

Self-concept and illness identity in adults with chronic dizziness. Participant Information Sheet (PIS)

You are being invited to take part in a research study to investigate self-concept and illness identity in adults with chronic dizziness, as part of a MSc research project.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish.

Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

Who will conduct the research?

Katherine Hargreaves, MSc Student in the Faculty of Biology, Medicine and Health, The University of Manchester. Debbie Cane, Lecturer of Audiology & Gabrielle Saunders, Professor of Audiology.

What is the purpose of the research?

The purpose of the research is to see how people with dizziness feel about themselves and their illness. We are hoping to see if there is an association between the topics and if further research in the area is needed. The better we understand how dizziness might affect someone, the better we can understand how to help them.

Am I suitable to take part?

We would like to consider taking part if you are:

- Over 18
- Living in the UK
- Experiencing ongoing dizziness for 6+ months

Will the outcomes of the research be published?

The outcomes of the research will be written about in my MSc dissertation. Data collected will be shared in the data repository figshare, the results are to be published in journals or used in conference presentations.

Who has reviewed the research project?

The ethics application was reviewed by the Division of Psychology, Communication and Human Neuroscience.

What would my involvement be?

What would I be asked to do if I took part?

If you consent to taking part:

1. You will first be asked to answer a few questions about your dizziness, it's nature and how long it has been ongoing.
2. You will then be asked 30 multiple choice questions on how you feel about yourself (5 mins) followed by 25 multiple choice questions on your dizziness and you (5 mins).
3. Once you have completed the questionnaire, your involvement will be complete.

Will I be compensated for taking part?

No compensation will be given for taking part in this research.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether to take part. If you would not like to take part, then **do not** complete the questionnaire. If you do decide to take part, you can retain this copy of the information sheet and will be asked to confirm your consent.

If you decide to take part, you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once the questionnaire has been submitted as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part, you do not need to do anything further.

Are there any risks to taking part?

The questionnaires ask questions about how you feel about yourself and your illness. In some people this may trigger strong emotions, if at any time you feel upset, you can simply stop filling in the questionnaire.

What to do if I feel distressed?

If following the study, you feel distressed please speak to family and friends or get in contact with balance support charities listed below.

- The Meniere's Society - The UK's leading charity for people with vestibular (inner ear) disorders causing dizziness and imbalance.
<https://www.menieres.org.uk/>
- Life on the Level - A support group for those with balance disorders.
<https://www.lifeonthelevel.org/>

If you require immediate help, call 111 to access 24/7 mental health support. If you or someone else is in danger, call 999.

Data Protection and Confidentiality

What information will you collect about me?

Within the survey, we will collect information on your age, gender and about any balance conditions you have.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

If you wish to make a complaint about the project, this can be taken to project supervisors Debbie Cane : debbie.cane@manchester.ac.uk or Prof. Gabrielle Saunders: gabrielle.saunders@manchester.ac.uk

If you wish to direct your complaint to someone independent of the research team, please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by email: research.complaints@manchester.ac.uk or by telephone 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

What do I do now?

If you agree to the terms, then please continue and complete and return the consent form. If you have any further questions, then please contact: katherine.hargreaves-2@postgrad.manchester.ac.uk