

An invitation to join a Stakeholder Research Group



Information Sheet (Phase 1a) – Version 1.0 – 18 March 2021

Introduction

This leaflet provides information about a research study that is titled “Improving anxiety in people with mild to moderate intellectual disability: Developing and testing a novel, co-produced, mental imagery intervention.”

Please feel free to talk to others about this study if you wish. Do ask questions if anything is unclear.

What is the purpose of this research?

We are conducting a research study about the psychological treatment of anxiety amongst people who are older than 18 years and who have mild or moderate learning disabilities.

In Britain, we tend to say learning disabilities, but we also use the phrase intellectual disabilities. The two mean the same thing.

We are going to adapt an existing treatment for anxiety for use with people with learning disabilities. One treatment for anxiety is using mental imagery (pictures

in our heads). By changing our mental images, it can change how we feel. We think mental images might be easier for people with learning disabilities to change than other types of thoughts such as verbal (or word-based) thoughts. However, we don't know much about the experiences of mental imagery in people with learning disabilities.

This project will find out more about mental imagery in people with learning disabilities. We will also look at different mental imagery interventions that are already used and see if we can adapt them for people with learning disabilities.

To make sure we are doing good quality research we are asking a group of people with learning disabilities to work with us and help us make sure the work is accessible. We also want a Stakeholder Group of family members, professionals and other interested people to oversee our project.

There are three parts to our study:

Part 1 – Learning about different mental imagery interventions. We will have some focus groups to discuss these together and think about which ones might be helpful for people with learning disabilities.

Part 2 – Holding a workshop to discuss the different interventions and try them out. We will work together to adapt one intervention, which the research team will go on to pilot with people with learning disabilities and anxiety

Part 3 – Feeding back the results. We will ask you what it was like being in the Stakeholder Group. We will write journal articles and present the results at a conference.



What are we asking you to do?

We would like to ask you to consider joining our Stakeholder Group. You are being asked to join because of your specific expertise and experience.

You are not being asked to be a participant in research.

Instead, we are asking you to help us adapt our research and make sure the intervention is appropriate for use with adults with mild to moderate learning disabilities who also have problems with anxiety.

If you decide to join our group, we will ask you to join a meeting approximately once every 6 weeks. Meetings might be in person or online. Each meeting may last a couple of hours, and we will have some breaks.

Our Stakeholder Group will be made up of carers, family members and clinicians. It will be chaired by Olivia Hewitt.

For each meeting, the research team will present their work to the group.

The group will be asked to make comments about what the research team are proposing and make any suggestions for changes.

We want the meetings to be interactive and helpful, with us working together collaboratively to co-produce an adapted version of the intervention and associated materials.

The researchers will act on the suggestions of the Stakeholder Group following each meeting, and then return to present our work at the next meeting.

Sometimes the Stakeholder Group and the Research Group (people with learning disabilities) will meet all together.

You might have some questions, and please do ask us. We will do our best to answer them.



Consent

If you want to join our Stakeholder Group, we will ask you for your consent to record the meetings online. The reason that we want to record each session is to

help us make sure that we have heard and understood everything that is said as we will need to revise our materials after each session.

When we record the session, we will record both the video and the audio. If you do not want your video recorded, you can turn off your camera for the meeting.

How long do I have to be involved?

If you decide to join our Intervention Adaptation Group, then you will be asked to be involved in regular meetings (once every 6 weeks) over three years. We understand that you may not be able to make every meeting, but would ask you to commit to attending as many as possible.

How long will the research last?

The entire study will last 3 years.

What will you do with my data?

In this research study we will use information from you. However, it is important that you understand that you are not a participant in this research, and instead, you will work with the research team to help them adapt their intervention and associated materials. We will only use information that we need to allow us to do this.

We will need some information from you. This information will include your name, and your role, along with your postal address, email address and telephone number. We need to know your email address because we will use this to set up any online meetings. We need your phone number because we may need to ring you, for example, to let you know that a meeting has been rescheduled or cancelled. We need to know your postal address to send you materials and information we will be discussing in the group. We need to know about your role, specifically, whether you are a clinician, a carer, or a family member. We will also need to know about your experience in working with people with learning disabilities. This is so we can accurately describe who made up our Stakeholder Group in the future.

The data that we keep about you will be stored using a code. Doing this is called pseudonymisation and we will

do this as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the data we hold and will be replaced with a participant number. The key to identification will be stored separately and securely to safeguard your identity.

To safeguard your rights, we will use a minimum of personally identifiable information and keep the data secure. This means that we will only collect the data we need to help us successfully adapt our intervention and associated materials for the later parts of our research.

Who will have access to my data?

Members of the research team will have access to your data. We will store a copy of your data on secure university and NHS servers. This includes forms indicating your agreement to join our Intervention Adaptation Group. This form will contain your name, email address, postal address and phone number and

will be stored separately from our recordings of each meeting.

Disclosure

We are required to store this to make sure that we have a record that you agreed to join our Stakeholder Group. We have a duty to keep your information secure and confidential. However, we are required to disclose information which suggests that someone may be at risk of harm. The reason for this is to work towards safeguarding and protecting others.

If we become aware that someone is at significant risk of harm, we may also share this information.

When sharing information, we will only do this when we genuinely believe there is a risk of harm. We may share this information with the local authority in your area or other statutory services who are meant to provide help.

Who is paying for the study?

This study is funded by the National Institute for Health Research.

What will happen to the results of this study?

We may publish the findings in a peer review journal, place them on the internet or talk about them at conferences. When the study is complete, we will write a report that we will share with the organisation paying for this research which is the National Institute for Health Research. We will ask you whether we can include your name within our reports that we write because we want to acknowledge you and the important contribution that you will have made. However, you can tell us not to do this if you would prefer.

Complaints

If you would like to make a complaint, we would like to ask you to speak to a member of the research team in the first instance.

However, if you do not want to speak to a member of the research team, there are other people who will help you with your complaint.

Olivia Hewitt's supervisor is:

Professor Peter Langdon,
Tel: 02476 522912
Email: Peter.Langdon@warwick.ac.uk
Centre for Educational Development, Appraisal
and Research, University of Warwick
Coventry CV4 7AL

If you would like to speak to someone who is not part of the research team, please address your complaint to:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Thank you for taking the time to read this invitation

RSVP Slip – Invitation to join our Intervention Adaptation Group

(Version 1.0 – 18 March 2021)

Title of the project: Improving anxiety in people with mild to moderate intellectual disability: Developing and testing a novel, co-produced, mental imagery intervention.”

IAG Member Identification Number

**Please initial
in the box**

I would like to join the Stakeholder Group.

I understand that some meetings will be online, and they will be recorded. I agree to this.

If I do not want my video recorded, I know I can keep my camera off.

I understand that the researchers want to include my name in future publications and conference talks. If I do not want my details included, I will tell the research team, and they will then not include my name when they write about the study.

Your details

Print your
name:

Signature:

Date:

Email:

Postal
address:

Tel:

You can send this form back in the post:

**Dr Olivia Hewitt,
Centre for Educational Development, Appraisal
and Research, University of Warwick
Coventry CV4 7AL**

You fill this form in and email to: Olivia.Hewitt@warwick.ac.uk

Or you can just email or ring us and let us know that you want to take part. If you want to find out more, have any questions, just get in touch.