

Participant Information Statement

Research Study: Experiences of sexuality post stroke in LGBTQI+ persons

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1. What is this study about?

We are conducting a research study about the experiences of sexuality post stroke in LGBTQI+ stroke survivors and their partners. We aim to identify if stroke has an impact on sexuality in the LGBTQI+ community to provide new findings to assist with the ongoing development of sexual rehabilitation for future stroke survivors within the LGBTQI+ community. Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by the following researchers:

- Dr Margaret McGrath (Lead investigator),
- Associate Professor Emma Power (Co-investigator)
- Dr Roxanna Pebdani (Co-investigator)
- Mr William Kokay (Doctor of Philosophy - Research, student)

Mr William Kokay is conducting this study as the basis for the degree of Doctor of Philosophy (Research) at The University of Sydney.

The research team includes members who are from the LGBTQI+ community and provide a safe LGBTQI+ safe space for participants.

3. Who can take part in the study?

You can participate in this study if you

- Are aged 18 years and older
- Currently live in Australia, New Zealand, USA, Canada or the United Kingdom
- Identify as lesbian, gay, bisexual, transgender, Queer/Questioning or intersex (LGBTQI+)
- Have experienced a stroke or are a partner of a person who has had a stroke

As this study is focused on the experience of stroke survivors and partners of stroke survivors' persons with a pre-existing diagnosis of brain injury, dementia or intellectual disability are not eligible to participate in the study.

4. What will the study involve for me?

If you decide to take part in the study, you will be asked to participate in an interview with the researcher. This interview will take place over Zoom and will be organised at a time and date most convenient to you.

We anticipate that the total interview time will be 60-90 minutes. Depending on your preferences the interview can be completed in one meeting or can be scheduled over two or more sessions.

During the interview we will ask you questions about your experiences of sexuality following stroke. These questions may include topics such as sexual functioning, dating and relationships, sexual counselling and rehabilitation and experiences within the LGBTQI+ community.

Questions asked within the interview will include topics such as sexual functioning before and after stroke, dating and relationships, treatment you received when you or your partner experienced stroke and experiences within the LGBTQI+ community before and after your stroke.

As we are interested in your personal experiences of sexuality after stroke it is possible that you may be asked questions about your personal involvement in 'legally problematic' activities (e.g. substance use, acts that may result in transmission of HIV).

You can choose what personal information you share with the researchers AND you can choose not to answer if a question makes you feel uncomfortable or concerned.

You can request to read the transcripts from the interview in order clarify any parts of the interview that may require clarification with the interviewer prior to the data being analysed.

5. Can I withdraw once I've started?

Being in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you take part in an interview you may refuse to answer any questions that you do not wish to answer

If you decide to take part in the study and then change your mind you can withdraw up until the point of data analysis by informing the researcher via email.

If you decide to withdraw, we will not collect any more information from you.

Any information that we have already collected will be kept in our study records and may be included in the study results. Reasons for this is that once the study data has been analysed, we will be unable to separate individual data from the analysis without compromising results for the study.

6. Are there any risks or costs?

It is possible that some participants may feel uncomfortable or distressed after completing the survey because they are asked to reflect upon their experiences of relationships, intimacy, and sexuality.

If this occurs, you can access support from the following organisations

Australia

Beyond Blue <https://www.beyondblue.org.au/get-support/get-immediate-support>

LifeLine 13 11 14

New Zealand

The Stroke Foundation NZ (0800) 787 653

United States of America

American Stroke Association (Stroke family warmline) 1-888-478-7653

Canada

Stroke recovery Canada warmline 1-888-540-6666

United Kingdom

Stroke Helpline (UK) 0303 3033 100

Some questions that may be asked within the interview may relate to your personal involvement in 'legally problematic' activities. You can choose what personal information you share with the researchers AND you can choose not to answer any questions that make you feel uncomfortable or concerned.

There are no expected expenses associated with participating within his study.

7. Are there any benefits?

You will not receive any direct benefits from taking part in the study.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Any information you provide us will be stored securely and we will generally not disclose that information but there may be circumstances where we have to do so for legal reasons. In that case, the information could potentially be used against you in legal proceedings or otherwise. For example, information about drug use may be considered relevant in a criminal investigation.

You should not tell us anything specific about events or activities such as crimes you have not been charged with or you have not been to court about. Please don't tell us things like names, specific dates, or specific places of illegal activities. Over many years of research, we have never been required by law to provide our research information to anyone else. If we are, we will do our best to tell you.

We cannot keep information confidential if we

- Think you are going to seriously harm yourself
- Think you are going to seriously harm someone else
- Are required to provide this information by a court of law
- Learn information concerning the protective safety of children

If we receive such information, we would contact relevant health services (in the case of potential harm to yourself), police services or child protection services. If this happens, we will do our best to tell you.

We are planning for the study findings to be published.

You will not be individually identifiable in these publications.

All data obtained during this study will be destroyed in 5 years after completion of the study.

9. Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You will be given a chance by the interviewer to express your interest in receiving feedback about the overall results of this study within the interview. This feedback will be in the form of a brief lay summary.

10. What if I would like further information?

When you have read this information, the following researcher/s will be available to discuss it with you further and answer any questions you may have:

- Mr William Kokay
william.kokay@sydney.edu.au
+61 2 8627 7766

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [2021/719] according to the *National Statement on Ethical Conduct in Human Research (2007)*.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep