

## PARTICIPATION INFORMATION LETTER

### Testing via online advertising

<b>Project title</b>	<b>Testing the 'Measure of Early Vision Use' (MEVU)</b>
<b>ACU HREC Project No.</b>	2018-178H
<b>Principal investigator</b>	Dr Belinda Deramore Denver

Dear Parent/Caregiver,

You are invited to participate in the research project described below.

### 1. What is this research project about?

This research project is testing a way to assess how children use vision in everyday activities with the recently developed Measure of Early Vision Use (MEVU).

MEVU is a 14-item questionnaire that asks parents/caregivers about children's visual behaviours.

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. MEVU might be helpful by giving:

- A language or way to describe how a child uses their vision; and
- A score to use in goal setting and planning and monitoring therapy.

MEVU has already been tested with over 100 children with cerebral palsy and/or vision impairment.

MEVU appears to be a good way to describe early visual behaviours in children using observations made by parents/caregivers from everyday activities, interactions, and environments. The focus of the current testing is to know: What does a score on MEVU mean? Is MEVU reliable? The research team need MEVU scores from more parents to test and understand if this measure is helpful.

### 2. Who is undertaking the project?

**Dr Belinda Deramore Denver** is the researcher leading this project, and this project is an extension of her PhD studies at Australian Catholic University. Belinda is an Occupational Therapist with twenty years' experience working with Australian 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.

The research team also includes others experienced in working with children with disabilities and their families and testing measurement tools for use with children and families: **Professor Elspeth Froude** (Australian Catholic University), **Professor Christine Imms** (Apex Australia Chair of Neurodevelopment and Disability, University of Melbourne, Australia), **Professor Peter Rosenbaum** (CanChild Centre for Childhood Disability Research, McMaster University, Canada), **Dr Sue Silveira** (Next Sense Institute – formerly the Royal Institute for Deaf and Blind Children, Australia) and **Professor Reinie Cordier** (Northumbria University, UK).

### 3. Research Funding

This research is partially funded by an Australian Catholic University Research Award for Academic Staff following Parental Leave. The Principal Investigator also had partial funding for an earlier phase of this research through the Cerebral Palsy Alliance Research Foundation (CDG7716).

#### **4. Who can take part in this study?**

To participate in this research project, we need to ensure that it is ok for you to take part in this study. We are seeking two groups of participants for this research:

- (1) Parents or caregivers of a child with cerebral palsy (CP), or high risk of developing CP, up to their 12<sup>th</sup> birthday (i.e. from birth to 11 years 11 months). In this group we need parents/caregivers of children with good visual abilities and poor visual abilities, and everything in-between.
- (2) Parents/ caregivers of children with vision impairment up to their 12<sup>th</sup> birthday. Children with vision impairment may also have additional disabilities.

You may fit into one, or both, of these groups. If you are unable to read and respond to questions in English, you will be unable to participate in this study.

#### **5. What will I need to do to participate in this study?**

If you decide to take part in this research, you will be asked to complete the Measure of Early Vision Use (MEVU) as an online survey. This may be completed via the survey link provided at the end of this letter, at a time that is convenient to you. Participation involves reading some instructions for completing the MEVU on your child, followed by the 14 MEVU questions, each with 4 response options to choose between. 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?). There is also a space for you to optionally write any comments/notes. You will also be asked some basic information about you as 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 mobility). The online completion of MEVU and answering the basic information questions may take up to 15 minutes to complete.

#### **6. Do I have to take part in this research?**

No. There is no obligation to participate in this research and if you do not wish to take part, you do not have to. Your participation is completely voluntary, and you may withdraw without consequences and reason at any stage. Your decision to participate or not, or to take part and withdraw, will in no way affect your relationship with the researchers undertaking this research, Australian Catholic University. Before deciding to take part in this research study, please read the information carefully and feel free to ask questions, or to talk things over with a relative, friend or health professional. If you agree to participate in this study, you will be asked to sign an online Consent Form and to keep a copy of this form. There is also an option for you to complete MEVU on your child without participating in the research project.

#### **7. Are there any risks associated with participating in this project?**

Whilst there are no foreseeable risks in this research, you find there to be some inconvenience. You may not like answering the online MEVU or basic information questions about yourself and your child. If you were to become distressed or upset by any of the questions you can skip a questions or simply stop/close your browser as this research is completely voluntary. You are encouraged to discuss your concerns with your local health service team or other support networks.

## **8. Are there any costs or reimbursements involved?**

There are no costs to participating in this study.

## **9. What are the benefits of the research project?**

The health professional/clinician within the clinic/service using the Measure of Early Vision Use (MEVU) can give you feedback about your child's visual abilities and any strengths and difficulties noted from your responses to the questions if you choose to share this information with them. This may form the basis of some goals and recommendations.

Your participation in this research may also help other families in the future. Your responses to the MEVU questions, together with responses from other parents/caregivers, will help us test MEVU and develop a scoring system. This may lead to earlier identification of difficulties in using vision and then the commencement of appropriate advice to families as to what visual skills need to be encouraged. MEVU may also be able to measure improvements in a child's visual skills and evaluate which intervention/advice is most effective. This will be beneficial for clinicians, researchers and for infants/children and their families.

## **10. Can I withdraw from the study?**

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences by closing the browser before submission, and your data will not be used for this study.

Being a participant in this study is your choice. If you change your mind after submitting your responses, the research team will be able to withdraw your responses if you have provided them with enough information to identify your response within the system e.g. the date of MEVU completion, and your child's date of birth. Without this, we will be unable to withdraw your survey because we will not know which information you completed.

## **11. Will anyone else know the results of the project or have access to my information?**

Any information or personal details gathered during this study are confidential and will not be shared with third parties without your consent or unless authorised by law e.g. a subpoena or search warrant. This project uses REDCap (Research Electronic Data Capture) – a secure online system designed for the capture of research data. The only information collected in this study that may identify you or your child is your child's date of birth, and your email address, if this is provided. All information shared with the research team will be stored by the researchers on the Australian Catholic University (ACU) secure server OneDrive for 15 years. ACU will manage your personal information and share data in accordance with its Privacy Policy and, where applicable, international regulations, such as the EU/UK's General Data Protection Regulation (GDPR). In limited cases, your data may also be viewable to ACU systems/software staff and administrators to address IT issues.

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.

## 12. Will I be able to find out the results of the project?

The results from this research will be published as a summary of responses from all participants, so your individual data will not be identifiable. We will publish the findings in a journal article. If you would like a copy of the results from the research project, please contact the Principal Investigator. We will only use these details (i.e. your email address) to send you the results of the research.

## 13. Who do I contact if I have questions about the project?

If you have any questions or concerns about the project, please contact a member of the research team.

### Research Team Contact/s

<b>Name</b>	Dr Belinda Deramore Denver
<b>Position</b>	Principal Investigator & Occupational therapist, Australian Catholic University
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<b>Name</b>	Professor Elspeth Froude
<b>Position</b>	National Head, School of Allied Health, Australian Catholic University
<b>Telephone</b>	+61 2 9739 2582
<b>Email</b>	elspeth.froude@acu.edu.au

### What if I have a complaint or any concerns about the research study?

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 Research Ethics and Integrity, the Office of the Deputy Vice Chancellor (Research and Enterprise). Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

<b>Name</b>	Manager, Ethics and Integrity
<b>Address</b>	c/o Office of the Deputy Vice Chancellor (Research and Enterprise) Australian Catholic University North Sydney Campus PO Box 968, North Sydney, NSW 2059
<b>Telephone</b>	+61 2 9739 2519
<b>Email</b>	Resethics.manager@acu.edu.au

## 14. I want to participate, what do I need to do?

Submission of the online survey (the Measure of Early Vision Use) is an indication of your consent. By clicking 'yes, I agree to participate' after the Consent statement in the RedCap Online Survey and clicking the submit button at the end of the survey, you are providing your permission for the research team to collect and use information provided by you within the research study. You can access the online survey here: <https://redcap.acu.edu.au/surveys/?s=AH4X4JYTD89XWHD7>

Yours sincerely,



Dr Belinda Deramore Denver  
Principal Investigator, *on behalf of the MEVU team*  
Australian Catholic University, North Sydney, Australia

- Please retain a copy of this Participant Information Letter