Centre for Eye Health

Guide Dogs NSW/ACT

UNSW SYDNEY

An initiative of Guide Dogs NSW/ACT and the University of New South Wales

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Development of an Enhanced Education Intervention for the Promotion of Health Literacy in Patients with Age-related Macular Degeneration (AMD) Using a Focus Group, End-User Approach

Elisa Li, Professor Michael Kalloniatis, Dr Angelica Ly

1. **What is the research study about?**
   You are invited to take part in this research study. The research study seeks to address how educational material might best be provided to maximise patient recall and adherence for people with AMD. You have been invited because you expressed interest in the study through contact from an email or research flyer advertising the project.

2. **Who is conducting this research?**
   The study is being carried out by the following researchers: Elisa Li, Professor Michael Kalloniatis and Dr Angelica Ly of the CFEH research team, School of Optometry and Vision Science, UNSW Sydney.

   Research Funder: This research is being funded by Guide Dogs NSW/ACT.

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 to recruit people who meet the following criteria:

   - 18 years of age or older
   - Qualified optometrist, ophthalmologist, or other relevant professional
   - Must be able to communicate effectively in English and be legally capable to provide consent to participate through written consent or online survey

4. **Do I have to take part in this research study?**
   Participating in this research is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at UNSW Sydney, Centre for Eye Health, or any other organisations that the researchers may be affiliated with.

   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);
   - Sign and return the consent form through email if you decide to participate in the study or tick the checkbox in the online consent form administered through UNSW Office 365 Form;
   - Save a copy of this form with you to keep.

5. **What does participation in this research require, and are there any risks?**
   If you decide to take part in the research study, you will attend one focus group with a maximum group size of 10 participants OR an individual interview session which will take up to 60 minutes to complete. This is hosted online using the audio-video teleconference platform, Zoom with audio recording.

   During the interview, you will be asked a series of open and close-ended questions to:
   - Your professional experiences with delivering health information related to AMD.
   - Different types of information resources considered helpful or unhelpful and why.
   - Your thoughts on when the key health information should be delivered i.e. at what stage of the disease journey to maximise patient adherence/motivation to change.

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There are no anticipated risks to your physical safety. You might find the topics of discussion to be potentially emotionally uncomfortable, and you may choose not to participate. If you are not comfortable to attend a focus group through Zoom, we will offer you an individual phone interview instead.

6. What are the possible benefits to participation?

We expect to use information gained in this research study to improve health outcomes for current and future AMD patients.

You will be reimbursed with a $30 groceries gift voucher to spend at either Coles or Woolworths for your time associated with this study.

7. What will happen to information about me?

You consent to the research team collecting and using information about you for the research study. The information you provide will be analysed anonymously through transcribed quotes for the purposes of this study, and all data will be de-identified with pseudonyms. No audio recordings will be published. Your data will be kept for a minimum 7 years after the project's completion. We will store information about you as de-identified, electronic records on a secure network server with access restricted by swipe card access at CFEH. This complies with the UNSW Policy and Procedures which is in accordance with the Australian Code for the Responsible Conduct of Research.

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 compliant 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**.

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

- What appropriate advice should be given to patients at various stages of the disease, and
- How the educational material might be best provided (content and form) to maximise patient recall and adherence.

8. How and when will I find out what the results of the research study are?

The research team intend to publish the research study results in a variety of ways. All information published will be done in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team by emailing Elisa Li (email below) at the end of the study listing your contact details within the consent form. We will only use these details to send you research results.

9. What if I want to withdraw from the research study?

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If you do consent to participate, you may withdraw at any time. You also have the option of withdrawal by leaving the teleconference at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or CFEH, or any other organisations that the researchers may be affiliated with.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

10. 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 of the research team:

Research Team Contact Details

Name	Elisa Li
Position	Student Investigator
Email	eli@cfeh.com.au

Name	Dr Angelica Ly
Position	Chief Investigator
Email	aly@cfeh.com.au

Name	A/Prof Gordon Doig
Position	Co-Investigator
Email	gdoig@cfeh.com.au

Name	Professor Michael Kalloniatis
Position	Co-Investigator
Email	mkalloniatis@cfeh.com.au

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Name	Karen Ly
Position	Co-Investigator
Email	kly@cfeh.com.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	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	

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Consent Form – Participant providing own consent

Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate in this research study;
- ☐ I have read the Participant Information Sheet or someone has read it to me in a language I understand;
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ I provide my consent for the information collected about me to be used for the research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ 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 would like to receive a copy of the study results via email, I have provided my details below and ask that they be used for this purpose only;

  Name: _____

  Address: _____

  Email Address: _____

- ☐ I understand that I will save copy of this document to keep;
- ☐ I understand I will give my consent through UNSW Office 365 Forms with the link provided to me through email OR sign below and return this from via email.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

- ☐ I have given an explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	

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Date	

[+]An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.
Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales or the Centre for Eye Health. As it may be difficult to remove my information in a group discussion, in withdrawing my consent, I acknowledge no further information from me will be collected.

Participant Signature

Name of Participant	
Signature of Research Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

Chief Investigator:	Angelica Ly
Email:	aly@cfeh.com.au
Phone	(02) 8115 0746
Postal Address:	Centre For Eye Health, Rupert Myers Building Sth Gate 14, Barker St, University of New South Wales KENSINGTON, NSW 2052