



Alström Syndrome UK

Strength for today, hope for the future

Patient & Public Involvement & Engagement (PPIE) Coordinator Person Specification

The successful PPIE Coordinator will be expected to have the essential experience, skills and abilities listed below. The items under the heading desirable will be valuable but people who do not have these should not be deterred from applying.

Knowledge, experience, skills and abilities

Essential

- Personal or professional experience of PPIE.
- Experience of delivering support which is inclusive and responsive to the needs of people from diverse communities.
- Some understanding of the complexities of rare conditions and the challenges faced by people with complex health conditions.
- Experience of working with people from diverse, marginalised or underserved communities.
- Experience of supporting children, young people, and/or families.
- A strong desire to improve the experiences and accessibility of services for people living with rare and complex conditions.
- Excellent people and interpersonal skills to build positive relationships and collaborative partnerships across diverse groups.
- Able to work independently, flexibly, manage a caseload and prioritise.
- Excellent communication skills, oral and written.
- Confident IT user.
- Ability to prioritise when faced with competing work demands.
- Ability to work on own initiative.
- Confident to appropriately challenge if required.

- Willingness to undertake some work during unsociable hours.
- Willing and able to travel long distances and to unfamiliar areas which may involve occasional overnight stays.
- Ability to develop good working relationships with individuals, support group representatives, colleagues, service providers and the public.

Desirable

- Previous personal or professional experience of genetics and/or complex health conditions.
- Previous involvement in research projects.
- Interpreting experience.
- Experience of working in a mentoring or advocacy role.
- Experience of working in a health, education or social care setting.
- Experience of developing accessible resources and services for individuals and families.
- Ability to speak English plus one other community language.
- Previous experience of project work.
- Experience of working from home.
- Previous professional experience of marketing, in particular social media.
- Good knowledge of digital and print-based materials.

Qualifications

Essential

- NVQ Level 3 in Health and Social Care or equivalent.