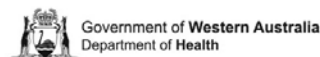


CENTRE FOR CLINICAL RESEARCH IN NEUROPSYCHIATRY



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Centre for Clinical Research in Neuropsychiatry-Australian Schizophrenia Research Bank (ASRB-CCRN)

INFORMATION SHEET

On-site Chief Investigator: Professor Assen Jablensky (08) 9224 0290
Chief Investigator: Professor Vaughan Carr (02) 4924 6610
ASRB Manager and corresponding researcher: Dr Carmel Loughland
(02) 4924 6611
On-site Clinical Assessment Officer Lisa Dawson (08) 9347 6415

You are invited to participate in the establishment WA arm of the Australian Schizophrenia Research Bank (ASRB). The ASRB is a unique and important Australian research databank, established in collaboration with the Schizophrenia Research Institute (SRI), the University of Newcastle, the Centre for Mental Health Studies, the Medical Genetics Laboratory, Hunter Area Pathology Service (HAPS), the Centre for Rural and Remote Health, the University of Queensland, the Queensland Centre for Mental Health Research, the University of Western Australian and the Centre for Clinical Research in Neuropsychiatry.

The aim of the ASRB, is to collect information looking at genetics (DNA), brain imaging (MRI), information processing, and clinical information from people with and without schizophrenia. The information collected and stored by the ASRB will be used in research that will increase our knowledge and understanding of schizophrenia and hopefully work towards better methods of diagnosis and treatment.

Your Rights

Participation in the ASRB is completely voluntary. You do not have to give a reason for why you wish to withdraw your consent and you can stop participation in this project at any time without affect yours, or your relative's treatment now, or in the future. If you decide to withdraw, your request will be respected and upon receipt of written notification, any information we have collected, along with the blood sample, will be destroyed.

What does participation in the study involve?

If you agree to participate in the ASRB, you will be invited to do the following:

- Participate in an interview regarding your own experience of any mental health problems throughout your life (e.g. worry, anxiety, depression, psychotic symptoms, and use of drugs and alcohol). We may request your permission to videotape the interview for a review by senior clinical researchers to ensure quality control. Strict confidentiality will be maintained at all times. The length of the interview is approximately 1 - 2 hours.
- Give a small sample of blood (approximately 40ml). (See information sheet - Genetic Testing and DNA Storage for Clinical Research). Since in approximately 5% of the people the process of removing the DNA fails, there is a small chance that we may ask you later for a second blood draw (you do not have to consent to a second blood draw, if you so decide). There is no hazard with the procedure except for the brief discomfort experienced



- when the needle is being inserted, and possible temporary bruising at the site of the draw.
- Participate in several tasks of attention, memory and concentration using a computer as well as pencil and paper. We ask about one in ten participants to complete a repeat assessment on one or more of the computer tasks to establish the stability of the measure. This task will take about 1-2 hours.
 - Participate in a brief neurological examination, involving testing your reflexes, sense of touch and coordination. It takes about 15 minutes to complete.
 - Participate in an interview which looks at your family history and events that you may or may not have experienced across your lifetime. This will take approximately 1 Hour to complete.
 - A percentage of participants, but not all, will be asked to have a brain image taken. A separate information sheet provides more details on the Magnetic Resonance Imaging process. This takes about 1 hour and will require an additional visit.

Who has access to my data?

ASRB site staff, management and committee members will have access to your data. The ASRB permits authorised researchers to access non-identifiable data for use in schizophrenia research but no identifiable information such as your name or address will be provided. Your data from the ASRB may also be released if requested by a court of law.

How will my data be used?

The ASRB is a non-profit medical research initiative established to aid schizophrenia research both in Australia and around the world. Researchers will be able to apply to the ASRB to access the data... Access will be through the Australian Schizophrenia Research Bank Access Committee. All researchers must have ethics approval for their project prior to approaching the ASRB. No identifiable information (i.e., name address or date of birth etc) will be provided to researchers, ensuring the privacy and confidentiality of your data. Nor will the ASRB use the genetic samples to determine your entire genetic make-up.

Privacy and confidentiality

The information and samples you provide will be stored on the ASRB database using a unique ID number. This number will be used to protect your privacy and confidentiality. All personal information that identifies you will be kept strictly confidential, and for security purposes will be stored separately from your all of your data using this unique identification code. Nor will personal information such as your name and address be passed on to a third person without your consent. Your data will not be sold or placed on a mailing list. Only anonymous (non-identifiable) data will be made available to approved researchers or presented at conferences or in manuscripts.

What happens to my samples if the ASRB closes?

The material stored by the ASRB is a precious and scientifically valuable resource. If in the future the ASRB would no longer be viable, then the stake-holders would seek to transfer your samples and clinical data to a third party willing to undertake the responsibility of maintaining the resource. The third party would have to adhere to the current guidelines as set out by the ASRB and the *National Statement on Ethical Conduct in Research Involving Humans (1999)*. Volunteers will be notified of any changes in 'ownership' of the ASRB and be given the opportunity to review their on-going involvement.

Should no third party exist, or if funding for this initiative ceased, then the ASRB will no longer operate. You (or if you are deceased, your nominated next of kin) will be contacted by mail and notified of the ASRB closure. Records and files pertaining to your participation will be returned to you or your next of kin upon written request, and all your genetic samples will be destroyed.

For further information

If you have any further questions, please do not hesitate to contact the Chief Investigator, Professor Assen Jablensky on (08) 9224 0290, or the WA Coordinator of this project, Sacha Pauly, on (08) 9347 6415. A toll free number for ASRB from anywhere in Australia is **1800 639 295**.

The following ethics committee has also approved this project and any concerns can also be addressed directly to them.

Secretary, North Metropolitan Area Mental Health Services Human Research Ethics Committee, Private Mail Bag No 1, Claremont WA 6910 – (9347 6618)