



Social, cognitive and motor functioning in individuals with movement conditions Information Sheet

Please read this information carefully before deciding whether you wish to take part in the study. If you have any further questions please contact Dr Jamie Talbot at jxt289@student.bham.ac.uk. If you have any medical/ other problems which make it difficult for you to read this information, please contact Jamie Talbot for a verbal explanation of the research.

When you are happy that you have all of the information you need to be able to decide whether or not you would like to take part in the study, on the day of your testing session we will ask you to complete our consent form.

Background

We would like to invite you to take part in a research study being conducted in the Department of Psychology at the University of Birmingham. This research work, being led by Dr Jamie Talbot looks at motivated decision-making in those with movement conditions and members of the general population. You have been contacted because you have a movement condition and therefore would participate in our movement condition group. We hope that this information will enable us to understand social, cognitive and motor behaviour in individuals with motor conditions.

Aims of the study

This study aims to further our understanding of social, cognitive and motor behaviour in individuals with movement conditions and healthy controls. Eventually we hope that our results will help to improve the quality of life of individuals with movement conditions.

What will happen if you decide(s) to participate?

Where will the research take place?

The research will take place at the University of Birmingham.

Who will be involved in collecting the data?

Members of the research team in Dr Jennifer Cook's and Dr Matthew Apps' lab including Dr Sophie Sowden and Bianca Schuster and Molly Gracey and Dr Jamie Talbot.

How long will participation in the study take?

Taking part in the study will take up to 4 hours for you spread over one occasion at the University of Birmingham.

We will be collecting information from participants between October 2020 and October 2025. After this we will spend some time understanding the information we have collected and writing reports. This means that the study will be finished in December 2025.

What will you be required to do during the study?

You will be asked to complete self-report rating scales of your thoughts and feelings and also some traits we are interested in based on your experiences of social interaction and movement.

During the study we will ask you to complete the dynamics of motivated decision-making task. In this task, you will be asked to make choices that either lead to physical effort or a monetary reward.

Are there any risks that individuals taking part in the study might face?

As part of the experiment, you will be asked to squeeze a handheld device with varying amounts of force. Although the requested levels of force should be achievable, the squeezing is intended to feel effortful and therefore may be uncomfortable at times. The experiment has been designed to include frequent rest blocks in order to minimise discomfort. Given that squeezing may aggravate conditions such as carpal tunnel syndrome, wrist or finger injuries, or arthritis of the small joints, it is important to inform the experimenter of any relevant conditions prior to the experiment. If you experience significant discomfort, the experimenter will terminate the experiment.

What are the potential benefits for participants from taking part?

You may if you wish receive a personalised feedback regarding you which will include the results from questionnaires and behavioural or cognitive tasks that you participated in. This study will help us to find out more about the lives of people with movement conditions. The results might help us to improve things for people with movement conditions in the future.

Please remember that we are not a clinic; we are a basic research facility. The results outlined in any feedback that we provide you will be completed for research purposes and therefore are not to be interpreted as part of a clinical evaluation. Your scores will provide you a general indication of your strengths and weaknesses across a few areas. However, if you have any concerns regarding your performance or development, other services that may be able to offer you support are available, including clinical and educational assessment and treatment services through the National Health Service (NHS), as well as local charities such as Parkinson's UK (<https://www.parkinsons.org.uk/>) or the Huntington's Disease Association (<https://www.hda.org.uk/>).

Where will data be stored?

The data collected will be kept in locked or password protected storage at the University of Birmingham. All information gathered about you will be stored separately from any information that would allow someone to identify who you are (this is known as personal identifying information, e.g. your full names, your address, your contact details). Your personal identifying information will be stored in a locked space at the University of Birmingham and only members of our research team will have access to it. We will only be able to trace the information we have collected about you back to you using a special reference number which we will store in a password protected database held at the University of Birmingham. Only members of our research team will have access to that database. Personal identifying information will be treated as strictly confidential and handled in accordance with the provisions of the General Data Protection Regulation 2018.

Will I be paid compensation for my time?

You will be paid for the duration of time you have participated in the study, at a rate of £11 per hour. You may also stand to receive a bonus payment of up to £16 based on your performance in the task. If you decide to come to the School of Psychology to complete the assessments, we can compensate for travel costs (only standard fares; we cannot cover costs for taxi). The researcher will also arrange for free parking in front of the School of Psychology during your visit.

If you decide to participate, what will happen after that participation?

You may, if you wish, receive an individual feedback report describing the results of the behavioural, cognitive and questionnaire assessments that were carried out during the study.

Sometimes after you have participated in the study, the first results may suggest to us that it would be useful for us to find out more information on the same kinds of things to make sure that the overall results of the study are as useful as possible. If this happens then we would contact you again before the end of the study to ask whether or not you would be willing to provide us with the extra information or if you might like to participate further in the study.

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The researchers will publish the findings from the study in scientific journals and will present the results at relevant conferences. You can request copies of the published papers by emailing jxt289@student.bham.ac.uk.

What will happen to the data afterwards?

The information that you provide will be locked in a filing cabinet at the University of Birmingham or held on a password protected database. All personal details will be kept separately from the information collected. Participants will be identified by a unique number so that it will only be possible to connect results to individuals via this number. This will ensure that results are kept anonymous. You will be able to decide whether or not you want to make your research data available to any professionals or clinicians working with you should they wish to see it.

For some studies, once the data are published, participant names and dates of birth will be removed from the databases, however, the remaining anonymous data will be kept indefinitely, along with information such as gender, age, date of test, and handedness information.

If you consent for us to make your data available online, the data will be anonymised and uploaded to a data sharing website such as the Open Science Framework (<https://osf.io/>). Anonymisation means that information that would enable people to identify you will be removed. For example, your name, age and contact details would not be uploaded, instead your name would be replaced with a participant ID code. We would like to make the data available online because this will allow other research teams to look at and analyse the data. This is important for scientific reproducibility because it means other teams can check our analyses. It is also often important for scientific progress because it means that other teams can suggest different ways to analyse the data.

At the end of the study, your personal details will be ***destroyed unless you tell us otherwise***. This means that we would no longer be able to trace the results of your assessments back to you. We also hold a Movement Conditions Research Database that we use to store the personal details of participants so that we can contact them about future studies. Please ask the experimenter if you would like more information about the database.

Confidentiality

The confidentiality of participants will be ensured. If published, information on the participant will be presented without reference to their name or any other identifying information. In the unlikely event of any evidence of abuse being identified, this information will be disclosed by the research workers.

Consent

After having read all of the information and having received appropriate responses to any questions that you may have about the study you will be asked to give your consent to participate in the study if you decide that you do wish to participate. For full information on the consent you will be giving, see each point on our consent form. We need to receive consent from you in order for you to participate.

Withdrawal

Even after consent has been granted, you can request to be withdrawn from the study and you will be able to decide if you would like your research data to be destroyed or retained by the project team. You will have up to 1 months after participation to indicate your withdrawal from the study, without giving a reason. This will not restrict access to other services and will not affect the right to treatment. After the study completion date (October 2025), your personal details will no longer be linked to the information collected as part of this study. This means that we would no longer be able to trace the results of your assessments back to you and withdraw you from the study.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact Matthew Apps at m.a.j.apps@bham.ac.uk in the first instance. If you remain unhappy and wish to complain formally, you can contact: Prof. Ed Wilding; Head of School; School of Psychology, University of

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Birmingham, Birmingham, B15 2TT, by email: hos.psychology@contacts.bham.ac.uk or by phone on 0121 414 4931

Review

The study has been approved by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

Further information

If you would like any more information about the study please contact Dr Jamie Talbot at jxt289@student.bham.ac.uk or Dr Matthew Apps at m.a.j.apps@bham.ac.uk or write to him at the School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.