

Candidate Information

Position:	Research Fellow (part-time)
School/Department:	Centre for Public Health
Reference:	23/110841
Closing Date:	Monday 15 May 2023
Salary:	£36,333 per annum, pro rata.
Anticipated Interview Date:	Thursday 1 June 2023
Duration:	16 months

JOB PURPOSE:

Globally noncommunicable diseases, including 'rare diseases' (RDs), cause 71% of all deaths. RDs are incurable, life-limiting diseases, most of which (80%) have a genetic component. Over half of all RDs affect children, 30% of whom die before age five. Although each RD affects fewer than 1 in 2000 people, they are a major public health issue affecting over 4.6 million people (including 110,000 in Northern Ireland or NI). RDs are currently targeted for policy action in Northern Ireland (NI) and the rest of the UK.

A neglected issue, however, is meeting the needs of informal or family carers of persons with an RD. Many RD carers look after one or more persons 24/7, resulting in stress that can worsen their mental and physical health. Additionally, RD carers face uncertainty when seeking:

- a diagnosis (the average wait time for an accurate diagnosis in NI is five years);
- treatment (90% of RDs have no approved treatment);
- information (which most health care providers do not have);
- psycho-social support (from peers and/or others).

Dedicated RD support groups exist in NI but are underfunded and focus on the needs of persons living with an RD, not helping informal carers (known as the "hidden patient"). Peers can provide carers information and support, but meeting in person is difficult. Studies show that online resources can help informal carers but are often developed without a strong evidence base or input from the intended beneficiaries. This project will address both shortcomings.

The aim of the "Co-developing the Rare Disease Carer Support Tool-Northern Ireland" (RD-CaST-NI) project is to improve the health and wellbeing of a vulnerable segment of NI's population (RD carers) by reducing their social isolation and loneliness and increasing their self-reported well-being and resilience.

MAJOR DUTIES:

1. Work with the RD_CaST-NI study team to complete project-specific administrative duties, particularly preparing and disseminating regular reports.
2. Support the research team by communicating and engaging with people with rare diseases, their families and other laypeople to enhance PPIE (Patient and Public Involvement/Engagement).
3. Conduct and support data analysis.
4. Participate and in some cases lead outreach activities on behalf of the group.
5. Ensure data are compliant with ethical and governance requirements.
6. Keep abreast of the research field and relevant developments.
7. Prepare, in consultation with the project team, material for publication in peer-reviewed journals, and presentations at national and international conferences.
8. Assist with the submission of further grant applications and the supervision of students.
9. Assist with preparation of relevant ethical and research governance documents.
10. Carry out routine administrative tasks to ensure the project is completed on time and within budget.

ESSENTIAL CRITERIA:

1. Have, or about to obtain, a PhD in health research or a related area.
2. At least 3 years' relevant research experience to include:
 - working closely with diverse stakeholders;
 - collection, analysis and dissemination of qualitative data; and
 - demonstrated ability to conduct dissemination activities and engage with the public.
3. A presentation and publication track record commensurate with the stage of career.
4. Strong analytical and problem-solving skills.
5. Excellent IT skills e.g. Microsoft Office suite.
6. Excellent interpersonal skills.
7. Evidence of excellent organisational skills.
8. Excellent oral and written communication skills.
9. Evidence of ability to write reports and meet deadlines.
10. Evidence of ability to deal competently with administrative tasks and contribute to broader management tasks.
11. Ability to communicate complex information clearly at local meetings, professional conferences, and to stakeholders.
12. Ability to build contacts and participate in internal and external networks.
13. Good teamwork skills.
14. Excellent problem-solving skills and able to use own initiative.
15. Evidence of excellent leadership skills.
16. Access to transport or ability to meet the mobility requirements of the post.
17. A willingness to travel to meet the needs of the post.

DESIRABLE CRITERIA:

1. First or Upper 2nd Class Honours Degree in a relevant discipline, a Master's degree and/or relevant professional qualification.
2. Experience with public engagement activities and disseminating research to non-academic audiences.
3. Experience working with laypeople, researchers and clinicians.
4. Track record of collecting and analysing qualitative data.
5. Experience managing a research project.
6. Experience developing a funding proposal.
7. Proven ability to participate in or initiate collaborative research.