

# Job description

Job Title: Senior UK CF Registry Systems Development Manager

Reporting To: Head of Healthcare Data & Pharmacovigilance

**Line Management:** Registry Development Manager, Software Analyst

**Department**: Directorate of Data & Quality Improvement

**Location**: Head Office, One Aldgate, London

### **Role Purpose:**

To take a leading role in the development of the Cystic Fibrosis Trust's world-leading UK CF Registry. The post-holder will be part of a dynamic team committed to maximising the use of Registry data for the benefit of the cystic fibrosis community.

The post-holder will lead the technical development of the UK Cystic Fibrosis Registry software and SQL database. This will include ensuring that changes to the system are patient-centred, secure and transparent, align with the strategic objectives of the UK CF Registry and Cystic Fibrosis Trust, and that they are delivered on time and within budget.

The post-holder will provide leadership for the Registry's Development team, proactively identifying areas for enhancement to optimise system usability and data quality, including consideration of impact and risks.

### Main duties

### **Registry Software Enhancement and Development**

- Initiate, lead and project manage major Registry development projects with support from Head of Healthcare Data. To produce business cases and project plans for internal and/or external stakeholders as needed. This will include:
  - a. Developing APIs aligning to appropriate standards for integration of external data with UK CF Registry data
  - b. Migrating UK CF Registry data to a Trusted Research Environment, including research-ready data curation.
- 2. Work with the Registry Development Manager to design the development roadmap for large projects and frequent core development releases, breaking up delivery into meaningful, achievable goals
- To take the lead role in requirement engineering (eliciting requirements through interviews, surveys, focus groups and workshops; writing needs log; writing use cases), delegating to Registry Development Manager and Software Analyst as suitable.
- 4. Lead on all work and be the first point of contact with third party developers at all stages of the development cycle providing clarification and support on all functional requirements and specifications
- Manage testing of all fixes, changes and new features in collaboration with Registry Development team; including writing test plans, allocation and performance management of testing, and review and sign-off of developed functionality. To support the team with testing as necessary.
- Lead, organise and unblock the development team with keen analysis and wellcommunicated decisions



- 7. Work with the Registry Development Manager to manage the backlog of software developments: Reviewing change requests to maintain the integrity of the Registry dataset; overseeing testing for solutions and changes to the Registry.
- 8. With the support of the Head of Healthcare Data, budget manage development projects, including reviewing quotes for project proposals and managing expenditure, ensuring cost effectiveness and controlling expenditure within budget.

## **Stakeholder Engagement**

- 1. Ensure that the needs of people with cystic fibrosis underpin development of the UK CF Registry at every stage.
- 2. Work with the Senior Statistician and other senior managers as required to interpret data quality analysis and guide data collection enhancement, supported by the Registry Development Manager
- 3. Work with the Registry Clinical Lead to ensure clinical input into Registry development activities.
- 4. To recognise and identity when stakeholder input is required in the co-design of Registry functionally. Lead communications with a range of stakeholders including commissioners, data managers, CF care teams and researchers.
- 5. With the assistance of the Registry Coordinator and Registry Development Manager, ensure all stakeholders are informed of relevant changes to the Registry software
- Lead on organisation and implementation of Registry user training sessions and workshops
- 7. Advise the Registry Team and Registry Committees as to the capabilities and limitations of system development, as well as needs for enhancement
- 8. Facilitate and support the ongoing Alliance membership with Health Data Research UK

## **Line Management**

1. To line manage, motivate and develop the Registry Development Manager and Registry Software Analyst, setting objectives, personal development plans and ensuring the overall strategic goals and targets are achieved.

## Working with other teams

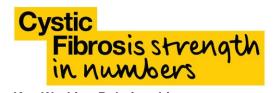
- 1. To recognise when the support of Project Management Office can be sought; to initiate and lead on PMO collaboration on projects.
- 2. Collaborate with Involvement team to enable meaningful patient engagement and involvement in Registry development and/or health data initiatives.
- 3. To provide input to Marketing and Communications colleagues as necessary to ensure dissemination of accurate and meaningful information.

### Legislative

- With support from Head of Healthcare Data, ensure that the Registry Development team comply with legislative and regulatory requirements including information governance, data protection and confidentiality to maintain confidence in, and the reputation of the Trust
- Support the Head of Healthcare Data to ensure UK CF Registry Standard Operating
  Procedures are compliant with the relevant laws and legislations, to undertake regular
  review of relevant SOPs and ensure compliance. To draft new SOPs related to area
  of work as needed.
- 3. Undertake and maintain Good Clinical Practice training for healthcare research

### Other Responsibilities

- 1. Proactively support the work of the Trust, taking an active part in corporate and fundraising functions as required
- 2. Undertake any other reasonable duties consistent with the skills, knowledge and level of the role as directed by the Trust

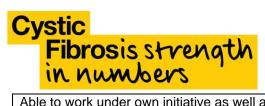


# **Key Working Relationships:**

- Head of Healthcare Data, Registry Development Manager, Software Analyst, Registry Clinical Data Manager, Registry Coordinator, Registry Statisticians and Director of Data and QI.
- Third party Registry software developers
- Other departments in the Cystic Fibrosis Trust
- Registry Committees and external stakeholders
- External research leads and Clinical Trial Units

## **Person Specification:**

Essential	Desirable
Education and Qualifications	
Degree educated in subject relevant to clinical data or software development; OR equivalent workplace experience	Good Clinical Practice Training
Experience	
Experience of data collection and reporting systems development	Experience of clinical registries and/or clinical audit or clinical trials
Experience of software development, including writing test plans	Experience of the design, set up and regulatory requirements of clinical trials and/or post-marketing surveillance
Experience working with large and complex datasets	Experience of clinical research
Experience of project planning and change management	Experience of working in or with the NHS
Experience of stakeholder and supplier management	Experience of working with medical case notes or Electronic Patient Records
Line Management experience	
Budget Management experience	
Knowledge	
In depth understanding of data collection methodologies	Understanding of SQL and Javascript
In depth understanding of data quality requirements and limitations	Knowledge of cystic fibrosis
Understanding of data reporting methodologies	Knowledge of NHS Quality Improvement initiatives
Information governance and data protection legislation	Understanding of clinical investigations and outcomes
Skills	
Interrogation of data	
Advance use of Microsoft Excel	
Tenacity, diplomacy and attention to detail	
Effective written and verbal communication skills, with the ability to motivate and inspire others.	
Self-motivated with the ability to manage conflicting priorities to meet planned and unplanned demands	
Personal Qualities	



Able to work under own initiative as well as part of a team	
Solution focussed and effective problem-solving skills	
Cross-team working and collaborative approach to delivering strategic and operational priorities	
Flexible approach to work, including being prepared to travel when necessary	