PARTICIPANT CONSENT

INFORMATION SHEET AND CONSENT FORM

AN AUSTRALIAN COHORT OF CADASIL

If you would like to go through the contents of this information sheet and consent form with a member of the study team, please contact Dr Danit Saks on 02 9348 1658.

1. What is the research study about?

You are invited to be part of the Australian CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy) Cohort since you have been diagnosed with CADASIL, OR there is a strong suspicion that you may have CADASIL, OR you have a family member with CADASIL and you have undergone genetic testing, OR you are a healthy control. Being part of this cohort requires that you are seen by a medical specialist and their medical associates, if you have not already been diagnosed by a specialist. Once the presence/absence of the CADASIL gene variant, has been established, you can choose to be part of the research cohort. A cohort is a group of patients with the same condition who will be followed up over time in relation to their health status. Since this is part of a national network, you will thereby be part of an Australian cohort. The cohort is being developed as a research activity of the Centre of Research Excellence in Vascular Contributions to Dementia (CRE-VCD), led by Prof. Perminder Sachdev, who is the Co-Director of Centre for Healthy Brain Ageing (CHeBA) at University of New South Wales (UNSW), Sydney. The team includes a number of other clinicians and researchers from all over the country who have a special interest in CADASIL as well as stroke in general.

Before you decide whether you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully, and discuss it with your family and/or others if you wish.

What is CADASIL?

CADASIL is an abbreviation for a long name describing a rare hereditary form of stroke (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy). The disease usually presents with multiple small strokes, but migraine can also be a prominent feature. CADASIL is a genetic condition caused by variant in a gene called *NOTCH3*. CADASIL is diagnosed based on clinical history, a physical examination, and other investigations which include a brain MRI scan and a genetic test.

What is the purpose of the study?

Many aspects of CADASIL are poorly understood, and we do not have effective treatments to cure it or stop its progression. More research is therefore needed. Since the number of affected individuals is small, several clinicians and researchers from around the country have agreed to collaborate so that there will be a large enough sample to address the various research questions being asked, including:

i. What are the main clinical features of CADASIL and which of these cause the most disability for patients?
ii. What are the main features of CADASIL identifiable on a brain MRI scan, and how do they relate to the clinical symptoms?
iii. Which individuals with CADASIL go on to develop memory and other cognitive problems, and what tests should be used to identify these problems early?
iv. What are the genetic features of CADASIL, and how do these relate to the clinical presentation?
v. Can we develop blood tests to detect CADASIL early and without genetic testing, and to identify those individuals who go on to develop cognitive and other deficits?
vi. Better understanding symptoms such as headache, depression, fatigue, and cognitive deficits in people with CADASIL, in the hopes that this may lead to future treatment options.

By agreeing to be part of this cohort, you are agreeing to the research assessment and to be contacted for further research studies to enable the above questions to be addressed.

2. Who is conducting this research?

Role	Name	Organisation
Chief Investigators	Professor Perminder Sachdev1, 2	1. University of New South Wales
Co-Investigators	Professor Christopher Levi 3 Professor Amy Brodtmann 4 Professor Michael O'Sullivan 5, 6 Professor Beata Bajorek 3 Professor Paul James 4, 7 A/Professor Adrienne Sexton 4, 7 Dr Jessie Huang-Lung 8 Distinguished Professor Lyn Griffiths 9 Professor Peter van Wijngaarden 10 Professor Ken Butcher 1, 2 A/Professor Romesh Markus 1,11 Professor Mark Parsons 1, 3, 7, 12 Professor Jason Kovacic 1, 11, 13 Dr Vibeke Catts 1 Dr Danit Saks 1 Dr Jiyang Jiang A/Professor Wei Wen 1 Dr Tharusha Jayasena 1 Dr Karen Mather 1 Dr Anne Poljak 1 Dr Adam Bentvelzen 1 Dr Robert Smith 9 Dr Russell Chander 1 Mr Patrick Clementson 14 Ms Gurpreet Hansra 1 Dr Ashley Park 7	2. Prince of Wales Hospital 3. John Hunter Hospital 4. Monash University 5. University of Queensland 6. Royal Brisbane and Women's Hospital 7. Royal Melbourne Hospital 8. School of Optometry and Vision, University of New South Wales 9. Queensland University of Technology 10. Centre for Eye Research Australia 11. St Vincent's Hospital 12. University of Melbourne 13. Victor Chang Cardiac Research Institute, Sydney 14. Patient Advocate
Research Funder	This research is being funded by a Centre for Research Excellence grant from the National Health and Medical Research Council	

Why have I been invited to participate in this study?

You have been invited because:

a) You have been diagnosed with CADASIL based on genetic testing OR

b) There is strong suspicion that you may have CADASIL based on your medical history and the results of your brain MRI scan; OR

c) A first degree relative of yours has been diagnosed with CADASIL and you are a carrier of the same gene variant.

3. What are the inclusion/exclusion criteria for this study?

To participate in this study, you must be:

1. Aged 18 years or older.
2. Have an adequate level of English to provide written consent and complete neuropsychological assessments which are administered only in English.
3. Be able to attend a test site to complete some of the assessments.
4. Diagnosed with CADASIL according to one of the following categories:

a) Confirmed diagnosis via genetic testing (*NOTCH3* mutation)
b) or suspected diagnosis based on medical history and brain MRI
c) **OR i**ndividual with a family history of CADASIL who has been previously tested and is:
   - Positive for *NOTCH3* genetic marker
   - Negative for *NOTCH3* genetic marker

5. Other non-relative control participants who have no *NOTCH3* mutation, or cognitive impairment

You must not:

1. Have significant cognitive impairment where the capacity to participate voluntarily cannot be established.
2. Have confounding comorbidities such as HIV/AIDS, multiple sclerosis, metastatic cancer, active autoimmune disease, and sarcoidosis. Requirement to exclude based on previous clinical investigations and discussion with treating clinician.

4. Do I have to take part in this research study?

Participation in this study is completely voluntary. If you decide not to participate, it will not affect the treatment you receive from the Neurology/CADASIL Clinic now or in the future. The decision you make will not affect your relationship with your medical attendees or the health care service/ University. We encourage you to discuss with your GP or treating physicians the study requirements as well as the potential health implications from any study findings. This study includes genetic testing for CADASIL, and it is important that you understand the implications of this testing. Your GP can help you with this decision. The study will also provide genetic counselling sessions to ensure you are well informed and supported. You can choose not to receive the results of this testing and/or the other assessment results. You can also choose to withdraw from the study at any time.

You can do so by completing the withdrawal of consent form, which can be found at the end of this document or provided through contacting the research team. Your decision not to participate or to withdraw from the study will not affect your relationship with the Neurology/CADASIL Clinic, any Health Service or any affiliated University. If you decide to leave the research study, the researchers will not collect additional information from you

for research. You can request that any identifiable information about you be withdrawn from the research project.

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 if you decide to participate in the study;
- Take a copy of this form with you to keep.

5. What does participation in this research require, and are there any risks involved?

Test	Time required
Health and Wellbeing Questionnaires	40 minutes
Medical and Family History Questionnaire	25 minutes
Blood Test	15 minutes
Cognitive Testing	Approximately 1 hour
Physical Exam	30 minutes
Brain MRI	1 hour
Vision Exam	1.5 hour
Genetic Counselling	Pre-test and Post-test sessions

The study involves attendance at an affiliated University/clinic/hospital for physical examination, assessment of cognition, undergoing a brain MRI, providing a blood sample and undergoing an ocular examination. All assessments are optional, however to participate in this study, at a minimum you must provide a blood sample, complete the online medical and family history questionnaire, complete a 20 minute neuropsychology battery and participate in genetic counselling (optional for individuals with a prior CADASIL diagnosis).

Assessments include an online component which can be completed in your own time, and you can choose to complete in-person assessments on separate days as suited.

1. You will have undergone a screening process and we have determined that you are eligible to take part in this study.
2. You will complete online health and wellbeing questionnaires (40 minutes), and medical and family history questionnaires (30 minutes). These are preferably done from your home computer, which we will enable by sending you a link. If that is not possible, these can be completed during your visit for assessment. If direct computer entry is not possible, you can complete them on paper while waiting for assessments.

3. You will see a health professional who may ask you further questions in relation to your health, and will perform a physical and neurological examination (30 minutes).
4. You will meet with a health professional who will take you through a number of tasks and puzzles to complete which help us assess memory and thinking. These surveys and tasks are broken into a number of components (about 1 hour each).
5. You will be asked at the end of this form to **provide a study partner**, someone who knows you well (usually a family member or a close friend) and who can provide responses to three questionnaires about your wellbeing and capability for daily activities.

Risks: If you do not wish to answer a question, or feel that a question is stressful or upsetting, you may skip it and go to the next question, or stop immediately. If you become upset or distressed as a result of your participation in this cohort, the study team will be able to arrange for counselling or other appropriate support.

You will also be asked to do the following tests:

1. Provide a morning fasting sample of blood. This will take ~ 15 minutes and will typically be performed at the pathology laboratory of a hospital. The amount of blood taken on one single occasion will be equivalent to approximately 45 mL or three tablespoons. The procedure will be performed by an experienced venepuncturist. In special circumstances we may also be able to organise for your blood to be collected at your home. A small portion of your blood sample will be sent for biochemical analysis to measure your blood chemistry. The blood will also be sent to an accredited genetics lab to identify the presence/absence of the *NOTCH3* gene variant (if not already done). The remainder of your sample will be frozen and stored in a secure biorepository managed by the Centre for Healthy Brain Ageing (CHeBA) at the University of New South Wales, Sydney, for future analysis including whole genome and epigenome sequencing and more complex analyses of lipids, proteins and the metabolic system.

It is important to note what information your blood sample will provide us. Blood samples give us useful information about your general health, such as cholesterol, triglyceride, high- and low-density lipoprotein, inflammation, and vitamin level, as well as kidney health. They will be used in the analyses to uncover whether these blood chemistry features are linked to brain vascular status.

Blood also carries numerous proteins and fats (lipids) which can be analysed in a research facility with state-of-the-art techniques, including proteomics, lipidomics, epigenomics, metabolomics, etc. to identify substances that are related to health and may function as markers of brain diseases. For this purpose, the blood and the DNA derived from it, will be stored and with your consent may be requested by researchers in the future for further analysis. Any of your blood or DNA samples shared with other researchers will not have any identifying information that can traced back to you, and your privacy will therefore be fully respected. In fact, any identifying information will be kept by your Clinic and not shared with the Biobank where the materials are being stored, for which you will be identified only by a number.

Risks: The medical risks of providing blood samples are minimal including minor transient pain, a slight possibility of infection or some bruising that may be present for a few days. During a blood draw, you may experience some discomfort or transient pain at the site of needle entry into the vein as during any routine blood test. There is a remote risk of fainting.

2. Genetic Counselling. We will arrange a telehealth (or in person if in Melbourne) session with a trained genetic counsellor who will help guide the participant through the process of receiving genetic testing or understanding how the genetic confirmation or otherwise of the CADASIL gene variant can impact their future health, and the implications for their close family members (1 hour). If prior to study enrolment, you have been identified as likely to have CADASIL due to clinical assessment with your doctor, we will offer counselling prior to receiving your genetic test result. We will also offer post-result counselling for all study participants. This process can be confronting. It is therefore important to make informed decisions about genetic testing and understand the associated implications. If participants have concerns about their disease this can be discussed in the genetic counselling session or with their clinician outside of the study constraints. You are under no obligation to complete the genetic testing after pre-test counselling, you are also under no obligation to receive the genetic testing result and can withdraw from the study at any time.

Risks: Pre-test genetic counselling will help support you through this process and explain the implications of this test. Post-test genetic counselling will help to explain the test results and support you through this disease. If you feel distress during the genetic

counselling session you can stop the session at any time and are under no obligation to complete it at a later stage.

3. MRI brain imaging: An MRI is a non-invasive test that provides a detailed image (scan) of body tissue, in this case the brain. It uses a large magnet, low-energy radio waves, and a computer to produce 2- or 3-dimensional images of body tissue. MRI scans measure the magnetic properties of molecules within the organ, and do not involve x-rays or any other forms of radiation. MRI tests for this study will not use any contrast agents.

An MRI scan of approximately 1 hour will be done at a mutually convenient time for you and the clinic. During the scan, pictures of your brain's structure and different aspects of the brain vessel system will be taken. You will be lying on a bed that moves into a tube-shaped 'dome' (a magnet). To obtain a scan, it is essential that you remain still in the dome, within the magnet. In order to help you hold your head still, and to produce the best images, there is a head holding frame with cushions.

Risks: Prior to making an MRI appointment, we will ask you questions to ascertain whether you may have any metal or shrapnel in your body, or implanted electronic devices, such as a cardiac pacemaker, or other metal implants (e.g., cerebral aneurism clips). If you have any of these, it is not considered to be safe to proceed with the MRI scan and we would exclude you from this part of the study.

At the MRI facility, just prior to entering the scanner room, you will be screened again to double-check that there is no metal in or on your body. You will also need to remove any metal jewellery prior to the scanning as we cannot allow you to proceed with an MRI scan if there is any metal in or on your body. Personal items will be locked away safely during the visit.

MRI scans are safe, but some people find lying in the scanner claustrophobic, and if you feel claustrophobic, you will be removed from the dome immediately.

4. If available, you will be invited to undertake a **retinal and vision examination** (currently offered at Sydney and Melbourne sites; approximately 90 minutes). This is because changes to the brain and blood vessels can often be seen in the eye. This examination will involve a few short assessments in an optometry/ophthalmology clinic, where you will be required to keep your head still as best you can by resting your chin on the chinrest and

follow the instructions of the trained staff. We will require eye drops for this exam so you will not be able to drive immediately after.

Risks: An ophthalmic examination is non-invasive and safe. It involves keeping the head still for images to be taken and often following light stimuli or other instruction from trained staff. Some people may find these tests cause fatigue and headaches from the light. If you feel like you need a break or wish to stop the examination, all you have to do is let the staff know. We will require eye drops for this exam which may result in blurred vision which can last up to 4-6 hours, so you will not be able to drive immediately after. This assessment is optional and you can opt out without it affecting your participation in other assessments for this study.

5. Follow-up: Following the assessment, you will receive a feedback report providing and overview of the study results. With your consent, the information will be formally conveyed to your GP and any other physician involved in your care. For your future treatment, you will be under the care of your GP or treating physician if already receiving treatment, who may wish to consult with the affiliated study clinics if necessary.

You will be invited for a **formal review once a year** following the initial assessment. At this assessment, the medical assessment will be repeated and you will be asked to complete a number of questionnaires to update the information that you provided at the initial assessment.

You will also be invited to return for an MRI brain scan, repeat eye test and repeat blood collection **after three years.**

Access to additional medical records

With your permission, we would also like to access information from your past and future health records from your GP and/or hospital if necessary. Linking your health records with the information we collect from you during the assessment gives us a greater understanding of the disease process. Any information obtained from linked health records will be treated completely confidentially and only used for the purpose of this research project. Each participant is allocated an anonymous ID number and any researchers using health data to undertake statistical analyses will NOT be able to identify individuals.

To access certain records we need to provide your identifying information to the relevant health care provider, Commonwealth or NSW Government Department. This is done under strict conditions of confidentiality to allow us to link your health records with our own data. With your consent we may wish to access and link data from the following sources containing information about your health, medication and treatment:

- Records held by your General Practitioner and/or other health service providers, with their consent.
- State Hospital and Emergency Department Records.
- Australian Institute of Health and Welfare (i.e., aged care services data and death records).
- Medicare Benefits Schedule
- Pharmaceutical Benefits Scheme.

Inclusion of first degree relatives

Since CADASIL is a genetic disorder, it can occur in multiple members of a family. If you have CADASIL it is quite likely that one or more of your family members also carries the gene variant. We would therefore like to invite your adult (18 years and over) family members to participate in the CADASIL cohort if they have already undergone genetic testing for CADASIL, regardless of the test result. We encourage you to pass the information about participation to all your first-degree relatives (parents, siblings, adult children), and invite them to contact us on the given phone number or email address to learn more about the study and potentially participate. While this will enhance the research, the family members do not have an obligation to participate and would do so of their own free will. We will only be recruiting family members who have a diagnosis of CADASIL or symptoms of CADASIL as recognised by their treating physician. Any family members who do not have CADASIL symptoms will need to have genetic testing outside of the study before we can include them in the cohort. If family members choose to participate in this study, they will need to provide consent and then will be invited to complete the same assessments discussed earlier in this information sheet. We will not inform you or any other family members who elect to participate in the study or not and we will not share any information you provide us during your study participation with your family members.

6. What will happen to information about me?

Data collected from you for this study will be stored for a minimum of 10 years after the publication of research results. Data and/or blood samples may be used for future research purposes or shared with other researchers or as part of future data linkage projects. Access to study data and blood samples in the future will be managed by the CHeBA Research Bank at UNSW. Your information will only be shared with your consent and in a format that will not identify you. In particular, your data will be given a unique code. Research teams receiving these data will not be provided with any information that can identify you.

A small portion of your blood sample will be sent for biochemical analysis to measure your blood chemistry. The remainder of your sample will be frozen and stored in a secure biorepository managed by the Centre for Healthy Brain Ageing (CHeBA) for future analysis, including whole genome and epigenome sequencing, and more complex analyses of lipids, proteins and the metabolic system.

Any personal information that can potentially identify you will be retained by CHeBA, UNSW and/or the Neurology/CADASIL Clinic and/or medical specialist. You will also be allocated a Research ID No. All research data collected from you will only have the Research ID, the key for which will be retained by the Clinic and/or your medical specialist. Research data will be stored electronically on secure, encrypted computers managed by CHeBA and/or the IT department of UNSW or as hard copy in locked filing cabinets accessible only to research staff. Paper files will be stored in locked filing cabinets in a secure building of the Clinic and be accessible only to the clinical staff directly responsible for your clinical consultation. Paper files may also be digitised for research purposes. Tasks that involve lists of words will be audio-recorded for accurate scoring. Audio files will be stored on password-protected university storage drive and with your consent may be shared with other researchers in an anonymised format. Research investigators, including staff involved in the analysis of data will only have access to the ID number. Only anonymised data will be shared with collaborators and participants will not be identifiable when results are reported or published.

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

The research team intends to publish the results of the research in scientific journals and present them at scientific meetings. Findings will also be communicated via newsletters and social media. All information will be published 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 know.

8. 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 so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document, or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or any of the organisations involved in this research. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

You are able to request the study to destroy your blood sample and delete all your data, if you withdraw from the study. If you do not want your blood samples to be used in future studies beyond the current one, you can indicate this in the consent form at the end of this document.

9. Will I benefit from this study?

Participation in this study provides us with the opportunity to also use clinical information and test materials you provide for research to advance knowledge about CADASIL and small vessel disease in the brain. The research is unlikely to be of any immediate benefit to you, except to the extent that some of your results may inform your future clinical care. You may also have the opportunity to participate in any treatment trials if and when they become available.

10. What are my healthcare rights?

The Australian Charter of Healthcare rights applies to all individuals within the healthcare system and provide the right to accessible services, safety, respect, partnership, privacy and the right to provide feedback to healthcare providers. You have the right to consent that is based on an informed decision and without influence. For more information on the Australian Charter of Healthcare Rights please visit:

https://www.safetyandquality.gov.au/consumers/working-your-healthcare-provider/australian-charter-healthcare-rights

11. What if I don't want to know the results from this study?

It is entirely your decision as to whether or not you decide to be told the results. Feedback is only provided to you and your GP if you consent to this option.

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

Ethics: This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2023/ETH01132.

Complaints about this research: Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: HNELHD-ResearchOffice@health.nsw.gov.au and quote the reference number: 2023/ETH01132.

13. 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	Dr Danit Saks
Position	Study Coordinator
Telephone	02 9348 1658
Email	auscadasil@unsw.edu.au

Chief Investigator

Name	Professor Perminder Sachdev
Position	Co-director of the Centre for Healthy Brain Ageing
Telephone	(02) 9385 7357
Email	p.sachdev@unsw.edu.au

Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Name/Organisation	NSW Mental Health Line
Telephone	1800 011 511

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

University of New South Wales

CONSENT FORM

[To be used in conjunction with a Participant Information Sheet]

AN AUSTRALIAN COHORT OF CADASIL

I,

.....

agree to participate as a subject in the study described in the participant information statement set out above.

- ☐ 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.
- ☐ I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
- ☐ I consent to my blood being collected and analysed.
- ☐ Optional: I consent to have my blood test results entered into my electronic medical record (eMR). This is not required for participation in this study.
- ☐ Optional: I consent to have my blood samples stored for future research usage beyond the completion of this project. This is not required for participation in this study.
- ☐ I consent to completing a cognitive assessment
- ☐ Optional: I consent to receiving an MRI brain scan. This is not required for participation in this study.
- ☐ Optional: I consent to receiving a vision examination. This is not required for participation in this study.
- ☐ I freely agree that data collected in this study will be stored for a minimum of 10 years after publication for future analyses and shared with other researchers at academic institutions, provided it is anonymised and does not contain identifying information.
- ☐ I freely agree that data collected in this study will be stored for a minimum of 10 years after publication for future analyses and shared with commercial entities, provided it is anonymised and does not contain identifying information.

- ☐ Optional: I freely agree that the AusCADASIL researchers may access my health records from external parties as described in the above Information Statement, provided the data obtained are treated confidentially. This is not required for participation in this study.
- ☐ Optional: I consent to receive the outcome of my genetic test whether positive or negative for the CADASIL gene variant. This is not required for participation in this study.
- ☐ Optional: I consent to have my assessment results provided to myself. This is not required for participation in this study.
- ☐ Optional: I consent to have my assessment results provided to my GP or referring clinician. This is not required for participation in this study.
- ☐ I understand that I will not receive any financial benefit for my participation. I will not be able to claim any payment, compensation, royalty or other financial benefit which may result from the current research.
- ☐ Please only tick this box if you are of Aboriginal and/or Torres Strait Islander Origin. If so, I understand that my details will be provided to the Aboriginal Hospital Liaison Officer who will contact me for further support opportunities.
- ☐ I have been given the opportunity to ask 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.
- ☐ I understand that if I have any questions relating to my participation in this research, I may contact Dr Danit Saks on 02 9348 1658 or auscadasil@unsw.edu.au who will be happy to answer them.
- ☐ I understand that I can withdraw from the study at any time without prejudice to my relationship to any affiliated health service or the affiliated university.
- ☐ I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Participant Signature

Name of Participant (please print)	
Signature of Participant	

Date	

Nomination of Study Partner *(individual who is known to the participant and who is able to complete questionnaires regarding the participant's wellbeing and capability for daily living activities)*

Name of study partner: _____

Contact number: _____

Contact email: _____

GP or referring clinician details

My GP/referring clinician's practice is called:

_____

Name of the doctor you usually see:

_____

Practice street address: _____

Suburb: _____

State and postcode: _____

Contact information: _____

University of New South Wales

AN AUSTRALIAN COHORT OF CADASIL

WITHDRAWAL OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with any affiliated health services, affiliated universities or any personnel.

I understand that:

- No further information about the participant will be collected for the study beyond the withdrawal date
- Information about the participant that has already been analysed and/or included in a publication may not be able to be destroyed.

I wish to have no further contact with the study but give permission for any participant data and biospecimens to be retained and continued to be used, subject to human ethics approval Yes q No q

OR

I wish to withdraw and have all participant data and biospecimens destroyed so they can no longer be used for research. Yes q No q

Signature of participant **Please PRINT name** **Date**

_____ _____ _____

The section for Revocation of Consent should be forwarded to:

CI Name:	**Prof Perminder Sachdev**
Email:	p.sachdev@unsw.edu.au
Phone:	(02) 9385 7357
Postal Address:	CHeBA, Discipline of Psychiatry & Mental Health Level 1, AGSM (G27) Botany Street UNSW Sydney, NSW, 2052 Australia