

Candidate Information

Position: Rare Disease Stakeholder Information Outreach and Impact Officer
School/Department: Centre for Public Health
Reference: 25/112827
Closing Date: Monday 8 September 2025
Salary: £35,136 - £36,184 per annum (pro rata)
Anticipated Interview Date: To be confirmed
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 sharing information and communicating with a broad range of stakeholders, promoting rare disease research to diverse audiences to deepen understanding of research, outcomes, relevance, and impact via multiple channels including website, social media, newsletters, videos, visual storytelling, briefings, reports, traditional scientific presentations and papers. 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. The role requires excellent interpersonal skills alongside scientific and technical understanding relevant for diagnosis and treatment of rare diseases.

This role provides a rare opportunity to work in partnership with academic and clinical colleagues, professional support teams, community groups, policy makers, and industrial collaborators. The post-holder will support the (i) the planning and delivery of events and engagement activities with stakeholders, (ii) the recording and reporting of outcomes and impact, (iii) the promotion, outreach and communication of rare disease research, (iv) liaising with local and international stakeholders, and (v) supporting the coordination and delivery of strategic projects. The post-holder will be based at the Centre for Public Health at Queen's University Belfast.

MAIN ACTIVITIES/RESPONSIBILITIES:

1. Be responsible for implementing effective information, communication, and impact activities aligned to our rare disease research.
2. Work directly with the research teams, 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, carers, and practitioners.
3. Contribute to management of relevant websites and social media platforms. Co-develop a plan to ensure the website and social media outputs are kept up-to-date and fully represent our rare disease research and engagement activities.
4. 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.
5. Support the preparation and maintenance of appropriate data/records/reports for recording of impact and outputs associated with relevant stakeholders.
6. Provide briefings/presentations/reports on various aspects of the project's information, outreach and impact to stakeholders.
7. Map existing routes to data access, rare disease registries, and access to rare disease medicines from a stakeholder perspective. Work with stakeholders to identify gaps, barriers, and enablers to progress of rare disease data-driven discoveries and access to therapies.
8. Develop tools and resources to raise awareness of rare diseases.
9. Work with colleagues to develop a detailed programme of engagement events (e.g. policy symposia and outreach workshops). This will include activities such as event planning, programme development, speaker liaison and marketing/publicity for events.
10. Any other duties as requested by the project lead (Prof AJ McKnight) that contribute to information, communication, and impact of rare disease research.

The duties of the post outlined above are not exhaustive and the post-holder is expected to be co operative and flexible, undertaking such other duties as may from time to time be reasonably expected of a member of staff in the University. These duties are subject to review in line with the changing requirements of strategic rare disease research projects, the University and with the development needs of the post-holder, as identified through regular review/appraisal processes. The post-holder will have to sign an undertaking of confidentiality.

PLANNING AND ORGANISING:

- The post-holder will plan and organise their own workload on a weekly, monthly and annual basis.
 - Collaboratively plan and organise a series of rare disease engagement events.
 - Collaboratively plan and organise updates to websites and social media.
 - Plan, organise, and support development of relevant information / dissemination activities
 - Plan, organise and implement regular dissemination and news to key stakeholders and partners.
 - Plan and deliver regular contact with rare disease stakeholders, developing and maintaining excellent two-way communication with a focus on PPIE and healthcare professionals.

PROBLEM SOLVING:

- Resolving issues that arise in the course of planning, organising and implementing communication activities, using own experience, and escalating issues to line manager when required.
- Identify and anticipate problems or issues that may arise and cannot be resolved by the post-holder alone and bring to the attention of the project lead.
- Juggle competing demands and deadlines on a weekly and monthly basis.

INTERNAL AND EXTERNAL RELATIONSHIPS:

- Be responsible for ensuring effective communication within QUB and externally.
 - Represent QUB's rare disease research at appropriate internal and external committees/working groups with delegated authority as appropriate.
 - Contribute to raising the profile of rare disease research both nationally and internationally and implementing strategies in order to meet these objectives through appropriate marketing, publications, and PR material and liaising with the University's communications team and other relevant Directorates.

DECISION MAKING:

- Independent decision-making using initiative and judgement to prioritise workload, and specialist knowledge to make professional decisions and provide advice and guidance to colleagues.
- Using experience and expertise, advise on the most appropriate communication channels for a specific audience or message.
- Recommend venues, accommodation, catering etc. for public events, and contribute to decisions about who is invited to attend and/or speak.
- Identify, in consultation with the rare disease management team, how best to promote understanding of the outputs and impact of rare disease research.

ADDITIONAL INFORMATION:

Individually rare, affecting less than 1 in 2,000 people, together rare diseases affect ~475 million people globally, with >110,000 people affected by rare diseases across Northern Ireland. Recent rare disease initiatives by our team include the development of an online support tool for carers of people living with a rare disease, socioeconomic appraisals, new approaches for molecular diagnostics, building digital infrastructure to support diagnosis and care pathways, and a recently funded £12 million LifeArc Centre for the Acceleration of Rare Disease Trials (RD-TAP).

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 an academic, multidisciplinary research environment.
3. *Experience in the use of social media tools for scientific communication purposes.
4. *Experience working with a range of stakeholders to effectively engage them on complex research topics.
5. *Experience producing effective communications in a range of mediums.
6. *Experience in delivering effective information and / or engagement activities and events.
7. Highly developed organisational, decision-making, problem-solving, time management and prioritisation skills.

8. Ability to explain complex ideas simply and effectively.
9. Excellent Information Technology skills including Microsoft Office Suite, and report writing.
10. Ability to work on own initiative and react to evolving project needs.
11. Excellent communication skills – ability to be understood by a range of stakeholders.
12. Creative mind and ability to find innovative solutions to complex problems.
13. Ability to work as part of a team.
14. Ability to use initiative and judgement to resolve many day to day problems independently working with minimal supervision and maintaining confidentiality.
15. High attention to detail with the ability to complete work accurately, on time and to appropriate standards.
16. Ability to travel as required by the post.

DESIRABLE CRITERIA:

1. *Masters or PhD in relevant field relevant to rare disease research such as genetics, molecular biology, biomedical sciences or health economics, data science, clinical trials.
2. *A relevant qualification in one of the following areas: design, communication or impact.
3. *Recent experience working with rare disease stakeholders, including 3rd sector organisations and / or commercial companies.
4. *Experience contributing to research reporting within a University Setting.
5. *Experience of event planning and running events.
6. *Experience in website design, content management and/or maintenance.
7. *Experience communicating with patients and families across the life-course.
8. *Experience developing animated videos, posters, and infographics.
9. *Experience of using Adobe Creative Suite or similar products.
10. Understanding of rare disease research.