

PARTICIPANT INFORMATION SHEET: Adults with dysphagia

More than a Meal: A Constructivist Grounded Theory of Mealtime Quality of Life and Inclusion for People with a Swallowing Disability [ETH19-3708]

WHO IS DOING THE RESEARCH?



My name is Rebecca Smith and I am a PhD candidate at UTS.

My supervisors are Professor Bronwyn Hemsley and Dr Lucy Bryant at UTS.

WHAT IS THIS RESEARCH ABOUT?

Swallowing difficulties (dysphagia) and how it impacts on your enjoyment of meals.

We want to find out what you think of your swallowing difficulties and the foods that you eat. We would also like to see how you feel about meals created using a 3D food printer.

FUNDING



Funding for this project is from the National Health and Medical Research Council (NHMRC) and the Research Training Program (RTP).

WHY HAVE I BEEN ASKED?

Because you:

- are able to provide informed consent to take part
- have swallowing difficulties
- need a special texture diet (e.g., puree food, soft foods, minced/mashed), and
- are able to swallow puree foods safely.

IF I SAY YES, WHAT WILL IT INVOLVE?

Stage	What will I do?	When?
Your mealtime management documents	We look at a copy of documents in your home health records relating to your mealtimes (e.g., mealtime plan, swallowing assessment report).	At the beginning of your involvement in the study.
Mealtime observation (online)	Rebecca Smith will observe you eating your usual food during one of your usual mealtimes. This is so we check you are able to swallow puree foods safely. This will take approximately 45 minutes.	At the beginning of your involvement in the study.
Interview (In person or online using Zoom, owing to social distancing)	An interview for 1-1.5 hours, to ask you about your swallowing difficulties and their impact of quality of life. You can be interviewed with a support person who may also answer questions if they help you at mealtimes. During the interview we will talk about any documents that we have related to your mealtimes (e.g., mealtime plan, swallowing assessment report).	At the beginning of your involvement in the study.
Experiencing the 3D food printing that occurs at Protospace (online using Zoom video)	You can take part in 3D food printing experience where you will be able to observe the researchers, prepare, create, and present 3D printed food. This will take approximately 1 hour. The picture below is an example of a 3D printed guacamole gecko! 	Towards the end of your involvement in the study.



All of the interviews, observations, and the 3D printed food experience will be audio and video recorded then transcribed (everything that is said will be written down).

ARE THERE ANY RISKS?



You might be embarrassed, upset, or get tired when talking about your swallowing difficulties.

If this happens – you decide whether to continue or not.

If you find the research difficult or stressful, a referral for further counselling can also be provided if needed.

If you come to UTS and taste the food, you might have a bad reaction to the ingredients in food prepared using the 3D food printer. We will only use ingredients you already eat.

The food prepared with the printer may have something in it you should not eat. Researchers have been trained in food safety and will take all precautions (e.g. wearing gloves, storing cold food in the fridge).

DO I HAVE TO SAY YES?



Taking part is voluntary.

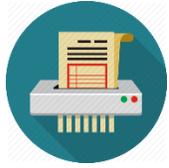
It is up to you whether you take part or not.

WHAT WILL HAPPEN IF I SAY NO?



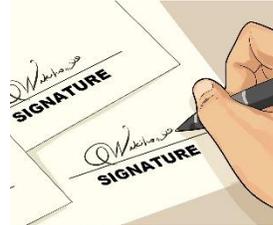
Nothing will happen.

If you want to stop at any time - contacting me on Rebecca.j.smith@student.uts.edu.au.



If you stop taking part, your research data will be removed from the study and destroyed.

CONFIDENTIALITY



Signing this form means you agree to the research team collecting and using your information for the research project.

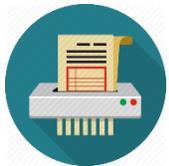


All of this information will be kept confidential so that you cannot be identified.

The information that is kept about you will be stored on secure computer software (STASH), that only the researchers can access.

We plan to publish results from our study, however your identity will remain confidential in any publication.

Your data will be kept for 5 years after the last research report is published.



It will then be destroyed securely and confidentially.

Your information will only be used for this research project.

HOW WILL I GET FEEDBACK ON THE RESULTS OF THE STUDY?



You will be invited to a 1 hour online seminar after the study results are known.

At the seminar we will tell people the results of the study.

Coming to the seminar is voluntary and your choice.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?



If you have concerns about the research that you think I can help you with, please feel free to contact me at rebecca.j.smith@student.uts.edu.au or my Primary Supervisor Professor Bronwyn Hemsley at Bronwyn.Hemsley@uts.edu.au

You will be given a copy of this form to keep.

NOTE:



This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC ETH19-3708].



If you have any concerns or complaints, please contact the UTS Ethics Secretariat:

Phone - +61 2 9514 2478, or

Email - Research.Ethics@uts.edu.au

Quote the UTS HREC reference number: ETH19-3708.

CONSENT FORM: Adults with dysphagia
More than a Meal: A Constructivist Grounded Theory of Mealtime Quality of Life and Inclusion for People with a Swallowing Disability [ETH19-3708]

I _____ (write your name) agree to take part in the research project “***More than a Meal: A Constructivist Grounded Theory of Mealtime Quality of Life and Inclusion for People with a Swallowing Disability***” [ETH19-3708].

I understand:



The research project is being run by Rebecca Smith (Work Address: level 9, Building 20, 100 Broadway, Ultimo NSW 2007; email: Rebecca.j.smith@student.uts.edu.au)



Funding has been provided by the National Health and Medical Research Council (NHMRC) and the Research Training Program (RTP).



What the research project is about, what I will do, and what the risks of taking part in the study are.



I am free to stop taking part at any time and this will not affect my relationships in any way.



I will be given a signed copy of this document to keep.



I have read the Participant Information Sheet.

Someone has talked about it with me so that I understand.

I have been able to ask questions.



I freely agree to take part in this research project.

I agree to be audio and video recorded.



I agree for copies of mealtime management documents to be collected

I agree that my research data may be published as long as it does not identify me in any way.

I am aware that I can contact Rebecca Smith or Bronwyn Hemsley if I have any concerns about the research.

Name and Signature [participant]

____/____/____
Date

Name and Signature [researcher or delegate]

____/____/____
Date

Name and Signature [witness*]

____/____/____
Date

*** Witness to the consent process**

If the participant, or if their legally acceptable representative, is not able to read this document, this form must be witnessed by an independent person over the age of 18. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. By signing the consent form, the witness attests that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the participant (or representative) and that informed consent was freely given by the participant (or representative).