



Job Description and Person Specification: Research Officer



Job Description and Person Specification: Research Associate or Research Officer

Job Title: Research Officer (homeworking)

Job Type: 12-month contract (with a view to be extended)

Responsible to: Research Manager

Working hours: Part Time – 22 hours per week with evening and weekend work as required. Candidates must be available to work on a Wednesday afternoon. Job shares may be available where matching candidates can be identified.

Start date: 11th September 2024 (open to discussing October start date).

Salary: £32175-£36075 p.a. (pro-rata), depending on experience.

Base: Homeworking

Deadline: Application deadline is 11th August at 12pm. Interviews will be conducted on 21st August 12pm-4pm.

Overview:

Pathfinders Neuromuscular Alliance is a user-led charity, run entirely for and by people with muscle-weakening conditions. We provide social and support services, a range of information guides, events and outreach, and campaign on issues that matter to adults living with muscle-weakening conditions.

Pathfinders aims to enable teenagers and adults with neuromuscular conditions to access the support they need to maintain good health, become independent, access social and work opportunities and contribute to their communities. We want to ensure standards of care and access to services and information is consistent across the country. We want to develop the skills and confidence of young people with neuromuscular conditions and empower them to take charge of their own health and to build a stronger community to get better services and support.

We are currently recruiting a Research Officer to lead The Pathfinders' Peer Researchers on a number of existing research projects. This will involve working with our existing research partners including the University of Sheffield; the University of Northumbria, and the University of East London. The Research Officer will also contribute to the development of our peer-research group by managing and coordinating the group's work and develop Pathfinders strategic goals by finding and applying for further funding opportunities.

The Research Officer will be managed by the Research Manager who will play a supporting role in project management and linking resources and contact into the projects.

Please note all aspects of this role will be carried out remotely, and the successful candidate will work from home. There may be opportunities for in-person dissemination of results.

We prioritise applications from adults with neuromuscular conditions. We also welcome other disabled adults, as well as those connected to neuromuscular conditions or disability more widely, through work, family, or friends. However, the role is open to all applicants, and we will interview and appoint based on the essential and desirable criteria.

It is essential that all of the people that we employ embody the values of Pathfinders, enabling and encouraging independence, being led by the people we support, rooted in the social model of disability and valuing the importance of sharing lived experience.

Key Objectives of this role:

- Recruiting and managing new and existing peer co-researchers with neuromuscular conditions, and facilitating their involvement in research design, fieldwork and analysis to ensure our work is fully co-produced
- Leading literature reviews, research design, fieldwork, and thematic analysis across our research, with guidance from the Research Manager, peer co-researchers and academic partnerships
- Participating and upholding ethics procedures and research governance with the support of the Research Manager
- Coordinating steering groups of academics, co-researchers and adults with neuromuscular conditions to guide projects
- Building relationships with research partners, including universities and other neuromuscular organisations
- Promoting research, recruiting research participants, and managing the relationship with our partners
- Publicising research outcomes and reporting to the community regarding progress across our work
- Identifying and pursuing funding opportunities for further relevant research alongside the Research Manager and other academic partners

Our approach to research:

Pathfinders are invested in creating an inclusive research environment for young adults with muscle-weakening (neuromuscular) conditions. To do this, Pathfinders strongly advocates and practices co-produced research which is conducted and managed by those with lived experiences of muscle-weakening conditions. We intend to continue our work with existing partnerships, including universities, other charitable organisations, and the pharmaceutical industry, but are also keen to develop further partnerships with the support of the incoming Research Officer.

We primarily use community-led peer research, applying qualitative and narrative research methods. We work alongside additional adults with muscle-weakening conditions who are paid as peer co-researchers, and who play a vital role in interviewing, data processing and analysis, bringing their own insights to each project, whilst also building skills for themselves.

Current research projects:

Crippling Breath: Towards a new cultural politics of respiration

This is a new 5 year interdisciplinary programme of research funded by a Wellcome Trust Discovery Award and led by Dr Kirsty Liddiard at the University of Sheffield.

The Crippling Breath project centres the lives of people who have had their lives saved and sustained by ventilatory medical technologies. Our explorations are led by disabled, chronically ill and ventilated people, in recognition that these growing communities of people are often absent from discussions around respiration/ventilation.

This project centres arts-informed, archival, narrative and ethnographic approaches to research, in order to develop Crip perspectives: forms of knowledge production which emerge from lived experiences of disability and chronic illness. More can be found about the project [here](#).

Work will include

- Represent the voices of neuromuscular community on the wider research team
- Support all stages of the project including recruitment of participants, analysis of data and sharing of the research findings.

Wellcome Anti-Ableist Research Culture

Alongside the Wellcome Trust and Sheffield University, Pathfinders is a project partner for research into the development of anti-ableist research cultures (or, research cultures free from disability-related discrimination).

Universities, funders and researchers are in the midst of an Equality, Diversity and Inclusion revolution, and are beginning to understand how exclusionary university research cultures can be. We hope that this research will contribute to the development of more inclusive equipment for disabled researchers. You can read more about this research [here](#).

Work will include:

- Data collection through case studies, focus groups and qualitative interviews.
- Working with the wider research team ensuring that the voices of the disabled community are heard.

Entering Adulthood with Duchenne Muscular Dystrophy (DMD).

Pathfinders has recently fronted an innovative research study which examines the transition to adulthood for individuals with Duchenne Muscular Dystrophy (DMD). The project is funded by PTC Therapeutics and the NIHR School for Social Care Research. In 2023, Pathfinders launched their findings of this research in the 'Entering Adulthood with Duchenne Muscular Dystrophy' report and video.

With the attainment of funding we would like to expand this work to include:

- Co-author a research paper with the academic steering group based on the findings of the [Entering Adulthood](#) research
- Co-developing resources that will benefit young adults transitioning to adulthood in the future
- Thematic analysis of European interview data alongside the co-researchers and research manager

Other projects

Pathfinders is currently in the application stage regarding a number of other potential research projects. If successful, the Research Officer will be informed of the nature of these projects, and play a central role in their development. These are primarily qualitative research studies about the experiences of adulthood with a neuromuscular condition. The research officer should have a broad understanding of life with a neuromuscular condition with particular interests in social care and independent living.

The ideal candidate will have strong academic research skills, a clear understanding of the experiences of adults with neuromuscular conditions, and a keen interest in co-production in research.

Experience and Skills:

Experience and Skills (Essential or Desirable)	<u>Application</u>	<u>Interview</u>
Essential		
Experience or background knowledge of neuromuscular conditions and the key issues affecting people with neuromuscular conditions	✓	
Experience managing a project requiring significant time-management, setting and meeting objectives and targets, working with colleagues, team members and/or participants and reporting on the completed project	✓	✓
Experience of working in an environment where you have had to demonstrate integrity, professionalism and adherence to policies and procedures to keep people safe. This does not need to have been a paid role and could include voluntary or advocacy experiences	✓	✓
<ul style="list-style-type: none"> • Either: A Bachelor's degree with a 2:1 or above, or equivalent, in a course with a strong focus on independent research and specific training in research skills • A Master's degree with specific training in research skills Experience in leading or working on some form of qualitative research including engaging in relevant methods of recruitment, data collection, and analysis	✓	
Desirable		
Undergoing or completed an MPhil or PhD or independent research at an equivalent level	✓	
Experience with applying for funding from academic or community partners, e.g. for research projects, community events, or as part of voluntary or paid work	✓	

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Experience translating academic findings for a range of lay and professional audiences, including in text, video, or speech / live presentation	✓	✓
Experience of being involved in research projects in a relevant field of interest to our work	✓	
A commitment to learning and engaging in co-production methodology	✓	✓
Experience in carrying out research interviews that are friendly, supportive, empathetic and professional, building positive relationships with research participants	✓	✓
Experience in engaging with ethical approval processes and data governance and management	✓	
Experience with qualitative data analysis software, such as NVivo	✓	
Experience in using IT and social media, particularly the use of apps such as Zoom or equivalent, WhatsApp, Facebook, X and Instagram, as well as Microsoft Office and/or Google Suite	✓	

In your application you will need to explain how you meet the essential *experience* and *skills*, and *where you meet the desirable ones if possible*. We welcome you to draw on a wide range of personal, voluntary, employment, and educational experiences and skills, and recognise skills and expertise that can be developed in many different environments.

Your application will be assessed against the points marked “Application” in this document, whilst the others will be assessed at interview

Application process

To apply, please submit a CV of no more than two pages along with a cover letter of no more than two pages to info@pathfindersalliance.org.uk

In your CV and cover letter, you must demonstrate how you meet the skills and experience criteria being measured at application stage.