

## ONLINE SURVEY INFORMATION SHEET

### **More than a Meal: A Constructivist Grounded Theory of Mealtime Quality of Life and Inclusion for People with a Swallowing Disability [ETH21-6568]**

#### WHO IS CONDUCTING THIS RESEARCH?

My name is Rebecca Smith. I am a PhD candidate at the University of Technology Sydney (UTS). My primary supervisor is Professor Bronwyn Hemsley and my co-supervisor is Dr Lucy Bryant. This project is running from 2019-2022.

#### WHAT IS THE RESEARCH ABOUT?

The purpose of this online survey is to examine the impacts of dysphagia (swallowing difficulties) and dysphagia-related interventions (e.g., food texture modifications) on quality of life, participation, and inclusion for people with swallowing difficulties. It will also explore the use of 3D food printing as a potential strategy to improve enjoyment of puree foods and the inclusion and participation of people with swallowing difficulties in mealtimes.

You have been invited to participate because you:

- Have swallowing difficulties (dysphagia), are on a modified diet (e.g., puree food, soft foods, minced/mashed), and are able to swallow puree foods safely  
Or
- Are a support person for someone with swallowing difficulties (e.g., direct support worker, family member) or a support and supervisory role (e.g., house manager, senior support worker).  
Or
- Are a health professional (e.g., speech pathologist, occupational therapist, or dietitian) and have worked with people with dysphagia for at least the last two years and have been involved in their mealtime management.

#### FUNDING

This project is funded through a National Health and Medical Research Council (NHMRC) Postgraduate Scholarship and a Research Training Program (RTP) Scholarship awarded to Rebecca Smith.

#### WHAT DOES MY PARTICIPATION INVOLVE?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. If you decide to participate, you will be invited to read the information on this form carefully before agreeing to take part in the survey. This should take approximately 20 minutes.

You can change your mind at any time and stop completing the survey without consequences.

At the end of the survey you will be given the option to provide your contact details if you or someone you know has swallowing difficulties and would like to take part in an interview to further discuss the impacts of dysphagia on their quality of life and the use of 3D food printing. Once again there are no negative consequences if you do not provide your contact details.

## WHAT ARE THE BENEFITS OF MY INVOLVEMENT?

We cannot guarantee there will be any personal benefits for completing this survey. We hope the results will help shape dysphagia management in the future.

## ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there are some inconveniences. You may feel **embarrassment** or **distress** in relation to talking about swallowing difficulties and mealtimes. If this happens – you decide whether to continue or not.

If you find the research difficult or stressful please contact:

- Lifeline: 13 11 14 or <https://www.lifeline.org.au/>
- Beyond Blue: 1300 22 4636 or <https://www.beyondblue.org.au/>
- Your mental health professional or your GP who is already familiar with your history. If you are in Australia, Medicare will cover 10 sessions of counselling per annum which you can access via a referral from your GP.
- If you are not in Australia, please contact your local networks of support including your local health service provider.

## HOW DO I TAKE PART?

Access to the online survey is via a secure online survey program. Submission of the online survey is an indication of your consent.

## WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

All this information will be treated confidentially. All data will be stored on secure UTS servers using a secure online storage platform. This data will only be accessible by the researchers involved in the project. You can choose to remain anonymous throughout the survey. Alternatively, if you provide your name and email at the end of the survey, you consent to the research team collecting and using personal information about you for the research project. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. A code label will be used to refer to information about you (e.g., P1 for participant 1).

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

## WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have any concerns about the conduct of this research, please feel free to contact me at [rebecca.j.smith@student.uts.edu.au](mailto:rebecca.j.smith@student.uts.edu.au) or my Primary Supervisor Professor Bronwyn Hemsley at [Bronwyn.Hemsley@uts.edu.au](mailto:Bronwyn.Hemsley@uts.edu.au)

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772 or [Research.ethics@uts.edu.au](mailto:Research.ethics@uts.edu.au) and quote this number [ETH21-6568].