

Evaluation of Macular Disease Foundation Australia's Eye Connect Service for people with macular diseases

1. WHAT IS THE RESEARCH STUDY ABOUT?

You are invited to take part in this research study being conducted by researchers at the University of New South Wales (UNSW). The purpose of this survey is to understand the impact of Macular Disease Foundation Australia's (MDFA) Eye Connect service on people living with age-related macular degeneration. We are especially interested in hearing about your experiences and how the program may have influenced your wellbeing after six months of participation.

2. WHO IS CONDUCTING THIS RESEARCH?

The study is conducted by UNSW researchers Professor Lisa Keay, Dr Sheela Kumaran, and Simon Wu on behalf of MDFA.

3. INCLUSION/EXCLUSION CRITERIA

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- 18 years of age or older
- Had previously participated or is currently participating in MDFA's Eye Connect Program for a minimum period of 6 months

4. DO I HAVE TO TAKE PART IN THIS RESEARCH STUDY?

Participation in any research study is voluntary. If you do not want to take part, you do not have to. If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Complete an online, postal or telephone administered survey.
- Express your interest to participate in an interview (online or telephone) by providing your contact details at the end of the survey

5. WHAT DOES PARTICIPATION IN THIS RESEARCH REQUIRE, AND ARE THERE ANY RISKS INVOLVED?

If you choose to take part in this study, you will be asked to complete a questionnaire either online, paper survey or over the phone, depending on your preference. The questions will ask about your experiences with the Eye Connect service, including how easy the resources were to access and how helpful you found them in building your confidence to manage age-related macular degeneration. The questionnaire should take up to 30 minutes to complete, depending

on your responses. The questionnaire is anonymous, and you can skip any questions you're not comfortable answering.

If you experience discomfort or feelings of distress while participating in the research and you require support, you can stop participating at any time. A list of support services and their contact details are provided below in Section 10.

6. WHAT ARE THE POSSIBLE BENEFITS TO PARTICIPATION?

By taking part in this project, you will help us better understand how the Eye Connect service is working. This research aims to explore whether the service helps users feel more confident in managing their macular condition, seek support when needed, and cope with challenges. Your participation will help improve the service for others in the future and show whether it is making a meaningful difference.

7. WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form, you consent to the research team collecting and using information about you for the research study. Submission of the online questionnaire, completion by telephone, or return post of the posted survey is an indication of your consent.

The research team will store the data collected from you for this research project for a minimum of 5 years after the publication of the research results. The information about you will be stored in a non-identifiable format where your identity will be unknown. No identifying information will be collected from you.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that:

- Will be an extension of, or closely related to, the original project; or is in the same general area of research.

8. YOUR INFORMATION WILL ONLY BE SHARED IN A FORMAT THAT WILL NOT IDENTIFY YOU.

- Information collected from you using paper-based measures will remain anonymous and be stored at the UNSW Kensington Campus and only the approved research investigators will have access to this information.
- Information collected from you over phone or in an electronic format will remain anonymous and be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.

9. HOW AND WHEN WILL I FIND OUT WHAT THE RESULTS OF THE RESEARCH STUDY ARE?

The research team intend to publish and report the results of the research. All Information will be published in a way that will not identify you.

A summary of the results will be made available on the MDFA website.

10. WHAT IF I WANT TO WITHDRAW FROM THE RESEARCH STUDY?

If you do consent to participate, you may withdraw at any time. You can do this by closing the questionnaire. If you withdraw from the research, we will destroy any information that has already been collected. Once you have submitted the questionnaire however, we will not be able to withdraw your responses as the questionnaire is anonymous.

If you have provided your contact details at the end of the survey to participate in the interview and later change your mind, you can withdraw your expression of interest by letting the researcher know by phone or email. If you would like to withdraw your interview responses after you take part, you can also let the interviewer know.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

1. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details

Name	Simon Wu
Position	Student Researcher
Telephone	0432457128
Email	<u>Z5419398@ad.unsw.edu.au</u>

Name	Sheela Kumaran
Position	Research Academic
Telephone	+61 2 9065 9964
Email	<u>z3532511@ad.unsw.edu.au</u>

Chief Investigator

Name	Lisa Keay
Position	Chief Investigator
Telephone	+61 2 9385 5372
Email	z9392143@ad.unsw.edu.au

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

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
Project ID	8977

Consent Form – Participant providing own consent

Declaration by the participant

By checking the I agree/start questionnaire option below:

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or it has been provided to me in a language that I understand;
- I provide my consent for the information collected about me to be used for future research purposes or shared with other researchers in a non-identifiable format.
- I understand that, if necessary, I can ask questions, and the research team will respond to my questions.
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can access results of this study through the MDFA website.

You do not need to send this page back.