



Island Study Linking Ageing and Neurodegenerative Disease (ISLAND)

PARTICIPANT INFORMATION SHEET

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1. Invitation

You are invited to sign up to the Island Study Linking Ageing and Neurodegenerative Disease (ISLAND) Project – a long term public health study aiming to reduce the risk of dementia.

2. What is the purpose of this study?

Through this study we aim to engage Tasmanians (aged 50 and over) in a State-wide public health strategy to reduce the number of people who develop dementia. Recent research suggests that living a healthy lifestyle can help reduce the risk of dementia. We think that if people have a better understanding of the factors that affect their chances of developing dementia, and access to opportunities to act on this information, they will make changes in their lifestyle to reduce their risk. Therefore, an important step towards dementia risk reduction is to improve public knowledge of major risk factors for dementia. In the ISLAND Project we aim to:

- i. Learn more about Tasmanians' knowledge and opinions about dementia risk, as well as their motivation to address personal risk
- ii. Provide a risk profile for each participant based on their dementia risk behaviour
- iii. Engage participants in education about dementia risk and determine whether this education leads to changes in behaviour and dementia risk profile.

This will be a long-term project which ultimately aims to reduce the number of people who develop dementia in Tasmania.

3. Why have I been invited to participate?

You are eligible to take part in this study because you are an ISLAND Member and you are a resident of Tasmania aged 50 years or over. You can remain on the ISLAND Member register for as long as you like and will continue to receive news, updates and invitations from the ISLAND team.

This invitation is for you to become a member of the ISLAND Project Cohort, which will unlock the opportunity to participate in research, courses and activities offered through ISLAND over the 10-year Project.

Your participation in ISLAND is voluntary, and you are not obligated in any way to take part. You can participate for as many years as you wish. You may also prefer to participate in only some aspects of the study, it is up to you.

4. What will I be asked to do?

To get started you will be asked to answer some online surveys to *establish your baseline* for ISLAND research. From then on, you will be asked to repeat these (or similar) surveys every year throughout the 10-year Project. You will also be invited to provide a blood sample and do some tasks that measure your thinking and memory every second year. As an ISLAND research participant you will receive information about dementia risk reduction activities and invitations to participate in additional (optional) research activities related to the ISLAND Project dementia prevention objectives.

Phase 1: Joining the ISLAND Project Cohort.

To become a member of the ISLAND Project Cohort you will be asked to consent to being part of the study for 10 years and to the use of your ISLAND data for research purposes. You can see the consent conditions at the end of this document (Section 11).

Phase 2: Completing the baseline surveys

Once you have provided your consent, we will invite you to complete a series of online questionnaires about your background, physical and mental health, knowledge of dementia risks, your motivation to change risk-related behaviours, and your social networks. We will also ask you to complete a Dementia Risk Profile (DRP) which will tell you things you can do to help reduce your risk of developing dementia. Once completed, you will be able to view and download your DRP for your personal use. You may want to share and discuss these results with a health care provider, such as your General Practitioner (GP).

It may take you up to 70 minutes to complete the baseline survey in one sitting. You can stop at the end of any of the questionnaires and return later. When you log back into the ISLAND Home page, your profile will show where you are up to and have a link that will take you to where you left off. Completing each of the surveys is entirely voluntary, you may elect not to do some or any of them if you choose.

Phase 3: Participate in the Preventing Dementia Massive Open Online Course

Once you have completed your surveys you will be offered the opportunity to participate in the **free** Preventing Dementia Massive Open Online Course (PD-MOOC) through the ISLAND Project. The PD-MOOC covers the latest research in dementia risk and protective factors. There are no exams or assignments.

Doing the PD-MOOC is recommended, but is entirely voluntary and you can choose to do it or not. The course is online, takes about 8 hours over five weeks and is offered twice a year. If you choose to participate in the PD-MOOC we may invite you to complete two brief surveys again when you complete the course, including the DRP.

Phase 4: Ongoing Engagement with the ISLAND Study

Whether or not you choose to complete the PD-MOOC, you will remain a research member of ISLAND and have ongoing access to your personal ISLAND Home page. Every 12 months we will invite you to complete some questionnaires similar to the ones you completed initially. You will also be invited to complete some assessments that test your cognitive functioning (e.g. thinking and memory) and/or to have some blood taken by clinicians at the ISLAND Clinic for research purposes.

Through the ISLAND Home page and our newsletter we will advertise new research projects that will help us better understand how to detect and prevent dementia, as well as social and educational opportunities and events. You will be under no obligation to participate in any of these projects or activities and information will be provided to help you make a choice.

5. How is the study being funded?

This 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. As the project expands additional funding will be sought for specific subprojects within ISLAND from external granting bodies and through philanthropic campaigns.

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 this study may help you to understand your risk of dementia and learn about ways to reduce these risks.

All of the data you provide through the ISLAND Project is used for research, not diagnostic purposes, so you will not receive any personal results from the assessments. However, if you do the surveys you will receive feedback via the Dementia Risk Profile, which links the information you give us about your behaviours and health with globally accepted guidelines for minimising dementia risk (e.g. World Health Organisation). We will offer you opportunities to get involved in various programs through the ISLAND Project and we hope to build stronger dementia aware communities through education and community engagement.

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 from participation in this study?

Some participants may experience concern about dementia risk due to the issues raised in the survey questions. 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 (available 7pm-midnight 7 days) or Beyondblue on 1300 22 4636 or online chat through 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. The Wicking Centre is also planning to establish a clinic in 2020 where you can be referred to by your GP if you are concerned about your cognitive functioning.

8. What if I change my mind during or after the study?

You are free to withdraw from the study at any time without consequence. To withdraw, log onto the website and select the self-serve "withdraw" option. If you would like your data to be removed from the dataset please contact 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 link the data you provide to the ISLAND Project. This ID will be used to identify all data associated with you and will be used for subsequent analysis rather than identifying information such as your name. All data will be managed according to the University of Tasmania Privacy Policy (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.

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 www.islandproject.utas.edu.au to access information and instructions for joining the ISLAND Research Cohort, participating in this current study and for the links to your surveys.

Before you can access the surveys you will be asked to indicate that you have read this Participant Information Sheet, confirm you are at least 50 years of age and that you reside in Tasmania, and that you understand and consent to the following conditions:

- Your involvement in this research will include completing questionnaires about you, your health and issues related to dementia risk.
- You will be invited to participate in the Preventing Dementia Massive Open Online Course.
- You will be invited at different time points in the future to complete surveys, cognitive tests and to register to donate a small blood sample.
- You will be presented with opportunities to join other dementia-related studies conducted as part of ISLAND. If you join these related studies, the data you provide will be combined with the data collected as part of the main ISLAND project.
- The results of ISLAND research will be published so that you cannot be identified as a participant.
- Your participation in this research is voluntary.
- You are free to withdraw at any time, without explanation or penalty and can do so using the self-serve withdrawal option on the ISLAND Home website.
- You may request that any data you have supplied be withdrawn from the research by contacting the Project team at island@dementia.utas.edu.au.
- You will not be able to withdraw data that has already been collated for analysis.
- 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 you give permission for it to be used to support other research in the future.
- Any questions that you have asked have been answered to your satisfaction.

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 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 on (03) 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H001864.

Thank you for your time
This sheet is for you to keep