

PARTICIPANT INFORMATION SHEET – Photovoice study

HREC Project Number	HRE2024-0283
Project Title	Digitally enabled lifestyle interventions for neurodivergent young adults.
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Student	Sarah Coutinho, <i>PhD Candidate</i>
Co-investigators	Associate Professor Ben Milbourn Dr Kevin Wernli Dr Valeska Berg Dr Bahareh Afsharnejad Professor Sven Bölte
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What is this project about?

Neurodivergent individuals experience a higher co-occurrence of mental health conditions, likely as a result of experiencing difficulties throughout life due to the impact of symptoms, the environment, and societal expectations. There are currently significant waiting times for diagnostic assessment (such as autism and/or ADHD assessments), with limited support available during waiting periods, further contributing to poor mental health. Whilst research highlights the positive impact of lifestyle interventions on mental health outcomes (including lifestyle psychiatry, allied health, and life skills-based interventions), current interventions are not individualised to neurodivergent populations, and fail in empowering individuals to self-manage their care.

The aim of this study is to identify the strategies and resources neurodivergent young adults utilize in working towards a healthy lifestyle and manage mental health. The findings of this study can then inform development of a digital intervention which incorporates useful tools. This research will involve 20 neurodivergent individuals with an autism and/or ADHD diagnosis, aged 18-30 years old.

Neurodivergent participants are being recruited as it is important for research for neurodiversity to be inclusive of the neurodivergent identity. This study uses the photovoice methodology, which is popular in neurodivergent groups where communication difficulties may be present. Photos allow participants to express answers to questions from their own perspective and facilitate discussion.

Why am I being asked and what do I have to do?

To help us understand what should be included in a support tool for people with ADHD and/or autism, we would like to hear your experiences or thoughts. Your participation will include:

- Attending 3 group sessions (1 hour each) either in person or online based on your preference.
- Each group will have 4-6 participants.

- Sessions will run 2-3 weeks apart, so you will be involved for a total of 8-12 weeks.
- Session 1: we will discuss topics like photographic techniques, how to analyse and then reflect on photos, and what are the ethical considerations involved.
- Session 2: we will discuss taking photos for this study and show you examples. You will then be asked to take photos as prompted of items which contribute to you maintaining a healthy lifestyle and supporting your mental health.
- At home between session 2 & 3: you will take your photos and fill out discussion questions which will be provided to you so you will have the opportunity to think about your responses prior to attending the group sessions. You can share this in the group sessions, share this 1:1 with the facilitator, or provide your written comments to the facilitator, depending on what is most comfortable for you. This will take no longer than 1 hour to complete at home. Please take as many photos as are appropriate for the topic discussed, with a minimum of 2 photos.
- Session 3: You will be asked to discuss these photos with the group based on the discussion questions if you are comfortable to do so.
- Whilst participation is encouraged, you can share as much or little as you would like in group sessions. You will be provided discussion questions prior to the session so you can decide what you would like to discuss beforehand if you'd like. If you would not like to participate in discussion, you can simply provide researchers with your filled out discussion prompts instead.
- You will be required to use a personal smartphone (with camera) or other personal camera and email photos to PhD student Sarah.
- Group sessions will be audio and video recorded.
- Upon signing the consent form and before the first meeting you will receive a package with more information about the sessions, dates and venues.
- You are welcome to bring a support person with you to the groups if you choose.

Where do I have to go?

Sessions will either be online or in person at Curtin University, building 401. If online, sessions can be completed anywhere you like (usually from home). You will be provided with free parking/ reimbursed for parking if attending the Curtin campus.

Is there a financial cost involved?

No, there is no cost involved. You will be awarded a \$40 gift card to reimburse you for your time.

Are there any benefits to being in the research project?

There is no direct benefit to you, however, you will be contributing to the collection of data on lifestyle interventions that support the mental health of neurodivergent individuals.

We anticipate the results of this research will mean that neurodivergent individuals seeking a diagnosis, or with a diagnosis, have better access to helpful mental health tools which are tailored to the neurodivergent population. You will have access to this intervention once completed.

Are there any risks, discomforts or inconveniences from being in the research project?

Apart from giving up your time, there are no foreseeable risks from this research project. We have been careful to make sure that the group sessions and activities involved do not cause you distress. As above, please note you will be asked to participate in group discussions with 4-6 participants. If you feel anxious about any of the questions, you do not need to answer them. If the questions cause any concerns or upset you or any unforeseen risks arise when participating in the focus group, we can refer you to a counselling service for support. The following resources are also free and available:

- Lifeline: counsellors are available to chat online 10pm-7am. You will need to complete a few pre-chat questions on their website before beginning. Go to: <https://www.lifeline.org.au/get-help/online-services/crisis-chat>
- Beyond Blue: webchat for brief online counselling services available 24/7. Go to: <https://www.beyondblue.org.au/>

To minimise the risks of COVID-19 exposure, please do not attend in person meetings if you are feeling at all unwell or have any flu-like symptoms. This is in line with WA State Government recommendations. These sessions can be attended online or in a make-up session later if needed.

Who will have access to my information?

- Whilst all care will be taken to maintain privacy and confidentiality of any information shared at a focus group or group discussion, you should be aware that you may feel embarrassed or upset if one of the group members repeats things said in a confidential group meeting.
- The information collected in this research will be re-identifiable (coded). This means that we will remove all personally identifying information on all data and replace it with a code. Only the research team will have access to the code to match your name, if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project. The only people that will have access to your information are the research team (student and supervisors) and the Ethics Committee at Curtin University.
- How will information be stored? Electronic data will be password-protected and hard copy data (including video or audio tapes) will be kept in locked storage on campus.
- How long will the information be stored and what happens at the end of the storage period? The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed.
- You have the right to access, and request correction of, your information in accordance with relevant privacy laws.
- The results of this research may be presented at conferences or published in professional journals but you will not be identified in any results that are published or presented.

Will you tell me the results of the research?

If you wish, at the end of the research (in about 18-24 months) we will contact you and provide you with a summary of the results. Results will not be individual but based on all the information we collect and review as part of the research.

We anticipate an online resource will be developed and can email participants who request this following development.

Do I have to take part in the research project?

Taking part in a research project is voluntary. If you choose not to take part or start and then stop the study, there is no penalty, and it will not affect your relationship with the project team and Curtin University. If you chose to stop the study, we will use any information already collected, unless you tell us not to. Your data will be removed if you request for it to be.

Who is doing the research?

The project is being conducted by the PhD candidate Sarah Coutinho and her supervisors – Professor Sonya Girdler, Associate Professor Ben Milbourn, Dr Kevin Wernli, Dr Valeska Berg, Dr Bahareh Afsharnejad, and Professor Sven Bölte.

The results of this research are part of Sarah Coutinho's study towards being awarded a Doctor of Philosophy at Curtin University and she is funded by the university.

What happens next and who can I contact about the research?

Should you have any questions about the research, please contact the researcher, **Sarah Coutinho** at sarah.coutinho@postgrad.curtin.edu.au to obtain further information or ask questions.

If you decide to take part in this research we will ask you to sign a consent form. By signing it, you are telling us that you understand what you have read and what has been discussed. Signing the consent form indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number: HRE2024-0283). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au