



Job description

Job title	National Congenital Anomaly and Rare Disease Registration Service Clinical Lead
Directorate	Health Improvement
Pay band	Medical consultant
Job type (ie permanent, fixed term)	Fixed term until 31 March 2021 (with the view to extend funding dependent)
Responsible to	Deputy Director, National Disease Registration
Hours/ sessions per week	4 Programmed Activities (PAs) per week (Applicants for job share or flexible working will be considered)
Location of Post	National

INTRODUCTION

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

National Disease Registration

National Disease Registration is one of the major parts of the Health Improvement Directorate with the teams and expertise, that in partnership with other groups across PHE and beyond, identifies, collects, collates and quality-assures detailed and rich population-level datasets for specific diseases and conditions. NDR is an international leader in population-based disease registration services, real-world clinical data quality assurance, surveillance and monitoring. We also have significant skills in data science, analytics and complex data processing systems.

NDR teams manage the National Cancer Registration and Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). For these population registration services we collect and quality-assure data from every patient in England diagnosed with cancer or a congenital anomaly and are expanding out to collect other rare diseases. Our analysis teams provide expert analysis and interpretation of the data we collect, often working in partnership with academic and third-sector colleagues. Within PHE we run the Information Governance and Policy Office and the Office for Data Release.

For our disease registration and analysis activities we work in partnership with others to:

- collect, curate and quality-assure, timely, high-quality data on a wide range of diseases and disorders.
- provide robust analysis and surveillance to monitor and detect changes in health and disease in the population.
- analyse and interpret complex data to provide information and knowledge on cancer, congenital anomalies and rare diseases.
- ensure that disease registration in England supports all those who need the data including, the NHS, clinicians, individual patients, the third sector and wider public.
- provide appropriate data to a wide range of users in ways that meet their needs while also ensuring compliance with the highest standards of information governance.
- ensure that patients and public are aware of our work and the collection and use of the data.
- support the Government Transparency Agenda to increase public access to data.

PHE PEOPLE CHARTER

- The way we behave as PHE members of staff will have the greatest impact in achieving our ambitions as an organisation. What we say matters but what we do matters more.
- Our effectiveness depends on how we behave so we have developed the PHE People Charter which outlines the values and behaviours expected.
- Our behaviours that underpin our values are to **COMMUNICATE** openly, honestly and clearly, **ACHIEVE TOGETHER**, working towards PHE's objectives, **RESPECT** each other and treat colleagues and customers how we would wish to be treated and **EXCEL** by providing an excellent service, leading by example and driving personal development.

JOB SUMMARY

A detailed job plan will be agreed between the post-holder and the Registry Lead for NCARDRS. The job plan will comprise 4 Programmed Activities (PAs) per week (applicants for job share or flexible working will be considered).

The post holder will:

- Achieve consistency and improve quality in coding congenital anomalies and standardisation of registration practices across the NCARDRS. Set minimum standards that all regional offices of the NCARDRS should meet.
- Standardise national and European surveillance. To include input into EUROCAT coding and classification committee and other relevant groups.
- Provide expert clinical input; including input to the NCARDRS annual statistics and data briefings as well as bespoke reports on particular topics or to specific stakeholders eg. National Screening Committee
- Contribute strategic input and design into the ongoing development and plans for the NCARDRS. Encourage and support a culture of integration and innovation, challenge the status quo and be accountable for strategic approaches and improvement across NCARDRS
- Liaison with data providers, including presentation of data to data notifiers through regular update days/ events and identifying/negotiating access to new data sources both locally and nationally.
- Provision of expert advice both locally and nationally as required, to ensure that NCARDRS remains clinically relevant and meets our aim of informing high quality care.

- Education and training for registration staff, registrars/ specialty trainees (from across a number of specialties/ sub specialities), PhD and MSc students in the registration, coding, analysis and interpretation of congenital anomalies and rare diseases.
- Supporting research; liaison with other researchers, planning/collaboration of local, national, international studies, development of national and international research portfolio.

Communication and key working relationships

Internal

- National Director Disease Registration
- Registry Lead NCARDRS
- Staff across all disciplines and at all levels within the National Disease Registration Division

External

- Department of Health and Social Care
- NHS England, Local Authorities and other Department of Health Arm's Length Bodies
- Clinicians – including Oncologists, Fetal Medicine, Paediatrics, Radiotherapists, Surgeons, Pathologists and Radiologists, Clinical Geneticists
- Genomics England
- National Institute for Health and Care Excellence (NICE)
- 3rd Sector rare disease charities– UK Genetics Alliance, Specialised Healthcare Alliance – and many others
- Industry including pharmaceutical and technology companies; trade associations
- Other Government Departments
- Health Research Authority
- International bodies such as EUROCAT and the International Clearing House for Birth Defects

The job plan will be reviewed at least annually, and either party may request a job plan review at any time.

Person specification

Description	Essential	Desirable	Assessment
Qualification			
Medical Degree		✓	C
Current or previous entry on GMC Specialist Register in related discipline	✓		C
Knowledge and experience Experience as defined by type/level (not length)			
Relevant clinical experience in the field of congenital anomalies and/or rare diseases	✓		A
Knowledge and understanding of disease registration	✓		A
Knowledge of the classification and coding of congenital anomalies and rare diseases in accordance with international standards		✓	A
Skills and capabilities			
Ability to interpret complex medical data and work with international coding systems to appropriately classify disorders	✓		I
The ability to communicate effectively with clinicians and academics, and researchers			I
Equality and diversity			
An understanding of and commitment to equality of opportunity and good working relationships, both in terms of day-to-day working practices, but also in relation to management systems	✓		I

Values and Behaviours			
	Essential	Desirable	Assessment
Commitment to and focused on quality, promotes high standards in all they do	✓		A/I
Consistently thinks about how their work can help and support clinicians and frontline staff deliver better outcomes for patients	✓		A/I
Values diversity and difference, operates with integrity and openness	✓		A/I

Works well with others, is positive and helpful, listens, involves, respects and learns from the contribution of others	√		A/I
Consistently looks to improve what they do, looks for successful tried and tested ways of working, and also seeks out innovation	√		A/I
Actively develops themselves and supports others to do the same	√		A/I

**Assessment will take place with reference to the following information
A = Application I = Interview C = Certificate**