

SHARING YOUR EXPERIENCES OF LIVING WITH NARCOLEPSY TYPE 1 (NT1)

A new research study is aiming to understand the social and economic impact of narcolepsy type 1 (NT1) on people living with the condition, their families, communities, and wider society. The study is looking to identify people living with NT1 and their family members to provide their perspectives and experiences.

WHO CAN PARTICIPATE?

- People living with NT1 (over age 18)
- Family members (over age 18) of people living with NT1

WHAT DO I NEED TO DO?

- Take part in a short survey conducted online.

WHAT QUESTIONS WILL I BE ASKED?

- What is your experience living with NT1?
- How living with NT1 affects your day-to-day life?
- How living with NT1 affects your family member's day-to-day lives?
- How has NT1 affected your mental health and wellbeing?
- How you think your experience of NT1 might change over time?
- Would reduced symptoms of NT1 change different parts of your life?



HOW WILL MY INFORMATION BE USED?

- Your responses will be used to develop a report on the broader human and economic impacts of living with NT1.
- This report will accompany a potential reimbursement submission for a new treatment. It may also be used to support access, fundraising and advocacy initiatives.
- The report may be shared publicly.
- We will not share your personal details. Your responses will be kept anonymous and any quotes will be de-identified.

This study is funded by a study sponsor and managed by the independent research agency **HTANALYSTS**. This study has been approved by Bellberry Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Human Research (2025) [HREC approval 2026-03-393].

Before taking part in the survey, information about privacy and ethics standards will be provided alongside a consent form.