

## **EXPLANATORY STATEMENT**

### **Workshop on building the foundations for an Australian Brain Pioneers network**

**Project Number: 52951**

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### **Project Title: Workshop on building the foundations for an Australian Brain Pioneers network**

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the email addresses listed above.

#### **What does this research involve?**

This project aims to support the development of an Australian Brain Pioneers Network. "Brain pioneers" is an emerging community identity that recognises people who participate in first-in-human clinical research involving neurotechnologies as partners and knowledge holders in the development of new medical technologies. Neurotechnologies are medical devices that function by modulating, monitoring, or decoding activity in the nervous system.

Several Brain Pioneers initiatives have been established internationally (e.g., UK BCI consortium, USA Brain Pioneers Coalition) to build community among participants and include their perspectives in the design and conduct of neural device research. However, Australia currently has no equivalent network.

This project seeks to lay the foundations for such a network by engaging people with lived experience of neural device research and related communities to identify what an Australian Brain Pioneers Network could provide, what value it would have outside existing disability or advocacy organisations, and what services, resources, events, or collaboration opportunities should be prioritised.

If you decide to take part in this study, you will be asked to participate in a half-day in-person workshop with other invited participants. The workshop will involve group discussion about the possible aims, values, activities, and future direction of a potential Australian Brain Pioneers Network. With your consent, the workshop discussion will be audio recorded and transcribed so that the research team can accurately analyse the deidentified transcripts of the discussion. You will not be required to answer any question that you do not wish to answer and may withdraw from the

study at any time without penalty. Audio transcription and analysis will involve using an AI-enabled software approved for use by Monash University. Photos of workshop activities will also be taken during the day, though you are entitled to request not to be photographed beforehand or during the workshop without this affecting your participation in the study. These photographs may be used in the reporting of workshops outcomes at academic conferences, academic publications, or online. Any use of these images that is public-facing will involve seeking explicit consent from participants photographed.

The findings from this workshop will be used to inform the development of an Australian Brain Pioneers Network dedicated website and resource hub run out of Monash Bioethics Centre, which will host future community events. The findings of this study will be included in subsequent funding applications to support the longer-term development of the network.

### **Why were you chosen for this research?**

You have been invited to participate because you have relevant lived experience or community knowledge relating to investigational neurotechnology research, neurological or mental health conditions, or community advocacy. This may include individuals who have previously participated in neurotechnology device research, people currently using brain-based devices for their physical or mental health, or people eligible or enrolled to participate in a neurotechnology trial in the future.

All of these perspectives are valuable because this project aims to ensure that any future Australian Brain Pioneers Network is informed by the needs, priorities, and experiences of the people and communities it is intended to support.

### **Source of funding**

This research is funded by the School of Philosophical, Historical and Indigenous Studies within the Faculty of Arts, Monash University.

### **Consenting to participate in the project and withdrawing from the research**

Once you have read the Explanatory Statement and have had any questions answered by the research team, you can consent to participate in the study by reading and signing the consent agreement that was emailed to you.

Participation in this research is voluntary. If you decide to participate, you may withdraw from the workshop at any time without penalty and without providing a reason. You may also decline to answer any question or take a break during the workshop.

If you wish to withdraw your data during the workshop, you may do so by informing a member of the research team. If you wish to withdraw your data after the workshop, you may contact the research team within two weeks of the workshop. Because the workshop will involve group discussion, it may not always be possible to remove comments that are closely connected to the contributions of other participants. However, where your identifiable contributions can be removed, the research team will do so.

### **Possible benefits and risks to participants**

The workshop may involve discussion of experiences with illness, disability, clinical research, medical devices, healthcare systems, or participation in neural device trials. Some participants may find these topics personal or sensitive. You are not required to discuss any personal experience that you

do not wish to share, and you may skip questions, take a break, or withdraw from the workshop at any time.

There is also a small risk that participants in a group workshop may hear personal information shared by others. All participants will be asked to respect the privacy and confidentiality of others and not disclose information shared during the workshop outside the group. However, because this is a group setting, the research team cannot absolutely guarantee that other participants will maintain confidentiality.

An indirect benefit of participating in this study is the opportunity to help shape the foundations of an Australian Brain Pioneers Network and contribute to a larger body of work aimed at improving community engagement, participant involvement, and responsible innovation in neural device research.

Participants will be reimbursed for costs associated with attending the workshop, such as travel and parking. Participants will also be compensated \$150AUD for their time participating in the in-person Workshop. Catering will also be provided during the workshop.

#### **Payment**

Participants will be compensated \$150 AUD for their participation in the workshop. Costs associated with attending the workshop, such as travel or parking, will also be reimbursed in accordance with Monash University procedures.

#### **Confidentiality**

Any information collected that can identify you will remain confidential. The information that you provide can only be disclosed if: (1) it is necessary to protect you or others from harm, (2) a court order is produced, or (3) you provide the researchers with written permission.

The research data collected from you will be de-identified wherever possible. Although the consent form will include your participant information, consent forms and research data will be stored separately in accordance with university guidelines.

By signing the consent form, you consent to the audio recording of the workshop being analysed by the project team. The workshop recording will be transcribed using transcription software and checked by members of the research team. The de-identified findings may be published in peer-reviewed journals, reports, websites, and book chapters, and may be presented at academic and community conferences or events.

Some participants may be invited to contribute to future project outputs, such as a public-facing report, conference panel, website resources, or academic publication. Any such involvement would be discussed separately with you, and your name would only be used in public outputs with your written permission.

The Monash Human Research Ethics Committee and its delegates may also have access to the study information. You have a right of access to, and a right to request correction of, information held about you by Monash University in accordance with the Freedom of Information Act 1982 (Vic).

#### **Storage of data**

Any physical data gathered from your participation in the study will be stored in a locked filing cabinet within secure Monash University premises. Electronic data files, including audio recordings, transcripts, consent forms, and analysis documents, will be password protected and stored on Monash University servers or computer systems.

Only members of the research team will have access to the research data. All study records will be retained for five years after the completion of the study. When the time comes to destroy the study records, this will be done using secure confidential waste disposal and/or secure deletion of electronic files.

### **Results**

A summary of the study results may be made available to you by email once the study is completed. The findings from the workshop may also be shared through a public-facing report, the Australian Brain Pioneers Network website, academic publications, conference presentations, and future funding applications. You can also enquire about the study results by contacting the Chief Investigator, Dr Nathan Higgins (nathan.higgins1@monash.edu).

### **Complaints**

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer

Monash University Human Research Ethics Committee (MUHREC)

Room 111, Chancellery Building D,

26 Sports Walk, Clayton Campus

Research Office

Monash University VIC 3800

Tel: +61 3 9905 2052      Email: [muhrec@monash.edu](mailto:muhrec@monash.edu)      Fax: +61 3 9905 3831

Thank you,

Signature



**Dr Nathan Higgins**

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