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‘Caring for the Carer’: implementing a comprehensive support service model for family caregivers looking after persons with age-related macular degeneration

PARTICIPANT CONSENT FORM

1. I,

of
agree to participate in the study above and described in the Participant Information statement attached to this form.
2. I acknowledge that I have read the Participant Information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.
3. I understand that as part of this study University of Sydney have partnered with Carers NSW to provide the therapeutic counselling component. I consent for Carers NSW to collect and record my personal information. I understand that this information will be used for statistical purposes only and is non-identifying, and remains confidential and will not affect my entitlements or access to Carers NSW services.
4. I acknowledge that I am able to access the information recorded in my file upon request, in accordance with the Privacy Amendment (Private Sector) Act 2000.
5. In order for the intervention programs to be assessed for cost effectiveness, I agree for the research team to access additional information from records (Medicare and the

Pharmaceutical Benefits Schedule) and I acknowledge that this access will remain entirely confidential. I understand that all personal information will remain confidential and secure except when:

- a. It is subpoenaed by a court; or
- b. Failure to disclose the information would place myself or another person at risk; or
- c. Prior consent has been obtained to share this information with nominated agencies for the purposes of supporting the referral/ counselling process within the scope of the National Carer Counselling Program.

- 6. Before signing this Consent Form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.
- 7. I understand that I can withdraw from the study at any time without prejudice to my relationship with the treating ophthalmologist and the Macular Disease Foundation Australia.
- 8. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
- 9. I understand that if I have any questions relating to my participation in this research, I may contact Ms Diana Tang (email: diana.tang@sydney.edu.au) on 02 86273337, who will be happy to answer them.
- 10. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Signature of Subject	Please PRINT name	Date
.....
Signature of Investigator	Please PRINT name	Date
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This study was given approval by the Human Research Ethics Committee of the University of Sydney in October 2016. Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).