





## PARTICIPANT INFORMATION SHEET AND CONSENT FORM



**Project title: Experiences of sexuality post stroke in LGBTQI+ stroke persons and their partners**

Invitation to participate in research	
<p>You are invited to participate in a research study about <b>relationships, intimacy and sexuality education</b> for stroke survivors and their partners.</p>	

Who is conducting this study?	
<p><b>Dr Margaret McGrath</b> Senior Lecturer, Occupational therapy University of Sydney</p>	
<p><b>Associate Professor Emma Power</b> University of Technology, Speech Pathology Honorary Senior Lecturer, University of Sydney</p>	
<p><b>Dr Roxanna Pebdani</b> Senior Lecturer, Rehabilitation Counselling University of Sydney</p>	

<p><b>Mr William Kokay</b> PhD Student University of Sydney</p>	
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<p><b>To decide if you want to participate.</b></p>	
<p>Knowing what is involved will <b>help you decide</b> if you want to take part in the research.</p> <p><b>Please read this document.</b> It is formatted to be easy for people with communication difficulties to read. <b>We will help you</b> to understand.</p> <p><b>You can ask questions</b> about anything that you do not understand <b>or discuss it with others.</b></p>	 

<p><b>1. 'What is the purpose of this study?'</b></p>	
<p>We want to find out about <b>how stroke impacts sexuality</b> in LGBTQI+ stroke survivors and their partners. The study will help to identify and understand <b>the effects of stroke on relationships, intimacy and sexuality</b> on LGBTQI+ stroke survivors and their partners.</p> <p><b>We want to know about:</b></p>	 

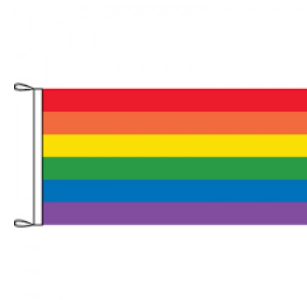
- Your sexual activity before and after stroke?
- Your experiences of dating and relationship before and after stroke?
- Your experiences of receiving health care for your stroke?



## 2. 'Why am I suitable to participant in this study?

You are suitable to participate because you have had a **stroke**.

If you give us permission, we will also invite your partner to be in the study.



### 3. What if I don't want to take part in this study, or if I want to withdraw later?

You can decide

You **do not have to** participate

You do **not** have to give a reason.

If you decide to participate ✓, **you can change your mind and stop at any time.** It may be hard to take out your data if we have removed your details.

If you wish to no longer be part of the study, you can tell us verbally or writing via email [william.kokay@sydney.edu.au](mailto:william.kokay@sydney.edu.au)





**Even if you do not want to participate, your partner still can if you give permission.**



### 4. 'What does this study involve?'

If you agree to participate in this study, **you will be**



<p><b>asked to sign the Participant Consent Form.</b></p>	
<p>The whole research will last for 6 months. You will not be required for all that time.</p> <p><b>YOUR part will involve:</b></p> <ul style="list-style-type: none"> <li>• <b>An interview</b> which we will complete via zoom (video conferencing).</li> </ul>	
<p><b>What is involved?</b></p> <p>1. <b>You will have a private interview with a research assistant.</b> They will give you some questions about how stroke has affected your relationships, intimacy and sexuality and questions about your experiences of health care services you have received for your stroke.</p> <p>This may take <b>1 hour. You can have breaks.</b></p> <p>The research team have members that are from the <b>LGBTQI+ community. Researchers Mr William Kokay and Associate Professor Emma Power</b> will conduct the interview with you.</p> <p>You can have a support person with you during the interview.</p>	  



<p><b>5. 'How is this study being paid for?'</b></p>	
<p>We have not been given any money to complete the study. That is it is not funded by a particular group or company other than the University.</p>	

<p><b>6. 'What are the alternatives to participating in this study?'</b></p>	
<p><b>You do not have to participate if you do not wish to.</b></p>	

<p><b>7. 'Are there risks to me in taking part in this study?'</b></p>	
<p><b>You may feel uncomfortable</b> talking about personal topics such as relationships, intimacy and sexuality.</p> <p><b>These topics may cause some distress and upset. If this happens the interviewer will stop and make sure you are okay before asking you if you</b></p>	

**want to continue.**

Some risks **may be unknown or unforeseeable.**

Any information you provide to us will be **stored securely.**

We will generally **not tell anyone else about the information** other than in our research articles and presentations.

**One exception** is for **legal** reasons.

For example, **if the information is about a crime**, we may be required to report it to police.

**So you should NOT tell us about any crimes** you have not yet been charged for or you have not been to court for.




**We also have a duty to ensure you are safe.**


We would have to contact health services, police or child protection services if you tell us:


- You might harm yourself
- You might harm others
  
- Information about the safety of a child.





<p><b>8. 'Will I benefit from the study?'</b></p>	
<p>The study information will not help you directly now.</p> <p>However the study information will hopefully help <b>other people with stroke in the future who identify as LGBTQI+.</b></p>	

<p><b>9. 'Will taking part in this study cost me anything, and will I be paid?'</b></p>	
<p>You will <b>not</b> get paid to be in this study.</p> <p><b>Your participation will NOT cost you anything.</b></p> <p><b>It is free.</b></p>	

<p><b>10. 'How will my confidentiality be protected?'</b></p>	
<p>Only the research team will know you are in the study.</p> <p><b><u>Your personal information will remain confidential.</u></b></p> <p>Only the research team <b>at the</b></p>	

**University of Sydney and the University of Technology Sydney can read the information.**

Your data will be held securely at **The University of Sydney (Camperdown campus).**

**We will share your information with the researchers listed above.**

All identifying information will be removed before it is sent. **You will be known as a number only.** We will **not** use your name.



## **11. 'What happens with the results?'**


The researchers **will look at the results.**

**We will present the results at conferences, workshops and in academic journals and websites to help others.**




We will not use your name.

**We will give you the results of the research if**



<p><b>you want.</b></p>	
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<p><b>12. 'What happens when the study is finished?'</b></p>	
<p>The research may be published but <b>your name will not be used.</b></p> <p>The information will be held for <b>5 years</b> before the data will be destroyed but <b>your name will not be within the data.</b></p>	

<p><b>13. 'What should I do if I want to discuss this study further before I decide?'</b></p>	
<p><b>Mr William Kokay can discuss the study with you further at any time.</b></p> <p> +61 2 8627 7766</p> <p> William.kokay@sydney.edu.au</p>	

<p><b>14. 'Who should I contact if I have concerns about the conduct of this study?'</b></p>	
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**This study has been approved by The University of Sydney Human research ethics committee.**

**If you are concerned** about the way this study is being conducted or you wish to make a complaint to someone not involved with the study,

**Please contact the research office** with the HREC reference number on:



+61 2 8627 8176



## To be involved

**Sign** the consent form

You can keep this information sheet.

