

Job Description

Paving the Way to Self-Management for Rare Conditions:

A series of podcasts to inspire health professionals and people with rare conditions

Job Title: Project Officer (Self-Management)

Responsible to: Assistant Director

Staff Reporting: None

Based at: home based

Term: 9 months full time, fixed-term contract

Salary: £28,000per annum, pro rata.

Main purpose of job:

To co-ordinate and deliver the *Paving the Way* project. The project involves the creation of a series of inspirational podcasts featuring people with rare conditions from across Scotland describing how they have become expert at self managing their condition. The aims of the project are to:

- Encourage healthcare professionals to acknowledge the expertise that people with rare conditions and their carers may have and accept that they can be expert and active participants in managing their care.
- Inspire and give confidence to people with rare conditions who wish to self-manage.
- Support people with rare conditions in self-managing through peer education, providing practical tips and strategies.

Key Responsibilities

1. Work with the Genetic Alliance UK team, particularly Development Officer Scotland as well as our member groups and other voluntary sector organisations, support groups and patient networks across Scotland to recruit approximately 10 people who are suitable “pioneers” of self management.
2. Work with participants to prepare and design in-depth interviews about their experiences.
3. Work with media consultants to organise video and audio recording and editing of interviews.
4. Create a web page for the podcasts, including written transcripts of the interviews, a directory that signposts users to specific issues and experiences and relevant links to related resources.
5. Work with partners in the NHS and the voluntary sector to plan the effective dissemination and long-term use of the podcasts by healthcare professionals and people with rare conditions.
6. Organise the launch and dissemination of the podcasts.
7. In consultation with Evaluation Support Scotland, plan and conduct an evaluation of the effectiveness of the project.
8. Produce and disseminate a written project report.

9. Work with Genetic Alliance UK's Finance Officer to monitor the project expenditure, ensuring that it remains in-line with the budget.
10. Schedule, set up and attend project Steering Group meetings.
11. Provide written and verbal progress reports to the project Steering Group, Genetic Alliance UK's Trustees, staff and funders, as required.
12. Occasionally contribute to other Genetic Alliance UK activities, for example our Annual Conference.

Person specification

Education and qualifications

- Degree or equivalent attainment

Essential qualities, skills and experience:

- Interviewing skills and experience of conducting interviews dealing with sensitive issues.
- Written communication skills including proven ability in writing reports.
- An appreciation of the issues experienced by people with rare conditions, of current issues in genetics and healthcare and their impact on people with rare conditions and families.
- Knowledge of how the NHS in Scotland is organised and operates.
- Excellent interpersonal skills: influencing skills and the confidence to approach and maintain relationships with a variety of people.
- Presentation skills and experience of presenting to a variety of audiences.
- Ability to manage deadlines, prioritise workload and maximise the use of time.
- Up-to-date skills and knowledge of IT and its implications in communications, including a good knowledge of Microsoft Office applications, websites and internet forums.
- The ability to use individual initiative and judgement as well as to work in a team.
- A commitment to the aims and objectives of Genetic Alliance UK.

Desirable qualities, skills and experience:

- Knowledge and understanding of rare conditions.
- Previous experience of similar communications-based projects.

Additional requirements

- To be able to work occasional evenings and weekends.
- To be willing to travel across Scotland and to other UK destinations.