

Participate in the Friedreich Ataxia International Burden of Illness Research

We would like to invite you to participate in a research survey commissioned by a pharmaceutical company that aims to evaluate how Friedreich Ataxia (FA) is currently impacting your daily life and overall health.

Who can participate?

- People aged 12 and older who have been diagnosed with FA.
- Caregivers of persons diagnosed with FA of any age.

A caregiver is someone who takes care of another person with short- or long-term limitations due to their condition. For example, parents, spouses, or other family members could provide care and support to persons with FA and be considered as caregivers.

What will my participation involve?

You will be asked to fill out an online survey that will take approximately 30 minutes to complete. You can find out if you're eligible and provide your consent to participate in this study through the survey link. A participation token in the form of a digital gift card of the value of £39 for people diagnosed with FA and of £19 for caregivers will be provided to those eligible to participate, as a thank you for your time and effort in completing the survey for this study.

What benefit might this research have?

The purpose of this study is to understand the experiences of people living with FA, and how FA impacts your daily life. The study will also collect information about the experiences of people who care for someone with FA. This study could provide important insights into the impact of FA on your daily life, which could help guide future research and healthcare decision making, and raise awareness of FA in your home country.

Do I have to participate?

Participation is entirely **voluntary**, and you may withdraw at any time without any consequences.

All your responses will be kept **confidential**, and your personal information will not be shared without your consent.

If you have any questions or need further information, please feel free to contact SayeliJayade@openhealthgroup.com.

Thank you for considering this invitation.

Are you interested in finding out if you can participate? Click on this link: [Friedreich Ataxia Survey Research \(FriedAtaxia674E@iqvia.com\)](mailto:FriedreichAtaxiaSurveyResearch(FriedAtaxia674E@iqvia.com))

When you click the link, it will generate an email to the survey organisers, which you can send expressing your interest in taking part. No additional information needs to be added to the email. Once sent, you will receive a personal link to the survey.