

PLAIN LANGUAGE STATEMENT AND CONSENT FORM



To: Parents/Guardians

Plain Language Statement

Date: 29/4/21

Full Project Title: Digital ethnography of Children with amblyopia – a methodological pilot

Principal Researcher: Dr Amanda Douglass, Dr Alexia Maddox, Dr Rosemary Woodcock, Dr Lienors Torre, Dr Shaun Bangay

Reference Number: HEAG-H 34_2021

Student Researcher:

Associate Researcher(s):

Dear Parent/Guardian,

Thank you for your interest in our project. We invite you and your child to trial our new journaling application, EyeStory, and a physical Toybox. We are researching how to engage a child and their family in a digital journaling project to learn about the child's experience through how they can play with eye-related games in the home. The application, EyeStory, and the toy box work together to provide six activities your child can play around the house and on the computer tablet. The EyeStory app, toybox and activities are designed to help your child share their experiences and thoughts about the vision-based activities with the research team, and have fun playing while doing it.

This project is a trial to test-run the application and find out how a family would use it in their daily life and what changes need to be made to improve the App. The app trial will run for three weeks where you will have the opportunity to test the EyeStory app and toybox within your home. You will be asked to do two activities per week. You can also expect to upload photos and videos taken during these activities. There will also be the opportunity for your child to record themselves speaking about doing the activities and what they may have thought about during them.

What we are looking to find out is whether the EyeStory app and toybox will work to help the child tell us their story across the three weeks in their own words and through their own eyes.

At the beginning, we will conduct our first interview with you to learn more about your family, including how your child likes to play, and what kinds of technology you are

comfortable having in your home and available for your child to engage with. We'll also be asking about how you and your child communicate about things that happen or what they are experiencing. We will do another interview halfway to see understand you and your child's experiences with the EyeStory app and then again at the end.

This test launch of the App with your family will help us to improve the journaling approach, the experience of the App and also make sure it's fun and engaging to do. The EyeStory app is intended to support families who have children experiencing eye conditions which alter their vision, such as amblyopia. Amblyopia is also referred to as "lazy eye" and occurs when the connections between the eye and the brain are not as strong as the child's better eye. It helps us learn more about their experience of the eye care journey they undergo and how life changes for them over the journey period.

To participate you will be required to enter your registration details online. The research team will contact participants to assess their eligibility for the study and then provide the family with a device that has the application pre-loaded.

Not everyone who registers will automatically become a study participant as we are looking for a family that includes a child between 5-8 yo who does not have a vision impairment, who can commit to the 3-week trial period, is willing to engage in the activities, participate in the interviews and does not need the instructions to be in a language other than English to participate. You will not be required to download the application. This will be mailed to you on a device provided along with the toybox. At the end of the study you are welcome to keep the toybox, however the device will need to be returned to the researchers via pre-paid post.

The data you share with the research team through the application will be used to improve the experience of the app. Please only share pictures and videos of yourself and your child. As this is a research project the data is required to be kept for five years, after which it will then be deleted. There will be no third-party providers involved in the data collection or transfer and your data will be held securely by Deakin University. Only the researchers listed will have access to the data.

The experiences you share during the interviews will be recorded and used to help us improve the research experiences for subsequent families. We may publish about the pilot in academic journals and use the interview information, however the information you provide will be anonymised.

We do not anticipate that there will be any risks for you or your child, however we will monitor and be in discussion with you about what is an appropriate screen time as the App will involve using a tablet at least twice a week for short bursts. We'll also be checking in as to whether your child is enjoying doing these activities or finding them too demanding or frustrating. If your child becomes upset and does not wish to continue the research will cease. You can easily contact us through the Application or directly through the research group's email eyestory@deakin.edu.au. If this project raises issues for you free counselling is available through Parentline <https://services.dhhs.vic.gov.au/parentline> or 132289.

If you've come to us through a pre-existing relationship, such as with Deakin Optometry, you should not feel pressured to take part. Participating, or not, in this research is entirely independent of any prior relationships.

You will be able to withdraw from this study at any point, including withdrawing your consent for us to use the data you have provided through the application or the experiences you have shared during the interview. As a thank you for engaging in this pilot study, we will provide you with a \$200 Woolworths voucher.

Complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Human Research Ethics Office, Deakin University, 221 Burwood Highway,
Burwood Victoria 3125, Telephone: 9251 7129, research-ethics@deakin.edu.au

Please quote project number HEAG-H 34_2021.



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TO: Parent/Guardian

Consent Form

Date: 29/4/21

Full Project Title: Digital ethnography of Children with amblyopia – a methodological pilot

Principal Researcher: Dr Amanda Douglass, Dr Alexia Maddox, Dr Rosemary Woodcock, Dr Lienors Torre, Dr Shaun Bangay

Reference Number: HEAG-H 34_2021

I have read, and I understand the attached Plain Language Statement.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

I agree for the researchers to use the video, images and audio we upload through the EyeStory application for testing and improvement purposes, knowing that they will be deleted after five years and not published in any form.

I also agree for the researchers to record the interviews and to use the information we provide during them for analytical and publication purposes, knowing that this data will be anonymised and we will not be identifiable.

I would like a copy of the results from this research. My email to provide this is

.....

Parent/guardian’s Name (printed)

Signature Date



PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Parent/guardian

Third Party Consent Form

(To be used by parents/guardians of minor children, or carers/guardians consenting on behalf of adult participants who do not have the capacity to give informed consent)

Date: 29/4/21

Full Project Title: Digital ethnography of Children with amblyopia – a methodological pilot

Principal Researcher: Dr Amanda Douglass, Dr Alexia Maddox, Dr Rosemary Woodcock, Dr Lienors Torre, Dr Shaun Bangay

Reference Number: HEAG-H 34_2021

I have read, and I understand the attached Plain Language Statement.

I give my permission for(name of participant)
to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my child’s identity and personal details, including where information about this project is published, or presented in any public form.

I agree for the researchers to use the video, images and audio we upload through the EyeStory application for testing and improvement purposes, knowing that they will be deleted after five years and not published in any form.

I also agree for the researchers to record the interviews and to use the information we provide during them for analytical and publication purposes, knowing that this data will be anonymised and we will not be identifiable.

Participant’s Name (printed)

Name of Person giving Consent (printed)

Relationship to Participant:

Signature Date



PLAIN LANGUAGE STATEMENT AND CONSENT FORM

To: Parent/guardian

Withdrawal of Consent Form

(To be used for participants who wish to withdraw from the project)

Date: 29/4/21

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Principal Researcher: Dr Amanda Douglass, Dr Alexia Maddox, Dr Rosemary Woodcock, Dr Lienors Torre, Dr Shaun Bangay

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I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University.

I wish to withdraw the activity we have provided through the application

I wish to withdraw the experiences we have shared in the interviews.

Participant's Name (printed)

Parent/guardian's name (printed).....

Parent/guardian signature

Date