

Evaluating a Written and Video Resource about Motor Imagery

You are being invited to take part in a research study looking to evaluate and gain feedback on a resource that was created to better describe and explain what Motor Imagery (MI) is. MI can be defined as imagining moving your body (-part) without any actual movement. It has been associated with brain areas involved in actual movement and has been shown to improve movement in sports person and people in a range of clinical groups including people with Parkinson's. The study will form part of a PhD. 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?

Charlotte Growcott, Dr Ellen Poliakoff and Dr Emma Gowen, Division of Psychology,, Communication and Human Neuroscience, The University of Manchester.

What is the purpose of the research?

We aim to gain feedback from several key groups who may use the resource:

- 1) people with Parkinson's,
- 2) researchers,
- 3) Health Care Practitioners,
- 4) people running an exercise/dance class for people with Parkinson's.

We want to evaluate the resource on areas such as clarity, length and fit for purpose. Your feedback will then be used to improve the resource further.

As you have identified yourself as a person from one (or more) of these groups your thoughts and ideas on this resource are invaluable to this research. We hope to recruit around 500 participants to take part in this survey.

> Will the outcomes of the research be published?

We aim to publish the outcomes of this research in journals, as talks at conferences and as part of a student thesis. An anonymised data set will also be available on an open science data repository/database at the end of this research project. Any potentially identifiable information will be removed. Results may also be presented to small relevant groups and will be shared on the BEAM (Body, Eye and Movement) lab website and social media.

Who has reviewed the research project?

The project has been reviewed by The University of Manchester Research Ethics Committee 5 (Ref: 2024-16888-37657).

What would my involvement be?

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

You will be asked to complete an online survey. This will involve reading and watching the resources created to describe what Motor Imagery is. The written resource 2 A5 pages long and the video resource is around 11 minutes long. You will then be asked questions evaluating areas of the resource such as if it is clear/the right length/ etc. There will be some tick box questions and some open-ended questions where you will be able to give your honest opinions and thoughts on the resource.

As the survey is online you can complete this in the comfort of your own home, and it will take around 20-30 minutes (including time to watch/read the resource). We ask that you complete this in one sitting.

All information will remain anonymous, and you can leave any questions blank that you do not wish to answer. There will be an opportunity at the end of the questionnaire to leave your email address to receive a finalised copy of the MI resource and/or sign up to the Body, Eye and Movement (BEAM) lab mailing list to receive news on upcoming research.

If you wish to take part in the survey but feel you may require some assistance, then we are able to provide an option where we will video call you and go through the survey with you. If you wish to discuss this option further, please contact the researcher Charlotte Growcott via email on charlotte.growcott@manchester.ac.uk.

Will I be compensated for taking part?

You will not receive any compensation 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 or not to take part. If you would like to take part, then please return to the questionnaire or click this link:

If you do decide to take part, you will be given this information sheet to keep and will be asked to complete some consent questions online.

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 it has been anonymised 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.

Data Protection and Confidentiality

➤ What information will you collect about me?

We will not be asking for any personal identifiable information such as name/address/etc. You will also have the option (at the end of the questionnaire) to leave your email address to be sent a finalised copy of the MI resource and /or add your email address to the BEAM lab mailing list so that you may be contacted in the future about other research projects within the BEAM lab that may be relevant to you or to provide you with a summary of the results of this study. It is optional whether you agree to this and it will not affect your ability to participate in the study. Any contact details you supply to the study will be removed from the main data set and will only be used for the expressed reasons you agree to. General demographic information such as ethnicity, gender, age, etc will also be collected.

To undertake the research project, we will need to collect the following personal information/data about you:

- Age, country, ethnic background and education background
- Information regarding which 'target demographic' you belong to e.g. person with Parkinson's/researcher/Health Care Practitioner/person running an exercise/dance class as well as some details on this e.g. how long have you been a part of this demographic.

Under what legal basis are you collecting this information?

We are collecting and storing this information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➤ What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our <u>Privacy Notice for Research</u> (https://documents.manchester.ac.uk/display.aspx?DocID=37095).

> Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential, and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following ways:

- Only the research team at The University of Manchester will have access to the data you provide
- Any identifiable information you may provide in the free text space will be anonymised/removed.
- If you choose to leave your email address then this will be removed when downloading the main data set from Qualtrics and be kept separate. Your email address will only be used for the purposes stated above and what you agree to and will be deleted following this

- Data will be stored on a secure University of Manchester data storage space for up to 4
 years
- Anonymised data (for example questionnaire responses and movement times) will be archived on the Open Science Framework enabling other researchers to use the data/findings to inform future research.

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. This may involve looking at identifiable data. 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 have a complaint that you wish to direct to members of the research team, please contact:

Dr Ellen Poliakoff- Email: ellen.poliakoff@manchester.ac.uk Tel: 0161 275 7333

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance, then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 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.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information: ico.org.uk/make-a-complaint Tel 0303 123 1113

What do I do now?

If you would like to take part then please return to the survey or click on this link: https://www.qualtrics.manchester.ac.uk/jfe/form/SV_5sSjGu2EMptyMZw

If you have any queries about the study, then please contact the researcher below.

Charlotte Growcott - Email: charlotte.growcott@manchester.ac.uk Tel: 0161 200 8715