INVESTIGATING OBESITY SURGERY IN TASMANIA

INVESTigating obEsity Surgery in Tasmania (INVEST): A prospective cohort study

Participant Information Sheet

1. Invitation
You are invited to participate in a research project that aims to help researchers and policy makers better understand the experiences and outcomes for people who are planning to have, or go on to have, weight-loss surgery.

2. What is the purpose of this study?
The INVEST study will follow over time the experiences and outcomes of people who have been referred to a surgeon for weight-loss surgery. Some will decide not to proceed with surgery, others will wait for surgery and some will go on to have surgery. The study will assist researchers to have a better understanding of the issues, pathways and outcomes experienced by people after referral for weight-loss surgery. This knowledge will be used to help plan health services for people whose weight is affecting their health.

3. Why have I been invited to participate?
You have been invited to participate in this study because you have been referred to see a surgeon for weight-loss surgery, either in the public or private hospital system.

If you choose to participate, this decision, along with personal information that you provide the researchers, will be confidential. Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the health professionals caring for you.

4. What will I be asked to do?
If you agree to participate in this study we will ask you to do the following:

1. We will ask you to complete two surveys a year over a three-year period. Each survey will take about an hour to complete. The surveys will ask questions about your health and wellbeing, your social supports, and costs associated with managing your weight and/or surgeries. If you go on to have surgery, we will also ask about your experiences after surgery. The surveys can be completed online, or paper copies of the survey can be mailed to you and returned in a reply paid envelope directly to the research team. A research assistant can also help you to complete the survey over the phone.
2. Sign a consent form allowing us to access your medical records through your hospital or treating doctor. An additional consent form will ask for your permission for us to access your Medicare and Pharmaceutical Benefits Scheme data. The information collected from all records will allow us to investigate the range of health problems experienced by obesity surgery patients before and after their surgery, and their health service use and medication needs.

5. How is the study being paid for?
The study is being funded by the National Health and Medical Research Council, and the Tasmanian State Government.

6. Will I benefit from the study?
Your participation will help determine how best to support people who are planning or who have received weight-loss surgery in Tasmania. The results may also influence policy and clinical practice interstate and internationally.

It is an opportunity to provide input into future research that will be done in this area.

7. Are there any risks from participation in this study?
Participation in this study does not change your treatment in any way. Answering questions about your experiences may upset you. If this does occur and you feel the need to seek professional advice we recommend that you see your general practitioner. Depending on your needs you may also want to contact support services such as those listed below:

- Beyondblue http://www.beyondblue.org.au/get-support/get-immediate-support or 1300 224 636
- Australian Psychology Society http://www.psychology.org.au/findapsychologist/ or 1800 333 497

8. What if I change my mind during or after the study?
You are free to withdraw from the study at any time, and you can do so without providing an explanation. After July 2019 it will not be possible to remove your data from the study as we expect to have begun the publication process by that time.

9. What will happen to the information when this study is over?
All information obtained in this study will be used for research purposes only. The study data will be kept for 5 years from the first date of publication in a secure location in the Menzies Institute for Medical Research. Your data will be treated in a confidential manner.

10. How will the results of the study be published?
If you give us your permission by signing the consent form, we plan to describe the results in summary form in scientific journals and at conferences or other professional forums. Results of the study will be provided to you, if you wish.

11. What if I have questions about this study?
If you have any questions about this study you can contact Dr Michelle Kilpatrick (Michelle.Kilpatrick@utas.edu.au, (03) 6226 4630), Menzies Institute for Medical Research, University of Tasmania.
This study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 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 HREC project number H0015561.
**Members of the research team**

Note: only the researchers marked * will have access to information that includes your name

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<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Institution</th>
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<tbody>
<tr>
<td>Professor Alison Venn*</td>
<td>Epidemiologist</td>
<td>Menzies Institute for Medical Research (Menzies)</td>
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<tr>
<td>Dr Stephen Wilkinson (*only if he is your surgeon)</td>
<td>Surgeon</td>
<td>Royal Hobart Hospital</td>
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<td>Dr Alexandr Kuzminov*</td>
<td>Surgeon/PhD</td>
<td>Royal Hobart Hospital/Menzies</td>
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<td>Professor Andrew Palmer</td>
<td>Health Economist</td>
<td>Menzies</td>
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<tr>
<td>Dr Amanda Neil</td>
<td>Health Economist</td>
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<td>Associate Professor Leigh Blizzard</td>
<td>Biostatistician</td>
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<td>Professor Mark Nelson</td>
<td>General Practitioner</td>
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<td>Mr Brian Stokes*</td>
<td>Manager, Tasmanian Data Linkage Unit</td>
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<td>Professor Doug Ezzy</td>
<td>Sociologist</td>
<td>School of Social Sciences, University of Tasmania</td>
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<td>Mr Martin Hensher</td>
<td>Director, Strategic Planning</td>
<td>Department of Health &amp; Human Services (DHHS)</td>
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<tr>
<td>Associate Professor Tim Greenaway</td>
<td>Director – Clinical Services Endocrinology, Diabetes and Endocrine Services</td>
<td>Royal Hobart Hospital</td>
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<td>Dr Kelly Shaw</td>
<td>Specialist Medical Advisor</td>
<td>DHHS</td>
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<tr>
<td>Dr Michelle Kilpatrick*</td>
<td>Project manager</td>
<td>Menzies</td>
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