

Job Title: Patient Researcher (Thoracic Aortic Disease)

Grade: 6

Salary: £32,546 to £37,174 per annum pro rata

Department: Cardiovascular Sciences

Hours/Contract: Part-time (0.2FTE, 7.5 hours per week), fixed term contract until 31 March 2030

Job Family: Management and Administration

Reference: 10634

Role Purpose

This post supports the work of the Department of Cardiovascular Sciences (CVS), the Leicester Clinical Trials Unit, and the Leicester Centre for Ethnic Health Research (LCEHR).

We are seeking to appoint an individual who has personal significant experience and/or previous engagement with those affected by Thoracic Aortic Disease. Reporting to the Cardiac Surgery Research Manager in the CVS and in collaboration with the Public Contributor Leads, your primary aim will be to develop methods that promote the inclusion of underserved groups in the DECIDE-TAD Programme. You will do this by creating public facing materials, as well as participation and dissemination strategies that work to overcome barriers to inclusion. You will be expected to work independently, but also as part of the wider trial team, working closely with community-based, and other research partners.

Thoracic Aortic Disease (TAD) is commonly caused by genetic mutations. Screening of the families of people with TAD using scans and genetic tests may lead to early detection, treatment, and a reduction in deaths.

Our preliminary work has identified barriers to the use of cascade screening in the NHS. To overcome these barriers, we will create a Decision Support Tool that defines treatment choices and provides information which empowers members of affected families to make decisions about screening that reflect their values and priorities. We think this will increase the number of people screened, improve early detection and treatment of TAD, address health inequalities in under-served groups, and improve quality of life.

DECIDE-TAD is a Programme Grant for Applied Health Research, funded by the NIHR.

Main Duties and Responsibilities

- Co-host workshops and advisory groups with ethnic minorities and other underserved groups to ensure their perspectives are heard in the development of recruitment techniques, paperwork, and other resources for engagement that work to mitigate social, cultural, educational, or language barriers to participation.
- By using well established connections in the community, take the lead in working with external agencies in delivering the trial, including recruitment of participants, organizing and conducting focus groups and interviews to produce research outputs
- Develop tools that anticipate how health inequalities interact to create barriers to inclusion among underserved groups and develop recruitment and dissemination materials that work to improve equality, diversity and inclusivity in the trial





- Assist with developing an effective dissemination strategy to promote the importance of the research findings to underserved groups. This will involve workshops after trial completion to identify how best to share our results and ensure they reach all communities and to develop an advocacy strategy to make sure that the results reach key stakeholders and decision makers, including by participating in a national stakeholder event to disseminate the trial findings and writing reports for dissemination through trials methods journals, social media, INVOLVE and the NIHR website.
- Develop methods and language to inform a strategy of trial result dissemination to participants that are designed to overcome barriers to communication that arise due to age, ethnicity, language, education and other causes of health inequality. The information will acknowledge the participants contribution to the trial, be consistent with existing HRA guidance, and include directions to the lay summary included in the NIHR report.
- Work collaboratively with community-based staff who engage with underserved groups. To ensure the trial research team are culturally competent and confident with engaging with different communities and underserved groups during this study the LCEHR will offer training to the Patient Researcher who will then disseminate this throughout the wider research team.
- Joint-host national workshops to road test an online toolkit that provides researchers with a framework to improve the participation in research, making it more diverse and inclusive.
- Where relevant, identify skills within the wider team and use other agencies to best support the trial, for example where interpretation and translation is needed

Internal and External Relationships

- Daily interaction with members of the public, NHS patients & staff, Centre for Ethnic Health Research (CEHR), UoL research staff, NHS organisations, and external contacts.
- Liaising with community, voluntary, and faith centre organisations and members.
- Liaising with other departments within the University of Leicester and University Hospitals of Leicester, other hospitals, as well as external collaborators as required by the job.

Planning and Organising

Plan and prioritise own work activities across the life of the trial, and to strict deadlines, to ensure operational efficiency responding to new priorities including those arising from non-standard work

Qualifications, Knowledge and Experience

Essential

- Educated to degree level (or equivalent work experience) *
- Evidence of significant prior engagement of those affected by Thoracic Aortic Disease & their carers*
- Previous experience of working with and have existing established connections with community and/or faith organisations*
- Knowledge, experience and understanding of equality and diversity practice and principles*
- Experience of working within higher education or health research





- Experience of working in a large health, voluntary or education setting

Desirable

- Knowledge of public services
- Experience of working in black and minority ethnic communities for research
- Experience of using virtual platforms to deliver training and engagement sessions

Skills, Abilities and Competencies

Essential

- Profound understanding of the issues of living with Thoracic Aortic Disease through personal experience*
- Able to empathise with patients and carers of those living with Thoracic Aortic Disease
- Outstanding written and verbal communication skills, with the ability to give and receive information effectively and to communicate at all levels*
- Well-developed organisational skills, and ability to work with minimum supervision*
- Ability to define priorities and work flexibly and effectively under pressure to meet demanding (and occasionally conflicting) objectives and deadlines
- Excellent general IT Skills and experience of using Microsoft Office and social media
- Ability to stay calm under pressure; resilience; confidence to act on own initiative; and an understanding of the need for confidentiality*
- Accuracy and attention to detail*
- Ability to assess problems and take the appropriate action
- The ability to maintain confidentiality and discretion with dealing with sensitive issues*
- Ability to work to tight multiple deadlines
- Ability to prioritise own workload*
- Ability to work independently and as a member of a team to achieve a common goal
- Willingness to travel to meetings and events as required by the role.
- Ability and willingness to work occasional evenings

Desirable

- Flexibility concerning the duties and hours required of the role

****Criteria to be used in shortlisting candidates for interview***

Reason for Fixed Term Contract

The reason for the fixed term contract is stated in section 1.9 in the summary of contractual terms in your contract of employment.

Criminal Declaration and Disclosure and Barring Service (DBS).

If you become an employee, you must inform your manager immediately, in writing, if you are the subject of any current or future police investigations/legal proceedings, which could result in a criminal offence, conviction, caution, bind-over or charges, or warnings.



This post is exempt from the Rehabilitation of Offenders Act 1974 because the appointee will have substantial access to young people and/or vulnerable adults. Therefore, an appointment to this post will be subject to checking through the Disclosure and Barring Service (DBS). The successful applicant for this post will, therefore, be required to give consent for the University to check and obtain appropriate clearance with the DBS for the existence and content of any criminal record in the form of a Standard Check.

Information received from the DBS and the police will be kept in strict confidence and will be destroyed once the University is satisfied in this regard.

NHS Research Governance

Where it is determined that the duties of this post for the purposes of research involve work with the NHS, it is necessary to ensure that the performance of the duties attached to the post are covered by NHS research governance arrangements and the appointee must comply with all such arrangements, which may include occupational health clearance and DBS clearance.

Supporting University Activities

As a University of Leicester citizen, you are expected to support key university activities such as clearing, graduation ceremonies, student registration and recruitment open days. We expect all staff as citizens to work flexibly across the University if required.

University Values

Inclusive - We are diverse in our makeup and united in ambition. Our diversity is our strength and makes our community stronger.

Inspiring - We are passionate about inspiring individuals to succeed and realise their ambitions. We challenge our community to think differently, to get involved, and to constantly embrace new ideas.

Impactful - As Citizens of Change we will generate new ideas which deliver impact and empower our community

Equity and Diversity

We believe that equity, diversity and inclusion is integral to a successful modern workplace. By developing and implementing policies and systems that challenge stereotypes across all aspects of our work, we have a culture that recognises and values the diverse contributions of our staff which benefits everyone. Our strong values of inclusivity and equity support our efforts to attract a diverse range of high quality staff and students, and identify our University as a progressive and innovative workplace that mainstreams equity, diversity and inclusion.

