

## **Information sheet regarding Optogenerapy research**

### **The purpose of the study**

The leader of this study is Laurenske Visser

The aim of this study is to measure the current quality of life and the health status of patients with multiple sclerosis in the Netherlands, France, Great Britain, Italy and Germany.

The study is being conducted by the Erasmus School of Health Policy & Management at Erasmus University Rotterdam, the Netherlands. It forms part of the OPTOGENERAPY project, which is an EU-funded Horizon 2020 project. The aim of OPTOGENERAPY is to develop a new optogenetics implant that ensures a controlled release of beta interferon for treating multiple sclerosis patients. In order to evaluate the cost-effectiveness of the OPTOGENERAPY implant in different European countries, it is important to gather information about the effect of the current treatment on the quality of life and health status of multiple sclerosis patients. The research data will be used in reports and scientific publications.

### **What is the procedure?**

You will participate in a study in which we will gather information by submitting a questionnaire to you via the Qualtrics program, which you can fill in digitally. The questionnaire has three parts. The first part is about demographics, the second part is specifically about multiple sclerosis, and the third part is aimed at measuring your general health.

### **Potential risks and inconveniences**

There are no physical, legal or economic risks associated with your participation in this study. You do not have to answer questions that you do not wish to answer. Your participation is voluntary and you can stop your participation at any time.

### **Reimbursement**

You will not be compensated for participating in this study.

### **Data confidentiality**

You have the right to make a request to view, change, delete or modify your data. You can do this by going to <https://www.eur.nl/disclaimer/privacy-statement> and submitting your request via the link to the Digital Desk (Digitaal Loket).

We do everything we can to protect your privacy as thoroughly as possible. We have tried to compile the questionnaire such that it is not possible to trace who gave the answers. No confidential information or personal data from or about you that would allow someone to identify you will be released in any way.

The data collected from you will only be used by researchers within the same research field at the Erasmus University. Your data will be pseudonymised, and used in a pseudonymised format. Your



data will only be used for investigations in other research fields if you give permission for this on the consent form. You can therefore choose for your data to be only used within the same research field.

Before our research data is released, your data will be made as anonymous as possible.

Anonymous data or pseudonyms will be used in a publication and presented in aggregate form during Optogenery project meetings and conferences. The audio recordings, forms and other documents that are made or collected for this study are stored in a secure location at Erasmus University Rotterdam and on the secure (encrypted) data carriers of the researchers.

The research data is stored for a period of 10 years. Either at the end of this period or earlier, the data will be deleted or made anonymous so that it can no longer be traced to a particular person.

The research data will be made available if necessary (for example, for a check on scientific integrity) to persons outside the research group, but only in an anonymous form.

Finally, this study has been assessed and approved by the Erasmus MC Ethics Committee (date of approval: 28-01-2019).

#### **Voluntary participation**

Participation in this study is entirely voluntary. As a participant, you can stop your participation in the study at any time, or refuse the use of your data for the study, without giving reasons. Stopping participation does not have any adverse consequences for you or any compensation already received.

If, during the study, you decide to end your cooperation, the information that you have already provided will be used until the moment that the consent is withdrawn.

Do you wish to cease participation in the study, or do you have questions and/or complaints? Then contact the study leader by sending an email to [l.a.visser@eshpm.eur.nl](mailto:l.a.visser@eshpm.eur.nl).

This study is conducted at the Erasmus School of Health Policy & Management (ESHPM) faculty of Erasmus University Rotterdam (EUR). Should you have specific questions about the handling of personal data, you can address these to the EUR data protection officer by sending an email to [fg@eur.nl](mailto:fg@eur.nl) You also have the right to submit a complaint to the Dutch Data Protection Authority (Autoriteit Persoonsgegevens).

Finally, you have the right to make a request to view, change, delete or modify your data. You can do this by going to <https://www.eur.nl/disclaimer/privacy-statement> and submitting your request via the link to the Digital Desk (Digitaal Loket).