

PARTICIPATION INFORMATION SHEET

Project title	Testing the 'Measure of Early Vision Use' (MEVU)
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: "Online testing of the 'Measure of Early Vision Use (MEVU): A parent completed questionnaire to assess a child's visual abilities". 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 have been involved in a previous step in this research project (between October 2018 to October 2019) – we thank you – and you are also invited to participate in this step. 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

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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 use vision in everyday activities. The Measure of Early Vision Use (MEVU) was developed for use with children with cerebral palsy, and the research team are also exploring its use with other groups of children e.g. children with a vision impairment.

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, and testing it online with parents/caregivers of children with CP. We are now ready to test it with a bigger group of parents and we need the parents/caregivers of 50 children with vision impairment and 50 children with cerebral palsy to complete MEVU about their child to help us further test it.

Can I participate in this research?

We are seeking two groups of participants for this research (Note: you may fit one, or both, groups):

- (1) Parents and caregivers of children with vision impairment up to the age of 6 years (from birth to 5 years 11 months)
- (2) Parents and caregivers of children with CP, or at high risk of developing CP, up to the age of 6 years. In this group 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?

Section 1: Participant information and consent

This section provides information you will need for deciding whether you will participate in the study. It seeks consent to use your responses for this research project.

Section 2: Can the research team contact you via email? And, is there a second caregiver the research team can contact?

This section contains 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.

There is also 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.

Note: You can still participate in this survey without providing your email address, or the email address of a second caregiver.

Section 3: Parent & Child Information

This section collects basic information about the parent/caregiver (e.g. relationship to the child, level of education & country of residence), and some information about your child (age, gender, diagnosis, level of functional abilities including vision and mobility).

Section 4: Measure of Early Vision Use (MEVU)

This section has information and instructions for completing the MEVU on your child, followed by the 14 questions, each with 4 response options. 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 the research project.

Section 5: Your child's visual function

This last section contains options for you to provide the research team with access to a clinical report of your child's visual function. This information will be used to look at the relationship between MEVU scores and visual function. Further information is provided below about how privacy and confidentiality will be maintained by the research team when using your child's report/s. Note: You can still participate in this survey without completing this section. There is also a request from the research team asking whether you can also complete a second questionnaire - the Participation & Activity Inventory for Children and Youth (PAI-CY), a new questionnaire from the Netherlands. Completing the PAI-CY will help us to understand how MEVU works by comparing responses on these similar questionnaires. It may also help us understand the validity of the PAI-CY for children with vision impairment and/or children with cerebral palsy in English speaking countries.

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, 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). The supervision team has extensive experience working with children with cerebral palsy and their families and developing measurement tools to use with children and families.

Kelsey Aquilina (Bachelor of Occupational Therapy honours student, Australian Catholic University) is leading the collection and analysis of data collected from parents of children with vision impairment within this project as the basis of her Bachelor of Occupational Therapy (Honours) at Australian Catholic University under the supervision of Belinda Deramore Denver, Associate Professor Elspeth Froude and Dr Sue Silveira. **Dr Sue Silveira** is an orthoptist and Research Fellow at the Royal Institute of Deaf and Blind Children and will also assist with interpretation of clinical vision reports.

What are the benefits of taking part in this study?

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 use their vision, and we hope that this may help inform interventions and 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, your email address, and information contained in your child's vision report (if shared), including your child's name. All information shared with the research team will be stored electronically with password protection.

If your child has a vision report which you share with the research team, or you provide permission for the research team to access a vision report from a nominated service provider, clinical data (e.g. diagnosis, visual acuity, refraction) will be extracted from the report by the research team and allocated a participation identification number, and stored separately. All data analysis will be completed after removal of identifying information (e.g. name). If you provide your email address, or the email address of a second person, this will also 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 (e.g. 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 identifiable information (e.g. your email address). 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 the study?

At the end of this study we aim to know whether MEVU is a good tool for assessing how children 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. De-identified data from this survey may also be combined with data from past/future research to further explore research questions relevant to children's vision and/or functioning, and this may involve new collaborations with other researchers in the future. 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 care of the Office of the Deputy Vice Chancellor (Research). Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

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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, but I agree that research data collected for this study may be published and/or may be provided to other researchers in a form that does not identify me, or my child, in any way;
- 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.

The survey is available here: <https://rdcap.acu.edu.au/surveys/?s=TXJ9MPC3JT>