



Invitation to participate in research project

PATIENT PREFERENCES

- Have you been diagnosed with myotonic dystrophy type 1, or with a type of mitochondrial disease?
- Are you eighteen years old or older?
- Or, are you a carer of someone that has the condition?

If so, you might be suitable to participate in this survey, which explores your views regarding the risks and benefits associated with potential treatments for your disease.

The patient perspective is important in medical research and the PREFER project wants to find ways to bring the voice of the patient into the process of developing new medical products for neuromuscular conditions.

This study is led by researchers at Newcastle University in the UK and is part of the international collaboration for the PREFER project (www.imi-prefer.eu).

What does this study involve?

- It involves completing some online questionnaires about yourself and about your views and preferences for potential treatments for your disease or those of the patient that you care for.
- All information obtained during the survey will be confidential.

To learn more about the project, please refer to the participant information sheet.

To access the survey please click the link below:

<https://uuc-app041.its.uu.se/sawtooth/jenvi150/NMDT0/login.html>

Email: PREFER.Project@newcastle.ac.uk

