

Appendix 2: Participant Information Sheet- Consumer

Health/Social Science Research – Young person providing own consent

SWSLHD Community Health Centres

Title	Oral health knowledge, attitudes, and practices of consumers and their carers
Short Title	
Protocol Number	
Project Sponsor	
Coordinating Principal Investigator/ Principal Investigator	Alisha Johnson
Location	<i>SWSLHD Community Health Centres</i>

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project. This research project is called: Promoting oral health among adolescents living with mental illness: A multi-phase mixed methods study to inform nurse-led interventions. You have been invited because you have been admitted to an adolescent mental health inpatient unit within the past 3 years. You have been contacted as you provided your interest in taking part in this study.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described

- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information Sheet to keep.

2 What is the purpose of this research?

People living with a mental illness can experience poorer oral health. This can impact quality of life and lead to problems later in life. This project aims to explore the views of adolescents who have experienced an inpatient admission, and their carers. This project will also explore potential supportive strategies.

The research has been initiated by the researcher, Alisha Johnson and is part of her Doctorate (PhD) degree.

3 What does participation in this research involve?

Before starting the project, you will be given the opportunity to sign a consent form. If you provide consent you will be asked to participate in an interview at a convenient time and place for you. You will have the option of taking part in the interviews either face-to-face, online, or via phone. The interview will be 30-45 minutes long and will explore your views about oral health. Questions will not explore mental health or mental illness experience. Questions will focus on oral health including what makes it hard and what makes it easier when looking after your teeth. You will be offered to have your interview separately to your parent/carers interview if you would like. This will allow you to express your views. However you may like to have your parent/guardian present during the interview if you feel more comfortable. You will also be given the option at the time of interview, if interested, to read over your responses at a later stage. This will be before the findings are reported.

There are no costs involved in this research project. You will not be paid, however you will be provided with a \$30 gift card for taking part.

This research project has been designed to make sure the researchers report the results in a fair and proper way.

4 Other relevant information about the research project

It is expected that 10-15 participants will take part in interviews.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you decided take part, you will be given this Participant Information and Consent Form to sign. You will also be given a copy to keep.

If you decide to take part or not to take part, or to take part and then withdraw, you will not be negatively affected. It will not affect your routine care, your relationship with professional staff or your relationship with SWSLHD.

6 What are the possible benefits of taking part?

We cannot promise that you will receive any benefits from this research. However, the information you provide will be used to inform supportive strategies. These strategies could improve the oral health of people with a mental illness.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question. You may also stop immediately. If you become upset or distressed while taking part in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge via Beyond Blue (1300224636) and/or Lifeline (131114).

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you. Personal information already collected will be kept. This is to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

The project team will take every effort to ensure this project is completed. However, this research project may be stopped for a variety of reasons. These may include reasons such as recruitment difficulties, or termination of the related PhD.

10 What happens when the research project ends?

It is planned for the project to be completed in 2025.

When the project is complete, copies of the results will be available to participants upon request. Contact details of the coordinating principle researcher will be provided to participants who wish to have these results.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

If you sign the consent form you consent to the research team collecting and using personal information. This information will only be used for the research project. Any identifying information obtained in connection with this research project will remain confidential. This includes all information that is provided being de-identified.

Your information will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law. There is the chance that information for this project may be made available on open access databases. This is part of the policies of participating institutions. All of this data will be non-identifiable and confidential. The research team will not collect or link any identifying information to your interview responses.

The results of this research project will likely be published and/or presented in a variety of forums. This information may be published in a research journal or at a conference. Information

will be presented in a way that you cannot be identified, except with your express permission. Any personal information will be de-identified. Information will be presented as group measures.

You have the right to request access to the information about you that is collected and stored by the research team. This is accordance with relevant Australian and/or New South Wales privacy and other relevant laws.

You also have the right to request that any information with which you believe is not correct. Please inform the research team member named at the end of this document if you would like to access your information.

Any information collected for this research project will be treated as confidential and securely stored. This includes information that may identify you. It will be disclosed only with your permission, or as required by law. All data will be kept for seven years. This is per NSW Health and Western Sydney University requirements and then destroyed.

12 Compensation

Please contact the research team if you experience any distress related with this project. The research team should be contact as soon as possible. You will be assisted with arranging appropriate treatment and support.

In the event of loss or injury, the parties involved in this research project have agreed to arrange appropriate care and support.

13 Who is organising and funding the research?

This research project is being conducted by Alisha Johnson. Alisha is a PhD candidate at Western Sydney University.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people. These people are called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of South Western Sydney Local Health District.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on (02) 87389354 or via email 17507699@student.westernsydney.edu.au

16. Complaints contact person

This study has been approved by the South Western Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research and Ethics Office, Locked Bag 7103, LIVERPOOL BC NSW 1871 on 02 8738 8304 / fax 02 8738 8310 / email SWSLHD-ethics@health.nsw.gov.au, website: <http://www.swslhd.nsw.gov.au/ethics/default.html> and quote [2023/STE00313].

**Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.**