Newcastle University

LifeArc Centre
Acceleration of Rare Disease Trials

Living with a rare disease, or a parent or carer for someone with a rare disease?

We want to hear your story

Our team at Newcastle University and the **LifeArc Centre for Acceleration of Rare Disease Trials (ARDT)** wants to hear about **your understanding, views and experiences of clinical trials**, **whether or not you have taken part in one**, and **what could be improved** to make clinical trials more accessible and better meet the needs of patients and families. We want to hear from you even if you have never been offered a trial.

Who can take part?

- Adults aged 18 or over, **living in the UK**
- People **living with a rare disease**, or a **parent or carer** for someone with a rare disease
- You (or the person you provide care for) must have a **clinical or genetic diagnosis** of a rare disease
- You can take part whether you have taken part in a trial, decided not to take part, wanted to take part but could not, or have never been offered one

What is involved?

- One interview lasting around 45–60 minutes. There are no right or wrong answers
- If you would like to, you can share up to three **photographs that represent your experiences** (optional)
- Taking part is voluntary, but as a thank you, you will receive **a £25 shopping voucher**

How will your views help?

By sharing your experiences, you will help us learn what works well, what could be better, and how clinical trials could become fairer, more inclusive and better meet the needs of patients and families.

We will share our findings with patients, families, professionals, researchers and charities.

To take part, or to find out more, contact Dr Basma Salem:

Call or text: 07584 003642

Email: Basma.Salem@newcastle.ac.uk

£25 shopping voucher as a thank you for your time

What you tell us will be treated confidentially, as explained in the Participant Information Sheet. Taking part will not affect your healthcare or your access to clinical trials. The research team cannot give medical advice or offer places on clinical trials. This study has been reviewed by the Newcastle University Faculty of Medical Sciences Research Ethics Committee.