

Exploring Treatment Preferences of Patients with Myasthenia Gravis



The purpose of the project

This research project aims to recruit patients diagnosed with Myasthenia Gravis for participation in focus group sessions. These focus groups aim to assist with the development of our patient preference experiment survey, which will explore the treatment preferences of people who have Myasthenia Gravis towards different treatment options. Through focus group interviews, we want to understand what parts of treatment people value and those parts that people find difficult or worry about. This might include cost, treatment side effects, and treatment benefits. Additionally, we seek to ensure that the questions presented in the experiment are clear and understandable from a patient perspective like you.

The information we get from this study will be used to design Discrete Choice Experiments (DCE). DCEs are research methods used to understand people's preferences by presenting a series of choice tasks in hypothetical but real-life scenarios. Each choice task consists of two or three alternatives described by its characteristics. For example, people might be asked to choose between a treatment that works quickly but costs more, or another treatment that takes longer to work but is less expensive.

Your participation is very important

Your participation is really important because when more people join in, our research findings become more robust and dependable. This helps doctors and patients, ultimately improving outcomes for those with MG. It's essential to note that while the research itself may not directly benefit any individual patient, your involvement contributes to advancing overall understanding and care for everyone with MG.

What does participation involve?

If you decide to take part, we will ask you to sign a consent form or give your verbal consent before the focus group sessions. You are invited to take part in 2 focus group sessions with up to four (4) other volunteers, plus Monash researchers. The focus group will be an online conversation that will last approximately one hour.

What will happen to your information?

Your information will only be used for research related to this project. We will keep the data on secure servers at Monash University, and it will be deleted seven years after the final results are published to ensure enough time to validate the research findings.

How is the research project being conducted?

We will hold focus group sessions with patients and clinicians. Your data will be kept private and made anonymous.

Who is organising and funding the research?

Professor Dennis Petrie from Monash University leads this research, funded by the Medical Research Future Fund (MRFF) Grant.

Reimbursement

As a small token of appreciation for your time and insights, you may choose to receive a digital gift voucher (\$50) for taking part in 2 focus group sessions. Vouchers will be provided by Prezzy (http://www.prezzy.com.au/). These vouchers can be converted to a retailer of your choice or donated to a charity of your choice.



If you are interested in participating in the study, have any questions or require more information, please contact us via email.

Email: value.ig@monash.edu