

JOB DESCRIPTION

GENERAL INFORMATION

Title: Cystic Fibrosis National Registry Coordinator
Band: Band 5
Job Base: RBH
Responsible to: Associate Centre Director, Adult Cystic Fibrosis Centre
Accountable to: Centre Director, Adult Cystic Fibrosis Centre
Disclosure & Barring Service (DBS) checks (please delete as appropriate):
Enhanced ☒

JOB SUMMARY AND KEY OBJECTIVES

The Royal Brompton Hospital has the largest adult CF Service in Europe (approximately 600 patients) and follows both the national and European standards of care for CF and the national service specification for CF. An individualised annual review is recommended for every patient. Additionally, the service is required by NHSE to send a completed, annual, clinical data set on every patient via the national registry for individual patient severity banding (1-4). Banding then determines the cost given for each patient for the following year. The national clinical data set is published annually and made public, including comparison between all UK CF centres on all data points.

The UK also contributes full registry data to the European CF Registry annually and compares clinical outcomes with the North American CF registries (Canada and America). The accuracy of the entered data is therefore crucial – locally, nationally and internationally.

- The post holder will have organisational and motivational skills, and will work on their own initiative. Their work will be managed rather than supervised, the data entered has implications for financial income, and national and international patient service development and decision making.
- The post holder will have an understanding of how to select complex clinical data from hospital databases.
- The post holder will work as an integral and active part of the adult Cystic Fibrosis (CF) multidisciplinary team (MDT) including liaising with consultants and senior members of the team on a regular basis.

- The post holder will attend the weekly MDT team and monthly MDT business meetings, presenting data when requested.
- The post holder will use Dendrite, Xero, EDM and EPR as source materials making informed decisions about which clinical data to select.
- The post holder will be responsible for collecting, analysing, collating and entering the requested clinical data into the national CF registry in a timely manner.
- The post holder will liaise regularly with the UK Registry Management Team at the Cystic Fibrosis Trust, attending meetings and conferences as required.
- The post holder will support the administration of the annual review service in partnership with the annual review administrator and the clinical nurse specialists.
- The post holder will act as an advocate for the patient and their family.
- The post holder will be flexible in approach and provide support for any areas specified, including data collection/retrieval, preparing reports and staff training for registry-associated commitments such as benchmarking, quality metrics and research.

MAIN TASKS & RESPONSIBILITIES

Communication

- To demonstrate a courteous and helpful approach to patients and their families, ensuring patients feel reassured and supported.
- To report issues regarding the CF registry or annual review service or any other relevant information immediately to appropriate staff in the CF MDT.
- To record telephone conversations with patients on EPR and telephone log.
- To assist in the development of information for patients and their families.
- To organise and motivate the CF MDT to take part in training for access and use of the registry.
- To present registry report data to the CF MDT and wider audience at least six monthly.
- To regularly liaise with the CF Trust regarding issues, training, research and reporting.
- To promote the corporate image of the Trust to all individuals, groups and organisations, both within the Trust and externally to the community at large.
- To participate fully as a team member, sharing knowledge and information and supporting colleagues, to promote a cohesive team.

Patient/customer care (both direct and indirect)

- To work effectively within the CF MDT in an integral and active role including liaising with consultants and senior members of the team to discuss issues, results, missing data etc on a regular basis.
- To attend monthly meetings with the Centre and Associate Directors to discuss progress (numbers entered) and arising issues in meeting the annual deadline.
- To provide customer care/patient-facing activities, such as having the skills necessary to take written consent for registry-based research, and identifying new patients (including transition patients) who need to consent to their data being on the registry.

- To liaise with patients and the CF MDT regarding the annual review service, both phone/email and face to face contact.

Policy and service development

- To be responsible for the RBH annual CF data report and feeding back any concerns to the appropriate members of the clinical team.
- To liaise with the UK Cystic Fibrosis Trust, specifically the Registry Management team on a regular basis, being aware of registry updates and changes.
- To be aware of and adhere to RBH Trust policies and procedures.
- To be aware of, adhere to and contribute to the CF MDT's policies and procedures, especially regarding the annual review service and the national registry.
- To take responsibility for providing training and writing pathways and procedures for all CF MDT staff in registry use and access.

Resource management

- To ensure accurate recording of patient numbers (and the consequent impact that accuracy has on the financial income to RBH), create and maintain a monthly, updated database of all adults with CF, indicating those who have recently transitioned from paediatric services, those who have moved away or joined the service, those who have had a lung transplant and those who have died.
- To liaise with the finance department monthly regarding accurate patient numbers.
- To report on a quarterly basis those patients who have attended annual reviews for the Specialised Services Quality Dashboard.
- To ensure working area including chair, computer, screens etc are in good working order and report any faults. This post requires extended time sitting at a desk accessing and entering data.
- To ensure that accurate and timely data entry is achieved to support data analysis, validation and submission of data to national audits.
- To provide administrative support to the annual review service.

Educational development, research development

- To gain and maintain the required knowledge and skills in finding, identifying, analysing and reporting the required information to support the national registry and annual review service.
- To gain knowledge of medical terminology, anatomical and physiological terms acquired through work-based training and stay updated.
- To gain knowledge about CF to be able to advance and develop the service.
- To train in taking written consent and understand the principles of good clinical research.
- To support and contribute to registry-based research and quality improvement initiatives.
- To contribute to and initiate contributions to national and international conferences.
- To attend and contribute to the annual CF Trust Registry conference.
- To participate in the Trust's appraisal and personal development plan schemes by meeting with a manager six monthly.

- To abide by the Trust's Core behaviours for staff and all other Trust policies, codes and practices including standing financial instructions, research governance, clinical governance, patient and public involvement, codes and practices, and health and safety.

Information management

- To participate in research, audit and quality improvement programmes within the CF MDT.
- To maintain efficient and accurate record systems.
- To have skills and knowledge of computer use and databases to collate, input and maintain the CF registry, the annual review database and the patient genotype database.
- To provide regular, timely reports on request from CF MDT and the UK CF Trust.
- To use all relevant IT systems in the accessing of patient data and the support of patient care, including PAS, Anglia Ice for the accurate labelling and handling of patient specimens and EPR, Dendrite and EDM to check patient results and record patient conversations.
- To keep the CF related diabetes database up to date so that patients are sent appropriate appointments.
- To keep the DEXA database up to date so that patients are scanned appropriately.
- To keep the genotype database up to date so that patients are offered new modulator drugs appropriate to the genetic mutation.
- To providing cover for the annual review coordinator when they are away.
- To update with all relevant training for electronic information systems in place and under development at both RBH and the UK CF Trust.
- To use the RBH intranet to enhance care and for professional development.

Other duties

- To undertake any other duties commensurate with the grade as requested.

This job description is intended as a basic guide to the scope and responsibilities of the post and is not exhaustive. It will be subject to regular review and amendment as necessary in consultation with the post holder.

ADDITIONAL INFORMATION:

Trust mission

To be the leading national and international centre for the diagnosis, treatment and care of patients with heart and lung disease, creating and disseminating knowledge through research and education.

Confidentiality

During the course of your employment you may have access to, see or hear information of a confidential nature and you are required not to disclose such information, particularly that relating to patients and staff.

In order to comply with the Data Protection Act 1998 you must not at any time use personal data held by either Trust for any unauthorised purpose or disclosure such as data to a third party.

You must not make any disclosure to any unauthorised person or use any confidential information relating to the business affairs of the Trusts, unless expressly authorised to do so by the Trusts.

Health and safety

You must co-operate with management in discharging its responsibilities under the Health and Safety at Work Act 1974 and take reasonable health and safety of themselves and others and to ensure the agreed safety procedures are carried out to maintain a safe environment for patients, employees and visitors.

Diversity

You are at all times required to carry out your responsibilities with due regard to the Trust's Equal Opportunities Policy and to ensure that staff receive equal treatment throughout their employment with the Trust.

Patient & public involvement

All staff would have a responsibility to contribute to the implementation of the patient and public involvement (PPI) strategy and associated action plans.

Risk management

All staff have a responsibility to report all clinical and non-clinical accidents or incidents promptly and when requested to co-operate with any investigation undertaken.

Conflict of interests

You may not without the consent of the Trust engage in any outside employment and in accordance with the Trust's Conflict of Interest Policy you must declare to your manager all private interests, which could potentially result in personal gain as a consequence of your employment position in the Trust. Interests that might appear to be in conflict should also be declared.

In addition, the NHS Code of Conduct and Standards of Business conduct for NHS Staff (HSG 93/5) required you to declare all situations where you or a close relative or associate has a controlling interest in a business (such as a private company, public organisation or other NHS voluntary organisation) or in any activity which may compete for any NHS contracts to supply goods or services to the Trust. You must therefore register such interests with the Trust, either on appointment or subsequently whenever such interests are gained. You should not engage in such interests without the written consent of the Trust, which will not be unreasonably withheld. It is your responsibility to ensure that you are not placed in a position, which may give rise to a conflict between your private patient's interest and your NHS duties.

CODE OF CONDUCT FOR PROFESSIONALLY QUALIFIED STAFF GROUPS

All staff are required to work in accordance with their professional group's code of conduct (eg NMC, GMC, DoH Code of Conduct for Senior Managers).

CRIMINAL RECORD BUREAU CHECKS (where relevant)

Any applicant who is short-listed for this post will be asked to complete a disclosure form as the post-holder will be required to have contact with vulnerable adults or persons under the age of 18. The successful candidate will be subject to a criminal record check from the Criminal Records Bureau prior to the appointment being confirmed. The disclosure will include details of cautions, reprimands, and final warnings, as well as convictions if applicable.

Core behaviours for all Trust staff:

All staff will commit to:

- Act with honesty and integrity at all times
- Demonstrate respect for others and value diversity
- Focus on the patient and internal and external customer at all times
- Make an active contribution to developing the service
- Learn from and share experience and knowledge
- Keep others informed of issues of importance and relevance
- Consciously review mistakes and successes to improve performance
- Act as ambassadors for their directorate and the Trust
- Be aware of the impact of their own behaviour on others
- Be discreet and aware of issues requiring confidentiality

In addition, all managers and supervisors will:

- Value and recognise the ideas and contributions of all team members
- Coach individuals and teams to perform to the best of their ability
- Delegate work to develop individuals in their roles and realise their potential
- Give ongoing feedback on performance, and effectively manage poor performance
- Provide support and guidance to all team members
- Encourage their team to achieve work/personal life balance
- Actively listen to comments/challenges and respond constructively
- Lead by example, setting high standards
- Ensure that there are sufficient resources for their team and rebalance priorities accordingly
- Provide a safe working environment

Confirmed as accurate by post-holder:

Date:

Confirmed as accurate by manager:

Date:

PERSON SPECIFICATION

GENERAL INFORMATION

Post: Cystic Fibrosis National Registry Coordinator

Band: 5

Department: Adult Cystic Fibrosis (Lung Division)

REQUIREMENTS	ESSENTIAL	DESIRABLE
<u>EDUCATION & QUALIFICATIONS</u>	<ul style="list-style-type: none"> ▪ Educated to degree level or equivalent knowledge. ▪ All staff are expected to take responsibility for their own continual personal development ▪ Basic Life Support 	<ul style="list-style-type: none"> ▪ Working towards a recognised administrative qualification/further education
<u>EXPERIENCE & KNOWLEDGE</u>	<ul style="list-style-type: none"> ▪ Ability to communicate well ▪ Ability to work as part of a team as well as on own initiative ▪ At least three years of experience working with databases ▪ Awareness of data protection laws ▪ Knowledge of the full range of administration procedures 	<ul style="list-style-type: none"> ▪ Experience of working in a multidisciplinary healthcare team ▪ Knowledge of cystic fibrosis
<u>SKILLS & ABILITIES</u>	<ul style="list-style-type: none"> • Good level of IT skills including a range of MS office skills • Good organisational skills • Excellent communication skills • Understanding own accountability • To be responsible for own time management • Ability to prioritise and manage own work load 	<ul style="list-style-type: none"> • Experience in Excel /Access databases • Experience in other database software • ECDL
<u>PERSONAL QUALITIES</u>	<ul style="list-style-type: none"> • Able to carry out assigned task effectively in a busy, ever changing environment • Flexible approach to work • Good communication – ability to motivate individuals • Team player 	<ul style="list-style-type: none"> • Smart appearance • Pleasant disposition • Motivated
<u>OTHER REQUIREMENTS</u>	<ul style="list-style-type: none"> • Reliable work record • Enthusiastic • Ability to work under pressure 	

Date: 30/08/2019