Perceptions of Brain Donation

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in this survey examining public awareness and perceptions of brain donation for research in Australia.

In Australia, post-mortem organ donation is undertaken for three distinct purposes: transplantation, teaching purposes, or for medical research into specific diseases. These all have different registration processes, with organ donation for transplantation the most well-known and widely practiced. Unlike organ donation for transplant which has one all-encompassing national register, organ donation for medical research is facilitated by various bio-banks across Australia. The NSW Brain Tissue Resource Centre at the University of Sydney is a brain bank that primarily focuses on facilitating research into the causes and development of alcohol use disorders, mental health disorders and ageing. Our mission is to enable advances in medical research into neurological illnesses to understand, treat and cure disease. We facilitate brain donations through the ‘Using our Brains’ program, with a focus on donors with certain mental health disorders, alcohol use disorders, and healthy people with no history of brain disease (controls). This study aims to collect information about public perceptions of brain donation in order to inform future campaigns to raise public awareness of the ‘Using our Brains’ donor program.

(2) Who is running the study?

The NSW Brain Tissue Resource Centre is a specialised brain bank based at the University of Sydney’s Charles Perkins Centre. The researchers involved in this project are Professor Jillian Kril, Alicia Sweeney and Donna Sheedy.

(3) What will the study involve for me?


You will complete the online survey about your perceptions of brain donation for research and donation of other organs for transplant and other reasons. Please be aware that some of the questions in the survey relate to topics that are of a sensitive nature.

(4) How much of my time will the study take?

This survey will take 15-20 minutes.

(5) Who can take part in the study?

Anyone who currently resides in Australia, is 18 years or over, and is able to communicate in English can participate in the study.

(6) Do I have to be in the study? Can I withdraw from the study once I’ve started?

Participating in this study is voluntary. Your decision on whether or not to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney. You can withdraw your responses at any time before you have submitted the questionnaire by exiting the survey window. Once you have submitted the survey your responses cannot be withdrawn because they are anonymous, therefore we will not be able to tell which one is yours.

(7) Are there any risks or costs associated with being in the study?

We do not expect that there will be any risks or costs associated with taking part in this study, however we will ask for your thoughts on issues that many consider sensitive topics. Should you experience emotional discomfort arising from participating in the survey, please get help or counselling from your GP, a psychologist/counsellor, or mental support team from your local hospital.

(8) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study.

(9) What will happen to information about me that is collected during the study?

The information collected during this study will be used to inform future campaigns to raise the awareness of the ‘Using our Brains’ brain donor program. The personal information collected will be used for the purpose of the study and will be kept strictly confidential. The study findings may be published, but you will not be able to be identified in these publications. The survey data are anonymous as no personal identifying information is collected, and the information provided will not be able to link you to any of the answers. The data collected will be stored securely on The University of Sydney server, accessible only to selected NSW BTRC staff. It will be stored for 5 years post publication and then removed.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study and they can complete the survey provided they meet the inclusion criteria.
(11) **What if I would like further information about the study?**

At the end of the survey if you would like more information about the NSW Brain Tissue Resource Centre or the ‘Using our Brains’ donor program you will be able to enter your email address. If you have any questions or concerns before or after completing the survey please contact Alicia Sweeney via phone on 02 9351 2410 or email: alicia.sweeney@sydney.edu.au

(12) **Will I be told the results of the study?**

Because of the anonymous nature of the survey you will not be provided with the results of the study. Once all of the data is collected and analysed, news of the study results will be shared on the ‘Using our Brains’ Website and Facebook pages which you are able to access at: <sydney.edu.au/medicine-health/using-our-brains> and <https://www.facebook.com/usingourbrains> respectively.

(13) **What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [Protocol number 2020/243]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:
- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information sheet is for you to keep*