LifeArc Centre

Acceleration of Rare Disease Trials

Scan the QR code here!

Would you like to make a real difference in shaping the future of therapy development for rare conditions?

Be a Part of our Rare Disease Lived Experience Advisory Panel (LEAP)

How Long?	The LEAP is expected to run until end of August 2029 (although it is possible to join for a shorter period of time)
What is my Role?	You will share your views and experience to help shape our research activities
Time Commitment?	Approx. 24 hours per year, with scope for more. Mostly online working
Compensation?	Time commitments will be compensated at a rate of £25 per hour.
Travel Expenses?	For in–person meetings, these will be reim-bursed

Our Centre is one of four new Rare Disease Research Centres funded by the charity LifeArc. It will speed-up the development of effective treatments for rare conditions. It is often difficult to test whether a medicine or other therapy for a rare condition actually works (and how well it works) - not least because of the small patient numbers involved. This often prevents or delays the development and adoption of promising therapies.

Applications welcome HERE until 11th April

Any questions? Please call 07749 126932 or email us at ardtcentre@newcastle.ac.uk

Newcastle University

UNIVERSITY OF BIRMINGHAM

QUEEN'S UNIVERSITY BELFAST

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What will the Lived Experience Advisory Panel (LEAP) do?

This Advisory Panel will guide and shape the work of the LifeArc Centre for Acceleration of Rare Disease Trials. This will involve:

- Co-creating processes and tools to make it easier and fairer for people to participate in research
- Developing better processes to bring effective therapies to the people who need them;
- Providing more equitable opportunities for patients across all 4 nations of the UK, by changing policy … and more!

The LEAP will meet at least 4 times a year, usually online, with occasional in-person meetings. You will also be invited to join advisory meetings and review documents for specific topics, like those in the bullet-points above, where these reflect your interests. We are looking for up to 15 people, including two to act as co-chairs.

Our new Centre will improve clinical trials and therapy development across the whole of the UK by developing a 'one-stop-shop' for trial design, delivery and support in rare conditions. This 5-year project brings together researchers from Newcastle University, Queen's University Belfast, and University of Birmingham, together with partners Alström Syndrome UK and Genetic Alliance UK.

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Who should apply?

We welcome applications from people living with a rare condition, their parents or carers and representatives of advocacy organisations. To ensure a well-rounded and diverse group, we are looking for people with a mix of experiences including:

- Rare conditions that begin in childhood OR adulthood
- Genetic AND non-genetic rare conditions
- Undiagnosed patients
- A mix of ages, genders and ethnicities
- A geographical mix (we would like representatives from all 4 nations of the UK)
- Individuals with prior experience of contributing to advisory groups on rare conditions
- People without prior experience in this area
- Direct experience of clinical trials/therapy development is welcomed but is NOT essential

The successful applicants will be supported by a patient and public involvement and engagement (PPIE) expert within the project. We can provide training and expenses will be covered. Time commitments will be compensated at a rate of £25 per hour.

This is your chance to make your voice heard in rare disease research!

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