



## The ISLAND Campus Study

### PARTICIPANT INFORMATION SHEET

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#### 1. Invitation

*You are invited to sign up to the ISLAND Campus study, through which you can enrol in courses and degree programs offered by the University of Tasmania with a full fee waiver. If you join ISLAND Campus and participate in the associated research you will gain access to university education, and the opportunity to obtain a university qualification, without incurring the usual Higher Education Contribution Scheme (HECS) student fees for the duration of your selected course.*

ISLAND stands for the Island Study Linking Ageing and Neurodegenerative Disease, a 10-year public health research program that aims to reduce the risk of dementia in the Tasmanian population. The ISLAND Campus study is a sub-study of the broader ISLAND project, and is investigating the potential beneficial, long-term effects of formal university education in middle and later life on the risk of developing dementia.

#### 2. What is the purpose of this study?

Through the ISLAND project we aim to engage Tasmanian residents aged 50 and over in a State-wide public health strategy to potentially reduce the number of people who develop dementia.

It is established that education is associated with better health, and recent research has shown living a healthy lifestyle can help reduce dementia risk. Therefore, our first aim is to test whether undertaking university education later in life leads to changes in lifestyle and behaviours linked with dementia risk, ultimately helping to reduce the risk of developing dementia. Research also suggests that educational attainment may help protect against age-related cognitive decline. The second aim of the Campus study is therefore to test whether university study undertaken later in life can reduce the risk of developing dementia by improving cognitive functioning.

#### 3. Why have I been invited to participate?

If you live in Tasmania and are aged 50 or over, you can join the ISLAND Project. All members of the ISLAND research program will be offered opportunities to participate in research, courses and activities throughout the 10-year ISLAND project. ISLAND Campus is one of these opportunities.

*If you are a member of ISLAND research (i.e. have already completed your baseline survey), you are eligible to enrol in the free University of Tasmania courses and degree programs available through ISLAND Campus.*

*If you are not yet a member of ISLAND research, but reside in Tasmania and are aged 50 years or over, you are invited to take advantage of the free University of Tasmania courses and degree programs available through ISLAND Campus, first by joining the ISLAND research program.*

#### **4. What will I be asked to do?**

It is a good idea to explore the course options available to Campus participants on the public ISLAND Campus website ([www.utas.edu.au/island-campus](http://www.utas.edu.au/island-campus)) and select course(s) you would like to enrol in. The university courses that are available include programs that are part of the Commonwealth funding for domestic places at Australian universities, and do not include courses that have limited enrolment places (e.g. medicine). You will find a step-by-step guide to enrolling in your course when you click on the "What's next" button on the public Campus website.

We recommend taking time to select your course of study in parallel with joining the ISLAND project and/or ISLAND Campus, or you can join the research now and enrol in your course later. At present the University has committed to offer free places for ISLAND Campus participants commencing study in Semester 2, 2020, and Semesters 1 and 2 in 2021.

##### *If you are a member of ISLAND research:*

- I. Join the ISLAND Campus study on your ISLAND Home page at [www.islandproject.com.au](http://www.islandproject.com.au).
- II. Check that your baseline surveys are complete  
If your ISLAND surveys are all in order you will be taken directly to the Campus Study launch page when you select the option to join the study. If you skipped or chose not to complete any of the first four surveys in the series, you will be given another opportunity to do these surveys to make you eligible for the Campus study. You will be guided through the completion of missing surveys, after which you will be taken to the Campus Study launch page.
- III. Provide your consent to the use of the information you provide for research purposes.
- IV. Complete four ISLAND Campus pre-enrolment surveys. Each survey takes about 5 minutes to do and when you have finished you will be returned to your ISLAND Home page.
- V. Follow the link on your ISLAND Home page to access the Campus course list and application guide to choose your university course, and proceed through the ISLAND Campus enrolment and admissions process.
- VI. Complete the ISLAND Campus assessments each year for the next five years.  
The annual assessments will include some cognitive tests as well as the ISLAND Campus surveys. The cognitive tests take about half an hour to complete.

##### *If you are not yet a member of ISLAND research:*

- I. Please visit [islandproject.utas.edu.au](http://islandproject.utas.edu.au) and register as a member of the ISLAND Project, then complete your baseline research surveys, following the instructions on your ISLAND Home profile.
- II. Once you have completed your ISLAND baseline you will be eligible to join the ISLAND Campus study.
- III. Please follow steps I to VI above.

##### *Once you have joined ISLAND Campus:*

Each year, for a period of 10 years, you will be asked to complete the ISLAND research assessments. Currently planned assessments involve online surveys and cognition tests, and in the future may include interviews and in-person health assessments.

It will always be optional for you to participate in ISLAND activities and the associated research, and you are able to withdraw from any aspect of the project at any time (see section 8 below).

#### **5. How is the study being funded?**

The ISLAND project is funded by the Wicking Dementia Centre, which is supported by core funding from the J.O. and J.R. Wicking Trust (Equity Trustees) and the University of Tasmania. The University of Tasmania is also directly supporting the ISLAND Campus study by waiving student fees for ISLAND members who enrol in its courses and degree programs.

## **6. Are there any possible benefits from participation in this study?**

Dementia is prevalent in the community and will affect most of us in some way. Participation in the ISLAND Project may help you to understand your risk of dementia and learn about ways to reduce these risks. The opportunity to enrol in university courses and degree programs through ISLAND Campus is offered as an initiative of the broader ISLAND Project based on evidence that sustained, stimulating cognitive activity may be beneficial in relation to building resilience to diseases that cause dementia, and addressing dementia risk behaviours. Long term, we hope to reduce the number of people who develop dementia in Tasmania. Other aspects of your health may also benefit from this study as many risk factors for dementia are also risks for other major chronic conditions and illnesses. However, our understanding of dementia risk is at an early stage and it may be that attending to these proposed dementia risk factors and undertaking various components of the ISLAND Project may or may not be of benefit to you personally.

## **7. Are there any possible risks?**

While embarking on a course of university study in mid-to-later life may bring with it some increase in anxiety or perceived personal risk, we do not anticipate any risks or harms associated with the research planned for the ISLAND Campus study. However, if you experience any distress due to the content of issues raised in this study, please contact your General Practitioner (GP) or other health provider. Alternatively, you may wish to seek assistance from Lifeline on 13 11 14 or online live chat through [www.lifeline.org.au](http://www.lifeline.org.au) (available 7pm-midnight 7 days) or Beyondblue on 1300 22 4636 or online chat through [www.beyondblue.org.au](http://www.beyondblue.org.au) (available 3pm-12am 7 days). The National Dementia Helpline provides free confidential phone and email information and a support service on 1800 100 500 or online chat through [www.dementia.org.au/helpline](http://www.dementia.org.au/helpline).

## **8. What if I change my mind or move out of Tasmania during the study?**

The ISLAND Project is studying dementia risk reduction in people who live in Tasmania. If you move away, you will no longer be eligible to participate in the research involved in the ISLAND Project, including the ISLAND Campus Study. You can withdraw from the whole ISLAND project, or any of its sub-studies or activities at any time. However, access to the HECS fee waiver, which enables you to undertake studies at the University of Tasmania at no financial cost to you, is linked to participation in ISLAND Campus for the duration of your course. If you withdraw from ISLAND Campus, your access to the fee waiver will cease. There are no other consequences to you, of withdrawing from the project.

To withdraw, log onto the ISLAND Home website ([islandproject.utas.edu.au](http://islandproject.utas.edu.au)) and select the self-serve "withdraw" option. The ISLAND Project team will confirm whether you wish to withdraw from the whole ISLAND Project, or some aspect of the Project and will then action your request. If you would like your data to be removed from the dataset please contact [island@dementia.utas.edu.au](mailto:island@dementia.utas.edu.au). Please note that if your data have already been collated and included in analysis it will not be possible to remove it. If you have concerns about the use of your data, you can also contact the Wicking Centre on the phone number or email above to discuss the matter with the Research Team.

## **9. What will happen to my data when this study is over?**

An ID code will be attached to the data you provide to the ISLAND Project. This ID will be used to identify all data associated with you rather than identifying information such as your name. All data will be managed according to the University of Tasmania Privacy Policy, available online at [www.utas.edu.au/privacy](http://www.utas.edu.au/privacy). Electronic data will be stored in password-protected files on secure University of Tasmania servers and will only be accessible to the authorised researchers and the authorised data manager of this study.

This is a long-term study, and in the consent conditions below we seek your permission to retain your data for up to 20 years. All data that is analysed for this study will be stored for five years after the publication of the results. Data will be destroyed after 20 years, or after 5 years have lapsed since publication of results derived using the data. Published data will not identify you. Data sets from which all personal identifiers have been removed, including your ISLAND Project ID, may be made available to collaborators of the Wicking Centre who may bring new methods of analysis, or capacity to meaningfully combine with other data sets, to increase opportunities for new insights into dementia risk reduction. A separate consent option is provided for you to let us know if you agree to the use of your data beyond the ISLAND project.

## 10. How will the results of the study be published?

No published data from this study will identify any individual participant. Summary data from this study may be reported in peer reviewed academic journals, conferences, reports and newsletters and will be communicated at public and community events and through the Wicking Centre and University of Tasmania websites. You will be notified of the results and outputs of this study through the ISLAND Home portal and the quarterly newsletter.

## 11. How can I agree to be involved?

Log into your ISLAND Home profile at [islandproject.utas.edu.au](http://islandproject.utas.edu.au) to access information and instructions for joining the ISLAND Campus study and for the links to your pre-enrolment assessments.

Before you can access the ISLAND Campus pre-enrolment assessments you will be asked to indicate that you have read this Participant Information Sheet and that you consent to the following conditions:

- I understand that my involvement in this research will include completing some online tests and questionnaires about myself, my health and issues related to dementia risk.
- I understand that as a participant in the ISLAND Campus study I will be able to enrol in a selection of University of Tasmania diploma or certificate course, or a degree program of my choosing, without incurring student fees.
- I understand this fee waiver is linked to my continued participation in the ISLAND Campus study and associated research.
- I understand that it is my responsibility to manage my own course choices, enrolment and progression in line with usual student administration and assessment procedures.
- I understand that the ISLAND Project research team will access my course enrolment and progression data from the University of Tasmania student administration systems.
- I understand that I will be contacted in the future to complete surveys at different time points, and that I will be presented with opportunities to undertake related studies.
- I understand that the results of the study will be published so that I cannot be identified as a participant.
- I understand that my participation in this research is voluntary.
- I understand that I am free to withdraw at any time, without explanation or penalty and that I can withdraw through the self-serve withdrawal option on the Island Study website.
- I understand that if I wish, I may request, by contacting the Wicking Centre Research Team, or through [island@dementia.utas.edu.au](mailto:island@dementia.utas.edu.au), that any data I have supplied be withdrawn from the research.
- I understand that I will not be able to withdraw my data if it has been collated with a larger data set and analysed for publication or other form of scientific communication.
- I understand that all study data will be securely stored for 20 years on University of Tasmania Servers, or for a minimum of five years from the final publication of results, after which time it will then be destroyed unless I give permission for it to be used to support other research in the future.

A separate consent question requests permission for the use of your de-identified study data to be shared and used for future (as yet unspecified) research purposes. If you wish to allow only the ISLAND team to use your data you can select 'no' to this separate consent condition.

## 12. What if I have questions about this study?

If you have any queries, concerns or issues with this study, please feel free to contact the ISLAND Project Manager by email at [island@dementia.utas.edu.au](mailto:island@dementia.utas.edu.au) or by telephone on 1-800-982600.

This study has been approved by the Tasmania Health and Medical Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC (Tasmania) Network by email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au) or on (03) 6226 6254. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H001864.

**This Participant Information Sheet is for you to keep.**