MEVU version 3.0 and ended when version 3.7 was ready for field testing. All interviews were conducted between April and August 2018 by the first author (BDD), recorded, and transcribed verbatim. Sampling continued until only minor changes were obtained from additional interviews.

Data analysis began after the first interview and continued throughout the data collection process, and analyses involved both interview data and responses to MEVU items. To increase trustworthiness of the data and changes made to the measure because of interviews, a verbal summary was provided to participants at the end of each interview on their feedback and the possible changes that might occur because of that feedback. Participants were asked for agreement on whether their thoughts had been captured, and interview transcripts were used within research team meetings when decisions were being discussed about the measure (items and instructions).

6.2.3 Results

From the survey of key stakeholders, a total of 246 sufficiently complete responses were received and have been used in the development of MEVU. The sample included 130 parents of children with a wide range of GMFCS, MACS and CFCS levels and a wide range of ages, and nearly half of the parents described their child's vision as good. Eight adults with a diagnosis of cerebral palsy participated, along with a diverse range of 108 clinicians. In the second study, nine interviews explored how parents understood and answered the items, with the objective of improving the validity and acceptability of the questionnaire. Tables 6.1 and 6.2 list the participant characteristics.

Table 6.1

Participant characteristics (Parents and Adults with cerebral palsy) – Online Survey and interviews

	Survey (Parents (n=130) + Adults (n=8)	Parents Interviews (n=9)
Location		
Australia	111 + 7 (85%)	7
Other countries	19 + 1 (14%)	2
Age of child		
Below 3 years	12	2
3 to 6 years	19	2
6 to 12 years	41	2
12 to 18 years	32	2
Adult	25	1
Adult with cerebral palsy	8	
Type of cerebral palsy		
Spastic hemiplegia	36 + 2	3
Spastic diplegia	17 + 2	2
Spastic triplegia/quadriplegia	40	3
Dyskinesia	11 + 1	1
Ataxia/Hypotonia	12	1
Unknown/Not reported	14 + 3	
GMFCS		
Level I	27 + 2 (21%)	1
Level II	26 + 2 (20%)	2
Level III	13 + 3 (12%)	1
Level IV	16 (12%)	1
Level V	35 + 1 (26%)	4
Unknown /Not reported	13 (9%)	
MACS/Mini-MACS		
Level I	20 + 1	1
Level II	40 + 5	2
Level III	14 + 1	1
Level IV	18 + 1	2
Level V	22	3
Unknown /Not reported	16	
CFCS		
Child is less than 2y	9	3
Level I	37 + 3	2
Level II	21 + 4	0
Level III	14 + 1	1
Level IV	21	2
Level V	10	1
Unknown /Not reported	18	
Gross description of visual ability		
Good	58 + 3 (44%)	2
Some limitations	43 + 4 (34%)	2
Poor	28 (20%)	5
Not reported	1	

Note. All data are parent and/or self-reported.

Table 6.2

Participant characteristics (Clinicians) – Online Survey (n=108)

	n (%)
Location	
Australia	60 (55%)
Other countries	45 (42%)
Not reported	3 (3%)
Profession [a]	
Eye specialist (Ophthalmologist/orthoptist/optometrist)	4 (4%)
Occupational therapist	27 (25%)
Orientation & Mobility specialist	4 (4%)
Paediatrician	13 (12%)
Physiotherapist	37 (34%)
Rehab Specialist	10 (9%)
Researcher	7 (6%)
Speech Pathologist	7 (6%)
Other [b]	12 (11%)
Years of experience	
<5 years	14 (13%)
5-10 yers	24 (22%)
10-20 years	28 (26%)
>20 years	37 (34%)
Not reported	5 (5%)
Clinical setting [a]	
Hospital, inpatient	33 (30%)
Hospital, outpatient	60 (55%)
Community outpatient	48 (44%)
School/education	41 (38%)
Family home	32 (30%)
Research facility	12 (11%)
Other	9 (8%)
Concerns about how at least some children use their vision:	
Yes	102 (94%)
No	6 (6%)
Current (or past professional role) assessing vision use (where assessment may be formal or informal):	
Yes	84 (78%)
No	18 (17%)
Not reported	6 (5%)
Methods or assessment tools:	
Informal observation of how vision is used	77 (71%)
Informal questioning of how vision is used	71 (66%)
Formal/Standardised assessments & Structured Questionnaires [c]	30 (28%)
Children seen sometimes have goals to improve use of vision:	
Yes	41 (38%)
No	33 (30%)
Not reported	34 (32%)
Provider of therapy/recommendations to improve vision use:	
Providing therapy/recommendations is a key role	20 (18%)

Providing therapy/recommendations is sometimes a strategy used to achieve other goals e.g. mobility or communication	36 (33%)
Never provide therapy/recommendations	
Not reported	19 (18%)
	33 (31%)
For providers of therapy/recommendations (n=56), evaluation method:	
Canadian Occupational Performance Measure (COPM)	15 (27%)
Goal Attainment Scaling (GAS)	15 (27%)
Other assessment tool/s [d]	15 (27%)
Informal evaluation	35 (62%)
No evaluation of effectiveness undertaken	6 (11%)
Change observed in how vision is used following therapy/recommendations:	41 (38%)
Yes	8 (7%)
No	19 (18%)
Unsure	7 (6%)
Have not seen a child who has received therapy/recommendation	33 (31%)
Not reported	

Notes. [a] Participants could report more than one profession and clinical setting. [b] Other professions include Clinical and Neuropsychologist, Educator, Manager, Neurologist, Neuropsychiatrist, Social Work, and Orthotist. [c] Includes: Atkinson Battery for Child Development in Examining Functional Vision, CVI Questionnaire, CVI Range, Erhardt Developmental Visual Assessment, tests of eye function and visual processing, and other questionnaires/checklists. [d] Includes: CVI Range. Further information is available from the authors on current assessment and management practices reported in this survey.

Comprehensiveness

The question of whether the ‘theoretical content’ represented a comprehensive list of visual behaviours was explored using the qualitative survey responses. No new visual behaviours were identified, but the language and definitions of the described behaviours were refined based on participant responses, with further changes, including the separation and renaming of items, resulting from interviews.

> [Do you think ‘looking between you and an object’, and ‘looking between options’, are two different abilities?] I think so…when they’re showing preference they’re generally being presented with something right in front of them, whereas looking at a parent and then looking at the task, they’re switching between attending socially and attending to maybe an oral communication and then refocusing on a task. Cognitive interview 4, Mother of 13yo GMFCS V

This discussion led to ‘looks between people/objects’ becoming two distinct visual behaviours: ‘shifts looking’ and ‘shares visual attention’. Other refinements included the alignment of ‘searches’ and ‘finds’ into one item because finding is the observable behaviour that indicates successful searching. ‘Frequency of use of vision’ was removed as a potential item because it is captured by the overarching focus on ‘typical performance’ and now forms a key part of the response options for all items i.e. “can do…but this is not a frequently seen behaviour”.

Whilst discussing whether any key aspects of visual ability are missing, one parent commented on a difference between MEVU and other visual measures that focus on factors that impact on how vision is used.

> One thing that’s different, as opposed to other vision questionnaires and everything that we’ve looked at, is [the absence of specific] colour preferences or shiny or moving, kind of object questions. Cognitive interview 6, Mother of 1yo GMFCS IV

Parents reported that it was appropriate that details on the ‘type of visual information’ (e.g. preference for red toys) and ‘location of visual information’ (e.g. need for uncluttered environments) were built into the response options of MEVU, without being too specific or limiting. They reported it can be difficult for an assessment to cover all variations and reported that the response options of ‘does do, but limited’ and ‘can do, or may do’ provided parents with options covering most children and situations.

Survey participants also provided responses considered to fall outside the construct of visual ability when it is defined as ‘observable visual behaviours’. These included (1) child factors (e.g. eye and visual functions, motivation, and age); (2) environmental and task factors (e.g. type, features and location of visual information); and (3) performance and participation in vision-related activities that provide evidence of the ability to use, or not use, visual abilities. These results, whilst important to an overall understanding of visual ability and the measurement of ‘vision use’, are not pertinent to this paper reporting on the development of MEVU.

Relevance

The relevance of using observable visual behaviours as the foundation for items in an assessment of ‘how vision is used’ was also explored using ratings from key stakeholders in the survey. Measurement of ‘vision use’ was reported as relevant (useful to assess) by 65% of parents in the online survey, whilst 19% of parents reported that it would not be useful. Non-relevance was often explained by parents having no concern with their own child’s vision. Sixteen percent of parents did not complete this last section of the survey. Relevance was primarily explored with parents by asking them to rate whether they considered individual visual behaviours to be observable in their child, and providing opportunity for qualitative explanations for their observations (e.g. “Due to also being on the autism spectrum it is more lack of interest (attention span) rather than being unable” ID373). Ratings were based on brief descriptions of the behaviours and are reported in Table 6.3. At most, 4% of parents reported themselves unable to determine whether a visual behaviour was observable in their child. Responses also provided evidence of variation in the abilities of children. For example, 62% of parents rated ‘I am sure my child does look at people/faces, and I have no concerns with how this is done’; 17% of parents rated ‘My child probably has some ability to…but there are limitations’; whilst 6% of parents rated ‘I am sure my child does not look at people/faces’. There was a similar number of missing responses across all the visual behaviours.

Table 6.3

Parent rated observability of visual behaviours (n=130)

Visual behaviour[1]	Rated as observable (%)			Rated as not observable (%)	Response missing (%)
	I am sure my child does...and I have no concerns with how this is done	My child probably has some ability to...but there are limitations	I am sure my child does not	I can't tell whether or not my child demonstrates this ability	
Can you tell if your child **responds or reacts** (in any way) to visual information? (Note: Visual information can include anything e.g. toys, faces, lights, or bright/shiny materials)	92 (71%)	17 (13%)	4 (3%)	1 (1%)	16 (12%)
Can you tell if your child **responds quickly** to visual information or has a delayed response?	58 (45%)	34 (26%)	19 (15%)	1 (1%)	18 (14%)
Can you tell if your child **keeps looking** at visual information (i.e. maintains visual attention)?	63 (48%)	37 (28%)	13 (10%)	0	17 (15%)
Can you tell if your child **shifts gaze** (looking), or changes visual attention from looking at one thing, to look at another, and perhaps back again?	76 (58%)	23 (18%)	11 (8%)	2 (2%)	17 (14%)
Can you tell if your child uses vision to **search** for a specific target? For example, does your child look for a missing toy or person?	78 (60%)	23 (18%)	10 (8%)	0	19 (15%)
Can you tell if your child uses vision to **explore**? For example, does your child look around a room or visually and curiously inspects the parts of a toy?	77 (59%)	22 (20%)	7 (5%)	5 (4%)	19 (15%)
Can you tell if your child **looks toward** or in the direction of visual information?	81 (62%)	27 (21%)	7 (5%)	0	15 (12%)

Can you tell if your child uses vision to **find** specific information? For example, does your child find a missing or dropped toy, find you in a crowd or find their classroom?	72 (55%)	22 (17%)	12 (9%)	4 (3%)	20 (15%)
Can you tell if your child visually **follows** moving targets? For example, does your child visually follow the movements of a dog or track a toy?	77 (59%)	26 (17%)	7 (5%)	2 (2%)	18 (14%)
Can you tell if your child **looks at people and faces**? For example, does your child look at a face and interact by smiling in recognition or in response to a smile?	80 (62%)	22 (17%)	8 (6%)	1 (1%)	19 (15%)
Can you tell if your child **looks at objects**? For example, does your child look at pictures in a book, toys, and their drink bottle?	84 (65%)	19 (15%)	7 (5%)	1 (1%)	19 (15%)
Can you tell if your child **looks across distance**? For example, does your child look across the room or playground and not just close up or within arm's reach?	64 (49%)	29 (22%)	13 (10%)	4 (3%)	20 (15%)
Can you tell if your child **uses vision together with hand use**? For example, does your child look whilst reaching? Do they look at what they are doing with their hands or what your hands are doing?	64 (49%)	25 (19%)	18 (14%)	2 (2%)	21 (16%)
Can you tell how **consistently** your child uses vision across the day? For example, does their ability to use vision fluctuate from hour to hour, or day to day, or do they often prefer listening, mouthing or touching?	67 (52%)	28 (22%)	13 (10%)	2 (2%)	20 (15%)
Can you tell how well your child does **activities that require vision**? For example, how well does your child use vision to recognise objects and people, to move	59 (45%)	37 (28%)	10 (8%)	4 (3%)	20 (15%)

around the environment, to read text or match pictures, or watch tv?		

Note. [1] The visual behaviours presented in this table are not MEVU items – the questions are theoretical content. The shaded column indicates the small number of parents reporting visual behaviours as 'not observable'.

Visual ability was rated as a relevant or useful construct to assess by each of the adult participants with a diagnosis of cerebral palsy and 68% of clinicians. Only 2% of clinicians said it would not be useful, but 30% did not complete this question. Most clinicians reported currently using informal observation and questioning in their current practice. Details on information collected on current assessment and management practices supporting the need for a new assessment are available in Table 6.2. Clinicians and adults were asked to rate the importance of each visual behaviour, and no clinician or adult with cerebral palsy rated any visual behaviour as ‘definitely not important’ (see Table 6.4).

Table 6.4

Clinician (n=108) and adult (n=8) ratings of importance (n=116)

Visual behaviour[1]	Rating of importance (%)				
	Definitely important	Probably important	Probably not important	Definitely not important	Response missing
Responding or reaction (in some way) to visual information	95 (82%)	5 (4%)	2 (2%)	0	14 (12%)
Looking towards (orienting too or generally locating) visual information	89 (77%)	12 (10%)	1 (1%)	0	14 (12%)
Maintaining visual attention with activities (keeps looking).	82 (71%)	18 (16%)	1 (1%)	0	15 (13%)
Shifting visual attention from one target to look at another.	77 (66%)	24 (21%)	1 (1%)	0	14 (12%)
Searching for a specific target using vision.	86 (74%)	16 (14%)	0	0	14 (12%)
Exploring using vision and being visually curious.	86 (74%)	14 (12%)	0	0	16 (14%)
Finding specific visual information.	71 (61%)	29 (25%)	0	0	16 (14%)
Following moving targets using vision.	79 (68%)	23 (20%)	0	0	14 (12%)
Responding quickly and without delay to visual information.	59 (51%)	38 (33%)	3 (3%)	0	16 (14%)
Looking at people and faces	81 (70%)	19 (16%)	1 (1%)	0	15 (13%)
Looking at objects.	80 (69%)	21 (18%)	1 (1%)	0	14 (12%)
Looking across distance.	63 (54%)	35 (30%)	3 (3%)	0	15 (13%)
Using vision together with hand use.	84 (72%)	15 (13%)	2 (2%)	0	15 (13%)
Consistently and reliably using vision within daily activities.	89 (77%)	11 (9%)	1 (1%)	0	15 (13%)
Efficiently performing activities that require vision.	83 (72%)	16 (14%)	2 (%)	0	15 (13%)

Note. [1]The visual behaviours presented in this table are not MEVU items – the questions are theoretical content. Shaded columns indicate the small number of clinicians/adults with cerebral palsy reporting visual behaviours as 'not important'.

Open-ended survey responses also provided information on who it might be important to measure and the purpose of measurement. The results suggest that visual ability is likely to be a construct relevant to many children, and participants suggested many time points and contexts suitable for assessment. Assessment of children at a young age was a common recommendation and was often linked to the potential use of assessment findings.

> [When would it be most useful to have an assessment of how your child uses their vision in daily activities?] As early as possible! If there is an issue it needs to be diagnosed as quickly as possible, so early intervention can begin. Survey ID 322 Parent of 6-12yo GMFCS III

Cognitive interviews with parents provided further evidence of item relevance for the full spectrum of functioning seen in children with cerebral palsy. Through this process it became clear that one item 'Notices and responds' was not focused on observable behaviours as it required parents to interpret or guess their child's ability.

> When you're asking a parent, you're asking for their opinion on what the child is noticing…which I wouldn't know until [he] was communicating a lot better and I can ask him. Cognitive interview 4, Mother of 13yo GMFCS V

This led to a major revision of this item and the response options of several items to provide options for parents of children whose visual behaviours that are more challenging to judge from observation.

Careful consideration was given to the item 'Visually attends to what the hands are doing' during interviews with parents of children MACS Level V to ensure it was assessing visual ability, and not manual ability. Parents reported that it was a relevant visual behaviour to assess.

> It's a stage in a baby's development when they bring those hands up in front of their face, and they're sitting there playing…It's a common thing that you see babies starting to do. Whether he never did that because of his tone, or whether he never did that because he could not understand what his brain was saying about his hands, we'll never know, but…I think it's a fair question. Cognitive interview 5, Mother of 11yo GMFCS V

> It is relevant…we have done so many of these [assessments]…there's oftentimes so many questions that don't relate to him, because he has a visual impairment or because he has [cerebral palsy]…He has the ability, maybe not to raise his hands in front of his eyes, but he can definitely look down. I think that being able to see himself or his extremities moving, I think that would be a big step. Cognitive interview 6, Mother of 1yo GMFCS IV

Parents identified challenges with some items for children with specific limitations, whilst still identifying their importance for inclusion in MEVU. The behaviour and item 'Uses vision over distance' was noted as posing more challenges for children with limited mobility.

> This [item is] difficult for non-mobile kids…For a mobile kid - if something's out of their immediate space, they're gonna (sic) travel to it. But for a non-mobile kid, well 'I can't travel to it anyway, so why would I pay attention to it?' Cognitive interview 8, Mother of 2yo GMFCS V

> One of the interesting things is that because she's less mobile, she just spends less time outside…because she won't be chasing a [ball] or the dog, or whatever, she won't be thinking in a 50 meter radius. She'll be thinking in a one meter radius...For a kid who's not mobile, ultimately that [distant] context is much less relevant from a functional perspective. Cognitive interview 7, Father of 9yo GMFCS II

The applicability of an item about visually attending to digital screens when there are public health policies recommending young children have no or very limited screen time (Straker et al., 2018) was also discussed. Parents expressed that in the current culture of technology it is relevant and recommended that the item remain in the measure.

Parents reported it was relevant that MEVU focused on identifying abilities, rather than what a child cannot do, and reported benefits in using this measure both to identify areas of difficulty and areas of strength. "Describing how well any child uses their vision" was identified as a pertinent use of the measure and was included in the introductory statement for using MEVU after receiving support in subsequent parent interviews.

> There is a lot of focusing on the deficit with kids with [cerebral palsy], so it's really nice. I think that's a really beautiful point actually. Cognitive interview 2, Mother of 3yo GMFCS I

In further support of the construct and items, throughout interviews parents also provided examples of meaningful improvements their children had made, as well as examples of how they, as parents, have developed their ability to observe their child's ability to use vision.

> I would say 'definitely and obviously reacts to visual things', but when she was younger, it would have been 'definitely reacts, however reactions can be subtle or inconsistent'. I remember watching her having vision therapy and they would give her two options. "Do you want this, or do you want that?" And she would give the teeniest tiniest glance to one of the options, and that would be interpreted as a yes, but I wouldn't have interpreted that. That was part of teaching her that she could make responses, but because I'm not trained in vision therapy and all that, I wouldn't have picked it as a response until I watched the therapists working with her. Cognitive interview 9, Mother of 12yo GMFCS III

Whilst still positive about the use of MEVU in future practice, parents also identified challenges to using this new measure based on their previous assessment experiences and thoughts on how scores might be interpreted.

> [Choosing the first or second option]…it's ranking him higher than he actually is in the general population. I mean, he has very, very poor vision. Compared to a lot of kids with [cerebral palsy]…he would be on the bottom of those scales, but the intervention we have done, he can actually attend to some pictures. It's a hard one [and] gives him a bit of a disservice...because if you saw that [response option reported] you could think 'oh yeah, some picture, I can give him anything'. Cognitive interview 5, Mother of 11yo GMFCS V

> "…her vision is terrible, but she uses it well. Is [a funding body] going to use [MEVU score] to say 'well, look how well she uses her vision. She doesn't need as much support as what you're saying. You can't have it…She uses it well. Therefore, she doesn't need support.' Whereas, I would argue she uses it well because she has support". Cognitive interview 9, Mother of 12yo GMFCS III

These risks are not likely to be mitigated until a framework for score interpretation is developed.

Comprehensibility

The comprehensibility of the MEVU name, instructions, items and response options was explored through cognitive interviews, and led to refinement of wording as well as major revision of some items and response options. Any changes made from one item were extended across items for consistency and overall readability where relevant. Responses from interview participants established that the questionnaire format and completing MEVU online via REDCap would be feasible. Items were modified in minor ways by adding examples and simplifying language. The inclusion of parents from North America in addition to Australia for the interviews highlighted the need to review the use of metric/imperial language in the 'uses vision over distance' item, and one parent provided a practical suggestion to overcome the challenge.

> If you're saying beyond immediate space, where parents are one to three meters…A meter is almost three feet isn't it?...Instead of saying immediate space, say within arm's length. Because a lot of parents, are gonna (sic) be like 'I'm not sure how far away this is'. But when you say, 'arms reach', they're like, oh yeah. Cognitive interview 8, Mother of 2yo GMFCS V

The wording "not a typical behaviour" was misinterpreted by one parent as being about 'atypical behaviour' and was changed to "not a frequently seen behaviour". Other wording changes such as the inclusion of parent language "hard to tell" was positively received by parents and provided a relevant option in the presence of complex and challenging visual behaviours.

> It's hard to tell if she's intentionally looking at something…[hard] to make a decision on whether she's just gazing…She does have a lot of roving eye movements and gazing. Cognitive interview 3, Mother of 5yo GMFCS V

> I really like that question, because [probably reacts to visual things, but it is hard to tell if he/she is reacting to visual things, or sounds and touch] is something that I usually have to explain…'the thing's moving, but it's also making a clicking sound or something like that - so it's hard to tell'. Cognitive interview 6, Mother of 1yo GMFCS IV

Clarification questions from parents, such as "toys or objects – does that include the iPad or just an actual toy?" (ID 408) led to minor changes such as the addition of instructional comments: “In this question please only consider toys and objects, not electronic devices or books. These will be asked about separately”.

Because the name of the measure was established by the authors, feedback was sought on its acceptability, especially to parents of children who are not young: parents report the name to be descriptive of the content and no changes were made.

> [Measure of Early Vision Use…if your son is 11, calling it early vision use? What do you think of that wording?] I see ‘early’ as in his development of his vision. He’s in the early stages of his vision. Would someone who’s 11 and only got mild [cerebral palsy]? I mean, they’re still early in age. Would you use it with someone who’s 40? Probably no. Cognitive interview 5, Mother of 11yo GMFCS V

6.2.4 Discussion

The reported studies describe the development of MEVU from initial item generation to the readiness of a version for field testing. MEVU intends, by means of a standardised approach to observing visual behaviours, to measure the ability of children with cerebral palsy to use vision in everyday activities, interactions and environments. MEVU measures visual ability at the Activity level of the ICF and measures typical performance. MEVU is not proposed as an alternative to eye/visual function tests (such as visual acuity and visual field), nor does it aim to measure best visual capacity. MEVU is proposed as a complement to existing measurement approaches by providing a method for quantifying the common practice of qualitatively describing visual performance (Casteels, 2016). MEVU is unique in that it focuses on observable visual behaviours and does not seek or require information about factors that explain a child’s level of ability. In this way, a child’s limitations in looking at people (as measured by MEVU) may be explained by factors including their level of motor ability, interest, visual (sensory) functions, or a co-diagnosis of autism spectrum disorder. The decision to construct a new measure was based on the research team’s understanding that there is no existing tool suitable for this purpose. Psychometric testing will be reported separately (Deramore Denver et al., 2021b).

This research proposes that to find out how a child uses vision in everyday activities we must ask parents or caregivers who knows the child well. MEVU asks questions about visual behaviours that can be observed by people familiar with the child.

Whilst some limitations have been identified in using parent-report to measure other constructs (Harvey et al., 2010), this approach to measurement recognises that parents provide a valuable perspective on everyday performance. MEVU assesses perceived performance. The possibility that a parent could complete MEVU on their child and 'misinterpret' visual abilities as evidence of adequate or good visual (eye) functions and/or visual cognitive skills may require further consideration. Future research to establish methods of score interpretation and potential predictive purposes for MEVU will inform this.

Parents completing MEVU on their child are not providing a proxy report. The measurable construct in MEVU is 'observable visual behaviours'. As such, a parent may perceive and rate a child's ability as "does not do", in contrast to a clinician reporting their ability to observe that behaviour in the same child. Recognition of the important perspective that parents provide in the assessment of performance exists in other areas of early intervention (Carey et al., 2020), and it aligns with approaches to early intervention whereby parents are educated on how to read the cues and behaviours of their child (Spittle & Treyvaud, 2016) so that they can support their development. The labelling 'early vision use' in the title of MEVU and the identification of young children as the primary target population for MEVU also align with priorities for early intervention (Novak et al., 2017), and knowledge on plasticity of the visual system suggests that an early focus on visual behaviours could be of significant benefit to some children with cerebral palsy (Berardi et al., 2015).

A major strength of this research has been the involvement of key stakeholders including parents, and the process of refinement adopted in the pre-testing phase that aims to minimise future measurement error. A strong conceptualisation phase preceding development of MEVU is also a strength, and the clear definition of visual ability and 'observable visual behaviour' helped the research team make decisions to exclude 'more complex' behaviours that were not readily observable, such as scanning, recognition and other visual processing abilities. The version of MEVU now ready for field testing has been built from descriptors provided by key stakeholders and the content has been found to be meaningful and comprehensible to the target population.

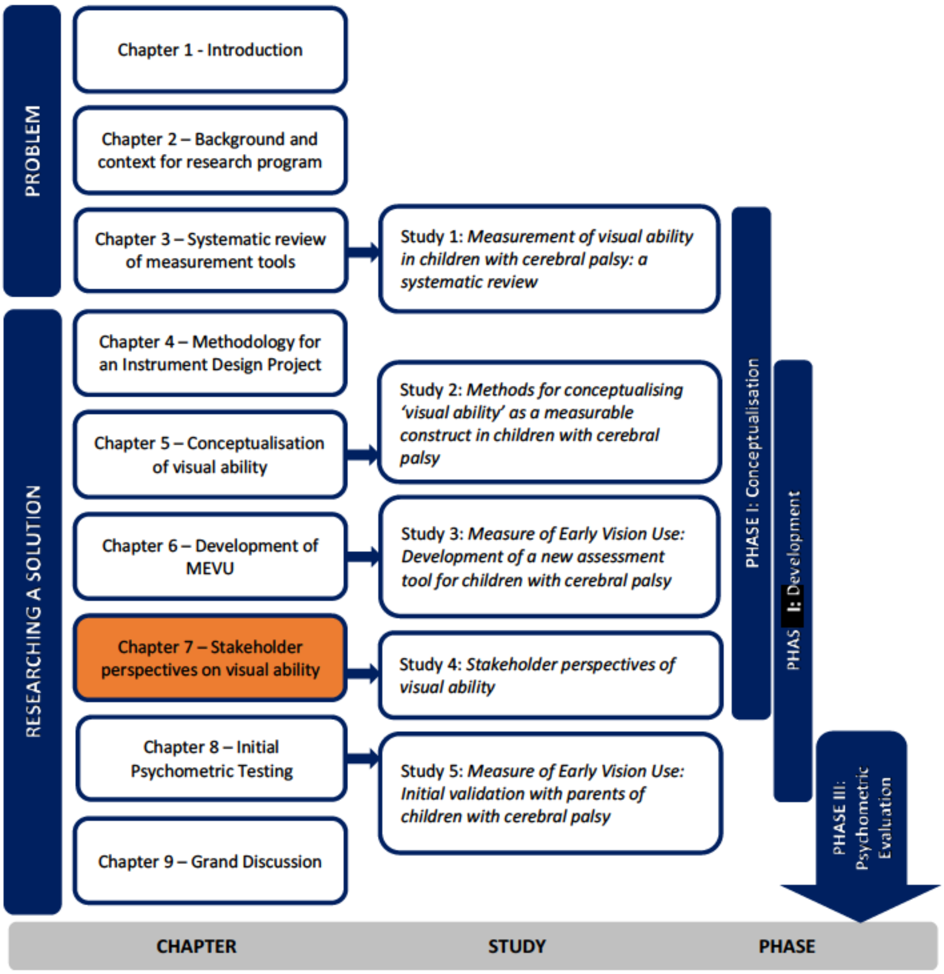
The selection of participants in this research for both the survey and pre-testing of MEVU was based on convenience, however the included parents seem to reflect parents of a wide spectrum of children with cerebral palsy. Whilst the parents of very young children, for whom visual behaviours may be most important to consider, were least represented, the opportunities in the survey and interviews for parents to provide retrospective information on visual abilities and changes in performance by their child at younger ages was highly valuable and may have mitigated this potential problem. A heterogenous sample of clinicians was included in the survey, however the unique perspectives of those specialising in 'eyes' were not well represented (e.g. orthoptists, teachers of the visually impaired and ophthalmologists). It is unclear whether the applicability of MEVU has been limited by this and does highlight the difficulty in using "cerebral palsy" recruitment networks to access vision specialists, possibly identifying a problematic gap between physical disability and vision services. The variety of clinicians accessed does, however, suggest that visual abilities are considered relevant to many people working with children with cerebral palsy.

In conclusion, MEVU is proposed as a new descriptive measure that places parents at the centre of describing how their children use vision in everyday activities. This paper is an important but preliminary step in introducing a new domain of assessment for children with cerebral palsy that may lead to new opportunities for optimising outcomes for these children and their families.

6.3 SUMMARY OF CHAPTER 6

The findings reported in this chapter provide evidence that how children use vision in typical daily activities can be quantified and demonstrates support for the content validity of MEVU as a 14-item parent-rated instrument. Further research is required to explore the performance of items by field testing MEVU.

CHAPTER 7: Stakeholder perspectives on visual ability



7.1 INTRODUCTION TO CHAPTER 7

Chapter 7 reports findings of a qualitative methods approach to exploring the connections between visual ability and related concepts (e.g. visual functions, environments, functional outcomes) from the perspective of key stakeholders. The findings reported in this chapter are referred to as Study 4; empirical data presented were collected and analysed concurrently with Study 3. Study 3 reported (in Chapter 6) on the development of the Measure of Early Vision Use (MEVU) as a new assessment of visual ability and included stakeholder perspectives and examples of observable visual behaviours to build the item and response options for MEVU. Chapter 7 explores the full range of data provided by stakeholders when asked about visual ability. In reporting this additional data, this chapter acknowledges that the use of observable visual behaviours to quantify 'how vision is used' is just one relevant way to describe the visual ability of children with cerebral palsy and contributes to the second objective: to define visual ability as a measurable construct.

7.2 STUDY 4: STAKEHOLDER PERSPECTIVES ON VISUAL ABILITY

Study 4 presents unpublished data and analysis. It is proposed that the reporting of this study be refined into a manuscript for publication in a peer-reviewed journal following submission of the thesis. A preliminary version of this work, entitled "Three perspectives for understanding how children with cerebral palsy use vision in daily activities", was presented as a free paper at the 30th Annual Meeting of the European Academy of Childhood Disability (EACD), 28-31st May 2018, Tbilisi, Georgia.

The research question for Study 4 was: How can we use stakeholders' multiple perspectives to describe visual ability to inform our understanding of this construct and its assessment in clinical and research practice? Whilst Study 3 (Chapter 7) utilised directed content analysis for the qualitative data from the online survey of stakeholders, this study used a second method for inductive qualitative analysis of data not aligned with operationalisation of visual ability as 'observable visual behaviours'.

7.2.1 Methods

Design

A qualitative approach using interpretive description methods (Thorne, 2016) was used to guide our approach in this study. Interpretive description is well suited to research questions that seek an “inductively derived description of a phenomenon, and one that deserves an interpretive lens” (Thorne, 2016, p.53). The applicability of this approach was identified during the initial stages of directed content analysis to explore data for examples of observable visual behaviours (see Chapter 7), where the research team were frequently pondering “Why is this here?” and “How is this relevant to understanding and describing visual ability?”. Interpretive description assumes a constructivist view of knowledge and recognises that multiple understandings may exist for a phenomenon from multiple perspectives. It thus provides a method to answer questions relevant to the implementation of findings into practice.

Interpretive description presumes that theoretical, clinical and scientific knowledge inform research. Knowledge presented previously, gained through the sequential conduct of the PhD research, provides the scaffolding for this study:

a) the researcher’s perspective and clinical experience were outlined in Chapter 1;

b) a review of existing conceptual models and empirical research related to visual ability for children with cerebral palsy were provided in Chapter 2;

c) the gaps in existing measures of visual ability were discussed in Chapter 3;

d) the role and importance of conceptual models/frameworks in measurement research and the need to determine if measurement will use a reflective or formative model were introduced in Chapter 4;

e) the place of this study within the multi-phase mixed methods instrument design project was outlined in Chapter 4;

f) the conceptualisation of visual ability as a measurable construct was provided in Chapter 6; and

g) the multiple perspectives provided by stakeholders when asked about ‘visual ability’ were introduced in Chapter 6.

This knowledge, whilst not repeated in this chapter, is important to the methodological approach.

Data collection

This study used data from open-ended questions in the online 'survey of key stakeholders' described in Chapter 6. A copy of the survey (for parents of children with cerebral palsy, adults with a diagnosis of cerebral palsy, and clinicians working with children with cerebral palsy and their families) is available in Appendix G. All data collected via survey was shared by participants with their knowledge that the research team were developing a new measurement tool to assess the visual ability of children with cerebral palsy.

Data analysis

Qualitative data from the online survey were managed and analysed within Excel spreadsheets by BDD (PhD candidate), supported by discussion with the supervision team. Data analysis began as the deductive content analysis described in Chapter 6, and in this study developed into an inductive interpretative description approach. Whilst in Chapter 6 open-ended data was explored for visual behaviours previously not defined, and examples of variations in visual behaviours, in this study all data was equally considered. Data analysis for this study occurred concurrent with the development of MEVU (Chapter 6).

The analysis process for this study involved: i) consideration of individual participant responses (by reviewing their demographics and survey responses), in addition to reviewing of all responses to each survey question to enable comparison and identification of contrasting perspectives; ii) reflexivity of the researcher; iii) reading and re-reading whilst making notes and reflections informed by the ICF conceptual framework and conceptual definition of visual ability ('constructing the data'); iv) developing themes ('working the data'); and v) finally 'transforming the data' into an organising framework of stakeholder perspectives on visual ability. This transformation aims to demonstrate connections between the themes and how they relate to our understanding of, and approach to, the assessment of visual ability in children with cerebral palsy. An example of the data analysis process is displayed in Table 7.1.

Table 7.1

Example of the data analysis process

Participant details	Survey question	Participant response to survey question	'Constructing the data': Notes & reflections on 'why this response'	'Working the data': emergent themes and sub-themes	'Transforming the data' into a framework of stakeholder perspectives on visual ability
ID 312 Parent of a child with cerebral palsy, aged 6-12yrs, spastic quadriplegia, GMFCS IV, MACS IV, CFCS IV Some limitations with visual abilities Australia, ACT	Please provide one example of the limitations your child has in looking at people or faces that you have observed.	Will look at people's faces if needing things. Will look at people's faces if requested. Does not maintain eye contact unless prompted or has incentive to do so.	Discrepancy between capacity to use vision and performance – role of prompting (requesting) and motivation (incentive) Personal factors – role of motivation "if needing things" is about communication Eye contact is part of looking at people and faces and communicating	Observable visual behaviour – Look at people's faces, eye contact (limitations) Prompting to look Motivation to look Vision for communication	Factors that explain or contribute to visual ability – internal motivation; external prompting Indicator of visual ability using observable visual behaviours – ability to maintain eye contact Reflection of visual ability in performance/participation in vision-related activities – look at people's faces for communication

Please add any further information you feel may be helpful here.	There is no access to [paediatric ophthalmology] locally. Communication difficulties with the child limit some assessments. Ability for early intervention and schools to implement strategies seems lacking.	Need for, access to, specialist service provision - paediatric ophthalmologists (Body Function level) Activity level – communication – impacts assessment of visual ability Parent perception of gaps in assessment, intervention, and strategy implementation.	Access to services Assessment Intervention Communication ability	Factors that explain or contribute to visual ability – communication ability; specialist service/assessment; interventions

The construct upon which the meaning of data was sought and interpreted in this analysis, 'observable visual behaviours' is reported as a theme and illustrated within the organising framework. However, participant data supporting the development of this theme is not repeated in this chapter. For the other themes, a description is reported in the text. Under each theme several sub-themes are labelled (in italics), accompanied by illustrative quotes. Perspectives from the three stakeholder groups have been integrated within the presentation of findings, and links between themes reported.

7.2.2 Results

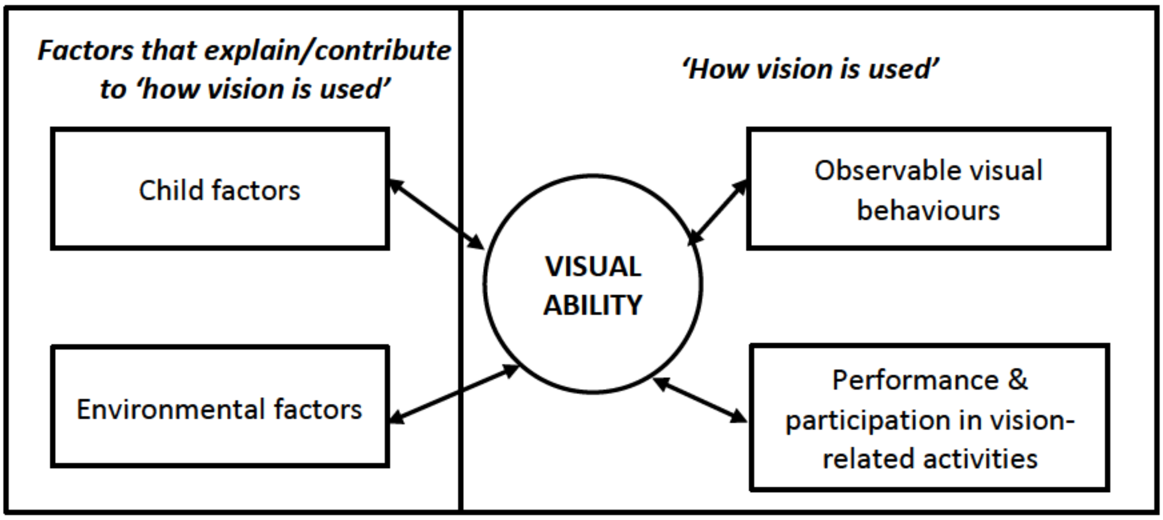
Of the 246 stakeholders who participated in the online survey, 227 contributed qualitative data via the open-ended survey questions. Participant characteristics are reported in Chapter 6. The data represents perspectives of parents, professionals and adults with cerebral palsy collectively.

Organising framework for the themes

Themes developed from participant data in the online survey have been organised in a framework wherein different perspectives or approaches to describing visual ability are presented – see Figure 7.1. In addition to descriptions of observable visual behaviours (the focus of this program of research), when asked about 'how vision is used' participants described a child's level of performance in vision-related activities and/or their level of engagement or participation as a reflection of a child's ability to use vision. Participants also described child and environmental factors that contributed to, or explained, a child' visual ability. In the organising framework, bi-directional arrows represent interaction between the themes. Data contributing to the themes of 'performance and participation in vision-related activities', 'individual child factors' and 'environmental factors' are reported in this chapter.

Figure 7.1

Perspectives on describing visual ability: An organising framework



Descriptions of performance and participation in vision-related activities

When describing 'how' children with cerebral palsy use vision, participants frequently provided examples of how children perform and/or participate in vision-related activities. A *vision-related activity* is an activity that 'typically' requires vision for performance (ability to complete the task) (World Health Organization, 2007) or participation (attending and being involved in the task) (Imms et al., 2016) with or without modifications and assistance. Participants reflected on examples of performance and participation representing good levels of visual ability, and limitations in how vision is used. Children were reported to be "independent" and "safe", to use compensatory strategies and modifications, or to be "unable" to participate in a range of activities. In addition to 'how well' children performed in vision-related activities, descriptions also referenced 'how often' participation in the task was observed, perceptions of enjoyment or frustration (elements of involvement), and a child's familiarity with the activity. Sub-themes relating to performance and participation in vision-related activities include mobility and exploration, learning, communication, play and leisure, and self-care tasks.

All participant groups provided examples of how children were seen to be using vision within *mobility and exploration* to illustrate how vision is used. The ability to see visual stimuli was described as important for motivating a child to move and explore beyond their immediate space, and to detect obstacles that may impede or endanger exploration. Vision was reported as offering children independent choices of where to explore, and children with poor vision were often described as having less independent and safe mobility; "children will often become passive and explore their environment less than child who has full vision" (ID130 Paediatric Rehabilitation Specialist). In children who walk, vision was described as potentially contributing to falls, particularly in unfamiliar or cluttered environments containing obstacles, uneven surfaces, and steps; "some stairs are not seen and depth perception is a problem when walking on unfamiliar ground" (ID237 Parent of 12-17yo, GMFCS I, with some visual ability limitations). Vision use was described as an important skill for children using powered mobility. Older children and adults had their vision linked to levels of community mobility. Good visual ability was considered helpful for orientation and navigation, for traffic safety including the ability to judge the movement of cars, and to enable driving a motor vehicle. Success in catching public transport and locating or identifying landmarks was also reported in relation to successful use of vision.

The ability to use *vision for learning* was an important reflection of a child's visual ability shared by participants. Both the timing of visual assessment (e.g., before starting school) and having knowledge of a child's vision, were reported by participants and interpreted as important contributors to being able to access educational activities visually and for educational outcomes. Vision-related learning in the early years included understanding cause and effect, imitation and copying, identification and *recognition*, discrimination, and matching, as well as learning specific activities or skills; "imitating play behaviours – using vision to learn new tasks" (ID34 Occupational therapist). Attention was identified as a prerequisite skill for visual learning; however, it was acknowledged that children can also use their other senses to learn. Learning of more complex information, including reading, spatial concepts and mathematics was also described as important and examples were shared as evidence both for and against good use of vision.

Reading was an activity frequently referenced by participants, with many parents reporting difficulties their children had in learning to read and reading throughout life; "reading is a huge challenge as letters are close together and particularly similarly shaped letters are very difficult to tell apart" (ID125 Parent of 12-17yo, GMFCS III with poor visual abilities). Adults with cerebral palsy also referred to the impact of vision limitations on the ability to read. The visual ability to track text across a page was specifically referenced as a skill important to successful reading; "A number of my children with [cerebral palsy] have trouble with smooth pursuit movements which results in problems reading, including reading/copying from a white board although they are assessed as having normal acuity" (ID134 Paediatrician).

Other subthemes were *visual communication* - enabling children to receive non-verbal messages and express their desires (e.g., eye-pointing to choose) and *engaged in social interactions*. The importance of using eye contact within social interactions was reported, however non-visual explanations were offered when a child did not engage in eye contact including the co-diagnosis of autism spectrum disorder or having a shy temperament. For some children with severe physical disability, the ability to use vision to communicate and interact was identified by parents and professionals as a strength, and eye-gaze technology was identified as assistive technology that provided children with limited verbal communication the opportunity to capitalise on good visual abilities.

> He regularly uses his gaze to communicate in his environment - we hold up a hand and indicate it means yes and the other means no or one means more dinner or ready for dessert and he very clearly looks toward his preference. (ID107 Parent of 12-17yo, GMFCS V with good visual abilities).

The sub-theme of *engagement in play* was reported as both an outcome sought by families and clinicians that may be influenced by visual abilities, and a context for the assessment and intervention of vision or vision-related performance and participation. The ability and interest of a child in watching television was reported to be commonly asked by professionals as a screening question about vision. Engagement in *watching* screen content was also a common example of how vision is used, including as a form of non-active leisure participation, including children watching live or televised sporting activities. Other examples of daily vision use included activities that typically require a child to use vision such as social play (e.g., peek-a-boo), object play, constructional play, drawing/painting and writing, 'reading' books, puzzles, tablet/computer games, switch activated toys, and visual games such as 'I spy' and hide-and-seek. The ability to locate toys and other resources visually within their environment was reported as a limitation for a child's level of performance or satisfaction in play; in addition, vision was reported as a factor impacting on a child's ability to learn and expand their play (e.g., "not able to visually attend on a toy long enough to then think or plan about how they may grasp or reach for the toy" (ID242 Occupational therapist)). Examples of active play and leisure activities typically requiring hand-eye coordination and/or high levels of accuracy or manipulation were also frequently shared. *Participation in social play, team sports and ball games* were reported to be especially impacted by limited visual abilities, including the ability to notice and recognise the location of other people, track moving targets, and respond to visual information quickly.

The final sub-theme describing a child's performance and participation in vision-related activities was about the use of vision within *everyday self-care tasks* such as dressing and eating. These were provided as examples within participant responses as tasks providing both a daily context for the observation of visual behaviours and opportunities for practice. Accounts provided by stakeholders included using vision to locate the objects required for tasks, such as a toothbrush in the bathroom or a fork on the table. Using vision to guide successful task completion was also shared in descriptions of performance that reflected how vision is used in everyday activities: "vision networking with hand function – looking at feet when putting socks on" (ID109 Parent of 18yo+, GMFCS III with good visual abilities).

Individual child factors that explain or contribute to the ability to use vision

Participants also provided descriptions of individual child factors that explain or contribute to the ability to use vision. Whilst not direct descriptions of 'how vision is used', data contributing to this theme provided some explanation ('the why') for vision use in individual situations. Participants described factors relevant to individual children as evidence of, or explanation for, their strengths and limitations in using vision. Sub-themes include diagnosis, visual function, age and developmental stage, motivation, fatigue, use of other senses, and a child's use of strategies. Parents provided descriptions of their own child with cerebral palsy, adults reflected on their personal experience, and professionals acknowledged the importance and uniqueness of individuality whilst also grouping children and sharing generalised statements about children with cerebral palsy. A child's ability to use vision "will depend on the individual child. May depend on overall attention, seating/positioning, comfort, cognitive/ developmental relevance" (ID14 Paediatrician).

A child's cerebral palsy *diagnosis*, including *type*, *distribution* and *aetiology*, was frequently reported by professionals as having implications for their ability to use vision. This sub-theme also provides a context for which groups of children may be more at risk of problems in using their vision; “bilateral [cerebral palsy] with good cognitive skills and tracking difficulties, and severe [cerebral palsy] with probable cerebral visual impairment” (ID134 Paediatrician). A child’s level of motor function, hand function and communicative function were all reported as factors contributing to visual ability, including frequent reference to the specific cerebral palsy functional classification systems: the Gross Motor Functional Classification System (GMFCS), Manual Ability Classification System (MACS), and Communication Function Classification System (CFCS). Parents and professionals also reported the influence of other diagnoses including general cognition, learning disabilities, intellectual disabilities, autism spectrum disorder, developmental delay, and epilepsy on visual ability. “Due to also being on the autism spectrum it is more lack of interest (attention span) rather than being unable” (ID373 Parent of 6-11yo, GMFCS I with poor visual abilities).

All participants identified the importance of vision and ‘how the eyes work’ for using vision. Impairments to visual functions, or the absence of impairment, were frequently described as explanations for variations in visual abilities. *Visual (seeing) functions* including visual acuity, visual fields, contrast sensitivity, accommodation, fixation, and ocular-motor control were all reported. Parents and professionals both referred to specialist vision services as the source of knowledge on their child’s visual functions: “He has had his eyes monitored since birth and sees an eye specialist every six months. His doctor says he uses his eyes equally and does not have a vision impairment. He has a slight strabismus” (ID 326 Parent of 3-5yo, GMFCS II with good visual abilities). Participants also frequently described *cerebral or cortical visual impairment* as a contributing factor or explanation for how a child uses vision.

A child’s *age and developmental stage* capture the context described by participants for whether a child’s visual abilities were ‘appropriate’: “In terms of age-appropriate visual behaviour there are significant limitations” (ID349 Parent of 3-5yo, GMFCS V with poor visual abilities). This sub-theme also captures the importance participants placed on the assessment and intervention of visual ability in the early years and stages of development. Although there was discrepancy in what was meant by ‘early’, both parents and professionals linked the importance of an early focus on visual ability to the neuroplasticity of the developing brain and the urgent need to promote a child’s development and visual understanding of the world: “As early as possible! If there is an issue it needs to be diagnosed as quickly as possible so early intervention can begin” (ID322 Parent of 6-11yo, GMFCS III with poor visual abilities), and "[for assessment] infants would be my priority e.g., 0-2 year olds while there is a lot of hand function, etc., developing" (ID242 Occupational therapist).

Motivation is needed for a child to engage in using vision in a task, and each child's interests, preferences and abilities are relevant to their internal motivation. One parent stated their child "will look at people's faces if needing things…faces if requested…[but] does not maintain eye contact unless prompted or has incentive to do so" (ID312 Parent of 6-11yo, GMFCS IV with some visual ability limitations). External motivation to use vision was reported to come from the type of visual information, prompts or rewards for using vision. Parents reported a need for children to be 'visually curious'. For professionals, understanding and utilising a child's preferences within the pursuit of vision-related goal achievement was identified as a necessary but challenging component of therapy services: "difficult to find toys to [visually] motivate a child to move" (ID232 Physiotherapist). A child's personality, temperament and preferences were also shared as explanations of vision use.

> "My child is very shy so although she knows she needs to look at people when she speaks to them etc, she sometimes doesn't if they are new to her. She is able to do it, she chooses to not do it" (ID137 Parent of 12-17yo, GMFCS II with some visual ability limitations).

In another sub-theme parents described how their child's level of physical, mental and/or emotional *fatigue* impacts on how much and how well vision is used. For example, one parent shared that "a range of factors affect consistency e.g., tiredness – it may be important to recognise that vision is one of the few 'controls' our child has – it compensates and works hard" (ID129 Parent of 12-17yo, GMFCS V with good visual abilities). Many participants reported that children were less visually responsive when tired or upset, and an appropriate *state of arousal* was identified as a prerequisite for using vision. The impact of medication, seizures, and general medical well-being were all reported as impacting on the child's readiness to use vision: "visual behaviours improve once there is a degree of autonomic stability (in our unwell infants)" (ID289 Occupational therapist). Activities with a high visual 'load', such as the visual scanning required for reading and communication, were identified as particularly fatiguing and impacting on sustained use of vision. Sub-optimal environmental conditions including timing and positioning were also reported as contributing to fatigue that impacts on the ability to use vision: “when she does eye tests at [the] hospital – long waits add to a decreased performance” (ID329 Parent of 6-11yo, GMFCS IV with some visual ability limitations).

Within their descriptions of visual ability, participants made frequent reference to the *use of other sensory modalities*. For example, descriptions of using hearing and touch instead of, or to compensate for, using vision to perform or participate in vision-related activities were common: “She tends to rely on other senses and particularly prefers to listen rather than look” (ID349 Parent of 3-5yo, GMFCS V with poor visual abilities). A child’s ability to use the other senses was identified as a challenge to understanding how well vision is used; “[It can be] very hard to ascertain to what extent vision was being used in parent and toy interactions in contrast to smell, sound and touch, as (we) can’t decipher or differentiate consistent physical responses or observe what was being visually attended to” (ID372 Physiotherapist). Whilst some children were reported to have difficulty using vision at the same time as another sense, vision was also identified as a superior and important sense for children with cerebral palsy: “seeing someone approach is a more complete way than only hearing a person approach” (ID274 Occupational therapist). In contrast to participant perspectives on the use of the other senses to compensate for limited visual ability, impairment to a non-visual sense (e.g., proprioception) was also reported as the reason for using vision: “due to sensory loss he often can’t tell what his limbs are doing unless he is looking at them” (ID271 Parent of 6-11yo, GMFCS IV with good visual abilities).

In the final sub-theme of child factors, a child’s performance and participation in vision-related activities were reported to be influenced by the *child’s use of strategies*. Some children were described as having their own strategies to optimise their use of vision: “when he started school he had already developed his own strategies for dealing with his low vision” (ID 106 Parent of 18yo+, GMFCS II with some visual ability limitations); and “compensatory strategies such as head movement or specific hard/gaze position” (ID288 Neurologist). Other participants described children who needed to be taught strategies they could use; “[By] learning strategies for orientation in the community, client has shown improved scanning (using their visual strengths) to allow a safer and more effective walk to school” (ID16 Physiotherapist)

Environmental factors that explain or contribute to the ability to use vision

In another theme about factors that explain or contribute to the ability to use vision, the environment was described as playing an influential role in a child's ability to use vision. These factors included aspects of physical, social and institutional environments. Whilst some participants shared examples of how aspects of the environment enabled improved use of vision, other factors were provided as examples of barriers to using vision. Sub-themes include the type and location of visual information, family, knowledge and information, vision services, assistive technology, modifications and supports.

Within a child's physical environment, a factor frequently reported as relevant to the ability to use vision was the *type and features of visual stimuli* being viewed. Elements suggested as important include the colour, pattern and size of visual information.

> My child uses his vision all the time to look at people and objects but has difficulty with further away objects. He needs a simple background, is easily distracted by seeing movement in the background. He cannot tolerate a 'busy, cluttered' learning environment. Sometimes he needs the window blinds closed because the light bothers him. Florescent lights bother him. He sees best close up with a simple background. (ID204 Parent of 3-5yo, GMFCS IV with some visual ability limitations).

Linked to 'what' a child is using their vision to see is the sub-theme of 'where' that information is located within the child's environment. The *location of visual information* is particularly relevant to consider for children with limited visual fields or children with limited motor function, as these children require visual information to be presented in specific locations for them to be able to perceive it. For children with more severe physical disabilities, appropriate positioning of the child was reported as something that needs to be considered in relation to the location of visual information: "he has powered wheelchair which limits peripheral vision and head turning, so fields are limited" (ID312 Parent of 6-11yo, GMFCS IV with some visual ability limitations). Another element of the location or physical environment that may influence a child's ability to use vision that participants shared was the presence of additional visual and non-visual elements including noise: "due to slower processing, and other various limitations – overwhelmed, new situations, lots of stimulus – she can be slow to respond" (ID199 Parent of 12-17yo, unknown GMFCS with good visual abilities).

Physical environments frequently referred to by parents are the home and school, with independent use of vision in the community becoming more important for adolescents and adults. The importance of these environments was further supported by professional perspectives on a child's typical environment as being ideal for incorporating strategies aimed at optimising the ability to use vision in their daily life: "intervention is most effective when activities are repeated regularly in the natural environment as part of the child's and family's everyday routines" (ID189 Orientation & Mobility Instructor).

The family is the primary social environment for a child, and the family was central to many descriptions and explanations of how children use vision. Professionals referred to the important role of the family, and families contributed their unique perspective on how their children use vision: "He tries to follow moving objects such as our cat. This makes him laugh" (ID204 Parent of 3-5yo, GMFCS IV with some visual ability limitations). Families were frequently identified by professionals as a vital source of knowledge about how vision is used in daily environments and activities.

> "I ask parents on how the child behave in different situation of daily life, if he/she recognises faces/objects, how he/she moves in the environment, how he/she reaches and manipulates objects" (ID165 Neurologist).

Other professionals shared a perception that parents may have limited knowledge to share about how vision is used: "Parents [and teachers] often have no idea what a child can see, how far they can see, or even if they can see anything" (ID143 Orthoptist).

Both parents and professionals shared a view that *knowledge and information* about vision is important and that its absence impacted on their understanding of how vision is used, as well as impacting on the ability to optimise a child's ability to use vision. Information on 'how the eyes work', the interpretation of visual information by the brain, and cerebral/cortical visual impairment were specifically mentioned by multiple participants; "Son's vision was assessed at about 4 years of age and I found it very helpful to know how he was using his eyes and how to encourage him to use [eyes] better" (ID338 Parent of 12-17yo, GMFCS V with some visual ability limitations).

A family's knowledge of and *access to vision services* for both assessment and therapy appears related to knowledge, information and availability, and was also referenced as a factor impacting vision-related outcomes for their children; "[current service provider is] under-resourced in area of cortical vision impairment" (ID23 Parent of

6-11yo, GMFCS V with poor visual abilities). Adult respondents to the survey also shared their view on the importance of therapy to achieve important vision-related outcomes.

> I have received therapy relating to my vision from birth. I am now 22. Early intervention therapies enabled me to walk, see, talk and function much better than I would have otherwise. Vision therapy has been helpful with practical tasks, including self-care. (ID352 Adult with a diagnosis of cerebral palsy, GMFCS I and good visual abilities).

Access and eligibility to supports that may optimise the ability to use vision were also related to the availability and accessibility of appropriate assessment methods. Barriers to accessing appropriate services included the availability of services with clinicians knowledgeable in vision-related problems and the lack of evidence-based interventions.

> I think that vision impairment and visual processing impairments in our patients with cerebral palsy is grossly under-identified and grossly under-treated. Unfortunately, since there are limited therapy opportunities, even the patients that are identified with such concerns do not have an opportunity to improve from such. (ID284 Rehabilitation specialist).

For many children, *assistive devices and technology* were identified as contributors to a child's ability to use vision. Wearing or needing prescriptive lenses (e.g., glasses) was mostly reported as a facilitator of vision; "wears glasses but no limitation to vision when glasses on" (ID235 Parent of 12-17yo, GMFCS I with good visual abilities), although parents also provided descriptions of children who did not benefit. For children with more severe physical and communication impairments, eye-gaze technology was identified as a means for optimising performance and participation that utilised good visual abilities. *Modifications and supports* emerged as another environmental subtheme with children reported to receive and benefit from practice, reinforcement, prompts, cues, wait-time, and suitable seating and positioning.

> "[He] needs to be set up at the right angle. Needs big text and the other lines of text to be covered or can't follow. In these situations, with us covering lines and pointing to the words for him he can read quite well" (ID271 Parent of 6-11yo, GMFCS IV with good visual abilities).

Modifications were mostly frequently described in relation to aspects of the physical environment such as lighting and reducing visual clutter.

7.3 SUMMARY OF CHAPTER 7

Building on the conceptualisation work presented in Chapter 6, the findings reported in this chapter add further detail and clarity for answering the research question ‘What is visual ability?’ by highlighting what it is not. It is important to think about constructs related to a target construct because clear definition and understanding of the measurable construct is crucial to an instrument design project (Polit & Yang, 2016). These findings are summarised in Table 7.2.

Table 7.2

Themes and sub-themes for describing concepts related to visual ability

Performance & participation in vision-related activities	Child factors that explain/contribute to ‘how vision is used’	Environmental factors that explain/contribute to ‘how vision is used’
Mobility & exploration Vision for learning Recognition Reading Visual communication Engaging in social interactions Engagement in play Watching Participation in social play, team sports & ball games Everyday self-care tasks	Diagnosis Visual (seeing) functions Cerebral/cortical visual impairment Age & developmental stage Motivation Fatigue State of arousal Use of other sensory modalities Child’s use of strategies	Type & features of visual stimuli Location of visual information Family Knowledge & information Access to vision services Assistive devices & technology Modifications & supports

The findings reported in this chapter acknowledge a range of concepts relevant to functional visual ability and go beyond the conceptualisation of visual ability as a measurable construct using descriptions of observable visual behaviours that is the focus of the instrument design project reported in this thesis. Key findings include:

- Observable visual behaviours are one way to describe a child’s visual ability or ‘how vision is used’.

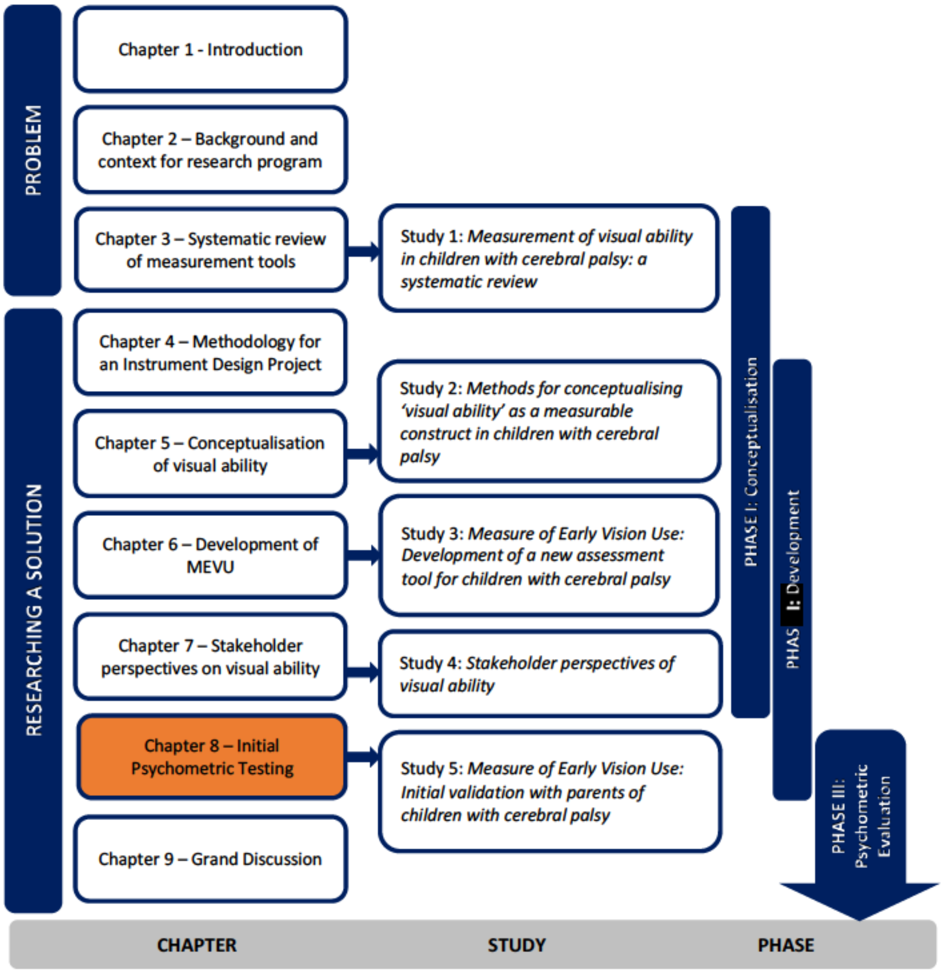
- Visual ability can also be described by a child's performance and participation in vision-related activities.

- Many and varied individual child factors are also relevant to describing visual ability, including visual functions such as visual acuity that explain or contribute to how a child uses vision.

- Environmental factors are relevant to descriptions and understanding of visual ability. Some of these factors may also be useful in future research focused on the development of effective interventions where evidence will be required about modifiable factors that may enhance visual ability.

This study strengthens the conceptualisation and operationalisation of visual ability as observable visual behaviours for describing 'how vision is used'; by differentiating it from the related constructs reported in this chapter. Knowledge of the relationships and differences between observable visual behaviours and these related constructs has been used in developing the construct validity hypotheses for testing MEVU as a measure of visual ability using observable visual behaviours. Findings from this study may also be important to future research and the implementation of MEVU into clinical and research practice.

CHAPTER 8: Initial psychometric testing



8.1 INTRODUCTION TO CHAPTER 8

Chapter 8 explores the performance of MEVU's items and scale in initial field testing with parents of children with cerebral palsy. It addresses the fourth objective in this program of research: to evaluate the measurement properties of this new measurement tool. This chapter comprises a published manuscript, Study 5.

8.2 STUDY 5: INITIAL VALIDATION WITH PARENTS MEASURE OF EARLY VISION USE

This manuscript has been accepted and published by Taylor & Francis in the journal *Disability & Rehabilitation*. Permission from the publisher to include the accepted version of this manuscript in this PhD thesis is available in Appendix I.

> Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2021b). Measure of early vision use: Initial validation with parents of children with cerebral palsy. *Disability and Rehabilitation*, 1-9. https://doi.org/10.1080/09638288.2021.1890243

For reasons of text consistency with other chapters in this thesis, some alternations may exist between the published manuscript and the version in this chapter.

Title

Measure of early vision use: Initial validation with parents of children with cerebral palsy

Authors

Belinda Deramore Denver[a], Elspeth Froude[a], Peter Rosenbaum[b] and Christine Imms[c]

Affiliations

[a] School of Allied Health, Australian Catholic University, North Sydney, Australia

[b] Department of Paediatrics, McMaster University, Hamilton, Canada

[c] Department of Paediatrics, University of Melbourne, Parkville, Australia

Corresponding Author

Belinda Deramore Denver ORCID ID 0000-0002- 9598-895X

Australian Catholic University, Level 3 8-20 Napier Street, North Sydney, NSW, 2060, Australia; belinda.deramoredenver@acu.edu.au

Keywords

Measurement, vision, cerebral palsy, Measure of Early Vision Use, validity, children

Abstract

PURPOSE To report initial psychometric evidence on the Measure of Early Vision Use.

METHOD Data on performance of the Measure of Early Vision Use scale were collected from 100 parents of children with cerebral palsy aged 0–12 years *via* online survey. Psychometric evaluation included assessment of scale dimensionality using Classical Test Theory and hypothesis testing for evidence of construct validity.

RESULTS Principal components analysis of the 14-item parent-rated Measure of Early Vision Use revealed one component with an eigenvalue of 9.343, explaining 66.7% of variance; internal consistency was high (Cronbach's $\alpha = 0.96$). Total scores ranged from 15–56 (Mean 42.8, standard deviation = 10.6). The results support seven pre-defined hypotheses including statistically significant differences in MEVU-total scores between children with and without parent-reported cerebral visual impairment.

CONCLUSIONS Measure of Early Vision Use is the first assessment tool to describe 'how vision is used' in children with cerebral palsy. Results provide preliminary evidence that the measure comprises a unidimensional construct, sufficient construct validity, and feasibility as a parent-completed online assessment. Findings on internal structure provide foundational evidence and require further testing with Confirmatory Factor Analysis or Rasch Analysis.

Implications for rehabilitation

- The Measure of Early Vision Use is a new instrument to describe the use of basic visual abilities and is feasible to use as a parent-completed online questionnaire.
- The Measure of Early Vision Use is a unidimensional scale with sufficient construct validity to supports its use as a measure of 'how vision is used' without confounding visual ability with the reason why it might be impaired (e.g., cerebral vision impairment, motor limitations, or cognition).
- There is potential for the Measure of Early Vision Use to support early intervention planning for children with (or at high risk of) cerebral palsy.

8.2.1 Background

By definition, children with cerebral palsy have a primary motor impairment (Rosenbaum et al., 2007). They are also known to be at risk to have visual (seeing) function impairments (Fazzi et al., 2012) and visual cognitive impairments including cerebral visual impairment (CVI) (Dutton et al., 2014). The motor impairments of cerebral palsy may also impact a child's ability to move their eyes or head into positions that enable seeing, and hence may limit opportunities for perceptual-motor integration. Environmental contexts further influence visual ability. There are, therefore, many reasons why the ability of a child with cerebral palsy to use their vision may be limited. Alternatively, visual ability may also be a child's strength: children's use of vision for communication and learning through eye-gaze control technology is one example (Borgestig et al., 2017).

How, and how well, a child uses vision is important for both assessment and intervention practices. The evaluation of many areas of development, including gross motor and cognitive skills, frequently presumes or requires that a child has some 'useable' level of visual ability when clinicians administer and score items. In addition, many interventions use strategies that are vision-based e.g., visual demonstration and cueing (Ryan et al., 2020). An International Classification of Functioning, Disability and Health (ICF) core set developed for children with cerebral palsy include 'use of vision' (*via* specification of the ICF code *d110* Watching) in the comprehensive core set (Schiariti et al., 2015), further highlighting the importance of visual ability for this population. Despite this, the assessment of visual abilities (that is, how vision is used) presents a challenge in clinical and research practice (Deramore Denver et al., 2016), and interventions to improve visual abilities are also lacking (Chorna et al., 2017; Williams et al., 2014).

To address this gap we developed an assessment tool that quantifies 'how vision is used' by children with cerebral palsy in everyday activities and interactions: the Measure of Early Vision Use (MEVU) (Deramore Denver et al., 2021a). MEVU has been developed for the purpose of *describing* visual ability. MEVU is not designed to explain any underlying impairments that may limit performance in vision-related activities; it is different from measures that describe performance or participation in vision-related activities (e.g., reading, locating objects, or using vision for social interaction); and it does not capture best performance. MEVU is designed to reflect a child's typical visual performance: their usual activity, or what the child 'does do' in everyday activities and interactions. To achieve this, MEVU has been designed for use with parents and caregivers of children with cerebral palsy – people who know the child well. MEVU comprises 14 questions about a child's observable visual behaviour and is completed *via* online questionnaire. This paper reports initial psychometric properties of MEVU, evaluated with a group of parents of children with cerebral palsy. The following specific research questions were addressed: (1) Is MEVU a unidimensional scale? (2) Do MEVU scores differ across subgroups of children with cerebral palsy as hypothesised? (3) Is there a relationship between the ability to use vision and other measures of vision? We conclude by discussing the readiness of MEVU for implementation into clinical and research practice.

8.2.2 Methods

This quantitative study explored the psychometric properties of MEVU in its initial field testing. Conceptualisation (Deramore Denver et al., 2017; Deramore Denver et al., 2016) and development (Deramore Denver et al., 2021a) phases preceded this study. Measurement development, psychometric testing and reporting on these procedures have been guided by consensus methods including the COSMIN Study Design Checklist for Patient-Reported Outcome Measurement Instruments (Mokkink et al., 2019), and other key authors in the field of health measurement scale development (DeVellis, 2017; Streiner et al., 2015). The development and evaluation of MEVU has been informed by both Classical

Test Theory (CTT) and Modern Measurement Theory or Item Response Theory (IRT). This preliminary study focuses on the results of analyses informed by CTT (Laver Fawcett, 2007). The study was approved by Australian Catholic University Human Research Ethics Committee (2018-178H).

Participants and recruitment

MEVU was field tested with an online questionnaire format. Parents and caregivers (hereafter referred to as parents) self-selected to participate in response to email or social media advertisements. Broad-based advertising occurred internationally *via* disability organisations, clinical practice settings and parent support networks, as well as through Australian cerebral palsy registers. Responses were deemed eligible for inclusion if they met the following criteria: (1) the respondent identified as a parent of a child with a diagnosis of cerebral palsy or “high risk of cerebral palsy,” and (2) their child was under the age of 12 at the time of survey completion. Parents of children with any level of visual ability or vision impairment were sought. The survey was only available in English. Recruitment will continue beyond this study because collecting data on reliability and validity is an incremental process (Streiner & Kottner, 2014). This paper provides evidence about the validity of MEVU from the first 100 participants.

Data collection

Interested parents were directed to a secure and customised online survey, designed using REDCap electronic data capture tools for data collection and management (Harris et al., 2009). First, parents were provided with information on the study and informed consent was sought. After confirming eligibility, parents answered demographic information questions about themselves and their child with cerebral palsy. Parent characteristics included relationship to the child with cerebral palsy, country of residence, and highest level of education; child characteristics included age, sex, type of cerebral palsy, prematurity, presence of visual impairment, and functional abilities. Gross motor function was collected using the Gross Motor Function Classification System (GMFCS) Family Report Questionnaire (with parents of children aged >2 years), a reliable and valid parent-completed questionnaire that contains the descriptors of the five GMFCS levels (Jewell et al., 2011). The child's functional challenges were also reported by indicating whether skills ('ability to use the hands to do activities', 'ability to move around', 'ability to communicate with others' and 'ability to learn new information or activities') are 'not a problem', a 'little problem' or a 'big problem' (Coster et al., 2011). Parents rated their child's current ability to use vision in everyday activities on a sliding scale (0–100) with anchors of 'does not use vision' and 'uses vision very well'.

All respondents then completed MEVU, our 14-item parent-report questionnaire that describes how children use vision in everyday activities. Each item has a named ability or 'observable visual behaviour' (e.g., 'visually attends to people'), a question for the parent to answer (e.g., 'How much does your child look at and attend to people?'), and the response options. The general meaning of the 4-point rating scale for responses is: 4 = does do; 3 = does do, but limited; 2 = can do, or may do; and 1 = does not do; however, parent respondents do not view the numeric scale, rather the questionnaire presents four descriptions of each visual behaviour. Parents chose the description that best describes their child's typical performance. Total scores range from 14 to 56, with a higher score indicating more visual ability. There is an introduction with information about 'What is MEVU?', 'Why would I complete the MEVU on my child?', and instructions. MEVU version 3.7 was used in this study.

The final section of the survey invited parents to complete a second parent-report measure of visual performance to be used in convergent validity analyses: the Preverbal Visual Assessment (Pueyo et al., 2014) for parents of children aged 0–4 years or the CVI Questionnaire (Ortibus et al., 2011) for parents of children aged 4–12 years. These measures were chosen for their utility as questionnaires that could be completed *via* online format, by parents, to assess visual ability (Deramore Denver et al., 2016).

The Preverbal Visual Assessment – a 30-item questionnaire with yes/no response options – was designed to assess visual cognitive abilities in infants aged less than 24 months, and has some evidence of validity and reliability (Pueyo et al., 2014). One validation study included a small number of children with motor impairment, however the impact of motor problems on the assessment was identified (García-Ormaechea et al., 2014). Positive answers are summed in four domains (visual attention, visual communication, visual-motor coordination and visual processing), and a higher score indicates higher levels of visual cognitive ability.

The CVI Questionnaire has 46 items, to which parents respond to binary (yes/no) statements that apply to their child, and positive answers can be used to screen for CVI (Gorrie et al., 2019; Ortibus et al., 2011). This questionnaire has shown good sensitivity and specificity (Ortibus et al., 2011), and recent exploratory factor analysis led to the revision of six domains into 5 'new' factors (Ben Itzhak et al., 2019). Analyses in the current study use both the total score and the 5 factor scores. A higher score represents more behaviours indicative of CVI.

Parents were also offered two opportunities in the survey to provide open-ended comments to the research team. The first was at the end of the MEVU and the other at the end of the second parent-reported measure in the final section.

Data analysis

Content validity of MEVU for describing vision use in children with cerebral palsy was first explored by visually inspecting whether all item response options were utilised. Descriptive statistics were used to summarise measures of central tendency and variation for all scale items. Numbers of children who received the minimum and maximum scores are reported descriptively. Floor and ceiling effects were explored by evaluating whether more than 15% of children received the lowest or highest score (Terwee et al., 2007). There were no missing data for the MEVU scale as a forced-response option was used in data collection.

Exploratory factor analysis was performed to assess the structural validity of MEVU, after first confirming that the data were suitable for factor analysis following standard protocols (Tabachnick & Fidell, 2007). Principal components analysis (PCA) was used to extract factors, and the number of factors to be retained was guided by three decision rules: Kaiser's criterion (eigenvalues above 1), inspection of the scree plot, and the use of Horn's parallel analysis (Horn, 1965). The eigenvalues obtained from PCA are compared with those obtained from a randomly generated data set of the same size (Watkins, 2000). Only factors with eigenvalues exceeding the values obtained from the corresponding random data set are retained for further investigation. Cronbach's alpha was then calculated to assess the internal reliability of the scale (Bland & Altman, 1997). Because evidence for structural validity (unidimensionality) of a scale is a prerequisite for the interpretation of internal consistency analyses, structural validity was evaluated first (Prinsen et al., 2018). Based on the preliminary work to develop a scale of the single construct (visual ability), it was expected that MEVU would be a unidimensional scale and that internal consistency would be high (Deramore Denver et al., 2021a). The possibility of item redundancy was explored using inter-item correlations.

Visual ability is a newly defined construct (Deramore Denver et al., 2017), and there is no gold-standard criterion available; hence, the exploration of construct validity was considered an important approach for this preliminary work and was investigated by the degree to which the sum scores of MEVU were consistent with predefined hypotheses. Prior to testing, hypotheses were generated based on findings from the conceptualisation and development studies that precede this work, clinical experience of the research team, and information from existing research literature. As per recommendations for evaluating construct validity with hypothesis-testing, when at least 75% of the results are in accordance with the hypotheses, the summary result will be rated as sufficient (Prinsen et al., 2018).

MEVU total scores were hypothesised to be lower (and therefore indicate less ability to use vision in everyday activities) for the following groups: (i) children reported to have visual (seeing) impairments (Hypothesis 1); (ii) children reported to have cortical or cerebral visual impairment (Hypothesis 2); and (iii) children reported to have less gross motor abilities (Hypothesis 3) (Delacy et al., 2016; Ferziger et al., 2011; Ghasia et al., 2008; Katsumi et al., 1995); indicating less ability to use vision in everyday activities. It was also predicted that there would be no significant difference in MEVU scores for girls versus boys (Hypothesis 4), in line with similar measurement research that found no difference between sex for hand use (Krumlinde-Sundholm et al., 2017). Whilst a positive relationship between age and MEVU scores could be expected based on developmental theories (Sharma & Cockerill, 2014), descriptive exploration of the relationship between age and MEVU scores was preferred to hypothesis testing.

MEVU scores were expected to have at least a moderate correlation (≥0.50) with other measures of vision. This aligns with recommendations for correlations between instruments measuring similar constructs (Terwee et al., 2018). A positive correlation was expected with the visual ability rating scale (Hypothesis 5) and the Preverbal Visual Assessment (Hypothesis 6), as in both measures high scores indicate better visual abilities.

A negative correlation was expected with the CVI Questionnaire (Hypothesis 7), as the presence of behaviours indicative of cerebral visual impairment is expected to be related to poorer visual ability as measured by MEVU.

Because data (MEVU total scores) were not normally distributed, non-parametric statistics were required for all analyses: Mann-Whitney *U* tests and Kruskal-Wallis tests were used to test hypotheses. We considered *p* values less than or equal to 0.05 as statistically significant. Construct validity was further explored by correlating MEVU with other measures of vision using Spearman's *p* correlation coefficient. IBM SPSS Statistics for Windows, Version 25.0 was used for all data analysis. Qualitative data from two optional comment boxes within the survey were analysed using content analysis (Hsieh & Shannon, 2005). This analysis was guided by keywords specific to the feasibility of a measurement tool (e.g., ease of completion, relevance for children with physical disabilities, and completion time) (Prinsen et al., 2016).

8.2.3 Results

MEVU was completed by 100 parents of children with cerebral palsy between October 2018 and July 2020. The characteristics of parent respondents and parent-reported child characteristics are shown in Tables 8.1 and 8.2, respectively, with parent-reported descriptions of vision collapsed into two categories: 'no or probably no vision impairment' and 'at least some vision impairment.' Twelve parents described their child as having 'severe vision impairment or blindness.'

Table 8.1

Respondent characteristics

	Total sample (%)
Total *n*	100
Respondent	
Mother	90 (90%)
Father	5 (5%)
Other parent/guardian	5 (5%)
Location	
Australia	56 (56%)
Other countries[1]	41 (41%)
Missing	3 (3%)
Education	
Postgraduate/graduate degree	68 (68%)
Certificate level or other post-school training	20 (20%)
High school or less	12 (12%)

Notes. [1]Other countries include: Canada (n=4), Denmark (n=1), Hong Kong (n=1), Ireland/United Kingdom (n=7), New Zealand (n=1), Serbia (n=1), South Africa (n=1), Switzerland (n=1), United States of America (n=24).

Table 8.2

Child characteristics

	Total sample (%)
Total *n*	100
Age of child	
Below 2 years	10 (10%)
2 to 4 years	24 (24%)
4 to 6 years	18 (18%)
6 to 12 years	48 (48%)
Premature (<36 weeks)	52 (52%)
Sex of child	
Male	62 (62%)
Type of cerebral palsy	
Spastic hemiplegia	32 (32%)
Spastic diplegia	13 (13%)
Spastic triplegia/quadriplegia	23 (23%)
Dyskinesia	13 (13%)
Ataxia	4 (4%)
Hypotonia	4 (4%)
Unknown/Not reported	11 (11%)
GMFCS	
Level I	26 (26%)
Level II	22 (22%)
Level III	8 (8%)
Level IV	16 (16%)
Level V	15 (15%)
Not reported or Child <2 years	13 (13%)
Ability to move around	
Not a problem	28 (28%)
Little problem	33 (33%)
Big problem	39 (39%)
Ability to use hands to do activities	
Not a problem	16 (16%)
Little problem	47 (47%)
Big problem	37 (37%)
Ability to communicate with others	
Not a problem	34 (34%)
Little problem	26 (26%)
Big problem	40 (40%)
Ability to learn new information/activities	
Not a problem	32 (32%)
Little problem	39 (39%)
Big problem	29 (29%)

Vision impairment[1]	
No or probably no VI	34 (34%)
At least some VI	66 (66%)
Severe VI or blindness	*12 (12%)*
CVI	*41 (41%)*
Wears glasses	*35 (35%)*
Strabismus	*34 (34%)*

Notes. GMFCS = Gross Motor Function Classification System; VI = vision impairment; CVI = cerebral/cortical visual impairment; [1]Data on vision impairment allowed parents to use multiple descriptors for their child. 'No or probably no VI' is a summation of children reported to have no vision impairment, probably no vision impairment and/or strabismus or wears glasses in the absence of other information. 'At least some VI' is a summation of children reported as having some vision impairment, severe vision impairment or blindness, and/or visual field restrictions, reduced visual acuity, nystagmus, optic nerve damage, eye disorder, or cerebral/cortical vision impairment. Children with 'at least some VI' may also wear glasses or have strabismus.

Table 8.3 reports the frequency (and percentages) of responses to the 14 MEVU items. The mean total score on the MEVU was 42.8 (SD 10.6: range 15–56). No child scored 14 (lowest ability) and ten children (10%) scored 56 (highest ability). Standard tests of normality indicated a skewed distribution (-0.655) with kurtosis -0.327) and a significant Kolmogorov-Smirnov statistic (p = 0.007), indicating violation of the assumption of normality (Pallant, 2016).

Internal structure

To explore the underlying structure of MEVU, and after confirming suitability for factor analysis with a highly significant Bartlett's Test of Sphericity (p < 0.001) and a high Kaiser-Meyer-Olkin (KMO) measure of sample adequacy value (KMO = 0.936), the fourteen items were subjected to PCA. PCA revealed only one component with an eigenvalue exceeding 1 (9.343) explaining 66.7% of the variance, and all 14 items loaded above 0.717 on this one component (see Table 8.3). The results of the scree test and parallel analysis also supported a single-factor solution. As expected, Cronbach's alpha value for the single scale was high (α = 0.96) and may indicate some item redundancy. Inter-item correlations ranged from (r = 0.38) between 'visually attends to what the hands are doing' and 'visually attends to digital screens,' to (r = 0.8) between 'shifts looking around and between things' and 'uses vision over distance.'

Table 8.3

Frequency of responses to each MEVU item by parents of children with cerebral palsy & Component Loadings from Principal Components Analysis (n=100)

Scale item	Does not do	Can do, or may do	Does do, but limited	Does do	Component 1
1. Reacts	1 (1%)	7 (7%)	32 (32%)	60 (60%)	0.822
2. Visually attends to people	3 (3%)	20 (20%)	12 (12%)	65 (65%)	0.732
3. Visually attends to toys & objects	2 (2%)	17 (17%)	36 (36%)	45 (45%)	0.865
4. Visually attends to what the hands are doing	12 (12%)	30 (30%)	25 (25%)	33 (33%)	0.717
5. Visually attends to books & pictures	6 (6%)	22 (22%)	26 (26%)	46 (46%)	0.810
6. Visually attends to digital screens	5 (5%)	14 (14%)	25 (25%)	56 (56%)	0.766
7. Uses vision over distance	12 (12%)	24 (24%)	24 (24%)	40 (40%)	0.857
8. Shifts looking	5 (5%)	26 (26%)	33 (33%)	36 (36%)	0.894
9. Follows	11 (11%)	16 (16%)	37 (37%)	36 (36%)	0.827
10. Searches for & finds	11 (11%)	23 (23%)	43 (43%)	23 (23%)	0.826
11. Shares visual attention	16 (16%)	13 (13%)	36 (36%)	35 (35%)	0.812
12. Responds to details	11 (11%)	18 (18%)	37 (37%)	34 (34%)	0.864
13. Time to respond	13 (13%)	15 (15%)	45 (45%)	27 (27%)	0.775
14. Overall use of vision	4 (4%)	17 (17%)	46 (46%)	33 (33%)	0.851

Construct validation

As hypothesised, between-group analyses found children with cerebral palsy and no vision impairment (i.e., no ocular or cerebral visual impairment), and children with cerebral palsy and ambulatory cerebral palsy (GMFCS levels I-III), have significantly higher MEVU total scores than children with vision impairments and/or non-ambulatory cerebral palsy (see Table 8.4). Median MEVU total scores were better (higher) in children with more gross motor ability compared to those for children with less motor ability (see Figure 8.1). There was minimal increase in median MEVU scores past the 2–4-year age group, however results of the Kruskal-Wallis Test indicate that there was a statistically significant difference across the four age groups. Inspection of mean rankings indicates that MEVU scores continue to increase with age in this cross-sectional sample. The overall correlation between age and MEVU total score was weak and positive, $r_s = 0.274$, $n = 98$, $p = 0.006$.

Table 8.4

Comparison of MEVU scores between subgroups of children with cerebral palsy

Alternate hypothesis	Parent reported characteristic	*n*	Median MEVU score	Statistical test & result	Hypothesis confirmed?
Children reported to have visual (seeing) impairments would score significantly lower on MEVU items (Hypothesis 1).	Vision impairment				
	No/prob no VI	34	52	U = 1823.5, z = 5.112, p<.001	Yes
	Yes VI	66	41		
Children reported to have cortical or cerebral visual impairment would score significantly lower on MEVU items (Hypothesis 2).	Cerebral/cortical visual impairment	59	49	U = 440.5, z = -5.397, p<.001	Yes
	No CVI	41	36		
	Yes CVI				
Children reported to have less gross motor abilities would score significantly lower on MEVU items (Hypothesis 3).	Gross Motor Function				
	GMFCS I-III	56	49	U = 316.5, z = -4.895, p<.001	Yes
	GMFCS IV-V	31	35		
Difference in MEVU total scores between male and female children would not be significant (Hypothesis 4).	Sex				
	Male	62	43	U = 923.5, z = -1.810, p=0.07	Yes
	Female	38	45.5		

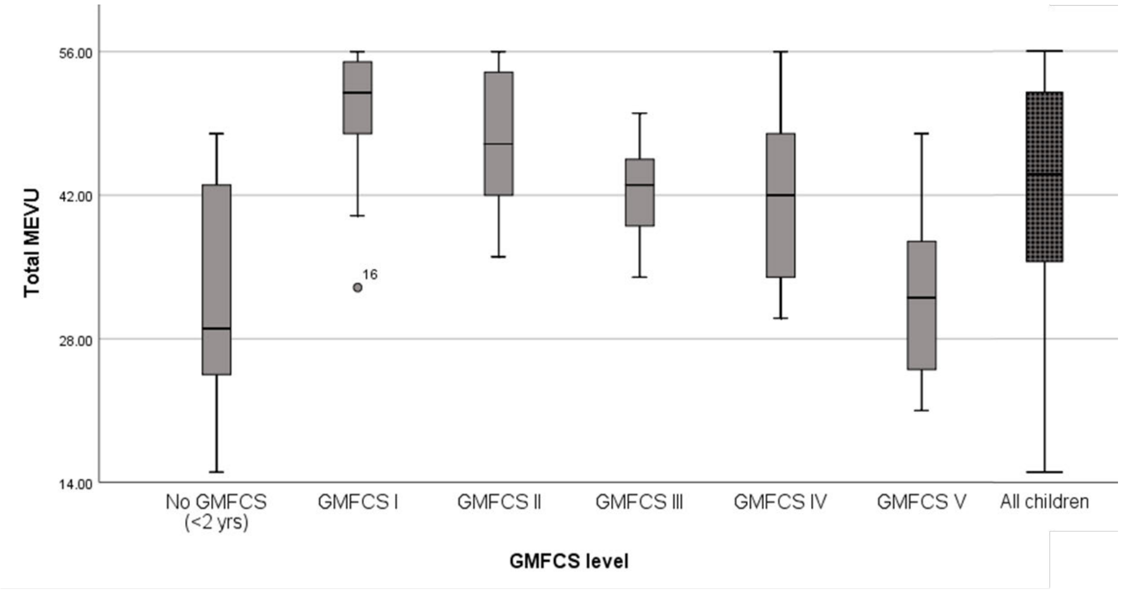
Exploratory analysis	Parent reported characteristic	*n*	Median MEVU score	Statistical test & result
MEVU total scores and age.	Age group			
	Below 2 years	10	34	$c^2(3) = 8.084$, p=0.04
	2 to 4 years	24	44.5	

	4 to 6 years	18	45.5
	6 to 12 years	48	45

Notes. GMFCS = Gross Motor Function Classification System; VI = vision impairment; CVI = cerebral/cortical visual impairment

Figure 8.1

Box and whiskers plot of MEVU Total Scores (14-56) for children with cerebral palsy who are GMFCS Level I (n=26), Level II (n=22), Level III (n=8), Level IV (n=16), Level V (n=15) and children aged less than 2-years who were not classified (n=10). The shaded box represents scores from all children (n=100).



Correlations between the visual measures and MEVU total scores are presented in Table 8.5. As hypothesised, there was a positive correlation between MEVU total scores and both the visual ability rating scale and the Preverbal Visual Assessment. There was also a hypothesised negative correlation between MEVU and the CVI Questionnaire. Furthermore, factors considered more like the construct measured by MEVU – namely ratings of 'object and face processing impairments'– demonstrated stronger correlations with MEVU scores than ratings of 'anxiety-related behaviours.'

Table 8.5

Correlation of MEVU scores with other measures of visual performance

A priori hypothesis	Scale/Item description	*n*	*Spearman correlation with MEVU total score*	Hypothesis confirmed?
Positive correlation (≥0.50) with visual ability rating scale as both measures indicate better visual abilities with high scores (Hypothesis 5).	How would you rate your child's current ability to use vision in everyday activities? *(1 = Does not use vision, 100 = Uses vision very well)*	100	.819**	Yes
Positive correlation (≥0.50) with the Preverbal Visual Assessment as both measures indicate better visual abilities with high scores (Hypothesis 6).	Preverbal Visual Assessment Scale - Total score (/30)	23	.886**	Yes
	Subscales:			
	Visual attention domain (/11)		*.811***	
	Visual communication domain (/5)		*.778***	
	Visual-motor coordination domain (/13)		*.883***	
	Visual processing domain (/20)		*.826***	
Negative correlation (≥0.50) with the CVI Questionnaire (total score) as the presence of behaviours indicative of cerebral visual impairment is expected to be related to poorer visual ability as measured by MEVU (Hypothesis 7).	CVI Questionnaire - Total score (/46)	51	-0.769**	Yes
	Subscales:			
	1. Object and face processing impairments		*-0.803***	
	2. Visual (dis)interest		*-0.750***	
	3. Clutter and distance viewing impairments		*-0.563***	
	4. Moving in space impairments		*-0.386***	
	5. Anxiety-related behaviours		*-0.350**	

Feasibility of MEVU

All respondents in this study completed MEVU using the online questionnaire format. Review of time stamp data for responses completed in 'one sitting' indicated that parents took an average of 4.53 min (SD 3.51) to read the instructions and complete the 14 items of MEVU. Completion time ranged from one to twenty minutes. Five other respondents started the questionnaire and returned to it within 1–2 days.

Thirty-seven parents provided qualitative data in the optional comment sections, and their responses have been grouped into six themes. The predominant type of feedback was parent descriptions of their child's individual profile in support or explanation of their MEVU rating (n = 23). One parent described difficulty answering the question about the visual behaviour 'shifts looking.' Other themes were: descriptions of their child's improvements in visual abilities over time (n = 4); content of MEVU (e.g., positive comments on examples and the 'OR' descriptions) (n = 4); challenges with the utility of Preverbal Visual Questionnaire or CVI Questionnaire for children with physical disability (n = 5); offers to provide the research team with other visual data (e.g., visual acuity) (n = 2); and one recommendation to include an 'other' demographic category for parent and child sex.

8.2.4 Discussion

The results from this study provide initial support for the 14-item MEVU scale as a descriptive assessment tool measuring parental perceptions of visual ability in children with cerebral palsy. Scored from observations of visual behaviours in everyday activities and interactions, MEVU describes 'how vision is used.' The analysis of score distribution in this quantitative study further supports findings of content validity reported in the development study (Deramore Denver et al., 2021a). Both structural validity and internal consistency findings from the current study infer MEVU reflects the one underlying construct of visual ability (i.e., a unidimensional scale), in line with the conceptualisation work that preceded this study (Deramore Denver et al., 2017). This supports scoring MEVU as a single scale and suggests MEVU is suitable for future analysis with Item Response Theory.

No floor or ceiling effects for the total score (sum of MEVU items) were found, suggesting that MEVU has the potential to discriminate among children with different levels of visual ability; however, both floor and ceiling effects were found at an item level. Whilst all response options were utilised by at least one participant in this study, the small numbers of parents rating their child using response options reflective of the lowest visual abilities may represent a problem with the scale, or it may result from limited inclusion of parents of very young children (under two years of age) and of children with severe vision impairment or blindness. It is these two groups of participants who would be expected to have the least visual abilities, and therefore no changes will be made to the scale before testing with a larger participant group including these children. At the top (ceiling) end of scores, the high number of children rated with 'does do' for visual behaviours may also be explained by the sample, with half of the children in this sample being school-aged (i.e., children expected by age and typical activities/environments to be using more complex visual abilities). In the development phase of MEVU, when observable visual behaviours were operationalised as the measurable construct, more complex visual abilities such as scanning and visual cognitive skills including recognition and discrimination were excluded from the construct definition. The focus on foundational visual skills in MEVU is reflected in the name of the measure: 'early vision use.' Whilst results from this study do suggest that MEVU should be targeted at young children, the absence of high scores in many children over the age of six years also supports its use with children of any age when there is a concern about basic visual abilities.

Construct validity for MEVU was demonstrated by hypothesis testing and can be rated as sufficient by this study (Prinsen et al., 2018). Each of the seven hypotheses established *a priori* were confirmed. This study also explored the relationship between visual ability and age; the frequency of parents reporting visual behaviours as 'does do' in this study suggests a hierarchy of visual skills with fewer children demonstrating more (developmentally) advanced visual behaviours. In this study, however, developmental age was not a strong predictor of MEVU score, which supports validation of MEVU scores for 'visual ability' rather than 'age' or 'development.' To further investigate how much MEVU scores reflect age-related development of vision, and to inform guidelines for the age at which the highest score could be expected, MEVU requires testing in a population of typically developing children and within longitudinal study designs. Furthermore, preliminary evidence from the results, suggesting that a hierarchy of visual behaviours may exist, will need exploration using Item Response Theory. An item difficulty hierarchy informed by Rasch analysis could be very useful for informing interventions to improve visual abilities in a manner similar to the way the Assisting Hand Assessment is used in clinical practice to select the next target for intervention (Holmefur & Krumlinde-Sundholm, 2016). Because visual behaviours are some of the earliest skills a child can independently demonstrate, MEVU has potential for highlighting active ingredients for very early intervention.

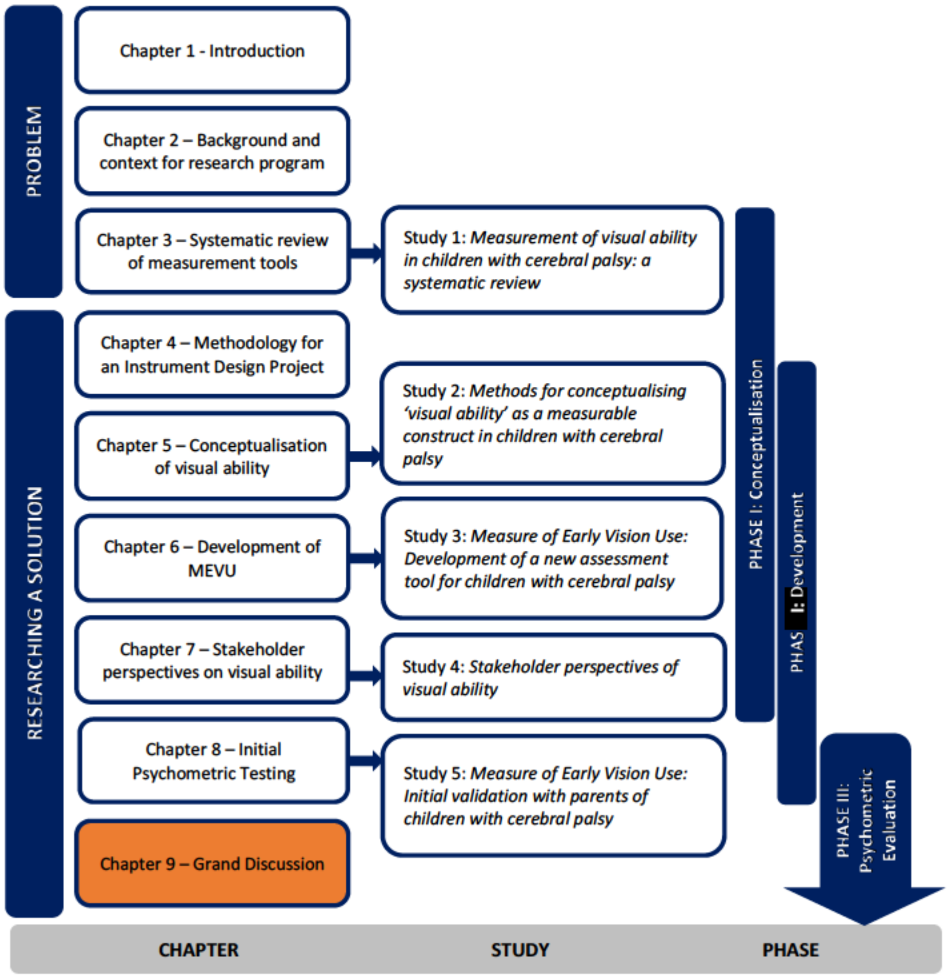
Although MEVU is not yet being presented as a responsive (change-detecting or evaluative 'outcome') measure, the development process did seek and include items that are both relevant and potentially responsive to change. MEVU's use as an outcome measure may, however, be limited by the small number of items and by ceiling effects found in this study. The large number of high scores may indicate a limitation of the measure to capture further improvements, or it may suggest that further improvement is not needed on many items for many children. The findings and challenges associated with ceiling effects align with findings from the assessment of other developmental domains for this population. For example, the Gross Motor Function Measure (GMFM-66) is an internationally accepted measure for quantifying gross motor abilities in children with cerebral palsy (Russell et al., 2013), however the measure's usefulness for describing more advanced motor skills can be limited in children with the highest classification of motor abilities (i.e., GMFCS Level I), with children above the age of 5-years typically achieving scores of 85% to 100% (Beckung et al., 2007). Thus, just as the purpose of the GMFM has been specified as measuring 'basic motor abilities' (Bartlett & Palisano, 2002) or foundational gross motor function, rather than high level skills, MEVU might be best seen as a measure of 'basic visual abilities,' and therefore such ceiling effects would be expected. This also distinguishes the purpose of MEVU from other assessments of 'higher' visual processing skills and CVI (Vancleef et al., 2020a). The large number of high scores also gives support to a second purpose of MEVU: to describe 'good visual abilities' and a child's strengths in using vision, which may be capitalised on in practice. Knowing that only one in ten children with cerebral palsy is expected to have severe vision impairment or blindness further validates the finding that a large percentage of a sample of children with cerebral palsy aged up to 12-years demonstrate high levels of 'basic visual abilities' (Novak et al., 2012).

A limitation in this study is the relatively small sample size of very young children with cerebral palsy or at high risk of cerebral palsy, and/or children with severe vision impairment or blindness. These two participant groups may have the most potential to benefit from assessment with MEVU, but they are arguably our most vulnerable and challenging group to involve in research. Only now, with initial evidence of validity, may it be ethically appropriate to target the involvement of these participant groups more directly in further testing of MEVU, including studying these groups separately. To recruit children under two years of age is likely to require collaboration with other researchers and projects currently underway with this age group. In the current study, it must be noted that participants self-selected to participate upon viewing an advertisement. All data were collected *via* anonymous self-report and these recruitment methods may have led to a selection bias of highly educated parents. As such, the results from this study may be limited in their generalisability, although good levels of participation may also be evidence of the meaningfulness of this research to parents of children with cerebral palsy. Implementing MEVU into clinical and research practice will require planning. Providing knowledge on the purpose, utility and availability of MEVU to potential users is a first step (Cunningham et al., 2018). In addition to publication of the development and initial validation processes, a website has been established to provide access to, information on, and links to studies that will further support the validation of this measure (https://measureofearlyvisionuse.com).

The development and availability of MEVU for use (initially in a research version) is timely given the recent publication of the Visual Function Classification System (VFCS) (Baranello et al., 2020). The VFCS defines five progressive levels of how children with cerebral palsy use visual abilities in their daily life; for example, children in VFCS Level I use visual function easily and successfully in vision-related activities. It is possible that MEVU may be helpful for both families and clinicians in classifying children's level of visual function. With similar timelines for development, these two measures (one an assessment and one a classification), demonstrate growing recognition of the importance of visual functioning in the childhood cerebral palsy population. Convergent validation of these tools will be a natural research progression. Together, these tools have the potential to promote a significant change to service delivery and functional outcomes for children and families.

MEVU provides a tool that is brief, user-friendly and clinically relevant. It is proposed as an assessment complementary to existing practices (e.g., clinical evaluations of vision). MEVU appears feasible as a parent-completed online assessment and is therefore likely to be cost and time efficient, and widely available. Whilst MEVU provides a method to quantify basic visual abilities, it is important to note that parents in this study also wished to provide qualitative comments to support or explain their child's score. This reflects the need for a child's individuality to remain part of the assessment process (O'Connor et al., 2021). It is recommended that open-ended comment boxes be retained alongside MEVU items to meet this need. The study reported here is just the first step in an ongoing process of validation and psychometric testing. Important next steps include further analysis of structural validity and reliability testing (test-retest, measurement error and inter-rater). As a descriptive measure, and until Rasch analysis is conducted, MEVU will be limited to ordinal scoring without an empirically derived framework for the interpretation of raw scores. Future examination of the utility of MEVU will look at the role of therapists in the assessment process, who in a child's team will initiate use of MEVU and what happens after a child has a MEVU 'score.'

CHAPTER 9: Grand discussion



9.1 INTRODUCTION TO CHAPTER 9

The research reported in this thesis makes an original and important contribution to the field of cerebral palsy, especially relevant to the early years and early intervention. This research sought a solution to the problem of measuring visual ability in children with cerebral palsy; the main outcome of this research program has been the development of the *Measure of Early Vision Use (MEVU)*. In this final thesis chapter, the main findings from this research program are summarised, strengths and challenges identified, and implications for clinical and research practice discussed.

9.2 SYNTHESIS OF RESEARCH FINDINGS

Research findings addressing the four objectives of this PhD are summarised and discussed in this section. Summaries are presented in dialogue boxes at the beginning of each of the four sub-sections to highlight key findings.

9.2.1 A gap in the availability of assessment tools for visual ability in children with cerebral palsy

The decision to develop a new tool to assess visual ability in children with cerebral palsy was based on the finding that there was no existing instrument available.

The first objective of this PhD was to identify and evaluate existing measurement tools that assess visual ability in children with cerebral palsy. This aligns with the recommendation that research about a measurement problem should start with the question 'Do we have a measure or scale that answers our research question?'. Researchers are strongly encouraged, first, to consider whether a measurement tool already exists that could be used or modified before developing a new one (Streiner et al., 2015). The decision to embark on the development of a new tool should not be made lightly. In this research, answering the question about the existence of a measure of Activity level 'use of vision' was complicated by the complexity of the construct, and no definite answer to the question about the availability of existing tools was found from the systematic review (Chapter 3). A second study analysing the content of existing instruments was undertaken before confirming the need for the development of a new measure (Chapter 5). The two studies reported in those chapters (3 and 5) defined the problem for which a solution was sought in the remainder of this PhD research: that is, that a method for quantifying ‘how vision is used’ was needed to answer clinical questions such as: “How does this child use /his/her vision?” “Is it important to consider his/her vision?” “Will use of vision improve?” and “What can be done to improve vision use?”.

A systematic review, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines, was undertaken to identify what tools were available to classify and/or measure the visual ability of children with cerebral palsy, and to review the evidence for validity and reliability of the available measurement tools (Deramore Denver et al., 2016). Whilst the systematic review found that all nineteen existing measures had limited psychometric properties, it was not this finding that led to a research project developing a new measurement tool; rather it was the absence of a well-developed and well-conceptualised measurement tool of ‘how vision is used’. Research to validate an existing tool would have been undertaken had there been a suitable tool, rather than embarking on the development of a new tool (Streiner et al., 2015).

The measurement tools located and analysed in the systematic review were varied, with no consensus on *what* should be measured. Furthermore, no existing measure had involved parents, caregivers or people with a diagnosis of cerebral palsy in the development of the tool. The involvement of key stakeholders and the target population for a measurement tool is important to ensure a tool is relevant and comprehensive (Terwee et al., 2018). These concerns led to the second study in this PhD: analysis of the content of all measurement tools identified in the systematic review by linking content to the International Classification of Functioning, Disability and Health (ICF) framework using linking methodology (Deramore Denver et al., 2017). This process resulted in the finding that existing visual ability measurement tools measure a wide range of constructs, and not specifically how vision is used, and this finding contributed to refinement of the definition for ‘*visual ability’*. The outcome of the refined visual ability definition (discussed further in Section 9.2.2) was that there was no existing instrument that could be used or modified to measure visual ability in children with cerebral palsy. Clinician perspectives from the online survey further corroborated this gap (Deramore Denver et al., 2021a). Existing instruments measured a range of factors including visual (seeing) functions or visual capacity, cognition and motor function, not just the ability to use vision.

The systematic review that led to the decision to develop a new measurement tool was published in 2016, and additional measurement tools have been published subsequently. However, the ongoing monitoring of this new research throughout this program of research also confirms the continued need for an assessment of visual ability for children with cerebral palsy, thereby supporting the relevance of this body of research. One notable advancement in the field since the beginning of this research is the publication of the Visual Function Classification System (VFCS) (Baranello et al., 2020). The benefits of complementary instruments for the assessment and classification of a construct have previously been reported for children with cerebral palsy in the domains of gross motor function and manual ability (Holmefur et al., 2010; Palisano et al., 2000).

9.2.2 Defining 'visual ability'

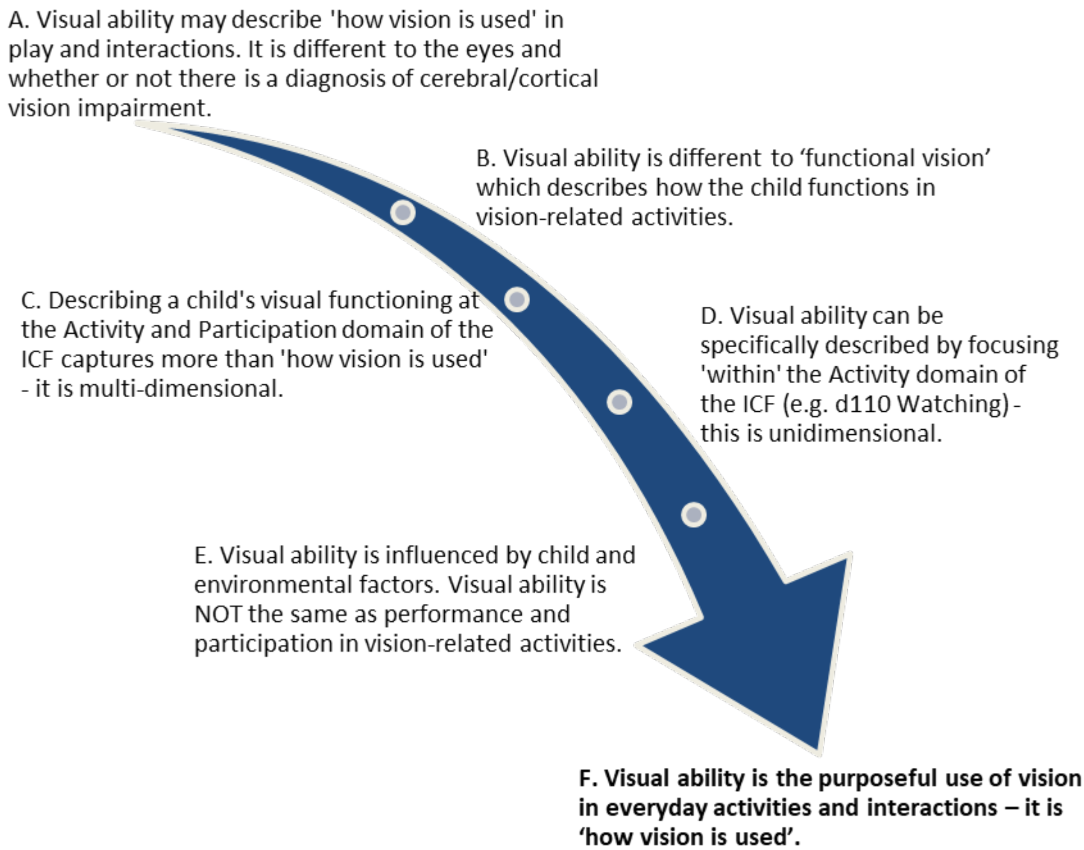
The construct of *visual ability* is defined as 'how vision is used' in everyday activities, interactions and environments. Visual ability is a construct at the Activity level of the International Classification of Functioning, Disability and Health. It is 'purposeful' use of vision.

The second objective of this PhD research was to define visual ability as a measurable construct. The importance of this stage in the research is supported by the COSMIN group who recently updated their guidelines on how to evaluate measurement tools to include a strong emphasis on design and clearly defining the construct of interest (Terwee et al., 2018). This section of the findings summarises 'what is visual ability' and is a clear strength of the research. How this construct was then operationalised as a measurable construct in the Measure of Early Vision Use will be discussed in Section 9.2.3.

The definition of visual ability evolved throughout this research (see Figure 9.1). The starting point for the definition of visual ability came from clinical observations in practice of how children with cerebral palsy use their vision and my occupational therapist focus on performance in everyday occupations (activities and participation). Visual ability was initially proposed to describe 'how vision is used' in play and interactions, an approach that is different from descriptions of the eyes, or whether there is a diagnosis of cerebral/cortical vision impairment.

Figure 9.1

Evolving (from A to F) definition of visual ability throughout this program of research



The preliminary conceptualisation of visual ability was largely influenced by Colenbrander's (2003) definition of functional vision. The most significant difference between this research's final definition of visual ability and Colenbrander's definition of functional vision is that his description of 'how the child functions in vision related activities' may also be reflective of other abilities (e.g., motor abilities), whilst 'purposeful use of vision in everyday activities and interactions' is specifically and only about 'how vision is used'. An important focus in this research has been the development of a definition of visual ability that is relevant to all children with cerebral palsy regardless of their motor, communication, or cognitive skills. To distinguish the construct from Colenbrander's definition, the term visual ability (rather than functional vision) was selected for use in this research. The use of the term 'ability' also aligns with terminology used in other assessment tools for children with cerebral palsy (e.g. Krumlinde-Sundholm

& Eliasson, 2003), and avoids the negative and impairment-laden term of disability, by describing vision using strengths-based language.

Whilst Colenbrander's definition of functional vision is aligned theoretically with the Activity and Participation domain of the ICF framework, in this research visual ability has been more specifically defined as a construct 'within' the Activity domain. Within the ICF, visual ability is an Activity level construct categorised at *d110 Watching*, and sometimes *d160 Focusing attention* and *d161 Directing attention*. By describing a child's ability to use vision with these specific Activity domain visual codes, this research has been able to define visual functioning as a single construct. This is different to existing multi-dimensional approaches that confound vision use with other skills and activity performance. This led to the hypothesis that visual ability defined 'within' the Activity domain in this way is more likely to be a unidimensional construct and thus suitable for testing with a reflective model of measurement. Structural validity testing has confirmed that visual ability assessed via MEVU is measuring one construct (Deramore Denver et al., 2021b).

Visual ability is defined as a child's purposeful use of vision in everyday activities and interactions, such that observable visual behaviours from within everyday activities and interactions can be used to describe their visual ability or 'how vision is used'. This definition aligns with that of the newly developed VFCS, where visual ability refers to how the child uses vision purposefully to see, direct gaze, recognise, interact with the environment, and explore it (Baranello et al., 2020). The alignment of these definitions will be important for future research and uptake of both tools in clinical and research practice. The word 'purposeful' within the definition of visual ability is important because it implies 'active use of vision' and therefore links nicely with theories of neuroplasticity that are important to modern intervention practices for children with cerebral palsy (Kleim & Jones, 2008; Morgan et al., 2021).

Equally important to establishing a definition of 'what is visual ability' is the definition of 'what visual ability is <u>not</u>'. The definition of visual ability as an Activity-level construct differentiates it from the more traditionally assessed vision functions (e.g., visual acuity and quality of vision), which are Body Function-level constructs. This research has highlighted that a child's visual ability as reflected in vision-related activities is not the same as their level of performance in an activity, or how they engage or participate in activities. For example, observations of how a child moves around their environment to find a toy are likely to provide insights on how they use vision, but this is not the same as describing their ability to move around their environment to find a toy. That performance is likely to have contributions from other factors including motor skills and how the environment is set-up.

9.2.3 The Measure of Early Vision Use

Measurement tool	**Measure of Early Vision Use (MEVU)**
Target population	Children with cerebral palsy
Purpose	Descriptive
Measurement construct ('what')	Visual ability ('basic visual abilities')
Focus ('how')	ICF Activity level Performance (perceived)
Administration/response format	Parent/caregiver completed online questionnaire 14 questions
Scoring	Sum of scores (ordinal level scoring) Range 14-56
Interpretation	High score represents more visual ability

The *Measure of Early Vision Use* (MEVU) is the outcome of the third aim of this PhD program: development of a new tool to measure visual ability in children with cerebral palsy. Knowledge about the target population, purpose, focus, format, scoring and interpretation for this new assessment tool are summarised here, followed in the next section by key findings on the measurement properties.

The target population for MEVU is broadly defined as children with cerebral palsy. Items were initially selected for the development of this new tool from the content of existing measurement tools used with children aged up to 18 years, but exploration of the visual ability construct with stakeholders via the online survey directed this research towards the importance of targeting early vision use in young children (Deramore Denver et al., 2021a). Defining the focus of measurement as 'observable visual behaviours', rather than the complex visual skills that are not easily assessed through observation (e.g., scanning, and visual cognitive skills), is also consistent with a focus on younger children. The initial testing of MEVU was undertaken with children with cerebral palsy aged birth to 12-years, and findings suggest that MEVU is likely to be most useful for young children or children who may have difficulties with 'early' visual skills (Deramore Denver et al., 2021b). The potential implications of assessing early vision use for addressing vision within the neuroplastic window associated with early intervention has influenced the targeted age group. Further research, however, with a larger sample size is needed to explore and refine the recommended age group for this tool. Until then, the target population for MEVU will be known as ‘children with cerebral palsy, or infants at high risk of cerebral palsy. The wording ‘early’ within the name of the MEVU tool is likely to communicate that MEVU is aimed at children in the early ages and stages of using vision in everyday activities and interactions.

In targeting children with cerebral palsy, and addressing the single construct of visual ability, the development of MEVU was focused on creating a population-specific tool that is relevant for children regardless of their other functional abilities e.g., motor skills. MEVU has been developed for use with all children with cerebral palsy, regardless of whether vision is a strength, or whether they have a cerebral/cortical vision impairment or an ocular vision impairment.

The aim of MEVU is to *describe* purposeful use of vision, and initial findings suggest that it is suitable for this purpose (Deramore Denver et al., 2021b). MEVU items and response options that are descriptive of a child’s current visual functioning were sought to improve our understanding and recognition of visual abilities in children with cerebral palsy and to have potential for use in intervention planning and clinical decision making (Laver Fawcett, 2007). Establishing MEVU as an outcome measure to evaluate a child’s responsiveness to interventions that aim to improve visual ability will be the focus of future research. MEVU’s future potential as an outcome measure has been considered throughout the development phase, including asking stakeholders for their perspective on visual behaviours that might change with time and intervention. This knowledge was incorporated into the development of the items and response options.

To assess a child’s ability to use vision, MEVU focuses on descriptions of observable visual behaviours from typical daily activities, interactions and environments. MEVU focuses on ‘how vision is used’ without the intention to explain ‘why’. During the development of MEVU care was taken not to include items that were focused on other constructs such as motor or cognitive skills, or performance or participation in vision-related activities such as mobility, hand use or communication. The development of a unidimensional assessment of visual ability was complex, however initial findings on MEVU’s measurement properties suggest this has been achieved (Deramore Denver et al., 2021b). MEVU is not proposed as an alternative to specialist assessment (e.g., eye/visual function tests), nor should MEVU scores be misinterpreted as evidence that there is nothing wrong with the eyes or with visual-cognitive functions.

MEVU is the first assessment tool that focuses exclusively on ICF Activity level assessment of vision use (Deramore Denver et al., 2017; Deramore Denver et al., 2021a). More specifically, MEVU is a new tool for the assessment of visual ability from the perspective of typical performance, not a child’s best capacity for using vision. The visual behaviours observable in everyday activities, behaviours that reflect a child’s visual ability and form the items in MEVU, are considered ‘basic visual abilities’ (e.g., responding, searching, following). Whilst these visual abilities are not new, their definitions within this tool may be a particularly useful innovation. For example, previous research has frequently used the terms 'visual tracking' and 'visual following' interchangeably yet depending on their definition they can be different behaviours.

The decision to assess visual ability from the perspective of parents is directly linked to MEVU’s focus on visual behaviours observed in typical daily activities, interactions and environments. Primed by the systematic review findings that existing measurement tools of visual ability use parent-completed questionnaires for knowledge on a child’s performance (Deramore Denver et al., 2016), MEVU was developed to seek the perspective of parents or caregivers with knowledge of what a child does in a typical day and environment. As a parent-completed assessment, MEVU is well aligned with family-centred practices and the principles that articulate that parents know their children best (Rosenbaum et al., 1998).

Whilst MEVU has been developed as a parent or caregiver completed online questionnaire, an interview-administered questionnaire may have been another suitable approach. It was determined that a clinical tool would not be appropriate, with that format better suited to assessing best capacity to use vision in a standardised environment. The format of the online questionnaire used by MEVU has been tested and initial findings suggest MEVU can be completed independently by parents via online format, taking on average less than 5-minutes (Deramore Denver et al., 2021b). In addition to recognising the expertise of parents in knowing the abilities of their child, an online questionnaire may be completed by parents at home or within clinical settings making it widely accessible at low cost.

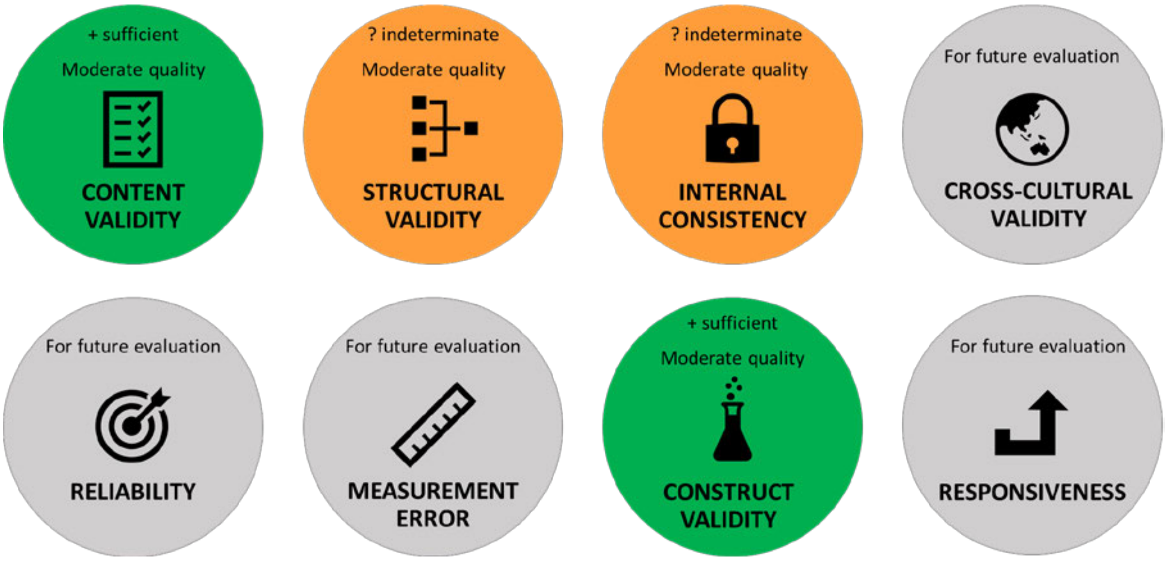
MEVU is a multi-item scale. There are 14 items or questions that make up the content of the scale, and each question has four response options. The order of the items was informed by parent perspectives during the initial testing with cognitive interviews and is not reflective of increasing complexity in visual behaviours. A copy of MEVU is available in Appendix F, however MEVU is currently only available as a research version whilst further evaluation is underway. The scoring system for MEVU is currently the sum of scores for each question resulting in a range from 14 reflecting the lowest levels of visual ability, to 56 reflecting higher levels of visual ability. Whilst ordinal level scoring could be considered a limitation of MEVU, the establishment of a scale that provides raw scores is an important development step in the creation of MEVU.

9.2.4 Measurement properties of the Measure of Early Vision Use for children with cerebral palsy

The fourth and final objective of this PhD research was to evaluate measurement properties of MEVU for children with cerebral palsy. The findings are summarised here as an accumulation of everything known about the measurement properties of this new assessment tool from this program of research. This includes the findings from Study 3 on the content validity (development) of MEVU (Deramore Denver et al., 2021a) and Study 5 on the structural validity, internal consistency and hypotheses testing for construct validity (Deramore Denver et al., 2021b). Evidence for MEVU's measurement properties for children with cerebral palsy is summarised by the coloured circles in Figure 9.2. The absence of evidence for some measurement properties, as depicted by the grey circles, is not a limitation of this research: cross-cultural validity, reliability, measurement error, and the responsiveness of MEVU for children with cerebral palsy are areas for future research. The approach used in this synthesis to summarise and report findings on MEVU's measurement properties reflects the COSMIN methodology for systematic reviews (Mokkink et al., 2017). The method is summarised in Appendix D. Recommendations for using MEVU in clinical and research practice based on the available evidence will be included in Section 9.4.

Figure 9.2

Infographic illustrating the measurement properties of MEVU for children with cerebral palsy at the conclusion of the PhD



Notes. The quality of evidence in measurement properties is rated as sufficient (+) , insufficient (-) , indeterminate (?) , or measurement properties are yet to be evaluated in future studies . The overall quality of that evidence is then rated as high, moderate, low or very low.

Evidence for the *content validity* of MEVU comes from the development phase of this research (Deramore Denver et al., 2021a). The quality of the one development study was evaluated as 'adequate'. Consideration was given to the use of both parents of children with cerebral palsy, and professionals, on appraisal of the relevance, comprehensiveness and comprehensibility of the MEVU items. This led to the content validity of MEVU being rated overall as *sufficient*, however the overall quality of evidence for content validity is graded as *moderate* (not high) because of the absence of a content validity study in addition to the one development study. It is also acknowledged that appraisal of content validity includes subjective assessment. As MEVU has been developed by the same researcher undertaking this appraisal, this increases the possibility of unintentional bias in the rating.

The *structural validity* of MEVU is limited by the absence of either confirmatory factor analysis or Rasch analysis and is therefore rated overall as 'adequate', with the quality of this evidence summarised as *indeterminate*. The structural validity analysis sought evidence that items in the MEVU scale measure a single construct as assessed using exploratory factor analysis. Evidence of unidimensionality is supported by the principal components analysis that found all fourteen items of the MEVU scale loading on one component above 0.717. The sample size (n=100) was appropriate for the number of items according to the COSMIN recommendation. The population of interest was reasonably represented, although the extreme lower end of the MEVU rating scale was not used by many, suggesting those with the lowest levels of ability may not have been included in the sample. The quality of this overall evidence is graded as *moderate* (not high) because of the risk of bias that may come from the availability of only one study of adequate quality; however the finding of unidimensionality is important for future interpretation and inferences of MEVU total test scores (Strauss & Smith, 2009). Whilst *internal consistency* findings were very good (Cronbach's alpha = 0.96), and the risk of bias from the analysis of the internal consistency of the unidimensional scale is low, the summary of evidence for internal consistency is impacted by the structural validity rating and is therefore also rated as *indeterminate*. The quality of this overall evidence for internal consistency is also graded as *moderate* (not high) because there is only one study on this measurement property.

Construct validity for MEVU was demonstrated by two types of hypothesis testing: comparison with other instruments (convergent validity) and comparison between subgroups (discriminative or known-group validity). Despite serious risk of bias arising from the insufficient measurement properties of some comparator instruments resulting in the rating of some study analyses as 'doubtful', the overall quality of the evidence for construct validity is summarised as *sufficient*. The seven hypotheses established a priori were all confirmed. The overall quality of the evidence for construct validity is graded as *moderate* (not high) because of the stated risk of bias.

9.3 LIMITATIONS OF THE RESEARCH

The research outlined in this thesis has sought to minimise bias that may impact the findings, but limitations do exist and require discussion. The limitations of each individual study that contributes to this research project have been outlined within their respective manuscripts and chapters, and will be considered in regard to future directions for further developing and evaluating MEVU e.g., Rasch analysis. There are however three limitations that may have broad implications for the findings and solutions contributed by this program of research.

Firstly, consensus on the definition of visual ability was not sought from key stakeholders. Whilst stakeholders were consulted and the definition did evolve throughout the program of research, key stakeholders (i.e., parents of children with cerebral palsy and professionals) were not presented with the researcher interpretation of results, and consensus on 'what is visual ability' and 'how can visual ability be assessed' were not sought. Consensus could have been sought through Delphi survey methodology (i.e. Hagen et al., 2008), and may have resulted in a different definition of visual ability and different items and/or response options.

Secondly, there are limitations to the sample of parents of children with cerebral palsy who contributed to Studies 3, 4 and 5. The final product, MEVU, is a measure of 'early' vision use, yet there were low numbers of parents of very young children (less than two years) and those with severe vision impairment. It is possible that the definition of visual ability and/or how visual ability is assessed using MEVU would have been developed and evaluated differently with further input from these sections of the target population.

Thirdly, there was only low levels of consumer (public and patient) involvement as part of the research team. Whilst parents of children with cerebral palsy were involved in the development of a new measurement tool through their participation in the development phase, involvement from the research design phase may have led to different decisions about methods of recruitment, data collection and interpretation of findings. Despite these three limitations, this program of research has used a strong multi-phase mixed methods instrument design to conceptualise, develop and evaluate a new measurement tool.

9.4 IMPLICATIONS AND RECOMMENDATIONS

The program of research presented in this thesis provides the 'initial' steps toward answering the question "Can we improve outcomes for children, and their families, by focusing on ‘how vision is used’ in everyday activities?”. This section discusses the significance and implications of the findings from this research before summarising key areas for future research.

9.4.1 Understanding ‘visual ability’

A prerequisite to the development of a measure for visual ability was the need to clearly define the construct of *visual ability*. This research outcome is just as important as the development of MEVU, and the knowledge created by this research on ‘What is visual ability?’ is likely to have significant implications. We now know that key stakeholders in the field of cerebral palsy practice and research, including parents of children with cerebral palsy and adults with cerebral palsy, consider visual ability an important construct. Understanding of this construct, if followed by actions to utilise this knowledge, may lead us to optimise outcomes for some children with cerebral palsy and their families.

By defining visual ability, this research has taken steps towards a new practice approach within early intervention practice that may optimise outcomes for children with cerebral palsy and their families. ‘How vision is used’ in everyday activities, interactions and environments is an Activity level construct that supports Activity level assessment and intervention. Findings from this research suggest that this type of ‘vision’ is understandable to families and the professionals who work with these families, and it aligns with current early intervention practices. In addition to defining visual ability, this research has also defined visual behaviours that reflect a child’s visual ability. Whilst not new, these visual abilities may be important for identifying specific skills for practice and repetition within visual training interventions based on the principles of neuroplasticity

Activity-level use of vision is also relevant to the practice areas of many professionals who work with children and their families i.e., occupational therapists, physiotherapists, and speech pathologists. Knowledge translation efforts will be required to encourage the uptake of this construct as a different, yet complementary, approach to understanding vision in children with cerebral palsy. The use of terminology from the ICF framework that has been endorsed worldwide and is familiar within the field of cerebral palsy, is likely to be helpful in these next steps.

9.4.2 MEVU's potential for use as an assessment in clinical and research practice

Taken in combination, the findings from the multiple studies within this PhD research suggest that MEVU has good potential for use, and that further research is warranted to assess its quality as a measurement tool (Mokkink et al., 2017). Whilst a strength of this research is the rigorous conceptualisation and design phases, and the sufficient evidence of content validity (considered the most important measurement property), there is not yet sufficient high-quality evidence for MEVU's internal consistency. Without acceptable validity and reliability for children with cerebral palsy, MEVU is not an evidence-based assessment that should be used to inform clinical decisions (O'Connor et al., 2016). Until further research has been undertaken MEVU cannot be recommended for use in clinical or research practice, as results obtained using the measurement scale may not be reliable and scores may lack interpretability (Polit & Yang, 2016). Rules to interpret scores are needed. There is preliminary evidence that MEVU may be useful for discriminative purposes, and no evidence thus far for predictive or evaluative purposes. MEVU is also currently unavailable in languages other than English and because initial validation was mostly undertaken with educated parents, its usefulness with parents lacking English literacy may also be limited.

At present MEVU may best be referred to as a 'tool' rather than a 'measure' as it provides a standardised set of questions and response options for describing how vision is used. There should not be a focus on the total raw score obtained by a child on MEVU, until further evidence about interpretability is obtained. Information gathered using the MEVU questions should be considered in conjunction with findings from clinical assessment of visual functions and clinical observations of how vision is used. Used together with information gathered on a child's best capacity to use vision, MEVU may play an important role in identifying areas for intervention (e.g., environmental modifications) that aim to reduce the gap between capacity and performance.

Within research, MEVU has potential future use as a measurement tool to describe the baseline visual abilities of included and excluded participants within intervention studies. This is important because the presence or absence of visual skills can impact on a child's ability to be assessed in a standardised and valid way using a study's outcome measures and to complete some interventions per the study protocol or with appropriate supports in place. It is therefore recommended that researchers should clearly describe the visual abilities of children within their studies so that the external validity of studies can be appropriately interpreted (Deramore Denver, 2019). As an online parent-completed questionnaire MEVU may not be a burdensome addition to the repertoire of measurement tools commonly used in intervention studies. In addition, MEVU may have some benefits over clinical assessments that require active participation from the child, as young children can become tired and unsettled resulting in missing data (e.g. Finlayson et al., 2020).

Pending evidence of its validity as a responsive measure, MEVU may also have future use as an outcome measure within intervention research that aims to improve the ability to use vision. The review of existing research as a background to this project suggested that vision is important to improvements in other developmental and functional areas, however it is rarely the focus of research. There will need to be a knowledge translation plan to share information with parents, clinicians and researchers on the availability and importance of visual ability as an outcome, in and of itself, before MEVU is likely to be sought for use as an outcome measure.

9.4.3 MEVU's potential for use in early intervention

Knowledge on 'what is visual ability' combined with MEVU's approach for describing visual ability may provide a new opportunity for starting intervention in the crucial early years. Visual behaviours are some of the earliest skills a child can demonstrate independently: purposeful use of vision typically precedes voluntary movement in infants. MEVU, and its description of visual behaviours, therefore, has potential for highlighting active ingredients for very early intervention. An increased understanding of a child's visual skills may be useful for goal setting and identifying opportunities for practice of visual behaviours within everyday activities, interactions and environments. The visual behaviours that are the MEVU items may help with the development and wording of goals for the purpose of evaluating a child's change following early intervention in the absence of MEVU's current ability to be used as an outcome measure (e.g., Goal Attainment Scaling) (Kiresuk & Sherman, 1968). In the future, following further research on the structural validity of MEVU, an item hierarchy of visual behaviours may assist with clinical decisions about the focus of intervention.

In addition to MEVU's potential for use in early intervention focused on optimising a child's ability to use vision, a greater understanding of visual ability may lead to further insights into which intervention approaches and strategies work best for which children. For example, it may be that only children with a MEVU score of "x" or above are found to benefit from a particular intervention for hand skills. In general, a greater understanding of visual abilities will enable clinicians and researchers to better tailor supports to families of children with cerebral palsy. For example, knowledge about a child's visual abilities will be useful within coaching and education sessions with parents and caregivers, and in choosing types of cues and prompts for strategies within interventions.

9.4.4 Future research directions

This body of research makes a significant and original contribution to the understanding of vision use in children with cerebral palsy with the major outcome of a new assessment tool – MEVU. MEVU provides a means to measure vision use, and with further development has the potential to inform the development of interventions; however, this research is only the beginning. As the title of this thesis suggests, the research undertaken within this PhD program of research includes only the 'initial' stages of validation of MEVU. Most of the clinical questions behind this research remain only partially answered or unanswered. Whilst MEVU has potential to answer "How does this child use their vision", we still do not know whether "use of vision" will improve or "what can be done to improve vision use". We can, however, say that it is "important to consider vision use". Whilst future research directions are likely to be broad, this section summarises key areas requiring the most urgent focus including the areas for future evaluation of MEVU properties illustrated in Figure 9.2.

The next steps for the further development of MEVU include further testing of the structural validity of MEVU. Evaluation of the structure using Item Response Theory and/or Confirmatory Factor Analysis is required before MEVU can be recommended for use in practice (Mokkink et al., 2017). Evaluation with Rasch analysis (a type of Item Response Theory analysis) may enable the establishment of sufficient evidence of MEVU's structural validity and internal consistency. Successful testing of MEVU's ability to meet the assumptions for the Rasch Model would result in confirmation of unidimensional and interval-scaled data (Bond & Fox, 2015). Rasch analysis also results in an item-and-person-map that would be very useful for interpretation, realistic goal setting and future intervention planning. This may also lead to re-ordering of the items within MEVU. As hypothesised in the conceptualisation phase of this research, it is expected that a hierarchical ordering exists among the visual ability items in MEVU. Interval level scoring would enable interpretability of total scores and change scores. The Gross Motor Function Measure and Assisting Hand Assessment are examples of assessment tools for children with cerebral palsy that have undergone Rasch analysis and subsequently clinical practice and families have benefited from the ordering of items to guide goal setting and decision making (Avery et al., 2003; Hoare et al., 2010; Krumlinde-Sundholm & Eliasson, 2003). Rasch analysis can be done with the minimum, and currently available sample size of 100 participants (Bond & Fox, 2015); additional recruitment of parents of children with cerebral palsy, including more parents of children aged less than 2-years and those of children with severe vision impairment, before undertaking further analyses is planned.

Whilst this research has focused on content and construct validity, understanding MEVU's inter-rater and test-retest reliability are important next steps. This testing will include inter-reliability between parents and will help establish whether the 'observability' of the visual behaviours in MEVU are dependent on the judgments made by the individual who is observing (i.e., assessment of the quality of their observational abilities and familiarity with the child). In the future it may also be relevant to evaluate inter-rater reliability between parents and health or educational professionals, however in the short term MEVU has been established as parent-rated questionnaire. Although cognitive interviewing with parents of children with cerebral palsy addressed the comprehensibility of MEVU in the development phase (Deramore Denver et al., 2021a), it is anticipated that future work may need to refine and simplify the wording and language used in the instructions, items and response options of MEVU to optimise reliability. Readability has not been assessed beyond cognitive interviews with nine parents.

Construct validation will be an ongoing process, and a natural next step will be correlation of MEVU with the newly developed VFCS. With more technology for recording and eye-tracking technology there may also be future opportunities to develop or expand this research to a naturalistic observational assessment using the visual behaviours identified in this study. It will be important to examine the validity of MEVU against visual function clinical assessments (e.g., visual acuity). Future studies could also explore relationships with, and differences between, MEVU and other constructs such as how well a child performs an activity, their level of participation/engagement in vision-related activities, and the factors that contribute to, or explain, the level of visual ability. In the longer term, the organisational framework presented in Chapter 7 may be tested more formally using structural equation modelling (Kline, 2010). Such testing may provide empirical evidence on factors that contribute to visual ability and lead to refinement of MEVU's target population and the interpretation of scores.

MEVU is a criterion-referenced assessment, however further research is warranted to develop normative data on MEVU and to explore the influence of age and/or time on the development of visual abilities. This requires testing MEVU within a population of typically developing children and within longitudinal study designs. Findings from that research would help inform decisions about the minimum and maximum age range for use of MEVU, facilitate the answering of prognostic questions related to improvement in vision use over time, and help families and clinicians to make informed decisions. Research with typically developing children is already underway as an extension of this PhD and the first phase of data collection undertaken as an occupational therapy honours research project was presented at AusACPDM 2020 in Perth, Australia.

Future research is also needed to establish effective interventions to optimise visual abilities in children with cerebral palsy. The background literature review, systematic review of measurement tools, and ongoing review of new research all indicate that the limited availability of vision-related interventions is a problem (Deramore Denver et al., 2016). The perspectives provided by stakeholders in the online survey further suggest there is lack of interventions available (Deramore Denver et al., 2021a). The online survey however did seek perspectives on visual behaviours that change, and their inclusion into MEVU items and response options may enable MEVU to play an important role in future intervention research as dependent variables. Combined with findings on the connections between visual ability and related constructs from the perspectives of key stakeholders (Study 4), we now have more insight into active ingredients that may improve how vision is used that can be used in intervention effectiveness research. Within intervention research MEVU may be useful for describing baseline abilities, for identifying visual behaviours to target in interventions, and/or for measuring change. The establishment of psychometric properties important for evaluative tools (test-retest reliability, measurement error and responsiveness) remains a pre-requisite to MEVU use for this purpose. Whilst a discussion of what an intervention to promote visual abilities in children with cerebral palsy might look like is beyond the scope of this PhD, it is likely that elements of early intervention programs known to be effective for other developmental domains are likely to be important e.g., active involvement of the child, goal directed, repetition and parent engagement.

It is anticipated that MEVU may be translated into languages other than English, requiring validation of MEVU in those languages and contexts of use. MEVU may also be relevant for use in other populations (e.g., children with vision impairment, Down syndrome, Rett syndrome), and will require validation with each new population before use. Research seeking an answer to questions about the content validity and potential for use with children with vision impairment (ocular or cortical/cerebral) is in progress. Once MEVU is being used in clinical applications, research questions about the clinical utility of the tool can also be explored. Within this research MEVU was completed independently by parents via an advertised online questionnaire, but future research may explore alternatives such as completion via interview with a health professional, who in a child's team will initiate use of MEVU, and what happens after a child has a MEVU 'score'. Although content validity related to the development of MEVU was a key focus within this research, future research should also pursue a second study of MEVU's content validity. That study should focus on optimising MEVU's comprehensibility. Dependent on findings, a second study could enable MEVU to be rated as having high-quality evidence of content validity. This is important as current recommendations for a measurement tool to be selected within a core outcome set state that the tool should have at least high-quality evidence of good content validity (Prinsen et al., 2016).

These recommendations for future research, some of which are in progress, will strengthen the psychometric properties of MEVU and expand its clinical and research applications. Strategies for the dissemination of the new knowledge created by this thesis PhD are being implemented. This includes the development of a website (https://measureofearlyvisionuse.com/) and a MEVU logo (see Figure 9.3) as a method to support communication about the tool. The focus of knowledge translation work must be sequenced in time with emerging evidence of the properties and utility of the tool.

Figure 9.3

Logo for the Measure of Early Vision Use

9.5 OVERALL THESIS CONCLUSIONS

The research documented in this thesis began with 'wondering' about the approach to addressing the visual abilities of children with cerebral palsy and how outcomes might be limited by current assessment and intervention practices. The new knowledge contributed by this program of research comes from five studies that together form a multi-phase mixed methods instrument design project. The outcomes are a definition of visual ability and a new assessment tool for the field of cerebral palsy research and clinical practice – the *Measure of Early Vision Use*. Whilst this research contributes an answer to the measurement problem about describing how vision is used, many questions remain. Building on the strong conceptual work undertaken in this research, the next steps include further psychometric evaluation of this new measure, and exploration into how to provide the most effective interventions that optimise children's ability to use vision.

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Appendices

Appendix A Statement of author contributions

This appendix acknowledges the contributions made by each of the listed co-authors on the four publications included in this thesis.

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2021a). Measure of Early Vision Use: Development of a new assessment tool for children with cerebral palsy. *Disability and Rehabilitation*, 1-11. https://doi.org/10.1080/09638288.2021.1890241

Author	Roles	Contribution
Belinda Deramore Denver	• Concept and design of the research and study methods • Construction of the Measure of Early Vision Use • Recruitment, data collection and management, data analysis and interpretation of findings • Planning, writing and submission of manuscript for publication • Corresponding author for communication	85%
Associate Professor Elspeth Froude	• Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings • Review and editing of manuscript	5%
Professor Peter Rosenbaum	• Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings • Review and editing of manuscript	5%
Professor Christine Imms	• Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings • Review and editing of manuscript	5%

Deramore Denver, B., Froude, E., Rosenbaum, P., & Imms, C. (2021b). Measure of early vision use: Initial validation with parents of children with cerebral palsy. *Disability and Rehabilitation*, 1-9. https://doi.org/10.1080/09638288.2021.

Author	Roles	Contribution
Belinda Deramore Denver	• Concept and design of the research and study methods • Recruitment, data collection and management, data analysis and interpretation of findings • Planning, writing and submission of manuscript for publication Corresponding author for communication	85%
Associate Professor Elspeth Froude	• Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings • Review and editing of manuscript	5%
Professor Peter Rosenbaum	• Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings • Review and editing of manuscript	5%
Professor Christine Imms	• Supervision related to concept and design of the research and study methods, data analysis and interpretation of findings • Review and editing of manuscript	5%

Deramore Denver, B., Adolfsson, M., Froude, E., Rosenbaum, P. & Imms, C. (2017). Methods for conceptualising 'visual ability' as a measurable construct in children with cerebral palsy. *BMC Medical Research Methodology, 17,* 46. https://doi.org/10.1186/s12874-017-0316-6

Author	Roles	Contribution
Belinda Deramore Denver	• Concept and design of the research and study methods • Development of study specific guidelines for linking & linking measurement tools to ICF-CY • Planning, writing and submission of manuscript for publication • Corresponding author for communication	70%
Associate Professor Margareta Adolfsson	• Assistance with development of study specific guidelines for linking & linking measurement tools to ICF-CY • Review and editing of manuscript	10%
Associate Professor Elspeth Froude	• Critical appraisal of content and discussion consistent with supervisory process • Review and editing of manuscript	5%
Professor Peter Rosenbaum	• Critical appraisal of content and discussion consistent with supervisory process • Review and editing of manuscript	5%
Professor Christine Imms	• Linking measurement tools to ICF-CY • Critical appraisal of content and discussion consistent with supervisory process • Review and editing of manuscript	10%

Deramore Denver, B., Froude, E., Rosenbaum, P., Wilkes-Gillan, S., & Imms, C. (2016). Measurement of visual ability in children with cerebral palsy: A systematic review. *Developmental Medicine and Child Neurology, 58,*1016-1029. https://doi.org/10.1111/dmcn.14090

Author	Roles	Contribution
Belinda Deramore Denver	• Development of systematic review protocol • Database and literature searches • Study selection, quality assessment, data extraction and analysis • Critical appraisal and discussion with supervision team • Planning, writing and submission of manuscript for publication • Corresponding author for communication	70%
Associate Professor Elspeth Froude	• Development of systematic review protocol • Study selection • Critical appraisal of content and discussion consistent with supervisory process • Review and editing of manuscript	10%
Professor Peter Rosenbaum	• Critical appraisal of content and discussion consistent with supervisory process • Review and editing of manuscript	5%
Dr Sarah Wilkes-Gillan	• Quality assessment of measurement tools • Review of manuscript	5%
Professor Christine Imms	• Development of systematic review protocol • Critical appraisal of content and discussion consistent with supervisory process • Review and editing of manuscript	10%

We declare that our contributions to each of the four published manuscripts, as outlined above, to be accurate and true.

PhD Candidate: Belinda Deramore Denver	Signature [redacted] Date 2/11/21

Co-Author & Primary Supervisor: Associate Professor Elspeth Froude	Signature [redacted] Date 10/11/21
Co-Author & Co-Supervisor: Professor Christine Imms	Signature [redacted] Date 9 November 2021
Co-Author & Associate Supervisor: Professor Peter Rosenbaum	Signature [redacted] Date November 9, 2021
Co-Author: Dr Sarah Wilkes-Gillan	Signature [redacted] Date 08/11/21

Co-Author: Dr Margareta Adolfsson	Signature [redacted] Date 3 Nov 2021

Appendix B Invited Commentary

This appendix contains a copy of the commentary published during the thesis candidature and a copy of permission from the publisher for its inclusion in the thesis.

> Deramore Denver, B. (2019). The validity of early intervention for children with visual impairment. *Developmental Medicine & Child Neurology*, *61*(6), 627-627. https://doi.org/10.1111/dmcn.14090

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Appendix C Supporting information for Study 1

This appendix contains:

- Published pdf version of the manuscript:

  Deramore Denver, B., Froude, E., Rosenbaum, P., Wilkes-Gillan, S., & Imms, C. (2016). Measurement of visual ability in children with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology, 58*(10), 1016-1029. https://doi.org/10.1111/dmcn.13139

- Permission from the publisher for inclusion of the pdf in this thesis

- Online appendices from published manuscript:

  - An example of the search strategy used in MEDLINE and modified for other databases

  - A list of the studies using the measures

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MEDLINE:

1. Classification/
2. Symptom Assessment/
3. classif*.ti,ab
4. measure*.ti,ab
5. instrument.ti,ab
6. assess*.ti,ab
7. tool*.ti,ab
8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9. exp brain damage, chronic/or cerebral palsy/ or exp brain injuries/ or *encephalomalacia/ or *leukomalacia, periventricular/ or *hypoxia, brain/ or *hypoxia-ischaemia, brain/ or *movement disorders/ or exp dyskinesias/ or exp dystonic disorders/
10. *hemiplegia/ or *quadriplegia/
11. dystoni*.ti,ab
12. spastic*.ti,ab
13. diplegi*.ti,ab
14. quadriplegi*.ti,ab
15. brain injur*.ti,ab
16. CP.ti,ab
17. neurologic*.ti,ab
18. dyskine*.ti,ab
19. atheto*.ti,ab
20. cerebral pals*.ti,ab
21. hemipleg*.ti,ab
22. 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21
23. exp Vision, Ocular/
24. exp Vision Disorders/
25. vision.ti,ab
26. visual.ti,ab
27. blindness.ti,ab
28. CVI.ti,ab
29. gaze.ti,ab
30. 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29
31. 8 AND 22 AND 30
32. limit 31 to humans
33. limit 32 to “all infant (birth to 23 months)” or “all child (0 to 18 years)” or “newborn infant (birth to 1 month)” or “infant (1 to 23 months)” or “preschool child (2 to 5 years)” or “child (6 o 12 years)” or “adolescent (13 to 18 years)”

21 full text papers meeting inclusion criteria

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Appendix D Summary of COSMIN's steps for evaluating a measurement tool

The methodological quality of Study 3 and 5 has been assessed by the PhD candidate using the COSMIN Risk of Bias Checklist (Mokkink et al., 2017). The checklist contains nine measurement properties (content validity, structural validity, internal consistency, cross-cultural validity, reliability, measurement error, criterion validity, hypotheses testing for construct validity and responsiveness). The checklist also contains a section on development of the measurement tool; development is not a measurement property, but it is considered when evaluating content validity (Mokkink et al., 2017; Terwee et al., 2018). The checklist is available via the COSMIN website: https://cosmin.nl/wp-content/uploads/COSMIN_risk-of-bias-checklist_dec-2017.pdf

Each measurement property was rated using a four-point rating system: "very good", "adequate", "doubtful" and "inadequate". Then, the overall score for each measurement property evaluated was determined by considering the lowest rating obtained in the checklist criteria for that property. Finally, the overall score was used to rate the quality of evidence of sufficient (+), insufficient (-) or indeterminate (?).

This assessment was then combined with an overall quality of evidence assessment using a modified version of the Grading of Recommendations Assessment, Development and Evaluate (GRADE) system with four criteria: (i) risk of bias (i.e., the methodological quality of studies); (ii) inconsistency (i.e., unexplained inconsistency of results across studies); (iii) imprecision (i.e., total sample size of the available studies), and (iv) indirectness (i.e., evidence from different populations than the population of interest).

Finally, one of three categories of recommendation is proposed according to the adequacy and quality of evidence. A measurement tool is placed in:

- Category A if there is sufficient content validity (any level) and at least low-quality evidence for sufficient internal consistency.
- Category C if there is high-quality evidence for an insufficient measurement property.
- Category B if the measure can be placed in neither Category A or C.

Only measures in category A can be recommended for use, with results seen as trustworthy. Measures in category B need further validation; however they can be recommended for use. Measures in category C should not be recommended for use.

Appendix E Examples of early versions of the items and response options

VISUALLY FOLLOWS

Definition from Study 2: *"This theme, and the observable behaviour, concerns* ***whether and how effectively the child follows or tracks moving targets****. It was derived from items also contributing to other themes, including the types of stimuli that are followed, the distances at which following occurs, and how often a child demonstrates following behaviours. The abilities that are unique to this theme are the direction and extent (e.g., how far) of following behaviours, and the quality of the following with eyes and/or head."* (Deramore Denver, Adolfsson, Froude, Rosenbaum, & Imms, 2017).

After confirming that 'follows' is a meaningful and clinically important item to include in an assessment of visual abilities, I have reviewed the open-ended responses from parents of children with CP, adults with CP, and professionals to identify variations of ability. Variations were reviewed for scaling ideas – differences in the ability to 'follow'. Initially these aligned with three groups: good abilities, some ability/limitations and no ability. The 'some limitations' group was then reviewed further, and split into two groups based on whether the visual ability is used within daily performance, or whether there is just some capacity that may be used in a few specific contexts.

From Study 3 'open responses':

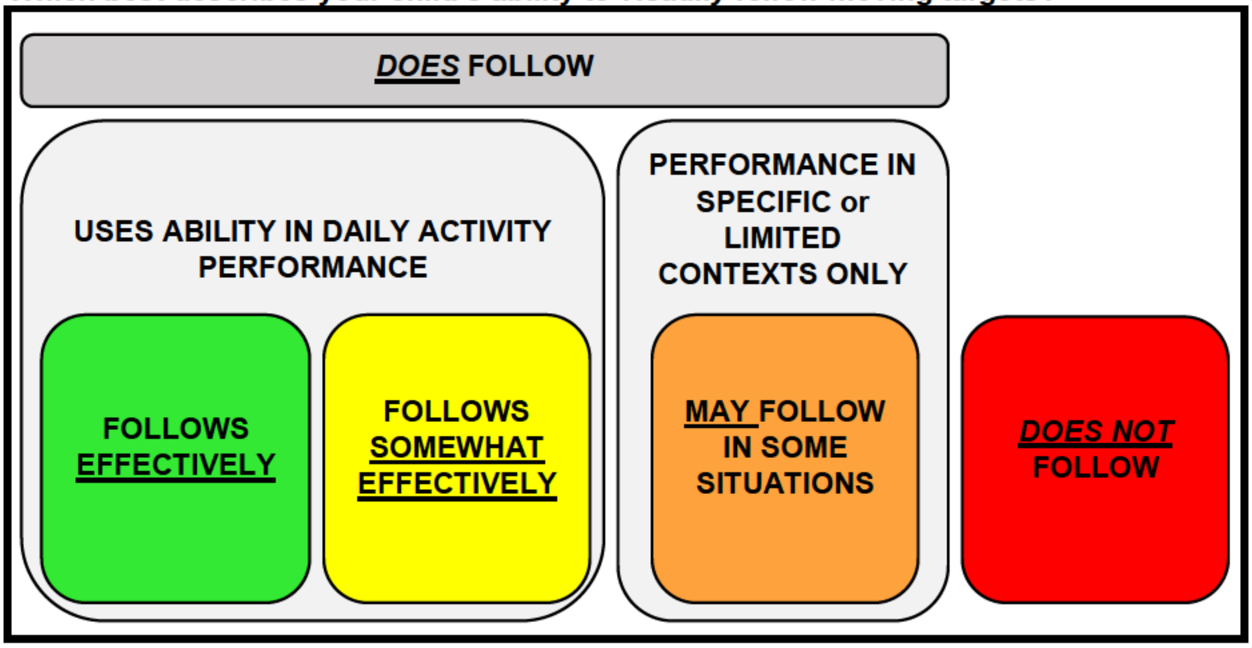
Internal/child factors that contribute to limited 'following' abilities:

Parents/Adults	Professionals
- Distance vision - Poor head control - Fatigue, energy levels - Involuntary movements - Distractibility, attention	- Jerky eye movements - Nystagmus - Fatigue - Motivation, salience of target - Visual acuity - CVI - Hemianopia – visual field deficit - fluid tracking relying on coordination between eye and head/neck movement

Examples of situations/contexts where following/tracking moving targets is commonly observed:

- Objects/toys that move, balls (rolling or thrown), toy car/vehicle (pushed or switch adapted/motorised), traffic moving cars
- Objects that are moved by another person e.g. toy/torch moved across visual field
- Face when moved side to side, people moving around a room
- Reading
- On a screen, computer games/Apps
- Pets moving around e.g. dog or cat

Which best describes your child's ability to *visually follow* moving targets?



4 Effective ability

- ☐ Child follows moving targets within daily activity performance e.g. follows parents moving around the room, or a ball that rolls away.
- ☐ The ability to follow is effective when targets moving in any direction can be followed, and the quality of eye and head/neck movements does not impact on performance e.g. smooth, fluid and unbroken.
- ☐ There are no limitations in the type of moving targets that can be followed e.g. a target does not have to be moving slowly in order to be followed.

3 Somewhat effective ability

- ☐ Child follows moving targets within most daily activities, however there are often limitations to their performance.
- ☐ Limitations may include the distance or direction of following (e.g., past 1 metre, right visual field, lower visual field, a segment of the target arc/trajectory); type of stimuli (e.g., motivating toys, food); and the quality of the following with eyes and head (e.g., slight delay/lag in eye or head movement behind the moving target, uncoordinated or jerky eye or head movements that impact the fluidity of ability to follow), or cannot follow visual targets that move quickly.

2 Limited ability

- ☐ Child does not typically use their visual abilities to follow a moving target, however they may ?be seen to follow in a few situations, e.g., controlled environment with minimal visual clutter and/or a specific/preferred visual stimulus.
- ☐ Or, the child is very restricted by limitations in ability to follow (see above – 3).

1 Does not do

- ☐ Child does not follow moving targets.
- ☐ A child who does not follow a moving target may not have the ability to see that the target has moved (in a timely manner, or at all). A child who does not follow moving targets visually may still effectively perform in activities by using compensatory abilities such as searching, finding and shifting vision, or through the use of other senses e.g., following the sound.

Direct quotes

Parents:	Professionals: child who follows moving targets fixation is maintained as the target moves. .. smooth .. eye movements, can smoothly fix and follow a target in all directions
He's generally OK, until it reaches the limit of his vision (1 meter or so) he is often a few seconds behind a moving object. Will sometimes track familiar objects side to side, but will not track if it moves to his lower field of vision.	the child follow for a short arc the target's movements consistently lagging behind the moving target cannot follow this object unless it moves slowly fluid tracking relying on coordination between eye and head/neck movement is missing.
He only sometimes follows, and only mom or dad I do not see him follow objects with his eyes very often. He still prefers to inform his experience with hearing and a mere glance at an object. Again he tries but loses the object and needs to look for it again	follow targets with multi-sensory input only if it has also sonorous findings
did not notice or visually follow the ball	child who just looks at only what is in front of them respond .. to moving target but have difficulty fixing and following

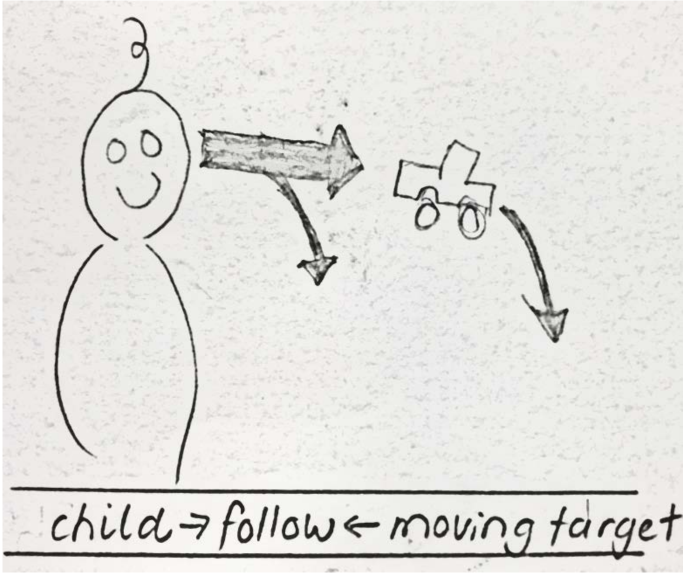
Summary of open-ended answers:

		Good ability	Some ability/limitations	No ability
Parents	*Direction/extent of following behaviours*		- Within field of vision – distance and direction (e.g. not beyond 1 meter or in left/right field of view, or in lower visual field). - Follows for a very short distance	
	Quality of the following with head/eyes		- Few seconds behind a moving object…head moves 2-3 secs later - Limited by head control - Takes concentration [effortful] - Energy levels - Short attention span - *[mobility of eyes/head or processing of information impacts ability to follow]*	- Does not follow because does not notice target moving - Target is lost once it moves – child needs to look for it again [requires searching/finding]
	Types of stimuli		- Needs audio/visual combination	
	How often		- Sometimes - Rarely done – prefers to inform experience with hearing and a quick glance at an object	
Profs	*Direction/extent of following behaviours*	- Able to follow in all directions.	- Close to eyes [not at distance] - Influenced by visual accessibility/complexity - Within intact visual field - For short arc of targets movement	- Child looks at what is in front of them [stationary target] but does not follow a moving target - No following

	Quality of the following with head/eyes	☐ Smooth/fluid/constant (unbroken) eye and head/neck movements used.	☐ Delayed, consistently lagging behind the moving target ☐ Need to move head in addition to eyes ☐ Larger movements, smooth ☐ Fluidity missing – eye and head movements not coordinated ☐ Jerky eye movements ☐ Can follow objects moving at slower or faster pace, but not both ☐ Not fast moving targets ☐ Cannot follow unless moves slowly	
	Types of stimuli	☐ No limitations in type of moving targets followed. Includes fast moving targets.	☐ Performance improves with auditory info, motivating/salient targets	☐ May respond/react to/attend to a moving target but unable to attend/fix on moving target to follow it. ☐ Only if sonorous
	How often			

FOLLOWS: How much does your child visually follow moving targets?

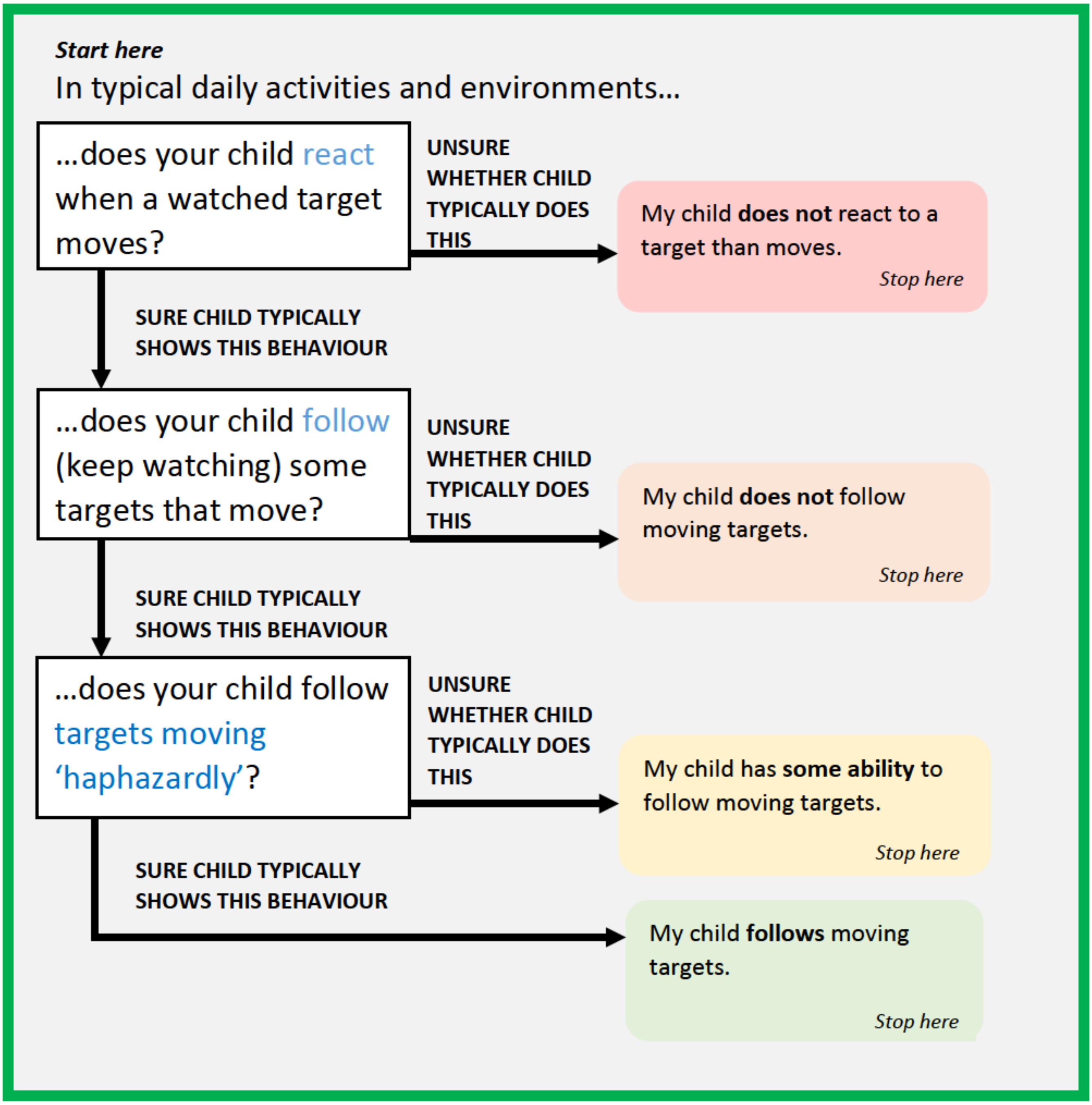
What this item is about?
This item refers to *whether* and *how much*



Daily activities and environments that provide opportunities for following moving targets include:

- Watching or playing with toys that roll e.g. balls, toy cars
- Watching people or pets move around the environment
-

Reacts/Visual interest	Children may react to visual information in different ways, depending on their motor capacity and developmental level. Some examples of observable behaviours that suggest a child is reacting, at some level, to visual information are: • Active behaviors e.g. reaching, pointing, making noise or talking about seen information; Extra body movements e.g. kicking legs or uncontrolled movements; Looking/glances towards or turning away from visual information • Subtle behaviours such as a change in rate of breathing, or becoming 'still' (ceasing movement), blinking, pupil responses Passive looking or staring behaviours may or may not reflect a reaction or interest in visual information.
Follows	The ability to keep visual attention on a target as it moves.
Targets moving 'haphazardly'	Different directions, speeds, and distances Not just a toy rolling slowly across the table in front of them.


Start here
In typical daily activities and environments…
…does your child react when a watched target moves?
UNSURE WHETHER CHILD TYPICALLY DOES THIS
My child **does not** react to a target than moves.
Stop here
SURE CHILD TYPICALLY SHOWS THIS BEHAVIOUR
…does your child follow (keep watching) some targets that move?
UNSURE WHETHER CHILD TYPICALLY DOES THIS
My child **does not** follow moving targets.
Stop here
SURE CHILD TYPICALLY SHOWS THIS BEHAVIOUR
…does your child follow targets moving ‘haphazardly’?
UNSURE WHETHER CHILD TYPICALLY DOES THIS
My child has **some ability** to follow moving targets.
Stop here
SURE CHILD TYPICALLY SHOWS THIS BEHAVIOUR
My child **follows** moving targets.
Stop here

Appendix F Measure of Early Vision Use (MEVU)

The Measure of Early Vision Use (MEVU) has been designed as an online questionnaire. MEVU [redacted] was presented to parents on one webpage in the following format:

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Appendix G Supporting information for Study 2

This appendix contains:

- Published pdf version of the manuscript:

  Deramore Denver, B., Adolfsson, M., Froude, E., Rosenbaum, P., & Imms, C. (2017). Methods for conceptualising ‘visual ability’ as a measurable construct in children with cerebral palsy. *BMC Medical Research Methodology, 17*(46), 1-13. https://doi.org/10.1186/s12874-017-0316-6

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- Two additional files published online with this manuscript:

  - Study specific guidelines: ICF-CY Linking rules and challenges
  - Body Function and Environmental factor ICF-CY codes identified in assessment tools

Deramore Denver et al. BMC Medical Research Methodology (2017) 17:46
DOI 10.1186/s12874 017 0316 6

BMC Medical Research Methodology

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Methods for conceptualising 'visual ability' as a measurable construct in children with cerebral palsy

Belinda Deramore Denver[1*], Margareta Adolfsson[2], Elspeth Froude[1], Peter Rosenbaum[3] and Christine Imms[4]

Abstract

Background: Vision influences functioning and disability of children with cerebral palsy, so there is a growing need for psychometrically robust tools to advance assessment of children's vision abilities in clinical practice and research. Vision is a complex construct, and in the absence of clarity about this construct it is challenging to know whether valid, reliable measures exist. This study reports a method for conceptualising 'visual ability' as a measurable construct.

Methods: Using the items from 19 assessment tools previously identified in a systematic review, this study used a two phase process: first, deductive content analysis linked items to the International Classification of Functioning, Disability and Health Child and Youth version (ICF CY), and second, vision specific 'Activity' level items were explored using inductive thematic analysis.

Results: The linking and content analysis identified that existing assessment tools are measuring vision across the ICF CY domains of Body Functions, Activities and Participation, and Environmental and Personal Factors. Items specifically coded to vision at the Activity level were defined as measuring 'how vision is used', and these items form the basis of the conceptualisation that 'visual ability' is measurable as a single construct.
The thematic analysis led to the identification of 3 categories containing 13 themes that reflect a child's observable visual behaviours. Seven abilities reflect how a child uses vision: responds or reacts, initiates, maintains or sustains looking, changes or shifts looking, searches, locates or finds, and follows. Four interactions reflect the contexts in which a child uses their vision to purposefully interact: watches and visually interacts with people and faces, objects, over distance, and with hands. Finally, two themes reflect a child's overall use of vision in daily activities: frequency of use, and efficiency of use.

Conclusions: This study demonstrates an approach to exploring and explaining a complex topic utilising World Health Organization language and building on existing research. Despite the complexity of vision, the concept of 'how vision is used' can be clearly defined as a measurable construct at the Activity level of the ICF CY. This study has identified observable visual behaviours that may be developed into items assessing how vision is used in daily activities.

Background

Vision is an important construct to measure in children with cerebral palsy for both health care research and clinical practice. The primary motor disorder of cerebral palsy may be accompanied by additional impairments including vision [1], and there is growing evidence of the relationship between vision and various aspects of functioning [2–6]. This is not surprising as visual skills play an important role in development for all children, and the absence of, or limitations in, vision are known to impact development and functioning [7]. Children with cerebral palsy may be diagnosed with visual impairment at the ocular (eye) or cerebral/cortical (brain) level. One recent publication reported a prevalence of 'some visual impairment' in 36% of the population, and 'functional blindness' in 6% [6]. Information on the rates of visual impairments (ocular or cerebral) vary greatly in the literature [8]; however, it is likely that vision impacts outcomes for at least some children with cerebral palsy and their families.

* Correspondence: belinda.deramoredenver@myacu.edu.au
[1]Australian Catholic University, School of Allied Health, Level 9, 33 Berry Street, North Sydney, NSW 2060, Australia
Full list of author information is available at the end of the article

Research in this area is expanding, but there are knowledge gaps and complexities to the assessment and management of vision for children with cerebral palsy [9–11]. Although valid and reliable assessment practices are required to evaluate and establish the effectiveness of interventions, there is currently limited clarity on *what* to measure, *how* to measure, *when* to measure and *who* should be measuring vision-related constructs for children with cerebral palsy. In the absence of clarity about the construct to be measured (i.e., the 'what'), it is challenging to answer the question of whether a measure exists to answer clinical and research questions; this in turn can impact clinical and research outcomes [12]. A prerequisite to instrumentation and measurement is to determine what concept(s) is (are) to be measured, and how to translate the concept into measureable phenomena [13]. In this paper the phase of defining and understanding the construct to be measured is referred to as *conceptualisation*.

Vision is a complex construct, and its influence can be considered from multiple perspectives. These include how effectively a child's eyes work, how well the child understands and interprets what they see, and how well vision is used in daily activities. The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (2001) and the Child and Youth version (ICF-CY) (2007) provide a framework that can be used to consider functioning and disability, including vision, from a dynamic bio-psychosocial perspective [14, 15]. This framework (Fig. 1) includes four domains: (1) Body Functions and Structures; (2) Activities and Participation; (3) Personal Factors; and (4) Environmental Factors. The ability of a child to function is the outcome of a dynamic interaction among elements of these domains and contexts [15]. Within the ICF-CY, the concept of vision is represented at the Body Function level (*Seeing functions* and *Perceptual functions*) and the Activity level (*'purposeful use of vision'*). These vision-related concepts interact in a process that is

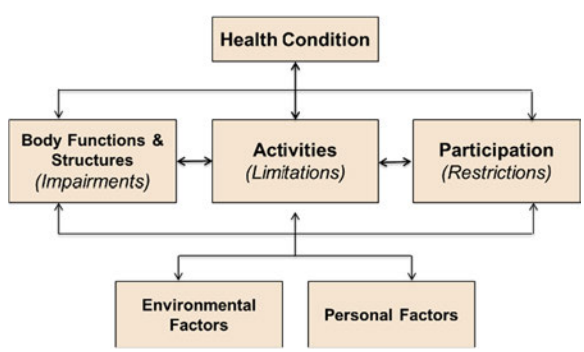

Fig. 1 Framework of Functioning, Disability and Health (ICF and ICF CY) [14, 15]

influenced by other factors including cognitive skills, motor abilities and aspects of the environment, and together they contribute to an individual's overall level or functioning or disability.

Our recent systematic review on the measurement of visual ability in children with cerebral palsy focused on identifying tools assessing "vision that describes a child's functioning at the Activity and Participation domain of the ICF-CY" p. 1018 [10]. This focus was driven by the need for clinicians to provide interventions at the Activity level, and the need for clinicians and researchers to have psychometrically robust methods to measure the effects of interventions. Measurement at the Activity level – that is, of 'visual ability' – is required to eliminate the need to make inferences or assumptions about levels of *functioning* in daily activities from an assessment limited to a Body Function (impairment) level e.g., visual acuity. Inclusion criteria for the systematic review were measures "addressing visual ability when the focus of the vision measurement was at the Activities and Participation domain of the ICF" p. 1019 [10], and the review included any tool designed or described as measuring "functional vision". The systematic review did not identify an existing psychometrically valid and reliable tool that could be used. Findings also suggested that attributes included in existing assessment tools were conceptually varied and may not be limited to the assessment of how vision is used. From the review it was not possible to make a decision as to whether an existing tool could be modified by researchers [12], or whether a new assessment specific to how a child uses their vision in daily activities was required [10]. Thus, the need for an additional conceptual study was identified. The current study expands on the systematic review by analysing the content of identified tools at an item level. Content analysis was beyond the scope and inclusion criteria of the previous systematic review; however, it is critical that a measurement concept be clearly defined and understood before determining what, when and how to measure a phenomenon. The detailed content analysis in this study enables the important step whereby attributes can be identified and established as indicators of how visual ability can be measured [13]. This process supports the overall goal of this research program, namely to identify an approach to the assessment of visual ability or to generate items for the development of a new measure.

The systematic review defined *visual ability* as "how someone performs in vision-related activities" (p. 1019) [10]; the aim of the current study was to explore the ways that existing assessment tools conceptualised this as a construct at the Activity level of the ICF-CY. The specific research questions addressed were: (1) What ICF-CY constructs do items in identified assessment tools measure? (2) How can items that specifically assess vision at the Activity level of the ICF-CY be described in terms of what they measure? (3) What observable behaviours indicate levels of visual ability in assessment tools for children with cerebral palsy?

The study was conducted in two parts. Part I identified the *content* of measures in previously identified tools that assess vision at the Activity level of the ICF-CY. Part II identified and analysed the visual ability *themes* in that content. The goal was to identify assessments, or assessment items, to inform the future development of a valid visual ability assessment. This paper reports on the conceptualisation process used in this instrumentation research.

Method

This two-part qualitative study used both descriptive content and thematic content analysis, and the sequential process is illustrated in Fig. 2. Our earlier systematic review [10] utilised a rigorous process to identify 19 assessment tools containing 266 items that formed the units for analysis in this study. Details of the assessments tools, including purpose, format, psychometric properties and limitations, are described in detail in the systematic review [10]. The 19 assessments are variable in their purpose, including screening for CVI (e.g., [16]), developmental assessment (e.g., [17]), and assessment of daily visual performance (e.g., [18]). All assessments have been developed for, or used with children (0–18 years) with cerebral palsy or a diagnosis suggestive of cerebral palsy. All 19 assessments are included in this study as the focus was to capture the constructs measured by assessment tools, rather than how well visual ability was measured. The type of content and number of items, scales or questions are provided for all assessments in Table 1.

Part I: process of linking visual ability assessments to the ICF-CY

Part I provided a descriptive content analysis of previously identified visual ability assessment items utilising established methodology for the linking of measurement tools to the ICF-CY. The ICF-CY classification contains categories and codes in two sections. The first part refers to functioning and disability and includes Body Functions (b) and Body Structures (s), and Activities and Participation (d). The second part refers to Contextual Factors and includes Environmental Factors (e) and Personal Factors [15]. The classification is an alphanumeric system. The letters b, s, d, and e refer to the category or domain of the classification and are followed by a numeric code that starts with the chapter number (a single digit), followed by the second level (two digits), and the third and fourth levels (one digit each) [15]. An example from the Activities and Participation domain is as follows:

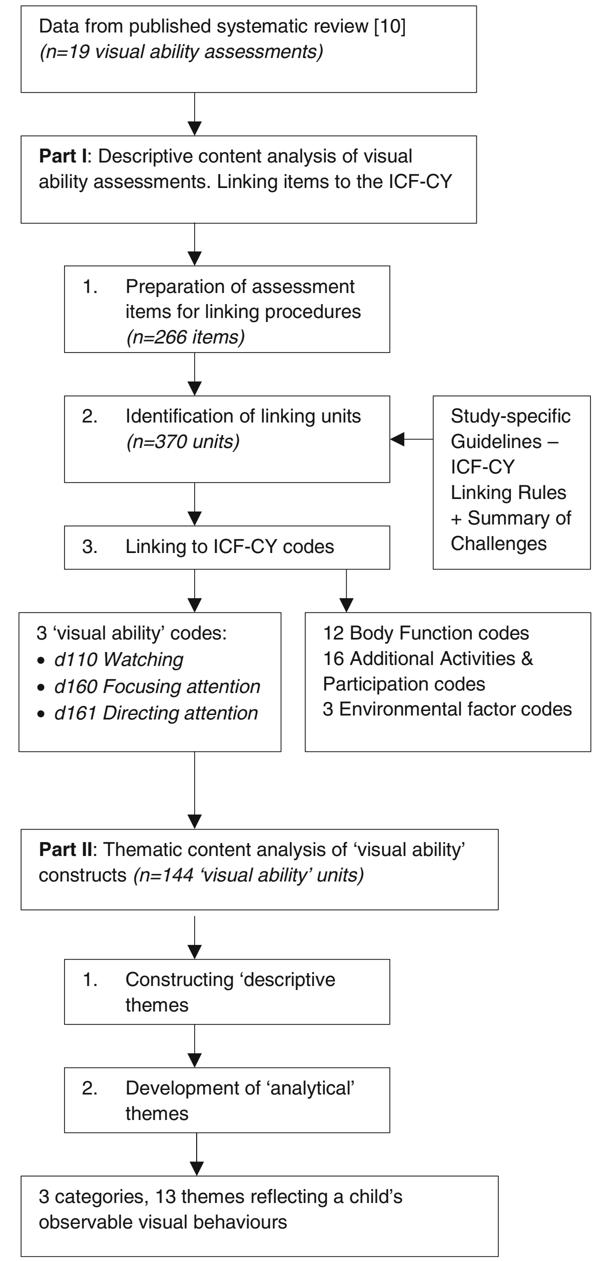

Fig. 2 Flow diagram describing methodological process and results

d1 Learning and applying knowledge (first or chapter level)
d160 Focusing attention (second level)
d1600 Focusing attention on the human touch, face and voice (third level)

Published *ICF Linking Rules* detail the steps for the process of linking measurement tools to the classification system. These rules include two key stages: 1) identification of 'linking units', and 2) linking the units to ICF-CY codes [19–21]. Table 2 summarises published

Table 1 Summary of included visual ability assessment tools

Assessment tool	Ref	Type of content[a]	Items/Scales	Linking units (N)	ICF CY Codes (N)[b]				Visual ability constructs[g] N (%)
					BF/BS[c]	ACT/PART[d]	ENV[e]	Other/Not coded[f]	
ABCDEFV	[35]	Clinical	22 Tests	28	20	8	0	0	6 (21.4)
Alimovic	[42]	Patient oriented	2 Scales	5	0	5	0	0	4 (80)
CAS	[33]	Clinical	33 Visual development items	41	14	26	0	1	18 (43.9)
CVI Q	[16]	Patient oriented	46 Items	56	11	41	0	6	28 (50)
CVI R	[31]	Clinical & Patient oriented	10 Characteristics	12	3	11	0	0	8 (66.7)
			1 Scale	1	0	1	0	0	1 (100)
EDVA	[32]	Clinical	7 Test Items	7	3	4	0	0	4 (57.1)
FVQ	[18]	Patient oriented	26 Questions	34	5	30	0	0	23 (67.6)
Hoyt	[43]	Patient oriented	1 Scale	2	1	1	0	0	1 (50)
HSCS PS	[38]	Patient oriented	1 Vision Sub scale	4	2	1	1	0	1 (25)
HUI III	[44]	Patient oriented	1 Vision Sub scale	5	2	2	1	0	1 (20)
IDP	[45]	Patient oriented	Visual competence 1 Scale	7	5	2	0	0	1 (14.3)
LVC	[30]	Clinical	8 Tests	10	2	8	0	0	4 (40)
PreViAs	[24]	Patient oriented	30 Questions	41	13	27	0	1	12 (29.3)
Short CVI Q	[34]	Patient oriented	12 Questions	15	5	10	0	0	4 (26.7)
SoGS	[17]	Clinical	22 Visual skill Items	25	13	12	0	0	10 (40)
VAP CAP	[37]	Clinical	19 Items	34	22	12	0	0	10 (29.4)
VSI	[36]	Patient oriented	22 Items	35	11	17	3	3	6 (17.1)
Wong	[46]	Patient oriented	1 Scale	2	1	1	0	0	1 (50)
15 D	[47]	Patient oriented	1 Vision Sub scale	6	1	3	2	0	1 (16.7)

ABCDEFV Atkinson Battery for Child Development for Examining Functional Vision, *CAS* Callier Azusa Scale, *CVI Q* CVI Questionnaire, *CVI R* CVI Range, *EDVA* Erhardt Developmental Visual Assessment, *FVQ* Functional Visual Questionnaire, *HSCS PS* Health Status Classification System Preschool, Vision scale, *HUI III* Health Utilities Index Mark III, Vision Scale, *IDP* Institutes' Developmental Profile Visual Competence Scale, *LVC* Low Vision Checklist, *PreViAs* Preverbal Visual Assessment, *Short CVI Q* Short CVI Questionnaire, *SoGS* Schedule of Growing Skills, Visual skills domain, *VAP CAP* Visual Assessment Procedure Capacity, Attention, and Processing, *VSI* Visual Skills Inventory, *15 D* 15 Dimension Questionnaire, Vision scale

[a]Type of assessment determines type of information to be linked: patient oriented measure (self report, caregiver report or health professional reported) or clinical assessment; [b]Number of domain codes may equal more than the number linking units as some linking units were given two codes; [c]Examples of constructs linked to Body Functions: seeing functions (visual acuity, visual field, and the ability to sense light, form, shape and colour, and eye functions), mental functions (orientation, memory, response time, visual perception and discrimination, visuospatial perception, knowledge and application of knowledge, recognition and object permanence), hearing functions, and neuromuscular functions such as reflexes and eye hand coordination; [d]Activities and Participation codes are expanded in Table 3; [e]Environmental factors include supports or barriers of adapted products including large print or glasses/contacts, light in the environment, or people providing support; [f]Other includes personal factors such as a child's interest or mood, the use of compensatory strategies, and interventions such as patching; [g] Number of 'visual ability' constructs is total number of linking units coded to the visual ability codes (d110 Watching, d160 Focusing attention, d161 Directing attention) as % of the total linking units

rules, together with examples specific to this study, and was used by the authors to undertake the process. Linking methodology has previously been used to compare and contrast information from outcome measures for the purpose of clarity about constructs (e.g., upper limb measures for children with cerebral palsy [22]).

The deductive linking process was completed by researchers with good knowledge of the concepts, definitions and structure of the ICF-CY. The first author (BD) is an occupational therapist with experience working with children with cerebral palsy and vision impairment, and had acquired relevant knowledge using the eLearning tool developed by the World Health Organization [23]. The second and last authors (MA and CI) are both knowledgeable in the ICF-CY and linking methodology, and all authors have clinical experience with the cerebral palsy population.

The first author initially prepared the data for linking by entering all 266 items from the 19 measures into a linking extraction table. Next, items were analysed independently by two authors (BD and either MA or CI) to identify linking units ('what the item is about'). Items were analysed for both main and additional concepts; this was done at an item and response level for patient-oriented measures, and by considering the aim in clinical assessments. This process was complex, with most measures containing some items whose meaning was unclear, making it difficult to know what the item was about, and as a result, the identification of linking units and ICF-CY codes was inconsistent between linkers. For

Table 2 Study specific ICF-CY linking rules

Identification of linking units

i. Determine the type of information to be linked: *patient oriented measure* (self report, caregiver report, or health professional reported) or *clinical assessment*.

ii. Identify linking unit(s). The linking unit of a measure answers the question: What is the item about?
The names of measures, the instructions, and subscale titles provide useful information to define the linking units.
e.g., *Item 17 from the CVI Questionnaire asks whether the child "Sits right in front of the television". This item needs to be considered in the context of being an item in a measure screening for cerebral visual impairment. The item falls in the section of 'Visual attitude' and the subscale of 'visual attention'. This item is not about 'sitting'.*
For Patient oriented measures:
• Refer to the item as it appears in the questionnaire
• Identify response options of items that contain linking unit(s)
For Clinical assessments:
• Refer to the aim of the clinical assessment
• Consider that the linking unit may change depending on the context in which the clinical assessment is used.

iii. Identify any relationship between concepts: when there are more than two linking units the relationship between the units is also provided.
e.g., *Item 21 in the Functional Visual Questionnaire asks whether the child "Looks at a toy or object while reaching/moving hand towards it". This item is about looking 'whilst' reaching. The relationship should be recorded.*

Linking of linking units to the ICF CY

a. Select the appropriate code(s) to describe the linking unit:
Is the linking unit an element of Body Functions, Body Structures, Activities and Participation, or Environmental factors?
Which chapter within the selected domain is the most appropriate?
Which category within the selected chapter is the most precise?

b. If the content of an item is not explicitly named in the corresponding ICF CY category, then the "other specified" is linked. This code allows for coding of functioning that is not included within any of the other specific categories. When an "other specified" code is used, the specification has to be annotated.

c. If the content of an item is insufficient to permit assignment of a more specific category, the "unspecified" is linked. The code has the same meaning as the second or third level term immediately above (b), without any additional information.
i.e., Use d199 Learning and applying knowledge, unspecified rather than d1 Learning and applying knowledge

d. If the linking unit is an element of 'Health condition' the code HC is used.

e. If the linking unit is an element of 'Personal factors' it would be considered to have a positive or negative influence on disability and functioning. To determine if a linking unit is a Personal factor ask: Can the linking unit be impaired, restricted or limited? If no, it is a personal factor.

f. If the content of an item is unclear or too general to permit assignment of any category or component, the "nondefinable" (nd) is used. The perspective is documented as General Health (nd gh), Quality of life (nd qol), Physical health (nd ph), Mental health (nd mh), or Life satisfaction (nd s).

g. If the linking unit is not a Health condition, Body function/body structure, Activity, Participation, Environmental factor or Personal factor, it is "Not covered" (nc).

example, Item 3 from the Preverbal Visual Assessment (PreViAs) asks "Is he/she able to look towards a sound source?" [24]. Different authors (linkers) considered that this item may be about 'looking', 'turning to look', 'hearing a sound' or 'sound localisation'. Five iterative rounds of independent linking were subsequently undertaken using a process of constant review, comparison and discussion until consensus was reached.

Consistent consensus-based decisions were made possible when a set of study-specific guidelines was developed from notes on discussions and refined continuously as suggested by other authors [25–28]. The guidelines are a summary of ICF Linking Rules [19, 20, 23] annotated with study-specific examples, in addition to a summary of solutions to commonly occurring challenges specific to this study (available in Additional file 1). Throughout the linking process, the guidelines were used to improve the consistency of the approach. Once consensus-based decisions could be reached by the first and second author using the guidelines, the first author completed the linking for all assessments. Units were linked to the most precise code in the ICF-CY, however most results are reported and discussed at the second level.

To present the results a tabulated descriptive summary is provided for assessment tools including details of the assessment tool and type of information to be linked, number of items and linking units, and the number of linking units for each of the ICF-CY domains. The number of linking units determined to be measuring 'visual ability' is presented for each assessment tool, and details of all Activities- and Participation-level codes at a two-level classification are presented to illustrate what constructs are measured by existing assessment tools. Details of the Body Function and Environmental factor codes are available in Additional file 2.

Part II: process of establishing 'visual ability' themes

Part II included thematic content analysis undertaken in two steps [29] to examine the 128 items that linked to specific codes identified in Part I as vision in the Activities and Participation domain. In addition to the ICF-CY code of *d110 Watching*, two additional second-level codes were commonly considered to be about the use of vision: *d160 Focusing attention*, and *d161 Directing attention*; however, care was taken in the analysis of items linked to these codes as they might not be exclusive to vision. The analysis involved (a) constructing 'descriptive' themes (e.g., 'tracking'), followed by (b) the development of 'analytical' themes (e.g., 'follows'). The results of this process were recorded in the same data management and extraction table used in Part I.

To construct descriptive themes, the first author (BD) immersed herself in the data and sought evidence for (1) verbs describing visual abilities, and (2) indicators, characteristics or specifications of different levels of visual ability. This decision was guided by the overarching aim of the study, namely that the results should inform the development of a new visual ability assessment. It was determined that words describing how vision is used (e.g., verbs) would be essential to the development of an ability measure. Table 3 provides four examples of the inductive process of constructing descriptive themes.

Analytical themes were developed by the first author (BD) from the descriptive themes by grouping similar verbs and indicators into clusters that could be identified using an over-arching label that reflected the 'observable visual behaviour/s'. This stage was influenced by knowledge of the literature, research, and clinical practice in the area. The results were confirmed by the co-authors (EF and CI) independently analysing 15% of the items and discussing themes until consensus was reached. Short descriptions of theme clusters were written and validated by referring back to the items. A final step involved the grouping of similar themes into overarching categories that reflected all themes within the group. The process of developing analytical themes and combining these into categories is also illustrated in Table 3.

The results of Part II are reported using a narrative description of the analytical themes as visual behaviours observable in daily activity performance of children with cerebral palsy. The themes are presented under their categorical headings, along with examples or extracts from items, responses or instructions from visual ability assessment tools that contributed to their development. Examples from a range of assessment tools are utilised to assist with the transparency and trustworthiness of the findings and interpretations. In line with the overarching goal of establishing a method for assessing the visual ability of children with cerebral palsy, examples that represented the themes were selected from included tools to describe *ability*, rather than what a child *cannot do* (e.g., "…keep looking" rather than "cannot keep looking" CVI Q) [16].

Decision points throughout both phases of this research were regularly discussed among the authors, ensuring a peer review process aiming to increase the confirmability of the results.

Results

Part I: constructs measured by vision assessments

In total, 266 assessment items, scales or tests were included in the analysis of constructs measured by existing assessment tools, and 370 units were linked to the ICF-CY. Items were linked to constructs across the ICF-CY domains including Body Functions, Activities and Participation, Environmental factors and Personal factors (see Table 1). This study found that all 19 previously-identified assessments contained items and linking units that were linked to one of the specific codes identified as 'visual ability' codes (*d110 Watching*, *d160 Focusing attention*, and *d161 Directing attention*) (see Table 4), but in addition to measuring vision, an additional 16 second-level codes from the Activity and Participation domain were also identified as constructs within the assessment

Table 3 Example of process to identify linking units and ICF-CY codes (Part I) and 'visual ability' themes & categories (Part II)

Part I				Part II			
				Descriptive theme		Analytical theme	
Measure	Item	Linking unit[a]	ICF CY code[b]	Descriptive word for visual ability	Indicator of visual ability	Theme: Observable visual behaviour	Category of visual ability behaviour
CVI Q [16]	Manipulates an object rather than look at it *(Item 40, Other senses domain)*	Use of other senses	d110 Watching d1201 Touching[c]	Look	Look at object Manipulate rather than look (other senses)	Watches and/or visually interacts with objects Frequency of use of vision in activities	Interactions Use of vision
FVQ [18]	Tracks an object/toy *(Item 2)*	Tracking	d110 Watching	Tracking	Tracks an object/toy	Follows	Abilities
						Watches and/or visually interacts with objects	Interactions
PreViAs [24]	Is he/she able to look towards a sound source? *(Item 3)*	Looking toward a sound source[d]	d110 Watching b2302 Localisation of a sound source	Look	Looks toward sound source	Searches	Abilities
VSI [36]	Does your child reach for a large, bright, silent object? *(Item 17)*	Reaching	d4452 Reaching	n/a			

[a]Linking unit = What is the item about?; [b]Only assessment items which have been linked to an ICF CY 'visual ability' code of d*110 Watching*, *d160 Focusing attention* or *d161 Directing attention* are included in Part II; [c]This is an example where the exact term in the ICF CY does not match the construct as described in the measure i.e., linked to *d1201 Touching* and not *d4402 Manipulating*; [d]Example of an item where it was not easy to identify what the item was about e.g., is it about 'Turning to look'?, 'Hearing a sound' or 'Looking'

Table 4 Act v ty and Part c pat on CF-CY categor es dent f ed n assessment too s

CF-CY Activities and Participation Chapters and Two- eve c assification[b]	Assessment too s with visua abi ity items[a]																			
	ABCDEFV	A imovic	CAS	CV Q	CV R	EDVA	FVQ	Hoyt	HSCS-PS	HU -	DP	LVC	PreViAs	ShCV Q	SoGS	VAP-CAP	VS	Wong	15-D	N
d1 LEARN NG AND APPLY NG KNOWLEDGE																				
d110 Watching and/or d160 Focusing attention[c, d]	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**19**
d120 Other purposefu sensing[e]				X	X		X										X			4
d130 Copying[f]			X										X							2
d131 Learning through actions with objects[g]	X		X										X							3
d161 Directing attention[h]	**X**	**X**		**X**																**3**
d166 Reading[i]										X	X			X					X	4
d170 Writing[j]													X							1
d2 GENERAL TASKS AND DEMANDS																				
d3 COMMUN CAT ON																				
d315 Communicating with – receiving – non-verba messages[k]				X			X						X				X			4
d335 Producing nonverba messages[l]							X						X		X					3
d350 Conversation[m]		X																		1
d4 MOB L TY																				
d440 Fine hand use[n]	X		X	X	X		X					X	X			X				8
d445 Hand and arm use[o]			X		X		X						X		X	X	X			7
d450 Wa king[p]				X								X		X						3
d460 Moving around in different ocations[q]												X							X	2
d499 Mobi ity, unspecified[r]			X	X																2
d5 SELF-CARE																				
d6 DOMEST C L FE																				
d7 NTERPERSONAL NTERACT ONS AND RELAT ONSH PS																				
d710 Basic interpersona interactions[s]			X	X			X						X	X			X			6
d8 MAJOR L FE AREAS																				
d880 Engagement in p ay[t]				X									X							2
d9 COMMUN TY, SOC AL AND C V C L FE																				
d920 Recreation and Leisure[u]				X																1

[a]Assessment too s identified in systematic review [10]; [b]On y two- eve c assification codes inked to items from visua abi ity assessment too s are presented in this tab e; [c] tems inked to codes *d110 Watching* and *d160 Focusing attention* are combined in this presentation due to difficu ties in discriminating between the constructs, and the three concepts which represent the concept of 'visua abi ity' are presented in bo d font; Examp es of constructs inked to Activities and Participation codes: [d]Focusing on or tracking a toy, [e]Mouthing, touching and sme ing, [f] mitation of facia expression, [g]Re ating two or more objects such as b ock bui ding or posting, [h]Keep ooking, [i]Reading crowded text, [j]Scribb e with pen on paper, [k]Responds to/understands facia expressions, [l]Smi es or demonstrates visua preference, [m]Starting/sustaining visua communication, [n]Picking up, Grasping or Manipu ating object, [o]Reaching for seen object, [p]Wa king around and over different surfaces and avoiding obstac es, [q]Moving about +/− guidance, [r]Moves to object, [s]Appropriate use of eye contact and differentiation of fami iar peop e/strangers, [t]P ay with objects, and [u]Memory game

tools (e.g., d445 Hand and arm use, for items about reaching). These findings support the previous decision for inclusion of all 19 assessments in the systematic review, and also confirm that these tools include measurement of a variety of constructs. Whilst vision measurement is varied, occurring across the ICF-CY domains, the results suggest that vision measured using specific 'visual ability' items could result in measurement of a single construct, and further analysis was indicated.

Part II: analysis of 'visual ability' items

Thirteen analytical themes emerged from the data to describe items that specifically assess vision at the Activity level of the ICF-CY. These 13 themes are clustered into three categories that reflect a child's observable visual behaviours (Table 5). The category *Abilities* includes seven themes reflecting how a child uses vision; *Interactions* includes four themes reflecting the contexts in which the child uses their vision to interact purposefully; and *Use of vision* includes two themes reflecting a child's overall use of vision in daily activities. These results provide the conceptualisation of the construct 'visual ability'.

Category I: abilities

Responds/reacts

The first theme incorporates the basic visual ability of responding or reacting to visual stimuli, and utilises *observations of behaviours that suggest a child is responding, at some level, to visual information*. The theme is derived from items describing a wide range of responses or reactions and includes both purposeful and non-purposeful use of vision, and both passive and active responses.

> …the light perception test is deemed positive if the patient shows some reaction to light, even high-intensity light…by moving his or her head, winking, or making a defensive or stopping movement (extract from LVC, Test 1 guidelines) [30].

Items that contributed to the development of this theme often appeared first in a measurement tool, and it is proposed that responding or reacting is a pre-requisite for other visual abilities i.e., if a child does not respond they will not be able to demonstrate other visual behaviours such as watching, finding, or following. Some items themed to 'responds or reacts' were additionally linked to b210 *Seeing functions* in Part I.

Table 5 Categories and related themes reflecting how visual behaviours are described in assessment tools

I. Abilities	II. Interactions	III. Use of vision
1. Responds or reacts 2. Initiates 3. Maintains or sustains looking 4. Changes or shifts looking 5. Searches 6. Locates or finds 7. Follows	8. Watches and interacts visually with people/faces 9. Watches and interacts visually with objects 10. Watches and interacts visually over distances 11. Watches and interacts visually with hands	12. Frequency of use of vision in activities 13. Efficiency of use of vision in activities

Initiates

This theme is about how quickly vision is used; the observable behaviour is *time to respond to visual information in a purposeful way*. Items contributing to this theme include descriptions of prompt or delayed responses.

> Exhibits a delayed response to visual stimuli (FVQ, Question 6) [18].

Maintains/sustains looking

This theme is about how much or for how long a child keeps looking. The observable behaviour is *the purposeful use of vision for a length of time appropriate to the activity*.

> …keep looking at objects or persons (extract from CVI Q, Item 9) [16].

Contextual information about type of visual stimuli or the environment where the visual behaviours occur reflects some of the variability in items about a child's ability to maintain/sustain looking, and these facilitators or barriers also apply to the previous theme of 'initiates'.

> … brief fixations on movement and reflective materials; Movement continues to be an important factor to initiate visual attention; Movement not required for attention at near…(extract from CVI Characteristic - Need for movement, CVI R) [31].

Changes/shifts looking

This theme addresses whether the child can initiate a purposeful change or shift in looking between objects, people and/or the surrounding environment. The observable behaviour is *the child easily disengaging attention from one stimulus to look at another*.

> …able to move the eyes quickly between two persons or two objects (extract from Question 4, PreViAs) [24].

> Shifts gaze between targets in near and middle space accurately (extract from 5-month Pattern Component, Gaze Shift - Visual Release, EDVA) [32].

Items contributing to the theme suggest variations in the ability to shift gaze, and may include use of internal strategies (e.g., blinking to facilitate visual release) and/or the need for physical support to prompt or redirect looking behaviours.

Searches

This theme considers whether the child uses a process of visually searching, scanning and exploring in a purposeful way. Searching may or may not result in 'finding' the desired target – that is themed separately. The observable behaviour is *the self-initiated ability of the child to explore visually by moving their visual attention around the information in the visual environment for a goal-directed purpose*.

> Visually seeks missing object or person (Item 9b, CAS) [33].

> Looks around when entering a room (Question 25, FVQ) [18].

By definition, this theme is suggestive of prerequisite skills including initiation, the ability to interact with different stimuli including over distances, sustained looking or attention, and shifting between stimuli.

Locates/finds

The theme 'locates/finds' is about whether and how easily a child uses their vision to locate or find specific information. The observable behaviour is *successfully locating the specified or required visual information*.

> Looks in correct place for fallen toy (Item 78, SoGS) [17].

Items that contribute to the development of this theme suggest that the ease with which a child locates or finds specific visual information may be impacted by the environmental context in which the behaviour occurs, including distance, background clutter, colour, low contrast/similar background, in addition to the prerequisite skills described under the 'searches' theme. Success in locating or finding a target are more likely to be observed if a child has good searching abilities.

> …find his teddy bear (or equal) amongst other cuddly animals (extract from Item 33, CVI Q) [16].

> …Finding parents or friends in a crowd (extract from Question 3, Short CVI Q) [34].

This theme was predominantly derived from assessment items designed to diagnose or screen for cerebral or cortical visual impairment (CVI), suggesting that locates/finds may contain significantly more cognitive requirements than some other abilities. In addition to items about locating or finding a person or object, this theme also included items about navigation.

> …find his/her way to the classroom, in his house [familiar environments] (extract from Item 26, CVI Q) [16].

Follows

This theme, and the observable behaviour, *concerns whether and how effectively the child follows or tracks moving targets*. It was derived from items also contributing to other themes, including the types of stimuli that are followed, the distances at which following occurs, and how often a child demonstrates following behaviours. The abilities that are unique to this theme are the direction and extent (e.g., how far) of following behaviours, and the quality of the following with eyes and/or head.

> …Either saccadic (jerky) tracking or smooth pursuit can be accepted but it should be noted which type of eye movement the child makes … For infants over 3 months, tracking should be easily elicited on the first trial in either direction, provided the child is reasonably attentive at the start of each trial (extract from procedure, Item 3, ABCDEFV) [35].

The content of items contributing to this theme, and the relationship between items in different themes, suggests that following has a number of prerequisite abilities including 'sustains looking'. There is also a suggestion that 'shifts looking', 'searches' and 'finds' may result in successful performance ('use of vision') in the absence of the ability to follow.

Category II: interactions

Watches and interacts visually with people & faces

The first 'interaction' theme describes whether the child watches or looks at people and faces; the observable behaviour is *purposeful looking at people and faces within everyday social interactions*.

> …Generally no regard of the human face…Regards familiar faces when voice does not compete… Smiles at/regards familiar and new faces… Typical visual/social responses (extract from CVI Characteristic – Visual Complexity, CVI R) [31].

> Focuses on a face when seated opposite him/her (Question 13, FVQ) [18].

The importance and relationship of this theme to a child's overall functioning is evident when revisiting the items and codes analysed in Part I of this study where additional related concepts included the variables such as responding to facial expressions and recognising faces.

Watches and interacts visually with objects

This theme explores whether the child looks at objects (e.g., inanimate stimuli such as toys and books) and includes the range of objects with which the child watches or visually interacts. The observable behaviour is *the child's purposeful response to the visual properties of objects*, in a manner which is appropriate to the child's motor capacity and developmental level.

> …reach for a drink bottle when you hold it in front of him/her…become excited but does not reach for the drink bottle (extract from Item 11, VSI) [36].

> Looks at/focuses on pictures in a book or on a communication board (Item 19, FVQ) [18].

Limitations in the range of stimuli with which a child interacts visually are suggested by items describing the need for specific characteristics to facilitate looking e.g., sound, light, colour.

> Requires an additional sensory modality (e.g. sound, touch, etc.) to focus on or respond to an object/toy (Question 7, FVQ) [18].

> …Objects viewed are generally a single colour…(extract from CVI Characteristic – Color Preference, CVI R) [31].

Watches and interacts visually over distances

This theme is about whether the child watches/looks at visual information over a range of distances. The observable behaviours are *responses indicating that visual information has been experienced*. It is about seeing/using vision to experience information beyond the child's immediate space, and the distance is considered in relation to the child's age.

> Visually attends in near space only … Visual attention extends beyond near space, up to 4 to 6 feet (extract from CVI Characteristic: Difficulty with distance viewing. CVI R) [31].

> Watches movements of people at distances or out of window with interest (Item 79, SoGS) [17].

Watches and visually interacts – with hands

The next theme is about whether there is an interaction between the child and the manual actions of his/her hands, or the manual actions done by the hands of another person. The observable behaviour is *whether there is purposeful and effective use of this interaction in everyday activities*. Whilst it is acknowledged that children with cerebral palsy have varying manual abilities, the interaction between vision and manual actions is a strong theme.

> …observe his/her own hands (extract from Question 6, PreViAs) [24].

> Visually explores the toy whilst you turn it over: The child looks interested in the toy but either because of physical disability or tactile defensiveness can't or won't take the toy, but visually examines the toy as the adult turns it over (extract from response option, Item 5, Low Vision Assessment, VAP-CAP) [37].

> Looks at a toy or object while reaching/moving hand towards it (Item 21, FVQ) [18].

The identification of relationships between linking units, as recommended in the ICF eLearning Tool [23], contributed significantly to this theme with many of the items contributing to this theme also being linked to another ICF-CY code (e.g., *d1201 Touching* or *d440 Fine hand use*).

Category III: use of vision

Uses vision in activities – Frequency of use

This theme is about observations of *the overall frequency or 'how often' the child uses their visual abilities*. This theme is derived from items describing the consistency and reliability with which visual abilities are used in daily activities.

> …Student functions with more consistent visual response…(extract from scoring, Rating I, Across CVI Characteristics, CVI R) [31].

> Attention is fluctuating from moment to moment and from day to day (Item 10, CVI Q) [16].

This theme was also developed from items suggesting a low frequency of use of vision by referring to the use of senses other than vision (e.g., listening, mouthing, touching, smelling, or tasting) when vision could be used.

> Manipulates an object rather than look at it (Item 40, CVI Q) [16].

Uses vision in activities – Efficiency of use

The final theme is about the efficiency with which vision is used in daily functioning. The observable behaviours are *how independently and easily a child has success when performing in vision-related activities*. Items contributing to this theme describe how performance in vision-related activities is affected by limited visual functions, and describe limitations in performance related to the need for assistance, guidance, time or prompting, a reduced level of independence, or difficulty in performance. As such, items contributing to this theme were commonly linked to codes in addition to the visual ability code in Part I, such as *b1561 Visual perception, b210 Seeing functions*, and *e1251 Assistive products and technology for communication*.

> …able to see well enough to recognise small objects and familiar people at a distance…Sees objects close to oneself - e.g. at arm's length, but has visual limitations at distance, even with glasses (extract from Vision (ability to see) subscale, HSCS-PS) [38].

Discussion

This paper presents a methodological approach applicable to research conundrums where definition and understanding of a complex issue are required. Our example involves the initial stages in instrumentation research to establish 'vision use' as a construct that is measurable in children with motor impairments. By utilising a two-part process this study demonstrates an approach to conceptualise complex constructs and operationalise how a concept will be measured. In this study the WHO's ICF-CY provided a framework for conceptualising a complex construct utilising terminology that has been endorsed world-wide [15], increasing the transferability of both the methods and findings. The outcome from this work is a conceptualisation of visual ability that is grounded in a common language and builds on, and takes advantage of, the work of previous researchers. It is an approach that other healthcare researchers, clinicians and policy makers are encouraged to consider when clarity is sought regarding complex or unclear constructs.

In the first phase of this study a deductive and explanatory method established 'visual ability' within the conceptual framework of the ICF-CY. The process built upon the focus of vision measured at the Activities and Participation level of the ICF-CY previously presented in a systematic review [10], and developed a refined definition of 'visual ability' as a construct measureable *within* the Activity level of the ICF-CY as 'how vision is used'. This finding arose from linking procedures that identified that existing assessment tools measuring visual ability in fact measure a wide range of constructs. This demonstrates the complexity and multidimensionality of 'vision', and provides valuable information about the need to define clearly which component(s) of functioning is (are) being measured at any given time. At an item level, existing visual ability assessment tools are measuring constructs across the ICF-CY framework, and these findings support the need for the development of a discrete assessment tool that measures 'visual ability'.

Whilst the ICF-CY provides a strong framework from which to develop the conceptualisation of visual ability, the process of linking items to the classification in this study was not straightforward. It is proposed that issues identified during linking in this study regarding 'what an item is about' likely reflect problems utilising the existing measurement tools in clinical practice and research. If the authors of this paper could not reliably link items, it is reasonable to assume that parents and clinicians may also be unlikely to respond consistently to items, thus potentially impacting both the reliability and validity of measurement. The development of study-specific guidelines was an important step in this study to establish trustworthiness in the findings, and a summary of key challenges encountered during the linking process is provided in Additional file 1. This information will be useful to researchers wishing to apply these methods in the future.

It must be recognised that the study results may not reflect the original intent of the authors of included measures. Linking the content of existing tools to the ICF-CY was completed in this study as one step in the methodological process of defining the concept of 'visual ability' and its place within the larger conceptual framework. The process of making conceptual distinctions within measurement tools and how this is important for content validity has previously been reported in quality of life research [39].

In the second phase, the application of an inductive and exploratory method resulted in a description of visual ability using 13 behaviours observable during typical daily activities. These behaviours are not new, but it is proposed that the act of identifying and describing these themes forms the step of item generation for a new assessment tool as this research moves from conceptualisation of visual ability to a measurement development phase. The analytical process and interpretation in this study also suggest the possibility of a hierarchy of visual abilities within the identified behaviours, that is, that careful ordering of the behaviours may reveal how a child functions in vision-related activities. This is a finding which could be explored in future instrumentation work using Item Response Theory [40].

Whilst the results of this study provide key foundational information for the development of an assessment of visual abilities in children with cerebral palsy, they are not yet operationalised in a measure. The observable behaviours are expected to be of interest to a wide range of researchers and clinicians, however they require further revision, development and validation before they can be considered an 'assessment'. In their current format the results of this study may only provide guidance to practitioners in relation to their informal observations of visual abilities in children, and will likely inform discussion and future research. The previously published systematic review provides a summary of currently available assessment options and recommendations for assessing children with cerebral palsy. However, it is important to note that the assessment tools reviewed in the systematic review do not measure the construct of visual ability as conceptualised in this methods paper.

Because this study used existing measures as the unit of analyses, whether all themes identified within this study are relevant, and whether they represent a comprehensive set of items about vision use, is an empirical question that requires further research. It is imperative that individuals with cerebral palsy, parents and carers, and the professionals who work clinically with the population contribute to future development of the visual ability construct, and the way it is measured [41]. It will be important to confirm the relevance of the observable behaviours across the diverse cerebral palsy population including people of different age groups, gross motor, manual and cognitive abilities. It is also likely that the definition of visual ability established in this study could be applicable to a range of health conditions other than cerebral palsy, however further investigation of the validity of this premise would be required.

Conclusion

Despite the complexity of vision, the concept of 'how vision is used' can be clearly defined as a measurable construct within the Activity level of the ICF-CY, so discrete measurement of this construct appears feasible. This construct is labelled 'visual ability', and this study has identified observable visual behaviours that may be developed into items assessing how vision is used in daily activities. The approach used in this study to explain and explore a complex construct may be useful in other health care research. Future research is required to confirm the results of this study and expand the findings through further instrumentation research. It is now planned that a tool be developed and validated to assess the construct of visual ability in children with cerebral palsy, and then used to establish effective interventions to optimise how vision is used.

Additional files

Additional file 1: Study Specific Guidelines: ICF CY Linking Rules and Challenges. This file contains a summary of the ICF Linking Rules annotated with study specific examples and a summary of solutions to commonly occurring challenges from Part I Linking visual ability assessments to the ICF CY. (DOCX 20 kb)

Additional file 2: Results table for Body Function and Environmental factor codes. This file contains the tabulated results for assessment items linked to Body Function and Environmental factor codes. These results are not pertinent to Phase II in this study. (DOCX 21 kb)

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Authors' contributions
BD conceived of the study and participated in all stages of study design, data collection, data analysis and writing the manuscript. MA participated in data analysis for Part I of the study. EF participated in data analysis for Part II of the study. CI participated in data analysis for Part I and Part II of the study. MA, EF, PR and CI contributed to the study concept and design, participated in the peer review process throughout data analysis and interpretation to establish trustworthiness in the findings, and actively contributed to the improvement and revision of the manuscript. All authors have read and approved of the final manuscript.

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Author details
[1]Australian Catholic University, School of Allied Health, Level 9, 33 Berry Street, North Sydney, NSW 2060, Australia. [2]Jönköping University, CHILD, School of Education and Communication, Box 1026 551 11 Jönköping, Sweden. [3]McMaster University, IAHS Building, Room 408, 1400 Main Street West, Hamilton, ON L8S 1C7, Canada. [4]Australian Catholic University, School of Allied Health, Level 2, Daniel Mannix Building, 17 Young Street, Fitzroy, VIC 3065, Australia.

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Study Specific Guidelines based on:

- Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G: ICF linking rules: an update based on lessons learned. *J Rehabil Med* 2005, 37:212-218.
- Cieza A, Fayed N, Bickenbach J, Prodinger B: Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. *Disabil Rehabil* 2016:1-10.
- Fayed N, Cieza A, Bickenbach J: Illustrating child-specific linking issues using the Child Health Questionnaire. *American Journal of Physical Medicine & Rehabilitation* 2012, 91:S189-S198.
- World Health Organization ICF Research Branch: ICF eLearning Tool. 2015.

Study Specific ICF-CY Linking Rules

Identification of linking units

i. Determine the type of information to be linked: *patient-oriented measure* (self-report, caregiver report, or health professional reported) or *clinical assessment*.

ii. Identify linking unit(s). The linking unit of a measure answers the question: What is the item about?

The names of measures, the instructions, and subscale titles provide useful information to define the linking units.

e.g. Item 17 from the CVI Questionnaire asks whether the child "Sits right in front of the television". This item needs to be considered in the context of being an item in a measure screening for cerebral visual impairment. The item falls in the section of 'Visual attitude' and the subscale of 'visual attention'. This item is not about 'sitting'.

For Patient-oriented measures:

- Refer to the item as it appears in the questionnaire
- Identify response options of items that contain linking unit(s)

For Clinical assessments:

- Refer to the aim of the clinical assessment
- Consider that the linking unit may change depending on the context in which the clinical assessment is used.

iii. Identify any relationship between concepts: when there are more than two linking units the relationship between the units is also provided**.**

e.g. Item 21 in the Functional Visual Questionnaire asks whether the child "Looks at a toy or object while reaching/moving hand towards it". This item is about looking 'whilst' reaching. The relationship should be recorded.

Linking of linking units to the ICF-CY

a. Select the appropriate code(s) to describe the linking unit:

Is the linking unit an element of Body Functions, Body Structures, Activities and Participation, or Environmental factors?

Which chapter within the selected domain is the most appropriate?

Which category within the selected chapter is the most precise?

b. If the content of an item is not explicitly named in the corresponding ICF-CY category, then the "other specified" is linked. This code allows for coding of functioning that is not included within any of the other specific categories. When an "other specified" code is used, the specification has to be annotated.

c. If the content of an item is insufficient to permit assignment of a more specific category, the “unspecified” is linked. The code has the same meaning as the second- or third-level term immediately above (b), without any additional information.
i.e. Use d199 Learning and applying knowledge, unspecified rather than d1 Learning and applying knowledge

d. If the linking unit is an element of ‘Health condition’ the code HC is used.

e. If the linking unit is an element of ‘Personal factors’ it would be considered to have a positive or negative influence on disability and functioning. To determine if a linking unit is a Personal factor ask: Can the linking unit be impaired, restricted or limited? If no, it is a personal factor.

f. If the content of an item is unclear or too general to permit assignment of any category or component, the “nondefinable” (nd) is used. The perspective is documented as General Health (nd-gh), Quality of life (nd-qol), Physical health (nd-ph), Mental health (nd-mh), or Life satisfaction (nd-s).

g. If the linking unit is not a Health condition, Body function/body structure, Activity, Participation, Environmental factor or Personal factor, it is “Not covered” (nc).

Summary of solutions to commonly occurring challenges from Part I: Linking assessments to the ICF-CY

Challenge	Example item	Discussion and Solution
Misleading terminology and unclear perspectives in items	Item 1 in the Short CVI Questionnaire: Are there problems in seeing an object on patterned background?	As per linking guidelines no. *ii*, linkers need first to consider whether a linking unit is an element of Body Functions, Body Structures, Activities and Participation or Environmental factors, and then select the most appropriate chapter and code within that domain. In this example, consideration needs to be given to the other available information i.e. this item is from a questionnaire about the presence of problems rather than an assessment of capacity or impairment, and there is mention of a potential environmental barrier. This item should be linked to the Activities and Participation domain. Note: There is a mismatch between terminology defined by the ICF-CY and how it is used in clinical and research practice. i.e. “seeing” is defined by the ICF-CY in the Body Function domain at Chapter 2 ‘Sensory functions and pain’ with b210-b229 *Seeing and related functions*, however seeing is a term commonly used to described the purposeful/intentional use of vision, and d110 *Watching* is the Activity and Participation level code for ‘seeing’.
Linking items about using vision to *d110 Watching* versus *d160 Focusing attention*	Item 4 of the Callier Azusa Scale: May look at caregivers face when held.	The Activity and Participation domain codes of *d110 Watching* and *d160 Focusing attention* (including *d1600 Focusing attention on the human touch, face and voice*; *d1601 Focusing attention to changes in the environment*; and *d1608 Focusing attention, other specified*) are both highly relevant to measures of visual ability, however it is difficult to differentiate between these codes reliably. In this example the item could be linked to *d110 Watching* and/or *d1600 Focusing attention on the human touch, face and voice,* as there is no exclusion criterion for linking to both codes. Items should be linked to the combined *d110*

		Watching and/or *d160 Focusing attention* when they are about 'using the sense of seeing intentionally to experience visual stimuli' and 'intentionally focusing on specific stimuli'.
A code for 'using vision' could be added to almost every item included in this study	Item 9a of the Visual Development subscale in the Callier Azusa Scale: May imitate movements of others.	To prevent excessive linking, and to maximise the usefulness of the results, items will only be linked when the linking unit is specifically about vision. All results will be considered with knowledge that the items are from measures of visual ability. In the example provided on the left here, the item is about using vision to 'imitate', and this can be coded as *d130 Copying*.
Interconnecting concepts need to be captured	Item 21 in the Functional Visual Questionnaire: Looks at a toy or object while reaching/moving hand towards it.	As per the WHO ICF eLearning guidelines, when items include a relationship between concepts in a linking unit, the relationship should be recorded, e.g. "and", "or", "while". If an item is about looking at something whilst reaching/moving hand towards it, the item is about two related concepts, and the connector e.g. "and" needs to be recorded. In this example the linking unit is <u>about both looking and reaching together</u>. Looking and reaching as separate but distinct constructs link to the Activity and Participation domain (e.g. *d110 Watching* + *d4452 Reaching*), whilst combining these constructs into one (e.g. eye-hand coordination) changes the construct to be about the 'coordination' and links to the Body Function domain (e.g. *b7602 Coordination of voluntary movements*).
Linking items about the use of vision for discrimination within a task, action or everyday life	Item 22 in the CVI Questionnaire: Does not recognise everyday objects such as an apple, bike, house, ball.	Items that are about the ability to visually recognise or perceive or discriminate, even within the situation of an everyday activity or task, are about the psychological function and will be linked to *b1561 Visual perception*. Note: *b156 Perceptual functions* and *b210 Seeing functions* are exclusive categories.

Linking items containing 'visual situations'	Item 3 in the Short CVI Questionnaire: Are there problems finding parents or friends in a crowd?	Assessments of visual ability contain items with reference to many 'visual stimuli' and 'visual environments'. Together these could be termed 'visual situations' and they include: ▪ type of visual stimuli, such as objects, people, pictures ▪ characteristics of visual stimuli, such as size, colour, brightness, location, distance, moving or kept still ▪ characteristics of physical environment, such as light, darkness, presence of other stimuli/clutter/distractions ▪ assistance, such as glasses, sound clues ▪ activities that provide a situation where vision may be used, such as reading In order to determine whether and/or where a visual situation should be linked, linkers are encouraged to ask: I*s the visual situation a linking unit (being assessed)? Or is the visual situation described, in order for assessment of some other function or action (e.g. looking)?* These 'visual situations' provide the characteristics or specifications of different levels of visual ability that provide key information in Part II of this study. In Part I, visual situation data which is not specifically linked should be recorded in the data extraction sheet under 'additional information'.

Table A Body Function ICF-CY Categories identified in assessment tools

ICF-CY Body Function Chpaters	Assessment tools																			
	ABCDEF	Alimovi	CAS	CVI Q	CVI R	EDVA	FVQ	Hoyt	HSCS-	HUI-III	IDP	LVC	PreViAs	Sh CVI	SoGS	VAP-	VSI	Wong	15-D	N
b1 MENTAL FUNCTIONS																				
b114 Orientation functions													X							1
b122 Global psychosocial functions				X																1
b144 Memory functions				X	X										X					3
b147 Psychomotor functions				X													X			2
b156 Perceptual functions	X		X	X			X		X	X	X		X	X	X	X	X			12
b163 Basic cognitive functions	X												X			X				3
b167 Mental functions of language														X	X					2
b2 SENSORY FUNCTIONS & PAIN																				
b210 Seeing functions	X			X	X	X	X	X	X	X		X			X	X	X	X	X	14
b215 Functions of structures adjoining the eye	X		X										X		X					4
b230 Hearing functions													X			X				2
b7 NEUROMUSCULOSKELETAL AND MOVEMENT-RELATED FUNCTIONS																				
b750 Motor reflex functions	X		X		X	X					X	X					X			7
b760 Control of voluntary movement functions	X			X			X								X	X				5

Table B Environmental factor ICF-CY Categories identified in assessment tools

	Assessment tools																			
ICF-CY Environmental factor Chapters and Two-level classification	**ABCDEFV**	**Alimovic**	**CAS**	**CVI Q**	**CVI R**	**EDVA**	**FVQ**	**Hoyt**	**HSCS-PS**	**HUI-III**	**IDP**	**LVC**	**PreViAs**	**ShCVI Q**	**SoGS**	**VAP-CAP**	**VSI**	**Wong**	**15-D**	**N**
e1 PRODUCTS AND TECHNOLOGY																				
e125 Products and technology for communication									X	X							X		X	4
e2 NATURAL ENVIRONMENT AND HUMAN-MADE CHANGES TO ENVIRONMENT																				
e240 Light																	X			1
e3 SUPPORT AND RELATIONSHIPS																				
e399 Support and relationships, unspecified																			X	1

Appendix H Supporting information for Study 3

This appendix contains:

- Ethical approval from Australian Catholic University for 2016-282E Survey on visual abilities in children with cerebral palsy
- Secondary approvals for advertising: NHMRC Centre of Research Excellence in Cerebral Palsy; Cerebral Palsy Alliance & NSW CP Register (2017-04-04); Victorian CP Register
- 2016-282E Participant Information Letter
- RedCap Survey (pdf format)
- Ethical approval from Australian Catholic University for 2017-313H Developing and testing a measure of vision use for children with cerebral palsy
- 2017-313H Participant Information Letter
- 2017-313H Cognitive Interview Guide

Dear Applicant,

Principal Investigator: Dr Elspeth Froude
Co-Investigator: Prof Peter Rosenbaum, Prof Christine Imms Student
Researcher: Belinda Deramore Denver (HDR Student) Ethics Register Number:
2016-282E Project Title: Survey on visual abilities in children with
cerebral palsy
Risk Level: Low Risk
Date Approved: 13/01/2017 Ethics Clearance
End Date: 31/12/2017

This is to certify that the above application has been reviewed by the Australian Catholic University Human Research Ethics Committee (ACU HREC). The application has been approved for the period given above.

Researchers are responsible for ensuring that all conditions of approval are adhered to, that they seek prior approval for any modifications and that they notify the HREC of any incidents or unexpected issues impacting on participants that arise in the course of their research. Researchers are also responsible for ensuring that they adhere to the requirements of the *National Statement on Ethical Conduct in Human Research,* the *Australian Code for the Responsible Conduct of Research* and the University's *Code of Conduct*.

Any queries relating to this application should be directed to the Ethics Secretariat (res.ethics@acu.edu.au). It is helpful if quote your ethics approval number in all communications with us.

If you require a formal approval certificate in addition to this email, please respond via reply email and one will be issued.

We wish you every success with your research.

Kind regards,

Kylie Pashley
on behalf of ACU HREC Chair, Dr Nadia Crittenden

Senior Research Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL

NHMRC Centre of Research Excellence in Cerebral Palsy
email: cre.cp@mcri.edu.au
phone: 03 9936 6087
www.cre-cp.org.au

Belinda Deramore Denver
Occupational Therapist & PhD Candidate
School of Allied Health
Australian Catholic University
Level 9, 33 Berry Street, North Sydney NSW 2060

9 December 2016

RE: Recruitment to research survey "visual abilities in children with cerebral palsy"

Hi Belinda,

Thank you for your enquiry regarding distribution of your research survey to the NHMRC Centre of Research Excellence in Cerebral Palsy (CRE-CP) network. On account of your affiliation with the CRE-CP, we would be more than happy to support recruitment to your survey by including information in our monthly newsletter. This newsletter is received by over 400 people; a mix of health professionals working in the field of cerebral palsy and people with lived experience.

Once you have received ethics approval from the ACU Ethics Committee we will work with you to ensure the message we include in the newsletter is correct. We can include the recruitment notice in two editions of the newsletter if you require.

The CRE-CP also hosts an online community engagement forum which involves parents, carers and persons with cerebral palsy who are interested in participating in research. We would be pleased to distribute your survey through this forum to assist with community participation.

We look forward to further supporting your research. If you have any questions at all, please don't hesitate to contact me or the CRE-CP Coordinator Tessa Devries on 03 9936 6087.

Kind regards,

[redacted]

Professor Dinah Reddihough
Primary Investigator on the Centre of Research Excellence in Cerebral Palsy
Developmental Disability and Rehabilitation Research, Royal Children's Hospital

19th May 2017

Belinda Deramore Denver
School of Allied Health, Australian Catholic University
Level 9, 33 Berry Street, North Sydney NSW 2060

Dear Belinda,

Final Approval – HREC REF NO 2017-04-04: *Survey on visual abilities in children with cerebral palsy*

Thank you for your application of the above project for consideration by the Cerebral Palsy Alliance Human Research Ethics Committee (HREC) at its meeting held on 3rd May 2017.

The Cerebral Palsy Alliance HREC is a fully constituted Ethics Committee in accordance with the *National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research (2007*). The approval of this project is conditional upon your continuing compliance with the *NHMRC National Statement*.

Your application has been considered and I am pleased to inform you that your project meets the requirements of the *NHMRC National Statement* and our Committee has granted ***final approval*** for this project.

Details of the approval are as follows:

- **Project approval number:** 2017-04-04. Please use this number in all subsequent correspondence to The Committee.
- **Approval period:** May 2017 to December 2021
- **The due date for your Annual Progress Report will be:** 1st May 2018-2021 inclusive
- **The due date for your Final Progress Report will be:** 1st May 2022
- **Authorised research personnel**: Dr Elspeth Froude; Belinda Deramore Denver; Prof Peter Rosenbaum; Prof Christine Imms
- **Approved documentation:** Please attach this footer to the information statements and consent forms (and labelling them according to the relevant version number): *"This study has been approved by the Cerebral Palsy Alliance Human Research Ethics Committee (2017-04-03). If you have any complaints or reservations about the ethical*

conduct of this research you may contact the Ethics Committee on (02) 9975 8000 or ethics@cerebralpalsy.org.au".

Accordingly, it is the responsibility of the Chief Investigator/s to:

- **Provide a summary of your progress on a yearly basis to the Committee, and a final report on completion including notification of any publications from this project. Failure to submit required reports will result in a suspension of consent for the project to continue.**
- Advise the HREC immediately in writing of any serious adverse events occurring during the course of the research.
- Advise the HREC immediately of all unforeseen events that might affect continued ethical acceptability of the project.
- Advise the HREC of any proposed changes to the research protocol, research personnel, information statement or consent form. All proposed amendments must be addressed in writing to the HREC, using the *Protocol Variation Request Form*, and must be approved by the HREC before continuation of the project.
- Advise the HREC immediately, providing reasons, if the research is discontinued prior to its completion, or has been abandoned.
- Request an extension of ethics approval should the project not be completed within the time period specified above, by using the *Protocol Variation Request Form*.
- Ensure that copies of all signed consent forms are retained and made available to the HREC on request.
- Provide a copy of this letter to any internal/external granting agencies if requested.
- Check our website for updated forms: https://research.cerebralpalsy.org.au/our-work/ethics/

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

Yours sincerely,

Dr Maria Mc Namara
Research Manager, Cerebral Palsy Alliance Research Institute, On behalf of

Dr Neroli Best
Cerebral Palsy Alliance Human Research Ethics Committee
Cerebral Palsy Alliance Ethics Committee is a NHMRC HREC: EC00402

VCPR recruitment

Sue Reid <sue.reid@mcri.edu.au>

Thu 20/04/2017 1:42 PM

To: Belinda Deramore Denver <belinda.deramoredenver@myacu.edu.au>

Hi Belinda

Our governance group has just met and we are happy to send out the information on your flier to individuals and families on the Victorian CP Register where we have an email address.

Can I just confirm with you that the REDCap survey opened on 17/4 and that it closes in 6 weeks? Is there a definite closing date?

Also, is there any way you can capture how many people participate as a result of the invitation through our register? If not, it's not important. We just like to keep the information for our own records.

Best wishes

Sue

Murdoch Childrens Research Institute

30 YEARS OF LIFE-CHANGING DISCOVERIES

Dr Sue Reid PhD MClinEpi
Senior Research Officer, Developmental Disabilities and Rehabilitation Research, Murdoch Childrens Research Institute
Manager, Victorian Cerebral Palsy Register
Senior Fellow, Department of Pediatrics, The University of Melbourne
Honorary affiliation with Dept Neurodevelopment and Disability, The Royal Children's Hospital, Melbourne.

Flemington Road Parkville Victoria 3052 Australia
T 03 9345 4807
E sue.reid@mcri.edu.au
www.mcri.edu.au

AUSTRALIAN CATHOLIC UNIVERSITY

PARTICIPANT INFORMATION LETTER

PROJECT TITLE: SURVEY ON VISUAL ABILITIES IN CHILDREN WITH CEREBRAL PALSY
PRINCIPAL INVESTIGATOR: A/PROF ELSPETH FROUDE
STUDENT RESEARCHER: BELINDA DERAMORE DENVER
STUDENT'S DEGREE: DOCTOR OF PHILOSOPHY

Dear Participant,
You are invited to participate in the research project described below.

What is the project about?
This survey forms part of a research project to develop and test a new way to assess visual abilities of children with CP. 'Visual ability' is defined as the 'use of vision' by children in their everyday activities.

This survey is an important step as we develop a new assessment. We need the opinions of parents and caregivers of children with CP, people with CP, and professionals who work with children with CP and their families. We want to know what they (you) think is important. This survey will help us to decide on the content and development of this new assessment of visual ability.

Who is doing the project?
The project is being conducted by Belinda Deramore Denver, an Occupational Therapist and research student at Australian Catholic University. She is also a Research Associate with the NHMRC Centre of Research Excellence in Cerebral Palsy (CRE-CP). This research is supported by Associate Professor Elspeth Froude (Australian Catholic University), Professor Christine Imms (Australian Catholic University, Centre for Disability & Development Research), and Professor Peter Rosenbaum (*CanChild* Centre for Childhood Disability Research, McMaster University, Canada).

Are there any risks in participating in this project?
We do not believe that there will be any risks associated with participation in this research. Anyone who feels confused or concerned by thinking about visual abilities in children with CP is encouraged to contact the lead researcher (Belinda Deramore Denver, belinda.deramoredenver@myacu.edu.au). People can also discuss their feelings with their local health service teams or other support networks.

What will I be asked to do?
To participate in this research you will be asked to complete an online survey. The survey has four sections: (1) information about the person completing the survey: whether you are an adult with CP, a parent or primary caregiver, or a professional. We will also seek additional information from parents/caregivers about their child with CP; (2) about visual abilities in children with CP, with questions about what is important about visual abilities; (3) about the development of a new assessment of visual

abilities; and (4) an invitation to people to add further information or comments. Each section has both 'closed' questions (where people choose one answer from the options available) and 'open' questions (where people can write their ideas). Everything in the survey will be confidential. No information will be collected during the survey that can identify who answered. All responses must be written in English. There are no follow-up requirements from this survey.

How much time will the project take?
The survey will take less than 30 minutes to complete, depending on how many comments you want to contribute. You may 'save' your responses as you progress and return at a later time to complete the survey.

What are the benefits of the research project?
There are no immediate benefits to survey respondents. However, we expect that what we learn from this survey will help us to develop a useful way to assess visual ability in people with CP. This can assist in providing best treatments for children in order to improve their outcomes. Your help in this survey, answering questions about visual ability, may lead to a better assessment by helping us understand how children use their vision.

Can I withdraw from the study?
Being in the survey is entirely voluntary. You are under no obligation to participate. If you agree to participate in the survey you can still withdraw at any time with no consequences. However, after you submit your ideas, the survey will be unable to be withdrawn. This is because the survey is anonymous and we will not know which survey you completed.

Will anyone else know the results of the project?
Survey responses will be stored in the computer. Each participant will be given their own identification number. The information will be password protected, and available only to the researcher and her supervisors.
The final results will be a collection of all responses. We will publish a report of the findings. Any comments from people who participate will be described as part of the information you provide, but no individuals will be identifiable. This is because of the large number of possible participants (e.g. parent of children with CP – GMFCS level III with a visual impairment, or Occupational Therapist in Australia), and the fact that no names will be kept in the computer files.

Will I be able to find out the results of the project?
Project updates and a link to any reports from this survey will be shared with participants who provide contact details for this purpose. The final section in the survey asks whether you want to provide your name and email address to the research team. Any contact information provided will be stored in a separate file to the other responses in the survey and no links will be made to other sections. No names

and addresses will be shared outside this study. Alternatively you can email the primary researcher at belinda.deramoredenver@myacu.edu.au and ask to be added to a contacts list.

Who do I contact if I have questions about the project?

If you have any questions, or would like further information about this project, please email or call Belinda Deramore Denver, +612 9739 2845 or email belinda.deramoredenver@myacu.edu.au

What if I have a complaint or any concerns?

The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2016- 282E) and the Cerebral Palsy Alliance Human Research Ethics Committee (review number 2017-04-04). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Manager, Ethics Office of the Deputy Vice Chancellor (Research) Australian Catholic University North Sydney Campus PO Box 968 NORTH SYDNEY, NSW 2059 Ph.: 02 9739 2519 Fax: 02 9739 2870 Email: resethics.manager@acu.edu.au	Chair, Ethics Committee Human Research Ethics Committee Cerebral Palsy Alliance PO Box 6427 FRENCHS FOREST, NSW 2100 Ph: 02 9975 8000 Email: ethics@cerebralpalsy.org.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up?

Thank you for wanting to take part. You do not need to complete a consent form to take part in this project. If you complete and submit the survey, this means you are giving your consent. You may open the survey in your web browser by clicking the link below: http://j.mp/2ovLAw8 or https://rdcap.acu.edu.au/surveys/?s=PLMHJ3YY97

Yours sincerely,

[redacted]

Belinda Deramore Denver
PhD candidate, Occupational Therapist
Australian Catholic University

Survey on visual abilities in children with cerebral palsy

Thank you for participating in this survey and sharing your opinions and experiences. This survey is about visual abilities in children with cerebral palsy (CP). It forms part of a research project that is developing and validating a new way to assess visual abilities of children with CP. ‘Visual ability’ is defined as the ‘use of vision’ by children in their typical daily life.

The survey may take up to 30-minutes to complete, depending on how many comments you want to contribute. All survey responses are anonymous.

You may ‘save’ your responses as you progress and return at a later time to complete the survey. You will need your 'Return Code' to be able to return and complete the survey. Each page does not need to be saved if completing it all at once.

Please complete the survey below.

SECTION 1: This section asks about you - Are you a parent of a child with CP? Do you have CP? Or do you work with families of children with CP?

Project description, ethics and consent information

[Attachment: "Participant information letter.pdf"]

Are you:	◯ A parent or primary caregiver of a child with CP, or infant who has been identified to be at high risk of CP ◯ An adult with CP ◯ A professional who works with children with CP and their families, and have at least 2 years of experience working within this field. ◯ Other interested person
Please explain why you wish to participate in this survey:	
Please select the option that is closest to a description of you: (Note: The type and wording of survey questions has been modified for each group of people).	◯ A parent or primary caregiver of a child or infant - no diagnosis of CP ◯ An adult with a diagnosis other than CP, or other person 18 years and older ◯ Other professional
Is Australia your country of residence?	◯ Yes ◯ No
Which state/territory in Australia is your usual residence:	◯ ACT ◯ NSW ◯ NT ◯ QLD ◯ SA ◯ TAS ◯ VIC ◯ WA
Please provide your country of residence: Please write your usual country of residence e.g. Canada.	

Please indicate your profession: You may select more than one option.	☐ Clinical psychologist ☐ Conductive educator ☐ Early educator ☐ General practitioner (GP) ☐ Manager ☐ Neonatologist ☐ Neurologist ☐ Neuropsychologist ☐ Nurse ☐ Occupational therapist ☐ Ophthalmologist (doctor) ☐ Optometrist ☐ Orientation & mobility instructor ☐ Orthoptist ☐ Paediatrician ☐ Physiotherapist/Physical therapist ☐ Rehabilitation/Physical medicine physician (doctor) ☐ Researcher ☐ Social worker ☐ Speech pathologist/Speech and language therapist ☐ Teacher/Education ☐ Teacher of the vision impaired (Special education) ☐ Other profession
Please specify your profession:	
Please indicate the number of years clinical experience you have working with children with CP:	◯ < 5 years ◯ 5-10 years ◯ 10-20 years ◯ >20 years
Please select the setting/s where you see children with CP and their families: Please check all that apply.	☐ Hospital, inpatient setting ☐ Hospital, outpatient/clinic setting ☐ Community outpatient/clinic/center setting ☐ School/education setting ☐ Family home ☐ Research facility ☐ Other
What is your current age?	◯ 18 to 25 years ◯ 25 to 40 years ◯ over 40 years
What type of cerebral palsy do you have? Please select the main type of CP, if known. Reference: https://www.cpregister.com/	◯ Spasticity - Left hemiplegia/monoplegia ◯ Spasticity - Right hemiplegia/monoplegia ◯ Spasticity - Diplegia ◯ Spasticity - Triplegia ◯ Spasticity - Quadriplegia ◯ Dyskinesia - mainly athetosis ◯ Dyskinesia - mainly dystonia ◯ Ataxia ◯ Hypotonia ◯ Unknown

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Gross motor function can be categorised into 5 different levels using a tool called the Gross Motor Function Classification System Expanded and Revised (GMFCS - E&R).

According to the GMFCS, what is your level of gross motor functioning?

If you don't know, please select 'Unknown' or refer to website for more details here

- ◯ Level I: Walks without limitations
- ◯ Level II: Walks with limitations
- ◯ Level III: Walk using a hand-held mobility device
- ◯ Level IV: Self-mobility with limitations; may use powered mobility
- ◯ Level V: Transported in a manual wheelchair
- ◯ Unknown

Ability to handle objects in everyday activities can be categorised into 5 levels using the Manual Ability Classification System (MACS).

According to the MACS, what is your level of manual ability?

If you don't know, please select 'Unknown' or refer to website for more specific details here

- ◯ Level I: Handles objects easily and successfully
- ◯ Level II: Handles most objects but with somewhat reduced quality and/or speed of achievement
- ◯ Level III: Handles objects with difficulty; needs help to prepare and/or modify activities
- ◯ Level IV: Handles a limited selection of easily managed objects in adapted situations
- ◯ Level V: Does not handle objects and has severely limited ability to perform even simple actions
- ◯ Unknown

The CFCS is a tool used to classify the everyday communication of an individual with cerebral palsy into one of five levels according to effectiveness of communication. It consists of five levels which describe everyday communication ability.

According to the CFCS, what is your level of communication ability?

If you don't know, please select 'Unknown' or refer to website for more specific details here

- ◯ Level I: Effective Sender and Receiver with unfamiliar and familiar partners
- ◯ Level II: Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners
- ◯ Level III: Effective Sender and Receiver with familiar partners
- ◯ Level IV: Inconsistent Sender and/or Receiver with familiar partners
- ◯ Level V: Seldom Effective Sender and Receiver even with familiar partners
- ◯ Unknown

What is the current age of your child?

Note: If you are the parent or caregiver of more than one child with CP, please select only one child to report on for the purpose of this survey. Additional information can be provided in the comment boxes and/or you may complete a second survey.

- ◯ Less than 4 months
- ◯ Between 4 months and 11 months
- ◯ Between 1 year and 2 years,11 months
- ◯ Between 3 years and 5 years,11 months
- ◯ Between 6 years and 11 years, 11 months
- ◯ Between 12 years and 17 years, 11 months
- ◯ 18 years +

(Age of child with CP.)

What type of cerebral palsy does your child have?

Please select the main type of CP, if known.

Reference: https://www.cpregister.com/

- ◯ Spasticity - Left hemiplegia/monoplegia
- ◯ Spasticity - Right hemiplegia/monoplegia
- ◯ Spasticity - Diplegia
- ◯ Spasticity - Triplegia
- ◯ Spasticity - Quadriplegia
- ◯ Dyskinesia - mainly athetosis
- ◯ Dyskinesia - mainly dystonia
- ◯ Ataxia
- ◯ Hypotonia
- ◯ Unknown

The gross motor function of children and young people with cerebral palsy can be categorised into 5 different levels using a tool called the Gross Motor Function Classification System Expanded and Revised (GMFCS - E&R). According to the GMFCS, what is your child's level of gross motor functioning? If you don't know, please select 'Unknown' or refer to website for more details here	◯ Level I: Walks without limitations ◯ Level II: Walks with limitations ◯ Level III: Walks using a hand-held mobility device ◯ Level IV: Self-mobility with limitations; may use powered mobility ◯ Level V: Transported in a manual wheelchair ◯ Unknown
The ability of children with cerebral palsy to handle objects in everyday activities can be categorised into 5 levels using the Manual Ability Classification System (MACS) or the Mini-MACS for children 1-4 years of age. According to the MACS or Mini-MACS, what is your child's level of manual ability? If you don't know, please select 'Unknown' or refer to website for more specific details 4 years old and over here or 1 to 4 years old here	◯ Child is less than 1-year-old ◯ Level I: Handles objects easily and successfully ◯ Level II: Handles most objects but with somewhat reduced quality and/or speed of achievement ◯ Level III: Handles objects with difficulty; needs help to prepare and/or modify activities ◯ Level IV: Handles a limited selection of easily managed objects in adapted situations (or in simple actions for young children) ◯ Level V: Does not handle objects and has severely limited ability to perform even simple actions ◯ Unknown
The CFCS is a tool used to classify the everyday communication of an individual with cerebral palsy into one of five levels according to effectiveness of communication. It consists of five levels which describe everyday communication ability. According to the CFCS, what is your child's level of communication ability? If you don't know, please select 'Unknown' or refer to website for more specific details here	◯ Child is less than 2 years old ◯ Level I: Effective Sender and Receiver with unfamiliar and familiar partners ◯ Level II: Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners ◯ Level III: Effective Sender and Receiver with familiar partners ◯ Level IV: Inconsistent Sender and/or Receiver with familiar partners ◯ Level V: Seldom Effective Sender and Receiver even with familiar partners ◯ Unknown

SECTION 2: In this research we are interested in 'visual ability' which describes how children use their vision in daily activities. This is different to how the eyes work or how the brain understands visual information. Some children with CP will have no problems using vision, whilst other children may have lots of difficulty.

This section is about your experiences.

How would you best describe your child's current visual abilities? (Consider: How well does your child use vision in daily activities?)	◯ Good visual abilities ◯ Some limitations ◯ Poor visual abilities
Please explain why you chose your previous answer: For example, please provide a reason or example of why you would describe your child's abilities as "good", "having some limitations" or "poor".	
Which option best describes your visual abilities? (Consider: How well you use vision in daily activities?)	◯ Good visual abilities ◯ Some limitations ◯ Poor visual abilities
Please explain why you chose your previous answer: Please provide a reason or example of why you would describe your visual abilities as "good", "having some limitations" or "poor".	
Do you ever have concerns about how at least some children with CP use their vision in daily activities?	◯ Yes ◯ No
Please briefly describe or provide an example of a concern about how vision is used: For example: describe a child or group of children and your specific concerns; describe a situation/situations where visual ability has impacted on child and family outcomes, your interaction or research outcomes.	
Do you currently (or in a past professional role) assess how children with CP use their vision? Note: Assessment of vision may be formal or informal. Informal assessment may include asking about vision or your observations of the child.	◯ Yes ◯ No

Please indicate if you use any of the following methods or assessment tools to assess how children with CP use their vision:

Note: Please check all that apply.

- ☐ Informal observation of vision use
- ☐ Informal questioning of vision use
- ☐ Structured Questionnaire of vision use
- ☐ Developmental assessment with vision section
- ☐ Atkinson Battery for Child Development for Examining Functional Vision (ABCDEFV)
- ☐ CVI Range Assessment (Roman-Lantzy, 2007)
- ☐ Erhardt Developmental Visual Assessment (EDVA)
- ☐ Functional Visual Questionnaire (Ferziger et al., 2011)
- ☐ Preverbal Visual Assessment (PreViAs)
- ☐ Visual Assessment Procedure - Capacity, Attention and Processing (VAP-CAP)
- ☐ Visual Skills Inventory (McCulloch et al., 2007)
- ☐ Other

Please describe or provide an example of what you do or look for in your informal observations:

Please describe or provide an example of what you ask in your informal questioning approach:

Please name or describe the Structured Questionnaire used:

Please name or describe the Developmental assessment used:

Please specify other assessment tools or methods used to assess how children with CP use their vision within everyday activities:

In your experience, how clinically important is it to know about the following visual behaviours in children with CP?

How important is it to know about these 15 visual behaviours among children with CP?

	Def n te y mportant	Probab y mportant	Probab y not mportant	Def n te y not mportant
Responding or reacting (in some way) to visual information.	○	○	○	○
Looking towards (orienting to or generally locating) visual information.	○	○	○	○
Maintaining visual attention with activities (keeps looking).	○	○	○	○
Shifting visual attention from one target to look at another.	○	○	○	○

Searching for a specific target using vision.	○	○	○	○
Exploring using vision and being visually curious.	○	○	○	○
Finding specific visual information.	○	○	○	○
Following moving targets using vision.	○	○	○	○
Responding quickly and without delay to visual information.	○	○	○	○
Looking at people and faces.	○	○	○	○
Looking at objects.	○	○	○	○
Looking across distance.	○	○	○	○
Using vision together with hand use.	○	○	○	○
Consistently and reliably using vision within daily activities.	○	○	○	○
Efficiently performing activities that require vision.	○	○	○	○

Are there any additional visual behaviours missing from this list of 15 that you consider to be important?

Note: Please describe additional behaviours in as much detail as possible.

Over the next three pages we will introduce you to 14 behaviours and ways to describe visual abilities. You may have observed them all in your child, or you may have observed only a few. We are interested in what you observe within daily activities with your child.

Can you tell if your child responds or reacts (in any way) to visual information?

(Note: Visual information can include anything e.g. toys, faces, lights or bright/shiny materials).

- ○ I am sure that my child does respond or react to visual information
- ○ My child probably has some ability to respond or react to visual information, but there are limitations e.g. unusual or inconsistent responses that lead to doubt about whether the response is a visual response
- ○ I am sure that my child does not respond or react to visual information
- ○ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has in responding to visual information that you have observed.

Can you tell if your child looks toward or in the direction of visual information?

- ◯ I am sure that my child does look toward visual information, and I have no concerns with how this is done
- ◯ My child probably has some ability to look toward visual information, but there are limitations e.g. may require specific set-up such as good lighting or positioning
- ◯ I am sure that my child does not look toward visual information
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has in looking towards visual information that you have observed.

Can you tell if your child keeps looking at visual information (i.e. maintains visual attention)?

- ◯ I am sure that my child does maintain visual attention in daily activities, and I have no concerns with how long he/she keeps looking
- ◯ My child probably has some ability to keep looking or maintain visual attention, but there are limitations e.g. not in all environments or it may only occur with a favourite toy
- ◯ I am sure that my child does not keep looking or maintain visual attention
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has in maintaining visual attention that you have observed.

Can you tell if your child shifts gaze (looking), or changes visual attention from looking at one thing, to look at another, and perhaps back again?

- ◯ I am sure that my child does shift looking from one thing to look at another, and I have no concerns with this ability
- ◯ My child probably has some ability to look from one thing to another, but there are limitations e.g. some environments or the need for prompts to look elsewhere
- ◯ I am sure that my child does not shift looking
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has in shifting gaze between visual information that you have observed.

Can you tell if your child uses vision to search for a specific target?

For example, does your child look for a missing toy or person?

- ◯ I am sure that my child does search using vision, and I have no concerns with this ability
- ◯ My child probably has some ability to search, but there are limitations e.g. he/she needs prompting
- ◯ I am sure that my child does not use vision to search
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has in using vision to search for specific targets that you have observed.

Question	Options
Can you tell if your child uses vision to explore? For example, does your child look around a room or visually and curiously inspect the parts of a toy?	◯ I am sure that my child does explore using vision, and I have no concerns with his/her visual curiosity ◯ My child probably has some ability to explore visually, but there are limitations e.g. he/she needs prompting ◯ I am sure that my child does not use vision to explore ◯ I can't tell whether or not my child demonstrates this ability
Please provide one example of the limitations your child has using vision to explore that you have observed.	
Can you tell if your child uses vision to find specific information? For example, does your child find a missing or dropped toy, find you in a crowd or find their classroom?	◯ I am sure that my child does find what he/she is searching for using vision, and I have no concerns with this ability ◯ My child probably has some ability to find specific information using vision, but there are limitations e.g. not if there is a lot of visual information to search within ◯ I am sure that my child does not find things using vision ◯ I can't tell whether or not my child demonstrates this ability
Please provide one example of the limitations your child has in using vision to find specific information that you have observed.	
Can you tell if your child visually follows moving targets? For example, does your child visually follow the movements of a dog or track a toy?	◯ I am sure that my child does follow moving targets using vision, and I have no concerns with this ability ◯ My child probably has some ability to follow moving targets using vision, but there are limitations e.g. only following the rolling ball a short distance ◯ I am sure that my child does not follow moving targets using vision ◯ I can't tell whether or not my child demonstrates this ability
Please provide one example of the limitations your child has in following moving targets that you have observed.	
Can you tell if your child responds quickly to visual information or has a delayed response?	◯ I am sure that my child does respond quickly and spontaneously to visual information ◯ My child probably has some ability to respond quickly to visual information, but there are limitations e.g. slower in new situations, or when tired, sick or overstimulated ◯ I am sure that my child does not initiate a quick response to visual information. My child has a delayed response to visual information. ◯ I can't tell whether or not my child demonstrates this ability.

Please provide one example of the limitations your child has in responding quickly to visual information that you have observed.

Some children with CP have good or effective visual abilities, whilst other children may have no ability at all. We are hoping to identify the range of visual abilities that can be observed in children with CP.

This section is your opportunity to contribute additional examples of behaviours observed in children with CP that demonstrate the variability of performance between good visual ability and no visual ability. Nine abilities are listed here.

You may have examples of behaviours for all nine, or some of them.
If you do not have any examples or comments please move to the next section.

The ability to respond or react to visual information:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. subtle moving in reaction to light, or no response unless there is noise).

The ability to look towards (orient to or generally locate) visual information:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. can only locate light or very big objects).

The ability to keep looking or maintain visual attention:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. only brief glances).

The ability to shift visual attention between two or more targets:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. requires a prompt to shift from looking at one toy to another toy).

The ability to use vision to search:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. requires a prompt to look for a missing toy or person).

The ability to use vision to explore:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. lack of visual curiosity, no observation of child looking around a room, no visually inspecting parts of a toy).

The ability to use vision to find specific visual information:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. finding missing toys, parents, or the way to a classroom when it is busy).

The ability to follow moving targets:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. following movement of the dog or a toy if it is moved quickly).

The ability to respond quickly to visual information:

Please provide examples of behaviours you have observed that demonstrate variability between good ability and no ability (e.g. typical or delayed responses).

Can you tell if your child looks at people and faces?

For example, does your child look at a face and interact by smiling in recognition or in response to a smile)?

- ◯ I am sure that my child does look at people and faces, and I have no concerns with how this is performed
- ◯ My child probably has some ability to look at people and faces, but there are limitations e.g. poor eye contact
- ◯ I am sure that my child does not look at people or faces
- ◯ I can't tell whether or not my child demonstrates this ability.

Please provide one example of the limitations your child has in looking at people or faces that you have observed.

Can you tell if your child looks at objects?

For example, does your child look at pictures in a book, toys, and their drink bottle?

- ◯ I am sure that my child does look at objects, and I have no concerns with how this is performed
- ◯ My child probably has some ability to look at objects, but there are limitations e.g. only a favourite or red toy
- ◯ I am sure that my child does not look at objects
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has with looking at objects that you have observed.

Can you tell if your child looks across distance?

For example, does your child look across the room or playground and not just close up or within arm's reach?

- ◯ I am sure that my child does look across distance, and I have no concerns with how this is performed
- ◯ My child probably has some ability to look across distance, but there are limitations e.g. how far or the type of environment
- ◯ I am sure that my child does not look across distance
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has with looking across distance that you have observed.

Can you tell if your child uses vision together with hand use?

For example, does your child look whilst reaching? Do they look at what they are doing with their hands or what your hands are doing?

- ◯ I am sure that my child does use vision together with hand use, and I have no concerns with how this is performed
- ◯ My child probably has some ability to use vision together with hand use, but there are limitations e.g. slower or increased visual attention to hands to compensate for physical disability
- ◯ I am sure that my child does not use vision together with hand use
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has with using their vision together with hand use that you have observed.

Can you tell how consistently your child uses vision across the day?

For example, does their ability to use vision fluctuate from hour to hour, or day to day, or do they often prefer listening, mouthing or touching?

- ◯ I am sure that my child uses vision consistently across the day
- ◯ My child probably uses vision across the day, but there are limitations e.g. fluctuations across the day
- ◯ I am sure that my child does not use vision consistently
- ◯ I can't tell whether or not my child demonstrates this ability

---

Please provide one example of the limitations your child has with using their vision across the day that you have observed.

Can you tell how well your child does activities that require vision?

For example, how well does your child use vision to recognize objects and people, to move around the environment, to read text or match pictures, or watch tv?

- ◯ I am sure that my child performs well in activities that require vision. They are independent and efficient in these activities.
- ◯ My child probably performs activities that require vision, but there are limitations e.g. slower, need for help, or only completes some activities efficiently using vision
- ◯ I am sure that my child does not use visual abilities to do any activities
- ◯ I can't tell whether or not my child demonstrates this ability

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Please provide one example of the limitations your child has performing an activity that requires vision (that you have observed).

SECTION 3: Some children with CP may benefit from interventions to help make the most of their visual abilities, and we need assessments so we know which interventions are best.

This section is about your experience of visual abilities that might change and could be important to an assessment of how vision is used.

Have you ever had goals to improve how your child uses their vision?

(Note: A goal might be formally set with a therapy team or be an informal goal or hope you have for making a change).

◯ Yes
◯ No

Have you ever had goals to improve how you use your vision?

(Note: A goal might be formally set with a therapy team or be an informal goal or hope you have for making a change).

◯ Yes
◯ No

Do the children you see in your professional role ever have goals to improve their use of vision?

(Note: A goal might be formally set with a child/family, or be an informal goal or aspiration for making change).

◯ Yes
◯ No

Please tell us about one goal. What was the focus or aim of the goal?

Has your child ever received therapy or recommendations to improve their use of vision?

◯ Yes
◯ No

Have you ever received therapy or recommendations to improve your use of vision?

◯ Yes
◯ No

Do you ever provide therapy or recommendations to improve how children with CP use their vision?

(Note: If there is another member of your team who provides therapy or recommendations, please also encourage them to complete this survey).

◯ Yes, providing therapy/recommendations to improve how vision is used is a key role for me
◯ Yes, providing therapy/recommendations to improve how vision is used is sometimes a strategy used to achieve other goals e.g. mobility or communication
◯ No, I never provide any therapy or recommendations to improve how children use their vision

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For specific interventions or strategies that aim to improve how a child uses their vision, how do you evaluate the effectiveness of the therapy or recommendations?

You may select more than one option.

☐ Canadian Occupational Performance Measure (COPM)
☐ Goal Attainment Scaling (GAS)
☐ Other assessment tool/s
☐ Informal evaluation
☐ No evaluation of effectiveness undertaken

Please describe your informal evaluation approach for establishing the effectiveness of interventions or strategies to improve how vision is used.

Please provide an example of an occupational performance problem identified using the COPM that relates to how vision is used.	
Please provide an example of a goal that has been scaled to evaluate how vision is used. Note: Whilst welcome, the full attainment scale does not need to be provided.	
Please specify what assessment tool you have been using to evaluate the effectiveness of interventions on how vision is used. Please list all assessment tools used to evaluate the effectiveness of interventions to improve vision use.	
Did your child's ability to use vision change following therapy and/or recommendations?	◯ Yes ◯ No ◯ Unsure
Have you ever seen a change in how vision is used by children with CP following therapy and/or recommendations?	◯ Yes ◯ No ◯ Unsure ◯ N/A - I have not seen a child who has received therapy or recommendations to improve use of vision.
Did your vision use ever change following therapy and/or recommendations?	◯ Yes ◯ No ◯ Unsure
Please describe or provide an example of how vision use changed (or might have changed) following therapy and/or recommendations:	
Do you think you there are children with CP who could benefit from therapy or recommendations to improve how they use their vision?	◯ Yes ◯ No
Do you think your child would (now, or in the past), benefit from therapy or recommendations to improve how vision is used?	◯ Yes ◯ No
What changes or benefits would you expect or like to see as a result of therapy to improve vision use?	
Do you think it is (or could be) useful to assess how well your child uses their vision in daily activities?	◯ Yes ◯ No
Do you think it is (or could be) useful to assess how children with CP use their vision in daily activities?	◯ Yes ◯ No

When would it be most useful to have an assessment of how your child uses their vision in daily activities?

Suggestions: At diagnosis? At a certain age? When you child is learning to move or communicate?

When or with which children with CP would it be most useful to have an assessment of how vision is used?

Suggestions: For certain diagnostic groups? At a certain age? For children with particular goals such as mobility or communication?

Why don't you think it would be useful to assess how vision is used?

SECTION 4: Thank you for participating in this survey. The information provided will help us to develop our approach to assessing visual abilities in children with CP.

Please add any further information you feel may be helpful here:

This is your last opportunity to provide comments.

Do you want to provide your contact details to the research team?

If so, you are encouraged to provide your details here. Providing your email address will allow us to keep you updated and tell you about future steps in this research project. You might want to be involved again!

Alternatively you can email the primary researcher at belinda.deramoredenver@myacu.edu.au and ask to be added to a contacts list.

Any contact information provided here will be stored in a separate file to the other survey responses and no links will be made to previous sections. As mentioned in the introduction, the responses to this survey are confidential. Responses received by the researchers will be assigned a unique number to keep them separate.

(Option to provide email address to research team.)

Dear Applicant,

Principal Investigator: A/Prof Elspeth Froude
Co-Investigator: Prof Christine Imms, Prof. Peter Rosenbaum Student
Researcher: Ms Belinda Deramore Denver (Doctoral)
Ethics Register Number: 2017-313H
Project Title: Developing and testing a measure of vision use for children with cerebral palsy (CP)
Date Approved: 22/02/2018
Ethics Clearance End Date: 30/06/2019

This is to certify that the above application has been reviewed by the Australian Catholic University Human Research Ethics Committee (ACU HREC). The application has been approved for the period given above.

Researchers are responsible for ensuring that all conditions of approval are adhered to, that they seek prior approval for any modifications and that they notify the HREC of any incidents or unexpected issues impacting on participants that arise in the course of their research. Researchers are also responsible for ensuring that they adhere to the requirements of the *National Statement on Ethical Conduct in Human Research,* the *Australian Code for the Responsible Conduct of Research* and the University's *Code of Conduct*.

Any queries relating to this application should be directed to the Ethics Secretariat (res.ethics@acu.edu.au). It is helpful if quote your ethics approval number in all communications with us.

If you require a formal approval certificate in addition to this email, please respond via reply email and one will be issued.

We wish you every success with your research.

Kind regards,

Kylie Pashley
on behalf of ACU HREC Chair, Dr Nadia Crittenden

Senior Research Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL

PARTICIPATION INFORMATION SHEET AND CONSENT FORM

Pre-testing with interviews

Project title	**Developing and testing a measure of vision use for children with cerebral palsy (CP)**
ACU HREC Project No.	2017-313H
Principal investigator	A/Prof Elspeth Froude
Student researcher	Belinda Deramore Denver
Student's degree	Doctor of Philosophy (PhD)

Dear Participant,

Thank you for taking the time to read this Participant Information Sheet. It is three pages long – please make sure you have all the pages. These pages contain information about the research project we are inviting you to participate in. The purpose of this information is to explain to you clearly and openly the steps and procedures for taking part in this phase of the project '*Developing and testing a measure of vision use for children with CP'*. This phase is called the *Pre-testing with interviews* study. This information is to help you decide whether or not you would like to take part in the research.

Please read this information sheet carefully. Ask questions about anything you don't understand or want to know more about. Your participation in this research is voluntary. If you do not wish to take part, you do not have to do so. If you decide you want to take part in the research project, you will be asked to sign a consent form. You will be given a copy of the Information Sheet and Consent Form to keep. By signing it you are telling us that you:

- Understand what you have read (or had read to you)
- Consent to take part in the research project

What is the project about?

We wish to develop a new measure of visual ability for children with CP. This measure is about how children *use* their vision in day to day activities – this is a bit different to whether or not children can see. Children show their ability to use vision in many ways. For example, when they look at you and smile, look for a favourite toy, or copy an action they have seen. For some children with CP vision may be a strength, however some children are limited in the way they use vision. If we could understand better how children with CP use vision this may help us work out how to improve their use of vision. We need a good measure before we can work out what would be an effective therapy.

Why have I been invited to participate?

You are being asked to take part in this project because you responded to our prior survey. From that survey we developed a draft measure. We now want people to look at this draft measure to help us improve it, before we use it with a larger group of parents and children.

Who is doing this project?

Belinda Deramore Denver is the Student Researcher leading this project, and this project is part of her PhD studies at Australian Catholic University. Belinda is an Occupational Therapist with thirteen years' experience working with children and their families in New South Wales, Victoria and South Australia. Belinda's primary clinical experience includes working with children with cerebral palsy and/or vision impairment. Belinda is a member of the Australasian Academy of Cerebral Palsy and Developmental Medicine and a Research Associate with the NHMRC Centre of Research Excellence in Cerebral Palsy (CRE-CP). She has partial funding for this project through the Cerebral Palsy Alliance Research Foundation (CDG7716). This research is supported and supervised by Associate Professor Elspeth Froude (Australian Catholic University), Professor Christine Imms (Australian Catholic University, Centre for Disability & Development Research), and Professor Peter Rosenbaum (*CanChild* Centre for Childhood Disability Research, McMaster University, Canada).

Are there any risks associated with participating in this project?
There are no known/expected risks to you participating in this study. Some people may not like being interviewed, and participation will take an hour of your time.

What will I be asked to do? How much time will the project take?
You will be shown the draft measure and you will be asked questions by the researcher about your thoughts on it. You might be asked about the wording of a question, what looks better, or to explain how you would answer a question in the measure. These questions will be asked in an informal interview. We will ask for your permission to audio-record the interview. The interview will take up to one hour of your time, and it will be done in-person (face-to-face). There may be an option to do the interview via Skype. The interview will occur in the first half of 2018 and it will be done with Belinda Deramore Denver (PhD student).

What are the benefits of the research project?
The development of this new measure will help us to understand how children with CP use their vision, and this may help us work out how to improve their vision use.

Can I withdraw from the study?
You do not have to take part in this project if you do not want to. If you decide to take part and later change your mind, you do not need to give a reason and your decision will not affect any services or care you receive. If you decide to withdraw from the project after your interview we will be *unable to completely withdraw your interview data after a two-weeks* because changes will be made to the measure based on your interview. You may withdraw any of your personal information (e.g. post code, gender, type of CP) at any time by contacting the research team.

Will anyone else know the results of the project?
Any information we collect from you will remain confidential. We will use your information only for this research project. Your signed consent form will be kept separate from all other information we collect, and that information will be 'coded'. This means we will use a number instead of your name on all documents, files and audio-recordings.

We will store all information in separate and password protected computer files, and it will be available only to the research team. All paper documentation will be scanned and stored as electronic data, with the originals shredded.

The results of this study will be published in the PhD thesis, and will also be used for conference publications, presentations, and professional journals. You will not be identified in these publications. Quotes from your interview will be used and labelled with information such as 'mother of a child with GMFCS III and good visual abilities'.

Will I be able to find out the results of the project?

You will get feedback at the end of the interview about the main points and how this might be used to change the measure. You will also be emailed updates in the future, and further information can be found on the research project web page http://www.cre-cp.org.au/research/visual-abilities/

Who do I contact if I have questions about the project?

If you have any questions, or would like further information about this project, please email or call Belinda Deramore Denver, +61 2 9739 2845 or email belinda.deramoredenver@myacu.edu.au

What if I have a complaint or any concerns?

The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2017-313H). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Manager, Ethics
Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
North Sydney Campus
PO Box 968
NORTH SYDNEY, NSW 2059

Ph.: 02 9739 2519
Fax: 02 9739 2870
Email: resethics.manager@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up?

Thank you for wanting to take part. Please complete the Expression of Interest form attached to the email invitation or by clicking on the link here: https://rdcap.acu.edu.au/surveys/?s=XXTDN9WNKW

Once the Expression of Interest form is received the research team will be in touch with you. Please note, we think we only need 10 people for this phase of the research, however we want a range of people with different perspectives e.g. parents of children with good and poor vision, different age groups, and adults with cerebral palsy. So, please tell us if you are interested to participate so that we can be sure to include a range of people.

Yours sincerely,

[redacted]

Belinda Deramore Denver
PhD candidate, Occupational Therapist
Australian Catholic University

CONSENT FORM
Pre-testing with interviews

Project title	**Developing and testing a measure of vision use for children with cerebral palsy (CP)**
ACU HREC Project No.	2017-313H
Principal investigator	A/Prof Elspeth Froude
Student researcher	Belinda Deramore Denver
Student's degree	Doctor of Philosophy (PhD)

I (participant name) ____ voluntarily consent to participate in the above research project.

Please indicate your consent by ticking each box that you agree with:

☐	I confirm that I have **read and understood the Information Sheet** (version 1.6) for *Pre-testing with interviews* which is a study within the research project *Developing and testing a measure of vision use for children with CP*. I have had the opportunity to consider the information, ask questions and have had these answered.
☐	I consent to **participate in a 60-minute interview**.
☐	I consent to the interview being **audio-recorded and transcribed** for the purposes of this research project.
☐	I understand and agree that data (e.g. direct quotations) from my interview may be **published in a form that does not identify me** in any way. ADDITIONAL CONSENT
☐	I give permission for the **scores from the measure to be used in future analyses**. *(Note: This point is only applicable to interviews whereby a parent rates their child using the measure).*
☐	I consent to be **invited** to future steps in this research project (e.g. follow-up assessments, therapy/treatment studies)

Signature of Participant____Date: __________

Signature of Researcher (Belinda Deramore Denver) _____________________ Date: __________

Cognitive Interviewing Guide

Note: This is a draft interview guide. No two interviews will be the same. An interview guide will be confirmed prior to each interview. The guide will be build on previous interviews and will be tailored for the type of participant e.g. A parent of a young child with CP may be asked to consider how they would answer a question for their child, whilst an adult with CP may be asked for more feedback on wording.

Preparation for the Interview

- Materials required:
    - ☐ Participant Information Sheet & Consent forms x2 (Copy for participant and copy for researcher)
    - ☐ Copy of 'Cognitive Interviewing Guide'
    - ☐ Copies of GMFCS, MACS, CFCS
    - ☐ Current version of draft measure
    - ☐ Pens
    - ☐ Data collection sheets
    - ☐ Digital audio-recorder with extra batteries (AAA)
    - ☐ Bottled water

- Location organization
    - ☐ Arrange location/room with privacy and minimal distractions.
    - ☐ Arrive before the interview time according the location and agreement with the participant (unless at participants own home). Interview may be done in a quite office or other location. Set chairs perpendicular to each other ???faciliate equal conversation. Arrange material so that they are accessible. Test audio-recorder. Fill in portion of data collection sheet that can be completed.
    - ☐ If the participant arrives late to the interview – ask if they still have available 60min before commencing, and adjust/prioritize accordingly.
    - ☐ If the participant does not attend the interview – call the participant and confirm data and time. Let them know I am still interested in them participating. Ask if they would like to reschedule the interview and if they do make a new time. Thank them for their interest in the project and answer any questions that they have.

Interview Schedule

Participant ID:	
Version of Draft measure:	
Date of interview:	
Scheduled time:	
Interviewer:	
Start time:	
Greet the participant	Introduce myself and thank participant for interest. If appropriate, show participant where to sit and offer bottled water.
Establish rapport	Ease anxiety participant may have about the interview by establishing some rapport. This might include asking whether the participant has even been involved in interviews for research in the past.
Remind participant about the project	Example script: The purpose of this project is to explore whether the draft measurement tool is clear and understandable. The best way to do that is to get feedback from key people such as yourself. Based on these interviews we will be revising the questions we are asking. Each of these pre-testing interviews will be slightly different as we build on the responses from the previous interview. This is the _______th interview in this phase. This project is being lead by myself and forms part of my PhD thesis.
Obtain informed consent	Review informed consent form. Allow participant to read through and answer any questions that they have. Key points to highlight: - This study involves looking at a draft measure of vision use for children with CP with the purpose of improving the measure before it is used with a larger group of parents and children. You will be asked questions in an informal interview. - Your participation is voluntary - If you participate in an interview you will be unable to completely withdraw the information you discuss after a two-week deadline because changes will be made to the measure based on your interview, but you may withdraw any personal information at any time. - Your contribution will be kept confidential - The interview will be audio-recorded and the researcher will take notes on what you say. ☐ Complete Consent Form or discontinue.

Collect participant demographic information	Provide participant with the 'Demographic collection form' and ask them to complete it, or complete it as an interview. Participants may leave any questions blank that they do not wish to answer. ☐ Demographic Collection Form
Introduction to what we are doing in the interviews	*We are not collecting information about <u>you</u> but are trying our questions out on people like you so that we can <u>make the questions better</u>* Our goal here is to get a better idea of how the questions are working. So I'd like you to think aloud as you answer the questions – <u>just tell me everything that comes to mind as you about answering them</u> If there are things you particularly like or don't like please do say! If any question is unclear, hard to answer or doesn't make sense please tell me that – <u>don't be shy</u>! There are no right or wrong answers. We will do this for about an hour unless I run out of things to ask you before then. You can take a break at any time. Please ask. Do you have any questions before we start? ____ ____ ____ ☐ Confirm consent to proceed with audio-recording interviewing.
TURN ON AUDIO-RECORDING DEVICE	
Start interview	"Today is (say date dd/mm/yyyy) ______________and this is an interview between PhD Research Student Belinda Deramore Denver and Participant (ID number)______________ . This interview is part of the Pre-testing Study with the 'Developing and testing a measure of vision use for children with cerebral palsy' project.
Prompts will be tailored for each individual interview. The following are some examples.	
Introduction to the measure	Show the participant the measure, or part of the measure. Begin with questions as per plan for individual interview, examples of possible questions below in italics.
Name of measure	*What do you think about the name 'Measure of Early Vision Use' or MEVU?* *What does **early vision use** mean to you?* *Do you have a preference for the word measure or assessment or test?*
Introduction	*What period of time is it ask about/what does that cover for you?* *What does **day to day activities** mean to you?* *Do you have a preference for the wording 'day to day activities' or 'daily activities'? Do you have any other suggestions?* *Can you tell me in your own words what the introduction is telling you?*
Instructions	*What is the instruction telling you to do?* *Is that easy or difficult to follow?* *What does the word **effective** mean to you?*
Individual items	*What does **x** mean to you?* *How well does this apply to your child?* *Was it easy or difficult to decide what answer to give?* *Do the response options apply to your child?*

	What day to day activities are you thinking of when answering this question? *Tell me why you chose x rather than y?* *In your own words what is this question asking?* *Is it useful or confusing having searches and finds as different questions?* *Note: Adults with CP will not be asked to apply the items to their child.*
Layout	*Do you like the layout?* *How did you find the order of questions? Would you prefer any questions to be in a different order?* *Do you like the font?* *Are the words big enough?* *Are the underlined/bold parts in correct/useful places?* *Do you like the coloured response options?* *What do the colours mean to you?* *Which of these two formats do you like better? Why?*
General notes/ considerations for interview	Providing encouragement to the participant - If the participant is having difficulty with the thinking aloud, interview style consider comments/ questions such as: o “Tell me what you are thinking” o “What thoughts are going through your mind right now?” o “I am interested in whatever you are thinking as your read and consider the questions in this tool. Do whatever you need to help you think aloud about the questions.” General probes: o In your own words, what is this question asking? o How did you come up with that answer? o Tell me more about that o What does the term….mean to you in this question? o What time period are you thinking of? o You hesitated a bit there, what are you wondering about? o How could we phrase that question better? o How would you phrase that in your own words? o How easy or difficulty did you find that question to answer? Why do you say that? o How confident/satisfied are you with the response options for that question? o How appropriate is that question for children with different types of cerebral palsy?
Summary of key points from interview	Recap key points of discussion that have been captured during the interview and how this information may be used in the development of the measurement tool.
Final questions	Ask for any final comments or questions before the audio-recorded is turned off.
TURN OFF AUDIO-RECORDING DEVICE	
Interview wrap-up	Thank participant for participating in this research and taking the time to talk with me about the measurement tool. Your involvement will help

	use to develop a measure that will be useful for both families and clinicians and researchers to optimize outcomes for children with cerebral palsy. Do you have any other questions or feedback that you would like to make with the audio-recorded turned off? How did you find the interview? ____ ____ ____
End time:	

Post-interview
Notes/comments on interview (factors that affected interview, general comments throughout interview):

Audio-recording saved to computer
Location:

File name:

☐ Deleted from audio-recorder

Appendix I Supporting information for Study 5

This appendix contains:

- Ethical approval from Australian Catholic University for 2018-178H Testing the Measure of Early Vision Use (MEVU)
- Secondary approvals for advertising: Cerebral Palsy Alliance (2018-10-02); Novita (18-3-S); Royal Institute for Deaf and Blind Children; ErinoakKids Centre for Treatment and Development; Grandview Children's Centre
- 2018-178H Participant Information Sheet
- RedCap Survey (pdf format)

Dear Applicant,

Principal Investigator: Assoc. Prof. Elspeth Froude, Professor Christine Imms, Prof. Peter Rosenbaum
Student Researcher: Belinda Deramore Denver (Doctoral Student)
Ethics Register Number: 2018-178H
Project Title: Testing the 'Measure of Early Vision Use' (MEVU)
Date Approved: 08/10/2018
End Date: 31/10/2019

This is to certify that the above application has been reviewed by the Australian Catholic University Human Research Ethics Committee (ACU HREC). The application has been approved for the period given above.

Researchers are responsible for ensuring that all conditions of approval are adhered to, that they seek prior approval for any modifications and that they notify the HREC of any incidents or unexpected issues impacting on participants that arise in the course of their research. Researchers are also responsible for ensuring that they adhere to the requirements of the *National Statement on Ethical Conduct in Human Research,* the *Australian Code for the Responsible Conduct of Research* and the University's *Code of Conduct*.

Any queries relating to this application should be directed to the Ethics Secretariat (res.ethics@acu.edu.au). It is helpful if quote your ethics approval number in all communications with us.

If you require a formal approval certificate in addition to this email, please respond via reply email and one will be issued.

We wish you every success with your research.

Kind regards,

Kylie Pashley
on behalf of ACU HREC Chair, Dr Nadia Crittenden

Senior Research Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL

7th November 2018

Ms Belinda Deramore Denver
Occupational Therapist and PhD Student
School of Allied Health
Australian Catholic University

Dear Belinda,

Final Approval – 2018_10_02: entitled **Testing the "Measure of Early Vision Use" (MEVY) with parents of children with cerebral palsy**

Thank you for your application for the above study for CPA to be a recruitment site. The research committee noted that the study has obtained ethics approval from Australian Catholic University, HREC Number 2018-178H and approve your application for CPA to be a recruitment site.

Details of the approval are as follows:

Project approval number: 2018_10_02. Please use this number in all subsequent correspondence to The Committee.

- **Approval period:** October 2018 to October 2021
- **The due date for your Annual Progress Report will be: October 24th**
- **The due date for your Final Progress Report will be: 24th October 2021**
- **Approved Documentation – as per the** Australian Catholic University, HREC Number 2018-178H **approval letter.**

Please liaise with SMcintyre@cerebralpalsy.org.au regarding advertising through the NSW/ACT register.

It is the responsibility of the Chief Investigator/s to:

- **Provide a summary of your progress on a yearly basis to the Committee, and a final report on completion including notification of any publications from this project. Failure to submit required reports will result in a suspension of consent for the project to continue.**
- Advise the HREC immediately in writing of any serious adverse events occurring during the course of the research.
- Advise the HREC immediately of all unforeseen events that might affect continued ethical acceptability of the project.
- Advise the HREC of any proposed changes to the research protocol, research personnel, information statement or consent form. All proposed amendments must be addressed in writing

to the HREC, using the *Protocol Variation Request Form*, and must be approved by the HREC before continuation of the project.

- Advise the HREC immediately, providing reasons, if the research is discontinued prior to its completion, or has been abandoned.
- Request an extension of ethics approval should the project not be completed within the time period specified above, by using the *Protocol Variation Request Form*.
- Ensure that copies of all signed consent forms are retained and made available to the HREC on request.
- Provide a copy of this letter to any internal/external granting agencies if requested.
- Check our website for updated forms: https://research.cerebralpalsy.org.au/our-work/ethics/

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

Yours sincerely,

[redacted]

A/Prof Karen Walker
Ethics Manager

Cerebral Palsy Alliance Ethics Committee is a NHMRC HREC: EC00402

Knowledge and Innovation

Project Agreement

Research Project Selection Committee

Name of the Project: Testing the 'Measure of Early Vision Use' (MEVU) with parents of children with cerebral palsy (reliability and construct validity)

Project Number: 18-3-S

Person submitting: Belinda Denver **Date discussed:** Out of session December 2018

Feedback from Research Project Selection Committee (RPSC)

Thank you for your interesting and relevant application to the RPSC. The committee consider this a valuable project that will inform Novita's program of research and knowledge translation supporting families of children and young people with Cerebral Palsy. The project methodology is well-suited to address the research aims and there is a record of successful collaboration between Australian Catholic University and Novita.

The Committee had one question around your inclusion criteria, namely whether parents/carers of children with a dual diagnosis (e.g. CP and ASD) are still eligible to participate?

We agree to support your research by promoting advertising to Novita's clients and families via the Novita website and on social media. Please can you draft content for the Novita website (general information about how children and young people with CP use vision during everyday activities as well more specific details about your study and a link to the online survey) and we will work with you to edit this and upload next year.

We wish you all the best with your research.

This project has been approved. You are required to provide:

- progress updates prior to quarterly RPSC meetings (dates TBC in Feb / May / Aug & Nov 2019);
- a Plain English summary of project findings (please note it is Novita policy to provide a summary of research findings to all our families and supporters);
- a copy of your final report and/or other publications for the Novita Library.

Signature: [redacted] Name: Dr Annemarie Wright Date: 11/12/2018

Chair of **RPSC**

I hereby agree to the requirements set out by RSPC

Signature:[redacted] Name: Belinda Deramore Denver Date: 02/01/2019

Project Lead/Investigator

Royal Institute for Deaf and Blind Children

361-365 North Rocks Road
North Rocks NSW 2151

Telephone (02) 9872 0218
Facsimile (02) 9873 1916

Email greg.leigh@ridbc.org.au
Web www.ridbc.org.au

Private Bag 29
Parramatta NSW 2124 Australia

25th July, 2019

Assoc. Prof. Elspeth Froude
Discipline in Occupational Therapy
Australian Catholic University
Level 3, 8-20 Napier Street
North Sydney NSW 2060

elspeth.froude@acu.edu.au

belinda.deramoredenver@myacu.edu.au

Dear A/Prof. Froude,

Re.: Your application to conduct research in RIDBC services titled *Testing the 'Measure of Early Vision Use' (MEVU) with parents of children with cerebral palsy*

I am pleased to advise that the application named above has been considered by the RIDBC Research Advisory Committee and approval has been granted as follows:

☑ Approval is granted for conduct of the project in the RIDBC services in accordance with the research protocol, associated participant information and consent forms, and proof of ethical approval by a properly constituted Human Research Ethics Committee, as submitted with your application.

Conditions: Nil

In order to progress your project, subject to any conditions outlined above being fulfilled, you should liaise with Ms Harzita Hashim, Best Practice Lead in Vision Impairment (harzita.hashim@ridbc.org.au; Tel.: 02 9872 0366).

In accordance with your Application to Conduct Research in RIDBC Services, you are obliged to keep this Committee informed of any changes to the approved protocol for the project and to provide such reports on progress as may be required by this Committee from time to time.

We wish you every success with the conduct of the project and look forward to hearing of the results.

Yours sincerely,

[redacted]

Professor Greg Leigh, AO, PhD, FACE
Director, RIDBC Renwick Centre

cc. Mr Bart Cavalletto, Director, Clinical Services, RIDBC
Ms Harzita Hashim, Best Practice Lead, Vision Impairment
Ms Belinda Deramore (belinda.deramoredenver@myacu.edu.au

RE: Research Participation Opportunity for Parent who have Children with CP

Leslie Styba <lstyba@erinoakkids.ca>

Thu 31/01/2019 3:03 AM

To: Belinda Deramore Denver <belinda.deramoredenver@myacu.edu.au>

Hi Belinda,
The review has been completed and approved. I'll be communicating with therapists this week to ask them to assist with disseminating. Hope we can assist in finding participants,
Leslie

Leslie Styba, MCISc
Clinical Services Supervisor
ErinoakKids Centre for Treatment and Development
1230 Central Parkway West, Mississauga, ON, L5C 0A5
Tel: 905.855.2690 ext. 2558 | C: 905-566-4606
lstyba@erinoakkids.ca | www.erinoakkids.ca

Donate now

From: Belinda Deramore Denver [mailto:belinda.deramoredenver@myacu.edu.au]
Sent: Wednesday, January 16, 2019 4:03 PM
To: Leslie Styba
Subject: Re: Research Participation Opportunity for Parent who have Children with CP

Hi Leslie,

Thank you for touching base. It is great to hear that it can be reviewed next week. The anticipated end date for data collection was February however that will be pushed out. Recruitment over the Christmas/summer period in Australia is quite problematic and I will not have enough numbers by February. So yes, I am very keen to still have ErinoakKids involved in advertising this study and I will adjust my timelines accordingly.

Belinda

Belinda Deramore Denver
Occupational Therapist & PhD Candidate
B Psych, B AppSc(OT), GradCert Ed(VI)
School of Allied Health
Australian Catholic University
Level 3, 8-20 Napier Street, Tennison Woods House
North Sydney NSW 2060
E: belinda.deramoredenver@myacu.edu.au
W: http://www.cre-cp.org.au/research/visual-abilities/
P: 02 9739 2845 0433 804 543

Affiliations:

RE: Opportunity for Parents with Children with Cerebral Palsy to Participate in a Research Survey

Angela Kielbowski <Angela.Kielbowski@grandviewkids.ca>
Sat 23/02/2019 1:28 PM
To: Belinda Deramore Denver <belinda.deramoredenver@myacu.edu.au>

Hi Belinda,
Thank you for this clarification. This all makes sense and I appreciate you providing the additional details.
I am now able to grant you approval. I will add your study to our website and ask our Marketing group to promote it via our digital signage, Facebook and Family Advisory Committee.
Should you have any questions, please do not hesitate to contact me.
Thanks and all the best,
Angela

Angela Kielbowski
Research Assistant
Grandview Children's Centre
600 Townline Road South, Oshawa, ON L1H 0C8
(905) 728-1673 x 2547
[angela.kielbowski@grandviewkids.ca]angela.kielbowski@grandviewkids.ca

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From: Belinda Deramore Denver [mailto:belinda.deramoredenver@myacu.edu.au]
Sent: February-19-19 1:44 AM
To: Angela Kielbowski
Subject: Re: Opportunity for Parents with Children with Cerebral Palsy to Participate in a Research Survey

Hi Angela,

I am well - thank you! Nice and warm here this time of year.

Thank you for the update in regards to my study. I have answered the questions below under each question. Please let me know if anything is still unclear or requires further discussion or negotiation. They are all very fair questions and this research benefits from considering such points.

1) How are you defining "typically developing" and "at high risk of CP" ? How will you ensure that you obtain participants who meet these criteria?
In this study it is all "parent report". If a parent identifies as a parent or caregiver of a child with CP, or high risk of CP, then they are invited to participate. This will be identified as a potential limitation of the outcomes from this study. Parents are asked to confirm their eligibility by answering this question:
Are you the parent or caregiver of a child with cerebral palsy, or a child at high risk of developing cerebral palsy?

Yes, my child has a diagnosis of CP, or my child is at risk of developing CP

No, my child does not have a diagnosis or risk for CP
I am not a parent, but I am interested in this research project

Parents are then asked about the type of CP. There is also a question asking whether the child was born before 36 weeks gestation.

In a separate study we are seeking parents of children with typical development however that is not the study I have asked Grandview for assistance with. In that study parents are asked whether their child has any diagnosis or disability that impacts on development, and they are asked whether they have any concerns with their child's developmental progress. There is an option to state the concern or diagnosis. Links are provided for parents who report a concern and they would not be included in the typical development study. There is also the question about gestation.

Please also note that MEVU has been developed for children with CP, and that this study is about children with CP. It is however likely that we will extend validation studies to other diagnostic groups in the near future - starting with parents of children with vision impairments (and not a diagnosis of CP). Parents of children with 'tricky' diagnoses will need to decide whether they feel comfortable ticking the box that their child has CP within this study. There is some spaces where comments can be added.

2) What are your exclusion criteria, if any (co-morbidities, etc)?
For participants identifying as a parent of a child with CP, or high risk of CP there are no exclusion criteria however there are no resources available for translation of the survey. There are questions about the presence of a vision impairment, and parents are asked about functional abilities including GMFCS level (using parent descriptors), and they are asked to rate their child's ability to use hand, move around, communicate with others and learn new information. The influence of these factors will be explored in item differential functioning in the future.

3) Would you be willing to include a statement in the survey itself directing families to GV's blind-low vision program or their family doctor if they have any other questions about their child's eye health (i.e. directing them to a resource where they can obtain more information should they have questions)?
The survey has been established for wide distribution and therefore local/specific contact details have not been included so far. The Participant Information Sheet advises parents to "discuss their concerns with their local health service team or other support networks" and/or "to contact the lead researcher" (which is myself). Families who participate in this research as a result of Grandview's assistance with advertising would likely already be aware of your services - or not? Please let me know if you feel differently.

I am keen to explore options for the inclusion of a contacts page for 'key' vision service organisations in the next iteration of this work. Given the potential usefulness of the tool for describing 'good visual abilities' in children with CP, in addition to describing limited visual abilities in children, the way this is approached needs further consideration.

Thank you,
Belinda

Belinda Deramore Denver
Occupational Therapist & PhD Candidate
B Psych, B AppSc(OT), GradCert Ed(VI)
School of Allied Health
Australian Catholic University
Level 3, 8-20 Napier Street, Tennison Woods House
North Sydney NSW 2060
E: belinda.deramoredenver@myacu.edu.au
W: http://www.cre-cp.org.au/research/visual-abilities/
P: 02 9739 2845 0433 804 543

Affiliations:
Centre for Research Excellence in Cerebral Palsy (CRE-CP)
Centre for Disability & Development Research (CeDDR)
2016 Career Development Grant awarded by the Research Foundation, Cerebral Palsy Alliance

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From: Angela Kielbowski <Angela.Kielbowski@grandviewkids.ca>
Sent: Tuesday, 19 February 2019 8:31 AM
To: Belinda Deramore Denver
Subject: RE: Opportunity for Parents with Children with Cerebral Palsy to Participate in a Research Survey

Hi Belinda,

I hope you are well!
The Research Committee has met and reviewed your study application. We have tentatively approved this study but have a few questions we'd like answered before we officially approve it.

1) How are you defining "typically developing" and "at high risk of CP" ? How will you ensure that you obtain participants who meet these criteria?
2) What are your exclusion criteria, if any (co-morbidities, etc)?
3) Would you be willing to include a statement in the survey itself directing families to GV's blind-low vision program or their family doctor if they have any other questions about their child's eye health (i.e. directing them to a resource where they can obtain more information should they have questions)?

If you could please answer these questions at your earliest convenience that would be great.

Thanks!

Angela

Angela Kielbowski, MES
Research Assistant |Grandview Children's Centre
600 Townline Road South|Oshawa, ON|L1H 0C8|(905) 728-1673 x 2547

From: Belinda Deramore Denver [mailto:belinda.deramoredenver@myacu.edu.au]
Sent: January-21-19 2:22 AM
To: Angela Kielbowski
Subject: Re: Opportunity for Parents with Children with Cerebral Palsy to Participate in a Research Survey

PARTICIPATION INFORMATION SHEET

Testing the ‘Measure of Early Vision Use’ (MEVU)

Project title	**Testing the ‘Measure of Early Vision Use’ (MEVU) with parents of children with cerebral palsy**
ACU HREC Project No.	2018-178H
Principal investigator	A/Prof Elspeth Froude
Student researcher	Belinda Deramore Denver
Student’s degree	Doctor of Philosophy (PhD)

Dear Parent/Caregiver,

Thank you for taking the time to read this information on our research project. This information aims to explain – clearly and openly – the steps and procedures for taking part in this project: "Testing the 'Measure of Early Vision Use' (MEVU) with parents of children with cerebral palsy". MEVU is a newly developed 14-item questionnaire that asks parents/caregivers about children’s visual behaviours. The information below is provided to help you decide if you would like to take part in this research.

You are welcome to contact the researchers to ask questions about anything you don't understand or want to know more about. Your participation in this research is voluntary. If you do not wish to take part, that is no problem. If you do want to take part, then all we ask is that you complete and submit the survey. There are no other consent forms required. All information will be collected via survey. By completing and submitting the survey you are giving your consent.

Contact person for this study

Belinda Deramore Denver
PhD Student & Occupational Therapist
Email: belinda.deramoredenver@myacu.edu.au
Phone: +61 2 9739 2845

What is this research project about?

This online survey is one part of a research project to develop and test a new way to assess how children with cerebral palsy (CP) use vision in everyday activities.

How well a child can use their vision has a big impact on all other areas of development and learning so it is important that we have a way to describe and measure this. Currently, there are no good ways to measure how a child uses their vision in everyday activities. This research project aims to develop a new way to do this. In the earlier parts of this research we have asked parents/caregivers, adults with a diagnosis of CP, and clinicians who work with children and families to tell us how children use vision, and the problems that they may have. We then developed the ‘Measure of Early Vision Use’ (MEVU), which we have tested and refined by talking to a small number of families. We are now ready to test it with a bigger group of parents.

We need the parents/caregivers of 100 children with CP to complete MEVU about their child to help us test it. We need parents/caregivers of children with a wide range of visual abilities to complete MEVU for us in this testing phase.

Can I participate in this research?

We are seeking parents and caregivers of children with CP, or at high risk of developing CP, between 3 months and 12 years of age. We need parents and caregivers of children with good visual abilities and poor visual abilities, and everything in-between.

What is involved in taking part in this study?

To participate in this research, you will be asked to complete an online survey. The online survey has six sections:

What is each section about?	Responses sought in each section
1. **Participant Information & Consent.** Information you will need for deciding whether you will participate in this study.	Consent to use your responses for this research project.
2. **Can the research team contact you via email?** A request from the research team for your email address so they can send emails related to the development and validation of the 'Measure of Early Vision Use'. If you provide your email address you may receive: i) updates on progress made by the research team; ii) reminders to complete the survey; and iii) invitations to other future steps in the research project.	Option to provide your email address, if you are happy for the research team to email you about this project. Note: You can still participate in this survey without providing your email address.
3. **Parent & Child Information** Collecting basic information about you (parent/caregiver), and some information about your child with CP.	About you: relationship to child (e.g. mother), level of education, country of residence. About your child: age, gender, type of CP, and some questions about functional abilities including vision and gross motor abilities.
4. **Measure of Early Vision Use (MEVU)** Information and instructions for completing the MEVU about your child, followed by the 14 questions. The questions will ask you about visual behaviours that you may observe your child doing in everyday activities (e.g. How much does your child look at and attend to toys and objects?). Responses to this section are the focus of this research project.	14 questions, each with 4 response options to choose from.
5. **Is there a second caregiver the research team can contact?** A request from the research team asking whether you can suggest a second caregiver (or person who knows your child well) who could also be invited to complete a survey on your child. This allows us to see whether another person describes your child's visual behaviours the same way.	Option to provide the email address of a second caregiver. Note: You can still participate in this survey without provided the name of a second caregiver.
6. **Can you also help by doing a second questionnaire?** A request from the research team asking whether you can also complete a second questionnaire. We can learn more about how the new Measure of Early Vision Use works by comparing it with a similar but different measure.	Option to complete a second questionnaire - either the Preverbal Visual Assessment (30 yes/no questions) or the CVI Questionnaire (46 questions), depending on the age of your child. Note: You can still participate in this survey without completing a second questionnaire.

The survey may take up to 40 minutes to complete. You may 'save' your response as you progress and return later to complete the survey. To do this you need to click on the 'Save and Return Later' option at the bottom of the page.

Who are the researchers doing this project?

Belinda Deramore Denver is the student researcher leading this project which is part of her PhD studies at Australian Catholic University. Belinda is an Occupational Therapist with thirteen years' experience working with children and their families in New South Wales, Victoria and South Australia. Belinda's primary clinical experience includes working with children with cerebral palsy and/or vision impairment. Belinda is a member of the Australasian Academy of Cerebral Palsy and Developmental Medicine and a Research Associate with the NHMRC Centre of Research Excellence in Cerebral Palsy (CRE-CP). She has partial funding for this project through the Cerebral Palsy Alliance Research Foundation (CDG7716). This research is supported and supervised by **Associate Professor Elspeth Froude** (Australian Catholic University), **Professor Christine Imms** (Australian Catholic University, Centre for Disability & Development Research), and **Professor Peter Rosenbaum** (*CanChild* Centre for Childhood Disability Research, McMaster University, Canada). The supervision team has extensive experience working with children with cerebral palsy and their families & developing measurement tools to use with children and families.

What are the benefits to you?

There are no immediate benefits to you or your child from participating in this survey, however many people feel good about participating in research to develop something that may help other families in the future. You may find that answering questions about your child gives you a different way to understand their everyday performance in activities; however, we will not be analysing and sharing the scores of individual children within this study. The overall aim of this research is to develop a new and useful way to describe how children with CP use their vision, and we hope that this may help to improve the outcomes for some children in the future.

What are the risks?

There are no known/expected risks to you participating in this study, including no financial costs to you. There may however be some inconvenience. Some people may not like answering online survey questions, and participation will take up to 40 minutes of your time. Anyone who experiences any distress from completing the survey is encouraged to contact the lead researcher (Belinda Deramore Denver). People can also discuss their concerns with their local health service team or other support networks.

How will my privacy and confidentiality be maintained?

Information collected in this study that may identify you or your child is your child's date of birth and your email address. All information collected will be stored electronically with password protection. If you provide your email address, or the email address of a second person, this will be stored separately so that your data remains confidential, and your responses will only be linked using an identification number. The findings from this study will be shared via publication in a journal article, but your individual results will not be identifiable within this summary.

Can I withdraw from the study?

Being a participant in this study is your choice. If you change your mind after submitting your responses, we will only be able to withdraw your responses if you have provided your email address to the researchers within the survey. Without this, we will be unable to withdraw your survey because we will not know which survey you completed.

What will happen with the results of this study?

At the end of this study we aim to know whether MEVU is a good tool for assessing how children with CP use vision. The results will be a summary of responses from all participants, so your individual data will not be identifiable. We will publish the findings in a journal article and MEVU may then become a new test available for use. If you provide your email address, we will keep you updated with the progress of this research.

Does this study have ethical approval?

The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2018-178H). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics Committee. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

Manager, Ethics
Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
North Sydney Campus
PO Box 968
NORTH SYDNEY, NSW 2059

Ph.: 02 9739 2519
Fax: 02 9739 2870
Email: resethics.manager@acu.edu.au

I want to participate. What do I need to do?

Thank you for wanting to take part. You do not need to complete a separate consent form to take part in this project. By completing and submitting the survey you are giving your consent to participate and agreeing that:

- I have all the information I need about this project and I know that I can ask more questions at any time using the contact details provided;
- I know that I do not have to take part in this study;
- I understand that no information about who I am, or who my child is, will be given to anyone or be published in a way that identifies me or my child;
- I understand that when I press submit at the bottom of each page any information entered will be sent to the research team;
- I have read and understood this consent form, and I agree (consent) to take part in this study.