

**IncludED STUDY – SEEKING BETTER UNDERSTANDING OF EATING  
DISORDER EXPERIENCES IN THE LGBTQIA+ COMMUNITY**

**PARTICIPANT INFORMATION STATEMENT**

<i>Protocol number</i>	X22-0419
<i>Project sponsor</i>	Sydney Local Health District
<i>Coordinating Principal Investigator</i>	Dr Jane Miskovic-Wheatley (InsideOut Institute, the University of Sydney)
<i>Principal Investigator</i>	Marcellinus Kim (Sydney Local Health District)
<i>Associate Investigators</i>	Dr Phillip Aouad, Kai Schweizer, Dr Sabina Vatter
<i>Location</i>	InsideOut Institute for Eating Disorders, The University of Sydney

**Introduction**

Eating Disorders are a range of complex mental illnesses which can have a significant impact on both mental and physical health. At present, we don't know much about the level of body shape and weight concerns, disordered eating and associated mental health issues within the LGBTQIA+ community.

This study aims to understand the experiences of LGBTQIA+ people with eating, body shape/weight, exercise and mental health concerns who may or may not have a formal diagnosis of eating disorder. Data collected from this study will provide deeper insights into the experience of our community. This research has been designed by members of the community, for the community, and aims to provide information to improve awareness, understanding, supports and treatments.

This Participant Information Statement (PIS) will tell you what is involved in the study and help you decide whether or not you wish to take part. Please read this information sheet carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask. Before you decide, please feel free to talk things over with a relative, a friend or your doctor. You do not have to join this study if you do not want to.

**What does this study involve?**

To be able to participate in the study, you need to be 16 years or over and identify as LGBTQIA+. If you agree to participate in the study, you will be directed to complete a one-off anonymous online survey (found here: <https://redcap.sydney.edu.au/surveys/?s=JRKF4C9CCACDMDJD>), which should take about 10-15 minutes. Completing the questionnaire shows that you have agreed to take part in the study.

You will be asked to provide information about you (e.g., age, gender identity, sexuality, etc.) and your experiences with mental health and eating behaviours. Access to a computer, mobile or tablet device with a reliable internet connection is required to access the survey. The survey is only presented in the English language. If you cannot complete the survey in one go, you can save your responses and return to the survey later by noting down a unique code generated on the survey page. When you are ready to continue with the survey, just enter the code and you can continue your survey where you left it off.

After submitting your survey responses, you will have the opportunity to enter your email address to request a copy of study findings and to express your interest about being contacted for future research. Please note your e-mail address will be stored separately to your responses and they will not be linked to your data in any way.

**Will there be any risks for me in this study?**

We do not anticipate any discomforts or risks associated with participation in this study. Because the questionnaire addresses personal circumstances and experiences, the main risk is that some participants may experience emotional discomfort or distress when answering the study questions. In addition, there may be risks associated with this study that are presently unknown and unforeseeable. If at any time you feel distressed, you can call the Butterfly Foundation at 1800 33 4673 to get support from an eating disorder specialist, the Mental Health Access Line for NSW at 1800 011 511, QLife at 1800 184 527 or Lifeline at 13 11 14 for crisis support.

**Will there be any benefits for me in this study?**

There will be no direct benefits to you of participating in the research. However, we hope that by conducting this study we will get a better understanding of the experiences of eating, body shape/weight, exercise and mental health concerns in the LGBTQIA+ community. We acknowledge the time and effort it takes to complete the survey. We hope this study will provide valuable insight into the experiences and needs of the LGBTQIA+ community.

**Will there be any costs?**

Participating in this study will not cost you anything, nor will you be paid.

**Do I have to take part?**

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can stop being in it at any time. All you need to do is let of the researchers know that you don't want to take part anymore. Please note, once you submit your survey responses, all data will be locked for analysis and reporting. Your responses, or your decision not to participate in the study, will not impact your current or future relationship with the InsideOut Institute for Eating Disorders, the University of Sydney or Sydney Local Health District.

**How will my privacy be protected?**

All the information collected from you for the study will be treated confidentially, only the investigators named above will have access to it. The data will be analysed by the investigators at the InsideOut

Institute. All data for use in reports, journal publications and presentations will be de-identified (meaning that you/your information will not be identifiable). The deidentified data collected will be stored for 7 years in a secure network data management system compliant with the University of Sydney Research Data Management Policy and then all files will be permanently destroyed in accordance with University's policy.

**Where will my data be stored?**

The University of Sydney software licence for REDCap (Research Electronic Data Capture) will be used to manage the collection and storage of research data. REDCap is a secure, web-based, non-commercial, data management tool designed for research purposes. Data collected by REDCap is stored on servers in the University of Sydney data centre. Data is secured, and privacy and confidentiality of your data is maintained at all times.

**What will happen to the study results?**

The data collected in this project may also be used in future research studies. Any stored data that is used for related or future research, defined in the National Statement on Ethical Conduct in Human Research (2007, updated in 2018), will first be reviewed and approved by an appropriately constituted Ethics Committee. The results of this study and de-identified data may be shared in the future with national and international collaborators.

**Who should I contact if I have any questions?**

This study is being conducted within this institution by Dr Jane Miskovic-Wheatley, Research Stream Lead at InsideOut Institute for Eating Disorders. If you would like to know more, or have any questions, please contact Research Officer Sabina Vatter on 02 8627 5690 or by email at [insideout.research@sydney.edu.au](mailto:insideout.research@sydney.edu.au). You can also ask your relatives to talk to us.

**Who should I contact if I have concerns about the study?**

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 or [SLHD-RPAEthics@health.nsw.gov.au](mailto:SLHD-RPAEthics@health.nsw.gov.au) and quote protocol number [X22-0419].

Thank you for your consideration.

This information sheet is for you to keep.