

## Participant Information Sheet

**Health/Social Science Research - Adult providing own consent**

*SWSLHD Community Health Centres*

<b>Title</b>	Oral health knowledge, attitudes and practices of consumers and their carers
<b>Short Title</b>	
<b>Protocol Number</b>	
<b>Project Sponsor</b>	
<b>Coordinating Principal Investigator/ Principal Investigator</b>	Alisha Johnson
<b>Location</b>	<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, which 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 a parent or carer of a young person that has been admitted to an adolescent mental health inpatient unit within the past 3 years. Your contact details were obtained as you have provided your interest in participating 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?**

Individuals living with a mental illness, experience poorer oral health compared to individuals without a mental illness. This can negatively impact quality of life and lead to various disadvantages later in life. This project aims to explore the views of adolescents who have experienced an inpatient admission, and their carers, about oral health and potential supportive strategies.

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

## **3 What does participation in this research involve?**

Before any activities for the project start, 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 participating 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 but will focus on oral health including barriers and facilitators to engage in oral health practices. Your interview will be offered to be conducted separately to your parent/carers interview to allow you to express your views independently, however you may like to have your parent/guardian present during the interview if you feel more comfortable. You will also be given the opportunity at the time of interview, to read over your responses at a later stage, prior to the findings being reported.

There are no costs associated with participating in this research project, nor will you be paid, however participants will be provided with a \$30 gift card for their time and effort in participating.

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

## **4 Other relevant information about the research project**

It is anticipated 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 do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, 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 guarantee or promise that the participant will receive any benefits from this research; however, the information you provide will be used to inform supportive strategies that could improve the oral health of individuals 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, or you may stop immediately. If you become upset or distressed as a result of your participation 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, although personal information already collected will be retained 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?**

Although the project investigators will take every effort to ensure this project is completed, this research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as recruitment difficulties, or termination of the associated PhD.

## **10 What happens when the research project ends?**

It is planned for the project to be completed in 2025. Upon completion of the project, copies of the results will be available to participants upon request. Contact details of the coordinating principle investigator will be provided to participants who wish to obtain these results.

# **Part 2 How is the research project being conducted?**

## **11 What will happen to information about me?**

By signing the consent form you consent to the research team collecting and using personal information about the participant for the research project. Any information obtained in connection with this research project that can identify them 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 and it will only be disclosed with your permission, except as required by law. As part of the policies of participating institutions, there is the potential that information gathered for this project may be made available on open access databases, however all of this data will be completely non-identifiable,

and your confidentiality will be kept in this process. The research team will not collect or link any identifying information to your questionnaire responses like your name.

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, except with your express permission. Any personal information will be de-identified and presented as group measures.

In accordance with relevant Australian and/or New South Wales privacy and other relevant 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.

Any information obtained for the purpose of this research project that can identify the participant will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law. All data will be retained for seven years as per NSW Health and Western Sydney university requirements and then destroyed.

## 12 Compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team 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, 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 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](mailto: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](mailto: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.**