



Metro South Hospital and Health Service via the Princess Alexandra Hospital

Information Letter for Patients

Dear Sir/Madam,

We kindly ask for your participation in the **TASMAN-study**, a medical scientific study on patients with movement disorders.

For permission or refusal, information on our part and careful consideration on your part are needed. For this reason, you have received this information letter. Take your time to read this information carefully. Before you make a decision, it is important that you have some information about the research project itself. Please read this information carefully and discuss this research project with your partner, friends or family. Participation is completely voluntary. If you still have questions after reading the information provided, you can always contact one of the researchers named at the end of this information letter.

Background and aim of the research.

Movement disorders come in many different forms. Sometimes movements can be increased (e.g., tremulous movements, jerks) and sometimes reduced (e.g., stiffness or slowness). When you see a neurologist, he or she will ask you several questions about your symptoms and will ask you to perform different movement tests. Based on these findings, it is sometimes possible to make a diagnosis after the first visit. However, there are often still doubts after the first evaluation, and it can take quite a while before a definite diagnosis is established. The current research aims to investigate whether certain patient factors might help to differentiate between several types of movement disorders. To do this, patients complete a questionnaire prior to their visit to the neurologist. After their visit to the neurology clinic, the neurologist will be asked to complete a questionnaire about the diagnostic process. We already know that certain factors are associated with movement disorders, but their ability to predict and differentiate between different conditions has never been investigated in this way before.

This research will be conducted in Queensland. To participate, you do not have to make an additional trip to the hospital the questionnaire is an online survey. If you have read the information and want to participate, please go to:

<http://redcap.link/tasman-australia>

You will first be asked for permission to participate and then the questionnaire will start automatically.

How will this study be executed?

Questionnaire

The survey consists of a questionnaire about your symptoms. This will take approximately 10 minutes. The questionnaire is not only about your movement problems but will also contain questions about your so-called 'patient features' (e.g., medical history, additional symptoms, general health). To avoid bias, it is important you complete the survey prior to your visit to the neurologist. The neurologist you visit afterwards is not aware of whether you have taken part in the study or not and does not have access to your answers.

Instructions

We would kindly ask you not to mention or discuss your participation in this study during your consultation with the neurologist. We will inform your neurologist after the consultation about your participation, so they will be 'blinded' at the time of your visit and information will not influence medical judgement.

Request information

After the outpatient visit, we ask your neurologist to fill in a short questionnaire about the diagnostic process. We also ask whether additional research is being carried out and which treatment has or has not been started. In addition, the researchers themselves will check your medical file after a few months. For this data the same applies as for all other data that you have entered yourself and is collected in this research, see the heading "Privacy". In a subset of patients, we will perform a one-year telephone review to evaluate how they are doing.

What are possible advantages and disadvantages of participation?

Participation will not give you a direct advantage. The information that will be obtained from this research will possibly contribute to a faster and more accurate diagnosis in movement disorder patients in the future. A disadvantage of this research is that the questionnaire takes some time to complete.

What happens if you do not wish to participate in this research?

It is your own decision to participate in this research project. Participation is voluntary. If you do not want to participate, there is nothing that you will have to do. You do not have to sign anything. You also do not have to tell us why you do not want to participate. You will receive the same treatment as normal. If you do wish to participate, you are able change your mind and leave the project at any point.



Metro South Hospital and Health Service via the Princess Alexandra Hospital

Privacy

Only a few other people are able to look into your data. These individuals/agencies are, for example: employees of the research team, members of the Human Research Ethics Committee. All research data will be handled according to the *'National Statement on Ethical Conduct in Human Research'*. All research data that is collected during this research will be assigned a code number. This is to make sure that your personal data will not be used in research documentation. Furthermore, it is not possible to retain personal data from a possible future publication of research results. Only the researcher who holds the key to the code knows who the person behind the code number is.

After closure of the research, your medical data will be kept for up to 15 years. It is possible that we will use research data for research that is not defined in this protocol but is in line with this research.

Is there anything else you want to know?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the project team, Dr Tjerk Lagrand on tjerk.lagrand@health.qld.gov.au or Dr Alexander Lehn on alexander.lehn@health.qld.gov.au

Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the MSH HREC Coordinator, Metro South Hospital and Health Service Human Research Ethics Committee (EC00167), telephone: (07) 3443 8047 or email: MSH-Ethics@health.qld.gov.au

Informed consent

If you decide to participate in this research, we kindly ask you to go to:

<http://redcap.link/tasman-australia>

You will first be asked for permission to participate and then the questionnaire will start automatically.

Kind regards,

Drs. Tjerk Lagrand, neurologist

Dr. A. Lehn, neurologist movement disorders, Princess Alexandra Hospital, Brisbane

Princess Alexandra Hospital, TASMAN STUDY_v3.0_10August2021