

CENTRE FOR CLINICAL RESEARCH IN NEUROPSYCHIATRY



Gascoyne House, John XXIII Avenue, Mt Claremont, WA 6010
Mail: PO Private Bag No. 1, Claremont WA 6910 Tel: (08) 9347-6429 Fax: (08) 9384-5128
<http://www.health.wa.gov.au/ccrn/>

The Western Australian Family Study of Schizophrenia

INFORMATION SHEET

Chief Investigator: Professor Assen Jablensky
Contact Phone Number: (08) 9224 0290

Project Coordinator: Ms Sarah Howell
Contact Phone Number: (08) 9347 6411

The Western Australian Family Study of Schizophrenia (WAFSS) is a series of inter-related research projects, which aim to increase our understanding of how genes and environmental factors influence mental function, symptoms and behaviour in people suffering from a psychotic disorder, such as schizophrenia. To achieve this aim, we invite the participation and cooperation of people diagnosed with schizophrenia, and may, on occasions, also ask for participation their close relatives. Since our research involves a comparison between the genetic makeup and mental function of people affected by the illness and that of people without the disease, we also invite volunteers from the community to participate in this research.

The WAFSS has been in progress for nearly 10 years, and has to date produced important new knowledge that has been recognised internationally. The study has been approved by the North Metropolitan Area Mental Health Service Ethic Committee and by the Human Research Ethics Committee of The University of Western Australia. Much of the WAFSS research is being funded by the National Health and Medical Research Council of Australia.

What does participation in the study involve?

If you decide to participate, you will be asked to:

- 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 about 1-2 hours but can be separated into shorter sessions, or ended on your request at any time.
- Give a small sample of blood (approximately 30ml). Our laboratory researchers will extract from the blood sample a tiny amount of DNA (DeoxyriboNucleic Acid – the chemical substance that carries the genetic information required for the reproduction, growth, development and function of the human body, including the brain) which will be stored in a secure freezer for later analysis. 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 3 hours, and is completed over 2 appointments.



- Participate in a brief neurological examination, involving testing your reflexes, sense of touch and coordination. It takes about 15 minutes to complete
- Complete a couple of questionnaires made up of statements people might use to describe their own personality/temperament, as well as more general. This takes about 30 minutes 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.
- For some, but not all, of the WAFSS projects, we ask participants to allow us to make a recording of their brain electrical activity (like an EEG) while they either listen to sounds through headphones, or do some simple tasks involving sounds. In this task the electrical activity of the brain is measured using a small headcap with sensors sewn in. During the same session we may also record the voluntary control of your eye movements by asking you to track the movement of a target on a computer screen. The entire session will take about 2 hours to complete.

We also ask parents to complete two additional interviews. The time taken to complete both of these interviews depends upon the amount of information known about the family or birth. Both of these interviews can be separated into shorter sessions, or ended at any time.

- The first interview involves drawing your family tree and asking some specific questions regarding the family history of physical and mental health problems.
- The second interview gathers information about the pregnancy and experience of any labor complications, and the development from early childhood through adolescence of the person diagnosed with a mental illness. (A lot of the information can be gathered from baby books and school reports if they are still available.)

As you can see our study includes a number of interviews and tests, however, not all participants are required to complete all of the steps. All of these activities can be scheduled at times to suit yourself, and a small payment can be made to cover time spent at our Research Centre.

What we will do...

Information collected from the interviews and tasks will be collated and analysed for evidence of behaviours and brain functions that might correlate with genetic differences. The genetic material (DNA) will be analysed in search of genes of possible importance to schizophrenia, and other related psychotic disorders. All information will be coded and kept strictly confidential. Video/audio-tapes will be stored in a secure area and where access limited to project staff. Information gathered during the course of the project will only be used for research, and no data that will be published in scientific journals will reveal the identity of participants. Although we will be happy to share with you whatever results we can, at present there are no known results that would directly benefit you, or your family

Your rights

You may withdraw your consent for this project at any time. In this event, upon receipt of written notification, any information we have collected, along with the blood sample, will be destroyed. If you choose not to participate in the project, this decision will not affect yours, or your relative's treatment now, or in the future.

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 Coordinator of this project, Sarah Howell, on (08) 9347 6411.