RECRUITMENT AND QUESTIONNAIRES MATERIALS

FOR AUTISTIC PARTICIPANT’S PARTNER

AUTISTIC PARTICIPANT’S PARTNER INFORMATION SHEET

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| HREC Project Number: |  |
| Project Title: | Personalised Dyadic Physical Activity Promotion Intervention for Autistic Adults: A Pilot Trial Evaluating Feasibility and Acceptability |
| Chief Investigator: | Associate Professor Joanne McVeigh (Curtin University) |
| Student researcher: | *Vu Duong – PhD candidate* |
| Version Number: | *1* |
| Version Date: | 19/08/2024 |

What is the Project About?

This project is about helping autistic adults become more physically active. Regular physical activity (PA) is good for your heart, can prevent obesity, and improves mental health. However, many autistic adults are less active than others. This can lead to health problems like heart disease and mental health challenges. This study is the final part of a larger project. It aims to test whether a new program can help autistic adults increase their physical activity. According to the recommended PA guidelines from the World Health Organisation, the intervention aims to (1) improve PA accumulation to at least 75 minutes of vigorous PA or 150 minutes of moderate PA, or a combination of both each week, (2) reduce sedentary behaviour (SB; like sitting or lying down) accumulation each week, and (3) improve motivation for PA. These outcomes will be measured using devices and self-report questionnaires.

Who is doing the Research?

Vu Duong, a PhD candidate at Curtin University, is conducting this research. He is supervised by Associate Professor Joanne McVeigh, Dr Craig Thompson, and Dr Marlene Kritz. The research is part of Vu’s PhD and is funded by a scholarship from the University.

Why am I being asked to take part, and what will I have to do?

You are invited to participate in this study as the partner of an autistic partner in a 12-week physical activity improvement program. Your role is essential in supporting, motivating and supervising the autistic individual to complete the program. Here’s what you need to do:

1. **Consent and Screening**:
   * First, you’ll review this information sheet.
   * You’ll complete a short screening test if you're happy to join.
   * You’ll need to sign a consent form online if you're eligible.
   * Demographic Information: We’ll ask for basic information about you, like age, gender, and living situation. This will take about 10 minutes via an online test.
   * Schedule Your First Meeting: If you’re eligible and we get consent from you and your autistic partner, we’ll send you all intervention materials and a link to schedule an in-person meeting at Curtin University. Please only sign up if you can travel to Curtin University for the first in-person meeting with your autistic partner.
2. **Your First Meeting (Week 0):**

* You and your autistic partner will meet with the researchers on the Curtin University campus.
* Physical Activity Survey (IPAQ): You’ll answer 27 questions about your PA over the past week. This will take about 15 minutes.
* Exercise Motivation Survey (BREQ-3): You’ll answer 19 questions about what motivates you to exercise. This should take about 10 minutes.
* SENS Device: Your autistic partner will get a small SENS device to wear for seven days to track their activity levels. They need to connect it to an app called Motus daily and send it back in a prepaid envelope at the end of the week. You will monitor your autistic partner to ensure they wear and return the device on time according to the procedure.
* WhatsApp Group: You’ll be invited to join a WhatsApp group where you’ll get updates, reminders, and support from the research team.
* Schedule Week 1 Workshop: We’ll also help you schedule an online workshop for Week 1.
* Intervention walkthrough: We will guide you through the intervention protocol and how to use devices and intervention materials.

1. **Your Activities During the Program (Weeks 1 to 12):**

* Week 1 Workshop: You and your autistic partner will join an online workshop. This workshop will help you learn more about PA and its importance. We’ll cover topics like the health benefits of PA, consequences of SB, fun ways to be active (like walking, dancing, or cycling), sharing public gym facilities, problem-solving strategies and scheduling your PA together.
* Planning Your Activities (Weeks 1, 3, 5, 7, 9, 11): At the start of these weeks, you will help your autistic partner choose the PA activities they want to do and help them develop a PA schedule for two weeks (week 1 and 2, week 3 and 4, and so on) using a template we provide in the Intervention Manual. You’ll share your plan with the research team through WhatsApp.
* Joining and supporting your autistic partner in the chosen PA as planned each week.
* Reflection Meetings (Weeks 3, 5, 7, 9, 11, 13): You and your autistic partner will have short meetings (online during weeks 3, 5, 9, and 11 and in-person during Weeks 7 and 13) with a researcher to discuss your autistic partner’s progress. We will discuss how much PA and SB (in minutes) your autistic partner had over the last two weeks. We will also discuss your challenges and how to overcome them.
* SEN's tracking: In week 7, we will meet at Curtin University or a convenient public location for you and your autistic partner. Your autistic partner will get the SENS device to wear again for a 7-day measurement period across week 7. You will support your autistic partner by ensuring they wear the device continuously for seven days and return it via a paid envelope.
* In the week seven meeting, you’ll complete the PA’s level survey (IPAQ) again.
* Fitbit Tracking: Throughout the 12 weeks, your autistic partner will wear a Fitbit to track their activity level. You’ll remind them to record what type of PA you did, the total minutes of active behaviours (Active Zone Minute data on Fitbit), and the total minutes of sedentary behaviours (Stationary Hour data on Fitbit) each week in an activity logbook in the Intervention Manual.
* Please remember: All devices used in this program, including the Fitbit and SENS devices, belong to the university and must be returned as instructed.

1. **After the Program (Week 13):**

- Final Meeting: You’ll meet with the researchers one last time to complete a few final steps:

* Physical Activity Survey (IPAQ)
* Exercise Motivation Survey (BREQ-3)
* Feedback Survey: You’ll answer a few questions about what you thought of the program. This will take about 5 minutes.
* SENS Device: Your autistic partner will wear the SENS device again for seven days to track activity. They need to connect it to an app called Motus daily and send it back in a prepaid envelope at the end of the week. You will monitor your autistic partner to ensure they wear and return the device on time according to the procedure.

1. **Thank You Gift**

- $50 Voucher: As a thank you for participating, you and your autistic adult will each receive a $50 voucher at the end of the intervention (After the SENS device is returned after week 13).

1. **Cost to you**

All the data we need will be collected electronically, and all devices and materials will be provided freely. However, you may need to pay small travel fees for three in-person meetings in weeks 0, 7, and 13. Also, the research team does not cover fees related to your chosen PA (such as gym membership).

Are there any benefits to being part of the research project?

Participating in this study may help you and your autistic partner become more active and improve your fitness and mental health. The results will also help us develop better programs to support autistic adults in becoming more physically active.

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

Participating in physical activity (PA) with your autistic partner and incorporating it into your daily schedule may lead to frustration or discomfort. There is also a possibility of discontent or conflict with your autistic partner, who may withdraw from the intervention for various reasons (e.g., interpersonal or scheduling conflicts). Additionally, engaging in PA carries a potential risk of injury or discomfort (e.g., muscle soreness), especially for individuals not accustomed to this activity level.

However, because your autistic partner is part of your social network, this familiarity can enhance comfort and ease. You will assist your autistic partner in planning and engaging in PA based on mutually agreed schedules. You and your partner will have full autonomy to choose PA activities that align with your interests and comfort levels. Furthermore, you will receive training in effective communication and conflict-resolution strategies to support collaboration. To address any challenges, you can access an online social support hub and one-on-one consultations with the research team for additional support.

Who will have access to my information?

The information collected in this research will be re-identifiable (coded). This means we will collect data that can identify you but remove identifying information on any data or sample and replace it with a code when we analyse it. Only the research team 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 unless otherwise specified. The following people will have access to the information we collect in this research: the research team and, in case of an audit or investigation, staff from the Curtin University Office of Research and Development.

All data will be protected with passwords and kept under secure conditions at Curtin University for seven years after the research is published, and then it will be destroyed. The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

Yes, we will write to you when the study is finished, which will be in about six months. The results will be based on all the participants’ information, not just yours.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay; you can withdraw from the project. If you choose to refrain from participating or starting and then stop the study, it will not affect your relationship with the University, staff or colleagues. We will destroy any information we have collected from you if you decide to withdraw from the study at any time.

If you withdraw, the research team will recruit volunteers, such as occupational therapy or sports science students, to serve as an alternative partner for your autistic partner. If your autistic adult wishes to continue with a volunteer, the research team will facilitate the transition by arranging an introductory meeting and providing ongoing support during the adjustment period. Any modifications to the intervention will be discussed with and approved by you and your autistic partner, ensuring your consent throughout the process. However, if your autistic adult withdraws, you must also cease participation, as the intervention primarily targets the autistic adult.

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

Please get in touch with Associate Professor Joanne McVeigh if you need further discussion about the research via this email: Joanne.McVeigh@Curtin.edu.au.

If you decide to participate in this research, please complete the screening questionnaire on the next page. If you are eligible, please sign the electronic consent form. The consent form has a checkbox indicating that you have understood the information in the sheet. Ticking the consent box tells us that you understand what you have read and what has been discussed. Signing the consent with your initials 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 before deciding 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 XX/XXXX). 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.

SCREENING AND CONSENT QUESTIONNAIRE

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| A black and white sign with white text  Description automatically generated  Thank you for volunteering to participate in this research study exploring the feasibility and acceptability of a 12-week health promotion dyad intervention for autistic adults. Prior to being invited to the study, please answer a few following questions to determine your eligibility.  The Curtin University Human Research Ethics Committee (HREC) has approved this study: Personalised Dyadic Physical Activity Promotion Intervention for Autistic Adults: A Pilot Trial Evaluating Feasibility and Acceptability (HRE2023-XXXX). | |
| 1. What is your current age? | \_\_\_\_\_\_\_\_\_\_\_ |
| 1. Have you been diagnosed with Autism Spectrum Disorder (ASD)? | * Yes   *(If yes, continue screening questions)*   * No   *(If no, continue screening questions)* |
| 1. Have you been diagnosed with an Intellectual Disability (ID)? | * Yes   *(If yes, cease questionnaire with thanks)*   * No   *(If no, continue screening questions)* |
| 1. Do you have access to a smart mobile device that can receive SMS text-messages?   (*or* do you have a touch-screen phone or tablet that has a SIM card installed?) | * Yes   *(If yes, continue screening questions)*   * No   *(If no, cease questionnaire with thanks)* |
| 1. Do you have access to the Wi-Fi on your smart mobile device? | * Yes   *(If yes, continue screening questions)*   * No   *(If no, cease questionnaire with thanks)* |
| 1. Do you currently have any health conditions that prevent you from being physically active? | * Yes   *(If yes, cease questionnaire with thanks)*   * No   *(If no, continue screening questions)* |
| 1. Are you happy to join and support your autistic partner during this 12 week program? | * Yes   *(If yes, cease questionnaire with thanks (01))*   * No   *(If no, cease questionnaire with thanks)* |
| If participants do not meet the inclusion criteria outlined. The survey will not progress further, and this note will be provided:  “Thank you for your time in completing this questionnaire, it is greatly appreciated. Based on your responses, you are not eligible to participate this study. If you have any questions or concerns, please feel free to contact the corresponding researcher via email (vungoc.duong@postgrad.curtin.edu.au).” | |
| If participants complete all initial screening questions, it is assumed responses are accurate and the participant will be included in the study (by meeting the criteria).  This note will be provided at the end of the survey for participants that have a partner:  "Congratulations! You are eligible to participate in this study. Please read the consent form in the next page and tick the boxes that you agree with. After that please complete the questionaire on your personal. An information sheet and consent form, demographic questionaire will also be sent to your autistic partner via the provided contact details. Once we get both the consents and information from you and your partner, we will contact with you soon to schedule an in person introductory session at Curtin University. Please only sign up if you can attend the session in person.  In this session, we will provide you more detailed information about the program. You will also be asked to complete several questionaires about your physical activity patterns.  If you have any questions or concerns, please feel free to contact the corresponding researcher via email (vungoc.duong@postgrad.curtin.edu.au).” | |
| CONSENT FORM   |  |  | | --- | --- | | HREC Project Number: | *The Ethics Office will advise you of this number after you have submitted your project* | | Project Title: | Personalised Dyadic Physical Activity Promotion Intervention for Autistic Adults: A Pilot Trial Evaluating Feasibility and Acceptability | | Chief Investigator: | Associate Professor Joanne McVeigh (Curtin University) | | Student researcher: | *Vu Duong – PhD candidate* | | Version Number: | *1* | | Version Date: | *18/08/2024* |   Please read these statements carefully and tick the boxes of the statements that you are agree with to indicate your consent:   * I have read the information statement version listed above, and I understand its contents. * I believe I understand the purpose, extent and possible risks of my involvement in this project. * I voluntarily consent to take part in this research project. * I have had an opportunity to ask questions, and I am satisfied with the answers I have received. * I understand that Curtin University Human Research Ethics Committee has approved this project and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2024). * I understand I will receive a copy of this Information Statement and Consent Form.  |  |  | | --- | --- | | Participant Name |  | | Participant Signature |  | | Date |  |   Declaration by researcher: I have supplied an Information Letter and Consent Form to the participant who has signed above.   |  |  | | --- | --- | | Researcher Name |  | | Researcher Signature |  | | Date |  | | |
| Thank you for your time and interest in this study. Your responses have been recorded and will be handled with confidentiality. Please proceed with the personal information questionaire in the next page. | |