Candidate Information

Position: Rare Disease Patient & Family Logistics & Experience Officer (PT 0.5 FTE)
School/Department: School of Medicine, Dentistry and Biomedical Sciences
Reference: 25/112790
Closing Date: Monday 25 August 2025
Salary: £35,136 - £36,184 per annum, pro rata
Duration: 24 Months

JOB PURPOSE:

This is an exciting opportunity for an experienced, highly motivated individual to join our vibrant, multidisciplinary rare disease research team. The post-holder will focus on mapping how people affected by rare diseases engage in clinical research both locally and internationally. They will seek and share information, communicating with a broad range of stakeholders to promote and support participation in rare disease research. They will be a primary point of contact for patients and families participating in clinical trials, developing material that supports their trial journey. In collaboration with senior colleagues, you will highlight strategic projects within a diverse portfolio, supporting a collaborative research environment that fosters a culture of trust and mutual respect between all those engaged in research. The role requires excellent interpersonal skills.

This role provides a rare opportunity to work in partnership with patients and families living with rare disease(s), academic and clinical colleagues, professional support teams, community groups, industrial collaborators. The post-holder will be based at the Centre for Public Health at Queen's University Belfast.

MAJOR DUTIES:

1. Be responsible for implementing effective information, communication, and impact activities aligned to rare disease clinical and translational research.
2. Work directly with stakeholders, across multiple strategic projects, in order to create and develop output materials in appropriate and attractive formats that can be easily understood by patients, families, and carers.
3. To work with centres delivering clinical trials where NI residents may participate, developing tailored patient and family focused material to support their participant in individual trials at individual sites.
4. To work with local investigators delivering clinical trials to provide bespoke information for people living with rare diseases that supports recruitment and retention in clinical and translational research opportunities.
5. Support organising and advertising events, helping write pre- and post-event dissemination materials. This may include codesign with stakeholders, poster / leaflet creation, web and social media updates, and other publicity.
6. To support the recruitment and retention of clinical research participation. This include collecting data from prospective study participants, gaining consent for participation, data collection, and entering relevant data into study information systems.
7. Provide briefings/presentations/reports on relevant findings to diverse stakeholders.
8. Work with stakeholders to map existing routes to clinical research participation, identifying barriers and enablers to participation in rare disease research and to access rare disease therapies. This may involve focus groups, surveys, workshops with quantitative and qualitative analyses.
9. Develop tools and resources to raise awareness of rare diseases.
10. Work with colleagues to develop a detailed programme of engagement events. This will include activities such as event planning, programme development, speaker liaison and marketing/publicity for events.
11. Any other duties as requested by the project lead (Prof AJ McKnight) that contribute to information, communication, and impact of rare disease research.

ESSENTIAL CRITERIA:

1. * A primary degree in a relevant subject, or substantial relevant experience in community outreach.

2. * 2 years recent, relevant experience working in a multidisciplinary clinical or translational research environment.
3. * Experience communicating scientific and / or medical information with patients and families or clinical research participants across the life course.
4. Experience recruiting, retaining, and engaging with research participants.
5. Experience working with a range of stakeholders to effectively engage them on complex research topics.
6. * Experience producing effective communications in a range of mediums
7. * Experience in delivering effective information and / or engagement activities and events.
8. Highly developed organisational, decision–making, problem-solving, time management and prioritisation skills.
9. Ability to explain complex ideas simply and effectively.
10. Excellent Information Technology skills including Microsoft Office Suite, and report writing.
11. Ability to work on own initiative and react to evolving project needs.
12. Excellent communication skills – ability to be understood by a range of stakeholders.
13. Creative mind and ability to find innovative solutions to complex problems.
14. Ability to work as part of a team.
15. Ability to use initiative and judgement to resolve many day-to-day problems independently working with minimal supervision and maintaining confidentiality.
16. High attention to detail with the ability to complete work accurately, on time and to appropriate standards.
17. Ability to travel as required by the post.

DESIRABLE CRITERIA:

1. * Masters or PhD in relevant field.
2. * Recent experience working with rare disease stakeholders, including 3rd sector organisations and / or commercial companies.
3. Experience supporting clinical trial participation.
4. Experience of governance issues relating to recruitment of study participants.
5. * Experience contributing to research reporting within a University Setting.
6. * Experience of event planning and running events.
7. * Experience in website design, content management and/or maintenance.
8. * Experience developing animated videos, posters, and infographics.
9. Understanding of rare disease research.
10. Understanding of clinical trial procedures.