



THE UNIVERSITY OF
MELBOURNE

Project Title: bipolar disorder aNd oThEr RelAted CondiTions (INTERACT) Research Registry

Primary Investigator: A/Prof Tamsyn Van Rheenen, Melbourne Neuropsychiatry Centre

Please read the information below carefully. It will provide a summary of what you can expect if you register to be involved. Before deciding whether or not to register, you may want to talk about it with a relative, friend or healthcare worker.

The bipolar disorder aNd oThEr RelAted CondiTions (INTERACT) Research Registry is a database of everyday people who wish to participate in research focusing on bipolar disorder and related mental health conditions like depression, anxiety, or schizophrenia spectrum disorders. You do not have to have a diagnosis of these conditions to be on the Registry, just an interest in research.

Joining this Registry simply means that you give permission for the storage of your personal information so that authorised researchers can contact you about potential research projects that you may be interested in participating in. By creating a central registry of individuals who are interested in research, researchers can spend less time finding participants and more time conducting larger, higher quality studies.

The Registry is specifically designed for participants that meet the following criteria:

- Have a diagnosis of bipolar disorder, depression, anxiety, or a schizophrenia spectrum disorder (e.g. schizophrenia, schizoaffective disorder or other psychotic disorder)
- Are a first or second degree relative of someone with any of these mental health conditions.
- Have not been diagnosed with a mental health condition but are interesting in participating in research as a comparison subject.

The Registry collects a range of demographic information to assist researchers to find participants who are relevant and eligible for particular studies. Information such as age, sex, geographic

location, country of birth, ethnicity, handedness, level of education, family history of mental illness, history of head injuries, and diagnostic information is collected.

When registering, you will be asked to specify what types of research (e.g. neuroimaging, blood collection, clinical interviews, etc.) you may or may not be interested in.

This will ensure that you are not contacted about research that is not relevant to you.

To join the Registry, you will need to complete an information form from which all fields must be completed.

After joining the Registry, authorised researchers may contact you in relation to studies about bipolar disorder and/or related mental health conditions. These researchers will also have access to secondary information about you, such as the date you were last contacted by someone from the Registry, the nature of the contact, and the number of studies you have previously completed through your association with the Registry. If you are contacted, you will be provided with all the necessary information to make an informed decision about whether or not you would be interested in taking part in that study at that time. You are under no obligation to participate in any study if you did not wish to.

Any research projects you are contacted about will first have been approved by an independent ethics committee and only authorised researchers will have access to your details contained in the Registry. All researchers with access to the Registry will have applied for and been granted permission prior to contacting you.

The potential risks associated with participation in the Registry are minimal. To ensure you are not overburdened, an eight week 'washout' period is enforced upon your completion of a study. This means that researchers who use the Registry must wait at least eight weeks before recontacting you about further research.

No information you provide to the Registry will be used for future analyses or publications, nor will any identifying information be made public. The information will be stored securely in an electronic database, unless you no longer wish to be a part of the Registry. You can review your information or withdraw and have your details removed at any point by contacting the Registry Manager (ausbipolarregistry@gmail.com).

Who can I contact?

For more information, any questions, or if you are without access to the internet and you'd like to complete the Registry over the phone please email ausbipolarregistry@gmail.com. You will receive a

prompt reply from either A/Prof Tamsyn Van Rheenen (Principle Investigator) or one of the other Registry staff.

If you have any problems that may be related to your involvement in the Registry, you can contact the Principle Investigator, A/Prof Tamsyn Van Rheenen, tamsyn.van@unimelb.edu.au or (03) 8344 1957

This project has human research ethics approval from The University of Melbourne [project 20321]. If you have any concerns or complaints about the conduct of this research project which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the following ethics ID number of the research project: 20321

Informed Consent:

- I have read the above information and I understand the purposes and procedures of the Registry.
- I understand that my personal and health information are confidential, will be used only to contact me with regard to future participation in research studies related to bipolar disorder and/or related mental health conditions, and that I can request the withdrawal of from this Registry at any time.
- I give permission for the following information to be recorded in the Registry, and for authorised researchers to access this information, as specified above.

Consent

I consent. I would like to participate